BUILDING THE NORMAL BODY:
DISABILITY AND THE TECHNO-MAKEOVER

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Introduction:

Neither Cyborgs nor Technotards

In July 2011, Oscar Pistorius, known as "Blade Runner" for his two prosthetic legs, qualified to run and compete in the world track championships against the best able-bodied runners alive — a story that has been extensively covered in the U.S. media.[1] Two months earlier, a similar story made international headlines; Austin Whitney, a paraplegic, used a robotic full-body suit called an "exoskeleton" to walk across the stage and accept his diploma to graduate from UC Berkeley.[2] You can read these stories in the local news and watch them on reality television shows like *Extreme Makeover: Home Edition* and *The Oprah Winfrey Show.* These stories, of people with disabilities enhanced by technology who overcome barriers and inspire us all, are quite common, even if the stories' narratives claim that these cases are quite extraordinary.

My goal is to flesh out just how common these stories are and explore the cultural purpose they serve. Technologies meant to normalize disabilities are promoted as a vision of progress, but I argue technological progress does not equal social progress. Many of the problems people with disabilities face stem not from a lack of nuts and bolts to provide a technological fix, but rather from social discrimination, inequality, and inaccessibility that results from living in an environment built for an able-body. However, these stories of "triumph over adversity," made possible through technology, obscure this fact. The narratives promote a neoliberal agenda, in which privatized

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[1] Andy Bull, "Humbled Pistorius Says He Never Expected to Make the 400M Final," *Guardian,* August 29, 2011. http://www.guardian.co.uk/sport/2011/aug/29/oscar-pistorius-400m-final.

[2] Nanette Asimov, "Exoskeleton Lets UCB Grad Take Big Step," *SF Chronicle*, May 15, 2011. http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2011/05/14/BARO1JFEP8.DTL

technological consumption is capable of solving the problems of disability, rather than have us address discrimination or offer social assistance.

Of course, the question of a body intertwined with technology is not limited to disabled communities. From machines in the workforce to luxury technologies like cell phones and iPods, it has become rare to encounter a body in the United States today that is not in some way intimately intertwined with technology, though the types of technologies vary greatly with social status. As science and technology continue to develop at an accelerating rate, each year brings new possibilities for what we can do *as* humans and *to* humans. We often use technology and science to expand the limits of the body, to help us go to new places previously impenetrable, to keep us alive at times when we otherwise would have perished, and to optimize our bodies to do new things imagined in the science fiction of the past. Innovations in science and technology have a profound impact on all of our bodies, what they can do and what we are culturally expected to do with them once a new innovation becomes routine and integrated into our culture. Many of these changes have improved humanity in praiseworthy ways, but not all.

The abundance of stories of people with disabilities altered and "made better" by technology is inseparable from this wider rise in biotechnology-merged bodies. In part, this intersection is obvious — some of the innovations that have come have been for people with disabilities, so technologies like Pistorius's prostheses or the exoskeleton are circulating because they mark technological progress. "Assistive technology" refers to any device used by a person with a disability to help with the challenges posed by impairment, and the assistive technology industry has experienced rapid growth in the past thirty years. Yet, the hunch with which I began this project is that these celebrations of disability technology circulate for a secondary purpose as well. As all of our bodies become intertwined with technologies in new interdependent ways, I believe we may be looking to people with disabilities to feel out what it means to rely on technology. These stories of people with disabilities and technological body modifications are made to sanitize our understanding of both disability and technology, but this story is misleading, certainly in the case of disability technology. What does it mean to intimately rely upon technology and how will this be changing as we become even more high-tech in the future? Do people with disabilities relate to technology differently than able-bodied people do? These questions have been taken up by scholars, though primarily in superficial ways.

A large amount of research into the body/machine interface stemmed off of the work of feminist science studies scholar Donna Haraway. She suggested that we can liberate marginalized people through reclaiming technoscience hybridized with the body in her foundational essay, "A Manifesto for Cyborgs," giving birth to an abundance of cyborg studies scholarship or "cyborgology."[3] Haraway appropriated the cyborg from its scientific origins and defines it to include any boundary breakdown between human and animal, animal/human and machine, and the physical and non-physical, recognizing the pervasive ways that bodies are hybrids, which cannot be understood as "whole" or "pure." She then argues that in the cyborg figure, we can recode and rewrite its text, allowing an escape for people living in bodies already written as "Other," including women, people of color, laborers, and/or the colonized, making her well known claim,

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[3] Donna J. Haraway, *Simians, Cyborgs, and Women: The Reinvention of Nature* (New York: Routledge, 1991).

"We are all cyborgs."[4] To free the cyborg from categories and dichotomies, as naming is exclusion, she sees the cyborg as post-gender and a "mestiza" that is full of contradictions and without origins. She hopes that through all these border breakdowns, embracing the cyborg will help us to rewrite cultural norms of the body, in effect subverting hegemony.

Despite Haraway's efforts to shift cyborg theory away from material bodies, she writes in a footnote, "Perhaps paraplegics and other severely handicapped people can (and sometimes do) have the most intense experiences of complex hybridization with other communication devices."[5] Though this statement may very well be true, this does not mean that people with disabilities embrace a cyborgian existence without ambivalence. N. Katherine Hayles also calls upon people with disabilities, stating, "Cyborgs actually exist. About 10 percent of the current U.S. population are estimated to be cyborgs in the technical sense, including people with electronic pacemakers, artificial joints, drug-implant systems, implanted corneal lenses, and artificial skin."[6] Chris Hables Gray even goes so far as to call people with disabilities who have not accepted their cyborg status "in denial" and calls anyone reluctant to embrace a posthuman future "technotards."[7] Technology scholar Bill McKibben sums up this perspective, stating:

> In their effort to end the debate before it's begun, some technozealots argue that it's too late to draw the line: we're already engineered. People with hearing aids or artificial joints are protorobots, they insist…. Stephen Hawking...uses a keyboard to communicate, so according to one philosopher [Sandy Stone] he's not entirely human anymore: 'Where does he stop? Where are his edges?'[8]

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[4] Haraway, *Simians, Cyborgs, and Women*, 149.

[5] Haraway, *Simians, Cyborgs, and Women*, 178.

[6] N. Katherine Hayles, *How We Became Posthuman: Virtual Bodies in Cybernetics, Literature, and Informatics* (Chicago: University of Chicago Press, 1999), 115.

[7] Chris Hables Gray, *Cyborg Citizen: Politics in the Posthuman Age* (New York: Routledge, 2001), 24, 190.

[8] Bill McKibben, *Enough: Staying Human in an Engineered Age* (New York: Henry Holt, 2003), 163.

Rather than evoke disability as metaphor, as is common in theory and literature, these examples instead locate disability in materiality without actually grounding this assumption in research.[9] What is especially unfortunate about these brief, uncritical uses of disability is that this is often the only place where disability appears in this conversation. If people with disabilities are the forerunner cyborgs or posthumans, as so many suggest, why is disability marginalized in this scholarship?

Scholars who presume what the relationship between technoscience and disability entails fail to consider how advances in science and technology increasingly stigmatize people with disabilities.[10] As the biotech industry continues to strive for "cures" and technological "fixes" to correct bodies, high-tech normalcy comes before more practical innovations that may still leave the body appearing disabled, though less impaired. The meanings of disability and impairment are changing with each innovation, as the pressure for normalcy heightens.

Some disabled public figures have wholeheartedly embraced a high-tech identity, such as John Hockenberry and Christopher Reeve. Yet, many others have not, but their voices are less frequently heard outside of disability scholarship and the disability rights

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[9] David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: University of Michigan Press, 2001).

[10] I use Donna Haraway's deployment of "technoscience," which she defines as a:

> Condensed signifier [which] mimes the implosion of science and technology into each other in the last two hundred years around the world… [it designates] dense nodes of human and non-human actors that are brought into alliance by the material, social, and semiotic technologies through which what will count as nature and as matters of fact get constituted.

With recent innovations in science and technology that increasingly impact cultural understandings of the body and everyday life, Haraway's usage of "technoscience" is incredibly useful, demonstrating that current science cannot be separated from its practical implications in technology, and nature cannot be separated from culture.
Haraway, *Modest_Witness@Second_Millenium.:FemaleMan©_Meets_ OncoMouse™: Feminism and Technoscience* (New York: Routledge, 1997), 50.

movement. For example, Simi Linton describes in her memoir, *My Body Politic*, her concerns about switching from a manual to a power wheelchair, comparing this transition to when Bob Dylan went electric.[11] A to-the-point paragraph out of Georgina Kleege's book, *Blind Rage,* offers a similar perspective, as Kleege states, "Many of us [people with disabilities] are reluctant to be too dependent – the power goes out, batteries run down, things get wet or fall on the floor…. Also, there's a problem of perception, the fear that our reliance on machinery makes us seem less fully human, part machine."[12] In an interview I did with a college student who uses a wheelchair, she voiced analogous concerns about innovations in wheelchair design that are too high-tech, explaining, "I just don't think they [able-bodied engineers] realize how much one has to physically rely on the technology, and it's scary to rely on technology like that." While these quotations say nothing about whether or not relying on technology as a disabled person makes you identify with the "cyborgian," they certainly suggest that we would be remiss to oversimplify and take for granted a celebration of the post-human for all people with disabilities.

A wider trend in rehabilitation therapy points to a fraught relationship between people with disabilities and technology. Previously referred to informally as "gadget intolerance" before any substantive research was conducted, rehabilitation therapists have documented a trend called "technological abandonment." Anywhere from 20% to 50% of the assistive technology devices distributed by rehabilitation professionals to people

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[11] Simi Linton, *My Body Politic: A Memoir* (Ann Arbor: University of Michigan Press, 2006), 173.

[12] Georgina Kleege *Blind Rage: Letters to Helen Keller* (Washington D.C.: Gallaudet University Press, 2006), 183-184.

with disabilities are discarded or never put to use, sitting in closets and collecting dust.[13] While stories of Oscar Pistorius and others enthusiastically praise what technology can do for impaired bodies, many with disabilities are less than enthusiastic about adopting technologies themselves. If people with disabilities are supposedly the forerunners of technologically enhanced bodies, what do we make of the fact that so many people are clearly uncomfortable with or even tossing out assistive technologies?

The answer, I suggest, lies in the fact that the stories we tell about people with disabilities are more directive than reflective. My project will not attempt to solve technological abandonment nor will it try to explain the psyche of people with disabilities using technology. Rather, I will argue in the chapters that follow that when we look to people with disabilities as the "forerunners" of technologically-dependent bodies, the stories we tell are off; they are about hegemonic, cultural values and norms, not accurate descriptions of disabled communities and bodies. Through these stories, technology and disability are co-constructed. In other words, when we think of technology, we use images of disability to celebrate what technology can do, and when we think of disability, we use images of technology to celebrate what people with disabilities can do.

I follow these stories across multi-sited cultural homes to show where a similar narrative repeats and to suggest the cultural function it serves. I have considered two related research questions throughout the project. First, where and how does hegemonic U.S. culture promote an understanding of disability as an imperfection to be corrected through technoscience and as a sign of technoscience progress? Second, is this story just

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[13] David B. Gray, Louis A. Quatrano, and Morton L. Lieberman, eds., *Designing and Using Assistive Technology: The Human Perspective* (London: Paulh Brookes, 1998), xix.
Marcia J. Scherer, *Living in a State of Stuck: How Assistive Technology Impacts the Lives of People with Disabilities* (Ann Arbor: Brookline Books, 2005).

about disability or is there something bigger at stake, underlying the popular interest in technology for people with disabilities?

A personal connection to disability and assistive technology brought me into this project, pushing me to confront my own ableist assumptions about what the body should do and what technology can do for it. I grew up with a mother living with Multiple Sclerosis (MS), a degenerative disease. Because she has lived with MS since before I was born, the adoption of assistive technologies into her life serve as benchmarks in my memories. Each new device increased my awareness of the fact that she was disabled: her first cane, then two canes, a walker, a motorized scooter, and eventually a wheelchair. Yet, when she started using a new piece of equipment, it caused a boost in her mobility, even though it made her appear more disabled to others. At first, I questioned why she didn't embrace the devices sooner, jumping straight to the motorized scooter to move at a faster pace. But she explained the anxiety she felt accepting her dependency on these devices, primarily because once you do, you can't go back. In our high-tech culture, this belief is not something we often encounter – we want the body to do more and we rely on technology to expand our capabilities, flaunting our latest gadget to our friends. But as I have learned through this project, assistive technology devices have different cultural meanings written upon them, tied to why technological abandonment occurs. For able-bodied people like myself, this is at first hard to understand but a valuable lesson that can help all of us adopt a more conscious relationship to the devices we use.

Disability and the Techno-Makeover:

A common thread throughout these stories lies in what I coin the "techno-makeover": a celebration of disabled bodies remade and "corrected" by technology and science in pursuit of high-tech normalcy. At times, the techno-makeover occurs through the gift of new technologies that can externally aid the body, such as wheelchairs or prostheses, and at other times the techno-makeover is more invasive, consisting of surgical procedures, which normalize deformities or impairments. The disabled body without technology is cast as techno-needy, encountering numerous obstacles and suffering. When technology intervenes, these problems disappear. The techno-makeover only addresses the individual; for example, providing architectural changes to a building that was previously inaccessible, putting in an elevator, and other social changes would not constitute a techno-makeover.

Calling this a "techno-*makeover*" references the abundance of television programs in which someone receives an ambush makeover — typically of new clothes, make-up, and hair — accompanied by instruction of a "proper" way of dressing or behaving.[14] While some people with disabilities play an active role in seeking out the techno-makeover, many of the stories focus on the techno-makeover as a charitable gift or a process through which the disabled makeover recipient is passive, requiring an able-bodied benefactor to make it possible. When the techno-makeover is complete, we are to assume that all of the person's problems have been resolved through technological means. The "techno-makeover" suggests that technological progress will bring with it social progress, forwarding an individualist model in which disability must be dealt with on the individual level through technological consumption.

In order to suggest that the technological fix is enough, "disability" in the techno-

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[14] For example, programs such as *Ready to Wear* and *Ambush Makeover* teach makeover recipients how to dress or carry themselves as unsolicited advice.

makeover story is really more about impairment, meaning the physical body and what it cannot do because of a biological condition, rather than disability, which includes the sociocultural factors in which a person is excluded or marginalized based upon inaccessible environments and discriminatory attitudes.

This impairment/disability split has long been used to articulate how disability is a social and political phenomenon (the "social model") in contrast to the mainstream lens through which disability is typically understood in the United States, where disability is synonymous with impairment, a deficit resulting from one's physical body alone (the "medical model").[15] In other words, a paraplegic may live with impairment but is not disabled until encountering the first staircase of the day. However, the field of disability studies has shifted away from these clear distinctions between disability and impairment because theories of social constructionism failed to recognize that some impairments are deeply significant in embodied ways that a fully-inclusive society would not eliminate.[16] Pain and fatigue, for example, cannot be written off as socially constructed. In addition, the impairment versus disability divide assumes that impairment is free of social construction when in fact it is also shaped by what medicine defines as an impairment and what cultural contexts shape what impairments get recognized.[17] My work adds to this conversation and explores the blurred lines between impairment and disability.

Assistive technology through the techno-makeover typically shifts what the impaired body is capable of to minimize impairment. Because impairment has been

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[15] John Gliedman and William Roth, *The Unexpected Minority: Handicapped Children in America* (New York: Harcourt Brace Jovanovich, 1980), 13-30.
[16] Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), 35-56.
[17] Ian Hacking, "Making Up People," *The London Review of Books*, 28:16 (2006): 23-26.

reduced, the techno-makeover narrative celebrates that all is now well for the disabled subject. When social discrimination is addressed, although it rarely is, the stories suggest that technological cures to the impairment will make these problems go away. The post-techno-makeover body may be free of impairment (or impairment has been greatly reduced by the help of technology), but the body still looks different than an able-body, and therefore, is still likely to experience being “disabled” through stigma.

The site of the techno-makeover helps bring about an intervention in both disability studies and science and technology studies, demonstrating the central importance of the disabled body/machine interface to both fields. Recent attention in science and technology studies to the body, especially from a Foucauldian approach, has initiated a debate over whether the technological body is a new means of body regulation or a site of transcendence from our bodies’ weaknesses. This work has helped me to develop and theorize much of my work, but disability has been misunderstood, as introduced above in regards to Haraway and others’ theories, a footnote in works that generally treat “the body” as an able body. Conversely, an examination of technology as cultural objects and technoscience as a source of power over the body has been largely absent in disability studies. This scholarship is especially relevant today, as new technologies such as cochlear implants to bionic eye implants offer to “cure” impairments previously thought incurable, changing the boundaries of who constitutes “people with disabilities.” Disability studies has long situated medicalization as the primary process through which normalcy and disability are made, but the walls between the hospital and the laboratory are more porous than they used to be. By blending disability studies with science and technology studies, this project demonstrates the productive overlap of these two fields, as it is undeniable that the disabled body does heavily rely upon technology, just not in the simplistic and homogenized way we think.

In addition to these scholarly approaches, looking at the techno-makeover is greatly influenced by the disability rights movement and disability activism. While the specifics of the movement have changed, much of the central concern has remained the same: society needs to change, and individual people with disabilities are not the problem. By eliminating discriminatory attitudes and inaccessible environments, disability equality can be achieved, and conforming to normalcy is not part of this equation. Disability activists have celebrated their bodies and physical differences, "crip pride," pushing back against assumptions that they should see their bodies as shameful. Yet since the passage of the Americans with Disabilities Act in 1990, progress has been slow; many public spaces and businesses remain inaccessible, and discrimination still looms large. It is entirely possible that if the disability rights movement was gaining more ground, then the techno-makeover would be a less popular narrative.

To make matters more complex, many people with disabilities do not buy into the ideology of the disability rights movement. Even some high profile people, such as Christopher Reeve, have publicly spoken out against it, arguing for cures to the body instead of social change. Many strive for normalcy and technological fixes above all else. In fact, most of the people who appear throughout this work illustrate this perspective, participating in the narrative that celebrates the techno-makeover for making all wider problems of disability injustice disappear overnight.

Many will ask why we cannot have both: techno-makeovers for those who want them but also disability rights and equal access. A fair question, except that currently, the discourse of the techo-makeover situates itself as diametrically opposed to disability rights. The stories of the techno-makeover, as I will show, suggest that technoscience for the individual can make disability rights obsolete, doing great harm to the movement, but also to the individuals who will always be disabled, regardless of technoscience innovations. If the reach of the disability rights movement was extended, the stories of the techno-makeover would lose much of their power – the narrative works precisely because it assumes social equality is out of the question.

Overview:

In the first four chapters, I pick up unique cultural sites in which some variation of the techno-makeover occurs, using different methods to extract the stories. The narratives, like the sites, vary in distinct and important ways, but there is also extensive convergence, and so part of my research agenda aims to illuminate the pervasiveness of this repeated understanding of disability and technology.

In my first chapter, "What Makes Do-Good T.V. So Good?: Popular Culture and the Techno-Makeover," I analyze the genre of "do-good" television, where "reality" programs focus on generosity and heartwarming stories. These stories frequently rely upon people with disabilities as a motivating source for "doing-good," in line with the ongoing trope of people with disabilities as either pitiable (for having a disability) or inspirational (for triumphing in spite of a disability).[18] Disabled subjects are put forth as techno-needy such that able-bodied benefactors, and often corporate sponsors, can generously donate technology for a techno-makeover. I trace the emergence of people

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[18] Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1993), 12-40.

with disabilities back to “do-good” television programs in the 1950s, namely *Queen for a Day*, but interestingly, these early shows went out of fashion, seen as exploitative. I look to the reemergence of “do-good” television in the 2000s, where disability plays a similar role as it did in the 1950s, and pursue the question: why do these stories rely on disability so frequently and what understanding of disability and technology do they promote? I provide examples of disability and the techno-makeover from *Extreme Makeover: Home Edition*, *Miracle Workers*, *Three Wishes*, and the *Oprah Winfrey Show*.

In my second chapter, “‘Developing’ Nations and ‘Undeveloped’ Limbs: The Techno-Makeover Reaches the Global South,” I show how the techno-makeover extends past nation-state borders. I look at popular media coverage of people with disabilities in poverty from the Global South who are invited into the United States to receive a techno-makeover as a charitable gift. These stories are quite common; conjoined twins born anywhere in the world, for example, are practically guaranteed an invite into the United States if separation surgery appears to be possible. To demonstrate the common narrative that appears, I offer three case studies: the first, a young man named Emmanuel Ofosu Yeboah who comes to the United States from Ghana; the second, Flory Tacle, a young woman from the Philippines; and the third, Juan Zapot, a toddler from Mexico. All three undergo surgical procedures that allow them to return to their home countries with state of the art prostheses. The disabled body without technology is cast as a worthy enough cause that Americans simply *must* interject, and the combination of disability with racial and national otherness allows for old tropes to be rejuvenated. As the disabled body of the poor Global South becomes modernized, due to U.S. technological superiority, it celebrates the benefits that Western technology will bring, sanitizing the rising concerns that U.S. involvement may cause harm. Physical deformities help bring people into the United States, and the techno-makeover is brought back as remittance.

In my third chapter, "Bringing Disability Back from the Future: Michael J. Fox and the Debate over Embryonic Stem Cell Research," I shift from technology to scientific research, yet still the techno-makeover plays a key role in garnering support for scientific freedom and development. I focus on media and political discourse surrounding Michael J. Fox's active role stumping for candidates who strongly support embryonic stem cell research. In particular, I look at the fallout that comes from Fox's campaign ads in 2006, a viral sensation on YouTube. While Fox visibly shakes, a common symptom of living with Parkinson's disease, he makes his case for stem cell research and urges voters to support candidates who are pro-stem cells. As I follow the surprisingly large role Fox's ads played in the political sphere, I suggest that the image of Fox's tremoring body helped give urgency to the stem cell debate, often at the cost of fairly representing life with a disability. As media and political discourse became focused on Michael J. Fox, several important issues surrounding stem cells and a more critical and complex understanding of disability were marginalized or nonexistent in the conversation, even going against some of Fox's own words explaining life with his disability. Fox, as an iconic image of disability, helped usher in support for stem cell technology, co-constructing disability and stem cells through this cultural moment.

In my fourth chapter, "Not Seeing Eye to Eye: The Rise and Fall of the iBOT," I show how the common understanding of people with disabilities as forerunner cyborgs has even influenced the devices designed for people with disabilities, especially clear in the case of the iBOT wheelchair. Invented by Dean Kamen, a famous inventor best known for the Segway human transporter, the iBOT celebrates a normalized understanding of disability, where the individual must change by way of technology rather than promote broader social changes. As the device plays up its robotic appearance, the designers, sellers, and media all took for granted that wheelchair riders would embrace the iBOT and the techno-makeover that was being sold along with it. Yet, the iBOT failed to garner enough support to stay on the market, in part because health insurance would not subsidize such a pricey device but also due to the fact that many would-be iBOT users were not enthusiastic about using such a high-tech, robotic machine. A closer examination of the rise and fall of this invention adds to science and technology studies conversations over the role of the inventor in constructing what can never be a "neutral" device. While the inventor wanted to offer techno-makeovers through the iBOT, this was not enough for the device to thrive, a ramification of the misleading understanding of disability as techno-needy.

My fifth and final body chapter, "Window Shopping at the Mall of Handicapitalism," looks at the assistive technology device industry through ethnographic research conducted at the Abilities Expos, large tradeshows for rehabilitation professionals, medical device vendors, and people with disabilities and their families and friends. This chapter expands upon the proceeding chapter by showing the limitations of the assistive technology industry. However, participants use the expos as a place to shape the assistive technology industry. In addition, the Abilities Expos have become a place where many people with disabilities can find empowerment and access technology that does not have to correspond with normalcy, resisting the techno-makeover. Disabled attendees come to the Abilities Expos to learn about technology and strategize how to gain access to the device that is best for their needs and desires.

Whereas my first four body chapters are primarily focused on illustrating popular representations of disability with technology, this final chapter continues this thread while also putting the people more centrally into the story. My work at the Abilities Expos brings to light a more complex understanding of how people with disabilities use technology — greatly stratified by minimal access to devices controlled by healthcare; shaped by one's personal identity and physical needs; and varying with one's comfort-level with high-tech dependency. While the Abilities Expos are a space of empowerment in many important ways, they are ultimately limited, as their inseparability from a commercial market continues to leave many people with disabilities in a powerless state. Because stories of the techno-makeover focus on the charitable gifting of assistive technology, it obscures the important fact that the medical device industry is an expanding industry in which profits dominate, making it difficult for many to get the devices they would most like.

Finally, in my conclusion, I suggest the implications of the pervasive disability techno-makeover trope for emerging biotechnologies and the role disability will play in ushering in controversial technologies on the horizon. While my methods and sites of study vary from chapter to chapter, these pieces come together to show what a central role disability plays in discourses of technology and in iconically representing technological progress. To chase this story down entailed a search from pop culture to science policy to an assistive technology engineering lab with many other stops along the way, but in its wide reach, the project gains importance.

Three Central Themes:

To answer my overarching questions — how does hegemonic U.S. culture promote an understanding of disability as an imperfection to be corrected through technoscience and is there something bigger at stake in the narrative's retelling? — my argument frequently returns to three central themes.

First, the techno-makeover is about promoting a narrative in which individualism is celebrated and maintained through technological solutions, suggesting that disability is a problem of individual impairments rather than social structure. Whereas the disability rights movement has called for interdependence over independence, these stories celebrate those who can use technology to no longer be a social "burden," upholding the liberal, individual subject.

Second, the techno-makeover is about normalcy, dictating that the high-tech disabled body is better than the disabled body without technology, even if both function at the same level. But only certain types of bodies and people get access to the techno-makeover, for "normalcy" is bigger than disability; as disabled subjects undergo the techno-makeover, the narrative plays up the fact that they can now embrace "normal" in other ways, tied to race, gender, and national identity. The techno-makeover is not fully successful unless physical normalcy accompanies social normalcy.

Third, these stories are all greatly supportive of capitalist, market solutions to disability inequality. This narrative falls in line with a contemporary context where social services have been steadily chipped away at with hopes that the market will instead provide services, purchased by the individual. The techno-makeover suggests that care, in the form of technology, will come for people with disabilities through individual benefactors, corporate sponsors, or technological consumption by people with disabilities themselves. People with disabilities have historically been excluded from capitalism, widely seen as the objects of charity – incapable of participating in the market as laborers. Therefore now, the narrative suggests, empowerment is about purchasing power and ownership of technological commodities. While the recent rise and diversification of the assistive technology industry celebrates "handicapitalism," an effort to recognize people with disabilities as consumers, higher poverty rates among people with disabilities restrict consumption, made worse by tremendous device markup in the industry. Yet the limits to the market go unaddressed in the techno-makeover story.

Together, these themes provide many important contributions to how we think about the body, technology, popular representations of science and technology, and the hegemonic work of preserving normalcy, even as changes in technology and science are constantly altering what normalcy might be.

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Celebrations of the techno-makeover are deeply influential in shaping cultural understandings of both disability and technology, but the effects are bigger than they first appear. Disability is being called upon to iconically represent what technology can do for the body to sanitize the public image of technology and circumvent some of the more critical questions that we need to be asking about technological enhancement: will technological enhancement make us happier or just further oppress everyone under the "tyranny of normalcy," as the bar for what's "normal" is optimized?[19] Who will benefit from technological enhancements and emerging biotechnologies and who will continue to

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[19] Lennard J. Davis, "Constructing Normalcy," in *The Disability Studies Reader,* ed. Lennard Davis, (New York: Routledge, 1997), 9-28.

be excluded or exploited to make technology possible for the privileged? I suggest that we like to tell these stories of disability and the techno-makeover because they make the viewer feel good — about the country, about technology, and about where we are heading — as an even more technologically advanced future looms near.

The techno-makeover story is put forth as a joyful celebration. Jack Brown on *Miracle Workers* can be "whole" again now that he has a new high-tech hand.[20] Emmanuel Ofosu Yeboah can return to Ghana and show off his state of the art prosthesis, covered in a pattern of American flags.[21] Some must wait for the techno-makeover; Michael J. Fox, for example, cannot be helped yet, but stories of the future techno-makeover circulate, promising that biotech cures are just barely out of reach. Even the assistive technology industry has picked up the story with some inventors crafting devices that promise a techno-makeover. Taken together, these seemingly disparate stories converge to show that disability plays an important role in signifying the good that technology can do. Simultaneously, technology helps suggest the good that people with disabilities can do, offering many a chance to assimilate into normalcy and become "productive citizens," as one techno-makeover story puts it.[22]

Yet, these narratives are at best limiting, and at worst misleading and exploitative of desperate people who turn to the techno-makeover because the social structure has failed them. It is a mistake to claim that people with disabilities are the "forerunner cyborgs" because it misses the fraught relationship many hold with technology and the profound stratification of access to assistive technologies. To speak about the disabled

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[20] *Miracle Workers*, "Brown/Valentino," Episode 4, first broadcast on March 20, 2006 by ABC.
[21] Lisa Lax and Nancy Stern, Dirs. *Emmanuel's Gift*. Lookalike's Productions: 2005.
[22] Lax and Stern, *Emmanuel's Gift*.

body/machine interface cannot be done in a universal, homogenized way, and though many are eagerly awaiting techno-makeovers and cures, many others prioritize social change, which would eliminate or minimize the need for these individualized technological solutions. I lay out these narratives of the techno-makeover with the aim of bringing the underside of the techno-makeover to light.

Chapter 1:

What Makes Do-Good TV So Good?: Popular Culture and the Techno-Makeover

In Katherine Dunn's novel, *Geek Love*, a character named Ms. Lick pays conventionally beautiful women, often erotic dancers, to get operations that give them a minor deformity such that they will no longer be trapped into being solely beautiful and can learn to be smart and successful instead.[23] Although undoubtedly bizarre, the real strangeness comes from the fact that Ms. Lick not only wants to provide these surgeries, but she also insists that she be allowed to watch, even recording footage of the surgeries so she can view them over and over. It is not enough to give the "gift"; it must be captured and viewed. I introduce the fictional character of Ms. Lick to make strange a non-fictional practice that is quite common: the public voyeurism of the techno-makeover. Although the techno-makeover of course goes the opposite direction of Ms. Lick's projects, instead removing physical anomaly to bring someone up to normalcy, the sheer number of opportunities in U.S. popular culture for watching these transitions occur suggests that Ms. Lick might not be so bizarre after all.

Disability is often something people think about when it is thrust upon them after they suddenly acquire an impairment from an accident or illness. For someone without a strong safety net already in place, acquiring an impairment can be economically catastrophic – you can lose your job, your ability to pay bills, and sometimes, the possibility of living in your own home. Though there are some structural supports to prevent this, many people fall through the cracks and find themselves in hopeless

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[23] Katherine Dunn, *Geek Love* (New York: Vintage, 1983).

situations. With nowhere else to turn, reality television comes to the rescue. Shows like *Extreme Makeover: Home Edition* (*EM:HE*) offer a way out for a few fortunate families down on their luck, specifically unable to live in their home because of life with a disability. As viewers tune in every week to watch these stories of woe and then the escape from hardship, the techno-makeover is front and center, providing feel-good stories that celebrate technology and its ability to normalize lives. What's at stake when we watch these programs and are moved to tears by these stories, week after week?

EM:HE is just one example of a wider genre of reality programs centered on people with disabilities accepting technology into their lives. T*he Oprah Winfrey Show* included episodes under the theme, "Dr. Oz Explores Medical Mysteries," featuring people with disabilities receiving medical technology. In 2005, a show called *Three Wishes* provided a spin-off of ABC's *EM:HE* on the rival network of NBC, where the show traveled to a town each week to grant three deserving town members' special wishes, often selecting people with disabilities in need of technology. Similarly, *Miracle Workers* was introduced by the producers of *EM:HE* in 2006, documenting charity-donated surgeries and medical technologies given to people with disabilities or illnesses.

In this chapter, I extract the cultural messages underlying the trope of the disabled body being enhanced by technological interventions, looking to contemporary popular culture. This trend spans from intrusive technologies, such as bionic arms and conjoined twin separation surgeries, to external enhancements, such as computer technology and household elevators. In addition, these images are not limited to one type of disability, though virtually all are physical impairments, allowing the viewer the visual satisfaction of watching the body's external transformation. Since occasionally these stories are about alleviating pain, more complex as the "cure" in these cases is less clearly linked to normalization, I restrict my focus to examples of normalizing procedures that serve the primary purpose of minimizing physical anomalies. Yet even excluding those procedures where pain is the primary motivation, there is a great range of physical anomalies receiving techno-makeovers to observe. These cases also vary in levels of mainstream success. Of the current television shows, *EM:HE* and *The Oprah Winfrey Show* are by far the most successful, whereas *Three Wishes* and *Miracle Workers* have both gone off the air. Even when a show failed to bring in enough viewers, there is still something worth noting about its themes, for they only failed because they were not as good at making a widely accepted narrative into entertainment. The cases further vary with regards to the disabled subjects' race, gender, and nationhood, and throughout my analysis, I theorize how post-makeover physical normalcy goes hand in hand with social normalcy.

Deconstructing these various media celebrations of the disabled body combined with technoscience helps illustrate the wider cultural messages of this techno-makeover discourse. First, we are directed to both pity the disabled makeover recipient and also respect their perseverance in the face of adversity, perhaps even inspiring us. Yet, both representations maintain traditional and limited representations of people with disabilities. Second, the iconic power of the disabled body in need neutralizes the technologies shown as well as the many corporations intertwined with these stories. From subtle product placement to direct intervention in funding the technological enhancements given to people with disabilities, these programs suggest that the free market, not the state, will solve our social problems through benevolent corporations and private benefactors. The benevolence of the techno-makeover, and the feel-good stories celebrating it, help moralize capitalism, technology, and the medical institution, using disability to garner support for these sometimes questioned sites of power. And finally, the post-makeover recipient with a disability comes to stand as a hero for us all, providing a clear message that celebrates technology for helping people with disabilities maintain autonomy. Through each of these four elements to the techno-makeover narrative, the solution to "the disabled problem" is always a technological product or procedure that can be bought, supposedly eliminating all social and physical struggles.

Because there are similarities and overlap with all the reality shows discussed here, I call upon each program to highlight a distinct component of the disabled techno-makeover in U.S. popular culture. Together, these cases suggest that U.S. popular culture has played a key role in promoting technology as a moral solution to disability, also strengthening the cultural perception of technology and capitalism through the image of "doing good."

Determining the Miserable: *Queen for a Day*

Though there is definitely something unique about the surge of makeover television we see today, these shows are not without historical precedents. *Queen for a Day* and *Strike It Rich!* were both immensely popular television game shows of the 1950s, known as "misery shows." These programs determined and then rewarded the most "miserable" contestants, providing an opportunity to alleviate their troubles through material consumption or money. Like the contemporary examples, these shows never claimed to focus on disability, yet disability frequently emerged as a site of misery.

When disability appeared, it was not just any reward desired but rather specific technological interventions to the disabled body, a wheelchair or hearing aid, for example. Although several scholars have written about the 1950s misery show genre, the predominant role of disability in classifying the miserable has not been examined. Instead, the work has focused on gender and consumerism post-war, only addressing disability to say that sickness and disability helped make the contestants appear especially miserable.[24] I look briefly at *Queen for a Day* to understand the historic roots of techno-makeover television today. From its outset, this genre was about more than disability; the disabled body gets a technological intervention, immediately followed by the woman receiving a washer and dryer – the two cannot be separated.

Beginning as a popular radio show in 1948, *Queen for a Day* first aired on television in May 1957 to the West Coast. Q*ueen for a Day*, hosted by Jack Bailey, brought in hundreds of women to be in the audience for the filming, who were asked to write down their most tragic stories, as well as a wish that they would like to see granted if chosen as the episode's "queen." The producers then narrowed it down to four women, who would appear on the show and share their stories with Bailey's guidance. The wishes were rarely selfish; if the contestant served to gain from the wish, it was only because the gift would allow her to be a better caregiver and housewife. After hearing all the tearjerker stories, the audience got the final word, clapping for the applause-o-meter to select the most deserving contestant. The three unsuccessful contestants were quickly

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[24] Marsha F. Cassidy, *What Women Watched: Daytime Television in the 1950s* (Austin: University of Texas Austin, 2005).
Amber Watts, *"Queen for a Day:* Remaking Consumer Culture, One Woman at a Time," in *The Great American Makeover: Television, History, Nation*, ed. Dana Haller (New York: Palgrave Macmillan, 2006), 141-157.

escorted off the stage, and the queen was overwhelmed with gifts, from a new wardrobe to new household appliances, as well as the promise that her specific wish would be fulfilled. Additionally, she was immediately whisked away for a special outing after the filming, treating her like a queen by pampering her in a spa or taking her to a fancy Los Angeles restaurant or movie opening. In total, the queen's prizes amounted to roughly $2,000 each episode.[25] By 1960, the show prided itself on having given away 2,282 washing machines, 918 vacuum cleaners, and 1,334 refrigerators, adding up to over $1,200,000 a year.[26] An early instance of product placement, the show gave away so much because the more they gave out, the more they brought in from advertisers, and the image of "helping the miserable" certainly helped sell the products in return.[27]

As media scholar Amber Watts has theorized, *Queen for a Day* helped reinforce cold war culture, promoting an image of femininity that was consumer-minded and domestic. Though many queens did not represent the "ideal" woman of the time, including poor, working women, women of color, women having children out of wedlock, or widows, the show suggested that through this brief taste of consumerism and the granting of their wish with a material product, a queen's life could be improved, one step closer to the model of femininity.[28] For this reason, most women selected to appear on the show had asked for a wish which would allow them to be better mothers, wives, or daughters in line with their proper domestic, caregiver role, and Jack Bailey also helped to extract this narrative by strategically guiding the interviews in this direction.

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[25] Watts, "Queen for a Day," 150.

[26] "Jack Bailey Mesmerizer of the Middle Aged," *TV Guide*, March 11, 1961.
"The Stuff that Tears are Made of," *TV Guide,* June 22, 1957. Cited in Amber Watts, "*Queen for a Day,*" 154.

[27] Cassidy, *What Women Watched*, 194.

[28] Watts, "Queen for a Day," 145.

Additionally, all the prizes given to the queen helped her become a "better woman" through technological interventions and consumption. From a new washing machine and kitchen to a new wardrobe of dresses and jewelry, the queen got made over in such a way that helped viewers learn how postwar femininity could be bought and consumed.[29]

But who were the "worthiest"? As television historian Marsha F. Cassidy points out, even though the audience was made up of women, their applause rewarded the contestant who best reflected the "rules of patriarchy."[30] Yet, disability repeatedly factored into women's stories in ways that boosted their chances of being selected as the queen, and thus the most miserable and therefore worthy. Disability appeared so frequently on the show that some episodes had more than one contestant share a disability-related story, then leaving the audience to look to the specifics of the disability to determine who was more deserving. For example, one episode featured contestant #1 whose son had Cerebral Palsy, asking for a wheelchair and a special exercise bike, which she failed to give him because she had to have an operation on her leg, rendering her temporarily disabled; contestant #2 had triplets, but one was a "little slower" and required special care, so she asked for diaper service; and contestant #3 requested a vacation, after caring for two "handicapped" sons, an elderly woman in a wheelchair, her parents, and her husband, all deceased.[31] The fourth contestant, who asked for a set of bunk beds to house her son's military friends during their leaves, received the lowest amount of applause. The winner? Contestant #1, who received an Everest and Jennings wheelchair

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[29] Marsha F. Cassidy theorizes how *Queen for a Day* was both empowering for women, as it created a feeling of solidarity, yet disempowering, as it showed them heightened expectations for women's conformity.

[30] Cassidy, *What Women Watched*, 120.

[31] *Queen for a Day: The Only Surviving Episodes of this TV Classic,* Disc 2, Episode 1, (First Look Pictures: 2005).

(a state of the art model during this time period) and a specialty exercise bike for her disabled son, as well as an array of prizes for herself, even including a Jamaican vacation. Though the first three women all introduced narratives that connected with disability as well, Contestant #1 introduced a problem that had the most clear-cut technological solution.

Another episode featured a contestant whose son recently had a brain tumor removed so she requested special educational toys and a dog for her son, and a second contestant, selected as the queen, wished for a special Wilcott bed for her paralyzed brother, who was mistaken for another person and shot eight times. Coincidentally, this episode featured a brief check-in from a past queen, who had received an electric bed for her disabled husband, all the while playing "When You Wish Upon a Star" from Disney's *Pinocchio,* an appropriate selection given Pinocchio's wish to become a "real boy." Again, physical disabilities that can be improved by technological means trump non-disability related wishes, as well as cognitive disability needs, which did not lend themselves to easy technological fixes. From 137 hearing aids to numerous wheelchairs, electric beds, and prostheses, *Queen for a Day* contestants were rewarded not only for conforming to patriarchy, but also for privileging disabled bodies receiving technology.[32] The woman most deserving of charity was often the contestant asking for help in returning her disabled family member to normalcy, and thus allowing her to more fully represent the culturally-defined, "ideal" woman.

David Serlin traces the significance of celebrating late 1940s and early 1950s rehabilitation technology in his book *Replaceable You: Engineering the Body in Postwar*

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[32] Watts, "Queen for a Day," 154.

America.[33] He shows that as socially deviant bodies came to be seen as a threat to the nation, the rehabilitated body provided a symbol of American nationalism; the disabled body normalized with medicine and technology, for example, was a sign that the United States could be successfully rehabilitated postwar as well. *Queen for a Day* participates in the popular American discourse Serlin uncovers, but as feminized nationalism. While Serlin shows disabled veterans being rehabilitated and interpellated into this nationalist discourse, *Queen for a Day* shows how women could participate as well; to be a good caregiver was to help your disabled family members strive for normalcy by welcoming technological interventions into their body and home. While she made this happen, she would receive her own technological makeover, getting a new fridge or a washer and dryer, both serving in their own ways as national projects as they celebrated postwar consumerism and thus anti-communism.

The show needed stories that were compellingly sad, but not too sad (for example, a woman who wanted a divorce from her husband because he attempted to rape their six-year-old daughter did not make it onto the show).[34] The disabled body-to-be-rehabilitated provided the perfect amount of sadness for the show's exploitation of misery to work because the misery could be quickly alleviated through the technological gift. *Queen for a Day* does not show the disabled body post-wish, as it is not really about helping people with disabilities, but rather their female caregivers. Disability, then, provides an ideal quantifier of worthiness (synonymous with miserableness) and offered

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[33] David Serlin, *Replaceable You: Engineering the Body in Postwar America* (Chicago: University of Chicago Press, 2004).

[34] Howard Blake, "An Apologia from the man who produced the worst program in the TV history" in *American Broadcasting: A Source Book on the History of Radio and Television,* eds. Lawrence W. Lichty and Malachi C. Topping (New York: Hastings House, 1975), 418.

a significant narrative through which to promote postwar femininity and consumerism.

Despite the show's popularity, *Queen for a Day* was not without criticism during its heyday. Television critics repeatedly labeled *Queen for a Day* "lowbrow" and criticized it for exploiting human suffering. *New York Times* journalist Jack Gould was the lead critic of both *Queen for a Day* and a similar misery show, *Strike It Rich!*. When *Queen for a Day* first aired on NBC, he wrote, "The awfulness lasted 30 minutes. Pray, what hath [the interim president of NBC] Sarnoff wrought?" and later made several attacks on the misery show genre on the grounds that "the crises that occur in the lives of individuals must not become grist for the morbid mill of TV."[35] Host Jack Bailey responded to critics, "We're always accused of running a crying show. Very few gals cry on this show. O, they cry after they're elected queen, but that's good…. I'd say their wishes are more human than sad…. It's not what they want but why they want it."[36] In the end, the critics persuaded the network that these shows were in bad taste, bringing the misery genre to a temporary end in the 1960s. But the misery show did not go away for good.

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On January 16, 2006, the *New York Times* pointed out a new trend within the reality television genre, calling it "do-good television," referring to shows that provided a break from the other "mean-spirited" reality programming.[37] Just as in *Queen for a Day*, disability plays a key role in the "good" that these shows offer. In this genre, much of the

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[35] Jack Gould, "TV Review: 'Queen for a Day' is Not for Crowning" *New York Times,* January 6, 1956, 47. Cassidy, *What Women Watched*, 105.

[36] John Fink, "Keeps His Sense of Humor Amid the Tears," *Chicago Daily Tribune,* August 17, 1957, C22.

[37] Adam Sherwin, "Now Reality TV Appeals to the Sick - with Hope of Miracle Cure," *The Times*, February 1, 2006, 27.
Laurie Ouellette, "Do Good TV?" *Flow TV,* 3:12 (February 24, 2006) http://flowtv.org/?p=197.

misery show resurfaces, specifically visible in *EM:HE, The Oprah Winfrey Show, Miracle Workers*, and *Three Wishes*. Unlike *Queen for a Day*, we no longer see the other contestants that do not get help, though they are abundant. In addition, the current shows focus on what happens once the wish is granted, dividing the programs into the before and after.

Yet the central component of the misery show, where people share their stories of misery in exchange for financial or material gain, is undoubtedly still present, more clear-cut than before. Even though the format of *Queen for a Day* led many women to cry while diverging their stories of woe, host Jack Bailey often discouraged women from crying on the show, something he previously called upon to defend the program to critics.[38] Current programs, on the other hand, explicitly discourage participants from holding back, and the stories of woe are even more drawn out and upsetting. In addition, *Queen for a Day* and *Strike It Rich!* shared the stories of miserable people with disabilities, but did not show them on the program, finding the visual too off-putting for television.[39] Today, the programs frequently show people with disabilities, but this inclusion is hardly a sign of progress, as the visual is often deeply exploitative, looking at physically anomalous bodies with a freak show-reminiscent gaze.

Media scholars Laurie Ouellette and James Hay make further comparisons, "TV's foray into the helping culture is now more intensely aligned with the rationalities of deregulation and welfare reform…. Its interventions can be sanctioned as providing a

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[38] Fink, "Keeps His Sense of Humor Amid the Tears," C22.

[39] In *Queen for a Day*, people with visibly apparent disabilities were the recipients of the Queen's aid, but never the Queen. If disability was shown, it was in the form of a picture. In *Strike It Rich!,* when people with disabilities wanted a chance to win, they wrote the television show, detailing a story of woe and explaining something that would help their lives. *Strike It Rich!* then solicited the help of a celebrity or public figure to appear on the show as a surrogate for the disabled person in need. The host read the letter of the disabled wisher and sometimes briefly show a photo.

public service in ways that *Queen for a Day* and other precursors were not."[40] This point that do-good television celebrates its role in public service has particular significance for exploring the continuing presence of disability on these shows in a neoliberal climate. When reality television programs with frequently mentioned corporate sponsors are named the solution for those in desperate circumstances, it disregards the need for a social system to support the needs of people with disabilities. In the 1950s, governmental support was not yet on the table, but today, following the gains of social welfare programs from Lyndon B. Johnson's Great Society, there are some protections for people with disabilities, albeit minimal. Technology and medical science, more than before, are promoted as the individual solution, and corporations will facilitate the distribution of these techno-makeovers to those in need. Within this climate, the misery show has come back even stronger than when it started, still strengthened through the techno-makeover for people with disabilities.

The *Oprah Winfrey Show*: Medical Miracles for Miracle Children:

The *Oprah Winfrey Show* first appeared on the air in the United States in 1986, though in its final years on the air, it had spread to 141 countries.[41] The show's format varies with the topic at hand. From celebrity interviews and fashion shows to couples' therapy sessions and topic-focused panels on a controversial issue, Winfrey kept her ratings consistently high by repeatedly piquing interest, often calling upon heart-warming

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[40] Laurie Ouellette and James Hay, *Better Living through Reality TV: Television and Post-welfare Citizenship* (Malden, MA: Blackwell Publishing, 2008), 33.

[41] Deborah Epstein and Deborah Lynn Steinberg, "Love's Labours: Playing It Straight on the *Oprah Winfrey Show*" in *Border Patrols: Policing the Boundaries of Heterosexuality*, eds. Deborah Lynn Steinberg, Debbie Epstein, and Richard Johnson, (London: Cassell Press, 1997), 32.

or feel-good narratives to do so. In addition, Winfrey's format offered "more or less tidy packages, lasting not more than an hour, in which complex issues are, almost inevitably, reduced to simplistic explanations and 'quick fixes.'"[42] Within this format, the program provided another media site for misrepresenting disability as solely physical impairment and a deficit, where technological fixes could cure all. In particular, disability appears in episodes entitled "Dr. Oz Explores [Sometimes Investigates] Amazing Medical Miracles," or shows focused on "Miracle Children."

Part medical documentary and part daytime talk show, audience voyeurism of anomalous bodies is encouraged on the *Oprah Winfrey Show* without shame. But how is this justified? People with disabilities have a long history as the objects of voyeurism, from the stares of the freak show to the stares many receive daily, but there is often a false assumption that the freak show-type gaze is a thing of the past, now deemed culturally unacceptable if not exploitative. However, I follow the arguments of several disability scholars to show that elements of the freak show are alive and well in the U.S. media, though the terms of display have slightly changed.

Talk show scholar Andrea Stulman Dennett explains that the historic freak show, like current daytime talk shows, encouraged viewers to form a self/other dichotomy through viewing "freaks" and then forming an inner monologue that says, "I'm so glad that's not me!"[43] Media studies scholar José van Dijck similarly argues that the freak show remains, looking to medical documentaries to illustrate this. She writes, "The difference between the freak shows of the 19th century and those in our time is that the

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[42] Epstein and Steinberg, "Love's Labours," 33.

[43] Andrea Stulman Dennett, "The Dime Museum Freak Show Reconfigured as Talk Show," in *Freakery*, ed. Rosemarie Garland Thomson (New York: NYU Press, 1996), 320.

fat man himself no longer draws large crowds; it is now the filmed operation on the fat man that appeals to a large audience. We would be embarrassed to openly gaze at the physically challenged exposing themselves on a stage, but we eagerly watch televised recordings of their salvation by medical professionals.'"[44] Technology is now part of the draw, and yet also a justification for the gaze that predates the techno-makeover. Whether showing a woman with a bionic arm or the separation of conjoined twins, the *Oprah Winfrey Show*, emblematic of the wider techno-makeover genre, illustrates Van Dijck's postulation.

A 2005 episode introduced an array of children with intriguing medical conditions, but the story of the "mermaid baby" most clearly demonstrates the lasting freak show rhetoric of the techno-makeover. Introducing the episode, Winfrey states, "The video is shocking: a baby born with mermaid syndrome. Nobody thought she could live," and later, she leads into the segment with "Only two cases like this have ever been recorded in human history. Meet the mermaid baby." In fact, both children born with this condition have appeared on the program. Before the section even begins, it is clear that Winfrey's role parallels the dime show barker, whose job was to extract the story of the freak and bring in the audience by inviting their stares.[45] The story that follows continues this relationship, as the child's anomalous body is visually displayed in close detail.

Sara Aracuo and Ricardo Cerron were living in Huancayo, Peru, described by Winfrey as a place where "most people live a very simple life," a stereotypical

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[44] Jose Van Dijck, "Medical Documentary: Conjoined Twins as a Mediated Spectacle," *Media Culture Society*, 24 (2002): 538.
[45] Dennett, "The Dime Museum Freak Show Reconfigured as Talk Show," 321.

representation of non-Western village life through Western eyes.[46] After being together for four years, they decided to start a family, and after nine months of carrying the child, Aracuo went into labor. They planned to have the baby in their home but when the labor pains grew too intense, the couple rushed to a nearby hospital. After a difficult labor, Aracuo gave birth to a child with Sirenomelia, also known as "mermaid syndrome," so named because the baby's legs are fused together so that the feet form a "T" to resemble a mermaid's tail.

A local legend warns that if a pregnant woman goes to the nearby lake, the home of a mermaid spirit, the spirit will enter her baby and affect the baby's features. This legend brought shame upon the parents, but they celebrated the birth of their daughter, who they named Milagros, Spanish for 'miracle.' The parents went on Peru's national news, seeking help to keep their child alive. Plastic surgeon Dr. Luis Rubio answered their call and brought Milagros to Lima for treatment. Shortly after her first birthday, having spent the first year of her life in a hospital, Milagros received the leg separation surgery while the entire surgery was televised across Peru.

While Winfrey narrates Milagros's story, a video montage provides visuals and interview clips to help flesh out her journey. After Winfrey has narrated the story of the birth, she states, "This is what the doctors saw," and after a dramatic pause, a naked photo of Milagros being held up by a doctor is displayed on the screen. The audience let out audible gasps, which Winfrey flatly confirms as shocking before moving on to explain the medical condition of Sirenomelia. She leads back into the video excerpt with "Take a look" – a look at the video, but also a look at Milagros's spectacular body.

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[46] *The Oprah Winfrey Show*. "Against the Odds." June 18, 2009.

The images presented to the viewer mix real footage of Milagros with images shot after her birth to accompany (and mostly dramatize) the narrative. The doctor who helped Aracuo deliver Milagros recalls, "We took her into the delivery room, and I noticed a strange green liquid coming out of her body, something that was really frightening and strange." As she says this, the viewer sees a camera pan over a typical hospital room, yet it is dark and daunting, playing up the mysterious, supernatural elements to the birth. When she describes the "green liquid," a visual shows green slime, which is recreated for the television program. The images participate in casting the birth as a monstrous event.

In addition, the camera shows several shots of the newborn baby being probed, stretched, and held in various ways to show her physical anomaly in detail, including an x-ray of her internal genitalia. As historian of medicine Alice Dreger points out, children born with anomalous bodies are frequently deprived of the privacy given to other children, breaking ethics of confidentiality by making their bodies public.[47] Specific to the talk show format, Vicki Abt and Mel Seesholtz note, "Traditional boundaries between very private matters and public discussions are continuously breached; i.e. matters that would exist between therapist/patient and the outside world," and in this case, it is worth adding "doctor/patient."[48] From the dramatization of Milagros's story to the close-up visuals, even permeating her body's boundaries through x-rays, Milagros's body is

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[47] Alice Domurat Dreger, *One of Us: Conjoined Twins and the Future of Normal* (Cambridge: Harvard University Press, 2004).
Alice Domurat Dreger, *Intersex in the Age of Ethics,* (Hagerstown, MD: University Publishing Group, 1999).

[48] Vicki Abt and Mel Seesholtz, "The Shameless World of Phil, Sally, and Oprah: Television Talk Shows and the Deconstructing of Society," *Journal of Popular Culture*, 28:1 (1994): 178.

displayed as spectacle with Winfrey as the barker, inviting our stares.[49]

Though Milagros's body elicits the gaze, the narrative offers up the parents and Peruvian doctors as part of the spectacle of difference. As Winfrey lays out Milagros's story, we are presented with two explanations for Milagros's condition: one of Western medicine and one of Peru. Winfrey tells us that Milagros was born with Sirenomelia, which she explains is a rare genetic disorder. Yet, the Peruvian doctors and Milagros's parents explain her condition in different terms. After the baby was born, a technician asked Milagros's mother if she had been to the lake, and the technician shares, "I started believing that the legend must be true." When father Ricardo Cerron appeared on the news after Milagros was born, he hid his face, ashamed because of the story of the lake, and mother Sara Aracuo later shared that her first thoughts after the birth were "Why, God? … Why did you send me my daughter like this? Maybe you should have kept her." As the technician describes the legend of the mermaid in the lake while eerie music plays in the background, they show the lake with a dreamlike, out of focus shot of Milagros's mother lying on her side, juxtaposed to look like an authentic shot, but again, clearly shot after the birth. Even the Peruvian doctors suggest that there is a higher power at work in Milagros's condition and recovery, apparently unconvinced by the genetic explanations that doctors in the United States offer. By framing the legend in this way, it is clear that the show is using racial and cultural otherness as part of the allure of Milagros, even though the parents never explicitly answer whether or not they went to the lake, nor whether they even believe in the legend. The parents do, however, express shame over

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[49] In *The Birth of the Clinic*, Michel Foucault theorizes the rise of medical power through technologies that allow seeing inside the body, namely the stethoscope and x-rays.
Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Vintage Books, 1994), 163-166.

the legend, yet Winfrey's program continues to play up the possibility that a visit to the lake caused Milagros's condition.

This discourse simultaneously makes Milagros physically Other and racially Other, as it contrasts the way of understanding her condition through folklore and religion from a genetic disorder, a "medical miracle" and not a miracle of God. In the end, the narrative Winfrey provides makes it clear that medicine saves the day. The surgeon, not God, is responsible for separating Milagros's legs, the narrative suggests, but the parents see it differently. While we would often feel icky about such blatant voyeurism, the emphasis on modern medicine helps justify it.

Though Milagros is situated as a freak pre-surgery, she is normalized post-surgery, the gift of the techno-makeover. When the parents and doctors all enter the studio, Winfrey immediately asks the doctors, "So the question is will Milagros ever walk? Will she walk?" That this is "the question" suggests it would not be a "miracle" to simply remove her of her mermaid appearance unless she can fully achieve normalcy post-surgery. In a later episode, entitled "Miracle Children with Celine Dion," Milagros returns to the show, which repeats the story of her birth. This time, however, she is able to walk out, accompanied by famous singer Celine Dion. Because Milagros does not speak English, she does not get to speak at all, and Celine Dion translates to her but not for her. Dion asks her to show her special talent and in a frilly pink dress, Milagros stands and does a ballet twirl while the audience enthusiastically applauds – undeniably adorable. While it is quite possible that Milagros selected this outfit and talent for herself, the whole ordeal is disturbingly reminiscent of Julia Pastrana, a famous turn of the century freak from Mexico, enslaved by her manager and billed as "the ugliest woman in the world." Pastrana frequently performed acts of white, bourgeois femininity, often performing ballet in a full, elaborate ballerina costume.[50] Whether or not it is called for to make such a reading of this moment, the image of Milagros performing normalcy is brought to us thanks to medicine and technology – a techno-makeover completed. And though the Peruvian doctors are the ones who did the procedure, it still manages to frame Milagros's story within a celebration of Western medicine and technology.

Milagros is not an unusual figure to the show, though a particularly vivid example of the presentation of physical difference corrected through medical technology. Another episode, for example, is introduced by Winfrey as "a show all about good news because don't we hear enough bad?" It describes the story of once conjoined twins, Kendra and Maliyah Herrin, who were "miraculously" separated. They too appeared on the show entitled "Miracle Children with Celine Dion," and after the separated twins ride out in matching tricycles, we are told that they are thriving as separate entities and will soon be able to have another surgery that will allow each of them to use a prosthetic leg (as both twins have only one leg). Like Milagros, it is not enough to remove the anomalous quality of their bodies, as the real celebration comes when they can stand and walk upright. And until that day comes, their use of tricycles rather than wheelchairs or crutches helps to distract from their current state as non-extraordinary, disabled bodies.

In an episode entitled "Medical Miracles: A Dr. Oz Report," Dr. Mehmet Oz provides the story of an Indian girl named Lakshmi Tatma, born with a parasitic conjoined twin attached to her body, causing Lakshmi to have four arms and legs. Neither Lakshmi nor her family actually appears on the show, so Dr. Oz leads us through

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[50] Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 74.

the narrative to provide all the details of her successful separation surgery, accompanied by plenty of images of Lakshmi's anomaly. He assures the audience that he has spoken with her physicians and she is doing well, although she still needs to have her clubfeet and spine corrected. Still, Dr. Oz comforts us, sharing that the physicians believe she will be able to walk and even have children, which Dr. Oz determines as "a testament to what a good job they did." Again, normalization must also entail not just physical normalcy but also the ability to be socially normal; not only will she no longer be seen as a "freak," but she can also participate in compulsory heterosexuality and reproduction.

In yet another example, Claudia Mitchell is deemed "medical history" on her Winfrey appearance to show off her $4 million bionic arm, earning her an introduction as "the first bionic woman." Frustrated with her original prosthetic and feeling "less than human" because she frequently had to use her feet in place of her arm, Claudia was accepted into a special study to test out the artificial limb. It has earned the "bionic" label because it is built to move in response to messages sent by the user's mere thought. Even if she was able to do various activities with her feet in place of her arm, once considered miraculous in and of itself with various limbless freak show performers who demonstrated their abilities, the celebration here is on the fact that now, with the help of a prosthetic, the body can function similar to an able-body. When viewed together, all of these episodes establish a trope in which Milagros's narrative is less unique, despite the shock around her unique physicality.

The stare is acceptable because, in the end, these bodies are no longer worthy of being stared at; the techno-makeover has ensured that normalcy is within reach. To stare in the do-good genre is to witness and reward those bodies once out of bounds now made uninteresting.

These stories are also constructed as heart-warming, rather than exploitative, by focusing on the individual's ability to overcome personal adversity, providing a medicalized trope of rugged individualism. A common representation for people with disabilities known as the "overcomer," the show highlights people with disabilities who should inspire us all for their ability to persevere in the face of adversity, in this case always a physical impairment. Extending past episodes on disability, successful achievements of the "American dream," achieved by a strong work ethic and individual perseverance, appears to be one of Winfrey's favorite topics. Perhaps the reason for this is because Winfrey herself is an "overcomer." Winfrey expert Dana L. Cloud traces the way Winfrey is repeatedly cast as a token of success in her biographies, putting forth a message that all African Americans should be able to achieve success as well.[51] Winfrey has been more than complicit in making this connection, once stating, "A black person has to ask herself, 'If Oprah Winfrey can make it, what does it say about me?' They no longer have an excuse."[52]

Similar to the work of other scholars who have theorized episodes featuring queer people, people in poverty, and people of color, Winfrey's interest in people with disabilities who have "overcome the odds" provides another embodiment for supposedly opening up the American dream – these overcomers are now on the right track. Because of the medicine and technology featured on these episodes, guests like Milagros and "the first bionic woman" can now supposedly function as able-bodied, autonomous

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[51] Dana L. Cloud, "Hegemony or Concordance?: The Rhetoric of Tokenism in 'Oprah' Winfrey's Rags-to-Riches Biography," *Critical Studies in Mass Communication,* 13 (1996): 115-137.
[52] George Mair, *Oprah: The Real Story* (Secacus, NJ: Carol Publishing, 1994), 183.

individuals. The fact that Milagros and several of the conjoined twins seen on the show are not from the United States, does not change the fact that the narratives are framed to define the techno-makeover a “success” through the attributes American culture deems most important. When medicalized in this way, the journey from disabled and dependent to normal and independent parallels the story of going from rags to riches, though factoring out the social structures that might still stand in the way of the perfect life we are meant to assume these people have ahead of them. Though Claudia Mitchell can now use her prosthetic arm with ease and independence, might someone who fears that her disability will be a nuisance still pass her over for a job and hire a less qualified but fully able-bodied worker? And though she is greatly enjoying the prosthesis, it is a test arm - will she actually have permanent access to the device? Or might Kendra and Maliyah still face ridicule and discrimination in school for their physical difference as one-legged amputees and prosthesis wearers, even though the ostracism will undoubtedly be less than they might have received as conjoined twins? These questions are not raised, instead promoting the idea that these people with disabilities have overcome impairments so others should be able to do the same, relying on technology to help.

Winfrey’s attention to “medical miracles” puts forth these disabled figures as heroic inspirations for undergoing technological normalization, though the individuals are largely without agency in the portrayal of these transformations, especially in the cases of the children, whose parents make the decision for technological interventions for them. These stories helped make the *Oprah Winfrey Show* into a feel-good program, but examining the unabashed voyeurism encouraged by the program, we should think twice about the heart-warming feel.

Miracle Workers: Heroic Doctors, Compassionate Nurses, and Disabled Patients:

The 2006 television show *Miracle Workers* has much in common with the medical miracles featured on the *Oprah Winfrey Show.* Both provide intimate and personal visuals of the disabled body in order to reward one's voluntary participation in the display of their disabled body. In addition, both shows suggest that "miracles" are really the work of modern technology and medicine, carried out by knowledgeable doctors. Yet, a closer look at *Miracle Workers* especially highlights the role of the doctor in normalizing disabilities in the media, fleshing out another component to the techno-makeover genre. It adds the question, "Who provides the fixing?" to my ongoing question, "why are we so fixated on people getting fixed?"

Produced by DreamWorks Television and Renegade 83, which are better known for *The Bachelor* and *Blind Date*, *Miracle Workers* first aired March 6, 2006 on ABC, ending after one season.[53] *Miracle Workers* appeared a few months after the debut of a similar NBC reality television show titled *Three Wishes*. The *Three Wishes* team would visit a small town, listen to thousands of wishes, and select three wishes to carry out for specific townspeople, providing, on occasion, techno-makeovers for people with disabilities.[54] The emphasis on medical professionals was *Miracle Workers*' attempt to carve out a niche for itself.

Miracle Workers followed a formula for each week's episode. First, it introduced

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[53] Kate O'Hare, "ABC Goes Medical to the Max with 'Miracle Workers'" *Buffalo News*. March 5, 2006, TV37.

[54] Although this show did not focus primarily on medical procedures, it did offer the Speak-Easy hearing device to grant the wish of a teenager with a speech impediment, fully curing his stuttering, and a cranio-facial reconstructive surgery for a girl whose face was deformed in an automobile accident.

two people with disabilities or illnesses with narratives that focus on what their lives lack, due to their physical condition, epitomizing the deficit model of disability. Next, the "miracle workers" team steps in to put forth the possibility of a cutting-edge procedure or technology that could cure, or at least drastically reduce, their disability or illness. Then, we see the patients receive the "miracle" surgeries from incredibly concerned and sympathetic doctors and nurses. Finally, the show presented the normalized/cured patient, happy with their families and now able to do what they once could not. The "miracle workers" have saved the day once again. As the show's tagline states, "When a person's life is on the line and doctors insist that nothing more can be done, it's time to turn to the Miracle Workers."

The "miracle workers" consist of two teams, one doctor and one nurse per team, featuring lead doctors Redmond Burke, a pediatric cardiovascular surgeon, and Billy Cohn, a cardiothoracic surgeon, alongside registered nurses Janna Bullock and Tamara Houston.[55] The doctors' and nurses' role is to oversee the procedures, rather than actually perform the surgeries, as well as to help look over the patients and connect them with other doctors who can treat them.[56] Producer David Garfinkle describes the purpose of the show, stating, "There have been so many breakthroughs in the last three to five years, if you go to your doctor, he might not be aware of what's going on in these other areas. Our job was to locate these state-of-the-art doctors and procedures and try to hook up these families with them."[57] Part of making this connection also necessitates finding truly needy patients who will allow their stories to be filmed and their bodies to be used

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[55] O'Hare, "ABC Goes Medical to the Max with 'Miracle Workers,'" TV.37.
[56] Scott D. Pierce, "It's a 'Miracle'," *Deseret News*, March 4, 2006, E.06.
[57] O'Hare, "ABC Goes Medical to the Max with 'Miracle Workers,'" TV.37.

as guinea pigs for experimental treatments. The cases must also have a high chance of success so that the end of the episode will provide a "miracle," so only patients with a 90% chance of success are selected, even though the fine print of the application form forewarns, "The results of any medical treatment cannot be assured."[58]

The episodes develop a clear contrast between the disabled patients – the recipients of charity – and the able-bodied doctors and nurses, who are all conventionally attractive, heroically and compassionately providing the charitable service. Looking first at the disabled patients, a man named Todd Heritage appears in the first episode, seeking a corneal stem cell implant that might give him his sight back, lost when an allergic reaction left him blind in his childhood. As they describe Todd's life, a line that stands out is a plea from Todd's son, wishing that Todd get his vision back so that they might play baseball together some day. In addition, Todd explains that he wants his vision back so that he can see the faces of his children. The techno-makeover is not only necessary to allow Todd to become able-bodied, but also because being able-bodied allows him to better fulfill his role in the traditional, nuclear family – he can play baseball and see the children he has produced.[59]

Another episode follows a man named Jack Brown, whose "miracle" is receiving a high-tech, bionic prosthetic for his arm, amputated at the elbow after an electrical accident.[60] The show emphasizes that Brown needs to have this surgery in order to support his family since they are at risk of losing their home. The *Miracle Workers* website drives home the image of Jack as dependent and emasculated by his disability,

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[58] Sherwin, "Now Reality TV Appeals to the Sick - with Hope of Miracle Cure," 27.
Ouellette, "Do Good TV?"

[59] *Miracle Workers*, "Heritage/Slaughter," Episode 2, first broadcast on March 20, 2006 by ABC.

[60] *Miracle Workers*, "Brown/Valentino," Episode 4, first broadcast on March 20, 2006 by ABC.

stating, "If the *Miracle Workers* team is successful, Jack may once again be able to provide for his family as a whole man."[61] Whether being a "whole man" means that you can fulfill your role as breadwinner or play baseball with your son, *Miracle Workers* suggests that technology is central to returning "wholeness," ignoring any structural or cultural factors that might be at work in taking away a disabled man's sense of wholeness.

Technology also provides a return to femininity for female patients on *Miracle Workers*. One episode follows a college-bound woman named Emily Bresler, who undergoes a procedure to have an electrical device implanted into her brain to send signals that can quell her Tourette syndrome tics. A "before" shot shows Bresler struggling to put on her makeup, coupled with a post-procedure shot of her doing so with ease. The device allows her to perform her proper gender role, which is cast as especially significant now that she can head off to college as a "normal girl." Similarly, Vanessa Slaughter, previously "wheelchair bound," can now walk again thanks to a device inserted into her spine, shown on the program.[62] Her sister asks the surgeon, "Will she no longer be grouchy?" and after the surgery, Vanessa reassures us that, "Because of them [the medical team], I'm a new person." "Grouchiness" is assumed to be rooted in the impairment rather than the wider discriminatory attitudes and environment that would certainly provide many wheelchair riders with a good reason for grouchiness (and of course, perhaps her grouchiness predates her impairment or disability). Post-surgery, she

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[61] "Miracle Workers Bios," *Miracle Workers*, accessed October 3, 2006 http://abc.go.com/primetime/miracleworkers/bios/105005.html.

[62] The epithet "wheelchair bound" flashes underneath her name whenever she appears on the screen, emphasizing the tragedy of her disabled life.
Miracle Workers, "Heritage/Slaughter," Episode 2, first broadcast on March 20, 2006 by ABC.

can now perform “normal” social behavior by no longer being a “grouchy” woman, and the doctors have made this transition possible through normalization.

As one television critic celebrated, “Beautifully filmed and told, ‘Miracle Workers’ is a love story as much as it is a technology story.”[63] Not surprisingly, this romance is heterosexual, deeply gendered, and rooted around the able-bodied nuclear family. Alternatively, the love story is that of the empathetic doctors toward their patients.

The two doctors on the team are white males, whereas both nurses are women, one white and one black, reproducing wider racial and gender hierarchies throughout the medical field. In all of the promo shots featuring the two doctors and two nurses, the nurses wear fuchsia scrubs while the doctors wear blue. Though both the doctors and nurses are caregivers in the *Miracle Workers* format, the doctors are the possessors of knowledge on the show, while the nurses’ role is to provide care and compassion, gender appropriate behavior. Together, the doctors and the nurses seem similar to those we see on fictional shows, such as *ER* and *Grey’s Anatomy*.[64] They are incredibly compassionate toward the patients, making house calls, listening to their fears about the operations, and above all, serving as their personal advocates for navigating medical knowledge and the bureaucracy to match them up with someone who can offer a “miracle.” It is quite likely that they really do care – but they are able to do all of these things because of the unique situation of being paid by the television company.

Though each episode celebrates people with disabilities for overcoming their

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[63] Alan Pergament, “Love, Technology are 'Miracle Workers' in ABC series” *Buffalo News*, March 3, 2006, C.5.

[64] Joseph Turow, *Playing Doctor: Television, Storytelling and Medical Power* (New York: Oxford University Press, 1989).

impairments, the show's narrative focuses above all on medical professionals as the heroic figures, practically held up as religious icons. Even the show's logo, an oversized and especially angelic caduceus (two snakes wrapped around a medical staff with two large wings coming out of the top of the staff), connects medical professionals with angels and God. As the doctors themselves appear as model "normates," they are celebrated as independent, autonomous, and yet generous, as they manage to bring others into normalcy.[65] Disability and the techno-makeover is still central, but the disabled subjects here do not even receive the – albeit problematic – "overcomer" label, which at least gives some agency in their transformation. In *Miracle Workers*, the disabled miracle recipients see their situation as desperate, and doctors are kind enough to come to the rescue.

Although the doctors come across as the stars of the program, lead doctor Redmond Burke had some early concerns about the ethics of the show, but later reflects, "I rarely encountered a situation where I felt uncomfortable about what was happening. We were pretty rigorous with the producers about what was ethical and what wasn't." He continues, "Were we taking advantage of these families, exploiting their ordeals in front of a voyeuristic audience? That worried me. I certainly didn't want to do that. But the strong impression I got from every family that I talked to was that they were empowered from being able to tell their stories."[66] Here, the doctor, who is being paid to deliver

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[65] Rosemarie Garland Thomson derives the concept of the "normate" from Erving Goffman's observation that "there is only one complete unblushing male in America: a young, married, white, urban, northern, heterosexual, Protestant father of college education, fully employed, of good complexion, weight and heigh, and a recent record in sports."
Thomson, *Extraordinary Bodies*, 8.
Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs, NJ: Prentice-Hall, 1963), 128.

[66] O'Hare, "ABC goes medical to the max with 'Miracle Workers'," TV.37.

miracles, also serves as ethicist. The experience may have been empowering for the patients, but given that ABC searched out desperate people who could not afford these procedures on their own, is "being empowered" through a television show really saying all that much? Especially suspect is that Burke's assessment of the patients' empowerment comes during the shooting, which certainly might change when they see their intimate stories and struggles broadcasted on television. Or, can we take empowerment in a literal sense, as the techno-makeovers allow them to physically pass as able-bodied, and thus, literally gain power? Or, was it empowering because a team of producers and doctors listened to their story and the troubles they've faced, which doesn't happen for many people struggling within the wide and complex medical institution?

We are meant to celebrate the fact that private interests care about the individual, and so people with disabilities need not worry about having healthcare or access to rehabilitation. Rather, a show like *Miracle Workers* will come along to help you get back up on your feet. Given the growing commercialization and bureaucratization of medicine since the 1980s, *Miracles Workers* suggests that the caring doctor is still out there.[67] Additionally, each commercial break during *Miracle Workers* included at least one advertisement for CVS pharmacy, the program's sponsor, with a common theme that CVS pharmacists deeply care about their customers. At the end of every episode, CVS demonstrates their concern by donating large sums of credit to the featured patient to cover their large prescription costs post-surgery, predominantly costs which they would not have had pre-surgery. ABC wanted people to see this as a reality television show

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[67] Carl Elliott, *A Philosophical Disease: Bioethics, Culture, and Identity*, (New York: Routledge, 1999), 4-7.
John Lantos, *Do We Still Need Doctors? A Physician's Personal Account of Practicing Medicine Today* (New York: Routledge, 1999).

with a heart, with Stephen McPherson, president of ABC entertainment, directly stating, "Even if the show gets no ratings we help a lot of people. In a day and age of mean-spirited, bug-eating shows, we've done something good."[68] But when the ratings disappointed, the show was canceled after its first season; apparently "doing something good" was not the primary motive after all.[69]

Laurie Ouellette and James Hay provide a useful analysis of *Miracle Workers* in their book, *Better Living Through Reality TV*, arguing that we must understand the emergence of "do-good TV" within the wider climate of advanced neoliberalism, where television studios and corporate sponsors are responsible for providing welfare, not the government. They argue that it is not enough to make a leftist critique of "false consciousness that things are being taken care of" with *Miracle Workers* and its corporate welfare work because we need to critically engage with why television doctors are playing this role for their television patients.[70] It is worth adding that it is not just about patients and medicine, but also people with disabilities and rehabilitation – miracles help relieve the state of their responsibilities.

By glorifying the medical professionals who normalize disabled bodies, *Miracle Workers* makes public, reinvigorates even, what disability scholars and activists have long addressed: the medical control that constructs disability as a deficit and a lack in need of medical correction. Despite the risks of all these procedures (and we are repeatedly told that there are real risks, including blindness, paralysis or death), the

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[68] Sherwin, "Now Reality TV Appeals to the Sick - with Hope of Miracle Cure," 27.

[69] Ouellette and Hay, *Better Living through Reality TV,* 39.

. Though a useful argument, when Ouellette and Hay point out that *Miracle Workers* does not acknowledge inequalities of class, gender, and race, it is unfortunate that they neglect to mention disability, so clearly central in the program.

[70] Ouellette and Hay, *Better Living through Reality TV,* 38.

program suggests that the procedures are worth it because a disabled life is not a "whole" life. The show presents narratives of patients who have hoped for a cure, despite being told by medical professionals (before the miracle workers step in) that nothing can be done. *Miracle Workers* does not show the alternative experience that many disability scholars have detailed: being pressured to pursue normalization regardless of how you feel about your disability, especially directed at parents with disabled children; undergoing pain and exhaustion just for you to "walk again" or function "normally" through physical therapy, sometimes leading to no difference or even additional disabilities; or struggling to have a doctor recognize your personhood, instead reducing you to an "interesting case" while displaying your anomalous body parts to medical students.[71] At a time when disability studies and the more widely known field of bioethics have both worked to increase patients' rights and challenge the power in the medical gaze, *Miracle Workers* allows doctors to regain power as the distributors of "miraculous" normalizing technologies, using the same representations of people with disabilities seen in *Queen for a Day* and the *Oprah Winfrey Show*, where disability makes you pitiful, in need of charity, and above all, in need of a technological cure. We celebrate the technology and the providers of technology together and leave the wider population of people with disabilities disempowered if left uncured.

Miracle Workers received mixed reviews from critics. Scott D. Pierce, for example, was entirely positive about the show, stating, "Imagine a television show that can make the blind see and the lame walk. Can you imagine calling it anything other

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[71] Alice Domurat Dreger, *One of Us*.
Denise Sherer Jacobson, *The Question of David: A Disabled Mother's Journey Through Adoption, Family, and Life*, (Create Space, 1999).

than ‘Miracle Workers’?” He continues, “Talk about your do-good reality show. Even the worst cynic among us can't help but feel a catch in his throat when a man sees his wife and children for the first time.”[72] Pierce was not alone in praising *Miracle Workers* for rising above the typical reality show.[73] A small number of critics raised concerns. Bioethicists Arthur Caplan and Glenn McGee publicly criticized the show in the popular press, “How can you tell when your nation's health care system has collapsed? One sure sign is the creation of a television program that offers access to health care to the desperately ill as a prize. The show has now materialized on American TV screens. Everything about it shows just how badly broken health care in America truly is.”[74] Similarly, bioethicist Peter Singer spoke out against *Miracle Workers* on the grounds that “the application's fine print tells the real story – medicine is not made up of miracles. The problem with miracle cures is that miracle cures don't always work.”[75] Although these critiques are important for looking at the macro-level significance of the program, both the positive and negative reviews assume that the procedures shown are medical necessities, rather than explore what motivates the need for the “needy” participants who seek normalization procedures.

Because it first aired mid-season, *Miracle Workers* only produced five episodes, and since ratings were not high enough (around 8 million viewers per episode), ABC did

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[72] Pierce, “It’s a 'Miracle',” E.06

[73] David Bianculli, “This Medical ‘Miracle’ Has Us in Critical State,” *New York Daily News*, March 6, 2006, 64.
Robert P. Laurence, “Broken Bodies and Broken System Need More than a Few ‘Miracles’,” *The San Diego Union – Tribune*, March 27, 2006, D.6.

[74] Arthur Caplan and Glen McGee, “‘Miracle’ TV Show Lacks Reality,” *Times Union: Three Star Edition*, March 19, 2006, B.1.
Mark McGuire, “The New Reality: Kinder, Gentler Shows,” *National Post*, August 6, 2005, TO.46.

[75] Vito Pilieci, “Reality TV Focuses on the Desperately Ill: Show to Match Human Guinea Pigs, Rare Treatments,” *The Ottawa Citizen*, February 1, 2006, A.1.

not sign on for another season. Regardless of its failure, *Miracle Workers* is still worth exploring, as it exemplifies yet another place in popular culture promoting a moral imperative for the normalized disabled body. Among all the possible explanations for why *Miracle Workers* failed, it is unlikely that people did not watch in protest of the ideology of ability that technological normalization proliferates; it is more likely that this narrative simply wasn't big enough. And despite *Miracle Workers*' failure, this has not stopped the genre of "do-good" television from continuing and expanding.[76]

From a House into a "Home": High-Tech Normalcy in *Extreme Makeover: Home Edition*:

Extreme Makeover: Home Edition first aired on ABC December 2003 and has since become a prominent, successful program with no end currently on the horizon. Like the *Oprah Winfrey Show* and *Miracle Workers*, *EM:HE* frequently (in roughly a quarter of the episodes) features people with disabilities selected to receive techno-makeovers, but the transformations that they undergo are predominantly extensions to their bodies in their homes, rather than directly intrusive surgeries and devices. Hosted by Ty Pennington, each episode begins with the introduction of the design team for that week, riding in what has now become a famous bus in route to the home of one deserving and needy family. The design team gathers around a television screen on the bus and supposedly learns for the first time about the desperate family who they are about to help, with several design members tearing-up every week at each family's story. They then hop off the bus and "sneak up" on the family, calling them out of their home on a megaphone, although it is unlikely anyone is really surprised with such a large cast and

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[76] *The Secret Millionaire.* UK: Channel 4. RDF Media, 2006.

crew out on their block.[77] After screams of joy, the family leads the design team around their house, describing personal stories of woe with enough detail to put most *Queen for a Day* contestants to shame. As they share their stories, the family members also get a chance to let designers know just enough about their personality and interests that the remodeled house will ideally reflect them in some way; a child who loves penguins will get a penguin-North Pole room and a mother who fondly remembers her travels to Morocco will get a "North African" living room. When the show features disabled participants, this segment of the show is used to establish the deficit model of disability. We learn about the intimate details of their physical impairment and the many things that it does not allow them to do from the perspective of each family member.

Next, the family is whisked away for an all-expense paid vacation, often to Disneyland or Disneyworld (since Disney owns ABC), though sometimes to vacations that correspond to the family's specific needs, such as a medical center that specializes in the family member's disability.[78] Even though they need to have a complete house standing by the time the family returns a week later, the actual housing makeover begins with much showiness and production. Hundreds upon hundreds of volunteers come together to build the house, and it all begins with an elaborate demolition of the old house, while the family watches from a video feed on a computer, away on their vacation.[79] One episode produced a demolition where racecars drove into the house to

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[77] Jake Halpern, "Emotional Buildup," *The New York Times*, October 5, 2008, MM.

[78] Sending the family away opens a tax loophole for the family at the end of the year; the family "rents" their house to ABC in exchange for the construction work and products that ABC provides, and because the rental is less than 15 days, they do not have to pay taxes on ABC's gifts.
Kristin J. Jacobson, "Renovating The American Woman's Home: American Domesticity in *Extreme Makeover: Home Edition*," *Legacy*, 25:1 (2008): 118.

[79] Early episodes remodeled existing houses and instead focused on demolishing the worst pieces of furniture or specific walls of the house.

dramatically tear the front wall down, and another demolition with a Disney theme included people dressed up as the Seven Dwarfs from *Snow White* attacking the house with sledgehammers. The demos are one element of *EM:HE* that has received some public criticism, as they take houses that would be perfectly suited for another family with different needs and tear it to shreds for the sake of a dramatic clip, often building the new house with materials of less quality than the original.[80] To achieve an "extreme" makeover, such practical matters need not be considered.[81]

From here, we continue to learn more about the impairment of the disabled family member(s), interspersed with scenes of construction, side charity projects by design team members, check-ins with the family on vacation, and a trip to buy things for the house at Sears or whatever store has sponsored the episode. As they near the end of the week, it always seems as though they will run out of time, but when the family returns on the 7th day, the house is seemingly complete. Ty Pennington, the design team, and throngs of onlookers welcome back the family with hugs and cheers, and once the family yells, "Move that bus!" it drives out of the way to reveal the family's new home, met by tears and screams that often have a religious zeal to them.[82] As the family tours their home and learns about their new devices, they cry, hug one another, and repeatedly thank the designers for "making their dreams come true." The designers ride off toward the sunset in their bus, presumably to their next family, and we see a parting shot of the family, standing together, in front of their new home. Their lives are back on track, and for the

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[80] Frank Norton, "Demolition Draws a Crowd," *News & Observer*, December 3, 2006, B.1.

[81] To be fair, on occasion *EM:HE* does lift and move the old house, explaining that it will be given to another needy family, but these occasions are rare and largely initiated by the family.

[82] Jacobson, "Renovating The American Woman's Home," 111.
Emily Askew, "(Re)Creating A World In Seven Days: Place, Disability And Salvation In *Extreme Makeover: Home Edition*," *Disability Studies Quarterly*, 31:2 (2011).

disabled family member(s), normalcy has been restored.[83]

After viewing over fifty hours worth of *EM:HE* episodes featuring people with disabilities, it feels as if there are endless points about the show to make, but here I explore how it functions as yet another pop culture home for fixing disabled bodies with technological solutions. In the program, disability is both a difference that needs to be erased, but also a sign of inequality tied to race, class, and gender. Once the makeover is complete and fully extreme, we are to believe that the disabled family will be free of any future challenges, serving the iconic purpose of normalcy and the nation restored.

EM:HE provided a perfect fit with ABC. It emerged after ABC had received complaints from religious viewers about ABC's daytime talk show *Ellen*, hosted by lesbian icon Ellen DeGeneres, as well as widespread criticism raised against the original *Extreme Makeover*, which featured "needy" people getting cosmetic surgery to feel better about themselves. E*M:HE* helped ABC and parent-company Disney to recapture some of their viewers. The show is filled with Christian themes, as the family members thank God so regularly that it feels scripted.[84] At the end of an episode, one makeover recipient reflected on his great fortune, "It was a gift from God and ABC."[85] ABC and Disney appear as generous benefactors, but in fact, their donations are minimal because most of the resources come from corporations in exchange for the good publicity in the form of product placement. In addition, most of the laborers, besides the design team, are unpaid

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[83] Though I am not the first scholar to look at *EM:HE* with a critical gaze, the reoccurring theme of helping people with disabilities with technology has been previously missed. Disability has come up in these works, but as an example of how the program uses "sentimental" or emotion-inducing themes, and it is entirely insufficient to leave it at this, in fact serving to reinforce the idea that people with disabilities are deserving of pity.

[84] Askew, "(Re)Creating A World In Seven Days."

[85] *Extreme Makeover: Home Edition*, Episode no. 48, First aired 20 November, 2005 by ABC.

volunteers from the community.[86] Although ABC may not have realized just how successful *EM:HE* would be in its conception, designed as an evening filler program, they are certainly aware now that *EM:HE* is a hit. In 2007, the show pulled in 13 million viewers, listed on the Nielsen's Top 20 programs of the year.[87] In addition, *EM:HE* has won the 2004 Family Television Award for best reality show, two People's Choice Awards for best reality show, and two Emmys for Outstanding Reality Program.[88] The program can also measure its success with the huge number of people applying to receive a home makeover with ABC receiving roughly 15,000 applications a week for a show that only helps about 12 families a season.[89] Whereas *Miracle Workers* and *Three Wishes* have both come and gone, *EM:HE* remains.

EM:HE has provided a model of how to take product placement to the extreme. Just as ABC used *EM:HE* to help boost its public reputation, Sears has donated endless amounts of products to the show to help boost their image as well, after sponsoring *Politically Incorrect with Bill Maher*, a stigmatized show after Maher offended many when he spoke of the courage of suicide airplane terrorists.[90] Since Sears teamed up with *EM:HE*, Sears has seen its sales go up 25%.[91] After any given episode, ABC posts a long list of all the sponsors that have contributed to the episode, from wood for the floors to clothing to stock the children's closets. With the growing popularity of DVRs and Tivos to help viewers zoom past commercials, *EM:HE* provides a much-needed strategy for ads

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[86] Ouellette and Hay, *Better Living through Reality TV*, 43.

[87] Alex Strachan, "Why Don't the Emmys Like Hits?; House is an Anomaly among Tonight's TV Award Nominees - It Has a Mainstream Audience," *The Gazette*. September 21, 2008, A.18.

[88] "Awards for *Extreme Makeover: Home Edition*" IMDB, accessed January 12, 2012, http://www.imdb.com/title/tt0388595/awards.

[89] Ouellette and Hay, *Better Living through Reality TV*, 43.

[90] John McMurria, "Desperate Citizens and Good Samaritans: Neoliberalism and Makeover Reality TV," *Television New Media*, 9:4 (July 2008): 317.

[91] Jacobson, "Renovating The American Woman's Home," 114.

that will still reach consumers, while also making the sponsors look socially concerned as generous "corporate citizens," who pitch in to help the needy.[92]

But *EM:HE* is inseparable from neoliberalism, not only because of its excessive corporate interests, but also for its promotion of volunteerism and private acts of charity as central to revitalizing the United States, suggesting that government care for the needy is no longer necessary. ABC even created the Better Community Outreach Program in 2005, now mentioned each episode, to encourage viewers to carry out their own volunteer projects. The role of reality television in celebrating neoliberal movements has been well theorized, but the functioning of disability in *EM:HE* raises new questions; why are disabled family members who are in need of high-tech houses so useful for facilitating American volunteerism?[93] And how does this neoliberal project work to ensure that people with disabilities must be situated as figures of private charity in order to access the techno-makeover?

In order to justify the techno-makeover, *EM:HE* must always have a "before" to complement the "after," and that "before" heavily relies upon making the disabled body without technology appear miserable. We learn about the intimate details of the makeover recipient's physical impairments, supplemented by testimonials on the burden for each family member. As soon as the design team meets the family, the family must surrender all privacy in exchange for the makeover; the designers do not hold back in extracting the stories of woe out of family members, and in one episode, the designers

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[92] Ouellette and Hay, *Better Living through Reality TV*, 42.
[93] Ouellette and Hay, *Better Living through Reality TV*.
McMurria, "Desperate Citizens and Good Samaritans.

even read aloud the diary of a disabled son who had recently passed away.[94] By featuring people with disabilities who are very new to their disabilities and still adjusting, the show has no problem finding people who will speak of themselves as a burden and "incomplete," wishing above all else to get their independence back to "overcome" the disability. Technology, we are told, will grant this wish, and though it's quite likely to help many makeover recipients, there's more to the story.

Just as *Queen for a Day* represented people with disabilities as a burden on the able-bodied mother/wife, we see the same dynamic persist in *EM:HE*, although the burden falls on different members of the family from episode to episode. In an episode featuring the Vardon family, the only able-bodied family member is the Vardons' teenage son, and the design team repeatedly names him a hero for tolerating this responsibility and even rewards him with a college scholarship, something that is not offered to his disabled sibling. In addition, the design team repeatedly explains to viewers that the biggest challenge for a disabled person is the loss of independence, as they must burden their family members. While losing independence is undeniably difficult for people who acquire disabilities, *EM:HE* interprets disability through a framework of liberalism that glorifies the fact that technology will restore independence to maintain the autonomous individual, rather than consider how many people with disabilities challenge the hegemonic pressure to be independent or never can be independent, regardless of techno-makeovers. The college scholarships so frequently given away on *EM:HE* do not go to the disabled children; the show celebrates charitable giving in the name of "independence" but does not do the type of giving that might have lasting, empowering

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[94] *Extreme Makeover: Home Edition*, Episode no. 46, First aired 6 November, 2005 by ABC.

effects.

EM:HE's charity exemplifies the theorized charity model of disability, relying as well on the deficit model. In *The Disabled State*, Deborah Stone suggests that in a capitalistic society, disability must be seen as an undesirable category, such that people will not want to fake disability and get out of work.[95] Similarly, historian Paul Longmore has argued that charity work for people with disabilities serves a central purpose in capitalism. As people make public donations to people with disabilities, or "conspicuous contribution" as Longmore coins it, the benefactors find morality in a system that rewards greed and selfishness, but at the unfortunate cost of situating people with disabilities as always desperate and in need of (Christian) charity.[96] *EM:HE* – along with *Miracle Workers,* the *Oprah Winfrey Show* and beginning with *Queen for a Day* – demonstrates the continuing ideology of disability as deserving of charity, rather than governmental support, although in the current neoliberal climate, this support comes from businesses and private entities. In watching businesses doing charitable work, we receive the same message Longmore discusses, a sense of morality despite corporate greed, maintaining neoliberal privatization.

Just as the "queen" on *Queen for a Day* received extravagance in her gifts whereas her disabled family member got practical gifts of technology, episodes featuring people with disabilities on *EM:HE* reiterate some variation of this quotation: "This episode isn't about giving them luxury, it's about practical things to make the house work

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[95] Deborah Stone, *The Disabled State* (Philadelphia: Temple University Press, 1984).

[96] Paul K. Longmore, "Conspicuous Contribution and American Cultural Dilemmas: Telethon Rituals of Cleansing and Renewal," in *The Body and Physical Difference: Discourses of Disability*, Eds. David T. Mitchell and Sharon L. Snyder, (Ann Arbor: University of Michigan Press, 1997), 134-160.

for the family." Whereas other families on the program are traditionally bombarded with over the top "extreme" gifts, this statement maintains the ideological pinning of disability as a site of charity; it implies that they will take what they can get. In reality, the techno-makeovers for people with disabilities are still plenty extreme. *EM:HE* seems to love giving people with disabilities luxurious, expensive assistive technology, rather than some of the more simple solutions that might show viewers that access and accommodations do not have to be expensive and extravagant to be effective.

At the end of the episode, the family traditionally thanks the corporate sponsors and ABC as their final word on the show. Despite all the efforts of the disability rights movement to work toward social support for people with disabilities, we are meant to be moved by these stories of hardship receiving charity, rather than see the underlying failure. For example, Paul Giunta, paralyzed in a car accident, cannot live in the same house as his family because their house is inaccessible; why isn't there support for them to make their house accessible or to move into accessible housing that doesn't come in the form of a reality TV show?

On occasion, the show comes close to promoting a progressive understanding of disability, though these brief moments are far outweighed by the problematic ones. Built into the program's most basic theme is the idea that other environmental factors, besides one's physical impairment, impact disability; a new house will make their lives better. However, the show does so much to focus on the physical impairments, regularly bringing in specialists who can explain the pathology in detail, that the household technology is seen as making up for the physical impairment, rather than suggesting that the house in and of itself might be a problem.

The program also deserves partial credit for thinking about accommodations, not only in building the house but also in making the formula of the show work for people with disabilities. For the Llanes family, the father and two daughters are blind and the son is deaf, so they have to figure out a way to show them the demolition, as they do for all the families on the show, in a way that accommodates each family member's needs. After some thought, they make a movie trailer capturing all the sounds of the demolition and providing audio descriptions for the blind family members while showing it with a special message in sign language for the deaf son. Furthermore, the show has mentioned the Americans with Disabilities Act a few times, as well as the concept of "universal design," though they are mentioned without a description of what these concepts mean.[97]

EM:HE also deserves credit for bringing in people with disabilities to help provide the makeovers. For example, Deaf actress and Oscar winner Marlee Matlin has appeared twice on the show, the second time filling in for Ty Pennington as the host. In addition, the show has occasionally brought in experts with disabilities, including a blind architect, a disabled demolition team, and various athletes with disabilities to teach the design team how sports are still possible after a disability, allowing the design team to pass this information on to the returning families. While these efforts are noteworthy, they could also consider: if we gained so much from a blind architect, why don't we get him on the show regularly, not just for a disability-themed week?

The program may occasionally get it right, but their motives should remain

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[97] *Extreme Makeover: Home Edition*, Episode no. 66, 71, 119 by ABC.
"Universal Design" refers to the construction of the built environment so that it is accessible to many different bodies, not just an able body. While efforts for universal design have primarily come from disability activists and scholars, universal design helps many people; people traveling with luggage, for example, benefit from elevators and ramps, along with wheelchair riders.

suspect, as the abundance of people with disabilities appearing on the show is no coincidence. The Smoking Gun, a watchdog website devoted to publishing morally-incriminating materials of public interest, exposed an email from the casting department of *EM:HE* in 2006. This email makes explicit the use of disabilities on the show to attract viewership while showing the hierarchy of disabilities that get media attention, implying that there is a cultural desire for seeing people with disabilities receiving technological help. In the leaked email, the casting department writes:

> We are open to any and ALL story ideas and are especially looking for the following:
>
> -Extraordinary Mom/Dad recently diagnosed with ALS
> -Family who has child w/ PROGERIA (aka "little old man disease")
> -Congenital insensitivity to pain with anhidrosis – referred to as CIPA by the few people who know about it. (There are 17 known cases in US- let me know if one is in your town!) This is where kids cannot feel any pain….
> -Family who has multiple children with Downs Syndrome (either adopted or biological).[98]

The list continues, naming three other desired disabilities for the show. Even though the leaked email brought some negative attention, it was quickly smoothed over, and two years after the email appeared on "The Smoking Gun," an episode featuring the Woodhouse family shared the story of Kayla, a girl with CIPA, one of the diseases that they were searching for "in your town!"[99] Without the email, it was already apparent that the frequent appearance of disability on the program was intentional, but seeing it written out like this, detailing those people likely to be desperate enough to require *EM:HE's* help, highlights what's wrong with "do-good" television. It is not just that people with

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[98] "ABC's 'Extreme' Exploitation," The Smoking Gun, accessed March 27, 2006, http://www.thesmokinggun.com/archive/0327062extreme1.html.
[99] *Extreme Makeover: Home Edition*, Episode no. 104, First aired 13 January, 2008 by ABC.

disabilities represent a higher proportion of the needy, leading to frequent disability themes on the program; the people working to make *EM:HE* a success clearly realize that the techno-makeover for a disabled family member makes for good television.

Once these sought after disabled families are found, the designers serve as the arbiters of normalcy by performing normalcy themselves. Although the design team is composed of a diverse constituency, including several women and two gay men including a man of color, they work within normalcy; departures from the normate are "tolerated" but normalcy still reigns. For example, we see the female designers sledgehammering and building on par with the male team members, yet they do so wearing heels and pink tool belts to maintain their appropriate gender role in some visible ways. In one episode, a male designer jokes that they should trade the female designers for a cool car.[100] Similarly, the show also includes an openly gay interior decorator, Michael Moloney, yet one episode features Ty Pennington and fellow team member Paul DiMeo, two heterosexual designers, playing dress up in women's clothing while making a girl's dress-up room, which quickly leads into homophobic taunts that DiMeo enjoys the dress-up too much. The show is generally campy so Moloney's feminine persona blends in with the other male designers' exuberant personalities, and all the men break from traditional masculinity as they cry frequently and openly. But because these slight transgressions happen within the domestic space of the heteronormative household, their subversive potential is minimal.[101]

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[100] *Extreme Makeover: Home Edition*, Episode no. 19, First aired 24 October, 2004 by ABC.

[101] This trope of homonormativity in support of the heterosexual household is similar to the basis of *Queer Eye for the Straight Guy*.
Katherine Sender, "Queens for a Day: *Queer Eye for the Straight Guy* and the Neoliberal Project," *Critical Studies in Media Communication,* 23:2 (2005), 131-151.

And in the end, Ty Pennington – the white, heterosexual male – is always seen as the ultimate hero of the show. He produces a "secret room" each episode, which he supposedly does entirely alone, without input from the other crewmembers. In addition, he often "calls in some friends," supposedly a surprise to the design crew, bringing in famous celebrities to the makeover site to help raise or donate money for the family. One season, which aimed to provide a makeover in each of the 50 states, opened each episode with Pennington doing some athletic sport, local to the featured state. While the design team works together, Pennington's independence and strength is celebrated. The show is not only about watching people with disabilities rise up to normalcy, but also about the design team mediating normalcy amongst themselves.

As elevators, wheelchair height-appropriate counters and appliances, voice-recognition software, and many other innovations – even technologies that more directly makeover the disabled family member's body, such as a hearing aid – are given to the families to complete the techno-makeover, the designers showcase the technologies that are going to restore normalcy for the families, the ultimate goal. Once technology is in place, one mother says at the end of the episode, "We can be a normal family and not have to worry about anything."[102] The normalcy that the family now enters into, or returns to, is always framed around the traditional, nuclear family. In the Hawkins family episode, for example, a woman who recently became a paraplegic, adjusting to life in a wheelchair, praises her renovated kitchen and the fact that she can now "give my husband home-cooked meals."[103] Another episode shows a father and son who have both recently become disabled, and after making over the father's garage workshop and providing

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[102] *Extreme Makeover: Home Edition*, Episode no. 87, First aired 22 April, 2007 by ABC.

[103] *Extreme Makeover: Home Edition*, Episode no. 69, First aired 8 October, 2006 by ABC.

accessible devices, the designers explain that now he can teach his son to build things again, without any mention of including the daughter in this masculine domain.[104] For people with disabilities, inclusion in the family is, in one sense, an achievement, as marriage and reproduction have been historically off-limits to people with disabilities.[105] However, *EM:HE* shows the limits of fighting for inclusion alone, as the techno-makeover is only open to those who can perform socially-defined normalcy as well as physical normalcy.

Particular attention is paid to ensure that the children will be returned to normalcy, emphasizing the importance of "letting kids be kids," yet in the proper, "normal" ways. *EM:HE* creates a panic around the loss of a normal childhood. In the case of a disabled child on the show, the design team emphasizes that "these are normal kids, so we're going to help them have normal kids stuff," bringing them into childhood consumerism as a means for normalcy.[106] When the children are able-bodied, but have a sibling or parent with a disability, the design team explains the need to reward the child, for giving up their own childhood to help their disabled family member.[107]

And just as the parents return to traditional roles post-makeover, the children can as well. For the Turner family, for example, the design team is appalled when they discover that the brothers and sisters are sharing a bathroom, so the makeover gives them separate places for doing gender appropriate stuff.[108] This is additionally clear through

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[104] *Extreme Makeover: Home Edition*, Episode no. 87, First aired 22 April, 2007 by ABC.

[105] Sharon L. Snyder and David T. Mitchell, *Cultural Locations of Disability* (Chicago: University of Chicago Press, 2006).
Martin S. Pernick, *The Black Stork: Eugenics and the Death of 'Defective' Babies in American Medicine and Motion Pictures* (Oxford: Oxford University Press, 1996).

[106] *Extreme Makeover: Home Edition*, Episode no. 46, First aired 6 November 2005 by ABC.

[107] *Extreme Makeover: Home Edition*, Episode no. 21, First aired 7 November 2004 by ABC.

[108] *Extreme Makeover: Home Edition*, Episode no. 66, First aired 21 May 2006 by ABC.

the theme rooms given to children, playing into gender stereotypes. Several boys on the show have received career-oriented themes; one boy wants to work in robotics to create artificial implants to let his blind father see again, and so he received a robotics-themed room as well as a scholarship to a nearby college with a strong robotics department.[109] Girls, however, typically get closets filled with clothing or dollhouses. We are not likely to ever see an "extreme makeover" where the design team gives a ten-year-old boy his dream Barbie-theme room, or a girl an NFL football-themed room.

The program suggests that post-makeover, everything will be better for the family, but what about when they leave the household? The technology will certainly help them to start or end their day, but an accessible house does not change the fact that we live in a wider society of exclusion toward people with disabilities, and the fairytale story of the techno-makeover will only be true if the disabled family member contains themselves within the private sphere of the household. They partially circumvent this criticism by leaving the family inside the household, creating individual solutions to the impairment, instead of intervening in the community.[110] For example, a female officer, paralyzed after a shooting, receives a rehabilitation room so she will not have to leave her house for her exercise, especially significant given that this episode repeatedly celebrated her desire to walk again, and praised that the rehabilitation equipment could help her on this path to recovery. Because we see the community volunteering to build the houses, there is an assumption that the community will continue to come to the disabled family's

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[109] *Extreme Makeover: Home Edition*, Episode no. 35, First aired 1 May 2005 by ABC.

[110] Occasionally, there is an intervention in the community, including an accessible baseball field, an accessible playground, and a stair lift up to a dance studio for a woman with MS, but these scenarios are rare, largely occurring because they directly relate to the families' stories, i.e. the mother started a disabled baseball team, justifying why she deserves a home makeover.
Extreme Makeover: Home Edition, Episode no. 56, 66, 71 by ABC.

need, without any need for people with disabilities to emerge outside their accessible homes into the non-accessible world. Of course, it is not fair to expect *EM:HE* to do it all; it is, after all, just a television program. However, the repackaging of these complex problems into tidy, fixable packages hides the many challenges that they cannot address in the name of good TV.

The post-makeover family is further normalized as the show promotes them as model Americans, an inspiration to us all. As disability historian Douglas Baynton theorizes, disability has historically justified the exclusion of citizenship rights in the United States.[111] Similarly, disability historians Paul Longmore and Lauri Umansky write, "Americans often perceive disability – and therefore people with disabilities – as embodying that which Americans fear most: loss of independence, of autonomy, of control; in other words, subjection to fate."[112] In a sense, *EM:HE* supports this concept as they detail the narrative of a family with a recently disabled family member, stating in one episode, "The Akers family seemed to be living the American dream, but then everything went wrong," a sentiment which is often restated in other episodes.[113] However, once the techno-makeover is complete, the program situates people with disabilities as iconic symbols of American pride, repeatedly naming them "heroes," hanging an American flag on some families' front lawns, and/or explaining that they are an "inspiration" to all of us, again placing them within the "overcomer" trope of disability. While filming a scene with a little girl in a wheelchair, a field producer

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[111] Douglas C. Baynton, "Disability and the Justification of Inequality in American History," in *The New Disability History: American Perspectives,* eds. Paul K. Longmore and Lauri Umansky (New York: NYU Press, 2001), 33-57.
[112] Longmore and Umansky, eds., *The New Disability History: American Perspectives*, 7.
[113] *Extreme Makeover: Home Edition*, Episode no. 119, First aired 5 October 2008 by ABC.

stopped shooting to do a retake because "She doesn't say the word 'Hero.'"[114] Clearly, this "hero" rhetoric is at least partially contrived in order to help the makeover become all the more touching, as a deserving "hero" is rewarded.

Just as *Queen for a Day* claimed to put the queen back on track toward the American dream, the techno-makeover on *EM:HE* allows people with disabilities to now be seen as "American" by using technology to become independent and autonomous, no longer exposing how exclusive the American dream is to people with disabilities. As discussed earlier, *Queen for a Day* was significant because it welcomed women into ideal femininity and consumerism within cold war culture. *EM:HE* appears on the air at a moment of cultural anxiety, post 9-11, and so again we see the misery show (now the "do-good" show) helping to lessen viewer concerns that the pursuit of the American dream might not be open to everyone by opening it up through technology.[115] As the makeover family is given an "extreme" amount of consumer products and traditional family roles are maintained, we again celebrate the maintenance of the nuclear family and normalcy by charity for the miserable, much like *Queen for a Day*. As they enter normalcy and become emblems of American nationalism, we are reminded that the nation holds strong.

A take away point that these episodes leave us with is that we can feel more comfortable with the idea of techno-bodies and techno-households. Surveillance equipment will be used to help prevent a child with autism from leaving the house at night, as seen in the Vardon family episode, rather than lead us to fear a Big Brother

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[114] The "she" here might refer to either the design team member or the little girl – it is unclear. Jake Halpern, "Emotional Buildup," MM.

[115] McMurria, "Desperate Citizens and Good Samaritans." Ouellette and Hay, *Better Living Through Reality Television.*

future, in which such devices are used to excessively track and monitor. Technological devices that permeate the household will empower people with disabilities, while fitting with their authentic identity, rather than create new mediums for discrimination or inaccessibility. The techno-makeover is a miraculous event, a gift from God and ABC, and a sign of national and technological progress that we are all meant to celebrate. This point is especially apparent in the "Family Reunion" episode, where design team members check in with some of the most popular families seen on the show, giving them additional gifts and bringing them all together to share their post-makeover success stories. In selecting these families, they did not show any of the unsuccessful makeovers – houses that had to be sold or even foreclosed because of "extreme" electricity bills or property taxes.[116] As we are reintroduced to the families, the design team repeatedly states that these families were not only the recipients of change for they also changed lives – that of the design team and extending to the program's regular viewers. The sentiment is clear: we get something out of viewing these families, and we watch to feel something. Part of this is undeniably about happy emotions, watching people with bad luck get things back on track, but we cannot separate this from the central role technology plays in making the change possible.

Conclusion:

This genre is troublingly significant, as it allows viewers to get their fix of people getting "fixed" without ever critically questioning why this is necessary, nor the

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[116] Mike Maciag, "Bank may give couple do-over in 'Makeover': 30-day hold: Owners of house built by 'Extreme' TV show work on agreement to take it off the auction block." *The Atlanta Journal – Constitution*, August 5, 2008, B.1.
Jake Halpern, "Emotional Buildup," MM.

aftermath where we see what the technological fix *cannot* provide, post-makeover. Far removed from normalcy, yet refusing to indulge in the race to embodied perfection, living with disabilities can provide a site for helping all of us, able-bodied and disabled, to question: why must we be normal anyway? Yet, the abundance of media fixated on disabled bodies made independent by technology makes this perspective invisible, if not impossible, showing instead only those disabled figures willing to maintain normalcy, both rooted around the body, but also gender, sexuality, and national identity. Maintaining normalcy is, unfortunately, the price of the techno-makeover.

What is particularly troublesome about this genre of television is the "do-good" label. While the shows may very well set out to do-good, these programs capitalize on the notion of altruism and search out people in desperate circumstances to make their desperation and tragedy public. This criticism came to be widely understood during *Queen for a Day*'s downfall, but today, it is not just widely accepted but even glorified. The viewers are complicit in the freak show-like nature of these shows, the celebration of pervasive normalcy, and the exploitation of hardship. Perhaps the most telling sign is on *Extreme Makeover: Home Edition*'s website, where their "About" page concludes, "*Sniff* Now excuse us while we go have a good cry."[117]

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What would a *good* show look like? It's worth noting that any show providing a more nuanced understanding of life with a disability would never make it on the air today, as it would obviously lack the flash and pizzazz of these current programs. But, it's fun to daydream. For starters, each episode would not try to wrap up with a perfect

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[117] "About the Show" *Extreme Makeover: Home Edition*, accessed January 1, 2011, http://abc.go.com/shows/extreme-makeover-home-edition/about-the-show.

conclusion: real-life techno-makeovers are a long process, bringing in new devices as one's impairment and everyday activities change with time. In addition, in a better show, the family would have a bigger role in the process. Yes, this would mean passing on the Disneyland vacation, but end-users would be involved in the process of obtaining technological accommodations that fit their personalities and desires, seen as active figures rather than charitable objects. A gadget-enthusiast family should get "extreme" gadgets, but the show would also present stories from those who are not as enthusiastic about high-tech dependency and desire more low-tech, personalized solutions. Most importantly, the show would move past the focus on impairment so that we would hear people's full stories and emotions, be it anger at the healthcare system that does not provide adequate rehabilitation to frustration with an employer that dismissed them because of the disability. Someone on this show might talk about the pressure they feel to be "normal" and call it out as discriminatory.

Imagine this: a makeover team heads out each week in search of a small town or city neighborhood with disabled residents who are not getting their legal rights met. The makeover team would then work with the disabled residents to fight for access, demanding that the local government or private businesses comply with the ADA, and helping think about the best types of technologies for access, sometimes low-tech, sometimes hi-tech. The tears that would be shed would be a mixture of tears of rage, as the audience encounters stories of heartbreaking discrimination, and tears of happiness, as the progressive techno-makeover pushes a small movement forward in making access more widely available – but importantly, these tears would not be based upon pity. Then, the show would end with shots of not only the disabled residents benefiting from these changes, but also of all the able-bodied town members who also stand to gain from universal design – a parent pushing a child in a stroller up a wheelchair curb cut, a tired worker using an elevator after a long day, a elderly person enjoying closed-captioning in the local movie theater.

Ending with this daydreaming illustrates how technology alone is not necessarily the problem; there are some technologies that represent both technological and social progress. Yet, the popular culture focus on techno-makeovers makes invisible the wider context of ableism at play, partially responsible for making many techno-makeovers necessary. But again, the progressive techno-makeover show would never air, existing only as a daydream, for there is currently no room for nuance and complexity in the techno-makeover's narrative.

Chapter 2:

"Developing" Nations and "Undeveloped" Limbs: The Techno-Makeover Reaches the Global South

Booked as "the ugliest woman in the world," an "ape-woman" and a "nondescript" for her hairy body and protruding jaw, Julia Pastrana spent most of her life on display in sideshows across the globe, a spectacle of racial and national otherness and studied by doctors and scientists as a "missing link" in evolution.[118] While the tribe she came from in Mexico, the Root Digger Indians, were cast as "primitive" and "exotic," Pastrana performed Westernized bourgeois talents for her audiences, from ballet to theater, raising curiosity in irony: a "civilized" primitive and progress embodied in an "atavistic" appearance.[119]

"She loved to travel," reported one pamphlet on Pastrana.[120] Freakery not only offered Pastrana class mobility, but also a heightened degree of global mobility. She traveled from Mexico to the United States and throughout Europe and Russia, establishing the spectacle of her racial and national background wherever she went until she passed away during childbirth.[121] While this travel was almost definitely out of her control, as she was considered the property of her manager (later her husband), the

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[118] Rosemarie Garland Thomson, whose work on Julia Pastrana I draw from here, states, "Although I could find no extant advertising actually using the term in reference to her, Pastrana is an early prototype of the abundant 'missing link' figures, popularizations of Darwinian though that flourished in exhibits throughout the century."
Rosemarie Garland Thomson, "Narratives of Deviance and Delight: Staring at Julia Pastrana, the 'Extraordinary Lady,'" in *Beyond the Binary: Reconstructing Cultural Identity in a Multicultural Context,* ed. Timothy B. Powell (New Brunswick: Rutgers, 1999), 92.

[119] Jan Bondeson, *A Cabinet of Medical Curiosities*, (New York: W. W. Norton, 1999).

[120] Bondeson, *A Cabinet of Medical Curiosities,* 221.

[121] The travel of Pastrana remains the most haunting part of her story. In 1860, Pastrana gave birth to a son, who shared her same physical traits and died shortly after being born. Pastrana, unable to recover from the childbirth, died shortly after. Both bodies were embalmed, and Pastrana's body once again traveled the world, now with son. The bodies continued to change hands while traveling around the United States as recently as 1971, and ending in Sweden when vandals damaged the bodies.

accounts of her travels are certainly extraordinary.

Once medical explanations emerged to demystify physical anomalies such as hers, the freak show declined and the monstrous became the pathological. Yet, the intrigue of doctors and the public to see such bodies persisted, facilitated by the ease of displaying anomalous bodies to Western audiences through television and news media.[122]

This not-so-distant past haunts us today, or perhaps simply lingers on, as the medical field and the American public are still drawn to stories of physical and national otherness. The focus here is not on Pastrana, as her life has already been explored by many, but beginning this chapter with her story should make strange the many freak show-like stories we see in the media today where race, nationality, and disability intersect to create a spectacle of "otherness." While no longer called "freaks," those with physically anomalous bodies from the Global South still pull in viewers. The global mobility that opens up in these cases, facilitating travel to places otherwise out of reach just as Pastrana did, is significant, as such global mobility is denied to many others with less visually intriguing disabilities.

An infant boy from Mexico travels to Tampa, Florida for an amputation and a new leg; a young woman leaves the Philippines for Minnesota and returns home with double leg prostheses after accomplishing her goal to walk around one of Minnesota's many lakes; and a Ghanaian man receives a high-tech prosthesis in the United States and returns to Ghana ready to start a family. In this chapter, I explore three contemporary cases from 2000 to the present, selected from a vast number of similar stories, where

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[122] Rosemarie Garland-Thomson, ed., *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: NYU Press, 1996), 3, 11.

people with physical anomalies living in the Global South are welcomed into the United States for treatment and technology that they did not have access to abroad.

It is not just the way that physical anomalies function as mobility capital, but more so the stories that emerge and circulate within the United States as a result that are worthy of analysis. These stories are held up as curiosity for the Global South's technological and medical atavism, and only through contact with the United States can they embody medical and technological progress. It is no longer acceptable for doctors and scientists to exhibit "freaks" in such a public way as Pastrana experienced; yet, it is perfectly acceptable to do so if this exhibition comes with monetary "gifts" and normalizing rewards in return. Physical anomalies function as capital, and normalcy through technology gets returned as a remittance.[123]

The heightened mobility of the people in these case studies, like that of Pastrana, contradicts a history of restricted migration for people with physical impairments and differences. National belonging has been historically tied to physical bodies with the assumption that a healthy nation requires healthy, able-bodied citizens. This assumption has led to a history of excluding people with disabilities from immigration into and citizenship rights within the United States.[124] While disability can serve as political grounds for limiting mobility, an extraordinary disability can guarantee a free ride in. At

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[123] The impairments that appear in these stories tend to be those rare or unseen in the United States, typically conditions that are erased or minimized at birth. Conditions like cleft lip and palate, conjoined/parasitic twins, or limb deformities – anything that can focus above all on physical "abnormality" and the need for a techno-makeover – are most common in this trope. I use the terminology of "the physically anomalous" here to make central why these stories grasp the public attention, but physical anomalies are included in the broader category of disability.

[124] Douglas C. Baynton, "Defectives in the Land: Disability and American Immigration Policy, 1882–1924," *Journal of Ethnic American History*, 24:3 (2005): 31-44.
For another example, see: Natalia Molina, "Medicalizing the Mexican: Immigration, Race, and Disability in the Early-Twentieth-Century United States," *Radical History Review*, (Winter 2006): 22-37.

a time of increased xenophobia toward immigrants of color, often centered on the fear that migrants will exploit the U.S. medical system, these contradictory cases are quite peculiar. This chapter adds to works on dis/abled bodies and nationalism to explore how the physically anomalous discursively represent the unhealthy nations of the Global South in order to then embody U.S. national progress after receiving an American "techno-makeover." As postcolonial theorist Ilan Kapoor puts it, "[O]ur representations of the Other say much more about us than the Other, or at a minimum, they construct the Other *only in as far as* we want to know it and control it."[125] Disabled bodies – with versus without technology – help represent the divide between the Global North and the Global South.

While in many ways this chapter continues the trope discussed in the previous chapter, the additional component of representing techno-needy people with disabilities from outside the United States extends the story in interesting ways. I move past Pastrana's story because the comparison fails; onlookers unabashedly gazed at her body at the turn of the 20th century, whereas today, we need the technology to justify the gaze and the techno-makeover makes that possible.

The Gift of a Limb:

Despite differences in home country, race, and gender, the three case studies have much more in common than a shared physical impairment.[126] The first case study comes from Tampa, Florida, covered in two newspaper articles by the *Tampa Tribune*, complete

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[125] Ilan Kapoor, *The Postcolonial Politics of Development* (New York: Routledge, 2008), 50.

[126] While the physical conditions that receive attention within this trope cover a wide range, I limit my focus to Tibial Hemimelia, a congenital condition where one or both legs do not fully develop, resulting in a withered and deformed leg that typically cannot bear weight.

with photographs.[127] Juan Balan Zapot was born in Isla Mujeres, Mexico in 1999 with Tibial Hemimelia, a congenital condition which caused both of his legs to be deformed and undeveloped. His mother, Cindy Madeline Zapot, was a single teenager when she got pregnant. When Juan was born, Cindy's relatives were ashamed that her child was born out of wedlock and encouraged her to kill him when they learned of his limb disfigurement. Despite this hardship, Cindy Zapot raised her son, struggling to earn enough income to get by until 1999, when Cindy Zapot happened to meet Cindi Delfin, a previous resident of Tampa, Florida. Delfin helped put the Zapots in touch with the Florida Shriners Hospital for Children. Through the generous help of a Shriner family, who hosted the Zapots in Tampa, and because of the Shriners' donation of free treatment, Juan Zapot received an amputation and prosthesis for his right leg as well as a corrective brace to twist the left into place, along with four months of physical therapy. Through this process, Juan Zapot gained the ability to walk.

The second case study is that of Flory Tacle, who in 2004 came from the Philippines to Edina, Minnesota to have her undeveloped right leg amputated, allowing her to receive prostheses for both legs (her left leg already ended at the knee). Previously, Tacle wore flip-flops on her knees, allowing her to walk. After receiving a college scholarship from a Minnesota charity called Outreach Asia, Tacle was introduced to the organization's co-founders Mike and Gina Peck while they were visiting the Philippines. The Pecks decided to bring Tacle back to Minnesota, where they found a family to host her and arranged for free medical care, prostheses, and physical therapy.

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[127] Cloe Cabrera, "Boy with Deformed Leg Given Hope by Shriners," *Tampa Tribune,* February 8, 2000, 1. Cloe Cabrera, "Able to Walk, Mexican Boy with Leg Defect to Go Home," *Tampa Tribune*, May 9, 2000, 4.

Tacle's journey was captured through an interactive web narrative on the *Star Tribune* website, which earned photojournalist Jenni Pinkley the 2005 National Press Photographer Association's "Best of Photojournalism on the Web" award.[128] Tacle's story was also covered in other major news outlets. After eight months in the United States at the age of 19, Tacle returned home to the Philippines walking with two prostheses and resumed college under her Outreach Asia scholarship.

The third and final case study is that of Emmanuel Ofosu Yeboah, born in Ghana in 1977 with Tibial Hemimilia deforming his right leg, such that he could walk and stand upright with the use of a wooden crutch. When Yeboah was born, his father left the family, not wanting to raise a child with a disability. Yeboah stayed in school until he was 13, at which point he started shining shoes in Ghana's capital to help support his family. Appalled at the number of beggars with disabilities, Yeboah decided that he wanted to draw attention to the neglect of people with disabilities in Ghana. Following the advice of a U.S. development worker, he wrote to an organization called the Challenged Athletes Fund (CAF) and asked for a bicycle in order to ride around Ghana and publicize his journey in the name of disability rights. After CAF granted his wish, also sending him additional biking gear and clothing, Yeboah rode 400 miles across Ghana in 2001. His ride also gained the attention of filmmakers Lisa Lax and Nancy Stern, twin sisters who decided to make a documentary that would come to be called *Emmanuel's Gift* (2005), though Yeboah's story was also more widely covered by the

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[128] The *Star Tribune* story seemed to have been quite popular when it was first available, as several other websites – from charity organizations to prosthetic companies – shared this link.
Karen V. Paurus, "Flory," *The Star Tribune,* November 16, 2005, http://www.startribune.com/flory/.

American press.[129]

Following his bike ride, CAF decided to fund a visit for Yeboah to the United States to compete in their annual 56-mile ride. CAF introduced Yeboah to their main sponsor, Loma Linda University, and together, they provided Yeboah with a fully funded amputation surgery, prosthesis, and physical therapy. *Emmanuel's Gift* received several awards, generating prominence and publicity for Yeboah that opened up many opportunities. After *Emmanuel's Gift* was released, Yeboah has continued to raise money for himself and his causes by returning to the United States to give inspirational speeches for schools, businesses, and religious organizations.

Yeboah has undoubtedly received the most public attention out of the three case studies, but his story converges with that of Tacle and Zapot in several ways.[130] The media presentations of Zapot, Tacle, and Yeboah offer a "before" and an "after," an overcomer celebration of triumph over physical adversity intertwined with a celebration of the American technology that helped make triumph possible. When Zapot, Tacle, and Yeboah return to their home countries, they return "normal." But like in the popular culture realm, physical normalcy goes hand in hand with social normalcy in the techno-makeover.

Good-hearted benefactors, who take it upon themselves to help someone less privileged, make the gift of a limb possible, and the criticism of the development

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[129] Lax and Stern, *Emmanuel's Gift*.

[130] There are undoubtedly many differences, but the stories are told in ways that erase difference, a mechanism of developmental discourse as Arturo Escobar notes, which relies upon "this discursive homogenization (which entails the erasure of the complexity and diversity of Third World peoples, so that a squatter in Mexico City, a Nepalese peasant, and a Tuareg nomad become equivalent to each other as poor and underdeveloped)."
Arturo Escobar, *Encountering Development: The Making and Unmaking of the Third World* (Princeton, New Jersey: Princeton University Press, 1994), 53.

narrative need not be critical of their good intentions. Rather, the problem lies in the retelling of the heart-warming story. When the narrative gets repeated, we tell the story in the way we best know how to tell it, and it becomes about something bigger – about nationalism, global capitalism, the normal body, and technological progress.

When you look at the numbers, the cultural significance of these stories is not immediately apparent. Zapot's story was covered in the *Tampa Tribune*, which had only 211, 274 daily readers that year.[131] Tacle's story likely reached more people because as a web story, it was easily spread and free to all, and it also appeared on *CNN*, a national media outlet. Yeboah's story was the most widely viewed, for his journey was covered in several national outlets, but even still the documentary was limited to select theaters and only grossed $23,578.[132] Yet, Tacle, Zapot, and Yeboah's stories are just the tip of the iceberg, exemplifying a wider trend that expands the number of people likely to have witnessed this cultural narrative play out. Despite different backgrounds, cultures, and social locations, as well as different media outlets presenting the stories, the lives of Tacle, Zapot, and Yeboah are presented as remarkably similar, and this is no coincidence.

The Discourse of Development, Disability, and the Global South:

The relationship between the Global North and South is built and maintained through the discourse of development; as countries like the United States seek to do "good," the visual imagery and narratives told over and over to garner support for development maintain an endless dependency of the Global South on their benefactors.

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[131] Christopher Boyd, "Sentinel Sees Rise in Readership," *Orlando Sentinel*, October 31, 2000, B7.
[132] "Emmanuel's Gift," *Internet Movie Database*, Accessed April 4, 2012, http://www.imdb.com/title/tt0447016/.

While Zapot, Tacle, and Yeboah's journeys are put forth as documentary, the framing of the stories, the images that accompany the information, and the very choice of these stories as "newsworthy" remind us that this discourse is a product of the American context in which it is made to circulate. As development theorist Arturo Escobar states, "Reality, in sum, had been colonized by the development discourse."[133]

Yet, development discourse here is richer and harder to extract because it also happens through representations of people with disabilities, cast as "undeveloped" in a different sense. Postcolonial disability scholar Mark Sherry has brought to light the tendency of both postcolonial theory and disability studies to borrow metaphors from each other without critically engaging with the intersections of what a postcolonial disability studies might look like.[134] For example, disability studies has too often appropriated the language of colonization, such as speaking of the patient-doctor relationship as that of "medical colonialism," while neglecting postcolonial theory in the field of study. Conversely, postcolonial theory has often relied on disability metaphors such as colonized subjects having "crippled minds" or invoking disabled bodies as a sign of colonial violence.[135] Both reduce the other to metaphor, eliminating the possibility of

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[133] Escobar, *Encountering Development*, 5.

[134] Mark Sherry, "(Post)colonizing Disability," *Wagadu*, 4 (Summer 2007): 10-22.

[135] Sherry, "(Post)colonizing Disability," 10-15.
Rebecca Dingo, "Making the 'Unfit, Fit': The Rhetoric of Mainstreaming in the World Bank's Commitment to Gender Equality and Disability Rights," *Wagadu*, 4 (Summer 2007): 10-22.

[135] Sherry, "(Post)colonizing Disability," 93-107.
Take, for example, a passage from Achille Mbembe's *On the Postcolony*, where even as he speaks of the discursive representation of Africa, he relies heavily on images of disability, "[T]he continent is the very figure of 'the strange.'…. Africa, a *headless figure* threatened with *madness* … a mixture of the half-created and the incomplete, strange signs, *convulsive movements* – in short, a bottomless abyss where everything is noise, yawning gap, and primordial chaos" (emphasis added).
Achille Mbembe, *On the Postcolony* (Berkeley : University of California Press, 2001), 3.
Robert McRuer's Haiti essay offers a more recent example of this.
Robert McRuer, "Reflections on Disability in Haiti," *Journal of Literary and Cultural Disability Studies,* 4:3 (2010): 327-332.

postcolonial disabled subjects who experience multiple systems of oppression simultaneously. To look at Zapot, Tacle, and Yeboah considers the intersection of disability and postcolonial subjects without letting either identity get metaphorized into another; their stories rely on fixed constructions of the "primitive" and of the "disabled" and must be critiqued through both lenses.

Linked with discourse theory is the need to question that which leads the viewer to take in the story, the "medical gaze" upon the physically anomalous with the "development gaze" upon the Global South. In the case of Zapot, Tacle, and Yeboah, the gaze is both through visuals as well as through text, as their life stories and physical impairments are displayed in intimate detail. In *Rhetoric of Empire*, discourse theorist David Spurr speaks of the "surveillance" that is used in colonial discourse and reminds us that the gaze in these types of journalistic reports begins with the journalist who holds "the privilege of inspecting, of examining, of looking at."[136] He continues:

> Although reporters tend to know better than anyone else the limitations inherent in their methods of work, the standard journalistic forms do not easily permit reflection on the conditions – technological, economic, historical – that make reporting possible…. even where the Western writer declares sympathy with the colonized, the conditions which make the writer's work possible require a commanding, controlling gaze. The sympathetic humanitarian eye is no less a product of deeply held colonialist values, and no less authoritative in the mastery of its object, than the surveying and policing eye.[137]

Eunjung Kim raises a similar point: "The prevailing images of disability in the Global South can be summarized, first, disability is produced as a result of poverty, lack of hygiene, or underdevelopment itself; second, disability is produced by armed conflict, factionalist struggles, and wars; and third, disabled people are subject to backward attitude caused by superstition, fear, 'premodern' or 'insufficiently modern' religious practices and unscientific misinformation." [This passage was not included in the final published essay, but was part of Kim's draft 9/1/2010, 34-35].
Eunjung Kim, "'Heaven for Disabled People': Nationalism and International Human Rights," *Disability and Society*, 21: 2 (March 2006): 93-106.

[136] David Spurr, *The Rhetoric of Empire: Colonial Discourse in Journalism, Travel Writing, and Imperial Administratio*n (Durham, NC: Duke University Press, 1993), 13.

[137] Spurr, *The Rhetoric of Empire,* 14, 20.

Whether in the newspaper article, the television news broadcast, or the documentary film, the efforts to capture the journey of the physically anomalous figure from the Global South get reduced to a simplistic form, a product of the medical and development gaze combined.

And the gaze is aimed at technology but also captured by technology. In the case studies, the gift of a prosthesis is cast as an undeniable good, and while it may offer great assistance to Zapot, Tacle, and Yeboah, it works in conjunction with another form of technology that is unseen and yet key to making the narrative possible: the cameras and photographs through which the American viewer learns about these stories through a development frame. Technology has historically been used to separate the "primitive" from the "civilized," and in these cases, the technologies of viewing help remind the viewer what side of the gaze they are on, "the god trick of seeing everything from nowhere," as feminist science scholar Donna Haraway puts it.[138] The viewer experiences the chaos of Mexico, the Philippines, or Ghana from the comfort of their own home.[139] And as the subjects of these stories are reduced to a spectacle, there is a certain degree of social harm, fallout from the visuality even if it may be the very best of intentions that brings these stories into being.[140] Even as the narratives of Zapot, Tacle, and Yeboah urge the viewer to be inspired by these impressive stories of achievement, the viewer maintains the upper hand.

But the camera is a small price to pay for high-tech improvements to the body, we are told. In order for these stories to succeed, they rest upon the assumption that the

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[138] Donna Haraway, *Simians, Cyborgs, and Women: The Reinvention of Nature*, 189.

[139] Spurr, *The Rhetoric of Empire,* 44-47.

[140] Escobar, *Encountering Development*, 191.

United States is a better place to be disabled and that technology is part of what makes this so. If the viewer questions this fact, the story immediately unravels, appearing more about the aesthetics of the body than desperation and suffering. In an interview with Ralf Hotchkiss, a wheelchair rider and founder of an organization that works to design and distribute wheelchairs to communities in the Global South, I asked him what it is like living in Berkeley, CA, widely known as a progressive site of incredible disability access.[141] He replied that while Berkeley is nice, some of the most accessible places he has ever been to are the rural villages he visits in Africa; without more modernized buildings, he encounters less barriers such as escalators and staircases.[142] In the techno-makeovers of the Global South, development discourse reminds us that *of course* development will be better for people with disabilities, and *of course* the United States is a better place to be disabled. These assumptions are so central to the narrative, they go without saying.

Before Prosthesis: Establishing the Native:

The techno-makeover mandates a clearly demarcated "before" and "after," allowing the viewer to watch the transition occur. The "before" for Zapot, Tacle, and Yeboah is achieved not only by showing the pre-techno-makeover subject as suffering, but also by connecting their suffering with their primitive lives within primitive cultures.

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[141] Ralf Hotchkiss, interview by Emily Smith Beitiks, March 14, 2005.

[142] A similar point is made by both Julie Livingston and Matthew Kohrman to suggest that development and modernity to not always improve the lives of people with disabilities because modernity fractures community.
Julie Livingston, *Debility and the Moral Imagination in Botswana* (Bloomington, Indiana: Indiana University Press, 2005).
Matthew Kohrman, *Bodies of Difference: Experiences of Disability and Institutional Advocacy in the Making of Modern China* (Berkeley, California: University of California Press, 2005).

Once the native is established, the techno-makeover becomes urgent. Looking at the "before" provides an answer to postcolonial disability studies scholar Eunjung Kim's question, "[C]an the description of circumstances of people with disabilities in the less developed world be free from the history of colonial rhetoric of backwardness...?" with an unfortunate "no," or at least "not here."[143]

One way in which the native is produced is through a description of rural surroundings. While Juan Zapot's hometown of Isla Mujeres, Mexico is described as an "impoverished village," "lack[ing] good hospitals" where "there was little hope," they leave out that Isla Mujeres is a popular tourist town, just five miles outside of Cancún. Similarly, in the online photo essay of Flory Tacle's journey, the background holds an image of a dense jungle of the Philippines, downplaying the fact that when reporters began following Tacle's life, she was already attending Southern Leyte University and obtaining a degree in Computer Science.[144]

The third case study shows the clearest hyperbole. The documentary on Emmanuel Yeboah offers several shots of rural Ghana and Yeboah in front of the African bush. Narrator Oprah Winfrey describes his home village of Koforidua as a "farming village with no electricity or running water. The family home was simple. Daily life difficult," and she explains that he grew up with a large family, living together "in a primitive compound." In reality, Koforidua is no such place. Unlike many places in Ghana, Koforidua has electricity and running water, as well as a booming marketplace

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[143] This passage was not included in the final published essay, derived from draft September 1, 2010, 4. Kim, "'Heaven for Disabled People'."
[144] Paurus, "Flory."

and transit hub.[145] Even the "primitive compound" in which Yeboah lives is a two-story building, something only visible in the less rural areas of Ghana. One does not have to travel to Koforidua to uncover these contradictions, as *Emmanuel's Gift* accidentally exposes them. The documentary notes that some of Yeboah's achievements include bringing wheelchair accessible phone booths and a library to Koforidua. Certainly his achievements do not also include getting the town the lines to connect the telephones nor the electricity to light up the library. The image of a rural, primitive disabled figure helps exaggerate the urgent need for the techno-makeover; it is not just the disabled body in need of technology but also the body of the Global South.

In illustrating Zapot, Tacle, and Yeboah's primitive homes, their stories also emphasize that the home countries are unable to help the disabled population, for they lack the innovations in medical technology required to do so. There is "little opportunity," "there was nothing they could do," and "there was little hope…. the impairment meant doom."[146] Doom, of course, is not death, but rather a life with twisted limbs. The viewer is presented with the same picture, whether of Mexico, the Philippines, or Ghana, to create these countries as places that are lacking what the United States can offer to escape the "doom" of the Global South.

The discursive creation of the native's environment falls in line with a common strategy of development, which Kapoor describes as the "basic needs approach." By calling upon lack of electricity, running water, and, in these cases, the removal of physical anomalies, the "basic needs approach" situates those in the Global South as childlike and dependent, requiring the United States to enter as the responsible parental

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[145] Research conducted by the author in Koforidua, Ghana, August 2006.
[146] Cabrera, "Boy with Deformed Leg Given Hope by Shriners," 1.

figure. "The narrative goes something like this: the poor of the South live in a state of nature and we, cultured policy advisors, must rescue them," Kapoor explains.[147] Even if it requires exaggeration, this image of a simplistic and sad rural life of the native is key to setting up the "before" of the techno-makeover. Establishing "basic need" has always relied on images of disability to establish the need for development. I have argued elsewhere with Denise Nepveux that "the imagined African body is not only starving but disabled: a stomach bloated with *kwashiorkor*, a body disfigured in inter-ethnic conflict, or a fragile body weakened by AIDS. Development policies and charitable campaigns have imagined the African body as always, in a sense, disabled."[148] The narratives of Zapot, Tacle, and Yeboah simply make the disabled image we already hold of the Global South in the United States more literal.

In addition to the rural environment, the "native" is also created through reports of the surrounding culture. The narratives suggest that Zapot, Tacle, and Yeboah's disabilities will guarantee a limited future for them, unlikely to have any chance of real success because of the discrimination and violence they will likely face. When Zapot was born, for example, his mother was encouraged to kill him to "put [him] out of his misery," and the article describes that without the Shriners' help, "Juan might spend his life crawling through the dust, unable to work, a social outcast."[149] A similar fate is predicted for Tacle and Yeboah until they receive the techno-makeover, and their stories detail how their home countries have neglected to provide them with the help they need to overcome their disabilities. These stories repeatedly suggest that to be disabled in the

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[147] Kapoor, *The Postcolonial Politics of Development,* 23.
[148] Denise Nepveux and Emily Smith Beitiks, "Producing African Disability through Documentary Film: *Emmanuel's Gift* and *Moja Moja*," *Journal of Literary and Cultural Disability Studies,* 4.3 (2010): 237.
[149] Cabrera, "Boy with Deformed Leg Given Hope by Shriners," 1.

Global South is a guaranteed life of suffering, though a technologically "fixed" disabled body will get along much better.[150]

The efforts to establish Zapot, Tacle, and Yeboah within this primitive setting fall in line with two common forms of colonial discourse, theorized by Spurr: "debasement" and "naturalization." First, the focus on the begging and the murdering of people with disabilities produces a rhetorical move in which "the obsessive debasement of the Other in colonial discourse arises not simply from fear and recognition of difference but also, on another level, from a desire for and identification with the Other which must be resisted."[151] These stories emphasize and homogenize the treatment of disability in the Global South, such that the American viewer can separate what *we* do to *our* people with disabilities from what *they* do to *theirs*.[152] This discourse makes invisible the many sociocultural problems that people with disabilities face today within the United States. The treatment of the disabled populations in the Philippines, Ghana or Mexico is looked down upon as barbaric, and of course, the murdering of children because of a disability is undeniably horrific, but it is also separated from, for example, the United States' recent history of institutionalizing disabled children with inhumane and horrific treatment or the high percentage of disabled beggars living on U.S. city streets.[153] This debasement also functions to homogenize the category of disability within Mexico, the Philippines, and Ghana; if you are disabled in the Global South, a life of doom is inevitably your fate, the narrative suggests, neglecting the ways that class, religion, and other important cultural

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[150] Kim also challenges homogenized assumptions about what "disability" is like in the Global South, Kim, "'Heaven for Disabled People': Nationalism and International Human Rights," 101-102.

[151] Spurr, *The Rhetoric of Empire*, 80.

[152] Nepveux and Beitiks, "Producing African Disability through Documentary Film," 243.

[153] Emily Smith Beitiks, "The Ghosts of Institutionalization and Pennhurst's Haunted Asylum," *Hastings Center Report*, 42:1, (January/February 2012), 22-24.

factors will influence one's social standing.[154] In order for the techno-makeover to seem significant and media-worthy, we must ignore all of this complexity and keep the story simple.

The second means of playing into the "rhetoric of empire" is through naturalization. Naturalization is achieved, Spurr argues, "…in both of these senses: while it identifies a colonized or primitive people as part of the natural world, it also presents this identification as entirely 'natural,' as a simple state of what is."[155] For example, the documentary on Yeboah opens with shot after shot of disabled beggar, and most of these people are likely disabled from polio, a disease which has long been eradicated in the United States but carries on in the Global South because of inadequate access to the vaccine. These stories neglect the fact that what is culturally understood as "normal" in a postcolonial context may very well be that which is disabled, as Clare Barker and Stuart Murray suggest, due to the injuries of colonial violence and the many illnesses borne from lasting poverty.[156] And the suffering and poverty that we see, especially among people with disabilities, is seen more in relation to the rural jungle than to the history of colonization or to global systems of power and inequality. The naturalization of the suffering combined with the viewers' ability to experience these stories from afar

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[154] This repetitive image of disability fails to incorporate a point raised by disability scholar Robert McRuer, who urges us to remember that a person with a disability in a metropole within the Global South might have more in common with someone with a disability in another nation's metropolitan area than with disabled rural villagers within the same country.
Robert McRuer, "Disability Nationalism in Crip Times," Special Issue on *Ablenationalism and the Geopolitics of Disability*, eds. Sharon L. Snyder and David T. Mitchell, *Journal of Literary and Cultural Disability Studies* 4:2 (2010): 163-178.

[155] Spurr, *The Rhetoric of Empire*, 157.

[156] Clare Barker and Stuart Murray, "Disabling Postcolonialism: Global Disability Cultures and Democratic Criticism," *Journal of Literary and Cultural Disability Studies*, 4:3 (2010), 229.

maintains the stability and direction of the gaze from North to South.[157] In desperate and urgent need, the stage is set for the United States to come to the rescue.

The rescue mission begins with the introduction of prostheses to Zapot, Tacle, and Yeboah by their white American donors. The narratives all suggest that the American donors are the ones to first bring up surgery and prostheses. Although perhaps it is true that this possibility had not occurred to Yeboah, Tacle, or Zapot's mother, stressing this information seems extremely relevant to the success of the narrative. If they were actively pursuing prostheses, the story would not have the same rhetorical power. Because they receive the techno-makeover without begging for it, it helps maintain an image of Zapot, Tacle, and Yeboah as of the deserving poor, and the viewer need not fear that the donor's heartstrings have been exploited to pull out their wallet. In addition, if Zapot, Tacle, or Yeboah were asking for such high-tech devices, it would contradict the image that seems so crucial to the success of the narrative: a "before" to the techno-makeover where the disabled figure lives a primitive life, aloof to the technological advances of modernity.

As the narratives progress and the viewer learns that Zapot, Tacle, and Yeboah will receive surgery and prostheses, the final step to creating the "before" entails intimate details of the "before" body. During these moments, the gaze most clearly replicates that of the turn of the century freak show. The physical anomalies are described and quantified, "one in a million," so the viewer understands just how spectacular this really is.[158] Because the video camera makes the visual more central with close-up shots on their legs, Tacle and Yeboah's bodies are displayed in a particularly invasive way. The

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[157] Spurr, *The Rhetoric of Empire*, 25.
[158] Cabrera, "Boy with Deformed Leg Given Hope by Shriners," 1.

most intimate shots come from within the doctor's office. The medical professional investigates the body to explore all aspects of the physical anomaly, and the viewer gets to watch as this happens, participating in this medical gaze. The medical field has a history of not only allowing media spectacles to arise around cases like this, but also actively participating. Alice Dreger provides a historic example of this, stating:

> It was safe and acceptable for the public to read that Millie and Christina [famous conjoined twins] had "separate bladders, but one common vagina, one uterus to be recognized, and one perfect anus," so long as this information came from a medical professional…. Medical discourse was deliberately used to ward off charges of pornography, even while it was used to titillate.[159]

Though the freak show has declined, the spectacle of freakdom has simply moved locations, giving medicine the authority to publicly display anatomically interesting bodies.[160]

These moments show the discourse of surveillance at work. As Spurr writes, "In classic colonial discourse, the body of the primitive becomes as much the object of examination, commentary, and valorization as the landscape of the primitive…. The body…is the essential defining characteristic of primitive peoples."[161] Spurr reminds us that while the physical anomaly is part of the viewer's gaze, we cannot separate it from the colonial gaze and its history.

And in order for medicine to successfully help the viewer distance themselves from the freak show gawker, the narratives must set up the prostheses as an answer to suffering, not the cosmetic nor normalcy. To have a good prosthetic should be a human

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[159] Alice Domurat Dreger, *One of Us*, 121, 123.

[160] Sumi Colligan, "Why the Intersexed Shouldn't Be Fixed: Insights from Queer Theory and Disability Studies," in *Gendering Disability*, eds. Bonnie G. Smith and Beth Hutchison (New Brunswick, New Jersey: Rutgers University Press, 2004), 47.

[161] Spurr, *The Rhetoric of Empire*, 22.

right, of great importance to many amputees that is not always about normalcy. But neither Zapot, Tacle, nor Yeboah is at risk of dying without the surgery or prostheses they receive, successfully functioning before the techno-makeover despite a physically anomalous appearance. But to make the techno-makeover rhetoric work, surgery is treated as medical necessity and the stories neglect or downplay what their bodies can already do, prior to intervention from United States benefactors. Zapot is still an infant, so we do not know if he might have found a way to walk, but Yeboah and Tacle are both fully developed adults, who were not just scraping by but rather achieving great things before prosthesis. Yes, Tacle got around by wearing flip flops on her knees and Yeboah with the use of a crutch (or bicycle), certainly non-normative ways of moving, but they were highly mobile and active nonetheless.[162]

Tacle explains, "Since I was a baby, I'm still practicing how to walk with my knees," something we see her demonstrating with what appears to be relative ease, but this ability is immediately erased as the newscaster states, "They brought Flory to Minnesota to give her [dramatic pause] the gift of walking."[163] Constructing a successful "before" image, one in which the U.S. gift is seen as unquestionably good, requires the assumption that the operations and prostheses for Zapot, Tacle, and Yeboah are, in fact, a "basic need" and essential. Therefore, it is unlikely that this narrative will ever include a more disability-conscious moment where they ask, "Is a prosthesis what you want? Is it what is best for you?" A prosthesis may very well be a life-changing device for Zapot, Tacle, and Yeboah – I do not want to underwrite the importance of prosthetic devices –

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[162] This trip did rely, of course, on the gift of American technology in the form of a bicycle. Interestingly, the Challenged Athletes Fund paid to ship a bicycle all the way from the United States to Ghana, rather than give him the money to purchase one available in Ghana.

[163] Nelson Garcia, "Minnesota Nice, Twice for Young Lady with New Legs," WCCO, 2005.

but it is not a matter of life or death, framed as such to hide the efforts to normalize the body inherent in these stories. And when they return to their home countries, where the climate is much hotter and air conditioning rare, a prosthesis may not be ideal.[164]

In an intersection of primitiveness and physical anomaly, the "before" relies upon standard development and normalizing discourse to suggest that Zapot, Tacle, and Yeboah's lives are in immediate need of American help. The stories set up the "before" to justify the techno-makeover and give us a clear image of the "progress" that has been made. Both disability and life in the Global South have been homogenized, as they overlap and are called upon to exemplify suffering. As the techno-makeover removes the suffering for these individuals, we are meant to believe the technological fix did the trick; the discrimination and poverty they experienced before-prosthesis will all just fade away.

During Prosthesis: Building the Consumer Body:

Because obtaining a prosthesis requires a good deal of time in limbo, spent recovering from the amputation surgery as well as extensive physical therapy sessions to learn a new way of walking, I call this section "during prosthesis." When the narratives document this period for Zapot, Tacle, and Yeboah, the transition to a new, high-tech body corresponds with an orientation and induction into capitalism, a transition made possible through the techno-makeover and the donors who financially support it.

People with disabilities have long been seen as legitimately "needy," and

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[164] I have written elsewhere about Canadian techno-makeover recipients, the once-conjoined Htut twins, who did not end up using their prostheses and preferred a crutch instead when they returned to Burma. Wong, Jan. "Twin Peaks." *Saturday's Globe and Mail*. June, 25, 2005.
Emily Laurel Smith, "The New Poster Children: Transnationalism and the Disabled Body," Paper presented at the Society for Disability Studies Annual Meeting, May 31 to June 2, 2007, Seattle, WA.

therefore as a *respectable* cause of charity – objects in, rather than participants of, capitalism.[165] While Zapot, Tacle, and Yeboah begin as charitable objects, the techno-makeover helps them transition into consumers and "productive citizens," as Yeboah himself puts it. And this shift is most noticeable as the stories cover the "during prosthesis" component of their journeys.

All three reports of Tacle's journey incorporate a moment where Tacle, post-surgery but pre-prostheses, goes to a mall to purchase her first pair of shoes. On the local news broadcast, the reporter explains, "She had never been to a mall before and never had to shop for something most teenagers love [shoes]." As the footage captures Tacle entering the mall, she reacts, "This is a big mall!" Reminiscent of Eliza Dolittle in *My Fair Lady*, Tacle is introduced to a new world and a new lifestyle, forever changed. Though of course there are big malls in the Philippines, it is important that this scene suggests Tacle is being introduced to such extravagant consumerism for the first time. During Tacle's *CNN* appearance, the anchor asks Tacle to describe her second experience of shopping, this time donning her new prostheses. Flory shares, "It was so nice that I was able to walk at the mall and go shopping and with my new leg prosthetics. Am so, so, so excited about that," to which the reporter replies, "I'm sure you are Flory. It's an incredible story." Tacle's upward climb from primitiveness is complete, now that she embraces the shopping mall.

Even for toddler Juan Zapot, it is not too early to start participating in US consumerism. The narrative explains, "Only hours after surgery, he was sitting up in bed,

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[165] Henri-Jacques Stiker, *A History of Disability: Discourses of Corporealities* (Ann Arbor: University of Michigan, 2000), 76-77.
Stone, *The Disabled State*.

playing with his new stuffed animals." Meanwhile, "[Zapot's mother] has received much-needed items, including a stroller and diapers, and she and Juan have become accustomed to luxuries such as television and air conditioning."[166] Like Tacle, charity introduces Zapot to the pleasure of material goods, but their rehabilitated bodies will soon allow them to participate as active consumers, another component to achieving normalcy.

Yeboah moves the most quickly from the "during" to the "after" stage, and from charity recipient to active consumer. From the start of *Emmanuel's Gift*, Yeboah stands in contrast to the disabled beggars in Accra, even as he too relies heavily on charity. CAF founder Bob Babbitt celebrates this distinction, "Why is he not asking for food or a job or personal help with something…. he asked for a bicycle…. It showed me that he wasn't thinking today…he's thinking big picture."[167] While of course the bicycle does in fact fall under "personal help with something," the narrative emphasizes that Yeboah asks for capital with a vision to turn it into more capital. Yeboah's most clear consumer-initiation moment comes soon after he has received a prosthesis and is given the Nike Casey Martin award, where he comes out to accept his award in head-to-toe Nike gear, rather than a suit or Ghanaian chief clothing, worn for special occasions. He is no longer a poor, rural African, and is now a Nike icon, marking his induction into the capitalist system.

The techno-makeover opens up the possibility of wealth and consumerism, and heightened physical mobility parallels upward mobility as well. As Zapot, Tacle, and Yeboah are introduced to a mentality of consumption and material abundance, it helps

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[166] Cabrera, "Boy with Deformed Leg Given Hope by Shriners," 1.
Cabrera, "Able to Walk, Mexican Boy with Leg Defect to Go Home," 4.
[167] Lax and Stern, *Emmanuel's Gift,* 2005.

prepare them for the prosthesis that will soon be attached to their body, a high tech device that offers far more than "basic needs."[168] The viewer is meant to feel excited about Zapot, Tacle, and Yeboah's experiences of affluence, rather than question how it might have ostracizing effects when they return to their home countries, especially after the charity stops.

The indoctrination into American consumerism promotes a vision of people with disabilities escaping their historic dependence on the system, as well as "developing" countries escaping their dependence on the United States. It is also about becoming part of the system; disabled beggars can become workers and these "developing" nations can become trade "partners" with the United States. Yeboah wears a Nike sweat suit, and this is meant to signify an exciting step forward for both Yeboah and Ghana, rather than remind us that the conditions within Nike's sweat shop factories are more likely to produce disabilities in the Global South than to help the world's disabled population.

In the end, the viewer is directed to feel good about Zapot, Tacle, and Yeboah's future. However, to offer a clear and bright vision of what lies ahead, the stories must leave out the many ways in which poverty and discrimination will continue to haunt these subjects, as well as the many others who have not received such international attention and generosity. Even with prostheses, Zapot, Tacle, and Yeboah will still be seen as disabled by many, and the structures of poverty in which Zapot, Tacle, and Yeboah lived pre-prosthesis have not been dramatically altered, so this newfound life of luxuries may

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[168] As prosthetics historian Katherine Ott explains, "Under capitalism, prosthesis wearers are the ultimate entrepreneurs, forced to adapt to ever changing economies both within their own bodies and in external bureaucracies of representation, assistance, and ideology."
Katherine Ott, "Sum of its Parts" in *Artificial Parts, Practical Lives: Modern Histories of Prosthetics*, eds. Katherine Ott, David Serlin, and Stephen Mihm (New York: NYU Press, 2002), 7.

very well be temporary.

After Prosthesis: Establishing Normalcy, American Virtue, and New Partnernships:

Once the wounds of surgery have healed and the prosthetic limbs are in place, the narrative shifts; the physical anomaly has been normalized and the discourse proclaims how significant and praise-worthy this transition is. Because the "after" of the techno-makeover provides such a happy ending, the viewer need not feel icky or self-critical about gazing at these deformed bodies; technology has now intervened and allowed them to walk (read: walk in a normal way) for the first time. The feel-good "after" to the techno-makeover is the grift that accompanies the gift, as Kapoor puts it. "On the one hand, the discourse of aid is constructed as non-reciprocated gift;" he writes, "but on the other, the discursive practice of aid is also closely tied to conditionalities, be they economic (tied aid), ideological (neoliberalism), or political (foreign policy objectives)."[169]

The most apparent result of the "after" phase is the visible normalization of the body, rather than the alleviation of physical suffering. While still disabled, the body is now impaired in a way that is less shocking to the American viewer, walking upright like an able body should. Technology is a cure-all, reducing the experiences of the disabled subject to problems of physical impairment, rather than problems with social and cultural roots. As the stories declare, Zapot, Tacle, and Yeboah now have a "new life" ahead of them.

The follow up story of Juan Zapot, after prosthesis, includes a picture of him

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[169] Kapoor, *The Postcolonial Politics of Development*, 78.

standing. Even though his second leg has a brace to try and correct the limb without surgery, he stands in such a way that hides the brace so that all the viewer sees is a completely "normal" child. The text drives this point home, "A toddler who arrived here unable to stand or walk will return home to Mexico today with a new future before him," adding that this is especially exciting as it is Mother's day, and his grandmother in Mexico will be given the gift of her grandson now walking.[170]

In one of the news broadcasts featuring Tacle's story, it shows her walking around one of Minnesota's many lakes while the voiceover claims:

> To a casual observer Flory Tacle is just a young lady out for a stroll through an Edina neighborhood. Look a little closer and know that you are witnessing someone on a journey…. Just look at her go. With each step, Flory is improving her life, experiencing things she never thought possible…. And she's just learning where her new legs and life can take her.[171]

Tacle herself joins the celebration, saying that she now feels "whole": "I am so excited that I can be a normal person like other persons." Two of Tacle's feature stories end with the same image; she stands in front of her Edina benefactor's home, wearing her first evening gown, completely hiding any signs of her impairment – normalcy achieved.

Emmanuel's Gift opens with an image of Yeboah "after" the makeover, as Yeboah's voice over explains, "Putting on a suit now, I never thought it could happen. I never thought of putting on a tie and being a gentleman…. I was like a new person. I was changed forever."[172] During the *Nightline* special on Yeboah, one of the directors of *Emmanuel's Gift* names one of her favorite scenes in the film as Yeboah's return to his family for the first time, "He's walking, walking with two shoes, wearing prosthesis with

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[170] Cabrera, "Able to Walk, Mexican Boy with Leg Defect to Go Home," 4.
[171] Garcia, "Minnesota Nice, Twice for Young Lady with New Legs."
[172] Lax and Stern, *Emmanuel's Gift.*

long pants."[173] The press photographs for the film celebrate this transition as well. Even as they flaunt rather than hide Yeboah's prosthesis, he stands strong, holding his bicycle in front of a dead tree on an African horizon, the contrast between his high-tech body and the tree behind him is apparent, celebrating the new body his U.S. makeover made possible.

The "after" that follows the techno-makeover is about more than physical normalcy when the final shots of Tacle and Yeboah bring gender into the story. For example, the final image of Tacle in her floor length, strapless evening gown, "Flory's first dress," stands in stark contrast to the gender neutral clothes we see her in up until that point. In addition, the attention to the outing of taking Tacle shopping also marks her indoctrination into the gender-appropriate pastime of shopping at the mall. Her prostheses open up a gendered performance that was previously closed to her.

Like Tacle, Yeboah's transition into a formal suit, complete with images of his muscular physique while he changes clothing, shows his transition into a more traditional masculine body. He even states that he never thought he would look "like a gentleman," as he now does. It is also significant that this powerful moment comes from him putting on a suit, rather than the fully embroidered outfit he wears briefly in the film, which is worn by "big men" for special occasions in Ghana. The suit conveys his gender to an American viewer, whereas the more feminine Ghanaian clothing would not have as strong of an impact.

The closing image of *Emmanuel's Gift* shows that he has gotten married to an able-bodied Ghanaian woman and together, "Emmanuel and Elizabeth Yeboah had a

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[173] *Nightline*, Episode No. 1047, First Aired on 20 October 2005.

healthy baby girl…named Linda, after Loma Linda University Medical Center." It is not only that he has married and had a child that make this ending the perfect completion to Yeboah's journey, but also the fact that the child is "healthy."[174] His techno-makeover has allowed him to participate in traditional masculine, heterosexual behavior, and his non-disabled child ensures that his normal life continues without difficulty.

Toddler Juan Zapot's story shows a post-techno-makeover transition to appropriate gender norms through his mother Cindy. In the "before" representation of this story, we learn that part of the suffering to be cured belongs to Cindy, who has been kicked out of her home for getting pregnant without being married. Yet, in the "after," without any explanation of what has changed, Cindy explains that she is eager to return to Mexico because she misses her family and cannot wait to show her mother that her son is now walking. Whereas Yeboah's makeover allows him to become more independent and rise up as a breadwinner for his new family, Juan Zapot's makeover allows Cindy an escape from her masculine role as sole caregiver for Juan and will perhaps help her recover the respectability that she lost.

With the techno-makeover complete, Zapot, Tacle, and Yeboah return home and become the harbingers of American technological progress. The story concludes with the return of normalcy to the homeland and a spectacularized display of the techno-body to the technologically "atavistic" of the Global South. Similar to the coverage of Yeboah and Tacle's trip back to their homelands, Zapot returns on Mother's Day to demonstrate his transformation to his grandmother as well as those friends and family members who

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[174] Nepveux and Beitiks, "Producing African Disability through Documentary Film."

we are told were never "really expecting Juan would ever walk."[175] As the families react with excitement and shock at the prostheses, the scenes suggest to the American viewer that helping these individuals access the techno-makeover will pave the way for technological progress in the Global South. We are meant to think about Zapot, Tacle, and Yeboah's poverty as tied to their physical anomalies alone. Spurr describes that this is commonly part of the formula for development discourse. He writes:

> This generic *Geographic* story nods briefly at social problems – illiteracy, family, revolution, what have you – but invariably concludes on an upbeat note about progress and modernization. The overall effect is to homogenize the Western experience of the Third World, to neutralize the disturbing aspects of social reality, and to minimize the importance of relations of power in creating the conditions under which people live.[176]

As the viewer is urged to feel relieved knowing that little Juan Zapot, for example, will now lead a normal life, they should not think deeper; to do so might expose that a normal life for Zapot might mean serving wealthy American tourists vacationing in his hometown, just outside of Cancún, Mexico. The techno-makeover undoubtedly changes the lives of Zapot, Tacle, and Yeboah, but there are many things that it will not impact.

Visually surprising physical anomalies are likely to make these stories "newsworthy," but by their conclusion, the physical anomalies of the body are erased or hidden, and correspondingly, "the native" has been transformed. Disability historian Henri-Jacques Stiker suggests, "In a liberal, prosperous and technologically advanced society, means can be found so that the disabled no longer appear different. They will be admitted on the condition that they are perfectly assimilated to the able-bodied."[177] Normalcy is inclusive of people with disabilities if, post-rehabilitation, the disability can

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[175] Cabrera, "Able to Walk, Mexican Boy with Leg Defect to Go Home."
[176] Spurr, *The Rhetoric of Empire,* 51.
[177] Stiker, *A History of Disability,* 132.

be kept to a minimized characteristic of one's appearance and identity, no longer a responsibility of the state, thanks to private benefactors.[178] And just as rehabilitation of disabled bodies must end with mitigated inclusion, so too must the rehabilitation of the colonized; as Spurr suggests, "…the ultimate aim of colonial discourse is not to establish a radical opposition between colonizer and colonized. It seeks to dominate by inclusion and domestication rather than by a confrontation which recognizes the independent identity of the Other."[179] The techno-makeover relies upon the physically anomalous and "primitive" as the input, such that the output is Zapot, Tacle, and Yeboah as icons of progress.

The techno-makeover narrative offers up these stories in tidy packages, in which post-makeover, normalcy has been fully provided. But sustaining this appearance of normalcy will require the benefactors' ongoing commitment to the maintenance of the prostheses, not mentioned in the coverage of Zapot's, Tacle's, nor Yeboah's story. Though the narratives suggest that no further charity will be needed, for Zapot, Tacle, and Yeboah can now provide for themselves, this assumption neglects the struggles with poverty they may continue to face regardless of their "normal" appearance. The techno-makeover story is less wrapped up than it claims to be, leaving Zapot, Tacle, and Yeboah somewhere in between their home countries and the United States, and also in between normalcy and disabled.

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[178] Stiker, *A History of Disability,* 152.

[179] Spurr, *The Rhetoric of Empire,* 32.

In fact, decolonization discourse also participates in the erasing of physical difference, as Pushpa Parekh states, "Decolonization, imagined as curing and healing, has a disturbing relationship with colonization in setting up an oppositional model, which ultimately imagines the progressive eradication of bodies that are marked by disability."

Pushpa Parekh, ed. "Editorial," *Wagadu*, 4 (Summer 2007): 8.

This Techno-Makeover is Brought to You by… :

While these projects are initiated by individuals or non-profit organizations, the narrative retellings of the techno-makeover promote American nationalism. Because the techno-makeover relies upon the journey into the United States, these stories simultaneously promote an image of American generosity, extending from its own borders abroad, as well as American superiority, in which our disabled population has been cared for, free of discrimination. While Stiker argues that we must look at how a given society situates disability to understand that society, we might also look at a given society's *representation* of how it situates disability to better understand that society, and these case studies offer that lens.[180]

People with disabilities have long been defined as that which is "non-American," for dependent bodies threaten American values. To repeat Longmore and Umanksy's adroit observation discussed in Chapter 1, "Americans often perceive disability – and therefore people with disabilities – as embodying that which Americans fear most: loss of independence, of autonomy, of control; in other words, subjection to fate."[181] However, the stories of Zapot, Tacle, and Yeboah open up "American" to a disabled body, even though not actually changing their legal citizenship, to demonstrate the way that rehabilitation has provided new access to normalcy for people with disabilities who can become "able-disabled." They stand, quite literally, as symbols of American pride and progress.

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[180] Stiker, *A History of Disability*, 14.
[181] Longmore and Umansky, eds., *The New Disability History: American Perspectives*, 7.
Snyder and Mitchell, *Cultural Locations of Disability*, 23.
Baynton, "Defectives in the Land."
Baynton, "Disability and the Justificiation of Inequality in American History."

For example, one article on Juan Zapot's journey from Mexico to the United States reports, "His mother…said her stay has been wonderful…. 'I love it here…. It's so peaceful and relaxed, and everyone has been so kind. There is so much opportunity here for Juan that he doesn't have in my country. I can work hard here and give my son a good education and good life."[182] While one might read this as Cindy Zapot's plea to remain in the United States, the context of the article puts this forward as a celebration of American generosity and superiority over Mexico; in Mexico, she was encouraged to kill her son and told that nothing could be done, but in the United States, her son's disability facilitated charity and new opportunities.

In *Emmanuel's Gift*, the American nationalism attached to Yeboah post-makeover is similarly blatant. In one scene, the viewer sees Yeboah staring out at the Statue of Liberty. Later, he makes a speech to a Ghanaian village about how the United States is free of the disabled beggars that Ghana's capital, Accra, has on the city streets. But the most telling moment comes as Yeboah receives his prosthesis with a fiberglass thigh covered in a pattern of American flags – a shockingly transparent reminder of what this prosthesis is meant to signify to the viewer and Yeboah, even though in later scenes, one might spot that he has added a Ghanaian flag sticker to his limb as well.[183]

After being introduced to American consumerism and normalized through the techno-makeover process, the disabled figure is now symbolically welcomed into nationalism while bolstering what disability scholars Sharon Snyder and David Mitchell coin "able-nationalism," noting how citizenship relies on the ideology of able-

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[182] Cabrera, "Able to Walk, Mexican Boy with Leg Defect to Go Home," 4.

[183] While Yeboah told me that he asked for this design to remind him of the great country that gave him this gift, the film does not explain his agency in it.

bodiedness.[184] Even though Zapot, Tacle and Yeboah are still disabled post-makeover, the celebration of their high-tech movement toward normalcy puts forth the rhetoric of able-nationalism. As Snyder and Mitchell suggest, "…recent able-nationalisms – those open rhetorical claims of a new era of inclusion for people with disabilities issued by the state – have situated some mutant bodies as effectively and normatively disabled. Disabled people now perform their representational work as a symbol of expansive neo-liberal inclusion efforts."[185] As Zapot, Tacle, and Yeboah are situated as symbols of American pride, the barriers of exclusion – against people with disabilities and people from the Global South – are erased while the imagined walls of the American nation-state are in fact strengthened through the techno-makeover's ability to distinguish the United States from those less advanced and less charitable countries elsewhere. As Kapoor says, "Nationalist discourse (in the West) and aid/development discourse are bosom buddies."[186]

But for this nationalist discourse to succeed, it rests upon the assumption that the United States is a better place to be disabled and that technology is part of what makes this so. The spectacle of giving the techno-makeover to the needy of the Global South propels a myth that within the United States, Americans with disabilities have ample access to the technology that will assist their everyday lives, which ignores the many inadequacies of the American privatized healthcare system and the hirer distribution of people with disabilities living in poverty.[187] Beggars with disabilities, the stories suggest,

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[184] Sharon L. Snyder and David T. Mitchell, eds, "Introduction: Ablenationalism and the Geopolitics of Disability" *Journal of Literary and Cultural Disability Studies* 4:2, (2010), 113-125.

[185] Snyder and Mitchell, "Introduction: Ablenationalism and the Geopolitics of Disability," 116.

[186] Kapoor, *The Postcolonial Politics of Development,* 86.

[187] For a useful investigation into what experiences of poverty and disability look like, see: Golfus, Billy,

only exist in the Global South and not in the United States. The techno-makeover for Zapot, Tacle and Yeboah promotes the assumption that if Americans are helping the disabled populations abroad, then people with disabilities have already obtained equality here, which is grossly inaccurate.

Given American generosity, the narratives conclude by celebrating newly formed global connections and partnerships, though of course these ties rest upon deeply asymmetrical power relations. The discourse signals a growing sense of community in globalization, based on friendships that span across nation-state boundaries, even as the techno-makeover simultaneously plays up the divisions between nations. Zapot's techno-makeover relies upon a "chance meeting," connecting Mexico and the U.S., just as Tacle's story hinges on a friendship "from a world away," linking the Philippines and the United States. Yeboah's story introduces several transnational friendships that blossom, but quadriplegic athlete Jim MacLaren forms a bond with Yeboah that receives prominent attention. MacLaren explains, "Both Emmanuel and I, even though to the world we look different, we speak differently, it is not a stretch to say that this man [pause] he's my brother." Zapot, Tacle, and Yeboah are the ones that travel to and from the United States, but the articles suggest that they build bridges and friendships that make the world a smaller place. The aim of colonial discourse, according to Spurr, has been accomplished, as the colonized have been subsumed into "the peoples of the world in the name of a common humanity."[188] These "transnational partnerships," as I have called them in previous work with Denise Nepveux, mask the underlying asymmetry that

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Dir. *When Billy Broke His Head…And Other Tales of Wonder*. Independent Television Series, 1995.

[188] Spurr, *The Rhetoric of Empire*, 32.

exists.[189] Zapot, Tacle and Yeboah rely on their alliances with their American benefactors to help acquire a visa, whereas the American counterparts can visit Mexico, the Philippines, and Ghana without restrictions. The point here is not to deny the depth or significance of these friendships, but rather to suggest their role in the wider story of American nationalism, erasing the power differentials underlying these narratives.

Once Yeboah, post-makeover, returns to Ghana, his father, who had abandoned his family at Yeboah's birth, returns to seek forgiveness. Yeboah explains that even though what his father did was wrong, he has chosen to forgive him because his message is about "bringing people together." It is hard not to feel that this carries wider significance; Yeboah is willing to forgive and forget, just as this wider trope suggests that people can be brought together without concerns of the history of Northern abuses of the Global South.

In a post-Cold War world, disability and the techno-makeover promotes American superiority at a time when there is less of a clear enemy to hold the U.S. above. Techno-makeovers for people with disabilities in the Global South allow for a return of paternalistic aid, while appearing as novel projects because innovations in disability technology make the techno-makeover possible. Because people with disabilities have historically been cast outside of society, the idea of providing aid makes for the perfect non-political project, while of course remaining deeply political underneath the narrative's surface.

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[189] Nepveux and Beitiks, "Producing African Disability through Documentary Film."

Conclusion:

As once-conjoined twins Sarah and Sarahi Morales were medically separated in a San Diego hospital with all expenses covered, a newspaper article described the bond that this story creates between Tijuana (the Morales twins' home) and San Diego.[190] A Sudanese boy with club feet receives medical treatment from an American team in Kenya, and the *Washington Times* article offering this story suggests, "America has had an uneasy time in the halls of public opinion overseas. Based on media reports, it would seem that America's work in the world goes unappreciated…. What needs to be better reported, both here at home and abroad, is the work of private American citizens who heal and empower the lives of the sick and the poor in the developing countries of the world."[191] While I singled out the media portrayals of Zapot, Tacle, and Yeboah, their stories are not uncommon, examples of a genre of techno-makeovers for the Global South.

The generosity of private citizens is noteworthy. However, when these stories get retold and packaged into a media narrative, the discourse goes too far, and these stories turn into something bigger: normalcy for the body signals normalcy for the nation, all thanks to technological progress. Why must these stories be so simplistic and nationalistic? Why must the techno-makeover come with so many requirements in order to make for a good "before" and "after" story? And how do these stories come to be seen as "heart-warming" when they are so inextricably linked to a problematic history of power inequalities and an interest that is inseparable from a freak show-like gaze?

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[190] Matthew Fordahl, "Siamese Twin Surgery Unites Cities San Diego, Tijuana Mend Ties," *Associated Press*, Jan 30, 1996, N.4.

[191] Robert H. Schuller and C. Scott Harrison, "America's Unsung Citizen Healers ; Goodwill Missions around the World Help the Helpless," *Washington Times*, November 23, 2004, A.17.

The addition of disability to a traditional narrative of poverty in the Global South allows these stories to bring back an old trope of U.S. development coming to the rescue, otherwise outdated. Disability strengthens the story, such that the viewer is likely to walk away, feeling a little better about what technology is capable of, as well as a lot better about the United States and our ability to do good. And because there are so many good feelings to go around, the significance of the gaze goes unexamined.

Just as in popular culture, these stories are made to be heart-warming, but we should rethink the underlying values that are being celebrated. Technological progress should not be synonymous with globalized social progress, but this gets lost here; this false premise is the cost of the techno-makeover.

Chapter 3:

Bringing Disability Back from the Future: Michael J. Fox and the Debate over Embryonic Stem Cell Research

Looking back on the career of Michael J. Fox, it is eerie that he should become the center of a national debate surrounding stem cell research, cloning, and medical progress. He helped us imagine the future of technology in the *Back to the Future* series, but also played a young republican in *Family Ties,* a doctor in *Doc Hollywood,* and a political master of spin in both *American President* and *Spin City*. Oddly, Michael J. Fox acted out many of the personas around which his current life as a stem cell activist has revolved. In 1989, years before he would be accused of advocating for human cloning, he even filmed a Diet Pepsi ad in which he appeared as a scientist, creating a clone of himself – only to have his clone steal his girlfriend and his soft drink. While the ties between Fox's past and present are mere happenstance, the convergences illustrate the many years that Michael J. Fox has lived in the public eye. In 1998, his image became more political and controversial once he publicly disclosed that he had been living with Parkinson's disease, coincidentally, the same year in which stem cell science officially arrived on the scene.

Fox has participated in politics in many ways since 1998, but it was not until 2006, however, that he gained momentous national attention for his role in the midterm elections. Fox endorsed several candidates backing embryonic stem cell research: Democrat Claire McCaskill in the senate race for Missouri (airing during the World Series), Democrat Ben Cardin in the senate race for Maryland, and Democrat Jim Doyle running for governor of Wisconsin. In these three tight races, he spoke on behalf of each candidate in television campaign ads airing the week of October 20, a crucial moment two and a half weeks before the election. As Fox spoke, his body shook and spasmed, signs of dyskinesia, a side effect of his Parkinson's medication L-Dopa. The ads also went viral after they were posted on YouTube. In the weeks that followed leading up to the November 7th election, the media became deeply focused on Michael J. Fox, and while some of the conversation certainly addressed stem cell research, it was preoccupied with the imagery of Fox so visibly showing the signs of Parkinson's disease.

The series of campaign ads became even more significant on October 23, when Rush Limbaugh suggested that Fox was faking the tremors to gain pity votes. As he made these claims, Limbaugh visibly acted out and mocked Fox's tremors. Even after Limbaugh learned that Fox commonly shakes, he suggested that Fox was being exploited, "shilling" for the Democrats' agenda.[192] In the days leading up to a significant election, why was the news and television media so fixated on Michael J. Fox and Rush Limbaugh when neither was actually running for office? And what brought so many people to seek out Fox's campaign ad on YouTube, gaining it over 1 million hits in the first five days it was posted, when many of the viewers were most likely outside of the states he was campaigning for?[193] That this campaign ad and Limbaugh's subsequent remarks became a "water cooler topic" is undeniable, but I work here to show how we might understand these memes, outside the limited terms through which the media and the political sphere structured the debate.[194]

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[192] Rush Limbaugh, "Stop the Tape," *The Rush Limbaugh Show*, October 23, 2006.

[193] Jake Coyle, "Tremor-Filled Michael J. Fox Appears in TV Ads," *Associated Press*, October 25, 2006, A.6.

[194] As evidence of the video's cultural significance, an *Associated Press* news article, published in several newspapers, declared it one of the top five culture-altering videos of 2006.

In the last two chapters, I have explored and critiqued the celebration of what the techno-makeover can do for people with disabilities in the U.S. media. Now, I turn to this specific science policy debate in October 2006 as another sign of a cultural preference for people with disabilities being normalized and cured by technoscience. Only in this case, a techno-makeover was not yet possible – the whole debate was based on a futures market in which people had to anticipate its possibility. This case raises the question: what do we do with people with disabilities when technoscience cannot yet offer any fixes for the body? The iconography surrounding Fox, who stood in as proxy for millions of Americans like him, promoted the future hope for a techno-makeover, not yet materialized. The hype that followed suggested that if hESC research gains support and federal funding, then Michael J. Fox would no longer shake as he does, and once again, this priority should come before any social or cultural changes that could be made to help people with disabilities.

The Political Presence of Fox and Disability:

The world of politics provides a home for a person with a disability willing to provide the right narrative – an image of suffering that justifies the need for biomedical progress.[195] Michael J. Fox is not the first to take on this role. He credits Christopher Reeve as his mentor, the first public fighter for embryonic stem cell research. Reeves fell into this narrative as well, publicly announcing that problems of disability access were unimportant to him. Reeve's priority was to walk again. He explained, "We were not

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Jake Coyle, "From Lonelygirl15 to Richards' Racist Rant: The Best of YouTube in 2006," *Associated Press,* December 16, 2006.

[195] Mary Johnson, *Make Them Go Away: Clint Eastwood, Christopher Reeve and the Case Against Disability Rights* (Louisville, Kentucky: Advocado Press, 2003), 52.

meant to be living in wheelchairs. We were meant to be walking upright with all of our body systems fully functional, and I'd like to have that back."[196] The point of looking at Christopher Reeve and Michael J. Fox is not to critique them on a personal level for they have both faced far too much of this already. Rather, we should question why the narrative they provide circulates so centrally in the story of embryonic stem cell research, and in doing so, what does the narrative leave out? Surely Michael J. Fox's celebrity status is part of the answer, but it is also the content of his message and the aesthetic of his body that makes his narrative go viral and gather so much attention, once again showing a privileging of disability as awaiting techno-science cures.

What role did Michael J. Fox play in garnering support for embryonic stem cell research? While it's obvious that his shaking would gain attention on account of his celebrity status, why does it have such a dramatic impact on everyone who sees it, as noted throughout the media discourse following the ad? Finally, how does Fox's hypervisibility come to make other people with disabilities, as well as other controversies surrounding stem cell research, invisible?[197] A critical examination of this cultural moment and the discourse reacting to Fox's campaign ad has much to offer, for it brings to light how disability is constructed through public understandings of technoscience and conversely how public understandings of technoscience come into being through disability.

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[196] Johnson, *Make Them Go Away*, 128.

[197] I am not the first to write about the 2006 Limbaugh-Fox controversy nor the impact of media images of disability in stem cell debates, although current scholarship on the latter has mostly been focused outside of the United States.
Shelly Tremain, "Stemming the Tide of Normalisation: An Expanded Feminist Analysis of the Ethics and Social Impact of Embryonic Stem Cells," *Bioethical Inquiry*, 3 (2006): 33-42.
Gerard Goggin and Christopher Newell, "Uniting the Nation?: Disability, Stem Cells, and the Australian Media," *Disability and Society*, 19:1 (January 2004): 47-60.

In this chapter, I answer these questions to suggest that the advertisement of Fox shaking created a halting stop to the debate, framed so that there is no place for critiquing the complexities of stem cell research. If you wanted to criticize the campaign ads, you were on par with the Rush Limbaughs of the country and must be against medical/scientific progress. Finally, I argue that Fox's narrative serves the rising biomedical industrial complex, promoting the idea that private cures (rather than social welfare systems) are most important. Fox need not concern himself with this neoliberal thinking, for as a privileged person with a disability, he will be able to afford both cures and whatever social/medical services he needs if a cure does not become available.

In an interview with Katie Couric, Michael J. Fox said, "…what I hoped was … that people would say, 'Hey, I know that guy,' that we'd 14 days out from an election be talking about stem cells. And we are."[198] I place Fox as the unit of analysis for this chapter to explore the way that his disability was widely used – by the media and politicians – at the center of this public, science policy debate.[199] But again, it is not about Fox, but rather about the institutional and cultural forces that restrict Fox to this problematic box, at times even at odds with his own statements about living with a

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[198] Michael J. Fox, interview by Katie Couric, *CBS Evening News*. October 26, 2006.

[199] My methods include various sites. I analyze the political ads themselves, Fox's autobiographies, the Rush Limbaugh broadcasts, and Fox's speeches before the senate committee meeting. In addition, I conducted a ProQuest database search of Fox, resulting in 654 articles from 1999-2010, to trace Fox's emergence as a celebrity activist/patient, as well as documenting the media attention Fox received in 2006, following his campaign spot. To provide a more in-depth look at Fox's campaign ads and the controversy that followed, I searched the five newspapers with the highest circulation in 2006 and conducted a database search pulling out any article from October 20, 2006 (the day that Michael J. Fox's campaign ad first appeared on the web) and November 7, 2006 (the day of the election).[199] In addition, I also explore all the articles in Missouri's most circulated newspaper, the *St. Louis Post-Dispatch*, during the same dates, contrasting Missouri's discussion in the media around stem cells, focused on Amendment 2 as well as Fox, to that of the five highest-circulated newspapers. Finally, I provide content analysis of Michael J. Fox's television interviews during the same dates, as well as of national news broadcasts discussing the Fox-Limbaugh debate, from Keith Olbermann to Glenn Beck.

disability.[200] HESC is important and the cures that could come are not just about normalization, but rather about alleviating suffering for many people – my work here should not ignore this fact. But the narrative promotes something bigger, not just about physical suffering but also about physical difference.

The Science, the Controversy, and the Political Context:

To discuss the history, science and controversy around stem cell research with concision is undoubtedly a challenge, as every aspect of the debate is deeply contentious.[201] Because the study of hESC requires an embryo (a blastocyst, formed around the fifth day following conception), hESC research overlaps with two other scientific fields, in vitro fertilization (IVF) and human therapeutic cloning, or more specifically, somatic cell nuclear transfer (SCNT). One way in which scientists can

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[200] Goggin and Newell have laid out a pathway in which biotech discourse around disability happens in the Australian media, which directly parallels what we see here, even if it is more grounded on a specific person. They describe the steps:

> 1. The tragic life of an individual or several devalued individuals is portrayed in a way designed to elicit maximum effect.
> 2. A technology is portrayed as delivering a person from disability, provided that society legalizes, funds or embraces such a solution.
> 3. Securing the technology means that disability has then been 'dealt with'; after deploying such rhetoric there is to be no more appeal to emotion, and the solution lies in the rational pursuit of technology identified in step 2 (effectively there is only one, inexorable step);
> 4. Disability as a political issue goes away, until next time it is needed in the powerful politics of media representation.

While the cult of celebrity and the American context fleshes out this paradigm in interesting ways, the pathway (and limitations along the way) are very much so the same here.
Goggin and Newell, "Uniting the Nation?" 51.

[201] Human stem cells can be found in three places - in embryos, in cord blood (collected from the umbilical cord immediately after birth), or from a fully developed adult body (from the intestine wall, bone marrow, or skin, for example) - though the forms vary in the types of cells offered and the promise they show for treating diseases. I restrict the focus here to human embryonic stem cell (hESC) research, as the 2006 political climate generally understood cord blood and adult stem cells to be non-controversial because these cells circumvent the morally explosive issue of the embryo.

obtain blastocysts is from leftover embryos at IVF clinics.[202] In order to carry out IVF, several embryos are produced, and clinicians then determine which is the most viable, cryogenically freezing the others. A couple must decide whether they want the unused embryos to be stored (cryogenically frozen in case they should want more children), put up for "adoption" allowing a couple that cannot conceive to have it implanted (producing children known as "snowflake babies"), or have the embryos destroyed. If a couple chooses to have their embryos destroyed, they are offered the option of donating their eggs to hESC research.

While IVF clinics have provided many embryos for forwarding hESC research, clinics must rely upon several contingencies before obtaining access. For this reason, many have advocated for SCNT, a more controversial process, which generates an embryo by implanting the nucleus of a cell from the adult body into an emptied out egg cell, thus a "clone" with the same genetic material as the adult body cell, which scientists would then use to retrieve blastocysts and new stem cell lines. Scientists call this "therapeutic cloning" because the aim is regenerative medicine, separating this from "reproductive cloning," in which the cloned embryo would be inserted into a woman's womb to create a human clone.[203] Both forms of obtaining embryos, through IVF leftovers and through SCNT, are filled with controversy – the former for destroying embryos, the latter also for destroying embryos but in addition, for relying upon women who sell or donate their eggs to science, which can be a dangerous procedure with little research on long term effects (for pro-choice feminists who raised concerns about SCNT,

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[202] IVF is the practice of extracting a woman's egg and a man's sperm, and fertilizing it outside of the womb before implanting the embryo into a woman's womb.

[203] Dolly the sheep and several animals since were cloned through this procedure.

this was their concern, not the pro-life opposition to embryo destruction).[204]

Diseases or conditions that may be affected by hESC research include Parkinson's, Alzheimer's, juvenile and adult Diabetes, Multiple Sclerosis, and spinal cord injuries, but the list goes on.[205] While some argue that the science does not show as much promise as the hype suggests, others argue that these cures would be available already if government policy had not interfered with scientific progress.[206]

Before stem cell research even arrived on the scientific/political scene, much of the rules of the game were already set, namely that such research was allowed by law, but to be done without federal funding, like IVF, and framed as a private matter, similar to the legal guidelines that made abortion acceptable under Roe v. Wade.[207] Yet, despite this legal context already contemplating the embryo, stem cells caught everyone by surprise when they became scientifically significant in 1998, developing much quicker

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[204] Egg selling varies state by state. New York, where recently the SCNT process was proved viable, allows women to get paid for "donating" their eggs.

[205] "Patient's Voices: The Powerful Sound in the Stem Cell Debate," *Science*, 287 (February 25, 2000): 1423.

[206] While Daniel Perry predicts that the number of people living with conditions or diseases that could be cured or ameliorated by stem cell research reaches over 100 million, this number is highly contested, though current research shows that it is still too early to tell.
Thomas Shannon, "From the Micro to the Macro," in *The Human Embryonic Stem Cell Debate: Science, Ethics, and Public Policy*, eds. Suzanne Holland, Karen Lebacqz, and Laurie Zoloth, (Cambridge, MS: MIT Press, 2001), 181.

[207] Although stem cell research was not yet in play, the story begins in 1973 with the Supreme Court decision of Roe v. Wade, making abortion a private issue and prompting the subsequent decision by the Department of Health, Education, and Welfare to place a moratorium on living embryo research. The following year, Congress followed up this moratorium with their own, blocking any federal funding for embryo research. Then, in 1975, the National Commission for the Protection of Human Subjects of Biomedicial and Behavioral Research (National Commition) was created, which extended "human subjects protection" to the protection of aborted fetuses and embryos. In addition to abortion policy, stem cell research is also intimately tied to the history of IVF. Moving rapidly forward through IVF's development, in 1993, a previous moratorium on federal funding for IVF research was ended by Congress, although this was quickly turned around in 1996, when a more conservative new Congress banned federal funding for embryo research, a ban which continues today.
DC Wertz, "Embryo and Stem Cell Research in the United States: History and Politics," *Gene Therapy*, 9 (2002): 675.
John C. Fletcher, "The Stem Cell Debate in Historical Context" in *The Human Embryonic Stem Cell Debate,* 27-34.

than anticipated.[208] By the presidential election of 2004, stem cell research had become one of the hot issues, separating voters along similar lines to the abortion debate. When President George W. Bush was re-elected, he continued to oppose embryonic stem cell research on the religious grounds that the embryo must be protected. After the bipartisan efforts and the passage of the Stem Cell Enhancement Act (H.R. 810) by both the House of Representatives and the Senate (with public support from Michael J. Fox), President Bush used his first veto in office to stop the bill, July 20, 2006. As reporters filmed the ceremony of Bush signing the veto, Bush invited several Snow Flake babies, children born from "adopted" frozen embryos remaining at IVF clinics, to surround him in the Oval Office, stating, "These boys and girls are not spare parts. They remind us of what is lost when embryos are destroyed in the name of research. They remind us that we all begin our lives as a small collection of cells."[209] By this moment, hESC had already been

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[208] November 14, 1998, President Clinton endorsed somatic cell nuclear transfer (SCNT), though he put the National Bioethics Advisory Commision (NBAC - a subsequent form of the National Commission) in charge of weighing the pros and cons around stem cell research. In September 1999, the NBAC offered their report, encouraging Clinton to support federal funding for the frozen, unused embryos that are held in IVF clinics, assuming that couples provide voluntary consent and that they only be offered this possibility after they have already noted their desire to discard the embryos. This decision was reached as a compromise, in which the NBAC explained the importance of "respect" for the embryos, but also felt that because these embryos are already tagged for destruction, then the importance of possible life-saving cures that could result from stem cell research should take priority. In 2000, in conjunction with the NBAC report, the NIH determined that they could fund embryonic stem cell research as long as it pertains to cells already derived from embryos conducted by a private industry - they cannot do their own distraction. While President Clinton set relatively loose guidelines for hESC, endorsing SCNT and supporting federal funding, as long as it was on discarded embryos from IVF clinics, stem cell policy shifted with George W. Bush. After president George W. Bush took office in 2001, he created the President's Council on Bioethics, seen as a more conservative collection of bioethicists, whose report (2004) recommended a four-year moratorium on stem cell research. In August 2001 on a nationally televised broadcast, President George W. Bush expressed his support for federal funding for the extant 60 stem cell lines, though the number of viable lines was later determined to be much closer to 20. This decision was intended as a compromise, but still widely critiqued by stem cell supporters, who felt that this did not offer enough support to fully propel the science forward.
Wertz, "Embryo and stem cell Research in the United States," 675.
François Baylis, "Human Embryonic Stem Cell Research: Comments on the NBAC Report," in *The Human Embryonic Stem Cell Debate*, 51-60.

[209] Herbert Gottweis and Barbara Prainsack, "Emotion in Political Discourse: Contrasting Approaches to Stem Cell Governance in the USA, UK, Israel, Germany," *Regenerative Medicine* (November 2006): 823.

framed as religion vs. science, right vs. left, because at the core, embryos were involved.

The 2006 Mid-Term Elections:

Supporters of stem cell research turned to the mid-term elections as a sign of hope; if the democrats could gain a majority in Congress to overturn a presidential veto, then they could overturn the ban on federal funding for embryonic research.[210] It is at this moment that Michael J. Fox, Rush Limbaugh, and a media obsession with stem cell research arose. Parallel to the rising controversy of hESC from 1998 to this 2006 charged moment, Michael J. Fox had also been gaining momentum in his political activist career. After being diagnosed with young-onset Parkinson's disease, Fox continued to act for ten years, developing various tricks that allowed him to hide his symptoms on set. He began to transition into the role of a Parkinson's advocate, with his first public venture a speech for the Senate Appropriations Subcommittee on Labor, Health and Human Services hearing on Parkinson's, September 28, 1999. Motivated by the possibility that he could someday be cured, Fox created the Michael J. Fox Foundation for Parkinson's Research, which funds several studies and projects, one of which being hESC.[211] Given President George W. Bush's restrictions on stem cell research, Fox was driven to take a more active role in politics for the 2006 midterm elections. He decided to deem himself a

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"Bush Vetoes Embryonic Stem-Cell Bill," *CNN.com*, September 25, 2006, www.cnn.com/2006/POLITICS/07/19/stemcells.veto/index.html.

[210] In total, Michael J. Fox participated in 19 house and senate campaigns, as well as one gubernatorial campaign, but his efforts for Democrat Claire McCaskill against incumbent Jim Talent in the Senate race in Missouri received the most attention by far. Missouri was the only state simultaneously voting on a stem cell amendment, but the McCaskill election also gained particular significance because Missouri's seat would be key in Democratic efforts to receive a majority in Congress, and Missouri has typically functioned as the bellwether for the nation.

[211] Michael J. Fox, *Always Looking Up: Adventures of an Incurable Optimist*, (New York: Hyperion, 2009), 35.

"one-issue man," getting involved in any close races for a Democrat or Republican, where a candidate was running against an hESC opponent, although in 2006, this was only relevant for Democratic candidates.[212]

The campaign ads for McCaskill, Cardin, and Doyle were filmed in a hotel suite at the Waldorf Historia. Many people with Parkinson's take Levadopa (L-Dopa), which supplies dopamine to make up for the their brains' inability to produce it on its own. L-Dopa alleviates the body from Parkinson's symptoms, namely an inability to move, as well as a mask face, unable to express facial emotions. However, L-Dopa is not without its flaws, chiefly that you cannot know at any given moment how much dopamine the brain has already chipped in. Too much medication causes dyskinesia, characterized by "rocking, bobbing and weaving," the symptoms that Michael J. Fox demonstrates in the campaign spots.[213] In each of the three ads, Fox sits in a chair of a dark hotel room, the rest of the room is muted, and he directly addresses the viewer about why hESC research (and thus the political candidate who pledges their support) matters. Aside from Fox's appearance, the ads are very similar to his 2004 ads for Specter and Kerry, though the effect was dramatically bigger.

While the ads immediately generated a large amount of public interest, they gained more momentum after conservative radio show host Rush Limbaugh's rant and offensive performance. Though Limbaugh learned shortly after that Fox had been seen demonstrating similar symptoms in several interviews in recent years, Limbaugh's apology was vague and still critical:

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[212] Fox, *Always Looking Up,* 112-114.
[213] Fox, *Always Looking Up,* 80.

> All I'm saying is I've never seen him the way he appears in this commercial for Claire McCaskill. So I will bigly, hugely admit that I was wrong, and I will apologize to Michael J. Fox, if I am wrong in characterizing his behavior on this commercial as an act, especially since people are telling me they have seen him this way on other interviews and in other television appearances.[214]

Limbaugh continues to suggest that Fox was letting his illness be exploited for the Democrats' agenda. Between Fox's shaking and Limbaugh's imitation of Fox's shaking, a cultural moment had been made, and despite the presence of midterm elections, the media became obsessed with replaying the story of the Fox-Limbaugh feud.

And the plot thickened further when a handful of celebrities and well-known athletes filmed a response ad, countering Fox, which aired in Missouri in opposition to Amendment 2, the stem cell amendment. Because so many states had begun to restrict or even criminalize hESC policy, Amendment 2's strategy was to ensure that Missouri's laws would be the same as the federal laws, also making research cloning legal though outlawing reproductive cloning. The Amendment 2 opposition ad brought together a diverse mix, from *Everybody Loves Raymond* star Deborah Heaton to James Caviezel, Jesus in *The Passion of the Christ,* along with several well-known athletes, including Jeff Suppan, a baseball player for the Cardinals who was playing in the World Series game in which the ad aired. While the response ad did not generate the same amount of attention that Fox's ad did, it added to the already focused media attention on hESC. Pulled in by the presence of so many diverse celebrities, viewers of these ads had to ask themselves what exactly was underlying hESC research with their favorite celebrities providing answers.

While there were many complexities of the policy, science, and 2006 election that

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[214] Rush Limbaugh, "Democrats Exploit Michael J. Fox's Illness," *The Rush Limbaugh Show*, October 23, 2006.

stemmed from hESC, the story that surrounds the 2006 campaign ads is quite simplistic. It's about Fox's suffering and Limbaugh's audacity. Are you team Fox or team Limbaugh? To understand the debate of Fox versus Limbaugh neglects how Fox's image and Limbaugh's response were not isolated events; rather, they are both illustrative of a wider cultural understanding of disability in tragic terms.

Suffering for Stem Cells: The Embryo vs. Michael J. Fox:

With the media poised and ready to disperse the visuals, part of the political controversy surrounding hESC was a battle over images, where supporters and opponents raced to find those that carry the most weight. For pro-life hESC opponents, this image has been that of a suffering embryo, seeking to make people envision a potential child and equate hESC with abortion.[215] As a secondary measure, they pulled out sci-fi images of a dystopian world in which reproductive cloning is made possible through hESC.[216] But in general, hESC supporters successfully challenged the rhetoric of cloning by highlighting the distinction between reproductive and therapeutic uses. However, the framing of hESC as another way to fight the abortion debate caught on.[217] As bioethicists Paul Root Wolpe and Glenn McGee point out, supporters tried to distance stem cells from the embryos, but in 2006, it was hard to deny that you need to destroy an embryo to derive stem cell lines, no matter how early the embryo was in its development ("No

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[215] Clare Williams, Jenny Kitzinger, and Lesley Henderson, "Envisaging the Embryo in Stem Cell Research: Rhetorical Strategies and Media Reporting of the Ethical Debates," *Sociology of Health and Illness*, 25:7 (2003): 802.

[216] Paul Root Wolpe and Glenn McGee, "'Expert Bioethics' as Professional Discourse: The Case of Stem Cells," in *The Human Embryonic Stem Cell Debate*, 188.

[217] Wolpe and McGee, "'Expert Bioethics' as Professional Discourse," 190.

bigger than a period [.]" or a "tiny ball of cells," supporters reiterated).[218] Similarly, when President George W. Bush used his first veto in office to limit hESC, he was surrounded by Snowflake babies, an effort to make these embryos come to life in the public's minds. Within this visual-based battleground, Fox's campaign spots lent an image that could hold up against the embryo, and the Left rallied behind it.

It is rare to find an article that does not include "suffers from Parkinson's," practically Fox's epithet, marking Fox as a pitiable victim of the disease, rather than someone "living with" Parkinson's.[219] Newspaper articles reporting on the ads made sure to paint the visual picture of Fox's suffering for readers who might not have seen it firsthand: "You look at him, and you see the effects"[220]; "…the boyish actor writhing uncontrollably, unable to stop his body or voice from quaking"[221]; "The campaign ad opens with a familiar boyish face, now atop a body that sways uncontrollably"[222]; "The plea is as disturbing – and arresting – as a hostage video from Iraq … actor Michael J. Fox calmly asks viewers to support stem-cell research … while his body sways back and forth uncontrollably like a sailor's being tossed around in a full-force gale"[223]; and put the most simply, "…Fox looks so debilitated."[224] The survey of articles yielded many more similar quotes. Sometimes, the suffering even made its way directly into the article

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[218] Wolpe and McGee, "'Expert Bioethics' as Professional Discourse," 190.
Williams, Kitzinger, and Henderson, "Envisaging the Embryo in Stem Cell Research," 801.

[219] Beth Haller, Bruce Dorries, and Jessica Rahn, "Media Labeling *versus* the US Disability Community Identity: A Study of Shifting Cultural Language," *Disability and Society*, 21:1 (January 2006): 61-75.

[220] Matthew Mosk, "Michael J. Fox Joins the Fray Via TV Ad For Cardin: Actor Questions Steele's Stance On *Stem Cell* Research Funding," *The Washington Post*, October 24, 2006, B.1.

[221] James Gordon, "Flak For Michael Fox over Stem-Cell Ads," *New York Daily News*, October 25, 2006, 15.

[222] Jake Coyle**,** "Fox Ads Create Backlash; Limbaugh Says 'He's Acting'," *Associated Press,* October 25, 2006.

[223] Alessandra Stanley, "Making Stem Cell Issue Personal, and Political," *New York Times*, October 25, 2006, A.15.

[224] Jake Coyle**,** "Fox Ads Create Backlash; Limbaugh Says 'He's Acting'," A.6.

titles, such as "Tremor-filled Michael J. Fox appears in TV ads"[225] and "Frail Fox stumps for stem cell advocates."[226] Article after article, journalists honed in on the visual of Fox's body.

In a different medium, television broadcasts replayed the campaign ad with lead-ins that sensationalized Fox's shaking. Keith Olbermann, for example, said, "You really don't get the full impact until you see it for yourself."[227] *Good Morning America!* co-anchors Robin Roberts and George Stephanopoulos spend a good deal of time considering the ad that has been "raising a lot of eyebrows" and call it, "quite an emotional ad, you see Fox visibly suffering." After they play it for their viewers, they move on by comparing the power of this imagery to a Republican ad using "the terrorism card" where statements from and images of Osama Bin Laden play with the accompanying sound of a ticking clock.[228]

Following all of these intense reactions to Fox's ad, Daniel Hellinger compares Fox's spot to Lyndon Johnson's 1964 "Daisy" ad – though the context is drastically different, the sense of fear and vulnerability stemming from both ads is similar.[229] Like the fear of terrorism or the fear of death, Fox's ad had tapped into people's fears of physical difference. Rather than try to critically understand what this shaking meant for Fox and for stem cell research, the media coverage instead focused on retelling just how "shocking" this image is while immediately presuming it shows Fox suffering.[230]

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[225] Jake Coyle, "Tremor-Filled Michael J. Fox Appears in TV Ads," A.6.

[226] "Frail Fox Stumps for Stem Cell Advocates" *Times Union*, October 25, 2006, A.2.

[227] Fox, Michael J. Interview by Katie Couric. *CBS Evening News*. October 26, 2006.

[228] *Good Morning America,* ABC, October 24, 2006.

[229] Dan Hellinger, "Emotions Ran High in Stem-Cell Advertising," *St Louis Journalism Review*, (November 2006): 14.

[230] In Missouri, the only state in the country with an actual vote in the election directly pertaining to stem cells, the newspaper discourse was far more focused on laying out the issues behind Amendment 2 and

The attention to Fox's condition as a state of permanent suffering is especially apparent among Michael J. Fox's critics, who seem to feel that before moving into their criticism, they must fully demonstrate their pity for Fox. Rush Limbaugh, for example, began one of his diatribes on the McCaskill ad by stating, "I know he's got it; it's pitiable that he has the disease. It is a debilitating disease, and I understand that fully. Just stick with me on this." He continued to offer his "apology" to Fox, concluding, "At some point the medication will not work, and the condition will become permanent, and there's nothing pleasant about it. It's one of the most frustrating diseases one can have. Pope had it. It's not pleasant in any way, shape, manner, or form."[231] Similarly, Glenn Beck began his critique of Fox with, "I think Michael J. Fox is a really nice guy. He's funny. And I hope that we can find a cure for Parkinson's. This is a horrible disease, and it is ripping him apart."[232] These statements show the apprehension opponents feel in criticizing Fox's politics because they are uncomfortable with the image of Fox's shaking, pitying the fact that he has Parkinson's.

Clearly, it was alarming for people who do not understand Parkinson's to see Michael J. Fox now showing the symptoms of the disease in ways that he had not in the past. After all, he spent ten years becoming an expert at hiding his symptoms, frequently working with props or putting his hands in his pockets to hide his tremors from the public. But it is worth taking a moment to break down why this image causes such strong reactions, even if it might seem obvious.

One answer is that Fox's shaking gets equated with physical suffering, and,

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soliciting a variety of perspectives with very little attention to Fox vs. Limbaugh. But unfortunately, the rest of the nation was interested in looking at Missouri's election through this celebrity-focused lens.

[231] Rush Limbaugh, "Stop the Tape."

[232] *Glenn Beck*, Fox News, October 25, 2006.

rightly so, we do not like to see someone in this state.[233] This link is easy to make given that Michael J. Fox is simultaneously making a plea for a cure to help alleviate Parkinson's. But Fox himself has said that in his experience, the dyskinesia is frustrating and uncomfortable, but it does not hurt.[234] The shaking is a side effect of L-Dopa, the drug that allows him to *maintain* mobility, so to understand this shaking as tragic is too simplistic. In a patriarchical and ableist climate, cures, not care, are all that matters.

And it should not be understood as a sign of existential suffering either because Fox commonly shares his view that he is "lucky" to live with Parkinson's, grateful for the way it changed his perspective on life. The shock and sadness with which the media responds to Fox's body shows what a long battle lies ahead in challenging normalcy, and the comparison of Fox's ad to a hostage video from Iraq or the terrorist threat of Osama

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[233] Even within the critical scholarship on hESC within bioethics, the "suffering" of people with disabilities has been treated as a given. As Beauchamp and Childress's "principles of bioethics" were weighed by many bioethicists, the principle of "benevolence" for hESC was quickly assessed to be the possible cures for people with disabilities without much conversation. This is not to neglect the fact that there are many with disabilities and diseases who desire cures for they experience deep and profound physical suffering. This point should not be forgotten, especially as a previous hole in disability studies scholarship has been to discount the physical suffering of many impairments. But resisting the conflation of disability and suffering is deeply important here and bioethics does harm to disability when it assumes, as disability scholar Shelly Tremain has observed, that the correction and erasure of disability is synonymous with "justice." Even as feminist bioethicists have raised concerns about hESC for the risks to women's health and rights, as women's bodies must facilitate the research through egg "donation," the alliance with a disability critique has been a missed opportunity. As J. Clapton states, "Ethics must attend to impaired theorizing rather than impaired people," developing a richer framework for understanding the impact of hESC on disability. We should not see the same assumptions about suffering in critical scholarship that we see in the media around Fox.
This can be seen, for example, in: National Bioethics Advisory Commission, *Ethical Issues in Human Stem Cell Research: Volume 1, Report and Recommendations of the National Bioethics Advisory Commission* (Rockville, Maryland: September 1999).
Tom L. Beauchamp and James F. Childress, *The Principles of Biomedical Ethics* (New York: Oxford University Press, 2001).
J. Clapton, "Tragedy and Catastrophe in Contentious Discourses of Ethics and Disability," *Journal of Intellectual Disability Research,* 47:7 (October 2003): 546.
Christopher Newell, "Disability, Bioethics, and Rejected Knowledge," *The Journal of Medicine and Philosophy*, 31:3 (July 2006): 269-283.
Tom Shakespeare, "Choices and Rights: Eugenics, Genetics, and Disability Equality," *Disability and Society*, 13:5 (1998): 670.

[234] Michael J. Fox, interview with Anderson Cooper, *Anderson Cooper 360 Degrees,* CNN (November 2, 2006).

Bin Laden speaks wonders to the widespread cultural assumptions about disability as tragedy.

Aside from his short stature, Michael J. Fox has served as a poster boy for normalcy throughout most of his life, so his disability comes across as all the more troublesome, similar to Christopher Reeve, Superman transformed into a quadriplegic.[235] The shock of seeing dyskinesia is hugely elevated by the fact that Michael J. Fox is recognizable to many. To see disability in a celebrity, who people imagine an intimate bond with, makes disability seem all the more real, and all the more tragic. If disability can happen to Fox and Reeve, then it can happen to me. As some of the news quotations indicate above, part of the shock also resulted from the contrast of impairment for someone whose image has always been "boyish," a heartthrob celebrity and childhood crush. Theological ethicist Amy Laura Hall assessed the reaction to Fox's Parkinson's in 2001 for the *Pittsburgh Post Gazette*, "Michael J. Fox is the `Peter Pan' of my generation. He represents perpetual youth and success. We look at him and are terrified."[236] His handsome appearance and masculine gender make it all the more troubling to see him struggle with Parkinson's; part of the fantasy of most male heartthrobs is, after all, their physical body and strength (even if they are short).

The identification that viewers feel with Fox (and feel threatened by when it comes to Fox's suffering) is what makes his ads go viral; it's bigger than Missouri, Maryland, and Wisconsin because Fox has cultural relevance outside of the local. While campaigning, Fox frequently challenged politician Tip O'Neill's catchphrase "all politics

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[235] Johnson, *Make Them Go Away*, 1-10.

[236] "A Life-and-Death Debate, Bush Has Good Reason To Agonize Over The Difficult Question Of Stem-Cell Research," *Pittsburgh Post – Gazette*, July 20, 2001, A.16.

is local," arguing that because the diseases that could be affected by hESC are national (rarely recognizing that they are actually, of course, global), a vote for one of the candidates he endorsed had macro-scale ramifications.[237] The power of Fox as a national icon made this possible, and even though Missouri was the only state voting on stem cells in the 2006 midterm election, it became central in national discourse.

When the media obsession branched out past Fox's body to equally obsess over Limbaugh's accusation that Fox had intentionally appeared this way, the debate was one-dimensional. Of course, no matter how undeniably wrong it was of Limbaugh to imitate Fox in the way he did, he was not entirely off base about the fact that Fox had some degree of control over his shaking. Fox admitted in his autobiography, *Lucky Man,* to intentionally foregoing his medication while appearing before the Congress subcommittee (although this led to different symptoms); "It seemed to me that this occasion demanded that my testimony about the effects of the disease, and the urgency we as a community were feeling, be *seen* as well as heard. For people who had never observed me in this kind of shape, the transformation must have been startling."[238] While Fox did not go without L-Dopa during his campaign ads, he did have the option of waiting until the dyskinesia had subsided. He responded to this point in an interview with Katie Couric, stating, "Well, when do you know that's going to be? You don't know when that's going to be."[239] However, he later writes that the campaign spot only captured a brief flashpoint of his condition or as he puts it, "It's like the weather in New

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[237] Tip O'Neill, *All Politics is Local: And Other Rules of the Game* (Holbrook, Massachusetts: Bob Adams, Inc, 1994).
[238] Michael J. Fox, *Lucky Man: A Memoir*, (New York: Hyperion, 2003), 247.
[239] Michael J. Fox, interview by Katie Couric, *CBS Evening News*. October 26, 2006.

England, wait a second, and it'll change."[240]

The point is not to question whether or not Fox knowingly showed his symptoms, as Limbaugh would have us do, but rather to question why his symptoms are understood so indisputably as powerful by both supporters and opponents of hESC. Dyskinesia is obviously a part of his life, even if it is not present all the time, so why shouldn't he be allowed to show these symptoms? But given the powerful weight that his shaking clearly held, it is clear why Limbaugh would want to cast doubt. To focus on Fox's pharmaceutical regimen puts too much emphasis on Fox, for the problem lies in the interpretation of the shaking, not the shaking itself.

In order to make Fox's suffering seem fully pitiable, Fox must be cast without agency, a victim to his disease, and so Limbaugh finds himself making a confusing case - is Fox exploiting his illness or are the Democrats exploiting Fox? In one of Limbaugh's tirades against Fox, he immediately followed the assertion that Fox is "allowing his illness to be exploited and in the process is shilling for a Democrat politician" with "Michael J. Fox is using his illness as a way to mislead voters."[241] Without a pause, he switches from casting Fox as completely docile to a political conspirator, but both statements assume that suffering is dangerous in politics - it holds the power to persuade, and this is somehow unfair.

While the mainstream media rightfully criticized Limbaugh's imitation of Fox, they also seemed to be criticizing that he attacked Fox at all. Fox himself makes this point, challenging the assumption that he was "caught in the political crossfire," for he feels, "Crossfire implies that I got caught wandering clueless and uninvited into the

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[240] Fox, *Always Looking Up*, 98, 120.
[241] Rush Limbaugh, "Stop the Tape."

middle of someone else's fight."[242] On both sides of the political debate and in the media, the image of suffering halts the conversation, not allowing a complex understanding of the wide space in between Fox and Limbaugh let alone the actual complexity within hESC research.

The Fallout from the Ads:

In response to the overwhelming power of Fox's visual, the opposition offered two noteworthy counter-visuals. First, the conservative response ad, opposing Amendment 2 in Missouri, attempted to fight celebrity with celebrity. Though this ad did gain some attention from the media and the American public, an abundance of articles in the mainstream media contemplating the "celebrity activist" mentioned that there is something about Fox that makes him stand out. Because he is an expert in the embodied experience of his disease, Fox holds political capital that makes the Patricia Healy-and-crowd campaign spot look trivial.[243] Illustrative of this distinction, Keith Olbermann mocks the response spot (referring to the famous baseball player who appeared in the ad), "I'm Jeff Suppan and I've suffered from blisters from a number of years."[244] A cluster of celebrities was not enough to overtake Fox's successful ad.

In a second strategy to take back the visual from Fox, Republican candidate Michael Steele, whose campaign spokesperson called Fox's ad in support of Steele's

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[242] Fox, *Always Looking Up*, 75.

[243] See, for example: Karen Thomas, "Celebs Press Hot Button Issues," *USA Today*, November 7, 2006, D.3.

[244] *Countdown with Keith Olbermann*, MSNBC, October 24, 2006.

opponent Ben Cardin "in poor taste," offered a counter ad.[245] Dr. Monica Turner directly addresses the camera and explains:

> [Cardin] is using the victim of a terrible disease to frighten people all for his own political gain. Mr. Cardin should be ashamed. There's something you should know about Michael Steele. He does support stem cell research, and he cares deeply for those who suffer from the disease. How do I know? I'm Michael Steele's little sister. I have MS, and I know he cares about me.[246]

But unlike Fox, Turner shows no symptoms of Multiple Sclerosis, so this ad could only do so much to dilute Fox's potency. Steele attempted to fight disease with disease but did not take into account that Fox's spot is about the power of a visual disease in the body of a cultural icon – a winning combination.

While the opposition fumbled to fight back, Fox himself explained that he was flabbergasted at the ads' viral success. Before the ads were released, they were tested with several focus groups, and when Fox was told of their successful results, he said he could not understand it until he witnessed how much he had been shaking.[247] He points out that minus the visual of his dyskinesia, they are more or less the same as the campaign ads he put out in 2004, which received little attention, and he writes that the drawback of the 2006 ads is that they represent only a thirty-second shot of his disease.[248] Although he expresses happiness that the ads helped make sure that stem cells were heavily discussed leading up to the election, even Fox points out in an interview with George Stephanopoulos that:

> …there has been, again, not as much focus on the content of the ad. It's really the appearance of the ad. But really, because all the statements are verifiable and to

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[245] Associated Press, "Actor Endorses Cardin, Slams Steele on Stem Cells," *Capital*, October 24, 2006, A.4.
[246] Campaign Advertisement for Michael Steele, featuring Doctor Monica Turner, (October 2006).
[247] Fox, *Always Looking Up*, 120.
[248] Fox, *Always Looking Up*, 98, 120.

> direct comparison, it is, in effect, an ad for their [the opponents of hESC] position. If you see the ad and you agree with their position, and there are people that do, then it should incentive you to vote for them.[249]

Fox resisted the efforts to see himself as a victim or pitiable although he framed this as a direct response to Limbaugh, rather than to the wider media which was fueling this representation.[250]

Despite Limbaugh's disdain for the ads, he inadvertently helped draw attention to them, adding to their viral nature and in the end, offering a boost for hESC support.[251] One report found that support for stem cell research increased among Democrats, Republicans, and Independents after viewing Fox's ad – the advertisement's reach transcended partisan divides.[252] If not through direct votes for stem cell research, at the very least the ad helped McCaskill to raise an enormous amount of money for the last leg of the election.[253] And come Election Day, McCaskill, Cardin, and Doyle were all

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[249] Michael J. Fox, interview with George Stephanopoulos. *This Week,* ABC (October 29, 2006).

[250] 2006 was not the first time he had been put in this position of tragic suffering, however. In 1998 when he first publicly shared news of his Parkinson's, he found himself in the middle of an argument between his wife Tracy Pollan and Barbara Walters, who was asked to break the story in an interview with him. Walters had seen Fox struggle to remove his jacket and wanted him to recreate this on air, but Pollan wanted to resist framing Fox in this light, a debate that was settled by the fact that unlike in the campaign ads, Fox's medicine was properly working by the interview, allowing him to appear asymptomatic. Fox reflects, "This was not a tale of woe, as Tracy would remind Barbara Walters; I sought no pity, or tears." Fox wants to put forth a more complex understanding of disability, but in 2006, this perspective gets lost in the media noise.
Fox, *Lucky Man*, 225.

[251] This corresponds with a new use of YouTube in political campaigns that happened in 2006, used to disperse campaign ads for free as well as to publicize an opponent's missteps.
Vassia Gueorguieva, "Voters, MySpace and YouTube: The Impact of Alternative Communication Channels on the 2006 Election Cycle and Beyond," *Social Science Computer Review*, 26 (2008): 288-300.
Robert J. Klotz, "The Sidetracked 2008 YouTube Senate Campaign," Paper given at "YouTube and the 2008 Election Cycle in the United States," (Amhearst, Massachusetts: University of Massachusetts, Amhearst, 2009).

[252] "Voters Increase Support for Stem Cell Research After Viewing Michael J. Fox Ad" *Business Wire*, October 26, 2006.

[253] Days after Fox's campaign ad aired, McCaskill had brought in an additional $100,000, which continued to rise up until the election.
Steve Kraske and David Goldstein, "Democrats Give Credit to an Unlikely Angel: Rush Limbaugh Remarks on Fox Ad Led to Interest and Money for McCaskill, They Say," *Knight Rider Tribune*, November 9, 2006.

winners, and Amendment 2 in Missouri passed, though Fox's precise effect cannot be determined. McCaskill's success over Jim Talent was a surprise, and the media repeated the suggestion that she had both Fox and Limbaugh to thank for her win.[254] While emotion is typically kept at a distance in the "objective" fields of science and technology, hESC supporters had successfully tapped into people's emotions through Fox to bring about support.[255]

The Political Economy of Hope and the Biomedical Industrial Complex:

Like Michael J. Fox, many people living with diseases or impairments believe that the top priority should be the pursuit of cures, and many of these patient groups have done important work, insisting that their voices be heard, and what's gained should not be undermined by my argument in this chapter. Sociologist Carlos Novas coins this emerging activity the "political economy of hope," "in which becoming knowledgeable about science, in addition to activism, fundraising and heightening awareness of a particular disease are significant locales for helping to realize the objects of individual and collective hopes."[256] While, on the one hand, this knowledge and voice represent an important development for patients, on the other hand, it can be co-opted to serve the biotech industry. Patients seeking hESC actively invest in their future through promoting

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Ben Cardin also reported a bump in fundraising thanks to Fox's help.
Jennifer Skalka and Jonathan Bor, "Steele Ad Hits Back on Stem Cell Issue: Sister Asserts that He Supports Research," *McClatchy Tribune*, October 26, 2008, 1.

[254] Kraske and Goldstein, "Democrats Give Credit to an Unlikely Angel."

[255] Unlike in the UK, Israel, and Germany, Herbert Gottweis and Barbara Prainsack suggest that in the United States, emotional polarization was central to how people came to understand hESC.
Gottweis and Prainsack, "Emotion in Political Discourse."
Kitzinger and Williams, "Forecasting Science Futures," 737.

[256] Carlos Novas, "The Political Economy of Hope: Patient's Organizations, Science, and Biovalue," *BioSocieties*, (2006), 289.

a vision of hope, while the urgency of suffering functions as capital.[257]

Michael J. Fox takes on a central role in the political economy of hope for Parkinson's disease. His voice in the political sphere literally invokes "hope" in practically every speech he makes, urging support for the research that might someday help Fox "dance at [his] daughter's wedding."[258] In one of many examples, Fox appeared on national news, shortly after his campaign ad aired, and explained, "[W]hat I'm talking about is about hope. It's about promise. It's about moving forward. It's a forward-looking attitude about what this country is capable of and what we can accomplish for our citizens."[259] Fox uses hope constantly as a rhetorical tool, arguing that his audience must invest, both mentally and financially, in this image of the future. When Stephanopoulos asks if this might be promoting false hope – a question that was unique in the media coverage – Fox replied:

> What is crueler, to not have hope or to have hope? And it's not false hope. It's a very informed hope…. And hope, I mean, hope is – I don't want to get too corny about it, but isn't that what the person in the harbor with the thing? (Fox mimes the statue of liberty) It's about hope. And so to characterize hope as some sort of malady or some kind of flaw of character or national weakness is, to me, really counter to what this country is about.[260]

Fox plays an important role in utilizing his suffering for his cause, aligning hope with patriotism along the same lines that the media connected his suffering with terrorism.

Fox provides a center, unifying people and resources around the hope for the cure. Within the political economy of hope, Fox's suffering is capital that provides a primary means of raising money, for his foundation and his candidates, to move hESC forward.

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[257] Novas, "The Political Economy of Hope," 291.

[258] "A Go for Stem Cell Research" *The Salt Lake Tribune,* January 8, 2000, A.8.

[259] Michael J. Fox, interview with George Stephanopoulos. *This Week,* ABC (October 29, 2006).

[260] Michael J. Fox, interview with George Stephanopoulos. *This Week,* ABC (October 29, 2006).

As Jenny Kitzinger and Clare Williams note, “hope” has become “a scientific word rather than a human action,”[261] and this point is exemplified in Fox’s expression of “informed hope.” Certainly hope can be informed with scientific evidence, indicating the likelihood of hypothesized outcomes. However, hESC research was in such an early phase that the likelihood of success really was unknown, and hope was indeed a human action of maintaining faith.

Religious studies scholar Thomas A. Shannon argues, “What we have yet to recognize is the immense and substantive gap between discovery and cure. This is not an argument against stem cell research per se. It is a call to recognize inflated claims that are used to justify commitment of money to a process that is highly experimental and untested. The claim is not the reality.”[262] Fox’s many speeches and his frequent suggestion that this is about more than hope – it’s an “informed hope” – promoted the idea that free of governmental regulations, hESC would be fully available already. The risk of such hype is that people will invest their livelihood on the promise of a cure. Nik Brown, who has studied Parkinson’s disease groups in particular, suggests that patient groups promote this hype to help gain support for research, but there is a harm that follows when the cures do not immediately become available. He states, “The welding together of painful pathological biography and the fate of a biotechnological promise takes place at enormous cost to those who, for however long, are persuaded to share in the hope.”[263] The possibility that cures might never come has been sorely missing from

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[261] Jenny Kitzinger and Clare Williams, “Forecasting Science Futures: Legitimising Hope and Calming the Fears in the Embryo Stem Cell Debate,” *Social Science and Medicine*, 61 (2005): 738.

[262] Shannon, “From the Micro to the Macro,” 181.

[263] Nik Brown, “Hope Against Hype: Accountability in Biopasts, Presents, and Futures,” *Science Studies*, 2 (2003): 8.

the debate, as “hope” functions as a PR tool for the hESC industry.

The rise of the political economy of hope is a project within what Carlos Novas and Nikolas Rose call “biological citizenship” or “all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as species.”[264] Or, to be more specific to the case of hESC, biological citizenship entails the active demands patient groups are placing on the political sphere to recognize and treat their physical hardships through technoscience, situating this issue as a national priority in line with government projects like fixing bridges and repairing roads.

Fox’s presence in the center of hESC provides a clear example of how biological citizenship can be enacted in powerful ways. In particular, he made a powerful disability rights statement, repeated in several speeches, in response to Limbaugh’s criticism of his campaign spot:

> It really brings up the specter of "Go away. Shut the windows. Shut the doors. Close the curtains, and suffer, and don't let us know," because it's a fearful response. And what the irony is, is that those people that are being pitied or being asked to suffer in silence don't want to suffer, don't see themselves as pitiable, don't see themselves as victims. [They] see themselves as citizens, participants in the process, and people with aspirations and hopes and dreams for the future.[265]

Here, Fox offers a politicized and historical understanding of disability and disease that was otherwise missing in his public media presence. He demonstrates the active solidarity arising around both biological conditions and the hope for cures, demanding the right to be heard in the political sphere.

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[264] Nikolas Rose and Carlos Novas, “Biological Citizenship” in *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, eds. Aihwa Ong and Stephen J. Collier (Malden, Massachusetts: Blackwell Publishing, 2005), 440.

[265] Michael J. Fox, interview with George Stephanopoulos. *This Week,* ABC (October 29, 2006).

But biological citizenship is not always empowering for it risks being appropriated for biotech and biomedicine profits. As patients put forth a rhetoric of hope that celebrates the end of suffering, science and biomedical research seem pure and altruistic, but we cannot neglect the huge profits and resulting stratification of access that will follow if hESC becomes viable as regenerative medicine. Like other biological material in emerging biotech industries, stem cells need to be understood in an economic context. Science studies scholar Catherine Waldby's concept of "biovalue" indicates both the potential in biological materials, such as tissues, organs and stem cells, to offer life as well as the market economies in which they function and hold a monetary value. She explains that within the economic framing of biological substances, stem cells have a particularly high biovalue, as "Stem cell technologies promise to turn scarcity into plenty," reproducing and creating more cells.[266] We cannot separate the hope of making tremendous profits from the hope that stem cells can save lives and cure the incurable.

The political economy of hope facilitates the economy of stem cells, and Fox actively participates in this biomedical industrial complex. Fox most directly addressed the economic factors of hESC in an interview with Anderson Cooper, shortly following Fox's campaign spots first aired. Cooper read Fox a viewer question, which asked, "Shouldn't the drug companies who stand to benefit from the research do the funding? Are the drug companies going to let us have the new cures for free?"[267] Largely dodging the question, Fox responded, "Well, first of all, anybody who is sick stands to benefit," then comparing the importance of federal support for curing diseases to government work

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[266] Catherine Waldby, "Stem Cells, Tissue Cultures, and the Production of Biovalue," *Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine*, 6:3 (2002): 311.

[267] Michael J. Fox, interview with Anderson Cooper, *Anderson Cooper 360 Degrees,* CNN (November 2, 2006).

of repairing roads. In advocating for federal funding, he did not address the fact that federal funding will not stop private interests from profiting off of hESC discoveries, as well as the possibility, contrary to his statement, that these cures might not be available to everyone, as many medical treatments and technologies are highly stratified today. Perhaps Fox has forgotten that he is no longer in his homeland, Canada.

Already, we see the American elite traveling abroad today for experimental stem cell procedures because they have the financial capital to do so, whether or not this does them any good (or even harm).[268] In November 2011, Geron, a leader in stem cells, announced that they were leaving the stem cell business, in the middle of a clinical trial no less, because they were not seeing enough profits, providing a wake-up call for many people that this is, indeed, a market-driven industry.[269] Back in 2006, while the country got caught up in a debate around Fox and Limbaugh, biotech firms sat back and watched, without having their role in lobbying for candidates supporting stem cell research and Amendment 2 in Missouri called into question.[270]

In part, Fox's story shows the difficulty of being a patient activist without serving

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[268] See, for example, 2012 Presidential Candidate Rick Perry's trip to Europe for an experimental stem cell procedure.
"Doctors Wary of Perry's Stem Cell Treatment," *Boston Globe*, August 20, 2011.
Scott Pelley, "Stem Cell Fraud: A *60 Minutes* Investigation," *60 Minutes*, (January 8, 2012).

[269] Michael Hiltzick, "California Stem Cell Agency Needs to Study Itself," *Los Angeles Times,* December 7, 2011, http://articles.latimes.com/2011/dec/07/business/la-fi-hiltzik-20111207.
Eryn Brown, "Economics, Not Science, Thwarts Embryonic Stem Cell Therapy," *Los Angeles Times*, November 21, 2011, http://articles.latimes.com/2011/nov/21/health/la-he-geron-stem-cell-20111121.

[270] Similarly, when Prop 71 was passed in California in 2004, corporate biotech firms had invested great amounts of money in the campaign and stood to gain it back with the results. The proposition, which issued $3 billion dollars of state money to go toward stem cell research, was also supported by a Fox television spot. The California Institute for Regenerative Medicine (CIRM), responsible for distributing California's stem cell money into projects has since been filled with controversy, surrounding the people from within CIRM with conflicts of interest, namely chair Robert Klein and board member John Reed. Even as this had already started to come to light by the midterm 2006 elections, it did not result in a more critical look at biotech profits around hESC in the midterm elections.
The Center for Genetics and Society, "The California Stem Cell Program at One Year: A Progress Report," (January 18, 2005) http://www.geneticsandsociety.org/downloads/200601report.pdf.

the biomedical-industrial complex, as most celebrities are so intertwined with consumerism. Michael J. Fox knew he was really "making it" when he saw his face on a children's lunchbox.[271] Fox once mentioned on a talk show that he misses Canadian Moosehead beer, and the next day, he received a huge shipment of beer from the company with the offer to endlessly replenish his stock.[272] As a celebrity patient, Fox's suffering offers highly valuable capital, translating fame into political and economic power for hESC.

Neither celebrities as activists nor celebrities as famous patients are new.[273] The rise of the 24-hour news cycle combined with the abundance of news media through the Internet makes capturing the public attention increasingly difficult, and celebrity activists have helped make an issue stand out.[274] Similarly, the public attention to celebrity patients is not new either, not even for Parkinson's disease.[275] Lerner explains that since the 1930s:

> [C]elebrities who became ill were increasingly 'supposed' to act in a certain manner, going public with their sickness, sharing details of their treatments and then becoming visible and optimistic spokespeople….By corollary, 'ordinary' patients were now supposed to act like ill celebrities - not starting foundations, necessarily, but becoming knowledgeable about their conditions and fighting their diseases.[276]

The presence of a celebrity in culturally defining illness exemplifies the convergence of

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[271] Fox, *Lucky Man*, 85.
[272] Fox, *Lucky Man*, 102.
[273] David Marsh, Paul 't Hart, and Karen Tindall, "Celebrity Politics: The Politics of Late Modernity?" *Political Studies Review*, 8 (2010): 337.
A. Trevor Thrall et al., "Star Power: Celebrity Advocacy and the Evolution of the Public Sphere," *Press/Politics*, 13:4 (2008): 363
Barron H. Lerner, *When Illness Goes Public: Celebrity Patients and How We Look at Medicine* (Baltimore: John Hopkins Press, 2006).
[274] Thrall et al., "Star Power," 363, 365.
[275] Lerner provides the history of *Life* photographer Margaret Bourke-White's public life with the disease from 1959 until her death.
Lerner, *When Illness Goes Public*, 62.
[276] Lerner, *When Illness Goes Public*, 271.

consumer capitalism with technoscience and biomedicine, and Fox certainly rose up to the celebrity patient responsibilities that Lerner lays out. But the risk is that the celebrity patient ends up doing harm, unjustly influencing research funding.[277] In Fox's autobiography *Lucky Man*, he boasts of this power, as he explains how slow the National Institute of Health distributes funding in contrast to his foundation, which has sped up the process so much so that, Fox proudly shares, the NIH now follows his foundation's model.[278] Fox is a powerful celebrity patient and biological citizen, but the risk is that the bubble can burst, especially if the results do not come as soon as we'd hope. Fox continues to shake, more with each year's passing, and it provides a visual image of the hopes that did not payoff.[279]

In some of Fox's speeches and writing, he seems to be conflicted on his own role in politics. For example, Fox writes:

> When I engage in public debate on these and other issues, I do so as a patient first, but there's no question my notoriety helps. One of the reasons I can raise funds and attract attention to the cause is because I am a celebrity. And yet I am wary of being regarded merely as a 'poster boy.' In fact, when we first launched the foundation, I didn't want it to bear my name.[280]

He continues to suggest that because celebrity is a currency, why not spend it in a useful way? While this puts Fox in a bind (should he not be able to speak his views simply because he is a celebrity and his voice therefore gains prominence?), it nods to the wider cultural and economic forces that privilege Fox's voice as a patient over others. Whether or not he is being paid for his endorsements, his vocal support for hESC helps bring in private profits, for political candidates, as well as the Michael J. Fox Foundation, and

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[277] Lerner, *When Illness Goes Public*, 272.
[278] Fox, *Lucky Man,* 249.
[279] Brown, "Hope Against Hype," 10.
[280] Fox, *Lucky Man,* 251-252.

therefore, for biotech companies. In 2001, his organization gave $4.4 million to stem cell line studies and has continued to give more each year.[281] A gift to Fox may very well be a gift to the private companies that will not be obligated to make cures widely available if they are successful.

While other celebrities were simultaneously being criticized regularly in the media for shamelessly linking their celebrity status with political causes, Fox was seen as having a legitimate right to a public voice - his status as a patient makes him an expert.[282] Yet Fox's ability to raise money and influence the future of research shows a unique status in the political economy of hope. While other patients must work collectively to establish a presence for themselves, Fox achieves a political presence overnight.

The media obsession with Fox and Limbaugh distracted from some deeply important issues and the inseparability of hESC research from biotech profits; as Shannon expresses, "Commitment to stem cell research is a commitment to business as usual in the medical community; that is, to the high-tech, very expensive rescue medicine."[283] In fact, following the pro-stem cell inclination of the American majority seen through the 2006 election, stocks of several biotech firms doing hESC work rose the day after the election, yet when an *Oakland Times* article reported this rise, the reporter suggested that the profits were not what made these firms happy, but rather the hope that they might

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[281] While Fox's political work must be separate from the Michael J. Fox Foundation for Parkinson's Research by law, it is likely that his political work in the public eye also helped raise money for his foundation, which then funds private research companies. However, it is important to recall that government restrictions on hESC had ensured that it was not possible to support hESC without supporting private research because only privately funded labs could destroy embryos in order to extract hESC. Mary Duenwald, "Fox Uses Celebrity Status to Push for Cure," *San Diego Union – Tribune*, May 18, 2002, E.6.

[282] See, for example: Karen Thomas, "Celebs Press Hot Button Issues," D.3.

[283] Shannon, "From the Micro to the Macro," 181.

start saving more lives.[284] With the rise of the biomedical industrial complex, and when the lives to be saved will likely be the lives of the rich and privileged, how can we make the distinction between scientific altruism in the name of helping people with disabilities and the capitalistic pursuit of profits?

Hypervisible Fox, Invisible Others:

The national attention to Fox's shaking merged politics, the media, and science with a campaign ad – created to be a simple message that should not hold an entire debate on its back. In particular, there were many important issues that a debate centered on Fox's ad left invisible (to the advantage of biotech companies and lobbyists, but also to the disadvantage of vulnerable populations). While Fox is hypervisible, the forces that give rise to his iconic power make other voices and perspectives invisible. This debate promotes a simplistic understanding of hESC that fails to recognize the many privileges Fox has which shape his relationship to scientific research.

Fox's rhetoric encouraged viewers to link his story with the "millions of Americans" who, like him, can purportedly benefit from hESC – a number that comes up in all three of Fox's campaign ads and also in almost all of Michael J. Fox's speeches, as well as the media reports on Fox. Again and again, Fox states variations on what he suggested in his Claire McCaskill ad, "What you do in Missouri affects millions of Americans - Americans like me."[285] Michael J. Fox lends a celebrity face to the "performance of suffering," the ultimate expression of authenticity as science and

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[284] David Morrill, "Stem Cell Stocks Riding the Wave," *Oakland* Tribune, November 9, 2006, 1.
[285] Campaign advertisement for Claire McCaskill, featuring Michael J. Fox, (October 2006).

technology studies scholars Nik Brown and Mike Michael point out.[286] Even with the diversity of conditions included in the "millions of Americans" figure, ranging from Diabetes to spinal cord injuries to Parkinson's, and despite the variety of people living with any one of these conditions (and a variety of opinions about the priority of cures), these ads suggest that Michael J. Fox can be understood as a universal image of suffering, and hESC will offer the cure for all the millions in the same homogenous way. But celebrities in the United States are a rare and privileged elite, hardly representative of the many he spoke for.

Even if cures do become available, there is no guarantee that they will reach the "millions of Americans" in need that Fox so often references. While disability and the existence of people with disabilities' suffering is key in motivating and solidifying support for hESC, the actual struggles people with disabilities currently face are overshadowed. A study by Melissa J. Bjelland et al. found that "in 2009, working-age people with disabilities were 2.7 times more likely to be in poverty when compared to working-age people without disabilities." Along the same lines, they found that "in March 2010, working-age people with disabilities were only 21 percent as likely to be employed as a working-age person without a disability."[287] Correlating with these lower rates of employment and higher rates of poverty, a 2010 study by Mary Ann McColl et al., based upon the National Population Health Survey, found that "disabled adults (aged 20-64) reported more than three times as many unmet health care needs as their non-

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[286] Nik Brown and Mike Michael, "From Authority to Authenticity: The Changing Governance of Biotechnology," *Health, Risk, and Society* 4:3 (2002): 259.

[287] Melissa J. Bjelland, Richard V. Burkhauser, Sarah von Schrader, and Andrew J. Houtenville, "2010 Progress Report on the Economic Well-Being of Working-Age People with Disabilities," Cornell University, February 2011.

disabled counterparts."[288] Michael J. Fox, however, can virtually guarantee that if some breakthrough procedure does become available, he will receive it immediately. The stratification of biomedicine and technoscience is obviously a tough, structural topic to tackle and so it would be foolish to place blame on something like Fox's campaign ad for neglecting it, but Fox's frequently repeated promise that this research will save lives needs to correspond with the question, "Whose lives will be saved?"

Fox's confidence that medical progress will come, and come to all, points to the many privileges that shape his worldview (in addition to his socioeconomic status) that need to be taken into consideration when assessing Fox's hypervisible position. As a celebrity, Fox is fully aware of the privileges he receives: he has gotten out of speeding tickets and he gets things for free wherever he goes.[289] Despite the very clear stigma he faced in response to his 2006 ad, the stigma of disability is accompanied by the positive stigma of celebrity. When Fox first came to embrace his identity as a person living with PD, he logged into online forums anonymously to learn about others' experiences, and he reflects, "I never logged out of the online PD forums without realizing how fortunate I was. My family, my relative youth, my financial situation, as well as my public position gave me a tremendous advantage in dealing with my illness."[290] But Fox does not seem to bring this perspective to his work around hESC, nor does he consider privileges around race and gender.

In his interview with Katie Couric following his campaign spot, Couric asks if he worries about the slippery slope with hESC research. Fox's response speaks to a

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[288] Mary Ann McColl, Anna Jarzynowska, and S.E.D. Shortt, "Unmet Health Care Needs of People with Disabilities: Population Level Evidence," *Disability & Society*, 25:2 (2010), 205-218.
[289] Fox, *Lucky Man*, 102-103.
[290] Fox, *Always Looking Up,* 26.

privileged trust in science and medicine that many do not hold, which becomes problematic when his voice is to stand in for so many others. He states:

> … everything is a slippery slope. Getting up in the morning is a slippery slope. You apply your best sense of intelligence and ethics, and planning and foresight, and oversight into what you do. I mean … why we have this lack of faith in our scientific community, I don't know. They have done such wonderful things for us over the years. Why people think they are automatically going to have some kind of ethical breakdown. And create monsters or hurt people. That is not their intention. Their intention is to move forward, and to progress. … Is it something you have to do with foresight and contingencies, with fallbacks and all those other things that go with it? Yes. But why do we believe that they wouldn't do that?[291]

As a spokesperson for hESC, Fox articulates confidence that the aim of science is always beneficence and non-maleficence, and so his fans and concerned public should follow suit.[292]

One issue that Fox helped suppress was a conversation about human cloning. In an interview with the *New York Times*, Fox responded to a question on the concerns of reproductive cloning, "With cloning, there is the question, 'What do you stay up at night worrying about?' An army of Hitlers coming down Madison Avenue? No. This is not going to happen, folks."[293] But many have suggested how thin the line between therapeutic and reproductive cloning is. Given the lack of widespread regulation against reproductive cloning, serious deliberation is required, rather than jumping to dismissal with the extreme example of "cloned Hitlers." The distinction between disability versus ability functions to make other distinctions: enhancement versus treatment and

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[291] Michael J. Fox, interview by Katie Couric, *CBS Evening News*. October 26, 2006.

[292] Similarly, Fox demonstrates this confidence again in a television spot in which Fox urges the public to participate in clinical research trials to help forward medical progress. Clinical trials still heavily rely on the labor of marginalized populations, inside and outside of the United States, and nearly forty years after the Tuskegee Syphillis experiments were brought to light, research trial abuses continue.
See: Carl Elliott, *White Coat Black Hat: Adventures on the Dark Side of Medicine* (Boston: Beacon Press, 2010).

[293] Mary Duenwald, "A 'Lucky Man' Puts His Celebrity to Work," *New York Times*, May 14, 2002, F.6.

therapeutic versus reproductive cloning.[294] But disability and ability do not have a clear divide; as a result, they should not serve as the basis for other splits in controversial biotech innovations.[295] Despite Fox's celebration of the fact that in the days before the election, the country was talking about stem cells, most of the country was not talking about the complexities of the issue in this way.[296]

His confidence in the good of science and medicine denies the history, which lingers today in and beyond issues of hESC, in which scientific "progress" has hinged on exploitation, especially of women, the poor, people of color and people with disabilities. As hESC research relies upon leftover eggs from private fertility clinics or on egg "donors" paid for the stimulation of their ovaries and the resulting eggs, stem cells intertwine with IVF in "embryonic economies," as science studies scholar Sarah Franklin calls it. Separate from the religious debate surrounding the embryo in stem cell research, hESC has raised lots of critical questions about the commercialization of eggs and embryos, where many question whether such basic forms of life and biological material should be bought and sold, especially raising concerns of the health risks and potential degradation posed to egg donors.[297] Many feminist scholars have opposed hESC because

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[294] Shelly Tremain, "Biopower, Styles of Reasoning, and What's Still Missing from the Stem Cell Debate," *Hypatia*, 25:3 (Summer 2010): 577-609.
Linda Hogle, "Enhancement Technologies and the Body," *Annual Review of Anthropology*, 34 (2005): 710.

[295] Bioethicist Erik Parens offers one example of how this blurring might occur in "reprogenetics," where the already built alliance between hESC and IVF clinics is used so that stem cell science can enhance an embryo's genetic makeup, pursuing perfection, and then using implantation through IVF to reproduce a genetically-altered child.
Erik Parens "Embryonic Stem Cells and the Bigger Reprogenetic Picture," *Women's Health Issues*, 10:3, (May/June 2000): 116-120.

[296] In Missouri's major newspaper, the conversation was richer with more detail, and even after Fox's campaign ad stole the national attention, several articles tried to break down the science underlying this complex amendment issue.

[297] Lisa Sowle Cahill, "Social Ethics of Embryo and Stem Cell Research," *Women's Health Issues*, 10:3 (May/June 2000): 131-135.

the research (through therapeutic cloning of donated eggs) may come at the expense of marginalized women, more likely to sell their eggs out of desperation while the least likely to enjoy the benefits of hESC outcomes.[298] HESC promises to alleviate suffering but given the very real (as well as unknown) risks of egg extraction, we need to explore the additional forms of suffering that may result from hESC.[299] While hESC opponents focus on the embryo's suffering and supporters give attention to Fox's suffering, other voices remain invisible, despite having much to lose.

Fox's hypervisibility brought invisibility for disability rights issues as well in the fight for social acceptance of disability over cures. With Fox's perspective representing the universal voice of the "millions of Americans," the media weighed Fox versus Limbaugh while taking for granted that people with disabilities are in need of cures. The few alternative voices from people with disabilities that challenged Fox in the mainstream media were from religious people, who opposed hESC on the grounds of the embryo.

While the emergence of biological citizenship and political economies of hope shows a new effort by patients to demand a central and loud representation, Heath et al. have pointed out how this shift is inseparable from Foucauldian notions of "technologies of the self," where biology is not only used to demand rights as a citizen but is also used to police (and self-police) bodies, running the risk of what Taussig et al. call "flexible

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Lisa Ikemoto, "Eggs as Capital: Human Egg Procurement in the Fertility Industry and the Stem Cell Research Enterprise," *Signs: Journal of Women in Culture and Society*, 34:763 (2009), 763 -781.
Diane Beeson and Abby Lippman, "Egg Harvesting for Stem Cell Research: Medical Risks and Ethical Problems," *Reproductive Biomedicine Online*, 13:4 (2006): 573-579.

[298] Suzanne Holland, "Beyond the Embryo: A Feminist Appraisal of the Embryonic Stem Cell Debate" in *The Human Embryonic Stem Cell Debate*, 73-86.

[299] Holland, "Beyond the Embryo," 83.

eugenics."[300] This concept reminds us of the risks of biological citizenship, especially in a neoliberal climate, where biological citizenship can help usher in a less empowering *responsibility* that one manage and optimize their biology in order to minimize the healthcare costs on the state. As new forms of life and biology obtain an economic value, hESC can be assessed with cost/benefit analysis, increasingly common in the neoliberal climate.[301] In other words, while hESC might cost money now to develop, it will save money later for the diseases and disabilities that are prevented.

The concern over Fox's shaking in the campaign ads might come with a lurking question: if we can't cure him, how much will he burden the state? In reality, not many will ask this question for Fox, nor should we, because his acting career has made him a rich man; but for many other people with diseases and disabilities, this economic logic for understanding disability is quite likely and dangerous. Private individual solutions are prioritized over cures rather than social services and care for people with disabilities.

If hESC becomes available, pushed forward by the many people with disabilities who do want cures, what repercussions will result for people who do not feel that they are suffering and do not want to be normalized? If hESC offers the cures that we are supposedly on the brink of discovering, will this usher in "flexible eugenics" through "biotechnological individualism" and neoliberal decision-making? Will the technology make possible a widespread expectation to self-regulate and thus cure oneself, making a

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[300] Karen-Sue Taussig, Rayna Rapp, and Deborah Heath, "Flexible Eugenics: Technologies of the Self in the Age of Genetics," in *Genetic Nature/Culture: Anthropology and Science beyond the Two-Culture Divide*, edited by Alan H. Goodman, Deborah Heath, and M. Susan Lindee, 58-76, (Berkeley, California: UC press, 2003).

[301] Roberto Rivera y Carlo, "Targeting the Disabled" *Boundless Webzine*, (2002), http://www.boundless.org/2002_2003/features/a0000685.html.

disability rights perspective increasingly unfavorable?[302] While these questions cannot be answered just yet, it is clear that the market, media and political forces that made Fox hypervisible also made invisible the many people with disabilities who articulate an identity that is not reduced to suffering and who would not be as likely to use a cure.

The coverage of Fox provides yet another cultural site where individualism reigns supreme above interdependence. HESC's allure is the promise that individuals can be treated for their illnesses and disabilities such that we can continue to postpone social change, a standard element in the techno-makeover narrative. But even if hESC cures do become available, much of the problems people with disabilities face are social in nature, and so technoscience cures will never be sufficient.

Ironically, the mainstream representation of disability put forth around Fox contradicts much of what Fox himself has said in other settings, invisible in the hESC debates. Michael J. Fox titles his first autobiography *Lucky Man* because he feels that Parkinson's has been a gift, giving him the best years of his life.[303] He says that if he was presented with the opportunity to have never been diagnosed with Parkinson's, he'd "tell you to take a hike," reminding his readers, "For everything this disease has taken, something with greater value has been given."[304] These clear articulations of what disability can offer get completely left behind when the country witnesses Fox's shaking for the camera - his suffering must be resolved, a techno-makeover must be pursued. These previous self-empowering statements by Fox only resurface when the media

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[302] Karen-Sue Taussig, Rayna Rapp, and Deborah Heath, "Flexible Eugenics: Technologies of the Self in the Age of Genetics" in *Genetic Nature/Culture: Anthropology and Science beyond the Two-Culture Divide*, eds. Alan H. Goodman, Deborah Heath, and M. Susan Lindee (Berkeley, California: UC press, 2003), 60.
[303] Fox, *Lucky Man*, 5.
[304] Fox, *Lucky Man,* 6.
Fox, *Always Looking Up*, *6*.

introduces Fox's self-proclaimed identity as an "incurable optimist," trying to look on the bright side of what is still framed as a bad situation.[305] A cure may be in the best of interests for many living with Parkinson's, Multiple Sclerosis, Alzheimer's, and so on, but suffering should not be universalized across disabilities, as even Fox acknowledges that in a disability-free world, something would be lost.

Perhaps there are those that suffer in such a way that warrants a commitment to the hope of alleviation through hESC research. But before we can make this call, we need to be able to weigh the pros and cons of hESC research and better understand what the science entails. The attention to hESC following Fox's campaign ads might have provoked such a moment, but instead, the debate was limited and reductive, even leaving out the complexity that Fox himself has provided around living with Parkinson's. If we need to trust in science and medical research, as Fox urges, we need to first consider the many rational perspectives of distrust that marginalized communities may hold. The possibility of a neoliberal techno-eugenics needs to be explored, so that protections can be created in advance to prevent mandatory cures if cures become available. And the alleviation of suffering should not come at the costs of other, less public suffering to fuel the research. As a man of many privileges, Fox cannot serve as the universal icon for hESC.

Bringing Disability Justice into the Future:

The political and media discourse surrounding Michael J. Fox situates disability

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[305] Of course, these statements by Fox also speak to his many privileges, as claiming pride in his condition is much easier if discrimination and economic injustice are minimized. "Incurable Optimist" was both the subtitle of his second memoir and the name of a one-hour television special, where Fox discusses his own optimism as well as that of other famous optimists.

as a condition of suffering in order to forward hESC and its potential profits. Other understandings of disability as well as other types of suffering tied to hESC consequences are erased. The end goal is to eliminate disability in the future, driven forward by the investment from patients who desire this outcome. There is one final problem to raise with the limited discourse of disability in the 2006 midterm elections: it promotes biotech through visions of the future that are not grounded in the present and past. The political economy of hope puts forth a prediction of the future in which hESC has made disability a thing of the past. We need to understand how this discourse influences how we think about disability today, working against the efforts of the disability rights movement to imagine a future free of ableism.

Proponents of hESC called upon Fox's shaking as a sign of the urgency for this science – we do not have time to stop and ask questions when people are suffering and, as is frequently repeated, cures are just around the bend. Fox first learned about the possibility of a cure for Parkinson's from a speech by Dr. Gerald Fischbach, who testified alongside Fox at a Senate subcommittee hearing and claimed that with enough money, Parkinson's could be cured within the next five to ten years, greatly motivating Fox's launch as an activist.[306] Fox writes in his first autobiography that he hired one of the top positions for his foundation with the warning that if she found herself "making plans for a Tenth Annual Fund-Raising Dinner, [she] could consider [herself] fired."[307] He repeats the same story in his second autobiography, although tellingly, it has been changed to a "Twentieth Annual Fund-Raising Dinner."[308] Fox explains his motivation, "It wasn't a

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[306] Fox, *Always Looking Up*, 28.
[307] Fox, *Lucky Man,* 248-249.
[308] Fox, *Always Looking Up*, 54.

question of if Parkinson’s could be cured, but when,”[309] and to validate the idea that hESC is driven by an “informed hope,” he compares the doubts around hESC to those commonly held before we put a man on the moon.[310] What all of this amounts to is a clear message, voiced by Fox but agreed upon by many, that hESC will deliver cures and these cures will result in the erasure of disability in the future. Scientists and policy makers call upon an imagined future to bolster support for the work being done today, and hESC is an example of this wider paradigm.[311]

The celebrity response ad against Amendment 2 pointed to how California scientists working around hESC have said it will take fifteen years to achieve cures. Fox responded to this criticism in his interview with Katie Couric:

> I had … lunch with a 17-year-old girl from Ohio, who has Parkinson’s, and is very symptomatic. She'll be in her early 30's in 15 years, and I don't think she'd write that off as a long time. I think if we can tell her in 15 years, that we'd have an answer for her in 15 years, I don't think she'd treat that lightly. I think that would give her strength and hope to hang on.[312]

If it will not be Fox who gets to reap the benefit of a cure, then it will be someone in the next generation, who will also be positioned as right on the cusp of a cure.[313] Supporters of hESC are making hyperbolic claims about hESC cures being just around the bend, while opponents argue that cures are further out, but neither group can ground this in scientific evidence because in 2006, the research was far too new to know what would materialize out of hESC.

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[309] Fox, *Lucky Man,* 233.

[310] Fox, *Always Looking Up*, 111.

[311] Joan H. Fujimura, “Future Imaginaries: Genome Scientists as Sociocultural Entrepreneurs” in *Genetic Nature/ Culture: Anthropology and Science beyond the Two-Culture Divide*, 193.

[312] Michael J. Fox, interview by Katie Couric, *CBS Evening News*. October 26, 2006.

[313] This discourse demonstrates Kitzinger and Williams’s claim that “controversies about biotechnologies often centre not so much on present scientific facts as on speculations about risks and benefits in the future.” Kitzinger and Williams, “Forecasting Science Futures,” 731.

Nik Brown observes that this point is bigger than hESC, as he states, "Biotech … is today synonymous with the language and imagery of futuristic breakthroughs. The whole area is literally spilling over with heated aspirations, promises, expectations, hopes, desires, and imaginings."[314] While Fox lends a face and a voice to the discourse of hype, he is part of a wider system in which hope is translated into promises for the future. As both proponents and opponents of hESC contemplate the future, we have "impoverished imaginaries," where disability is ideally erased, whether or not embryos get us there.[315] The limited thinking about disability we hold today pervades the future, meanwhile constructing disability in the present as a site of suffering that will soon be gone rather than a site of political and cultural activism demanding disability justice.[316]

The construction of the future relies as well upon the assumed inevitability of science, and the assumption that scientific developments are equal to "progress." Fox stumped frequently during the 2006 campaign season for the progression of science, suggesting, for example, "I believe that science should move forward in this country. Science is a big part of the American story, and we need to start writing a new chapter."[317] In part, this comes from the idea that if the United States does not move forward with hESC then some other country will, a claim that Fox often promotes.[318] This logic continues the long-standing paradigm of technological determinism, in which an innovation's possibility translates to inevitability, out of the hands of cultural forces. It may very well be the case that another country develops hESC before the United

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[314] Brown, "Hope Against Hype," 4.
[315] Presentation by Charis Thompson at "Reinvention of Time: Articulations of Past and Future in a Scientific Present," UC Berkeley, May 6, 2011.
[316] Brown and Michael, "From Authority to Authenticity," 3.
[317] Michael J. Fox, interview by Katie Couric, *CBS Evening News*. October 26, 2006.
[318] Michael J. Fox, interview with Anderson Cooper, *Anderson Cooper 360 Degrees,* CNN (November 2, 2006).

States, but because of the ramifications for disability and other marginalized populations lurking within hESC, this endless pursuit of progress should not circumvent a more critical debate of whether hESC should move forward. Philosopher Hans Jonas explains what's at stake:

> Let us not forget that progress is an optional goal, not an unconditional commitment ... Let us also remember that a slower progress in the conquest of disease would not threaten society, grievous as it is to those who have to deplore that their particular disease be not yet conquered, but that society would indeed be threatened by the erosion of those moral values whose loss, possibly caused by too ruthless a pursuit of scientific progress, would make its most dazzling triumphs not worth having.[319]

Scientific progress in the lab must not be automatically extended to presume progress for people with disabilities for this will require far more work.

As this 2006 hESC debate is waged over and through the future, and hESC supporters help develop a cultural imagination of the future based upon the erasure of disability, the political economy of hope divides patients seeking cures from those fighting for an end to disability discrimination. These groups need not be separate, but the heavy circulation of disability as uniformly synonymous with physical suffering puts cures before care.[320] If disability is to be erased in the future, why would we invest in accessible buildings or efforts to improve the quality of life of disability in the present? Disability in the present becomes a state of limbo, waiting for cures. And who knows, the cures may very well be just around the corner. But if they are not, the lives that were passed waiting for a cure lost on two fronts – not only from the cures that never came, but also from the inequality they likely faced in their daily lives, living with disabilities.

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[319] Hans Jonas, *Philosophical Essays: From Current Creed to Technological Man* (Chicago: University of Chicago Press, 1980), 135.

[320] Newell, "Disability, Bioethics, and Rejected Knowledge," 269-283.

As explored previously, the techno-makeovers of do-good television and the narratives of people with disabilities from the Global South privilege the celebration of the individual rising up through technoscience over social change that extends past the individual. Although such techno-makeovers are not yet available for Fox, the story is still remarkably similar. We should concern ourselves with Fox alone – not even all of Fox but rather Fox's physical body, separate from its cultural context. We should trust that technoscience will deliver the solution to this technological, not social, "problem." This message is strengthened by Fox's support and commitment to the future techno-makeover he envisions for himself, and his voice is used to represent the larger population of people with disabilities who, we are to assume, all share his desires. The techno-makeover promise suggests there are no other options, so naturally, we will invest in the techno-makeover futures market by supporting hESC.

The placement of disability as a problem for the future neglects the importance of the past. As discussed above, there are many invisible populations and voices that have historically been under-served if not exploited by scientific "progress" throughout history and continuing today. If hESC is to offer significant progress for people with disabilities, we must contemplate history more than we have and in particular, know that we have moved past eugenics.[321] If we are to believe these assumptions that hESC will be available to the people who most need it, and if we are to share in Fox's confidence that this science really just wants to help people, rather than exploit in the name of tremendous profits or take us down a neo-eugenic road, we must be able to bring

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[321] As Shelly Tremain writes, "…if remedial interventions that utilise these phenomena were to become widely available, would governments introduce policy to make these interventions mandatory for certain disabled people as a way of reducing projected long-term social service expenditures?"
Tremain, "Stemming the Tide of Normalisation," 38.

disability – forgive the reference – back from the future and develop a deeper understanding of disability injustice in the present.

Conclusion:

From embryo suffering vs. physical suffering to Fox vs. Limbaugh, both polarized debates leave little room for the many complex ways in which hESC poses threats to marginalized people, including but not limited to people with disabilities. Fox's body out of bounds created a halt in the debate. Politicians who opposed hESC quickly sought out disabled family members and friends to help them avoid being seen as heartless. The media obsessed over Fox - the boyish heartthrob now icon of tragedy - and bought into the polarization of the issue: you are either for or against Michael J. Fox. And the result is that we are left with little room for making demands about disability in the present. Instead, people with disabilities are to wait for technoscience cures (and erasure) in the future.

Looking back on this 2006 hESC cultural moment from 2011 has made it easier to shed light on these issues. We now know that cures have not yet come from hESC for millions of Americans despite the increased government and public support for hESC, especially coming once President Obama took office. Though some clinical trials are emerging for stem cell medicine, the hype around hESC certainly overestimated the speed with which cures would develop.[322] Meanwhile, the debate over hESC has simmered. The discovery that adult stem cells could become induced pluripotent stem (iPS) cells meant that we no longer needed to rely on human embryos for their

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[322] Eryn Brown, "Stem Cells: CIRM Funds Geron Corp. Spinal Cord Injury Trial" *Los Angeles Times*, May 4, 2011.

pluripotency, though since 2011, the attention to hESC seems to be returning, as iPS cells proved less productive than scientists originally thought.[323] Finally, we know that the links between hESC and biotech profits were not imagined, especially clear in the fallout of California's Proposition 71 and Geron's departure from the stem cell field. Yet, despite the slow "progress" of hESC, both the hope and the hype continue, and the media still celebrate each miniscule sign of progress by explaining what it might someday offer for people with disabilities.

The hypervisibility, and yet invisibility, of disability in propelling hESC forward is not specific to the 2006 election moment nor to this specific biotech issue. Disability as an image of suffering has been used and will continue to be called upon frequently in ethical debates over biotech.[324] It is a powerful tool in this biotech realm for it provides drama and urgency that can translate scientific innovations into people's everyday lives. Yet, much is at stake for disability in emerging biotechnologies, which can provide new mediums for eugenic outcomes.

Even a recent sci-fi film, *Surrogates*, touches on the prime location of disability in ushering in questionable technologies. In a vision of the future where people use surrogate robots to carry out their everyday activities, keeping their actual bodies safe

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[323] A recent article suggests this may not be as successful as scientists originally hoped, perhaps reviving the debate. Andrew Pollack, "Setback for New Stem Cell Treatment," *New York Times,* May 13, 2011.

[324] For example, the efforts to map the human genome were led by hopes for gene therapy. If we could determine the genetic markers for specific conditions, we could work to eliminate them, both through preimplantation genetic diagnosis and through gene therapy. Jose Van Dijck touches briefly on a similar paradigm for genetics as seen with hESC, stating, "Public interest in a scientific issue never arises 'naturally' from scientific developments, or from an increase in victims affected by a disease. In order to gain public recognition, a scientific issue needs a sense of urgency - a potential for human drama. Science that entails a solution to a pressing human need has a better chance to appear on the political priority list than science that does not." And like hESC, gene therapy has never been just about offering help for people in need, but rather goes hand in hand with efforts to bring in new sorts of biotech industry and profits and to create increasingly "perfect" humans.
McKibben, *Enough*.
Jose Van Dijck, *Imagenation: Popular Images of Genetics* (New York: NYU Press, 1998), 8.

inside, the film opens with a speedy montage of how the surrogates came into widespread use. It started with surrogates for people with disabilities, allowing the appearance of an able-body while secretly disabled at home, and then it gave rise to a larger commercial market for the able-bodied as well.[325] *The Rise of the Planet of the Apes* similarly begins with the pursuit of a cure for Alzheimer's, applied to gorillas with damaging consequences, leading to the end of the human species.[326] Yet, even in these sci-fi films, biotech profits are noted as the primary aim, and these innovations do more harm than good, so why can't we consider these risks adequately with the technologies right in front of us?

That people with disabilities will be key forerunners in technoscience progress is widely taken for granted, but the deeper ramifications for people with and without disabilities are rarely part of this conversation. The biotech cure-of-the-year is likely to change, but the underlying assumptions – that people living with disabilities are desperately awaiting cures – will remain. The deeper risks to those whose bodies typically must fuel the research will continue to lurk underneath the surface.

As biotechnology scholar George Annas has noted, we hear again and again that "the future is now," but where are the many innovations that we have been promised?[327] Techno-makeovers are not yet available for everyone, but the investment in the hope that they may someday be plays a key role in science policy. Before we continue to hop on the bandwagon for whatever the next biotech/biomedicine cure may be, we need to question: what is lost in this paradigm in the representation and the politicization of

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[325] Jonathan Mostow, Dir., *Surrogates,* Touchstone Pictures, 2009.

[326] Rupert Wyatt, Dir. *Rise of the Planet of the Apes,* Twentieth Century Fox, 2011.

[327] George Annas, Presentation on "Grounding Our Concerns," at the Tarrytown Meetings, Tarrytown, New York, July 27, 2010.

disability? To do so is to bring various power dynamics under the microscope, no longer allowing disability-as-suffering to circumvent a more critical look into technoscience hopes.

Chapter 4:

Not Seeing Eye to Eye: The Rise and Fall of the iBOT Mobility System

The iBOT mobility system, a state of the art wheelchair, started to capture attention long before it was even released, immediately praised by the press as a solution to so many wheelchair riders' problems. The iBOT literally stood out from other wheelchairs for its ability to stand on two wheels to elevate in height and climb stairs. The ability to climb stairs was truly remarkable in a technological sense and could obviously have deep significance for reaching previously inaccessible spaces. Yet, the device offered a high tech fix to the social problem of the inaccessible built environment, though this concern did not come up much in reporting on the iBOT. Quite cumbersome, looking less like a wheelchair and more like something you'd encounter in science fiction, the iBOT would not enable its users to completely enter normalcy. But it would allow the body to act more like an able body and independent. Looking at the narrative surrounding the iBOT provides another variation on the techno-makeover; technology provides a better way to be disabled, coming closer to normalcy, such that individual solutions can come before social change.

In 2006, I followed around an iBOT regional sales representative named Mike, as he demoed the iBOT to the University of Minnesota Disabled Student Cultural Center (DSCC), as well as to the Disability Services office. While students at the DSCC sat and ate lunch, some in wheelchairs, some not, Mike sat patiently in the iBOT, keeping all his gimmicks hidden until he was asked to begin his presentation. Once introduced, he instantly switched the iBOT into its most impressive function, balancing on two wheels to elevate to the height of an average able-bodied person and quickly captivate the audience. Like any good salesman, he began a well-practiced script about how the iBOT is the "father" to the Segway scooter, both invented by Dean Kamen through a shared application of gyroscope technology. After completing his sales pitch, he provided rehearsed answers for all of the audiences' questions, from concerns about safety and repairs to costs and insurance. Saving the big trick for the end, he then asked, "So who wants to see it go up the stairs?" leading us out of the DSCC to one of the primary stairwells at the center of campus and increasing our crowd as an onlooker exclaimed, "That's that wheelchair from television!" Though the crowd expressed various reactions to the iBOT, everyone seemed impressed by its technological abilities.

Mike and I left the DSCC to demo the iBOT at the next location of the day, the University of Minnesota Disability Services office. Again, Mike began his product pitch, concluding by climbing the stairs. As the employees returned to work, Mike turned to me and said, "Alright, now it's your turn," encouraging me to test out the iBOT. After calibrating the device to my measurements and center of gravity, and a quick course on the controls, I was able to play around with the basic functions. With Mike spotting me, I attempted to climb the stairs, though I found it disconcerting when Mike informed me of the risks while I was nervously perched on the center of the staircase, too late to get out. I recalled a friend's concerns, a wheelchair rider herself, when she first saw the iBOT on display by a team of able-bodied riders. Unlike her, the able-bodied designers and sellers of the iBOT know that they can jump out at a second's notice if the product malfunctions. Indeed, I also felt this privilege and though I was uneasy in the iBOT, I could certainly see why it would be even more intimidating for her.

The iBOT is remarkably different than the types of wheelchairs people in the disability community have defined as "significant" and "empowering," yet the iBOT vendors had an unwavering confidence that this device would revolutionize life for wheelchair riders. Would the iBOT have the success that Mike and the other iBOT vendors I had met so confidently believed it would? In this chapter, I explore the rise and fall of the iBOT, as [spoiler alert] the iBOT revolution did not come. The story of the iBOT shows another quest to provide normalcy for people with disabilities through technological means while deeming social change unnecessary. The iBOT promised a techno-makeover, yet this was not enough to help the iBOT succeed.

Before diving into the iBOT's story, I offer two examples of "successful" wheelchairs, as defined by many wheelchair riders. Though most wheelchair designers go to able-bodied occupational and physical therapists to learn about their consumers, a company called Quickie goes straight to the intended users and has made incredibly popular chairs because of this. Frustrated with the "stainless steel dinosaur" wheelchairs after being paralyzed in a hang-gliding accident, Marilyn Hamilton asked her hang-gliding friends to help her design a wheelchair, using lightweight aluminum. After her deep satisfaction with this device, she went on to start Quickie and reinvented both manual and power wheelchairs, working to make high-powered but lightweight designs in various colors to help destigmatize it. In particular, her bright, neon-pink wheelchair was understood by many in the disability rights movement to be a key sign of forward progress for disability pride, giving the wheelchair a more “sexy” appeal.[328]

In a similar story of device innovation, Ralf Hotchkiss, a wheelchair rider himself and a Macarthur “genius” award recipient, started a non-profit organization called Whirlwind Wheelchair International. Hotchkiss and his organization travel the world inventing low cost, low-tech wheelchairs in cooperation with local disabled communities. His team works closely with each community it visits to design a wheelchair that is unique and culturally relevant. In a rural village in Africa, for example, they invented a wheelchair that offered a lower step that women could easily transfer to and sit on, allowing them to participate in the important cultural ritual of cooking with other women while sitting on the ground.[329] Whirlwind Wheelchair International begins with an understanding of disability that is located within culture, carrying through the overall design efforts.

Rare in the wheelchair industry, both Quickie and Whirlwind Wheelchair International provide technology that is made *by* wheelchair riders *for* wheelchair riders, helping them achieve high success and popularity. These wheelchairs incorporate the

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[328] Shapiro, *No Pity*, 212.
[329] Ralf Hotchkiss, interviewed by Emily Smith Beitiks, March 14, 2005.

everyday experiences of living in a wheelchair into design innovation to make a device that is practical and yet desirable. The story of the iBOT, however, is quite different.

The iBOT is the invention of famous engineer and tinkerer Dean Kamen, more commonly known for his high school robotics competition FIRST and the invention of the Segway scooter. In reality, the iBOT was a team effort of several engineers at DEKA, Kamen's company with its name derived from his own (DEan KAmen). Though the idea came to Kamen in 1992 and the device was completed in 1999, the iBOT did not come on the market until 2003, severely delayed because of the challenge faced in getting it approved by the FDA as a Class 3 medical device, meaning that it has higher risks because of the stair-climbing function.[330] While the iBOT got stuck in this approval process, a separate team branched off within DEKA to create the Segway scooter, spawned from the iBOT gyroscope technology. In the end, neither the iBOT nor the Segway had the impact that the people at DEKA and Kamen hoped for, yet these devices captured a great deal of media and public attention along the way, far more than a wheelchair like Marilyn Hamilton's ever has. While the iBOT is unique, the cultural forces that brought about such a technology and hyped its potential are quite common, another cultural home to the techno-makeover.

In this chapter, I examine the rise and fall of the iBOT wheelchair to suggest that this technological object is a product of an able-bodied-centric ideology. The team of

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[330] "FDA Approves Futuristic Wheelchair: Advanced Wheelchair Can Safely Climb Stairs, Move On Various Surfaces And Elevate User," *U.S. Newswire,* August 14, 2003, 1.

engineers, marketers, and mainstream media all assumed that this device would succeed because it offers normalcy to disabled bodies, but this preoccupation with normalcy and the iBOT-as-techno-makeover hurt the iBOT's chances for success. Continuing my argument thread, I problematize the assumption that technological consumption can offer significant change, illustrating how it primarily serves to undercut the need for social services while framing disability through cost/benefit analysis. And once again, the disabled body cured by technological means is cast as the "right" way to be disabled, taking precedence over disabled ways of being that resist (or just don't have access to) high-tech cures.

While fleshing out the story of the iBOT, I develop three pillars of the plot that help my argument take shape. First, I explore how DEKA, with Dean Kamen at its core, fosters a culture of ability and masculinity that influences and produces the technology they create. Just as science studies work has shown the laboratory walls to be porous to sociocultural context, the engineers' workshop is similarly influenced by hegemonic culture and the priorities of the engineers, ensuring that technology is never neutral. This point does not essentialize nor suggest that because the engineers are able-bodied that their device is somehow inherently ableist. Rather, I will show how DEKA's celebration of ability projects onto the iBOT. The iBOT's story is inseparable from Kamen's story. Second, I examine the media hype surrounding the iBOT, where despite the occasional nuanced perspective, the iBOT is generally praised with exuberant enthusiasm, centered on a normalizing discourse. Third, I consider how the design of the device and discourse surrounding it often goes past normalcy - focusing on the iBOT as a futuristic and robotic technology, necessitating a cyborgian relationship between the user and the wheelchair. In the end, the reasons for the iBOT's failure are complex, and I will not be able to offer any definitive explanations to its downfall. However, I will argue that through these three threads, several possible answers emerge to suggest why the iBOT just wasn't all that it was cracked up to be.

Studying the iBOT:

Using the iBOT as the unit of analysis, I combine ethnographic work, discourse analysis of iBOT public relations, media analysis, and secondary source information about DEKA culture to support my argument of the iBOT. As I have briefly introduced at the start of this chapter, my ethnographic fieldwork was conducted at two trade shows (the subject of the subsequent chapter) where the iBOT was on display, as well as at the University of Minnesota, where I followed the iBOT regional sales representative making his iBOT pitch. IBOT public relations materials include press releases, informational brochures, and a promotional DVD, put out by Independence Technology, the sect of Johnson and Johnson who manufactured and sold the iBOT, following DEKA's development of the device. The media analysis includes over 200 articles from 1999-2011, pulled from a range of national papers to small local papers, which covered the iBOT.[331] Finally, the research into DEKA culture and Dean Kamen comes from

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[331] Articles compiled through ProQuest database.

Kamen's public appearances, interviews, and speeches, as well as journalist Steve Kemper's book on the development of the Segway, *Code Name Ginger: The Story Behind Segway and Dean Kamen's Quest to Invent a New World*.[332] Put together, these methods help me to understand how the designers and marketers conceptualized the iBOT and how the media presented this innovation.

In a general sense, this work connects to the overall aim of technology studies to challenge the assumption that technology can ever be neutral, while still resisting theories of technological determinism. As philosopher James C. Edwards explains, "Technology is a frame that blinds us to itself as a frame. It is a way of revealing that makes us forget that it is a way of revealing."[333] In examining the iBOT, I seek to make this frame visible.

In a more specific sense, my argument is greatly shaped by and in conversation with those STS scholars who show the ways that technoscience is intertwined with the culture of its knowledge producers.[334] The work in feminist technology studies in particular has worked to uncover the masculinist culture of engineering and the

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[332] Steve Kemper, *Code Name Ginger: The Story Behind the Segway and Dean Kamen's Quest to Invent a New World* (Boston: Harvard Business School Press, 2003).
Because Kamen became increasingly concerned about idea-theft while working on the iBOT and Segway, DEKA is a closed-off space. Even Kemper, who spent over a year at DEKA in order to write his book, was eventually kicked out by Kamen. Therefore, relying on Kemper's research and Kamen's public persona will have to suffice for this component of my research.

[333] James C. Edwards, "Concepts of Technology and Their Role in Moral Reflection" in *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality*, eds. Erik Parens (Baltimore: John Hopkins University Press, 2006), 55.

[334] Examples of this line of thought can be seen in:
Stefan Helmreich, *Silicon Second Nature: Culturing Artificial Life in a Digital World* (Berkeley: University of California Press, 1998).
Emily Martin, "The Egg and the Sperm: How Science Has Constructed a Romance Based on Stereotypical Male-Female Roles," *Signs* 16:3 (1991): 485-501.

production of machines, and my work both speaks to this while also expanding to consider how masculinity and ability work together to guide the development of the iBOT.[335] This cannot suggest that there is something innate in the male engineer that influences the design, but rather must show how one's cultural identity and social location influence what "styles" they bring to their work.[336] Gender, ability, and technology are co-produced.

Yet, my work also challenges some of the work in STS that has situated disabled bodies as forerunner cyborgs without exploring what that means. As discussed in my introduction, when scholars like Donna Haraway and Sandy Stone – along with many others such as N. Katherine Hayles and Chris Hables Gray – define people with disabilities as preexisting examples of cyborgs without a critical look at what this identity means, they neglect the anxiety people might have towards a technology like the iBOT.[337] While the technology is definitely cast as cyborgian, as I will show, I argue that this cyborgian interface is precisely what limited the desire for the device for many people. Yet, this cyborgian character is also what makes this device so sexy to the media, bringing Dean Kamen into the limelight along with the device and fueling the development of the Segway. From the critique I am making of cyborg studies to the

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[335] Wendy Faulkner, "The Power and the Pleasure?: A Research Agenda for 'Making Gender Stick' to Engineers," *Science, Technology, and Human Values*, 25:1 (Winter 2000): 87-119.
Helmreich, *Silicon Second Nature*.
Sharon Traweek, *Beamtimes and Lifetimes: The World of High Energy Physicists* (Cambridge: Harvard University, 1999).

[336] Faulkner, "The Power and the Pleasure?" 99.

[337] Haraway, *Simians, Cyborgs, and Women*, 178.
Hayles, *How We Became Posthuman*, 115.
Gray, *Cyborg Citizen,* 24, 190.

support I offer of feminist technology studies, this work is in conversation with important scholarship in STS, theories of the body, and normalcy.

It Started at a Mall: Dean Kamen's Vision and the Birth of the iBOT:

The origin story of the iBOT has been frequently repeated throughout DEKA-lore, the media coverage of the iBOT, and the sales pitch for the iBOT. The story goes like this: one day, Dean Kamen saw a man in a wheelchair causing a traffic build-up because he was riding his wheelchair in the street in front of a mall, unable to get up on the curb. Then, Kamen saw that same man inside the mall struggling to purchase an ice cream cone because of the store's high counters. Putting these two moments together, Dean Kamen declared to himself, "I'll fix it."[338] He wanted to develop a wheelchair that could climb stairs or curbs (avoiding the problem outside the mall) and also elevate in height (climbing to the height of those tall ice cream counters), but as he poured through patents of past wheelchairs, nothing seemed capable of overcoming the instability required to tackle these challenges. A second epiphany moment for Kamen came one day in the shower. As he started to slip on the wet floor while getting out, he instinctually swung his arms back the other way, saving himself from falling and regaining his balance. This moment gave rise to his idea to develop a wheelchair with gyroscopic technology, responding to the wheelchair rider's center of gravity the way that the human ear keeps our bodies balanced without our conscious thought just as it does in those slippery-shower moments.

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[338] This pitch helped Dean Kamen generate funding for the iBOT and the Segway. Kemper, *Code Name Ginger*, 20, 49. Also repeated to the author by iBOT sales representatives.

DEKA had previously focused on biomedical devices, such as Kamen's portable insulin pump, which helped put DEKA on the map, but the iBOT was a new sort of device. Kamen selected a special team that brought in engineers from all over the country for the job, working in isolation and secrecy from the rest of the DEKA team. The final product was 250 pounds, officially known as the Independence ™ 3000 IBOT™ Transporter, and capable of going up to six miles per hour.[339] The iBOT is a complex system, including three computers and six gyroscopes to allow for all of its different functions. The device can be used with all of its wheels on the ground, like a standard motorized wheelchair, but at the click of a button, the device can climb up to balance on two wheels. Once in the balancing function, it climbs in height, making it easier to look into the eyes of able-bodied standing adults or to reach things intended for able-bodied persons. It can also move around in balance mode, something that can be extremely helpful for making sure that the wheelchair rider is seen by motor vehicles. The gyroscope technology is key to making this possible. If the wheelchair rider leans forward in balance mode, the iBOT automatically compensates to keep the iBOT upright, and even if someone pushes or shoves the wheelchair rider, the gyroscope will immediately react to help maintain its balance.

This same technology makes stair climbing possible. The wheelchair rider approaches the staircase backwards, holds onto the railing, and shifts their weight to the back of the chair, signaling to the iBOT that it should shift its weight onto the stairs. As it follows these instructions, the iBOT's wheels flip over each other, moving like a

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[339] In 2005, an iBOT 4000 model was released, smoothing out many of its previous functions, using a new type of wheel, and increasing the usability of the device, such as new swing-away footrests to make it easier to enter and a new way to ride the wheelchair while in a car.
"Independence Technology Unveils New iBOT(TM) 4000," *PR Newswire*, August 3, 2005.

Slinky. Alternatively someone can assist the wheelchair rider up the stairs by placing pressure on the back of the wheelchair, which can be used when a railing is not available or if the wheelchair rider does not have adequate strength (measured by the ability to hold a baseball bat). For better or worse, the iBOT is undeniably a unique type of wheelchair in its design and function.[340]

After putting up a good deal of his own money for the iBOT project, Kamen obtained a new "sugar daddy," as he and the others at DEKA refer to Johnson & Johnson.[341] Even after Kamen's large investment to get the iBOT up and rolling, Johnson and Johnson put over $100 million more into its development.[342] The investments from both Kamen and Johnson and Johnson were made because there was such confidence that this wheelchair would outshine all others and tap into a huge market of the 7 million wheelchair users worldwide.[343]

The first sign of trouble came about in clinical trials. They had hoped to get the iBOT on the market by 2000, but found too many problems with the device, from the computer software to its overall safety in the stair-climbing function. After Kamen and Johnson and Johnson poured in more money and labor, the FDA approved the device August 14, 2003.[344] The second battle was over insurance. The iBOT was priced around

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[340] Ron Winslow, "For the Disabled, Upward Mobility: J&J Wheelchair That Can Climb To Begin Trials," *Wall Street Journal*, July 1, 1999, B.1.
Daniel Sforza, "$29,000 Wheelchair Goes Where None Has Gone Before: The Motorized iBOT Negotiates Stairs, Sand, Snow" *The Record,* November 11, 2002, A.01.
Ethnographic data from tradeshow vendors.

[341] Kemper, *Code Name Ginger*, 27.

[342] Winslow, "For the Disabled, Upward Mobility."

[343] Johanna Bennett, "Wheelchair Will Give Users New View: Eye Level," *Wall Street Journal*, November 7, 2001, B.11.
David L. Chandler, "Finally, Eye to Eye 'IBOT' May Revolutionize Life in Wheelchair," *Boston Globe.* November 18, 2000, A.1.

[344] "FDA Approves Futuristic Wheelchair; Advanced Wheelchair Can Safely Climb Stairs, Move On Various Surfaces And Elevate User," *U.S. Newswire,* August 14, 2003, 1.

$26,000, making it one of the most expensive wheelchairs on the market. However, Medicare only approved paying for a fraction of the chair, around $5,000.[345] Johnson and Johnson had hoped that they would be able to lobby for more insurance coverage of the chair, and while they did have some initial success getting approval by the Veteran's Administration to cover the chair for a small population of vets, wider insurance coverage never did come.[346]

During this phase of bringing the iBOT to market, one of the DEKA engineers of the iBOT had taken to riding an earlier prototype of the iBOT around the workplace, giving Kamen the idea to use the gyroscopic technology developed for the iBOT to create a new invention for the able-bodied, eventually giving rise to the Segway human transporter.

The Segway is not the first technology to develop out of an invention originally intended for people with disabilities. Disability studies scholar Mara Mills traces the development of the sound spectrograph in early telephone engineering, which was originally developed for deaf education in oralism. As the engineers began to see the profit opportunities beyond deaf people, they ended their collaboration with deaf students and educators.[347] Even some common household devices were first intended for people with disabilities before shifting into an able-bodied technology, as design historian Bess

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[345] Kerry Young, "Climbing Wheelchair Can't Scale Medicare Obstacles," *Chicago Tribune,* July 23, 2006, 1.

[346] Winslow, "For the Disabled, Upward Mobility."
"Low-Reimbursement Rate Threatens Wheelchair for Wounded Vets," *PR Newswire*, May 13, 2009.
Lauran Neergaard, "Once-Hailed Stair-Climbing iBOT Wheelchair Ends Its Run," *The Charleston Gazette*, May 26, 2009, B.10.

[347] Mara Mills, "Deaf Jam: From Inscription to Reproduction to Information," *Social Text 102*, 28:1 (Spring 2010): 39.

Williamson has shown in the history of the Cuisinart food processor.[348] When the opportunity to broaden one's profits arises, expanding past technology for people with disabilities, few would pass up the opportunity, and Kamen was no different.

While the iBOT had generated a fair amount of media hype, the Segway hype spiraled out of control, mostly because of the secrecy surrounding the project, leading the media to guess what "IT" might be. Kamen had once stated that the iBOT would change the experience of living with a disability, but now he dreamed even bigger. He felt that the Segway would revolutionize city life and eventually impact the world.[349] Kamen claimed that the Segway "will be to the car what the car was to the horse and buggy."[350] On December 3, 2001, the Segway was released to the public, but like the iBOT, the Segway never lived up to these high expectations.

Laying out the story of the iBOT's origins paints a picture of a passionate inventor, taking an observation from an everyday problem and fixing it through invention and engineering. It also shows the transition from conception to commercialization, and the challenges that stood in Johnson and Johnson's way. Yet, what this origin story does not include is a moment from Dean Kamen, DEKA, or Johnson and Johnson where they questioned how likely the iBOT was to revolutionize disability; this was simply taken for granted.[351] Because the iBOT tackles undeniable obstacles for wheelchair riders, stairs and out of reach objects on high shelves, the creators presumed a widespread desire for the iBOT. They failed to anticipate the structural forces that would also be key in

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[348] Bess Williamson, "Getting a Grip: Disability in American Industrial Design," *Winterthur Portfolio*, (forthcoming).
[349] Derek Rose, "Future Rolls In Mysterious 'It' a People Mover," *New York Daily News*, December 3, 2001, 8.
[350] Rose, "Future Rolls In Mysterious 'It' a People Mover," 8.
[351] Bennett, "Wheelchair Will Give Users New View: Eye Level," B.11.

determining the iBOT's success, as insurance problems have long plagued the wheelchair industry and should not have come as a surprise. None of the key actors involved in bringing the iBOT to the market had a background in assistive technology or in thinking about disability, and this was a key component to the downfall of the iBOT. The desire for high-tech gadgets that is pervasive in the United States today does not necessarily carry over to the same celebration of high-tech wheelchairs by wheelchair riders.

The Culture of DEKA is the Culture of Dean Kamen:

The origin story I have just laid out is inextricably linked to the culture of DEKA, where engineers celebrate the high tech and shoot for the cyborgian, greatly constructed around and by Kamen himself. The priorities the designers and engineers had in mind in creating the iBOT — normalcy and high-tech — replaced research into what wheelchair riders most need from their devices.

This prioritizing of normalcy permeated even the earliest stages of the iBOT when Dean Kamen's vision of the struggling disabled man led him to believe technology could be the best path to "shattering barriers," as iBOT product literature boasts, rather than making the environment more accessible, as urged by a disability rights perspective. And this continued as Kamen publicized the iBOT, explaining how moved he was seeing iBOT users climb to able-bodied eye level again. The iBOT sellers, outside of DEKA, also repeated this story. Mike, the Minnesota regional sales representative, shared of a young man with Cerebral Palsy who had recently learned to use the iBOT, recalling, "He goes into balance function and for the first time in his life, he was eye level with his mother and father. It was hard to keep a dry eye." This story fits into a common trope of disability, where people with disabilities overcoming obstacles are meant to inspire us all, heavily criticized by disability activists and scholars for prioritizing the individual's efforts without addressing the wider social context that necessitates overcoming, rather than living with, disability.[352] In other words, the mainstream understanding of disability celebrates Mike's story, as the disabled man can for the first time look his parents in the eyes, whereas a disability rights perspective would rather us question: why haven't his parents just bent down to be at his eye level before? As the sales representative explained, "The iBOT does not eliminate barriers, but it addresses them," articulating the iBOT's design ideology, continued through its sales. While a technology that can overcome these barriers is noteworthy, the iBOT is exalted as the sole solution to the "disabled problem," leaving structural discrimination intact and failing to acknowledge what a technology cannot offer.

An informational DVD sent out to anyone considering the iBOT helped disperse this image of the iBOT "shattering barriers." As the video follows and interviews three iBOT users, the narrative focuses on how the wheelchair allows full inclusion into able-bodied life. A lawyer, who is interviewed, states, "What this chair has allowed me to do is continue my practice," and the narrator follows, "whether approaching the bench or approaching the bar, you won't be craning your neck to talk with friends and associates any longer." The iBOT helps him to overcome inaccessible spaces, such as the high judge's bench, rather than tackle the social issue. Even the logo for the iBOT celebrates normalcy: a stick figure of an able body next to a stick figure of an iBOT user in the

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[352] Rosemarie Garland Thomson, "Seeing the Disabled: Visual Rhetorics of Popular Disability Photography," in *The New Disability History American Perspectives*, eds. Paul Longmore and Lauri Umansky (New York: New York University Press, 2000), 335-74.

balance function, both arm and arm and equal in height. The iBOT promises that you will quite literally rise up to normalcy.

The confidence in the techno-fix is the primary job of any engineer; thinking about change through technology is what engineers do best, often with world-changing beneficial results. The iBOT did help some of its users, who embraced the high-tech device, especially as widespread disability access does not seem to be fast approaching, the iBOT offers useful assistance. However, it is important to know the limits of what a device can offer, for engineers are not likely trained to consider the social and cultural context in which a technology will be used. Or at least, they certainly were not aware of it at DEKA.

As the DEKA team developed the wheelchair, they treated the device as if it was any other high-tech toy. Kamen encouraged inventors to run wild with their imaginations, tinkering with any vision that might pop into their mind.[353] Stories of the iBOT attacking or ejecting the user circulate as DEKA-lore, told for laughs. Journalist Steve Kemper describes witnessing this storytelling at DEKA, as the iBOT came into being; while the early models were incredibly unsafe and such dangers would pose special risks for wheelchair riders, Kemper writes, "The team was having too much fun experimenting to worry about the grueling terrain ahead," or in other words, the phase when they would have to make this gadget applicable to its intended disabled user.[354] High-tech gadgetry is prioritized here, and disability is an afterthought.

A rare critical voice stands out in Kemper's book, detailing the rise of the iBOT and the Segway. He interviews an engineer named Doug, who raised concerns with the

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[353] Kemper, *Code Name Ginger*, 27.
[354] Kemper, *Code Name Ginger*, 21-22.

iBOT, suggesting that the team got so focused on "how" it could be done that they forgot to ask "should it be?"[355] The mainstream understanding of disability in need of a technological fix gave rise to Kamen's vision and DEKA's conviction that this technology would revolutionize the experience of being a wheelchair rider. But while the origin story circulated throughout DEKA culture, an understanding of the perspectives of wheelchair riders appears to have been absent.

This limited understanding of disability also hurt the designers as they assumed the desirability of a cyborgian dimension to the device. For the engineers at DEKA, this is what they were most proud of – a symbol of the wheelchair's advanced robotics. Before the iBOT was called the iBOT, it had many names. Its primary name was "Fred," or "Fred *Upstairs*," a nickname the iBOT took on after it malfunctioned in a dance-like move, similar to Fred Astaire. But the iBOT also had less human names, including "the transporter," "R2D2" (after the droid robot from *Star Wars)*, and "No. 5" (after the robot in *Short Circuit*).[356] The final decision of "iBOT" seems peculiar given the resemblance to *I,Robot*, the sci-fi book and film where robots intended to be humans' helpers violently take over.[357] If the tech-focused pathway to its name did not already make clear how this technology was to be understood, the inventor Dean Kamen helped make it explicit, telling everyone that he did not want it to be seen as a wheelchair and preferred that it be called a "robot" or, as used by the iBOT sellers, "a mobility system."[358] These names,

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[355] Kemper, *Code Name Ginger*, 37.
[356] Kemper, *Code Name Ginger*, 26.
[357] Isaac Asimov, *I, Robot* (New York: Gnome Press, 1950).
Alex Proyas, Dir. *I, Robot* (20th Century Fox, 2004).
[358] Kemper, *Code Name Ginger*, 6.
Also confirmed during ethnographic research with Minnesota regional sales representative.

and especially the final choice of "iBOT" seek to play up the robotic and futuristic elements of the device, fueling the image of people with disabilities as already cyborgs.

The creation of a cyborgian relationship between the iBOT and its user not only happens through discourse but also through the iBOT's design. The gyroscope technology functions like the inner ear to correct for shifts in the rider's balance, developing a closely interconnected feedback system. Marketing the wheelchair, Johnson and Johnson note, "Sensors send 10,000 instructions a second to the vehicle's computer so that it responds instantly."[359] In addition to responding to the rider's movement, the iBOT also strengthens its feedback loop by putting some of the rider into the machine. When the regional sales rep invited me to try the iBOT, he warned that before I could use it, we would have to recalibrate it to my body size. After putting it into a new mode, the machine took over for a few minutes, shifting into each of its different positions to test out my body, assess my center of gravity, and update its software to these measurements. By ensuring that a little bit of me was in the machine, this began blurring the boundaries between myself and it.

However, the iBOT has the ultimate power over the body in the end. Without warning, Mike demonstrated this while I was in the chair's upright balance function. He came up behind me and began vigorously shaking it, causing the chair to instantly shift into its most stable position with all wheels on the ground. He explained, "If it does not trust your judgment, it will take over." This mechanism seems particularly worrisome given the earlier models of the iBOT, where it frequently ignored commands and went out of control, once ejecting the rider and chasing him down, on another occasion

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[359] Winslow, "For the Disabled, Upward Mobility."

attempting to climb a designer's leg like a staircase, and on a third occasion, repeatedly slamming an engineer into a glass wall. For the end-users who will not have the option to jump out like the engineers did, these stories might raise a good deal of concern, even if these kinks have been worked out and FDA approval obtained. Kamen and his team seem to tell these stories with frivolity; they must be assuming people will not connect the iBOT with *I, Robot* and feel deep discomfort from this body/machine interface. For users who may be seeking to gain control lost because of impairment, the iBOT's high-tech functions may enhance what the user can do, but they may also make the user wary.

While the iBOT had once been the pride and joy of DEKA and Dean Kamen's attention, Kamen's realization that the technology could be used outside of the medical device industry shifted much of his excitement to this new invention. Soon, Fred-the-iBOT took a backseat to Ginger-the-Segway, named after Ginger Rogers, Fred Astaire's dancing partner. As Kamen puts it, "Who wouldn't rather make ice cream than broccoli?"[360] This shift in priorities was even mocked at the DEKA Christmas party, known for its playful jabs at Kamen each year. DEKA workers hung posters with an image of Fred Astaire in a dungeon while Ginger Rogers danced ethereally above in the clouds with gumdrops.[361]

To develop the Segway, the DEKA team also switched their approach and placed newfound attention to "Man Max, Machine Min," as one of the engineers puts it, prioritizing design aesthetics. This ideology was lacking with the iBOT's cyborgian aesthetic.[362] What the privileging of the Segway over the iBOT within DEKA shows is a

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[360] Kemper, *Code Name Ginger*, 173.
[361] Kemper, *Code Name Ginger*, 173.
[362] Kemper, *Code Name Ginger*, 34.

celebration of ability over disability, and machines as toys over machines as tools. While the iBOT was exciting to some at first, it was confined by important constraints – the disabled body, limited health insurance, the FDA – whereas the Segway had a wider potential market. The Segway was exciting because of its commercial and mainstream potential, and this meant that it got top billing at DEKA.

The comfort with the cyborg in DEKA culture is linked to the culture of masculinity of the engineering lab. Steve Kemper's book on the rise of the Segway provides several stories of Kamen's work recruiting engineers and the challenge convincing the wives to move.[363] From Kemper's descriptions inside the lab, otherwise a closed-off, secretive space, he describes a team of only male engineers. Women do appear in the DEKA lab but through discourse. One designer, obsessed with an early model of the Segway, which was then called "Mary Ann," is described by his colleagues as having a "crush" on Mary Ann. Frustrated with the machine, he states, "She can really be a bitch sometimes."[364] As they get the Ginger the Segway ready for its debut, one engineer states, "What's left is to dress her up and get her ready for her coming out party," and later describes her as "in her wedding dress."[365] The gendered descriptions of the Segway must be understood in conjunction with the tinkerer-culture that left disability out of the iBOT until the end and that put the Segway before the iBOT. Both show a desire for dominance – conquering the stairs, getting that "bitch" to behave like a proper machine should – and a celebration of the machine over the body, something that has typically been much easier for the group most associated with designing and controlling

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[363] Kemper, *Code Name Ginger*, 33.
[364] Kemper, *Code Name Ginger*, 33.
[365] Kemper, *Code Name Ginger*, 144.

machines to begin with. While much has been written about the role of masculinity in machine culture among engineers, gender and normalcy work together here in shaping how the designers understand the iBOT and the Segway.[366]

In part, I have painted a picture of the culture of the DEKA team, but as the company is deeply centralized around Kamen who insists on being involved and of approving every step in the design process, "the culture of DEKA" is often more accurately "the culture of Kamen." Within DEKA, he surrounds himself with engineers willing to trust him and his vision. DEKA employees often complain about "getting Deaned" when their work is slowed down dramatically after Kamen intervenes, something that caused both the iBOT and Segway to develop behind schedule.[367] All in all, Kamen is a clear individual, and even as he must work collaboratively to further his work, he has built a structure at DEKA, from the name of the company to the focus of the Christmas parties, that reminds his workers who is at the company's center.

Kamen's background is relevant in the story of the iBOT, as his rugged individualism and independence parallel the same cultural traits that are prioritized in the iBOT. As one journalist describes it, "The atmosphere at DEKA is Dean-all-the-time," guiding both the culture of DEKA but also the devices themselves.[368] Thinking back to the origin story of the iBOT once more, it seems that Kamen's solution to fix the "disabled problem" with technology, rather than with social change, demonstrates the privileging of the individual over the social, independence over interdependence. The

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[366] Faulkner, "The Power and the Pleasure?"
Helmreich, *Silicon Second Nature*.
Traweek, *Beamtimes and Lifetimes*.

[367] Kemper, *Code Name Ginger*, 122.

[368] Nathan Cobb, "Mystery Science 2001 Inventor – Entrepreneur Dean Kamen Piques the World's Curiosity with his Project Ginger, Then Takes Cover," *Boston Globe*, February 1, 2001, C.1.

man reaching up to get an ice cream cone needs a high-tech wheelchair to solve the problem, rather than a little extra help from the ice cream vendor, privileging independence over interdependence. The media eats up the image of Kamen as an individual inventor, coining him a "Thomas Edison" style of inventor that is now rare, although this sentiment denies Kamen's unavoidable dependence on his design team. Kamen's personality traits built a culture at DEKA in which able-bodied assumptions thrive and the individual is best, influencing the machines they produce.

Kamen's priorities stand in stark contrast to those of Marilyn Hamilton and Ralf Hotchkiss, where the wheelchair rider came first in the design process. It is not solely because Marilyn Hamilton or Ralf Hotchkiss is disabled that they invent a very different type of wheelchair than Kamen and his team did. In fact, Ralf Hotchkiss is a big fan of the iBOT and enjoyed using the gyroscope technology to dance when he tried it. Rather, what distinguishes Hamilton and Hotchkiss from Kamen is their understanding of the complexity of the situation wheelchair riders face, navigating an able-bodied culture in their everyday lives. Hotchkiss argues, "Though the low-tech fixes are not nearly as sexy to a high-tech-adoring society… there is more bang for the buck."[369] Similarly, Hamilton prioritized flashy colors and chic frames that were lightweight over heavier models because it helped show the user's identity first, a clear difference from the 250-pound, mechanistic-appearing iBOT. The culture of ability and the celebration of individualism through the technological fix distracted Kamen and the DEKA team from seeing this or seeking out the information that Hamilton and Hotchkiss did not need to seek out, which could have DEKA anticipate the iBOT's shortcomings.

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[369] Shapiro, *No Pity*, 225.

“The iBOT : Wheelchair as Internet : Pigeon”:[370] The Media Hypes the iBOT:

When the time came for the iBOT to leave the DEKA lab, it had no problem capturing the public’s eye. Following its media debut on *Dateline*, the iBOT received a flurry of media attention.[371] Though never materializing, Stephen Spielberg wanted to use the iBOT in his sci-fi film, *Minority Report*.[372] The iBOT appeared on *The Colbert Report*, where Stephen Colbert appeared in the iBOT to demonstrate its capabilities, and also on a primetime comedy show, *Ugly Betty*, where a boss in the world of fashion demanded the fashionable iBOT while faking an impairment.[373] Outside of the television world, newspaper coverage was equally extensive, some articles based directly on press releases put out by the iBOT’s manufacturer, Johnson and Johnson. While the types of media varied, the message was more or less the same: the iBOT was going to change the world.

Newspaper stories focused overwhelmingly on the normalizing aspects of the wheelchair. “Dean Kamen is determined to make sure that never again will anyone look down on people with disabilities. Literally”[374]; “A kiss is just a kiss now for Sarah Yuhas of Marcellus, N.Y., who no longer strains to meet her husband's gaze thanks to the iBOT wheelchair”[375]; “Independence Day came early this year for 22-year-old Rebekah

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[370] This comparison was made by Dean Kamen.
Kemper, *Code Name Ginger*, 91.

[371] Kemper, *Code Name Ginger*, 53.

[372] The use of the iBOT in the film never actually came through.
Kemper, *Code Name Ginger*, 65, 129.

[373] *The Colbert Report*, Episode 142. First aired on November 9, 2006 on Comedy Central.
Ugly Betty. Episode number 26. First aired on October 11, 2007 on ABC.

[374] Chandler, “Finally, Eye to Eye ‘IBOT’ May Revolutionize Life in Wheelchair.”

[375] Thom Marshall, “Houston Facility 1 of 3 to Roll Out iBOT Wheelchair,” *Houston Chronicle,* January 27, 2004), 15.

Stevens. No longer will this witty, intelligent young woman with cerebral palsy have to dodge lighted cigarettes dangling at the sides of smokers who don't see her … in her wheelchair — eye level with their burning smokes."[376] Similar quotations can be found throughout the iBOT's media coverage. In line with Kamen's way of thinking about the iBOT, the media plays into and helps distribute a mainstream understanding of disability, where the high-tech is always desirable. The problem is with the disabled body, which ought to travel at an able-bodied height and stand-up in order to be treated like an adult. Apparently, kissing while in a wheelchair does not really count.

This line of thought falls in line with the popular overcomer trope of disability. People with disabilities, as individuals, must be the ones to go out of their way to return to normalcy and overcome barriers, and technology can help make this possible. The best example of this is the attention to the iBOT's climb to the top of the Eiffel Tower.[377] Even though the rider, Dean Kamen, was able-bodied, this story promotes the iBOT's potential to help people with disabilities overcome, paving the way for people with disabilities to make similar triumphs. Disability access can be dealt with at the individual level through technological consumption.

Reiterating the idea that the iBOT is about independence and individualism, the media emphasis on Kamen – of equal interest and hype to the iBOT in most stories – celebrates Kamen for bringing back the "Thomas Edison" type of inventor. One article notes, "…more than 1500 articles in 16 languages were printed about Kamen and his new

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[376] Dennis McCarthy, "Aspiring Actress Gets New Mobility," *Daily News,* July 2, 2006, N.3.
[377] Chandler, "Finally, Eye to Eye 'IBOT' May Revolutionize Life in Wheelchair."

invention in the second week of January [2001] alone."[378] *New York Times* reporter Amy Harmon states, "At a time when 'invention' seems to imply intangibles like DNA sequences or the electron streams that make computers compute, Ginger seems to call forth the industrial era and a comforting American icon: the lone Edisonian inventor in a workshop, creating out of nuts, bolts and gears a mechanism to change the world."[379] While Kamen inserts himself into all steps of the design and invention process, this statement enforces a false image of Kamen as sole inventor, rather than the leader of a hard-working team of engineers who all bring different contributions to DEKA's projects. It is only fitting that as the media builds hype around individualized techno-fixes and independence for wheelchair riders, it also erases the collaborative process through which the iBOT (and Segway) came into being to exalt Kamen as an independent individual.

Just as the DEKA lab prioritized normalization through the iBOT, the media also celebrated the iBOT's normalizing potential. The popular celebration of the iBOT bolstered the image of the "able-disabled" wheelchair rider, overcoming barriers for the individual while largely neglecting the limitations to the iBOT and the barriers that it leaves intact.

Wheelchair Riders Meet the iBOT:

Kamen describes the first moment when wheelchair riders test out the iBOT as such, "They go up and down a curb and say, 'Wow, that's really neat…Then they go up

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[378] Michael McCormack, "Stirling's Engine Has Its Day: Legendary US Inventor Picks Up on the Genius of a Scots Minister," *The Herald,* March 26, 2001, 19.

[379] Amy Harmon, "Inventing a Future Just Like the Past," *New York Times,* January 21, 2001, 4.4.

and down stairs – 'Wow, that's really practical, that's great.' And then they stand up, and they cry. All of them."[380] Despite Kamen's hyperbolic claims, many wheelchair riders had no interest in trying the device, and the largest proportion of wheelchair riders never had access to it to make a call one way or the other. Kamen's statement suggests one type of wheelchair rider – one who longs for the experience of able-bodiedness and would be moved to tears while climbing in height, but there are other stories to tell — not "all" cry for the iBOT.

Most of the media stories hyping the device included quotes from wheelchair riders who were eager to test it out or receive one. One wheelchair rider shares, "I feel that I have started a new chapter in my life today with the delivery of my own iBOT…I look forward to expanding my world and all that I am able to do with my family, my career and my life." Another rider suggests, "As a woman with a disability, seen as the weakest of the weak, it'll be nice for a change to show the guys I have better toys than they do."[381] Certainly, the iBOT can and did do wonderful things for some people. But only rarely did divergent perspectives surface in the press. One disabled columnist writes:

> Do we wheelchair users really need a power wheelchair that will balance on two wheels while raising up the seated person high enough to reach a top shelf? How frightening is it to look down a flight of stairs while this robot-like chair takes you up to the second story? How much risk of further injury to their already battered and damaged bodies should paralyzed persons take?…As for reaching the Wheaties on that top shelf, I will continue to do it the old fashioned way: "Would you please hand me that item up there? Thank you.[382]

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[380] Chandler, "Finally, Eye to Eye 'IBOT' May Revolutionize Life in Wheelchair."
[381] McCarthy, "Aspiring Actress Gets New Mobility," N.3.
[382] Jerry Daniel, "New Wheel Chair Gives Users a Big Lift," *Columbian*, September 1, 1999, A.11.

Another article includes the perspective of a wheelchair rider who participated in a clinical trial of the iBOT and felt that the iBOT was "a trade-off," getting increased mobility at times, but often losing mobility because of how large and cumbersome the device is.[383]

These less-iBOT-obsessed stories parallel the responses to the iBOT I observed at disability-technology tradeshows, where the iBOT was for sale. The first time I learned of the iBOT, I was attending a tradeshow with my mother, a motorized scooter user. The iBOT was definitely succeeding at capturing the most attention, as six, able-bodied sellers demoed the various gimmicks of the machine to crowds of onlookers. But upon seeing the iBOT climb stairs, my mother instantly responded that there was no way she would try something like that because it looked too scary. Five months later, I attended my second Abilities Expo in Santa Clara, California and spoke with a college freshman who uses a motorized wheelchair. While she was much more inclined to use technology in her everyday life than someone of my mother's generation, she had a similar response, reflecting, "If I fell as opposed to them [able-bodied sellers who were demoing the iBOT], 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's weird. It scared me." This reminded me of a poignant statement from disability activist Patty Berne, who questions why, despite all the efforts to enhance what technologies can do, wheelchairs are not yet fully waterproof.[384] The iBOT may offer increased

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[383] Yudhijit Bhattacharjee, "Users Discover Pros and Cons In Stair-Climbing Wheelchair," *New York Times,* August 19, 2003, F.7.

[384] Regan Brashear, Dir. *Fixed: The Science/Fiction of Human Enhancement* [A rough cut screening, July 6, 2011 at the Center for Genetics and Society].

independence, but many people may have other concerns that come before stair-climbing and elevated height.

Even if a wheelchair rider did want to use the iBOT, Johnson and Johnson stated that sales would be restricted to those who undergo special training, administered by licensed doctors and rehabilitation therapists "to ensure [iBOT riders] are physically capable of handling the machine and have the right judgment skills to discern obstacles."[385] This restriction is an important safety precaution, but it speaks to the wider attitude with which the device was designed; the machine comes first. The restrictions in place before purchasing the iBOT suggest a very different story, short of the revolution for wheelchair riders that Kamen and other DEKA engineers imagined. Instead, the iBOT will perhaps offer a revolution for wheelchair riders (a portion of the wider community of people living with disabilities) who are capable of holding out a baseball bat (a much smaller number), who have the insurance and financial capital to have access to the iBOT (an even smaller number), and who have the "right judgment skills" to obtain it (who knows what this number looks like?). A true revolution through technology cannot come from the device itself, but rather through its deployment by users.

The overzealous celebration of the technology by Kamen, the DEKA team, and most of the media coverage on the iBOT, focused on what the iBOT would offer for wheelchair riders without considering what it might take away: a sense of identity as separate from a machine and the stigma that wheelchairs too often carry. Kamen shares his memories from the iBOT's first debut at a tradeshow, boasting that they stole all the attention away from the other wheelchair vendors, as he was able to tackle all the terrains

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[385] Lauran Neergaard, "FDA OKs Wheelchair that Will Climb Stairs," *Associated Press*, August 14, 2003. This article appeared many times. Here Neergaard quotes Independence Technology.

that other devices couldn't. Yet, it is possible that Kamen was focused more on the vendors than the intended users, and capturing attention does not necessarily mean that people were universally celebrating the iBOT.[386] "Man Max, Machine Min" was taken into consideration with the Segway, but to capture this population of wheelchair riders who are anxious with the highly advanced body/machine interface, it would have been necessary to consider in crafting the iBOT. The iBOT failed for many reasons, but part of the story is that there was only a limited population of wheelchair riders who even wanted the iBOT, so when the time came to fight for insurance coverage of the iBOT, the revolution Kamen predicted did not come.

Like the iBOT, the Segway failed to live up to Kamen's predictions that it would "revolutionize city living."[387] Or, if the revolution came, the movement consisted of mall cops, airport workers, and tourists. However, in an ironic twist of fate, the Segway was a very popular device among many people with disabilities. Especially for people with disabilities who are capable of standing but struggle to walk long distances, the Segway offered an affordable alternative to a motorized wheelchair, selling for under $3,000 and allowing the user to minimize the appearance of having a disability.[388] Because the Segway allows the user's identity to be seen first before the machine, this device appealed to many, a population who would most likely have passed on the iBOT, even if it had been offered without the large price tag.

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[386] Kemper, *Code Name Ginger,* 54.

[387] Kemper, *Code Name Ginger*, 154.

[388] Rachel Metz, "Oft-Scorned Segway Finds Friends Among the Disabled," *New York Times,* October 14, 2004, G.5.
Cynthia Yeldell, "Segway Rolls into Segue: Transportation Device Aids Business Owner Who Has Birth Defects" *News Sentinel,* July 27, 2005.

Just because the iBOT was not for everyone does not mean that it should not have been developed and brought into the market, as well as made available to wheelchair riders who would feel comfortable using the device. However, the many anxieties raised by the thought of using the iBOT show that we need to complicate the assumptions about disability technology. Normalization and independence through a device may not be the primary concerns and a cyborgian relationship may seem technologically impressive, but these features come with several trade-offs. The problem is not the wheelchair itself, but rather the expectations that come with the wheelchair, once again feeding into a cultural celebration of techno-makeovers and technological consumption for people with disabilities. The iBOT's failure helps to tell a different story.

Though the iBOT did not offer a complete return to normalcy for its users, as they would still appear to be wheelchair riders, the story surrounding the iBOT still falls in line with the techno-makeover genre. The iBOT captured media attention because it promised a technological solution to the problem of disability. The individual should be corrected and "improved" by technological means, rather than explore social changes that could be done to address disability beyond the individual. Like other techno-makeovers, the iBOT offered a solution that bolstered the capitalist system – normalcy is a commodity that can, and therefore must, be purchased. While Kamen and his team made many missteps in crafting the iBOT, the assumptions that DEKA made about people with disabilities and wheelchair technology were far from surprising. Rather, their assumptions were consistent with the widespread beliefs circulating in American culture, in which people with disabilities homogenously sit in waiting for techno-makeover cures to come.

Conclusion: The iBOT Falls, Kamen's Philosophy Holds Strong:

While many celebrated the iBOT as a unique device, it was still constrained by the structural challenges that all medical devices must face. Because the device was so expensive, ranging from $26,000-$29,000, it proved difficult to get insurance companies to subsidize it. Johnson and Johnson had hoped that they might successfully lobby and persuade insurers to cover the iBOT, but failed to make a big enough change, and even the gains that had been made to get veterans access to the device were reversed.[389] A handful of articles covered the end of the iBOT, though certainly far fewer than the number covering its rise, all noting the limitation of insurance in helping the iBOT succeed. While this coverage was important for drawing attention to the stratified access to assistive technology devices, it still took for granted that wheelchair riders homogenously desired the iBOT. The iBOT's issues were bigger than access, and the fact that the access problems came as a surprise is part of the problem. By 2006, fewer than 1,000 iBOTs had been sold, and the last iBOT was sold in the spring of 2009.[390] In part, the iBOT's failure was tied to the fact that the revolution it promised did not materialize. While some wheelchair riders joined in to fight the insurance companies, the pressure of their voices, along with Johnson and Johnson's, was not enough to make change. In the end, the iBOT's story suggests a clear critique of the ideology that built the device: the technology alone could not escape the sociocultural dimensions of living with a disability. There were some barriers that the iBOT could not shatter.

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[389] Winslow, "For the Disabled, Upward Mobility – J&J Wheelchair That Can Climb To Begin Trials," "Low-Reimbursement Rate Threatens Wheelchair for Wounded Vets."

[390] "Low-Reimbursement Rate Threatens Wheelchair for Wounded Vets."

As the media celebration moved on to hype up new technologies, the iBOT left the public's eye, and as the existing iBOTs soon start to age and die off, the iBOT will soon disappear completely. Yet, the lesson of the device was clearly limited for Kamen and the DEKA team. Now, they are hard at work on a new project with military funding from DARPA to build the most advanced prosthetic arm yet. Once again, Kamen pulls from sci-fi in naming the arm "Luke" after Luke Skywalker's prosthesis in *Star Wars*. And once again, he has built an incredibly expensive prosthesis, technologically advanced and focused on offering normalcy through robotics. Though DEKA engineers report that they aim to keep the costs down, current predictions suggest that it will be around $100,000, comparable to other bionic and highly advanced prostheses.[391] The media is heavily tracking the device, much like with the iBOT, without recognizing the hurdles that the Luke arm will have to overcome in order to succeed where the iBOT failed. Many prosthesis users are excited to use the Luke arm, but I imagine it is fair to predict that many are less enthusiastic. Even though the Luke arm has one thing going for it that the iBOT didn't — DARPA funding — it still seems likely that this device will never affect the majority of prosthetic arm wearers.[392]

Since I began doing research on the iBOT in 2005, I predicted that the device would fail to catch on. To celebrate that my predictions were accurate, however, would distract from what is deeply disheartening about the iBOT's failure. Though far short of the numbers that Kamen anticipated, hundreds of people did still purchase the iBOT, which expanded what they were capable of doing in their everyday lives with the device.

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[391] Priya Ganapati, "Bionic Arms Gain Power, Dexterity, Sensititivity," *Wired,* (December 1, 2009), http://www.wired.com/gadgetlab/2009/12/bionic-arms-gallery/2/.

[392] Dean Kamen, "Dean Kamen Previews a New Prosthetic Arm," *TedTalks*, August 2007.

In the iBOT promotional video, for example, a high school senior shares that she doesn't have to think about accessibility in choosing a college because of the iBOT. I hope that she, like the many other iBOT users, found other strategies for continuing her life without the iBOT; but, I fear that many iBOT users most likely faced great challenges once the iBOT went away, learning that despite the promotional claims that the iBOT "shatters barriers," the barriers were not shattered for good. The iBOT did offer help to many people and that this device is no longer available is an unfortunate way to be reminded of the fact that technological progress did not translate to social progress.

While the iBOT is just one device, my analysis brings to light the many cultural forces influencing its development, demonstrating that the wider culture in which normalcy is prioritized infiltrates the device industry. Even though Kamen and the DEKA team may have had the best of interests at heart, the design of the iBOT and the engineering culture surrounding it show an effort to define what wheelchair riders *should* want, another site where the techno-makeover is at play. Normalcy is prized and a cyborgian relationship to get one there should be embraced. Individualized solutions such as the iBOT are worth celebrating for solving "disabled problems," neglecting the wider social problems that will remain in place, such as the widespread limited access to assistive technology devices. Normalcy and assistive technology are too often co-produced.

To conclude, I offer the story of Dean Kamen promoting the iBOT on *The Colbert Report*. The interview begins with host Stephen Colbert riding an iBOT, demonstrating all of its alluring bells and whistles. A "Putin '08" bumper sticker has been added to the back of the wheelchair - Colbert's satirical way of personalizing it. After Colbert asks Kamen several playful questions about the device, including "Is this an internal combustion engine?" he ends the discussion with a characteristically rhetorical jab, which elicited a poignant and telling response. Colbert inquires, "Now, let me ask you the most important thing. Now that these are available for the disabled, why should they get those prime parking spaces? Isn't this going to put an end to that?" Kamen replies, "Yeah, well this is a win-win, everybody wins, now that we're all equal, you can go after those spots." Perhaps Kamen's answer was just rolling along with Colbert's iconic brand of humor, but given the grandiose visions that Kamen and others held for the iBOT, which at the time were very much still alive, perhaps not.[393]

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[393] *The Colbert Report*, Episode 142. First aired on November 9, 2006 on Comedy Central.

Chapter 5:

Window Shopping at the Mall of Handicapitalism

"So what's your deal? You're young, able-bodied, and you keep circling around here – so what are you doing here?" I was being called over by Todd, a man in his 30s in a TiLite manual wheelchair. While doing research at the Abilities Expos, large tradeshows where people with disabilities get to scope out assistive technology, many vendors like Todd tried to capture my attention. He spotted me as an outsider and was intrigued. After I explained my presence and my interest in the assistive technology industry, Todd had a lot to say. His story – as he fully realized – is emblematic of wider problems.

Though Todd is now in a wheelchair, he began working for TiLite long before he was disabled himself. After a spinal cord injury left him paralyzed from the waste down, he suddenly required the use of the devices that he had already learned so much about. As he underwent rehabilitation, he was deeply troubled to find that the types of wheelchairs that he knew would work best for him were never presented as an option. And he knew why. TiLite wheelchairs were expensive and therefore extremely challenging to get most insurance companies to subsidize, so rehabilitation therapists did not bother introducing this option. Even TiLite's website includes a bleak section on "funding" which states:

> TiLite understands that recent developments in our industry (HIPAA, Medicaid cutbacks, etc) have raised significant funding obstacles for our customers—both rehab suppliers and wheelchair users. Unfortunately, these developments have resulted in increased pressure to give wheelchair users lower quality products that result in reduced mobility and worse health outcomes for wheelchair users. TiLite is committed to helping our customers overcome these funding

> challenges.[394]

Because Todd had the know-how to ask for exactly what he wanted and fight back against the insurance companies, he was able to obtain a TiLite wheelchair – light, unobtrusive, and sleek in design.

Todd's struggle is common, but his happy ending – ending up with the perfect wheelchair for his needs – is unique. Far more often, people end up with devices that are subpar. At best, such a mismatch can be a mild inconvenience, leaving the user to either grow accustomed to an insufficient device or simply toss it out to join the fate of many assistive technology devices that face what rehabilitation therapists have coined "technological abandonment." At worst, a poor assistive technology match can have serious complications and health risks. Using a wheelchair that does not fit, for example, can result in dangerous pressure sores, which can cause life-threatening infections. To have an assistive technology device that is less than ideal is a missed opportunity.

The preceding chapters have analyzed the stories that circulate in mainstream culture, from reality television to the news media. I have shown how the narrative of the techno-makeover over-celebrates people with disabilities being normalized by the high-tech. But outside of the media spotlight, how do people with disabilities learn about and access technology? In this chapter, I explore the expos and the alternative representation of assistive technology that they bring to light. I draw from ethnographic research conducted at these tradeshows, which provide the largest public space for negotiation and interaction with assistive technology devices.[395] After attending two Abilities Expos in

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[394] TiLite, "Funding," Accessed April 20, 2012, http://www.tilite.com/fund_rp.php.

[395] I conceptualized my research based on several ethnographies from science and technology studies, where scholars have sought to uncover the "culture of no culture" of scientists, artificial intelligence

2004 and 2005, which prompted my fieldwork, I have since spent approximately 40 hours[396] divided between three expo locations – Minneapolis, Minnesota, New York Metro (located in Edison, New Jersey), and Anaheim, California.[397]

Contrasting the techno-makeover genre, there are other stories, comparable to Todd's, that indicate a more fraught and complex relationship between people with disabilities and assistive technology devices. They show an industry where access is deeply stratified and corporate profits come first. The Abilities Expos, the space where I first met Todd, provide a home for many of these stories to circulate, where many people

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designers, or nuclear physicists, to name a few. As Annette Weiner suggested in her 1993 presidential address to the American Anthropological Association, we need "critiques that embody scientific knowledge with the stuff of lived experiences as people everywhere are faced with growing contradictions about the way they have named and come to know the natural world." Ethnographies within science and technology studies provide a lens into this perspective, where science and technology need not be understood solely by the terms of the laboratory, but rather by how they are understood and shaped within wider non-expert cultures as well. To understand the significance of the Abilities Expos is to follow this line of thought, as the expos help a technological community to form that seeks to influence the technologies and the industry. The community within the expos is less about celebrating the pure existence of assistive technology, so much as it is a celebration of being *involved* with the devices, choosing them for oneself and talking back to the people behind the scenes.

Emily Martin, *Flexible Bodies: The Role of Immunity in American Culture from the Days of Polio to the Age of AIDS* (Boston: Beacon Press, 1995).

Karen-Sue Taussig, *Ordinary Genomes: Science, Citizenship, and Genetic Identities* (Durham, North Carolina: Duke University Press, 2009).

Sarah Franklin, "Science as Culture, Cultures of Science," *Annual Review of Anthropology*, 24 (1995): 163.

[396] The expos typically begin on a Friday morning and conclude Sunday afternoon, and I spent the entire time circling at each of the showroom floors, conducting interviews and attending workshops.

[397] Note on methodology: By the final expo that I attended in Anaheim, I knew many of the vendors from the previous shows, who had even spread word of my presence and introduced me to friends or colleagues. As a petite, 5'4 woman who is frequently told how "young" I appear, it was clear that those who did not know me did not seem threatened by my presence, merely curious about my circling presence. Once I explained my research, I was repeatedly asked how I found my project, and so I explained that my mother has had a disability all my life, and that I got interested in this because of her own anxieties around using assistive technology. When I explained my dissertation, it was predominantly met with great enthusiasm by people who explained the importance of getting the word out about the huge inadequacies within the assistive technology field. Although my presence did not seem to threaten most people, I decided to focus on interviewing the vendors and supplementing this with participant observation in the showroom and in the workshops to ensure that I did have access to the disabled attendee voice. As I will argue, the expos serve an important cultural function for attendees, so I decided that I would not take people out of that in order to talk to me, as a temporarily able-bodied outsider of the community. Because those in attendance represented a diverse crowd, my presence as an able-bodied ethnographer wandering in circles each day within the crowd often went unnoticed, but whenever someone directly asked me why I was at the expo or what I was writing about, I always disclosed.

have faced similar challenges accessing and learning about the technology that is right for them. Additionally, the expos attempt to make change, encouraging people with disabilities to have a voice in the assistive technology industry. The stories that surface are illustrative of what's missing in the techno-makeover genre; they shed light on what Dean Kamen didn't understand with the iBOT, and what viewers of *Extreme Makeover: Home Edition* do not get to see.

Technology can be about empowerment, and not normalcy, if people with disabilities are fully encouraged to consider what is best for their bodies' personal needs and the environment they live in, and the expos help attendees pursue this. Importantly, a variety of assistive technologies are showcased that are dramatically divergent from the sexy devices like the iBOT. One can explore different models of catheters, for example, and one of the most popular booths sells cup holders that can be easily attached to wheelchairs or scooters. The space attempts to remove the stigma that typically comes with assistive technology to allow people to celebrate what technology can offer to make their lives easier. As people play with devices, they learn about what is out there and what they most need, using this to make demands on insurance companies and the dealers who sell devices. Workshops and showroom activities all cater to fostering a culture of empowerment, although there are also significant limits to what the expo space can achieve.

The material realities of insurance limitations, paired with the exorbitant costs in the assistive technology industry, limit what the expo space can achieve. Much of the Abilities Expos is about building a community that puts people with disabilities on top, celebrating what technology can do for people with disabilities without forgetting its limitations and room for growth. Yet, the expos also provide many reminders of how far there is to go, as the rules of normalcy and capitalism infiltrate the space. Put together, the Abilities Expos show a more accurate picture of the current state of assistive technology than the overzealous stories put forth in the techno-makeover genre.

The Abilities Expos: The Background

Entering the expo, the first glimpse looks like a car show, but soon after, certain details on the cars that fill the front of the expo pop out – an accessible ramp that can be extended at the push of the button, a steering wheel with knobs that lets the driver not only move the wheel from left to right but also in and out to accelerate. Entering the showroom floor, it is much more apparent that this is a tradeshow for a disabled clientele. There are high-powered wheelchairs on constructed obstacle courses, accessible exercise machines of many varieties, and other gizmos and gadgets that would be foreign to most able-bodied adults. A large crowd moves from booth to booth, testing things out along the way. The mix of bodies is remarkably more diverse than one typically sees; alongside able-bodied people of all ages, there are also wheelchair riders and prosthetic users, people with visual impairments and others with cognitive disabilities, some who are highly independent and others with severe physical or cognitive disabilities, requiring a personal assistant.

Manual and power wheelchair manufacturers make up the largest portion of the show's vendors. The vendors – able-bodied and disabled – sit in the wheelchairs and do their best to show off the products. Top mobility device companies like Permobil, Colours, and Rascal tend to get the most central booth locations, but many small companies are represented at the expo as well, selling various products for use in the everyday lives of people with disabilities. From "spoke art" inserts for wheelchair wheels to easy-to-use silverware for people with limited dexterity, these smaller businesses more often sell products created by a disabled inventor, who needed the product for themselves and then decided to open a small business to sell it to others.

Even though the Abilities Expos are billed as technology tradeshows, they have much more to offer than the devices for sale, encouraging attendees to easily pass a full day or even the whole weekend there. One edge of the showroom floor has a space designated for accessible sports, and in another corner, there's a fashion show – complete with an accessible ramp – providing shows throughout the day to celebrate fashion designers specializing in clothing for people with disabilities. Outside of the showroom, the convention center provides rooms that are constantly occupied with workshops, some intended for physical and occupational therapists only, but most intended for expo participants with disabilities. From support groups to information sessions on accessible travel, sexual empowerment, and device selection, the expo provides information that can be hard for people to access elsewhere. Together with the local activist groups and disability policy organizations dispersed throughout the showroom floor, the workshops ensure that if an attendee comes solely with technology on their mind, she will likely encounter much more, and perhaps even gain an understanding of the inequality people with disabilities face (if they have not already thought about this).

The attendees present represent a diverse crowd, largely connected to the fact that anyone, regardless of race, class, gender, political affiliation or age can become disabled at any moment. The 2009 Abilities Expo in Anaheim, California, known as the mostvisited location, had 4,034 attendees over the age of 18, as well as many children.[398] And just as the people vary, so too do their impairments, though the most commonly visible impairments were mobility-based. Disabled attendees are matched in number by non-disabled attendees. This includes family members and friends of someone with a disability, as well as the many occupational therapists, physical therapists, personal attendants, and special-education teachers and workers. Though primarily able-bodied, the vendors also include some people with disabilities. Some vendors will explain a close connection to disability communities, articulating a passion for their work. Others seem like you could find them in any tradeshow across the country. In both what the expos offer and the people they bring together, it is a remarkably heterogeneous mix of people, devices, and priorities.

The first Abilities Expo was held in 1979, the only show of its kind. Founder Richard (Dick) Wooten and his wife Pat Wooten took out a mortgage on their house in order to fund it – a risk they were willing to take because they so strongly believed that people needed a better way of accessing information about technologies for the disabled community. Disabled at age 15 from polio, Dick had already been involved in disability activism as a founder of the California Association of the Physically Handicapped, but he saw the Abilities Expo as less directly activist-based and more about addressing the practical needs of people with disabilities.[399] Pat described her husband's motivation for founding the expos:

My husband, being in a wheelchair, … was finding it difficult to find certain

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[398] "Hot Off the Press" Abilities Expo, accessed January 14, 2011, http://www.abilitiesexpo.com/press_room.html.

[399] Now called "Californians for Disability Rights."
Pat Wooten, interview by Emily Smith Beitiks at the Anaheim Abilities Expo (May 29, 2009).

> products. He knew they were out there, he had seen them or read about them, but he couldn't find them in any of the stores. He couldn't handle them. … He felt there had to be a better way to bring the information to the consumer to make their lives better. ... And most of the time, there are ways to do that, you just have to find them, and this was his idea of getting the manufacturers and the organizations that work with the different groups together and bring the disabled population to one place where they could see and try all the products and get some of the information.[400]

Dick and Pat soon realized that founding the Abilities Expos would not be easy. First, they struggled to find a venue that could meet the access needs of the predominantly disabled attendees, more than 10 years before the passage of the Americans with Disabilities Act. Next, they were faced with convincing vendors to come, as the manufacturers were not used to dealing with people with disabilities directly. However, the expos quickly became a useful site for even the smallest of inventors to develop or sell their innovations. The Wootens sold the Abilities Expos in 1991 because Dick was facing post-polio symptoms, and the expos have traded hands several times since, varying in success with each management team.[401] The complex network of attendees, assistive technology vendors, and healthcare practitioners present at the expos today shows that the Wooten's dream has in many ways been carried through.

Technological Progress and Technological Failures:

The expo space is not a utopia. Yet, despite the limitations to what it can accomplish, it still provides an important venue that forwards disability rights and empowerment. Even if just for the weekend, people with disabilities come together to

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[400] Pat Wooten, interview by Emily Smith Beitiks at the Anaheim Abilities Expo (May 29, 2009).

[401] In fact, it switched hands while I was conducting my research and went from a management company widely known to be "in it for the money" to its current management, led by president of 5Net4 Productions David Krouse, who seems ambitious about making it the best it can be.

articulate a relationship with devices that is fraught and complex. Technology is assumed as central to life with a disability, but this is both rejoiced and lamented. The expos tell a conflicting story about the limitations of the devices themselves and the networks of power in which technology is embedded, standing in the way of people getting what they most need. What results is an understanding of technology that does not buy into mainstream assumptions of the technological fix. In other words, unlike the techno-makeover genre, the expos let people with disabilities talk back.

Author and motivational speaker Gary Karp plays a key role in encouraging an atmosphere and language for disability empowerment within the expos. Offering workshops and selling his books on the showroom floor, Karp, a paraplegic who rides a manual wheelchair, strongly believes in the need to improve the assistive technology industry. To lead his workshop on "wheelchair selection," he began sharing a picture of himself from 1973 in his first Everest and Jennings wheelchair, an innovative and commonplace model in its prime but now considered a heavy, unattractive clunker. Karp likes to start off with this picture, he explained, because "wheelchairs have come a long way, baby." As a wheelchair rider passed by in the hallway, the sound of her screeching tires distracted Karp, who joked, "For example, you can get screech-free tires." Pervasive throughout the expos are moments such as these, where Karp both celebrates how far the industry has developed and diversified, yet points to the fact that technological development has not yet translated into widespread access.

I spoke with another man in a wheelchair, who both works for the industry and also as an activist seeking to change insurance practices regarding assistive technology subsidies. After listing many complaints about the assistive technology industry, he still made sure to note, “I’ve been in a wheelchair 25 years, and there wasn’t a tenth of the stuff that we have now. Recreation for someone in a wheelchair 30 years ago was to wheel them out to the curb and let them watch the cars go by, but now there’s so much to do.” Technology is praised while still maintaining that the growth in devices alone does not signal progress.

While expo participants frequently remarked on the observable technological progress within the industry, the vast technological frustrations and disappointments that many hold are also not forgotten, especially coming out into the open through the workshops. Sometimes, the complaints voiced are specifically focused on the devices. One woman interrupted Karp’s workshop on wheelchair selection to ask, “Why do we sit in black wheelchairs? It’s dangerous in the dark!” At other times, these types of complaints are directed at vendors, when current users of a product do not hold back their unsolicited advice on how to make a device better.

Pat Wooten and her husband saw the importance of user feedback from the beginning, as Pat explained:

> Bring the consumer together with the manufacturer of a product, showing the consumer what it can do and letting the consumer have a feedback in product manufacture of what the consumer really needs. If [a vendor has] a widget and 42 people look at the widget and three people say, “Oh I could use that!” and the other 39 say, “That’s of no value to me, I can’t use it; even if I could physically use it, it serves no purpose,” so maybe your widget isn’t what you need to do. Maybe you need to tweak it and make it something else and incorporate what you were doing, find something else, but most of these products, one way or the other, a lot of the products for the disabled came out of somebody’s need.

To allow potential users of the device to shape the device may seem like common sense, but this collaboration has been long neglected in the assistive technology field and continues to be neglected today, as illustrated by the iBOT wheelchair. As disability scholar Marcia J. Scherer writes, "A particular technology should never become the place to start; the needs, desires and goals of the user should be the beginning point."[402] The Abilities Expos provide a site for making this claim heard – complaints are voiced alongside compliments of the industry's progress.

One moment captured the frustration with technology many attendees feel. At a workshop on finding the "right" assistive technology device, the presenter's PowerPoint presentation was interrupted by a Microsoft Windows update. The presenter simply said, "Well, that's technology for you!" met with laughter from the crowd. While we all know the frustration of computer glitches and the like, within the context of the expo, where so many stories of the inadequacies of assistive technology were voiced, this moment seems all too appropriate, explaining why the crowd's laugh was a little more hearty than you might typically receive from this comment. Technology can do a great deal of good, but it can also fail you when you need it most, and for a person with a disability who may rely on a device to go about their day to day life, the irritated sentiment of "that's technology for you!" hits close to home.

At other times, participants' articulated frustrations were less about the actual devices and more about the limited access people hold to assistive technology. Several attendees use the workshops to share their ongoing struggles with insurance companies, frequently concluding that they were denied a certain device based on an insurance company's efforts to restrict what counts as a "medical necessity." As one attendee explained with outrage, "Leaving your house is apparently not a 'medical necessity'!" which is, in fact, true with low-coverage insurance. Or, if it's not a problem of medical

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[402] Marcia J. Scherer, "The Change in Emphasis from People to Person: Introduction to the Special Issue on Assistive Technology," *Disability and Rehabilitation*, (2002): 3.

necessity, it's a problem of assuming "one size fits all." Physical therapist Ann Eubanks clarified this for me, "Medicare slashes funding based off one picture of a person in a wheelchair that says [to them] 'that wheelchair fits for him, so it can fit for everybody.'" Because devices are so expensive, people have little chance of securing them without insurance money, especially since people with disabilities have a higher likelihood of living in poverty.

One disabled vendor voiced his anger, "I had a Golden Boy lift on my van and they stopped making them. It worked beautifully for years and now my new van doesn't work for me. Big business has taken away a lot of innovation because of the dollar sign. The dealers and distributors want a 50% mark up because they're a bunch of whores adding to a middle man." Like this man, many expo participants warn other attendees about just what you are up against when seeking out a new assistive technology device, often with similar anger and frustration. Technology is placed within its wider context, and celebrations of assistive technology do not forget this.

Technological progress and the limitations of technology always go hand in hand at the expos. The Abilities Expos provide a space for celebrating the rapid progress of the assistive technology industry since the late 1970s, while not overstating the significance of technological progress. What good are advanced devices if they are only available for looking at, rather than taking it home? In comparison to the mainstream assumptions about people with disabilities as always techno-needy, the stories that the expos bring to light show what gets left out. It is not a question of whether one embodies a "cyborg" nor is it about the tear-jerking techno-makeovers and the normalcy they provide. Rather, the expo community shows, more accurately, that reality for many people with disabilities is a struggle to access basic devices, long before one can even contemplate a high-tech body/machine interface.

The Abilities Expos at Their Best:

Participants throughout the expos articulate complex relationships toward technology, coming together to vent among peers, and for some participants, to mobilize for change. In the best moments, the Abilities Expos provide a space that encourages disabled attendees to push back against normative structure and find empowerment. Though there are limitations to what the expo space can achieve, the expos do make important gains in rewriting the stigma of devices and providing people with disabilities with technological knowledge, both fostering an environment of empowerment.

Walking past the downtown Apple store on a Friday night would at first glance lead you to believe you were in front of a popular nightclub or restaurant, but inside, people are mostly there just to play with the newest gadgets, whether or not they intend on purchasing them. Brookstone stores provide a similar draw, where people can test and play with a range of technological innovations, from NASA-designed mattress foam to household robots that clean your floors. "Technological play," as I use it here, allows you to test out a device in the least threatening way – you do not have to start using it or purchase it, you just get a chance to figure out what it's all about through hands-on experience. What does a device feel like when you use it? What are its strengths and weaknesses?

But what forms of technological play are available to people with disabilities seeking to test out assistive technology devices? Within the techno-makeover trope, people with disabilities are typically the passive recipients of the techno-makeover, not actively seeking devices out for themselves but rather being told by "experts" what they need while being excluded from the process. Recall that in *Extreme Makeover: Home Edition*, for example, the disabled family member gets whisked away for a vacation while the able-bodied design team chooses all their new assistive technology devices. A new device might change the way you move and interact with the social world, often shifting the degree of one's disability, so it is important for the user to be comfortable with a new device. The Abilities Expos provide such an opportunity by allowing people with disabilities to play around with and try out devices, much like how we play with other devices.

Research within the rehabilitation field has shown that "Trialability, the degree to which the user can experiment with the technology prior to acquisition, [is] related to continued use of technology…However… individuals with disabilities are not often given the opportunity to try out assistive technology devices prior to purchasing them."[403] Unlike shopping for a car or cell phone, the idea of the "right match" for the individual user has serious ramifications for people with disabilities; a poor fit can, at its mildest, increase fatigue, but at its worst, cause a decline in the physical impairment. To fully understand what the "right match" is requires the opportunity to play with devices, learning more about them through the embodied act of testing them out. Technological play at the expos provides an otherwise rare occasion to test out devices, and for disabled attendees, this opportunity increases the chance that they will be able to find a device that

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[403] Marti L. Riemer-Reiss and Robbyn R. Wacker, "Factors Associated with Assistive Technology Discontinuance among Individuals with Disabilities," *Journal of Rehabilitation*, 66:3, (July/August/September, 2000): 45.

best fits their personal needs (whether or not these needs are to appear "normal").

Anthropologist Victor Turner theorizes the importance of studying "the human seriousness of play." In his book, *From Ritual to Theatre*, Turner pulls from anthropological theories of rites of passage to explore liminal spaces that are created in industrialized cultures, through the separation of work and leisure. He writes, "Liminality is a temporal interface whose properties partially invert those of the already consolidated order which constitutes any specific cultural 'cosmos.'"[404] In other words, liminality provides a phase in which normative structure is temporarily on hold, allowing subversive "play" to occur by either physical or culturally-imagined separation from mainstream society.[405] Some liminal spaces include burlesque shows or Mardi Gras, where the everyday rules that govern society are flipped upside down. The liminal space provides freedom to critique and satirize the everyday, as burlesque does through satirical dance performances, for example, in order to parody what is "beautiful," "proper," and "normal" otherwise. Play can be subversive, or alternatively, it can strengthen cultural norms if the parody only reminds people of the norm's presence.

Because it is an established space of play, the Abilities Expos provide another example of a liminal site.[406] To apply Turner's theory of play and liminality to the Abilities Expos suggests that in the showroom, play and work are one and the same; together, they collaborate to rewrite mainstream understanding of assistive technology and put forth something more complex. Because the Abilities Expos exist in a semi-

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[404] Victor Turner, *From Ritual to Theatre: The Human Seriousness of Play* (New York: Performing Arts Journal Publications, 1982), 41.

[405] Turner, *From Ritual to Theatre*, 27.

[406] He uses the liminoid to contemporize the theory of liminality, attaching the liminal to agrarian or pre-industrial cultures in which there is a rite of passage. The liminoid is freed from this link and is more relevant to spaces where liminality is made in between work vs. leisure.
Turner, *From Ritual to Theatre*, 53-54.

private, semi-public space, physically removed from the realm of everyday life, the expos achieve liminality from the non-expo world where these devices are sources of stigma or pity.

Technological play is serious work. It helps to challenge the stigma of disability, often connected to assistive devices that are traditionally cast as emblems of pity (people are "confined" to wheelchairs) or as tools that overcome and normalize disability. Play happens in a number of ways. Most visibly, the act of testing out the different models and devices is embraced with a playful attitude for many attendees. In a particularly comical example, one man tested out a motorized scooter with a headlight by riding up and down the aisle, switching the light on and off while shouting, "I'm a flasher! Flasher coming through!" In other less flamboyant moments, it was clear that getting into a new wheelchair or device was largely embraced as an opportunity to size up what a device could or could not do in a non-threatening environment. Several attendees even took pictures or videos as they tested out a device, later reposting these on blogs or YouTube to share their observations and experiences with the wider disability population. This is not to say that testing out devices is always fun or playful, as many are deeply uncomfortable with the act of obtaining a new wheelchair, fitness machine, gait walker, and so on. However, because attendees have chosen to come to the Abilities Expo often with this purpose in mind, the playful experiences seemed to outnumber the serious/frightful, and laughs and smiles were easy to come by.

The Minneapolis expo provided a particularly lucid example of the culture of play. Otto Bock, a German wheelchair company, brought an accessible ATV for off-roading. A conversation between two strangers, both wheelchair riders, illustrates the culture of play that attendees contribute to at the expos:

> Woman: (With a laugh) I could do so much damage in that!
> Man: That's what I was thinking. (Man turns to Otto Bock vendor and asks him to compare it to a regular ATV)
> Vendor: Well a regular ATV is about $8,000 and this is $30,000.
> Woman: I guess I should work on my 401K first. That is just cool!
> Man: Just sneak it out in a plastic bag and take it home!
> Woman: (Laughing) I know, I'd like to just take it out around the block. I wouldn't have enough room for it in my apartment though and you can't exactly just leave it outside!

Though this dialogue touches upon the financial limitations that limit the subversion through play, what is interesting is that two complete strangers came together in this playful daydream around the technology, where it is celebrated, free of stigma, and about empowerment without normalcy. In the Abilities Expo, attendees share similar moments as they get to define assistive technology as "cool," even as they express the many downsides of the systems of power in which assistive technology is embedded elsewhere at the Abilities Expo.

Technological play extends past disabled attendees to include able-bodied friends and family members as well, who also test devices. I witnessed countless able-bodied family members testing things out and being laughed at by disabled parents, children, or siblings for being unable to properly maneuver the device. Often failing to use a device with any success, these moments turn normative structures upside down; the disabled attendee gets to be the technology expert, laughing at the 'disability' of the able-bodied companion who struggles to use assistive technology. One group shared a fit of laughter, as an able-bodied woman struggled to ride a tandem bicycle with her disabled companion in the second accessible seat, yelling, "Beep! Beep!" as they rode around the showroom floor. Whether or not the able-bodied attendee fails or succeeds in using the device, the fact that they embrace it shows how the expos create a different understanding of assistive technologies without stigma. In the outside world, most able-bodied people wouldn't dare get in a wheelchair voluntarily, for they would risk being read as disabled by fellow able-bodied people around them. But in this space, the technology is seen as non-threatening, and at the center of this environment is the disabled attendee who can laugh at and with their able-bodied companions for being "outsiders" to this world of fun devices. The disabled attendee has gone from "pitiable" to "expert," whose lived experiences put him/her on the cutting edge of this industry, while the able-bodied struggle to everyone's amusement.

A culture of play is established in many planned out ways at the expos as well, through the sports arena and the fashion show. Most notably, the expos celebrate the talent of Aaron Fotheringham, an eighteen-year-old male, who became famous after receiving the Guinness World Record for the first 360-degree back-flip in a wheelchair, which was made popular through YouTube, gaining over three million views. Since then, wheelchair company Colours sponsors Fotheringham to promote their wheelchairs, including a reenactment of his wheelchair flip at the Abilities Expos. When he is going to do his flip, the rest of the expo stands still, vendors leave their booths unattended, and people rush to crowd around the ramp that has been constructed just for this trick. After warming up with a few tricks that are already quite impressive – a handstand while still sitting in his wheelchair, for example – Fotheringham pulled off the full 360, met by an immediate uproar from the crowd. When his act is over, able-bodied and disabled children gathered around to get his autograph on posters with his picture. You could not think up a better example of technological play than this, for his act immediately crushes past stereotypes of wheelchair users as weak or dependent.

This achievement partially resonates with the sports discourse around people with disabilities, which privileges the overcomer who, in spite of a disability, can do incredibly able-bodied things. However, there is something important about the wheelchair flip that breaks with the overcomer trope. Fotheringham's stunt does not try to minimize the disability in order to do able-bodied achievements, bolstering normalcy. Rather, he invents new athletics through the disability. This stunt promotes the idea that a wheelchair can be a source of pride and fun, contrary to mainstream perceptions of these devices. Fotheringham's website states, "He enjoys showing young kids with disabilities that a wheelchair can be a toy, not a restriction. He loves helping younger children learn how to handle their chairs in new and different ways and teaching them a trick or two."[407] Of course, for many at the expos, death-defying athletics are clearly out of the question; they seek technologies for day to day life in combination with much more severe disabilities than Fotheringham's. Yet, within the expo space where this performance is for a predominantly disabled audience, it is less about overcoming; people of diverse disabilities cheer him on, celebrating this impressive and fun use of assistive technology. And it sets the tone for attendees to see the other devices in this destigmatized light as well.

The second example of expo-sponsored technology play can be witnessed on the other side of the showroom floor in the expo fashion shows. Both male and female models participate, including a range of disabilities varying in severity, to market a unique design approach to clothing. Just as the models are a mixed crowd, so too is the

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[407] Aaron Wheelz Fotheringham personal website, "Bio." Accessed on January 14, 2012, http://www.aaronfotheringham.com/bio/.

audience, cheering on this component of the wider expo community. Consisting of only disabled participants, each model comes up onto the catwalk and the announcer explains not only why their clothing is "chic" and fashionable, but also how it is personalized to the disabled model's body.[408] The female-led fashion show avoids the pitfalls of mainstream fashion shows – it highlights a number of body types, tells you about the background of each model to avoid objectification, and allows models to demonstrate a range of fashion, from the feminine to the masculine. Whereas most fashion shows in fact display women who are disabled by fashion, the expo fashion on display is all about clothing that is made to increase the ease of use for disabled consumers.

The fashion show extends past clothing and ties into the technological culture of the expo. The models are done up with new clothes, professional make-up (for the female models), and to match this perfect look, they also use brand new wheelchairs, borrowed from the sales floor. When models in wheelchairs come out on the catwalk, the announcer slips in a mention of the wheelchair brand, but instead of emphasizing its technological capabilities, the focus is on its style or color and what makes it chic or fun. Devices are not about normalcy, but rather about an expression of the user's unique body and personality.

The devices are recast as part of the fashion show in playful ways. Whether featuring leopard print fabric or light-up wheels, the fashion shows celebrate technology as fashionable and use this theme as part of what makes the event fun. When a device seems too high-tech, it is playfully taunted. One of the male models in the fashion show came out in a borrowed, motorized Permobil wheelchair, elevated to a full standing

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[408] Only one of the designers showcased designs for men, and each fashion show involved at most 2 male models, as opposed to around 10 female models.

position. The announcer shared with the crowd, "Here comes George, and it makes us a little nervous when George comes out in his Permobil chair!" Then, she teased, "Hey George, do you have lights on that thing?" Whereas the mainstream discourse would celebrate such a wheelchair for being the most technologically advanced to offer high-tech normalcy, in the fashion show, they challenge these assumptions.

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Undoubtedly, technological play has a secondary purpose – to bolster support for technology so that people will buy it. Testing out devices and seeing them on display in such celebratory ways is likely to make people buy into technological consumerism, if they have the financial capital to do so. Yet, even if market interests help create the environment, technological play is still noteworthy in its ability to resist stigma. Whether testing out devices or watching them on display in Fotheringham's flips or in the wheelchair fashion show, the Abilities Expos open up a non-threatening atmosphere in which assistive technology can be seen as fun, contrasting this from the stigma attached to assistive technology in everyday life. As Turner theorizes, play can produce subversive cultural work, and the alternative understanding of assistive technology is a productive byproduct of the Abilities Expo playground, even though it simultaneously serves the market.

Assistive Technology 101:

At the end of one workshop, the presenter boasts, "Because you've been in this workshop you'll know more than most designers, most contractors and most PTs [physical therapists] or OTs [occupational therapists], so you have to get out there and share the knowledge." Though this statement is likely hyperbole, the sentiment illustrates the exciting atmosphere built around the vast amount of knowledge available at the expos. People congested the aisles by stopping to talk to a stranger about a device they were using – was it on display today? And significantly, the pursuit of knowledge does not stop at the devices. Attendees sit in on various rights-based workshops aimed at addressing the social experiences of living with a disability, which reminds attendees that liberation for people with disabilities cannot be purchased in the devices available at the expos.

Many attendees will not purchase anything at the expo. Rather, they come annually to access the abundance of education available, hard to encounter elsewhere. As I spoke with attendees and vendors, I repeatedly heard variations of the same phrase, "If they just knew this was out there!" Because assistive technology is not widely available and people must often rely on the dealers to find the right device for them, many make assistive technology purchases with incomplete knowledge. Most troubling, dealers have a stake in selling devices that have the biggest payoff for them through insurance companies, whether or not they are selling the ideal device for the end user. A variety of workshops at the Abilities Expos cater to this struggle and provide education on topics, such as how to navigate the insurance industry and get the best device for you; DIY modifications that can be made to more affordable, mainstream devices; maintenance and repair of common assistive technology devices; and finding the "right" device to match a user's specific needs.

One workshop leader included a slide that read, "Oppression vs. Empowerment," from which she introduced the disability rights slogan of "Nothing About Us Without

Us" as relevant to assistive technology. She was well versed in the language of disability activism and scholarship and although the rest of her presentation was focused on the nuts and bolts of finding a suitable device to meet each user's needs, she recognized the political importance of doing so, a part of disability empowerment when done correctly.

While the expos provide several opportunities for assistive technology 101, this knowledge includes placing devices in their wider political context. The techno-makeover suggests that technology alone can help people with disabilities overcome life's obstacles. The expos, alternatively, teach that technology can only help part of the time, but accessing equality will be a bigger struggle, and the expos also bring attendees together with the advocacy organizations already engaged in this political effort. But for many attendees, this struggle begins with demanding access to assistive technologies as a basic human right.

Another disabled workshop leader explained that his aim was to prepare people with the good questions to ask in order to take control while interacting with vendors on the showroom floor. One disabled attendee explained that the expos are about "letting people know that they have to be an advocate for themselves. Unfortunately, a lot of people know only what the dealer tells them." The dealers too often function as the gatekeepers of assistive technology knowledge, leaving people with no choice but to take whatever device has been recommended to them. As many of the vendors are able-bodied, white men – the traditional arbiters of technology – staking out a space for diverse disabled attendees to gain knowledge of assistive technology and determine their own needs has clear significance for disability equality.

Furthermore, the able-bodied physical therapists, occupational therapists, and other care-workers who attend the expos also participate in the education, as their primary purpose for attending (in addition to the paid day off work, granted by most of their employers) is to learn about new innovations in the field that they might recommend to their clients and patients. Just as vendors encourage disabled attendees to try out their devices firsthand, these other attendees are invited to hop into the devices and learn for themselves how it moves, feels, and changes one's abilities. One would assume that this is common, but shockingly, it is not. As I struggled while testing out a power-assist wheelchair, the vendor explained to me that "[PTs and OTs] aren't much better. They spend all day doing this stuff with people in wheelchairs, but they can't use them themselves!" a sentiment confirmed by other expo vendors. Testing out these devices alongside disabled attendees – typically the more experienced AT-users – might have a significant impact on the future of the industry, as disability practitioners learn that the feel of a device is just as important as the mechanics.

What these examples add up to is a culture developed within the expos in which technological knowledge is not only an act of assuming power for people with disabilities, but also non-threatening, non-stigmatizing, inclusive to able-bodied PTs, OTs, or professionals from within the assistive technology industry, while also celebrating the disabled attendee's experience as of primary importance. Technological progress goes hand in hand with social progress for people with disabilities in stark contrast to the techno-makeover narrative. From information about the devices themselves to a wider disability rights consciousness, attendees spoke with a sense of pride that they could attend the expo every year to learn what's out there and stay up-to-date on innovations in and around the field.

But in part, this knowledge is also central because consumption at the expo is so out of reach. These devices cost so much while catering to a population that typically holds higher rates of poverty, so for many, looking, learning, and playing is all that is available. This speaks to what the Abilities Expos are not able to change – the limitations of the market-based forces that make the expo come about.

The Abilities Expos at Their Worst:

There is much to celebrate at the Abilities Expos in the way they encourage an empowered role for people with disabilities within an industry that so often thinks of disabled end-users as only an afterthought. Much of the expo space inverts traditional power hierarchies – people with disabilities celebrate what technology can do without emphasizing normalcy, and on the flipside, able-bodied people even jump in wheelchairs to get a feel for the devices. However, the expos are not always so empowering, lessened by market forces.

While mainstream commercialism has mixed effects, it has received some attention in the media, celebrating the emergence of yet another market. In 1999, the term "handicapitalism" first emerged, soon thereafter made public by Joshua Harris Prager, who wrote an article for *Wall Street Journal* that reads:

> Handicapitalism: It's a brand-new term that describes what's behind a dawning realization in business: People with disabilities shouldn't be viewed as charity cases or regulatory burdens, but rather as profitable marketing targets. Now, mainstream companies, from financial services to cell phone makers, are going beyond what's mandated by law and rapidly tailoring products to attract them.

The question that must be asked here is what is gained and what is lost in this shift from understanding these devices as medical products to a capitalist ideology where research and development in AT should move forward because there is money to be made?

Handicapitalism does have some benefits for people with disabilities and perhaps even the disability rights movement. The undeniable upside is that with a market comes a diversity of products, and in fact, most of the innovations present at the Abilities Expos, unlike 30 years ago, have developed from the emergence of handicapitalism, now taking off more rapidly. In addition, with consumerism comes a decline in stigma around assistive technology; as Prager suggests, disability technology is not a sign of charity nor immobility (i.e. being wheelchair-bound) but a cool and innovative *product* or *commodity*. This line of thinking is fleshed out in Graham Pullin's book, *Design Meets Disability*, where Pullin argues that assistive technology needs to follow the path that eyeglasses have taken, once a sign of shame as a "medical device," now understood as an object of expression, so fashionable that some people with perfect vision wear eyeglasses with non-prescription lenses.[409] Once assistive technology is seen as a commodity, the personalization of devices will become common, as additional companies will strive to offer devices that match the user's personality.

Handicapitalism can also be seen in a positive light because the focus on people with disabilities as consumers defies the historic construction of people with disabilities as objects of charity and beggars. As introduced in proceeding chapters, disability historian Paul K. Longmore argues that people with disabilities have historically existed as objects of capitalism, rather than actors, used to bolster the selfishness of the capitalist system as the rich make public donations to people with disabilities, the objects of

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[409] Graham Pullin, *Design Meets Disability* (Cambridge, MIT Press: 2009), 19-21.

capitalist charity.[410] Because people with disabilities have long fought off this image of being the "disabled beggar" rather than potential workers, some will welcome this attention to handicapitalism, as it creates a place for people with disabilities within capitalism.

In fact, the Abilities Expos predecessors were World's Fairs with extravagant displays to praise the current innovations in technology and science, while simultaneously selling "the future" and what further innovations might offer to an expanding American empire. Yet, people with disabilities were far removed from this realm. From the fairs' freak show exhibits to eugenic displays of "the typical American family," the World's Fairs regulated the body and normalcy, alongside the future of science and technology.[411] People of color, especially those from Africa, South America or Southeast Asia, were on display at the fairs, caricatured and made to perform as "savages" or "primitives."[412] Similarly, people with physical anomalies and impairments were objects of consumption at the fairs' midway, presented as "freaks" from all over the world. While technology was part of what was learned and purchased, normalcy was also a lesson offered at the World's Fairs. For people with disabilities at the Abilities Expos to now be the attendees indicates a relatively recent shift. It took the discovery of antibiotics in 1929, the expansion of a rehabilitation movement with World War I and II, and the disability rights movement to create a social and cultural environment in order for

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[410] Longmore, "Conspicuous Contribution and American Cultural Dilemmas," 134-160.
[411] Robert Rydell, *World of Fairs: The Century-of-Progress Expositions* (Chicago: University of Chicago Press, 1993).
Christina Cogdell, *Eugenic Design: Streamlining America in the 1930s* (Philadelphia: University of Pennsylvania Press, 2004).
[412] Thomson, ed. *Freakery*.

handicapitalism to come about.[413] Given this history, the mere existence of the Abilities Expos indicates a certain degree of progress.

Yet, there are important losses, as this newly popular title of "handicapitalism" hides the fact that assistive technology remains a very different type of market, always tipped in favor of suppliers. Most notably, despite the celebration of an emerging market of handicapitalism, the fact remains, though downplayed, that people with disabilities are largely unable to purchase these devices for themselves without assistance from the government or insurance companies. A simple explanation for this fact is that to be a non-subsidized consumer, you also have to be a worker and so many people with disabilities are unemployed or underemployed. Being un/underemployed makes people less likely to have the financial capital necessary to buy assistive technology, but also less likely to have good health insurance, which would cover top-end devices. Even when people with disabilities are employed, many cannot access insurance based on their pre-existing conditions. As disability scholar Marta Russell puts it, "Often a disabled person is locked into an economic straightjacket and out of the workforce by insurance exclusions and affordability; much needed care becomes obtainable only through a public insurance program, such as Medicaid or Medicare, which imposes eligibility work restrictions and limits earned income."[414]

To maximize the money to be made in the AT industry, assistive technology devices are over-priced, much like prescription drugs or medical care, seeking to extract as much as possible from insurance companies. Therefore, insurance companies play

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[413] Brian Woods and Nick Watson, "A Short History of Powered Wheelchairs," *Assistive Technology*, 15:2, (2003): 164-180.

[414] Marta Russell, *Beyond Ramps: Disability at the End of the Social Contract*, (Monroe, MN: Common Courage Press, 1998), 80.

such a central role in allowing handicapitalism to thrive that whatever technology they approve is increasingly likely to succeed in the market, unlike typical supply and demand forces that would allow the disabled users' voices to be heard. The Abilities Expos work as a partial cure for this problem, as attendees voice their needs, and yet also as a symptom, as the vendors rarely sell directly to the consumer and are mostly looking for rehab specialists to endorse their products and make insurance more likely to reimburse.

The disempowering components to handicapitalism cause many frustrations that disabled attendees voice throughout the expo space. Vendors with disabilities struggle with their position, as they are both part of the industry yet also the users of the devices. For example, one man I spoke with, a wheelchair rider but also a vendor, stated, "It sucks because I go to these rehabilitation centers and hospitals and it's sad because people ask, 'Where can I get a chair like that? And they pretty much can't. I take that back, you can. You just have to pay for it out of pocket." He continued, "It's this huge corporate thing, politically corrupted, and so people don't get the things they need." A vendor of Permobil, a popular brand of high-end motorized wheelchairs, explained, "Usually it's good to be the 'Cadillac' of something for customers, but it's tough in this industry because of insurance and funding issues, so we need savvy people to get our chairs."

Because wheelchair manufacturers now provide so many options for upgrading wheelchairs with functions that are often a medical necessity for the user, it is hard to state exactly how much any given wheelchair costs. For example, the Permobil website promotes the M4000 Corpus 3G, which starts at $8,540 but could easily reach over $18,000 depending on the optional features a user requires. A tray for a ventilator, for example, adds $1,385 to the total cost. These add-ons explain why the vender compared

Permobil to a Cadillac, a luxury car, but because people cannot afford to pay out of pocket, these "luxuries" make it increasingly difficult to get Permobil wheelchairs subsidized.[415]

The media deemed this emerging market of handicapitalism a sign of success for disabled consumers, but it also marks a new problem for the AT industry; if there is money to be made, the industry will focus on what insurance will deem "good technology" rather than the perspective of people with disabilities, and the number of people in the industry who prioritize disability empowerment is likely to plummet.

While the Abilities Expos provide a potential space for change and redefinition for people with disabilities and their relationship to assistive technology devices, handicapitalism serves to water down all of this, even influencing the expo managers themselves. When Dick and Pat Wooten put together the first Abilities Expo in 1979, they had to take out a second mortgage on their house in order to pay for it, but they were so passionate about their mission that they were willing to take that risk. However, Pat explained that the expos have varied greatly over the years, depending on the outlook of the management team. She and many others expressed excitement at the new managers, but she warned, "You can't think of it as just a business, that's why we started the show. If you do think of it as a business, it's not a good business. You can get by alright, but you've got to be willing to focus on what it is and make sacrifices." To illustrate this concept, she pointed to how big the aisles are in the showroom; while a good capitalist would want to jam more booths in to make a higher profit, the need for access must outweigh the pursuit of money.

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[415] "US Order Form," Permobil, Accessed April 21, 2012, http://www.permobil.com/USA/Products/Rehab/M400-Corpus-3G/.

*S*imilarly, handicapitalism threatens to bring in industry professionals who are seeking profits above all else, often leaving them clueless about how to best interact with their disabled customers. These venders made mistakes that were insensitive to disability etiquette, such as talking to a disabled attendee's able-bodied companion (assuming the disabled attendee could not speak for themselves) or leaning on people's wheelchairs without respect to their personal space. These vendors, overwhelmingly male, were also the ones who called me over with "pretty lady" or "girl," asking if they could demonstrate their "machine" for me, sometimes slipping a wink into our conversation. In general, they fell in line with the "used car salesman" caricature, rarely soliciting attendees' concerns or needs and instead just returning to their same pitch to show off their most expensive products' bells and whistles. They were there to sell the product and aimed to sell the products that would provide the most payoff, rather than what was best for the user. While this is what one would expect at other tradeshows, the assistive technology industry requires additional sensitivity to the attendees' needs. Many venders entered the field precisely because of a passion to serve the disabled community, but handicapitalism has changed this.

Perhaps the most vivid sign of handicapitalism's limitations came at the Anaheim Abilities Expo. The new management team thought up an exciting addition to the expo opportunities and offered an "ADA career fair," helping bring companies that have disability friendly workplaces together with the community, as there continues to be higher rates of unemployment or underemployment among people with disabilities. However, when I walked into the Anaheim expo on the first day, a sign read, "ADA career fair has been canceled."[416] When I asked expo manager about this, he responded, "The economy is bad. What can you do?" If the assistive technology industry is based upon handicapitalism, then what does this mean for people with disabilities in times of recession? Though the market has greatly expanded with many useful new innovations, this growth is only useful if made accessible to end-users. Currently, what must be remembered is that if the Abilities Expo represents the mall of handicapitalism, then there are far more window shoppers than clients. "Handicapitalism" may seem like progress, given the newfound opportunity for people with disabilities to be consumers. However, it does not signal meaningful change, for it conveys an industry in which profits still come first, threatening the initial dream that started the expos.

The community that is formed at the expos has much to add to the wider efforts of the disability rights movement, but its influence is limited if it is simply a byproduct of what marketing researchers Nina M. Ray and Mary Ellen Ryder recommend: "For disabled groups with a strong sense of community like the deaf, marketers should look for ways to tap into the strong social bonds already present."[417] Disability community and empowerment can be celebrated, as long as it can be understood in dollar signs. Handicapitalism marks this shift; people with disabilities can be consumers, and therefore, it is no longer necessary that government subsidize assistive technology devices. Handicapitalism is both responsible for the expos' existence and yet also the reason for its limitations.

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[416] ADA is an acronym for the Americans with Disabilities Act

[417] Nina M. Ray and Mary Ellen Ryder, "'Ebilities' Tourism: An Exploratory Discussion of the Travel Needs and Motivations of the Mobility-Disabled," *Tourism Management,* 24 (2003): 66.

Conclusion:

The Abilities Expos provide a venue for witnessing how the relationships between the assistive technology industry and their potential customers play out, even as new relationships emerge because of the expo space. The Abilities Expos offer a truly unique site in three particular ways. First, the Abilities Expos allow for a degree of redistribution of power, through knowledge, that people with disabilities struggle to access outside of the Abilities Expos. The crash course in assistive technology then allows users to make demands of dealers, healthcare practitioners, and insurance companies, based on the experiential knowledge they obtained by viewing cutting edge innovations in action. Second, attendees are given the chance to play with and test out assistive technology devices, allowing expo participants to learn more about what assistive technology can or cannot do through firsthand experience. They need no longer rely upon an able-bodied practitioner or insurance company to prescribe what's best. In this play, many attendees use the liminal space of the expo to rewrite the stereotypic associations of these devices as objects of pity or, alternatively, romanticized normalcy. Further, the Abilities Expos allow a community to form among attendees who are present in order to celebrate innovations in the field of assistive technology, while simultaneously demanding that there is much more work to be done in order to make technological progress correspond with social progress for people with disabilities.

What emerges through this unique space is a complex site of negotiation for those in the expo community. Attendees are constantly oscillating between celebrating innovations in assistive technology to suggest that they are like any other mainstream technology, and yet at other moments, working to remind inventors and industry professionals that assistive technology cannot be seen as just another sect of technology – for users who physically rely on the devices, there are more complex matters to consider. Attendees also oscillate against the mainstream assumption that people with disabilities are trapped or confined by these devices, while simultaneously sharing stories about how many people truly are confined by the devices – not because of an impairment, but rather because of the inefficient system in which many have limited access to the devices they need. And to make matters even more complex, attendees also face the mixed effects of handicapitalism, bringing new attention to assistive technology while also leaving many behind who cannot afford to be consumers in this market.

Yet, in this complexity, what is most important is that the Abilities Expos provide a far more accurate picture of the relationship between people with disabilities and assistive technology than that of the mainstream discourse in popular culture, the mainstream media, or science policy debates. Unlike the techno-makeover, the expos offer a more complete picture, where attendees are negotiating technology use to mixed ends. There are of course some attendees in desperate need of assistive technology, but this does not mean that they fit into the mainstream representation of the "techno-needy" seeking techno-makeovers. In the expo space, obtaining technology is not about normalcy, but rather about what works best for the individual. These malls of handicapitalism are limited in numerous ways, but there is still something gained in the act of window-shopping.

Conclusion:

The Techno-Makeover's Future in Biotech

Since its inception, disability scholarship and activism has rallied against medicalization, the process through which the medical establishment has traditionally defined disability in a restrictive and debilitating way by focusing entirely on the physical impairment as a deficit. While this focus has brought about important work, the techno-makeover genre shows that technology and science are equally culpable for how cultural frames regulate disabled bodies today. Technoscience has opened up normalcy to many people with disabilities, provided they will embrace technology to make their bodies perform in an able-bodied way. However, this shift has also put forth new norms about how the disabled body must behave, the more high-tech (or scientifically altered) the better. Between the rapid growth of the assistive technology industry in the past 30 years and similar expansion in the biotech industry, medicalization alone fails to capture the forces directly defining and regulating disabled bodies in the present day. The game has been changed.

I have examined the way that technoscience is shaping cultural understandings of the disabled body in many cultural locations: first, reality makeover television; second, news stories following the charitable "gift" of a techno-makeover to people with disabilities in the Global South; third, political discourse over stem cell research, where the promise of techno-makeovers drives research; and fourth, in the disability technology industry, where the rise of the iBOT aimed for the cyborgian to increase "normal" functioning. Through these sites, my dissertation illustrates the many realms in which we repeat the same story about disability – as always in need of high tech normalcy above all else, leaving little room to consider social change that goes deeper than the techno-fix.

If the hype around emerging biotechnologies is to be taken seriously, the examples that I have explored are quite mild in comparison to what is on the horizon. Innovations currently underway promise to normalize not only the physical appearance of the body, but also rebuild the body at the molecular level. Synthetic biology, an emerging genetic engineering technique, aims to build artificial organisms using the genetic "building blocks" of life, hoping that this will one day have human applications. Proponents of synthetic biology, most notably George Church and Drew Endy, envision copious positive outcomes, which treat disabilities and illnesses at the molecular level so that we can live to 150 years old without our bodies failing us.[418] The science itself is currently far from having any real human applications. Regardless, I fear that as synthetic biology continues to develop, disability will once again be deployed to celebrate the best of what technoscience can do. After all, like stem cells, synthetic biology must dodge the many concerns that have been raised around synthetic biology, or, as it is has been dubbed, "genetic engineering on steroids."[419] The hype around nanotechnology, now seeming to fade into the shadows behind synthetic biology, made similar promises. Nanotechnology scientists dreamed that the applications of their work could develop prostheses controlled solely by the brain, while many environmental justice activists raised concerns that we were proceeding with nanotechnology without

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[418] Karen Weintraub, "Will We All be Tweaking Our Own Genetic Codes?" *BBC News*, September 18, 2011, http://www.bbc.co.uk/news/technology-14919539.
"Engineering Biology: A Talk with Drew Endy," *Edge: The Third Culture,* 2008, http://edge.org/3rd_culture/endy08/endy08_index.html

[419] ETC Group, "Extreme Genetic Engineering: An Introduction to Synthetic Biology," January 16, 2007. http://www.etcgroup.org/en/node/602

adequate precaution.[420] One further example: to promote genetically modified rice in the Global South, a biotech company called Syngenta used images of blind children who supposedly could have had their blindness prevented had it been for the Vitamin-A rich Golden Rice, a crop which threatened biodiversity while providing less vitamin A than other local, sustainable plants.[421] While innovations in biotech promise a future in which we have technologies currently unfathomable, the overwhelming focus on minimizing physical difference through biotech rings closer to eugenics than it does to the alleviation of human suffering.

And while biotech increasingly calls upon the promise of the techno-makeover, technological devices for people with disabilities are also growing increasingly high-tech in ways that put the iBOT to shame. The exoskeleton, a cumbersome robotic suit that may allow people with paralysis to walk again (and looks like something out of *The Matrix*), has been extensively praised in media coverage, and though the current model is struggling with basic functionality – far from usable in everyday circumstances – some have already begun dreaming bigger and promising future advances. At Duke University, Dr. Miguel Nicolelis is working to make an exoskelton that will be moved by the mere thought of its user.[422] He hopes that even quadriplegics will use the device to walk again someday.

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[420] Mihail C. Roco and William Sims Bainbridge, Eds. *Converging Technologies for Improving Human Performance: Nanotechnology, Biotechnology, Information Technology and Cognitive Science*, (Arlington, VA: National Science Foundation, June 2002).
Gregor Wolbring, "Scoping Document on Nanotechnology and Disabled People for the Center for Nanotechnology in Society at Arizona State University," http://cns.asu.edu/cns-library/documents/wolbring-scopingCDfinaledit.pdf

[421] Michael Pollan, "The Way We Live Now: The Great Yellow Hype," *The New York Times Magazine*, March 4, 2001, http://michaelpollan.com/articles-archive/the-way-we-live-now-the-great-yellow-hype/.
McKibben, *Enough*, 140.

[422] Melissa Healy, "Body Suit May Soon Enable the Paralyzed to Walk," *Los Angeles Times*, October 6, 2011, http://articles.latimes.com/2011/oct/06/health/la-he-brain-machine-20111006.

Technoscience aims to warm our hearts by suggesting that high-tech innovations will improve people's lives by making disabilities go away. Though good intentions may very well be what drive the research, we cannot presume that techno-cures are always best, neither for people with disabilities nor for society. The specific innovations fueling the techno-makeover are likely to change over the years to come, perhaps quite rapidly given the quick pace of biotechnology, but the cultural assumptions and forces behind the techno-makeover are likely to remain the same, namely rugged individualism, capitalism, and normalcy.

When we tell stories about people with disabilities being fixed by technology, we are putting a new twist on "pulling yourself up by the bootstraps." Even though, ironically, these stories showcase a great deal of dependence and charity from others in order to rise up, the message insinuates that once technoscience enters the picture, the disabled individual can now function in complete independence, no longer a burden on society. Independence is of great importance to many people with disabilities, I do not neglect this reality, but these stories promote a hierarchy in which those capable of independence and individualism (the able disabled) are ranked above those who cannot. The iBOT users are deemed "good," whereas those who, even with the best high-tech devices out there, still remain dependent are "bad." Michael J. Fox is a hero because of his work for technoscience cures, hoping that before he becomes deeply dependent, a cure will come, whereas disability activists unlike Fox, who promote social change now over cures that may or may not ever come, continue to struggle to get the message out in the media. And Emmanuel Ofosu Yeboah received international attention for escaping life as a beggar in Ghana by overcoming adversity with technology, now able to fully support himself, but people who remain beggars because of their disabilities but also because of global poverty go largely unaddressed. We ignore the plight of the many because we insist on celebrating the success of the few.

Given the popularity of individualism that runs rampant through mainstream narratives of high-tech disabled bodies, at the end of the day, we must remember that individualism only works for a privileged minority – many others do not even have access to the devices that would make this possible, or they have disabilities too severe to ever be self-reliant and solely independent. Independence by itself may not be a bad thing, but the assumption that anyone can achieve it if they try hard enough will always isolate many people with disabilities.

Next, these stories are always about capitalism in conjunction with neoliberalism. It is not just that *Extreme Makeover: Home Edition*, for example, will make high-tech living possible for people with disabilities but that it will be very publicly brought to the viewer via Sears and other large corporations. For stem cells, the public saw biotech as being all about helping the Michael J. Foxes of the world, neglecting the fact that profit was an undeniable part of the industry's aim, recently illustrated when the top stem cell biotech firm Geron pulled out of the game in 2011 on the grounds that it was simply not as profitable as some of their other ventures. The iBOT inventors dreamed that their work was about something bigger, a revolution for people with disabilities, but once the device proved unmarketable, it faded away. The techno-makeover is widely present because it encourages technological consumerism and therefore profits, these market forces cannot be forgotten though they are hidden in the mainstream narratives.

The stories I look at are both products of capitalism and also advertisements for capitalism. In line with the celebration of individualism, they suggest that technological consumption by people with disabilities will help them become productive capitalists as well, rather than financially burden the government or their fellow citizens. And stories such as these are common to many underrepresented groups, in addition to people with disabilities. The neoliberal climate provides the perfect backdrop for these stories of technologically-corrected people with disabilities to rise up, for they show a shift away from government support, even though government support has already always been minimal. Instead, private citizens and charitable corporations aid those in need, and once people with disabilities obtain high-tech objects, they too can function independently of state support. With Medicare and Social Security declining, the takeaway message in all of the cultural locations I have looked at is that physical difference will be tolerated, so long as it is dealt with at the individual level. The disability rights movement's efforts to make changes to social structure and physical environments become harder to pursue with this mindset.

Finally, underlying all of the examples I have explored is normalcy – not just because looking at disability always entails looking at normalcy, but rather because at their core, these narratives actively teach how to be normal in a high-tech world and praise when normalcy is obtained. The popularity of the techno-makeover narrative provides a key site in which we move further toward an understanding of the body, where it is our personal responsibility to optimize and enhance in order to maximize what the body can do. However, it is ironic that people with disabilities should be the emblems of this trend, for the disability rights movement has been so transgressive in challenging this ever-forward march towards perfection, instead urging that we all ask, "What's so great about being normal, anyway?"

Developments in assistive technology have had immeasurable significance for people with disabilities and the disability rights movement. Were it not for the makeshift development of motorized wheelchairs on the UC Berkeley campus by a group that came to be known as the "Rolling Quads," it is uncertain whether the disability rights movement in the Bay Area would have launched as it did. However, the popularity of cultural narratives that celebrate not what technology can do for *empowering* people with disabilities, but rather what it can do for *normalizing* the disabled body drastically cuts the significance of technological progress.

And normalcy is bigger than physical disabilities. To fully celebrate the development of high-tech normalcy, the subject of the narrative must also demonstrate they are normal in other social ways, by their gender, sexuality, and/or social class. In the case of the techno-makeover, a good story includes a fairytale ending, which means that we must buy into the idea that once technology enters the life of a person with a disability, their life will be otherwise back on track with unlimited chances for success. To be a good hero – an emblem of technological progress – you have to be normal, even if physically, you may still be a bit different.

From reality television to media coverage to U.S. political debate to engineering labs, a remarkably similar story circulates that claims to be about people with disabilities but instead tells us much more about the hegemonic persistence of individualism, capitalism, neoliberalism, and normalcy. But my research has not yet considered what direct effects this trend has on those who take it in. Many have consumed "do-good" television shows that suggest if you are down on your luck, technology and normalcy will provide a way out, as it does for people with disabilities. Others have read newspaper articles on people with disabilities from the Global South who receive techno-cures, and collectively, these stories suggest that technology and medical interventions are what makes the United States strong. Our celebrity culture has also been influenced with the techno-makeover rhetoric, as Michael J. Fox became a beacon of technoscience hopes that his disability would be erased. And stories of the iBOT wheelchair suggested that if you have a problem with the way your body navigates in society, technological consumerism will offer a way out so that you can once again fit in. What impact does the pervasive techno-makeover story have?

The abundance of techno-makeover stories is deeply troubling, not only for what they reflect in cultural assumptions around disability today, but also because of where they indicate we are heading. Might the techno-makeover genre encourage others to consider undergoing their own techno-makeovers, whether treating impairments or other "undesirable" traits? If a viewer of *Extreme Makeover: Home Edition*, for example, is not doing as well as they would like in achieving success, might the techno-makeover story help them feel a little bit better about the idea of altering themselves with technology to go after it? And might the techno-makeover genre also begin to influence people, such that they no longer weigh the choice of pursuing normalcy, but rather feel direct social pressure to do so?

I began this project after learning about Americans' growing use of enhancement technologies. As Carl Elliott argues, the abundant use of enhancement technologies, particularly in the U.S., suggests that it is not enough to be normal anymore. Instead, many strive to be "better than well."[423] I began asking, "If the able-bodied are striving to become 'better than well,' what impact will this have on people with disabilities, widely seen as not 'well' to begin with?" Though the research I have conducted did not attempt to directly link the enhancement technology craze to the popularity of the techno-makeover, I see the two as closely coupled. Not only are people with disabilities being included in this trend toward better than well, they are often situated as the trend's icons, put forth as forerunners of embodied technological progress.

The able-bodied do not need to look to people with disabilities to understand what tech dependency feels like. Many of us already know the feeling of forgetting our phone at home for the day and feeling not just inconvenienced but actually amiss as a result. Our bodies are connected to the objects around us, and any break in that routine can pull us out of the trance. We feel outraged when technologies that we rely upon fail us or let us down. Yet when it comes to technology dependency, the stories we tell of people with disabilities are overly disconnected from the ways in which we are all connected to machines, sometimes for better and sometimes for worse, and very often in ways that are about power, normalcy, and body regulation.

The representations of disability and the techno-makeover are misleading. The illustrations of the Abilities Expos and the decline of the iBOT wheelchair provide brief hints into why. Rather than pursuing high-tech normalcy or techno-makeover cures, many people with disabilities are simply trying to access basic devices without any bells and whistles, often to no avail. While the public image suggests that people with

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[423] Carl Elliott, *Better than Well: American Medicine Meets the American Dream* (New York: W.W. Norton, 2003). The term "better than well" was originally coined in: Peter Kramer, *Listening to Prozac: A Psychiatrist Explores Antidepressant Drugs and the Remaking of the Self* (New York: Viking Press, 1993).

disabilities are on the cutting edge of technological progress, a more accurate picture shows deep stratification. Even when technologically advanced devices are desired, they are often completely out of reach. We must break out of the technoscience-and-biotech-induced trance that has us believing people with disabilities will be the first to profit from innovation and, instead, expose how disability is a profitable rhetorical tool used to pave the way for widespread technological enhancement of the body. We have become focused on how the miracles of technology can make certain bodies "right," and in the process, completely ignored the baseline question of what was "wrong" to begin with.

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