Two years after Celeste received her first electric wheelchair, I picked her up from school in our Toyota Sienna RampVan, one of many financial investments necessary in our new lives with muscular dystrophy. Clearly upset, Celeste asked, “Why is it that every middle school in the country teaches the history of the Civil War, and then jumps to the history of the Civil Rights Movement, racial discrimination, and then suddenly stops with the assassination of Dr. Martin Luther King, Jr.?” It was a thoughtful question. I responded, “Well, it’s because the history of the United States is in part based on slavery, and the connection between slavery and racial discrimination is…” Impatient with my reply, Celeste interrupted, “No, it’s because teachers in America can’t talk about other types of discrimination beyond race, like gender, being lesbian or gay, and especially discrimination against people with disabilities!”

Although the Civil Rights Movement launched different types of public discourse, including disability concerns, Celeste’s point was clear. Civil rights discourse represents a broad spectrum of subjectivities that are all too often unevenly distributed across the body politic, as demonstrated by the most recent election campaign rhetoric in the United States. Moreover, most people are oblivious to the cultural agency of disabled persons, or that disability culture produces unique types of knowledge useful in expanding the range of what constitutes civic space. Despite the soft discrimination imposed by the physical and psychological make-up of the social body, disability culture is among the most pervasive of minorities, as it cuts across racial, gender, and socio-economic profiles, among many other identities. To engage in disability discourse therefore includes revising concepts of beauty,
completion, personhood, and the deep structures of difference within difference.

**CONSERVATION OF ENERGY**

While the value of design is exponentially increasing within an exploding global consumer culture, the ability for the urban imagination to conceive of a wider range of human and non-human difference remains tightly bracketed within a uniform conception of fitness where athleticism and physical endowment preside. *The Asclepius Machine* intervenes in this homogenous context; by dispensing with the pretense of authority caught up in architecture’s allegedly “postcritical” moment, the currencies of rough-trade and street-speed confront the academic perpetuation of soft discrimination against disability practices. Indeed, such practices are acutely aware of the importance of the conservation of energy, and can thus locate pressure points that are often neglected or remain unseen. In this regard, the currency of disability is non-denominational and produces market practices that seldom coincide with political and economic forces that are predictive or established. Disability markets more volatile forms of risk that range from basic human rights to euphoric, flamboyant excess. As Elaine Scarry explains with respect to the mechanics of torture in *The Body in Pain*, disability practices fundamentally question the structuring of entire worlds.² From challenges to the medical-industrial complex and the oppression of compassion, the politics of disability have the advantage of leveraging debate about public space, questioning the ethics of civic formation, and producing urban evolution—if indeed the city should evolve at all given its uneven trajectories and contested legacies. One wonders, in fact, if we should even bother to imagine the evolution of an entity so tied up with the idealized proceduralism, and the idealized bodies, such imaginaries imply, which are easily traced all the way back to Aristotle. If the city is—as trajectories of both ancient and contemporary political thought contend—the site for the realization of the “fully human,” then perhaps it must be reevaluated in proximity to a more vivid, vital, and exemplary account of its human occupants as well.

In this regard, despite the many good efforts to generate substantive disability discourse within the United States, this crucial discussion—if one exists at all—remains at the fringe of current politics. From a disabilities perspective, the inadequacy of design innovation beyond compliance-based approaches perpetuates the soft discrimination of urban environments on the social body generally, and on disabled bodies specifically. This is because it is not enough to simply repeat the mantras of “access for all,” or Universal Design; instead, a complete reconsideration of the actor-object interface between humans and things demands a higher standard and a more sustained consideration of design ambitions. If mobility and access remain the sole concerns in disability design, such a limited view will inevitably guarantee that disability remains trapped within an institutionally situated structure. And given the extent to which bodies are distributed, bought, sold, and distended across borders, a disabled figure rendered in twenty-first century space should appear quite normal. The issue is, it doesn’t.

**E ON THE B**

This past year we went to a renowned performing arts center to see Phillip Glass and Robert Wilson’s opera *Einstein on the Beach*. Upon entering the theatre from the parking structure, a uniformed attendant, adorned with a Secret Service coiled earphone, immediately identified Celeste as a person of need. Although we arrived to the event early to check out the scene of the pre-performance crowd, the management protocol, literally hardwired into the telemetry of the institution, deemed it a priority to shuttle us to our seats, bypassing the lobby, down an ancillary hallway to the accessible elevator. The process was efficient and well intended, but it showed that in order for a disabled body to be fully immersed in the
experience of the theatre, it must be oriented through a series of rehearsed routines, exercised and directed at specific bodily profiles. While the rerouting from lobby to ancillary hallway happened in only a few minutes, the choreography of the incident suggests only a few degrees difference from segregationist practices that were intact less than 50 years ago. And, once in the theatre space itself, social opportunities available for disabled persons are dictated by wheelchair-designated seating in the back of the house, tucked away under the balcony. By contrast, E on the B was ethereal, offering a world of what might be possible if one dared to dream beyond reality. Celeste mentioned it was one of the best experiences in her life, which led to her meeting Robert Wilson, who has established a profound correspondence with disability in his creative works.

These types of civic-institutional situations pose an additional challenge to design when the standards and routines of social interaction are legislated based on specific topologies of fitness. This is partly due to the perception that having a disability is an individual problem, not part of a cultural formation. In the civic schema, the perception of disability is filtered predominantly through a medical model, the idea that disability is a condition to be treated or ameliorated. This can be contrasted with an idea of disability within a social model, where it is understood as a unique culture that produces specific types of knowledge. What if disability was perceived as a creative practice rather than framed as a challenging life of hardship? How might the perception and classification of disabled bodies migrate from medical to social models? And, what impact could this social orientation have on design?

Presently, public health policy efforts directed at improving accessible building codes and establishing the metrics of Universal Design and “applied systems thinking” tend to frame disability culture within a medical model. The aesthetic strategy of most design for disability is thus to blend in and not differentiate, effecting a veritable cover-up of the presence of disability. By contrast, strategies that engage with accelerated and complex action suggest that more explicit responses are required by design to engage in the dynamics of disability as a culturally productive network.

INTRO THE APPARATUS

How might design thinking suggest alternatives to the disappearance of disability aesthetics by increasing its resolution? In order to develop methodologies in these areas, designers must re-evaluate civic-aesthetic codes and radically augment ideas about the fitness of the social-civic body. For example, a dominant perception is that disabled bodies are slow bodies, and that to be slow in the high-speed world of work is tantamount to being unfit. Given the statistics on increasing life expectancy rates, as well as urbanization trends concen-
trating higher a proportion of disabled persons within the city, it is clear that disability culture is developing rapidly. The growing number of disabled persons with longer life expectancies will place a significantly higher demand on the technologies and infrastructures of speed and access. As disability discourse transitions from medical to social models, it will be necessary to redirect design attention toward a world of augmented bodies, and by extension the augmentation of urban environments.

In 2005, I had the opportunity to direct an architecture studio class in Beijing for a group of graduate students from Taubman College. The pervasive exuberance and mounting momentum of construction in pre-Olympics Beijing was mind-blowing. It was as if the entire late nineteenth- and early twentieth-century City Beautiful Movement from the United States was compressed into a five-minute video animation in China. Qing Dynasty siheyuan (traditional courtyard houses) were demolished to widen ancient streets for the staging of an Olympic marathon—an event lasting only a few hours eradicating generations of physical history. Roses were planted along the Airport Expressway. Cloud seeding produced a deluge of artificial weather, and seemingly overnight everything was blooming. The regime of civic fitness wreaked havoc on the city in a delirious euphoria of new architecture and landscape meant to express, or even dramatize, a modern China on a world stage. A month into the trip, my partner Dawn and our daughter Celeste joined me in Beijing for ten days of visiting the usual suspects: the Forbidden City and Tiananmen Square, Da Dong (the infamous roast duck restaurant), the Pearl Market, the Great Wall, the 798 Art Zone, among others. Celeste was walking then, but seemed exhausted and out of it, and we attributed it to jet lag. As a few days passed with no change, so we went to the emergency room at the s.o.s. Hospital in the Embassy District. As Celeste rested with an IV drip of electrolytes in her arm, the physician pulled us aside and explained how just a few
months earlier she had lost her five-year-old son to cancer. Without much explanation, she said that we should be very careful with Celeste. There was a strange, haunting pause, something in the way the physician’s words channeled a deeper wisdom, perhaps more holistic and philosophical than atomized or medical—and, of course, with the careful insight of a mother who had lost her only child. That moment resonated profoundly, and still does today. Celeste perked up enough for a day trip to the Great Wall, and the next day she and Dawn returned to Detroit, while I remained in Beijing to complete the program.

After over 50 medical appointments during the course of the next year, Celeste was eventually diagnosed by genetic testing with FSHD, or facioscapulohumeral muscular dystrophy, a neuromuscular disease that is the most prevalent form of muscular dystrophy. FSHD is an autosomal dominant dystrophy inherited from either parent: in this instance, the author. My genetic test results suggested a spontaneous mutation—a 4q35 deletion—meaning that a part of my genetic sequencing was incomplete. In less than a year, Celeste’s body had transformed from a badminton-playing adolescent to a young person effortlessly navigating a 200-pound electric wheelchair around her school. We were all reeling to simply keep up with the demands of our teaching and practice, given our new lives with neuromuscular disease.

Fortunately, we teach at a large public research university with supportive colleagues, a medical apparatus that understands the impact of chronic disease on people’s lives, and a site of research in neuromuscular disorders. When the Dean of Taubman College, Monica Ponce de Leon, launched a new “Research Through Making” faculty grant program in 2009, I used the opportunity to redirect my research efforts toward disability and the role of design as it implicated architecture and civic space. Even though I teach courses in construction technology, including issues of ADA (Americans with Disabilities Act) and building codes, it had never occurred to me in my previous teaching that design thinking could be applied in the area of disability practice just as robustly when one is considering structure or form. I started documenting the passive infrastructure, such as ad-hoc wheelchair ramps, hospital air-locks, and other institutional thresholds. The research grant opened up trajectories of thinking about architecture that were previously unavailable to me, and with them the awareness that contemporary architectural discourse was inadequate to fully apprehend disability culture within the context of the twenty-first century.

My research agenda had three main components. First, I canvased the market of existing structures and technologies, from assistive devices to building systems, with an emphasis on pedestrian infrastructure and responsive environments. Second, my work involved developing a series of design prototypes, such as pneumatic artificial muscles and actuated, biomechanical structures. I was interested in how assistive devices, like bulky electric wheelchairs or service dogs, were extensions of one’s body and performed numerous functions for an individual. Beyond function, the work also evaluated the complexities of civic space from a disabilities perspective as a composition of auto-mobile bodies, hazard detection devices, fashion accessories, and materials embedded in the everyday civic performance of the city. The work considered the ways institutions contribute to the framing of civic space, for example, the entry sequence from a bus stop into a children’s hospital. Third, the research led to a design proposal, developed for such a site, in the form of an interactive wheelchair accessible ramp. Resembling a deviant entertainment ride more than a standard concrete ramp with galvanized steel handrails, the proposal garnered excessive design attention for a structure typically obscured in the civic realm.

The Asclepius Machine, the outcome of this project, is so named for the Greek god of the medical arts whose symbol is the serpent wrapped around a staff, the iconic image associated with medical facilities. One review of the project by Tobin...
Siebers, critically acclaimed author of *Disability Theory* and *Disability Aesthetics*, offered the following description:

*The Asclepius Machine* is part amusement park ride, part public sculpture, and part portable handicap ramp. Resembling a giant grasshopper, the Machine may be attached to any building requiring ramp technology. The Machine is composed of a translucent skin, held in place by arms controlled by pneumatic technology. When the machine is entered, it responds by opening and expanding the outer membrane before the wheelchair user and by initiating light patterns and the sound of inhalation. As the wheelchair user moves through the ramp, the membrane closes and contracts behind the user, accompanied by the sound of air gushing out in exhalation. When more than one user moves through the ramp, the Machine responds with the same pattern but more rapidly, producing an oscillation of the arms and outer membrane and quickened breathing. The wave-like movements and breathing sounds produce in the user a mild sense of euphoria and weightlessness, transforming the handicap ramp, a piece of technology often associated with stigma, into an amusement park ride that stirs in the user a sense of liberation. The magical appearance of the Machine is designed to attract users, whether disabled or nondisabled, persuading people entering the building to abandon the separate but equal doctrine of ramp technology. The Machine also has a transformative effect on the architectural style of any building to which it is attached—a transformation best imagined by thinking about the effect that the pyramid entrance has on the Louvre.

Though its site is not quite the Louvre, *The Asclepius Machine* is unlike any standard accessible ramp. I tend to think of the project as a large, dynamic piece of urban furniture. It makes a scene within civic space; it produces debate. I have often thought of it as a proto-architecture bridging civic space and institutional logic, a threshold that is not properly on either side; it is the entrance to a theatre, a children’s hospital, or simply an unexpected situation within the civic realm. Even if it is not quite the famous staircase of the Palais Garnier, as an architectural device it intercepts and annexes the function of urban theatre as a complex choreography distributed across a spectrum of simultaneities, and of bodies in space—all of which are vital to public, intellectual, and creative life.

In a world of increasing specialization, what practices of public life remain available? I think the forms they take into our unknown futures should involve the design of other types.
of civic apparatuses—without collapsing the differences between social groups and cultures, or the extreme range of augmented bodies, buildings, technologies and governance—which can maintain the right to practice the art of civic space, vividly.

ENDNOTES

1  I had the good fortune of meeting Tobin Siebers, Professor of English at University of Michigan, two years ago. Siebers described Gordon Matta-Clark’s Splitting (1974) as an action that produced not only a structural destabilization of the house, but also as a disabling tactic whereby the wooden staircase itself was sawn in two, creating a vertigo of spatial discontent for abled bodies. Siebers’ reading of Matta-Clark broadens the range of disability discourse across networks of people and objects that articulate the potential of disabled territories.


3  “After conducting a study of theatre seating configurations, we found parallels between the designated wheelchair seating zones and genetic deletions, whereby existing seats in the theatre plan have been deleted to make space for spontaneous mutations in sequencing in the genetic profile of any drama.” [See Adams and Gilpin, Research Notes, Book 2.0, 2011.]

4  This led to Celeste being cast as the therapist in Cassandra, a performance piece conceived by Helga Davis, who has worked with Wilson on numerous projects. Cassandra will debut in Brooklyn at BRIC Arts Media in February 2014.

5  In our first conversation, Siebers described a world of disability that initially seemed counter-intuitive. Despite the oppression of compassion—i.e. “if only I could be in your shoes”—by those who perceive disability as a life of hardship and suffering, Siebers’ suggests that disability is another form of creative practice. This shift in emphasis paradigmatically alters the terms of engaging disability as an extremely insightful lens by which to understand the complexity of urban and architectural formations.

6  The Asclepius Machine has been developed through the cooperation and contribution of many people. This collective project acknowledges the following contributors: Sara Dean, Sen Liu, Robbie Linkner, Mark Stanley, Micah Rutenberg, Daniel Nissimov, Kendra Byrne, Andrew Norskog, Ben Telian, Ben Smith, and others from Taubman College. Funding for this research has been generously supplied by the Taubman College Research Through Making grant and Dean Monica Ponce de Leon, the Graham Foundation, and the Office of the Vice President for Research at the University of Michigan. A special thank you to Prof. Tobin Siebers for helping to construct the intellectual framework around this project, Dawn Gilpin for providing a compassionate substrate as we explore the world together, and Celeste Twigg Adams, whose vibrant tenacity continues to teach us many important things. Thank you to the editorial and design team at Scapegoat for their good work, and the opportunity to contribute to Currency. Kindly, RA

FIGURES


2. The Asclepius Machine, version 1.0 simulation model (2010). The simulation model was used to test the mechanics of The Asclepius Machine, and is played like a musical instrument. Similar to the full-scale design, people engage the model tactically to operate and experience the project from a relational and aesthetic perspective. Below, the plan of the ancient medical centre, Asklepieion in Pergamon, Turkey.


BIO Robert Adams is Associate Professor of Architecture at the University of Michigan, Taubman College of Architecture and Urban Planning, and partner in Adams + Gilpin Design Studio. He is a designer who makes things that seek to transform how we engage the physical world, and his work has primarily taken the form of installations and exhibits in which artifacts, constructed apparatuses, and architectural spaces are used to reveal and interrogate the social, political, and experiential aspects of the public realm.