What Can a Body Do?: How We Meet the Built World

Sara Hendren, 2020

“Disability is not a brave struggle or courage in the face of adversity. Disability is an art—an ingenious way to live.” - Neil Marcus

Defining Disability, history of normativity, fear of dependence

“Before the nineteenth century in Western culture, the concept of the ‘ideal’ was the regnant paradigm in relation to all bodies,” writes disability scholar Lennard Davis. “So all bodies were less than ideal.” In the absence of a norm, any human body was just a shadow of the admirable perfection of superhuman bodies—the ones gods and goddesses or other hero figures possessed. The emergence of modern statistics shifted the point of comparison from a lofty abstraction that no one was expected to achieve to a side-by-side analysis, assessing “normal” by observing people relative to one another. This familiar, comparative idea of normal is so common that perhaps it feels timeless and universal, but it wasn’t until around 1840 that the word was even used to describe human qualities in European languages. (Prior to that time, normal referred to being perpendicular or square, a technical term that would have been used, for example, by a carpenter.) French statistician Adolphe Quetelet adapted the practice of scientific averaging—used by astronomers to minimize errors in measurement, for example—to the science of human traits made into statistics. Quetelet claimed that his idea of l’homme moyen, or “the average man,” could be measured and therefore ranked, both in physical and in moral qualities.

…

It took the whole of the nineteenth century for normalcy to shore up the pernicious force of a broad and encompassing mandate, a legacy that has been passed on to us: the average conjoined to the desirable, the most common range of height and weight and other qualities considered not only good but obligatory. Ideas like Charles Darwin’s “natural selection” were culturally (and mistakenly) interpreted as hereditary directives from nature—a normalcy that could be identified, and then perhaps overtly enhanced and encouraged, with average taking on the conceptual heft of better and best. Quetelet’s legacy was to make the average, what started as unremarkable by definition, into a paradoxical ideal. When the average is laden with cultural worth, everything changes: what was common began to be seen as what was “natural,” and what was “natural” came to be seen as right. The cult of normalcy reached its ugliest expression in the eugenics movements of the early twentieth century, with an aggressive pursuit of normalcy that brought violent measures for disabled people: mass sterilization campaigns and

euthanasia, to ensure that only the “right” kinds of individuals and family units would genetically flourish, in the hopes that nations might flourish as well. This wasn’t a sinister idea promoted by a few thinkers on the fringe; eugenic thinking spread in the 1920s in the United States in utterly benign-seeming forms, like genetic “contests” held at state fairs in the Midwest. In them, “Better Babies” and “Fitter Families” were evaluated for their relative heritable qualities, not unlike the competitions among livestock and garden specimens that were staged nearby. Signs that promoted these contests made the high stakes for an optimized population unmistakably clear: “Some People Are Born to Be a Burden on The Rest.” In nations eager to promote the overall health and thriving of the “we,” eugenic thinking superimposed the value of correctness and acceptability—even civic responsibility—on the concept of normalcy. Even if the darkest chapters of this history are behind us, the tacit equation of normalcy with human progress and perfectibility has settled quite comfortably into our daily speech and rote decisions. The aggregative fallacy shows up every time we assess whether we’re “measuring up,” whether we have what it takes to “get ahead,” whether we’re demonstrably on or off the charts, by comparison with others. Davis sums up the impact: “The introduction of the concept of normality . . . created an imperative to be normal, as the eugenics movement proved by enshrining the bell curve (also known as the ‘normal curve’) as the umbrella under whose demanding peak we should all stand.

Ability and disability may be in part about the physical state of the body, but they are also produced by the relative flexibility or rigidity of the built world, its capacity to bend or adapt in a dance with bodies in a range of states and stages. Disability in part results when the shape of the world—buildings and streets but also institutions, cultural organizations, centers of power—operates rigidly, with a brittle and scripted sense of what a body does or does not do, how it moves and organizes its world. Disability studies identifies two mental models that serve as useful contrasts for understanding these relationships between the body and the world. In a purely medical model, the body is the location of impairment, which suggests that the person with the impaired body bears the responsibility for it—for telling a story of coping, or surviving, or overcoming, or any number of other possibilities, all of which require the individual person to contend with a personal condition. A social model of disability, by contrast, invites you to widen the scenario from the body itself to include the stuff around it: the tools and furniture and classrooms and sidewalks that make it possible or impossible for the body, however configured, to do its tasks, and the larger structures of institutions and economies that make human flourishing possible. In a social model, it’s the interaction between the conditions of the body and the shapes of the world that makes disability into a lived experience, and therefore a matter not only for individuals but also for societies.* The condition of disability is present whenever a body finds itself in what scholar Rosemarie Garland-Thomson has called a pointed “misfit” relationship with the world—not the melodrama of a tragedy to overcome, not merely a “defect” of the flesh, but a misfit: a disharmony that runs both ways, body to world and back. Garland-Thomson is a pioneer in disability studies professionally, but she also understands misfit status in her own body. She has two atypically shaped arms, hands, and sets of fingers,

so she lives between a body and a designed world that make her job and her life both frictionful and, by necessity, deeply and flexibly adaptive. She lives life—eating and drinking and opening doors and using the voice-activated features of her smartphone—as “a square peg in a round hole,” which is different from understanding her body as broken. Simple medical diagnostics could never fully capture her particular tango with dishes and doorbells, to say nothing of composing her short emails and long books using voice-dictation software. Misfitting encompasses not just the shape of her body, but the shape of the world, too, together and also working against one another—peg and hole mutually at odds, as the saying suggests, and then perhaps arriving at other, creative ways to work in something like concert. But misfitting nonetheless. It’s a deceptively casual word, even something like slang. Misfitting provides a bracing shorthand to stand for all kinds of bodies in a clash with the built environment—the obvious collisions and the quieter ones, hiding in plain sight.

Redefining independence, in the legacy of the ILM and the technologically mediated life of a man like Steve, helps nondisabled people to reconsider their own tacitly held ideas about asking for help. But redefined dependence—as a plain fact of our lives that might also, in part, be salutary? This is its own profound lesson. Dependence, perhaps especially when it comes to cognitive disability like Sesha’s, is its own kind of misfitting, because it always implicates far more than one person. Dependence creates relationships of necessary care—care that may be undertaken by individuals, families, local communities and municipal organizations, churches and mosques and temples, states or nations, or all of those in some mix. Kittay has understood from her own experience of acute dependency that her daughter’s situation is distinctive, but it’s also, in the perspective of any human life span, utterly common. “People do not spring up from the soil like mushrooms,” Kittay writes. “People need to be cared for and nurtured throughout their lives by other people.” In her relationship with Sesha, Kittay describes a mutuality more mysterious than transactional. Reciprocity that is “not in the same coin” forms an attachment that might look, from outside, asymmetrical: one party giving and the other receiving. But dwelling together, offering and accepting forms of help, is never a mechanical, zero-sum exchange. Dependency and the care it requires may be the most distilled definition of disability and also the most universal. Some scholars claim that disability may well be “the fundamental aspect of human embodiment.” The fundamental aspect? What a notion—that the universalizing experience of disability, states of dimensional dependence from our infancy through the end of life, might be the central fact of having a body, or rather being a body. It’s an idea that could alter one’s very sense of self, if we let it.

And yet, these scholars note, nondisabled people perpetually go to great intellectual and emotional lengths to distance their own bodies from the experience of disability in others: “The disabled body is imagined not as the universal consequence of living an embodied life, but rather as an alien condition.”

DeafSpace at Gallaudet

For students taking classes, holding club meetings, working and living there, the architecture—walls and furniture and doorways—is designed to support the deeply embodied, three-dimensional, complex social structures of sign. There are the wood benches—an old and commonplace technology, long used as a tool for somatic communication—but, all over campus, in wall heights and atrium structures and color choices, there was evidence of newer designs inspired by deafness: it's called DeafSpace. Gallaudet's architecture emphasizes the particular capacities and assets of deafness, an utter reversal of even the most generous and well-meaning interpretation of "inclusion." DeafSpace isn't a plea to "make room" for deafness. It's an unapologetic and joyous expression of the integrity and beauty of deaf experience, codified in a series of strong principles that inform the way the rooms here look and operate and feel.

As we walked a length of sidewalk with cars parked perpendicular to its edge, he turned to me, his pace still brisk and his eyes trained on mine as they would be for signing, and said: "Now—what's about to happen here?" I'd spotted the hood of a car in my peripheral vision, parked so close to the curb that its nose jutted far into the sidewalk. "I need to alert you that this obstruction is coming up," I offered. "Right," he said. "You need to physically reach out and cue me that it's in my path. I'd be pissed off if you didn't." That social awareness—not just for oneself but for the other—is a naturalized set of behaviors that come with the social work of sign. In a group, one person will often take the role of wayfinding, scanning the environment for barriers or approaching changes in direction. The designated guide will interrupt the flow of conversation among the group only when necessary. Design for the DeafSpace category of "mobility and proximity" can do its work here, too. DeafSpace recommendations include extra-wide hallways that allow for sustained conversations without group collisions and stair treads with extra depth that make for a slower ascent or descent, built to accommodate ongoing talk at a more leisurely pace without tripping. Ramps in place of stairs, where possible, also mitigate the focused stepping that detracts from signing in motion; ramps also extend access, of course, to people who use wheelchairs. Matthew Malzkuhn, a Gallaudet alum and researcher on deafness and design, has said that this three-dimensionality in language and the body is integral to what it means to be deaf. "[We're] spherical people," he told an interviewer in 2007, so it makes sense that the architecture here should beautifully bear out deafness as a way of being.

Like Malzkuhn, Bauman describes the "spatial kinesthetic" of sign language as particularly conducive to architectural thinking. Signing is three-dimensional by nature, so it implies not just

words in a line, but heights and widths and depths for making language the rich repository of communication that it is. The unidirectionality, even “linearity,” of spoken language seems paltry by comparison. Never had my spoken English felt more comparatively impoverished than on my visit. I was painfully conscious of fumbling for what suddenly struck me as the pallid choices of a word-based vocabulary, and of how my every wispy utterance seemed to disappear immediately into thin air as soon as the words exited my mouth. I was aware then of what Bauman’s brother, Dirksen Bauman, head of the Deaf Studies department at Gallaudet, has called “deaf gain,” a pointed corrective to the commonplace usage of “hearing loss.”

the idea of DeafSpace isn’t so much about the features—what the design looks like—but instead about the qualities of attention that DeafSpace practices as its process of design. The granular, intimate details that make up the patterns of culture and communication happening outside the normative human sensorium are an invitation: to look closely at what communities people build, outside the mainstream, and to formalize an often invisible but long-held tacit knowledge of the world. DeafSpace, on display at Gallaudet, offers a way for architects to keep returning to all the languages of the body, to how we all might hear and see one another better; to prioritize relationships and the social dimensionality of embodied languages; to reexamine the standard structures for living and ask where opportunities for refashioning might make a more livable series of rooms. Surely the rooms built on DeafSpace principles embody what philosopher Gaston Bachelard means when he writes that “all really inhabited space bears the essence of the notion of home.” To inhabit—from its roots in habitare, or “to dwell,” which has its further roots in habere—“to hold or have,” or even “to give or receive.” The giving and receiving that is so acute in spherical, socially interdependent sign makes a habitable home for the students who gather there.

Other disabled students made the connection: Must we accept and bend to the norms of the institution? Or can we insist, together, that the institution also bend for us? The PDSP provided services that were more than practical. They were articulating the seeds of a new definition of independence entirely, one that transcended wheelchair use. These students were taking stock of the built environment—classrooms and streets and homes—and looking for ways those structures could be made more accessible. At the same time, they rejected the rehabilitation paradigm in which they’d grown up—in which their independence was measured only by their capacity to do things literally for themselves. They maintained that the need for physical care would always be present in their lives, but they insisted on a way to live with chosen forms of help while keeping decision-making power. Instead of defining independence as “self-sufficiency,” the standard for independence in the clinical settings where they’d been treated as patients, they claimed that their independence would be understood instead as “self-determination.” **The difference separated the dignity of authority and choice from the action itself.** Asking for and receiving help with self-care tasks like buttoning a shirt, for example, was understood as a high degree of dependence in a rehabilitation paradigm. But if a person needed fifteen minutes of assistance with the shirt and with getting out the door to the

bus, that person would be less dependent than a person who took two hours to dress on their own and could not leave the house. Uncoupling assistance from dependence—or perhaps bundling assistance together with a richer idea of independence—changed everything for these activists, because now they could press for a whole array of products and services that would support a desirable life. Judith Heumann, one of the instrumental voices for independent living, said in 1978 that "to us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent on a normal body."

Sensory & stim tools as prosthetics

It's a form of what's been labeled Sensory Processing Disorder, a common challenge found in the cognitive profile of autism, and some of the **prosthetics** designed for it are things you've probably never heard of: body socks, pressure vests, rocking stools, chew toys. Objects like these are usually low-tech designs for "tuning" the sensory nervous system, what a physical therapist will sometimes call "getting organized." With the assistance of prosthetic tools, getting organized is a process designed to help the body and mind attend to the "executive functioning" required for essential daily tasks. Sequential decision making, sustained focus, and linear problem solving are skills required to carry out even mundane operations like getting dressed and out the door in the morning. All can be hampered by dysregulation. Sensory processing anomalies run the gamut from hypersensitivity that can make a light caress feel like an assault, or the tag on a shirt a painful, irritating friction, to hyposensitivity, where the body underregisters cold, heat, or pain.

… These devices are for subtler uses, the less visible but nonetheless real misfits between our bodies and our constant negotiations as we move through private and public spaces, long waits and loud gatherings, large crowds and small groups.

… the tools for tuning the sensory phenomena of the world come in all kinds of unexpected but also familiar forms. Even without a diagnosis of Sensory Processing Disorder, we navigate the built environment of industrialized life in hundreds of small ways, adjusting our bodies to the spaces we inhabit and the spaces, in turn, to our bodies. To quiet our nervous system, we wear earplugs, dig in the garden to relax, invite the sensory changes in our body that a run over pavement brings. Plenty of people who are not autistic would say they need certain physical conditions, and perhaps especially certain kinds of sensory input, to function well intellectually, to make creative choices, to feel calm and, yes, "organized." The state of the physical corpus is deeply tied up with the health of the brain; an overwhelming amount of research says so. We just have to find the right mix for our individual constitutions. … The sensory world is a weird mix for human bodies, each of us moving around in a singular flesh envelope. We traverse the rooms and streets we like and we hate, turning the little knobs of the world's sensations by our choices of what to wear, how to walk, what to include and what to shut out. Augmented by headphones or a hat pulled low, decked in seamless socks or technical Lycra or fuzzy sheepskin, wrapped tightly or loosely, rocking or fidgeting or chewing our nails—each body

makes a stream of conscious and unconscious choices, knitting together a habitable personal universe minute by minute by minute.

Making public space work for us: 1990s rights movement

Long before the Americans with Disabilities Act of 1990 mandated curb cuts at all street corners, disabled people had pointed to the design of the street as a key locus of their political rights—the sidewalk that stands for being in public space, and therefore in the public sphere. …

In the late 1960s, disability activists in Berkeley, California, including Center for Independent Living leader Ed Roberts and his circle, were rumored to have mixed and poured concrete to smooth the passage from sidewalk to street in a DIY "editing" of the city. It was a hacker-style approach to creating the conditions of the future. Others took a more forceful tactic, smashing the concrete curb away to create the cut required in guerrilla-style street action, even if the resulting plane would be rough-edged. You can see the remnants of this form of design protest in the Smithsonian today—a preserved bit of sidewalk taken out in 1978 by disability activists in Denver who were smashing away curbs as an unignorable public gesture, one that was both pragmatic and pointedly expressive. It's a hunk of concrete that stands for so much: the insistence that access would not just await new architecture but must be created by unmaking and remaking the inherited street itself. Disability scholar Aimi Hamraie recounts this history as an example of disabled people redesigning their own worlds, efforts they took on themselves as a call to action for their own civil rights, without the paternalism of rehabilitation. In the present day, curb cuts are so common, both ordinary and even mundane, that most people know nothing of this history. But the resistance to their widespread implementation was protracted and fierce. Outside a few small communities like Berkeley, where vocal activists won some local implementation, there was little understanding of the chicken-or-egg problem of accessible design. "When we first talked to legislators about the issue, they told us: 'Curb cuts, why do you need curb cuts? We never see people with disabilities out on the street. Who is going to use them?'" recalled Roberts. "They didn't understand that their reasoning was circular."

The fight culminated in a dramatic day of protest in March 1990. At the "Capitol Crawl," people using wheelchairs, leg braces, and canes made their way to the hundred steps in front of the U.S. Capitol building in Washington, D.C. Then they began to climb those stairs, leaving behind whatever gear couldn't come with them, using their arms or whatever body parts they had available for mobility. Children as young as ten participated in what became a very public, strategic spectacle. That protest is considered by historians to have been the tipping point; the Americans with Disabilities Act was passed in 1990, guaranteeing curb cut changes at every city sidewalk corner and ramped entrances at all newly constructed buildings, among other new provisions.

… Hayward and Swanstrom argue that when injustice is tied up with the physical spaces of cities and the policies that create them, it becomes "difficult to assign responsibility for it—and hence difficult to change." That's why the curb cut's history—a successful "editing" of the built

environment that arrived via mandate of federal law—is so impressive and historically profound. The careful reshaping of the sidewalk allowed more kinds of bodies on the street but also into public life. “When disabled people enact politics,” writes Hamraie, “they also design and build new worlds.”

… The very solidity of the built world gives it stubborn staying power. The guarantee of infrastructure—its reassuring layout as a networked system—can turn into thick injustice when planned for abstractly determined human populations, without consideration for a variety of actual bodies. Rectifying forms of thick injustice doesn’t come easily; assigning accountability and making legislative change is the work of decades. When I’m up and down on the curbs in my own city now, tackling the stairs or taking the elevator, observing the kneeling bus as it lowers for easier entrance and watching for who sits and who stands on public transportation, I think of those protesters on the steps of the Capitol building, insisting on a wholesale reshaping of cities and demanding a legally binding promise to make it so, one edit at a time.

Disability and Time

[Author’s son has down syndrome:]

“…at every point in his life, people have asked us, or sometimes announced to us, where Graham lives in this conspicuous and maybe totally arbitrary standard of timing that results in a label of “high” or “low.” The reasons and metrics vary, depending on context, but the spatial measurement of high or low isn’t really about heights or depths. It’s always about time. What people want to know, when they ask about “functioning” in an unconsciously roundabout way and covered in so much friendly goodwill, is whether and how much he is retarded. Most people don’t dare use that language anymore, because it’s considered rude and out of date. But high or low is actually about fast and slow. Retarded is ordinarily a neutral and descriptive term about slowness in time. But it says so much—not about Graham but about the bald truth of contemporary life! How strange and yet how telling: slowness can so easily exit the realm of pure description and transform into its popular use as an insult, a clock word weaponized to diminish a human being. Living with questions about time—about Graham and the diagnostics of his delays, but more urgently, the unknowns about his future—was the loneliest feature of our early months. Was it just families like ours who were facing down the clock, relentlessly (and resentfully) allowing it to measure our lives? It took me a while to see that our tiny family unit was connected to ideas far bigger than ourselves. It was more readily apparent for us upon Graham’s arrival, but the clock measures productivity for everyone now, in a manner so internalized it feels all but natural to our bodies.

“The medical field . . . has a long tradition of describing disability in reference to time,” writes disability scholar Alison Kafer. “‘Chronic’ fatigue, ‘intermittent’ symptoms, and ‘constant’ pain are each ways of . . . describ[ing] disability in terms of duration.” Time is everywhere in disability language, writes Kafer: “‘Frequency,’ ‘incidence,’ ‘occurrence,’ ‘relapse,’ ‘remission’: these, too, are the time frames of symptoms, illness, and disease.” How long, at what speed or slowness, how often, when it started, what the future prognosis will look like—these are the temporal words doctors possess and use for talking with patients about what’s happening in their bodies, whether describing the slow creep of change that happens with age or puzzling out a new and mysterious set of symptoms. The words acquired, congenital, and developmental start to get more abstract, with developmental doing even more complex work, Kafer observes. A condition may be developmental in that it extends over the life span, but the term may also be used to describe another kind of friction with respect to time: a “developmental delay” to describe a child or adolescent always has a standardized and normal idea of individual progress as its background. **How long should it take** for a child to learn to crawl, or begin to speak, or read independently? To occupy the tail ends of the bell curve is either to be precocious—that is, early and therefore advanced—or to be delayed and therefore behind.

Kafer notes the temporal speech that arises in even our most casual questions to one another about our bodies: Were you born this way? How soon will you recover? The differences and deviations in disability, short-term and long-term, physical or cognitive, are unquestioned references to the apparent fixity of time.

Kafer notes that the universal nature of disability itself is premised on the clock: “Disability studies’ well-rehearsed mantra—whether by illness, age, or accident, all of us will live with disability at some point in our lives—encapsulates this notion, suggesting that becoming disabled is ‘only a matter of time.’”

Among disabled people there’s a bigger catch-all term, a slang for this particular mismatch: it’s called life on **“crip time.”** Crip is short for cripple, a name that disabled people have repurposed in an act of political reincarnation, dropping the degradation attached to a word that was used to describe them in the past, cripple, and investing it with in-group pride. “Crip time” is flexible shorthand in disability culture, used to indicate a range of uneasy relationships to the pace of contemporary industrialized life, with its relentless and clock-driven organization of hours and days. As a disabled person, to say you’re “on crip time” on a Tuesday might signal the extra time that it takes you to get to the train platform or in and out of a public bathroom. It can also stand for bigger systemic fits and starts—the spiky, unpredictable time it might take a person to proceed through a fairly rigid K–12 education that’s built on all kinds of normative chronologies. Crip time can also be “time travel,” writes disability scholar Ellen Samuels—forward and backward motion through ages and stages brought on by misfit conditions. Samuels was in her early twenties when her body changed swiftly and dramatically with disabling illness, and her doctors had no real answers. The dissonance between her age and her bodily state caused her clinicians to speak of her life as unnaturally skipping in time: “You’ve lost so many things already in your life: your parents, your health, your independence. You have a level of loss we would usually expect to see in someone in their seventies.” Samuels writes that she went from someone “with health problems” to “being a problem, apparently insolvable.” To be so young

and so beset by physical illness ejected her from any ordinary timeline, and she knows she's not alone in this state: Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings. Some of us contend with the impairments of old age while still young; some of us are treated like children no matter how old we get. The medical language of illness tries to reimpose the linear, speaking in terms of the chronic, the progressive, and the terminal, of relapses and stages. But we who occupy the bodies of crip time know that we are never linear, and we rage silently—or not so silently—at the calm straightforwardness of those who live in the sheltered space of normative time. **Crip time, then, can describe an out-of-sync plotting of life in its mismatched state.** But the term can wield a pointed critical bite, too. How long does it take, or should it take, for a body to move through the world, the forty-plus-hour workweek, the demands of caregiving for children or ailing parents, the daily commute of the body with its changing needs over the life span—a pregnant body, an aging one, a body in recovery after a bad injury? And then there are situations of crisis, conditions that alter both our bodies and the work we do as a measure of our worth. Is the clock of industrial time built for bodies at all?

The pace set in contemporary schools and workplaces presumes a form of able-bodied productivity, an ideal of speed and efficiency. That's not a literal clock but the one in the background, invisible yet always ticking. It's a mismatch for all kinds of people, because it's not simply a timepiece. It's an economic instrument. The body and mind are a combined organism with infinite complexity, but the measures at hand are those of the clock: whether and how the social-cognitive mind and body of a person is checking off the milestones for a given set of skills in a timely way. It makes us obedient to the demands of competition—for getting through reading levels and standardized tests and job interviews by "getting ahead," by getting through faster than others, becoming compliant with the unquestioned ideals of productive worker time—worker time established for an encompassing identity of worker beings. Many of us tend to accept the expectations of the industrious clock, with its minutes ticking away and announced to us everywhere, as fixed and permanent. But crip time announces the possibility of another way of thinking, outside economic time. Crip time is not just a call for the values of family-friendly schedules or work-life balance, important as those may be. "Crip time is flex time not just expanded but exploded," writes Kafer—exploded by the raw disruption of disability, the atypical body or mind that refuses to be the insolvable problem, and indicating instead a larger social and political mismatch at hand. The extended crosswalks in Singapore are the faintest signals of a bigger design confrontation with time, a misfit scenario that may be the most diffuse and intractable of all. A disabled person, caught up at odds with the mechanized and economic tempo of life, isn't merely apologizing for lateness. **That person is diagnosing not the slowness of a body but the unyielding, ossified containers for quick and efficient productivity**—the expected time that life will take, life for everyone.

High and low are spatial words. They're a way to rank humans, you could say, in assessments that arrive relatively up or down, intended euphemistically to sum up a report about performance that is actually about time. How quickly was Graham doing infantlike things, and how normally fast was he getting them done? The logic is pernicious, sublimated, and sweeping in its interpretation: If he walked on the "early" side, the thinking went, did that mean he would be "high functioning," and therefore he would also understand, say, addition and subtraction on the early side? And did that also mean he might understand all abstract concepts in schooling in a timely fashion, his functioning attended by only modest delays? Would all of that therefore mean he'd have an ordinary and dignified job in adulthood, be less dependent on other people because he would be generally, overall, somehow, quicker? Meaning—quicker and therefore more normal, more worthy of respect? The language of high or low is an unavoidably global and totalizing assessment of achievement, and therefore, implicitly, a judgment. How "high functioning" one may be is a commentary on worth—how high a person's value will turn out to be in the eyes of the wider culture.

History shows that the early uses of clocks arise from both familiar and unexpected sources. Mechanical clocks, before setting up the rigidity of industrial time, made an early appearance in the monasteries of Europe. They were employed by men seeking the order of their daily "offices"—not the physical workplace offices of our own day, but the liturgical offices, the rituals of prayer designed for marking the early-morning, noontime, evening, and sleeping hours. For some forty thousand Benedictine monks in the thirteenth and fourteenth centuries, obedience to time was liberation by practice and rule, marked by clocks before they were commonplace, before there were clock towers, for instance, marking official city times. Lewis Mumford, in his classic history of technology, Technics and Civilization, reminds us of the social and emotional work of this early clock, keeping a desirable life set apart by spiritual habits that were measured by marking the hours. "Within the walls of the monastery was sanctuary," he writes. "Under the rule of order surprise and doubt and caprice and irregularity were put at bay." Clocks marked the rhythms of sacred time for men who deliberately chose life outside the mainstream, and, in so doing, paradoxically helped create the normalcy of timekeeping that would overtake the entire industrializing world. Mumford includes this history to remind his original readers in 1934 of a truth that needs retelling in our own time: that tools and technologies both follow, and lead, and follow again from the ideals that cultures value. Monasteries, full of men whose life's work would never be economically efficient, "helped to give human enterprise the regular collective beat and rhythm of the machine; for the clock is not merely a means of keeping track of the hours, but of synchronizing of the actions of men." Synchronizing, of course, took on a life of its own in the centuries that followed. Clock towers, and eventually home clocks and watches, made it possible to carry this instrument everywhere and to measure the hours of everyone by its instructions. The clock made it possible not just to mark the passing of minutes but to imagine time as preceding other metrics for life. "Abstract time became the new medium of existence," writes Mumford: "one ate, not upon feeling hungry, but when prompted by the clock: one slept, not when one was tired, but when the clock sanctioned it." For centralized industry to work—organizing factories and farms, of course, but then dramatically, suddenly, with the vast expansion of the railroads—time had to exist outside locality. Standardized time, as agreed

upon in the United States and Canada and rolled out on November 18, 1883, established a national agreement about time that echoed trends elsewhere in the world: the industry clock was king. The Indianapolis Sentinel reported the day's implications with a grin you can hear, but the prophecy also makes its way through: Railroad time is to be the time of the future. The Sun is no longer to boss the job. People—55,000,000 of them—must eat, sleep, and work as well as travel by railroad time. It is a revolt, a rebellion. The sun will be requested to rise and set by railroad time. The planets must, in the future, make their circuits by such timetables as railroad magnates arrange. Industrial time is useful! We can hardly imagine life without it. But outsourcing authority to the mechanical clock has severed time from all connection to the body or the season by breaking life into a series of discrete units—the effect of which, writes Mumford, "helped [to] create the belief in an independent world of mathematically measurable sequences." Mathematics, that is, soon wed to the directives of industry. It's this matter of belief that is so consequential, because even the twenty-four-hour day, examined empirically, is an average at best. There's nothing about the rotation of the Earth, the organization of the monthly calendar, or the real expanse of longer and shorter seasonal days that's remotely as precise as the mechanical clock. Its units are mathematical, but its origins are cultural. And the clock will certainly never represent the strange experience of time in our lives—the ways that it is fundamentally interactive and ephemeral, the time travel of memory and expectation. Physicist Carlo Rovelli writes that the nature of time is so hard to characterize that it's more accurate to call it an event rather than a structure, "more like a kiss than a stone." All physicists will tell you the same: that time is a slippery thing appearing every day in the guise of the exacting clock, unable to yield its measures for us, "waiting for no one" and all the rest. Each of us has to decide, insofar as we can, whether to let the economic clock dictate our minutes and hours, and how we'll know if we measure up. But where does that leave, in Alison Kafer's words, a future for crips? Looking back can help us look forward.

The designed segregation of the asylum for intellectually disabled people (along with the asylum for people with mental illness, in parallel) was largely a response to industrialization. With families more transient, a new service economy emerging, and a more distinct separation of home and workplace, the care of family members whose capacities hindered the efficiency and centrality of the nuclear family became untenable for some, necessitating formal state intervention for care. For what we now call intellectual disability and was then called "idiocy," there were both social and economic reasons for segregation. Prior to the nineteenth century, intellectually disabled people would have either remained within family structures or been under the care of almshouses, a community resource that brought a mix of both vulnerability and protection. But once census data of the mid-nineteenth century showed the prevalence of intellectually disabled people in almshouses or prisons in aggregate, suddenly those numbers appeared threatening as a social problem. Fears about intellectual disability coincided, too, with general fears about cultural "degeneration" that plagued the Victorian era: the squalor and poverty in newly crowded cities and the applied understanding of Darwin's natural selection in a social and political frame, with social "fitness" newly articulated as an achievement. A new

association of “idiocy” with pathology necessitated and raised the stakes for more centralized care. “Idiocy” was recast from its status as a relatively benign pity to a more serious social threat, linking intellectual deficiencies to both physical and/or moral deficiencies, especially in poorer families. Historian James Trent, in Inventing the Feeble Mind: A History of Intellectual Disability in the United States, writes that this association between disability and poverty was key. It was the economic vulnerability of these children and adults, a vulnerability that extended to their families, that made them “feeble,” indistinguishable from their status as unproductive. As a group, then, “idiots” were increasingly managed by custodial supervision in a designed campus for care, outside the locality of families and communities.

My son doesn’t need a gentle and pacifying form of “inclusion.” Inclusion is necessary, but it will never be sufficient. He needs a world with a robust countervailing understanding of personhood and contribution and community in it, human values that are alive and operational outside the logic of the market and its insistent clock. He needs it, and so do the rest of us.

“We already accept that most couples don’t want a Down child,” said James Watson, a geneticist who was deeply involved with the discovery of DNA and the Human Genome Project. “You would have to be crazy to say you wanted one, because that child has no future.” No future, meaning that child will be a forever-child, with no temporal horizon, no imaginable life that grows and changes and matures in the long arc of time. That’s the assumption, anyway—that having some basically permanent needs for support automatically renders a person in a permanently stunted state. “Once a child and always a child” is what people say; it’s what people have unthinkingly, casually said to me. Watson is known for mouthing off about social topics just for sport, in ways most people would find alarmingly objectionable. But here he’s speaking something many people think but won’t voice aloud—that the prospect of having a child who lacks normative intelligence fails the most important demand of the clock. The idea of a person without established “high functioning” economic worth just doesn’t seem like someone who will access a meaningful future.

I can only think that this blank, futureless prospect is partly driving the global majority of parents to opt out of having children with Down syndrome via selective termination—the most invisible and everyday form of eugenics, shaping and culling the future by means of one privately held, economically distinct family decision at a time. In my own country, where healthcare isn’t guaranteed and social infrastructure is unevenly distributed, many families may well terminate because they lack supports for raising a child with disabilities. I’ve talked to and read about many women who conceived a fetus with Down syndrome and decided to terminate; there are dozens of reasons why they do so. Some feminist philosophers frame these decisions—whether

to birth and raise any child or terminate a pregnancy—as life choices that defy the category of mere “choice” itself. Instead, they say, these decisions are each options that play out in a wider frame of “reproductive justice” that includes matters of rights but involves much more. Choices about pregnancy are inherently contextual, involving deep racial and class-based differences and inequities. A vision of reproductive justice, first articulated by alliances built by women of color, includes reproductive choices not only to conceive and birth children, but also to raise them and educate them for the long term in cultures where they may thrive.

…

“So how does a pro-choice mother like me voice a simultaneous claim against the silent and even unwittingly eugenic process happening in contemporary pregnancy? How does a mother support the worth of her child living on an alternate clock? There are no easy answers. Many days I feel stymied into silence by the conflict in my own convictions and by the absence of reproductive justice that relegates the matter of selective termination to a narrow definition of private choice. But on those days with the EPIC service warriors, I watched the young people considered forever-children, the ones just a few years ahead of Graham, looking to build their future, young people both aspiring to and at odds with a prescribed notion of adulthood and the economic productivity that is its only goal. I glimpsed, at least, the face of a different clock unfolding to a time somewhere out there, somewhere ahead of now.”

A graffiti overlay forces a reimagination of the International Symbol of Access—and of disability and accessibility by implication—at an early stage of the Accessible Icon Project”

“Many things in our lives are created by designers with the idea that they should be useful without people having to notice them—kitchen tools or software applications, for example, that intuitively suggest the steps for their use without taking too much of our attention or brain power. Their invisibility is meant to be their virtue. But some design is made to be emphatically visible, bringing new attention to its subject. That aim was the heart of what became the Accessible Icon Project, the only technically illegal street art I’ve ever done. …

““In early 2010, I was heavily pregnant with my third child and four years into a steep learning curve about disability rights, law, history, and more. …The street features were particularly alive to me in those years, because I was often pushing two toddlers in a stroller and, later, also carrying a baby in a sling, up and down the curb cuts and into and out of subway elevators. Their bodies, traveling with mine, made me marvel with fresh eyes at something that I'd tacitly known but had never truly seen: evidence of the edited city. Curb cuts and ramps and elevators, infrastructure hard won in the generations preceding mine, had made my own passage through public space smoother. And now I was the parent of a child who would be asking for more and different accommodations, a more flexible world for his growing up. So for the first time, too, I started to really see **the International Symbol of Access.**

The International Symbol of Access (ISA) is one of the most mundane and powerful symbols in public space: the image of a person using a wheelchair depicted on signs outside a café or city hall or preschool, protecting parking spots or indicating the presence of ramps and accessible doors. The ISA is a standardized and rote image in public, doing its pragmatic work by being readily available and easy to spot, always in the same blue and white tones, internationally legible because it doesn't depend on text of any kind. Its recognizability makes it a symbol for physical access for wheelchairs but also for generalized assistance, physical or otherwise, at the airport or doctor's office. It's what graphic designers call an isotype—a simple two-dimensional graphic that city planners and architects often employ to signal the purposes of built space, like the symbols of human bodies you see on the doors for bathrooms and emergency exits. The standards for what isotypes should look like are formalized and deliberate, because they have to provide maximum contrast, consistent scale in their repetition, and easy legibility even from a distance. The practical details matter.

But the ISA is also an abstract idea made concrete, and that bigger idea gets lost when infrastructure does its handy work of becoming invisible, part of the background. The ISA holds a big promise: **an image that permanently, reliably reserves and protects bits of public space for people whose bodies meet the world in a clash.** The nearest parking spaces and curbside entrances, guaranteed for those who need them—that's the hardscape, making room. But the symbol stands for something bigger still. It stands not just for these accessible material features of the world but also for everything that material access makes possible: entryways to public life, school and transportation and workplace. The very idea of legally protected access is exceedingly rare in the world and only came to be commonplace in recent decades, and it is still a historical anomaly. A symbol isn't ever intended as a literal picture of a singular person in a singular kind of world. The ISA isn't just for wheelchair users. Instead, it gathers a whole set of ideas. It collects and stands in for accessible goods and services that it captures and holds together, organizing them in a simple, intelligible way.

Still—so much of what becomes ubiquitous also goes to sleep in our consciousness. That's what infrastructure does best, after all: it performs its steady public work ideally without fanfare, only drawing attention to itself when the joints or systems break. The image was a wake-up call to me in those early years parenting a child with Down syndrome. Even though none of us was—or has yet been—a wheelchair user, it stood for physical entry, and it stood for much more. Misfit bodies had been clashing with the built world for a long time, and my son's story was part of this larger narrative that was literally and figuratively under construction. The ISA, together with ramps and curb cuts, was a daily reminder that the features of the built world could

be changed, because here was the evidence, right in front of me, that they had been. I started an informal collection of variations on the image by other designers, admiring and comparing their features, and remained frustrated by how invisible each was in the built environment. **I wanted to wake these politics once again.**

I worked with a graffiti artist slash philosopher, Brian Glenney, to try out some possibilities for a new and altered image of wheelchair access that could sit on top of the old one, precisely to draw attention to it: What might its features look like? How might we emphasize the figure, the symbolic person in the icon, more than the wheelchair? And what would it be made of? Vinyl? Spray paint? We arrived at a sticker with a clear backing, designed at a scale to fit neatly on top of standard signs that featured the original ISA. To fit neatly, that is, but not exactly. We wanted to show the old symbol transposed with a new one, to make it demonstrably, un-ignorably visible once more—to evoke its history and its work as a symbol, to pose the meaning of icons in public as a series of questions in the way that street art has always done. I'd already been influenced by interrogative design, a term coined and an idea practiced by an industrial designer and artist at MIT named Krzysztof Wodiczko who later became my mentor. Interrogative design—making things not only for solving problems, but to ask questions. That's what street art, stickers or graffiti in the built environment, can do so effectively: you stumble upon its manifestations unannounced, and maybe they catch your eye or even cause you to do a double take. Street art often resists the kind of slick messaging that advertising specializes in. It does its best work when it's got a strong quality of enigma, when it enters the visual field of the street as a surprising bit of grit. That's what we were aiming for. If you were someone who thought the ISA wasn't for you, and you happened upon this new-upon-old layering, would you look at the symbol with new eyes? **Would it make you pause to think—not about graphic design, exactly, but about disability, in the street and in the square? Who is the world built for?"**

"We started with a very modest experiment: placing a few dozen (removable) stickers on signs around greater Boston. It wasn't exactly under cover of night—stickers appear on infrastructure all the time—but we were surreptitious about it, vaguely worried about getting caught in the act. It was a test-and-see effort, informal, a design for learning how the idea might be received. We offered some for free to others to test in a few additional locations. We got outsize press for such a small project, and people started asking us for a more formal version of the image—one that would be compliant with the Americans with Disabilities Act regulations and usable on official signage. Our street art campaign morphed into a fully fledged new isotype entirely, requested by and co-designed with many disabled collaborators, expertly rendered by graphic designer Tim Ferguson Sauder, and offered as a symbol for taking up these bigger questions. The new image, now meeting the standards of formal isotypes everywhere, became an icon in the public domain. It's now free for use by anyone; we neither own it nor lobby for its use. The Accessible Icon Project has become a resource employed by others all over the world—on taxicabs in Manhattan and on custom hospital signage in Delhi, on accessible gondolas in Venice and on posters and graphics made by Saudi disability rights advocates. It's used in U.S. government buildings and held in the permanent collections of two museums. It became not just the work of a couple of street artists but a public thing, something that has never been a commercial product for us. A lot of people loved it and some people hated it and let us know, as with any public thing. We were surprised by its success and by the criticism. But we were glad,

most of all, for the newly awakened debate it raised about disability, a subject of unfinished rights and unscripted futures that must continually be brought into the public eye. Nearly ten years on, the project has mostly exited our authorship. It's a free tool, practical and symbolic, and it belongs to anyone or any organization in the ways they decide—people like and unlike us. But the work began and endures in my mind in that rowdy provisional early stage: as interrogative design."