Epilogue

Many of them have almond-shaped eyes, obliquely set; and this feature, with the squat nose and wiry hair, gives the Mongol aspect from which they derive their name. The hands are usually broad and the fingers short, and often the little finger is incurved. The feet are also characteristically clumsy. There is reason to believe that they are essentially unfinished children, and that their peculiar appearance is really that of a phase of foetal life.

—G. E. Shortleworth, Mentally Deficient Children: Their Treatment and Training, 1900

Food parents will frequently insist that their Mongol child can speak when his vocabulary is limited to a repetition of such sounds as “dada,” and “mamma” to which he associates no meaning... Parents often state that their Mongol child began to talk at 3 or 4 years of age, or rather to repeat a few words but after a few months the child ceased to speak and vocalization became limited to grunts and harsh cries.

—Kate Brouseaux, Mongolism: A Study of the Physical and Mental Characteristics of Mongolian Infants, 1928

I couldn’t believe my eyes. It was worse than any institution I have seen in visits to a dozen foreign countries... In our country, we would not be allowed to treat cattle like that.

—Niels Erik Bank-Mikkelsen, director of Danish national services for mental retardation, on visiting Sonoma State Hospital in California, just before Governor Ronald Reagan had cut $17 million from the state budget for state hospitals and mental institutions, 1967

It is really about how much love and compassion that you have. That’s what really counts about values.

—Mitchell Levitz, a twenty-one-year-old man with Down syndrome, November 1992

In March 1995, Harper’s magazine ran a letter from Steven Pinker in which he responded to an essay that marked my first attempt to write about Jamie. In his reading of my discussion of the textual representation of people with Down syndrome, Pinker apparently took me to be saying that “words and phrases” were to blame for unsavory political attitudes. Accordingly, he set out to set me straight, lest I fall into the English-professor trap of thinking that language is coextensive with thought: “Béroué notes,” he wrote, “that although ‘retarded’ and ‘delayed’ are synonyms, neither with any literal pejorative sense, the former (and older) word has become an epithet. Exactly so: any unpleasant or emotionally charged concept will soon taint the word that denotes it, calling for a ‘polite’ replacement. Unfortunately, the replacement does
not cleanse the concept, but rather becomes tainted itself." The letter overall was eloquent and friendly, and closed with a few words of advice to those of us who might want to change what we consider to be unsavory political attitudes: "I take the point of Bérubé's essay to be that there is a greater range of functioning among Down syndrome children than most people think and that, for both ethical and practical reasons, every Down's child ought to be treated as if he or she were in the upper part of this range. Focusing on words and phrases is misspent energy. Once the message gets out, the language will change accordingly."

The reason Pinker wrote to Harper was that I had asked the magazine to send him a copy of my manuscript, thinking that we might have the grounds for an engaging discussion of the competing claims of biological determinism and social constructionism—nature, nurture, and everything in between. But I was surprised that he'd associated my argument with the now discredited Sapir-Whorf hypothesis that our language absolutely determines our thoughts. All I'd said was that there are "intimate links between words and social policies," and I never suggested that one always dictates the other.

But when it comes to the political potential of mere linguistic change, I'm afraid I have to disagree with Pinker on other grounds. When a word becomes an epithet and is eventually supplanted by a "polite replacement," the replacement word may become "taunted" in turn—or, as people argue over whether the replacement is an improvement, it may briefly make us self-conscious about what the epithet might mean. Then there are words like "nigger" that mysteriously persist no matter how often people of African descent demonstrate their humanity, thus casting doubt on the proposition that our language changes once the message gets out. Speaking of which, what does it mean when people take up the terms in which they have been dehumanized,

when black folk call each other "nigger" and gay and lesbian people nominate themselves "queer"? Has the language changed, in these cases, simply because a message has gotten out, or are people trying to change the very meaning of the message that dehumanizes them?

My thoughts about thought, language, and change might be neatly summarized by Ludwig Wittgenstein:

In a law-court, for instance, the question might be raised how someone meant a word. And this can be inferred from certain facts.—It is a question of intention. But could how he experienced a word—the word "bank" for instance—have been significant in the same way?

Suppose I had agreed on a code with someone; "tower" means bank. I tell him "Now go to the tower"—he understands me and acts accordingly, but he feels the word "tower" to be strange in this use, it has not yet "taken on" the meaning.

So we may someday call banks "towns" and retarded people "delayed," but there will undoubtedly be a period during which the new terms have not yet "taken on" their meanings even though people seem to be using them correctly; and in that interim period, there will surely be debate, reflection, and general self-consciousness about what "stigma" is and how it operates. Thus, even when people like me and Steven Pinker disagree over theoretical accounts of linguistic change, it's like the song says in Oklahoma!—the cognitive psycholinguist and the postmodernist literary critic can be friends.

This particular disagreement may seem like a classic case of nitpicking academics missing the boat (or, as they say in ASL, train go sorry), but as a matter of fact, the question at hand here is
central to everything we say (and everything I’ve written so far). How do we represent ourselves to ourselves, and what is the material and political force of our representations?

Think of it this way. Much of the literature on “political correctness” in the past few years has focused precisely on the production of elaborate euphemisms, “nonjudgmental” phrases that are easy to parody: differently abled, vertically challenged, feitically compromised. It’s weird that there should have been a national scandal and media feeding frenzy about this kind of thing, not only because it’s relatively innocuous as social changes go but especially because it’s been going on for decades, ever since “Negroes” became “black” and congresswomen asked to be called congresspersons. Of course, some of these semantic niceties are trivial, and of course some of them amount to rearranging the deck chairs on the Titanic—haggling over “physically challenged” or “differently abled” while Congress considers repealing both the Americans with Disabilities Act and the Individuals with Disabilities Education Act. For its part, the Down syndrome community has its own versions of these disputes. As far as I understand the current status of our language, it’s more proper to say “child with Down syndrome” than to say “Down syndrome child,” on the grounds that the child should come first. We’ve even been known to have heated arguments that center entirely on an apostrophe, bickering over whether to say Down or Down’s (the issue here having to do with whether our children should be semantically possessed by J. Langdon Down, as if they were DS versions of Jerry’s Kids). And we never, never say that someone “suffers from” or “is afflicted by” Down syndrome, because it’s preposterous to speak as if you know someone is “suffering” from his or her disability.

As this book demonstrates, I care more about social policy than about “Down syndrome child,” more about whether Jamie can say possessive “s” than whether he is marked by one. But you can talk about potatoes and tomatoes all you want; I see no reason to call the whole thing off. In our society, representation matters. Some linguistic differences, like some cognitive or genetic differences, are indeed too tiny to make a difference, but some can help to make all the difference in the world. Put that another way: If Steven Pinker is right in suggesting that “once the message gets out, the language will change accordingly,” then how can the message get out in the first place, except by way of the medium we call “language”?

I don’t mean “language” here in the restricted sense that Hamlet uses when he’s asked what he’s reading—“words, words.” Visual representations are a language, too, which is why we can “read” them. In the 1950s, one of the textual instruments that fundamentally changed the “normal” person’s perception of people with Down syndrome was Angel Unaware, Dale Evans Rogers’s memorial book about her daughter Robin, who was born with Down syndrome and died of mumps at the age of two; in the 1990s, one of those textual instruments was the character of Corky, a teenager with Down syndrome played by Chris Burke on ABC’s prime time TV series, Life Goes On. Whatever the differences between them, these representations were effective because they made it possible for nondisabled folks to imagine, understand, and sympathize with people who have Down syndrome. For some reason we don’t yet understand, we seem incapable of empathizing with other humans in the abstract, and we need to have them represented to us before we can imagine what it might be like to share their feelings and their dreams. Part of the burden of representation, for human populations that have long been “dehumanized,” is precisely to demonstrate that “dehumanized” people do in fact have feelings and dreams—just as you do.
Jamie dreams, too. He knows he does—or at least he says so. He likes to pretend to be asleep, and he likes to pop up and say, "Wake up!" Lately, he especially likes doing this in Nick's bed. Last year, he made the epochal transition from a crib to the lower half of a bunk bed with Nick, and this year, he learned, much to my distress, how to climb up into Nick's half of the bunk. Somewhere along the way, he also learned what a dream is, and he learned it in part by seeing textual representations of dreams—one in the exquisite Japanese children's film The Adventures of Milo and Otis, from a scene where Milo the cat falls asleep in an owl's dreaming nest, and one in the book Sleepy Dog, in which the sleepy dog in question dreams that he is running and eating hot dogs. Jamie's gradual recognition of these scenes was almost tangible: So that's what's going on when I think I'm awake but I'm really asleep. What a revelation to know that other creatures do it, too. It wasn't long after Milo and Otis became Jamie's favorite film that I could ask him, upon greeting him in the morning, if he'd had a dream, at which he would perk up, say, "Hm!" and claim (in answer to my next question) that he'd dreamed about a whale and a dolphin. Although I have no doubt that whales and dolphins are important components of his private mental life, I place little faith in these reports of his. Still, I know he knows he can dream. And now you do, too.

The question of how we represent each other to each other, in other words, is both an aesthetic question and a deeply ethical one. The only thing odd about this is that we live in an age when aesthetics and ethics are considered—at least by the self-proclaimed "traditionalists" in my field, like Harold Bloom—to be two utterly different realms of value. But if we take a step back from our own century and look at the emergence of something called "aesthetics" in the seventeenth and eighteenth century, we'll find something curious. As literary historian and theorist John Guillory points out, the discourse of "aesthetics" was once deeply intertwined with other discourses of cultural value, like moral philosophy and political economy. Only recently—say, about two hundred years ago, when artists began working under market conditions vastly different from those which prevailed in the era of court patronage—did people start making the argument that aesthetic value was a form of value unto itself, referable to no other scale of evaluation.

In many ways this development was a welcome one, since it freed art (and criticism) from being judged solely for how it served the church or the state, but in one way it's given us a sadly impoverished way of talking about textual and visual representations—as if we could judge their "intrinsic" aesthetic value without any reference at all to their representational content. Such was the sorry outcome of the deliberations over the presentation of the United States' first Bollingen Prize for Poetry, awarded in 1948 to Ezra Pound for his Pisan Cantos. The poems in question contain some of the most revolting, virulent anti-Semitism ever put in verse form, and at one point Pound even says, in so many words, that the Jews are leading the hapless Gentiles to slaughter in great numbers. This is a strange thing to say under any circumstances, but in the wake of the Holocaust it might well be called obscene. Nonetheless, the Bollingen Committee, headed by T. S. Eliot, held that it was artistically illegitimate to judge a work of poetry for its "content." These were simply great poems, and could not be gauged by the same measure we use to evaluate mere "ordinary" language. Some fifty years later, this decision may look as obscene as the poetry it once glorified. Still, it would be a mistake to think that this kind of understanding of "the aesthetic" has passed from the scene. On the contrary, recent years
have seen a minor publishing industry form around the project of protecting the purity of “aesthetic value” from the depredations of depraved, politically correct critics like me who would dare to apply “extrinsic” criteria to mere textual representations.

Let’s pause a moment over the proposition that “representation” is always both a political and an aesthetic matter. After all, many humans do tend to live under governments that claim to be “representational,” and most of us tend to read texts (of whatever kind) with at least one eye on their representational content. Aesthetics was always a matter of discerning the beautiful, but until the nineteenth century, the project of discerning the beautiful was indistinguishable from the project of discerning the good. Aesthetic excellence involved the creation of artistic forms that were fit and pleasing (whatever that might mean); likewise, justice involved the creation of social forms that distributed goods in a way that was fit and pleasing (whatever that might mean). This link between aesthetics and justice did not necessarily produce either artistic or social forms we might consider pleasing today. For instance, the notion of the Great Chain of Being, which holds that everything has its proper place from lower to higher orders, could authorize brutal social hierarchies every bit as easily as it ranked the genre of epic higher than the genre of lyric on the grounds that the former dealt with more elevated subject matter. If you believed in the Great Chain of Being, as did most European intellectuals in the eighteenth century, you could very well believe as a result that it is right, just, and pleasing that the common people starve and freeze while we superior, learned folks sit in Baroque drawing rooms and discuss aesthetics with wit and discernment.

To say this is not to say that the ancient idea of aesthetics was by any means blinkered or primitive. It was simply a way of apprehending and evaluating our representations of the world and of each other. The purpose of art, as the Latin poet Horace famously put it two millennia ago, was to delight and instruct. Accordingly, it should not take much imagination to suppose that, under these criteria, art was supposed to instruct us about something, and to delight us for some reason. Thus, it would be no more illegitimate to applaud a work of art because it showed you the way the world was (or the way the world might be) than to applaud a work of art because it showed you that despite all their faults, humans can create artifacts of stunning and remarkable beauty.

Here in the twentieth century, whatever we may believe about aesthetics and politics, we Americans argue about representations all the time: the representation of poor people in Congress, the representation of Arabs in Disney movies, the representation of African-Americans in the wake of the O.J. trial, the representation of African-Americans who aren’t represented by the best lawyers that money can buy. In the past four years I have found that I have a vested interest in some of our representations, so much so that I now feel compelled to see any movie or read any book that depicts a character with a developmental disability. In practical terms, this means renting What’s Eating Gilbert Grape? from our local video store and looking again at One Flew Over the Cuckoo’s Nest. It means being disturbed that Educating Peter, a documentary about a boy with Down syndrome, inadvertently suggests that all kids with Down’s have behavioral problems; and it means arguing about Forrest Gump for a few hours with my parents.

My father, who spoke out against the Vietnam War as early as 1965, largely agreed with conservatives’ assessment of the film, but from the opposite side of the aisle. It was reactionary; it
pathologized the entire 1960s counterculture; it left the impression that antiwar protesters were foul-mouthed, ill-clad, violent adolescent jerks. "You saw the movie, Michael," he said to me on my last visit home. "Did you see Robert Lowell in the antiwar scenes? Did you see Martin Luther King saying he wasn't gonna study war no more? No. All you saw was an Abbie Hoffman caricature." I told my father he was absolutely right and that furthermore, the movie's last half hour was maudlin and manipulative beyond endurance, marked by not one but two heartrending deaths, almost pathetic enough to lead you to expect little Forrest Junior to be struck and killed by the school bus that picks him up in the final scene. But Dad, I said, I just don't have the emotional apparatus I once had. There's a great deal I find aesthetically objectionable about the film, on formal and on ethical grounds, but still, this is a movie that just might change the meaning of "mental disability" in our culture. From Sally Field's declaration "there is no normal" when she's told that Forrest is five IQ points below the norm, to Forrest's sag, pragmatist insistence that stupid is as stupid does, this is a movie that refuses any correlation between achievement and "intelligence." So for me, the question is not, What does this movie say about postwar American history? The question is, What bizarre turns in postwar American history have made it possible for Forrest Gump and The Bell Curve to appear in exactly the same cultural moment?

Representations matter. That's why advocates of the disabled are so concerned about polite words, popular movies, and visual and textual representations of every kind. Our world, as William Wordsworth once put it, is that which our eyes and ears half create and half perceive; and it is because Wordsworth is right that we need to deliberate the question of how we will represent the range of human variation to ourselves. Will we think it outrageous to hear of disabled children in regular classrooms, or odd to come across a child with Down syndrome modeling T-shirts in a flyer for Sears? Or will we think it objectionable to see no disabled children in regular classes, no children with Down syndrome in mail order catalogues? In either case, what will then become, to paraphrase Forrest's mother, of what we normally think of as "normal"?

Jamie has come a very long way since the days he spent supine in the ICU. He also has a very, very long way to go. He's just starting to learn to dress himself and to go to the bathroom, and once he manages that, his work is far from done. He will be a teenager before we know it, and we will have to talk to him about adolescence, sexuality, responsibility, and maturity. Not long after that, we will have to worry about whether he will live independently, whether he will find employment, whether he will live in a country that provides health care along with employment, or whether he will live in a country that discourages some of its poor and disabled people from working precisely because it is incapable of imagining national health care as something other than an evil, coercive government program. And then, when he's thirty or forty, we can begin to worry about the incidence of Alzheimer's in people with Down syndrome, and we can agonize over which scenario might bring us more emotional pain: the thought of our outliving him, or the thought of his outliving us.

Along the way, Jamie will learn that he has Down syndrome, and that although we do not know the limits to what he can achieve, we know that there are limits. Hardly a day goes by that I do not pause over this conundrum. It took the planet almost five billion years to create organisms that were conscious of being or-
ganisms. It took hominids another five million to produce children with Down syndrome who could grow up to know that they have Down syndrome. Only in the past few decades has there been a world in which people with Down syndrome know about Down syndrome—its biochemical causes, its developmental effects, and its various textual representations. What will come to pass, I wonder, when my child becomes a man, a man who knows he has a developmental disability that will be with him all his life?

I have read the words of adults with Down syndrome who say that they are tired of having Down syndrome, that they wonder what it would be like if they were born without a disability, that they’re proud of what they’ve accomplished but frustrated by the effort it takes them to fulfill their desires. One of the reasons I’ve read these words—aside from my vested interests—is that people with Down syndrome have lately begun to represent themselves in public, in books, on television. Here, for instance, are the words of Mitchell Levitz, who not only gives me the inspiration for this epilogue but also testifies to an emotional maturity greater than that of any hundred nondisabled adults I know:

I do want to drive, but it’s difficult for me to have the skills to drive. My father doesn’t see me driving until a certain age. Dad, he sees me driving at twenty-three, which is next year, but I think that’s not going to happen. I don’t think I’m gonna have the skills by twenty-three or twenty-four. Or at all.

There will be other methods of transportation. I don’t think I’ll ever get those skills. It’s difficult for me to face, but I’m learning to accept the fact that I may not be able to do some things that my sisters are doing. Which is a main fact which I will understand.

Not every adult with Down syndrome has Mitchell’s sublime equanimity, but if we’re concerned with the relation between social justice and textual representation, then that’s not important. What’s important is that in the face of incalculable odds, we humans have fashioned a social-political-discursive-medical-legal apparatus that not only produces better and better representations of people with Down syndrome but also produces textual representations of people with Down syndrome authored by people with Down syndrome. Chris Burke published his autobiography, Special Kind of Hero, in 1991; Mitchell Levitz and Jason Kingsley published their collaborative book, Count Us In: Growing Up with Down Syndrome, in 1994. Until these books appeared, people with Down syndrome had to rely for their representation on the talents and good will of people without Down syndrome; henceforth, Jason and Mitchell and Chris and their peers can—and will—speak in their own voices.

In these pages, I have tried to represent James to the best of my ability. I have done so in the belief that my textual representations of him might make his claims on the world as broadly and as strongly as possible. I know full well that textual representation is only one form of representation. Nothing I write will re-draw a political district; nothing I write will change the chemical composition of Jamie’s cells; nothing I write will affect his ability to hear. He has had, to date, two ear operations to combat chronic ear infections; and as I write, he sleeps soundly in the room next to our study, his aural passages kept clear by surgically implanted tubes. As he sleeps, and as I write, we debate the value of physical “treatment” of people like him: tongue surgery, vitamin therapy, nootropic drugs that combat the overproduction of oxidants and free radicals in the cells of persons with Down syndrome. And as he sleeps, and as I write, we debate the meaning of words like
“normal,” “retarded,” “disability,” and, underwriting all these, “justice.” My task, ethically and aesthetically, is to represent James to you with all the fidelity that mere language can afford, the better to enable you to imagine him—and to imagine what he might think of your ability to imagine him.

When Jamie was younger and just learning to feed himself, we eagerly anticipated the day when he would be able to eat at a “big” table—in a restaurant, in our dining room, in the houses of our friends. We used to say that we were setting a place for him at our table, and we meant it as literally and as metaphorically as our language would allow. In the past two years, as he’s grown, he’s learned to eat tacos, burgers, and pizza—and, more recently, potatoes, rice, and corn. He’s even learned to take vitamins. Most of all, though, he’s learned how to set a table. Although he folds the napkins badly and distributes the silverware somewhat randomly, he knows where to put the plates and where to get the forks, and he knows how to set his own place, with his own plate, with his own fork and spoon that say “Jamie.” My job, for now, is to represent my son, to set his place at our collective table. But I know I am merely trying my best to prepare for the day he sets his own place. For I have no sweeter dream than to imagine—aesthetically and ethically and parenthetically—that Jamie will someday be his own advocate, his own author, his own best representative.

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