The Meaning of Life

One thing in my world has changed radically over the past twenty years, quite apart from Jamie growing up to be big. When I published Life as We Know It, there was no such thing as “disability studies” in the humanities. Lennard Davis had published his groundbreaking book, Enforcing Normalcy, in 1995; Rosemarie Garland-Thompson published the collection Freakery: Cultural Spectacles of the Extraordinary Body in 1996; David Mitchell and Sharon Snyder published the collection The Body and Physical Difference in 1997; Simi Linton published Claiming Disability in 1998. These are generally regarded as some of the first major works in disability studies, and rightly so. But at the time I was writing my book, I had no idea that I might be contributing to a new academic field. I wanted to write something that would be more than just an account of Jamie’s life, something that explored the political, cultural, and philosophical implications of Down syndrome and intellectual disability. But I never thought of it as a book in “disability studies,” because disability studies didn’t exist.

I was also trying, in my way, to help make the world a more welcoming place for my son and everyone like him. Unsurprisingly, some readers responded to that aspect of the book by suggesting that I was “cheerleading,” painting a mostly shiny happy picture of Jamie’s early life. (For my part, when I go back and look at that book now, I am struck by how much sorrow and worry it testifies to.) And I suppose that people who cannot imagine the value and delight in raising a child like Jamie
will inevitably think of this book as more cheerleading, this time laced with accounts of literal cheering for his accomplishments at school and his victories in Special Olympics.

The odd thing is that despite the rise of disability studies as an academic discipline, a discipline to which I now claim some allegiance and to which I hope I have made a substantial contribution in my previous book, *The Secret Life of Stories: From Don Quixote to Harry Potter, How Understanding Intellectual Disability Transforms the Way We Read*, I suspect that I am more likely to find people who cannot imagine the value and delight in raising a child like Jamie in academe than outside of it. In one way that is not terribly odd, since academe values intelligence (or claims to) above everything else. In the humanities, Licia Carlson writes, intellectual disability has often been treated as "the philosopher's nightmare": "Rather than promoting ideals of assimilation and normalization, many who bring the intellectually disabled into the philosophical fold mark this group out according to its departure from the normal and highlight its profound otherness, its radical alterity." We are about to see just how right Carlson is. But in another way this phenomenon seems quite strange: in American popular culture, it seems to me, the public image of people with Down syndrome is pretty good, even if their representation sometimes takes the icky form known to theorists and activists as "inspiration porn." For the most part, when someone with Down syndrome is the sibling of an athlete or a celebrity, or when someone with Down syndrome accomplishes something substantial, the press coverage goes into heartwarming mode, and we as a society give ourselves a collective pat on the back for being inclusive, caring, and sensitive to difference and diversity. Whereas in the subfield of philosophy known as bioethics, things are decidedly bleaker. Which is why, for a couple of years, I would offer an academic lecture entitled "Bioethics: Much Too Important to Be Left to Bioethicists."

Bioethicists sometimes bristled at that title, so I suppose I should preface my argument with a hashtag such as #notallbioethicists. But the people I discuss are pretty mainstream, influential figures; they are not fringe characters housed in some makeshift Quonset hut adjacent to the main Bioethics Building. And I begin with a book I have mentioned
earlier, Jonathan Glover’s Choosing Children: Genes, Disability, and Design. On the book’s opening page, Glover asks:

Progress in genetics and in reproductive technologies gives us growing power to reduce the incidence of disabilities and disorders. Should we welcome this power, or should we fear its implications?

The answer turns out to be something like “welcome this power, with some reservations”; notably (and sensibly enough), Glover rejects the idea that there is a bright line between using genetic technology to restore or maintain a person’s “normal” level of functioning and using genetic technology to enhance functioning well beyond that level. His book can thus be seen as a reply to (or, at the very least, I teach it alongside) Michael Sandel’s The Case Against Perfection, which makes precisely that argument against “designer babies.” For Sandel, going beyond that “normal” level, blurry as the line might be, violates something important about our humanity; instead, Sandel insists that we must retain our “openness to the unbidden” and that the attempt to extend our mastery over uncertainty paradoxically diminishes our freedom. Glover, by contrast, argues that

it is common to say that genetic choices are acceptable when they are to avoid a disability or disorder, but objectionably “eugenic” if they are to enhance “normal” functioning. The medical boundary may seem the obvious line to defend against “designer babies.” But making some enhancements may add to flourishing as much as eliminating some disabilities. If we are not motivated by the ugly attitudes [toward disability], if what we care about is really not disability but flourishing, the medical boundary may be impossible to defend.

The medical boundary may be impossible to defend no matter what the rationale, because Sandel’s argument unfortunately relies on an unquestioned and highly problematic idea of the “normal.” I was struck by this reliance the first time I taught Sandel’s book to undergraduates, precisely because they unanimously agreed with Sandel: genetic and
medical interventions are OK if they are a means to restoring someone to a baseline of normal, but not if they are used to enhance our abilities and take us into the realm of comic-book superheroes. "Now I find this curious," I said in one class. "For ten weeks in this course you've challenged and historicized and deconstructed the idea of the 'normal.' You've learned how the idea of the 'normal' has served as the primary tool of oppression not only for people with physical and intellectual disabilities but also for gay, lesbian, bi, and trans populations. And suddenly now you want it back? Seriously?" Besides, what norm are we talking about? I have mentioned my need for reading glasses. Can I have restorative surgery that brings me back to the species norm for eyesight? And is 20/20 the species norm or the species ideal? And what of the fact that in my prime, my eyesight was closer to 20/15? Do I get that back instead of the species average? And as for the students who complained that we are "playing God" with these genetic and medical techniques, I presume they are not taking that attitude toward antibiotics.

Two things strike me as remarkable about Glover's book. The first is that he does not come to his pro-enhancement conclusion without taking into consideration a wide variety of accounts of the lives of people with disabilities. For instance, even though Glover begins a discussion of blindness by writing, "Since sight enriches our lives so much, it is hard not to see blindness as an obstacle to flourishing," he proceeds to recount the stories of John Hull, whose terror at going blind was gradually replaced by a wholly new and surprisingly pleasant sense of himself and his world, and of "S.B.," who became severely depressed after an operation restored his sight. "When blind he had lived with energy and enthusiasm," writes Glover, "but when given sight he lost his peace and self-respect." Glover's opening chapter begins from the premise that "since the 1980s, ethical debate about disabilities and disorders has been transformed by the participation of those who have these conditions," and he credits the disability rights movement with having "brought out the extent to which society's response to a medical condition contributes to whether or not it is a disability."

The second remarkable thing is that despite this seemingly careful consideration of the disability studies critique, Glover can nevertheless
write, in a later chapter, “In this book disability has been contrasted with human flourishing.” Obviously, if your goal is to enhance human flourishing, and you see disability as inimical to flourishing, there is no way to account adequately for the ways in which some people with disabilities might enjoy their lives more fully and thoroughly than some people without disabilities.

How does Choosing Children do this? How does it credit people with disabilities for having transformed the debate and then wind up back in the pre-transformation position of arguing that disabilities are to be contrasted with human flourishing? I think there are two distinctive problems with the book. One is that, like so many discussions of disability and bioethics, it conflates disability and disease at a key moment in the argument. The other is that it relies, at other key moments, on thought experiments and hypothetical questions that make no sense except in the “what if” world of bioethicists.

The first key moment involves Glover’s dismissal of what is known as the “expressivist” argument: “Choosing to have a child without certain disabilities need not come from any idea that disabled people are inferior. Nor does it entail that the world, or the gene pool, should be cleansed of disabled people.” This much is true; some prospective parents might feel, reasonably enough, that they are ill-equipped to raise a child with certain disabilities, and that this is more a judgment on them than on anyone with such disabilities. Moreover, Glover argues that we can contest the “ugly attitudes” toward disability so that such decisions about childbirth are not motivated by fear, prejudice, or stigma. Here, however, is where the argument gets knotty.

I think that, other things being equal, it is good if the incidence of disabilities is reduced by parental choices to opt for potentially more flourishing children. But we should not deny the potential cost to which the expressivist argument draws attention. And we should try to reduce that cost as far as possible.

To do this, we need to send a clear signal that we do not have the ugly attitudes to disability. It is important to show that what we care about is our children’s flourishing; that this, and not shrinking
from certain kinds of people, or some horrible prospect of cleansing
the world of them, is what motivates us. To think that a particular
disability makes someone's life less good is not one of the ugly at-
titudes. It does not mean that the person who has it is of any less
value, or is less deserving of respect, than anyone else.

There are two ways in which we can show this. One is by mak-
ing the comparison with other medical programmes. We want to
defeat cancer, not because we lack respect for cancer and want to rid
the world of them, but because of what cancer does to people. The
existence of doctors, hospitals, and pharmaceuticals is not an insult
to the sick, just a sign of the platitude that illness impairs human
flourishing. And the same goes for programmes that aim to reduce
the number of children born with HIV. The harm the expressivist
argument points to comes through communication. And so, if we
have the right attitudes, clear communication should reduce or even
eliminate the harm.

One might reasonably question whether thinking "a particular dis-
ability makes someone's life less good" is not one of the ugly attitudes
toward disability—or, if not "ugly," at least "unjustified." But what I want
to point out is that the analogy to cancer and HIV construes disability
as disease—indeed, as life-threatening disease. This seems to me to be
a decisive mistake. Are we racing to "cure" autism because it is like can-
cer? Do we want to "defeat" Down syndrome the way we want to "defeat"
cancer? Glover argues carefully against many of the ugly attitudes that
would stigmatize or seek to eliminate people with disabilities, but the
idea that disability is best thought of as analogous to cancer cannot be
called an "attractive" attitude.

As for those thought experiments and hypothetical questions: In his
chapter "Parental Choice and What We Owe to Our Children," Glover
relies on the work of influential bioethicist Derek Parfit. At one point
Glover discusses a hypothetical question in the context of determin-
ing what counts as a life worth living. In the course of asking whether
"prospective parents [should] be under some moral pressure, at least,
to consider whether it is right to bring into the world a child whose
life is, by a small margin, just worth living," Glover argues against the "zero-line view"—in which a life is just barely tolerable—in favor of a "minimum level" of flourishing. First, he poses an open-ended ethical question. "Some victims of horrendous abuse as children may later still find their lives worth living and be glad to have been born. Does this mean that a couple with a persistent record of terrible child abuse should still be serious candidates for fertility treatment? Should there not be some minimum level above the zero line?" This should make us squirm: Who among us wants to approve that couple for fertility treatments? But wait. How do we apply that question to matters of genetics and prenatal screening?

By way of bioethicists' thought experiments:

Many think the zero-line view sets the standard far too low. Where should the minimum level be set, and on what basis? Frances Kamm has suggested the line be normality. She discusses a hypothetical case (introduced by Derek Parfit) of a woman who knows that, if she conceives now, her child will have a life worth living but will be mildly retarded. The woman also knows that, if she waits, she will be able to have a normal child. Frances Kamm accepts that, having a life worth living, the child with mild retardation will not be harmed by being created. But she thinks the woman will still have done wrong by not waiting. This is not just a comparative point, based on the fact that the alternative child would have a better chance of flourishing. She says "even if she could produce no child except a mildly retarded one, it might be better for her not to produce any" and that the woman "would do wrong to produce a defective child when she could have easily avoided it."

There are three things to be said about this passage. The first is that Kamm is saying, in so many words, that it may be better that children with mild retardation—children who have lives worth living—not be born. (See how blinkered and destructive the concept of the "normal" child can be?) The second is that the Parfit-induced hypothetical that leads Kamm to this stunning conclusion is totally implausible. There
is no scenario—I repeat, no scenario, none whatsoever—in which any woman knows that, if she foregoes conception now, she will have a normal child later on.

Earlier in the chapter, in the course of demonstrating that some children's disabilities truly do place crushing emotional burdens on parents, Glover had presented the case of Julia Hollander, mother of a child with significant brain damage: "The cause of her problem was not genetic," Glover notes. "When she was born, the placenta peeled away early, and this destroyed her cerebral cortex."

Imogen has fits, and will never walk or talk. She will need help with feeding. She will be in and out of hospital all her life. She cannot smile or make eye contact. She cannot communicate except by crying. Her expectation of life is about twenty years.

Imogen Hollander was sentenced to a life of much pain and many limitations—and Hollander had almost no social supports for her child. Glover is right to conclude that "such a severe disability brings out how the thought that a parent is 'selfish' to hope for a child without disability can be cruel and unfair. No one should be criticized for wanting to escape the problems faced by Julia Hollander"—or, for that matter, the problems faced by Imogen. But this example of severe disability caused by birth trauma should give pause to bioethicists who concoct scenarios in which women decline to initiate a pregnancy now in the assurance that they will have a normal child if they only wait.

The world in which bioethicists propose such things, the world in which Kamm can chastise a woman who produces a "defective" child "when she could have easily [...] avoided it," is a world without birth trauma, without conditions undiagnosable before birth (autism, pervasive developmental delay), without any sense of contingency—let alone an openness to the unbidden. Such what-if hypotheticals profoundly distort what it is like to contemplate having a child who may have a disability; indeed, they distort what it is like to have a child.

So the third thing to be said about this discussion is that bioethics is much too important to be left to bioethicists.
I focus on Glover—and I teach his book—not because he is the most emphatic of the pro-enhancement bioethicists but because he is one of the most moderate. It is not hard to find, in the “let a thousand enhancements bloom” camp, people who not only advocate unregulated genetic engineering but deride skeptics as Luddites and superstitious fools. And then there is the “transhumanist” group, who can’t wait until we all fuse with computers and solve everything. That sounds like a party I will be happy to miss.

None of the advocates of enhancement are deterred by counterarguments that their programs and visions amount to a form of eugenics. For them, the evil aspect of eugenics, from the early days of social Darwinism to its culmination in the Holocaust, was that it involved state coercion—not that it promoted deeply mistaken and ultimately catastrophic beliefs about genetics, evolution, and disability. This time, we are assured, we have the science all figured out, and we owe it to ourselves and to the future of our species to let people choose whatever enhancements they desire—more or less. This position is commonly known as “liberal eugenics,” and the term is not meant as a criticism. It accurately expresses the position that for its proponents, eugenics would be perfectly all right—indeed, a great good—if only it did not involve state officials, laws, and institutions. Glover does not go quite that far; he endorses Joel Feinberg’s idea that, as a species, we have “a right to an open future,” one key component of which is the permission for individual parents to choose what they believe to be best for their children. (This might also be part of Glover’s response to Sandel, even if Sandel is not explicitly addressed in Glover’s book: You want an openess to the unbidden, you say; all right then, I’ll see you an individual’s openess to the unbidden and raise you a species’ right to an open future.) But Glover acknowledges that an untrammeled, free-market liberal eugenics might be undesirable:

Could leaving people free to choose genes for their children at the genetic supermarket have serious social costs? If so, we may need a regulated market, on a European model. On this system, there
would be no state plan to change people's genes or to improve the
gene pool, but there might be limitations on genetic choices thought
to be against the public interest. Social intervention would act only
as a filter. Which choices, if any, should be excluded would be part
of democratic debate.

On one hand, this position is considerably more circumspect than
that of famed biologist James Watson, who reliably embarrasses himself
every few years by delivering himself of the opinion that African people
are inferior to the rest of the species, that it would be desirable to screen
for "pretty" girls and to abort fetuses found to be gay, and that "you
would have to be crazy to say you wanted" a child with Down syndrome,"because that child has no future." As Watson put it in 2003, "I am
against society imposing rules on individuals for how they want to use
genetic knowledge. Just let people decide what they want to do." Glover
cites this remark and takes his distance from it—hence his admission
that we may need "a regulated market, on a European model." But on
the other hand, Glover's position is remarkably vague—and remark-
ably naive, politically. Apparently, the mechanism that will determine
which enhancements are acceptable will be democratic deliberation—
not just on a European model, but everywhere on the globe, in order to
thwart "genetic tourism" as people shop for enhancements their own
nations forbid.

Glover acknowledges the difficulties of regulating such a market.
Surely we would find ourselves in the world of Gattaca before we knew
it, screening not only for all "major inheritable diseases" but also for
things like myopia, baldness, obesity, and addictive susceptibility—all of
which are mentioned, and treated as unambiguously undesirable, by the
film's genetics counselor, who just happens to be black (the surprising
implication is that he lives in a society obsessed by genetics but utterly
indifferent to race)—and, as no one but me seems to have noticed, bald.
Lest I sound like one of those wearisome scolds who wanders into ge-
tetics debates from their homes in the humanities armed with nothing
but copies of Huxley's Brave New World and Hawthorne's short story
"The Birthmark," I assure you that the *Gattaca* scenario is well within the realm of possibility in Glover's book. He writes:

Sometimes disabilities arouse a special revulsion, creating a desire to cleanse the world of them. But, without this special revulsion, the case for reducing the incidence of disorders and disabilities is that they are obstacles to people having flourishing lives. And this is equally a reason for making other choices, including genetic ones, to remove non-medical impediments to flourishing. Eliminating a genetic disposition to shyness or laziness might help someone flourish, as might making them more cheerful or boosting their ability to sing or to learn languages.

Shyness? Laziness? These are traits to be eliminated from the species now? But some of my best friends are shy and lazy! Why, I myself spent the first twelve years of my life being shy, and the next twelve being lazy!

I joke, but this is very serious business. I should make clear that I have no problem with people taking medication for severe shyness or social anxiety—or for a wide range of psychiatric conditions from depression and PTSD to schizophrenia. (Indeed, my late mother once refused to believe that I was the only member of our family not taking some form of medication.) I strongly suspect that such medications are overprescribed, especially to parents of unruly children, but I have no doubt that the underlying conditions they seek to mitigate are real and that palliative measures are not to be rejected merely because they might be applied too widely. I do, however, have grave doubt that ordinary shyness or laziness constitute threats to human flourishing so substantial that we as a species would be better off without them. And I note that this anti-shyness-and-laziness position follows, curiously, from Glover's conflation of "disorders and disabilities," which is very close to the conflation of disability and disease entailed in the analogy between disability and cancer. It appears that once you start enumerating human traits you find undesirable, and once you start thinking of them as if
they constitute disorders or diseases, you just can’t stop yourself from imagining what it would be like if we could “cleanse the world” of them.

Again, there are many diseases I would like to see disappear, and I can say this without sounding like Victor Frankenstein, dreaming that he might “banish disease from the human frame, and render man invulnerable to any but a violent death.” And one of the traits enumerated by Gattaca’s genetics counselor, and targeted for screening, happens to be a propensity for violence—something whose elimination I would find relatively unproblematic, though I strongly doubt we will locate a genetic sequence for violent temper, and I tend to think that some forms of violence (though not all) are responses to severe social injustice. But thinking of shyness and laziness in these terms, as obstacles to flourishing, seems to me another category error. It’s not quite as bad as thinking of disability as something that is to be contrasted with human flourishing, but it’s still not a good thing to think with.

In 2012, I had the good fortune to meet someone who could explain for me exactly why: Glenn Treisman. It was at the Conference on World Affairs in Boulder, Colorado, an extraordinary week-long festival of panels on “everything conceivable” (as it quite accurately bills itself). I was assigned to eight panels in four days, on subjects ranging from Shakespeare to sports to “Ethics and the New Genetics,” for which my copanelists were Joseph McInerney, director emeritus of the National Coalition for Health Professional Education in Genetics; Vivian Siegel, director of Scientific Education and Public Communications at the Broad Institute of MIT and Harvard; and Treisman, professor of psychiatry and behavioral sciences and internal medicine at the Johns Hopkins University School of Medicine. The presentations of my copanelists were every bit as terrific as you might imagine, and unlike every academic conference I have ever attended, everybody kept to the strict time limit. (In every panel!)

Treisman’s talk swiftly and decisively put to rest the claims of “liberal eugenics,” pointing out not only that we have no idea how to go about eliminating things like shyness or laziness but also, and more important, that we have no idea whether some of the traits we now consider undesirable or harmful actually have survival value for us as a species. In other words, for all we know, our capacity for depression is what got us
through the Pleistocene. Likewise, for all we know, shyness and laziness are, in evolutionary terms, two of our saving graces.

Just over a year earlier, in January 2011, I had a similarly instructive exchange, this one online, courtesy of the National Humanities Center’s On the Human project. My contribution to that multiyear project was a version of the critique of Glover I have offered here, and it drew this response from Tom Shakespeare, one of the founders of the disability rights movement in the United Kingdom (and yes, a distant descendant of that Shakespeare). I will quote it at length, because it underlies much of my thinking in this book:

To me, disability is not neutral, it is a decrement in health. Not a tragedy, granted, but not just another difference like sex or ethnicity. Disability may sometimes open one up to other possibilities (as might poverty, HIV and divorce) but that does not make it less of a predicament. Of course, environments contribute mightily to the burden, and it is a matter of justice for us to try and lessen those physical and attitudinal barriers. People are indeed disabled by society—but by their bodies too. (I also find the distinction between illness and impairment ultimately unhelpful.) Those of us born with our disabilities are used to our form of life, and we rarely bother worrying about it—we cannot imagine any other way of being. But ask any disabled person how they would feel about losing further abilities, and most would be less sanguine, I think. (I was broadly happy to spend forty plus years with restricted growth. But I regret deeply spending the last couple of years as a paraplegic, despite the fact that I am probably as happy today as I have ever been.)

I would like to deconstitute the disability category a little. I think there is a danger in equating disability, as some utilitarian bioethicists do, with all the worst and most difficult forms of life—Tay Sachs or Lesch Nyhan or other profound limitations in which the possibility of flourishing seem[s] truly remote. But I also think there is a danger, as some disability advocates do, of equating disability with the other end of the scale—with Deafness, or dwarfism, or Down syndrome, conditions which hardly diminish flourishing at all.
Where I part company with Jonathan Glover is his perfectionism—his hope that we can not only put disability behind us, but that we can, and should, improve on average human nature and human embodiment. My messy, possibly incoherent, position is that we should accept a measure of diversity and difference, because human frailty is unavoidable, but that where the balance tips into suffering and restriction, we should do whatever we can to avoid it. While still valuing, supporting and including all those individuals who end up, despite our efforts, with profound disability.

Shakespeare misreads me in one important respect, attributing to me the position that disability is never a decrement in health (my actual position: sometimes it is and sometimes it isn’t). And his critique of the “social model” of disability, expressed here as skepticism about the usefulness of the distinction between illness and impairment, will be troublesome for many people in disability studies. (Shakespeare was one of the people who developed the idea of the social model of disability decades ago; he now finds that model inadequate for people with intellectual disabilities and psychiatric conditions, and I think he is right about that.) But I love the rest of this rich and thoughtful response.

Shakespeare’s comments on “additional disability” strike me as salutary reminders not to romanticize disability or to pretend that all disabilities are merely “differences” like other identity categories. (Think again, as I have, of Jamie almost losing a foot.) And yet even Shakespeare’s description of his paraplegia is ambivalent: he regrets being paraplegic after living his life happily with achondroplasia . . . and yet he remains as happy as he has ever been. As for his final paragraph, I agree with every word. But it’s the middle paragraph I cherish most, for its enumeration of conditions that “hardly diminish flourishing at all”—Deafness, dwarfism, and Down syndrome. That is the whole enchilada, right there. If you see things like Deafness, dwarfism, and Down syndrome as unremarkable aspects of human diversity and difference, part of ordinary intraspecies variation, you will never make the mistake of thinking that their eradication constitutes an unambiguous species-wide good. You will never make the mistake of thinking of these conditions in the terms you
would apply to fatal diseases. And you will never embarrass yourself in public by proclaiming that people with these conditions have no future.

Yet I know there is not a chance in the world I will ever be able to win universal support for this position among my fellow humans. For every Tom Shakespeare who says, "Meh, Down syndrome, no big deal," there will be dozens of people, some of them prospective parents, who think of Down syndrome with horror and revulsion and who will seek prenatal testing precisely to ensure that they will not give birth to a child with trisomy-21. Over the past twenty years, I have taken every available opportunity to say two things about this: the right of a woman to terminate a pregnancy must be respected, regardless of the reason (this is an especially important argument in states whose legislatures are trying to outlaw abortion when the fetus has Down syndrome); and people shouldn't be snookered into believing that prenatal screening can catch every kind of significant disability. I realize, however, that for some people this second argument amounts merely to kicking the can down the road a piece. Yes, yes, screening can't catch everything, they will say. But it can very well catch Down syndrome and other genetic anomalies, and that's precisely why we're availing ourselves of it—because we don't want our children to have anything like that.

In my contribution to the fourth edition of the Disability Studies Reader, edited by Lennard Davis (an essay on genetic screening and democratic deliberation), I mention the work of Rayna Rapp, whose 1999 book Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America has been such a huge influence on the way I think. Indeed, one reason it has made such an impact on my thinking is that it introduced me to a wide array of people who do not think as I do. Some of them go ahead with pregnancies that I think might warrant termination, as when one woman received a diagnosis that the fetus had partial trisomy-9; some of them decide that other anomalies might be fine but Down syndrome is not, because, as one woman puts it, "If I had this baby at 44, and it had Down's, who would inherit it? Oh, not Alex, not Stephan—it's always the girls, the girls who get caught. If I had that baby, it would be Livia who inherited the family problems." Still others decide, "Meh, Down syndrome, no big deal," while others tell Rapp,
“Having a 'tard, that's a bummer for life," and that if the baby "can't grow up to have a shot at becoming the president, we don't want him."

That last remark comes from prospective parents whose fetus was diagnosed with Klinefelter syndrome, a trisomy involving an extra X chromosome. It is even milder in its effects than Down syndrome; here's the Genetics Home Reference description of it, courtesy of the National Institutes of Health.

Affected individuals typically have small testes that do not produce as much testosterone as usual. Testosterone is the hormone that directs male sexual development before birth and during puberty. A shortage of testosterone can lead to delayed or incomplete puberty, breast enlargement (gynecomastia), reduced facial and body hair, and an inability to have biological children (infertility). Some affected individuals also have genital differences including undescended testes (cryptorchidism), the opening of the urethra on the underside of the penis (hypospadias), or an unusually small penis (micropenis).

Older children and adults with Klinefelter syndrome tend to be taller than their peers. Compared with unaffected men, adults with Klinefelter syndrome have an increased risk of developing breast cancer and a chronic inflammatory disease called systemic lupus erythematosus. Their chance of developing these disorders is similar to that of women in the general population.

Children with Klinefelter syndrome may have learning disabilities and delayed speech and language development. They tend to be quiet, sensitive, and unassertive, but personality characteristics vary among affected individuals.

Personality characteristics vary among all individuals, one might add, including people who will abort a pregnancy if they believe their prospective child does not have a chance of becoming president of the United States.

I have thought long and hard about that remark as Jamie has grown, precisely because I never expected him to become president and never
imagined that as a criterion for a life worth living. In my *Disability Studies Reader* essay, I wrote, "I remain unpersuaded that there are transcendent moral virtues to be advanced by compelling such parents to bear children with disabilities, even though the disabilities in question are relatively benign; indeed, I shudder to think how such parents will treat their disabled children if they are compelled to bear them against their will." On my blog, I was somewhat more colloquial, as befits the discourse of blog posts: "In both the deontological and utilitarian traditions," I suggested, parents who say such things "are technically known as 'assholes.'" But the underlying point should be clear: one reason I argue that prospective parents should be trusted to make their own decisions about prenatal screening is that some of them may decide that they cannot be enlightened, humane, and welcoming parents if it turns out that their child has a disability. And one reason I argue that people should have access to prenatal screening but not to genetic enhancement is (you guessed it) that some of them do not, in fact, have enlightened, humane, and welcoming attitudes toward children with disabilities.

At the same time, I agree with Tom Shakespeare that Tay-Sachs and Lesch-Nyhan are "profound limitations in which the possibility of flourishing seem[s] truly remote," and I do not see any reasonable grounds for preventing prospective parents from screening for those conditions. I think they are more accurately described as diseases rather than disabilities, and I place them in the category of diseases whose eradication would constitute a species-wide good. This position has earned me sharp criticism in some disability studies circles. I remember a forum at Columbia University in 2010 at which I was told that my advocacy of screening for Tay-Sachs was indistinguishable from the Nazi designation of "life unworthy of life," *Lebensunwertes Leben*, which underlay Hitler's extermination of the disabled. It is never a pleasant experience being likened to Hitler, though analysts report that on the Internet, someone is likened to Hitler three thousand times every minute. (Perhaps I exaggerate, though Godwin's Law clearly states that any long comment thread on the Internet inevitably produces a comparison to Hitler.) I replied, calmly (I hope), that I was not saying that children with Tay-Sachs disease were unworthy of life. I was simply acknowledging that children
with Tay-Sachs experience short, sometimes excruciatingly painful lives in which they gradually succumb to a devastating degenerative disease and that you, my aggrieved interlocutor, do not have the moral authority (nor do I, and nor does anyone else) to bar anyone from seeking prenatal screening for the condition.

I could also have referred my interlocutor to the remarkable writing of Emily Rapp (no relation to Rayna), whose account of her son Ronan, in the New York Times and in the 2013 book At the Still Point of the Turning World, is testimony to the fact that the parent of a child with Tay-Sachs can feel as much love and tenderness as any other parent. Rapp’s work also demonstrates that the parents of a child with Tay-Sachs can feel as much anguish and sorrow at their child’s death (Ronan almost made it to his third birthday) as anyone else, and can find powerful and enduring significance in their child’s brief and difficult life. But that is not the same thing as suggesting that Ronan’s life arguably fell below that “zero line” at which life is, by a small margin, just worth living—as Rapp herself has suggested.

In a 2012 essay for Slate, she wrote:

I love my son more than any person in the world and his life is of utmost value to me. I don’t regret a single minute of this parenting journey, even though I wake up every morning with my heart breaking, feeling the impending dread of his imminent death. This is one set of absolute truths.

Here’s another. If I had known Ronan had Tay-Sachs (I met with two genetic counselors and had every standard prenatal test available to me, including the one for Tay-Sachs, which did not detect my rare mutation, and therefore I waived the test at my CVS [chorionic villus sampling] procedure), I would have found out what the disease meant for my then unborn child; I would have talked to parents who are raising (and burying) children with this disease, and then I would have had an abortion. Without question and without regret, although this would have been a different kind of loss to mourn and would by no means have been a cavalier or uncomplicated, heartless decision. I’m so grateful that Ronan is my
child. I also wish he'd never been born; no person should suffer in this way—daily seizures, blindness, lack of movement, inability to swallow, a devastated brain—with no hope for a cure. Both of these statements are categorically true; neither one is mutually exclusive.

This is precisely why we need, following Tom Shakespeare, to "deconstitute the disability category": Ronan Rapp's experience of life was nothing remotely like James Bérubé's. And this is precisely why we need to leave the decisions about prenatal testing and so-called "selective" abortion to the women who will be most affected by them.

And here, at last, is why I don't see Down syndrome as something whose eradication from the population would be a good thing. It is not because people with Down syndrome bring joy into "our" lives. Though they may and often do, as Jamie has often done in my life, we must treat all people as ends in themselves, not as means to an end (even if that end is the augmentation of our collective joy and our sense of human potential). And it is not because anyone or anything in this world has "intrinsic" worth; things and people have only the worth we assign to them. That is what "value" is: it is the expression of a social relation. Rather, it is because on the whole, people with Down syndrome enjoy being here, now that we are no longer institutionalizing them and consigning them to horrible lives in unspeakably filthy conditions. Jamie, for his part, is so far above the zero line he might as well be airborne. The world is a better place for his being in it. I am quite sure of that, but the most important metric is his enjoyment of the world, not the world's enjoyment of him.

Am I cheerleading? Am I sugarcoating? I don't think so, but just to make sure, I will admit the obvious: raising Jamie was more difficult than raising Nick. It remains more difficult to this day, insofar as we are not raising Nick anymore. As I hope this book has made clear, Janet and I worried far more about Jamie's health, his development, and occasionally his whereabouts than we worried about Nick's. And there were smaller difficulties along the road. One was Jamie's fascination with wads of gum people had left under countertops and tables in practically every public
place we entered. You could say that the real problem is that people leave their goddamn gum under countertops and tables in practically every public place, and you would be right. But it still required us to carry hand sanitizer for Jamie at all times. Another was his occasionally inappropriate behavior in crowded public spaces. On one trip to New York when he was eighteen, I had to stop him from swinging a glass bottle around a busy midtown street, and when I took him to the culinary mecca that is Katz’s Deli on the Lower East Side, he very maturely ate only half his gargantuan pastrami sandwich, leaving the rest for later—and then got up and pranced to the men’s room, nearly colliding with a waiter laden with a tray of many, many pastrami sandwiches. That time, I took him by the shoulders to stop him in his tracks and hissed, “Be! An! Adult!” No doubt some of the diners in Katz’s that evening thought I was a Bad Dad haranguing his disabled son. But Jamie had to learn that there are some places in which it is not OK to cavort, just as he had had to learn, a few years earlier, that it is not OK to laugh when someone falls down and gets hurt. These are some of the indices of his maturity as a young man: he does not laugh at others’ misfortunes, he is circumspect in public places, and he has weaned himself from his interest in touching other people’s wads of gum. And then there are other difficulties and challenges that, like the story of the day Jamie was sad, will always be Jamie’s private business.

I realize that such incidents and issues can arise with almost any child, and that we are very far indeed from talking about the soul-devouring struggles of a Julia Hollander or an Emily Rapp—or, for that matter, a Marianne Leone, whose brilliant, searing memoir, *Jesse: A Mother’s Story*, offers an unflinching look at what it is like to be the parent of a child with a seizure disorder, a wonderful child who dies in his sleep at the age of seventeen. No one, I suspect, not even the biggest assholes in the whole wide world of parenting, thinks, “I will terminate this pregnancy if there is a reasonable chance that my child might someday collide with a waiter in Katz’s Deli.” I should add that Jamie’s moments of inappropriate behavior are relatively rare, and that he himself is faintly horrified by children who misbehave egregiously in public. I recall the dinner in a Friendly’s restaurant near Harrisburg in 2005, just after Jamie’s volleyball tournament and his first night away
from us, during which he and I watched a toddler crawl all over his family’s table, squealing and wreaking havoc with the meal. Jamie looked at me questioningly: he seemed to be asking, *Is this a thing? Can people really do this?* To which I replied, “Jamie, believe me, you were never like that. You were such a well-behaved kid in restaurants; you always were.” More recently, one night twenty-two-year-old Jamie announced to us out of the blue that “crying babies piss me off.” (“He was very clearly trying out the phrase,” Janet said as we talked this over that night.) A few days later, when we saw *L’Incroyable Voyage des Papillons* at Le Musée de la Civilisation in Ottawa, we endured one of those crying babies for the final five or ten minutes of the film. When the family was out of earshot, I asked Jamie, “Did that crying baby piss you off?”

He turned to me with a raised eyebrow as we got on an escalator. “You know it,” he shot back.

Or take the classic parental struggle of trying to get your kid to wear appropriate winter outergear. Once again, we are in the realm of the ordinary, the mundane, the quotidian; we are not in the world of Julia Holland, Emily Rapp, or Marianne Leone. Me, getting Jamie ready to head out to work one morning: “Jamie, it’s 28 degrees outside—you need to wear your puffy jacket.”

Jamie, blowing me off: “Leather jacket will do.”

Me, sighing, having gone through years of this with both children: “Jamie, the leather jacket will not do. It is freezing outside.”

Jamie: “Michael! It is not freezing.”

Me: “Excuse me? It is literally freezing. It is 28 degrees. You know water freezes at 32.”

Jamie, snorting: “That’s a hoax.”

So much for the lessons of seventh-grade chemistry! Somewhere along the way, Jamie had become a climate change denier, at least with regard to the freezing point of water. But the only notable thing about this exchange, involving a young adult with Down syndrome who has the same resistance to prudence in cold weather as any number of his non-disabled peers, is that it represented Jamie’s first use of the word “hoax.”

There is no question that Jamie is relatively easy to take care of, as people with disabilities go. I have lost track of the number of times I
have been told that Jamie is not representative of people with Down syndrome because he is “high-functioning” (a phrase I can’t abide, since it evokes a hierarchy that makes some people with disabilities more “acceptable” than others). But I have never argued or imagined that Jamie is representative of people with Down syndrome. I have insisted only that Jamie is Jamie. In fact, I strongly endorse Shelby Peacha’s suggestion that there is no one quite like him. And yes, he is really quite bright. He has his limitations, but within those limitations, he can astonish. As his mentor Lindsay said, he never ceases to surprise all of us with his abilities. A case in point: On a vacation in Scotland in 2015, Janet, Jamie, and I stopped into a lovely pub in the Highlands town of Stirling. We were hoping for lunch, but the wait was half an hour. Janet clearly wanted to stay and spend a pleasant half hour at the bar; I demurred, saying I just couldn’t manage to play animal hangman for thirty minutes at the bar and then another round at a table. (I was a bit grumpy that day. So was Jamie.) So that’s the “limitation” part: He has his routines, and most of the time, they must be honored. Within that limitation, the animals Jamie would ask us to identify, letter by letter, would include creatures like the lowland anoa, the Sumatran muntjac, and, your favorite and mine, the Indian crested porcupine. That’s the “astonish” part.

So if I were faced with Emily Rapp’s question—I love my son, but would I have him again, knowing what I know, or would I have terminated the pregnancy?—I would answer in a fraction of a heartbeat. I would do it all over again, joyfully. I am grateful for Jamie’s presence in my life, I take pride in his accomplishments, and I enjoy his companionship. I can say the same of Nick, in precisely the same terms—which, for me, settles the question of Jamie’s value as a human being.

I have no regrets about having Jamie; quite the contrary. But at one point in our lives together, I did feel a pang of regret about the way I was raising him. It was at the 2005 conference of the Canadian Down Syndrome Society, and one of the keynote speakers was talking about how and why we need to attend to the “spiritual development” of children and young adults with Down syndrome. One of her examples involved bringing a
young man with Down syndrome to the cemetery in which his grandparents were buried, so that he could come to terms with their death.

I caught my breath. Jamie’s maternal grandfather, Bradford Lyon (known to his four grandchildren as “Duke”), had died the previous autumn, and Jamie had watched attentively as Janet grieved through Duke’s final year. He had also comforted his aunt Cynthia as she sobbed through the funeral service. But I had not spoken to Jamie about Duke since his death. I had done what I could to prepare him for the fact that his beloved grandfather, with whom he got on so famously from infancy to tweendom, would no longer be with us. In the seven months between the funeral and the conference, though, I had not brought it up. Jamie very clearly had taken his grandfather’s death hard, and I did not want to make things any harder for him. He and Duke were exceptionally close, as Jamie’s response to this fifth-grade writing assignment can attest (he composed it with the help of his teachers):

If my parents went on a trip, I would like my grandfather to stay with me. We could go to the movies and eat pizza. We could go out to lots of restaurants. He could take me swimming and we could go shopping. We could go to Lowe’s and buy Christmas gifts. We could go to Target and buy socks and underwear. We could shop at Best Buy and get videos. After we are done eating and shopping, we could go to see the fish at the Hub at Penn State. He could also take me to the playground.

To that point in his life, Jamie had never experienced the death of a family member. Then, too, there is the fact that I do not often speak or think of our “spiritual” development. I do not often speak or think of spiritual anything. I am a devout agnostic, though reasonably literate in Catholic intellectual and religious traditions, and I fear that if I say the word “spiritual” my tongue will cleave to the roof of my mouth.

But this was a form of “spiritual” development I recognized, and I immediately regretted not being more aware of Jamie’s possible needs in this respect. I had told him, quite honestly and accurately, that no one knows what happens after we die: some people believe in a heaven and
hell, some people believe in a less punitive afterlife, some people believe we return as other humans or forms of life, some people believe we become part of the universe, and some people believe that there's nothing after death, that we just die. I had not dared to ask him what he thought and felt about all this.

So at some point during the conference, I asked Jamie what he thought about Duke—and the fact that Duke was no longer with us. He did not want to talk about it.

Fair enough, I thought. I told Jamie he could talk to me about it anytime (just as he could always talk to me about being sad, a potentially related subject), and I left it at that.

Later that summer, he wanted to talk about it. Without warning, without context. We were in the men's locker room at Welch Pool (and why have so many of our heart-to-heart talks taken place after swimming? Is there something about swimming that is tied to Jamie's spiritual development?), and as we dried off and put on our clothes, Jamie said, "You know...maybe Duke could come back."

I fought back tears. "Oh, oh, Jamie," I said. "That's the hard part. That's what everyone has so much trouble with. We don't know what happens after people die, but we do know that the people don't come back. It really is final, for once and for all. And that is why we have religion, and beliefs about God and the universe—to help us deal with the fact that the people we love die and don't come back, and that every living creature dies and doesn't come back. I hope you can understand this. I hope you are not waiting for Duke to come back. He can't come back, Jamie. I am sorry. I am so, so sorry."

Jamie waited patiently through this little disquisition on mortality. Today, I like to think of him tapping his foot and whistling, but I know he did no such thing. He was just waiting quietly for his father to stop talking. And when I stopped talking, Jamie put his hand on my shoulder, tilted his head, and gently said, "Michael. I said maybe."

I'm not sure how I retained my composure, but I had the presence of mind to remember that Jamie and I had just made our way through the scene in *Harry Potter and the Half-Blood Prince* in which Harry and Dumbledore encounter the Inferi, dead bodies reanimated by dark magic.

“Oh no, Jamie, that’s not something you would want. You would not want Duke to come back like that.”

“Or like zombies,” Jamie replied, totally getting the point.

“Or like zombies. Yes. Because zombies are just dead bodies with no spirit”—I said the word! And I was not smitten!—“like ghosts are spirits with no bodies. Jamie, we make up stories about ghosts and zombies because we do not know what happens after we die. But you would not want Duke to come back as a zombie.”

“No way,” Jamie agreed.

Suddenly I realized how to revive a cliché—if not a dead body. Duke lives in our memories. “Duke had a very lively spirit, Jamie,” I said. Jamie nodded again. “And you have his spirit too.”

“I do?”

“You do. Duke had a sweet, sweet heart, just like you. He was friendly to everybody, just like you. And he was a total goofball, just like you.”

Jamie laughed. This is, in fact, a completely accurate description of Bradford Lyon.

“And that is why you two loved each other so much. You have the same spirit. So in a way, Duke’s spirit lives in you.”

Jamie straightened up. It was almost as if I had promoted him to colonel. “It does?”

“It does. And of course we will always remember him, and as long as we remember Duke, his spirit is alive in our hearts.”

Jamie nodded emphatically. It was an impromptu sermon in a men’s locker room at a local pool, but it was the best I could do.

On that summer day in 2005, Jamie was asking some of the fundamental questions about what it means to be human. Why do we die? Can we come back? And he was expressing one of the fundamental emotions that make us human—love for one’s goofy, genial grandfather.

It is a truism, among people who love and care for humans with intellectual disabilities, that our interactions with people with intellectual disabilities lead us to startling and valuable perspectives on the meaning
of human life. That truism is a truism because it happens to be true. But it has some profound and unsettling corollaries for everything else we think we know. I am going to have to put this bluntly: I have become convinced that societies that incorporate and accommodate people with intellectual and physical disabilities are better than societies that exclude, ostracize, and seek to eliminate people with intellectual and physical disabilities.

I am aware that this belief disqualifies me from membership in the campus Cultural Relativist Club—and I am aware of why cultural relativism exists in the first place. For most of human history, the determination that X society is "better" or "more advanced" than Y society has not taken the form of the belief your society is superior to mine and I seek to emulate it, but, rather, that of my society is superior to yours and that is why I rule over you. It has also been made overwhelmingly by Western societies seeking to justify their domination of the rest of the peoples of the world, though the belief in one's own racial or ethnic superiority can also be found in the East and any number of areas in between. And the toxicity of this attitude is matched by its persistence, as William Henry demonstrated when he wrote, "It is scarcely the same thing to put a man on the moon as to put a bone in your nose."

But I am getting old and crotchety, and increasingly impatient with people who spend their lives justifying inequality and oppression, no matter where on the globe they might happen to live. After decades of thinking about the question, I am still failing to see why limitations on the sexual and political freedom of women or gays and lesbians are any less objectionable in one geographical location than in another; nor do I understand why the lives of people with intellectual and physical disabilities should be less valuable at one latitude and longitude than they are at another latitude and longitude.

This is not, you should note, grounds for American triumphalism and chest-thumping. In the twentieth century, the United States was among the very worst offenders against the principle of treating the disabled with respect and dignity. We embraced eugenics wholeheartedly, to the point at which our Supreme Court could craft a rationale for the involuntary sterilization of the so-called "feebleminded." We created
hellish institutions that shocked our colleagues overseas—and eventually shocked us, after a series of exposés and investigations forced us to acknowledge what we were doing. Even today, we have not really come to terms with the atrocity of MIT and Quaker Oats teaming up to feed irradiated oatmeal to children with intellectual disabilities at the Walter E. Fernald State School in Massachusetts. (If you haven’t heard about that experiment until now, that’s probably because we have still not really come to terms with it. Though in the late 1990s, MIT and Quaker Oats did agree to pay the experiment’s subjects $1.85 million in compensation.) Even today, we have not really come to terms with the killing of Ethan Saylor, the young man with Down syndrome who was wrestled to the ground and asphyxiated by police as he called vainly for his mother. (In fairness, the police were dealing with a hardened criminal: Saylor had tried to remain in a movie theater and watch a film twice without paying for the second showing.) And even today, we are failing to acknowledge how many people harmed or killed by tasers are people with disabilities—sometimes deaf people, who are punished for not complying with police orders they cannot hear.

I am weighing the United States by the same measures I would use with any country—not holding it out as a shining example. And by those measures, a capacious and supple sense of what it is to be human is better than a narrow and partial sense of what it is to be human, and the more participants we as a species can incorporate into the determination of what it means to be human, the greater the chances that we will enhance our collective capacities to recognize each other as humans entitled to human dignity—and the greater the chances that we will devise an adequate understanding of our profound interdependence with the nonhuman world, as well. As Jamie has reminded me time and again throughout his life, most Americans had no idea what people with Down syndrome could achieve until we’d passed and implemented and interpreted and reinterpreted a law entitling them all to a free appropriate public education in the least restrictive environment. With the help of that law, as well as with the help of his teachers and aides and family members and animal companions, Jamie got to the point at which he could meditate on life and death with the rest of us.
And I got to this point with the help of two feminist philosophers. One is Nancy Fraser, whose theory of democracy, derived in part from the German philosopher Jürgen Habermas, involves the idea of “participatory parity” and the imperative that a democratic state should actively foster the abilities of its citizens to participate in the life of the polity as equals. Fraser’s work does not address disability, and in one way, it shows: she writes as if the promise of democracy entails the promise to enhance participatory parity among citizens, which it does, and she writes as if we know what “participatory parity” itself means, which we don’t. This is why the promise of disability rights is so open-ended. Jamie has his place at the table, as I had hoped at the end of *Life as We Know It*, but who knows what will happen when everybody gets a place at the table?

The idea of participatory parity does double duty in Fraser’s work, in the sense that it names both the state we would like to achieve and the device by which we can gauge whether we’re getting there. For in order to maintain a meaningful democracy in which all citizens participate as legal and moral equals, the state needs to judge whether its policies enhance equal participation in democratic processes. Yet at the same time, the state needs to enhance equal participation among its citizens simply in order to determine what its democratic processes will be. This is not a theoretical quibble. On the contrary, the point is central to the practical workings of any democratic society. One of the tasks required of egalitarians is to extend the promise of democracy to previously excluded individuals and groups, some of whom might have a substantially different understanding of participatory parity than that held by previously dominant groups and individuals.

Put it this way: Imagine a building in which political philosophers are debating the value and the purpose of participatory parity over against forms of authoritarianism, monarchy, oligarchy, plutocracy, or theocracy. Now imagine that this building has no access ramps, no Braille or large-print publications, no American Sign Language interpreters, no elevators, no special-needs paraprofessionals, no in-class aides. That may sound horribly self-contradictory, but it’s a reasonably accurate picture of what contemporary debate over the meaning of democracy actually looks
like. Only when we have fostered equal participation in debates over the ends and means of democracy can we have a truly participatory debate over what "participatory parity" itself means. And the meaning of participatory parity, in turn, sets the terms for more specific debates about the varieties of human embodiment. These include debates about prenatal screening, genetic discrimination, inclusive education, stem-cell research, euthanasia—and, with regard to physical access, ramps, curb cuts, kneeling buses, and widened doorways.

The other philosopher I’m relying on is Eva Feder Kittay, who has written so compellingly about her daughter Sessa—and about what her life with Sessa has taught her about life and about the practice of philosophy. Sessa is not (cough) "high functioning." She is nonverbal and needs assistance with most things, including eating. And precisely because she needs assistance, she has taught her mother that we are all interdependent to one degree or another (especially at the beginnings and ends of our lives), and that the ideals of independence and autonomy, essential as they have been for both liberal social theory and the disability rights movement, inevitably set performance criteria for being human—performance criteria that some humans will not meet.

I first met Sessa in 2008, when Eva and her husband, Jeffrey, invited Jamie and me to spend a weekend at their house in upstate New York. It struck me vividly, at the time, that I was hanging out with Sessa and observing her keen enjoyment of her surroundings, her companions, and the music of her favorite composers (Bach and Beethoven) just a few weeks before Eva and I would speak at a conference she had organized, "Cognitive Disability and Its Challenge to Moral Philosophy." (Jamie still asks about Sessa, and he remembers who her favorite composers are.) Utilitarian philosophers Peter Singer and Jeff McMahan had also agreed to speak at that conference, where they would explain to all and sundry why people like Sessa do not meet their performance criteria for being human. Eva had put together the conference, she told me, as the result of her years of frustration over philosophy as an academic discipline and its inattention to, or outright revulsion at, people with intellectual disabilities. She had considered leaving the field altogether but then, inspired partly by Sessa, decided to stay and fight.
I discuss Singer and McMahan briefly in my 2015 book, *The Humanities, Higher Education, and Academic Freedom: Three Necessary Arguments* (written with Jennifer Ruth), in which I take issue with their conviction that a creature's moral worth is directly proportional to (their estimates of) that creature's cognitive capacity. I won't reprise that argument in full here, but I will cite again the passage of Singer's talk I found most ludicrous:

If it happens that one of you is an alien who has cleverly disguised yourself in a human shape, but you are capable of understanding this argument, I am talking to you just as I am talking to members of my own species. In important respects, I have much more in common with you than I do with someone who is of my species but, because he or she is profoundly mentally retarded, has no capacity for verbal communication with me at all.

I dutifully pointed out, in that book, that Singer could be having these pleasant interspecies-bonding thoughts about creatures who, like the aliens in the *Twilight Zone* episode “To Serve Man,” do not share Singer's aversion to meat eating and cannot wait to cook up a juicy batch of Singerburgers. But I did not tell the story of how, listening to Singer's talk in the spillover room while Jamie played a *Harry Potter* game on my computer, I burst into laughter when Singer said this, “What's so funny, Michael?” asked Jamie. “It's hard to explain,” I replied, “but this man just said something very silly. He thinks he has more in common with some space aliens than with some of his fellow human beings.” “That is weird,” Jamie agreed. By the time the conference speakers gathered for our group photo late that afternoon, I was ready to address Singer's argument, however informally. I announced to the gathering that I am in fact an alien who has cleverly disguised himself in human shape (“That explains a great deal,” said someone), that I was capable of understanding Singer's lecture earlier in the day, and that I saw no reason whatsoever to believe I had anything important in common with him.

I try to carry this kind of thing lightly, but of course it is no laughing matter that one of the world's foremost philosophers, a passionate
defender of animal rights and blistering critic of economic inequality, is so cavalier about the lives of some of the most vulnerable humans on the planet—and so woefully, willfully underinformed about the capabilities of people with intellectual disabilities.

As for McMahan, his paper the following day made much of the fact that there seems to be an enormous and obvious difference between killing a human being and killing a squirrel: clearly, therefore, there must be some correlation between cognitive capacity and moral standing. But this argument proves nothing, as I replied in my contribution to the question-and-answer period. Not very long ago in human history, there seemed to be an enormous and obvious difference between killing a nobleman and killing a slave. It is entirely possible that, in the future, we will shudder in horror at the killing of a squirrel. And why, if we should want to grant some rights and some sense of dignity to certain sentient animals, should we do so at the expense of any humans? Every attempt to boot some people out of the human family has been disastrous, and with regard to people with intellectual disabilities, those attempts involve brutal mistreatment on a massive scale within living memory. McMahan and Singer are right to argue that we have undervalued the lives of many animals. When they argue that we have somehow overvalued the lives of people with intellectual disabilities, they are as wrong as it is possible for a person to be.

And so, when I think about life and death and everything in between, I think about Peter Singer and Jeff McMahan on the one hand, and Jamie Bérubé and Sesha Kittay on the other. I think of Jonathan Glover and Rayna Rapp and Eva Kittay and Tom Shakespeare and Emily Rapp and Nancy Fraser and Marianne Leone. I think of everyone I know, everyone I have ever met. I know that Jamie and Sesha are not able to express themselves as eloquently as most people, but I do not think that is important. I think, instead, that maybe it would be a good idea if we humans stopped trying to come up with reasons not to treat each other as equals. I think that maybe it would be a good idea if we tried instead to treat people with intellectual disabilities, mild to severe, as if they are people who matter, people worthy of attention, support, and care. And I think maybe it would be a good idea to try to create
societies, here, there, and everywhere, in which all humans, no matter what their individual characteristics, can flourish to the greatest extent possible. You never know. We might just find out that people with intellectual disabilities have something to teach their fellow human beings about being humans.

I know it sounds unlikely. It might even sound impossible. But I said maybe.