



APPLYING THE SOCIOLOGICAL
IMAGINATION: THREE MODELS



5

A Wrong Child

Analyzing the Unanalyzable

“Art is not alone in holding the dignity of humanity in its hands.”

—*Ernst Bloch*.¹

In a discussion of Theodor W. Adorno’s (1903-1969) ethical philosophy, J. M. Bernstein states that, for Adorno, dignity lay in the “indigent particular.”² Writing self-consciously “after Auschwitz,” Adorno’s concern was always for the small and frail—the parts of the system that did not, as a matter of course, fit smoothly or function correctly—for these had not only been the victims of the Holocaust but they had also been the grist in the mill of the eugenics movement that helped prepare the ground for the Holocaust.³ Indeed, not just the eugenics movement but, for Adorno, the whole of modernity seemed like a machine hell bent on stuffing square pegs into round holes or, better, seeing to it that standardized round pegs became the norm. In modern society, damaged parts, or parts otherwise resistant to integration, were to be efficiently retooled or extruded lest they gum-up the works. But for Adorno, a subversive, ethical resistance to this form of rationalization entailed a defense of the seemingly irrational; a defense, as it were, of square pegs in a round hole society. While Adorno never wrote about disabled children per se (nor did Mills), the meaning of his attention to the “indigent particular” is clarified in such a study, as is the moral significance in postmodern times of what Mills called “biography.”

Consider the singular case of James Lyon Berube, or “Jamie,” who is Michael Berube’s son and the focus of the elder Berube’s 1996 book, *Life as We Know It: A*

*Father, a Family and an Exceptional Child.*⁴ Jamie was born with Down's syndrome. Most people know someone with Down's or some other birth defect. As Berube notes, "Down Syndrome alone accounts for one of every 600 to 800 live births; it's one of the most common birth 'defects' on the planet."⁵ In the United States, roughly 2.5 percent of children younger than the age of three experience a disability; between the ages of three and five years, the percentage climbs to 5.2 percent, and among those aged six to fourteen years, the percentage is 12.7 (but only 1.9 percent are severely disabled). For people fifteen years of age and older, roughly 24 percent have some disability, with about half of these being severe. In total, then, there are roughly 50 million people in the United States who are in some manner "disabled," about half of whom are severely disabled, while in the world as a whole, there as many as 500 million people who are disabled.⁶ Jamie Berube is among this number. He did not choose this form of human existence; he was just born this way.

This chapter is dedicated to the following proposition: any possessor of the sociological imagination today, "after Auschwitz," must labor to understand Jamie Berube, the social structures and cultural patterns that determine and define "disability," and the complicated relation between the two. This chapter aims to depict such an understanding and in so doing provides one model for how the sociological imagination works in practice.

Getting to know James Lyon Berube

In the interest of full disclosure, as journalists say, I should immediately note that I write these words with my own son, Patrick, sitting next to me in his wheelchair and not very happy to be watching me "work." I know this because he is frowning and fussing and smacking with his hand the clear plastic tray that attaches to his wheelchair. And then he looks cross at me and says, "play." After seven years of being with Patrick, I know that he wants me to stop working at the computer and play with him or, better still, let *him* work at the computer. I would be rather daft, after all, and probably an especially inattentive father, if I did not understand the meaning of these gestures and words. Patrick has learned to communicate many things, his being bored prominent among them.

Like Jamie Berube, Patrick is disabled. Patrick was born with cerebral palsy and epilepsy and experiences numerous resulting "challenges" such that he cannot feed, bathe, walk, or dress himself independently. Patrick is also probably mentally retarded, although given his physical limitations, it is difficult to measure his cognitive abilities since he cannot readily take IQ tests nor otherwise communicate with much precision or complexity. Both Down's syndrome and cerebral palsy are, of course, commonly thought of as "birth defects." Although such conditions can and

do have considerably varying results for the person who, as it were, has them, in the cases of Jamie and Patrick, the results are very significant. But are they defining and determining? Are Jamie and Patrick really defective from birth, as the terminology implies? Should they be objects of pity? Should they be exterminated? Are they, as a result of their defective nature, wrong children? Do we even know what they are, what should be done, or what they tell us about ourselves?

These are the types of questions that Jamie poses to his father. Michael Berube relates the following story about Jamie. The setting is Maine's Old Orchard Beach amusement park, which the Berubes were visiting as part of a family vacation. Michael Berube wrote:

We strolled among bumper cars, cotton candy, games of chance and skill, and a striking number of French-Canadian tourists. . . . James, however, wanted nothing to do with any of the rides, and though he loves to pretend-drive and has been on bumper cars before, he squalled so industriously before the ride began as to induce the bumper cars operator to let him out of the car and refund his two tickets.

Jamie finally settled in next to a train ride designed for children five and under or thereabouts. . . . I found out quickly enough that Jamie didn't want to *ride* the ride; he merely wanted to stand at its perimeter, grasping the partition with both hands and counting the cars—one, two, three, four, five, six—as they went by. Sometimes, when the train traversed the bridge, James would punctuate it with tiny jumps, saying, 'Up! up! up!' But for the most part, he was content to hang onto the metal bars of the partition, grinning and counting—and, when the train came to a stop, pulling my sleeve and saying, 'More, again.'⁷

This experience causes James's father to experience a moment of reflection apart from the immediate and usually very consuming work of taking care of Jamie at the amusement park. He feels a terrible sinking feeling as he wonders who or what Jamie really is.

Almost as a form of emotional exercise, I have tried, on occasion, to step back and see him as others might see him, as an instance of a category, one item on the long list of human subgroups. *This is a child with Down syndrome*, I say to myself. *This is a child with a developmental disability*. It never works: Jamie remains Jamie to me. I have even tried to imagine him as he would have been seen in other eras, other places: *This is a retarded child*. And even: *this is a Mongoloid child*. This makes for unbearable cognitive dissonance. I can imagine that people might think such things, but I cannot imagine how they might think them in a way that prevents them from seeing Jamie *as* Jamie.⁸

Jamie often surprises his father with what he is thinking and doing, but he also remains something of an enigma, a puzzle whose inner world, whose ultimate mean-

ing, is ineffable in some basic sense. Moreover, the gaze of onlookers in public places and the tools of conceptualization, both of which Jamie's father is expertly conversant with, provide only limited means to sort out what is going on with Jamie. In fact, they often appear as roadblocks to any true understanding of what Jamie is all about.

Later that same day, the Berubes dined in a local family restaurant. Jamie started to pretend that he was a waiter, taking orders and retrieving the designated fare from "the kitchen," a fireplace hearth dormant in late June. Jamie's father was distracted by his interest in watching the Stanley Cup, which was playing on a television in that part of the restaurant, but he was also half-attending to his son's busy activity. As Jamie's activity crept in on his mind and as he began to understand what Jamie was doing, he was astounded, for experience tells him that Jamie does not usually engage in such highly complex symbolic play: "Can you get me . . . let's see . . . a tuna sandwich? 'Tuna!' he half-shouts in a hoarse little voice and heads back to the fireplace. Did I imagine him pretending to write that down? I must have imagined it."⁹

Jamie's play adds to his father's cognitive dissonance. He knows that most people do not know Jamie as

the distinct little person with whom I went to the restaurant that evening—a three year old whose ability to imitate is intimately tied to his remarkable ability to imagine, and whose ability to imagine, in turn, rests almost entirely on his capacity to imagine *other people*.¹⁰

For most people, like the people they had encountered earlier that day at Old Orchard Beach, Jamie is invisible, and if not invisible, then merely a "retarded child," a "disabled child," or a "child to be pitied."¹¹ Jamie's father is therefore pushed to use this splinter in his eye, as it were, to see all the dimensions of reality laid out before him. He cannot usually do this when immersed in the minute-by-minute care of Jamie; it occurs to him, instead, "after we got back to our motel room, after New Jersey had won the Cup, after the kids were finally asleep."¹²

In this moment of reflection on the day's experience—which included the sinking feeling that Jamie was in fact "limited," the amazement with Jamie's imaginative abilities, and the recognition that Jamie is not generally recognized or understood as he really is, which is just himself—Michael Berube thought the following to himself:

As Jamie was fussing about bumper cars, serving entrees to imaginary diners, and splashing in the waves, the 104th Congress was debating how to balance the federal budget by slashing programs for the disabled and the mentally handicapped; electricians and construction workers in New Haven were putting the final touches on

preparations for the 1995 Special Olympics World Games; researchers with the Human Genome Project were trying to locate the biomedical basis for all our variances; and millions of ordinary human beings, all of them women, were undergoing prenatal testing for “severe” genetic defects like Down syndrome.

Jamie has no idea what a busy intersection he’s landed in: statutes, allocations, genetics, reproduction, representation—all meeting at the crossroads of individual idiosyncrasy and sociopolitical construction.¹³

Jamie, a three-year-old child, has no idea (but his father does) how practical, how real, are the menacing social and cultural forces that are work at varying distances around and through him. Michael Berube’s questions, his thinking, his imagination, is spurred on by his concern for a single human being: “Jamie has compelled me to ask these questions anew, just as I know how crucial it is that we collectively cultivate our capacities to imagine our obligations to each other,” wrote James Lyon Berube’s father.¹⁴

Identities and Nonidentity

I cannot possibly “know” Jamie Berube. Although Jamie’s father is a professor of English at the University of Illinois and an extremely gifted writer, and although Michael Berube is also an expert analyst of the way we have in our culture commonly understood and acted toward people with disabilities, it is not, strictly speaking, possible to know someone by reading about them in a text, even a particularly moving and well-crafted text, even a text written by a father about his own son and his own family. (I cannot know Janet or Nicholas Berube either, Jamie’s mother and older brother.) In *Life as We Know It*, Jamie appears as “Jamie,” a figure of language and an image depicted in photographs. The stories that his father writes are just that, stories. They are staged, crafted, and have gone through many phases of editing.

If I were to write about Patrick as Michael Berube writes about Jamie Berube—which, in fact, I have done—it would not be Patrick that the reader comes to know but, rather, just my—or in our particular case, me and Patrick’s mother’s—interpretation of Patrick, what we think Patrick is, has been, and could be.¹⁵ Ours, then, would be a gloss on Patrick, not Patrick *pe se*, in-himself, as he is to himself. This is unavoidable, for neither Jamie nor Patrick speak for themselves like “normally developing” children do and certainly not like parents and, needless to say, professors tend to do. Even if Jamie and Patrick did speak for themselves, the fact that they are not the authors of their own texts would place distance between them and their interpreter’s representation of them. And even if they did write their own texts—some day, perhaps—it would still be their representation of themselves and not themselves, strictly speaking, that resulted from their own writing or speaking. Words on

paper, utterances floating in the air, and bodies in wheelchairs or struggling with walkers are not equivalent to one another, and there is no transparent medium that sews these dimensions of reality seamlessly together.

This is to say that words are not the same type of thing as what the words are apparently making reference to. What linguistic theorists often call *the signified* refers to what we talk (or write) *about*, as opposed to what we actually say (or write). Simply, words have *referents*. We do not just talk; we talk about something. What we say or write are *signs* whose meaning is derived from their relation to other signs in a system of signs, like a language. The signified, then, is what we are trying to “signify” with signs, such as words and gestures.

If I configure my hand, for example, in such a way that my middle finger is extended but all the rest are doubled-up in a fist, and I turn the back of my hand toward another person while maintaining this configuration, the other person (if he or she has learned to interpret the meaning of this gesture as I mean for him or her to interpret it as my “giving them the finger”) will know that I am telling him or her something that might, depending on the situation, lead them to understand my gesture as an indication of my unfriendliness toward him or her. However, if this person is not familiar with this sign, he or she may simply be puzzled by it. It will not mean anything in particular; my sign will not signify to the person the signified I was aiming at. Or if I perform this gesture to a group of students in a classroom, they are likely to interpret my having done so as a pedagogical technique, and therefore they will not understand my sign as a rebuke or insult. What is signified in this case is my object lesson in which I am not so much giving them the finger as I am giving them an example of how symbolic interaction works in everyday life. In fact, they are more likely to chuckle at my sign than be upset by it, for professors are not normally supposed to use vulgar gestures in professional settings. The transgression of this implicit prohibition often evokes mild amusement, the form that anxiety takes when no real threat is evident.

The point of this illustration is, of course, that the meaning of the gesture or any sign is not “in” the gesture or sign itself. Meaning is not sealed in a sign of any kind but, rather, is a product of many indeterminate and particular interpretations. Established and systematically learned understandings of signs and situations reduce this indeterminacy, but it is the ever present and unavoidable possibility of indeterminacy that we need to examine more closely.

What is signified, what we are trying to communicate, and what we are aiming at with our words, utterances, or gestures—Jamie or Patrick, say—is always already different from the words we choose and greater than any words. Adorno called this the principle of nonidentity, which in this context can mean the impossibility of words—and the minds that fashion them—to identify wholly and completely with

their referents. That is, just because we know words, write books, and use language to conceptualize anything or everything does not mean that we fully know what it is that we are talking about. There is always a remainder, something left out. This is especially true of indigent particulars. They stand apart and say to us in their silence, “you cannot fully know me with your words.” Animals are like this, as are all natural phenomena. Disabled children who cannot speak in normal ways say this emphatically because they have human minds, and we know that they are thinking, thinking something, and perhaps thinking something about us. This is part of what makes particulars—and especially indigent particulars—so important for the would-be possessor of the sociological imagination: they teach humility.

Arrogant Categories

Jamie is, of course, a real person, not a fictional character, but he is also a real person whose reality inevitably “stands for” others such as himself (i.e., he symbolizes “the disabled”). While inevitable, this leap from real and particular to symbolic and general is fraught with danger. If the latter gains precedence over the former (i.e., if known categories come to dominant over unknowable people, if neat and clean round holes are imagined more important than the oddly shaped pegs actually existing), then conceptual or symbolic thought becomes menacing.

“Disabled” is one grouping or category. It refers to no one and to nothing in particular. It literally means, of course, to be “not-abled,” presumably, to be not able to do something. But what is the something that one is not able to do? We normally think of a loss in the major senses or body functions as constituting disability, such as not being able to see or not being able to walk. We also recognize as disabled those who have limited cognitive and emotional capacities, but the boundaries are clearly murky. Is a woman disabled if she is nine months pregnant? Is one disabled if he or she is colorblind? Is one disabled if he or she can walk only with the use of a special supporting device and only then for brief periods? Is one disabled if, though unable to hear sounds with his or her ears, he or she is possessed of a sign language and is immersed in a community of similarly skilled people, such that interpersonal communication is as complex and rich as it is for those who depend on utterances as their primary means of communication? In other words, are hearing-impaired people “disabled”? Is the professional golfer disabled who, due to a rare disease, cannot walk 18 holes without experiencing severe pain? Is a person disabled if he or she does not possess a sociological imagination? Where does disability start and stop? How do we draw these distinctions?¹⁶ Many people are surprised to learn, for example, that many members of the hearing-impaired community do not consider themselves, nor wish others to consider them, as disabled.

The concept of disability and the disabled—not to mention handicapped, crippled, cripp, mongoloid idiot, differently abled, gimp, challenged, retard, handicapable, and vegetable—are expansive generalizations meant to capture an aspect of particularity common across a range of general phenomena. To “conceptualize” something means to abstract from real things to produce imaginative groups and mental categories. For example, each disabled person is unique and in fact has abilities, but if he or she is viewed as sharing in common some general characteristic or quality, some inability or inabilities, then it is on this basis and this basis alone that he or she is conceptually grouped with others. This conceptual grouping, then, is the act of an active mind. The signified does not exist outside of our conceptualization of them. In other words, my phrase “people who are disabled” is a mindful construction, not an independent reality whose meaning is fixed outside of my conceptualization or, more to the point, a collectively accepted and routinely enforced conceptualization, some bit of “common sense.”

Amid the welter of things to attend to with our minds, some things are attended to and others not and some inabilities are noted and others are not. Furthermore, after we attend to something, we have to name it and understand its meaning in one or another way. Choices must be made about what to attend to with our minds (i.e., what to define, distinguish, and categorize). Choices have to be made about what to understand by what we have defined. Historically and even today, in our own culture and in other cultures as well, the boundaries for what is and is not considered—common sensically and also legally—a disability have been drawn in as widely varying ways. The notion of the human variety includes not just the cultural diversity of the species but also the diversity in the ways that humans have understood themselves. In some cultures, what we might regard as mental illness is regarded as a sign of special spiritual power. A postmodern adult who, due to some physical or mental limitation, cannot drive an automobile faces a “challenge,” whereas an inability to ride on horseback is not viewed as a disabling condition.¹⁷

It is, however, important to bear in mind that the people being referred to as being members of “a group” are in fact overwhelmingly different from one another and will always, in all likelihood, be perfect strangers to one another. For example, a disabled child in Outer Mongolia and a disabled child in Brookline, Massachusetts, other than their relation to one another via the alien concept of disabled child, could not be more different. Perhaps even the concept of “child” does violence to their own experience, given that the concept of “child” is historically and culturally constructed and, for the most part, the product of modern European development. Perhaps, *violence* is too harsh a term for use in this context. More to the point is the fact that only twenty-five years ago in the United States, children with Down’s syndrome were commonly referred to as “mongoloid idiots,” even by professionals—in fact,

especially by professionals, who invented the terminology.¹⁸ Mongoloid idiots in Outer Mongolia and mongoloid idiots in Brookline, Massachusetts are not, however, really part of a group at all, at least not part of a group of disabled children worldwide because no such group exists. This is the case even though some people may conceive of them as so being and in this process may define them in ways that are both symbolically as well as materially harmful to them.

All concepts are like this: they are simplifications and distortions of what really obtains. In some varying degree, they violate the reality of every particular thing. To think of Jamie Berube as a “mongoloid idiot,” a stigmatizing and dehumanizing concept, is damaging. But to conceptualize him as “having” Down’s syndrome is also potentially stigmatizing and dehumanizing, even if this label is more sterile and clinical in origin. When concepts are dehumanizing in any way, their inherent simplification and distortion can legitimize action that renders actual what before was only symbolic. For example, when disabled people were sent to the Nazi’s death camps along with “the Jews,” “the Gypsies,” and “the homosexuals,” they were not officially full-fledged human beings in the eyes of their murderers. They were defects; they were aliens. They were infections in the body politic, members of a mongrel race, and otherwise deemed unfit for life in the “New World” imagined in Nazi ideology. The symbolic dehumanization of these people paved the way for their material slaughter.

Writing in his study *The New Genocide of Handicapped and Afflicted People*, Wolf Wolfensberger analyzed such dehumanizing processes under the concept of “deathmaking,” which he defined as “any actions or pattern of actions which either directly or indirectly bring about, or hasten, the death of a person or group.”¹⁹ For Wolfensberger, Nazi-style deathmaking is just the tip of iceberg because subtle, indirect, and sanitized forms of deathmaking are far more common and, due to their “detoxified” appearance, much more difficult to confront. The clearing of the Brazilian rainforest is a form of such deathmaking for tropical species of plants and animals, as is the systematic production of stark inequalities in food and medicine worldwide deathmaking for hundreds of millions, if not billions, of “the wretched of the earth.” But Wolfensberger is more interested in how words such as *wheelchair-bound* and *birth defect* contribute subtly to dehumanization, or how comedians who make jokes about “being mental” and kids riding in “small school buses” diminish people, the least powerful among us to withstand this diminishment.

If you think about it, everything in this book, and everything in every book, is the product of some type of conceptualization presented via some language that harbors the potential for deathmaking. Books, especially high-brow books, are well suited for detoxifying reality. Intellectual jargon helps fashion a reality onto itself. When not doing battle with big words, the ease with which our eyes pass over facts,

even disturbing facts, contributes to the sanitation of the realities that the facts are referencing. A scholarly book about disabled children could easily, even unintentionally, render the lives of disabled children specimens for analysis, and instill in the mind of the reader a sense of the less-than-fully-human quality of the object of analysis. Once “presented,” “constructed,” or “staged,” signs must therefore be critically interpreted, decoded, or deconstructed by some reader. But this process—reading—is itself a sticky wicket because writing does not control or determine reading. Every book is read differently by every far-flung reader, far-flung in both time and space. Reading *Life as We Know It* means one thing to me now, but it might mean something significantly different to someone from Japan reading the book in translation a hundred years from now, or even to me next year, when I come to it with different eyes. The meaning of a person in a wheelchair today in Germany is certainly very different than what was the case fifty years ago; such a person is usually “read” differently, perhaps as an object of pity more than as an object of scorn or revulsion, but even as an object of pity, symbolically nudged toward a dehumanized status. The process of reading and writing and, generally, interpreting the meaning of all symbolic things is a process that never ends and that never produces the exact same results twice. It is also a political process, one that contributes to or resists dehumanization and, ultimately, deathmaking.

The Necessity of Conceptualization and Communication

With so much indeterminacy and danger inexorably infused in the processes of conceptualizing and communicating, should we simply give up trying to make sense of things, not to mention trying to share our understandings with others? We can analyze until the cows come home, but if we are always battling indeterminacy and running such risks with our stabs at conceptual knowing, then why think that we really know anything at all? Why take the chance of doing more harm than good? Why write books and read them if it is never certain that what is being written and what is being read match one another or form an “identity”? And what if there is a match, but it is a match that leads to the destruction of what we are talking about? In other words, with so much nonidentity afoot, isn’t everything particular and unknowable except, perhaps, as a particular thing in itself and on its own terms? Are our many efforts to use conceptualization, to overshoot reality and inevitably to simplify and distort it, themselves indigent and lame and maybe even harmful or lethal?

C. Wright Mills once wrote, “The first rule for understanding the human condition is that men [or, as we would say today, people] live in second-hand worlds.”²⁰ Mills continued,

Everyone lives in a world of . . . meanings. No man stands alone directly confronting a world of solid fact. No such world is available. The closest men come to it is when they are infants or when they become insane: then, in a terrifying scene of meaningless events and senseless confusion, they are often seized with the panic of near-total insecurity. But in their everyday life they do not experience a world of solid fact; their experience itself is selected by stereotyped meanings and shaped by ready-made interpretations. Their images of the world, and of themselves, are given to them by crowds of witnesses they have never met and never shall meet. Yet for every man these images—provided by strangers and dead men—are the very basis of his life as a human being.²¹

This insight should help us deal with the indeterminacy and danger of the process of trying to know and communicate. As Mills noted, the absence of “solid fact” and the presence of “ready-made” images and interpretations are perfectly mundane features of human life.

For the possessor of the sociological imagination, there is no Alpha and Omega, no solid beginning and no solid end, that is experienced in human life. Everything, including ourselves, is, as philosophers sometimes say, “always already”; there is no way to simply step out of our secondhand reality and know or experience something directly or as radically “other.” We ought not, therefore, be afraid of what is unavoidable and, in fact, constitutive of what we are. If our knowing has limits simply because we are human beings who are struggling to know but always already enmeshed in ongoing systems of meaning, then we may simply accept these givens and move on. We may then choose to actively pursue the knowing that we can accomplish, analyzing even what we know is, in any ultimate sense, unanalyzable. And if we have learned to be moral people, we will develop and use our concepts while being mindful of the harm that can result from damaging forms of knowing, which, ironically, often result from fear and anxiety before the unknown and unknowable. We will thus work “from within,” as Adorno once wrote, to “break out” of the prevailing “context of delusion,” even if we can never fully be free of where and whence we originated.²² We will do this with a mixture of humility and urgency because urgency is demanded by the evident harms before us and humility is dictated by our self-awareness as imperfect knowing beings.

Despite his recognition that we always already live in secondhand worlds, Mills, like Adorno and every other possessor of the sociological imagination, remained an obstinate believer in conceptualization. Indeed, as we have seen, Mills advocated a form of conceptualization that would demand nothing less than the complex conceptual interweaving of history, biography, and social structure, the interplay of the most particular with the most general. Furthermore, Mills hinted that at the extremes of experience, such as in infancy or insanity, we are at a loss without

our ability to conceptualize, subject to the terrors of a world experienced as flowing in as though through a breach in the levy, which, if left unchecked, will overwhelm our senses and eventually our minds.

In a sense, Mills offers us sociological conceptualization as a means to thwart the potentially damaging effects of the symbolic-constructed social world. In effect, the sociological imagination is a type of self-consciousness that holds the world at bay, if just for a conceptual instance. Our learned ability to simplify and distort what would otherwise overwhelm us is a type of conceptual shield. Who, after all, would really want direct contact with the vastly and forever unknowable but nonetheless real and threatening nature of social reality? Who, after all, would really want to know Auschwitz? Most of the people who did know Auschwitz died as a result. Better to know “Auschwitz,” that is, the concept of Auschwitz. This may be a terrible lesson, as Mills said, but it is not likely to be a lethal one. In fact, the concept of Auschwitz, if properly and deeply conceptualized, may be useful to us as we struggle from within the culture that produced it in the first place, useful and necessary lest we forget how damaging concepts such as “the Jews” and “mongoloid idiots” can be.

We therefore confront a paradox. On one hand, conceptualization distorts reality and is potentially dangerous. On the other hand, we cannot break free from our secondhand world, nor would we want to since this is the means by which we make sense of the world and control our relationship to it. Is there any other way to establish an intelligent if also moral relationship to others in such a paradoxical situation?

Mimesis

I do not know Jamie, but in knowing Patrick, such as I do, and less well Patrick’s school mates in his “special education” class, I can imagine what Jamie is like. My experience allows me to read Michael Berube’s description of Jamie and all things relating to Jamie’s and his family’s experience and say to myself, “I know what he means.” By this, I really mean to say,

I do not know exactly and completely know what Jamie is all about, but I know enough to allow me to understand, not perfectly, but well enough, what he is like, and this brings me into a human relationship with him that might not heretofore have existed.

Besides, Jamie and I both live in and are a product of virtually the same society and culture. Beyond our immediate and individual experience—he lives in Illinois and I in Ohio and he is younger than I am; he is a body with an extra twenty-first chromo-

some, which I apparently lack; Jamie likes to make “lists” of anything and everything, whereas my Patrick likes the sheer fact of letters, dollar amounts, and the groans associated with the “bankrupt” space more than the strategy displayed by contestants on “Wheel of Fortune”—we share a lot in common. We share the same language, breathe the same air, and go to similar hospitals staffed by professionals who are trained in similar ways. We have both been to Old Orchard Beach and we share French-Canadian ethnic roots. There is no congruence, just meaningful similarities, but meaningful enough, that is, to permit the best communication possible given our inevitably human situation.

The fact that there always exists an ineffable dimension to particular experience leads to, or should lead to, caution in every attempt “to know.” Michael Berube even formulates an ethical principle based on this self-awareness, which is meant as a guide for all human beings who are compelled to conceptualize but who wish not to suffocate the existing ineffability of the significant “other.” Berube wrote, “Sign unto others as you’d have them sign unto you. Pass it on.”²³ This could be thought of as a golden rule for the postmodern age, in which we are self-aware of our own participation in ongoing, secondhand worlds not of our own creation, worlds of established meaning that we must work from within but that we recognize can do as much harm as good.

In writing his book, then, author Michael Berube means to affect the world of established meaning by challenging words, such as *mongoloid idiot*, which are a false representation of Jamie and a damaging symbol for all who are disabled or potentially disabled (which is, of course, everyone). Therefore, Berube’s, is not a simple story of a child who is an apparently wonderful, joyous, puzzling, walking, talking, frustrating, creative, demanding, imaginative, amazing presence in the Berube household but is, rather, an intervention into the minds of all people who would aspire to a liberating form of social understanding and, simultaneously, to an understanding of the meaning of a liberated society. Michael Berube is therefore self-consciously engaged in social and cultural critique. He is working from within, in close partnership with the indigent particular, to change what it means to be a human being. His primary technique for accomplishing this feat is to tear down our preconceived notion that we know what we are talking about. In this sense, *Life as We Know It* is an ironic title.

Berube is hardly a lone voice in this regard. In an essay titled “The Limits of Life,” the French social theorist and psychoanalyst Julia Kristeva echoed Berube’s call for new and urgent rethinking about what it means to be a human being.²⁴ Of “humanity,” she wrote that “nobody really knows what it means any more, yet we experience a vague ‘consensual’ feeling when the subject of ‘crimes against humanity’ crops up.” Kristeva reported that therapists working with people once thought

“unanalyzable” (i.e., terminally ill patients and the severely disabled) “have been able to isolate a fundamental human anxiety: What is the norm?” For Kristeva, this fundamental human anxiety cannot be dispelled without

an atheistic compassion of a most radical kind. . . in which the value of life is not dependent on its bio-programmable performance, but in the meaning that the patient can continuously give it himself, aided by those close to him who become fully involved.

As with Berube’s ethical principle, Kristeva touched on what Adorno called “mimesis.” In addition to conceptually analyzing something—say, wrong children or a work of art—Adorno advanced a second way of knowing where, in the words of one commentator, “the ‘other’ is identified with the self *by making the other like the self*.”²⁵ This is *mimesis*, a term linked to mimicry or imitation. In mimetic knowing, one undercuts “the overly subjective nature of conceptualization by bringing forth more of the ‘voice’ of the object itself.”²⁶ In other words, one makes the other comprehensible and establishes a moral bond *against* concepts that encourage arrogant categorization or even deathmaking. One listens instead of just looks; one learns from passivity and humility before “the other” previously thought mute and retarded. One comes to see “the other” not as “them,” but as “me.” One plays his or her games—“up! up! up!”—and makes his or her world one’s own world. This may be much easier for the parent of a severely disabled child, who might simply call mimesis “love” or the knowledge born of love. But Kristeva, like Berube and Adorno, thought there was a more general lesson to be learned by everyone.

Kristeva wrote that “the everyday inquiry into ‘what life is’ ” is greatly facilitated by close analysis of the “so-called ‘useless citizens,’ ” who are “threatened with death by a more or less disguised form of eugenics.” She believed that this everyday inquiry was “truly the task for our times, since it is a question of deciding on the kind of world we want to live in.” Kristeva continued that “in this sense, people who are ill [and disabled] and those who look after them are spearheading the cause of human dignity, which otherwise would not necessarily survive into the next millennium.” The great task, according to Kristeva, is to “recognize as human someone who is at the very border of what generally is deemed human, to relate to the modest and ordinary, and not to despair.” Of course, for parents of disabled children such as Michael Berube, this task is both necessary and unavoidable because to do otherwise is to condemn one’s own child to oblivion. For those millions who live in close proximity to the “border” of humanity, Kristeva’s message is not simply a question of morality and an opportunity for personal growth, it is a compelling dilemma and task. Mimetic learning and mimetic understanding are for people built into their par-

ticular social roles and situations. For Kristeva, such simple acts of being with indigent others constitute a blow against the general tendency toward dehumanization, and therein lies the seeds of what she calls “hope.”

World-Historical Mimesis?

If cultivating this type of hope were all that was incumbent on the possessor of the sociological imagination, life would be easier and sociology would not be so melancholy of a science after all. We would simply keep our eyes and ears open to the blind and to the deaf and set about to learn from losses of all kinds. But to our appreciation for our own conceptual limitations, for the difference and indeterminacy of the world, and for the significance of work in the borderlands of human experience, we must add historically specific analysis of a relevant history and a specific set of social structures. In the case of Jamie, we must understand that Jamie exists today as he does only because of certain large-scale social and cultural developments, just as we must understand that a life worth living for Jamie and for all kindred spirits is constantly and systematically threatened. The big picture, as it were, is dispiriting. The lessons derived from a mimetic identity with the life conditions of the world’s disabled are anything but “hopeful.”

According to the United Nations, there are, as mentioned above, roughly 500 million people worldwide who are labeled as “disabled.” People are counted as disabled, generally, either if they experience a significant functional limitation or if they are treated as disabled in their own society. This includes, then, people who are missing limbs due to their having stepped on land mines as well as those whose cognitive abilities are deemed socially inferior in the context of their own society. Of these 500 million people, probably as many as 400 million live in the so-called Third World.²⁷ These latter people are, as James I. Charlton wrote, “the poorest and most powerless people on earth.”²⁸ They represent about 12 percent of the world’s human population.

Charlton’s path-breaking 1998 book *Nothing About Us without Us: Disability Oppression and Empowerment* is a handy reference for those who do not like sifting through verbose United Nations studies. Charlton also includes the data from his own extensive interview research with disability rights activists in every major region of the world. Based on these studies, Charlton is able to provide a picture of life for the world’s “poorest and most powerless” human inhabitants.

Drawing mainly from studies sponsored and funded by the United Nations, Charlton reports that, in the world’s poorest countries, as many as 90 percent of children with disabilities die before the age of twenty, while more specifically, 90 percent of children with *mental* disabilities die before the age of five.²⁹ Furthermore,

Charlton reports that roughly 100 million people have disabilities due, in the first place, to malnutrition, whereas those who are injured and have resulting disabilities, such as in the particular case of spinal cord injuries, “usually die within one or two years after becoming paralyzed, often from severe pressure sores or urinary tract infections.”³⁰ Land mines alone, worldwide, have disabled roughly 700,000 people as of 1994; this is of course exactly what land mines—the 110 million land mines estimated to exist in 64 countries—are designed to do.³¹ Beyond being maimed and killed or left to wither and die, disabled people in poor societies also face, of course, severely limited opportunities for a life worth living. For example, of the estimated 2 million children who are blind in India, only 15,000 receive any education whatsoever, with most of these few being boys because in India, like elsewhere, girls are generally regarded and treated as inferior to boys. Systematic infanticide is also widely practiced in countries such as India and China.³² Girls, especially disabled girls but also disabled boys, are regularly subjected to this form of prebirth death.

These figures are only vague indications of the state of disabled people worldwide. To them we could add facts concerning unemployment and poor health care, political marginality, and culturally defined inferiority. But this would even be true of the roughly 100 million people who are disabled by First World standards. For example, in the United States, roughly half of all people with disabilities are unemployed, and more than 87 percent of people with severe disabilities are unemployed.³³ Americans who are disabled and who are also black have unemployment rates that are closer to 75 percent.³⁴ In Britain, in contrast, the unemployment rate for disabled adults is only about 21 percent, although this is still three times the rate for nondisabled people.³⁵ In both Britain and the United States, people with disabilities who are employed, not surprisingly, typically are employed in low-paying jobs and thus receive incomes that cause them to live in poverty at rates much higher than their nondisabled fellow citizens.³⁶

Statistics such as these only tell part of the story because the lives of disabled people, in both poor and rich countries alike, are also significantly affected by socially imposed invisibility and abandonment. In *Nothing About Us without Us*, Charlton depicts this experience through his interviews with disability rights activists worldwide. Koesbionon Sarmandhadi, associate secretary of the Indonesia Disabled Peoples’ Association, said, “Children with disabilities are hidden because of an inferiority complex of families,” while Fernando Rodriguez, the founder of the Mobility International chapter in Mexico City, noted, “By and large, people with disabilities in Mexico are very isolated, both because of their family’s attitudes and because of all the access issues.”³⁷ Alexander Phiri, the chairperson of the National Council of Disabled Persons in Zimbabwe, said the following of his own experience:

After my accident, my parents visited two or three times and then I was abandoned. When I was to leave the hospital, the hospital people tried to locate my parents but failed. It was clear that they did not want a child they considered useless. . . . They also did not want to deal with the social implications in their village for having a disabled child, because they would be ostracized and maybe even ridiculed.³⁸

In Brazil, where there are estimated to be 30 to 40 million children who have been abandoned by their parents, disabled children and their mothers are especially vulnerable to abandonment.³⁹ Rosangela Berman Bieler, president of the Center for Independent Living in Rio de Janeiro, related the case of Vera Henriques in the following statement:

Vera Henriques, married for twenty years and mother of a fourteen-year-old girl with cerebral palsy, told me that she believes the vast majority of women with disabled children are abandoned by their husbands or companions because they do not accept the child's disability and they are so poor.⁴⁰

Apparently, the combination of culturally accepted prejudice against disabled people, patriarchy, and widespread poverty produces predictable results.

It is important here to stress "apparently produce" because, admittedly, the data presented thus far provides at best only a sketch of the lives of people with disabilities worldwide. We would want a more complete and exact empirical description, but such does not, unfortunately, yet exist. Charlton's book and several others, plus a handful of recent United Nations studies, together constitute the best research to date. This fact itself, of course, is an indicator of the relative powerlessness and marginality of disabled people. Research of the type we would want would entail the expenditure of considerable resources and imply an interest and commitment on the part of researchers and research-funding organizations.

For example, in the United States and Britain, both highly developed countries, public concern for the rights of disabled people is of relatively recent origin, and comprehensive research into their lives and experiences and into the effectiveness of social policies designed to improve these lives is more recent still. The disability rights movement in the United States, for example, usually marks its origin in the 1973 founding of the Berkeley Center for Independent Living.⁴¹ Up until then, most political organization by and on behalf of disabled people remained at a local or grassroots level. Modeling itself along the lines of the American civil rights movement, the disability rights movement developed quickly and established many national and international organizations. As a result of this political mobilization, the United Nations designated 1981 as the International Year of the Disabled. In 1990, the Americans with Disabilities Act was passed into law, which is described by some

researchers as “the most extensive piece of anti-discrimination legislation anywhere in the world.”⁴² The United Kingdom’s history is in many ways parallel to the American experience: the United Kingdom’s Disability Discrimination Act was passed in 1995. These and other legislative acts, and the international attention focused on disabled people by the United Nations, also encouraged the development of an expanding number of researchers and research organizations. A 1998 cover story in *The Chronicle for Higher Education* featured disability studies as the latest hot thing sweeping through America’s colleges and universities.⁴³

The invisibility and marginality of disabled people, and in addition, our studied ignorance of their lives, is a product of social and cultural oppression. But the growth, especially in the rich societies of the world, of the disability rights movement and of disability studies and the related expanding visibility, political voice, and growing knowledge of disabled people are indicators of how socially defined meanings and lived realities can and do change. In other words, our sense for the constraining nature of prevailing social structure (e.g., in terms of the adverse and lethal effects of global economic inequality) must also include an appreciation for how the mobilization of concern and power can change prevailing institutions and attitudes. The medium of this change is history or, more specifically, history making. The disability rights movement, like the civil rights and women’s movements, is nothing if not an organized group of people working from within their society and culture to not only change that society and culture in ways that will improve the lives of a specific group (in this case, disabled people) but also to redefine what it means for all people to live as human beings. They seek to make history, and in so doing, make humanity.

In this regard, consider one instance of history making. It was only in 1840 that the concept of “normal” acquired its current meaning. As Lennard J. Davis, the editor of the 1997 *The Disability Studies Reader*, noted, the concept of normality as indicating “constituting, conforming to, not deviating or different from, the common type or standard, regular, usual” came into widespread usage at roughly the same time that the eugenics movement became popular in Europe and the United States.⁴⁴ Among the many supporters of eugenics were such luminaries as Alexander Graham Bell, George Bernard Shaw, and Theodore Roosevelt. The goal of the movement was to use enforced sterilization and selective breeding to eliminate people and types of people who did not contribute to the development of a “normal” and, indeed, superior human type. As Davis noted, “We have largely forgotten that what Hitler did in developing his hideous policy of eugenics was just to implement the theories of the British and American eugenicists.”⁴⁵ By way of evidence, Davis noted that in 1933, “the prestigious scientific magazine *Nature* approved the Nazis’ proposal of a bill for ‘the avoidance of inherited diseases in posterity’ by sterilizing the

disabled.”⁴⁶ Davis also stated that “the magazine editorial board said ‘the Bill, as it reads, will command the appreciative attention of all who are interested in the controlled and deliberate improvement of the human stock.’”⁴⁷ Such opinions were as common among learned people only one human lifetime ago as was the opinion that most “races” of people in the world were inferior to those of western European “stock.”

Most people today do not support an active eugenics policy against disabled people or against anyone regarded as “abnormal.” Yet the fact that some 400 million people in the world who are disabled face life-threatening conditions on a daily basis belies the optimism this otherwise notable social and cultural change in rich societies might encourage. After all, inaction toward the situations faced by the vast majority of the world’s poorest and least powerful people is akin to a policy of passive eugenics—what Kristeva called a “more or less disguised form of eugenics”—for to die of neglect and abandonment because your body is damaged and because your well-being is relatively unimportant is to die under the auspices of a world that is still fixated on the high value of normalcy. Deathmaking is deathmaking no matter if progress has been made or not. IN other words, some people’s lives are worth more than others, and poor disabled people living in poor societies are not worth, evidently, very much, if anything at all.

The fact that even the more fortunate people who are disabled and lucky enough to have been born in rich societies at a time of growing concern and positive social change for disabled people continue to face significant barriers to a life worth living (e.g., significant material inequalities, significant stigma and prejudice) should cause us to pause before any premature celebration of our progress. Progress it is, to be sure, but progress enough? The possessor of the sociological imagination could hardly accept the past thirty or so years of advancement in one corner of the world without weighing these historical changes in a comparative balance with the experience of the majority of similar people worldwide, without attending to the fate of those millions for whom time has already run out, or without looking ahead to a time soon when the problems of a dying world will significantly erode the possibilities for the inclusion of the world’s hundreds of millions of disabled human beings in a true community of humankind.

The Shadow Cast by “Christmas in Purgatory”

We might here pause to recall the words of the late Burton Blatt, who was among the first leaders in the struggle to salvage the lives of people with mental retardation in the United States and who, at the time of his death in 1985, was also the dean of the School of Education at Syracuse University.⁴⁸ Blatt gained initial fame on the basis

of a 1966 exposé titled “Christmas in Purgatory: A Photographic Essay on Mental Retardation,” which included the photographs taken by Fred Kaplan of the conditions in America’s institutions for the mentally retarded. Blatt wrote, “There is a hell on earth, and in America there is a special inferno.”⁴⁹

Following is a description by Blatt and Kaplan of one institution that they visited in December 1965:

In each of the dormitories for severely retarded residents, there is what is euphemistically called a day room or recreation room. The odor in each of these rooms is overpowering. After a visit to a day room we had to send our clothes to the dry cleaners to have the stench removed. The facilities often contribute to the horror. Floors are sometimes wooden and excretions are rubbed into the cracks, leaving permanent stench. Most day rooms have a series of bleacher benches, on which sit unclad residents, jammed together, without purposeful activity, communication, or any interaction. In each day room is an attendant or two, whose main function seems to be to “stand around” and, on occasion, hose down the floor “driving” excretions into a sewer conveniently located in the center of the room.⁵⁰

Conditions such as those that Blatt and Kaplan described were commonplace for disabled people locked away in institutions and “hospitals,” kept at a safe distance from public consciousness and the public’s conscience. Indeed, Blatt and Kaplan’s exposé played a part in the deinstitutionalization movement, which put a stop to the unquestioned institutionalization of people with severe mental and physical disabilities and encouraged community and home-based care as a progressive substitute. In 1955, there were roughly 558,000 people in state mental hospitals; by 1980, this number had fallen to 140,000.⁵¹

At first, this deinstitutionalization movement was regarded as a progressive initiative, its point being to free thousands from de facto imprisonment and systematic neglect and encourage the assimilation of disabled people into mainstream society. The mid-1970s were its hay day. Disabled Americans started showing up in grocery stores and living in neighborhoods, and disabled kids started appearing in regular classrooms with normally developing peers. But after many significant political and policy successes, Blatt still maintained the following perspective: “As you will see, everything has changed during the past decade. As you will see, nothing has changed.”⁵² The conditions inside the remaining institutions were not significantly improved, nor were the lives of those, as it were, set free from the institutions necessarily any better.⁵³

Indeed, in the late 1990s, more than ten years down the road from Blatt’s dismal assessment of the progress of his day, research suggested that roughly 40 percent of America’s homeless (citizens without shelter in the richest society in the world) are

affected by one or another form of mental disorder. In this regard, it would seem that Blatt and Kaplan's purgatory has simply changed venue, and it is now a kind of open air prison instead of scenes from behind the bars and in the back wards of "One Flew Over the Cuckoo's Nest" institutions. In this way, responsibility for this social problem is dispersed into the thin air, except for those who possess the sociological imagination and who therefore see the straightforward connection over time between deinstitutionalization on one hand and homelessness on the other, the well-intended half solution to one hell on earth becoming the basis for another. But even for the nonhomeless, things were not good. Care given in homes, even by parents, is tenuously supported by social programs. It is difficult, for example, for the parents of the estimated 800,000 people in the United States living at home with schizophrenia and bipolar illnesses to manage a household conceived as a small-scale mental hospital.⁵⁴ An indicator of the stress caused by the "family-centered" care of a severely disabled person is the fact that, in Britain (where data are available) the divorce rate is roughly 10 times higher in families with children with learning difficulties than the national average. Disabled children are also more likely to be abandoned, physically and sexually abused, and passed over for adoption.⁵⁵

Seen in this light, Jamie Berube, like my own son, is simultaneously very fortunate and very unfortunate indeed. Due to changes enacted during the course of the past thirty years, we can safely say that we have no more mongoloid idiots among us (although the concept lingers in many minds, and in this way, as a sort of nightmare, remains a hectoring presence). Jamie certainly benefits from a new and emerging language; he benefits from people stopping to consider, for example, whether it makes sense or whether it is subtly dehumanizing to say he "has" Down's syndrome. Jamie has access to expensive medical and therapeutic services, which in our society are available to most professors' kids. Prejudicial attitudes are also changing and, when need be, laws are now on the books to mandate equal education and equal access to all of society's benefits and opportunities. Jamie and kids like him, not to mention adults, do not as a matter of course spend much time in institutions such as those that Blatt and his pioneering colleagues condemned by exposing them to a wide public audience. Indeed, Jamie could not have picked a better place and a better time to be born. Through the use of conceptual thinking about history and society, I know this without even being able to fully know Jamie.

But when they conjure the meaning of a child like Jamie, the possessors of the sociological imagination imagine also the mongoloid idiots of the past locked in their institutions, remember the eugenics movement, and see the disabled children today abandoned in Brazil, left in hospitals in Zimbabwe, or cared for by overstressed parents in the lands of milk and honey. They understand, too, the broad economic, political, and cultural bases for these myriad individual, particular experi-

ences. The sociological imagination—this type of mind that relates history and biography through an analysis of social structure and that works back and forth from the most particular to the most general—sees also many people the world over struggling to change their own lives and the situations that define their lives. Michael Berube’s book fits in here, and so does the one you are reading.

The initial concern in this chapter with what we can know takes on new meaning when given practical expression in the form of knowledge sought and knowledge gained in an ongoing struggle for particular life against systematic and predictable death. Adorno’s concept of the indigent particular itself takes on new weight when the flesh of particular living and actually indigent people is added on to it and then related to today’s myriad forms of deathmaking. Likewise, the notion of nonidentity is deepened considerably if, instead of turning it over for discussion in a philosophy seminar, we relate it to the ongoing experience of people who, by virtue of their obstinate bodies, cannot identify with what is imposed on them as normal. In this interplay between abstract ideas and concrete human lives, we have before us what is perhaps at the heart of the sociological imagination. The sociological imagination is not just a conceptual apparatus, pure and simple. It is also a means to achieve a mimetic—humble, respectful, awe-filled—relationship to the borderland experiences of human existence, what we have also called the “liminal” aspects of postmodern experience. Wrong children, for example, can teach us this form of knowing *if* we are prepared to listen and learn. “I am not suppose to be like this, but it’s okay,” sing R.E.M.⁵⁶ It is, alas, a terrible and magnificent lesson.

Notes

1. Ernest Bloch, *Natural Law and Human Dignity* (1961; reprint, Cambridge, M.A.: MIT Press, 1986), 280.

2. J. M. Bernstein, “Why Rescue Semblance?,” in *The Semblance of Subjectivity: Essays in Adorno’s Aesthetic Theory*, eds. Tom Huhn and Lambert Zuidervaart (Cambridge, M.A.: MIT Press, 1997), 195.

3. On the idea of “after Auschwitz,” see Theodor W. Adorno, *Negative Dialectics* (1966; reprint, New York: Continuum, 1987) and “Education after Auschwitz,” in *Critical Models*, ed. Henry W. Pickford (New York: Columbia University Press, 1998), 191-204.

4. Michael Berube, *Life as We Know It: A Father, a Family and an Exceptional Child* (New York: Pantheon, 1996).

5. *Ibid.*, 19. Berube also noted, however, that “80 percent of fetuses with Down’s are eventually miscarried,” meaning that Down’s syndrome would be even more common if this were not the case.

6. Bureau of the Census, *Statistical Abstract of the United States: 1999* (Washington, D.C., 1999), 151. On worldwide estimates, see James I. Charleton, *Nothing About Us without Us* (Berkeley: University of California Press, 1998).

7. Berube, *Life as We Know It*, x-xi.

8. *Ibid.*, xi-xii.

9. Ibid., xvii.
10. Ibid., xviii.
11. Ibid.
12. Ibid.
13. Ibid., xviii-xix.
14. Ibid., xix.
15. See Chapter 3 of Steven P. Dandaneau and Maude Falcone, *A Wrong Life: Studies in Lifeworld-Grounded Critical Theory*, titled "Dried Beans and Beethoven: The Art of Parenting the Ineffable" (Greenwich, C.T.: JAI Press, 1998).
16. This question is explored in detail by Simi Linton in her book, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998), with a foreword by Michael Berube.
17. For a cross-cultural overview of disability, see Benedicte Ingstad and Susan Reynolds White, eds., *Disability and Culture* (Berkeley: University of California Press, 1995).
18. As Michael Berube wrote, "Right through the 1970s. 'Mongoloid idiot' wasn't an epithet; it was a *diagnosis*. It wasn't uttered by callow, ignorant persons fearful of 'difference' and Central Asian eyes; it was pronounced by the best-trained medical practitioners in the world, who told families of kids with Down's that their children would never be able to walk, talk, dress themselves, or recognize their parents. Best to have the child institutionalized and tell one's friends that the baby died at birth." See Berube, *Life as We Know It*, 27.
19. Wolf Wolfensberger, *The New Genocide of Handicapped and Afflicted People* (bound manuscript, Syracuse University, 1987), 1. See also David J. Vail, *Dehumanization and the Institutional Career* (Springfield, I.L.: Charles C Thomas, 1966).
20. C. Wright Mills, "The Cultural Apparatus," in *Power, Politics, & People: The Collected Essays of C. Wright Mills*, ed. Irving Louis Horowitz (1959; reprint, Oxford, U.K.: Oxford University Press, 1963), 405.
21. Ibid.
22. Adorno, *Negative Dialectics*, 406. Adorno's own formulation (in translation from the original German) is as follows: "Dialectics is the self-consciousness of the objective context of delusion; it does not mean to have escaped from that context. Its objective goal is to break out of the context from within."
23. Berube, *Life as We Know It*, 249.
24. Julia Kristeva, "The Limits of Life," viewed online (11 Nov. 1999) at www.unesco.org/drg/human-rights/pages/english/Kristeva.html. All Kristeva quotations are from this document.
25. T. Sherratt, "Negative Dialectics: A Positive Interpretation," *International Philosophical Quarterly* 38 (Mar. 1998): 60, emphasis in original.
26. Ibid., 64.
27. See Charleton, *Nothing About Us without Us*, 24.
28. Ibid.
29. Ibid., 43.
30. Ibid., 43-4.
31. Ibid., 43.
32. Ibid.
33. Charleton, *Nothing About Us without Us*, 45.
34. Colin Barnes, Geof Mercer, and Tom Shakespeare, *Exploring Disability: A Sociological Introduction* (Cambridge, U.K.: Polity Press, 1999), 112.
35. Ibid., 111.
36. Ibid., 112. See also Charleton, *Nothing About Us without Us*, 45.
37. Charleton, *Nothing About Us without Us*, 85.
38. Ibid., 86.
39. Ibid.
40. Ibid.

41. See Barnes, Mercer, and Shakespeare, *Exploring Disability*, 160-4, and Charleton, *Nothing About Us without Us*, 130-6.
42. Barnes, Mercer, and Shakespeare, *Exploring Disability*, 161.
43. Peter Monaghan, "Pioneering Field of Disability Studies Challenges Established Approaches and Attitudes," *The Chronicle of Higher Education*, 23 Jan. 1998, A15-6.
44. Lennard J. Davis, "Constructing Normality," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 1997), 10.
45. *Ibid.*, 19.
46. *Ibid.*
47. *Ibid.*
48. Steve J. Taylor and Steven D. Blatt, eds., *In Search of the Promised Land: The Collected Papers of Burton Blatt* (Washington, D.C.: American Association on Mental Retardation, 1999).
49. *Ibid.*, 5.
50. *Ibid.*, 7.
51. See Ann Braden Johnson, *Out of Bedlam: The Truth About Deinstitutionalization* (New York: Basic Books, 1990), 115.
52. *Ibid.*, xx.
53. See Rael Jean Isaac and Virginia C. Hunt, *Madness in the Streets: How Psychiatry and the Law Abandoned the Mentally Ill* (New York: The Free Press, 1990).
54. *Ibid.*, 250.
55. Barnes, Mercer, and Shakespeare, *Exploring Disability*, 103.
56. R.E.M., "The Wrong Child," *Green* (Warner Brothers, Inc., 1988). Lyrics by W. T. Berry, P. L. Buck, M. E. Mills, and J. M. Stipe.