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On the Cultural Representation of People With Disabilities

By Michael Berube

My wife, Janet, and I recently saw the movie *Sling Blade*. The film had been released many months earlier, and its star, Billy Bob Thornton, had received a great deal of attention at the Academy Awards. But thanks to a daily regime of rigorous personal discipline and sacrifice, I had managed to hear nothing at all about the subject of the movie until I saw it in early April. (A few years ago, I developed this regime during the long months it took for *The Crying Game* to make it to east-central Illinois.)

When we emerged from the theater that evening, I was silent for perhaps half an hour, and Janet, thoroughly unaccustomed to such a thing, assumed I was profoundly moved. In some ways, I was. Janet and I have a child with a disability -- James, who was born in 1991 with Down syndrome -- and we've grown particularly sensitive to the portrayal of characters with mental or developmental impairments. That doesn't mean we scour every film and TV show for "acceptable" representations of mental retardation, but it does mean, at the very least, that whenever we encounter a disabled character who is particularly dangerous, embittered, angelic, pathetic, cruel, or (as in the case of Thornton's character, Karl, in *Sling Blade*) simple, courageous, and "good," we have to ask ourselves how we feel about it. As, for instance, when Janet first attempted to crack my silence by asking, "Parts of that movie were kind of *Forrest Gump*-y, didn't you think?"

On balance, we prefer stories in which mentally retarded characters are innocent and kind to stories in which they are alien and threatening, so on that scale *Forrest Gump* is tolerable to us, *Rain Man* is challenging, *Of Mice and Men* is profoundly annoying, and *The Sound and the Fury* brings me to tears without fail -- not because Benjy is mute and pathetic but because his sister Caddy loves him neither with reservation nor with pity. But why should my concerns about these characters make any difference to people who do not have children -- or cousins or nephews or aunts or friends -- like James, like Karl, like Benjy Compson? And even if movies such as *Sling Blade* might affect the lives of "normal" people in some way, why should we bother to study such things in the humanities and liberal arts?

The answer to the second question enfolds the answer to the first: The cultural representation of people with disabilities affects us all. In the broadest possible sense, it affects our understanding of what it means to be human; in more-practical terms, it affects public policy, the allocation of social resources, and the meaning of "civil rights."

These may seem to be somewhat sweeping assertions: After all, *Sling Blade* makes no explicit claims on public policy, I

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reckon. But every representation of disability has the potential to shape the way "disability" is understood in the general culture, and some of those representations can in fact do extraordinarily powerful -- or harmful -- cultural and political work.

Take, for instance, the former ABC show "Life Goes On," which featured Chris Burke as "Corky," a young adult with Down syndrome. Unlike Billy Bob Thornton or Dustin Hoffman, Chris Burke actually has the disability he portrays -- and therefore, at a minimum, he demonstrated with each episode of "Life Goes On" that people with Down syndrome can become actors. That in itself is a triumph in a world where medical practitioners believed -- right through the mid-1970s -- that people with Down syndrome could not even learn to read. All too often in our past, parents of children with Down syndrome were told that their babies would never grow up to have "a single meaningful thought." But what made "Life Goes On" so exemplary was not merely that it hired Chris Burke to play Corky, but that it portrayed Corky's life as being just as complicated and contradictory as any young adult's -- a life in which disability was one important variable among many.

And yet not every sympathetic rendering of persons with disabilities advances our understanding. In the early months of 1997, Janet and I received a letter from the National Down Syndrome Society, informing us that the hit show "E.R." was considering the possibility of adding a character with Down syndrome to its permanent roster of characters. We were urged to write to "E.R." and encourage its producers to do so; we were also informed that in an upcoming episode, a character with Down syndrome would arrive needing a heart-lung transplant. So we made plenty of popcorn and settled in for what we hoped would be some serious consciousness-raising in the exhilarating, narratively taut "E.R." mode.

Unfortunately, the episode, which aired in February, wound up perpetrating some of the moldiest stereotypes about people with Down syndrome, including, incredibly enough, the erroneous (and, on the show, uncontested) claim that people with Down syndrome never progress beyond the mental age of 8. A generation ago, that kind of "information" was conventional medical wisdom, but that was before we had any reasonable idea of the cognitive and emotional range of adults with Down syndrome.

The episode was all the more disappointing in that it was clearly based on a real-life drama in medical ethics -- the Sandra Jensen case, which briefly attracted national attention in the winter of 1995. Sandra Jensen, then 35, was a candidate for a heart-lung transplant but was turned down by two California hospitals on the grounds that she was not capable of following the post-operative regimen necessary after a double transplant. The decision hinged on her mental disability, despite the fact that she'd been living independently for 14 years, and despite the fact that many patients fail to follow their post-operative regimen regardless of their I.Q.

Ms. Jensen's case eventually made the pages of *People*

magazine, and, thanks to the court of public opinion, justice was finally done: In January 1996, Stanford University reversed its earlier decision that people with Down syndrome are not "appropriate candidates" for such surgery, and performed the double transplant successfully.

Her case raises a host of excruciating questions about disability, health care, and social justice; and no doubt many people who consider themselves open-minded about disability might nevertheless question Ms. Jensen's eligibility for life-saving surgery. Interestingly, however, the "E.R." episode chose to obfuscate those questions. Although various hospital staff members debated whether to perform a heart-lung transplant on a person with Down syndrome, the show concluded when the patient's mother refused to let her child undergo the operation. Looking to the future, she could not imagine her daughter surviving without the mother's care.

That's a primary concern for the aging parents of adults with disabilities, to be sure, but by contrast, the Sandra Jensen case proves that some adults with Down syndrome are perfectly capable of living on their own. (The Jensen case also points to our pressing national need for universal health care -- an issue unfortunately skirted by the "E.R." plot.)

As for the "information" that people with Down syndrome have a peak mental age of 8, I cannot say for sure what research the writers for "E.R." conducted. But it's noteworthy that in late 1995, the Associated Press carried a story about Luke Zimmerman, a football player at Beverly Hills High School who has Down syndrome. The story described how Luke is an inspiration to his teammates -- but it also included, in its fourth paragraph, the mistaken claim that "Down's syndrome children are severely retarded and rarely develop beyond the age of 8 mentally." As developmental specialists know, "severely retarded" is a label reserved only for the most seriously impaired -- and therefore particularly inappropriate to a class of people whose functions range from "severely retarded" to "educable mentally handicapped" to "learning disabled" to "normal."

Janet wound up writing to "E.R." not to ask that they include a character with Down syndrome, but to demand that they get hold of more-accurate and up-to-date information on people with disabilities.

But isn't our response to "E.R." just one more example of "symbolic" or "cultural" politics, another instance of how people like me spend more time worrying about the content of TV shows than about the law of the land? Instead of writing to "E.R." -- or writing about *Sling Blade* -- wouldn't we be better off lobbying our legislators in Washington?

The short answer is No. As it happens, there are complex reasons that the representation of disability is so intimately linked with our social policies concerning disability. Most of these have to do with what I call the politics of disavowal: the psychological distance most people put between themselves and disability. Any number of white men like me support

affirmative action regardless of whether it serves our self-interest in a narrow sense. But, curiously enough, fairly few non-disabled people support disability rights, even though disability law may apply to *them* some day.

Why is that? Why isn't disability seen as a potentially universal condition -- as it most assuredly is? For those of us who are relatively sound of mind and body, the "disabled" are always *other people*, other people to whom we can be kind if we so desire, or other people whom we can ignore, personally or politically. Understanding disability as an integral part of the human condition, by contrast, means imagining ourselves in their places -- and that may be too much of a psychological burden for us to bear.

"What is critical," writes Nancy Mairs, a brilliant essayist who has multiple sclerosis, "is an understanding of the realities disability imposes, and the only way finally to develop the necessary empathy is through knowing disabled individuals." This much could be said of any form of empathy, but as Mairs points out, "most non-disabled people I know are so driven by their own fears of damage and death that they dread contact, let alone interaction, with anyone touched by affliction of any kind." Indeed, all too many non-disabled people will "interact" with disability only by way of TV shows and movies -- which is why it is crucial that media representations of people with disabilities allow us, however fleetingly, to *identify* with the characters we see on the small or big screen.

The political and educational stakes could not be higher. In the past year, the United States has simply dropped *legal* immigrants with disabilities from the welfare rolls; even worse, new federal regulations, sponsored by Florida Republican Representative E. Clay Shaw, will prevent mentally disabled immigrants from becoming naturalized U.S. citizens. (Shaw favors a phaseout program of block grants, during which, as he put it, "the death rate will see that that population shrinks in those two to three years." At long last we have a Scrooge who knows exactly who the surplus population is, and why -- and even when -- they should die.)

On campuses, the political climate for people with disabilities is much better, for now; but as an academic subject, disability is commonly dealt with in applied fields, such as social work and special education, which is to say that disability usually is not seen as an issue fundamental to our understanding of the humanities and liberal arts.

Perhaps it is no surprise that people with disabilities are as politically invisible as they are; we live, after all, in a political culture that places a great deal of emphasis on individual autonomy. In such a culture, disability has to be seen as something abnormal, exceptional, and, finally, avoidable. But over the long term, especially as the population of the United States ages, that attitude toward disability will show itself to be not only inhumane, but poor public policy as well.

Schools and colleges, then, seem to me among the most appropriate social institutions through which we can begin to

foster a sense among our fellow beings that disability is too multifarious and common to be considered "abnormal." But we must study disability and its representations in a way that shows us how our culture understands "non-disability," and why it is such a uniquely tenuous condition, subject to change at any time by a virus, a car crash, or a legal decision. That means that we cannot continue to sequester the study of disability in courses such as "Abnormal Psychology" or in the applied fields of social science. It is in the humanities and liberal arts that we stand the best chance of understanding disability as something essential to being human.

As Simi Linton argues in her forthcoming book *Claiming Disability* (a volume I recently accepted for the cultural-studies series I edit for N.Y.U. Press), a liberal-arts education can, and *should*, include anthropology courses on the cross-cultural understanding of physical and mental disabilities, history courses on the definition and management of mental illness, and literature courses on the representation and thematic function of disability in work by authors ranging from Shakespeare to Flannery O'Connor. The finest example of disability studies in literature would surely be the scholarship of Rosemarie Garland Thomson, whose new book, *Extraordinary Bodies*, builds on the important scholarship she began with her groundbreaking essay on the meaning of disability in the novels of Toni Morrison. Other recent books, by Lennard Davis (*Enforcing Normalcy*), James W. Trent, Jr. (*Inventing the Feeble Mind*), and Nancy Mairs (*Waist-High in the World*) bear mention as well.

As Mairs eloquently points out, "the more perspectives that can be brought to bear on human experience, even from the slant of a wheelchair or a hospital bed, or through the ears of a blind person or the fingers of someone who is deaf, the richer that experience becomes." And if we bring those perspectives to bear on the humanities, perhaps we will better understand humanity. Perhaps, too, if we are fortunate, we can help to create a political climate in which all persons with disabilities are recognized and valued, even if they're not as charming as Forrest Gump or as heroic as Billy Bob Thornton's Karl.

Michael Berube is a professor of English at the University of Illinois at Urbana-Champaign. His most recent book, Life as We Know It (Pantheon, 1996), chronicles his family's experience with Down syndrome.

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Disability Goes Cultural: The Cultural Model of Disability as an Analytical Tool. (pp. 19-28). Anne Waldschmidt. Even today, with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) adopted in December 2006 and disability-related discourses, structures, and practices gradually changing throughout the world according to the new human rights approach, there are many people who still take disability as a simple natural fact. Not only myself, but probably other critical disability studies scholars also feel that Lennard J. Davis expresses a common experience: "When i Jenny Morris's very popular and influential book, *Pride Against Prejudice* (1991) blurred the distinction between impairment and disability in several ways: she discussed the role of impairment and personal experience in the lives of disabled people; she talked about cultural representation; and she used terminology inconsistently, sometimes talking about "disability" when in strictly social model terms she was talking about impairment." For example, the Liberation Network of People with Disabilities developed the concept of disabled people as an oppressed Disability culture offers ways for people with different disabilities to pursue their own, as well as shared goals. Tony Doyle suggests the following outcomes from naming disability culture: debate is stimulated[,] myths are challenged[,] cultural contributions are made, which shatter the image of people with a disability being only "needy" and the reality is reinforced that people with a disability are not only consumers of services but have something to give. Disability culture is already being advanced by developments in technology, which are facilitating communication in ways unh