

LIFE

As He Knows It

By KAREN WING

Michael Bérubé is an ardent voice for disability rights

Over 54 million strong, people with disabilities are considered America's largest minority group. They're also more than twice as likely to live in poverty than other Americans and only half as likely to be employed, according to David Stapleton, director of the Cornell University Institute for Policy Research. And that's the good news.

The situation was much worse before the 1960s, when the Disabilities Rights Movement began to dismantle structural and attitudinal barriers in society. The landmark Americans with Disabilities Act of 1990, which mandated curb cuts, wheelchair ramps, kneeling buses and widened doors, has helped make the physical environment more habitable, but it has had little impact on the ways in which social institutions and attitudes affect the lives and choices of those with disabilities.

Dr. Michael Bérubé, Paterno Family Professor of Literature in the Department of English and co-director of the Disability Studies Program at Penn State, is one of today's most ardent voices for disability rights. He has worked to increase awareness of disability issues and disability rights in a wide variety of forums, from advocacy groups and local organizations, to public-policy journals and *The New York Times Magazine*, to his acclaimed book "Life As We Know it: A Father, A Family, and an Exceptional Child." In the book, Bérubé combines his family's personal experience—his son has Down syndrome—with the larger public issues of disability in America.

"Michael is the father of a disabled son in a community, nation, world that has long needed to understand, if not appreciate, disability," said Dr. Robert L. Caserio, head of the Department of English. "Michael has devoted a large part of his life at Penn State to educating the academy, the institution and

the community in the historical legacies and current needs of the disabled. It is impossible to understate the importance of this contribution to Penn State and the much wider community."

Increasing Attention for Disability Studies

Housed in the Rock Ethics Institute, Disabilities Studies is a richly interdisciplinary field that draws from the humanities, social sciences, arts and medicine. The program is co-chaired by Bérubé and his wife, Dr. Janet Lyon, associate professor in Penn State's Department of English. Founded in 2003, the Disabilities Studies Program will be offering an undergraduate minor within the next couple of years.

"Disability studies is not only about access issues; rather, it seeks to show how questions about physical access raise broader questions about social participation and/or exclusion, including very thorny questions about how much a morally responsible society should do to foster the full participation of its citizens with physical or cognitive disabilities," said Bérubé.

Rock Ethics Institute Director Dr. Nancy Tuana noted that while there is a group of scholars responsible for the development of the relatively new field of disability studies, "few have been as successful as Bérubé in both having an impact on the academic field and influencing public agencies."

Creating Enabling Environments

According to Bérubé, what constitutes a disability may depend on the way you look at it. For example, “When you and others around you are fluent in American Sign Language, deafness is not disabling in that environment,” he said. “The idea behind the ‘social model’ of disability is that certain disabilities are not disabling; rather, it’s the environment that’s disabling.”

It’s this line of thought that Bérubé brings to his prolific outreach efforts, which focus on how to create a larger world of enabling environments.

Bérubé has played key roles in various community organizations, including ARC (formerly the Association of Retarded Citizens) of Centre County, where he serves on the executive board. He has worked with the Pennsylvania Association of Rehabilitation

Facilities, speaking at the organization’s annual convention and helping to organize plenary sessions. In addition, he is co-organizing a Penn State conference on Alzheimer’s and dementia for March 2007.

His outreach efforts extend well beyond Pennsylvania, taking him to conferences of the St. Louis Down Syndrome Association,

Dr. Michael Bérubé explores society’s responsibility to the disabled.

Steve Tressler—Mountain View Studios

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the Connecticut Down Syndrome Association and the Canadian Down Syndrome Association, where he has delivered keynote addresses.

As he explores the full range and potential of human life, he has also contributed to public discussions about Terri Schiavo, early intervention, genetics, inclusive education, living wills and end-of-life issues.

“Michael has done an enormous job taking disability public, bringing into sharp relief the forces that oppress and alienate disabled people,” said Dr. Simi Linton, president of Disability/Arts, an organization that works with artists and cultural institutions to help shape the presentation of disability in the arts and to increase the representation of works by disabled artists. Linton, who is disabled herself, writes and teaches in the field of disability studies and is involved in the Rock Ethics Institute.

Personal Experience, Professional Growth

Bérubé’s work is informed by his own experience of raising a son with Down syndrome. Jamie Bérubé sounds like a well-adjusted seventh grader, hanging out at the YMCA after school, struggling with the irregularities of French grammar and traveling with his family. Bérubé attributes some of this successful inclusion to the fact that they have chosen to live in a place where Jamie’s needs can be met. The State College Area School District provides a variety of services that strive to help every student achieve his or her full potential—from assisting with speech and language development, to working with autistic children, to providing emotional support.

For the more than 54 million Americans with disabilities, there’s still much more work to be done. To learn about Penn State’s Disabilities Studies Program, visit <http://rockethics.psu.edu/disability>. ▀