

Sunday Review | NEWS ANALYSIS

Giving a Name, and Dignity, to a Disability

By DAN BARRY MAY 7, 2016

IDIOT. Imbecile. Cretin. Feebleminded. Moron. Retarded.

Offensive now but once quite acceptable, these terms figured in the research for a lengthy article I wrote in 2014 about 32 men who spent decades eviscerating turkeys in a meat-processing plant in Iowa — all for \$65 a month, along with food and lodging in an ancient former schoolhouse on a hill.

These were men with intellectual disability, which meant they had significant limitations in reasoning, learning and problem solving, as well as in adaptive behavior. But even though “intellectual disability” has been the preferred term for more than a decade, it gave my editors and me pause.

We wondered whether readers would instantly understand what the phrase meant. What’s more, advocates and academicians were recommending that I suppress my journalistic instinct to tighten the language. I was told that it was improper to call these men “intellectually disabled,” instead of “men with intellectual disability.” Their disability does not define them; they are human beings with a disability.

This linguistic preference is part of society’s long struggle to find the proper terminology for people with intellectual disability, and reflects the discomfort the subject creates among many in the so-called non-disabled world. It speaks to a continuing sense of otherness; to perceptions of what is normal, and not.

“It often doesn’t matter what the word is,” said Michael Wehmeyer, the director and senior scientist at the Beach Center on Disability at the University of Kansas. “It’s that people associate that word with what their perceptions of these people are — as broken, or as defective, or as something else.”

For many years, the preferred term was, simply, idiot. When Massachusetts established a commission on idiocy in the mid-1840s, it appointed Dr. Samuel G. Howe, an abolitionist and early disability rights advocate, as its chairman. The commission argued for the establishment of schools to help this segment of society, but made clear that it regarded idiocy “as an outward sign of an inward malady.”

“It seemed impious to attribute to the Creator any such glaring imprecation in his handiwork,” Howe wrote in 1848. “It appeared to us certain that the existence of too many idiots, in every generation, must be the consequence of some violation of the natural laws; that, where there was so much suffering, there must have been sin.”

After Howe established the Experimental School for Teaching and Training Idiotic Children — the first of its kind — there gradually developed a profession to provide services to people with intellectual disability, as well as efforts to diagnose, define and categorize. “The term ‘feeble-minded’ began to be used as a catchall,” Dr. Wehmeyer said — as in, say, the Pennsylvania Training School for Feeble-Minded Children.

With the pseudoscience of eugenics finding traction by the turn of the century, some came to perceive people with intellectual disability as a threat to the American stock. The eugenicist Henry H. Goddard provided the cautionary tale of an American Revolutionary War soldier he called Kallikak (a twinning of the Greek words for beauty and bad), who was said to have fathered children with his virtuous Quaker wife and with a feeble-minded barmaid. His “legitimate” heirs were held out as upstanding citizens, while the “illegitimate” descendants were said to be criminals, paupers and dull-witted wastrels.

This supposed link to immoral behavior led to the infamous sterilization of Carrie Buck, a 17-year-old girl with short-cropped dark hair who had been raped while in foster care. After she gave birth at the Virginia Colony for Epileptics and Feeble-minded, the state determined that she was intellectually deficient and

petitioned to have her sterilized as a way to test a new Virginia law, the Eugenic Sterilization Act of 1924, which was ultimately upheld by the United States Supreme Court.

Buck was sterilized and released. Her daughter, Vivian, died of intestinal complications at the age of 8, and Carrie herself died at 76 in 1983. There was no evidence that either had cognitive impairments.

Goddard later backed away from some of his work, but not before coining a term that became another catchall: “moron,” from the Greek word for dull. According to the author Daniel Okrent, who is researching a book about immigration and eugenics in the early 20th century, Goddard took pains to emphasize that a moron could look “normal” — an “extremely potent” concept, Mr. Okrent said, in feeding the era’s rampant xenophobia.

Each succeeding term that entered the lexicon developed a pejorative connotation; consider the idiot-and-moron banter of the Three Stooges. At the same time, the medical community continued to refine its understanding of — and language for — intellectual disability.

“A lot of this has to do with the terminology for what you think normal is,” Douglas Platt, curator of the Museum of Disability History in Buffalo. “Normal meaning me, or you, or us. People who aren’t like us are something. So let’s come up with a name for them.”

By the 1950s, the accepted term had become mental retardation. At one point the National Association for Retarded Children — now known as the Arc of the United States — ran full-page magazine advertisements featuring a portrait of Barbra Streisand over the caption: “My next child could be retarded. So could yours.”

But no matter how well intentioned, this term also devolved into a pejorative, posing a problem for groups and government agencies whose names included the r-word. And as people with intellectual disability moved out of institutions and took their rightful place in the community, they began to advocate for themselves — and to express their loathing for the word “retarded.”

Their message was “loud and clear,” said Peter V. Berns, the chief executive of the Arc. “The word was offensive and they didn’t like the fact that it was part of our name, so we changed our name in 1992.”

OTHER organizations and state agencies have done the same, most of them joining the medical and scientific communities in adopting the term now in favor: intellectual disability.

Dr. Wehmeyer said the change made an important break from the connotations of past terminology. “It’s the first term that doesn’t refer to the condition as a defective mental process — slow, weak, feeble,” he said. “Intellectual disability conveys that it is not a problem within a person, but a lack of fit between that person’s capacities and the demands of the environment in which the person is functioning.”

But even Dr. Wehmeyer did not immediately care for the term (“I would have gone with cognitive disability,” he said). And not everyone embraces what is called people-first language — as in “people with intellectual disability.” Advocates in the blind and deaf communities, for example, argue that such constructions are unnecessarily defensive and hinting of shame.

The question now is whether “intellectual disability” will remain the preference, or, like its predecessors, devolve into a derogatory taunt. The answer seems to hinge on society’s ability to shed its prejudices and move past that stigmatizing sense of otherness.

One of the men I wrote about, Keith Brown, lived for many years in Texas institutions before working for more than three decades in that turkey-processing plant in Iowa. His job was to “pull crop” — that is, to yank out part of the digestive systems of dead birds swinging past on shackles.

When he and the other men were finally removed from their squalid schoolhouse dormitory in 2009, after repeated failures of government officials to heed warnings, Mr. Brown was found to have suffered significant physical and emotional consequences, including post-traumatic stress.

Today he is the sole resident of an apartment in Arkansas. He is a commuter, a

pallet-jack operator, a pet owner, a Dr Pepper drinker, a brother, an uncle. He is many things, he says, “but I am *not* retarded.”

Correction: May 9, 2016

An earlier version of this article misidentified the 1924 law under which a 17-year-old girl, Carrie Buck, was sterilized. It was the Virginia Eugenical Sterilization Act, not the Racial Integrity Act of the same year.

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