

Defining disability up and down: The problem of “normality.”

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[Smith, J.D.](#) & Polloway, E.A. (2008). Defining disability up and down: The problem of “normality.” *Intellectual and Developmental Disabilities*, 46(3), 23-27.

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Abstract:

In 1993 an article that has become a classic in public policy was published in *The American Scholar*. In this essay, U.S. Senator Daniel Patrick Moynihan discussed the ways through which behaviors that have been considered deviant subsequently come to be accepted by society. In “Defining Deviancy Down,” Moynihan asserted that these behaviors were being ignored, tolerated, or even normalized. His examples included the deinstitutionalization of people previously considered incapable of community living, the increased presence of homeless people on the streets of American cities, various changes in the acceptance of diverse sexual behavior, and differences in the meaning of marriage and family in the United States.

Keywords: developmental disabilities | public policy | normality | cultural practices | disability definitions

Article:

In 1993 an article that has become a classic in public policy was published in *The American Scholar*. In this essay, U.S. Senator Daniel Patrick Moynihan discussed the ways through which behaviors that have been considered deviant subsequently come to be accepted by society. In “Defining Deviancy Down,” Moynihan asserted that these behaviors were being ignored, tolerated, or even normalized. His examples included the deinstitutionalization of people previously considered incapable of community living, the increased presence of homeless people on the streets of American cities, various changes in the acceptance of diverse sexual behavior, and differences in the meaning of marriage and family in the United States.

In a response to Moynihan's article, Andrew Karmen countered that, for a number of decades, some groups and movements have been pushing hard to “define deviancy up” (Karmen, 1994, p. 106). He stated that if “defining deviancy ‘down’ means ignoring, normalizing, tolerating, or

even accepting behaviors that used to be stigmatized and punished, then defining deviancy ‘up’ means discouraging, deterring, forbidding, and outlawing behaviors that used to be overlooked or tolerated” (Karmen, 1994, p. 106). His examples included what had earlier been considered as parental prerogative in disciplinary practices being defined up as child abuse, what had been considered acceptable flirtation and joking being defined up as sexual harassment, and what had been the humorous figure of the drunk driver being defined up as a criminal.

Just as Moynihan and Karmen made their cases regarding deviancy, a similar argument can be made concerning cultural practices in defining disability. There is clearly a history of disability being defined both up and down. When a disability category is defined up, more people are identified as having that disability. When a disability is defined down, fewer people are identified as having that disability.

The practice of defining deviancy down can be seen, for example, in the continuing efforts by the American Association on Intellectual and Developmental Disabilities to periodically redefine the condition on which it focuses. Perhaps the most notable change reflected in these periodic definitions was in 1973. Mental retardation (i.e., intellectual disability) was defined down by the stroke of a pen in that year when the cut-off IQ score in the definition was changed from one standard deviation below the mean, as had been established in 1959 by the committee chaired by Rick Heber (Heber, 1959), to two standard deviations below the mean by the committee chaired by Herbert Grossman (Grossman, 1973). Burton Blatt and his colleagues noted the irony that with this change in the definition of mental retardation, millions of people were “cured” of the condition overnight (Blatt, Bogdan, Biklen, & Taylor, 1977).

The dramatic increase in some disability categories in recent years illustrates the phenomenon of defining disability up. This is clearly the case with attention deficit hyperactivity disorder (ADHD). Perhaps the most compelling example, however, is the autism spectrum. The creation of this concept and category, along with other, not well understood phenomena in our society, have resulted in significant increases in the identification of persons with autism, Asperger syndrome, and other conditions included under that umbrella term (Autism Society of America, 2006). The defining up of the autism spectrum has resulted in positive changes in public understanding of these conditions and the availability of interventions for these children and adults. The defining up of autism also has resulted in gains in the effectiveness of advocacy for those whose lives have been changed by the level of definition given to it.

Vietnam and Defining Disability Down

It is important to understand, however, that defining disability up or down can have very negative consequences. It is also important to recognize that defining disability up or down is not always done through the efforts of professional organizations. It is often done by social or political forces. This may happen when these forces are responding to what is thought to be necessary for the accomplishment of certain social goals. Compelling examples of modifications in the definition of disability to achieve specific utilitarian ends are changes made in times of war.

The defining of disability down for military purposes has a rich tradition in the United States. Recently, Smith and Lazaroff (2006) described in some detail the experiences of persons with intellectual disabilities in World Wars I and II. An even more compelling example of defining intellectual disabilities down occurred, however, during the Vietnam War.

On August 23, 1966 in a speech before the Veterans of Foreign Wars, Secretary of Defense Robert McNamara declared:

The poor of America have not had the opportunity to earn their fair share of this Nation's abundance, but they can be given an opportunity to serve in their Country's defense, and they can be given an opportunity to return to civilian life with skills and aptitudes which for them and their families will reverse the downward spiral of human decay. (as cited in Sellman, 1990, p. 2)

Two months later, McNamara launched Project 100,000. It was presented as a facet of President Lyndon Johnson's War on Poverty. It consisted of a plan to induct into the military men who previously would not have qualified for the armed services because of low scores on the Armed Forces Qualification Test (AFQT). McNamara's plan is one of the most straightforward efforts in American history to define disability down, as a way to enhance the number of individuals available to fight the war in Vietnam.

In 1950 the U.S. military initiated the AFQT, a battery of tests that every recruit is still required to take. The AFQT results are used to classify each individual into five categories from high to

low aptitude. The AFQT consists of verbal and mathematical items and yields a measure of what is considered general trainability for military service. Category I includes those applicants scoring at Percentiles 93–100; Category II includes those scoring at Percentiles 65–92; and Category III includes Percentiles 31–64. Categories I and II are considered indicative of above-average trainability, and Category III is considered average. Categories IV and V had usually been considered to be below average and not eligible for military service prior to Project 100,000 (Sellman, 1990).

McNamara created the project for what he asserted were important social purposes. Among these were greater equity in what he described as the opportunities and obligations of military service and recognition that the military had unique capabilities to produce competent military personnel among disadvantaged men who had previously been rejected for service (Sellman, 1990). By 1971 when the program ended, more than 340,000 men had entered the armed services under Project 100,000 (the original goal of the program was to induct 100,000 men each year). Their average age was 20, and 41% were from minority backgrounds. They all came from Category IV, meaning they fell between the 10th and 30th percentiles on the AFQT. According to Hedlund (1957), Category IV percentile scores are equivalent to IQ scores between 70 and 91 on the Wechsler Adult Intelligence Scale (Wechsler, 1955). This means that many of these men would have been categorized as being mentally retarded by the IQ standard of 84 and below used at that time, and some might have been under more recent guidelines of an IQ score of 70 + 5 points (e.g., Grossman, 1973; Luckasson et al., 1992). The average reading ability of the men in Category IV was at the sixth-grade level, with 13% of them falling below the fourth-grade level (Sellman, 1990; Sticht et al., 1987).

The program, also referred to as “New Standards,” was not met with unanimous acceptance in the military. There are reports that it was referred to within the Pentagon and in Vietnam as “McNamara's Moron Corps” (Sticht et al., 1987, p. 38).

Baskir and Strauss (1978), in speaking of Project 100,000, argued that it failed.

It was a failure for the recruits themselves. They never got the training that military service seemed to promise. They were the last to be promoted and the first to be sent to Vietnam. They saw more than their share of combat. ... Many ended up with greater difficulties in civilian society than when they started. For them, it was an ironic and tragic

conclusion to a program that promised special treatment and a brighter future, and denied both. (p. 131)

Iraq and Defining Disability Down

The war in Iraq has also produced reports of difficulties facing military recruiters and related reports of changed enlistment standards. For example, Hodierno (2006) reported that the Army fell short by 7,000 in its attempt to reach the goal of 80,000 new soldiers in the year ending September 30, 2005. Although the Army felt that this goal would be reached in the subsequent year, Hodierno reported that it was likely to be achieved by increased enlistment bonuses as well as by modifications in standards. As Hodierno (2006) noted, the Army has “had to relax medical standards, forgive more minor criminal offenses, raise the age limit for new recruits, ... and accept more people who did not finish high school” (p. 1). Hodierno concluded his observations by indicating that an annual average of 126 recruiters (up from an average of 93 earlier) have been caught in some form of impropriety in their recruitment efforts over the last 3 years.

Among the examples of the interaction of recruitment needs for the war in Iraq and disability definitions is the case of Jared Guinther. Jared was diagnosed with autism when he was 3 years old. He was not aware of the war in Iraq until his parents explained it to him after an army recruiter stopped him on his way home from school (Roberts, 2006).

Jared, who received special education services since preschool, was offered a \$4,000 signing bonus to join the military, \$67,000 for college, and “more buddies than he could count” (Roberts, 2006). After Jared signed enlistment papers, his parents attempted to intervene and prevent his induction. They reported that he did not understand that he was committing to 4 years of service or that he would not be paid the signing bonus until after basic training. A newspaper reporter investigating Jared's enlistment found that he was recruited to become a cavalry scout, “engaging the enemy with anti-armor weapons” (Roberts, 2006). After the story of his enlistment was published, the recruiter denied knowing of Jared's autism. His parents were waiting to hear if he would be released from enlistment (Roberts, 2006).

A similar case is that of Eddie Brabazon. Eddie was diagnosed with bipolar disorder and attention deficit disorder at Age 10. He spent his early teenage years in a psychiatric hospital and a series of group homes, and he required psychotropic medications (Kauffman & Chedekel, 2006).

Eddie's adoptive parents were amazed when he was accepted into the Army's elite 505th Parachute Infantry Regiment based at Fort Bragg, North Carolina, and handed an M-4 rifle. Although his mother protested, Eddie also stopped taking his medications because he "wanted to be like everyone else" (Kauffman & Chedekel, 2006).

Unfortunately he died in Iraq on March 9, 2004. He shot himself in the head with his rifle at a palace compound in Baghdad (Kauffman & Chedekel, 2006).

Another example of the "normalizing" effects of war comes from the endemic violence in Iraq. Amar, not yet 20 years old, was born with Down syndrome or, as it was reported that Iraqis say, "mongoli." He died after insurgents strapped explosives to his chest and guided him to a voting center on the day of the first national election (McGeough, 2005).

After voting in the early morning, Amar's parents joined other family members for a lunch celebration. Amar had been left at home to wander the neighborhood as he usually did under the protective eyes of friends. The sound of an explosion interrupted the party. Then news came that a "mongoli" had been the bomber. His parents raced home and found Amar laying in broken pieces on the pavement. The next day, before sunrise in Baghdad, "His grieving parents loaded his remains on the roof of a taxi to lead a sorrowful procession to the holy city of Najaf" (McGeough, 2005). Sadly, one can conclude that, on all fronts in this war, there is evidence of disability being defined down to provide warriors for the battle.

The Problem of Normality

Efforts to define disability up or down have their foundation in the elusive concept of normality in our society. There may be no better example of this concept than from the stories that surround our nation's most renowned study of "feble-mindedness," the study of the Kallikak family (Goddard, 1912; Smith, 1985).

The woman to whom Henry Goddard gave the pseudonym "Deborah Kallikak" lived 81 of her 89 years in two institutions in Vineland, New Jersey. From the time she entered the Vineland

Training School for Feeble-minded Boys and Girls at Age 8 until she died at Age 89 at the Vineland State School, she would never know life free of institutional influence. Yet, people who knew her consistently remarked on her beauty, charm, and competence and her seeming normality. The pioneering psychologist J. E. Wallace Wallin, during a visit to the school, found her in charge of the kindergarten class and mistook her for a teacher (Doll, 1983). Deborah worked in the home of the superintendent of the school and assumed child care responsibilities for the assistant superintendent of the state school. Children from both families visited and corresponded with her throughout her life. A woman in one of the families named one of her own daughters after Deborah (Doll, 1983).

Deborah sometimes accompanied these families to the Jersey shore for vacations. Her favorite vacations, however, were a series of trips she took with Helen Reeves, a social worker at the Vineland State School (Reeves, 1945). On a bus trip to Niagara Falls in 1942, Deborah took note of a new passenger who boarded at one of the stops along the way. According to Reeves,

Deborah was especially interested in one frowsy young woman, unkempt and unwashed, who got on the bus carrying a huge bag of groceries and at the same time managing a small child as dirty as herself. After surveying every detail as the young woman paid her fare, Deborah turned to me with the comprehensive diagnosis: 'Feeble-minded—and yet not.' There are some clinics that might spend hours in coming to the same psychological conclusion—borderline mentality. (Reeves, 1945, p. 7)

Reeves concluded her description of her vacations with Deborah with an interpretation of the significance of the trips.

All of these wider horizons mean a great deal to Deborah and have brought her improved stability as well as general happiness. I believe her when she says 'Those three days sees me through the whole year long.' I also believe those three days mean even more than a good time in new and exciting surroundings because for that space of time Deborah lives under the illusion she is normal ... What is the essential need of the human soul? 'Love' says Freud; 'Security,' says Jung; 'Significance,' says Adler. As far as Deborah Kallikak is concerned she has found out she can get along without the first and will take a chance on the second provided she may be given the third for a little while each year. (Reeves, 1945, p. 9)

How can it be that a social worker who had such close and continued contact with a woman who, by all indications, was inaccurately diagnosed as having an intellectual disability and who was needlessly institutionalized for 81 years failed to see these tragic mistakes? Perhaps Deborah herself provided the best answer to this question in another conversation with Helen Reeves.

I turn to Deborah Kallikak, who happens to be spending the weekend with me at my home. Soon Deborah and I are deep in discussion of some institution matters. ... The discussion comes to an abrupt end as she suddenly remarks: “D’you know, its normal people who are the real problems. *They* think us feeble-minded people are problems, but *they’re* the real ones. They got so much to think about, half the time they don’t know what to think. Yessir, normal people are the real problems—I been watching ‘em a long time, now!”

“But, Deborah, as you know, the feeble-minded problem is considered very depressing by a lot of folks. Of course, it isn’t, but what about the problem of normal people. Is that depressing?”

“Sometimes yes, and sometimes no,” replies Deborah, warily. ‘I’d say most generally always, yes.’ (Reeves, 1948, p. 183, italics in original)

Deborah's insights on the concept of normality provide an excellent perspective on society's efforts to understand and respond to disability. Defining disability down or up has frequently been done without input from those individuals most directly affected by those changes. It has been done by “normal” people. It has often been done in service of what normal people have deemed to be in their own best interests. Deborah's wisdom provides us with direction for the future in seeking not only self-determination for individuals with disabilities but their leadership in terms of creating a society that truly affords appropriate support and broad opportunities for all people. Perhaps if we do so, there will be less coercion and violence in our world.

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