Mental Retardation and the Problem of “Normality”: Self-Determination and Identity Choice

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Abstract: The meaning of the category and concept of mental retardation is explored through the words of a fictional character, and the accounts of real people who have been injured and stigmatized by the label. Examples of the extremes to which people have gone to avoid or escape the term mental retardation are provided. The classification of retardation is presented as a fabrication with no coherence in the characteristics and needs of the people placed under its conceptual umbrella. A call for new terminology and, more importantly, new thinking about this misunderstood and nearly forgotten population of children and adults is issued.

How has the label mental retardation influenced the feelings and self-esteem of people who have been so labeled? For decades investigators have conducted research on this question and have generally reported no direct relationship between labeling and self-concept (MacMillan, et. al., 1974). Foxx and Roland (2005), in fact, claimed recently that labeling and the “obsession with self-esteem” constitutes a fallacy in educational practice, particularly in special education. The arguments presented here, however, are contrary to these reports in relation to the label of mental retardation. The evidence offered consists of the voices of people whose lives have borne the impact of the retardation designation, and who have struggled with the stigma associated with it. One of these voices is that of a fictional character, his words based on the perceptive observations of an acclaimed writer. Others are the words of real people who give voice to their own struggles with an identity that was not of their own choosing.

The stories and voices presented here are intended to provoke questions about the meaning of mental retardation and the people to whom the term and concept has been assigned. Change has already come to the terminology applied to these people. The more important question is how the mind of the public can be changed regarding who they are and what they need in order to claim their citizenship.

Forrest Gump: His Original Voice

The 1994 film, Forrest Gump, was a humorous and yet moving portrayal of a man diagnosed during childhood with physical disabilities, and an IQ that categorized him as mentally retarded. This highly romanticized saga of life with disabilities unfolds with Forrest attending regular public school classes due to the persistence of his mother, his becoming a college football star, decoration as a Viet Nam War hero, business success yielding millions of dollars, and his elevation as a spiritual cult figure. Most importantly, it depicts him as a sensitive and strong friend, husband, and father.

The most famous line in the movie is in the first scene. Forrest offers a chocolate to a nurse sitting next to him at a bus stop. He explains to her, “My momma always said, life is like a box of chocolates. You never know what you’re gonna get.” In the book by Winston Groom on which the movie was based, however, Forrest’s reference to a box of chocolates is quite different. It provides a contrasting portrait of his struggle with being classified as retarded.

Let me say this: bein a idiot is no box of chocolates. People laugh, lose patience,
treat you shabby. Now they says folks sposed to be kind to the afflicted, but let me tell you—it ain’t always that way. Even so, I got no complaints, cause I reckon I done live a pretty interestin life, so to speak.

I been a idiot since I was born. My IQ is near 70, which qualifies me, so they say. Probly, tho, I’m closer to bein a imbecile or maybe even a moron, but personally, I’d rather think of mysef as like a halfwit, or somethin not no idiot—cause when people think of a idiot, more’n likely they be thinkin of one of them Mongolian idiots—the ones with they eyes too close together what look like Chinamen an drool a lot an play with theyselfs.

Now I’m slow—I’ll grant you that, but I’m probly a lot brighter than folks think, cause what goes on in my mind is a sight different than what folks see. For instance, I can think things pretty good, but when I got to try sayin or writin them, it kinda come out like jello or something...

Now I know somethin bout idiots. Probly the only thing I do know bout, but I done read up on em—all the way from that Doycheeveskie guy’s idiot, to King Lear’s fool, an Faulkner’s idiot, Benjie, an even ole Boo Radley in To Kill a Mockingbird—now he was a serious idiot. The one I like best tho is ole Lennie in Of Mice an Men. Mos of them writer fellers got it straight—cause their idiots always smarter than people give em credit for. Hell, I’d agree with that. Any idiot would. HeeHee (Groom, 1986, pp.1-2).

The words that Winston Groom has Forrest speak regarding being labeled with the terminology of mental retardation have been spoken repeatedly through fictional characters. They are so numerous and insightful that they constitute evidence of a shared understanding of mental retardation as a label and its consequences by some of the world’s greatest novelists and short story writers (Halliwell, 2004). They are too numerous to be cited here.

The Problem of “Normality”

The woman that Henry Goddard gave the pseudonym Deborah Kallikak lived 81 of her 89 years at two institutions in Vineland New Jersey. From the time she entered the Vine- land Training School for Feebleminded Boys and Girls at age eight until she died at age 89 at the Vineland State School, she would never know life free of institutional influence. And 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 Training School found her in charge of the kindergarten and mistook her for a teacher (Doll, 1983). Deborah worked in the home of the superintendent of the Training 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 New 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. These excursions included trips to Washington, D.C., the New York World’s Fair, Luray Caverns and Philadelphia (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: ‘Feebleminded—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’!” (Reeves, 1948, p. 183).

‘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).

In his 1912 book, The Kallikak Family: A Study in the Heredity of Feeblemindedness, Henry Goddard portrayed Deborah as the prototype of his conception of the moron, the term he created for mild mental retardation. He argued that her institutionalization at the Vineland Training School was necessary for her own well-being and for the protection of society. He asserted that if she were released she would almost immediately fall into a life of depravity and promiscuity. He also talked of the positive effects on her life of the institution. He presented pictures of her in the book which displayed not only her handiwork (sewing and woodworking), but which also exhibited her attractiveness. According to Goddard, she was thriving and growing because she was institutionalized.

Here is a child who has been most carefully guarded. She has been persistently trained since she was eight years old, and yet nothing has been accomplished in the direction of higher intelligence or general education. Today if this young woman were to leave the Institution, she would at once become a prey to the designs of evil men or evil women and would lead a life that would be vicious, immoral, or criminal, though because of her mentality she herself would not be responsible. There is nothing that she might not be led into, because she has no power of control, and all her instincts and appetites are in the direction that would lead to vice (Goddard, 1912, pp. 11—12).

Deborah was in a wheelchair during her final years. She was often in intense pain because of severe arthritis and was unable to continue the crafts she had loved throughout her life. In her last years, she was offered the alternative of leaving the institution to live in the community she had been denied most of her life. She declined the opportunity. She knew she needed constant medical attention (Smith 1985). Emma Wolverton, her real name, had also come to believe deeply the story that had been told of her in the name of Deborah Kallikak.

The book, Mother, Can You Hear Me?, by Elizabeth Cooper is the story of a psychologist who searches for her birth mother. This journey led her to the discovery that her mother was deaf, had been misdiagnosed as mentally retarded and had been institutionalized. In the book Cooper speaks of her internship in psychology at the State School at Vineland and her relationship with Emma Wolverton.

. . . Sometimes I felt as though I were one of the residents in the small barren institutional room where I spent my nights and
several weekends. Emma was one of the residents, and she had interesting stories to tell me. Her job was to do some of the hand ironing, and she had been allowed to set up a small space like a tiny apartment for herself. She was very friendly toward me. From her I learned firsthand about the classic study of two branches of the Kallikak family, from which she was descended. . .She was devoted to the people who conducted the study, as though they were her family. Test results found her to be retarded, but I found her to be informative and interesting to talk with. She was considerate and personable and certainly not what I would think of as a retarded person. . .Emma was tall and reticent in her manner. She reminded me of anyone’s elderly aunt. . .The people who [studied] her wanted to show a genetic basis for her mental deficiency. They traced her roots back to Revolutionary War days—she could have belonged to the D.A.R. . .Emma was taken into her training school at an early age and, I believe, “trained” to fulfill the prophecy of deficiency (Cooper, 1983, p. 79).

Indeed, she had been trained to think of herself as deficient, she and thousands of others in America’s schools and institutions.

The State School Boys, the Label and the Rebellion

Orphaned and then left alone by the death of his foster mother in 1949, eight-year-old Freddie Boyce was given an IQ test. On the basis of this one test score he was sent to the Fernald State School in Massachusetts. He and other children like himself who were diagnosed as having mild mental retardation (feeblemindedness), were denied appropriate educational opportunities and were frequently abused. There were repeatedly told by staff members of the institution that they were incapable and incompetent.

In his book, The State Boys Rebellion, Michael D’Antonio describes the humiliation that Freddie experienced along with other boys who had been committed to Fernald under similar circumstances.

By the time they were ten or eleven, the State Boys understood that nearly everyone on the outside considered them to be “retards.” This word hurt them as much as the word “nigger” hurt blacks. When they were angry they flung it at each other.

Attendant McGinn reduced boys to tears by calling them retards as they waxed the floors and buffed them. . .More than one would recall, as adults, how McGinn whispered into their ears that they were “worthless” or “stupid” and that “no one gives a shit about you.”

Another bit of torture, which McGinn began to use after Freddie had been at the [institution] for a couple of years, was reserved for those who talked during meals in the downstairs dining room. He would grab a slice of bread from the boy’s tray and tear off enough to wad into a ball the size of a large marble. He would then yank the boy to his feet, and tell him to get down on the floor and push the bread with his nose. McGinn would laugh and say, “Look at the retard” (D’Antonio, 2004, p. 77).

After hearing these words of belittlement and degradation so often from authority figures, some of the boys began to believe they were true.

The humiliation and constant name-calling—retard, lifer, moron—were difficult to ignore. This barrage beat down Albert Gagné until he began to believe that he was defective and destined to spend his entire life inside the institution. He became more and more withdrawn from the other boys (D’Antonio, 2004, p. 78).

Others of the boys, however, resisted and challenged the derogatory labels with which they were constantly bombarded. Usually their challenges did not lead to changes in their status, even when the facts uncovered through their challenges belied the names they were being called and the necessity for their being institutionalized. The experience of Joey Almeida illustrates this futility.

Every act of defiance was a challenge to the “retard” label. In a few rare cases, these challenges worked, and some on the Fernald staff were forced to recognize that a diagnosis or assessment might be wrong. Soon after he was admitted, Joey Almeida began insisting that the state had gotten his age wrong, that he was really ten, not
eleven. In a meeting with a social worker, he was so adamant that the social worker finally agreed to look it up. It turned out that Joey was right.

Intrigued by the way Joey had calmly asserted himself in conversation, the social worker gave him a new IQ test. In his subsequent report, he wrote that he found “no real evidence of this boy being significantly retarded, particularly to a degree that requires institutionalization.” Joey’s problem “seems to be emotional rather than his being retarded. . . if guided correctly, in a place other than Fernald, he would have a better opportunity in life.” Nothing was done in response to this report. Joey remained in Fernald, in the Boys Dormitory, perpetually worried that the daily taunt—You’re a lifer—was his fate (D’Antonio, 2004, pp. 82-83).

The State Boys were inspired by radio and television reports about the Civil Rights Movement. This led them to protest their verbal and physical abuse by the staff and even their institutionalization at Fernald. After pleading for better treatment to no avail, they ran away. Caught and brought back, they seized control of their ward and demanded that their rights be recognized. Although they were imprisoned and otherwise punished for their actions, they were eventually released to fend for themselves.

While there were tragic life stories for some of the State Boys, others managed to build strong and productive lives for themselves after leaving Fernald. In the late 1990s they became aware through news coverage that they had been used as human guinea pigs while at the institution. They had been fed radioactive oatmeal as part of an experiment on the physiological effects of radiation. This brought the Boys together again and they sued the State of Massachusetts and won a multimillion-dollar settlement (D’Antonio, 2004).

The drive of the State Boys to free themselves from the label of mental retardation has been found to be shared widely by those to whom it has been assigned. In an important study and excellent review of the literature Finlay and Lyons (2005) found that escape from being labeled in this manner is a common quest for those who are asked for their own opinions of the diagnosis of mental retardation that has been assigned to them by others.

Escaping the Label at All Costs: The Rape at Glen Ridge

In 1989 a group of male high school athletes in the affluent town of Glen Ridge, New Jersey, were accused of sexual assault of another student. She was assaulted with a broom handle, stick, and baseball bat. The young woman had been labeled mentally retarded. Rape charges were brought against seven of the young men. When the victim was called upon for testimony one of the attorneys defending the accused young men said to her that some people thought of her as being mentally retarded. She agreed saying, “Lots of kids in school said that.” But she also agreed when he said that she “was proving (herself in court) . . . not retarded.” His intent was to show that her performance as a witness was evidence that she was not retarded, and therefore that she had not been taken advantage of by the boys. She supported his argument by saying, “If I was retarded, I could never answer all these questions” (Haney, 1992, p. 36). More important to her than the conviction and punishment of those who had assaulted her was to be seen as competent and articulate. She was driven by the wish to escape the label and to be accepted as a “normal” person.

In spite of her struggle to prove her competence, however, the victim of the Glen Ridge rape became the person she had been labeled to be in the judgment of the court and others. Expert witnesses, her family, and others who testified portrayed her (in support of the charges against her rapists) as fitting the stereotype of mental retardation, she was described as defective, weak, and unable to protect herself. And so the price of justice in her case was the loss of the identity she craved, to be “normal” instead of “retarded.” In the words of one of her convicted abusers, “I now understand. . .how sick she really is, and I just feel great feelings of guilt and shame and I wish nothing had ever happened” (Lefkowitz, 1997, p. 162). Even though her articulate testimony was central to the conviction, she had
become to her rapist and others a subject of pity, a person “sick” with retardation.

Mental Retardation: It’s Like a Box of Chocolates. You Never Know What You’ve Gonna Get

In 1992, the American Association on Mental Retardation (now the American Association on Intellectual and Developmental Disabilities) listed more than 350 causes of mental retardation. This list of causes does not, of course, take into account the varying degrees of retardation or other disabilities associated with each of the etiologies. When those variables are considered the universe of human conditions subsumed under the term mental retardation is overwhelming. The staggering list of causes of mental retardation illustrates the allure and power of typological thinking. This is the belief that complex individual variations can be reduced to underlying human types or essences. Stephen Gelb (1997) has found that definitions of mental retardation regardless of their particulars are grounded in typological thought.

The term mental retardation has been used to describe people who are more different than they are alike (Gelb, 1997). It has been used as an amalgam for very diverse human conditions. The core of mental retardation as a field has been the assumption that somehow there is an “essence” that eclipses all of the differences that characterize people described by the term. It has truly been a box of chocolates, however, “you don’t know what you’re gonna get” when you reach into the category. Maybe it will be someone who needs constant care, or maybe it will be someone much like yourself but who needs help with academic skills. Maybe it will be someone with severe physical disabilities, or maybe it will be someone who you would pass on the street without notice.

What is certain about the category is that it has been a stigmatizing label with universally negative connotations. That may be the only “glue” that has held it together. According to James Dudley (1997) people with the label, particularly those with the mild mental retardation designation have found that they are not even embraced as part of the disabilities rights movement in the United States. A perspective on the meaning of the term disability that has been articulated in recent years is that the definition must be changed in a very fundamental way. According to Triano, “I define disability as a natural and beautiful part of human diversity that people with disabilities can take pride in” (Triano & Obara, 2003, p. 3). Listening to the voices of people who have had the mental retardation label it is hard to imagine how they could see it as “natural and beautiful.” Triano, in fact, acknowledges that a person with a “cognitive disability” is likely to be “excluded and left out” of the disabilities rights movement (p.2). Speaking of the special difficulties faced by people with mental retardation in becoming part of the movement for self-advocacy and civil rights she says:

Hannah Arendt once said that, “the most radical revolutionary will become a conservative the day after the revolution.” Since its founding, the disabilities rights movement in the US has served as a strong voice for radical revolutionary change. But no radical revolutionary force can remain so as long as it refuses to constantly evaluate itself and adapt according to the demands and needs of the changing times. When the strategies we use start to exclude and offend key segments of our community, allow participation by only those privileged members who can afford to participate, and rely on a tactic of secrecy to the point where it becomes an access barrier for members of our community with cognitive and other disabilities, then we have ceased to be radical and revolutionary (Triano & Obara, 2003, p.3).

Changing Names or Changing Minds?

There has been much discussion and some action in recent years regarding the use of the term mental retardation. Mental retardation has been questioned as both a concept and as a description. It has been called a myth (Smith, 2005). On the other hand, caution has been advised in changing the terminology of mental retardation given the potential funding and service implications of a major change (Luckasson and Reeve, 2001). Changes in language are already evident in the titles, policies, and mission statements of a number of the organizations (ARC, 2004; Stodden, 2002). The American Association on
Mental Retardation became the American Association on Intellectual Disabilities in January, 2007. A change in terminology is a move in a very positive direction. Mental retardation became the most stigmatizing of the disability labels and laundering the term itself of its stigma is impossible; it has had too many negative connotations for too long. People who have been labeled with the term mental retardation, and their families, should be asked how they wish to be known. I can find no evidence that they have ever been asked. Dudley (1997) has pointed out that other minority groups have determined for themselves how they wish to be known and when changes in language about them should be made (e.g. the historical changes in terminology from Negro, to Black, to Afro-American to African American). Mental retardation must become only an historical footnote. And yet changing the label alone will not serve the people currently categorized as mentally retarded very well. Changing our thinking about people is even more important than what we call them.

It is widely recognized that changes in the field of special education have had a direct and causative influence on the numbers of students in the retardation category, and on the interest and resources invested in the field. Many of the students who would have been designated as mildly retarded and served a generation or two ago are now served in learning disabilities contexts. Unfortunately there has also been a “forced migration” of others of these students from special education into a neverland of no service at all. It is not uncommon to find significant numbers of students who are unofficially considered to be simply and unquestionably “slow learners,” not eligible for special education. Many special educators, including myself, have stood by in relative silence while many of these students have been “disenfranchised” from special services. Inordinate numbers of these students are, of course, children and adolescents from poverty, minority, and language disadvantaged backgrounds.

Polloway (2004) asked whether the time has come for a eulogy for the field of mild mental retardation. I think he then answers his own question not only about mild retardation but about retardation as a whole. Yes, the term is dead and deserves a decent burial. But no, we cannot allow recognition of the needs of large numbers of children and adults to “pass away.” It is incumbent upon the many of us who began our careers in the field of mental retardation that we strive to rekindle interest in and commitment to the students who have escaped a negative identity, but who may now be adrift with little help for their significant learning needs.

Thus, in our appropriate efforts to downplay the deficits associated with mental retardation and emphasize the importance of a supports-based model, we may lose sight of the educational and life needs of persons traditionally identified as having mild retardation. The movement to inclusion is admirable, but a parallel commitment to ensuring the success of these individuals is also essential. . . the question is unanswered as to whether the passing of this category is best classified as lack of interest, lack of awareness, or deliberate attempts to bring about its demise. Regardless of cause, it is important that we continue to focus on making sure that these students will not be disadvantaged by our ignorance of their educational needs (Polloway, 2004, p.8).

The time is overdue for professionals, professional organizations, parents, self-advocates and others to reinvigorate the dialogue, to engage in the research, and push for the funding that will bring new life to the field that gave birth to special education. This is the legacy of Jean Itard, Maria Montessori, Elizabeth Farrell, Lloyd Dunn, Sam Kirk, and others who saw potential and possibilities where most educators saw obstacles. To repeat myself, even more important than changing a name is changing our minds, and the minds of others, about a largely misunderstood population of children and adults.

References


