Abandoning the Myth of Mental Retardation

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The “Retarded Retarded,” the “Normal Retarded,” and the “Minimally Gifted”

One of the great teachers I had during my doctoral studies at Teachers College, Columbia University was Professor Ignacy Goldberg. As great teachers often do, Dr. Goldberg engaged his students with stories from his own life. I remember clearly his accounts from early in his career of working in an institution for persons diagnosed as mentally retarded. He recalled that during his first days there an experienced staff member explained to him that there were actually three different populations of people in the institution, the “retarded retarded,” the “normal retarded,” and the “minimally gifted.” The retarded retarded needed constant care. The normal retarded and the minimally gifted often provided this help to them. The normal retarded were the mainstream population of the institution. They lived relatively independent lives within the culture of the institution. They were often given the most basic and unpleasant work to do (cleaning and caring for the retarded retarded). The minimally gifted made certain that things ran smoothly in the wards of the institution. They occupied the upper echelon of the residential society and were rewarded by the institution’s staff for doing things the employees were actually paid to do. Their rewards included cigarettes, money, privileges and other favors. The quality of institutional life often depended on the abilities, sensibilities, and compassion of the minimally gifted. Dr. Goldberg discussed the degrading nature of the terms used to describe the institution’s residents, particularly the sarcastic designation “minimally gifted.” The concept underlying the terms, however, he found to be valid. There were distinctly different groups of people in the institution, yet all of them were referred to as being the retarded. He used his story to question the monolith that mental retardation had become in the thinking of the public and in many professional circles (Smith & Mitchell, 2001).

Told in the Drooling Ward

A striking confirmation of Dr. Goldberg’s recollection came to me recently when I read a short story by Jack London. It was written from the perspective of a resident in a state mental retardation institution in the early twentieth century. London was an admirer of eugenics, and his philosophy included the assumption of innate human limitations of both racial and social class origins. London’s character in the story, Tom, repeats several times that the institution is the right place for him to be, and he implies that the outside world is too complex and competitive for him. On the other hand, London has Tom explain the ways in which he is superior to others within his institutional world and how they rely on his abilities for their well being. Tom’s description of the differences among the people in the institution make the story, “Told in the Drooling Ward,” a compelling reading experience for anyone interested in the sociology of institutionalization.

Me? I’m not a drooler. I’m the assistant. I don’t know what Miss Jones or Miss Kelsey could do without me. There are fifty-five low-grade droolers in this ward, and how could they ever all be fed if I wasn’t around? I like to feed the droolers. They don’t make much trouble. They can’t. Something’s wrong with most of their legs and arms and they can’t talk. They are very low-grade. I
can walk, and talk, and do things. You must
be careful with the droolers and not feed
them too fast… Miss Jones says I’m an ex-
pert. (London, 1916, p. 87)

Tom goes into further detail about his spe-
cial place in the hierarchy of the institution.
He also divulges the fact that there are people
in the institution who have been placed there
because of epilepsy and he doesn’t like them.
He clearly thinks that they don’t belong in
what he calls the Home.

But I am a high-grade feeb. Dr. Dalrymple
says I am too smart to be in the Home, but
I never let on. It’s a pretty good place. And
I don’t throw fits like lots of the feebs. You
see that house up there through the trees.
The high-grade epilecs all live in it by them-
selves. They’re stuck up because they ain’t
ordinary feebs. They call it the club house,
and they say they’re just as good as anyone
outside, only they’re sick. I don’t like them
much. (London, 1916, p. 88)

Tom also describes several of his fellow res-
idents according to the etiology of their retar-
dation. His description of the characteristics
and prognosis associated with each diagnosis
is interesting and, in some cases, moving.

Do you know what a micro is? It’s the kind
with the little heads no bigger than your fist.
They’re usually droolers, and they live a
long time. The hydros don’t drool. They
have the big heads, and they’re smarter. But
they never grow up. They always die. I never
look at one without thinking he’s going to
die.

Tom fantasizes about how his life could be
improved if the staff of the institution openly
recognized his abilities. He believes that if he
were treated fairly he could have a “normal” life.

Some day mebbe, I am going to talk with
Doctor Dalrymple and get him to give me a
declaration that I ain’t a feeb. Then I’ll get
him to make me a real assistant in the drool-
ing ward, with forty dollars a month and my
board. And then I’ll marry Miss Jones and
live right on here. And if she won’t have me,
I’ll marry Miss Kelsey or some other nurse.
There’s lots of them that want to get mar-
ried. (London, 1916, p. 103)

The Elusive Essence of Mental Retardation

Typology is the study of groups of individuals
whose individual differences are eclipsed by
underlying types or essences. In anthropolog-
y, it asserts that homogeneous and valid classi-
fications can be established for people who
share critically defining characteristics. Gelb
(1997) has found that definitions of mental
retardation, regardless of their variations or
details, have all been established on the as-
sumptions of typological thought. From this
perspective, the axis or core of the field of
mental retardation is the conviction that there
is an “essence” of mental retardation. This
essence overshadows all of the individual dif-
ferences that otherwise characterize the peo-
ple who are classified by the term.

Even a glance at the panoply of etiologies
associated with the term mental retardation is
illustrative of the reductionistic allure and
power of typological thinking. In 1992 the
AAMR delineated more than 350 causes of
mental retardation (Luckasson et al., 1992).
This list does not, however, take into account
the varying degrees and specific types of dis-
abilities associated with these etiologies. If
these variables are added, the multiple and
complex meanings of what is called mental
retardation is staggering. The only conceptual
“glue” that holds mental retardation together
as a category of human beings is the typolog-
ical notion that there is some fundamental
essence to the universe of characteristics and
the vastly differing needs of the people iden-
tified by this term. Clearly, however, mental
retardation is a term used to describe an ag-
gregation of diverse human circumstances.
The only rationale for this aggregation ap-
pears to be the typological reasoning that
Gelb (1997) has described.

The Invention of Mental Retardation

Burton Blatt once described mental retarda-
tion as an “invented disease” (1999, p. 86). In
these remarks published after his death, he
further describes it as a story about a large
group of people that is both unnecessary and
untrue, and he compared it to the invention
of old age as a disease. As usual, Blatt was
ahead of his time.

He repeated that mental retardation is an
invented disease. “The only treatments possible for invented diseases are those which are themselves invented. And in that sense, all treatments for mental retardation are abusive” (Blatt, 1999, p. 95). He acknowledged that there are people with problems for whom a caring society must provide care and treatment and some of them have been described by the term mental retardation. He included many people who may not “read well ... or think well” in this category (p. 95). “But in each instance, the ‘disease’ is not mental retardation, but something else . . . . The best way to cure an invented disease is to forget it. The best way to reduce abuses of those people unlucky enough to have ‘caught’ invented diseases is to offer no treatment, because abuse is the only treatment for an invented disease” (Blatt, 1999, p. 95).

The Myth of Mental Retardation

In The Conquest of Mental Retardation, Burton Blatt (1987) wrote of the importance of stories. Every story can enhance life or destroy it. Every story can lift us or depress us. Stories sustain if not make a person’s world. And thus, the storyteller holds a certain power (and responsibility). (p. 141)

In very important ways, stories of mental retardation have created and sustained the concept. Sometimes the stories have been positive. The stories of Itard and Victor, of Samuel Gridley Howe and Edward Sequin have encouraged generations of parents and professionals who care deeply about children and adults described by the term mental retardation. More often, however, the nature and intent of mental retardation stories have been negative. The pessimistic and cynical tales of the Kallikaks and Jukes questioned the efficacy of providing education and social services for people identified as retarded (Smith, 1985). The story of Carrie Buck became central to the argument for institutionalizing and sterilizing thousands of people labeled with the term (Smith & Nelson, 1989).

In speaking of the meaning of the term mental retardation, Trent (1994) defined it as a “construction whose changing meaning is shaped both by individuals who initiate and administer policies, programs and practices, and by the social context to which these individuals are responding” (p. 2). He argued that the term has sometimes been used in the name of science, sometimes in the name of protecting people, and sometimes in the name of economic necessity. In every case, however, it has been used for the purpose of controlling people perceived to be a threat, an inconvenience or a societal drain.

In 1961, Thomas Ssasz rocked the psychiatric world by proclaiming the “myth of mental illness.” He asserted that the medical terminology associated with the vast array of emotional and social difficulties that people may encounter in life was inaccurate and misleading. According to Ssasz, although the term mental illness “made good historical sense—stemming as it does from the historical identity of medicine and psychiatry—it made no rational sense. Although mental illness might have been a useful concept in the nineteenth century, today it is scientifically worthless and socially harmful” (Ssasz, 1961, p. ix).

Mental Retardation: Disaggregation as a Paradigm Shift?

The authors of the 1992 AAMR manual characterized their revisions to the definition and classification of mental retardation as a paradigm shift. This shift was presented as consisting of two facets. The first of these was a change in the conception of mental retardation from a trait existing in an individual to an expression of the interaction between a person with limited intellectual and adaptive skills, and that individual’s environment. The second element of the shift was an emphasis on the pattern of the person’s needs rather than deficits (Schalock et al., 1994).

Paradigm shifts may be critical to advancement and improvement in any field of endeavor. Thomas Kuhn (1962), in his classic book The Structure of Scientific Revolutions, defined paradigms as shared world views. Kuhn argued that these shared views eventually become so strong and institutionized that only a sudden and dramatic break from these conventional perspectives can bring on a positive revolution in thinking.

It must be recognized, however, that unlike physics, where a paradigm shift from the
world view of Newton to that of Einstein did nothing to change the reality of the physical universe, a paradigm shift in mental retardation is likely to have profound implications for the education, care and treatment of millions of human beings.

The effort to define mental retardation in a way that is scientifically accurate has been continuous for centuries. The effort to define it in a way that promotes greater sensitivity to the needs of people described by the term has also been continuous. A scientifically sound and socially helpful definition of the term mental retardation, however, may not be achievable. Perhaps the paradigm shift that is needed is an even more dramatic one than that which was achieved in the 1992 AAMR manual. What shift might best serve the interests of the people who are and those who could be defined in the future as having mental retardation? The most positive paradigm shift might be the deconstruction of mental retardation. The best definition of mental retardation may be no definition.

In my opinion, it is time to admit that the term mental retardation is, to use Szasz’s words “scientifically worthless and socially harmful.” It is time to face the reality that it is a manifestation of typological reasoning that has created a false and unhelpful categorization of people with very diverse needs and characteristics. Perhaps the plurality of the term developmental disabilities would better describe the heterogeneity of the people who have been labeled mentally retarded. It would be a more accurate term, and it would likely be less stigmatizing because of its generality.

Although the implications of abandoning the term for resource allocations and the provision of services must be carefully addressed, the term mental retardation should become an historical artifact of the evolution of our thinking about children and adults with developmental disabilities. The millions of people within the spectrum of developmental disabilities who have been described as mentally retarded deserve this change in the manner in which they are regarded and treated. A disassembling of the aggregation that mental retardation may provide an opportunity to enhance our vision of who these people are as individuals, and our understanding of their rightful place in our communities.

Last January, I received the ballot concerning the name change of the MRDD Division of CEC. I voted in favor of the Division of Developmental Disabilities title, I hoped that the change would occur. I also hoped that the movement away from the term mental retardation would provide us an opportunity to enhance our understanding of the people who have been described by the term, and our appreciation of their rightful place in the human community. Our division did the right thing. We have helped our world, I believe, take the first critical steps toward forgetting an invented disease, toward abandoning the myth of mental retardation.

References