

# Perspectives

## President's Address 2007

### The Past is Prologue: "MR," Go Gentle Into That Good Night

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The title of this paper requires apologies to two well-known authors: William Shakespeare and Dylan Thomas. The first phrase, "The Past is Prologue" is from William Shakespeare's *The Tempest*. I confess I first learned this phrase at the National Archives building in Washington, DC. It is carved in stone over the grand entrance to the building that holds our Constitution, Bill of Rights, and the letters of Benedict Arnold in its vast archives, which remind us that everything that has happened to us as a nation thus far (good and bad) has occurred to prepare us for that which follows. I feel that this is also the case for our Association today. We have a long, strong, and impressive past. All of our past (even the less glorious moments) has served as prologue.

The second phrase in the title "MR, Go Gentle Into That Good Night" is taken from the work of poet Dylan Thomas, and, although I hope it is self-evident, I will clarify my reference to his classic poem *Do Not Go Gentle Into That Good Night* in the second half of this paper.

#### The Past is Prologue

##### *The Past is "MR"*

In this paper, I use the phrase "MR" quite frequently. I am fully aware that the term is going out of vogue, and I am using it purposefully. By using "MR," I include our old association name, American Association on Mental Retardation—AAMR, the journal formerly known as *Mental Retardation* (now *Intellectual and Developmental Disabilities*), the *American Journal on Mental Retardation* (scheduled to be called the *American Journal on Intellectual Disabilities*), the *Terminology and Classification Manual of Mental Retardation*, and the construct of MR. I also include the millions of people sometimes re-

ferred to as *the retarded* and even those pop culture epithets of *retarded* and *retard*.

By MR, I mean all that is associated with the stigmatizing and labeling that happens to people on the basis of intellectual difference—the personal and phenomenological experiences of those called "the retarded."

Even as we rush to embrace the replacement term *intellectual disabilities*, "ID"—I will stick with MR for now. This is the disability we have addressed together, the field that has united us all, the human condition that we have deemed our primary concern.

##### *MR as Metaphor and Administrative Convenience*

Over the years, there has been much discussion about the social meaning of MR. Burton Blatt (1975) told us decades ago that MR is merely a metaphor. He warned us to be cautious of overextending the metaphor for problem-solving purposes. He also said that MR was a term of administrative convenience rather than a reality and should only be used to the extent that it serves people. Mental retardation is a label, an artifact of funding categories, not an independent reality.

*MR as synecdoche.* More recently, Ferguson and Ferguson (1997) reminded us of an old grammatical device you may have studied in English 101, called *synecdoche*. *The American Heritage Dictionary* defines *synecdoche* as, "A figure of speech in which a part is used for the whole as *hand* for *sailor*."

If a person has, as one aspect of his or her life, what Luckasson et al. (2002) defined as "significant limitations in intellectual functioning" (p. 1) and so on, as our definition goes, then we identify ID as a trait that we have been calling MR. If that trait (the part) becomes life-defining, and the individual (the whole) is totally defined by the one character-

istic, then we say an individual is MR; we refer to the group as “the retarded,” or (in the past), as “retardates.” The implication is that their very being is “MR.” The one part—intelligence—becomes the representation of the whole person: synecdoche.

*Mental retardation as liable.* Gunnar Dybwad took great pains to teach his students that MR is a label that is liable (Dybwad & Bersani, 1996). That is, the label itself makes negative statements about the person to whom it is applied. It is, in fact, liable. We know it can do harm.

My argument here is not that we should not use the term MR (or its much preferred successor, ID. I do believe there is a need for a term to be judiciously applied for specific purposes. There are educational, medical, social, and even forensic reasons to preserve our ability to accurately identify the people formerly referred to as having MR. I am not politically naïve on this point. I understand all too well that this matters, from eligibility for early childhood services to mitigation of capitol punishment. Rather, I am asking us to look beyond those important, but neatly circumscribed concerns and to also direct our attention, our scholarship, our advocacy, and even our personal commitments to the larger issues as well.

### Two Worlds of MR

Currently, there are two worlds of MR: (a) our world—those of us who define MR; and their world—those who are defined by MR. In our world, MR has given us jobs, careers, and professional status; MR provides us reasonably comfortable incomes, often with health plans and, occasionally, a retirement plan.

Mental retardation has been the name for our field, the fabric that holds us together; MR has given us a national organization, with state and regional chapters, and professional disciplines. Mental retardation has been the name of our Association and our journals. It has given us annual meetings, a collection of colleagues, a professional agenda, and an *esprit de corps*.

Mental retardation has given many of us life in academia: advanced degrees, publications, faculty appointments with rank and tenure, fellowships, and national and even international consultancies; MR has been my training, my professional home, my academic specialty, and my calling.

At the same time, MR has drawn narrow lives for people defined by it—lives devoid of any of the facets that we find lend our lives dignity, afford us

respect, and make our lives comfortable. People with MR continue to live well below the poverty line, receive second-rate medical services, have shorter life expectancies, live in inferior housing, have one of the highest unemployment rates in the country, and have far too little say in the matters that affect the quality of their lives.

People labeled MR have been isolated from their families, segregated from their peers, and congregated together on the basis of their label and under the guise of “for their own good” on the assumption that they are “happier with their own kind.” They were placed in “schools” and “development centers” that neither taught nor fostered development. Even the so-called *asylums* in which they were forced to live offered no respite from danger or hardship as the word implies IT WOULD. We know now that in the name of helping, they have been done harm.

It has been nearly 5 decades since Dybwad (1964) asked rhetorically, “Are we retarding the retarded?” People with MR continue to be subjected to labeling for life and stigmatized in every aspect of their life, from their medical and psychological records to the names of the facilities in which they receive services. It is pervasive, inescapable, and life-limiting.

To really change what it means to live with the label MR, we need to change that reality.

### We Were Wrong

Part of seeing our past as prologue is to understand that we have made mistakes—as an Association and as individuals. From my perspective, two of our greatest mistakes in recent years were borne out of sincere efforts, hard work, and perhaps a bit too much optimism.

*Institutionalization.* In 1965, Bobby Kennedy stood in tears on the front steps of Willowbrook and called it “a snake pit.” He referred to the residents there as “citizens,” and he called for reform. That was followed by Blatt’s *Christmas in Purgatory* (Blatt & Kaplan, 1965), a compelling story in *Look* magazine (Blatt & Mangle, 1967), and the *Family Papers* (Blatt, McNally, & Ozolins, 1979).

In the same time frame, Geraldo Rivera televised his first exposé of Willowbrook in 1973. He interviewed Bernard Carabello, who grew up in Willowbrook, and called it a disgrace. Rivera revisited Willowbrook 10 years later. Finally, Willowbrook closed, as did many other institutions. In his most recent annual report, Braddock (2006) re-

ported that an ever-increasing percentage of service system funds are going into the community. We let ourselves believe that the drive to institutionalize was over, that we had fought the good fight, and won that battle; but we were wrong.

Institutions continue to exist. People have been trans-institutionalized into newer, nicer places, but they are institutions nonetheless. We have yet to achieve the broad-based access to inclusive community living that we promised to provide to literally tens of thousands of people and their families.

Just this year, the state of Washington began admitting people, children as young as age 7, into their remaining institutions, back into the federally certified containment center euphemistically referred to as “Fircrest Developmental Center.” Remarkably, the decision to place children in the institution was based on professional assessments of complex needs and was responsive to parental choice.

We thought we had eliminated the arguments for institutionalization—parental choice and the lack of community support—but we were wrong.

We thought that parents, politicians, and policymakers all understood the value of community living for everyone. After all, hundreds of them joined many of us and signed the Community Imperative published by the Center on Human Policy at Syracuse University. We thought we were done and could move on. We did move on, lost in our false security. We were wrong.

We thought that by refining the definition of MR to include the importance of the environment, and promoting support intensity as a construct, service providers would see that everyone can live in the community. However, our most recent terminology and classification manual and our Supports Intensity Scale were used as data sources for the clinical decisions to institutionalize 18 people in the state of Washington.

*Ashley X.* After discussing sterilization in our journal, which was a practice as early as 1880 and actually referred to as de-sexualization; after passing, then repealing forced sterilization laws; after pointing out that sterilization of people with ID had been a tool of the Nazis; and after promoting dignity, privacy, and reasonable human sexuality as a part of self-determination, we thought that the issue of sterilization was settled. Certainly, we were sure the de-sexualizing mutilation of young women was finished. We were wrong.

We thought that Institutional Review Boards at universities were uniformly protecting the rights of vulnerable people. We were wrong.

This year, our Association jumped into the deep waters of the controversy surrounding the little girl known as “Ashley X.” In an article published in the *Archives of Pediatrics & Adolescent Medicine*, Gunther and Diekma (2006) described what they called *growth attenuation therapy* for this little girl, who had severe and multiple disabilities.

In the name of “therapy” and under the misnomer of “growth attenuation,” at the request of her parents, and with the oversight of the hospital’s human subjects protection committee, Ashley was “un-sexed.” Her healthy uterus and ovaries were removed and her undeveloped breast buds, cut out. Her still sexually immature body was bombarded with mega-doses of estrogen, tricking the body into arresting growth and preventing future development.

This so-called “therapy” was designed to “spare her the “discomfort” of having the mind of a child trapped in a woman’s body. They feared that breast development would be uncomfortable and encourage sexual abuse. They claimed that preserving her small stature would make her easier to hold and carry, thus increasing the ability of the family to care for her at home. She was, after all, described by her parents as their “pillow angel.” She would always have the mind of a child.

We thought decades of fighting the infantilization of people with MR had been successful. We talked about adults. We let ourselves believe that we had won that battle. We were wrong. In many arenas, so called “mental age” still reigns supreme. We thought that after years of normalization, stressing the appropriateness of chronological age appropriateness, social role valorization, and so forth, we were past all that. We were wrong.

This Association acted quickly. We immediately sent a rejoinder to the journal (Bersani, 2007); without delay, we posted on our website a longer, strong, clear denouncement of this scheme to mutilate Ashley in order to “save” her. That statement was recently published in *Intellectual and Developmental Disabilities* (Bersani et al., 2007).

The physicians said that the procedure was done for her own good and the well-being of her parents and that it was a private matter, not open to review by advocates or activists, such as members of our Association. The parents said it would keep her safe and ensure easier, better care. They said that

those of us opposed to the procedures just did not understand. Members of the Institutional Review Board at the hospital asserted that all protection protocols were followed. The notorious bio-ethicist Peter Singer supported the parents' right to choose. We thought those days were gone, but we were wrong.

### **Intellectual Disability: Semantic Substitution or Conceptual Reconstruction?**

#### *If a New Name Is the Answer, What Is the Question?*

This is the 131st anniversary of the first meeting of the group that became this Association. At the time they first met, they called themselves The Association of Medical Officers of American Institutions of Idiotic and Feeble-minded Children. I have every reason to believe that they were as proud of their new name as we are of ours now. They published the *Journal of Psychoaesthetics* with the following statement: "Devoted to the care, training and treatment of the feeble-minded and epileptic." I believe these were good individuals, as dedicated to people with disabilities as we are today, people who chose their words with the utmost of care. I feel no need to judge their 19th century efforts by 21st century sensibilities. In subsequent iterations, we changed names again and again in an effort to find less stigmatizing terms. When I joined, we were the American Association on Mental Deficiency, and I was involved when we made the (then controversial) change to American Association on Mental Retardation, which seemed like a good idea at the time.

What's next? Whether metaphor, synecdoche, administrative expediency, or libelous label, MR must be eliminated not just linguistically, but phenomenologically as well in all of its manifestations. The recent name change provides us with an excellent opportunity, one that I fear we are missing. I do not take issue with the excellent work done by my good friends and colleagues on the Terminology and Classification Committee, nor do I minimize all of our efforts to find a mutually agreeable new name for our Association. The work is excellent, but leads us to ask, "What's next?"

#### *Is ID the New MR?*

Now that our Association has solved the name issue (for the time being), I hope we can turn our

attention to the complex constellation of issues that we have previously grouped as MR. I submit that the same potential exists with ID. If this change is only a semantic shift, it will result in the same outcomes for the people to whom it is attached.

In a recent press release, our Association declared "MR is no more." Would that it were so easy. The death of MR is greatly exaggerated. I fear that treating ID as a semantic substitution for MR will resolve little.

Certainly, it gets us away from the so-called R word and all of its permutations: retarded, the retarded, and of course retard! I fear, however, that if we change nothing else about the lives of people, this polite substitution with the same definition, using the same assessments, and applying the same diagnostic criteria, to describe the same rates of incidence and prevalence, distributed across same terminology and classification schema, we will have done very little. The absence of any other change indicates not a death of MR but, rather, the semantic equivalent of a heart transplant or some other modern miracle that, in fact, breaths new life into a moribund label.

We know that MR is offensive to people. The people who have been so labeled have told us so, and we listened. I think if we truly listened, we heard them say that more is wrong than the R word. We must admit that we selected the easiest message to hear and to respond to. People living with the label MR have also told us that their lives need dramatic change. Being called by an out-of-date term is only the easiest problem in their lives that we could change. The term is by far not the most salient problem. In claiming that we have responded to their requests, we are being disingenuous.

If we merely now refer to someone as having ID where we once said MR and all the while they continue to live the same stigmatized, isolated, marginalized lives, then I believe we will have made a science of missing the point.

Yes, the new formulation preserves eligibility for critical services, supports, and rights. Yes, there was resistance to the so-called R word, and this substitution meets the demand that we change it. No, ID does not lend itself to easy pejorative terms. It may never carry the same sting to hear a child on the playground shout "He's so ID!" or "She is such an iddy." But, however they say it, they will be meaning the same thing. Ultimately, we need to change what it means to have ID. The true stigma

is not in the label but in the reality of the lives of these individuals.

Why is it stigmatizing to be called “it,” whether “it” is MR or ID? We have decades of labeling theory that seems to indicate that a stigmatizing label leads to the stigmatization of the people who are so labeled and that if the label can be changed, the stigma will be eliminated.

The easy response is that we value intelligence (I admit I do), and thus significantly subaverage general intellectual functioning and so on, will be problematic under any nomenclature. Executing one global, universal search and replace program to substitute ID as a totally exact replacement will merely be a semantic red herring, substituting one label for another. It will only distract the stigmatizers, segregators, and stereotypers for a short time. For years I have accepted the premise that if we can destigmatize the label, or find a less stigmatizing label, that the people so described will be more accepted. If that is so, then our recent name change may be a good start; but I now must confess that I have fallen away from that religiously held belief.

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### Stigma and Label: Which Is the Chicken and Which Is the Egg?

In the past, efforts to destigmatize MR have focused on public relations campaigns: attempts to convince people that it is OK to have MR, or to be MR. In fact, this is not a public relations issue. No degree of “spin” will change the stigma associated with MR. All of the publicists on Fifth Avenue cannot make the term (or its successor) appealing.

The fact of stigma is that the status of the lives of these individuals transfers in society to the label. In reality, their lives speak louder than any advertising campaign. If their lives are narrow, limited, and unfulfilled, it will be stigmatizing. If they are isolated, congregated, and segregated, whatever they are called, that term will absorb the stigma that is their lives.

The way to make MR less stigmatizing is to change both the term and the reality of the term. In philosophical terms, the name change is necessary, but it is not sufficient to bring about the change that I believe is our intent. Mental retardation is stigmatizing, not because it is an old label, not even because intelligence is valued and low intelligence is devalued. Mental retardation is stigmatizing because of the lives of the people to whom it is applied. If the label MR were applied to people

who are tall, handsome, wealthy, and even privileged, then it would soon become valorizing. The label reflects the experience of those who are labeled, just as the moon has no glow of its own, but only reflects the ambient light that falls upon it. That is like the “light” of people’s lives that fall onto the label and then is reflected back. That is how the label ultimately archives value or stigma. Of course, they have what we now call ID, and these disabilities are difficult; but as a group of self-advocates wrote in the *Beliefs, Values and Principles of Self-Advocacy* (International League of Societies, 1996), “It is the sadness related to the disability that we struggle with, not the disability.”

That, I believe, is what Shakespeare meant in *Romeo and Juliet* in the line “a rose by any other name would smell as sweet.” Put more bluntly, if their lives of these individuals smelled sweet, no label could detract; if their lives stink, no label can deodorize that fact.

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### “MR,” Go Gentle Into the Good Night

In 1951 (coincidentally the year of my birth), poet Dylan Thomas wrote “Do Not Go Gentle Into That Good Night.” Composed in a demanding poetic form known as a *villanelle*, the 19 lines are written to his beloved, dying father. The overt message is to not die without putting up a struggle. Resist death; fight against the inevitable, even in the face of imminent demise. Dylan’s meaning is that death cannot be forestalled, only resisted. I have appropriated these lines (or misappropriated them if you wish) to address the much heralded demise of MR.

In its day, the term MR, the label mentally retarded, and even the synecdoche the retarded had appropriate use, as did idiot, imbecile, and moron; but those days are gone. To defend them now is not to conserve our heritage; it is, rather, to deny our future.

The name change is necessary, but not sufficient. Changing what we call ourselves and how we label people is a long overdue good start. It is beneficial and necessary, but it is far from sufficient. Calling our organization the American Association on Intellectual and Developmental Disabilities will not safeguard a single person with “ID.”

Calling our journal *Intellectual and Developmental Disabilities*, and the *American Journal of Intellectual Disability* (the proposed name change for *American Journal on Mental Retardation*) will not reduce the number of families now asking for the “Ashley

treatment” for their children. Our new letterhead, logo, color scheme, and initials make bold statements, but they will not change the perception of ID. Our press release declaring the death of MR has not changed anyone’s life.

Having the authors of the next edition of the *Terminology and Classification Manual* offer ID as a semantic substitution for MR will not liberate the children from the Fircrest center.

Mental retardation is more than a term, more than a label. It is a metaphor whose time has come and gone. More important, it is a social condition marked by substantially subaverage quality of life that is associated with high levels of marginalization from society. This is what we need to aggressively remediate by providing systematic opportunities for the kind of high quality lives to which we all aspire.

As long as we segregate individuals on the basis of intelligence, MR will be with us. As long as we medicate, punish, and mutilate individuals with ID “for their own good,” the retarded will be with us. As long as we assume we can describe a person by knowing their IQ, adaptive behavior, and age of onset of their disability, MR will be with us.

I thank our excellent board, with whom I have been proud to serve; our talented staff; our leaders and thinkers who edit our journals, write our manuals, and develop our measures. This Association does excellent work, and these last several years have been extraordinary ones because of the efforts of its members. We have set the stage. The past is prologue; but to MR, I say “Go gentle into that good night.”

It is time for MR in all of its abbreviations, denotations, and connotations to quietly step aside and take its place in history.

*MR, Go Gentle Into That Good Night*

MR go gentle into that good night,  
Do not burn and rave at close of day  
Do not rage against the dying of the light  
Be wise and know the dark is right  
And you, MR, there on that sad height  
Embrace, embrace, the dying light  
MR go gentle into that good night

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