

Editorial

Understanding the Shift Toward Intellectual Disabilities

Ivan Brown

A small item in a corner of the newspaper caught my eye this morning as I sat with my coffee at the kitchen table. It was an obituary for Gene Moss, a writer of the 1960s superhero cartoon series Roger Ramjet. Immediately, I remembered watching the series on television in my youth, even though the main character, Roger Ramjet, never really quite "made it" as a successful superhero. But just as clearly, I remembered how kids on the streets and in the playground used to sing what was probably the theme song, to the tune of Yankee Doodle Dandy, with the words altered "for fun". Without hesitation, I began to sing it softly to myself:

*Roger Ramjet, he's our man,
The hero of our nation,
The only thing that's wrong with him,
Is mental retardation.*

It seemed strange to think back to Roger Ramjet after all this time. I have spent much of the three decades since then working with and for people who would then have been called "mentally retarded" and I have tried to do what I can to promote respect for them. But with the passage of time I had forgotten that, even back in the 1960s, there was something quite insulting about the use of the term mental retardation. Associating a somewhat lame superhero like Roger Ramjet with mental retardation was a joke of sorts to us, because it was a derogatory dig at a character whose "superhero" traits would usually be described in just the opposite way. We all clearly understood that superheroes were not supposed to be mentally retarded, and that people who were mentally retarded were certainly not considered superheroes.

We also understood that superheroes possessed characteristics that were, presumably, highly admired in our society. People with mental retardation, by definition, did not. This difference was the source of the "joke" for us as kids, but, in addition, it was the source of a much larger problem for using the term mental retardation in a dignified way — its very use had become an insult. It is hardly surprising to us, when we think back this way, that the term mental retardation was gradually replaced in the 1970s and 1980s throughout Ontario by mental handicap and developmental handicap, and in the late 1980s by developmental disabilities. Mental retardation had outlived its usefulness as a term to describe a group of people for whom we were trying to promote respect. Still, it remained in official use in Ontario for a number of years after it had fallen badly out of favour in the field, and, oddly, a few professionals still continue to use the term today despite its continuing derogatory connotations —

perhaps because it is well-known and has been clearly defined in the United States over the years. Use of the term mental retardation evolved differently in the United States, where it has continued to be used up to the present time without undue insult. There are probably several reasons for this, but among the most important are:

- The American Association on Mental Retardation is a strong professional organization that has considerable influence on its field, including the use of terms. The very name of this organization worked to keep the term respectable. In Ontario, all leading organizations had changed their names to exclude mental retardation by the late 1980s.
- Legal and service definitions in the United States have differentiated between developmental disabilities and mental retardation. Developmental disabilities is a significantly broader term than mental retardation in that it includes a wide range of disabilities, but is narrower in another respect in that it is defined as two or more areas of severe impairment. Thus, many people who do not have mental retardation could be classified as having developmental disabilities, but many other people who have mild or moderate mental retardation could not be described as having developmental disabilities because their intellectual impairment is not severe. In Ontario, no such widely-used definitions or differentiations have emerged.
- During the 1990s, people-first language was adopted throughout the United States. This eliminated the troubling practice of calling people "mentally retarded" and instead referred to them more respectfully as persons or people with mental retardation. In Ontario, this same trend occurred, although the terminology became persons or people with developmental disabilities.

There is nothing intrinsically wrong with any of these words or any of these terms. What is wrong is that negative connotations become attached to them over time, and those of us who work in the fields associated with such terms have not been successful in promoting positive connotations. Perhaps we will be in the future.

In the meantime, terms for populations that are devalued in some ways are still time-limited. In recent years, the term mental retardation has become increasingly less acceptable in the United States, and in the spring of 2002 the Board of Directors of the American Association on Mental Retardation voted to change its name to the American Association on Intellectual Disabilities. If this name change is accepted by the organization's membership in a vote in September 2002, it will no doubt mean that the use of mental retardation will become outdated in the United States and other countries that still use it, and that intellectual disability will become the term of choice. People who had formerly been "people with mental retardation" will be referred to as "people with intellectual disabilities" in the future.

Will this name change affect our use of terms in Ontario? At first glance, it seems that it should not. Over the past few decades, Ontario, other regions of Canada and other countries, have adopted the terms intellectual disability or developmental disability quite independent of the use of terms in the United States. This time, however, it may be different. In intellectual disability, the United States has opted for a term that is already widely used internationally and, in addition, does not appear to have negative connotations to Canadians or people in other countries. Thus, it seems likely that the use of the term intellectual disability will increase in Ontario as a synonym to developmental disability over the next few years.

If this does occur, it remains to be seen whether or not our understanding of the population we support will change as a consequence. On one hand, it seems unlikely that we will understand intellectual disability to be substantially different from developmental disability. After all, our clinical understanding of developmental disability has been loosely similar to that of mental retardation in the United States all along. On the other hand, intellectual disability is a more precise and descriptive term than developmental disability. And this is where I begin to worry. The adjective "developmental" is just vague enough to suggest the entire range of abilities that are developed by humans, and this vagueness has been useful to us by not singling out intellectual deficits. By contrast, "intellectual" as an adjective seems to focus our attention specifically on lower intellectual functioning as the source of the disability.

An increased focus on lower intellectual functioning will mean that professionals in the field of developmental disabilities in Ontario will have to work diligently in at least two important areas. First, we will have to be careful not to allow a measure of intellectual functioning to become the dominant criterion for diagnosis, and, more important, for eligibility for services. The more comprehensive approaches to assessment that have been developed by professionals over the past few decades have proven to be much more useful, both to services and to individuals with developmental disabilities and their families. These approaches need to be encouraged and expanded. Second, we will have to work to maintain the momentum that has been building toward inclusion and respect for people with developmental disabilities. The danger is that the term intellectual disability may well suggest to people in the general population an inability for intellectual activity. If interesting and enjoyable to reflect back on it this morning as I finish my coffee.

Ivan Brown
Editor

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The name change proposed by the Board of Directors of the American Association on Mental Retardation was not adopted. It was voted down by the AAMR membership, by a considerable margin.