Published in final edited form as:

Intellect Dev Disabil. 2013 April ; 51(2): 122–126. doi:10.1352/1934-9556-51.2.122.

Disability, Disorder, and Identity

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Abstract

The World Health Organizations International Classification of Diseases is the most important diagnostic tool, worldwide, to ensure that people with intellectual and developmental disabilities receive the supports they need to live richer, fuller lives. And yet, the ICD has naming conventions that create a conundrum for the field, requiring that all “conditions” in the ICD be named as a “disorder.” This article discusses the effect of naming on how people with intellectual disability are perceived by others and how they perceive themselves. The importance of continuing to move the field toward the adoption of functional/person-environment fit models of disability is discussed.

“What’s in a name? That which we call a rose by any other name would smell as sweet.”

William Shakespeare, *Romeo and Juliet* (II, ii, 1–2)

In Juliet’s soliloquy from *Romeo and Juliet*, she suggests, in essence, that names are artificial conventions without meaning—Montague or Capulet, her love is for Romeo, not his family or his family’s name. In the world of disability services and supports, however, names and naming matters (Schalock et al., 2007; Wehmeyer et al., 2008). Other articles in this issue discussing the role of naming conventions in disability supports. In this article, I want to examine a sometimes overlooked consequence of naming: the fact that what we name and call a condition far too often has consequences for how others perceive the person and how the person perceives him or herself; on the person’s identity, in other words.

So, in contrast to Juliet’s supposition, a rose by any other name might *not* smell as sweet in our efforts to balance the need to speak about people in respectful ways and still ensure that people who need supports because of intellectual disability receive them. Which brings us to the dilemma precipitating this special issue of *IDD*, that being what name is used to describe the state of functioning AAIDD refers to as intellectual disability in the next revision of the International Classification of Diseases (ICD), which will be ICD-11. The ICD-10 was promulgated in 1990. At that time, the term mental retardation was widely used, and that terms long history as referencing, essentially, a disorder of the mind, made its inclusion in ICD-10 as a “disorder” noncontroversial. As the AAIDD Terminology and Classification committee noted in discussing the theoretical underpinnings of the “old term,” mental retardation, and the “new” term (as of the 11th Edition of the AAIDD manual), intellectual disability, these terms reflected different theoretical underpinnings for understanding the condition or state of functioning. Mental retardation, and preceding terms, referred to defects of mind (e.g., mental deficiency) that resulted in impaired mental performance characterized by mental slowness (e.g., mental retardation), inferior mental performance (e.g., mental subnormality).

When in 1992, the AAMR T&C adopted a ‘functional’ model of “mental retardation” that proposed that the ‘disability’ was manifested as a ‘state of functioning’ that existed within the fit between the person’s capacities and limitations and the context in which the person functions, Luckasson and colleagues (1992) introduced a conceptualization of the construct that was dramatically different from the construct underlying the term “mental retardation” with regard to where the “disability” resided; the former (mental retardation) viewed the disability as a defect within the person, while the latter (1992 classification system) views the disability as the fit between the person’s capacities and the context in which the person is to function. I should note that although the term did not change to intellectual disability until the 2010 classification system, it should have changed in 1992 to be consistent with the alterations in conceptualizing the construct introduced in that edition. Mental retardation referred to a “condition” internal to the person; a deficit or defect within the person: intellectual disability refers to a state of functioning, not a condition. Parenthetically, I would argue that it is inappropriate to refer to a person “with” intellectual disability. Intellectual disability is not a condition or a disease, it is a state of functioning. As awkward as it may sound, I believe the more accurate way to refer to this is that a person manifests intellectual disability. I don’t expect this to catch on any time too soon, however!

Fast forward to 2013, as the ICD is undergoing its first revision since 1990. It is important to understand what the ICD is before considering the inclusion of intellectual disability among its entries. The ICD is, as its name would suggest, an international classification of diseases. It is a diagnostic tool used for epidemiological, health management, and clinical purposes. According to the WHO, about 70%, or \$3.5 billion U.S. dollars, are allocated using the ICD (WHO, n.d.). As per the WHO-International Union of Psychological Science survey of practicing psychologists, 70% of clinicians in the world use the ICD-10 in their day-to-day clinical work.

But—and here’s the rub—the ICD, by its own description, defines the universe of diseases, disorders, and other related health conditions. In 1990, when ICD-10 was released, mental retardation was a disorder. Today, as the revisions that will become ICD-11 are being discussed, intellectual disability is not a disorder. It is a state of functioning. [As a brief aside, the last three AAIDD T&C manuals have increasingly aligned the definition and conceptualization of intellectual disability with the World Health Organization’s International Classification of Functioning, Disability, and Health, or ICF. The ICF is within the WHO’s family of international classifications, and is intended as a framework for measuring health and disability-related domains. As a theoretical model for reframing how disability is understood, the ICF has been powerful. It is not, however, intended to replace the ICD and its reach in terms of clinical impact is much less extensive than the ICD.]

And, here is our conundrum. The ICD is a listing of disorders and diseases. Intellectual disability is no longer a disorder, and is best understood within the ICF model for disability. A clear understanding of these two terms (disability, disorder) as used by WHO is important. The ICF defines disability within a context of typical human functioning. Within ICF, *functioning* is an umbrella term for all life activities of an individual and encompasses body structures (anatomical parts of the body) and functions (physiological and psychological functions of body systems), personal activities (the execution of tasks or

actions), and participation (involvement in a life situation) areas. Problems or limitations in functioning are labeled a ‘disability.’ Disability can result from any problem in one or more of the three dimensions of human functioning; problems in body structures and functions are referred to as impairments; problems in personal activities are referred to as activity limitations; problems in participation are referred to as participation restrictions. The ICF situates these impairments, activity limitations, and participation restrictions within the interactions between health conditions, environmental factors, and personal factors.

Shifting back to the ICD, the term disorder is used as synonymous with disease. Diseases are pathological processes manifesting in characteristic signs and symptoms and affecting health. Within the ICD-11 there is a naming convention that requires that all “conditions”—since diseases and disorders are conditions—be referred to as a disorder. In ICD-10, mental retardation was used as a category name because it was understood to be a disorder. Intellectual disability cannot, however, be used in the ICD-11 naming convention because ICD is not a classification system for disability (that’s ICF), it is a classification system for diseases and disorders.

So, what to do? One option is to exclude intellectual disability from ICD, including it only in ICF. The outcome from that would, however, be catastrophic for people with intellectual disability around the world whose health practitioners use the ICD to allocate health resources. Make no mistake, at this time, across the world, there is no more important diagnostic tool than the ICD to ensure that people with intellectual disability receive the supports they need.

As explained by Tasse, Luckasson, and Nygren (this issue), early recommendations for the ICD-11 have floated the term “Intellectual Developmental Disorder” to replace “mental retardation.” Tasse and colleagues note three objections to this term (lack of consistency with terminology in use across the world; redundancy; and potential harm to people currently ‘diagnosed’ in educational, service, and judicial settings).

I want to point out an additional objection to Intellectual Developmental Disorder or, indeed, any term ending in “disorder” to refer to intellectual disability. That is, the term disorder as a part of the “name” immediately takes us back to pre-1980 conceptualizations of intellectual disability that viewed the person as the problem and what we now call intellectual disability as a disease or disorder. While the progress in changing how intellectual disability is conceptualized and understood since the 1992 manual has been slow, there has been progress. The term mental retardation, which had acquired a great deal of stigma even in its non-adjectival form, has been replaced. In its place is not just another term describing a mental disorder, but a term describing a state of functioning that views disability, and intellectual disability, as a function of the fit between personal capacity and the demands of an environment or context. The term paradigm is overused, but this is, indeed, a paradigm shift. It changes how we should think about disability and, importantly, people with disability. This shift moves us away from service provision models based upon homogeneity and diagnosis, to systems of supports that take as their starting point considerations of what it will take to enable people to function successfully in typical environments. These new conceptualizations of disability are strengths-based, eschewing the deficits emphasis of

previous models and beginning with the person's strengths, interests, and abilities to consider how to enhance personal capacity and to change the demands of the context so as to ensure that a person will be successful in typical environments. If, in fact, we can reduce and eliminate the gap between personal capacity and the demands of an environment or task, then the "disability" becomes, at the very least, irrelevant.

We have at our disposal a set of tools to narrow and reduce this gap. I'll cite a recent personal example. I was riding with a friend, sitting in the passenger seat while he parallel parked his car into a very tight parking space. My first thought was that I'd never had had the guts to try to get into that space, until I noticed that my friend's hands were completely off the steering wheel. The vehicle was, in fact, parking itself. No longer would his (or my) incapacity to parallel park be a deterrent to successful parking. There will come a day, and it may not be that far off, in which disability, whether intellectual or physical, will not present a barrier to driving a vehicle.

We have a long way to go to move the professional and popular understanding of the state of functioning we now call intellectual disability from its historic meaning pertaining to disorder and disease to a current understanding of disability as a function of the fit between the person's capacities and the demands of the environment, but if we're consistent and persistent, I think we will, someday, get there. Anything that sets that course of action back, including naming the state of functioning as a disorder, is a problem. Given the prominence of the ICD in the world, it is especially harmful.

Of course, it's not just how the construct is understood that is important, it is how the people so labeled are both perceived and perceive themselves. The reason that terms like idiot, retarded, or moron—all, at one time or another, legitimate diagnostic categories—become pejorative is that they reflect how others think about or perceive people with those labels. In a recent chapter I related a story that illustrates how pervasive this problem is (Wehmeyer, in press). In the late 1980s, the then-named Canadian Association for the Mentally Retarded released a one-minute public service announcement (PSA) featuring the then immensely-popular hockey star, Wayne Gretzky, and a young man with Down syndrome named Joey who worked as the locker room attendant for the team on which Gretzky played, the Edmonton Oilers. The PSA was intended to make the point that people with Down syndrome were valued community members. The PSA shows Gretzky and Joey in the Oilers' locker room, with shots of Joey stacking hockey sticks, taking out towels, and lacing skates, while Gretzky talks about the many things that Joey, and other people with Down syndrome, can achieve if given an opportunity.

The PSA closes with Gretzky saying: "Open up your life. Let people who are mentally handicapped be a part of your community." Gretzky points at the camera and then he and Joey turn to look at one another. Gretzky raises his hand and scratches the side of his head (or sort of waves his hand behind his ear, the gesture is difficult to distinguish). This is obviously a game that he has developed with Joey, who immediately imitates the action and says "Gretzky!" with evident joy, followed by a laugh and hand clap. Gretzky laughs as well, puts his arm over Joey's shoulder, and the PSA closes.

Because of his Down syndrome, Joey's attempt to say "Gretzky" is garbled... if you know that's what he's saying, as you do in the context of this PSA, you recognize it, otherwise you'd be hard pressed to identify what it was that Joey had said.

What was the lasting cultural impact from this heartfelt and well-intentioned video? I'm sure many people were touched. Perhaps someone actually let someone who was "mentally handicapped" be a part of his or her community. Hard to tell. What wasn't hard to tell was that for a period of time, children and young people would scream "Gretzky" in a garbled way and wave behind their ears as an insult to suggest that a friend was "retarded." Further, the term "Joey" began to be used to refer to all people with Down syndrome, as in "he's a Joey."

Perhaps it is inevitable that the term 'intellectual disability,' or some derivation thereof, will join the ranks of idiot, imbecile, moron, and retard as stigmatizing slang terms shaping public perceptions. I'm actually hopeful that this will not be the case if people understand that intellectual disability refers to a state of functioning, and not to a problem within a person. Whether I'm overly optimistic or not, I'm fairly certain that returning to use of the term disorder does not move us forward.

British Novelist Salmon Rushdie, once noted "our lives teach us who we are" (1991, p. 55). As a developmental psychologist by training, I would have said that our lives form our identity. If we define identity in the simplest and most straightforward manner, an identity is "an explicit theory of oneself as a person" (Moshman, 1999, p. 78). This "theory of oneself" is derived from multiple sources, including important input from peers and others. Thus, one's understanding of self is derived not only from personal attributions of identity, but also from understanding others' perceptions. This metarepresentational process (thinking about how others are thinking about you) is particularly salient when one of the primary "descriptors" of oneself is "person with a disability." How disability is understood and viewed by peers and others in society is a key component of the construction of identity for people with disabilities, as discussed previously. But not to be missed is the role of life experiences in the formation of identity.

This is true for people manifesting intellectual disability as well, and for much of history, what they have learned about themselves from their lives is that they, in some way, shape, or form, are the problem. They are the disability, the disability resides within them. They are disordered. Only in recent history have people with disability begun to challenge assumptions of incompetency and to demand both equality and access. It is not coincidental, I think, that what I'll call the self-determination movement began roughly at the same time that early versions of these "person-environment fit" models of disability began to emerge. As Schalock (in press) noted, "the importance of this evolutionary change in the construct of disability is that intellectual disability is no longer considered entirely an absolute, invariant trait of the person ... and allows for the pursuit and understanding of 'disability identity' whose principles include self-worth, subjective well-being, pride, common cause, policy alternatives, and engagement in political action." A return to a name that implies that the problem lies within the person, as any iteration of intellectual or cognitive disorder would, places this progress at jeopardy.

And so, I again ask, what shall we do. Eliminating intellectual disability from the ICD-11 is simply not an option. Our most important call to action is to do no harm. Intellectual disability is not a disorder, and yet we must include it in a compendium of disorders. As you will know from the article by Tasse, Luckasson, and Nygren (this volume), our compromise was to recommend the use of the term *Disorders of Intellectual Disability*. The benefit is that “intellectual disability” remains intact and, thus, holds on to its full meaning as a state of functioning. If WHO accepts the recommendation, it will be the only use of the term disability in the ICD-11. It is an imperfect solution, to be sure, but an important one, in my estimation. Perhaps there will come a time when ICF classification systems matter more than medical classification systems, but that time is not here yet. That is work that we must yet do.

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