

Beyond Terminology: The Policy Impact of a Grassroots Movement

Marty Ford, Annie Acosta, and T. J. Sutcliffe

Abstract

This article discusses the history of the grassroots movement led by self-advocates and their families to replace the stigmatizing term *mental retardation* with *intellectual disability* in federal statute. It also describes recent and pending changes in federal regulations and policy to adopt the new terminology for Social Security and Medicaid.

Key Words: *intellectual disability; terminology; grassroots; Rosa’s Law; regulations; Medicaid; Social Security*

As members of the American Association on Intellectual and Developmental Disabilities (AAIDD) and readers of the journal *Intellectual and Developmental Disabilities* are aware, there have been significant changes in terminology and classification over the last several decades. The growth of the self-advocacy movement has brought heightened awareness of the personal impact on people with disabilities and their families of the terminology used by medical, educational, governmental, and other bodies to identify or classify impairments. With this knowledge, policymakers and entities wishing to adopt new terminology must act with extreme caution and care.

The most recent change from “mental retardation” to “intellectual disability” was unique in that much of the impetus came from people with intellectual disability and their families. This impetus grew in the public realm and played out in open debates in the organizations devoted to their interests, in the halls of state legislatures and Congress, resulting in terminology changes in federal law through Rosa’s Law (P.L. 111–256 [2010]).

Terminology plays a crucial role in how people with intellectual disability are perceived and treated in society. Further, in the public policy realm, even minor changes in terminology or criteria can mean important differences in eligibility for support programs. Therefore, consistent use of appropriate terms and diagnostic criteria for the Americans with intellectual disability is critical to

help ensure that they are treated with dignity and respect and have access to needed services and supports.

The use of AAIDD’s now widespread term *intellectual disability* (Schalock, Borthwick-Duffy, Bradley, et al., 2010) is growing throughout federal law as a result of Rosa’s Law. Consistent use of this term is important for the protection of eligibility for benefits, services, and supports and must be maintained. Recommendations to adopt variations of the term are misguided and run the risk of causing harm to people through loss of eligibility for crucial benefits; causing confusion in the field for diagnostics, assessment, and eligibility determination; and undermining the hard work of people with intellectual disability and their families to bring about critical change in federal public policy.

What’s In a Name?

Various terms have been used over the years to describe the condition of intellectual disability. Often, the terms have acquired a pejorative connotation, with *mental retardation* being the most recent term to reach this point. Self-advocates and their family members and friends advocated to adopt a more appropriate, accurate, and less stigmatizing term.

The Arc’s network of 700 state and local chapters was engaged with self-advocates and their families on the issue of terminology for many years. In 1992, The Arc of the United States changed its name from the Association for Retarded Citizens to

eliminate the “r-word” from its name. This came after substantial debate by self-advocates and family members who were concerned about identification with the name of the organization.

Over time, many states began to change the names of agencies and programs; by the early 2000s, a hodge-podge of terms had developed and not all were accurate descriptions of the individuals served. It was clear that one term was needed that could be used consistently across the country to avoid the confusion that was developing at the state level. The Arc was regularly engaged with self-advocates, families, and state and local communities to consider an appropriate term; they ultimately concluded that AAIDD’s term *intellectual disability* is the most fitting term.

On July 25, 2003, an early indication of the emerging consensus on new terminology came when President George W. Bush signed Executive Order 13309, which renamed the President’s Committee on Mental Retardation as the President’s Committee for People with Intellectual Disabilities. Many states began enacting legislation to eliminate the “r-word” in state law. The issue continued to gain national momentum in 2009 with the enactment of Rosa’s Law in Maryland. The Marcellino family of Maryland began this campaign in response to the coding on Rosa Marcellino’s education plan at her elementary school. Rosa’s mother Nina Marcellino expressed the family’s pain in this way: “So, when my daughter’s IEP [individualized education program] coding was changed to ‘Mentally Retarded,’ I wondered how a society that had become so empathetic regarding the language it used to describe so many of its members, had not recognized the offensive language still used to describe one of its most vulnerable populations” (The Arc of Maryland, 2009). A solid consensus in the disability community grew out of the Maryland advocacy campaign. *Intellectual disability* is the most accurate and preferred term to replace the outdated term *mental retardation*. This deeply felt and carefully considered change resulted from years of frustration by advocates, which is well summed up by Rosa’s then-14-year-old brother Nick in his testimony to the Maryland General Assembly:

What you call people is how you treat them. What you call my sister is how you will treat her. If you believe she’s “retarded,” it invites taunting, stigma. It invites bullying and it also invites the slammed doors of being treated with respect and dignity.

Key elements of Rosa’s Law:

- Replaces the term *mental retardation* with *intellectual disability*.
- Applies to federal health, education, and labor laws
- Does not change eligibility for services.
- Does not apply to the Social Security Act (which includes Medicaid, Medicare, Social Security, and Supplemental Security Income [SSI]).

Rosa’s Law at the Federal Level

Senator Barbara Mikulski (D-MD) worked with the Marcellino family, The Arc, and other advocates to move Rosa’s Law to the federal level. Rosa’s Law gained broad support in Congress as well as in the disability community. The bipartisan measure passed the Senate by unanimous consent and the House of Representatives by voice vote. It was signed into law by President Obama on October 5, 2010, with the endorsement of 44 national disability organizations that serve or advocate on behalf of persons with disabilities (see Table 1).

Rosa’s Law replaced the terms *mental retardation* and *mentally retarded* with *intellectual disability* and *intellectually disabled* in federal health, education, and labor statutes. These statutes include such critical laws as the Public Health Service Act, the Individuals with Disabilities Education Act (IDEA), and the Rehabilitation Act. For Congressional jurisdictional reasons, it does not, however, apply to other critical laws for people with intellectual disability, namely, the Social Security Act authorizes Social Security, Medicare, Medicaid, and SSI. The intent of the advocacy community was to have subsequent legislation introduced that would apply to the Social Security Act.

Status of Implementation

The law made changes in terminology to the Higher Education Act, Individuals With Disabilities Education Act, Elementary and Secondary Education Act, Rehabilitation Act of 1973, Health Research and Health Services Amendments of 1976, Public Health Service Act, Health Professions Education Partnerships Act, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Sickle Cell Anemia, Cooley’s Anemia, Tay-Sachs, and Genetic Diseases Act, and Genetic Information Nondiscrimination Act of 2008.

Table 1
National Disability Organizations That Endorsed Rosa's Law (2010)

ACCSES (formerly the American Congress of Community Supports and Employment Services)
American Association of People with Disabilities (AAPD)
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Counseling Association
American Network of Community Options and Resources (ANCOR)
Association of University Centers on Disabilities (AUCD)
Autism National Committee
Autism Society of America (ASA)
Autistic Self Advocacy Network (ASAN)
Best Buddies
Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
Council for Exceptional Children (CEC)
Council of Parent Advocates and Attorneys (COPAA)
Council on Quality and Leadership
Disability Rights Education and Defense Fund (DREDF)
Easter Seals
Helen Keller National Center
Joseph P. Kennedy Jr. Foundation
Judge David L. Bazelon Center for Mental Health Law
Learning Disabilities Association of America
National Association for Down Syndrome
National Association of Councils on Developmental Disabilities (NACDD)
National Association of Private Special Education Centers National Association of School Psychologists
National Association of School Psychologists National Association of State Directors of Developmental Disabilities Services (NASDDDS)
National Association of State Directors of Special Education
National Center on Learning Disabilities
National Coalition on Deaf-Blindness
National Council on Independent Living (NCIL)
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Down Syndrome Society
National Fragile X Foundation
National Organization on Fetal Alcohol Syndrome (NOFAS)
National PTA
NISH Parent to Parent USA (P2P)
School Social Work Association of America
Self-Advocates Becoming Empowered (SABE)
Special Olympics
TASH
The Arc of the United States
United Cerebral Palsy (UCP)
United Church of Christ Disabilities Ministries

Although Rosa's Law does not apply to the Social Security disability programs or to the Medicaid program, both the U.S. Social Security Administration (SSA) and the Centers for Medicare and Medicaid Services (CMS) have initiated these important terminology changes.

On May 16, 2012, CMS published a final regulation, "Medicare and Medicaid Programs: Regulatory Provisions to Promote Program Efficiency, Transparency, and Burden Reduction." This regulation, among other things, changes the terminology of the Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR) program to Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). The regulation notes, "We have replaced all references in CMS regulations to the unflattering term 'mentally retarded' with 'individuals who are intellectually disabled' that has gained wide acceptance in more recent disability laws" (Department of Health and Human Services, Centers for Medicare & Medicaid Services, 2012). Across the nation, approximately 87,000 people live in ICF/IIDs (Larson, Ryan, Salmi, Smith, & Wuorio, 2012).

On January 28, 2013, SSA issued a notice of proposed rulemaking to replace "mental retardation" with "intellectual disability" in the agency's listing of impairments and in other appropriate sections of SSA's rules. The Listings, as they are known, form a major part of the regulations for determining eligibility on the basis of disability for the Social Security disability and SSI programs. This is a change in terminology only and will not affect benefits eligibility. SSA's adoption of current terminology will have widespread impact: more than 800,000 beneficiaries of Social Security have a primary diagnosis of intellectual disability (SSA, 2012a) and more than 130,000 child and 940,000 adult beneficiaries of SSI have a primary diagnosis of intellectual disability (SSA, 2012b).

Federal Regulations

The language of Rosa's Law anticipated some delay in the issuance of regulations to implement all of the changes in terminology for the covered statutes. To address those delays, the law established rules of interpretation for the period of time between passage of Rosa's Law and updating of relevant regulatory language. Essentially, the term *mental retardation* would be deemed to mean *intellectual disability*.

Impact on State Policy

Rosa's Law does not require any terminology change in state law. Many states, however, are already using the new term, because many of the affected federal laws relate to state programs. Most states have changed some terminology voluntarily and by statute, but the changes vary in scope. For example, the vast majority of states have changed the names of their respective state agencies, abandoning the term *mental retardation* and replacing it with the related, and sometimes overlapping, term *developmental disabilities*.

Value of Consistent Terminology

The consistent use of the term *intellectual disability* in U.S. federal and state laws and implementing regulations is essential. Failure to adopt consistent terms and consistent definitions would likely mean that eligibility for services for people with intellectual disability would vary across programs and services – with people qualifying in some cases, but failing to qualify in others. Additionally, self-advocates, their families, and the broader disability community have achieved true consensus on the need for common terminology and the use of the term *intellectual disability*. Federal and state laws and programs should reflect this consensus; much of the need for modern, respectful terminology derives from the stigma and prejudice experienced by people with intellectual disability.

Avoiding Unintended Problems

The World Health Organization has suggested the use of the term *intellectual developmental disorder* (IDD) to refer only to people who were previously diagnosed using the term *mental retardation*. There are numerous reasons why this term would be a mistake, including the confusion caused by using different terms in eligibility determinations and benefits programs and among policy makers. Because of the already widespread acceptance of the term *intellectual disability* or ID in the United States, when that term is used within the phrase "intellectual and developmental disabilities" to indicate the broader population, the acronym used is I/DD. Over the last several years, use of the acronym I/DD has become widespread, and it designates the population of all people with intellectual disability (ID) and developmental disabilities (DD). It encompasses many people with DD who do not have ID. Therefore, promoters of the term *intellectual developmental disorder*, intending

to refer *only* to people with an intellectual disability, will be inadvertently including all people with ID *and* DD in the discussion whenever they use the acronym IDD in the United States.

Terminology and the Movement Forward

From the earliest grassroots rumblings that eventually led to a name change for The Arc in 1992 to the groundswell that led to the federal Rosa's Law and the subsequent initiatives by CMS and SSA, it is clear that the most recent change in terminology had a basis in the needs and desires of self-advocates and their families. Efforts to abandon this long-sought change will be soundly rejected by self-advocates, families, and the organizations in which they play major roles, as well as by service providers and professionals who support them. Future changes in terminology must advance their cause; no retreat is acceptable.

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Résumés en Français

Quels sont les enjeux dans la vie des personnes ayant une déficience intellectuelle? Partie I: Le pouvoir de nommer, définir, diagnostiquer, classifier et planifier le soutien

Robert L. Schalock et Ruth Luckasson

Cet article met l'accent sur le pouvoir de nommer, définir, diagnostiquer, classifier et planifier le soutien pour les personnes ayant une déficience intellectuelle. L'article résume la pensée actuelle en ce qui concerne ces cinq fonctions, précise la question fondamentale découlant de chaque fonction et donne un aperçu des enjeux importants pour les personnes ayant une déficience intellectuelle, leur famille et le domaine de la déficience intellectuelle, et ce, selon la réponse à la question.

Quels sont les enjeux dans la vie des personnes ayant une déficience intellectuelle? Partie II: Recommandations pour nommer, définir, diagnostiquer, classifier et planifier le soutien

Ruth Luckasson et Robert L. Schalock

Cet article se concentre sur les recommandations pour nommer, définir, diagnostiquer, classifier et planifier le soutien pour les personnes ayant une déficience intellectuelle. L'article donne un aperçu des questions essentielles abordées par chacune de ces fonctions et fournit une série de recommandations spécifiques qui répondent à des enjeux importants pour les personnes ayant une déficience intellectuelle, leur famille et le domaine de la déficience intellectuelle.

La législation considérant la déficience intellectuelle comme une incapacité

James W. Ellis

La déficience intellectuelle (DI) est décrite différemment et de manière valide par différentes professions. Les légistes considèrent qu'il est plus utile de considérer la DI comme une incapacité plutôt qu'un trouble. Parce que la loi dicte les actions des individus dans une société et les actions d'une société sur les individus, la principale préoccupation de la loi lorsqu'il est question de personnes avec une DI est presque toujours en lien avec ses habiletés fonctionnelles et ses limitations

dans la société. Cette préoccupation se reflète dans les nombreux aspects de la loi civile et criminelle, bien que les méthodes utilisées pour évaluer les habiletés fonctionnelles et les limitations aient changé dans le temps. La loi n'a pas toujours été sensée ou humaine dans le traitement des personnes ayant une DI, mais son focus sur les habiletés fonctionnelles et les limitations nous permet d'aider les personnes avec une DI à utiliser leurs habiletés et à participer socialement à leur plein potentiel.

Au-delà de la terminologie: l'impact des mouvements populaires sur les politiques

Marty Ford, Annie Acosta et T. J. Sutcliffe

Cet article discute de l'histoire d'un mouvement populaire dirigé par des défenseurs des droits et de leur famille pour remplacer le terme stigmatisant «mental retardation» pour le terme «intellectual disability» dans le statut fédéral. Cet article décrit aussi les changements récents et ceux en attente de politiques fédérales pour l'adoption de cette nouvelle terminologie pour l'assurance maladie et la sécurité sociale.

La définition de la déficience intellectuelle dans les affaires pénales

J. Gregory Olley

Les définitions et les descriptions associées à la condition maintenant communément connue sous le nom de déficience intellectuelle servent à plusieurs fonctions. La décision de la Cour suprême des États-Unis dans *Atkins v Virginia* (2002) a attiré l'attention sur l'importance de la formulation d'une définition claire, objective et mesurable. Cet article discute du risque potentiel de malentendu et d'interprétation erronée de mots tels «habileté» et «cognitif», de l'importance de clarifier le rôle de l'erreur de mesure et des facteurs socioculturels, et de la relation de non causalité entre la déficience intellectuelle et les comportements adaptatifs.

Qu'y a-t-il dans un nom?

Marc J. Tassé

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