



SOCIAL SECURITY ADMINISTRATION

20 CFR Parts 404 and 416

[Docket No. SSA-2012-0066]

RIN 0960-AH52

Change in Terminology: “Mental Retardation” to “Intellectual Disability”

AGENCY: Social Security Administration.

ACTION: Final Rule.

SUMMARY: This final rule adopts, without change, the notice of proposed rulemaking (NPRM) we published in the Federal Register on January 28, 2013. We are replacing the term “mental retardation” with “intellectual disability” in our Listing of Impairments (listings) that we use to evaluate claims involving mental disorders in adults and children under titles II and XVI of the Social Security Act (Act) and in other appropriate sections of our rules. This change reflects the widespread adoption of the term “intellectual disability” by Congress, government agencies, and various public and private organizations.

DATES: This final rule is effective [INSERT DATE 30 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER].

FOR FURTHER INFORMATION CONTACT: Cheryl Williams, Office of Medical Listings Improvement, Social Security Administration, 6401 Security Boulevard, Baltimore, Maryland 21235-6401, (410) 965-1020. For information on eligibility or filing for benefits, call our

national toll-free number, 1-800-772-1213, or TTY 1-800-325-0778, or visit our Internet site, Social Security Online, at <http://www.socialsecurity.gov>.

SUPPLEMENTARY INFORMATION:

Background

On January 28, 2013, we published an NPRM that proposed replacing the term “mental retardation” with “intellectual disability” in our listings that we use to evaluate claims involving mental disorders in adults and children under titles II and XVI of the Social Security Act (Act) and in other appropriate sections of our rules.¹ We are finalizing the proposed rule without change.

Why are we changing the term “mental retardation” to “intellectual disability”?

The term “intellectual disability” is gradually replacing the term “mental retardation” nationwide. Advocates for individuals with intellectual disability have rightfully asserted that the term “mental retardation” has negative connotations, has become offensive to many people, and often results in misunderstandings about the nature of the disorder and those who have it.

In October 2010, Congress passed Rosa’s Law, which changed references to “mental retardation” in specified Federal laws to “intellectual disability,” and references to “a mentally

¹ 78 FR 5755.

retarded individual” to “an individual with an intellectual disability.”² Rosa’s Law also required the Federal agencies that administer the affected laws to make conforming amendments to their regulations. Rosa’s Law did not specifically include titles II and XVI of the Act within its scope, and therefore, did not require any changes in our existing regulations. However, consistent with the concerns expressed by Congress when it enacted Rosa’s Law, and in response to numerous inquiries from advocate organizations, we are revising our rules to use the term “intellectual disability” in the name of our current listings and in our other regulations. In so doing, we join other agencies that responded to the spirit of the law, even though Rosa's Law did not require them to change their terminology.³

Public Comments

In the NPRM, we provided the public a 30-day comment period, which ended on February 27, 2013. We received 76 comments. Seventy-one commenters enthusiastically supported our proposal to replace the term "mentally retarded" with intellectual disability or another term, while only five opposed the change. The comments came from national advocacy and disability rights groups, professional organizations, disability examiners, parents, and members of the public. We summarized and paraphrased the significant comments in our responses below. We carefully considered all of the comments. However, we did not make any changes to the final rule.

² Public Law 111-256.

³ See 77 FR 29002 and 77 FR 6022-01.

Support for replacing the term "mental retardation."

Comment: Seventy-one commenters enthusiastically supported replacing the term "mentally retarded" and 66 commenters supported the use of the term "intellectual disability." Organizations including The Arc, The Consortium for Citizens with Disabilities, The National Disability Rights Network, American Association on Intellectual and Developmental Disabilities, and National Association of State Directors of Special Education, Inc., commented in support of our proposed changes.

Almost all commenters noted the negative connotations and offensive nature of term "mental retardation." Often, commenters referred to the word "retarded" as "the R-word." Several provided personal stories about the effect the words "retarded" and "mental retardation" have had on a loved one with a disability and expressed their gratitude for our proposing to remove the term from the listings. One organization observed that the "change in terminology is consistent with the widely expressed desire of people with intellectual disability for the use of modern, respectful language." Another organization stated, "We appreciate SSA's commitment to eliminate outdated terminology and the negative stereotypes that they perpetuate for people with disabilities." One commenter, a graduate student in vocational rehabilitation, observed how "'labeling' an individual can hinder them from participating in the community... Let's give this population the respect and dignity they deserve."

Most commenters also supported our proposed adoption of the term "intellectual disability." One organization noted how our adoption of "intellectual disability" would "align

SSA's medical listings and other rules with terminology used by many federal agencies under Rosa's Law. This change is long overdue and [they] are glad SSA is taking this important step which will help fight stigma in this country." Another organization observed how "people will be able to file a claim for Social Security benefits based on having an 'intellectual disability,' rather than being forced to identify themselves with a label that many find offensive and degrading." In supporting the change, one individual commenter stated that "'intellectual disability' is much more respectful than 'mental retardation.'" Another commented, "It is critical that SSA treat applicants respectfully, and using the term 'intellectual disability' is the respectful terminology."

Response: We are glad that the overwhelming majority of commenters favored our proposed change and we decided to finalize the proposed rule without change.

Keep the term "mental retardation" in our rules.

Comment: Three commenters, all parents of adult children with profound intellectual and developmental disabilities, asked that we not replace "mental retardation" with the term "intellectual disability." They regard "mental retardation" as the medical term that best describes their children's conditions. The commenters expressed concern about the "imprecise and vague" nature of the term "intellectual disability." They fear that the loss of the term "mental retardation" could contribute to a lessening of public awareness and concern for individuals like their children and possibly the elimination of the public institutional service support systems that their children require. A fourth commenter said that while the change in terminology may make people feel good, the new term is not as descriptive as the current terminology.

Response: We did not adopt this suggestion. While we appreciate the concerns expressed in these comments, the term we use to describe a medical disorder does not affect the actual medical definition of the disorder or available programs or services. The American Psychiatric Association (APA) is responsible for naming, defining, and describing mental disorders.

In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the APA replaced “mental retardation” with “intellectual disability (intellectual developmental disorder).”⁴ The APA included the parenthetical name “(intellectual developmental disorder)” to indicate that the diagnosed deficits in cognitive capacity begin in the developmental period. The authors of the DSM-5 explain that these revisions bring the DSM-5 into alignment with terminology used by the World Health Organization’s (WHO) International Classification of Diseases, other professional disciplines and organizations, such as the American Association on Intellectual and Developmental Disabilities, and the U.S. Department of Education.⁵

Use a term other than “intellectual disability.”

Comment: Three individual commenters, for different reasons, offered alternatives to “intellectual disability.” One preferred “developmental disability,” because it is “a much more

⁴ American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition: DSM-5 (Washington, D.C.: American Psychiatric Publishing, 2013).

⁵ DSM-5 Intellectual Disability Fact Sheet, APA, 2013.

<http://psychiatry.org/FILE%20library/PRACTICE/DSM/DSM-5/DSM-5-intellectual-disability-fact-sheet.pdf>

recognized and acceptable term over ‘intellectual disability.’” Another wanted us to “make the right change,” and asked, “What is wrong with calling it what it is, ‘developmental disability,’” which the commenter said, “fits a lot better than either mental retardation, or intellectual disability.” Another commenter said that, “‘intellectual disability’ is really no better than ‘mental retardation’ because it highlights a defect in intellect or IQ. Perhaps a different choice of words – such as ‘cognitively impaired’ – would be more appropriate.”

Response: We did not adopt these suggestions. While there are several terms that could effectively replace “mental retardation” in our current listings and related regulations, we believe that it is appropriate to use the term adopted by other Federal agencies in response to a Federal statute.

The term “intellectual disability” is too broad and, therefore, unclear.

Comment: One commenter observed that there are “many gradations” in the type or severity of intellectual disabilities, which the term “intellectual disability” could encompass. The commenter was concerned that blanket use of the new term by various entities could result in its becoming a “catch-all term” in the way that “mental retardation” became a pejorative term. He suggested that we include an explanation about the breadth of conditions encompassed by the new term in a definitions section.

Response: We did not adopt this suggestion. In conjunction with publication of this final rule revising the name of current listings 12.05 and 112.05 and related regulations, we are

notifying our regional offices and state disability determination services regarding the change in terminology. As explained in the NPRM, however, the change does not affect how we evaluate a claim based on “intellectual disability” under listing 12.05 or 112.05, nor any of our other current listings or rules pertaining to other mental disorders.

The change in terminology has unclear implications for disability policy and adjudication.

Comment: One commenter suggested that the change in terminology from “mental retardation” to “intellectual disability” could generate confusion among adjudicators, including possible misinterpretation and misapplication of other listings. Another commenter expressed concern that the “prominent use of the term ‘disability’ in a body system listing” could prompt some people to assume or infer that we would find a person disabled under program rules “simply because the term ‘disability’ is used . . . to describe, or designate, an alleged condition.” A third commenter expressed concern that, given our legal definition of “disabled,” the term “intellectual disability” is prone to confuse the lay reader, since “‘intellectually disabled’ persons might not qualify for disability benefits because of the manner in which SSA defines disability.” This commenter suggested that we use a qualifying term “to distinguish between ordinary intellectual disability and intellectual disability grave enough to warrant disability benefits.” He suggested that a term such as “SSA-qualified intellectual disability” would facilitate greater lay understanding of the difference between the terms.

Response: We did not adopt these suggestions. The final rule will apply to only the name of listings 12.05 and 112.05 and will not affect how we interpret or apply any other listings. We will fully train our adjudicators on the effect of this name change.

As we noted in the NPRM, unlike other agencies, we are bound by a legal definition of the word “disability.” The Act and our regulations define “disability” in specific terms and outline the requirements that an individual must meet in order to establish entitlement or eligibility to receive disability benefits.⁶ An individual may have a medically determinable intellectual impairment, such as intellectual disability, but not be "under a disability" within the meaning of the Act. The name of any disorder, whether mental or physical, in no way directs our findings regarding disability. We advise all claimants that they will not be found "disabled" for the purposes of our programs until we determine that their impairments satisfy all of the statutory and regulatory requirements for establishing disability.

The proposed term will become outdated and require more SSA resources to change.

Comment: One commenter, although appreciating SSA’s effort to use non-offensive terms, expressed the view that doing so is a waste of agency resources because of the “euphemism treadmill.” He noted that the terms “mental retardation” and “mentally retarded” were created in the mid-20th century to replace other terms that had become offensive. By the end of the century, however, the new terms were also used in derogatory ways. The commenter

⁶ Sections 216(i)(1) and 1614(a)(3)(B) – (C) of the Act.

predicted that the current change to “intellectual disability” is “merely another attempt to create a term without a prejudicial history . . . and that this term will . . . eventually be used as a pejorative and require more agency resources to change again.” He recommended keeping the current wording.

Response: We did not adopt this suggestion. Speculation about the future use of the term "intellectual disability" or the subjective value of this change will not dictate our policy. The term “intellectual disability” is gradually replacing the term “mental retardation” in both the public and private sectors, and we believe it incumbent upon us to make this change in order to ensure that our listings and other rules reflect current terminology.

Regulatory Procedures

Executive Order 12866, as supplemented by Executive Order 13563

We consulted with the Office of Management and Budget (OMB) and determined that this final rule does not meet the criteria for a significant regulatory action under Executive Order 12866, as supplemented by Executive Order 13563.

Regulatory Flexibility Act

We certify that this final rule will not have a significant economic impact on a substantial number of small entities because it affects individuals only. Therefore, the Regulatory Flexibility Act, as amended, does not require us to prepare a regulatory flexibility analysis.

Paperwork Reduction Act

While this rule will not impose new public reporting burdens, it will require changes to existing OMB-approved information collections that contain the language referenced in this rule. We will make changes to the affected information collections via separate non-substantive change requests.

(Catalog of Federal Domestic Program Nos. 96.001, Social Security—Disability Insurance; 96.002, Social Security—Retirement Insurance; 96.004, Social Security—Survivors Insurance; and No. 96.006, Supplemental Security Income.)

List of Subjects

20 CFR Part 404

Administrative practice and procedure; Blind, Disability benefits; Old-Age, Survivors, and Disability Insurance; Reporting and recordkeeping requirements; Social Security.

20 CFR Part 416

Administrative practice and procedure, Medicaid, Reporting and recordkeeping requirements, Supplemental Security Income (SSI).

Dated: July 26, 2013

Carolyn W. Colvin,
Acting Commissioner of Social Security.

For the reasons set out in the preamble, we amend 20 CFR chapter III as follows:

PART 404—FEDERAL OLD-AGE, SURVIVORS, AND DISABILITY INSURANCE

Subpart P—Determining Disability and Blindness

1. The authority citation for subpart P of part 404 continues to read as follows:

Authority: Secs. 202, 205(a)-(b) and (d)-(h), 216(i), 221(a), (i), and (j), 222(c), 223, 225, and 702(a)(5) of the Social Security Act (42 U.S.C. 402, 405(a)-(b) and (d)-(h), 416(i), 421(a), (i), and (j), 422(c), 423, 425, and 902(a)(5)); sec. 211(b), Pub. L. 104-193, 110 Stat. 2105, 2189, sec 202, Pub. L. 108-203, 118 Stat. 509 (42 U.S.C. 902 note).

§ 404.1513 [Amended]

2. Amend § 404.1513(a)(2) by removing the words “mental retardation” and adding in their place “intellectual disability”.

Appendix 1 to Subpart P of Part 404 [Amended]

3. Amend Appendix 1 to subpart P of part 404 by:

a. Removing the words “mental retardation” and adding in their place “intellectual disability” wherever they occur;

b. Removing the words “Mental retardation” and adding in their place “Intellectual disability” wherever they occur; and

c. Removing the words “Mental Retardation” and adding in their place “Intellectual Disability” wherever they occur.

Subpart U—Representative Payment

4. The authority citation for subpart U of part 404 continues to read as follows:

Authority: Secs. 205(a), (j), and (k), and 702(a)(5) of the Social Security Act (42 U.S.C. 405(a), (j), and (k), and 902(a)(5)).

§ 404.2045 [Amended]

5. Amend the example in § 404.2045(a) by removing the words “mentally retarded children” and adding in their place “children with intellectual disability”.

PART 416—SUPPLEMENTAL SECURITY INCOME FOR THE AGED, BLIND, AND
DISABLED

Subpart F—Representative Payment

6. The authority citation for subpart F of part 416 continues to read as follows:

Authority: Secs. 702(a)(5), 1613(a)(2) and (d)(1) of the Social Security Act (42 U.S.C. 902(a)(5) and 1383(a)(2) and (d)(1)).

§ 416.645 [Amended]

7. Amend the example in § 416.645(a) by removing the words “mentally retarded children” and adding in their place “children with intellectual disability”.

Subpart I—Determining Disability and Blindness

8. The authority citation for subpart I of part 416 continues to read as follows:

Authority: Secs. 221(m), 702(a)(5), 1611, 1614, 1619, 1631(a), (c), (d)(1), and (p), and 1633 of the Social Security Act (42 U.S.C. 421(m), 902(a)(5), 1382, 1382c, 1382h, 1383(a), (c), (d)(1), and (p), and 1383b); secs. 4(c) and 5, 6(c)-(e), 14(a), and 15, Pub. L. 98-460, 98 Stat. 1794, 1801, 1802, and 1808 (42 U.S.C. 421 note, 423 note, and 1382h note).

§ 416.913 [Amended]

9. Amend § 416.913(a)(2) by removing the words “mental retardation” and adding in their place “intellectual disability”.

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