

Research

Outdated Language: Use of 'Mental Retardation'
in Medicaid HCBS Waivers Post-Rosa's Law



Running head: OUTDATED LANGUAGE

Outdated language: Use of ‘mental retardation’ in Medicaid HCBS waivers post-Rosa’s Law

Carli Friedman, PhD
Email: cfried6@uic.edu
Disability and Human Development
University of Illinois at Chicago
1640 W. Roosevelt Road, M/C 626
Chicago, IL, 60608, USA

Journal of Intellectual and Developmental Disabilities

Acknowledgments:

This paper was sponsored in part by a grant from the Administration on Intellectual and Developmental Disabilities (90DN0296).

Citation: Friedman, C. (2016). Outdated language: Use of “mental retardation” in Medicaid HCBS waivers post-Rosa's Law. *Intellectual and developmental disabilities*, 54(5), 342-353. <https://doi.org/10.1352/1934-9556-54.5.342>

Abstract

Rosa's Law, which changed references of 'mental retardation' to 'intellectual disability' within federal legislation, marked recognition by the federal government that 'mental retardation' is outdated and pejorative. However, Rosa's Law did not apply to many notable federal programs related to disability, such as Medicaid. This manuscript explored if and how 'mental retardation' was used within Medicaid Home and Community Based Services 1915(c) waivers, as they are the most prevalent provider of long-term services and supports for people with intellectual and developmental disabilities. Although an overwhelming majority of waivers used 'mental retardation,' we found 'mental retardation' was used less for later benchmark dates. Waivers provide some of the most advanced community services; the language used in waivers should reflect this.

Keywords: Rosa's Law, intellectual and developmental disabilities, Medicaid Home and Community Based Services waivers, terminology

Outdated Language: Use of ‘Mental Retardation’ in Medicaid HCBS Waivers Post-Rosa’s Law

Although once a prominent medical term, ‘mental retardation’ is now considered an outdated pejorative and has since been replaced by ‘intellectual disability’. Many people with intellectual and developmental disabilities (IDD) have noted the ways continued use of ‘mental retardation’ and ‘retarded’ has negatively affected them (Caldwell, 2010, 2011; Caldwell, Arnold, & Rizzolo, 2012; Jones, 2012; SABE, 2014; Taylor, 2007). For example, Jones (2012) describes responses by participants in their study saying,

‘participants reacted very strongly when asked about their understanding of the term mental retardation, often stating that it was a ‘mean’ thing to say or a ‘bad’ word that meant ‘stupid.’ One student said, ‘I don’t like the ‘R’ word. A teacher called me that once and I was about to punch her.’ ... [Another participant’s] response was quite telling: ‘I hate being MR because people make fun of me.

They call me names and laugh and talk behind my back’ (p. 35)

A participant in Caldwell’s (2011) study similarly described the stigma associated with ‘mental retardation’ saying, people with physical disabilities “don’t have, you know, the ‘retarded’ word and that kind of stuff pounded on them, and told they are not worth anything... That is why some people don’t want to interact with people who have that label, because of the stigma” (p. 322).

A large problem with the ‘R-word’ (i.e., retarded) is its co-opting by the mainstream as a slang term akin to stupid for anything bad or problematic (Senate Committee on Health, Education, Labor, and Pensions Committee, 2010). Siperstein, Pociask, and Collins (2010) explain, “by actually calling someone a retard or saying that something is retarded, the person or object of the insult is equated with the marginalized group and subjected to the effects of that

stigma.” (p. 127). As such, in addition to promoting shame, stigma, and marginalization of people with IDD (Degeneffe & Terciano, 2011; Mikulski, 2009a, 2010), Self-Advocates Becoming Empowered (SABE) (2014), the largest advocacy groups for and by people with IDD, explains the ‘R-word’ “makes us feel we are not people” (p. 1).

Because of the stigma associated with ‘mental retardation’ adoption of anti-R-word campaigns are less about policing politically correct language, and more about “how people with intellectual disabilities are perceived and treated in society” (Ford, Acosta, & Sutcliffe, 2013, p. 108; Mikulski, 2010). People with IDD have been advocating against the ‘R-word’ since the 1970s (Lyle & Simplican, 2015). The Special Olympics, which began campaigning against the word in 2004, calls use of the ‘R-word’ hate speech and a form of bullying (Lyle & Simplican, 2015; Special Olympics, 2015). Many states have since also created public awareness campaigns and adopted People First Language (Caldwell, Arnold, & Rizzolo, 2012). Rosa’s Law (Pub. L. 111-256), which changes references of ‘mental retardation’ to ‘intellectual disability’ within federal statutes marked recognition by the federal government that ‘mental retardation’ is outdated and pejorative (Civic Impulse, 2016). Noting the history of forced institutionalization and segregation, Senators Barbara Mikulski and Mike Enzi (2009), who sponsored the bill, explained “our maintenance of terms ‘mental retardation’ or ‘mentally retarded’ (MR) communicates a fundamental disconnect between our intent and our values” (p. 1). Senator Mikulski (2009a) purported the bill was “on behalf of all of the children of the United States of America who are labeled, stigmatized and bear a burden the rest of their lives because of the language we use in the law books” (n.p.).

Rosa’s Law applies to all federal health, education, and labor laws (Office of the Press Secretary, 2010), including:

the Higher Education Act of 1965; the Individuals with Disabilities Education Act; the Elementary and Secondary Education Act; the Rehabilitation Act of 1973; the Health Research and Health Services Amendments of 1976; the Public Health Service Act; the Health Professions Education and Partnerships Act of 1998; Public Law 110-154; the National Sickle Cell Anemia, Colley's Anemia, Tay-Sachs, and Genetics Diseases Act; and the Genetic Information Nondiscrimination Act of 2008. (Senate Committee on Health, Education, Labor, and Pensions Committee, 2010, n.p.)

Since the passage of Rosa's law the majority of states have also passed anti-R-word legislation at the State level (see Table 1). However, noticeably missing from Rosa's law reach are the Social Security and Medicaid programs. Medicaid, particularly Medicaid Home and Community Based Services (HCBS) 1915(c) waivers are the largest provider of long-term services and supports (LTSS) for people with IDD (Braddock et al., 2015; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013).

Stakeholders such as the federal government have a unique power "to facilitate attitude change" (Lyle & Simplican, 2015). Terminology plays a *crucial* role because "categories convey truths about those labeled. Defining and naming is a judgment on the human condition" (Fujiura, 2013, p. 83; Ford, Acosta, & Sutcliffe, 2013). Thus, because of the critical role it plays in providing LTSS for people with IDD, the purpose of this manuscript was to explore use of the outdated term 'mental retardation' (and its derivatives) in Medicaid HCBS 1915(c) waivers for people with IDD. Examination of states' Medicaid HCBS waivers also serves as a proxy analysis of states' adoption of the principles of Rosa's Law. In doing so, this analysis used the following key time points as benchmarks: 1) the signing of Rosa's Law (October 5, 2010); 2) Medicare and

Medicaid Services’ Regulatory Provisions to Promote Program Efficiency, Transparency, and Burden Reduction Rule (July 16, 2012); 3) the Center for Medicare and Medicaid clinical standards and quality letter noting further application of and adherence to Rosa’s Law (May 3, 2013); and, the Social Security Administration “Change in Terminology: ‘Mental Retardation’ to ‘Intellectual Disability’” Rule (September 3, 2013).

Medicaid, ‘Mental Retardation,’ and Rosa’s Law

As aforementioned, the Social Security Administration, and the Centers for Medicare and Medicaid (CMS) were not required to implement terminology changes as a result of Rosa’s Law. However, since the enactment of Rosa’s Law both have begun changing terminology (Ford, Acosta, & Sutcliffe, 2013). The official rules and comments applicable to Social Security Administration, CMS, and terminology changes are described below.

Medicare and Medicaid Regulatory Provisions Rule

The Medicare and Medicaid Services’ Regulatory Provisions to Promote Program Efficiency, Transparency, and Burden Reduction Rule (RIN 0938–AQ96) implemented July 16, 2012 noted that although the Social Security Act did not fall under the jurisdiction of Rosa’s Law in response to advocacy it would be changing language to reflect Rosa’s Law (Department of Health and Human Services, 2012; Centers for Medicare and Medicaid Services, 2013). The rule explains,

We proposed to change the terminology we use in the program currently called Intermediate Care Facilities for the Mentally Retarded. Section 1905 (d) of the Act states that, “The term ‘intermediate care facility for the mentally retarded’ means an institution (or distinct part thereof) for the mentally retarded or persons with related conditions...Rosa's Law did not specifically list the Act within its

scope, and therefore did not require any change to existing CMS regulations.

However, consistent with Rosa's Law and in response to numerous inquiries from provider and advocate organizations as to when CMS will comply with the spirit of Rosa's Law, we proposed to adopt the term “intellectual disability” (as used under Rosa's Law) in our regulations at § 400.203 [definitions specific to Medicaid]. We proposed to define the term “individuals with intellectual disabilities” to mean the condition referred to as “mentally retarded” in section 1919(e)(7)(G)(ii) of the Act. This nomenclature change does not represent any change in information collection requirements or other burden for the provider community or the State survey agencies. Current forms may be used by the State survey agencies until current supplies are exhausted. The change will require revision of forms CMS-3070G and CMS-3070H. (Department of Health and Human Services, 2012, pp. 29021-29022)

This CMS requirement marks recognition that ‘mental retardation’ is outdated language and a movement towards adopting ‘intellectual disability’ in its place. Although this description focuses more on Intermediate Care Facilities for the Mentally Retarded (ICF/MRs) CMS (2013) later clarified,

The enactment of Rosa’s Law on October 5, 2010 changed all references to ‘mental retardation’ in Federal law to ‘intellectual disability’ and changed all references to a ‘mentally retarded individual’ to ‘an individual with an intellectual disability.’ These changes were codified in regulation by the Centers for Medicare & Medicaid Services (CMS) on May 16, 2012. (p. 1)

On May 3, 2013, CMS Center for Clinical Standards and Quality/Survey & Certification Group issued a letter (Ref: S&C: 13-28- ICF/IID-QIDP) noting in response to Rosa's Law Qualified Mental Retardation Professionals (QMRP) were required to be changed to Qualified Intellectual Disability Professionals (QIDP) (Centers for Medicare and Medicaid Services, 2013); CMS explained,

Regulations at 42 CFR 483.430 (a) require that each client's active treatment program must be integrated, coordinated and monitored by a qualified mental retardation professional and define the minimum qualifications for this position...

Pursuant to Rosa's Law, the nomenclature for QMRP is changed to QIDP. Please ensure that all conversations, correspondence, and statements of deficiency use the correct nomenclature... **Effective Date:** Immediately. This policy should be communicated to all survey and certification staff, their managers and the State/Regional Office training coordinators within 30 days of this memorandum. (emphasis original; Centers for Medicare and Medicaid Services, 2013, pp. 1-2).

Social Security Administration Terminology Change Rule

On September 3, 2013, the Social Security Administration implemented the Change in Terminology: 'Mental Retardation' to 'Intellectual Disability' rule (RIN 0960-AH52). The rule explains:

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... 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. (Social Security Administration, 2013, p. 46499)

Medicaid, and by extension HCBS 1915(c) waivers, fall under Title XIX of the Social Security Act. Although this Social Security Administration (2013) rule did not mention title XIX, it does suggest language changes should be made “in other appropriate sections of our rules” (p. 46499). No specific statements about terminology changes from ‘mental retardation’ to ‘intellectual disability’ have been made specifically about title XIX.

Methods

Medicaid Home and Community Based Service (HCBS) 1915(c) waiver applications were collected from the Centers for Medicare and Medicaid (CMS) Medicaid.gov website over a two-year period (June 2013 to June 2015); see figure 1 for detailed tree of methodology. After exclusion of 1115 and 1915(b) waivers, 1915(c) waivers whose target groups did not include intellectual disability (ID), ‘mental retardation’ (MR), developmental disability (DD), and/or autism (ASD) were then excluded. Age limitations were not imposed. Next, the waivers that did not include fiscal year (FY) 2014 were excluded. Although most often states used the state FY (July 1, 2013 to June 30, 2014), some states used the federal FY (October 1, 2013 to September 30, 2014), while others used the 2014 calendar year (January to December). We use the term FY

for consistency. This process resulted in the collection of 110 IDD HCBS waiver applications from 45 states and the District of Columbia for FY 2014.

CMS requires waiver applications include: CMS assurances and requirements; levels of care; waiver administration and operation; participant access and eligibility; participant services, including limitations and restrictions; service planning and delivery; participation direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and cost-neutrality demonstrations. We examined waivers for any usage of the term ‘mental retardation’ or ‘MR’ throughout the waiver. All instances of mental retardation were recorded.

Although the waivers examined were all for FY 2014, waiver applications generally extend for five years. In addition to updating these plans every five years, states often amend their waiver programs more frequently to modify any number of waiver application parts. For example, Alabama amended their Home and Community-Based Waiver for Persons with Intellectual Disabilities in October of 2009 to:

1. To change the name of this waiver from the Alabama Home and Community-Based Waiver for Persons with Mental Retardation to the Alabama Home and Community-Based Waiver for Persons with Intellectual Disabilities. The short name will be ID Waiver rather than MR Waiver.
2. To modify the number of slots in reserve categories...
3. An additional modification is that the name of the reserve category Children in State Custody is being changed to Children in State Care and Custody to reflect that not all children in this category are committed to the custody of the State.

Thus, we next noted when FY 2014 waivers were last amended. We then used the amendment dates to determine if the use of ‘mental retardation’ continued throughout important benchmarks: 1) the signing of Rosa’s Law (October 5, 2010); 2) Medicare and Medicaid Services’ Regulatory Provisions Rule (July 16, 2012); 3) the CMS clinical standards and quality letter (May 3, 2013); and, 4) the Social Security Administration Terminology Change Rule (September 3, 2013). This data was used to track terminology changes in the HCBS waivers over time and determine if states continued to use the language ‘mental retardation’ even after these important regulations and letters.

Findings

Out of 110 FY 2014 Medicaid 1915(c) HCBS waivers for people with IDD, 85.5% of waivers ($n = 94$) used the language ‘mental retardation’ in their waiver. Eighty-eight waivers, or 80.0%, had been amended since the enactment of Rosa’s Law on October 5, 2010. Sixty-six waivers (60.0% of all waivers) using ‘mental retardation’ had been amended since the Medicare and Medicaid Services’ regulatory provisions rule came into effect (July 16, 2012). Fifty-two waivers (47.3% of all waivers) using ‘mental retardation’ had been amended since the CMS clinical standards and quality letter (May 3, 2013). Forty waivers (36.4% of all waivers) using ‘mental retardation’ had been amended since the Social Security Administration terminology change rule (September 3, 2013).

Incidences of ‘mental retardation’ appeared the following places in the waiver: the title of the waiver; participant access and eligibility (waiver target groups); discussion of QIDPs (formerly QMRPs); and, discussion of ICF/IIDs (formerly ICF/MRs). See table 1. Seven FY 2014 waivers included ‘mental retardation’ or ‘MR’ in the title of the waiver itself:

- New Mexico’s Mi Via - ICF/MR Renewal Waiver

- Oregon’s Behavioral (ICF/MR) Model Waiver
- South Carolina’s Mental Retardation and Related Disabilities Waiver
- Tennessee’s Home and Community-Based Services Waiver for Persons with Mental Retardation
- Tennessee’s Home and Community-Based Services Waiver for the Mentally Retarded and Developmentally Disabled
- Wisconsin’s Family Care MR/DD
- West Virginia’s Mental Retardation/Developmental Disability Waiver

Of these seven waivers, six had been amended since the signing of Rosa’s Law, five had been amended since the Medicare and Medicaid Services’ regulatory provisions rule, one had been amended since the CMS clinical standards and quality letter, and one had been amended since the Social Security Administration terminology change rule.

In ‘Appendix B: Participant Access and Eligibility’ states are required to specify the target groups or subgroups the waiver application will serve. Fifty-one of FY 2014 waivers used the language ‘mental retardation’ in ‘Appendix B: Participant Access and Eligibility.’ Forty-five waivers using ‘mental retardation’ as a target group had been amended since the signing of Rosa’s Law. Twenty-two waivers using ‘mental retardation’ as a target group had been amended since the Medicare and Medicaid Services’ regulatory provisions rule. Seven waivers using ‘mental retardation’ as a target group had been amended since the CMS clinical standards and quality letter. Two waivers using ‘mental retardation’ as a target group had been amended since the Social Security Administration terminology change rule.

Of FY 2014 IDD HCBS waivers, 90 waivers used the term ‘Intermediate Care Facilities for the Mentally Retarded (ICF/MR)’ instead of ‘Intermediate Care Facilities for Individuals

with Intellectual Disabilities (ICF/IID)’ at least once in their waiver application. Seventy-eight waivers that used ICF/MR had been amended since Rosa’s Law. Fifty-seven waivers that used ICF/MR had been amended since the Medicare and Medicaid Services’ regulatory provisions rule, which particularly required the change to ICF/IID. Forty-four waivers that used ICF/MR had been amended since the CMS clinical standards and quality letter. Thirty-one waivers using ICF/MR had been amended since the Social Security Administration terminology change rule.

Thirty-one HCBS IDD FY 2014 waivers mentioned ‘Qualified Mental Retardation Professional (QMRP)’ rather than ‘Qualified Intellectual Disabilities Professional (QIDP)’ somewhere in their waiver application. Twenty-eight of these waivers had been amended since the signing of Rosa’s Law, 20 had been amended since the Medicare and Medicaid Services’ regulatory provisions rule, 19 had been amended since the CMS clinical standards and quality letter about the change to QIDP, and 15 had been amended since the Social Security Administration terminology change rule.

Figure 2 maps the use of ‘mental retardation’ throughout waivers with particular attention to the dates waivers were amended.

Discussion

The passage of Rosa’s Law marked recognition by the federal government what self-advocates had been saying for years, that the term ‘mental retardation’ is outdated and offensive and needs to be replaced with a less pejorative term. Rosa’s Law replaced ‘mental retardation’ with ‘intellectual disability’ in many important pieces of federal legislation. Despite the wide reach of Rosa’s Law, it was not all encompassing; for example, Social Security did not fall under this new statute. This manuscript explored if and how ‘mental retardation’ was used within Medicaid, specifically Medicaid Home and Community Based Services (HCBS) waivers as they

are the most prevalent provider of long-term services and supports for people with intellectual and developmental disabilities. In doing so we found the overwhelming majority of HCBS waivers for FY 2014, approximately four years after the passage of Rosa's Law, continued to use the language 'mental retardation' in their waiver. In fact, approximately 86% of the FY 2014 HCBS waivers for people with IDD used 'mental retardation' at least once in their waiver.

In their waiver applications states lay out plans for five years of HCBS waiver services. However, simply because a waiver serves FY 2014 does not necessarily mean it has been updated recently. For this reason, in addition to noting which waivers used 'mental retardation' in FY 2014, we also tracked when these FY 2014 waivers were last amended. The dates the amendments were last approved were then compared to four important benchmarks that related to changing terminology, particularly within the Social Security Administration and the Centers for Medicare and Medicaid:

- The signing of Rosa's Law;
- A Medicare and Medicaid Services' regulatory provisions rule about the use of 'mental retardation,' particularly focusing on changing ICF/MR to ICF/IID;
- A CMS clinical standards and quality letter about replacing the term QMRP with QIDP;
- The Social Security Administration Terminology change rule about Rosa's law and 'mental retardation.'

While our data cannot make claims about the *direct* impact of these benchmarks, these benchmarks mark important moments in time as they reflect official federal government disapproval of the term 'mental retardation.' Thus they were valuable moments to track how language in HCBS waivers changed.

Although the majority of FY 2014 waivers used the language ‘mental retardation,’ we found a downward trend in the usage of ‘mental retardation’ wherein ‘mental retardation’ was used less the later the benchmark date (see figure 2). For example, ‘mental retardation’ was used in 60% of waivers that were amended since the Medicare and Medicaid Services’ regulatory provisions rule came into effect, while it was used in 36% of waivers amended since the Social Security Administration terminology change rule. Moreover, although we found ‘mental retardation’ became less common as time went on, the rate of reduction did differ slightly depending on the location of ‘mental retardation’ within waivers. For example, the use of ICF/MR dropped more sharply than the use of QMRP over time. However, both continued to be used in some waivers even after direct regulations about replacing these terms.

While there are a number of possible reasons for the continued use of ‘mental retardation’ within waivers, it is important to note that unlike the CMS clinical standards and quality letter, the Medicare and Medicaid Services’ regulatory provisions rule mentions states may continue to use forms with this outdated language until they are exhausted. It is likely many of the waivers using ‘mental retardation’ in FY 2014 were doing just that. Although this may be interpreted as a limitation of our study, we believe examination of states use of ‘mental retardation,’ even if it simply marks their lack of attention to revising these applications, is important because this pejorative language reinforces negative and harmful attitudes towards people with IDD. Moreover, states should be amending their waivers for language, even just to replace outdated forms, both to respect the advocacy done by self-advocates and other anti-R-word advocates, and to lead by example. Disability studies scholar Simi Linton (1998) argues, “there are various consequences of the chosen [disability] terminology...” it often “convey[s] the idea that...people with disabilities as a group are inferior to nondisabled people” (pp. 9-10). Thus it is critical to

pay attention to “linguistic conventions” because they “structure the meanings assigned to disability and the patterns of response to disability that emanate from, or are attendant upon, those meanings” (Linton, 1998, p. 8). HCBS waivers are providing some of the most advanced services for people with IDD in the community; the language used in waiver application should also reflect that.

References

- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession*. Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*, 49(5), 315-326. <http://dx.doi.org/10.1352/1934-9556-49.5.315>
- Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, 54(11), 1004-1014. Doi: 10.1111/j.1365-2788.2010.01326.x
- Caldwell, J., Arnold, K., & Rizzolo, M. K. (2012). *Envisioning the future: Allies in self advocacy*. Washington, DC: Association of University Centers on Disabilities.
- Centers for Medicare and Medicaid Services. (2013). *Intermediate care facilities for individuals with intellectual disabilities (ICF/IID) –nomenclature change (qualified intellectual disabilities professional (QIDP))*.
- Civic Impulse. (2016). *S. 2781 — 111th Congress: Rosa's Law*. Retrieved from <https://www.govtrack.us/congress/bills/111/s2781>.
- Degeneffe, C. E., & Terciano, J. (2011). Rosa's law and the language of disability: Implications for rehabilitation counseling. *Rehabilitation Research, Policy, and Education*, 25(3-4), 163-171. <http://dx.doi.org/10.1891/216866511805000966>
- Department of Health and Human Services. (2012). *Medicare and Medicaid Program: Regulatory provisions to promote program efficiency, transparency, and burden*

reduction (RIN 0938–AQ96).

Ford, M., Acosta, A., & Sutcliffe, T. (2013). Beyond terminology: The policy impact of a grassroots movement. *Intellectual and Developmental Disabilities, 51*(2), 108-112.

<http://dx.doi.org/10.1352/1934-9556-51.2.108>

Fujiura, G. T. (2013). The demarcation of intellectual disability. *Intellectual and Developmental Disabilities, 51*(2), 83-85. <http://dx.doi.org/10.1352/1934-9556-51.2.083>

Jones, J. L. (2012). Factors associated with self-concept: Adolescents with intellectual and development disabilities share their perspectives. *Intellectual and Developmental Disabilities, 50*(1), 31-40. <http://dx.doi.org/10.1352/1934-9556-50.1.31>

Linton, S. (1998). *Claiming disability, knowledge and identity*. New York: New York University Press.

Lyle, M. L., & Simplican, S. C. (2015). Elite repudiation of the R-Word and public opinion about intellectual disability. *Intellectual and Developmental Disabilities, 53*(3), 211-227. <http://dx.doi.org/10.1352/1934-9556-53.3.211>

Mikulski, B. A. (2009). Senator Mikulski's statement on introduction of Rosa's Law [Press release]. Retrieved from <http://www.mikulski.senate.gov/newsroom/press-releases/senator-mikulski-and-39s-statement-on-introduction-of-rosa-and-39s-law>

Mikulski, B. A. (2010). Mikulski applauds committee passage of Rosa's Law [Press release]. Retrieved from <http://www.mikulski.senate.gov/newsroom/press-releases/mikulski-applauds-committee-passage-of-rosa-and-39s-law>

Mikulski, B. A., & Enzi, M. B. (2009). *Rosa's Law*. Retrieved from [https://www.aucd.org/docs/Rosa's%20Law%20-%20Dear%20Colleague%20\(2\).pdf](https://www.aucd.org/docs/Rosa's%20Law%20-%20Dear%20Colleague%20(2).pdf).

Office of the Press Secretary. (2010). *Remarks by the President at the signing of the 21st Century*

- Communications and Video Accessibility Act of 2010*. Retrieved from <https://www.whitehouse.gov/the-press-office/2010/10/08/remarks-president-signing-21st-century-communications-and-video-accessib>.
- Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities*, 51(1), 1-21. doi: 10.1352/1934-9556-51.01.001
- Rosa's Law, Pub. L. No. 111-256 (2010).
- Self Advocates Becoming Empowered. (2014). SABE policy statement on the R word. Retrieved from <http://www.sabeusa.org/wp-content/uploads/2014/02/SABE-Policy-Statement-on-the-R-Word.pdf>
- Senate Committee on Health, Education, Labor, and Pension. (2010). *Rosa's Law*. (111-244). Retrieved from <https://www.gpo.gov/fdsys/pkg/CRPT-111srpt244/html/CRPT-111srpt244.htm>.
- Siperstein, G. N., Pociask, S. E., & Collins, M. A. (2010). Sticks, stones, and stigma: A study of students' use of the derogatory term "retard". *Intellectual and Developmental Disabilities*, 48(2), 126-134. <http://dx.doi.org/10.1352/1934-9556-48.2.126>
- Social Security Administration. (2013). *Change in terminology: "Mental retardation" to "intellectual disability" (RIN 0960-AH52)*.
- Special Olympics. (2015). Spread the Word to End the Word action kit: Key messages and talking points. Retrieved from <http://www.r-word.org/uploadedFiles/r-word/Resources/2015-STW-Key-Messages-and-Talking-Points.docx>
- Taylor, S. (2007). Editor's note. *Intellectual and Developmental Disabilities*, 45(1).

Table 1. Location of ‘Mental Retardation’ in FY 2014 Medicaid HCBS 1915(c) IDD Waivers.

Figure 1. Detailed methodology tree for collection of HCBS 1915(c) waivers for people with IDD in FY 2014.

Figure 2. Location of ‘mental retardation’ within FY 2014 waivers by amendment benchmark dates. October 5, 2010 = signing of Rosa’s Law; July 16, 2012 = Medicare and Medicaid Services’ regulatory provisions rule; May 3, 2013 = the CMS clinical standards and quality letter; September 3, 2013 = the Social Security Administration Terminology change rule.

Table 1

Location of 'Mental Retardation' in FY 2014 Medicaid HCBS 1915(c) IDD Waivers

State	Waiver	State anti-R-word legislation	Location of 'mental retardation' in waiver			
			Title of waiver	Participant access and eligibility	ICF/MR	QMRP
Alabama	AL0001.R06.01	X		X	X	X
Alabama	AL391.R02.01	X		X	X	
Alaska	AK262.R04.01	X				X
Alaska	AK260.90.R2	X			X	X
Arizona	AR188.R04.04	X		X	X	X
California	CA336.R03.00	X		X	X	X
Colorado	CO434.R01.01	X				
Colorado	CO0007.R06.03	X				
Colorado	CO293.R03.02	X				
Colorado	CO4180.R03.02	X		X	X	
Connecticut	CT437.R02.01	X			X	X
Connecticut	CT426.R02.01	X			X	X
Connecticut	CT881.R00.02	X			X	X
District of Columbia	DC307.R03.00	X		X	X	
Delaware	DE009.R06.03	X			X	
Florida	FL40205.R01.00	X		X	X	
Georgia	GA323.R03.02	X			X	
Georgia	GA175.R05.01	X			X	X
Hawaii	HI0013.R06.00	X		X	X	X
Idaho	ID76.R05.03	X			X	
Idaho	ID859.R00.00	X		X	X	X
Illinois	IL473.R01.03	X			X	X

Illinois	IL464.R01.02	X		X	X
Illinois	IL350.R03.00	X	X	X	X
Indiana	IN378.R02.05	X		X	X
Indiana	IN387.R02.04	X		X	X
Iowa	IA242.R04.04	X	X	X	
Kansas	KS224.04.04	X		X	
Kansas	KS476.R01.02	X	X		
Kentucky	KY314.R03.04	X		X	
Kentucky	KY475.R01.00	X	X	X	
Louisiana	LA401.R02.02	X	X	X	
Louisiana	LA361.R02.06	X		X	
Louisiana	LA453.R01.02	X	X	X	
Louisiana	LA472.R01.00	X	X	X	
Maryland	MD23.R06.00	X			
Maryland	MD339.R02.00	X	X	X	
Massachusetts	MA40207.R01.02	X		X	
Massachusetts	MA828.R01.00	X	X	X	
Massachusetts	MA826.R01.00	X	X	X	
Massachusetts	MA827.R01.00	X	X	X	
Maine	ME159.R05.02	X			
Michigan	MI4119.r05.00	X	X	X	X
Michigan	MI0167.R05.00	X	X	X	X
Minnesota	MN0061R06.00	X			
Mississippi	MS282.R04.01	X		X	
Missouri	MO698.R01.00	X	X	X	
Missouri	MO4185.R04.00	X	X	X	
Missouri	MO40190.R03.03	X		X	
Missouri	MO178.R05.03	X	X	X	
Missouri	MO404.R02.02	X	X	X	

Missouri	MO841.R01.01	X	X	X	
Montana	MT208.R05.00	X	X	X	
Montana	MT1037.R00.00	X	X	X	
Montana	MT667.R01.01	X		X	
North Dakota	ND842.R00.00	X			
North Dakota	ND0037.R06.02	X	X	X	X
Nebraska	NE394.R02.00	X	X	X	
Nebraska	NE396.R02.00	X	X	X	
Nebraska	NE4154.R05.00	X	X	X	
Nevada	NV125.R05.02	X			
New Hampshire	NH53.R05.00	X	X	X	X
New Hampshire	NH397.R02.00	X	X	X	X
New Mexico	NM448.R01.01		X	X	
New Mexico	NM173.R05.00			X	
New York	NY470.R01.00	X	X	X	
New York	NY238.R04.03	X	X	X	
North Carolina	NC662.R01.00		X	X	
North Carolina	NC663.R01.00		X	X	
North Carolina	NC423.R02.00			X	
Ohio	OH231.R03.04	X		X	X
Ohio	OH383.R02.01	X		X	
Ohio	OH380.R02.02	X		X	X
Ohio	OH877.R00.00	X	X	X	X
Oklahoma	OK351.R03.00	X			X
Oklahoma	OK343.R03.00	X			X
Oklahoma	OK179.R05.00	X		X	X
Oklahoma	OK399.R02.00	X		X	X
Oregon	OR117.R04.06	X		X	
Oregon	OR375.R02.07	X		X	

Oregon	OR40194.R02.00	X	X	X	X	
Pennsylvania	PA593.R01.02	X				
Pennsylvania	PA354.R03.01	X				
Pennsylvania	PA147.R05.01	X				
Pennsylvania	PA235.R04.00	X		X	X	
Pennsylvania	PA0324.R03.00	X		X	X	
South Carolina	SC456.R01.02	X				
South Carolina	SC676.R01.01	X			X	
South Carolina	SC237.R04.04	X	X		X	
South Dakota	SD44.R07.01	X				
South Dakota	SD338.R03.00	X		X	X	X
Tennessee	TN427.R02.00	X			X	
Tennessee	TN357.R02.02	X	X	X	X	
Tennessee	TN128.R04.04	X	X	X	X	
Texas	TX110.R05.05	X			X	
Texas	TX281.R03.00	X				
Texas	TX221.R04.03	X			X	X
Texas	TX403.R02.00	X		X	X	
Utah	UT158.R05.04	X				
Virginia	VA358.R02.01	X				
Virginia	VA430.R01.01	X			X	
Virginia	VA372.R02.11	X			X	X
Washington	WA40669.R01.00	X		X	X	
Washington	WA411.R02.00	X			X	
Washington	WA0410.R02.00	X			X	
Washington	WA0409.R02.00	X			X	
West Virginia	WV133.R05.01	X	X	X	X	
Wisconsin	WI368.R02.03	X	X		X	
Wisconsin	WI414.R02.00	X		X	X	

Wyoming	WY253.R04.02	X	X
---------	--------------	---	---

Note . This table does not factor in waiver amendment date.



