PEJORATIVE LANGUAGE: A NATIONAL ANALYSIS OF CONTINUED USE OF 'MENTAL RETARDATION' BY STATES POST-ROSA'S LAW

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PROBLEMS WITH THE R-WORD

Although once a prominent medical term, "mental retardation" (MR) is now considered an outdated pejorative.

Stigma and Other Negative Effects

- The term MR negatively affects people with intellectual and developmental disabilities (IDD) (Caldwell, 2010, 2011; Caldwell, Arnold, & Rizzolo, 2012; Jones, 2012; Self Advocates Becoming Empowered [SABE], 2014; Taylor, 2007).
  - "I hate being MR because people make fun of me. They call me names and laugh and talk behind my back" (Jones, 2012, p. 35).
- There is a stigma associated with 'MR'.
  - 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" (Caldwell, 2011, p. 322).

A Co-Opted Insult Producing Shame, Stigma, & Marginalization

- A large problem with the R-word 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 Pension, 2010).
- "The person or object of the insult is equated with the marginalized group and subjected to the effects of that stigma" (Siperstein et al., 2010, p. 127).
- Self Advocates Becoming Empowered (2014), the largest advocacy groups for and by people with IDD, explains that use of the R-word "makes us feel we are not people" (p. 1).

Anti-R Word Progress

- 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).
- 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disability" within federal statutes, marked recognition by the federal government that the term "mental retardation" is outdated and pejorative (Civic Impulse, 2016).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 term MR communicates a fundamental disconnect between our intent and our values" (p. 1).

Purpose

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" (Ford, Acosta, & Sutcliffe, 2013; Fujiura, 2013, p. 83).Thus, because of the critical role it plays in providing LTSS for people with IDD, the purpose of this article was to explore use of the outdated term MR (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.

ANTI-R-WORD LEGISLATION AND REGULATIONS

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 Pension, 2010)
- The majority of states have also passed anti-R-word legislation at the state level (see Table 1).
- 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 et al., 2013).
  - Since the enactment of Rosa's Law, both Social Security and the Centers for Medicare and Medicaid (CMS) have begun changing terminology (Ford, Acosta, & Sutcliffe, 2013). The official rules and comments applicable to Social Security Administration, CMS, and terminology changes are described in this section.

Medicare and Medicaid Regulatory Provisions Rule (RIN 0938–AQ96)

- Implemented July 16, 2012
- Noted that in response to advocacy it would be changing language to reflect Rosa's Law (Centers for Medicare and Medicaid Services, 2013; Department of Health and Human Services, 2012).
- 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."

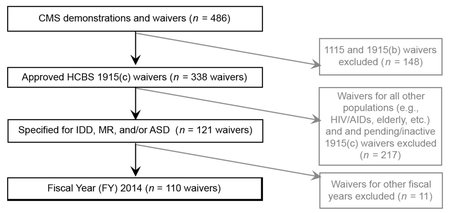
Center for Medicare and Medicaid Clinical Standards and Quality Letter (Ref: S&C: 13-28- ICF/IID-QIDP)

- Implemented May 3, 2013
- Noting that Qualified Mental Retardation Professionals (QMRP) were required to be changed to Qualified Intellectual Disability Professionals (QIDP) in response to Rosa's Law (Centers for Medicare and Medicaid Services, 2013).

Social Security Administration Terminology Change Rule (RIN 0960–AH52)

- Implemented September 3, 2013
- The rule explains changing MR to intellectual disability in the "Listing of Impairments (listings)… under titles II and XVI of the Social Security Act (Act) and in other appropriate sections of our rules"
- 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 2-year period (June 2013 to June 2015); see Figure 1 for detailed tree of methodology.

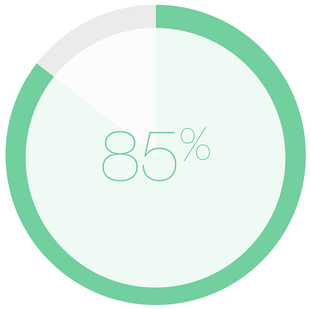
We examined waivers for any usage of the term "mental retardation" or "MR" throughout the waiver. All instances of mental retardation were recorded. We next noted when FY 2014 waivers were last amended. We then used the amendment dates to determine if the use of "mental retardation" continued throughout important benchmarks, that is:

- the signing of Rosa's Law (October 5, 2010);
- the Medicare and Medicaid Services' Regulatory Provisions rule (July 16, 2012);
- the CMS clinical standards and quality letter (May 3, 2013)
- the Social Security Administration Terminology Change rule (September 3, 2013).

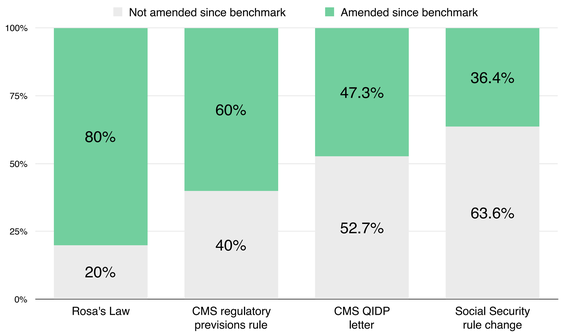
The data were used to track terminology changes in the HCBS waivers over time and determine if states continued to use the language "mental retardation" even after the enactment of these important regulations and letters.

FINDINGS: THE CONTINUED USE OF MR

USE OF MR IN HCBS WAIVERS



USE OF MR BY AMENDMENT DATE



Incidences of "MR" appeared in the following places within 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 "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

LOCATION OF MR

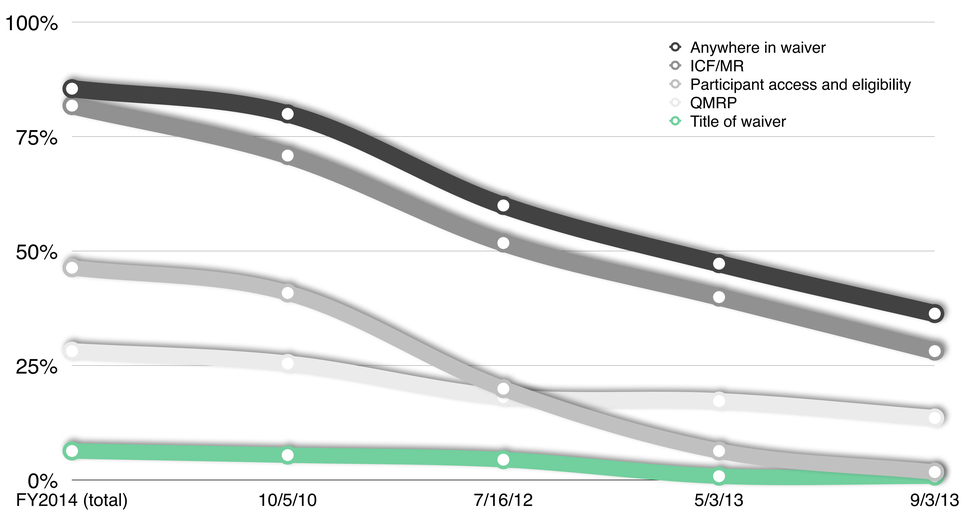


Table 1. Location of 'MR' in FY 2014 Medicaid HCBS 1915(c) IDD Waivers

			Location of 'MR' in waiver			
State	Waiver	State anti-R-word legislation	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	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 account for amendment date.

DISCUSSION

Use of MR by the Majority of HCBS Waivers

- Approximately 4 years since the passage of Rosa's Law, the overwhelming majority of HCBS waivers for FY 2014 continued to use the language "MR" in their waiver.
  - 86% of the FY 2014 HCBS waivers for people with IDD used "MR" at least once in their waiver.

Downward Trend in MR Usage

- "MR" was used less the later the benchmark date
  - For example, "MR" was used in 60% of waivers amended since the Medicare and Medicaid Services' regulatory provisions rule came into effect, but only in 36% of waivers amended since the Social Security Administration terminology change rule.
- The rate of reduction differed depending on the location of "MR"
  - 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 following direct regulations focused on replacing these terms.

Continued Usage a Reflection of Continuing Outdate Forms?

- 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 "MR" 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 the term "MR," 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.

States Need to Respect Calls from Self-Advocates

- States should be amending their waivers for language, even if 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.
- "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" (Linton, 1998, pp. 9-10).
  - Language "structure[s] 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.

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