Title Page

AT LAST – EMPIRICAL PROOF THAT THE 'R-WORD' REALLY MUST GO: THE INFLUENCE OF TERMINOLOGY ON TOLERANCE *Gayle L. Garcia, Darcy H. Granello, Karly D. Boehm*

Corresponding Author: **Gayle L. Garcia,** MA Email address: garcia.671@osu.edu Institutional Affiliation: The Ohio State University Departmental Affiliation: Counselor Education Street Address: 1437 Presidential Dr. City, State, Zip, Country: Columbus, OH 43212 USA

Darcy H. Granello, PhD

Title: DR. Institutional Affliation: The Ohio State University Departmental Affliation: Counselor Education City, State, Zip, Country: Columbus OH 43210 USA

Karly D. Boehm, BS

Affiliation: Lincoln Public Schools City, State, Zip, Country: Lincoln, NE, 68516 USA

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7	At Last - Empirical Proof that the 'R-Word' Really Must Go:
8	The Influence of Terminology on Tolerance

1 Abstract 2 College undergraduate students (N = 259), were given a measure of tolerance toward people with 3 intellectual disability. Half of the sample was given a version that used the term 'mentally 4 retarded,' and half was given a version that used 'person with intellectual disability.' Individuals receiving the version with 'mentally retarded' had lower levels of tolerance on all four subscales 5 6 of the instrument. They scored significantly higher on the subscales of Exclusion and Sheltering 7 and significantly lower on the subscales of Empowerment and Similarities than their peers who 8 received the version using the term 'person with intellectual disability.' 9 Keywords: Individuals with intellectual disability; mentally retarded; tolerance, stigma

1 At Last - Empirical Proof that the 'R-Word' Really Must Go: 2 The Influence of Terminology on Tolerance 3 The American Association on Intellectual and Developmental Disabilities, in 1921, 4 initially used the term 'mental retardation' to assure individuals with the diagnosis would receive 5 the accommodations and care needed (Siperstein, Polciask, & Collins, 2010). This term became 6 the most commonly used word to describe intellectual disability in the 1950s and is still used 7 today (Goode, 2002). Before continuing, a note on terminology must be stated, throughout this 8 paper the authors will use the phrase 'R-word' in lieu of the term 'mental retardation,' unless 9 absolute necessary, out of respect for people with intellectual disability. 10 In 2010, the enactment of Rosa's Law replaced the R-word with 'intellectual disability' 11 in all federal health, education, and labor policy (United States Congress, 2010). According to 12 the Federal Register, which tracks public comments and agency responses to federal law, the 13 change in terminology was made because "Advocates for individuals with intellectual disability 14 have rightfully asserted that the term 'mental retardation' has negative connotations, has become 15 offensive to many people, and often results in misunderstandings about the nature of the disorder 16 and those who have it" (Rosa's Law, 2013, p. 46499). In spite of this change to federal law, 17 some states and local jurisdictions still have not enacted the new terminology (Friedman, 2016), 18 and the it can still be found in the media and even within academia (e.g., Baroff & Olley, 2014; 19 Barrett, 2013; Krishnan & Archana, 2014). 20 The move to the updated language reflected the concern that these outdated terms have 21 been perceived as negative (Senate Committee on Health, Education, Labor, and Pension, 2010). 22 As a result, the label 'mentally retarded' became an insult "equated with the marginalized group

and subjected to the effects of that stigma" (Siperstein, Pocjask, & Collins, 2010, p. 127). The

term itself promoted shame, stigma, and marginalization of individuals with intellectual
disability (Friedman, 2016). Within that context, it is perhaps not surprising that the advocacy
group Self Advocates Becoming Empowered, the largest advocacy group for and by people with
intellectual disability, stated that the use of the R-word "makes us feel we are not people" (2014,
p. 1).

6 Advocates have pushed for the elimination of the R-word since the 1970s, and the 7 Special Olympics went so far as to declare the use of the term a type of hate speech and a form 8 of bullying in 2004 (Ford, Acosta, & Sutcliffe, 2013). Each year, the Special Olympics 9 spearheads a campaign in schools across the country asking students to pledge not to use the 10 term and to take appropriate action when they hear the word used by others (Special Olympics, 2017). In spite of this long history of advocacy, it was only with the publication of the 5th edition 11 12 of the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric 13 Association) in 2013 that the term was officially removed and replaced with intellectual 14 disability for the psychiatric and behavioral healthcare system in the U.S and in 2018 with the 15 release of the ICD-11 the rest of the U.S. healthcare system followed (International Classification of Diseases, 11th edition; ICD-11; World Health Organization, 2018). It is worth 16 17 noting, however, that it took the U.S. 23 years after the initial publication of the ICD-10 in 1992 18 to officially adopt and require its use in 2015. Therefore, although the ICD-11 was released in 19 2018, it is reasonable to expect that it will be many years before the updated system, with its updated terminology for intellectual disability, will be adopted within the U.S. In fact, according 20 21 to a U.S. Senior Official for Coding and Compliance in Healthcare, the adoption of the ICD-11 22 in the U.S. will take "15-20 years, at least" (Frieden, 2015). Thus, even as U.S. social, 23 educational, and legal environment moves away from the R-word and toward 'intellectual

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disability,' the U.S. healthcare system will continue to use the old terminology, at least for the
 foreseeable future.

3 Within this environment of changing language and terminology, the actual impact of 4 these different words on the lives of people with intellectual disability remains unclear. Friedman 5 (2016) argued that the use of the updated terminology is not about policing politically correct 6 language, but about how people with intellectual disability are perceived and treated in society. 7 Although anecdotal evidence supports her argument, there is very little research to indicate the 8 tangible role that language and terminology play in society's perceptions toward and treatment of 9 people with intellectual disability. In fact, nearly all of the available research conducted within 10 the U.S. about attitudes and perceptions of individuals with intellectual disability consists of 11 qualitative interviews with people with disabilities and their families, teachers, or caretakers 12 (e.g., Araten-Bergman, & Werner, 2017; Caldwell, 2010; Dykens, Schwenk, Maxwell, & Myatt, 13 2007; Monteleone, & Forrester-Jones, 2017; Jones, 2012; Jones, Oseland, Morris, & Larzelere, 14 2014). The quantitative studies that exist about attitudes and tolerance are primarily surveys that 15 measure attitudes, with comparisons of tolerance based on gender, age, or contact with 16 individuals with intellectual disability (Goreczny, Bender, Caruso, & Feinstein, 2011; Gormley, 17 2015: Nevill & White, 2011; Shalev, Asmus, Carter, & Moss, 2016). 18 Only one study investigated the use of language in relation to tolerance and acceptance

toward people with intellectual disability (Albert, Jacobs, & Siperstein, 2016). A survey of 2,297
high school students from three different states found that the use of the 'R-word' continues to be
commonplace in school buildings, with 82% reporting that they had heard the word at school
within the past year. Nearly all of the students who heard the term responded that they had heard
til directed at a person without an intellectual disability (94%). Fewer than half of the respondents

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1 (41%) reported that they had heard the word directed at a person with an intellectual disability. When respondents heard the term directed toward a person without an intellectual disability, only 2 about one-third (33%) reported taking any action, such as telling others to stop using the word, 3 4 comforting the person, or telling a teacher. However, when they witnessed a person with an 5 intellectual disability being called the 'R-word,' nearly two-thirds (65%) reported that they took 6 some action. Results from this study indicate that most students recognize the harmful effects of 7 the term and recognize their responsibility to intervene, particularly when the target is a person 8 with an intellectual disability.

9 What is lacking in all of this research is an attempt to understand the specific role that language and terminology plays in public perceptions toward individuals with intellectual 10 11 disability. More than 40 years after the initial recommendations for changes in terminology, the 12 use of the R-word continues, at least in some segments of society. Significantly, without 13 empirical data and information to help understand the effects of the use of the 'R-word," calls for 14 its elimination can be seen as irrelevant or simply as evidence of political correctness. Thus, it is 15 time to find out whether the use of the term intellectual disability yields any tangible difference 16 in tolerance toward individuals with intellectual disability.

Although no empirical research exists on the effects of language and terminology on tolerance toward people with intellectual disability, similar studies were conducted in 2016 on the effects of language on tolerance toward people with mental illnesses (Granello & Gibbs, 2016). In those studies, three different respondent groups (undergraduate students, licensed professional counselors and counselors-in-training, and adults in a community sample) all received an instrument that measured tolerance toward individuals with mental illnesses. One half of the surveys used the term 'the mentally ill' and the other half used the term 'people with mental illnesses.' The two versions of the survey were randomly distributed within each
participant group. All other study variables remained constant. Results found significant
differences in tolerance among all three participant groups based on the version of the survey
received. In all cases, recipients who received a survey using the term 'the mentally ill' were
significantly less tolerant than those who received a survey that used the term 'people with
mental illnesses.'

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Methods

8 In the current study, college undergraduate students (N=259) were given a survey to 9 measure attitudes toward persons with intellectual disability. Respondents were randomly 10 divided, and half were given a version of the survey that used the old terminology ('mentally 11 retarded') and half were given a version that used the currently endorsed terminology 12 ('individuals with intellectual disability'). There were no other differences in the instrument or 13 between the two subsets of recipients who received each version of the instrument. Any 14 differences that emerged on the measure of tolerance between the two subsets within the group, 15 therefore, could be attributed only to the use of the language contained within the instrument. In 16 this way, the effects of terminology used on tolerance toward people with intellectual disability 17 could be isolated as a variable. This study was reviewed and approved by the Institutional 18 Review Board where the study was conducted.

19 **Participants**

A sample of 259 college undergraduate students at a large Midwestern university was given the survey in several large courses designed to fulfill the general education requirements for non-majors (e.g., history, science, math). The majority of participants was male (58%) and Caucasian (67%), with 12% identifying as Asian American; 4% as African American; 3% as

1	Hispanic; 2% as Mixed Race; 1% as Native American; and 11% as Other/Prefer Not to Say.
2	Participants were divided among undergraduate ranks (25% freshmen; 14% sophomores; 17%
3	juniors; 44% seniors), with a mean age of 21.76 years. The sample was randomly divided in half
4	in each classroom by alternating the versions of the survey when it was distributed so that every
5	other student received version A or version B. As a result of this distribution method, 129
6	students completed the instrument with the term 'the mentally retarded' (version A) and 132
7	completed the instrument with the term 'people with intellectual disability' (version B). Six of
8	the surveys were discarded due to missing data, resulting in 124 (version A) and 129 (version B)
9	participants (total $\underline{N} = 253$)
10	Measure
11	Respondents received a single survey, the Community Living Attitudes Scale, Mental
12	Retardation Form (CLAS-MR; Henry, Keys, Jopp, & Balcazar, 1996). As hard copies of the
13	surveys were distributed in classrooms, they were alternated between the 'mentally retarded' and
14	'intellectual disability' versions, so half of each classroom surveyed randomly received each
15	version of the survey. Minimal demographic information was collected to ensure basic
16	equivalence between the two halves of the sample.
17	Community Living Attitudes Scale, Mental Retardation Form. The CLAS-MR
18	(Henry et al., 1996) is a 40-item self-report instrument scored on a 6-point Likert-type scale. The
19	CLAS-MR is intended to measure a person's attitudes toward individuals with intellectual
20	disability. Respondents are asked to indicate the degree to which they agree with a particular
21	item, with responses ranging from 1 (strongly disagree) to 6 (strongly agree). Thirteen of the 40

22 items are reverse-scored to minimize the possibilities of response set bias. All reliability and

validity information is based on the original version of the instrument, which used the term
 'mentally retarded' unless otherwise noted.

3	Respondents are asked to respond to questions regarding their beliefs about intellectual						
4	disability and people with intellectual disability based on a statement in the instructions to the						
5	survey that reads, 'mentally retarded' [version A] or 'persons with an intellectual disability'						
6	[version B] "refers to people with impairments in their mental ability that affect the extent to						
7	which everyday tasks are managed." There are four separate subscales on the CLAS-MR:						
8	Empowerment, Exclusion, Sheltering, and Similarity. There are no individual items used in more						
9	than one subscale.						
10	1. The Empowerment Subscale, which consists of 13 items, concerns the view that						
11	people with intellectual disability should be able to have their opinions factored into						
12	decisions and policies that affect their lives. The content specifically addresses self-						
13	advocacy, self-direction, and choice. Possible scores range from 13-78.						
14	2. The Exclusion Subscale centers on the desire to segregate people with intellectual						
15	disability from community life, and all items have a distinctly negative affective tone.						
16	The Exclusion Subscale has 8 items, and possible scores range from 8-48. Two of the						
17	items on this scale are reverse scored.						
18	3. The Sheltering Subscale measures the degree to which respondents believe that						
19	people with intellectual disability need to have others supervise them in their daily						
20	lives or protect them from the dangers of community life. Although high scores may						
21	reflect an endorsement for separation from the community for protection, this						
22	subscale does not have the same negative affective tone as the Exclusion subscale.						
23	The Sheltering Subscale has 7 items, and possible scores range from 7-42.						

1	4. The Similarity Subscale, which consists of 12 items, measures the extent to which
2	respondents perceive people with intellectual disability as basically like themselves
3	and other people, in areas as diverse as life goals and basic human rights. Possible
4	scores range from 12-156, and 7 of the items are reverse scored.
5	The CLAS-MR yields four specific subscale scores and no overall score. Higher scores
6	on each subscale indicate the degree of agreement with the general concept expressed in the
7	subscale, such that more positive and tolerant attitudes toward persons with intellectual disability
8	would yield higher scores on the Empowerment and Similarities subscales and lower scores on
9	the Exclusion and Sheltering subscales.
10	Confirmatory factor analysis of the CLAS-MR demonstrated an adjusted goodness-of-fit
11	(sometimes called the 'normed Chi-Square') index of .92, with values of this index above .9
12	generally considered acceptable (Baumgartner & Hombur, 1996). Although goodness-of-fit and
13	adjusted goodness-of-fit indices are both commonly used, adjusted goodness-of-fit divides χ^2 by
14	the degrees of freedom to reduce the effects of sample size (for more information, on strategies
15	to assess goodness-of-fit in confirmatory factor analysis, see Sun, 2005). Construct validity of
16	the scale was calculated through correlations between the CLAS-MR subscales and other attitude
17	scales that measure similar constructs, such as the Scale of Attitude Toward Disabled Persons
18	and the Community Attitudes Toward Mental Illness. Correlations were moderate, significant,
19	and in the expected direction (for more detailed information about the development of the
20	CLAS-MR, including studies of reliability and validity, see (Henry et al., 1996)).
21	Alpha coefficients for the scores on the subscales of the CLAS-MR ranged from .75 to

.86 in the original scale development study (Henry et al., 1996). In the current study, alpha
coefficients were: Empowerment α = .82, Exclusion α = .86, Sheltering α = .76, and Similarity α

1	= .82. To determine whether changing the language of the survey affected its internal
2	consistency, Cronbach's Alpha was run on scores for each subscale for the two versions of the
3	instruments. For three of the subscales, differences were small (Empowerment, version A: α =
4	.81, version B: $\alpha = .78$; Exclusion, version A: $\alpha = .85$, version B: $\alpha = .85$; Similarity, version A:
5	α = .82, version B: α = .81). For one subscale, the difference in the alpha coefficient was a bit
6	larger (Sheltering, version A: $\alpha = .80$, version B: $\alpha = .70$), indicating that there may be slightly
7	less tendency to give consistent responses with version B ('intellectual disability'). It should be
8	noted that Sheltering is the subscale with the fewest number of items ($N = 7$). When the sample
9	is divided into the two survey versions, the smaller sample size would have the greatest effect or
10	this subscale, resulting in the least stable alpha coefficients. An analysis was run to see the
11	interscale correlations between subscales in the current study and they ranged between .6372.
12	This suggests that there is possible overlap between the subscales on the CLAS-MR.

13 Data Analysis

14 The goal of this study was to determine if there were significant differences on a measure 15 of tolerance toward persons with intellectual disability between individuals who received the two 16 versions of the survey. There was no attempt to measure tolerance by any demographic variable 17 nor to compare results with any universal norms, as the study was not intended to make broad 18 statements or generalizations about tolerance within the sample of undergraduate students. To 19 measure differences in tolerance, a series of four independent sample t-tests was run, one for 20 each of the four subscales on the CLAS-MR. The grouping variable was version of the survey. 21 Minimal demographic information was collected to ensure basic equivalence between the 22 two halves of the sample (Version A: Male = 53%; Caucasian = 65%; African American = 4%; Hispanic = 3%; Asian American = 15%; Mixed Race = 3%; Other/Prefer Not to Say = 10%; 23

1	Year in School: Freshman = 26%; Sophomore = 15%; Junior = 14%; Senior = 38%; 5 th Year+ =
2	6%; Version B: Male = 57%; Caucasian = 69%; African American = 4%; Hispanic = 3%; Asian
3	American = 10%; Mixed Race = 1%; Other/Prefer Not to Say = 11%; Year in School: Freshman
4	= 24%; Sophomore = 12%; Junior = 17%; Senior = 40%; 5^{th} Year + = 6%.
5	Results
6	There were statistically significant differences between respondents who received the two
7	versions of the instrument on all four subscales in the anticipated direction.
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9	Insert Table 1 here
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12	College undergraduate students in the sample who received version A of the CLAS-MR
13	('mentally retarded') were statistically significantly more likely to score higher on the subscale
14	of Exclusion (16.87 vs. 14.54) than their peers who received version B of the instrument ($t =$
15	2.86, $p = .005$, $d = .358$. observed power = .99). College undergraduate students who received
16	version A of the CLAS-MR also were statistically significantly more likely to score higher on
17	the subscale of Sheltering (23.49 vs. 21.93) than their peers who received version B ($t = 2.28$, $p =$
18	.023, $d = .287$, observed power = .57).
19	College undergraduate students in the sample who received version A of the CLAS-MR
20	were statistically significantly more likely to score lower on the subscale of Empowerment
21	(48.48 vs. 54.61) than their peers who received version B of the instrument ($t = -5.33$, $p < .000$, d
22	= .670, observed power = .99). College undergraduates who received version A of the CLAS-
23	MR also were statistically significantly more likely to score lower on the subscale of Similarities

1 (58.81 vs. 61.93) than their peers who received version B of the instrument (t = -3.32, p = .001, d2 = .415, observed power = .85).

3

Discussion

4 For the college undergraduate students in this sample, language and terminology had a 5 significant effect on tolerance toward persons with intellectual disability. Regardless of overall 6 levels of tolerance, students who saw the R-word reacted differently than those who saw the term 7 'person with intellectual disability.' In all cases, those who encountered the R-word responded 8 with lower levels of tolerance, even though the definition of the two terms was identical at the 9 top of each survey. It appears that the reaction to the label overrode the standardized definition 10 and resulted in differing levels of tolerance. These results support the belief that it holds negative 11 connotations and continues to justify the implementation of Rosa's Law.

What is perhaps most striking is the effect sizes that correspond to these differences. In 12 13 general, those who received version A of the instrument were more likely to endorse negative 14 views of individuals with intellectual disability, with effect sizes that were equivalent to 15 approximately one-third of a standard deviation (Exclusion d = .358; Sheltering d = .287). 16 Importantly, however, they were far less likely to endorse positive views of individuals with intellectual disability, with effect sizes that were even higher (Empowerment d = .670; 17 18 Similarities d = .415). In other words, when people saw the R-word they scored more than two-19 *thirds* of a standard deviation lower on Empowerment, which is the belief that people with 20 intellectual disability should be able to have their opinions heard and validated, that they should 21 be allowed and encouraged to advocate for themselves, and that they should be allowed input 22 into how to live their lives. Thus, the effect of the outdated terminology was even more powerful 23 in diminishing positive beliefs than it was in increasing negative assumptions.

Based on these effect sizes, it is easy to see why the Special Olympics declared the 'Rword' hate speech (Ford, Acosta, & Sutcliffe, 2013). It implicitly supports the exclusion of people with intellectual disability. These results start to establish that using the appropriate terminology is not only about politically correctness, it is about changing how people with intellectual disability are viewed and treated (Friedman, 2016). With the simple transition to the term intellectual disability in policy, legislation, and everyday language, society can move in forward towards inclusion.

Finally, although this study provides strong and convincing initial evidence regarding the effects of terminology on tolerance toward individuals with intellectual disability, more research could further our understanding of this phenomenon. It would be interesting and important to discover, for example, whether language affects individuals from different races or genders differently, or whether it impacts actual behaviors, or what specific assumptions people make when they see the R-word that may contribute to the decreased levels of tolerance. There is clearly more work to be done to better understand how language affects tolerance.

15

Limitations

16 There are several limitations to this study. First, the study sample of 259 college 17 undergraduate students cannot be assumed to be representative of all college students nor of the 18 general population. Nevertheless, the use of general education classes helps make the sample 19 more representative of the general college population than a study of all education majors. In this way, it can be assumed to be more indicative of the overall perceptions of the college population. 20 21 Clearly, however, a larger sample from more than one university would help strengthen the 22 conclusions that can be drawn from these findings. A second limitation is the construct validity 23 of the CLAS-MR instrument. Interscale correlations (ranging from .63-.72 in the current study)

1 raise the concern that there is some construct overlap and the subscales do not measure discrete 2 attitudes. For future research, it would be beneficial to look for other instruments that have 3 subscales with lower interscale correlations and less construct overlap to help support the 4 findings that language used does influence tolerance. 5 Implications 6 After more than 40 years of advocacy and even a modification to federal law to eliminate 7 the use of the term 'mentally retarded,' there is now empirical evidence to support this change. 8 The magnitude of the effect sizes and the significant differences across all four subscales on the 9 instrument support the finding that terminology affects tolerance. Terminology matters, and it is 10 not just about hurt feelings or hate speech. It matters because when people see these words, they 11 make assumptions about the people to whom they are referring. At least for the college 12 undergraduate students in this study, the R-word prompted respondents to be far less likely to 13 believe that people with intellectual disability should be listened to, that they should have a voice 14 in the decisions that impact their lives, or that they should be given any choices. Respondents 15 who saw the outdated term were more likely to want to exclude persons with intellectual 16 disability from the community, to believe that they require protection, and to hold a paternalistic 17 belief that the world is a dangerous place from which people with intellectual disability must be 18 protected. Finally, the results provide evidence that the it dehumanizes people. Respondents who 19 saw this term were significantly less likely to believe that people with intellectual disability were 20 basically like themselves, like all of us, and deserve basic human rights. Although these findings 21 are perhaps not a surprise to anyone who understands the power of language, the results of this 22 study provides concrete evidence that terminology is an issue that requires increased awareness 23 and action.

1 The finding that the outdated language can increase negative beliefs clearly aligns with the widely-held belief that the 'R-word' promotes shame and stigma and is equated to negative 2 3 perceptions and beliefs. Undoubtedly, most people understand that the it has negative 4 connotations. However, the results of this study clearly demonstrate that the real damage of the 5 word may in fact be the effect it has on *diminishing positive perceptions*. Participants who 6 encountered the 'R-word' were far less likely to believe positive attributes about individuals with 7 intellectual disability, to believe that they should have a voice, and to believe that they share the 8 same basic humanity as everyone else. In many ways, the diminution of these positive attributes 9 is even more insidious and harder to recognize than the increase in negative beliefs. The effect 10 of reducing positive beliefs represents a form of implicit bias and underscores the importance of 11 using language that promotes dignity and worth.

12 Ultimately, the findings from this study support the belief that terminology can increase 13 negative beliefs and reduce positive beliefs about people with intellectual disability. The results 14 lend significant support for changes to terminology in policy, in federal and local jurisdictions, 15 and in the media and give concrete evidence that these terms have very real implications. The 16 words used determine the level of acceptance of individuals with intellectual disability in spaces 17 where their voices need to be heard. This study emphasizes the potential impact that changing 18 two simple words in written policy, educational spaces, and social events can have on the 19 acceptance and inclusion of people with intellectual disability, giving us empirical evidence that, 20 at last, the 'R' word really must go.

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22	

Table 1

Means, Standard Deviations, and t-test Results for the Four CLAS-MR Subscales

2	2
2	3
Z	1

1

CLAS-MR Subscale	п	М	SD	t	p	d	Power
Similarities				-3.32	.001	.415	.85
Version A: M.R.	124	58.81	8.27				
Version B: I.D	129	61.93	6.62				
Empowerment				-5.33	.000	.670	.99
Version A: M.R.	124	48.48	9.64				
Version B: I.D.	129	54.61	8.64				
Sheltering				2.28	.023	.287	.57
Version A: M.R.	124	23.49	6.03				
Version B: I.D.	129	21.93	4.76				
Exclusion				2.86	.005	.358	.99
Version A: M.R.	124	16.87	7.20				
Version B: I.D.	108	14.54	5.72				

5

6 M.R. = Version A, Mentally Retarded

7 I.D. = Version B, Person with Intellectual Disability

8