

Testimony in Support of AB 20: Terminology Changes for those with an Intellectual Disability in Administrative Rules

Assembly Committee on State Affairs

March 13, 2019

Chairman Swearingen and members of the committee, thank you for holding a hearing on Assembly Bill (AB) 20. I appreciate the opportunity to provide written testimony in support of this bill.

AB 20 removes the phrase "mental retardation" and its derivatives from all state administrative code, replacing it with the phrase "intellectual disability." People with intellectual disabilities and their loved ones find the 'R-word' incredibly offensive; it should have no place in Wisconsin's administrative code.

This change follows 2011 Act 126, which deleted the offensive phrase from all state statutes. However this offensive terminology can still be found in the state's administrative code in rules promulgated by numerous state agencies. I'm pleased to partner with Rep. Jagler to address this issue to ensure that Wisconsin's administrative code is more inclusive and respectful towards citizens with disabilities.

Thank you for your consideration of this legislation.

Public Comment - AB 20 Abigail Lowery March 13, 2019

Thank you for holding this hearing on an important issue and allowing me to speak on it. My name is Abigail Lowery. This issue affects me personally as I have a brother who is one year younger than I am and has autism. Growing up I was very close to my brother. It was partly because we were close in age and partly because I was often charged by my parents to help look out for him. Sometimes I was the only person who could understand what he was trying to communicate.

High school was a brutal time for my brother and I. He was regularly harassed because he has special needs. It was perhaps worse because my brother so desperately wanted to fit in and make friends that he did not always recognize when someone was being mean to him. Also, I was not always around to protect him. Some of this harassment included inciting my brother to ask girl out as a joke, exposing their genitals to my brother, and the classic standby- calling him the r-word. Classmates would use the r-word to harass me as well. One time they shouted at me across a parking lot to ask if my brother was retarded.

This word goes beyond typical harassment. It automatically signifies inequality, inhumanity, and inferiority. I do not think my brother is less than anyone else. In fact, oftentimes he is better. He is honest, empathetic, and nonjudgmental. He just understands the world differently and needs help with certain life activities.

Please abolish the r-word from Wisconsin Administrative Code because government is supposed to be the model for human decency and equality. Using a more accurate and less stigmatizing term like "intellectual disability" will send the message that we value ALL of our Wisconsin residents. It will also show my four-year-old daughter who is here with me today that government <u>does</u> work <u>for</u> the people... <u>all</u> the people. Thank you.

March 13, 2019 Testimony – AB20 Yael Kerzan

Hi Everyone,

I'm Yael Kerzan, and I am a proud self-advocate.

I was born with Williams Syndrome. I will always have this disability.

It is hard for me to learn easy things, but I work hard and never give up.

I am proud to say that, with support, I have two jobs and earn two paychecks. I am even proud to say that I am a taxpayer.

I think the "R" word is horrible. It makes me feel bad.

When I was in high school, the mean kids would call me the "R" word behind my back. I felt terrible!!!

My parents and I are here today to show our support for AB20.

We want to thank you for removing the "R" word from state rules.

We appreciate your hard work for people with disabilities like me.

Thank you for listening to me today.

March 13, 2019 Testimony – AB20 Dallas Kerzan

Good Afternoon Everyone.

I am Dallas Kerzan. I am the proud mom of this young lady and a member of the A-Team. The A-Team is a grassroots advocacy group created to give a voice to individuals with unique abilities. There are 14 A-Team Chapters in Wisconsin and 14 member states across the nation.

Our family would like to thank you for this opportunity to show our support of AB20. The "R" word is offensive and demeaning. It makes me cringe every time I read the word or even worse, when I HEAR it spoken. The "R" word is NEVER used in our household.

We commend you for eliminating it from state rules and replacing it with "intellectual disability." This action demonstrates Wisconsin's dedication toward ensuring the integrity of people with disabilities.

Thank you.

Now, my daughter has her own personal statement to read.



To: Representative Rob Swearingen, Chair Members of the Assembly Committee on State Affairs

From: Lincoln Burr, CEO

Date: Wednesday, March 13, 2019

Re: Testimony in Support of Assembly Bill 20

My name is Lincoln Burr and I am the CEO of the Disability Service Providers Network. DSPN represents organizations across the state of Wisconsin that support persons with Intellectual or Developmental Disabilities. I am here today to voice our support for Assembly Bill 20.

Language is a living thing. Meanings change over time. Terms that are fully reasonable at one point in time often become a pejorative through popular culture. While some people may decry demands to amend this use of language as politically correct, it is far more than that. Consider this, until the 1970s physician's routinely labeled people imbeciles, morons and idiots. These grossly offensive terms were struck down because of the connotation later attributed to them through popular culture. In 2010 our federal government recognized that mental retardation was equally offensive and replaced it with intellectual disability. We strongly favor mirroring this effort in Wisconsin and would like to see the elimination of the term mental retardation from our legislative lexicon.

In addition, DSPN would also like to see the antiquated term "sheltered workshop" eliminated. This term, which was replaced by Community Rehabilitation Program or CRP two decades ago is also woefully out of date and we ask that consideration be given to expanding this bill to include that language change.

Thank you.

disabilityrights WISCONSIN Protection and advocacy for people with disabilities.

- Representative Swearingen & Members of the Assembly Committee on State Affairs To:
- From: Disability Rights Wisconsin, Barbara Beckert, Director Milwaukee Office
- Date: March 13, 2019
- 2019 AB20 Relating to: terminology changes for those with an intellectual disability Re: in administrative rules.

Disability Rights Wisconsin (DRW) is the statewide protection and advocacy system for children and adults with disabilities in Wisconsin. DRW is pleased to support AB20 and thanks Representative Jagler and Senator Fitzgerald for advancing this change. We also want to recognize and thank the many self advocates with intellectual disabilities who have helped to educate us about the importance of respectful language.

Approximately seven to eight million Americans of all ages experience some level of intellectual disability and one out of every ten children who need special education has some form or level of intellectual disability. In Wisconsin approximately 9,453 children qualify for special education services with a cognitive disability diagnosis. Disability Rights Wisconsin provides advocacy assistance to many students with special education needs, and their families. Many have experienced bullying and discrimination, and this often includes use of the "r" word. This type of hurtful language and bullying has major implications and contributes to discrimination and trauma, in school as well as in the workplace.

While people with intellectual disabilities have made a significant amount of progress in Wisconsin, our terminology has not kept pace. This bill is very important to individuals with intellectual disabilities who find these terms insulting and derogatory and will continue the work that began in 2011 when Wisconsin policymakers approved this change to language in state law.

DRW commends this effort to move Wisconsin forward in using respectful language regarding people with intellectual disabilities in our administrative rules. Thank you for the opportunity to share our support.

MADISON	MILWAUKEE	RICE LAKE	
131 W. Wilson St. Suite 700 Madison, WI 53703	6737 West Washington St. Suite 3230 Milwaukee, WI 53214	217 West Knapp St. Rice Lake, WI 54868	disabilityrightswi.org
608 267-0214 608 267-0368 FAX	414 773-4646 414 773-4647 FAX	715 736-1232 715 736-1252 FAX	800 928-8778 consumers & family



WISCONSIN BOARD FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

March 13, 2019

Representative Swearingen (Chair) Assembly Committee on State Affairs Wisconsin State Capitol, Room 123 W Madison, WI 53708

Dear Rep. Swearingen and Committee members:

The Wisconsin Board for People with Developmental Disabilities (BPDD) thanks the committee for the opportunity to provide testimony in support of Assembly Bill 20.

Many state agency administrative rules still have the outdated and offensive term "mental retardation" on the books. This bill replaces the phrases "mental retardation" with "intellectual disabilities" in state administrative rules. Language is important, and our laws should reflect terminology to which our community identifies.

Unfortunately, many people with intellectual or developmental disabilities (I/DD) can recall times when professionals, adults, or peers used this outdated term as a descriptor that defines them as a person. This word is never used as a compliment; by its definition it is a label that implies lesser-than, and in common usage it has been regarded as an insult. The term also harkens back to public policies that are rooted in segregation, discrimination, and views of people with disabilities that see only limitations and diagnosis rather than individuals and capacity.

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities (more about BPDD https://wi-bpdd.org/wp-content/uploads/2018/08/Legislative_Overview_BPDD.pdf).

Our role is to seek continuous improvement across all systems—education, transportation, health care, employment, etc.—that touch the lives of people with disabilities. Our work requires us to have a long-term vision of public policy that not only sees current systems as they are, but how these systems could be made better for current and future generations of people with disabilities.

Thank you for your consideration,

Beth Sweden

Beth Swedeen, Executive Director Wisconsin Board for People with Developmental Disabilities **The Arc.** Wisconsin The Arc Wisconsin P.O. Box 201 Stoughton, WI 53589

T 608.422.4250 Lisa Pugh, State Director pugh@thearc.org arcwi.org

March 13, 2019

To: Chairman Swearingen Members, Assembly Committee on State Affairs

- From: Lisa Pugh, State Director
- Re: Support for Assembly Bill 20: terminology changes for those with an intellectual disability in administrative rules.

Thank you for the opportunity to present testimony today on Assembly Bill 20 that would remove the R-Word from state administrative rules.

This is important legislation that my organization, The Arc Wisconsin, supports. The Arc is the state's oldest organization supporting people with intellectual and developmental disabilities and their families. We have 14 local chapters statewide that offer supports, resources and services to people disabilities. The Arc Wisconsin works to develop programs and advocate for public policy giving people with I/DD the opportunity to learn, live, and work inclusively in their communities.

In my personal life I am also a mom to a daughter with intellectual disabilities who has been called this term. As you have heard today, this term is hurtful, outdated and no longer acceptable.

By making this change to administrative rules Wisconsin will be in line with the medical community, federal law and the leading academic institutions that have developed policy for people with intellectual disabilities since the early 1900s. Perhaps the biggest sign that the R-word was outdated was when a group of academics from the American Association on Intellectual and Developmental Disability - AAIDD, (formerly AAMR) agreed to change their name back in 2007. Shortly thereafter, the American Psychiatric Association (APA) changed its definition and diagnostic criteria for what was previously referred to as MR.

In 2010, both houses of Congress unanimously passed, and the President signed Rosa's Law, a bill that removes the "R" word from all federal health, education and labor policy and replaces it with "intellectual disability." Nick, Rosa's eleven-year-old brother said during the hearings, "What you call my sister is how you will treat her.... It invites taunting, stigma and bullying."

The Arc has been a strong advocate for the removal of the R word from federal and state law and policy across the country.

Words are powerful. While the r-word may not have the same emotion and meaning behind it to everyone, it's a hurtful, disrespectful, and unacceptable word to people with intellectual and developmental disabilities. And that's enough to remove it from our state policy.

Changing how we talk about people with disabilities is a critical step in promoting and protecting their basic civil and human rights.