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SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE Testimony in Support of SB 397 February 15, 2012

Thank you for the opportunity to present testimony in support of eliminating the "R-word" from Kansas statutes and instead using more appropriate people first language and the term "intellectual disability." We strongly support this effort and the focus this committee is bringing to this issue. My name is Rocky Nichols, I am the Executive Director at the Disability Rights Center of Kansas (DRC). The DRC is a public interest legal advocacy agency, part of a national network of federally mandated and funded organizations legally empowered to advocate for Kansans with disabilities. As such, DRC is the officially designated protection and advocacy organization for Kansans with disabilities. DRC is a private, 501(c)(3) nonprofit agency, whose sole interest is the protection and enhancement of the rights of Kansans with disabilities.

We wish to commend the committee for agreeing to hear this bill and for helping Kansas to join most of the other states in the country who have adopted similar legislation including but not limited to Missouri, Arkansas, Wisconsin, New Jersey, Arizona and many others. In New Jersey the short hand for their new law is the "Words Matter Law." That says it all. Words do matter. For people with intellectual disabilities, the R-Word is incredibly offensive. It is an archaic term and the state of the art from the stakeholder and research fields clearly states that the term intellectual disability is far more accurate and effective.

We do have three suggested improvements as you act on this bill:

#1 – Use Person First Language:

Over the past several decades, the field of disability has experienced numerous changes, including the identification of new disabilities, new civil rights protections, a growing self advocacy movement and a shift in how society views disability. Professional and advocacy organizations working on behalf of people with intellectual disabilities have changed the names of their organizations to reflect these advances in our culture and our modern-day desire to show more proper respect toward our fellow citizens who also happen to have a disability.

One request we have for the committee is that it ensures the language in the bill is "person first," ensuring that the terms in law focus on the person first in an appropriate way. Specifically, we respectfully point out that he term "intellectually disabled" is not the state of the art term. As a friend of mine and national intellectual disability advocate Joe Meadors often told me, something that is "disabled" refuses to operate and is broken. The bill currently uses the term "intellectually disabled." This term should be replaced with the term "intellectual disability" or "person with an intellectual disability." Intellectual disability the term the other states and the federal law, Rosa's law, uses. Also, if it is feasible, whenever you are already amending a statute in this bill to take out the R-word, and you also see that words in that same statute are not "person-first" (like the instances where the term "handicapped" is used in the same sections of the law this bill uses), you might want to consider cleaning that up to make it more state of the art by using the term "person with a disability." To us, changing intellectually disabled to intellectual disability is absolutely needed, and the other changes would be welcome.

#2 – Ensure you are setting the policy that wherever the R-word comes up in state rule and regulation, that it should be read to mean intellectual disability:

We further request that in order for the change to have substantive meaning to Kansans, that the committee set the official state policy going forward on this issue and further ensure that whenever the R-word is used in rule and regulation that term intellectual disability be considered in this place. You can do this without requiring every rule and regulation to be written, which could be cost prohibitive to reprint all the KARs (Kansas Administrative Regulations). <u>We might suggest</u> <u>amending the bill to include similar language as below:</u>

New Section: It is hereby declared to be the official policy of the state of Kansas that the term intellectual disability be used in place of the term mental retardation and the term person or persons with an intellectual disability be used in place of the term mentally retarded. Whenever the term mental retardation or retardation appears in the Kansas Administrative Regulations, state agencies are hereby directed to read and use the term intellectual disability. State agencies are further directed that in the normal course of conducting their planned updates or changes to language in rules and regulations that agencies update the terminology of their rules and regulations to be consistent with this policy. Nothing in this policy will require state agencies to change all rules and regulations immediately. The changes to the new policy and new terminology can take place as rules and regulations are naturally updated.

#3 – Clear up Technical Problem or Confusion by deleting New Section 1:

The first paragraph in the draft bill appears to try to clarify the new definition of intellectual disability. We appreciate the apparent intent of this section. However, as it is written it is technically confusing because it cites the age of onset as being 18, when in the federal law says it is 22, and it uses two of nine standards as a predetermining factor, where other laws uses three of seven standards to be met.

We may be missing something, but because we do not see a need for new Section 1, and because the standards outlined in it might be confusing, we would suggest that all of new Section 1 be stricken. The substantive change in the bill is to change the terms in statute from the R-word to intellectual disability. Other states that have changed this terminology have not needed a section like this one, so we would suggest striking it.

One final technical question, on page 47, line 25 of SB 397 it inserts the new term "pro-rata." This change has nothing to do with eliminating the Rword. We would inquire why this unrelated change appears in this bill?

Thank you for your attention to this important issue. I will stand for questions.