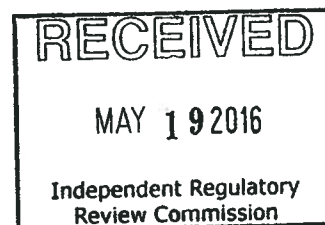


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**Testimony of Maureen Cronin, Executive Director, The Arc of Pennsylvania
Before Independent Regulatory Review Commission,
May 19, 2016**

Thank you for the opportunity to support *Department of Human Services #14-539 Intellectual Disability Terminology Update*. I am Maureen Cronin, the Executive Director of The Arc of Pennsylvania. The Arc ecstatically supports changing the language in 24 chapters of Title 55 to replace the pejorative terms with the appropriate term of intellectual disability.

It was The Arc of Chester County Self-Advocates who spurred Senator Dinniman to introduce SB 458 amending the language in the Mental Health and Mental Retardation Act of 1966. Governor Corbett signed the bill into law as Act 105 of 2011. We are thrilled that the Department of Human Services committed the time to make these language changes in all of its effected regulations.

This action is not merely a matter of keeping up with the latest politically correct phase but it is an expression of the Department values and commitment to serve people with intellectual disability and their families.

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The Arc of Pennsylvania is part of The Arc US, the largest disability rights organization in the nation, advocating for and serving people with intellectual and developmental disabilities and their families. We encompass all ages and many types of disabilities including autism, Down syndrome, and other developmental disabilities. For 66 years, The Arc of Pennsylvania has worked to ensure that children and adults with intellectual and developmental disabilities receive the supports and services they need, are included in their community, and have control over their own lives. The Arc of Pennsylvania has 33 local chapters with over 8,000 members.



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TESTIMONY

Regulation #14-539 Intellectual Disability Terminology Update

Presented to
THE INDEPENDENT REGULATORY REVIEW COMMISSION
by
Scott Spreat, Ed.D, President and CEO
Woods Services

May 19, 2016

Good morning, and thank you for the opportunity to address the commission. My name is Dr. Scott Spreat, and I am a member of the Board of PAR, an organization of intellectual disability and autism provider companies in Pennsylvania. I am also a member of the American Association on Intellectual and Developmental Disabilities (AAIDD) task force that introduced the term "intellectual disability" as a replacement for the term, "mental retardation." This task force wrote the book "Intellectual Disability" as a means of introducing the term. I am here today to endorse Pennsylvania's efforts to replace the term "mental retardation" with the term "intellectual disability" in all pertinent Commonwealth regulations.

It is perhaps tempting to suggest that persons diagnosed with "mental retardation" and their families have requested this change to reduce the stigma associated with the diagnosis of "mental retardation." This is accurate, however, this argument presents only part of the picture.

"Mental Retardation" and all the similar terms that preceded it (feeble-mindedness, mental deficiency, etc.) were based on the construct that the condition resided entirely within the individual who had that diagnosis. That is, the person with mental retardation had a disability because his brain didn't work right. Disability resided within the individual.

The World Health Organization, in its 2001 International Classification of Functioning, Disability, & Health, stressed the importance of contextual factors such as environmental and personal factors in defining a disability. Disability was no longer viewed as residing within the individual, but rather being the product of the interaction of the individual and his/her environment. With regard to Intellectual Disability, it is believed that the disability derives from a dissatisfactory fit between a person's capacities and the context in which the person is to function. Thus, a person may have an intellectual disability in some environments but not necessarily in others. The argument is basically that if an environment placed lesser demands on someone, they might be able to meet the demands of the environment. Consider someone with a 69 IQ. Place them in an agrarian setting where they took care of the chickens and helped bale the hay, one could argue that they didn't have an intellectual disability. They still had an IQ of 69, but if they met the demands of their environment, they didn't have a disability. This emphasis on functionality directly suggests areas for support and remediation, whereas the older construct offered nothing but a finite diagnosis. It is largely this change in the construct of disability that has led to the recognition that the diagnostic term of "mental retardation" needed to be changed.

"Intellectual Disability" has emerged as the preferred term to replace mental retardation for several reasons. First, it better reflects the construct of disability proposed by the World Health Organization. Second, it aligns more properly with current professional practices that focus on functional behaviors and contextual factors. Third, it is more consistent with international terminology. The term mental retardation is dated and no longer permitted in professional journals within this field. In addition, self-advocates (i.e., person who have intellectual disability) find the term less offensive (although history suggests that this term will eventually become a pejorative).

Of significant import, the term "intellectual disability" covers precisely the same population of individuals who were previously diagnosed with "mental retardation." Adopting this term within all Pennsylvania regulations will incur no additional costs because adoption of the term will not result in the identification of more individuals. It will ensure that Pennsylvania's terminology is consistent with professional practices both within the United States and internationally.