



**Testimony on LB 495
Before the Health and Human Services Committee
Nebraska Legislature
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**Bradley A. Meurrens
Public Policy Director
Disability Rights Nebraska**

Good afternoon Senator Riepe and members of the Health and Human Services Committee. For the record, my name is Brad B-R-A-D Meurrens M-E-U-R-R-E-N-S and I am the Public Policy Director for Disability Rights Nebraska, the designated Protection and Advocacy organization for people with disabilities in Nebraska. There are some parts of the bill that are positive and some that raise some concerns, which we wanted to make the committee aware, thus I am here today in a neutral capacity regarding LB 495.

Definition of Developmental Disability

First, the definition of developmental disability. We continue to press for the inclusion of mental illness as a sole determinant of a developmental disability. Federal law does this; Nebraska law does not. For if the key determinant of developmental disability is the onset of a disabling condition prior to age 22, a disabling mental illness can be a solely disabling condition; onset prior to age 22 seems to square with the language and intent of the definition of developmental disability. However, we can agree on the inclusion of mental illness as an attributable impairment as people with a non-mental illness disability can over time develop mental illness before the age of 22 with a similar

134 South 13th Street, Suite 600 Lincoln, Nebraska 68508
402-474-3183 fax: 402-474-3274

1425 1st Avenue Scottsbluff, NE 69363
Office: 308-633-1352 Cell: 308-631-5367

TDD Available 1-800-422-6691
www.disabilityrightsnebraska.org
The Protection and Advocacy System in Nebraska

impact on their development. We would also suggest removing “other than mental illness” from line 9 as it seems redundant with lines 13-14.

Additionally, the language in 71-1107 (page 1, lines 8-9) “Developmental disability means a severe, chronic disability, including an intellectual disability”, could be interpreted as requiring both a severe, chronic disability and an intellectual disability occur simultaneously, thus limiting out some people who have a disability who have a severe, chronic disability but no intellectual disability.

We like the addition of the language “acquired condition” (page 3, lines 3-4) as it is more inclusive of people with disabilities (prior to age 22) who would otherwise be excluded, for example people who have an acquired brain injury.

We again must raise issue with the existing definition of intellectual disability found in 71-1108.01 (page 3, line 15) specifically with the issue of the IQ score of 70 or below. As we stated previously on LB 1039 (2016), we would prefer that the language be changed to a range of IQ scores rather than a static cut-off score of 70.

Entitlement to Services

Recognizing the difficult work of advocates to insert an entitlement to services in existing statute and the key role that this can and does play in the receipt of services for people with developmental disabilities, we would prefer that Nebraska retain its entitlement language. Our position is that this is an actionable “right” that parents and individuals can utilize to procure services, and that the removal of this language in LB 459 essentially removes this right. We understand that this may be problematic for the Centers for Medicare and Medicaid Services, and might impact federal matching funds; in turn affecting the provision of necessary disability services. We have heard from the Division of Developmental Disabilities assuring that removing this entitlement will enable Nebraska to serve more people generally through waivers. We certainly want Nebraska to maximize the number of people receiving necessary developmental disability services. This underscores the importance of legislative oversight and program evaluation to ensure that things progress as planned and promised. We are further

concerned about this because once this entitlement is removed, it may very well be difficult to re-insert it and peoples' rights in this area may be lost indefinitely. If service provision or process begins to lag, or additional difficulties arise regarding serving Nebraskans with developmental disabilities under the proposed entitlement removal, Nebraska may need to revisit the entitlement language.

Additionally we would suggest removing the word "federal" from the legislative intent language found on page 4, line 5 or replacing it with "federal and state" or "all". An interpretation of this proposed language could allow the state to shrink its funding responsibilities and increase reliance on federal-only funding. Nebraska does have a major role and responsibility in providing adequate levels of funding to serve its residents with disabilities fully and should not be given easy "outs". For example, under the *Olmstead* requirements, it matters not who is the funder but rather that the services provided are in the most appropriate settings.