



**Human Service Interim Committee
64th Interim Session**

**In Regards to: Eligibility for Developmental Disabilities Waiver pursuant to Section 1 of
2015 Senate Bill No. 2234
Tuesday, November 3, 2015**

Madam Chair Hogan and Members of the Interim Human Services Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes represents 140 individuals with Down syndrome and their families across the state of North Dakota, which is about a quarter of the state's 600 residents with Down syndrome. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

Our organization worked with state legislators to attempt to address the issue that the state has had young children with Down syndrome who have not been found eligible for DD Program Management and the Intellectual Disabilities/Developmental Disabilities (ID/DD) Home and Community Based Waiver. In addition, we were and still are concerned about the requirement for extensive cognitive testing in some parts of the state for this population as well as other young children with disabilities.

Our original ask was that SB 2234 would establish that persons with a diagnosis of Down syndrome be automatically eligible for Developmental Disabilities (DD) services without the undue burden of additional cognitive and functional testing, after the age of 3. The Department of Human Services presented information that this would not be allowable under Center for Medicare and Medicaid rules, so the language in the original bill was changed to the current study.

We would also like to request that the Department explore other states' definition of the term "related condition" which is included in the administrative code language for eligibility. Many states include certain diagnoses and the language may read like Minnesota's:

Related condition is a diagnosis of severe, chronic disability that meets all of the following conditions:

1. Is attributed to cerebral palsy, epilepsy, autism, Prader-Willi syndrome or any other condition other than mental illness* or an emotional disturbance.
2. Is found to be closely related to developmental disability because the condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with developmental disability and requires treatment or services similar to those required for persons with developmental disability.
3. Is manifested before the person reaches 22 years of age.
4. Is likely to continue indefinitely.
5. Results in substantial functional limitations in three or more of the following areas of major life activity:

- Self-care
- Understanding and use of language
- Learning
- Mobility
- Self-direction
- Capacity for independent living

We continue to question if other states include certain diagnoses such as CP and autism, then why would CMS not allow a diagnosis of Down syndrome to be considered under “related conditions”. We question why the diagnosis is not included in the federal language and are continuing to explore this. We would suggest that generally speaking it would be rare that persons with Down syndrome would be excluded from ID/DD waivers across our country due to the undeniable link between the diagnosis and a cognitive disability.

During the session, I was told that autism can be considered because individuals are “tested” to have autism. This answer continues to be confusing since my daughter has a medical, genetic panel that indicates that she has Down syndrome. She has been tested and found to have Down syndrome. In both cases – with autism or Down syndrome – no one can predict cognitive potential, no matter the diagnosis.

In exploring how to address this issue, we would also like to suggest that the Department consider the language relating to young children from the federal Developmental Disabilities Assistance and DD Bill of Rights Act which states that a child be considered to have a developmental disability without meeting 3 or more of the of the substantial functional limitations (as listed above) when they have a high probability of meeting these criteria later in life.

All children with Down syndrome, age birth to 3, are eligible for services through DD and are screened for the ID/DD waiver if their parents chose this service. Because of the services that are delivered during that time, children with Down syndrome and other disabilities acquire extensive amounts of information about their functioning. We would request that the state discuss how to use the information on hand without requiring families and children go through the cognitive testing that typically does not generate accurate information about a young child’s functioning.

In addition, I would like to address the need for continued collaboration between the DHS programs that provide supports to children with special health care needs and developmental disabilities. While all of the programs (DD, Medical Services, Autism, and Children and Families) are working to try to address the issue of serving children with special health care needs and/or developmental disabilities, expanded collaboration on the issue between the DHS departments and with the public would insure that we are creating systems that work effectively and efficiently for children and their families.

Thank you for your time. I’d be willing to answer any questions.

Roxane Romanick
Executive Director
Designer Genes of ND, Inc.
701-391-7421
romanick@bis.midco.net