



SB 2276

Senate Appropriations – Human Resources Division
Wednesday, Feb. 8, 2023
Senator Dick Dever, Chair

Chair Dever and Members of the Senate Appropriations – Human Resources Division:

My name is Roxane Romanick and I am writing as the representative for Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 230 individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

SB 2276 – Designer Genes is advocating for SB 2276 and respectfully requests your vote in favor of the bill. Our organization played a role in developing SB 2276, as we believe it will greatly benefit families with loved ones who have Down syndrome. While working on this bill, our goal was to simplify it as much as possible, while acknowledging that changes to Medicaid Waiver programs are complex. We appreciated the feedback from the Department of Health and Human Services on this bill.

Goals – The main intent of SB 2276 is to allow families, mainly parents, to be paid for the care that is above and beyond what they would do for a loved one without extraordinary needs. I encourage you to listen to the family testimonies during the Senate Human Services hearing. These stories highlight the challenge of balancing employment with the demanding and often overwhelming care needs of their children, compounded by difficulties in finding quality staff, the severity of the child's needs, and managing their education and healthcare.

Eligibility – SB 2276 aims to provide a service option for individuals who are already eligible for in-home supports or care under ND Medicaid Waiver. This option would be available through Medicaid 1915c Waivers and will not change current eligibility or services. Currently, ND does not have a provision for parents of children with disabilities to be paid as service providers. The Aging and Disabled Home and Community Based Waiver does offer this option, reimbursed at a daily rate, but does not serve individuals under 18.

Our aim is to keep the requirements for this option simple, without requiring a tedious demonstration of unsuccessful staffing or placement attempts. The decision to access this option should be based on the individual's person-centered plan, considering any new or annual assessment information. The annual assessment mentioned in Section 1, Subsection 3 is similar to the annual application for In-Home Supports used by ND Developmental Disabilities Section to assess the needs and authorize In-Home Supports for individuals with intellectual disabilities or developmental disabilities under the DD Waiver.

Background – While initially discussing options, it was our hope reimbursing families as service providers could become another provider option under the already existing self-directed In-

Home Supports service; however, getting input from the Department, more general terminology of a “service option” as discussed in Section 1, Subsection 2 was chosen to allow flexibility to the Department in meeting the requirements for the Centers for Medicare and Medicaid (CMS). I’ve included a link of to a CMS presentation on Leveraging Family Caregivers:

<https://www.medicaid.gov/medicaid/home-community-based-services/downloads/leveraging-family-care.pdf> . This presentation indicates that just over half of states allowed legally responsible individuals to provide a personal care service. While complicated, it appears that the Centers for Medicare and Medicaid understand the critical urgency to consider this issue and is creating guidance to support the approach.

Section 1, Subsection 4 excludes the Aging and Disabled Waiver from the changes in this bill. We want to ensure that the option exists in all of our waivers that are or will be available to eligible children. From that perspective and by a recommendation by DHHS, we did not want to affect anything within the Aging and Disabled waiver by the language in Section 1, Subsection 2.

Utilization – As you’ve listened to the Department’s testimony, especially Developmental Disabilities and considered the roughly \$13 million in underutilization, please remember that the families you are hearing from today have **undelivered services** represented in that amount. In regards to the fiscal note, I would ask the committee to consider what duplications in cost may already exist in SB 2012 that could offset this fiscal note. For example, some of the families that may benefit from this option are already self-directing and are probably figured into the Department’s budget for the intermediary fiscal agent costs.

Family Finances – While preparing this testimony, I did so with a single father in mind who is trying to maintain his professional career while managing two major surgeries for his child with Down syndrome as well as his ongoing care. He has had difficulty finding consistent staff for over a year now and is constantly worried about having to take leave without pay, putting his job at risk. SB 2276 opens the door for ND to support him and keep his family intact which we understand is way more beneficial and much cheaper than an institutional placement for his son. Many families are in a similar situation, just barely hanging on.

Thank you for your consideration of SB 2276. I am available to answer any questions.

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