



SB 2276
House Human Services
Wednesday, March 8, 2023
Representative Robin Weisz, Chair

Chair Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I am here today 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 as well as many of individuals with disabilities. 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 all of the family testimonies that have occurred during the hearing of this bill. These stories highlight the challenge of balancing employment with the demanding and often overwhelming care needs of their children, compounded by difficulties in managing the workforce shortage, finding quality staff, considering the severity of the child's needs, and managing demands of 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 by the family. 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 Individuals with Intellectual Disabilities/Developmental Disabilities (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 are allowing a 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 individuals. 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 – In other testimony, the Department has reported roughly \$13 million in underutilization in the area of In-Home Supports with in the DD Waiver. It’s important to remember that the families you are hearing from today have **undelivered services** represented in that amount. Families are going without care, that’s the plain simple truth. 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. We would also like to assure equity across the waivers in how this service option is paid out.

Family Finances – SB 2276 is aimed to support families who do not have a broad array of options open to them for caring for their loved one, many of them unable to attend child care, day programming, or even school. 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 or even any staff at all for over a year. He 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.

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

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