



**SB 2276**  
**Senate Human Services**  
**Tuesday, January 24, 2023**  
**Senator Judy Lee, Chair**

Madam Chair Lee and Members of the Senate Human Service Committee:

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.

Designer Genes is in support of SB 2276 and asks for your consideration of a "yes" vote. Our organization assisted in the creation of SB 2276 and acknowledge that it will be a benefit to some of our member families who have a loved one with Down syndrome. Our challenge in crafting the language of this bill was to keep it as simple as possible, while recognizing that there is nothing simple about a change to a Medicaid Waiver program. We appreciate the input from the Department of Health and Human Services (Department) on this important topic of allowing families to be paid service providers.

The main intent of SB 2276 is to allow families, most particularly parents, to be paid for the care that is above and beyond what they would do for a loved one without extraordinary needs. As you will hear from family members who support this bill, the burden to maintain employment and meet the extensive and extraordinary needs of their children is heavy and sometimes unmanageable. This tension can be exaggerated by the inability to employ quality staff (heightened now due to workforce shortage), the intensity and fragility of the child's needs, and high demands of managing a child's educational and medical needs.

The vision is that this service option would be available through our Medicaid 1915c Waivers and the language of the bill would not alter who is presently eligible and/or served. For the most part, the individuals that we are targeting for this option already have service authorizations for some type of In-Home Support or care under a ND Medicaid Waiver. Presently, ND does not have an option for a parent of an eligible child with disabilities to be paid as a service provider. While initially discussing the option, 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 1.2 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> . Offered in October, 2021, 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.

To incorporate this bill if it passes as currently written, the Department will need to draft Waiver amendments for any of our state's Medicaid Waivers which provides a self-directed In-Home services service option. Section 1.2 and 1.3 creates assurances that the option to include families as paid service providers is available to the widest population possible.

It is the hope that requirements for this option will not include an onerous demonstration of failed staffing and/or placement attempts, but instead that a decision about accessing this option stems from the development of the person-centered plan for the individual including the use of any new and/or annual assessment information. The annual assessment in Section 1.4 is meant to represent something similar to the annual application for In-Home Supports that the ND Developmental Disabilities Section uses to determine need and service authorization amounts for In-Home Supports in the DD Waiver.

Finally, Section 1.5 is a placeholder to assure that rates established for paying families would be equitable to rates paid out for a similar service to a non-family member or a provider.

In regards to the fiscal note that was filed last evening, I would ask the committee to consider what duplications in cost there 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. Remembering there is not an ask for an expansion of eligibility and since these are individuals that are already being served, I would expect current service authorizations are already figured into SB 2012 which would be underutilized if families are able use this service option. In addition, presently to my knowledge, no single service option under our 1915c waivers has a solely dedicated manager.

As this concept and bill were being developed, families expressed an interest and wanted more information. 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.

For his sake and for all of the families that are asking, please consider the passage of SB 2276 and I will be willing to answer any questions.

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