

SB 2305

Senate Human Services Committee

January 27th, 2025

Madam Chair Lee and Members of the Senate Human Services Committee.

My name is Vicki Peterson, I am a Family Consultant for Family Voices of ND. Family Voices of ND is the statewide Family to Family Health Information and Education Center in ND. My role as a consultant is to support families who have children and youth with chronic health conditions, disabilities, and special health care needs. Family Voices of ND connects families to resources, application assistance, navigate systems of care, education, training, and emotional support.

I am here today to give my testimony in favor of SB2305 that would establish the Family Paid Caregiver Service Program in the ND 1915c Medicaid Waivers and serve as a modality choice of caring for a child with extraordinary needs, these needs go beyond a typical care in both medical or behavioral on which a legally responsible person would typically provide. These needs would involve complex medical or behavioral care that surpass the standard of care that is not considered normal parenting responsibilities that may require extra training or expertise. If passed this bill would make the option available in a Medicaid Waiver program that many other states have implemented in some form. ND currently has not and only created a pilot program outside of a 1915c Medicaid Waiver.

Why is this important for ND families caring for their child with those extraordinary needs? This service would be a win for everyone. It will allow family member, legally responsible adult, to be compensated for the remarkable time, care, and effort for their child with complexity in care. The service could alleviate financial strain on a family as well as the financial strain a state may have by providing those services in a nursing home care or other type of institutionalized care. Can also reduce a family having to seek out other programs if this service modality was in our 1915c Medicaid Waivers (excluding Aged and Disabled which already offers a similar option). This option in a service could allow a legally responsible adult who would

be compensated at a wage that would allow to maintain financial stability and promote comprehensive well-being when considering the demanding nature of care. A fair wage, in proportion to a professional self-directed support staff would receive, would be the right choice to make. Beyond reducing financial burden, a fair wage can improve the quality of care by dedicating more time and energy to providing exceptional care, more personalized care by meeting emotional needs as having the deep understanding of their child. Consistent and personalized care is a key importance which is beneficial for the care recipient and keeping the family unit together.

During a ND Cross Disability Advisory Council (CDAC) it was reported that there were 444 applications with a waitlist of 182 for varied reasons, on the pilot for family paid caregiver program. Many states have created this new modality of service or modifying their program that was created during the public health emergency. The workforce shortage has made this program essential for filling the gaps to ensure necessary care.

I receive many calls from families who are desperately seeking help. You heard many remarkable stories during the 2021-2023 Legislative session that provided you with the day to day lives these families lead with children that require this service to exist. There are more.

I encourage you to have a DO Pass on SB 2305 for the children with complex and extraordinary needs along with their families to be able to utilize this service.

Thank you for your time and consideration.

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