

Testimony on HB 1067
2025 Legislative Session
House Human Services Committee
Chairman Representative Mathew Ruby
January 13, 2025

My name is Donene Feist, I am the Director for Family Voices of North Dakota. I come before you today to request support for HB 1067 and to additionally provide information on issues that we are seeing at Family Voices.

Family Voices of North Dakota is statewide health information and education center who serves families of children with special health care needs in ND. Each state in the country and our territories has one family organization that has been designated as a family to family health information and education center by HRSA federally. We are that entity for ND.

We provide emotional and informational support to many families across North Dakota who have a child who has an ongoing medical diagnosis such as asthma, heart conditions, physical disabilities, and emotional/behavioral issues. Our staff, who all are parent to children with special health care needs, provides assistance to families by helping them access and navigate services; explaining what the services mean, how systems work, and where the funding comes from; and by providing emotional support to assist with their unique and individual needs.

We are very supportive of the bill as it extends the age limit for the medically fragile waiver and the autism waiver to the age of 21. We are also supportive of expanding Medicaid coverage to children who are lawfully present in the U.S. but whose parents have not met the five-year waiting period or obtained forty qualifying quarters of Social Security coverage.

An area of concern that we have is this:

The majority of North Dakota's children with disabilities who are being served under one of our various 1915c Medicaid Waivers (Autism Waiver, Developmental Disabilities Waiver, Medically Fragile Waiver, Children's Hospice Waiver) must be on Medicaid. North Dakota recognizes this fact and allows for a FAMILY income and asset disregard for Medicaid eligibility. Only child income would count and in almost all cases, the child does not have any income and/or assets. Unfortunately, this changes in families where there is divorce resulting in child support or death of a parent (or a parent drawing a social security benefit), then child support and/or Social Security survivor or retirement benefit are determined child income and the state assesses a cost share or a recipient liability.

In a recent scenario, a mother found out after the sudden death of her spouse, that her child with complex health needs would now have a cost share when accessing In-Home Supports through one of our 1915c Medicaid Waivers. The cost share was so large that the Social Security benefit barely covered the cost. On top of the loss of income in her home and dealing with grief, she

then had to pay for a service that she did not have to when her husband was alive. These families not only take a loss of income, most times the Recipient Liability is at least as much as or higher than the SS benefit or child support.

Because of the dire circumstances of these families we consulted with one of our national partners is the Catalyst Center at Boston University who is the National Center for Health Insurance and Financing for Children and Youth with Special Health Care Needs (CYSHCN). Their role is to: promote universal, continuous, and affordable coverage for all CYSHCN; close benefit and financing gaps; promote payment for additional services; and build sustainable capacity to promote financing of care. They could not identify another state who as a death benefit or from child support utilize this as income for the child which changes their Medicaid eligibility.

As HB 1067 opens up the section on Medicaid eligibility, we are asking the House Human Services Committee to work with the Department and Legislative Council to draft an amendment that would exclude Social Security survivor and/or retirement benefits as well as child support payments as child income for purposes of Medicaid eligibility.

We thank you for your consideration.

Donene Feist
FVND Director
L# 292
701-493-2634;
fvnd@drtel.net