

Testimony

SB2012

Senate Appropriations Human Services

01/24/2023

Chairman Dever and Members of the Committee.

My Name is Jessica Neigum Dargis, and I reside in District 30. I am here on behalf of my daughter Belle who is 4 years old and is developmentally delayed due to being born with an occipital meningocele. I also serve as member of the Special Health Services Advisory council. I also serve as CFO for a local DD provider, and a local business owner so I can respect all angles of budgeting from a fiscal perspective. That is why I am here to address the general funds for SB 2012 and how they relate to the Children and Family Services Budget more importantly how they relate to the Family -to- Family Support Organizations and the grants they receive.

Family Voices of North Dakota holds a contact with DHS to provide Family-to Family Support across the state of North Dakota. They help so many families find their way when they receive a medical diagnosis, long before the state or anyone else reaches out to families. Many physicians in the state know about Medicaid, however when parent is given a diagnosis about their child, they rarely offer information on where to seek additional emotional, medical, and financial support.

In 2018 I was a mother to be, I found out about Belle's medical diagnosis when I was 22 weeks pregnant and was told my grim options and the likelihood that Belle may never make it out of the hospital alive, for the next 5 weeks I walked in darkness and sadness.

At 27 weeks I met someone that would link me to Family Voices and their regional coordinator for Bismarck.

Family Voices of North aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

The regional coordinator informed me about so many services that I had never heard of and who to call to access those services once my daughter was born, but most of all I was given the peace of mind that I wasn't going to have to do this journey alone, that I would have whole new "Family" to guide Belle, my husband, and I during this process.

Family Voices doesn't just help you in the beginning, they will stick by your side as your child grows, when my daughter had brain surgery, they were there to guide my family on the next steps. Having a child with special health care needs and/or disabilities doesn't just end, they understand it is a lifelong commitment for the family and they are willing to help them navigate it.

Family Voices provides families tools to make informed decisions and serves as a trusted resource on health care.

So, I ask you to vote in favor for the fiscal increase for the Family-to Family Support services within the general fund for SB2012 as we need Family Voices of ND to help guide future families with children with special health care needs and/or disabilities.

Thank you for your time and consideration, and as I close, I would like to leave you with one final thought.

If it takes a village to raise a child, it also takes a village to support the parent and family.

If your child or grandchild was given a complex medical diagnosis, who would you call to help support your child, your family and yourself all in one call?

I know I would call Family Voices of ND.

Jessica Neigum Dargis
Parent of a child with a disability
612.695.8150
jess.neigum@gmail.com