

Family Voices Leader in North Dakota

Donene Feist, a parent activist who lives in North Dakota, didn't think statistics were good for much until she went to a Family Voices training a few years ago and learned some things that piqued her interest. Since then, she's been a strong advocate for the power of data to support and strengthen the stories parents and caregivers have to tell about the challenges of caring for children with special needs.

In the last state legislative session, Donene supported two bills. One would authorize a study of children with special health care needs using Medicaid and Blue Cross Blue Shield data. The other bill involved creating a model Medicaid waiver for families who have private insurance and/or do not meet Medicaid income guidelines, but face excessive medical costs for the care of children with special needs. Medicaid and Blue Cross data will be used to identify the number of children who are medically fragile in both groups.

Donene prepared a slide show with vignettes and photos, and peppered it with data from the National Survey of Children with Special Health Care Needs, which she found on the Data Resource Center website. The survey data enhanced the stories in the presentation by demonstrating that they occur not just once or twice, but all around North Dakota. As she left the room after testifying, staff from the Department of Human Services stopped Donene and asked where she got the information!

With the effort of many advocates, both bills were enacted. Donene continues to be involved in their implementation.

Postscript:

Donene included information from the Data Resource Center in a weekly newsletter which goes to about 1000 families around the state, and produced a 1-page information sheet about CSHCN in North Dakota. Additionally, information from NS-CSHCN has been distributed through FVND's snail mail newsletter which is distributed to over 2800 across the state.

She created a slide presentation for the North Dakota Disability Advocacy Consortium. Titled "Leave No Child with Special Needs Behind," the program included information from the Data Resource Center. It was used to educate the group about the needs of future special needs consumers and how to advocate on their behalf. To for a copy of Donene's presentation please click here: "[Leave No Child Behind](#)".