



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.

Post script:

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.



MASSACHUSETTS MOM STORMS THE STATE HOUSE

If you spent any time in the Massachusetts State House during the past year, chances are you are familiar with Carrie Howland. Carrie and her husband Bob are the parents of two beautiful children, 7-year old Caitlin and Bobby, who turned 5 last February. Caitlin is a happy, bright, healthy girl. Bobby was born with Down Syndrome and several chronic medical diagnoses including hypothyroidism, epilepsy and long segment Hirschsprung's disease.

After Bobbie's birth Carrie, who had temporarily (she thought) suspended a successful career in secondary market research, found herself and her family suddenly plunged into a world of medical terminology, doctors, surgery, emergency rooms and home health care. She learned firsthand just how slow, inefficient and incomplete health care systems can be.

Carrie credits Meg Comeau, now at Boston University, with understanding and helping channel her frustration by introducing her to the Massachusetts Consortium for Children with Special Health Care Needs. It was at one of their meetings that Carrie learned about the Data Resource Center and the National Survey of Children with Special Health Care Needs. She logged on to the DRC, hoping to find information she could add to testimony she was preparing for a legislative budget hearing.

Faced with screen after screen of topics and questions about a whole range of issues, Carrie wasn't sure how to start. So she clicked on "Ask a Question." With help from Deb Read of the Data Resource Center, Carrie learned how to identify and locate the information she needed, copy and paste it into her document, and how to understand and communicate the meaning of the results.

Carrie presented her testimony with DRC screen shots and statistics for Massachusetts and the nation at a budget hearing in the fall of 2004 and again in March, 2005. After the March testimony flexible funding for support to families with special needs children was increased for the fiscal 2006 budget year. Her testimony was later used by a legislator to confront state government about lack of services for CYSHCN.

Post script:

In June of 2005 Carrie included data from the DRC in a presentation at the National Respite Coalition event in Washington DC, in support of the National Lifespan Respite Care Act. In November she spoke again at the Massachusetts State House. She continues to work tirelessly to increase medical and support services for families of children with special needs, who, regardless of their income or socioeconomic status, need and deserve support for their efforts to provide a safe and nurturing environment for the lifetime of their children with special needs, siblings, parents and other caregivers.



SAVE THE CDRC!!

In the Spring of 2005 Oregon's governor presented a budget that included a \$4.5 million reduction in funding for Oregon Health and Science University's Child Development and Rehabilitation Center. The CDRC serves more than 8,000 children, youth and adults with special health care needs from all parts of the state. Over half of the families served have Medicaid insurance, or no health insurance at all. The budget cuts would have reduced by over one half the number of children and youth served by CDRC, forcing many families to pay out-of-pocket or forgo needed services.



While preparing for a legislative hearing on the proposed budget cuts, CDRC director Dr. Brian Rogers learned about the Data Resource Center. He called upstairs (the DRC is located in the same building that houses CDRC) for help. DRC Research Associate Dana Zive flew to the rescue with a mini-lesson on how to locate state by state comparisons for the National Survey of Children with Special Health Care Needs (NS-CSHCN). Dr. Rogers was able to add to his testimony the fact that **before** the proposed cuts Oregon ranked lowest among the states in the proportion of children with special health care needs whose families have adequate support services, and fifth from the bottom for meeting the needs of CYSHCN for specific health care services.

The information Dr. Rogers found at www.cshchdata.org was included in materials posted on a CDRC website that was developed specifically to support the effort to restore the CDRC budget. The website is still up, but now its message reads, "SaveCDRC.org would like to thank everyone for their support... State legislators have approved our funding... we couldn't have done it without YOU!"

Post Script:

Information from the Data Resource Center for Child and Adolescent Health now appears in several CDRC documents, including an article in the Doernbecher Children's Hospital newsletter and the CDRC web page on the Oregon Health and Science University website.