



## *Helping Families of Children with Special Health Care Needs: Summary of Activities: 2005 – 2008*

### Background

**F**amily Voices of North Dakota (FV of ND) is a parent-run organization that provides information and support to families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. It is estimated that 12% of all children under the age of 18 in North Dakota have a special health care need, representing almost 20% of all households<sup>1</sup>. FV of ND provides assistance to these families and the professionals who serve them through direct contact (telephone, email, in-person), through publication development and dissemination, through workshops and trainings, and finally through partnership activities with the state's Title V program and other state agencies and professionals.



This report summarizes the activities of FV of ND over the past three fiscal years: July 2005-June 2006, July 2006-June 2007, and July 2007-June 2008. Significant accomplishments are highlighted; data on requests for assistance, individuals served, type of information provided, and problems with health care are summarized; and broader outreach activities are described.

### Significant Accomplishments

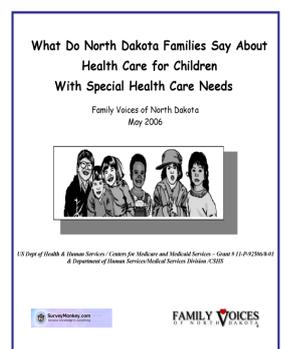
#### 1. Establishment of a Family-to-Family Health Information Center in North Dakota

FV of ND has been assisting families of CYSHCN since 1997, when Executive Director Donene Feist, a mother

of a young child with hearing impairment, recognized the need for family assistance in navigating health care systems. With grants from CSHS, ND Department of Human Services and private donations, FV of ND became established as a resource for families and professionals. In 2000, FV of ND became a 501(c3). From 2004-2007, FV of ND was awarded \$50,000 annually from the Centers for Medicare and Medicaid Service (CMS) to run a Family-to-Family Health Education and Information Center, and continued to receive funding from CSHS. In 2007, FV of ND was awarded \$95,700 annually by the Maternal and Child Health Bureau to continue and enhance its operation as a Family-to-Family Health Information Center (F2F HIC) through 2010. With this additional funding FV of ND hired 3 part-time staff, resulting in outreach to more families in North Dakota.

#### 2. Survey of Families of CYSHCN in ND

Recognizing that many of the issues facing families were related to broader healthcare policies, FV of ND conducted an electronic survey of 90 families to identify health and service experiences of families of



CYSHCN in North Dakota. Based on a national survey conducted by Family Voices and Brandeis University in 2000 ("Your Voice Counts"), FV of ND worked with Family Voices to adapt and implement this tool. Families were asked about their understanding of their child's health care program, the care their child receives and their relationship with their child's doctor(s). In

addition, the survey obtained feedback from families on their areas of concerns, needed improvements and other suggestions. A report was written and shared with ND legislators, Title V staff, and other professionals, resulting in discussions and new partnership activities to improve services for families. Key findings included:

- 46% did not feel at all comfortable or felt somewhat comfortable with their knowledge of health care financing programs.
- 41% did not feel at all satisfied or felt somewhat satisfied with the quality of primary care, obtaining referrals & appointments for needed services and coordination among both primary and specialty care.

### 3. Family Opportunity Act (FOA) Passed in ND



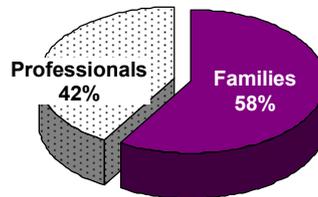
When Congress passed the Family Opportunity Act (FOA) in 2006, the groundwork was laid for states to expand coverage of Medicaid to include more families, ND wasted no time in pursuing this opportunity. Having established relationships with ND legislators, FV of ND helped them understand the plight of families and the critical needs addressed by the FOA. Reaching out to the FV of ND network of families, and other parent-led organizations, FV of ND helped families share their experiences with legislators. As a result, North Dakota was the first state in the nation to implement a state Medicaid buy-in program for children with disabilities, a component of the FOA. FV of ND also helped to ensure that this legislation also included funding for a medically fragile waiver.

## Data on Assistance Provided

### 1. Requests from Families and Professionals

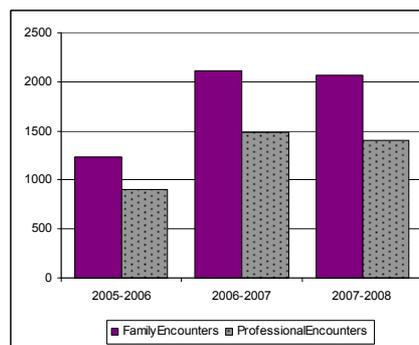
The core component of FV of ND, as an F2F HIC, is to serve families of CYSHCN and the professionals who care for them. These families need assistance finding and providing care for their children and youth with special health care needs. Professionals also seek assistance from family centers in order to work more effectively with families, children and youth, and other family organizations. Charts 1-3 provide information on the requests for assistance made by families and professionals.

Chart 1. Individuals Requesting Assistance



As shown in Chart 1, 58% percent of all individuals requesting assistance were family members; 42% were professionals. Examples of

requests from families included finding payment for medical care, learning about Early Intervention (EI), seeking to talk with another parent, or looking for help navigating public programs. Examples of requests from



professionals included seeking a family perspective on materials, identifying parents to serve on advisory

committees, looking for information to help a family find community resources, or requesting a media interview.

**Chart 2. Comparison of Requests for Assistance by Year**

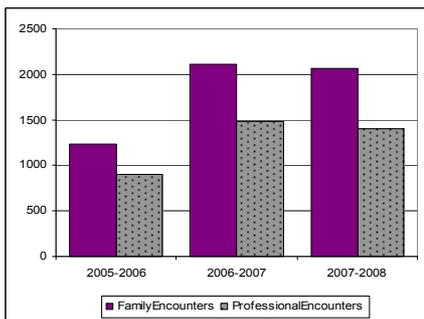
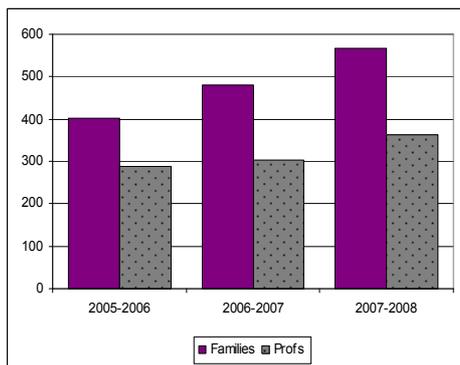


Chart 2 shows the change in requests for assistance from families and professionals over the past three years. Although

FV of ND saw an increase of 37% in requests from the 2005-2006 fiscal year, this number has remained constant over the last 2 years. To put this in perspective, Chart 3 shows the comparison in individuals served over the last 3 years. Although the # of requests was approximately the same over the last 2 years, the number of individuals served increased.

**Chart 3. Comparison of # of Individuals Served**



Charts 2 and 3 relate the # of requests made by an individual to FV of ND in order to obtain

needed assistance. Families and professionals in need most often contact FV of ND by phone but also by email and through direct personal contact, such as at meetings, conferences or workshops. Many family members or professionals made contact with FV of ND more than once in order to obtain the assistance they needed. In 2007-2008, families and professionals needed less contact with FV of ND to obtain needed assistance than in previous years; however individual and new requests continued to rise. On average, FV of ND received 14 requests for assistance per day.

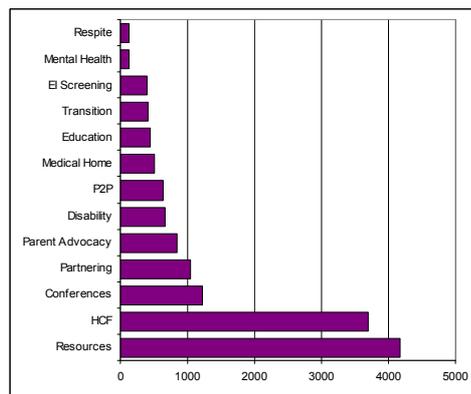
FV of ND estimated that, on average, 30% of the families with whom they were involved were from underserved communities, including African, Hispanic, Bi-

racial, Native American, Low-income, and rural and migrant workers and their families.

**2. Specific Information and Assistance Provided**

Parents rarely have the time to prepare themselves to care for a child with special needs. Often, mothers, fathers, and other caretakers are thrown into an overwhelming world of medical technology, insurance bureaucracy, and a social services maze when they learn that their child has a special need. Many families call FV of ND not knowing what they need to help themselves or their child. Staff at FV of ND, having traveled this road themselves as parents of CYSHCN, is in the best position to listen, understand, and help. The chart below indicates some of the kinds of information and assistance that FV of ND provided.

**Chart 4. Information Provided during Requests for Assistance**



As shown in Chart 4, FV of ND reported providing many kinds of information to families and professionals in response to

requests for assistance, including helping parents to find and pay for services, to identify and learn about community resources, and to find emotional and other kinds of needed family support.

Information about community resources, followed by health care financing were the most frequently reported type of assistance provided. Information about conferences, partnering with professionals, parent advocacy, disability-specific resources, parent-to-parent support, medical home, education-related services was also frequently provided.

The President's New Freedom Initiative Report, "Delivering on the Promise" (March 2002)\* sets forth a goal of eliminating barriers that prevent people with disabilities from fully participating in their community. One way that family centers work toward the President's goal is by providing information to families and professionals related to six performance measures (PM) of appropriate systems of health care for CYSHCN through one-to-one contacts as well as through meetings, workshops, conferences, etc. Over the past 3 years, FV of ND indicated that they provided assistance about:

- **Health Care Financing** (Medicaid, EPSDT, SCHIP, SSI, other public financing programs, related services in IEP/504/IFSP, and private insurance) in 3,696 encounters and 230 meetings (PM 4)
- **Community Services and Parent Support** in 4,801 encounters and 14 meetings (PM1)
- **Partnering with Professionals** in 1,046 encounters and 107 meetings (PM 2)
- **Medical Home** (access to care, care coordination, partnering with doctors) in 506 encounters and 47 meetings (PM 3)
- **EI/ Screening** in 403 encounters and 37 meetings (PM 5)
- **Transition to Adult Services** in 418 encounters and 29 meetings (PM 6)

\* <http://www.hhs.gov/newfreedom/final/hhspart3.html#sol3c>

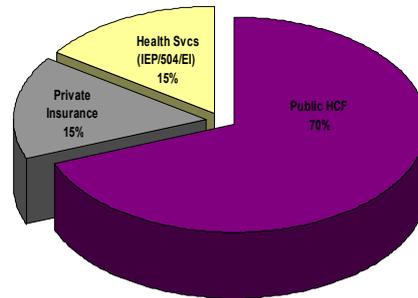
Family centers are often asked to review materials to provide a family perspective. These requests may solicit staff opinion and comments on surveys, agency reports, family-targeted materials, and other kinds of publications. FV of ND received 73 such requests from professional organizations and 55 requests from family organizations.

### 3. Reported Problems with Health Care Financing

Adequate health care financing is a critical component of quality care for a child or youth with special needs. The chart below indicates the distribution of problems by program reported by families in obtaining financing for needed services.

**Chart 5. Problems with Health Care Financing by Program**

Families seeking help from FV of ND reported 286 problems related to health care financing.



- 70% of the problems reported (198) were about public financing programs,

such as Medicaid, SCHIP, Title V, and SSI.

- 18% of the problems reported (44) were about health-related services in schools or early intervention programs.
- 12% of the problems reported (44) were related to private insurance.

Examples of health care financing problems reported include limits in amount or duration of needed services, denials of referrals to specialists, denials of eligibility for programs, lack of providers, and waiting lists for programs and services.

Of public health care financing programs, more problems were reported related to Medicaid than any other program.

## Reaching Out to Families & Professionals



Beyond providing one-to-one assistance to individual families and professionals, staff at the FV of ND engage and educate many people in a

variety of ways about many issues. FV of ND reported the following activities over the last 3 years:

### 1. Meetings

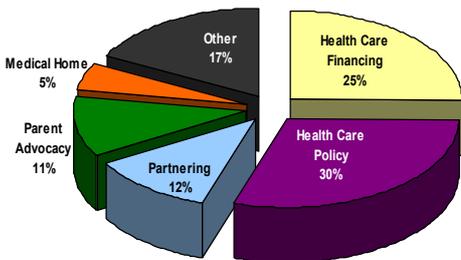
Education, training and support are provided to both family members and professionals through meetings, workshops, conferences, support groups, and other

group gatherings. Staff at FV of ND reported participating in **727 of these meetings and other group events**, attended by **15,098 family members and/or professionals** providing many opportunities to reach out, educate, and collaborate with others.

FV of ND both sponsor events and are sought out for their expertise as family leaders to participate in events. They serve on committees, conduct presentations at conferences, and develop and provide trainings to both parents and professionals. Their breadth of knowledge and experience allow them to share valuable information across a variety of topics at these meetings and other events.

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**Chart 6. Topics of Meetings**



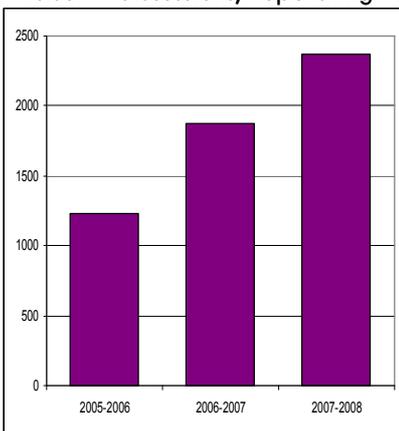
As shown in Chart 6, the two topics of information most frequently provided at

meetings were related to Health Care Policy and Financing and Partnering with Professionals, critical skills needed by families to help them obtain and provide care for their children and youth. Other category included such topics as Transition, Screening, etc.

**2. Listservs, Websites, Newsletters & Handouts**

FV of ND also engages in a number of other activities in order to reach people. This includes participating in listserv discussions, operating a website, producing a

newsletter, and developing hardcopy materials.



**Chart 7. Growth in Listserv Membership**

As shown in Chart 7, the listserv has grown 48% over the past three years.

Other examples of growth in outreach to families and professionals include:

- The dissemination of hardcopy handouts has increased by 68% over the past 3 years. During this past year, over 32,000 materials were distributed.
- Similarly the distribution of newsletters has increased by 78% over the past 3 years. During this past year, over **110,000 newsletters**, containing articles written by FV of ND were distributed.
- The FV of ND website has been re-launched under its own domain, [www.fvnd.org](http://www.fvnd.org), and as a result, web page requests have increased 68% over the last 3 years. Additionally, FV of ND has added a Bulletin/Discussion Board to the website, to increase family support and information. The website provides access to over **49 publications and 31 resources** of particular interest to North Dakotans.



For more information about us, please contact

**Health Information and Education Center**  
**P.O. Box 163, Edgeley, ND 58433**  
**888-522-9654 ♦ 701-493-2634**  
**Email: [fvnd@drtel.net](mailto:fvnd@drtel.net)**  
**Website: [www.fvnd.org](http://www.fvnd.org)**



*"FVND has been a great resource to myself as well as for the families I serve".....a Provider*

*"FVND has been very helpful with information that you have already provided to me. You led me in the right direction and provided follow up to assure that we were okay, this meant a lot to us as a family" ..... a Parent*

*"We have been so fortunate to have found FVND!" "you have explained things in a way that it made sense, so I understand and can be a better advocate for my child... THANKS SO MUCH"..... a Parent*