

## Health Information and Education Center *Creating Partnerships for North Dakota Families*

*A newsletter for families and professionals raising children with special health needs*



### Welcome Spring



Volume 3, Issue 16

Spring 2006

---

#### Inside this issue:

Thank You	1
Resources	2
Annual Report	3
Annual Report	4-5
Annual Report	6
Access to Health Records	7
Gift Card	8

*"The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy."*—Dr. Martin Luther King Jr.

**THANK YOU FOR ALL YOUR SUPPORT IN 2005!!** We have completed a busy year full of trainings, new publications, revisions and activities to help FVND grow. We are thankful for the dedication of volunteers and the Board and all those who are friends of FVND. It is each of you who have assisted us, in helping more and more families.

In this issue we have enclosed the FVND annual report. We wanted you to see first hand the number of calls we receive, what types of calls and information are coming into the FVND office. Additionally, other meetings and activities that we have participated in.

FVND has several new workshops available coming to a site near you. Look for announcements regarding workshops that will be held in your area. We plan to hold workshops regionally, however, if you in rural ND and want to hold a workshop in your area just let us know. Additionally, if you participate in a support group and would like us to attend with one of our workshops, let us know and we are also happy to accommodate. Just give us a call. **We can post your events through the weekly Share the Wealth:** Contact [fvnd@drtel.net](mailto:fvnd@drtel.net) OR 888-522-9654



### Legislative Action Center

Family Voices, as a leader in helping families of children and youth with special health care needs, has created a Legislative Action Center to keep families and others informed of what is happening in Congress that impacts health care policy and programs.

The Legislative Action Center provides a fast and convenient way for families and friends to learn about legislative issues, write letters to specific Senators and Representatives, and journalists, read background information on policymakers, voting records and other features. Please check out our new Legislative Action Center at [www.familyvoices.org](http://www.familyvoices.org) The Center is funded entirely by private funds.

*And every one of us has the responsibility to act as if all our thoughts, words and deeds matter. For really, they do. " Dalai Lama*



## Resources For You to Use

The annual ND Family Connections Conference will be held in Bismarck, ND - Ramkota Inn, Pre-conference 06/13/06 Conference 06/14-16/06!! The annual ND Family Connections Conference brings together families who have children with delays, disabilities and/or chronic physical and mental health challenges with partners and professionals who provide support. The theme for this year's conference is *Building Community by Sharing Responsibility*. The conference creates opportunities to learn about best practice, and build welcoming ND communities by sharing responsibilities.

"We believe that families and professionals together can create the kind of communities we need to welcome and support diverse families and children in North Dakota," said Cathy Haarstad, a conference leader.

This year's conference features the first Open Space forum where participants will have an opportunity to; based on the conference theme; **post any thoughts, ideas, questions or passions as conversation topics** that, in minutes, become the Open Space agenda. Thus, people talk about what they're most passionate about and are willing to take responsibility for once they leave the session. Topics are posted on the wall titled The Marketplace of Ideas and everyone checks it out to **decide what is of interest to them**.

Conference costs are \$50 for professionals, \$50 for first family member and \$10 for each additional family member. Conference support dollars for families are available. Professionals may call 1-866-759-2663 or visit [www.conted.und.edu/connections](http://www.conted.und.edu/connections) to register. Families should call 1-800-233-1737 to register.

### Presenters: Pre-Conference:

**Pat Rydell**, - a national expert on the SCERTS Model on Autism

**Phillip Schweigert** - national expert on tangible symbol systems and cognitive development

### Conference:

**Patti Hackett** - director of the national Healthy and Ready to Work program

**Bob Rutten** - North Dakota Director of Special Education

**Nick Martin** - a national expert on conflict resolution, effective IEPs and family systems

**Horatio Sanchez** - a national speaker on resiliency, at risk children and the application of brain research in classroom instruction



Many other in-state speakers on topics of importance to families and professionals. **Targeted Audience** families of children with special needs, teachers, early intervention specialists, case managers, psychologists, child

## CMS WEBSITE

The Centers for Medicare and Medicaid Services (CMS) has launched a redesigned website. The new website employs a user friendly design to get visitors the information they need with the least amount of clicks. It introduces one stop shopping "centers" targeted to specific professionals such as providers and partners, who frequent the site. CMS worked with consumers, providers, and other users to get their advice on upgrading the original site. The redesign has resulted in improved navigation and content organization. You can check it out at:

[www.cms.hhs.gov](http://www.cms.hhs.gov)

# Family Voices of ND Health Information and Education Center Annual Report

## Background

The Family Voices of North Dakota (FVND) Health Information and Education Center is a parent-run organization established to provide 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 12.4% 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>. FVND 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. FVND was funded by the Centers for Medicare and Medicaid Services (CMS) in July, 2004 to operate such a center for four years.

This report summarizes data reflecting the information and assistance provided by FVND during the time period July 2004 – June 2005, the first year of funding. This data includes requests for assistance, individuals served, type of information provided, problems with health care financing, and involvement in broader-scope activities such as meetings, listservs, newsletters, etc. Data is submitted quarterly by the FVND to Family Voices, Inc, a national family organization that provides training and technical assistance to these family centers as well as opportunities for them to work collaboratively with each other and with other family leaders throughout the country.

## Summary

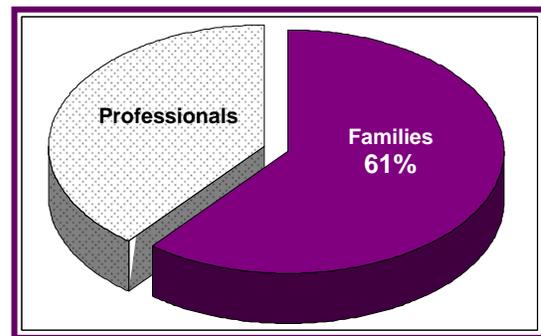
Data reported indicate that FVND is an important source of information and support for families and professionals. The number of requests for assistance from families and professionals to FVND increased in this first year of funded operation. This increase is most likely due to: improvements in the quality of data tracking; growth in FVND's outreach and visibility; and an increase in families/professionals seeking assistance. Of all the individuals seeking assistance, 61% were family members and 39% were professionals

during 2004-2005. In response to requests for assistance, FVND provided more information about health care financing than any other topic. Of the health care financing problems reported by families, the largest increase was in problems with public health care financing programs. Through meetings, websites, listservs, newsletters, and handouts, FVND reported reaching a wide variety of people with a wide range of information.

## Families and Professionals Needing Assistance

Many 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 and 2 provide information on the requests for assistance made by families and professionals.

**Chart 1. Individuals Requesting Assistance**



Sixty-one percent of all individuals requesting assistance were family members and 39% 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 3. Comparison of Requests for Assistance by Year**

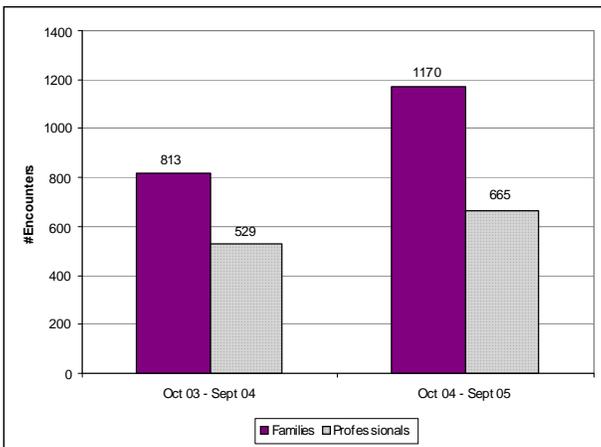
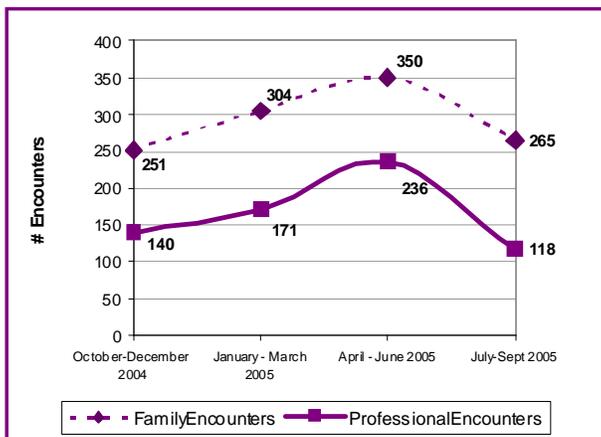


Chart 3 shows an increase of requests for assistance to FVND from the previous (un-funded) year, indicating a 44% growth in requests from families and a 26% growth in requests from professionals.

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



Within the funded period, requests for assistance showed a steady increase from October, 04 through June, 05 followed by a slight decrease, most likely due to the summer season. The increase over the first three quarters may indicate increasing numbers of families needing assistance, but certainly can also be attributed to the outreach efforts and resulting recognition of FVND as a place for families and others to find help. FVND actively pursues this goal of outreach through dissemination of its organizational brochures and online newsletter.

Families and professionals in need most often contact FVND 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 FVND more than once in order to obtain the assistance they needed. On average, staff at FVND was in contact with each family or

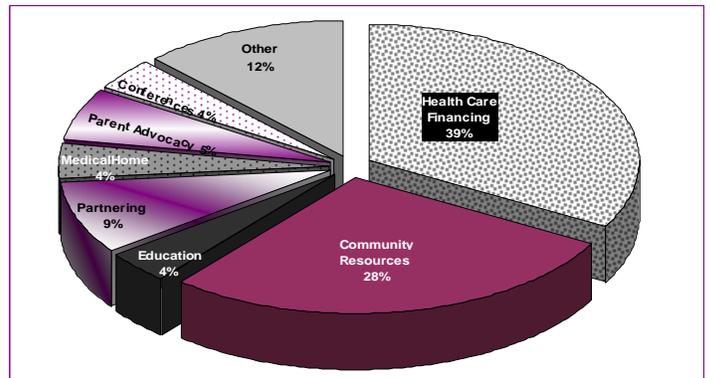
professional twice in order to complete the assistance that was requested or to provide additional information. On average, FVND received 6.9 requests for assistance per day.

FVND estimated that, on average, 31% 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.

**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 FVND not knowing what they need to help themselves or their child. Staff at FVND, having traveled this road themselves as parents of CYSHCN, are in the best position to listen, understand, and help. The chart below indicates some of the kinds of information and assistance that FVND provided.

**Chart 3. Topics of Information Provided**



In response to requests for assistance, FVND reported providing many kinds of information to families and professionals, 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 health care financing was the most frequently reported type of assistance provided. Information about Community Resources was the next most frequently reported category, followed by Education, Partnerships, Medical Home, Parent Advocacy, Conferences, and Transition. Topics under

“Other” included Mental Health, Respite, Oral Health, Parent-to-Parent, Screening, and Disability-specific information.

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. In data collected from July 2004 through June 2005, FVND 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 1,142 encounters and 49 meetings (PM 4)
- **Community Services and Parent Support** in 1,052 encounters and 22 meetings (PM1)
- **Partnering with Professionals** in 303 encounters and 51 meetings (PM 2)
- **Medical Home** (access to care, care coordination, partnering with doctors) in 139 encounters and 20 meetings (PM 3)
- **El/ Screening including hearing and metabolic** in 49 encounters (PM 5)
- **Transition to Adult Services** in 117 encounters and 13 meetings (PM 6)

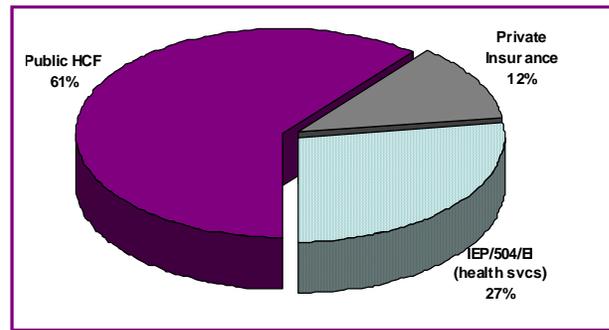
\* <http://www.hhs.gov/newfreedom/final/hhspart3.html#sol3c>

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. FVND received 28 such requests from professional organizations and 14 requests from family organizations.

### Assistance 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

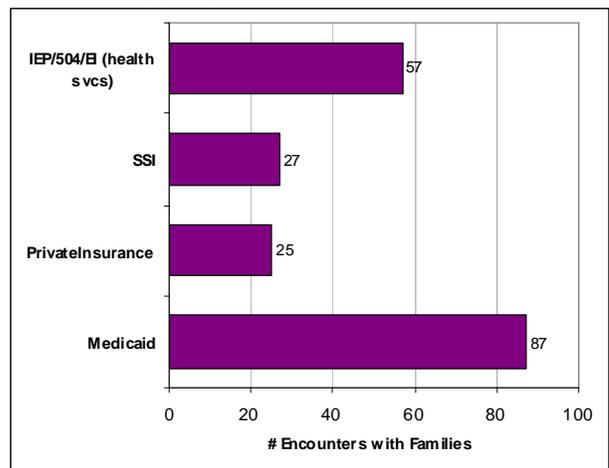


Families seeking help from FVND reported 210 problems related to health care financing.

- 61% of the problems reported (128) were about public financing programs, such as Medicaid, SCHIP, Title V/Children’s Special Health Services, and SSI.
- 27% of the problems reported (57) were about health-related services in schools or early intervention programs.
- 12% of the problems reported (25) 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.

Chart 6. Health Care Financing Programs with Most Reported Problems



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

*“A week doesn’t go by that I don’t receive information from Family Voices about services and supports available to families whose children have disabilities or chronic health care needs. I feel fortunate to be able to pass this information on to area families. Also your leadership and efforts on behalf of ND families through the legislative process and in statewide workshops and training opportunities has been tireless and exemplary.”*

A Parent Leader

## Reaching Out to Families and Professionals



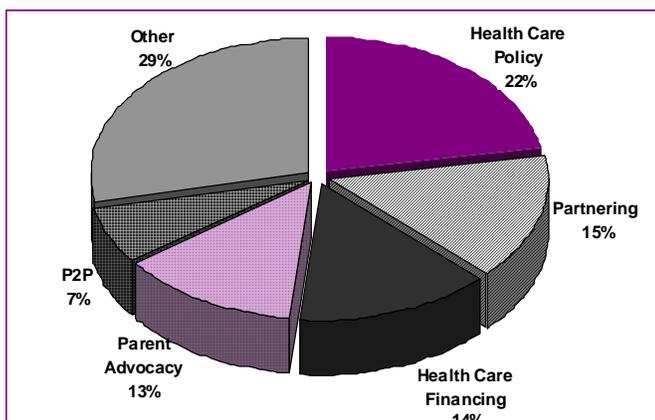
Beyond providing one-to-one assistance to individual families and professionals, staff at the FVND engage and educate many people in a variety of ways about many issues. FVND reported the following activities during 2004 – 2005:

### ➤ 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 FVND reported participating in **185 of these meetings and other group events**, attended by **7,255 family members and/or professionals** providing many opportunities to reach out, educate, and collaborate with others.

FVND 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, as shown in Chart 7.

Chart 7. Topics of Meetings



As shown above, the two topics of information most frequently provided at meetings related to Health Care Policy 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 Medical Home, Transition, Education, Screening, etc.

### ➤ Listservs, Websites, Newsletters & Handouts

FVND also engages in a number of other activities in order to reach people and this includes participating in listserv discussions, operating a website, producing a newsletter, and developing hardcopy materials. During the period July 2004 – June 2005:

- FVND now has over **1200 listserv participants** which were provided with information from FVND, growing from 377.
- The FVND website, [www.geocities.com/ndfv/](http://www.geocities.com/ndfv/), provides access to **25 publications and 31 resources** of particular interest to North Dakotans.
- FVND distributes a quarterly newsletter to over **2800** participants. Additionally, FVND submitted articles with distribution to over **42,000**.
- FVND distributed almost 7,000 **handouts**, containing information about resources for families.

*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**

**[fvnd@drtel.net](mailto:fvnd@drtel.net)**

**<http://www.geocities.com/ndfv/>**

#### OUR WORK:

- Assist families as they navigate public and private systems, including health systems and insurance plans
- Provide assistance to families in accessing services and resources for their children and how to partner with providers and caregivers
- Listen to families as they describe their encounters with systems and help guide them to possible solutions
- To work with families, health care providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes for children with special health care needs
- To promote discussion and linkages among families, providers, managed care programs, and government to better serve the health care and related needs of children and families in North Dakota

## Access to Your Child's Health Records

**You have the right to see records-** Health records include information about your child's diagnosis, treatment, and prognosis. You have the right to request and see your child's complete and current health records and to receive the information in understandable language. Your child's doctor may, however, withhold any written speculations about your child's health condition. This right applies to records held by most health care professionals, facilities and agencies, including doctors, mental health professionals, hospitals and home care agencies.

**You have the right to copies of records-** To receive a copy of your child's health records, you must ask for it in writing. The records you can request include laboratory reports, x-rays, prescriptions, and other technical information. The hospital, clinic or doctor's office may have a record request form that you can fill out.

**Timing-** The law does not give a time limit that outlines exactly how long the office may take to send you the records, but the records must be sent promptly.

**Summary of the record-** Your child's doctor may want to give you a summary of the health record and not the entire file. The doctor may do this only if you agree. Otherwise you must be given copies of the original records.

**Fees-** If you want a copy of the health records in order to review the current medical care of your child you must not be charged a fee. If you request copies of the health record for a reason other than to review the current medical care, then you may be charged a reasonable fee for copies and the administrative time.

**Notice about access to records-** You must be given clear written notice about how you can have access to your child's health records and what your rights are regarding records. The notice may be posted in the office or given directly to you. If you have any questions about receiving your child's health records, ask for a copy of the notice.

**Access may be restricted in limited circumstances-** In certain limited cases your child's doctor does not have to give you access to health records but may instead give the information to another appropriate person. That person may choose to release the information to you. This is limited to cases in which the doctor reasonably determines that the information could be damaging to your child's physical or mental health, or it is likely to cause your child to harm himself or herself or to harm another person.

**Transfer of records-** To have your child's health record transferred from one health care professional to another, you must make a written request. You may be charged a fee for the reasonable costs of providing the information.

**Strategies for requesting records-** Call the office before you send in the written request to confirm the address with staff and notify them that the request is coming. Note the name of the person you speak with so you can follow up later if necessary. Keep a copy of all written requests. Keep notes of all phone calls regarding the request. Note the date, time, name of the person you spoke with, and the outcome of the conversation. If you requested a transfer of records to another health care professional, call to confirm that the transfer was completed.

Fact sheet provided by the Health Information & Advocacy Center, a project of PACER Center, Inc. 8161 Normandale Blvd. Minneapolis, Mn. 55317

(952) 838-9000 or [pacer@pacer.org](mailto:pacer@pacer.org)— [www.pacer.org](http://www.pacer.org)

This fact sheet contains information about ERISA (29 USC 18 and CFR 2560). It is provided for informational purposes only.

If you need a great tool to track all of your child's health records. Visit the Family Voices of North Dakota Website at [www.geocities.com/ndfv/](http://www.geocities.com/ndfv/) and download a copy of the Care Notebook.

Additionally, you will also find many of the FVND publications available. Or you may call FVND at 888-522-9654 and request a CD of materials.



Donene Feist, Director

Join us today!  
PO BOX 163  
EDGELEY, ND 58433

Phone: 701-493-2634  
toll-free 1-888-522-9654  
fax: 701-493-2635  
E-mail- fvnd@drtel.net

PRST  
NON-PROFIT  
PAID PERMIT  
#27  
EDGELEY, ND  
58433

This newsletter is funded in part by the ND Department of Human Services, Medical Services Division, Children's Special Health Services and Centers for Medicare and Medicaid Services 11-P-92506/8-01



### Gift Card

Send to: FVND PO Box 163, Edgeley, ND 58433



Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Please Check if you are interested in:  Volunteering at Family Voices of ND event OR  Have a Family Voices of ND staff member speak to your group

I would like to make a contribution to Family Voices of North Dakota

To be used wherever needed     Endowment     In memory/honor of

Your thoughtful gift will be acknowledged to the person (s) indicated:

Name: \_\_\_\_\_ Address: \_\_\_\_\_

Please check if you do not want your name to be published as a contributor

Enclosed is my tax deductible donation:  \$100     \$50     \$25     \$10     \$5     Other

THANK YOU FOR SUPPORTING FAMILY VOICES OF NORTH DAKOTA