



Listening and Responding:

North Dakota Survey of Agencies Serving Children and Youth with Special Health Care Needs At a Glance

The intent of this project was to help identify the experiences families of children and youth with special health care needs may face as they search for resources, information, financial support, emotional support, and access to services. The project sought to identify what was working well and how that was influencing the family capacity to access information. Barriers encountered by families serve as real life examples of specific challenges faced by families as they navigate the system of care for CYSHCN. A brief glance at the outcomes of the study and our recommendations follow.

Specific “helping” behaviors included:

- Referrals to county offices
- Referrals to FVND and other family support agencies
- Offers to make calls on behalf of the family
- Willingness to check back to see how they were doing
- Follow up emails
- Active listening

Some responses and behaviors that were not found helpful included:

- Multiple “baton tosses”; passing the parent caller on to other programs and services
- Referrals to other programs that were not knowledgeable or helpful
- Not referring to their own agency’s programs
- Offering websites, but not asking if the family had internet access
- Offering information without the contact information
- Using incorrect names such as “Human Resource Center” instead of “Human Service Center”
- “Good Luck” wishes when they were unable to assist

Table 1. Data Collection Results	
Number of programs called	215
Number of calls completed (multiple individuals within the same program)	324
Number with wrong 800#	8
Number with wrong local number	13
Number disconnected	14
Number totally unreachable	15
Number answering to a different name	11
Number rated as responsive	235
Number rated as respectful	146

Response and Respect Scale

1. Not responsive or respectful; gave no information or help on where to go or what to do.
2. Somewhat responsive or respectful, but not both; gave no information or help on where to go or what to do.
3. Responsive and respectful, offered some information, but it was not the best or was lacking in contact information
4. Responsive and respectful, gave information, but did not give all needed information
5. Responsive and respectful, gave correct information on who to call or connect to or what to do.

FVND Recommendations

FVND recognizes their role and responsibility in working in collaboration with other partners to create an accessible and accurate information system for families.

Training that facilitates:

- **Information sharing and cross training within an agency** on the various programs, including the full scope of the agency, not just a specific program.
- **Orientation and ongoing training** for all front line/first contact staff, such as operators, receptionists, or outreach workers.
- **Cross training and sharing of information and resources between agencies**, programs, organizations, and service providers within the state's communities.
- Staff that are **trained on accessing family support partners**, such as FVND.
- Utilization of **FVND training on family-centered practices** and encourage agencies to have FVND staff present at staff meetings, trainings, and conferences.

Partnerships that:

- **Encourage networking opportunities** between agencies and service providers.
- **Promote statewide information and resource partnerships** that will promote consistent and predictable methods for sharing information.
- Ensure that **agencies and programs include families and youth** on advisory boards and committees.
- **Provide families with information on FVND** and other family organizations with all referrals.

Tools that promote:

- **Quality improvement** for monitoring and improving the information and resource system.
- The use or development of a **shared database of information** for families and providers with accurate contact information.
- The **utilization of data from family support partners** such as FVND to evaluate program and agency effectiveness in supporting families.

Accountability that will:

- Identify and use **regular "check points"** between critical partners within the CYSHCN system of care to identify gaps in the provision of information and resources.
- Lead to a **strategic plan** for a family centered and culturally and linguistically competent approach to addressing the needs of families.
- Assure that **family support partners such as FVND are included** in all levels of planning, implementation, and evaluation.
- Utilize **FVND as an outside evaluator** of the information and referral system.
- Continue to **discuss available opportunities for family support organizations** to provide information regarding family perspective in accessing services and support.

For more information on this study, a full report of the outcomes and recommendations, or to learn more about Family Voices of North Dakota, Contact us at:

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