


Responses and Reflections

North Dakota Survey of Agencies





Families of children, youth, and young adults with special health care needs in North Dakota have consistently identified the need for access to timely, high quality health care and community services and supports.



Purpose of the Survey:

- To identify the experience that families may face as they search for resources, information, financial support, emotional support, and access to services.
- We hope to identify :
 - 1) What is working well
 - 2) Barriers that families encounter with specific examples
 - 3) A celebration of success and ongoing dialogue to identified barriers that families may be facing.



The Process:

- Identify organizations and agencies across ND to gather information from.
- Identify a family scenario.
- Call agencies and various providers across the state.
- Document the comments and responses
- Aggregate findings
- Share information at meeting TBA with agency directors and partners



Informational Letter

- Before the survey was conducted a letter was sent to administrators of the main agencies that were going to be called to let them know about the upcoming survey.



Survey Scenario

- A mother who has a 2 1/2 year old daughter. The mom is concerned about upcoming medical tests, developmental delays , medical bills and is feeling isolated.



How Data was Collected

- The caller documented each call individually by typing the responses she received from each person (at each agency). The caller also rated each call on both responsiveness and respectfulness.
- Once all the calls were made a group of individuals from across the state rated each agency, based on the comments only, on a scale of 1-5 looking at things such as the type of information given as well as if the agency was responsive and respectful.



Highlights/Themes

- Willingness to help and find information.
- Genuinely cared about the situation.
- Followed up with emails.
- Thorough and covered the needs of the family
- Good responses from a variety of agencies.
- Referrals to County Offices
- Referrals to Family Voices of ND and other family support agencies
- Referrals to pediatricians



Where to go from here....

- Additional Training for the “person answering the phone” – often the receptionist.
 - Family Voices of ND is working on a “North Dakota Roadmap” to assist with this.
- Work on partnering together, sharing information across agencies.
- Tools to assess Family Centered Care



Tools to Assess Family Centered Care

- **Self Assessment**
 - Family Voices Family Centered Self Assessment Tool
- **Client Assessment**
 - Family Friendly Checklist by the Family Support Council

FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

- http://www.familyvoices.org/pub/projects/fcca_UsersGuide.pdf

Developed by

FAMILY  VOICES®

*...keeping families at the center
of children's health care*

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Within that framework, ten components of family-centered care have been identified. (National Center for Family-Centered Care (1989); Bishop, Woll and Arango (1993)) Family-centered care accomplishes the following:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

10 Components to Family Centered Care



DESCRIPTION OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

The tool is divided into three major sections:

1) Family/Provider Partnership, 2) Care Setting Practices and Policies and 3) Community Systems of Services and Supports. Within each major section, there are several subtopics that address family-centered care.

Sample of the Tool

COMMUNITY SYSTEMS OF SERVICES AND SUPPORTS

Information and Referral and Community-based Services

FCC Component: 5

1. Does your provider:

- | | | | | |
|---|-----------------------------|--|--|------------------------------|
| A. Work with your family to identify needed community-based services? | <input type="radio"/> Never | <input type="radio"/> Some of the Time | <input type="radio"/> Most of the Time | <input type="radio"/> Always |
| B. Help your family make the first contact with community-based services? | <input type="radio"/> Never | <input type="radio"/> Some of the Time | <input type="radio"/> Most of the Time | <input type="radio"/> Always |
| C. Follow up to see if your family/child/youth has successfully connected with the service? | <input type="radio"/> Never | <input type="radio"/> Some of the Time | <input type="radio"/> Most of the Time | <input type="radio"/> Always |
| D. Follow up to see if the service was easy to access? | <input type="radio"/> Never | <input type="radio"/> Some of the Time | <input type="radio"/> Most of the Time | <input type="radio"/> Always |
| E. Follow up to see if the service was useful? | <input type="radio"/> Never | <input type="radio"/> Some of the Time | <input type="radio"/> Most of the Time | <input type="radio"/> Always |
| F. Follow up to see if the service was respectful of your family's culture and values? | <input type="radio"/> Never | <input type="radio"/> Some of the Time | <input type="radio"/> Most of the Time | <input type="radio"/> Always |

Family Friendly Check List



Is your organization family friendly?

find out, with the

 **Family Friendly Check List**

A self-assessment tool developed by the *Family Support Council*

Family Edition

<http://www.fcf.ohio.gov/dotAsset/7128.pdf>

A family friendly agency gives families the chance:

- ✓ to help decide how the agency runs.
- ✓ to help decide how the agency is made up.
- ✓ to help decide how the agency does its job.
- ✓ to help decide if the agency is doing its job.

Answer yes, no, or don't know to the questions in the check list below, to help you decide if an agency is family friendly. Together, families and agencies can use this check list to help make an agency family friendly.

Agency Administration

Yes No Don't know

- | | | | |
|--------------------------|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Are families on the agency's board of directors? |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Do the agency's rules on how they do their work make things better for families? |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Do you or other families help write or ok the rules when they are made or changed? |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Does the agency tell the staff people that it is important to listen to families? |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Do you or other families help train the new staff people? |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Do you or other family members work at the agency? |

Questions???

Thank you.

Family Voices of North Dakota
PO Box 163 Edgeley, ND 58433

www.fvnd.org

fvnd@drtel.net

1-888-522-9654