



**Children With Special Health Needs**

**Needs Assessment**

**A Research Study Conducted On Behalf Of:**

**North Dakota Department of Human Services**

**Summer 2004**

**Research Study Conducted By:**

**Marketing & Advertising and Business Unlimited, Inc.**

*doing business as Agency MABU*

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## Acknowledgements

The North Dakota Department of Human Services contracted with Marketing & Advertising Business Unlimited, Inc., (dba Agency MABU) to conduct a market research study in the summer of 2004. The purpose of the study was to assess the needs for children with special health care needs and their families.

The research team extends sincere thanks to representatives from the North Dakota Department of Human Services, Children's Special Health Services Unit. Special appreciation is presented to Tamara Gallup-Millner, Unit Director, and Terry Bohn, SSDI Coordinator, for providing guidance, direction and support throughout the entire research process.

The research team also acknowledges the individuals who participated in the research study by attending focus group sessions, completing written surveys and taking part in telephone interviews. The data gathered through these research methodologies were used to prepare the findings and recommendations for this study.

Funding for this project was provided through the North Dakota Department of Human Services. For more information or to receive copies of this report, contact:

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Respectfully submitted,

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## Conduct Of Study

In the Spring of 2004, Marketing & Advertising Business Unlimited, Inc. (dba Agency MABU) was commissioned by the North Dakota Department of Human Services to conduct a market research study to assess needs relating to children with special health care conditions, especially chronic illnesses.

The primary objective of the study was to obtain qualitative information from pediatric providers and families of children with special health care needs (CSCHN).

Agency MABU used a variety of research methods to gather data including:

- A series of six (6) focus group sessions with parents of children with special health care needs.
- A mail back survey of pediatric providers
- A telephone survey of pediatric providers

These research methodologies which were employed by Agency MABU are described in the following sections:

### **FAMILIES OF CSHCN: FOCUS GROUP SESSSIONS:**

In June 2004, *Marketing & Advertising Business Unlimited, Inc.* (doing business as Agency MABU) conducted a qualitative research study to assess needs relating to children with special health conditions.

The project included six (6) focus group sessions held throughout the state of North Dakota. Mike Mabin, owner of Agency MABU, served as the lead researcher in developing the research plan and facilitating the focus group sessions. Mabin was assisted by Sarah Franke, Tiffany Mittleider, Amanda Bakkedahl and Annette Tait, MABU employees who coordinated various aspects of the project including recruiting focus group participants, arranging the focus group sessions and documenting results.

### **Focus Group Sessions Continued:**

From June 1 - 14, 2004, Agency MABU conducted a total of six (6) focus group sessions with up to 12 participants in each group. The sessions were held at the following locations and times:

#### **Bismarck**

Date: Tuesday, June 1  
Time: Noon – 1:00 p.m.  
Place: St. Alexius Medical Center (Telemedicine Conference Room)  
Status: 12 registered, 11 participated

*Note: 8 participated from Bismarck and 3 participated via teleconferencing from Dickinson and Ashley*

#### **Minot**

Date: Thursday, June 3  
Time: Noon – 1:00 p.m.  
Place: Trinity Health Center  
Status: 12 registered, 11 participated

#### **Bismarck - UTTEC**

Date: Monday, June 7  
Time: Noon – 1:00 p.m.  
Place: United Tribes Technical College (Jack Barden Center)  
Status: 9 registered, 4 participated

#### **Williston**

Date: Tuesday, June 8  
Time: Noon - 1:00 p.m.  
Place: Mercy Medical Center  
Status: 12 registered, 12 participated

#### **Fargo**

Date: Friday, June 11  
Time: Noon - 1:00 p.m.  
Place: MeritCare  
Status: 12 registered, 10 participated

#### **Grand Forks**

Date: Monday, June 14  
Time: Noon - 1:00 p.m.  
Place: Altru Health  
Status: 8 registered, 6 participated

### **Focus Group Sessions Continued:**

Focus group participants were recruited through a variety of means including, but not limited to, the following strategies:

1. News release sent to all media statewide
2. Letter and flyer to participating hospitals/clinics (pediatric and family practice)
3. Phone calls to health-related associations
4. Phone calls to family organizations
5. E-mail message to Human Service case managers
6. Cover letter and flyers to daycares statewide
7. E-mail, letter and flyers to Community Resource Coordinators
8. Mailing to Special Education Units

Several days prior to each focus group, participants were contacted by Agency MABU to confirm their attendance. Each focus group session lasted approximately one and a half hours, and participants received lunch and an incentive payment of \$25. Mike Mabin served as the discussion facilitator. He used a written discussion guide to assure specific topics were addressed. Agency MABU staff documented the comments in writing. Recordings were also made on videotape and used as reference for capturing feedback from the focus group participants. Participants were also invited to complete a written questionnaire (based on the discussion guide) to document any feedback that they preferred to share in writing rather than verbally.

**PEDIATRIC PROVIDERS: MAIL-BACK AND TELEPHONE SURVEYS:**

Agency MABU utilized two proven research methods to assess the capacity of pediatric service providers throughout the state.

First, a series of 40 telephone interviews were conducted with a minimum of one (1) and maximum of three (3) representatives from each of the pediatric professional groups identified in the request for proposals (RFP). The names and contact information for prospective interviewees were obtained primarily through professional membership associations; however, yellow page directories and organizational websites were also used as resources in identifying telephone survey respondents. Using a stratified random sample process, the selected individuals represented the geographic diversity of the health care system in North Dakota.

Secondly, a written questionnaire was direct mailed to a simple random sample of 1,000 representatives from a combined list of pediatric professional groups identified in the request for proposals (RFP). The mailing included a cover letter, questionnaire and postage paid return envelope. The questionnaire was a condensed version of the telephone survey, and was designed to be completed easily and quickly by survey respondents. A total of eight (8) closed-ended and five (5) open-ended questions were included on the questionnaire. By keeping the survey brief, a goal of securing a 12%-15% response rate was established.

A total of 308 written surveys were completed and returned within the established deadline. This represents a 31% response rate. Thus, it was determined that the results of the mail-back study represents a margin of error of plus or minus five (5) percentage points from the total population due to the relatively high response rate and homogenous

nature of the sample group. This means that if 95% of the respondents to the survey answer “yes” to a particular question, somewhere between 90% and 100% of the total population would answer the same.

The survey instrument used for both the telephone and mail-back questionnaires included questions to assess perceptions of pediatric providers as identified in the RFP (e.g. barriers and challenges).

# **EXECUTIVE SUMMARY**

Throughout June and July 2004, *Marketing & Advertising Business Unlimited, Inc.* (doing business as Agency MABU) conducted a market research study to assess issues relating to children with special health care needs. Agency MABU researched the perceptions and opinions of two distinct groups:

- Families of children with special health care needs
- Pediatric providers.

A series of six (6) focus group sessions were held throughout the state with family members of children with special needs. Pediatric providers were surveyed using a combination of telephone interviews and direct mail surveys. A summary of key findings from each research study group is presented as follows:

## **Families of Children with Special Health Care Needs**

### **Focus group findings:**

#### **General Feedback**

Participants greatly appreciated the opportunity to share their thoughts and opinions regarding ways to improve the coordination of care for their children. However, several participants at each session voiced concerns that their feedback would not be taken seriously. They questioned whether or not any positive change would occur as a result of the research study and needs assessment.

Many participants expressed frustration regarding the difficulty with accessing information, services and support for themselves and their children. They talked about the difficulty associated with caring for a child with special needs. Many of the participants talked

about “burning out” both emotionally and physically due to the demands of caring for their child(ren), while at the same time having to “fight” for any services or support from State agencies and other related organizations.

The majority of the participants made favorable comments regarding the professionals who are directly involved with the care and coordination of services for families and children with special health needs. This list includes physicians, therapists, case workers and support staff.

Opinions varied from region to region regarding overall satisfaction with the coordination of care; however, there was a common theme that emerged. Many of the participants felt they are looked “down upon” by people who administer financial assistance programs. Comments were shared such as: “they treat us as if we’re trying to take advantage of the situation for our own financial gain,” “we have to fight for everything we get,” and “these employees should be our best advocates, not our worst adversaries.”

The highest level of concern and frustration was expressed by parents of children with chronic and/or multiple health care conditions, especially those children requiring specialized, ongoing care and attention by parents, pediatric providers and others. Parents of children with less complex or less comprehensive needs were far more likely to speak favorably of programs and services available to meet their child’s needs. The biggest gaps in service, support and funding appeared to be among families of children with severe, complex and chronic disabilities.

### Accessing Information About Programs/Services

Participants gather and receive information about programs and services for themselves and their children from a wide variety of sources and mediums. Many participants access information directly from their case manager(s), physicians and other caregivers, and family support networks.

Families expressed a need for a centralized source for information. They are often confused as to where to get information. A great deal of their time and energy is spent researching information regarding services, financial assistance and other support. Concerns were also expressed regarding inconsistencies with the information received from various sources.

### Working With Health Care Professionals

Many professionals are involved in working with families and their children. This list of professionals includes, but is not limited to: health care professionals, public health agencies, case managers, special education staff.

Participants expressed concerns about a lack of coordination among these various professional groups. Frustration is greatest in areas relating to the duplication of paperwork required by the various professionals.

On a positive note, the participants felt that health care professionals, in general, are sincerely concerned about the well being of children and their families.

### Assuring Quality Care

According to the participants, the primary means currently in place to assure quality care for children with special health needs is oversight by their parents/families. Parents stated that they often know their children's changing needs better than any other professionals involved in the coordination of care. Thus, many parents expressed a desire to be more involved in the treatment process for their child(ren). They expressed concerns that health care professionals often overlook or under value the input and advice that parents can provide to improve the quality of care for their child(ren).

Other means of assuring quality care include: treatment plans, IEP in schools, respite care, specialty clinics, and family care networks.

### Access To Needed Services

Many of the participants have sought services for their children from out-of-state providers and programs. The most frequently referenced locations included Minnesota and Colorado. Participants expressed serious concerns about the lack of medical coverage when seeking support outside of North Dakota. They are often forced to stay in North Dakota due to funding restrictions when they know that more specialized care is needed and available elsewhere. As a result, several participants mentioned that they seek care outside of the state and pay for services on their own. Those without the means to do so feel that their choices are limited, and they need to accept sub-standard care as a result.

As for services lacking in their community, the participants identified the following: 1) training for parents/families to deal with caring for children with special needs, qualified respite care professionals, pediatric specialty providers (especially in smaller communities), mental health care professionals, and OT and PT rehab professionals.

## Family Involvement

Participants say that there exists a need for more respite care. Many families are overwhelmed with the responsibilities associated with caring for children with special health needs. They need support from qualified and well trained respite care providers. However, they are adamantly opposed to assuming the coordination of respite services for their children. They believe other organizations should provide this service on their behalf.

Families believe that they are the primary coordinators of care when it comes to their children. They believe that this should remain their role, and that others (especially doctors and therapists) should more actively involve them in the decision and treatment process. Too often, their input and opinions are not considered or valued.

## Role of Children's Special Health Services (CSHS) Unit

The majority of participants were not aware of the existence of the Children's Special Health Services (CSHS) Unit.

When asked to identify the potential role for such a Unit, the participants offered the following ideas: centralized source for information, advocate for families and children, coordinator of care (much like an admissions counselor at a college), training for daycare providers to care for children with special health needs, and resource for questions about financial assistance.

## Financial Matters

Numerous stories were shared regarding the stressed financial situations experienced by many of the families caring for children with special health needs. A great deal of frustration exists with the system associated with receiving financial assistance. Common concerns expressed by participants include: “too much paperwork,” “assistance continues to be cut,” “we have to fight for everything we get, and “it’s better to be poor and single. That’s the only way families can get the help they need.”

Very few of the participants stated that their child(ren) have been denied health services; however, many were denied coverage for seeking care outside of the state. Also, many stated that they don’t seek coverage for many services because the process is far too encumbered and degrading.

## Other Feedback

The session attended by people of Native American descent expressed concerns that they are looked down upon by people who are supposed to be providing assistance. They don’t feel that their unique cultural needs and concerns are being addressed.

Participants expressed a desire to have more workers with minority status as employees of the State and other agencies.

## **Pediatric Providers**

### **Direct mail and telephone survey findings:**

#### **Pediatric Providers**

A cross section of pediatric providers from across the state participated in the telephone and direct mail surveys. A total of 40 telephone calls and 308 direct mail surveys were completed by pediatric providers including:

- Physicians (pediatricians, pediatric specialists, child & adolescent psychiatrists and family practice doctors)
- Occupational Therapists and Physical Therapists
- Speech/Language Therapists
- Insurance/Payers (Medical Directors, case managers at BCBSND, IHS and Medicaid)
- CSHCN Case Managers and Care Coordinators
- Mental Health Professionals
- Public Health Nurses and Administrators
- Special Education Professionals
- Durable medical equipment providers
- Directors of inpatient pediatric departments
- Home health nursing directors
- Audiologists
- Community Resource Coordinators (CRC's)

This group of professionals serve patients and clients throughout North Dakota in cities both large and small. Those who participated in the survey process are representative of the total population of pediatric providers across the state.

The majority of pediatric providers who completed the survey process have positions which require them to work with children with special health care needs and their families on a regular basis (46.8%). Furthermore, the majority of those who participated in the research study, have provided professional services in North Dakota to children with special health care needs for six (6) or more years (69.1%).

### Availability of Resources

When asked to rate the availability of resources in their community to meet the needs of children with special health care needs, the largest majority responded “fair” (37%) or “good” (26.3%). A smaller percentage rated this category “poor” (10.4%), “very good” (17.9%) or “excellent (4.9%).

### Barriers to Providing Services:

When asked to identify barriers to providing services to children with special health care needs and their families, pediatric providers identified four major areas of concern:

- #1 – Lack of awareness about available services
- #2 – Lack of adequate public and/or private health insurance coverage
- #3 – Lack of respite services or other family support services
- #4 – Lack of knowledge about accessing the health care system

Transportation and travel was also identified by numerous survey respondents in written comments to this question. Other frequently mentioned barriers in written comments included:

- Lack of child psychiatrists and other mental health professionals
- Costs not covered by Medicaid or insurance

### Barriers Within the Delivery System:

When asked to identify barriers within the delivery system relative to children with special health care needs and their families, pediatric providers identified five major areas of concern:

- #1 – Lack of coordinated funding system
- #2 – Fragmentation of services
- #3 – Lack of information on community and state resources
- #4 – Lack of multi-disciplinary clinics
- #5 – Lack of family-centered approach to care

Other barriers identified by a number of survey respondents in written comments to this question include:

- Unmotivated parents or too busy to apply for services
- Lack of culturally-relevant services
- Lack of coordinated funding system

### Service Needs Within Communities:

When asked to identify services that are lacking within their community to provide comprehensive care to children with special health care needs and their families, pediatric providers identified four major areas of concern:

- #1 – Respite care or other family support services
- #2 – Mental health services
- #3 – Community education about children with special health care needs
- #4 – Support and discussion groups for families

Other services which are lacking that were identified by survey respondents through written comments to this question include:

- Mental health services
- In-home services
- Specialty pediatric care
- Daycare

## Role of Children's Special Health Services (CSHS) Unit:

When asked to identify the role that the CSHS unit should serve relative children with special health care needs and their families, pediatric providers identified five primary roles:

- #1 – Building awareness and linking families to available services
- #2 – Partnering/Coordination/Collaboration with other organizations
- #3 – Payment of care for eligible patients and families
- #4 – Case management
- #5 – Sponsoring multi-disciplinary clinics

## **General Recommendations**

Based on the research findings from the focus group sessions, telephone interviews and direct mail surveys, the following recommendations are presented for consideration:

- Increase the availability of trained respite care providers
- Simplify the process for getting financial assistance, especially relative to getting medical equipment for children with special health needs and reducing paperwork requirements.
- Improve the attitude and perception among State employees as it relates to families and children with special health needs. Encourage them to become advocates rather than adversaries.
- Establish a statewide resource network for families and children with special health needs.
- Establish higher income levels for people on Medicaid or prorate the eligibility based on income guidelines rather than simply denying coverage.
- Establish a central resource, possibly an online website, that parents and providers can access for current information about services, programs and funding that is available for children with special health care needs and their families.
- Enhance cultural sensitivity among State employees and pediatric providers, especially relative to Native American cultures.
- Expand funding and/or allocate priority funding to families with a child that has multiple, complex and/or chronic health needs.
- Study the sections of the report which asked respondents to identify one change that they would recommend relative to improving care for CSHN.

## **Bismarck Session – Comments From Participants**

- **Attitude**
  - The attitude of the Human Service workers needs to be better and more open to helping the parents and families of the child
  - NDHS should have support groups to hear the voices of the parents and understand what the parents and families are going through
  - Case Managers need to have a better attitude and be more informed
- **Legislative Action**
  - More aggressiveness in legislature for additional funds
  - They need to hear the parents and make a difference
  - They need to be more informed about the issues that are affecting the families of a child with a special need
- **Hoops to go through**
  - Parents feel as if there are so many hoops they have to jump through to get anything for their child
- **Justify everything**
  - Parents feel that everything has to be justified
  - They have many questions why some things do and some don't
  - Would like to know what Medicaid covers
  - MRDD qualifications are unclear
- **No one there to help**
  - Feel very alone and don't know where to go for help and comfort
- **Hitting a brick wall**
  - Feel as if they can go so far and then hit a wall and don't know where to go from there
  - All they try and change just does not get taken care of
- **Does anyone listen or care**
  - Can only talk so much with pediatrician, then do not know whom else to console with
- **Support groups**
  - Need some kind of network to share with others feelings about their child and know that there are others out there with the same thoughts
  - Need to be able to voice their opinions to others
- **Lack of awareness**
  - Parents do not feel informed about support and information that could benefit their children
  - Need a solid and reliable source of information

## Children's Health Focus Group Notes – Bismarck

### **I. Methods of awareness**

#### **Bismarck**

St. A's Pediatric department  
St. A's Respiratory Therapist  
Letter from school  
Early intervention program  
Family voices – 2 people  
Telemedicine Coordinator

#### **Ashley**

Telemedicine Coordinator

#### **Dickinson**

Family Voices

### **II. Accessing information about Programs/Services**

#### **A. Bismarck**

Word of mouth, other parents, teachers, the Magic foundation, SSI, hard to find people to talk to, no one tells us, from sister, you're given the run-around, you have to talk to a lot of people, pattern in which they give info. is ineffective, fed up with the state, state doesn't want us to bother them (legislators), inquiry not welcomed, I've had to initiate everything by talking to networks, lack of awareness

Early intervention from birth-3 years old – there is a lot of information.  
After 3, little info. sent through IEP, not a good clearinghouse for info. It is screened – they don't give us all the info.

I feel alone – the problem solving isn't there  
I have a lot of resources but I still feel alone

Doctors don't know what my daughter has – very frustrating  
Not enough information and knowledge from the doctors to give general information to us families

#### **B. Dickinson**

IAP teacher in school  
Network with organizations around the state

#### **C. Ashley**

Had to initiate oneself

### **III. Accessing Information – Additional comments**

Depends if NDHS wants to tell us  
Case Managers need to be more informed  
5 out of 8 in Bismarck have Case Managers  
2 out of 2 in Dickinson have Case Managers  
0 out of 1 in Ashley have Case Managers  
Case Managers need to be more proactive and knowledgeable  
North Dakota is lacking in care and needs for children  
Knowledge – in ND there is not enough knowledge about my daughter's problem  
Doctors don't know what to do – stuck with school system and social services and  
they don't see anything wrong with her  
Hard to get 2<sup>nd</sup> opinion in ND – difficult to get approval to get an out-of-state opinion  
Medicaid won't cover past age 3  
Medicaid and SSI see it as parents are getting ND money and trying to live off the system  
Medicaid and SSI have different financial criteria - inconsistent  
One mom confined to stay at home or child would lose medical coverage and they don't  
qualify for other assistance  
Can't take stock option at work because there are too many assets – we can't save – we  
will have to work the rest of our lives – haven't worked for 11 years

### **IV. Working with Health Care Professionals**

#### **A. Bismarck**

Trying to get on Medicaid is a nightmare  
No main entity for care of child  
Respiratory care should not be up to the parents, it should be up to agencies like Easter  
Seals – parents cannot handle that kind of pressure  
Easter Seals is a good program, but it comes back to the State wanting to do it  
Cutting back of funds hurts  
Need support for the families and siblings to understand what is going on  
Need fun activities for their child – they need it for mental health – make it a family affair  
Children and families need better information about what is wrong and needs to be done  
Need quality care to come in and support our children  
I have an excellent system but they don't always have a qualified staff  
I deal with school districts – I am in a different situation  
Social service agencies need to step up and coordinate care  
I deal with school districts and a psychologist– I am in a different situation  
Funding for Human Services should be for Human Services and not turned back at the  
end of the year  
Dept. of Developmental Disabilities sets families up, but then lets the family go  
Need more aggressiveness in the legislature for additional funds  
We have so much reliance on medical money, but the legislature is restricted  
You shouldn't have to beg them for help

**B. Dickinson**

We have an excellent system, but we do not always have a qualified staff

**C. Ashley**

I deal with school districts and psychologists

Social service agencies need to step it up and coordinate care

**V. Access to Needed Services**

**A. Bismarck**

Make the programs you already have work for the families and the child

Attitude needs to change – they don't trust you

They make you feel like you're not worth anything medical, respite, etc.

MR services – many people don't qualify

We don't use telecommunications enough – we need to use technology

**B. Dickinson**

Need adequate mental health care – you can't afford it and you don't have a choice of Doctors

**C. Ashley**

No specialists close by – need to travel 3 hours to get specialized care

**VI. Miscellaneous**

**A. Bismarck**

CSHS use to be named Crippled Children's Services

Epilepsy is not covered

2 of 8 in Bismarck have heard of Children Special Health Services

0 of 1 in Ashley had heard of Children Special Health Services

2 of 2 in Dickinson had heard of Children Special Health Services

CSHS should be there to answer our questions

CSHS should be a resource for information

Nothing ever gets accomplished

One hour is not enough to hear our opinions

Someone from Human Services should be here to listen – people who vote these issues need to be here and need to know about us

In an article in Tribune "Desperate Measures" - couple shouldn't have to get a divorce to get medical help for a child

Can't take my child to a daycare once they turn 12 – you end up relying on older siblings for help babysitting and you can't expect them to do that

Care providers need to be more aware of what is available for daycare needs

My daughter can't go to daycare because she can't be around the public and risk the chance of getting sick

Siblings of special children need to have knowledge

We are always blazing trails

The attitude isn't "How can I help you?" but "What are you going to do?"  
We're all a priority – every kid is important – every need is unique and NDHS needs to be more open with all cases and providing care  
The state doesn't understand that we're in this situation by chance – we didn't ask for it and we need their support  
The state will have to be more involved – cost of care keeps going up  
The whole legislative process needs to be educated  
Protection & Advocacy has a group that meets to raise issues in the legislature for children with special care needs – they meet monthly

#### **B. Dickinson**

Family-to-family network located in Grand Forks  
-this is a way to network families that have children with the same type of special needs  
Family Voices is very good

#### **VII. Closing Comments**

We feel like nothing is getting accomplished – we have these meetings and nothing changes  
It's too much for the families  
NDHS needs to have meeting more often to hear the voices of parents and to understand what parents are going through and then provide follow-up

Many things are kept a secret from parents – case managers don't tell

You keep hitting a wall – you get excited thinking you're going to change things and then nothing happens

Have to get pre-authorization  
-inconsistency in whether you have to get it or not  
MDA people assume MDA will cover everything, but they don't  
We need to know what Medicaid covers  
Parents need to know of where to go  
MRDD qualifications are unclear  
Need a comprehensive health care plan for special care children  
CSHS won't pay for everything

All this doesn't make sense to the families of how they care for the children up to 3 years old and then drop them and leave the care up to the families

\*\*\*\*Please tell us the results from this meeting! We are willing to be at other meetings!\*\*\*\*

**Notes from parent who attended the focus group session – called Mike after meeting and visited for 30 minutes.**

- daughter has muscular dystrophy
- something should be put together in a binder in a simple understandable language for parents to understand what is covered and what is not
- give to each person on medical assistance
- when things occur, send out to replace in their binder
- haven't worked for 11 years – I have no future!
- parents need to be informed of changes
- article “Desperate Measures” series that ran the Tribune in April – needs to be sent to Conrad and Dorgan
- a small group needs to get legislators, House, Senate and Congress to hear the needs
  
- SSI - \$500/month – recipient liability a problem
- hard to send SSI – must check back after getting “Make a wish”
- they watch them like a hawk – focus on disqualifying them
  
- many jobs aren't flexible for families with kids with special needs
  
- all they care about is getting best possible care
  
- can't put more pressure on families
- need support for other kids
  
- they make you feel like you are nothing
- we are fighting for everything
- do they really care?
- Life is all very complicated
  
- MD & MS's not enough education out there
- people want to be self-sufficient

## **Bismarck Session – Written Feedback**

1. In what ways do you find information about programs and services available to you and your child?

- State very hesitant about releasing any information to help us
- From other parents (3)
- Case Manager
- Agencies like hospital and schools
- Improvement: Hire parents to coordinate information and get info to patients  
Advocate for additional state family subsidy dollars  
Why wouldn't we request more?
- Magic Foundation
- Internet
- Usually through the school or just what I do on my own
- Word-of-mouth

2. Who is the service provider who primarily coordinates care for your child? (by title or profession)

- We as parents need agencies to coordinate hiring and training people
- Our Case Manager helps (2)
- Ourselves (2)
- Dr. Sirwiwan, Neurologist
- Mainly my husband and myself
- Dr. Ocejó – her Pediatrician Doctor
- I am the main person who does her care
- Through the school, her classroom schedule and IEP team

3. What other health care professionals or service providers assist in organizing or coordinating care for your child?

- Physicians
- Parents
- Case Managers
- Pediatrician
- She is in early intervention
- Her OT

4. What do you like about the way your child's care is coordinated?

- What is coordination?
- I don't feel I see a lot of coordinating
- Not much – I do a lot for her by myself
- I am lucky to have a great classroom teacher who works with my daughter

5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?

**5**

**Human Services 2-3**

**Physicians 5**

**By our family 4-5**

**Insurance Company 2-3**

**3**

**3**

**1 ½ -no one here in ND knows a lot about what Russell Silver Syndrome is**

**2**

6. What methods are currently in place to help assure quality care for your child?

**-Parents**

**-None that I can think of**

**-We are pretty much on our own when it comes to the care of our daughter**

7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?

**-Yes – Dr. Appointments in Minneapolis**

**-Yes – Children's hospital in Houston for cardiac services**

**-No (2)**

**-Yes**

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

**-Case Manager**

**-Family subsidy**

**-Easter Seals – Respiratory Care**

**-I knew about it, but there were no services that fit our needs**

**-DD Case Management**

**-Medicaid**

**-We have received no services.**

**- I have never heard of Children's Special Health Services**

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

**-Family subsidy**

**-We could apply for MR-DD/DDCM and then be eligible for family subsidy in MA and family support**

**-Medicaid**

**-I have never gotten any information**

10. Have you ever been denied health care services because of financial barriers?

**-Yes (2)**

**-No – we are very lucky**

**-No (2)**

11. What one recommendation do you have for improving the care provided for your child and family?

**-Complete reversal of attitude of Human Services and the Legislatures**

**-Change their attitude**

**-No good coordination occurs – someone to help in this process would be needed**

**-Assistance to families in the area of problem solving through difficult times**

**-More funding in the DD Program**

**-Develop a comprehensive system of care for all children with special health care needs, not just kids with MR/DD – including MA coverage**

**-Improve DD case management's knowledge or willingness to help**

**-I would like for whomever to really look at my daughter instead of just look at how she is now. She has NO choice but to get medical needs. Without medical care she will suffer a lot in life! She needs to have people be aware of what she has and know what her syndrome is. We are at a loss here and need help! Where do we go from here? HELP!**

**-More communication between caregivers and the state**

**-Better attitude from officials when inquiring**

**-To help families and change financial guidelines**

## Fargo Session – Comments From Participants

How did you find out about the focus group?

- Family Voices email
- Southeast Human Service Center
- Cass County Health Coordinator

Major problem:

- No support group – I need to talk about feelings, not just medical stuff
- Family to family works well, but I have to seek it out
- Docs and nurses don't know what you're going through
- Doctor didn't help me besides medical help – I need more info

How do you access info about programs/services?

- Internet
- Books
- Called DD case mgr.
- Shriners hosp. is helpful
- Go out of state a lot – they give you so much info
- ND has nothing for social camps or resources, teachers don't have much info
- MN has way more services
- When the school has events there's not room for special needs
- Need to get kids integrated between "special needs" and "normal"
- Grafton State School is way ahead of Fargo
- My son is not potty trained and not changed enough because they're too busy
- My daughter is paired with a mobile student and the first week of school there was no para so I had to be there – legally they don't have to have a 1 on 1 para
- Living in a small town (Hillsboro) my daughter is integrated with kids, the smaller school system is more accommodating
- We need to know what our rights are (blue book – tells you everything but what you need to know)

What other ways would you like to access information about services for your children?

- see it right in the school system
- NICU – right from the beginning in the hospital
- whoever gave the diagnosis
- have to have its own entity or it will be influenced by school
- before kids start school, there's lots of info
- had to tell case workers about the waiver because I was denied two times
- had to ask a bunch of times (pediatrician) to get the diagnosis
- run a bunch of tests and get therapy, but no diagnosis
- gotten more positive results from alternative medicine and they don't pay for it
- takes a long time to get mail prescriptions
- behavior changed through alternative medicine (also horseback and music therapy) (works well but you pay for it out of your pocket)

What other ways would you like to access information about services for your children?

- try to keep problems away from your children
- want to work outside of the home at least part time, but don't have enough time
- get 6 hrs. or respite care so I have to quit work
- daycare around town – don't like to take kids with special needs
- people talk about doing it but don't follow through
- we don't have child care (did daycare out of my home for special needs)
- they discriminated against my daughter because of her special needs and daycare didn't take her – put in a complaint at Capitol and didn't hear back
- We want our kids with normal kids
- Meritcare has Halloween party for disabled kids and I thought it was terrible (got feeling of circus with the news media)
- Media maybe brings awareness of these kids
- I feel positive about services I've received, but I'm not in school system yet
- Made the doctor ways until he talks to me – we shouldn't have to push for help that much

Additional comments?

- Need to know what can we do together to make changes instead of getting them to help us
- Parents like us should be working at human services
- Keep having to rearrange our work schedules for our kids – I've been lucky to have an accommodating employer, but a lot aren't accommodating
- Why can't Meritcare come after hours? My insurance also won't pay for that anyway. Why can't PT's work a couple nights?
- They won't pay for us to travel the extra miles for services
- Need to get help obtaining specialized services out of state
  - o MA denied us to go to children's hospital in Gillette because there's a part time sleep disorder specialist in Bismarck – not going to help her
- Exhausting emotionally – need to pick and choose what I fight for
- I feel like an outsider – CLS and AARC services were horrible – my daughter is at Anne Carlson in Jamestown and she's doing great – I was worn out and couldn't do it any longer – now my daughter is role model there for other kids who can't do as much as her
- Every time if my daughter's gone out of state for over 30 days she loses her benefits – what can we do if there aren't services here?
- Why don't we have better child group home in Fargo (Anne Carlson is good but is in Jamestown)

### Role of Children's Special Health Services (CSHS) Program?

- 4 people have heard of it
- What should they be doing?
  - o Have team of parents involved
  - o MA programs
  - o Providing grants for child care
  - o Money provided
  - o Communicate with state insurance companies in health insurance
  - o Why are these agencies for families NOT hiring families?
    - All of our time is volunteered and we have to work also – we're busy with money, work and taking care of kids
    - Any major profit company has consumer boards
    - Some meetings and groups need to take place on evenings and weekends with child care available

### Other comments?

- self insurance through companies could be a valuable way to make medical payments other than regular insurance
- insurance will not pay for speech therapy because they say it's educational, not medical
- Medicaid won't pay for services of they're in schools, no matter how bad the services are
- Child needs speech therapy badly but it isn't covered – not getting enough at school
- Therapists need to be stationed in schools – they're floating right now
- My son needs to be changed at school to go to the bathroom, but he's 9 and doesn't want a woman – he needs to go every hour

### What one thing would you want to change?

- have a network set up to help direct people to go for services, support and finance and play dates
  - o children need to interact with normal kids and with kids with special needs and get medical staff involved (therapists, nurses)
- permission slips to exchange information but it never happens
- made a booklet of how to care for my child – wanted it worded that way in IHP
- We need a pediatric surgeon in Fargo – we have to go to Minnesota
- We need higher income guidelines for people on Medicaid
- Our of all states, ND income guidelines are so high that they move out of state to get better care – why does a family have to suffer until the child is 18?
  - o We have no retirement or college fund because we're not allowed to
- Need AF/AC type thing where if you need this you get this much
- These kids are our future, why won't the state help us more?
- The financial burden on families is the biggest problem
- It costs the state \$127,000 to keep my daughter in Anne Carlson, but I had to fight for every penny to keep her at home

## Fargo Session – Written Feedback

1. In what ways do you find information about programs and services available to you and your child?
  - Books
  - internet
  - papers
  - DD case manager
  - Easter Seals
  - School
  - South East Human Service Center – Barb Stanton
  - Cass Public Health – Jo Lawrence (more than one mentioned her)
  - School resources
  - through other people
  - agencies
  - Family to Family network
  - PATH, pediatrician
  - other parents
  - Beth Schable – infant development
  
2. Who is the service provider who primarily coordinates care for your child? (by title or profession)
  - me (6)
  - school special needs director
  - Kathy Williams – Jefferson elementary
  - Jo Lawrence – Cass County Public Health
  - Anne Carlson
  - myself and the father
  
3. What other health care professionals or service providers assist in organizing or coordinating care for your child?
  - Dr. Clutter (PCP)
  - me
  - school therapists
  - Jo Lawrence@ Cass Public Health
  - Shriners, Dr. Patrick Well (Meritcare Southwest Clinic)
  - Southeast Human Services
  - ARC
  - Dr. Welle, Meritcare
  - Andrea Schoeder, CLS (Community Living Services)
  - pediatrician
  - Cass County Health Services Coordinator
  - pediatrician – Dr. Blehne
  - Ortho – Dr. Klava
  - Shriners Hospital
  - Therapist

4. What do you like about the way your child's care is coordinated?
  - case manager and Medicaid that paid
  - Macy and I are in the center
  - the school is open to all ideas and suggestions to help my son learn and become a better person
  - Jo is absolutely wonderful about directing us to where we need to go
  - all in one place
  - I am in control – otherwise it can be very difficult at times
  - pediatrician, school and speech therapist exchange info.
  
5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?
  - 1, 5 (because I do the best I can), 2.5, 2, 2, 4, 5, 4, 4
  
6. What methods are in place to help assure quality care for your child?
  - Me
  - School, DD Case mgr., Easter Seals
  - My determination, assistance from Jo Lawrence, Kathy Williams and Barb Stanton
  - there are no methods
  - me and my husband
  - follow up with professionals
  
7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?
  - Shriners, experience, 2<sup>nd</sup> opinion, least invasive treatment
  - no (2)
  - Gillette Children's Hospital – our pediatric neurologist left Meritcare
  - yes – Shriners Hospital, her lets – Hennepin Co. Hospital, Minneapolis for a sleep clinic
  - Shriners – for prosthetic devices and equipment
  - Yes, FL massage therapy
  - Allergis – unique place in LaCrosse Wisconsin
  
8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?
  - educational needs
  - Early childhood intervention came into my home weekly for speech and OT from age of 2 till 3 then helped transition to special ed public preschool
  - my DD case mgr. at Southeast has been a good resource
  - none, not at all to my knowledge (4)
  - Medicaid, respite from Easter Seals

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

- none
- none
- MA
- none
- Medicaid
- none

10. Have you ever been denied health care services because of financial barriers?

- no
- no
- yes
- no
- No – I don't care what the cost, whatever I need for my son
- denial coverage
- yes – speech therapy

11. What one recommendation do you have for improving the care provided for your child and family?

- Emotional needs are not treated as part of program, both for parents and children
- Better flow of info between all those working with her, and better info on what services and financial assistance are available to us.
- Child care is a huge issue – need grants for child care
- One agency separate from other insurance, hospital or Southeast, and one person or agency that knows about all the services
- Networks within communities
- There needs to be a network setup to help direct people/families on where to go for services, financial assistance, etc. (support groups, play dates)
- Be open to natural medicine (supplements, massage)
- Activities, child care (educated)
- Include parents so we are best informed about our child's needs
- Have all the services available in one place
- pay for education for parents

## **Grand Forks Session – Comments From Participants**

How did you find out about the focus group?

- DD case manager
- Independent Living Centers should be contacted in future
- Email – family voices
- Public health
- NE human service center

How do you access information about programs and services?

- PACER – publication from MN – produced by Pacer – like Pathfinders in ND
- Family Voices
- Family
- DD case mgr.
- Infant development or public health care nurse
- ARC
- NDAD
- Options
- If you want useful info for your kids it's hard to find – general info is easy to find
- You don't hear about financial help – can't get info very easily locally
- Entities (parents) get frustrated when they don't get an answer – or a right answer
- At the local level we can't get info
- Dealing with gov't is difficult – redundant with info needed to provide best care
- Hard to get the medical community to listen
- They say you'll always be denied on paper the first time
- Get burnt out very fast – if you have a good DD case mgr., that helps
- County Social Services – good in north part of state, but it's not up to date with programs
- New parents need an advocate – some case mgrs. don't know anything
- Parents need to be proactive in gathering info
- Need an all-encompassing document with all resources
- Special Ed. Depts. in schools are a real challenge
  - o They can't have summer programs because they can't prove regression
  - o Schools aren't prepared for special needs kids – don't have the money – federally mandated program but no money
  - o Until teachers have a child with the disorder, you have to be their teacher
  - o You have no choice – you have to teach them because they don't know

How do you access information about programs and services?

- Special Ed coop – parents want their kids to stay in their home school district rather than busing them to larger town
  - o Kids graduate then go home and have not friends, no socialization with the home community
- Families don't know about expensive equipment not being used that could be given to other families – need a better network
- We ask for medical assistance and repeatedly get denied
- People fall through the cracks who have no credit to get loans and in turn get reimbursed – here's where they need a DD case manager
- Parents are the care coordinators
- Need to educate providers on what parents need
  - o Physicians are listening to patients more

What services are lacking in communities?

- pediatric neurology – we lost one out of Fargo
- a majority of my doctor care is in Minneapolis – we've gotten so much more care there
- doctors haven't told me certain things – I've had to read it in my child's file]
- Medicaid denied our son going to Mayo when the doctor recommended it
- If the specialist says the child should go to Minneapolis, Medicaid should pay for it
  - o It seems like Medicaid thinks it's better for them to die at this point
- Respite comes, but not when you're at work
- We need daycare – what do they do from age 12 to 18? Couldn't we get rid of respite care and go to aged care?
- Have to give up my kid to get him service or more to Minnesota

After hours notes

- They say school isn't socialization – that's untrue – socialization is a big part of kids with disabilities
- Grand Forks has good transition program from 14-21, but in Cavalier, it's not like that
  - o There's a divide in services from 18 to 21 up north if they graduate at age 18
- It almost depends on who you are and who you know as to what you get
- If you make waves as a parent you'll be branded and discriminated against
- When you give your child up to adult care, you don't have control any more – don't know how they're doing

Role of Children's Special Health Services Program (CSHS) – have you received support from this?

- Depends upon case manager – things go well with a good case manager
- Would like to see more PT – only get it once a week and I do the rest
- Need care coordinator – parents are overwhelmed
- Need more emotional support for parents

What's one recommendation you have for improving care?

- getting medical equipment approved
- more respite care
- Doctors and nurses and the state need to be educated from us as parents as to what we go through
  - o Some nurses don't know how to do things for my son – I sometimes have to tell them
- financial help and manage ourselves
- MA – label some things so they don't have to find it – find a way to deny it
  - o Things are coded to get help – ex. Personal hygiene cleansing cloths are covered but not diaper wipes
- Dr. Sobus – physiatrist – wonderful – the state denies her requests also
- The only thing that changes over the years is the type of battle
- Other parents don't know to keep fighting against certain things

## Grand Forks Session – Written Feedback

1. In what ways do you find information about programs and services available to you and your child?
  - From our special ed dept. and North East Human Services
  - From our social worker/case mgr. at NorthEast Human Services
  - Research on the internet
  - Developmental DD case management, only the good ones pass on the info to parents
  - Through other parents
  - Friends, co-workers
  - Internet, calling NE Human Services, calling other service providers, talking to other parents, contacting “knowledgeable people” and chaining names until you run out or get an answer
  - Through infant development and public health
  
2. Who is the service provider who primarily coordinates care for your child? (by title or profession)
  - Marilyn Arneson from Northeast or Wert (Case Manager) for our children
  - Dr. Eric Lunn, Dr. Sobus (from Altru)
  - Myself – I type the letter to the pediatrician with doctors dates, times of appointments and he forwards it to the state for approval
  - audiologists – Altru, GF school system, SLP-Central Valley School
  - No one – various organizations can provide limited coordination – I provide all the actual coordination
  - Me, the mother, my public health nurse, infant development
  
3. What other health care professionals or service providers assist in organizing or coordinating care for your child?
  - Just our normal physicians and physical therapist for Lorie
  - Independent living centers, like the one I work at gives parents info and walk them through the process
  - Primarily ND and myself
  - I use DD case management. Other organizations are consulted if needed. Currently ED, DD and welfare and the school are committed to planning for my daughter’s return home
  - Public health, infant development, support systems, Meritcare Home nursing

4. What do you like about the way your child's care is coordinated?
  - Well actually, we don't presently have a lot of health care concerns
  - Very good. Dr. Sobus and Dr. Lunn coordinate our son's care very well
  - I like myself doing this. I can present how important and being in charge and know if it is being done.
  - Nothing – mostly directed and guided by myself
  - it can be done by a parent still if persistent. I worry that the option with become unavailable.
  - Overall, it's good. But I do run into snags
  
5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?
  - 4, 4/5 (the health care with Altru is very good. They will refer if they feel my son's needs cannot be met at Altru. Need pediatric neurology), about 1-2 in ND – in Minneapolis about 5, 5, 2-3, 3.5 (I get a lot of health care, but there are some needs that are not met)
  
6. What methods are in place to help assure quality care for your child?
  - I'm not sure other than my wife and I
  - Parents and health care professionals
  - I try to doctor as much in the area for tests and evaluations and then take that info with me. I feel the state wastes more in testing and medications than going to a specialty facility that knows what to do and is aware of non-necessary testing
  - Myself
  - Laws, personal integrity
  - Medicaid – insurance wise, infant development until 3 years
  
7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?
  - Yes – St. Paul for surgery
  - Yes – Minneapolis for specialized mental health services – none useful in ND after several trials. Moorhead for psychiatric services – available and specialized
  - No
  - Yes - usually Minneapolis to the specialty hospitals and clinics
  - Yes, we initially went to the sister Kenny Institute to have a ? pump. Now Altru does this procedure.
  - Yes – Jamie went to Abbot North East in the Twin Cities for a Rizotonic about 10 years ago.

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

- None
- Voluntary placement of my child in Residential Treatment Center – good service, ACT team – bad outcome, not useful
- Money for hearing aides and appointments
- Medicaid has been really limited on approvals for out of state care
- DD case management
- Family subsidy
- For just about all their needs and services related to their needs. Angie has Down Syndrome and Jamie has cerebral palsy.

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

- Medicaid, northeast, NDAD
- yes – none except the voluntary placement
- CSHS
- Family subsidy, Medicaid
- Medical assistance, family subsidy, NDAD

10. Have you ever been denied health care services because of financial barriers?

- No
- The only barrier is that I can't afford all of it – too high income, and services are \$9,000/month
- No – except with hearing aides unless we paid for them – had to borrow that money from grandparents
- No
- No
- No

11. What one recommendation do you have for improving the care provided for your child and family?

- More financial support
- Information and referral that is accurate, timely and accessible
- Educating providers and their nurses regarding financial and emotional support for parents
- We don't need care coordination but more emotional, financial help
- Medical assistance needs to look at things that parents feel are medically essential. We have been denied a toilet seat because they said it is a personal hygiene device. To our son, this device is medically essential for him to function properly
- Pull-ups. Medical assistance only pays for the cheapest pull-ups – these do not meet our son's needs. He had to come home wet at times from school. We now purchase the better ones for him
- More respite care opportunities

## Minot Session – Comments From Participants

### **Awareness of Focus Group**

- Pathfinders Conference
- Pathfinders
- Family to Family network
- Daycare provider
- CRC
- Special Services (Minot public schools)
- NOMI
- ND Paths e-mail
- Friend
- Direct mail

### **Accessing information about Programs/Services**

- Newspaper
- Clinics should put information in their lobbies about services offered by Children's Special Health Services
- Need a central coordinating center
- Letter from supervisor
- Case managers, Pathfinders
- Even with Pathfinders, we have to pay co-pay, etc.
- Information isn't available (on the base either)
- County case workers aren't being provided knowledge
- Dr. at Trinity has been good source of information
- Psychiatrist in Minot is good
- Souris Valley won't follow Dr Recommendations
  - they don't want to travel to rural school districts where we are (Kenmare)
- Limited staff in rural schools – lacking services
- Should not be right when schools will not follow Dr Orders
- One lady contacted Byron Dorgan to get information and was treated and acted upon quickly
- Military helped pay for evaluation of a child – school system did not
- Air Force Base has been after the school to get them to comply
- Doctors need to be willing to give out information
- Orthodontist needs to provide information and not base decisions of giving information on compensation
- When paid for by me and my insurance the Doctor recommended different treatment – services sometimes based on money rather than the best treatment
- Doctor dropped us when we didn't want our daughter in treatment with drug addicts
  - we filed a complaint with the Medical Board
- CAPH (Child Adolescent Partial Hospitalization) program is geared towards teens and young adults not towards kids with mental disabilities
  - took her daughter out of the program, then lost Medicaid

## **Working with Health Care Professionals**

- Don't use our children as guinea pigs – Doctors sometimes do not know what is wrong, so they try and use meds to solve the problem
- Need to educate the Doctors of all conditions
  - go to conferences
  - get brochures, etc.
  - trial and error is all they know what to do
  - side effects can be permanently damaging
- Referral process is frustrating– Minot wanted to send daughter to MSP instead of Fargo or Bismarck
  - Minot sends kids to Minneapolis when the same specialties are offered in North Dakota
- We have to take our own initiative
- Everyone thinks Minneapolis is the best place to go, but we had better care in Fargo
- People skip Doctors in ND because of the mentality of Doctors not knowing anything here
- Minot doesn't have the services available, very comprehensive in Grand Forks
- Services aren't provided in rural schools
- One mother wanted a full-time sign language teacher, but Glenburn would not pay for it
- One family thought the small school system would be good – but they were wrong, now they want to move out of the school district because of lack of care they have received

## **Lacking Services**

- Training for parents with special needs
- Brothers and sisters need someone to talk with
- SIB Shop
- Schools and teachers need to know what to do in the special cases
- Teachers are scared to stand up for the battle to get staff for special needs kids
  
- Need reimbursement for travel
  - gas
  - meals
  - hotel rooms
  - we have no family here to help
  - others with extended family use them to death
  - taking off time from work
  - daycare for other children
  
- check into gambling organizations for money with NDAD
- NDAD don't know who to refer you to
- NDAD and Animal places
  - bad at returning calls and do not know who to refer you to
- Visible disability is what they base Medicaid on
  - this is wrong because many children are mentally disabled
- Friends and neighbors look at you as trying to get money for the government
- They think if you're dressed nice, you don't need help financially
- Medicaid form – you no longer have to provide assets and income
- Denied right away – then tried back and got help

- SSI personnel treats people differently
  - all need to be trained the same
  - they treated many families terribly
  - they point fingers all the time and do not take responsibility

### **Role of Children's Special Health Services (CSHS) Program**

- Only 2 of the 9 knew about CSHS
- Helping families, coordination of care, know who the families need to contact for more information, advertise what services they offer
- They are limited to certain health conditions – they do not cover mental disorders
- Why don't they pay parents to help kids if there is no one to help in the schools?
- Parents are unprepared to deal with kids: they are not doctors and teachers, etc.
- One mother found out info. and had to educate the school and Doctor, but then they view us parents as nothing like we don't know anything
- One mother was turned in for educational neglect when we didn't send her to school when she has having thoughts that were inappropriate
- Need to meet families with kids who have the same problems so we can talk and e-mail
  - family picnic – to get people together
  - forums where daycare would be provided
- Provide training for day care providers to help children with special needs
  - the providers now do not feel equipped
- Ward County takes money away if a meeting (such as this focus group) is considered work and it is not "earned"
- You can never get ahead – you earn money and they take it away
- Elks have been good to work with

### **Financial Matters**

- SSI – I don't even try anymore – I end up paying back because I make \$1 over the limit
  - it's based on what the whole family makes
  - you can't save any money
  - you feel terrible – they know everything you have in your accounts, etc.
  - it should be based on child not family income or you'll never get ahead
  - we have to prove our needs all the time
  - it is better to be single and poor
  - the entire family suffers for one child's condition
  - Family subsidy keeps getting cut – you're lucky if you get half of what you ask for
    - it's never enough
  - too much paperwork – it is hard to be a good parent and work at the same time
  - we should not have to prove we get Medicaid every day of our lives
  - we don't need someone second-guessing us

### **Financial Matters continued...**

- Elks works well helping families
- People don't realize the cost of having a child with special needs
- You don't have a life – you can't go out and do anything fun because of the restrictions of the child
- No one should be put in the situation of an uncomfortable life
- I've had to quit my job – I needed to be close to home
- One mother was told they were above the threshold – didn't qualify for Medicare and couldn't find respite care
- Mostly all of the coordination and care falls on the mom of the child
- You get to the point of where you think "Why do I have insurance?"
- I was trying to make ends meet and I was told to drop insurance and not go back to work
- Inclusion – shouldn't have to send our children to institutions
- Can't trust just any babysitter
- I need someone trained who I can trust to leave my child with
- It would be nice to know where to get money from
- These special needs programs continue to get cut
- No one will fight for us
- This country has forgotten about their families

### **Programs**

- SIB SHOP
- ND Infant Development
- Job Service – Brenda Helgremson
- Northwest Ventures
- ND Interagency Coordinating Council

## **Minot Session – Written Feedback**

1. In what ways do you find information about programs and services available to you and your child?

- ND Pathfinders and ND Pass, NCHSC
- Other parents
- County Social Services
- Diabetes Association
- Case Manager at North Central Human Services Center in Minot
- Networking – friends, co-workers, etc. – teachers have been helpful
- Pediatrician has been helpful
- DD Case Manager (2)
- School (2)
- Family physician (3)
- Call agencies we've worked with for assistance (example: referrals)
- Internet (2)
- PATH
- Partnerships
- Pathfinders
- It helps us provide better special care for her cerebral palsy needs when it is in a brochure or in the Sunday's tribune as an insert
- Newspaper
- Social workers

2. Who is the service provider who primarily coordinates care for your child? (by title or profession)

- Case Manager with partnership
- Johnson Clinic providers – Dr. Schovebery, Dr. Selland, Dr. Nieme – Dentist
- Self...some help from DD Case Manager
- Beth Feist – Development Disabilities Case Manager (2)
- Mom
- Psychologist
- Psychiatrist
- LSW
- Dr. Laura Schield – Pediatric Psychiatrist
- Dr. Kristen Sobus and Dr. Jeff Haasbeek

3. What other health care professionals or service providers assist in organizing or coordinating care for your child?

- Pathfinders, ND Pass, Peace Garden Special Services
- Dr. Gentile
- Dr. Melissa Moilan
- ND School for the Deaf
- Partnerships
- PATH
- Pediatrician
- Garrison Family Clinic/Garrison Hospital – Denise Gradin
- Great Plains Rehab – Bismarck – Peter Davidson – PT
- Key Care Medical – Minot
- Dr. Gomez, who is the child psychiatrist at Trinity Riverside. He will be taking Gene's case when we get back from Minnesota

4. What do you like about the way your child's care is coordinated?

- Group approach
- Good communication with school and doctors, poor follow through from SVSS fro recommended services based on evaluations by independent providers
- Convenience – we can stay in the state, we actually have a great school system and programs in the hospital
- Beth and others try their best but sometimes being over worked and expected to do more with less does tend to stretch people's patience with the system

5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?

**5 (2)**

**2 – Orthodontist was poor in quality as well as the overall attitude and availability of appointments**

1 ½

**4 (3)**

3

**Since Gene was recently in residential care – and we have seen the difference in health care systems, we do tend to be very concerned about North Dakota's health care system. We realize that Minnesota has more revenue to work with but it does tend to make a parent very concerned**

6. What methods are currently in place to help assure quality care for your child?

- IEP at school (2)
- None
- Treatment Plans
- School IEP
- Military exceptional family members program
- Periodically visits to specialty doctors
- Physical Therapist 1/week for 1 hour
- Respite care, psychiatrist, school is still an issue

7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?

- No (5)
- No – nothing has been recommended and we don't know
- Yes –St. Paul for heart surgery
  - Minneapolis for immune system problems
- Yes – Santa Monica, California for an eye specialist
  - Staten Island, New York for the research center
  - Iowa City, Iowa for a neurologist (synesthesia)
  - Fit Simmons in Denver, Colorado for diagnose
- Grand Forks – multidisciplinary evaluation
- Yes – he is currently in residential care because North Dakota did not have room for him

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

- Currently have partnership services
- Infant Development
- Insulin diabetes supplies not covered by all health insurance
- Orthodontist care (2 years of braces)
- DD Case Manager – has found some services
- Medicaid (2)
- Family subsidy
- Respite care
- DD
- Infant Development
- First District Health Unit – Health tracking (braces)
- Partnerships
- None – Souris Valley Special Services provides OT through school environment
- We receive medical benefits to help pay for what our BCBS policy does not pay for
- Setting up with various programs for Gene

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

**-Family subsidy (4)**

**-Medicaid (3)**

**-SSI (2)**

**-Children's Special Health Services**

**-Elks have helped us with travel and lodging**

**-NDAD has helped with software programs**

**-None (2)**

**-I am unaware of any except for medical benefits to help pay for what BCBS does not cover**

**-Since Gene is adopted we received a subsidy of him being on Medicaid**

10. Have you ever been denied health care services because of financial barriers?

**-I actually just cancelled appointments or asked for different types of prescriptions, etc.**

**-Haven't qualified for some services because of our "high income"**

**-No – PATH is hard because we have to pay our BSND copay and coinsurance**

**-Yes**

**-No (2)**

**-We have been denied Medicaid because of financial reasons**

11. What one recommendation do you have for improving the care provided for your child and family?

- Centralized information center which could direct you to the appropriate facilities and care centers for the type of problem the family is meeting – then coordinating the care**
- I feel sometimes I don't even know what's available or what is reasonable to ask about. We all need a central person to advocate for us and our individual needs...someone with time and money resources to look out for information on what's out there. Coordination!!**
- More financial assistance**
- More local resources**
- Coordination of services – more dialogue between professionals**
- Individualize!**
- Centralized resource center**
- Wrap around services to include support for siblings and parents. Everything is geared around the affected child! But we haven't found anything to teach and support siblings and parents.**
- Availability of a multidisciplinary evaluation team in Minot for psychology, OT, PT, education and speech**
- Travel reimbursement for those of us that do not have care in our community – not all communities can provide special care and needs for all special needs. If it is far enough away hotel and meals also would be helpful.**
- Understanding that everyone has individual needs and it is very hard to send a child away who has been abandoned earlier in his life but we had to think of what would be best for him. It did not turn out to be quite the blessing but we would not recommend it for any family to have to struggle through.**

## United Tribes Session – Comments From Participants

### **Awareness of Focus Group**

- Letter in the mail
- Classroom
- Email that an instructor had received

### **III. Accessing Information About Programs/Services**

- Doctor at the clinic
- Pursue ourselves
- Instructors
- Student Health clinic on campus
- Occasional pamphlet
- West Central Human Service Center
- No help at all at Fort Yates
- Negative feelings about Bismarck Social Services
- Child had to go to foster care (PATH Family Services)
  - they helped find programs, but it's hard for them to go out on a limb and do something different
- I had to go to the reservation to find services
- It's hard if you don't know where to go or what to do

### **Improvements to be made**

- should be something for Native American families from reservations, they are willing to take our kids away and no advance notice that you have to pay
- it cost \$17,000 for child to be taken away for 11 months and had to pay that to Prairie Learning Center
- they don't tell you the negative side of things
- they don't tell you certain meds can affect the jobs you can get – nephew can't get into military
- need more awareness about children with behavioral problems – then the law gets a hold of them and it's too late
- more information about how to cope with children with behavioral problems
- most Native Americans don't realize the care that is needed for these children
- needs to be a packet for parents that contains information about what to expect, sign and symptoms of the special needs
- a hotline for parents to call and have one-on-one contact
- need to utilize the same people you already have – don't need new programs – just be there for the parents
- may kids have been misdiagnosed
- we have parent night classes for ADHD but no one knows anything about ODD
- we have a bad stereotype in Bismarck as either drunks or hell-raisers – social services gives this impression to us
- should be a Native American program so we are not looked down upon
- parents need a helper to help them out with the day to day activities
- \*\*people understand from people, not documents\*\*

### **Additional Suggestions For Improvement**

- An Outreach program would be very helpful
- We need structure from a professional or other parents (support group)
- One lady has a really good case worker, so she is never looked down upon
- One lady says she despises the Bismarck Social Services
- We need Native American communication – they don't have cultural sensitivity they make you repeat yourself over Andover to explain yourself
- Social Services are unclear about what is going on
- Social Services employees said discriminating remarks against Native Americans
- Prejudice feelings are there – based on stereotypes
- Approach of the Social Services is by the book and no care and cultural sensitivity
- No leeway and immediately get out the paperwork for foster care
- They need to have a Native American working in the Social Services office
  - parents would feel more welcome to attend with a Native American professional working in the office

### **Indian Health Services**

- I would prefer to go to IHS than local clinic – we should have one in Bismarck – they have one in Rapid City
- IHS is more welcoming to us
- IHS in Fort Yates refers you back up to Bismarck
  
- This would be good for relations between Native Americans Doctors and Bismarck Doctors
- Dr. Baker and Dr. Tincher at FMCN – I'm comfortable around them – can be truthful with them – they know where you're coming from

### **Children's Special Health Services (CSHS)**

- No one aware of the unit
- Different nationality working there – diversity
- Someone needs to work there that will do something for Native Americans
- It is hard for Native Americans to say what is on their minds

### **Services Which Are Lacking**

- Asthma care and information
- Asthma support group
  - reassuring to the kids, but who reassures the parents
- Oppositional Defiant Disorder information
- Big Brother/Big Sister and Youthworks – must wait at least 2 years to be in the program
  - age limitations for these support group
  - need more programs like these for all ages
- We need a go-between person
- Anger management classes
- More awareness of drugs and their effects – more education
- Need to be support groups for parents and families
- A good source of reliable information and more resources

### **One Change**

- More Native American support
- Reduced waiting times
- More prescription choices for their children
- One mother can't work because she would go over the limit
- This keeps the parent on welfare
- Vicious cycle
- There is a lot of information out there and programs, but sometimes it's hard to find it
- It's a lot of work to get help for children with special needs
- They have different standards – Native Americans have our own parenting skills

\*\*\*Those in attendance commented that a possible reason why not many Native Americans showed up for the meeting is because they feel that they are looked down upon already and then to have a child with a special need they are looked down upon even more. They also may feel that no change ever comes from these meetings, so why come waste their time.

## **United Tribes Session – Written Feedback**

1. In what ways do you find information about programs and services available to you and your child?

- Through Wona @ reservations, where I worked
- If necessary through Dr. Biron Baker
- Asking through who knows
- My son and I have been involved with social services and West Central Human Service Center
  - they have directed us to PATH Family Services, Mental Health, Doctors, the Internet and the Student Health Clinic at UTTEC

2. Who is the service provider who primarily coordinates care for your child? (by title or profession)

- BCSS – Sue
- Dr. Biron Baker
- It's been from Social Services, the Case Manager and legal guardian Tracy Mertz, Ad Litum, West Central Coordination person Dawn Pierceson, Counselor Sue Herzog

3. What other health care professionals or service providers assist in organizing or coordinating care for your child?

- MedCenter One
- We are on Medical Assistance through the state of North Dakota
- Mental Health, Pediatrics, Safe beds

4. What do you like about the way your child's care is coordinated?

- I don't like it for both my sons and granddaughter
- Dr. Biron Baker does make time especially if it's urgent so we don't wait if our children are having an asthma attack
- I'm a single parent and it helps to have more people with more ideas.
- Things to discipline and reward only work for a short time

5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?

**1**

**2 - only because I don't really know much about asthma other than it being scary**

**2 - they don't use many avenues**

**- I've been trying to get West Central to have my son go through a Bio-feedback program**

6. What methods are currently in place to help assure quality care for your child?

**-Through the Medicaid - for low income - TANF**

7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?

**-If I was on the reservation, maybe, but there are no neutral needs**

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

**NO**

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

**-I don't know!**

10. Have you ever been denied health care services because of financial barriers?

**-Yes, dental things - the agency (dental) did not accept Medical Assistance**

11. What one recommendation do you have for improving the care provided for your child and family?

**-Educational items or handouts**

## **Williston Session – Comments From Participants**

### **Awareness of Focus Group**

- Oral Johnson – Upper Missouri Health Unit
- Social Services sent out a flyer (4 people)
- Family-to-Family e-mail
- Parenting coalition in Williston
- Dr. Cook's office pop-up stand
- Phone call from Social Services in Crosby

### **Accessing information about Programs/Services**

- I call Social Services and find pamphlets at clinics
- PATH office
- Special needs teachers
- Doctors, schools, other parents
- Networking with others
- Being bold and proactive in finding resources – this is frustrating – it takes time, we have no central location for information – Social Services doesn't even know about some of this stuff
- We need someone to coordinate “What should I do for my child at this stage?”
- Need someone who knows the kid (comprehensive file) to coordinate care
- Internet (obtain worldwide information, but ND wants to distinguish all in state before recommending out of state care)
- ND should put more information on the Internet
- Care is disjointed
- Frustrated with filling out same information all the time
- You hear about a program and you go through all the paperwork and then find out you don't qualify
- It is hard to find services that apply to your child

### **Additional comments regarding access to information**

- have a case manager that takes responsibility for coordinating care
- ND should put more information on the Internet
- Can find information, but not the right kind of care here in ND
- Information is not released from one agency to another – they won't even release it to the parents, but have no problem releasing the information to the schools and other physicians
- It would be nice to have that information so there was continuity in care
- We feel as though we have to answer the same questions over and over
- ND state will not pay medical assistance to go out of state, but will not look at her child here in ND

### **“Medical Home” –A Central database**

- Central database so physicians anywhere (country-wide) could look at the file – primary Doctor at home could follow up after seeing a specialist in another state
- Password access only
- Computer or phone access (a variety)
- We need someone to help coordinate what to do with the child and what to expect
- Someone needs to have a comprehensive file about our children
- Right now it is a very disorganized system
- Have to fight ND to go out of state for care – have to fight for medical assistance
- Unanimous support as long as it is private
- Parents should be allowed to add information to files or reports – they are the primary source of information – the parent knows the child more than the doctor
- A “comment” section so you document if treatment worked or not
- Coordinator needs to know about travel opportunities, Angel Flight, Wings of Mercy, etc., gas assistance Ronald McDonald house, hotels and airline discounts available for each family

### **Assuring Quality Care – How would you grade this?**

- A - gone above and beyond, receive mailings from the clinic
- A – received help, but would like to know of more financial help
- A – Dr. in Minot
- C – Drs. in Billings – do not provide information
- A – very helpful, good school system
- A – medical
- C – Ward County Social Services – very lax about information
- D to a B – use to get information myself, but now receiving more
- A – medical staff
- C – programs and obtaining information
- A – medical staff
- C – coordination of information, no team approach
  - people don’t think outside the box
  - they don’t look at individual plans for their child
  - people are willing, but do not follow through
- B – care and no pediatric specialist, no knowledge beyond basic knowledge
  - we will lose our social worker after our daughter is adopted
  - we will also lose our qualification issues
  - we will have to start all over building a file when the Doctor leaves and we have to get a new Doctor – no files are transferred
  - misinformation across the board – referrals are a problem – sometimes I need them and didn’t know it

### **Services Which Are Lacking**

- Lacking OT/PT, need home-based therapy, therapists are spread too thin – they are willing, but they don't have enough time, no pediatric psychiatrist or psychologist
- No audiologist in this area – have to travel to Minot
  - Williston Doctor will not see her daughter until after she has been to Minot
- Dr. Olson will see her after she has been to Billings
- Need a pediatric specialist
- No one can help with chemical intervention (Depression, ADHD)– have to travel to Minot
- We need more doctors here

### **Family Involvement**

- More respite care givers – very little here
- Social Services use to have respite care, but not anymore
- Opportunity foundation in Minot – will pay for daycare – funded by the state
- One family was given the funding, but could not receive the care, not enough qualified caregivers
- Easter Seals no longer represented in Williston
- Lack of information in this area

### **Role of Children's Special Health Services (CSHS) Program**

- 2 of 12 aware of the program
- Coordinator of care like an admissions counselor at a college helps you plan
- Someone to discuss care needs with
- More publicity
- More information
- Keeping an updated list of Doctors who provide what care services
- Advocate ND and encourage physicians to move here
- Advocate fighting for changes that take place (laws)
- Advocate fighting to keep the services we do have

## **Financial Matters**

- Medicaid, private insurance (special programs that policy didn't cover), reimbursement for travel from county, I was denied social security
- Medicaid – primary care Doctor always has to write referral letter
- I was denied to leave the state because there was a specialist in the state
- Need pre-approval too far in advance
- By the time the paperwork goes through, the condition of the child has changed
- We have no specialist here for my child, but we are expected to get care in ND
- In California, they would pay me to stay home and take care of my child
- Insurance should be for medical care – babysitting shouldn't be added to cap for insurance
- Northwest Human Services drops the child after age 3
- After 3, they are rolled over to the next program
- One family is state and federally funded because she is a therapeutic foster parent
- She would like to have financial assistance for out-of-state conferences
- Families are exhausted by the end of the day, just from the daily care – they have no time to coordinate care
- One lady will not trust IEP people until all have same view of her children
- One parent not waiting for IEP, it takes too long to organize
- The parent is the primary care giver, but we need someone provide resources and tell us where to find help or information
- There are courses people can take to become certified caregivers under respite care
- We need more funding from North Dakota
- Various needs but they all get the same funding
- Financial assistance should be based on unique health problems

## **Recommendations for Improvement**

- Really good information on the web – online discussion groups – Mayo clinic
- Family-to-family network – they pair you up with same medical problems but no other situation similarities (i.e. going to Minneapolis for care, etc.)
- It's hard to find time to go to support groups on-line – I can do it when it's convenient for me
- A central coordinator for each community that can connect families with each other
  - parents could talk to other parents who have already been through the situation
- A Minot hospital showed a parent what a 10 year old looks like, so she knew what to expect (clef palette)
- General community awareness of other families that have special needs children
- More awareness about special needs in the community
- More awareness equals more acceptance
- Inform the community so know what cerebral palsy is, so others know what the condition looks like
- Integrate the special needs children into the classroom more
- Educate the teachers
- Kids want to know, so the sooner they are informed about the child, the better

### **Additional Recommendations for Improvement**

- Special needs should get extra money
- Assistance should be upon the specific need of the child
- Therapeutic foster parent is state and federally funded
- Money in investments should not be counted in for income
  - you are then disqualified for assistance when you have retirement accounts, savings, etc.
- You can never get ahead
- You cannot even save for future needs of the child (wheelchair lifts, etc.)
- Welfare system (healthy kids get the stuff, not the special needs children)
- There is that gap where you can't afford to go to work
- We need more social workers to lighten the load so they have time to check up on cases
- Parents need help getting their feet on the ground and get started with their child

## **Williston Session – Written Feedback**

1. In what ways do you find information about programs and services available to you and your child?

- Social Services (3)
- Through our social worker
- Physicians
- Other families – asking everyone and anyone
- OT
- I find my privacy constantly being invaded by questionnaires. Programs are available, but the issue of what it covers and what a parent's obligation is very large. Often to be told we don't qualify.
- Rely on the Doctor
- Through Opportunity Foundation
- Special needs teacher at school
- PATH office
- Flyers received at my school where I work
- Williams County Social Services
- Pamphlets in clinics
- Oral Johnson (2)
- Flyers, teachers, school, doctors, friends

2. Who is the service provider who primarily coordinates care for your child? (by title or profession)

- Dr. A Wilder
- Social Worker
- Licensed Social Worker
- Heew Limbo
- Mother
- Opportunity Foundation
- Williston City Social Services
- School
- Pediatrician
- Jared Cvarchara – Case worker
- Jeni McCann – Ward County
- Theresa Triebull – Path Social Worker
- Dr. Code
- Dr. Ramage
- Oral Johnson – Social Services in Williston
- Cleft Palate Team in Minot (yearly)
- NW Infant Human Development Services
- Linda Hill

3. What other health care professionals or service providers assist in organizing or coordinating care for your child?

- Dr. Mills
- Dr. Staton
- Northwest Human Services Center
- Trinity Mental Health
- Family Therapists
- Psychologist
- CAPH Program
- School counselors
- Some respite care
- Barb Olson
- Clyde Vinger
- Sonia Owan – professional coordinator of Opportunity foundation
- Mavis Salla – family support services
- Dr. Duchock – play therapist from Dickinson
- Dr. Kleman
- Dr. Joshi
- Cleft lip/palate clinic in Minot
- OT
- PT
- Speech
- Dr. Souis
- Dr. Haasheer
- Dr. Reiner – orthodontist
- Physicians TCC – Western Dakota
- Mayo clinic

4. What do you like about the way your child's care is coordinated?

- Everyone seems concerned about our child's wellbeing.
- It's not coordinated well between organizations.
- Duplication of paperwork, no teamwork
- Mom has to coordinate and be on my toes all the time
- Someone will find someone to watch my child if I can't
- The Doctor's are always available when we need them by phone or in person.  
We're always given choice.
- We as foster parents are allowed to include our feelings and desires, with regards to the programs that are put together for his care.
- OT and PT are on the ball to send and suggest what could be done
- I like that some services are available and the providers are willing

5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?

**5 (3)**

**3**

**1**

**3 ½ to 4**

**4**

**1 ½**

6. What methods are currently in place to help assure quality care for your child?

**-The county allows us to contact our child by telephone and tech-wired visits.**

**We are in constant touch with the staff that is caring for her.**

**-Mom being demanding in addition to educating professionals to think "outside the box"**

**-Respite care (2)**

**-LD Resource Room in school**

**-Family Support Services**

**-Play Therapy**

**-ED Resource Room at school**

**-Ward County Social Services**

**-PATH**

**-Cleft Palate Clinics – they are wonderful!**

7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?

**-No (2)**

**-We took our child to the U of M for studies and MRI's**

**-Yes – Philadelphia, Pennsylvania. The program that works best for my two special kids is based in Philadelphia.**

**-Rochester, Mayo Clinic**

**-Specialists in Medical field**

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

**-Suggested a residence she could go to to be further watched**

**-Respite. Also interference due to lack of knowledge of autism**

**-I am on the parent advisory board for CSHS**

**-Early Childhood Screening**

**-Partnership Program**

**-Respite Care**

**-No**

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

**-Our insurance, but it is limited to 2 months. We had to sign our child over to the county, so now we are liable for child support to the county.**

**-Medicaid (5)**

**-Private Insurance**

**-Medical Assistance**

**-We also applied for SS and were denied**

10. Have you ever been denied health care services because of financial barriers?

**-No (7)**

**-Yes, because there are some specialists in ND**

**-No duplicate care will be covered out of state**

11. What one recommendation do you have for improving the care provided for your child and family?

**-Having someone coordinating all the services for my child so she gets all the services she can get that she qualifies for. Also, make the services easier to obtain.**

**-Need a central information point so information about our child can be shared with other agencies that deal with our child.**

**-Coordination of information about my children and services available.**

**-Counselor who knows and can advocate and find ways to make all services available**

**-Listen to the parent he/she knows their child best**

**-More financial services for traveling to and from Doctors**

**-Referral Resource Center where we can search out assistance**

**-I would like to see Doctors communicate with me more**

**-Knowledge of programs**

**-Sharing of information among Doctors, parents and specialists**

**-A list of services and providers for those services**

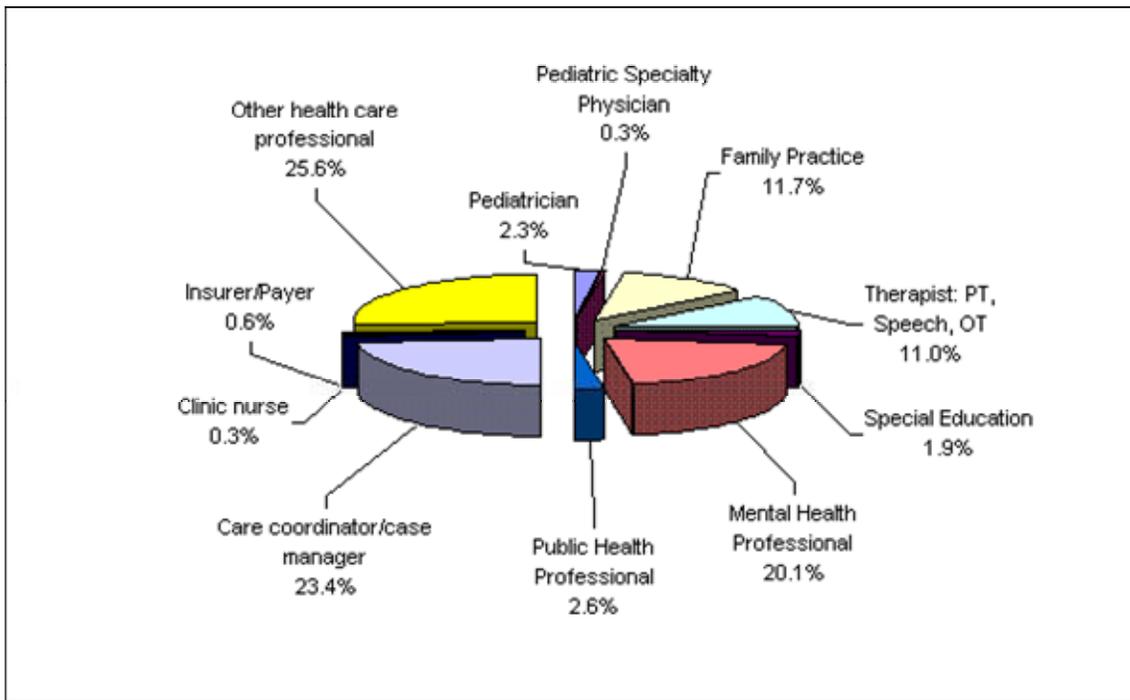
**-Special Care Doctors come to Williston so parents are not traveling these many miles – this is very hard on the children and families**

**-A person I could talk to about my child's ACC (Agenisis of the Corpus Colussium) and help me get the most care, chemically nutritionally, physically and emotionally that he will need starting now and ongoing.**

## PEDIATRIC PROVIDER RESEARCH RESULTS – MAIL SURVEY

1. Please indicate the category which best describes your professional classification.

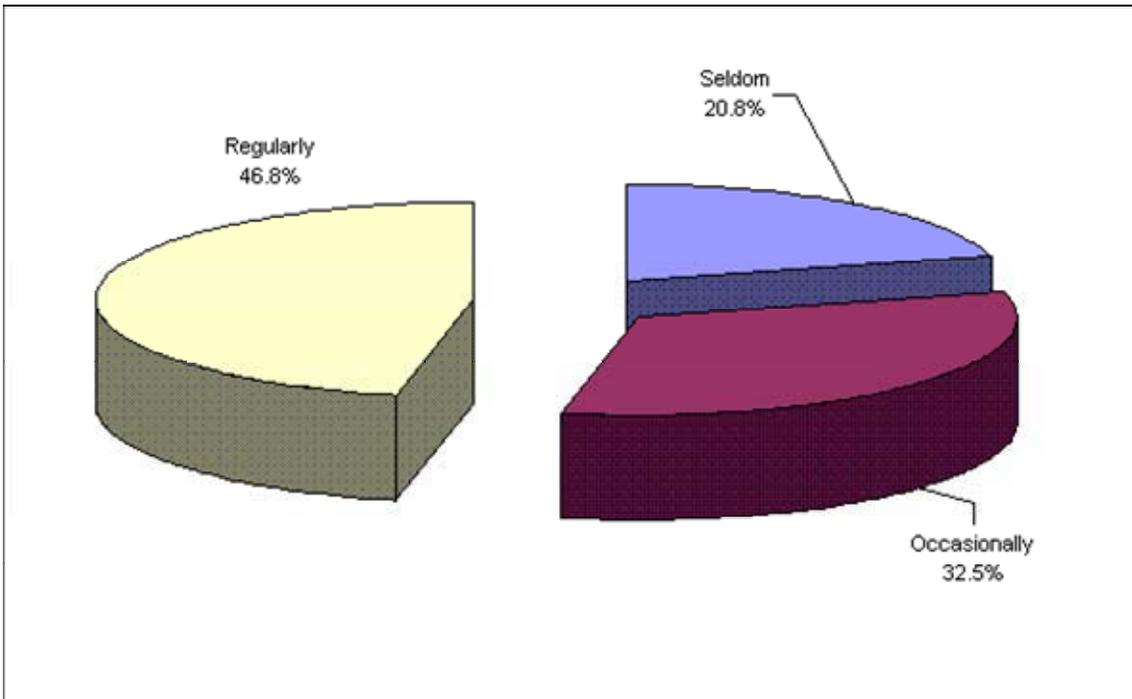
	N	%
Pediatrician	7	2.3%
Pediatric Specialty Physician	1	0.3%
Family Practice	36	11.7%
Therapist: PT, Speech, OT	34	11.0%
Special Education	6	1.9%
Mental Health Professional	62	20.1%
Public Health Professional	8	2.6%
Care coordinator/case manager	72	23.4%
Clinic nurse	1	0.3%
Insurer/Payer	2	0.6%
Other health care professional	79	25.6%
Total responses	308	100.0%



2. In what North Dakota city/town is your office located?	N	%
Belcourt	3	1.0%
Bismarck	56	18.2%
Bottineau	3	1.0%
Bowman	1	0.3%
Breckenridge	1	0.3%
Cando	1	0.3%
Carrington	1	0.3%
Cavalier	2	0.6%
Cooperstown	1	0.3%
Devil's Lake	8	2.6%
Dickinson	16	5.2%
Dunseith	1	0.3%
Ellendale	1	0.3%
Fargo	60	19.5%
Forman	1	0.3%
Grafton	7	2.3%
Grand Forks	32	10.4%
Harvey	1	0.3%
Hazen	3	1.0%
Hettinger	2	0.6%
Hillsboro	1	0.3%
Jamestown	17	5.5%
Lakota	2	0.6%
Lamoure	1	0.3%
Larimore	1	0.3%
Linton	1	0.3%
Lisbon	1	0.3%
Mandan	4	1.3%
Mayville	1	0.3%
Mayville	1	0.3%
Minot	26	8.4%
Napoleon	1	0.3%
New England	4	1.3%
New Rockford	2	0.6%
New Town	3	1.0%
Northwood	1	0.3%
Oakes	1	0.3%
Park River	1	0.3%
Rolette	2	0.6%
Rolla	3	1.0%
Sentinel Butte	2	0.6%
Valley City	4	1.3%
Wahpeton	6	1.9%
Washburn	2	0.6%
Watford City	2	0.6%
West Fargo	1	0.3%
Williston	10	3.2%
Not stated	6	1.9%
Total responses	308	100.0%

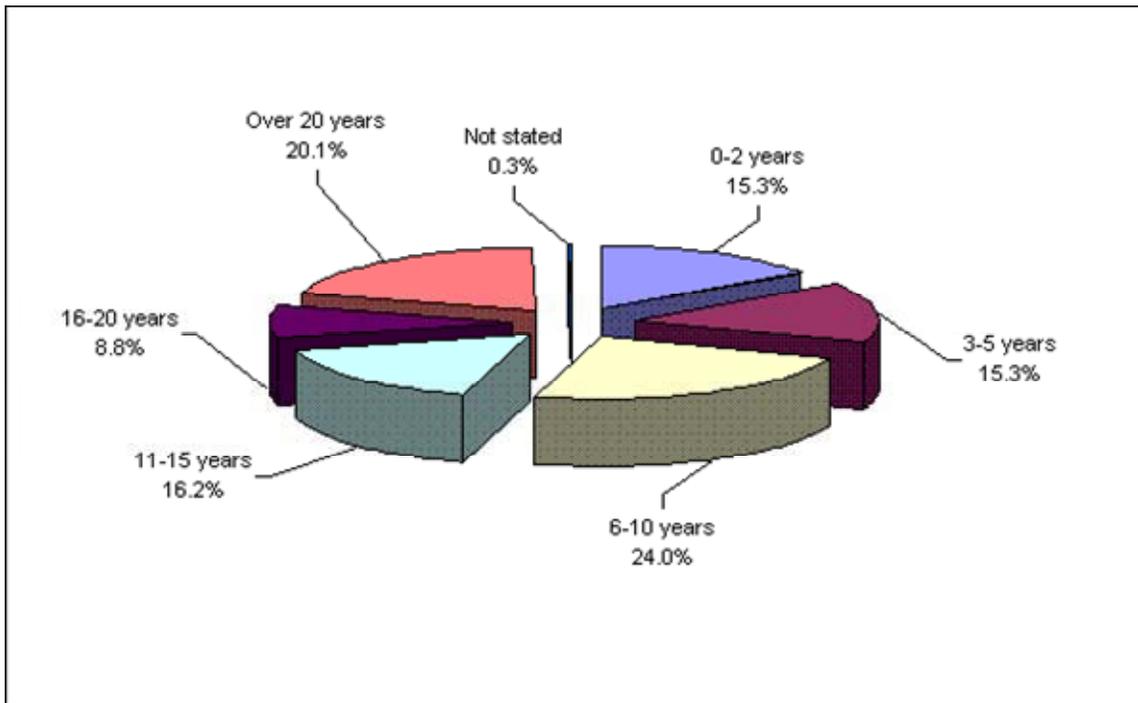
3. To what degree does your job require you to work with children with special health care needs and their families?

	N	%
Seldom	64	20.8%
Occasionally	100	32.5%
Regularly	144	46.8%
Total responses	308	100.0%



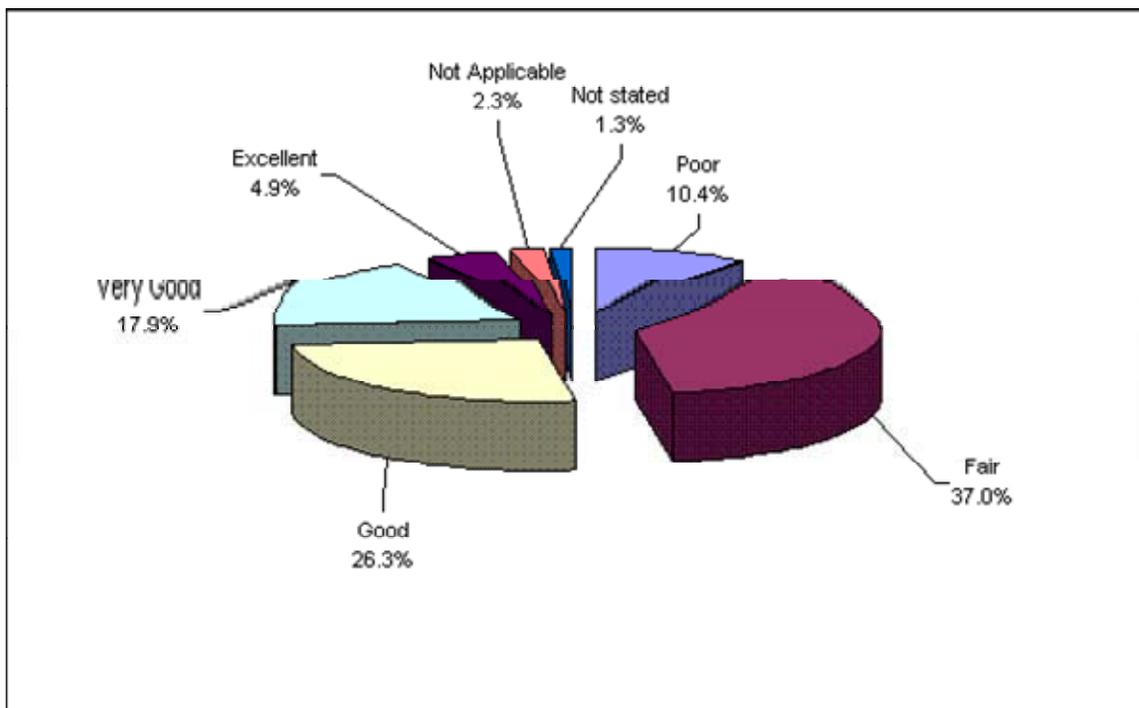
4. For how many years have you provided professional services in North Dakota to children with special health care needs and their families?

	N	%
0-2 years	47	15.3%
3-5 years	47	15.3%
6-10 years	74	24.0%
11-15 years	50	16.2%
16-20 years	27	8.8%
Over 20 years	62	20.1%
Not stated	1	0.3%
Total responses	308	100.0%



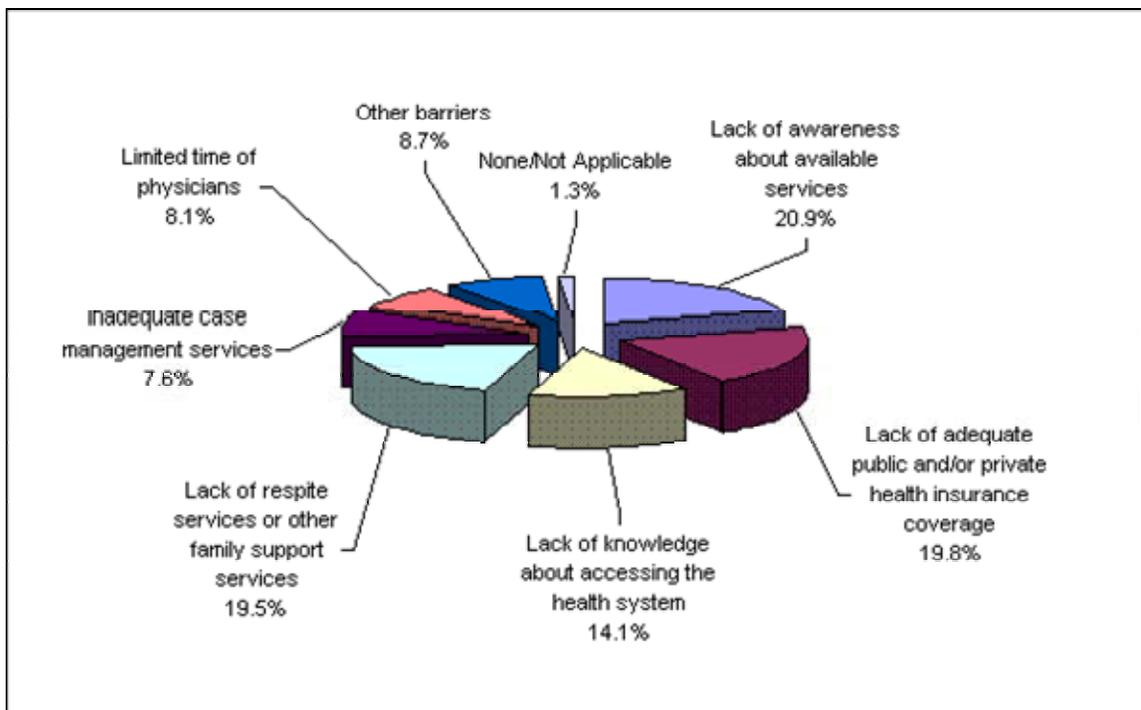
5. How would you rate the overall availability of resources in your community to meet the needs of children with chronic physical, developmental, behavioral, or emotional conditions and their families (as defined above).

	N	%
Poor	32	10.4%
Fair	114	37.0%
Good	81	26.3%
Very Good	55	17.9%
Excellent	15	4.9%
Not Applicable	7	2.3%
Not stated	4	1.3%
Total responses	308	100.0%



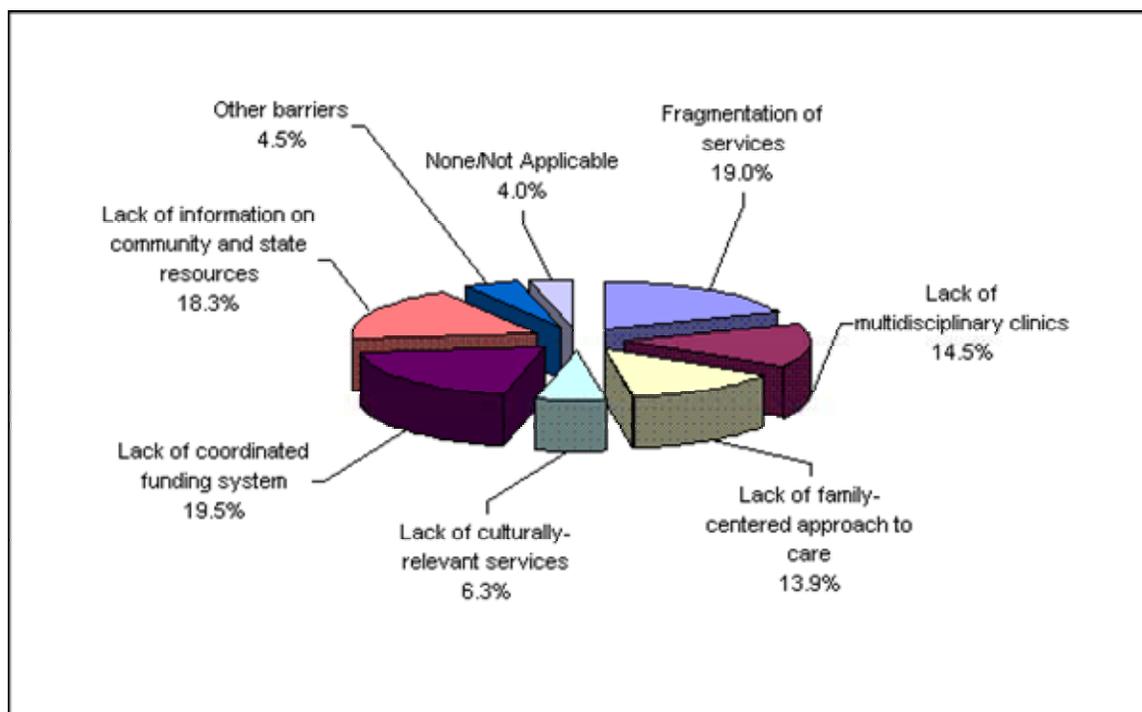
6. What, if any, barriers do you see to providing services in your community for children with special health care needs and their families?

	N	%
Lack of awareness about available services	192	20.9%
Lack of adequate public and/or private health insurance coverage	182	19.8%
Lack of knowledge about accessing the health system	130	14.1%
Lack of respite services or other family support services	179	19.5%
Inadequate case management services	70	7.6%
Limited time of physicians	74	8.1%
Other barriers	80	8.7%
None/Not Applicable	12	1.3%
Total responses	919	100.0%



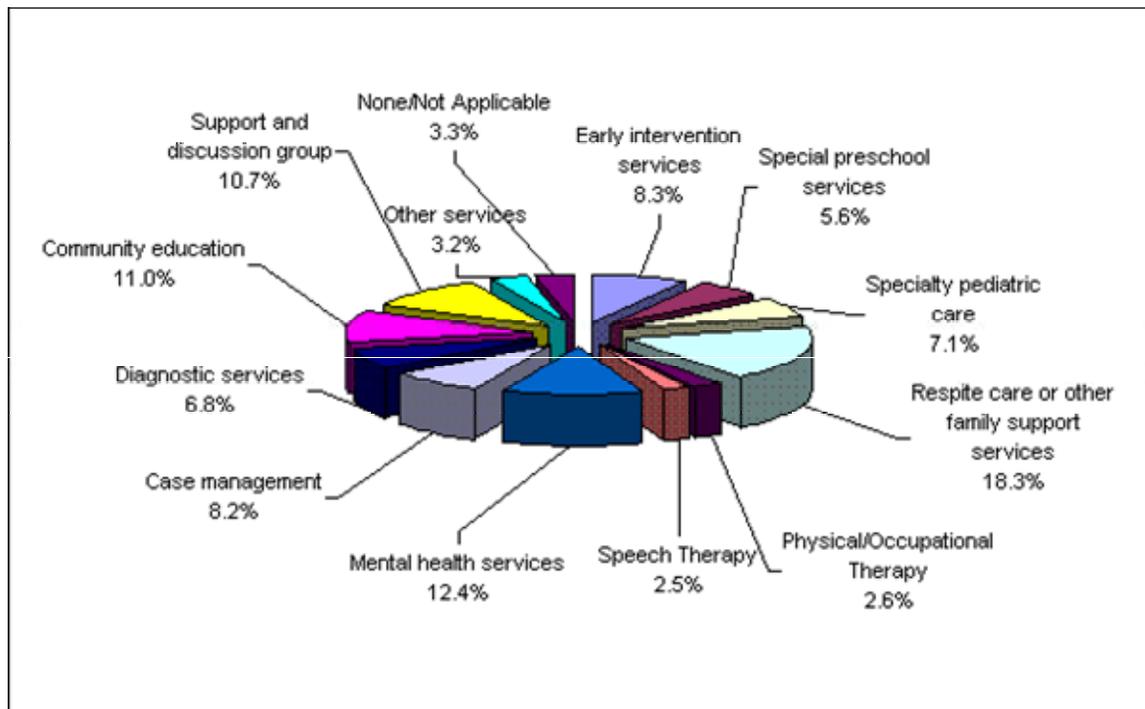
7. What, if any, barriers do you see in the delivery system relative to providing quality care to children with special health care needs and their families?

	N	%
Fragmentation of services	134	19.0%
Lack of multidisciplinary clinics	102	14.5%
Lack of family-centered approach to care	98	13.9%
Lack of culturally-relevant services	44	6.3%
Lack of coordinated funding system	137	19.5%
Lack of information on community and state resources	129	18.3%
Other barriers	32	4.5%
None/Not Applicable	28	4.0%
Total responses	704	100.0%



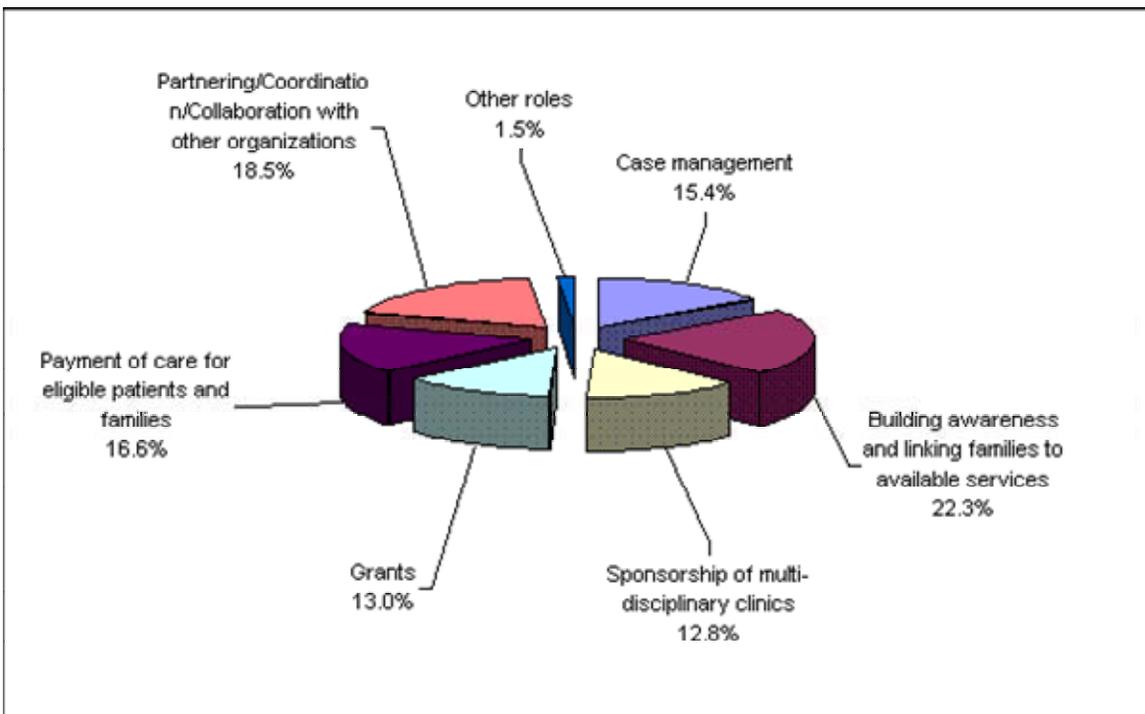
8. What, if any, services are lacking in your community and should be made available in order to provide comprehensive care for children with special health care needs and their families?

	N	%
Early intervention services	70	8.3%
Special preschool services	47	5.6%
Specialty pediatric care	60	7.1%
Respite care or other family support services	154	18.3%
Physical/Occupational Therapy	22	2.6%
Speech Therapy	21	2.5%
Mental health services	104	12.4%
Case management	69	8.2%
Diagnostic services	57	6.8%
Community education	93	11.0%
Support and discussion group	90	10.7%
Other services	27	3.2%
None/Not Applicable	28	3.3%
Total responses	842	100.0%



9. What role(s) do you believe the North Dakota Department of Human Services, Children's Special Health Services Unit, should fulfill in serving the children with chronic health conditions and their families?

	N	%
Case management	162	15.4%
Building awareness and linking families to available services	235	22.3%
Sponsorship of multi-disciplinary clinics	135	12.8%
Grants	137	13.0%
Payment of care for eligible patients and families	175	16.6%
Partnering/Coordination/Collaboration with other organizations	195	18.5%
Other roles	16	1.5%
Total responses	1,055	100.0%



## **PEDIATRIC PROVIDER RESEARCH RESULTS**

### WRITTEN COMMENTS – MAIL SURVEY

#### Question #1:

Please indicate the category which best describes your professional classification.

Other health care professional responses:

- Program Admin.
- Adoption agency
- Long term social worker
- PT
- Social worker
- PT
- Social Worker
- PT
- Addiction counseling
- DME supplier
- Psychiatrist
- PT
- PT assistant
- RN, MSN – Health Coordinator for Head Start
- Social worker
- Audiologist
- PT
- Social worker
- Social work administration
- Medical social worker
- PT
- County social services clinical supervisor
- Juvenile group home manager and case worker
- CPS social worker
- Social worker – intensive in home therapy
- Treatment foster care
- Social worker
- Foster group home
- Social work
- Social worker
- RN – OB/Nursery coordinator
- Psychologist, clinical
- RN
- Administrator/CEO
- Speech pathology
- QMRP/LSW

- Licensed social worker
- Child advocate
- Social worker
- RN
- Speech therapist
- PD case manager
- Social work
- Physical therapist
- Physical therapy
- Long term care social worker
- Medical social worker
- Medical social worker
- Disabilities advocate
- Family social worker
- PT
- Social work
- Grief counselor
- Physical therapy assistant
- Social worker/hospital
- Physical therapist
- Speech/language pathologist
- LSW
- Long term care social work
- Social work
- LSW
- Foster care supervisor, social worker
- LSW
- LSW
- Family services – child protection
- Social worker
- Social services
- Clinic coordinator
- PT
- Social worker

Question #6:

What, if any, barriers do you see to providing services in your community to children with special health care needs and their families. Additional comments:

- State general fund allocation
- Lack of child psychiatrists
- Transportation
- Lack of parental motivation and assuming responsibility
- Not enough services for children who fall in between “too good for this but not bad enough for that”
- Education of physician
- Distance to services
- We could use more money for respite care services for kids
- Dental services for those on public assistance
- Poor availability of psychiatric services and dental services
- Availability of treating professionals (psychiatrists, psychologists, etc.)
- Transportation
- Travel
- Lack of adequate community based specialty beds at intensive care level
- Specific child psychiatrists
- Transportation – financial help so parents can take time off work to go to appts.
- Specific offender groups (sexual)
- Transportation
- Not enough providers
- Don’t know what a normal, healthy home is anymore. Transportation. Family unit education. Not taking responsibility. Addiction. Enablers, lazy, no morals. Disorganized, chaotic lives.
- Transportation to appointments is problematic. No centralized school clearing house for services
- Limited social workers/services
- Residential placement in the community for children with severe profound needs.
- Limited number of providers
- Lack of rec/leisure. Child care after age 12 and sometimes even younger
- Distance needed to travel for services
- Many children who need services do not qualify. MA doesn’t cover certain services
- Accessible housing for young adults
- Transportation/scheduling and work conflicts with providers
- Lack of service providers
- Transportation
- Lack of adequate funding streams, regulations that develop/sustain services
- Home care nursing when medically needed at home (shortage of nurses and staffing problems)
- Transportation

- Having to drive long distances
- Due to travel for services, the need or help with costs and childcare
- Specialists not available
- Waiting periods to see professionals. Lack of funds and resources
- Funding
- Lack of transportation
- Appropriate and early referrals, lack of parental knowledge and information to follow up, untreated mental health needs of parents
- Transportation to services
- Limited physicians specializing in mental health
- Costs not covered by MA/Insurance
- Cost of services- The clients I serve can not afford services or even Medicaid co-pays
- Rural access
- In-school services very limited
- Lack of brain injury programs for children – for example: long term care facility other than a nursing home
- Diagnosis specific eligibility
- Lack of local resources, although slowly improving
- Families living in very rural areas
- Rural, poverty, lack of transportation
- Number of physicians, lack of behavioral services, lack of family support services, not enough foster care availability, funding cuts or caps, little skills training in Fargo area
- Not enough facilities
- Costs for available services
- Daycare
- Local services are not available as needed
- Barrier between private sector and school district
- Lack of resources for timely accessibility, including screening. Fragmented resources. Payment often an issue.
- Transportation for consultation
- Lack of parental cooperation
- Transportation
- Not enough providers
- Limited local resources
- Transportation
- Limited services available
- Access to services – transportation
- Insurance – both MA and private. Parents are trying to do the best they can for their child and the insurance and its rules deplete them financially, emotionally and tolerance.
- No third party payment.
- Transportation

- Limited services/resources. Transportation/distance becomes an issue.
- Distance to providers
- Insurance company limitations on services necessary/appropriate.
- South valley special ed refuses to consider physical needs/physical therapy. Also restrictions from insurance providers.
- Respite care is available but is often times difficult to find caregivers that are specially trained or willing to get training
- Travel/transportation to get to providers since very few in the community. Lack of services in rural areas.
- Poor insurance coverage for mental health services
- Funding for after school services, daycare for special needs in summer, after school, before school and also for kids with mental health needs

Question #7:

What, if any, barriers do you see in the delivery system relative to providing quality health care to children with special health care needs and their families?

- Other barriers
  - Competition between agencies to minimize financial exposure in service poor/working poor
  - Lack of transportation/childcare
  - Distance/lack of transportation
  - Lack of psychiatric hospital for day treatment
  - No local services to meet needs
  - Unmotivated parents or parents too busy trying to put bread on the table to apply for services.
  - Lack of specialists.
  - Not enough providers, waiting lists
  - Need to get physicians one day to rural sites, need rural grants
  - More psychiatrists specializing in adolescent mental health
  - Budget
  - Limited resources/specialists
  - Inadequate funding at all levels
  - Responsible adults – lacking. Addictions. Parent in jail.
  - Distance
  - Limited providers
  - Parents/providers get a run-around when calling human service centers
  - Waiting list
  - Lack of interagency team meetings
  - Funding
  - Funding lack for adequate service providers
  - So many agencies involved – time to keep everyone informed
  - Inadequate financial resources
  - Jurisdictional, regional
  - Travel for services – an outpatient treatment is not cost effective for family because of travel expenses
  - Lack of trained mental health providers who specialize in children
  - Insurance
  - Daycare and education
  - No local services outside of school available
  - Time restriction. Too often direct time is the focus. Case management time is not considered important.

- Lack of culturally-relevant services
  - Mentoring and translation service availability
  - As relates to Native Americans
  - Native American programming
  - Interpreters, CEV's on cultural issues
  - New American immigrants
  - Lack of cultural competency
  - High refugee population
  - Native American culture not respected
  - Prejudice and lack of awareness regarding native issues is still prominent
  - There are limited interpreter services in state. Also, Native American families don't always ask questions and then people just let that go rather than giving information
  - Native American culture
  - Cultural miscommunications and conflicting values
  - No Native specialists, none in tribal/IHS at Ft. Berthold
  - Language barriers, Native American
  - Not specific to native American population
  - Lots of Native Americans through systems that are unfamiliar with culture, cultural differences. Lots of different populations in Fargo – Moorhead area.
  - Providers do not appear to be sensitive to cultural needs/behaviors of families
  - Low population – don't deal with it on regular basis. Language barriers – foreign language – need interpreters. Some sense of community stereotyping.
  - Lack of relevant knowledge by leaders/legislators, etc.
  - Native American
  - Translators can be difficult to access
  - Education for providers
  - At times, especially for non-Indian minorities
  - Lack of awareness and education for health care providers on how other cultures view illness, death, grief and loss
  - A lot of my patients don't speak English
  
- Lack of coordinated funding system
  - It is a nightmare for parents to get funding

Question #8:

What, if any, services are lacking in your community and should be made available in order to provide comprehensive care for children with special health care needs and their families?

- Early intervention services
  - For kids over 3 who don't qualify for SN preschool
- Mental Health services
  - Need increased number of MH professionals trained to treat children and their families – care needs to be at least adequate
  - Psychiatrists/psychologist
  - Behavior intervention
  - Therapy/family therapy/psychiatric/volunteer drivers/anger groups/sexual abuse groups
  - Access to affordable psychiatric and psychological services
  - Mostly regular resources
  - Pediatric psychiatrist, sexual offender specialist, more group work (anger management, social skills, drug and alcohol)
  - Children's therapy
  - Need to focus more on family
  - Early intervention as lifelong challenges
  - Appropriate counseling for children and parents
  - Very limited access
  - The wait time for appointments/referrals is long!
  - Child/adolescent care (specialists hard to access)
  - Therapists
  - Too long of wait to see
  - Child psychiatry
  - Not enough physicians/appointments out 3-4 months at a time
  - Our small town doesn't have capability for variety of services. I am not aware of what's available. Limited HIS services/lack of psychiatrists, psychologists, funding primarily adults only
  - Psychiatric and therapy for kids
  - Child psychiatry
  - Counseling- have to travel at least 30 miles or more
  - Child psychology
  - In-home parent training
  - Very minimal resources and too specific criteria for youth with SED. Long wait to get services at times – has improved over past 10 years
  - From counseling to psychiatry
  - Overload causes delays
  - Groups, therapy
  - Sexual abuse-individual/group
  - More child psychologists
  - Additional providers

- For those with no insurance
  - Diagnosis/treatment lacking
  - Adequate psychiatric/psychological assessment beds, TRC licensed through corrections adequate sexual responsibility program relapse/support services in communities
  - Long waiting period to be seen by a provider who specializes in pediatric issues
  - In-home services
  - More specialists
  - Family therapy, individual therapy
  - Waiting list for even intake is 6-8 weeks long
  - Long-term psychiatric care group care, RCCF, RTC for younger children
  - Funding is decreasing, resulting in cutbacks.
  - Medication gets expensive even if a person has insurance and a supposedly adequate salary
  - Schools should make more info available to children on death, dying, grief and loss from experts in these fields
  - Psychiatric – behavioral based
- Diagnostic Services
    - Lack of integrated assessment of cases by multiple disciplines
    - Overload causes delays
    - Most specialties
    - Screening processes
    - More autism specialists
    - Not enough child psychiatrists
    - Dental
    - Most sent out
    - Psychiatric services
    - Not always available
    - Across the board, esp. neurology
    - Better physician contact
    - Employability tests
    - Staff availability and time
    - Placement options
    - Testing
    - More expertise – seizure disorder genetics
    - Screening services for MH issues that can be accessed timely
    - Psychiatry and pediatric neurology

- Specialty Pediatric Care
  - Psychiatrist
  - Pediatrician
  - Pediatric orthopedic physicians
  - Ortho, GI
  - Orthopedic issues
  - Closest facility 90 miles away
  - Nursing care
  - Neurologist
  - Ped. Neurologist, ped. Orthopedic surgeon
  - Evaluations
  - Neurology and ortho
  - Pediatric cardiology and pediatric urology
  - Emotional and behavioral and dental
  - None locally – need to go to Bismarck
  - Pediatric neuromuscular support with neurologist
  - Limited pediatric specialists: ped. Neurologists, ped. Orthopedics
  - Lack pediatric care much less specialty pediatric
  - Psychiatric care prior to foster care placement and during
  - Sound, experienced providers
  - Endocrinology, pay care
  - Only one pediatrician in town
  - Endocrinology
  - Additional early Headstart openings, additional specialized caregivers
  
- Support and discussion group
  - For spina bifida
  
- Community Education
  - Parenting instructional courses
  - Need more money to get message out
  - Parenting
  - Let community know of services available
  - Juvenile court, doctors, mental health providers
  - Lack of knowledge regarding how to work with mental health challenges
  - What youth need
  - Where services are located. What kind of services are available.
  - More reminders to parents about things to watch for that may be delays.
  - On topics that are relevant to special needs.
  - Awareness of services available to families
  - Across the board, never see or hear of any

- Other Services
  - More group home settings for kids who are between things
  - Dental for those on public assistance
  - Behavior training that can be implemented by parents for the benefit of the child
  - Services to children with TBI/organic brain impairment
  - Transportation to services in larger communities like Williston, Minot, Bismarck and Fargo
  - Special needs daycares
  - Young adult transitional living
  - Dentists. Education in schools. Poor diets by choice – live on junk food by choice – pop in schools. Society’s problem – TV teaching poor morals, movies not family oriented, advertising glamorize alcohol, prescriptions and nudity.
  - Services are available, but at very low levels. Transportation is a big issue.
  - Child care and rec/leisure – very big problem as child grows older
  - Transportation, funding
  - Day programs/care for when children are out of school – shortage of sites that will take special needs children/adolescents
  - Fitness classes or 1 on 1 fitness at fitness centers such as the YMCA for children with special needs who no longer need or qualify for therapy services or as an additional service. This is a definite area of need in Bismarck.
  - Facility to provide care to brain injured children (long term with therapy services)
  - Insurance coverage/public assistance programs to make specialists affordable for all
  - More VR workers
  - Assessment center in each region to determine appropriateness of placement for foster care for children with more needs
  - Day care for working parents
  - Prime time daycare for summer and school age
  - There is a shortage of qualified professionals – only two major resources: school and HIS
  - Residential placements that have openings for severe behavior disordered children
  - Funding, increase in services
  - Coordination of services and resources
  - Funding is seriously lacking

Question #9:

What role(s) do you believe the North Dakota Department of Human Services, Children's Special Health Services Unit, should fulfill in serving the needs of children with chronic health conditions and their families?

- Should provide leadership in developing, implementing and managing a long-term plan – 10-20 years for improvement in services to children and their families
- Provision of medical coverage to assist with cost associated with the condition
- Partnership/wrap around program
- Funding additional staff
- Establish special needs daycares
- Prevention. Need programs before child bearing years so can take better care of children and be responsible, otherwise don't have kids!
- Too much abuse of system
- Funding/various programs
- Used to do better job of promoting the whole family's involvement but that requires money, time and staff.
- Provide training for mental health professionals on assessment and treatment of children
- Lack of cooperation with D.D. in grants for children who are not qualified for medical assist. Parents are just over the guidelines.
- To challenge the restrictions of categorial services
- Education
- Advocating human service centers to provide outreach services

Question #10:

If you could make only one change relative to improving care in your community for children with special health needs and their families, what would it be?

- More money available for respite care to provide support services to all families that are requesting respite.
- Need in-home/respite services. Anything that gives the family added support and a break from the situation.
- A pot of money to pay for travel to counseling/medical appointments.
- Less emphasis on private third party payers, however this would require a significant increase in reimbursement from the Medicaid program
- The ability to share information across professionals from different clinics/sites. Also provide parenting classes for those parents who need it.
- More affordable and accessible without long waits to get a child to see a psychologist or psychiatrist
- Making those services more accessible and affordable to those who need them.
- I would have a parent/child advocate go with to the first several appointments to assist the parents in understanding what is going to need to be done and that the advocate will be with them until everything is in order and how the parent can tend to the problem without being overwhelmed.
- People to go into the home to help with care on a long term bases, parenting classes, respite care and specialized day care for older children who can't be left alone.
- Less hassle for children to receive long term care. Insurance companies see therapy services on medical model which requires monthly preauthorization.
- More regular therapies.
- To have one application process for all agencies and to keep caregivers informed of process. Also educate professionals on process.
- Increase funding in all areas.
- Provide home based care and pay for it.
- Multidisciplinary, coordinated care. Family physician/pediatrician, speech, OT, PT, mental health, case management, family therapy.
- Expand knowledge base for professionals in community about the resources that are available for faster referrals.
- Someone who can be available to parents as needed to help them navigate the whole system – medical, financial and on going. Much of what happens is out of the experience, training and time a DD case manager has available to provide.
- More adequate services to children with neuropsychological problems – diagnosis, case management, funding for treatment, rehabilitation.
- I would like to see more focus on early intervention/prevention in the area of mental health. It seems that our current programs are designed to respond after a problem is identified, rather than moving rapidly into high risk families.
- More awareness among parents of signs of delays and acceptance that if delays are noted, therapy is necessary.
- Improved mental health services.

- Funding opportunities – existing local staff in all areas are getting stretched to the limit.
- Just make a simpler system of getting these services rather than every agency having their own set of rules/paperwork/procedures.
- Having a behavioral child psychologist and psychiatrist employed in Williston.
- Easier access to diagnostic services and also more intense/faster diagnosing. Some families struggle for months trying to access an appropriate diagnosis.
- Long term support for parents who are DD
- I would increase funding so more services are available to more families.
- Better accessibility for families needing the services.
- Acting all professionals on the same page.
- More awareness of programs to families that may need the service and promotion of programs to the public – educate
- Have a respite or family support program for families.
- Building awareness. More physicians.
- One barrier I often see is families who need respite hours or support but are unable to get support due to income and not being eligible for MA which restricts services .
- Improve health care for natives on the reservation.
- Educating rural communities as to the importance in finding individuals locally to assist families in their area so that children can remain in their homes, communities and schools. Educating families to advocate for themselves to get the services they need at home, school, etc.
- To have comprehensive services closer not only for children
- Sponsorship of multi-disciplinary clinics
- We have a mental health psychiatrist who comes to our school .some of our children do not qualify for medical assistance. (HIS) will not acknowledge outside prescriptions for these children.
- Funding for support groups
- It's hard for parents to get off work and drag siblings along for appointment one hour drive away. Have child psychiatrists available in town 1-2 times per month.
- Additional group homes. Emergency holding facility (short term holding while awaiting placement)
- Increase funding
- Have more money for DD services. More educational programs. Parents are unaware of what is available to them.
- Coordinated efforts/services
- Alternative funding sufficient to provide level of care needed for the child
- My specialty is mental health and I can only repeat my appeal for training because treatment by competent providers is so critical when working with children, especially very young children
- Easier access to information on where and how to get necessary services.
- Case management follow up; advocate services
- Find dollars to pay for the services provided to children's special needs
- Better access to funds

- More specialists. Dental care is one issue (big time)
- Respite care programs
- More public awareness of programs, support groups, resources, etc.
- I really think multi-disciplinary clinics are a need in this state. Awareness is also a major issue.
- Work with/collaborate with agencies regarding special needs of children and teens when a loved one is ill, dying or has died
- North Dakota is a rural state and families have access to services around the state, but due to limited funding and the distance to get to services and finding services right within your area is limited in the more rural parts of the state.
- Prioritize the populations to be served and the levels of care and then match the priorities to the resources available.
- Increase awareness of available funding for adaptive devices/equipment
- Increased number of physicians, therapists, dentists, psychiatrists that specialize in dealing with children and adolescents and take MA.
- Add child psychiatry
- More group homes for mentally handicapped
- More availability of mental health professionals specializing in adolescents (psychologists/psychiatrists) to low income families. Also, focusing more on inclusion of all family members in treatment when their child is in counseling for behavioral issues (ex: how to parent an ODD/ADHD child)
- Referring them to sources where they would be taken care of adequately
- Speakers to provide information about teenage parenting, services available in the community and how to get youth involved in the community.
- Make health insurance available and affordable to families of children with special health care needs
- Provide support and education to parents
- More services or options for families to go to in times of need, right now there is a need for more child psychiatrists in the Fargo-Moorhead area and also in the outreach areas.
- Some of our physicians are starting to refer to the infant development program. It would be great if we saw more referrals from that area
- Cut through the red tape, make accessing help more pleasant – paperwork is overwhelming and intimidating (as is the dark lobby and glass cage at Minot Human Service office)
- Help for the family with transporting
- Increased psychiatric and therapy services
- Developing additional supports and assistance for families with emotionally disturbed and behaviorally challenging children. Respite and in home supports are not adequately meeting the needs of these parents.
- Education of services available is so important. Also, income at times limits what is available (especially an average income). Sometimes it eliminates a service because of eligibility guidelines. Shouldn't all children be allowed to participate regardless of family resources?
- Help children/families alleviate poverty

- Preventative services
- Better funding (public and private) to all levels
- Comprehensive diagnostic clinics
- Combination of service availability and education
- Seamless case management that is intensive and can go for several years if need be with overlap into other systems the family/child move within – such as with school
- Better assessments and more placement options for this population
- For youth with serious emotional disorders and their families, I would like to see readily available and accessible respite care, mentors and natural supports in the community
- More coordination between existing clinics/facilities
- Addition of staff
- Community education to build awareness and linking the families and patients to services
- It would be nice to see respite care hours increased for families who need more hours. 13 hours is not always sufficient for families
- Access locally to psychiatric or developmental evaluation in a timely fashion
- Transportation
- Services would be more family friendly. Families would have a bigger voice in developing the plan of care.
- More resources
- Better funding in health care. Free or income based services have too long wait to get in.
- Availability of special needs daycare sites with trained staff
- Improve funding for equipment, supplies, caregivers for children and families
- Drug/alcohol free programs/parties. Wholesome activities for children/families. Back to “family units” – picnics, etc.
- More respite care service available to the families. More public awareness about services available to the families.
- Local pediatrician contact via satellite clinics
- Create a centralized office with information on all services (at the school too)
- Having specialists more available in the area (Williston)
- Since many families are living in rural areas accessibility to major health care facilities is difficult (travel, lodging and childcare costs); funding to assist them is needed.
- Transportation!
- Providing ongoing support for families (i.e. respite, financial, emotional)
- Increased case management such that services more centralized/coordinated with providers more in contact with each other – families get more consistent information/treatment and don't need to search out assistance/care needed.
- Secure adequate funding to offer some of the above services.
- Additional providers for less wait time to see provider
- Rec/Leisure activities for older children especially during the summer
- Help with transportation costs

- I would make it easier for parents to navigate the system. These are parents with enormous stress – they don't have the time or energy to figure out how to get funding – nor do I!
- Accessible housing for families
- Financial resources for parents
- I think there are some wonderful services in our community. The biggest problem is knowing all of them as a professional.
- Follow up and supportive services
- Funding to upgrade technological needs for programs serving children with special health care needs.
- Support groups for families
- Having the appropriate specialists locally so that families wouldn't have to travel long distances for care, surgery, etc. and there would be better communication between the physicians and those that actually know and treat the child.
- Early intervention allowing for multi/interdisciplinary services vs. transdisciplinary or encouraging families to access the missing services and better communication between EI and medical therapy services.
- Provide financial assistance and case manage children with special health care
- More mentoring
- More awareness of the services that are available out there – specialized possibly
- Leadership collaboration and education to increase advocacy at the legislative and state dept. level, adequate development/coordination of volunteer, charitable, other community projects – services, understanding of services, needs and reduce adversarial relationships (at service level?)
- More respite care for families
- Less hassle in insurance companies – esp. BCBS
- More in-home services, so services are more accessible
- Respite services readily available to parents/caregivers, especially to allow them opportunity to attend education opportunities
- We have absolutely no service for children who are DD w/mental health issues. We need more parenting programs for DD parents to deal with their children.
- Respite for special needs children and siblings. Help with costs to seek available services when not in area.
- To have a physician practicing in this area (Sentinel Butte)
- Have the funds available to provide the services we know we need
- Building awareness and linking families to available services
- More facilities; group homes for 15-25 year olds that are not severe. North Dakota offers only 6 beds for the entire state! Openings are rare. We are have to look out of state – away from family!
- Multidisciplinary clinics staffed with specialists
- One-stop shopping
- Affordable transportation
- Adequate respite care and support services
- More funding for psychiatrists
- Increasing awareness of programs

- Improve health care – a better variety of physicians to choose from
- Facilitate ease of communication (family, provider, and payor)
- County involvement for follow-up services when 960's are filed
- Better collaboration of services for clients/families with diagnosed mental illnesses and easier access to services
- Additional services for psychiatric hospitalizations and residential treatment centers for grade school aged children. Some children are moved multiple times because foster homes cannot provide care for the multiple psychiatric issues children have the multiple psychiatric issues children have in foster care.
- Larger group providing wrap around services for wider ranges of special needs, including physical.
- Exercise programs, sports, etc. that don't cost an arm and a leg and are for learning instead of competition.
- Making it affordable for families to utilize these services
- Provide support and educational training to family caregivers who provide the primary care
- Develop a system of supervision whereby masters level mental health professionals can provide services to children and youth – if they are appropriately supervised by a licensed psychologist – and that medical assistance allow payment for those services.
- The greatest barrier is the time it takes to talk to all the payers. Coordinating communication would be a great help.
- Bring more services to Park River
- Decrease/eliminate violence and explicit sexual matters from easily accessible media, ie. TV, video games, computers, internet
- Increase rural awareness and programs/money available to these communities
- Somehow, to let families be aware of this program. Majority of them are not aware of this program until someone mentions it to them.
- Difficult questions for me as I don't work with children very often. The patients I see who are under 18 are usually involved in some type of accident. It is a challenge to find appropriate facilities/care for those teenagers who have sustained a brain injury. A lot of these patients end up going to Minneapolis for further care and brain injury programs. It would be nice if Fargo could have such a facility that would specialize in long term care for teenagers and young adults.
- That individuals know about the services
- The cost of service being decreased so it would be affordable to our low-income clientele
- More flexibility in accepting children based more on need than just diagnosis for either children's special health services and or DD case management
- Additional respite care funding
- More availability of all levels of care for children and their families, up and including necessary out of home care.
- Increase awareness of services/availability
- Better case management

- Working in a residential treatment center, the biggest challenge is after care planning. We have children that need homes to go to, but there's a lack of funding and availability. Foster care/PATH homes are crucial for some children's care, however they're utilized greatly in this community. It would be ideal for facilities/agencies to partner to assist with after care. Without homes available or other facilities, the courts, counties, DHS are left to make decisions of placement which can mean further placement in a state facility or out of state...meaning more money spent for longer term higher structured care that may not be necessary. Managed care also makes planning difficult at times a year of placement is not always enough. This is of course dependent on each case. We have seen some that did not continue in care based on the "1 year: and have seen them to go back into facilities, out of state, in state, higher structure – which can cost the state more money in the long run.
- Have more multi-specialty clinics in Grand Forks so patients don't have to travel
- Better insurance coverage so children with special needs can take full advantage of the variety of services available out there.
- Daycare opportunities for kids with special needs in their own home
- Consider out reach clinics in Grafton area.
- Preventative programming. Respite care services.
- To have a multi-disciplinary clinic available on ongoing bases, but to also include ones for children and families to receive basic assessment and hooking up for services in the community. Right now wait time to get info evaluations is long (several weeks to months) which is also reflective of a service availability in the community.
- Accessibility – ease to get them in to see specialists
- Therapist be given "okay" for case management time. Many of these children and families require time outside the therapy hour.
- Educate schools, families and individuals on mental health issues and services
- Area schools, drugstores, clinics, hospitals receiving pamphlets about CSHS
- Setting up satellite clinics so less travel is required for families.
- Case management.
- More awareness and understanding of complex behavioral and emotional problems
- Expanded health care coverage for families
- Communication between case management and other agencies involved in care.
- Making sure both families and providers are aware of available services.
- More in-home assistance.
- Building awareness of available services.
- Education and available access to services.
- Increase funding for services with case management
- More child specific providers (mental health) especially more services for childhood sex offenders.
- Having a pediatric specialist.
- Community awareness
- Public information and education

- More respite care services
- Streamlined easy to access services – especially specialist in MD field and mental health field.
- More availability of pediatric specialists within ND, less travel for parents to MN for specialty care.
- Availability of services – less wait
- Continue to inform case managers about resources and programs available. Continue to inform families of available services – especially those underserved or under/non-insured families
- Increase awareness of how to access PT services then they have concerns
- Require schools to adequately consider physical needs of students. Require insurance to adequately cover pediatric therapy.
- Provide more pediatric physician specialists, especially pediatric orthopedist
- Provide coverage for health care/testing/services that insurances refuse to or poorly cover
- Services/specialists should be closer
- Psychiatric hospital for emergencies that would also provide day treatment such as schooling and group work with children who are not stable enough to attend public school. I believe the ND state hospital could fulfill this need.
- Make it a priority to inform families with special needs children of what services are available including respite care.
- Continuity of support across service settings for people in crisis. Need more transition support to and from hospitals and/or specialized residential services.
- Be able to make one phone call to get child enrolled in special health needs assistance. Also, more multidisciplinary appointments.
- Educate the public and professionals about needs of these families how to access services and what service are available.
- Revitalize children care coordinating bodies and allow them to be run by non-public entities
- Increases grant money for services. More respite services for families. Better health insurance coverage. Affordable health insurance.

Question #11:

Do you have any additional recommendations relative to improving services in your community for children with special health care needs and their families?

- As a community, region and state, we need to increase and unify leadership and decrease as much as possible the politics of the delivery system. There are too many systems, political and resource distractions that significantly decrease the level of service we can provide. In the DHS system there is tremendous waste in the documentation requirements, both in the electronic and written formats. As with population and level of care, documentation needs prioritization to significantly decrease the time required to bill and describe what has been provided. This will result in an increase in time to serve clients and their families.
- Have money designated for school nurses.
- Encouraging more cultural sensitivity and training for staff working with minorities such as immigrants and Native Americans, as well as recognizing the barriers these populations face.
- Sexual abuse group for children
- More awareness of CSHS needed.
- SEHSC needs to do a much better job of meeting chemical dependency needs for adolescents – they only offer individual therapy – all research supports a group therapy structure.
- Improved awareness of available services/programs in the community and the state
- 1. Physician knowledge of MC ped therapies 2. Provide pamphlets at easily accessible places i.e. malls, movie theater, doctors offices, etc. 3. Increase parent awareness/knowledge to ask/inquire regarding specific fine motor and speech services appropriate for child's age.
- Transportation to services in Grand Forks can be hard at times
- Coordination of services by involved agencies.
- Case management with sufficient diligence and authority to follow through and see that companies and agencies are covering needs of students/policy holders.
- Adequate payment for services.
- Parents do not have an understanding of CSHS and if they would qualify for services and what services are available. Physicians do not assist parents in making application for CSHS.
- Transportation/distance is a real issue. Dental access is spotty at times.
- Services need to be timely and accessible. Families rarely know that a situation is brewing and can wait six weeks for assistance. The situation is generally a crisis and it is nearly impossible to access services for weeks if not longer.

- Your statement that completing the survey will require approximately three minutes of your time may be true, but to take a serious look at the issues involved and to review the multitude of barriers/gaps takes a significant time investment. Additionally, there have been multiple surveys, town meetings, needs assessments done in the past six years (mostly mental health and substance abuse) that have identified the same needs/gaps and have offered similar recommendations. For public sector services, the main barrier continues to be the allocation of state resources, general fund and the state match for federal programs. In my opinion, there are multiple solutions, however each requires making tough but well informed decisions and strong consistent leadership.
- Flexible funding to help with transportation costs and other costs that Medicaid will not pick up. Additional funding for things that insurance will not provide for.
- More and better foster care
- I have a younger brother who is mentally challenged but because he is not bad enough he doesn't qualify for things yet he is not good enough for other things. We need a better system equipped to handle these kids. His age will be 18 but his mind is anywhere from an 8-10 year old. Thank you.
- Funding. Insurance authorization for pediatric home health services.
- Family approach in case management to be handled by special unit within the state level that have specialized training and direct link to medical care – multidisciplinary approach that wraps around the families' needs
- Directory of all pediatric therapy providers in North Dakota or a district number to call to get a referral (name of provider in certain area)
- Not to take over the parent's role – do more educating and teaching to them on how to handle their unique child. Dependence on the system is somewhat of a concern. I work with behavioral problem in children. Parents consistently tell me they are receiving no education in ways to parent their children when they have an ODD, ADHD diagnosis such as behavior mod plans or parenting techniques.
- Increase recreational sports for children with disabilities on an organized bases.
- Overall, I think CSHS does a super job with funding that's available. There is overlap with other programs and this might be a helpful way to rework involvement. The grants are key to keeping clients and professionals connected.
- Payments for health care for families who are just below the guidelines.
- I work a small community clinic in New Town and there is also a HIS clinic. We do run the WIC program for native children but I do not see a large number of children who need special services. I would find data on the number of children and what their needs are of great value. Demographic, epidemiology information on children of special needs in my area.
- Utilizing some type of multidisciplinary paperwork packet so families aren't constantly filling out similar paperwork for agencies who are likely working together.
- Need for more activities/adapted recreational programs for special needs.
- We do OK in Williston but in some of our more rural areas finding respite care providers is tough. It would be nice to have additional funding for respite care as we do have some money but our budgets have been cut

- Increase services for diagnosis and evaluation and follow-up care due to lengthy waiting periods. Many times, it takes months to see a treating professional. Unfortunately, many children ultimately end up needing a higher level of care.
- Respite care is so important – caregivers that are required to be on 24-7 need time to rejuvenate their own spirits. Also income is often lost as children are taken to appointments or if there is a crisis. Would a grant help in this area?
- Partnership between tribal/state government to address special needs of children. Children’s needs on reservations are multiplied due to poverty and access issues
- Services should be provided to the individuals who need them rather than who can pay
- Expand funding possibilities for those non-covered medical and other expenses
- Increased funding
- Support and discussion groups
- Often resources are lacking to assist local people from accessing specialty services in Fargo – the usual poverty, single and or unsupported families
- More mid-range (1-6 months) residential care sites for children 13 and younger
- I’m not sure why I was chosen for this survey. I am out of the loop. (social worker)
- There are lots of wonderful services! There is lack of morals – responsible adults not doing their job – they let someone else raise their kids and etc. Human life is not as valued. Bad attitudes. People don’t enjoy what they have! Always want more – ads, put you down if you don’t have everything. Lots of children suffer because of drugs, alcohol during pregnancy and lack of adequate, loving care as babies and toddlers. Services then help, but are too late sometimes for a healthy, normal child/adult.
- Why can’t the elder bus system also be used for disabled kids?
- More in-home support options
- The electronic communications reg. by HIPAA has resulted in many of my colleagues refusing Medicaid/Medicare cases. I work for the state and as such am relatively unaffected.
- Stop assessing normal kids through right tracks program! This should be done at well-baby physician visits! It is a nice idea, but when kids are going without services because of lack of funding we should not be duplicating developmental screenings for normal children. The “hit” rate on this (funding disabled children who have not already been identified by a physician) has to be exceedingly low. Maybe only screen at-risk babies?
- Providers need flexible schedules so that families can be seen other than 8-5 p.m. Medical/dental health care should be available to all children. Funding needs to be expanded.
- Need more dollars for all areas. Severe gap for children age 10-21 regarding speech and rehab services. Also respite and day services for working parents.

- Educate physicians and OB/GYN about the developmental problems “high-risk babies” may endure the rest of their life. Prevention is #1. We want to be proactive vs. reactive in our care. Early intervention is critical in the development of high-risk newborns. Academics start before the birth of a child, not when a child enters school. Prenatal care for “mothers to be” to prevent developmental problems.
- Grants for braces for those families that don’t qualify for CSHS
- Frequently, children no longer require the services or even if they do (insurance is frequently denying the need); but these children don’t have fitness classes/centers that are available to them or who will modify their classes so they can participate. Where do these children go to maintain or increase their fitness?
- Have one entry point to refer parents/families too. Also, be more out in the community.
- Many parents have problems finding day care providers for when they return to work. Also difficult to find adequate day care providers for older children who are developmentally delayed.
- Family support group. Respite care
- We need to quit saying to legislators that we don’t have any unmet needs – so we can have more money budgeted to make services available to all children and families with needs
- We need to find ways to get parents/families of emotionally ill/troubled kids involved more in improving their own mental health
- More funding for intensive in-home therapy
- Support agencies for children of parents with mental illness. Workshops for families to understand issues of family members with illness
- We have the child-adolescent partial hospitalization program but then the children have no place to stay in the evenings. In order for children to remain in our community and even North Dakota, at this young age, we need more services. In foster care, when children are removed from the parental home, the parents lose Medicaid, which makes it difficult to access the services needed for reunification. Parents can make appointments at a HSC but there is a waiting list, so children drift in foster care until services can be accessed. The foster care placement ends up being longer and the children develop more issues which need more services – what a cycle! Never ending for many families. Resources are very limited in the foster care system.
- Make medications less burdensome on all not just the so-called low income/welfare people.
- More community awareness – sending information to agencies so they can share it with their clients
- Medicaid to develop rules and guidelines for: 1.) supervision of master’s level psychologist and clinical social workers to be supervised by doctoral level licensed psychologists 2.) Develop payment schedules appropriate for masters level professionals when they are supervised by a licensed psychologist
- More information and education in the schools and for the families on mental health needs

- Adequate and financially accessible day care and health care
- Increase funding for preventative services
- Open forums – flyers and increase in referrals from area physicians to services outside the medical field to help families receive respite services. Also grant money for special needs equipment not covered by insurance or medical assistance. Such as respite costs or bath equipment, home modifications or vehicle modifications.
- It would be great to have a stand alone pediatric care clinic to address these special needs.
- Pending the county I am working with, I feel that there needs to be consistent follow through of services provided for children once being discharged from a rehab center
- Children with autism often don't qualify for MI or DD services so have limited supports for families. Also, I work with a large number of children who do not qualify for ME or DD but would benefit from long term group care. There are also children who would benefit from a MI group home long term which are not available. We often struggle with utilization of DD group homes due to waiting lists and over a years waiting list these children often need these services before an opening occurs.
- Dickinson has excellent programs and services in place.
- There are lots of positive resources in our community. I believe that learning what there is and how to utilize them should be more coordinated and centralized. This would be helpful as sometimes one agency can cause barriers for being successful in accessing other services. Also, addressing several life domains of the family could be helpful.
- Better coordination of services – they are way too fragmented and parents are often poorly informed as to their right to access and what other service might assist them.
- I think you do a pretty good job overall.
- Need to educate people of service available. As a therapist even I don't know what's available to pass this info to families and I have live in this state for five years!
- Developmentally delayed children with behavioral issues need better accommodations in school and more community resources so they can stay at home. If we spent what we pay for hospitalization and group home care on the family these children could stay home.
- More community education regarding available services
- I think parents should be expected to be more involved with their children's appointments, recommendations made by the professionals, etc. If they persistently are not home at appointed times or don't do the homework, perhaps the courts need to become involved.
- Educate physicians and other health care providers about available services for such families so proper referrals can be made.

## PEDIATRIC PROVIDER RESEARCH RESULTS – TELEPHONE SURVEY

1. What is your profession/job?

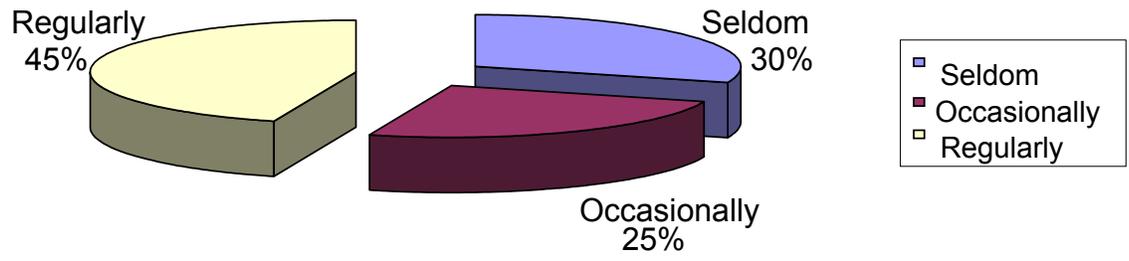
<b>Profession/job</b>	<b><u>Surveys conducted</u></b>
Case Manager	3
Public Health	3
Special Education	2
Speech Therapist	2
Social Worker	2
Community Resource Coordinator	3
Occupational Therapist	2
Physical Therapist	1
Family Practice	2
Psychologist	3
Human Services professional	2
Medical Equipment	2
Psychiatrist	2
Pediatrician	2
Insurance/Payers	2
Clinical Coordinator	2
Directors of inpatient pediatric. Departments	2
Audiologist	<u>3</u>
<b>TOTAL:</b>	<b>40</b>

2. In what North Dakota city/town is your office located?

<b>City</b>
Minot – 4
Fargo – 6
Bismarck – 5
Lisbon
Valley City – 2
Portland
Grafton
Dickinson -3
Devils Lake
Garrison
Cooperstown
Jamestown – 3
Grand Forks – 5
Wishek
Hettinger
Williston – 3
Carrington
<b>Total: 40</b>

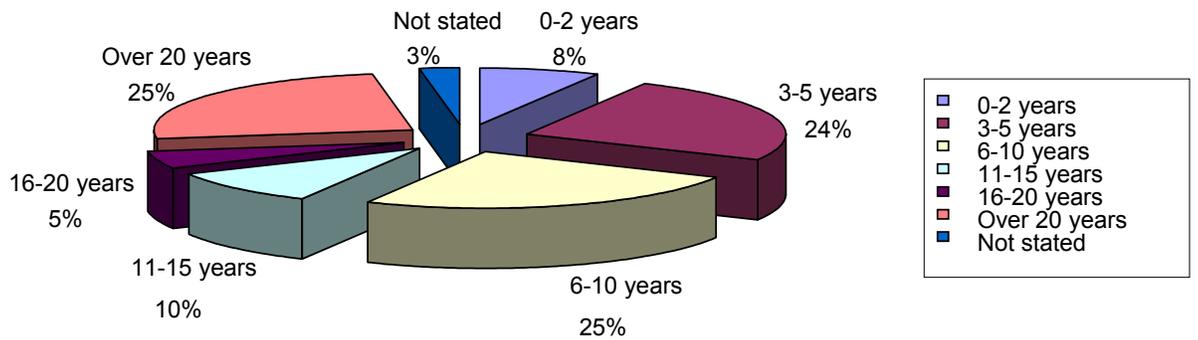
3. To what degree does your job require you to work with children with special health care needs and their families?

	<b>N</b>	<b>%</b>
Seldom	12	30.0%
Occasionally	10	25.0%
Regularly	18	45.0%
<b>TOTAL</b>	<b>40</b>	<b>100%</b>



4. For how many years have you provided professional services in North Dakota to children with special health care needs and their families?

	N	%
0-2 years	3	7.70%
3-5 years	10	25.60%
6-10 years	10	25.60%
11-15 years	4	10.30%
16-20 years	2	5.20%
Over 20 years	10	25.60%
<b>TOTAL</b>	<b>39</b>	<b>100%</b>

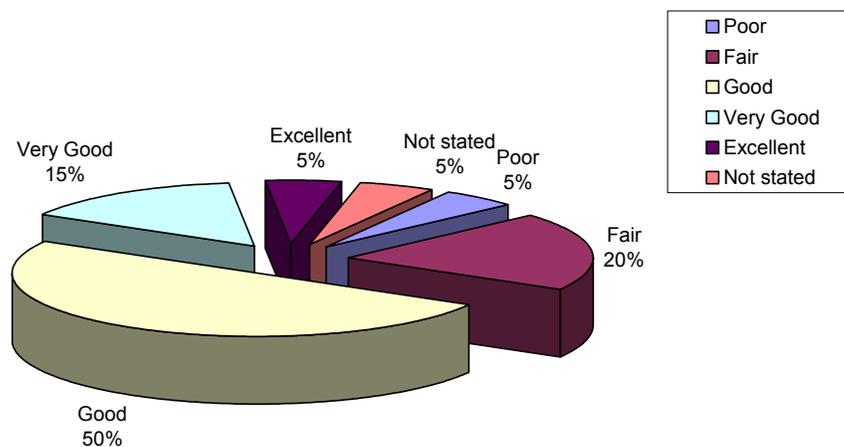


5. Please answer either “yes” or “no” as to whether or not you or your organization typically provides services to children with such conditions.

	<b>Yes</b>	<b>%</b>		<b>No</b>	<b>%</b>	
A chronic illness or health condition	31	86.1%		5	13.9%	<b>100%</b>
A developmental or physical disability	33	91.7%		3	8.3%	<b>100%</b>
An emotional or behavioral condition	27	75.0%		9	25.0%	<b>100%</b>
<b>TOTAL</b>				<b>36</b>		

6. How would you rate the overall availability of resources in your community to meet the needs of children with chronic physical, developmental, behavioral, or emotional conditions and their families (as defined above).

	N	%
Poor	2	5%
Fair	8	20%
Good	20	50%
Very Good	6	15%
Excellent	2	5%
Not stated	2	5%
<b>TOTAL</b>	<b>40</b>	<b>100%</b>



**Comments:**

*-Good-however, some obvious gaps about emotional and behavioral  
-also gaps in those that require skilled nursing around the clock*

*-Good, but would be nice if there was a list of services available to hospital workers  
-would like the OB dept. to know where to send parents for conditions and contact information*

7. Is there anything that you think keeps children with special health care needs and their families in your community from accessing needed services?

- Not that I can think of (2)*
- No comment (2)*
- Resource limits on some things like medicals and severe chronic illnesses*
- Medical insurance limits –sometimes claims are denied (3)*
- Co-pays and recipient liabilities*
- Limitation of population*
- Lack of knowledge and support in getting involved (7)*
- Financial reasons (9)*
  - family falls in the middle income bracket*
  - social economic status*
  - funding help to find qualified providers*
- Stigmatism with developmentally disabled*
- Financial resources for kids with emotional disabilities*
- Lack of coordination between similar providers*
- Support groups for families*
- Lots of hoops to jump through and families are not willing or able to do that*
- Legislative limits to appropriate money – can't get everything they want*
- Children with special health care needs are not always identified*
- More education about what is "Special Needs"*
- Availability of services – providers, parents and communities need to know what community and state resources are available and how to access (14)*
- Bad cases will get help, medium cases fall through the cracks because of access problem*
- Distance – service providers are not in rural areas - must transport out to Fargo, Jamestown, and Bismarck (9)*
- In rural areas, a child may wait up to 2 months to see a counselor because provider in town is too busy and lack of availability when needed-this is too long*
- A rural troubled family has less chance to be seen, when in fact they are in higher need*
- Lack of multidisciplinary clinics*
- Referrals are not always correct; some parents think the school can do it all*
- Parents get frustrated and find out things word-of-mouth*
- Need a stronger referral base at the physician's end*
- Tell parents it is Ok to get another opinion or supplemental health*
- Psychiatric problems with themselves*
- Parents with personality*

8. After each statement, please tell me whether you agree or disagree with the statement.

a. In general, children with special health care needs and their families lack awareness about available health care services.

	<b>N</b>	<b>%</b>
Agree	30	76.9%
Disagree	9	23.1%
<b>TOTAL</b>	<b>39</b>	<b>100%</b>

**Comments:**

*-agree – more of a problem in outreach areas, cities have a better grasp*  
*-agree – but better awareness now*

b. In general, there exists a lack of adequate public or private health insurance coverage for children with special health care needs.

	<b>N</b>	<b>%</b>
Agree	17	45.9%
Disagree	20	54.1%
<b>TOTAL</b>	<b>37</b>	<b>100%</b>

**Comments:**

*-disagree – usually coverage, but hard to get that coverage*  
*-disagree – I have seen a very nice change*  
*-disagree – most are medical assistance, Blue Cross Blue Shield Insurance clients are seen more regularly*  
*-disagree – medical assistance limitations are causing problems for families with high needs*

c. In general, children with special health care needs and their families have a lack of knowledge about how to access the health system.

	<b>N</b>	<b>%</b>
Agree	33	82.5%
Disagree	7	17.5%
<b>TOTAL</b>	<b>40</b>	<b>100%</b>

**Comments:**

- disagree – but a lot of people are not told enough*
- agree – medical – it is up to them, mental – people don't know who to talk to or where to go*

d. In general, there exists a lack of respite services or other support services for families of children with special health care needs.

	<b>N</b>	<b>%</b>
Agree	29	74.4%
Disagree	10	25.6%
<b>TOTAL</b>	<b>39</b>	<b>100%</b>

**Comments:**

- disagree – services are available, but not always staffing*
- disagree – the older the children get, the less quality of care they receive*
- agree – respite available, but only a certain number of people can access it, many more could use it*
- sometimes agree – we have a respite system set up, but not always enough staff for the respite system to go around*

9. The following is a list of statements relating to the delivery of services for children with special health care needs and their families. Once again, please tell me whether you agree or disagree with the statement.

a. In general, there exists a fragmentation of services as it relates to children with special health care needs.

	N	%
Agree	29	72.5%
Disagree	11	27.5%
<b>TOTAL</b>	<b>40</b>	<b>100%</b>

**Comments:**

*-disagree – school speech services are fragmented*  
*-agree – because of being in a rural area, certain services are not available on a regular basis – we have hearing services only once a month, special needs are not being met, psychological needs services only twice a month*

b. In general, there exists a lack of multidisciplinary clinics as it relates to children with special health care needs.

	N	%
Agree	26	66.7%
Disagree	13	33.3%
<b>TOTAL</b>	<b>39</b>	<b>100%</b>

**Comments:**

*-disagree – there are clinics in Grand Forks and Fargo, but they are too far away, the reservation can access their clinic, non-native Americans have a hard time accessing services*

c. In general, there exists a lack of a coordinated funding system as it relates to children with special health care needs.

	<b>N</b>	<b>%</b>
Agree	31	81.6%
Disagree	7	18.4%
<b>TOTAL</b>	<b>38</b>	<b>100%</b>

**Comments:**

- agree – must go to a variety of places for funding*
- agree – money is not what the community always wants to go for*

d. In general, there exists a lack of public information about community and state resources as it relates to children with special health care needs.

	<b>N</b>	<b>%</b>
Agree	35	89.7%
Disagree	4	10.3%
<b>TOTAL</b>	<b>39</b>	<b>100%</b>

**Comments:**

- agree – the general public doesn't know where to find it*
- agree – we don't know what is available*
- agree – but getting better*
- disagree – we should spend money on services and salaries for new hires, not advertising; we need a professional in the community that would get information out about services, but first of all we need services here to get the word out, we are a small community, so news travels fast*

10. What, if any, services are lacking in your community and should be made available in order to provide comprehensive care for children with special health care needs and their families?

- Don't know (3)*
- We have all the services we need here in Fargo*
- Hettinger has all that they can have in their community; our kids are referred if needed to Bismarck and maybe even Dickinson*
- Gap in services from age 3 and up – behavioral and special health care coordination*
- Early intervention services*
- Specialty pediatric care- pulmonary, peds. Rehab, ped. Surgery, ped. Development Dr.*
- Wrap around*
- More organization and comprehensiveness*
- Case management (3)*
- Respite services and difficulty of finding good respite care staff (10)*
- Speech therapy*
- Nutrition clinic in Bismarck
  - many of these children are failing to grow and there is a need to have a nutrition clinic to address their needs**
- Summer programming – therapies are not available for children during the summer*
- Emotional support and discussion groups for parents and families (4)*
- Multidisciplinary treatment centers (2)*
- Center for children's mental health*
- Center for treatments and evaluation of pervasive developmental disabilities for childhood obesity*
- Daycare services willing to take special needs children so it does not always have to a one-on-one setting – working parents need a break (4)*
- Behavioral health*
- Need help in placing high school age kids for work-related experiences*
- Specialized care in rural areas – mentally ill (4)*
- Money for mentally handicapped*
- High school graduates move away from rural areas because of limited resources*
- Head Start limited to certain income level and certain number of kids – we could easily double that number*
- Direct psychological services*
- More involvement with kids*
- Coordination of services (8)
  - One facility or person to coordinate regions services (5 of 8)**
- Coordinated funding system (2)*
- Financial help to find qualified providers (3)*
- Jumping through hoops and complicated financial support leads patients to give up*
- Public education and information about community and state resources (8)
  - who to go to for help and what they provide*
  - need information to give to clients on where to go for help**
- Greater outreach so families do not have to travel (4)*
- Better referral process for special health care needs*

- More screenings that are regular, free, educational and held at schools (2)*
- People think the only route to take is social services and pride keeps them sometimes from going there*
- Psychiatric help for kids under 18 is hard to access*

11. What role(s) do you believe the North Dakota Department of Human Services, Children's Special Health Services Unit, should fulfill in serving the needs of children with chronic health conditions and their families?

- No opinion*
- Continue to do what they do*
- Education - Make families and public aware (3)*
- The Overseer*
- Advocates*
- Need a contact person and location within each community (3)*
- Resource specialist training and physician training*
- Provide information and resources (6)*
  - have a list of resources available and give to providers*
- Human Services has worked really hard, 10 years ago it was a problem*
- Money should go to services for children*
- Summer programming*
- Equipment issues (schools already cover some, but then cannot use those in the community)*
- Services are fragmented throughout the state (2)*
  - Funding for respite comes from one area while another service's funding comes from another part of the state – not working well together*
- Need one single case manager that would cover a variety of disciplines*
- Whatever gets marketed there needs to be funding to follow and families get a product that is helpful to them*
- Assessment, assurance and lack of duplication*
- Provide collaboration of efforts in multidisciplinary approach (2)*
- Coordination for kids in rural settings*
- Provision of services*
- Take a leadership role in evaluating the needs and looking at what is out there to help coordinate the programs*
- Develop or encourage providers to provide respite or daycare*
- Awareness to families of where kids can go (2)*
- More variety of residential placements for cognitive care where the kid is in a safe environment*
- Provide adequate funding for programs and services (2)*
  - should cover complete cost*
- Case management (26)*
- Building awareness and linking families to available services (32)*
- Sponsorship of multi-disciplinary clinics (20)*
  - in rural settings (2)*
- Grants (24)*
- Payment of care for eligible patients and families (27)*
- Partnering/Coordination/Collaboration with other organizations (30)*
  - schools and homes (2)*
- Assessing needs and surveying health care providers (dentists, optometrists)*
- Insurance for hearing aids*
- Limited ongoing relationships with medical services*

12. If you could make only one change relative to improving care in your community for children with special health care needs and their families, what would it be?

- Technology provided for kids is limited to Medicaid dollar amount – Kids need the best quality we can deliver*
- Develop a brochure that clearly establishes which children qualify and what are they entitled to receive under these services*
- Information for providers and clients via a newsletter or something of that nature to inform*
- One place to get information and not be intimidated*
  - most families don't get information until they are forced to*
- Improve delivery of support services in natural environments*
- More community services*
- Better case management with improved coverage and expanded course of treatment (2)*
- One contact person that can concentrate on just children with special health care needs and their families (6)*
  - information about resources that can educate parents about available resources*
  - coordinate the care between all providers involved, all payment services involved and the school system (2)*
- Centralized services under one umbrella*
- Coordination and integration providers*
- Easier financial support*
- Better follow through coordination*
  - often parents are minimally responsible*
- Knowledge that families are not alone and that help is available – support groups (2)*
- Encourage collaboration between hospitals and individual providers, schools and community based programs, etc. (2)*
- More outreach programs to rural areas*
- Continuity of services and equipment all year long*
- Respite-Daycare*
- Respite care for behavioral and health problems (2)*
- Better networking between all providers*
  - Children are our best resource and we need to do things for them!*
- Increase access to transportation so can readily and easily access services to the community (2)*
- Recognizing reimbursement in state funding in the area of Occupational Therapy*
- If the provider was reimbursed at a level to cover the cost of care – the limit to the number of visits is a good thing – this may open up more funds*
- Schools shouldn't be funded by medical dollars*
- Send a kid to Human Services center and be seen within a week for counseling and have availability of services and support*
- More rural resources (medical) in specialty care so they don't have to travel (6)*
- More services available for low-income families*
- Resource awareness to physicians – more open ended dialog with medical services*
- Overall easier access and resource awareness from health professionals as to the services that are offered in our community (2)*

13. Do you have any additional recommendations relative to improving services in your community for children with special health care needs and their families?

*-No (25)*

*-Training on specific medical and emotional issues – specific to certain cases*

*-State is doing a great job in giving back to children*

*-MR or mentally ill students need to have more money for assisted living –need apartment money for these kids – lack of funding*

*-Need Case managers to be helpful and coordinate services and keep the public informed*

*-Need Case managers with appropriate/directive contact, less focus on “requirements” of their job*

*-Communication between those involved*

*-Support groups*