What Do North Dakota Families Say About Health Care for Children With Special Health Care Needs

Family Voices of North Dakota
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Acknowledgment

First and Foremost, a special thank you to the families of children and youth with special health care needs who participated in this survey. All families of this population are the heart and soul of the work of Family Voices of North Dakota. Families hold within them a wealth of information, of which we congratulate them on their wisdom, expertise and willingness to share and educate others. It is for the children, not in spite of the children of which we are so passionate.

Also a special thanks to the FVND funders, Centers for Medicare and Medicaid, and Children's Special Health Services of the Department of Human Services. Without them we wouldn't be able to do the much needed work on behalf of families and children.

Introduction

There are approximately 20,000 children and youth with special health care needs or nearly 1 in 5 (19.4%) in North Dakota who have special health care needs that include some type of functional limitations. A priority goal for Family Voices of North Dakota was to identify health and service experiences for families. A survey was developed and sent out to families from across the state. Ninety families provided valuable input. This report compiles the information provided to us by families.

Children and youth with special health care needs whose families participated in this survey have a wide variety of conditions. Some of the children had more than one condition and utilized health care and related services frequently. The children had coverage paid for by employers, families and/or state programs. For many families having a child or youth with special health care needs has a significant impact to the family which affects their finances, jobs and time spent providing health care. The children lived in families with different income levels in a variety of communities.

While some aspects of the health care financing and delivery system are serving children well, other parts are not meeting their needs. Family Voices of North Dakota provided this survey to identify what was working and what needed improvement to health care for this population of children. Many families who have children and youth with special health care needs struggle to navigate a complicated mix of services from health plans, public programs and private agencies.

Additionally, Family Voices of North Dakota assists agencies and families in family/professional collaboration efforts. Survey questions also identified areas of concerns for families, improvements and suggestions.

Children and youth with special health care needs are a small but significant part of our nation's and states population of children. Though not well understood by many health plans, policy makers, nevertheless their experiences are reflections of how well our systems are performing and should be monitored carefully.

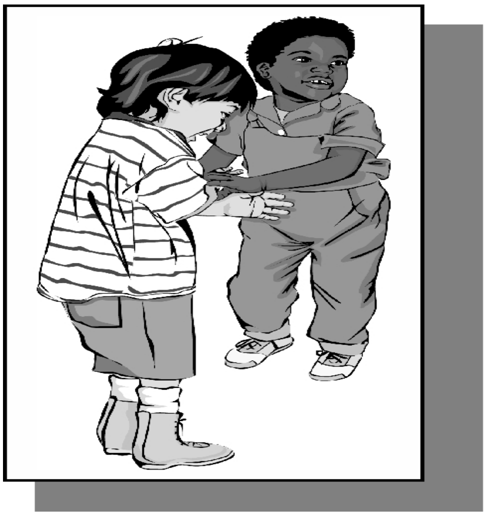
Medicaid is an essential program for children and youth with special health care needs. Its benefits should serve as a model for all children needing specialized health care services, whether publicly or privately funded. For some children whose primary health coverage benefits are limited, secondary health care coverage, like Medicaid is essential.

Parents want and need clear information from health plans about health plan benefits and how to get the covered services for their child, where to go with complaints and appeals, and about other available resources that will help them meet their child's needs. The majority of families of children with special health care needs in this study feel positively about the quality of their doctors.

Many children who need other specialty providers do not have adequate access; children and youth with special health care needs require flexibility in health care plans such as streamlined procedures for getting specialty care and care coordination or case management.

Many families provide complicated health care for their children at home and need more support that they receive now. The impacts of a child with special health care needs on a parent's job, finances and time must be recognized and public policies must address these impacts. Children and youth with health conditions that are unstable and severe, have needs that are not well met by the present approaches of health plans, government programs, and community agencies.

Families of children and youth with special health care needs require more information and help in order to ensure a health system that works well for their child and family. In the survey families consistently spoke about how other families were often their most important source of information. An established means for parents to learn from other parents needs to be assured.



What Did Families Share With Us

1. **Are you satisfied with the quality of primary care, obtaining referrals & appointments for needed services and coordination among both primary and specialty care?**

Not at all- 9%
Somewhat-32%
Satisfied-34%
Very satisfied-23%
Not Sure-1%

Families face a confusing maze of services from health plans, school systems, state agencies and private agencies that are not well coordinated. For families who had a case manager, some case management services were helpful. Many families, however, reported not getting the care coordination they needed. When care coordination worked, families found it helpful. Many parents reported that they coordinated the numerous systems and payers of health care for their children themselves, sometimes with great difficulty.

> ***"It seems that all services are directed towards children with physical, emotional and mental disabilities. Children who are "normal" on the outside are left behind. It took us 6 years to get a diagnosis for our son. Our medical provider did not take our concerns seriously. He is delayed 2.5 years in gross motor skills. School won't provide any services because "he can function within the classroom setting." I work a fulltime job during the week. I work a second job on the weekends to pay for the medications and keep up with the medical expenses.***

> "I am the mother of four young boys with extensive disabilities, and medical conditions. I have found alot of help getting connected with services through our primary care physician, Dr. Stephen McDonough and our West Central Human Service Center Partnership Program Service Manager, Tracy Schlag. The community here is phenomenal in their support of families in need and having those people to connect to is a great help."

2. **Does your child have a Care plan? Yes-44.3%; No-55.7%**

It is important for families to have coordination of care. Coordination of care and communication among providers are essential and must be improved to ensure quality care for children and youth with special needs. These services need to be improved within individual health plans, agencies and programs, as well as across all systems that serve children and youth with special health care needs.

> ***"We are constantly battling BCBS of ND and ND MA for coverage of specialty services and therapy for our daughter. What would make our experience better is if BCBS of ND and ND MA would honor and respect our pediatrician's recommendations and referrals. We have one of the best pediatricians in the Midwest and the reviewers continually question and deny his requests and medical recommendations."***

What Did Families Share With Us

> ***"I have been in a professional field of some sort that works with children with disabilities as well as having my own child with disabilities and I have been really surprised at how few referrals and suggestions for help come from the staff that have worked with my child. I feel like the medical community doesn't know all the options for alternate services for children and therefore they do not make referrals. I also feel that County workers have caseloads that are so large that it is not always possible to have regular contact with families and therefore not see what the families need."***

3. **Are you satisfied with the level of your input and involvement when working with your primary care provider? (Do you feel your input is valued?)**

Not at all- 6%
Somewhat-26%
Satisfied-29%
Very satisfied-34%
Not Sure-5%

The majority of families of children with special health care needs in this study feel positively about the quality of their doctors.

> *"Working with our primary Doctor and his support in directing us to other specialists has been very helpful."*

4. **Do you understand the steps to the formal grievance or appeal when you are not satisfied with your child/family services?**

Not at all-18%
Somewhat-36%
Understand-30%
Understand fully-7%
Not sure-9%

Parents want and need clear information from health plans about health plan benefits and how to get the covered services for their child, where to go with complaints and appeals, and about other available resources that will help them meet their child's needs.

5. **Does your child receive most of their health care services through a primary provider or specialist?**

Primary Provider-66%
Specialist-34%

Children and youth with special health care needs receive services through a variety of providers, coordination of care between all involved is essential. Nearly 50% of the families answering questions in the survey have children and youth who require medical services who specialize in various aspects of care. With this in mind, the Medical Home Concept becomes imperative to these families.

What Did Families Share With Us

6. **Is the care your child receives satisfying for you, communicating in a way that is clear and understandable?**

Not at all-4%
Somewhat-25%
Satisfied-45%
Very Satisifed-26%
Not sure-0%

The majority of families of children with special health care needs in this study feel positively about the communication with the various providers who care for their child or youth with special health care needs. Most families gave high ratings to their child's primary care provider and to the doctor they identified as most important to their child's care.

7. **Are you presently satisfied with the covered costs of needed services for your child including: mental health, dental, well child checks, durable medical equipment, prescriptions, therapy services etc?**

Not at all-17%
Somewhat-36%
Satisfied-31%
Very Satisfied-15%
Not sure-1%

It is often left to families to figure out who will provide and pay for services such as physical, occupational, speech, and mental health therapies. Payment responsibility needs to be clarified among the multiple possible payers so that children are not left un-served while agencies and programs try to decide who will pay for what. Additionally, as private insurance does not cover some of the needs for children and youth or have capitation limitations, many children and youth are underinsured. Attention is needed to assure comprehensive care between both private and public systems. Over half of the families gave lower ratings to certain aspects of their child's plan.

> *"My daughter has a terminal diagnosis. A progressive and degenerative disorder, but does NOT qualify for DD services because she is not MR. Medical costs are tremendous, and should her insurance change, or run out, our family will be in poverty because there are no services in the state that she qualifies for."*

> *"Many health care providers feel that if you have insurance, there isn't a need for concern...but with many families there are still concerns financially. WE need to reach out to those middle income people that aren't involved in any other areas of service. For us, it was a difficult decision in some ways to ask for help, yet the financial help we received has allowed us to continue to work and be productive members of our state. The state needs to consider ways to support families and not make the "hoops" so difficult."*

What Did Families Share With Us

8. Does your insurance provide timely approval for needed care overall, clear information about coverage, resources and complaint procedures?

Yes-64.9%
No-35.1%

"If a child is disabled, it would be a relief not to have to get referrals for every specialist. The Medicaid Referral process is no fun. Its one more thing, I have to do. I work full time and am a single parent. I get very tired of paperwork and phone calls. You'd think it could be streamlined."

"Referrals to specialty doctors out of our state (example specialized neurology, sleep specialist and continued metabolic testing) are denied. Our daughter is undiagnosed to this day (9 years). Also we are continually denied medically necessary therapy (PT, OT and Speech)."

9. Are you satisfied in the way your child's development is being monitored?

Not at all-9%
Somewhat-24%
Satisfied-50%
Very Satisifed-12%
Not sure-4%

It is vital that all children and youth with special health care needs development are monitored frequently and continuously. Well child checks, immunizations, regular exams etc. are an important aspect of normal growth and development.

"Families need to ask questions. We can't make assumptions. I feel the easiest way is through our primary care physicians. We see them more often through check-ups. If they're aware of programs that could assist, they could direct families in the right direction."

"I would love MEDICAID program benefits waiver to continue past 3 years of age. I would like qualifying him for Social Security with our income waived. We tried to get Social Security for him but were denied. They would pay for him to be in a facility... but not for me to quit my job and stay at home with him to make sure he gets the in-home therapy (pt, ot, speech) that he needs. Crazy!"

"Primary care physician's often use a "Band-Aid on a broken arm" approach. Mine doesn't seem to look into things too much, and if I express a concern, I feel like it is downplayed."

What Did Families Share With Us

10. Are you having financial stress due to your child's health care needs?

Yes-45%; No-55%

For many parents, having a child with special health care needs has a significant family impact, affecting their finances, jobs and time spent providing direct health care. This could be due to out of pocket expenses, medications, travel and transportation costs, or having to decrease employment hours to care for a child.

"Travel time & expenses, time off work, having to wait 2 months for an appt. School systems not helping at all."

"Financial ability to make payment to our clinic was VERY DIFFICULT. When someone has a bill, after insurance, of a few thousand dollars and you can not pay the entire bill in their 3 month time frame and they are not willing to extend that out, you are forced to make a decision of your child's health care or food on the table, losing your vehicle to get to work because you can't make the payments, what are you suppose to do. This clinic is more of a business out to make money than they are to help people with their health!"

11. Are you comfortable accessing comprehensive community based services for your child and family and know who to call to locate information and services for your family?

Not at all-14%
Somewhat-30%
Satisfied-41%
Very Satisifed-12%
Not sure-3%

Families of children and youth with special health care needs require more information and help in order to ensure a system that works well for their child and family. Families need clear, unbiased information in order to make informed decisions. When communication between providers and families becomes a barrier it leaves families with feelings of animosity and isolation.

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"I can't even begin to tell you... lots. Not being referred to the Infant Development program (SHSC) by our son's physician was probably the biggest gap. This wait and see attitude does such a disservice to families. Meanwhile the child suffers.

"It seems that organizations are working so independently and not sharing information on complete services that are available in the community. Especially if your child is not a child that causes disruptive behavior, but has problems such as social anxiety. More information should be shared without parents having to ask questions or search on their own. If you don't know services are available, how do you know what questions to ask or even search for information? I have been very lucky to be the "investigative" type, but even then, there are services available that I just happen to come across by chance."

Families of children with special health care needs require more information and help in order to ensure a health system that works well for their child and family. Parents consistently spoke in the survey about how other families were often their most important source of information. An established means for parents to learn from other parents needs to be assured.

12. **Do you feel comfortable in your knowledge in health care financing i.e.: Medicaid, Health Tracks (EPSDT), SSI, Children's Special Health Services, private insurance?**

Not at all-13%
Somewhat-33%
Understand-44%
Understand fully-7%
Not sure-3%

It is vital for families to understand the programs that are available in the state, how they work and who to contact. Family Voices of North Dakota Health Information and Education Center has worked diligently to provide information to families but much work is needed. While families frequently discuss formally in this survey and informally how other families are an important source of information, it also means families need to be provided access to family organizations consistently to provide emotional and informational support by providers and agencies in order to meet the needs of families.

Many families provide large amounts of complicated health care for their children at home, and need more support than they now receive. The impacts of a child with special health care needs on a parent's job, finances and time must be recognized and public policies must address these impacts.

> *"When my daughter was born, I felt it would have been very helpful to have ONE person I could go to who is knowledgeable about the needed and available services for special-needs individuals and how they fit together, like some sort of case worker who knows about all pieces of the puzzle. It was so confusing having to compile all the fragmented info I received from various doctors, specialists, therapists, social workers, SSI workers, Medicaid, private insurance, Early Intervention, Public Health, etc. I never knew who to ask what questions to, and I was especially confused about how SSI, Medicaid, Early Intervention, and WIC all worked together (meaning, sometimes qualification for one will qualify you for one or several of the others). The people that worked within each separate program didn't seem to always realize that or at least didn't always communicate it. For instance, because my baby qualified for Medicaid, I could have had WIC since the time she was born. But I never knew that until she was about 6 months old so I missed out on 6 months of it."*

> *"Family Voices has been a huge help to our family from the day that I called. I know that if I need information on a service, I can call FV and they will find the info for me if they do not already know."*

Partnerships are important

Many families serve on committees, task forces, advisory boards to assist in program development, policymaking efforts etc. It was important for us to know how these efforts were working and how did families feel.

13. **As a family member, have you been supported financially, emotionally for your involvement from providers or agencies in state and local activities?**

Not at all-15%
Somewhat-38%
Satisfied-30%
Very Satisfied-9%
Not sure-8%

Families of children and youth with special health care needs provide an important aspect to services, identifying needs, concrete ideas on what is working and what isn't working. In order for families to participate they often volunteer, need child care, transportation, meal costs and emotional support. They need to clearly understand expectations and what is being asked of them.

14. **If you are actively involved as a family member in policymaking at the state, local or national level, do you feel you are an equal partner?**

Not at all-20%
Somewhat-34%
Satisfied-11%
Very Satisifed-3%
Not sure-32%

Families can be involved in many ways. Examples are: in-service training, committees, families as employees, grant reviews, policy developments etc. In the survey families identified that they did not always feel an equal player. As a state we must assure that all hats worn to the table are respected for the assets that they bring.

> *"I really felt devalued and like I was just the dumb parent when my son was younger; however, as the years have passed and long standing relationships have developed I feel like there is a little more respect there."*

Families Share Their Thoughts

Families shared with us a great deal of information. Some of the excerpts have been weaved into the survey results. We felt it important to share the family dialogue with the open ended questions that were asked, as they contain a wealth of information.

15. If you are satisfied in participation with agencies and providers, share with us what activities you are involved and those who do a great job. If you are not satisfied, share with us what would make the experience better.

"I do not have an opinion that would help."

"I am involved in Arc governmental and legislative activities."

"It seems that all services are directed towards children with physical, emotional and mental disabilities. Children who are "normal" on the outside are left behind. It took us 6 years to get a diagnosis for our son. Our medical provider did not take our concerns seriously. He is delayed 2.5 years in gross motor skills. School won't provide any services because "he can function within the classroom setting." I work a fulltime job during the week. I work a second job on the weekends to pay for the medications and keep up with the medical expenses."

"Anne Carlsen Center does a good job."

"Primary care physician's often use a "Band-Aid on a broken arm" approach. Mine doesn't seem to look into things too much, and if I express a concern, I feel like it is downplayed."

"As a PTI director, we are exposed to a wide range of needs of families and children with health care or other problems which require medical involvement and supervision of medications. My first recommendation to all parents is...do not take anything at face value, question and persist, keep a notebook of what occurs when your seeking or your child is receiving medical services, question if the level of services and the amount of PROFESSIONAL time invested in delivery is adequate to support your child's improving, constantly watch for additional needs which may not seem to be a priority but left unattended these in combination with other more obvious primary needs can increase delay in improvement for children. Monitor the time spent, if you receive home visits, note HOW that time is invested....is it mainly showing you what you should do yourself for your child??? Is it mainly a show and tell session placing ongoing and often major responsibility on you the parent to perform needed therapies etc.??? IF so....join with other parents in similar circumstances and challenge the "quality of and the extent of care" actually delivered by any agency or program. If you have home visits how much of your time is consumed in questions you are asking and note taking by the provider??? Minimal care produces minimal results; it is a determining factor in outcomes produced. Federal and state dollars are paying for delivery of services and those services should meet the highest standard of quality."

"Family Voices of North Dakota has done a wonderful job of helping families get involved in testifying to the lawmakers and I think that has directly improved some services. We currently are having issues in regards to special education on a "gray area child" and that is very difficult...but without the involvement of FVND, we wouldn't have a clue as to where to turn."

Families Share Their Thoughts

Continued… If you are satisfied in participation with agencies and providers, share with us what activities you are involved and those who do a great job. If you are not satisfied, share with us what would make the experience better.

"Health Care through IHS is very minimal. There are not enough medical doctors. The solution is idealistic and may never happen. IHS should provide our people with well-qualified doctors that actually are concerned with the health of each patient. Funding is a very big issue with IHS. More money is needed. This is a big issue that is frustrating."

"I am involved at all levels and I feel keeping connected to other families is the most important. I also feel that joining an organization at each level is also important. I feel that Family Voices has helped me at all levels, local state and national, so that has been the most helpful of all. I believe that if you do not speak out for what you know and truly believe, you are doing an injustice to your child and also your family. "Special Needs" affects the "whole family", not just the child with a diagnosis.

"RICC - Betty Omvig does a great job."

"I am on the Children's Special Health Services Family Advisory Council. I truly feel that CSHS does their very best to help families. They are constantly trying to help educate families on services in our state. CSHS tries to simplify things for families as much as they can by providing the Multidisciplinary Clinic Program. CSHS of North Dakota deserves a great big pat on the back!"

"We are constantly battling BCBS of ND and ND MA for coverage of specialty services and therapy for our daughter. What would make our experience better is if BCBS of ND and ND MA would honor and respect our pediatrician's recommendations and referrals. We have one of the best pediatricians in the Midwest and the reviewers continually question and deny his requests and medical recommendations."

"North Dakota Interagency Coordinating Council - more parent voice at the table. Regional Interagency Coordinating Committee - needs more organization State Genetics Task Force - needs more clarity."

"If a child is disabled, it would be a relief not to have to get referrals for every specialist. The Medicaid Referral process is no fun. Its one more thing, I have to do. I work full time and am a single parent. I get very tired of paperwork and phone calls. You'd think it could be streamlined.

I am on the Board for Family Voices. I feel Family Voices does an excellent job.

"I am on the committee to draft a Medicaid waiver"

"Working with Family Voices in ND – they have excellent advocates. Currently working on FOA in ND as well.

"It took until my son was 2-1/2 yrs. old to get his diagnosis: a rare genetic syndrome. We were not referred to Infant Development until his was 1 yr. His physicians should have referred us. The team at the Mayo Clinic should have caught the diagnosis. We feel like we slipped through the cracks along the way in many aspects of his care."

"Getting needed information back faster instead of waiting for days to find out answers."

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Families Share Their Thoughts

16. We feel it is important for families to have access and links to a variety of public and private resources and family support from the day a child is diagnosed. Tell us your thoughts in how families can receive this information and how Family Voices can assist new families in this process or share your experience.

"Make information available at the program plan meeting, or when a person applies for services. Another option, provide a brochure of the services available."

"Educate the medical providers and hospital staff about the availability of and how to access resources as they are the first to be in contact with the child and family from day 1. "

"There is no support for my child's diagnosis in ND. Everything seems to be focused on those children with physical, emotional and mental disabilities (cerebral palsy, muscular dystrophy, Russell Silver Syndrome, seizure disorders, etc). Nothing is focused on the child with endocrine disorders such as growth hormone deficiency, hypothyroidism, and panhypopituitarism. My child is 2.5 years delayed in gross motor skills yet we don't qualify for any services.

The school won't allow an IEP because he "can function within the classroom setting." We go out-of-state for support (networking with other families, educational opportunities through the Magic Foundation) because there is nothing that I have found in ND. Our health care provider referred us to the Magic Foundation in Chicago right away because there is nothing in ND."

"I am the mother of four young boys with extensive disabilities, and medical conditions. I have found alot of help getting connected with services through our primary care physician, Dr. Stephen McDonough and our West Central Human Service Center Partnership Program Service Manager, Tracy Schlag. The community here is phenomenal in their support of families in need and having those people to connect to is a great help."

"Have a booklet made up with ALL possible services for the child and families and make sure that the social worker meets with the family and explains in detail the services that are available. Be sure that the family gets the booklet and have them sign that they got it. Also give the booklet to the social workers and DD case managers for later use after the diagnosis are made at a later date/age. Have social workers make follow-up calls and offer services and train Dr's and nurses to also give these booklets and offer services to the families."

"Families need to ask questions. We can't make assumptions. I feel the easiest way is through our primary care physicians. We see them more often through check-ups. If they're aware of programs that could assist, they could direct families in the right direction."

"Development of a one-stop type of system"

"We don't seem to be able to get any state help, not sure why, because other families we know with children in the ASD do."

Families Share Their Thoughts

16. Cont.

“Flyers, local radio stations, local bulletin boards.”

“It is hard to find all of the resources out there. Our pediatrician gave our child a diagnosis and then gave us the name of a psychologist to verify that diagnosis. We did not like that psychologist and it took us a few months to interview and research psychologists, therapists etc. before we found one we were happy with.”

“We got my son's severe diagnosis when he was 7 months old... I didn't have a clue that there was any type of support to help us deal with the emotional upheaval that our family faced. We operated on survival mode... just trying to get through the next day. I realize now that we were grieving, and still am to a certain extent. My son's therapists at Anne Carlsen Center (outpatient) were my support. When Brock was about 2 years old, I was finally given a brochure that told about Family to Family network. Even then, it took me about 6 months to "make the call". I was not used to confiding in a total stranger, so this was a very hard call for me to make. Of course, in hindsight, I wish I would have done it sooner. EVERY PERSON that I have spoken to since... moms who have been there, have been so supportive, so compassionate. I am still not fully free to pick up the phone and unload my day on someone. I hold too much inside and have my crying times. We have a very good rapport with our family doctor, but he never said, "You are going to need some emotional support to get through this." I wish he would have encouraged it... I wish he would have had family support information to pass on to me. My son is almost 4 years old. We have worked on alot on our own, but during those horrible months of family separation when Brock and I were in Mpls. and the rest of our family was shell-shocked at home, that's when we really needed help.”

“Give out information at schools, clinics, online etc.”

“Give as much information as you have on a local/bi-state level. Many of us are now having to go out of state and the details can be scary.”

“Everything was fine until my daughter turned 3 then it was like "your on your own see yaw" need more info or tracking after 3yo.”

“Pediatricians and/or specialists should give newly diagnosed families at least a business card of someone who can help them through these new challenges. Parents should NOT be required to search the internet and various social service agencies for assistance. I have had several experiences of seeking assistance and being told "have you tried calling ___?" by every one of the people I called. Each pointed me to another organization, repeat over 4-6 calls, until finally get referred back to the original number I dialed for assistance. Sigh.

“Family Voices needs to keep doing the great job you are. Collaborating and referring to other agencies and programs is key to helping.”

“Primary care physicians should be made more aware of all the services out there.”

“Family Voices has been a huge help to our family from the day that I called. I know that if I need information on a service, I can call FV and they will find the info for me if they do not already know.”

“The medical team should help families gain access to the resources they need, or a hospital or clinic social worker.”

Families Share Their Thoughts

16 Cont.

"Many health care providers feel that if you have insurance, there isn't a need for concern...but with many families there are still concerns financially. WE need to reach out to those middle income people that aren't involved in any other areas of service. For us, it was a difficult decision in some ways to ask for help, yet the financial help we received has allowed us to continue to work and be productive members of our state. The state needs to consider ways to support families and not make the "hoops" so difficult."

"I feel Family Voices does a great job now! I do feel the weekly news letter is great also. I do feel that workshops are needed especially in the more secluded rural areas. I think that teleconferencing on national issues is a great way to let the families know what is happening on the national scene so that they may listen and gather ideas from those areas. My son is Autistic and their is always national news that we do not always know or hear about and if you do not belong to an organization, you may never know the breaking and latest news. This news may be helpful or it may not, but I think that it should be brought to the forefront anyway possible. I do think that Family Voices does an excellent job!"

"I think Family Voices gets the word out there."

"Via e-mail"

"If a child is under three I think Early Intervention systems should help with this and help us connect with others. I think that a few brochures listing resources would be helpful (medical, financial, parent support, etc.)

"Getting information out to the rural areas."

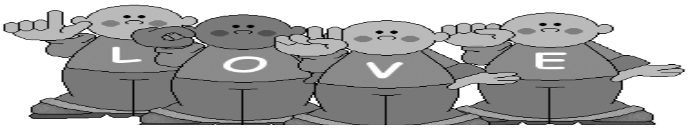
"It seems that organizations are working so independently and not sharing information on complete services that are available in the community. Especially if your child is not a child that causes disruptive behavior, but has problems such as social anxiety. More information should be shared without parents having to ask questions or search on their own. If you don't know services are available, how do you know what questions to ask or even search for information? I have been very lucky to be the "investigative" type, but even then, there are services available that I just happen to come across by chance.

"I like the emails from FVND. I can read on my own time."

"I have used the SHARE Network from the jobsnd.com website to look for resources. I also know that I can call Family Voices for assistance and my daughter's DD Case Manager. I have also received useful information from the staff at Easter Seals in Fargo."

"My child is not eligible for any of the services mentioned."

"Team people up with families with similar diagnosis. Have a meet & greet play date at the Head Start Gross Motor room once a month. Send out a FAST FACTS sheet listing 1. Program 2. Who qualifies 3. Contact info. 4. Advocacy group for problems. Etc."



Families Share Their Thoughts

16 Cont

"A family to family approach is helpful. Children Special Health Services brochures were helpful early on.

Family voices could offer fact sheets on their website. Family Voices could work with employers so families can attend workshops and trainings."

"Education could be provided to healthcare and daycare providers."

"Your Family Voices newsletter is very good at providing information but there is so much on it that it is somewhat intimidating to parents and they do not read all of it. It may be better to have simpler format with just the most current information. Need to know about the various opportunities/agencies that are available to those children that are reaching the graduation into adult services and what is open to them. This is very confusing and even though the case managers provide information you could do a great service by having a synopsis of the various agencies and where they are located and what their strengths might be."

"I have been in a professional field of some sort that works with children with disabilities as well as having my own child with disabilities and I have been really surprised at how few referrals and suggestions for help come from the staff that have worked with my child. I feel like the medical community doesn't know all the options for alternate services for children and therefore they do not make referrals. I also feel that County workers have caseloads that are so large that it is not always possible to have regular contact with families and therefore not see what the families need."

"Through infant development, they could refer from day 1 to family organizations such as Family Voices, from docs who should have nurses or social work refer right away."

"When my daughter was born, I felt it would have been very helpful to have ONE person I could go to who is knowledgeable about the needed and available services for special-needs individuals and how they fit together, like some sort of case worker who knows about all pieces of the puzzle. It was so confusing having to compile all the fragmented info I received from various doctors, specialists, therapists, social workers, SSI workers, Medicaid, private insurance, Early Intervention, Public Health, etc. I never knew who to ask what questions to, and I was especially confused about how SSI, Medicaid, Early Intervention, and WIC all worked together (meaning, sometimes qualification for one will qualify you for one or several of the others). The people that worked within each separate program didn't seem to always realize that or at least didn't always communicate it. For instance, because my baby qualified for Medicaid, I could have had WIC since the time she was born. But I never knew that until she was about 6 months old so I missed out on 6 months of it."

Families Share Their Thoughts

17. Tell us what would have been helpful for you and your family? Also share with us what ongoing informational needs that you may have.

“Behavioral issues and how to best handle them.”

“It is nice to have coverage for my children since I am a working mother, but with the price of medical care, I could never afford to put them on my insurance policy or pay for it!

“Being involved in the Arc and National Down syndrome congress has been helpful. There are ongoing needs as the child grows & develops and goes through succeeding stages in life. New questions and challenges arise.”

“Well I think one of the most important things was the frustrating switchover from state-to-state healthcare when we moved from Montana to North Dakota. There was a real lack of communication between states, and knowing how to switch and how it worked.”

“Working with our primary Doctor and his support in directing us to other specialists.”

“It would be helpful have one person who knows the systems and has access to the services needed.”

“It would have been helpful if somebody would have given us a list of all of the help available to children diagnosed under the Autism umbrella. I'm not sure where this information would come to parents from - maybe a pediatrician or an autism website or handout.”

“Physicians should be able to point us out to the agencies or an organization to contact so that you can learn what help is available; there should be more information easily accessible to parents of ASD kids.”

“We were hooked up with outpatient therapy as soon as Brock was diagnosed. Children's Hospital in Mpls. helped set that up, or I wouldn't have known where to turn. We were also given a DD case manager. Even if SHE would have pointed us to some support, that would have been great. I think maybe everyone assumed that we knew where to turn for this kind of help, but we were clueless.”

“Having more readily available information.”

“I wish I would have had a complete list of more local support groups or online support.”

“Having "medical" experienced parents would be great. Some have been through so many loopholes and could help others navigate the medical/insurance maze.”

“Transitional tracking for the 3-5 year olds.”

“The above would be helpful.”

Families Share Their Thoughts

17. Continued

"It would be helpful if doctors were able to direct newly diagnosed families to an APPROPRIATE list of resources, or to an organization like family voices, who can help families determine what resources are available and thereby determine which would be most useful for a particular family."

"Family to Family has been WONDERFUL, it was so helpful to talk to someone else with similar situations."

"It would have been nice to have an organization such as Family Voices available when my child was diagnosed. They have been very helpful to our family!"

"To know and understand the systems from the beginning, instead of struggling for years. Understanding how to communicate with the education world."

"Continuing education for the medical community... Respite care Diagnosis specific support groups."

"Sibshops are always helpful and new ways to help the whole family and not just the diagnosed child. My biggest challenges now days are dieting and gastrointestinal problems, so medical issues are the problems and finding the right Dr.'s in North Dakota to lead me to the right specialists is a challenge."

"We feel fortunate that we started in the foster care system. We had a great social worker that really went the extra mile to get us services that were needed. Without her help it probably would have been overwhelming. We also have a great OT and PT that have helped us find the specialists we need."

"Our ongoing need is to find a way to get the state of ND to include Medically Needy children in with their services."

"At the time of our daughter's birth there was no guidance or support offered from the medical community or social workers. We had to learn from the school of hard knocks."

"Being able to meet another parent/family in a similar situation in the beginning."

"Information from the point of entry or be referred to Family Voices from the beginning."

"Having the psychologist or even primary care provider provide a list of options or organizations available."

"My DD Case Manager has been helpful in finding resources. Need more info on treatments for Scoliosis, ADD and Autism tendencies."

Families Share Their Thoughts

17. Continued

“I would like more information on child care options for my child who is 13 years old. She is too old for many child care centers and too young for other programs. Fortunately, Easter Seals has been able to advocate for my child to get the hours I need for respite care.”

“I always need information about good questions to ask the doctor. I could use a protocol for giving antibiotics to youth with Down syndrome. Some providers don't give these as early and often as my child needs them.”

“Financial assistance provided through SE human services”

“Information on adult services for those who will be entering adult services upon graduation.”

“I really felt devalued and like I was just the dumb parent when my son was younger; however, as the years have passed and long standing relationships have developed I feel like there is a little more respect there.”

“We needed information right away and someone to talk to. We had to find everything ourselves and didn't know who to call. Having Family Voices makes that better for all families.”

“I still feel that having one "go-to" person would be really helpful, someone that understands the programs out there including medical, financial, and legal implications of each.”

Families Share Their Thoughts

18. Tell us what have been the biggest barriers, challenges and gaps in services you have faced with your child with special health care needs.

“Getting appointments in a timely manner, having a knowledgeable doctor not just someone who thinks he knows what is wrong with you.”

“Sometimes lack of communication between staff and myself, sometimes with the child himself.”

“Health care coverage”

“Still getting bills from medical facilities.”

“Unable to find well trained care providers willing to work for low pay/no benefits.”

“Everything focuses on children with physical, mental and emotional disabilities such as cerebral palsy, MD, RSS, etc.”

“Communication between most healthcare providers is okay, but it needs to be better. They get so busy that they don't have time to communicate with other doctors and that is really, really important, especially in dealing with children and adults with disabilities.”

“Trained professionals who are willing to say "I don’t know but let me send you to someone who specializes in this". and then refer them.”

“Biggest challenge is being bounced from place to place.”

“My husband's mental health insurance was horrible to deal with. They were so uncaring and considered my son's Asperger diagnosis "temporary" and would only let us see one provider so we had to pay out of pocket to interview and do initial assessments with different providers until we found one we were satisfied with. Our regular health insurance is easy to deal with but they don't handle any of his autism issues/appointments.”

“No services for children who are high functioning and should not be left alone because of the illness he has. There are also to many services that you don't qualify for because of income guidelines and too high functioning.”

“Agencies and organizations that don't seem willing to help - no advocacy from organizations that advertise as being available for assistance to disabled persons, yet for ASD children, there seems to be nothing.”

“Travel time & expenses, time off work, having to wait 2 months for an appt. School systems not helping at all.”

“Having to find a specialist that cares for the child and family and not a house payment. We think that our case is as important as a quadruple bi pass heart surgery and we feel that some of the doctors are in such a routine that our case is just another day at the office. This is our child’s life not another file.”

“Medical coverage should be 100% covered for all children with medical diagnosis. We shouldn't have to apply for Medicaid, have a waivered service to keep Medicaid when the child turns 3, have to have our income be an issue, etc.”

Families Share Their Thoughts

18 Continued

“Determining options for services such as respite care, occupational therapy, music therapy, partnerships, etc. Where are these services available and who will be required to pay for them. Also why should some people receive free services, and others pay out of pocket based on income? Finding appropriate & affordable childcare for autistic children in the Fargo Moorhead area is nearly impossible. Obviously I could hire Easter Seals or similar to watch the kids, but I cannot afford $12-15/hour for childcare while I work outside the home.”

“Financial ability to make payment to our clinic was VERY DIFFICULT. When someone has a bill, after insurance, of a few thousand dollars and you can not pay the entire bill in their 3 month time frame and they are not willing to extend that out, you are forced to make a decision of your child’s health care or food on the table, losing your vehicle to get to work because you can't make the payments, what are you suppose to do. This clinic is more of a business out to make money than they are to help people with their health!”

“Health care costs, prescription meds. Education issues, awareness, and inclusion. Peers and siblings issues. Transition issues.”

“It begins at the top....document and challenge at that level. Request documentation that reflects levels of care to nature and severity of child's needs and insist on "statements of progress" or notations of "regression."

“Working with Medicaid to get referrals to out of state providers was difficult and challenging at times, and Medicaid was the secondary payer for our son. The Unknowns of his disease...that we are still facing. Not being HEARD by physicians, (one's covering for our primary care MD) the distance to travel to find an expert that has experience with our disease.”

“The biggest gaps for my child's health care needs have been the slow process of "wait and see"." He will grow out of it" I would like to have a good nutritionist and an excellent pediatric gastro. Take a good hard look at my Autistic son and look at ALL the facts.”

“Is getting out of state approval in dealing with Medicaid to see specialists that know what they are doing.”

“The biggest challenges would have to be the traveling we have done. We have been to Billings, Bismarck, Grand Forks, Minot and Sidney (MT). Also having to take time off work for appointments and traveling. It becomes stressful at times to find overnight daycare for her 4 year old sister when we have to travel.”

“My daughter has a terminal diagnosis. A progressive and degenerative disorder, but does NOT qualify for DD services because she is not MR. Medical costs are tremendous, and should her insurance change, or run out, our family will be in poverty because there are no services in the state that she qualifies for.”

“Receiving adequate health care in ND. All the specialists we see are out of state.”

“There have been many, but the lack of care coordination and assistance.”

“The change over in doctors.”

Families Share Their Thoughts

18 Continued

“I can't even begin to tell you... lots. Not being referred to the Infant Development program (SHSC) by our son's physician was probably the biggest gap. This wait and see attitude does such a disservice to families. Meanwhile the child suffers.

“Referrals to specialty doctors out of our state (example specialized neurology, sleep specialist and continued metabolic testing) are denied. Our daughter is undiagnosed to this day (9 years). Also we are continually denied medically necessary therapy (PT, OT and Speech).”

“The biggest gap is trying to link a physician or psychologist’s recommendation to school life. I have a very conscientious school & am very happy w/ their services, but things could have gone a lot smoother and quicker if there was better ease of sharing info between the two identities.”

“My son is 8 yrs old, been to St. A's, Gillette’s, and Shiners. He was recently dx with Scoliosis at Medcenter that's been there since birth. The standard hip x-ray should include a spine one for extra needs kids. In a rural area, I have an extremely hard time finding a sitter. I work and live in town and will have to drive 22 miles this summer for daycare. My son's meltdowns can be very mean. He is on Concerta, but today I got scratched with a fork. When he doesn't get his way, he tries hard to you. The meltdowns don't last long, but can be a wild 5 minutes.”

“As mentioned above, child care is a huge challenge for my child with special needs.”

“It took us a year to get a good treatment plan for her mental health needs. It took that long to figure out what was going on make three different medication changes and get her and our family into an appropriate support program.”

“Referrals for out of state care .. transfers from one hospital to another.. one hospital not having the financial/medical information that the primary hospital has .. having to repeat myself to each hospital/clinic I visit. It would be nice if they were all linked and could access the health care information no matter where you go .. also getting authorization for PT/OT/Speech seems inconsistent depending on who is the reviewer .. having to appeal and appeal really bites.”

“The children I am guardian for are receiving excellent care=concerned if they will be able to keep receiving this high level of care as they leave this school and enter the adult services world.”

“Eligibility criteria, we are always just over the income guidelines so we struggle every day.”

“My daughter's hearing aids were not fully covered by private insurance, and Medicaid refused to pick up the remainder. Thankfully I am able to get subsidized for the remainder through Early Intervention, but I don't think this option will be available to me once my child reaches age 3. Hearing aids are very expensive and a huge financial burden for so many families. If I would have had to rely on Medicaid alone, my daughter would have had to settle for sub-par hearing aids according to the audiologist--this at the time when hearing is SO critical for speech and general mental development (under two years of age).”

“A health care plan should be available for all children even with working parents. At the college we do not have an adequate health insurance. My child is not included in this so called insurance.”

Families Share Their Thoughts

19. **Tell us what would assist you as a family to better meet the needs of your child's healthcare? Examples: eligibility criteria changes, a Medicaid Buy-in program, waiver etc.**

"Look at eligibility and make it easier to get on."

"We have great health insurance with Blue Cross Blue Shield of ND. We struggle with the co pays and coinsurance. Our son is on one medication that costs $1,500/month of which we pay $324/month. There are also co pays and coinsurance for office visits (medical, psych and physical therapy). I work a second job just to keep up with the medical expenses. I don't expect insurance to "pay for everything" because my child has special healthcare needs. It is my responsibility."

"More help with other medical equipment such as special shoes that are needed for preventative measures."

"Now, that we're aware of the assistance program through Medicaid, it's been very helpful to us. The stress of making ends meet etc. has been helpful."

"I know family members and children would benefit if ND would develop a Medicaid Buy-in program for children."

"All of these would help."

"Question nine should identify the financial stresses: child care is a stress; finding outside extra-curricular programs is a stress, and can be costly if you have to hire a specialist because there are no public available programs."

"Income levels and eligibility changes. I have 3 children and all 3 have problems. In the past week I have had to make a 110 mile round trip to Fargo 5 times in 4 days for doctor's appointments."

"Eligibility changes for one and daycare assistance so that we can both work to pay the ungodly high medical bills, more specialty pediatric doctors in the state to defray travel expenses on top of the medical expense."

"We've been bounced between Medicaid and Healthy steps based on our income, so we were forced to apply for a waivered service to remain Medicaid eligible, and are having difficulty getting respite help when we need it. Very frustrating!!

"KNOWLEDGE OF WHICH PLANS EXIST, what are the qualifications for them, and who to contact with further questions regarding a particular program."

"HIGHER financial limits to be able to be qualified, especially since my husband pays child support for two other children that don't live with us that should be part of the equation when trying to meet the limits."

"Changes that allow all children to receive good health care. Some families do not have health insurance."

"Waivers, eligibility criteria changes"

Families Share Their Thoughts

19. Cont.

"Appropriate mental health care for children. Not enough providers in this area. Eligibility criteria and waivers would be helpful to families. Prescription costs, finding a way to get medication at a reasonable cost for our children."

"Eligibility criteria changes... Assistance with co-pays and out of pocket expenses."

"For our situation he met criteria but they keep denying due to whatever facts they come up with for Medicaid, so I guess I would have to say I need a waiver. I want my son to be able to travel to see a top Autistic Gastroenterologist, and they do exist, but they are in Texas and other states. My son is in pain every day, I want to alleviate that pain and I want the chance to "heal is gut" which in turn could also" heal some of the brain". This is a proven science and I feel that I should have a right to pursue this path with Medicaid's approval."

"More money into respite services and family subsidy"

"Medicaid denied a $15 deductible on glasses because they were not frames approved by Medicaid. They were glasses recommended by the rep from School of the Blind. Our insurance paid for the exam, etc., but Medicaid would not pay the $15. They should not deny payment when our insurance company has paid out over $200 (saving the state this cost)!

"Eligibility Criteria changes would be WONDERFUL! Diagnosis HAS to be considered. A Medicaid Buy-in would help, and a waiver for Children with Extraordinary Medical needs would also help if it is not too restrictive. Institutionally deemed is TOO strong of a term. My daughter does not need 24 hour nursing care, but does need her infusion to continue to survive and thrive. We want her to be able to be a typical child as often as she can be and for as long as she can be. As long as she gets her medication, and a good quality of care, she just may surprise the Dr.'s and prove their prognosis wrong. If there is a waiver for medically needy children, diagnosis and prognosis MUST be considered!

"ND Medical Assistance has not paid for special services out of our state of ND. Bottom line is we have a 9 year old daughter with multiple disabilities, undiagnosed with constant changes in her physical and neurological state. We have done our research and ND DOES NOT have the specialized medical team that we NEED. I understand they don't want the business leaving ND, but it may come down to our tax paying family MOVING to MN to get the services our daughter needs."

"Eligibility criteria change - don't limit it to only MR children, possibly a Medicaid buy in program or waiver."

"A Medicaid waiver and a Medicaid Buy-in program are vital!"

"My child's health care needs are mostly anxiety and social communication. Programs outside of school for children who don't quite fit in to the current "special needs" programs (look like "typical" children, but have some "minor" special needs), but aren't advanced enough to fit in to their current grade level (such as sports)."

Families Share Their Thoughts

19. . Cont.

"Family Support used to have money for equipment, travel expenses, seminars, etc. Now it's just transportation. What you request, normally gets cut so doesn't cover all expenses. SSI money for disabled kids should be given each month like they do for kids whose dad dies. The 26K income limit is crazy. There is a lady whose husband died, and gets a SSI check for all 5 of her kids. She remarried and works full time and is sitting pretty. I make 30K gross, however, after taxes, insurance, etc. comes to 24K, but SSI just looks at Gross, 3 pay days in a month, etc., so don't receive it. I think the gov't doesn't realize that Everything that is made for extra needs kids is more expensive. How many walkers do we all have, sensory tools, books, videos?? Don't forget buying different shoes to fit over braces. When my son had leg surgery, had to get him new pants to fit over casts. Also not potty trained, so still buying wipes. It's like the expenses of a baby, although they are not. We have plenty to eat and have a roof over our head, so thank god for that. I am however, in lots of debt. Thanks for listening."

"Our child has a rare disorder, and we need to take her out of state for care. It would be helpful if we could authorize someone to compile records for her from all the specialists so we could have one file to take with her."

"I have a co-worker whose child has significant asthma and lung damage. She desperately needs respite. I wish I could share some of mine."

"Assistance with appeals for denials for PT/OT/Speech .. One on one meeting with someone who can help with the health care needs and be an advocate."

"My children are Medicaid recipients so not as great a burden as some families have. Although there are some limitations on what is available to them."

"Eligibility criteria-we look like we have a large income on paper, but our expenditures are equally as large."

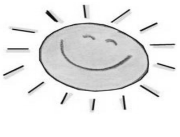
"All that you have included in the above would make life better not just for my family but alot of families."

"A continuing Medicaid Waiver for children over age 3 who still have special health or developmental needs, even if not labeled "MR/DD." Another huge help would be if we could receive benefit statements from Medicaid like we do with private insurance. I am left guessing as to what Medicaid has covered and what they have not, which makes record-keeping a real nightmare."

"One consistent pediatrician or physician"

"I would love MEDICAID program benefits waiver to continue past 3 years of age. I would like qualifying him for Social Security with our income waived. We tried to get Social Security for him but were denied. They would pay for him to be in a facility... but not for me to quit my job and stay at home with him to make sure he gets the in-home therapy (pt, ot, speech) that he needs. Crazy!"

"Information on well checks should be done and a schedule of immunizations."



National Survey of Children with Special Health Care Needs, 2001

North Dakota State Profile

Children ages 0-17 years old

State Profile Indicators	CSHCN whose health conditions result in elevated need for medical, mental health, educational services AND/OR dependence upon Rx meds to manage chronic condition	CSHCN whose health conditions include functional limitations in addition to elevated service needs AND/OR dependence on Rx meds to manage chronic condition
1) % of CYSHCN whose health conditions consistently and often greatly affect their daily activities	9.7% 921	53.1% 2336
2) % of school-aged CYSHCN who missed 11 or more days of school during the past year due to illness	9.8% 931	31.0% 1364
3) % of CYSHCN without insurance at some point during the past year.	11.9% 1131	17.3% 761
4) % of CYSHCN currently uninsured.	4.8% 456	4.0% 176
5) % of currently insured CYSHCN with coverage that is not adequate.	28.8% 2736	40.7% 1791
6) % of CYSHCN with 1 or more unmet needs for specific health care services.	10.9% 1036	21.7% 959
7) % of CYSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services.	11.4% 1083	24.4% 1074
8) % of CYSHCN needing specialty care who had problems getting a referral.	16.1% 1530	28.7% 1263
9) % of CYSHCN without a usual source of care (or who rely on the emergency room).	11.4% 1083	11.8% 519
10) % of CYSHCN without a personal doctor or nurse	11.3% 1074	10.8% 475
11) % of CYSHCN without family-centered care.	26.7% 2537	40.3% 1773
12) % of CYSHCN whose families pay $1,000 or more in medical expenses per year.	11.6% 1102	24.9% 1096
13) % of CYSHCN whose families experienced financial problems due to child's health needs.	19.7% 1872	43.7% 1773
14) % of CYSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child.	10.5% 998	34.2% 1505
15) % of CYSHCN whose health needs caused family members to cut back or stop working.	17.8% 1691	40.2% 1769

Source: Child and Adolescent Health Measurement Initiative (2005), "National Survey of Children with Special Health Care Needs," Data Resource Center for Child and Adolescent Health.

North Dakota Children with Special Health Care Needs

CSHCN screener definition categories		Income Level			Total CSHCN
		Below 133% FPL	133-300% FPL	400% FPL or more	
Functional limitations	**Estimated number of CSHCN**	**1,272**	**1,069**	**866**	**3,207**
	% within screener definition categories	*39.7%*	*33.3%*	*27.0%*	*100.0%*
	% within Income Level	*23.2%*	*15.2%*	*15.5%*	*17.7%*
Rx meds ONLY	**Estimated number of CSHCN**	**1,182**	**2,569**	**2,563**	**6,314**
	% within screener definition categories	18.7%	40.7%	40.6%	100.0%
	% within Income Level	21.5%	36.6%	45.9%	34.9%
Service use ONLY	**Estimated number of CSHCN**	**1,381**	**1,023**	**802**	**3,206**
	% within screener definition categories	*43.1%*	*31.9%*	*25.0%*	*100.0%*
	% within Income Level	*25.2%*	*14.6%*	*14.4%*	*17.7%*
Rx meds AND service use	**Estimated number of CSHCN**	**1,654**	**2,364**	**1,354**	**5,372**
	% within screener definition categories	*30.8%*	*44.0%*	*25.2%*	*100.0%*
	% within Income Level	*30.1%*	*33.7%*	*24.2%*	*29.7%*
Total	**Estimated number of CSHCN**	**5,489**	**7,025**	**5,585**	**18,099**
	% within screener definition categories	*30.3%*	*38.8%*	*30.9%*	*100.0%*
	% within Income Level	*100.0%*	*100.0%*	*100.0%*	*100.0%*

Source: Child and Adolescent Health Measurement Initiative (2005), "National Survey of Children with Special Health Care Needs," Data Resource Center for Child and Adolescent Health.

CAHMI
The Child and Adolescent
Health Measurement Initiative

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North Dakota Data 2003-2004

12.4% of children in North Dakota between birth and age 17 have a **Special Health Care Need**. One in five has functional limitations. *Based on current census data*, **North Dakota has nearly 19,651 kids with Special Health Care Needs**[1]

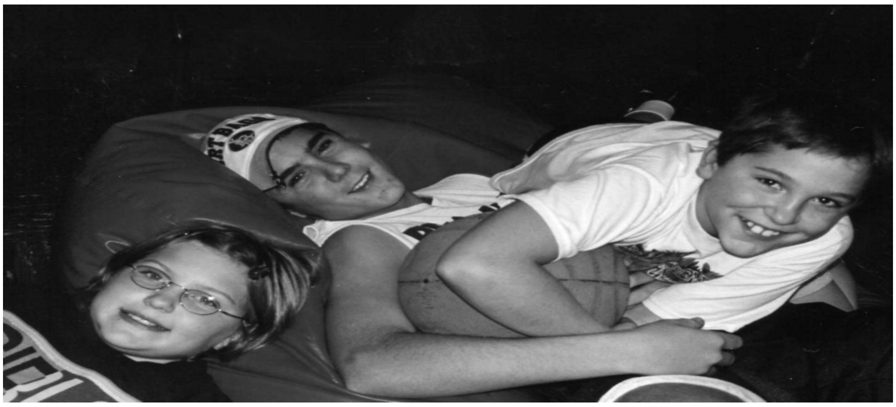
CHILDREN WITH SPECIAL HEALTH CARE NEEDS

> Children with Special Health Care Needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. [2]

31% of CSHCN who have insurance through public insurance, SCHIP in North Dakota is not adequate; with **12.9% of CSHCN** in North Dakota have had no insurance in the last 12 months.[1]

19.1% CSHCN needed some type of special services, equipment or other care for their health in the past 12 months.[1]

21.8% of North Dakota families with a CSHCN had someone in the family who had to quit their job; not take a job or greatly change their job due to problems with child care for their child in the past 12 months; while **24% of North Dakota families** experience financial problems due to child's health needs[1]



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[1] http://www.cdc.gov/nchs/about/major/slaits/nsch.htm

[2] Adopted by the AAP (October 1998). McPherson M, Arango P, Fox HB, A new definition of children with special health care needs. Pediatrics 1998; 102:137-140

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In Summary

While some parts of the health care financing and delivery system are serving children well, other parts are not meeting their needs. Many families who have children with special health care needs struggle to navigate a complicated mix of services from health plans, public programs and private agencies.

Children and youth with special health care needs are a small but significant part of our state's population of children. Though not well understood by many health plans, nevertheless their experiences are reflections of how well our health systems are performing, and should be monitored carefully.

Medicaid is an essential program for children and youth with special health care needs. Its benefits should serve as a model for all children and youth needing specialized health care services, whether publicly or privately funded.

For some children and youth whose primary health coverage benefits are limited, secondary health care coverage, like Medicaid, is essential. Additionally, children and youth with special health care needs require flexibility in health care plans such as streamlined procedures for getting specialty care and care coordination or case management.

Parents want and need clear information from health plans about health plan benefits and how to get the covered services for their child, where to go with complaints and appeals, and about other available resources that will help them meet their child's needs.

The majority of families of children and youth with special health care needs in this survey feel positively about the quality of their doctors. However, many children and youth who need other specialty providers do not have adequate access to them.

Families face a very confusing maze of services from health plans, school systems, state agencies and private agencies that are not well coordinated. This leaves families with an overwhelming roller coaster of emotions. It is often left to families to figure out who will provide and pay for services such as physical, occupational, speech, and mental health therapies. Payment responsibility needs to be clarified among all the multiple possible payers so that children are not left un-served while agencies and programs try to decide who will pay for what.

Additionally families need and require complete unbiased information to make informed decisions.

Many families provide large amounts of complicated health care for their children at home, and need more support than they now receive. The impacts of a child with special health care needs on a parent's job, finances and time must be recognized and public policies must address these impacts. Children with health conditions that are unstable and severe, have needs that are not well met by the present approaches of health plans, government programs, and community agencies.

Policies such as waivers and new opportunities through the Deficit Reduction Act need to be explored and implemented.

Coordination of care and communication among providers are essential and must be improved to ensure quality care for children with special needs. These services need to be improved within individual health plans, agencies and programs as well as across all systems that serve children with special health care needs.

Families of children with special health care needs require more information and help in order to ensure a health system that works well for their child and family. Parents frequently discussed how other families were often their most important source of information. An established means for parents to learn from other parents needs to be assured. Additionally, in the survey it was quite evident that families did not feel an equal partner in establishing policies, serving on committees. The families voice needs to be assured as an equal team player at advisory meetings, committees, policy making etc. in order to build a comprehensive system of care for children and youth with special health care needs.

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