Family Voices of North Dakota

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

A comparison of data May 2006-Oct 2009

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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.

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Introduction

There are approximately 17,000 children and youth with special health care needs (12.2%) of the child population in North Dakota who have special health care needs that include some type of functional limitations. One in five households has a child with special health care needs or a disability.

Children with special health care needs are those children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

The above definition was developed by the Maternal and Children Health Bureau, Division of Services for Children with Special Health Care Needs in collaboration with many experts in child health including parents, and has become widely accepted. This definition includes children with a broad range of conditions or chronic illnesses such as cerebral palsy, developmental delay, ADHD, depression, asthma, sickle cell anemia or cystic fibrosis as well as children who develop a significant medical problem that is expected to last at least twelve months. The Maternal and Child Health Bureau definition helps to identify children based on the impact of their special health need and their need for health and related services, rather than only on their diagnosis. Many children have more than one special health need.

A priority goal for Family Voices of North Dakota is to identify health and service experiences for families. With this in mind a survey was developed and sent out to families from across the state. In 2006, ninety families provided valuable input; and in 2009, 171 families participated in this survey via internet Survey Monkey Tool. An additional 13 families participated via focus groups, which were completed by NDCPD with 6 family members participating in Minot and 7 family members participating in Spirit Lake. This report compiles the information provided to us by 184 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 unbiased 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 than 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?**

In 2006 families responded
Not at all- 9%
Somewhat-32%
Satisfied-34%
Very satisfied-23%
Not Sure-1%

In 2009 families responded
Not at all-6.7%
Somewhat-33.5%
Satisfied-37.2%
Very Satisfied-21.3%
Not Sure-1.2%

Focus Groups in Minot
Yes__No__(6)__

Focus Group in Spirit Lake
Yes_(7)__ No____

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

Quality health care gives every child access to primary and specialty care. If a child has access to a medical home this model delivers well child and preventative care through guidelines from the American Academy of Pediatrics. It is important that the primary provider knows about the child's special health condition and how to find resources; communicates effectively with specialists and other providers.

Equally important is that the child receives appropriate care from pediatric specialists, based on efficient referrals. The family can choose primary and specialty providers, including a specialist as the primary provider.

For those families participating in the focus groups who responded that they were not satisfied with services provided feedback of the following:

- Need for medical home.
- Primary doctors do not work together.
- The doctor who is doing medical home is not taking any new patients.
- No coordination of services, parents end up been the specialists and coordinators of services.
- Parents must be the specialists.
- Problems with health care.
- Case workers do not know what to do to qualify children for DD waiver.
- No pediatric specialists in the state.
- Training for pediatricians in developmental disabilities and what services are available in the state.

2. Does your child have a Care plan?

In 2006-Yes-44.3%; No-55.7%;

In 2009 Yes-49.7%; No-50.3%

Focus groups in Minot

Yes___No__(6)__

Focus groups in Spirit Lake

Yes_(5)__No__(2)__

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.

Coordination of the child's health care, related services and payment is explained and provided is extremely important. If the family has access to care coordination, care

coordinators need to understand the range of services and communicate with one another and the family. Additionally, it is vital that health services be coordinated with other services important to the child and family.

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 is important that the child's care plan is developed by the family and providers and is monitored often; and that the health care team honors the family's culture, language, customs, and decision-making processes. As the child ages into adulthood, the plan of care should include assistance in the transition from pediatric to adult health services.

Families do the best when they are full members of health care teams, participating in all decisions. The plan of care should include supports the direct care given by families and describes the child's role in self-care. It is also important for providers and health systems give families and children opportunities to comment frequently on care they receive.

For those in the focus group who responded no, they felt:

- Need training to educate parents and medical doctors on what a care plan is for parents and medical personnel.

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?)**

In 2006 families responded:
Not at all- 6%
Somewhat-26%
Satisfied-29%
Very satisfied-34%
Not Sure-5%

In 2009 families responded:
Not at all- 1.8%
Somewhat-23.6%
Satisfied-38.8%
Very satisfied-34.5%
Not Sure-1.2%

The majority of families of children with special health care needs in this study feel positively about the quality of their doctors. In comparison of the two surveys there has been a slight increase of family satisfaction.

Other consideration for families is to receive information about their child's diagnosis, services, expected outcomes, ways to pay, and their rights and responsibilities. It is important for families to have easy access to medical records and other important information and documents; and that information is communicated in family-friendly language and formats.

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

In 2006 families responded:
Not at all-18%
Somewhat-36%
Understand-30%
Understand fully-7%
Not sure-9%

In 2009 families responded:
Not at all-23.3%
Somewhat-37.4%
Understand-27%
Understand fully-8%
Not sure-4.3%

Focus groups in Minot

Yes___No__(6)__

Focus groups in Spirit Lake

Yes_(6)__No__(1)__

Overall there has been little change in this area. 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.

Additionally, the plan of care should allow and describe standing referrals, access to out-of-network providers, extension of benefits, exceptions to policy, and supports for a family to care for the child safely at home. It is important for families to easily find and use information about grievance and appeals processes. All health systems should regularly review and address gaps in coverage and services, based on family feedback.

For those in the focus group responding no they felt and questioned:

- Is there a process and if so how do you access these services?
- Information needs to get out to parents. Now the parents have to do their own research.

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

In 2006 families responded:
Primary Provider-66%
Specialist-34%

In 2009 families responded:
Primary Provider-58%
Specialist-42%

Focus groups in Minot

Primary Provider _(6)__Specialty__

- Health care is through local physicians and nurse practitioners.

Focus groups in Spirit Lake

Primary _(5)__Specialty __(1)__Both __(1)

There is a slight shift in the number of families who utilize a specialist for the care of their child. 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.

Many children who need other specialty providers do not have adequate access to them, particularly to quality mental health providers, therapists and home health providers.

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%

Not at all-3.1%
Somewhat-25.8%
Satisfied-41.1%
Very Satisifed-29.4%
Not sure-0.6%

Focus groups in Minot

Yes_(6)__No__

Families in Minot reported:

- Health care, yes.
- Mental health, yes.
- Educational, no.

Focus groups in Spirit Lake

Yes Satisfied_**(7)**__No___

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%

Not at all-12.2%
Somewhat-37.8%
Satisfied-28%
Very Satisfied-20.7%
Not sure-1.2%

Focus groups in Minot

Yes___No__(6)__

Families in Minot reported:

- Need more coverage for heart conditions, hearing loss, etc.
- Hearing loss is only covered till age 18.
- Medical equipment not covered for all ages.
- At age 13 children are required by the BCBS to sign the form even though the child has a developmental disability and cannot sign her name.

Focus groups in Spirit Lake

Yes/Satisfied_(7)__No__

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.

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

It is important for public and private policies assure that families can afford their child's health care and that families are assisted in understanding and utilizing all payment options. Families have roles in making cost decisions, including vendor selection each and every day and can be looked to for information on how to be the most effective.

Likewise, payers compare hospitalizations or other expensive treatments to alternatives, such as out-of-network services that might cost less or produce a better outcome at almost the same price and can assist families to make informed choices. Insurance plans can assist families in monitoring overall costs to the family, including out-of-pocket expenses and could communicate to make sure that payments are made on time.

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%

Yes-69.4%
No-30.6%

Focus groups in Minot

Yes___No__(6)__

Families in Minot shared:

- Therapy is limited to predetermined number of visits, after that is out of parents pockets.
- Need more medical coverage for children.
- If no MR diagnosis no Medicaid available.

Focus groups in Spirit Lake

Yes_(6)__No__(1)__

Quality health care includes flexible, family-centered health benefits. Health insurance plans could aide in this by identifying and following children with special needs. Covered benefits need to include the services that children with special health care needs require.

Children 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 have shared with us one of the most difficult was to obtain approval for out of state visits to specialty care providers for their child's care.

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%

Not at all-8%
Somewhat-33.1%
Satisfied-37.4%
Very Satisifed-19.6%
Not sure-1.8%

Focus Groups in Minot

Yes__No__(6)__

Families in Minot shared:

- Rural states do not attract specialists. The medical system does not support parents with children with special needs.
- Need a system that is seamless.

Focus Group in Spirit Lake

Yes_(7)__ No____

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.

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

Yes-45%; No-55%

Yes-45.6%; No-54.4%

Focus Groups in Minot
Yes_(6) _ No__

Focus Group in Spirit Lake
Yes_(2)__ No__(5)__

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.

While this is not a comfortable topic for many families research is now telling us that over 70% of all bankruptcies are due to medical expenses for individuals.

The causes of financial hardship for families of CYSHCN are complex and often intertwined. Some relate directly to a lack of health insurance, while others result from underinsurance—the gaps in coverage that result when a public or private insurance policy doesn't cover all of the services that are medically necessary for a child.

Although the percentage of uninsured CYSHCN has declined, just over one third of families still report that their child with a special need has inadequate health insurance coverage. These families most commonly report that the costs that are not covered by their health plan are unreasonable (28%), or that their health plan does not offer the benefits or services their child needs (12.2%). Inadequate insurance coverage is reported most often among the lowest income families, families with private insurance coverage, and families whose child's condition is most likely to affect his or her functional abilities. Research also documents significant state variation in underinsurance.

The data reveal patterns of hardship that are complex. They reflect characteristics of children, families and the system itself. What that means for policymakers and others concerned with the well-being of children and families is that preconceptions about who is likely to experience hardship may be misleading. Families living in varied

circumstances, with children who have a range of different conditions, encounter significant financial challenges.

Across America, a substantial proportion of middle-class families raising CYSHCN are experiencing material hardship. Some families have to make hard spending choices and difficult sacrifices to ensure adequate care for their children. Other families, who do not have the resources even to consider these choices, experience severe financial hardship and medical debt while their children are placed at high risk for adverse outcomes that do not need to happen.

Financial hardship is common among all families of children and youth with special health care needs — regardless of income. Financial hardship is not linked only to the most severe cases of disability, the most complex medical needs, nor the most significant medical expenses. Families are linked to financial hardship through three interconnected pathways: higher health care costs, higher routine expenses, and the loss of employment income. *(Catalyst Center, Breaking the Link)*
http://www.hdwg.org/files/resources/Catalyst_Center_Breaking_The_Link.pdf

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%

Not at all-7.3%
Somewhat-40.9%
Satisfied-37.2%
Very Satisifed-14%
Not sure-0.6%

Focus Groups in Minot
Yes__No_(6)_

Focus Group in Spirit Lake
Yes_(7)__ No__

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.

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.

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

It is important to families that quality health care is also family-centered. Health care services that allow the child to live at home, attend local schools, and be part of the community is essential. Families also need to be connected and receive information about parent-to-parent support groups and other family organizations that will provide the necessary emotional and informational support that they may need.

Health care serves families best if it is delivered in locations and at times convenient for families. If necessary, families receive transportation assistance to get to medical appointments. Health care sites need to be culturally competent and accessible, providing translation services and family-friendly information.

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%

Not at all-8.6%
Somewhat-45.4%
Understand-33.7%
Understand fully-9.2%
Not sure-3.1%

Focus Groups in Minot
Yes__No_(6)_

Families in Minot shared:

- Need a coordinator that will manage the system.

Focus Group in Spirit Lake
Yes_(7)__ No__

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.

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%

Not at all-21.5%
Somewhat-30.7%
Satisfied-34.4%
Very Satisfied-9.8%
Not sure-3.7%

Focus Groups in Minot
Yes__No_(6)_

Focus Group in Spirit Lake
Yes_(4)__ No_(3)_

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%

Not at all-20.4%
Somewhat-16.3%
Satisfied-22.4%
Very Satisifed-7.1%
Not sure-33.7%

Focus Groups in Minot
Yes__No__

Families in Minot responded:

- No. Not equal partner.
- I am not actively involved.

Focus Group in Spirit Lake
Yes_(3)__ No_(4)_

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.

Quality health care builds on strong family-professional partnerships. Families have an increase in satisfaction when they and providers make decisions together with the child participating as much as possible. This works best when administrative policies and practices support long-term relationships between families and providers.

Families are very useful to professionals and should be encouraged to help develop and use tools that measure quality of care and family satisfaction; participate in in-service trainings with providers, agencies and health plans and serve on statewide and local public and private policymaking boards.

Quality health care also needs to be cost-effective. Across the country family leaders help set capitation rates that cover real costs for children with special health care needs and serve on commissions reviewing expenditures. Real costs are tracked to assure that children receive necessary benefits.

Families as Partners- Successful implementation of family centered care requires that outmoded ideas or prejudices about families be replaced by a view that supports the central role of families in care giving and decision-making. It is a view that assumes families are partners with professionals and that decisions involve a team process. Optimal teamwork requires: Open communication; Sincerity; Trust; Objectivity; Empathy; Honesty; Respect; Shared vision and goals. Operationalizing these qualities is easier said than done. For professionals, it means relinquishing some control and operating in a more flexible manner. Family-centered care applies to every level concerned with services for children with special needs: in the care of an individual child, in the way services are organized and delivered at a clinic or hospital, and in the development of policies and programs at the local, state, and national levels.

Family-Centered Strategies- There are some very practical strategies that service providers can use to become more family-centered in their approach: Conduct periodic surveys of your client families to ask what things you might change about your services…and then act on the recommended changes and communicate these decisions. Establish an advisory group of families for whom you provide services. Be clear about your expectations and support the group to make decisions about when, where, and how often they meet. Again, act on recommendations from the group. Become familiar with the range of service options that could benefit the children and families you serve. Make available informational brochures about these other services and programs. Ask families if they need other services and then help refer or connect them to resources they need. Group practices or provider groups should have a staff member who understands the service systems potentially needed by client families. Consider hiring a parent or family member to serve in a direct role assisting families and helping coordinate services.

Reaching Out to Families-Sometimes the efforts of professionals to involve families in policy planning and committee work fail to get the desired level of involvement by families. Here's a simple checklist that may help address potential barriers to participation:
Are meetings set for times and places convenient for families at least some, if not all, of the time? Are there provisions for childcare or stipends to cover costs for sitters or other forms of assistance families need such as transportation, parking, meals, etc.? Are families' more than token or isolated members of the group? Is their participation valued in meaningful ways e.g., leadership roles, paid participation, agendas that address their concerns, etc.? Are there tasks or committee activities families can work on between meetings? If meeting attendance is not practical, can families participate by phone conferencing?

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 am amazed at all that Donene and the staff have accomplished. My work and family commitments have made it more difficult to be as active as I would like.
♥ND Autism Connection, NDCPD, YMCA, Special Needs Committee for the board of the United
♥I am disappointed by empty promises. I've initiated meetings with officials at state, county, and city levels regarding children's health services. I'm told that I'd be great on an advisory board, but then never hear anything, very frustrating. It's frustrating to always have to fight so hard and fill out so much paperwork and take so much time to get our child's needs met.
♥Pediatric specialists are needed in the state!!!
♥ I AM PLEASED WITH THE SERVICES/COORDINATING EFFORTS THAT DAWN SCOTT-LARSON HAS PROVIDED MY FAMILY. THANK YOU YOLANDA
♥Anne Carlsen Center for children is so important in our life!!
♥ Very satisfied with Family Voices, P2P network. Everyone works very hard to make sure questions are answered and to assist families until every avenue has been exhausted.
♥ DPI's Special Education doing a great job of trying to stay ahead of kid's needs.
We use early intervention and they are doing a great job.
♥ The state case managers and administration is very reluctant to truly share all information regarding funding/ priority/costs/reason for decisions etc. One must get the information piece meal bit by bit from many different staff etc. to get information desired.
♥CSHS, FVND
♥ND Dual Sensory Project, Sherri Nelson
♥ ND School for the Blind/Vision Services and ND School for the Deaf (all involved!)
♥ I think the state needs to rethink their model for early childhood intervention and allow more direct therapies to be provided and not only on a consultation basis.
♥ We have 3 special needs children. Not really able to get to activities that much.
♥ Head Injury Association of ND - State Secretary
♥Parent to Parent
♥Family Voices of ND
♥Helped pass a bill to create ND's Head Injury Association.

♥The Arc of Bismarck is doing a great job of keeping parents, etc. posted of legislative actions relating to services to individuals with disabilities.
♥TURN OVER RATE IS VERY HIGH ONCE WE GET SOMEONE THAN WE HAVE SOMEONE ELSE THAT IS NEW
♥Do a good job: FVND; The Arc of Bismarck; Legislative Working committee and BECEP
♥I think what would help to make experiences that I am not satisfied with better is to make sure that I'm aware of the information ahead of time, make sure I understand the information, not waste my time on mission and vision work - but instead work on projects that are tangible and help families.
♥ Need more programs for mentally ill children as there are very few options in the state.
♥ I am part of the Family Advisory Council at MeritCare. Cathi Chial is a huge asset to Merit Care.
♥ Pride Manchester House has done an outstanding job of helping my child and our family!
♥ NDICC - Roxane Romanick, she keeps the people active and aware of different policies, etc. I am 2.5 hours away from her and she still keeps in touch by phone and email.
RICC
♥Involved in the Experienced Parent project support group, led by Jane Nelson, who does a wonderful job. I also serve on the Cass Co ARC Board.
♥ Cathy Haarstad is the best advocate I have met in the state for families affected by autism.

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.

♥ Through email or websites.
♥Perhaps this information can go home through the schools, churches and other community organizations, clinics etc. Not enough families know about the valuable resource of information and referral that FVND provides families.
♥ Having health care providers in the hospital know who families can contact would be a great start. Not one health care provider in the hospital suggested Pathfinder or any other resource.
♥The person who diagnose should prove contact to right person from when they can get all the information. Many times the case worker doesn't have all the information and they don't keep their knowledge up to date.
♥I believe you are doing a nice job already.
♥ I did find out about services from a MSU educator
♥ I feel that if there are programs out there to assist families in any way/shape/or form they should be given to the families instead of families having to wait and ask questions to find out the information.
♥ Do you have a Facebook?
♥There should be more supports for families with undiagnosed conditions, suspected conditions and rare disorders. There are many support services for Downs, Autism, etc. However when you have a rare disorder, often times there isn't a National organization and thus living in a rural state makes support even more difficult.
♥ I have lived in North Dakota and have yet to be connected with a provider that can assist our son (he has Asperger's Syndrome)with adolescent daily living skills and social skills (changing body-driver's education-riding a bike...) Possibly a folder with all the area resources available to the child & family. Someone who can go over these resources, explaining why it would serve their needs and how to go about getting those services.
♥ Our daughter was in the NICU so the hospital social worker gave us most of the info we needed and contacted our DD case worker to get that process started and give us the rest of the info. I didn't have to search or find anything on my own. It was wonderful.
♥ Working with physicians, I would like to see more information available to families in the physician's office.
♥ There should be support groups where people can go or that we should be notified that someone just got diagnosed and someone should call that family to encourage them.
♥ There doesn't seem to be much for families with hearing impaired children. Most efforts seem to be based on kids with Autism, ADHD, or more complicated physical disabilities such as cerebral palsy, etc.

♥ Handbook with resources for Parents of children with Special needs and/or a separate listing of this on your website.
♥By word of mouth from the medical field as to whom the family could contact for added support.
♥ I think that families often live day to day when their children are very young, and don't get to a point of being able to explore resources until there is some type of plateau in their child's development or they have time to do this (like when their child starts school, etc.)
♥ The only way family support could be improved is if groups, service providers, parent organizations could get these families contact info early on and THEY make the initial contact to let families know what they can offer. Several families will have requests right away and those who don't are more likely to make a contact when they do because you initiated a contact early on and they will remember you.
♥ This is what I've been telling everyone! At time of diagnosis, there should be an advocate available to meet with family/patient and say this is what you need to do, who you need to contact. Just as an adult diagnosed with cancer is immediately given access to countless services, the same should be available for children and their diagnoses. We were alone, and I SEARCHED for resources and made calls and went to meetings and filled out paperwork. I spent more than two years searching for help, including at social services, and they never even told me about CSHS. Very sad and frustrating at how much money and stress it could've saved our family. All agencies need to know what the others are doing and can help with. Accessing existing programs should be a simple, streamlined process.
♥ I think one of the things that would help is if the provider diagnosing the child had at least a pamphlet with all the resources in the state that are available and then set up an appt with the hospital systems social worker to go over all the information with you again would be helpful. Family Voices could help in this by helping get all the resources in a compact hand out that could easily be handed to a parent.
♥ IF THER WERE A WAY IN WHICH DIFFERENT FAMILIES WOULD NETWORK WITH ONE ANOTHER KEEP EACH OTHER ABREAST OF HOW TO HANDLE CERTAIN THINGS THAT SEEM HARD TO THEM.
♥ Big tent is a good resource
♥ When a child is born in the hospital with disabilities or born premature the social workers at the hospital should set the parents up with family voices immediately before discharge to home and also have someone check periodically with the family by a social worker who is trained on all the services available to them.
♥ This is a tough one. A universal system that all agencies could access, almost like the 211 but specific to disability would be helpful. A system where all agencies have access to a data base search for the best options for a family. There are so many services available, it isn't possible for all agencies or workers to know of everyone.
♥ It would be nice to have a "directory" of sorts that might have support groups, different support needs.
♥ I think FV does a great job organizing the information and having it available for people.

♥ Perhaps FV pamphlet could available at all physician's offices and Special Ed units. Some I've been to had them and some didn't.
♥ I did not know where to go. My daughter went through so many traumatic experiences as a young girl being diagnosed so incorrectly. We were at Prairie St John's and then I decided to go to Merit Care and they told me she was overmedicated and that is why she was being so horrible. I feel you can't trust doctors.
♥ I think that it should be mentioned at the time of diagnosis from their primary physician.
♥ Family Voices is great and contacted me as soon as they got my name and number. The problem we are having is getting a diagnoses, everyone says the obvious: he has definite delays in speech, behavior, and other areas. but no one wants to say what a diagnosis is they just want to keep retesting.
♥ periodic advertisements in newspapers about what Family Voices is.
♥ letter to all primary care practices in the state about what FV is
♥ Educate nurses that work in labor and delivery. I have had phenomenal experiences from social services, doctors, Designer Genes support group. I had one good nurse while I was in the hospital for delivery and a few that had no idea what to say or how to help me cope.
♥ Families should receive information when child is diagnosed. Especially to support organizations. Info. should be available at social services, schools, medical facilities, and possibly pharmacies.
♥ Give us one phone number of who to call to help direct us in the right direction for what we need. not a bunch of numbers and different people to figure it out. just one person.
♥ I think Early Intervention is the first link. We need to get children with special needs seen as quickly as possible so they can receive the help and support they need! I think more information is needed at time of delivery in the form of a "care package" for families when they take babies home from the hospital!
♥ A listing a available therapy providers that are willing to cover rural communities email information such as you provide and training opportunities
♥ I found it very hard to learn about services for children with special healthcare needs. I was always given the run around and always had to wait for answers. For new families I would suggest sending out a packet of information containing information for all services available and support groups for families dealing with a child with special healthcare needs.
♥ Contact should be made personally and privately and information regarding possible assistance/family support should be shared before the family has left the hospital with a newborn. Much is lost when information is shared via written material. Information should be spoken.
♥ The email information received is very helpful.
♥ I was told about Family Voices (what they do and their website--which is great) from Infant Development right away and was also given handouts about various resources at the Merit care Coordinated Treatment Clinic so I never had a period when I was searching for information. Therefore, I don't have advice for improving the process because my experience was great.

♥ Information in one hand out? I have had to call many places looking for help myself and usually I get, "that is not what we do" or "you do not qualify". Maybe a central place with information on resources or a computer program that you can input you information and it gives you what services would then be available? We seem to slip through the cracks, even with 3 children in the Autism Spectrum.
♥ There needs to be a centralized resource for families with children with special health care needs. We were referred from agency to agency to agency and did not receive help from most of them - we just got the run around.
♥ Families are busy with all aspects of their child's needs. I think the best way would be to have someone available at a medical facility.
♥ We were living in another state at the time my son was born and their services were different at the time of his birth. He is now 44 years old I do feel services should be accessed from time of birth to have developmental levels monitored and therapies that are needed.
♥ through the hospital or medical provider institutes they should have brochures.
♥ Our boys were adopted through the AASK program - so even with them being aware we would have issues down the road, we were not told who to contact and they didn't have anyone follow up on us later. We had to struggle with things and eventually figure some things out - sometimes too late.
♥ I feel at the time of diagnosis the family should be offered all resources from somebody.
♥ Perhaps the providers need to be held accountable for that information. I don't know how else to speed the process. I had to get on the phone and do all the research myself which is difficult since at the time I was single and the only caregiver for a mentally disabled child.
♥ A cheat sheet or list of agencies or resources available, with a brief description about each one.
♥ Have medical facilities provide you with facts on their services and facts on actual outcomes.
♥ Have medical assistance send out any changes to any policy!!!
♥NEED TO MAKE IS EASIER ONE PLACE HERE IS THE INFO. WITH THE LINKS IF YOU NEED THEM OR PHONE NUMBERS ONE PLACE
♥ More training on Medicaid
♥ We have to continue to "ping" on the gatekeepers - those people that make diagnosis, deliver diagnostic news, or make special education categorical decisions - they hold the key to getting information to families, but are still the hold-outs in this.
♥ It needs to become a priority of providers to know or have accessible the necessary resources and information so families can connect and/or research on their own
♥ I feel that I have received very good information since my child was diagnosed. I was lucky to have physical and occupational therapists who knew where to send me for more information and help. I was connected with a very good case worker at West Central

Human Services, and have been very happy with the help and advice I have received from them.
♥ I feel it's the social service departments to address the issues while you are still in the hospital. --Inform you of all the services that are available to you.
♥ Actually talk with the parents and ask what they are needing.
♥ Family Voices has done a wonderful job with us at providing us the information that we need.
♥ 3 years later I am comfortable in the knowledge that I have gained on my own. Initially I felt very alone and that no one understood. I am happy to be a support parent.
♥ I am a Registered Nurse and still I do not know what agency to start with re: Medicaid, SSI, etc for my son.
♥ My daughter has a very rare blood disorder and we have received no support outside of our doctor and the national website for families who have this condition. Not sure would have been nice if the doctors in Minneapolis could have pointed us in the right direction.
♥ In the NICU or PICU and through Early Intervention services.
♥ Need to have doctors or case workers give more resources and options to family so they can make proper choices.
♥ It starts in the hospital or at the Dr. Office. Families need to be referred to FVND and SEHCS at the time of diagnosis. The social workers need to be on top of things and follow-up with the families to make sure they are receiving the services and support they need from providers and agencies.
♥ Face to face communication, written FAQ's, name/contact for follow-up ?'s, website
♥ no matter how much info is provided a lack of knowledge to look for and find seems difficult. -Also a lot of people may think they cannot participate due to income so don't even bother checking. Internet seems to be a very good tool.
♥ Well my first experience was in the hospital. I think the question you just asked "from the day a child is diagnosed" which is in the hospital. I was introduced to a Social Services person who had brought me information in my area. I live in a rural area and the information she had brought to me was information where my child was born. I guess what I am saying a lot of mothers usually give birth come from all over the city, rural areas, & need more information in their area. I mean they are not going to move just because the information given is just for the city only. Information should be given out mailed out or work with the hospitals, clinics, Social Services to find out where the children are living and give information our pertaining their disability.
♥ personal visit from a veteran parent who is dealing with the same diagnosis. A complete list of resources available and where to find them, given to you when child is diagnosed.
♥ This has been an issue we have discussed at many levels. It is imperative the parents get this information upon diagnosis. The parents are going through a traumatic event and in most cases do not know how to deal with it personally let alone how to deal with Services. I think the medical communities must be the first contact with information. The doctors are the ones who make the diagnosis and are the first to know of a child with special needs.

♥ Internet is the primary place I looked for information. Using your website partially as a way to access info on various trusted sights.
♥More needs to be done in the hospital - teaching for medical professionals on how to deliver the diagnosis - we rec'd NOTHING in the hospital re: our diagnosis. It was handled very poorly.
♥ The resources are very limited even if the sky is the limit with finances.

From Minot focus groups:

♥I think a good job is done in networking families with agencies in town linking other agencies. The chain is only as strong as the weakest link.

♥A child with a disability can divide a family. Often one of the parents also have a similar disability but many times that disability was undiagnosed. To alleviate the blame, jealousy among siblings for the extra time that the disabled child receives, and other conflicts from added stress, families should have time with a trained professional who can recognize these conflicts and help reduce some of the stresses associated with a family who has a member with disability.

From Spirit Lake focus groups:

♥Call and find out where you can find info

♥Letters

♥One good thing is Early Tracking-a step toward services now-positive experience

♥If you know your healthy and you should contact the people who help you stay healthy.

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.**

♥I feel Connie Booth does her best with helping me.
♥ I do believe our families experiences may have been different particularly my children's with the right, timely information and supportive medical care during those early developmental years.
♥ Any referrals/information on resources would have been helpful. We got nothing from the doctors or nurses, either in clinics or the hospital. We are still facing the issue of how to get him to a point he can live successfully and independently.
♥ There is not a lot of information or resources for cardiac patients.

♥ I am never really sure what is covered by our insurance or what services are available here in
♥ As our son gets older it would be great to have information on what programs or activities are welcoming to children with special needs or are provided specifically for those with special
♥ IDEA part C was a life saver. Not all children with Special Health care needs qualify for Special Education services, therefore information on planning and care during school would be helpful. 504 plans and other resources for these children is a big need.
♥ After leaving the military it would have been very helpful to have a point of contact once we moved to Dickinson and also a list of providers and services that we could access for our son.
♥ Instead of depending on case workers and teachers deciding what was a need for our family, give us the choice of what our family needs and allow us to pick and choose, with assistance, what we think we need.
♥ I think we had all the help that we needed...sometimes too much info right away.
♥ To have a place where our children could go to learn to be social and have friends. Could write much more, not enough room. Positively, not negatively.
♥ Hearing and sharing with other families
♥ A support group for parents of hearing impaired children.
♥ more info on "what to expect down the road"
♥ We were very fortunate to have an excellent doctor for the granddaughter here in town. He gave us all the information and then some that we needed. Along with other agencies to contact.
♥ People and agencies coming to me instead of me having to seek them out it more comfortable for me.
♥ Needs: Continuous in-service on the changes in all of these support services/programs and how families can best gain access to them and do the paperwork.
♥ Someone LOCAL to listen and tell us what we needed to do after diagnosis. Anything would have been better than nothing.
♥ Knowing what services that are out there and how to access them.
♥ SOME SORT OF GUIDE AS A PARENT OF AN AUTISTIC CHILD, "WHAT TO DO NEXT" SORT OF THING.
♥ It would have been more helpful for us if the public health office and the primary physician's office had been better at screening for developmental disabilities and referred us to specialized services earlier. If we had not moved to a more urban area and persisted exploring the system ourselves, we would have been without services until much later.
♥ more financial help
♥ The Anne Carlsen Center is incredible and needs to be available to families forever!
♥ To have had important information and referrals from the beginning. Everything was left to me to search for. I provided his case management while others were being paid for the job I did.

♥ Having an experienced parent to lean on. And being referred to services earlier.
♥ I need information on community based mental health resources--social skills groups, parent information on ADHD, anxiety, ODD, etc. Support group information would also be helpful.
♥ My child is 22 now, so things have changed a lot. But, when my child was small, no one would listen when I said there was something wrong. I still think that if we'd had a better diagnosis earlier, we would have a better outcome now. I wish I would have had a family voices contact then.
♥ It would have been nice to know that I was not alone. I had my faith in the doctors that prescribed the medication and thought she was in the best care. The doctors at Prairie St John's are very good, don't get me wrong, but my daughter was so out of control that I didn't know where to go, where to turn or who to contact. It was a blessing in disguise when I switched to Merit Care.
♥ We asked our physician about services but he seemed very vague and did not offer to provide us help in any way.
♥ Medical professionals never saw symptoms of mild Asperger's until we called it to their attention.
♥ We would have really like an in-service on how Medicaid works. We would have also liked information from our Dr. on who to contact for special services and support for our daughter's condition. If it wasn't for my wife's disability, we wouldn't have had any idea on who to contact or where to start.
♥ I got so much support while in the hospital. Med Center One was great for supplying information both health related and emotional support related. There were a couple of young nurses that needed a bit more education with dealing with people who have a special needs child.
♥ Residential and day programming costs and funding seem to be kept in a black box with information only given out stingily.
♥ One place to get most answers, and a specialist to call when you're having troubles or At the beginning, if the doctor would have listened. It would be helpful to have info. for older children reaching transition age to adulthood. Medical personnel should help keep parents reminded of appointments or tests to be needed as the child grows.
♥ We have had such an amazing experience, partly because our daughter was in the NICU for a long length of time. Most information was provided by our Developmental Disabilities case manager and the hospital social worker at Trinity Hospital. We had a WONDERFUL experience!
♥ our DD coordinator has been helpful trying to locate ST services .....having Medicaid as a secondary insurance has lifted a big financial burden.....also Easter
♥ Occasionally finding a physician that cares.
♥ I would greatly like to receive a packet of information containing names and numbers of people or places to call for help in finding programs or support groups to attend with a child who has special healthcare needs. Would be nice to have directed information for certain types of special healthcare i.e.: autism, cp, or all the different kinds of diagnosis.

♥ There was no family with a similar health problem anywhere nearby - that would have been helpful but not within Family Voices power. We did get linked with some other helpful families.
♥ Sometimes we run across people in the school system not well informed as to the needs of special needs children. Only very few, but a few don't care.
♥ It would have been helpful if anyone would have had any information to share with us on Traumatic brain injury. I have had to quit my job and spend many hours a week researching my questions on the internet. Who out there could tell me what to expect, what to do to help us, what resources are available! No one did.
♥ Residential and Employment services are Provided by Pride Inc that the agency keeps me abreast of needs and changes in services. Am satisfied with his placement.
♥ We for many years were house bound because we did not know about respite care and also filed bankruptcy because of the medical costs.
♥ If it is a special needs adoption - the state should provide families with resources to contact. --The county social worker should do something - anything. The county director sends out the Medicaid renewal - we haven't talked to the last 2 social workers that were even assigned to our file.
♥ Right now I am trying to figure out the SSI options. Since my daughter quit school the day she turned 16 the IEP had not covered transition. I would really like the law to once again start transition at 14 since 16 is to late if they choose to quit school. Then you as parents are left hanging with not much guidance on what to do next.
♥ Where you need to go first. I found that sometimes I would go somewhere too soon. I had to go back to someone else and then return.
♥ Every parent deserves to be able to pick the best possible route of care for their child, we just want options with all the facts.
♥ IF YOU HAVE A FAMILY TREE SYSTEM THAT IF YOU'RE KIDS HAS THIS NEED THEN CALL THIS FAMILY WHO HAS BEEN IN THE SYSTEM AND THEY CAN HELP. SHARE THEIR STORY AND MAYBE ABLE TO HELP. LIKE A BIG BROTHER SYSTEM.
♥ We don't really have support I don't feel. My son has Aspergers, learning disabilities and memory glitches. Can't afford the help he needs. Don't know what all help he needs and where to get it.
♥ A packet of information and contact phone numbers of other families with similar issues, even internet resources.
♥ Right now, I just need to stay up on what technology supports there are to assist with learning - it's my new area of informational
♥ It would have been nice to have someone coordinate services outside of the typical medical model - social model would have been preferred. Health is obviously important but making sure your child is safe and happy is just as important!
♥ As I said before, my case workers with West Central and therapists both at school and the hospital have been wonderful resources. They always seem to be looking for ways to help us out in our situation. Without their help, there is no way of knowing what we would have been able to do on our own.

♥ I think social service could have been better at informing us of all the services available, or at least told us who to contact.
♥ More support in what we feel is right for our child.
♥ I wish there would have been a support parent with our same issues available at the time of diagnosis. Also our primary care provider had some (little) knowledge about our diagnosis. I am very happy that she has taken it upon herself to learn more and stay updated.
♥ It would be helpful to have a website contact, pamphlet, etc provided via the Special Ed for families moving into a school district of the services available, contact info, etc.
♥ More information from a family who was going thru this. We did after 3 years attend a camp in Maine for families who have this blood disorder.
♥ Being able to visit with parents who were in a similar situation as soon as possible.
♥ Someone helping us with documentation of meetings and events and organization of information.
♥ If someone would of told us about FVND and SEHSC. Also if the DD case manager would have informed us to reapply for SSI and told us about the DD Waiver when it came available. --Need ongoing communication about the changes being made within the DD programs.
♥ Having Pride Manchester team available before, during and after treatment.
♥ Insurance information. What is covered, how to go about making sure out of state visits are covered. Right now it is a learn as you go process.
♥ I have experience a lot of health care needs for my son and experienced a lot of disappointments with doctors also, but have learned from experience and found out the hard way of who I can trust with my child's medical needs. I believe truly Merit care Hospital - Fargo, ND. has helped me in my son's medical needs. We still travel 6 hours for his medical needs, as a parent you do what you have to do!!
♥ More explanation of all the medical problems that can be associated with my child's condition. -We need info on how to handle a child with ADHD & OCD as well as being deaf and having Down Syndrome.
♥Ongoing needs are to find out what other specialists are available to help our child and others to do an analysis and come up with a plan for her development and care.
♥ I have found several websites that clearly explain various health conditions but there are some that provide a packet/folder of information. Even if the parents don't look at it after birth, at least are they have it for later when they are ready.

From Minot focus groups:

♥We have had a great DD case manager who always helps us get in touch with who we need assistance from.

♥It would have been helpful to have access to professional family counseling to address the extra stress associated with a child who needs the extra time and attention. It would

also have been helpful to realistically encourage the family and the disabled individuals to set high, but realistic goals and do not lower expectations if they are within the capabilities of the person with the disability. Many families do not believe a child with a learning disability is capable of attending college and being a professional. So much depends on the person, his personality, capabilities and experience.

From Spirit Lake focus groups:

♥The concern of other people noticing

♥The transportation

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

♥ Having insurance but high deductibles and coinsurances, still high balances to pay, two children that are now young adults and still need services for their health conditions, it is very hard to balance all of these needs.
♥ the only doctor in town who deals with my son's condition has an average aged patient of 50+. There are children in town with this condition, and I know a few of them see him, but from what I've heard, the majority travel to Bismarck or to the pediatric gastroenterologist in GF/Fargo.
♥ Limited Insurance coverage. Many therapies are not covered and very limited number of visits allowed. Timely approval from insurance.
♥ Communications between specialists (out of the area) and local primary care. The specialists would rather you come to their facility (which is not financially feasible). There is no communication to assist care locally.
♥ knowing exactly what services are available.
♥ There seems to be a lack of providing activities such as sports or other activities for kids who have physical limitations but are not entirely handicapped. There are things out there for kids with autism for example but my son would have a hard time competing with them physically.
♥ Income over guidelines for financial help, but not enough net income to pay for services.
♥ The biggest barrier is location to healthcare facilities. Living in a rural area we have to travel many hours to see specialist on a regular basis.
♥ getting referrals, and run around, having to ask the questions when you don't know what to ask (no direction)
♥ We continue to hit road blocks and ineligibility for services as Jacob's needs are medical, however the qualifying criteria does not reflect the body areas that we assess and monitor.

♥ Education has focused on IEP's however not all children with special health care needs qualify for special education services...thus there should be some emphasis on those children and education regarding 504 plans.
♥Information on pandemics i.e. H1N1 and natural disasters will be extremely helpful. During the Flood in the RR valley, Jacob's medications were due to be shipped and there was a delay in the shipment. I had to drive when there was no travel in the Fargo area and go to Fed Ex and pick up Jacob's meds...I actually helped the staff look through all the next day air shipments to find his meds. Due to insurance requirements, we couldn't order our shipment and have more supplies on hand...That made things stressful.
♥ We have always faced, from the civilian sector, the attitude that because we are military retiree's that our entire son's needs will be covered by our medical insurance. It has been very hard leaving the tight knit military community and enters the civilian world where we have to fend for ourselves and try and figure out where we go for services for our son.
♥ Daycare, No communication with speech, occupational and physical therapy that the daycare does
♥ Moving from another state and transferring services was a bit difficult. Insurance doesn't cover allergy meds even when the child is an asthmatic! We were unaware that support services were available to us, even though a need was mentioned to a case worker. She later enrolled us because of the changing law and that we had to have support services to continue with Medicaid and the DD waiver. This service could have been used way earlier when mentioned before.
♥ We have been lucky. Everyone has really stepped up and taken care of any problems right away. Our DD case worker is great if I have any questions or problems she takes care of it immediately.
♥The school system has been a barrier with their reluctance in providing timely and adequate care and referrals. The school system does not seem to listen to the parents.
♥ Not having a company where experienced professionals come to your home and help you work with your child. School is not enough. Our children need "on going" interaction.
♥ Because we live in a smaller area, some of the special services my child needs are not available.
♥ Not getting financial support for all the medical trips every 2 weeks sometimes every week!
♥ Getting Medical assistance to cover anything. Not being explained the process by which Medical assistance approves or disapproves medical treatments, hearing aid devices and equipment.
♥ Specialists are always a challenge, as you travel to them. Biggest barriers -- MEDICAL EQUIPMENT!
♥When we have to have the granddaughters medication filled before it is actually due. The state won't let us fill it before the actual date. They say that it has to be exactly 30 days. But we have tried to point out that there are times when we have 31 days or 28 days in a month. They won't listen and insist that it has to be 30 days.

♥being a social worker sometimes community members assume that you know the system.
♥ Always having to seek out help, ideas, services, etc for my child. By this time, I would expect more people to be aware of what our kids need and incorporate ideas, offer suggestions, etc. without the parents having to always advocate/ask.
♥ Financial-my monthly responsibility is way too high, that I don't reach it so CSHS doesn't kick in.
♥ Mountains of paperwork, verifying the same info to countless agencies, agencies not knowing about each other... A social service worker did not know about the program coordinated by the person across the hall, and we were told no one could help--but the person across the hall could have helped alleviate so much financial and emotional stress! Children and families need a local liaison/advocate/social worker. We are not criminals trying to 'milk' the system; we are a family with a child with a legitimate need.
♥The social service agency just not helping us and not offering the right programs!
aging out
♥ THERE ARE CERTAIN THINGS WE JUST DONT DO BECAUSE I AM UNCLEAR ABOUT THE PROCEDURES NEEDED TO GETTING IT DONE.
♥Our biggest challenges have been lack of coverage for therapy services under our medical insurance because our needs are related to a developmental disability (autism) and not a "medical necessity"
♥ doctors not taking responsibilities like they should.
♥ Lack of adequate childcare, lack of family respite.
♥ Trained staff in homes
♥ Social service agencies only work with families of low income.
♥ Lack of mental health services and providers, no dental coverage. Family members not taken seriously about know their child best.
♥ Not referred in a timely manner, no help/info on SSI, not getting timely referrals from doctors
♥ being in a very rural area and not having access to the best services for our son. Not enough educators that are qualified enough.
♥ Inadequate or non-coverage by insurance company. If you're unable to get most social services due to finances then you have to rely on private insurance and that can be very difficult to get things covered.
♥ insurance coverage for mental health/counseling. Finding group therapy/social skills groups.
♥ I don't know if this is helpful, because what were barriers then aren't necessarily so now. But I lived in a Special Ed unit that would not use the POHI category, which was where my son best fit.
♥ I paid out of pocket for evaluation and recommendation from the University of Minnesota, so I could "force" the unit to correctly categorize him. It was hard; I wasn't certain I was doing the right thing, and I had no peer group or mentor with which to collaborate.
♥ The biggest barrier and gap was not having my daughter diagnosed correctly. She has

Asperger's and she was diagnosed with OCD, ADHD, etc.
♥ Our private insurance only offers 20 therapy sessions per year and we had used them up already in the first 6 months. So we just went without.
♥ Medicaid has been the biggest barrier. We needed a medically urgent consult to get a second opinion and I had to call Medicaid every day up until the day before our appointment to ensure that it was approved. Our daughter has a vision disability. Everyone that dealt with our daughter's case didn't feel it was urgent because it won't a life or death situation. After a ton of frustration and aggravation, our trip to the University of Minnesota was approved. All of our frustration with the system could have been avoided if the employees at Medicaid were more understanding of our situation.
♥ not getting a diagnoses
♥ willingness of families to enroll in support organizations
♥ Lack of educated people in the disability to talk to and ask questions
♥ dental and eyewear costs, adult health cost for my son(how will he pay?), finding new specialist after one leaves, convincing professionals of ongoing needs, reminding doctors of health issues to look for when my child becomes an adult.
♥ transition out of Early Intervention, gaps in services if child is not MR., what happens when she turns three?
♥Transitioning into the school system.
♥The fact that we live in a rural area and lack of providers that are willing to service rural areas.. Also the state of ND's model on therapy on a consultation basis and not providing direct therapy/better frequency of therapies...that ND is an age 3-21 education state for "free and appropriate education" and that they do not realize that ages birth to 4 are an critical age for development
♥Finding a specialist and travel to the specialist (400+ miles), specialist changing appointments after we have lodging reservations
♥The hospitalist program where your own doctor is not in charge and the hospitalist is not knowledgeable about specific conditions.
♥Seems like we are always waiting to hear back for places when applied for assistance or not knowing answers when testing is done. I always have to follow up and check back to make sure things are be done. I would appreciate timely assistance and answers for medical providers or state assistance regarding programs applied for.
♥Lack of understanding, ability to get appointments or get in touch with local doctors.
♥My biggest problem is not getting anywhere with medical assistance (secondary coverage) picking up co-pays when we see our daughter's specialists in the Cities or Mayo Clinic. I continue to be told that Fargo has doctors that can meet the needs of my daughter but she has a metabolic disorder that 1 in 80,000 people has our primary doctor in Fargo admits he has never treated someone with the condition and the lab doesn't have the capability to run the routine tests that need to be done (they need to send specimens to Mayo). We feel we have no choice but to travel to an "expert" and medical assistance doesn't accept that.
♥We make just over the limit for help. We use our vacation times to take our children to

their therapy sessions. And the requirement that a child has to be mentally retarded for DDS Case management is a big barrier. In the Autism spectrum, very few are in the retarded level, but they have so many other needs that DDS could really help with.
♥The biggest gap: When we were referred to the Human Service Center - they did one test and billed us $900 but we were not able to obtain any services. No one offered us support, no one offered us any information other than our daughter did not qualify for DD services. We drive and drive and drive - Drs in GF, Bismarck, Fargo. I have had to seek out physicians who could help with TBI.
♥The on going battle of our private insurance battling what they will pay and how it changes from visit to visit. The other would be the distance we have to travel to get her services in Fargo.
♥Payment and treatment for ABA Service for our son with Autism
♥ Move to ND when son was 5 found state lacking in educational opportunities that were available at an earlier age in prior state. Became active advocate to get education system changed.
♥cost of health insurance coverage
♥He does not speak but our insurance will not cover speech therapy which is actually adaptive equipment use and then Medicaid will not pay for this either.
♥Not being informed of available services - early intervention, mentoring, respite care. Fighting with the school system every year over the IEP.
♥Limits to mental health insurance coverage. There should not be a limit to days, visits etc. The cost of medicines when you are a middle income family and do not qualify for assistance. The lack of providers in NW ND. When a child needs inpatient services and is placed with adults who only make matters worse. When placed for mental health they are given the same set of rules as adults with no concern for what they need as children (special blanket, different group counseling sessions, different videos to watch that do not have adult situations used as learning. The teachers being able to view a child's diagnosis, entire file at the beginning of the year not having to wait for IEP meeting to be told everything. I could go on and on about the lack of common sense when it comes to mental illness and I have dealt with it for 10 years.
♥Trying to get everyone on the same page. Who is doing what, where and when? Medical assistance! Our son qualifies for medical home and yet we are "waiting" for the second round of flu shots to come in. His cardiac surgeon told us he needs RSV shots for every season till his next surgery, yet at his pediatricians office the nurse in charge of the shots is not sure if our son qualifies and will get back to us in a month. We have yet to get therapy in the home because "we are out of the traveling area.
♥IF A SERVICES WILL HELP YOU AND IF THEY CAN'T THEN WHEN YOU ASK WAY TO GO NEXT NO ONE KNOWS. THE AGENCIES NEED TO WORK BETTER TO GUIDE PEOPLE ON WHERE TO GO AND WHAT IS NEXT STEP. I HAVE TO MAKE AT LEAST FIVE CALLS TO GET MY ANSWERS AND WITH A SICK KID THAT IS ALOT OF TIME
♥Nutrition and Sleep strategies and specialists to access in this area of need
♥Information and a counselor that can help us, lead us to what we need to do to help our

son.
♥Inclusive setting for preschool
♥Pediatrician who wouldn't listen to me
♥Turn-over in IEP team
♥Community Activities that don't get it
♥Peer interaction
♥Public accessibility, finding reliable and consistent staff, recreational opportunities
♥Because of surgery, my son is unable to attend school or any other functions at this time. It is very difficult to even take him out of the house at this time. My husband or I must be home with him at all times. We live in a very rural area and don't have someone who can stay with him full time. I know this is a temporary situation, so I don't know what can be done. However, in our "normal" situation, we still have some issues. Because our jobs are not close to home, we must leave home by 7:00 which does cause problems with getting him to school. Next year will be even a bigger issue for us since our oldest daughter will be going off to school and won't be able to help us out. We do have respite care, but that is only 60 hours per month, and not always available before and after school.
♥Trying to get reimbursement and home care.
♥Getting the doctors to listen to us.
♥Out of state approvals for Medicaid, it is so frustrating especially when this has been a part of your child's life since birth.
♥The biggest gap has been the past quarter; we have not been able to utilize family support $ to purchase approved equipment because our DD cannot give us answers as to how to purchase items online. We are also unable to purchase nutritional supplements and eye patches because DD does not have approval for supplies under the new system. We have spent the entire quarter waiting for answers.
♥hard to get Medicaid and not much is known about how to qualify my child financially
♥My son doesn't qualify for services in our area because we had a late diagnosis and he just doesn't meet the guidelines.
♥The worst was that our insurance does not recognize need for early intervention types of services. There for they pay for no speech therapy for speech delay and only pay for certain # of OT visits a year. Jumping through the hoops to get Medicaid was very frustrating as well as having no coverage to be able to have Out pt services for 5 months.
♥A referral base of health care providers who are versed in the special needs children and related health care concerns i.e. bowel and bladder training
♥The financial burden. Also we are doubled covered thru BC/BS and this has been a blessing but the costs to travel for her medical appointments add up.
♥The lack of Deaf Ed Classrooms throughout the state. The School for the Deaf is great, but I cannot move my son to the area, nor would he be able to function away from a home environment. The same type of quality deaf education needs to be provided throughout the state so parents do not have to make these types of decisions.
♥To find the specialized services necessary for our child and get them in a timely manner.

The referral process was really messed up in our situation. We drove over 4 hours for a 20 minute appointment in horrible weather to be told we should have been referred to a different clinic first and that they couldn't help us at this point. Very Frustrating!
♥ No services available in the state. We were forced to move out of state due to lack of options and resources.
♥ We travel out of state to St. Paul for specialty cares. MA continually denies coverage stating that these specialty services can be provided in the state...which they cannot.
♥ No reimbursement through insurance to offset our travel costs to take part in family therapy and other treatment services.
♥Fighting with insurance to obtain needed services out of state for my child. I could switch to a closer out of state hospital for my child, but do not want to face insurance obstacles again.
♥just trying to get everyone on the same page as to what is going on with her.
♥having to drive 4 hours for GOOD quality specialized care--peds neurosurgery, peds ortho, peds urology, peds gastro, peds endo, peds, peds Ophthalmology, etc.
♥Finding someone in with the knowledge and connections to refer our daughter to specialists that can help her, i.e. she had surgery a year ago on her feet to help her walk. She was nine when the surgery was done. Why did it take that long for someone to step forward and let us know that help was available? I will tell you, because in most cases the medical community does not want that information disseminated.
♥The biggest difficulty is dealing with Medicaid. I feel like it is almost a full time job managing what they have approved, paid for, etc. I have received a lot of bills that Medicaid needs to pay for and I am constantly calling and having them resubmitted.
♥Lack of communication with specialty docs and primary doc - no care plan established on either side. Therapy services are not covered well under most insurance plans - we are hoping Medicaid will pick up the costs but there's never a good answer, which worries us.
♥Communication between his primary physician in ND and his Urologist in Minneapolis.
♥The public has misconceptions about autism. They do not know that insurance refuses to cover care. This disorder is thought to be untreatable which is not true.

From Minot Focus Groups:

♥The lack of communication between vendor and specialty health care clinic when ordering equipment. I constantly have to call to make sure things are progressing for ordering equipment. We were ordering a new wheelchair through Great Plains rehab in Bismarck. They said they faxed the info to Gillette Children's in St. Paul. Gillette said they had faxed it to Great Plains. I questioned why nothing had been done for two months. Somewhere, someone dropped the ball and nothing had been done.

♥There are not appropriate services available. Intensive, effective social skills training and coordination between schools and health care.

♥A more seamless system.

♥Specialists.

♥Medical home.

From Spirit Lake Focus Groups:

♥I work full time and this can be a barrier. I can't get away all the time for appointments. It's more with me than services.

♥Transportation is bad

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.**

♥Medicaid buy in waiver that lets you keep your insurance, perhaps pay a premium for the Medicaid based on young adult's ability to contribute (with mental illness it is difficult to know month to month what that might be...)
♥More flexibility in scheduling doctor appointments... taking time off work to go to the doctor and have lab work performed is hurting us financially.
♥We need to get more services for our child for the speech and OT. Currently my private insurance has limited sessions (60 per calendar year total for SLP and OT combined together). This is too less. Also after her 6th birthday we may lose this too. MA supports only some additional sessions, and really required more in order to get better progress.
♥NO Preexisting conditions, no lifetime caps, Lower deductibles, lower out of pocket maximums. Affordable premiums for young (just out of college) people, with good coverage.
♥I am just on this list in case any of the services, workshops, etc offered would pertain to or be available for us. Thanks for all you do.
♥sometimes it is difficult to understand the wording and explanation of insurance companies
♥Programs to assist what Medicaid doesn't cover (like "recreational activities"--gymnastics, swimming, etc.)
♥Eligibility for the Medically Fragile Waiver is too tight and does not address many body systems. It lacks proper coding and assessment of other types of infusions. I believe if there were the appropriate means of quantifying the care that I provide for Jacob that he would qualify. He receives weekly infusions of a blood product, yet there isn't a means of quantifying this. He has significant bowel and gut issues...and there isn't any means of

quantifying that. He is now diagnosed as hypohydrosis (decreased sweating) so he requires temp monitoring and intervention during activity, especially out doors...there is no way to quantify this. The qualification form is strongly focused on the neuro and respiratory systems and tube feedings, however a child like Jacob has gut issues and nutritional issues requiring nutritional supplements and Pediasure, however since he is not tube fed, we cannot take credit for these activities. It was very disappointing to get the call that you meet one level, but not the other.
♥To have someone who really knows about Asperger's and can connect us with some services that will help our teenage son with his needs as he grows up and navigates his teenage years.
♥I am not sure but do wish somebody would cover the hippo therapy cost. We are currently paying out of pocket for this service.
♥As of now, our needs are met. If any changes occur, we would need assistance.
♥More communication between the healthcare provider, medical assistance and the family.
♥We ended up paying for our child's hearing aids out of pocket, because the medical provider neglected to get the hearing aids approved before purchasing...we had no clue how this worked, just trusted the medical provider...then we find out 5 months later after the aids were purchased that they now weren't covered.
♥Unsure at this time. Except for continuously having to do paperwork, my child's healthcare needs have been easier to meet than educational, social, and community
♥Eligibility-criteria too high
♥SIMPLIFY application process. Clarify eligibility criteria. Someone to help us navigate 'the system' without having to research for hours and read all the fine print and make countless calls and applications.
♥training the social service agency in Minot
♥LIKE I SAID WE JUST DONT DO CERTAIN THINGS.
♥eligibility criteria changes
♥better trained delivery Dr's
♥Dental program for children that take a lot of medications. Their teeth are affected so badly and we don't have access to any dental coverage. The cost for dental care is unattainable for many families and coverage that can be afforded doesn't allow for many of the services our children need. Eligibility criteria for Medicaid needs to be changed so that children with special needs have access to all services including dental and eye care.
♥We are OK now, but we did have financial stress and trouble paying our medical bills for a number of years.
♥We were having financial hardship when my daughter needed to be at doctor appointments weekly and you had to pay the $30 co-pay. She would see the psychiatrist along with the psychologist. It was always hard to get off work as well as pay the co-pays. A lot of people don't understand how hard it is to pay all these medical bills when you are in the 'middle' class family.
♥Do not like that individual with DD need to live in HUD or section 8 housing because they are low income. Case managers and agency administration make reference to "living like in

college" The difference is this is their home for the rest of their lives, not for a year or two.
♥waivers
♥More eligibility for dental and eye care. Our insurance only covers the exam for eyes and half of dental. The costs of all health care including dental and eyeglasses is definitely too high! I think there needs to be caps or better coverage. Insurances are high and so many of us do not qualify for government programs.
♥Eligibility Criteria changes,
♥What exactly makes her eligible? What are the criteria at age three? how can I keep her Medicaid
♥More allowable and covered visits per calendar year for Occupational and Speech Therapy.
Therapy needs to be based on the needs of the child, allowing those who live on/near state borders to seek services out of state
♥Specialists throughout state, much more affordable prescriptions, BCBS doesn't seem to pay the 80/20 on a lot of our prescriptions - they seem to fall into the 40/60 range more often.
♥A healthcare system instead of a sick care system.
♥Eligibility criteria changes for all types of income (low-middle income families), Assistance with daycare costs that are directly related to families with children who have special health care needs and supplying food for direct care programs that don't offer a food program. Extra help with buying special equipment and not having to wait for money received from state agency.
♥We have a case manager now through BCBS and I believe that will be helpful. Wish I would have know about that possibility before and requested it sooner.
♥DDS eligibility criteria, Financial limits that a family can make change and also address if you have more than one special needs child.
♥ When I called Benson County Social Services to inquire about the Medicaid buy-in program or the TBI waiver, the social worker knew nothing about the programs and said that I would have to send her information on them.
♥A 3-way commitment from Insurance-School-and federal or state funding to pay for ABA treatment of Autism.
♥Help regardless of income would be nice. We have never received any help because we are said to make too much money even though we have debt.
♥They should have a medical program that every Hospital is aware of the limits or what costs are covered and that facility then be tied to these things and costs.
♥We do have Medicaid until they are 18 but not sure what the process or outlook is after that.
♥Pharmacy program for any child who is disabled with a better way to determine the family's true income. Education to all school systems about different disabilities with the requirement that they bend for the situation/diagnosis. School nurses are a must!! To leave the secretary mind altering medications and expect them to distribute properly

watch for side effects etc. is very difficult as a parent and I am sure the secretary. The school system was the biggest hurdle I had to deal with for my daughter. One example to prove how ridiculous their thinking was; My child needed counseling sessions twice a week, instead of the school providing them I had to leave work drive 45 miles to get her and then drive 45 miles back to town for the services and then they actually though I should drive her back to school after services if she had anything above 1 hour left in the day. Providers do not have flexible schedules so the school should work with us or be required to provide a counselor to her then.
♥Too difficult to fill out forms for Medicaid etc when self employed with fluctuating income
♥Eligibility, maybe even a separate program or group. My child needs help but does not fall into the group that qualifies.
♥eligibility criteria changes for sure
♥WAIVER TO START WITH WOULD BE NICE AND ALOT OF THE TIMES IT'S AWAIT AND SEE IF YOU ARE APPROVED THEN WE WILL HELP. MOST FAMILIES NEED HELP NOW NOT LET'S WAIT AND SEE
♥Out-of state transportation costs covered with a referral
♥Eligibility criteria changes, Medicaid eligibility or other private fund knowledge that can help us with medical, educational and emotional, social needs our son has.
♥More In-state specialists
♥Lose the institutional bias for Medicaid waiver programs
♥Have pre-existing conditions covered so there is an addition coverage option.
♥My child currently needs constant care due to surgery recovery time. This requires one of us, as parents to be home at all time. Loss of work means loss of income at this time. I really don't know what can be done to change this.
♥Some way for Medicaid to except some circumstances for out of state health care. North Dakota does not always provide the best care out there for some illnesses.
♥He covered under Medicaid for now, but after he is 3 I think we are out of luck.
♥West Central needs to get answers from the state so that we can move forward with purchase of needed items that will be reimbursed.
♥Medicaid to help with cost - do not qualify for Medicaid buy in
♥The Medicaid buy-in would be a great program if you knew that you would always need health needs. No matter what you pay a fee. Increasing the autism waiver to include all ages would be our best chance.
♥More Simplicity in initiating the Medicaid Buy-in process. SSI was a nightmare.
♥Right now, we need to know the resources available and how to access them.
♥Assistance financially for all the trips to Minneapolis and New York.
♥A better referral process to specialized services. If some of these specialized areas would take their "show on the road" for clinics and screenings. To be able to access individualized Medicaid information on-line.
♥Insurance runs the show. We need more support as parents to take with and track what insurance company is doing. North Dakota should not have a surplus of funds left over

when the state doesn't have the programming or options for mentally unstable children.
♥ND Medical Assistance approving specialty care services out of state when necessary. Also adequate reimbursement for providers from Medicaid i.e. diapers and g-tubes.
♥Providing outreach services in a home and community based setting, with reimbursement to the residential treatment through insurance.
♥Eligibility criteria changes
♥Having more services covered. Also worry about my child's future, whether he will be able to obtain insurance coverage due to his 'pre-existing' condition.
♥Well my child is on Medicaid for his medical needs. My son relies on his feeding tube for don't have any problems with healthcare
♥Training on the SSI/SSDI, Medicare vs. Medicaid and how medical assistance flows into the mix
♥More healthcare professionals that specialize in special needs kids.
♥Having someone help manage the Medicaid issues would be good. It is difficult preparing to be out of state for a surgery and having to work out the Medicaid details and trying to get all the paperwork done. It would be nice if someone else could help out with these issues while the family is preparing emotionally and logistically.
♥Something needs to be done with insurance companies and therapy services. i.e., our insurance co. is capping all therapy services at $1K/year in 2010. My son will reach $1K in about 3 months (PT/OT/Speech). It is always black/white with insurance. There has to be a gray for our children. Exceptions need to be made.
♥Education is a big part of helping kids with autism improve. I wish there was someone holding school staff accountable for what they are doing for kids with autism. I wish insurance was billable for behavioral therapy to be provided in schools

From Minot focus groups:

- Accessible services.
- Training case workers.
- A way to assist families for travel outside North Dakota, ie: mileage, food, lodging.
- Protection and Advocacy to advocate for child's needs
- Help paying for out of state travel.
- Lack of funding prevents children from receiving appropriate services.
- Sing language an issue in Minot.
- Intensive social skills training.
- Different diagnosis, supports depend on partnerships.
- Budgeting and financial information may also be helpful.

From Spirit Lake focus groups:

- To have more people working so we can see the doctor right away
- One parent would like assistance
- Meeting with the teacher on a regular basis
- To have more working at the clinic so we can see the doctor right away
- The rest of the parents had no suggestions

20. **All parents try to help their child get a good education. Sometimes that can be challenging. Tell us about challenges that you have had in helping your child in school. For each challenge, tell us about a solution that has been helpful to you in overcoming those challenges?**

♥My daughter had a mental illness and we tried homeschooling only to have that be unsuccessful, she went on to get her GED. I am proud of her. My son went to an alternative school and graduated recently
♥His PE Teacher wanted him to be back in the pool for swimming the week he got out of the hospital... The teacher didn't understand that his condition left him weak and exhausted, and he would have bouts of weakness/fatigue/exhaustion on and off for the rest of his life... Had to have his doctor write a prescription stating clearly that he is on limited physical activity until a new prescription is written.
♥ Need to provide better socialization - Need to access to join other typical peers. so need make groups where people can come together.
♥ I feel with the No Child Left Behind that elementary age students are being sent home with too much homework.
♥ The college setting. There is not much individual concern. It just seems to be a money making business. Hard on students without obvious needs.
♥ social skills, speech therapist at the school works with my son on this
♥Having enough staff help for my son at school, currently sharing Para with entire kindergarten class and hard to keep him on task.
♥ Our public school switch Special Ed units this past year. We were forced to send our child to a new school district which was less convenient for our family. The new school district has never worked with someone with the same disorder as the previous one. It has been an adjustment for all but we have been optimistic and it is working out.
We home school
♥disagreeing with the teacher, when I KNOW my child knows something but they have to follow a certain way
♥Having 2 children with special needs makes things more difficulty. Kyleigh has had significant regression in her motor abilities and an increase in her anxiety related to school. Despite multiple medical assessments suggesting IEP services, the school continues to indicate that she does not qualify for any services based solely on her MAP scores. This has been very frustrating. In the past we did have a mediated IEP meeting after her

services were pulled in Mandan that was helpful. I have recently made contact with Freedom Resources and they will be present at our next meeting with our school district as we are in the process of requesting a full and complete evaluation to determine eligibility for special ed. Currently her gross motor abilities are that of a 4-6 y/o and she is almost 10.

♥ We have had problems with advocating for our son in a way that he receives the services that he needs. We have fought long and hard and have had to be a constant in the schools as our son has grown and moved in order to get the services that our son needed to succeed.

♥we have had an IEP throughout my child's school years; he is now a senior in high school, looking at secondary education. I have expressed several years I wanted my child to go to college; I have come to find out the school wasn't encouraging college for him and did not encourage him to take the classes he needed to pursue his dreams.

♥ We are blessed to have a great team surrounded by our daughter to help her in school. She is able to be successful in her learning. That is of now. We hope it will continue with a great team as she gets older.

♥ School doesn't believe anything was really wrong with my child so they do not help him properly!

♥ The school system has been awesome in handling and helping us with our child's education. No complaints or challenges. We keep good communication with our child's teachers and workers and they with us. That has been the key to us avoiding any challenges.

♥ We have been very fortunate that the school our granddaughter attends and her 1st grade teacher have been wonderful so far. They seem to understand the mood swings and the medication changes.

♥ When school employs good staff and encourages information sharing from family to school staff, peers, etc.

♥ She was on a 504 in 4th and 5th grades and then placed on IEP for 6th grade that continues now in 7th grade. It was a lot of work. 4th-5th grades were wonderfully supportive. 6th grade was a nightmare regarding compliance. My husband and I were at several IEP meetings; a lot of disagreements and hard feelings. Had to get letters from various specialists and have a doctor attend IEP meeting. This year has been much better with this coordinator.

♥ We have had a really hard time getting an aide in the classroom for him and one of the things we had to do is wait and see what would happen and when it wasn't working we had to say okay this needs to be changed Michael didn't get a one on one aid but there is now a classroom aid for him and a second student,

♥ poor interpretation of autism laws by schools the ambiguity allows too much interpretation toward the system

♥One challenge was lack of communication between school and home. When our daughter was in elementary school, I was able to volunteer at the school (in a different area) and I think the informal familiarity with school personnel helped to make me more accessible to

them as a resource. We also had a communication notebook that went back and forth in the backpack. Now that she's in High School, the communication with school staff is minimal and I don't feel like we work together as a team.
♥it would have helped to have a tutor more.
♥ Nothing because he is at the Anne Carlsen Center which is where they get the BEST services that they NEED
♥C: Carrying heavy books in a backpack each day -- S: having a set of textbooks at home and in the classrooms. C: Moving from classroom to classroom in 3 minutes -- S: having an elevator key and teachers allowing early departure or late arrival w/o counting tardy.
C: Taking notes with CP S: get notes from teacher with major details blank to fill in, rather than write all the notes. Use a voice recorder.
♥Educators do not listen to parents. They are quick to label a child without accurate assessment. My son was not hearing and I kept asking the school about hearing tests or where I could go for something more than the standard "beep" test. No suggestions were made to me and they kept telling me his hearing was normal. Through many searches I found a pediatric audiologist and it was determined that my son has Central Auditory Processing Disorder; he was also going deaf in his right ear. Too much time was lost because the school didn't refer me to their audiologist. My solution is I never take the schools word on anything. I follow up myself on any questions I have and do the research myself.
♥Not enough educators who have enough knowledge to help us with his severe needs. Not enough PT, OT and specialized support.
♥The most challenging thing for us has been the length of time it takes for changes to occur. A meeting usually takes at least a month to schedule and the changes made at the meeting take another month. So it's 3 months before the necessary needs can be met.
♥I would like more information about what services are available under a 504 plan. For now, open communication with my child's teacher has been the most helpful, but I suspect as he gets older and the curriculum gets more difficult and he has take more responsibility of his education, that we will have more difficulty and need more accommodations.
♥Well, to be honest, we moved to "better" school district and it made all the difference. As hard as it was for the family, it was worth it in the end.
♥I am my daughter's advocate. I contact the school when I know of a problem or situation that arises that she is unable to handle. I try to let her handle all of her own problems but sometimes I do have to interject occasionally. She has come a long ways - she is 13 now.
♥ I met with the school principal, teacher, special ed. and psychologist and the best they could offer us was a "behavior chart". Since then, I have had to pick my child up early from school, had to find childcare for my youngest so I could attend his tests (and help manage his behavior)... but they still don't think he should a candidate for an IEP. I think ALL school districts receiving federal funding should have to show a willingness to offer services where needed.
♥ School counselor has been fairly helpful.
♥lack of knowledge in teachers and school staff

♥My child is not yet in school.
♥Transportation for child with emotional/behavioral problems. Bismarck school only offers such for physical disabilities if home school. Went to state dept and after three managers, found staff that solved problem with a phone call to district.
♥Educating staff in disability, challenging the student, learning the best way to educate the kids, lack of $$ for best therapies and lack of educated professionals
♥Getting a one-one Para: Shared with school other situations where this has worked. Now they have them for other students too. 2.Behavioral issues: Have brought in written examples of POSITIVE plans to share, tried to convince school of trying the plans(no go), I finally had to bring in P&A. I still hear concerns with this issue from other families. 3.High school education: The adequate resources or teaching personnel are not always available in rural schools. I try to find teaching programs or info. that may work and share them with the school. I really have to convince them of Modifying and accommodating regular criteria for my child to be able to attend classes with peers. Transition info. is usually shared with schools thru my intense searching.
♥ School administrators need to understand that parents of Children with special needs are in crisis mode 90% of the time...They need to know how to deal with people in crisis.
♥ Transitioning from early intervention to preschool services. We ended up needing to relocate our family and were lucky that our jobs allowed us to do that. I know this is not an option for all families but it has been the best thing for our daughter. She has overcome many obstacles due to the services we were able to get in a more urban area.
♥ My child is delayed with expressive/receptive speech and we have difficulty getting ST services---our coordinator is exhausting all leads
♥referring for Special Ed services - this was awful even though I work in the field. I turned in referral in August and IEP wasn't until November, teachers who don't understand that the IEP also applies to them - eventually met with teacher although I still don't think teacher understood why I was so upset
♥1:1 instruction and therapy are the key to growth and success at an early age. The burden of proof always is on us to show the need. At BECEP, the age where intervention can stimulate the most growth, the least amount of help was offered. It was a struggle to get appropriate amounts of 1;1 therapy. There was no solution.
♥K-2 has improved somewhat, but there could still be more 1;1 and therapy time.
♥we are attending the WF Special Education programs and they are excellent with children.
♥ contact between school and pediatrician
♥For a day camp I signed my son up for, run by teachers, I explained that he is in the spectrum. What challenges he had, offered advice and asked them to please contact me with any questions. They took him out of camp and had him sit for two hours, refusing to talk to him because he kept being loud. Which in the spectrum it is very hard for them to know how loud they are and it does take many reminders. I showed my note I gave to the teachers in advance to see if I had not conveyed the information in an easily understandable format. She said I did. I then wrote a letter to the teacher explaining my

disappointment in the situation. She said maybe the camp wasn't right for him or next time she could talk with the specialist. So next time I'll see if she can speak with her.
???? Almost the same situation with T-ball coach. He is also the gym coach. I offered to be in the dugout and help out. They said no. Then grabbed them by the arms in front of everyone and took them out of the first game. We just never went back. Dr. Stanton offered to talk with the park board and help them in anyway. They would not call back.
♥ Home school turned out to be the best answer. due to frequent and excessive absences for illness and appointments.
♥The new science teacher told me that we "have to quite treating our daughter like she is disabled"! We had to go through the HS principal and the Special Ed teacher to get him to work with our daughter and follow her IEP.
♥Andrew was too ill to attend middle and high school. He took the GED test.
♥I have not really had any challenges the school works well with me
♥Know your rights and the rights of your child - don't be intimidated by the school.
♥ Prior questions I addressed the main challenges, my biggest issue I want to stress is education!! Very few of the teachers even knew she had an IEP!! I am not sure of the communication chain and how it is suppose to work in the school system but it seems to me that administration does not share the proper information with their staff.
♥I have not found a solution yet. Biggest challenge is trying to find someone who understands his need. Not have to educate before he receives his education.
♥GETTING PEOPLE TO HEAR WHAT YOU WHAT FOR THEM A PIECE EQUIPMENT THAT YOU KNOW WILL HELP BUT PEOPLE HAVE TO MEET AND THEY DECIDE YES OR NO AND THEN IF IT IS A YES ANSWER AFTER YOU HAVE FOUGHT FOR IT THAN YOU HAVE TO WAIT FOR IT COME IN AND ONLY IF THEY BOTHER TO CALL YOU TO LET YOU KNOW THAT IT CAME IN
♥Although I feel my child has age appropriate intelligence, he is unable to read because of tracking difficulties. He has incredible listening and memory skills. When his homework is read to him, he does very well. When working on things that he must be able to read, we often write it on an erasable white board in large letters. Also, his visual exposure to many things that other kids are normally exposed to is often very limited. When intelligence tests were done with him, those things had to be taken into consideration. The only challenge I still have trouble with is time. Because it takes him longer to get through his schoolwork, much of it comes home. Unfortunately, with work, and our other kids to help too, the amount of time spend helping with his homework can be very overwhelming.
♥Social Skills Programming. A program was created to teach children social skills in a school setting and also created a Peer program
♥Our son home schools because of his OCD, high anxiety of being in social situations.
♥Turn-over in professional staff - making sure IEP's Present Level of Performance is adequate
Scheduling of aide time and professional staff - continuing to call administrator; asking for staffing to coordinate schedules

♥Participation in music, gym, recess...got a new gym teacher!, found adaptive music options, had accessible playground equipment put in, partnered with students for baseball (adaptive pitching machine) and kickball...not ideal but child loves it.
♥The biggest challenge is staff underestimating the potential of my child. We have taken on the education that we see fit ourselves.
♥communication folder to know what is happening
♥he is starting a social skills class at school. I wish that would have been there a long time ago
new teacher I asked for a meeting at the end of the school year but they didn't have the teachers assigned. There has to be better communication for our special needs children.
♥Putting a child with severe food allergies into a school that has very little knowledge about how fatal it can be. I have done lots of education at the school with everyone--including teaching staff, cooking staff, and students. Education is ongoing. The school has also agreed to be peanut free (but has difficulty following this at times.)
♥After school care is a challenge.
♥My daughter does well academically but now that she's in High School earning credits we'll see how it goes.
♥I will reiterate my concern with the lack of Deaf Ed classrooms throughout the state. We have a school in Minot that educates Teacher's of the Deaf, and yet, we do not have those teachers in specific classrooms educating the children.
♥I have a very close relationship with my son's teachers, Hearing Specialists and Minot State. But I am intent on finding a true "Deaf Ed" classroom for my son that does not require him to move away from his home. Apparently, we used to have these programs in Minot and Bismarck for sure. Then the emphasis became Mainstreaming or the NDSD. This is no longer practical and the needs of the families need to be taken into consideration.
♥Communication between the staff and home can be a problem. We use a notebook that travels with our child so everyone can write notes and read how her day is going.
♥Insufficient IEP and programming for our child. Our solution was to leave this state and we really didn't want to but were left with no other options.
♥SMH programming was only available at 1 elementary school, 1 middle school and 1 high school. That means Hannah will never go to school in her own school district. Hannah is in 6th grade and has attended 5 different schools because of the relocation of the SMH program and special needs pre-school. This year we were told Hannah would have to travel 20 miles round trip to attend middle school. I met with John Yates and other school officials and they agreed to start an SMH on the south side closer to Hannah's home.
♥ Having the teachers understand mental health issues in children. Having Manchester meet with me and the school to resolve differences.
♥Not in school yet. But with early childhood, the biggest challenge is hearing how far behind my child is when it is time for assessment. It is so much better hearing what my child is able to do. It would be nice to have children qualify for services in a positive way.
♥moving her up in grade levels, keeping her routine and schedule consistent and rigid. Solutions are still being worked on.

♥we had our child in a private school. they had no services for him. He is now in the public school setting and is more closely monitored and feels less like an outsider.
♥Our daughter cannot speak, feed herself, or dress herself. She also had behavioral issues. In the beginning they saw her as an inconvenience that was resolved by my wife and I setting up meetings with staff and stressing our expectations to have her integrated in to the school student body. The behavioral issues have currently been resolved with medication.
♥The case manager is more concerned about cost than my child's education. Bringing in a consultant to explain that most of the recommendations will not cost a thing was a big help to get accommodations in place. Autism is difficult because there is no "fix" such as a wheelchair ramp, hearing aids, medication, etc....it is behavioral all time which people do not understand.

From Minot Focus Groups:

- Making sure he is getting his therapies as scheduled at school.
- Having to go to Gillette Children's Hospital in St. Paul.
- Having to go to Bismarck for baclofen pump refill.
- No services available for high-functioning autism. They need instruction in social skills and behavioral plans from a trained professional.
- Parents need to push to get services.
- School administrator told the parent "we don't have the resources" Even thought the IEP requires services to be provided, children do not receive them and the parents have to pay out of pocket.
- Teacher misconceptions assuming the child is not capable of understanding the concepts or learning the information presented and treating the child according to their misconceptions.
- What happens when my son turns 21? Will he ever want to live away from home? I'm unsure about his transition after high school.
- Lack of funding creates a financial albatross that affects my child's self –esteem as well.
- Housing issues when they become adults.
- Behavioral and social issues that preclude them from learning, developing friendships and overall quality of life.
-

From Spirit Lake Focus Groups:

- Just the people and the communication of them
- Good speech
- Meeting with his teachers on a regular basis to have knowledge on what is going on at all times
- The team have given me good services
- To get a job and get my kids in school

- Just keeping up and follow through. I have been satisfied.

21. **Many communities have agencies or people that families rely on to get information to help their children with special needs. These could be your child's school, his or her doctor or another agency you work with to help your child or family. It could be a relative or friend who knows your community well and is respected. Someone you trust and go to regularly for information or help with problem solving. Who are the people or agencies in your community that your family trusts?**

♥Holly Major at Pathfinder has been a wonderful resource. I believe FVND already works with Holly.
♥1) Case worker at Human resources, 2) School teachers; 3) Private therapist
♥Primary physician
♥Vocational Rehabilitation Services.
♥religious education leaders (many are volunteers), are not sure how to work with special needs children.
♥MCRS, Social Services, REACH, the ARC
♥RICC, Program managers, physicians, all past team members. I keep a log of all team members that have come into our life.
♥physical therapist and pediatrician
♥FVND, Freedom Resources and Make a Wish
♥I also use www.primaryimmune.org as a resource for Jacob's immune deficiency
♥The school case worker right now is the only person in our community that has worked with us to help our son receive the services that he needs to be successful academically and socially. My husband and I are concerned with what the future holds for our son after high school and the fact that we are constantly told that his future will be addressed when he gets to high school. We have always been proactive in his education and feel that in the past 3 years since we have moved to North Dakota he have not received the same services that he received while his father and I were on Active Duty. I feel that in order for our son to be successful he needs to have someone come and talk to him, besides mom and dad, about how his body is changing - shaving that will need to be done in the near future, making sure his body is cleaned properly and daily, deodorant usage, toenail clipping, fingernail clipping - How he will be able to obtain a driver's permit/driver's license, how he could one day learn to ride a bicycle, and so on. We don't know anyone to contact or the people that have obtained services in these areas just tell us who to go to when we could really use someone to go with us and help us ask for the right services or people.
♥ARC
♥Doctors, nurses, teachers, case workers Some sort of system that shares and works together with information instead of repeating things over and over

♥Our case worker and early interventionist.
♥churches, medical social workers
♥We trust family voices. We send people to call and connect there. I know the ND Autism Connection is another source where people can go for information along with NAA of North Dakota and Red Door Pediatric Therapy.
♥BECEP - Kris Cleary
♥Tammi Iszler - Parent and infant outreach program through ND School for the Deaf.
♥Traci Wagner and Cindy Wetzel - Bismarck Public Schools.
♥Agencies would be: Pathfinder Parent Center, FVND, NAMI, etc.
♥infant development.
♥DD case manager
♥Other parents with older children who have special needs and my DD program manager has been helpful.
♥I don't know who that person would be. The resources that we know about we discovered the hard way--after much research and footwork. Many agencies that helped us weren't even in our community or state. Locally, I think I could call Brenda Jo Gillund (Altru), Pat Berger (United Way), Keith Berger (GFCSS), Mayor Brown, Sue Hafner (Altru NP), Ken Carlson & Brenda King (Lipp, Carlson, Lommen, Witucki), Carrie Olson (CSHS) to ask questions and get some idea of where to turn.
♥I call Holly at Pathfinder on a very regular basis to get information and support to be a better advocate in the education setting.
♥THERE IS NO ONE
♥We have been very pleased with our DD case manager Jodi Haugland - she has helped connect us to agencies and information that supports our family in all areas of need. I know that she already uses the Family Voices newsletter to share information - I don't know any other strategies that you could help her with.
♥Children's special health services
♥Anne Carlsen Center
♥Med center One Pediatric Rehab, its therapists, and Dr. Kevin Murphy.
♥Cerebral Palsy Support Group
♥Family Voices is the only agency I truly trust. If I can't give them recommendations, I refer them to Family Voices.
♥Infant Development is the only service we are personally familiar with. I think it would be great to get FVND and ID more involved, there isn't enough knowledge of FVND in our community.
♥His new school - Anne Carlsen School and his prior school
♥School SLP, OT, Lonetree Social worker, family physician. Make them knowledgeable about FV!
♥staff at Anne Carlson Center; HSC Case managers. CCND guardianship division.
♥The person that has helped us out is Dr. Barb Stanton. Barb has been very helpful in getting Morgan her IEP at school in fifth grade. If we did not have her IEP, she would be where she is at in 7th grade. I would be able to tell her teachers that she does not help on

tests if she was struggling.
♥His doctor --I think that more information should be provided to physicians and they should play a larger role in referring their patients to those services and show a better willingness to help fill out applications, etc.
♥Longfellow school in Fargo was very helpful with needs.
♥Leslie Streed at West Central Human Services
♥Jana at early intervention
♥BECEP
♥clinic staff, physical therapists
♥Med Center One, West Central Human Services (our whole care team is amazing!), Roxane Romanick is a lifesaver!
♥NEHSC, Psychologists, Schools
♥Mayor-he is involved with providing info. and making our community a better place. He has been a big plus for us. I usually find info. through FVND or Pathfinders- then I share it with the school and other families.
♥Early Intervention staff, FVND
early intervention and experienced parent. I trust they will help advocate for my child
♥WIC coordinator
♥Family - I don't have any more suggestion
♥West Central
♥BECEP
♥Casework at South East Human Services
♥North Dakota Autism Center
♥support groups, doctor, schools
♥Daycare is awesome. Little Buckaroo's in Kindred. Owned by Tammy Erickson in Kindred. She is awesome and is always happy to help.
♥We don't feel we have anyone in that role.
♥Infant Development has been helpful to us. We also use Pediatric Therapy partners which are very skilled in understanding our child's needs and they know about opportunities in the community. Quarterly roundtable discussions with these organizations would be a good way to open lines of communication.
♥The special education teacher in Leeds is fantastic. Jana Darling was our best resource and gave us ideas of people to help. We have found the Lake Region Special Ed team to be our best resource. Those people have information on TBI and are willing to listen when we have concerns or challenges.
♥Tori Johnson-GF Public Schools
♥Dr. Catherine Yeager-Psychologist
♥Anne Carlsen Center
♥Dr. Jon Bradbury-Meritcare
♥Pediatric Nurse practioner was helpful. Not sure how you could work with them.
♥West Central Human Services DD Manager, Support Systems Respite care.
♥Vicki Peterson at Family Voices has been a God-send-Thank You! Also our school social

worker has been an awesome advocate!
♥Deb Lukenbill FNP Pediatric Mental Health
♥Janelle Olson Protection and Advocacy
♥Katie Shannon Social Worker NW Human Service Center
♥Shawn Huss WilMac Special Ed Unit
♥Parents and advocates. They have been where we are.
♥NO ONE
♥In our small community, we depend on the therapists who come into the school to work with my son. These people come from Bismarck and work with many other kids. We also depend a lot on his doctor and therapists at St. A's in Bismarck. They have much experience working with kids like ours. I also depend a lot on our case worker at West Central. She has much information to offer me. All of these people are very willing to work with us to make my son's life better. If they do not have the answer to a question I might have for them, they always take the time to find the answer. We also do a lot with the Shriner's Hospital in Minneapolis. I know a few people from this general are who utilize the Shriners, but in talking with some parents, I have found that many of them are not aware of the services that the Shriner's provide. I have nothing but good to say about any experience I have had there.
♥Family Voices
♥Experienced Parents
♥Federation Of Families
♥Trusted Members of my IEP team
♥Trusted friends
♥We are not connected with anyone, besides a counselor. Need help.
♥Her team at school - especially her OT right now
♥Her pediatrician - love him!
♥FVND
♥Our Down syndrome community - Designer Genes
♥Our niece and her husband, plus other extended family
♥My other "experienced" parent friends!
♥P&A, IPAT, Universities, Policymakers, Community Options, Pride, SCDD, ...FVND already does a good job of working together with most of them!
♥Dr. Houle
♥Not Social Services they are terrible here. Very demeaning if you apply for any kind of assistance. I don't even try applying for assistance anymore. Especially the way we were treated when our one son died. She told us since we didn't run every approval through her we would have to pay for everything. We were terrified. Our son was dying and she is yelling at us over the phone because we didn't ask her permission to see a specialist.
♥The independent living centers
♥We rely on our child's therapists to get information.
other parents, support group, Red Door Pediatric Therapy
♥The KIDS program in Dickinson initially helped us start with services through Badlands

Human Services and WIC. Missi Baranko has been an awesome resource and support as well.
♥In our rural community it is the Special Ed staff and the DD case manager (and she is so busy that it is difficult to connect with her for any immediate questions/concerns).
♥We have worked with the specialist in Minnesota and with the camp for families in Maine-Camp Sunshine
♥Holly Pedersen at Minot State is a key advocate in my son's education
♥HOPE Inc, Easter Seals, Our Church. I think you are in most areas, probably not the church end. There is a group called Inclusion Ministry Network in the FM area that would be a good connections. Judy Siegle heads up that group.
♥Advocacy center had some assistance but lacks more depth. SEHSC Case Manager was helpful but as a parent we had to ask and dig before realizing what was available to us.
♥Southeast Human Service Center
♥Dr. Welle, Meritcare
♥Fargo Public Schools
♥Family Voices
♥Pride Manchester House, Pride Youth Mentor program, Dr. Dahmen and Dr. Bennett
♥Early Childhood -continue to share information
♥DD case management, Family Voices, Easter Seals and her doctors.
♥FVND is doing a great job about getting information out to other groups.
♥Kristen Van der Vorst - she is awesome
♥Katherine Obergon - her doctor (I have not trusted her doctors in the past)
early intervention @ BECEP
♥The best help and information I have received has come from TACA.
♥I utilize our Infant Dev. case worker a lot - she is great - and if she doesn't know the answer, she seeks it for us.

From Minot Focus Groups:

- Easter Seals
- Minot Public Schools
- Minot State Communications
- NDCPD
- Pathfinders
- Dreamcatchers
- Nancy Gassman
- Dan Olson
- Trinity Hospital-Hippotherarpy
- Medicaid
- Disabilities Clinic
- Dr. Messrly
- MedCenter One-Bismarck
- Great American Bike Race

- Vocational Rehab has been somewhat helpful.
- Parents do not have a lot of support. Need groups that will support them with similar disabilities.
- There is a need for respite care and people that are qualitfied.
- GPAST does not feel accessible.
- Family Voices

From Spirit Lake Focus Groups:

- Early tracking
- Head Start

22. **Children change and grow every year. Their needs change too. We can't see around the next curve in the road, but sometimes we think about what might happen next. We try to prepare. What challenges do you think your son or daughter will have in school in the near future? What supports or services would help your child and family respond to those challenges?**

♥More information about supported higher education for kids with disabilities. Many kids with disabilities are choosing to go to college, which can be a reality with the right supports in place.
♥he is almost 18, so getting him ready to move out and live on his own is a huge challenge that I don't see happening anytime soon. Medication management assistance, life skills assistance, financial management
♥1) Other children might make fun about michild.2) Need to get support from other typical children to make progress.
♥We are on the last leg of schooling. We are much more worried about how to get established after completing school.
♥ my son has difficulty in social setting and any type of group sports
♥Having a Para or helper available to him to better help him adapt to the challenges of completing tasks in the classroom.
♥ We might be having to switch to another new school district. That will be three schools in the past 3 years. Like I answered earlier, I keep in contact with those that have worked with my son in the past and I always call them if I have questions or need support.
♥ Staying healthy in a classroom setting
♥Kyleigh would greatly benefit from PT and OT services to address fine and gross motor delays and sensory integration issues. She is in an amplified classroom and will have needs as she enters middle school. She may need someone to take notes for her and other assistance as she progresses. Other issues we may face is home bounding due to pandemics. This would not just be for Jacob, but to adequately protect Jacob all of our school age children could require homebound tutoring.

♥We fear that our son will just be passed along when he enters high school and eventually graduate and then be in the civilian sector without any skills or means of supporting himself. We fear that his daily living skills will not be sufficient to support himself as an adult on his own. We fear that because Dickinson does not have a bus service he will not be able to be a self-sufficient adult once he graduates from high school.
♥Socialization is difficult as is math and social studies. Making good friends is tough and understanding that some kids will take advantage of you is really hard for him to understand. Support services has helped as do the teachers.
♥She is still too young to even think about that.
♥it would be nice to have voc rehab involved with the children when they enter high school; not at the end of high school.
♥We hope that the aides/teachers in the schools will be properly trained and patient with our children as they are trying to learn. Education cannot continue to be taught the same way to help our children with autism.
♥ There is no specialist in my child's disability in the school my child will attend
♥Will not get the special classes they need!
♥ I think the school is already set up to meet any challenges in the future.
♥ The challenges I feel the granddaughter will have in school in the near future would be peer pressure. She is a very sensitive little girl about her ADHD but seems to understand it at the same time. However, other kids can be very cruel when they find out she takes medication. They tease her about being a drug addict.
♥ being included socially when they are not able to participate in the sports programs the other kids do. I really appreciate it when a school staff person sees this and works with the peer group whenever they see an opportunity to bridge this gap and finds ways for my child to be included.
♥ An advocate/liaison/social worker would be beneficial so that they can help keep track of what services/checkups are needed, to be a sounding board... It can be very lonely and time-consuming to navigate the systems on my own.
♥ Changes in his diet and some new allergies found will be a new challenge as to how to go forward with them in a school setting and what to do with his meals so he is still one of the other kids
♥My daughter is getting ready to transition from school to a vocational training setting. My concern is that the school personnel are reluctant to deviate from the usual vocational preparation track. Instead of looking at her individual skills/needs and devising a vocational training program based on that, they have been just grouping her with other students in a cleaning crew at the school campus. The attitude seems to be that there is no other model for community integration for someone who needs direct supervision other than the cleaning crew option. I am trying to encourage them to look at additional evaluation from outside sources (ACC and voc. rehab) to help determine an individualized vocational training program, and to start teaching specific skills to ensure her success in future placement. I know I need to advocate for what I think is best, but I'm

uncomfortable and feel I should be more informed. An outside person to help us advocate for what we need would be helpful.
♥ trying to get all his credits to get his diploma, more tutoring.
♥ continued care at the Anne Carlsen Center which provides consistency for the children so that they get the most benefits. Staying in the same services with all the services provided under one roof. No changes in their environment, meaning not having to leave their home/school/Dr it is all under one roof.
♥ Better mental health and behavioral supports and understanding need to happen in the school, including administrators and educators.
♥ Still learning how to behave appropriately and be appropriate socially.
♥Challenges in the area of social acceptance. Not sure what else to do at this point, trying to work it out with SPL
♥He will need help managing his schedule, homework assignments, getting his backpack/homework ready to come home, getting to and from school, maybe reduction in the amount of homework, accommodations for testing (quiet environment, testing in the morning vs. the afternoon, someone to make sure he's on task, etc.)
♥ appropriate adult placement when graduates from ACC, also placement if behaviors/condition deteriorates and ACC no longer able to meet his needs.
♥The in-home family support was a key for us.
♥In the near future, my daughter will have struggles in high school dealing with subjects such as science and math. I do not know the future brings but I know that it will be difficult for her as her speech is hard to understand and her verbiage.
♥I worry that his needs won't be addressed in time simply because they aren't cognitive and are more behavioral. I fear that will set attitudes from children and school staff against him and he will have a very hard time proving himself and getting past stereotypes in the future. A better willingness for our school district to address behavioral needs -- OT etc. would help alleviate this.
♥In middle school, teachers are not as willing to help with kids (at least not all of the teachers). Kids with minor problems are not very high priority to administrators. Need an IEP to get much response. 504 is not very useful.
♥Our daughter's left eye will most likely look different then her right eye. With society the way it is today, we are afraid that our daughter will be made fun of because she will look different then the other kids. We feel that more needs to be done in schools and in the community as a whole to educate people on accepting people who are different and accept them for who they are inside not on the outside.
♥his attention span is not where it should be so that would be a big concern
♥acceptance by other children
♥Vocational Tech should be offered at younger grades for students that opt for nonacademic track
♥Skills for jobs in the future, and social and community skills
♥My child will be 18yrs, and a junior in school next year. HE struggles in school because of regular classes, and especially feelings of loneliness. Special ed. needs to provide small

schools with more assistance and small schools need to provide better qualified educators. Government needs to help these schools out too because the cost is more for them. A family should not have to send a child to another school to get better services. I wish there were services that could provide teen support for kids with special needs, and schools would utilize it by teaching "regular" peers to be more understanding and open to friendships outside of class time. In a small town, there are few kids with special needs, it would be nice if all children were taught to help each other and be friends rather than forget about those who need them most. This is one issue that always saddens me--my child being lonely.
♥It is too overwhelming to think about
♥a Para in school would be helpful
♥Communication obstacles and learning to advocate for herself.
♥My child may need a Para-professional /aide in school
♥learning to write despite severe language impairment
♥Social skills
♥School social skills groups
♥handicap accessible travel/busing
♥Programs to make sure the child has everything that he or she needs to succeed in school daily programs. Equipment process program or help with the extra expenses for families in a medical crisis.
♥adjusting to next school and losing favorite teachers/friends
♥Challenges: Socialization, transitions
♥Support and services: Getting into the school more and informing all teachers what is going on so that those who do not understand do not think it is just another parent making excuses but that it is very real. Sometimes talking to the whole group together helps people see it as a real hurdle for kids. Maybe make special needs training for schools and park boards and coaches a requirement.
♥Relating to peers; "fitting in". I don't know what will help.
♥Our daughter is age 2 so it's hard to know how things will change in years to come. Due to her metabolic disorder, she exhibits significant attention problems and self control. She lacks problem solving skills and is significantly delayed in speech/language. I predict she may need a small group setting to focus on her individual needs as well as have someone trained in her diet management. The school nurse and dietary staff will need to be involved in a plan.
♥ Hannah will be graduating high school in May - I have been talking to anyone I can about how to help her when she leaves home. How to support her in college, how to find the college that would be the best for her, etc.
♥.Andrew is of college age now and will be challenged to be able to handle part time work and classes. More help with his needs not based on our income.
♥He may possibly need a wheel chair in time due to his tight muscles in his upper legs. Also his trade interests not certain if we have it together yet on that

♥My 5th grader getting close to middle school and they are all ready talking about cutting aide support. The school district needs to have aides where needed and not use the excuse that there is no funding - too bad, this is federally funded and they need to realize that the IEP needs to be followed and stop lying to parents. Also, not sure where we go after high school and into adulthood.
♥College and not knowing what services if any are available. The possibility of job training or being placed on permanent disability.
♥How to cope with change and growing up.
♥Physical activity will always be a problem. We may need help advocating and training staff for a possible emergency situation.
♥Because of my son's disability, he needs total care all of the time. He would like to be more independent, and tries very hard. He is in a power wheel chair, and maneuvers it very well. His classmates are very good about including them in their play time. However, his aide at school can be very controlling with him which he finds very frustrating. I have seen this problem grow over the last couple of years and only feel that it is getting worse. I know she has his best interest at heart, I don't think she realizes how much he wants to be a part of his own decision making. I would like to see a better program for helping to train the aides in school to better understand the psychological part of what the growing child is going through.
♥Challenges: bullying, environmental transitions; inclusion; lower cognitive ability
♥Universal design/ family support for children and youth in special education, peer mentoring programs
♥Hates school. Doesn't always understand his studies. He could use some special services that other Asperger kids get in a resource room, social books or videos. I can't afford to buy them. Help in getting a drivers license when afraid to join the defense drivers class at school. Need help figuring out what kind of help we really need.
♥ We're going to need more and more technology intervention - I foresee the need for her to have her own laptop and access to curriculum/materials online
We've got puberty coming up - want to make sure that she stays healthy and independent through this - will also need information/support
♥Transferring, participation in general outside of academics, social outlets, bath rooming, stigma/stereotypes.
♥ being able to do breathing treatments when needed. School does not have a trained health care person
♥His speech and hearing. I have no idea.
♥We need to make transitions in the school more appealing to students, wanting to leave at 18 and sit at home until adult services start
♥Our child is homebound and thus homeschooled. Creating appropriate learning materials is our biggest challenge. It is time-consuming and a financial burden.
♥ Middle school transition
♥too old for daycare but needing constant supervision with two working parents

♥As my child enters grade school I am not sure how the school will handle meals as my child has several and severe food allergies. As well as avoiding exposure to allergens in the classroom setting.
♥What is available to my son once he is 21 y/o and needs to leave the school IEP, etc.
♥Keeping up her attendance if she becomes ill
♥Again, I need him to have ongoing specialized deaf education. The same that is provided in Devils Lake but in a specially designed classroom in Minot with trained Teachers of the Deaf - full time.
♥Enough qualified staff available to meet her needs. Access to the latest technology for use at school and transition that use to home.
♥ More knowledgeable teachers and job skills coaches. Also technology support staff to help child gain more skills in computer area.
♥ I worry about health care - pre-existing condition denials if my husband changes jobs, Hannah may be denied coverage and/or Hannah reaching her cap on our private insurance.
♥Transitioning from child to adult services, particularly 18-21.
♥ Lack of funding in school may hinder technology my child will need to be successful in school.
♥continued success with academics. Getting her schedule under control and transition times.
♥Keeping her integrated.
♥As the other children grow older their interest in her will decrease.
♥As her body becomes a woman it will bring on a whole set of issues because she will not know what is happening to her I see this creating issues at school as well as at home.
♥ the most difficult part will be having to explain the health condition as it is rare.
♥ consultants to come in and observe the child across settings and report back to the IEP team. Then the consultant needs to come back to see that recommended strategies have been put in place. Help make changes, provide feedback to the pares, the teacher, etc.
♥Being teased? Not sure. Create an environment where the other children see the "different kid" as doing normal things - and that taking them out for special classes is considered no big deal, introduce that at an early age.

Families have shared many concerns with this survey. Their voices are very important as agencies, policymakers plan ahead

2005/2006 National Survey of Children with Special Health Care Needs
North Dakota Chartbook Page
Estimated number of CSHCN: 16,541

Percent of children who have special healthcare needs-12.2%
CSHCN Prevalence by Age
Age 0-5 years **6.4%** Age 6-11 years **14.6%** Age 12-17 years **15.3%**
CSHCN Prevalence by Sex-Male **14.1** Female **10.3**
CSHCN Prevalence by Poverty Level
0-99% FPL **14.2;** 100-199% FPL **13.0;** 200-399% FPL **10.9;** 400% FPL or more **12.8**
CSHCN Prevalence by Hispanic Origin and Race-Non-Hispanic **12.1;** White **12.2;** Black **9.7;** Asian 6.3; American Indian/Alaskan Native **12.1;** Multiple Races **12.8;** Hispanic **11.4;** Spanish Language Household **5.1;** English Language Household **12.6**
Child Health
CSHCN whose conditions affect their activities usually, always, or a great deal **20.4** CSHCN with 11 or more days of school absences due to illness **12.8**
Health Insurance Coverage
CSHCN without insurance at some point in past year **9.6;** CSHCN without insurance at time of survey **5.3;** currently insured CSHCN whose insurance is inadequate **25.9**
Access to Care
CSHCN with any unmet need for specific health care services **10.9**
CSHCN with any unmet need for family support services **3.5**
CSHCN needing a referral who have difficulty getting it **15.6**
CSHCN without a usual source of care when sick (or who rely on the emergency room) **6.3** CSHCN without any personal doctor or nurse **7.3**
Family Centered Care
CSHCN without family-centered care **30.9**
Impact on Family
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child **21.9**
CSHCN whose conditions cause financial problems for the family **18.5**
CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care **9.1**
CSHCN whose conditions cause family members to cut back or stop working **18.1** CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive **63.0**
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home **51.2** CSHCN whose families have adequate private and/or public insurance to pay for the services they need **68.2**
CSHCN who are screened early and continuously for special health care needs **57.5** CSHCN whose services are organized in ways that families can use them easily **92.3**
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence **51.2**
Citation format: Child and Adolescent Health Measurement Initiative. *2005/2006 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved [11/01/09] from www.cshcndata.org