

NORTH DAKOTA FAMILY STORIES
RAISING & CARING FOR CHILDREN AND YOUTH
WITH SPECIAL HEALTH NEEDS
What's Working.... What's Not...

"As each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child's most basic human rights." Polly Arango

Purpose

Family Voices of North Dakota provides information and resources to families who have children and youth with special health care needs and disabilities. During this past year, when staff spoke with families, attended or presented at statewide and regional conferences, many families had stories to share, ideas to suggest and problems that needed solutions. We asked that they send these to the office and were surprised by the volume we received.

As legislators, program managers and others who make decision about the levels of funding, types of programs to keep, fund or in some cases limit or worse eliminate, we thought this collection of real stories from real families from North Dakota would be helpful to share.

Families want what is best for their child, they want to be able to go to work and stay employed and to be tax payers instead of tax recipients.



Information regarding services

Quote from Mom from Ypsilanti, North Dakota....'We aren't born knowing about any of these programs or services, just stumble along, and so much depends upon some perceptive and compassionate social worker stepping up to bat for us, because that is the person who knows what is out there for us when we haven't got a clue and are way too overloaded to guess where to look next. "

DISCLAIMER: The Comments and opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of Family Voices of North Dakota, the funding agency or its working partnerships.

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Stuart Family Story

Health Issue:

Severe Developmental Disability

Issue:

Respite Care

Allows single mom to stay employed

Insurance Coverage:

Medicaid, Development Disability Waiver, Private Insurance

Recommendation's:

Continue funding that provides capable caregivers for daughter and respite for single mom to be able to be a tax payer.

Medicaid Buy-In for other families.

Family Story from

Tammy G. Stuart

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Macy required care for every aspect of her life. She is in a wheelchair; she has very limited gross motor skills and is non-verbal. She receives diapers; medication and respite care because of Medicaid, along with all of the medical services. Because her needs are so extensive she requires many appointments to ensure that her needs are being met. The costs would be too much for me to bear.

My goal is to have Macy reach her full potential and provide all of the services needed to ensure that it happens. I cannot do this alone. I need the help of the services that we receive through Medicaid. I am a single parent and work full-time for the State of North Dakota.

If it were not for the Development Disability waiver for Medicaid, Macy would not qualify for Medicaid. My income and assets combined are over the limit. But because of the services of Medicaid I am able to work full-time and be an active member of my state and community. I am able to keep my job because of Respite Care, and I can provide for the needs of my family. Macy needs to have caregivers that are mature and qualified to care for the special health care needs that she has. Because Macy is 12 years old she is getting bigger and needs to be transported more. This requires someone who is able to lift and position her the proper way.

My name is Tammy Stuart and I have a 12-year-old daughter, Macy, who receives Medicaid services. Macy qualifies for Medicaid because she has a severe developmental disability. Macy has Cerebral Palsy. Macy would not be able to receive many of the medical services that she is currently getting if we did not receive Medicaid because

I would be happy to discuss Macy's needs in more detail if is would assist you understanding the value of Medicaid to our family. Macy is the most wonderful blessing in my life. It is important to me that I am able to provide her with the care and services that she needs. I need help in order to do this and Medicaid has provided that help. Please feel free to contact me if you have further questions or comments.

"If it were not for the Development Disability waiver for Medicaid, Macy would not qualify for Medicaid. My income and assets combined are over the limit."



Reflection

Do you ask??
Or turn away??
Do you really see me??
Or just turn away??
Am I really different than you??
Or am I a reflection of you??
Am I someone else's problem??
Or am I gift for everyone??
Do you feel sorry for me?
Or wish you would help??
Do you seek the strength to help??
Or do you turn away??
Do you see me as a burden??
Or do you see me as a blessing??
If God made you,
Did he not make me??
Are you big enough,
To put your world aside??
Then take the time
To see inside mine??

Will you share your best??
Then open yourself to see my best??
Will you make a difference today??
Or will you turn away??
How do you see yourself??
Do you wish to share??
Do you want someone to care??
Or just have them turn away??
If you searched your soul,
What would it say??
Give all that I can,
Or turn away??
Will you be one
To seize the day??
Or one of the many,
That turn away??

Rick Rask '06

The Watt Family Story

Health Issue:

Kidney transplant

Issue:

High Out of Pocket Expenses for Prescription Drug

Insurance Coverage:

Private through employer

Recommendation's

Adjust income guidelines for working families. Medicaid Buy-In program

Family Story from

Karen Watt

1415 S 15th St., Grand Forks, ND 58201

701-775-2922

To Whom It May Concern,

We are a family of 5 who currently live in Grand Forks North Dakota. Our oldest son, age 5, was born with a diagnosis of end stage renal failure resulting in a kidney transplant at the age of 18 months, my husband was the donor. We were eligible for Medicaid benefits 3 years post transplant,

these benefits ran out as of October 2004.

Since that time, my husband and I have been paying extremely high medication bills to help with the immunosuppressant medication that our son requires for the rest of his life. Both my husband and I work full time in professional occupations and make a decent living (middle class), we have insurance that pays 70/30; however the cost of his medication is outrageous.

With this being said, we are over qualified for any type of assistance including Medicaid due to our income; even with one parent not working we would still not qualify for any type of assistance.

I believe that the income guidelines for these programs should be adjusted to fit the middle class families who are working and not taxing the system. I believe that children born with any type of chronic or congenital disease should automatically be qualified for medical assistance of some sort; they did not ask to be born with these health problems; families are struggling just trying to keep their heads above water in order to provide there children with the medications and health care they deserve.

"Families are struggling just trying to keep their heads above water in order to provide there children with the medications and health care they deserve."

Sloan Family Story

Health Issue:

N/A

Issue:

Lack of information and resources made available to families

Insurance Coverage: N/A

Recommendation's):

Physician offices need to make available packet of resources to help families after the diagnosis.

Family Story from:

Jocelyn Sloan

832 Oak St, West Fargo, ND 58078

The biggest problem I have had is figuring out who offers the resources I seek. I would like to see the diagnosing pediatricians also have a packet of information that they give, along with the diagnosis. There would be a packet or handout for autism, another for Down's, and so forth.

Doctors give you a handout when you have bronchitis or strep throat, but not these "life-changing" kinds of diagnoses. Such a handout or packet should contain a list of resources available, from respite care to counseling to support groups. Perhaps a brochure from each organization, or simply a list of available resources.

If I don't get detailed information from the doctor's office, where will I get it? The answer is anywhere I can, whether a reputable source or not.

How about the doctors at least point us in the right direction, instead of putting us on the road and wishing us "good luck".

Thanks for your time and consideration

Beck Family Story

Health Issue:

ADHD, ODD and a mood disorder.

Issue: High out of pocket expense for Rx, Unable to qualify for Medicaid by income was \$10 over limit

Insurance Coverage: Private Insurance through employer

Recommendations:

Need Medicaid Buy-In or Medicaid waiver for families

Family Story from:

Brad Beck

302 1st Ave. NE, Mandan ND 58554

We are a lower middle class family with private insurance. Our six year old son has been diagnosed with ADHD, ODD and a mood disorder.

The private insurance is a help but does not keep us out of financial problems. We have had Medicaid in the past. However, there were months if my wife worked 2 more hours than the previous month, we were not eligible and had a huge recipient liability. We could go from our son being totally covered one month to having a RL of \$850 the next month because my wife made \$10 more. Now our son is on three different medications and sees two different mental health doctors. Again, the insurance is nice, but you start adding up the co-pays, and that is why we have to put groceries and gas on a credit card, because our checks barely pay for the bills.

I am supposed to be on a daily medication too but have chosen for my son's sake not to fill mine so we could afford another one of his. A person should not have to be faced with making that decision.

We constantly have to make decisions like these. It is because of that gap that we cannot make it up and ever get ahead.. It feels like we are being penalized for having a special needs child and for being poor, (but not poor enough).

There is one more little story I would like to mention. Our son is involved with the Partnership Program. Because we had a recipient liability, we are responsible for the full amount of services. I was told if we did not have the Medicaid Assistance but just private health insurance this would be written off and there would be no cost to us. So again, if we had more money, we would owe nothing, but because we are lower income and had a RL, we are responsible for the full amount? Is this not a little backwards?? This is a great example of the system just not working.

Thank you for reading our story, and please consider any action to help families like ours.



Baranko Family Story

Health Issue:

Schizencephaly

Issue:

Can not qualify for DD Waiver because daughter is not MR

Over the income guidelines to qualify for Medicaid

Can not afford physical therapy out of pocket costs

Insurance Coverage:

Private Insurance through employer

Recommendations:

Need an MA Buy-In program or waiver for children with special health needs

Family Story from:

Missi Baranko 2123 Hwy 85 Belfield ND 58622

My name is Missi Baranko. I have a 7 1/2 year old daughter named Tashina. She was born with a brain disorder called Schizencephaly and is also missing her septum pellucidum. Schizencephaly is a disorder of brain formation which resulted in abnormal clefts in the hemispheres of her brain.

Because of this she is developmentally delayed in all areas of development. She was enrolled in Early Intervention at the age of 9 months and continued until she turned three. She also participated in outpatient therapy 9 times per week for over 2 years. She is not MR so we did not qualify for Medicaid. We are also over the income guidelines to qualify for Medicaid. We do have our own private insurance and pay out of our pocket for what insurance doesn't cover.

When Tashina was first in therapy we did not think or consider what the cost was as we were just trying to do everything we could for her. Before we knew it we had thousands of dollars in medical bills and were continuing to add more to the amount each month. We could not keep up with the medical bills. Eventually we ended all therapies as we just simply could not afford them anymore.

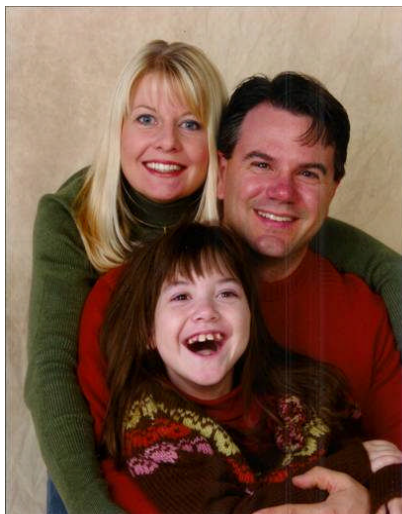
When we saw our pediatric neurophysiologist this summer, she once again questioned why Tashina was not receiving the direct therapy that she needs, I simply stated that it was too expensive. (right now for 1/2 hour of speech it costs of \$30 - that is after insurance has paid their portion).

On a side note - Tashina is a thriving, active, fully integrated in society, little girl who the doctors tell us without the help (Early Intervention and Direct Therapy) that she received at such a young age, she would not be where she is - which makes me wonder what a difference we could make in her life if we could afford to put her back into the therapies that she needs.

The attached pictures are of Tashina in the hospital after one of her surgeries and of her enjoying a boat ride on cousin's boat



Schmid Family Story



Dear State Legislators,

My name is Brenda Schmid and I am a proud mother of our 9 year old daughter Hannah. Hannah was born in Fargo, ND on June 4, 1997. She has multiple physical disabilities and a seizure disorder. To date Hannah is still undiagnosed. We have traveled to Rochester Mayo Clinic, Boston Children's Hospital and frequent Meritcare Children's Hospital here in Fargo. I am not going to go into detail about Hannah's medical condition and disability because that is not who she is. Her undiagnosed disease and disabilities are only a small part of who she is today. I am writing you today in hopes of helping you understand the challenges of raising a child with special needs in the state of ND.

When Hannah was born there was no one in the medical community who directed us to the services we needed (i.e. childcare and/or respite care, infant development). Thanks to God and our own common sense and resourcefulness we found the services on our own.

Financial assistance was unavailable to us until the Wavered MA Program came into existence. We are a middle class family living in Fargo, ND. We were advised by the MA office that my husband's 401K was included in the asset portion of the qualifying process. My husband has been with his company for 14 years and has participated in the 401K program since day one. It is wrong to ask a family to deplete their retirement funds. Considering before the waived program we cashed in everything, all of our investments, savings and my retirement just to make ends meet (as I had to quit my job in order to take care of Hannah – a decision I certainly do NOT regret), all because we didn't qualify for MA due to my husband's 401K. Today I am left with no retirement and all of the stock I had earned while employed is gone. Again, all these funds were used for Hannah's medical bills and cost of living.

Since Hannah is undiagnosed and with a constant changing medical condition we continue to search for a diagnoses and/or effective treatment to provide her with a quality of life. This requires us to access specialty medical services which are not available in our state (ND). We are currently denied Hannah's Neurology services at Gillette Children's Hospital in St. Paul, simply because there is a "Pediatric Neurologist" in ND. However, where there was an absence of a "Pediatric Neurologist" in ND we were referred out to Gillette Children's where Hannah has established a solid medical team actively working on a diagnostic plan and have successfully treated her movement disorder and seizure disorder. It would be detrimental to Hannah to leave her medical team at Gillette and start over with a new less qualified Pediatric Neurologist.

Childcare: My husband and I have struggled to survive on one income for the last nine years. I am very grateful that we are able to survive financially on one income, but many families are not. Currently there is no "Childcare" provided for children with special needs. There is respite care through agency's but the shortage of staff makes it next to impossible to work outside of the home full or even part time. I believe the reason for the shortage of staff is the low compensation for the very important job they do. Caregiver is a profession and is a very important job. The wage for these individuals should be \$12 - \$15 per hour plus benefits.

Special Education – This is a huge issue in it's self. Where do I start? Under qualified staff, lack of funds for equipment, resource materials and therapies. In closing. We have strongly considered moving to Minnesota. In Minnesota we believe Hannah would receive a better education, her medical team is there and would eliminate the denial and appeal process. She would receive therapy services again and more funds available for medically necessary equipment.

Thank you for your time and consideration. I pray you understand the challenges families with special children face in the state of ND and make the right decision to help those in need. We are not looking for hand outs, just a helping hand. Feel free to contact me with any questions and/or need a testimonial.

Health Issue:

multiple physical disabilities and a seizure disorder

Issue: Services are not easily found or known. Wrong to ask a family to deplete their retirement funds. Currently denied Neurology services at Gillette Children's Hospital in St. Paul, simply because there is a "Pediatric Neurologist" in ND. No "Childcare" provided for children with special needs. Shortage of staff for respite care

Insurance Coverage:

Private Insurance

Recommendations: Caregiver is a profession and is a very important job. The wage for these individuals should be \$12 - \$15 per hour plus benefits.

Medicaid Buy-In program/Waiver Program

Family Story from:

Brenda Schmid 3411 43rd
Ave. S, Fargo, ND 58104
701-235-1781

Smith Family Story

Health Issue:

Pervasive Developmental Disorder

Issue:

Lack of services

Insurance Coverage:

Private Insurance

Recommendations:

Medicaid Waiver, Medicaid Buy-In

Services for all children with special health care needs

Family Story from:

Sandy Smith 165 23rd Avenue E.
West Fargo, ND 58078

Work 701-492-3524

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Home 701-282-7714

ssmit@microsoft.com



My son was diagnosed in December 2004 with Pervasive Developmental Disorder which is on the Autism Spectrum when he was 19 months old. Although, we sensed something was wrong, it was still devastating to hear the news. However, what was even more devastating was to find out how inadequate the services for children diagnosed with a disability in North Dakota

Fortunately, I work at Microsoft and they have an Autism therapy benefit as part of their National Premier Blue Cross and Blue Shield insurance program. They would pay 80% of the costs for 40 hours of ABA therapy per week. However, I found out very quickly that there was no one in the state of North Dakota was certified by Microsoft's Premier Blue Cross to provide this service for my son. Again, I was devastated! I had someone who would pay but no certified providers. I went on a personal crusade to find someone that could help. I networked with every person I knew of that had a child with autism and anyone I knew that had connections to the West Fargo and Fargo Public School special education departments. I finally got the name of the Fargo Public School autism consultant and a para-professional who was trained in ABA. Unfortunately, the autism consultant didn't have the qualifications needed to become certified for my insurance. However, since the days were ticking by, I privately paid this consultant and the para-professional to start an in home ABA therapy program in June of 2005. Six months precious months had passed since my son was diagnosed!!! I eventually did find an autism consultant in Grand Forks, ND that met the strict requirements of my insurance and she has been certified since December of 2005 and my insurance has been paying for the therapy since then.

My son has made amazing progress! He currently receives 20 - 25 hours of ABA therapy, 2 hours speech therapy, 1.5 hours occupational therapy and .75 hours of physical therapy per week and since he turned three in April 2005, he is also enrolled in the West Fargo Early Childhood Special Education program. He has gone from being in his own little world of making very little eye contact with us and only 1 or 2 words to a very interactive 4 year old with to 8-10 word sentences and more and more spontaneous speech. He counts into the 20's, can recognize and say his numbers into the 100's, knows all of his colors and shapes, writes his name and can even site read three letter words!! None of this would have happened with out the intensive therapy he received.

1 in 166 children are now diagnosed with Autism and there are published research studies documenting the fact that early intervention is key to a good prognosis. It is imperative for ND to recognize the fact that these children need intensive therapy and need much more than the current Infant Development Program can offer and waiting until these children are 3 before we put them into a structured Early Childhood Special Education program is too little too late. I also believe the state of ND should work hard with the insurance companies in North Dakota to include autism therapy into their standard benefits.

I consider myself very lucky to work at Microsoft and have this benefit available. I am writing this letter for the ND families who aren't this fortunate. However, even with this benefit, I had to scratch, claw and dig to find someone who could help me. It should not be this difficult. It is very painful to watch other families struggle with trying to find services for their child with autism. I have personal experience that early intervention with intensive therapy has a significant impact!! It is a shame that it is not available for everyone!

Restemeyer Family Story

Health Issue:

Mucopolysaccharidosis type 1

Corneal Clouding, moderate hearing loss/requires hearing aide,

Mitral Valve thickening, irregular heartbeat, limited range of motion in all joints, and a weakness in her cervical spine

Issue: Cost of infusion Aldurazyme (Enzyme Replacement Therapy) Exceed income limits for Medicaid. Family recipient liability would be \$3,600.00 per month before Medicaid would start helping.

Insurance Coverage:

Private through employer plan in MN.

Recommendations:

Need an Medicaid Buy-In program or Medicaid waiver for these children

Family Story from:

Jennifer Restemeyer 2217 E. Capitol Ave, Bismarck, ND 58501

(701) 222-0493

jennmarie@bis.midco.net

www.caringbridge.org/nd/allison



My name is Jennifer Restemeyer. My daughter, Allison, is 5 years old and was diagnosed with Mucopolysaccharidosis type 1 on January 8, 2003. I am writing in attempt to plan for the future medical needs of my daughter Allison. I would appreciate your help in finding any assistance for medical costs.

MPS 1 is an inherited lysosomal storage disorder caused by the deficiency of an enzyme called alpha-L-iduronidase. This enzyme is required for the breakdown of certain substances in the body known as glycosaminoglycans (commonly referred to as GAGs). Glycosaminoglycans are complex substances produced by the body that are found in all types of connective tissue. Connective tissue provides structural support to organs and tissues and makes up the cartilage of growing bones, joints, and heart valves. Without sufficient quantities of this enzyme, GAGs accumulate in virtually all organs of the body, causing progressive disease. The incidence of MPS I is estimated at about 1 in 100,000 births. Even though many patients with this disease may have the same enzyme deficiency, patients with this disease can have a wide range of symptoms and experience variable degrees of disease severity.

April 30th, 2003 was a HUGE day for children with MPS 1. A treatment called Aldurazyme was passed by the FDA. Aldurazyme is an Enzyme Replacement Therapy. It gives these kids a synthetic version of the enzyme they are missing! Aldurazyme slows the progressive accumulation of GAG (glycosaminoglycans) and may help control the disorder and improve certain symptoms. MPS 1 is now treatable. Allison received her first infusion of Aldurazyme on May 28th, 2003! She has now had 165 weekly infusions. Infusions of Aldurazyme take around 5 hours to complete from preparation to the end of the infusion. The actual infusion time is 4 hours. Allison had her first 89 infusions at the clinic, and then spent 6 months with a home health nurse coming to our house to administer the infusions. I was trained for about 2 months, and am now administering her infusions myself.

I have seen significant improvements in Allison since she has started on Aldurazyme. Her Liver and Spleen have gone back to normal size, she has an increased Range of motion, the thickening of her heart walls has decreased, and her Lung capacity has improved resulting in increased energy! Unfortunately, the cost of Aldurazyme is very high; it is over \$800.00 per vial. The dosage is based on weight; Allison is 44lbs and requires 4 vials for a cost of over \$3,200.00 per infusion. As Allison grows and gains weight, she will require more vials of Aldurazyme and our weekly bill will increase.

Our insurance policy is through Blue Cross Blue Shield of MN. For right now we can handle what insurance does not pay, but should our insurance decide to change the way it covers these treatments, we will be in great need of assistance. If BCBS decides to pay 90% and leave 10% as our responsibility, we would be looking at \$16,640.00 as our responsibility per year JUST for the Enzyme Replacement Therapy.

Allison has been in the Doctors office more than most children. She started with ear and sinus infections at 2 months old. The ear and Sinus infections have been constant and now usually progress to chronic respiratory infections. Allison has mild Corneal Clouding, a moderate hearing loss, Mitral Valve thickening, an irregular heartbeat, limited range of motion in all joints, and a weakness in her cervical spine, all of which need to be monitored closely. We are scheduled to take Allison to Fairview Medical Center in Mpls, MN approximately every year to monitor her conditions. where the experts are.

Restemeyer Family Story Cont. Pg. 8

Fairview Medical Center has more experience with MPS children than any other Medical Center in the U.S. We must also go to Fairview if there are any surgical procedures that Allison needs. Her Cervical Spine issues and her very narrow airway make it too risky to have her sedated anywhere but where the experts are.

My daughter, Allison, is 5 years old. Allison is a very bright and active child. She amazes me every day with her unique personality, persistence and curiosity. Allison was involved with BECEP's Infant Development program, home based services, and preschool services. Her involvement in the Infant Development Program qualified her for a Home and Community based Medicaid Waiver in the state of ND. Alli's diagnosis of MPS qualified her for this program. She received an hour of both Speech and PT each week. I see the help Allison has received through BECEP as preventative. Developmentally, Allison tested well within her age range, however, due to MPS, she is at very high risk for delays. The services Allison received through the Department of Disabilities, stopped as soon as she turned three on Feb 5, 2004. Allison no longer qualified because she is NOT developmentally delayed. Allison lost the Medicaid waiver.

I have been in touch with Medicaid to try to find a way to keep the Medicaid benefits for Allison, but with the income limits for qualification being in the \$30,000 per year range, and the fact that developmentally she is doing so well, our recipient liability would be \$3,600.00 per month before Medicaid would start helping. Income is looked at before medical need. I have also contacted the Social Security Administration. The income guidelines are 17% higher but again, we do not qualify. The Healthy Steps insurance program is another avenue I tried, but, in order for Allison to qualify for assistance, she would have to have no other insurance. I have found that because Allison is fortunate enough NOT to be developmentally delayed as a result of MPS, she does not qualify for any services after the age of three.

I have the same dreams for Allison that any mother has for her daughter. I dream of Proms and High School graduations, of helping her move into her college dorm. I dream of her College graduation, her wedding, and the birth of her first child. With the help of the Enzyme Replacement Therapy, good medical care and preventative services such as Speech therapy and Physical Therapy, these dreams can come true for my baby. Without them, Allison's physical well being and mental capacity will deteriorate and her life expectancy will be in her teens. It is my hope that somehow we can help fill the gap our state has in providing services to medically needy children who are not developmentally delayed.

"It is my hope that somehow we can help fill the gap our state has in providing services to medically needy children who are not developmentally delayed."



Goldade Family Story

Health Issue:

Truncusarteriosis, a congenital heart disease, Cardiolfacial Syndrome, open heart surgery, VP shunt

Issue:

Unable to maintain SSI eligibility, Difficulty in accessing services, having to find information on our own

Insurance Coverage:

Children's Special Health Services Program, Private Insurance

Recommendations:

Help in accessing services for children who are medically fragile

Family Story from:

Joanne Goldade, Mother
408 Cherry St
Grand Forks, ND 58201
blendseasy1@yahoo.com

Daughter, Ashley-10
Son, Christopher-5

Both of my children have Truncusarteriosis, a congenital heart disease, which also has Cardiolfacial Syndrome (DiGeorge Syndrome) that causes learning delays, speech impairments, and fine and large motor delays. My son also has Hydrocephalus, otherwise known as Water on the Brain. They both have had two open heart surgeries at the present time as well as many precautionary procedures and exams. My son has also had two surgeries for the VP shunt for proper drainage of the fluid from the brain.

When my daughter was born I was not aware that there was an Infant Development program that allowed a therapist to come to my home to work with my child. I was only doing the mail surveys. I think her speech delay would have been caught sooner had I been told about this service. My son received it from birth and it was a godsend. I feel it is very important for the hospitals and clinics to have someone who can share this type of information with parents that have children with special needs. I know they have Social Workers but they don't always make contact with these families. This was our situation. This should be mandatory before they leave the hospital or as soon as a child is diagnosed. The family can decide if they want the information or not but at least it will have been offered.

The children had both been receiving SSI but were told that they were no longer considered disabled. This was a financial burden as they are both constantly doctoring and are both very susceptible to illness. This means more doctor bills. We do participate in the Children's Special Health Services Program which helps pay for the surgeries and exams. But we have to travel to Rochester, MN for all surgeries and some of the preventative exams, which is expensive. We are not always able to get into the McDonald house so the hotel and food bill adds up.

The biggest struggle we've had if accessing services has been the SSI. Initially getting it was smooth, but once they started receiving it, it became difficult to continue as they were always behind on their paperwork and at the time our income fluctuated so we would end up with under or over payments. So you'd never know what to plan on receiving or if you owed them money back.

I have had a very good team within the school for my daughters IEP but I do worry about Middle School and High School. They are not always as accommodating as the elementary level.

The things that I foresee needing will be information on SSI for them as they get older, what medical insurance help will be there for them when they are on their own, what options they have available for post high school opportunities.

As you can see, making ends meet is very difficult when you have the extra medical expenses. Adding this on top of just the emotional things we must deal with each day, sometimes it gets to be too much. So, if there is anyway to making the process to receive Social Security, accessing other necessary services any easier and less waiting time would be a blessing. Also, making sure that all schools have the knowledge to deal with all different learning levels and be willing to work with the parents. Together we can give these children the best life we can and they deserve.



Gadnestad Family Story

Health Issue: autism, speech and language disorders and MR.

Issue: Unable to qualify for DD services at age 18

Insurance Coverage: unknown

Recommendations: Services for children who are DD eligible prior to age 21

Family Story from:

ShawnDell Gadnestad
319 7th Ave. SE, Jamestown,
North Dakota 58401
(701) 952-9133
(mother of Andy Erickson)

Our son Andy is 18 years old with autism, speech and language disorders and MR. He would like to have a job. He wants to earn his own money now. He sees all his friends from school working now and he wants to be like them.

Unfortunately Developmental Disability services won't begin for him until he is 21. Which means that he won't have a job trainer or access to one until then? I would like to see this adjusted. Instead of waiting for the golden age of 21, why can't there be options at 18. Especially since for these children it is not mandatory that they stay in school until he is 21. That is a voluntary decision.

All of his life I've tried to keep his life as "normal" as possible. I was told he would never learn to read. Today he reads at a 3rd grade level and enjoys it. I was told he would never learn his numbers much less do simple math. He is able to multiply and do simple division.

I cannot understand why when we have encouraged him all of his life to be a productive member of society....why should the system hold him back now. This has been our biggest problem and gap in service.

Mikkelson Family Story

Health Issue: Severe tactile defensive sensory issues and anxiety disorder

Issue:

The future

Insurance Coverage:

Medicaid

Recommendations: Fear of losing necessary services

Family Story from:

Jolene Mikkelson

2002 S 38th St. Grand Forks, ND
58201

jomikkelson@msn.com

Have you ever had a child that absolutely could not bear to open his mouth for the Dentist? To have sensory issues so severe that the very touch on his mouth makes his heart pound, his alert system go off, immediately turn on his fight or flight response? The trip to the dentist turns our developmentally delayed, sweet young teenager into an anxiety ridden basket case. Because the dentist can't even understand this I don't expect you to, but let me explain how stressful a trip to the dentist can be for our family.

Sometimes we prepare for it by warning my 14 year old that he's going to the dentist. Sometimes we spring it on him. Sometimes we try to relax him with valium (it hasn't worked yet) and sometimes we try more valium (it hasn't worked either). Although he has gone to the dentist 2-3 times a year since he was two, he has yet to let them get into his mouth for a full evaluation, or a proper cleaning which he so badly needs. Obviously, he barely tolerates tooth brushing. He barely tolerates food in his mouth, which is why is in the bottom 3% for his weight as well. This is not easy for us as parents to watch. We beg him to eat. We used to sit on him to let him brush his teeth, but that is no longer an option. He screams, cries, and makes bedtime tearful every night.

This boy must be sedated/anesthetized for any dental procedures. The fact that the average kid can tolerate touch to his mouth and he can't is not fair. The fact that the full price of this anesthesia falls on us is also not fair. This year we qualified for assistance with this procedure through Medicaid. It scares me to think that the few things he tolerates eating will be harder and harder to eat when he can no longer afford proper dental care (or should I say when his teeth fall out).

Axtmann Family Story

Health Issue: Rare Chromosome disorder

Issue: Medicaid would not cover any of her prescriptions, as they were written out by doctors out of state. Unpaid therapy bill of \$5,000.00

Insurance Coverage: Private through employer, Medicaid until she is 3

Recommendations: Waiver Program for Children with special health needs, Medicaid Buy-In program

Family Story from:

Arel Axtmann 229 4th St., Richardton, ND. 58652

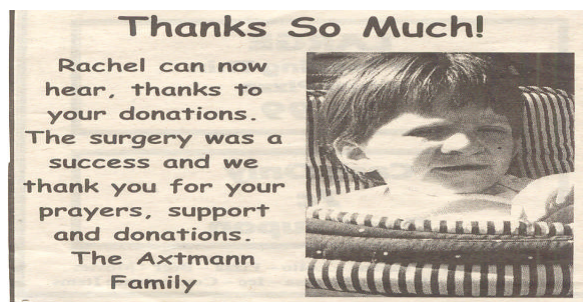
Hi,

My child has a very rare chromosome disorder and does not qualify for social security because our income is too high, we can not get any of the typical "charity" organizations to help us out either, as her diagnosis is not recognized as one the different places help with. We qualified for "respite" care, but do not use it, as we have several other children, and we would have to have them out of the home while the respite worker came, and that really wouldn't help us out any. We have been told by several social services people that we should quit our jobs and stay home, and then we would qualify for assistance, but until we are willing to "work" with them on this, we are on our own. Our daughter needs to go out of state for her care as we do not have the genetic professionals in our state, and Medicaid would not cover any of her prescriptions, as they were written out by doctors out of state. In order

to get our daughter the help she needs, we often need to educate the doctor's and therapists who are working with her. We have been turned away at a few different hospitals, as they do not have the equipment or staff to deal with a child like ours. When she stopped breathing and was blue, we had a doctor at one ER. tell us that "some babies just turn blue". After I revived her, the Dr. ordered an x-ray of her heart and discharged her. She ended up in a different hospital 2 days later with Pneumonia. If I sound angry, it is because I am. If we are not fighting with the insurance company, we are fighting with the medical field itself, and we still have no acceptable answers.

A new update: Rachael is covered by Medicaid until she is 3, due to her disability. She has been going to therapy 3-4 times a week for over a year, and Medicaid had always covered it. In October I added Rachael onto by insurance: Blue Cross and Blue Shield. My insurance refused to pay for therapy because it was not "pre-approved" with them. Since they are considered Rachael's primary insurance, Medicaid refused to pay for therapy as well, even though they have always paid it before. Not only did they refuse to pay for therapy in October, they went back for 3 months prior to our having any other insurance, and refused payment on that as well. I was never contacted by anyone, and I had no idea that there was any issue at all with payment until I took my daughter in for her standing appointment and the therapist told me that their director would not let them work with Rachael until we paid the bill, which was over \$5,000.00! After 2 weeks of no therapy, and a great deal of regression on Rachael's part, the therapists agreed to meet with her anyway, as the insurance company and Medicaid are still arguing over who should pay the bill, and I have still not been contacted by either one of them directly, they are only dealing with the agency that needs to be paid.

Angry in North Dakota!



"Disability is.....a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society."

Tweten Family Story

Health Issue: heart problems, feeding tube, trach and on ventilator

Issue: Unable to qualify for ND Medicaid, Had to move to MN to get Medicaid, Inconsistent child support, Can not qualify for heart transplant, Living at Ronald McDonald in MN for a little over 2 years

Insurance Coverage:

MN Medicaid

Recommendations: Help for ND families, so we can eventually come home

Family Story from: Sandy Tweten

stweten@netscape.net

Annaleis was born on June 6, 2003, she was born at St. Alexius in Bismarck. She was 5 days old when we found out she had heart problems. Children's in Minneapolis flew to Bismarck to pick her up and bring her to Minnesota. She was in Children's Hospital for 4mos, she had heart surgery, and had a feeding tube placed in her stomach. She was on North Dakota medical assistance. We received from weeks to a month of help with food and lodging and then they wouldn't help anymore. Children's hospital picked up the bill. My husband and I also had to refinance our home in Bismarck twice to help cover the expenses of being here.

In January 2004 Annaleis needed a new shunt placed in her heart and was here for a month. Again North Dakota did not help with any expenses, so Children's again helped us.

July 2004 Annaleis needed her heart repair because she was

lung collapsed and she had to be placed on an ecmo machine. She was not expected to live, she developed pulmonary bleeding to which they couldn't find the cause, she was blind from the ecmo machine. Again Children's helped us with food and lodging and parking. In Oct of 2004 North Dakota refused to help Annaleis anymore by Medicaid stating they had gone over and above what they had done for anyone else. To save Annaleis and get the help she needed Crystal was forced to switch residency to Minnesota. The social worker at the time she had at Children's tried to work with North Dakota, but it didn't do any good. The social worker got her switched to Minnesota. North Dakota wouldn't help her with anything. We were very ashamed of our state that Minnesota had to take care of life time residents and taxpayers of North Dakota. Child support in North Dakota will also do nothing to help Annaleis, her father pays very little when he does pay and has a very good job working at a power plant there in Bismarck.

We have been at the Ronald McDonald for a little over 2 years, we have not been able to pay for staying here. We need to find a home where it will be better for Annaleis, but have no way of doing so, money wise. I contacted the Governor in July, but have not received any advice from them. But they do know of our situation. In May 2005 Annaleis developed restrictive cardiomyopathy, there is no cure except a heart transplant which she cannot have because of only having one lung. They are using a new medication and all we can do is hope and pray it works. She has a trach and is on a ventilator to help her breath so her heart doesn't work so hard. She has to have 2 trained people with her at all times. Which is why I am with her and her mother, neither one of us can work because of the care it takes for Annaleis. We are facing losing our home in Bismarck. Annaleis was on SSI at the time North Dakota dropped her from Medical Assistance.



"We have been at the Ronald McDonald for a little over 2 years, we have not been able to pay for staying here. We need to find a home where it will be better for Annaleis, but have no way of doing so, money wise."

Kaseman Family Story

Health Issue: undiagnosed with severe DD

Issue: Not eligible for nursing care because she is not "home bound" according to insurance. Can not qualify for SSI due to too many assets. Unable of paying for nursing care out of our pocket. NDMA denied medical care in MN

Insurance Coverage:

Medicaid

Recommendations:

Better access to necessary services

Family Story from:

Teresa Kaseman

1115 8th Ave W, West Fargo, ND 58078

I have three beautiful children named Ariana, Alex and Lucas. Ariana and Lucas have an undiagnosed neurological condition causing severe global developmental delay. Ariana also has various medical complications that keep us hospitalized much more often than we would like. She has many spells where she becomes ill with flu-like symptoms. When I take her to the hospital I am frustrated with the lack of acknowledgement regarding Ariana's issues. The doctors, in their bewilderment, suggest that I go home because they don't know how to help her. From the start I have felt isolated. Ariana's medical team, who I would have expected to provide me with information regarding various programs available to our family, like infant development, NDMA, and other types of financial and supportive assistance, failed me. Even after we had Lucas, I still wait patiently to hear a doctor offer this type of support. I was introduced into the infant development program because of a daycare provider who was intuitive enough to pick up on Ariana's struggles. Luckily, through this program, our family has been provided with essential support

Beyond that I've learned what other services are available via word of mouth, from parents and through my own research. Along the way, I've had many professional ask if I need anything. But what I really need is someone to tell me what I have available as a parent of a child with difficulties. Many programs have a budget or age limit. Because of this, all too often, I never realize what I need until it is too late.

Insurance has always been a fight. I spend countless hours calling, appealing and battling for things that Ariana and Lucas require in order to lead a normal life. In my attempt to help provide Ariana proper medical care, I looked into getting nursing staff for her. So far this school year, she has spent 60 of her 75 school days in the hospital. We were denied from insurance because she is not homebound. We have caregivers who come to our home to help but they are underpaid and rarely prepared for my children. I am fearful to leave my children but I am forced to in order to provide for my children financially.

I have also checked in to SSI as a supplement to our income. Based on our income guidelines we would qualify, but we have too many assets. We would be forced to sell a vehicle and deplete our 401k plan and savings accounts. It is an item we are being forced to use before we can obtain help for our children. I considered doing it for a moment but then asked myself what would happen when we retire or if we have some sort of emergency and needed those funds? Will the government take care of my house payments and bills then? Will they be there for us or will they abandon us as they have on so many other occasions? Our experience with NDMA has been just as futile. When Lucas was born we were swept into the race to find a possible diagnosis again. Ariana had been to every medical professional in North Dakota so we were told to go out of state to Mayo where they were better prepared to deal with complicated children like Ariana and Lucas. We submitted a prior authorization request to NDMA and both Ariana and Lucas were denied. We were told that Ariana was denied because she had already gone through extensive testing and there was nothing more that anyone could do. Lucas was denied because he needed to be seen by the North Dakota medical community before he would be authorized to go out of state. I went to the Protection and Advocacy Agency and we added another appeal to our already full slate. Everyday I come closer to moving to Minnesota.

Having 3 children, two with the same medical condition, has created a new and unique facet in our lives. I love each of my children to the capacity that only a mother's heart can know but with that love comes a heavy burden. There is never enough time to spend with them. Ariana and Lucas take up so much of my day that Alex is often left to play on his own. Ariana is sick so much that I spend my time trying to comfort her pain while Lucas cries in the background begging for me to hold him as well. Therapies, laundry, stretches, proper placement and the multitude of tasks that I should be doing with my children are thrown to the wayside. I find that I barely have time to make supper, give baths, and sit down to read a book with them before a brand new day has come upon me. I wish that I could spend my time being a mother instead of fighting for what they so badly require.



Dudgeon Family Story

Health Issue:

Cerebral Palsy

Issue:

Access to services

Insurance Coverage: Private insurance

Recommendations: Better access to meet the needs of the child

Family Story from:

Jill M. Dudgeon, LSW

jdudgeon@gra.midco.net

Grand Forks ND/East GForks, MN

I have two many stories... but I will share a few with you. The first being making \$1.00 over the SSI eligibility criteria; if you can imagine this my ex-husband and I were very young, both working several jobs to make ends meet and I remember someone telling us we should apply to SSI because of Torey's disability.

At that time we had two small children and I was making minimum wage working two jobs and Bob was making a little more than minimum. Any ways, we applied and went through the whole process and it came back stating we were over qualified for eligibility by \$1.00. At that time being young and so frustrated about all the information we were getting and never qualifying for anything we completely gave up. Especially when you have to take time off of work to do most of these but when you try to utilize them so simply say "I'm sorry, the budget's been cut and I don't think we have

the money for that".

Okay, to make a long story short, for years I have been told that MA will cover a van lift for Torey all I have to do is apply for it. With that being said I always told myself that I wouldn't put a lift in my van until I absolutely needed it. As long as I was able to carry Torey and lift his wheelchair I would let others have the opportunity before me. So...approximately four years ago I decided Torey was getting a little to big for me to life every day, multiple times a day into my suburban, not to mention his wheelchair.

At the time Torey was 12 years old and getting rather big, not necessarily heavy in weight size but he had grown in height and was about 50 lbs dead weight. So I decided it was probably time to get a lift so I wouldn't hurt my back. Knowing that I am a single mother and had full custody that Torey needed me and what would happen if I hurt my back.....so...I decided to apply for a lift. At that time, they said they didn't have any money...They always seem to have the money when you don't need anything but when you decide to apply for something...miraculously they don't have any then. So for approximately 6 months I fought with them. I searched the internet; I made hundreds of phone calls until I finally spoke to an individual that helped me tremendously. She led me in the right path...bless her soul...Long story short, I was given an attorney's name that fights for peoples right that have a disability...she told me "tell them you spoke to me, and see what happens"...Tah~dah~ I was approved for a lift, within a couple of days....

Those are only two stories as I mentioned earlier I have thousands and thousands of stories.



"Being young and so frustrated about all the information we were getting and never qualifying for anything we completely gave up."

Clohan Family Story

Health Issue: multiple needs: g-tube fed colostomy care, seizure disorder, non-verbal, can't walk or sit unaided.

Issue: Denied SSI due to savings account

Insurance Coverage: Medicaid and Shiners for son, None for family

Recommendations:

Access to health care

Family Story from:

Tina Clohan
10216 19th St. SE
Rogers, ND 58479
701-646-6672

Our son, who is 4 years old, has multiple needs: g-tube fed colostomy care, seizure disorder, non-verbal, can't walk or sit unaided.

We applied for Social Security Disability, and were denied. We were told that even though Brock is permanently disabled, and our income falls into the amount allowable, we have too much in our savings account.... Here's why this is frustrating. We are a one-income family. My husband works for a farmer. He doesn't get vacation or sick pay. He only gets paid for the time he works. If he were to get sick, we would not have any income coming in, so we needed a safety net. We don't smoke. We don't drink. I can't remember the last time we went to a movie theater. We rarely go out to eat -- usually only when we have a long shopping day in Fargo. We

started putting anything extra into savings in case Frank were not able to work. We don't have medical insurance for anyone but Brock, who is on Medicaid, so we use our savings account for doctor and dental visits, too.

Shiners helped us get a wheelchair for Brock... which gave us a new problem. We are a family of 6. The wheelchair is great, but heavy and bulky. After trying many different ideas, we finally decided that our vehicles weren't working, and we had to get a wheelchair van. Even the used van that we purchased was expensive. Brock's DD case manager was able to get \$2000 to help us put a down payment on the van. We got a loan through NDAD so our interest rate was good. But we feel those monthly vehicle payments. Social Security Income would have made a huge difference in this situation.



"We don't smoke. We don't drink. I can't remember the last time we went to a movie theater. We rarely go out to eat -- usually only when we have a long shopping day in Fargo."



Kulink Family Story

Health Issue: Duchenne Muscular Dystrophy, heart problems and scoliosis

Issue: Denied Developmental Disabilities Waiver, Unable to pay for caregivers, Parents employment in jeopardy

Insurance Coverage: Private insurance through employer, Medicaid

Recommendations: Respite Care, access to services

Family Story from:

Dale & Brenda Kulink

1319 N 3rd St, Bismarck ND
58501

qualifies in 5 out of the 7 categories but he doesn't qualify because he doesn't have the diagnosis of mental retardation. Right now we are trying to juggle 3 people's schedules so someone is home with him since he is losing a lot of muscle strength and needs assistance with his self help skills. He also has heart problems and scoliosis.

My husband works full-time and I work part-time and when our kids don't have school our 16 year old daughter stays with him. We should not have to count on our 16 year old daughter to stay with her 14 year old brother. We both work at the same place and our boss has been very flexible so far but we believe this is also causing a hardship for them also. If we do not qualify for some type of services for him his mother may have to quit her job again. We can get respite care but they don't help when you are at a job. His mother is just starting back in the work force after not working for 10 years.

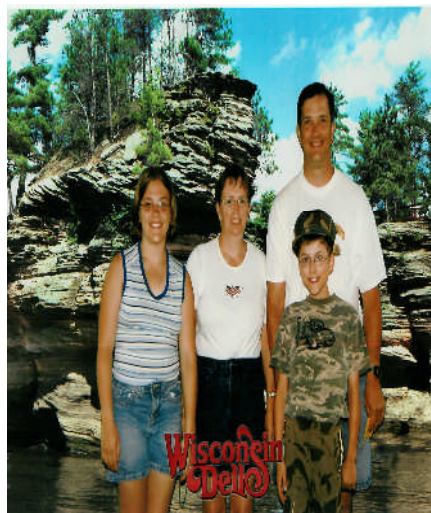
We have more stress from fighting the system and the schools than we have from our son's illness. We as parents are getting tired of fighting the system for services. It takes forever to get things covered. Our doctor is recommending a trip to St. Paul Gillette's Children's Hospital for an initial evaluation on the scoliosis and possible surgery.

We would like to receive the best possible care for our son. Wouldn't you want the same for your child? We were denied by Medicaid for this service even though our doctor is recommending surgery be done in St. Paul since they do more of these surgeries at Gillette's Children's Hospital in St. Paul., Minnesota. Our health insurance is approving these services. We as parents believe we need to make changes in the system so more parents like ourselves can get some help with services for our children with special health care needs.

To whom it may concern:

We are the Kulink family and we have a child named Thomas who has Duchenne Muscular Dystrophy which is a progressive muscular disease which has a life expectancy of 20 to 30 years old. He receives SSI and Medicaid based on our income. We are trying to receive help to have someone come into our home to help us out with his care. We have tried to receive help from our insurance and Medicaid and neither one will help with a child unless he is on a feeding tube or an IV. We could pay for the help ourselves but at \$20.00 an hour we just can't afford to pay that kind of money. We don't make enough to pay that.

We were denied Developmental Disabilities because our son is not mentally retarded. He



Wohl Family Story

Health Issue: Spinal Muscular Atrophy, Type II

Issue: No longer qualifies for Medicaid DD Waiver because she is not MR, Time lost from work, Financial debt, No help paying for van

Insurance Coverage: Private insurance through employer

Recommendations: Need Medicaid Buy-In program to have low premiums

Family Story from:

Rick & Lynette Wohl

3009 Cody Drive, Bismarck ND 58503

To Whom It May Concern:

We are the parents of two daughters, ages 12 & 3. Our 3 year old daughter, Ashley, has Spinal Muscular Atrophy, Type II. This is a neurological disorder that causes muscle weakness throughout the body and grows progressively worse with age. Intellectual ability is not affected. Ashley is able to sit upright, but is not able to walk or crawl. Weakness of the respiratory muscles makes her susceptible to pneumonia and other lung problems.

Up until the age of 3, Ashley was considered developmentally disabled and qualified for Medicaid as well as other human services programs. Presently, she no longer qualifies due to state requirements that anyone over the age of three must be diagnosed as mentally retarded to be considered developmentally disabled.

After concern for our daughter's health & well-being, our next biggest concern is our ability to deal with the financial issues associated with caring for a child with special health care needs. We both work full-time, have decent jobs and earn a very average middle class

income. The only standard under which we would ever be considered wealthy seems to be that used to determine eligibility for programs to help with our daughter's needs.

Though we have employer provided Blue Cross/ Blue Shield health insurance, many expenses are uncovered or annual benefits for certain types of claims are exceeded. About a year ago, Ashley got a power wheelchair. Our share of the cost that insurance didn't pay was approximately \$6000. Fortunately, a local charity was able to help us out with this. Every year there is the cost of deductibles & co-pays. Ashley is in physical therapy to help maintain her strength as long as possible. The amount of therapy she receives is in excess of what insurance will pay and that amount becomes our responsibility.

There are also a lot of expenses associated with a child with special needs that are not necessarily medical, but still stress a family's finances. We recently purchased a mini-van with a wheelchair accessible conversion. This added over \$15,000 to the cost of the van. To keep the payments as low as possible, financing for the conversion was stretched out for 10 years. I sure hope the van lasts as long as the loan. We are also facing the need for a different home due to accessibility issues. Our current home is a two-story with all of the bedrooms on the upper floor. Whether we build an addition on our current home, or purchase a different home, we are sure to add \$400 to \$600 per month to our mortgage payment. Other issues such as lost time from work due to medical appointments, more sick days used for the care of your child and the inability to work extra hours can be a detriment to advancement in your career.

We have heard about a bill that may be submitted in the state legislature this year regarding a Medicaid Buy-In program for children with special healthcare needs. While we are not familiar with the details of this bill and some issues probably remain to be settled, we would like to offer some insight into what we feel would be helpful to families in situations similar to ours. For us, a buy-in program for Medicaid would probably not be a great help unless the cost is quite low. The last thing we need is another substantial monthly payment. For those children with other health insurance where Medicaid would be secondary, the value of the primary health insurance (whether purchased directly or an employer furnished benefit) should be considered as the contribution to the buy-in. For those without any other insurance, a cash buy-in to Medicaid would probably be more beneficial.

One of the biggest frustrations in trying to get help from any of the various programs is the ridiculous maximum income limits. The idea that \$40,000 per year is enough for a family of four to live on and provide for the needs of a handicapped child is outdated by about 20 years. Considering all the costs that families in these situations must bear, the financial issues are a concern regardless of income. Our belief is that the buy-in costs for families with incomes up to even \$80,000 per year will need to be very minimal to provide a real benefit.

There are many families out there struggling with the same issues we have discussed here. Hopefully, there will be a way to ease their burden. Thank you for your time & consideration of our concerns.

"Considering all the costs that families in these situations must bear, the financial issues are a concern regardless of income."

Rask Family Story

Health Issue:

Issue: Not enough qualified respite staff, Running out of respite hours, Mother's employment is in jeopardy

Insurance Coverage: Private insurance, Medicaid

Recommendations: Need more respite care

Family Story from:

Rick Rask
1225 E Coulee Rd.
Bismarck North Dakota 58504

Good morning,

Respite Care hours and Respite Care Givers are a huge concern for many of us.

For instance, the care giver we have now is trying to find a job in her field. However, there doesn't appear to be anyone else to take her place. We are also running out respite hours per quarter. If these two things come together, her job and running out of hours, Paula will likely have to quit her job to take care of Laryssa.

As a family this is a concern financially as well as Paula really loves her job. She only works part time due to the respite hour constraints.

I have to believe there are others out there that are dealing with this type of issue.

Thanks for all your help.

Haarstad Family Story

Health Issue: Down Syndrome, Seizure disorder, hearing impaired

Issue: Grateful for Medicaid

Insurance Coverage: Private Insurance through employer, Medicaid

Recommendations: Better Coordination of Care

Family Story from: Cathy Haarstad

NDCPD at Minot State University

Consumer Affairs

500 University Avenue W.

Minot, ND 58707

1-800-233-1737 or 701-858-3230

cathy.haarstad@minotstateu.edu

Our daughter does have MR and did qualify for Medicaid. When she needed new hearing aides BCBS insurance covered \$1500 out of the \$2700 for each aid. That left us with a bill of \$2400. At least three case managers told us that Medicaid would never pay for digital aides – the kind Sara needed.

After submitting a claim to Medicaid and waiting two weeks I called the office in Bismarck. They protested that the price was outrageous and while they didn't mind the company making a profit that the cost was ridiculously over that amount.

I reminded them that that was easy for them to say. They could refuse to pay more than a set amount and the company had to comply. As a consumer, I was stuck with whatever the company wanted to charge. My daughter could not afford to go without the service (I explained why).

Medicaid paid. I found out later they paid only \$400 for both aides together. Something seems wrong with this picture but I am not sure what it is. All I know is that I am very grateful for Medicaid and their support. I don't have \$2400 in chump change hanging around at the end of the month.

I forgot to mention that after Medicaid approved the aides, the hearing aide company called and wanted me to pay the difference. Fortunately, I knew my rights and declined. They didn't press the issue but if I had not declined they would have taken the money.

Feist Family Story

Health Issue: Hearing Impaired, compromised immune system

Issue: Medical Care Costs

Insurance Coverage: Private Insurance

Recommendations: Build a comprehensive system

Family Story from:

Donene Feist PO Box 163,
Edgeley ND 58433

We are a family of 5, with 2 children with special health care needs. Along the way we have had many trials, but because of strength, emotional support and tenacity we have made it.

Our story is not unique, Zachary our 16 year old is hearing impaired. He medically qualified for SSI, but we were over the income guidelines. We never qualified for anything. Therapy services paid out of pocket really **put us under** financially. Would I have done anything differently? Without a doubt NO! He is fully included in every aspect, he is able to talk, able to excel in sports.. he is one remarkable young man. (which I might add one doctor told us he would never do) He is one of my hero's! Was it tough?...You bet and it still is! Do I think there needs to be changes for families? Absolutely! We need a comprehensive system to meet the unique needs of these children. Can we as a state do better? YES... Without a doubt! Every child has unlimited potential, may they all soar! Families don't want or need a hand out, that is not what we ask. We do need a hand to hold on to, to keep from drowning. Believe me, families can drown in a matter of a moment. As North Dakotans we can do better and do what is right for our children. Let us begin!



Peterson Family Story

Health Issue: Autism

Issue: Trouble paying for respite worker due clerical error

Insurance Coverage: Medicaid

Recommendations: Help! Need Respite Care

Family Story from:

Vicki Peterson, 319 Aspen Ave.
Bismarck, ND

I have self directed supports for respite care and the contracts are written for month- to-month, well anyway my contract accidentally got written for a three month period so the money allocated to me from this program was for the \$287.00 per month looked like \$287.00 for 3 months to the fiscal agent who actually pays the worker. So there was not

enough money to pay her. This happened over 3 weeks ago and my respite care worker has not been paid because the Department of Human Services has not sent the contract to my DD Case Manager for me to sign and without this the fiscal agent cannot pay my worker.

Today my respite care worker informed me she would have to quit because of not being paid! Now I am out of respite Again!! Just because of a silly paper that could have been done in a matter of hours. I have called about his matter many times, so today I finally called P&A. I am desperate to keep my respite care worker since it took me forever to find her and Aaron adores her. She did not want to quit but she felt this issue went to long and she needs the money and she is afraid this was going to take to long to get resolved. She took another job and now I am going to try to pay her out of my own pocket just to keep her. What a mess.



Wilz Family Story

Health Issue: brain injury and subsequent disabilities.

Issue: Placing child away from home, cannot take increase in pay

Insurance Coverage: Medicaid DD waiver, private

Recommendations: Consider the importance of the Family Opportunity Act or a Medicaid Buy In program for families.

Family Story from:

Grant & Angie Wilz

3160 Manchester Place, Bismarck ND 58504

receive. A trained caregiver comes into our home to help with some of the special care required for Jordan. Funding for excess needs specifically related to Jordan's disability is also provided by that program.

Shortly after Jordan's brain injury and release from the hospital, he did live at the Anne Carlson Center for Children in Jamestown. ACCC is an ICF/MR facility. Though Jordan's care was very involved, we were determined to have him home with us. After almost 2 years, we brought Jordan home. The cost of Jordan's stay at the ACCC was, at one point, about \$10,000 per month. I am not sure what the cost would be now. I don't have the exact figure for the cost of our family support, but I have so say \$500-\$1000 a month on average is a high estimate. If we were to take an increase in pay in any form we would lose all that we have for Jordan.

I guess you know by now that we are asking you to consider the importance of the Family Opportunity Act or a Medicaid Buy In program for families. Please consider for a moment, having to send one of your children away from home because you do not have the necessary resources to care for them at home. Please pass the Medicaid Buy-in so Jordan and other children can stay home and so families do not have to file bankruptcy to receive assistance.

To Whom It May Concern:

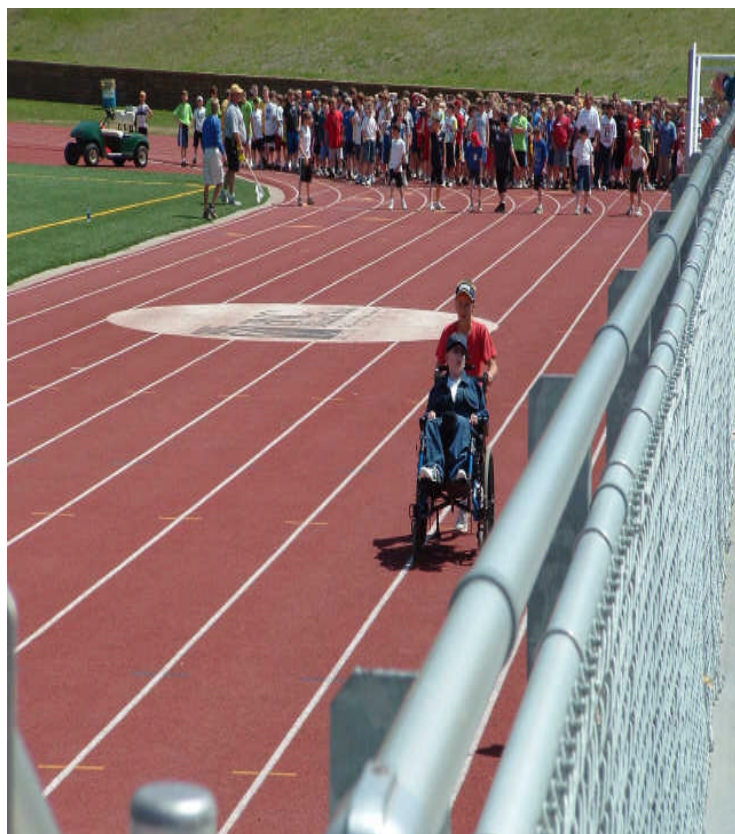
We are the parents of three children. Our son Jordan, a normally developing, beautiful little boy had a very prolonged seizure at the age of 16 months, which left him with a devastating brain injury and subsequent disabilities.

I'm sure you realize we could write a book about the days, months, years, following Jordan's injury, and in our minds it could never all be said.

There is so much parents of children with disabilities face on a daily basis that only parents and family members who have shared the same experience can relate. I say that because I too was once someone who did not truly understand the day to day duties involved in having a family member with a disability

We have chosen to keep Jordan at home with our family, which is, as you well know, where all children have a right to be. One of the things that keep our family together is the family support services we

"If we were to take an increase in pay in any form we would lose all that we have for Jordan."



Milbrath Family Story

Health Issue:

Issue: Searching for assistance with our special needs child is that we either make too much money or have too many assets.

Insurance Coverage: private insurance

Recommendations: Please pass the Medicaid buy-in program.

Family Story from:

Dawn Milbrath

2016 Parkside Dr., Minot North Dakota 58701

I am a parent of a special needs child. My daughter Makenzie was born 3 weeks early on November 2000, and immediately there were problems. Since that time we have been seeking assistance from any avenue we had been referred to or that we could find, and so far we have been turned down by nearly everyone. We are a young couple with two other children which makes us a family of 5.

I had been a full time student trying to get an education so we could better our future for ourselves and our children; we have very little in the bank. The problem we have continued to encounter as we have been searching for assistance with our special needs child is that we either make too much money or have too many assets. I would like to know how a family of 5 with one income, under \$6000 in the bank, a mortgage, vehicle loans, student loans, medical bills and day to day living expenses has too many assets.

We are not asking for miracles, we are simply asking for the assistance that our daughter needs. Her initial hospital bill from birth was over \$55,000...does anyone out there honestly think we have the assets to cover this type of medical bill for one child? I think the system needs to be reviewed and something needs to be changed. If you want to judge me on my assets to see if I am eligible in your minds for assistance then perhaps you should also judge me on my liabilities as well because they certainly outweigh the assets. Please pass the Medicaid buy-in program.

Thompson Family Story

Health Issue: Grade 4 IVH

(brain bleed), significant brain damage and hydrocephalus, cerebral palsy

Issue: Unable to work full time

Insurance Coverage: Medicaid

Recommendations: Medicaid buy-in option would give me the option of working sometime in the future without having to worry about losing Medicaid

Family Story from:

Rachel Thompson

455 B 22nd St. E, West Fargo, ND 58078

(This testimony was provided to the original FOA bill in Congress)

To Whom It May Concern:

I have a disabled son who will require therapy for years and continuing medical supervision or treatment for the rest of his life. Jake was born 13 weeks early and a grade 4 IVH (brain bleed). He has significant brain damage and hydrocephalus, which requires him to have a shunt in his brain to release the extra fluid. The shunt is a life long necessity and there is no guarantee at how long they will last. He had 10 brain surgeries for shunt malformations or shunt infection in his first 18 months of life. All of his shunt surgeries have to be done at Mayo in Rochester, MN because he also has a cyst in his brain and they don't have all the equipment here in Fargo to puncture it. One hospitalization in Rochester was for almost a month and the bill was well over \$100,000.00. He then was a third of the way toward his lifetime maximum for Blue Cross of ND.

The brain damage has caused cerebral palsy (his whole right side is affected), developmental delays, vision impairment, speech impairment and seizures. He receives numerous therapies. He has numerous doctors here in town: neurologist, pediatrician, optomologist, pediatric orthopedic surgeon and rehabilitation doctor. Like I mentioned before, his neurosurgeon is at Mayo in Rochester, MN. Almost all of these doctors have him come back every 4-6 months for rechecks to keep an eye on him.

Thompson Family Story Cont. pg. 22

I care for Jake because there is no day care who will take him with his medical conditions. We have Medicaid right now, which is a huge help. But with the guidelines, our future is limited. I have training as a legal assistant and emergency medical technician. I doubt I could work full time because some of the financial assistance we are on would be cut off and we would be just as broke as we are now, the only difference would be that I'd have someone else caring for Jake so I could work. I

am a very independent person and before Jake's birth, I worked two jobs when I needed extra money. I was used to handling everything on my own and not asking for assistance, until now. I decided that my pride would suffer long before Jake would go without. Having a Medicaid buy-in option would give me the option of working sometime in the future without having to worry about losing Medicaid. That would make our home situation better and give me a way to improve our lives. As it stands right now,

this is as good as it gets and I can't change anything for fear of losing Medicaid.

Everyday I am thankful for my son. I am determined to do all I can to make life as good as it can be. Please consider a Medicaid buy-in program for families of children with special health care needs. It would do so much for families in our situation.

Larson Family Story

Health Issue:**Issue:**

Insurance Coverage: Medicaid

Recommendations: Need waiver or Medicaid Buy-In program, to prevent loss of coverage

Family Story from:

Rhonda Larson

Lakota North Dakota

r_lars@yahoo.com

submitted with original Family Opportunity Act legislation

pay in a month, I am required to pay a liability which is very high. I try to keep my income down for this reason. I could not imagine trying to pay for all the medical expenses that go along with children with special needs. If they were not covered under some plan, I would not have been able to see the specialists who diagnosed my children.

I strongly believe all children should be covered under some medical plan. Families today can hardly afford medical insurance so many go without. I myself would love to be able to have medical insurance but cannot afford it. I avoid going to the doctor for myself because I cannot afford the expense. I wish there were a way to help us parents also. What would my children do without their mother if I became ill? Who would take care of my special needs children then? I am one who has swallowed pride to apply for medical assistance. Many people believe this is charity so they will not get assistance

for their children. I wish there were a program that every child could be covered no matter what their income. Maybe there would be more children getting their health needs met. The children are our future. We need to help them stay healthy and show them we as a society will come together to help them grow strong.

If there were a Medicaid Buy In program perhaps I could work more, get insurance for myself and not have to worry about losing Medicaid for my own children.



To Whom It May Concern:

My children have been covered under Medicaid for quite some time. I have three children with medical conditions which require many appointments with specialists at a distance. Of the three, two are required to take medications daily which I have found costly.

My concern: If I receive more

Roorda Family Story

Health Issue: prenatal heart condition known as "WPW" and severe fetal hydrops

Issue: Oldest son's trust for college makes family assets too high to qualify for SSI – this led to \$8500 overpayment.

High cost to make house accessible

Insurance Coverage: private

Recommendations: Support for a Medicaid Buy-In program

Family Story from:

Cindy & Kevin Roorda

4325 100th Ave. SE, Marion ND 58466

I am writing to request your support for a Medicaid Buy-In program which was passed in the Deficit Reduction Act as the Family Opportunity Act. As parents of a child with special needs, we have personally experienced the many challenges and difficulties parents with special children encounter in getting the services their children need. This bill would allow families the opportunity to buy into the Medicaid program. Even if the family has private insurance coverage, most do not cover the special services and equipment needed on a daily basis by people with disabilities.

I would like to share a personal story to clarify the need for such a bill. When our first son was born, my husband and I, as conscientious parents, decided to start a future college fund for him. Three years later our second son was born. Due to a prenatal heart condition known as "WPW" and severe

fetal hydrops, Jamison was born with many problems including cerebral palsy, due to the lack of oxygen to his brain. As all parents whose children have disabilities we started down the long, frustrating path to obtaining the services Jamison needed.

We learned that Jamison's disability qualified him for SSI. We applied for that benefit to help some of the many additional expenses we would accrue in providing for our son's needs. After receiving the benefit for about 18 months, we were informed that our oldest son's trust, which had to be in our name to secure it until he reached a mature age to use it responsibly, was inadvertently missed by everyone, during the SSI qualifying stage. Our oldest son's savings put us over the qualifying resource level to receive the SSI benefits. WE were instructed to pay back the amount we had already received from SSI, somewhere in the amount of \$8500.00. We asked an employee from Social Security if we needed to hit rock bottom before receiving assistance she replied "Yes you basically have to be at rock bottom and be a "welfare case" before you can be eligible!!! The same story applies for Medical Assistance, we were found to be slightly above the eligibility level. Thankfully we did not have to pay that back. We have repaid the Social Security "overpayment".

We are now struggling to procure the finances necessary to make our home accessible to our son. Most newlyweds are

not planning for accessibility when they purchase or build their first home. Many however, just like us, have to make those very costly changes.

I guess the bottom line is simple. If you succeed or even maintain financially, you are not afforded the opportunity to access the absolutely essential benefits for your child. One thin I think we can be sure of...after a few more years, given the special needs our child has, we will definitely hit rock bottom and be the "welfare case" we need to be in order receive the support and services we need for our child.

Please support a Medicaid Buy-In program, and encourage all your colleagues to do the same.



"I guess the bottom line is simple. If you succeed or even maintain financially, you are not afforded the opportunity to access the absolutely essential benefits for your child."

Hoffmann Family Story

Health Issue:

Issue: Medical assistance terminated after father died at age 37 and left life insurance. Family and business would be in financial jeopardy, run the risk of losing our home and farm, if the insurance money had to be spend down in order to qualify for Medicaid

Insurance Coverage: unknown

Recommendations: Please give our situation some consideration when considering the Medicaid Buy-In program.

Family Story from:

Patricia Hoffmann 3225 55th
Ave. SE, Medina, ND 58467
701-486-3155

(Written as testimony to the original Family Opportunity Act congressional legislation)

To Whom It May Concern:

I write this letter not to asking for sympathy, but to help a situation that I and my family have had to struggle with during one of the darkest, most difficult times in our lives. I write this knowing that we are not the first, nor will we be the last to face such a dilemma, unless, of course, changes can be made through democratic process.

I am Patty Hofmann, mother of three children Zachary, Addison and Camden. My husband and I lived in rural North Dakota and have been involved in farming and ranching since our marriage in 1985. Our husband and father Kendall, age 37, died

suddenly Saturday, December 30, 2000 of a heart attack. Kendall grew up on the family farm near Medina, ND. We have been in a farming partnership with Kendall's parents, which makes our situation, not unique by any means, but certainly more complex than many.

As a responsible caring husband and father, Kendall had life insurance to help sustain his family in the event that something tragic happened....just as something tragic did! By now you may be thinking this certainly is too bad, but what does it have to do with writing to legislators? I have only to begin the real problem and what undoubtedly will prolong our tragedy for months, maybe years to come.

Our oldest son Zachary was born with multiple disabilities. He has many special needs and, as with most children with special needs, the day to day expense with medication, durable medical equipment, etc. are very costly. Zach qualified for medical assistance, which allowed us to sustain a very basic lifestyle.

After Kendall's death I realized I had to seek legal council to get out affairs in order in regard to our business and farming partnership. I also went to Social Services to inform them of our loss and ask if I needed to take care of any legalities involving Zach's medical assistance. It was then that I was told Zachary's medical assistance would be terminated effective January 31st, in view of the money coming in! If you understand anything about farming, I think you will understand that no sum of money can replace Kendall as a farming partner and provider. The life insurance money will be but a drop in the ocean of farming operational expense. I have lost my husband; my children have lost their father, my husbands parents have lost a son and business partner. When I needed financial assistance the most, I was told my son will lose his medical assistance, the only health insurance he has! Oh yes there is a solution. If I hurried and spent all the money the same month we get it, I can start the process of reapplying for medical assistance! In other words, put my family and our business in financial jeopardy, run the risk of losing our home and farm, and then I guess we will qualify!

Just as an aside. I might also remind you that families whose children have disabilities can not have any kind of savings for the future of any of their children, with or without disabilities. We are in dire need of changes from the "one formula fits all" mentality of our social programs. We need to support programs which allow families to maintain their dignity and plan for their future. Plans that will help families help themselves instead of allowing or even facilitating failure and total dependence on programs. It is most important that the whole family be taken into consideration when a family member has a disability.

Please give our situation some consideration when considering the Medicaid Buy-In program.

Kupferschmidt Family Story

Health Issue: neurofibromatosis

Issue: Farm assets disqualify son for SSI and Medicaid. Family gave up custody so son could qualify for coverage

Insurance Coverage: private insurance

Recommendations: Access to services, Medicaid waiver program or Medicaid Buy-In program

Family Story from:

Mary Kupferschmidt
8644 44th St SE, Ypsilanti ND

When my son was an infant certain things were very wrong with him and we started seeing Doctors in Jamestown, then specialists in Fargo. We took him in for Pre-school Special needs assessment at 4yrs 4 months, which ended up getting referrals for full testing, with findings of 'severe delays in speech/language ,motor and cognitive skills'. The result was that I was allowed to take him to our school for speech and PT where the teachers from Buffalo Valley Special Ed would come to work with him.

At five he had surgery and finally got a positive diagnosis for neurofibromatosis, so then we started adding semi-annual trips to the University of Minnesota to our monthly (when they weren't weekly) trips to Fargo to see neurologists, psychiatrists, skin specialists, etc. On a discharge statement after a hospitalization when he was 6 yrs old, I see mention of extreme stress on the home front, holes kicked in walls and doors, marital/parenting/sibling relationships all a disaster. The Doctor commented that there is no follow-through with recommendations. Duh --there was no possible

way to orchestrate change when surviving each day was barely possible. The Doctor did note that hospital stays had a secondary benefit for mom...hmmm...

Throughout all of this we were under the impression that because we owned our land, buildings and machinery, and had savings, that we couldn't qualify for any sort of assistance until all that was eaten up, and with four other children to raise that was not an option. (My husband was in his mid-40's when he married, mid-50's by the time Matt came along and had built up savings, etc. --a substantial amount, but not really, considering that his savings would need to serve as the basis for his 'pension' some day, and certainly not a substantial amount when you look at the funds that go into our son each year now) We were given the impression that we would have to liquidate our cattle herd, and mortgage the farm in order to qualify for help. How could this be fair?

Would they require a doctor to sell his X-ray equipment, stethoscopes, clinic, before he qualified or a mechanic to sell all his tools before he qualified?

One thing was for certain: we could not afford help with housework, or babysitters, and besides, there was no such thing as a babysitter who would look after a kid like Matt AND even if we ever did get one for Matt, we still would need to hire an additional one for the rest of the kids. Who could begin to afford such things? We're not even talking about how to finance the marriage counseling, family therapy and parenting classes the Doctor recommended, so we plugged on.

When we finally got to the point where Matt was bigger than me (and I could no longer restrain him when he had tantrums) the process we had to go through was

to put him on SSI so that his financial status could be considered independently from ours. But that status, as you know, meant that he technically became a ward of the state. I had to give him up, put him out of my home. If I should decide to bring him back home to live, the money gets cut off.

He is stabilized to the point now to where he could probably be at home. But do you think I will try it? Not unless I am absolutely sure I can get him back onto SSI in a minute should we fail. So the answer is: probably not. They will have to keep spending \$116,800 just for his room and board because I know that when he gets upset it takes two strong men to restrain him, and I can't count on getting \$320 a day in help if we find ourselves going through a rough spell.

Isn't it a shame that for us to need \$320 a day in assistance would be considered a failure, and mismanagement of funds, but for them it is considered business as usual? Don't get me wrong: I am not trying to criticize the Anne Carlsen Center, because they do a great job with my son; I am only trying to say that, given a chance, and given assurance of access to all the support I might feasibly require, I think I could do it for less and maybe have a better outcome at this point.

Here's what makes it so hard to deal with families: 1) we aren't born knowing about any of these programs or services, just stumble along, and so much depends upon some perceptive and compassionate social worker stepping up to bat for us, because that is the person who knows what is out there for us when we haven't got a clue and are way too overloaded to guess where to look next. I'm telling you one thing; the internet has simplified things tremen-

Kupferschmidt Family Story Cont. pg. 26

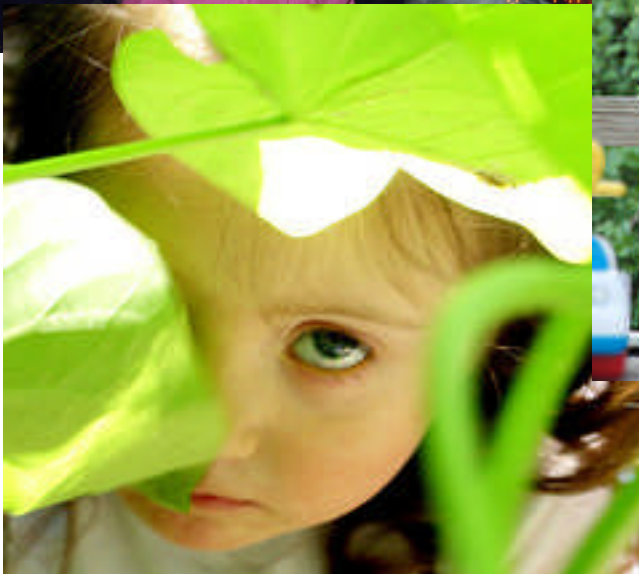
has simplified things tremendously, opened up doors and helped put an end to a lot of the isolation that happens when one is involved in being a caretaker. I had put 98% of my energy into finding medical/psychiatric solutions for my son. Perhaps if we had not had Blue Cross someone would have taken notice earlier and given me a heads up on some programs, or maybe we appeared to be too self-sufficient/wealthy. But the kind of care we really needed in order to keep Matt would have bankrupted us in two or three years.

I have just been flying by the seat of my pants here. I had no idea other programs existed until I met Chuck, didn't get a case manager until Matt got on SSI and he was on IEP's from Kindergarten.

It was only while Matt was on the waiting list to go to live at the Open Door Center, after we had qualified him for SSI that we finally got into the Easter Seals respite program, so we were able to use that for a few weeks. **Somebody did mention that we ought to have been told about it before. Well, we hadn't.** I remember thinking ruefully what

a difference it might have made if I could have been using it all along --ah, what bliss it would have been to get an afternoon off or an actual night of rest!

When I visit with parents at the ACCC I find my story isn't unique at all. That's why I get kind of passionate about this stuff now --because my story isn't unique at all, many families are in the same boat.



Walters Family Story

Health Issue: brittle bone disorder, stroke

Issue: Lot of red tape to go through to get treatment in MN as specialist in ND, has refused to treat her.

Insurance Coverage: unknown

Recommendations: Access to services

Family Story from:

Teri Walters 4999 B 16th Ave. W, Williston, ND 58801

Submitted with original Family Opportunity Act legislation

To whom it may concern,

I have a 15 year old daughter who has been a special needs child almost since birth. Danielle has multiple conditions. When we need to travel out of state to see a doctor we may need to see many specialists. One incident sticks in my mind very vividly.

In June of 1996, Danielle was in Grand Forks to have rods placed in her femurs for a brittle bone disorder that she has. Surgery was very stressful on her body and she ended up having a stroke. We were air ambulated to Mayo Clinic in Rochester MN where she spent six days on the critical list in the ICU and then another week on the pediatric floor. The Orthopedic Surgeon checked on the surgery that was done to make sure that the transport to MN did not mess anything up. After returning to ND the specialist here said "he would not see Danielle anymore because we

had another physician look at his work." Now whenever we need to see an Orthopedic specialist we have a lot of red tape to go through because we have to go out of state, while there is a specialist in ND, he refused to see her.

In the summer of 2004, which in Rochester for check ups, Danielle needed to see the pain clinic for management of her arthritis pain. I guess ND has a pain clinic but they did not specialize in pediatrics. My primary care physician had to call the pain clinic and verify they did not do pediatric pain management, then call Medicaid to report her findings, and then call me in Rochester so that I could set up something in the pain clinic there. All this takes time away from their other patients and essentially we nearly were denied a vital need....to control Danielle's pain.

Every situation needs to be reviewed individually. I can see where there is the person who may milk the system. I get that. But then you have these children with special needs that do need the extra help and they are treated like we are milking the system and that just isn't fair. You cannot expect the status quo for these children as you do for the "general children". The needs are different, in many ways.

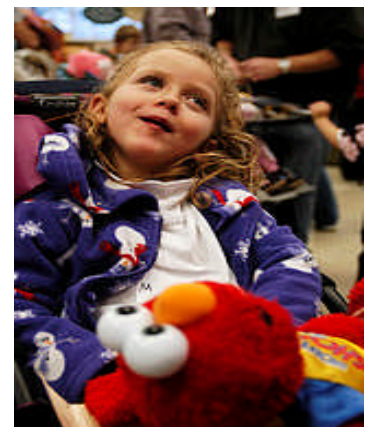
There needs to be better communication between the case worker and the client. Don't wait until it is too late and there case is nearly closed. So many things I have discovered from trial and error

and on my own. Who told us? We wouldn't make it without Medical Assistance, and are thankful but what about the other families. Who is looking out for children with special health care needs? We need a Medicaid Buy In program.

Rural areas, like western North Dakota, suffer the worst. We have to travel very far to get to specialists, education opportunities to learn more. In the winter it can be almost impossible to get to the eastern side of the state, not to mention the time it takes, time off work and the expense. How on earth do other families do this?



"You cannot expect the status quo for these children as you do for the "general children". The needs are different, in many ways."



Klimpel Family Story

Health Issue: Bone Disease

Issue: Lack of support

Insurance Coverage: private, IHS

Recommendations: Medicaid Buy-In

Family Story from:

Evelyn Klimpel

305 18th St. NW, Minot ND 58701

To Whom It May Concern:

The financial strain is immense because my husband hasn't been able to work for the last year and half due to health reasons. All family, home and medical expenses are coming out of one salary.

In the last two years our family was hit hard with health issues. My husband had a heart attack which resulted in depression and panic attacks. He is currently in psychotherapy. My son who is college was diagnosed with a rapid heart beat. He is now on medication to slow it down. This past spring, our other son Clifford had leg lengthening surgery due to a rare bone disease he was born with. He missed the last nine weeks of school. He had to be at Gillette's Children's Hospital, St. Paul, MN every other week from March - May. Besides the medical costs we had transportation costs getting back and forth to the cities.

Clifford has had numerous surgeries since he was diagnosed at the age of two. His follow up care after each surgery is intensive daily care plus it takes one to two years of healing. We applied for respite care but we were denied because our son did not fit the disability criteria of being deficit in two areas and income level.

We have our private insurance and Indian Health Services. Despite receiving authorizations for our son's medical care, Indian Health Service payments are slow (sometimes a year or so behind if they pay at all) and our medical

bills go to collection. Our credit is bad due to the medical bills. Family members tell us to hound I.H.S. Contract Health Services daily but I work and I can't be knocking on their door daily plus I.H.S. is 75 miles away. The majority of the time we pay the bills when they go to collection however we are not reimbursed for those payments by I.H.S.

I called North Central Human Service Center and spoke to the person in charge of respite care. Over the phone she told me we were not eligible.

The best help we received was from Family Voices. They not only answered questions but followed through on their services. Through the help from Family Voices, we were able to have the school put our son on a 504 plan for accessibility to the school. Also, she has been a referral source for my husband who has applied for disability. She referred him to Independence Inc. in Minot for assistance in completing the paperwork. Independence Inc. has been an excellent resource in help my husband fill out the paperwork and answer his questions about filling for a disability.

Our son's specialist was the only pediatric orthopedic surgeon in North Dakota. Two years ago he went back to school leaving no pediatric orthopedic surgeon in ND. Our son tends to have fractures and breaks in the bone that is affected by the bone disease. Despite his 504 plan at school to limit his physical activity, he received a fracture in P.E. We had no specialist in ND, so we were referred to Gillette's Children's Hospital in St. Paul, MN. The Gillette's Children's Hospital is the best place for our child as well as us. They are so family friendly!!! We felt well taken care of as our son.

The main difficulty we have is our hospital is not referring to local medical care. When our son was first diagnosed they wanted to send him to send his biopsy to the Mayo Clinic. We would have to wait six weeks to find out if our child had cancer or a

bone disease. We took him to Med-center One - Bismarck and he was diagnosed within a week. Families are caught in the middle of medical facilities competition.

We need case management to help us with our medical paperwork, service available, and bills. It is endless. When our son has corrective surgery it involves pin cleaning. The daily cost is \$10. We were able to get the supplies from I.H.S. The problem was two things;

1. The supplies were generic and low quality. The gauze frayed and it was painful to pulled it out of his pin sites.
2. They would only give enough supplies for a couple days. The cost to drive 75 miles to I.H.S. Clinic was hard on an already tight budget.

The majority of the time we would buy the supplies in Minot. The quality supplies lessened the pain for our son.

-Case management services for over income families. It could be short term to get them started in the process of management the school, medical and service agency system.

-Respite care for all families with children with special health care needs. The stress is overwhelming at certain times. Respite care could in some cases save a marriage. In our case, easy the stress contributed to my husband's heart attack and depression.

-The state medical system work with Indian Health Services to meet the needs of the child.

We would buy into the Medicaid for a sliding fee premium if we were eligible for social security.



Romanick Family Story

Health Issue: Down Syndrome

Issue: Inclusion

Insurance Coverage: private insurance

Recommendations:
Inclusion for all children
Partnering with families

Family Story from:
Roxanne Romanick

When we first learned about our new baby's diagnosis of Down syndrome, one of the most immediate thoughts is whether or not it was fair to bring her into the world, someone who potentially will require care from her community to raise her. In many cultures and throughout history, this decision was removed from a child's parents. Children with disabilities have been shunned from communities, killed at birth, or taken from parental control and placed in government institutions. Having a child with a disability historically was associated with shame, guilt, and embarrassment. While having a disability is challenging, often children had to grow up feeling like a burden, feeling worthless and unable to contribute, and knowing that the perception of their disability often changed the very

fabric and lifestyle of their family and their community in mostly a negative fashion.

If it were up to me, we'd build a national memorial for all of the families and persons with disabilities in our country that went against "best practice" and pushed forward the message that there is a place in our communities for everyone. As I held my baby for the first time, knowing full well that her diagnosis of Down syndrome was a much a part of her as her fuzzy black hair and her cute button nose, I literally mouthed a prayer of thanks for those pioneers who said it's wrong to tell someone that the best thing for their new baby is to place her in an institution. Have we ever been right when we've promoted segregation?

So what about my initial thoughts...is it right to bring someone into the world who we know will require more support than just her family can provide for her? Is it OK that someone may have a little less net income because of needed taxes to support services? Is it OK that someone's child will have to help her out at school, give of their instructional time, or have to wait a little bit longer until she finishes? Is it OK that our group medical premiums are affected to accommodate for special health care needs? These are tough questions and are often the reasons families with children with special health care needs succumb to shame, guilt, and embarrassment.

I absolutely refuse to allow shame, guilt, or embarrassment to define my daughter. I'm highly convinced that what she gives back to our community far outweighs what the costs are. In addition, if designed right, the supports that she needs can also benefit others. If we start thinking about how to structure our communities so that they accom-

modate the most vulnerable, the ease in accessibility will benefit many others that we hadn't even thought of assisting.

Is creating a community that has a place for everyone cheap? Is it easy to design? The answer is no, but if I ask "Is it the right thing to do? Is it worth the effort? Will we all benefit?" The answer is yes. I hope that we can partner with each other and I don't walk away feeling like I had to revert to shame, guilt, and embarrassment because I have a child with Down syndrome...that I didn't have to beg and plead. I want to walk away knowing I was at the table because I have the most intimate knowledge of how to create this inclusive community and was a full partner in helping with the ultimate design.

"I absolutely refuse to allow shame, guilt, or embarrassment to define my daughter. I'm highly convinced that what she gives back to our community far outweighs what the costs are."



Rennich Family Story

Health Issue: Lissencephaly, Autism Spectrum Disorder

Issue: Child not DD eligible, needs assistance, narrowly defined DD Definition

Insurance Coverage: Medicaid, Private Insurance

Recommendations: Access to appropriate medical supplies

Family Story from:

Mary Rennich 7060 Horseshoe Bend, Bismarck, North Dakota

Thank you for taking the time to read our stories and working hard to find the necessary funds we need to raise our children in our own homes, as it should be for all families.

My name is Mary Rennich, and along with my husband David, we are raising our two sons who both have disabilities. Our son Sammy, is now 16, and has severe seizures almost daily, and a rare and severely disabling brain malformation called Lissencephaly. Our 18 year old adopted son Jesse, has been diagnosed with autism spectrum disorder, or Asperger syndrome, and severe progressive scoliosis. Over the last 16 years, we have had incredible medical expenses which we could not begin to add up, but we know that without the help of the state of North Dakota, the federal government and our private insurance through my husband's employer, we would not be able to keep our children in our own home.

We are so very grateful for the D. D. subsidy and Medicaid for

Sam, who has a diagnosis qualifying him for D. D. services, and the respite care we cannot live without for work, and for time to recharge. As for Jesse, he is not able to receive D. D. services for his disability needs because of the mental retardation status required by Human Services. Although he is able to function in some areas independently, - but- areas such as taking required mood stabilizing medications, keeping safe with others, maintaining a job, etc, Jesse will need some assistance / funding throughout his life to help him to be a happy, healthy, productive, working tax payer. some of these services will be, mental health counseling, Voc. Rehab., and life skills assistance. Many, many individuals in our state need funding that cannot be accessed because they currently do not fit into the narrowly designed guidelines. The state needs to find a way to help those children who do not fit neatly into the D. D. guidelines.

Please continue to learn more about the children in our state that need funding for special health concerns, particularly in the area of mental health. At

times it appears it is an invisible disability, but can be devastating and costly if it is not addressed. Thank you- all of you, for working for our families again- in this legislative session.



"Many, many individuals in our state need funding that cannot be accessed because they currently do not fit into the narrowly designed guidelines."



McMahon Family Story

Health Issue: Tourette Syndrome

Issue: process for applying for Medicaid

Insurance Coverage: MA

Recommendations: annual application process for Medicaid/MA waiver of Buy-In so people can go to work

Family Story from:

Sheri McMahon

717 7th Ave. N., Fargo ND
58102

MA is a nightmare if you have income or assets that fluctuate. It took us 4 months to get eligibility the first time. This year the case has been closed and I have reapplied 3 different times. The first 2 times I wasn't able to get all the documentation done in time. This happens because there are too many pressing issues at the same time. I spend hours working on the MA application, I get an appt several weeks later, there is more to turn in, a crisis intervenes and the case ends up closed.

You really need to document everything but to do that with any kind of efficiency you need to have a printer/copier at home and it has to keep working and you have to buy ink. Otherwise you will have ten more miles a day to run around on foot or burning gasoline to get copies made.

During these times I pay cash for Rxes which are very expensive. I don't always get everything reimbursed later on. Also, when a child has any kind of chronic condition, mental or physical, every time health care access gets disrupted you have disrupted treatment and/or have all this retroactive financial stuff to take care of. It is simply NOT POSSIBLE to do everything

you have to do to access all the services you are entitled to. Because I have to get cash to pay for medicine while eligibility is established, I have had to sell assets and the current worker is thinking this may count as income and make me ineligible even though we would be eligible if I already had the eligibility and could keep assets intact.

Financially, this creates constant flux and harder to budget. I have bad credit because of medical bills, including bills that would have been covered but a referral wasn't done in time or a claim generated while I was applying did not get filed after eligibility was established.

You have to be an accountant and a claims specialist to keep track of it all while you are dealing with a child whose disability results in instability and so on. Working outside the home has been out of the question for 3 years. I am starting to look for work but honestly have doubts that I will be able to sustain work outside because of the involvement needed by my son.

Every time before I have had to eventually leave a situation that generated income, take family leave, and/or had to restrict the hours I worked. I read that family caregivers provide care worth \$600 billion a year in this country and the rate of disability and stress-related illness among them is far greater than the general population. \$600 billion a year is, believe it or not, more than the cost of the Iraq war. We just do it and don't ask for a dime for doing it. We just want to be able to keep our heads above water. our heads above water.

Now I have asked a CIL person to help me through the MA process. I have made duplicates of every piece of paper that goes to the

county, one for her and one for me, and I put her name as well as mine on the application form. Hopefully this will help make it less of a nightmare.

When we have the MA eligibility life is so much easier while it lasts. But it never lasts, and recertification has happened as often as three months after eligibility was established. I would like to be able to have this set for a year at a time.

"I read that family caregivers provide care worth \$600 billion a year in this country and the rate of disability and stress-related illness among them is far greater than the general population. \$600 billion a year is, believe it or not, more than the cost of the Iraq war."



National Survey of Children with Special Health Care Needs, 2001

North Dakota State Profile

Children ages 0-17 years old

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

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

North Dakota Data 2003-2004

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

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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

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

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

21.8% of North Dakota families with a CSHCN had someone in the family who had to quit their job; not take a job or greatly change their job due to problems with child care for their child in the past 12 months; while **24% of North Dakota families** experience financial problems due to child's health needs¹

	Nationally	North Dakota
CSHCN in SSI	1.4%	0.6%
CSHCN without private insurance		
100-200% of FPL	980,281	1601
200-300% of FPL	284,963	433
CSHCN with private insurance		
100-200% of FPL	1,122,724	2,973
200-300% of FPL	1,448,167	3,944
% CSHCN without private insurance		
100-200% FPL	10.5%	8.1%
200-300% FPL	3.0%	2.2%
% CSHCN with private insurance		
100-200% of FPL	12.0%	15.1%
200-300% of FPL	15.5%	20.1%
<i>In part from the Catalyst Center</i>	<i>"Improving Financing of Care for Children and Youth with Special Health Care Needs</i>	<i>Funded through Maternal and Child Health Bureau of the Health Services and Resources Administration</i>

<http://www.cdc.gov/nchs/about/major/slats/nsch.htm> Adopted by the AAP (October 1998). McPherson M, Arango P, Fox HB, A new definition of children with special health care needs. Pediatrics 1998; 102:137-140