

Health Information and Education Center *Creating Partnerships for North Dakota Families*

A newsletter for families and professionals raising children with special health needs



Let It Snow!



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In October HHS Secretary Tommy G. Thompson announced \$31 million in grants to 31 states to help families of children with special health needs and people with disabilities or long-term illness live in their homes and participate fully in community life.

Family Voices of North Dakota received funding to develop and implement an information and referral network for families of children with special health care needs.

We're here to assist with you needs because..

Families need information to make good decisions for their children.

Families must know how to survive in our changing health care environment; and families can

learn best from other families who have "been there."

Family Voices of ND features: Toll-free number, newsletters, links to other organizations, training and workshops, resources and information and much more.

Run by and for families, the Center will:

Assist families and providers as they navigate public and private health systems in the state;

Help families and providers understand options for health insurance;

Educate families and providers about ways to make good choices of health providers and resources;

Listen to families as they describe their encounters with systems and help guide them to possible solutions;

Work with families, providers, public and private agencies and advocacy or support groups to promote family-centered care and medical homes for all children with special health care needs;

Act as a link among all involved to better serve the health care and related needs of children;

Work with agencies to gather and share information, monitor health care and identify ways to improve public and private health



"Our intention creates our reality"

Wayne Dyer

Inside this issue:

Resources	2
Teen Resources	2
CATCH Grant	3
Picky Eaters	4
Breaking the Cycle	5
Talking to your Doc	6
Teams	7

Resources For You to Use

Resource for Caregivers CaringRoad.com

Caring Road is an Internet community for caregivers featuring information and personal stories, and advice. The Caring Road Support Network helps caregivers meet other caregivers, based on geography, diagnosis, or family relationship. Founded by Karen Mintz, a New Jersey documentary producer. By phone contact 609-773-0773. On the web: <http://www.caringroad.com>

Disabilities Studies for Teachers

The Center on Human Policy's Disability Studies for Teachers website contains lesson plans and materials designed to help teachers integrate disability studies into social studies, history, literature, and related subjects in grades 6-12.

The plans and materials also can be adapted to use in postsecondary education.

For further information about the project, contact the Center on Human Policy, School of Education, Syracuse University.

Website:

<http://www.disabilitystudiesforteachers.org>

E-mail: info@disabilitystudiesforteachers.org



Resources for Teens Whose Parents Have a Disability

Online Support Group for Children of Disabled Parents Especially for children of disabled parents between the ages of 13 and 25. It's essentially an e-mail group for people to share their experiences and discuss things with others who understand. [Http://www.groups.yahoo.com/group/childrenofdisabledparents/](http://www.groups.yahoo.com/group/childrenofdisabledparents/)

"Families after Spinal Chord Injury - A Child's View"

The article can be found at: <http://www.spinalchord.uab.edu/>

Brochure—When A Parent Has MS: A Teenager's Guide.

Diane O'Connell with the Pro-

grams staff of the National MS Society explore the experiences of some people whose parents have MS. This can be found at <http://www.nationalmssociety.org/>

Inside MS

Online magazine article with a group of kids who have parents with MS discussing four things that had been the most important to them when learning their parent had MS.

[Http://www.nationalmssociety.org/IMSOct02-KidstoParents/asp/](http://www.nationalmssociety.org/IMSOct02-KidstoParents/asp/)

When Mom or Dad has Seizures: A Guide for Young People

Book -Designed as a companion guide to "Parenting and You," this guide discusses children's feelings about their parents disorder. It is designed for children of all ages. [Http://www.epilepsyfoundation.org/](http://www.epilepsyfoundation.org/)

Family Voices of North Dakota would be happy to send you any of these articles if you are unable to access the web.



Medical Home—CATCH Grant Update

In February 2003, several people from North Dakota attended a meeting in Portland, Oregon. The focus of the meeting was on building health systems of care for children and youth with special health care needs. One of the results of that meeting was a 2004 Community Access to Child Health (CATCH) Grant application. The CATCH Program is an initiative of the American Academy of Pediatrics that provides funding to help pediatricians with community-based health initiatives.

Funding was received for a CATCH planning grant in North Dakota that focused on medical homes for children with special health care needs. The CATCH team implementing the grant includes:

Myra Quanrud, Pediatrician

Pam Gallagher, MeritCare Hospital

Kora Docktor, Children's Special Health Services

Tammy Gallup-Milner, Children's Special Health Services

Kathy Twite, ND Family to Family Network

Donene Feist, Family Voices of North Dakota

Steady progress has been made on activities outlined in the grant application. The first activity undertaken by the team was the completion of a medical home needs assessment.

In fall 2004, health care providers, community partners, and families in three ND communities were surveyed to assess their knowledge about the medical home concept as well as their interest in working with others in their community to improve delivery of primary care for children with special health care needs.

Overall, findings indicate that there is limited knowledge about the medical home concept, but high interest in learning more about it from the identified groups. Practice areas that could be addressed to better serve children with special health care needs and their families were identified.

The CATCH team is now in the midst of planning community meetings in Bottineau March 8th, 2005 at the Norway House from 4:30-6:30 p.m., Jamestown February 22nd, Anne Carlson School 6:30-8:30 p.m., and Bismarck

January 24 2005 6:30-8:30 p.m. Veterans Memorial Public Library.

Survey results will be shared with interested stakeholders and additional information on the medical home concept will be presented to encourage discussion. The CATCH team hopes that through these efforts, champions will be identified who are willing to take the next steps to develop medical homes in practice.

For additional information about CATCH grant activities that address medical homes for children with special health care needs, please contact Donene Feist, Director of Family Voices of North Dakota, Inc. at 1-888-522-9654

We encourage you to find more information regarding Medical Homes at:

www.medicalhomeinfo.org

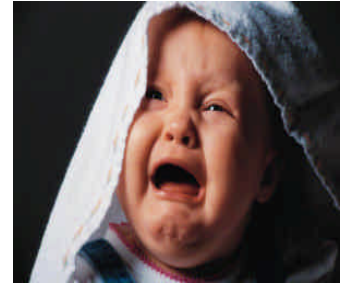


What is a Feeding Disorder?

All children go through periods of fluctuating appetite. Concerns result when a child is not taking enough food to maintain adequate growth and development. Primary care physicians become concerned when there is a persistent history of rejection of eating and/or the caregiver cannot get the child to take enough food to support calorie needs. A child diagnosed as a "failure -to-thrive" means that their weight parameters are consistently at or below the 5th percentile on the growth chart.

Assessing the Child with Feeding Difficulties

If the child has persistent feeding problems, (i.e. reflux, coughing, sneezing and choking) further objective testing may need to be done to rule out inhalation of food in lungs (aspiration), defects in swallowing abilities (dysphagia), or difficulty adequately digesting food (gastric emptying delay). Working with a GI (gastroenterologist) specialist, objective testing can be conducted to begin to rule out areas of difficulty.



Oral-Motor Feeding Assessment

The oral-motor feeding therapist and/or speech-language pathologist will be asked to evaluate the child to determine what factors are affecting the child's ability to feed. An oral-motor/feeding specialist will conduct a thorough evaluation which should include extensive review of medical history, feeding diary, parent interview, and observation of child feeding. The specialist will observe the child feeding and when appropriate will attempt to feed the child as well. Some trial therapy techniques may be explored at that time to assess the child's response to handling sensory input as well as general developmental levels. The therapist must look at motor, sensory, cognitive, and other skills that affect the feeding situation.

Some areas to Be Assessed During the Feeding Evaluation

Motor Skills-refer to the child's overall ability to use well coordinated movements for all aspects including feeding. A child with motor impairments (as in CP) may have poor control over oral mechanisms. Food may easily fall into the airway, choking the child. Food may fall out of the oral mechanism due to poor "lip closure." The tongue may move slowly and poorly, unable to direct food safely to the sides of the mouth for chewing. The swallow may be delayed and the child consistently loses control over fast moving liquid.

Abnormal "Motor Patterns" may persist that interfere with the child's ability to feed effectively. (i.e., abnormal bite reflex may be triggered when a feeding utensil is placed in the mouth. "Tongue thrust" may persist and appear as though the child is rejecting food; when in fact, the child has no other effective pattern to move or transfer food safely.)

Sensory Deficits-are observed when a child persistently grimaces, moves the head out of the way, bats at the spoon and cries in response to bottle, cup, or food. The sensory child seems most like the definition of a "Picky Eater." The degree of sensory involvement varies. The child may do fine on the bottle, but once transitioned to initial baby food textures and taste, the dislikes surface. This child may also demonstrate discomfort with liquid or food in the stomach. They may complain that eating "hurts."

The feeding specialist will combine the above information into a written report. It is her job to come up with a tentative diagnosis as to which issue seem most influential and seem to have the greatest impact on feeding skills. Based on the feeding specialist's written assessment, which should include therapy goals and outline techniques, a child may work with a specialist to improve oral-motor skills and increase overall ability to obtain adequate nutrition for growth and development. ♥

Reprinted with permission of the author, Robin A Rudin, MNS, CCC-SP, Scottsdale AZ

Breaking the Cycle of Rude Comments by April Blotske

I'm sure, as a group, we could put together a monster of a book of stories in which people (family, friends & strangers) have been completely inappropriate and insensitive to our children with disabilities...no mater the type. I, as a mother, have also been angry, hurt, protective, and ended up in the car crying with my heart breaking...why can't others see the beautiful angel in my daughter that I do?? But realistically, I know why....she looks and acts a lot different then the children they are used to! (Especially when she loses it in public!)

The way I see it, I have two choices as a parent of a child with such differences. Just as in all difficult situations, I can react positively or negatively. I can smile, be approachable, take the time to educate, etc....or I can ignore them, glare back, or respond with quick witted comments to surprise and stop them in their tracks. Unfortunately, that's exactly what I'm doing! Stopping them....from ever again wanting to approach or even interact with someone with a disability. I'm teaching them NOT to want to get to know my daughter and all the fabulous things she has to offer! Just think about it. Would you ever want to get to know someone who reacts in a negative way, especially on first impression. And as unfair as it may be, it is quite human for the general public to lump their experiences with people with disabilities together. I know that's not right or fair, but nothing about disability is fair...but it is life...not easy, but worth every

bit of hardship...the rewards are priceless.

So I'd like to apologize to each of you who may someday have an encounter with someone I once reacted negatively towards in the past. I hope and pray that I have not encouraged them to judge you on my poor actions/words.

I want each person who sees and meets my daughter to have left that experience with a good, enlightened, even encouraging feelings. For example, even something small, like when I am pushing Saige down the mall and I see a couple of rude, judgmental stares walking towards us.

..My first reaction is to give the evil eye stare until their eyes finally meet mine. It's a good feeling when I catch them being rude and they know it! That's the last time they will stare at my daughter!

Unfortunately, that's also the last time they'll approach her and I've shattered the chances of them ever wanting to get to know her. So now I do it a bit differently. I still stare at them and wait until they finally look at me...but now I'm smiling. Most of the time, they give a little shameful look and then quickly look away. But now I get genuine smiles back too. Sometimes they even want to meet Saige! And that's my goal!

I want other mothers and teachers to teach their children no to state and turn away when they see my daughter. I want them to feel comfortable enough to walk up to Saige and say "Hi". I don't want anyone to learn to ignore people with disabili-

ties. I'd never teach my children to politely ignore anyone else...but we've started teaching the general public to leave us alone. I know life is tough, but don't we teach our typical healthy children to politely respond when someone asks them a question, even if they don't feel like it. Now I'm holding myself to the same expectations. I can cry about it and beat my pillow in anger in private, at home. However, I've found that when I make myself respond positively, even on a really bad day, I usually don't feel like crying or yelling by the time I get out of the car. It's turned my immediate attitude around as well.

I've been on my soapbox long enough. I'm not trying to judge or preach to anyone. I need it more than anyone! But the more you each respond positively to others who may be ignorant of disabilities, the easier my daughters' life will be....and likewise, I promise to each of you that I will do my best to try and make this world a little more pleasant for your precious children as well....One person at a time!
♥ Reprinted with permission from April Blotske, Basalt, CO. Mother of 5 year old Saige with a craniofacial syndrome, CP and a beautiful smile; and a 1 1/2 year old Kohl who thinks his big sister is the best!



FAMILY VOICES
OF NORTH DAKOTA

Quick Tips When Talking with Your Doctor

Research has shown that patients who have good relationships with their doctors tend to be more satisfied with their care—and to have better results. Here are some tips to help you and your doctor become partners in improving your health care or in the case of those of us with children with special health care needs these tips will help in our relationships with our children's doctors as well.

Give Information. Don't Wait to Be Asked!

♥ You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know. It is important to tell your doctor personal information—even if it makes you feel embarrassed or uncomfortable.

♥ Bring a "health history" list with you, and keep it up to date. You might want to make a copy of the form for each member of your family. Always bring any medicines you are taking, or a list of those medicines (include when and how often you take them) and what strength. Talk about allergies or reactions you have had to your medicines. Tell your doctor about any herbal products you use or alternative medicines or treatments that you receive. Bring other medical information, such as x-ray films, test results and medical records.

Get Information

♥ Ask questions. If you don't, your doctor may think you understand everything that was said. Write down your questions before you visit. List the most important ones first to make sure they get asked and answered. You might want to bring someone along to help you ask questions. This person can also help you understand and/or remember the answers. Ask your doctor to draw pictures if that might help to explain something. Take notes!

♥ Some doctors do not mind if you bring a tape recorder to help you remember things. But always ask first. Let your doctor know if you need more time. If there is not time that day, perhaps you can speak to a nurse or physician assistant on staff. Or ask, if you can call later to speak with someone.

♥ Ask if your doctor has washed his or her hands before starting to examine you. Research shows that hand washing can prevent the spread of infections. If you're uncomfortable asking this question directly, you might ask, "I've noticed that some doctors and nurses wash their hands before touching people. Why is that?"

Take Information Home

♥ Ask for written instructions. Your doctor may also have brochures and audio and video tapes that can help you. If not ask how you can get such materials.

Once You Leave the Doctor's Office, Follow Up

♥ If you have questions call. If your symptoms get worse, or if you have problems with your medicine call.

♥ If you had tests and do not hear from your doctor, call for your test results. If your doctor said you need to have certain tests, make appointments at the lab or other offices to get them done. If your doctor said you should see a specialist, make an appointment. Remember quality matters, especially when it comes to your health.

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Build a Team for Your Children's Good Health

Why a team? Raising children is important and rewarding hard work. Parents need partners—a team! Your team might meet, or could be a “virtual team.”

1. Commit yourself to work for excellent outcomes for your children.
2. Develop good working relationships with everybody who is key in your children's lives
3. Enlist them! Tell them how important they are to your children's health and well-being. Let them know what you hope and need.
4. Respect the knowledge, skills, experience and qualities that each of these partners brings.
5. Build trust over time; it's fundamental to relationships that matter.
6. Talk openly, respectfully and constructively. Consider what parts of your life/your children's lives you want to keep private.
7. Ensure that your goals and values are known. Your background culture, and interests are important.
8. When things are going well—Cheer! Let your team know the good news.

9. Do your best to work out differences and problems. Expect some ups and downs in life and in relationships. Get help if needed to settle issues.
10. Be there as a partner for others—for all children! Others may need you on their team.

Your Team

Partnerships can be formal or informal, short-term or lifelong. Partnerships grow and change as your needs, interests, and circumstances do.

What can your team do? Different team members do very different things...Some are key players with special skills, some cheer, some coach, some pinch hit. Some are there every day, others just from time to time. Some partners change over time. Your job is to build your team in a way that makes sense for you and your family.



Who are possible players on your team?

- ♥ Family and friends—people who care about you and your children!
- ♥ Doctors, nurses, dentists, and other health care workers—through your health plan, your Head Start program, Early Intervention or school, individual at your job
- ♥ Teacher and childcare workers
- ♥ Organizations you're part of that offer partnering information and support such as parent organizations etc.
- ♥ Neighbors and others in your community
- ♥ People you feel good talking with about your children.
- ♥ Don't forget...children themselves!



Donene Feist, Director

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Eight Gifts That Don't Cost A Cent

Give these gifts freely and your riches will grow.

The Gift of Listening-But you must really listen. Don't interrupt, don't daydream, don't plan your response. Just listen.

The Gift of Affection-Be generous with appropriate hugs, kisses, pats on the back and handholds. Let these small actions demonstrate the love you have for family and friends.

The Gift of Laughter-Clip cartoons. Share articles and funny stories. Your gift will say, "I love

to laugh with you."

The Gift of Solitude-There are times when we want nothing better than to be left alone. Be sensitive to those times and give the gift of solitude to others.

The Gift of Favor- Every day, go out of your way to do something kind.

The Gift of a Written Note-It can be a simple "Thanks for the help" note or a full sonnet. A brief handwritten note may be remembered for a lifetime.

The Gift of Compliment-A simple and sincere, "You look great in red," "You did a super job," or "That was a wonderful meal" can make someone's day.

The Gift of a Cheerful Disposition-The easiest way to feel good is to extend a kind word to someone.

May 2005 be filled with much happiness to all of you!

