

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

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



Welcome Spring



Volume 3, Issue 13

Spring 2005

An excerpt from Linda Rowley FV Wisconsin

In 1984 President Reagan signed the Baby Doe provisions of the Child Abuse Act which extended legal protections to infants born with handicapping conditions. Ensuring that those infants would not be denied life-saving treatment because of a disability.

All over the United States there are thousands of young people who have medically complex disabilities and are coming of age. They are the first generation of individuals with severe disabilities to survive adulthood.

These are the kids who five years earlier would not have survived infancy. Their parents have learned to operate complicated medical equipment, provide skilled nursing care on a daily basis, and provide treatments and procedures at home that weren't even

done in hospitals 10 years ago.

While we learned how to care for our children, we also learned much from them. Walking, it turns out, is not everything. And wheelchairs, rather than being an instrument of confinement, are a means for freedom.

We saw through our children's example, that the capacity to experience a quality of life resides in the heart and mind, not the physical body. And we learned that our children share the same hopes and dreams that all children have: to attend their neighborhood school, make friends, grow up, fall in love, find a job, make a home. In short a chance to live a regular life.

Key to that opportunity to live a full life is Medicaid, the critical lifeline for people with disabili-

ties. Because he no longer is a helpless infant protected by the Baby Doe Act, will Medicaid still be there to assure his medical care? If not....then what?!

From the Director:

As family members we are always trying to find balance. Our children's health are constantly in the balance. Sometimes we forget how fragile some of our children are, until one little thing—a cold, pressure sore, urinary tract infection etc. will trigger a chain of events that leaves children struggling.

There are also environmental, political barriers that we also face. We are in very serious times. I am grateful, that families and professionals partnering together will find balance and we will continue to see that these children reach their goals!!!!



No act of kindness, no matter how small, is ever wasted.

Inside this issue:

Resources	2
Transition/IDEA	2
Oral Health	3
Grand parent	4
Parents/Conference	5
Emergencies	6
Health Coverage	7
EIF Form	9-10
Family Advocates	11
Blossom/Resource	12

Resources For You to Use

"Riding on Angels Wings"

The program began in 2002, and offers therapeutic horseback riding to children with disabilities.

Benefits: Children with physical disabilities benefit in this form of therapy due to the fact that, a horse's gait is similar to the human walk, which helps to strengthen muscles and improve posture and coordination and increase joint mobility.

Children with mental and emotional disabilities benefit from the discipline and concentration that is required to master

from the discipline and concentration that is required to master the horseback riding and benefit from developing a relationship with horses.

Children experience a new type of freedom and mobility that the horses provide. They learn they can travel and experience new sounds and sensations that a wheelchair or braces cannot provide to them.

Children also have an opportunity

to achieve their hopes and dreams, while improving their social skills and overcoming anxieties.

To learn more about the program, dates of sessions, participant fees and scholarships—please contact

Bette Shipley 218-287-8137 or
701-793-5153/
5062 120th Ave.
N., Felton MN
56536



Transition and IDEA

On December 3, 2004, President George W Bush signed H.R. 1350 (IDEA 2004) into law.

The National Center on Secondary Education and Transition (NCSET) has developed a web-based document that identifies the major changes between IDEA 1997 and H.R. 1350 (IDEA 2004) concerning transition services. (bold text indicates language changes from IDEA 1997).

The document is available on the NCSET Web site at: <http://ncset.org/publications/related/ideatransition.asp>

One major difference from IDEA 1997 and H.R. 1350 (IDEA 2004) is the age at which

transition issues need to be addressed in an IEP. The old rule was that transition planning started at age 14. Under the new legislation, "beginning not later than the first IEP to be in effect when the child is 16, and updated annually thereafter", the IEP needs to include transition issues.

The new legislation also specifies that his plan include (aa) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills; and (bb) the transition services (including courses of study)

needed to assist the child in reaching those goals



ACCESSING WEB RESOURCES

More and more we have been including web resources in our newsletter. Please remember if you **DO NOT** have access to these web based resources and information, Family Voices of ND would be pleased to send you whatever information you would like printed out.

888-522-9654 or (701) 493-2634

Oral Health

Oral health is an important issue for all children and families. A child's oral health impacts life at home, school, meals and play.

What is oral health?

Oral health is more than teeth. Oral health also includes the mouth, face, nutrition, speech, chewing, swallowing, appearance, well-being and confidence. Families don't have to wait until the baby's first tooth arrives to start thinking about oral health. Practicing healthy oral habits should happen as early as infancy.

Bright Futures in Practice-Oral Health: is a publication that offers an excellent overview for families and professionals on oral health. To view online visit www.brightfutures.org/oralhealth/about.html

Bright Futures Family Pocket Guide Raising Healthy Infants, Children and Adolescents: also has great tips for families from birth to adolescence. Visit www.brightfutures.org to view the pocket guide.

The American Academy of Pediatric Dentists: offer helpful hints for families on topics from thumb, finger and pacifier sucking to teenagers' diets and snacking. Visit their website at www.aapd.org and click on "media information." A listing of pediatric dentists is also available through this site.

What are challenges for families?

Aside from the obvious such as

getting their children to brush their teeth, thumb sucking and eating right, there are other issues some families face: Families may not be familiar with new dental procedures and treatments that weren't around when they were young. Experiences and beliefs about oral health vary among cultures (especially for immigrants).

Cost and coverage may be barriers to care that include high costs of care, co-pays, lack of information about how to get services covered, red tape and delays in determining what is covered, pre-approval process etc. Some providers don't accept Medicaid or certain dental plans. Family-centered in some, but not all dental practices-understanding families' roles in day to day care and special situations, providing information to families offering support for children and families.

What are the issues for families of children with special health care needs? In addition to the challenges affecting all families, the following are issues families with children with special health care needs may face:

- *Modification and appropriate accommodations of dental offices for children with special needs.
- *Staff attitudes and comfort caring for children with special health care needs.
- *Staff training to address information, support, and specific treatment for children with spe-

cial health care needs.

- *Coordinating dental appointments and care with other health care appointments and therapies.
- *Appropriate recommendations for using anesthesia during procedures that might not otherwise require it.
- *Cost for oral health treatments, equipment and supplies, in addition to other regular health care costs.
- *Communication and coordination of all health and oral health providers in order to provide quality, family-centered care and a Medical Home.

Families and professionals can visit the National Oral Health Information Clearinghouse for more information for a patient with special needs. Visit www.nohic.nidcr.nih.gov/ for more information.



GrandParents from Bright Futures

"Nobody can do for little children what grandparents do. Grandparents sort of sprinkle stardust over the lives of little children." **Alex Haley**

GRANDPARENTS

Grandparents are a very important piece of the family puzzle. According to the American Association of Retired Persons (AARP) Grandparents Study in 2002, most grandparents (68%) said they see a grandchild every one or two weeks. Another 24% said they see a grandchild once a month to once every 2 months. Two major obstacles preventing them from seeing grandchildren are living too far away (45%) and their grandchildren's busy schedules (22%). They identified the role of family historian and spoiling their grandchildren as key grand-parents' roles. Respondents are likely to speak to grand-children about day-to-day issues such as school (84%), morals and values (78%), planning future visits (72%) and daily activities (72%).



Grandparents were asked to judge how important they are to their grandchildren. More than half (58%) said they play a very important role in the lives of their grand-children. Thirty percent reported that they feel they play a somewhat important role.

Grandparents have participated in the following activities in the last six months with their grandchildren: 86% had them over for dinner; 84% go out to dinner; 76% watch TV; 75% read to them or with them; 75% go shopping
Information adapted from

The Grandparents Study 2002: http://assets.aarp.org/rgcenter/general/gp_2002.pdf

GRANDPARENTS RAISING GRANDCHILDREN

According to 2000 Census Data, 2.4 million grandparents are the primary caregivers to approximately 4.5 million children under the age of 18. This often happens because of a sudden event involving the natural parents. Nearly 30% of all grandchildren being brought up by grand-parents are under the age of four. Between 1990 and 2000, the number of US children in grandparent-headed households increased by 30%. Most grandparents are between 55 and 64, and almost 25% are over 65. For grandparents, the full-time care of their grandchildren is sometimes a surprise; and almost always a return to responsibilities that they had thought were finished. Some grandparents are in their thirties or forties, but many are old enough to collect Social Security, and their plans do not usually include raising children again.

GRANDPARENTS RAISING GRANDCHILDREN WITH SPECIAL NEEDS

Grandparents raising grandchildren with special needs face similar challenges as other grandparents raising grand-children, but they also tackle additional issues, such as finding accessible housing, obtaining needed health care and receiving legal support. Additionally, since school policies are usually geared toward local families, grandchildren may not be eligible for transportation to other school districts.

Guiding children through life can also be emotionally draining. Grandparents may be at a loss when it comes to dealing with the mental health issues that trouble their grandchildren. Caregivers must be strong enough to set firm limits, but they also need to be tender enough to offer plenty of praise and encouragement.

Information from this section adapted from: <http://chhs.gsu.edu/nationalcenter/welcome.html>,
<http://www.aarp.org/life/grandparents/helpraising/Articles/a2004-09-01-grandparents-behavior.html>

For more information, see the links below... <http://www.aarp.org/life/grandparents/>
<http://www.uwex.edu/ces/flp/grandparent/>
http://www.aoa.gov/prof/aoaprof/caregiver/careprof/pr_ogguidance/background/program_issues/Fin-Heller.pdf

Where Are the Parents by Sue Stuyvesant

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents?

They are at home, diapering their 15 year old son, or trying to lift their 100 lb. daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sitting, bleary eyed and exhausted, in hospital and emergency rooms, waiting for tests results to come back and wondering: is this the time when my child doesn't pull through? They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ. They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the

family, harm. They are sitting at home with their child because family and friends are wither too intimidated or unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of their own.

Where are the parents?

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their child disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer. They are working 2 and sometimes 3 jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything. They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and families.

Where are the parents?

They are busy, trying to survive
Permission to duplicate or distribute this document is granted with the provision that the document stays intact



Save the Date!!!

ND Family Connections Spring Conference: When Children Have Special Needs

June 8, 9, 10, 2005
Best Western Doublewood Inn
Fargo, North Dakota

The *North Dakota Family Connections Spring Conference: When Children Have Special Needs* seeks to strengthen ties and enhance family support by bring together **families** with children who have delays, disabilities and chronic mental and physical health needs and the **professionals** who support those families.

If your family would like a Family Connections Stipend, please call the North Dakota Center for Persons with Disabilities at 1-800-233-1737. NDFC Stipend are offered on a "first ask, first receive" basis. Find information on the web: <http://www.conted.und.edu/connections/index.html>

You can call for registration information: 701-7772663 or toll free 866-579-2663 (credit card payments only)

FVND will have 2 training sessions: Healthcare Finance and Health Care Visits and You.....**SEE YOU THERE!**
SIGN UP SOON!

FAMILY VOICES
OF NORTH DAKOTA

Knowing These Ten Things Could Save Your Child's Life

- 1. Know How to Spot an Emergency Situation:** An emergency situation is if you think your child could die or suffer permanent harm unless prompt care is received. If you are not sure, **MAKE THE CALL!**
- 2. Know How to Contact Your Local Emergency Service:** DIAL 9-1-1 this connects you to Emergency Medical Services (EMS), the police and fire.
- 3. Learn CPR and Choking Rescue Procedures for Infants and Children.:** Knowing how to perform CPR procedures on a child who has stopped breathing could provide your child with the life saving support that he or she needs before the professionals arrive.
*Understanding basic choking rescue procedures is essential to saving the life of any child whose airway is blocked by objects lodged in the throat. *The American Heart Association and the American Red Cross chapter has information on CPR courses offered in your area. Also check with your local hospital, EMS, for CPR training, first aid, and child safety courses.
- 4. Learn Basic First Aid :** Knowing how to stop serious bleeding from an open wound, manage shock, handle fractures and control a fever could provide your child with the right amount of help during an emergency.
- 5. Immunize, Immunize, Immunize:** Get all your child's immunizations on time. Failure to do so places your child at serious risk of permanent disability and even death from a preventable illness!
- 6. Remember What To Do If Your Child Is Involved In A Car Crash:** DO NOT MOVE your child unless they are in further danger. Moving the child unnecessarily could result in permanent injury.
Keep the child warm and if conscious, keep him or her still.
- 7. Understand What To Do If Your Child Is Poisoned:** If your child has been poisoned, bring the poison (and child, if possible) with you to the phone when calling the poison center. Post the poison control center's number by the phone
- 8. Learn What To Do If Your Child Has A Serious Fall:** Do not move any child who is unconscious or has stuck their head.
- 8. Doing so may result in more serious injury.** Call 911 in cases involving any loss of consciousness, blood or watery fluid coming from the ear or nose, and or a seizure. Cover your child with blankets and if conscious keep them still.
- 9. Know How To Treat Your Child IN Case Of A Burn-Stop The Process:** For minor burns without blisters, place the burned area into cold water until the pain is gone (about 15 minutes.) DO NOT use ice. For burns with blisters, call your doctor immediately. DO NOT use butter or petroleum jelly. Large and deep burns require an immediate call to 911. Keep the child warm with a clean sheet and then a blanket until help arrives.
- 10. Be Prepared To Act In Case Your Child Has a Seizure:** Perform rescue breathing if your child is not breathing. If breathing, lay your child on their side.

On pages 9 and 10 we have provided an Emergency Information Form produced by the American Academy of Pediatrics. This has been brought to you compliments of North Dakota Emergency Medical Services for Children (NDEMSC). We encourage all families and providers alike to utilize these forms, complete and provide them to your schools, EMS, place in back packs to assure that the unique needs of your child are understood in the event of an emergency and you are not present, or so that EMS systems are prepared if called. We thank NDEMSC for this opportunity!!

Low-Cost/Free Health Coverage

Do you know of a child, grandchild, friend or patient who lacks health insurance?



Children without health coverage don't always get the medical care they need. All children should have the brightest future.

There may be help...

Covering Kids and Families in North Dakota can assist you.

One Toll Free Help-line is available.

1-877 KIDS NOW or
877-543-7669

Covering Kids and Families can assist you in locating a program that may meet your needs.

They can assist with applications for the Caring Program for Children, Healthy Steps (the State's Children's Health Insurance Plan) and Medicaid; screening and resources. Most of all information is confidential.

Do you want more information?
An application?

WHY WAIT??
Today is too important to waste.

Give them a call or you can check it out on the web at:
www.dakmed.org/coveringkids

SAVE THE DATE!! GRAAIN:

Global Rural Autism Asperger Information Network

3rd Annual Conference
on
Autistic Spectrum Disorders

ASD: Sensory Issues, Educational Implications, and the Brain

August 1-2, 2005

The Memorial Union
University of North Dakota
Grand Forks, ND

Sponsored by

The GRAAIN Organization/
Marj Bock

www.und.nodak.edu/org/grain/

(701) 777-2863 or

marjorie.bock@und.nodak.edu



Children in North Dakota

From the National Survey of Children with Special Health Care Needs/Maternal and Child Health Bureau

Percentage of children and youth with special health care needs, 0-17 years old in ND 12.4%

Percentage of Households with children that have one or more children and youth with special health care needs(CYSHCN), 0-17 years old 19.7%

17.4% of CYSHCN are those whose health conditions consistently and often greatly affect their daily activities.

13.6% of CYSHCN are those with 11 or more days of school absences due to illness.

12.9% of CYSHCN have been without insurance at some point in the last year. Nationally 11.6%
31% of currently insured CYSHCN have coverage that is not adequate.

12.8% of CYSHCN have 1 or more unmet needs for specific health care services

16% of CYSHCN are those whose families needed but did not get all respite care, genetic counseling, respite care, and/or mental health services.

19.1% of CYSHCN need specialty care who had problems getting a referral.

11.5% of CYSHCN are without usual source of care (or who rely on the emergency room), Nationally 9.3%

14% of CYSHCN families pay more than \$1000 or more medical expenses per year. Nationally 11.2%

24% of CYSHCN families' experienced problems due to a child's health needs. (nationally 20.9%)

14.7% of CYSHCN families' spend 11 or more hours per week providing and/or coordinating health care for child (nationally 13.5%)

21.8% of CYSHCN had health needs which caused family members to cut back or stop working.

From the Children's Defense Fund

In ND a child is abused or neglected every 6 hours

In ND a child is born in poverty every 6 hours

In ND a child dies before his or her first birthday every 5 days

In ND a child or teen is killed by gunfire every 2 months

ND ranks 5th among state in percent of low birth weight babies.

14th among states in the percent of babies who received early prenatal care

21st among states in percent of children who are poor.

42nd among states in per pupil expenditures

45th among states in infant mortality

(1st represents the best state for children and 51st represents the worst state for children)

13.3% of all children in ND are poor

63% of eligible persons receive food stamps

68.5% of children under age six with all parents in the labor force

68% of fourth graders are reading below grade level

66% of fourth graders below level in math

8.2% of children in ND are without health insurance

22.3% of two year olds in ND are not fully immunized

4.8% of 16-19 year olds are not enrolled in school and are not high school graduates

94.4% have completed high school

Which leads us to the question.....How are the children in ND?



Families As Advocates

Being A Health Advocate For Your Child with Special Health Needs

Parenting a child with special health needs is not easy! The 40,000 + members of Family Voices across the country, most of us parents of kids with disabilities or chronic conditions, want you to know you're not alone on this amazing journey. We're there to. And we know that the sooner we parents become knowledgeable and strong advocates for our children, the smoother life becomes for the entire family. Our advocacy tips focus on health issues, because it is the mission of Family Voices. But you can use these ideas at your child's preschool, child care center, classroom, in the community, and with extended family and neighbors. We begin with one child.

◆ Believe with all your heart that your child, like all children, is wonderful—even when she or he gobbles up so much of your time and energy. Tell all the world about this precious gift! Remember, though, that your child with special health care needs is not the heart of your family, but a part of your family, sage advice from veteran mom, Florene Poyadue.

◆ As soon as possible, make contact with another family who also has a child with special needs. Hearing from another parent who never sleeps, feels inadequate, and is also frightened about the future will change your life. We know it's not easy to talk with a stranger about your child, but it's worth it. Some groups bring parents together around a certain diagnosis, Cerebral Palsy, for example. Parent groups provide free peer support and are excellent resource for learning all about this new world.

◆ Find out everything you can about your child's diagnosis from your pediatrician, early intervention program, parent group, local library, state program for children with special health care needs. Surf the Internet, where every imaginable diagnosis has a website full of information and resources. If you lack a computer or don't know how to surf, ask someone for help.

◆ Learn about the hospitals, specialists, therapy centers, equipment banks, early childhood programs, and state and private agencies that your child may use.

◆ Keep records. Of all phone calls, doctor visits, insurance bills, Medicaid notices, and forms related to your child. (See page 12 for a Care Notebook you can use) Take notes. Request copies of everything. Put this paperwork in one place.

◆ Become an expert on your child's health insurance plan, whether it's through your employer or Medicaid, especially the benefits paid for by the plan. If you've moved into a managed care system, make sure you ask lots of questions about how it works.

◆ Insist that all your child's providers, from pediatricians to social workers, practice family centered care, which acknowledges and supports families as they raise their children in their homes and communities. Ask us for family centered care materials.

◆ Develop strong partnerships with health and other professionals in your child's life, so that you can work together and use the expertise and skills each of you brings to the care of your youngster. It's especially helpful to have one professional who knows you, your family, and your child very well, and who will advocate with you as a partner.

◆ Know that YOU are your child's best advocate. No one else will do the job as well. Use all the information, contacts, friends and skills you have gathered to practice your advocacy firmly but with kindness and humor. As your child grows up, teach her or him to be an advocate, or prepare a sibling or friend to do so. Because you won't be around forever. In the meantime, it's wise to take care of yourself, even when you think you can't.

◆ Ask Family Voices of North Dakota for help Call us tollfree (1-888-522-9654) to find resources, brochures, websites about family centered care, family professional partnerships, support groups, trainings and conferences. **NOW, GO FORTH AND ADVOCATE**

Donene Feist, Director

Join us today!

PO BOX 163
EDGELEY, ND 58433

Phone: 701-493-2634
toll-free 1-888-522-9654
fax: 701-493-2635
E-mail- feist@daktel.com

PRST
NON-PROFIT
PAID PERMIT
#27
EDGELEY, ND
58433

This newsletter is funded in part by the ND Department of Human Services, Medical Services Division, Children's Special Health Services and Centers for Medicare and Medicaid Services 11-P-92506/8-01



Have You Been Wondering When Your Child Will Blossom?

Some children have a more difficult time achieving in school. In many cases, these children are "late bloomers", who will have success in the future. Many important people have had rough beginnings, yet persevered and went on to greatness. The following are outstanding examples of "late bloomers":

*Beethoven's music teacher said, "As a composer, he is hopeless."

*Isaac Newton's work in elementary school was rather poor.

*Einstein couldn't speak until the age of four, and he couldn't read

until age seven.

*Winston Churchill failed sixth grade

*Walt Disney was fired by a newspaper editor because he had "no good ideas".

*Edison's teacher told him he was unable to learn.

*Henry Ford was evaluated as "showing no promise"



NEW RESOURCE

Family Voices of North Dakota now has: **Family Voices of North Dakota Care Notebook** available for families.

This notebook can be used to track all of your information for your child with special health care needs. Examples are medical, school, therapies, nutrition, providers, appointments etc. We hope you will be able to utilize this valuable resource. You can download a copy at <http://www.geocities.com/ndfv/>

