

Creating Partnerships for North Dakota Families

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



Summer Fun Ends Back to School Begins

Check out the National Family Voices Web Site

Partnering with professionals and families to advocate for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent.

NATIONAL PROJECTS

- ♥ Projects focused on Increasing Leadership
- ♥ Projects focused on sharing information about health care services for and about families

- ♥ Projects focused on supporting essential partnerships between families and professionals

PUBLIC POLICY

- ♥ Pending legislation
 - ♥ Reauthorizing legislation
- ♥ Proposed legislation
 - ♥ Public Laws
 - ♥ Court Cases

INFORMATION & PUBLICATIONS

- ♥ Newsletters
- ♥ Conference Listing-National and State
- ♥ Tele-medicine
- ♥ Medicaid

Waiver ...and more

RESOURCES AND LINKS

- ♥ Diversity/Outreach Resources
- ♥ Health Provider Organizations/Associations
- ♥ Child Health Policy Resources
- ♥ Help with insurance

<http://www.familyvoices.org>



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“To the world you might be one person, but to one person you might be the world”

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Resources For You to Use

Famous Fone Friends Making Children Smile

Famous Fone Friends is a non-profit organization that provides bright moments in the lives of children who are hospitalized or home-bound due to serious illness or injury. Celebrities telephone these children to talk to them about hobbies, friends, school and other subjects of interest. Famous Fone Friends can be an actor, athlete, musician...

Or even Mickey Mouse, Sponge Bob or Bart Simpson!

Hospitals or physicians phone/fax in the name of the child, giving age, brief medical description, phone number and request for specific celebrity. Every effort is made to have the child called as soon as possible, especially if the child's condition is becoming more serious.

If you would like to learn more about this organization call

310-204-5683 or on the web
h t t p : / /
www.thenancysshow.com/volunteer_fff.html



An Interview With Julie Beckett By Donene Feist

As families and advocates share their thoughts, feelings and opinions on changes within Medicaid, we thought it might be helpful to hear some of the history from Julie Beckett.

Julie is mom to Katie Beckett, who was the first child to benefit from a federal waiver that would allow her to keep her Medicaid benefits upon leaving the hospital—even though her parents income made them financially ineligible for Medicaid. North Dakota does NOT have a “Katie Beckett” waiver. However, many of you have inquired about it.

Would you give us some history regarding what was happening medically with Katie when you found yourself pursuing a way to bring her home from the hospital?

Katie had just started breathing a

little bit on her own (an hour every shift) when they approached us about thinking about taking her home, vent and all. We were informed by social services in the hospital that Katie had reached her cap on major medical insurance and she had only Medicaid and they did not pay for home care. That is when we pursued the exception to policy-first, creating a care plan and cost effectiveness of that compared to inpatient pediatric intensive care.

When the waiver was granted by Medicaid who were the kids that were eligible for this option?

When the exception was granted in November of 1981—the Department of Health and Human Services, HCFA administrator knew that they would have to grant other waivers if other cases came forward. The process they set up was

that states could file on behalf of individuals who would meet the institutional level of care, who could be served at home with services and that the cost of those services would be equal or less than the cost of institutional care.

A review board made up of the Surgeon General, assistant to the HCFA administrator and the assistant to the Secretary reviewed each case. (cont. on next page)



An Interview with Julie Beckett (cont from pg. 2)

It became clear that this process would take to long and so the process was formalized into types of waivers both of which states could apply for on behalf of beneficiaries. Model waivers were designed for 50 beneficiaries (later increased to 200) and regular waivers, where the states would determine the type of population they wished to serve (MR/DD, PD, Mental Health and later Aids). The other differences between the two waivers is that the model added additional waiver services, while the regular waiver made beneficiaries eligible for whatever the state had in their Medicaid state plan. These distinctions were later tweaked to meet the specific needs of the populations the state primarily served.

States could apply for as many of wither waiver that they wished, but they had to have the state match to meet the federal match for payment.

Has the eligibility changed at the federal level?

Eligibility has not really changed, but broader options were allowed as long as the costs remained equal to or less that what the population served would have spent in an institution in lieu of the waiver. TEFRA in 1982 even allowed states to serve their under 21 kids without having to apply for a waiver, but they had a box to check off in their Medicaid state plan.

In the beginning waivers were scrutinized for cost effectiveness but even some of that was eased upon by allowing states to aggregate costs. The three criteria never really changed—that they would be eligible in an insti-

tution in Medicaid, they could receive the services needed at home and that the costs would be equal to or less that institutional costs. The feds approve state waivers for 3-5 years and there was a great deal of paperwork involved. Documentation was critical for approval of waivers.

Do you have any suggestions regarding Medicaid options or pending legislation that may be helpful for these families?

If a child is currently eligible for Medicaid in lieu of the waiver the family would face the choice of institutional care. That does not mean they could not try to keep their child at home for awhile but eventually would realize that the care is too much for them to handle without assistance—both in cost and sweat equity.

The point is Medicaid needs to know that the child would truly be Medicaid's again if the family stay qualified by reducing their income or assets. That is still keeping them Medicaid eligible. When the only option for families is to institutionalize their child for those services, then they should be eligible for a waiver. The cost on institutional care is still higher than home care costs even though home care costs have grown by leaps and bounds.

The Family Opportunity Act, which allows families to buy into Medicaid by paying a premium, is currently being discussed in Congress. With its passage states could easily adopt this and use it as an alternative to

wavers. Many families would be glad to pay for the Medicaid services rather than go without. It is a good alternative to those on waiting lists for waiver programs, and for those states with no waiver programs. It is not good policy to force families to reduce income to maintain Medicaid benefits.

Thanks Julie for giving us some history on waivers.

For more information on waiver programs across the country see the Family Voices web page at www.familyvoices.org

**Listen! The wind is rising,
And the air is wild with leaves,
We have had our summer evenings,
now for October eves!**
Humbert Wolfe (1885-1940)



Using Insurance Effectively May Help Obtain Services

By Carolyn Allshouse/FV

Families of a child with a disability or special health care need usually rely on insurance more often than others. Although health insurance can be complex, knowing how to use it effectively can make a difference in obtaining services that will help your child.

Following are some tips on using insurance:

1 Obtain a copy of your insurance contract or certificate of coverage. If an employer provides your family's insurance, ask the benefits or human resources department for a copy. If you purchase insurance privately, ask your insurance agent or company to assist you.

2 Read the contract/certificate of coverage to understand what is covered. It can be overwhelming, so study it by sections. Begin with the parts that address the services that your child needs. There should be a section with definitions to help you understand particular phrases or terms. There will also be a section to explain the appeals process. The certificate of coverage will also include phone numbers to call if you have questions about your insurance and what is required.

To understand how to use your health insurance effectively, look for this type of information: a) when you are required to make co-payments and pay deductibles, b) when and if you need referrals from your child's primary doctor to see a specialist or receive specialized tests or treatments, c) limits on services such as therapies, d) where you can go for certain types of services, e) when and if prior authorization is needed, and f) yearly or life-time caps on insurance.

Learn how to use your insurance. Insurance is designed for medically necessary services and will not pay for others, such as educational services. Therefore, you must have a doctor's order for any services that will be billed to your insurance. Many insurance companies offer case management services for individuals with complex health needs or disabilities. **3** Your family may find it helpful to request an insurance case manager to help use insurance effectively.

4 Appeal, if your insurance denies payment for a service. It is not difficult to do an insurance appeal. Because many families are successful, it is worth a try. If your insurance company denies a service, you should receive a written notice that tells you why you were denied. One of two reasons is typically given: a) it is not a covered service or b) it is not medically necessary.

A rule of thumb: Always base your appeal on the reason given by the insurance company in writing for the denial.



Supplemental Security Income (SSI)

The National Center on Secondary Education and Transition has co-produced with the PACER Center three Parent Briefs on SSI. Below is a description of the briefs. These can be found on NCET's website at <http://www.ncset.org/publications/default.asp#parent> or if you would like a copy call Family Voices of North Dakota at 1-888-522-9654

Supplemental Security Income (Part 1): A Bridge to Work

This brief gives parents of youth with disabilities practical information about how youth can use Social Security work incentives to facilitate a gradual transition from dependence on Supplemental Security Income (SSI) to partial or complete financial independence.

Social Security work incentives allow a recipient of Supplemental Security Income to earn wages while maintaining SSI cash benefits and Medicaid. Background information, definitions, and specific financial criteria for using SSI work incentives are included.

Supplemental Security Income (Part 2): So You Have Decided to Apply

The brief is tailored for parents of youth with disabilities and provides a detailed description of the process for applying for Supplemental Security Income (SSI). The brief outlines four elements, including a) the process of making an appointment with a Social Security Administration representative, b) the specific steps in applying for bene-

fits, c) criteria that the Social Security Administration uses to determine an applicant's eligibility, and d) information about the evaluation conducted if the Social Security Administration cannot initially make a decision about your child's eligibility.

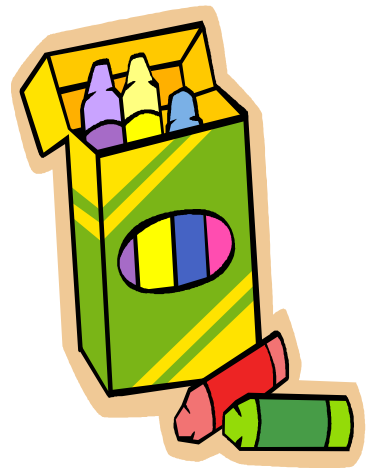
Supplemental Security Income (Part 3): Your Right to Appeal

This brief describes parents through the Supplemental Security Income appeals process, providing information about why many applications are denied, how the decisions are made and how applicants can respond effectively. The brief provides detailed information about the four levels of appeal and discusses three case studies.

Stuff Your Mother Should Have Told You But Didn't

- ♥ Place a slice of apple in hardened brown sugar to soften it
- ♥ Spray your Tupperware with nonstick cooking spray before pouring in tomato-based sauces and there won't be any stains.
- ♥ Run your hands under cold water before pressing Rice Krispies treats in the pan and the marshmallow won't stick to your fingers.
- ♥ To keep your potatoes from budding, place an apple in the bag with the potato
- ♥ To determine whether an egg is fresh, immerse it in a pan of cool salted water. If it sinks, it's fresh, but if it rises to the surface, throw it away.

- ♥ Now look at what you can do with ALKA Seltzer;
Clean a toilet-drop in two Alka Seltzer tablets, wait twenty minutes, brush, flush.
Clean a vase-to remove a stain from the bottom of a glass or cruet, fill water and drop in two tablets.
Polish jewelry-Drop two tablets into a glass and immerse the jewelry for two minutes.
Unclog a drain-clear the sink drain by dropping three tablets down the drain followed by a cup of white vinegar. Wait a few minutes, then run the water.
Makes you wonder what is in those things!!!!



FAMILY VOICES
OF NORTH DAKOTA

ND Family Connections Conference

9/30/04-10/2/04

The *North Dakota Family Connections Fall Conference: When Children Have Special Needs* will be held at the Doublewood Inn in Bismarck on September 30, October 1 and 2. Visit www.conted.und.edu/connections for more information. The conference is planned by the following organizations: Family Voices of ND, ND Federation of Families for Children's Mental Health, ND Association for the Disabled, ND Center for Persons with Disabilities, ND Department of Human Services, ND Department of Public Instruction, ND Protection & Advocacy Project, ND State Improvement Grant, Path ND, Inc., Pathfinder Family Center, Inc., The Arc, Upper Valley and the UND Center for Rural Health Family-to-Family Network.

The *ND Family Connections (NDFC) Fall Conference* seeks to strengthen new ties and enhance family support by bringing together families with children who have delays, disabilities and chronic mental or health needs and the professionals who support those families. It will include a pre-conference session, three keynote addresses, roundtable discussions and over 20 concurrent sessions throughout the three-day event.

Scheduled to present is Dr. Stanley D. Klein, a clinical psychologist, educator, and founder/director of DisABILITIESBOOKS, Inc. He also serves as the series editor for the People with Disabilities Press. Dr. Klein will present "Reflections from a Different Journey: What Adults with Disabilities Want All Parents to Know" which highlights essays written by successful adults with many different disabilities. The essays describe something these adults wished their own parents had read or been told while they were growing up. Dr. Kline illustrates how successful adults who have lived the disability experience can serve as role models and provide essential information about the possibilities for children with disabilities.

Throughout the *NDFC Fall Conference*, participants will learn new strategies, tools, processes, and programs that will address family support issues. Topics include: early intervention, intervention, education, building community and family support. More than 100 professionals and 50 families from North Dakota and the surrounding area are expected to attend.

Families, educators, early interventionists, family support specialists, social workers, childcare workers, child developmental specialists, legislators, therapists, administrators, counselors and other professionals who provide support to families are encouraged to participate in this event. Continuing education credits for educators, social workers, counselors and CEUs will be available (pending approval).

A complete registration brochure will be available in mid-August. Call the ND Center for Persons with Disabilities at 800-233-1737 or e-mail amiller@minotstateu.edu to be added to the mailing list. You may also visit the *Fall Family Connections* website at www.conted.und.edu/connections for the most up to date information.



Safe Backpacking

When children say their schoolwork is back-breaking, they just might be right! The problem is their backpacks—heavily loaded with notebooks, schoolbooks, supplies and sports equipment.

It's not just a hassle to carry a heavy backpack; it can be dangerous. Most physicians believe that children are at risk of muscle fatigue or injury to the spine or shoulders when they carry backpacks that weigh more than 20 percent of their body weight. That means a 100-pound child should be carrying no more than 20 pounds. Yet many elementary and middle school students are lugging around backpacks far heavier than 20 pounds. Taking action to reduce the risk for injury is important.



GET OUT THE SCALE. Weigh your children's backpack when it is full. Then weigh your children. Is the backpack more than 20 percent of their body weight?

LIGHTEN UP. Do your children carry a lot of unnecessary "stuff" in their bags? Check to see what really must go to school each day.

A PLACE FOR EVERYTHING. Show your children how to load their backpacks so that the heaviest items (books, notebooks) are next to their backs with lighter things farther out.

BUCKLE UP. Get your children backpacks with hip straps that connect in front like a belt. Have them use the hip strap for additional support whenever they are carrying heavy loads.

A CUSHY SOLUTION. Look for backpacks that have wide padded straps to help keep them from digging into your child's shoulders. Some packs even come with padded backs.

ROLLING ALONG. Older kids (the ones who need them the most) might balk at the idea, but backpacks with wheels are a back saver.

TWO ARMS ARE BETTER THAN ONE. While it may look "cool" to sling a backpack over one shoulder, it's a serious mistake when the pack is heavy. Instruct your kids to always use both straps.

MAKE IT FIT. The bottom of the backpack should rest two inches above your child's waist. Adjust the shoulder straps accordingly.

LIFT IT RIGHT. Teach your children how to lift with their knees, not their back muscles, when picking up heavy loads—backpacks included

Adapted from "Reports to Parents" by the National Association of Elementary School Principals

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Join us today!

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But what do apples have to do with disability?
One off the five apples is green. One American in five is a person with a disability. A green apple is more like red apples than different. An individual with a disability is more like people without disabilities than different.
Apples are natural. Having a disability is a natural experience of the human condition.
The sun shines equally on all the apples in the bowl, and it's time for the light of inclusion, opportunity, freedom and dignity to shine equally on all people-including people with disabilities. Welcome to the Disability is Natural website! Find good news, new ways of thinking and much more<http://www.disabilityisnatural.org>



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