

Family Voices of Wisconsin

*The Home of Wisconsin's Family to Family Health Information and Education Network
in Partnership with the Wisconsin Children and Youth with Special Health Care Needs Program*

How Do Policy Makers Learn About Children with Disabilities and Special Health Care Needs? From the Voices of Families!

The systems of services and supports for children with significant disabilities and special health care needs in Wisconsin, including generous Medicaid eligibility and benefits, a strong Birth to 3 Program, Children's Long Term Support waivers, the Regional Centers for Children and Youth with Special Health Care Needs, and the Family Support Program, make it possible for families to care for children at home and participate in their communities. While available to some, these programs are not integrated as one system, eligibility and funding varies and a lack of coordination can make it difficult for families to find and utilize these programs. Even with these programs, many families can experience significant challenges that impact their quality of life.

The National Survey of Children with Special Health Care Needs (NS-CSHCN), 2005/2006¹ documented the experiences families face throughout the US. The survey showed that in Wisconsin:

- 20% of families pay over \$1000 out of pocket each year in medical expenses for their child
- 17% of families indicate that their child's condition causes financial problems for the entire family
- 21.7% of children with special health care needs have a condition that cause family members to cut back or stop working
- 37% of families with a child with special needs report that they had inadequate private and/or public insurance to pay for the services they need

In Wisconsin, 15.3% of all children age 18 and younger have a special health care need (approximately 197,700). This compares to 13.9% nationwide.

Children with special needs live in households at all economic levels. 18% live in a household with income 0-99% of federal poverty level (FPL), 14% live in households at 100%-199% of FPL, 14.8% at 200%-399% of FPL, and 14.9% at 400% FPL or more. (In 2010, 100% of FPL = \$22,050 annually or \$1,837 per month for a family of 4.)

Elected officials and policy makers may not be familiar with issues for children with disabilities and special health care needs. Families and providers have an important role to educate elected officials and policy makers that families want to care for their children with special needs and continuing to fund programs and services, including BadgerCare Plus and other Medicaid Programs, the Family Support Program and Children's Long Term Support waivers, is critical to family and child well-being.

In the coming year of tight state and local budgets, the voices of families and providers will be even more important to ensure that financial hardship does not increase for families caring for children with disabilities and special needs.

Additional Resources:

For more information on Medicaid, Family Support, Birth to 3 and other programs, go to the Family Voices website, under *Information, Assistance and Advocacy Resources*, www.fvofwi.org/res_ia.html. Another good resource is the Catalyst Center, a national center for improving insurance and financing for children with special health care needs at www.hdwg.org/catalyst/.

To view the complete National Survey results go to: www.childhealthdata.org and go to the state profile for Wisconsin under NS-CSHCN.

1. Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website, www.cshcndata.org





WEB WATCH

For additional resources related to the articles in this newsletter, you can visit the following sites:

Family Voices of Wisconsin
www.fvofwi.org

National Office of Family Voices
www.familyvoices.org

Wisconsin Genetics
www.slh.wisc.edu/genetics

Catalyst Center
www.hdwg.org/catalyst/

Health Care Reform
www.healthcarereform.wisconsin.gov
&
www.HealthCare.gov

Learn the Signs, Act Early
www.actearly.wisc.edu

Did You Know? Now You Know!

Can My Child's School Bill Medicaid for Therapy and Other Services?

If your child receives therapy or other services as part of his or her IEP during the school day and your child is covered by Medicaid (also called BadgerCare Plus, MA, and Title XIX) his or her school can bill Medicaid for these special education services.

A recent Department of Public Instruction (DPI) bulletin states, "DPI believes that public benefits and insurance are important resources for local educational agencies (LEAs) to assist in meeting their obligation to make a free and appropriate public education (FAPE) available to all students who are eligible to receive services. If a student is covered by a public

benefit or insurance and there is no cost to the family or the student ... to support a service included in a student's IEP then the LEA is encouraged to use the public benefits or insurance to the extent possible. (www.dpi.state.wi.us/sped/bul07-02.html)

Schools must receive parental consent before billing Medicaid and this consent can cover the services your child will receive throughout the school year rather than needing consent each time the school submits a bill to Medicaid. For more information contact Courtney Jenkins at DPI at 608-267-9183 or Courtney.Jenkins@dpi.wi.gov.

Resources for Families and Providers

Wisconsin Genetics Website: A Resource for Families and Professionals

Wisconsin has a newly designed Genetics website at www.slh.wisc.edu/genetics. Features include a Google map to locate medical genetics providers in WI, frequently asked questions like who would benefit from a genetics evaluation, family stories showing how genetic services have benefited Wisconsin families, and information about genetics and family history. The website also has a "For Healthcare Providers" section that has information about indications that are appropriate for a genetics referral, how to refer a patient to a genetics provider, and educational opportunities about genetics. Contact Michelle Kempf-Weibel, State Genetics Coordinator, at michelle.kempfweibel@wi.gov or 608-267-7148 for more information.

Family Voices Fact Sheets Available

Fact sheets on a variety of topics are available on our website (www.fvofwi.org/factsheets.html). The fact sheet on Diapers/Incontinence Supplies and Medicaid is included as an insert to this newsletter.

Opportunities Around the State

2nd Annual Knowing Autism Conference - January 28

The Western Wisconsin Autism Advocacy and Consulting Center, in collaboration with the UW River Falls Communicative Disorders, Counseling & School Psychology and Social Work Programs, will be hosting its annual **Knowing Autism Conference** with keynote address "Lessons Learned from my Autism Journey" by Mary Lynch Barbera. For more information go to www.wwaacc.org or call 715-381-8454.

2011 Wisconsin Transition Conference

The Eighth Annual WI Transition Conference will be held Feb. 17-18 at the Kalahari Resort, Wisconsin Dells. More information and on-line registration are available at www.WSTI.org.

Community on Transition Meeting in 4 locations - January 20th, 9-12:00

A Community on Transition meeting, *Creating a Meaningful Life: Developing Transition Experiences For Youth With Significant Disabilities*, will be held in Madison and remotely at CESA 1 (Pewaukee), CESA 6 (Oshkosh), and CESA 11 (Turtle Lake) on January 20th. Go to http://wsti.org/documents/2010/CoT_January_meeting_flyer.pdf for more information or contact Beth Swedeen at swedeen@waisman.wisc.edu or 608-263-6745.

Children and Youth with Special Health Care Needs News

Track your Child's Developmental Milestones

Are you looking for one simple, family-friendly website to learn more about child development, assessment, or community resources? If so, visit www.ActEarly.wisc.edu to get answers to three basic questions:

“Where can I find information about my child’s development?”

“What can I do if I’m concerned about my child’s development?” and

“How can I find other community resources?”

This website also provides links to the Centers for Disease Control and Prevention’s “Learn the Signs. Act Early” campaign site, where you can download or order free fact sheets, milestone checklist, posters, a growth chart, materials in other languages, and more!

HEALTH REFORM UPDATE

The US Department of Health and Human Services has several new brochures on the health care reform law. “*The Affordable Care Act, What It Means to You*” is available at www.healthcare.gov/center/brochures/for_you.pdf. Other brochures, including “*The New Health Care Reform Law - What It Means for Young Adults*,” are available at www.HealthCare.gov/center/brochures/index.html. For information on health care reform and its impact in Wisconsin contact the Office of the Commissioner of Insurance at 608-266-3585 or go to www.healthcarereform.wisconsin.gov.

Two Important Components of the Health Care Reform Law

1. As of September 23, 2010, health plans cannot limit or deny benefits or deny coverage outright for a child younger than age 19 simply because the child has a “preexisting condition.” In 2014, the Act will prohibit insurance companies from denying coverage or charging more to any person based on their medical history.
2. As of September 23, 2010, the Affordable Care Act prohibits health plans from putting a lifetime dollar limit on most benefits you receive. The Act also restricts and phases out the annual dollar limits a health plan can place on most of your benefits and does away with these limits entirely in 2014.

OTHER NEWS

You Tube Videos Produced by WBPDD

The Wisconsin Board for Developmental Disabilities (WBPDD) has produced several inspiring videos now available on You Tube. “My Transition Story” features Ben Fleischman’s transition from high school to the workforce (Ben is Family Voices Co-Director Barbara Katz’s son). “Self-Directed Supports” features Jerry Cywinski and shows how self-directed supports have made a positive impact on his life. To view these and other videos go to <http://www.youtube.com/user/WBPDD>.

Parents in Partnership (PIP)

The Wisconsin Statewide Parent-Educator Initiative (WSPEI) is seeking proposals from schools, communities, parent groups and agencies that would like to host a Parents in Partnership training for 2011-2012. There is no cost to parents except for their commitment of time. Go to <http://dpi.wi.gov/sped/doc/par-pip-proposals-2011-12.doc> for information and application forms. Applications must be submitted by February 28, 2011 to: WSPEI, Attn: Martha DeYoung, P.O. Box 564, Portage, WI 53901.



Children and Youth with
Special Health Care Needs

CYSHCN CENTERS

**Call with your
questions!**

Northeast Region

Children’s Hospital of
Wisconsin - Fox Valley

1.877.568.5205

Northern Region

Marathon County Health
Department

Wausau

1.866.640.4106

Southeast Region

Children’s Hospital
Milwaukee

1.800.234.5437

Southern Region

Waisman Center
Madison

1.800.532.3321

Western Region

Chippewa County Dept of
Public Health

Chippewa Falls

1.800.400.3678

Great Lakes Inter-Tribal Council (GLITC)

Lac du Flambeau

1.800.472.7207



Family Voices of Wisconsin

c/o The Arc Wisconsin
2800 Royal Avenue #209
Madison, Wisconsin
53713

Late Fall 2010

Volume 5, Issue 3

This newsletter is funded in part by the MCH Title V Services Block Grant, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services through a grant from the Wisconsin CYSHCN Program and with funds from the federal Maternal and Child Health Bureau, grant #H84MC07995-02-00.

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About Family Voices of Wisconsin

Family Voices of Wisconsin is the home of the Wisconsin Family to Family Health Information and Education Network. Family Voices of Wisconsin is part of a national grassroots network of families and advocates who support children with disabilities and/or special health care needs. We provide information, training and support around health care and community supports to families throughout Wisconsin, including the well received "Did You Know? Now You Know!" training program. Family Voices is dedicated to strong collaborative partnerships between families and essential allies to improve the systems of supports and services for children. A core commitment of Family Voices is to involve and support parents in decision making roles that affect program design and policy recommendations on local, regional and statewide levels.

Feedback Welcome

We want to make sure that this newsletter is an effective resource for you. If you have any comments, or wish to provide news and information for us to publish, please contact Barbara at barb@fvofwi.org. We look forward to your ideas and suggestions!

Would you prefer to have this newsletter emailed you? If so, contact the Family Voices newsletter editor at Lynn@fvofwi.org.

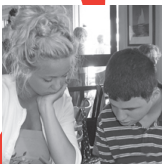
Diapers/Incontinence Supplies and Medicaid



Some children and youth with disabilities and/or special health care needs use diapers or other incontinence supplies for a longer time than typically developing children. Some will use them throughout their lives. This fact sheet provides useful information on covering the cost of these supplies for families who have Medicaid or BadgerCare Plus coverage. We will also explain the new requirement that all supplies be ordered from **J & B Medical Supply**.



Please note: If you are enrolled in an HMO or managed care organization (MCO), you need to work directly with that HMO or MCO to receive incontinence supplies. You do not have to order your supplies from J & B Medical Supply.



The medical term for diapers is incontinence supplies. This includes briefs (diapers that open on each side), pull-up/pull-on type diapers and other belted garments. Incontinence supplies also include disposable under pads, liners, disposable gloves, catheters, lubricants and other related supplies.

Does Medicaid cover diapers for children of any age? No. Wisconsin Medicaid will pay for diapers and other incontinence supplies starting when your child turns 4. Please note, Medicaid does NOT pay for wipes.



Can I go to my local retailer or pharmacy to get my diapers? No. Unlike in the past when you could go to any pharmacy or other retailer who accepted Medicaid, starting May 1, 2010, you must receive your diapers through **J & B Medical Supply**. J & B Medical will deliver these supplies to your home every 30 days via Federal Express (FedEx). You CAN, however, still receive both disposable gloves, and skin barrier wipes and swabs from ANY provider you choose, including J & B Medical Supply.



The Medicaid contract with J & B Medical also includes urological supplies such as catheters and drainage bags.

J & B Medical Supply's contact information is: 1.866.674.5850 or www.jandbmedical.com/. Their office is open Monday - Friday, 7:00am – 5:00pm.



What do I need to do to have Medicaid cover these supplies? You should contact your child's primary care doctor and explain that you are seeking coverage for diapers and/or other incontinence supplies. Next, contact J & B Medical Supply and a nurse will work with you on intake information and an assessment of your child's needs. You will need your child's Forward Health Identification card number, the name and address of your doctor, and an estimate of how many diapers you use each day. J & B Medical will then contact your doctor directly to approve your order. You will need to fill out standard paperwork and make a choice of what products work best for your child. Once this process has been completed, J & B Medical can fill your order and send out your incontinence supplies. (Over)



**A “Did You Know?
Now You Know!”
FACT SHEET**

Can I receive samples from J & B Medical? Yes. After the intake process, you can request samples of their products so you and your child can determine which diapers will work best. We encourage you to request samples before a month’s supply is shipped to you!

What brands or types of diapers are available? Under the current Medicaid contract, J & B Medical Supply has only certain manufacturers available to families covered by Medicaid or BadgerCare Plus. They may not have the specific brand of diaper that you used in the past, but they do have several brands and manufacturers to choose from. You will need to contact J & B Medical (see contact information) and request samples. Try to be as specific as possible to explain what works best for your child. You may also want to explain specific concerns (absorbency at night, chafing or irritation, etc.).

How many diapers will be covered? Is there a limit on the number of diapers? During the intake process you will work with a J & B Medical Supply nurse to determine how many diapers you need each day. If that number changes, contact J & B Medical. They will work with you to deliver the quantity that you need each month. **The monthly limit is 300 diapers.**

What if I am not satisfied with the quality of the diapers or other products? If the diapers or other products that you received from J & B Medical Supply do not work well for your child, the first step is to call J & B Medical directly and explain the problem. They may be able to provide another product that meets the needs of your child. If you cannot resolve the problem with J & B Medical, the next step is to contact that State Medicaid Program or your Regional Center for Children and Youth with Special Health Care Needs (see contact information below). You may be able to receive a different product or brand if your doctor completes a prior authorization (PA) and the reason for a different product is medically necessary.

If my child is covered by a Children’s Long Term Support (CLTS) waiver can I use waiver funds to pay for diapers ? In most cases, No. Diapers and incontinence supplies are a Medicaid card covered service, so CLTS waiver funds cannot be used. During the transition to the new contract with J & B Medical some families were able to receive funding through the waiver (until May 1, 2010). This is no longer available. **Please note: If the quantity of incontinence supplies you need exceeds the limit that Medicaid will pay for, waiver funds may be used to purchase the rest of your supplies.**

Why did the Medicaid Program make this change? The Department of Health Services (DHS), which administers the Wisconsin Medicaid Program, needed to find ways to decrease the overall budget for the Medicaid Program. Moving to one vendor that charges a lower cost per item saves the Wisconsin Medicaid Program millions of dollars each year. In addition, DHS expected to improve customer service by using a vendor that could deliver supplies directly to families via the mail.

How can I give feedback? We encourage you to contact Forward Health Member Services at **1.800.362.3002**, Matt Fanale, Wisconsin Medicaid Program at **608.266.7415** or **Matthew.Fanale@wisconsin.gov** or, if your child is covered by a Medicaid waiver, contact Theresa Walske at 608.267.7285 or **Theresa.Walske@wisconsin.gov**.

If you have questions or cannot get your concerns resolved through J & B Medical, call your Regional Center for Children and Youth with Special Health Care Needs. To find the Regional Center closest to you call **800.642.7837**.