

Summer
2011

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*

2011 Medicaid Policy Changes

Families who have children with disabilities and special health care needs may already be feeling the impact of recent Medicaid changes. Some of these changes are a result of the state biennial budget and others were policies adopted by the Department of Health Services this year. **Family Voices will be following these changes closely. We want to hear from families and providers so that we can work with the Department to provide feedback on how these changes are impacting your life and your ability to care for your child with special health care needs and disabilities.**

The State Budget:

The 2011-2013 State Budget was signed into law by Governor Walker in late June. The budget reduces Medicaid funding by \$446 million and allows the Department of Health Services (DHS) to determine how and where to make these cuts without hearings or regular oversight by the Wisconsin Legislature. To date, DHS has not announced what changes will occur.

The budget also puts a freeze on all new enrollment for long term care programs including Family Care, IRIS and Partnership and delays expansion of these programs to new counties. For young adults who are leaving the school system, this freeze will mean a longer wait for supports and services. The Department of Health Services estimates that wait lists will grow to 16,000 people by mid-2013. More details on the state budget and how it will impact families and people with disabilities can be found at: DAWN - www.dawninfo.org and the WI Council and Children and Families - www.wccf.org.

Included in this newsletter is a report card on disability issues developed by the Survival Coalition of Wisconsin Disability Organizations. Family Voices of Wisconsin is an active member of this coalition and advocates for children's issues.

Other Medicaid Policy Changes:

Non - Emergency Transportation: Starting July 1, the Wisconsin Medicaid Program contracted with Georgia-based LogistiCare to administer rides and transportation reimbursement to Medicaid covered appointments. In the past, individuals who needed a ride with a common carrier or used their own vehicle and needed mileage reimbursement worked with their local county human services agency. Now all non-emergency medical transportation must be requested from LogistiCare. To schedule a ride or request mileage reimbursement call LogistiCare at 1-866-907-1493. More details can be found on page 2 and from the Forward Health Update at: www.forwardhealth.wi.gov/kw/pdf/2011-24.pdf

Medicaid Personal Care Screening Tool: If your child qualifies for personal care services through Medicaid, you may experience changes in the number of hours your child will receive due to clarification of policies related to the personal care screening tool. One clarification is a new interpretation of the term "rare condition" which is used when determining the number of hours an individual qualifies for. The new interpretation of criteria will be applied to the personal care screening tool that will be used when your child goes through his/her annual recertification. More details can be found at: www.forwardhealth.wi.gov/kw/pdf/2011-02.pdf

If you have questions about these changes, and the impact on access to services for your child, we encourage you to contact your Regional Center for Children and Youth with Special Health Care Needs (see phone numbers listed on page 3).

Remember, we need to hear from you! Please let us know how these changes are affecting your ability to care for your child/children. Contact Barbara Katz at Barb@fvofwi.org or by calling 608-220-9598.





Did You Know? Now You Know!

If your child is covered by Medicaid (including BadgerCare Plus) and you drive them to a Medicaid covered appointment, you can receive mileage reimbursement. The current reimbursable rate is \$.24 per mile. Starting July 1, all non-emergency medical transportation (NEMT), including mileage reimbursement, is administered through LogistiCare.

How do I get reimbursed? Two days before the appointment, call LogistiCare and let them know that you will be driving your child to their medical appointment and you need to be reimbursed. You will be asked if there is a financial hardship (e.g., family member lost their job or no funds to pay for gas). Keep in mind, YOU DO NOT NEED TO GIVE A SPECIFIC REASON!

A mileage log will be sent to you, or can be faxed to the doctor's office, and must be signed by the doctor.

How do I contact LogistiCare? Call 1-866-907-1493.

What if they deny my request for reimbursement or I have a complaint about LogistiCare? You can file an appeal and ask that they reconsider your request by contacting LogistiCare (**1-866-907-1494**) or contact Greg DiMiceli at 608-266-9815 or **Gregory.DiMiceli@dhs.wisconsin.gov** the Wisconsin Medicaid Program Transportation Analyst.

Watch for our new LogistiCare Fact Sheet.

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

PACER Center
www.PACER.org

Resources for Families and Providers

New Resource for Wisconsin Families

A new resource called, *Finding Your Way: A Navigation Guide for Wisconsin Families Who Have Children and Youth with Special Health Care Needs and Disabilities*, is available online and from Family Voices. This guide can assist families who have questions or concerns about their child's development or have a child who has recently been diagnosed with a special health care need. The guide is available at: www.waisman.wisc.edu/cedd/products.php.

Medicaid and Its Role for CYSHCN - A Family Perspective

A report released by Georgetown University's Center for Children and Families provides data on why Medicaid continues to be critical to children with special needs and it outlines options to increase access to Medicaid. Family Voices (national office) worked with the researchers to conduct interviews with families to provide a family's perspective on the importance of Medicaid coverage for all or part of a child's health care coverage. The report is available at: <http://ccf.georgetown.edu//index/medicaid-children-and-youth-with-special-health-care-needs>.

Financial Guide for Parents of Children with Disabilities

The updated booklet *Possibilities: A Financial Resource for Parents of Children with Disabilities* is now available online from the PACER Center at www.PACER.org/publications/possibilities. The guide offers tips on organizing financial records, managing money, dealing with debt, understanding health, life and disability insurance and provides links to resources where parents can go for additional help.

Opportunities Around the State

PALS, PIP and YIPPE Now Taking Registrations

Parents as Leaders (PALS), Parents in Partnership (PIP) and Youth in Partnership with Parents (YIPPE) are now taking registrations for the 2011-2012 school year. These are excellent leadership training opportunities. For details go to: http://www.dpi.wi.gov/sped/par_partn.html or go to the Family Voices website under "Parent/Youth Leadership."

Care in the Community Conference, Making Connections

The Southeast Regional Center for Children and Youth with Special Health Care Needs will be hosting its annual Care in the Community Conference on Sept. 21 at the Radisson Hotel, Wauwatosa. To register and for more information go to: www.maxishare.com/conferences.

Children and Youth with Special Health Care Needs News

2011 Family Voices Fall Training Schedule

For a complete list of trainings and registration information go to www.fvofwi.org

Did You Know? Now You Know! Trainings

- Chippewa Falls, Sept 12 - contact the Western Regional Center
- Wausau, Oct. 4 - contact the Northern Regional Center
- Madison, Oct. 20 and Nov. 3 - contact the Southern Regional Center
- Jefferson, Oct. 24 - contact the Southeast Regional Center
- Manitowoc, Nov. 5 - contact the Northeast Regional Center

What's After High School - Training on Transition

- Milwaukee and Webinar Option, Sept 7 - contact Adoption Resources of Wisconsin
- Madison, Oct. 12 - contact Family Voices at Lynn@fvofwi.org

Health Reform/Federal Legislative Update

Medicaid Spared For Now! In Washington, DC, a deal to increase the debt ceiling and avoid default was finally reached. Deep cuts to Medicaid were avoided, however cuts in the future are still possible. The budget bill establishes a "super committee" that must report back to Congress by Thanksgiving with recommendations to trim at least \$1.2 trillion in federal spending over the next decade. For more details on the potential impacts on health spending, including funding for Medicaid, go to Kaiser Health News - www.kaiserhealthnews.org. To learn about the Family Voices' advocacy efforts to preserve Medicaid funding go to www.familyvoices.org.

What Is An Exchange? One part of the national health care reform law passed last year are health insurance exchanges. Exchanges will allow families and small businesses to pool their buying power and negotiate better prices for insurance coverage. A recent document by Families USA called, *Why We Need A Health Exchange*, states that exchanges will make the insurance market more competitive and insurers will be monitored to make sure they are not unreasonably increasing their premiums. More information and examples of how an exchange would work in Wisconsin can be found at the Wisconsin Office of Free Market Health Care - www.freemarkethealthcare.wi.gov.

Incontinence Survey Reveals Absorbency, Leakage Problems

Thank you to all the families who completed our on-line survey about your experiences with J&B Medical Supply for incontinence products. This is what we heard: 60% said that the products available from J&B did not meet their needs and were of inferior quality; poor absorbency and frequent leakage were cited most often; 50% indicated that there was a disruption of or increased difficulty with the family's routine related to incontinence products. A report summarizing the survey was sent to the Department of Health Services and is available on the Family Voices website.

Circles of Life Listening Session - What Families Are Experiencing

On April 28, over 75 parents, family members and providers participated in the 6th Annual Family Voices Listening Session as part of the Circles of Life Conference. Representatives from the Department of Health Services, the Board for People with Developmental Disabilities, the Survival Coalition and Family Voices heard from families about the challenges they face as they care for their children. A detailed summary of the listening session can be found on the Family Voices website - www.fvofwi.org/policy. Participants talked about problems with coordinating care when they see different specialists, lack of access to dental care and their concerns about cuts in the state budget.



Children and Youth with
Special Health Care Needs

CYSHCN

REGIONAL 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

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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.

A Report Card: How People with Disabilities Fared in the 2011-2013 Biennial Budget

The state budget recently passed with the message that Wisconsin is facing challenging financial times and all residents must share the pain. However, focused analysis shows that people with disabilities were disproportionately harmed in this budget. In fact, disability advocates count this year as the most dismal in recent history and anticipate dire consequences for some of the state's most vulnerable residents.

In reality, there is an imbalance in shared sacrifice in this budget. Despite reports of falling revenues and the call for significant cuts in education and health care, the budget contains new or expanded tax breaks for corporations and the wealthy at a cost of more than \$90 million over the biennium and \$1.6 billion over the next 10 years. At the same time the budget raises taxes on the working poor and prioritizes spending for highways and voucher schools.

The Survival Coalition of Wisconsin Disability Organizations specifically analyzed budget issues impacting people with disabilities and developed this report card to increase awareness among both advocates and policymakers.

Budget losses and expected impacts for people with disabilities include:

- A freeze on Family Care, IRIS and other community long-term care programs, ending more than a decade's worth of bipartisan work to improve long-term care for our state's elderly and people with disabilities and resulting in the creation of waiting lists in counties that have not had a wait for vulnerable people in years.
- An increase, acknowledged by the Legislature, of people forced into expensive nursing homes.
- A freeze on new slots for children with disabilities in need of long-term supports, despite the commitment of previous governors and legislatures to reduce the children's wait list.
- Historic cuts to education expected to impact children with disabilities through larger class sizes, more clustering of students and self-contained classes, and an elimination of community-based transition programs.
- Flat funding of categorical aids in special education, resulting in overall lower funding to local districts while costs continue to rise.
- Deep cuts to local transit services, which many people with disabilities rely on to live, work and participate in their communities.
- Major reductions in shared revenue to counties, resulting in systemic impacts on people with disabilities who rely on county funding for mental health services and other programs, for their daily support.

*Disability advocates count this year as the **most dismal** in recent history and anticipate **dire consequences** for some of the state's most vulnerable residents.*

The Legislature's Grade



Community-Based Long-Term Care for Adults

The budget freezes all enrollment in Family Care, IRIS and Partnership and cancels expansion to any new counties. Current wait lists exceed 9000 people and DHS estimates that wait lists will grow to 16,000 people by mid-2013. New graduates from high school will have few, if any, options. DHS also anticipates that approximately 484 more people will enter nursing homes over the next two years as a result of the freeze. The legislature added \$5 million GPR each year for individuals in crisis, which advocates consider inadequate. Nursing home care costs an average of \$4000 per month compared to \$2800 for Family Care.



Community-Based Long-Term Supports for Children

Funding to serve those currently receiving supports is maintained, but no new funding to reduce the wait list for children with disabilities. Approximately 2000 children continue to wait. In addition, the freeze on adult long-term care means more young adults will remain on the children's waivers until 21 rather than 18, delaying available funds to serve children who are waiting.



Medicaid – Incomplete

The budget reduces Medicaid by \$446.58 million in unspecified cuts that will be developed behind closed doors at the Department of Health Services (DHS). Some savings measures will override state statute. No hearings are required when these changes are made. The legislature gave away their authority to provide input on these changes, except through passive review. It is premature to issue a grade before the DHS proposal for savings is made public.



Education

The legislature enacted an historic \$800 million cut in general school aids, which impacts all public school students and has particular ramifications for students with disabilities in Wisconsin. Cost-savings that districts are implementing include larger class sizes, more self-contained programs, fewer resources to address challenging behavior, and elimination of community-based transition programs that prepare students with disabilities for employment and independence after high school. The legislature's flat funding of special education categorical aids amounts to an additional cut in services and supports to students with disabilities.

At the same time cuts were made to public schools serving the vast majority of students with disabilities, the legislature voted to expand school voucher programs that siphon off public school dollars to fund private institutions that offer no legal protections, no assurance of certified special education teachers or established curriculum, and no guaranteed supports or specialized services for students with disabilities. Historically, these voucher programs do not serve students with the most significant needs.



Counties

Cuts to shared revenues, youth aids and the Family Care freeze will impact counties by reducing revenues they use to provide services to people with disabilities. The potential for additional cuts in Medicaid may exacerbate this. Property tax limits constrain the ability of counties to increase their local revenues, which have taken a hit from the national recession. All in all counties will be challenged to maintain current programs, much less address emerging needs. The only bright spot is that the Governor's proposal to privatize income maintenance was modified by the Legislature to retain a significant county role and more individualized supports to people with disabilities seeking help.

The Legislature's Grade



Mental Health

Because counties provide half of all funding for public mental health services through tax levy and shared revenues, the cuts to shared revenues and youth aids in the budget, along with stringent requirements related to property tax increases are likely to negatively impact people who require mental health services. The Family Care freeze also increases potential financial liability for counties which, again, can jeopardize the availability of funds for mental health services. The exact impact is impossible to know until counties develop their budgets for CY 2012. Since Medicaid is also a significant funder of mental health services, the required cuts in that program have the potential to negatively impact mental health services. Additionally, reductions in school funding are expected to impact the ability of local schools to adequately address the needs of students with behavioral health issues.

However, the budget does increase funding for mental health services in the correctional system and maintains funding for the Becky Young fund, which has been successful in reducing the rate at which individuals are returning to prison by ensuring that, among other things, they are receiving adequate mental health treatment.



Health Care - *Incomplete*

The budget bill outlines expected cuts to BadgerCare Plus and Medicaid that include reducing income eligibility, reducing services covered, increasing premiums and co-pays, ending eligibility for anyone with access to any sort of employer coverage, and increasing the frequency of reviews of eligibility. DHS must get federal permission for many of these changes. Advocates predict an increase in the number of uninsured people requiring care, as well as an increase in emergency use and cost-shifting as a result of an increase in uncompensated care. It is premature to issue a grade before DHS releases its federal waiver request.



Transportation

The legislature rejected the Governor's harmful proposal to move transit funding from the segregated fund to the general fund. At the same time a 10% cut in state transit aids to local transit systems will result in dramatic service cuts that will cut people with disabilities off from their jobs and communities and limit their access to caregivers and local businesses. The 85.21 Specialized Transportation Program funding remains flat. A new \$5 million paratransit fund was created that will provide some limited help to maintain services, however the combined impact of the reduction in local shared revenue and state transit aids creates significant pressure particularly on small communities who nonetheless have to provide for 20% to 50% of the cost of transportation services. While overall the budget significantly decreases support for transportation services, public education and other supports for people with disabilities, it allocates an additional \$350 million for road construction.



Vocational Rehabilitation (Employment) Services

Flat funding by the legislature for VR services at the minimum maintenance of effort level allowed Wisconsin to keep its federal standing and avoid penalty. However, people with disabilities waiting for these services are penalized by the state's unwillingness to invest enough to draw down full federal match dollars, which means significant waiting lists will continue to exist for people with disabilities who want to work but require support in order to find and/or keep jobs.



Guiding Principles: Survival Coalition is a cross-disability coalition which works in partnership with local organizations, coalitions, consumers, advocates, and families throughout the state and makes intensive efforts to ensure that our priorities promote and advance the wishes of people with disabilities and their families. The Coalition will promote policies, programs, and practices that advance integrated, individualized, community-based supports and services.

Our Vision: The Survival Coalition of Wisconsin Disability Organizations is committed to creating a society in which people with disabilities of all ages receive the services and supports needed, throughout their life span, and can choose to live their lives as they wish and be full participants in community life.

Organizational Structure

- Co-Chair Lynn Breedlove; lynnb@drwi.org
- Co-Chair Beth Swedeen; beth.swedeen@wisconsin.gov
- Co-Chair Maureen Ryan; moryan@charter.net

