





*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*

Special State Budget Edition





The Wisconsin Legislature is in the midst of debate on the 2015 - 2017 state budget. Whether your child receives services through their local public school, has supports at home through the Family Support Program or will someday receive long term supports through Family Care, the proposed changes could have a profound impact on you and your family.



Family Voices encourages you to learn more about the state budget proposals and then contact your Legislators. To find your legislator's contact information or who represents you go to <http://legis.wisconsin.gov>



IF YOU DON'T EDUCATE YOUR LEGISLATOR, WHO WILL?



One way to provide input is to attend one of the public hearings of the powerful Joint Finance Committee. If you cannot attend, comments or testimony can be submitted to BudgetComments@legis.wisconsin.gov or sent via mail to: **Joe Malkasian, Rm 305 East, State Capitol, Madison, WI 53702**

Budget Proposals that Impact People with Disabilities

Family Care & IRIS



The budget proposal contains a complete redesign of Wisconsin's long term care system for adults with disabilities and elders. Changes include: moving IRIS into the Family Care Program; adding primary care into the service package and requiring Managed Care Organizations (MCOs) to provide services statewide. None of the current MCOs provide services statewide. To learn more go to the Survival Coalition's *Frequently Asked Questions* resource on changes to long term care at www.survivalcoalitionwi.org

Family Support Program

The budget proposes to eliminate the Family Support Program and create a new Children's Community Options Program (COP). This proposal could be beneficial if current language in the budget is modified to include: a focus on supporting the whole family; and maximum flexibility in services.

Medicaid Personal Care Services

The budget proposes cutting personal care services by \$19.5 million as well as making administrative changes to the program. A new independent assessment would be required to determine the number of hours and level of services. Personal care is a Medicaid benefit that provides individuals with assistance in their home with activities of daily living (eating, bathing, dressing).

Education

The budget proposal cuts funding for public schools by \$98 million over the next two years. Most school districts will need to cut spending by \$150 per student in 2015 - 2016. The budget also proposes to expand school vouchers, which allows families to send their child to a private school using public dollars. Under the voucher program, private schools are not required to provide special education services; do not have to abide by IDEA (Individuals with Disabilities Education Act); and can choose whether or not to take students with high needs. To learn more about these and other proposed changes go to the Family Voices website under "State Budget" <http://fvofwi.org/public-policy/state-budget> or go to www.survivalcoalitionwi.org

Joint Finance Committee Hearings

3/18 Brillion High School (Calumet Cty): 10:00 - 5:00

3/20 Alverno College (Milwaukee): 10:00 - 5:00

3/23 UW Barron County (Rice Lake): 10:00 - 5:00

3/26 Reedsburg High School (Sauk Cty): 9:30 - 4:00



Did You Know? Now You Know!

Effective Legislative Advocacy

Before you contact your elected officials, spend a few minutes planning what you are going to say and use the tips below to create your message.

Your Are the Expert: Keep in mind that legislators know a little about a lot of topics. You are the expert on the programs that help your family. Your experiences and your personal story can have a significant impact on a legislator's understanding of that program or service.

Your Message:

- Say who you are, where you live and what (if any) group you represent.
- In 1 to 2 sentences explain the issue or problem that concerns you (*"I want to talk to you about the waiting list for the Family Support Program."*)
- Share a personal story or experience about how the issue or problem is affecting your life (*"We have been waiting 3 years and I can't get my child's wheelchair in our house - all we need is help so we can build a ramp."*)

- Ask the legislator for something he or she can do something about and be specific. (*"Please add funding to eliminate waiting lists for children with significant disabilities."*)

- Overall, keep your message short and to the point. Follow up with a thank you and additional information.

Bipartisanship: At the recent Family Voices Advocacy event, Lynn Breedlove (a nationally known advocacy teacher) stated "In this time of partisan politics, advocating for better systems and supports for people with disabilities is a bipartisan effort. Disability can affect anyone, regardless of their political party, income, cultural heritage, religion or sexual orientation, so the Disability Movement cannot become the property of any political party or group."

Lynn told the group, "We must keep in mind that our stories and our voices count more than the voices of lobbyists and our voices are what get bills passed!"

To learn more go to the Family Voices website under Advocacy Tools - <http://fvofwi.org/public-policy/advocacy-tools/>

WEB WATCH

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

National Office of Family Voices

www.familyvoices.org

Family Voices of Wisconsin

<http://fvofwi.org>

Survival Coalition of WI Disability Organizations

www.survivalcoalitionwi.org

WI Budget Project (a program of WCCF)

www.wisconsinbudgetproject.org

HealthWatch WI

www.healthwatchwisconsin.org

Proposed BadgerCare Changes May Impact Young Adults with Special Needs

The state budget includes a number of changes to the BadgerCare Program, including coverage for "childless adults" (those who do not have dependent children). For families who have an adult child (age 18 or older) who is eligible for Medicaid and has a chronic medical condition or mild disability, BadgerCare can provide health care coverage to pay for medical services that are needed to stay healthy. BadgerCare coverage is particularly important for young adults who may still be in school, do not have access to private health insurance, or do not qualify for Medicaid based on a disability.

Proposed BadgerCare changes include:

- ⇒ Limiting eligibility for BadgerCare to only four years
- ⇒ Adding new monthly premiums for most recipients
- ⇒ Requiring health risk assessments and drug testing for those applying for coverage

The Wisconsin Council on Children and Families (WCCF) has a helpful analysis of the budget proposal's impacts on health care, available at www.wisconsinbudgetproject.org/an-overview-of-health-care-issues-in-the-2015-17-budget

Children and Youth with Special Health Care Needs News

Family Voices of Wisconsin Training Schedule

- ◆ **Milwaukee:** March 21 - a *Did You Know? Now You Know!* training session for Spanish speaking families at Alianza, 1615 N 22nd St, Milwaukee, WI 53204
To register contact Alianza at **414-643-0022** or Alasinc@Alianzalatinawi.org
- ◆ **Madison:** April 11 - a *Did You Know? Now You Know!* training session for Spanish speaking families at the Catholic Multicultural Center, 1862 Beld St., Madison WI 53713. To register contact Lilliam at **608-441-3257** or lilliam@cmctoday.org

Circles of Life Conference - April 10th Deadline for Registration

Circles of Life, the annual conference for families who have children with disabilities/special health care needs, will be held **April 30 - May 1** at the Holiday Inn, Stevens Point. As part of this conference, Family Voices will be hosting a listening session at 5:00pm on Thursday, April 30th - Join us! More details and online conference registration is available at www.colwisconsin.org

News from Family Voices of Wisconsin

Family Impact! Grant Initiative

Is there a change you want to make in your community that will improve the lives of children and youth with special health care needs or a disability? Here's your opportunity! In support of family partnerships and leadership, Family Voices of Wisconsin is pleased to announce the launch of its **Family Impact!** Grant Initiative.

- ◆ **What is the Family Impact! Grant Initiative?** This is an opportunity for family members (including siblings and self-advocates) to receive funding and learning from Family Voices of Wisconsin. Funding will support family-led initiatives that improve local, regional or statewide policies, practices, systems, or programs designed to support the health, well-being and community connections of children, youth and families with special health care needs and disabilities age birth to 21.
- ◆ **What is Unique About This Opportunity?** *Family Impact!* is specifically designed to support projects and activities conceived and carried out by families working together to effect change.
- ◆ **What Can I Expect?** Grants in amounts of \$500-\$3000 will be awarded in late spring 2015, with proposed projects to be completed by December 2015.
- ◆ **How Can I Learn More?** Additional information and grant applications will be posted on Family Voices website (<http://fvofwi.org>) in April. For more information, please contact Rachel Crites, Rachel@fvofwi.org or **608.444.4992**



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

Included in this newsletter are several budget issue papers developed by the Survival Coalition, a coalition of over 40 state and local disability-related organizations and groups, including Family Voices of Wisconsin. Issue papers on mental health, transportation, employment and workforce are also available on the Survival website (see Web Watch).



Family Voices of Wisconsin

Post Office Box 5070
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About Family Voices of Wisconsin

Family Voices of Wisconsin (FVW) is a state affiliate organization of the national Family Voices organization and serves as Wisconsin's Family-to-Family Health Information Center. Additionally, FVW is recognized as the Family Leadership Hub for Wisconsin's Children and Youth with Special Health Care Needs (CYSHCN) partnership.

Family Voices focuses its work on health care and community supports in three areas:

- Education and information development and dissemination, including trainings, fact sheets, and newsletters;
- Family leadership activities, including the annual Advocacy for Change institute; and
- Public policy and systems change activities.

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 Lynn at Lynn@fvofwi.org. We look forward to hearing from you!

**LIKE US ON FACEBOOK AND JOIN THE FAMILY ACTION NETWORK LISTSERV
(join-fan@lists.wisc.edu)**

**Would you prefer to have this newsletter emailed to you?
Contact Lynn at Lynn@fvofwi.org**

MARCH 2015

ADULT LONG TERM CARE

ISSUE:

Survival Coalition advocates for a community-based support system that allows adults with disabilities to live inclusive lives in the community with individualized and appropriate services to meet their needs.

BACKGROUND:

Wisconsin's system of Long Term Supports helps people with disabilities and elderly residents maintain better health and independence through support/services in their own homes, and other community-based settings.

Family Care and IRIS currently serve nearly 55,000 older adults and individuals with developmental or physical disabilities, all of whom qualify for a nursing home level of care. These programs, unlike acute and primary health care, provide daily personal supports (such as help with bathing, dressing, and meal preparation), and transportation and support for work and community activities.

People in 57 of Wisconsin's 72 counties now have access to comprehensive supports through Family Care/IRIS, with an additional 7 counties transitioning into these programs. Thanks to Family Care/IRIS, reliance on costly nursing homes and other institutions has been dramatically reduced, and adult waiting lists for home-based support have been eliminated in Family Care/IRIS counties.

Even though Family Care/IRIS is not fully implemented statewide, the programs have generated tremendous savings to the Medicaid budget while improving health and the quality of people's lives. Annual Medicaid nursing home days dropped from 8.8 million in 2002 to 5.7 million in 2012, a 35% reduction saving taxpayers well over \$300 million/year. The number of older adults in WI nursing homes has decreased by 9,000 since the reforms were put in place. The portion of the overall

Medicaid budget spent on nursing homes dropped from 62% to 31% over the same period.

The Department of Health Services (DHS) oversees Wisconsin's Long Term Care programs including Family Care/IRIS, Aging and Disability Resource Centers (ADRCs), and several community-based Medicaid waiver programs. ADRCs, Managed Care Organizations, IRIS Consultant Agencies, and direct service provider businesses (including employment, residential, transportation, personal and home health care, etc.) all work to help people stay independent, gain more independence, and live in the community.

SURVIVAL RECOMMENDATIONS:

- Preserve and build upon the current cost-effective system. Remove the proposed changes to Family Care & ADRCs from the budget.
- Remove the proposal to eliminate IRIS from the proposed budget.
- Keep the types and levels of services that are included in Family Care/IRIS the same.
- Expand Family Care/IRIS statewide using the existing Family Care, IRIS, and ADRC models.
- Pursue integrated care through expansion of the existing Family Care Partnership program.
- Involve and engage all stakeholders through a transparent process if there are changes planned to long term care programs.
- Consolidate Wisconsin's two remaining Long Term Centers for the Developmentally Disabled.

FOR ADDITIONAL INFORMATION CONTACT SURVIVAL COALITION CO-CHAIRS:

Maureen Ryan, 608-444-3842; moryan@charter.net
Beth Swedeen, 608-266-1166; Beth.Swedeen@wisconsin.gov
Kit Kerschensteiner, 608-267-0214; Kitk@drwi.org

Visit the Survival web site at:
www.survivalcoalitionwi.org

**Real Lives, Real Work, Real Smart, Wisconsin
Investing in People with Disabilities**

MARCH 2015

EDUCATING STUDENTS WITH DISABILITIES

More than 120,000 students have disabilities in Wisconsin – about 12% of students in our state. Research shows that, with supports, students with disabilities can learn and reach academic proficiency just like students without disabilities.

ISSUE:

Achievement of students with disabilities lags behind other groups. All schools must ensure that students with disabilities graduate ready for college and work, but 20 years of eroded funding has taken a toll. High expectations and quality education focus for students with disabilities will have a positive impact in other public benefit programs, as students with disabilities become competitively-employed adults.

BACKGROUND:

Investments in education should result in college and workforce readiness for students with disabilities; however, Department of Public Instruction data shows:

- Students with disabilities are 2.5 times less likely to be proficient in reading and math than their peers.
- More than 1/3 of students with cognitive or emotional and behavioral disabilities and nearly 1/4 of students with autism reported never being employed or enrolled in school/training one year after graduation.
- 92% of youth ages 18-21 who receive Medicaid-funded long-term care are not employed.

The state's share of special education funding has eroded from 44% to 26% over the last 20 years with no increase in 8 years.

RECOMMENDATIONS:

- Increase special education funding. Fund districts at the original state promise of 44%. Fully fund high cost students (those above \$30,000/year).
- Oppose voucher expansion including Special Needs Voucher proposals that do not ensure parent rights or quality education practices and drain funds from public schools.
- Address policies that keep students with disabilities out of certain schools (i.e. charter, voucher) and that significantly increase the special education population in public schools.
- Support Pay for Performance policies (the Rep. Rob Brooks Better Bottom Line bill) that give schools an incentive payment when they prove students are getting jobs or enrolled in school after graduation.

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**Real Lives, Real Work, Real Smart, Wisconsin
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MEDICAID

ISSUE:

Adults and children with disabilities rely on Medicaid to pay for needed health and long-term care services. Medicaid access is vital to the health and well-being of individuals with disabilities and should not undergo funding cuts, changes in eligibility, or reductions of hours of services or supports provided. To address the shortage of providers, Medicaid reimbursement rates must be maintained or increased.

BACKGROUND:

Medicaid provides affordable, quality health coverage to individuals with disabilities. Many people with disabilities do not have access to private health insurance or cannot have all of their needs met through private insurance plans—this is especially true for people who rely on non-emergency medical transportation, home care services or need comprehensive mental health and substance abuse services. Medicaid helps people with disabilities see primary care doctors, receive personal care services, go to the dentist, see therapists and obtain other needed medical services and equipment. In Wisconsin, individuals with disabilities may access the Medicaid program in many different ways. Some people may use a specialized long-term care program such as Family Care or IRIS while others use a more general program like BadgerCare. There are also programs designed to help children with significant disabilities and working adults with disabilities gain access to Medicaid.

SURVIVAL RECOMMENDATIONS:

- Ensure that Medicaid reimbursement rates adequately reflect the current costs of providing care. Many health care providers no longer accept Medicaid patients due to inadequate reimbursement rates.

- Improve access to dental care. Support the Governor's proposal to create pilot programs to increase the MA reimbursement rate for dental care in Brown, Polk and Racine counties.
- Expand Medicaid to adults between 100% and 133% of the Federal Poverty Level. Maintain current coverage for childless adults below 100% FPL and oppose the Governor's proposal to impose premiums and time-limited coverage on this population.
- Oppose efforts to transition personal care determinations to a third-party vendor. It is estimated that this change will result in a \$19 million cut to personal care services over two years.
- Support changes to the Medicaid Purchase Plan (MAPP) program that allows individuals with disabilities to work and save money while still maintaining Medicaid eligibility.
- Increase the Medically Needy Maximum Monthly Income Limit for both individuals and couples. Currently, the Maximum Monthly Income limit is set at \$592.
- Support efforts to implement the ABLE Act in Wisconsin, which allows people with disabilities to save money in tax-free accounts and use their savings to pay for qualified disability expenses.

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