



Respite Report

WINTER/SPRING
2007

Lifespan Respite Act of 2006: Wisconsin Has the Edge

Every day more than a half-million Wisconsin citizens step forward to provide care for someone they love—a spouse, partner, sibling, child or parent—but over time and without support, constant care can exact a price on the physical, emotional and financial well-being of the caregiver or family. Respite provides a much needed temporary break from the often exhausting challenges imposed by constant caregiving.

Respite Care Association of Wisconsin (RCAW) is a lead member of a coalition of national and state organizations working to support a national respite policy. A capstone goal was achieved in December when President Bush signed the Lifespan Respite Care Act of 2006, intended to:

- Expand and enhance respite care services to family caregivers;
- Improve the statewide dissemination and coordination of respite care; and
- Provide, supplement, or improve access and quality of respite care services to family caregivers.

The new law would authorize up to \$289 million over five years for grants to states to develop Lifespan Respite Programs to help families access quality, affordable respite care. Specifically, the law would authorize funding to:

- Develop or enhance lifespan respite care at the state and local levels

- Provide respite for family caregivers caring for children or adults
- Train and recruit respite care workers and volunteers
- Provide information to caregivers about respite and support services
- Assist caregivers in gaining access to services

Nearly eight years ago, Wisconsin became the third state in the nation to implement a lifespan respite program. Today, five pilot programs serve seven counties across the state and help family caregivers access quality, affordable respite care. "RCAW has been working for unfettered access to quality respite care across the lifespan since 1999. The bipartisan effort to pass this legislation supports the conviction that family caregivers are indeed the backbone of Wisconsin's—and all states—long-term care system," stated Jim Schroeder, executive director.

Family caregivers are providing 80% of long-term care in the United States, a level of care valued at \$306 billion a year, more than what is spent on nursing home and paid home care combined, according to the National Family Caregivers Association. In Wisconsin, 549,279 people are engaged in caring for a family member—a responsibility taken seriously, joyfully and with respect to allow a family member to remain at home. Many caregivers are thrust into the role because of a life-changing event such as stroke, accidental disability or debilitating disease. Becoming a caregiver isn't always a choice, it's simply the right thing to do. ■



Did You Know...

- One out of every 11 people in Wisconsin is a caregiver.
- \$5.8 billion is the estimated value of caregiving service delivered annually by Wisconsin family caregivers. ■



PRESIDENT'S C O L U M N

ABC News reporter Bob Woodruff is back on the air after being seriously wounded by an IED in Iraq more than a year ago. Wearing body armor and helmets, Woodruff and cameraman Doug Vogt suffered extraordinary harm that required they learn how to read, walk and talk all over again.

And with each of them the entire way was a family caregiver. Like so many of Wisconsin's caregivers, Lee Woodruff and Vivian Vogt were thrust into the role because someone they loved needed them. All across the country the mantra is the same—"I do this because (he is) my husband...my child...my wife...my parent...".

The numbers don't lie. All across the country caregiving is on the rise. If we look in terms of sheer numbers, Wisconsin has the 18th highest number of family caregivers in the country, California has the most at 3.4 million. Imagine the entire city of Los Angeles are comprised of all caregivers. Or five times the population of San Francisco are caregivers. However, as a percent of population, Wisconsin and California are on the same plane—10% of the total state population is engaged in family caregiving.

What does this all mean for lifespan respite care in Wisconsin? The growth of caregivers must have a parallel curve of respite care providers and support. The strain on the system, both in terms of financial and human resource, cannot be sustained without funding and without a pool of trained providers.

I am encouraged by the Lifespan Respite Act of 2006 and urge you to connect with your legislator. Working together we can make lifespan respite care a common, readily available resource for everyone. ■

—Nichole Hunkins

Lifespan Respite Act of 2006: What Happens Next?

*I'm just a bill
Yes I'm only a bill,
And I got as far as Capitol Hill.
Well, now I'm stuck in committee
And I'll sit here and wait
While a few key Congressmen discuss
and debate
Whether they should let me be a law.
How I hope and pray that they will,
But today I am still just a bill.*

"I'm Just a Bill"—Schoolhouse Rock

The first step to making lifespan respite care accessible across the nation was achieved in December. By signing the Lifespan Respite Act of 2006, the president authorized Congress to fund the legislation by the necessary amount (\$289 million) to fulfill the tenets of the legislation. The next—and equally crucial step—is to ensure Congress acts to include the full amount of funding articulated in the bill in the next fiscal year.

Beginning now through October 2007, RCAW will work with the national respite coalition to educate members of the House and Senate Appropriations Committees about the value of respite care and advocate for full funding for the Lifespan Respite Care Act in the FY 2008 appropriations bill. Congressman Dave Obey (D-WI) chairs the House Committee on Appropriations and Senator Herb Kohl (D-WI), member of the Senate Committee

on Appropriations, is a senior member of the sub-committee on Labor, Health and Human Services.

The House and Senate typically hold appropriations hearings in late March or early April to consider all funding for programs housed in the Departments of Labor, Education, and Health and Human Services. The House and Senate separately pass their version of a funding bill in June or July. The two bills are then reconciled in conference with the goal of passing the appropriations bill before the new federal fiscal year 2008 begins on October 1.

Inclusion in Congressional appropriation bills is vital. The Department of Health and Human Services can not begin the process to implement the Lifespan Respite Act without Congressional funding. We urge you to contact Wisconsin's Congressional Delegation to express support for funding. For more information, please contact Jim Schroeder at (608) 222-2033 or via email at: jschroeder@respitecarewi.org. ■

Family Caregiving in Wisconsin: Back to the Future

Dennis Hopper is stumping for investment services, Warren Beatty received a "Lifetime Achievement" award at this year's Golden Globe Awards, and Bob Dylan captured Billboard's top spot last September. Google the term "baby boomer" and get more than 1.75 million hits.

Boomers are turning 50 at the rate of one every 10 seconds.

The number of family caregivers is also "booming" in Wisconsin. According to the National Family Caregivers Association, Wisconsin added about 29,000 people to the

ranks of caregivers over the previous year. Just imagine if the entire population of Milwaukee were family caregivers, or combine everyone in Stevens Point, Madison, Green Bay, Kenosha, Racine and Appleton and the breadth of family caregiving in Wisconsin becomes clear.

With more than half a million people serving the state's long-term health care system, the future for Wisconsin is vested in family caregivers and respite care support services. ■

Preparing for and Choosing the Right Camp

Spring in Wisconsin is always a surprise. One minute we are shoveling snow and the next, crocuses are popping up. Another harbinger of spring is planning for summer camp. Children and adults with special needs are unique customers and as such, additional thought and preparation are required to create the best possible experience.

The following tips from Easter Seals of Central California can help in the selection process:

- Review interests and abilities to determine what type of camp setting may be most appropriate (e.g., day, residential, special interest or inclusive camps).
- Find out if the camp is accredited by the American Camping Association (ACA) and if “standards for persons with special needs” have been met. ACA accreditation ensures that camps meet recognized requirements for safe and stimulating programs.
- Talk with the director about the camp’s philosophy. Can the camp provide the type of experience you and your child anticipate? Ask about the director’s training and experience in working with children who have similar disabilities to those of your child.
- Check on the camp’s health and safety procedures and facilities, e.g., is there a registered nurse in residence and have emergency arrangements been made with a nearby hospital?
- Determine the age, training and experience of counselors. Are they at least 18 years old? Have they had experience working with children with

disabilities? Camps having a tie-in with professional schools or offering college courses to counselors are optimal.

- Refer to the return rate of campers and counselors as an indicator of quality. An extremely low rate may be a bad sign.
- Inquire about the ratio of counselors to campers. For children with severe disabilities, the ratio should be at least one counselor for every two or three campers.
- If possible, visit the camp to observe the quality of its facilities and programs. Is it accessible to children with limited mobility? Are its activities interesting, stimulating and appropriate for your child’s age, interests and abilities? Are campers encouraged to choose and plan their own activities? Since many children with disabilities have had little opportunity to make choices, this can be great experience. Others can benefit from learning that living with a group can sometimes limit choices.
- The expense of attending camp is not necessarily an indication of quality. Many camps for children with disabilities charge only a fraction of actual costs.
- Remember that a child–or adult–included in all stages of camp selection will be better prepared and have a more enjoyable camp experience.

For a list of camp opportunities, please visit the RCAW website and click on File Downloads. The list is available courtesy of UCP-SE Wisconsin. ■

EXECUTIVE DIRECTOR’S COLUMN

As a result of the November elections, there are many new faces at our state Capitol—four new state senators and 17 new members of the Assembly. These new legislators will be faced with many policy and budget decisions as they work through their first term of service. They can’t possibly be experts on every issue.

If you live in a district represented by a new senator or representative, now is a great time to share your expertise on the issues faced by families caring for a family member with special needs. Come to think of it, returning policymakers can always use more information as well! Once you’ve helped policymakers understand the issues and problems, it’s only natural to offer possible solutions.

If you haven’t already done so, please consider establishing a relationship with your elected representatives in Madison. Despite the cynical comments you may have heard or read about politicians in general, you might be pleasantly surprised to learn that your representative truly does want to understand the issues and make a positive difference for his or her constituents. It all starts with your phone call, email or letter.

The legislature website has a tool for obtaining contact information of your legislators. Simply enter your home address in the search form, hit the search button, and you’ll be provided with contact information. To access the search form, go to: <http://waml.legis.state.wi.us>.

The most powerful tool available to make a difference for someone you love—whether it is for an IEP or in-home assistance—is you. So go ahead and tell your story, Wisconsin’s legislators are ready to listen. ■

—Jim Schroeder

Calendar of Events:

2007 Board of Directors meetings:

March 22 - Johnson Creek

June 21 - location TBD

September 20 - location TBD

December 13 - location TBD

Respite Care Training Manual Available

The Respite Care Association of Wisconsin has released a new version of the popular respite care training manual. The updated and expanded manual is designed to provide materials that will build the capacity of lifespan respite care providers. The manual is intended to give a frame for delivering more detailed information on core competencies of respite care including an understanding of respite care, first-aid and emergency procedures, agency policies and procedures, and how to identify and report suspected abuse or neglect of a child or senior citizen.

To order the manual for just \$65, please log on to the RCAW website: www.respitecarewi.org. ■

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Visit us on the web at:
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Lifespan Respite Network Programs

Western Region

Program Contact: Terri Larson-Baxter
Coordinating Agency: United Cerebral Palsy of WCW
Phone: (715) 832-1782

Northeastern Region

Program Contact: Linda Kimple
Coordinating Agency: Creative Care Options
Phone: (920) 906-5174

Northern Region

Program Contact: Deanna Yost
Coordinating Agency: New Horizons North
Phone: (715) 682-7171 x 35

Southeastern Region

Program Contact: Nichole Hunkins
Coordinating Agency: United Cerebral Palsy of SEW
Phone: (414) 329-4500

Southern Region

Program Coordinator: Karla Jensen
Coordinating Agency: Epilepsy Foundation of SCW
Phone: (920) 356-9870

A Gift to RCAW Is a Gift to THOUSANDS of Wisconsin Families

Budgets are tight for nonprofit organizations, and we are no exception. RCAW needs your help to sustain our efforts toward promoting, supporting and expanding quality statewide respite care across the lifespan. Our efforts impact thousands of Wisconsin families caring for a family member with special needs. Please consider a gift to RCAW as a way of showing your support for our ongoing efforts. As we say, you don't have to give until it hurts, just give until it feels good! ■

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