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Visit us on the web at:
www.respitecarewi.org

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! ■

RESPITE CARE ASSOCIATION OF WISCONSIN
6320 Monona Drive, Suite 407
Madison, WI 53716



Respite
Report SUMMER 2007

Take 5 Wisconsin Starts in September

"You never truly know someone until you've walked a mile in his shoes"—suggested text, Native American proverb

Every day tens of thousands of people across Wisconsin meet the responsibility of being a family caregiver for a child with a disability or special need such as chronic or terminal illness.

Without a pause, family caregivers handle feeding tubes, catheters, perform personal hygiene care (bathing, dressing, brushing teeth), monitor medications and take the child to school. Imagine doing all of this before leaving for work, then repeating much of this care—perhaps more than once—upon return. Now, overlay this responsibility with the functions of managing a typical household—grocery shopping, cooking, house cleaning, laundry, paying bills—and the unique job of a family caregiver begins to come into focus.

The mission of "Take 5 Wisconsin" (formerly known as "Give Mom a Break") is to build thoughtful relationships with policymakers regarding family support programs such as respite, as related to families that include a child with a disability. Personal stories help to illuminate the economic impact, service barriers and community opportunities that may exist for

families that include a child with a disability.

Here's how it works—T5 (Take 5) coordinators work with families and elected officials to structure a short visit. The intent of the visit is to spend time with a family that includes a child with a disability. The visit may take place in the home, a park, a restaurant over coffee or any place that works for everyone. Once the visit is done, T5 coordinators will shepherd the relationship between the families and thought leaders to continue the dialogue.

Respite Care Association of Wisconsin has partnered with T5 because it is important that consumers of respite care establish relationships with policymakers to confirm the enormous value of respite as a critical family support service.

On September 4, 2007 an invitation to participate in "Take 5 Wisconsin" will be delivered to every legislator in Madison. Materials will also be available online to use with local officials such as members of the school board, the mayor, county board and others.

To learn more about this program and how you can get involved, please log on to: www.take5wisconsin.org or contact Jim Schroeder, RCAW executive director at (608) 222-2033. ■

Did You Know...

• Funding for the national Lifespan Respite Care Act of 2006 is in peril? Contact Congressman Dave Obey (D-WI), chair of the House Appropriations Committee at (202) 225-3365 to urge full funding. ■



PRESIDENT'S C O L U M N

The Power of Conversation

How quickly our vocabulary has changed over the last five years. Thanks to the advent of text messages, thoughts and phrases are distilled into a series of letters—"IDK" (I don't know), "OMG" (oh my god), "SNF" (so not fair), and so on. Google is no longer a brand, it's a verb, and the FCC is struggling with the boundaries of decency versus free speech.

These words remain unchanged—the dignity of caregiving and the need for respite services. Respite care is becoming an integral part of the local and global conversation about caregiving. In one-tenth of a second, Google News finds more than 1,000 stories with a relationship to respite. From Australia to Wisconsin, respite services are woven into stories about financial assistance in Georgia, dementia services in the UK and why Napa County needs respite care to support foster parents.

In this issue, we cover the "Take 5 Wisconsin" project. The initiative is born out of the movement to put a face to the Wisconsin's children living with a disability, and the family members who care for them. The project aims to connect families and policymakers in the place where they live (not by coming to Madison, but in the district), and through fruitful discussions, dispel the myths and confirm the facts facing children with disabilities.

"Take 5 Wisconsin" is reaching beyond legislators into the fabric of our communities. School board members decide special education funding and program issues, city officials vote on accessibility projects and county board members balance state mandates with family services. A supplemental goal of the project is a better understanding of the other side of the coin—the challenges associated with program support and resource allocation in a world of shrinking funding.

While the aim of the program is to connect policymakers with families of children with a disability, the concept is applicable for any person caring for another, be they a husband caring for a wife with dementia, a grandparent caring for grandchildren or one friend caring for another. Making introductions in a positive and thoughtful way will advance the overall position that caregiving knows no boundaries, and respite care is a valuable service across the lifespan.

By talking to *each other* instead of *at each other*, we are building bridges of collaboration and trust because the words we use reflect the character of our person. I encourage you to incorporate respite care into your everyday conversation. ■

—Nichole Hunkins

Special Events and Fundraising: How Efficient Are We?

Every community calendar in Wisconsin is rich with creative events, offering something for everyone—you can run, walk, dine, dance, serve, golf, bike, bowl, telephone, bid, get your car washed and buy a brat, pray, taste, play trivia with Bucky—all in the name of charity.

Wisconsin citizens are generous by nature and by deed, making special events common in a crowded field of worthy causes.

But how efficient are special fundraising events?

According to a recent report published by *Charity Navigator*, the answer is "special events are inefficient in comparison to overall fundraising activities." In reviewing more than 5,000 charities across the nation, Charity Navigator concludes:

The field is packed—about half of all charities use special events as a way to fundraise. Generally speaking, special events are inefficient in comparison to overall fundraising activities. On average, nonprofits spent about \$1.33 to raise \$1 in special events revenue. This compares to an average overall fundraising rate of \$0.13 to raise \$1. Many

health organizations would benefit from shifting their fundraising focus away from special events. These organizations were found to be the most inefficient, spending about \$1.84 to raise \$1 in contributions.

It is important to keep in mind when analyzing the efficacy of special events there are other benefits or reasons to do special projects. For instance, "friend raising" may be as important as "fundraising." Building awareness or cultivating prospective donors are benefits that are impossible to measure, and can vary from organization to organization.

But beware of mission shift, warns one agency. When an organization ends up spending a disproportionate amount of its human—and financial—resources on special events, it can easily take valuable time, money and energy away from its core mission.

Establishing the goal of the event or project beforehand is vital, and will provide a benchmark for assessing success. ■

Lifespan Respite Care Northern Network—Self-Directed Success

"Ashland is a beautiful, close-knit community..." so reads the Ashland Visitors Bureau website. Those words resonate in the work of the Lifespan Respite Care Northern Network serving Ashland and Bayfield counties in the northern corner of the state.

Of Wisconsin's 72 counties, Ashland and Bayfield counties rank 60th and 64th respectively in terms of population (Menomonee County is the least populated with 4,597 people.) Since 2000, the lifespan project in northern Wisconsin has been working with county partners to bring respite care to family caregivers regardless of age, disability or income.

Perhaps this project is successful because of the intimacy created when people and resources are so modest. Collaboration is an expectation because there is simply not enough time or money to be all things to all people. A unique requirement of the five respite projects (see the back of the newsletter for contact information) is to leverage funds in

order to reach more caregivers. The Northern Network has creatively built bridges with county partners to bring respite care to an average of 50–60 families each year, and has built ongoing relationships with no fewer than nine area organizations, an outstanding achievement.

What makes this network project unique is the commitment to self-directed supports. "We believe individuals, families or caregivers should have as much information (as possible) about this flexible and family centered option," states Deanna Yost, project manager. "We promote family-centered, self-directed services...because it is easiest for the family...and most fiscally efficient."

Capacity building in the sector is critical, especially with regards to respite services for children with mental health issues. In addition to wrap-around programs, the staff will often become team members around families and their children.

"We have witnessed so many positives...it's really meaningful and rewarding work." ■

In the Eye of the Donor— Top 10 Practices of Savvy Donors

There are more than 31,000 nonprofits in Wisconsin. Donors, be they individuals, foundations or corporations, are generous and motivated by the desire to make a difference. The days of giving based on a handshake and the intent to do good are evaporating; foundations and philanthropists are motivated by *impact and assessment*.

To illuminate the "other side" of the coin, here are some recommended "best practices" for donors in assessing their giving:

Be Proactive—smart givers generally don't respond to the first organization that appeals for help. Donors take the time to identify which causes are most important to them and about the *change they want to affect*, i.e. generic cancer charities versus a targeted outcome goal of mammograms for at-risk women.

Be careful of sound-alike names and imposters—how many of us can tell the difference between the National Cancer Center and National Cancer Coalition? (Hint—the National Cancer Coalition is rated 4-star while the National Cancer Center is 0-star)

Confirm 501(c)(3) status

Get copies of financial records—an informed donor knows the financial health of a charity is an indicator of its programmatic performance, with the most efficient organizations spending at least 75% of their budget on programs and services and less than 25% on fundraising and administrative fees.

Review executive compensation—put the CEO compensation into context by examining the overall performance of the organizations.

Investigate programmatic results—talk with the charity to learn about its accomplishments, goals and challenges. Be prepared to walk away from any organization unable or unwilling to have this kind of conversation.

Concentrate your giving—spreading your money across multiple organizations not only results in your mailbox filling with appeals, it diminishes the possibility of any of those groups bringing about substantive change.

Make a long-term commitment—smart donors see themselves as a partner for the long haul in the effort to bring about change. ■

Source: *Charity Navigator*

Calendar of Events:

October 3–5, 2007
National Respite Conference
"Help Is on the Way"
Huntsville, Alabama

EXECUTIVE DIRECTOR'S C O L U M N

It's Crunch Time

As I write this, there have been several disappointing developments in the effort to secure funding for the federal Lifespan Respite Care Act. You may recall that the Lifespan Respite Care Act was adopted by both houses of Congress with tremendous bipartisan support and signed by the President this past December.

Adoption of the Act did not guarantee funding for its implementation—implementation that could provide funding for significant expansion of Lifespan Respite to communities in Wisconsin that aren't currently served. And this is where the disappointments have come into play. The House and Senate Appropriations Committees have been less than supportive as we look to secure \$40 million in fiscal year 2008 to provide relief and support for family caregivers.

Apparently, members of Congress haven't heard often enough and loud enough from family caregivers and advocates regarding the importance of this program to families. When the President signed the bill, one of the sponsors said, "help is on the way." And help is needed for families as each day they confront the challenges of caring for a family member with special needs. It's crunch time, and now is the time to make your voices heard. ■

—Jim Schroeder