

MORE

EXPECT

DISABILITY RIGHTS WISCONSIN | REPORT TO COMMUNITY 2013

Letter from the Executive Director

Expect more. For more than 35 years, Disability Rights Wisconsin has been helping people with disabilities and traumatic brain injuries, the deaf community and individuals living with mental illness do just that, expect more from service providers, themselves and their community. Your belief in the inherent dignity of every person, regardless of disability, has driven extraordinary social change. During this past year, for example, DRW worked with advocates across the state to develop new resources for supportive community-based mental health care and integrated employment opportunities.



I am thankful for your belief in DRW and for the trust you have placed in me as the newest steward of this accomplished agency. I am appreciative of my predecessor

Joan Karan's strong leadership and I am especially grateful to all of our clients, who have shared their stories and struggles, believing that together we could improve the quality of life for all people with disabilities.

DRW employs every style of advocacy to advance the human and legal rights of people with disabilities and challenge society to improve the lives of people with disabilities.

- *Education and Training*
- *Self-Advocacy*
- *Negotiation & Mediation*
- *Litigation, and*
- *Public Policy*

By putting the DRW mission into action, we strengthen our ability to advocate with and for the disability community. We must diversify the organization's funding base, improve quality measures, and increase outreach and accessibility efforts so that many more Wisconsinites can benefit from our advocacy efforts.

I look forward to our future together at DRW. Let us continue to believe all people can live together with dignity, that each of us brings gifts and talents of benefit to the community, and everyone is better off when we support one another. Let us continue to expect more of ourselves and of DRW.

I hope you are inspired by the stories that follow, stories

about advocating for people who believe in themselves and in the power of advocacy to transform their lives. As you do, please consider how you can strengthen your support for Disability Rights Wisconsin. We need your help and partnership.

A handwritten signature in black ink, appearing to read 'Daniel Idzikowski', with a long horizontal line extending to the right.

Daniel Idzikowski
Executive Director

OUR VISION

All persons with disabilities and their families shall be empowered to exercise and enjoy the full extent of their rights and to pursue the greatest possible quality of life.

Letter from the Board

After nearly six years on the Board of Directors for Disability Rights Wisconsin, including two years as President, I recognize the strength and tenacity of the organization's advocacy on behalf of all people with disabilities in Wisconsin. The unwavering focus of DRW on clients and mission was especially impressive in the midst of organizational transition last year. Under

the shared leadership of the Board, Acting Executive Director Joan Karan and the entire management team, DRW produced remarkable accomplishments in 2013, many of them spotlighted in this annual *Report to Community*.

Following previous Executive Director Tom Masseau's departure at the end of 2012, the Board took time to assess the organization's needs and initiate a deliberate recruitment

effort. The Board's selection of Daniel Idzikowski provides DRW with an Executive Director who has a wealth of nonprofit leadership experience and a passion for social justice. Dan's credentials include serving as a legal aid attorney, executive director of a regional social services agency and Assistant Dean for Public Service at Marquette University Law School. The Board is confident in Dan's ability to guide DRW as it enhances its services to individuals and strengthens its impact on systems change.

DRW staff members clearly sustained their focus in 2013. Among many accomplishments was dramatic action toward eliminating employment discrimination. Dogged advocacy for access to better jobs in the community is beginning to bear fruit in Wisconsin. At last there are increased resources for job development, vocational counseling and informed employment choices for people with disabilities. Helping young people prepare for these opportunities is the purpose of targeted transition training DRW piloted last fall.

Another achievement was the push to reverse notorious underfunding of mental health services in Wisconsin. Legislation passed last year expands resources and improves services for both children and adults living with mental illness. This is a huge victory that will resonate for years to come.

Read more about these efforts here along with news about an end-of-life case brought by DRW that protects the human rights of individuals with intellectual and developmental disabilities. DRW's legal advocacy brought about policy changes at one of Wisconsin's most prominent health care systems.

Such success requires the determination of committed disability advocates. In Wisconsin, we are fortunate that many of the best belong to our advocacy team. These talented professionals maintained momentum last year toward positive social change while picking up added responsibilities during the executive search. They further demonstrated their commitment to the organization's mission through hundreds of individual advocacy cases that connect DRW with the people we serve.

DRW stayed true to our mission in 2013 despite leadership changes, tighter budgets and greater community need. Thanks to the commitment of Board and staff members, DRW ended the year financially stable and determined as ever to advocate for disability rights. I invite you to join in our work to build a Wisconsin that offers a high quality of life, free of discrimination, for all people with and without disabilities.



Frank A. Sterzen
Board President, 2012-14

Fair employment gains ground

“In all my years of working on this issue, I’ve never been more hopeful.” Cathy Steffke speaks for many when the Disability Rights Wisconsin Advocacy Specialist describes progress last year on gaining more access to fair employment for people with disabilities. “There is greater awareness of the fact that society pays a cost when it saddles a group of people with low expectations,” Steffke says. “We can show instead that when individuals are part of the community and have competitive jobs in the community, they contribute to it in many ways.”

Bipartisan legislation

Evidence of progress toward equal opportunity included a commitment by the state in 2013 to increase funding for programs that help people with disabilities join the workforce in competitive-wage, community-based jobs.

DRW advocates and other members of the Survival Coalition of Wisconsin Disability Organizations had urged lawmakers for some time to give the state’s Division of Vocational Rehabilitation (DVR) more resources to do its job. Finally, last September, the legislature passed a bipartisan bill that expands support for DVR by almost \$4 million. Signed into law by the Governor four months later, this state allocation allows Wisconsin to claim more than \$14 million in matching federal dollars to support jobs programs for those who face obstacles to integrated employment because of a disability.

DVR estimates it can now assist 2,000 more people with employment counseling and the search for good jobs in their communities or opportunities to start a business. DRW Policy Coordinator Lisa Pugh calls it “a big win” for people with disabilities who want to work and get out of poverty. Pugh worked on the issue with Steffke and with Attorney Jodi Hanna, who directs DRW’s Rice Lake office and sits on the Wisconsin Rehabilitation Council (WRC), a state-appointed group that oversees the work of the DVR.

Numbers tell the story

Tenacious advocacy and a data-focused information campaign on the benefits of employment for people with disabilities were critical in persuading policymakers to take



Governor Scott Walker, above left, visits a community-based business where people with disabilities are an integral part of the workforce. Such worksite visits strengthened his support last year for successful bipartisan legislation that expanded funding for state resources to assist those who face obstacles to integrated employment due to a disability.

up the legislation, Pugh says. The campaign emphasized that people with disabilities are an untapped, skilled labor force ready and able to add value to an employer’s bottom line.

DRW and its advocacy partners, the Wisconsin Board for People with Developmental Disabilities (BPDD) and People First Wisconsin, distributed policy briefs outlining labor market data showing that while 80 percent of people with disabilities in Wisconsin want to work, barely 19 percent are employed compared to 68 percent of people in the general population. Meanwhile, the turnover rate for employees with disabilities is only 8 percent, much lower than the 45 percent for general workers.

Pugh references one more statistic that illustrates how competitive employment saves money. Calculated by cost per hour worked, competitive wages earned in the community by a person with disabilities cost taxpayers about 75 percent less than facility-based employment that may pay less than a dollar per hour.

Steffke pressed that point often during media appearances last year with other advocates to discuss and debate the issue. The outreach helped DRW educate the general public about the scarcity of competitive employment opportunities for people with disabilities.

Community model

The message came through loud and clear: People with disabilities are reliable, committed employees who contribute to the economy. Pugh underscores the fact, saying that employment supports through DVR bring community-based employers who are hiring into contact with a group of prospective employees prepared to work.

“Wisconsin is part of a national movement that is working toward better competitive, integrated employment rates for people with disabilities,” she observes. “Research shows that people who work in the community lead healthier lives. There is a lot of room for improvement in Wisconsin.”

Work site visits

Giving policymakers a closer look at employment in the community for people with disabilities was the goal behind a related grassroots effort in 2013. DRW helped people tell their stories about competitive, community-based employment while BPDD organized visits for legislators to businesses that employ them. Governor Walker also visited these worksites, an experience Pugh says he credits with his support of the final bill.

As Pugh recalls, “We were out to change hearts and minds, give people who had a limited view of what people with disabilities can do a chance to see for themselves how people and businesses thrive when we match skills with the right job and meet a workforce need.”

Quality support

Disability advocates say the increased funding will allow DVR to provide more quality support to people with disabilities. Hanna describes the infusion of new funds as a chance for DVR to improve the caliber of its counseling services and reduce caseloads.

“Wisconsin is at a tipping point on this issue as the public starts to understand that with the right supports and services, people with disabilities are capable of working in the community at a competitive wage,” she notes. “As a member of the Rehabilitation Council, I see the dedication of DVR senior management and their commitment to supporting people with disabilities in the general workforce. These additional resources make that possible.”

Right to expect

Another sign of progress is tighter coordination of services by the Wisconsin Department of Workforce Development, agency home of DVR, with the Department of Public Instruction and the Department of Health Services. Such cooperation promises to connect young people earlier in their transition planning to integrated, competitive employment resources, Hanna says.

The agency collaboration also involves administering a \$32.5 million federal Promise Grant awarded in 2013 to increase the education, career and income prospects for children with disabilities receiving federal assistance. DRW sees this as another step forward in directing more employment resources to young people, giving them a chance to experience the independence that comes with community-based, well-paid work.

Many tools

Progress on the employment front benefited from the many tools available to DRW as a protection and advocacy organization. Working at the grassroots, advocacy partnerships, good working relations with state and local agencies, and the means to take legal action when necessary all play a part, says Hanna.

As the organization works with DVR and other agencies to help them develop their new capacity to serve and support people on the path to meaningful employment, DRW continues setting an example of advocacy others can follow. ●

Media Watch

Advocacy by Disability Rights Wisconsin raised media attention in 2013. We share headlines and excerpts from around the state.

State should do better for disabled looking for jobs "...thousands of people with disabilities must wait for months to access state employment services, although the Division of Vocational Rehabilitation has not requested its full allotment of federal funds for the past three years." *Milwaukee Journal Sentinel* editorial, July 2013

Pocan announces \$400,000 grant to Disability Rights Wisconsin to address domestic abuse and sexual assault of people with disabilities "Our project strives to ensure... support by people and systems that reflect person-centered, safe and accessible responses." *Amy Judy, Project Coordinator, DRW, in Wisconsin State Journal, September 2013*

Change in federal rules would help workers with disabilities "How could anyone argue against...a focus on allowing people with disabilities to work alongside others out in the community?" *Op-Ed by Dan Idzikowski, DRW Executive Director, and other advocates in La Crosse Tribune, October 2013*

Wisconsin legislators agree to boost mental health services "Wisconsin lags far behind where we need to be when it comes to providing mental health services, in part because of a system that decides access to care based on where someone lives, which shouldn't be the case." *Milwaukee Office Director Barbara Beckert, Milwaukee Public Radio, January 2014* ●



Training prepares youth for transition

Thanks to a grant from supporters interested in smoothing the transition from high school to community life for youth with disabilities, Disability Rights Wisconsin introduced a series of transition trainings in 2013. These sessions help students and their parents understand how to make effective use of a tool created by the Wisconsin Department of Public

Instruction (DPI) to streamline the transition planning process.

The process, which governs the move from secondary education to opportunities that meet their future goals, is an exacting but important one for students with disabilities, says Sally Flaschberger, DRW Advocacy Specialist and coordinator of the training program. She says DPI worked hard to develop a more comprehensive transition process. "Our goal is to give students a hands-on experience so they get the most out of the computer-based tool and better understand the importance of taking serious charge of planning their own future."

Goal setting

DPI introduced its new computerized tool in late 2012. Known as the Postsecondary Transition Plan (PTP) system, it takes students and parents through a series of goal-setting steps to identify the education, training and other options that will prepare them for employment and adult independence.

Flaschberger explains many parents and students did not understand the system well enough to use it with confidence. So DRW developed a transition training program to fill the knowledge gap and a guidebook (above) that outlines the transition process for students who receive special education.

"Compliance with the transition process is not a new requirement, but it's never been easy for people to manage," Flaschberger explains. "The PTP tool can help change that and we want to be sure parents and students can use it successfully." The training course also explores employment services provided by the Wisconsin Division of Vocational Rehabilitation and long term care coverage available through the state's Family Care and IRIS programs.

Best advocates

Results from the first training sessions in southeast Wisconsin last year were positive, Flaschberger reports. People came to recognize their role in creating a transition plan and saw firsthand the benefits of mastering a useful technology tool. Plans for 2014 include expanding the geographic reach of the trainings and working with DPI on other ways to distribute DRW's *Key to Your Future* guide.

Becoming their own best advocates is something DRW promotes for people with disabilities and it is a central goal of the transition training project, notes Flaschberger. "The more involved students and parents are in individualizing the transition plan, the more likely it is that the goals they define will support the young person's independence after high school." ●

Lawsuit brings policy changes to major hospital

Disability Rights Wisconsin negotiated a settlement with the University of Wisconsin Hospital in February 2013 that protects patients with severe intellectual and developmental disabilities (IDD) against perfunctory decisions to withhold or withdraw life-sustaining medical treatment.

The settlement resolves one part of a lawsuit DRW filed in May 2009 against the hospital, the UW School of Medicine and Public Health, and six physicians. The settled claims alleged discrimination under federal statutes that prohibit hospitals and physicians from treating some groups of people differently from others.

DRW brought the case after investigating reports of a child with IDD who died after doctors denied him basic treatment and care for a minor respiratory complaint. A similar case, in which an adult patient survived despite the hospital stopping treatment after her family accepted the physician's recommendation, also figured in the complaint.

Defining quality of life

These examples expose the sometimes difficult dynamic between physicians and the families or guardians of patients with disabilities who are judged as unable to communicate their own wishes, says Attorney Mitch Hagopian, who led the case for DRW with assistance from Appleton Attorney Sara Buscher.

Doctors unfamiliar with treating patients with a long-term disability might not know how to define quality of life for those patients, he adds. Without understanding the “day-to-day” of a patient's disability, physicians cannot fairly assess any decision to withhold life-sustaining treatment.

The agreement DRW reached with the hospital spelled out changes they will implement to help ensure people with IDD receive appropriate treatment.

“UW Hospital is a highly respected medical institution and their willingness to acknowledge the need to do more to mediate situations like those we cited in our lawsuit is important,” Hagopian explains.

The key policy change encourages physicians to seek advice on cases from members of a newly established panel of physicians who have specific experience providing care for

people with IDD. The hospital, which benefits from access to UW-Madison Waisman Center resources on developmental disabilities, also will include a person with IDD expertise on its ethics committee. It is a critical change Hagopian says goes beyond issues of life-sustaining treatments because it means the committee will apply the IDD perspective to all questions it considers.

Physicians hold the key

Success of the settlement depends on acceptance and use by physicians of the resources provided by the hospital's IDD physician consultants, and whether they abide by clearly outlined, stricter policies regarding decisions on withholding or withdrawing treatment.

DRW Attorney Kit Kerschensteiner, who also worked on the case, notes that most physicians leave medical school unprepared to manage care for people with profound disabilities. Making treatment decisions for individuals seen as incapable of exercising choice, or guiding families in those decisions, she says requires realistic knowledge of each individual's life and disability.

Limits on authority

As part of the agreement, DRW will meet annually with the hospital for the next three years to monitor progress on implementing the policy changes.

The protection and advocacy organization continues to pursue another aspect of the original case, asking the courts to address the responsibility of the physicians in the case to comply with Wisconsin law that states unless someone is in a persistent vegetative state, family members or a guardian cannot authorize withdrawal of treatment.

“We believe patients and their families will choose from the options presented to them by their doctor,” Hagopian says. “For that reason, it is vital physicians understand and respect the limits on the authority they have to offer withholding or withdrawing treatment from a person with IDD who is not in a persistent vegetative state.” ●

Hope for more access to mental health services



Advocates for community-based, recovery-focused mental health resources, including Kit Kerschensteiner and Barbara Beckert of Disability Rights Wisconsin (across table left to right), meet regularly with Deputy Secretary of the Wisconsin Department of Health Services Kevin Moore (foreground right) to discuss effective implementation of services. Beckert describes Secretary Moore's consistent championing of improved mental health resources around the state as a welcome response to repeated calls for better access.

Disability advocates monitoring access to mental health services in Wisconsin over many decades describe a system that is uneven and inconsistent. It is a delivery system that relies more on a crisis response than proactive support and is only as good as the mental health resources each county in the state allocates, says Barbara Beckert of Disability Rights Wisconsin.

After years of promoting an approach that emphasizes community-based, recovery-oriented mental health services and supports, DRW saw those efforts pay off in 2013 when Governor Walker took the initiative, working with advocates, to develop a budget that included an increase of more than \$16 million to expand funding for effective programs that reach into every corner of the state.

Welcome response

The new funding gives Wisconsin residents better access to community-based, recovery-focused mental health resources. Beckert, who is Milwaukee Office Director for DRW, says a coalition of advocates began meeting two years ago with the governor's office and with Kevin Moore, now Deputy Secretary of the Wisconsin Department of Health Services, to share ideas and discuss solutions. The budget proposal that emerged in 2013 received a positive reception in the legislature and passed with bipartisan support in June. The Assembly Speaker's Mental Health Task Force put other proposals forward at the same time that provided additional funding for peer-run respite, employment supports and other programs recommended by DRW and its advocacy partners.

Beckert and DRW Attorney Kit Kerschensteiner continue to participate in regular meetings convened by Deputy Secretary Moore to explore opportunities for improving mental health services in Wisconsin and the process for implementing the budget initiatives.

This welcome response to repeated calls for change signals a growing awareness among policymakers that the state must play a role in expanding access to community mental health services, says Beckert. She notes that progress toward closing long-term care facilities at the Milwaukee County Mental Health Complex and providing residents with services and supports to live in the community is evidence of an important shift in thinking.

Every community

Funding to support expansion of Comprehensive Community Services (CCS) to all Wisconsin counties is one of several advocacy priorities included in the budget proposal. CCS provides essential supports to children and adults where they live. It funds services that assist with recovery and with community skills that support independent living, employment-related skill training, peer support and all aspects of community life.

Beckert hails the state investment in CCS as “significant” given the uneven availability of many mental health services across Wisconsin. “It takes a regional approach that asks counties to build new collaborations and use them to develop supports that are accessible to people in every community,” she explains. “It’s no longer OK that quality and choice in mental health services depends on where you live.”

Supports for children

Attention to the specific needs of children was another important goal for DRW and its partners in advocacy. The newly created Office of Children’s Mental Health, which reports directly to the governor, will coordinate supports for youth and families across multiple systems at the state level, including health, child welfare, education and corrections.

Kerschensteiner calls it crucial for a state that lags behind others in services for children with mental health issues. She notes that continuity of care for children is

complicated by the fact their lives intersect with so many different service systems in school and in the community. They need mental health services that are integrated across all those settings to meet their individual needs throughout the day.

“The fragmentation that has long characterized mental health services in the state only makes matters worse for children with mental health issues,” says Kerschensteiner. “They risk becoming ensnared in a system that ignores individual needs and frustrates recovery.”

Growing a peer-run model

A major element in DRW’s advocacy for increased mental health resources is the need to provide services that promote recovery, especially for people in crisis. Advocates proposed the idea of peer-run respite centers, which can give individuals a supportive place with services that focus on steps to recovery. “It is a great model we can grow into a network of strong alternatives to psychiatric hospitals,” says Kerschensteiner. “A peer-run setting can serve as a good source of supportive crisis intervention that allows people to stay connected to their community and individual support systems.”

More to do

Kerschensteiner and Beckert say one of the most meaningful results of the 2013 budget action was recognition that expanding community mental health services as an alternative to crisis and institutional care is important for people who need those services and a good investment for the state. That hopeful step forward takes Wisconsin in the direction it needs to go, they add, but there is more to do. DRW advocacy for consumer choice of adequately funded and effective resources for every segment of the population moves ahead with renewed vigor. ●

Recognition



Milwaukee Office Director **Barbara Beckert** received the *In Search of Excellence Award* from the Wisconsin Family Based Services Association at the group's May 2013 conference. The award recognized Beckert for her "tireless efforts" on behalf of persons with disabilities, and her commitment to advocating for individual justice and systems change.



Amy Judy, Coordinator for the Violence Against Women with Disabilities and Deaf Women Project, received the *2013 Justice Award for Outstanding Achievement in Domestic Abuse* from the Governor's Council on Domestic Abuse late last year. The Council, which advises the Wisconsin Department of Children and Families and the legislature on abuse issues, applauded Judy's long-standing commitment to raising awareness of violence against women with disabilities and improving their access to services.

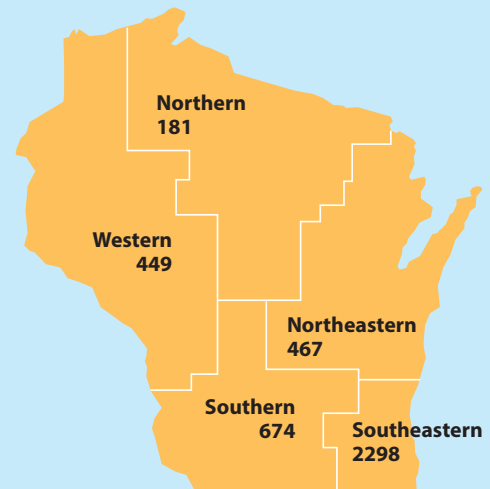


Managing Attorney **Kit Kerschensteiner** received the *2013 Distinguished Service Award* from the Equal Justice Fund last November. The award honors an individual who is a zealous advocate for the civil and human rights of low-income Wisconsin citizens. The Fund praised Kerschensteiner's effective advocacy in cases that had a major impact on the rights of people with disabilities.



Lisa Pugh, Public Policy Coordinator, received the *Elliott Shaw Distinguished Professional Award* at the April 2013 Circles of Life Conference, a gathering for families of children with developmental and related disabilities, and the professionals who support them. The conference lauded Pugh as an advocate committed to ensuring access to quality services and programs for all.

Financial and service highlights 2013



Total Individuals Served Statewide in 2013

One-on-One Advocacy (cases and I&Rs) – 8786*

Medicare Part D Information & Referrals (I&Rs) – 901

Training & Consultation – 8207

* *The map does not include the additional Medicare Part D and Benefits Attorney I&Rs because client county statistics are unavailable for those contacts.*

Foundation/Corporation Partners

Dane County Pro Bono Trust Fund

Equal Justice Fund

First Business Bank

Greater Milwaukee Foundation—

Edith C. and J. Oscar Greenwald Fund

Otto Bremer Foundation

Wisconsin Trust Account Foundation

Board of Directors 2013

Statement of Revenue and Expenses for FY13 and FY12

	FY13	FY12
Revenue		
Federal Grants	\$1,855,814	\$2,006,124
State grants	2,063,527	1,654,986
Foundations & Corporations	233,618	189,464
Legal Fees	42,097	365,203
Consulting Fees & Contracts	417,756	648,741
Other	2,223	7,525
Revenue Total	\$4,615,035	\$4,872,043
Expenses		
Personnel	\$3,505,845	\$3,893,396
Subcontracts	60,535	37,152
Occupancy	310,074	289,589
Travel, Meetings, & Conferences	188,567	167,065
Other Operating Costs	432,556	389,438
Settlement Expense	176,648	0
Depreciation	73,500	76,115
Expense Total	\$4,747,725	\$4,852,755
Net Income (loss)	(132,690)	19,288

Statement of Financial Position for FY13 and FY12

Assets

Current Assets

Cash & cash equivalents	\$310,150	\$309,702
Accounts receivable	64,107	40,468
Grants receivable	350,025	325,500
Prepaid expenses	115,757	129,825
Total current assets	840,039	805,495
Property and equipment, net	150,117	210,374

Total Assets

\$990,156	\$1,015,869
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Liabilities and Net Assets

Current liabilities

Accounts payable	86,644	61,699
Accrued payroll	55,308	56,436
Amortized rent	-	570
Settlement Payable	32,000	
Capital lease payable	2,714	3,422
Leasehold improvement payable	26,269	26,269
Accrued vacation	129,797	118,237
Grant funds received in advance	77,375	45,661
Deferred revenue	107,354	209,301

Total current liabilities

517,461	521,595
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Long-term liabilities

Settlement Payable	128,000	-
Capital lease payable	9,380	-
Leasehold improvement payable	48,115	74,384
Total long-term liabilities	185,495	74,384
Total liabilities	702,956	595,979

Unrestricted net assets

287,200	419,890
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Total Liabilities and net assets

\$990,156	\$1,015,869
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Sandra Ahrens
Eau Claire

Gary Arms
Oshkosh

John Donnelly
Madison

Susan Gramling
Milwaukee

Wayne Griffiths
Ashland

Jeanette Herrera
Milwaukee

David Keech
Wisconsin Rapids

Cathy Kunze
West Allis

Patrick Mateer
Abbotsford

Saphronia Purnell-Carson
Green Bay

Leslie Riggs
Appleton

Christopher Sigl
Hartford

Ted Skemp
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Disability Drug Benefit Helpline: 800-926-4862 statewide

* for persons with disabilities and their family members

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