



# The Iris

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NAMI Wisconsin  
— the State's Voice  
on Mental Illness*

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## NAMI Wisconsin Conference Preview

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Xavier Amador, PhD



Dominic Carter

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**NAMI Wisconsin  
Annual Conference  
May 29-30, 2009**

## Wisconsin's grade slips in "Grade the States" report

NAMI National's "Grade the States" report card issued in early March showed Wisconsin slipping from a B to a C for the quality of its public mental health system. The report is a follow-up to a NAMI report published three years ago to measure the progress of states achieving the goals of a presidential commission that called for transformation of the mental health care system. In the previous report, Wisconsin received a grade of B. This year it is one of 12 states that saw their grades decline. The national average is D, remaining stagnant from three years ago. Six states received Bs. Six received Fs. No state got an A.

Terry Schnapp, Executive Director of NAMI Wisconsin, commented, "Falling from a B to a C is a great disappointment. We should be moving forward, not retreating. State budget cuts threaten to make things worse."

According to the report, Wisconsin's slippage can be attributed to, "the limited access and availability of services; the inequities of the state's complex, decentralized system; slowness in implementing evidence-based practices (EBPs); and inattention to cultural competence. The system's sluggishness hinders progress."

"The state funds services in 72 counties," the report continues, "but the counties provide the non-federal share of Medicaid funding and are responsible for providing or purchasing most services. Counties and localities contribute varying amounts to mental health care spending, above what the state provides. The decentralized nature of the system limits

the Division of Mental Health and Substance Abuse Services' (DMHSAS) control over local services. Availability and quality vary widely."

All of the news is not negative, however. The report card cites Wisconsin as a "national leader on wellness and recovery. DMHSAS promotes the concept that mental health is essential to overall health by working to integrate primary care medicine and mental health services. It supports smoking cessation programs in the two state hospitals and in community programs. It also promotes inclusion of peer specialists in provider care and directly funds 10 consumer-run community programs."

"The state funds consumer, family, and public education. Working with Wisconsin United for Mental Health, a coalition of consumer, provider, and agency groups, DMHSAS provides education and awareness training to employers, schools, health care providers, news media, and the general public.

Although the state is known to value consumer and family views, it does not promote the use of consumer and family monitoring teams to review conditions in its hospitals and community programs."

"Wisconsin supports five "Fountain House" model certified clubhouses and a limited number of high-quality Assertive Community Treatment (ACT) teams. However, the state's 79 Community Support Programs (CSPs), which are generally based on ACT principles, fall far short of national ACT standards.

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# Executive Director's Corner

by Terry Schnapp, Executive Director




Terry Schnapp, Executive Director

system. The current report was a follow-up to a NAMI report published three years ago to measure the progress of states in achieving the goals of a presidential commission that called for the transformation of the mental health care system. In the previous report Wisconsin received a B grade. Falling from a B to a C is the kind of report card that kids usually are afraid to take home to their parents. Wisconsin is slipping. Instead of moving forward, the state's mental health care system is falling behind. Wisconsin has good ideas. The challenge is turning them into realities.

What are some of the key reasons that the grade decreased? Our county-based delivery system has inequities in services available county by county. Wisconsin has a lack of evidence-based practices, lack of mental health courts, few jail diversion and reentry programs, and limited workforce development with cultural competence planning.

What can we do to move in the right direction? We need to notch up our advocacy roles at both the state and local affiliate level.

We need to express our concerns with our state and county elected representatives and officials. We have done a pretty good job with our support and education goals but not so well with our very important advocacy goal. It is time to get energized and get that fire in our bellies again. 

The NAMI Board of Directors has completed their recruitment process for a new Executive Director. I would like to welcome your new Executive Director Lannia Syren to NAMI Wisconsin. She will be starting on May 4, 2009.

The past six months as your Interim Executive Director have been very rewarding for me. It was a pleasure to be able to help advance NAMI's goals of support, education, and advocacy for consumers and their families. Now that summer is rapidly approaching with warmer weather, however, I am looking forward to having time for biking trips and spending time at our home in Vernon County.

The National Alliance on Mental Illness (NAMI National) issued a national report card last month that gave Wisconsin a C grade for its public mental health care

## NAMI Wisconsin County Affiliates

Barron .....	(715) 736-0089
Brown .....	(920) 430-7460
Chequamegon Bay.....	(715) 274-8403 (Ashland, Bayfield)
Dane .....	(608) 249-7188
Dodge .....	(920) 887-7211
Door .....	(920) 493-2912
Douglas .....	(715) 378-2772
Fond du Lac .....	(920) 922-0566
Fox Valley .....	(920) 954-1550 (Outagamie, Calumet, Waupaca, Winnebago)
Green .....	(608) 328-9376
Iron .....	(715) 476-2172
Jefferson .....	(920) 262-7887
Kenosha.....	(262) 605-9038
La Crosse .....	(608) 784-7532
Manitowoc .....	(920) 683-3363
Marinette (WI) and Menominee (MI) .....	(906) 864-1933
Mid Central .....	(608) 408-0177 (Adams, Green Lake, Juneau, Marquette, Waushara)
Milwaukee .....	(414) 344-0447
Northwoods .....	(715) 298-2553 (Marathon, Lincoln, Langlade)
Oshkosh.....	(920) 651-1148 (Winnebago)
Ozaukee.....	(262) 241-3929
Portage/Wood .....	(715) 592-4522
Racine .....	(262) 637-0582
Richland .....	(608) 604-4535
Rock.....	(608) 758-8144
Sheboygan .....	(920) 803-6193
South Central .....	(608) 254-7092 (Sauk, Columbia)
Southwest Wisconsin.....	(608) 348-6136 (Grant, Iowa, Crawford)
St. Croix Valley .....	(715) 307-1921 (St. Croix, Pierce)
UW Madison .....	(608) 268-6000
Walworth .....	(262) 495-2439
Washington .....	(262) 338-2393
Waukesha .....	(262) 524-8886
Wishigan.....	(715) 336-2744 (Florence, WI, Dickinson, MI)

**The mission of NAMI Wisconsin is to improve the quality of life of people affected by mental illnesses and to promote recovery.**

**NAMI of Wisconsin will accomplish its mission through the following:**

- Establishing local Affiliates in keeping with NAMI National's principles and guidelines.
- Supporting Affiliates by providing follow-up advice and counsel; educational and training programs and materials; access to financial resources as appropriate; and by offering conferences, seminars, and presentations.
- Advocating at all levels of government and throughout the public sector.
- Promoting public education and understanding of mental illnesses.

# New Executive Director ready to meet challenges ahead

by Geoff Greiveldinger and Pat Rutkowski, Co-Presidents

Spring means new beginnings. That's especially true for us in NAMI Wisconsin. Perhaps the most significant new beginning is the arrival of a new Executive Director, Lannia Syren. (Those of us with difficult names are especially aware of pronunciation. Lannia pronounces hers Lah-NEE-ah Sir-REN.)

Lannia was the Board's choice from a remarkably attractive and qualified group of persons interested in serving as our Executive Director. The Board's Executive Committee led the search process, with Secretary Sandy Hall pulling the laboring oar.

The 40+ applications were culled down to 20 possibilities. The Executive Committee collectively scored those 20, ultimately settling on seven candidates that it interviewed. From that group, two candidates were presented to the full Board, which interviewed both and then made the final selection.

A graduate of the University of Northern Iowa, Lannia has a strong and varied background in non-profit/human services work. After several years in counseling and case coordination, including work with youth, families, and dual diagnosis clients, she joined Big Brothers and Big Sisters of Northeastern Iowa. There, her talents moved her quickly from Case Manager to Program Director and, ultimately, to Executive Director.

For personal reasons, Lannia moved to Dane County, where she now holds a position as Grants and Government Relations Manager for Easter Seals Wisconsin. Lannia will wrap up her tenure with Easter Seals at the end of the month and will join NAMI Wisconsin full time on May 4th. Meanwhile, she's staying abreast of all that's happening at NAMI Wisconsin.

If you come to the state conference, please make a point of meeting this remarkably energetic and talented young woman. Lannia

will fit in well with NAMI Wisconsin's highly professional staff, as well as with the consistently dedicated and enthusiastic volunteers who are the backbone of our organization. She truly represents a new beginning.

And there are other new beginnings. We have been awarded a grant from NAMI National to bring the NAMI Connection consumer-led support group program to Wisconsin. We look forward to helping our state join those that have already implemented the program.

In Wisconsin spring in an odd-numbered year also means the biennial budget. NAMI Wisconsin's Public Policy & Advocacy Committee is far more authoritative on these matters than we. However, based on the Governor's budget as it currently stands (first week of April), we do want to note a couple of items of importance to NAMI members—consumers, families and friends alike.

The first involves a shift of Medicaid costs from the State to counties, for young persons (generally, 21 and under) and seniors (generally, 65 and older), placed in the state's two mental health institutes: Mendota and Winnebago. Medicaid is a Federal-State program; the Federal share has been 59%, the State's share has been 41%. The Governor's budget would require each county to pay the State share of its youngster/senior placements in Mendota and Winnebago.

This shift could substantially increase county costs for needed mental health services. It could cause counties to seek less intensive services for some individuals who truly need in-patient care, or it could cause counties to reduce other services to make up the cost difference.

The Governor's budget does contain some additional funds for new or enhanced community-based services. This may present opportunities not merely for improved services, but for services that truly meet the standard of "evidence-based."

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**NAMI Wisconsin, Inc**  
4233 West Beltline Highway  
Madison, WI 53711

## Office Staff and Volunteers

Bob Fox  
Vaunceil Kruse  
Jennie Lowenberg  
Kurt Monson  
Sarah Mroz  
Terry Schnapp  
Dennis Wilder

Office Phone: (608) 268-6000  
(800) 236-2988  
FAX (608) 268-6004  
nami@namiwisconsin.org

[www.namiwisconsin.org](http://www.namiwisconsin.org)

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# Decline in state's mental health programs a call to advocacy

by William R. Benedict

As a father of a son with serious mental illness, I was saddened to see how my state's mental health program scored in a recent national study. It received a fair-to-poor grade of C. In 2006 our state received a B and since no state earned an A, this performance went largely unnoticed, in part because Wisconsin is the birthplace of a preeminent national mental health advocacy organization — the National Alliance on Mental Illness.

NAMI has led the nation both in mental health advocacy and in the promotion of the most innovative and effective community-based service program model in the nation. Now known nationally as the Assertive Community Treatment (ACT) program, it has been copied throughout the world. This program has undergone rigorous evidence-based efficacy studies and has been proven over and over again to be a program that consistently works. I can't begin to tell you how grateful my family and I are both for NAMI and for ACT. It hurts me to see a mental health service culture so innovative and cost-effective for so long, receive a C grade.

Clearly, when compared nationally, Wisconsin continues to be a leader in wellness and recovery. Having been both a program evaluator for over thirty years in Wisconsin and in a family which has suffered from mental illness, I can testify to the strong mental health foundation that has been laid in Wisconsin. With such auspicious beginnings taxpayers in Wisconsin should not stand for anything less than excellence.

In 2006 NAMI National conducted and published its first Grading the States Report: "Grading the States 2006: A Report on America's Health Care System for Serious Mental Illness." This past week NAMI released its Grade the States 2009 report. In it they used the 2006 findings for baseline comparisons. This report measures each state's progress—or lack of progress in many cases—in providing evidence-based, cost-effective recovery-oriented services for children and adults living with serious mental illness.

In NAMI's 2006 progress report the nation's grade was D and Wisconsin scored a B. In this more recently released report the nation again scored a D while Wisconsin's grade slipped downward from a B to C. Wisconsin was one of twelve states who fell back while 23 states stayed the same. Wisconsin has over 188,000 residents with serious mental illness.

This state scorecard and survey methodology graded each state in four weighted sub-categories: 1) health promotion and measurement; 2) financing and core services; 3) consumer and family empowerment; and 4) community integration and social inclusion. Wisconsin scored lower on three of these four categories when compared with the 2006 results: D, B, C, D compared to C, B, B, and B respectively.

Category 1 measures had to do with the extent that the state mental health program had a workforce development plan, state mental health insurance parity laws and mental health coverage in programs for the uninsured. Other significant measures for this category included the state's ability to provide accurate data on a variety of services including evidence-based practices, ACT outcomes, and demographic data. Such measures undergird NAMI's fundamental assertion that public funding for mental health treatment services must be tied to outcome performance measures.

Inasmuch as I spent more than three decades of my professional life working to help introduce program outcome evaluation practices into private and public sector mental health programs in Wisconsin, I am both surprised and deeply disappointed to see so little accomplished in this area during the past thirty years. Wisconsin's D in this category is nothing more than dismal. This score reflects, I think, an alarming lack of reliable data seriously inhibiting program improvement, accountability and transparency.

Financing and core service measures also included Wisconsin's 79 Community Support Programs (CSPs) which are generally based

on ACT principles, and were found to fall far short of national ACT fidelity standards. Funding in part by state Medicaid funds, but also heavily dependent on local county tax dollars in varying amounts, results in a wide range of service quality and performance outcomes throughout the state.

The lack of consumer and family monitoring teams to review conditions in Wisconsin's hospitals and community programs, and the absence of mental health courts, acted to lower grade levels in categories 3 and 4 respectively.

The Division of Mental Health and Substance Abuse Services (DMHSAS) is the state mental health agency that works directly with county mental health agencies. In addition to coordinating federal funding to the counties, DMHSAS has recently initiated an integrative service model which relies heavily upon collaboration with other state agencies and programs to deliver more efficient and accessible community-based services.

Called Comprehensive Community Services (CCS) this model is presently being used to fill the gap between office-based outpatient counseling and CSP intensity. While DMHSAS 2008-09 program plans are well intended, they fail to address the critical deficiencies found in the Grading the States 2009 evaluation report. Ironically, this conclusion was also supported in an earlier August 2007 Wisconsin Council on Mental Health letter.

Members of the Council expressed concern "about the bluntness and ineffectiveness of the DMHSAS State Plan indicators as measures of state progress toward meeting important mental health goals and objectives." This state planning and review public watchdog agency also expressed its "concern about the quality and sources of data collected." Its concern was particularly acute with respect to reports of services by counties who were delegated much of the responsibility for the plan's implementation.

Let me quote the Council: "Both the DMHSAS indicators and DHFS data are critical for the

State and Council to identify and support appropriate funding recommendations and decisions. Our recommendations are unfortunately undercut by inadequacies in both."

So what has caused Wisconsin's once innovative and dynamic mental health program to sink into mediocrity? The 2009 Grade the States report suggests: limited access and availability of services; insufficient funding; inequities of the state's decentralized funding system; and a still broken information system that cripples the state's ability to effectively plan, evaluate and account for its spending and service delivery decisions.

If this isn't a call to action what is? Won't you join with NAMI consumers and their families, and as concerned taxpayers simply say, "We are not going to take this anymore!"

## New, *continued from page 3*

Your local state legislators will want to hear your views on these and other budget matters important to you.

Another new beginning, of sorts, is NAMI National's recent release of its **Grading the States** report. Released in March, **Grading the States** is NAMI's third, and probably most solidly grounded, assessment of mental health services across the nation.

Unfortunately, Wisconsin did not fare as well in this version as it did in 2006; our state dropped from a B to a C. There is some solace in the fact that only 24 states (including D.C.) had a B or C, while 27 were graded

D or F; no state had an A. Nonetheless, this more detailed review of Wisconsin's program shows that it no longer leads the nation. This is truly a call for new beginnings. To read the full report visit the NAMI National Web site at [www.nami.org](http://www.nami.org) and enter "Grading the States" in the Search engine.

We look forward to seeing you in Madison at the end of May.

## NAMI Greater Milwaukee, NAMI Waukesha sponsor first walks of 2009

The first two NAMI Walks for the Mind of America events in Wisconsin in 2009 will be held May 16 in Milwaukee and Waukesha. Participation comes in many ways. Individuals may form their own team, may walk on someone's team, or make a donation.

### NAMI Greater Milwaukee

This year's Honorary Walk Chairs are Greg and Nicole Jennings (of the Green Bay Packers).

**Location:** Veteran's Park on Lincoln Memorial Drive, Milwaukee, Wisconsin

**Date:** May 16, 2009

**Distance:** Three miles

**Check-in:** 9:00 am

**Start Time:** 10:00 am

**Website:** <http://www.namigrm.org>

For more information about this event, please contact:

Peter Hoeffel

[peterh@namigrm.org](mailto:peterh@namigrm.org)

Phone: 414-344-0447

FAX: 414-344-0450

### NAMI Waukesha

This year's Family Team Chair is Candy Parr.

**Location:** Frame Park, Waukesha, Wisconsin

**Date:** May 16, 2009

**Distance:** Five Kilometers

**Check-in:** 10:00 am

**Start Time:** 11:00 am

For more information about this event, please contact:

Jana Hockerman

[jananamiwauk@aol.com](mailto:jananamiwauk@aol.com)

Phone: 262-524-8886

FAX: 262-547-1321



# Family-to-Family Education Program study shows significant positive impact

by Lynn Sisco

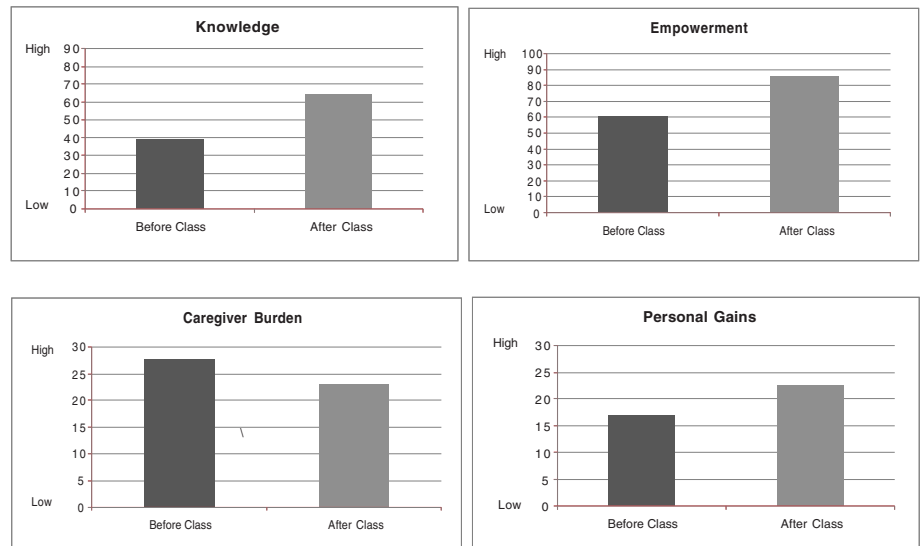
A recent study on the effectiveness of the Family-to-Family Education program demonstrated a number of significant positive impacts on class members. The study, undertaken by the UW-Madison School of Social Work under the direction of NAMI Wisconsin Board of Directors member, Jan Greenberg, PhD, featured a detailed questionnaire that was distributed to Family-to-Family class members from six NAMI Wisconsin affiliates.

Individuals filled out the questionnaire before beginning the twelve week course and again following the completion of the course. The first set of questions asked about participants' knowledge of mental illness and its treatment. For example, participants were asked about their knowledge of different diagnoses, medications, and mental health services. Participants responded to each question on a scale from 1 (*Not at all*) to 10 (*Very Knowledgeable*).

The next set of questions asked in the evaluation concerned the respondent's feelings of empowerment. There were 33 statements asking about different ways that the participants in Family-to-Family might feel a greater sense of control and empowerment in coping with their relative's illness as a result of participating in this educational program. For example, participants were asked the extent to which they knew what steps to take if their relative was receiving poor service or the extent to which they understood how the mental health system was organized. For each statement, participants were asked to indicate the extent to which the statement was true for them (from *Not true* at all to *Very true*).

A third part of the questionnaire asked about feelings of caregiver burden. These questions asked about the extent that providing support to their loved one was stressful, created conflicts in the family, caused financial strains and so forth. In the final section of the questionnaire participants reported on

## Family-to-Family Impact



the extent to which their lives had been positively transformed as a result of coping with their relative's illness. For example, respondents were asked the extent to which they had become more aware of their inner strengths or had become closer to their family as a result of coping with the challenges of mental illness.

Over 100 people participated in this evaluation, with the majority being women (73%). Many were parents (65%) but over 20% were either a spouse or sibling of the loved one with mental illness. They were, on average, 52 years old. About 40% lived with their loved one with mental illness.

The participants in Family-to-Family reported many positive changes as a result of attending Family-to-Family (See "Family-to-Family Impact" on this page.). They reported a significant increase in knowledge of mental illness and its treatment, in feeling an increased sense of empowerment and personal growth, as well as a significant decrease in "levels of family burden." A similar study done by the Center of Mental Health Services Research, University of

Maryland, and reported in an article, "Benefits and Changes for Family-to-Family Graduates," by researchers Lucksted, Stewart and Forbes cited comparable results.

It is hoped that studies like these will build upon the Family-to-Family program as a valuable community resource by showing not only that the program does work, but how it works.

Asked for her reaction to the findings in the UW Madison study, Gail Auerbach, State Director of Family-to-Family Programs, said, "Participants and teachers always felt Family-to-Family taught insight and understandings that truly empowered those dealing with mental illness. This study confirms our views, and that's very empowering as well!" She added, "Dr. Joyce Burland, clinical psychologist, and parent and sister to individuals with schizophrenia, developed this curriculum especially to help alleviate family burden when dealing with mental illness. She succeeded." ❁

# NAMI Connection roll-out brings signature program to Wisconsin

NAMI National will bring the NAMI Connection program to Wisconsin with a training in Milwaukee, July 31-August 2, 2009. NAMI Connection is a weekly recovery support group for people living with mental illness in which people learn from each others' experiences, share coping strategies, and offer each other encouragement and understanding.

NAMI Connection groups meet weekly for 90 minutes, are free of charge, follow a flexible structure, and do not recommend or endorse any medications or other medical therapies. The groups are confidential—participants can share as much or as little personal information as they wish. NAMI Connection meetings are facilitated by consumers trained to follow the NAMI Connection **Principles of Support**. NAMI National's goal is to have a group within driving distance of every consumer in the United States—every day of the week.

The weekly meeting format requires a fairly large pool of facilitators, so the NAMI Connection program will be officially launched in NAMI Wisconsin's four urban affiliates: NAMI Dane County; NAMI Fox Valley; NAMI Greater Milwaukee; and NAMI Racine. Facilitators from those four affiliates will be trained by the National NAMI Connection training team. NAMI National will supply all materials, lodging, meals and a mileage allowance for the facilitators. Consumer Support Group Facilitators from other Wisconsin affiliates who have been trained in the NAMI C.A.R.E. or NAMI Connection model may also attend the training.

After facilitating NAMI Connection support groups for five to six months, three facilitators will be sent to St. Louis to be trained as state trainers. These trainers may then train facilitators in Wisconsin adding to the pool of NAMI Connection facilitators, and, hopefully, expanding the program into other areas of the state.

For NAMI members familiar with the NAMI C.A.R.E. model, some of the differences

between that model and the NAMI Connection model include: Connection groups meet weekly rather than once or twice a month; Connection has a Support Group Emergency Procedures section; Connection has the Problem Solving Process included in every training; Connection has added one **Principle of Support** and changed two of the **Principles of Support** (See **Principles of Support** on this page); Connection Facilitators send in data postcards after each group to help with identifying demographics of Connection groups. Connection groups are listed on the national website [www.nami.org/connection](http://www.nami.org/connection) and have assigned Field Managers who host monthly facilitator calls.

Another new component of the NAMI Connection program is the use of Champions to work with facilitators and local affiliates to distribute NAMI Connection marketing materials to agencies, mental health centers, and other local locations. Champions may also identify sites for NAMI Connection support groups and may identify potential champions and support group facilitators, as well.

The Field Manager for NAMI Wisconsin is Anna Goodwin, who will lead a workshop outlining the NAMI Connection program and the specifics of the Wisconsin roll-out at NAMI Wisconsin's Annual Conference on Friday, May 29.

For a concise overview of the program the NAMI Connection outreach video can be found on YouTube. To view the outreach video, along with six brief testimonials from NAMI Connection participants, go to NAMI's YouTube channel at <http://www.youtube.com/user/NAMIvideo>.



## NAMI Connection Principles of Support

1. We will see the individual first, not the illness.
2. We recognize that mental illnesses are medical illnesses that may have environmental triggers.
3. We understand that mental illnesses are traumatic events.
4. We aim for better coping skills.
5. We find strength in sharing experiences.
6. We reject stigma and do not tolerate discrimination.
7. We don't judge anyone's pain as less than our own.
8. We forgive ourselves and reject guilt.
9. We embrace humor as healthy.
10. We accept that we cannot solve all problems.
11. We expect a better future in a realistic way.
12. We will never give up hope!



# NAMI Wisconsin members attend National Leadership Conference

by Jack Rose, NAMI Wisconsin Board of Directors

Mandy Krahenbuhl, member of the NAMI Wisconsin Consumer Council and Jack Rose, NAMI Wisconsin Board member and President of NAMI Kenosha, represented NAMI Wisconsin at NAMI National's 2009 Annual Leadership Conference, **Charting Our Course through Rough Water: Building Strong NAMIs, Building Strong Advocates**. The purpose of the conference, held in Washington DC, February 5-8, 2009, was threefold: to meet with legislators and their staffs on Capitol Hill and distribute current NAMI issue packets; to receive updates on the NAMI Strategic Plan, Standards of Excellence and Grading the States (GTS); and to network and share ideas with the 119 NAMI members from 40 states attending the conference.

Andrew Sperling, Director of Federal Legislative Advocacy, and the NAMI national staff presented conference attendees with a package of issue briefs in preparation for visits with their legislators. (See *Mental Health Care Reform 2009* on page 9.)

Jack met with Paul Ryan on Wednesday afternoon. Ryan commented early in his meeting with NAMI representatives that he had voted for the final version of the Federal Parity Law. One benefit of the conference was the strengthening of relationships. Working with Matt Hoffman, the Legislative Director on Ryan's staff, and Debby Ganaway, the Executive Director of NAMI Racine, Jack was able to help out one of Paul Ryan's constituents who was having a problem navigating the mental health system in Wisconsin.

Jack met with members of Herb Kohl's, Russ Feingold's, Dave Obey's, and Jim Webb's staffs on Thursday. Jack shared Wisconsin's recent Audit on Inmate Mental Health Care with an old friend on Senator Jim Webb's staff. Webb's article in the Sunday *Parade* magazine, (3/30/09), "What's Wrong With Our Prisons?" dealt with the deterioration of America's criminal justice system. The Senator from Virginia asked, "How can we better diagnose and treat mental illness?" as one of the key questions for a Federal Commission

that he is in the process of creating.

While on the Hill, NAMI members also had the opportunity to attend a briefing on the Healthcare Reform plan that Senator Kennedy and Senator Baucus are sponsoring.

Lyn Borton, NAMI National's Chief Operating Officer, provided a NAMI Strategic Plan and Standards of Excellence update. This effort began in New Orleans, site of last year's Leadership Conference, and continues to move forward. A timeline was developed in March 2009 for further implementation of the Standards of Excellence. Borton thanked the State-level and Affiliate-level leaders who helped to bring the organization this far, commenting that, "NAMI National looks forward to working together to help NAMI grow and be strong." Efforts are being made to spread the NAMI brand and raise its visibility while continuing the profound rejection of the injustices associated with mental illness.

Mike Fitzpatrick, Executive Director of NAMI National, stressed that in these tough economic times the organization must continue efforts to improve the quality of life for those affected by mental illness. NAMI is the only mental health advocacy group to push back at bad policy and Fitzpatrick urged that NAMI leaders continue to do so.

NAMI National arranged gatherings on the Hill Thursday evening and Friday evening to allow attendees to meet and greet fellow NAMI leaders and to share ideas and compare programs. Among the insights into programs and issues from around the nation were: NAMI New Jersey's great advocacy program led by Phil Lubitz; NAMI South Carolina's attempt to get a significant earmark to support their work in mental health; NAMI Arizona's providing Family-to-Family classes to family members of returning Iraq and Afghanistan veterans. NAMI Pennsylvania did a study on the cost of incarceration in their state prisons and found the cost per inmate to be \$80 per day, while inmates with severe mental illness cost \$140 per day. Jack also learned that New Jersey's State Treasurer visits their state mental hospitals, while

Rochester, Buffalo and New York, New York have started Vet courts and Lake County, Illinois has recently established a mental health court. Not all of the reports were positive. North Dakota's state mental health clinics shut down until the end of March due to funding restraints, North Dakota being the only state that did not participate in the GTS program.

Among the break-out sessions Jack attended were **Advocating for Effective Crisis Intervention for Youth**, where the CIT model is being emulated to help youth in San Antonio and Chicago, and **Psychosocial Rehabilitation and Recovery Oriented Services for Veterans**, a review by the VA of their efforts to improve the system and recovery services. The VA reported that North Chicago VA Hospital has the best five week in-patient PTSD program in the nation. Jack also attended the break-out session entitled, **Protecting Mental Health Funding in an Economic Crisis: Sharing Strategies, Finding Solutions** that provided some creative ideas for new funding and for better use of current funding.

Jack attended the Veteran Council where NAMI is reaching out to veterans to provide support through Peer-to-Peer groups and Family-to-Family programs. A Memorandum of Understanding between NAMI and the VA is complete in 14 states with 22 in the works. Recently, nine combat veterans, who were police officers in Tennessee, committed suicide, underlining the importance of providing more and better mental health services for veterans.

The 2009 NAMI National Leadership Conference gave NAMI leaders excellent opportunities to strengthen relationships with legislators, NAMI National policy-makers, and other NAMI members from around the nation.



# Mental Health Care Reform 2009

NAMI's priority goal in 2009 is to *ensure that mental health care is an integral part of health care reform*. Our underlying message as part of health care reform is that:

- Millions of people with mental illness do not have access to life saving health care, and
- Untreated mental illness devastates our families, our communities, and our future.

NAMI Leadership Conference attendees were asked to emphasize the following four points during their visits to Capitol Hill:

1. **Health care reform must ensure mental illness parity.** NAMI commends the recent enactment of the federal Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008. Consistent with this legislation, health care reform should ensure that mental illness and substance abuse services are covered in the same way as services for all other health conditions in all public and private health plans.
2. **Health care reform must ensure that mental illness and physical health are integrated.** People with serious

mental illnesses die, on average, 25 years younger than the rest of the population. Health care reform must promote integrated mental and physical healthcare to ensure that children and adults with serious mental illnesses have access to adequate primary health care and chronic disease management that promotes wellness and reduces premature death.

3. **The mental health care provider shortages must be addressed.** There are severe shortages of qualified psychiatrists, psychologists, and other vital mental health professionals all across America. Health care reform must include mechanisms to increase the availability of qualified mental health care professionals in both urban and rural communities.
4. **Health care reform must center on evidence-based, cost-effective services and supports.** Despite effective treatments, there are long delays—sometimes decades—between first onset of symptoms and when people seek and receive treatment. Health care reform must emphasize early intervention and evidence-based services and supports that promote

recovery for children and adults living with mental illnesses.

Additional legislative issues were addressed in briefs on the following topics:

- Decriminalizing Mental Illness
- Children, Adolescents and Transition-age Youth
- Housing
- Veterans
- Economic Recovery and Stimulus Package
- Discretionary Funding (SAMHSA/NIMH)

To access full texts of the issue briefs go to the NAMI National Web site [www.nami.org](http://www.nami.org) and enter "Leadership Conference 2009" in the "Search" engine. 🌿

*Information provided by the NAMI Policy Team*



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## Grade, *continued from page 1*

DMHSAS has acknowledged that the pioneering 1989 CSP standards, the first in the nation to create a Medicaid ACT benefit, need to be upgraded. Other community programs such as integrated dual diagnosis treatment, supported employment, and other EBPs also lack fidelity to national standards."

"DMHSAS is seeking to fill a gap between office-based outpatient counseling and CSP intensity. A new level of care called, Comprehensive Community Services (CCS), is being implemented, but it will take some time to know how well CCS fills the need. Access to medication is restricted under

Wisconsin's Medicaid program. A prior authorization process exists for psychiatric medications that are not on the state's preferred drug list, but waiting times can impede clinical response and recovery."

"Many counties lack police Crisis Intervention Teams (CIT) and mental health courts. Only two jail diversion programs and one reentry program exist in the entire state."

"Wisconsin is one of the lower-performing states on cultural competence. DMHSAS is working on a plan for improvement. It also seeks ways to improve critical event reporting and analysis, and to address workforce

shortages in rural areas. The challenge, however, lies in turning plans into reality."

Seeing the report as a call to action, NAMI Wisconsin Board of Directors Vice-President, Ken Herrmann, MD, noted, "This report brings to light an opportunity to improve mental health care in Wisconsin. Now is the time to contact our elected officials in state and county government to ask how we can improve mental health care."

To read the full "Grade the States" report visit the NAMI National Web site at [www.nami.org](http://www.nami.org) and enter "Grading the States" in the Search engine. 🌿



# Proposed Agenda

## Mind, Body, Spirit: One Journey

**NAMI Wisconsin Annual Conference**  
**Co-hosted by NAMI Dane County**  
**May 29-30, 2009**

Agenda will be updated on the NAMI Wisconsin Web site as information becomes available.

### Friday – May 29

- |               |  |
|---------------|--|
| 7:30 – 8:30   | Registration and Continental Breakfast             |
| 8:30 – 9:00   | <b>Opening of Conference and Welcome</b>           |
| 9:00 – 10:15  | <b>Keynote Speaker – <i>Xavier Amador, PhD</i></b> |
| 10:15 – 10:30 | Break  |
| 10:30 – 11:45 | Breakout I A 1 – Stress Management                 |
|               | Breakout I A 2 – Ask the Doctor: Schizophrenia     |
|               | Breakout I A 3 – Veterans Issues                   |
|               | Breakout I A 4 – Advocacy                          |
| 11:45 – 1:00  | <b>Lunch and Awards</b>                            |
| 1:00 – 2:15   | Breakout I B 1 – Transitional Employment           |
|               | Breakout I B 2 – Ask the Doctor: Dual Diagnosis    |
|               | Breakout I B 3 – Suicide Prevention                |
|               | Breakout I B 4 – Evidence-Based Practices          |
|               | Breakout I B 5 – NAMI Connection Panel             |
| 2:15 – 3:00   | Break  |
| 3:00 – 4:15   | Breakout I C 1 – Ask the Doctor: Depression        |
|               | Breakout I C 2 – Person-centered Planning          |
|               | Breakout I C 3 – SOAR /PATH                        |
|               | Breakout I C 4 – CIT                               |
| 4:15 – 4:30   | Break  |

- 4:30 – 5:45      Breakout I D 1 – Research on Schizophrenia  
 Breakout I D 2 – Waitlist Alternatives  
 Breakout I D 3 – Native American Storytelling  
 Breakout I D 4 – Affiliate Networking
- 6:00 – 7:00      **Annual Meeting, Reception**

## **Saturday – May 30**

- 7:45 – 8:15      Registration and Continental Breakfast
- 8:15 – 8:45      **Welcome, Introductions**
- 8:45 – 9:00      Transit time
- 9:00 – 10:15    Breakout II A 1 – Children’s Mental Health  
 Breakout II A 2 – Dual Diagnosis & Recovery  
 Breakout II A 3 – Board Public Policy  
 Breakout II A 4 – Cultural Issues  
 Breakout II A 5 – Consumer Council Open Meeting
- 10:15 – 10:30    Break
- 10:30 – 11:45    **Featured Speaker – *Dominic Carter***
- 11:45 – 1:00     **Lunch and Awards**
- 1:15 – 2:15      Breakout II B 1– Ask the Doctor: Bipolar Disorder  
 Breakout II B 2 – Consumers as Providers  
 Breakout II B 3 – Spirituality  
 Breakout II B 4 – CSP Panel
- 2:15 – 2:30      Break
- 2:30 – 3:30      Breakout II C 1– Ask the Doctor: Borderline Personality Disorder  
 Breakout II C 2 – Dance Therapy  
 Breakout II C 3 – Clubhouse & Recovery  
 Breakout II C 4 – Presidents’ Session

# Affiliate Leaders guided into the new fund raising climate

Twenty NAMI Wisconsin affiliate leaders gathered at the Chula Vista Resort in Wisconsin Dells, March 21st for a full day of fund raising, grant writing, and sustainability guidance from expert, Boris Frank. Frank, who has served non-profit organizations in fundraising, grant writing, and establishing “best practices” for over twenty-five years, offered affiliate leaders solid advice on achieving sustainability for their affiliates in the current unstable financial climate.

Frank reminded affiliate leaders that sustainability must always be grounded in a solid strategic plan that evolves into a clear development plan. These plans are the “road map” to the future, keeping affiliates financially sound and able to fulfill NAMI’s important mission of education, advocacy and support for Wisconsin’s citizens affected by mental illness. A strategic plan will outline clear roles for everyone from the Board of Directors, officers and staff, to volunteers and will help establish the key to good fundraising—relationships.

While grants from foundations, corporations, and government sources are important, 75% of the funding for non-profit organizations is provided by individuals. Frank added, “Do not forget that the individual’s donation is a grant.” Many organizations are offering a monthly giving plan to their members and supporters, allowing individuals to donate more substantial amounts than they may feel able to give at one time. Vital to the success of non-profits is the establishment of visibility in the community and a solid base of “friends” that may be relied on for endorsements and consultation as well as for funds.

In the current financial climate, Frank emphasized the need to re-think approaches to fundraising. Every fund raising campaign and grant writing session should begin with the writing of an “elevator pitch.”

The proposed project or program can be “pitched” to potential funders in a clear, two minute presentation that includes the “nuts and bolts” of the project as well as a “wow

factor” to get the funder’s attention. Organizations should think about expanding their base to include young people, founders, past board members, and community leaders. Digitizing communications will save paper and offer opportunities for new memberships and donations through credit cards, electronic transfers and direct deposits. Planned giving and bequests are also viable avenues toward financial sustainability.

Affiliates seeking grant opportunities from corporations and foundations were directed to several good sources of information. Frank cited the UW-Madison Memorial Library Reference Collection as the number one source for grant information in the state of Wisconsin. Under the guidance of reference librarian, Nikki Busch, grant seekers will find a wealth of information by visiting the library or through the Grants Information Center Web site, <http://grants.library.wisc.edu>. Marquette University also has a Grants Information Center and related Web site. Another online source of grant information is the Foundation Finder at <http://Inp.fdncenter.org/finder>.

Once prospective funders are identified, being careful to select prospects whose goals and interests match those of the grantee, a triage list of prospects should be constructed focusing on those the research shows to be most likely to fund the project or program. According to Frank, the number one reason proposals are rejected is that the project goals do not match those of the prospect. When sending a proposal or one page “pre-proposal” to a prospect, be sure to concisely outline your organization’s background, mission and capabilities.



A prospect’s unfamiliarity with an organization is the number two reason proposals are rejected.

Frank led affiliate leaders through a working lunch giving them the opportunity to fill out the “Agency Assessment” tool, a guide to “Policies, Principles, Guidelines” and “Best Practices.” Frank reminded the group that the bottom line on fundraising for all non-profits is the establishment of a solid strategic plan, a marketing plan for community visibility, and a base of good relationships both inside and outside the membership. “People give money to people,” added Frank. “Never forget the importance of one-on-one contact and the equal importance of a prompt thank-you once funds have been received from a donor.” 🌿

# Eight candidates nominated for seats on the NAMI Wisconsin Board of Directors

A field of eight candidates is proposed to fill seats on the NAMI Wisconsin Board of Directors. The Board is comprised of at least twelve and not more than eighteen members, including the officers, the majority of which are consumers or family members of persons with mental illnesses.

Election of the NAMI Wisconsin Board of Directors is held at the Annual Meeting. The Annual Meeting will be held at the close of the first day of the NAMI Wisconsin annual conference, Friday, May 29, 2009.

This year's field of candidates includes current Board members as well as a number of candidates seeking a first term.

## **William R. Benedict**

William R. Benedict is a retired social worker who now advocates for campaign finance reform and state funding of stem cell research. He also does free lance writing as a citizen journalist. He presently serves on the Wisconsin Democracy Campaign and Wisconsin Coalition of Aging Groups boards. He would like to contribute his time and experience partly as payback to NAMI and the mental health community for the excellent services his family has and continues to receive, and to help NAMI Wisconsin continue as a leader in mental health advocacy and education.

## **Lindsey Fitzgerald**

Lindsey Fitzgerald is a consumer and is now in full recovery. She is currently a student at UW-Milwaukee with a major in theatre. She works at Charlotte Russe as a shoe specialist and at First Weber as a receptionist. She is a member of NAMI Waukesha and also a member of Clubhouse. Both NAMI and Clubhouse mean a great deal to Lindsey and she would like to do what she can to help these organizations.

## **Eric D. Garland**

Eric Garland is a survivor of a family suicide. His son, Brandon, died February 15, 2006. Since that time, Eric has been involved in many efforts supporting suicide awareness

and prevention. He is currently on the Board of Directors for H.O.P.E.S. (Helping Others Prevent and Educate about Suicide) and serves as fundraising coordinator and public relations consultant. He is a member of NAMI Dane County and is a member of the Dane County Task Force on Suicide. Eric also serves on the fundraising committee for NAMI Wisconsin. He is involved with SPAN USA (Suicide Prevention Action Network) and AFSP (American Foundation for Suicide Prevention). Eric was the recipient of the NAMI Wisconsin 2007 Wisconsin Community Education Award.

## **Geoff Greiveldinger**

Geoff Greiveldinger has served one term on the Board of Directors and currently serves as Co-President. From 1999 to 2003 he was Executive Director of NAMI Racine County. He is presently the Chief of Staff to the County Executive of Racine County. He is retired from the U.S. Navy. He and his wife, Peg, live in Racine. They have four children, one of whom is a consumer, and four grandchildren. He is an affiliate of NAMI-Racine.

## **Sandy Hall**

Sandy Hall holds a Master's Degree in Rehabilitation Counseling from the UW-Madison. She has worked at Goodwill Industries, DVR, UW Whitewater, and currently is the Director of Disability Resource Services at Madison Area Technical College. Her work has involved significant experience in supported and transition employment, and working with people with psychiatric disabilities. She has been on the NAMI Wisconsin Board of Directors for the past three years and is the current Secretary.

## **Sandy Pharis**


Sandy Pharis has been with NAMI Fox Valley for five years, four of those as a volunteer, and for the last 13 months she has been employed with the affiliate as the Project Coordinator. She is in charge of the Veterans project and is the Peer-to-Peer Coordinator. Sandy is responsible for Fox Valley being the

first affiliate in the nation to take Peer-to-Peer into a state mental hospital. She is a Peer-to-Peer mentor and state trainer, and a NAMI Connection facilitator and trainer. She was also the first to initiate a Veterans support group for NAMI in Wisconsin. She sits on the NAMI Wisconsin Consumer Council and the National Veterans Council. Sandy received the Volunteer of the Year Award from NAMI Fox Valley last year and received the Consumer Council Peer Award from NAMI Wisconsin last year.

## **Patti Jo Severson**

Patti Jo Severson is an affiliate of NAMI La Crosse and served on their board for five years (2001-2006). She is a Family-to-Family teacher and has been very involved as an advocate for individuals with mental illness. She is past member of the La Crosse County Criminal Justice Management Council, La Crosse County Mental Health and AODA Redesign Committee, and Domestic Violence Intervention Program. Patti Jo is currently a board member of The Mental Health Coalition of the Greater La Crosse Area. She is a registered dietitian and has a master's degree in Community Health Education. She previously served on the NAMI Wisconsin board from 2004-2006.

## **Terry Ryan**

Terry Ryan is currently on the NAMI Board of Directors. He is a consumer and a long-time advocate for consumers and mental health care. As a Board member, he has served on the education and public policy committees and currently chairs the fund raising committee. Terry also serves on the NAMI Wisconsin Consumer Council. 



**NAMI Wisconsin Annual Conference**  
**May 29-30, 2009**  
**Co-Hosted by NAMI Dane**

**Madison Marriott West**  
**1313 John Q Hammons Dr, Middleton WI 53562**

1-888-745-2032 for hotel room reservations only  
 (Ask for the "NAMI Wisconsin" rate – Deadline for special hotel rate is May 12, 2009)

**PLEASE SEND A SEPARATE REGISTRATION FORM FOR EACH PERSON REGISTERING.**

FIRST NAME \_\_\_\_\_ LAST NAME \_\_\_\_\_  
*(This is the name that will be printed on your name badge)*  
 STREET OR PO BOX \_\_\_\_\_  
 CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_  
 PHONE \_\_\_\_\_ / \_\_\_\_\_ LOCAL AFFILIATE \_\_\_\_\_

Do you require vegetarian meals? \_\_\_\_\_

Check the days you plan to attend (Required):

Thursday, May 28 - \*Optional    Friday, May 29    Saturday, May 30

**Members, Parents, & Caregivers**

Full Registration (2 days) -- \$115.00    -----    = \_\_\_\_\_  
 One Day Registration -- \$70.00    -----    = \_\_\_\_\_

**Professionals & Non-Members**

Full Registration (2 days) -- \$195.00    -----    = \_\_\_\_\_  
 One Day Registration -- \$105.00    -----    = \_\_\_\_\_

**Low Income**

Full Registration (2 days) -- \$65.00    -----    = \_\_\_\_\_  
 One Day Registration -- \$45.00    -----    = \_\_\_\_\_

**\*OPTIONAL: Consumer Leadership Summit – Thursday, May 28\***

Summit Registration -- \$15.00    -----    = \_\_\_\_\_  
 The Summit is from 6:30-9:00 pm. Registration includes dinner  
 and keynote speaker. Space is limited so register now.

Total = \_\_\_\_\_

**REGISTRATIONS WILL NOT BE PROCESSED WITHOUT PAYMENT:**

Enclosed is my check for \$ \_\_\_\_\_, payable to **NAMI Wisconsin**.  
 Enclosed is my donation of \$ \_\_\_\_\_ to the Consumer Scholarship Fund, payable to **NAMI Wisconsin**.  
 Please bill my credit card for \$ \_\_\_\_\_. Visa    MasterCard    Acct# \_\_\_\_\_  
 Exp. Date \_\_\_\_/\_\_\_\_    Signature: \_\_\_\_\_

**Conference Scholarships:** A limited number of scholarships will be available for consumers with a co-payment of \$10. Please call the NAMI Wisconsin office at 800-236-2988 **after March 13**, to receive information regarding the scholarship application process.

**Registration Deadline is Friday, May 22, 2009. No refunds after this date.**

**Mail this form with payment to:**  
 NAMI Wisconsin, Inc.  
 4233 W. Beltline Hwy  
 Madison WI 53711

**Or FAX it to:**  
 (608) 268-6004  
 (Payment by credit card  
 required for fax registrations)

DATE RCVD: _____
AMOUNT: _____
CHECK #: _____
DB ENTRY: _____

## IMPORTANT CONFERENCE INFORMATION

- The conference will be held on May 29-30, 2009 at the Madison Marriott West, 1313 John Q Hammons Dr., Middleton, WI.
- **Registration deadline is Friday, May 22.** No refunds will be made after this date. There will be a \$5 per day late registration fee.
- There will be no on-site registration.
- There will be a \$10 service fee for cancellations after May 22.
- For hotel reservations, please call the Madison Marriott West at 800-228-9290 or 608-831-2000 and ask for the NAMI Wisconsin Conference rate of \$99 per night for a single room and \$109 per night for double occupancy.
- The deadline for reserving your hotel room at the NAMI Wisconsin Conference rate is May 12, 2009.
- All rooms are non-smoking rooms. There are designated areas for smoking outside the hotel.
- A limited number of scholarships will be available with a co-payment of \$10.
- Please call the NAMI Wisconsin office at 800-236-2988 to receive information regarding the application process for scholarships.
- **Scholarship applications are due by April 24, 2009.**

## NAMI Wisconsin Annual Conference

Madison Marriott West  
1313 John Q. Hammons Dr.  
Middleton, WI 53562

### Driving Directions

Take Interstate 90/94 to Highway 12/18 West (Beltline Highway) exit 142A.

Travel 15 miles to Greenway Boulevard exit 252.

Turn left on Greenway Boulevard and left again onto John Q. Hammons Drive.



## NAMI Wisconsin Annual Conference Alternate Hotels

Country Inn & Suites by Carlson  
2212 Deming Way  
Middleton, WI 53562  
608-831-6970

Courtyard by Marriott West  
2266 Deming Way  
Middleton, WI 53562  
608-203-0100

Fairfield Inn by Marriott  
8212 Greenway Blvd.  
Middleton, WI 53562  
608-831-1400

Hilton Garden Inn West  
1801 Deming Way  
Middleton, WI 53562  
608-831-2220



4233 W. Beltline Hwy., Madison, WI 53711

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### Return Service Requested

## Help NAMI Wisconsin bring vital education programs to people affected by mental illness.



Yes, I want to support NAMI Wisconsin with the following gift:

\$100     \$75     \$50     \$35     Other \$ \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_

Please charge \$ \_\_\_\_\_ to my:     Visa     MasterCard

Acct# \_\_\_\_\_ Exp. Date \_\_\_\_\_ / \_\_\_\_\_

Signature \_\_\_\_\_

Is your donation being made in memory or in honor of someone special? If so, please complete the following:

In Memory of: \_\_\_\_\_

In Honor of: \_\_\_\_\_

I'd like more information about the following:     a local NAMI affiliate in my area     becoming a NAMI member

**Your gift to NAMI Wisconsin will change minds, raise voices, and help many individuals and families affected by mental illness.**

*"I received a scholarship for the conference in Racine. It was my first NAMI Conference or any NAMI related program. The conference was enlightening and inspiring. I hope to attend the next one."*

*"The Family-to-Family Education Course gave me the information and support I needed to not only better support my daughter, but to bring a more stress-free environment into our home."*

**Consider making a generous gift today.**