



The Official Newsletter of NAMI Illinois

Issue 1

September 2009

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Heroes in the Fight



Heroes in the Fight is a recognition partnership program that celebrates dignity, courage, hope, and recovery in the ongoing treatment of people with severe and persistent mental illness. Designed to recognize those who provide exemplary care and support for patients and their families, Heroes in the Fight has been established by Eli Lilly and Company and sponsored by Lilly USA, in partnership with local and national advocacy organizations.

Once again, NAMI Illinois will be the lead organization for Heroes in the Fight in Illinois. We will again be working with premier partner organizations that include:

- Community Behavioral Healthcare Association of Illinois
- Illinois Association of Rehabilitation Facilities
- Illinois Hospital Association
- Illinois Psychiatric Society
- Mental Health America of Illinois
- Mental Health Summit
- Sankofa Organization of Illinois, Inc, and
- Supportive Housing Providers Association.

Specific individuals who best exemplify ongoing care and dedication will be selected from nomination forms submitted by members within the mental health community, like you. Exemplary heroes will be selected within each of the following categories:

- Individual Psychiatrist
- Individual Allied Health Professionals (multiple awards)
- Individual Community Supporters (non-healthcare professionals; multiple awards)
- Individual Media Professionals (journalist, reporter, etc.)
- Treatment Team (broad category from a small group to an entire facility)

Each nominee will be recognized with a congratulatory letter and an invitation to an upcoming recognition luncheon to take place on November 9, 2009. A selection committee will select exemplary "heroes" to be recognized during the event.

To submit a nomination, go to www.heroesinthefight.org and click on the "Nominate a Hero" link. Nominations must include all of the basic information on the nominator and person nominated including a short essay that describes the ongoing heroic efforts of the nominee within the community to help persons with severe and persistent mental illness, as well as their families and caregivers, fight for the best possible mental health and quality of life. Incomplete forms will not be accepted.

Nominations can be filled out online or you may print the form and mail it to:

Heroes in the Fight
c/o VMS
8425 Woodfield Crossing Blvd., Suite 370
Indianapolis, IN 46240

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Proud Member of



Major NIMH Research Project to Test Approaches to Altering the Course of Schizophrenia

The National Institute of Mental Health (NIMH) is launching a large-scale research project to explore whether using early and aggressive treatment, individually targeted and integrating a variety of different therapeutic approaches, will reduce the symptoms and prevent the gradual deterioration of functioning that is characteristic of chronic schizophrenia.

The Recovery After an Initial Schizophrenia Episode (RAISE) project is being funded by NIMH with additional support from the American Recovery and Reinvestment Act (ARRA). RAISE is a model example of how money from the Recovery Act can accelerate science related to public health problems and potentially benefit those citizens most in need.

"This new initiative will help us determine whether intervention that is started early, incorporates diverse treatment and rehabilitation approaches, and is sustained over time, can make it possible for more people with schizophrenia to return successfully to work and school," said NIMH Director Thomas R. Insel, M.D. "Moreover, the interventions being tested will be designed from the outset to be readily adopted in real-world health care settings and quickly put into practice."

Despite the availability of moderately effective treatments, such as antipsychotic medications and various psychosocial interventions, people with schizophrenia often do not receive treatment until the disease is already well-established, with recurrent episodes of psychosis, resulting in costly multiple hospitalizations and disabilities that can last for decades. Periods of unemployment, homelessness, and incarceration are common, making schizophrenia a costly disease for individuals, their families, and the community at large.

RAISE will test approaches that involve intervening immediately upon first diagnosis, systematically incorporating the range of options that are now available in a more piecemeal fashion to people with schizophrenia. These options include medications, psychosocial treatments, and rehabilitation, including teaching patients and families how to manage the disease. The hope is that such a coordinated approach tailored to each individual and sustained over time may make lasting differences in the acceptability of treatment and overall function.

Agencies and organizations that play a role in providing health care and other services to people with schizophrenia will have an opportunity to participate in the design of the interventions to be evaluated by RAISE. Federal organizations, including the Substance Abuse and Mental Health Services Administration, the Social Security Administration, the Centers for Medicare and Medicaid Services, the Department of Veterans Affairs, the Walter Reed Army Medical Center, and the National Institute on Drug Abuse, will be involved along with mental health care consumers and family members, private health care providers, additional scientific experts, and state and local agencies. Other agencies may become involved as the project proceeds. Involving these stakeholders will help ensure that, if successful, this evidence-based approach can be disseminated and adopted rapidly, thus significantly speeding the transition between research findings and their use in real-world practice.

Two research groups will work in parallel to develop and test potential intervention approaches. One group will be led by John M. Kane, M.D., of The Zucker Hillside Hospital and the Feinstein Institute for Medical Research, Manhasset, N.Y. The second group will be led by Jeffrey Lieberman, M.D., of the Research Foundation for Mental Hygiene, Inc. at the New York State Psychiatric Institute and Columbia University, New York City. The research teams feature national and international collaborations, with treatment to be delivered in up to 30 clinical sites across the United States.

Recovery Act funds will underwrite the initial two phases of the trial, during which the investigators will refine the interventions with input from stakeholders and conduct a feasibility study to demonstrate that each intervention can be fielded in real world community treatment settings and be evaluated in a randomized clinical trial design. With long-term funds committed by NIMH to complete these phases plus a full-scale clinical trial, funding for the study is \$40 million.

"Depending on the study's outcome, RAISE could help set the stage for a paradigm shift in the way schizophrenia is treated in the United States. The ultimate goal of the initiative is to eliminate the chronic form of schizophrenia that is so costly and devastating to the individual, family members, and society as a whole," said Robert Heinssen, Ph.D., acting director of the NIMH Division of Services and Intervention Research and project officer for RAISE. "This Recovery Act-supported project will hire and help train many mental health researchers and care providers for a project that is likely to help some of our most vulnerable citizens lead more productive and satisfying lives."

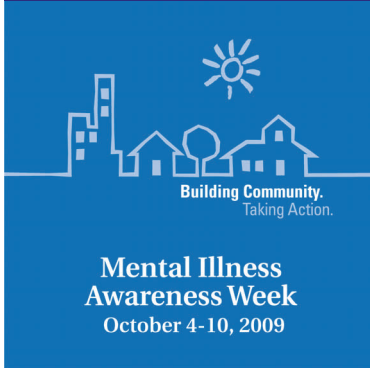
NIMH is using Recovery Act funds to carry out objectives identified in its Strategic Plan. Among these objectives is to develop new and better interventions that incorporate the diverse needs and circumstances of people with mental illnesses and to strengthen the public health impact of NIMH-supported research.

The mission of the NIMH is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery and cure. For more information, visit www.nimh.nih.gov.

The National Institutes of Health (NIH) -- The Nation's Medical Research Agency -- includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

CONTACT: Charlotte Armstrong, NIMH Press Office, 301-443-4536, e-mail: NIMHpress@nih.gov.

**Mental Illness Awareness Week
October 4-10, 2009**



In 1990, the U.S. Congress established the first week of October as "Mental Illness Awareness Week" (MIAW) in recognition of NAMI's efforts to raise mental illness awareness. Since 1990, mental health advocates across the country have joined together during the first week of October to celebrate.

What will you be doing in your community on MIAW? Send us an email and let us know– we'll help promote it on a special affiliate sharing page!

Here are some ideas: display NAMI posters, hand out NAMI brochures, hold a candlelight vigil, co-host a mental health screening, donate books to your local library or school on mental illness, participate in a walk, etc.

Looking for more ideas on how to celebrate MIAW? Go to www.nami.org.

NAMI Illinois Announces its New 2009-2010 Board of Directors

Verla Demopoulos, President
NAMI Kankakee Co.

Hugh Brady, Vice President
NAMI Barrington Area

Cindy Janicak, Secretary
NAMI Greater Chicago

John Mayes, Treasurer
*NAMI Metro Suburban
NAMI Greater Chicago*

Linda Virgil, At Large
NAMI Decatur

Mary Rottmann, At Large
NAMI Madison County

Carolyn Jakopin, Imm. Past President
NAMI Tri-County

Carl Alaimo, Sr.
NAMI Greater Chicago

Brian Allen
NAMI Springfield

Mike Geiger
NAMI Springfield

Shirley Helm
NAMI Greater Chicago

Debra Howard-Frye
NAMI South Suburbs

Judy Kruger
*NAMI Metropolis/Southernmost
Illinois*

Virginia Lake
NAMI Kankakee Co.

Dan Martin
NAMI Southeastern IL

Laurie Perry
NAMI Will Co.

Keith Stone
NAMI Tri-County

Sylvia Westbrook
NAMI South Suburbs

Congratulations to our new executive committee! We sincerely thank those members who have retired from the Board this year for their dedication and exemplary service: James Doyle, Margaret Elmer, Greg Coughlin and Bill Meade; your contributions are greatly appreciated!

New Public Act 096-0181: Health Benefits for Workers with Disabilities

Assuring All Workers with Disabilities Continue to Have Access to Affordable Health Care

Health Benefits for Workers with Disabilities (HBWD) is a program that allows individuals with disabilities who work to purchase Medicaid coverage. This Program is mostly utilized by individuals who receive or received Social Security Disability Insurance and return to work. It allows them to afford Medicaid without a large spend-down and receive "extra help" in paying for Medicare Part D prescription drugs.

By law, enrollees in this Program are subjected to Continuing Disability Reviews. While very rare, some individuals are found to be medically improved through these reviews. When this happens, the individual loses eligibility for cash benefits for Social Security, Medicare, Medicaid and Health Benefits for Workers with Disabilities (HBWD), if applicable. However, federal law does allow Medicaid Buy-In Programs such as HBWD to continue to cover these individuals under a category called "medical improvement."

When an enrollee is found to be medically improved, the resulting loss of medical benefit is devastating. These individuals have successfully made the transition back into the workforce and are using HBWD to obtain needed medications and healthcare to maintain that job. Then, after this Review and an unfavorable decision, they lose access to the very healthcare that made the work transition possible. This can easily lead to lose of the job and a worsening of their medical condition just at a time when they are transitioning back to being active members of their community.

Public Act 096-0181 assures that all individuals with disabilities who have successfully transitioned to employment can maintain eligibility to HBWD and its needed healthcare. Adding this category of coverage to Medicaid costs very little as only a small number of working individuals are ever found medically improved each year. Providing these individuals with continuing access to healthcare does allow them to continue working, paying taxes to the state, and feeling empowered and productive.

The President's Corner—Verla Demopoulos From the Executive Director – Lora Thomas

Donations were received in Memory Of and/or In Honor

Of
 William D. Belter
 Linda Benson
 Keith Carlen
 Brice Clendinging
 Margaret Cook
 William Csakai
 Erin Doyle
 Mike Garvey
 Timothy Guffey
 William Lampi
 Joanna Lowry
 Rick Luczak
 Edward McCann
 Jim McIndoe
 Melinie McLaughlin
 Nancy Powers
 Dorothy Rowley
 Raymond Smith

Partners

Adapt of Illinois
 Chestnut Health Systems
 Community Behavioral Health Association
 Community Counseling Centers of Chicago
 Heartland Health Outreach
 Heritage Behavioral Health Center
 Janet Wattles Center
 Pioneer Center for Human Services
 Sertoma Centre, Inc.
 Southern Illinois Regional Social Services, Inc.
 Victor C. Neumann Association

Colleagues

Association for Individual Development
 Call for Help, Inc.
 Community Counseling Center Pillars
 Sinnissippi Centers, Inc.
 Turning Point Behavioral Health Care Center

We're pooling resources – and columns – today to emphasize a couple of very timely issues! Heroes In the Fight is a program NAMI Illinois has taken the lead – and worked with other statewide partners - over the past several years! It's featured today on page 1 of this issue of Stateline. What you haven't heard is that this is the last year that the Heroes In the Fight program will be sponsored by Eli Lilly and Company. It's been a phenomenal program that has recognized heroes in a field where it's not common to think of the word "hero" – yet what is more heroic work than easing the lives of others?

Think back to the tag line: ***The fight against mental illness is waged in countless ways by countless heroes.*** From the mother fighting to reclaim her son, to the social worker looking for clients lost to the streets, to the policeman who knows when someone needs medical help, not prison time—these are the souls who make a difference. By making one life better. One family stronger. One burden lighter. And by giving us one more reason to believe in heroes again.

Each one of us knows heroes! Please take a moment and nominate those you know today. Know that a nomination alone is priceless – it's a public reflection that they have made a difference in someone's life! Nominate them at: www.heroesinthefight.com – **nominations close on October 12th!**

Next – we want to share extraordinary work that is being done throughout Illinois by local affiliates – so we've come up with a new feature on NAMI Illinois' web site called: Affiliate Offerings! You can navigate to the section from the link on our home page - NEW-Affiliate Offerings. Look for programs, products, ideas and other information and be sure to let us know when you wish to have something posted! All too often it's only by accident that we hear of great things... this will certainly be a rich resource for all NAMI members, so check it out!

In addition, we want to encourage you to consider three educational opportunities that are mission driven to NAMI education, outreach and advocacy. NAMI Illinois' 2009 Educational Conference is a rich resource for everyone. This year's speakers are exceptional; the range and variety of topics is unparalleled; there is truly something for everyone! Please join us for renewal, energy and a new commitment to the challenges before us.

We would like to highlight two of the intensive skill building workshops scheduled for Sunday, October 18th. Both workshops are guaranteed to build your skills and strengthen you and your affiliate through outreach and advocacy.

NAMI Illinois' Hospital Guides are not a new resource, but only a handful of affiliates have learned to use them effectively in their local communities. For those who have seen the Guide, you know it's an invaluable resource for family members of individuals who have been hospitalized. Sunday's skill-building session will feature successful partnerships that have been built with that resource as a cornerstone – but more importantly - it is designed to help you develop your own affiliate step-by-step plan to effectively incorporate it into your own community outreach endeavors. Most families who have been with NAMI for a while only WISHED they had had this tool available when they needed it. Let's reach out and help more families out. If we mentor them along through more effective outreach, everyone wins; stigma doesn't stand a chance!

Last, but certainly not least important – we're going to focus on advocacy! We encourage you to sign up for NAMI Smarts for Advocacy: Telling Your Story. Last year one of our most repeated requests was: advocacy, advocacy and advocacy... and we'll bet dimes to donuts that we're not done with that refrain! Let's face it... we HAVE to tell our stories! The squeaky wheel gets the grease, and it will soon be time for us to start squeaking again! And since we HAVE to speak... let's be good! Let's be credible! Let's be articulate! And let's have fun doing it! The very best way for you to be good, credible, articulate and have fun is by investing a few hours in NAMI Smarts for Advocacy: Telling Your Story. Hugh and Linda, the session's leaders will help you develop that story, practice telling it and you will leave with a set of tools that empower and prepare you for truly effective advocacy!

We hope to see you there!
 Verla & Lora

NAMI Illinois Affiliates

- NAMI Barrington Area
- NAMI Champaign
- NAMI Cook County North Suburban
- NAMI DeKalb, Kane South, & Kendall Counties
- NAMI of DuPage County
- NAMI East St. Louis
- NAMI Elk Grove/Schaumburg
- NAMI Greater Chicago
- NAMI Greater Decatur
- NAMI Grundy County
- NAMI Hanover Township
- NAMI Jackson County
- NAMI Kane County
- NAMI Kankakee County
- NAMI Lake County
- NAMI Livingston/McLean Counties
- NAMI Macomb West Central IL
- NAMI Madison County
- NAMI McHenry County
- NAMI Metro Suburban
- NAMI Metropolitan/Southernmost IL
- NAMI Morgan/Scott Counties
- NAMI Mt. Vernon
- NAMI Northern IL
- NAMI North Central IL
- NAMI Northwestern Memorial
- NAMI Northwest Suburban
- NAMI Quincy
- NAMI Rock Island/Mercer Counties
- NAMI Sauk Valley
- NAMI Southeastern IL
- NAMI South Suburbs of Chicago
- NAMI Southwest
- NAMI Springfield
- NAMI Stark County
- NAMI Tri County
- NAMI UIUC
- NAMI Vermilion County
- NAMI Will County

Parental Rights of People with Mental Illness

By Barry C. Taylor, Legal Advocacy Director at Equip for Equality

Historically, people with mental illnesses have faced enormous societal biases concerning their fitness to maintain parental relationships. Persons with mental illness continue to lose their children under circumstances that would rarely result in termination of parental rights for parents without disabilities. This is for at least two reasons. First, the prejudices and stereotypes of society about persons with mental illness are frequently reflected in the opinions of professionals and judges in the child welfare system. Second, parents with mental illness often lose their children because they are denied reunification services based on incorrect presumptions that they are incapable of learning to parent. The damaging effects of such biases extend not only to parents with mental illness, but also to the children who are unfairly and unnecessarily separated from loving parents, and whose families are frequently destroyed as a result.

Equip for Equality receives many calls from people who are facing restrictions on their parental rights because of their mental illness. In many cases, judges make stereotypical assumptions that a person is unable to care for a child because of a mental illness diagnosis or believes that a person with a mental illness poses a danger to the health or safety of the child.

Recently, Equip for Equality and the Bazelon Center for Mental Health Law filed an *amicus* (friend of the court) brief with the Illinois Appellate Court in Chicago. The case was brought by the Family Defense Center on behalf of a mother with bipolar disorder and a post-partum depressive episode who had thoughts of harming her child, but she did not actually harm the child. (Pursuant to doctor's orders, the mother had stopped taking her medication during pregnancy.) Following the episode, the mother immediately sought treatment, but her child was removed from her care. Thereafter, the mother resumed her medication, and despite being medication compliant for ten months and overwhelming favorable testimony as to the mother's current mental state and her ability to parent, her child was not returned to her. We are hopeful that the appellate court will issue a decision that rebuts the pervasive stereotypes that many people have about the ability of people with mental illness to parent.

For more information about this case, parental rights generally, or other disability legal issues, contact Equip for Equality at: 800-537-2632 (v), 800-610-2779 (tty), or www.equipforequality.org.

Awakenings Art Show and Exhibits at the 2009 Conference



Be sure to check out the amazing exhibits and the Awakenings Art Show at the 2009 NAMI Illinois Conference held at the Westin Chicago Northwest in Itasca, IL! A reception will be held in honor of the Awakenings Project artists on Friday October 16th from 5:30-6:30pm.



2009 NAMI Illinois Conference Hotel Change

UPDATE: The 2009 NAMI Illinois conference hotel location has changed. We will no longer be at the Hilton in Lisle, IL. The new hotel is the WESTIN CHICAGO NORTHWEST in Itasca, IL. Please call the hotel at 630-773-4000 to make your room reservations.

2009 NAMI Illinois Conference Enhanced Educational Sunday

NAMI Illinois is offering you the opportunity to attend one of three skill building workshops immediately following the educational conference Sunday, October 18. These skill building workshops are not covered in your conference registration fee; an additional registration is required.

- NAMI Smarts for Advocacy Training
 - NAMI Hospital Guide
- Parents and Teachers as Allies Training

NAMI Smarts for Advocacy: Telling Your Story

There's never been a more critical time – or need – for great mental health advocates! Those who effectively make their voices heard this year will be in a much better position to influence state and national initiatives! Health care reform is at the heart of the national dialogue and debate – and you know the state of the state from this year's budget address!

Join us to become better advocates – to hone our messages and to make sure that we can collectively work together to make a difference and avoid dramatic cuts to community based programs we need!

NAMI Illinois Hospital Guide: What Families Need to Know About Mental Health Treatment

NAMI Illinois' Hospital Guide is a valuable tool created to assist families of persons with mental illness with their treatment. This guide helps family members become the most informed and understanding member of their loved one's recovery team.

NAMI Illinois' goal is to distribute this guide to all Illinois hospitals, reaching out to families to assist in their navigation of the journey of treatment and recovery.

In this session we will share with you successful endeavors in distributing this important guide, and work to develop other ideas.

Parents and Teachers as Allies

Parents and Teachers as Allies is a NAMI signature program designed to help teachers understand the early warning signs of mental illnesses and to help the child and family link to appropriate services. It is a wonderful presentation to bring into your local school system to help all school personnel!

Parents and Teachers as Allies is a two-hour in-service program focusing on helping school professionals and families within the school community better understand the early warning signs of mental illnesses in children and adolescents and how best to intervene so that youth with mental health treatment needs are linked with services. It also covers the lived experience of mental illnesses and how schools can best communicate with families about mental health related concerns.

This program responds to the recommendations included in Goal 4 of President Bush's New Freedom Commission report on mental health that calls for schools to play a larger role in the early identification of mental health treatment needs in children and in linking them to appropriate services. Our program is based on NAMI's highly successful Parents and Teachers as Allies (P&TA) publication. **This training is filled.**

For more information and registration forms, go to <http://il.nami.org/conference>.

Go Direct Program

Go Direct is sponsored by the U.S. Department of Treasury and the Federal Reserve Banks to educate and encourage people who receive government benefits to switch to direct deposit.

Go Direct feels that deposit is simply the best way for people to get their Social Security, SSI and VA Compensation and Pension payments because it eliminates the risk of stolen checks, reduces fraud and gives individuals more control over their money. Plus, direct deposit allows immediate access to funds from virtually anywhere.

A simple action like enrolling in direct deposit can offer much-needed peace of mind to seniors and people with disabilities who rely on federal benefits.

In addition, there is a long term projection: direct deposit saves taxpayers money. If everyone who currently gets a federal benefit check switched to direct deposit, it would save taxpayers millions of dollars annually. Money saved as a result of *Go Direct* will be used to cover the costs of future Social Security payments -- a benefit to all Americans for generations to come. This is especially relevant today, given that the first wave of baby boomers has started reaching retirement age.

The campaign makes it easy for people to sign up for direct deposit -- they can call the *Go Direct* helpline at (800) 333-1795, visit www.GoDirect.org to sign up online or stop in their local financial institution or Social Security Administration office to make the switch.

Don't have a bank account? *Go Direct* also offers the **Direct Express® Debit MasterCard®** – a prepaid debit card that offers another safe and convenient alternative to paper checks for Social Security and SSI payments. To sign up for the Direct Express ® card, please contact their enrollment center between the hours of 7:00AM to 11:00PM at 1-877-212-9991 or visit their website at <http://www.usdirectexpress.com/edcfdtclient/index.html>.

A “Greener” NAMI Illinois

In an effort to think green– environmentally and from a budget perspective– we are moving towards electronic communication. Don't miss out– please provide your email address:

Please print clearly: _____

NAMI Illinois communications you can receive via e-mail: please check all that you would like to receive:

- Legislative Updates/ Action Alerts
- Stateline– Quarterly Newsletter
- General E-mail announcements
- Notices about NAMI Illinois workshops and educational opportunities

Please provide your name and address to help us keep our records up-to-date:

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____

ZIP: _____

If you did not receive this newsletter directly from NAMI Illinois please complete and mail to:

NAMI Illinois 218 West Lawrence Ave. Springfield, IL 62704