



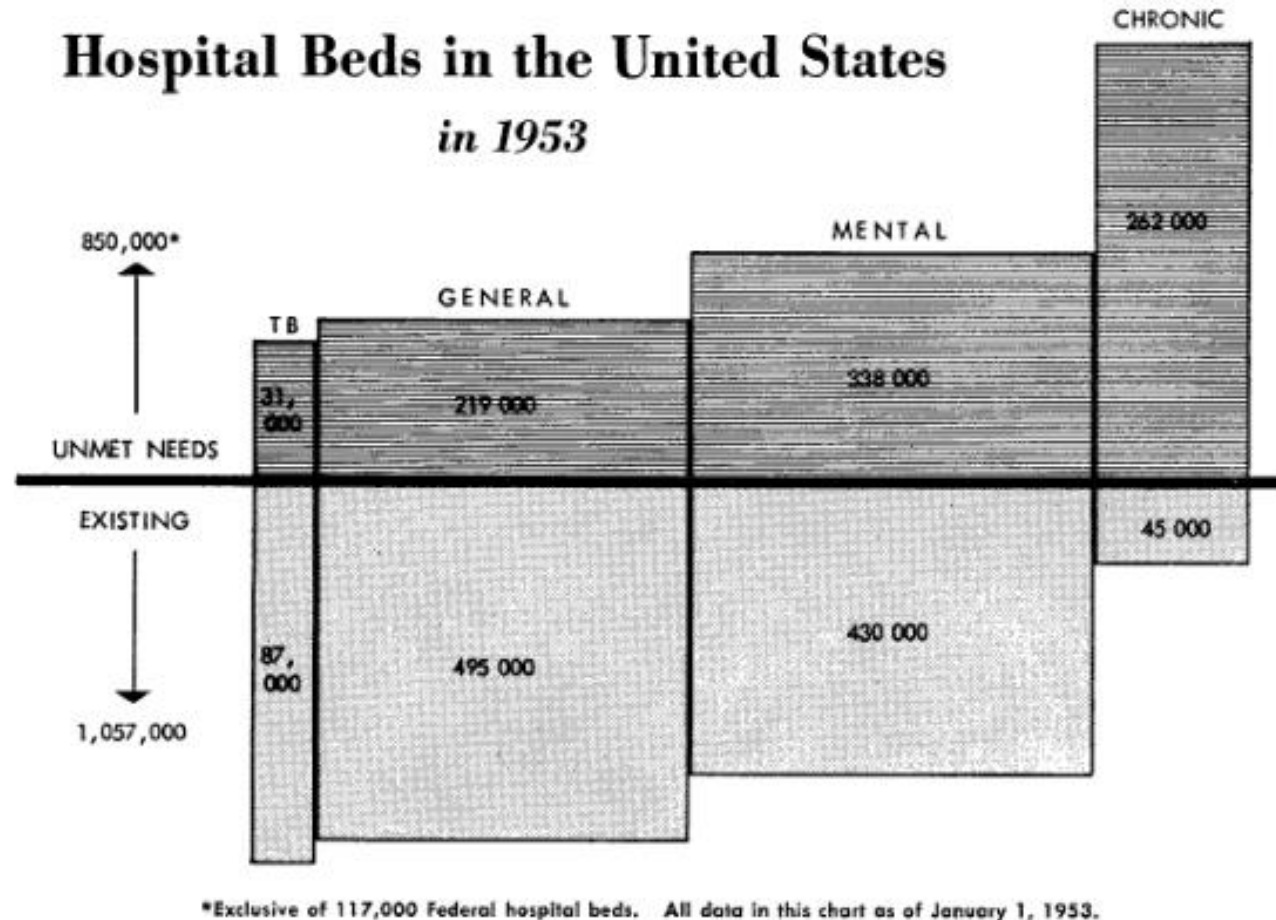
The History of NAMI in Illinois - The Family Movement



Mary Gilbert, CEO of the National Alliance for the Mentally Ill (left) and Vi Orr, a founder of NAMI-IL National Alliance for the Mentally Ill IL.

Created by John Fallon – NAMI Illinois Board Member

In the 1950's, people with mental illness and other diseases went away to specialized Sanitariums away from the local communities.



The State of Illinois had 33,000 State Psychiatric Beds in the 1950's.

The State of Illinois today (Feb 2024) now has 1,200 beds in 7 facilities:

Madden, Chicago-Read, Elgin, McFarland, Chester, Alton, and Choate.

Most state beds are now used for forensic patients (400 NGRI and 340 UST). Only 400 people are in state civil beds.

Private psychiatric beds have not increased and have very short stays. Treatment is now community based.

1. <https://www.jstor.org/stable/4588438> -National Number
2. <https://mentalhealthsummit.wordpress.com/summit-policy-positions/medicaid-medication-access/> - Illinois Numbers

History of NAMI in Illinois – Mental Health

In the 1960's much of psychiatry attributed mental illness to be caused by defects in the way a child was raised. Parents were to be blamed and professional doctors knew best.

People were whisked to sanitariums far out in the country. **This was the period of Institutionalism.**

In the 1960- 1970's, Thorazine allowed thousands of people to manage their voices and people began to return to the community. **This was the period of shrinking institutions and creating community group congregate spaces.** (intermediate care facilities and group homes)

We began to understand mental illness as a biologically based illness for which medication could control symptoms. The illness struck only some members of a family and so the birth of the biologic model was developed.

There was little to no utility to blaming a family. Only advantage was to help the family unit to manage the symptoms. Mental illness was recognized as a lifetime illness to be managed and medication was acknowledged as nothing to be ashamed of.

NAMI began with a strong emphasis on educating the individual, family, and community about the effectiveness of psychiatric advances in allowing people to live normal lives. There were side-effects but aberrant behaviors could and would be controlled in community settings.

History of NAMI – Individual Family Groups

1. In the 1940's, concerned parents from the Brooklyn State Hospital began to meet in the apartment of Max Schneiner and formed the nucleus of a group later named the New York Federation of Parents Organization.
2. By 1979, there were lots of mental health family support, education and advocacy groups forming all across the country.
3. The first official **AMI Group** was in Madison WI in 1977. **AMI** was French for friend and they would be advocating for persons with mental illness.
4. In May of 1979 in Highland Park, Illinois, the **Society of Schizophrenia and Related Illnesses (SSRI)** change their name to **AMI-Illinois**. (led by Vi Orr) This was the first use of the AMI name in Illinois.
5. Studies showed hundreds of these groups and 59 attended the first convention from 29 states.
6. NAMI was founded in 1979 in Madison, Wisconsin, by [Harriet Shetler](#) and Beverly Young as a national coalition of these family organizations. The two women both had sons diagnosed with [schizophrenia](#),^[9] and "**were tired of being blamed for their sons' mental illness**".^[10] Unhappy with the lack of services available and the treatment of those living with mental illness, the women sought out others with similar concerns. The first meeting held to address these issues in mental health led to the formation of the National Alliance for the Mentally Ill^{[11][12]} in 1979. In 1997, the legal name was changed to the acronym NAMI by a vote of the membership due to concerns that the name National Alliance for the Mentally Ill did not use [person-first language](#). In 2005, the meaning of NAMI was changed to the [backronym](#) National Alliance on Mental Illness.^[13]
7. NAMI was almost headquartered in Chicago before the national convention elected to locate in Washington DC.



The Original NAMI Founders – Madison, WI



NAMI was formed in 1977, when Harriet Shetler and Beverly Young, two mothers, each with a son with schizophrenia, met over lunch to discuss the similar challenges they shared raising a child with a serious mental illness. At a second lunch, the women, both active in civic and charitable activities, decided to assemble people with similar concerns.

In April 1977, about 13 people met at a nightclub in **Madison, Wisconsin**. Mrs. Shetler suggested a name, Alliance for the Mentally Ill, partly because its acronym, AMI, meant “friend” in French. Within six months, 75 people had joined.

NAMI Families Informed National Public Policy from Its Very First Meeting



<https://www.youtube.com/watch?v=RNUeCEPryos>

NAMI Mourns Passing Of One Of Its Founding Members, Eleanor Owen

2/7/2022

NAMI was saddened to hear of the passing of Eleanor Owen, 101, an influential founding member of NAMI whose journey as an advocate began when her son was diagnosed with schizophrenia.

Her advocacy for her son grew into a loving, powerful movement of families. She established the **Washington Advocates for the Mentally Ill (WAMI) in 1978** and was one of the founding members of NAMI the following year. Eleanor dedicated her long life to uplifting the voices of individuals and families affected by mental illness.

History of NAMI– Individual Family Groups - An Example

Family groups in many communities since the 1950's helped to build our current mental health system with research, advocacy, and community education.



In 1953, the **Lake County Mental Health Society** was formed at the urging of the Lake County Council on Churches. There were no mental health services in far northern Chicago exurbs of Lake County.

This group eventually established and later managed the first Community Mental Health Counseling agency in Waukegan for Lake County with an assist from families in Rockford who already had a community Mental Health Center.

This is the Jane Dowst Lake County Hospital (1934 – 1964). As it was closing, the Society petitioned the City of Waukegan to create the counseling center inside a portion of that building. They used surveys to establish the need for MH services.

In 1967, St Therese added a 30-unit psychiatric bed facility to the hospital, progressive for the time.

The Counseling Center would become the County's **Lake County Behavioral Health Department** of today!

Paul Kaiser, President of the Lake County Mental Health Society, was one of the original 28 people agreeing to form a statewide Alliance of AMI in Illinois. This was a piece of history by NAMI Lake County discovered during this 40th Year NAMI IL Celebration.

- *Picture – Credit Waukegan News Sun – March 4, 1950*
- *Info from Waukegan – by the League of Women's Voters - 1967*

Waukegan's Municipally-Owned Emergency Hospital



Waukegan's Jane Dowst Emergency hospital, shown above, was deeded to the city by the Dowst family, early Waukegan residents, in 1931, along with a trust fund of about \$63,000 for the operation of the institution. Staff-

Waukegan News-Sun photo
ed by three nurses, the hospital is available for emergency treatment of accident victims in Waukegan. The hospital, originally the Dowst family home, was remodeled and equipped by the city at a cost of about \$15,000.



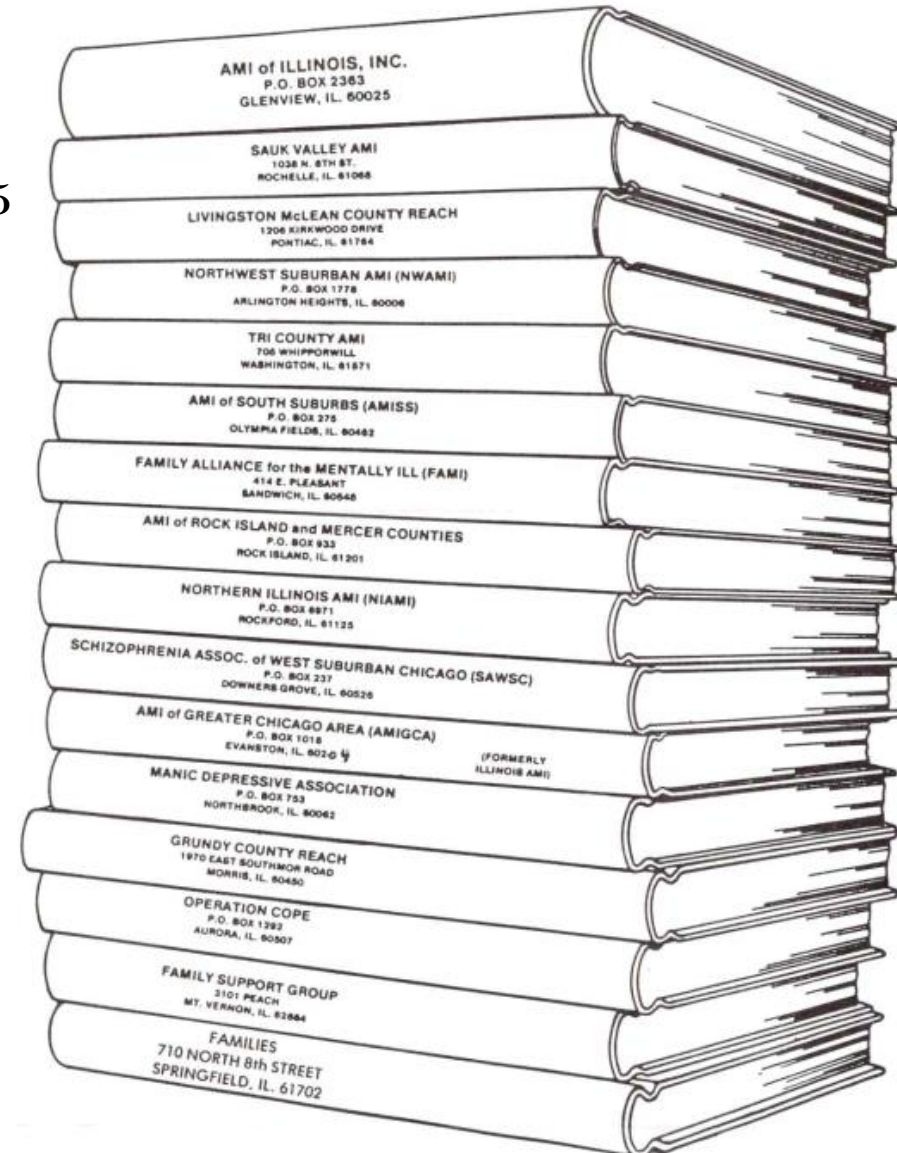
History of NAMI Affiliates in Illinois –
Early Individual Family Groups Joining the AMI Illinois State Coalition
(the date is earliest reference found)

1. Lake County Mental Health Society – Waukegan / Libertyville – 1966 – AMI member 1984
2. The Schizophrenia Association of West Suburban Chicago – Downers Grove - 1976
3. SFI – Schizophrenia Foundation of IL – Highland Park - 1976
4. SSRI- Society of Schizophrenia and Related Illnesses – Highland Park - 1976
5. NASS – North Area Schizophrenia Society 1976
6. Livingston – McLean Reach – Pontiac – 1983 (Frank Plesko – First Treasurer of NAMI IL)
7. Tri-County – Peoria - 1983
8. FAMI - Family Alliance for the Mentally Ill – Sandwich – 1983 (Later Sandwich / Dekalb AMI – Bob Dell First NAMI IL VP)
9. Operation COPE – Aurora
10. Manic Depressive Association - Northbrook 1983
11. Sauk Area AMI – (Sinnissippi Mental Health – Sterling, Dixon, & Rochelle) - 1981
12. NWAMI - NW Suburban AMI – 1983 (Arlington Heights)
13. Rock Island / Mercer AMI – 1983 (Frank Ware – First ED of this affiliate)
 - A. Had AMI Restaurant & Home in 1984
14. AMISS – AMI of South Suburbs – Olympia – 1983
15. Northern IL AMI – Rockford – 1984
16. AMI Greater Chicago – Evanston – 1984
17. Grundy City Reach - Morris – 1984
18. Mt Vernon Family Support Group - 1984



History of NAMI in Illinois – Individual Family Groups before Affiliation with AMI (the date is earliest reference I found)

- 19. Southern Illinois AMI – Belleville – 1984
- 20. Supportive Families of the Mentally Ill – Champaign – 1983
- 21. Vermillion Mental Health and Developmental Center– Danville– 1985
- 22. AMI of Effingham – Effingham – 1985
- 23. AMI of Dupage County – Claredon Hills – 1985
- 24. Northern Madison County / Parent Support Group – Alton – 1986
- 25. AMI of Madison County – Edwardsville – 1986
- 26. Southwest Alliance for the Mentally Ill– Hometown, IL – 1986
- 27. AMI of Jacksonville – Jacksonville – 1986
- 28. AMI of Kankakee – Kankakee – 1986
- 29. Families on Focus – Springfield - 1986



At left, the first AMI-Illinois logo

At right, the 1986 graphic of the State Coalition members.

History of NAMI in Illinois

There are 2 women who deserve credit for founding the AMI and NAMI movement in Illinois

1. **Vi Orr** utilized the AMI name first. She was instrumental in the AMI movement **across Illinois**.
 - A. The **Society of Schizophrenia and Related Illnesses (SSRI) of Highland Park** changed their name to **AMI-Illinois**. (led by Vi Orr) This was the first use of the AMI name in Illinois. (over 150 members)
 - B. Vi Orr proposed a merger of **AMI-Illinois and VOICES** of Chicago led by Shirley Starr. The combined organization would be called **AMI-VOICES**
 - C. Following the merger, VI Orr set about creating a statewide Alliance of organizations. She would leave the Board of AMI-Voices to form what is now NAMI Illinois, initially in her home in Glenview.

2. **Shirley Starr** led the Chicago VOICES Group and was instrumental in **NAMI at the National Level**. Shirley led the newly merged **AMI-VOICES** which became **NAMI Greater Chicago**.
 - A. Shirley Starr was the Board President of **VOICES (Voices of Interested Citizens for Emotional Stability)** in Chicago. Based in Chicago, they were formed by 5 couples and were intimately involved with Thresholds and its ED, Jerry Dincin who ran a support group for persons with mental illness at the time and promoted the family movement.
 - B. Shirley was named the Treasurer after the first National NAMI convention. Oct 1979
 - C. Shirley was chair at the Bismark Hotel in Chicago for the second national conference
 - D. Shirley Starr pushed to have the NAMI offices in Washington DC and not Chicago (her home) and rented a studio apt in DC to start NAMI National's first office in the basement of the National Society on Autism.

History of NAMI in Illinois – The History of NAMI State Organizations

In 1977, seven family groups formed the first state association in California (the California Association). They had their first State conference in 1978.

In 1983, there were 7 state NAMI organization; California, Wisconsin, Colorado, Ohio, Massachusetts, New York, and Maryland.

NAMI Illinois was formed in 1984 and eventually was based in Springfield (after multiple years in Glenview). NAMI Illinois relocated to Chicago in 2019 after losing its entire paid staff due to budget cuts.

NAMI Illinois in Springfield was really important to Central & Southern Illinois. In 2018, due to budget, cuts the office moved back to Chicago as the State Board tried to staff an office with volunteer staff.

NAMI in Illinois was often divided by I-80, because of the two separate media markets and the perceptions within the state of Chicago being the Center of the State. This always creates statewide tension.

NAMI Greater Chicago, like many states, had a larger media presence and is often seen as the Statewide representative for NAMI. It created tension and resentment when it excluded other parts of the state. Other affiliates were created around Chicagoland area to represent other parts of the Metro area including:

1. NAMI Dupage (the Republican Stronghold)
2. NAMI Cook County Suburban to try and recognize other parts of Cook County

Eventually, NAMI Greater Chicago becomes NAMI Chicago. It remains a huge presence in NAMI in Illinois and has great contacts within the largest media market. NAMI Illinois, when strong, speaks with a voice reflecting all of the affiliates.

NAMI at the national level, because of its membership structure often ends up pitting affiliates against the state and national organization.

This remains an issue today.

History of NAMI in Illinois

NAMI is at its best when the organization has all three levels working well.

1. National – National Policy and Research creates a basis for local policy
2. State – Since 1964 and the advent of Medicaid, the States determine the state budget for mental health funding. Each state needs a strong statewide bi-partisan advocacy network. It is important to have both grassroots support coupled with professional trade organizations, providers, and statewide organizations to advocate successfully.
3. Local – Direct service is always local although we have learned the power of virtual programming supported by local networks.

NAMI in 1988 was really an organization representing the families of persons with mental illness. Professionals and Family Members (primarily Parents) were the creators of programming.

Siblings became a greater part of the discussion in the mid-1980's.

Beginning in the 1990's, the Consumer Survivor movement began to change the focus of NAMI to more clearly include the voice of persons with lived experiences. **This is the Recovery Movement.**

The President's New Freedom Commission on Mental Health Increases the National Focus on Recovery as a Mental Health Focus of Treatment

Beyond the addition of peer staff members and recovery supports, more work remains to be done in achieving the transformation to recovery called for by the **President's New Freedom Commission on Mental Health in 2003**.⁴ The commission's report resulted in development of a federal action agenda that describes the vision of a transformation to recovery as "nothing short of revolutionary," implying "profound change—not at the margins of a system, but at its very core." [37\(p5\)](#) In terms of the nature of this "profound change," the federal agenda suggests that "a keystone of the transformation process will be the protection and respect of the rights of adults with serious mental illnesses." [37\(p3\)](#) Apparently there is more to the restoration of rights to people with mental illnesses reflected in the ADA than the provision of accommodations through Medicaid expansion to fund peer and other recovery supports.

2003

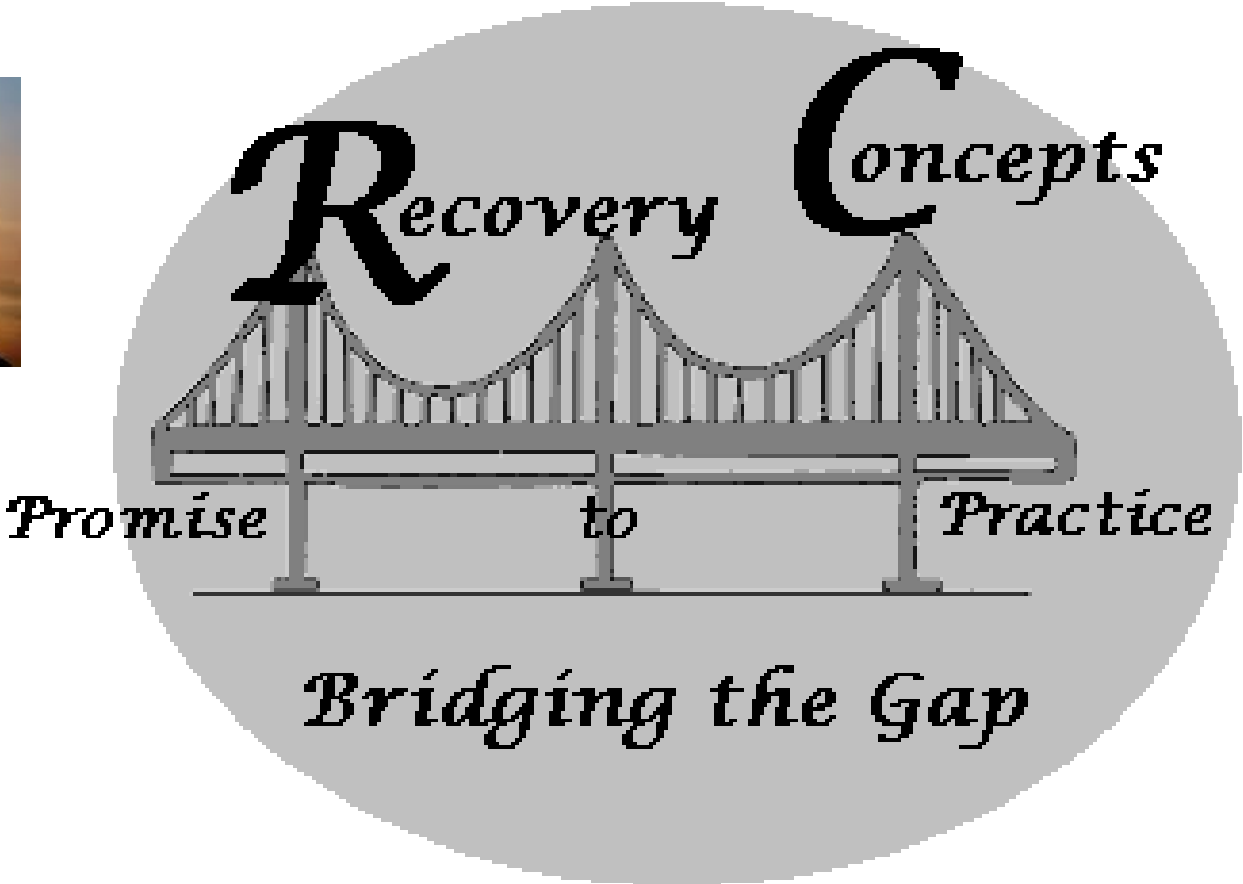


I'M PROOF...
RECOVERY
IS POSSIBLE!!!

"The medical labels are not a core part of who I am — they are sticky notes on my chest that I work to remove."

The Theme of the NAMI Illinois Conference (Recovery Concepts) reflected the changing nature of the field. NAMI Illinois encouraged the use of Person First Language, discouraged the message that medication was a lifetime requirement, and focused on a person's strengths. People told their story "In Their Own Voice" and the focus in the field was to begin to better listen and understand that there were multiple paths and choices to a person's recovery. NAMI and the Field tried to make sure that all parts of the field included people with lived experiences in all parts of the field.

2006



History of NAMI in Illinois

After 2003, the Recovery Movement led to a greater recognition of 3 groups to the Alliance of Mental Illness

1. Professionals
2. Family Members and Loved Ones impacted by mental illness and advocating for better services
3. People with Lived Experience or Consumers of Mental Health Services

More recently, Peers in Recovery have begun to blur lines. Often they are now recognized as:

1. Parents themselves
2. Professionals delivering effective mental health
3. Effective advocates for their own recovery and demanding a seat at the table determining the design of future services.

History of NAMI in Illinois

2016 – 2019 – Life under Gov Rauner

4 years of Budget Cuts & Constant Budget Stalemates

Many Mental Health Agencies Statewide Closed their Doors

The Downstate and Central Illinois MH System was Devastated

1. NAMI Illinois lost more than half of its budget when the State of Illinois cut its allocation.
2. They operated for more than a year with a volunteer Executive Director (Sue Spears from Peoria) & no staff. Sue drove to Springfield once or twice a week to get and respond to mail & get bills paid.
3. The Board kept the Annual Conference alive.
4. The State had already been cutting Mental Health services for over a decade. They tightened requirements for whom could get services and cut the types of services that were offered.
5. The pressure of pension debts and the failure to approve a state income tax increase caused dramatic cuts under Gov Blagojevich and Gov Quinn to the mental health system.
6. The State of Illinois only funded services delivered by agencies billing Medicaid. This is a Medical Based funding model that did not cover the full cost of services, did not promote recovery, and often made it difficult to deliver high quality evidence-based services to the populations most in need of services.
7. During 2016 – 2019, the State Division of Mental Health permitted mental health agencies flexibility to cut services just to try and stay in business. Many agencies pulled out of large swaths of the state.
8. NAMI Illinois is forced to close its Springfield office and relocates to Chicago to be closer to a volunteer base that can sustain it. At one point, they are housed within NAMI CCNS.

The 2016 NAMI Illinois Conference Theme Reflects a Shift of Tone.

The MH community needs to Speak Up, Be Organized, and Work Together.

2016 NAMI Illinois Annual Conference & Convention - “We are Stronger When We Speak with One Voice”

October 14 & 15, 2016



By 2017 at the Conference, this humorous slide was designed to remind legislators that Our Families Vote!



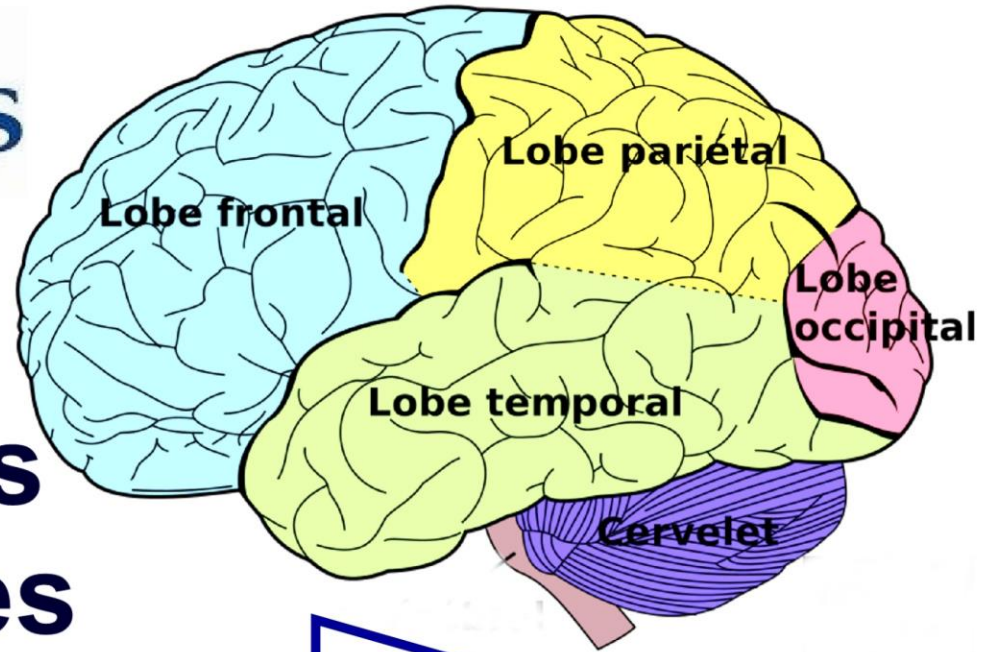
We're the Families

#NAMI-IL-WTF

**2017 NAMI Illinois Annual
Conference & Convention**

Changing Minds in Difficult Times

Oct 13 - 14 , 2017- Techny, IL



- 1. Understanding policy and advocacy
(now more than ever)**
- 2. Peers make the difference**
- 3. NAMI Affiliates foster ideas for support**
- 4. New Research, practices & innovations**

Save the Date!

NAMI Illinois: Making a Commitment to Better Lives

2019 NAMI Illinois Annual Conference

October 18 - 19, 2019 (Friday & Saturday)

at the historic Techny Towers in Northbrook, IL

**In 2019, A new Governor
and his Leadership was
at the State Conference.**

**Mental Health
Legislation has become
a priority for the State.**

**The State begins to
rebuild a broken system.**



***Featuring Grace Hou- Illinois
Secretary of the Department of Human
Services as Keynote Speaker -
"Moving Ahead in 2020."***



Welcome!

2020



Driving Change:

The New Future
of Mental Health

By 2020, The Financial Update NAMI Illinois Rebuilds!

Leveraging Your Contributions

Thank you donors

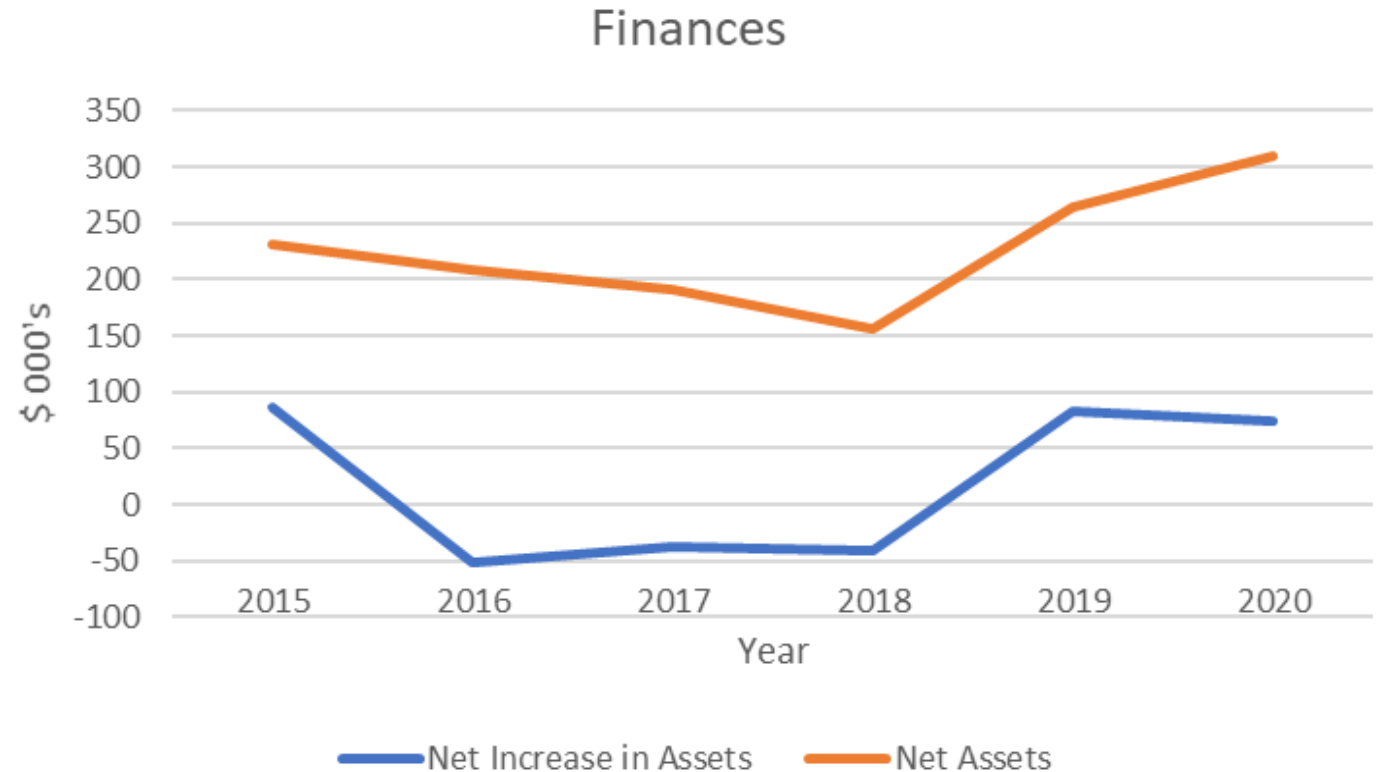
State of Illinois Funding Continues

Thank you legislators and IDHS

COVID 19 Grants Support Transition

Virtual Operations and Outreach

Current Focus – Rebuild Capacity, Diversity, Smart Growth



This fall we will ask donors for \$100,000 to keep our momentum

Tax deductible gifts may be made at
www.NAMIIllinois.org

Under Andy Wade, NAMI Illinois is Growing Quickly in a sustainable fashion today.

We are expanding more than our staffing. We are expanding the field.

1. As a State, we are still implementing huge legislative wins and need the workforce to utilize allocated resources on the ground
2. Advocacy is ahead of implementation statewide!
3. NAMI Illinois is now on sound financial footing. The State Affiliate is now helping Affiliates statewide with small start-up grants to rebuild and create new affiliates and expand NAMI signature programs statewide.
4. NAMI Illinois is helping to expand the Recovery Movement to include Professional Peers as Partners in the Workforce. NIAPP is a separate group staffed by NAMI Illinois to represent the MH Peer workforce.
5. Now expanding the workforce and recovery to include more communities, more voices, more images, and more input beyond the traditional middle class served by the mental health system.
6. Now expanding virtual programming and hitting more of the state and better utilizing existing volunteers
7. The entire human service sector is better organized and interested in growing all services. NAMI Illinois is organizing NAMI to utilize its geographical reach better
 - It can improve
8. Now Expanding in ways that complements and does not compete with the work of local affiliates
 - Adding expertise and resources and improving the product that can be delivered by volunteers at the local level.
9. We are still building the bones to make for a stronger organization.
10. We are now building the staff to expand programming statewide.

It is a time of celebration of all of our collective work of 40 Years.

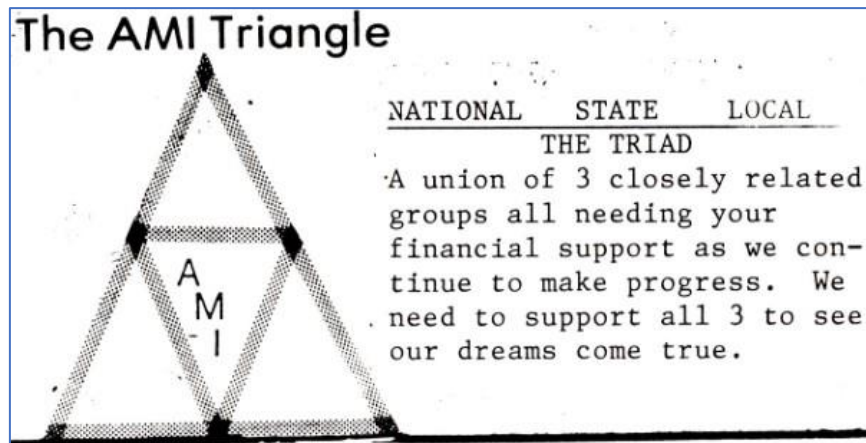
Take this time to learn about your affiliate's history and the contributions of so many in our communities. Add that history to this presentation.

Join us for this year's 2024 NAMI Illinois State Conference. We will have a nice formal dinner at the end to celebrate 40 Years of Impact.

Thank You Vi Orr and Shirley Starr for your part in making your NAMI great.

See the AMI Triangle below created by Vi Orr in **1985** in the NAMI Illinois Stateline.

We are Stronger When We Speak with One Voice.



Mary Giliberti, CEO of the National Alliance for the Mentally Ill (left) and Vi Orr, a founder of NAMI-IL National Alliance for the Mentally Ill IL.

