Organization Background & Current Status of Mental Health Services

NAMI IOWA was formed in 1988 by family members of people with serious mental illness who needed help and support. NAMI Iowa is part of a national organization with 50 state chapters and over 600 local affiliates. Iowa currently has 15 local affiliates and nearly 1,000 members.

Mental illnesses are brain disorders. Untreated, they can cause severe disturbances in thinking, feeling and relating. This results in substantially diminished capacity for dealing with the ordinary demands of life and can result in loss of jobs, relationships, freedom and even life.

Historically about one in five Iowans, or around 600,000 people, are affected by a mental health challenge every year. With the pandemic in 2020, the estimates are now closer to one in four. What that really means is most Iowans are affected in some way. A smaller subset --- 130,000 Iowans -- deal with serious and chronic mental illness.

Iowa has a critical lack of providers and services to address this need. Iowa is ranked 48th in the nation overall in the provision of mental health services; 89 of 99 counties are federally designated as Mental Health Professional Shortage Areas by the Health Resources and Services Administration. Iowa has fewer than 100 psychiatrists accepting clients in the entire state, 31 of whom are child psychiatrists, most of whom live in six counties. Iowa also lacks community-based clinical and wrap-around social services necessary for people with severe and chronic mental illness to live in recovery such as transportation and supported housing.

These gaps in services are exacerbated by the upheaval in the mental health and Medicaid payment systems in our state. Over the past seven years there was a complete reorganization of the adult mental health management and payment system, from 99 counties to 14 Regions. The state also has completely privatized its Medicaid management, which is now in the hands of two private MCOs (Managed Care Organizations).

There is currently no funded system for children’s mental health. Services are provided, but in a patchwork, fragmented way. There is a particular need for crisis services for children ages 10-17.

Jails and prisons in Iowa have become the mental health providers of last resort. Data shows that approximately 50 percent of the 4,000 prisoners in our 97 counties jails at any given time have a mental health diagnosis, with about the same percentage of the 8,000 inmates in our state prisons (45 percent of men and 85 percent of women) having at least one condition. Jails and prisons are doing the best they can, but they are not designed to be therapeutic environments. Our lack of services has resulted in the criminalization of mental illness.
With the changes brought by COVID-19 and the resulting mitigation measures, NAMI Iowa finds itself serving a deeply impacted community. Iowa currently has one of the fastest transmission rates of coronavirus in the nation, making protective measures crucial to these 600,000 Iowans who may face increased medical vulnerability on top of susceptibility to mental health symptoms due to isolation and lack of access to help.

Because of all these factors, connecting Iowans to services, resources, and each other has never been more important. With a largely rural population, NAMI Iowa has the unique challenge of how to get programing and supports to areas without providers, medium or large population centers and local NAMI affiliates. NAMI Iowa is uniquely positioned to provide mental health education and support through programs and outreach for individuals, affiliates and the greater community (i.e. providers, law enforcement, schools, churches and non-profit partners).

**Mission**

NAMI Iowa serves as a leader through advocacy, education and support so that Iowans affected by mental illness can lead better lives stigma free.

- Advocating for a comprehensive and fully funded mental health system in Iowa
- Educating the public about mental illness and reducing stigma
- Supporting those with mental illness and their loved ones through evidence-based programs such as support groups, presentations, and classes

**Core Programs & Services**

- **Advocate** for a comprehensive mental health system that provides timely access to quality services. This is accomplished through cultivation and activation of a statewide grassroots advocacy network, direct lobbying at the Statehouse and the US Capitol, involvement with programs at the Governor’s Office and state Departments of Human Services, Corrections, Public Health and Public Safety. We also work closely with the Mental Health and Disability (MHDS) regions and with other statewide provider and advocacy organizations.

  Advocacy happens year-round, but has been historically focused on legislative advocacy, which is concentrated in the winter months. NAMI Iowa offers a yearly Day on the Hill experience to provide an education and advocacy experience for individuals. Additionally, several staff members serve on committees and coalitions pertaining directly to advocacy and the executive director is heavily involved in this work year-round.

- **Educate** Iowans about mental illness, thereby reducing stigma. This is accomplished through in-person outreach at statewide meetings and conferences, media events, fundraising and educational events, and social media.
NAMI Iowa offers an annual conference in November of each year and several educational events (peer support and affiliate capacity building) throughout the year. We offer state trainings for six NAMI programs, twice yearly. Finally, NAMI Iowa runs Ending the Silence and Provider programs at the state level, allowing for program leader recruitment and programing across the state, even in areas that currently do not have a local affiliate serving their county.

- **Support** those with mental health conditions and their loved ones. NAMI Iowa does this through local affiliate support, state and national partnerships and direct engagement with individuals.

NAMI Iowa provides at least 12 state trainings for hundreds of teachers, presenters and facilitators for **NAMI signature programs** that are delivered free of charge across the state. The classes include **Family to Family** (for those supporting loved one), **Peer to Peer** (for those living with a mental illness), **Homefront** (for families of veterans) and **NAMI Basics** (for parents of children with a mental health condition). **Connection Recovery** and **Family Support** are the two support group programs. **In Our Own Voice** (storytelling based on lived experience), **Family and Friends** (intro program for loved ones) and **Ending the Silence** (designed to support youth) are the presentation type programs.

NAMI programing also includes **Provider**, a professional development class for health care and social service clinicians. It is the one class where participants are charged a small fee, since this course is considered professional development and CEUs are available. The partnership NAMI Iowa created with Des Moines University beginning in 2018 to train all 3rd year medical students has shown innovative collaboration and adaptation of NAMI programs to both create significant impact and relevance for statewide and national audiences.

NAMI Iowa provides direct, one-on-one resource and referral services to individuals and family members through management of the **Office of Consumer Affairs**, a state-funded program. This program funds a warmline staffed during business hours and extensive outreach across the state for resources and referral.

Beginning in 2018, NAMI embarked on capacity building work to strengthen the state organization as well as local affiliates, funded by the Anonymous Donor. This work has provided opportunities to create strong relationships with the 15 local affiliates across the state through programing, coaching and networking opportunities. Also in 2018, NAMI entered into a partnership grant project with Iowa Coalition Against Sexual Assault to develop programing to support sexual assault survivors with mental illness.

**How does NAMI Iowa define and assess success?**

NAMI Iowa aims to be the recognized leader in providing a respected and trusted voice in advocating for the development of a state-of-the-art mental health system for all Iowans.
Objectives include:
(1) Assure that advocacy goals are strategically and vigorously pursued in the Iowa Legislature, cultivate relationships with the executive and judicial branches as well as key stakeholder group leaders, and undertake grassroots education and mobilization of advocates to achieve our public policy goals.
(2) Meet or exceed annual revenue goals through events, grants, contracts, direct mail and social media outreach.
(3) Maintain sound financial management and fiscal oversight of the organization
(4) Cultivate a diverse and engaged board of directors that is supported, motivated, informed and involved in achieving the goals of the organization.
(5) Assure staff performance and support through a robust performance management system and clear communication.
(6) Build outreach and communication efforts through a variety of strategies to make NAMI Iowa a leading voice in mental health system knowledge and advocacy.
(7) Optimize training opportunities for NAMI signature programs.
(8) Continue capacity building with affiliates and foster new affiliate opportunities in unserved areas of the state.

Partnerships and Collaborations

In order to successfully achieve the mission of NAMI, multiple partnerships are required. For NAMI Iowa to be a leader in a statewide movement to develop a quality and accessible mental health system for all Iowans, a range of partnerships is essential. Such partnerships need to be both public and private, local and national, individual and organizational. These partnerships must be strategically developed and maintained. Development and maintenance of partnerships is time intensive, requiring a significant investment by both staff and volunteers.

Categories of partnerships and examples of key relationships are as follows:

Key volunteers

NAMI Iowa has a strong volunteer governing board made up of 19 clinicians, peers, family members, law enforcement officials, advocates and business leaders from across the state. In addition, we have a committee structure that brings in dozens of volunteers beyond the Board. The committees open to non-Board members are Program, Advocacy, Walk and Beautiful Minds.

Local Affiliates

As of early 2021, there will be 15 local affiliates statewide covering 46 counties.
Public agencies
MHDS Regions
University of Iowa
Department of Human Services
Governor’s Office
Iowa Department of Public Health
Iowa Department of Corrections

Providers
Des Moines University

Collaborative partnerships
Iowa Coalition Against Sexual Assault
Employee and Family Resources (new in 2020)
4-H (new in 2020)
Iowa Hospital Association
Iowa Sheriffs and Deputies Association
National Association of Social Workers (NASW) Iowa Chapter

National partnerships
NAMI
NAMI state organizations

Partnerships to be developed
Iowa Behavioral Health Association
Iowa Primary Care Association
Iowa State Extension Service
Unity Point
Mercy One
Broadlawns
Orchard Place
Proteus
Abbe Center
State Judicial Branch
Iowa Association of Chiefs of Police
Iowa Coalition for Family and Children’s Services
Iowa Association of Community Providers
Iowa State Association of Counties
Iowa League of Cities
Iowa Emergency Medical Services
Iowa Firefighters Association
Iowa Interfaith Alliance
Major religious denominations and clergy groups
Labor unions
Professional provider associations such as the Iowa Medical Society

**IMPACT**

**Desired long-term impact of our work**

NAMI Iowa seeks to improve the lives of those living with and supporting loved ones with mental illness by tackling stigma and improving access to care. This will be accomplished through stakeholder partnership, addressing cultural differences and societal sensitivity around mental illness, and identifying and overcoming barriers in disadvantaged populations. If each subsequent generation is more sensitive, over time, this will change the trajectory.

NAMI programing is grassroots led and focuses on a local service model. This creates community, camaraderie, networks and community partnerships. Through the capacity building work with local affiliates, NAMI Iowa empowers local leadership to deliver programing and education that ultimately leads to community (and individual) empowerment.

We recognize that system change is critical to changing the quality of life for individuals with and loved ones supporting those with a mental illness. The right treatment at the right time is required to live healthy, productive lives. We know that untreated mental health conditions affect nearly every area of a patient’s life and the lives of those close to them. System advocacy and change will assure accessibility to quality treatment while expansion of NAMI programs and supports throughout the state will allow people to live in wellness and recovery in their communities.

**Outputs and Outcomes**

- Programing in all 99 counties by 2023, specifically focused on efforts to promote Ending the Silence and Provider statewide
- State program trainings for local affiliates, 12+ per year scheduled (2021), virtual or in-person
- Growth of affiliates, 2 Model A in 2021, including increasing service areas for NAMI South Central and NAMI Central Iowa (2021-2023)
- Addition of Model B affiliates (programs of NAMI Iowa), 4 by 2023 (Marion County-2021, Carroll Area-2021, Fort Dodge Area-2021-22, Sioux City-2022)
- Support to Greater Des Moines region, support groups and programming to fill gap in affiliate services (2021 and on)
- Emphasis on program fidelity, responding to complaints in a timely and effective manner to coach and encourage program consistency and excellence.
- Expansion of programing options to include virtual options, coordinated through state office (2021)
• Ending the Silence
• Provider
• Support Groups
• Family-to-Family
• Support to affiliates converting programing at local level

• Ending the Silence, promote the program statewide, focusing outside of central Iowa (2021)

• Retention and support of volunteers (2021-2023)
  • Ending the Silence presenter network
  • Provider teacher network

• Provider marketing to other medical and health sciences universities and colleges within Iowa (2021-2023)

• Capacity Building for Affiliates (2021)
  • Capacity Building Retreat
  • Monthly calls

• Education opportunities
  • Annual conference (to be offered in November of 2021-2023)
  • Peer Support conferences (Peer support collaborative contract with University of Iowa ends in early 2021, but NAMI Iowa intends to bid on the new RFP.)
  • Day on the Hill (to be offered in February or March of 2021-2023)

• Public Safety
  • Engage the judicial branch to fund more mental health courts, both criminal and civil, and work with providers to offer Assisted Outpatient Treatment (AOT).
  • Work with law enforcement and emergency responder groups as well as state and local government to provide and strongly encourage CIT training statewide and establish crisis intervention teams in every area of the state for both adults and youth.
  • Require mental health staff training in both county jails and the state correctional system.

• Peer Support
  • Continue educating key stakeholders and policymakers about peer support and its value
  • Expand the peer and family peer support work force in Iowa, focusing on training and then placing people in specialty areas like senior, youth and forensic peer support
  • Identify and expand funding sources
  • Provide ongoing education and support to peer and family peer support specialists as well as their supervisors

• Advocacy
  We are pursuing a vision for a state-wide mental health system that is:
  • Adequate and sustainable funding, accessible to all Iowans, best-practice services with a governing system that includes clarity of authority, responsibility and accountability
- Fully integrated with other societal systems – health, public health, criminal justice, education, child welfare
- Culturally competent – race, ethnicity, age, gender/sexuality identification, socio-economic status, personal beliefs, stigma free.
- Responsible to individual, family and community needs that incorporates best medical and public health practices, based on population health policies driven by social determinants.
- Outcome-driven, continuous improvement driven by self-evaluation

This will be established through a variety of strategies including grassroots education and mobilization, establishing long-term relationships in the executive, judicial and legislative branches of state government, and employing a savvy and sophisticated professional lobbying team.

- Office of Consumer Affairs
  - Work with the Department of Human Services and interested stakeholders to both refine and expand the scope and effectiveness of this outreach, advocacy and support service through the contract period (ends June 2023).
- Office of Violence Against Women/Iowa Coalition Against Sexual Assault (ICASA)
  - Successfully complete the initial phase of the project (ends September 2021) and apply for a continuation grant to fully implement.

**How outputs and outcomes will be measured**

- Program data submitted to NAMI 360
- Setting and holding to meetings (capacity building, programs calls)
- Trainings offered (state trainings and program update trainings)
- Affiliates approved by NAMI
- Data around volunteer retention and engagement on presenter/teacher networks ETS and Provider
- New legislation that supports NAMI Iowa’s goals