



NAMI Illinois Action Agenda 2018

NAMI Illinois is the state organization affiliated with the National Alliance on Mental Illness, the nation's largest grassroots organization for people with mental illness and their families.

NAMI Illinois' Action Agenda outlines key objectives and accompanying policy positions that form a basic foundation to support our goal of ensuring that people with mental illness receive the treatment and supports they need to increase resiliency, experience recovery and to lead full and satisfying lives as valued members of the community.

NAMI Illinois takes positions on specific legislation as issues or legislation arises; those positions are posted on the NAMI Illinois website: namiillinois.org. This document, however, outlines all of Illinois' key policy objectives. We urge the Illinois Department of Human Services (DHS) and the DHS Division of Mental Health to partner with NAMI Illinois and other stakeholder groups to advance each of these key objectives. NAMI Illinois stands as a willing partner.

Key Policy Objectives

1. Increase Access to Effective Mental Health Care
2. Promote an Integrated Delivery System
3. Maximize Federal Financial Support for Mental Health Care
4. Strengthen the Mental Health Workforce
5. Eliminate Disparities in Mental Health Care
6. Ensure Transparency and Accountability
7. Improve the Mental Health of Children and Youth
8. Provide Housing for People Living with Mental Illness
9. Facilitate Employment Opportunities for People Living with Mental Illness
10. End the Inappropriate Involvement of People with Mental Illness in the Criminal Justice System.

1. Increase Access to Effective Mental Health Care

- Illinois must invest in mental health services and fund improved access to an extensive array of mental health treatment and supports.
- As Illinois rebalances its service system and shifts its spending patterns for healthcare from institutional to community-based care, the need for community-based residential services must be addressed.
- Illinois must provide sufficient acute care mental health inpatient beds.
- Reimbursement rates must be high enough to ensure both quality and quantity *of* mental health services.
- Illinois must create a revenue system sufficient to fund mental health programs without reducing funding levels for existing services.
- Illinois must expand outreach to disadvantaged individuals to ensure maximum participation in benefit programs to which they are entitled.
- Illinois must implement an effective system of tele-psychiatry and other mental health services.
- All mental health programs must be delivered without regard to a person's race, ethnicity, religion, economic status, gender or gender identity.

Medicaid

Medicaid is the single largest payer of mental health services in Illinois. It provides vital coverage for persons who are severely affected by mental illnesses. NAMI Illinois encourages Illinois to maximize benefit sets in all Medicaid programs, including the state Medicaid mental health benefits plan, to provide a full array of effective, evidence-based services that are needed for children and adults to experience resiliency and recovery and to reduce reliance on costly institutional care.

- Coordinated care programs developed as a result of Medicaid reform must provide a comprehensive array of effective mental health services that promote recovery and community inclusion and which are based on individual needs.
- The Medicaid 1115 Waiver being sought by Illinois must cover the widest possible array of mental health services.
- Illinois must raise Medicaid reimbursement rates enough to significantly increase the number of psychiatrists and other mental health professionals who will treat people with mental illnesses.

Community Mental Health Programs

The Illinois Division of Mental Health (currently residing in the Illinois Department of Human Services) has historically been funded to provide community mental health services and supports for children and adults, along with crisis services, medication treatment, acute care and state hospital and longer-term care. These programs were designed to play a critical role in serving children and adults with serious and chronic mental health needs who are uninsured and, importantly, for children and adults who have exhausted private insurance coverage or are awaiting eligibility for Medicaid. Many programs also provide needed supports that are not Medicaid-billable for people with serious mental illness who are enrolled in Medicaid.

Illinois' state funding of mental health services over the past several years has been inadequate to meet demand. Illinois has cut services, and restricted eligibility for community-based services to those who are already enrolled in Medicaid. Illinois needs adequate and stable funding for non-Medicaid mental health services and supports, including acute care inpatient and longer-term care and psychosocial rehabilitation, to ensure children and adults get timely treatment and support in communities where they live.

- **Illinois must ensure adequate and stable funding to meet community needs for public mental health services, including acute care inpatient, longer-term care, and psychosocial rehabilitation - especially for those who are homeless and who are not enrolled in Medicaid.**
- **Illinois must create a system of 24-hour crisis centers so that first responders have an alternative to taking a person in mental health crisis to an emergency room or jail.**

Recovery-oriented community mental health systems provide an array of effective services and supports that meet varying needs, including evidence-based practices such as Assertive Community Treatment (ACT) teams, integrated dual-diagnosis treatment and Illinois' Individual Placement and Support / Supported Employment programs that have proven records of success for people who live with severe mental illnesses or co-occurring disorders and promising practices and technologies. Such an array is essential for Illinois to comply with the community integration requirements set forth in the U.S. Supreme Court's *Olmstead Decision*.

- **Community mental health programs must be funded to provide a comprehensive array of evidence-based services and supports that promote recovery and community inclusion.**
- **Promising new practices should be considered in the array of services.**

Illinois' Individual Placement and Support program must be fully funded. This evidence based program is recovery oriented – as noted in 2003 by the President's New Freedom Commission Report: "Work is the most direct step to recovery, and Individual Placement and Support (IPS) is the only evidenced-based practice for helping people get work."

Private Insurance

Over half of Illinoisans have employer or individual insurance coverage, yet many continue to experience unequal coverage of mental health and substance use conditions. The Patient Protection and Affordable Care Act should bring parity to individual and small group plans offered through insurance exchanges, but strong state leadership is needed to ensure implementation and enforcement of state and federal parity requirements.

- **Illinois must ensure full implementation of and compliance with mental health and substance abuse parity legislation at the state and federal levels.**

Private health care has developed many of the most effective treatments for common health conditions--with the notable exception of most treatment for severe mental illnesses. Public mental health systems, in contrast, have long been on the forefront of developing and implementing promising and evidence-based practices for a range of serious mental health and co-occurring disorders.

To improve health outcomes and prevent unnecessary and costly disability, private health plans, particularly those offered through insurance exchanges, must provide coverage for and develop capacity to deliver an array of effective treatments, including care coordination and case management services, for children and adults with serious mental health and co-occurring disorders.

- **Private health care plans must provide a readily available array of effective, evidence-based mental health services.**

Medications

For many individuals with mental illness, medications are an important element of successful treatment. Individual patients have unique responses to medications and need more, not fewer, choices. In contrast, restrictive formularies, prior authorization requirements, lack of coverage, and cost sharing for vulnerable populations can result in poor health outcomes and greater expense to local resources, including increased emergency room visits, hospital care, and institutionalization.

- **Illinois must ensure flexible and timely access to a comprehensive array of mental health medications based on individual need in all health plans and community mental health programs.**

2. Promote an Integrated Delivery System

Primary Care Integration

Individuals with serious mental illness are at increased risk for co-morbid medical and substance use conditions, yet few receive integrated treatment to address co-occurring conditions. It has been well documented that people with serious mental illness die an average of 25 years earlier than other Americans, largely of treatable health conditions. Additionally, older adults and others with chronic medical conditions, such as heart disease, diabetes and cancer, are at increased risk of depression, which can shorten life expectancy and increase healthcare costs. Despite its prevalence, only about 50 percent of depression cases are correctly identified in primary care.

Many individuals with serious mental illness also experience co-occurring substance use disorders, which contribute to poorer outcomes. Integrated mental health and substance abuse treatment facilitates recovery and improved overall health while reducing negative effects on family, friends and our communities. Integrated delivery systems of care and especially the integration of mental health, addictions, primary health care and housing show promise in improving both access to care and health outcomes for children and adults who experience mental illness.

- **Integration of expert mental health, addictions primary care and other medical services must be the norm in all health care settings. Special care must be taken in developing integrated healthcare and care coordination initiatives to make sure that all parties understand and have critical knowledge about the special needs of this sometimes vulnerable population.**

"Social determinants of health" are the social conditions in which people live and have the single most powerful impact on the individual's health. Examples of social determinants of health include income, education, employment and working conditions, food supply, housing, the physical environment, race/ethnicity, early childhood development, access to health services and social supports. The lack of appropriate, safe and affordable housing is an especially significant social determinant of health for individuals with a serious mental illness.

- **The integrated delivery system must address the individual's social determinants of health.**

3. Maximize Federal Financial Support for Mental Health Care

- **Illinois must aggressively pursue federal funding opportunities and revenue**
- **Illinois must pursue the best in mental health service delivery, for example – development of the Section 1115 Waiver and implementation of evidence-based practices.**

4. Strengthen the Mental Health Workforce

Workforce Development

A shortage of mental health professionals, especially psychiatrists, throughout Illinois often impairs access to needed mental health treatment--and contributes to inadequate care and unsafe conditions in many facilities. Youth and adults living in communities of color and in areas outside of Chicago are disproportionately affected by workforce shortages, with shortages of bicultural and/or bilingual mental health professionals creating significant barriers for individuals with limited English proficiency. Adding to the problem, few academic training programs and provider systems provide in-depth training on the treatment of individuals with severe mental illness or on cultural competence in service delivery.

- Illinois must actively recruit and train psychiatrists and all other healthcare professionals in effective and culturally competent treatment interventions for children and adults with serious mental illness.
- As many people seek help for mental health problems from their primary care physicians, Illinois must ensure that primary care physicians and their staffs understand and recognize mental illnesses well enough to make appropriate referrals.

5. Eliminate Disparities in Mental Health Care

Cultural and Linguistic Competence

Mental illnesses affect Illinoisans throughout the lifespan, in all geographic regions, and across all racial and ethnic groups. Unfortunately, individuals living in racially and ethnically diverse communities, as well as many rural areas of the state are less likely to receive needed mental health care. With racial/ethnic minorities projected to be the majority of the population by 2040, cultural and linguistic competence should be an expectation of the mental health care delivery system.

- Illinois must continue to incorporate cultural and linguistic competence standards in requirements for mental health funding, with a focus on reducing geographic and other disparities among racial and ethnic groups.

6. Ensure Transparency and Accountability

Data Collection, Analysis, Sharing and Accessibility

Reliable data is critical for informed decision-making and quality improvement. And yet, data collection in Illinois' mental health system lags far behind other disciplines. Standardized data collection, analysis, sharing and accessibility including meaningful performance, process and outcome measures, would position Illinois to better assess the performance of its mental health system, including how well the needs of children and adults who live with mental illness are being met.

- Illinois must begin to collect and share standardized statewide data collection and public posting of meaningful performance, process and outcome measures, including data by race and ethnicity and geographic regions.
- Illinois must continue to promote data sharing across related systems to improve the continuity of services as well as examining the effectiveness of interventions and programs. Persons with mental illness often are treated in expensive emergency systems, including: private or public emergency rooms; state, federal VA, and private psychiatric and medical hospitals. They often find themselves in institutional settings such as jails, prisons or nursing home settings. Medical, psychiatric, public safety and emergency personnel need to be able to share information to effectively treat related illness. The Division of Mental Health's Jail Data Link, for example, is a model program that needs to be expanded to prisons.

7. Improve the Mental Health of Children and Youth

Early Identification and Intervention

Half of all lifetime cases of mental illness begin by age 14, three-quarters by age 24. Despite effective treatments, most children and young adults go without treatment. Early detection and treatment of mental illness can result in a much shorter and less disabling course of illness, as well as promote success in school and the community. Early intervention is also critical to address our nation's high rate of youth suicide.

- **Elementary and secondary teachers must receive training such as “Ending the Silence” or “Mental Health First Aid” or take coursework in mental health awareness to better recognize, understand and teach students with mental illness or serious emotional disturbance.**

The U.S. Preventive Services Task Force recommends screening of adolescents (12-18 years of age) for major depression to ensure diagnosis and treatment. In June 2010, the American Academy of Pediatrics (AAP) called for mental health screening in primary care settings and noted the increasing need for primary care clinicians to manage children with mental health concerns. Medicaid also requires early screening and intervention under the Early Periodic Screening, Diagnosis and Treatment (EPSDT) provision of the federal law.

- **Screening, assessment and early intervention of mental health conditions for children and youth must be an integral part of health care delivery systems.**
- **Illinois must cover treatment of first episode psychosis through Medicaid and Medicare and require private insurers to cover it as well**

Home and Community-Based Services

Today, one in 10 children and youth experiences a mental health condition severe enough to cause significant impairment in their day-to-day lives. Without appropriate treatment, youth struggle with peer and family relationships, drop out of school, become entangled in juvenile justice systems - or most tragically - die by suicide. Too many youth end up in hospitals or facility-based care--or in the custody of child welfare. A comprehensive array of timely and effective home and community-based (including residential) services - particularly proven, evidence-based interventions - is necessary to provide youth the opportunity to live successfully with mental health conditions.

- **Illinois must provide effective home and community-based services that help children and youth succeed at home, in school and in their communities.**

Custody Relinquishment

Illinois has recently enacted legislation to end practices that forced families to give up custody of children and adolescents to child welfare and juvenile justice systems to secure necessary treatment for mental illnesses. Illinois must comply with this legislation and interested parties must monitor implementation of the new law.

- **Illinois must successfully implement the Custody Relinquishment Prevention Act to end the practice of forcing parents to relinquish custody in exchange for treatment. If the legislation does not eliminate the practice completely, the law must be amended and strengthened.**

Juvenile Justice Diversion

Nationwide, there are more than 106,000 teens in custody in juvenile justice facilities. Research has found that 70 percent of youth in state and local juvenile justice systems have at least one mental disorder; yet juvenile facilities routinely fail to adequately address mental health needs. We have no reason to believe that Illinois statistics or resources are any different. Routine mental health screenings and opportunities for diversion to effective services and supports could keep our youth from falling into a system that is ill-equipped to serve their needs.

- **Illinois must identify and divert youth with serious mental health conditions from detention to appropriate community treatment.**

8. Provide Housing for People Living with Mental Illness

Permanent Supportive Housing

Lack of safe and affordable housing is one of the most significant barriers to living in the community for people with serious mental illness. A safe place to live is essential to recovery. Without this basic need, too many cycle in and out of homelessness, jails, shelters and emergency departments—or remain institutionalized. Supportive housing and “Housing First” models are cost-effective and result in housing stability and a marked reduction in shelter use, hospitalizations and involvement with the criminal justice system.

- **Illinois must significantly expand and consistently fund affordable permanent supportive housing for people living with serious mental illness to meet demand created by settlement of Illinois Court Cases, i.e. the Williams Consent Decree, the Colbert Consent Decree and proposed closure of state facilities.**
- **Illinois must provide a dedicated source of funding for affordable housing and individualized supportive services to deflect or discharge people with mental illness from institutional placement who do not need that level of care.**
- **35-50% of homeless individuals are estimated to have a mental illness; Illinois must fund homeless assistance programs that can help adults stabilize in community settings.**
- **It is estimated that 15% of individuals leaving jails and prisons have a severe mental illness. In order to avoid repeated hospitalization and/or corrections involvement, they must have adequate wrap around services, including treatment for both medical and mental health conditions, supportive housing and job placement services through the IPS or other evidence-based model.**

- **The supply of permanent supportive housing must be sufficient to meet the needs of all age groups, including seniors**

9. Facilitate Employment for People Living with Mental Illness

Individual Placement and Support/Employment (IPS)

Only one in three adults with serious mental illness is employed, even though the majority wants to work. This loss of productivity and loss of human potential is costly and unnecessary. Supported employment models show that with effective supports, 60% of adults with serious mental illness can work and achieve independence, yet too few have access to successful employment programs (See NAMI's *"Road to Recovery: Employment and Mental Illness"*).

- **Illinois' Individual Placement and Support program must be fully funded. This evidence based program is recovery- oriented – as noted in 2003 by the President's New Freedom Commission Report: "Work is the most direct step to recovery, and Individual Placement and Support (IPS) is the only evidenced-based practice for helping people get work."**

10. End the Inappropriate Involvement of People with Mental Illness in the Criminal Justice System

Diversion from the Criminal Justice System

Disproportionate numbers of people with mental illness end up in our criminal justice system, often as a result of untreated or undertreated illness. People with mental illness often fare poorly in jails and prisons. The Cook County jail is now the largest psychiatric ward in Illinois, housing well over 1,500 inmates with serious mental illness. Jail diversion programs have shown that many individuals with mental illness who are charged with lesser offenses can be diverted to more appropriate -and cost-effective - comprehensive community care. The current network of mental health courts is promising, but those courts enroll only a small fraction of defendants with mental illness, and the resources available to the courts are limited.

- **Illinois must divert people with serious mental illness from the criminal justice system to appropriate community treatment and supportive housing. Appropriate treatment coupled with supportive housing reduces incarceration and recidivism.**
- **Illinois must expand mental health courts to jurisdictions that do not have them.**
- **Illinois must enact legislation to expand mental health court reciprocity across jurisdictions.**
- **Crisis Intervention Training (CIT) for police officers must become community norms. Illinois must assume more of the financial burdens local police departments face when sending officers to CIT training.**

- **The curriculum at the Illinois Police Academy must be expanded to include the full CIT curriculum.**
- **The treatment resources available to mental health courts and other jail diversion programs must be sufficient to meet the treatment objectives specified by the court.**
- **Local institutions, governmental entities and community stakeholders should work together for community-based problem solving.**

Individuals deemed Not Guilty By Reason of Insanity (NGRI) or Unfit to Stand Trial (UST) often languish in jails for months without access to treatment.

- **Illinois must expedite the transfer of NGRI and UST individuals to appropriate treatment.**

Ongoing Contact while in Corrections and Services upon Release

While some people will be diverted from the correctional system, there may continue to be a disproportionate number of people with mental illness in jails and prison. The mental health system must remain in contact through case management contacts and prepare a person for release. Programs like the Thresholds Jail Project have shown dramatic reductions in arrests, hospitalizations and jail time through ongoing intensive casework while in jail and following release. This type of service must be expanded to the prison and initiated in other jails.

Connection to Benefits

The rate of serious mental illness within our jails and prisons is two to six times higher than the rate among the general population. At release, most individuals are without benefits that are necessary for the treatment and supports they need to live successfully in the community and, instead, end up cycling in and out of jail. Ensuring that people with mental illness are connected to benefits upon release would promote successful re-entry and result in safer communities and efficient use of tax dollars.

- **Illinois must ensure enrollment (or automatic re-enrollment) in federal SSI/SSDI, Medicaid and other benefits upon release from jail or prison for eligible individuals with serious mental illness.**
- **Processes to do this should begin prior to release.**

NAMI Illinois supports Governor Rauner's goal of reducing the overall prison population by 25%, but to do this, 1) adequate funding and services must be available to mental health and other jail diversion programs, 2) local jails and state prisons must provide adequate health and mental health care to inmates and prisoners, and 3) adequate health and mental health care, supportive housing, employment assistance and other necessary social services must be provided to individuals upon their release.