

## state action agenda

### policy objectives

NAMI is the National Alliance on Mental Illness, the nation's largest grassroots organization dedicated to building better lives for the millions of Americans affected by mental illness.

NAMI's State Action Agenda 2012 outlines nine policy objectives and positions that support our goal of ensuring that people living with mental illness receive the treatment and supports they need to lead full and satisfying lives as valued members of the community.

### Policy Objectives

1. Protect public mental health services
2. Expand access to mental health coverage
3. Ensure that effective mental health services are available
4. Promote integration of mental health, addictions and primary care
5. Improve the mental health of children, youth and young adults
6. Meet the mental health needs of service members, veterans and their families
7. Provide homes and jobs for people living with mental illness
8. Eliminate disparities in mental health care
9. End the inappropriate jailing of people living with mental illness

### Protect public mental health services

#### Medicaid

As the single largest payer of mental health services in the country, Medicaid provides critical treatment and supports for many children and adults who live with severe mental illness.<sup>1</sup> When Medicaid budgets are cut, people living with mental illness lose the stable services they need to maintain their recovery. In tough economic times, the need for mental health services doesn't go away; in fact, more people than ever need help.

Stable and adequate funding for Medicaid is an essential investment that helps individuals with mental illness when they need it most.

- States should provide stable and adequate funding for Medicaid that ensures continuity of services and eligibility for children and adults living with mental illness.

#### Public mental health services

Public mental health programs provide important community-based mental health services for children and adults living with serious mental health needs who are uninsured, who have exhausted private insurance coverage, or who are awaiting eligibility for Medicaid. Public mental health systems also provide crisis services, psychiatric hospitalization, intensive services and supports and longer-term care that are vital for individuals living with serious mental illness.

Stable and adequate funding for public mental health programs is necessary to make sure that children and adults get the help they need.

- States should provide stable and adequate funding for public mental health programs that meets community needs for mental health services.

## Expand access to mental health coverage

### Medicaid Eligibility

About one in six low-income uninsured adults lives with serious mental illness—and many more need help for less severe mental health conditions.<sup>2</sup> However, Medicaid coverage is unavailable in most states to low-income adults who are not receiving federal disability benefits. As a result, thousands of Americans living with mental illness are left without the option of Medicaid coverage.

Increased access to Medicaid plans that include an array of proven, cost-effective services for serious mental illness will help low-income Americans get the mental health care they need to successfully manage their mental illness and live healthy lives.

- States should promote enrollment of low-income children, adults and families in Medicaid plans with mental health benefits that meet enrollees' needs.

### Affordable coverage with parity

Well over 50 million Americans have no coverage for health and mental health care<sup>3</sup> and others are just a pink slip away from losing their coverage. Over one in four young adults is uninsured—at a time in life when many will experience a mental health or substance use condition for the first time.<sup>4</sup> Still others find that their health plan does not cover mental health or substance abuse care in the same way it covers other medical care.

To provide the coverage they need to live healthy, productive lives, Americans need access to affordable health insurance that includes parity, or fair and equal, coverage for mental health and substance use conditions.

- States should support competitive health insurance marketplaces that provide parity coverage for mental health and substance use conditions.

## Ensure that effective mental health services are available

### A range of services

The right treatment at the right time helps children and adults living with mental illness experience success and get on with their lives—and we all benefit. Unfortunately, many don't get the mental health services they need to be productive and healthy.

A range of proven mental health services, such as supported housing, crisis services, care coordination and case management, medications, intensive home and community-based services, and peer support services are indispensable to promoting health and recovery.

- States should ensure that community mental health programs, Medicaid plans and essential health benefits for private insurance all provide a readily available range of effective mental health services.

## Community integration

The U.S. Supreme Court, in the 1999 Olmstead decision, ruled that unjustified segregation of people living with disabilities violates the Americans with Disabilities Act. Since then, many individuals living with serious mental illness have experienced success living in their communities.

Unfortunately, many individuals living with mental illness still remain unnecessarily isolated in state hospitals, nursing homes and residential facilities when they could succeed in more integrated settings with the right services and supports.

A commitment to providing a full range of intensive home and community-based services, including interventions, such as Assertive Community Treatment, supported housing, crisis services, and when necessary, acute care hospital treatment, is integral to promoting community integration and fulfilling the promise of Olmstead.

- States should ensure intensive home and community-based services to support the successful community integration of individuals living with serious mental illness.

## Medication access

For many individuals living with mental illness, medications are an important part of successful treatment. Because individuals have varying symptoms and unique responses to mental health medications, people need more, not fewer, choices.<sup>5</sup>

In contrast, restrictive formularies and barriers to getting the right medication can result in poor health outcomes, increased emergency room visits, hospital care, and institutionalization for vulnerable populations.<sup>6</sup>

- States should ensure flexible and timely access to a comprehensive range of mental health medications in all Medicaid and Exchange health plans and community mental health programs.

## Workforce development

A significant shortage of mental health professionals<sup>7</sup> keeps individuals and families from getting needed treatment—and contributes to inadequate care and unsafe conditions in many mental health facilities. Youth and adults living in communities of color and in rural or frontier areas are disproportionately affected by workforce shortages.

Adding to the problem, few academic training programs and provider systems provide in-depth training on the treatment of individuals living with severe mental illness<sup>8</sup> or on cultural competence in service delivery.

- States should ensure active recruitment and training of health professionals skilled in effective and culturally competent treatment interventions for children and adults living with serious mental illness.

## Data collection

Reliable data is crucial for informed decision-making and improving the quality of mental health care. Unfortunately, data collection in mental health systems lags behind other health care disciplines.<sup>9</sup>

Standardized data collection, including meaningful performance, process and outcome measures, will promote the effectiveness of health systems that serve children and adults who live with mental illness.

- States should require standardized, statewide data collection and public posting of meaningful performance, process and outcome measures for mental health care.

## Promote integration of mental health, addictions and primary care

### Integration of care

Individuals living with serious mental illness frequently live with other medical and substance use conditions, yet few receive integrated treatment that addresses their whole health needs. Disturbingly, people living with serious mental illness die an average of 25 years earlier than other Americans, largely of treatable health conditions.<sup>10</sup>

In addition, about half of Medicaid enrollees living with disabilities who have a chronic health condition, such as asthma, diabetes or heart disease, also have a mental illness.<sup>11</sup> Health care costs are up to 75 percent higher for individuals with co-occurring chronic health conditions and mental illness.<sup>12</sup>

Effective models of integrated mental health, addictions and primary health care, such as health homes and other collaborative care models, show promise in both improving health outcomes and in controlling health care costs for individuals with complex health and mental health care needs.<sup>13</sup>

- States should require effective models of integrated care, such as health homes, in all health and mental health care and addictions treatment settings.

## Improve the mental health of children, youth and young adults

### Early identification and intervention

Half of all chronic serious mental illness begins by age 14, three-quarters by age 24.<sup>14</sup> Despite effective treatment, most youth go without. Early detection and treatment of mental illness can result in a shorter and less disabling course of illness, as well as promote success in school and the community. Early intervention is also critical to address youth suicide, the third leading cause of death for people ages 15 to 24.<sup>15</sup>

The U.S. Preventive Services Task Force recommends screening of adolescents for major depression to ensure diagnosis and treatment. The American Academy of Pediatrics (AAP) calls for mental health screening in primary care settings and Medicaid also requires early screening and intervention under the Early Periodic Screening, Diagnosis and Treatment (EPSDT) provision of the federal law.<sup>16</sup>

- Screening, assessment and early intervention of mental health conditions for children, youth and young adults should be an integral part of health care delivery systems.

### Home and community-based services

Today, about one in 10 youth experiences a mental health condition severe enough to cause significant impairment in their day-to-day lives.<sup>17</sup> 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 wind up in hospitals or facility-based care—or in the custody of child welfare.

A comprehensive range of timely and effective home and community-based services is necessary to provide youth the opportunity to live successfully with mental health conditions.

- States should provide effective home and community-based services that help children, youth and young adults succeed at home, in school and in their communities.

## Juvenile justice diversion

More than 106,000 teens are 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. Alarming, the U.S. Department of Justice has found that juvenile facilities fail to adequately address mental health needs.<sup>18</sup>

Routine mental health screenings and opportunities for diversion to effective services and supports could keep our youth from falling into juvenile justice systems that are ill-equipped to serve their needs.<sup>19</sup>

- States should identify and divert youth living with serious mental health conditions from detention to appropriate community treatment.

## Transition-age mental health services

Serious mental illness often emerges during teen years and young adulthood. Too frequently, young adults fall through the gaps between child and adult mental health systems. As a result, young adults with psychiatric diagnoses are about four times less likely to be engaged in employment or enrolled in college or trade school.<sup>20</sup>

Care coordination, continuous mental health treatment, peer support services and supports for education, employment and housing<sup>21</sup> can fill pressing needs<sup>22,23</sup> and ensure better lives for young adults who live with serious mental illness.

- States should ensure that young adults living with serious mental health conditions receive coordinated, developmentally-appropriate services to support successful transitions to adulthood.

## Meet the mental health needs of service members, veterans and their families

### Mental health service collaboration

One in four of America's service men and women who returned from Iraq and Afghanistan live with a mental illness.<sup>24</sup> Conditions such as depression and PTSD complicate integration into civilian life and place tremendous stress on service men and women and military families.<sup>25</sup>

Worse, mental illness contributes to high rates of suicide. From 2005 to 2010, one service member died by suicide every 36 hours.<sup>26</sup> Although only one percent of Americans have served during the wars in Iraq and Afghanistan, veterans represent 20 percent of suicides nationally.<sup>27</sup>

Collaboration between state-funded public mental health programs and state National Guard and Veterans Affairs entities is imperative to provide mental health screening, diagnosis, services and supports that address the needs of those who have served our nation.

- States should ensure early identification and access to community-based mental health services and supports for service members, veterans and their families.

## Provide homes and jobs 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. With average disability incomes of just 19 percent of the median income, most cannot afford decent housing.<sup>28</sup> Without housing, too many cycle in and out of homelessness, jails, shelters and emergency departments—or remain institutionalized.

Supportive housing and “Housing First” models combine housing with support services to provide stability and reduce shelter use, hospitalizations and involvement with criminal justice systems.<sup>29</sup>

- States should provide affordable permanent supportive housing for people living with serious mental illness.

## Supported employment

Fewer than one in six adults living with serious mental illness is employed,<sup>30,31,32</sup> even though most want to work.<sup>33</sup> An estimated \$92 billion is spent annually for state and federal disability payments to people living with mental illness.<sup>34</sup> The loss of productivity and loss of human potential is costly and unnecessary.

Supported employment models show that with effective supports, most adults living with serious mental illness can work and achieve independence,<sup>35</sup> yet too few have access to successful employment programs.

- States should have policies and statewide programs that lead to competitive employment for people living with serious mental illness.

## Eliminate disparities in mental health care

### Cultural and linguistic competence

Mental illness affects Americans throughout the lifespan, in all geographic regions and across all racial and ethnic groups. Unfortunately, individuals living in racially and ethnically diverse communities are less likely to receive needed mental health care and, when they do receive treatment, more likely to receive poor quality of care.<sup>36</sup>

With racial and 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.

- States should incorporate cultural and linguistic competence standards in requirements for mental health funding.

## End the inappropriate jailing of people living with mental illness

### Diversion from incarceration

Disproportionate numbers of people living with mental illness are in our criminal justice systems,<sup>37</sup> often as a result of untreated or undertreated illness. Tragically, jails and prisons are now the largest psychiatric wards in the nation, housing well over 350,000 inmates living with serious mental illness.<sup>38</sup>

Jail diversion programs are needed to divert offenders living with mental illness from incarceration to more appropriate and cost-effective community-based treatment and supervision.<sup>39</sup>

- States should divert people living with serious mental illness from jail to appropriate community treatment.

### Care in custody

Jails and prisons frequently fail to provide effective treatment to individuals living with serious mental illness and substance abuse disorders. Worse, many individuals are housed in solitary confinement as a result of their symptoms.<sup>40</sup> Without appropriate treatment, individuals living with mental illness experience

significant suffering and worsening of their condition and, too often, horrifying deaths.

States like Colorado, Indiana and New York are reducing the use of solitary confinement and improving treatment for individuals living with serious mental illness who are incarcerated. All states should follow their lead.

- States should eliminate solitary confinement and ensure continuous and effective mental health, addictions and medical care for inmates living with serious mental illness.

### **Connection to benefits**

People in jails and prisons experience serious mental illness at a rate two to six times higher than the general population.<sup>41,42</sup> Typically, inmates living with mental illness are released without access to the mental health treatment and supports they need to live successfully in the community and, instead, end up cycling in and out of jail.<sup>43</sup>

Ensuring that people living with mental illness are connected to benefits and treatment upon release promotes successful re-entry, safer communities and more efficient use of tax dollars.

- States should ensure connection to treatment and supports and enrollment in federal SSI/SSDI, Medicaid and other benefits for eligible individuals living with serious mental illness upon release from custody.

## Resources

### Mental Health Financing

Mental Health Financing in the United States: A Primer  
Kaiser Commission on Medicaid and the Uninsured

State Mental Health Cuts: The Continuing Crisis  
NAMI

### Effective Mental Health Services

Adult Mental Health Service and Support Array  
NAMI

Child and Youth Mental Health Service and Support Array  
NAMI

Evidence-Based Practices KITS  
SAMHSA

### Access to Medications

Access to Medications Toolkit  
NAMI

### Workforce Development

Understanding the National Health Service Corp: A Guide for Community Behavioral Health Providers and Primary Care Partners  
SAMHSA-HRSA Center for Integrated Health Solutions

Primary and Behavioral Healthcare Integration: Guiding Principles for Workforce Development  
SAMHSA-HRSA Center for Integrated Health Solutions

### Data Collection

Increasing Access to Behavioral Healthcare: Managed Care Options and Requirements  
National Council for Community Behavioral Healthcare

### Primary Care Integration

Integrated Care Models  
SAMHSA-HRSA Center for Integrated Health Solutions

Integrating Mental Health and Pediatric Primary Care: A Family Guide  
NAMI

### Early Identification and Intervention

TeenScreen®  
National Center for Mental Health Checkups at Columbia University

## **Child & Adolescent Home and Community-Based Services**

Reinvesting in the Community: A Family Guide to Expanding Home & Community-Based Mental Health Services and Supports

NAMI

The Remedy: The Pathway to Home-Based Services

Center for Public Representation

## **Juvenile Justice Diversion**

Blueprints for Violence Prevention

Center for the Study and Prevention of Violence

## **Military, Veterans and Family Support**

Military Families

SAMHSA

## **Supportive Housing**

Corporation for Supportive Housing

## **Supported Employment**

Supported Employment Evidence-Based Practices Kit

SAMHSA

## **Cultural and Linguistic Competence**

National Standards on Culturally and Linguistically Appropriate Services

The Office of Minority Health

## **Criminal Justice Diversion**

Diversion from Incarceration and Reentry

Bazelon Center for Mental Health Law

## **Connection to Benefits**

Ensuring Timely Access to Medicaid and SSI/SSDI for People with Mental Illness Released from Prison

Re-Entry Policy Council of the Council of State Governments

\*Citations can be found at [www.nami.org/citations](http://www.nami.org/citations).