



State Action Agenda

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

NAMI's State Action Agenda outlines eight key objectives and accompanying policy positions that form a basic foundation to support of 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.

Key Policy Objectives

1. Increase Access to Effective Mental Health Care
2. Promote Integration of Mental Health, Addictions and Primary Care
3. Strengthen the Mental Health Workforce
4. Eliminate Disparities in Mental Health Care
5. Ensure Transparency and Accountability
6. Improve the Mental Health of Children and Youth
7. Provide Homes and Jobs for People Living with Mental Illness
8. End the Inappropriate Jailing of People with Mental Illness



1. Increase Access to Mental Health Care

Medicaid

Medicaid is a joint federal-state program that covers low-income children, seniors, and people with disabilities.¹ Medicaid is the single largest payer of mental health services in the country and provides vital coverage for persons who are severely affected by mental illness.² Because each state develops its own Medicaid program(s), services vary from state to state. Fortunately, a number of new Medicaid options and increased program flexibility provide attractive incentives to states to provide a needed set of community-based treatment services in their Medicaid plans.

In addition, the federal Affordable Care Act expands Medicaid eligibility in 2014 (or earlier for states that phase in expansion) to Americans whose incomes are less than 133 percent of the federal poverty level. Many people living with mental illnesses will benefit from this expansion. However, the law permits, but does not require, states to cover a full Medicaid benefit set for Medicaid expansion "benchmark" plans. A full benefit set is needed in all

Medicaid programs, including benchmark plans, to provide the array of effective services that allow children and adults to experience resiliency and recovery and to reduce reliance on costly institutional care.³

- **State Medicaid programs and Medicaid expansion benchmark plans should provide an array of effective mental health services that promote recovery and community inclusion.**

Community Mental Health Programs

State mental health agencies are 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 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.

When funding is inadequate to meet demand, state agencies and community mental health programs cut services, restrict eligibility for care or both. Adequate and stable funding for non-Medicaid mental health services and supports, including inpatient, psychosocial rehabilitation and longer-term care, is needed to ensure children and adults get the help they need.

- **States should ensure adequate and stable funding to meet community needs for non-Medicaid mental health services, including inpatient, psychosocial rehabilitation and longer-term care.**

Recovery-oriented community mental health systems provide an array of effective services and supports that meet varying needs, including evidence-based practices such as ACT teams and integrated dual-diagnosis treatment, that have a proven record of success for people who live with severe mental illness or co-occurring disorders. Such an array is essential for states to comply with the community integration requirements set forth in the U.S. Supreme Court's *Olmstead Decision*.

- **Community mental health programs should provide a comprehensive array of effective services and supports that promote recovery and community inclusion.**

Private Insurance

Over half of Americans have employer or individual insurance coverage,⁴ yet many experience unequal coverage of mental health and substance use conditions.⁵ While passage of the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act in 2008 brings insurance parity to over 82 million Americans covered by plans subject to federal law and the Patient Protection and Affordable Care Act will bring parity to individual and small group plans offered through insurance exchanges in 2014, strong state leadership will be necessary to ensure proper implementation and enforcement of state and federal parity requirements.

- **States should ensure full implementation of and compliance with mental health and substance abuse parity legislation.**

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 illness. 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, should provide coverage for and develop capacity to deliver an array of effective treatments, including care management, for children and adults with serious mental health and co-occurring disorders.

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

Medications

For many individuals with mental illness, medications can be an important element of successful treatment. According to the National Institute of Mental Health, individual patients have unique responses to medications and need more, not fewer, choices.⁶ In contrast, restrictive formularies, lack of coverage, and cost-sharing for vulnerable populations can result in poor health outcomes, increased emergency room visits, hospital care, and institutionalization.⁷

- **States should 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 Integration of Mental Health, Addictions and Primary Care

Primary Care Integration

Individuals with serious mental illness are at increased risk for comorbid medical and substance use conditions, yet few receive integrated treatment to address co-occurring conditions. Disturbingly, people with serious mental illness die an average of 25 years earlier than other Americans, largely of *treatable health conditions*.⁸

In addition, 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.⁹

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.

Integration of mental health, addictions and primary health care, including collaborative models of care, 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 and primary care should be the norm in all health care settings.**

3. Strengthen the Mental Health Workforce

Workforce Development

A nationwide shortage of mental health professionals¹⁰ 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 rural and frontier areas 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.¹¹

Adding to the problem, few academic training programs and provider systems provide in-depth training on the treatment of individuals with severe mental illness¹² or on cultural competence in service delivery.

- **States should actively recruit and train health professionals in effective and culturally competent treatment interventions for children and adults with serious mental illness.**

4. 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.¹³ 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.

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

5. Ensure Transparency and Accountability

Data Collection

Reliable data is critical for informed decision-making and quality improvement. And yet, data collection in mental health systems lags far behind other health care disciplines. Standardized data collection across states, including meaningful performance, process and outcome measures, positions states to better assess the performance of their mental health system, including how well the needs of children and adults who live with mental illness are being met.

- **States should have standardized statewide data collection and public posting of meaningful performance, process and outcome measures, including data by race and ethnicity.**

6. 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 treatment, most children go without. Early detection and treatment of mental illness can result in a much shorter and less disabling course of illness,¹⁴ 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. In the Latino community, one out of every seven Latina teens attempts suicide.¹⁵

The U.S. Preventive Services Task Force recommends screening of adolescents (12-18 years of age) for major depression to ensure diagnosis and treatment. And, 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.¹⁶ Medicaid also requires early screening and intervention under the Early Periodic Screening, Diagnosis and Treatment (EPSDT) provision of the federal law.¹⁷

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

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.¹⁸ Without appropriate treatment, our 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 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 services--particularly proven, evidence-based interventions--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 and youth 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.¹⁹ 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.²⁰

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

7. 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. 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. Nearly one million adults with mental illness have been homeless. With average disability incomes of just 18 percent of the median income, most cannot afford decent housing.²¹

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.²²

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

Supported Employment

Only one in three adults with serious mental illness is employed,²³ even though the majority want to work.²⁴ An estimated \$25 billion is spent annually for disability payments to people with mental illness.²⁵ The loss of productivity and loss of human potential is costly and unnecessary.

Supported employment models show that with effective supports, 60 percent of adults with serious mental illness can work and achieve independence,²⁶ yet too few have access to successful employment programs.²⁷

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

7. End the Inappropriate Jailing of People with Mental Illness

Diversion from Incarceration

Disproportionate numbers of people with mental illness end up in our criminal justice system,²⁸ often as a result of untreated or undertreated illness. People with mental illness often fare poorly in jails and prisons. Tragically, our jails and prisons are now the largest psychiatric wards in the nation, housing well over 350,000 inmates with serious mental illness compared to approximately 70,000 patients with serious mental illness in hospitals.²⁹

Yet, jail diversion programs have shown that many offenders with mental illness can be diverted to more appropriate—and cost-effective—comprehensive community care.³⁰

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

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.^{31,32} At release, most find they are without benefits 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.³³

- **States should ensure enrollment in federal SSI/SSDI, Medicaid and other benefits upon release from jail or prison for eligible individuals with serious mental illness.**

Resources

Medicaid

Kaiser Family Foundation

Medicaid: A Primer

<http://www.kff.org/medicaid/7334.cfm>

Centers for Medicare & Medicaid Services (CMS)

Dear State Medicaid Letter (May 20, 2010)

<https://www.cms.gov/smdl/downloads/SMD10008.pdf>

National Alliance on Mental Illness

Medicaid Toolkit

http://www.nami.org/Template.cfm?Section=issue_spotlights&template=/ContentManagement/ContentDisplay.cfm&ContentID=54910

Community Mental Health Programs

National Mental Health Information Center

Mental Health Transformation State Incentive Grant Program

<http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/mentalhealth/default.asp>

Primary Care Integration

The National Council for Community Behavioral Healthcare

Resource Center for Primary Care and Behavioral Health Collaboration

http://www.thenationalcouncil.org/cs/new_at_the_resource_center

American Academy of Pediatrics (AAP)

Children's Mental Health in Primary Care: Collaborative Projects

<http://www.aap.org/mentalhealth/mh3co.html>

Workforce Development

The Annapolis Coalition on the Behavioral Health Workforce

<http://www.annapoliscoalition.org/pages/>

Comprehensive Service Array

National Alliance on Mental Illness

Grading the States 2009

http://www.nami.org/Content/NavigationMenu/Grading_the_States_2009/Grading_the_States_20091.htm

National Mental Health Information Center

Evidence-Based Practice Kits

<http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/toolkits/about.asp>

Medications

National Alliance on Mental Illness

Access to Medications Toolkit

<http://www.nami.org/medtoolkit>

Cultural and Linguistic Competence

The Office of Minority Health

National Standards on Culturally and Linguistically Appropriate Services (CLAS)

<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15>

Substance Abuse and Mental Health Services Administration (SAMHSA)

Cultural Competence Standards in Managed Care Mental Health Services

<http://mentalhealth.samhsa.gov/publications/allpubs/SMA00-3457/default.asp>

The Annapolis Coalition

Cultural Competencies and Disparities Issues

http://www.annapoliscoalition.org/pages/default2.asp?active_page_id=98

Data Collection

National Association of State Mental Health Program Directors

Research Institute

<http://www.nri-inc.org/>

Substance Abuse and Mental Health Services Administration (SAMHSA)

National Performance Outcome Measures (NOMs) and State Data

<http://www.nationaloutcomemeasures.samhsa.gov/>

Early Identification and Intervention

National Center for Mental Health Checkups at Columbia University

TeenScreen

<http://www.teenscreen.org/>

American Academy of Pediatrics

Evidence-Based Child & Adolescent Psychosocial Interventions

<http://www.aap.org/mentalhealth/>

Rosie D.

EPSDT Case Website

<http://www.rosied.org/>

Child & Adolescent Home and Community-Based Services

National Alliance on Mental Illness

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

<http://www.nami.org/Content/ContentGroups/CAAC/FamilyGuideReinvestingFinal.pdf>

National Alliance on Mental Illness

Child & Adolescent Action Center

Research, Services & Treatment: Evidence-Based Practices

http://www.nami.org/Template.cfm?Section=Research_Services_and_Treatment&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=73&ContentID=37843

National Center for Children in Poverty

Towards Better Behavioral Health for Children, Youth and their Families: Financing that Supports Knowledge

http://www.nccp.org/publications/pub_804.html

Juvenile Justice Diversion

National Center for Mental Health and Juvenile Justice

Blueprint for Change

<http://ncmhjj.com/Blueprint/default.shtml>

Center for the Study and Prevention of Violence

Blueprints for Violence Prevention

<http://www.colorado.edu/cspv/blueprints/>

Supportive Housing

Corporation for Supportive Housing

<http://www.csh.org/>

National Alliance to End Homelessness

<http://www.endhomelessness.org/>

Technical Assistance Collaborative, Inc.

<http://www.tacinc.org/>

Supported Employment

Dartmouth IPS Supported Employment Center

<http://www.dartmouth.edu/~ips/>

Association for Persons in Supported Employment (APSE)

<http://www.apse.org/about/>

National Mental Health Information Center

Supported Employment

<http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/toolkits/employment/default.aspx>

Diversion from Incarceration

National GAINS Center

<http://www.gainscenter.samhsa.gov/html/>

Bazelon Center for Mental Health Law

Diversion from Incarceration and Reentry

<http://www.bazelon.org/Where-We-Stand/Access-to-Services/Diversion-from-Incarceration-and-Reentry-.aspx>

National Alliance on Mental Illness

Criminal Justice Center

<http://www.nami.org/criminaljustice/>

Connection to Benefits

Reentry Policy Council

<http://reentrypolicy.org/>

Criminal Justice/Mental Health Consensus Project

<http://consensusproject.org/>

Endnotes

- ¹ Kaiser Commission on Medicaid and the Uninsured, *The Medicaid Program at a Glance*, March 2007. Publication #7235-02.
- ² New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. pp. 21, 58-59.
- ³ Department of Health and Human Services, Centers for Medicare & Medicaid Services, State Medicaid Director Letter dated May 20, 2010, SMDL#10-0008.
- ⁴ Kaiser Commission on Medicaid and the Uninsured, *Health Insurance Coverage of the Total Population (2005)*. Retrieved on April 22, 2007 from www.statehealthfacts.org.
- ⁵ NAMI National, *State Mental Health Parity Laws 2007*.
- ⁶ National Institutes of Health, National Institute of Mental Health, *NIMH Perspective on Antipsychotic Reimbursement: Using Results From The CATIE Cost Effectiveness Study*, December 2006.
- ⁷ Tambllyn, R. et al., "Adverse Events Associated with Prescription Drug Cost-Sharing among Poor and Elderly Persons," *Journal of the American Medical Association*, 285(4):421-429, January 2001; West, Joyce C., Ph.D., M.P.P., et al, "Medication Access and Continuity: The Experiences of Dual-Eligible Psychiatric Patients During the First 4 Months of the Medicare Prescription Drug Benefit," *Am J Psychiatry*; 164:789-796, May 2007.
- ⁸ Parks, Joe, MD, et al., National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council. Morbidity and Mortality in People with Serious Mental Illness. October 2006.
- ⁹ Mitchell AJ, et al. (2009). Clinical diagnosis of depression in primary care: a meta-analysis. *Lancet*, 22;(374):609-19.
- ¹⁰ U.S. Department of Health & Human Services, Health Resources and Services Administration (HRSA), *Designated Health Professional Shortage Areas (HPSA) Statistics*, June 22, 2010. Accessible on the Web at http://ersrs.hrsa.gov/ReportServer?/HGDW_Reports/BCD_HPSA/BCD_HPSA_SCR50_Smry&rs:Format=HTML3.2.
- ¹¹ U.S. Department of Health and Human Services. *Mental Health: Culture, Race, and Ethnicity. A Supplement to Mental Health: A Report of the Surgeon General*, 2001.
- ¹² The Annapolis Coalition on the Behavioral Health Workforce, *Severe Mental Illness*. Access on the web at http://www.annapoliscoalition.org/pages/default2.asp?active_page_id=102, June 2010.
- ¹³ U.S. Department of Health and Human Services. *Mental Health: Culture, Race, and Ethnicity. A Supplement to Mental Health: A Report of the Surgeon General*, 2001.
- ¹⁴ National Institutes of Health, National Institute of Mental Health, *Mental Illness Exact Heavy Toll, Beginning In Youth*, June 2005. NIMH 301-443-4536.
- ¹⁵ Centers for Disease Control and Prevention, 2007 Survey on High school Students.
- ¹⁶ American Academy of Pediatrics. Accessed online at <http://www.aap.org/mentalhealth/>.
- ¹⁷ U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), *EPSDT Program Background*. Accessible on the Web at <http://www.hrsa.gov/epsdt/overview.htm>.
- ¹⁸ National Institute of Mental Health, Child and Adolescent Mental Health, information accessed at www.nimh.nih.gov.
- ¹⁹ Skowrya, Kathleen and Cocozza, Ph.D., Joseph J., National Center for Mental Health and Juvenile Justice, *A Blueprint for Change: Improving the System Response to Youth with Mental Health Needs Involved with the Juvenile Justice System*, (June 2006).
- ²⁰ *Ibid.*
- ²¹ New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. pp. 30-31.
- ²² Culhane, D.P., et. Al., *The Impact of Supportive Housing for Homeless People with Severe Mental Illness on the Utilization of the Public Health, Corrections and Emergency Shelter Systems: The New York-New York Initiative*.
- ²³ New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. p.34.
- ²⁴ Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, *Evidence-Based Practices: Shaping Mental Health Services Toward Recovery*. Accessible on the Web at <http://mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/employment/>.
- ²⁵ Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, High Unemployment and Disability for People with Serious Mental Illness, Accessible on the Web at <http://mentalhealth.samhsa.gov/publications/allpubs/NMH02-0144/unemployment.asp>.
- ²⁶ Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, *Evidence-Based Practices: Shaping Mental Health Services Toward Recovery*. Accessible on the Web at <http://mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/employment/>.
- ²⁷ New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. p.34.
- ²⁸ James, Doris J., and Glaze, Lauren E., Bureau of Justice Statistics Special Report, *Mental Health Problems of Prison and Jail Inmates*, September 2006, NCJ 213600.
- ²⁹ Honberg, J.D., Ron, NAMI, Presentation at Illinois Forum on Partnerships and Solutions, October 18, 2006.
- ³⁰ New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. pp.43-45.
- ³¹ *Report of the Re-Entry Policy Council: Charting the Safe and Successful Return of Prisoners to the Community*. Council of State Governments. Re-Entry Policy Council. New York: Council of State Governments. January 2005.
- ³² Steadman, Ph.D., Henry J. et al., *Prevalence of Serious Mental Illness Among Jail Inmates*, Psychiatric Services, June 2009.
- ³³ *Report of the Re-Entry Policy Council: Charting the Safe and Successful Return of Prisoners to the Community*. Council of State Governments. Re-Entry Policy Council. New York: Council of State Governments. January 2005.