National Alliance on Mental Illness

NAMI Policy Priorities and Comprehensive Mental Health Reform Legislation

Introduction

Two federal bills in the 114th Congress, *The Mental Health Reform Act of 2015* (S. 1945) and *The Helping Families in Mental Health Crisis Act of 2015* (H.R. 2646), contain numerous provisions intended to improve mental health care. Several of the key topics and provisions in the legislation that reflect NAMI policy priorities are outlined below.

NAMI Priority: Enforcing Insurance Parity

Mental health care is frequently denied by health plans at higher rates than other health care despite the federal mental health parity law. Stepped up enforcement of the parity law is needed so that Americans aren't unfairly denied treatment for mental health conditions.

- S. 1945 and H.R. 2646 increase transparency by requiring a Government Accountability Office (GAO) report to Congress on how well health plans are complying with parity requirements and how proper enforcement can be used to ensure full compliance.
- S. 1945 also requires annual reports summarizing all federal investigations regarding compliance with parity.
- S. 1945 requires federal regulations or guidance on disclosure requirements for health insurance plans, including how non-quantitative limits for mental health care (limitations that cannot be counted, such as placement of medications on tiers or provider networks) are being applied comparably with medical care.
- S. 1945 requires clarification of the timeline and process for complaints.
- S. 1945 authorizes random audits of health plans and health insurance issuers for compliance with the federal parity law.

NAMI supports the requirement in both S. 1945 and H.R. 2646 for a GAO report to Congress on compliance with the federal parity law.

NAMI supports the additional provisions in S. 1945 for reporting on prior federal investigations, for issuing regulations or guidance on disclosure requirements, including the application of non-quantifiable treatment limits for mental health care as compared with medical care, clarification of the timeline and process for complaints and for random audits of health plans and health insurance issuers to determine compliance.

NAMI's ask:

With multiple agencies enforcing the federal parity law at both federal and state levels, there is currently no clear path for individuals who believe their rights under this law have been violated to file complaints. NAMI therefore supports the proposal in Representative Joseph Kennedy's bill, the *Behavioral Health Transparency Act of 2015* (H.R. 4276) to establish a one-step Internet website portal for submitting complaints alleging violations of the law. Such a site will make it easier both for individuals to submit complaints and to monitor the status of their complaints.

NAMI Priority: Increasing the Availability of Effective Mental Health Care

Half of children and adults with mental illness go without any treatment. Others get too little, too late. In many communities, there aren't enough providers or services to meet needs. Without effective treatment, people end up in emergency departments and hospitals, in custody, out of school, out of work or on the streets.

NAMI Priority: Increasing the Availability of Effective Mental Health Care (Continued)

- S. 1945 and H.R. 2646 provide funding for the BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative at the National Institute of Mental Health to advance understanding of the human brain and psychiatric conditions.
- S. 1945 and H.R. 2646 authorize innovation grants to fund promising practices and demonstration grants to expand evidence-based practices for mental health screening, early diagnosis, intervention and treatment for children and adults.
- S. 1945 and H.R. 2646 require federal Mental Health Services Block Grant plans to include integration of physical and mental health services and a detailed list of services available in each county.
- S. 1945 and H.R. 2646 require state reporting of data on outcomes for people with serious mental illness, including rates of suicide, emergency hospitalizations, arrests, housing, employment, educational attainment, etc.
- S. 1945 and H.R. 2646 create a minority fellowship program to improve the quality and availability of culturally competent mental health and substance use services.
- S. 1945 and H.R. 2646 create a national suicide prevention hotline program.
- S. 1945 and H.R. 2646 permit "same-day billing" of Medicaid for mental health and physical health services provided on the same day at the same facility.
- S. 1945 and H.R. 2646 establish an Interagency Serious Mental Illness Coordinating Committee to annually summarize advances in research and update a strategic plan for advancing use of effective mental health services and adherence to treatment.
- S. 1945 requires states with community mental health block grants to have outreach and engagement programs, such as peer support services, Wellness Recovery Action Plans, Early and First Episode Psychosis and Housing First and to promote use of Psychiatric Advance Directives.
- S. 1945 funds a grant program to enhance integration between primary and behavioral health care.
- H.R. 2646 expands Medicare discharge planning requirements to include patients in psychiatric hospitals or units.
- H.R. 2646 provides a grant program for ten states to train primary care physicians on identifying and treating mental illness and for reimbursement of tele-mental health consultations.

NAMI supports all the provisions that are in both S. 1945 and H.R. 2646 as important means of improving mental health services and supports for people living with mental illness.

NAMI supports the requirements in S. 1945 for states to have outreach and engagement programs, to promote use of Psychiatric Advance Directives and to fund a grant program to enhance integration of care.

NAMI supports the provisions in H.R. 2646 to include patients in psychiatric hospitals or units in Medicare discharge planning requirements and for training of primary care physicians and reimbursement of tele-mental health services.

NAMI's ask:

Millions of Americans provide care to an adult living with mental illness—and many more care for a child living with a mental health condition. Family caregivers of people with mental illness experience particularly high levels of stress and isolation and experience significant challenges finding services.

NAMI recommends the addition of language that provides federal support for family caregivers of children and adults with serious mental illness, including addressing the need for peer support and assistance with understanding mental health conditions, medications and side effects, navigating the mental health system, engaging the treatment team and communication and coping strategies. Federal support should be provided to community organizations with proven expertise and experience working with families, individuals with mental illness and related stakeholders.

NAMI Priority: Promoting Early Identification and Intervention

Half of all lifetime cases of mental illness begin by age 14; three-quarters by age 24. The quicker people get treatment, the better the outcomes. Yet, the average delay before getting treatment for early or first episode of psychosis in the United States is about 74 weeks, while in the United Kingdom the delay is just 7 weeks. Promoting earlier identification and intervention is critical to building better lives for youth and young adults who experience mental illness.

- S. 1945 and H.R. 2646 renew block grant set-aside funding for evidence-based interventions, such as those based on the RAISE study (Early and First Episode Psychosis programs).
- S. 1945 and H.R. 2646 authorize innovation grants for promising practices and direct one-third of funding to serve children and youth under the age of 18.
- S. 1945 and H.R. 2646 authorize demonstration grants to expand evidence-based practices to enhance screening, early diagnosis, intervention and treatment and direct at least half of funding to serve individuals under the age of 26.
- S. 1945 and H.R. 2646 authorize grants for early childhood intervention and treatment and amend the Public Health Service Act to include child and adolescent mental health professionals in programs to promote workforce development.
- S. 1945 reauthorizes and increases comprehensive community mental health services for children with serious emotional disturbances.
- S. 1945 creates grants to promote pediatric tele-mental health consultation and support for pediatric primary care.
- H.R. 2646 reauthorizes the Garrett Lee Smith Act for suicide prevention and intervention and increases funding for campus mental health services.

NAMI supports the provisions in both S. 1945 and H.R. 2646 that support First Episode Psychosis programs

NAMI supports the provisions in both S. 1945 and HR 2646 that support grant programs to promote promising and evidence-based practices for children, youth and young adults and for early childhood intervention and treatment and provisions to increase the availability of child and adolescent mental health professionals.

NAMI supports the provisions in S. 1945 to reauthorize and increase community mental health services for children with serious emotional disturbances and to promote pediatric tele-mental health services.

NAMI supports the reauthorization of the Garrett Lee Smith Act and increased funding for campus mental health services in H.R. 2646.

NAMI's ask:

NAMI asks that the block grant set-aside be expanded from five percent to ten percent to make it consistent with the Congressional budget for fiscal year 2016. We further urge that use of these funds be limited to supporting programs that follow the RAISE study models, such as First Episode Psychosis (FEP) programs.

The establishment and funding of a national technical assistance center for early and first episode psychosis programs to disseminate the model, promote quality and uniformity of training, ensure program fidelity and inclusion of people living with mental illness and families, and data collection and reporting. Federal support should be provided to community organizations with proven expertise and experience working with families, individuals with mental illness and related stakeholders.

NAMI Priority: Reducing Criminalization

Two million Americans with mental illness fill our country's jails instead of getting the treatment and support they need to live in the community. It's time to reverse this shameful trend through commitment to reducing the incarceration of people living with mental illness.

- S. 1945 and H.R. 2646 require regular reports on how many people with serious mental illness are arrested or incarcerated, how grant programs are affecting rates of arrest and incarceration and also require community mental health block grant plans to describe case management services and how they will reduce poor outcomes, including arrests and incarceration.
- S. 1945 and H.R. 2646 require a plan to end incarceration of individuals with serious mental illness for non-violent offenses within ten years and to reinvest savings into mental health and substance use services.
- S. 1945 requires regular statistical reports of outcome measures in each state, including arrests and incarceration, for people living with mental illness, substance use disorders and co-occurring disorders.
- S. 1945 requires a study on the effectiveness of outpatient program models for people with serious mental illness, including rates of arrest and incarceration.
- S. 1945 requires states with community mental health block grants to have evidence-based outreach and engagement programs, such as Assertive Community Treatment (ACT), Forensic Assertive Community Treatment (FACT) and Housing First, which improve outcomes for individuals with serious mental illness, including reducing arrest and incarceration.
- H.R. 2646 includes crisis intervention grants for training of police and first responders.

NAMI supports the requirements in both S. 1945 and H.R. 2646 for reporting on rates of arrest and incarceration, descriptions of case management services and the development of a plan to end incarceration of individuals with serious mental illness for non-violent offenses within ten years.

NAMI supports additional requirements in S. 1945 for a study of program effectiveness, regular statistical reports of outcome measures in each state and for evidence-based programs resulting in reduced rates of arrest and incarceration.

NAMI supports the additional provision in H.R. 2646 for crisis intervention grants.

NAMI's ask:

The establishment and funding of a national center for CIT excellence to disseminate the model, promote quality and uniformity of training, ensure program fidelity and inclusion of people living with mental illness and families, and data collection and reporting. The center should include community organizations with proven expertise and experience working with families, individuals with mental illness and related stakeholders.

Additional Key Issues

The comprehensive mental health reform bills in Congress, particularly the House bill, H.R. 2646, include some provisions that have generated sharp opinions. NAMI's analysis of these issues is outlined below:

- **Institutions for Mental Disease (IMD) Exception**
  Currently, Medicaid does not cover services for Medicaid enrollees aged 21-64 when those services are provided by a psychiatric inpatient or sub-acute facility of more than 16 beds.
    - S. 1945 modifies the IMD exclusion by permitting Medicaid billing of acute psychiatric care for adults ages 21-64 in acute care units of state hospitals or in psychiatric facilities if the unit or facility has an average length of stay of fewer than 20 days on an annual basis.
    - H.R. 2646, as amended, permits states to include coverage of inpatient psychiatric services in Medicaid managed care plans provided in an inpatient hospital facility or sub-acute crisis facility for a short term stay of no more than 15 days in a month.

  NAMI supports modifying the IMD exclusion. Both S. 1945 and H.R. 2646 will help address the shortage of psychiatric acute care, reduce long emergency department stays (emergency department "boarding"), provide more appropriate care and avoid the frequently tragic consequences when people do not get the crisis stabilization services they need.

  Brief acute psychiatric stays do not represent a return to institutionalization. Rather, the current policy of not covering certain acute psychiatric facilities represents a lack of parity, or inequitable coverage of inpatient care for mental health conditions.

  NAMI's ask:
  NAMI supports adding requirements to collect and report on quality measures, including hospital readmission rates, follow-up after hospitalization, use of seclusion and restraint and patient surveys on quality of care.

  NAMI would like to see coverage of short-term acute psychiatric stays applied to both Medicaid managed care *and* fee-for-service programs.

- **Assisted Outpatient Treatment (AOT)**
  NAMI supports the availability of a full continuum of services and supports that allow individuals to reach and maintain recovery and to live full and productive lives in the community. AOT serves a role as the last resort in a continuum of care in certain circumstances for people who lack the capacity to make an informed decision, are experiencing serious symptoms and are likely to deteriorate substantially without timely treatment.
    - S. 1945 and H.R. 2646 promote AOT by extending an existing grant program and authorizing a funding increase of $5 million for this program.
    - H.R. 2646 specifies that 80 percent of the grant dollars be made available for new AOT programs. In addition, H.R. 2646, as currently amended, provides a 2 percent financial incentive to states that have an operational AOT law.

  NAMI supports extending and increasing the existing grant program to support implementation of AOT programs.

  NAMI's ask: NAMI supports adding requirements that AOT programs include a variety of strategies to engage people voluntarily in services throughout the process, including utilizing shared decision-making strategies, peer supports, and involving consumers and families meaningfully in treatment planning and service delivery.

- **Protection and Advocacy for Individuals with Mental Illness (PAIMI)**
  Protection and advocacy programs provide vital protection for vulnerable individuals with mental illness. They have been instrumental in helping reduce harm to individuals living with mental illness and in promoting recovery and non-discrimination. At the same time, some PAIMI programs have counseled individuals to exercise their right to refuse treatment when the individuals were not capable of making an informed decision. In some cases, this refusal of treatment has led to tragic outcomes.
    - H.R. 2646, as amended, defines PAIMI work to include both safeguarding against abuse and neglect and advocating for continuity of care for people transitioning from institutions to the community and for access to evidence-based treatment and services.
    - H.R. 2646 permits lobbying, other than with federal funds (already prohibited by law) and includes support for training of PAIMI staff to work effectively with individuals, families and caregivers.

  NAMI supports permitting PAIMI programs to lobby and supports training of PAIMI staff on how to work most effectively with people living with mental illness, families and caregivers.

  NAMI's ask:
  NAMI would like language defining PAIMI program work to reflect their current scope of work, which includes assistance with a wide range of important issues.

  NAMI would like legislation to include a clarification that PAIMI staff should not advise clients to refuse treatment based on their personal beliefs about medications and mental health treatment. Consistent with their professional ethical obligations, PAIMI staff should actively work with clients to educate them on treatment options that avoid poor outcomes. NAMI further recommends that the Secretary of HHS be directed to issue guidance on factors that PAIMI staff should consider when advising clients on medication issues, including their right to refuse treatment.

- **Health Insurance Portability and Accountability Act (HIPAA)**
  The Health Insurance Portability and Accountability Act (HIPAA) is intended to protect private health information. However, varying interpretations of HIPAA have created barriers to appropriate information sharing and participation in treatment by families and caregivers. This can compromise treatment and discharge planning, lead to adverse outcomes, and cause stress on families and caregivers.
    - S. 1945 and H.R. 2646 promote greater uniformity of HIPAA interpretation by directing the Secretary of HHS to develop model training on the circumstances in which protected health information may be appropriately disclosed, including without patient consent.
    - H.R. 2646 explicitly permits caregivers of people with serious mental illness to receive certain health information (diagnosis, treatment recommendations, appointment scheduling, medication and medication instructions, but no psychotherapy notes) without patient consent if:
      - The provider believes disclosure to the caregiver is necessary to protect the health, safety or welfare of the patient or the safety of one or more other individuals; and
      - The absence of information will lead to a worsening prognosis or an acute medical or mental health condition.

- H.R. 2646 defines a caregiver as an immediate family member, a person who assumes primary responsibility for providing a basic need of the patient, or a lawful personal representative and who does not have a documented history of abuse of the individual.
- H.R. 2646 defines a person with serious mental illness as someone who is 18 years or older and:
  - Has diminished capacity to fully understand or follow a treatment plan or who may become gravely disabled without treatment; and
  - Has a mental illness that results in functional impairment that substantially interferes with or limits one or more major life activities.

NAMI supports language in S. 1945 and H.R. 2646 requiring HHS to develop model training programs on HIPAA, including circumstances in which protected health information may be appropriately disclosed without patient consent.

NAMI's ask: NAMI recommends that HHS should develop guidance on factors to consider in determining when an individual or program meets the criteria for serving as a "caregiver" in the context of being given access to protected mental health information.

NAMI supports incorporating the language of H.R. 2690, a bill introduced by Congresswoman Doris Matsui, which requires HHS to issue regulations that promote a clear understanding of what is allowed under HIPAA in disclosing protected health information.

NAMI strongly supports inclusion of language that repeals 42 CFR Part 2, federal regulations restricting the disclosure of individual's alcohol and drug records. NAMI believes HIPAA provides sufficient patient protections and that this separate regulation creates barriers to integration of care and improved health outcomes for people living with co-occurring mental health and substance use disorders.

- **Assistant Secretary for Mental Health and Substance Use Disorders**
  H.R. 2646 and S. 1945 establish an Assistant Secretary for Mental Health and Substance Use Disorders as a high level position within HHS. The rationale for creating this position is to elevate mental health and substance use disorders to a higher level of visibility within HHS as well as to facilitate more effective cooperation and coordination among the multiple HHS agencies that administer programs and services for people with mental illness and substance use disorders.

  - S. 1945 specifies that that the Assistant Secretary shall report directly to the Secretary of HHS but retains the role of the SAMHSA Administrator, specifying that the Administrator shall report directly to the Assistant Secretary.
  - HR 2646 specifies that the Assistant Secretary shall report directly to the Secretary of HHS and shall assume all the duties and responsibilities currently held by the Administrator of the Substance Abuse and Mental Health Services Administration (SAMHSA).

  NAMI supports establishing an Assistant Secretary for Mental Health and Substance Use Disorders who reports directly to the Secretary of HHS. NAMI further supports assigning responsibility to the Assistant Secretary for coordinating services among the multiple HHS agencies that administer programs and services for people with mental illness and substance use disorders.

  NAMI supports retaining the SAMHSA Administrator's position to minimize disruptions in the programs and services administered by SAMHSA.