

Overview

Affordable coverage for mental health care opens doors that help people with mental illness get the treatment they need to succeed at work, at school and in the community. Under the Affordable Care Act, millions of Americans gained coverage for mental health and substance use conditions. Research from Ohio shows that people enrolled in Medicaid expansion are getting more mental health care, managing chronic depression better and using costly emergency department care less. The research also suggests that Medicaid makes it easier for people to stay working or to seek work.

Medicaid

In 2014, Medicaid covered 1 in 5 adults with mental illness—about 12.8 million Americans.ⁱ Medicaid is the foundation of our community mental health system and the primary provider of mental health services for people with the most severe mental illnesses. In 2011, 48%ⁱⁱ of Medicaid dollars were spent on people with mental health or substance use conditions.

Health reform legislation, such as the House-passed American Health Care Act (AHCA), would cap Medicaid spending. Medicaid caps pose the single biggest threat to mental health care in decades. Per capita caps may sound reasonable, but the nonpartisan Congressional Budget Office estimates these caps would cut hundreds of billions of dollars from Medicaid by 2026. Capping Medicaid would result in millions losing their Medicaid coverage and force states to ration care for those who remain covered—even for children and adults with the most severe mental illnesses.

Stable Medicaid financing allows states to provide consistent mental health care, lower costs and improve outcomes. Medicaid caps lock states into program cuts. While cuts may reduce some spending in the short term, people not receiving mental health care will shift costs to other systems like jails and hospitals. For example, 20% of people in local jails have a serious mental illnessⁱⁱⁱ and, without access to quality, affordable mental health care, that number could grow significantly. In 2012, hospital stays for a primary diagnosis of mental illness cost \$4.6 billion.^{iv} Costs for hospitalization and emergency department visits for mental illness could grow, too, with fewer people getting the mental health care they need.

Medicaid expansion

Thirty-one states, plus the District of Columbia, have expanded Medicaid to cover people with incomes up to 138% of the federal poverty level. Nearly one-third of the Medicaid expansion population has a mental health or substance use condition.^v Medicaid expansion is covering people who fall through the cracks, including:

- Young adults with first symptoms of a serious mental illness who are not ill enough to be eligible for Medicaid but need intensive services;
- People with serious symptoms of mental illness who cannot navigate the federal disability system to become eligible for Medicaid; and
- People with serious mental illness whose symptoms have stabilized with psychiatric hospitalization and don't meet criteria for Medicaid at discharge.

Medicaid expansion removes barriers for people with mental illness by allowing people to qualify for coverage based on income, rather than a disability determination. This helps people get mental health services and allows for a path to work and self-sufficiency, while reducing growth in the federal disability system. Currently, over 1 in 4 people who receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) payments are on disability as a result of mental illness. Medicaid expansion could help lower this ratio.

Insurance safeguards

The Affordable Care Act (ACA) provided important insurance safeguards by requiring coverage of mental health and substance use conditions—and at the same level of coverage as other health conditions. Today, everyone can get coverage regardless of whether they have a mental health condition, such as depression or anxiety. Once a person is covered, there are safeguards to ensure quality coverage and that a person can't be dropped from their plan or turned down for renewal just because they are ill or using services. People cannot be charged more based on their health status, have annual or lifetime limits on their coverage or be subject to exorbitant deductibles or out-of-pocket expenses.

Insurance safeguards are vital to help ensure that people can get and keep health coverage—and can access the mental health care they need to lead healthy, productive lives and contribute to our communities and economy. This is important because mental illness costs our nation an estimated \$193.2 billion in lost earnings alone every year.^{vi} Mental illness is a leading cause of disability and is the third most costly medical condition in terms of overall health expenditures, behind only cancer and traumatic injury.^{vii} Congress should work to stabilize the individual and small group health insurance market, not remove insurance safeguards for people with mental illness.

NAMI's ask

Preserve Medicaid funding and protect mental health coverage. Oppose any health reform legislation that:

- **Caps Medicaid**, which will force states to ration mental health care as funding fails to keep pace with the needs of individuals and communities;
- **Ends Medicaid expansion**—a lifeline for single adults with mental illness who fall through the cracks, including young adults with early psychosis;
- **Carves away insurance safeguards**, such as allowing mental health and substance use treatment to be an optional benefit; or
- **Leaves fewer Americans covered** for mental health care.

ⁱ Garfield, R. and Zur, J., *Medicaid Restructuring Under the American Health Care Act and Implications for Behavioral Health Care in the US* (June 2017), The Henry J. Kaiser Family Foundation.

ⁱⁱ *Ibid.*

ⁱⁱⁱ Glaze, L.E. & James, D.J. (2006). Mental Health Problems of Prison and Jail Inmates. Bureau of Justice Statistics Special Report. U.S. Department of Justice, Office of Justice Programs Washington, D.C. Retrieved March 5, 2013, from <http://bjs.ojp.usdoj.gov/content/pub/pdf/mhppji.pdf>

^{iv} Heslin KC, Elixhauser A & Steiner CA. (2015). Hospitalizations Involving Mental and Substance Use Disorders Among Adults, 2012. HCUP Statistical Brief #191. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb191-Hospitalization-Mental-Substance-Use-Disorders-2012.pdf>.

^v Mir M. Ali et al., Substance Abuse and Mental Health Services Administration, *The CBHSQ Short Report: State Participation in the Medicaid Expansion Provision of the Affordable Care Act: Implications for Uninsured Individuals a Behavioral Health Condition* (November 18, 2015), https://www.samhsa.gov/data/sites/default/files/report_2073/ShortReport-2073.html.

^{vi} Insel, T.R. (2008). Assessing the Economic Costs of Serious Mental Illness. *The American Journal of Psychiatry*. 165(6), 663-665

^{vii} Soni, A. (2015). *Top Five Most Costly Conditions among Adults Age 18 and Older, 2012: Estimates for the U.S. Civilian Noninstitutionalized Population*. Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. Retrieved from: https://meps.ahrq.gov/data_files/publications/st471/stat471.shtm.

Overview

NAMI supports high priority federal programs that provide mental health research, services, criminal justice collaboration and supportive housing. With one of five Americansⁱ affected by mental illness, making investments in mental health research and services is vital to improve the lives of millions of Americans who live with mental health conditions and their families.

NAMI remains extremely concerned that funding for important discretionary programs is at risk in the absence of a comprehensive budget agreement. This agreement should:

1. Eliminate the threat of an across-the-board “sequester” in FY 2018;
2. Raise the current Budget Control Act (BCA) caps; and
3. Maintain the principle of “parity” between defense programs and “Non-Defense Discretionary” (NDD) programs.

NAMI is troubled by many of the deep reductions proposed in the Trump administration’s FY 2018 budget request. Among the most damaging proposed cuts are:

- \$5.8 billion to the National Institutes of Health (NIH)
- \$400 million to mental health and substance abuse programs (including a \$116 million cut to the Mental Health Block Grant program)
- \$6.2 billion in cuts to housing programs

These cuts would only add to the social and economic costs associated with mental health conditions. Untreated mental illness costs the nation as much as \$300 billion each year.ⁱⁱ Investment in mental health research, services, criminal justice collaborations and supportive housing is essential to helping people with mental illness lead healthy, productive lives.

NAMI’s asks

NAMI supports the following priorities and funding levels for FY 2018:

National Institute of Mental Health (NIMH)

- **NAMI supports \$36.2 billion for NIH in FY 2018**, including funds provided through the *21st Century Cures Act*, which was signed into law with strong bipartisan support in 2016. This \$2 billion increase to the NIH base would enable real growth over biomedical inflation in the nation’s research capacity.
- **NAMI supports an increase above the FY 2017 funding level of \$1.602 billion for the National Institute of Mental Health (NIMH)**, with continuation of the \$6 million Early Psychosis Intervention Network (EPINET) program. NAMI also seeks continued funding for the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative above the current \$260 million level.

Substance Abuse and Mental Health Services Administration (SAMHSA)

NAMI supports a range of critical priorities at SAMHSA for FY 2018, including:

- \$562.6 million for the Mental Health Block Grant and continuation of the 10% set aside for First Episode Psychosis (FEP) programs
- \$56 million for the Projects for Assistance in Transition from Homelessness (PATH) program
- \$119 million for the Children's Mental Health program
- \$50 million for the Primary-Behavioral Health Care Integration program

Housing & Urban Development (HUD)

- NAMI supports additional funding for FY 2018 to ensure that there is sufficient budget for the renewal of existing units across the array of rental assistance programs at HUD, including the Section 8 Tenant-Based Rental Assistance program (\$21.8 billion) and Project-Based Rental Assistance program (\$19.9 billion).
- NAMI opposes the \$25 million cut proposed for the HUD Section 811 program, which provides funding to develop and subsidize rental housing with supportive services for very low- and extremely low-income adults with disabilities, as well as the proposal to impose higher minimum rent and tenant contributions.
- NAMI opposes the proposed \$298 million cut to the McKinney-Vento homeless assistance programs, projected to result in as many as 25,000 individuals falling back into homelessness.
- NAMI opposes elimination of funding for the new Veterans Affairs Supportive Housing vouchers for homeless veterans and for the US interagency Council on the Homeless.

Bureau of Justice Assistance (BJA)

- NAMI supports \$15 million in funding for FY 2018 for the Mentally Ill Offender Treatment and Crime Reduction Act of 2004 (MIOTCRA), which provides grants to support collaborative efforts to reduce incarceration of non-violent offenders with mental illness and establish community-based treatment alternatives.
- NAMI supports \$403 million in funding for the Edward Byrne Memorial Justice Assistance Grant (Byrne JAG) program, which provides grants to state and local jurisdictions to support a wide range of initiatives in many states, including Crisis Intervention Teams and veterans' treatment courts. Funding in FY 2017 was \$375.3 million, but the President's budget proposes a cut of \$42.8 million.

ⁱ National Institute of Mental Health. (2017) *Any Mental Illness (AMI) Among U.S. Adults*. Retrieved from: <http://www.nimh.nih.gov/health/statistics/prevalence/any-mental-illness-ami-among-adults.shtml>.

ⁱⁱ National Institute of Mental Health (2017). *Annual Total Direct and Indirect Costs of Serious Mental Illness (2002)*. Retrieved from: <https://www.nimh.nih.gov/health/statistics/cost/index.shtml>.

Overview

In a mental health crisis, people with mental illnesses are more likely to encounter police than get medical attention. Nearly 2 million people with mental illness – including many veterans with PTSD or other mental health conditions – are booked into jails each year, resulting in people with mental illness being disproportionately represented in U.S. jails and prisons. When in jail, people with mental illness stay almost twice as long as other individuals facing similar charges.

Most people with mental illness in jails are non-violent offenders, committing minor offenses. Correctional systems are not equipped to provide mental health treatment, and correctional officers are often not trained to deal with these situations effectively. In many cases, people with mental health conditions are segregated and isolated, which research shows only triggers or worsens psychiatric symptoms.

It is time to stop using jails and prisons as default mental health facilities. Instead, we should divert non-violent offenders with mental illness and substance use disorders into treatment instead of incarceration. This would save lives, foster recovery and reduce costs.

We should also invest in community-based treatment that keeps people with mental illness out of jail in the first place—and ultimately saves taxpayer money. Proposals in Congress to reduce Medicaid will only make things worse by reducing access to mental health care for people who encounter law enforcement.

Finally, we should train law enforcement officials on how to appropriately respond to people with mental illness, which would help de-escalate crises and increase safety. States and communities that have invested in these programs have seen dramatic drops in deaths, serious injuries and other costly and tragic outcomes.

NAMI's asks

- **Support \$15 million in funding for FY 2018 for the Mentally Ill Offender Treatment and Crime Reduction Act of 2004 (MIOTCRA)**, which provides grants to state, local and tribal governments to support collaborative efforts to reduce incarceration of non-violent offenders with mental illness and establish community-based treatment alternatives. MIOTCRA has supported more than 120 mental health courts and other community programs to reduce incarceration since its inception. Funding in FY 2017 is \$12 million.
- **Support \$403 million in funding for the Edward Byrne Memorial Justice Assistance Grant (Byrne JAG) program**, which provides grants to state and local jurisdictions to support a wide range of initiatives in many states, including Crisis Intervention Teams and veterans' treatment courts. Funding in FY 2017 was \$375.3 million, but the President's budget proposes a cut of \$42.8 million, which would reduce funding for criminal justice/mental health initiatives that are reducing arrest and incarceration of people with mental illness.

Facts about mental illness and the criminal justice system

- 1 in 4 people who die in officer-involved shootings are in a mental health crisis.ⁱ
- Approximately 17% of U.S. jail inmates have serious mental illnesses, including schizophrenia, bipolar disorder, major depression or post-traumatic stress disorder (PTSD).ⁱⁱ
- People with serious mental illness are incarcerated at four times the rate of the general population.ⁱⁱⁱ
- The cost of health care for inmates with mental illness is two to three times greater than for people without mental illness.^{iv}
- People with mental illness stay in jail almost twice as long as other individuals facing similar charges.^v

ⁱ Lowery, W., Kindy, K., Alexander, K. L., Tate, J., Jenkins, J., & Rich, S. (2015, June 30). Police shootings: Distraught people, deadly results. *The Washington Post*. Retrieved from: <http://www.washingtonpost.com/sf/investigative/2015/06/30/distraught-people-deadly-results/>

ⁱⁱ Steadman, H., Osher, F., Clark Robbins, P., Case, B., & Samuels, S. (2009). Prevalence of Serious Mental Illness Among Jail Inmates. *Psychiatric Services*, Vol. 60, No. 6.

ⁱⁱⁱ Lurigio, A. J. (2011). People with serious mental illness in the criminal justice system: Causes, consequences, and correctives. *The Prison Journal*, 91(3), 66S-86S. doi: 10.1177/0032885511415226

^{iv} The Council of State Governments Justice Center. (2012). *Improving outcomes for people with mental illness involved with New York City's criminal court and correction systems*. Retrieved from: https://csgjusticecenter.org/wp-content/uploads/2013/05/CTBNYC-Court-Jail_7-cc.pdf; See also: Swanson, J., Swartz, M., Gilbert, A., Frisman, L., Lin, H.J., Rodis, E., ... Henson, A. (2011). *Costs of criminal justice involvement among persons with severe mental illness in Connecticut*. Retrieved from: http://www.pacenterofexcellence.pitt.edu/documents/Costs_of_Criminal_Justice_Involvement_in_Connecticut_-_Final_Report_Dec_28_2011.pdf

^v Levin, A. (2016, May 20). County Leaders Step Up To Reduce Incarceration Of Mentally Ill People. *Psychiatric News*. Retrieved from: <https://stepuptogether.org/updates/county-leaders-step-up-to-reduce-incarceration-of-mentally-ill-people>

Overview

Military service members and veterans struggle to access adequate mental health treatment, face high rates of mental health conditions and suicide and experience unique barriers to care not commonly found in the civilian population.

NAMI supports VA Secretary David Shulkin's recent and ongoing efforts to enhance mental health services for veterans within the walls of VA and through Choice providers in the community, including establishing veteran suicide prevention as VA's top clinical priority, offering urgent mental health care services to veterans with Other-than-Honorable discharges, and streamlining veteran medical records with the Defense Department for interoperability.

However, more needs to be done to ensure all veterans with mental health conditions receive the best treatment possible. NAMI urges Congress to work with VA on employing evidence-based treatments. Research shows that cognitive behavioral therapies, such as Cognitive Processing Therapy (CPT) and Prolonged Exposure therapy (PE) are among the most effective evidence-based treatments for PTSD. Although VA currently recommends cognitive behavioral therapies as first-line treatments for PTSD, many VHA mental health providers have not been properly trained or do not administer them.

Congress must act to reform and reauthorize the Veterans Choice Program to ensure America's veterans have timely access to the best mental health care available. When Congress reauthorizes and constructs the foundation for Choice 2.0, the program should promote effective culturally-competent treatment, rather than focusing on the current 40-mile distance and 30-day wait time. With only 13% of mental health care providers in the community currently meeting a minimum level of military cultural competency, all Choice program providers should be required to take yearly continuing education credits on military culture.

Additionally, NAMI strongly urges Congress to broadly reject the proposed 5% cut to the VA Medical Research budget. At a time when science and innovation could be the key to unlocking life-saving treatments for America's veterans living with mental health conditions, it is unacceptable to cut any federal funding for medical research. The VA Office of Medical Research is tasked with investigating medical conditions unique to veterans. With no other government research agency pursuing this research, progress on treating these conditions will be significantly halted.

NAMI's asks

- **Support H.R. 874, Sgt. Brandon Ketchum Never Again Act**, sponsored by Rep. David Loebsack (D-IA-2). This legislation would require VA, upon the request of a veteran who is enrolled in the VA health care system and entitled to in-patient psychiatric care, to provide the veteran with in-patient psychiatric care at the closest VA facility or at a non-VA facility if VA lacks such capacity or capability.

- **Support H.R. 918, Veteran Urgent Access to Mental Healthcare Act**, sponsored by Rep. Mike Coffman (R-CO-6). This legislation directs VA to provide veterans with an Other-than-Honorable discharge with an initial mental health assessment and the mental health care services required to treat the veteran's urgent mental health care needs, including risk of suicide or harming others.
- **Support S. 992 / H.R. 2652, Veteran Overmedication Prevention Act of 2017**, sponsored by Sen. John McCain (R-AZ), Rep. Mike Coffman (R-CO-6) and Rep. Seth Moulton (D-MA-6). This legislation requires VA to complete a thorough analysis of the number of veterans who died by suicide in the last five years and the number of instances in which the veteran was on multiple medications prescribed by VA physicians or non-VA physicians.

NAMI's budget and appropriations recommendations

- \$8.4 billion for Veterans' Mental Health Services
 - \$186.1 million for Suicide Prevention
- \$713 million for the VA Research Program
- \$17 million for Emerging Research Needs, including post-deployment mental health care concerns such as PTSD, depression, anxiety and suicide
- \$65 million for the VA Million Veteran Program

This is consistent with the Independent Budget (IB) recommendations.

Facts about military & veteran mental health

- About one in five veterans returning from Iraq and Afghanistan have post-traumatic stress disorder (PTSD) or depression.ⁱ
- The VA estimates that 30% of Vietnam veterans will experience PTSD in their lifetime.ⁱⁱ
- According to a VA Office of Suicide Prevention report from 2016, approximately 20 veterans per day die by suicide—and only 6 of the 20 veterans are utilizers of Veterans Health Administration (VHA) services.ⁱⁱⁱ
- The rates of suicide among younger veterans (ages 18-29) are the highest among all age-adjusted veteran population groups.^{iv}
- The risk for suicide among female veterans is 240% higher than their civilian counterparts.^v

ⁱ Substance Abuse and Mental Health Services Administration. (2014). Veterans and Military Families. Accessed online at <https://www.samhsa.gov/veterans-military-families>.

ⁱⁱ U.S. Department of Veterans Affairs. (n.d.) PTSD: National Center for PTSD. *How Common is PTSD?* Accessed online at <http://www.ptsd.va.gov/public/PTSD-overview/basics/how-common-is-ptsd.asp>.

ⁱⁱⁱ U.S. Department of Veterans Affairs. Office of Suicide Prevention. (2016). *Suicide Among Veterans and Other Americans 2001-2014*.

^{iv} *Ibid.*

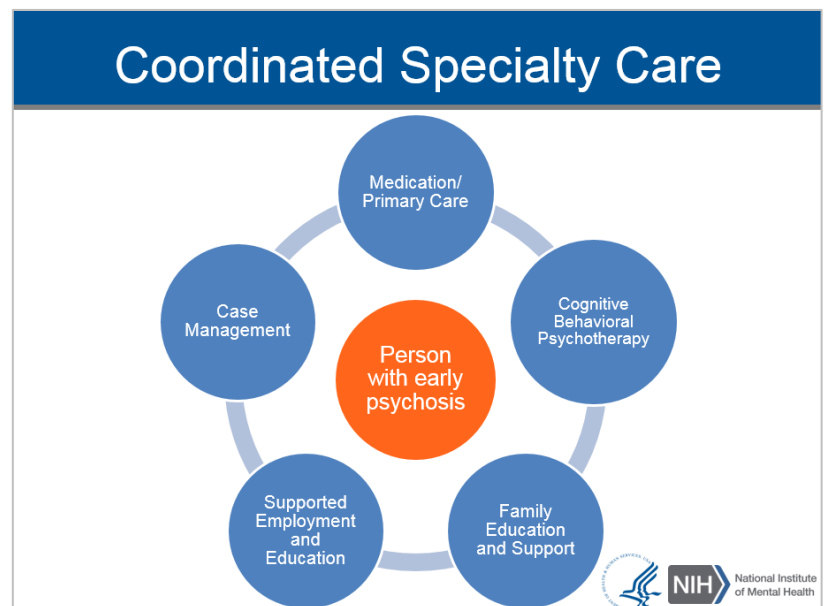
^v *Ibid.*

Overview

Schizophrenia is a serious mental illness that typically develops early in life and costs our economy an estimated \$155.7 billion a year.ⁱ Recent research shows that youth with psychosis die at a rate 24 times higher than their peers in the 12 months after their initial diagnosis,ⁱⁱ making early and effective treatment essential.

Fortunately, the major, multi-site Recovery After Initial Schizophrenia Episode (RAISE) study by the National Institute of Mental Health (NIMH) showed that by intervening early and providing Coordinated Specialty Care (CSC), young people with psychosis get significantly better.ⁱⁱⁱ They remain in school, continue working and stay on track with their lives. This is a game-changer because schizophrenia has typically resulted in high rates of disability and costly struggles for individuals, families and communities.

Early psychosis programs delivering CSC are setting a new standard of care and positively changing the trajectory of mental illness. Importantly, the RAISE study shows that the earlier youth get effective treatment, the better the outcomes—and the lower the cost.



Historically, there have been long delays in accessing treatment. But important progress is being made through the Community Mental Health Block Grant (MHBG) program. Congress recently required states to set aside 10% of MHBG funds to expand early psychosis programs. As states use MHBG funding to develop and expand early psychosis programs, they are making a positive difference in the lives of many youth and young adults—allowing them to reach recovery and a full life. Continued federal funding of early psychosis programming will be essential to continue to tackle the high cost of schizophrenia seen in high mortality rates, unemployment, lost productivity and direct health care costs.

NAMI's ask

- Continue the \$50 million investment in expanding early psychosis programs through the 10% set-aside of the Community Mental Health Block Grant program, which provides important funding to states to develop and expand these programs.

Facts about early intervention

Mental illness starts early in life. Research shows that the earlier youth get effective treatment, the better the outcomes—and the lower the cost. Yet, there are often long delays before youth get the mental health care they need.

- 50% of all serious mental illness begins by age 14 and 75% by age 24.^{iv}
- 1 in 5 children experience a serious mental health condition.^v
- Close to 50% of youth with mental health conditions received no treatment in the past year.^{vi}
- Mental illness leads to high rates of school dropout, unemployment, substance abuse, arrest, incarceration and early death.^{vii}
- Suicide is at a 30-year high and is the 2nd leading cause of death for youth ages 15 to 24.^{viii}

ⁱ Cloutier, et. al, The Economic Burden of Schizophrenia in the United States in 2013. *J. Clin. Psychiatry*, 2016 June: 77(6): 764-71. Doi: 10.4088/JCP.15m10278.

ⁱⁱ Schoenbaum, M., Sutherland, J., Chappel, A., Azrin, S., Goldstein, A., Rupp, A., Heinsen, R. Twelve-Month Health Care Use and Mortality in Commercially Insured Young People with Incident Psychosis in the United States. *Schizophrenia Bulletin*, April 6, 2017.

ⁱⁱⁱ NIMH Study: Recovery After an Initial Schizophrenia Episode (RAISE):

https://www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml?utm_source=rss_readers&utm_medium=rss&utm_campaign=rss_full

^{iv} Kessler, R.C., et al. (2005). Prevalence, Severity, and Comorbidity of 12-Month DSM-IV Disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62(6), 593–602.

^v National Institute of Mental Health. Retrieved from <http://www.nimh.nih.gov/health/statistics/prevalence/any-disorder-among-children.shtml#sthash.TkpDl14T.dpuf>.

^{vi} Use of Mental Health Services and Treatment Among Children. (n.d.). Retrieved January 16, 2015, from

<http://www.nimh.nih.gov/health/statistics/prevalence/use-of-mental-health-services-and-treatment-among-children.shtml>.

^{vii} U.S. Department of Education. (2014). 35th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2013. Washington, DC: U.S. Department of Education.

Glaze, L.E. & James, D.J. (2006). *Mental Health Problems of Prison and Jail Inmates*. Bureau of Justice Statistics Special Report. U.S. Department of Justice, Office of Justice Programs Washington, D.C.

National Association of State Mental Health Program Directors Council. (2006). *Morbidity and Mortality in People with Serious Mental Illness*. Alexandria, VA: Parks, J., et al.

Substance Abuse and Mental Health Services Administration, *Results from the 2014 National Survey on Drug Use and Health: Mental Health Findings*, NSDUH Series H-50, HHS Publication No. (SMA) 15-4927. Rockville, MD: Substance Abuse and Mental Health Services Administration. (2015).

Alison Luciano, MPH and Ellen Meara, PhD. The employment status of people with mental illness: National survey data from 2009 and 2010. *Psychiatr Serv.* 2014 Oct 1; 65(10): 1201–1209. doi: 10.1176/appi.ps.201300335.

^{viii} Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/nchs/products/databriefs/db241.htm> and https://www.cdc.gov/injury/images/lc-charts/leading_causes_of_death_age_group_2015_1050w740h.gif.

Overview

Mental illness is a leading cause of disability in our country, costing the U.S. an estimated \$300 billion a year.ⁱ Many of the one in fiveⁱⁱ Americans living with a mental health condition recover, work, have families and lead full lives. But many others have complex or treatment-resistant conditions that do not respond to available treatments.

There is an urgent need for new medications to treat the wide array of mental health conditions. Existing medications can be helpful, but they often have significant limitations; in some cases requiring weeks to take effect, failing to relieve symptoms in a significant proportion of people or resulting in debilitating side effects. However, developing new medications is a lengthy and expensive process. Many promising compounds fail to prove effective in clinical testing after years of preliminary research.

We need to rapidly accelerate the pace of drug discovery through an ‘experimental medicine’ approach to evaluate novel interventions for mental illnesses. Collaboration between government-funded research and the private sector is needed to move forward on a “fast-fail” strategy that is designed to quickly identify targets that merit more extensive testing. In addition, engagement with the FDA is needed to identify and validate biomarkers for disorders such as schizophrenia.

Finally, Congress must build on the success of the *21st Century Cures Act* that was passed in 2016 to advance medical discoveries and create a regulatory framework that ensures that patients can get access to innovative therapies. The important investments in research in the *Cures* law – in particular, funding for the BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) – offer enormous promise. These efforts will be severely undermined if Congress fails to sustain funding at the NIH or pass the FDA user fee agreements before they expire.

NAMI’s asks

- **Support increased investment in the National Institutes of Health (NIH)**
NAMI supports \$36.2 billion for NIH in FY 2018. This \$2 billion increase to the NIH base would enable real growth over biomedical inflation as an important step to stabilizing the nation’s research capacity over the long term.
 - For the National Institute of Mental Health (NIMH), NAMI supports an increase above the FY 2017 funding level of \$1.602 billion with continuation of the \$6 million Early Psychosis Intervention Network (EPINET) program.
 - NAMI also supports continued funding for the BRAIN Initiative above the current funding level of \$260 million.
- **Support timely passage of S. 934 / H.R. 2430, the FDA Reauthorization Act, before the current user fee agreements for prescription drugs and medical devices expire on September 30, 2017.** Failure to pass this legislation will result in as many as one-third of the clinical review staff at the FDA to be laid off. This would abruptly impact approval of new medications and surveillance of ongoing safety reviews, compromising the agency’s role as the world’s leading public health agency.

Facts about mental illness

- Over 40,000 American lives are lost each year to suicide,ⁱⁱⁱ making it the 2nd leading cause of death for Americans age 15-24 and the 10th leading cause of death for adults.^{iv}
- Between 10%-30% of people with major depression do not respond to typical antidepressant medications.
- Mental illness is the third most costly medical condition in terms of overall health expenditures, behind only cancer and traumatic injury.^v
- The cost of mental illness is only expected to sharply increase, not decrease over the coming decades.^{vi}
- Without investment in research and appropriate services and supports, the social and economic costs associated with mental health conditions are enormous. Communities devote enormous resources to addressing the human and financial cost of untreated illness through law enforcement, homeless shelters and emergency medical services.

ⁱ National Institute of Mental Health (2017). *Annual Total Direct and Indirect Costs of Serious Mental Illness (2002)*. Retrieved from: <https://www.nimh.nih.gov/health/statistics/cost/index.shtml>.

ⁱⁱ National Institute of Mental Health. (2017) *Any Mental Illness (AMI) Among U.S. Adults*. Retrieved from: <http://www.nimh.nih.gov/health/statistics/prevalence/any-mental-illness-ami-among-adults.shtml>.

ⁱⁱⁱ Center for Disease Control and Prevention (2015). *Suicide Facts at a Glance 2015*. Retrieved from: <http://www.cdc.gov/violenceprevention/pdf/suicide-datasheet-a.pdf>.

^{iv} Center for Disease Control and Prevention (2015). *10 Leading Causes of Death By Age Group, United States, 2015*. Retrieved from: https://www.cdc.gov/injury/images/lc-charts/leading_causes_of_death_age_group_2015_1050w740h.gif.

^v Soni, A. (2015). *Top Five Most Costly Conditions among Adults Age 18 and Older, 2012: Estimates for the U.S. Civilian Noninstitutionalized Population*. Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. Retrieved from: https://meps.ahrq.gov/data_files/publications/st471/stat471.shtml.

^{vi} Bloom, D.E., Cafiero, E.T., Jané-Llopis, E., Abrahams-Gessel, S., Bloom, L.R., Fathima, S., Feigl, A.B., Gaziano, T., Mowafi, M., Pandya, A., Prettnner, K., Rosenberg, L., Seligman, B., Stein, A.Z., & Weinstein, C. (2011). *The Global Economic Burden of Noncommunicable Diseases*. Geneva: *World Economic Forum*. Retrieved from: http://www3.weforum.org/docs/WEF_Harvard_HE_GlobalEconomicBurdenNonCommunicableDiseases_2011.pdf.

Overview

More than 8.4 million Americans, including family members of veterans, provide care to an adult relative living with mental illness.ⁱ With national shortages of mental health services, the role of caregiver often falls on families—with little or no support or training.

Family caregivers provide emotional and financial support and frequently manage medications, search for mental health services, make appointments, prepare meals, shop, arrange transportation, complete paperwork and respond to crises. Because of the demands of mental illness, caregivers devote an average of 32 hours a week to caregiving, about 8 hours more than other caregivers.ⁱⁱ This takes a heavy toll; over half experience a high level of emotional stress, and more than 75% are in poor or fair health.

In addition, caregiving responsibilities cause many to arrive late, leave early and take unpaid time away from work, costing the U.S. economy an estimated \$25.2 billion annually in lost productivity.ⁱⁱⁱ This also places a significant financial strain on already overwhelmed family caregivers.

Notably, over 5.5 million families in the U.S. care for a military service member or veteran, many of whom have mental health conditions. Among post-9/11 veterans, half live with post-traumatic stress disorder (52%) and/or major depression (46%).^{iv}

Typically, post-9/11 military caregivers are young (37% are under the age of 30), nonwhite (43%), employed (76%) and isolated from family and friends who could share caregiving responsibilities (53%).^v Most military caregivers (90%) spend at least 40 hours per week in caregiving tasks.^{vi}

The demands of caregiving—on top of work, child-rearing and other responsibilities—take a toll on military families. The stresses of caregiving lead to poorer physical and mental health, strains in family relationships and workplace problems. Nearly 40 percent of military families meet criteria for major depressive disorder (MDD) themselves, over four times higher than in the general population.^{vii}

NAMI's asks

- **Support S. 591 / H.R. 1472, the Military & Veterans Caregiver Services Improvement Act of 2017**, sponsored by Sen. Patty Murray (D-WA) and Rep. Jim Langevin (D-RI-2), which expands the VA caregiver program and includes caregivers of veterans with serious injuries or illnesses, including traumatic brain injury, psychological trauma or other mental illness.
- **Support S. 1028, the RAISE Family Caregivers Act**, sponsored by Sen. Susan Collins (R-ME), which would create a national family caregiving strategy and establish a federal Family Caregiving Advisory Council.

Facts about mental health caregiving

- 1 in 4 caregivers have difficulty finding a mental health professional or a doctor who understands mental health.
- In addition to worries about finding services, caregivers face concerns about other risks:
 - 7 in 10 caregivers report the person they care for has been hospitalized or in an emergency department due to a psychiatric crisis.
 - Almost 1 in 3 caregivers report the person they care for has been arrested.
 - 1 in 5 caregivers report that the person they care for has been homeless for a month or longer.
 - 2 out of 3 caregivers are worried that the person they care for will attempt suicide.

Caregiving challenges ^{viii ix}	Caregivers of adults with mental illness	All caregivers
Duration of care	9 years	5 years
Hours per week spent caregiving	32 hours	24 hours
Care recipient lives with caregiver	45%	34%
Caregiver in poor or fair health	77%	52%
High level of emotional stress	53%	38%
Caregiving results in financial strain	25%	16%

ⁱ Hunt, G; Greene R; Whiting, G; Reinhard, S; Feinberg, L; Choula, R; Green, J; Houser, A. (2015) *Caregiving in the U.S. 2015*. National Alliance for Caregiving, AARP. Retrieved 5/30/16: http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

ⁱⁱ Hunt, G; Greene R; Whiting, G; (2016) On Pins & Needles: Caregivers of Adults with Mental Illness. National Alliance for Caregiving. Retrieved 5/30/16: <http://www.caregiving.org/mentalhealth/>.

ⁱⁱⁱ Witters, D (July 27, 2011) *Caregiving Costs U.S. Economy \$25.2 Billion in Lost Productivity*. Gallup Poll. Accessed 5/30/2017: http://www.gallup.com/poll/148670/Caregiving-Costs-Economy-Billion-Lost-Productivity.aspx?g_source=position1&g_medium=related&g_campaign=tiles

^{iv} Ramchand, R; Tanielian, T; Fisher, MP; Vaughan, CA; Trail, TE; Epley, C; Voorhies, P; Robbins, MW; Robinson, E; Ghosh-Dastidar, B (2014) Hidden Heroes: America's Military Caregivers. Elizabeth Dole Foundation. Accessed May 30, 2017: http://www.rand.org/content/dam/rand/pubs/research_reports/RR400/RR499/RAND_RR499.pdf Ibid. p.48

^v *Ibid.*

^{vi} *Ibid.*

^{vii} *Ibid.*

^{viii} Hunt et al (2016) On Pins & Needles: Caregivers of Adults with Mental Illness.

^{ix} Hunt et al (2015) Caregiving in the US, 2015.