

How NAMI Families Can Help Effect Change at the Public Policy Level

Families have a much valued perspective. Families may know their loved one living with a mental illness—their strengths and challenges, better than any treatment professional could ever determine. We also know of the difficulties in navigating a sometimes complex mental health treatment and support system.

Personal experience with mental illness allows families to know what the important issues are. This puts family members in a unique position to act as advocates. NAMI families can educate elected officials charged with development of public policy and funding priorities.

This fact sheet offers tips for effective strategies for NAMI families to get involved in local, state or federal advocacy efforts.

Write or e-mail a letter to your elected representative.

- Representatives rely on communication from their constituents to keep them informed and to know where constituents stand on critical or controversial issues.
- A personal letter or e-mail is an effective method to get your message across.
- Write legibly, type or e-mail your message and try to keep your communication to one brief page.
- Make your message to the point. Example: “I’m writing in support of/ or opposition to” (Refer to the bill name or number, if you do not know the number contact the NAMI Southwestern Pennsylvania office for assistance or search for the bill number via www.namiswa.org and click on Legislative Affairs/Electronic Bill Room or the General Assembly website at www.legis.pa.us and clicking onto Session.)
- Give a reason for your position (support or opposition). A personal experience is powerful in establishing your case.
- Let them know what you expect. Example: “I hope I can count on your support for this bill. Please write back and let me know your position on this important issue.”
- Include your name and address on both the letter and the envelope or within your e-mail message.
- Target and time your letter. Representatives will give the most weight to letters from their own constituents. However, if a bill is to be heard in a particular committee or subcommittee, you may need to communicate with the committee leadership (e.g., Chairperson of the Senate Health and Human Services Committee). In this case, explain that while you are not from the legislator’s own district, you hope that the needs of all citizens will be considered in reaching a decision on the bill. Naturally, timing the letter before a vote is taken is critical.
- Follow up by thanking your representative when his/her actions support your position.

Make a Phone Call

When time is of the essence, a phone call can be a practical way to convey your concern to an elected representative. The most effective calls are to the Capitol offices, particularly when a vote is imminent.

- Introduce yourself and give your NAMI affiliation. Be sure to mention if you are a constituent.
- Don’t expect to speak to your representative directly. Most likely, you will speak to a receptionist or legislative staff. These individuals are responsible for keeping the legislator informed.
- Explain why you are calling. Example: “I’m calling to register my opposition to the proposed budget cuts for mental health funding. Please be sure that the Senator/Representative is informed of my concern as a constituent and a family member.”

- You may need to communicate your position to a committee which is hearing a bill or budget item. If you are not sure of the committee name or hearing schedule, you can ask staff at your own representative's office.
- *Where to Phone:* Capitol Switchboard Washington DC, (202) 244-3121. The operator will refer you to any U.S. Senator or U.S. Representative (Congressman/woman). In Pennsylvania, the Chief Clerk can help you reach any member of the state house. The Senate Secretary will provide phone numbers for any Pennsylvania State Senator.
- Faxing is also an effective way of sending your letter as all state legislators and members of Congress have Fax machines. Fax numbers can be obtained from the same sources as legislative and Congressional telephone numbers.

Visit Your Elected Representative

Meeting face-to-face with a legislator or designated staff is an excellent way to establish a relationship and convey your point of view.

- State legislators often go home to their district offices on Thursday or Friday. Meetings at the State Capitol are best set for Tuesday or Wednesday.
- Congressional Representatives in Washington, DC are more likely to come home on the weekend or on extended holidays or periods of Congressional recess. Contact the Capitol office to determine the best time to make an appointment.
- Plan ahead. Legislators' schedules fill up weeks in advance. Plan your first visit before there's a "crisis" to establish a friendly rapport.
- Do not set your hopes on meeting with your representative in person. Legislators are busy and schedules often change at the last minute. An effective meeting can be held with a legislative staff aide (often the very people who craft legislation or brief their bosses on important issues).
- When you call, ask to speak to the scheduler. Introduce yourself, explain the nature of the visit, give the names and number of other people who will come along on the visit (try to limit that to four or five people), how long you will need (15 to 30 minutes), and when you would like to come. You may be asked to send a request in writing.
- After an appointment has been scheduled, it is wise to confirm the information by mail, e-mail or phone (correspondence should be addressed to the legislator him/herself, even if the meeting is scheduled with staff).
- If scheduling more than one meeting at the Capitol in one day, leave 30 minutes between appointments to get from one room to another.
- Do your homework by learning something about the person you will visit. Rehearse what you will say, keeping in mind the legislator's background and interests. You may wish to begin by sharing your own personal story. Show your knowledge by mentioning any action taken or bills authored/supported by the legislator in a similar area, if appropriate.
- Be clear about the purpose of the meeting. *Example: "I am here today to familiarize you with the needs of individuals living with a mental illness and their families," or "I would like to know if I can count on your support for improving the quality and access to evidence based treatment."*
- Add your voice to others who share similar concerns by joining a larger group or organization going to visit the Capitol. This way you can coordinate with existing efforts and increase your clout.
- Understand that current fiscal constraints make it difficult to advocate for increased funding for programs and services. Do not apologize for this fact. Instead, be clear about the importance of a program or service to you and your family. *Example: "I know funding is tight and not everything can be considered a priority, but I am here to tell you what a critical issue this is for me and others like me."*

- Bring a few brief written materials, if available, to leave in the office which relate to the purpose of your visit.
- Bring a camera. Even if a legislator cannot meet with you in person, he/she may be pulled out of a meeting momentarily for a photo opportunity.
- Remember to thank the legislator or staff for your meeting. It is also a good idea to send a thank you letter addressed to the legislator.

Other Activities

Stay informed: Sign up for NAMI Southwestern Pennsylvania “Call to Action” e-mail alerts by contacting info@namiswpa.org and indicate “Action Alerts request” within message. Visit the Legislative Affairs link on the NAMI SWPA website: www.namiswpa.org.

Contribute your ideas and energy: Participate in a NAMI Southwestern Pennsylvania committee, local county Community Support Program (CSP), county MH Advisory Board or a cross disabilities campaign. Such groups may work on a single issue or a variety of issues. Tasks might include organizing a public event or drafting policy recommendations. Even if you don’t attend committee meetings you can still lend your support to a letter writing campaign.

Write a letter to the editor or opinion editorial “op-ed” piece stating your views in your local news-paper: This is an excellent vehicle to help educate the public about the prevalence of mental illnesses, the reality of recovery-when people can access effective treatment and supports, and an effective anti-stigma tool.

Testify at a hearing: Both State Legislative and Congressional committees often hold hearings to gather support and expert opinions while drafting legislation. NAMI members can provide compelling stories of their own or their loved one’s daily challenges in securing effective treatment and supports. Be sure to contact the committee the day of the hearing; last minute schedule changes occur frequently.

All federal bills can be searched and downloaded from the Library of Congress website <http://thomas.loc.gov/>. You can also request copies of bills from your member of congress. Pennsylvania bills are available at the www.legis.pa.us

Contact Sharon Miller, Director of Education and Advocacy at NAMI Southwestern Pennsylvania: 412-366-3788 or toll-free:1-888-264-7972 or smiller@namiswpa.org for additional information on effective advocacy efforts.



Messages and Talking Points

Having a consistent, memorable and personal message is key to a successful advocacy effort. You will want to use these messages as often as possible in all of your communications efforts. Leaders and other advocates should to add personal stories and examples that illustrate key points.

Messages

- Mental illness affects all families and treatment works.
- In our state, X# of children and X# of adults face serious mental illness.
- You really save lives when you protect mental health care funding.
- More cuts to state mental health care are devastating individuals, families and our communities.
- When state mental health care funds are cut, we all pay even more for the consequences.
- Our state's mental health care budget crisis is everyone's problem and the solution is everyone's responsibility.
- We must protect and strengthen our state's mental health care system - it's a real investment that returns real benefits.

Talking Points

- The face of mental illness isn't some stranger. It's our co-workers, our neighbors, our friends, our families and sometimes ourselves.
- State and local funding for mental health care has never been adequate, so budget cuts now just make a bad situation even worse.
- We know cuts are hitting every state program, but tough choices shouldn't be bad or unfair choices.
- Mental health cuts actually end up costing us all even more-lost jobs and careers, broken families, more homelessness, higher insurance costs, more welfare and much more expensive costs for hospital emergency rooms, nursing homes, schools, police and courts, jails and prisons.
- The governor, state legislators and other officials really need to protect and strengthen mental health care. We need to invest in proven, cost-effective, community-based treatment and services that really promote recovery.
- The state's Medicaid budget, especially, is a lifeline for thousands of people in our state who face mental illness.
- Lives are at stake. Treatment works-if you can get it. Without it, more people will end up hospitalized, in shelters, in nursing home, on the street, in jail or dead.
- Cuts are coming while the need for help is only increasing.
- We've all been hit by the worst economic times and highest unemployment in more than 25 years. Those unemployed workers are reporting symptoms of severe mental illness four times more than people who still have jobs. Four times as many report thoughts of suicide.
- Returning combat veterans are experiencing very high rates of serious mental illness, suicide, addiction, homelessness and incarceration related to posttraumatic stress disorder.
- One in three young adults is uninsured, even though-three quarters of all lifetime cases of mental illness occur by age 24.
- Mental health agencies already operate with inadequate resources and have worked hard to cut administrative expenses as well as imposed hiring freezes and added managed-care restrictions. More cuts can only mean deeper cuts in treatment and services.
- Preserving mental health services preserves jobs, keeping people working and well rather than overlooked, marginalized, trivialized, stigmatized and sick.
- Mental illness does not discriminate. It affects adults, children and people of every ethnic, socioeconomic and religious or political background.
- It affects Democrats, Republicans and Independents alike. It can hit anyone at any time, including the families of public officials.
- One out of every four Americans experiences mental illness at some point in his or her life, and 10 percent of children and youth have serious impairments from mental illness that impact their day-to-day lives.
- Please protect all our families and all our communities now. Protect state funding for mental health care. Treatment works. Cuts kill.

The High Costs of Cutting Mental Health

Homelessness

Cutting mental health budgets can contribute to higher costs resulting from increased homelessness. When adults living with serious mental illness cannot get adequate treatment or services, they often end up on the street. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), about one in four homeless persons struggle with severe mental illness.¹

Lack of housing causes people with serious mental illnesses to cycle among hospitals, shelters, the streets or jails at very high costs.² According to a large 2001 study, homeless New Yorkers diagnosed with a mental illness used an average of \$40,449 in services annually.³

Addressing homelessness for people with serious mental illness requires "supportive housing," a combination of both affordable housing and mental health services. The most successful approach, "housing first," provides permanent housing followed by voluntary, supportive services.⁴ Federal support alone does not meet local needs. State, county and local investments are needed both to help address needs and to avoid making current problems greater.

Housing is unaffordable for many who live with serious mental illness. The average Supplemental Security Income (SSI) payment in 2008 was almost 30 percent below the federal poverty level for a one-person household. Federal housing affordability guidelines state that low income households should pay no more than 30 percent of monthly income for housing. Yet, the average cost of a studio/efficiency apartment is more than 99 percent of the monthly income of an individual with a psychiatric disability who relies on SSI—and a modest one bedroom rental averages over 112 percent.

By the Numbers

26% of the homeless population lives with severe mental illness—more than four times the rate of serious mental illness in the general population.⁵

About 150,000 to 200,000 chronically homeless individuals nationwide use more than 50% of the services. Individuals who are chronically homeless often have a serious mental illness, a complex medical problem and/or alcohol or drug addiction.⁶

An estimated 131,000 Veterans are homeless on any given night. 45% of these Veterans live with mental illness.⁷

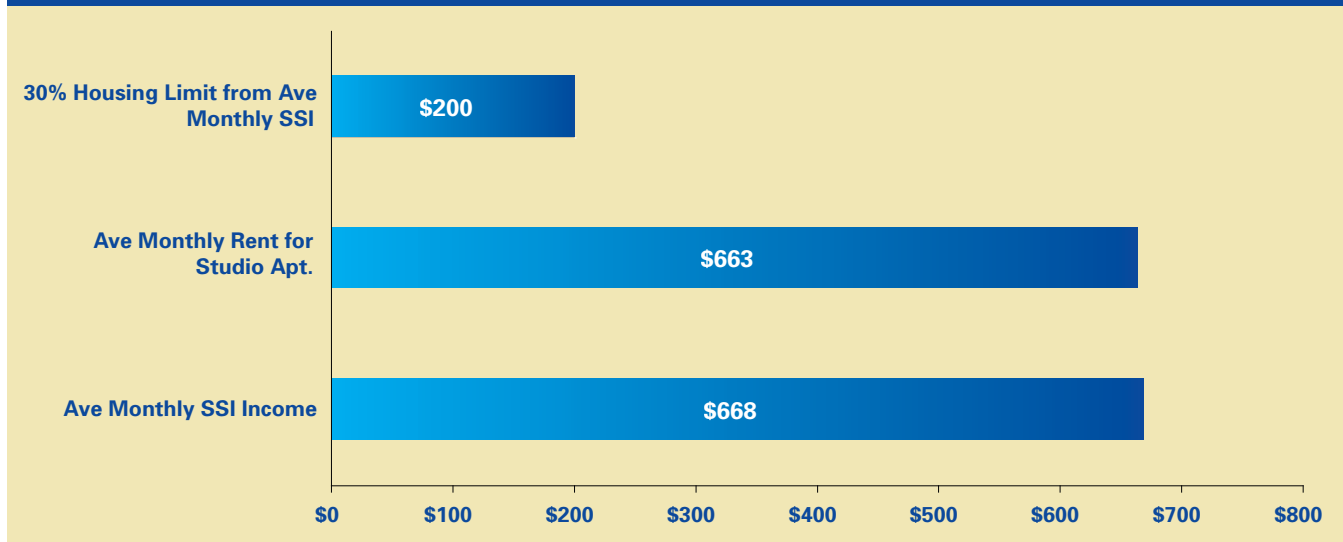
75% of the most frequent users of health and criminal justice services were diagnosed with a mental illness or substance use problem. 54 individuals in a study accounted for an average yearly cost of \$171,292 in criminal justice encounters alone.⁸

Saving Money, Saving Lives

Spending money saves lives, but investment in supportive housing and mental health services also saves money.

- In New York, a study of 10,000 homeless people found that homeless persons living with mental illness cost \$40,449 in publicly funded services a year for use of emergency rooms, hospitals, shelters and incarceration. After placement in supportive housing, there was an 86 percent drop in the number of shelter days per person, a 60 percent drop in state hospital use and an 80 percent drop in the number of public hospital inpatient days. Researchers also found that housing cut incarceration rates in half for homeless persons living with mental illness.⁹
- The city of Portland, Ore., found that 35 chronically homeless individuals each required over \$42,000 in public resources per year. After these

Comparison of Cost of Monthly Rental to Average SSI Income of \$668



individuals entered permanent supportive housing, the city saved over \$16,000 per program participant.¹⁰ Similarly, New York's Housing First initiative produced annualized savings of \$16,281 per housing unit.¹¹

- Without mental health care or supportive housing available at the front end, too many Americans living with mental illness end up in the nation's jails and prisons.¹² The cost is high: an average of \$65.25 per day in local correctional facilities.¹³

- Inmates diagnosed with a mental illness are homeless at the time of arrest at more than twice the rate of other inmates.¹⁴ Participants in a supportive housing program experienced an 85 percent reduction in days spent incarcerated in prison.¹⁵

Endnotes

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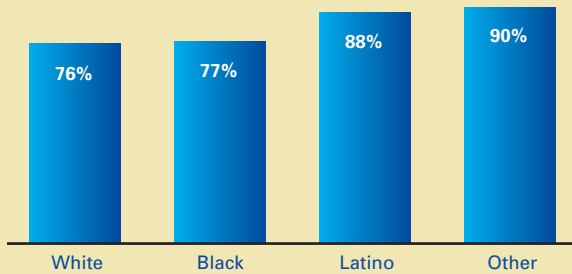
The High Costs of Cutting Mental Health

Children and Youth

Our nation's future depends on the health and well-being of its children. Today, one in 10 children struggles with mental illness severe enough to cause significant impairment in their day-to-day lives.¹ Mental illness begins early in life and interferes with development and functioning.

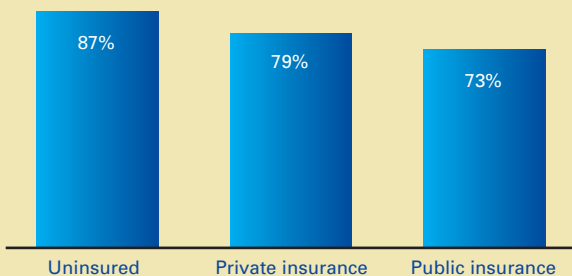
Despite the availability of effective treatment, there are long delays from the onset of mental illness to treatment—on average eight to 10 years. Only about one-half of youth living with mental illness receives treatment.² For a child, this means the loss of childhood and critical developmental years.

Unmet children's mental health needs, by race/ethnicity



Source: Kataoka, S.; Zhang, L.; & Wells, K. (2002). Unmet need for mental health care among U.S. children: Variation by ethnicity and insurance status. *American Journal of Psychiatry*, 159 (9), 1548-1555.

Unmet mental health needs of U.S. children, by insurance status



Source: Kataoka, S.; Zhang, L.; & Wells, K. (2002). Unmet need for mental health care among U.S. children: Variation by ethnicity and insurance status. *American Journal of Psychiatry*, 159 (9), 1548-1555.

We need to protect and strengthen community mental health services for children, teens and young adults. Without treatment, the consequences are costly. Young people drop out of school, become entangled with the juvenile justice system or die by suicide. They are left behind in developing the skills and experiences necessary to lead independent and productive adult lives.

By the Numbers

50% of lifetime mental illness cases begin by age 14, 75% by age 24. Treating cases early reduces disability, before mental illnesses become more severe.³ The majority of depressed youth go undiagnosed and untreated. The U.S. Preventive Services Task Force recommends screening of adolescents (12-18 years of age) for major depression to ensure diagnosis and treatment.⁴

Approximately 50% of students ages 14 and older with mental health conditions drop out of high school—the highest dropout rate of any disability group.⁵ Children in elementary school may miss as many as 22 days during a school year. Suspension and expulsion rates are three times higher than their peers.⁶

Suicide is the third leading cause of death for youth aged 15-24, with more than 4,000 young lives lost in 2006.⁷ 90% of those who die by suicide suffer from a mental health disorder.⁸

More than 500,000 children live in foster care.⁹ 50% of youth in the child welfare system live with mental health problems.¹⁰

70% of youth in state and local juvenile justice systems have mental disorders, with at least 20% experiencing symptoms so severe that their ability to function is significantly impaired.¹¹ At the same time, the U.S. Department of Justice has found that juvenile facilities fail to adequately address mental health needs.¹²

Saving Money, Saving Lives

There are many proven, cost-effective treatments for children and youth that can reduce the unnecessary and costly consequences of untreated mental illness. Mental health treatment works and investment in services is a critical investment in the future of our children and youth.

- Youth living with major depression who received combined cognitive behavior therapy and medication have significantly better treatment outcomes than those who do not receive combined treatment. The greatest reduction in suicidal thinking occurs in those who receive both medication and therapy.¹³
- Evidence-based practices like functional family therapy (FFT) and multi-systemic therapy (MST) for youth in the juvenile justice system reduce costs,

crime and re-offending rates while allowing youth to safely return to their homes, schools and communities.¹⁴ Benefits minus costs per participant are \$18,213 for MST and \$31,821 for FFT. Despite this very high return on investment, relatively few communities offer them.

- Multidimensional treatment foster care is highly effective for children in out-of-home placements who have mental health problems. The benefit minus cost per participant is \$77,798.
- Brief strategic family therapy is a form of therapy that focuses on improving interactions between children and their families. Strategies include building conflict resolution skills, providing parent coaching and guidance and improving family interactions. The therapy has shown significant reductions in behavior problems.¹⁵

Endnotes

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The High Costs of Cutting Mental Health

Criminal Justice

Without state and local mental health services, too many people living with mental illness end up in encounters with police or warehoused unnecessarily in jails and prisons.

In United States prisons alone, approximately 24 percent of inmates live with serious mental illness.¹ Seventy percent of youth in the juvenile justice system also experience mental health disorders, with 20 percent experiencing disorders so severe that their ability to function is significantly impaired.²

At the same time, state spending on correctional systems has increased 350% in the past 20 years (from \$10 billion to \$45 billion), contributing significantly to state budget crises.³ What is needed, instead, is investment in mental health treatment and recovery services to minimize costly criminal justice involvement of persons living with serious mental illness.

By the Numbers

30% of female and 15% of male inmates in local jails live with a serious mental illness such as schizophrenia or bipolar disorder.⁴

70% of youth in the juvenile justice system also have mental health disorders.⁵

50% of previously incarcerated individuals living with serious mental illness are re-arrested and return to prisons not because they have completed new offenses, but because they have not been able to comply with conditions of probation or parole, often due to mental illness factors.⁶

Florida spends *one-quarter of a billion* dollars annually to treat 1,700 individuals charged with crimes who have been determined incompetent to stand trial or not guilty by reason of insanity.⁷

Pennsylvania estimates that it cost approximately \$60 *per day more* for the state to incarcerate inmates living with serious mental illness compared to other inmates.⁸

Saving Money, Saving Lives

Investment in proven, cost-effective mental health services can help reduce burdens on the criminal justice system. It also is an investment in recovery and saving lives of persons who struggle with medical illnesses.

- Mental health courts have emerged throughout the country to divert individuals with serious mental illness from incarceration into treatment. Pittsburgh's county mental health court has shown that costs over time resulting from declines in incarceration more than offset increased costs of treatment.⁹
- Intensive community mental health services provided to high risk individuals diagnosed with serious mental illness in three California counties revealed significant reductions in days of incarceration, homelessness and hospitalization. Days incarcerated dropped 85 percent, hospital days dropped 78 percent and number of days spent homeless dropped 69 percent.¹⁰
- Forensic Assertive Community Treatment (FACT) combines intensive treatment, rehabilitation and support services in a coordinated team approach. Fact teams have proven effective in reducing jail days, arrests and hospitalization.¹¹ One FACT team in Rochester, N.Y., saved \$39,518 per year due to reduced hospitalization and incarceration.¹²
- Youth and adults living with serious mental illness in criminal justice systems have high rates of co-occurring substance abuse disorders. Integrated mental health and substance use treatment services have resulted in lower rates of involvement in the criminal justice system or reincarceration and reduced criminal justice involvement.¹³
- Multi-systemic therapy (MST) is an intensive, home-based approach to addressing the comprehensive needs of youth with mental illnesses and their families,

characterized by small caseloads and 24-seven service availability. MST has been successful in reducing costly out-of-home placements and criminal recidivism.¹⁴

- Studies consistently demonstrate a very high correlation between homelessness and criminal incarceration among people living with serious mental illness. Lack of stable housing significantly increases chances of recidivism. Supportive housing models with a “housing first” approach, in which individuals are first provided housing and are then offered services, has proven effective in enhancing residential stability and community reintegration.¹⁵

| Cost Savings | | | | |
|---|-------------------|----------------------|-------------------------------------|-------------------------|
| Jail/Hospital costs per person | | | | |
| Program | # of Participants | PRIOR to involvement | DURING involvement (+ program cost) | Cost savings per person |
| Thresholds Jail Program (Cook County, IL) | 30 (two years) | \$53,897 | \$35,024 | \$18,873 |
| Project Link (Monroe County, NY) | 44 (one year) | \$73,878 | \$34,360 | \$39,518 |

Source: Criminal Justice Mental Health Consensus Project

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Mental Illness and the Workplace

Mental illness has a significant impact on the workplace that often goes unrecognized. It is a critical dimension for any discussion of mental health care.

Depression is the most common mental health disorder in the workplace¹ and affects about one in 10 employees.² Despite its prevalence, depression frequently goes undetected or undertreated. It has been estimated that 75 percent of persons with depression do not receive a diagnosis; of these, 72 percent are in the workforce.³ Despite the prevalence of mental illness, less than one-third receives any level of mental health treatment.⁵

Mental illness, when untreated or under-treated, often manifests as a performance issue, such as absenteeism or compromised productivity. This comes at a high cost to employers: in the U.S., the annual economic, indirect cost of mental illnesses is estimated to be at least \$79 billion. Most of that amount--approximately \$63 billion--reflects the cost of lost productivity.⁴ Mental illness causes more days of work loss and work impairment than chronic health conditions such as diabetes, asthma, arthritis, back pain, hypertension, and heart disease.⁵

Depression is also a common co-occurring condition among individuals with chronic medical conditions. This is important because left untreated, people with co-occurring depression have higher health care

expenditures. For example, about 27 percent of people with diabetes also have depression, and their health care expenditures are four times higher than those with diabetes alone.⁶

Fortunately, mental illness is highly treatable. Between 70 and 90 percent of individuals with mental illness have significant reduction of symptoms and improved quality of life with a combination of medication, talk therapy and other supports. For major depression, studies have indicated that a combination of medication and psychotherapy may be the most effective approach to reducing the likelihood for recurrence.⁷

People who experience mental illness are a significant portion of the workforce—and failure to invest in their mental health care is costly to a company's bottom line. Effective mental health treatment provides real dividends; businesses can see significant returns on investment with decreased medical and disability costs and increased workplace performance.

By the Numbers

Each year, 217 million workdays are completely or partially lost due to mental disorders.⁸

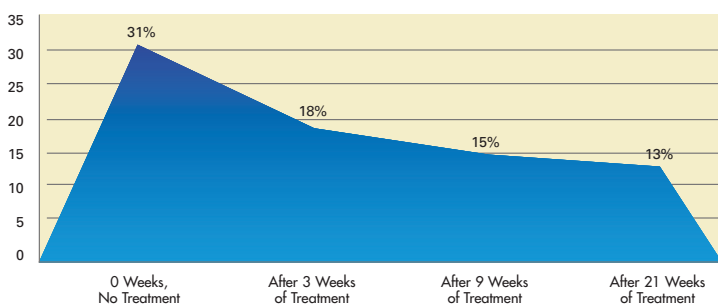
Workers with depression lose an average of 5.6 productive hours per week, compared to an average loss of 1.5 hours per week for workers without depression.⁹

Workers who have depression cost employers \$44 billion per year in lost productive time.¹⁰

Employees with co-occurring medical and mental health conditions use more health care resources and have longer durations of disability.¹¹

Absence, disability and lost productivity related to mental illness cost employers more than four times the cost of employee medical treatment.¹²

Percentage of Employees Work-Impaired Before and After Treatment



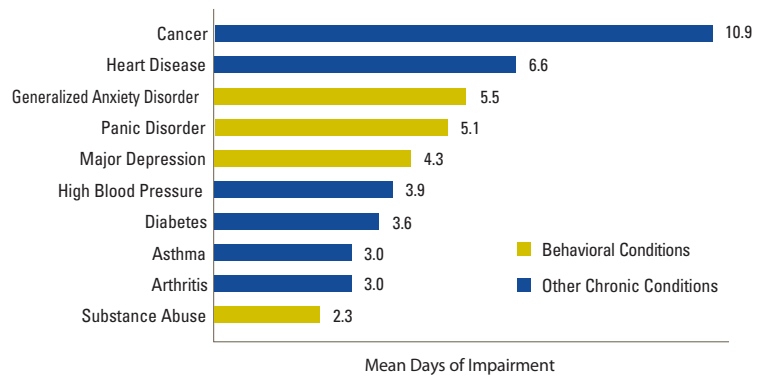
Source: Behavioral Health Care: A Worthwhile Investment?, by ER Jones, GS Brown. *Employee Benefit Plan Review*, August 2003, pp 13-14.

Saving Money, Saving Lives

Treatment for mental illness works and is cost-efficient. Providing effective treatment reduces the impact of mental disorders and saves employers and employees significant costs in medical care, productivity and disability.

- Mental health outpatient treatment programs can produce cost savings for employers by reducing worker impairment. After just three weeks of treatment, work impairment of employees living with mental illness was cut nearly in half, from 31 percent to 18 percent.¹³
- Depression treatment has been shown to pay for itself in terms of savings in lost earnings, not even taking into account other indirect costs such as increased productivity at work or reduction in other medical costs. Depression treatment provided by mental health specialists provided a net annual profit of \$877 per patient in regained earnings alone.¹⁴
- Employee Assistance Programs (EAPs) produce direct cost savings for employers with reduced medical, disability, and workers' compensation claims and even more indirect cost savings through improved work performance.¹⁵ EAPs increase worker productivity and decrease absenteeism.¹⁶ The return on investment (ROI) of EAP services is about a \$2 to \$4 savings for every dollar invested.¹⁷

Estimated Mean Number of Days of Impairment in Past 30 Days Among Individuals with Chronic Conditions



Source: Kessler, R.C., et al. (2001). The Effects of Chronic Medical Conditions on Work Loss and Work Cutback. *Journal of Occupational and Environmental Medicine*, 43(3), 218-225. As cited in National Business Group on Health. (2005). *An Employer's Guide to Behavioral Health Services: A Roadmap and Recommendations for Evaluating, Designing and Implementing Behavioral Health Services*. Washington, DC: National Business Group on Health.

Endnotes

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- ¹⁷ Hargrave, G.E., & Hiatt, D., "The EAP Treatment of Depressed Employees: Implications for Return on Investment," *Managed Health Network*, (2007).



