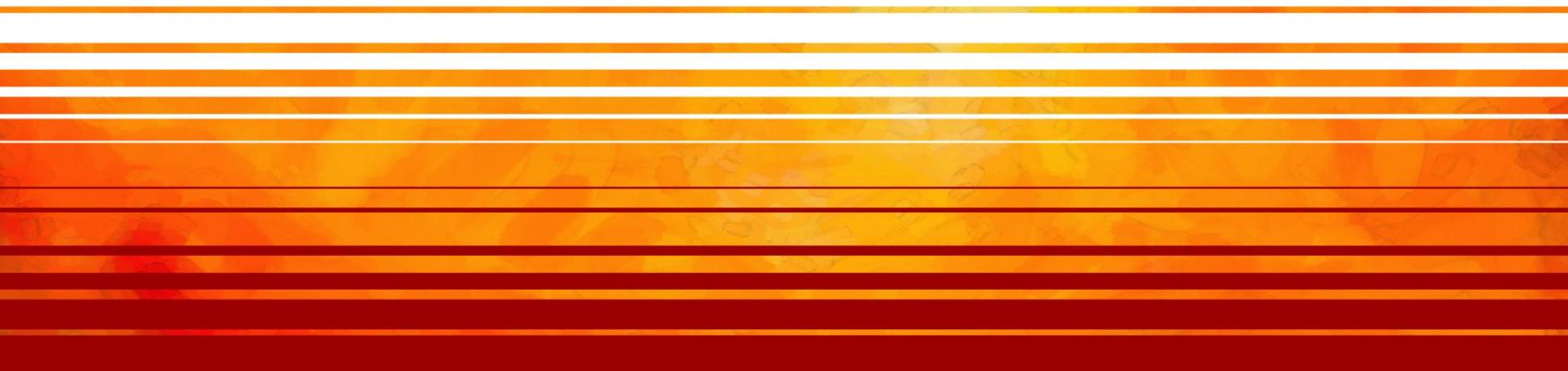


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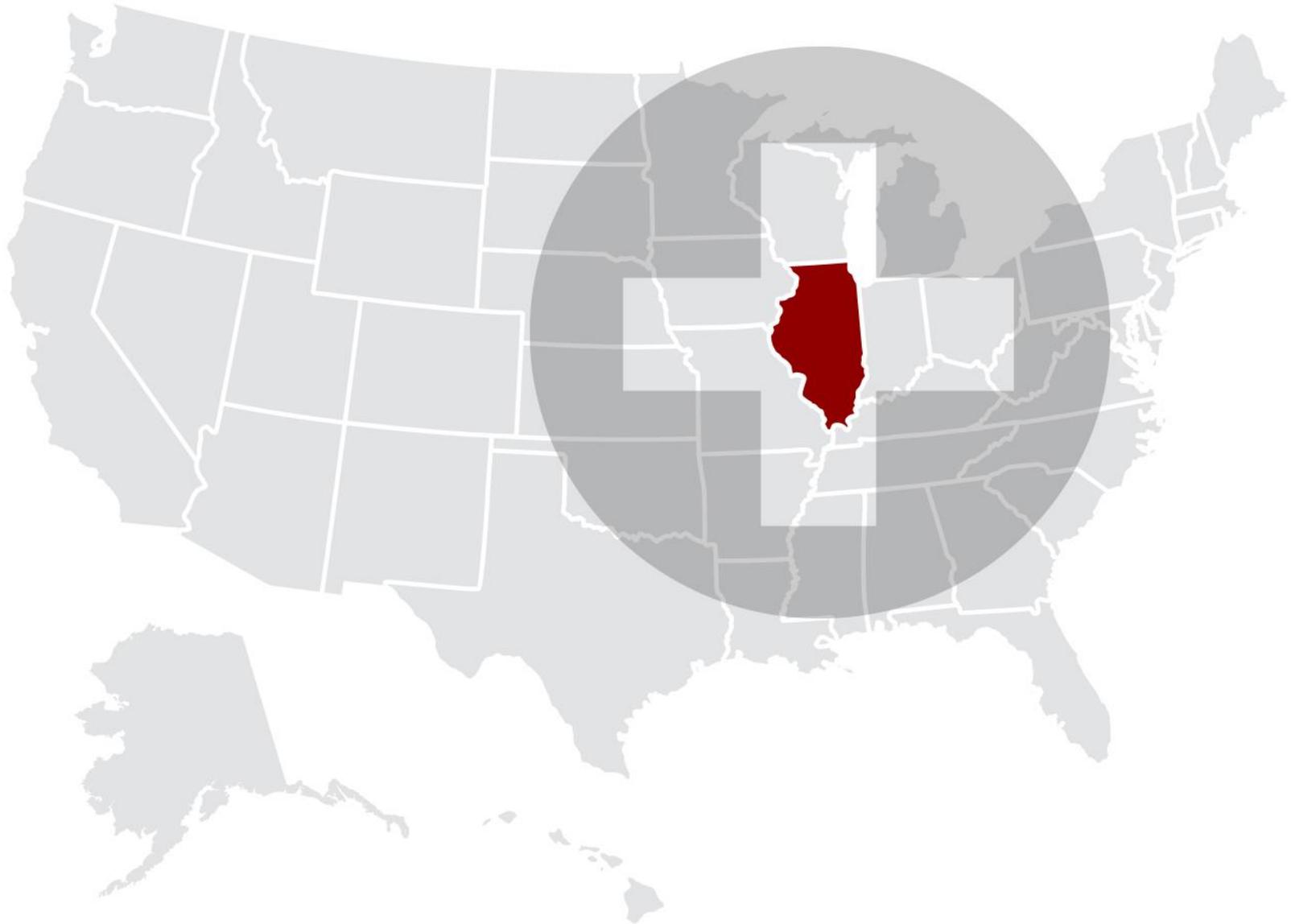
Leonard D. Schaeffer Center
for Health Policy & Economics

THE COST OF MENTAL ILLNESS: ILLINOIS FACTS AND FIGURES

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March 2019



ILLINOIS



INTRODUCTION

Improving access to high-quality medical and behavioral health care for patients with mental illness remains one of the most vexing problems facing the health care system in the United States. Illinois is no exception, with some commentators reporting a mental health care “crisis” in the state¹.

This chartbook attempts to quantify the magnitude of the challenges facing Illinois in terms of the economic burden associated with behavioral health issues. We describe the size and characteristics of the population with mental illness and show the impact on the health care system based on high rates of hospitalization. We also note the unmet need in terms of behavioral health care professionals and discuss the implications for the criminal justice system in Illinois.

¹ <http://www.chicagotribune.com/suburbs/daily-southtown/opinion/ct-sta-kadner-mental-st-0529-20150528-story.html>

INTRODUCTION

Key findings include:

- Illinois has a high rate of hospitalizations of patients with serious mental illness, which imposes a large cost on the health care system due to the relatively long length of stay, despite the general absence of procedures.
- Illinois's state mental health agency spending per capita on community-based treatment programs is low in relationship to the U.S. average.
- Whereas Illinois has a high number of hospital beds available to provide inpatient care to patients with serious mental illness, there is a shortage of behavioral health care professionals, particularly in the criminal justice system.
- People living with mental illness are more likely to encounter the criminal justice system, resulting in a large number of arrests and incarcerations. The overall annual cost of incarcerating people with serious mental illness in state prisons in Illinois exceeds \$250 million.

The data presented in this chartbook are publicly available and represent the most recent numbers to which we had access. The term “behavioral health” is used to describe data related to mental illness and substance abuse, whereas “mental health” does not include substance abuse.

The data and methods are described in more detail in the appendix:

http://healthpolicy.usc.edu/Keck_Schaeffer_Initiative.aspx

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QUANTIFYING THE POPULATION LIVING WITH MENTAL ILLNESS IN ILLINOIS AND THE U.S.

KEY POPULATIONS OF INTEREST

SERIOUS PSYCHOLOGICAL DISTRESS (SPD)

When someone experiences serious psychological distress, he or she may have a diagnosed or undiagnosed mental health condition, such as major depressive disorder, bipolar disorder, or schizophrenia (described below). Serious psychological distress is determined by six questions on the Kessler-6 screening instrument, which measures the frequency of symptoms of depression, anxiety, and emotional distress during a specific time period

MAJOR DEPRESSIVE DISORDER

A mental illness that severely impairs a person's ability to function, characterized by the presence of depressed mood, feelings of worthlessness, guilt, or helplessness, reduced concentration, ability to think, sleep problems, loss of interest or pleasure in activities, and/or recurrent thoughts of suicide

BIPOLAR DISORDER

A mental illness characterized by extreme shifts in mood and energy levels. During manic episodes, a patient has abnormally high energy and activity levels that lead to impairment in daily functioning or requires hospitalization to prevent harm to self or others. Delusions or hallucinations can also occur. Manic episodes may be alternated with major depressive episodes

SCHIZOPHRENIA

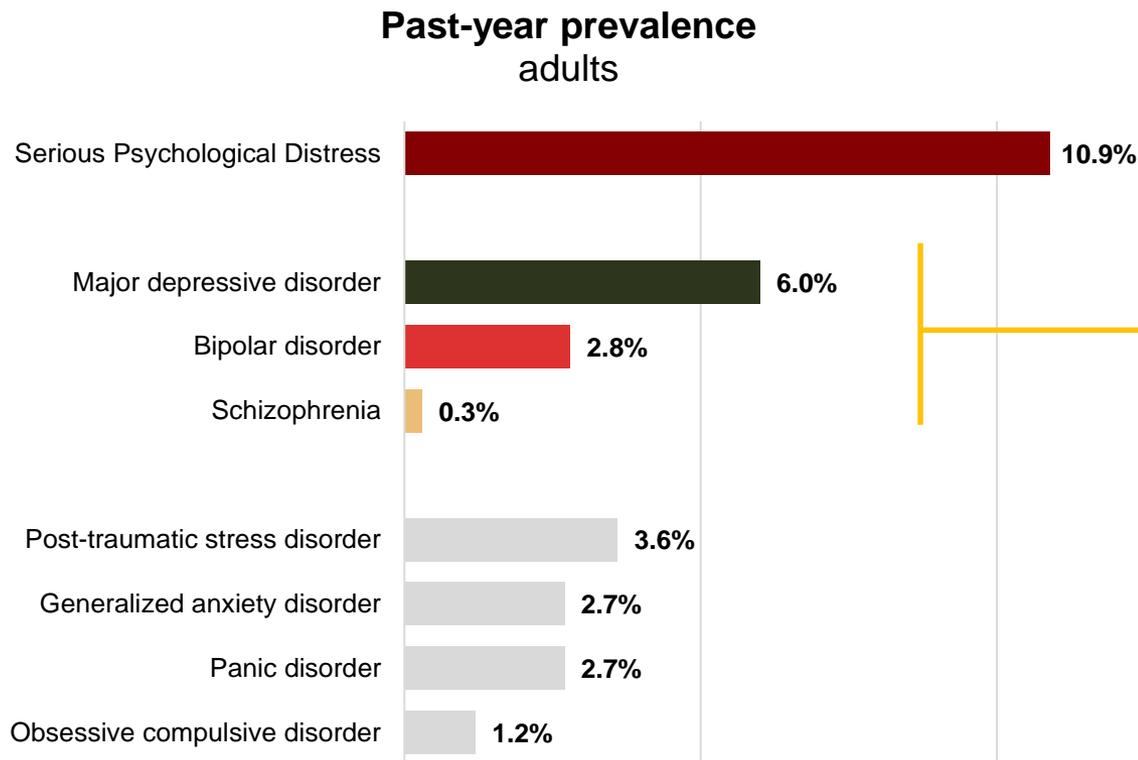
A debilitating mental illness that distorts a patient's sense of reality. Symptoms of schizophrenia include hallucinations, delusions, confusion, cognitive and mood impairments, and extremely disorganized thinking

RISK FACTORS: GENETIC & EXTERNAL FACTORS

Many different genetic factors may increase risk, but no single genetic variation causes a mental illness by itself; Specific interactions between the individual's genes and environment are necessary for a mental illness to develop

Prevalence of mental illness

UNITED STATES 2017



Many mental health conditions are fairly common in the general population.

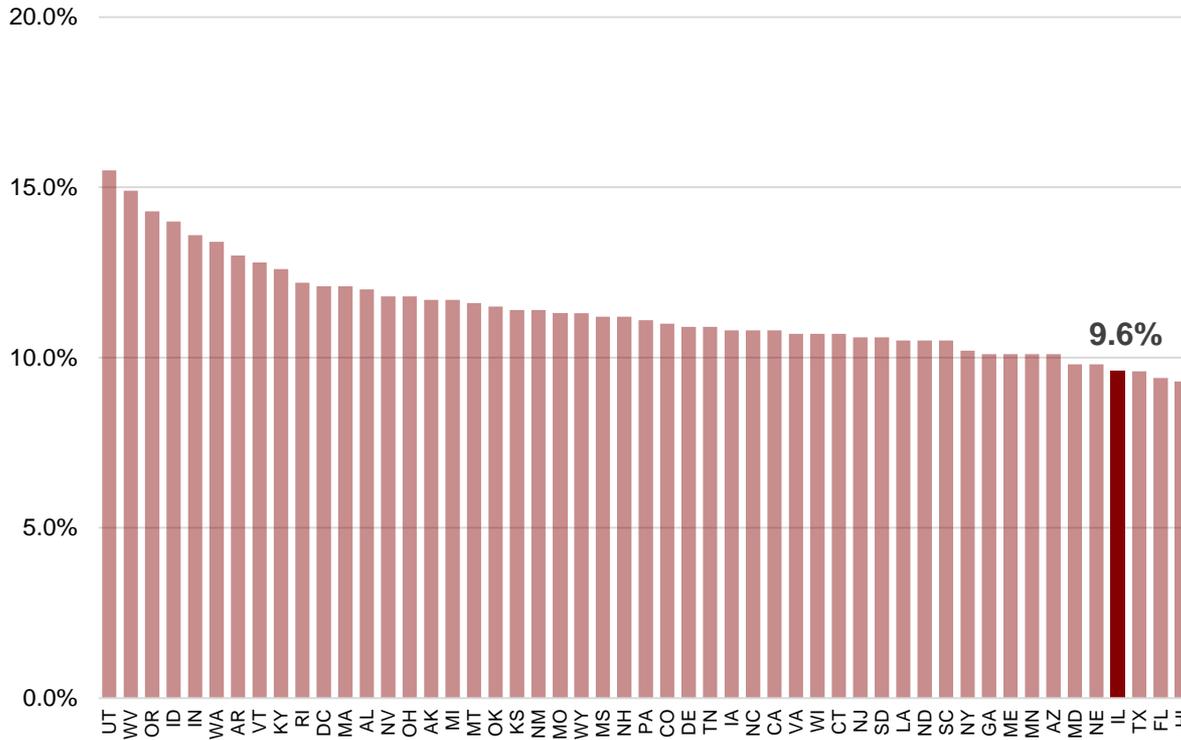
*Whereas any of these conditions can severely limit someone's normal daily activities, three disorders are often labeled as **serious mental illness**: **major depressive disorder**, **bipolar disorder** and **schizophrenia**. These three disorders will be the focus of this chartbook.*

*NB: Due to symptom overlap, diagnoses of mental illnesses are not mutually exclusive
Source: National Survey on Drug Use and Health (NSDUH, R-DAS) 2016-2017 (SPD),
NSDUH Mental Health Surveillance Study 2008-2012 (major depressive disorder) and
National Institutes of Mental Health (other conditions – see appendix for original sources)*

State variation in prevalence of serious psychological distress

ILLINOIS AND UNITED STATES 2017

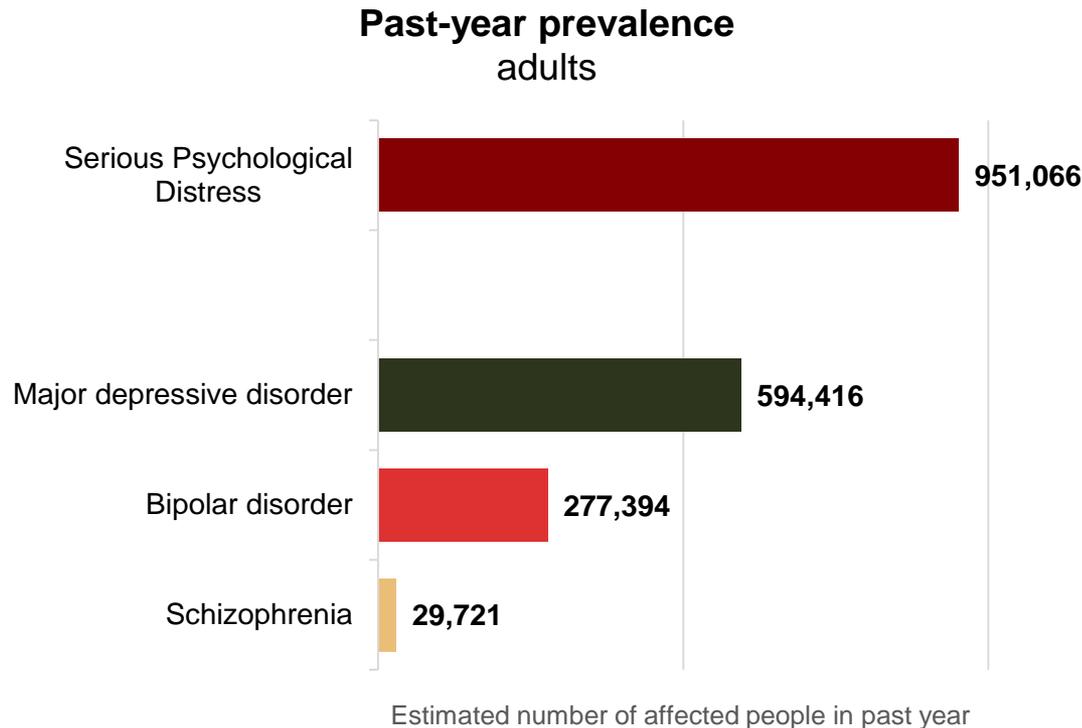
Past-year prevalence of serious psychological distress
Adults



The prevalence of serious psychological distress in the past year in Illinois is estimated at 9.6%, one of the lowest rates of all states in the U.S.

Estimated number of people living with mental illness

ILLINOIS 2017



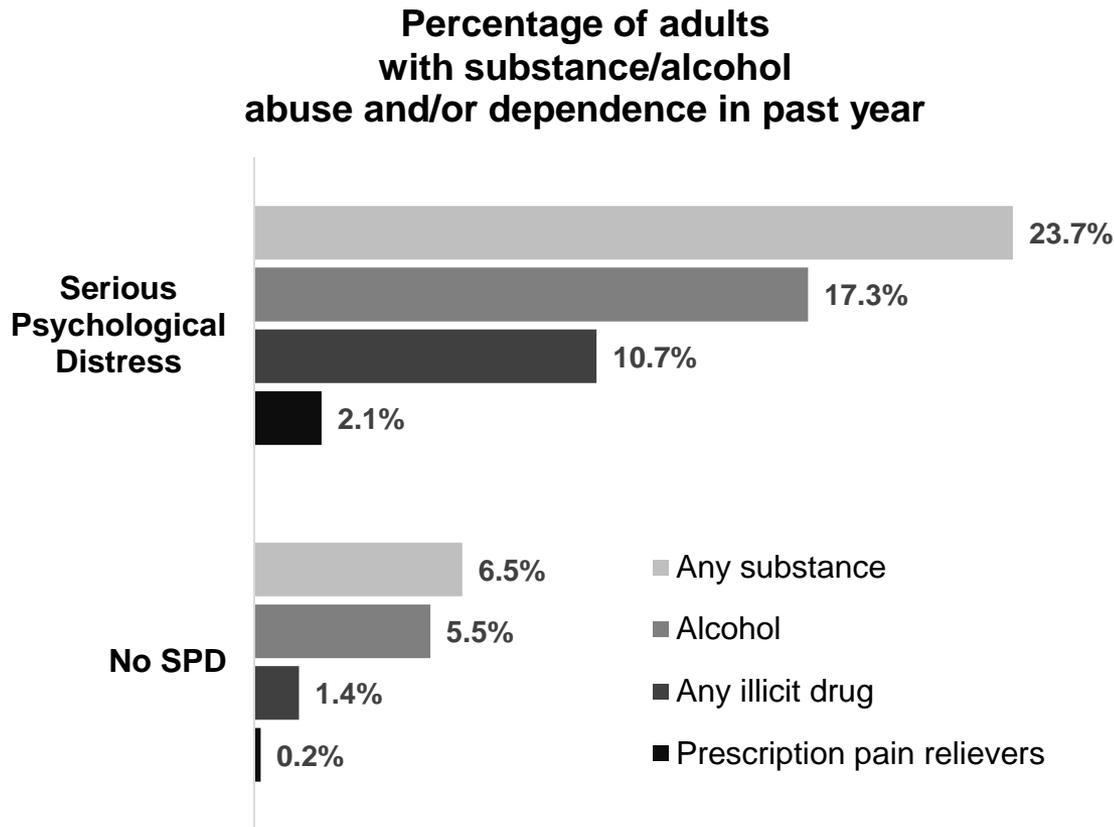
We estimate that almost one million adults in Illinois experienced serious psychological distress in the past 12 months.

Note that a patient can receive multiple diagnoses of a serious mental illness due to a high degree of overlap between the mental health conditions.

Source: Source: National Institutes of Mental Health, National Survey on Drug Use and Health (NSDUH, R-DAS) 2016-2017, and NSDUH-MHSS 2008-2012. Estimated number of people affected based on total state population of 9,906,933 (18 years and over), Census Bureau data (2017)

Substance abuse in people with serious psychological distress

ILLINOIS 2017



People who experienced serious psychological distress in the past 12 months are more likely to abuse or be dependent on alcohol or illicit drugs during that same time period.

MENTAL HEALTH CARE COVERAGE, UTILIZATION & COSTS

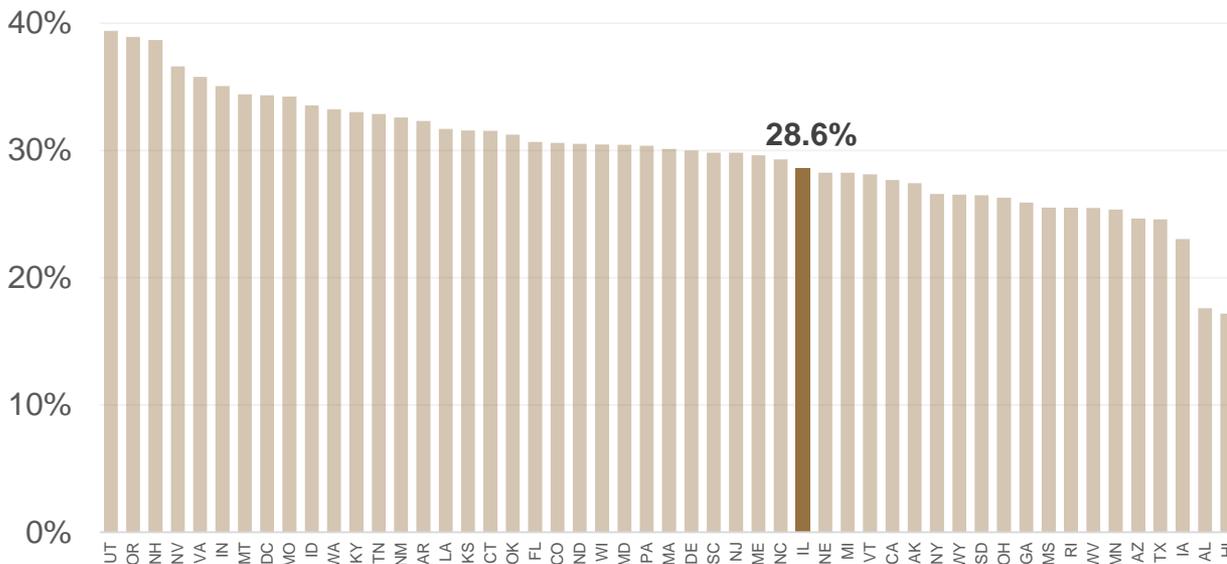
Unmet mental health care needs

More than a quarter of adults with serious psychological distress in the past year reported an unmet need for mental health care. A common reason for not receiving care was the inability to afford mental health treatment, especially for people who do not have health insurance.

Unmet need of mental health treatment

ILLINOIS AND UNITED STATES 2017

Percentage of adults
who have an unmet need of mental health treatment
among those
with past-year serious psychological distress



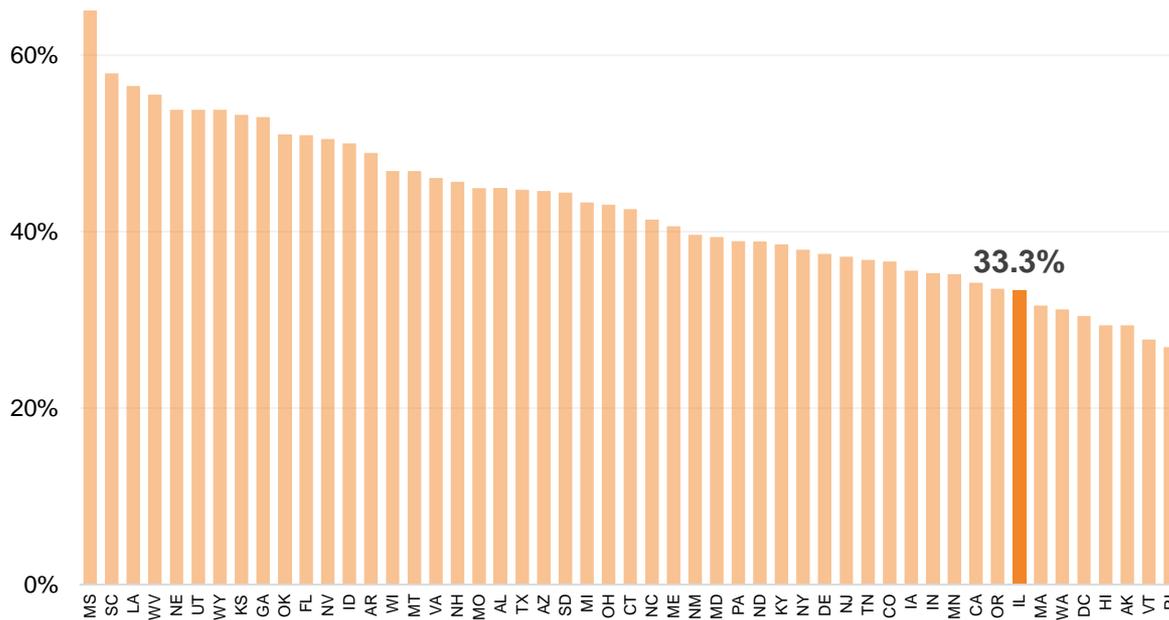
In Illinois, almost a quarter of people with serious psychological distress have an unmet need of mental health treatment.

In the general adult population of Illinois, 4.4% of people have a unmet need of mental health treatment.

Unmet need of mental health treatment due to costs

ILLINOIS AND UNITED STATES 2017

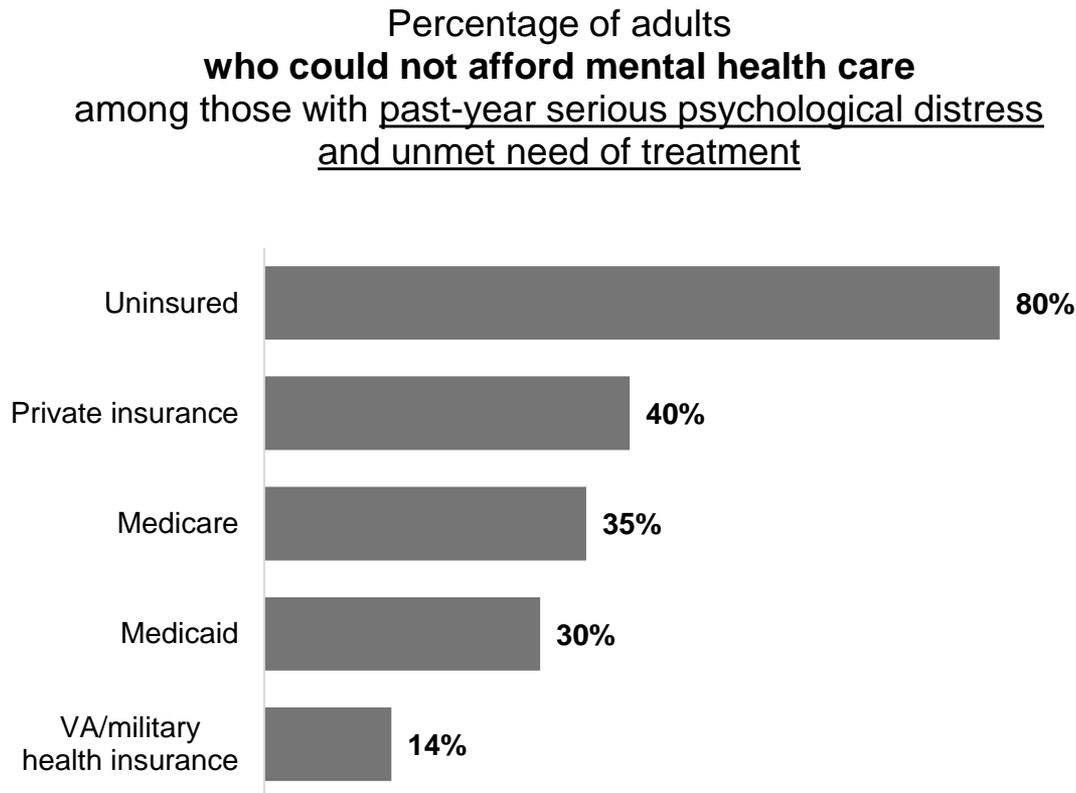
Percentage of adults
who could not afford mental health care
among those with past-year serious psychological
distress and unmet need of treatment



In Illinois, a third of people with serious psychological distress and an unmet need of mental health treatment, did not receive this treatment due to costs.

Unmet need of mental health treatment due to costs differs by insurance coverage

UNITED STATES 2017

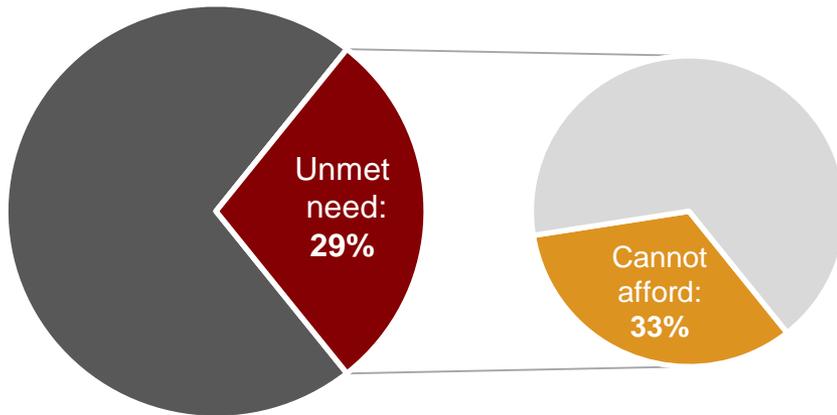


On a national level, the extent to which cost was a factor in driving unmet need for mental health care among those with serious psychological distress, varied by insurance status. People without health insurance were most affected by the inability to afford mental health treatment (80%), while those with VA/military health insurance coverage were least affected (14%).

There is significant unmet need for mental health care in Illinois

ILLINOIS 2017

Among adults who experienced serious psychological distress during the past year:



29% indicates an **unmet need of mental health treatment**

And 33% of these people did not receive mental health treatment, **because they could not afford it**

Among adults who experienced serious psychological distress in the previous year in Illinois, more than a quarter reported an unmet need for mental health care.

A third of the people with a perceived unmet need reported that they did not receive treatment because they could not afford it.

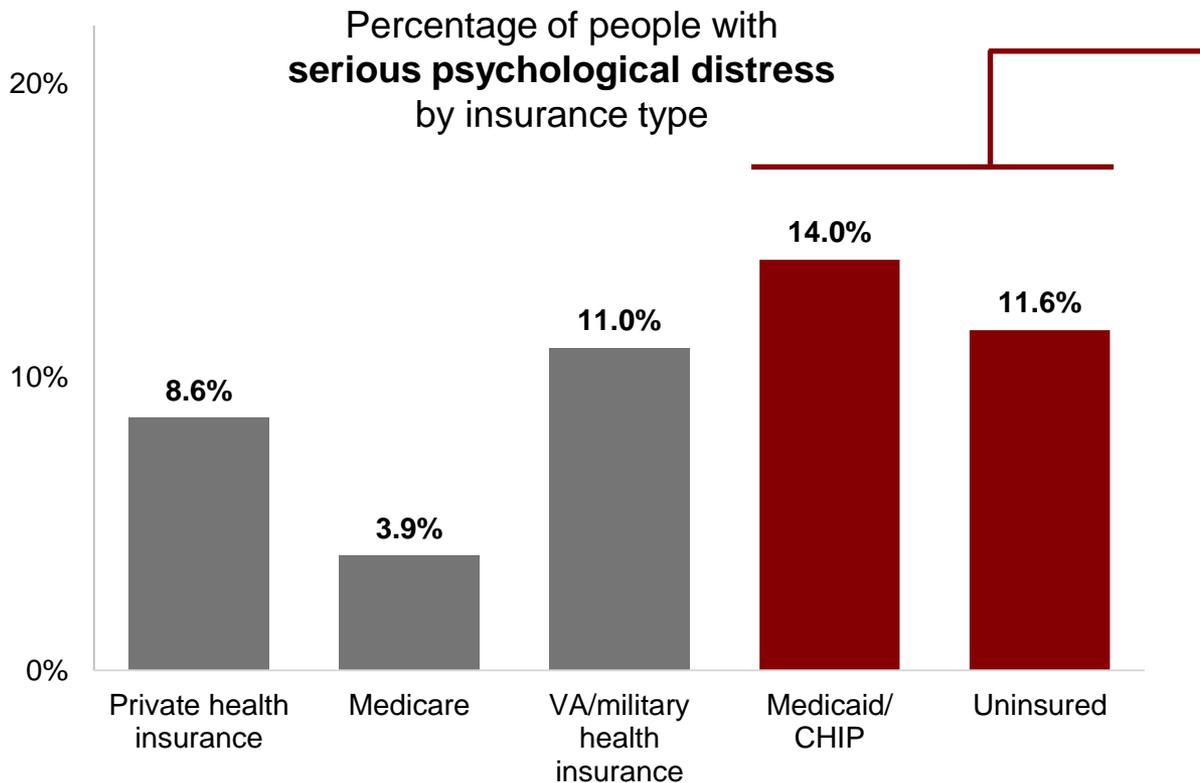
MENTAL HEALTH CARE COVERAGE, UTILIZATION & COSTS

Medicaid & behavioral health care needs

Medicaid provides a safety-net for people with low income or qualifying disabilities, and a large percentage of people with Medicaid coverage experience behavioral health issues. However, it is often a financial burden for physicians to accept Medicaid patients since reimbursement rates are generally lower than for other patients. This can lead to access barriers for patients with Medicaid coverage that prevent them from receiving the behavioral health care they need.

People with mental illness have greater reliance on the safety net

ILLINOIS 2016



*In the **Medicaid and uninsured population**, a higher percentage of adults in Illinois reported serious psychological distress (SPD) during the past year compared to people with Medicare, VA/military, or private health insurance coverage.*

Medicaid reimbursement rates to physicians are low

ILLINOIS AND UNITED STATES 2016

Medicaid-to-Medicare fee ratio, 2016



Low reimbursement rates are a disincentive for individual physicians to accept patients with Medicaid coverage and mental health problems. Compared to Medicare fee levels, Medicaid reimbursement rates are low in most states. Illinois has one of the lowest Medicaid-to-Medicare fee ratios, which may further limit physician's willingness to accept Medicaid patients. **This can be a barrier for these patients to obtain access to mental health care.**

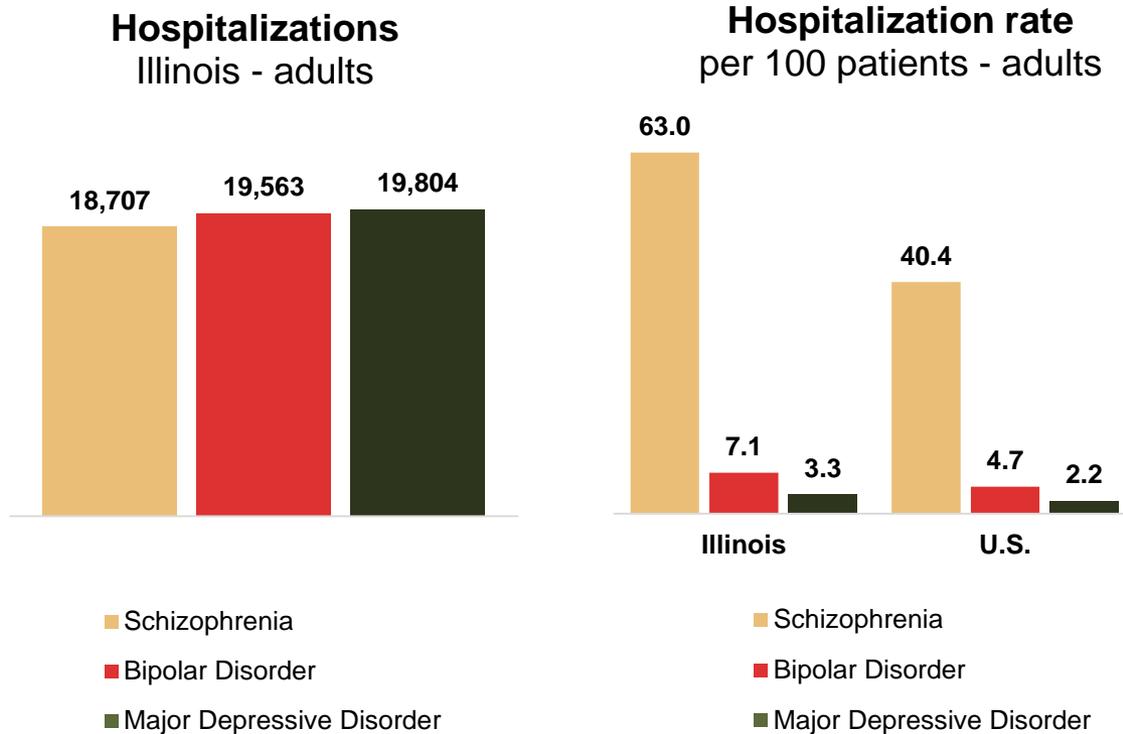
MENTAL HEALTH CARE COVERAGE, UTILIZATION & COSTS

Hospital utilization & charges

For every 100 patients with a serious mental illness, there were approximately 47 hospitalizations in the U.S. in 2014. In Illinois this number is approximately 1.5 times higher. The average length of stay for these hospitalizations is long compared to other hospital stays. Relatively little progress has been made in reducing the length of stay for a serious mental illness over the last decade. This imposes a large financial cost on the health care system and potentially diverts resources away from other sites of care.

Hospitalizations for mental illness

ILLINOIS AND UNITED STATES 2014



In Illinois, the number of hospitalizations of adults with schizophrenia, bipolar disorder, and major depressive disorder are approximately equal. However, patients with schizophrenia have a much higher rate of hospitalizations.

Compared to the rest of the U.S., hospitalization rates in Illinois for adults with serious mental illness are approximately 1.5 times higher.

4.5 % of all hospitalizations are due to SMI

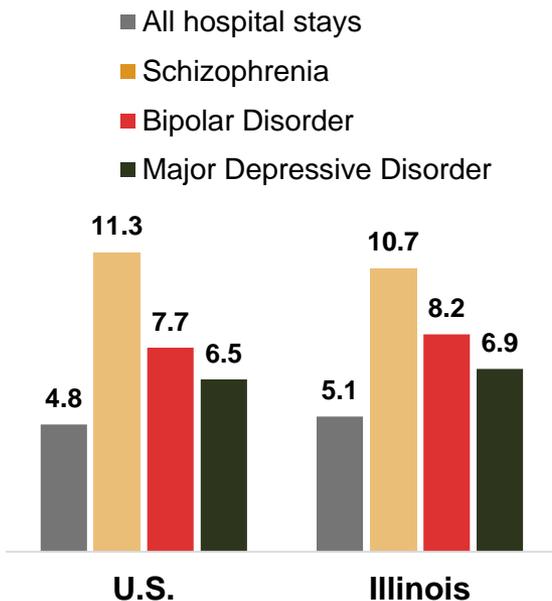
Source: Healthcare Cost and Utilization Project (HCUPnet) 2014

Estimate of hospitalization rate: based on total state population (Census bureau data, 2014) and prevalence estimates reported previously

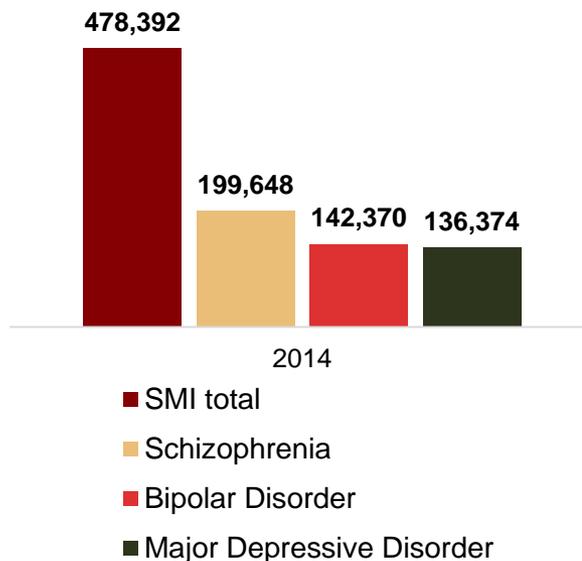
Length of stay for mental illness hospitalizations

ILLINOIS AND UNITED STATES 2014

Average duration of hospital stays (days) adults



Total number of hospital days in 2014 Illinois - adults



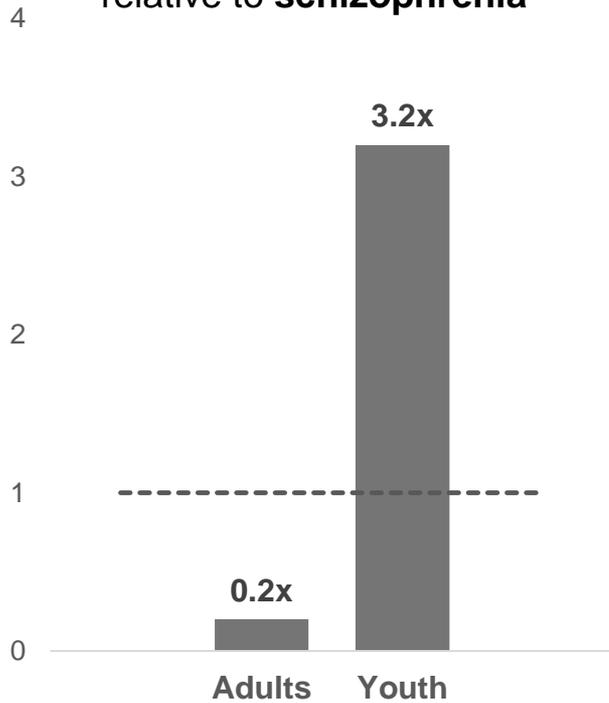
The average hospital stay duration for adult patients with serious mental illness is high compared to all hospital stays, especially for patients diagnosed with schizophrenia.

The total time spent in the hospital by adults with a primary diagnosis of schizophrenia, bipolar disorder or major depressive disorder almost reaches half a million days each year in Illinois.

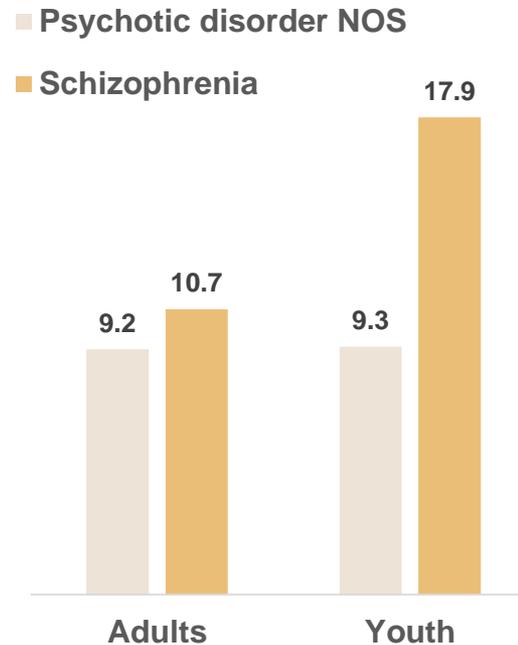
Hospitalizations of young patients with psychosis

ILLINOIS 2014

Number of hospitalizations for **psychotic disorder NOS** relative to **schizophrenia**



Average length of hospital stay (days)



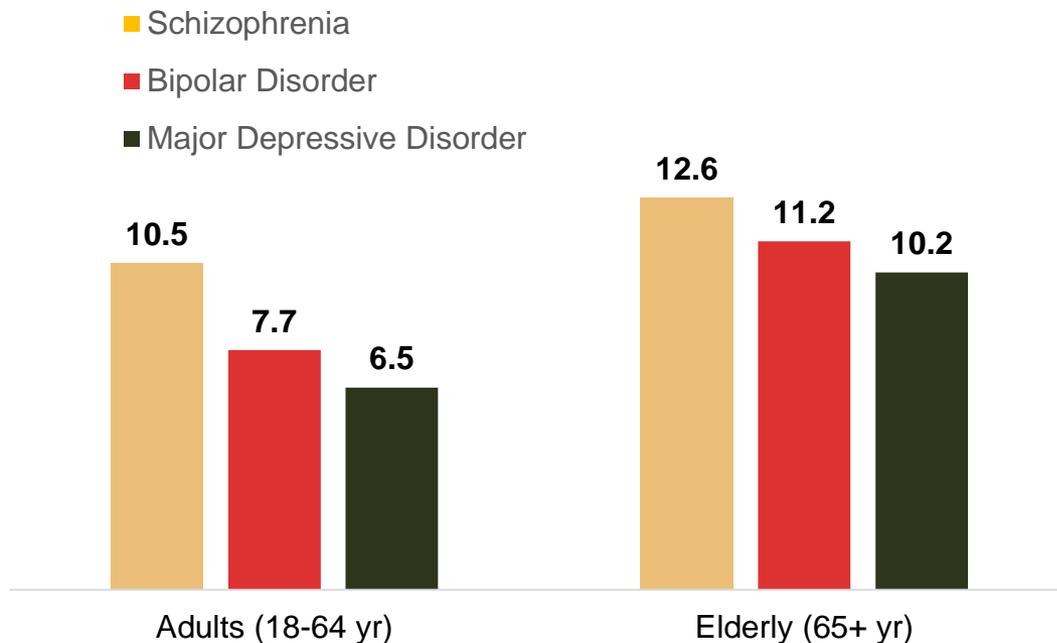
In contrast to in adults, “psychotic disorder, not otherwise specified (NOS)” is diagnosed more often than schizophrenia in the younger population (1-17 years) during hospitalizations, possibly to prevent stigmatization.

For younger people with a diagnosis of schizophrenia, the average length of stay in Illinois is at least a week longer than for adults, illustrating the challenges in treating and establishing an environment with appropriate follow-up care for this especially vulnerable population.

Hospitalizations of elderly patients with serious mental illness

ILLINOIS 2014

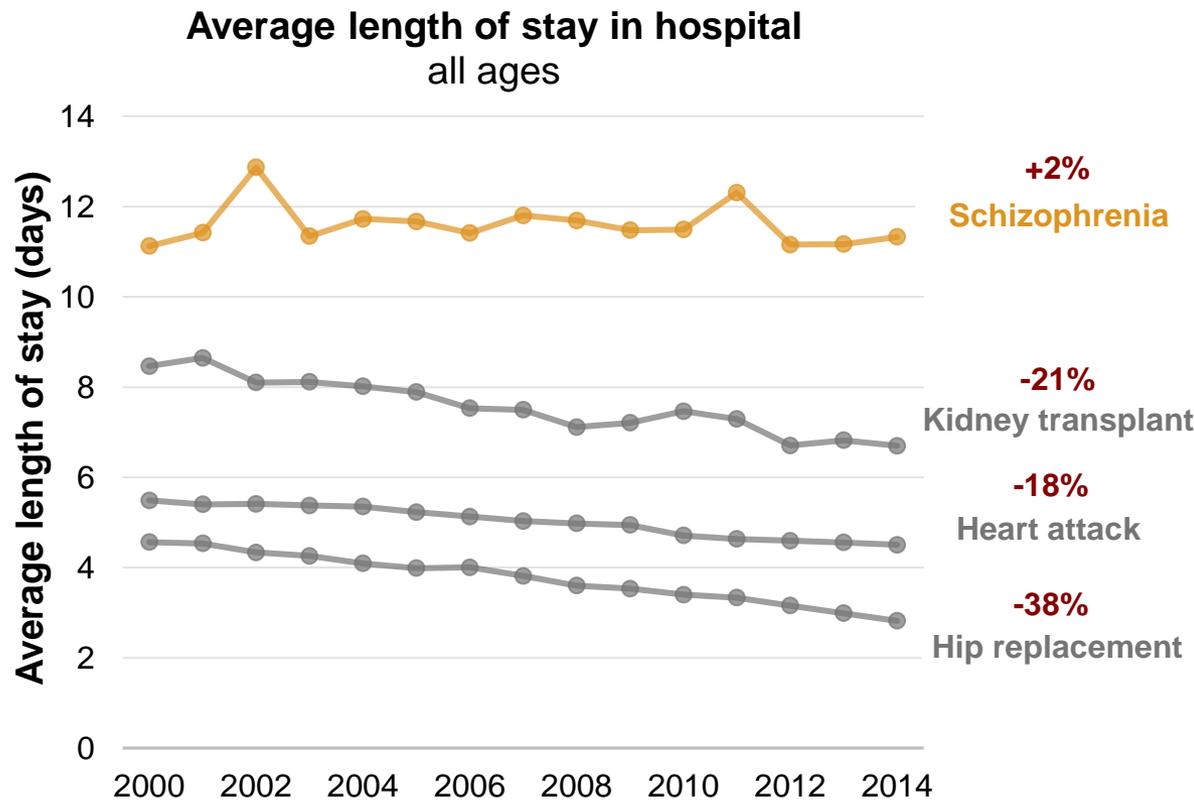
Average duration of hospital stays (days) Elderly (65+ yr)



The length of stay in the hospital for serious mental illness in elderly patients is at least 20% higher on average than for younger adults with a similar diagnosis. Treatment of medical comorbidities due to aging, as well as difficulty finding long-term care environments may be at the root of this disparity.

Trends in length of stay for schizophrenia hospitalizations

UNITED STATES 2000-2014

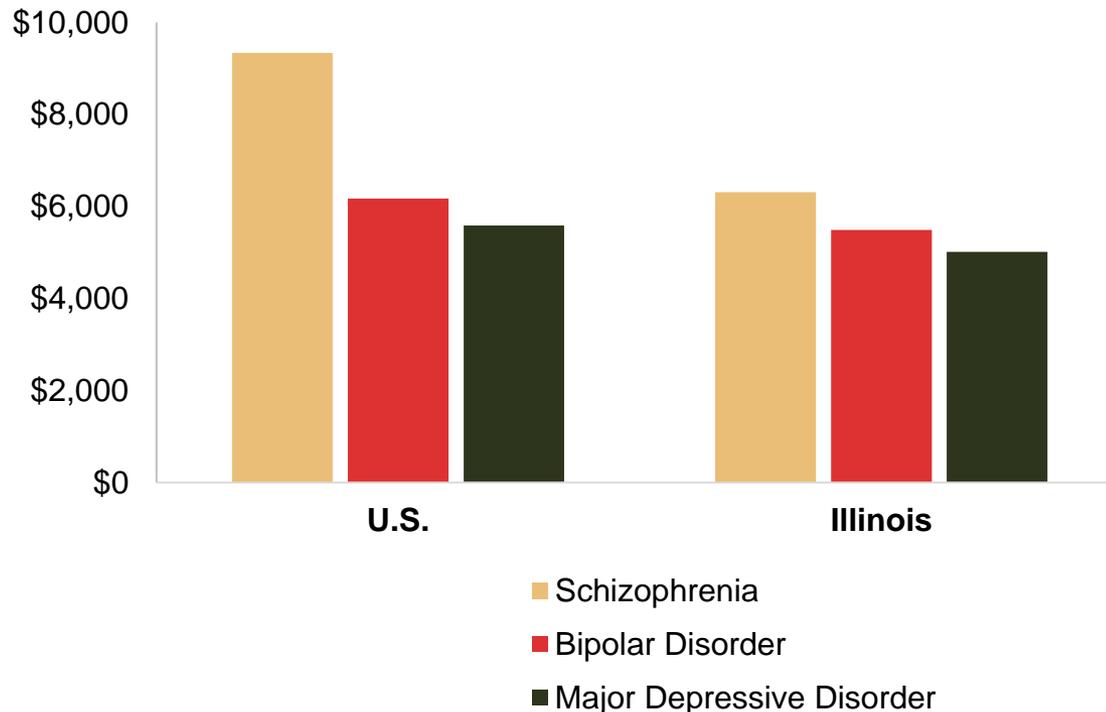


The average length of stay for a schizophrenia hospitalization was longer than those for kidney transplants, heart attacks or hip replacement surgeries. Moreover, the average duration for these other conditions all declined by at least 18% from 2000 to 2014 while for schizophrenia the duration increased slightly.

Average hospital costs for mental illness hospitalizations

ILLINOIS AND UNITED STATES 2014

Average hospital cost per stay
(all ages, in 2018 U.S.\$)

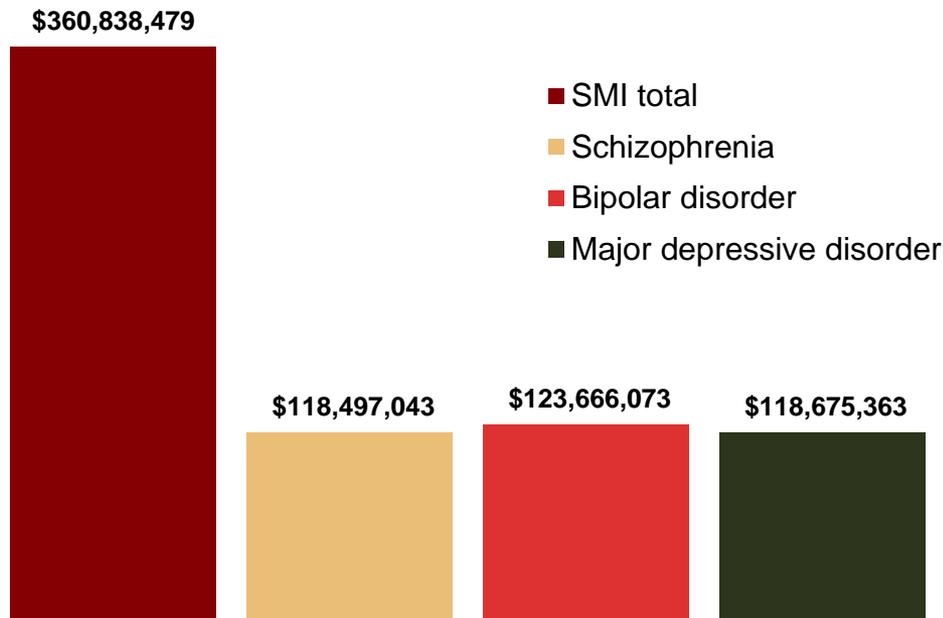


*Hospital costs in the U.S. and Illinois ranged from \$5,000 to \$9,000 per stay for patients with serious mental illness. This is despite a **general absence of procedures or surgeries** during a hospitalization for symptoms of serious mental illness.*

Total hospital costs for mental illness hospitalizations

ILLINOIS 2014

Total hospital costs
(all ages, in 2018 U.S.\$)



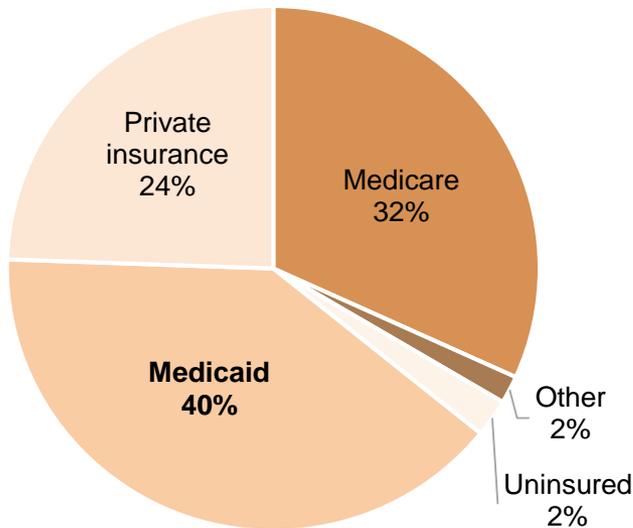
Total hospital costs in Illinois for hospitalizations for serious mental illness together exceeded \$360 million in 2014.

Total hospital costs for serious mental illness hospitalizations by insurance type

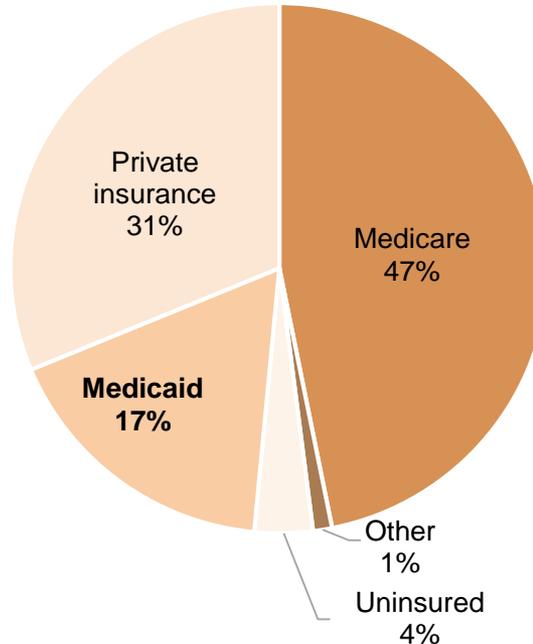
ILLINOIS 2014

Total hospital costs
(all ages, in 2018 U.S. \$)

Serious mental illness
\$361 million



All hospitalizations
\$17 billion



Compared to all hospitalizations, the expected payer for hospitalizations involving serious mental illness is much more likely to be Medicaid and less likely to be Medicare or a private insurer.

Only a small fraction of the \$361 million in total hospitalization costs is covered by other programs (including VA/military health insurance), or paid by patients without health insurance.

Source: Healthcare Cost and Utilization Project (HCUPnet) 2014.

'Other' includes Worker's Compensation, TRICARE/CHAMPUS, CHAMPVA, Title V, and other government programs. 'Uninsured' includes 'self-pay' and 'no charge'.

MENTAL HEALTH CARE COVERAGE, UTILIZATION & COSTS

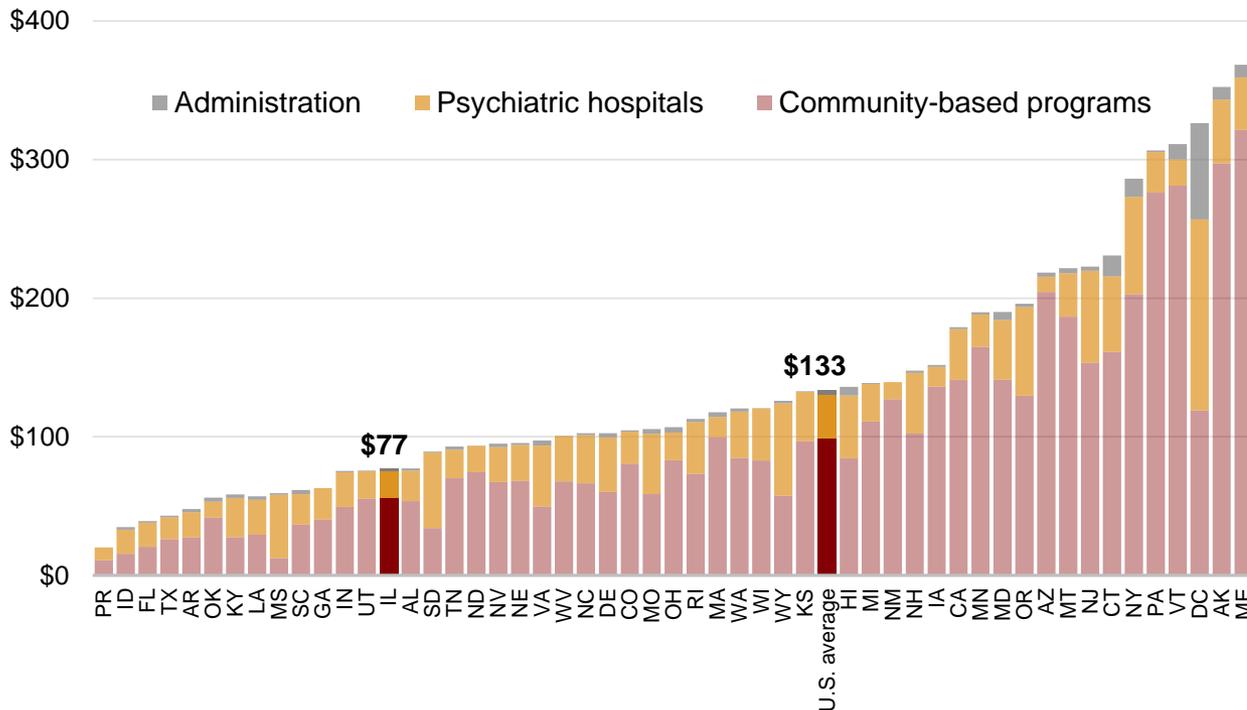
Investment in community-based programs

For several decades, a shift from hospital inpatient care towards community-based clinic outpatient treatment has taken place, as is exemplified by the budget trends of state mental health agencies. On average, approximately 72% of their budgets is now spent on community-based programs, compared to 33% in the early 1980s. Compared to the U.S. average, the Illinois Department of Mental Health spends a very low amount per capita on community-based programs.

State Mental Health Agency spending

ILLINOIS AND UNITED STATES 2013

**Per capita
State mental health agency expenditures**
(in 2018 U.S. \$)



Illinois's state mental health agency spends a very low per capita amount on mental health services, compared to the rest of the U.S.

Expenditures include (on average):

- 72% Community-based mental health programs funded and/or operated by state mental health agencies
- 26% Mental health services in state psychiatric hospitals
- 2% Administration/training/research/evaluation to support these services

Source: State Mental Health Agency-Controlled Expenditures for Mental Health Services, FY 2013
National Association of State Mental Health program Directors Research Institute, Inc (NRI)

AVAILABILITY OF BEHAVIORAL HEALTH CARE PROFESSIONALS

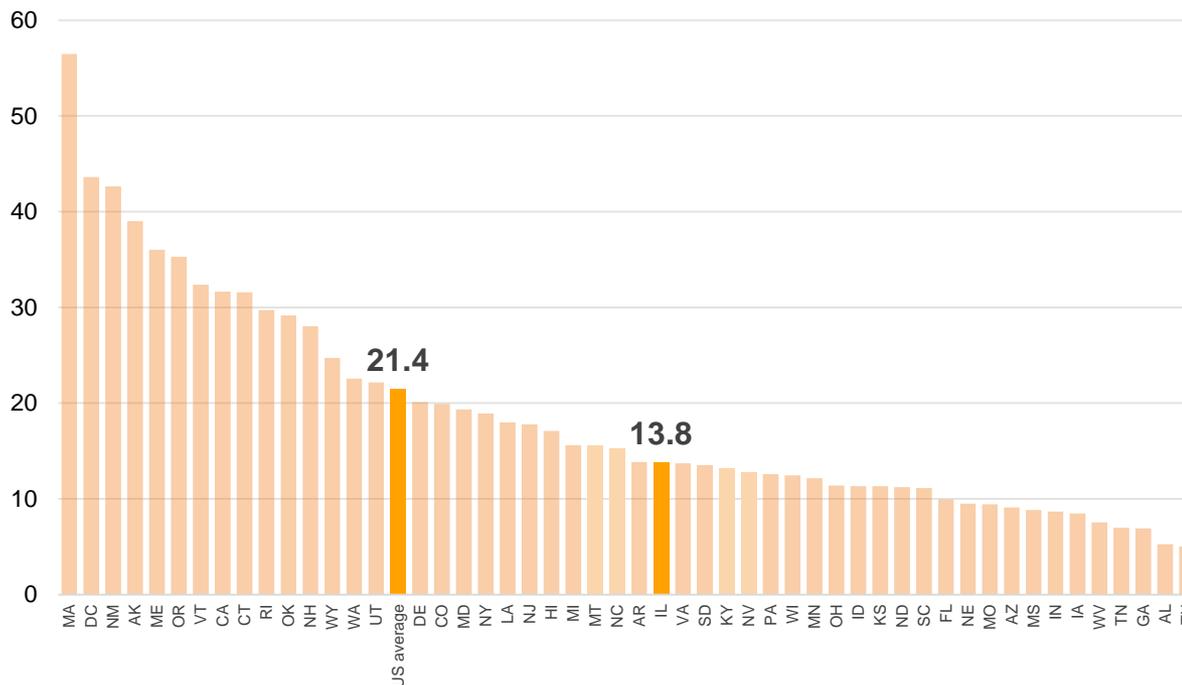
In Illinois, the number of behavioral health care professionals is lower than the U.S. average. There are slightly more hospital beds and primary care physicians per capita than the national average. However, these average ratios are not optimal, and are not sufficient to serve the population with behavioral health needs.

In Illinois alone, 225 full-time professionals are needed in addition to the current workforce in designated “shortage areas” to reach an acceptable provider-to-patient ratio. This shortage is also acute in the criminal justice system, where many people are in need of behavioral health treatment.

Availability of behavioral health care professionals

ILLINOIS AND UNITED STATES 2018

Number of behavioral health care professionals per 10,000 residents



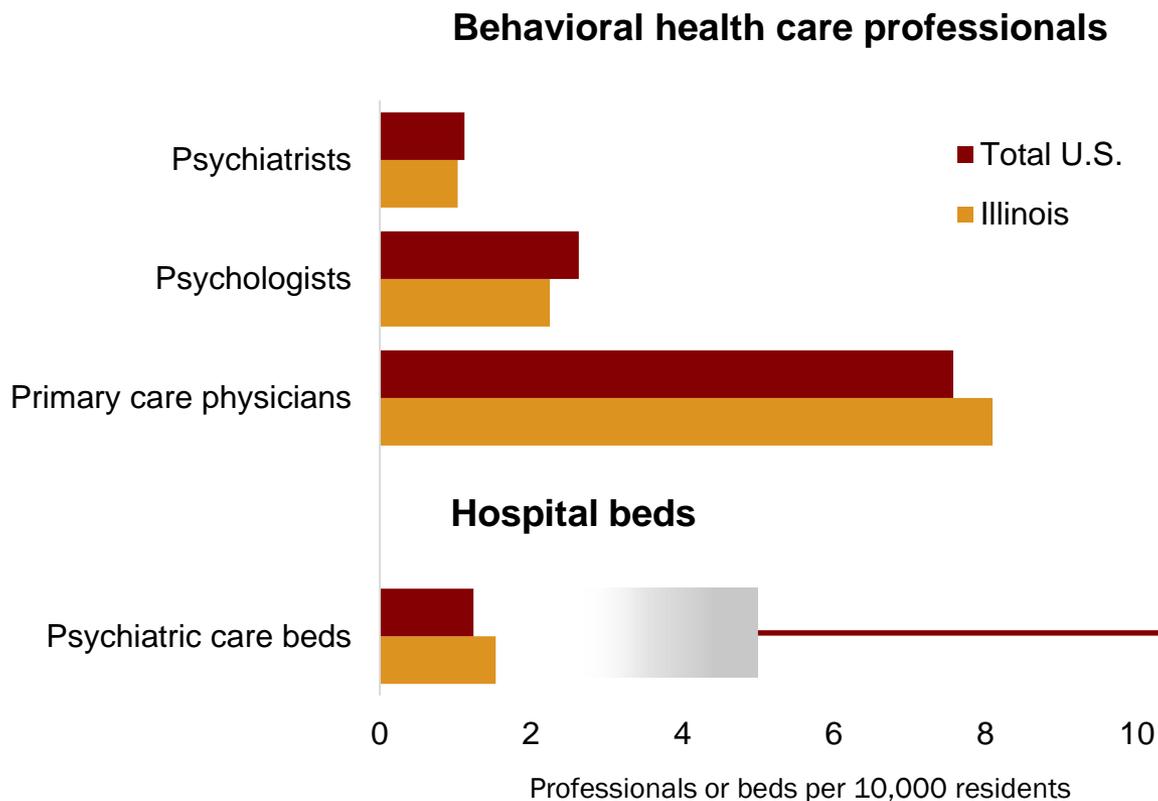
There are 14 behavioral health care professionals for every 10,000 residents in Illinois, which is significantly lower than the average in the U.S.

Note that the U.S. average does not represent the optimal number of behavioral health care professionals.

Behavioral health care professionals include: psychiatrists, psychologists, licensed clinical social workers, counselors, marriage and family therapists, and advanced practice nurses specializing in behavioral health care.

Availability of behavioral health care professionals and hospital beds

ILLINOIS AND UNITED STATES 2013



Per resident, Illinois has fewer psychiatrists and psychologists compared to the U.S. average. However, Illinois has a higher number of primary care physicians and hospital beds dedicated to psychiatric care.

Note that the U.S. average does not represent the optimal number of behavioral health care professionals or hospital beds.

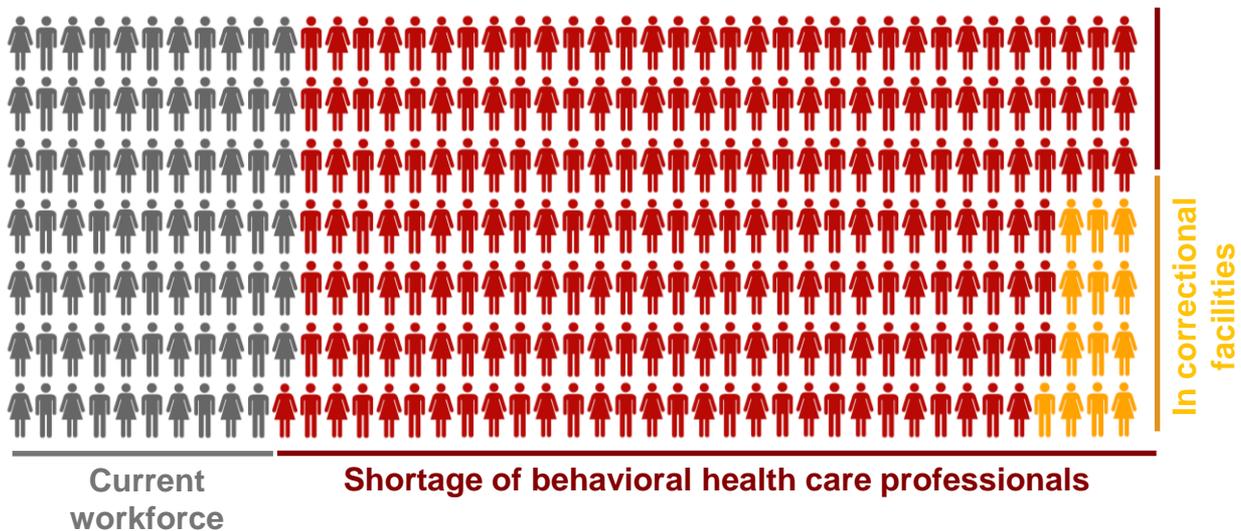
Although the optimal number of beds is unknown in our current health care infrastructure, there are estimates that 5 beds per 10,000 residents are minimally required assuming sufficient availability of outpatient programs for long-term treatment.

Source: Area Health Resource Files 2013 (psychiatrists, physicians and psychiatric care beds), and 2005-2013 Demographics of the U.S. Psychology Workforce, American Psychological Association (psychologists)

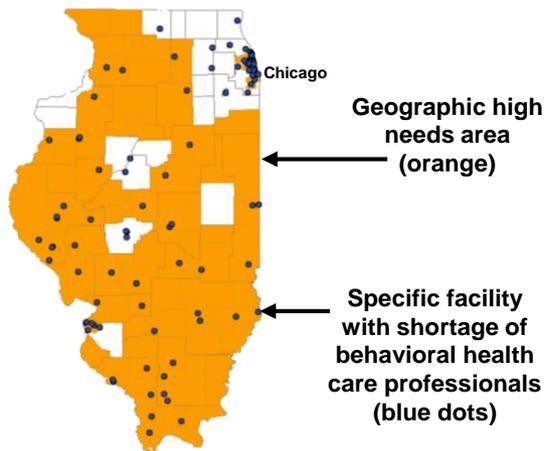
Treatment Advocacy Center, "The Shortage of Public Hospital Beds for Mentally Ill Persons"

Shortage of behavioral health care professionals

ILLINOIS 2019



Currently, Illinois has 64 full-time equivalent behavioral health care professionals in designated shortage areas and facilities with behavioral health care professional shortages. In order to address the shortage issue, 229 more full-time professionals are needed in these areas, 12 of whom are needed in correctional facilities.



Behavioral health care professionals: psychiatrists, clinical psychologists, clinical social workers, psychiatric nurse specialists, and marriage & family therapists

Facilities: Federal & state correctional institutions, state & county mental hospitals, community mental health centers, and other public or nonprofit private facilities

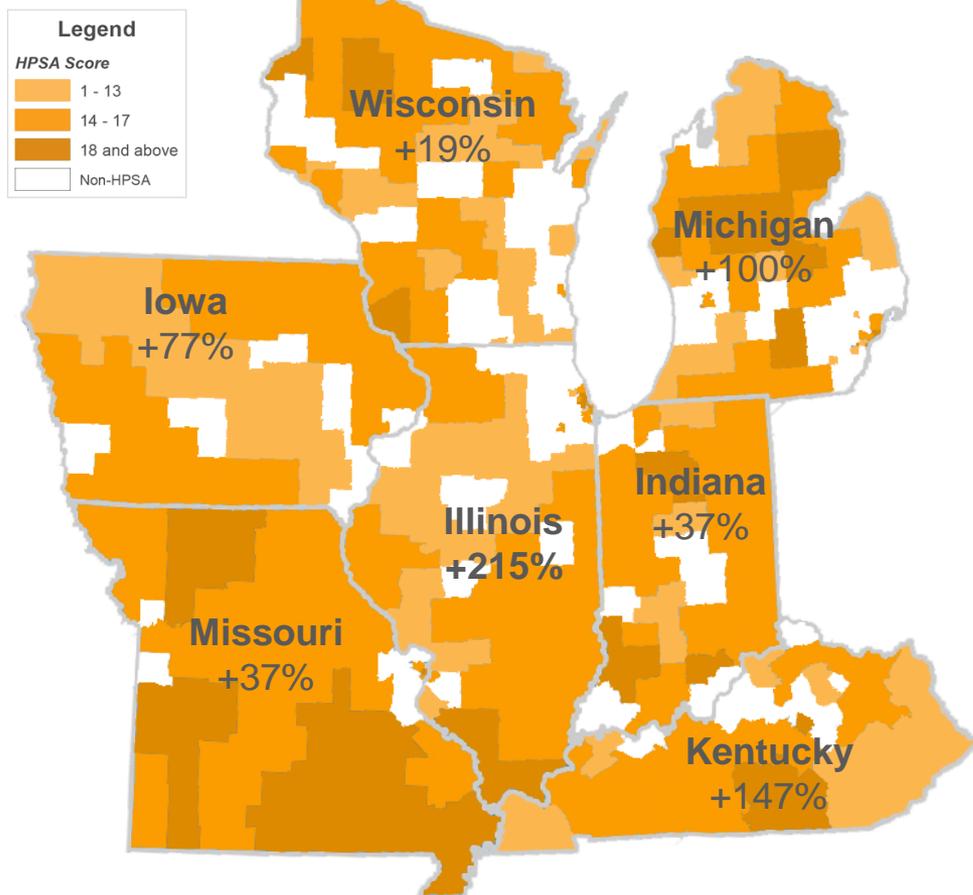
Geographic high needs area based on population-to-provider ratio, poverty levels, elderly and youth ratio, alcohol and substance abuse prevalence, and travel time to nearest source of care outside area

Source: Health Professional Shortage Areas (HPSA), HRSA Data Warehouse data as of 01/13/19

Shortage of behavioral health care professionals in the Illinois region

ILLINOIS 2019

Increase in shortage of behavioral health care professionals 2017-2019



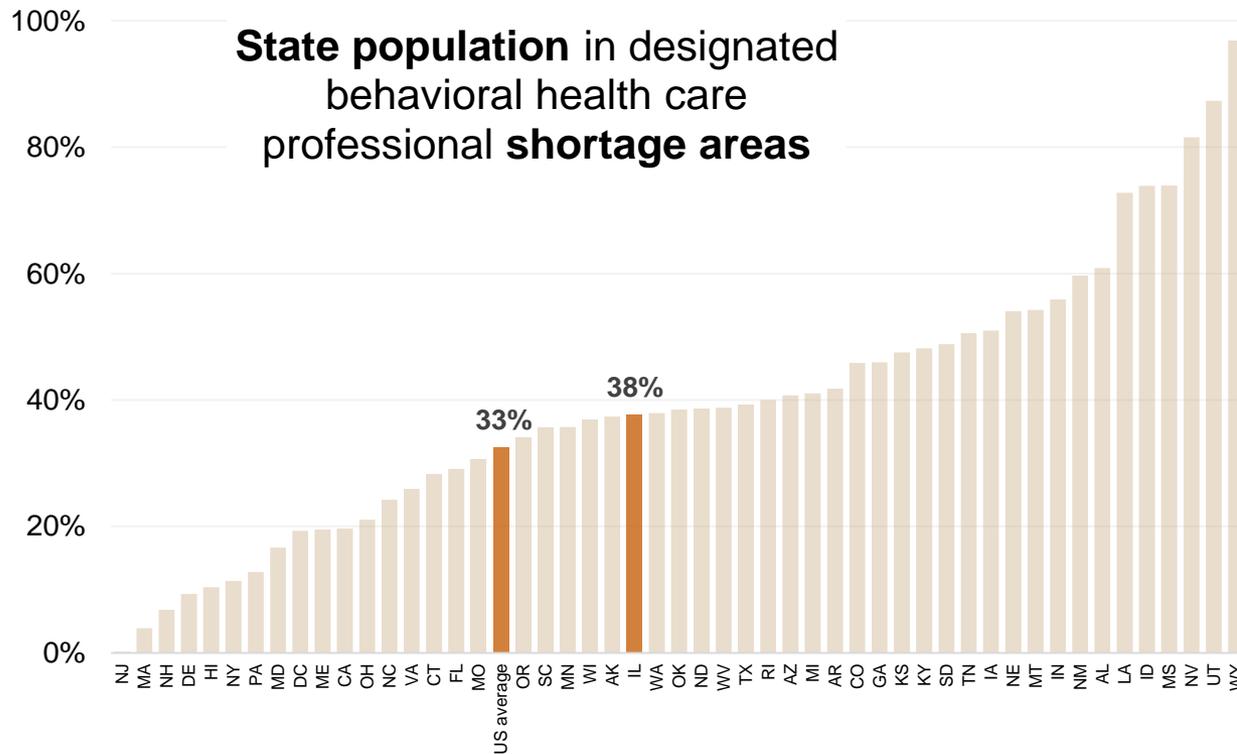
The number of behavioral health care professionals needed to remove the shortage designation in Health Professional Shortage Areas is high in all states surrounding Illinois, especially in rural areas. However, Illinois has seen the highest increase in these shortages between 2017 and 2019.

The severity of the shortage on this map is measured on the Health Professional Shortage Area scale from 0 to 25, with 0 indicating no shortage, and 18 and above a severe shortage.

Source: Health Professional Shortage Areas (HPSA), HRSA Data Warehouse data as of 01/13/19

State population in behavioral health care professional shortage areas

ILLINOIS AND UNITED STATES 2019



4,827,306 people in Illinois (38% of the state population) reside in designated shortage areas and/or are served by a facility with shortages of behavioral health care professionals. This is higher than the U.S. average of 33%.

Source: Health Professional Shortage Areas (HPSA), HRSA Data Warehouse, 01/13/19, and Census Bureau data (2017)

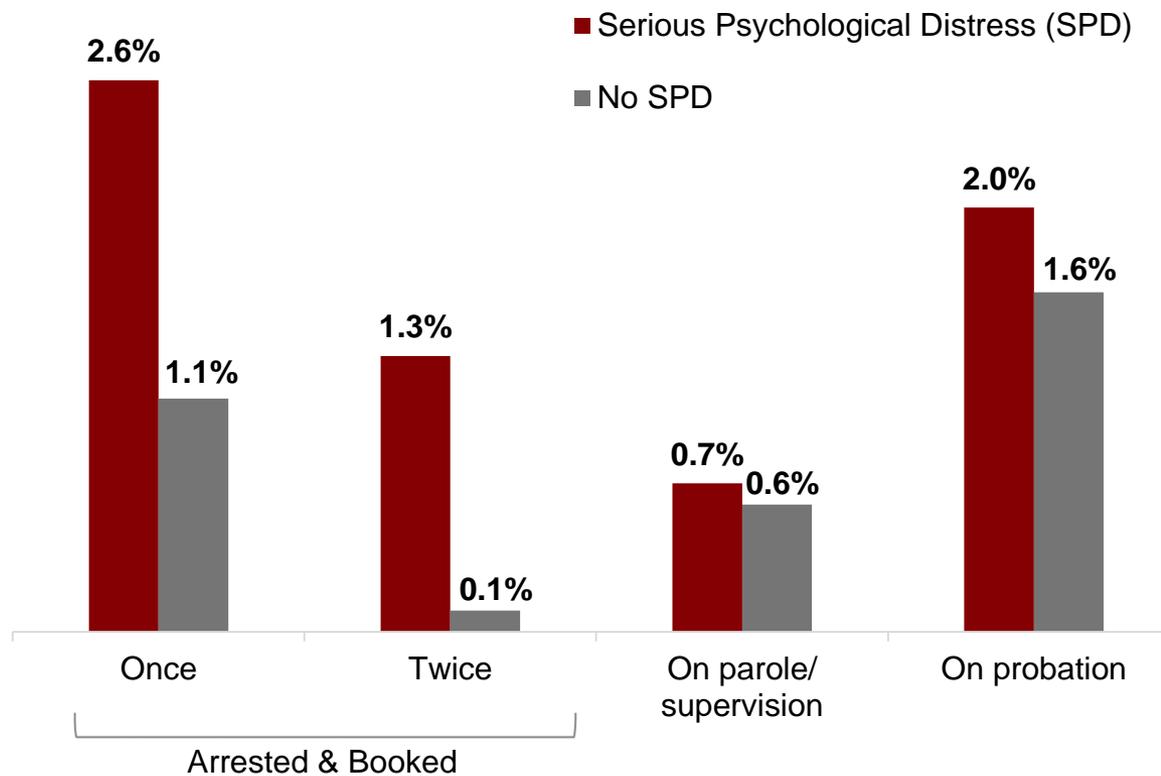
MENTAL HEALTH CONDITIONS & THE CRIMINAL JUSTICE SYSTEM

People living with mental illness are more likely to encounter the criminal justice system and to be arrested, suggesting that mental illness is a factor in incarceration risk. Whereas state and federal prisons have resources to provide mental health care to prisoners who were not receiving this before incarceration, local jails appear particularly unable to meet the health care needs of people with mental illness.

The overall cost of incarceration of the 7800+ prisoners with serious mental illness in the state of Illinois exceeds \$250 million per year.

Contact with criminal justice system

ILLINOIS 2017

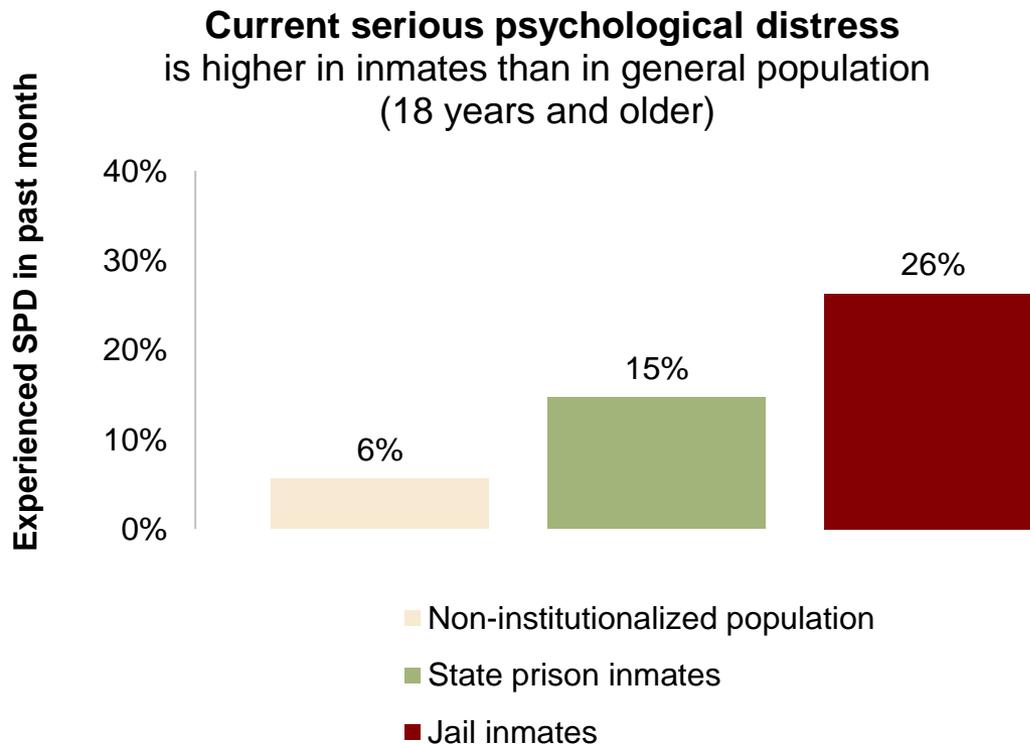


People who experienced serious psychological distress (SPD) are more likely to have been arrested or be on parole or probation in the past year.

Source: National Survey on Drug Use and Health (NSDUH, R-DAS) 2016-2017
Survey does not include current institutionalized population

Mental health issues in prison and jail populations

UNITED STATES



A large percentage of the U.S. adult prison and jail inmate population currently experiences serious psychological distress compared to the non-institutionalized population.

Additionally, these mental health issues are observed at higher rates in local jails than in prisons.

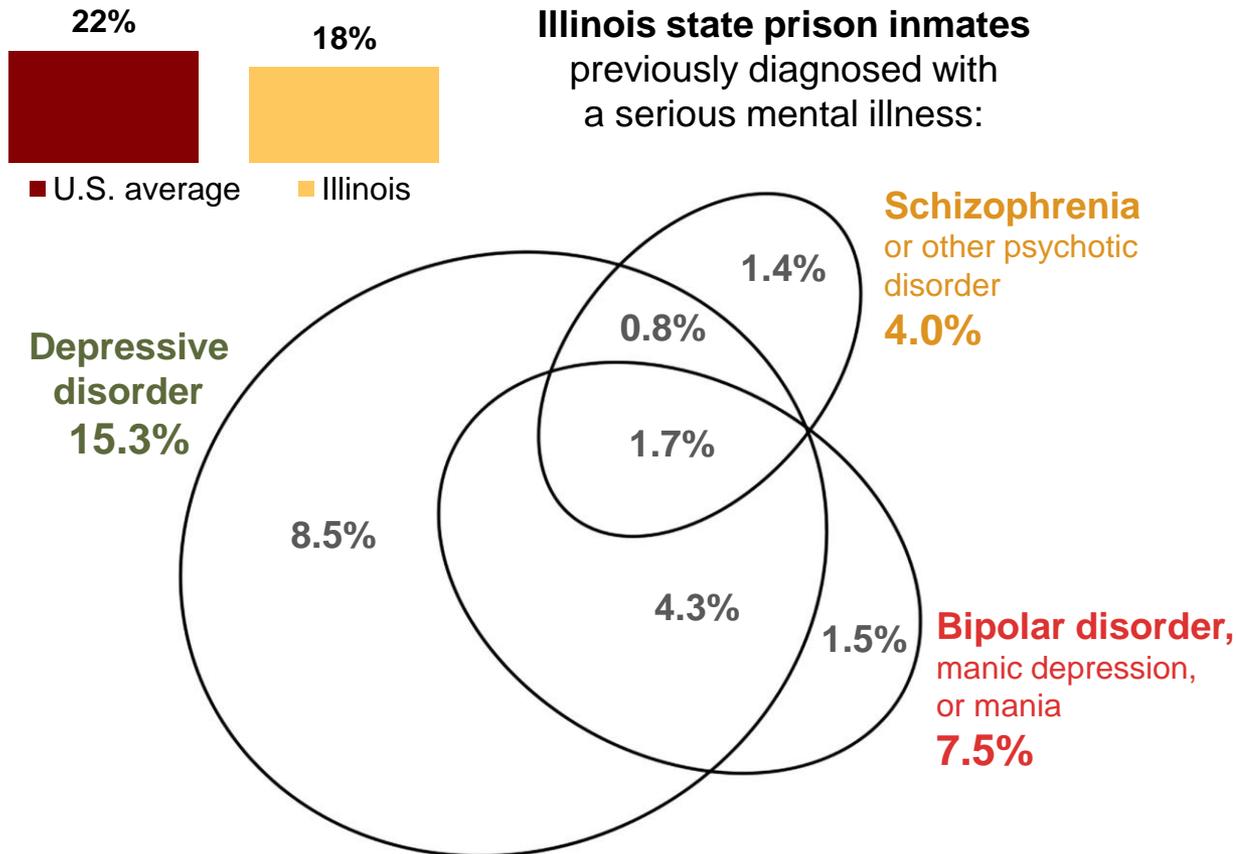
Source: National Survey of Drug Use and Health (NSDUH, R-DAS) 2016-2017

Bureau of Justice report: Sexual Victimization in Prisons and Jails Reported by Inmates, 2011-12, based on data from the National Inmate Survey

State prison population with serious mental illness

ILLINOIS

Illinois state prison inmates
previously diagnosed with
a serious mental illness:



In Illinois state prisons, approximately 18% of prison inmates previously have been diagnosed with a serious mental illness, which is relatively low compared to the overall U.S. prison population. Many patients have been diagnosed with two or three mental illnesses, confirming the presence of overlap in symptoms in this population.

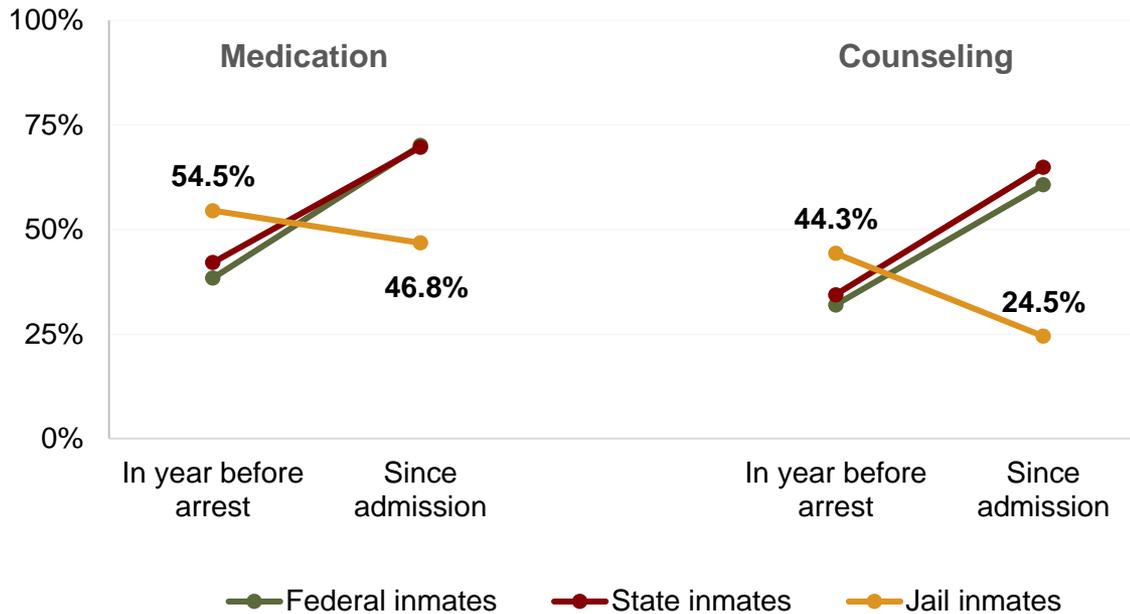
Source: Survey of Inmates in State Correctional facilities, BJS, 2004. Includes juveniles
Due to rounding, percentages of separate parts may not add up to the total percentage

Change in treatment before and during incarceration in prison and jails

UNITED STATES

Lack of access to mental health treatment in local jails

Among inmates with a previously diagnosed serious mental illness and who have ever received respective treatment before incarceration



The increase in mental health care treatment in federal and state prisons after admission to prison suggests that these institutions are making up for the gaps in mental health treatment in the general health care system.

At the same time, local jail inmates do not have the same access to medication and counseling while incarcerated as federal and state prisoners.

Mental health conditions include prior diagnosis of depressive disorder, bipolar disorder, and/or schizophrenia. Medication and counseling data includes treatment for any mental illness.

Estimated number of
Illinois state prison inmates in 2017,
previously diagnosed with serious mental illness:

7,883

Estimate of overall annual costs in 2017:

\$253,894,069

(in 2018 U.S.\$)

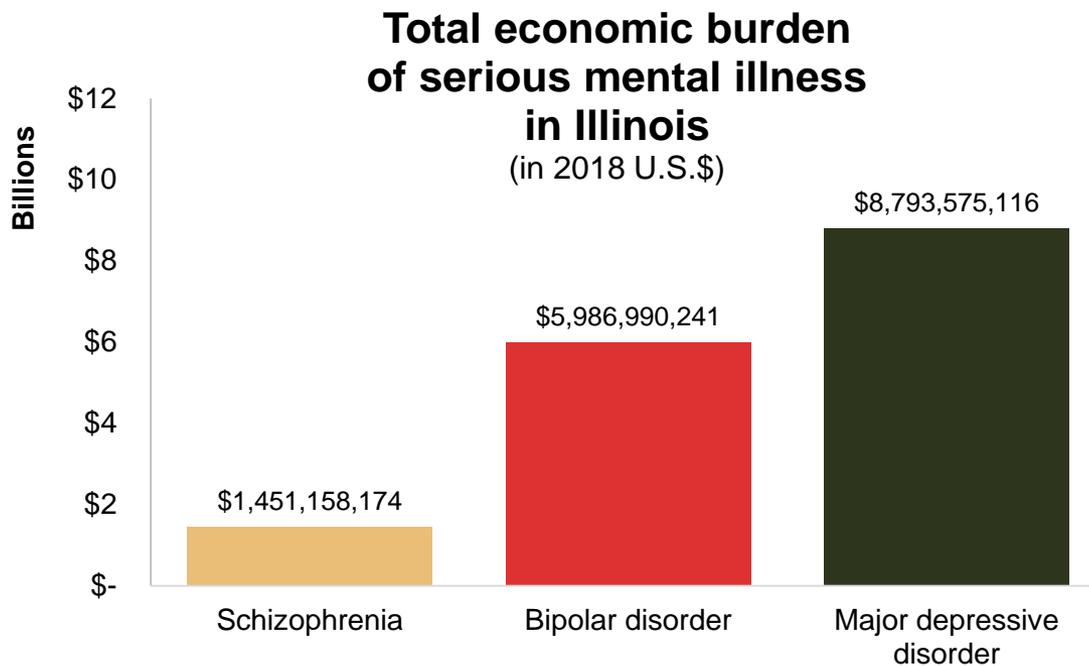
*Overall annual costs based on 2016 average of all state prison inmates in Illinois
Source: Annual Survey of State Government Finances 2016
Survey of Inmates in State/Federal Correctional facilities, BJS, 2004
Illinois Department of Corrections - Fiscal Year 2016 Annual Report*

TOTAL ECONOMIC BURDEN OF SERIOUS MENTAL ILLNESS

The economic burden of each serious mental illness in adults is estimated to be at least \$36 billion for the U.S. and \$1.4 billion for Illinois per year

Economic burden of serious mental illness

ILLINOIS 2018



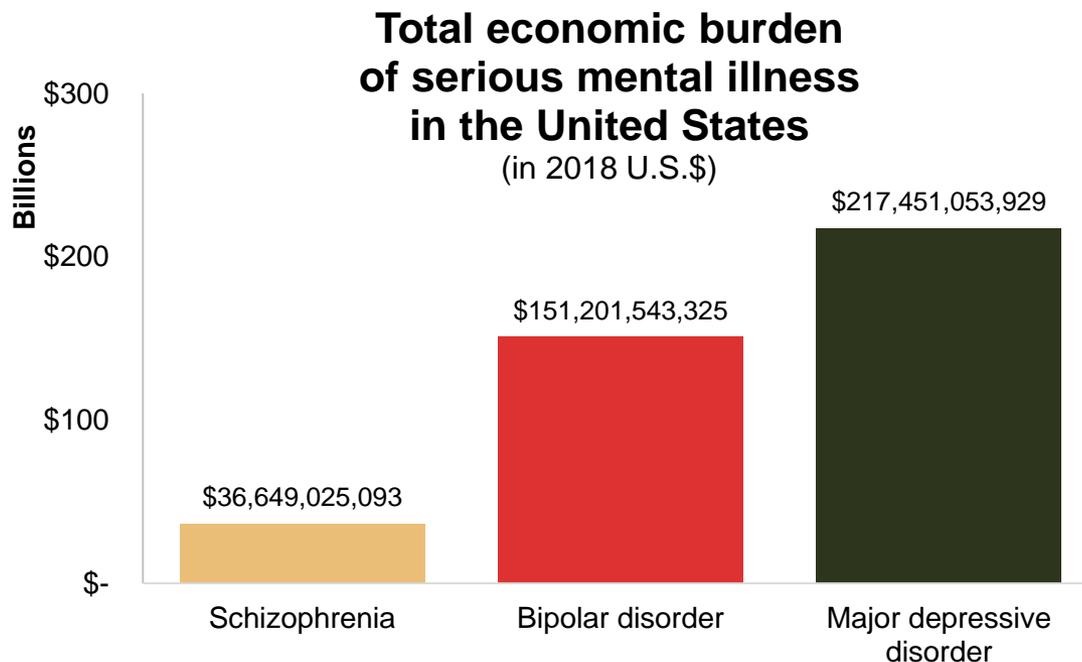
*The economic burden of schizophrenia, bipolar disorder, and major depressive disorder in adults in Illinois is estimated to be at **least \$1.4 billion for each serious mental illness***

Due to symptom overlap, diagnoses of mental illnesses are not mutually exclusive, therefore, patients with two or more diagnoses may be represented in multiple categories.

Source: MacEwan JP, Seabury S, et al. *Pharmaceutical innovation in the treatment of schizophrenia and mental disorders compared with other diseases. Innov Clin Neurosci.* 2016 Aug 1;13(7-8):17-25. See appendix for original sources

Economic burden of serious mental illness

UNITED STATES 2018



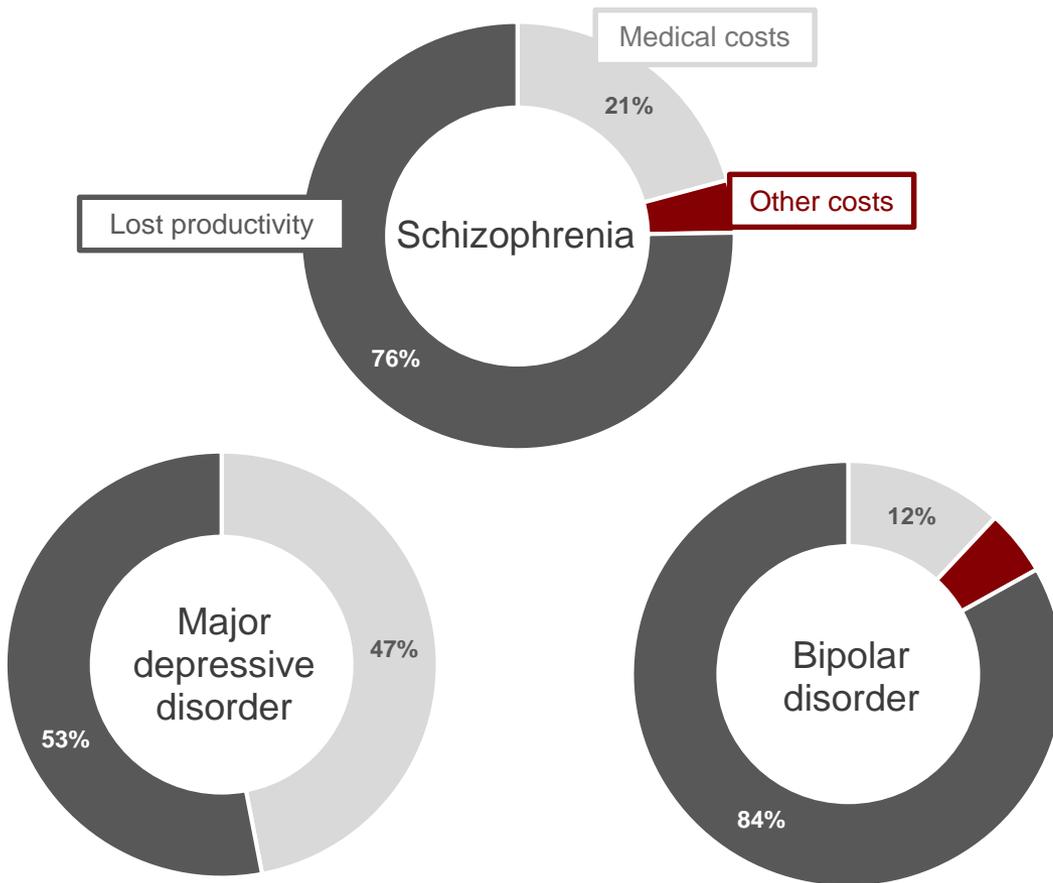
*The economic burden of schizophrenia, bipolar disorder, and major depressive disorder in adults in the U.S. is estimated to be **at least \$36 billion for each serious mental illness***

Due to symptom overlap, diagnoses of mental illnesses are not mutually exclusive, therefore, patients with two or more diagnoses may be represented in multiple categories.

Source: MacEwan JP, Seabury S, et al. *Pharmaceutical innovation in the treatment of schizophrenia and mental disorders compared with other diseases. Innov Clin Neurosci.* 2016 Aug 1;13(7-8):17-25. See appendix for original sources

Lost productivity is the largest contributor to economic burden of serious mental illness

UNITED STATES



*Most of the total economic burden of serious mental illness is due to **lost productivity** (unemployment, lost compensation (incl. caregivers), or early mortality). Only 12 to 47% of the total burden is resulting from direct **medical costs** (including substance abuse treatment), and an even smaller percentage from law enforcement, incarceration, shelters, or research & training (**other costs**).*

This highlights the large potential economic and societal benefits from improving treatment for serious mental illness even if it means spending more on care.

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References, data sources and methods are described in more detail in the online appendix.

This chartbook and the appendix can be downloaded at:

http://healthpolicy.usc.edu/Keck_Schaeffer_Initiative.aspx

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