THE COST OF MENTAL ILLNESS: ILLINOIS FACTS AND FIGURES

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INTRODUCTION

Improving access to high-quality medical care for patients with mental illness remains one of the most vexing problems facing the healthcare system in the United States. Illinois is no exception, with some commentators reporting a mental health care “crisis” in the state\(^1\).

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

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 mental health providers, 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 all publicly available and represent the most recent numbers to which we had access.

The data and methods are described in more detail in the appendix that can be found at: 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.
Many mental health conditions are fairly common in the general population.

Of the three conditions that are often labeled as Serious Mental Illness (SMI), major depressive disorder is the most prevalent, followed by bipolar disorder and schizophrenia.

NB: Due symptom overlap, diagnoses of mental illnesses are not mutually exclusive

Source: National Survey on Drug Use and Health (NSDUH) 2015 (SPD), NSDUH Mental Health Surveillance Study 2008-2012 (major depressive disorder) and National Institutes of Mental Health (other conditions – see appendix for original sources)
We estimate that more than 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.


Estimate of # of people affected using total state population of 9,899,810 adults (18 years and over), Census Bureau data (2015)
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.

Source: National Survey on Drug Use and Health (2015)
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.
There is significant unmet need for mental health care in the U.S.

UNITED STATES 2015

Among adults who experienced Serious Psychological Distress during the past year:

- Unmet need: 27.1%
- Cannot afford: 42.6%

27.1% indicates an unmet need of mental health treatment.

And 42.6% of these people did not receive mental health treatment, because they could not afford it.

More than a quarter of adults who experienced Serious Psychological Distress in the previous year in the U.S. reported an unmet need for mental health care. Almost half of the people with a perceived unmet need reported that they did not receive treatment because they could not afford it.

Source: National Survey on Drug Use and Health (NSDUH) 2015
Unmet need of mental health treatment due to costs

The extent to which cost was a factor in driving unmet need for mental health care varied by insurance status. People without health insurance were most affected by the inability to afford mental health treatment (71.1%), while those with VA/military health insurance coverage were least affected (19.0%).

Source: National Survey on Drug Use and Health (NSDUH) 2015
MENTAL HEALTH CARE COVERAGE, UTILIZATION & COSTS

Medicaid & mental health care needs

Medicaid provides a safety-net for people who are living in poverty or have qualifying disabilities, and a large percentage of people with Medicaid coverage experience mental illness. However, it is often a financial burden for physicians to accept Medicaid patients since reimbursement rates are often lower than for other patients. This can lead to access barriers for patients with Medicaid coverage that prevent them from receiving the mental health care they need.
People with mental illness have greater reliance on the safety net

UNITED STATES 2015

In the Medicaid and uninsured population, a higher percentage of people reported Serious Psychological Distress (SPD) during the past year compared to people with Medicare, VA/military, or private health insurance coverage.

Source: National Survey on Drug Use and Health (NSDUH) 2015
Medicaid reimbursement rates to physicians are low

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.

Source, Kaiser Family Foundation, Medicaid-to-Medicare Fee Index, FY 2014
Hospital utilization & charges

For every 100 patients with a serious mental illness, there were approximately 18 hospitalizations in the US 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.
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: Health Care 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

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.

Source: Health Care Utilization Project (HCUPnet) 2014
In contrast to 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.

When schizophrenia is the primary reason for a hospitalization, the average length of stay for younger people is one week longer than in adults, illustrating the severity of symptoms in these patients.

Source: Health Care Utilization Project (HCUPnet) 2014
Trends in length of stay for schizophrenia hospitalizations

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.

Source: Health Care Utilization Project (HCUPnet) 2014
Hospital charges in the U.S. and Illinois ranged from $17,000 to $31,000 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 charges for mental illness hospitalizations

ILLINOIS 2014

Total hospital charges
(all ages, in 2015 U.S. $)

- SMI total
- Schizophrenia
- Bipolar disorder
- Major depressive disorder

1,131,393,102

$368,314,012
$358,473,447
$404,605,644

Total hospital charges in Illinois for hospitalizations for serious mental illness together exceeded one billion dollars in 2014.

Source: Health Care Utilization Project (HCUPnet) 2014
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 with other states, the Illinois Department of Mental Health spends a very low amount per capita on community-based programs.
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)
Availabilty of Mental Health Care Providers

Illinois has a larger number of hospital beds and primary care physicians per capita compared to the rest of the U.S. However, the number of mental health care providers is currently not sufficient to serve the population with mental health needs. In Illinois alone, 70 full-time providers are needed in addition to the current workforce in designated “shortage areas” to reach an acceptable provider-to-patient ratio.

This shortage is particularly acute in the criminal justice system, where many people are in need of mental health treatment.
Availability of mental health care providers

There are 18 mental health providers for every 10,000 residents in Illinois. This is lower than the national average, and not sufficient to serve the population in need of mental health treatment.

Mental health providers include: psychiatrists, psychologists, licensed clinical social workers, counselors, marriage and family therapists, and advanced practice nurses specializing in mental health care.

Source: County Health Rankings & Roadmaps, by the Robert Wood Johnson Foundation and the University of Wisconsin Population Health Institute.
Availability of mental health care providers and hospital beds

ILLINOIS AND UNITED STATES 2013

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

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)
Currently, Illinois has 155 full-time equivalent mental health providers in designated shortage areas. In order to address the shortage issue, 70 more full-time providers are needed in these areas, 14 of whom in correctional facilities. 39% of the total population of Illinois resides in designated shortage areas (4,993,948 people)

Source: Health Professional Shortage Areas (HSPA), HRSA Data Warehouse data as of 7/31/2016
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 8000+ prisoners with serious mental illness in the state of Illinois exceeds 200 million U.S. dollars per year.
Contact with Criminal Justice System

UNITED STATES 2015

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 of Drug Use and Health (NSDUH) 2015
Survey does not include current institutionalized population
Mental health issues in prison and jail populations

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) 2015
Bureau of Justice report: Sexual Victimization in Prisons and Jails Reported by Inmates, 2011-12, based on data from the National Inmate Survey
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.
Change in treatment before and during incarceration in prison and jails

UNITED STATES

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 regular 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.

Source: SISFCF (Survey of inmates in states and federal correctional facilities) 2004 & SILJ (Survey of inmates in local jails) 2002
Number of Illinois state prison inmates previously diagnosed with serious mental illness: 8,925

Overall annual costs: $258,113,561 (in 2015 US$)

Overall annual costs based on 2014 average of all state prison inmates in Illinois
Source: Annual Survey of State Government Finances 2014
Survey of Inmates in State/Federal Correctional facilities, BJS, 2004
Illinois Department of Corrections - Fiscal Year 2014 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 125 billion dollars for the U.S. and 5 billion dollars for Illinois per year.
The economic burden of schizophrenia, bipolar disorder, and major depressive disorder in adults in Illinois is estimated to be at least $5 billion dollars 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.

The economic burden of schizophrenia, bipolar disorder, and major depressive disorder in adults in the U.S. is estimated to be at least **125 billion dollars** 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.

**Total economic burden of serious mental illness in the United States**

<table>
<thead>
<tr>
<th>Illness</th>
<th>Billions (2015 US$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>$126,995,542,392</td>
</tr>
<tr>
<td>Bipolar disorder</td>
<td>$132,686,323,622</td>
</tr>
<tr>
<td>Major depressive disorder</td>
<td>$209,878,413,196</td>
</tr>
</tbody>
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ACKNOWLEDGMENTS

Funding for this project was provided through an unrestricted grant from Alkermes.

This work was done as part of the Keck-Schaeffer Initiative for Population Health Policy. We also acknowledge comments and contributions to this work from the National Council for Behavioral Health and the Behavioral Health + Economics Network.

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