



## FACTS ABOUT SCHIZOPHRENIA

### Description and prevalence

- Schizophrenia is a spectrum of serious neurodevelopmental brain diseases in which people interpret reality abnormally. It can cause hallucinations, delusions and extremely disordered thinking and behavior that impairs daily life.
- If left untreated or improperly treated, people with schizophrenia can develop psychosis, in which hallucinations, delusions or other symptoms become so severe that they lose complete touch with reality.
- As many as 5.3 million people in the U.S. live with this debilitating brain disease.

### Treatment

- People with schizophrenia typically require lifelong treatment. With access to proper treatment, approximately half of people improve or achieve remission.
- Many current treatments are old and can cause debilitating side effects, including massive weight gain, movement disorders and diabetes.
- There is only one FDA-approved medicine for treatment-resistant schizophrenia, and it is heavily restricted by the agency.
- Up to 98% of people with schizophrenia have anosognosia, a symptom that prevents them from recognizing they have the disease and the most common barrier to seeking treatment.

### Consequences

- Schizophrenia shortens a person's life expectancy by an average of 28.5 years. This is largely the result of a lack of proper treatment, which can, in turn, lead to:
  - An increased rate of suicide
  - High rates of other chronic diseases such as diabetes and heart disease
- Just as with Alzheimer's and Parkinson's diseases, schizophrenia can result in significant brain and cognitive deterioration – especially when not properly treated.
- People with schizophrenia are believed to make up:
  - 1/3 of the homeless population
  - 15% of those in jail and 20% of people in prison
  - More than 50% of people in nursing homes and other inpatient facilities.
- Schizophrenia costs the U.S. \$281.6 billion annually, including healthcare costs, caregiver expenses and those stemming from criminal justice system interactions.

## References

Aleman A, Denys D. Mental health: Road map for suicide research and prevention. *Nature* (2014) 509:421–3. doi:10.1038/509421a

Bronson J, Berzofsky M. Indicators of Mental Health Problems Reported by Prisoners and Jail Inmates, 2011-12. Bureau of Justice Statistics;2017.

James D, Glaze L. Mental Health Problems of Prison and Jail Inmates. Bureau of Justice Statistics Special Report. 2006.

National Institute of Mental Health. <https://www.nimh.nih.gov/health/statistics/schizophrenia>

Schizophrenia & Psychosis Action Alliance. About Schizophrenia. <https://sczaction.org/about-schizophrenia/>

Schizophrenia & Psychosis Action Alliance. [Societal Costs of Schizophrenia & Related Disorders](#). 2021.

## Additional resources

Schizophrenia & Psychosis Action Alliance: <https://sczaction.org/>

American Association of Psychiatric Pharmacists: <https://aapp.org/psychpharm>

American Association of Psychiatric Pharmacists research page: <https://aapp.org/psychpharm/research>

## Saving Money & Lives

# FY2024 Funding for Study on the Costs of Serious Mental Illness

The public mental health system in our country is struggling to meet the needs of Americans with schizophrenia and other severe mental illnesses.

This citizen population experiences extraordinarily high rates of severe illness and premature death. But they are often blocked from proper treatment and as a result, end up in county jails, state prisons, homeless shelters, community hospital emergency rooms and even nursing homes.

This can lead to more severe disease – and burdens our governments and healthcare system with enormous financial expenditures. In 2021, in the absence of up-to-date data, S&PAA financed the Societal Cost of Schizophrenia and Related Disorders study, which found **that the cost of schizophrenia to the United States exceeds \$281 billion each year.**

This is the cost of “re-institutionalizing” people with schizophrenia into inappropriate, wildly expensive settings – where their health actually gets worse.

These expenses do not even include federal or state grant programs or the costs of research funding.

On a bipartisan basis, Congress built on S&PAA’s study by enacting Sec. 1124 of the Consolidated Appropriations Act, PL 117-164 which authorized the Department of Health and Human Services to undertake a comprehensive nationwide study on the cost of serious mental illnesses. The following proposal would provide financing for that study.

## FY 2024 Serious Mental Illness Study Funding

**Pursuant to Section 1124 of the Consolidated Appropriations Act, PL 117-164 the Committee allocates \$8 million and directs the Assistant Secretary for Planning and Evaluation to select an outside contractor to conduct a thorough study of the cost impact of serious mental illnesses in the United States.**

**This study shall take a multi-systemic approach examining the fiscal implications of untreated or poorly managed schizophrenia and other severe mental illnesses on the health care system, criminal courts, and penal facilities, including county jails, housing programs, and nursing facilities. Because of the breadth of the proposed study, the Committee anticipates that the inquiry will require several fiscal years to complete.**

# Need for New Prevalence Surveys of People with Schizophrenia

*How can we help people if we can't even count them?*

## How many people in the U.S. are living with schizophrenia?

### We don't know.

There is no consensus on the prevalence of schizophrenia. Various studies estimate it at anywhere between 800,000 and 5.3 million people in the United States.

This is more than a sixfold discrepancy.

### To make it worse, our best estimate of schizophrenia prevalence is more than 30 years old.

(National Comorbidity Study – Replication, 1990-92)

## Why is it so hard to know how many people have schizophrenia?

**Many people with schizophrenia live in settings that previous studies haven't reached.** People with schizophrenia are believed to make up:

- 1/3 of the homeless population
- 15% of those in jail
- 20% of people in prison
- More than 50% of people in inpatient treatment facilities.

These people have a severe brain disease that requires comprehensive treatment – yet most of those on the streets or in jails and prisons are getting no treatment at all. Meanwhile, they have been excluded from current estimates of the prevalence of schizophrenia.

They have been invisible.

## Why should policymakers care?

### ➤ Accurate prevalence estimates are necessary to send funding to the right places.

The proposed surveys will show where there is greatest need, from what settings people live in (the street, jails, nursing homes), to their severity of symptoms, to their geography. If funding is informed by accurate data, it can be directed more appropriately – increasing the chances that people will get the care they need, which could reduce the current cost burden on our government.

### ➤ Prevalence studies are needed to evaluate Congress-funded national innovations.

Over the last 10 years, Congress has funded the growth of coordinated specialty-care clinics to treat people with schizophrenia at a crucial moment: when they suffer their first episode of psychosis. These programs could be game changers, substantially reducing the percentage of people who develop long-term disability from schizophrenia. Regular prevalence studies are critical to evaluating the impact of these programs.

## The need: S&PAA seeks reintroduction of Section 3 of HR 7483 from the 117<sup>th</sup> Congress.

These provisions authorize the completion of prevalence surveys for schizophrenia and other serious brain diseases every 5 years, including in settings that historically have been excluded from epidemiological surveys.

People with schizophrenia deserve healthcare just like everyone else. But we can't help them if we don't count them.