Need for Regular Surveillance Surveys of Persons with Schizophrenia

## How many people are living with Schizophrenia?

In making public policy recommendations, the Schizophrenia and Psychosis Action Alliance (S&PAA) follows several fundamental principles: *If you can’t count it, you can’t fix it.* In the case of people with schizophrenia, there is active controversy about the number of Americans living with this highly disabling condition.

A broad consensus on the prevalence of schizophrenia is unavailable due to the lack of reliable data. Various studies report prevalence estimates in the US ranging from 0.24% to 1.6%, between 800,000 and 5.3 million of the total US population with schizophrenia.

Determining the prevalence of schizophrenia is complicated by both clinical and methodological challenges. A diagnosis of schizophrenia typically follows initial episodes of psychosis in an individual’s late teens or early twenties. But even before the first episode of psychosis, individuals may show slight changes in their behavior or thought process. Many individuals with schizophrenia do not seek care or diagnosis as they suffer from anosognosia (the inability to believe they have a condition with their symptoms or diagnosis).

In addition to diagnostic limitations, many individuals with schizophrenia do not always live independently in the community or other settings commonly included in population estimates, such as long-term care facilities. Many of this hidden population can live in structured residences, are homeless, or are incarcerated – complicating prevalence estimates.

This controversy has a substantial impact on our nation. In 2021, S&PAA published a study entitled the Societal Cost of Schizophrenia and Related Disorders, which found that the total annual cost of schizophrenia to the United States exceeds $281 billion – again, that is per year. Without accurate prevalence estimates, federal, state, and local policymakers cannot fully understand the effect of untreated or poorly managed schizophrenia on our healthcare system, criminal courts, penal facilities, housing programs, and long-term care facilities.

In 2019, The Substance Abuse and Mental Health Services Administration (SAMHSA) funded a prevalence study of serious mental illness, including Schizophrenia, across all settings. Conducted during the COVID-19 Pandemic, the interpretation of the findings from the survey will be impacted by the influences of the pandemic on how the study was implemented. Additionally, this study was considered a pilot study and not fully nationally representative. While valuable, it may be 30 or 40 years before another such study is undertaken compared to more regular prevalence surveys of conditions like HIV/AIDS and sexually transmitted diseases.

**Reintroduction of Section 3 of HR 7483**

**In view of these difficulties, S&PAA seeks the reintroduction of Section 3 of HR 7483 from the 117th Congress. These provisions would authorize the completion of schizophrenia and severe mental illness prevalence survey every five (5) years.**

Saving Money & Lives

FY2024 Funding for Study on The Costs of Serious Mental Illness

What data exists shows that the current public mental health system is struggling to meet the needs of Americans with schizophrenia and other severe mental illnesses. This patient population experiences extraordinarily high rates of mortality and morbidity. Moreover, because of a lack of access to mental health services and efficacious psychotropic medications, people with serious mental disorders have effectively been “re-institutionalized” in various inappropriate treatment settings ranging from county jails to community hospital emergency rooms to homeless shelters and nursing facilities.

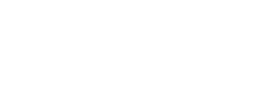
In 2021, because of an absence of up-to-date data, S&PAA took it upon itself to finance a study entitled the Societal Cost of Schizophrenia and Related Disorders, which found that the total annual cost of schizophrenia to the United States exceeds $281 billion – again, that is per year. These costs represent additional costs of schizophrenia on top of costs already incurred by those without schizophrenia. Excess healthcare spending attributed to persons with schizophrenia is $27.2 billion annually. Individuals with Schizophrenia and related disorders receive an excess of $24.7 billion spending annually for supporting annually compared to other populations. These costs do not include federal or state grant programs, costs of research funding,

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

**FY 2024 Serious Mental Illness Study Funding**

**Pursuant to Section 1124 of the Consolidated Appropriations Act, 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.**



**We Are a Global Impact Organization Moving Individuals, Families, and Policies Forward to Improve and Save Lives**

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