

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 117th 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.