

Position Statement Discrimination and Stigma

<u>Note</u>: There are many different definitions of discrimination and stigma. In this statement, stigma refers to negative beliefs and stereotypes about people with schizophrenia, while discrimination involves actions and laws that result in harm for those with schizophrenia.

Discrimination and stigma harm people with schizophrenia across key areas of life.

People with schizophrenia are often viewed and treated as dangerous, socially undesirable, untreatable and incapable of leading productive lives.^{1,2} These harmful misconceptions are widespread, even among mental healthcare providers, and are often internalized by those with the disease.^{1,3} Globally, up to 90% of people with schizophrenia report experiencing discrimination in key areas of life such as social interactions, employment, housing and healthcare.³ Discrimination can include being treated with condescension, excluded from conversations or consistently overlooked for opportunities. However, discrimination goes beyond individual interactions; it is built into the very systems and policies that govern access to care, housing and employment. These systemic barriers severely marginalize people with schizophrenia.

The stigma associated with schizophrenia compounds this marginalization and can even contribute to poorer disease outcomes, as in many cases, it makes people reluctant to seek treatment or even information about the disease. Among those who are treated, many studies have shown that internalized stigma lowers rates of adherence to antipsychotic treatment.^{4–6} Stigma also can prevent those with the disease from seeking support from family and friends.⁷

The healthcare system is riddled with discrimination and inequity.

Policy failures in healthcare are a core contributor to the systemic discrimination faced by individuals with schizophrenia:

- The underfunding and underdevelopment of community-based services such as First
 Episode Psychosis Programs, Assertive Community Treatment (ACT) and other specialized
 outpatient programs results in a lack of access to comprehensive, coordinated, personalized
 care for most people with schizophrenia.
- Significant disparities in funding for research and services (compared with other conditions such as autism and Alzheimer's disease)⁸ and insufficient healthcare provider training exacerbate these inequities.
- The absence of policies to address anosognosia a common symptom in which people don't realize they are ill and thus a) don't seek care or b) refuse care prevents many people who desperately need treatment from receiving it.^{9,10}

Compounding these issues, discriminatory federal policies such as the "Institutions for Mental Disease" (IMD) exclusion contribute to a severe shortage of hospital beds for those in urgent need. No physical health conditions have this limitation. Additionally, Medicare beneficiaries are limited to 190 days of lifetime inpatient psychiatric hospital care, while no other specialty inpatient service has this type of arbitrary cap on Medicare benefits. These are examples of policies that must be changed to create an equitable, effective system of care for schizophrenia.

Many healthcare providers harbor stigmatizing, discriminatory beliefs toward those with schizophrenia, including pessimism about their potential for recovery.¹

The fact that many providers who treat people with schizophrenia don't believe their patients can recover and thrive is a systemic failure for this vulnerable population. Examples of provider discrimination include frequent misdiagnoses, exclusion from treatment decisions (along with their family members) and denial of best-practice treatment.^{11–13} Sadly, people with schizophrenia often expect this discrimination, leading them to delay or avoid seeking medically necessary care.¹⁴

Treatment discrimination for people with schizophrenia is compounded by the severe underfunding of the mental health workforce, leading to low pay, inadequate support, poor advancement opportunities and substandard facilities. These issues result in burnout and high turnover as workers struggle with a complex patient population and insufficient resources. Urgent and comprehensive reforms across all levels of healthcare are necessary to address these deeply rooted forms of discrimination.

Stigma and discrimination contribute to loneliness and isolation in schizophrenia.

Many people with schizophrenia express a strong desire for social interaction, and more than 80% report feelings of loneliness.¹⁵ Unfortunately, the general public is often reluctant to meaningfully connect with them.^{15,16} This is driven by stigma and misconceptions about the illness, but also by the impact of ineffectively treated symptoms such as hallucinations, negative symptoms, cognitive difficulties and social skill challenges – all of which make social interactions more difficult. Painfully aware of how they are perceived, many people with schizophrenia choose to hide their diagnosis. In fact, one international study found that 72% of people with schizophrenia felt the need to conceal their condition from others.¹⁷ Internalized stigma can lead people with schizophrenia to withdraw from social situations even if they deeply desire connection. Studies suggest that loneliness in schizophrenia is linked to more severe symptoms, more physical health problems and a decreased quality of life.^{15,18,19}

Discrimination leads to the loss of employment and education opportunities.

Most people with schizophrenia want to work.²⁰ However, especially without treatment, schizophrenia derails educational and employment opportunities:

- Evidence-based education and employment interventions have high success rates, placing up to 60% of those with schizophrenia in jobs for an average of eight to 10 months, compared with other programs that have much lower success rates. But there is little funding for these evidence-based programs. ^{20,21}
- The structure of Social Security Disability, Medicaid and SNAP benefits creates practical barriers to employment, including income thresholds that can cause someone to lose these benefits even when their income is very low.

 Many employers and healthcare providers hold misconceptions about the capabilities of people with schizophrenia, believing they cannot work or attend school and often refusing to provide necessary accommodations. They also may react negatively to someone disclosing their diagnosis.^{22,23}

These factors contribute to why less than 10% of people with schizophrenia are employed. Without sufficient protections, incentives and the understanding of others, people with schizophrenia will remain chronically unemployed, which affects their ability to live independently and engage in social activities.²³

Discrimination can be lethal.

Discrimination and stigma play a key role in schizophrenia-related violence. Violent behavior in people with schizophrenia is most often driven by inadequate or lack of treatment, frequently compounded by co-occurring substance use.^{24–27} Thus, federal and state policies that fail to provide proper treatment for psychosis-related illnesses contribute to the misperception that people with schizophrenia are inherently violent.

In fact, people with schizophrenia are actually more likely to be *victims* than perpetrators of violence.²⁸ They also are more likely to harm themselves than others, and are about 20 times more likely to die by suicide over the course of their lifetime.²⁹ The shame, depression and loneliness associated with internalized stigma contributes to this suicidality.^{19,30,31}

The stereotype of people with schizophrenia as highly violent and unpredictable also contributes to increased police violence during mental health crises^{28,32} and harsher sentencing from judges and jurors.

Many people with schizophrenia are part of other marginalized communities and thus face multiple layers of stigma and discrimination.

As described in <u>our statement on care for diverse populations</u>, schizophrenia disproportionately impacts people of color and immigrants, and common consequences of untreated schizophrenia – including poverty and homelessness – compound the discrimination these populations experience. For example, about one-third of the U.S. homeless population has schizophrenia or a related condition, and studies show they face compounded stigma for both their homelessness and their disease. Similarly, people of color with schizophrenia may deal with discrimination resulting from both of these identities. This can lead to deep disillusionment, making it even harder to get the care and support they need. Addressing these overlapping challenges is crucial for building a more inclusive and supportive environment for people with schizophrenia.

Call to Action

When people with schizophrenia receive the care and support they need, their strengths, skills and capabilities can flourish, improving both their quality of life and the wellbeing of the communities they contribute to. S&PAA supports funding from the relevant federal, state and/or local resources to accomplish the following aims:

- 1. Change policies that discriminate against and harm those with schizophrenia. Our position statements on integrated care and decriminalizing schizophrenia highlight discriminatory policies within the healthcare and criminal justice systems. Beyond this, we must implement policies that promote employment and education for those with schizophrenia and ensure the availability of effective dual-diagnosis programs that treat both substance use and schizophrenia. Recognizing that people with schizophrenia have diverse needs, it is vital to ensure that funding and resources are allocated to those at all levels of functioning.^{35,36}
- 2. Reduce provider discrimination and stigma. Comprehensive anti-stigma training and policies are needed to ensure healthcare providers receive the necessary support to deliver best-practice schizophrenia care without prejudice. Federal support for graduate medical education and internships should include requirements that mental healthcare providers be trained appropriately. There also must be clear systems in place to report neglect and abuse of existing policies intended to protect those with schizophrenia.
- 3. **Transform media representation of schizophrenia.** Media outlets play a critical role in how schizophrenia is perceived. Those in the media must use their tools to shift away from portraying people with schizophrenia as violent and unpredictable,^{37–39} and instead examine the role of our broken healthcare system in negative outcomes for people with this brain disease. In addition, a public education campaign is needed to communicate truthfully and honestly about what schizophrenia is and is not. This effort should start in schools and expand to healthcare provider offices through a SAMHSA-funded campaign.
- 4. **Fund research on new methods to measure and reduce discrimination and stigma.** Antistigma and discrimination initiatives for schizophrenia have had limited success, which highlights the need for innovative approaches. Efforts in this area should prioritize practical, scalable outcomes that can inform clinical practice and health policy. We support multi-level interventions that address societal, provider and self-stigma and discrimination including the promotion of strong peer-support programs and exploring the renaming of schizophrenia, a scientifically inaccurate term that has been shown to be heavily loaded with stigma and misunderstanding. A2,43

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