



Schizophrenia
& Psychosis
Action Alliance

Position Statement

Increase Federal Research Funding for Schizophrenia – and Improve the Balance to Increase Long-Term Impact

Since 2015, federal funding for schizophrenia research has declined (after adjusting for inflation^a). In 2015, the National Institute of Mental Health funded schizophrenia-related grants totaling \$255 million, which represented 14% of its budget.^{1,2} By 2023, this had decreased to grants, with \$206 million allocated, that accounted for only 9% of the NIMH budget.^{1,3}

This decline in funding is deeply concerning, given schizophrenia’s significant health and economic burden. In the United States, the annual excess cost of schizophrenia in 2020 (compared with those without the illness) was estimated at \$281.6 billion.⁴ Only 10% of this was attributed to direct healthcare costs. The remaining costs resulted from the downstream effects of untreated schizophrenia, such as caregiver burden (37%), lower quality of life (26%), lost wages (15%) and housing-related issues (9%).⁴ With the U.S. population projected to reach 383 million by 2054 and cannabis use linked to increased psychosis risk, the prevalence of schizophrenia – and its economic burden – are expected to rise in upcoming years.⁵⁻¹⁰

Progress in other diseases demonstrates the transformative potential of increased federal funding. Between 2015 and 2022, annual NIH funding for Alzheimer’s disease grew from \$613 million to \$3.5 billion.¹ This funding powered groundbreaking advancements, such as FDA approval of the first disease-modifying treatment in 2023.¹¹ This inspiring success highlights what is possible when robust funding supports a coordinated research effort. With appropriate funding, schizophrenia research has the potential to achieve similar breakthroughs.

As our nation’s investment in schizophrenia research declines, funding also has shifted away from studies on real-world treatment delivery. Only 10% to 15% of those with early psychosis have access to coordinated specialty care, the current best-practice treatment.¹² Meanwhile, clinical research aimed at improving treatment accessibility and effectiveness has declined.¹³ While basic research explores biological mechanisms to inform future treatments, clinical research translates these discoveries into real-world therapies. Both are essential, but the growing imbalance raises concerns that declining investment in treatment-focused research will slow progress for those currently living with this severe brain disease. A key consideration is exploring the most effective treatment models, specifically determining how to maximize community-based, voluntary care to support recovery, and when compulsory care – such as

^a Adjusted using Biomedical Research and Development Price Index (BRDPI) Inflation Factor from 2015 to 2023 dollars.

Assisted Outpatient Treatment (AOT) or involuntary hospitalization – may be necessary as a last resort to promote positive long-term outcomes.

Studies that *are* funded do not always reflect real-world concerns.

- People with lived experience of schizophrenia are critical in shaping how the disease is treated. For example, individuals with schizophrenia played a pivotal role in driving a focus on recovery, from seeing patients as having a lifelong disability to treating them as able to live meaningful lives, with self-determination and person-centered care.¹⁴ So it is important that research address the many facets of schizophrenia – including recovery goals, symptoms and side effects – that people directly affected by the disease find most challenging. This could improve the quality of treatments and increase current low medication adherence rates (estimated at 40-50%).^{15,16}
- Treatments that tackle key challenges raised by those affected by schizophrenia – such as stigma, discrimination and an insidious symptom of schizophrenia that makes people unaware they are ill – remain underfunded. Research funding should prioritize all of these perspectives to guide treatment approaches that improve treatment adherence and overall health outcomes.

Research does not fully reflect the populations most affected by schizophrenia. Differences in risk factors, treatment availability and outcomes are well documented across ethnoracial groups, immigration status and geographic regions,¹⁷ yet many clinical trials do not include people from these varied groups. In addition, medication trials for schizophrenia often exclude people with co-occurring conditions such as substance use disorders, low insight into their disease, homelessness or legal entanglements, resulting in a skewed research population that overlooks those most affected. This lack of representation limits the relevance of research findings and hinders progress in developing treatments that address real-world challenges.

Research funding does not yet reflect the lifelong impact schizophrenia has on individuals, their families and society. Although recent research efforts have rightly emphasized early detection and intervention – supported by major federal initiatives that target early psychosis and clinical high-risk (CHR) populations^{18,19} – these programs include only a small subset of those affected by the disease. For example, only about 25% of people considered to be at clinical high risk actually develop schizophrenia,²⁰ meaning that significant resources are allocated to a group in which most will not experience the illness. While early intervention has demonstrated the value of team-based care, its long-term impact varies, and we currently lack reliable methods to predict who will require ongoing, intensive support. While some people do improve over time and may not require intensive ongoing services, others experience significant decline, and current research cannot yet predict these trajectories.²¹⁻²³

Comprehensive research and intervention strategies are essential to address the lifelong needs of individuals with schizophrenia and their family members.

Call to Action

S&PAA calls for more federal funding for schizophrenia, with a focus on initiatives that:

1. **Translate research to practice.** Scientific discoveries and their impact should be disseminated to key stakeholders, including providers, payers and policymakers, and implemented effectively in real-world clinical practice.
2. **Center the needs of people with schizophrenia and their family members.** Study aims, designs, outcomes and dissemination should be shaped by the diverse perspectives of people with schizophrenia and their families. Effective models for this inclusion include community-based participatory research, advisory boards and patient-focused drug development.^{24,25}
3. **Broaden access to optimal care for the highest need-populations.** Research must examine risk factors, barriers to treatment and care and strategies to improve care quality for underserved communities, including ethnoracial minority groups and those in rural areas.
4. **Evaluate treatment delivery models.** Research should determine how to optimize voluntary, community-based care to support recovery and how to determine when compulsory care – such as Assisted Outpatient Treatment (AOT) or involuntary hospitalization – is necessary to promote positive long-term outcomes. Studies also must examine ways to minimize trauma and maximize use of recovery-oriented principles to ensure all treatment pathways provide meaningful, person-centered support.
5. **Represent the full clinical complexity of schizophrenia.** People with co-occurring illnesses, housing instability and/or legal challenges should be fully represented in clinical trials.
6. **Focus on both early intervention and lifelong care.** Research should balance efforts to improve early detection and intervention with strategies that address the chronic treatment needs of people with schizophrenia. We must develop predictive models to identify those at higher risk for chronic impairment and use those learnings to tailor long-term care strategies. A sustained, longitudinal and integrated^b approach – extending beyond the early course of the disease – should be the standard for all individuals with psychosis disorders.

^b Integrated care is a collaborative approach in which healthcare professionals across disciplines—mental health treatment, medical care, substance use treatment, and social services—coordinate to provide whole-person, recovery-oriented care. This model ensures that individuals receive comprehensive, accessible, and continuous support to improve both mental and physical health outcomes.

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