



Roadmap for Change: Advocating for Schizophrenia in the Policy Arena

Advocacy Toolkit



The Schizophrenia Policy Action Network is solving foundational problems that create barriers to treatment, support and survival for people living with schizophrenia. An important way we do this is to advocate for public policies that will help break down these barriers.

Our advocacy efforts focus on laws and policies that address these realities:

- The impact of schizophrenia is often devastating and chronically disabling.
- Multiple barriers stand in the way of successful treatment.
- More effective treatments with fewer side effects are urgently needed.
- People with schizophrenia are not treated with urgency or understanding.

The voices of our community are critical to help us tell the stories of the discrimination people with this severe brain disease face every day. Join us to tell your story and help create meaningful policy change.



Policy Priorities

1 • A robust, quality continuum of care is medically necessary for people with serious brain diseases.

Summary.

The siloed, under-resourced system for treating schizophrenia falls woefully short of meeting the complex needs of people with this serious, TREATABLE brain disease, particularly at crucial moments when early intervention and comprehensive treatment could alter the trajectory of the illness. These harms are amplified for people from historically marginalized communities.

Call to Action

A paradigm shift is needed to create one integrated system of care that prioritizes early detection, coordinates care across health and social services and ensures equitable access. Funding and policies are urgently needed for:

- Early detection of schizophrenia and connection to care.
- Building a well-trained schizophrenia workforce.
- National integrated care centers to treat the health and social needs of people with schizophrenia.
- Removal of barriers to care (e.g., IMD exclusion).
- Caregiver support.
- Data collection & sharing.
- Funding to promote intensive case management and care coordination among (currently siloed) facilities, agencies and providers.
- Supportive housing.



Policy Priorities

2. Schizophrenia and other serious brain diseases must be decriminalized.

Summary.

The incarceration of people with schizophrenia and other serious brain diseases is discriminatory, punishing people for having a TREATABLE brain disease instead of providing treatment.

Call to Action

People with schizophrenia and other serious brain diseases should receive effective treatment that prevents their involvement in the criminal justice system in the first place. Until then, we call for:

- More resources for diversion programs.
- Improved diagnosis and treatment in jails and prisons.
- Discharge plans that include housing, connections to Medicaid and other social services etc.
- Uniform judicial guidelines that reflect the impact of schizophrenia.
- Improved data collection on people with schizophrenia in jails and prisons.
- No death penalty for people with schizophrenia and other serious brain diseases.
- Mandatory disease education and training for judges, attorneys, first responders and clinicians.



Policy Priorities

- 3. Federal research funding for schizophrenia and other serious brain diseases should be significantly increased to align with research funding for other serious brain diseases.**

Summary.

Schizophrenia and related psychosis disorders affect at least 1 in 100 people in the United States – or about 2 million adults. The prevalence is thought to be even higher when people with schizophrenia in homeless shelters, jails and prisons and nursing homes are included.

The cost of schizophrenia to the United States exceeds \$281 billion each year. Yet federal research funding for schizophrenia lags far behind that for other serious brain diseases, including Alzheimer's disease.

Call to Action

Given the high prevalence of schizophrenia – and the enormous cost to federal, state and local governments, the healthcare system and families – more resources should be invested in federal research to seek earlier diagnosis, better treatments and someday, a cure.



How to Advocate for Public Policy Change

GS&PAA advocates for laws and policies aimed at shattering the barriers to treatment, survival and recovery for people with schizophrenia. Your voice is critical to help us tell the stories of the discrimination people with this severe brain disease face every day.

Public policy advances can be achieved in many ways, including regulations and legislation at the federal, state and local levels. Being an effective advocate can make a major difference in educating lawmakers about issues that are important to our schizophrenia community and encouraging their support for change. This guide provides an overview of the most effective ways to advocate.

- **Know the issue yourself.** You don't have to be an expert, but make sure you know the important facts, including whether your concern is a federal, state or local issue. You can build on this knowledge with your lived experience, which will bring the issue to life for lawmakers.
- **Know your elected officials.** You can find your U.S. House and Senate members through an online search using your zip code (e.g., "US Congress member zip code 15201"). A similar search will identify your state lawmakers and relevant local officials. You'll be most effective if you contact the officials who represent your state or region, as it's their job to be responsive to constituents.
- **Write a letter.** Elected officials value hearing from constituents. Although a letter can take 2-3 weeks to arrive at the U.S. Capitol (all mail is opened offsite for security), hard-copy letters are still valuable. Consider sending a letter to the lawmaker's district office, as well. Addresses are available on lawmakers' websites. If they list an email address, feel free to send your letter that way if you prefer.



What should my letter say?

- **Briefly and clearly state your concerns upfront.** A clear message is an impactful one.
- **Get to the point.** Explain why the issue is important to you, then state your request. Do you want them to co-sponsor a specific bill? Vote for it? Write a bill? The more specific you are, the easier it is for them to be responsive.
- **Explain why the issue is important for them.** Make it local: provide information and statistics related to their district/state/city. Include any potential cost savings. Even if you are only describing a single incidence of injustice or problems with care, write about it. That counts!
- **Tell a personal story.** True stories about a constituent make the issue real and carry much weight.
- **Be brief.** Keep your letter to one page. Lawmakers receive many letters and emails; make yours the one they read from start to finish. If you want them to take action on a specific bill, provide the bill number and the names of co-sponsors. If you want them to write a bill, provide specific wording if you have it.
- **End with thanking them** for taking the time to read your letter and offer to speak with them or their staff. Sometimes a staff member will call you for more information.
- **Send the letter.** Communication only works if you communicate it!

Phone calls. Phone calls are important when a specific bill is coming up for a vote. A federal lawmaker's Washington office will have staff trained to understand the legislation, but the district office staff is often more responsive and attuned to the "pulse" of their district and state.

Should I ask for a meeting? Yes – especially if you are representing an organization and you can bring others. Don't worry about traveling to Washington. If you get a meeting in a federal lawmaker's district office, your voice will still be heard. When requesting a meeting, follow the same rules as when writing a letter. Ask to meet with the member and explain why. Don't worry if you meet with a staff member vs. the elected official. The staff are the ones who track all communications, advise the lawmaker and write the legislation.



What to do at a meeting.

First, thank them for their time. Then get right to the point.

- Share anecdotes that illustrate what the issue means to you and why it should matter to them. Include potential cost savings.
- Stick to the issue. You will have only a short time to make your case.
- Ask how you can help. The member may ask you to work with their staff to provide more information.
- Always follow up with a thank-you letter to whom you met with. If a staff member was particularly helpful, a letter to the lawmaker complimenting the staff member is valuable.

Be patient. Legislation takes time – but it’s also OK to communicate the cost of delaying change. With schizophrenia, delaying support costs money – and lives. Provide statistics about these costs whenever possible. (S&PAA can help with this.)

Follow up. Write an op-ed or letter to the editor of your local or state-level newspaper about the issue. State why it’s important and why you value lawmaker support for a specific bill. Tell a brief story about why it’s important for the communities the newspaper covers. The same goes for social media; consider writing a post about the issue whenever concerns about mental health/brain disease are in the news. Depending on the social media channel, you may be able to “tag” your elected official in your post.

What should I avoid doing?

- **Never get angry.** It’s OK to voice your frustration, especially if you have a personal story of the tragedies you’ve encountered. But always do so politely and as calmly as possible.
- **Never talk about campaigns or politics.** It’s against the law for elected officials to use their offices for campaign purposes, so avoid any discussion of campaign contributions or support.
- **Don’t go off message.** If the member asks about your position on other issues (especially divisive ones), simply restate your original concern. (“Thank you for asking our opinion, but today we are here to discuss an issue that is critical to people living with schizophrenia.”)
- **Don’t nag.** Repetition can be valuable, but if you contact the office every day, you become the person staff members want to avoid.



Stay in touch. An active elected official often attends parades and other public events. Feel free to say hello and re-introduce yourself on such occasions. Thank them again for meeting with you and remind them of the topic. (“Hello, Congresswoman Jones! Nice to see you here! You were kind enough to meet with me to discuss criminal justice diversion programs for people living with schizophrenia. Thank you!”) If you have enough time when you see them, go ahead and raise your concern again.

Invite the official to speak to your group, if applicable. If you are a member of a local advocacy organization, this can be very valuable. It doesn’t have to be an auditorium packed with people, but elected officials do understand the value of numbers. It goes a long way when you can gather multiple people to show concern for an issue. Send the member/staff some briefing materials ahead of the meeting.

Watch what you say elsewhere. The impact of many good conversations has been undermined by what a person says to others verbally or in a social media post. Members’ staff often will search your social posts, and any negative comments about officials or their political party can wipe out your impact in an instant.



Quick Tips: Actions You Can Take to Advocate

Lay the groundwork

- Sign up for the Advocacy Alerts many advocacy organizations send when important legislation is pending. When possible, take the actions the alerts recommend.
- Sign up for a few legislators' newsletters, especially the chairs of key committees (such as health or appropriations committees). Include lawmakers from different political parties to be sure you understand all points of view.
- Identify examples of positive legislation to share with your legislators and their staff.
- Create a packet of information to educate lawmakers about schizophrenia and the need for the policy changes you seek.
 - Include materials from websites (S&PAA, TAC, NAMI, NIMH) and even books that provide helpful information.
 - Send your packet to relevant elected officials and/or others who influence policy in your state/region. (If you include a book, you can use cheaper USPS Media Mail rates.) Bring a packet to any meeting you attend.
- Consider registering as a lobbyist in your state. It's easy to do and usually is free for those who are advocating for a personal cause (vs. being a professional lobbyist). In some states, being a registered lobbyist provides increased ability to secure meetings with lawmakers and access to some building spaces that are not open to the general public.

Make connections

- Identify/develop relationships with staff of policymakers who handle mental health issues.
- Request a meeting with your legislators ahead of the legislative session to share your priorities and discuss bills you hope they might sponsor. Invite legislators to any events you are involved in locally or at the state level.
- Send lawmakers thank-you notes for every action that is helpful, especially for voting for your bills and filing bills on your behalf.
- Build relationships with other lobbyists and advocacy organizations and support their legislation when appropriate.
- Connect with reporters (print, TV, radio) to offer yourself as a resource on schizophrenia and related policy issues. Create a media list and update it as needed.



Amplify your message

- Write op-eds and letters to the editor for your local and/or state capital newspaper to support legislation or to suggest different ways of solving problems.
- Share articles and research that support your suggested policy solutions with your lawmakers.
- Share relevant articles and ideas on your social media channels and “tag” your lawmakers whenever possible. (Many legislators have public profiles on these channels.)
- Accept as many speaking engagements as possible to help spread your message.
- Seek opportunities to testify at committee hearings and other governmental forums.
- When you meet with a legislator, take pictures and send them to their staff so they can post them on their social media channels and include them in constituent newsletters.
- Participate in peaceful rallies that promote your policies at the local, state and federal levels.
- If you are focused on particular programs, request outcomes data whenever possible to determine program effectiveness.
- If a lawmaker’s staff reaches out to you for help, do everything you can to fulfill their request.



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Advocating Through Social Media

The basics

- Vary your content (photos, articles, your story etc.).
- Your call to action should be practical and easy to digest.
- Interaction is key (share, comment, post, respond on your own and others' posts).
 - Stay calm and polite:
 - Be prepared for respectful debates and discussions.
 - Do not engage with disrespectful comments.
 - Do not post angry/disrespectful responses to others' posts.

Avoid:

- Too many hashtags
- Sharing links to articles where there is a paywall
- Multiple calls to action
- Jargon or other words not easily understood by your target audience(s)

Engaging on Facebook

- Join Facebook groups relevant to your cause.
- Get personal (share your story).
- Share both good and bad news (reach out to your community).

Engaging on Twitter/X

- Stay in the "now" (comment, post and share the most up-to-date news).

Anatomy of a perfect social media post:

- Keep it short and sweet.
- Include visuals.
- Use hashtags and tag others (groups, articles, publications) to get their attention.
- Use verbs and the active voice.
- Be direct with your call to action.



Writing Opinion Articles (Op-eds) & Letters to the Editor

What are they and when should I write one?

Op-eds are opinion-based articles published in newspapers, magazines and other print and online publications. They are written by members of the general public vs. the publication's staff. As a general rule, these articles:

- Express a point of view and are designed to persuade readers
- Are 700-800 words long
- Are relevant to current news or public discourse
- Include a call to action

Letters to the editor are responses to articles that have appeared in the publication. They are much shorter (about 150 words) and either support or take issue with the published article. They also may address an issue even if it has not previously been written about.

Op-ed structure

- A compelling lead (“hook”) to attract the reader’s interest
- Your argument: What is the problem or need, and why should readers care?
- Point 1: Evidence* to support your argument
- Point 2: More evidence to support your argument
- Point 3: What do your opponents believe and what evidence refutes that?
- Conclusion/Call to action

**Evidence can include your personal experience, studies, news items or other references.*

Before you begin

- Choose a target publication based on what audience(s) you want to reach.
- Research that publication’s guidelines for rules on length, where and how to submit etc.
- Read other op-eds/letters in the publication to get a sense of its style and interests.

Submitting your op-ed or letter to the editor

- Follow the submission instructions carefully. Respect any length restrictions and be sure to apply to the contact person/email provided.
- Do not submit your op-ed to multiple publications at once unless those outlets expressly allow it. Most require exclusivity to consider publishing your piece.





Sample Op-ed #1

Mother paints heart-wrenching picture of son's struggles with mental illness

Leslie Carpenter
Iowa View contributor
Feb 13, 2018

Being the mom of a 27-year-old son who has a schizoaffective disorder, I have witnessed a significant amount of suffering in multiple psychiatric facilities in Iowa. A schizoaffective disorder is a combination of schizophrenia and bipolar disorder in which a person often has auditory hallucinations (hearing voices) and persistent delusions. At the same time, this disease can move from depression to mania, and often psychosis.

During episodes of psychosis, my son has believed he was Jesus, the sun, a prophet, and God – where he has felt the need to save people and save the world. During treatments, he often enters a phase in which he isn't sure what was real and what was just his brain "fooling" him into believing he was God, etc. This is always a painful phase.

During the summer of 2016, he experienced his worst psychosis to date. Even though he was hospitalized in a psychiatric unit, it took a few weeks for the medical staff to figure out that he wasn't taking his medications. Even in psychosis, he's still quite capable of convincing people that he's taking them. His condition deteriorated over those weeks. He was distraught and terrified of everyone and everything. He stood, for weeks, in the doorway of his hospital room. He was afraid to be in his room. He was afraid to be near the staff and patients outside of his room. He was afraid of bed linens, so they took them away. He was afraid the water could somehow get inside of his body, so he wouldn't shower or use the bathroom facilities. He was afraid the hospital food was poisoned, so he would only eat what my husband and I would take him to eat. He looked for messages from the birds that flew outside the window of his room. Day after day, night after night, he stood on that threshold, terrified and suffering.

We visited, day after day, as the staff finally got him to take his meds, hoping to find him better. But, unfortunately, the medications didn't work this time. It took ECT (electro-convulsive therapy) before he finally improved, and his suffering lessened.

This is the description of just one young person's suffering. Sadly, across our state, there are many more people suffering. There are people with mental illnesses waiting in emergency rooms, hoping for a bed. There are people on our streets, homeless and untreated. And worst of all, there are people in our jails and prisons who ended up there due to being untreated and committing a crime while being very, very ill.

(cont.)



As I write this essay, we are “standing on the threshold” of making significant changes to how Iowa provides treatment for the seriously mentally ill. I’m hopeful that more people across our state will step over the threshold of their own comfort levels and contact their legislators to insist that we do everything we possibly can to improve our ability to take care of people with serious mental illnesses. Families like mine need help to prevent their loved ones from suffering, as our son did for all those days and weeks, while literally standing on the threshold of his hospital room.

We can do better. We now have the opportunity to do better. We all need to cross this threshold together and change the trajectory of mental health care in Iowa. We should feel proud of how we treat our most vulnerable citizens. As a fellow advocate says, these illnesses are horrific enough — getting care shouldn’t be, as well.

There are several bills before the Iowa Legislature this week that can improve the way we provide mental health care in our state: SF 2212, SF 2250, SF 2252 and HF 2176. I encourage all Iowans to contact your legislators to support these bills (legis.iowa.gov/legislation). I urge our legislators to vote for them and, with any luck, have our governor sign them into law.

Leslie Carpenter is an advocate for people with serious mental illnesses. She volunteers as a NAMI Family to Family Teacher and on the NAMI Johnson County Board of Directors, currently as the president-elect.



Sample Op-ed #2

A Serious Defect in The Inflation Reduction Act Will Hurt My Son

By Sherri McGimsey

March 21, 2024

As the parent of a child who suffers from schizophrenia, I've slowly become acclimated to the necessary -- and extremely difficult -- task of caring for someone whose psychiatric symptoms prevent him from living a fully normal life.

I wouldn't be able to do it without medications that alleviate my son's worst symptoms. I'm hopeful that potential new drugs on the horizon could provide him -- and countless other patients -- with unprecedented relief from this devastating disease.

But I'm also worried that those medicines, though scientifically promising, may never actually come to fruition -- all because of a provision buried in the Inflation Reduction Act (IRA).

That legislation contains a fatal flaw in how it regulates classes of medicines that come in pill form. If Congress fails to fix this error, it could significantly undermine the development of new therapies for psychiatric conditions like schizophrenia -- robbing people like my son of future treatments that could dramatically improve their lives.

Most medicines that can be taken orally, in pill or tablet form, are chemically synthesized small molecule drugs. By contrast, most medicines that are administered by infusion or IV are grown from living cell cultures and called large molecule medicines or "biologics."

While the IRA allows Medicare to negotiate prices for certain brand-name prescription drugs, it wisely exempts newly approved medicines from price setting for a time -- which protects incentives for research and development. But it doesn't treat small and large molecule drugs equally. The IRA protects new large molecule medicines for 13 years, but small molecule drugs for only nine.

That disparity seriously imperils people with psychiatric diseases such as schizophrenia and bipolar disorder. Almost all psychiatric medicines are small molecules, since these drugs can readily penetrate the blood-brain barrier to treat those disorders' neurological underpinnings. By providing these therapies with four fewer years of protection from government price setting than biologics, the IRA could force many biotech investors to cease funding psychiatric drug research and development.

(cont.)



Sample Op-ed #2

In fact, a recent survey found that over 80% of bioscience firms currently researching mental illness expect the law to hinder their R&D, and more than 60% report planning to shift away from the small molecule category altogether. It's not hard to see why. Developing any new drug costs an average of \$2.6 billion. Drug manufacturers need to recoup those enormous upfront investments to stay in business and fund the development of future therapies. Arbitrarily constraining biotech companies from generating a return on small molecules will inevitably lead them to bet on biologics instead.

The same survey also found that 95% of companies expected to develop fewer new uses of existing drugs, a process that often brings promising psychiatric medicines to new patient populations.

Ultimately, the IRA's disparate treatment of small molecules has major implications for the future of all pharmaceutical development. A study from the University of Chicago found that the law's distorted incentive structure will lead to 79 fewer small molecule drugs coming to market over the next two decades.

The IRA risks entrenching a two-tiered system that further marginalizes patients with psychiatric illness, many of whom already face stigma, affordability challenges, and other onerous barriers to care. Through my son, I've seen firsthand just how debilitating schizophrenia can be. It often prevents sufferers from holding a job, going to school, having friends, or even leaving the house.

The human and societal costs of psychiatric diseases are also enormous, and on par with many physical ailments. According to the National Schizophrenia & Psychosis Action Alliance, schizophrenia alone cuts average life expectancy by around 15 years and costs the United States more than \$280 billion each year. Those expenses largely stem from caregiver burden, homelessness, and incarceration, all of which are exacerbated when people with schizophrenia lack access to the best medicines available.

Fortunately, it's not too late for Congress to fix this dangerous mistake. In fact, North Carolina Reps. Don Davis and Greg Murphy -- a Democrat and Republican, respectively -- recently introduced the bipartisan EPIC Act, which would provide small molecule drugs with the same 13-year protection already afforded to biologics. This minor change would leave all of the IRA's existing benefits intact.

Honing the IRA to restore incentives for small-molecule drug development will help ensure that millions of patients living with serious psychiatric conditions -- including my son -- can access medicines that enable them to live more normal, fulfilling lives.

Sherri McGimsey, mother of a son living with schizophrenia, lives in Morganton, NC.



***Advancing Policies That Shatter Barriers
to Treatment, Survival and Recovery***

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