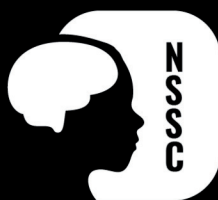


A photograph of two women in a grand, classical-style interior, likely a government building. The woman on the left is older, with grey hair tied back, wearing a green blazer. The woman on the right is younger, with dark hair, wearing a dark blazer over a pink shirt. They are engaged in a conversation. The background features large marble columns and a high, arched ceiling with recessed lighting.

Guide to

# Advocating for Policy Reform

*Recommendations for Meeting with  
Your Federal, State and Local  
Government Officials, and  
Leveraging Your Messages*



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Silence Coalition publication

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# ADVOCATING

## FOR POLICY REFORM

### MAIN TAKEAWAY

*To advocate effectively for issues such as serious mental/brain illness and schizophrenia policy, combine a formal preparation and professional in-person approach with long-term relationship building and modern communication channels such as social media and letters to the editor. The following recommendations integrate standard advocacy best practices with nuanced, field-specific guidance from experts and advocates.*

### SCHEDULE YOUR MEETING

*Plan ahead to maximize influence and attendance:*



STEP	DETAILS
PLAN EARLY	Request your meeting 2-4 weeks in advance. Target times when the Congress in your state or in Washington, D.C., is in recess—lawmakers are then in home districts. Request a meeting ahead of the legislative session to share your priorities and discuss bills you would like them to sponsor.
WRITTEN REQUEST	Email or fax your meeting request, detailing your name, affiliation, attendees, and goals. Create and send beforehand a packet of information to educate lawmakers and their staff about serious brain diseases and the reasons and need for seeking policy changes you are recommending. Then follow up by phone.
EMPHASIZE CONSTITUENT STATUS	State clearly that you are a constituent, which significantly increases your credibility.
FLEXIBILITY ON ATTENDEES	Accept meetings with staffers—they often have substantial legislative influence and insight. Ask for the staffer responsible for mental illness/health policy. The legislator relies on staffers to brief them on bills/policy matters as they cannot be experts in every area.

# ADVOCATING FOR POLICY REFORM

## PREPARE FOR THE MEETING

*Being prepared boosts both your confidence and the impact of your message:*

STEP	DETAILS
RESEARCH THOROUGHLY	Know the details of your issue—rely on your expertise, lived experience, and current data/evidence. Learn the Congress member's positions and voting record on these topics.
DEFINE SPECIFIC GOALS	What exactly do you want? (e.g., co-sponsorship, a vote, introducing a bill). Prepare focused, actionable asks.
PLAN TALKING POINTS	Select 1-3 key issues to focus on. Allocate talking roles if with a group. Practice delivering concise messages and supporting points.
PREPARE MATERIALS	Bring a short briefing packet—ideally 1-2 pages—summarizing issues, key statistics, fact sheets, and personal stories.
PRACTICE	Rehearse your presentation. If advocating as a group, plan who will cover each topic.
DRESS PROFESSIONALLY	Wear business attire to reinforce credibility.



# ADVOCATING FOR POLICY REFORM

## DURING THE MEETING

*Take a purposeful, respectful, and results-oriented approach:*

STEP	DETAILS
BE PUNCTUAL	Arrive on time. Congressional schedules are packed.
MAINTAIN PROFESSIONALISM	Stay polite and respectful, even in disagreement. Avoid political debates or discussions of campaigns.
OPEN POSITIVELY	Thank them for their time and acknowledge past or ongoing positive efforts.
STICK TO YOUR AGENDA	Focus strictly on your priority points. Limit discussion to 1-3 issues for clarity and brevity.
PERSONALIZE YOUR MESSAGE	Explain how the issue affects you, your family, or your community directly.
MAKE A DIRECT REQUEST	State precisely what action you seek—reference bill numbers, provide supporting details, and current outcome data on the programs you are bringing to their attention.
RESPONSIVENESS	Answer questions honestly. If unsure, promise prompt follow-up.
ENGAGE STAFF	Treat staff as vital partners—often, they drive policy formulation and legislative drafting.
RELATIONSHIP BUILDING	Establish yourself as a future resource—be constructive and memorable.
CONCLUDE ON A HIGH NOTE	Restate your thanks and willingness to remain involved.

# ADVOCATING FOR POLICY REFORM

## SPECIAL CONSIDERATIONS

*Keep in mind these considerations when advocating for Serious Mental/Brain Illnesses:*

- **Tell Stories:** Personal experiences and constituent narratives are uniquely powerful—legislators recall stories, not statistics alone.
- **Localize and Quantify:** When possible, provide district/state-specific impacts and data—it makes the issue “real” and relevant to the member. Legislators are always looking for ways to please their constituents and save money for their districts/states with an eye towards reelection.
- **Patience:** Policy change is slow. Emphasize urgency with data on human and monetary costs of delay (e.g., deaths, hospitalizations, financial waste).
- **Stay Calm:** Express frustration only respectfully and never show anger, sarcasm, or hostility.
- **Avoid** divisive or off-topic remarks.
- **Avoid Campaign Talk:** Never discuss re-election, fundraising, or campaign work—it is illegal for legislative offices to do so.
- **Time Constraints:** Be aware that meetings are often brief (15–30 minutes) and may be interrupted. Be prepared with a shorter version of your remarks.
- **Flexibility:** Congressional schedules can change unexpectedly, so be prepared for potential delays or adjustments.

## AFTER THE MEETING

*Establish credibility and reinforce your message with proactive follow-up:*

STEP	DETAILS
GROUP DEBRIEF	If part of a group, immediately review outcomes and next steps.
THANK-YOU COMMUNICATION	Send prompt, personalized thank-you notes/emails to the member and staff, reiterating key messages.
SEND ADDITIONAL INFO	Provide promptly any resources or answers you promised to deliver.
TRACK COMMITMENTS	Monitor relevant legislative activity and follow up at key moments (e.g., before votes).
STAY ENGAGED	Maintain periodic, positive contact—don’t let the relationship drop after a single meeting.

# ADVOCATING FOR POLICY REFORM



## AMPLIFYING YOUR MESSAGE BEYOND THE MEETING

*Leverage Additional Channels to Advance Your Message:*

TACTIC	DETAILS
WRITE LETTERS/ OP-EDS	<p>Publish well-crafted commentaries or letters to the editor (LTEs) to local/state capital/national newspapers to highlight your issue, support legislation or offer solutions to problems and why it matters to constituents.</p> <p>Do not send the same piece to multiple outlets. Follow the submission rules.</p>
SOCIAL MEDIA ENGAGEMENT	<p>Use platforms like LinkedIn, X or Facebook to amplify calls to action. Keep posts short, visual, positive, and jargon-free. Tag lawmakers, reporters, share news, and tell your story.</p>
BUILD BROADER RELATIONSHIPS	<p>Connect with other advocates, lobbyists, and organizations to synergize efforts and reinforce your message.</p>
CONNECT WITH MEDIA	<p>Offer yourself as a resource to reporters; create and maintain a media list for outreach. This includes radio, podcasts and network T.V.</p>
LEGISLATIVE ALERTS/ NEWSLETTERS	<p>Sign up for alerts from advocacy orgs and lawmakers—stay informed and ready to act on fast-moving legislative news.</p>
LEGISLATIVE TESTIMONY & EVENTS	<p>Offer to speak at committee hearings, community forums, and public rallies—bring materials and stories to share</p>

# ADVOCATING FOR POLICY REFORM

## DO'S AND DON'T'S FOR ADVOCACY MEETINGS AND SOCIAL MEDIA

DO	DON'T
Be persistent, patient, and positive – <i>relationships matter</i> .	Threaten, berate, or show hostility.
Stay on message – Stick to your core issue (especially if prompted to discuss others).	Shift to divisive or unrelated topics.
Follow up professionally and promptly; Stay visible and helpful.	Exclude lawmakers from advocacy events or forget to send briefing packets to them ahead of time.
Celebrate legislative wins and thank advocates and lawmakers for their actions.	Nag or contact excessively; balance persistence with respect.
Sign up for a few legislators' newsletters. Include both parties. Of special interest, send to the chairs of key committees like health and appropriations.	Undermine your advocacy with negative remarks, online or offline.
Protect your credibility – Be accurate, polite, and consistent in public and social posts.	Distribute the same op-ed or Letter to the Editor (LTE) to multiple outlets (unless allowed).
Keep social media posts short, include visuals, use hashtags and tag other groups, publications, and reporters.	Use too many hashtags, acronyms or share links with a paywall.
Use verbs and active voice; Be clear and direct with your call to action.	Include your political affiliations in your postings. Remember, mental/brain illnesses are bipartisan issues—we need to work with all parties to enact positive change.
Create a packet of information to educate and share with state and federal lawmakers including materials from websites (TAC, NAMI, NIMH) and books. Send your packets to relevant elected officials in your state. You can use cheaper media mail rates if you include a book.	Engage in or post hostile, aggressive, or disrespectful messages. Remember, everything you post on social media platforms may be noted by savvy staff members who often research contacts across the internet.

# ADVOCATING FOR POLICY REFORM

## SPECIAL GUIDANCE: PUBLIC POLICY ISSUES IN SCHIZOPHRENIA/MENTAL ILLNESSES

*When advocating for schizophrenia and related brain disorders, consider these high-priority legislative goals:*

- Policies designating schizophrenia and related psychotic disorders as treatable brain diseases.
- Reforms to inpatient payment and care exclusions, including eradication or modification of the discriminatory Institution of Mental Disease (IMD exclusion).
- Changes to confidentiality in the Health Insurance Portability and Accountability Act (HIPAA) to improve family-provider communication while respecting privacy.
- Legislation targeting homelessness and alternatives to imprisonment for those with serious psychiatric illness.
- Reforming judicial practices such as solitary confinement for mental illness populations.
- Stay informed on what the ACLU and Disability Rights Groups are advocating for in the treatment of serious brain diseases. Educate and push back accordingly.
- Stay informed and partner with specialized advocacy organizations for guidance and resources.

### APPENDIX: SAMPLE TABLE OF ADVOCACY ESSENTIALS

ADVOCACY PHRASE	KEY ACTIONS
PRE-MEETING	Research, goal-setting, written request, practice, prepare materials.
IN-MEETING	Professionalism, conciseness, storytelling, specificity, staff engagement.
POST-MEETING	Thank-yous, follow-up with info, issue monitoring, further relationship building.
ONGOING ENGAGEMENT	Letters to editor, social media, event invitations, participation in rallies, staying current via alerts/news.

*By integrating strategic preparation, professional meeting conduct, effective follow-up, and broad-based outreach (letters, media, social channels), you maximize the likelihood that your advocacy—especially in complex areas like mental/brain illnesses—will have a real, lasting impact on legislative action and public policy.*

*This, in turn, will help knock down archaic laws and system practices barring access to the medically necessary lifesaving care with supportive therapies and housing that people living with these treatable diseases face.*

*Remember our goal: help these folks live their very best lives instead of rotting on our streets or in cells due to our country's neglect, ignorance, and discrimination against those with a psychotic illness.*

# MORE FROM NSSC

SPEAKING OUT - INSPIRING CHANGE  
FOR SEVERE MENTAL ILLNESS/BRAIN DISORDERS



The National Shattering Silence Coalition offers more guides on our website ([nsscoalition.org](http://nsscoalition.org)) – including:

**Psychosis and Psychotic Illnesses (A Peer's Perspective)**  
**Member-Exclusive Resource Guide (join us today for your free issue)**  
**SMI Caregivers in Crisis: What You Need to Know (But No One Ever Tells You)**

These and more resources on our website and social media.



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- We're here on [X \(formerly Twitter\)](https://twitter.com/nsscoalition), ([twitter.com/nsscoalition](https://twitter.com/nsscoalition)) adding to the conversation on Serious and Severe Mental Illness. Come join us!
- We're here on our website: [NationalShatteringSilenceCoalition.org](https://www.NationalShatteringSilenceCoalition.org) or [NSSCoalition.org](https://www.NSSCoalition.org). Check out our updates and news from Who We Are (including our Index of State Policy Directors, Partners, and Team) to Media (blog posts) to Events, to exclusive and free Resources!
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