

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. |

AMPLIFYING YOUR MESSAGE BEYOND THE MEETING

Leverage Additional Channels to Advance Your Message:

| TACTIC | DETAILS |
|---------------------------------|---|
| WRITE LETTERS/ OP-EDS | 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. Do not send the same piece to multiple outlets. Follow the submission rules. |
| SOCIAL MEDIA ENGAGEMENT | 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. |
| BUILD BROADER RELATIONSHIPS | Connect with other advocates, lobbyists, and organizations to synergize efforts and reinforce your message. |
| CONNECT WITH MEDIA | Offer yourself as a resource to reporters; create and maintain a media list for outreach. This includes radio, podcasts and network T.V. |
| LEGISLATIVE ALERTS/ NEWSLETTERS | Sign up for alerts from advocacy orgs and lawmakers—stay informed and ready to act on fast-moving legislative news. |
| LEGISLATIVE TESTIMONY & EVENTS | Offer to speak at committee hearings, community forums, and public rallies—bring materials and stories to share |

DO'S FOR ADVOCACY MEETINGS AND SOCIAL MEDIA

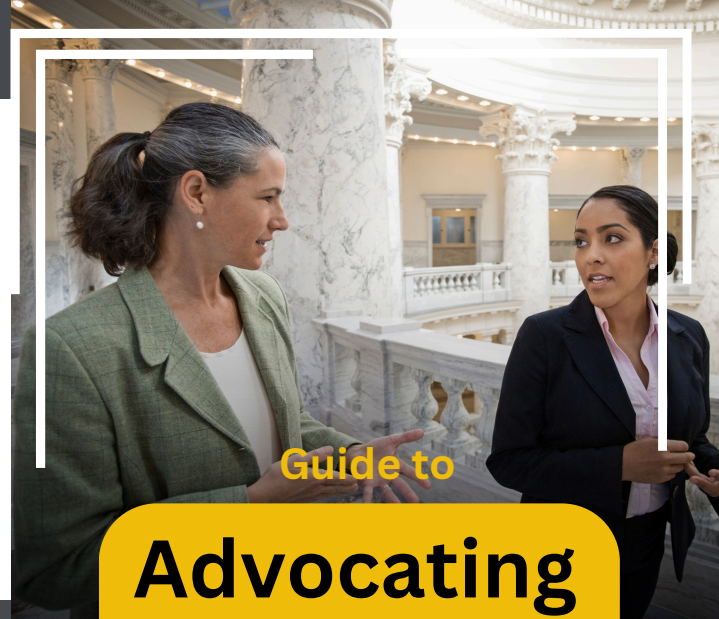
- Be persistent, patient, and positive – *relationships matter*.
- Sign up for a few legislators' newsletters. Include both parties. Of special interest, send to the chairs of key committees like health and appropriations.
- Create a packet of information to educate and share with state and federal lawmakers 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.
- Stay on message – Stick to your core issue (especially if prompted to discuss others).
- Use verbs and active voice; Be clear and direct with your call to action.
- Follow up professionally and promptly; Stay visible and helpful.
- Keep social media posts short, include visuals, use hashtags and tag other groups, publications, and reporters.
- Celebrate legislative wins and thank advocates and lawmakers for their actions.
- Protect your credibility – Be accurate, polite, and consistent in public and social posts.

DON'T'S FOR ADVOCACY MEETINGS AND SOCIAL MEDIA

- Threaten, berate, or show hostility/Shift to divisive or unrelated topics.
- Use too many hashtags, acronyms or share links with a paywall.
- Nag or contact excessively; balance persistence with respect.
- Distribute the same op-ed or Letter to the Editor (LTE) to multiple outlets (unless allowed).
- 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.
- Undermine your advocacy with negative remarks, online or offline.
- Exclude lawmakers from advocacy events or forget to send briefing packets to them ahead of time.
- 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.

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.



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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INTRODUCTION

The National Shattering Silence Coalition developed this guide to help families, caregivers, and advocates turn their experiences into meaningful policy change. It provides practical tools to navigate the legislative process, raise awareness, and push for reforms that improve treatment access and outcomes for those living with severe mental illness/severe brain disorders. We hope this guide empowers you to advocate for a stronger, more responsive system that truly supports recovery and families in need.

**The National Shattering Silence Coalition is not liable or responsible for any information provided in this guide. This guide is not intended to provide legal advice and is for informational purposes only.*

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. |

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. |

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 min) 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.

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. |

ABOUT THE AUTHOR

Linda Mimms is Director of Government Affairs/Public Policy and Co-chair of the Policy Action Committee, and as Lobbyist and Senate Staffer, has more than a decade of experience advancing reforms to improve treatment access for people living with serious brain diseases. As a national policy speaker, she has addressed major forums on treatment barriers, telehealth, and the criminalization of severe mental illness. She holds a master's degree in Public Policy from Duke University and founded a Lawrence University internship fund focused on severe mental illness advocacy.

