

11. What should I not do?

- a. *Never, never, never, threaten the member* (never say “if you do not support this bill we will organize against your next election”). Follow the golden rule. Be cordial and friendly. It is ok to voice your frustration, especially if you have a personal story of the tragedies you’ve encountered.
- b. Never be rude. Insults, sarcasm and hostile comments about past votes may close doors that you want open. If the member has not agreed with your position before, perhaps it’s because they did not have all the information they needed.
- c. Never talk about politics, or campaigns. It is against the law for members to use their offices for campaign purposes. If you bring up a conversation about asking how to contribute to their campaign or work for their re-election they should tell you they cannot discuss it, and merely give you a phone number or address to contact.
- d. Don’t go off message. If the member uses that opportunity to ask you your position on other issues (especially divisive ones) get back on topic and restate your original concern (“Thank you for asking our opinion, but today we are here only to talk about the issue of serious neuropsychiatric illness (SPI). These are people who are too often forgotten and our goal is to help you remember how important your support is for them”).
- e. Don’t be a nag. Repetition is valuable, but if you are contacting the office every day, remember the staff and member are juggling multiple issues.

12. Stay in touch. An active member will often attend parades and public events. Go up to them, say hello and reintroduce yourself. Thank them again for meeting with you, and remind them why. If they are walking in a parade they may only have a few seconds to speak with you. Make those seconds memorable! (“Hello, congressman! Nice to see you here! You were kind enough to meet with me to discuss reforms for hospitalization of psychiatric patients! Thank you!”). If you have more time when you see them at a local event, go ahead and talk about your concern again.

13. Invite the member to speak to your group. If you have a local brain health organization, it can be very valuable to invite the member to come by and talk. It does not have to be an auditorium packed full of people, but members understand the value of numbers. When you can gather several people to show their concern it goes a long way. Prior to the meeting it is very important to send the member and staff some briefing materials. Chances are very good they will read what you sent if they are expected to talk about it.

14. Watch what you say elsewhere. The impact of many a good conversation has been undermined by what a person says to others verbally, or in a social media post. *Staff often will search your social media posts. Your negative comments about the member or their political party can wipe out the impact of any good you tried to do.*

ISSUES: SARDAAs considers the following issues to be of very high importance:

1. Legislation that influences CDC, HHS, NIH, NIMH and other relevant agencies to consider schizophrenia spectrum as a brain disease.
2. Legislation that lifts the IMD exclusion.
3. Legislation that makes small but important changes to HIPAA laws allowing better communication between family and providers that improves care while still protecting confidentiality of records.
4. Legislation that reduces homelessness for those with SPI.
5. Legislation that offers alternatives to imprisonment, stops solitary confinement and other judicial system reforms for those with SPI.
6. If you are unsure, contact SARDAAs to ask for guidance.



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SARDAAs Schizophrenia and Related Disorders Alliance of America



How to Influence Government Policy by Dr. Tim Murphy

SARDAAs was founded to make lives better for those afflicted with schizophrenia and related brain illnesses. Improving access to care requires changes in several policies. On the federal level, some changes can be made by executive order, some through regulatory changes within various federal departments (such as Health and Human Services), and some can only be changed through congressional action to change a law. You have a right to petition congress for changes in the law, an issue so important that the founders of our nation made the right to petition the government the first amendment of our constitution. But like any right, it is only of value if you exercise that right. Being effective at communications make a major difference in educating members of the House and Senate about issues, as well as encouraging their support for change.

What to do:

No elected official is an expert in everything. Your knowledge and voice are essential to help them understand the what, why and how of issues important to you. Here is how you do it.

1. Know the issue yourself. Through your experience, expertise, reading and studying, make sure you know the issue itself. You don’t have to be the expert on an issue, but your knowledge is valuable. Know the facts, but you don’t have to wait until you know everything possible about an issue to act. At least know if your concern is a federal or state issue.
2. Know your legislator. It is easy to find your US House and US Senate member by a web search of your zip code (e.g. “US congressman zip code 15201”. If you write to someone

other than your own legislator, it may only be forwarded to another office. Unless you are representing an organization of special interest to the member.

3. Write a letter. *The letter you never write is the letter they never read.* Elected officials do value getting communication from constituents. Even though a member may receive several thousands of letters each year, yours still counts! But only if you send it.
4. US Mail or E-mail? A letter in regular US mail may take 2-3 weeks to arrive at the US Capitol because all mail is scanned and opened off site for security purposes. However, hard copy letters are also valuable. Consider sending a letter to the district office address as well. Addresses for their offices are available on their web site.
5. What should the letter say?
 - a. Thank them for reading the letter, and briefly state your concerns in the opening paragraph. If your description is confusing, your impact is diminished.
 - b. Be direct and to the point. Explain why the issue is important to *you*: if you have a family member with serious neuropsychiatric illness, state you are a member of SARDAA or another organization of interest, then explain what you would like them to do (again be specific). Do you want them to co-sponsor a specific bill? Vote for it? Write a bill? Join the mental health caucus? Whatever it is, the more specific you are, the easier it is for them.
 - c. Let them know why it is important for them. Make it local: *Bring it to the level of their home district*: give information and statistics related to their district/state. Even if you are only describing a single incidence of injustice or problems with care write about it. That counts!
 - d. Tell a personal story: True stories about a constituent are very valuable. These carry a lot of weight.
 - e. Be brief: Keep your letter to one page if you can. Staff have a lot of communications to deal with from many people. You want your letter to be the

one they read from start to finish. If you want them to co-sponsor, or vote for a specific bill, then give them the number and names of other co-sponsors. If you want them to write a bill, give them specific wording if you have it. But if you do not have specific wording, that's ok, still tell them your message.

- f. End with thanking them again for taking the time to read the letter, and say you will be happy to speak more with them or their staff if they would like. Sometimes a staff member might call you back to get more information, particularly if your story was interesting or compelling. But even if you don't think your story is compelling, send it anyway. It might be far more valuable than you think. The number of letters received on a topic is valuable to the member to know how many people really care about it.
 - g. Send the letter. Don't let it sit on your desk or computer. Communication only works if you communicate it.
6. Calls: Calls are important when a specific bill is coming up for consideration for a vote in committee or on the floor. You can call the district office or their Washington DC office. The Washington office will have more staff trained to understand legislation, but the district staff is usually more aware of the pulse of their district and state.
 7. Should I ask for a meeting? Yes. Especially if you are representing an organization, or you have knowledge of specific concerns. A meeting where you bring a few people shows strength in your issue. Don't worry about traveling to Washington. If you get a meeting in the district office, you still are building support. 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 "only" meet with a staff member and not the actual Representative or Senator. The member might be juggling multiple meetings at the same time. And staff are often the ones tracking all the communications, advising their member and writing the bills.

- a. If I meet directly with the member what should I say? First, thank them for giving you time. Then get to the point about why you are there.
 - b. A face to face meeting might involve multiple short stories about what the issue means to you and why it should matter to the representative.
 - c. Stick to the issue. You only have a brief time, and you want the member and staff remembering what you came there to talk about.
 - d. Ask how you can help. Many times, the member will ask you to work with their staff to assist with more information in the future.
 - e. Always follow up with a thank you letter directed to whoever you met with. If you found that staff member particularly helpful, a letter to the member complimenting their staff for the meeting is valuable.
8. Be patient. Legislation takes time. But its ok to let them know what delays cost. With 70,000 drug overdoses each year, 45,000 suicides, and 350,000 neuropsychiatric illness related deaths each year, delays costs lives. And they cost money. Its ok to bring this up to the member. If they do not vote in support or do not sign their name on as a cosponsor, it is ok to voice your disappointment. But note, there may be another day to vote on it again. You want to win them back.
 9. Follow up. Write a letter to the editor on the issue. State why it's an important issue and why you value the support of congress for a specific bill. Tell a brief story of why it is important for the people from the communities the paper covers. Same for their social media, consider writing a post about the issue whenever concerns about mental illness come up in the news. There is always something in the news.
 10. Should I write/visit more than once? Yes. *Be there, be brief, be kind and be back.*