

Systems Advocacy: What It Is and How to Do It

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Hello, everyone; this is Joseph Rogers and I'm your presenter today, along with Annette Williams, my co-presenter. We're presenting on systems advocacy: what it is and how to do it.

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Advocacy is the act of pleading or arguing in favor of something, such as a cause, idea or policy. It's finding your voice, being able to speak out and give evidence, not only for yourself but maybe for a group.

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There are generally three kinds of advocacy: self-advocacy, individual advocacy, and systems advocacy.

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Many of the tactics in the different kinds of advocacy are the same: deciding what you want, getting the facts, planning your strategy, gathering your support, being firm and persistent, and maintaining your credibility.

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Systems advocacy is attempting to change government, organization or agency policies, rules, and laws.

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Grassroots organizing brings people together. Society only recognizes the rights of people when they stand up and speak in one voice. Organize to gather people together and help them raise that voice.

Examples of grassroots organizing over the years have been the civil rights movement, the women's movement, and the antiwar movement. Those are movements that involve literally thousands of people.

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Grassroots organizing helps the people take power. We live in a democracy, and the voice of the people is what we're talking about. But many times it's very hard for the voice of the people to be heard, unless that voice has been organized and comes together in unity to speak out.

Grassroots organizing is continuous. It's an investment you're making, and it really alters the relationship of power. Many of us in the mental health consumer movement have, over the years, felt powerless. We would be engaged in a mental health system that pretty much told us what to do and where to do it; but it's through grassroots organizing that we begin to be able to have our voices heard and establish some power for the consumer in the mental health system.

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One of the things you start out doing is finding others who are experiencing the same problem you are. It's really hard to do it alone. When you find those folks, you have to spend some time talking to each other and finding out the nature of the problem. See if you really understand, in common, the nature of the problem. Then you've got to get some people who are committed to an effort to change the situation. It's got to be people who want to *do*, not just *talk*. The group doesn't have to be a large group, at least in the beginning. A small group can make a lot of things happen. You can work on involving others later.

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There are a lot of things you need to do to keep the members involved. Make it easy for people to get involved. Sometimes the tendency of somebody starting or being the leader of an activity is to want to do it all, because it's easier sometimes. It's better to think of ways to divide the tasks up, and find ways to delegate so that people feel like they're involved and it's not just your project but everybody has some sense of ownership.

You need to create a general sense of purpose. One of the ways you do that is to define clear and specific goals. One thing to do is make sure that your goals are achievable in a reasonable time period. The reason for that is that people need to feel they are making progress. If you start with a goal that's too big, you find yourself spending a lot of time just getting started and you may lose people. If you can do something in the beginning that is short and gets some quick results, you can help people feel like they're part of something that's going to make a difference.

One of the things we did here in Philadelphia was a lot of organizing around homelessness issues. That's a huge issue. One of the things we did to get things started was to pick a really doable activity – something that could be done and could be supported by the government relatively quickly. We wanted to see some specialized housing for people who were diagnosed with mental illness and were homeless, since there really wasn't any in the area. And we started with the idea of a small amount of

housing, and not necessarily everyone was going to get this housing but we could do it on an experimental, prototype basis.

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You've got lots of tools out there. One of the best tools is online networking. One of the things to always do when you're out there is – if you have a meeting or you have a discussion or you have an event – get people's names and addresses, particularly their e-mail addresses. We find that that's been very helpful, because you can quickly get in touch with people and keep them informed. People want progress reports; people want to hear what's going on. They don't want to be left in the dark for long periods of time.

One thing you can do is establish a discussion list. This is sometimes very good for rural areas or trying to do statewide organizing. You can have day-to-day contact with people through a discussion list. Those kinds of things are available pretty easily through the Internet now. You can even create a Web site. With the technology now, individuals who never thought they could do that are doing Web sites.

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Prioritize your goals. Start with the goal that has the greatest potential for achievement. Success will bind the group. Success will create motivation for continued efforts. Stick with it: never give up.

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Gather information. Who has authority to make the needed changes? It's good to do the research. Nowadays, we're lucky in that we have the Internet; even if you don't have a computer, you can go to the library and use the Internet there. Also, the library is a good place to get books on the information that you need.

If you're talking about state government, you need to find out who in state government is making the decisions for mental health policy, and how those decisions get made. Many times it's a cabinet-level person who reports to the governor. And they, on an annual basis, submit a budget. You've got to find out those things because if you know what time and where to make your voice heard, and to whom to make your voice heard, you're going to be more effective.

Find out what laws, rules and policies are in place that affect a particular cause or situation. Maybe they're actually not following the rules. One time, looking at the issue of boarding homes here in Pennsylvania, we were concerned that the people in the boarding homes were living in very bad conditions. We found out that there were lots of rules and policies in place but the state wasn't following them. So if you can find out what rules and policies are in place, many times you can advocate that they follow those policies. But sometimes you find out that you have to change the policies.

Find out what rights you already have and what complaint procedures exist. Most government, non-profit and provider agencies have a grievance procedure, and that's a

good place to start. Find out the facts; make sure you have the facts on your side. Facts are important to support the need for change.

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Who has the power? That's always an important question. How will those in power benefit by the change? And that's an interesting angle. Many times we think of advocacy as totally oppositional. But, a lot of times, the person in power actually *wants* to see some changes, and to see an advocacy voice, like a consumer group, speaking out, that's beneficial to them. They see the need for change but, believe it or not, somebody even in a high-powered position in government may not have the ability to change and to deal with the legislators in an effective way because of the way the government is organized. You can sometimes be the voice for the change that the people in high power might want help with seeing that change become possible. You need to create positive incentives that make change attractive to those in power.

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Knowledge is power. Learn as much as you can about the government/non-government organization or agency you are trying to change. Again, the Internet is helpful here, but also is going to some meetings. In almost every state, there is some sort of advisory committee. In every state there is a required block grant planning committee. You need to find out where some of those meetings are and attend some of them. In many cases, you can attend as a guest.

Again, read: ask people to send you information about policy. If you're trying to advocate for specific change, say, in your local agency, they should have a written policy available. If something is happening that you're not happy with, or a group of you are not happy with, ask them what the specific policy is so that you can see what's in writing. Sometimes that's where you begin: by asking for the policy to be changed.

Attend meetings, public hearings and conferences. Go to board meetings. Finding out where the decisions are being made – at least, where the citizens are hearing about those decisions – and attending those meetings is a way to learn. I always advise people to go to a few meetings before they start speaking out, so that they know the lay of the land. And then they can go to that meeting and present the issues that they find important.

Always try and figure out the staff. Even if you're trying to change the mind of, say, a secretary or a commissioner or somebody high up in government, there are usually some staff people who you can work with who may have more time. Maybe it's their job to work with consumers and make sure the consumer voice is heard. In a lot of states it's the Office of Consumer Affairs, or there's somebody who's a public liaison. These are people who can be very helpful in your efforts.

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Create an advocacy plan. That's a written plan. Determine your goal. Sit down and write some of your goals down. Frame your goals in a positive way – not that we are opposed

to something, but we're *for* something. We want to see changes that are *for* improved mental health services, *for* community integration. This way, you get beyond the idea that you're just seen as a troublemaker or a naysayer. You're bringing positive ideas to the forum.

Research what it will take to achieve the goal. Don't assume that the people in the system, even very high-up people, really fully understand their own system. Sometimes you can bring a new perspective and make some suggestions that they haven't even thought about. If you do some research about what's happening in other states or other communities, sometimes you can find out some very interesting ways – new ways – of doing business, so to speak, and you can bring that to your community.

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Be ready to negotiate. Study the offer. Find out what they're talking about. If they're talking back to you, that's good. The first thing you need to do is get a conversation going with whoever it is whose mind or whose policy you're trying to change.

Don't accept an initially offered solution too quickly. Sometimes when we're just starting out in advocacy, we want to have success; but you've got to think about it. It's always good to say you've got to go back and talk to the group.

Think about ways you can figure out middle ground. Think about alternatives. If you're coming in with one position or one idea, think about what would be an acceptable alternative to that idea.

We've worked here in Philadelphia in a lot of areas. One of the things we've worked on is trying to change how the police interact with people who have been diagnosed with mental illness. We've had some very tragic situations. What we wanted to see was the establishment of Crisis Intervention Teams in the city of Philadelphia and we made that demand. They came back to us and said they couldn't do it for the whole city. We suggested to them that they might start as a pilot program, and that gave them an alternative to trying to do it on a citywide basis. And it was more realistic and more doable, and we got agreement eventually to trying to do it on a pilot basis.

So, again, consider accepting the offer on a trial basis. Agree on some criteria for success. Sit down and have some time to review your outcomes, and push to see where you can go next.

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Strategy development: What do you want? What are your long-term goals? What are your short-term goals? Again, this is a good group exercise. Think of the content goals: what are the specific policy changes that are needed? Think about process goals: how do you build the people to be involved?

One of the things to think about is getting not necessarily large numbers of people involved but having more than yourself or a handful of people involved. You might want

to organize your own public hearing or have a demonstration or go down to the state legislature in a group and present your issues.

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Who can give it to you? Those with formal authority (legislators). You can also influence policy makers: key aides, the media, key constituencies.

It's not necessarily that you have to get legislative change; they can make policy change on a departmental level in state government. In city government, you might be able to get change by going to your city council and getting someone to at least talk about the issues. One of the things we've found here is that a lot of times the change comes more or less by simply getting people to be aware of an issue, be conscious of an issue, and come together and talk about the issue. So having a city council hearing or having a legislative hearing – that may not be specifically changing the legislation but opening up a discussion about the problem.

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What do they need to hear? You need to create a message specific to your audience. In creating your message, it's good to put a "human face" on the issue. One of the things we've done here is find someone who is willing and able to speak about their own situation. An individual talking about their struggle with homelessness – what helped and what didn't help – makes it more direct and human. That's the neat thing about the consumer movement: we're the ones mostly impacted by the problem. So we almost automatically get some credibility because we're the ones facing the impact of a policy or program. And by speaking out and being willing to speak out, we make the issue much more "see-able" and human.

One example is appealing to your audience's self-interest. For example, in Philadelphia, the Police Department's self-interest was in reducing injuries to officers and civilians. So our message stresses the fact that employing the Crisis Intervention Team model (which was developed in Memphis, Tennessee) would do that. There was good research that said that this model was the right thing to do, not only for consumers but for the police themselves.

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Who do they need to hear from? You need to have some experts. You need to have the authentic voices. Again, because we're consumers organizing, we many times can present the authentic voice. When you're talking about homelessness, for example, having people who have been homeless or are presently homeless be part of the group and part of the speaking-out effort gives an authentic voice to the discussion.

If you're not being listened to, there are a lot of ways to begin to make sure you're heard. One way is phone campaigns: making phone calls and getting lots of people to make phone calls. One time when we were looking at the conditions in our state hospital and were very concerned about them, we just flooded our governor's call line to the point that

they actually shut the line down, with people calling up and complaining about the conditions in the state hospital. We probably only got a couple dozen people to call, but by the time we had a couple dozen people call, it's all of a sudden an emergency and an important issue. We were able to get a blue ribbon task force appointed by the governor.

Letter-writing campaigns are good, and having meetings. One thing we used to do a lot here is letters to the editor and op eds. Call up your newspaper and find out how to do an op ed. Find out who the editorial board is and ask for a meeting with the editorial board.

Direct action is always good. Direct action is a demonstration: taking it to the streets. You can do this in lots of different ways. You don't necessarily have to have a negative picket. You can do a positive educational program where you invite speakers and you are educating the public about the issues.

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You've got lots of resources. One thing you can look at is other past advocacy work. If you contact the Clearinghouse, we can get you a lot of information about other people's advocacy efforts, and what worked and how they made it work.

Figure out who your allies are. Are there existing alliances out there? Are there people already working on mental health issues who might see the importance of your issue and join with you?

Always look for the staff and volunteers involved in mental health programming. A lot of times you can find that key staff person or maybe even a key volunteer – board members, for example, are volunteers – who takes an interest in what you're talking about and they can open doors for you.

The media is always a good way to make your voice heard.

These are lots of ways that you can get out there and find and use existing resources.

Think about the gaps. What alliances haven't been developed? Have you talked to the media? What kind of research do you need to do?

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How do we begin? Again, we talk about achieving goals to build a constituency. In Philadelphia, when we first started organizing, we wanted to find something that was a doable goal, that not only accomplished what we wanted to accomplish, but it had a broad appeal. More than a few people would be interested in it. That's always important when you're looking at your goals. Is it something that just concerns you? Or can you expand your goal so that lots of other people might be interested in it?

Work on laying your groundwork.

How can we tell if it's working? Sometimes you can work with outside evaluators to find out what you've done. You can send out questionnaires to people and see if they've heard your message. Or if they haven't heard your message, what's gotten in the way? Be ready to make strategy changes from the feedback that you get.

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Increase your group's visibility. Join forces with like-minded organizations in coalition efforts. The Internet, again, is something you can use. Reach out to the media. When we're talking about the media, we're not necessarily saying front-page articles. You can look at the local shopper's news or the weekly newspaper and get them to do a feature article. Or if you can raise enough money, you can do an ad, advertising where your next meeting is going to be. One time we wanted to start a self-help group and we put an ad in the local newspaper and it wasn't that expensive, and we got people to turn out for the self-help group.

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Your "do be" list is: be prepared, brief and concise; be clear about what it is you want; always be honest; be accurate; know what the facts are. If you don't know the facts, it's okay: you can say to people, "We're concerned about this issue. We don't understand why it isn't being done better. Is it a matter of funding? Is it that you never thought about change?" You don't necessarily have to come with all the answers, but be accurate: don't make assumptions or statements when you don't really know the facts. Always be polite, be persuasive, be in there.

The consumer voice is a very important voice in decision-making. More and more it is being recognized as an important voice. So you have a role to play in this. Try to act in a timely manner: if you hear about something and it seems like an important issue, sometimes there's an opportunity there. So, if you move quickly, get the letter right into the editor or the policy maker, you can use the opportunity that the situation presents.

Be grateful. People do want to help, and when they help you, let them know that you appreciate it.

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Say "thank you" before "please." Create an "affirmation sandwich." You begin with praise. You come in and say, "We really like the way the program has been improving. We think it's really great that you're now listening to consumers. By the way, we'd like you to do something about X-Y situation."

Even if it's only that they accepted a meeting or accepted your phone call, you can say thank you for that. You can continue with expressing your goals. And don't forget to end with thank you.

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Don't be argumentative. State your case. You may not get an immediate result. One thing that has been a lesson for me to learn is that sometimes I'll call up and I'll want to get a result, and I want it now. Well, sometimes you present the case and the person you're talking to can't give you a decision, or they're just not prepared to make a decision. And it may take a little while for them to get back to you. So don't push your discussion beyond the point that it becomes argumentative or demanding.

Don't bluff. Don't say, "If you don't listen to me, I'm going to do such and such." It doesn't work. If you can't follow through, it destroys your credibility.

Don't promise rewards. Don't say, "If you do what I want you to do, we'll do something else for you." And don't put down the opposition. If there's somebody that you're dealing with who is in opposition to the point you're making, don't get into personal arguments or discussions about that. Try to stick with your positive viewpoint.

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Before you make your first call, write down a description of your problem or need. This can be a good group exercise.

One thing I've seen advocates do is they come to a meeting, or they're on the phone talking to some policy maker, and they want to tell him the whole story, from the beginning to the very end. Most people don't have the time or the patience to listen to the whole story. Pick out the important facts and details that establish what the issues are and stick to those facts and details. Gather background information. Include some rationale for your request. There's got to be a reason for the change. People don't change just because you want them to change. You've got to show that there's some evidence base for a new practice or a new model. Or you've got to show that there's a large number of people who are very concerned about the issue.

Know the counter-arguments so you can respond. This is something you can practice with other people. When you're making your case, make it to a friend and have them argue back so that you can think of ways to respond to someone with whom you're discussing these issues. Make sure you're talking to the right agency and person. You can ask, "Are you the person who is able to help me with this issue? And, if you're not, who can?"

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The phone is a great tool, so you're making calls to get a lot of information initially. Make sure you tell them who you are, your address and your contact information. It's interesting that sometimes you're excited about an issue and you don't tell them how to get in touch with you to respond to the issue. Again, concisely tell them about the issue that prompted your call, and what's the action you're asking for.

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When you finally get through to somebody, write down their name so that you can remember. With most advocacy issues, it's going to take more than one phone call, and you may have to call your way up the chain of command. So if you know whom you've talked to previously, that helps, because the individual that you're talking to now can recognize that you've taken the time and that you're working your way up.

Write down the date and time of the call, so that you have some evidence to remind you that you've made these calls. You might have to call back, so it's good to be able to say, "I called, I talked to this person on this date and time." It keeps moving the ball forward.

Express yourself clearly and assert yourself calmly.

You're going to have to follow up. You're going to have to call back once or twice a week until you have achieved the desired action or set up a meeting to discuss your goals further. Sometimes the way to move it forward is to ask for a meeting. The phone call can just be an initial discussion, and asking for an in-person meeting at least moves it to the next level. And then in an in-person meeting, the person you're meeting with may have to prepare and talk to people and get some more facts.

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Writing letters is very important; it's a way to get in writing what you want. Identify your issues clearly. State your position and why you care. State how the issue will affect you and others. Tell the decision-maker what you would like him or her to do. Again, just stating the problem is not really going to be very helpful. I've seen a lot of advocates who are really good at complaining; they tell you what the problems are. But it's good if you can come up with some solutions.

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Keep your letter simple, as short and simple as possible. It's good to use letterhead, if you have letterhead. You can also make letterhead; on most computer programs, you can create a letterhead.

It's good to send copies to people. That lets people know that you're interested and you're talking to other people and you're going to carry through on this. You can put a "carbon copy" list of the people who might also be interested at the bottom. But keep it short and realistic. I've gotten letters from people who are advocating and they wrote the White House and everybody and their brother. Well, that's not necessarily going to be that helpful. A short list of people who are going to pay attention – particularly, say, the boss of the person whom you're talking to or writing to – is better than too long a list. Make sure you keep a copy for your records. And, when you write the letter, it's good to say, "I'm going to follow up with a phone call," or "we'd like to have a meeting."

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In face-to-face meetings, be organized. Practice what you plan to say. Bring others with you if that would help. Make sure everyone in the group is prepared. If you can dress neatly, that's good. And it's always important to be on time.

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It's good to have a face-to-face meeting. That's a good way to get to know the person, get to look them in the eye. Shake hands firmly. Call the person by their name. Be aware of your body language.

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Prepare anecdotes to illustrate your points. It's good to rehearse. If you are going as a group, agree in advance what roles different people are going to play. Who's going to start the discussion? Are you going to take turns speaking? It's good to seem united and ready and together to talk about the issues. Definitely don't start any arguments with each other when you're talking to the person you're advocating with.

If you are part of a coalition, make sure everyone agrees on the message; that's good to do beforehand. Send something out in writing and make sure everybody has a chance to look at it. That way, you know that when you're going to the meeting, everyone is in agreement with the position you're taking.

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State your message clearly and simply. Don't be argumentative; be reasonable. Be prepared to politely answer questions and concerns. If you disagree, that's okay: make your point and move on. I've seen people get locked in; they present an issue and somebody says, "No, that's not the way it is." Okay, fine: let's see what we can do. Maybe people perceive it that way. Maybe we're wrong. What can we agree upon?

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If you don't know the answer to a question, just say so; say you're going to go back and find out the answer and get back to them. Then try to get back with the answer in a reasonable time period.

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Don't do all the talking. Make sure you listen. Make sure the policy maker has time to ask questions and express his or her viewpoint. When you're nervous and you're meeting somebody for the first time, you can talk too much. It's good to sit back and listen to what the person has to say; they may be agreeing with you. If you don't understand something, ask a question to clarify. Don't make assumptions.

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Avoid jargon and acronyms. Ask the policy makers for their support. Be direct. Say, "Can you support us on this?" If they do, thank them. At least thank them for their time.

Follow up with a note thanking them for the meeting and, if you can agree to some points, write those down so that, later, there is no misunderstanding. For example, “We went to this meeting and you agreed that we were going to do a new program and that you were going to talk to the county officials about the new program.” A follow-up letter is a way to record what took place in the meeting and also a way to clear up any misunderstandings.

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It’s good to bring packets of information: your fact sheets and any newspaper clippings. Definitely have your contact information written down. If you have business cards made up, those are always helpful.

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If you’re not satisfied, ask why the person can’t help. Ask for another person or agency who might be able to help you. Again, remain calm and respectful. They’re probably telling you the truth if they’re telling you they can’t help you. A lot of times I’ve dealt with state policy persons and they say, “This is a legislative mandate. We’re doing what we’re doing because the legislators have said that it must be done that way.” That’s giving me the information I need; I know now where to go to see about making the changes that need to be made.

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Keep in touch, especially with key staff. Involve policy makers in celebrating your accomplishments. If you get something out of them, they want to hear about it. For example, if funding for a new drop-in center actually finally comes through, invite all the people you talked to to come to the celebration. And thank them! We’ve gotten plaques made up so that people can be thanked. Years later, I’ll go to their office and the plaque that we gave them to thank them will be on their wall.

Invite policy makers to your public forums or even to your meetings as a way to get to know them. You don’t necessarily even have to have an issue that you want them to resolve. Many times, people like state legislators are happy to go to a meeting of anybody from their constituency.

It’s sometimes better if you can meet with them before you have an issue so they know who you are and they can take you more seriously. And, again, giving credit where credit is due, thanking them publicly, is very important. If you get what you’re looking for, make sure you let the people who helped you know that you’re really appreciative.

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Advocacy is the art of compromise: You may not achieve everything you want, but you can achieve some of what you want and use that to build on. In almost every case where I’ve been involved in an advocacy effort, we generally didn’t get what we wanted the first time or the second time or even the tenth time. It was persistence that paid off.

For example, with the Philadelphia Police Department, we found that we had to come back time and time again. In fact, we had to wait for the change of the police chief. When the new police chief came in, we were able to finally get what we wanted.

Remember: administrations change. Policy makers change. Sometimes with the current policy maker, you may not be able to get what you want, but a new administration may be more willing to work with you on an issue. Stay positive; stay focused.

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We've got a wonderful program at the Clearinghouse that has taught self-advocacy skills to Thresholds members in Chicago, and my co-presenter has been involved in that program. So I'm going to now turn this over to Annette Williams, a recovery specialist at Thresholds in Chicago, who will talk about what she learned.

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Hi. My name is Annette Williams and I'm going to talk about using self-advocacy skills in everyday life to make recovery work even better.

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I learned that I have the right to speak up for myself.

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In my family life, my mother used to say anything to me that she wanted. And I began to speak up for myself, and told my mother that I'm not a child and not to treat me like a child. So she changed the way that she spoke to me.

My son made me feel guilty about not babysitting the way he wanted me to. And so I sat down and talked with him and told him that I dote on my grandchildren and I could see them when I wanted to see them and not when he wanted me to see them.

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With the system, I advocated to get my psych medication. I had to spend down my insurance for \$486 a month and I advocated for myself. I talked with my case manager about my prescription. That wasn't any help for me. So I talked with my psychiatrist: he told me about the Wal-Mart program for \$4 each prescription. But it didn't cover my psych meds. So I went on the Internet, and I found a free medicine program, which supplied me with my psych medication, so I don't pay anything for my psych meds now.

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I apply my self-advocacy skills daily. Self-advocacy helps you regain power. It puts you on the path to recovery. If you believe you have the power, your positive self-image will let others know that they need to respect you.

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On the job, for example, speak to your supervisor about problems. If you don't, this can stress you out and lead to depression, anger, and you might bust out at the wrong time.

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To help me self-advocate, I use affirmations. Affirmations will help you build hope and faith in yourself. Every day, I would say one or two or three affirmations to myself in the mirror: "I love myself." "Today is going to be a good day." They help me feel good about myself. You will start loving and believing in yourself. You will start to speak up for yourself. People will notice and respect you.

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Speaking up for yourself can make things happen for yourself. First learn to advocate for yourself; then you can advocate to change the system.

To conclude the Webinar, I'd like to turn it back over to Joseph Rogers.

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Joseph Rogers: A couple of last words here: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." That's from Margaret Mead. "One person can make a difference, and every person must try." And that's from President John F. Kennedy.

One of the things we want to make sure you see is the resources, bibliography, and presenters' contact information on the following slides.

Thank you very much and we hope that you have gotten something from our program. Please be in touch.

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Resources:

- Google:
 - 72,000 Web sites for "Advocacy tips" in a tenth of a second
 - Not all of the sites will be useful, but many will. (See slides 54-60 for some useful sites.)
- National Mental Health Consumers' Self-Help Clearinghouse (215-553-4539)
- Public library

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