



Knowledge is the key to open new doors

Technical Assistance Guide

Self- Advocacy

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Introduction

As consumers of mental health services, we face many obstacles in our lives, and often we must face these obstacles alone. Therefore, it is important for us to learn about *self-advocacy*, a process that involves identifying the obstacles that we face, developing strategies to overcome them, and then implementing these plans. Although we are often discouraged from standing up for ourselves, self-advocacy is possible for every consumer.

To help train consumers nationwide in self-advocacy skills, the Clearinghouse has collaborated with local and national organizations to create the Freedom Self-Advocacy curriculum. Together with the National Mental Health Association (NMHA) and the National Association of Protection and Advocacy Systems (NAPAS), the Clearinghouse trains people throughout the country to offer a set of three Freedom workshops in their own communities. This Technical Assistance Guide is distributed at all Freedom workshops, and if you are interested in attending a workshop near you, contact the Clearinghouse to learn about opportunities to further develop the skills taught in this guide.

Self-advocacy is essential for two basic reasons. An obvious reason is that there are insufficient advocacy resources to fully assist every mental health consumer: although advocates such as medical professionals, social workers, and lawyers can help us with some of our needs, many of our needs go unmet. “There is never enough rights protection,” says Clearinghouse executive director Joseph Rogers. “Funding is inadequate, and even if there was enough money, even the best system could not guarantee you twenty-four-hour-a-day coverage.”

“People often have their rights abused behind closed doors in the middle of the night,” he continues. “Under those circumstances, it would be impossible to reach an advocate on the phone anyway.” For Rogers, the solution to such situations was to learn how to assert his own rights. “Even if you enlist the help of an outside advocate, you have to know how to help them make the case. Self-advocacy allows you to know when your rights are abused and know how to document the abuses and assert your rights,” he says.

Author and lecturer Mary Ellen Copeland offers another reason that self-advocacy is essential: “The number one reason is that I’m the only person who has to live my life. Nobody else can know what I *really* need. Other people can look at me and say what they think, but it is very important for me to ask for what *I* want.” Even when you do have an advocate working for you, you’ll find that self-advocacy—in the form of active participation in the process—will help you obtain what you want.

This Technical Assistance Guide provides an overview of the attitudes and skills that you can use to improve your self-advocacy abilities. However, there are many other sources of information that will help you grow as a self-advocate. Often, other consumers can offer advice because they have faced similar obstacles. Therefore, networking with other

consumers can be an enormous help, and the Clearinghouse can put you in touch with local, state, and national consumer organizations.

We have also listed a number of outside resources that can help you further refine the attitudes and skills necessary for self-advocacy, as well as locate information that will help you overcome a particular goal. For example, your state's Protection and Advocacy (P&A) organization can provide you with information about issues such as preparing an advance directive or gaining access to your medical records. Agencies such as Mental Health Associations (MHAs) can help you learn about the services available in your community and how to obtain them.

Attitudes necessary for self-advocacy

Many consumers worry that they can't advocate for themselves. Janet Paleo, who works in the Office of Consumer Affairs in Lubbock, Texas, says, "*Anyone* can be an advocate! My two-year-old is an advocate—when he wants something, he lets me know." Of course, advocacy is not always so simple, but time and time again, consumers tell stories of surprising themselves with their own power to advocate.

As a preliminary step to achieving your self-advocacy goals, you might need to work on developing the attitudes necessary for self-advocacy. For some people, it means being more assertive, while for some it means taming aggression. Above all, self-advocacy requires believing in yourself.

Believing in yourself

In self-advocacy, attitudes and beliefs are as important as skills are. "Self-advocacy requires an internal belief that you are someone who is worth advocating for," says Clearinghouse program director Marie Verna. "As mental health consumers, we are often led to believe that we're *not* worth advocating for," she continues, "and we have to change this belief in order to take advantage of advocacy training. A belief in the value of ourselves allows us to take advantage of other aspects of self-advocacy training, such as learning our rights and learning how to write effective letters."

Many consumers have used positive beliefs to achieve things that they had been told would be impossible. Mary Ellen Copeland, a well-known author and lecturer, and herself a consumer, says, "In the mental health system, people are consistently told what they *can't* do." However, says Copeland, "I've talked with people who've become wonderful parents, who've become doctors and lawyers, and who run corporations. Nobody else but you can determine the course of your recovery."

Other consumers who are self-advocates and peer advocates echo Copeland's sentiment that by believing in themselves, consumers can unlock their potential. Andrea Stephenson, a consumer who offers advocacy training in Washington State, says that it "involves helping people to realize their own strengths." By teaching consumers about advocacy, she's learned that, "It didn't matter what level people were at in their recovery, everyone had skills within themselves."

Consumers who have gotten involved in self-advocacy also agree that once you become involved in advocacy, the rewards multiply. Success serves to further bolster your self-esteem. Says Copeland, "The more we reach out and get what we need, the better we feel about ourselves. As our symptoms are relieved, we feel better, but also when we get what we need, we feel better about ourselves."

Howard Trachtman, a self-advocate and peer advocate from Massachusetts, agrees. “I like challenges,” he says, “and when I feel like I’ve mastered something, I can move on to something else.” He notices that being able to achieve advocacy goals also helps other consumers. “For the purpose of empowerment, it’s best that people do as much as they can to the best of their ability,” he continues.

Keep in mind that although self-advocacy means taking responsibility for getting what you want, it doesn’t mean that you have to be alone: you shouldn’t ignore your existing support systems. In her Texas training sessions, Janet Paleo stresses the importance of peer support. Self-help groups can help you deal with uncomfortable situations that you might encounter in your self-advocacy efforts. If you’d like to locate self-help groups in your area or start one of your own, contact the Clearinghouse and we can assist you.

Being assertive

Once you begin to believe in yourself, you will find yourself becoming more assertive. While self-esteem is internal, assertiveness shapes the way we deal with others. It is an important skill for consumers to learn, because for some of us, a lack of assertiveness is a primary obstacle to obtaining the services that we want and need. Teaching assertiveness strategies is a key component of the Freedom Self-Advocacy curriculum.

“When someone is struggling with a psychiatric disability, the idea of standing up to the system is scary,” says Clearinghouse executive director Joseph Rogers. To learn more assertive behaviors, we must learn why we are not assertive. For some of us, the moods we experience such as depression or anxiety might make us less willing to stand up for ourselves. Some of us might fear reprisals such as revocation of benefits or other punitive measures.

Rather than allowing these emotions or fears to translate into procrastination or silence, many consumers have learned to overcome these obstacles to become assertive self-advocates. Rogers suggest that for many people, “The first step might be simply asking, ‘Why?’ It’s a three-letter word that can make a huge difference. When conditions aren’t what they should be, it’s often a result of inertia.” When consumers disrupt this inertia by asking “why,” Rogers says, “A lot can happen when things are set in motion.”

Mary Ellen Copeland says that she’s found that she can use rewards to make herself more assertive. She suggests that if you have to make a difficult phone call, for example, you can set up a reward (such as something you like to eat) to give yourself after you make the call. “Self-advocacy is hard work, and you deserve a reward,” she says.

You don’t have to rely solely on yourself: you can become a much more effective self-advocate by working with other people to improve your assertiveness skills. “Assertiveness is really more than an attitude, it’s a skill,” says Rogers. “You don’t need ‘assertive genes,’ you just need to practice the skill and move on to the next level.” Many

counselors specialize in assertiveness training, and joining a self-help group is another good way to work on your assertiveness skills in a supportive setting.

The motto of the Clearinghouse states, “Knowledge is the key to open new doors,” and building your knowledge of rights and entitlements is perhaps the best way to make yourself more assertive. If you know the facts and policies underlying decisions affecting you, then you can more assertively advocate for favorable results.

Don Roberts, a consumer who advocates for himself in Kodiak, Alaska, reports that he uses public legislative information centers (similar to law libraries) to do research about his mental health rights. His knowledge allows him to be a much more effective self-advocate. “Because I’ve demonstrated that I am able to find information and go to the next level, the staff of the local community mental health center make an extra effort to meet my requests if they seem reasonable.”

An old adage says, “The squeaky wheel gets the grease.” People are more likely to respond to you if they fear that you might cause them trouble in the future. Self-advocacy requires persistence but offers great rewards. As Copeland says, “The people who advocate for themselves are the ones who achieve the highest level of recovery.” In later sections of this Technical Assistance Guide, we’ll examine how to be assertive when using the phone, meeting in person, and writing letters.

Managing your anger

Remember that assertiveness is *not* the same thing as aggression: you should be a persistent and tireless advocate for yourself, but you should not shout at or insult others in the process. As Andrea Stephenson explains, “Assertiveness is being able to say what you need to say in a respectful and dignified manner.”

When we perceive something as an injustice, our anger can be an asset if we use it to motivate ourselves to engage in self-advocacy. However, we must be careful not to let our anger become a liability for us. If you don’t let your anger transform into shouting or character attacks, then the other people involved won’t be able to use your behavior as an excuse for denying what you want.

Sometimes, you must teach yourself tricks to control your anger. Mary Ellen Copeland suggests that one way to keep your anger in check during a meeting is to “go home and pound pillows” after a meeting. Although learning to control your anger might take hard work, doing so will make you a much more effective advocate. Some of the resources listed at the end of this guide contain helpful exercises in anger management.

Having a good support system in place is another way to work on controlling your anger. Just being able to talk with supportive people might help you diffuse some of your anger before you make any decisions that you’ll later regret. A self-help group is also an excellent way to work on your anger management: others in your group likely will have the same goal.

Problem solving strategies

With the right attitude, you can be an effective self-advocate, but you also need to develop a plan for handling the obstacles that you encounter. As you learn to surmount these obstacles, you'll find that you develop certain skills that make problem solving easier.

Educating yourself

A common sentiment among mental health consumers is that each of us has gotten an education at the "School of Hard Knocks." There's some truth to this, but consumers who make extra efforts to educate themselves can become much more effective self-advocates.

Take every opportunity to educate yourself—don't wait for a problem to arise. Take advantage of educational programs at consumer-run services and special events. "State, regional, and national meetings," says Clearinghouse program director Marie Verna, "are great opportunities for learning from other consumers and from professional advocates. We post a list of conferences on our web site, and you can also contact the Clearinghouse for information about conferences near you."

You should also prepare yourself by creating your own resource library. Ask your doctor, therapist, or health plan for information about diagnoses, treatments, and medications; often, they have free informational brochures to give you. Table 1 lists some other sources for free or low-cost publications for consumers.

Mary Ellen Copeland says that you must form your own opinions and develop your own goals. "You really need to educate yourself," she says. "Read every viewpoint from conservative to radical and then decide *for yourself* what you can or can't do."

Verna also urges you to contact the Clearinghouse if you are looking for information on a particular topic. "Ever since its beginnings, the Clearinghouse has maintained an extensive library of mental health information, especially information that is useful in advocacy efforts. People can call, write, or e-mail us and get information on dozens of topics," she said. Some of the many topics on which the Clearinghouse can provide information are listed in Table 2.

Table 1. Sources of Publications for Consumers	
National Mental Health Consumers' Self-Help Clearinghouse	http://www.mhselfhelp.org (800) 553-4539
National Association of Protection and Advocacy Systems (NAPAS), as well as your state's P & A organization	http://www.protectionandadvocacy.com (202) 408-9514
National Mental Health Association (NMHA)	http://www.nmha.org (800) 969-6642
Center for Mental Health Services	http://www.mentalhealth.org (800) 789-2647
Social Security Administration	http://www.ssa.gov (410) 965-0945
President's Commission on the Employment of People with Disabilities	http://www.pcepd.gov (202) 376-6200
Equal Employment Opportunity Commission	http://www.eeoc.gov (800) 669-4000

Table 2. Selected Topics in the Clearinghouse Library	
Abuse of Patients	Adolescent Issues
Advance Directives	Americans with Disabilities Act
Case Management	Children's Issues
Co-dependency	Commitment
Community Based Services	Community Organizing
Confidentiality/Privacy	Consumer Movement
Consumer-Run Services	Crime
Cultural Diversity / Minorities	Deinstitutionalization
Diagnosis Information	Drop-In Centers
Electro Convulsive Therapy (ECT)	Elderly Issues
Employment	Family Issues
Fundraising	Gay / Lesbian Issues
Housing & Homelessness	Informed Consent
Insurance Reform	Involuntary Treatment
Legal Issues / Policy / Legislation	Mental Health/Illness (General)
Mental Health Care Reform	Patients Rights
Peer Counseling	Physical Disabilities & Mental Health
Protection & Advocacy	Provider training
Psychiatric drugs	Psychosocial Rehabilitation
Recovery	Self-Help Services
Sexual Abuse / Harassment	SSI/SSDI
Starting a Self-Help Group	Stigma / Discrimination
Substance Abuse	Using the Media
Vocational & Educational Support	Women and Mental Health

In addition to building your own resource library, you should prepare a list of contacts so that you'll know where to go if you ever need help. Useful phone numbers to have on hand might include protection and advocacy (P & A) organizations, state departments of mental health, consumer groups, drop-in centers, and Social Security offices.

Rather than preparing your own contact list, you can use the *Advocacy and Government Contacts Booklet*. The Clearinghouse developed this publication in conjunction with the Freedom Self-Advocacy program, and it is distributed at every Freedom workshop. If you haven't attended a workshop and would like a copy, please contact the Clearinghouse or visit our web site.

Today, the Internet has emerged as a powerful tool for finding the information that you need to know. On the worldwide web, you can find the web sites of organizations that provide information, as well as the agencies that you'll need to contact to achieve your advocacy goals. Using tools such as e-mail lists and newsgroups, you can seek advice from people who have been in the same type of situations that you face.

If you don't have access to the Internet at home, try a local library, many of which now offer Internet access. You can learn more about using the Internet for self-advocacy by consulting the Clearinghouse Technical Assistance Guide, *Advocacy and Recovery Using the Internet*. If you need help learning how to use the Internet, you can ask a librarian for help. Additionally, many consumer-run organizations now offer both Internet access and training.

Identifying your rights

In the United States, we all have rights as citizens. As consumers, however, we have often been led to believe that we don't have rights or should be afraid to exercise them. Mary Ellen Copeland, who has lectured throughout the nation about her own recovery, tells a powerful story about a visit to Mississippi. "I spoke to a group of about 500 people, who were all dressed in matching uniforms depending on the facility that they were from. They had to ask for permission to go to the restroom. I couldn't believe it."

As Copeland spoke to the group, she began to spell out the rights that everyone has when he or she is in a psychiatric facility. At first, the crowd seemed to be in disbelief, but then they began to stand and cheer. After being led to believe that they had checked their rights at the hospital door, they realized that they had the right to stand up for themselves. Copeland uses a "Personal Bill of Rights" (included in Table 3) in her "Dealing with and Recovering from Psychiatric Symptoms" training sessions.

Table 3. "Personal Bill of Rights"

1. I have the right to ask for what I want.
2. I have the right to say no to request or demands I can't meet.
3. I have the right to change my mind.
4. I have the right to make mistakes and not have to be perfect.
5. I have the right to follow my own values and standards.
6. I have the right to express all my feelings, both positive and negative.
7. I have the right to say no to anything when I feel I am not ready, it is unsafe, or it violates my values.
8. I have the right to determine my own priorities.
9. I have the right not to be responsible for others' behavior, actions, feelings, or problems.
10. I have the right to expect honesty from others.
11. I have the right to be angry at someone I love.
12. I have the right to be uniquely myself.
13. I have the right to feel scared and say, "I'm afraid."
14. I have the right to say, "I don't know."
15. I have the right not to give excuses or reasons for my behavior.
16. I have the right to make decisions based on my own feelings.
17. I have the right to my own needs for personal space and time.
18. I have the right to be playful and frivolous.
19. I have the right to be healthier than those around me.
20. I have the right to be in a non-abusive environment.
21. I have the right to make friends and be comfortable around people.
22. I have the right to change and grow.
23. I have the right to have my needs and wants respected by others.
24. I have the right to be treated with dignity and respect.
25. I have the right to be happy.

This list of rights could perhaps best be classified as "natural rights," which might or might not be spelled out by any particular law, but nonetheless exist for everyone. "The people who wrote the Declaration of Independence asserted the rights of life, liberty, and the pursuit of happiness," says Marie Verna, "and on the most basic level, as consumers, we too should assert these rights because they are rights that we have as citizens."

As a consumer of mental health services, you also have more specific rights spelled out by local and state laws. "Many of your fellow consumers are working to reform the system so that consumers will have more rights and better services," says Joseph Rogers. "To take advantage of the rights and services that these people have fought for, you must learn to demand them," he continues.

Many states have a "bill of rights" for consumers, and in some states, each individual facility is required to develop its own bill of rights. At Freedom Self-Advocacy workshops, the workshop leaders present information about states laws and policies.

Another good way to educate yourself about the rights you have under local or state law is to contact your state's P & A agency.

You also have many rights under federal law. The Clearinghouse can provide you with information about your rights at the national level. Verna says, "We get many calls from people who want to know more about their rights. Our library is filled with information on rights issues." Some important rights guaranteed by federal laws and regulations include:

- The right to employment without discrimination based on disability, under the Americans with Disabilities Act.
- The right to public services without discrimination based on disability, under the Americans with Disabilities Act.
- The right to seek housing without discrimination based on disability, under the Fair Housing Amendments Act.
- The right to financial support (as determined by various Social Security laws and regulations).
- The right to healthcare (as determined by Medicaid or Medicare laws and regulations).
- The right to employment supports, under the Rehabilitation Act and the Work Incentives Improvement Act.

Breaking down the problem

Sometimes, our problems seem overwhelming: Have you ever replied "everything" when someone asked you what was wrong? When you feel overwhelmed by a problem, you should try to break it down into smaller "chunks" so that you can more effectively plan your strategy.

Say, for example, that you have been attending a job training program, but you have been arriving late because you can't wake up on time. The director of the program has told you that if you can't show up on time, you will be kicked out. You have told your doctor that your medication is making you sleepy, but your doctor is unwilling to change your medication.

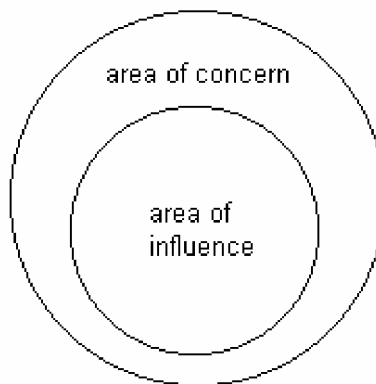
In that example, you could break down the problem into smaller problems:

- § You are sleepy because of the medication;
- § You have been arriving late to your training program;
- § You have been threatened with being kicked out of the training program; and
- § Your doctor won't change your medications.

By breaking a problem down into smaller segments, you have greater insight into what steps to take. In the above example, you might find that parts of the problem are easier to deal with than others are. Depending on the circumstances, it might be better to see whether you can transfer to a training program that doesn't begin quite so early; on the other hand, it might be better to think ways of ways to convince your doctor that you need to switch medications.

By deciding which parts of the problem you can most easily solve, you can save yourself time and effort. "Not all problems can be solved," says Brian Cooper, director of consumer advocacy at the National Mental Health Association. "You have to ask yourself two questions, 'Which problems matter most?' and 'Which problems have a chance of being solved?'"

Cooper uses an example created by author Stephen Covey: Picture two circles, one inside the other. The inner circle is your "area of influence" and the larger outer circle is your "area of concern." The point is that you need to analyze whether something that is bothering you is something that you can do something about. If not, you should concentrate on the things that you *can* change.



Based on *The Seven Habits of Highly Effective People*, by Stephen Covey, 1990.

In the job training example, you might decide that both the prospect of being kicked out of the program and your doctor refusing to change your medications are in your area of concern. However, you might find that your area of influence includes your doctor's actions, but not the training program's attendance policies. If so, then you would proceed by working to change your doctor's decision regarding your medications. In other words, says Clearinghouse executive director Joseph Rogers, "You've got to pick your battles."

Developing a solution

After you've figured out what your rights are and have broken down the problem, then you're ready to look for a solution. An old adage says that each problem has a unique

solution. Nevertheless, by using a systematic approach, you'll do a much better job at finding the solution that fits your problem.

Preliminary steps

The first step in developing your desired solution is to determine what *you* want to happen. While consulting other people is extremely helpful here, you must make up your own mind, rather than relying exclusively on suggested strategies or predicted outcomes. "Ask yourself what you need," says Jo Halberstadter, director of advocacy services for the Mental Health Association of Southeastern Pennsylvania. "Do you have emotional needs, such as an apology, or do you need something concrete?"

In researching your rights, you might have learned some of the possible solutions that are available. For example, if your advance directive is ignored, your state's law might allow you to sue for money damages in court. However, *you* might be more satisfied with an apology and the hospital's promise of future compliance than you would be with the expense and time of a trial that might not be successful.

In determining what you want to happen, you should definitely consult with other people. Ask questions and find out whether others have faced the same problem, and what happened in their cases. However, ultimately it is *you* who must decide what *you* want to get out of *your* self-advocacy efforts.

Often, you'll be able to score a partial victory even if you don't obtain your ideal solution. Ask yourself in advance what alternatives you would be willing to accept. This will help determine the course of your self-advocacy efforts. For example, say that at your job, you make a request for an adjustment in working conditions (such as a later starting time).

If, in this example, your supervisor says "no," then a lawyer might tell you that the Americans with Disabilities Act entitles you to such an adjustment in working conditions. (You are entitled to a "reasonable accommodation" if you can prove you need it as a result of your disability, and it won't harm your employer too much.) However, a lawsuit might not be worth your time or money; perhaps you'd be willing to accept a transfer to another supervisor instead.

After determining what you want to happen, you must identify which people you'll need to contact in resolving your situation. Try to follow the established "supervisory ladder": if you take your problem "straight to the top," then you run the risk that the person will say "no," and you'll be left with no recourse.

However, you should keep your eye open for potential allies who might be able to help you with your problem. Don Roberts, a self-advocate from Alaska says, "When I come up to a brick wall, I don't beat my head up against it. There may be allies on the other side of the wall, and even though you might not be able to break through, they might be

able to do some damage on the other side of the wall.” After realizing that nobody at the local community health center was willing to help him, he began looking for allies in the state department of mental health.

Building your case

Having decided what you want and whom to contact, you can begin building your case. Ask yourself about the strengths of your side of the story: Do you have legal rights that have been violated? Has an established policy or procedure been ignored to your detriment?

You should also ask yourself what the other side has to gain by resolving the problem in your favor. Sometimes, the other side might want to avoid negative publicity or complaints to supervisors, and sometimes—if you are persistent enough with your efforts—the other side might decide to give you what you want rather than continue to hear from you. When dealing with managed care companies, you might choose to show how something you want might save them money, compared to the hospitalizations that might result if you receive substandard care.

Perhaps the most important part of building your case is assembling all of the documentation that you’ll need as you proceed with your self-advocacy efforts. Although the relevant documentation will vary from situation to situation, you should always keep copies of any document concerning health care, insurance, benefits, or anything else involving money.

Examples of important documents might include:

- § letters of support from doctors, therapists, or case managers;
- § photocopies of laws or regulations;
- § insurance policies; or
- § pay stubs.

Remember that as you build your case, you *must* be completely accurate with all of your facts and claims. Mistakes or misrepresentations often provide an excuse for people to deny you what you want.

As you build your case, you also must look at the other side of the argument. Why is the other side acting the way that it is acting? Is there a rule or policy that they are following? Being able to acknowledge the other side’s viewpoint as you advocate for yourself shows that you appreciate the other side’s needs, and this will help you maintain relationships. As Massachusetts advocate Howard Trachtman says, “In many cases, you’ll continue to deal with an agency [regarding other matters], so you can learn the tricks to dealing with them in the future.”

Planning your strategy

There are usually a variety of ways to approach any given problem. Sometimes, there is an established procedure for resolving a problem, such as filing a particular form, but often you'll find that you need to "buck the system" to see results.

You don't need to plan your strategy alone. Joseph Rogers recommends that a "reality-check group" can help you plan your strategy. "We all need checks and balances," he says, "or you run the risk of losing perspective. You might think that you have your case well constructed, but talking to others can help you identify and improve upon weaknesses."

Consulting with others can help you plan more effectively. Becky Smith, a consumer who also is an advocate for Tennessee's P & A system, says, "If I'm too emotionally attached, I'll ask for outside help. I might need someone to be more objective."

You should also spend some time reflecting on what you plan to do before you do it. Jo Halberstadter, director of adult advocacy services for the Mental Health Association of Southeastern Pennsylvania, says, "Before you make your first contact, sit back and think. Don't just act impulsively."

"Plan how you are going to phrase your words when you talk to someone," she continues. "Develop a concise story about what you need. Take out the parts of the story that may have been emotional for you, but might not be relevant to the resolution of the problem."

When planning your problem-solving strategy, you should take into account the various methods that might be at your disposal, including:

- § Making phone calls;
- § Holding an informal meeting;
- § Writing a letter of complaint;
- § Filing a formal complaint.

You can use the Sample Action Plan as your guide.

Sample Action Plan

Problem: _____

I will call/meet with/write to _____ by the following date: _____

If this person does not resolve the situation by the following date, _____, then I will call/meet with write to _____.

Documentation that I will need:

Other people who can help me:

Follow-up strategies:

What I expect the other side to do:

Advocacy on the telephone

We all know how to use the telephone, but we can learn to use it more effectively as a tool for getting what we want. Many people—understandably—lose patience when dealing with large bureaucracies such as insurance companies or government agencies: more and more, callers must navigate automated menus before reaching a live person. Some people have feelings of fear or anxiety when making phone calls. However, we all can work to improve our telephone skills.

Phone manners/managing anger

Resolving a problem by phone is oftentimes the quickest and most straightforward way to resolve a problem. However, the process still takes some time and causes some frustration. If you are able to control your anger at the delays and frustrations that you experience, then you'll be a much more effective advocate for yourself.

Using the telephone for self-advocacy is fairly common when dealing with managed care organizations (MCOs), insurance companies, hospitals, community mental health centers, and government agencies. With all of these different organizations, your first point of contact will often be one of those pre-recorded phone menus that asks you to press keys to be connected to the right department. When you finally do reach a live voice, it is often a low-level employee who might not have the authority to resolve your request.

Certainly, this is frustrating. Say for example, your MCO denies your request to see a certain doctor, or your benefit check is reduced without explanation. Your first inclination might be to scream at the first person you talk to—anger is natural. However, your ability to handle this anger might have an impact on how well (or poorly) the organization resolves your problem.

Of course, you should express your concern, but there's no need for name calling or shouting at the person on the other end. Also, the person will probably absorb the information better and be able to resolve the situation more efficiently if he or she doesn't feel under attack. Mary Ellen Copeland cautions, "Don't say anything attacking the other person's character." Instead, concentrate on explaining why you need the person to act.

Keep in mind that the person on the other end of the phone is just that—a person. He or she has good days and bad days just like you and looks forward to pleasant calls more than unpleasant ones. If it is the case that your problem was caused by an innocent mistake—a computer error for example—the employee might be much more helpful and make it a higher priority if you are pleasant on the phone.

By managing your anger, you can avoid developing a reputation as a "difficult caller." Most of the organizations that you deal with keep records that phone personnel access

when you call them. By avoiding being labeled obnoxious or insulting, you are likely to get better service on future calls.

If you experience a problem that makes you very angry, how can you prevent the anger from boiling over into the phone conversation? The easiest way might be to take some time to cool off; Mary Ellen Copeland recommends that you do a relaxation exercise before making a stressful phone call. She also has a unique suggestion for managing your anger while you're on the telephone: "Have a friend with you when you make the call, that way you can make faces with your friend but remain calm on the phone."

Before making your call, you can also take time to plan what you are going to say, and gather the information that you might need. For example, it is common for someone to receive a hospital bill for services that were supposed to be covered by insurance; these situations are often caused by paperwork errors. If this happens to you, your first inclination might be to call the hospital or the insurance company and yell at someone.

Instead of doing so, take some time to calm down, gather the bill, your insurance policy, and the paperwork you received at the hospital. Then call your insurance company and find out why the bill wasn't paid. With this information, you are more likely to be able to calmly, but assertively resolve the situation. Let's now look at how to use the phone assertively.

Being assertive

A big part of assertiveness when using the phone is being persistent enough to get in touch with someone who can help you. When calling large organizations, it's not always easy to reach live people, says Brian Cooper, but one alternative is to "call them once a day until they realize that you won't stop calling until they resolve the situation." If you're having trouble reaching someone, you should leave a message each time, including the dates and times that you are available to speak.

Your assertiveness must continue once you are speaking with a live person. Learning to be assertive without raising your voice or being rude is a skill to be learned, and one that will make you a much more effective advocate. We discussed assertiveness generally in *Attitudes necessary for self-advocacy*, but now let's look at specific ways to be assertive on the telephone.

- *Do your research.* If you are told that you cannot do something or qualify for certain benefits, you should know the standards. For example, you might say, "My insurance policy says that I have the right to appeal this decision, and I would like to appeal."
- *Set minimum standards.* Often, you will be dealing with low-level employees who do not have the power to compromise; therefore, if anyone compromises, it will have to be you. If a low-level employee cannot meet your minimum demands, ask to speak to his or her supervisor.

- *Recognize the other side of the argument.* If you demonstrate that you understand the other person’s point of view, then he or she cannot dismiss you as being irrational. You might say, for example, “I can see why you don’t normally authorize that medication because it is more expensive. But it’s worked for me in the past, and it is cheaper than paying for my hospital bills.”
- *Ask for clarification.* Don’t let the other person confuse you with jargon or vague statements. Whenever the other person says something that you don’t understand, ask for clarification. You can’t win a dispute if you don’t understand what the other person is saying.
- *Leave the door open.* State that you would like to reserve the right to submit additional information. If you become flustered on the phone, you can strengthen your case later.

Table 4 contains some more examples of assertive responses. These are just a few examples of the statements that you can make to assert yourself. One effective way to work on your assertiveness is to role-play advocacy situations with a friend. Ask your friend to give you feedback about whether you were acting assertively. Role-plays are an important component of Freedom Self-Advocacy Workshops.

Table 4. Assertive Responses	
Statement	Assertive Response
<i>Insurance company customer service representative:</i> “I’m not the person who deals with this.”	“Tell me the name and number of that person. I called the number listed in my policy, and if you can’t help me, it’s your responsibility to tell me who can.”
<i>Social security representative:</i> “I don’t have all of the information about your application, so I can’t answer that question.”	“When can I expect to hear back from you? I will call back if I don’t hear from you by then.”
<i>MCO executive assistant:</i> “I don’t think that there are any openings on the advisory board right now.”	“I was told that there are no consumers on the advisory board, and the law says that there must be consumer representation. Who is in charge of the selection?”
<i>MCO customer service representative:</i> “We can’t pay for the treatment because it is not medically necessary.”	“I would like you to send me an explanation of how you determine whether a treatment is medically necessary.”

Talking to the right person

As we mentioned in the previous section, when you're talking to someone on the phone, it is often someone who won't be able to resolve your situation for you due to lack of authority. Other times, the person on the other end of the line just happens to be a generally unhelpful person.

Author Brandon Toropov offers many helpful suggestions for resolving a problem by phone. His book, *The Complete Idiot's Guide to Getting along with Difficult People* (don't be put off by the sarcastic title), recommends that you seek a new contact person if the person with whom you've dealt:

- § is new to the job, based on what the person has said or your best guess;
- § has not gotten in touch with you after you've left three messages;
- § has told you three times that he or she must appeal to a supervisor for information or authority, without results;
- § hesitates before answering important questions;
- § asks you to supply the same information or file the same forms more than once; or
- § is defensive, moody, or combative without being provoked by you.

When you're not getting anywhere by talking to lower-level employees, you might need to "go up the supervisory ladder." Advocate Howard Trachtman says that he recommends the "judicious" use of appeals to supervisors, especially in cases when it's your first point of contact with an agency. Going to a supervisor before you've given someone a fair chance to resolve your problem can create bad feelings, and you can always go to a supervisor later.

If someone fails to resolve a problem to your satisfaction, then you should go up the supervisory ladder, one level at a time. In other words, always ask to speak with someone's immediate supervisor.

Some advocates recommend going straight to the top of the supervisory ladder, but there is an obvious advantage to moving one level at a time: you give more people the opportunity to give you what you want. If, on the other hand, you go straight to the top, and that person says "no," you probably won't get what you're after.

Keeping records

With any form of self-advocacy, it is important to keep records, but it is especially important to keep accurate and complete records of your telephone conversations. Often, your records will be the best documentation of your attempts to resolve a situation or another party's suggested solutions.

You should keep an accurate record of every person with whom you spoke, as well as their titles and what they said. Sometimes, it will strengthen your position if you can

demonstrate that the other party was unhelpful, and so you should also document every time that you couldn't get through to someone on the phone, as well as when you left messages for a person. Doing so will prevent someone from saying that your inactivity is the cause of the problem. You can use the Sample Phone Log as your guide.

Sample Phone Log

<u>Outgoing Phone Log</u>	<u>Incoming Phone Log</u>
Date: Number called: Person called: Referred by: Was call answered? Left message? Person spoken with: Title: Fax number: Summary of conversation: Action suggested: Action agreed upon? Deadline:	Date: Person Calling: Title: Phone Number: Fax Number: Summary of conversation: Action suggested: Action agreed upon? Deadline:

Following up

As with any form of advocacy, it is important to follow up when you are advocating by phone. The follow-up usually includes additional phone calls to ensure that agreed-upon actions will be taken, but might also include supplying written documentation or sending follow-up letters or faxes.

Following up on a phone conversation should begin during the conversation itself. For example, if the person with whom you are speaking cannot respond to your request immediately, you should ask when they will get back to you *and* the date on which you can expect action on what you've requested. If the person promises to take a specific

action, then ask when that action will be taken. Be sure to record this information in your phone log.

Once you've established dates for responses and/or action, you should make sure that the person sticks to those dates. You can mark a calendar to keep track of the dates. If you haven't heard back or seen results by the agreed-upon date, you should call back.

Be polite but firm. Remind the person that he or she promised to respond or take action by a certain date and ask why this hasn't happened. You should persist until you get what you want, and if you don't see results, then you should proceed up the supervisory ladder one level at a time.

Usually people are handling multiple requests at a time, and one way to ensure that your request gets special attention is to follow a phone call with a fax. When speaking with someone, ask for the fax number where he or she can be reached. After speaking with a person, send a fax summarizing the action requested and the agreed-upon follow-up dates.

If the person does not seem to be responding adequately, then a fax can be an especially effective tool. Obtain the name of the person's supervisor, and send the fax both to the person with whom you've spoken and his or her supervisor. At the bottom of the fax, write "cc:" followed by the supervisor's name so that the employee knows that the supervisor has also seen the fax. We'll examine written communications more closely in the next section, *Advocacy in writing*.

Advocacy in writing

Being able to write a short, direct, and assertive letter will aid your advocacy efforts. Learning to write letters is a skill that must be learned, but fortunately it is easier to learn than almost any other style of writing. And the good news is that, as a general rule, the shorter your letter, the better. In this section, we'll discuss how to write an effective letter, as well as provide some sample letters.

Keep in mind that every letter you write should become a part of your files on the matter in question. In *Advocacy on the telephone*, we stressed the importance of keeping detailed records of phone conversations. Keeping records of your letters is easier, but equally important, so be sure to keep a photocopy of each letter.

The format of a business letter

When you write a letter for advocacy purposes, you should follow the standard format for business letters. Although there is some variation in the format used for business letters, Sample Letters A and B provide a good model to follow. Include your return address, the date, the other person's address, greeting, and signature in a manner similar to that in the sample letters.

Another feature to note is the "cc:" (copies circulated) line. Says Janet Paleo, "When you're writing a letter to someone, 'cc' it to someone who is that person's boss or peer, because if you send a letter that's not cc'd to someone, then it's easier for the person to put your letter aside. If it *is* cc'd to someone important, then the recipient will give it a lot more credence."

However, keep in mind that cc'ing someone's supervisor puts that person on the defensive. It can therefore be counter-productive to cc a person's supervisor before you've given the person a chance to resolve the problem. Says Jo Halberstadter, "When you cc someone right off the bat, it shows anger. You have to decide whether expressing anger at such an early stage will end up hurting you."

Below the "cc" line is the "Encl." (enclosures) line. To show the recipient what you've sent, and to remind yourself when you look at a photocopy of the letter, use the "Encl." notation and a brief description of what you've sent.

Although the standard business letter is typewritten, it is acceptable to hand-write a letter if you cannot type your letter or find someone else to type it for you. Try to write as neatly as possible, and again, be sure to keep a photocopy.

The content of the letter

The *Sample Letters* included here also provide an idea of what to include in your letter. People who attend the Freedom Self-Advocacy workshops have the opportunity to

practice their letter-writing skills, and some useful books are listed in the *Resources* section of this guide. When you write a letter, you should:

- Open by explaining to the recipient why you are writing. For example, in Sample Letter B, the writer wants his insurance company to pay a hospital bill.
- Include photocopies of relevant documents or offer to provide whatever documentation is necessary. In Sample Letter A, the writer offers to provide documentation from her health care professional, and in Sample Letter B, the writer includes a copy of the hospital bill.
- Explain the reason why you are asking for action by the recipient. The writer of Sample Letter A explains that the Fair Housing Amendments Act requires that landlords make “reasonable accommodations” for tenants with disabilities. In Sample Letter B, the writer explains that he had obtained a referral for the services; therefore, the insurer should pay for them.
- If the action needed is urgent, explain why. In Sample Letter B, the writer is facing a negative credit report if the problem is not solved swiftly.
- If applicable, summarize steps that you have taken to resolve the problem. In Sample Letter B, the writer summarizes phone conversations and documents times that he tried to reach the insurance company.
- If you are considering legal action or a formal complaint, note that you are considering it. However, reserve this tactic for situations in which you feel that you have a valid case and could follow through; otherwise, the other party could call your bluff.
- In the closing paragraph, give a time by which you expect the recipient to respond or take action. This should be a reasonable amount of time in relationship to the urgency of the situation.
- Also in the closing paragraph, thank the recipient, or if the recipient has not proven helpful so far, then express your hope that they will resolve the matter as soon as possible.

Other considerations

As you grow as a self-advocate, you will feel more comfortable writing letters, and you'll learn what works and what doesn't work. Here are some other things to think about when writing letters as a part of your advocacy efforts:

- When writing your letter, pay special attention to your tone. Put yourself in the place of the writer of Sample Letter A: although she was probably angry at the insurance company's broken promise, she is not rude or insulting. She simply states why the recipient has done wrong and explains what the insurance company should do in order to rectify it. By not antagonizing or insulting the recipient of the letter, you reinforce that you are in the right and that your request should be granted.
- For a few extra dollars, you can send a letter via certified mail, return receipt requested. Not only will this make your letter stand out to the recipient, you'll know exactly when the letter arrived. Depending on the severity or urgency of the situation, you might also consider faxing your letter or using express delivery.
- You shouldn't hesitate to ask friends for help in writing letters. You can rely on friends to help with the writing and to check your letters for errors in spelling or grammar. "Having someone else to be supportive and objective can help make the letter less antagonistic," says Brian Cooper, director of consumer advocacy at the National Mental Health Association.

Once source of assistance in writing a letter might be your state's P & A system. According to Cooper, "When I was working in the P & A system, the service requested of us was writing a letter for a consumer. I usually asked the person to try writing the letter, and then we would go over it together. Helping the person write the letter took more time than simply writing the letter for the person, but letter writing is an important skill for consumers to learn."

Sample letters

Sample Letter A

Elizabeth Martin
127 Maple St.
Apartment 105
Yorktown, MD 22038

April 1, 200-

Mr. Edward Peters
Peters Property Management
13 E. Main St.
Yorktown, MD 22038

Dear Mr. Peters:

I am a tenant in your building at 127 Maple Street. I am writing to request, as a reasonable accommodation required by the Fair Housing Amendments Act (FHAA), that I be allowed to keep a service dog in my apartment. The FHHA requires that landlords provide “reasonable accommodations” to tenants with disabilities.

I understand that the building has a “no pets” policy, however, health care professionals have recommended that I use a service animal for emotional support. I would be happy to provide written documentation of my disability and my providers’ recommendations.

Please contact me within ten days to let me know whether my request has been granted because I need to proceed with finding a suitable service dog. You may reach me by telephone at (410) 555-2525. Thank you for your prompt consideration of my request.

Sincerely,

Elizabeth Martin

Sample Letter B

Steven Jones
14 Broad Street
Springfield, CT 04567

January 2, 200-

Mr. Evan Brown
Claims Services Representative
Acme Insurance Company
2121 Lincoln Ave.
Brookwood, CT 04848

Dear Mr. Brown:

I am writing to request the immediate payment of the enclosed hospital bill, for services provided on October 12. As you can see, the hospital is threatening to refer my account to a collection agency, and I am very upset that Acme Insurance has not paid this claim. I am considering referring this matter to the state insurance commissioner.

I had received a referral for the services in question. The referral number is BB 9854. Therefore, Acme should have paid this claim. When I spoke with you on the phone on November 20, you assured me that the bill would be paid within 10 days. After that time passed, I have been trying unsuccessfully to reach your department. I left messages on December 5, 10, 13, 15, and 19.

Please respond within five days of receipt of this letter. You can reach me by phone at (203) 555-2828. I am looking forward to the prompt resolution of this matter.

Sincerely,

Steven Jones

cc: April Jackson,
President, Acme Insurance

Encl: Hospital bill (photocopy)

Advocacy in person

For some forms of self-advocacy, such as participating in your own health care decisions, in-person advocacy is only natural. Mary Ellen Copeland says that meeting face-to-face with the person you're trying to influence is the most effective form of self-advocacy. By working to improve your in-person advocacy skills, you can help overcome the anxiety that many people experience when preparing for a meeting.

Preparing for a meeting

Preparing in advance of a meeting not only helps to reduce anxiety, but preparation also helps you to become a much more effective self-advocate. Perhaps the first step in preparing for a meeting is writing down the appointment as soon as you've made it.

Although recording an appointment is a simple step, it is an extremely important one because it helps you keep the appointment. "Once you've scheduled a meeting, you have to write it down and keep it," says Howard Trachtman. "The person you're meeting with has other commitments," he continues, and if you don't keep your appointments, then the person "is going to spend more time with the people who *are* keeping their appointments and following through. That's just how it works."

If you absolutely cannot make a scheduled appointment, call in advance to cancel or reschedule it. Try to give the other person as much notice as possible; you shouldn't cancel a meeting on the same day unless it is a sudden, unanticipated emergency.

At the time you schedule your meeting, you should also ask for information that will help you prepare. Always ask if there is any type of documentation that you will need to bring to your meeting. Ask if you must meet certain qualifications in order to get what you're asking for. If the other party initiated the meeting, make sure that you understand the purpose of the meeting completely.

Another important step for planning a meeting at which you will advocate for yourself is to find a friend who can come with you. Although it helps to pick someone who knows something about advocacy, it's not necessary to do so. "Don't go in alone," says Brian Cooper, "because the presence of another person will make the people you're meeting with behave."

Mary Ellen Copeland agrees, saying, "With doctors and professionals, you often have to take someone else with you. They act differently, even if your friend doesn't say anything. It's still self-advocacy because you're in control. It's a way to get around the system."

Another important part of preparing for a meeting is to think hard about what could happen at the meeting. Trachtman suggests that you ask yourself the following questions:

- § What do I want to happen at the meeting?
- § What do I want to learn at the meeting?
- § What could happen as a result of the meeting?

By knowing what you want to happen, but preparing yourself for what could happen, you can better think through your strategy for the meeting. You should prepare an agenda for what you'd like to say, what you'd like to ask the other person, and how you would respond to the other party's suggestions of what they'd like to happen.

In addition to bringing your agenda with you, you should bring photocopies of all relevant documents (unless the other party says that you need to bring an original). Also, if you will be citing particular laws or regulations, you should bring photocopies of those as well. Says Alaska self-advocate Don Roberts, "Don't just say, 'There's a law somewhere.' A photocopy gives people a chance to look at the law." By demonstrating that you know your rights, it makes it much more difficult for the other person to ignore your rights.

Holding a successful meeting

An obvious but important first step in holding a successful meeting is to show up *on time*. Once you're there, you have many tactics that you can use to improve your chances of a successful outcome. Some of the tactics you'll find particularly helpful include body language, active listening, and negotiation skills. Although these skills require practice, once you learn them, you'll be a much more effective self-advocate.

Body language

In an ideal world, justice and fairness would govern everyone's actions. However, in the real world, image is important, and the way in which you present yourself at a meeting can have a major impact on its outcome. Using positive body language conveys confidence and assertiveness. Here are some examples of positive body language:

- *Dress and groom yourself appropriately for the meeting.* Poor grooming or sloppy dress can leave a negative impression regardless of the strength of your case. Brian Cooper explains, "Dress as nicely as you can. Not only does it show respect for people, but it reduces the power differential." If you dress nicely, people will—consciously or unconsciously—treat you with more respect.
- *Shake hands firmly.* When you introduce yourself at the beginning of the meeting, give the other person a firm handshake while you look the person in the eyes.
- *Do your best to maintain eye contact.* Although this can be difficult if you are shy or nervous, you will find that maintaining eye contact helps you maintain control over the meeting. Don't "stare down" the other person, but do look him or her in the eyes while either of you is talking.

- *Use good posture.* By sitting straight in your chair, you show respect for the other person and also convey confidence in what you are seeking.
- *Try not to fidget.* You should try to avoid some of the things people often do when they are nervous, such as wringing their hands or squirming in their chairs. Such actions convey your nervousness, making the other person feel more confident in his or her position.
- *Practice these skills.* Before an important meeting, you can practice your body language either with a friend or in front of a mirror. If positive body language does not come naturally to you, you should practice this skill. You can learn positive body language in the same way you learned to jump rope, hit a baseball, or play video games.

Listening

When you are meeting with someone, active listening can mean the difference between being spoken to and being “spoken at.” Active listening means that you take steps to find out the information that you need, rather than simply listening to what the other person says.

The simplest form of active listening is to ask for clarification if you don’t understand something. For example, if the person uses jargon or an abbreviation that you don’t understand, be sure to ask what it means. For example, if someone says, “well, we don’t usually get involved in these types of situations until DDM has contacted us,” you won’t really know what to do next if you don’t know what DDM stands for. Don’t be afraid to ask for this information; if you try to find out after the meeting, you will miss important points during your discussion.

Active listening requires that you restate a person’s position so that you both understand what the person is offering or requiring. In the above example, you might respond, “So what you’re saying is that I should contact DDM and ask them to review my case.” By restating the other person’s position, you can make sure that you are both “on the same page” as you negotiate.

You should also ask for clarification if you don’t understand someone’s reaction to what you say. For example, if someone replies, “I see,” it might mean that the person understands your position, but the person might mean, “I see that you are being difficult.” When someone is vague, don’t guess at his or her meaning; instead, *ask*.

Finally, to have a record of exactly what went on during the meetings, you should take careful notes of what was said. Be sure to write down:

- § any promises that the other person makes;
- § any actions that you must take;

- § any explanations that the person makes for granting or denying your requests; and
- § anything the person says that is supportive of your position.

Using a tape recorder allows you to keep an exact record of your meeting. Although some people might permit you to tape record a meeting, others are put off by this suggestion.

Negotiation

Learning to negotiate successfully is the centerpiece of self-advocacy. All of our preparations feed into the negotiation process. As with other advocacy skills, negotiation is a skill that can be learned through study and practice. Here are some pointers for getting what you want through negotiation:

- *Lead with the strongest part of your argument.* For example, if you are dissatisfied with the treatment you have been receiving, you might start by pointing out that a doctor or staff person has violated your state's patients' bill of rights.
- *Keep your presentation short by focusing on relevant facts.* Often, we want to tell our life story when we are trying to spur people to action. But by taking up too much of someone's time, you run the risk of alienating that person. Instead, focus on details that are the responsibility of that person. In other words, if you are experiencing problems with a certain program or service, focus on that program or service rather than other problems that you might be experiencing.
- *Focus on remedies, not complaints.* Unless your goal is simply to make someone feel sympathy for you, then you should have an action plan for what you want to happen. For example, rather than complaining about your housing, you should state that you want housing in a safer area.
- *Control your emotions.* No matter how much the other person upsets you, don't resort to yelling or name-calling. If you need to ask for a break to compose yourself, do so. You can go home and punch pillows after the meeting, but "blowing up" during the meeting reflects poorly on you, and people often use your behavior as an excuse for denying you what you want.
- *Have in mind a minimum that you are willing to accept.* To be a good negotiator, you should ask for more than what you really want, but keep in your own mind a minimum that you would be willing to accept.
- *Acknowledge the other person's position.* Demonstrate that you understand the limitations faced by the other person. This will help you keep your demands realistic and make the other person feel more comfortable in negotiating with you. For example, you might say, "I realize that the medication that I want is more expensive than other medications," or "I know that you have a limited amount of housing available."

- *Stick to your guns.* Just because you should acknowledge the other person's position doesn't mean that you should accept it. The best way to stick to your guns is to reiterate your position using "I" statements. If you have tried other medications unsuccessfully, you can say, "I need a medication with fewer side effects." If you need a safer place to live, you can reiterate "I need a safer place to live" in response to the other party's suggestion that he or she thinks your current arrangements are adequate.
- *Point out weaknesses or liabilities to the other person.* Give the other person a reason to want to help you. For example, you could say, "I have been trying for months to get safer housing. If something happens to me, your agency could face problems."
- *Ask for the chance to offer additional information.* Meetings sometimes put pressure on us, making it difficult to remember everything we have to say. You might wish to reserve the right to provide additional comments or support later.
- *Restate any actions decided upon.* If the other person makes any promises to you, restate them as you end your meeting. Equally important, if you make promises, restate those promises as well, so that you are sure of what you need to do.
- *Set a timeline for action.* A promise to "look into the problem" or "get to it as soon as we can" doesn't help you very much. By insisting on a timeline for action, you can contact the person if deadlines are not met.
- *Be prepared to walk out without resolving the negotiation.* Brian Cooper suggests, "If the meeting isn't going smoothly, don't agree to something just because of the urgency of the moment. Be prepared to get up and walk away—*politely*."
- *Practice negotiating with friends or support groups.* There are many books that provide negotiation exercises that you can practice with a group; we have listed some of them in the *Resources* section at the end of this Technical Assistance Guide.

Follow-up

As with any form of self-advocacy, following up is important after you meet with someone face-to-face. After your meeting, write a short letter thanking the person for his or her time. In your letter, you should also restate any agreements that were made in the meeting.

After your meeting, read over your notes and make sure that you understand them. While your memory is still fresh, you should also fill in any information that you might have forgotten to write down. Keep your meeting notes with other documentation, such as copies of letters and your phone log.

If the person with whom you met promises results by a certain time and these things do not happen, then you should contact the person. When you call or write to the person, be sure to refer to the date of your meeting and restate what you had agreed upon.

Beyond self-advocacy

No matter what your needs, self-advocacy can be a powerful tool throughout your life. If you are just beginning your personal recovery process, you might find that self-advocacy helps you take small steps. As your self-advocacy efforts continue, you will surprise yourself with what you have achieved.

At times, our individual needs must take center stage. However, as we grow as advocates, we often find that we can help others as well. Many people who began as self-advocates are now working as advocates for others.

National Mental Health Association director of consumer advocacy Brian Cooper explains, “Self-advocacy is one step along a continuum of support groups, self-advocacy, peer advocacy and systems advocacy.” Peer advocacy means consumers helping each other with their own advocacy needs, while systems advocacy refers to attempts to reform local, state, or national policy.

Through systems advocacy, says Cooper, “You are able to change the system to benefit people you don’t even know. It’s a very rewarding use of your time.” The Clearinghouse Technical Assistance Guide *Systems Advocacy* contains helpful information for consumers interested in the subject.

Remember that you are part of a growing movement of mental health consumers who no longer will remain silent while decisions are made for us. The most important way you can stand up for yourself is by asserting your existing rights through self-advocacy. But eventually you won’t be satisfied with your existing rights and you’ll want to demand better rights. That’s where systems advocacy comes in.

In the words of Clearinghouse executive director Joseph Rogers, “The reason that we’re teaching self-advocacy is not only to benefit individual consumers, but to create a better-informed consumer constituency. If people can assert themselves and let it be known that the status quo is unacceptable, then we can work together to change the system.”

This Technical Assistance Guide should give you a head start in your self-advocacy efforts, but if you ever get stuck, please feel free to contact the Clearinghouse. Also, if you haven’t taken a Freedom Self-Advocacy Workshop, contact us to learn about training opportunities in your area.

Resources

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Books marked with a key (B) can be ordered through the Clearinghouse on-line bookstore at <http://www.mhselfhelp.org/bookstore.html>.

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Organizations

Organizations marked with an asterisk (*) have local and/or state affiliates.

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street, Suite 1207
Philadelphia, PA 19107
(800) 553-4KEY (4539)
<http://www.mhselfhelp.org>

***National Mental Health Association/ National Consumer Supporter Technical Assistance Center**

1021 Prince Street
Alexandria, VA 22314
(800) 969-NMHA
<http://www.nmha.org>
<http://www.ncstac.org>

***National Association of Protection and Advocacy Systems, Inc.**

900 Second Street, NE, Ste. 211
Washington, D.C. 20002
(202) 408-9514
<http://www.protectionandadvocacy.com>

***National Depressive and Manic-Depressive Association**

730 N. Franklin Street, Suite 501
Chicago, IL 60610
(800) 826-3632
<http://www.ndmda.org>

***National Alliance for the Mentally Ill**

2107 Wilson Blvd., Suite 300
Arlington, VA 22201
(800) 950-NAMI
<http://www.nami.org>

***International Association of Psychosocial
Rehabilitation Services**

10025 Governor Warfield Parkway, Suite 301
Columbia, Maryland 21044
(410) 730-7190
<http://www.iapsrs.org>

CONTAC (Consumer Organization & Networking Technical Assistance Center)

1036 Quarrier Street, Suite 208A
Charleston, WV 25301
(888) 825-8324
<http://www.contac.org>

National Empowerment Center

20 Ballard Road
Lawrence, MA 01843
(800) POWER 2 U
<http://www.power2u.org>