

Chapter 6
***Skills and Strategies for
Effective Self-Advocacy***



New Partnerships for Women

INTRODUCTION

What is Advocacy?

“Advocacy” can mean many things, but in general, it refers to taking action. Advocacy simply involves speaking and acting on behalf of yourself or others. There are several types of action that a person can take:

- *Self-advocacy*: taking action to represent and advance your own interests;
- *Peer advocacy*: taking action to represent the rights and interests of someone other than yourself;
- *Systems advocacy*: taking action to influence social, political, and economic systems to bring about change for groups of people; and
- *Legal advocacy*: taking action to use attorneys and the legal or administrative systems to establish or protect legal rights. (Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), p. 1.)

This *Advocacy Tool Kit* provides individuals with information and skill building exercises to develop and enhance self and peer advocacy skills. The information contained in this Kit has been gathered and developed to assist individuals in Wisconsin, but may be helpful to those in other states as well.

The goal of this tool kit is to teach people with disabilities and others who are advocating for them, the skills and strategies necessary to be an effective advocate.

- *Skills* are techniques for becoming competent in an area.
- *Strategies* are plans for an approach to address an issue or solve a problem.

This Kit reviews Informal and Formal Advocacy Strategies. For the purposes of this Tool kit, **Informal Advocacy Strategies** are strategies that do not involve bringing in an outside decision maker. **Formal Advocacy Strategies**, on the other hand, typically involve an outside decision-maker. Examples of formal processes include court hearings, grievance procedures or complaint processes.

Although some of the sections in this publication are written with the self-advocate in mind, peer advocates (including family, friends and service providers) will benefit from the advocacy information and techniques throughout the publication.

Why advocate for myself or someone I know?

Whether you attempt to get a service provider to listen and respond to a concern or you try to get a landlord to fix the broken light in a stairwell of your apartment building, advocacy is practiced by people for many different reasons. For people with disabilities, frequent interaction with service providers, family members, friends, colleagues and others who may not recognize you as a decision-maker can disempower you. Learning about and practicing self-advocacy and peer advocacy skills can enhance your role and confidence in making the decisions that affect your life.

While there's no guarantee, advocating for yourself is the most direct way to secure change. And that change can mean more than getting the stairwell light replaced. Self-confidence, a healthier self-esteem and newly-gained respect from others can all be surprising by-products of the advocacy process.

How do I advocate for myself or someone else?

This *Advocacy Tool Kit* is designed to assist you in learning strategies and practicing some skills so that you feel comfortable and confident as an advocate. Everyone is different and has different life experiences. Because of these differences, there is not one magic formula that tells you how to be an effective advocate. Experiment with different styles and choose the ones that you feel are both comfortable and effective for you.

Now, turn the page and let's get started!¹

¹ This *Advocacy Tool Kit* was originally developed in cooperation with the New Partnerships for Woman Project of Madison, WI in 2002. It was modified in 2007 to use as a training tool for people with disabilities, their families and friends to help build and support strong advocacy skills. We use it here because people with mental health and substance use problems are considered one of the disabled groups served by DRW. We thank Dianne Greenley and others who participated in its development through Disability Rights Wisconsin, the State of Wisconsin Department of Workforce Development, as well as the members of the Long-Term Support Subcommittee of the Brain Injury Advisory Council.

For more information on additional copies of the *Advocacy Tool Kit* or other resources from the Community Mental Health Protection and Advocacy project, please visit DRW's web site located at <http://www.disabilityrightswi.org> or contact DRW by telephone at 608-267-0214 (voice) or 888-758-6049 (TTY), and request a brochure of available resource materials and videos.

BUILDING AN ADVOCACY STRATEGY

You've been introduced to various forms of advocacy; including self-advocacy, peer advocacy, systems advocacy, and legal advocacy. As a reminder:

- Self-advocacy is representing and advancing your own interests;
- Peer advocacy is representing the rights and interest of someone other than yourself;
- Systems advocacy is influencing social, political, and economic systems to bring about change for groups of people; and
- Legal advocacy is using attorneys and the legal or administrative systems to establish or protect legal rights (Advocacy Training Manual: Wisconsin Coalition for Advocacy (1996), p. 1.)

Effective advocacy, of any kind, requires building a solid **strategy** or plan and practicing **skills** to help you feel comfortable and confident in reaching your advocacy goals.

Why is having a plan so important? Because it allows you to take action as an advocate in a thoughtful way. By really thinking about what you want to advocate for and how you will take action, you are more likely to resolve the problem as quickly as possible.

This section focuses on building a strategy to identify what you want to advocate for, and four things you should do before you begin. The goal of a strong advocacy strategy and developing strong basic advocacy skills (discussed in the next chapter) is to help you resolve your complaint **informally**, without legal or outside agency involvement. Generally, you should start your advocacy using these basic techniques.

There are times when starting with **formal** advocacy strategies are necessary. Formal advocacy strategies typically involve getting an outside agency, like a court or an investigator, involved in resolving your problem. Formal advocacy strategies are discussed in a later chapter.

In order to make your advocacy efforts effective you should:

1. Break down the problem
2. Educate yourself
3. Identify your rights
4. Develop a solution (goal) and strategy to address your problem

This planning process takes time. Sometimes even the best laid plans fail to achieve the identified goal. It requires that you clarify your goal, identify who you will communicate with to achieve your goal, determine what methods or strategies you want to employ and figure out what steps you need to take for follow-up.

Learning how to negotiate a compromise or can be an important components to effective advocacy. This section and the next section called Informal Advocacy Skills provides information and worksheets that you can use to build advocacy skills and try out different self-advocacy strategies.

Informal Advocacy Plan - Step by Step

Step 1: Problem Analysis

Questions to ask yourself:

- What is the problem or issue? If there is more than one, focus on one at a time.
- What is my goal?
- What facts do I know?

We all have been overwhelmed at one point or another by something or some things that we want to change in our lives. All good advocacy starts with a good understanding of the problem. You have to understand *what* you want before you can do anything about it. It sounds simple, right? Well, not necessarily. Sometimes the problems can be complicated to break down.

First, it's a good idea to keep your issues separate. Have you ever heard the phrase "when it rains it pours?" Life is often complicated. There can be more than one problem at a time. For example, you might be frustrated because your boss denies your request to change your work schedule, your roommate is not paying her half of the utility bill, and your sister is not pulling her weight in caring for your older parents. When planning how to advocate for yourself on an issue, you should make sure that you notice each separate problem. To help you, you can complete a separate Advocacy Plan for each problem that you want to address.

Once you identify the basic issue, you may need to break down the problem even further. Let's say that you asked your boss if you could work from 9:00 AM until 5:30 PM instead of from 7:00 AM until 3:30 PM because the symptoms from your disability are worse in the early morning hours. Your boss is aware of your disability, but still denies your request, stating that he does not want to give you any special treatment over other employees. You have spoken to your doctor about your concerns, but you feel she has not taken you seriously. To make matters worse, your doctor has been out of town, and so you have not had a chance to talk with a medical professional about the change in your symptoms and you are feeling worse by the day.

The problems you are having at work can be broken down into smaller parts such as:

- Your request for an accommodation has been denied;
- You have not been feeling well;
- Your doctor is on vacation and your symptoms are getting worse;
- You feel your doctor has not been taking your medical concerns seriously.

To resolve the problem, you may choose to advocate for your employer to allow you to change your schedule, for your doctor to take your concerns seriously, or to be seen by another doctor right away. You also may want to change your doctor all together.

Once you clarify the problem you should ask yourself the question "what is my goal?" If your goal is to feel better, for example, you may decide to focus your energy on working with your doctor or finding a new doctor with whom you are better able to

communicate, rather than to work with your employer to permanently change your work schedule, because once you feel better you hopefully will be able to function well in the early morning hours.

When deciding what aspects of your problem you want pursue, it is important to remember:

- Some problems are easier to resolve than others
- Not all problems can be solved, or easily resolved.
- You may decide you do not want to address all the problems that you identify, and that's ok. Remember, you should pick the battles that you want to fight.

The key is to pick out the problems that are the most important to you and address those first. In any event, breaking down the problem will help you to move on to the next stage in the advocacy process.

Once you know which problems you want to work to take action, you should **identify the facts** that you know. Identifying the facts you know is as simple as recalling what you know about the situation and outlining the events of what has happened so far.

Using the example above, some facts of the problem are:

- You have told your boss you would like to modify your work schedule;
- Your boss is aware you have a disability, but you did not tell her that you want to change your schedule because of the symptoms you are experiencing;
- You spoke to your doctor about the increase in severity of your symptoms;
- Your doctor is out of town.

When you answer the question "what facts do you know?" you should avoid inserting judgments such as "my boss is a jerk," or "my doctor does not care about me" as facts of the problem. These statements are not helpful, and will distract you from focusing on what is most important -- resolving the problem you face.

Once you have outlined the problem, identified your goal, and identified the facts of your problem, you are ready to move on to the next step - information gathering.

Step 2: Information Gathering

Questions to ask yourself:

- What additional facts or information might you need regarding this situation, such as laws, rules or policies?
- How can I go about gathering this information?
- Who are the decision-makers that I need to influence to solve this problem?
- Are there other people who can help me?

In order to be able to effectively advocate, you must have a clear understanding of the facts that you know, and also a firm grasp of what information you might need to gather. Educate yourself about the laws, rules, and, policies that apply to your situation.

Identifying your rights

In the United States, we all have rights as citizens. As people with disabilities, we have often been led to believe that we don't have rights or should be afraid to exercise them. Some rights are governed by laws or rules, while others are not. Therefore the term "rights" can sometimes be confusing. It is important to understand the differences in the types of rights that you may have so that you can determine the best advocacy strategy. To do this, let's first identify different types of rights.

Laws: Some rights that we have are legal rights, and therefore may be enforceable in a court of law or through a formal grievance procedure. There can be Federal, State, or local laws. For example, a federal law called the Health Insurance Portability and Accountability Act of 1996 (HIPAA) makes it illegal in most instances for a health care provider to share your private health care information with others. Therefore, according to this law, you have the right to private health care records.

Contracts: You can also have rights under a contract that are enforceable through a court of law. One example of a contract is a rental lease. A lease outlines the rights and responsibilities of tenants. If you feel your rights under a lease have been violated, your case can be heard in small claims court.

Rules and Policies: Sometimes there are rules or policies that outline your rights. The rules or policies may not be law, but may be governed by law or may simply be a set of guidelines that an agency or an individual claims to follow. In either case, if a rule or policy has been broken, there typically is a way to file a complaint or formal grievance to address your concern. For example, your doctor may have a policy that states that you have up to 30 days to pay the balance of your bill.

Preferences and Social Expectations: Every society has a set of social expectations or rules that are followed, and everyone has personal preferences in how they would like to be treated. *Preferences and social expectations are typically not illegal, and therefore are not the same as a right that someone has under a law or a policy.* It is very important to understand the differences between enforceable rights - rights that are governed by a policy or law - and things that we may refer to as being a "right", but that are not covered under any law or policy. For example, how often have you said or heard people say "I have the right to be listened to" or "I have the right to make a mistake." Although expressed as rights, the right to be listened to or the right to make a mistake are really preferences of how we would like to be treated, and they are not likely to be a right we have under a policy or law.

It is important to remember that not all behavior we don't like is against the law or a formal policy that can be enforced. This does not mean that you cannot address a concern you have about being treated rudely. For example, let's say you were stood up two times by someone who is coming to give you an estimate on painting your bedroom. Although they did not break any law by making you wait for them, you could call or write a letter to the owner of the business letting them know that you

were dissatisfied with how you were treated. Writing a letter or placing a phone call may or may not change the painter's behavior.

Exercise:

Can you pick out what might be considered a law versus a social expectation or preference versus a rule or policy versus a contract? There may be more than one answer to the question. Take a few minutes to complete this exercise:

- 1) The right to employment without discrimination based on disability, under the Wisconsin Fair Employment Act.
- 2) The right to be happy.
- 3) The right to be "treated with dignity and respect" by your physical therapist as identified by the rehabilitation facility where she works.
- 4) The right to have a painter complete painting your house, as identified in the agreement.
- 5) The right to not be abused by your home health care aide.
- 6) The right to say "I don't know".
- 7) The right to seek housing without discrimination based on disability, under the Fair Housing Amendments Act.
- 8) The right to choose your health care provider.*

* Answers:

- 1) The Wisconsin Fair Employment Act is a law.
- 2) The right to be happy is generally considered a preference.
- 3) The right to be treated with dignity and respect in a rehabilitation facility might be governed under a rule or policy set by the rehabilitation facility, and being treated with dignity and respect is also a social expectation.
- 4) The right to have a painter complete a job she or he promised in an agreement is governed by a contract.
- 5) The right not to be abused by your home health care aide is a right that is governed by a rule and policy and is against the law!
- 6) The right to say "I don't know" is considered a preference.
- 7) The Fair Housing Amendments Act is a law.
- 8) The right to choose your health care provider may be governed by a rule or policy, however, not necessarily. To some it may be considered a preference.

When you still have questions or need more information, how can you go gather additional facts. Finding an answer to your question is as simple as **contacting the right person**. You'll be surprised with the amount of progress you can make by placing a few phone calls. Even if the first person you call cannot answer your

question, they are likely to point you in the right direction. Some useful places to start include: the protection and advocacy (P&A) organization for Wisconsin (Disability Rights Wisconsin); the Wisconsin Department of Health and Family Services; consumer groups; drop-in centers; and Social Security offices.

The **Internet** is another tool. You can search the Internet on various topics of interest, or use it to find phone numbers to local, state, or national resources. If you don't have access to the Internet at home, try a local library, many of which now offer Internet access. If you need help learning how to use the Internet, you can ask a librarian for help. Additionally, many disability-run organizations now offer both Internet access and training. If you are more familiar with how to use the Internet, you can also see if there is a coffee shop nearby that has Internet access. Many coffee shops offer free access. To learn more information about legal research, see the chapter called "Legal Research - The Basics" starting on page 203 of the Toolbox.

The next question is who are the key decision-makers in your situation? Often, going straight to a decision-maker can result in a decision without hassle. If you are not sure who has the authority to make the decision, ask!

Advocating for yourself takes effort. Surrounding yourself with people who can help you can make all the difference. Ask from friends, family, other advocates, professionals and others to support your efforts to navigate the system and can listen and give advice when you are frustrated.

Step 3: Solution Analysis

Questions to ask yourself:

- What are some possible solutions to this problem/issue? (be specific)
- What are some barriers to these solutions?
- What do I expect the other side to do?

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. By using a systematic approach, you're more likely to find the solution that fits your problem.

Preliminary steps

First, consider what you want to happen. While consulting other people is extremely helpful, you must make up your own mind, rather than relying exclusively on suggested strategies or predicted outcomes. Ask yourself, "what do I need?" 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.

While 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. 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 you determine the course of your self-advocacy efforts. For example, maybe, you make a request for a later starting time at work due to your disability. 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. Also, consider potential allies who might help you with your problem.

Building your case

Once you decide what you want and whom to contact, you can begin building your case. Ask yourself about the strengths of your position: Have your legal rights been violated? Has an established policy or procedure been ignored?

Ask yourself what the other side has to gain from 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 collecting all of the documentation that your position. Although the relevant documentation will vary from situation to situation, you should always keep copies of documents 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.

As you build your case, you also must look at the other side of the argument. Why is the other side acting the way it is acting? Is there a rule or policy that they are following? Acknowledging 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.

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. Consulting with others can help you plan more effectively.

You should also spend some time reflecting on what you plan to do before you do it. Before you make your first contact, sit back and think.

Plan how you are going to phrase your words when you talk to someone. 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; or
- Filing a formal complaint.

A sample Informal Advocacy Plan Worksheet follows and can help you develop your action plan for a specific self-advocacy goal you identify. The Informal Advocacy Plan is an adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum published by the National Mental Health Consumers' Self-Help Clearinghouse. In addition, information about the methods you can use to carry out your problem-solving strategies is discussed in the next section.

INFORMAL ADVOCACY PLAN

Sample Action Plan Worksheet

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), p. 18.)

What is the problem or issue? If there is more than one, focus on one at a time:

What is your goal?

What facts do you know?

What additional facts or information might you need regarding this situation, such as laws, rules or policies?

How can you go about gathering this information?

Who are the decision-makers that you need to influence to solve this problem/issue?

What are some possible solutions to this problem/issue (be specific)?

What are some barriers to these solutions?

Pick one solution and discuss the strategies and tactics you will use to achieve this solution. Complete the information below to assist you in initiating your action plan.

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:

What I expect the other side to do:

Strategies for what's next:

Debriefing: who will I call or how will I take care of myself following this encounter?

Keep in mind that the strategy you use to obtain the advocacy goal may not be successful. It is helpful to think about what you will do if you don't get what you want the first, second, or even third time around.

If your plan does not work, you may need to review your strategy, what went wrong and alternative ways to resolve your concern. You may want to revisit some of the information-gathering questions listed above and consider asking yourself the following questions:

What will I do if the strategy doesn't work? What is the backup plan?

What went wrong? Why didn't the strategy work?

INFORMAL ADVOCACY SKILLS

This section is a brief overview of some basic tools to help you to become a better advocate. You will find worksheets and tools to assist you in developing advocacy skills and taking action to address your concern. You will learn how to:

- Stay organized,
- Properly document and keep records, and
- Be an effective advocate on the phone, in writing, and in-person.

By understanding, practicing and using these skills, you will be better organized, prepared, and able to respond to unexpected things that come your way. Generally you should start your advocacy using these informal techniques; however, there are times when starting with formal advocacy strategies are necessary. Formal advocacy strategies and additional communication skills are discussed in other sections.

Before we begin, let's review some important tried and true advocacy tips. The following tips were originally created to address concerns within a treatment setting, but can be applied to most any advocacy situation.

Exercise: After you review them, take some time to think about how you've used these strategies to advocate for yourself in the past. Were they helpful? What strategies might have helped you to resolve your problem sooner had you tried them?

How to be an Effective Advocate

(Adaptation from Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), p. 26, from a presentation by Nina Gagnon, National Project Director, Mental Health Advocacy Training, National Paralegal Institute, San Francisco, CA.)

1. Try not to be intimidated by authority; learn to question responses with which you do not agree.
2. Try to resolve the dispute informally first. Why spend more time than you need to? Most of the time if you address your concern directly with a person who can do something about it your complaint will be resolved.
3. Find out what the authority is for the agency's decision. Ask the worker what regulation her/his decision is based on. Public agencies must follow written regulations and procedures. Members of the public have a right to see these regulations. Insist on checking the rule book yourself. Perhaps you can find it online.
4. Find out who in the bureaucracy has the power to make the change you want, and insist on dealing with that person. Don't give up because the person you are dealing with does not have the power to make the change you are requesting. Find out who does, and go up the "chain of command."

5. Use your imagination to come up with solutions to problems. If, for example, you cannot locate a document you need, think of alternate ways to prove the fact. Use a declaration (sworn statement) or an affidavit (sworn, notarized statement).
6. Take full advantage of all appeal rights. Request decisions in writing and inquire specifically about methods of appealing unfavorable decisions. Be aware that deadlines exist for filing appeals. Be sure to read the small print carefully in any official notices received.
7. Always get the name of any person within an agency with whom you deal. Keep accurate notes of dates, content of conversations, and the identity of the worker who gave you the information. If questions arise later, this is your proof that the conversation you remember did, in fact, take place.
8. When possible establish and nurture contacts within the agency with people you find helpful. Try to deal with or get helpful information from workers with whom you have established a cooperative, friendly relationship. They can be of great assistance.
9. Utilize other existing advocacy resources in your community. Locate other organizations advocating for low income, elderly, and people with disabilities. Establish contacts with other advocates in your community, and explore the possibility of setting up training together. When you are stymied or confused as to what to do next, call a more experienced advocate for advice.
10. Use all available methods for increasing your legitimacy as an advocate.
11. Remember that it takes time to develop highly skilled advocacy approaches. Even the best advocates don't always win; losing may be as much a reflection on the target system as on the advocate. Evaluate your activities periodically. Give yourself credit for good, effective approaches, and outline areas of your advocacy skills in which you would like to heighten your skills. Remember that change is a long, slow process, but that all contributions to progressive change in our systems and human services are important.

Documentation and Taking Notes

(Adaptation from Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), pp. 8, 18.)

Creating a paper trail means having in writing events and decisions which are important to your advocacy effort. Experience has shown that having a written record of what went on and when is crucial to building an agreement and substantiating your position. Paper trail skills include documentation and note taking.

Documentation

Documentation is a critical component of good advocacy. Good documentation includes:

- Keeping notes of all conversations (phone and in-person) that you have regarding the situation beginning with the initial contact. Later in this section, we have developed a sample contact list and phone log that you can use to document and take notes of your activities.)

The information you should have as part of the log or contact sheet is the following:

- Date;
- Time;
- Full name of the person(s) you contacted;
- Person's title;
- Agency name;
- Agency telephone number; and
- A description of what was discussed.

If there is a question about the accuracy of conversation, follow up with a letter to the party summarizing your understanding of the conversation. Keep a copy of the letter for your documentation.

Keep all letters and copies of information you receive from agencies and individuals. Do not make any marks on copies received from other parties because those parties may claim the documents were tampered with.

Keep copies of all letters and information that you send out regarding the situation.

When you fax copies of documents, you should also mail a hard copy and make a note of this on your letter.

Taking Notes

Note taking is a tool that provides a written record of what happened at a meeting or during a phone conversation. Note taking signifies to others that you are an active participant in what is occurring. When you are taking notes people around you are more likely to feel accountable. They become more productive and responsible and pay more attention to you. If you have never taken notes, it may at first seem like a lot of bother. But once you practice it becomes an effortless activity that you can easily do while fully participating with others in a group. If you have difficulty taking notes and participating in the meeting, bring someone with you to the meeting to take the notes for you. Take notes at every advocacy meeting and conference you attend as a record of all the information you receive. Also, keep a notebook by the phone so that you can keep a record of everyone you talk to and anything said which should be documented.

It is helpful to keep the following points in mind when taking notes:

1. At the beginning of your notes, list the names and role of those spoken to, and list the day, place and time of the conversation. State the primary purpose of the call or meeting in one or two sentences.

2. Use an outline format and modify it to meet the needs of each particular call or meeting.
3. Write key words and abbreviations rather than long sentences. The fewer words written, the more time is available for thinking and actively participating.
4. Leave space along the left-hand margin for filling in answers to questions and for clarifying points which are not initially understood. Ask the speaker to clarify what s/he is saying if you don't understand.
5. Use a colored felt tip pen to underline important terms and phrases. This is very helpful when you go back later to review your notes.
6. Before you end the communication, if possible, review your notes, be sure they are dated, and ask for any clarifications that are needed. It's sometimes a good idea to remind everyone that what they have said is documented. If you type your rough notes, be sure to save the originals in case of later misinterpretation.
7. File your notes in a home file.

The way in which you organize your home file is up to you. However, it is important for you to keep copies of every letter or other piece of correspondence which you write and receive regarding your case, copies of records and notes you take at meetings, or during telephone conversations.

Advocacy on the Telephone

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 19-24.)

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 calls.

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 those pre-recorded phone menus that ask you to press keys to be connected to the right department. When you finally do reach a live voice, it is often a front-line employee who might not have the authority to resolve your request.

Certainly, it 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. Longtime advocate, 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 people. If you have not heard back by the next day, call again and leave another message until you get a return call. 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 discuss assertiveness throughout the *Tool Kit*, 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.

The table below contains some more examples of assertive responses. These are just a few examples of the statements that you can make to assert yourself.

Exercise:

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.

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 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 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." You should be aware that going to a supervisor too soon can backfire. 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.

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 communication more closely in the next article, *Advocacy in Writing*. Before we explore advocacy through written communication, we have included two worksheets for you to use in documenting your contacts and telephone calls that you make.

TELEPHONE LOG WORKSHEET

Outgoing Phone Log

Date:

Person called:

Telephone Number:

Referred by:

Was call answered?

Left message?

Person spoken with:

Title of person you spoke with:

Fax number:

Summary of conversation:

Action suggested:

Action agreed upon?

Deadline:

Incoming Phone Log

Date:

Person calling:

Telephone Number:

Title of person you spoke with:

Fax number:

Summary of conversation:

Action suggested:

Action agreed upon?

Deadline:

Advocacy in Writing

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 25-29.)

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 segment, 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. Keeping records of your letters is easier than keeping detailed records of phone conversations, 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* on pages 34 and 35 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. The "cc" line is a way to record that you've sent a copy of the letter to someone else. So, if you see "cc: April Jackson," it means that you sent a copy of the letter to April Jackson. When sending a letter to someone, it can be good practice to also copy their boss or other person in authority because it can help to get your concern addressed sooner.

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.

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. 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 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 resolved 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 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 B*: although he was probably angry at the insurance company’s broken promise, he is not rude or insulting. He 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. They can also give you feedback on if the tone of the letter is polite.

Sample Letter A

Elizabeth Martin
127 Maple St.
Apartment 105
Beloit, WI 53511

January 2, 2007

Mr. Edward Peters
Peters Property Management
13 E. Main St.
Beloit, WI 53511

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 FHAA 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 provider's 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 (608) 555-2525. Thank you for your prompt consideration of my request.

Sincerely,

Elizabeth Martin

Sample Letter B

Steven Jones
14 Broad Street
Fond du Lac, WI 53945

January 2, 2007

Mr. Evan Brown
Claims Service Representative
Acme Insurance Company
2121 Lincoln Ave.
Milwaukee, WI 53201

Dear Mr. Brown:

I am writing to request the immediate payment of the enclosed hospital bill, for services provided on October 12, 2006. 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, 2005 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, 2006.

Please respond within five days of receipt of this letter. You can reach me by phone at (920) 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

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), pp. 30-35.)

For some forms of 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, a self-advocate and peer advocate from Massachusetts. "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, director of advocacy at the National Mental Health Association, "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 Dan 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. There is additional information on this topic in the Communication Skills section of this *Tool Kit*.

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. Negotiation is when two groups who disagree work together to resolve a problem. 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 demand 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 basic needs.* 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 basic needs 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 these 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. (Additional information on negotiation is available later in this section.)

Follow-up

As with any form of 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.

More on Negotiation as a Tool for Change

(Adaptation from Taylor, Steven, *Negotiation: A Tool for Change*, DD Rights Center, Center of Human Policy, Syracuse, NY (1979), reprinted from the *Advocacy Training Manual*. Wisconsin Coalition for Advocacy (1996), pp. 27-30.)

Any time two groups with conflicting interests meet to discuss the issues between them, they are negotiating. Sometimes the negotiations are explicit; that is, the groups consciously draw on negotiating strategies. Usually they are not. Too often, those who advocate for change enter into negotiations with only a vague sense of what they hope to accomplish and how to accomplish it. This piece is designed to enable consumers, parents, and advocates to negotiate effectively.

Short term -- Long Term

You can use negotiations to work for either short term or long term change. Short term change usually means helping one or a small number of people without radically altering the conditions that create the problems. Some examples of short term, limited change are gaining access to previously undisclosed information or records; obtaining entry to an institution; advocating for special ramps, toilet facilities, or prosthetic devices for a small group of persons with physical disabilities; or working for the establishment of a community residence for a small number of people. Each of these short term changes represents a challenge to the usual policies and practices of many service systems, but they do not represent broad sweeping reforms.

Long term change involves confronting systemic problems. Architectural barriers, institutional abuse, segregation -- all are symptomatic of underlying problems in societal attitudes and human services. In advocating for long term change, negotiations should be used together with a larger set of strategies mapped out beforehand. For instance, negotiating may be used along with media coverage, investigations, public forums, letter writing campaigns, and litigation (see Biklen, Douglas. (1974) *Let Our Children Go: An Organizing Manual for Advocates and Parents*. Syracuse, NY: Human Policy Press.).

Approaches

Your approach should be determined by the intransigence, or willingness to change, of the opposite side. As Des Jardins (1971) notes, "If a bureaucrat gives you what you are entitled to, he is your friend. If he doesn't, he is your enemy." (Des Jardins, Charlotte. (1971) *How to Organize an Effective Parent Group and Move Bureaucracies*. Chicago, IL: Coordinating Council for Handicapped Children.)

You will sometimes need to take a "hard line" approach. When the opposing side actively resists change, you will have to be confrontational. Often a conciliatory approach will be most effective. For instance, when the opposition demonstrates willingness to change through its actions, you can afford to adopt a softer approach. But do not abandon your goals for the sake of getting along with bureaucrats and officials. As Saul Alinsky (1972) noted, "Reconciliation means when one side gets the

power and the other side gets reconciled to it, then we have reconciliation.”
(Alinsky, Saul D. (1972) *Rules for Radicals*. New York, NY: Vintage.)

Preparation

1. *Know when to negotiate.* Negotiations should be held prior to more dramatic or public actions, such as press conferences, demonstrations, or litigation, in order to provide agencies with an opportunity to meet your demands before you “go public.” You should enter into negotiations when informal approaches fail; for example, when a parent’s requests for services are denied.
2. *Obtain the backing of a group or a coalition of groups.* Make sure you identify yourself with consumer interests.
3. *Setting up the negotiation.* Request a meeting in writing. Your letter should establish your own credibility, explain the general purpose of the meeting, and specify which agency representatives should attend. Don’t give too much information on your position beforehand. Save your demands and documentation for the negotiation session. Follow up the letter with a phone call to confirm the arrangements for the meeting. Be sure to find out which agency representatives will attend.
4. *Target.* You should only negotiate with persons who have the authority to make decisions. In most negotiations, you will want to meet with the head of the agency.
5. *What if they refuse to meet?* First, appeal to their superiors; for example, state officials when local agency representatives balk at meeting. Second, go public: hold a press conference; organize a sit-in or demonstration.
6. *Form a negotiating team.* Any negotiating team should include at least one consumer, a person well-versed in the law, and an “expert” in substantive issues (someone who can respond to clinical or professional issues).
7. *Prepare for the negotiation:*
 - Map out a set of strategies. What will you do if the negotiations do not meet with immediate success?
 - Hold planning sessions. Identify the issues, formulate your demands and fall-back positions, collect the facts, anticipate the opposition’s responses.
 - Role-play the negotiation session.

Strategies for Effective Negotiation

1. *Control the negotiation session.* You should define the issues and set the tone of the session.
 - Set the agenda. You might even come with a written list of agenda items.
 - Choose your seating carefully. Don’t let an agency official hide behind a desk or sit at the head of a table. This gives control over the meeting.

- Refer to them as they refer to you. Titles carry authority. Don't let them call you by your first name if they refer to themselves by their titles (i.e., Mrs. Ms., Dr.).
 - Bring your documents, such as letters, to the session.
 - Chair the meeting. Review the circumstances or case leading to the meeting, the law, or other facts.
 - Present your demands or positions clearly.
2. *Numbers.* Never negotiate when you are out-numbered. Leave if they try to overwhelm you with sheer numbers of people.
 3. *Select a spokesperson.* While all members of the negotiating team should participate in the session, there should only be one person able to make compromises.
 4. *Present a united front.* Make sure that members of the team do not contradict each other. The opposition will use this to resist change.
 5. *Know and cite the facts.* Pay attention to officials' defenses or responses. Challenge them on the facts. Ask for specifics.
 - Know the agency and its services (budget, types of programs, etc.).
 - Know the law and legal precedents.
 - Be familiar with model programs elsewhere.
 - Know their philosophy. Point to discrepancies between philosophy and actual practices. Hold them to what they say.
 6. *Know how people resist change* (see also Biklen, 1974). Anticipate "cool outs" and have your responses ready. Here are some of the more common "cool outs" used to resist change:
 - Double talk. "I agree with your philosophy, but . . ." (Challenge them to act on their beliefs.)
 - Passing the buck. "I agree with you, but I'm not in a position to make that decision." (Passing the buck is an age-old tactic used to maintain the status quo. Force them to accept responsibility.)
 - The money game. "We'd like to do what you ask, but we just don't have the money." (There usually is enough money; it's a matter of priorities. Further, a lack of money does not excuse violations of people's rights.)
 - Expert knows best. "Most doctors say that . . ." or "according to research . . ." (The fact of the matter is that research on these kinds of complex problems has failed to provide conclusive answers.)
 - Cover up. "We have one of the best programs in the country." (Know the facts about programs elsewhere.)

- Blaming the victim. “These people are too retarded to live in the community.” (Confront them on their backward attitudes. Don’t let them blame the client for the system’s failures.)
 - Turning the tables. “You’re too emotional,” or “You just have to be patient.” (Don’t feel guilty about working for change. Why not feel emotional and impatient about people’s rights?)
7. *Be assertive, but don’t attack people personally.* Distinctions between “good” and “bad” or “friendly” and “unfriendly” officials or professionals are useless in a negotiating session. What is important is whether they yield to your demands. Don’t be afraid to challenge “nice” people. Don’t hesitate to be conciliatory with “unfriendly” bureaucrats who are forced to accept your position.
 8. *Avoid being put on the defensive.* Don’t beg; services should be available as a matter of right, not charity. Don’t feel guilty; you are only asking for that to which people are entitled. Refuse to discuss your own past actions and other irrelevant issues (e.g., “That’s not the issue . . .”).
 9. *Use your anger strategically.* Don’t express anger simply to vent your frustrations. Show anger to make a point or to break a deadlock.
 10. *Create a record.* Take a tape recorder to the meeting so that you have a record of the proceedings. If you don’t have a tape recorder or if this is too threatening to the officials, one of the members of your group should act as a note taker. Don’t hesitate to ask a bureaucrat to repeat something “for the record.” This will put them on notice that you mean serious business.
 11. *Latch on to any concessions.* Refer to any concession, however tentative, as a firm agreement on their part. Don’t let them back off. Chances are the opposition is not as organized as you are. Its members may not agree with each other. Treat the most conciliatory member as the spokesperson and his or her statements as binding.
 12. *Establish firm timetables and standards of performance.* Don’t accept vague promises and empty statements. Ask them to be specific and to set firm deadlines.
 13. *Don’t agree to do their work for them.* Don’t write their policy statements; if they aren’t committed enough to write them, they aren’t committed enough to implement them. Don’t agree to establish programs; that’s their job.
 14. *Know what you will and will not accept.*
 - Prior to entering the negotiations, set maximum and minimum goals where the mini-mum is the very least with which you would be satisfied. Never compromise on the minimum.
 - Make high demands and few concessions (Manus, Roger. (n.d.) *Negotiation*. Chapel Hill: Developmental Disabilities Training Institute.).