

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