

# Advocacy Tool Kit

## Skills and Strategies for Effective Self and Peer Advocacy

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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.

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# 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!

# 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.

<b>Assertive Responses</b>	
<u>Statement</u>	<u>Assertive Response</u>
<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 minimum 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.).
- Never settle for less than 100% of your demands. But don't turn down less. Just don't settle for it. Keep the pressure up until you get the full 100% (Des Jardins, 1971).
- Never compromise without any thought of future consequences (Manus, n.d.).
- If you are not sure whether or not a proposed compromise is satisfactory, don't be forced into a premature agreement. Tell them you need time to think about it.

15. *What if the negotiation session deadlocks?*

- Let them know you don't think you're getting anywhere.
- Walk out. A carefully orchestrated "walk out" may break the deadlock and force concessions.
- Threats. Don't hesitate to threaten other action, such as media coverage or litigation. "The threat is usually more terrifying than the thing itself (Alinsky, 1972)." Subtle threats are probably most effective since they allow an official to "save face;" for example, "Look, the press is really interested in these kinds of issues," or "We don't want to have to go to court to resolve this issue."

## **Follow-Up**

1. *Write a letter to the agency summarizing the major points discussed during the negotiating session.* The letter should highlight major agreements reached during the session, agreed upon timetables and standards for performance, and, if the session was unsuccessful, disagreements and glaring examples of agency unresponsiveness. Carbon copies of the letter should be sent to agency "higher-ups" as well as your own allies, whether consumer groups or attorneys. The letter should clearly state that if the official's recollection of the meeting differs from your record (based on carefully

recorded notes or a tape recording), he or she should write you immediately. A certified letter carries an official and formal aura.

2. *Successful negotiations.* If you win your objective through negotiation, hold a press conference and send out an “action bulletin” to your constituency announcing a “major policy breakthrough.” Your negotiations can serve as a precedent for other groups.
3. *Further negotiations.* Continue to negotiate only as long as you are making significant progress. Don’t waste your time by negotiating with intransigent officials. When negotiations seem to drag on and on, with no end in sight, tell the officials that you want a firm decision within a specific time period.
4. *Buck-passing.* It is sometimes successful to negotiate around an issue with representatives of more than one agency. When you find officials continuing to engage in passing the buck, call a meeting among all of the buck passers to locate responsibility for providing services.
5. *Unsuccessful negotiations.* Long-term change is seldom accomplished through negotiations alone. Do not be discouraged if negotiations do not result in immediate systemic victories. By increasing your understanding of the system and creating a record of attempts to resolve on a face-to-face basis, negotiating paves the way for other strategies: press coverage, lobbying, appeals to other authorities, litigation, public forums, and others.

## **Bureaucratic Tactics of Avoidance**

(Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), pp. 16-17.)

All of us, at one time or another, have experienced dealing with a bureaucracy. Whether we are dealing with an insurance company, our social service agency or the Social Security Administration, for example, each of these “systems” or bureaucracies can increase our frustration when we try to solve a problem or address a concern. The following piece describes some of the common obstacles or tactics that individuals who seek resolution to a problem might experience within a bureaucratic setting.

This article not only identifies these “bureaucratic tactics of avoidance,” but also describes useful strategies that you can apply to seek resolution to your concern or problem. Bureaucratic tactics of avoidance are also very common when trying to change a system. Systems advocacy is trying to bring about change for groups of people, such as changing a

policy or a law. To make such a change often involves influencing a bureaucracy. For this reason, both individual and systems advocacy examples are described below.

## **1. Refuse to give out the information.**

This tactic is a basic tool for any bureaucrat. By refusing to give you the facts, the bureaucrat hopes you will go away.

In order to reform the system or bring about a change, you need the facts. If you have the facts, the system is forced to deal with you more openly and on a more equal footing.

Democracy depends on people having the facts. The refusal to give out the information may sound like this:

- We don't have that information.
- I'm sorry, but s/he is not in today, is on vacation, is out sick, has not authorized me to give out that information.
- Our computer is down.
- It's confidential.
- We can only give out a summary. (They decide what is included and excluded).
- I'm sorry, but we don't think you need that information.

Whenever you hear any of these statements, be on guard. Ask for a complete explanation of why the information can't be given. Ask when it will be available. Ask who it is available to. Then check with several other sources to find out if the information you have been given (or the excuse) is correct. If information is being withheld from you, use this as an issue to organize around. A lot of pressure can be brought on someone who is withholding information to which you have a right.

## **2. Give them a Red Herring to eat.**

Whenever you are confronting the system, watch out for Red Herrings. When a bureaucrat tries to get the subject changed from what you are concerned about to what s/he wants you to focus on, s/he is trying to give you a Red Herring. You can tell a Red Herring because it doesn't smell right. The bureaucrat may sound like this: "Why are you interested in that issue; it's not

very important. Why don't you start working on..." "Your issue is beside the point; it's extremist; you haven't done the research; that point isn't practical; etc." Suppose you ask your favorite bureaucrat to publish data by name, age, date, sex, types of problems, etc. S/he might answer you with the statement that such data would violate the right of individual privacy. Then s/he moves into a discussion of first amendment guarantees, U.S. civil rights, etc. In the heat of debate, she might hope that you a) get tired and go home, or b) forget the key issue.

When confronted with this tactic, immediately label it a Red Herring and don't get involved. Stick to the issue you want to discuss. You can always talk about the other person's issue at some later time.

### **3. Give the appearance of action without doing anything.**

When faced with an obvious need for change, bureaucrats may try to give the appearance of action without actually doing anything. This tactic may sound like:

- "We have decided to appoint a committee to study the problem."
- "We would like to set up a commission to handle the problem and want members of your group to volunteer assistance because we don't have any money for staff."
- "We would like several members of your organization to join an advisory committee for this problem to help us work out solutions."
- "We plan to issue a policy statement of that problem next week so that everyone will know what to do in the future."

Don't accept these excuses. Set a reasonable amount of time for some real action, and then tell everyone that you expect action by that date. Don't join any study committees or advisory groups which have no real power to do anything.

### **4. Make it impossible for people to be involved.**

A simple and common technique for the bureaucracy to maintain its control is to set things up so that others can't be involved. Some common examples are:

- Scheduling meetings during times when working people can't attend.

- Holding meetings in places which are difficult to reach or where people don't feel safe.
- Using language and terms which are difficult to understand, intimidating, highly technical, etc.
- Giving out guidelines or instructions which are too complicated to understand, or too long and detailed that others become frustrated in reading through them.

A key element in these tactics is to make it appear that the problem comes from consumers, not the system. The bureaucracy sets up an opportunity to participate and then points out that consumers are apathetic. When many consumers experience the same problem like meeting time and place, excessive guidelines, etc., then you have to put pressure on the system to find the solution. Make them responsible.

### **Some general suggestions and guidelines**

Before you confront any bureaucracy, you should try to determine what kinds of tactics are likely to be used. As soon as a tactic has become apparent, LABEL IT. When you name the tactic publicly, it loses some of its power. When everyone involved recognizes the tactic, you can counter it with a minimum of wasted effort.

Hopefully this chapter helped to beef up your advocacy skills, and you feel more comfortable with the do's and don'ts of advocating for yourself. The next section, Formal Advocacy Strategies, will discuss more formal ways to address your concerns by including an outside agency to help resolve the problem.



# FORMAL ADVOCACY STRATEGIES

Sometimes informal advocacy strategies are simply not enough to resolve your problem. This may be because you have not been able to resolve your concern using these advocacy strategies, the strategies are not the appropriate way to resolve your issue, or your concern is serious or urgent enough that you want to start with a more formal process. This section identifies formal strategies to address your concerns including grievance procedures, complaint processes, fair hearings, and legal action. We also discuss some other strategies such as contacting elected officials, going to the media, and developing coalitions with other individuals or organizations.

## **Formal Advocacy Strategies**

Formal advocacy strategies generally involve bringing in an outside decision-maker. This generally occurs after you have been unable to resolve things informally with the person or agency with whom you have the problem. Examples of formal advocacy strategies include grievance procedures, agency complaint processes, fair hearings, or court action. Each of these will be briefly described below with more detailed information later in this chapter.

A grievance procedure is a process for resolving problems within an organization. After a person files a grievance, there usually is an internal investigation (i.e., by someone in the organization) to determine whether a right, policy, or procedure was violated. If no violation is found, there is often an opportunity to appeal this decision. An example is the patient rights grievance procedure for persons receiving mental health, developmental disability, or substance abuse services in Wisconsin.

An agency complaint process usually involves an agency that has some level of oversight over an individual or organization. After a complaint is filed, the oversight agency usually investigates it to determine if a law, policy, or procedure was violated. If so, it then may take some sort of enforcement action against the individual or organization that was the subject of the complaint. Examples are complaints about a nursing home filed with the Bureau of Quality Assurance in the Wisconsin Department of Health and Family Services or an ADA complaint filed with the U.S. Department of Health and Human Services.

A fair hearing is a process involving a neutral decision-maker. Both sides have the opportunity to present their case in person. Most fair hearings involve someone called a hearing officer, who is an employee of a government agency. An individual who believes his/her rights were violated can request a fair hearing. After the hearing officer hears both parties, he or she

makes a decision. If either side of the dispute disagrees with the decision, frequently it can be appealed to a court or to an appeals body which is part of the administrative agency. An example is a Medical Assistance fair hearing to contest a denial of a service. An article “Wisconsin Fair Hearing Process” by Molly Bandt starting on page 207 details the fair hearing process in greater detail.

Court proceedings can be either civil or criminal. In many civil cases an individual files a lawsuit against someone else whom he or she believes violated his or her legal rights. In other cases a government agency may sue an individual or organization in order to enforce a law or agency regulation. Going to court is a very complicated process with many formal rules; thus, having an attorney to help you is critical. Criminal cases require a district attorney to file charges against someone who is believed to have broken a criminal law. The district attorney has discretion about whether to file a criminal case. Not all possible criminal code violations are actually pursued.

Advantages of using these procedures may include getting someone who was not involved in the problem to investigate and make a decision that is unbiased, getting a regulatory agency or court to take action against the person or agency that is causing the problem, and getting more attention to your problem or issue. Disadvantages may include a need to be better prepared and organized, the time involved in using more formal procedures, and the emotional toll that may result from a more adversarial process.

You should also be aware that many cases end up in a settlement after negotiation between the parties. Settlements can be very useful in that you do not have to go through all the formal procedures, thus saving time and energy. However, you may have to “settle” for an outcome that is somewhat less or different from what you initially wanted. If you do get involved in settlement negotiations, review the material in this handbook on successful negotiations.

### Getting Started

Whether you use a grievance procedure, an agency complaint process, a fair hearing, or the courts, there are several basic actions that you must take.

*First, try to figure out if any of your rights have been violated.*

Not every bad thing that happens to people is a violation of a law, policy, or procedure. However, formal advocacy procedures generally require that there is such a violation. For example, under Wisconsin state law patients in a psychiatric hospital have the right to make a reasonable number of telephone calls. However, they do not have an explicit right to send email messages. Thus, filing a grievance or complaint about the inability to send email

messages would not be successful, even though sending email may be the person's preferred method of communication. In this situation more informal advocacy, such as meeting with hospital staff to see if emailing a family member in a distant state could be arranged, might be more successful than filing a grievance or complaint.

You do not have to be a lawyer or legal expert in order to file complaints or grievances, but it helps if you have some basic understanding of what may or may not be considered a violation. You can get this information by asking your service provider or an oversight agency for information about your rights, contacting an advocacy agency, such as Disability Rights Wisconsin, or doing some basic legal research, either by using some of the reference materials that have been written about the rights of people with disabilities or looking up legal material on the web or through a law library. For more information on finding out about laws and legal research, see page 203 of the Toolbox.

In some situations it may be possible to use a grievance procedure to raise issues about an agency's internal policies or about the failure to follow certain required procedures. For example, many employers have employee grievance procedures which can be used to handle disputes which involve an employer's internal policy, such as requests for vacation time. In such cases it will be important to be knowledgeable about the policy. You can always ask for a copy.

*Second, learn about the process you are considering.*

Find out whether there are time limits for filing your grievance, complaint, or court action or for requesting your fair hearing.

Learn what will happen after you file your case or request your hearing.

- What information will you have to provide?
- Is there an investigation? If so, who conducts it?
- Can you appeal a decision you don't like?
- If so, to whom and when?

Understand and consider the possible outcomes from the action you are taking.

- Will the individual or agency be made to change their behavior?
- Can you get any money damages?
- Will the individual or agency be punished in some way, possibly have to pay a fine or lose their license to operate?

Always ask for a written copy of an organization's grievance procedure, of an agency's complaint process, and of the fair hearing process. Study the process and if you don't understand it, ask someone from the organization to explain it or contact a knowledgeable

advocacy agency. It is very easy to miss a deadline or not provide the correct information and thus, lose your case even though you may have been right.

Think about the outcome you want to achieve and whether this particular strategy can get it for you. For example, if you want an apology and an agreement from an agency to stop doing something, a grievance procedure may get you this result. However, if you want money damages, you will probably have to go to court.

*Third, understand the facts of your case.*

The more formal the strategy you choose, the more important it will be for you to have gathered and organized your factual information. For example, in a fair hearing or a court case the burden is on you to prove your case. The proceedings are not about what you feel or what you think; they are about what someone can prove. Thus, you need good factual information to present to the decision-maker. This may include documents as well as testimony from witnesses. In some situations you may need an expert to back you up.

When filing a grievance or complaint, you may need less complete factual information since someone else may conduct an investigation. However, the more information you can give the investigator, the better. Investigators may not have the time to thoroughly look into every case. They may not have access to information that you have. It also helps if your information is well organized so they do not have to dig through a large stack of papers to find key documents. The Informal Advocacy section of this manual has many tips for how to find and organize factual material.

*Do your homework!*

As discussed in the Informal Advocacy section of this manual, it is very important to do your homework before starting to advocate for yourself or someone else. Thus, look at the Formal Advocacy Worksheet.

- Clearly define your problem and your goals - what do you want to achieve?
- Review your facts - what do you know? What additional information do you need?
- Determine, to the best of your ability, whether any laws or agency policies have been violated.
- Think about what formal advocacy strategies might be available to you - grievance procedure, agency complaint process, fair hearing, or court proceeding.
- Determine whether this strategy will get you the result you want.
- Think about possible barriers, including the time involved and possible emotional toll on you.

After you have done your homework, you can then decide whether to proceed and if so, what your next steps will be. Using formal advocacy strategies can be successful; however, you often have to be patient and diligent.

## **More Information about Grievance Procedures, Agency Complaint Processes, Fair Hearings and Court Proceedings**

### *Grievance Procedures*

Grievance procedures are a way to resolve disputes within an organization. An example is the patient rights grievance procedure that every agency in Wisconsin that provides services for mental illness, developmental disabilities, or substance abuse must have. This procedure requires that the agency investigate all internal complaints of patient rights violations and write a report about whether a violation occurred. If the consumer disagrees, he or she can appeal it within the agency and if still dissatisfied, can appeal the decision to the county and then the state.

Many other service providers or funders are required by law to have grievance procedures; these include nursing homes, community based residential facilities (CBRFs), HMOs, and insurance companies. Other organizations, including many employers, may have grievance procedures because it is a useful way to resolve internal disputes.

Some grievance procedures are very formal with strict time lines; others are more informal. Some include appeals to an organization outside the service provider, such as a county or state agency; others are confined to the organization with no outside appeal. Some focus on legal rights violations; others focus on internal organizational policies.

In all cases it is important to get a copy of the grievance procedure so you can know what to expect. Some key questions are:

- What issues/problems can be handled by the grievance procedure?
- When do you have to file your grievance?
- Does it have to be in writing or can you tell your problem to someone?
- How will it be investigated?
- Will you get a written report of the investigation and agency decision?
- Can you appeal the agency decision? To whom? When?
- What is the final stage of the grievance procedure, meaning when are there no more appeals?

## *Agency Complaint Processes*

Many local, state, and federal government agencies have complaint processes. An individual can file a complaint about a violation of a law or regulation. Examples are:

- a local government housing agency where one can complain about violations of the building code
- the Bureau of Quality Assurance in the Wisconsin Department of Health and Family Services where one can complain about violations of nursing home regulations or other health care provider regulations
- the Equal Rights Division in the Wisconsin Department of Workforce Development where one can complain about employment or housing discrimination
- the Wisconsin Department of Regulation and Licensing where one can complain about licensed professionals, such as doctors, nurses, or social workers
- the federal Department of Health and Human Services where one can complain about human services discrimination in violation of the Americans with Disabilities Act.

In addition, many professional agencies have complaint procedures if one of their members is believed to have violated that profession's code of conduct. For example, a person can complain to the National Association of Social Workers about a social worker, who is a member, who has violated his or her confidentiality or another provision of the NASW code.

In some circumstances one can file both complaints and grievances. For example, a violation of patient rights can be grieved within an agency. It can also be the basis for a complaint filed with a government oversight agency, such as the Bureau of Quality Assurance. If the issue is covered by a professional organization's code of conduct, a complaint can also be filed there. Thus, you need to think broadly about where complaints may be filed. You may be able to complain about the same issue in multiple places. However, you should find out about how the various complaint processes work and the amount of time and effort involved in filing the complaints. See pages 132 through 143 of the Toolbox for a listing of various places to file complaints.

While complaint processes vary, many have similar components. They are an intake stage, an investigation stage, a hearing stage, and an appeal stage. However, not all complaint processes have an ongoing role for you, the person filing the complaint. Some oversight agencies, such as the Bureau of Quality Assurance (BQA), will take your complaint, investigate it, and take direct enforcement action against the organization, such as a nursing home. You do not have an ongoing role; you cannot appeal if you do not agree with the action of BQA. Instead it is the nursing home that has a right to a hearing and to appeal. In other complaint processes you do have a role. For example, the Equal Rights Division will investigate your

employment discrimination complaint and make an initial determination about whether discrimination occurred. If either you or the employer disagrees with this determination, either party can request a hearing and can appeal the outcome.

Intake Stage - At this stage information is gathered regarding your particular concern. Some agencies will take complaints over the phone or you may be asked to fill out a form or write a letter. The agency will screen the complaint to make sure it is an issue they can deal with. If not, they may refer you to another agency.

Investigation Stage - During this stage agency staff will review the information you have given them and may gather more information. They may visit a facility to determine if a rule has been broken or they may interview people or ask for documents. Thus, it is important for you to give them as much information as possible about the nature of the violation, when it occurred, who was involved, etc. This will help in their investigation. At the end of this stage the agency will usually determine if a rule or law has been broken. As stated above, this is the point where complaint processes differ. In some complaint processes, the person making the complaint can request a hearing to review the agency's findings. In others only the entity complained about can request a hearing.

Hearing Stage - At this stage the party that has appeal rights, can question the agency's determination and have a hearing before a neutral person, often called a hearing officer. At the hearing the person contesting the agency's action has the burden of proving their case. While administrative hearings are less formal than court proceedings, it is usually good to have a lawyer representing you. Sometimes, before the hearing the agency will try to have the parties mediate their differences, meaning they will see if they can come to a settlement agreement without having a hearing. For additional information on the administrative hearing process see "Practice Tips for Representing Clients at Administrative Hearings," starting on page 211 of the Toolbox.

Appeal Stage - Most complaint processes allow for an appeal after the hearing. Usually this is to a higher level agency official or panel; sometimes it is directly to the courts.

Since complaint processes differ it is very important to get information about how a particular process works. You can request this information from the agency or organization; often it is available on the internet. As with a grievance procedure, it is important to find out if there are time limits for filing complaints. Complaint processes have the advantage of a government agency or professional organization being able to take action to get your problem resolved. However, the time for investigation and action may be considerable. Also, if you get involved in a hearing you may need legal assistance to be successful.

## *Fair Hearings*

Many state programs involving government benefits, such as Medical Assistance or Food Stamps, give an individual the right to a hearing if they are denied the benefits or the benefits are reduced or terminated. These hearings may be called “fair hearings”. Usually the person is notified of the right to a hearing when they receive written notice of the denial, reduction, or termination of the benefit. The hearing is usually before a government agency employee called a hearing officer. The person whose benefits were affected has the right to appear at the hearing in person and to have an advocate or attorney representing him or her. The government agency will also have a representative at the hearing. After listening to presentations from both sides the hearing officer will render a written decision. In some cases the person can request a rehearing of the issue or can appeal the decision to court.

The time frame for requesting a hearing may vary by program. Thus, it is very important to review the notice you receive to find out when the request for a hearing must be filed. Also make sure that you are delivering or sending the request to the right place. You may miss your opportunity to have a hearing if the request for a hearing is not received by the right office by the deadline.

If the hearing request concerns a reduction or termination of current benefits, you should read the notice carefully. Determine when you need to request the hearing so that the benefits will not be reduced or stopped pending the outcome of the hearing. Often this is a shorter time period than the regular time frame for requesting a hearing. Be aware that if you continue to get the benefits and lose at the hearing, you may have to pay them back.

Requests for hearings may be made verbally, but should always be followed up in writing. Forms for requesting hearings are available through county economic support offices or online at <http://dha.state.wi.us/home/WFSHrgReqForm.pdf>. You can also just send a letter which identifies the decision at issue and includes a clear statement of why you are requesting a review of the decision.

After your request for a hearing has been filed, the agency that made the decision will be notified and will have 10 days to submit a brief summary of the date of the decision, reasons for the decision, relevant facts, and the rule or policy relied on when making the decision. You should also receive a copy of this summary. You need to review this summary very carefully since it is the basis for the other side’s case. If any documents are referenced that you don’t have, you should request copies.

Since a hearing involves both sides having to put forth their side of the case, it is very important for you to be well prepared. You need to have all your factual information organized and you need to have a theory about why you are right. You need to be prepared to present this information to the hearing officer. Since these hearing are somewhat formal proceedings, you may want to involve someone, such as a benefit specialist, who has been trained to represent someone at a fair hearing. Benefit specialists are available through the Aging and Disability Resource Centers as well as through some local programs.

After the hearing, the hearing officer will give a written decision. The time frame varies by the type of benefit at issue. Either party can request a rehearing if they believe that there is a material error of fact or law or if important new information has recently been discovered. The request for a rehearing must be made within 20 days of the date of the hearing decision. The decision to grant a rehearing is discretionary. Initial hearing decisions and rehearing decisions may be appealed to court. However, this is a complex process and an attorney should be involved.

Note that this section and the information in this manual only relates to fair hearings for state benefits. Social Security hearings are covered by federal law and follow different procedures, which are not discussed here. For additional information on the fair hearing process see the article starting on page 207 of the Toolbox.

### *Court Proceedings*

In certain situations you may not believe that filing a complaint or grievance will resolve your issue. For example, if you want money damages because of an injury or rights violation, you will need to go to court. Also, if the action is very serious or dangerous, you may need to contact the police and have the problem investigated as a criminal matter. Both of these actions may involve court proceedings.

There are two types of court proceedings - civil lawsuits and criminal cases. Civil cases often involve a violation of a statutory right or a common law right. In a civil lawsuit the individual retains an attorney to file a lawsuit involving a violation of the individual's rights or an injury sustained by the person. Criminal cases involve a violation of a criminal statute. In a criminal case the individual must take the case to the police or district attorney and ask them to take action against the person who is believed to have violated the law. They have discretion about whether or not to proceed. Thus, a criminal case may or may not be filed depending on their assessment of the facts and whether they believe a violation can be proven in court.

Settlement of both civil and criminal cases is very common. Thus, you should be prepared to enter into some negotiations to settle your civil case. Some settlements involve court approval and others are outside of the court process. In some situations a person called a mediator may be involved to help reach a settlement agreement. In criminal cases the settlement discussions are between the district attorney and the lawyer for the person accused of committing the crime. However, you should be informed of a settlement agreement. The judge will have to ultimately agree to any settlement of the criminal case.

### Civil Lawsuits

In the area of disability law there are a number of different types of civil lawsuits that may be filed. One may file a lawsuit for a violation of patient rights under state law. If you have been injured by the negligent action of a professional, you may be able to sue for malpractice and seek money damages. Other types of cases may involve employment or housing discrimination, violations of confidentiality, or violations of Constitutional rights. Regardless of the type of case you have to take the initiative to file it in court. This usually means finding an attorney who is willing to file the case. While there are a few public interest law firms that file cases for free, most civil cases are filed by private attorneys. This means that you need to find an attorney with expertise regarding your issue and work out arrangements to pay for his/her time and expenses. Court actions have very strict time lines and are usually complex. Thus, it is important to contact an attorney in a timely manner and to have your factual information organized as well as possible. You also need to be prepared for the length of the court process and the emotional toll that may be involved.

### Criminal Cases

There are a number of crimes that relate directly to persons with disabilities. These include abuse or neglect, including sexual assault, by various different service providers, sexual exploitation of a patient by a therapist, illegally taking the property or money of a patient, abuse or neglect of a vulnerable adult, and violations of certain provisions of the patient rights and confidentiality laws. Of course, all other criminal laws, such as robbery, battery, murder, etc also apply to persons with disabilities.

As discussed above, the decision about whether to pursue a criminal code violation rests with the police and district attorney. Not all cases are pursued. It is important to contact the police or district attorney soon after the incident so that evidence can be collected in a timely manner. You also need to be prepared to give them all the factual information that you have.

Crime victims and witnesses have extensive rights under Wisconsin law. Law enforcement agencies and district attorney offices are required to give you information about your rights and to offer assistance. You should receive information about procedures to be followed in your case. In certain circumstances you may be eligible for compensation due to the injuries you suffered as a result of the crime. Many offices have a victim-witness coordinator who can help you. Also in the case of sexual assault or domestic violence, advocates in local sexual assault or domestic violence service agencies can help you.

## **Additional Advocacy Strategies**

### Contacting Your Legislator

Sometimes you may feel like you are not getting an appropriate or timely response from a governmental agency or you may not understand where or how to complain about a problem. State and federal legislators usually have staff to help constituents with their problems with government programs. They can be very helpful in providing information about government agencies and various complaint processes. Sometimes they will look into your problem for you or request information from a government agency. When this happens the agency may respond more quickly than when you have made an inquiry. However, be aware that elected officials are not primarily there to solve constituent problems. They have many other duties. Thus, if you know where to complain, it is generally best to start there. Only contact your elected representative when that does not seem to produce any results.

Local government officials, such as county board supervisors or city council alderpersons, can also be helpful. However, they generally do not have staff and thus, may have less time available to help, but they can direct you to other resources.

On the state level you have an assembly representative and a state senator. You can find out who they are and how to contact them by calling 800-362-9472 or by looking on the web at <https://www.legis.state.wi.us>.

On the federal level you have a congress person and two senators. You can find them by looking on the web at <http://www.senate.gov> or <http://www.house.gov>.

On the local level you will usually have a county board supervisor and if you live in a city or village, an alderperson. You can find who they are by contacting your local county board office or your city or village town hall.

While it is not totally necessary, it may help speed things along if you have done some background research and have figured out which level of government is responsible for helping solve your problem. For example, it will only delay things if you contact your federal senator about an issue that is really handled by the county. They may be able to give you some information, but will not be able to help solve the problem.

### Contacting the Media

Many newspapers or radio or TV stations have places where people can complain about consumer issues or problems with government programs. In addition, sometimes your situation is so egregious that it is newsworthy. Contacting the media can get attention for your problem that just calling an agency and complaining cannot get. It is important to be as factual as possible with the information that you give the media. If you embellish it, you may end up looking like someone who is not entirely truthful.

You need to be aware that the media does not have any power to solve your problem; they can just publicize it. Sometimes this publicity can be helpful in getting the attention of a government agency. However, at other times it can make government officials angry and thus less likely to want to help you.

You should carefully weigh whether going to the media will help or hurt your situation. In general, it is best to try to solve problems through established procedures, like those discussed above. The media should usually be contacted only when these procedures are unresponsive or not working correctly. A negative media story can lead to the agency being even more unresponsive. However, if you feel you have no good relationships and nothing to lose, the media attention may be helpful.

### Forming Coalitions with Others

Sometimes you are not alone in having a problem with a particular agency or program. Getting together with other people or groups can be very effective in putting pressure on decision-makers. However, it is important to be clear about your mission and to have as much agreement as possible among the participants. It will also be critical to have a plan of action that others agree to.

### Systems Advocacy

Systems advocacy generally means trying to change a law, rule, policy, or practice that affects a number of people. Sometimes your advocacy on behalf of yourself or someone else can lead

to such a change. This may be especially true if you join with others to try to seek change. Many of the skills and strategies discussed in this manual can be the basis for effective systems advocacy. However, there may be other skills and strategies that will make your systems advocacy even more successful.



# FORMAL ADVOCACY PLAN

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

**What is your goal?**

**What legal rights might be involved in this situation? Think about:**

- Wisconsin Statutory rights - see Wisconsin Statutes
- Wisconsin Administrative Regulations - see Wisconsin Administrative Code
- Federal laws and /or regulations - see United States Code and /or Code of Federal Regulations
- City/County Ordinances - available at your local library
- Other (for example, agency policy or procedures): \_\_\_\_\_

**What rights, if any, might have been violated in this situation?**

(Write down the statute/administrative code/agency policy or procedure that you think might have been violated and a brief description of the right violated.)

**If you don't know or are unsure, who might you contact to get the information about whether a legal right has been violated?**

**What facts do you know?**

**What additional facts or information might you need regarding this situation?  
How can you go about gathering this information?**

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

**Who are some allies or potential allies in helping you resolve this problem/issue?**

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

**What informal advocacy strategies (for example, a letter, phone call or meeting)  
have you tried, if any?**

**If these strategies didn't work, what do you think the problem was?**

**What formal advocacy strategies might be available?**

- Grievance procedure within the agency/program
- Complaint with a government oversight agency
- Fair hearing (for various benefit programs)

- State Courts
- Other: \_\_\_\_\_

**What information about these procedures do you know? What do you need to find out?**

(For example time frames, investigation process, hearings, appeals, etc.)

**What other advocacy strategies might be available?**

(For example, contacting your legislator or the media or forming a coalition with others)

**What advocacy strategy do you think will be most effective to achieve your chosen solution to your problem?**

**What are the potential risks or barriers to using this strategy?**

**What do you plan to do? When? (Be specific)**

**What will you do to take care of your-self while pursuing this strategy?**

**What will you do if this strategy doesn't achieve the solution to your problem?**



# PEER ADVOCACY

## Understanding Your Role as a Peer Advocate

As stated at the beginning of this *Tool kit*, peer advocacy means representing the rights and interests of someone other than yourself. For many individuals, deciding whether and how to speak up or take action in response to a problem can be a scary process to undertake alone. Knowing there is someone available to assist you can provide great comfort throughout the resolution process. This “someone” can be a peer advocate – a friend, family member, co-worker or other person whom you ask to act as a peer advocate.

There are two distinct functions of peer advocates:

1. To work jointly and collaboratively as a knowledgeable supporter of an individual seeking resolution to a problem; or
2. To work at the request of and on someone else’s behalf.

## The “With” Function: Role of Knowledgeable Supporter

The primary responsibility of a peer advocating jointly and collaboratively is **knowledgeable support**. Your role is to assist that individual and be supportive of him/her. In this role, the peer advocate provides support and assists an individual with information regarding the advantages and disadvantages of various options to resolving the problem. Regardless of the circumstances of the situation, the ultimate decision of what to do and how to do it is made by the individual – not the peer advocate. While you need to feel comfortable with your understanding of the situation and your role in its resolution, you should not direct the individual’s decisions about how that resolution should or should not be achieved. Instead, communicate together about the advantages and disadvantages of the various strategies that could be applied. Clarify the goal that the individual has identified, and work together to determine what strategies and actions might best achieve that goal. While a chosen goal or strategy might differ from what you believe is the best course of action, the individual with whom you advocate gets to choose the resolution they will try to achieve as their advocacy goal.

## The “For” Function: Representational Peer Advocacy

While any form of peer advocacy involves working together, advocating on someone else’s behalf combines providing knowledgeable support with actually representing another person’s interests. When a person has a problem that demands representational peer advocacy, they might be in a state of crisis, or feel that having someone else advocate for them will be more effective. An individual might need and/or want someone to act on their behalf – to advocate for them and in consultation with them.

The key to being an advocate is having an interest in the welfare of the individual, a willingness to become knowledgeable about the situation at hand, as well as about the relevant rights and remedies, and an ability to speak out on behalf of the individual. (Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996).)

Of primary importance in being an advocate for another individual is always remembering that you are the spokesperson for that individual. If the individual has the mental capacity to express her/his own wishes, it is your responsibility to assist her/him to implement those desires whenever possible. You may not always be in total agreement with the person for whom you are advocating, but you must put aside your own opinions and represent those of the individual. You should not continue to act as an advocate for another person if you cannot separate your opinions from those of the individual. Of course, you can discuss your perceptions and ideas with the person you are helping, but the individual ultimately makes the decisions about her/his situation. When you as an advocate meet and talk with other persons regarding the individual you represent, you must present the individual’s wishes and opinions, not your own. In many situations, you will have to deal with persons who disagree with the individual’s wishes and opinions. This situation can make being an advocate challenging, especially if you also disagree with the person but have agreed to advocate for her/him. (Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996).)

### Peer Advocacy Blueprint for Success

Regardless of which peer advocacy function you and another person choose to employ in any given situation, there is a common guide or blueprint that should be followed for success of the relationship.

1. *Have and utilize effective advocacy skills and strategies.* Before undertaking any peer advocacy relationship, learn and practice the skills and strategies contained within the Informal and/or Formal Advocacy sections of this manual.

2. *Ask yourself probing questions* about your involvement in a peer advocacy relationship.
  - What are *my interests and motivations* in this peer advocacy relationship?
  - Do I feel comfortable undertaking this role, with this person?
  - When and how are my interests and motivations the same as the person I am advocating for or with?
  - When and how are they *different*?
  - Am I *enabling and empowering the individual* to be her/his own advocate? (Fernandez, Happy Craven. The Child Advocacy Handbook. The Pilgrim Press, New York (© 1980).)
  
3. *Develop a Peer Advocacy Plan*. Deciding what your function will be as a peer advocate is just as important as talking about advocacy goals and strategies. Will you primarily serve as a supporter or a representative for the person? The peer advocate and the person requesting assistance should meet to decide on a peer advocacy plan. This plan involves jointly figuring out the “ground rules” of the peer advocacy relationship. The next section discusses strategies and steps to take to set up these ground rules.

### **Setting the Ground Rules**

In order for a peer advocacy relationship to be mutually successful, both individuals involved need to create and then agree to a set of ground rules for how the relationship will operate. While it might feel unnecessary to clarify the issues described below at this early stage of the peer advocacy process, it is better to discuss these issues up front so that everyone is “on the same page.” Clarify answers to the following questions as specifically as possible. The more time and discussion the advocate and individual have about these issues, the less confusion and miscommunication there will be.

Once the ground rules are set, you should go through the Informal and/or Formal Advocacy Plan process that is outlined earlier in the Tool Kit. These worksheets will assist you (along with the person you are advocating for, if agreed upon) in detailing the appropriate advocacy strategy.



# PEER ADVOCACY GROUND RULES WORKSHEET

## Issues to Consider and Ground Rules to Set

1. What is the person asking you to do – function as a knowledgeable supporter or as a representative on her/his behalf? If both, under what circumstances will you function as a supporter working with the person and when will you actually act as a representative of the individual?

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2. What is the problem needing a peer advocacy response?

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3. Does the peer advocate feel clear about and comfortable with the topic?

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4. What is the goal or outcome the person would like to achieve?

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5. What does the person expect the peer advocate to do? Be specific.

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6. What ideas and strategies have the person and advocate mutually agreed upon?

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7. In what order will these steps be taken and by what date? Who will decide when strategies should be employed?

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8. What if the peer advocate chooses to no longer participate as a peer advocate?

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9. What happens if there is a disagreement between the advocate and the person: on strategy, on the goal(s)?

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10. If the advocate is representing the person, what process is agreed upon for informing the person of what is happening? How often should that communication take place?

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11. Does the representational advocate need to check-in with the person after completing each task before starting another one?

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12. Are there any decisions that the advocate should make on her/his own? If so, what if the person changes their mind after an action has been implemented?

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13. Is there anything specific that the individual wants the peer advocate to keep confidential?

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14. What documentation should the peer advocate keep? What is the process for providing this documentation to the person?

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## **Do's and Don'ts of Peer Advocacy**

(Ideas for this piece originated from [How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies](#).  
Family Resource Center on Disabilities, Chicago (© 1993).)

Peer advocacy can be a tremendously rewarding experience for the advocate and the person for and with whom they are advocating. Yet, peer advocacy also involves many pitfalls. Care and caution are required in order to make the relationship mutually beneficial. Review the lists below and write down your thoughts about how and why each of the items listed can be helpful and/or harmful – to you and the person for and with whom you are advocating.

### **As a Peer Advocate, it's okay to:**

- Help individuals help themselves;
- Build confidence so individuals are able to practice self-advocacy;
- Provide necessary tools and support to promote informed decision-making;
- Assist individuals to learn about their rights;
- Take action as requested by a person for whom you are advocating;
- Be persistent in advocating on a person's behalf;
- Assist with analyzing a problem and deciding on strategies for resolution;
- State options that might be the most effective for solving a problem;
- State your opinions as long as you are clear that you act on the other person's desires, not your own;
- Decide that the peer advocacy relationship is too stressful or unworkable for whatever reason; and
- Assist individuals to find and use resources available to them.

### **As a Peer Advocate, it's not okay to:**

- Take over someone's life or problem and make all of the decisions for them;
- Down play or squelch someone's efforts at self-advocacy;
- Reinforce feelings of dependence and helplessness;
- Keep the person in the dark while doing everything for them;
- Make excuses for your lack of agreed to action;
- Deny the existence of a problem or complaint that the person has communicated to you;
- Speak disparagingly about the person to individuals that you are working with on a person's advocacy goal;
- Share information about the person without their consent;
- Decide for the person what they need and want as a resolution to a problem or situation; and
- Assert your own personal agenda under the guise of acting on someone else's behalf.

### **Ways to Resolve a Dispute**

(Adapted from Wisconsin Coalition for Advocacy. [Where to Now?: A field guide to resolving complaints within the mental health system](#), (© 2000). Reprinted with permission.)

Described below is a summary list of ways to resolve a dispute. Although this list is generally organized in order of least aggressive to most aggressive forms of action, how you as a peer advocate and the person for or with whom you are advocating choose to approach resolving a concern or dispute is up to you. It is not necessary that you follow the order listed below.

Learn about the rights, complaint procedures and available resources applicable to the type of situation in which the person for whom you are advocating is involved. (See the Toolbox for information resources on rights and complaint procedures.) This should help you to decide

what information you need to gather and whether the facts you obtain indicate that a right has actually been violated.

## **Before You Begin**

The *Informal and Formal Advocacy Plan Worksheets* should be used to develop a clear plan for addressing a person's problem or situation. You should also use the Contact List Worksheet and the Telephone Log Worksheet in the Tool Kit to help you to keep organized. Remember that the activities you undertake as a peer advocate are on behalf or with someone else. Any communication, whether written or verbal, should be discussed and reviewed with the individual with whom you are advocating. Also, remember to document everything!

- Keep a file of all of your notes, any correspondence you send or receive, and all written records you may obtain. These documents should be reviewed with the person for or with whom you are advocating.
- Make written notes during all meetings and telephone calls.
- When you are meeting in person or speaking on the phone with anyone about a complaint or concern, write down the date of the communication, the name of the person and her/his position (if any), and the facts you obtain from the discussion. During the communication, it may seem easy to remember what was said, but keeping written notes at the time is very important.
- Write letters confirming and summarizing important phone calls and meetings. Always make a copy of any letter you send.

## **Try to resolve the dispute informally**

The majority of disputes are resolved informally. As a peer advocate, think about talking directly to the individual your peer has a dispute with. Trying to resolve issues or disputes directly and informally can often resolve the person's concern quickly, effectively, and without much time.

When discussing a concern or complaint with someone, it is useful to be prepared. Below are some suggestions that may help you when you talk with someone regarding specific concerns.

- *Decide whether you would prefer to address the issue verbally or in a letter.*  
Depending on your personality, you may feel more comfortable about addressing

your concern in writing instead of verbally or vice versa. Use the strategy that works best for you, and talk over your decision with the peer for whom you are advocating.

- *Make an outline of what you want to say.* Often writing down what points you want to make when you meet with someone can assure that you will not forget to mention an item that is important to you. Bringing in a “cheat sheet” with your points outlined will help you to stay on track. Work with your peer to develop this “cheat sheet.”
- *Be clear about what you want to accomplish.* Before you address an issue with a provider, be prepared to answer the question, “What do I want to accomplish in this meeting? What is my desired outcome?” Your answer may range from just wanting to get the complaint off your chest, to receiving an apology. Although there is no guarantee that you will get the response you are looking for, being aware of what you want will clarify your role and the purpose of bringing it to their attention.
- *Rehearse what you want to say.* Rehearsing what you want to say will give you an edge in the meeting, particularly if you are nervous about addressing someone about the issue. Some people are more comfortable rehearsing by themselves in front of a mirror, while others prefer to have an audience. The more comfortable you are with what you want to say, the more effective you will be as a peer advocate in conveying your points.
- *Take notes during the meeting.* Make sure you write down the date of the meeting, who was present, and any agreements made during the meeting. Often summarizing what has been decided at the end of the meeting insures both parties are in agreement with the course of action if there is one.

# COMMUNICATION SKILLS

Advocacy involves representing and advancing your own or others' interests. The foundation of effective advocacy is communication: how you connect, interact and transmit your thoughts and feelings to another.

There are many forms of communication, such as verbal, written or non-verbal (what you do and how you do it). For each form of communication, there are unique styles that each of us use to communicate. For example, I might write a letter that is more formal and wordy in style. Another person could write a letter on the same topic and use more informal language to describe a situation. Think about any group conversation that you've been a part of. Think of all the different styles of conversation that were used. Add to that picture the body gestures, how they physically positioned themselves, how they used their hands when talking, or where they focused their eyes when listening or talking . . . all of these characteristics represent the many styles of communication we experience.

## Intentional Communication

(Sweet, Mark. Intentional Communication. Disability Rights Wisconsin (2006).)

Communication refers to many kinds of contact. People communicate for a variety of reasons. So, let's focus. This chapter is not about casual conversations or talking with friends. **This chapter is about communicating for a specific reason.** You want something or you don't want something. Maybe you want something to change. It might be that you want someone to know how you feel, that you are upset or angry. The specific issue might be related to where you work or live, to your health care, to family or personal relationships. In all of these situations, you want to represent yourself and your interests well.

- **You want to be taken seriously, understood, and respected.**

Maybe you want a different job or need a reasonable accommodation. Maybe you want permission to have a pet at your rented apartment. You might not like the way someone talks to you or you are having trouble arranging the kind of health care you believe will be beneficial. You want an outcome. *How* you communicate about these desired outcomes is a method. **Communication is a method** of trying to achieve your goals. **You can decide how you will communicate** about your desired outcome.

The personal energy that builds in our minds and bodies when we want a particular outcome can make each contact seem very intense. When communicating about something big and important, some people mistakenly think they have to be demanding or loud. They think they have to tell their whole story to each new person. They think that force will help them appear strong.

Children and adolescents sometimes think they can get their way if they are loud or whine. They might try pleading. Maybe they resort to being mean or insulting. The young person's assumption might be that if they become bigger, louder, nastier, and carry-on longer, the other person will concede.

In grown-up relationships, we are supposed to have learned that these (younger) approaches do not result in our being taken seriously, understood, and respected. When one adult hears another adult yelling, calling names, or carrying-on, those actions are generally described as rude, insulting, juvenile, or out-of-control. And, the people who engage in those actions might be described as rude, insulting, juvenile, or out-of-control. Not all methods of communication are the same.

After you know **what** you want to achieve, it is time to consider **how** you want (to try) to achieve it. The reason we have to learn how to communicate clearly is because other people will not know what we value and want to accomplish until we make it clear. You cannot assume that anyone else knows what you think, what you want, or how you feel.

We communicate with *intention* when we want something to happen or change. Intention refers to having a purpose. When we have a purpose, **we want to represent our own interests as well as possible.**

## WHAT IS COMMUNICATION?

Communication is surprisingly complicated. Communication is not just what you say or write. Consider all of these aspects of communication.

- ▶ The Sender is **you** - the person trying to deliver a message.
- ▶ The Message is what you want someone else to understand.

**What** do you want? What do you want to change or stop? Do you want assistance or advice? Do you want someone to understand how you feel? What is the topic of your message? What is the outcome you want to achieve?

- ▶ The Receiver is the person you want to understand your message.

**Who** can help? Who will care? Who do you trust? Who has authority? Not everyone needs to know all of your business and not everyone can help. But, someone will care. Someone will try to understand and will try to be of help. Do you want one or several people to receive your message? Who?

- ▶ The Method is the way you will try to deliver the message.

**How** will you communicate your message? Face to face, by phone, by letter, by email, by appointment, by dropping in?

- ▶ The Place is a location.

**Where** should this communication take place? Is the topic personal or private? Would this topic be better addressed in an office, in a lobby, in a parking lot, in a restaurant, on a side walk, in the restroom, grocery store, movie theater?

- ▶ The Time refers to both clock time and duration.

**When** would it be convenient to have this contact for both the Sender and the Receiver? Will you want someone's attention during work hours, during a lunch break, when she still has her coat on, when there are other people present?

**How long** would you guess you will need? Will you need about 10 minutes, 20 minutes, half hour, and hour?

- ▶ Tone, Volume, and Attitude

The **message and style of delivery** will influence a Receiver. Messages include the words that are used (content) as well as how they are delivered (style). A message that seems straight forward to a Sender might be perceived as blaming, judgmental, accusing, threatening, hostile, and more by a Receiver based on the style of delivery. Sometimes people report that *it wasn't what s/he said it was the way s/he said it*.

**Most adults have to practice throughout their lives** to communicate so that others will notice and understand them. Below are some of the questions to consider.

**What is my message?**

**What is my natural tendency as a communicator?**

**Who should receive my message?**

**How can my message be presented?**

**What would help me feel more comfortable?**

**What can I do to be clear?**

**What should I expect? And, What's next?**

**How can I take care of myself in the middle of conflict?**

## **WHAT IS MY MESSAGE?**

Begin with a simple statement or request. To begin, think about your message as a Topic and a Desired Outcome. What is **the topic** you want to focus on? What is **the outcome** you want to achieve? Consider the following examples.

Topic: I want to talk about my hours.

Outcome: I want to work more (hours).

Topic: I want to talk about my medication.

Outcome: I want to feel better.

Topic: I want to talk about respect.

Outcome: I feel uncomfortable when you ... and I want you to stop.

Topic: I want to talk about my lease agreement.

Outcome: I would like to have a companion animal in the apartment.

**Your initial contact is to get the Receiver's attention.** Provide the basics. Remember that if you flood someone with too much information before you have the person's attention s/he might be distracted from your main point.

The Receiver might have questions that will help her/him consider your particular situation. When someone asks questions, consider it a sign of interest in your situation. **Be prepared** with supporting information you might need or want to share. This is not the last opportunity you will have, it is the beginning.

*Think about your life now. Is there an outcome you want to accomplish?*

- *What is the topic?* \_\_\_\_\_
- *What is the desired outcome?* \_\_\_\_\_

If you have trouble describing the topic or desired outcome, consider those questions a bit longer before making contact. That sometimes happens. **Be patient with yourself.** It is an important and sometimes difficult step to **clarify your message.**

Think about your life. If “your life” seems too big, focus on one aspect of your life. Think about your work or school life; maybe your home or social life. Consider your health and well being. Is there something you want, don’t want, or want to change? Do you have feelings that are important to let someone else know?

While you might not be ready to make contact with a supervisor or coworker, a landlord, or a health worker, you might feel ready to talk with someone else to help you clarify your message. **Who do you trust?** Is there a friend, family member, co-worker or other person who listens to you without telling you what to do? Sometimes, **it helps to talk about your thoughts and feelings with a person you trust.** Tell that trusted person that you are *trying to clarify what needs to be communicated to someone else.* Ask her/him to listen to you for awhile. If you want this person to ask questions or if you just want someone to listen, let her/him know what you want.

The beauty of a trusted person is that you can say *I want you to listen and let me talk.* If you are not looking for advice, you can say, *I’m not looking for advice right now.* If you want this person to ask questions that help you to think about the issue, you can say, *it might be helpful if you ask me some questions after I finish talking.* Being honest with trusted people about how they can help is great practice for communicating with other people in your life.

## **WHAT IS MY NATURAL TENDENCY AS A COMMUNICATOR?**

A natural tendency is what we do when we are not being particularly careful. A natural tendency is like being on automatic. The advice so often given *Be just be yourself* is only good advice if you are most often considerate and think before you try to express yourself on important matters. More helpful advice is to

- **be yourself *Be* only more attentive and more calm**

Some ways of communicating are just differences in style. They are not good or bad but might be more or less helpful to a Receiver. *If you are curious, ask someone you trust to describe your communication characteristics.* Here are a few examples.

\_\_\_ talks a lot \_\_\_ talks a little \_\_\_ talks fast \_\_\_ talks slow \_\_\_ talks loud \_\_\_ talks soft  
\_\_\_ provides details in sequence \_\_\_ provides details in random order  
\_\_\_ includes a lot of emotion \_\_\_ includes a lot of assumption  
\_\_\_ includes a lot of details \_\_\_ asks a lot of questions \_\_\_ makes a lot of statements

Some ways of communicating are just considered rude. Name calling, yelling, street language, gossiping, threatening are all considered rude and might even be considered dangerous. Some threats are considered criminal. People whose natural tendency has been to interact in ways that are perceived as rude can do better.

Communicating because you want someone to help you is a unique situation. Some people confuse asking with telling, directing, or ordering. They think that making demands is a sign of strength and asking questions is a sign of weakness. Neither is true.

Our natural tendencies are not a good choice in all situations. **The mature communicator thinks about the Message and the intended Receiver.** A Sender (you) can decide how a particular issue could be presented to a specific person. The Sender can decide what method of communication might be clearest and most suitable.

*What do you want people to say about you after you have made contact?*

- *I want people to say about me, s/he is \_\_\_\_\_.*
- *What could you do so that people might say those things about you?*
- *I could \_\_\_\_\_*

## **WHO SHOULD RECEIVE MY MESSAGE?**

When you want to achieve a specific outcome, you want your message to get to the 'right' person. The right person is usually someone who has the experience to advise you (so that you can make decisions) or the authority to influence a change. A person with authority does not necessarily mean the president of the company (or the United States) or the person in charge

of everything. In fact, if you aim too high you might be ignored. **Start with a person who has some knowledge of you and your situation.**

The person who answers the phone or is at a front desk when you call or go to an office is often there to direct you to the correct person. S/he might need to ask you some questions. This is one reason it can be helpful to have thought about the topic of your message. That person might ask, *what is this about?* That is when you express the topic you want to discuss with someone. Setting communication in motion with the right person requires from each of us **a certain degree of patience and respect.** (When the situation is an emergency, you do not wait patiently you contact a crisis line.)

Another part of this discussion about who you should direct your message to is how many people you should talk to about the same situation. Talk with people to increase your clarity and comfort. Talk with people you trust. Do your best to talk mostly about yourself and what you want. But, not everyone you encounter has to hear everything about your situation. When in doubt, you can say, *I want to talk about \_\_\_\_.* *Are you the right person?* If not, s/he might be able to guide you to someone else.

## **HOW CAN MY MESSAGE BE PRESENTED?**

Before you decide *how* to communicate, remember the topic and your comfort. You might be more comfortable addressing some topics in person and feel that some are better in writing or in some combination. **No lengthy message should be delivered by voice mail, email, or fax.** After an initial contact, if someone asks you to provide information via voice mail, email, or fax, you can decide if you want to do that.

**Write anything procedural, legal, or formal that you want to request or say in a letter** with a date on it. Keep a copy for yourself. Take the time to write exactly what is important. In a letter, you can avoid some of the excess emotion that you might be feeling. Also, you can ask someone you trust to review a letter to make sure that it is clear and says only what you want it to say. The Receiver will have time to consider the issue and what you want to accomplish. If you want a response, you can request a response in a reasonable amount of time.

A problem with voice mail and email is that the potential to say things that you will wish later you had not said is tremendous. A click of a mouse or an answering machine *with no reminders* that there is another person who will hear your voice or read your words is risky, especially when you have strong feelings. Another problem with voice mail and email is that

they are one sided. There is not an immediate opportunity for the Receiver to ask a question in order to better understand.

Some people prefer **face to face contact**. With face to face contact there are visual and other factors that will influence the Receiver's impression of you. Try to look and smell clean and neat. People notice these things and you do not want other factors to compete with your message if you can help it.

**Phone contact** requires the same clarity of message as face to face contact. Some people find it easier to talk on the phone because they do not have another person looking at them. Depending on the issue, you might consider phone contact.

Whether you are face to face or on the phone, listen to what the other person has to say. Ask questions. Try to understand. Asking questions and listening to the answers does not mean that you agree, it only means that you are an active participant in the interaction. **Trying to understand the other person is as important as being understood.**

Whether you have phone or face to face contact, you will need **permission and time**. You might be thinking *why do I need permission - I can say whatever I want*. It's true that you can say what you want but that does not mean that another person has time to listen. Permission does not always have to be formal. You can knock on someone's door and ask *do you have time to talk with me about (the topic)?* If you are told that it is not a good time, you can ask when it would be better.

Sometimes, you do not have access to knock on someone's door because a receptionist tells you that person is busy or not available. With people who work on a schedule, **make an appointment**. Having a time when someone agrees to meet with you means that the focus is supposed to be on you. Having an appointment does not mean the person will agree with you, only that you will have a chance to deliver your message. Communicating clearly with the right person is sometimes complicated. If you are prepared with a topic and desired outcome it might be easier for you to focus.

## **WHAT WOULD HELP ME FEEL MORE COMFORTABLE?**

Many people have learned that emotions sometimes cause them to forget their primary message. Consider having **notes** with you. Some people mistakenly think that notes make them appear unsure of themselves or less smart. Don't believe it. Notes demonstrate that you have put some thought into what you are saying and that you respect the person's time.

**An ally** is someone you trust who is willing to support you. In some situations, you can consider having an ally with you. One kind of ally is someone who is quietly by your side. Another kind of ally is **an advocate** (e.g., a peer or professional) who will more actively try to help you represent your message.

Some people like to deliver a difficult message without interruption. Others do not mind being asked questions. If you would prefer to explain something first without being interrupted, you can ask for that. You could say something like, *it would be helpful if I could explain first and then I can answer your questions. Would that be OK?*

### **WHAT CAN I DO TO BE CLEAR?**

When we are with friends or having casual contact, we do not have to practice. When you want to be clear and understood about a significant issue, **prepare yourself. Think ahead** about the topic and desired outcome. Write your message down (even if you are not going to mail it). Read your message out loud. Ask someone you trust to read it to you so you can hear how it sounds. With both face to face and phone contact you will want to **have a clear and understandable message.**

When someone has a lot of emotional energy but no clear message, it can result in talking only about dissatisfaction and blame and frustration. Frustration, anger, and disappointment are common emotions. It is sometimes wise to **acknowledge and name the emotions you feel.** For example, if you want someone to know that you are angry you can say that you are angry without yelling. You can say, *I'm angry, I'm frustrated, or I'm disappointed* and it does not require behavior that will cause you to be judged poorly.

If you notice that you are starting to ramble or raise your voice, you can take a deep breath, exhale and say out loud, *I hear myself getting loud I apologize. Or, I notice I'm talking a lot. Do you understand my concern?* People understand frustration, disappointment, and anger. **When others know you are taking care of yourself it can help them focus on your message** rather than your behavior. Remember, this person is not your last chance to achieve your outcome.

Gossip, e.g., talking about how awful and stupid other people are, is not productive. Gossip rarely helps anyone become clearer. **You can take good care of yourself without trashing everyone else.** Certainly, if the issue you want to address is that someone is mistreating you, be specific about what that person has done that you experience as mistreatment.

## WHAT SHOULD I EXPECT?

## And, *What's next?*

Remind yourself that making contact and delivering your message does not mean that a decision will be made immediately or that you will get what you want. Communication is a method of trying to achieve your desired outcome. There are others you can contact for guidance or assistance. A difficult lesson to learn is that decent people can hear the same words about the same situations and understand them differently. It is too much to expect that everyone we talk to will share our perspective. The point here is that even when we are clear and responsible, we do not always get what we want. It is still important to try. And, some of the time, we can improve our situations by being clear and assertive.

If you are rude, insulting, threatening - people will notice. If you are respectful, responsible, and clear - people might notice that. There is still no guarantee that you will get what you want. **If you say or do nothing, nothing will change. If you present yourself and your position, change might happen and if it does not, you can try another way** and perhaps enlist the support of others.

*A man was referred to a sleep specialist to talk about the effects of a prescribed medication. The doctor complained about the HMO his patient was affiliated with and how they do not let him prescribe all of the medications he wants available to his patients. He apparently did not hear his patient explain that he hadn't slept in almost four days. He was very tired, trying very hard to stay focused, and needed his doctor to understand that the prescribed medication was not helping and was possibly making his situation worse. While the patient listened to the doctor talk about the HMO's formulary and then talk to his interns, he could hear the words forming in his mind. He felt his own energy rising. You f-----g idiot. I told you I can't sleep. I look like sct. The medication you prescribed is making me feel worse. Don't talk to me now about the damn formulary. He held back both the tears and the insults. He remembered his goal. He needed information about how to safely consider withdrawing from the medication he was taking.*

What do you think? Should this man have said everything that was on his mind?

*The patient, even though tired and feeling weak, remembered his own message. He remembered that he had to try to understand and be understood. The patient said, I heard what you said about the formulary. Today, I need your help because I'm not sleeping and the medication you prescribed is making me feel worse. I need your help with just my situation. Can we talk about that? The patient did not learn what he needed to know from the doctor that day. He was able to get the information he needed from the pharmacist.*

What should you expect? Be prepared for anything. Sometimes you will be pleased and other times you will be disappointed. One thing is certain, if you expect that you will always get what you want the way you want it, when you want it, you will live your life with ongoing disappointment. By acknowledging this, you are not giving up. You are not being weak. You are acknowledging the obvious.

What's next? In formal situations, you will have appeal processes to try again. If you believe that you are being treated unfairly or illegally, you will have grievance procedures. Being calm and respectful does not mean you are in agreement with what you are told. It is not a sign that you are weak. It means that you are an adult who should be taken seriously. Sometimes when we thank people, we are not thanking them for their answer. We are thanking them for their time. If you want to be clear on that point, you can say, *thank you for your time*.

### **HOW CAN I TAKE CARE OF MYSELF IN THE MIDDLE OF CONFLICT?**

It would be wonderful if other people could anticipate our needs. And, if circumstances could converge to make our lives easier, that would be helpful too. In reality, when things do not happen as we hoped they would, it is harder to think clearly and to feel at ease. This is stress - and stress has effects. Our thinking might be affected. The sensations in our bodies might change. Even our vision might be influenced. When events don't happen as we want them to, it can seem as though we have been pushed off balance - physically, mentally, and emotionally. From that moment, the things we do to restore balance and clarity are called coping strategies.

**Stress** is anything, positive or negative, that puts us off balance.

**Coping** is what we do to try to restore balance.

All coping strategies are not of equal value. There is skillful coping. For example, it is skillful to anticipate challenging events, notice when they are happening, and use them as reminders to take care of ourselves. There is also unskillful coping. For example, it is unskillful to call people names, throw things, drink and use drugs, or hurt ourselves. It takes effort to cope skillfully while trying to be your own advocate.

We have to practice being aware of ourselves and others. We have to distinguish between what we need and what we want. We have to decide which things are most important. We have to let the right people know what those things are in ways that they understand. And sometimes, we have to negotiate and adjust to disappointment. A high school principal wanted to put one of life's big lessons on a message board in the front of the school that said, *this isn't Burger King, you can't always have it your way*.

Balance is important in social interaction and advocacy. People will say and do things you don't like. You might not like the message (i.e., the substance) or the way a message is delivered (i.e., the style). Long term advocates learn not to react to every unwelcome detail. This too, takes some effort and practice. You have to learn how to take care of yourself in order to be a strong and effective advocate. **You can actually use the events you don't like to cultivate balance and improve your coping strategies.**

**Step 1: Name the events that you wish would not happen.**

Think about the events that put you off balance. "Events" are the things that you wish you would not see or hear again. They don't have to be the biggest or most dramatic events, just the ones that have a significant effect on you. "Off balance" refers to those situations in which your anger or sadness or frustration goes from a zero to a ten and you find yourself agitated or shut down. Make a list of these events that you wish would not happen. Or, finish the following sentences.

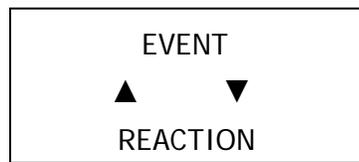
- I don't like it when I hear \_\_\_\_\_
- I don't like it when I see \_\_\_\_\_
- I don't like it when I feel \_\_\_\_\_

**Step 2: Notice how you react?**

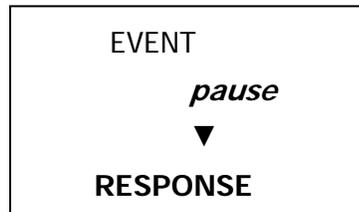
Stressful and challenging events might result in comments like, *I was beside myself* or *I don't remember a thing*. In order to communicate and advocate effectively, a person has to be present and attentive. Notice what is stressful and how it affects you - the events and your reactions.

First there is an event and then your reaction. Without thought or planning, the reaction happens. Maybe you yell or cry, call someone names. Maybe you shut down and say nothing else. This is automatic behavior, not conducive to good advocacy or helpful communication. If we don't learn to respond with more awareness, we might find ourselves reacting to events when they happen and when they don't happen. Maybe you wish that you would never see someone again. Not only do you find yourself having a reaction when you actually see that person, but you start to have the same reactions when you think that you

*might* see the person. You experience the full affects even without the event. This can't be good.



Learn to pause. The goal is to respond rather than react.



It is neither indulgent nor selfish to pay attention to yourself in this way - it is wise. Passengers on airplanes are reminded to secure their own oxygen masks during an emergency before attempting to help anyone else. On a daily basis, you can take care of yourself while advocating on your own behalf.

When I first started learning about skillful and unskillful coping, one of the events I wished would not happen, was hearing someone respond to my ideas by saying, *that's a nice idea, but...* This seemed like such a small event, I was embarrassed to admit it was having such a significant reaction. My reaction was to stop listening. My mind became busy with judgment which changed to self-doubt. I thought, *You're a jerk. You're not listening. You're not even trying to understand. Maybe I'm not smart enough to explain this.* I noticed that I was not seeing the speaker. I could only see a moving mouth or hair, but I was not seeing the person. I noticed physical sensations too, tightness in my chest and pressure in my head.

Refer to your list. What do you wish would not happen? How do those events affect you?

**When IT happens,**

**How does it affect your thinking** - what are your thoughts?

**How does it affect your body** - what do you feel and where do you feel it?

**How does it affect your vision** - what do you see?

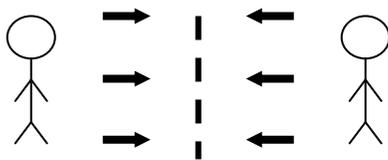
If you are not sure how you react to a particular event, make a commitment to notice what happens to you the next time that event occurs. Unfortunately, just because you make a list of

the events you wish would not happen, they are still likely to happen again. We cannot control everything that happens. However, we can learn how to cope with events, as they happen, in more skillful ways.

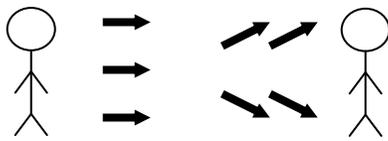
## INTERACTION STYLES

Consider the following interaction styles and how you participate.

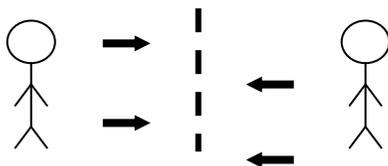
### Characterized by



two people talking at the same time  
often with raised voices  
competing - not conversing

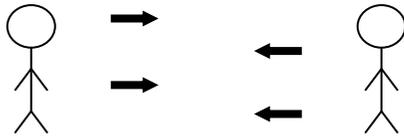


one person talking  
the other person feeling overwhelmed  
the message is lost



two people taking turns  
neither is listening for content  
each is waiting to say, "that's wrong"

In addition, each of the above interaction styles can be characterized by assumptions and a surprising absence of questions. None of these represents a genuine exchange of ideas or a curiosity to understand one another. **(How can there be better understanding without questions or discussion?)** Each of these interactive styles can be a bit intimidating. None of the examples above offers the opportunity to learn or be creative. Imagine what might happen if one of the people in any of these examples paused to consider what was said and then asked a genuine question.



This example is characterized by a slower pace. Each person considers what the other said. Questions are asked to ensure understanding. The opportunity for creative solutions and new ideas exists.

**Step 3: Learn to pause - What might remind you?**

Some people are afraid that if they pause to consider what is said or ask a question, or if they do not react with a loud angry voice, they will be perceived as passive or in agreement. Learning to pause has nothing to do with passivity or agreement. You pause to notice clearly what you heard and how you feel in order to decide how to respond. The goal is to change from reacting to responding. Rather than being either swept away or beside yourself - **you pause to recover your sense of balance and decide how to represent your interests.**

The events that you wish would not happen, can serve as reminders to take care of yourself. They can be reminders to pause. Instead of reacting, when you see or hear what you wish you wouldn't, let it be like a traffic light, an alarm clock, or a tap on the shoulder - let it be a personal reminder. The reminder is saying, *time to pause. Take care of yourself. What do you want to say or do next that might be helpful?*

After noticing my aversion and reaction to *that's a nice idea, but...*, I decided to anticipate it. I wrote the word "but" on the top of my notepad at meetings as a reminder, and then checked it off when it arrived. I acknowledged it. There it is. I let it remind me to exhale, to loosen my shoulders and jaw, to listen carefully to what was said next, and to ask questions. The same events that have, in the past, caused you to be thrown off balance, can remind you to recover your balance and focus your attention. How might you remember to use an event that you have dreaded to help you? \_\_\_\_\_

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**Step 4: Select a Response - What will you do?**

You probably know how it feels to be reactive. We get caught in a moment and either do too much or not enough, and then wish we had the chance to do that moment over, to try again. Although you will not get that moment back, you probably will be in a similar challenging situation. Decide beforehand how you want to participate in difficult situations. What will you do to represent yourself and your situation well? \_\_\_\_\_

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## SUMMARY

- Step 1:** Name the events that you wish would not happen?
- Step 2:** Notice how you react.
- Step 3:** Learn to pause. What might remind you?
- Step 4:** Select a response. What will you do?

## More Communication Tips

(Advocacy Training Manual. Wisconsin Coalition for Advocacy (1996), p. 108.)

1. **Be Direct.**
2. **Don't lose your composure.**

When you get emotionally upset, you lose respect, trust, logic, and momentum. That's costly.

3. **Use the Formula: "When You..., I Feel..., Because...."**

One strategy to let someone know how you feel is to use the formula: "When you X, I feel Y, because Z." For example, "I feel angry when you forget to call when you're going to be late because I worry and can't get to sleep."

This pattern includes all of the variables – real and verifiable, X has to be an observable behavior. Y has to be a feeling, not an opinion. Z has to be an observable consequence.

Here's an improperly phrased statement that will bring argument: "When you act like a prima donna, I feel you don't care whether this company turns a profit or not because you get your commission no matter what the profit margin on what you told the customer we'd do." Such a comment won't work. "Acting like a prima donna" is a subjective statement. "I feel you don't care..." is an opinion, not a real feeling.

Here's the same sentiment expressed in a way that both parties can deal with: "When you fail to ask me about special discounts you want to offer your customers, I feel angry because we lose money on anything sold more than 20 percent below the retail price." That's a specific behavior, a true feeling, and a verifiable consequence.

**Example:** “When you bring up my mistakes during a staff meeting, other people begin to blame me for things I had no control over. I feel helpless to defend myself or explain. As a result, they disregard my authority on the shop floor.”

**Example:** “When you miss your deadline with the numbers on Friday, I can’t close out my books and forward the final reports to Denver. And when they don’t get the report by Monday morning, they can’t issue checks to our suppliers, who add an interest charge on late payments. I feel really angry that I get grief from the Denver people for a delay caused by you.”

Such a structure (1) describes the actions, not labels it, (2) lets the other person know the consequences of the action, and (3) brings the related emotion out in the open. The resulting discussion will most likely, then, focus on the issue rather than personalities.

#### 4. **Own Your Own Feelings.**

Accusations frequently begin with “You make me feel \_\_\_\_.” Fill in the blank with angry, inadequate, dumb, useless, ridiculous. Think about the meaning of such a line: One individual is saying the other person has control over his or her emotions. The other person will then usually counter with “It’s not my fault that you feel \_\_\_\_\_.” The conversation then degenerates into whose fault it is.

Prefer to make statements that show you have control and choice in the matter and at least center on the problem rather than who’s to blame. Example: “I feel stupid when you remind me over and over of a deadline. I’d prefer that you state the deadline once and then drop it.” Only you can decide how you feel. Choose differently. Better yet: “I don’t like you to remind me over and over of deadlines. Once is sufficient.”

#### 5. **Treat Silence as Golden – or Yellow or Amber.**

As an accessory to negotiations, silence changes colors as you need it. Silence is golden when you use it for reflection to avoid popping off without forethought. On other occasions, it may be yellow or amber; it may be taken as agreement or disagreement. When you don’t want to commit yourself, simply listen and think about what the other person is saying.

#### 6. **Don’t Interrupt the Other Person, and Don’t Let the Other Person Interrupt You.**

Some people think they are saving time by interrupting you in a recitation of the details when they already know them. Don’t permit such interruptions: “Margie, I want to finish explaining

what I consider to be the problem.” Say it in a matter-of-fact tone and keep talking. This assertiveness establishes you as a person with a right to be heard. And remember if you’re the person doing the interrupting, the issue is not time, nor even “your version.” The goal is to hear both versions of an event or situation, to piece the truth together, and to sort out the feelings.

## 7. **Take Turns for Airtime.**

For all the griping and complaining from drivers ensnarled in traffic or those people taking mass transit, most would agree that the time involved is their own – at least mentally. It is uninterrupted time for listening to the radio, reading, talking or thinking.

When involved in a conflict, try the same principle. Give each other uninterrupted time to talk, say five or ten minutes, and then take turns. You’ll have the best results if one person agrees to paraphrase what the other says to show that he or she listened. Only after the first person “signs off” that the other person has heard correctly does the second person get a turn to talk.

The process has these four benefits:

- It stops arguments because the other person loses immediacy – he/she can’t interrupt impulsively with a counterattack or denial;
- The other person has to listen;
- The plan builds in cool-off periods for emotions; and
- It helps people to summarize and focus on the most important comments and issues because they can’t remember the entire five-minute talk verbatim.

## 8. **Develop Trust.**

To resolve a conflict, both people have to want to resolve it. When both people in a negotiating situation trust each other, they have a natural inclination to want to come to consensus and resolve any differences. When they distrust each other, one person may decide he or she doesn’t care if they ever come to agreement. And typically, they won’t.

## 9. **Say What’s On Your Mind Without Shifting to a Hostile Tone.**

When anger threatens to overcome you, breathe deeply, slow down, and lower rather than raise your voice. Your words and opinions will sound firm and factual, not emotional and irrational.

## 10. **Examine the Payoffs in Continuing Conflict.**

Psychologists have counseled parents for years that sometimes children misbehave because negative attention is better than no attention. The same can be said of adult conflict. Ask yourself what you or the other person has to gain for refusing to end a running conflict. Does a continual uproar in the department create excitement for the group? Does the conflict feed someone's ego? Does the conflict serve as someone's excuse for not getting a task done or done well? Once you know what the payoff is, you can decide if you can meet the need – ego gratification, excitement, or success – in a less emotionally draining or disruptive way.

## 11. **Determine the Nature of the Conflict.**

For the most part, conflicts can be divided into five categories: conflicts over personalities, conflicts over goals, conflicts over circumstances, conflicts over facts, and conflicts over values.

- Conflicts over personalities can be solved by pinpointing traits that annoy or work patterns that irritate and by accommodating the other person's trait or style. Because personalities are difficult to change, the best coping strategy may be to limit contact with this person or overlook the habit or trait.
- Conflicts over goals can be best handled by compromise. Create alternatives that allow both people to get their needs met. If both people can't reach their goals, the goals can be modified.
- Conflicts over circumstances are easier than most to handle. Creative thinking will usually generate new limits, new details, or new choices to alter the bad situation.
- Conflicts over facts fade easily. Facts can be verified or refuted. When both people become clear on the facts, their conflict goes away.
- Conflicts over values cannot be resolved. The difference between attitudes and values is generally time. Attitudes change; values have taken root in a person's life over a long period of time. Values form the basis for how people look at other people, at work, at ideas, and at life in general. If you consider a situation or action immoral or offensive, that judgment is based on values and you will not likely be satisfied with a compromise.

Once you have categorized the kind of conflict staring you in the face, you'll have a clear understanding about the effort involved in resolving it and the potential for a successful

solution. Some will be quick; some will be never-ending. Plan your future actions and reactions accordingly.

#### **12. Deal With Conflicts Promptly.**

Like hot coals, angry words or bad situations tend to grow hotter when they're allowed to smolder. Friends of mine, a married couple, have a long-time rule in their household of five (two mothers-in-law and a father-in-law, plus the husband and wife): They must deal with any conflict within an hour. If they decide they're too emotional to discuss something immediately when it happens, they call the one-hour-cool-down rule, and then resume their conversation about the problem. Things unattended fester. Hearsay happens. Intentions become suspect. Hurt humiliates. The faster you broach the subject, the less infected the wounds.

#### **13. Appreciate the Value of What You Have to Bargain.**

Sometimes people undervalue what they have to trade. Don't forget the intangibles. Attach value to everything before you begin your discussions. For example, as an employee you may own your own transportation to work and so can work early or late on special projects when asked without undue hardship. If that flexibility happens to be important to an employer, consider it a bargaining chip. Other assets of value include dependability, ethical behavior, responsiveness, contacts and networking opportunities, emotional ownership – not to mention any number of other skills or attitudes. Take a fresh look at what you have to offer in any situation.

#### **14. Research Your Position and the Situation.**

Take time and make the effort to support your position or requests. Read. Gather statistics. Talk to experts. Survey others for majority opinions. When you get ready to talk, you'll have adequate facts and opinions to support what you want done. And the more you know, the better your position to negotiate a win for everybody involved.

# SELF AWARENESS

## Getting Started

Effective advocacy begins with you. Before you can begin to build skills for speaking out and taking action for yourself or others, you need to understand and educate yourself about yourself so that you can identify how your characteristics interact with advocacy. The following articles and exercises will assist you in identifying these characteristics: your style, how you communicate, how you feel about yourself, and identifying your strengths. By recognizing your unique characteristics, you have identified the most important “tool” you can use as an advocate -- you.

The initial focus of this section includes articles and exercises to assist you in recognizing the central role you have in the advocacy process. Next, the focus shifts to the importance of believing in yourself to effectively advocate, and the impact that stigma and self-stigma have on our lives. Finally, this section will finish with suggestions and an exercise to assist you in identifying and assessing your unique approach to problem solving.

## Being the Expert on Yourself

(Adaptation from Copeland, Mary Ellen. “Being the Expert on Yourself,” HelpHorizons.com (© 1995-1999). Reprinted with permission.)

You are the best expert on yourself. You have, by far, more knowledge about yourself than anyone else. No one else lives inside your body or inside your brain. No one else has ever experienced exactly what you have experienced. And no one else can know what you want to do with life – your goals and dreams. (I remember when a vocational counselor showed me my file and it contained goals for my life and how I was going to meet those goals – a document I had never seen. I was flabbergasted.)

If you are like most of us, when you come upon troubling times, experience distressing symptoms or need to make some life changes, you look outside yourself for answers. And you will find that there are many people who will be delighted to direct you, make decisions for you and take action in your behalf. You may reach out to your partner or another family member, friends, colleagues, a religious or spiritual advisor, a counselor or therapist, a medical doctor or medical specialist like a psychiatrist, a nutritionist, an acupuncturist – the list goes on and on. And while all of these people may be able to provide some help, information or guidance, you may overlook the most important authority – yourself. If you overlook your own inner guidance as a source of wisdom, your course of action may prove to be less than helpful.

Since I was diagnosed with a disability, I have reached out to many other sources for help and guidance. They include:

- A doctor who prescribed me medications,
- A nutritionist who told me that I needed more B vitamins and some amino acids,
- A minister who felt my problems would be eased by more involvement in a religious community – that I was out of touch with God,
- Various counselors who told me I should try to heal my relationship with my husband, or that I should leave my husband, and tried to direct me in and out of other relationships,
- A family member who told me that I should “pull myself up by the bootstraps,”
- A well-meaning friend who said I should go home and bake pies for my family,
- A benefits provider that accused me of malingering and being non-compliant.

Looking back I know that I should have asked more questions about my diagnosis. Then I could have decided the best course of action for myself. I could have asked my doctor if he thought other issues in my life – like being in an abusive relationship, being overworked and overwhelmed much of the time, bad things that happened to me when I was a child, lack of close friends and supporters, being kept from doing the things I wanted to do with my life – might be causing or worsening my symptoms. I know now that I definitely should have asked him the possible short and long term side effects of the recommended medication, how much water to drink when taking this medication, if there are times I should not take it, what would happen if I took too much of the medication, etc. Based on what I felt and learned, I could have decided whether I wanted to follow his direction and take the medication.

The most important lesson that I learned from all of this is that in making decisions about me and my life, I first must listen to myself. I must ask myself what I know and feel about myself. Then, if I want to, I can reach out to others for their ideas. As each of them shares their opinion or gives their advice, I can weigh it carefully and see how it resonates with me – does it feel right to me or doesn't it? If it feels right I can do or believe as they suggest. If it doesn't feel right, I don't need to.

You may have received so much advice and been told so many things about yourself over the years that you have no idea how to access your inner knowledge. While it takes time and

patience, you can learn, or improve your ability, to listen to yourself and to determine what is best and right for you. Some of the following ideas may be helpful to you. As you work on this, you will discover other ways that help you to know yourself and what you need.

1. **When another person makes a suggestion of something you should do or says something about you, make sure it feels right to you before acting on it.** You may ask yourself, is it a “bing” (right) or is it a “thud” (wrong)? If it is about some action, you could write the options on sheets of paper. Shuffle them. Then choose a sheet of paper. By noticing your emotions about what the paper says, you will know whether or not it is the right answer for you.
2. **Educate yourself so that you know all there is to know about the issue or issues at hand.** As you learn, make sure what you are learning feels right to you. Remember, just because it is in a book by a prestigious author or is on an internet site does not mean it is right, or that it is right for you. For instance, many people who have a psychiatric diagnosis are given erroneous information like: you will never get well, you can never have children, you can never be in an intimate relationship, you can never go to college, or you can never have the career of your choice. Education will help you make your own assessment of each issue. You may decide that you don’t even agree with the diagnosis or that anyone has the right to diagnose you with anything. You may prefer to think about your symptoms as feelings rather than a diagnosis.
3. **Discuss the issue in depth with a person or people you trust, even an “expert” like a doctor or counselor.** Then decide for yourself how you feel about the input you received and what action you are going to take.
4. **Before making a major decision about anything, decide to wait a specified amount of time,** for instance three days (or longer for more major decisions). Often, after reflection, you will change your mind. My mother once jotted down a note that said, “If you haven’t changed your mind lately, maybe you don’t have one.”
5. **Journaling.** The process of writing can be helpful in gaining understanding of how you really feel about something. Don’t worry about penmanship or grammar. Write anything you think or feel. It doesn’t have to be right. It can be pure fantasy. It can be thoughts, feelings, expressions of emotions, ideas, plans – anything you want. You never have to show it to anyone if you don’t want to. Others should respect the privacy of your writings. Read your writings when you feel like it.

6. **Peer counseling.** Ask a friend that you trust to peer counsel with you. Decide how much time you can spend (most people do it for one hour but it could be more or less time). Divide the time in half, and each of you spend your half of the time talking, laughing, crying, ranting, raving – anything that feels right to you – while the other person listens closely without interrupting you.

As you work on accessing the inner knowledge that you possess, and taking action based on what you know about and want for yourself, you may find, as I have, that the quality of your life improves and that your life becomes richer than you could have ever imagined.

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## **Believing in Yourself**

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), p. 6.)

In self-advocacy, attitudes and beliefs are as important as skills are. "Self-advocacy requires an internal belief that you are someone who is worth advocating for," says Clearinghouse program director Marie Verna.

By believing in themselves, people can unlock their potential. Andrea Stephenson, an advocacy trainer, says that it "involves helping people to realize their own strengths." By teaching people about advocacy, she's learned that, "It didn't matter what level people were in their recovery, everyone had skills within themselves."

People who have gotten involved in self-advocacy also agree that once you become involved in advocacy, the rewards multiply. Success serves to bolster your self-esteem. Mary Ellen Copeland, a well known author and lecturer who has a psychiatric disability says "The more we reach out and get what we need, the better we feel about ourselves. As our symptoms are relieved, we feel better, but also when we get what we need, we feel better about ourselves."

Howard Trachtman agrees. "I like challenges," he says, "and when I feel like I've mastered something, I can move on to something else." He notices that being able to achieve advocacy goals also helps other people. "For the purpose of empowerment, it's best that people do as much as they can to the best of their ability," he continues.

Keep in mind that although self-advocacy means taking responsibility for getting what you want, it doesn't mean that you have to be alone: you shouldn't ignore your existing support systems. Self-help groups can help you deal with uncomfortable situations that you might encounter in your self-advocacy efforts.

## Oppression and Stigma

Issues of oppression and stigma affect people on a daily basis. The next few pieces discuss issues related to oppression, stigma and self-stigma. While it might seem unusual to some that these issues and articles are addressed in this *Advocacy Tool Kit*, recognition of the existence and impact of oppression and stigma cannot be overstated. How we view ourselves and others impacts our effectiveness as self-advocates.

### Self Disclosure as a Stigma-Buster

(Hopkins, Cindy. "Self Disclosure as a Stigma-Buster." Austin Travis County Mental Health Mental Retardation Center. Website: <http://www.atcmhr.com>. Reprinted with permission.)

*While the author describes her journey as a person diagnosed with a mental illness, other types of disabilities can be equally as difficult to reveal. It may be particularly difficult to let others know about a medical, mental, physical, developmental, learning or other disability that is "hidden" and not immediately noticeable to others. If you have a disability and you wish to share your experiences with others, Cindy's tips may come in handy.*

My name is Cindy Hopkins. I am 33 years old. I live in Austin, Texas. I work at the Texas Department of Mental Health and Mental Retardation as the Mental Health Coordinator of Consumer Affairs. I am diagnosed with bipolar disorder and have struggled with the symptoms of mental illness in my life for 25 years.

When I was 23 years old, I attended a Texas Mental Health Consumers' (TMHC) Conference. This was my first experience seeing and hearing other persons talk about their experience with mental illness. Instead of seeing illness and despair, I saw hope and life. I saw people having fun and sharing strength. I left this conference with confidence. As a result of hearing other persons talk about their mental illness, I lost some stigma I held about my own illness.

After the TMHC Conference, I ran for and was elected Vice-Chair of the TMHC Board. I was later hired as Executive Director of TMHC. Through my involvement with TMHC, I had many opportunities to share my experience as a mental health consumer. These opportunities have built my self-esteem, strengthened my courage, and built me up as a role model for the community, not just for persons with mental illness.

This reduction of my stigma about my mental illness encouraged me to work at MHMR with persons who don't have mental illness and feel equal with my non-disabled co-workers. Working around me has helped eliminate stigma about mental illness in my non-disabled co-workers.

I understand that revealing mental illness can be a difficult challenge, primarily due to the stigma persons face when they are open about their disability. It is especially difficult to be open about a hidden disability, particularly one that faces as much discrimination as mental illness. Revealing a mental illness can be one of the most courageous actions a person takes, but can also be one of the most rewarding, both personally and for the mental health community.

There are some important tips to remember when revealing your disability:

- Be brief – keep it to the key facts so you don't lose your audience.
- Don't exaggerate – mental illness is stressful enough without trying to make it sound too terrible
- When telling your story, provide balance – tell the good and the bad parts
- Shatter myths – use your opportunity to rid the community of untruths about mental illness. This is a key stigma-busting tool in story telling.
- Offer hope – remember that you are a role model when you disclose your disability whether you choose to be or not and you effect the entire mental health disability community, for good or for bad.

Remember, when you self-disclose your disability you send a message to the world that you are OK. Maybe if enough people tell the world that it is OK to have a disability, the world will accept it and stigma will end.

## **Self-Awareness of Problem-Solving Strategies**

In order to become an effective self-advocate, first you need to understand how you feel and respond to problems. This understanding might assist you to determine what strategies and skills you want to focus on throughout this *Advocacy Tool Kit* to enhance your role as a self-advocate. For example, if I learn from this self-awareness exercise that I am more comfortable and effective problem-solving by writing letters and less comfortable talking with someone, I might want to focus building my advocacy skills around communicating over the telephone or at face-to-face meetings. Also, I might decide that enhancing my letter writing skills to effectively address strategies to solve a problem would be useful.

How each of us feels and responds to problems that arise in our daily lives differs. The following exercise is designed to reflect the diversity of problem-solving strategies that people employ. Keep in mind that while there are many different ways to solve problems, there is no "right" way. Please complete the *Self-Awareness Tool Worksheet* below to assist in assessing the problem-solving strategies you currently employ.

## Self-Awareness Tool

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

Think about some of the obstacles that you've faced recently. How do you react to obstacles? This isn't a test and there are no "right" answers! The purpose of this exercise is to help you learn more about yourself.

1) *Check one.* When I face a problem, I usually:

- |  |  |
|--|--|
| <input type="checkbox"/> Blame myself                | <input type="checkbox"/> Investigate who's responsible |
| <input type="checkbox"/> Blame others                | <input type="checkbox"/> Feel numb                     |
| <input type="checkbox"/> Blame the system            | <input type="checkbox"/> Get teary eyed and feel down  |
| <input type="checkbox"/> Blame no one                | <input type="checkbox"/> Other: _____                  |
| <input type="checkbox"/> Get motivated to resolve it |  |

2) *Check all that apply.* When I face a problem, I usually:

- |  |  |
|--|--|
| <input type="checkbox"/> Try to find solutions   | <input type="checkbox"/> Feel sad or discouraged           |
| <input type="checkbox"/> Feel angry              | <input type="checkbox"/> Try to ignore it                  |
| <input type="checkbox"/> Can't concentrate       | <input type="checkbox"/> Feel overwhelmed about what to do |
| <input type="checkbox"/> Turn to others for help | <input type="checkbox"/> Other: _____                      |

3) *Check all that apply.* When a doctor, government employee or service provider tells me something, I usually:

- |  |   |
|--|---|
| <input type="checkbox"/> Believe the person            | <input type="checkbox"/> Look for information on my own |
| <input type="checkbox"/> Ask them additional questions | <input type="checkbox"/> Other: _____                   |
| <input type="checkbox"/> Ask someone else              |   |

4) *Check all that apply.* I discuss problems with:

- |   |   |
|---|---|
| <input type="checkbox"/> Doctors, nurses & therapists | <input type="checkbox"/> A case manager |
| <input type="checkbox"/> Friends and/or family        | <input type="checkbox"/> Peers          |
| <input type="checkbox"/> Co-workers                   | <input type="checkbox"/> Other: _____   |

5) *Check all that apply.* I find the following helpful:

- Written materials from Social Security, Medicare, or Medicaid or other government agency
- Written materials from consumer groups or other advocacy groups
- Written materials from my doctor, therapist or service provider
- Information on the Internet
- Books from the bookstore or library

Talking with other people to learn more

Other: \_\_\_\_\_

6) *Check all that apply.* When I face a problem, I make lists of:

Important facts

What I will do

People to contact

I don't make lists, I \_\_\_\_\_

What I want

7) *Check all that apply.* When I use the phone to solve a problem:

I am confident

I give up if my calls are not returned

I am nervous

I sometimes ask to speak to a supervisor

I don't lose my temper or shout

I usually get good results

Other: \_\_\_\_\_

8) *Check all that apply.* When I need to write a letter:

I am confident

I ask a friend to proofread the letter

I am nervous

I send copies to other people

I ask for help to write it

Other: \_\_\_\_\_

I give a deadline for the person to write me back

9) *Check all that apply.* When I hold a meeting to solve a problem:

I am confident

I bring a friend along

I am nervous

I send a letter afterward

I don't lose my temper or shout

Other: \_\_\_\_\_

I have a written plan for the meeting

10) *Rank 1<sup>st</sup>, 2<sup>nd</sup>, and 3<sup>rd</sup>.* My top three choices for resolving a problem are:

1. Using the phone \_\_\_\_\_

4. Other: \_\_\_\_\_

2. Writing a letter \_\_\_\_\_

3. Scheduling a meeting \_\_\_\_\_

11) *Check all that apply.* If a problem isn't solved right away:

I get motivated and continue to advocate

I give up or put it off

I talk to people's supervisors

I get angry

I try to get more information

I ask someone for help

Other: \_\_\_\_\_

I feel hurt, blame myself, or assume I did something wrong

12) *Check all that apply.* When someone makes a promise to me but doesn't keep it:

I give up

I contact the person's supervisor

I get angry

Other: \_\_\_\_\_

I contact the person

13) *List ways.* I feel effective solving a problem by:

| \_\_\_\_\_

| \_\_\_\_\_

| \_\_\_\_\_

| \_\_\_\_\_

14) *List your goals.* Based on what I learned from this self-awareness exercise, I would like to focus my advocacy skills on:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Reflecting on what you learned in the Self-Awareness Exercise

(Adaptation from Teacher's Guide, Freedom Self-Advocacy Curriculum, National Mental Health Consumers' Self-Help Clearinghouse (April 2000 Pilot Version), p. 26.)

Look over your answers to the *Self-Awareness Tool*. Think about the following questions as you review your answers:

- When do you feel most effective when trying to solve a problem? Would you like to build on that identified strength?
- How satisfied were you with the way you react when something goes wrong? Would you like to work on this?
- How confident do you feel in analyzing the problems that you face? Would you like to work on this?
- Do you feel like you know how to solve the problems that you face? Would you like to work on problem-solving skills?
- Do you feel like you follow through until a problem is solved? Would you like to work on this skill?

Many of the strategies and skills contained within this *Advocacy Tool Kit* will assist you to build on your personal strengths and enhance your problem-solving skills. Again, there is not one way or "right" way to solve problems. The most important concept to remember from the *Self Awareness* exercise is learning about what works for you and how you can build on those identified strengths to become an even more effective advocate.



# EMOTIONAL SELF-CARE

An important and often overlooked component of self-advocacy is emotional self-care. Remember, self-advocacy means representing and advancing your own interests. Although self-advocacy relies on you, you do not have to experience this process in isolation. In order to effectively speak and advocate for yourself, think about the people, information and resources you might want or need to achieve your advocacy goal:

- who you can share strategies and ideas with,
- what resources might assist you in gaining the confidence and experience you want or need to be effective, and
- what would assist you to prepare for and debrief following a self-advocacy experience?

The following articles and exercises will assist you in identifying some tools you might want or need as you build and enhance your skills and initiate actions on your own behalf. The initial focus of this section includes articles and exercises to assist you in identifying ways to promote emotional self-care. Next, this section focuses on the importance of sustaining yourself as you encounter success and resistance along the way.

Self-advocacy is not always a benign process: it can be tiring, frustrating, and sometimes risky – depending on the situation. This section will assist you to acknowledge and identify concrete ideas and steps that you can take to help you stay emotionally well or feel better through any advocacy situation you might encounter.

## **Presents to Give Yourself**

(Adaptation from [81 Presents to Give Yourself](#). Mental Health Association of Oregon.)

- Walk instead of ride
- Give yourself a compliment
- Break a bad habit, if just for today
- Read a poem aloud
- Visit someone who cannot leave the house
- Use a new word
- Walk to the nearest park
- Take yourself to lunch
- Sign up for a class
- Enjoy silence
- Search out a long-lost friend
- Look at the stars
- Be thankful
- Frame a picture
- Forget an old grudge
- Help a stranger

- Try a new food
- Take a risk
- Tell someone you love him or her
- Do something you've always wanted to do
- Contact someone you've been thinking about
- Surprise a child
- Sing in the shower
- Walk in the rain
- Give away something you don't like
- Curl up before an open fire with some cocoa
- Return something you've borrowed
- Organize some small corner of your life
- Draw a picture, even if you can't draw
- Keep a secret
- Go wading
- Smell a flower
- Send a card to someone for no reason
- Take an early morning walk
- Tell a joke
- Walk barefoot
- Visit a lonely person
- Go for a swim
- Build a sandcastle
- Write a poem
- Volunteer some time to a good cause
- Reread your favorite book
- Take a different road to get home
- Let someone do you a favor
- Hide a love note where a loved one will find it
- Go to a fair
- Do something hard to do
- Get up before anyone else
- Hum
- Go to the library
- Jump in a pile of leaves
- Take a rainy day nap
- Meditate
- Learn something new
- Hug someone
- List 10 things you do well
- Pay a compliment
- Waste a little time
- Buy a ticket to a special event
- Pop popcorn
- Turn off the TV and talk
- Practice courage in one small way
- Eat with chopsticks
- Bake bread
- Kiss someone
- Clean out your wallet
- Laugh at yourself
- Look at old photos
- Talk to a pet
- Encourage a young person
- Give yourself a present
- Follow an impulse
- Start a new project
- Have breakfast in bed
- Give your dog a bone
- Watch the sun set
- Allow yourself to make a mistake
- Make a surprise gift
- Lie on the grass
- Rearrange a room
- Let someone love you
- Go shopping





# EMOTIONAL SELF-CARE

## Boundaries

Another aspect of emotional self-care involves recognizing and maintaining healthy boundaries. Whether we are asking for help, breaking down barriers of isolation, or advocating, boundaries play a key role in how we interact with others and they with us. List below some ways that you can maintain healthy boundaries while pursuing your self-advocacy goal.

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## Patience, Perseverance and Sustenance: Self-Advocacy for the Long Haul

Taking care of ourselves emotionally is critical to the success of self-advocacy strategies; however, all of our effort, skill development and action might not result in success. As the self-advocate, you control only half of the process! The person, agency or entity with whom you are self-advocating has her/his/its own response to your efforts. You have control only over your actions, not theirs. As a result, achieving a self-advocacy goal that you have set is limited in some degree by the other party. That is why it is important for your self-esteem, confidence and focus to be patient with the often-slow wheels of change, to persevere when you meet resistance, and to sustain yourself over time for the long-term solution – not the quick fix.

As you learn or enhance self-advocacy skills, it's most gratifying to experience immediate results. Sometimes the absence of immediate resolution to a situation, despite your best advocacy efforts, can feel disheartening, discouraging and defeating. Because it might take an extended period of time and repeated efforts on your part to achieve your goal, you might feel "stressed out" or "burned out" about the situation.



# TOOLBOX

The Toolbox contains additional information and activities that expand on both advocacy and legal information you learned in the Advocacy Toll Kit. The Toolbox contains scenarios for you to practice your advocacy skills as well as information to help guide you to additional resources and places to file a complaint if you wish. The Toolbox further explains legal rights and processes and will guide you on how to conduct legal research.

# Additional Advocacy Information

## Scenarios to Practice Self- and Peer Advocacy Skills

Effective self-advocacy or peer advocacy requires building and practicing skills to help you feel comfortable and confident in reaching identified advocacy goals. This section provides you with opportunities to practice applying some of the skills that you have learned to some real-life scenarios.

Below are several brief vignettes of common complaints. The first four scenarios include a summary of different actions one could take to resolve the issue. Please be aware that more formal actions, such as filing a complaint or a grievance, do not guarantee you will achieve your desired outcome. For example, in Scenario 1, Jacob may decide to file a complaint with the Department of Regulation and Licensing with the desire to have the psychiatrist's license taken away; however, the Medical Examining Board may decide instead to issue a written warning to the psychiatrist.

### **Note to Peer Advocates:**

The strategies employed to assist an individual in the scenarios described below might differ in a peer advocacy role. Therefore, it will be most useful to understand those differences by first reviewing the scenarios from a self-advocate's perspective. Write down your thoughts and responses. Then, go through the scenarios again and review each situation and develop responses from a peer advocate's perspective. Go back through and compare how the strategies and/or information vary between being a self-advocate and a peer advocate.

### **Scenario 1: Confidentiality**

Jacob is looking for information on what action, if any, he could take against his previous doctor whom he had seen as an adult, but who shared confidential information about him with his parents and his wife without obtaining his written consent. He was not able to file a grievance under the Patient Rights Grievance procedure because the incidents had occurred several years ago.

*Pretend you are Jacob*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Jacob could write a letter to the doctor.
- Jacob could contact the Medical Examining Board in the Wisconsin Department of Regulation and Licensing (DORL) which would be able to investigate the doctor's breach of confidentiality which is in direct violation of the state mandated Administrative Code all doctors must follow as licensed practitioners.
- Jacob could also contact the State Medical Society. These professional organizations might be able to assist him in confronting the doctor in an informal meeting, or they might write a letter reprimanding the doctor for not respecting a patient's right to confidentiality that is a violation of the professional code of ethics.
- If the doctor is an employee of a clinic or hospital, Jacob could file a complaint with the Bureau of Quality Assurance in the Department of Health and Family Services which has the authority to review confidentiality practices at the clinic or hospital.
- Jacob could contact a lawyer to discuss filing a lawsuit against the doctor for violating his right to confidentiality.

*What else might Jacob try to do in this situation?*

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- \_\_\_\_\_

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## **Scenario 2: Insulting, Disrespectful Comments from Therapist**

Martha believes that the social worker made negative, judgmental comments about her and her daughters during meetings. Instead of working in a supportive, therapeutic way with the family, Martha felt that the social worker was “blaming the victims” who had sought help from her.

*Pretend you are Martha*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Martha could decide that meeting with the social worker and discussing her concerns about the social worker’s behavior might be useful.
- Martha could file a patient rights grievance regarding these comments, as a violation of her right to be treated with dignity and respect.
- If the therapist failed to address Martha’s grievance she could contact the Grievance Examiner in the Division of Supportive Living of the Wisconsin Department of Health and Family Services who monitors any problems or complaints that can not be resolved because a program’s grievance procedure is deficient.

- The Wisconsin Department of Regulation and Licensing could be called to determine if the social worker involved has violated a provision of the Social Work Administrative Code.
- Martha could also call the Wisconsin Chapter of the National Association of Social Workers to file a complaint, or to see if someone could facilitate an informal meeting to resolve the issue.
- If the incident took place in a certified mental health clinic, Martha could contact the Bureau of Quality Assurance to file a complaint against the facility for not following the state mandated grievance procedure or for violating her right to be treated with respect and dignity.

*What else might Martha try to do in this situation?*

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- \_\_\_\_\_

### **Scenario 3: Landlord/Tenant conflict**

Angela has concerns about the fact that the windows in her first floor apartment don't lock. She didn't notice that the windows didn't lock when she viewed the apartment before signing her one-year lease. She recently talked with her landlord and he promised that her windows would be replaced. Three months have gone by, and still the windows haven't been replaced.

*Pretend you are working with/for Angela as a peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does Angela want to achieve?
- What rules/ordinances/laws govern this situation?
- Who are some of the key decision-makers?

- What strategies have you and Angela agreed you could use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Angela could set up a meeting with her landlord, you as the peer advocate, and herself to talk over her concerns.
- You and/or Angela could write a letter to the landlord.
- Angela and/or you could file a complaint with the housing authority and copy the landlord.

*What else might you/Angela try to do in this situation?*

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- \_\_\_\_\_
- \_\_\_\_\_

**Scenario 4: Sexual abuse**

Karen is an incest survivor who was in therapy with a psychologist who told her that he was attracted to her. He told Karen that he needed to “bring that out in the open so that they could move on from there”. Karen got involved with support groups and read books on the subject of sexual abuse. As time passed, she realized how inappropriate it was for her therapist to tell her he was attracted to her. Karen would like to file a complaint even if no action is taken against the psychologist so that at least there is a record for others who may experience the same thing with him.

*Pretend you are Karen*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*Possible Actions:*

- Given Karen's desire to have a record of her complaint on file, she should contact the Wisconsin Department of Regulation and Licensing, which licenses psychologists.
- If Karen decided to pursue action against her psychologist within 45 days of the incident, she could file a grievance with the agency or business where the psychologist is employed.
- Karen could also contact the Wisconsin Psychological Association to file a formal complaint against her former psychologist for an ethics violation.
- If the incident took place in a state mental health certified clinic, Karen has the option to contact the Bureau of Quality Assurance in the Wisconsin Department of Health and Family Services to file a complaint.

*Karen has stated the outcome she wants to achieve. If she hadn't wanted to file a complaint, what other self-advocacy strategies might Karen try to do in this situation?*

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## Scenario 5: Medications

John talks with you about helping him resolve some concerns he has about his medications. He feels like he's not being listened to, and he wants your help as a peer advocate. John has been put on a new medication, and has been experiencing blurred vision for the last several days. John believes that there is something wrong with his vision and that he may be losing his eyesight. John talks with his physician about his vision on several occasions and is told that his vision is fine. John continues to experience blurred vision and is very concerned about it. When he went to see the doctor about the medication and his vision, the doctor was rushed and did not have time to discuss John's concerns. He doesn't know what to do and hope that you, as the peer advocate, can help him out.

*Pretend you are John's peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does John want to achieve?
- What rules/ordinances/laws govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

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## Scenario 6: Overwhelmed

Mahalia has been in the hospital for the last two weeks. She was living in a shelter prior to her hospitalization because she lost her apartment due to not being able to pay her rent. Mahalia's immediate plans are to stay with her sister upon discharge, but she can't stay with her long. She needs a longer-term housing solution. Mahalia would like assistance in finding housing and also would like to receive a referral to an outpatient AODA program, information on employment opportunities and emergency income assistance. She feels overwhelmed with all of the issues that she feels need to be addressed. She doesn't know where to begin or where to go. She asks you to assist her as a peer advocate.

*Pretend you are Mahalia's peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does Mahalia want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

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## Scenario 7: Gaining Independence

Irma has had an agency-based payee for the last three years. During this time, the agency staff that Irma had started working with left the agency, so she's been working with a new staff

person for about nine months. Irma wants to be more actively involved in the budgeting of her finances and has told the staff person about her desire to move to a different apartment. The staff person/payee states that Irma's apartment is fine and that there is no need for her to move. The payee also states that Irma doesn't need to be more involved with her own financial concerns, since it's the payee's job. What strategies might Irma and you try in this situation?

*Pretend you are Irma's peer advocate*

*Think about:*

- What additional information do you need?
- Where can you get more information?
- What outcome(s) does Irma want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

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- \_\_\_\_\_
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### **Scenario 8: A Friend**

Jessie is 17 years old. She was admitted to a Child Caring Institution six weeks ago under a court order as a child in need of supervision. A teacher at the Institution called you because Jessie continually comes to class wearing outdated, ill-fitting clothing. Jessie's self-image was poor from the start and the teacher believes that the clothing has made matters worse. The only person Jessie says she cares about is you.

*Pretend you are Jessie's friend who has been contacted by the teacher*

*Think about:*

- As a Peer Advocate, who is the person for whom you are advocating?
- What additional information do you need?
- Where can you get more information?
- What outcome(s) do you want to achieve?
- What outcome(s) does Jessie want to achieve?
- What outcome(s) does the teacher want to achieve?
- What rules govern this situation?
- Who are some of the key decision-makers?
- What strategies could you use to achieve the desired outcome(s)?
- What barriers might you encounter/have to overcome?

*List Possible Actions:*

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## Where to File a Complaint

If you feel you have been wronged, you may wish to file a complaint. Below is a list of entities that process complaints on a variety of different common concerns. This list is not a complete listing of places you can file a complaint. Depending on your circumstances, there may be other places for your complaint to be filed.

### Complaints Regarding Health Programs or Residential Care Programs

#### State of Wisconsin, Department of Health and Family Services

##### Office of Quality Assurance

*Regulates mental health, developmental disability and AODA programs for adults, adolescents and children. Such programs include adult day care facilities, adult family homes, alcohol and other drug abuse treatment programs, ambulatory surgical centers, caregiver background and criminal check requirements, community based residential facilities (CBRF), corporate guardianships, end stage renal dialysis providers, facilities serving people with developmental disabilities, home health agencies, hospices, hospitals, laboratories, mental health treatment programs, nursing homes, outpatient rehabilitation facilities, residential care apartment complexes, and rural health clinics.*

P.O. Box 2969

Madison, WI 53701-2969

Phone: (608) 266-8481

Fax: (608) 267-0352

Website: [http://dhfs.wisconsin.gov/ri\\_DSL/bqa.htm](http://dhfs.wisconsin.gov/ri_DSL/bqa.htm)

#### State of Wisconsin, Department of Health and Family Services

##### Bureau of Regulation and Licensing

*Regulates child care and child welfare facilities, which include family child care centers, group child care centers, day camps, group foster homes for children, residential care centers for children and youth, shelter care facilities, and child placing agencies.*

1 West Wilson Street – Room 534

P.O. Box 8916

Madison, WI 53708-8916

Phone: 608-266-9314

TTY: 888-692-1382

Fax: 608-267-7252

Website: [http://dhfs.wisconsin.gov/ri\\_dcfs/](http://dhfs.wisconsin.gov/ri_dcfs/)

## Complaints against Professionals

### State of Wisconsin Department of Regulations and Licensing

*Regulates and monitors professionals that require a license or certificate. Credentialed health professionals monitored by the Department of Regulations and Licensing (DORL) include nurses, physicians, psychologists, social workers, ect. Each profession is regulated by the DORL is governed by a statute and administrative code, which are rules of professional conduct and ethical practice for the profession.*

1400 East Washington Avenue, Room 112

Madison, WI 53703

Phone: (608) 266-2112

Website: <http://drl.wi.gov/>

### State Medical Society of Wisconsin

330 E. Lakeside Street

Madison, WI 53715

Phone: (866) 442-3800 (toll-free)

Fax: (608) 442-3802

Website: <http://www.wisconsinmedicalsociety.org/>

### Wisconsin Psychiatric Association

330 E Lakeside St.

Madison, WI 53715

Phone: (608) 283-5491

Website: <http://www.thewpa.org/>

### Wisconsin Psychological Association

126 South Franklin Street

Madison, WI 53703

Phone: 608-251-1450

Fax: 608-251-5480

Email: wispsych@execpc.com

Website: <http://www.wipsychology.org/>

Wisconsin Chapter of the National Association of Social Workers

16 North Carroll Street Suite 220

Madison, WI 53703

Phone: (608) 257-6334

Toll Free: (866) 462-7994

Fax: (608) 257-8233

Email: [naswwi@tds.net](mailto:naswwi@tds.net)

Website: <http://www.naswwi.org/>

Wisconsin Nurses Association

6117 Monona Drive

Madison, WI 53716

Phone: 608.221.0383

Fax: 608.221.2788

Email: [info@wisconsinnurses.org](mailto:info@wisconsinnurses.org)

Website: <http://www.wisconsinnurses.org/>

## **Other Health Care Complaints**

State of Wisconsin Office of the Commissioner of Insurance (OCI)

*A state agency that regulates insurance companies.*

125 South Webster Street

Madison, Wisconsin 53702

Phone: (608) 266-3585 (Madison)

Toll Free: (800) 236-8517 (statewide)

TDD: 711 (ask for 608-266-3586)

Website: <http://oci.wi.gov/>

Joint Commission on Accreditation of Health Care Organizations

*JCAHO is a private, non-profit, accreditation organization that evaluates the practices and procedures of hospitals and other health care services, networks, and organizations.*

Complaint Hotline: 800-994-6610

Website: <http://www.jointcommission.org/>

## Complaints Concerning Health Benefits

*For assistance with Disability benefits related problems, you may want to contact a Disability Benefit Specialist if available in your county (see page 156 of the Toolbox).*

Medicaid (Family Care, BadgerCare, COP/CIP, etc.)

*Contact Medicaid recipient Services: 1(800) 362-3002. Also see information on Medicaid appeals and fair hearings on page 207 of the Toolbox.*

Medicare

*For assistance with Medicare Parts A and B or supplementary payers you may want to contact the Medigap Helpline (see page 160). For assistance with Medicare Part D, you may want to contact the Disability Drug Benefit Helpline if you are under age 60 (see page 157) or the Prescription Drug Helpline (see page 164).*

1(800)MEDICARE [1(800) 633-4227]

Health Insurance Risk Sharing Plan (HIRSP)

*If the policyholder or applicant disagrees with HIRSP's decision, the individual may request a review by the plan administrator. The individual has 60 days after the date of HIRSP's decision to request in writing a further review by the plan administrator. To request the review, the policyholder must submit a written request including pertinent information such as name, identification number, date and place of service, and reason for the review.*

*Clearly indicate that the written request is for a review. This will help HIRSP process the request. Mail the request for review to the address below:*

HIRSP

Appeals Department

1751 W. Broadway

PO Box 7062

Madison, WI 53707-7062

(800) 828-4777

Website: <http://www.hirsp.org/>

## Complaints Concerning Other Benefits

### Social Security Administration (SSA)

Social Security Administration, Office of Public Inquiries

Windsor Park Building

6401 Security Blvd.

Baltimore, MD 21235

Toll Free: 1-800-772-1213

Website: <http://www.ssa.gov/>

OR

Social Security Administration – Regional Office

PO Box 8280

Chicago, IL 60680-8280

Toll Free: 1-800-772-1213

Website: <http://www.ssa.gov/chicago/>

OR

Contact your local SSA Office

### State of Wisconsin, Department of Workforce Development, Division of Equal Rights

*Takes complaints regarding the State of Wisconsin Family Medical Leave Act.*

201 East Washington Avenue, Room A300

Madison, WI 53708-8928

Phone: (608) 266-6860

TTY (608) 264-8752

Fax: (608) 267-4592

OR

819 North 6<sup>th</sup> Street, Room 255

Milwaukee, WI 43203

Phone: (414) 227-4384

TTY (414) 227-4081

Fax: (414) 227-4084

Website: <http://www.dwd.state.wi.us/er/>

United States Department of Labor

*Takes complaints regarding the Federal Family Medical Leave Act.*

Madison District Office

US Dept. of Labor

ESA Wage & Hour Division

740 Regent Street, Suite 102

Madison, WI 53715-1233

Phone: 1-866-4-USWAGE (1-866-487-9243)

Website: <http://www.dol.gov/esa/whd/fmla/>

## **Employment Discrimination Complaints**

State of Wisconsin, Department of Workforce Development, Equal Rights Division

201 East Washington Avenue, Room A300

Madison, WI 53708-8928

Phone: (608) 266-6860

TTY (608) 264-8752

Fax: (608) 267-4592

OR

819 North 6<sup>th</sup> Street, Room 255

Milwaukee, WI 43203

Phone: (414) 227-4384

TTY (414) 227-4081

Fax: (414) 227-4084

Website: <http://www.dwd.state.wi.us/er/>

Equal Employment Opportunity Commission (EEOC), Milwaukee Area Office

Reuss Federal Plaza

310 West Wisconsin Avenue, Suite 800

Milwaukee, WI 53203-2292

Phone: 1-800-669-4000

TTY: 1-800-669-6820

Fax: 414-297-4133

Website: <http://www.eeoc.gov/milwaukee/> or <http://www.eeoc.gov/>

**\*\* A few cities have a Civil Rights Department that investigate complaints, contact your city to see if there is a complaint process.**

## Housing Complaints

### United States Department of Housing and Urban Development

Henry Reuss Federal Plaza  
310 West Wisconsin Avenue  
Milwaukee, WI 53203-2289  
Phone: (414) 297-3214  
TTY: (414) 297-1423  
Fax: (414) 297-3947  
Website: <http://www.hud.gov/>

### State of Wisconsin, Department of Workforce Development, Equal Rights Division

201 East Washington Avenue, Room A300  
Madison, WI 53708-8928  
Phone: (608) 266-6860  
TTY (608) 264-8752  
Fax: (608) 267-4592  
OR  
819 North 6<sup>th</sup> Street, Room 255  
Milwaukee, WI 43203  
Phone: (414) 227-4384  
TTY (414) 227-4081  
Fax: (414) 227-4084  
Website: <http://www.dwd.state.wi.us/er/>

### Metropolitan Milwaukee Fair Housing Council

*Takes housing discrimination complaints as well as complaints on predatory lending practices statewide.*

600 E. Mason Street, Suite 200  
Milwaukee, WI 53202  
(414) 278-1240  
(877) 647-3247 (toll free)  
Fax: (414) 278-8033  
Website: <http://www.fairhousingwisconsin.com>  
Provides services statewide

## Vocational Rehabilitation Complaints

### Wisconsin Client Assistance Program (CAP)

Department of Agriculture Trade & Consumer Protection

*CAP takes complaints against the Division of Vocational Rehabilitation Services (DVR) and the eight Independent Living Centers around the state.*

2811 Agriculture Drive

P.O. Box 8911

Madison, WI 53708-8911

Toll Free: 1-800-362-1290

Phone: 608-224-5070 or 608-224-5071(V/TTY)

Website: <http://www.dwd.state.wi.us/dvr/cap.htm>

### State of Wisconsin, Department of Workforce Development, Division of Vocational Rehabilitation (DVR)

201 East Washington Avenue,

PO Box 7852

Madison, WI 53707-7852

Phone: (608) 261-0050

Toll Free: (888) 877-5939

TTY: (800) 442-3477

Fax: (608) 266-1133

Website: <http://www.dwd.state.wi.us/dvr/>

## Education Complaints

### Section 504 of the Rehabilitation Act

U.S. Department of Education

Office for Civil Rights

Chicago Office

Citigroup Center

500 W. Madison Street, Suite 1475

Chicago, IL 60661

Telephone: (312) 730-1560

Fax: (312) 730-1576; TDD: (877) 521-2172

Email: [OCR.Chicago@ed.gov](mailto:OCR.Chicago@ed.gov)

Website: <http://www.ed.gov>

State of Wisconsin Department of Public Instruction (DPI)

125 S. Webster Street

P.O. Box 7841

Madison, WI 53707-7841

Toll Free: (800) 441-4563

Website: <http://dpi.state.wi.us/>

State of Wisconsin, Department of Workforce Development, Equal Rights Division

*Takes complaints regarding discrimination in post-secondary education.*

201 East Washington Avenue, Room A300

Madison, WI 53708-8928

Phone: (608) 266-6860

TTY (608) 264-8752

Fax: (608) 267-4592                    OR

819 North 6<sup>th</sup> Street, Room 255

Milwaukee, WI 43203

Phone: (414) 227-4384

TTY (414) 227-4081

Fax: (414) 227-4084

Website: <http://www.dwd.state.wi.us/er/>

## **Access Complaints**

Americans with Disabilities Act (ADA), Title II

*Contact if your concern is regarding equal access State or local government program, service, or activity.*

U.S. Department of Justice — Civil Rights Division

950 Pennsylvania Avenue, N.W.

Disability Rights Section – NYAV

Washington, D.C. 20530

Toll Free: (800) 514-0301

TTY: (800) 514-0383

Website: <http://www.ada.gov> or <http://www.usdoj.gov/crt/ada/>

## **Complaints regarding Public Transportation**

Americans with Disabilities Act (ADA), Title II

Office of Civil Rights

Federal Transit Administration

U.S. Department of Transportation  
400 Seventh Street, S.W., Room 9102  
Washington, D.C. 20590  
Toll Free: (888) 446-4511 (voice/relay)  
Website: <http://www.fta.dot.gov/ada>

Americans with Disabilities Act (ADA), Title III

*Contact if your concern is regarding access to a private or non-profit business such as a restaurants, retail stores, hotels, movie theaters, private schools, convention centers, doctors' offices, homeless shelters, transportation depots, zoos, funeral homes, day care centers, and recreation facilities including sports stadiums and fitness clubs.*

U.S. Department of Justice — Civil Rights Division  
950 Pennsylvania Avenue, N.W.  
Disability Rights Section – NYAV  
Washington, D.C. 20530  
Toll Free: (800) 514-0301  
TTY: (800) 514-0383 (TTY)  
Website: <http://www.ada.gov> or <http://www.usdoj.gov/crt/ada/>

Section 508 of the Rehabilitation Act

*Contact if your concern is regarding access to electronic and information technology developed, maintained, procured, or used by the Federal government.*

U.S. General Services Administration Center for IT Accommodation (CITA)  
1800 F Street, N.W. Room 1234, MC:MKC  
Washington, DC 20405-0001  
Phone: (202) 501-4906  
TTY: (202) 501-2010  
Website: <http://www.gsa.gov/section508>

State of Wisconsin, Department of Workforce Development, Equal Rights Division

201 East Washington Avenue, Room A300  
Madison, WI 53708-8928  
Phone: (608) 266-6860  
TTY (608) 264-8752  
Fax: (608) 267-4592  
OR  
819 North 6<sup>th</sup> Street, Room 255  
Milwaukee, WI 43203  
Phone: (414) 227-4384

TTY (414) 227-4081

Fax: (414) 227-4084

Website: <http://www.dwd.state.wi.us/er/>

## **Complaints on Tribal Lands**

Federally recognized tribes are often exempt from state and federal discrimination laws. Sorting out if a law covers you can be complicated. If you have been discriminated against by tribal program that receives direct federal funding, you may be able to file a complaint under Section 504 of the Rehabilitation Act. Also, many tribes have an internal complaint or grievance process.

### Section 504 of the Rehabilitation Act

U.S. Department of Justice — Civil Rights Division

950 Pennsylvania Avenue, N.W.

Disability Rights Section – NYAV

Washington, D.C. 20530

Phone: (800) 514-0301

TTY: (800) 514-0383

Website: <http://www.ada.gov>

## **Voting Complaints**

### State of Wisconsin Elections Board

17 West Main Street, Suite 310

PO Box 2973

Madison, Wisconsin 53701-2973

Phone: 608-266-8005

Fax: 608-267-0500

Email: [seb@seb.state.wi.us](mailto:seb@seb.state.wi.us)

Website: <http://elections.state.wi.us/>

### U.S. Department of Justice — Civil Rights Division

*Takes complaints regarding access to polling places for Federal Elections*

950 Pennsylvania Avenue, N.W.

Voting Section – 1800 G

Washington, D.C. 20530

Toll Free: (800) 253-3931 (voice/TTY)

## Other Complaints

State of Wisconsin Department of Agriculture, Trade and Consumer Protection

*A state agency that takes complaints regarding unfair business practices, the safety and quality of food, agricultural and commerce complaints, and other consumer protection issues.*

Consumer Protection Hotline: 800-422-7128

Website: <http://datcp.state.wi.us/index.jsp>

To file complaint online, click here:

[http://datcp.state.wi.us/cp/consumerinfo/cp/complaint-form/cp\\_complaint\\_form.jsp](http://datcp.state.wi.us/cp/consumerinfo/cp/complaint-form/cp_complaint_form.jsp)

# Glossary

## **Advocacy**

Speaking and acting on behalf of oneself or others; pleading a cause.

## **Access**

The extent to which an individual who needs care and services is able to receive them. It is more than having insurance coverage or the ability to pay for services. Access also is determined by the availability of services, acceptability of services, cultural appropriateness, locations, hours of operation, transportation needs and cost.

## **Accreditation**

An official decision made by a recognized organization that a health care plan, network, or other delivery system complies with applicable standards.

## **AODA**

Alcohol or Other Drug Abuse.

## **BadgerCare**

BadgerCare offers the same health care coverage as Medicaid to low-income families without access to health insurance whose income exceeds the MA guidelines, but is below 185% of the federal poverty level. There is no asset test.

## **Barriers**

An obstacle; something that separates or keeps away.

## **Bureaucracy**

An administrative structure that is often difficult to navigate.

## **Centers for Medicare and Medicaid Services (CMS)**

A federal agency formerly known as Health Care Financing Administration (HCFA) HCFA. CMS oversees the federal Medicaid and Medicare programs.

## **Client Rights Specialist**

Mental health, developmental disability, and substance abuse programs must have a Client Rights Specialist (CRS) to work with consumers who file grievances. It is the job of the CRS to meet with the consumer to assist him/her with filing a grievance. The CRS must investigate the grievance by meeting with the consumer and any parties involved in the grieved incident, reviewing records and

other materials and taking other needed actions. A Clients Rights Specialist cannot have any involvement in the incident which the client is complaining about.

### **Community-Based Residential Facilities (CBRF's)**

With some exceptions, a CBRF is a place where 5 or more adults, who are not related to the operator, reside and in which care, treatment or services above the level of room and board but not including ongoing nursing care are provided as a primary function of the facility. Typically, ongoing nursing care would have to be provided from an outside source not connected to the facility operator. CBRF's are licensed under HFS 83, Wis. Admin. Code.

### **Complaint**

A complaint is filed with a governmental agency or professional organization to resolve a dispute or a violation of state law.

### **Complainant**

A complainant is the individual who is filing the complaint. The complainant usually is the user of the services; however, others such as family members, friends, or other professionals may file a complaint on behalf of someone else.

### **Conflict Resolution**

Strategies and efforts to address and resolve disputes; might also involve negotiation and/or mediation.

### **Consumer**

Any individual who does, could or has received health care or services. Includes other more specialized terms, such as beneficiary, client, customer, eligible member, recipient, or patient. Also, consumer might refer to someone who has been diagnosed with a mental illness and has received treatment in some manner. (See "survivor")

### **County Human Services**

The county departments of human services are responsible for developing and implementing programs and services for children and adults with mental illness, substance abuse and developmental disabilities, as well as providing child welfare and other social services in Wisconsin.

### **Deductible**

The amount an individual must pay for health care expenses before insurance (or a self-insured company) begins to pay its contract share. Often insurance plans are based on yearly deductible amounts.

## **Department of Health and Family Services (DHFS)**

Wisconsin's Department of Health and Family Services, located on the web at <http://www.dhfs.state.wi.us>.

## **Disability Determination Bureau (DDB), Wisconsin Department of Health and Family Services**

The state bureau that determines whether an individual has an illness, injury or condition that meets the legal definition of disability in the Social Security Act. The DDB reviews cases for initial entitlement and medical Continuing Disability Reviews. Individuals determined to have a disability may be eligible for assistance through programs such as SSI, SSDI, Medical Assistance and the Medicaid Purchase Plan. For more information go to <http://www.dhfs.state.wi.us/ddb/index.htm>.

## **Division of Vocational Rehabilitation (DVR), Wisconsin Department of Workforce Development**

Located within the Wisconsin Department of Workforce Development, DVR is the agency that administers vocational services created by the Rehabilitation Act of 1973. For information about DVR, go to their Website located at <http://www.dwd.state.wi.us/dvr/>.

## **Entitlements**

Any type of benefits guaranteed to be provided to a certain group or groups by the government.

## **Formal Advocacy Strategies**

Solutions or strategies that bring in an outside decision-maker to resolve problem(s). Examples of formal advocacy strategies include filing a complaint with the state or federal government, taking court action or filing a grievance.

## **Grievance Procedure**

A special procedure set up by the State of Wisconsin to resolve patient rights disputes for any individual receiving mental health, drug/alcohol, or developmental disability services. A grievance is filed with a Clients Rights Specialist at the program or facility involved with the dispute.

## **Health Care Financing Administration (HCFA)**

A federal agency now called Centers for Medicare and Medicaid Services (CMS). See definition for Centers for Medicare and Medicaid Services above.

## **Health Insurance Portability and Accountability Act (HIPAA)**

A law that requires coverage of pre-existing conditions for people who change employer group health plans.

**Health Insurance Risk Sharing Plan (HIRSP) of Wisconsin**

A plan to provide major medical and Medicare supplement health insurance to Wisconsin residents with mental or physical disabilities. The contents of the insurance plan are established by state statute and administrative rules. All plan participants must pay a premium, annual deductible and some co-payments.

**Health Maintenance Organization (HMO)**

A health plan that also is involved in how your health care is delivered. Managed care refers to health plans coordinating your health care with you and the providers that participate in that health plan.

**Hospital**

A building, structure, institution or place that offers inpatient, overnight care on a 24-hour basis, and is devoted primarily to maintaining and operating facilities for diagnosing, treating and providing medical or surgical care to 3 or more unrelated individuals who have a physical or mental illness, disease, injury, a rehabilitative condition, or are pregnant, and which regularly makes available at least clinical laboratory services, diagnostic x-ray services and treatment facilities for surgery, obstetrical care, or other definitive medical treatment.

**Informal Advocacy Strategies**

Ways to resolve a problem without bringing in an outside decision-maker such as a state or federal investigator, a judge, or other entity to help resolve the problem.

**Legal Advocacy**

Using attorneys and the legal or administrative systems to establish or protect legal rights.

**MCO**

Managed Care Organization.

**Mediation**

A process for resolving disputes and conflicts in which a neutral third party acts as a moderator for the process.

**Medicaid**

A program, also known as Medical Assistance, MA, Title XIX, T-19 and the Wisconsin Medical Assistance Program (WMAP) that provides medical assistance for certain individuals and families with low income and resources. It's a joint federal/state program established to pay for medical services for people with disabilities, people 65 years and older, children and their caretakers, and pregnant women who meet the program's financial requirements. The purpose of Wisconsin Medicaid is to

provide reimbursement for and assure the availability of appropriate medical care to persons who meet the criteria for Medicaid.

### **Medicaid Purchase Plan (MAPP)**

Many people with disabilities want to work but worry that doing so could jeopardize their vital health and long term care coverage. MAPP offers people with disabilities who are working or interested in work the opportunity to buy their Medicaid coverage. Program benefits include the same benefits as those available through Wisconsin Medicaid, the opportunity to earn more without the risk of losing health care coverage, higher asset and income eligibility levels, and increased personal and financial independence.

### **Medical Assistance (MA)**

Wisconsin's name for Medicaid.

### **Medicare**

The national health insurance program for all Social Security recipients who are either over age 65 or permanently disabled. Individuals receiving Railroad Retirement benefits and people with end-stage renal disease are also eligible for Medicare coverage. Eligibility is not based on financial need. Procedures should not vary significantly from state to state and coverage is similar to that provided by private insurance companies: it pays a portion of medical costs. Often, deductibles and co-insurance (partial payment of initial and subsequent costs) are required of the beneficiary (person receiving medical services). Medicare Part A is Hospital insurance, and Medicare Part B is Supplemental Medical (outpatient) insurance.

### **Medicare for Working People with Disabilities**

When SSDI beneficiaries lose their Medicare entitlement because they have worked past their Extended Period of Medicare Coverage (EPMC), it is possible for them to buy Medicare insurance.

### **Medicare Supplement Insurance**

Medicare supplement insurance is also known as Medigap insurance. Although Medicare covers many health care costs, you still have to pay Medicare's coinsurance and deductibles. There also are many medical services that Medicare does not cover. A Medigap policy provides reimbursement for some of the out-of-pocket costs that are not covered by Medicare and which are the beneficiary's share of health care costs.

### **MH**

Mental Health.

**Negotiation**

Any time two groups with conflicting interests meet to discuss the issues between them, and seek resolution.

**Nursing Home**

With limited exceptions, any place which provides 24-hour services to 3 or more residents who need more than 7 hours per week of nursing care or personal care. This definition overlaps with that of CBRF; the central distinction is that a CBRF cannot provide nursing care as a “primary function” of the facility. The term “nursing home” includes both nursing facilities licensed under HFS 132, Wis. Admin. Code, and facilities for the developmentally disabled licensed under HFS 134, Wis. Admin. Code. A facility must be licensed in order to be certified for Medical Assistance funding as a skilled nursing facility (SNF) or intermediate care facility (ICF).

**Ombudsman**

A person who is appointed to investigate complaints and/or assist an individual in filing a complaint. An ombudsman also assists in settling disputes.

**Peer Advocacy**

Representing the rights and interests of someone other than yourself.

**Psychiatrists**

A licensed physician, who earns a medical degree such as the M.D. (Doctor of Medicine) or D.O. (Doctor of Osteopathy), and then undertakes a psychiatric residency during which time they learn to apply medical skills, such as prescribing drugs, to treating psychological disorders. They may practice psychotherapy. Most psychiatrists rely on interviews for diagnostic purposes but may refer clients to psychologists for psychological testing.

**Psychologists**

Have at least a master’s degree, and in most states must have a doctoral degree (Ph.D., Ed.D., Psy.D.), to use the label psychologist. They use interviews, behavioral observations, and psychological tests to diagnose psychological disorders and adjustment problems, and use psychotherapy to treat them. Most psychologists have been trained extensively in research methods, neuroanatomy, statistics and various types of therapeutic techniques. They are more likely than other helping professionals to be critically acquainted with psychological theory.

**Recovery**

The process of getting better. The term “recovery” has a unique meaning in the mental health community and involves the process of defining or redefining oneself as a person with hope who is empowered and whose mental illness does not define who they are as a person.

## **Respondent**

The respondent is the individual or agency against whom a complaint is filed.

## **Rights and Reality II**

An Action Guide to the Rights of People with Disabilities published in 2001 that provides a comprehensive guide on all the laws, rights, and services affecting adults and children with disabilities in Wisconsin. Includes practical self- and peer advocacy strategies, and citations to applicable statutes, regulations and case law. Spiral manual: 400 pages - \$30 for consumers and families; \$40 for others; CD-ROM version – key word search capability; increase screen image size to 800%; can be run on Windows or Macintosh platforms; print directly from CD-ROM - \$30 for consumers and families; \$40 for others. Contact Disability Rights Wisconsin at 608-267-0214 / 800-928-8778 (for consumers and their families), or 888-758-6049 (TTY).

## **Self –Advocacy**

Representing and advancing one's own interests.

## **Social Security Disability Insurance (SSDI)**

The federal program that provides benefits to disabled individuals who have earned credits under the Social Security system.

## **Supplemental Security Income (SSI)**

A federal and state program based on need that provides benefits for aged, disabled or blind individuals who are low-income.

## **Survivor**

Used in this document, someone who has been diagnosed with a mental illness and has been treated for their diagnosed illness in some manner and endured and come through those experiences. (See "consumer")

## **Systems Advocacy**

Influencing social, political, and economic systems to bring about change for groups of people.

## **TANF (Temporary Assistance to Needy Families)**

TANF is overseen by the Office of Family Assistance (OFA) which is located within the U.S. Department of Health and Human Services, Administration for Children and Families. It was created by the Welfare Reform Law of 1996. TANF became effective July 1, 1997, and replaced what was then commonly known as welfare: Aid to Families with Dependent Children (AFDC) and the Job Opportunities and Basic Skills Training (JOBS) programs. TANF provides assistance and work

opportunities to needy families by granting states the federal funds and flexibility to develop and implement their own welfare programs.

**W-2 (Wisconsin Works)**

The public assistance program, that replaced AFDC, for parents who live with their children. It provides work experience, training education, counseling, childcare, transportation and other assistance to parents so they can find and keep a job. (from *W-2: Your Right to Receive Assistance* published by Legal Action of Wisconsin, Inc.)

## Resources

### Wisconsin Advocacy and Disability Resources

#### **ADAPT**

Website: <http://www.adapt.org> (national website)

Wisconsin ADAPT

Steve Verriden

(608) 249-4308

Email: [adaptsteve@charter.net](mailto:adaptsteve@charter.net)

Karla Smith

(608) 242-5690

Email: [angel53717@yahoo.com](mailto:angel53717@yahoo.com)

Southeast Wisconsin ADAPT

Tobie Tyler & Roxan Perez

(262) 792-1478

Fax: (262) 792-1484

Email [ttobielaw@aol.com](mailto:ttobielaw@aol.com) or [travelroxy@aol.com](mailto:travelroxy@aol.com)

#### ***AIDS Network***

Website: <http://www.aidsnetwork.org>

##### Madison Office

600 Williamson St.

Madison, WI 53703

(608) 252-6540

Fax: (608) 252-6559

##### Janesville Office

101 E. Milwaukee, Suite 96

Janesville, WI 53545

(608) 756-2550

Fax: (608) 756-2545

##### Beloit Office

136 W. Grand Ave. Suite 202

Beloit, WI 53511

(608) 364-4027

Fax: (608) 364-0473

AIDS NETWORK'S SERVICE AREA: Adams, Columbia, Crawford, Dane, Dodge, Grant, Green, Iowa, Juneau, Lafayette, Richland, Rock, and Sauk Counties

### ***AIDS Resource Center of Wisconsin***

The AIDS Resource Center of Wisconsin provides resources and advocates on behalf of all people living with HIV and AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS.

820 Plankinton Ave.

Milwaukee, WI 53203

Website: <http://www.arcw.org>

(414) 273-1991

(800) 359-9272

Fax: (414) 273-2357

(Serving Milwaukee, Ozaukee, Washington, and Waukesha counties)

#### Additional Offices:

APPLETON – 920-773-2068/800-773-2068 (Serving Calumet, Fond du Lac, Green Lake, Marquette, Outagamie, Sheboygan, Waupaca, Waushara and Winnebago counties)

EAU CLAIRE – 715-836-7710/800-750-2437; Fax 715-836-9844 (Serving Barron, Buffalo, Burnett, Chippewa, Clark, Dunn, Eau Claire, Pepin, Pierce, Polk, Rusk, St. Croix and Washburn counties)

GREEN BAY – 920-437-7400/800-675-9400; Fax 920-437-1040 (Serving Brown, Door, Kewaunee, Manitowoc, Marinette, Menominee, Oconto and Shawano counties)

KENOSHA – 262-657-6644/800-924-6601; Fax 414-657-6949 (Serving Kenosha, Jefferson, Racine and Walworth counties)

LA CROSSE – 608-785-9866/800-947-3353; Fax 608-784-6661 (Serving Jackson, La Crosse, Monroe, Trempealeau and Vernon counties)

MADISON – 608-258-9103/800-518-9910; Fax 608-258-9136 (Serving Adams, Columbia, Crawford, Dane, Dodge, Grant, Green, Iowa, Juneau, Lafayette, Richland, Rock and Sauk Counties)

SUPERIOR – 715-394-4009/877-242-0282; Fax 715-394-4066 (Serving Ashland, Bayfield, Douglas, Iron and Sawyer counties)

WAUSAU – 715-355-6867/800-551-3311; Fax 715-355-0640 (Serving Florence, Forest, Langlade, Lincoln, Marathon, Oneida, Portage, price, Taylor, Vilas and Wood counties)

### ***Alzheimer's Association – Wisconsin***

#### Southeast Wisconsin Chapter

6130 W. National Ave., Suite 200

Website: <http://www.alzheimers-sewi.org>

Milwaukee, WI 53214-3254

(414) 479-8800

Fax: (414) 479-8819

Helpline: (800) 272-3900

South Central Wisconsin Chapter

517 N. Segoe Rd. Suite 301  
Madison, WI 53705  
(608) 232-3400  
Toll Free: (800) 272-3900  
Fax: (608) 232-3407  
Email: familysupport@alzwissc.org

Website: <http://www.alzwissc.org/>

Greater Wisconsin Chapter

2900 Curry Lane, Suite A  
Green Bay, WI 54311  
(920) 469-2110  
Toll Free: (800) 272-3900  
Fax: (920) 469-2131

Website: <http://www.alzgw.org/>

***ARC-Wisconsin***

600 Williamson Street, Suite J  
Madison, WI 53703  
(608) 251-9272  
Toll Free (877) 272-8400  
Fax: (608) 251-1403  
E-mail: arcw@chorus.net

Website: <http://www.arc-wisconsin.org/>

***Autism Society of Wisconsin***

P.O. Box 165  
Two Rivers, WI 54241  
(920) 553-0278  
Toll-free: 1-888-4-AUTISM (1-888-428-8476)

Website: <http://www.asw4autism.org/>

***Badger Association of the Blind and Visually Impaired***

The Badger Association of the Blind is an independent organization, governed by its members, promoting personal development, career growth, and community awareness through specialized services and programs for people who are blind and visually impaired.

912 N. Hawley Road

Website: <http://www.badgerassoc.org/>

Milwaukee, WI 53213

(414) 258-9200

Toll Free (877) 258 -9200

Fax: (414) 256-8748

Email: info@badgerassoc.org

***Brain Injury Association of Wisconsin Inc.***

The Brain Injury Association of Wisconsin helps to create a better future through brain injury prevention, research, education, and advocacy.

N35W21100 Capitol Dr., Ste. 5

Email: [biaw@execpc.com](mailto:biaw@execpc.com)

Pewaukee, WI 53072

Website: <http://www.biaaw.org>

(414) 778-4144

(800) 882-9282

Fax 262-790-9670

***Center for Deaf-Blind Persons***

The Center serves youths and adults with combined hearing-vision impairments by providing support groups, social groups, rehabilitation training, community support, and community education

3195 S Superior St.

Milwaukee, WI 53207

(414) 481-7477 (voice/ TTY/TDD/TeleBraille)

Fax (414) 481-7481

***Community Advocates Inc.***

Community Advocates was founded in 1976 to work with low income and destitute persons and families to gain and ensure access to programs and services that they need to meet their basic needs and to live in dignity.

4906 West Fond du Lac

Milwaukee, WI 53216

(414) 449-4777

Serves Milwaukee County

***DAWN (Disability Advocates: Wisconsin Network)***

A statewide grassroots cross-disability network of people who care about disability issues. DAWN supports legislative change in the programs and systems affecting people with all disabilities. The Wisconsin Council on Developmental Disabilities funds DAWN as part of the State Plan on Developmental Disabilities.

Website: <http://www.dawninfo.org>

***Disability Benefit Specialists***

Benefit Specialists provide confidential assistance at no charge to adults ages 18 to 59 with physical disabilities, developmental disabilities, mental illness and/or substance abuse disorders on benefits related questions. (Individuals age 60 and older can contact the Elderly Benefit Specialist Program in their county.) Currently, there are Disability Benefit Specialists in 21 counties throughout the state:

- Barron, Brown, Calumet, Fond du Lac, Forest, Green, Green Lake, Jackson, Kenosha, La Crosse, Manitowoc, Marathon, Marquette, Outagamie, Portage, Richland, Sheboygan, Trempealeau, Waupaca, Waushara, and Wood

Website: <http://www.dhfs.state.wi.us/Disabilities/benspecs/program.htm>

Benefits Planning, Assistance and Outreach (BPA&O) for individuals receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), and are Ages 16-64

Health and Employment Counseling (HEC): The Health and Employment Counseling Program (HEC) allows individuals with disabilities who are not yet working to enroll in the Medicaid Purchase Plan (MAPP) while looking for employment.

Pathways to Independence, a State Partnership Initiative (SPI) Project, is a 5-year research and demonstration project aimed at removing barriers to employment for individuals with disabilities. For individuals age 16-64 who have a physical, developmental, mental health disability or HIV/AIDS and are currently receiving either Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) and are authorized to receive Division of Vocational Rehabilitation (DVR) services.

A map showing benefits counselors available in Wisconsin by county is available at:

Website: <http://www.eri-wi.org/map/>

***Disability Drug Benefit Helpline***

The Helpline helps anyone with disabilities under age 60 (or their friends or guardians) with questions about the new Prescription Drug Benefit under Medicare Part D.

1(800) 926-4862

***Disability Rights Wisconsin (DRW)***

The Disability Rights Wisconsin is the state's protection and advocacy agency for persons with developmental disabilities, serious mental illness, or physical/sensory disabilities.

Madison Office

131 W. Wilson St., Ste. 700  
Madison, WI 53703

Website: <http://www.disabilityrightswi.org>

(608) 267-0214 voice/TTY

Toll-free (800) 928-8778 (Toll free: voice/TTY for consumers and family members only)

(608) 267-0368 (Fax)

(800) 926-4862 (Medicare Part D)

Milwaukee Office

Summit Place  
6737 W. Washington Street, #3230  
Milwaukee, WI 53214

(414) 773-4646 voice/TTY

Toll free (800) 708-3034 (Toll free: voice/TTY for consumers and family members only)

(414) 773-4647 (Fax)

Rice Lake Office

801 Hammond Ave.  
Rice Lake, WI 54868

(715) 736-1232 voice/TTY

(877) 338-3724 (Toll free: voice/TTY for consumers and family members only)

(715) 736-1252 (Fax)

***Down Syndrome Association of Wisconsin***

9401 West Beloit Road, Suite 311  
Milwaukee, WI 53227

Website: <http://www.dsaw.org/>

(414) 327-3729

Toll Free: (866) 327-DSAW

Email: [info@dsaw.org](mailto:info@dsaw.org)

***Easter Seals Wisconsin***

Easter Seals Wisconsin provides services to children and adults with disabilities and support to their families.

101 Nob Hill Road, Suite 301

Website: <http://wi.easterseals.com/>

Madison, WI 53713

608-277-8288

Toll Free: 800-422-2324

TTY: (608) 277-8031

Fax: (608) 277-8333

Counties served: All counties not served by Easter Seals SE Wisconsin.

***Easter Seals Kindcare Southeastern Wisconsin***

Easter Seals Kindcare provides exceptional services to ensure that all people with disabilities or special needs and their families have equal opportunities to live, learn, work and play in their communities.

1016 Milwaukee Avenue

Website: <http://wi-se.easterseals.com/>

South Milwaukee, WI 53172

(414) 571-5566

TTY: (414) 571-9212

Fax: (414) 571-5568

Counties served: Milwaukee, Racine, Kenosha, Ozaukee, Washington and Waukesha counties.

***Epilepsy Foundation of Central and Northeast Wisconsin***

1004 First St, Suite 5

Stevens Point, WI, 54481-2627

(715) 341-5811

Toll Free: (800) 924-9932

Website: <http://www.epilepsyfoundation.org/cnewisconsin/>

***Epilepsy Foundation South Central Wisconsin***

1302 Mendota Street, Suite 100

Madison, Wisconsin 53714-1024

(608) 442-5555

Toll Free: (800) 657-4929

Fax: (608) 442-7474

Website: <http://www.epilepsyfoundation.org/socentralwisc/>

***Epilepsy Foundation – Southeast Wisconsin***

735 N. Water Street, Suite 519

Milwaukee, WI 53202

(414)271-0110

Fax: (414)271-0800

Email: [epilsew@aol.com](mailto:epilsew@aol.com)

Website: <http://www.epilepsyfoundationsewi.org/>

***Epilepsy Foundation Southern Wisconsin***

205 North Main Street, Suite 106

Janesville, WI 53545-3062

(608) 755-1821

Toll Free: (800) 693-2287

Website: <http://www.epilepsyfoundation.org/southwisc/>

***Epilepsy Foundation of Western Wisconsin***

1812 Brackett Ave, Suite 5

Eau Claire, Wisconsin 54701-4677

(715) 834-4455

Toll Free: (800) 924-2105

Fax: (715) 834-4465

Email: [kbergefww@sbcglobal.net](mailto:kbergefww@sbcglobal.net)

Website: <http://www.epilepsyfoundation.org/westernwisc/>

***Grassroots Empowerment Project***

The Grassroots Empowerment Project works to create opportunities for people with mental illnesses in order to exercise power in their lives. They provide systems advocacy, information and funding opportunities to consumer run organizations around the state.

P.O. Box 8683

Website: <http://www.grassrootspower.org>

Madison, WI 53708-8683

(800) 770-0588

***Governor's Committee for People with Disabilities***

The Governor's Committee is dedicated to enhancing the health and general well being of disabled citizens in Wisconsin.

1 W. Wilson Street, Room 1150

Post Office Box 7851

Madison, Wisconsin 53707-7851

(608)266-7974

TTY: (608) 267-9880

Fax: (608) 266-3386

Website: <http://www.dhfs.state.wi.us/Disabilities/Physical/gcpd.htm>

***Independent Living Council of Wisconsin (ILCW)***

201 W. Washington Ave. Ste. 110

Madison, WI 53703

(608) 256-9257

Toll Free: (866) 656-4010

TTY: (608) 256-9316 Toll Free: (866) 656-4011

Fax: (608) 256-9301

Email: <http://www.ilcw@ilcw.org/>

***March of Dimes – Wisconsin Chapter***

1126 S. 70<sup>th</sup> Street, Suite S221A

West Allis, WI, 532143124

(414) 778-3500

Fax: (414) 778-3503

Website: <http://www.marchofdimes.com/wisconsin>

Email: [WI657@marchofdimes.com](mailto:WI657@marchofdimes.com)

***Medigap Helpline***

The Medigap Helpline (State Health Insurance Assistance Program) can help with questions about health insurance; primarily Medicare Supplements, Long Term Care Insurance, Medicare Advantage plans and other health care plans available to Medicare beneficiaries.

Toll Free: (800) 242-1060

***Mental Health America of Wisconsin***

734 N. 4<sup>th</sup> Street  
Milwaukee, WI 53203  
(414) 246-3122  
Toll Free (877) 642-4630  
Fax (414) 276-3124  
Email: [info@mhamilw.org](mailto:info@mhamilw.org)  
Website: <http://www.mhamilw.org>

MHA of Wisconsin – Office of Public Policy  
133 S. Butler Street, Room 330  
(608) 250-4368  
Fax (608) 442-7907

Brown County

734 N. 4<sup>th</sup> Street  
P.O. Box 1016  
Green Bay, WI 54305  
(920) 468-6720  
Email: [BRBRNMSN@aol.com](mailto:BRBRNMSN@aol.com)

Calumet County

P.O. Box 62  
Chilton, WI 53104  
(920) 849-4882  
Fax: (920) 894-4552  
Email: [forward@ppcws.net](mailto:forward@ppcws.net)

Sheboygan County

2020 Erie Ave.  
Sheboygan, WI 53081  
(920) 458-3951  
Fax (920) 458-3441  
Email: [mhasheb@mcleodusa.net](mailto:mhasheb@mcleodusa.net)  
Website: <http://www.mhasheboygan.org>

***Mothers United for Moral Support (MUMS)***

MUMS is a National Parent to Parent Network whose mission is to help parents who have a child with any disorder, medical condition, mental or emotional disorder or rare diagnosis make connections with other parents whose children have the same or similar condition.

150 Custer Court  
Green Bay, Wisconsin 54301-1243  
(920) 336-5333  
(877) 336-5333 (Parents only please)  
Fax: (920) 339-0995

Website: <http://www.netnet.net/mums/>  
E-mail: [mums@netnet.net](mailto:mums@netnet.net)

***Muscular Dystrophy Association, Wisconsin Regional Office***

2670 South Ashland Avenue  
Green Bay, WI 54304  
(920) 490-0478  
Fax: (920) 490-0491

Website: <http://www.mda.org/>

***National Alliance on Mentally Illness (NAMI) of Wisconsin***

The National Alliance for the Mentally Ill of Wisconsin (NAMI-Wisconsin) provides support, education, advocacy and research on mental illness to consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorder, and anxiety disorders.

4233 W. Beltline Highway

Email: [nami@namiwisconsin.org](mailto:nami@namiwisconsin.org)

Madison, WI 53711

Website: <http://www.namiwisconsin.org>

(608)268-6000

(800)236-2988 (in-state only)

Fax (608) 268-6004

***National Federation of the Blind – Wisconsin***

The National Federation of the Blind- Wisconsin works to educate the public about people who are blind and helps people who are blind and their families by providing support, advocacy services, referral services, resources, job opportunities, adaptive equipment, and protection of civil rights.

P.O. Box 783.

Madison, WI 53701-0783

Email: [president@nfbwis.org](mailto:president@nfbwis.org)

(608) 758-4800

Website: <http://www.nfbwis.org>

***National Spinal Cord Injury Association of Wisconsin***

Works with local and national officials and agencies to develop programs and services and act as community advocates for improved access, housing, transportation, employment, and leisure time activities for disabled people.

1545 S Layton Blvd., Ste. 320

Website: <http://www.nsciagmac.org>

Milwaukee, WI 53215

National Website: <http://www.spinalcord.org>

414-384-4022

800-962-9629 (Nationwide)

### ***New Partnerships for Women***

The New Partnerships for Women project is a continuation of the Women and Mental Health Study Site of Dane County (WMHSS). The purpose of the project is to continue to build the capacity of the community to promote healing and recovery for women who have histories of trauma, mental health, and/or substance abuse problems, including women who are TANF eligible. The scope of the project includes: (1) training activities, (2) consumer involvement and empowerment activities, (3) the dissemination of information from the needs assessment of Dane County women who have used mental health and/or substance abuse services, and (4) advocacy activities on behalf of women who have experienced trauma, mental health, and/or substance abuse problems.

128 E. Olin Ave., Ste. 202  
Madison, WI 53713  
(608) 268-1042

Email: [npw@choiceonemail.com](mailto:npw@choiceonemail.com)

### **National Multiple Sclerosis Society, Wisconsin Chapter**

1120 James Drive, Suite A  
Hartland, WI 53029  
(262) 369-4400  
Toll Free: (800) 242-3358  
Fax: (262) 369-4410

Website: <http://www.wisms.org>

Email: [info@wisms.org](mailto:info@wisms.org)

### **Parent Education Project of Wisconsin, Inc.**

2192 South 60<sup>th</sup> Street  
West Allis, WI 53219  
(414) 328-5520  
Toll Free: (800) 231-8382 (in WI)  
TTY: (414) 328-5525

Website: <http://members.aol.com/pepofwi/>

### **People First Wisconsin**

3195 S Superior St  
Milwaukee, WI 53207  
(414) 483-2546  
Toll Free: (888) 270-5352 (toll free)

Website: <http://www.peoplefirstwi.org>

### **Prader-Willi Syndrome Association of Wisconsin**

2701 N. Alexander St.  
Appleton, WI 54911-2312  
(920) 882-6371  
Toll Free: (866) 797-2947

Email: [wisconsin@pwsausa.org](mailto:wisconsin@pwsausa.org)

Website: <http://pwsausa.org/WI/>

### **The Prescription Drug Helpline**

The Prescription Drug Helpline is a service operated by the Elder Law Center of the Coalition of Wisconsin Aging Groups. Helpline counselors are available to provide assistance to Wisconsin Medicare beneficiaries age 60 and older regarding prescription drug benefits.

Toll Free: (866) 456-8211

### **Respite Care Association of Wisconsin, Inc.**

6320 Monona Drive, Suite 407

Email: [info@respitecarewi.org](mailto:info@respitecarewi.org)

Madison, WI 53716

Website: <http://www.respitecarewi.org/>

(608) 222-2033

Toll Free: (866) 702-RCAW (7229)

Fax: (608) 222-2034

### **Spinal Cord Injury Association, Southeastern Wisconsin**

1545 S. Layton Blvd., Rm. 320

Website: <http://www.nsciasew.org/>

Milwaukee, WI 53215

(414) 384-4022

Fax: (414) 384-7820

### **United Cerebral Palsy**

UCP of Greater Dane County

1502 Greenway Cross

Email: [ucpgdc@ucpdane.org](mailto:ucpgdc@ucpdane.org)

Madison, WI 53713

Website: <http://www.ucpdane.org>

(608) 273-4434

Fax: (608) 273-3426

UCP of Southeastern Wisconsin

7519 West Oklahoma Avenue

Email: [info@ucpsew.org](mailto:info@ucpsew.org)

Milwaukee, WI 53219

Website: <http://www.ucpsew.org/>

(414) 329-4500

Toll Free: (888) 482-7739

TTY: (414) 329-4511

Fax: (414) 329-4510

UCP of West Central Wisconsin

206 Water Street  
Eau Claire, WI 54703  
(715) 832-1782  
Fax: (715) 832-8203

Email: [ucpwcw@charterinternet.com](mailto:ucpwcw@charterinternet.com)  
Website: <http://www.ucpwcw.org/>

***Wisconsin Association for the Deaf***

Works to ensure that a comprehensive and coordinated system of resources is accessible to Wisconsin people who are Deaf and hard of hearing, enabling them to achieve their maximum potential, through independence, productivity, and integration into the community.

P.O. Box 382  
Waukesha, WI 53186-0382

Website: <http://www.wi-deaf.org>

***Wisconsin Association on Alcohol and Other Drug Abuse***

6601 Grand Teton Plaza, Suite A  
Madison, WI 53719  
(608) 829-1032  
Toll Free: (800) 787-9979  
Fax: (608) 829-3473  
Email: [waaoda@tds.net](mailto:waaoda@tds.net)

Website: <http://www.waaoda.org/>

***Wisconsin Coalition Against Domestic Violence***

The Wisconsin Coalition Against Domestic Violence (WCADV) is a statewide membership organization of domestic abuse programs, formerly battered women, and other individuals, that offers technical assistance and trainings geared towards ending domestic violence.

307 S. Paterson St., Ste 1  
Madison, WI 53703  
(608) 255-0539  
(608) 255-3560 (Fax/TTY)

Website: <http://www.wcadv.org>

***Wisconsin Coalition Against Sexual Assault***

The Wisconsin Coalition Against Sexual Assault (WCASA) works to promote the social change necessary to end sexual violence in Wisconsin and to support a statewide network of concerned individuals and organizations as they work towards this goal.

600 Williamson St., Ste. N-2  
Madison, WI 53703  
(608) 257-1516 (voice/TTY)  
(608) 257-2150 (Fax)

Email: [wcasa@wcasa.org](mailto:wcasa@wcasa.org)  
Website: <http://www.wcasa.org>

***Wisconsin Coalition of Independent Living Centers (WCILC)***

Independent Living Centers (ILCs) are private, non-profit, consumer-directed, community-based organizations that provide services and advocacy by and for people with all types of disabilities. They provide an array of services including peer support, information, referrals, independent living skills training, advocacy, and community education. WCILC can refer you to one of the eight Independent Living Centers (ILCs) nearest you.

201 W. Washington St., Ste. 110

Email: [ilcw@wisilc.org](mailto:ilcw@wisilc.org)

Madison, WI 53703

Website: <http://www.wisilc.org>

(608) 251-9151

(608) 256-9316 (TTY)

(866) 656-4010 (Toll Free)

(866) 656-4011 (TTY Toll Free)

(608) 256-9301 (Fax)

**Wisconsin Community Action Programs (WISCAP)**

1310 Mendota St., Ste 107

Email: [wiscap@wiscap.org](mailto:wiscap@wiscap.org)

Madison, WI 53714

Website: <http://www.wiscap.org/>

(608) 244-4422

Fax: (608) 244-4064

**Wisconsin Council on Children and Families**

A nonprofit, multi-issue child and family advocacy agency headquartered in Madison and Milwaukee. The Council's mission is to promote the well-being of children and families in Wisconsin by advocating for effective and efficient health, education, and human service delivery systems.

16 N. Carroll Street, Suite 600

Website: <http://www.wccf.org>

Madison, Wisconsin 53703

608.284.0580

Fax: 608.284.0583

***Wisconsin Council on Developmental Disabilities***

WCDD plans and advocates for adequate and appropriate supports for people with developmental disabilities in Wisconsin.

201 W. Washington Street, Ste. 110

Email: [help@wcdd.org](mailto:help@wcdd.org)

Madison, WI 53703

Website: <http://www.wcdd.org>

(608) 266-7826

(608) 266-6660 TTY/TDD

(888) 332-1677 (Toll Free)

Fax: 608/267-3906

Disability Advocates Wisconsin Network (DAWN)

Advocacy website sponsored by the Wisconsin Council on Developmental Disabilities.

Website: <http://www.dawninfo.org/>

***Wisconsin Early Childhood Association***

744 Williamson Street, Suite 200

Website: <http://www.wecanaeyc.org/>

Madison, WI 53703

(608) 240-9880

Toll Free: (800) 783-9322

Fax: (608) 663-1091

Wisconsin Early Childhood Association – Milwaukee Office

1556 N. Farwell Avenue

Milwaukee, WI 53202

(414) 278-9322

Fax: (414) 278-9336

***Wisconsin FACETS***

Wisconsin Family Assistance Center for Education, Training and Support (Wisconsin FACETS) provides advocacy, resources, and training on education for children and adults with disabilities and their families.

2714 N. Dr. Martin Luther King Drive

Website: <http://www.wifacets.org/>

Milwaukee, WI 53212

(414) 374-4645

Toll Free: (877) 374-4677

Fax: (414) 374-4655

TDD: (414) 374-4635

Email: [wifacets@wifacets.org](mailto:wifacets@wifacets.org)

***Wisconsin Family Ties, Inc.***

Wisconsin Family Ties works with families that have children with severe emotional and behavioral disturbances and the professionals that work with these families.

16 N. Carroll St., Ste. 630

Email: [info@wifamilyties.org](mailto:info@wifamilyties.org)

Madison, WI 53703

Website: <http://www.wifamilyties.org>

(608) 267-6888

(800) 422-7145

Fax: (608) 267-6801

***Wisconsin Front Door Housing***

The mission of wifrontdoorhousing.org is to assure every resident of Wisconsin is granted an opportunity to obtain affordable housing. They assist low to moderate income households with locating rental units by providing detailed and user-friendly information.

Website: <http://www.wifrontdoorhousing.org/>

***Wisconsin Head Start Association***

122 East Olin Avenue, #110

Website: <http://www.whsaonline.org>

Madison, WI 53713

(608) 442-6879

Fax: (608) 442-7672

***Wisconsin Economic Development and Housing Authority (WHEDA)***

201 W. Washington Ave., Ste. 700

Email: [info@wheda.com](mailto:info@wheda.com)

Madison, WI 53703

Website: <http://www.wheda.com/>

608-266-7884

TTY: 1-800-943-9430

Toll Free: 1-800-334-6873

Fax: 608-267-1099

***Wisconsin Independent Living Centers***

Access to Independence

2345 Atwood Ave.

Email: [info@accesstoind.org](mailto:info@accesstoind.org)

Madison, WI 53704

Website: <http://www.accesstoind.org/>

(608) 242-8484 (v)

TTY: (608) 242-8485

Fax: (608) 242-0383

Counties served: Columbia, Dane, Dodge, Green

Tribes served: Ho-Chunk Nation

Center for Independent Living for Western Wisconsin

2920 Schneider Avenue East

Email: [cilww@cilww.com](mailto:cilww@cilww.com)

Menomonie, WI 54751

Website: <http://www.cilww.com/>

715-233-1070 Voice / TTY

Toll Free: 1-800-228-3287 Voice / TTY

Fax: 715-233-1083

Counties served: Barron, Chippewa, Clark, Dunn, Eau Claire, Pepin, Pierce, Polk, Rusk, St. Croix

Tribes served: Ho-Chunk Nation, St. Croix Band of the Lake Superior Chippewa

Independent Living Resources

4439 Mormon Coulee Road

Email: [advocacy@ilresources.org](mailto:advocacy@ilresources.org)

La Crosse, WI 54601

Website: <http://www.ilresources.org/>

(608) 787-1111

Toll Free: (888) 474-5745

TTY: (608) 787-1148

Toll Free TTY: (888) 378-2198

Fax: (608) 787-1114

Counties served: Buffalo, Crawford, Grant, Iowa, Jackson, Juneau, La Crosse, Lafayette,

Monroe, Richland, Sauk, Trempealeau, Vernon

Tribes served: Ho-Chunk Nation

Independence First

600 West Virginia Street, 4<sup>th</sup> Floor

Website: <http://www.independencefirst.org/>

Milwaukee, WI 53204-1516

(414) 291-7520 (V/TTY)

Fax: (414) 291-7525

Counties served: Milwaukee, Ozaukee, Washington, Waukesha

Tribes served: Forest County Potawatomi

Midstate Independent Living Center

3262 Church Street, Suite 1

Website: <http://www.milc-inc.org/>

Stevens Point, WI 54481

(715) 344-4210 V/TTY

Toll Free: (800) 382-8484 V/TTY

Fax: (715) 344-4414

Counties served: Adams, Florence, Forest, Langlade, Lincoln, Marathon, Oneida, Portage,

Taylor, Vilas, Wood

Tribes served: Lac du Flambeau Band of Lake Superior Chippewa, Forest County Potawatomi

Tribe, Sokaogon Mole Lake Chippewa

North Country Independent Living Center

2231 Catlin Avenue, Suite 16

Email: [ncil@superior-nfp.org](mailto:ncil@superior-nfp.org)

Superior, WI 54880

Website: <http://www.northcountryil.com/>

(715) 392-9118 V/TTY

Toll Free: (800) 924-1220 V/TTY

Counties served: Ashland, Bayfield, Burnett, Douglas, Iron, Price, Sawyer, Washburn

Tribes served: Bad River Band of Lake Superior Chippewa, La Courte Oreilles Band of Lake Superior Chippewa, St. Croix Band of Lake Superior Chippewa, Red Cliff Band of Lake Superior Chippewa

Options for Independent Living

555 Country Club Road

Email: [info@optionsil.com](mailto:info@optionsil.com)

P.O. Box 11967

Website: <http://www.optionsil.com/>

Green Bay, WI 54307-1967

(920) 490-0500

Toll-Free: (888) 465-1515

TTY: (920) 490-0600

Fax: (920) 490-0700

Counties served: Brown, Calumet, Door, Fond du Lac, Green Lake, Kewaunee, Manitowoc, Marinette, Marquette, Menominee, Oconto, Outagamie, Shawano, Sheboygan, Waupaca, Waushara, Winnebago

Tribes served: Stockbridge-Munsee Band of Mohican Indians, Oneida Nation, Menominee Indian Tribe of Wisconsin

Societies Assets

5200 Washington Avenue, Suite 225

Website: <http://www.sai-inc.org/>

Racine, Wisconsin 53406

(262) 637-9128 V/TTY

Fax: (262) 637-8646

Counties served: Jefferson, Kenosha, Racine, Rock, Walworth

Tribes served: Ho-Chunk Nation

***Wisconsin Paralyzed Veterans of America***

2311 South 108<sup>th</sup> Street

West Allis, Wisconsin 53227-1901

(414) 328-8910

Fax: (414) 328-8948

Website: <http://www.wisconsinpva.org/>

Email: [info@wisconsinpva.org](mailto:info@wisconsinpva.org)

## Government Resources in Wisconsin

### ***County Human Services***

Refer to the blue government pages in the telephone book for your county Human Services Agency.

### ***Office of the Governor***

115 East State Capitol

Website: <http://www.wisgov.state.wi.us/>

Madison, WI 53702

(608) 266-1212

TTY: (608) 267-6790

Fax: (608) 267-8983

### ***State of Wisconsin Board on Aging and Long Term Care***

1402 Pankratz Street, Suite 111

Website: <http://longtermcare.state.wi.us/home/>

Madison, WI 53704-4001

Medigap Helpline: 1-800-242-1060

Ombudsman Program: 1-800-815-0015

Fax: (608) 246-7001

Email: BOALTC@ltc.state.wi.us

### ***State of Wisconsin Department of Administration***

101 East Wilson Street

Website: <http://doa.wi.gov/>

Madison, WI 53702

### ***State of Wisconsin Department of Agriculture, Trade and Consumer Protection***

*A state agency that takes complaints regarding unfair business practices, the safety and quality of food, agricultural and commerce complaints, and other consumer protection issues.*

Division of Trade and Consumer Protection

PO Box 8911

Madison, WI 53708-8911

(608) 224-4949

Toll Free Consumer Protection Hotline: (800) 422-7128

Email: [hotline@datcp.state.wi.us](mailto:hotline@datcp.state.wi.us)

Website: <http://www.datcp.state.wi.us/>

**State of Wisconsin Department of Corrections**

3099 East Washington Avenue

Website: <http://www.wi-doc.com/>

Post Office Box 7925

Madison, Wisconsin 53707-7925

Phone: 608-240-5000

Fax: 608-240-3300

Email: [docweb@doc.state.wi.us](mailto:docweb@doc.state.wi.us)

**State of Wisconsin Department of Health and Family Services**

The state agency responsible for programs related to the health of individuals and families in Wisconsin, with offices that specialize in developmental disabilities, physical disabilities, sensory disabilities, psychiatric disabilities and issues relating to the elderly.

1 W. Wilson St.

Madison, WI 53702

Website: <http://www.dhfs.state.wi.us>

(608) 266-1865

(608) 267-7371 (TTY)

Directory of Department Services: <http://www.dhfs.state.wi.us/data/servicesearch.asp>

Directory of Hotline Numbers: <http://www.dhfs.state.wi.us/data/hotline.asp?ref=hp>

**State of Wisconsin Department of Public Instruction (DPI)**

125 S. Webster Street

Website: <http://dpi.state.wi.us/>

P.O. Box 7841

Madison, WI 53707-7841

Toll Free: (800) 441-4563

**State of Wisconsin Department of Regulation and Licensing**

Regulates and monitors professionals that require a license or certificate. Credentialed health professionals monitored by the Department of Regulations and Licensing (DORL) include nurses, physicians, psychologists, social workers, ect. Each profession is regulated by the DORL is governed by a statute and administrative code, which are rules of professional conduct and ethical practice for the profession.

1400 E. Washington Ave., Rm 112

P.O. Box 8935

E-mail: [web@drl.state.wi.us](mailto:web@drl.state.wi.us)

Madison, WI 53708-8935

Website: <http://www.drl.state.wi.us>

(608) 266-2112

**State of Wisconsin Department of Workforce Development, Division of Vocational Rehabilitation**

A federal/state program designed to help find, retain, and improve the quality of employment for people with disabilities.

201 E. Washington Ave.

P.O. Box 7852

Madison, WI 53707-7852

(608) 261-0050 (voice)

(608) 243-5601 (TTY)

(800) 442-3477

(888) 877-5939 (TTY Toll Free)

Fax: (608)-266-1133

Email: [dwdvdr@dwd.state.wi.us](mailto:dwdvdr@dwd.state.wi.us)

Website: <http://www.dwd.state.wi.us>

**State of Wisconsin Elections Board**

17 West Main Street, Suite 310

PO Box 2973

Madison, Wisconsin 53701-2973

Phone: (608) 266-8005

Toll Free: (866) VOTEWIS (866-868-3947)

Fax: (608) 267-0500

Email: [seb@seb.state.wi.us](mailto:seb@seb.state.wi.us)

Website: <http://elections.state.wi.us/>

**State of Wisconsin Office of the Commissioner of Insurance (OCI)**

*A state agency that regulates insurance companies.*

125 South Webster Street

Madison, Wisconsin 53702

Phone: (608) 266-3585 (Madison)

Toll Free: (800) 236-8517 (statewide)

TDD: 711 (ask for 608-266-3586)

Website: <http://oci.wi.gov/>

**Social Security Administration in Wisconsin**

Toll-Free: (800) 772-1213

TDD: (800) 325-0778

Website: <http://www.ssa.gov>

***USDA Rural Development – Wisconsin Office***

4949 Kirschling Ct.

Website: <http://www.rurdev.usda.gov/wi/>

Stevens Point, WI 54481

Phone: (715) 345-7615

TTY: (715) 345-7614

Fax: (715) 345-7669

Email: RD.Webmaster@wi.usda.gov

***Wisconsin Medical Assistance Information***

Website: <http://www.dhfs.state.wi.us/medicaid/index.htm>

***Wisconsin SSI Supplemental Security Income Information***

Dept. of Health and Family Services

Website: <http://www.dhfs.state.wi.us/ssi/>

Division of Disability and Elder Services

1 W. Wilson St., Rm 450

PO Box 7851

Madison, WI 53703

(608) 266-6890

***Wisconsin State Law Library***

120 Martin Luther King Jr Blvd, 2<sup>nd</sup> floor

Website: <http://wsll.state.wi.us/>

Madison WI 53703

608-266-1600

Reference: (800) 322-9755

Circulation: (608) 267-9696

Fax: 608-267-2319

Email: wsll.ref@wicourts.gov

***Wisconsin State Legislature***

Legislative Hotline: In Madison: 266-9960 Toll-free: 1-800-362-9472

Website: <http://www.legis.state.wi.us>

## Wisconsin Legal Advocacy and Legal Services Resources

### ***ABC for Health***

Advocacy and benefits counseling for health.

#### Madison office

152 W. Johnson St. Suite 200

Website: <http://www.abcforhealth.org>

Madison, WI 53703

(608) 261-6939

(800) 585-4222 (outside Dane County)

Fax: (608) 261-6938

#### Barron County Office

1443 E. Division St.

Barron, WI 54812

(715) 537-3471

Fax: (715) 537-6274

#### Polk County Office

300 Polk County Plaza

Balsam Lake, WI 54810

(715) 485-8525

Fax: (715) 485-8501

### ***AIDS Resource Center of Wisconsin***

The AIDS Resource Center of Wisconsin provides resources and advocates on behalf of all people living with HIV and AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS.

820 Plankinton Ave.

Milwaukee, WI 53203

Website: <http://www.arcw.org>

(414) 273-1991

(800) 359-9272

Fax: (414) 273-2357

Serving Milwaukee, Ozaukee, Washington, and Waukesha counties

### **Additional Offices:**

*APPLETON* – 920-773-2068/800-773-2068 (Serving Calumet, Fond du Lac, Green Lake, Marquette, Outagamie, Sheboygan, Waupaca, Waushara and Winnebago counties)

*EAU CLAIRE* – 715-836-7710/800-750-2437; Fax 715-836-9844 (Serving Barron, Buffalo, Burnett, Chippewa, Clark, Dunn, Eau Claire, Pepin, Pierce, Polk, Rusk, St. Croix and Washburn counties)

*GREEN BAY* – 920-437-7400/800-675-9400; Fax 920-437-1040 (Serving Brown, Door, Kewaunee, Manitowoc, Marinette, Menominee, Oconto and Shawano counties)

*KENOSHA* – 262-657-6644/800-924-6601; Fax 414-657-6949 (Serving Kenosha, Jefferson, Racine and Walworth counties)

*LA CROSSE* – 608-785-9866/800-947-3353; Fax 608-784-6661 (Serving Jackson, La Crosse, Monroe, Trempealeau and Vernon counties)

*MADISON* – 608-258-9103/800-518-9910; Fax 608-258-9136 (Serving Adams, Columbia, Crawford, Dane, Dodge, Grant, Green, Iowa, Juneau, Lafayette, Richland, Rock and Sauk Counties)

*SUPERIOR* – 715-394-4009/877-242-0282; Fax 715-394-4066 (Serving Ashland, Bayfield, Douglas, Iron and Sawyer counties)

*WAUSAU* – 715-355-6867/800-551-3311; Fax 715-355-0640 (Serving Florence, Forest, Langlade, Lincoln, Marathon, Oneida, Portage, price, Taylor, Vilas and Wood counties)

### ***Disability Rights Wisconsin (DRW)***

The Disability Rights Wisconsin is the state's protection and advocacy agency for persons with developmental disabilities, serious mental illness, or physical/sensory disabilities.

#### Madison Office:

131 W. Wilson St., Ste. 700

Website: <http://www.disabilityrightswi.org>

Madison, WI 53703

(608) 267-0214 voice/TTY

Toll-free (800) 928-8778 (Toll free: voice/TTY for consumers and family members only)

(608) 267-0368 (Fax)

(800) 926-4862 (Medicare Part D)

#### Milwaukee Office:

Summit Place

6737 W. Washington Street, #3230

Milwaukee, WI 53214

(414) 773-4646 voice/TTY

Toll free (800) 708-3034 (Toll free: voice/TTY for consumers and family members only)

(414) 773-4647 (Fax)

#### Rice Lake Office:

801 Hammond Ave.

Rice Lake, WI 54868

(715) 736-1232 voice/TTY

(877) 338-3724 (Toll free: voice/TTY for consumers and family members only)

(715) 736-1252 (Fax)

### ***Elder Law Center of the Coalition of Wisconsin Aging Group***

A public interest legal services program serving persons aged 60 and over, operated under the umbrella of the Coalition of Wisconsin Aging Groups (CWAG). The Center engages in systems advocacy for issues affecting people over age 60, and provides initial and on-going training, legal support, and on-site supervision to a network of Benefit Specialists in 65 of Wisconsin's 72 counties. Each of these counties has at least one Benefit Specialist. The Center also operates the Wisconsin Guardianship Support Center, which is a state-wide clearinghouse for information about guardianships, protective placements, and advance directives. As part of this project, the Center operates a toll-free telephone hotline at 1-800-488-2596. The toll-free line works on a call back system. When you call, a message is taken with your name, phone number and description of your question.

2850 Dairy Drive, Ste. 100

Madison, WI 53718

(608) 224-0606

(800) 366-2990

(888) 758-6047 TTY/Textnet

Fax: (608) 224-0607

Email: [cwag@cwag.org](mailto:cwag@cwag.org)

Website: <http://www.cwag.org>

#### Altoona Office:

2427 N. Hillcrest Pkwy., Ste. 205

(715) 836-2287

Fax: (715) 836-5810

E-mail: [pgibson@cwag.org](mailto:pgibson@cwag.org)

#### Milwaukee Office:

2601 W. Howard Ave.

(414) 817-0030

E-mail: [gmacinnes@cwag.org](mailto:gmacinnes@cwag.org)

#### The Prescription Drug Helpline

The Prescription Drug Helpline is a service operated by the Elder Law Center of the Coalition of Wisconsin Aging Groups. Helpline counselors are available to provide assistance to Wisconsin Medicare beneficiaries age 60 and older regarding prescription drug benefits.

Toll Free: (866) 456-8211

### ***Lawyer Referral and Information Service of the State Bar of Wisconsin***

Provides free referral to an attorney, legal agency, or other legal service with the specialty needed.

(800) 362-9082

(608) 257-4666

Website: <http://www.wisbar.org/bar/sblris.htm>

***Legal Action of Wisconsin***

Provides civil legal services to low income people.

Website: [www.badgerlaw.net](http://www.badgerlaw.net)

Milwaukee Office:

230 W. Wells St., Room 800

Milwaukee, WI 53203-1866

(414) 278-7722

(414) 278-7156 FAX

(888) 278-0633 Toll Free

Serving: Milwaukee and Waukesha counties

Madison Office:

31 S. Mills St.

Madison, WI 53715

(608) 256-3304

(608) 256-0510 FAX

(800) 362-3904 (outside Dane County)

Serving: Columbia, Dane, Dodge, Green, Iowa, Jefferson, Lafayette, Rock and Sauk counties

Green Bay Office:

201 W. Walnut, Ste. 203

Green Bay, WI 54303

(920) 432-4645

(800) 236-1127 Toll Free

(920) 432-5078 FAX

Serving: Brown, Calumet, Door, Kewaunee, Manitowoc and Outagamie counties

La Crosse Office:

205 Fifth Ave. S., Ste. 300

La Crosse, WI 54602-2617

(608) 785 2809

(800) 873-0927 Toll Free

(608) 782-0800 FAX

Serving: Buffalo, Crawford, Grant, Jackson Juneau, La Crosse, Monroe, Richland, Trempeleau and Vernon counties

Oshkosh Office:

404 N. Main St., Ste. 702

Oshkosh, WI 54901

(920) 233-6521

(800) 236-1128 Toll Free

(800) 947-3259 TTY or TDD

(920) 233-0307 FAX

Serving: Adams, Fond du Lac, Green Lake Marquette, Ozaukee, Sheboygan, Washington Waushara and Winnebago counties

Racine Office:

521 6<sup>th</sup> St.

Racine, WI 53403

(262) 635-8836

(800) 242-5840 Toll Free

(800) 947-3259 TTY or TDD

(608) 782-0800 FAX

Serving: Kenosha, Racine and Walworth counties

***Legal Aid Society of Milwaukee, Inc.***

Provides legal representation to persons with mental illness and others with civil legal services in Milwaukee County.

Website: [www.lasmilwaukee.com](http://www.lasmilwaukee.com)

Downtown Office:

521 N. 8<sup>th</sup> St.  
Milwaukee, WI 53233-2404  
(414) 765-0600  
(414) 291-5488 FAX

Children's Court Center:

10201 Watertown Plank Rd.  
Wauwatosa, WI 53226  
(414) 257-7159  
(414) 257-7742 FAX

Metropolitan Milwaukee Fair Housing Council

*Takes housing discrimination complaints as well as complaints on predatory lending practices statewide.*

600 E. Mason Street, Suite 200  
Milwaukee, WI 53202  
(414) 278-1240  
(877) 647-3247 (toll free)  
Fax: (414) 278-8033  
Provides services statewide

Website: <http://www.fairhousingwisconsin.com>

***State Bar of Wisconsin***

The State Bar of Wisconsin offers legal technical assistance and information. State statutes, regulations and some court cases are available on their website.

P.O. Box 7158  
Madison, WI 53707-7158  
(608) 257-3838  
(800) 728-7788 or (800) 444-9404 Toll Free  
(608) 257-5502 FAX

Website: <http://www.wisbar.org>  
E-mail: service @wisbar.org

***State Public Defender's Office***

Provides legal representation to low income individuals who are facing criminal charges or who are the subject of civil commitment or protective placement proceedings.

Administrative Unit  
314 N. Henry, 2<sup>nd</sup> Floor  
Madison, WI 53703  
(608)266-0087 – Call this number for information about local offices.

Website: <http://www.wisspd.org>

***Western Wisconsin Legal Services – Dodgeville Office***

Provides civil legal services to low income people in Crawford, Richland, Sauk, Grant, Iowa, & Lafayette Counties.

202 N. Main Street

Dodgeville, WI 53533

(800) 873-0928 (608) 935-2741

***Western Wisconsin Legal Services – La Crosse Office***

Provides civil legal services to low income people in Buffalo, Trempealeau, Jackson, LaCrosse, Monroe, Juneau, & Vernon Counties.

205 5<sup>th</sup> Ave. South, Ste. 300

LaCrosse, WI 54601

(800) 873-0927 (608) 785-2809

(608) 782-0800 FAX

***Wisconsin Judicare – serving northernmost 33 counties in Wisconsin***

300 3<sup>rd</sup> Street, Ste., 210

P.O. Box 6100

Wausau, WI 54402

(800) 472-1638 (715) 842-1681

Email: [info@judicare.org](mailto:info@judicare.org)

Website: <http://www.judicare.org>

## National Resources

### ***ADAPT***

Advocates so people with disabilities can live in the community with real supports instead of being locked away in nursing homes and other institutions.

Website: <http://www.adapt.org/>

### ***Alzheimer's Association***

Organization that fights against Alzheimer's and advocates for effective treatments, research, prevention, and other issues surrounding Alzheimer's.

Website: <http://www.alz.org/>

### ***American Association of People with Disabilities***

The largest national nonprofit cross-disability member organization in the United States, dedicated to ensuring economic self-sufficiency and political empowerment for the more than 56 million Americans with disabilities. AAPD works in coalition with other disability organizations for the full implementation and enforcement of disability nondiscrimination laws, particularly the Americans with Disabilities Act (ADA) of 1990 and the Rehabilitation Act of 1973.

Website: <http://www.aapd-dc.org>

### ***American Council for the Blind***

The Council strives to improve the well-being of all blind and visually impaired people by: serving as a representative national organization of blind people; elevating the social, economic and cultural levels of blind people; improving educational and rehabilitation facilities and opportunities; cooperating with the public and private institutions and organizations concerned with blind services; encouraging and assisting all blind persons to develop their abilities and conducting a public education program to promote greater understanding of blindness and the capabilities of blind people.

Website: <http://www.acb.org>

### ***American Counseling Association***

5999 Stevenson Avenue

Alexandria, VA 22304-3300

(703)823-9800

(703) 823-6862 TDD

(800) 347-6647 Toll Free

(800) 473-2329 FAX

Website: <http://www.counseling.org>

***American Nursing Association***

8515 Georgia Ave., Ste. 400  
Silver Spring, MD 20901  
(800)274-4262

Website: <http://www.nursingworld.org>

***American Psychiatric Association***

1000 Wilson Blvd., Ste. 1825  
Alexandria, VA 22209-3901  
(703) 907-7300

Website: <http://www.psych.org>

Email: [apa@psych.org](mailto:apa@psych.org)

***American Psychological Association***

750 First Street, N.E.  
Washington, DC 20002-0202  
(800)374-2721 (202)336-5500  
Fax: (202)336-5997

Website: <http://www.apa.org>

***Autism Society of America***

The national voice of the Autism community whose efforts promote education, awareness, and advocacy on critical issues.

Website: <http://www.autism-society.org/>

***Bazelon Center for Mental Health Law***

Legal advocacy for the civil rights and human dignity of people with mental disability.

1101 15<sup>th</sup> St., NW  
Suite 1212  
Washington, DC 20005  
(202) 467-5730 (Voice)  
(202) 467-4232 (TDD)  
(202) 223-0409 (FAX)

Website: <http://www.bazelon.org>

Email: [info@bazelon.org](mailto:info@bazelon.org)

***Brain Injury Association USA***

The leading national organization serving and representing individuals, families and professionals who are touched by traumatic brain injury (TBI).

Website: <http://www.biausa.org/>

### ***Center for Mental Health Services***

CMHS leads Federal efforts to treat mental illnesses by promoting mental health and by preventing the development or worsening of mental illness when possible. CMHS is a component of the Substance Abuse & Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services. Specific information for consumers/survivors also is available on the Center's website.

PO Box 42557

Website: [www.mentalhealth.samhsa.gov](http://www.mentalhealth.samhsa.gov)

Washington, DC 20015

(800) 289-2647

(866) 889-2647 (TDD)

(240) 747-5470 (FAX)

### ***Center for Psychiatric Rehabilitation***

The Center for Psychiatric Rehabilitation is a research, training, and service organization dedicated to improving the lives of persons who have psychiatric disabilities by improving the effectiveness of people, programs, and service systems.

940 Commonwealth Ave.

Website: <http://www.bu.edu/cpr>

Boston, MA 02215

(617) 353-3549

(617) 353-7700 (FAX)

### ***The Copeland Center***

Mary Ellen Copeland is a mental health recovery educator and author. Her focus is on self-help. Her teachings and writings include topics like getting a sense of hope, Wellness Tools, Wellness Recovery Action Planning, Relapse Prevention, Crisis Planning, Developing a Strong Support System, Education, Personal Responsibility, Self-Advocacy, Building Self-Esteem, Healing from the Effects of Trauma, and Relieving Loneliness and Worry.

Website: <http://mentalhealthrecovery.com>

### ***DisAbility.gov***

In 2000, the Presidential Task Force on Employment of Adults with Disabilities created this site, [www.disAbility.gov](http://www.disAbility.gov), to provide one-stop online access to resources, services, and information available throughout the Federal government.

(800) 333-4636 (Voice /TTY)

Website: <http://disability.gov>

Email: [disabilityinfo.dol.gov](mailto:disabilityinfo.dol.gov)

### ***Easter Seals***

Easter Seals provides exceptional services to ensure that people living with autism and other disabilities have equal opportunities to live, learn, work and play.

Website: <http://www.easterseals.org>

### ***Epilepsy Foundation***

The Epilepsy Foundation is the national voluntary agency solely dedicated to the welfare of over 3 million people with epilepsy in the U.S. and their families.

Website: <http://www.epilepsyfoundation.org>

### ***Great Lakes ADA Center***

This is a program of the Dept. of Disability and Human Development under the College of Applied Health Sciences at the University of Illinois at Chicago. The purpose of the Great Lakes ADA Center is to provide technical assistance, materials and training on the American Disabilities Act to businesses, people with disabilities, and their care givers.

1640 W. Roosevelt Rd.

Chicago, IL 60608

(800) 949-4232 (voice/TTY)

Website: <http://www.gldbtac.org>

### ***Job Accommodation Network (JAN)***

A free consulting service designed to increase the employability of people with disabilities by: 1) providing individualized worksite accommodations solutions, 2) providing technical assistance regarding the ADA and other disability related legislation, and 3) educating callers about self-employment options.

Website: <http://www.jan.wvu.edu>

### ***Medicare Rights Center***

Through the Consumer Hotline (800-333-4114), MRC provides counseling to individuals who need answers to Medicare-related questions or help getting care. Hotline counselors are available Monday through Friday, 9AM – 1PM.

MRC operates a national Medicare HMO Appeals hotline (888-HMO-9050) to assist Medicare HMO members who are appealing HMO denials of care or coverage.

Website: <http://www.medicarerights.org>

***National Alliance on Mental Illness***

NAMI's efforts focus on support to persons with serious brain disorders and to their families; advocacy for nondiscriminatory and equitable federal, state, and private-sector policies; research into the causes, symptoms and treatments for brain disorders; and education to eliminate the pervasive stigma surrounding severe mental illness.

Website: <http://nami.org>

***National Association of the Deaf***

The mission of the National Association of the Deaf (NAD) is to promote, protect, and preserve the rights and quality of life of deaf and hard of hearing individuals in the United States of America.

Website: <http://www.nad.org>

***National Association for Down Syndrome***

The oldest organization in the country serving individuals with Down syndrome and their families.

Website: <http://www.nads.org>

***National Association for Rights Protection and Advocacy***

NARPA, an independent organization, is a unique mix of people who've survived these institutions, advocates, civil rights activists, mental health workers, and lawyers.

Website: <http://www.connix.com/~narpa>

***National Association of Social Workers***

750 First Street NE, Suite 700

Washington DC 20002-4241

Phone: (800)638-8799 (202)408-8600

Website: <http://www.naswdc.org>

***National Consumer Supporter Technical Assistance Center***

NCSTAC was established in 1998 by a grant from the Center for Mental Health Services. Our purpose is to strengthen those organizations supporting mental health consumers, survivors and ex-patients by providing technical assistance in the forms of research, informational materials, and financial aid.

Website: <http://ncstac.org>

### ***National Council on Disability***

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities.

NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature of severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Website: <http://www.ncd.gov>

### ***National Empowerment Center***

Recovery is real and this website is filled with practical information that will help you recover if you have been labeled with a mental illness.

Website: <http://www.power2u.org>

### ***National Federation of the Blind***

The National Federation of the Blind is the largest organization of blind people in the United States. The NFB improves blind people's lives through advocacy, education, research, technology, and programs encouraging independence and self-confidence.

Website: <http://www.nfb.org/>

### ***National Institute of Mental Health***

NIMH has heightened the priority it gives to four broad areas: (1) fundamental research on brain, behavior and genetics; (2) rapid translation of basic discoveries into research on mental disorders; (3) research that directly impacts the treatment of individuals with mental disorders, including clinical trials and studies of treatment and preventive interventions in "real world" settings; and (4) research on child development and childhood mental disorders.

Website: <http://nimh.nih.gov>

### ***National Mental Health Association***

The National Mental Health Association (NMHA) is the country's oldest and largest nonprofit organization addressing all aspects of mental health and mental illness. With more than 340 affiliates nationwide, NMHA works to improve the mental health of all Americans, especially the 54 million individuals with mental disorders, through advocacy, education, research and service.

Website: <http://www.nmha.org>

### ***National Mental Health Consumers' Self-Help Clearinghouse***

The National Mental Health Consumers' Self-Help Clearinghouse is a consumer-run national technical assistance center serving the mental health consumer movement. We help connect individuals to self-help and advocacy resources, and we offer expertise to self-help groups and other peer-run services for mental health consumers.

Website: <http://mhselfhelp.org>

### ***National Multiple Sclerosis Society***

National MS Society is committed to building a movement by and for people with MS that will move us closer to a world free of this disease.

Website: <http://www.nationalmssociety.org>

### ***National Parkinson Foundation***

The mission of the National Parkinson Foundation is to find the cause of and the cure for Parkinson disease through research, to improve the quality of life for persons with Parkinson and their caregivers, and to educate persons with Parkinson, their caregivers, healthcare professionals, and the general public about Parkinson disease and its treatment.

Website: <http://www.parkinson.org>

### ***National Spinal Cord Injury Association***

At NSCIA, we educate and empower survivors of spinal cord injury and disease to achieve and maintain the highest levels of independence, health and personal fulfillment.

Website: <http://www.spinalcord.org/>

### ***March of Dimes***

Their mission is to improve the health of babies by preventing birth defects, premature birth, and infant mortality, through research, community services, education and advocacy to save babies' lives. March of Dimes researchers, volunteers, educators, outreach workers and advocates work together to give all babies a fighting chance against the threats to their health.

Website: <http://www.marchofdimes.org>

### ***Muscular Dystrophy Association***

National voluntary health association dedicated to conquering more than 40 neuromuscular diseases that affect a million Americans of all ages.

Website: <http://www.mda.org/>

### ***Paralyzed Veterans of America***

Paralyzed Veterans of America works to maximize the quality of life for its members and all people with SCI/D as a leading advocate for health care, SCI/D research and education, veterans' benefits and rights, accessibility and the removal of architectural barriers, sports programs, and disability rights.

Website: <http://www.pva.org>

### ***Policy.com***

Online policy news and information service.

Website: <http://www.policy.com>

### ***Prader-Willi Syndrome Association U.S.A***

Prader-Willi Syndrome Association (USA) is dedicated to serving individuals affected by Prader-Willi syndrome (PWS), their families, and interested professionals. To provide information, education, and support services to its members

Website: <http://www.pwsausa.org>

### ***Protection and Advocacy System***

Federally mandated system in each state and territory which provides protection of the rights of persons with disabilities through legally based advocacy. (See Wisconsin Coalition for Advocacy under State Resources – Wisconsin's protection and advocacy agency.)

Website: <http://www.protectionandadvocacy.com>

### ***Sidran Institute***

The Sidran Institute, a leader in traumatic stress education and advocacy, is a nationally-focused nonprofit organization devoted to helping people who have experienced traumatic life events.

200 E. Joppa Road, Suite 207

Towson, MD 21286 USA

410-825-8888

Website: <http://www.sidran.org>

### ***Substance Abuse and Mental Health Services Administration***

SAMHSA is the Federal agency charged with improving the quality and availability of prevention, treatment, and rehabilitative services in order to reduce illness, death, disability, and cost to society resulting from substance abuse and mental illnesses.

Website: <http://www.samhsa.gov>

### ***Trauma Resource Guide***

The Association of Traumatic Stress Specialists' Trauma Resource Guide provides information on resources available that address trauma, healing and stress reduction for caregivers and survivors.

Website: <http://www.atss-hq.com/pages/resourcepages/rsrccgiversurvivor.html>

### ***United Cerebral Palsy***

United Cerebral Palsy (UCP) is the leading source of information on cerebral palsy and is a pivotal advocate for the rights of persons with any disability. As one of the largest health charities in America, the UCP mission is to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network.

Website: <http://www.ucp.org/>



# Additional Legal Information

## Legal Basics

(Excerpts from Arbetman, Lee P., M.Ed., J.D. and O'Brien, Edward L., J.D. Street Law: A Course in Practical Law, 6<sup>th</sup> ed., West Educational Publishing Co. © 1999. Reprinted with permission.)

### **What is Law?**

The question “what is law?” has troubled people for many years. An entire field of study known as jurisprudence (the study of law and legal philosophy) is devoted to answering this question. Many definitions of law exist. For our purposes, however, law can be defined as the rules and regulations made and enforced by government that regulate the conduct the people within a society.

As a child, you learned about rules first at home and later at school. At home, adults made and enforced rules concerning issues like chores and bedtimes. Rules made and enforced by the government are called laws. The government makes laws that affect almost every aspect of daily life.

One thing is certain: Every society that has ever existed has recognized the need for laws. These laws may have been unwritten, but even preindustrial societies had rules to regulate people’s conduct. Without laws, there would be confusion and disorder. This does not mean that all laws are fair or even good, but imagine how people might take advantage of one another without a set of rules.

A democratic system of government cannot function effectively unless its laws are respected. In other words, society must be based on the “rule of law.” This means that all members of society – average citizens and government officials such as senators, judges and even the president – are required to support the legal system and obey its laws. No one is above the law.

### **Human Rights**

Human rights are the rights all people have just because they are human beings. We violate human rights when we treat people as though they were not human beings. To advocate human rights is to demand that the dignity of all people be respected. Both government and private individuals can violate human rights. Human rights apply in people’s homes, schools,

and workplaces. In fact, they apply everywhere. We have our human rights from the moment we are born until the moment we die.

### **Balancing Rights with Responsibilities**

The emphasis on rights in the United States has led some people to criticize America for being too concerned with citizens' rights, while neglecting their responsibilities. Some say that "with every right there goes a responsibility" and urge citizens to act more responsibly toward one another, their families, and their communities.

Critics cite America's emphasis on individual rights as evidence of "radical individualism," which has resulted self-centered focus and the loss of a sense of community. While individual rights are important, they must be matched by social responsibilities, these critics say. For example, if people wish to be tried by juries of their peers, they must be willing to serve on such juries. If they want to be governed by elected officials who respond to their values and needs, they must not only vote, but also get involved in other ways: attend election forums, work for candidates, and run for positions on school boards, county councils, and community associations.

Americans justifiably have great respect for laws extending rights to citizens, including women, minorities, and persons with disabilities who were previously excluded from full participation in society. Many laws, however, also require citizens to act responsibly. Parents must provide their children adequate food, shelter, and clothing; drivers must obey traffic laws; and all workers must pay taxes.

Rights also imply responsibilities. For example, it is the responsibility of everyone not to violate the human rights of others. This means that people need to understand what human rights are, and then treat others with the dignity every human being deserves.

Other critics of the emphasis on rights in America point out that just "because you have a legal right to do (or not to do) something does not mean it is the right thing to do." For example, the First Amendment guarantee of freedom of speech sometimes gives people the right to say hateful and abusive things to others, but it does not make such speech "right." Summarizing the situation, one critic said, "Rights do not automatically make for rightness."

### **Kinds of Laws**

Laws fall into two major groups: criminal and civil. Criminal laws regulate public conduct and set out duties owed to society. A criminal case is a legal action brought by the government against a person charged with committing a crime. Criminal laws have penalties, and offenders

are imprisoned, fined, placed under supervision, or punished in some other way. Criminal offenses are divided into felonies and misdemeanors. The penalty for a felony is a term of more than one year in prison. For a misdemeanor the penalty is a prison term of one year or less. Felonies are more serious crimes such as murder or robbery. Misdemeanors are less serious crimes such as simple assault or minor theft.

Civil laws regulate relations between individuals or groups of individuals. A civil action (lawsuit) can be brought by a person who feels wronged or injured by another person. Courts may award the injured person money for the loss, or they may order the person who committed the wrong to make amends in some other way. An example of a civil action is a lawsuit for recovery of damages suffered in an automobile accident. Civil laws regulate many everyday situations such as marriage, divorce, contracts, real estate, insurance, consumer protection, and negligence.

Sometimes behavior can violate both civil and criminal laws and can result in two court cases. A criminal case is brought by the government against a defendant, the person accused of committing the crime. A civil case is brought by the plaintiff (the person or company harmed) against the defendant (the alleged wrongdoer).

## **Our Constitutional Framework**

The U.S. Constitution is the highest law of the land. Drafted over two hundred years ago, this remarkable document is the longest-lasting written constitution in the world. It sets forth the basic framework of our government. It also lists the government's powers, the limits on those powers, and the people's freedoms that cannot be taken away by the government.

Integral to the Constitution is the principle of limited government. Before the U.S. Constitution was written and ratified, the individual states were reluctant to give up power to the national government. After all, a revolution had just been fought against the government of the king of England to preserve individual liberty and the freedom to govern without interference. As a result, the Constitution created a national government of limited powers, with authority to pass laws only in the areas specifically listed in Article I of the Constitution. Those who criticize the power and reach of the federal government today often cite these historic reasons for limiting its power.

Perhaps nothing is more important in the Constitution than the division of lawmaking power among the three branches of government: the executive (the president and federal agencies), the legislative (Congress), and the judiciary (the courts). This division is known as the separation of powers.

## **Lawmaking**

The laws that U.S. citizens are expected to obey come from many sources. Constitutions set forth laws and also establish the structure of government. Legislatures, of course, make laws. In some situations, voters can act directly as lawmakers. Administrative agencies make many laws. Finally, laws are sometimes made by courts when they decide appeals.

## **Legislatures**

As you have seen, the U.S. Constitution divides the power to make laws between the federal government and the state governments. At both the federal and state levels, legislatures are the primary lawmaking bodies. The U.S. Congress – the federal legislature – is made up of two houses: the Senate (100 members, two from each state) and the House of Representatives (435 members, each state represented according to the size of its population). The U.S. Constitution gives Congress the power to pass laws that are binding on the people in every state. States have the power to pass laws that apply within their boundaries.

The lawmaking authority of Congress is exercised through the passage of laws known as federal statutes. When Congress passes a federal statute, it affects people in every state. Federal statutes deal with issues of national impact, such as environmental quality, national defense, labor relations, veterans affairs, public health, civil rights, economic development, postal services, and federal taxes.

The states' lawmaking powers are vested in their legislatures, which pass laws called state statutes. Except for Nebraska, every state has a two-house legislature. Most states' legislatures meet on an annual basis; in a few states, the legislatures meet every two years. States pass laws with statewide impact in such areas as education, traffic, state taxes (including how they will be spent), marriage and divorce, most criminal laws, and the powers and duties of state government officials. Although tribal governments of Native Americans vary a great deal, many place legislative authority – and sometimes executive authority as well – in a body known as the tribal council.

In addition to the U.S. Congress and state legislatures, cities, towns, and counties have lawmaking bodies. These are called county or city councils, boards of aldermen, local boards of education, or other names. Local governments pass laws known as ordinances or regulations. Legislative issues that concern local governments include land use, parking, schools, and regulation of local business. Laws passed by local governments apply only to a county, city, or

town. The local lawmaking body has been given the power to enact ordinances by the state. Many of the laws most important to us in our daily lives are passed by local governments.

Legislatures and other lawmaking bodies try to respond to the needs of the citizens they represent by introducing legislation in the form of bills. Bills are used to enact new laws or amend or repeal old laws. Ideas for bills can come from legislators, the executive branch, individual citizens, or citizens' groups. The courts also sometimes identify problems that legislatures need to address. If a bill is passed by the legislature and not vetoed by the executive, it becomes law.

## **Agencies**

Many of the laws that affect you are made by government agencies. Legislative bodies usually deal with problems only in a general way. They authorize administrative agencies to develop rules and regulations to make laws more specific. These regulations influence almost every aspect of our daily lives and have the force of law.

The administrative agencies with the greatest impact on your daily life are those at the state and local levels. For example, a zoning commission and other local agencies where you live may have developed a plan that determines what kind of buildings can be located in specific parts of your town. A local agency may hold public hearings to determine whether a new restaurant can serve alcohol and feature live music.

## **Courts**

Law is also made by courts. [T]hink about courtroom scenes you have watched on television. These courts were conducting trials. The person who loses a trial can sometimes ask a higher court to review and change the result of the trial. These higher courts are called appeals or appellate courts. When an appeals court decides a case, it issues a written opinion that sets a precedent for similar cases in the future. All lower courts in the place where the precedent was issued must follow it. For example, if a state's supreme court ruled that the state's constitution required that school funding be equalized throughout the state – richer and poor school districts would each have to spend the same amount per student – then all lower courts in that state would have to follow that precedent.

## **Methods for Solving Disputes**

Among the most common methods for solving disputes out of court are negotiation, arbitration, and mediation.

*Negotiation* is the process by which people involved in a dispute talk to each other about their problem and try to reach a solution acceptable to all. This informal means of settling disputes should be familiar to about everyone. You negotiate when you have a disagreement with your parents, your friends, or your teacher and you work out an agreement. The informality of negotiation makes it ideal for many types of problems. Sometimes people hire attorneys to negotiate for them. For example, people involved in auto accidents sometimes hire attorneys to negotiate with the insurance company over payments for injuries or damages to their cars. Even if you use an attorney to negotiate, you must approve any agreement before it becomes final. Attorneys sometimes file a case in court and then attempt to work out a settlement (agreement) before the case goes to trial. A large number of civil cases are settled this way, saving both time and money.

In *arbitration*, both parties to a dispute agree to have another person listen to their arguments and make a decision for them. The arbitrator is like a judge, but the process is less formal than a trial. Arbitrators, like judges, have the authority to make the final decision, and the parties must follow it (except in what is called nonbinding arbitration). Arbitration is common in contract and labor-management disputes and in some international law cases. Agreements between labor unions and employers include arbitration clauses. This means that the union and the employer agree in advance to submit certain disputes to arbitration and to be bound by the arbitrator's decision.

*Mediation* is another method of alternative dispute resolution. It takes place when a third person helps the disputing parties talk about their problem and settle their differences. Unlike arbitrators, mediators do not impose a decision on the parties. The agreement is the result of the parties' willingness to listen carefully to each other and come up with a reasonable settlement.. The mediator acts as a neutral third party by listening carefully to both sides and trying to help the parties understand each other's positions and find ways to resolve the dispute. Mediation is voluntary; therefore, the mediator has no power to impose a decision on the parties. Mediation allows the disputants to air their feelings, avoids placing blame, and concentrates on the future relationship between the parties.

###

## Legal Rights

Legal rights can come from the state or federal Constitutions or statutes, meaning those laws passed by our state Legislature or the U. S. Congress. Sometimes these laws are better defined or expanded upon in state or federal administrative rules. Also legal rights can be found in cases decided by the courts. Some of this case law is an interpretation of the Constitutions, statutes or regulations. In other situations the rights come from the cases themselves. Malpractice or other cases involving negligence are examples of this type of case law.

The following is an example of legal rights that come from Wisconsin statutes and administrative rules. These rights apply to all persons receiving services in Wisconsin for mental illness, developmental disability, or substance abuse.

### **Rights for Consumers of Disability Related Services**

When you receive any type of service for mental health, alcoholism, drug abuse, or a developmental disability you have the following rights under Wisconsin law (section 51.61, Wis. Stats. and HFS 94, Wis. Admin. Code):

#### **Treatment and Related Rights**

- You must be provided *prompt and adequate treatment* appropriate for you, subject to certain funding limitations.
- You must be in the *least restrictive setting* necessary, subject to certain funding limitations.
- You must be allowed to *participate in the planning* of your treatment and care.
- Staff must *inform you* of your treatment and care, including alternatives and possible side effects of medications.
- *No treatment or medication* may be given to you *without your informed consent*, unless it is needed in an emergency to prevent serious physical harm to you or others, or a court orders it. [If you have a guardian, however, the *guardian* will make those decisions for you.]
- You must not be given *unnecessary or excessive medication*.

## Record Privacy and Access

- Staff must keep your treatment information *private* (confidential).
- Staff *cannot release your records* without your consent, unless the law specifically allows them to do so.
- You can ask to *see your records*. Staff must show you any records about your physical health or medications. Staff may limit how much you can see of the rest of your records while you are in treatment. They have to give you reasons for any such limits. You can challenge those reasons in the grievance process. After discharge, you can see your entire record if you ask to do so.
- If you believe something in your records is *wrong*, you can *challenge its accuracy, completeness, timeliness, or relevance*. If staff will not change the part of your record you have challenged, you can put your own version in your record.

## Communication Rights

- You may use the *telephone* daily. \*
- You may see (or refuse to see) *visitors* daily. \*
- You may *send and receive private mail*. [Staff cannot read your mail unless you or your guardian asks them to do so. Staff may check your mail for contraband. They can only do so if you are watching.]
- You can *call or write to public officials* or your *lawyer advocate*.

## Personal Rights

- Everyone must treat you with *dignity and respect*, free of any verbal or physical abuse.
- Staff must make *fair and reasonable decisions* about your treatment and care.
- You cannot be *filmed or taped* unless you agree to it.
- You can *make your own decisions* about things like getting married, voting, and writing a will.

- *No one may treat you differently* because of your race, national origin, sex, age, religion, disability, or sexual orientation.
- You can decide whether you want to participate in *religious services*.

### **Financial Rights**

- Staff *cannot make you work* except to clean up after yourself in your room or in common areas. If you agree to do other work, you must be *paid*.
- You must be *informed of any costs* of your care and treatment that you or your relatives may have to pay.
- You may *use your own money* as you choose within some limits.

### **Rights Relevant to In-Patient Treatment Facilities**

- Staff may *restrain* you or place you in a *locked room* (seclusion) only in an emergency if it is necessary to prevent physical harm to you or to others or when part of a treatment program.
- You cannot be subject to any *drastic treatment measures, electro-convulsive treatment, or experimental research* without your *informed consent*.
- The environment in the facility must be *psychologically and physically humane*.
- Your surroundings must be kept *safe, clean, and comfortable*.
- You must be given the chance to *exercise and go outside for fresh air* regularly and frequently.
- You must have *privacy* when you are in the *bathroom*. \*
- You can *wear your own clothing*. \*
- Staff must arrange for you to have your *clothes washed*. \*
- You can keep and use your own *belongings*. \*

- You must be given a reasonable amount of *secure storage space*. \*

### **Denials or Limitations of Rights**

*Staff may limit or deny some of your rights for treatment or safety reasons.* [See the rights with a \* after them.] Staff will decide if this is necessary. However, your wishes and the wishes of your guardian should be considered. If staff limit or deny any of your rights, they must give you reasons for doing so. You may ask to talk with them about it. You may also file a grievance about any limits of your rights.

### **Grievance Resolution Process**

- If you feel your rights have been violated, you may file a grievance.
- You cannot be threatened or penalized in any way for filing grievances.
- The service provider or facility must inform you of your rights and how to use the grievance process; the program's Client Rights Specialist must be available to help you with your grievance.
- You may, at the end of the grievance process, or any time during it, choose to take the matter to court.

### **What Informed Consent Is**

1. The individual must be given specific, complete, and accurate information and the time to study the information or to seek additional information.
2. Information must be given about:
  - a. Benefits of proposed treatment and services.
  - b. The way treatment is to be administered and the services are to be provided.
  - c. Expected treatment side effects or risks of side effects which are a reasonable possibility, including side effects or risks of side effects from medications.
  - d. Alternative treatment modes and services.

- e. Probable consequences of not receiving the proposed treatment and services.
  - f. Time period for which the consent is effective, which shall be no longer than 15 months from the time the consent is given.
  - g. The right to withdraw the consent at any time, in writing.
3. The individual must be competent, i.e., substantially able to understand all significant information which has been explained in easily understandable language.
  4. No retaliation may be threatened or carried out for refusing to give consent or for withdrawing it.
  5. The individual must be given a copy of the consent document, upon request.

HSS 94.03, Wis. Administrative Code.

Persons with disabilities have many other legal rights. These include the Constitutional and basic civil rights that all U. S. citizens have. In addition there are special rights such as the right to special education, the right to be free from discrimination in housing, employment, and other areas, and the rights to services and benefits. You can learn about your rights from books that summarize these rights, such as Rights and Reality II, published by Disability Rights Wisconsin, or by learning to look them up yourself.



## Legal Research – The Basics

This piece describes the major sources of statutes and administrative regulations. All the following works are available at the University of Wisconsin and Marquette University Law Libraries and the State Law Library. Most of the state and local volumes also are available at the Legislative Reference Bureau Library in Madison, your local public library, and county law libraries. State and federal laws and regulations and many court decisions also are available through the Internet.

### **Federal Statutes and Regulations**

#### *United States Code:*

This work contains a consolidation and codification of all the general and permanent laws of the United States. It is arranged by title, e.g. Agriculture, Food and Drugs, Labor, Public Health and Welfare. There is an index of acts cited by popular names, as well as a general index.

Website: <http://uscode.house.gov/>

#### *United States Code Annotated:*

Like the U. S. Code, this work contains all the general and permanent laws of the United States. In addition, the annotated edition adds the interpretation which the courts have placed upon these laws. Historical data are also given, showing the antecedents of the particular acts or sections, with comments on the sources and the character of the changes. It is arranged by title; also there's a general index and a popular name (of the statute) index.

#### *Code of Federal Regulations:*

The Code of Federal Regulations (CFR) is a codification of the general and permanent rules published in the Federal Register by the Executive departments and agencies of the Federal Government. The Code is divided into fifty titles (like the U. S. Code and the U. S. Code Annotated) which represent the broad areas subject to federal regulations. Each title is divided into chapters which usually bear the name of the issuing agency. Each chapter is further subdivided into parts covering specific regulatory areas. Each volume of the Code is revised at least once each calendar year.

The CFR is kept up to date by the individual issues of the Federal Register. These two publications must be used together to determine the latest version of any given rule. To determine whether there have been any amendments since the revision date of the CFR volume, the following two lists must be consulted: (1) cumulative "List of CFR Sections Affected," issued monthly, and (2) "Cumulative List of Parts Affected," appearing daily in the Federal Register. These two lists will refer the user to the Federal Register pages where he or she may find the latest amendment of any given rule. The subject index to the Code, which is

revised annually and supplemented periodically, is contained in a separate volume entitled "General Index."

Website: <http://www.gpoaccess.gov/cfr/index.html>

## **State Statutes and Regulations**

### *Wisconsin Statutes:*

This work contains all general statutes in force in Wisconsin. A new edition is prepared after the end of each general session of the legislature. You can generally find what you are looking for by using the table of contents in the front of the book or the index in the back.

Website: <http://www.legis.state.wi.us/rsb/stats.html>

### *Wisconsin Statutes Annotated:*

This work is the state counterpart of the U. S. Code Annotated. Wisconsin Statutes Annotated (W.S.A.) contains the general and permanent laws of Wisconsin along with the court cases interpreting them. The Titles, Chapters, and Sections conform to the official text, numbering and arrangement of the Wisconsin Statutes. In addition to the Notes of Decisions covering judicial interpretation and the administrative rulings of the Attorney General, W.S.A. incorporates other annotative materials such as source notes and explanations of legislative amendments, library references, and citations to the Wisconsin Administrative Code. A General Index to the text of the Constitution and the text of the Statutes is published in separate volumes.

Website: <http://www.legis.state.wi.us/rsb/stats.html>

### *Wisconsin Administrative Code:*

The Wisconsin Administrative Code contains all the regulations issued by state administrative agencies. The code is published in loose-leaf volumes and kept current by means of new and replacement pages. The pages are issued monthly, together with notices of hearings on proposed rules, emergency rules, and new rules. This monthly service is called the Wisconsin Administrative Register.

Website: <http://www.legis.state.wi.us/rsb/code.htm>

You can purchase copies of the current Wisconsin Statutes and Wisconsin Administrative Code from:

Department of Administration  
Document Sales and Distribution  
202 S. Thornton Avenue  
PO Box 7840  
Madison, WI 53707-7840  
Phone: 608/266-3358 or 800/362-7253

## **City/County**

### *City/County Ordinances:*

Check your local public library for the city and/or county ordinances applicable to your locale. You also will find many counties, and some cities and villages, in Wisconsin have their code of ordinances available through their website. For county websites in Wisconsin, type in [http://www.co.\(name of county\).wi.us](http://www.co.(name of county).wi.us).

**Law is also found in cases. Some cases interpret Constitutions, statutes and regulations. References to these cases can be found in the United States Code Annotated and the Wisconsin Statutes Annotated. You can often look up these cases by using some of the websites mentioned below. It is more difficult to do legal research for cases that do not interpret statutes, such as negligence or malpractice cases. You may need a lawyer or law librarian to help you with this.**

## **Internet Websites for Access to Laws, Regulations and Court Decisions**

There is a wealth of information on the internet right at your fingertips. If you have access to a computer, this may be your best bet to find information about your rights or the laws or even phone numbers and addresses.

One way to search for something is to go to a search webpage such as <http://www.google.com> or <http://www.yahoo.com> and put in some key words pertaining to what you want to find. One helpful tip is to put quotation marks around phrases that you want to search for as a unit. Let's say, for example, that you want to find out the phone number for the State of Wisconsin Department of Regulation and Licensing, if you type in "Wisconsin Department of Regulation and Licensing" with quotes around it your search will be narrowed to websites that have the words in consecutive order. You will be more likely to find what you need in a shorter amount of time.

### **A few words of warning about the internet.**

- Don't confuse opinion with fact. Many people go onto the web and put up their opinion on a topic. When searching on the web, make sure you keep in mind that not everything on the web is fact. Much of it is opinions. Opinions can be helpful to you, but just make sure you don't mistake them for facts.

- Beware of misinformation. Certain sites are more reputable than others. When collecting information, be aware that some websites do not contain accurate information. It is your job when you are researching to figure out which sites are likely to contain accurate information. One way to determine

To help you out, below is a list of websites that contain legal information:

- **Wisconsin Legislature: Info Bases**  
<http://folio.legis.state.wi.us/>
- **Wisconsin State Bar**  
<http://www.wisbar.org>
- **Wisconsin Revisor of Statutes Bureau**  
<http://www.legis.state.wi.us/rsb/>
- **Federal Legislation provided by the Library of Congress**  
<http://thomas.loc.gov>
- **The Center for Regulatory Effectiveness**  
<http://www.thecre.com/>
- **Cornell University Law School's Legal Information Institute**  
<http://www.law.cornell.edu/>
- **Legal Resources: FindLaw**  
<http://www.findlaw.com>

# Wisconsin Fair Hearing Process

(Molly L. Bandt, Attorney, Disability Rights Wisconsin, 2006)

## Background

A “fair hearing” is the forum in which recipients of public assistance and social services have the opportunity to challenge adverse decisions. In practical terms, a fair hearing consists of an administrative proceeding at which an individual has the opportunity to present reasons to an impartial administrative law judge (ALJ) as to why a particular agency or department action should be corrected.

In general, recipients of public benefits have the right to appeal any denial, reduction, termination, or delay in processing of benefits. However, there may be program-specific limitations on the right to a fair hearing. For example, under the Medicaid Waiver programs recipients may not appeal denials of benefits that are related to lack of available funding.

These training materials provide an overview of the state fair hearing process only. Benefit counselors who will be providing representation to clients at hearings should also review the Practice Tips for Representing Clients at Administrative Hearings, as well as the materials covering appeals of Social Security Administration benefits.

## Administration

In Wisconsin, the Department of Administration’s Division of Hearings and Appeals (DHA) is the designated adjudicative body for administrative appeals. <http://dha.state.wi.us/home/>. Within DHA, the Work/Family Services Unit handles all appeals involving Medicaid, Food Stamps, Wisconsin Works (W-2), and the Low Income Energy Assistance program. <http://dha.state.wi.us/home/WFS/wfsunit.htm>.

## Sources of Law and Policy

The rules governing Fair Hearings are found at Chapter HA-3 of the Wisconsin Administrative Code. A link to this chapter is included on the DHA website and is also available on the State Bar of Wisconsin’s website – [www.wisbar.org](http://www.wisbar.org). The role of the County Economic Support Unit in the appeal process is explained in Part II, Chapter G of the Income Maintenance Manual (IMM). The IMM is not available online, but may be ordered through the Department of Health and Family Services.

The statutory authority for fair hearings is found in Chapter 227 of the Wisconsin Statutes. Fair hearings are sometimes referred to as “227 hearings.”

## **Appeal Deadlines**

Medicaid and Fuel Assistance – The individual requesting the hearing, also referred to as the “petitioner,” has **45 days** from the effective date of the adverse action to file a hearing request.

Food Stamps – Petitioners have **90 days** from the effective date of the adverse decision to file a hearing request.

Ongoing benefits – If a fair hearing request is filed within **10 days** of a termination/reduction notice, benefits will continue pending the outcome of the appeal. If the appeal is ultimately denied, benefits paid pending the decision will likely be considered an overpayment and may be subject to recovery.

## **Filing Appeals**

DHA: Hearing requests should be sent directly with DHA at the following address: P.O. Box 7875, Madison, WI 53707-7875. DHA will also accept hearing requests by fax at (608) 264-9885. If sent by fax, the consumer or representative should always follow-up with a phone call (608-266-3096) to ensure that the hearing request was actually received within the relevant appeal deadline.

Economic Support Office: County economic support offices will also accept hearing requests and will then forward them to the Division of Hearings and Appeals.

Form of Request: When necessary, a hearing request may be made verbally, however, it should always be confirmed in writing. The hearing request can consist of a letter that identifies the decision at issue and includes a clear statement that the individual is requesting review of the decision. It is also acceptable to submit a Request for Hearing form (DHA-28). Request for hearing forms are available at from the county economic support unit or online at - <http://dha.state.wi.us/home/WFSHrgReqForm.pdf>. While the form is acceptable, an appeal letter may be preferable because it provides an opportunity to give a more detailed explanation of the issue to be heard on appeal.

Authorized Representatives: Attorney representative are permitted to request a hearing on the client’s behalf without a signed statement of representation. Non-attorneys will be required to submit a signed statement of representation before he or she will be permitted to file a hearing request on the client’s behalf.

Note: There is no five-day mailing presumptions like the one in effect for Social Security appeals. This means that the request for hearing must be **received** by the County Economic Support Office or the Division of Hearings and Appeals within 45 days of the date of the notice of decision.

### **Fair Hearing Process:**

Case Summary: After an appeal is filed, DHA will notify the local agency that an appeal has been filed and that the decision maker has 10 days in which to submit a brief summary of the issue on appeal. A copy of the summary should be sent to the petitioner or his or her representative. A good summary will include the effective date of the decision, the reason for the decision, the relevant facts and dates that led to the decision and the specific policy that was relied upon in reaching the decision. Sometimes the information in the case summary will lead to a resolution of the case. For example, it may become clear the decision maker is relying upon erroneous facts that can be corrected by the petitioner without the need for a hearing. It's also possible that the case summary will explain the decision in a way that will make is clear to the petitioner that the agency decision was actually correct. If the case is resolved informally to the satisfaction of the petitioner, he or she should notify DHS immediately to inform them that a hearing will not be necessary. A written request to withdraw may be necessary.

Hearing Procedure - fair hearings generally take the following format:

- The ALJ will introducing himself or herself and give a brief explanation of how the hearing will proceed, including the fact that the hearing will be tape recorded.
- Next, the ALJ will ask for the names of all people who are present and will swear in (take an oath from) anyone who will be providing testimony.
- The ALJ will then turn things over to the representative from the agency, typically the Economic Support Worker assigned to the case.
- The agency will explain the decision at issue and will submit any evidence or witness testimony that supports the rationale for its decision.
- The ALJ may or may not ask questions of the agency regarding its actions.
- After the agency has stated its case, the ALJ will turn things over to the petitioner to explain why he or she thinks the agency position is wrong.
- The petitioner will have the opportunity to present evidence and witness testimony.
- When all evidence has been submitted, the petitioner and/or agency may request the opportunity to make a closing statement (summary of their position).
- After closing statements, if any, the ALJ will indicate whether the record will be closed, or that the record will be held open for additional evidence.
- When the record is closed the ALJ will issue a written decision, typically within two or three weeks of the hearing.
- Occasionally, an ALJ will issue an "on the record" decision at the close of the hearing.

Rules of Evidence: ALJs are not bound by statutory rules of evidence. This means that they must admit any evidence that has reasonable relevance to the issue at hand. Although ALJs rarely exclude evidence, they do have discretion as to how much weight to give to specific pieces of evidence.

Time Frame for Decision: In Medicaid case, DHA is required to hold a hearing and issue a decision within 90 days from the date of the hearing request. In Food Stamp cases, the time period between hearing request and decision should be no longer than 60 days. HA 3.09(11), Wis. Admin. Code. These time frames will be extended in situations where the petitioner requests a postponement of the hearing or in situations where the parties agree that the record should be held open for additional evidence. For example, extensions are often necessary in cases involving Medicaid disability determinations.

Medicaid Disability Determination Cases: In cases where the issue on appeal involves the denial of a disability determination by the Disability Determination Bureau (this is the state agency charged with making disability determinations for all Social Security Disability Insurance, Supplemental Security Income and Medicaid application filed in Wisconsin), there is an additional level of appeal prior to a fair hearing. Applicants who have been denied at initial application have 45 days in which to request a “reconsideration” of their disability determination. If the case is denied at reconsideration, the applicant then has 45 days to request a fair hearing before an administrative law judge.

### **Rehearing**

Once a hearing decision is issued, either party (petitioner or agency) may request a rehearing of their case. Requests for rehearing must be filed with DHA within 20 days of the date of decision. A rehearing will only be granted in cases where a material error of law or fact was made, or in situations where discovery of new evidence is sufficient to reverse or modify the decision. A supervisor at DHA will review the initial decision and will determine whether or not the request for a rehearing will be granted. As a general rule, rehearing request are more likely to be granted in cases that involve misapplication of the law, as opposed to factual determination that rely upon the discretion of the ALJ.

### **Court Review:**

To appeal an initial hearing or rehearing decision, the petitioner must file a petition (lawsuit) in the circuit court in their county of residence. The petition must be filed with appropriate court within **30 days** from the date of DHA's initial or rehearing decision. Although the right to court review exists, courts generally do not “retry” cases. Considerable judicial deference is given to the legal interpretations and factual findings made by agencies.

# Practice Tips for Representing Clients at Administrative Hearings

(Molly L. Bandt, Attorney, Disability Rights Wisconsin, 2006)

**Check the appeal period:** Identify the date of the most recent denial or negative notice so that you are aware of when the appeal period will lapse. Mark the appeal deadline in your calendar. If you are beyond the appeal deadline, determine whether or not there is a “good cause” argument for failure to timely appeal.

**Be knowledgeable about the relevant administrative appeal procedures:** Each agency has its own set of rules. While all agency procedures are generally informal and fairly flexible it is good practice to follow a particular agency’s rules to the maximum extent possible. Acquire copies of the statutes, regulations, and agency policies that cover hearing procedure for the agency before which you are representing clients. Talk to other advocates who regularly practice before the agency to get a feel for how the court “rules” actually work.

**File the hearing request:** Hand Delivery - if hand delivering a hearing request, always be sure to ask the person accepting the request to date stamp it and provide you with a copy. Mail Delivery - if request is made by mail, provide the agency with a self-addressed stamped envelope and an extra copy of the request so that they can mail you a date-stamped copy. Fax Delivery – Check with agency to make sure it accepts requests by fax. If this is done, be sure to call the hearing office to make sure that your fax was actually received.

**Gather the necessary facts:** Ask the client to explain what happened, and ask the client to provide any paperwork he/she has on the situation. The client should sign a release of information so that you will have access to the client’s file and will be able to contact entities that might have information on your client’s situation. If it’s a Social Security case, you will need an Appointment of Representation form (SSA-1696) before the SSA will provide you with any information on the case or allow you to review the client’s file. Make arrangements to review the client’s file and to make copies of all relevant documents.

**Review the Appropriate Sources of Law and Policy:** Review the relevant manual provisions found in sources such as the SSA’s Programs Operational Manual, Medicaid Eligibility Management Handbook, or Food Stamp Handbook. Keep in mind that in some situations, the agency manual may not be consistent with the actual law. It may be necessary to review the actual law and/or regulation (i.e. State regulations, State Statutes, Code of Federal Regulations, United States Code, and when appropriate, hearing decisions and case law).

Develop a theory of the case: After applying the law to the facts, decide if you have merit to proceed. If there is merit, make sure your client also wants to proceed, and explain to your client how the hearing process works so that your client knows what he/she is undertaking. Plan your strategy on how to proceed. Determine which facts you will need to prove in order to support your position. Will the evidence needed to prove these facts come from documents or witness testimony?

Prepare written arguments: Finalize your legal theories and decide how you will present them. Will you prepare a pre-hearing brief, written and/or oral arguments at the hearing; or will you need to request the opportunity to submit post-hearing written arguments? In fair hearings, be sure to provide the social service agency with a copy of any written arguments (i.e. letter briefs) or written correspondence sent to the Hearing Examiner to be made a part of the file. In SSA cases, some ALJs will require representatives to file prehearing briefs.

Prepare your witnesses: Always interview your witnesses in advance so that you know how they will respond to your questions and so that the witness will know what to expect at the hearing. Write down the questions you will need to ask of witnesses to prove the facts. Keep your questions simple and organize them in a logical manner (typically in chronological order).

Arriving at the hearing site: After you receive notice about the time and place of the hearing, make sure you know where to go, and your client knows where the hearing will be held. Always plan to arrive early to go over any last-minute issues with your client (30 minutes should be sufficient unless there are several issues to discuss with your client). Instruct your client to dress appropriately.

Questioning your witnesses: Background questions include name, address, and relationship to the case. Substantive questions should be asked in an open-ended manner that allows the witness to tell his/her version of the relevant events. Avoid asking leading questions if at all possible (i.e. questions that allow for only a "yes" or "no" answer). Keep questions simple and organize in a logical manner, preferably chronological. If possible, prepare a complete list of written questions prior to the hearing. Pay attention to the questions the ALJ or Hearing Examiners asks of witnesses so that you can avoid needless duplication.

Questioning adverse witnesses: Many hearings do not require you to question adverse witnesses (i.e. a witness whose testimony can be presumed to be detrimental to your client's case). It is often not necessary (and potentially harmful) to ask questions of an adverse witness. However, if you determine that it is necessary, be sure to ask "leading questions." Leading questions are those that can be answered with a simple "yes" or "no." This will limit the potential for the adverse witness to elaborate with additional harmful testimony.

Entering Evidence into the Record: Hearing Examiners and ALJs are not bound by statutory rules of evidence which means that they must admit all evidence that has reasonable relevance to the issues. Always bring enough copies of documents you wish to submit into evidence – one for the ALJ/Hearing Examiner, one for the opposing party (if there is any), one for any witness who may be testifying about the document, and one for you and your client. Be sure that the Hearing Examiner/ALJ marks the document with an exhibit number. Write down the exhibit numbers so that you can refer to them when questioning witnesses or arguing your case. Maintain your own “Exhibit List.” Keep track of documents that have been entered as exhibits as the examiner receives them. See Exhibit List Handout. When necessary, use witness testimony to explain documents – ask the witness to identify the document and explain its relevance to the issue at hand.

Opening statements: Opening Statements are generally not necessary because the Hearing Examiner/ALJ typically begins the hearing with a statement about the case before him/her and the issue/s at hand. An opening statement may be necessary, however, if you disagree with how the agency is framing the issues or if there is a procedural issue that must be dealt with before addressing substantive issues. Opening statements should not be too detailed because you don’t want to inaccurately describe what you expect the testimony to be.

Closing statements: Closing statements are very useful in summarizing the facts and legal arguments presented. You should generally prepare your closing statement in advance and then, if necessary, revise in accordance with what was presented at the hearing. A typical closing statement will summarize the relevant law; identify the facts that are relevant to the law and concisely state the relief desired. Closing statements give the advocate an opportunity to “make sense” of all the information – both legal and factual – that the examiner has received. You do not have to memorize opening or closing statements. Preferred practice is to outline your opening or closing statement and speak from the outline. It’s also acceptable to write them down and ask that the written statements be included in the record. As a last resort you can just read the statement into the record, but that can be BORING and many examiners do not like it. After all they too can read.

Closing the record: In some cases, you will want to request that the record be left open in order to allow you to submit additional evidence or to submit a written argument. This will be of particular importance in cases where the agency presents new evidence or arguments at the hearing that you have not yet had the opportunity to respond to. Such requests are routinely granted by examiners.

**EXHIBIT LIST**

Case Name \_\_\_\_\_ Time Hearing Started \_\_\_\_\_

Case Number \_\_\_\_\_ Time Hearing Ended \_\_\_\_\_

Date of Hearing \_\_\_\_\_

Exhibit #	Document	<i>Received</i>	
		Yes	No
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			

# RIGHTS & REALITY II

An Action Guide to the Rights of People with Disabilities in Wisconsin

**NEW EXPANDED AND REVISED EDITION!** 46 chapters covering every major program, funding source, and rights issue affecting adults and children with disabilities in Wisconsin. All sections of the original 1986 Rights and Reality guide have been updated. New sections on the Americans with Disabilities Act (3 chapters), Federal Fair Housing Act, Assistive Technology, W-2, Family Care, BadgerCare, Rights of Inmates in Correctional Settings, and Abuse and Neglect of People with Disabilities. Written primarily by attorneys specializing in disability law, the guide includes citations to applicable statutes, regulations, and case law.

----- Rights and Reality II Order Form -----

Name \_\_\_\_\_ Phone \_\_\_\_\_  
Address \_\_\_\_\_ E-mail \_\_\_\_\_  
\_\_\_\_\_ Zip Code \_\_\_\_\_

Please indicate if you are: consumer \_\_\_ family member of a person with a disability \_\_\_  
attorney \_\_\_ human service professional \_\_\_ other (please specify) \_\_\_\_\_

**SPIRAL MANUAL** - 400 pages; user-friendly format; detailed Table of Contents; sturdy, long lasting binding and durable cover; lays flat for ease in copying individual sections.

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For quantities of 10 or more, contact us for volume price and billing arrangements (608-267-0214). Prices include postage and handling.

\_\_\_\_\_ **TOTAL ENCLOSED**

\_\_\_\_\_ Check enclosed. Make check payable to: Disability Rights Wisconsin, 131 W.  
Wilson Street, Suite 700, Madison, WI 53703. Please allow 4-6 weeks for delivery.  
\_\_\_\_\_ Agency purchase order enclosed (for quantities of 5 or more)  
\_\_\_\_\_ Charge my \_\_\_\_\_ MC \_\_\_\_\_ Visa Card # \_\_\_\_\_ Exp. \_\_\_\_\_