**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.

This Advocacy Tool Kit provides individuals with information and skill building exercises to develop and enhance self and peer advocacy skills.

The goal of this tool kit is to teach people 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.

**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. Any 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!

**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**

Communication refers to many kinds of contact. People communicate for a variety of reasons. So, let’s focus. This is not about casual conversations or talking with friends. This 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.

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 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 “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, 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 the 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, swear words, 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 their message and their intended receiver. You can decide how a particular issue could be presented to a specific person. You 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 I am a \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_.

What can you do so that people might say those things about you?

I can \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_.

**Self-Awareness Tool**

Think about some of the obstacles that you’ve faced recently. How did 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. When I face a problem, I usually: *(Check one)*

 \_\_ Blame myself \_\_ Investigate who’s responsible \_\_ Blame others \_\_ Feel numb
\_\_ Blame the system \_\_ Get teary eyed and feel down \_\_ Blame no one
\_\_ Get motivated to resolve it \_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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

 \_\_ Try to find solutions \_\_ Feel sad or discouraged \_\_ Feel angry \_\_ Try to ignore it
 \_\_ Can’t concentrate \_\_ Feel overwhelmed about what to do \_\_ Turn to others for help \_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. When a doctor, government employee or service provider tells me something, I usually:
*(Check all that apply)* \_\_ Believe the person \_\_ Look for information on my own \_\_ Ask someone else
 \_\_ Ask them additional questions \_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. I discuss problems with: *(Check all that apply)* \_\_ Doctors, nurses, and therapists \_\_ A case manage r \_\_ Friends and/or family
 \_\_ Peers \_\_ Co-workers \_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
3. I find the following helpful: *(Check all that apply)*
 \_\_ 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: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. When I face a problem, I make lists of: *(Check all that apply)*
 \_\_ Important facts \_\_ What I will do \_\_ People to contact \_\_ What I want
\_\_ I don’t make lists, I \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
5. When I use the phone to solve a problem: *(Check all that apply)*
 \_\_ 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: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
6. When I need to write a letter: *(Check all that apply)*\_\_ 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
\_\_ I give a deadline for the person to write me back
 \_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
7. When I hold a meeting to solve a problem: *(Check all that apply)*
 \_\_ I am confident \_\_ I bring a friend along \_\_ I am nervous \_\_ I send a letter afterward \_\_ I don’t lose my temper or shout \_\_ I have a written plan for the meeting
 \_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
8. My top three choices for resolving a problem are: *(Rank 1st , 2nd , and 3rd )*
\_\_\_\_\_\_\_\_ Using the phone
\_\_\_\_\_\_\_\_ Writing a letter
\_\_\_\_\_\_\_\_ Scheduling a meeting
\_\_\_\_\_\_\_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
9. If a problem isn’t solved right away: *(Check all that apply)*
\_\_ 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 \_\_ I feel hurt, blame myself, or assume I did something wrong
 \_\_ Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
10. When someone makes a promise to me but doesn’t keep it. *(Check all that apply)* \_\_ I give up \_\_ I contact the person’s supervisor \_\_ I get angry
 \_\_ I contact the person \_\_ Other:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
11. I feel effective solving a problem by: (*List ways*)
I \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ I\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ I\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ I\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
12. Based on what I learned from this self-awareness exercise, I would like to focus my advocacy skills on: *(List your goals)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**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

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 is to help you resolve your issues without creating more problems.

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.

 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 can be an important component to effective advocacy. 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 somethings 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 you 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 AM until 5:30 PM instead of from 7 AM until 3:30 PM because you need time to drop your child off at daycare. Your boss denies your request, stating that he does not want to give you any special treatment over other employees.

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 family obligations;
* Extended hours at daycare are costly ;

To resolve the problem, you may choose to advocate to your employer to allow you to change your schedule, for your spouse, partner, or family member to take of your child, or to switch to another job or daycare that is more flexible.

Once you clarify the problem you should ask yourself the question “what is my goal?” If your goal is to stay with your current employer and daycare, for example, you may decide to focus your energy on working with your family networks to drop off your child, rather than to work with your employer to permanently change your work schedule.

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.

When you answer the question “what facts do you know?” you should avoid inserting judgments such as “my boss is a jerk,” or “my family doesn’t want to help 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, although 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 review of the business letting them know that you were dissatisfied with how you were treated. Writing a review 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 Fair Employment Act.
2. The right to be happy.
3. The right to be “treated with dignity and respect” by your physician as identified by the 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 spouse or partner.
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 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 doctor’s office might be governed under a rule or policy set by the 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 spouse or partner 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.

The Internet is useful 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, which offer Internet access. If you need help learning how to use the Internet, you can ask a librarian for help. 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.

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 friends, family, other advocates, professionals and others to support your efforts to navigate the system and to 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.

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.

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.

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.

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.

**INFORMAL ADVOCACY PLAN**

Sample Action Plan Worksheet

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? W

hat 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)? 14 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?

 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?
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*

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 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.

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.

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. 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.

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.

*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.”

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.

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).

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.
* 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.

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;

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.”

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 40 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 Coopper 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.

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.