

Becoming An Effective Advocate

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Introduction

To advocate means to take action, to do something in order to make something else happen. There are different kinds of advocacy. “Systems advocacy” is to influence the way things are done for everyone in a county, a school district, or a state. “Individual advocacy” is to influence what happens for one person, which could be yourself. This chapter is primarily about individual advocacy.

Some people talk about advocacy as speaking up or standing up for yourself or someone else. Advocacy is better understood as action taken to effect a desired change or outcome. Effective advocacy does more than whine. Good advocacy helps to define the outcome you want to achieve. In this section, we will explore some aspects of tying action to a desired outcome.

**Some advocacy is about “rights”,
some about making a life better**

Some advocacy is about “rights”. The law requires that eligible people have certain opportunities and services available to them in a timely manner. When those opportunities, services, or time lines are not honored, this represents a violation of legal or procedural rights. There are other aspects of service, support, or accommodation that are not legal requirements but would help to make a person’s life better. These things could also be the focus of a person’s advocacy efforts.

Advocating For Yourself

What do you want?

What do you want? Some people know the answer to that question. Others, when asked, “What do you want?” or “What is your dream?” do not know the answer, at least not right away. Advocating for what you want is a process that starts with considering your life as it is. Where do you live and who lives with you? Where do you work and what do you do there? Who are the friends and other people in your life? What do you do for fun, or want to do? Where do you go, or would you like to go? What personal, material, and technical accommodations might be helpful in your life?

Consider your life

Consider your life. Some people find it helpful to talk about their lives while others might find it easier to avoid language initially. If you like, try drawing whatever comes to mind related to each topic (i.e., home, work, people, fun, places, and accommodations) on a piece of paper. The purpose is not to include every detail or to create great art. Rather, it is to help you consider your life as it is. Whatever comes to mind, say it, and write it down (or ask someone you trust to write it down). Or, draw first and then describe what you have drawn.

What else do I want? What else do I want? What else might help? After you describe your life as it is, think about what else you might want or what you would like to change. Try to fill in a blank, for example, "When I consider work, I want ____." Or, "When I consider the people in my life, I want ____." This kind of consideration can lead to some desired outcomes, some wants. Because advocacy means taking action, once you know what outcome you want, then you can make a plan.

Invite an ally Invite an ally. You can ask someone to work with you. Hopefully, no one has to pursue advocacy goals alone. An ally is someone you trust. An ally can be another advocate, a friend or coworker, or a family member. **An ally is someone who will listen to what you want, rather than tell you what you need.** An ally can ask good questions that help you to be clear about your goals.

Make a plan Make a plan. Think about your desired outcome and ask, "What can I do to get started?" Is there someone to tell? Is there a request to make known? Is there information to get? Are there skills to learn? Think of many things that you could do, and then decide what you will do first. If you get stuck, ask someone you trust to help you figure out what to try first. And then do it.

Advocating For Someone Else

Make every effort to include the person in the process

Make every effort to include the person in the process. Some people will be able to actively communicate with you about their advocacy goals using language. Others will communicate what they enjoy and do not enjoy by their actions; what they want more or less of. When someone does not have ease of communication, pay attention to the person's affect. Under what conditions do you witness the most positive participation as compared to dullness or distress. **Advocate for outcomes the person values.**

When advocating for someone else, it is very important to keep the person at the center of your efforts. It is sometimes a challenge to keep personalities off to the side. Try not to get lost in personal struggles. You do not have to agree with other opinions or like the way everyone else communicates. Do not let your personal dislike for someone interfere with your efforts on behalf of the person who wants a change through advocacy.

General Advocacy Strategies

Distinguish outcomes from methods

Distinguish outcomes from methods. There is a difference between an outcome and a method of achieving it. Improved communication between a person with a disability and others is an outcome. Improved communication at work and in a restaurant, are focussed outcomes. Speech therapy is a method. Use of picture cards or a computer to communicate are methods. **Clarify your outcomes before you invest too much time and energy on one specific method.** Attention to

communication throughout a person's day (or specifically at work and in the restaurant) can be more effective for some people than time with a therapist a few times a week. You might invest a lot of time advocating for a method, get it, and still not achieve the desired outcome. First, decide on the desired outcome. Then, consider methods that might be the best match for the person. In other words, avoid wasting valuable time debating one set of street directions versus another, when you are not certain about the destination.

Prepare yourself There are several ways to prepare yourself. Be aware of your personal sensitivities. Notice the kinds of comments or actions by others that you can predict will upset or anger you. Ask yourself what you hope will not happen in a meeting (because it probably will). Many advocates say they lose focus and effectiveness when certain things happen because they become too upset. In order not to be surprised and thrown off balance, make note of the things you hope will not happen, that are likely to upset you, and then just check them off when they happen. Exhale. Take a short break. Take care of yourself.

Know the players Know the players. Learn who is involved in making decisions, what each person's role and responsibilities are. Know who has the authority to make decisions and make contact with the right person. If there is an order of authority, respect it. However, if you are not satisfied at one level, inform that person that while you appreciate their time or help so far, you will be contacting another person as well. While there will be people along the advocacy path who you might not enjoy or who do not offer the help you want, it is also true that people will not leave their jobs because you do not like them or their decisions. Parents, educators and administrators, county workers, and others all might be around for a long time. This should not dissuade you from advocating, but remind you that **you can respectfully disagree**.

Use questions to invite discussion Use questions to invite discussion. People who disagree tend to argue or be silenced by someone else's position. Avoid becoming polarized. One of the best ways to avoid becoming locked into opposing positions is to ask questions. When you feel ready to pounce or withdraw, ask a question instead. Asking questions does not mean that you are conceding; it means that you are willing to understand another perspective. Be curious. The better you understand what someone else is and is not considering the more able you will be to work with the information.

Keep focus of discussion on specific person Focus. Advocacy is about someone's life. Keep the focus of discussion on the relevant person. Ask any speaker to **directly connect suggestions to what is known about a specific person**, and do the same yourself. Something that might be a good idea for one person, might not be a good idea for another. Discuss how a proposal does or does not match what is known about this one person.

- Individualize** Individualize. Represent the person you are advocating for in terms of learning and performances characteristics, temperament, what the person values, communication methods and style, what brings on a smile, etc. Avoid the short cut of using diagnostic labels or measures of severity (e.g., mild, moderate, profound) to make support or program decisions. **When participation, rather than total independence, is a valued outcome, most things are possible for an individual.**
- Seek outcomes that enhance a person's participation** Seek outcomes that enhance a person's participation in all aspects of life. Think in terms of functional options. A functional option means that if the person does not achieve more than this one outcome, s/he will still be participating in ordinary daily life. Avoid goals that remove or hold someone back from ordinary daily life and places until "prerequisite skills" have been mastered. Special places and activities that are supposed to lead to more functional participation in life are not as solid a foundation as regular places and regular activities that could be emphasized immediately with the proper support for participation. **Participation in ordinary activities is the best foundation for continued and improved participation in ordinary activities.**
- Keep a written record** Document. Keep a written record of your requests and the decisions that are made before leaving meetings. Document your understanding of what will be done next, who will be responsible, and how much time will be taken. Follow verbal exchanges in person or on the phone with memos reflecting your understanding of things.
- Actively participate** Actively participate. Most advocacy is ongoing. If you want a particular topic brought up, or time to speak at a meeting, contact the person who leads the meetings you attend so that these requests can be made part of the agenda. **Ask for and provide explanations and examples** when you want to achieve more clarity. A simple request, such as "please say that in another way" or "please provide an example of what you mean" could make a positive difference for you. If you are nervous about interrupting, try it anyway. It will get easier.
- Be selective about the issues you challenge** Be selective about the issues you challenge. What is the advocacy issue you want to pursue? When there is disagreement about methods, remember that there is always more than one way to achieve a desired outcome. Consider trying something other than your first choice (or asking someone else to try something) for a set period of time, and then notice the value of that method. Unless it is harmful to do so, be flexible.
- Avoid asking "why?"** Avoid asking "why?". People in advocacy disputes often say they dislike when others become defensive. Asking someone why something was done is an invitation to defend a position. Questions that begin with the word "why" invite defensiveness. If you want to understand, **ask "how" a decision was made.** What were the considerations?

Notes For Self-Advocacy Helpers

Advocating and teaching someone to advocate for him/herself are not the same thing. The phrase “self-advocate” should not be used as a synonym for a person with a disability. A person is not an electrician, a store clerk, or even a friend, simply because someone calls them by that title. Each of those titles, including “self-advocate,” is earned based on learning and using specific skills.

Advocacy takes commitment to a desired outcome and energy. If the goal is not personal, there will not be the energy or commitment to carry out a plan. **Be careful not to insert your goals into someone else’s mind and expect them to carry out an energetic advocacy plan.**

While learning to answer the question, “What do you want?” one person might decide that a blue sweater is an important goal. Someone else might identify a workplace that she can walk to rather than take a bus, or a place to live other than a nursing home. Another person might identify more contact with family members and friends, and someone else might want his social worker to be his girlfriend. The role of the helper is not to interfere with someone trying to achieve his/her chosen goal.

The role of helper includes doing your best to help someone understand that we do not always get what we want, and we can still try. The role might include both helping a person find the words to invite someone on a date and also being available to hear about his sadness when she tells him that she is married and not available to be his girlfriend. Teaching people to advocate includes helping them learn to cope with disappointment, rather than protecting them from it. In some situations, it means providing the emotional support that enables someone to persevere.