



What Should I Know About Advocacy?

NOTE: In addition to the person needing supports, “you” also refers to the family member or friend who will assist him or her to get the needed supports and services.

What is Advocacy?

- Advocacy is trying to get something for yourself or other people and persuading people of your position on an issue.
- Advocacy is making sure others know that your issue is important and helping people to understand things from your point of view so they can take actions that will help you to get what you want and need.
- Advocacy is not exclusive to the disability community. Historically people of color advocated for the right to ride in the front of buses and not to be segregated from the rest of society; women and people of color advocated for the right to vote. Advocacy continues to occur around many issues in our society.

Who Are Advocates?

An advocate around developmental disability issues can be anyone who cares about people with disabilities and wants to help other people better understand their opinions, needs and desires. A variety of people are advocating around these issues.

- Self-advocates advocate for what they need and want in their lives.



- Parents, siblings, grandparents and other relatives learn to become advocates in order to get what is needed or wanted for their family member.
- Professional advocates are people who work for organizations where advocacy is the purpose of the organization. Some of the people are paid to do this advocacy work and others do this as volunteers. Pennsylvania Protection and Advocacy (PP & A) and The Arc of Pennsylvania are examples of advocacy organizations.
- People whose job it is to support people with disabilities such as Supports Coordinators and others who work in the mental retardation system also can be advocates.

As a Self-Advocate, What is My Advocacy Role?

We all are self-advocates at times in our lives. When we ask our boss for a raise in salary because we feel we are doing a good job and deserve an increase, we are being self-advocates. When we visit the doctor who tells us that we have a particular condition and we ask her to explain what that means, we are advocating for ourselves.

In the area of disability, you play a very important role. You know what you want so you can tell your story to others so they can understand and help you. As a self-advocate you can clearly and convincingly make known your needs to people who create policies and to elected officials. When you speak up, it reminds people in positions of authority why they should be concerned about disability issues and how these issues should be addressed.

Sometimes you may need someone to support you in being a self-advocate by reading to you, assisting you in writing letters and doing role-playing with you.

Can I Be a Self-Advocate and Advocate for Other People?

- You can be both a self-advocate and an advocate for other people. Just keep in mind that when you are advocating for other people, you need to pursue what they want, even if it is different from what you might want for yourself or what you think the person may want or should want for himself or herself.
- Remember to listen to what the people you are helping want. Always check in with them to be sure that you are doing what they want and how they want it to be done.

What are the Advocacy Roles of Parents and Other Family Members?

Parents and other family members (siblings, aunts, uncles and grandparents), who take on a supporting role, are an important consumer voice since you have first-hand knowledge of what it's like to support a person with a disability.

You can be very important in legislative and political advocacy since you are the experts in the area of disabilities. When you tell legislators your family story, you are able to explain how policies and decisions affect real people.

Are There Different Kinds of Advocacy?

There are various kinds of advocacy.

- **Self Advocacy** is trying to get what you want and need in your own life.
- **Individual advocacy** is speaking on behalf of one person other than yourself. For example, there may be times that you want to have someone else that can speak to people on your behalf.
- **Group advocacy** is speaking on behalf of a group of people who have similar needs. The various advocacy groups in Pennsylvania usually look at what many people in Pennsylvania need and want, rather than concentrating on the needs and wants of one individual. However, these groups may also be involved with individual advocacy.



- **Systems advocacy** looks at the global picture on the local, state or national level and how the system affects everybody. With this type of advocacy, you are working in an effort to improve the system, often together with other people from within the system. You can use your personal experiences of using the system to explain how things either work or don't work for you, and suggest ways that the system can become more user-friendly and responsive to your needs.

If you want to advocate within a system, first you need to be invited or work to get yourself invited so you can participate in committees, councils and workgroups where decisions concerning the system are made.

Once you understand how the system works and who has the power, then you can look at issues from your point of view while taking into consideration what influences the decisions of people who work within the system. This is important so that what you are advocating for is reasonable and possible. Sometimes it takes much back-and-forth communication before an agreement is reached that is acceptable to everyone involved.

Some other ways you can advocate within a system are by writing letters, sending e-mail, making phone calls, and talking with various people within the system. When you advocate for people who rely on system supports, you are advocating within the system. As the result of helping one person, changes may occur on a broader level so that other individuals who need systems supports also will benefit.

- **Public policy/legislative advocacy** is educating and providing information to public officials. This can be on the local, state and national level. You need to be informed of the issues and understand them in order to be involved in this type

of advocacy. Once you understand the issues, then you can write letters, make visits and perhaps get involved with writing position papers on specific issues.

- **Voting** is another way to advocate and it is a civil right. A young man watches the news on television and talks to people about current issues. He understands about voting and exercises his right to vote. Before he goes to vote, he decides for whom he wants to vote and writes the name of the person he has chosen on an index card. He takes the card with him when he votes so he can match the name on his card with the name on the ballot.

Even though voting is everyone's right, people who vote should be informed about the candidates and understand the issues. For example, a young lady does not understand enough to decide for whom she should vote. At her annual Individual Support Plan (ISP) meeting, her new supports coordinator asked if the lady is registered to vote. The response from the rest of her planning team was, "No, because the lady is unable to make an informed choice of candidates and the vote would not be reflective of her wishes but that of someone else." This would be an abuse of the right to vote.

- **The arts** are another way some people advocate. People who create movies, plays, drawings, paintings or other visual arts sometimes use these mediums for advocacy purposes. Writers sometimes advocate through the literature or materials they create.

How Do Health and Safety Fit Into Advocacy?

Even though being self-determined means that you have control over your life, remember that when you or other people are supported with government funding, being self-determined needs to be balanced with concerns for health and safety. For example, a lady got a job in a grocery store and she needed to find a new apartment. She, with the help of her circle of support, checked the ads in the newspaper to find places she could afford to rent. They visited several and found two apartments that she really liked. One apartment was on a bus route and the other was not. The circle discussed the fact that it would be dangerous to walk to work from the one apartment since there was so much traffic on the road where the store was located. After the discussion, the lady chose the apartment on the bus route.

How Can I Become a Good Advocate?

Advocacy begins with your concern about the person or group of people whose lives you are trying to improve. Everyone needs to learn certain skills in order to be an effective advocate.

To be a good advocate you should:

- Have passion and be committed to the subject of your advocacy. If you are advocating for people who have developmental disabilities to be able to determine the kind of life they want to live and to be self-determined, then you will share the knowledge you have, based upon your experience, concerning why people should be self-determined and how this might be accomplished.
- Know the rights of the person for whom you are advocating.
- Be informed and understand the organization or system in which you are advocating. At first you may attend meetings where you just listen carefully and ask questions when you don't understand something.

To be a good advocate you should:

- Really listen. Let the person or people with whom you are interacting know that you have heard them and you understand and respect their point of view. Sometimes the way you advocate is to just be a good listener.
- Take advantage of opportunities to speak up for what you believe. Work on developing good communication skills since you will be working with people with various needs, opinions and professions, including people with authority.
- Be positive; look at and acknowledge the good things that happen. Thank people for coming together to make progress and celebrate your successes.
- Offer suggestions for action on the issue about which you are advocating.
- Realize that some changes take more time than others.
- Be able to work cooperatively with other people who are needed to achieve your goals. They may include the general public, decision makers or other advocates. Often this means that you will need to be flexible.
- Develop good negotiation skills that can be used when working with several groups of people. Through negotiation, you hope to have both sides coming away from the table feeling good about the final decision.
- Develop strong relationships with the people with whom you are working. In the future, you might need support for your advocacy efforts from these people.
- Be skilled in dealing with people. If you are considerate and sensitive to what is proper and appropriate, then you will not offend others.
- Provide reliable information. People need to be able to trust that the information you give them is correct.
- Challenge things that don't work.



To be a good advocate you should:

- Not be intimidated by people in positions of authority; or at least you do not allow the person's intimidating position to stop you from advocating.
- Be able to use advocacy skills in more than one system and for various supports. Focus on your issue and go where it leads until the right people are informed and understand the situation or issue fully enough to act upon what you have defined. You do not stop because you need to talk with people from other funding streams or systems.
- Keep records, notes or document conversations, including when the conversation took place, with whom and the result of the conversation. After an important meeting takes place between you and one or several people, it is a good idea to send a letter stating what you believe happened at the meeting and ask if this is an accurate picture. Remember to keep a copy of the letter you sent.
- Continue to learn. You bring certain skills with you when you become an advocate. The more experiences you have with different people and in different situations, the more you learn.
- Choose your battles; prioritize; decide which issues are worth fighting for and which issues are not.
- Learn from other people. You can ask other people how they got something that you would like to have. A self-advocate who is part of the Independent Monitoring for Quality (IM4Q) process met a young man who was living in his own apartment and learned from him how he was able to move from his family home and live on his own.

To be a good advocate you should:

- Develop self-confidence. This happens by being an active participant in meetings and processes, becoming comfortable and letting other people know the support you need in order to understand the issues.
- Sometimes take someone else along to meetings. The person you take doesn't have to know a lot about the issues, just be there and take notes. If you feel more comfortable taking someone along to meetings, it doesn't mean that you are not doing a good enough job by yourself.
- There are times when it works best for you to work together with other advocates to solve issues. For example, if you and several other people with the same concerns meet with systems people or government officials it makes your position more powerful.
- Create agendas for important meetings with people of authority. Taking a written agenda that you have prepared helps you to stay focused and the people you are meeting with will know that you value the opportunity to meet with them. Remember to take enough copies of the agenda for the number of people that you expect to be there.
- Ask for help when you need it. Times when you might need assistance are when advocating is new to you or when you are advocating in a new area or system.

When May I Want or Need an Advocate?

You and your friends, staff or family may have differing ideas about your life. These people usually are acting out of concern for you and want to prevent bad things from happening to you. When what other people want for you is not what you want then you ought to look for someone who can advocate on your behalf.

It is all right to disagree with someone who is representing or advocating for you. If the person has difficulty understanding your point of view, then you need to attempt to get your advocate to understand or find a different person who will better understand you and advocate for what you want.

As a family you may also need the help of an advocate such as when you are having difficulty getting needed supports for your family member.

Where Can I Find an Advocate?

There are various places where you might look for an advocate to help you. Some advocacy organizations you can contact are: Speaking for Ourselves (1-800-867-3330); The Arc of Pennsylvania and local chapters of The Arc (1-800-692-7258); the Pennsylvania Self Determination Consumer and Family Group (1-800-459-1838); Pennsylvania Protection and Advocacy (1-800-692-7443); and the Centers for Independent Living (1-800-984-7492).

What Needs to Happen to Include All Advocates?

There are some things that can be done so that all advocates are truly included and able to participate in meetings. Advocates need to:

- Be welcomed so they feel that they are part of the group.

- Receive information, written in simple language, in advance of the meeting date so they can get help in understanding it, if necessary.

They need to know when the meeting is scheduled, where it will be located, is the meeting place accessible, and what transportation is available and how arrangements can be made.

- Have people listen to each other and value what everyone has to say.
- Have people be patient and respect the particular pace of each person.
- In some cases, have assistants available at meetings to read and to rephrase things so information is understandable.
- Have microphones available so everyone can hear what is being said.
- Have accommodations made for special dietary needs.
- To have enough space, if using a wheelchair, to be able to move around and have adequate space at the table.
- Have the amount of information that is provided at one meeting limited so it can be absorbed, with additional meetings set up if necessary.

Why Is It Important to Have Advocates?

Advocates are important because they play an important part in getting people what they need. They express the choices, concerns and wishes of the people for whom they are advocating. This happens on various levels. Sometimes this means getting something specific for an individual and at other times it means having the legislature pass a budget or legislation that will have a positive impact upon a large group of people.

ADVOCATES WORK TO IMPROVE THE LIVES OF PEOPLE.



You can download a copy of this FAQ pamphlet and any other FAQ by going to the Everyday Lives Web site www.everydaylives.net and then click on the PA Self Determination Consumer and Family Group or call the Office of Mental Retardation Toll Free telephone number: **1-888-565-9435** to request to have it sent by e-mail or for a hard copy.

This informational pamphlet was created by a work group of the Pennsylvania Self Determination Consumer and Family Group and the Pennsylvania Office of Mental Retardation.

For more information or other assistance from the Pennsylvania Self Determination Consumer and Family Group, call 1-800-459-1838.