



Section 1

How to be an Effective Advocate for Your Child



Being an Effective Advocate for Your Child

Goals for this Section

- ◆ To learn about advocacy
- ◆ To learn how to be a more effective advocate for your child

What You will Find in this Section

- ◆ Information about:
 - Why advocacy is important
 - How service systems work
 - Tips for being an effective advocate
 - Tips for working with professionals
- ◆ Checklist for Preparing for Meetings
- ◆ **Worksheet 1** – Contact List of People Willing to Help Advocate for My Child
- ◆ **Worksheet 2** – Sample Log for Recording Discussions
- ◆ A List of Additional Resources

Our Journey So Far

- ◆ Families have led the charge for change and opportunities for people with disabilities.
- ◆ Families have come together and created organizations (such as the Association for Community Living) to combine their voices. This has led to significant change in the systems that people with disabilities encounter on a regular basis.
- ◆ People with disabilities have been supported to speak up for themselves.

Introduction

This section reviews some of the important aspects of advocacy for families who have a son or daughter with a disability. In essence, advocacy is the process of supporting and standing up for another person. Good advocacy on behalf of a child with a disability may be necessary for a number of reasons:

- Your child may have difficulty speaking for him or herself because of communication difficulties or other reasons.
- Your child may not be afforded the same opportunities in life because of other people's attitudes, or because of physical or other barriers that may exist.
- Your child may have greater needs for support in order to enjoy life or to be involved in school or other learning opportunities, employment in the community, or other community activities.

How much and what kind of advocacy may be required will depend on each individual's or family's own circumstances and needs. Regardless, advocacy can be more effective when families learn the skills and steps that can help you get results. This section provides valuable information that will assist families with the advocacy process.

Advocating for What?

Advocacy can be used for many purposes. Advocating for and with a loved one with a disability may:

- Help your child stand up for his or her individual rights (for example, the right to make decisions, the right to dream and set goals, the right to have meaningful relationships, the right to be safe, etc.).
- Help your child have and maintain opportunities for meaningful involvement in the community (including school and learning, employment and recreation).
- Help your child gain access to the supports and disability related services that he or she may require to have a good life.

A good starting point for effective advocacy is to know and be clear about what you and your child want and need. It may be harder to get good results when you are unclear about what you want to see happen in your child's life. There are a few important things that you, your child, and others can do:

- You can help your child develop and tell others about his or her vision or dreams for the future. At times, especially when your child is younger, you may need to talk about your vision for your child. It is this vision that should inform and drive your efforts to achieve good things for your child.
- You can help your child develop and set some short and long term goals. Goals may involve the areas of education and learning, employment, recreation and so on. Goals should be positive but also realistic and achievable.
- You can help to identify what actions or steps need to be taken to achieve your child's goals. Knowing what needs to happen is a critical part of effective advocacy. Remember that there may be other people that need to be involved in helping to figure out what actions need to take place.

Fortunately, there are planning processes that can help you and your child identify dreams, goals and actions. Many people with disabilities have benefited from planning processes such as PATH and MAPS. For more information on these planning processes, please read Chapter 5 or contact NACL.

A Note about Service Systems

Over the course of your child's life you will encounter a number of different service systems. There are many different types of service systems including early child care, education, medical and mental health, disability services, employment, and income support. Some services are provided by government while others may be provided by community agencies (which are usually funded by government). Each of these systems is unique but most have some common features, including:

- Its own set of rules and regulations that set out what services can be provided and by whom.
- Professionals and support staff who are hired to provide services that you and your child may need. (For more about working with professionals see the information at the end of this chapter).
- A "hierarchy". This means that there are levels of authority that can range from "front line" workers to supervisors, managers, directors and often other layers of people who are in control of the organization. Working with these kind of systems can be frustrating but it is important to know the "chain of command" if you are going to be an effective advocate.

- A budget or set amount of money that someone decides will be available to provide services and supports. How this money is used is important. Service systems are often challenged by the demand for services that exceeds the money that is available.
- Sometimes (or perhaps often) services systems are disconnected from one another and work independently (some call this working in “silos”). This can cause considerable frustration for families as they often have to try and work with a number of different systems at the same time. Governments are looking for ways to better “integrate” their service systems in order to make them more effective to those they serve.

Tips for Being an Effective Advocate

Becoming an effective advocate may require learning about good advocacy practices as well as having a lot of patience and perseverance. Some people are naturally better at advocacy than others. Those who tend to be better advocates are people who are not easily intimidated by difficult people or situations and who have little difficulty in speaking up for themselves or others. Some people, however, learn to be good advocates over time (often because they feel they have to be to achieve good things for their child).

There are a number of good practices that will help you to become an effective advocate. These practices can be broken down into four main areas: preparation, communication, documentation or note taking, and follow up. It is important to remember that what you may need to do as an advocate may depend greatly on the issue or situation. Some situations will be more difficult and trying. They may require action over a period of weeks, months, or sometimes years. Other situations may be resolved more easily and therefore require less effort. Below are a few tips that you can consider as you advocate on behalf of your child

Preparation

Good preparation is a very important aspect of effective advocacy. Here are a few tips to help you become more prepared:

◆ **Remember that information is power.**

The more more that you can inform yourself about a particular issue or situation the better you will be able to speak on behalf of your child.

Depending on the situation, you may need to become better informed about your child’s rights, how different service systems operate, how other families have achieved similar things for their child, and so on.

◆ **Have specific goals or things you would like to achieve for your child.**

Sometimes goals can be broadly stated (for example, to help my child find a job) but goals may also be much more specific. Good preparation usually involves trying to be as specific as possible about what you want to achieve and, if possible, what specific actions you would like to see happen.

- ◆ **Identify the key issues or problems that you and your child are encountering.**
Often, people with disabilities face barriers that may result from other people's attitudes, a lack of effective supports and services, etc. When you are able to clearly identify the problems or barriers that may exist, you can focus your advocacy on what needs to be addressed.
- ◆ **Identify some possible solutions that you see as workable.**
Sometimes, solutions may not be easily identified or can only be identified by talking things through with others.
- ◆ **If possible, identify what you are willing to accept if you cannot get exactly what you want.**
This will require thinking about what you may be willing to compromise with. This is not always easy but it is sometimes necessary. Having a "fall back" position will allow you to still negotiate for something that may be acceptable, even if it is not the perfect solution.
- ◆ **Identify people who may be able to help you.**
Often, advocacy is more effective if you have allies. This may be simply someone who agrees to attend a meeting with you to support your cause or to simply take notes. It may also be someone who has some particular expertise in the issue you are dealing with or in advocating for people with disabilities (for example, a volunteer or a staff person from a disability organization). Remember, being a good advocate does not mean that you have to do everything on your own.
- ◆ **Identify the people that you need to talk with to achieve results for your child.**
These may be people who have some authority to make some decisions or who can help make things happen. Depending on the circumstances, key people might include someone who works for government, a politician, someone from a service agency, an employer or a human resource manager in a company, and so on.

Communication

Effective advocacy also requires good communication. Communication can take many forms including phone calls, face to face meetings, group meetings, letters and emails. Here are a few tips to remember about communication:

- ◆ **Be clear and concrete.**
This means making sure that your messages or requests are stated as clearly and briefly as possible. If your message or request sounds confused, other people may not know what it is that you want for your child. What is the most important information that you need to convey? At times, other information may be useful to support your request. Too much information, however, may get you side-tracked on other issues that may not be as important.

◆ **Be assertive.**

When you communicate with others, they should understand that you have expectations that you expect to achieve. Assertive communication also means talking in a firm (but not harsh) tone of voice. In face to face meetings, try to keep your body erect but also relaxed and use eye contact. Remember that assertive communication is not aggressive.

◆ **Listen carefully to what other people are saying.**

Listening is simply a respectful way to communicate. This means paying close attention to what people are trying to tell you and not interrupting when other people are talking. In addition, listening may also provide you with information or clues about how to solve a problem or to get what you want for your child.

◆ **Ask questions.**

If something is not clear to you, ask for a better or clearer explanation. Asking questions is also a good way to get valuable information that may assist you in your advocacy. Asking questions may also be a useful way to have a conversation with someone who may be able to help you. A key part of effective advocacy is building good relationships with people who are in the position to make decisions or to offer help. If possible, prepare the questions you want to ask before a conversation or meeting.



◆ **Where appropriate, use stories or visual ways to communicate information.**

Often, people remember personal or other kinds of stories more than anything else. Stories can be helpful in providing a sense of the real life issues that may be at stake. They can also be helpful by providing examples of how situations or issues may be resolved.

Documentation and Note Keeping

Keeping good notes and records can be a great aid to the advocacy process. We like to call it the “power of the paper trail”. Here are some tips that may be helpful:

◆ **Keep a notebook, log or a diary to record your discussions.**

Whether you have talked with someone on the telephone or in person, it is important to keep track of the name, contact information and title or position of the person with whom you spoke. Also, record the date and any responses you have received. This information will be particularly helpful to you if you need to do a follow up or talk with someone else who is higher in the “chain of command” within an organization, government or company.

- ◆ **Keep a file of written responses and other documents.**
Sometimes you will receive written responses to requests or will want to ask for a written response. This may be in the form of letters or emails. It is important to keep track of these in case you need them in the future. Sometimes, people will say or promise things verbally but not later act upon. Having a written record of what was agreed to may be very helpful. Also, when a request is being refused, it is helpful to have the refusal (preferably with the reasons for the refusal) spelled out in writing. This may be particularly important if you are asking someone else to review the decision or have the opportunity to make an appeal.
- ◆ **Use e-mails as a follow up to meetings.**
After meetings it may be useful to send an e-mail message to the people you met with to summarize what was agreed upon. If so, send your message as soon as possible after the meeting and print your message and any responses and keep them in your document file.

Follow Up

Often, advocacy does not provide immediate results. Some situations may require persistence and effort to achieve success or have things resolved. Often the adage “the squeaky wheel gets the grease” is very true when families are trying to accomplish things for their child with a disability. Keep the following points in mind:

- ◆ **Try not to be too frustrated or intimidated if you are not getting the response or results that you are seeking.**
Continue to follow up until you feel that your issues have been resolved to your and your child’s satisfaction.
- ◆ **Sometimes, following up your issues may require that you talk with a more senior person with the organization.**
This person may have more authority to make decisions or may have an interest in helping you resolve your issue.
- ◆ **At some point, you may feel that you have done all you can on your own.**
Following up your advocacy may require that you involve other people, particularly from a disability organization to assist you.
- ◆ **When dealing with government systems or agencies, you may need to contact elected officials.**
This kind of follow up should normally be done only when you have gone through all of the regular channels in the government system.
- ◆ **Lastly, there may be times that you are not successful no matter how hard you try.**
Remember that advocacy is about negotiation. What are the things that you are willing to compromise with or settle for if you cannot get what you want or need? Sometimes, the next best solution is better than no solution at all.

Working with Professionals

From the time of the birth of your child, you may be involved with a number of professionals. These may be medical professionals, social workers, early intervention specialists, educators, and others. Your relationships with these professionals will be important. The best kind of professional–parent relationships are those where there is trust, respect and open communication. Parents are recognized for the central role they play in the life of a child with a disability and on that child’s growth, development and well being. Professionals are recognized because they have some special knowledge to contribute.

It is sometimes easy to feel that professionals know best and that parents should not challenge what professionals are saying or suggesting. At the same time, however, it is important that parents’ ideas and concerns are respected. There may be times when you and professionals will not agree on important issues concerning your child. In a good parent-professional relationship, these differences are often resolved by talking openly. Sometimes, however, parent-professional relationships break down, and you may need to find other people who can help you and your child.

The National Information Center for Children and Youth with Disabilities in the United States has provided a number of useful suggestions for parents on working with professionals:

- If you are looking for a professional with whom you can work well, ask other parents of children with disabilities.
- If you do not understand the words that a professional uses, be prepared to ask questions. For example, say “What do you mean by that?” or “I don’t fully understand, can you please explain that again?”
- If necessary, write down what professionals are saying. This can be particularly helpful in medical situations when a medication or therapy is to be given.
- Learn as much as you can about your child’s disability. This will help you to better understand what professionals are saying and to be better informed in discussions with professionals.
- Prepare for visits to professionals by writing down a list of questions or concerns you would like to discuss during the visit.

The best kind of professional–parent relationships are those where there is trust, respect and open communication. Parents are recognized for the central role they play in the life of a child with a disability and on that child’s growth, development and well being. Professionals are recognized because they have some special knowledge to contribute.

- Keep a notebook in which you write down information concerning your child's particular needs or your concerns. This can include notes about your child's medical history, results from tests that may have been given, observations you have made about your child, and so on. A loose-leaf binder is easy to maintain and add information to.
- If you do not agree with professional recommendations, say so. Be as specific as you can about why you do not agree.

Adapted from: *Parenting a Child with Special Needs: A Guide to Reading and Resources*.
Available from www.kidsource.com

It is also important to remember that as a parent you have rights. You have:

The right to be fully informed about and involved in decisions affecting your child.

The right to ask for or seek a second opinion, if you believe it is necessary.

The right to ask questions and to receive accurate and timely information.

The right to have your opinions and concerns count.

The right to ask that people be held accountable for their actions or lack of actions.

The right to have you and your child treated with respect and dignity.



Checklist for Preparing for Meetings

Before the meeting

- I have identified what I am asking for
- I have identified the “key players” that need to be involved
- I have a supporter to go with me to the meeting
- I have written down any points I wish to discuss or questions I would like to have answered
- I have the following information: the day, date, time frame, and place of the meeting, who will be in attendance, and whether I must bring any materials
- The scheduled meeting time allows enough time to cover the issue(s) that need(s) to be addressed
- I have gathered and prepared any materials that I think are necessary for the meeting

During the meeting

- I arrive a few minutes before the meeting time
- I record (or have your supporter record):
 - the date and place of meeting
 - who is in attendance with contact information, if possible
 - key points of information, decisions made
 - the date and details of any future meetings
- I ask participants to clarify any terms or points I don’t understand

After the meeting

- I have asked for minutes to be sent out regarding the meeting with a summary of decisions that were made and issues that were addressed

OR

- I have sent out an email to all participants summarizing what I understood to be the decisions made and issues that were addressed, with a request for their confirmation my summary

Worksheet 1

***Contact List of People Willing to
Help Advocate for My Child***

Name: _____

Telephone #: _____

E-mail: _____

Name: _____

Telephone #: _____

E-mail: _____

Name: _____

Telephone #: _____

E-mail: _____

Name: _____

Telephone #: _____

E-mail: _____

Name: _____

Telephone #: _____

E-mail: _____

Worksheet 2

Sample Log for Recording Discussions

Date: _____

Names of people involved: _____

Contact information for people involved: _____

Questions asked / What was discussed? _____

Result of Discussion: _____

Follow-up steps required: _____

Additional Resources

Available from NBACL (free to families)

Opportunity Link – Module 4 – Advocacy Skills for Families.

Available on-line at www.nbacl.nb.ca

Other Resources

Advocacy Handbook, Fredericton Association for Community Living (1997)

Assertiveness and Effective Parent Advocacy, Marie Sherrett.

Available on-line at www.fetaweb.com/01/assert.sherrett.htm.

Introduction to Self Advocacy, Disability Rights California.

Available on-line at www.disabilityrightsca.org/pubs/507001.pdf.

Strategies: A Practical Guide for Dealing with Professionals and Human Service Systems.

Shields, Craig V. Ontario: Human Services Press (1987) (Book)

Ten Steps to Being an Effective Self Advocate, Advocacy Center for Persons with Disabilities.

Available on-line at www.advocacycenter.org/documents/Ten_Steps_Brochure.pdf.

Websites

www.childrensdisabilities.info/advocacy/index.html.

This site contains various articles on advocacy from a parent's perspective.

www.wrightslaw.com/info/advo.index.htm

Articles on advocacy and education.