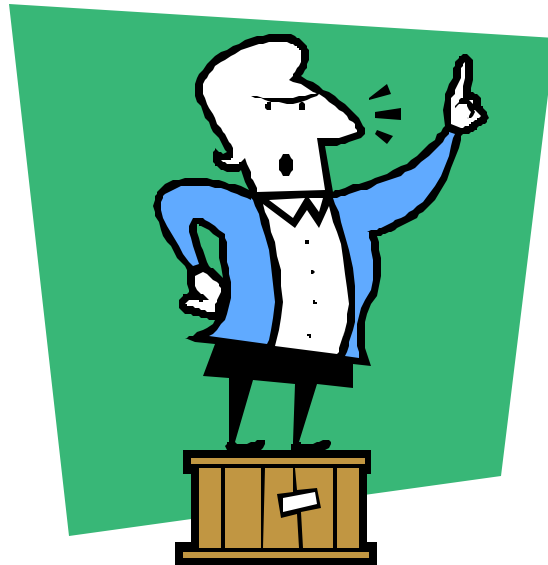


MENTAL HEALTH ADVOCACY



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INTRODUCTION

Consumers of mental health services face many obstacles and often we must face these obstacles alone. Therefore, it is important to learn about *self-advocacy*, a process that involves identifying the obstacles, developing strategies to overcome them, and then implementing these plans. Although we are often discouraged from standing up for ourselves and our loved ones, advocacy is possible for every consumer.

Self-advocacy is essential. An obvious reason is that there are insufficient advocacy resources to fully assist every mental health consumer: although advocates such as medical professionals, social workers, and lawyers can help meet some needs, many needs go unmet.

Author and lecturer Mary Ellen Copeland offers another reason that self-advocacy is essential: “The number one reason is that I’m the only person who has to live my life. Nobody else can know what I *really* need. Other people can look at me and say what they think, but it is very important for me to ask for what *I* want.” Even when you do have an advocate working for you, you’ll find that self-advocacy – in the form of active participation in the process – will help you obtain what you want.

ATTITUDES NECESSARY FOR ADVOCACY

Many consumers worry that they can’t advocate for themselves. Janet Paleo, who works in the Office of Consumer Affairs in Lubbock, Texas, says, “*Anyone* can be an advocate! My two year old is an advocate – when he wants something, he lets me know.” Of course, advocacy is not always so simple, but time and time again, consumers tell stories of surprising themselves with their own power to advocate.

The first step to achieving your advocacy goals, is to work on developing the attitudes necessary for self-advocacy. For some people, it means being more assertive, while for some it means taming aggression. Above all, advocacy requires believing in yourself and your child.

❖ **Believing in yourself:**

In advocacy, attitudes and beliefs are as important as skills are. “As mental health consumers, we are often led to believe that we’re *not* worth advocating for,” she continues, “and we have to change this belief in order to take advantage of advocacy training. A belief in the value of ourselves allows us to take advantage of other aspects of self-advocacy training, such as learning our rights and learning how to write effective letters.”

Consumers who have gotten involved in self-advocacy also agree that once you become involved in advocacy, the rewards multiply.

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

❖ **Being assertive:**

Once you begin to believe in yourself, you will find yourself becoming more assertive. While self-esteem is internal, assertiveness shapes the way we deal with others. It is an important skill for consumers to learn, because for some of us, a lack of assertiveness is a primary obstacle to obtaining the services that we want and need. Don't allow emotions or fears to translate into procrastination or silence.

You don't have to rely solely on yourself: you can become a much more effective self-advocate by working with other people to improve your assertiveness skills. "Assertiveness is really more than an attitude, it's a skill." You need to practice the skill to get better at it and feel comfortable stating your wants and needs to others. Assertiveness is about open, honest communication with others.

The motto of the National Mental Health Consumer's Self-Help Clearinghouse states, "Knowledge is the key to opening new doors," and building your knowledge of rights and entitlements is perhaps the best way to make yourself more assertive. If you know the facts and policies underlying decisions affecting you, then you can more assertively advocate for favorable results.

An old adage says, "The squeaky wheel gets the grease." People are more likely to respond to you if they fear that you might cause them trouble in the future. Self-advocacy requires persistence but offers great rewards.

❖ **Managing your anger:**

Remember that assertiveness is *not* the same thing as aggression: you should be a persistent and tireless advocate for yourself and your child, but you should not shout at or insult others in the process. As one expert explains, "Assertiveness is being able to say what you need to say in a respectful and dignified manner."

When we perceive something as an injustice, our anger can be an asset if we use it to motivate ourselves to engage in self-advocacy. However, we must be careful not to let our anger become a liability for us. If you don't let your anger transform into shouting or character attacks, then the other people involved won't be able to use your behavior as an excuse for denying what you want.

Sometimes, you must teach yourself tricks to control your anger. Although learning to control your anger might take hard work, doing so will make you a much more effective advocate.

Having a good support system in place is another way to work on controlling your anger. Just being able to talk with supportive people might help you diffuse some of your anger before you make any decisions that you'll later regret. A self-help group is also an excellent way to work on your anger management: others in your group likely will have the same goal.

PROBLEM SOLVING STRATEGIES

With the right attitude, you can be an effective self-advocate, but you also need to develop a plan for handling the obstacles that you encounter. As you learn to do away with these obstacles, you'll find that you develop certain skills that make problem solving easier.

❖ Educating yourself

A common sentiment among mental health consumers is that each of us has gotten an education at the "School of Hard Knocks." There's some truth to this, but consumers who make extra efforts to educate themselves can become much more effective self-advocates.

Take every opportunity to educate yourself – don't wait for a problem to arise. Take advantage of educational programs at consumer-run services and special events.

You should also prepare yourself by creating your own resource library. Ask your doctor, therapist, or health plan for information about diagnoses, treatments, and medications; often, they have free informational brochures to give you.



TABLE 1: SOURCES OF PUBLICATIONS FOR CONSUMERS

National Mental Health Consumers Self-Help Clearinghouse	http://www.mhselfhelp.org (800) 553-4539
National Association of Protection and Advocacy Systems (NAPAS), as well as your state's P&A organization	http://www.protectionandadvocacy.com (202) 408-9514
National Mental Health Association (NMHA)	http://www.nmha.org (800) 969-6642
Center for Mental Health Services	http://www.mentalhealth.org (800) 789-2647
Social Security Administration	http://www.ssa.gov (410) 965-0945
President's Commission on the Employment of People with Disabilities	http://www.pcepd.gov (202) 376-6200
Equal Employment Opportunity Commission	http://www.eeoc.gov (800) 669-4000

TABLE 2: SELECTED TOPICS IN THE CLEARINGHOUSE LIBRARY

Abuse of patients	Adolescent issues
Advance directives	Americans with Disabilities Act
Case management	Children's issues
Co-dependency	Commitment
Community based services	Community organizing
Confidentiality/Privacy	Consumer movement
Consumer-run services	Crime
Cultural diversity/Minorities	Deinstitutionalization
Diagnosis information	Drop-in centers
Electro Convulsive Therapy (ECT)	Elderly issues
Employment	Family issues
Fundraising	Gay/lesbian issues
Housing & homelessness	Informed consent
Insurance reform	Involuntary treatment
Legal Issues/Policy/Legislation	Mental health/illness (general)
Mental health care reform	Patients rights
Peer counseling	Physical disabilities & mental health
Protection & advocacy	Provider training
Psychiatric drugs	Psychosocial rehabilitation
Recovery	Self-help services
Sexual abuse/Harassment	SSI/SSDI
Starting a self-help group	Stigma/Discrimination
Substance abuse	Using the media
Vocational & educational support	Women and mental health

In addition to building your own resource library, you should prepare a list of contacts so that you'll know where to go if you ever need help. Useful phone numbers to have on hand might include protection and advocacy (P&A) organizations, state departments of mental health, consumer groups, drop-in centers, and Social Security offices.

Today, the Internet has emerged as a powerful tool for finding the information that you need to know. On the worldwide web, you can find the web sites of organizations that provide information, as well as the agencies that you'll need to contact to achieve your advocacy goals. Using tools such as e-mail lists and newsgroups, you can seek advice from people who have been in the same type of situations that you face.

If you don't have access to the Internet at home, try a local library, many of which now offer Internet access. If you need help learning how to use the Internet, you can ask a librarian for help. Additionally, many consumer-run organizations now offer both Internet access and training.

❖ Identifying your rights

In the United States, we all have rights as citizens. As consumers, however, we have often been led to believe that we don't have rights or should be afraid to exercise them. Mary Ellen Copeland, who has lectured throughout the nation about her own recovery, tells a powerful story about a visit to Mississippi. "I spoke to a group of about 500 people, who were all dressed in matching uniforms depending on the facility that they were from. They had to ask for permission to go to the restroom. I couldn't believe it."

As Copeland spoke to the group, she began to spell out the rights that everyone has when he or she is in a psychiatric facility. At first, the crowd seemed to be in disbelief, but then they began to stand and cheer. After being led to believe that they had checked their rights at the hospital door, they realized that they had the right to stand up for themselves. Copeland uses a "Personal Bill of Rights" (included in Table 3) in her "Dealing with and Recovery from Psychiatric Symptoms" training sessions.



TABLE 3: “PERSONAL BILL OF RIGHTS”

1. I have the right to ask for what I want.
2. I have the right to say no to requests or demands I can't meet.
3. I have the right to change my mind.
4. I have the right to make mistakes and not have to be perfect.
5. I have the right to follow my own values and standards.
6. I have the right to express all my feelings, both positive and negative.
7. I have the right to say no to anything when I feel I am not ready, it is unsafe, or it violates my values.
8. I have the right to determine my own priorities.
9. I have the right not to be responsible for others' behavior, actions, feelings, or problems.
10. I have the right to expect honesty from others.
11. I have the right to be angry at someone I love.
12. I have the right to be uniquely myself.
13. I have the right to feel scared and say, "I'm afraid."
14. I have the right to say, "I don't know."
15. I have the right not to give excuses or reasons for my behavior.
16. I have the right to make decisions based on my own feelings.
17. I have the right to my own needs for personal space and time.
18. I have the right to be playful and frivolous.
19. I have the right to be healthier than those around me.
20. I have the right to be in a non-abusive environment.
21. I have the right to make friends and be comfortable around people.
22. I have the right to change and grow.
23. I have the right to have my needs and wants respected by others.
24. I have the right to be treated with dignity and respect.
25. I have the right to be happy.

This list of rights could perhaps best be classified as “natural rights,” which might or might not be spelled out by any particular law, but nonetheless exist for everyone. As a consumer of mental health services, you also have more specific rights spelled out by local and state laws. Many states have a “bill of rights” for consumers, and in some states, each individual facility is required to develop its own bill of rights.

Another good way to educate yourself about the rights you have under local or state law is to contact your state’s P&A agency.

❖ Breaking down the problem

Sometimes, our problems seem overwhelming: Have you ever replied “everything” when someone asked you what was wrong? When you feel overwhelmed by a problem, you should try to break it down into smaller “chunks” so that you can more effectively plan your strategy.

For example, your child has been placed in a new school program, but has been arriving late. The director of the program has told you if your child does not show up on time, they will be expelled from the program. You have told your child’s doctor the medication is making him sleepy, but he won’t change it.

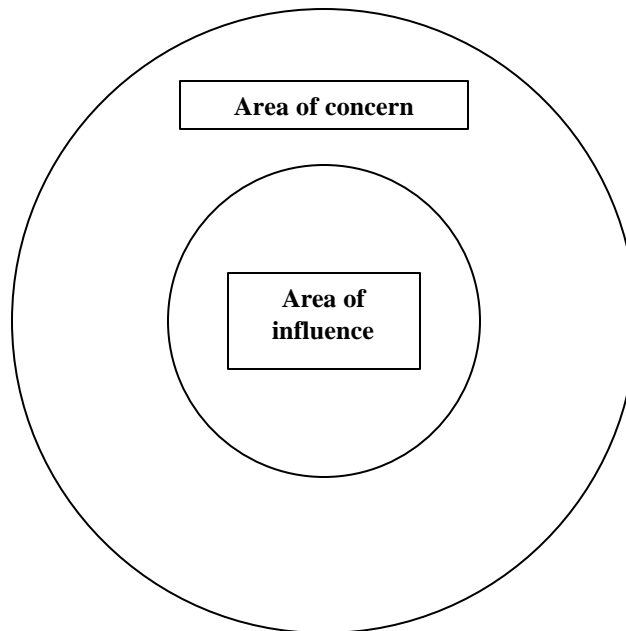
In that example, you could break down the problem into smaller problems:

- Your child is sleepy because of the medication;
- Your child has been arriving late to school;
- Your child has been threatened with being kicked out of the school program; and
- Your doctor won’t change your child’s medications.

By breaking a problem down into smaller segments, you have greater insight into what steps to take. In the above example, you might find that parts of the problem are easier to deal with than others are. Depending on the circumstances, it might be better to see whether you can transfer to a school program that doesn’t begin quite so early; on the other hand, it might be better to think of ways to convince your doctor that your child needs to switch medications.

By deciding which parts of the problem you can most easily solve, you can save yourself time and effort. “Not all problems can be solved,” says Brian Cooper, director of consumer advocacy at the National Mental Health Association. “You have to ask yourself two questions, “Which problems matter most?” and “which problems have a chance of being solved?”

Cooper uses an example created by author Stephen Covey: Picture two circles, one inside the other. The inner circle is your “area of influence” and the larger outer circle is your “area of concern.” The point is that you need to analyze whether something that is bothering you is something that you can do something about. If not, you should concentrate on the things that you *can* change.



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Based on *The Seven Habits of Highly Effective People*, by Stephen Covey, 1990.

In the school example, you might decide that both the prospect of being kicked out of the program and your doctor refusing to change your medications are in your area of concern. However, you might find that your area of influence includes your doctor’s actions, but not the school program’s attendance policies. If so, then you would proceed by working to change your doctor’s decision regarding the medications. In other words, “You’ve got to pick your battles.”

❖ Developing a solution

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.

❖ Preliminary steps

The first step in developing your desired solution is to determine what *you* want to happen. While consulting other people is extremely helpful here, you must make up your own mind, rather than relying exclusively on suggested strategies or predicted outcomes.

In researching your rights, you might have learned some of the possible solutions that are available.

In 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. However, 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 determine the course of your self-advocacy efforts.

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 other alternatives.

However, you should keep your eye open for potential allies who might be able to help you with your problem; other parents, other consumers, interested parties, etc.

❖ Building your case

Having decided what you want and whom to contact, you can begin building your case. Ask yourself about the strengths of your side of the story: Do you have legal rights that have been violated? Has an established policy or procedure been ignored to your detriment?

You should also ask yourself what the other side has to gain by resolving the problem in your favor. Sometimes, the other side might want to avoid negative publicity or complaints to supervisors, and sometimes – if you are persistent enough with your efforts – the other side might decide to give you what you want rather than continue to hear from you. When dealing with managed care

companies, you might choose to show how something you want might save them money, compared to the hospitalizations that might result if your child receives substandard care.

Perhaps the most important part of building your case is assembling all of the documentation that you'll need as you proceed with your self-advocacy efforts. Although the relevant documentation will vary from situation to situation, you should always keep copies of any document concerning health care, insurance, benefits, or anything else involving money.

Examples of important documents might include:

- Letters of support from doctors, therapists, or case managers;
- Photocopies of laws or regulations;
- Insurance policies; or
- Pay stubs.

Remember that as you build your case, you *must* be completely accurate with all of your facts and claims. Mistakes or misrepresentations often provide an excuse for people to deny you what you want.

As you build your case, you also must look at the other side of the argument. Why is the other side acting the way that it is acting? Is there a rule or policy that they are following? Being able to acknowledge the other side's viewpoint as you advocate for yourself shows that you appreciate the other side's needs, and this will help you maintain relationships.

❖ Planning your strategy

There are usually a variety of ways to approach any given problem. Sometimes, there is an established procedure for resolving a problem, such as filing a particular form, but often you'll find that you need to "buck the system" to see results.

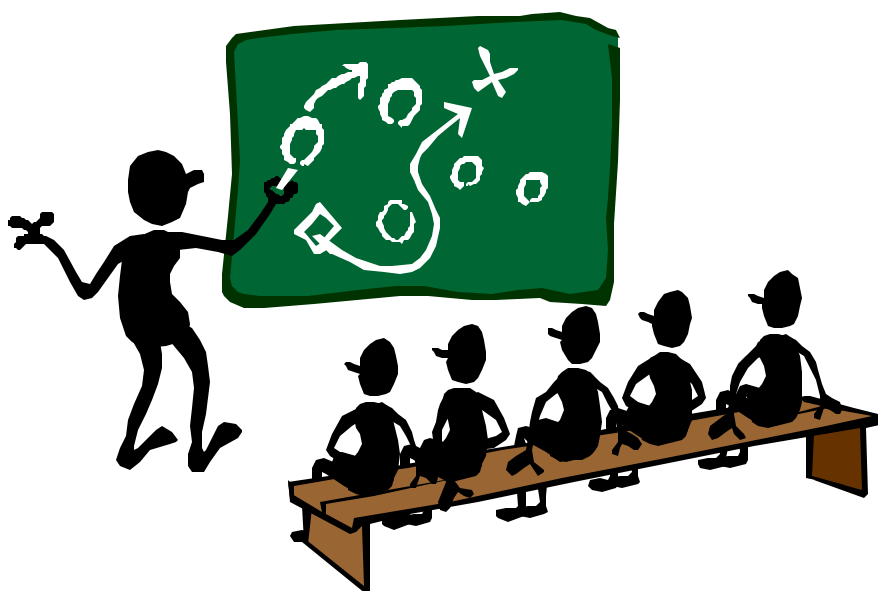
You don't need to plan your strategy alone. A reality-check can help you plan your strategy. You might think that you have your case well constructed, but talking to others can help you identify and improve upon weaknesses.

You should also spend some time reflecting on what you plan to do before you do it. Think before you act.

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;
- Filing a formal complaint.

You can use the Sample Action Plan as your guide.



SAMPLE ACTION PLAN

Problem: _____

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:

Follow-up strategies:

What I expect the other side to do:

ADVOCACY ON THE TELEPHONE

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 skills.

❖ Phone manners/managing anger

Resolving a problem by phone is oftentimes the quickest and most straightforward way to resolve a problem. However, the process still takes some time and causes some frustration. If you are able to control your anger at the delays and frustrations that you experience, then you'll be a much more effective advocate for yourself.

Using the telephone for self-advocacy is fairly common when dealing with managed care organizations (MCOs), insurance companies, hospitals, community mental health centers, and government agencies. With all of these different organizations, your first point of contact will often be one of those pre-recorded phone menus that asks you to press keys to be connected to the right department. When you finally do reach a live voice, it is often a low-level employee who might not have the authority to resolve your request.

Certainly, this is frustrating. Say for example, your MCO denies your request to see a certain doctor, or your benefit check is reduced without explanation. Your first inclination might be to scream at the first person you talk to – anger is natural. However, your ability to handle this anger might have an impact on how well (or poorly) the organization resolves your problem.

Of course, you should express your concern, but there's no need for name calling or shouting at the person on the other end. Also, the person will probably absorb the information better and be able to resolve the situation more efficiently if he or she doesn't feel under attack.

Keep in mind that the person on the other end of the phone is just that – a person. He or she has good days and bad days just like you and looks forward to pleasant calls more than unpleasant ones. If it is the case that your problem was caused by an innocent mistake – a computer error for example – the employee might be much more helpful and make it a higher priority if you are pleasant on the phone.

By managing your anger, you can avoid developing a reputation as a “difficult caller.” Most of the organizations that you deal with keep records that phone personnel access when you call them. By avoiding being labeled obnoxious or insulting, you are likely to get better service on future calls.

If you experience a problem that makes you very angry, how can you prevent the anger from boiling over into the phone conversation? The easiest way might be to take some time to cool off. Do a relaxation exercise before making a stressful phone call. “Have a friend with you when you make the call, that way you can make faces with your friend but remain calm on the phone.”

Before making your call, you can also take time to plan what you are going to say, and gather the information that you might need. For example, it is common for someone to receive a hospital bill for services that were supposed to be covered by insurance; these situations are often caused by paperwork errors. If this happens to you, your first inclination might be to call the hospital or the insurance company and yell at someone.

Instead of doing so, take some time to calm down, gather the bill, your insurance policy, and the paperwork you received at the hospital. Then call your insurance company and find out why the bill wasn’t paid. With this information, you are more likely to be able to calmly, but assertively resolve the situation. Let’s now look at how to use the phone assertively.

❖ Being assertive

A big part of assertiveness when using the phone is being persistent enough to get in touch with someone who can help you. When calling large organizations, it’s not always easy to reach live people, says Brian Cooper, but one alternative is to “call them once a day until they realize that you won’t stop calling until they resolve the situation.” If you’re having trouble reaching someone, you should leave a message each time, including the dates and times that you are available to speak.

Your assertiveness must continue once you are speaking with a live person. Learning to be assertive without raising your voice or being rude is a skill to be learned, and one that will make you a much more effective advocate. Let’s look at specific ways to be assertive on the telephone.

- ***Do your research.*** If you are told that you cannot do something or qualify for certain benefits, you should know the standards. For example, you might say, “My insurance policy says that I have the right to appeal this decision, and I would like to appeal.”
- ***Set minimum standards.*** Often, you will be dealing with low-level employees who do not have the power to compromise; therefore, if anyone compromises, it will have to be you. If a low-level employee cannot meet your minimum demands, ask to speak to his or her supervisor.
- ***Recognize the other side of the argument.*** If you demonstrate that you understand the other person’s point of view, then he or she cannot dismiss you as being irrational. You might say, for example, “I can see why you

don't normally authorize that medication because it is more expensive. But it's worked for me in the past, and it is cheaper than paying for my hospital bills."

- **Ask for clarification.** Don't let the other person confuse you with jargon or vague statements. Whenever the other person says something that you don't understand, ask for clarification. You can't win a dispute if you don't understand what the other person is saying.
- **Leave the door open.** State that you would like to reserve the right to submit additional information. If you become flustered on the phone, you can strengthen your case later.

Table 4 contains some more examples of assertive responses. These are just a few examples of the statements that you can make to assert yourself. One effective way to work on your assertiveness is to role-play advocacy situations with a friend. Ask your friend to give you feedback about whether you were acting assertively.



TABLE 4: ASSERTIVE RESPONSES

Statement	Assertive response
<i>Insurance company customer service representative: “I’m not the person who deals with this.”</i>	“Tell me the name and number of that person. I called the number listed in my policy, and if you can’t help me, it’s your responsibility to tell me who can.”
<i>Social security representative: “I don’t have all of the information about your application, so I can’t answer that question.”</i>	“When can I expect to hear back from you? I will call back if I don’t hear from you by then.”
<i>MCO executive assistant: “I don’t think that there are any openings on the advisory board right now.”</i>	“I was told that there are no consumers on the advisory board, and the law says that there must be consumer representation. Who is in charge of the selection?”
<i>MCO customer service representative: “We can’t pay for the treatment because it is not medically necessary.”</i>	“I would like you to send me an explanation of how you determine whether a treatment is medically necessary.”

❖ Talking to the right person:

As we mentioned in the previous section, when you're talking to someone on the phone, it is often someone who won't be able to resolve your situation for you due to lack of authority. Other times, the person on the other end of the line just happens to be a generally unhelpful person.

Author Brandon Toropov offers many helpful suggestions for resolving a problem by phone. His book, *The Complete Idiot's Guide to Getting Along with Difficult People* (don't be put off by the sarcastic title), recommends that you seek a new contact person if the person with whom you've dealt:

- Is new to the job, based on what the person has said or your best guess;
- Has not gotten in touch with you after you've left three messages;
- Has told you three times that he or she must appeal to a supervisor for information or authority, without results;
- Hesitates before answering important questions;
- Asks you to supply the same information or file the same forms more than once; or
- Is defensive, moody, or combative without being provoked by you.

When you're not getting anywhere by talking to lower-level employees, you might need to "go up the supervisory ladder." However, going to a supervisor before you've given someone a fair chance to resolve your problem can create bad feelings, and you can always go to a supervisor later.

If someone fails to resolve a problem to your satisfaction, then you should go up the supervisory ladder, one level at a time. In other words, always ask to speak with someone's immediate supervisor.

Some advocates recommend going straight to the top of the supervisory ladder, but there is an obvious advantage to moving one level at a time: you give more people the opportunity to give you what you want. If, on the other hand, you go straight to the top, and that person says "no," you probably won't get what you're after.

❖ Keeping records

With any form of self-advocacy, it is important to keep records, but it is especially important to keep accurate and complete records of your telephone conversations. Often, your records will be the best documentation of your attempts to resolve a situation or another party's suggested solutions.

You should keep an accurate record of every person with whom you spoke, as well as their titles and what they said. Sometimes, it will strengthen your position if you can demonstrate that the other party was unhelpful, and so you should also document every time that you couldn't get through to someone on the phone, as well as when you left messages for a person. Doing so will prevent someone from saying that your inactivity is the cause of the problem. You can use the Sample Phone Log as your guide.



SAMPLE PHONE LOG

Outgoing phone log	Incoming phone log
Date:	Date:
Number called:	Person calling:
Person called:	Title:
Referred by:	Phone number:
	Fax number:
Was call answered?	Summary of conversation:
Left message?	
Person spoken with:	
Title:	Action suggested:
Fax number:	
Summary of conversation:	
Action suggested:	Action agreed upon?
Action agreed upon?	
Deadline:	Deadline:

❖ Following up:

As with any form of advocacy, it is important to follow up when you are advocating by phone. The follow-up usually includes additional phone calls to ensure that agreed-upon actions will be taken, but might also include supplying written documentation or sending follow-up letters or faxes.

Following up on a phone conversation should begin during the conversation itself. For example, if the person with whom you are speaking cannot respond to your request immediately, you should ask when they will get back to you *and* the date on which you can expect action on what you've requested. If the person promises to take a specific action, then ask when that action will be taken. Be sure to record this information in your phone log.

Once you've established dates for responses and/or action, you should make sure that the person sticks to those dates. You can mark a calendar to keep track of the dates. If you haven't heard back or seen results by the agreed-upon date, you should call back.

Be polite but firm. Remind the person that he or she promises to respond or take action by a certain date and ask why this hasn't happened. You should persist until you get what you want, and if you don't see results, then you should proceed up the supervisory ladder one level at a time.

Usually people are handling multiple requests at a time, and one way to ensure that your request gets special attention is to follow a phone call with a fax. When speaking with someone, ask for the fax number where he or she can be reached. After speaking with a person, send a fax summarizing the action requested and the agreed-upon follow-up dates.

If the person does not seem to be responding adequately, then a fax can be an especially effective tool. Obtain the name of the person's supervisor, and send the fax both to the person with whom you've spoken and his or her supervisor. At the bottom of the fax, write "cc:" followed by the supervisor's name so that the employee knows that the supervisor has also seen the fax. We'll examine written communications more closely in the next section, *Advocacy in Writing*.



ADVOCACY IN WRITING

Being able to write a short, direct, and assertive letter will aid your advocacy efforts. Learning to write letters is a skill that must be learned, but fortunately it is easier to learn than almost any other style of writing. And the good news is that, as a general rule, the shorter your letter, the better. In this section, we'll discuss how to write an effective letter, as well as provide some sample letters.

Keep in mind that every letter you write should become a part of your files on the matter in question. In *Advocacy on the telephone*, we stressed the importance of keeping detailed records of phone conversations. Keeping records of your letters is easier, but equally important, so be sure to keep a photocopy of each letter.

❖ **The format of a business letter**

When you write a letter for advocacy purposes, you should follow the standard format for business letters. Although there is some variation in the format used for business letters, Sample Letters A and B provide a good model to follow. Include your return address, the date, the other person's address, greeting, and signature in a manner similar to that in the sample letters.

Another feature to note is the "cc:" (copies circulated) line. "When you're writing a letter to someone, "cc" it to someone who is that person's boss, because if you send a letter that's not cc'd to someone, then it's easier for the person to put your letter aside. If it *is* cc'd to someone important, then the person will give it a lot more attention.

However, keep in mind that cc'ing someone's supervisor puts that person on the defensive. It can therefore be counter-productive to cc a person's supervisor before you've given the person a chance to resolve the problem.

Below the "cc" line is the "encl." (enclosures) line. To show the person you're writing to what you've sent, and to remind yourself when you look at a photocopy of the letter, use the "Encl." notation and a brief description of what you've sent.

Although the standard business letter is typewritten, it is acceptable to hand-write a letter if you cannot type your letter or find someone else to type it for you. Try to write as neatly as possible, and again, be sure to keep a photocopy.



❖ The content of the letter

The *Sample Letters* included here also provide an idea of what to include in your letter. When you write a letter, you should:

- Open by explaining why you are writing. For example, in Sample Letter B, the writer wants his insurance company to pay a hospital bill.
- Include photocopies of relevant documents or offer to provide whatever documentation is necessary. In Sample Letter A, the writer offers to provide documentation from her health care professional, and in Sample Letter B, the writer includes a copy of the hospital bill.
- Explain the reason why you are asking for action. The writer of Sample Letter A explains that the Fair Housing Amendments Act requires that landlords make “reasonable accommodations” for tenants with disabilities. In Sample Letter B, the writer explains that he had obtained a referral for the services; therefore, the insurer should pay for them.
- If the action needed is urgent, explain why. In Sample Letter B, the writer is facing a negative credit report if the problem is not solved swiftly.
- If applicable, summarize steps that you have taken to resolve the problem. In Sample Letter B, the writer summarizes phone conversations and documents times that he tried to reach the insurance company.
- If you are considering legal action or a formal complaint, note that you are considering it. However, reserve this tactic for situations in which you feel that you have a valid case and could follow through; otherwise, the other party could call your bluff.
- In the closing paragraph, give a time by which you expect the person to respond or take action. This should be a reasonable amount of time in relationship to the urgency of the situation.
- Also in the closing paragraph, thank the recipient, or if the recipient has not proven helpful so far, then express your hope that they will resolve the matter as soon as possible.

❖ Other considerations:

As you grow as a self-advocate, you will feel more comfortable writing letters, and you'll learn what works and what doesn't work. Here are some other things to think about when writing letters as a part of your advocacy efforts:

When writing your letter, pay special attention to your tone. Put yourself in the place of the writer of Sample Letter A: although she was probably angry at the insurance company's broken promise, she is not rude or insulting. She simply states why the recipient has done wrong and explains what the insurance company should do in order to rectify it. By not antagonizing or insulting the recipient of the letter, you reinforce that you are in the right and that your request should be granted.

For a few extra dollars, you can send a letter via certified mail, return receipt requested. Not only will this make your letter stand out to the recipient, you'll know exactly when the letter arrived. Depending on the severity or urgency of the situation, you might also consider faxing your letter or using express delivery.

You shouldn't hesitate to ask friends for help in writing letters. You can rely on friends to help with the writing and to check your letters for errors in spelling or grammar.



SAMPLE LETTER A

Elizabeth Martin
127 Maple St.
Apartment 105
Yorktown, MD 22038

April 1, 200_

Mr. Edward Peters
Peters Property Management
13 E. Main St.
Yorktown, MD 22038

Dear Mr. Peters:

I am a tenant in your building at 127 Maple Street. I am writing to request, as a reasonable accommodation required by the Fair Housing Amendments Act (FHAA), that I be allowed to keep a service dog in my apartment. The FHHA requires that landlords provide “reasonable accommodations” to tenants with disabilities.

I understand that the building has a “no pets” policy, however, health care professionals have recommended that I use a service animal for emotional support. I would be happy to provide written documentation of my disability and my providers’ recommendations.

Please contact me within ten days to let me know whether my request has been granted because I need to proceed with finding a suitable service dog. You may reach me by telephone at (410) 555-2525. Thank you for your prompt consideration of my request.

Sincerely,

Elizabeth Martin

SAMPLE LETTER B

Steven Jones
14 Broad Street
Springfield, CT 04567

January 2, 200_

Mr. Evan Brown
Claims Services Representative
Acme Insurance Company
2121 Lincoln Ave.
Brookwood, CT 04848

Dear Mr. Brown:

I am writing to request the immediate payment of the enclosed hospital bill, for services provided on October 12. As you can see, the hospital is threatening to refer my account to a collection agency, and I am very upset that Acme Insurance has not paid this claim. I am considering referring this matter to the state insurance commissioner.

I had received a referral for the services in question. The referral number is BB 9854. Therefore, Acme should have paid this claim. When I spoke with you on the phone on November 20, you assured me that the bill would be paid within 10 days. After that time passed, I have been trying unsuccessfully to reach your department. I left messages on December 5, 10, 13, 15, and 19.

Please respond within five days of receipt of this letter. You can reach me by phone at (203) 555-2828. I am looking forward to the prompt resolution of this matter.

Sincerely,

Steven Jones

cc: April Jackson,
President, Acme Insurance

Encl: Hospital bill (photocopy)

ADVOCACY IN PERSON

For some forms of self-advocacy, such as participating in your own health care decisions, in-person advocacy is only natural. By working to improve your in-person advocacy skills, you can help overcome the anxiety that many people experience when preparing for a meeting.

❖ Preparing for a meeting

Preparing in advance of a meeting not only helps to reduce anxiety, but preparation also helps you to become a much more effective self-advocate. Perhaps the first step in preparing for a meeting is writing down the appointment as soon as you've made it. Although recording an appointment is a simple step, it is an extremely important one because it helps you keep the appointment.

If you absolutely cannot make a scheduled appointment, call in advance to cancel or reschedule it. Try to give the other person as much notice as possible; you shouldn't cancel a meeting on the same day unless it is a sudden, unanticipated emergency.

At the time you schedule your meeting, you should also ask for information that will help you prepare. Always ask if there is any type of documentation that you will need to bring to your meeting. Ask if you must meet certain qualifications in order to get what you're asking for. If the other party initiated the meeting, make sure that you understand the purpose of the meeting completely.

Another important step for planning a meeting at which you will advocate for yourself is to find a friend who can come with you. Although it helps to pick someone who knows something about advocacy, it's not necessary to do so. They act differently, even if your friend doesn't say anything. It's still self-advocacy because you're in control. It's a way to get around the system."

Another important part of preparing for a meeting is to think hard about what could happen at the meeting. Ask yourself the following questions:

- What do I want to happen at the meeting?
- What do I want to learn at the meeting?
- What could happen as a result of the meeting?

By knowing what you want to happen, but preparing yourself for what could happen, you can better think through your strategy for the meeting. You should prepare an agenda for what you'd like to say, what you'd like to ask the other person, and how you would respond to the other party's suggestions of what they'd like to happen.

In addition to bringing your agenda with you, you should bring photocopies of all relevant documents (unless the other party says that you need to bring an original). Also, if you will be citing particular laws or regulations, you should bring photocopies of those as well. A photocopy gives people a chance to look at the law. By demonstrating that you know your rights, it makes it much more difficult for the other person to ignore your rights.

❖ Holding a successful meeting:

An obvious but important first step in holding a successful meeting is to show up *on time*. Once you're there, you have many tactics that you can use to improve your chances of a successful outcome. Some of the tactics you'll find particularly helpful include body language, active listening, and negotiation skills. Although these skills require practice, once you learn them, you'll be a much more effective self-advocate.

❖ Body language:

In an ideal world, justice and fairness would govern everyone's actions. However, in the real world, image is important, and the way in which you present yourself at a meeting can have a major impact on its outcome. Using positive body language conveys confidence and assertiveness. Here are some examples of positive body language:

- ***Dress and groom yourself appropriately for the meeting.*** Poor grooming or sloppy dress can leave a negative impression regardless of the strength of your case. Dress as nicely as you can. If you dress nicely, people will – consciously or unconsciously – treat you with more respect.
- ***Shake hands firmly.*** When you introduce yourself at the beginning of the meeting, give the other person a firm handshake while you look the person in the eyes.
- ***Do your best to maintain eye contact.*** Although this can be difficult if you are shy or nervous, you will find that maintaining eye contact helps you maintain control over the meeting. Don't "stare down" the other person, but do look him or her in the eyes while either of you is talking.
- ***Use good posture.*** By sitting straight in your chair, you show respect for the other person and also convey confidence in what you are seeking.
- ***Try not to fidget.*** You should try to avoid some of the things people often do when they are nervous, such as wringing their hands or squirming in their chairs. Such actions convey your nervousness, making the other person feel more confident in his or her position.

- **Practice these skills.** Before an important meeting, you can practice your body language either with a friend or in front of a mirror. If positive body language does not come naturally to you, you should practice this skill. You can learn positive body language in the same way you learned to jump rope, hit a baseball, or play video games.

❖ Listening:

When you are meeting with someone, active listening can mean the difference between being spoken to and being “spoken at.” Active listening means that you take steps to find out the information that you need, rather than simply listening to what the other person says.

The simplest form of active listening is to ask for clarification if you don’t understand something. For example, if the person uses jargon or an abbreviation that you don’t understand, be sure to ask what it means. For example, if someone says, “well, we don’t usually get involved in these types of situations until DDM has contacted us,” you won’t really know what to do next if you don’t know what DDM stands for. Don’t be afraid to ask for this information; if you try to find out after the meeting, you will miss important points during your discussion.

Active listening requires that you restate a person’s position so that you both understand what the person is offering or requiring. In the above example, you might respond, “So what you’re saying is that I should contact DDM and ask them to review my case.” By restating the other person’s position, you can make sure that you are both “on the same page” as you negotiate.

You should also ask for clarification if you don’t understand someone’s reaction to what you say. For example, if someone replies, “I see,” it might mean that the person understands your position, but the person might mean, “I see that you are being difficult.” When someone is vague, don’t guess at his or her meaning; instead, *ask*.

- Finally, to have a record of exactly what went on during the meetings, you should take careful notes of what was said. Be sure to write down:
 - Any promises that the other person makes;
 - Any actions that you must take;
 - Any explanations that the person makes for granting or denying your requests; and
 - Anything the person says that is supportive of your position.

Using a tape recorder allows you to keep an exact record of your meeting. Although some people might permit you to tape record a meeting, others are put off by this suggestion.

❖ Negotiation:

Learning to negotiate successfully is the centerpiece of self-advocacy. All of our preparations feed into the negotiation process. As with other advocacy skills, negotiation is a skill that can be learned through study and practice. Here are some pointers for getting what you want through negotiation:

- ***Lead with the strongest part of your argument.*** For example, if you are dissatisfied with the treatment you have been receiving, you might start by pointing out that a doctor or staff person has violated your state's patients' bill of rights.
- ***Keep your presentation short by focusing on relevant facts.*** Often, we want to tell our life story when we are trying to spur people to action. But by taking up too much of someone's time, you run the risk of alienating that person. Instead, focus on details that are the responsibility of that person. In other words, if you are experiencing problems with a certain program or service, focus on that program or service rather than other problems that you might be experiencing.
- ***Focus on remedies, not complaints.*** Unless your goal is simply to make someone feel sympathy for you, then you should have an action plan for what you want to happen. For example, rather than complaining about your housing, you should state that you want housing in a safer area.
- ***Control your emotions.*** No matter how much the other person upsets you, don't resort to yelling or name-calling. If you need to ask for a break to compose yourself, do so. You can go home and punch pillows after the meeting, but "blowing up" during the meeting reflects poorly on you, and people often use your behavior as an excuse for denying you what you want.
- ***Have in mind a minimum that you are willing to accept.*** To be a good negotiator, you should ask for more than what you really want, but keep in your own mind a minimum that you would be willing to accept.
- ***Acknowledge the other person's position.*** Demonstrate that you understand the limitations faced by the other person. This will help you keep your demands 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 guns.*** 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 guns 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 a different educational plan. If something happens to my child, your agency could face problems."
- ***As 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 those 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.*** "If the meeting isn't going smoothly, don't agree to something just because you're at a meeting. 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.

❖ Follow-up:

As with any form of self-advocacy, following up is important after you meet with someone face-to-face. After your meeting, write a short letter thanking the person for his or her time. In your letter, you should also restate any agreements that were made in the meeting.

After your meeting, read over your notes and make sure that you understand them. While your memory is still fresh, you should also fill in any information

that you might have forgotten to write down. Keep your meeting notes with other documentation, such as copies of letters and your phone log.

If the person with whom you met promises results by a certain time and these things do not happen, then you should contact the person. When you call or write to the person, be sure to refer to the date of your meeting and restate what you had agreed upon.

BEYOND SELF-ADVOCACY

No matter what your needs, self-advocacy can be a powerful tool throughout your life. If you are just beginning, you might find that self-advocacy helps you take small steps. As your self-advocacy efforts continue. You will surprise yourself with what you have achieved.

At times, our individual needs must take center stage. However, as we grow as advocates, we often find that we can help others as well. Many people who began as self-advocates are now working as advocates for others.

Through systems advocacy, “You can change the system to benefit people you don’t even know. It’s a very rewarding use of your time.”

Remember that you are part of a growing movement of mental health consumers who no longer will remain silent while decisions are made for us. The most important way you can stand up for yourself is by asserting your existing rights through self-advocacy. But eventually you won’t be satisfied with your existing rights and you’ll want to demand better rights. That’s where systems advocacy comes in. If people can assert themselves and let it be known that the status quo is unacceptable, then we can work together to change the system.



**GETTING
REASONABLE
ACCOMMODATIONS
FOR YOUR
CHILD
AT SCHOOL**

WHAT ARE REASONABLE ACCOMMODATIONS?

Introduction:

Most students need some adjustments to help them perform at their best. A parent who works full-time needs a day off to get a sick child from school, or a student needs an extension on a term paper because he has a family emergency that requires him to make an unscheduled trip out of town. Both employee and student have the necessary skills to do what's required if these adjustments are made.

For people with a disability, such changes are often critical to their success. Although some of the adjustments might be different from those that work for other people, they accomplish the same goal -- allowing qualified students to do the best job they can. These strategies are often just good educational practices. Reasonable accommodations are those adjustments within a school site that allow an otherwise qualified student with a disability to perform the tasks required.

Educators are **not** expected to provide opportunities to those who cannot do what is necessary. The laws do not require them to lower the standards of performance or change the qualifications needed to gain entry into a school program. What they **are** expected to do is be flexible about the way the work gets done.

Educators are required to provide reasonable accommodations under 2 separate laws: The Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973. Recently, the Equal Employment Opportunity Commission (EEOC) issued Enforcement Guidance on the ADA and Psychiatric Disability.

REASONABLE ACCOMMODATIONS FOR PEOPLE WITH PSYCHIATRIC DISABILITY

It's usually easy to tell what kind of accommodation someone with a physical disability needs. Someone who uses a wheelchair needs a higher desk. Someone with visual problems needs to receive all written material in large print. But since mental illness is often invisible, it can be hard to tell what will help a person with a psychiatric disability do his or her job better.

The first step in identifying the accommodations your child needs is to know the demands of the coursework. The second step is to figure out your child's "functional limitations" -- that is, how your child's disability may make it hard for them to meet those demands. For example, your child's symptoms or the side effects of their medication may cause problems with memory, concentration, relating to others, managing or experiencing emotions, or organizing and managing time.

Effective accommodations include changes in schedules, instructions, tasks or other procedures, and ways the instructor interacts with your child. Not all of these accommodations will work for everyone; each situation should be taken on an individual basis. Many people with psychiatric disabilities may not need accommodations of any kind.

MENTAL ILLNESS AND PSYCHIATRIC DISABILITY

"Mental illness" describes a variety of psychiatric and emotional problems that vary in intensity and duration, and may recur from time to time. Mental illnesses become disabling when they interfere significantly with a person's ability to work, learn, think, care for oneself, or interact with others. Mental illness is not mental retardation or brain injury.

BENEFITS OF REASONABLE ACCOMMODATIONS

In our lifetimes, one in four of us will know someone who has experienced a mental illness - a family member, friend, neighbor, employee, manager, student, or teacher. Many talented people have made significant contributions despite having had a mental illness: President Abraham Lincoln, writer Ernest Hemingway, actress Patty Duke, Senator Thomas Eagleton, artist Vincent Van Gogh, scientist Isaac Newton, athlete Lionel Aldridge, and businessman Ted Turner, to name a few, have accomplished many things in spite of having a mental illness.

Reasonable accommodations may help your child return to school from disability or medical leave sooner. Costs for treatment of mental illness may be reduced the sooner one returns to a productive role, and many people want to become productive again. Often, these adjustments -- flexible schedules, time off for medical appointments, or changes in communication, feedback and/or supervision -- are not much different from the changes available to any employee or student. They can benefit everyone, not just the employee with a disability.

Sources : Job Accommodation Network; National Alliance for the Mentally Ill; President's Committee on the Employment of People with Mental Illness; Zuckerman, Debenham & Moore, (1993) *The ADA and People with Mental Illness: A Resource Manual for Employers*.

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WHAT LAWS PROTECT SOMEONE WITH A PSYCHIATRIC DISABILITY?

Several different laws apply to people with disabilities and require that educators provide reasonable accommodations. All employers with 15 or more employees, including for-profit and non-profit businesses, state and local governments, religious entities and the United States Congress, must comply with the ADA.

Federal agencies of the Executive branch, Federal government contractors and those who receive Federal financial assistance must comply with the Rehabilitation Act of 1973.

Although not specifically requiring accommodations, the Family Medical Leave Act provides for 12 weeks of unpaid employee leave in the event of illness, which may be used by you as an accommodation.

FILING COMPLAINTS ABOUT DISCRIMINATION IN THE CLASSROOM

You've made sure a documentation letter is on file at your school, tried to negotiate appropriate accommodations, and discussed your child's needs and problems with the appropriate administrative services office or counseling center. But if you still feel you're facing discrimination at school, it may be time to file a formal complaint.

❖ **Filing a Complaint under the Rehabilitation Act of 1973**

Section 503:

If your educational institution has a contract of more than \$10,000 a year with the federal government, Section 503 of the Rehab Act requires it to provide reasonable accommodations for your documented disability. If you don't feel you're getting the accommodations you need, you can file a complaint under Section 503 by contacting the U.S. Department of Labor's Office of Federal Contract Compliance Programs at (202) 219-9423 (voice/relay).

Section 504:

If your school receives money from the federal government (including federal financial aid), Section 504 of the Rehab Act requires it to make "appropriate and reasonable" modifications to policies and practices. (It does not, however, require schools to develop special education programming for students with disabilities.)

This applies to almost all public schools and many private ones.

To file a complaint under Section 504, contact the [Disability Rights Section of the U.S. Department of Justice's Civil Rights Division](#) at (800) 514-0301 (voice) or (800) 514-0383 (TDD)

❖ **Filing a Complaint under the Americans with Disabilities Act**

Title III of the ADA prohibits private and nonprofit entities, such as private schools and colleges, from excluding, segregating, or treating your child unequally because of your child's disability. Your child must be able to physically access these places. They must provide reasonable modifications to policies, practices, and procedures and use effective communication methods to inform people with disabilities. Courses and exams must be provided in an accessible place and manner, or alternative accessible arrangements must be available.

To file a complaint under Title III, contact the [Disability Rights Section of the U.S. Department of Justice's Civil Rights Division](#). You must file your complaint within 180 days (six months) of the date of the discrimination. You also do not need to wait for the Disability Rights Section to agree that you're a victim of discrimination to file a lawsuit in federal court. For details, contact the Disability Rights Section at (800) 514-0301 (voice) or (800) 514-0383 (TDD).

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HOW DOES MENTAL ILLNESS AFFECT THE WAY MY CHILD FUNCTIONS AT SCHOOL?

Mental illnesses may interfere with your child's ability to function at school -- or they may have no effect at all. If your child's mental illness is affecting his/her ability to do things such as concentrating or communicating effectively, you're probably aware of it. Then again, you may not have made the connection between your child's disability and problems functioning. Under Section 504 of the Rehabilitation Act and the ADA, educational personnel only need to provide accommodations for limitations that can be directly connected to your child's disability. You should document the types of functional limitations caused by your child's disability to show the need for academic adjustments. Here's a list of some of the limitations your child may be experiencing. If your child has a psychiatric disability, they may have trouble doing some of these things.* Please remember that since there are many different types of mental illnesses, this isn't a complete list -- and that not everyone experiences all, or even any, of these limitations. Here's how your child might cope:

- **Inability to screen out environmental stimuli:** Stimuli such as sounds, sights, or smells, which distract you. For example, it may be hard for your child to pay attention to a lecture while sitting near a loud fan or to focus on studying in a high traffic area.

Possible solutions: Have your child moved away from the fan; ask the teacher to shut off the fan during the lecture.

- **Inability to concentrate:** Your child may feel restless, have a short attention span, be easily distracted, or have a hard time remembering verbal directions. For example, your child may have trouble focusing on one task for extended periods, reading and retaining course material, or remembering instructions during an exam or a classroom exercise.

Possible solutions: Break large projects into smaller tasks; ask permission for your child to take short, frequent breaks to stretch or walk around; ask for a tutor to help with study skills and information retention; ask for assignments to be given one task at a time or in writing.

- **Lack of stamina**: Your child may not have enough energy to spend a full day in class, or take a long exam in one sitting. You may also find your child's medication makes them drowsy.

Possible solutions: Look in to having your child attend school as a part-time student; schedule class attendance during high-energy hours; ask to take exams in sections.

- **Difficulty handling time pressures and multiple tasks**: Your child may have trouble managing assignments, setting priorities, or meeting deadlines. For example, your child may not know how to decide which assignments to do first, or how to complete assignments by the due date.

Possible solutions: Break larger assignments and projects down into manageable tasks; ask for a course outline detailing class topics, assignments, and due dates for the entire semester.

- **Difficulty interacting with others**: It may be difficult for your child to talk to other students, get notes or discuss assignments, participate in class, meet students outside of class, chat with other students at class breaks, and make friends.

Possible solutions: Ask for help finding a mentor or "buddy" who can introduce your child around and help him/her fit in.

- **Difficulty handling negative feedback**: Your child may have a hard time understanding and interpreting criticism. For example, they may get defensive when someone tells them their work isn't up to standards. It's hard for them to figure out what to do to improve. They might want to give up or even drop out of school because of a poor grade.

Possible solutions: Ask your child's teacher to talk with you and your child about their performance and suggest specific ways to improve; find out whether your child can make up for poor grades with alternative assignments or extra credit projects; ask the teacher to meet with you and your school's disability services counselor (may be the Area Education Agency Staff) to facilitate feedback.

- **Difficulty responding to change:** Unexpected changes in your child's coursework, such as new assignments, due dates, or teachers, may be unusually stressful for your child.

Possible solutions: Ask your child's teacher for advance warning of any changes in the classroom if possible

*Adapted from Mancuso, L.L. (1990) Reasonable accommodations for workers with psychiatric disabilities. Psychosocial Rehabilitation Journal, 14(2), 3-19

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ACADEMIC ADJUSTMENTS

In educational settings, reasonable accommodations are referred to as academic adjustments. If your child is a student with a psychiatric disability, academic adjustments might include adaptations in the way specific courses are taught, the use of auxiliary equipment and support staff, and modifications in academic requirements. However, specific adjustments are not mandatory; instead, they should be negotiated, selected, and arranged in consultation with you, the teacher, and the school's administrative services personnel, as the case may be. Below is a list of some possible aids and services, with a brief description of each.

❖ Classroom Accommodations

- Preferential seating

Seating in front, by door, helps reduce audio/visual distractions

- Accompanier

Having someone (another student, or a counseling staff member) to go with your child to class and sometimes stay in class with them.

- Assigned classmate as volunteer assistant

Similar to an accompanier, an assistant may help your child take notes or provide informal support.

- Beverages permitted in class

Helps alleviate dry mouth or tiredness caused by medications.

❖ Lecture Accommodations

- Tape Recorder

Alleviates pressure of notetaking, freeing your child to attend and participate more fully in class.

- Notetaker

Similar to above, having someone in class to take notes alleviates anxiety of having to capture all the information; sometimes the anxiety of attending class interferes with effective notetaking.

- Photocopy of another's notes

If notetakers are not available, then securing notes from another student helps free your child to attend and participate more fully in class.

❖ Testing Accommodations

- Change in test format

Altering an exam from a multiple choice format to an essay format may help your child to demonstrate what they know more effectively and perhaps reduce interference from anxiety or the effects of learning disability.

- Permit use of computer software programs or other technological assistance

May assist your child to write if physical handwriting is difficult due to medication side effects that create muscular or visual problems.

- Extended time

Negotiating permission for a specific extra amount of time before the exam might help your child to focus on the exam content instead of the clock, and lessens the chance that anxiety or other symptoms will interfere with your performance.

- Segmented

Dividing an exam up into parts taking them in two or three sessions over 1-2 days helps to reduce the effect of fatigue and focus on one section at a time.

- Have exams read orally, dictated, scribed or typed.

As you know, symptoms, such as anxiety; medication side effects; or a learning disability may interfere with your child's mental focus, concentration, ability to retrieve information, and/or writing capacity during a typical paper-pencil test. Having an exam read or typed might help reduce the amount of external pressure and distractions, and give your child more of an equal opportunity to demonstrate his or her expertise without the disability skewing the results.

❖ Assignment Accommodations

- Substitute assignments

Asking for written exercises or other out-of-class exercises may be better ways for your child to demonstrate their grasp of the required knowledge in a course.

- Advance notice of assignments

Having a course outline helps you to anticipate and plan with your child to set aside time, energy, and workload, as well as to arrange for any support or academic adjustments.

- Delay in assignment due dates

If your child has had to be hospitalized for reasons related to their disability or if other unforeseeable events have interrupted the semester, extra time on a due date might be all that is needed for your child to pass the course. Your request for an extension should be very specific; i.e., a new due date should be negotiated and formalized, not be left open-ended.

- Handwritten rather than typed papers

If your child does not yet have typing skills, they might benefit from asking to have papers handwritten instead of typed.

- Use alternative forms for students to demonstrate course mastery

Your child may be better able to demonstrate knowledge in ways that don't require lots of writing (e.g., a narrative tape instead of a written journal) or time pressure (an essay exam rather than only multiple choice, or an extra paper if your child has not performed well on the exam due to their disability).

- Textbooks on tape

May be helpful to listen to a textbook instead of reading it, if your child's vision or concentration interferes with reading ability.

DOCUMENTING YOUR CHILD'S DISABILITY FOR AN EDUCATIONAL INSTITUTION

By law, if your child meets a school's admission requirements, the school cannot refuse to admit them -- even if they require accommodations for their disability. You do, however, have to document your child's disability in order to be eligible for those accommodations and other disability-related services at the school. This page will help you determine what you need for documentation and how to get it.

❖ **What qualifies as a disability?**

In order to be considered disabled, your child mental illness must substantially limit one or more "major life activities." For someone with a mental illness, that might include the following:

- learning
- thinking
- concentrating
- interacting with others
- caring for yourself
- speaking
- performing manual tasks
- working
- sleeping

Who provides the documentation of my child's disability?

Documentation needs to come from a licensed psychiatrist, a psychologist with a Ph.D., or another qualified mental health professional who has treated your child, either as an individual patient or through a community agency. If you've seen several licensed professionals, ask the one you believe will have the most accurate picture of your child's abilities and needs.

❖ **What should the documentation include?**

Your documentation must include information about your child's diagnosis, specific functional limitations, and how they might affect your child in an academic setting. It must also include the reasons why your requested accommodations are **necessary**. In addition, the person writing the letter needs to mention when your child started seeing him or her, when they stopped, what his or her credentials are (including license or certification), and his or her area of specialization or expertise.

Your documentation does not need to include how your child's disorder affects your child or the side effects of any medication your child may take -- but having

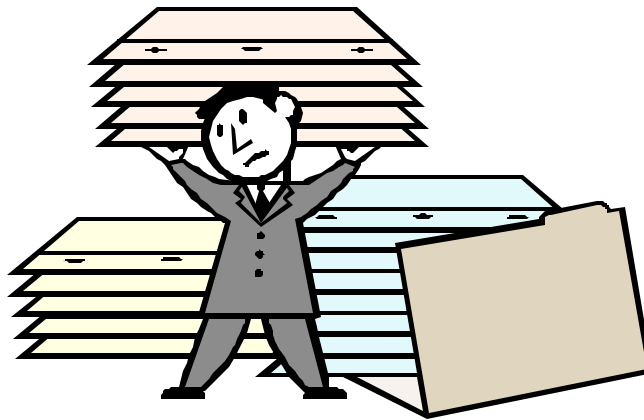
that information could be quite useful to support your request for accommodations.

❖ Who has access to this information?

Disability-related information must be treated and handled as medical information: collected and maintained on separate forms and stored in secure files with access limited to only members of the administrative services office. The information is not allowed to be shared with other people outside the school. Even within the school, people not in the administrative services office can only access the information with your permission or if there is a compelling reason to do so.

Teachers should not have access to your child's disability records! In general, the most they will know -- and then usually only if you tell them -- is that your child has a verified disability and needs accommodation. You need not give them any further details.

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GLOSSARY OF TERMS

CHILD AND ADOLESCENT MENTAL HEALTH

This glossary contains terms frequently used when referring to the mental health needs of children and adolescents. The list is alphabetical. Words in *italics* are defined separately within the glossary. Since the words *service* and *services* are used frequently throughout the glossary, it may be helpful to begin by reading the definition for *service*.

The terms in this glossary describe ideal services. These services may not be available in all communities. The Comprehensive Community Mental Health Services Program for Children and Their Families, administered by the Center for Mental Health Services (CMHS), has grantees in communities across the country that are demonstrating these services. For more information about children's mental health issues or services, call SAMHSA's National Mental Health Information Center at 1-800-789-2647.

➤ **Accessible services:**

Services that are affordable, located nearby, and open during evenings and weekends. Staff is sensitive to and incorporates individual and cultural values. Staff is also sensitive to barriers that may keep a person from getting help. For example, an adolescent may be more willing to attend a support group meeting in a church or club near home than to travel to a mental health center. An accessible service can handle consumer demand without placing people on a long waiting list.

➤ **Appropriate services:**

Designed to meet the specific needs of each individual child and family. For example, one family may need *day treatment*, while another may need *home-based services*. Appropriate services for one child and family may not be appropriate for another. Appropriate services usually are provided in the child's community.

➤ **Assessment:**

A professional review of child and family needs that is done when services are first sought from a *caregiver*. The assessment of the child includes a review of physical and mental health, intelligence, school performance, family situation, and behavior in the community. The assessment identifies the strengths of the child and family. Together, the *caregiver* and family decide what kind of treatment and supports, if any, are needed.

➤ **Caregiver:**

A person who has special training to help people with mental health problems. Examples include social workers, teachers, psychologists, psychiatrists, and mentors.

- **Case manager:**
An individual who organizes and coordinates services and supports for children with mental health problems and their families. (Alternate terms: service coordinator, advocate, and facilitator.)
- **Case management:**
A service that helps people arrange for *appropriate services* and supports. A *case manager* coordinates mental health, social work, educational, health, vocational, transportation, advocacy, *respite care*, and recreational services, as needed. The *case manager* makes sure that the changing needs of the child and family are met. (This definition does not apply to *managed care*.)
- **Child protective services:**
Designed to safeguard the child when abuse, neglect, or abandonment is suspected, or when there is no family to take care of the child. Examples of help delivered in the home include financial assistance, vocational training, homemaker services, and daycare. If in-home supports are insufficient, the child may be removed from the home on a temporary or permanent basis. Ideally, the goal is to keep the child with the family whenever possible.
- **Children and adolescents at risk for mental health problems:**
Children are at greater risk for developing mental health problems when certain factors occur in their lives or environments. Factors include physical abuse, emotional abuse or neglect, harmful stress, discrimination, poverty, loss of a loved one, frequent relocation, alcohol and other drug use, trauma, and exposure to violence.
- **Continuum of care:**
A term that implies a progression of services that a child moves through, usually one service at a time. More recently, it has come to mean comprehensive services. Also see *system of care* and *wraparound services*.
- **Coordinated services:**
Child-serving organizations talk with the family and agree upon a *plan of care* that meets the child's needs. These organizations can include mental health, education, juvenile justice, and child welfare. *Case management* is necessary to coordinate services. Also see *family-centered services* and *wraparound services*.
- **Crisis residential treatment services:**
Short-term, round-the-clock help provided in a non-hospital setting during a crisis. For example, when a child becomes aggressive and uncontrollable, despite in-home supports, a parent can temporarily place the child in a *crisis residential treatment service*. The purposes of this care are to avoid *inpatient hospitalization*, help stabilize the child, and determine the next appropriate step.

- **Cultural competence:**
Help that is sensitive and responsive to cultural differences. *Caregivers* are aware of the impact of culture and possess skills to help provide services that respond appropriately to a person's unique cultural differences, including race and ethnicity, national origin, religion, age, gender, sexual orientation, or physical disability. They also adapt their skills to fit a family's values and customs.
- **Day treatment:**
Day treatment includes special education, counseling, parent training, vocational training, skill building, crisis intervention, and recreational therapy. It lasts at least 4 hours a day. *Day treatment* programs work in conjunction with mental health, recreation, and education organizations and may even be provided by them.
- **DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition):**
An official manual of mental health problems developed by the American Psychiatric Association. Psychiatrists, psychologists, social workers, and other health and mental health care providers use this reference book to understand and diagnose mental health problems. Insurance companies and health care providers also use the terms and explanations in this book when discussing mental health problems.
- **Early intervention:**
A process used to recognize warning signs for mental health problems and to take early action against factors that put individuals at risk. *Early intervention* can help children get better in less time and can prevent problems from becoming worse.
- **Emergency and crisis services:**
A group of services that is available 24 hours a day, 7 days a week, to help during a mental health emergency. Examples include telephone crisis hotlines, suicide hotlines, crisis counseling, *crisis residential treatment services*, crisis outreach teams, and crisis respite care.
- **Family-centered services:**
Help designed to meet the specific needs of each individual child and family. Children and families should not be expected to fit into services that do not meet their needs. Also see *appropriate services*, *coordinated services*, *wraparound services*, and *cultural competence*.
- **Family support services:**
Help designed to keep the family together, while coping with mental health problems that affect them. These services may include consumer information workshops, in-home supports, family therapy, parenting training, *crisis services*, and *respite care*.

- **Home-based services:**
Help provided in a family's home either for a defined period of time or for as long as it takes to deal with a mental health problem. Examples include parent training, counseling, and working with family members to identify, find, or provide other necessary help. The goal is to prevent the child from being placed outside of the home. (Alternate term: in-home supports.)

- **Independent living services:**
Support for a young person living on his or her own. These services include *therapeutic group homes*, supervised apartment living, and job placement. Services teach youth how to handle financial, medical, housing, transportation, and other daily living needs, as well as how to get along with others.

- **Individualized services:**
Services designed to meet the unique needs of each child and family. Services are individualized when the *caregivers* pay attention to the needs and strengths, ages, and stages of development of the child and individual family members. Also see *appropriate services* and *family-centered services*.

- **Inpatient hospitalization:**
Mental health treatment provided in a hospital setting 24 hours a day. Inpatient hospitalization provides: (1) short-term treatment in cases where a child is in crisis and possibly a danger to his/herself or others, and (2) diagnosis and treatment when the patient cannot be evaluated or treated appropriately in an outpatient setting.

- **Managed care:**
A way to supervise the delivery of health care services. *Managed care* may specify which *caregivers* the insured family can see and may also limit the number of visits and kinds of services that are covered by insurance.

- **Mental health:**
How a person thinks, feels, and acts when faced with life's situations. *Mental health* is how people look at themselves, their lives, and the other people in their lives; evaluate their challenges and problems; and explore choices. This includes handling stress, relating to other people, and making decisions.

- **Mental health problems:**
Mental health problems are real. They affect one's thoughts, body, feelings, and behavior. Mental health problems are not just a passing phase. They can be severe, seriously interfere with a person's life, and even cause a person to become disabled. Mental health problems include depression, bipolar disorder (manic-depressive illness), attention-deficit/ hyperactivity disorder, anxiety disorders, eating disorders, schizophrenia, and conduct disorder.

- **Mental disorders :**
Another term used for *mental health problems*.
- **Mental illnesses :**
This term is usually used to refer to severe mental health problems in adults.
- **Plan of care :**
A treatment plan especially designed for each child and family, based on individual strengths and needs. The *caregiver(s)* develop(s) the plan with input from the family. The plan establishes goals and details appropriate treatment and services to meet the special needs of the child and family.
- **Residential treatment centers :**
Facilities that provide treatment 24 hours a day and can usually serve more than 12 young people at a time. Children with *serious emotional disturbances* receive constant supervision and care. Treatment may include individual, group, and family therapy; behavior therapy; special education; recreation therapy; and medical services. Residential treatment is usually more long-term than *inpatient hospitalization*. Centers are also known as *therapeutic group homes*.
- **Respite care :**
A service that provides a break for parents who have a child with a *serious emotional disturbance*. Trained parents or counselors take care of the child for a brief period of time to give families relief from the strain of caring for the child. This type of care can be provided in the home or in another location. Some parents may need this help every week.
- **Serious emotional disturbances :**
Diagnosable disorders in children and adolescents that severely disrupt their daily functioning in the home, school, or community. Serious emotional disturbances affect one in 10 young people. These disorders include depression, attention-deficit/hyperactivity, anxiety disorders, conduct disorder, and eating disorders.
- **Service :**
A type of support or clinical intervention designed to address the specific mental health needs of a child and his or her family. A service could be provided only one time or repeated over a course of time, as determined by the child, family, and service provider.

IMPORTANT MESSAGES ABOUT CHILDREN'S AND ADOLESCENTS' MENTAL HEALTH

- Every child's mental health is important.
- Many children have mental health problems.
- These problems are real and painful and can be severe.
- Mental health problems can be recognized and treated.
- Caring families and communities working together can help.

For free information about child and adolescent mental health, including publications, references, and referrals to local and national resources and organizations, contact SAMHSA's National Mental Health Information Center at 1-800-789-2647 (toll-free), 866-889-2647 (TDD), 301-984-8796 (fax), or <http://www.mentalhealth.samhsa.gov/child>.



RESOURCES

Bibliography

Much of the material in this guide was adapted from the Technical Assistance Guide on Self-Advocacy published by the National Mental Health Consumers' Self-Help Clearinghouse. This guide and other materials are available on the Clearinghouse website: www.mhselfhelp.org

Books marked with ** can be ordered through the Clearinghouse on-line bookstore at <http://www.mhselfhelp.org/bookstore.html>

**Baugh, Sue. *How to Write First-Class Letters: The Handbook for Practical Letter Writing*. Chicago: NTC, 1994.

**Bilodeau, Lorraine. *The Anger Workbook*. Center City, Minnesota: Hazelden, 1992.

**Bower, Sharon, and Gordon Bower. *Asserting Yourself: A Practical Guide for Positive Change*. Reading, Massachusetts: Perseus, 1991.

**Copeland, Mary Ellen. *Living without Depression and Manic Depression*. Oakland: New Harbinger, 1994.

**Covey, Stephen. *The 7 Habits of Highly Effective People: Powerful Lessons in Personal Change*. New York: Fireside, 1990.

**Fisher, Roger, William Ury, and Bruce Patton. *Getting to Yes: Negotiating Agreement without Giving In*. New York: Penguin, 1991.

**May, Debra Hart. *Everyday Letters for Busy People*. Franklin Lakes, New Jersey: Hart, 1998.

Miller, Ivan. *Mental Health Consumer Protection Manual: A Guide to Solving Problems with Insurance and Managed Care*. Commack, New York: National Coalition of Mental Health Professionals and Consumers, 1999. Available by calling (888) 729-6662, or on-line at <http://www.nomanagedcare.org>

National Mental Health Consumers' Self-Help Clearinghouse. *Advocacy and Recovery Using the Internet*. Philadelphia: National Mental Health Consumers' Self-Help Clearinghouse, undated. Available by calling (800) 553-4539, or on-line at <http://www.mhselfhelp.org>

Systems Advocacy. Philadelphia: National Mental Health Consumers' Self-Help Clearinghouse, undated. Available by calling (800) 553-4539, or on-line at <http://www.mhselfhelp.org>

**Toropov, Brandon. *The Complete Idiot's Guide to Getting Along with Difficult People*. New York: Macmillan, 1997.

**Ury, William. *Getting Past No: Negotiating with Difficult People*. New York: Bantam, 1993.

Organizations:

Organizations marked with an asterisk (*) have local and/or state affiliates.

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street, Suite 1207

Philadelphia, PA 19107

(800) 553-4KEY (4539)

<http://www.mhselfhelp.org>

***National Mental Health Association/**

National Consumer Supporter Technical Assistance Center

1021 Prince Street

Alexandria, VA 22314

(800) 969-NMHA

<http://www.nmha.org>

<http://www.ncstac.org>

***National Association of Protection and Advocacy Systems, Inc.**

900 Second Street, NE, Ste. 211

Washington, DC 20002

(202) 408-9514

<http://www.protectionandadvocacy.com>

***National Depressive and Manic-Depressive Association**

730 N. Franklin Street, Suite 501

Chicago, IL 60610

(800) 826-3632

<http://www.ndmda.org>

***National Alliance for the Mentally Ill**

2107 Wilson Blvd., Suite 300

Arlington, VA 22201

(800) 950-NAMI

<http://www.nami.org>

***International Association of Psychosocial Rehabilitation Services**

10025 Governor Warfield Parkway, Suite 301

Columbia, Maryland 21044

(410) 730-7190

<http://www.iapsrs.org>

CONTAC (Consumer Organization & Networking Technical Assistance Center)

1036 Quarrier Street, Suite 208A

Charleston, WV 25301

(888) 825-8324

<http://www.contac.org>

National Empowerment Center

20 Ballard Road

Lawrence, MA 01843

(800) POWER 2 U

<http://www.power2u.org>

American Academy of Child and Adolescent Psychiatry

www.aacap.org

Bazelon Center for Mental Health Law

www.bazelon.org

Center for Mental Health Services Knowledge Exchange Network/SAMSA

www.mentalhealth.org

Federation of Families for Children's Mental Health

www.ffcmh.org

Mental Health and Aging

www.mhaging.org

National Institute of Mental Health

www.nimh.nih.gov

Speaking for Ourselves

www.speaking.org