

SELF-ADVOCACY GUIDE & & ABOUT OUR SERVICES

> M E M B E R ' O F ' T H E NATIONAL' DISABILITY R I G H T S ' N E T W O R K

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All laws are subject to change by legislation and by court decisions. This information is not intended to be legal advice. It is a public education resource. Readers should use the guide for information and then ask questions about their own individual needs.

## This booklet is meant to serve two purposes.

- 1. To give you some information on how to best advocate for yourself (or for your friends and family) without the assistance of a professional advocate or attorney.
- 2. To tell you a little bit about the Disability Law Center and the services we may be able to provide if self-advocacy fails.

## What does advocacy mean?

When you advocate for something it means you try to get other people to see and agree with your point of view. Another way to say that you are advocating is to say that you are sticking up for what you need or what you believe.

There are people who work as professional advocates—their job is to try to get other people to agree with the point of view of their clients.

Self-advocacy means that you are speaking for yourself.

Learning to advocate for yourself, whenever possible, can be an important and rewarding thing to do.

Self-advocacy skills make <u>you</u> the problem solver.

These skills can be helpful in solving problems with:

- doctors;
- case managers;
- employers;
- friends;
- and even family!

Self-advocacy skills will increase your chance of getting what you need, when you need it.

Simply put, being a self-advocate means sticking up for your rights!

## 9 Steps to Great Self-Advocacy

- 1. Define the Problem
- 2. Know Your Rights
- 3. Identify Possible Solutions
- 4. Find Out Who to Talk With
- 5. Be Prepared

## 1. Define the Problem

6. Document Everything

- 7. Evaluate and Follow Up
- 8. Be Assertive
- 9. Ask Questions

Before a problem can be fixed, it has to be clearly defined.

It is important to be clear and precise when defining the problem or issue you want fixed. The more specific you are when you define the problem, the easier it will be to identify where you need to go to solve your problem and come up with possible solutions.

Not convinced about how important this step is? Consider the difference between the following statements you might make to your doctor:

"I'm not feeling well."

or

"I'm running a temperature of 101 degrees and have a sore throat."

It's likely that the second statement will get you the help you need, and get it more quickly.

From *Self-Advocacy* by the National Mental Health Consumer's Self-Help Clearinghouse (2000)

## 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.

By breaking a problem down into smaller segments, you have a greater insight into what steps to take.

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 Coopper, 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?"

In other words, says Clearinghouse executive director Joseph Rogers, "You've got to pick your battles."

## 2. Know Your Rights

Before you can advocate for your needs, you must understand your rights.

Find out what laws, regulations and policies address your situation. Many advocacy agencies in Alaska, including the Disability Law Center, can help you to better understand your rights.

You can find some information about your rights on our website at:

www.dlcak.org under Publications

#### 3. Identify Possible Solutions

Along with clearly identifying the problem or issue, it is important to identify possible solutions.

What would you like to see happen in order to fix the problem?

Consider many possible solutions and the advantages and disadvantages of each. Then, decide which solution(s) you would like to pursue. Keep your goal in sight but be flexible about how to get there.

Understand the difference between what you want and what you need.

For instance, you may *want* to sue someone for money because they didn't provide something you requested. You may be angry about that, which is understandable. But maybe what you <u>need</u> is the service or thing you originally asked for.

#### 4. Find Out Who to Talk With

Start with the person closest to the problem. That person may be a classroom teacher, case manager, health professional, or social worker.

If you don't get the outcome you're seeking, ask how and with whom you would appeal that person's decision.

Climb the agency's chain of command to make sure a supervisor or someone else with authority has a chance to work with you on the problem and your proposed resolution.

From *Self-Advocacy* by the National Mental Health Consumer's Self-Help Clearinghouse (2000)

## Talking to the right person

When you're not getting anywhere by talking to lower-level employees, you might need to "go up the supervisory ladder." Advocate Howard Trachtman says that he recommends the "judicious" use of appeals to supervisors, especially in cases when it's your first point of contact with an agency. 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.

## 5. Be Prepared

It is important to be prepared before you meet with someone, whether it's in person or on the phone. The more prepared you are the more likely you will be able to get what you need.

- Bring (or have handy) any papers that show the problem:
  - o Bills;
  - Receipts;
  - Contracts;
  - Copies of regulations or policies;
  - o Notes, etc.
- Bring or have a note pad and pen or pencil, or audio recorder (but you must ask permission before you record a meeting);
- Bring a friend.\*

\*Having a friend or family member with you at in-person meetings can be helpful in many ways. They can remind you of things you wanted to ask. They can also be a witness to things that were agreed upon in the meeting. Just having another person with you for support can make it easier to say what needs to be said. Sometimes, it may also make the person you're meeting with more likely to cooperate.

## 6. Document Everything

Write down what happened each time you talk to someone while trying to solve the problem. Pay close attention to what is being said to you and take notes.

This history can come in handy if the issue is one that lasts a long time before being fixed. In part, it can provide evidence of your advocacy efforts if you should need to take legal action.

Things to write down:

- Face-to-face conversations,
- Telephone calls;
- Any incidents concerning your situation.

A record can be made by simply writing down who you spoke with or met, where and when you talked with that person, and a brief description of your exchange – what you asked for, what you reported on, what action needs to be taken. For example:

Who:	Jane Jones Early Intervention Coordinator
When:	6/28/08, 11:00 a.m.
Where:	Mat-Su Valley School Fair
What:	Asked her about programs available at my school. I was told she would need to check and let me know. I gave her my telephone number and address. She gave me her business card.
Action to be taken:	Should receive contact from Ms. Jones within a week. Call her on July 8 <sup>th</sup> if I don't hear from her.

Keep copies of everything. If you need to show someone a document, don't give them your original – ask them to make a copy. Then write down who took the papers, what the papers were, and when they were taken.

## 7. Evaluate and Follow Up

If you did not get what you were seeking when you started your advocacy efforts, what other steps do you need to take to be successful?

Have you followed through to find out how your request has been handled and that you have done what is required of you?

You may want to look at achieving another solution through a different plan of action.

Decide which issues you are willing to compromise on and the minimum you are willing to accept.

If you're not happy with the outcome, find out about your rights to file an official appeal or complaint.

Pay attention to timelines for appeals. You might lose the right to appeal a decision that you are unhappy with if you don't make the appeal in time.

#### 8. Be Assertive

Show assertiveness, but talk respectfully and professionally to others and avoid slang or negative comments.

Be prepared to explain your concerns in a clear, specific manner.

Check to make sure the person you are speaking with has understood what you have said. It is OK to ask people to repeat back to you what you have told them.

From *Self-Advocacy* by the National Mental Health Consumer's Self-Help Clearinghouse (2000)

## Managing your anger

Remember that assertiveness is *not* the same thing as aggression: you should be a persistent and tireless advocate for yourself, but you should not shout at or insult others in the process. As Andrea Stephenson 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.

## 9. Ask Questions

Making sure you understand what you have been told is just as important as making sure the other person understands your concerns.

It is your responsibility to ask questions when you are unsure of something.

Do not accept vague or incomplete answers to your questions. If this occurs, ask the person to clarify or let you speak with someone who can better assist you.

Whenever possible, ask to have things put in writing.

## Conclusion

These are 9 good steps to get you started, but there is much more information available.

If you would like to read more, we suggest the booklet called *Self-Advocacy* by the National Mental Health Consumer's Self-Help Clearinghouse. There is a link to this publication on our website at: www.dlcak.org under <u>Publications</u>, then <u>Other Resources</u>.

Advocacy skills help increase your ability to obtain the goals you have set for yourself.

These skills can help you take control of your own life. It may seem hard at first, but advocating for yourself gets easier with practice.

As a self-advocate, you have the decision-making ability and the power to change circumstances in your life.

No one is better than determining what is best for you, than YOU.

## What is the Disability Law Center?

We are an independent non-profit law firm providing legal advocacy for people with disabilities anywhere in Alaska.

Each state and territory has an agency like ours and together our agencies make up a group called the Protection and Advocacy System. This system was put in place to help protect the rights of people with disabilities.

Being an independent agency means that, although we do receive money from the government to do our work, we are not part of the Alaska State government or the United States (federal) government. We operate independently.

Being a non-profit agency means our focus is on protecting the rights of people with disabilities (rather than concentrating on making money).

We don't generally charge for our services.

## What Services does DLC Provide?

- Information & Referral;
- Investigation of abuse and neglect allegations;
- Education & Training;
- Direct advocacy & legal representation;
- Monitoring of places where people with disabilities live and/or receive services to make sure people there are safe.

We help protect the legal rights of people with disabilities when they are facing an issue that only someone with a disability would have.

Advocacy means that we help by sticking up for your rights—or advocating—for what it is that you need as long as you have a legal right to ask for it.

Sometimes we help by giving you the information to solve a problem on your own.

Sometimes we help by giving classes where we educate a lot of people about their rights and responsibilities all at one time.

And sometimes we help by providing a person—an advocate or an attorney—to speak for you to whomever can fix the problem.

If you are a person with a disability and you have a legal issue related to your disability, we may be able to help you.

## Will you take my case?

The best way to find out if we can take your case is to call and speak with our Intake Advocate. The advocate will ask you some questions about yourself, your disability, and the legal problem you are having.<sup>1\*</sup>

Here are some examples of the types of cases with which we <u>may</u> be able to help:

- Social Security benefits appeals when you have been denied SSI or SSDI;
- Disability-related employment discrimination;
- Medicaid/Medicare appeals;
- Disability-related housing discrimination;
- Disability-related financial exploitation;
- Access to appropriate Special Education programs;
- Physical barriers/access to businesses or services;
- Complaints about the Division of Vocational Rehabilitation (DVR) or an Independent Living Center;
- Access to voting.

<sup>1 \*</sup> See further details on requesting help from the Disability Law Center on page 12 of this booklet.

Unfortunately, we cannot help with every kind of legal problem. There are many different kinds of law and no lawyer can be an expert in every kind of issue. So we can't help with some cases because we are not experts in those areas and also because we are given money by our grantors to do only certain kinds of cases. For those reasons, here are some of the kinds of cases we can NOT help with:

- Divorce, custody, child support, and other family law matters;
- Wills, trusts, and estate planning;
- Criminal issues/proceedings;
- Legal or medical malpractice;
- Workers' Compensation or collective bargaining;
- Products liability;
- Bankruptcy;
- Indian/Tribal law;
- Native Allotments;
- Subsistence issues;
- Automobile accidents/traffic violations;
- Consumer protection;
- General Tax matters;
- Pension and ERISA issues;
- Property disputes or real estate;
- Insurance disputes.

In order to decide if we can take your case, we will have to ask you some questions about yourself and about the problem with which you need help. Once we have the details we need, we still have to think about these things:

## • Do we have enough money?

Helping people defend their legal rights can be expensive. We don't usually take payment from our clients, but we still do need money to pay our staff members and keep the office open. To do that, we get grant money from places like the United States government. Grant money is money that is given to us to use in a certain way. We don't have enough money to take every case and we can only take the kinds of cases that the grantors (the people who give us the money) want the money spent on.

## • Do we have enough staff?

Our agency usually has between 15 and 20 staff members to help people with disabilities all over Alaska. There are a lot of people with disabilities in Alaska who ask for our help—we receive about 1,500 requests for help every year—and since there aren't very many of us, sometimes we have to say no. Unfortunately, we can't help with every case.

## • Does the case match our checklist?

We have a checklist of things that we call "case selection factors". This is a list of questions we ask in order to decide if a case is one we can take. In order for us to take a case, all of the following questions have to be true:

True or False	
	1. The person has a disability and the problem they need help with is related to the disability.
	2. The person is not represented by another attorney, firm or agency (Nobody else is currently helping you).
	3. The problem <u>is not</u> one where the person is <u>entitled by law</u> to appointed counsel (In other words, if you have been charged with a crime you would already have been given a lawyer to represent you in court).
	4. There is nobody else that can help you. (Like a private attorney, Alaska Legal Services Corporation, or another agency).
	5. The person lives in an area where no other services are available.
	6. The legal problem has an immediate and/or large impact on the person's life, health, or safety.
	<ol> <li>The person (or another individual like a friend, family member, or case worker) is unable to advocate on the person's behalf to resolve the issue.</li> </ol>
	8. It is possible that the problem can be, or is likely to be, fixed.

If all of those questions can be answered "True", then lastly - we look at our list of priorities.

## • Is it a priority for people in Alaska?

Since there are so many kinds of problems and we can't fix them all—every year we ask people from all over Alaska to help us decide what the most important things should be, then we focus on those things. In other words, we ask for help making a list of priorities. It's just like when you go to the grocery store; you may want 20 things but you may only have the money for 10 things. So you have to decide (or prioritize) which things are most important and only get those things.

You can help us decide which things are most important at any time during the year by contacting our Anchorage office (see contact information on the back of this booklet). We take the opinions of all the people who contact us and see what seems to be the most important to the largest group.

## How do I ask for your help?

The Disability Law Center of Alaska (DLC) has no application for services. Instead, we ask that you call to speak with an Intake Advocate who will gather information to determine if your issue is one which we may be able to assist.

Also, it is important for you to know that faxing, calling, mailing, or e-mailing DLC does not create an attorney-client relationship between DLC and you. In other words, just requesting our help does not mean we will take your case.

The Anchorage office is our main branch and can be reached toll-free from anywhere in Alaska at **1-800-478-1234**. You may also email us at akpa@dlcak.org or send us mail at one of the addresses below:

#### Anchorage

3330 Arctic Blvd., Suite 103 Anchorage, AK 99503 Phone: (907) 565-1002 Fax: (907) 565-1000

#### Juneau

230 South Franklin, Suite 206 Juneau, AK 99801 Phone: (907) 586-1627 Fax: (907) 586-1066 **Fairbanks** 1949 Gillam Way, Suite H Fairbanks, AK 99701 Phone: (907) 456-1070 Fax: (907) 456-1080

If you write to us rather than calling, please be sure to include your name, a daytime phone number (if you have one) and the best time to reach you.

The Anchorage office has an Intake Advocate available during regular business hours to give general information, make referrals to other agencies, and answer questions about DLC. This advocate is also available to interview callers about their particular legal issues and refer the matter to DLC attorneys to figure out if we will be able to provide legal representation.

If you call and are asked to leave a voice mail message, you can expect a call back within 2 working days. (This means that we don't return calls outside of our regular office hours, on weekends, holidays, or other times when the office is closed.)



# 1-800-478-1234

# ANCHORAGE OFFICE:

3330 Arctic Blvd., Suite 103; Anchorage, Alaska 99503 (907) 565-1002 phone • (907) 565-1000 fax

# FAIRBANKS OFFICE:

1949 Gillam Way, Suite H; Fairbanks, Alaska 99701 (907) 456-1070 phone • (907) 456-1080 fax

# JUNEAU OFFICE:

230 South Franklin, #206; Juneau, Alaska 99801 (907) 586-1627 phone • (907) 586-1066 fax

## ALL NUMBERS ARE BOTH VOICE & TDD www.dlcak.org • e-mail: akpa@dlcak.org