

Speaking Out for Yourself—A Self-Help Guide

Acknowledgements

This publication was funded by the U.S. Department of Health and Human Services (DHHS), Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), and prepared by Mary Ellen Copeland, M.S., M.A., under contract number 99M005957. Acknowledgment is given to the many mental health consumers who worked on this project offering advice and suggestions.

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Foreword

It contains information, ideas, and strategies that people from all over the country have found to be helpful in relieving and preventing troubling feelings and symptoms. The information in this booklet can be used safely along with your other health care treatment.

You may want to read through this booklet at least once before you begin working on developing your own action plans for prevention and recovery. This can help enhance your understanding of the entire process. Then you can go back to work on each section. You may want to do this slowly, working on a portion of it and then putting it aside and coming back to it at another time.

After you have finished developing your plan, you may want to review and revise it on a regular basis as you learn new things about yourself and ways you can help yourself to feel better.

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Introduction

If you experience troubling emotional or psychological symptoms—like depression, bipolar disorder or manic depression, schizophrenia, borderline personality disorder, obsessive-compulsive disorder, dissociative disorder, post traumatic stress disorder, an eating disorder, or an anxiety disorder—you may be looking for some information and support on speaking out for yourself.

Perhaps you have forgotten that you have the same rights as other people. Maybe, you may have come to feel that you have lost the power to ask for what you want and need. You may have struggled so much that you have become discouraged—just a little, or maybe deeply.

If you have been having a very hard time, others may have taken control over your life; they may be making most or all of your decisions. They may be doing a reasonable job of this, but you want to take back control. Perhaps you simple want others to treat you with the dignity and respect you deserve.

Whatever your situation, you should know that you have rights, power, and worth that no one, and no system, can interfere with for long if you effectively speak for yourself.

Even if you feel you have never advocated effectively for yourself, you can learn to become your own best champion. Being a good self-advocate means taking personal responsibility for your own life—putting yourself back in charge and staying there. Speaking out means insisting that others respect your rights and treat you well.

A little bit of hope and self-esteem can help you take the first steps to speak for yourself, and your actions in your own behalf will then increase your sense of hope and self-esteem. This upward spiral helps to relieve troubling psychiatric symptoms and supports you so you can do the things you need to do to make your life the way you want it and do the things you want to do. It all starts and ends with you; you have the right to ask for as much help as you need.

People who have been disabled for many years have taken back responsibility for their own lives. As they have done this, their lives have changed dramatically. A man from Seattle has had episodes of major depression for many years and has found that being a strong advocate for himself and others has been essential to getting his depression under control. He says, "People need to know and demand their rights in all types of situations from treatment to housing to employment; and they need to know the alternatives available in different situations. Empowerment and recovery start from the inside when you begin to take charge of all aspects of your life."

You are a unique and valuable person. You have the right to advocate for yourself, to protect your rights and insist that others treat you well.

The steps that follow will lead you through the process of becoming an effective advocate for yourself. You probably will want to work on these steps slowly, one at a time. With persistence, you will find you become better and better at speaking out for yourself.

Steps to Being an Effective Self-Advocate

Believe in yourself.

The first step to become an effective self-advocate is to believe in yourself. Believing in yourself means you are aware of your strengths, know that you are worthwhile, and are willing to take good care of yourself. Many people who have troubling emotional symptoms or who have a disability struggle with self-esteem. To ask for what you need and want and to protect yourself when others treat you badly, you will need to support your self-worth.

You will want to assess, appreciate, support, and improve the way you feel about yourself.

- **Assess:** On a 1-10 scale, what is your self-esteem? If you're undecided, give yourself a 5.
- **Appreciate:** Give yourself credit for as much self-esteem as you do have. It can be really hard to hold one's own in the world, and you deserve appreciation for every point you've been able to hold on to. Forgive yourself for the points that lie between you and a 10. You've done the best you can. Also give yourself credit for reading this booklet.
- **Support:** What do you do for yourself that supports your well-being? Write down those things, like eating well, making sure you have fun regularly, or pursuing your goals. Write only the good things you do right now, appreciate yourself for them, and vow to continue.
- **Improve:** Think of something you'd like to change to improve your well-being. It can be just one small thing that's easy for you that you'd like to stop doing or begin to do such as exercising more, signing up for a class, or watching less television. It may even be getting out of bed. Sometimes deciding is enough, but here, it is helpful to make a step-by-step plan of how you are going to change if you need to.

Exercises to raise Self-esteem

- Get together with a trusted friend. Divide a block of time in half, for instance, 20 minutes divided in half would be 10 minutes each. Then, take turns telling the other person everything good about them. Just think, 10 minutes of compliments!
- Go to the library and get a book on building self-esteem. Do any of the suggested activities that feel right to you.
- Repeat over and over the affirmation: I am a unique and valuable person. I am worth the effort it takes to advocate for myself, to get what I want and need for myself, to protect my rights and to insist that others treat me well. Think of other affirmations that you could say to yourself.

- Set a timer for 10 minutes. Then, write everything good you can think of about yourself. After your time is up, read what you have written. Then, fold it up, and put it in a convenient place, like in your pocket, purse, or next to your bed. Then, read it over before you go to bed, when you get up in the morning and every time you have a spare moment. If you can't think of enough things to write in this exercise, ask your friends for ideas before you begin.
- Do something nice for someone else or for your community. Take fresh flowers to a friend, visit a person in the hospital or in a nursing home, or clean up the trash in a park.

If you don't believe in yourself because you are feeling so badly, have a trusted friend or health care provider remind you that they believe in you.

Decide what you want or what needs to change.

Think about your life. What is it that you need and want for yourself? Make a list of these things. For instance, you may want to—

- get a job, or a better job
- find housing in a safe neighborhood
- take some educational courses or go back to school
- change your medications or treatments
- make more money
- get a raise
- lose weight
- buy a new car
- have a partner
- take some sick time
- be treated as an equal by your health care provider
- not be subjected to inappropriate sexual talk in your workplace

Your list may be very long. Review the list. Which of these things could you achieve, or try to achieve by advocating or speaking out for yourself? Circle those. Which of your circled needs and wants is most important to you? Put #1 beside that want or need. Number the others in order of priority. For instance, your #1 might be going back to school. Your #2 might be getting a better job and #3 might be making more money.

Through this simple process you have identified your needs or goals and how important they are to you in your life. It would be a lot of work to begin working on all of your goals at the same time. Start working on meeting these needs and goals by beginning with your top priority-#1. After you have met that goal, or are coming along well with that one, you can begin using the steps in this booklet to begin work on another need or goal. Keep in mind that your needs and goals may change from time to time. What seems like a high priority now may not seem like such a high priority in several months when something else may have taken precedence over it.

Get the facts.

When you speak up for yourself, you need to know what you are talking about. You need to gather information and make sure the information you have is accurate. There are many ways to get information—

- ask people who have done something similar or who have been in a similar situation—a peer, co-worker, or friend
- ask someone who has special expertise in the area you are working on. (For instance, if you want to go back to college, go visit with a college advisor, disability official, or a student support program. If you need safe housing, talk to someone in the housing authority in your town.)
- study books and other resources you can access through your library, related organizations and agencies, or the Internet

- contact various agencies and organizations, especially those that specialize in advocacy and education and that serve people with disabilities

If this is hard for you to do, ask someone you trust to help you—like a friend, family member, or health care provider. Once you have the facts you think you need, write them down or make copies and keep them in a file or other safe place where you know you can find the information when you need it.

Use your own common sense to decide whether a source of information should be believed. If you are unclear, ask someone you trust or someone with expertise in the area to help you decide if the information you have found is accurate.

Plan your strategy.

Now that you know what you want and you have information about it, what do you think is your best strategy for getting what you want or for achieving your goal? What steps would you need to take? You may want to set a timeline and even small goals to achieve by certain dates. You may want to think of several ways to address the problem in case one way doesn't work out. Ask supporters for suggestions. Get feedback on your ideas. Then choose the strategy or strategies.

Examples

Tom, a man in his forties, had been out of work for 10 years due to recurring severe depression and anxiety attacks. He wanted to return to work part time in his field as a graphic designer. Through his research he found that there were openings for graphic designers in his community. However, he also learned that in the years that he had been unable to work, all graphic design work had become computerized. His computer design skills were very limited. His strategy was as follows—

Goal 1: Learn needed computer skills

- To be achieved in 1 year

Objectives to meet goal:

- Inquire about availability of courses through adult education programs and local colleges, and services and accommodations for people with disabilities.
- Find funding for courses through vocational rehabilitation programs and financial aid.
- Develop study schedule and enroll for classes.

Goal 2: Get employed

- To be achieved in 18 months

Objectives to meet goal:

- Meet with people at local employment agencies.
- Become familiar with possible employment options.
- Develop a resume.
- Update wardrobe by frequenting thrift shops or other shops for good buys.
- Talk with other graphic designers about possible employment.
- Fill out applications.
- Set up interviews.

Jane, a woman in her thirties, had always had trouble speaking up for herself. She was often harassed at her workplace, a large discount store, by a co-worker. This co-worker teased her about her disability and went out of her way to make Jane's job hard for her. She had not spoken up about this for fear of losing her job.

Goal: Get better treatment from her co-worker without losing her job

- To be achieved in one month

Objectives to meet goal:

- Ask her friends, family, healthcare provider to get recommendations on how to proceed.
- Call the state agency of protection and advocacy or the Job Accommodation Network at (800) 526-7234 and get recommendations on how to proceed. (see Resources in back of booklet)
- Ask her co-worker to stop harassing her (teasing her about her disability and making her job hard for her).
- If necessary, file a complaint with her employer to ask that the harassment be stopped, or ask to be moved to a position away from her co-worker.
- Read books on assertiveness dealing with difficult people.

Gather support.

It is easier and usually more effective to work on getting what you want and need for yourself if you have the support of one or several friends, family members, or health care providers. You may even want to start or join a group of people with issues similar to yours such as a self-help or peer support group. If necessary, call your protection and advocacy organization for support. A good supporter is someone who—

- you like, respect, and trust, and who likes, respects, and trusts you
- allows you the space to change, grow, make decisions, and even mistakes
- listens to you and shares with you, both the good and the bad time
- respects your need for confidentiality so you can tell them anything
- lets you freely express your feelings and emotions without judging, teasing, or criticizing
- gives you good advice when you want and ask for it, assists you in taking action that will help you feel better, and works with you to figure out what to do next in difficult situations
- accepts help from you when they need it
- you want to be with, but don't desperately need to be with
- doesn't ever take advantage of you

Tell them you are working on becoming a better advocate for yourself. Ask them if they would be willing to help you in this effort by listening to you, giving you advice and feedback from time to time, and being with you when you are taking some difficult steps. If they agree, put their names and phone numbers on a list and post it in a convenient place where you can easily find these phone numbers when you need them. However, don't overwhelm your supporters with your problems and needs. And be there for them when they need your help.

Keep in mind that even the very best friend may inadvertently let you down from time to time. No one is perfect. Try to forget the incident and continue with the good relationship you have.

Target your efforts.

Who do you need to deal with to get action on this matter? Talk directly with the person or people who can best assist you. It may take a few phone calls to discover which organization, agency, or person can help, and to find who is in charge, but it is worth the effort. Keep trying until you find the right person. Maybe the right person is someone as close as your spouse or another family member. It could be the head of your local town council. Perhaps it is a State official. It might even be a Congress person. Maybe it is the head of the company you work for. Keep going up the chain of command until you reach the person that can help you. **Remember that you are a very important and valuable person, and insist that the right person make the time to deal with you and your issues.** Treating the person who is helping you in a respectful way will help you to get what it is you need for yourself.

Ask for what you want.

Make an appointment to see the person or people who can help you get what you want. Don't just show up. Once you have made the appointment, be sure to keep it. If something comes up so you can't make it, call ahead and reschedule.

Dress neatly for the appointment. This gives the person the message that this is an important meeting. Be on time. Look the person in the eye and shake hands firmly in greeting. Call the person by name. How you say something often makes a greater impression than what you say. Use the person's formal name (Mr. Jones or Mrs. Corey) or ask them how they would like to be addressed.

When you are asking for what you want and need, be brief and concise. Say what you need to say as clearly and with as few words as possible. Give only the information that the other person needs. Don't confuse them with things they don't need to know. Don't go on and on about it—just say it. Stick to the point. Don't allow yourself to be diverted. State your concern and how you want things changed.

State your message clearly and simply. Tell the person exactly what you want from them. Explain why you need it. Tell them why it is in their best interest to respond to your request. Speak loudly enough to be heard, without shouting. Expect a positive response. Plan ahead of time what points you need to make. Practice with the help of friends, tape recorders, or mirrors if you feel unsure of yourself. Consider the following good examples of a person telling someone else what it is they need or want:

"I have learned that many people who have taken certain medications for long periods of time need a complete battery of thyroid tests. I would be happy to share this information with you. I also know that I have many symptoms which are common to people who have certain thyroid disorders. By reviewing my records, I have found that I have not had any thyroid tests. Therefore, I would like you to order a complete battery of thyroid tests for me."

"I live in one of your subsidized housing units. The locks on the front door and several of the windows are broken. I have asked the building manager to repair them three times in the last month. It has not been done. In addition, the high crime rate in the area is making it difficult for me to sleep. I need to be transferred to a housing unit in a safe area where the building, especially the locks, are kept in good repair."

Listen to the other person's response. If you don't understand, ask questions for clarification. If you feel you are not getting anywhere, tell the other person that you wish to pursue your issues further and ask to speak to the person's supervisor.

Sometimes the person you are speaking with will try to divert your attention by talking about something that is not directly related to your request, or will tell you that what you want is not possible. Politely bring their attention back to your request by restating what you want.

At the end of the meeting, restate any action that has been decided upon so you both understand each other clearly. For instance, you might say, "As a result of this meeting you are going to order a thyroid test for me." Or, "As a result of this meeting, I understand you are going to change my status to active."

Send a follow-up note, thanking them for meeting with you and summarizing any agreed-upon action. This will be a reminder and provide assurance that you both have the same understanding of the result of the meeting.

In some cases it may not be possible for you to ask for what you want "in person." Distance, lack of transportation, lack of resources, and illness or disability may make that difficult. You may have to make your request by phone, in a letter, or by e-mail.

Don't take "no" for an answer. Persist until you get what you want and need for yourself.

Letters

If you are going to make your request by letter, make the letter short, simple, and clear. One page is best. Long letters may not be read. Make sure the letter is easy to read. If possible, use a typewriter or computer to write it.

In the first paragraph, tell them exactly what you want. Then add details or more information in the rest of the letter.

If appropriate, send copies of your letter to others you want to inform such as your legislator or advocacy agency. Put “cc” (which means copies circulated) at the bottom of the letter with a list of others to whom you are sending copies. You may also choose to send “blind” copies—copies that you don’t inform others about. Keep a copy of the letter in your file for future reference. It’s a good idea to follow up a letter with a phone call to make sure the person got the letter and to discuss the situation further.

Make sure you keep a record of all your contacts and calls.

Phone calls

You may need to make your request by phone. Letters and visits may be initiated with or followed by phone calls. Use phone calls to gather information, to keep track of what’s going on, and to let people know what you want.

When calling

- Make a list of the points you want to make in your call and have it in front of you to refer to during the call.
- Identify yourself. Ask the name and position of the person you are talking to.
- Briefly describe the situation to the person who answered and ask if they are the right person to deal with such a request. If they are not the right person, ask to be transferred to a person who is more appropriate. If that person is not available, ask that they return your call. If you have not heard from them by the next day, call back. Don’t be put off or give up because your call is not returned. Keep calling until you reach the person you need to speak to.
- Once you have reached the appropriate person, make your request for action brief and clear.
- If the person cannot respond to your request immediately, ask when they will get back to you or by what date you can expect action.
- Thank the person for being helpful when that’s the case.
- In some cases when a person has been particularly helpful, it is a good idea to send a card of thanks. This opens the door for further contact on related issues.
- Keep a written record of your calls in your file. Include the date of your call, who you spoke to, issues addressed, and promised action.
- If you do not hear back from the person when expected, the promised action is not taken, or the situation is not resolved, call them back. Persist until you reach the person, the promised action is taken, or resolution is reached.

Assert yourself calmly.

When you are speaking up for yourself you may get very frustrated and angry if the other person is very negative or difficult to deal with. Stay cool. Don’t lose your temper and lash out at the other person, their character, or the organization. If you lose your temper, it may make it more difficult to get what you want and need for yourself. It will help if you treat the other person or people courteously.

Repeating these affirmations over and over may help:

In the process of advocating for myself, I will keep calm because this increases my effectiveness. In the process of advocating for myself, I am committed to speaking out and also respecting the rights of others and listening to what they have to say.

Be firm and persistent.

Don't give up! Keep at it until you get what you want, need, and deserve. It may take a very short time and little effort, but more often, it takes persistent effort over time. Repeat the following affirmation:

I will be firm and persistent. I will stick with it until I get what I need for myself.

Debrief

After your appointment, arrange to meet a friend so you can tell someone what happened. It will help reduce your stress and keep you feeling well.

Be sure to write down what the next steps are to resolve the issues that may still be outstanding after the appointment.

Know Your Rights

Everyone is entitled to the same civil rights and equal treatment, including people with disabilities or distressing psychiatric symptoms. This is a list of some of your personal rights. You have the right to—

- ask for what you want, to say yes or no, to change your mind and to make mistakes
- follow your own values, standards, and spiritual beliefs
- express all of your feelings, both positive or negative, in a responsible manner
- be afraid and uncertain, and to do what you want and need to do for yourself anyway
- have the friends and interests of your choice
- be uniquely yourself and to change and grow
- have your own personal space and time
- be safe
- be treated with dignity, compassion, and respect at all times

In addition you have, health care rights which will depend on Federal and State laws.

These health care rights much include—

- know the side-effects of recommended medications and treatments
- decide for yourself treatments that are acceptable to you and those that are not and to refuse medications and treatments that are unacceptable to you
- a second opinion without being penalized
- change health care providers - although this right may be limited by some health care plans
- have the person or people of your choice be with you when you are seeing your doctor or other health care worker

If you are in a hospital setting or residential treatment program, in addition to the rights listed above, you may have the right to—

- communicate in person, by sending and receiving mail, and by reasonable access to telephones, with the people of your choice
- wear your own clothing
- keep personal possessions, including toilet articles
- privacy to perform personal hygiene tasks
- a written treatment plan that you develop with input from your health care providers that is updated as your condition or treatment changes

- be represented by a lawyer whenever your rights may be affected (you may have to pay a fee to be represented, unless you find a lawyer who will not charge you.)
- the same civil rights, respect, dignity, and compassion, and in the same manner and with the same effects, as a person not in such a facility

The only time your rights may not be honored is if you are making unsafe requests or indicating in some other way that you may hurt yourself or someone else.

If you know that your rights are being violated, the first thing to do, if possible, is to ask the person, people, organization, agency, or institution that is violating your rights to stop doing that. If they don't stop, reach out for help. Depending upon the kind of violation, you could contact a counselor, mental health agency, law enforcement officials, or your State office of protection and advocacy. (see Resources at the back of the booklet). If you are unsure whether your rights have been violated, contact the agency of protection and advocacy in your State.

Addressing Daily Issues

Speaking up for yourself sometimes will be needed on a more personal and subtle level. Maybe you have a friend who talks too much. Maybe your child is having trouble at school and you think the teacher is blaming the child. Maybe you got a bill for more than what you were told you'd be billed. Maybe your doctor, or some other health care provider, has made disparaging remarks, such as "Do you really think you need this appointment?" Maybe your spouse always talks you out of doing something that you want to do by saying something, like "You're no good at that, I'll do it." Maybe your neighbor is accusing you of a problem you are not responsible for. Maybe your landlord hasn't fixed something he says he would.

Everyone has these kinds of problems. Having to advocate for oneself is a fact of life. Consider the following list of actions you can take to speak up for yourself—

- take a class in conflict resolution or assertiveness. Learn how to calmly, firmly, and effectively speak for yourself
- join a self-help, or peer support group, because there is power in collective action
- call a mediator
- consult a lawyer or advocacy agency
- tell your friends, family, and neighbors what is going on. Spread the word
- take a friend with you when you must stand up to an aggressive person
- consider how you would want to see someone else handle the situation, then follow your own advice

When advocating for yourself, avoid—

- taking out all your frustration on one person or the wrong person or situation
- breaking the law
- anger and/or threats
- "one-upping" anyone or doing things that will make the situation worse
- giving up

When Others Need to Take Over

Part of being a good advocate for yourself means making advance plans for what you want and need others to do for you when you are not able to do things for yourself. Certainly, you hope that this will never be necessary, that you will always be able to take care of yourself. However, even with your best intentions and efforts, this may not be the case. While difficult times may lessen in frequency or intensity as you learn how to better manage severe symptoms, they may continue to be an issue from time to time.

When you are feeling well, write a plan that describes what you want others to do for you when you cannot take care of yourself. This keeps you in control even when it feels like things are out of control. Laws about the legality of these documents differ from state to state. Check with your attorney or the Protection and Advocacy Agency in your State to see what kind of document is legal in your State. Even if the document is not legal in your State, it will be a helpful guide for your chosen supporters.

Begin by learning about all treatment options suggested including information that expresses a variety of viewpoints. Discuss them with your physician and other health care professionals.

Think about things that have been helpful or not helpful in the past.

Then develop a document that might be called a **Document of Treatment Preference, Mental Health Advanced Directive, or a Crisis Plan**.

You can get a copy of a model form. (See Resources). Discuss your plan with your doctor or health care provider. Include the following information—

- a list of those symptoms that show others you can no longer care for yourself or make good decisions in your own behalf
- the names of people whom you would want to take over for you, like family members, friends, and health care providers (designate whom you would want to make final decisions if your supporters can't agree)
- medications you are currently taking, those that might be used in a crisis, and those that must be avoided
- treatments and treatment facilities that would be helpful and those that should be avoided
- a plan for being cared for in your home or in the community
- things that others can do that would help you to feel better and things that might make you feel worse
- chores or tasks you need others to take over for you like, child and pet care and paying bills
- a listing of indications that you are well enough to take care of yourself and that your supporters no longer need to follow this plan.

Sign and date the plan. Give each of your supporters, your health care providers and your doctor a new copy of the plan each time you change it.

Give copies of this plan to anyone who might be assisting you now. Update your plan as necessary.

In Closing

Speaking out for yourself often is difficult. Give yourself a pat on the back for each action you take. When you do something that is very hard or that is a major accomplishment, give yourself a treat, like taking a walk, calling a friend, or visiting a museum. Don't be discouraged by setbacks. Applaud yourself for starting again. And always keep in mind—

You are a unique and valuable person. You have the right to speak out for yourself, to protect your rights, and to insist that others treat you well.

Further Resources

Substance Abuse and Mental Health Services Administration (SAMHSA)

Center for Mental Health Services

Web site: www.samhsa.gov

SAMHSA's National Mental Health Information Center

P.O. Box 42557

Washington, D.C. 20015

1 (800) 789-2647 (voice)

Web site: www.mentalhealth.samhsa.gov

Consumer Organization and Networking Technical Assistance Center

(CONTAC)

P.O. Box 11000

Charleston, WV 25339

1 (888) 825-TECH (8324)

(304) 346-9992 (fax)

Web site: www.contac.org

Depression and Bipolar Support Alliance (DBSA)

(formerly the National Depressive and Manic-Depressive Association)

730 N. Franklin Street, Suite 501

Chicago, IL 60610-3526

(800) 826-3632

Web site: www.dbsalliance.org

National Alliance for the Mentally Ill (NAMI)

(Special Support Center)

Colonial Place Three

2107 Wilson Boulevard, Suite 300

Arlington, VA 22201-3042

(703) 524-7600

Web site: www.nami.org

National Empowerment Center

599 Canal Street, 5 East

Lawrence, MA 01840

1-800-power2u

(800)TDD-POWER (TDD)

(978)681-6426 (fax)

Web site: www.power2u.org

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street, Suite 1207
Philadelphia, PA 19107
1 (800) 553-4539 (voice)
(215) 636-6312 (fax)
e-mail: info@mhselfhelp.org
Web site: www.mhselfhelp.org

The Bazelon Center for Mental Health Law

(for model form for Advance Directive or Crisis Plan)
1101 15th Street, N.W.
Washington, D.C. 20005
(202) 467-5730
Web site: www.bazelon.org

National Association of Protection and Advocacy Systems, Inc. (NAPAS)

900 Second Street, N.E. #211
Washington, D.C. 20002
(202) 408-9514
(TDD) (202) 408-9521
Fax: (202) 408-9520
Web site: www.napas.org

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