

Teachers' Guide

Freedom Self-Advocacy Curriculum

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In cooperation with:

National Mental Health Association National Association of Protection and Advocacy Systems

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Introduction

Self-advocacy skills are absolutely essential for any consumer of mental health services. By learning to protect their own rights and assert their own preferences, consumers can combat discrimination and inadequate or harmful treatment.

In recognition of self-advocacy's central importance, the National Mental Health Consumers' Self-Help Clearinghouse, the National Mental Health Association (NMHA), and the National Association of Protection and Advocacy Systems (NAPAS) have joined forces to create self-advocacy training opportunities for consumers nationwide.

The Clearinghouse, NMHA, and NAPAS communicated with consumers, advocates, and providers throughout the country to assess consumers' self-advocacy needs and identify current self-advocacy training practices. Based on what was learned, we designed the Freedom Self-Advocacy program, which is a train-the-trainer curriculum.



This Teachers' Guide will walk you step by step through the workshops that you'll be teaching in your community. If you need additional help, technical assistance is available from the National Mental Health Consumers' Self-Help Clearinghouse at (800) 553-4539.

You'll be teaching three workshops designed to help consumers take control of their own recovery processes and assert their rights. Before you can offer your workshops, you'll have to do a little preparation. Because the Freedom curriculum is national in scope, it will be up to you to gather some information that will be especially useful for mental health consumers in your city and state. This preparation is summarized in *Preparing for the workshops*.

The focus of the first workshop is changing **attitudes**. Like other people with disabilities, mental health consumers face the barrier of discrimination; however, many consumers lose sight of the reality that, despite this discrimination, they can be successful by taking charge of their lives. You'll help your students raise their awareness of—and change—self-defeating attitudes by asking them how they react to situations and demonstrating how they can change their responses for more effective results. By using a few examples, you'll demonstrate to students that, with a positive attitude, they'll be much more successful in reaching their self-advocacy goals. At the end of the first workshop, the students will get a copy of the Clearinghouse's *Self-Advocacy* Technical Assistance Guide. This guide will provide assistance for the following two workshops, and it will be a tool they can use in their future efforts in self-advocacy.

In the second workshop, you'll help your students with **knowledge** development. Using Advocacy Modules, you'll demonstrate how seeking information and assistance from outside sources makes self-advocacy easier and more effective. You will show the importance of researching a problem and targeting the right decision-maker. Students will finish the training with a Legal Background that will assist them in their future self-advocacy endeavors.

The third workshop concentrates on the **skills** necessary for successful self-advocacy, using the same Advocacy Module that you chose in the second workshop. You'll demonstrate such skills as writing letters, making effective phone calls, keeping records, and appealing decisions.

By offering the Freedom workshops to consumers in your community, you will be helping them assert rights that long have been denied them. If you yourself are a consumer, then your own experiences will serve as additional motivation to your students.

Although teaching self-advocacy might seem like a daunting task, we've tried to make your job easier by designing the curriculum around short self-contained workshops and offering students valuable resources to take with them, enabling them to grow as selfadvocates. We're also offering ongoing technical assistance to both you and your students to help consumers practice their new-found skills even after they complete your workshops.

Advocacy Modules: a unique feature of the Freedom curriculum

The Freedom Self-Advocacy Curriculum is based on a unique and effective system of building blocks called Advocacy Modules. An Advocacy Module is a way to teach selfadvocacy skills and ideas, using scenarios and exercises that students will be able to relate to: each Advocacy Module illustrates a specific issue that is commonly experienced by mental health consumers.

An Advocacy Module consists of:

- § A Consumer's Story: The Consumer's Story presents a problem. It is a description of a consumer's struggle within one aspect of the mental health system. It is designed to be applicable to many people's lives. Students read the story and are able to apply the situation to problems they might have had in their own lives. This association will make it easier to learn the skills that come with the Advocacy Module because the students will be able to relate to the situation.
- § Legal Background: The Legal Background is material that the students take away from the workshop. There is space for the teacher to write contact information so that the students are prepared with places to go when they deal with that issue. This is the part of the Advocacy Module that will reinforce what the students learned in the second workshop, preparing them for the third.
- § **Class Exercises**: The Class Exercises give students the chance to practice active skills in response to the Consumer's Story. Students learn how to write a letter, or the best ways to confront a person (on the phone or in person). These Class Exercises allow the students to interact with each other and the material, so that they are dealing with the Advocacy Module in a "hands-on" way.

The Advocacy Modules are introduced in the second workshop, where you choose the topic that will best suit the needs of your class. You can pick from insurance treatment denials, advance directives, or housing rights:

Advocacy Module AAdvocacy Module BAdvocacy Module CInsurance Treatment
DenialsAdvance DirectivesHousing Rights\$4-

Choose one module

National Mental Health Consumers' Self-Help Clearinghouse *Teachers' Guide*, Freedom Self-Advocacy Curriculum Page 5 of 11 You will continue with the same Advocacy Module in the third workshop, where you build on what you learned in the second workshop. In the second workshop, you will teach the students how to analyze a problem, formulate a solution, and then decide on an action plan. In the third workshop, you will go a step further and implement that action plan while you teach the students two forms of communication: written and verbal.

The Advocacy Modules allow for freedom – they allow teachers to create a learning experience that will best help their students. Each consumer has unique self-advocacy needs, which vary according to the consumers' treatment situation, benefits eligibility, income, family status, and many other factors. Picking the one Advocacy Module to use throughout the curriculum will help your students fully understand the best ways to approach a problem in the mental health system because they will see a problem through.

We also will continue to develop additional Advocacy Modules to give you greater flexibility in your workshop. Check the Clearinghouse web site or call 800-553-4539 to find out which additional Advocacy Modules are available.

Preparing for the workshops

Offering any workshop will require some degree of preparation. Because the Freedom curriculum is national in scope and self-advocacy is inherently local, you'll also have some preparation work ahead of you that will ensure that the Freedom workshops are tailored to consumers in your community.

Setting up

The Freedom workshops are designed to be most effective when offered to groups of 6-10 consumers at a time. The Clearinghouse, NMHA, and NAPAS believe that participation in the workshops should be a voluntary undertaking, rather than part of a treatment plan or as a prerequisite for obtaining other services. Therefore, you will need to recruit students for your workshops.

By offering the classes at a drop-in center or similar program, you should be able to interest people in the workshops by posting flyers (like the sample flyers provided at the national institutes) and listing the workshops in the center's calendar of events and newsletter. Make an extra effort to reach people who might need self-advocacy skills but are not immediately interested in the workshops.

You should also reach out beyond the drop-in center. For example, send marketing materials to local community health centers; you might ask if you could place materials in the waiting rooms.

You'll also need to find a place to hold your workshops. The room that you select for your workshops should have a chalkboard or flip chart available so that you can write down students' suggestions—teaching the Freedom workshops is a very interactive process.

Gathering local and state information and resources

Another task that you must take care of in preparation for teaching the Freedom workshops is completing the local and state advocacy listings for distribution to your students. In the *Advocacy and Government Contacts* booklet, the Clearinghouse has compiled a list of national contacts and resources helpful to consumers, but it will be up to you to provide your students with a list of local and state contacts. (The Clearinghouse will be happy to provide assistance with this process.)

An important piece of advice is to see if someone has already done your work for you. In many places, Protection and Advocacy (P&A) agencies, Mental Health Associations (MHAs), or other organizations have already prepared resource guides for mental health consumers, and you can use these in preparing your own.

If you have access to the Internet, another good starting point is the Center for Mental Health Services' State Resource Guide for your state. Available online at http://www.mentalhealth.samhsa.gov/publications/browse.asp, it lists advocacy resources in your state under the heading State/Territory Resources.

Here are some suggestions for completing the *Advocacy and Government Contacts* booklet for your students.

- *Health Care/Insurance*. Most of this information can be found in the "blue pages" section of your phone book. We recommend that you contact each agency and ask if there are any specific numbers for consumer complaints; list these numbers rather than the general numbers.
- *Financial Assistance/Transportation*. Again, these numbers should be available in the blue pages.
- *Housing*. In addition to government agencies listed in the blue pages, there might be advocacy agencies listed in the "Human Services" section of the phone book.
- *Employment*. The government agencies will be listed in the blue pages, and you can also call the Social Security hotline at (800) 606-7787, or your state's Client Assistance Program (CAP). You might wish to see if your area has a Jewish Employment Vocational Services (JEVS) office.
- Advocacy/Ombudsman Programs. To locate consumer-run programs, you can contact the Clearinghouse. Call the national organizations listed at the end of the Advocacy and Government Contacts booklet to see about local chapters. Local advocacy groups or your state's P&A agency should be able to help you locate specific ombudsman programs.
- *Legal Help.* You can locate your state's P&A agency by calling the National Association of Protection and Advocacy Systems (NAPAS), which is listed at the end of the *Advocacy and Government Contacts* booklet, or visiting their website at www.napas.org. Legal assistance agencies are listed in the blue pages of the phone book.
- *Elected officials*. All elected officials should be listed in the blue pages. You can also use the Internet to locate contact information for state and federal elected officials.

Building a resource library

While you're filling out the information for the *Advocacy and Government Contacts* booklet, you should also contact the following state and local organizations and ask about free or low-cost materials that you can use to supplement your self-advocacy workshops:

- § State P&A agency;
- § Local or state MHA;
- § Local or state NAMI chapter; and
- § Local and state consumer groups.

In many states, P&A agencies and other organizations offer—for little or no cost—guides for consumers on such topics as:

- § Transportation rights;
- § Advance directives;
- § Guardianship and competency standards;
- § Patients' bill of rights;
- § Right to examine medical records;
- § Right to refuse treatment;
- § Benefits management for working people with disabilities;
- § Vocational rehabilitation opportunities;
- § Independent living programs; and
- § Voter education and empowerment.

Many federal agencies also offer free or low-cost publications for consumers, and you might want to obtain some of these publications as well. The *Advocacy and Government Contacts* booklet lists some of these agencies, such as the Center for Mental Health Services, Equal Employment Opportunity Commission, and Social Security Administration. Also listed are national organizations—such as the Clearinghouse, NAPAS, and NMHA—that offer free or low-cost publications. The Clearinghouse also maintains a library of information; contact us if you're looking for more information on a particular topic.

Class materials

Make sure that you have the following materials for use in your workshops:

- Teachers' Guide;
- Self-Advocacy Technical Assistance Guide
- Advocacy and Government Contacts booklet;
- Advocacy Modules (A, B, C);
- HANDOUTS A M;

General teaching guidelines

The Clearinghouse, NMHA, and NAPAS have created a set of workshops that maximizes the effectiveness of the self-advocacy training. The workshops are extremely interactive, in order to motivate your students about the idea of self-advocacy. We've also planned for your students to take home a great deal of written information to help them absorb and apply what they've learned.

Always remember that confidentiality must be addressed at the beginning of each workshop. Students must be aware that what they say in the workshops will remain in the workshops. By telling your students that confidentiality will be respected at all times, you will allow more room for dialogue, and the discussion will move more smoothly.

Keep in mind that some of the issues discussed in your workshops may stir up negative feelings of fear, anger, or frustration in some of your students. Make sure everyone knows that, if they need a break, they're free to take one.

Drawing upon personal experiences

One way to ensure that your Freedom workshops will have a great impact upon your students is to use your own experiences to illustrate how self-advocacy principles can work in practice. Of course, the manner that, and extent to which, your experiences will help you will depend on your unique circumstances; however, we can offer the following guidelines:

- If you yourself are a consumer, we recommend that you disclose this to the class. Stories of how you overcame advocacy obstacles will demonstrate to your students that their position is not as powerless as they might have been led to believe. If there is an additional Advocacy Module available that mirrors a situation that you yourself faced, you might consider using it to demonstrate that there are real-world solutions to the problem.
- If you are not a consumer, you might nonetheless have your own stories of feeling powerless, such as dealing with an insurance company, or legal or credit problems. You should use stories to illustrate that consumers are not alone in feeling that their position is powerless, and that persistence is required to reach self-advocacy goals.
- Use stories of how you helped someone help himself or herself, rather than stories of helping someone. The point of these stories is to illustrate that support is available, but when people put hard work into self-advocacy, they are more likely to be successful.
- The workshops rely on encouraging student participation. Use a chalkboard or flip chart to record your students' ideas. Your students will become more engaged with the material, and you can also use their suggestions as a basis for further explanation. Whenever possible, encourage your students to share their self-advocacy stories.

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Helping your students get the most out of the workshops

Consumers who become involved in the mental health system find themselves constantly being given advice (and orders), and they might have heard the term "advocacy" dozens of times without really seeing too much improvement in their position. How, then, do you make a short set of workshops an effective tool for consumers?

We have attempted to make the Freedom workshops different from other advocacy trainings. Your students will take with them a new attitude—that they can achieve self-advocacy goals—as well as a set of basic skills, written information, and outside resources that they can use to put this new attitude into practice. Rather than bombarding consumers with information that they might not remember, you will focus on the basics and give them tools to find information for themselves. To the extent you or your organization are able, you should provide follow-up technical assistance, and your students will be able to use the Clearinghouse (800-553-4539) for help as well.

Respecting your audience's diversity

Whether you are a consumer or consumer supporter, you are most likely familiar with working with a consumer audience. However, you are likely to be new to teaching self-advocacy. Here are some principles to keep in mind:

- Your students are likely to be skeptical—based on past experiences—that selfadvocacy goals can be achieved. Be realistic, and portray achieving self-advocacy goals as something that can be accomplished with effort, rather than as a simple matter.
- Even if you yourself are a consumer, your experiences will have differed widely from those of your students. You will have experienced different levels of disability, as well as different obstacles in the mental health system. Help them to overcome any apprehension that they might have by listening to their concerns and remaining positive that everyone can achieve their self-advocacy goals.
- Be aware that students from different socioeconomic backgrounds and of different races, ethnicities, genders, and sexual orientations will have had different experiences and different perspectives on self-advocacy. The personal experiences that students share with the class might be influenced by these factors.
- There might be great variations within your class in terms of education and writing ability. Don't sell your students short, but instead recognize that some of your students might need more help than others with skills such as letter writing or record keeping. You might be able to find a local organization that can offer tutoring or mentoring in these areas—perhaps even your own organization.