



Teachers' Guide

Freedom Self-Advocacy Curriculum Module B-- Second Workshop

**National Mental Health Consumers'
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In cooperation with:

**National Mental Health Association
National Association of Protection and Advocacy Systems**

With grateful acknowledgement to the Community Support Program (CSP) of the federal
Center for Mental Health Services.

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Advocacy Module B—advance directives

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IV.A. A real-life scenario

(10 minutes. Materials: The Consumer’s Story for Advocacy Module B about advance directives).

1. Distribute photocopies of the Consumer’s Story for Advocacy Module B about advance directives.
2. Read aloud “Alice’s story” about the person who wants to prepare an advance directive.

IV.B. Practice analyzing the problem

(10 minutes. Materials: The Consumer’s Story for Advocacy Module B about advance directives).

1. Ask your students whether any of them have prepared advance directives.
2. Facilitate a discussion of the question, “What specific actions by other people have caused problems for Alice?”

While preparing her advance directive, Alice should consider her past bad experiences with:

- § Electroshock;
- § Restraints when administered by male staff members;
- § Restraints being administered for extended periods;
- § Injections of tranquilizers;
- § Side effects from tricyclics; and
- § Side effects from Wellbutrin.

IV.C. Practice formulating a solution

(10 minutes. Materials: The Consumer’s Story for Advocacy Module B about advance directives).

1. Facilitate a discussion of the question, “What factors should Alice consider in naming her health care agent?”

Most advance directive forms allow you to select a primary and alternate health care agent. If the person whom you most trust isn’t around often, you can select him or her but provide a reliable alternate. For example, if Alice most trusts her brother, she can name him as her primary agent and select someone else as an alternate.

Trust and a full explanation of your wishes are essential. In Alice's case, she probably shouldn't name her boyfriend as an agent if she is not comfortable discussing all of her treatment preferences with him.

2. Facilitate a discussion of the question, "What type of instructions can someone make about medications?"

Some of the advance instructions that people make about medications include:

- § Not consenting to a particular medication or class of medication;
- § Consenting to a particular medication, but setting a maximum dosage;
- § Consenting to medication only when prescribed by particular physicians;
- § Not consenting to certain combinations of medications;
- § Not consenting to drugs that cause certain side effects; or
- § Consenting to drugs so long as certain side effects are not present.

IV.D. Practice deciding on an action plan

(5 minutes. Materials: The Consumer's Story for Advocacy Module B about advance directives).

1. Facilitate a discussion of the question, "What is the best way for Alice to proceed?"

She could ask friends who have been in similar situations who they chose as their agent. She could make a list to help organize herself so that she is clear about what she does and does not want to happen as a result of this advance directive.

What method of communication would be the most effective in this matter?

IV.E. Learning more about the Legal Background

(5 minutes. Materials: The Legal Background for Advocacy Module B about advance directives.)

1. Make sure that you filled in the sources in the Legal Background for this Advocacy Module.
2. Distribute the Legal Background for Advocacy Module B about advance directives to everyone in the class.
3. Explain to them that this can help prepare them for the third workshop. It provides a good source to learn more about advance directives and their relationship to mental health consumers.

IV.F. Wrapping-up (5 minutes)

1. Thank your students for coming. Tell your students that they will continue with the same Advocacy Module in the third workshop.
1. In the third workshop, they will learn skills that will help them advocate for themselves when they are preparing an advance directive.
3. Remind them that they can use the *Self-Advocacy* Technical Assistance Guide they were given in the first workshop to help them prepare for the skills they are going to learn in the next workshop.

Advocacy Module B

Advance Directives

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Consumer's Story

Over the past 25 years, Alice has been hospitalized several times and has been given various diagnoses, including paranoid schizophrenia, bipolar disorder, and major depression. She has been through some terrifying experiences during her hospitalizations that have left her very bitter and untrusting. Many times, when she protested actions taken by the hospital staff, her pleas were ignored.

The experiences that were the most difficult for her included:

- § Undergoing electroshock treatment and suffering some memory loss as a result;
- § Being put in restraints by four male staff members and feeling “violated”;
- § Being left in restraints for extended periods without being given the opportunity to go to the restroom;
- § Being forcibly given injections of tranquilizers in her buttocks;
- § Having a seizure while taking Wellbutrin (bupropion hydrochloride);
- § Experiencing muscle spasms and severe constipation while taking Haldol (haloperidol); and
- § Suffering blurry vision and bouts of anxiety while taking tricyclic antidepressants, as well as suffering withdrawal symptoms—aches and vomiting—after discontinuing them.

In the past few years, she's felt much better and avoided hospitalization with the help of peer support groups, friends, and a few family members who have been supportive. After what she's been through, she's vowed that she will never return to the psychiatric ward of a hospital, but she fears that someday she will be forced to do so.

Recently, her state consumer newsletter contained an article about a document called an “advance directive.” According to the article, by filling out an advance directive, she could specify the types of treatment that she did and did not want if she had another crisis.

The article also reported that state law required that her advance directive name someone to serve as her “health care agent.” She thought about people whom she could name. She has a boyfriend, Rob, but she isn't comfortable in discussing with him everything she's been through. Her brother Jake knows everything, but he travels a lot for his job. She doesn't think his brother's wife Sandy could handle making these kinds of decisions because she tends to get flustered. Her friend Melissa might be a good choice because

she's been through some of the same things. Alice wants to fill out an advance directive, but isn't sure who to pick as her agent.

Analyze the problem

Class discussion: What specific actions by other people have caused problems for Alice?

Formulate a solution

Class discussion: What factors should Alice consider in naming her health care agent?

Class discussion: What type of instructions can someone make about medications?

Decide on an action plan

Class discussion: What is the best way for Alice to proceed?

Advocacy Module B

Advance Directives

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Legal Background

When a consumer verbally expresses treatment preferences, these wishes are often ignored by hospital staff, who can use the explanation that the consumer is not legally competent to make treatment decisions. However, by preparing an **advance directive** prior to a time of crisis, a person is able to demonstrate that his or her wishes were made with forethought.

Under a federal law called the **Patient Self Determination Act**, any hospital receiving Medicare or Medicaid reimbursement must:

- § Inform patients of state laws regarding advance directives;
- § Note in a patient's record whether he or she has an advance directive; and
- § Follow the state's law regarding advance directives.

If you prepare an advance directive in accordance with state law, you can therefore seek legal recourse if your wishes are ignored. Be aware, however, that each state's laws put limitations on the scope of psychiatric advance directives.

A good advance directive might not completely take away the possibility that you will receive treatments that you don't like, but it might provide a "lesser of two evils" alternative. Even if you don't want to take *any* medication, you can use an advance directive to keep yourself from those particular medications that you find most objectionable.

Here are some additional hints about preparing and enforcing advance directives:

- Be as specific as possible, including your reasons for having certain preferences;
- Find out whether your state's law requires you to appoint a health care agent;
- Make sure you discuss your treatment preferences fully with your health care agent;
- Talk over your choices with your current provider and case manager, if applicable;
- Find out whether your state's law allows you to revoke your advance directive if you are declared incompetent;
- To prove that you were legally competent when you made your advance directive, you can have a mental health professional conduct a "mental status exam";

- You can specify your preferences of providers or facilities;
- Make sure that your advance directive reflects your own wishes rather than another person’s assessment of your “needs”—don’t sign an advance directive that was prepared for you unless it truly reflects your own opinions; and
- You cannot be forced to prepare an advance directive—it’s your choice alone.

Appointing a health care agent:

Some states require you to appoint a “health care agent” who will make decisions for you when it is determined that you cannot make decisions for yourself. The National Empowerment Center recommends that your health care agent be:

- § Someone you trust deeply, who cares about your welfare, and who knows you well;
- § Someone who knows your wishes regarding physical and mental health care through discussions and through access to your instructional directive;
- § Someone who is easily reachable night or day (for instance someone with a phone or better yet a beeper) and who is willing and able to speak with health care personnel;
- § Someone who is a strong, articulate advocate and is well informed about the types of treatments proposed;
- § Someone who the health care providers will take seriously;
- § Someone whose role will be undisputed. Some states prevent certain people from becoming agents [, such as] your treating provider, and the operators of certain care facilities. These provisions help prevent conflicts of interest.

Source: “Making Advance Directives Work for You”

Inform others of your advance directive:

If your treatment providers don’t know about your advance directive or what’s in it, they won’t be able to follow your instructions. To help ensure that your advance directive is noticed, you can send copies to:

- § your health care agents;
- § your current providers;
- § hospitals where you might be taken for emergency treatment; and
- § close friends and family members who will know if you have been hospitalized.

The Bazelon Center recommends that you carry a card, available by calling (202) 467-5730 or on-line at <http://www.bazelon.org>, explaining that you have filled out an advance directive.

Local resources (to be supplied by workshop leader)

State P&A agency's phone number:

Citation of state law regarding advance directives:

Number to call to get a form valid in this state:

Sources

Advocacy, Incorporated. *How to Make an Advance Directive*. 1998. Available by calling (800) 252-9102 or on-line at <http://www.advocacyinc.org> (covers Texas law)

Bazelon Center for Mental Health Law. *Psychiatric Advance Directive*. 1998. Available by calling (202) 467-5730, or on-line at <http://www.bazelon.org>

Fisher, Daniel. "Making Advance Directives Work for You," National Empowerment Center newsletter. Available by calling (800) POWER-2-U or on-line at <http://www.power2u.org>

Fleishner, Robert. *An Analysis of Advance Directive Statutes and their Application to Mental Health Care and Treatment*. National Association of Protection and Advocacy Systems, undated. Available by calling (202) 408-9514.



Teachers' Guide

Freedom Self-Advocacy Curriculum Module B -- Third Workshop

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Advocacy Module B—advance directives

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III.A. A real-life scenario

(10 minutes. Materials: The Class Exercises for Advocacy Module B for advance directives.)

1. Distribute photocopies of the Class Exercises for Advocacy Module B for advance directives.
2. Review “Alice’s story” about the person who wants to prepare an advance directive, whose problem the students analyzed in the second workshop.

III.B. Practice written communication

(15 minutes. Materials: The Class Exercises for Advocacy Module B for advance directives.)

1. Ask your students to fill in the empty spaces in the sample advance directive.
2. Tell them that they have 15 minutes to complete the exercise.
3. Circulate and help your students with the form if they need help.

Based on Alice’s experiences, some of her likely responses include:

- § *Appointment of health care agent.* A logical choice would be her brother Jake as her agent, with her friend Melissa as an alternate. Other choices are possible.
- § *Psychoactive medications.* Alice would definitely not consent to taking Wellbutrin because of her seizures. She’d probably also not consent to taking Haldol or tricyclic antidepressants. She can increase the effectiveness of her directive by listing the reasons for her objections.
- § *Electroconvulsive treatment.* Alice would probably not consent to electroconvulsive treatment (ECT). She should explain that she’s been given ECT in the past with bad results.
- § *Preferences for emergency treatment.* Alice would probably prefer seclusion over medication and restraint. She could specify that medication not be given in injection form. As to restraint (which she could specify as a last resort), she could request restrictions such as monitoring or a maximum time limit, as well as request that male attendants not put her into restraints.

III.C. Practice verbal communication

(15 minutes. Materials: The Class Exercises for Advocacy Module B for advance directives.)

1. Divide students into groups of three.
2. Explain that you will now practice verbal communication. Your students should pretend that Alice has filled out her advance directive and now will discuss it with her doctor.
3. Explain that there are three jobs in the group, and that they will take turns doing each one:
 - § One person will play Alice.
 - § One person will play her doctor.
 - § One person will observe.
4. Ask your students to pick a role to start with and role-play a short meeting.
5. After a few minutes, ask the observers to provide feedback.
6. After a few minutes, ask the students to switch roles.
7. Repeat steps 5-6.
8. You can circulate and offer assistance, based on the advice given to the observer in the Class Exercises for Advocacy Module B for advance directives, under “When you are the observer.”

Resources for advance directives

Advocacy, Incorporated. *How to Make an Advance Directive*. 1998. Available by calling (800) 252-9102 or online at <http://www.advocacyinc.org> (covers Texas law)

Bazelon Center for Mental Health Law. *Psychiatric Advance Directive*. 1998. Available by calling (202) 467-5730, or on-line at <http://www.bazelon.org>

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Fleishner, Robert. *Analysis of Advance Directive Statutes and their Application to Mental Health Care and Treatment*. NAPAS, undated. Available by calling (202) 408-9514.

<u>Skip ahead to Section IV!</u>
