

## How To Get Extraordinary Things Done

#### Challenge the Process

Search for Opportunities

Experiment and Take Risks

#### Inspire a Shared Vision

Envision the Future

**Enlist Others** 

#### Enable Others to Act

Foster Collaboration

Strengthen Others

#### Model the Way

Set the Example

Plan Small Wins

#### Encourage the Heart

Recognize Individual Contribution

Celebrate Accomplishments

#### WHAT ADVOCACY IS

Heiping clients help themselves.

Building confidence so clients are able to help themselves.

Supporting efforts toward independence.

Providing necessary tools for appropriate decisions and appropriate action.

Informing clients of their rights.

Analyzing a problem and pinpointing areas of responsibility.

Stating options available to resolve a problem.

Providing technical assistance and training.

Providing assistance in locating appropriate services.

Referring to appropriate agencies.

Organizing for change.

Initiating new services.

Investigating grievances.

Following up on complaints.

Going to court when other avenues have failed to get results.

Bringing clients and groups together for mutual support and action.

Advocating and/or interceding on behalf of clients ONLY when they are unable to help themselves.

A partnership with clients, with mutual sharing of information, tasks and action.

Lobbying for necessary legislation.

Agitating to get legislation implemented

#### WHAT ADVOCACY IS NOT

-Taking over a client's life (or problem) and making all decisions for him or her.

Accepting the status quo when legislation is not implemented.

Squeiching efforts of self heip.

Seeking individual solutions to group problems.

Reinforcing feelings of helplessness and dependence.

Accepting unavailability or inadequacy of services.

Keeping clients in the dark, while doing everything for them.

Denying the existence of problems reported.

Keeping clients uninformed about their rights, so they will have to rely on the advocate for everything.

Dropping a complaint after initial contact.

Discouraging clients from becoming activists.

Filing a lawsuit as the first approach to a problem.

Making decisions for clients.

Working ONLY with individuals when others share a mutual problem.

Controlling clients.

Interceding on behalf of clients who can help themselves.

Persuading clients to accept "Make Do" Services.

A "parent/child" relationship.

Keeping "hands off" to politics.

Closing the door to clients because "there's nothing I can do to help."

#### 1 ADVOCACY

# L DESCRIBE YOUR PROBLEM AND IDENTIFY THE POSSIBLE SOLUTIONS. 1. What exactly is the problem? 2. How often has the problem occurred? 3. Have I tried to resolve this problem before, and, if so, what was the result? 4. Do others share this problem? 5. Has anybody else tried to solve a similar problem? 6. What has worked in the past? 7. What hasn't worked in the past? \_\_\_\_\_\_ 8. Does the law address my problem?

If so, which laws?

	WHO to contact?
	WHAT information to give this contact?
	WHERE to contact this individual?
	WHEN to contact this individual?
	WHY this individual is being contacted?
10.	Share contacts and resources.
	Find out how the system works:
DEVE	LOP AN ACTION PLAN
A. Ex 1. 2.	LOP AN ACTION PLAN  Identify possible solutions.  comples:  File formal complaint. Follow Grievance Procedure, if established  Hold informal meeting to negotiate solution  Write a letter of complaint
A. Ex 1. 2. 3.	Identify possible solutions.  comples:  File formal complaint. Follow Grievance Procedure, if established  Hold informal meeting to negotiate solution  Write a letter of complaint  Other
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#### **EXERCISE**

The following questions may be used as guidelines for group discussion or individual questioning:

- 1- What beliefs do you have concerning mental illness? What do you believe are some possible causes? What are some possible treatments? Discuss.
- 2- Do you believe your attitudes concerning mental illnesses differs from those held by the rest of society? If so, in what ways? Discuss.
- 3- Where did you get your beliefs? That is, how did you form your beliefs?
- 4- Have your beliefs about mental illness changed over time? Discuss.
- 5- How may have your beliefs about mental illness affected your:

Self esteem,
Independence,
Ability to question,
Personal choices,
Treatment.

BEHAVIOR? RECOVERY?

6- Have you ever behaved "like a mental patient" because you believed it was expected of you? If so, why did you think you did so? Discuss.

#### SYSTEMS ADVOCACY

Systems Advocacy is what we do when we attempt to improve services, policies or laws, to develop needed services not available or to do away with programs or services not relevant to the needs of service recipients.

The "tools" used to advocate for change and improvements are basically the same for mental health services and agencies as they would be for changing a law. Some of the methods used to make systems change can include (but are not limited to) the following:

- 1- Making formal and informal contacts by telephone, letter or in person with lawmakers, agency decision makers, or community leaders.
- 2- Holding forums to educate people, be they professionals, administrators, direct service staff, the general pubic or consumers of services.
- 3- Giving testimony at public hearings or before fact finding commissions.
- 4- Lobbying state and federal legislators.
- 5- Getting the media interested in your perspectives and to help arouse public concern in your cause.
- 6- Becoming an effective voice on various advisory boards, task forces, councils or fact finding commissions.

To be an effective advocate requires you know and understand how the system you are working to improve operates. Knowledge of the policies and laws affecting the Mental Health System, for example, is necessary. You need to know who makes critical decisions and how they are developed as well as knowing where consumer representation is required by law. Examples of letters and documents that can help to be more effective in Systems Advocacy will be found in this section.

In Connecticut, Regional Mental Health Boards were established by the General Assembly to review and evaluate the quality of community based mental health services. Any citizen may attend meetings of Regional Boards and each municipality is required to ippoint a "Consumer" to serve as a representative to each of these Boards. Phone numbers for each Regional Board Office can be found in another section of this manual.

#### GUIDELINES FOR TESTIFYING BEFORE THE LEGISLATURE

Keep your tastimony <u>short</u> - no longer than I to 5 minutes. <u>SPEAK FROM YOUR OWN</u> PERSONAL EXPERIENCE.

Guidelines for your statement:

- a. Identify yourself and the organization you represent.
- b. State your position as for or against the proposed bill; identify the bill by name and number.
- c. Summarize your recommendations first and then add explanation.
- d. Restate your position at the end of your testimony.
- e. Thank the committee for the opportunity to speak.
- . Type on only one side of the paper and double-space all your testimony for easy reading.
- Rehearse your testimony. Anticipate questions you might be asked and practice answering them.
- 3. Arrive early and sign up indicating that you wish to testify. Speakers will testify in the same order as their names appear on the sign-up sheet.
- 5. Bring enough copies of your prepared statement for the entire committee. Be sure the clerk has a copy for the record.
- If your testimony is very technical, ask the committee clerk to hand out copies of te testimony to the committee before you testify.
- 3. If there is a microphone, speak directly into it (about 6 inches from the mike) and, if necessary, move the microphone. If you cannot be heard, your testimony will not be effective, regardless of how carefully your statement was prepared.
- 9. Do not repeat points made by speakers ahead of you. If all of the points you wanted to make have been made, tell the committee you agree with the testimony given by the preceding speakers and urge them to take the appropriate action.
- 10. Answer only those questions that you can answer correctly. Offer to find the answers to other questions and promptly get back to committee members with the information.
- 11. If several people are speaking from the same organization, divide up the points to be made with each speaker addressing different areas.
- 12. Do not ergue with members of the committee or with people giving opposing testimony.
- 13. Put copies of your testimony in the mail boxes at the Capitol of committee members who were not at the hearing.
- 14. Keep a copy of your statement in your files.
- 15 If you have a valid, inceresting testimony, but have not prepared a statement, or if you discover after listening to others, that there is something you urgently wish to contribute, at the end of the hearing, ask to speak.

### Informed Consent to Medications and Treatment

#### For Persons With Mental Illnesses

#### What is Informed Consent?

informed consent means an agreement by a person or her, his legal representative to participate in an envity based on an understanding of:

- Is a full explanation of the procedures to be followed, including an identification of those that are experimental:
- 2 a description of the attendant discomforts and risks;
- 3) a description of benefits to be expected; and
- 4) a disclosure of appropriate alternative procedures.

References: Iowa Administrative Code (IAC) 441-22.1, 24.1, 33.1, 35.1; IAC 481-62.1.

#### What are Other Aspects of Informed Consent?

- 1) Informed consent recognizes the importance of the individual's input into the treatment process.
- 2) The treatment professional has the responsibility to provide the information in language the person or her, his legal representative\* can understand.
- 3) For informed decision-making, the person or her/his legal representative\* needs to be told of the risks and benefits of no treatment.
- 4) The person or her/his legal representative\* has the right to accept or refuse treatment unless it has ordered by the court, or under certain circumstances during the commitment process.
- consent must be voluntary, not coerced.
- 6) The treatment professional ordinarily must disclose to the person or her/his legal representative\* all material risks involved in a procedure.
- 7) If a person gives consent when she/he is not capable of making an informed decision, that consent may not be legally binding.

#### When Must the Person or Her/His Legal Representative\* Give Informed Consent in Writing?

Although informed consent is expected for all activities and procedures to treat individuals with mental llnesses, the Code of Iowa and the Iowa Administrative Code list specific circumstances in which informed consent must be documented in writing, including medical and surgical procedures (such as electro-convulsive therapy) that entail certain risks, participation in experimental research, unusual rentment procedures with intrinsic risks, aversive conditioning, and release of mental health records.

References: Code of Iowa 147.137, 228; LAC 441-28;4(5), 33,4(1); LAC 481-57,35(8), 58,39(9), 59,44(9), 62,23(5).

#### What are Some Examples of Exceptions to Informed Consent?

- 1) Emergency: In certain life-inreatening situations, treatment may be provided without prior consent.
- 2) Court Order: The person does not have to give consent to court-ordered treatment, but is still entitled to information about the treatment, its risks and benefits.
- 3. Warmer: The person may waive the right to refuse treatment by failing to object, but only when it is hat she he knew of the potential dangers of the treatment and of the right to refuse treatment, peutic Privilege. In some cases, the treatment professional need not provide complete information to the individual it so doing might harm his/her physical or psychological well-being. However, that decision must be documented.

Logal representative is defined, for these purposes, as a legal guardian appointed by the court.



# Fact Sheet

#### Questions for Informed Consent

ve the right to 1sk about medication or treatment being suggested for your what it is, its expected benefits, possible and atternatives. You have the right to accept or refuse treatment, except where that right is specifically taken away by law. These questions may assist you in making decisions about your treatment.

#### General:

- 1. What is my liagnosis' What does this mean'
- 2. What is my prognosis (course of my illness) with and without treatment?

#### Treatment:

- 1. What treatment are you suggesting?
- 2. Who will provide it? Where?
- How often will it be needed?
- 4. What are the chances it will help me? How painful is it?
- 5. How long do you expect it to last? Will I be laid up or imited in any way afterwards?
  - What do you expect from me? What is my part in this treatment?
- 7. What are the possible side effects, complications and risks of this treatment, and how often do these occur?
- 8. What are the alternatives? Why is this one better?
- 9. What is the cost? Do you accept my medical coverage (insurance, Medicaid, Medicare)? Do you have a sliding fee scale based on income?
- 10. Is this a generally accepted treatment or procedure, or a controversial or experimental one."
- 11. Will I need to be hospitalized? If so, why
- 12. Does this treatment require the use of anestnesia? If so what will be used and why? What are the risks and side effects? How will I feel when I wake up!

#### Medications:

- What is the name of this medication? What is its generic name?
- 2. Why are you prescribing it?
- 3. How is it given? In what dosage? How often?
- 4. What does it do? How do you expect it to heip me?
- 5. How long does it take to start working?
- 6. What are the side effects? (If I'm pregnant, how might it affect my baby?)
- 7. Are there any restrictions or limitations in areas such as diet, alcohol, activity or other medications?
- 8. What are the risks involved with taking this medication, and how likely are they to occur?
- 9. How will adjustments be made in the dosage? May I make some adjustments on my own?
- 10. Are there alternative medications or other treatments? Why is this one better?
- II Is this a generally accepted medication, or a controversial or experimental one?
- 12. What may happen if I stop taking the medication without medical supervision?
- 13. How expensive is this medication?
- 14. How long will I probably need to take it?

This fact sheer is not intended to be a substitute for legal advice. For additional information, consult an attorney or call otection & Advovacy Services, Inc., 3015 Merle Hay Road, Suite 6, Des Moines, Iowa 50310, 12/8-2502.

# Identity: oppressor

by Six-Pack Rat \*



I used to make a living throwing people in the mental hospital.

It's not something I'm proud of, and if I had it to do over again, I wouldn't. Still, I learned a hell of a lot during my brief tenure as one of the oppressors.

Florida law (the Baker Act) says that a person may be put in the mental hospital against their will if they are "dangerous to themselves or others."

This determination is made by a psychiatrist, judge, cop or "licensed mental health professional."

The signature of a judge and psychiatrist are required to keep you there longer than ten days, but it only takes one of the four professionals listed above to stick you there in the first place.

Unfortunately, the Baker Act doesn't mention that the person who does most of the actual work of putting people away is the student intern at a local mental health service's emergency services department.

That was me.

My first semester of graduate school, when I had a grand total of 20 weeks experience working at a mediocre telephone hotline. I was designated to decide the fate of the psychotic and suicidal. I was only very loosely supervised.

After the first month or so, no one from the actual staff sat in on my Mental Status Examinations. I quickly learned that when I reported to the psychiatrist I had only to throw in a buzzword or two, and I automatically got the outcome I wanted.

The psychiatrist was from India. He spoke very little English, and could not do the MSE's himself. He was useful to the agency only because he could legally sign commitment orders and prescriptions. It was my job to decide who was hospitalized, and his job to sign off on it.

He is not a bad man, but is the tool of a bad system.

As gatekeeper of the mental ward, I covered up the failure of one of our treatment units by hospitalizing a boy for a "psychotic episode" instead of the suicide attempt he was able to make because staff were not alert.

I threw a girl inside because the governor's wife didn't want the girl in her daughter's class, causing trouble.

I helped declare a woman incompetent so that her husband could marry another woman and screw the first wife out of her alimony.

I put people inside because the cops told me to, and kept people out when they needed help because the cops wanted them in jail.

I put homeless people inside to keep them away from our town's Spring Festival.

I helped put people in the mental hospital because their counselors wanted to "teach them a lesson."

Worst of all, when the psychiatrist asked me what medications I thought a client needed, I helped him prescribe.

What's the point of the confession? Well, I feel better having said it all. And taxpayers who support the mental health system should know how it is run.

When I worked there, I believed. The system may screw up, I thought, but we deserved a free hand to try to help people.

It was a long time after I became disillusioned that I realized that only oppressive systems try to "help" people by taking away their human dignity.

I'm much better now.

George Ebert
The Alliance
826 Euclid Avenue
racuse, New York 13210
(315) 475-4120



"self-help, mutual support and advocacy

December 3 1993

Beth Goldberg
Director of Public Information
Hutchings Psychiatric C-nter
620 Madison St.
Syracuse, NY 13210
Both

Dear Ms. Goldberg:

I am writing representing The Alliance (Mental Patients Liberation Alliance, Inc.) to request copies of any and all directives, memoranda, letters, or other records which relate to the Office of Consumer Affairs project by your agency. Information to include proposals submitted for consideration, memoranda about the decision process, and all information and proposals pertaining to that project to this date.

In the unlikely event that access is denied to any part of the requested records, please describe the deleted material in detail and specify the statutory bases for the denial, as well as your reasons for believing that the alleged statutory justification applies in this instance. As we expect to appeal any denial of information, please specify the office and address to which an appeal should be directed.

We anticipate that you will make the requested material available to us within the statutory prescribed period of ten (10) working days.

We also request that you waive any fees since disclosure meets the statutory standard for waiver of fees in that it would clearly be "In the public interest because furnishing the information can be considered as primarily benefiting the general public." In this regard, we point out that The Alliance is a nonprofit organization which intends to give the requested information wide public circulation.

With sincerity.

George Ebert

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# **DETAILED BUDGET/LINE ITEMS**

Intern Salaries - Spring \_\_\_\_ Summer \_\_\_\_ Fall

Six: Sec. taxes -

Office Supplies - Labels, files, pens, paper, etc.

Program Supplies - Certificates, plaques, other supplies

Printing - newsletters, barehares, annual reports

Media Advertising - print, broadcast, etc

Office Stationery -

Promotional Materials - booth, booth supplies, annual meetings decorations, other supplies

Photographic Materials - audio-visual equipment, film, processing

Registration Fees - conferences, associations

Local Meetings - any chapters or organizations

Employee Expense - Employee of the year award, plaques, certificates, employee parties

Travel, Lodging, Meals - airfare and other conference costs

Subscriptions - media guides, industry related pubs.

Organization Dues - any organization or association annual dues

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#### 10 POINTERS FOR SUCCESS

Know what you are talking about Know who you are talking to Don't bluff Keep it simple Lobby the right people Lobbying isn't only done in Albany Know the budget cycle Leave something behind (not your gloves) Follow up with a letter

Don't forget staff