Technical Assistance Guide

Systems Advocacy

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Introduction

At some point in your life, you've heard an exasperated person say, “You can't fight City Hall!” As a consumer of mental health services, you have certainly thought, “The system is working against me.” The National Mental Health Consumers’ Self-Help Clearinghouse has developed this Technical Assistance Guide as a tool for you to start changing “the system” so that you and other consumers can better benefit from the resources that our society has to offer. We explain the context in which health care decisions are made, and then discuss the various ways that you, as a consumer, can influence decisions affecting you and other consumers.

In the United States, we receive health care from doctors, nurses, and other professionals, but our interaction with these health care providers is defined by a complicated system that doesn't always work in consumers' favor. The local, state, and federal governments each set health care policies that affect everyone. Additionally, depending on who pays for our health care, each of us is part of the private or public health care systems. In both systems, insurance companies play a large role in determining what care is available. In the private system, employers often determine benefit levels, and in the public system, government agencies play an expanded role.

After we tell you who's who in the system, we tell you the easiest way to get involved in changing the system. By cooperating with an existing advocacy group that addresses your needs as a consumer, you can quickly become involved in influencing the policies that affect you and other consumers. The Join an Advocacy Group section explains how to identify groups that work for your needs, what they do for you and other consumers, and why it's so important for you to get involved in the consumer movement.

For those of you who are already involved in the movement, we explain some advanced strategies for influencing decision-making. The Effective Advocacy Skills section discusses how to best develop a strategy for influencing an issue that affects you and other consumers, how to identify the parties responsible for making decisions on that issue, and finally how to communicate your opinion in writing, in person, and through other means.

The final resort for consumers seeking to bring changes to the health care system is Legal Advocacy. If a health care policy adversely affects consumers and their most dedicated efforts fail to alter the policy, consumers can sometimes use the court system to address their grievances. This is a time-consuming and expensive process, but it often can achieve superior results. We will discuss some of the types of lawsuits that can benefit consumers, as well as some of the agencies assisting consumers with court cases.
Health care in the United States: an overview

Having made the decision that as a mental health consumer, you should be involved in making the decisions that affect you and other consumers, you have made an important first step. Your efforts can make a significant difference, according to Joseph Rogers, Executive Director of the Clearinghouse. “People usually get involved in advocacy because they have seen an injustice and want to make it right.” When you face injustice, “you can either become discouraged or angry, or you can try to direct your energy into something positive.”

The first step in working for change is to identify the parties whom you’ll need to influence. Important decision-makers include providers, insurance companies, local agencies, state agencies and legislatures, federal agencies, and the U.S. Congress.

We’ll briefly discuss the important categories of mental health decision-makers, but their identities will differ depending on where you live. You’ll need to identify the parties on your own; the best place to start is the government “blue pages” of your local phone directory, and the Internet and public libraries are other valuable resources. To help you manage all of this information, we’ve included an “Advocacy Workbook” as Appendix C, which you can use to record the information that you find. (Finding and recording contact information will be a common theme in this Guide, and its importance cannot be overstated.)

Providers and provider groups

At the front line of the healthcare system are the providers who actually interact with us consumers. Some of the many types of providers whom we might encounter are medical doctors (including psychiatrists), psychologists, various types of therapists, nurse practitioners and other nurses, and hospital staff. Many consumers also come into contact with police and other law enforcement employees, who may or may not have any training with mental health issues. Of growing importance are peer-run services for consumers, including self-help mutual support groups, drop-in centers, and clubhouses. Some of the major types of providers are summarized in Table 1, but you are likely to encounter other types of professionals.
Table 1. Selected types of professionals in the mental health system

<table>
<thead>
<tr>
<th>Profession</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>A physician who has attended medical school and is licensed by a state medical board. A psychiatrist is able to prescribe medications and specializes in mental health treatment.</td>
</tr>
<tr>
<td>Psychologist</td>
<td>A mental health professional with a degree (often an M.S. or Ph.D.) in psychology. A psychologist offers mental health assessment and therapy but is unable to prescribe medications.</td>
</tr>
<tr>
<td>Primary Care Physician</td>
<td>A physician, such as a family physician or internist, who has attended medical school, is licensed by a medical board, and is able to prescribe medications. Although they are trained to spot mental health problems and often prescribe medications, they do not specialize in mental health treatment.</td>
</tr>
<tr>
<td>Physician Assistant</td>
<td>A professional who is licensed to practice under the supervision of a physician. May perform physical examinations, diagnose illnesses, and in most states write prescriptions. The education program is shorter in duration than medical school.</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>A nurse who has completed advanced training and may perform physical examinations, take medical histories, and prescribe certain medications.</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>A professional who has received training in helping people recover and gain or regain skills for entering the workforce.</td>
</tr>
<tr>
<td>Social Worker</td>
<td>A professional who has earned a degree in social work and meets state legal requirements. Professional social workers practice in many settings including family service agencies, community mental health centers, hospitals, and public and private agencies. Professional social workers are the nation’s largest group of mental health service providers.</td>
</tr>
</tbody>
</table>

On a personal level, you can work to change your providers’ attitudes so that they better understand your needs as a consumer. Depending on your health care plan, you might also have the alternative of switching to providers who are more responsive to your needs. Of course, peer-run services welcome your input--they are run by consumers like you and seek to be as responsive as possible to consumers’ needs.

If you’d like to find out about peer-run services in your area, please contact the Clearinghouse by calling (800) 553-4KEY or e-mailing info@mhselfhelp.org. Technical Assistance Coordinator Elizabeth Knapp says, “We handle calls from all over the
country, and we are able to put people in touch with a wide variety of services in their communities.”

On a more system-wide level, we consumers can work with provider groups to help educate their members about consumers’ needs and preferences. The American Medical Association, for example, is a large and influential organization that sets national policies according to its internal procedures. For example, its Statement of Principles on Mental Health (H-345.999) states that the “AMA has a deep interest in fostering a general attitude within the profession and among the lay public more conducive to solving the many problems existing in the mental health field.” As promising as this sounds, professional organizations will not be responsive to consumers until we consumers give them our input.

Professional organizations are designed to meet the needs of their members rather than their clients, and unfortunately, consumer groups and professional groups often work for opposite goals. As consumers and advocates, we can work to educate provider groups in areas of disagreement such as forced treatment, restraints, and electroconvulsive therapy. In some instances, we even work together with provider groups for similar goals, such as supporting extended insurance coverage for mental health treatment. A list of professional organizations is included in Appendix B.

Another important group for consumers to influence is the police. Although not commonly thought of as providers, “police tend to be the first-line responders in mental health crises,” according to Scott Snedecor of the Office of Consumer Technical Assistance in Portland, Oregon. For several years, Snedecor and colleagues have worked training police volunteers to become part of a “crisis intervention team.”

Although ten percent of officers have participated in the training program, Snedecor points to an incident in which no crisis intervention team members were available and a consumer died in police custody as evidence that training should be done with a larger percentage--ideally one hundred percent--of the force. Snedecor urges consumers to get in touch with local police forces to help them understand what happens when someone is having a mental health crisis.

**Health insurers**

Another category of decision-makers important to consumer advocacy includes the insurers who pay for our health care. Depending on your situation, you might be part of the private healthcare system (you or an employer pays for your health care or insurance), or part of the public healthcare system (your health care is funded--and perhaps controlled--by government programs). In recent years, the two have become more similar as state governments have contracted with managed care organizations.
(MCOs)--which place limits on services in order to control costs--to provide health care in the public system.

Because health insurers pay for health care, they have an interest in keeping costs lower. Traditionally, insurers have provided lower benefit levels for mental health services than for other services. (The fight against this practice is known as the battle for parity, and we’ll examine this important issue in several contexts.) In recent years, the increasing prevalence of MCOs, which use techniques such as volume discounts, per-patient spending limits, and limits on services, have further curtailed the availability of services to consumers.

The private healthcare system

In the private healthcare system, not too many years ago, the typical employer-provided health insurance plan was an indemnity plan. These plans require the employee to pay out-of-pocket for most health services and then seek reimbursement for all expenditures beyond the annual deductible for which the employee is responsible. Indemnity plans may also include a coinsurance provision, meaning that the insured person must pay a certain percentage of total health care costs.

In recent years, MCOs rapidly have gained market share in the private sector, and now most health insurance plans are offered through an MCO, which can take any of several forms. Although there are some differences between the various forms, each type of MCO places limits on the consumer’s ability to make healthcare decisions.

Health Maintenance Organizations (HMOs) are MCOs that offer health benefits for a set monthly fee. Each visit requires a co-payment, usually $5-$15. Some HMOs rely on a staff of employees to provide care, while others contract with a network of private medical offices. If you have this type of plan, your primary care physician will make healthcare decisions, including referral to specialists.

Some MCOs, known as Point-of-Service (POS) plans, allow participants to choose providers not participating in the network. However, benefits are reduced through higher co-payments, deductibles, and coinsurance.

With a Preferred Provider Organization (PPO), the MCO negotiates deals with a network of providers. The insured person can use one of these providers, or choose other providers, with higher deductibles and co-payments.
The public healthcare system

Many consumers who are not covered by private health insurance are covered by one of the many government programs that make up the public healthcare system. We will briefly discuss some of the more important programs to expose some advocacy opportunities, but keep in mind that more comprehensive information about these programs is available, and that many other more specialized programs exist.

The largest public healthcare program administered by the federal government is Medicare. This program covers people who are 65 or older, as well as people who have collected Social Security Disability Insurance (SSDI) for more than two years. Medicare is administered by the Health Care Financing Administration (HCFA), which is a division of the Department of Health and Human Services (HHS).

For those who are eligible, Medicare pays portions of hospitalization costs as well as outpatient care. However, Medicare does not cover 100% of costs, and for this reason, many people covered by Medicare purchase supplemental health insurance from private insurers to fill in the “gaps” of Medicare coverage.

Another very important public healthcare program is Medicaid, which is funded jointly by the states as well as the federal government. Medicaid programs vary from state to state, but must follow federal guidelines, which are administered by HCFA.

To be covered by Medicaid, a consumer must be receiving some sort of public financial assistance, or in some states, be financially unable to pay for necessary medical treatment. Consumer advocates can work to increase Medicaid eligibility for consumers.

Increasingly, governmental bodies responsible for providing health care in the public system are turning to MCOs as an attempt to reduce costs. This has become an important area of consumer advocacy, as consumers have attempted to block moves to MCOs or to influence the types of MCO services for which states have contracted.

Depending upon the state, Medicaid might not cover certain types of treatment, which then becomes the responsibility of state or local programs. Such treatments can include inpatient mental health services, clinic outpatient services, and pre-authorized medications. Another issue important to consumers is the prescription drug formularies, which restrict the types and amounts of medications that consumers can access.

For mental health services not covered by Medicare or Medicaid, many consumers rely upon state, county, or community mental health programs. These programs vary from state to state even more than Medicaid programs. Therefore, it is important for consumers in each state to understand how their state’s system works.
Some of the parties who could be responsible for making decisions in your state include state mental health directors, state Medicaid departments, legislators, governors, mayoral staff, and others. As a consumer involved in advocacy—even if you are not a part of the public healthcare system—you should learn who has responsibility for making mental health decisions in your area. Again, the blue pages of the phonebook is an excellent place to start, and you also can obtain information from Knowledge Exchange Network of the Center for Mental Health Services (see Appendix A), and the National Association of State Mental Health Program Directors (see Appendix B).

**State legislatures**

Although state and local agencies (also known as “authorities”) make many day-to-day decisions, it is important for us to understand the role that state legislatures play in setting broad policies affecting consumers.

Each state has a legislature, which in most states comprises two houses, much like the United States Congress. Legislatures do not have time to make every healthcare decision, and they therefore establish agencies dedicated to the task, such as the agencies responsible for the public health care system. Keep in mind, however, that these agencies are subject to the guidelines established by the legislature, and thus State House advocacy is very important.

The first step, if you haven’t already taken it, is to know which legislators represent your district in each house. They have been elected to represent you, and more importantly, they depend on your vote, so they are more likely to be responsive to your concerns. Don’t forget to record their contact information (from the blue pages) in Appendix C.

As you grow as an advocate, you will learn more about your state’s legislature. You can probably obtain public information by contacting your legislature in the state capital, and you might also find information at your local library or on the Internet. Reading a newspaper from a large metropolitan area or one from the state capital is another excellent way to keep track of what’s happening in the state legislature.

Another important figure in each state’s legislative process is the governor. Your governor generally has the power to approve or veto any piece of legislation passed by the legislature. Additionally, the governor proposes legislation, frequently with the assistance of task forces devoted to a particular topic (e.g., mental health). Therefore, an advocate should know how to contact the governor and be aware of any task forces that might be working on mental health issues.

Each state has a different legislature and governor, and therefore consumers must form coalitions in each state to accomplish their goals. However, as we will see, many of the
same issues come up state to state, and national organizations can be an excellent resource for state house advocacy.

According to Clare Miller, manager of the National Mental Health Association’s Advocacy Resource Center, many of the issues that come up at the state level also are important at the national level. However, advocacy at both levels is important: action at the state level influences national debate, and federal legislation affects a larger number of consumers.

Some of the important state legislative issues are described in Table 2, but this is only a small selection of the many issues that affect consumers. Keep in mind that some of these issues could also be debated in the United States Congress.

| Table 2. Some of the many important issues in state legislatures and the U.S. Congress |
| Broad-based parity | Consumers are uniting with providers and other groups to fight for an end to discriminatory differences between insurance coverage of mental health needs and other conditions, usually in the form of limits on numbers of visits or higher deductibles and co-payments. |
| Formulary restrictions | Consumers are fighting to prevent Medicaid programs and private insurers from limiting the types of medications that may be prescribed to consumers, or from requiring that consumers fail on less expensive medications before obtaining the most effective medications. |
| Consumer protection | Often discussed in terms of a “patients’ bill of rights,” we are fighting for the right to challenge MCOs’ decisions denying treatment and to sue MCOs for making healthcare decisions with adverse effects. |
| Outpatient involuntary commitment | Consumers continue to fight against legislation that requires forced outpatient treatment, either at the request of third parties or as a condition of placement in community treatment programs. |
| Sexual predator laws | Some consumers are fighting state laws requiring that convicted sex offenders be placed in mental health treatment settings. These laws ignore the fact that many covered by this law do not respond to treatment, and that the programs place dangerous criminals in programs designed for people needing help and further stigmatize consumers. |
| De-institutionalization | A long-term goal of the consumer movement is closing state hospitals and replacing them with community-based treatment. |
Records confidentiality

As more parties become involved in providing mental health services, consumers’ records are more widely distributed. Consumers are seeking to control access by placing limits on the parties that see records, and under what circumstances.

Medicaid MCO contracts

Consumers can become involved in states’ decisions to contract with MCOs for providing Medicaid mental health services (if a state has not already), and can also become involved in the types of services that will be provided under the contracts.

Seclusion and restraints

Traditionally, mental health institutions have used seclusion and restraints inappropriately, including for punitive purposes. Consumers are seeking to have their use strictly curtailed or eliminated.

Ombudsman programs

Many states are instituting programs in which ombudspersons advocate for consumers in the public healthcare system.

Children’s’ Health Insurance Programs (CHIP)

As states begin to implement the federally mandated CHIP program to provide health insurance to children of low-income families, consumers are advocating for comprehensive coverage of mental health needs under these insurance plans.

Tobacco settlement money

As states decide how to use proceeds from a settlement of major litigation against the tobacco industry, consumers are seeking to allocate a portion of the money for mental health services.

The federal government

Consumers have many opportunities for advocacy at the federal level. The two divisions of the United States Congress (the House of Representatives and the Senate) each have numerous committees, many of which work on mental health issues. The President and many people within the White House do similar work. Often overlooked, but perhaps even more important, are the federal agencies that administer federal mental health programs and make many decisions important to all consumers.

On the federal level, advocates might work on many of the same issues that arise on a state level. However, at the federal level, the stakes are much higher because decisions at the federal level affect consumers in every state and territory. Because of this heightened importance, consumers face even greater challenges than at the state level: consumers often face groups that can devote vast resources to combating pro-consumer legislation, such as the health insurance industry and small business associations, which oppose parity. The consumer movement is growing, but we need more advocates to get involved.
Another challenge for consumer advocates at the federal level is learning to navigate the often-confusing legislative and regulatory process. This is a process that can be learned truly only through experience—and even then, the learning process never ends. With so much to learn, the best time to get involved in advocacy is right now!

The United States Congress

The basic structure of the United States Congress is a subject of study from elementary school through high school. However, very few people learn the intricacies of the legislature. We’ll point you in the right direction, and we hope that you’ll use existing resources to learn more about the legislative process. More importantly, you’ll begin to learn from experience.

Each of us who lives in one of the fifty states has two Senators and one Representative. As is true with the state legislature, the best place to start with federal legislative advocacy is with those people who have assumed a duty to represent you (and who depend on your vote in the next election!) You can find out how to contact your legislators by using the blue pages, and detailed information is available on the Internet at http://www senate.gov and http://www house.gov. Again, Appendix C is a convenient place to record information about contacting your federal legislators.

Routinely contacting your own legislators is an excellent way to advocate for specific positions, but you can become even more effective as you begin to understand the committee system. Each house is divided into major committees, which are in turn divided into subcommittees. Any legislation will begin its life in a subcommittee and must pass muster there, then in a broader committee, and finally on the full floor of each house of Congress before it can become law.

As you might imagine, only a small percentage of legislators serve on any given committee, with an even smaller percentage serving on each subcommittee. If you are lucky enough to have one of your own legislators on a committee or subcommittee that concerns you, the importance of contacting this legislator multiplies: the debate in subcommittees and committees most often makes or breaks a legislative effort.

As an advocate, you should familiarize yourself with the committees and subcommittees that debate consumer issues; we’ve listed some of the more important ones in Table 3. You should take time to learn the members of these committees and subcommittees, either by visiting the House and Senate web sites or by contacting the committee offices directly using the information provided in Appendix A.

You should also know the committees and subcommittees in which each of your legislators participates. Call your legislators’ offices and ask for this information; this is
an excellent way for you to identify yourself to the legislators’ staff and demonstrate interest in the legislators’ activities. Even if your legislators are not involved in the committees that are most important to consumer issues, you should consider your legislators’ staffs to be valuable resources.

Table 3. Important Committees and Subcommittees in the U.S. Congress

<table>
<thead>
<tr>
<th>Selected House Committees</th>
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<tbody>
<tr>
<td><strong>Appropriations Committee</strong></td>
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<tr>
<td><strong>Subcommittee on Housing and Community Opportunity</strong></td>
</tr>
<tr>
<td><strong>Committee on Commerce</strong></td>
</tr>
<tr>
<td><strong>Committee on Ways and Means</strong></td>
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<table>
<thead>
<tr>
<th>Selected Senate Committees</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Finance Committee</strong></td>
</tr>
<tr>
<td><strong>Appropriations Committee</strong></td>
</tr>
<tr>
<td><strong>Committee on Health, Education, Labor, and Pensions</strong></td>
</tr>
<tr>
<td><strong>Committee on Banking, Housing, and Urban Affairs</strong></td>
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</table>

The White House

Unlike Congress, the President of the United States cannot make laws, but rather can veto or approve laws passed by Congress. Nonetheless, the President is obviously an
important figure in American politics, and advocacy opportunities at the White House level are not limited to influencing the President’s decision whether to veto or sign a bill.

One powerful avenue of advocacy—and one in which consumers have seen recent success—is advocating for executive orders. The President has limited power to issue orders concerning the operation of the federal government. In the summer of 1999, consumer advocates scored a major victory in the fight for parity when the President issued an executive order guaranteeing equal mental health insurance coverage for all federal employees.

The President can also play an active role in introducing legislation. One major issue for which the Clinton presidency will be remembered is healthcare reform. Ultimately, the comprehensive healthcare reform package envisioned by the administration was unsuccessful. However, if consumers can influence White House policy, then not only does the legislative proposal enter the legislature with momentum, but the media will pay much more attention to the debate. The White House Conference on Mental Health, at which the parity executive order was announced, was an excellent example of how the White House can call attention to mental health issues.

Of course, influencing White House policy is no simple matter. The President is elected by the entire nation, and any presidential policies are necessarily the result of compromise. On a more practical level, the Presidential offices are much less accessible than Congressional offices, and there are much greater demands on the President’s attention.

It is better, then, to think of influencing the President as not a primary focus, but as part of the puzzle. It is appropriate to write to the White House about pending legislation, asking for support. Any major legislative campaign should also attempt to reach out to White House staff: like Congress’s committees, the White House devotes groups of staff members to particular policy topics. The White House also has standing committees with which consumers can become involved, such as the President’s Committee on Employment of People with Disabilities.

Federal agencies

The President is the head of another major arena for consumer advocacy: the federal agencies. Congress has created a number of agencies to handle complicated issues, but these agencies are part of the executive branch of government and therefore fall under the authority of the President for their operations. However, Congress can pass laws that increase or limit the agencies’ authority.

We’ve already discussed one federal agency, HCFA, or the Health Care Financing Administrations. Consumer advocates should also know about a number of other
“alphabet agencies,” including HHS, NIMH, CMHS, SAMHSA, EEOC, and HUD. Don’t worry—we’ll explain what each of these abbreviations stands for as we discuss what the agencies do. We’ve also included contact information in Appendix A.

The Department of Health and Human Services (HHS) is an enormous agency with many divisions, some of which deal specifically with mental health issues. In addition to HCFA, some of HHS’s subdivisions that are relevant to consumer advocacy include the National Institute of Mental Health (NIMH), the Center for Mental Health Services (CMHS), and the Substance Abuse and Mental Health Services Administration (SAMHSA), which oversees CMHS.

The National Institute of Mental Health is primarily a research organization. Not only does NIMH employ many research scientists, but it also funds grants nationwide for researchers studying mental health issues. Because NIMH controls how federal tax dollars are spent on mental health research, the agency has a great influence on mental health.

The Center for Mental Health Services is involved in many facets of mental health. Most significantly, CMHS provides grants to states and has some oversight of their mental health services. CMHS also funds consumer-run initiatives (including the National Mental Health Consumers’ Self-Help Clearinghouse), makes information available to the public, and assists in developing effective mental health services.

Obviously, CMHS is an important agency to consumer advocates, and the agency provides opportunities for consumers to become involved. CMHS has an office of Consumer Affairs and also requires that each state maintain a mental health planning board that includes consumers in its membership. Valuable information for consumers is available from the National Mental Health Services Knowledge Exchange Network.

CMHS’s parent agency, the Substance Abuse and Mental Health Services Administration (SAMHSA), also includes the Center for Substance Abuse Prevention and the Center for Substance Abuse Treatment. Additionally, SAMHSA has offices that examine women’s and minority concerns, as well as the challenges faced by consumers with HIV and AIDS.

The Equal Employment Opportunity Commission (EEOC) is the agency in charge of enforcing the Americans with Disabilities Act (ADA) and other federal laws prohibiting discrimination based on race, gender, or other factors. When an employer discriminates against a consumer, the consumer can file a complaint with the EEOC and seek relief. The EEOC is also an important policy-making organization, and consumer advocates can try to exert their influence on EEOC’s regulations and employer guidelines.

The Department of Housing and Urban Development (HUD) enforces federal housing laws, including those that prevent discrimination against persons with disabilities in
lending practices, renting property, and other housing practices. Consumers can file complaints directly with HUD’s **Office of Fair Housing and Equal Opportunity**.

The **National Council on Disability**, unlike some other federal agencies, is less involved in regulation. The Council exists primarily to study issues affecting Americans with disabilities and make recommendations to the President and Congress. Its overall purpose is to empower people with disabilities and improve their lives, and to do this, it studies how the Americans with Disabilities Act and other civil rights laws are being implemented.

Like Congress, federal agencies effectively make laws, even though they are called “regulations” rather than laws. Usually, before an agency can issue a regulation, it must allow the public a period of time to comment on the proposed regulation. You can find out information about upcoming regulations through the agencies web sites or by contacting their public information offices.
Joining an existing advocacy group

Now that you’ve had a quick overview of the healthcare system in the United States, you probably think that systems advocacy must be pretty complicated. You’re right! Fortunately, you don’t have to tackle the system alone. The quickest way to become a consumer advocate is to join an existing advocacy group.

Joseph Rogers, executive director of the National Mental Health Consumers’ Self-Help Clearinghouse, encourages joining forces with other advocates. “It’s very difficult to do systems advocacy as ‘the lone ranger.’ It’s not as effective, and it can also be an isolating experience.” Although it is possible to start up an advocacy group with people you meet, most new advocates will become associated with a group that already has some advocacy programs in place.

As you look for advocacy groups to join, you might find that you do not necessarily agree with all of their principles. With some groups, you might find that you do not agree with many of their specific ideas or even with their overall philosophy, and yet you might be able to achieve some advances for consumers by cooperating with that group.

As Joseph Rogers explains, “I’ve gone into organizations thinking that I wouldn’t gain anything except maybe some contacts, but I ended up with positive results.” The key to working with such groups is sticking to specific goals, which you can achieve even if you don’t end up influencing the group’s overall philosophy. “Sometimes revolutions happen,” but when they do, they are the result of people ardently working on specific goals.

Finding advocacy groups

A quick way to find a group through which you can become an advocate is to find a state or local affiliate of a national organization. Several mental health groups have affiliates in most parts of the country, and there’s probably one in your area. These organizations all have different structures and approaches, so it is probably best to investigate the various advocacy opportunities that you might have. We have included contact information for national organizations in Appendix B, including their web sites, which generally contain contact information for local affiliates.

The first and oldest mental health advocacy group in the U.S. is the National Mental Health Association (NMHA), which was founded in 1909 by a consumer named Clifford Beers. Although neither the NMHA nor very many of its several hundred affiliates are strictly consumer-run, NMHA invites consumer involvement in its advocacy and public education campaigns.
Another powerful advocacy group is the National Alliance for the Mentally Ill (NAMI), which began as a group of consumers’ family members and, in many consumers’ opinions, continues to favor family interests over consumer interests. However, NAMI’s official policy is to welcome consumer involvement at the national level and with state and local AMIs.

You should also be able to locate local affiliates of organizations with more specific mental health concerns, such as the National Depressive and Manic-Depressive Association and the Federation of Families for Children’s Mental Health.

Even if you do not find the local affiliates of national organizations to be helpful, you should nonetheless consider the national organizations to be a helpful advocacy resource. For example, both NAMI and NMHA offer “action alerts” on pending legislation or litigation of interest to consumers. You can sign up for these alerts by contacting the national headquarters, or by signing up on their web sites for the information to be delivered to your e-mail addresses by automated “listservs.”

Other groups exist to offer support to consumer advocates nationwide even though they do not have local affiliates. A perfect example of this type of group is the National Mental Health Consumers’ Self-Help Clearinghouse, which provides advocacy materials and consultations to individual consumer advocates and local advocacy groups. The Bazelon Center for Mental Health Law in Washington, DC is another valuable advocacy resource. Both the Clearinghouse and the Bazelon center offer listservs on advocacy topics.

Another important service that the Clearinghouse provides is referrals to local advocacy groups. According to Technical Assistance Coordinator Elizabeth Knapp, “We maintain a large database of local organizations, many of which aren’t affiliated with national organizations. Consumers in your area might have already formed independent advocacy groups, and the Clearinghouse is always happy to refer advocates to local groups.”

**Getting involved**

By now, you might have the impression that a lot of people are already working on advocacy campaigns, and these people know a lot more than you do. That might be true, but it shouldn’t discourage you from getting involved in advocacy efforts. As Brian Coopper, NMHA Director of Consumer Advocacy says, “The voice of the people at large is needed most of all.”

Although many consumer advocacy groups have trained, paid staffs, there are limits on the amount of work that they can do. Consumer advocacy groups simply do not have the resources to compete with other interests, such as business or insurance groups, that might be battling against pro-consumer initiatives. If you think that advocacy groups
don’t need your help, look back at Table 2 to remind yourself of everything that we as consumers still have to accomplish!

As a person and a voter, you can offer advocacy campaigns another voice. You can help national campaigns by providing a voice from your state and Congressional district. You can help state campaigns by providing another voice in the state speaking in favor of consumer issues.

As a consumer, you lend credibility to your advocacy efforts. Marie Verna, program director of the Clearinghouse, says, “Because we’ve suffered some of the torments ourselves, we can say with absolute certainty that people with mental illness deserve better treatment. Our authenticity gives us authority to assert what the issues should be in mental health care reform.”

More importantly, as a consumer, you can work to dispel stereotypes as you advocate. Legislators, regulators, and staff have grown up in a society that looks down on mental health consumers. By preparing well and presenting your case effectively, you can work to dispel the image that we consumers cannot work on our own behalf. By appearing as an effective consumer advocate, you can impress people to favor programs that help consumers achieve much greater goals.

Our ability to dispel stereotypes is vital to pro-consumer advocacy. Despite the many trained advocates and family members working on our behalf, only by becoming advocates ourselves do we demonstrate to decision-makers that we are willing and able to take on the full responsibilities and privileges of citizenship.

Hopefully, you understand the importance of consumer advocacy and are wondering what types of help you can offer to advocacy groups. At the most basic level, you can wait until you receive action alerts about upcoming legislation and write to members of Congress. This is relatively uncomplicated and not very time-consuming, and is effective when enough other people take action.

However, advocacy groups offer the opportunity for a much greater impact on the system. You might be able to alert the groups to problems that you perceive, or be an early-warning resource for legislation in your home state. Advocacy groups can provide resources for organizing demonstrations and media campaigns, both of which can draw attention to issues and influence decision-makers. You might also learn how to become involved in local citizens’ task forces or other organized bodies. In the following section, we’ll take a deeper look at various strategies for becoming a more effective advocate.
Effective advocacy skills

Whether you choose to lead your own advocacy initiative or join an existing one, there are certain skills that you’ll need to develop. At first, it will be difficult. “It’s a long and complicated process to make real systems change,” says Clearinghouse executive director Joseph Rogers, “and if you come in with an attitude that nothing can change, nothing will change. You’ve got to believe that you can fight City Hall.”

Remember that advocacy is an ongoing battle: if your campaign is not successful, don’t think of it as a battle that’s been lost, but a battle that’s yet to have been won. Mary Hurtig, Director of Policy Development for the Mental Health Association of Southeastern Pennsylvania, stresses the need to keep after legislators from session to session. If your initiative is defeated, remind legislators, “We will be in touch.”

By taking a systematic approach, you’ll be able to measure your success in terms of what you’ve accomplished and what you’ve learned. You can use your knowledge in future efforts, either on the same or other consumer issues. As you work on any advocacy issue, be sure to keep good records: keep copies of every letter that you send or receive, and record dates, names, and subjects for all phone calls and meetings. Brian Coopper, NMHA Director of Consumer Advocacy, recommends using a 3-ring binder to stay organized. “Being able to show someone you are keeping accurate notes is a powerful tool. For example, including a line in a letter such as, ‘Based on your letter of January 17 and our telephone conversation of January 20,’ shows that you are a force to be reckoned with.”

Preliminary steps

We’ve already discussed some of the preliminary steps of advocacy: how to identify some of the issues that affect consumers and how to identify decision-makers who can help. Don’t forget those steps! The same passionate feelings that can make you an effective advocate when you have specific goals in mind can make you an ineffective advocate if you don’t plan what you’re doing.

Most often, beginning advocates learn about issues from other advocates, through action alerts, newsletters, meetings, etc. “At the Clearinghouse,” says program director Marie Verna, “a primary goal has always been to encourage advocates to network with each other. In recent years, we’ve been encouraging the use of Internet technology to make this process easier. We urge consumers to contact us at info@mhselfhelp.org, and we’ll put them in touch with consumer networks.”

Often an issue will arise based on government action, such as a state deciding to contract with a managed care organization for its Medicaid program or proposed spending cuts.
Other times, an issue “arises” when advocates decide that enough is enough and that they want to change the status quo. A good example of this type of issue is the fight against restraints and seclusion: this is not so much a reaction to a recent event, but a fight to end decades and decades of abuses. Many times, a consumer will face an adverse situation, seek help, and find out that advocates are waging a legislative battle on that very issue.

Going after the right decision-makers is another basic but essential step to effective advocacy. Tom Liebfried, a former program director at the Clearinghouse, made it clear that the easiest way to find out who’s in charge is to “follow the money.” Say for example, that your state mental health authority has been downsized in recent years, and most funding decisions are now made by the state’s Medicaid agency. Obviously, you and your fellow advocates will be much more effective if you concentrate your efforts on the Medicaid agency because that agency is now making the decisions about money.

You don’t need to do a financial analysis to follow the money, but when you investigate a problem, you should ask a lot of questions. If you find out that services are being cut, ask the providers of that service who is responsible for that decision, and keep asking questions until you find out who stands to gain financially by the decision. If an agency is shifting its money away from mental health services, you should appeal to that agency. If on the other hand, the agency’s budget is being cut by the legislature, you should concentrate on legislative advocacy.

**Writing a letter**

Writing a letter to decision-makers is something that you can do from home, and it is a surprisingly effective tool. In fact, based on a study done in the early 1990s, Independent Sector’s *Nonprofit Lobbying Guide* rates letters written by individuals to their U.S. Senators and Representatives as the most influential source of communication with Congress. Letter-writing campaigns (in which many people send the same or similar letters) are less effective, but still have an impact. We’ll discuss strategies both for writing for your own letters and for organizing letter-writing campaigns that **will** be effective.

**Personal letters**

While noting the overall effectiveness of personal letters, Independent Sector warns that Congress collectively receives over 200 million pieces of mail per year, and that any letter you write should be well thought out. This advice also applies to letters to decision-makers who receive a much smaller volume of mail—you shouldn’t underestimate the power of first impressions.

Letter writing is a skill, but it is one that can be learned. Fortunately, the most important rule is one that actually makes your job easier: *Keep it simple!* Make your letter as direct
as possible by limiting extraneous information. You’ll be tempted to write more than you should because you feel passionately about the subject; otherwise, you wouldn’t want to be an advocate.

No hard and fast rules govern what you should and shouldn’t include in a letter, but Independent Sector offers the following guidelines for a brief but effective letter. First, limit yourself to one page and cover only one issue. Legislators are inundated with information and the only way to ensure that they pay attention to your letters is to make them easy to read and understand.

Second, use a simple structure comprising: your home address; the issue with which you are concerned, including bill number or other identifier if possible; a brief request for specific action; and a request for a response stating the decision-maker’s position.

Alan Marzilli, Educational Specialist at the Clearinghouse, suggests one more element. “As consumers, we should add a personal touch to each letter we write. If you’re writing a letter about insurance parity, for example, you might mention how much of your after-tax income you must spend on mental health care, as evidence of disparity’s burden on working Americans. In a letter about restraints, a consumer advocate might relate a particularly dehumanizing personal experience. Being able to tell our own stories makes our letters much more poignant.”

Brian Coopper offers additional useful advice: avoid mudslinging even when you are upset, and get a friend to proofread your letter. Most of all, “Don’t be afraid to write letters to important elected officials and public servants. That’s what they’re there for—to serve the public!”

Letter writing campaigns

Although massive letter writing campaigns are less effective than personal letters, according to the statistics cited by Independent Sector, a campaign of this sort can nonetheless be effective. If you are lucky enough to be tied into a network of consumers working for change, you can work to mobilize them writing letters. The key to a successful effort is to encourage people to add their own words and experiences to the letter that they write.

Many advocacy groups send a sample letter to their constituency, each of whom then retypes the letter onto personal letterhead and sends it to a decision-maker. Legislative staff then can pile up all the identical letters into a stack and read only the first one in the pile! A much better approach is to contact the people in your network and ask each of them to write a letter explaining the personal consequences of the decision.

For example, say that the issue is restrictive prescription drug formularies. Instead of sending out a form letter, instead ask people to write letters telling how they had been
greatly helped by a drug that would be omitted from the formulary. Ask them to frankly discuss their condition before and after they had access to the medication. You should also of course give enough information for each person to clearly identify the legislation or regulation at issue, as well as the position that the decision-maker should take.

**Telephoning decision-makers**

Telephoning decision-makers who represent you is another effective method of advocacy, according to Independent Sector’s *Nonprofit Lobbying Guide*. The rules for communicating by phone are fairly similar to the rules for letter writing in that calls should be brief and accurate and should clearly state the position you favor. Depending on the type of decision-maker whom you are trying to influence, you are often likely to speak to a staff member. If it is a current issue, the staff person is likely to be keeping a “pro and con” tally of phone calls, so it is vital that you make your position clear.

Remember your phone manners. Don’t be afraid to be firm, but never come across as rude, argumentative, or angry, and never raise your voice or hang up on someone. Of course you feel passionate about the issue, but don’t let your emotions get the better of you!

**Effective meetings**

Letter writing and using the phone are important tools, but in-person meetings are a way to ensure that decision-makers know who you are, allowing you to build an ongoing relationship rather than being a tally in individual debates.

Independent Sector’s *Nonprofit Lobbying Guide* recommends that advocates try to meet with a federal legislator only if: (1) one of the advocates at the meeting lives in the legislator’s district, or (2) the advocates are there to offer their help supporting a bill being sponsored by the legislator. This advice also makes sense at the state level, and it underscores the point that advocates can be more effective when they join forces with advocates in other districts.

It should not surprise you that state and federal legislators are much more willing to meet with their own constituents than with others. You and your fellow advocates should not be intimidated by the prospect of meeting with elected officials because they rely on their constituents’ votes and will listen to their concerns. Consider meeting with members of Congress in your home state: they may have more time to devote to you then.

Independent Sector offers three valuable pieces of advice. First, make an appointment by telephone: it’s easier to find a time and more difficult for the office to ignore your request. Second, call as a person rather than an organization when meeting with your personal representative. Third, don’t turn down the opportunity to meet with staff...
members who work specifically with health care issues: they spend a much greater portion of their time on mental health issues than legislators do. When you are dealing with regulators, however, be persistent about meeting with higher-level officials rather than meeting people with no decision-making authority.

Advocacy experts disagree on the ideal number of people who should meet with a decision-maker. Independent Sector sees the value in individual meetings, but the National Mental Health Association views sending a group as essential. You’ll have to make your own decision, based upon your level of confidence and whether you think that you can adequately convey the facts necessary to be persuasive. As a consumer advocate, you bring a personal perspective to mental health issues, and this asset is extremely powerful. However, having “facts and figures” is also essential to persuading decision-makers, and you might want to bring along an ally for that part of the presentation.

While it’s not clear whether you’ll be better off meeting alone, or with a group of other consumers or professionals, one ironclad rule governs group visits. Make sure that one person acts as moderator of the presentation and ensures that the others adhere to the agenda and time frame of the meeting. Pay careful attention to the latter point: legislators are very busy, so try to keep the meeting as brief as possible.

Other general rules include honesty, politeness, and tact. If a decision-maker asks a question, give an honest answer, even if it is “I don’t know.” Remain calm and non-accusatory, polite but firm. Respond to the arguments of the other side, but don’t bad-mouth your opposition.

Another key element of a meeting is leaving written materials when you leave the meeting. Alan Marzilli, Educational Specialist at the Clearinghouse, stresses the need for the cover sheet to be informative and brief. “There’s an unwritten rule in Washington that you should always use bullet points and try to limit them to three. Decision-makers simply don’t have time to read a long document looking for the main point.” However, you should attach supporting material such as statistical studies and articles or editorials.

**Follow-up**

Whether you’re doing advocacy by phone, letter, or personal visits, follow-up is an essential element of your activity. Always thank decision-makers for their time and for considering your position. Be absolutely sure to send thank-yous for favorable decisions, and also send letters politely expressing disappointment at unfavorable decisions. Follow-up is the key to continuing to build momentum as an advocate.
Using the media

Using the media is another important advocacy tool. Not only do decision-makers read the newspapers, watch television, and listen to the radio, but so do many other people in the public. Many times, media reports will stir up public outrage that spurs decision-makers to act.

A good example is the battle on Capitol Hill against the use of seclusion and restraints. The Hartford Courant ran a series of articles detailing the deaths of 142 people who had been restrained, many of them children. Soon afterward, members of Congress introduced bills into both houses restricting the use of seclusion and restraints. Sponsors of the legislation credited the Courant series with alerting them to the seriousness of the situation. Additionally, the publicity generated by the series spurred many phone calls from constituents: some were shocked by what they read, and some had personally experienced restraint but now felt that their legislators would be more understanding.

The easiest way to alert the media to a mental health issue is to issue an effective press release. It’s like a short news article—no more than 400 words, if possible. The body of the press release should begin by answering the five W’s: Who, What, Where, When, and Why. For example: “A group of people who have mental illnesses and their supporters will rally at the State Capitol on Monday, January 12, at 9 a.m. to demand that the Governor reinstate the funds cut from the budget for Mental Health Services.” In the body of the press release, you should include some background on the issues. You may also include some quotations from organizers of the event.

An effective press release should also follow standard form. It should be on your group’s letterhead, and underneath the letterhead (or typed address) should be the words, “Press Release.” Follow this with another line reading “For immediate release.” Next comes a headline, e.g., “Rights group to rally at State Capitol to protest mental health budget cuts,” and a dateline, including the city where your organization is located, or the city at which the event will take place. At the top, include one or two reliable contact people, who should remain available for comment.

You should direct your press releases to assignment editors at local media outlets, but once you develop relationships with reporters, you can send them the releases directly. Never send a release to more than one individual at any outlet. For daily newspapers, radio, and television, 24-hour advance notice is appropriate, but weekly papers obviously need longer.
Staging a demonstration

Excerpted from “Organize a demonstration to make your voice heard,” *The Key*, vol. 4 no. 1.

When action is desperately needed, and the media and decision-makers are not listening, it might be time to organize a demonstration. This means attracting as many people as possible—united in purpose and accompanied by flyers, picket signs, a bullhorn, and the media—to the same place at the same time.

“At the very least, collective actions boost participant’s self-esteem and sense of community, and increase public awareness of the problems we face,” says Joseph Rogers, Clearinghouse executive director. “At best, they can turn the system upside down.” Non-violent direct action (resulting in arrest) requires special considerations and legal counsel, but demonstrations can be extremely effective when they stay within the boundaries of the law.

You might have a year, or hours, to organize; the only difference should be the size of your crowd. While a cast of thousands will usually capture the most media attention, a small group may also accomplish its goal.

Although each demonstration will have different goals, different organization, and different methods, a number of rules guide any effective demonstration. The Clearinghouse can provide more in-depth technical assistance about organizing a demonstration, but here are some general guidelines.

1. **Determine your goal.** Your goal can be broad or specific, but keep in mind the relationship between the site/target of your demonstration and your goal.
2. **Frame your goal in positive terms.** Joseph Rogers believes, “It’s always better to demonstrate for something than against something.” He cites the successful example of demonstrating for a civilian police review panel rather than against police brutality.
3. **Be ready to negotiate.** In “Rules for Radicals,” Saul Alinsky writes, “the price of a successful attack is a constructive alternative.” If your opponent asks you for an alternative, you must be able to give one or you will lose your fight.
4. **Think of a gimmick.** If you can think of a clever twist for the demonstration, the media will be more likely to cover it.
5. **Choose a date, time, and place.** This is obvious, but choose wisely so as to maximize participation.
6. **Develop and disseminate a flyer.** Publicize the time, date, place, and purpose with all technologies, such as fax, e-mail, web sites, and old-fashioned methods too.
7. **Follow up with phone calls.** Call as many people as possible to join the event.
8. **Alert the Media.** Beforehand, send out a press release and bring press packets to bring to the event. At the event, assign a press liaison to look out for and meet with the media.
9. **Find out if you need a permit.** The First Amendment protects our right to demonstrate in public places, but your city or county can make reasonable permit regulations.

10. **Decide whether to notify the police.** Don’t antagonize the police and make a conflict the center of attention rather than the issue at hand.

11. **Write slogans and chants.** This will communicate your message and unify the participants.

12. **Make picket signs.** Try to communicate your message succinctly as possible.

13. **Develop a handout.** Provide written information both to participants (for more background) and passersby (to garner support).

14. **Follow through.** Call the press, especially if you have achieved goals or had a greater turnout than expected. Publicize any promises that were made to your group. Don’t lose your momentum: additional demonstrations might be necessary.

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**Constructing a coalition**

As the stakes get bigger in an advocacy issue, you might find that even a dedicated team of advocates is not able to accomplish its goals. Often, advocacy is effective only when individual advocates and advocacy groups band together in coalitions.

The obvious advantage to coalitions is that there is strength in numbers. Not only are more people available to do the work, but the presence of many voices gives more credence to the position in the eyes of the decision-makers. This is especially true when the coalition includes many types of groups and individuals.

Of course, the tricky part of coalitions is that not all groups will agree completely. For example, different groups might have different opinions of which types of conditions should benefit from parity. Furthermore, groups that cooperate on one issue will disagree passionately on others: for example, psychiatrists and consumers can join together to fight for parity, but might take opposite positions on legislation limiting the use of restraints.

Whenever possible, advocates should try to create coalitions. Even if organizations do not decide to participate, individual constituents may decide to do so. You might even feel that a group with whom you are associated has wrongly decided not to participate in a coalition.

Clearinghouse program director Marie Verna says, “Learning to compromise is an essential skill for advocates to learn. Consumers need negotiation skills to deal with policy-makers, legislators, and funding sources. Getting what you want requires give and take—and the ability to make it appear as though you’re giving more than you’re taking.”
When building a coalition, the obvious starting ground is mental health organizations, such as local AMI chapters, Mental Health Associations, DMDA chapters, and independent consumer associations. General disability groups and United Way chapters can also be helpful. Other groups to consider, depending on the issue, might include provider groups (doctors, social workers, nurses, etc.), bar associations, education associations, labor unions, and the American Association of Retired Persons.
Legal advocacy

Legal advocacy should be considered the last resort for systems change. Often legal advocacy is the only route for vindication of individual rights when a right already exists and someone is being deprived of that right.

Legal actions can also be a vehicle for making changes to the system. Some of the reasons that they should be considered a last resort are that they are time-consuming, require expert assistance, and are often bitter and draining experiences. Most importantly, a lawsuit might destroy chances of an amiable resolution, so you should make sure that no amiable resolution is available before you decide to use legal advocacy.

This is not to say that you should block legal advocacy from your mind. Chris Koyanagi, director of governmental affairs for the Bazelon Center, says, “When you can’t move the system, I think it’s an essential tool for advocacy.”

One type of lawsuit that can bring about widespread change is a class action suit. In such suits, particular persons are named as plaintiffs, but the suit is brought on behalf of other, unnamed people who are similarly situated to the named plaintiffs. For example, the Bazelon Center brought suit on behalf of consumers in several states, charging that the states had failed to provide necessary services. Although a successful suit will change the way that a state conducts its programs, Koyanagi stresses that you need a legal or constitutional basis for your suit. “Sometimes you may have a moral right, but if you don’t have a legal right, you can’t win.”

Although we all have the right to go into courts representing ourselves, legal advocacy is almost entirely the domain of lawyers, and so we’ll concentrate here on providing some ideas on where to find legal assistance. Some public interest law firms make their services available for no cost, and some private attorneys will do “pro bono” (free) work or work for a contingency fee (they get paid only if you recover money.)

The most obvious place to seek legal help is your local bar association. The bar can provide referrals to attorneys who will be willing to listen to you and help you to decide whether you have a legal basis to pursue a lawsuit. Their answer might not always be final, and you might not be able to find an attorney who is willing to take your case.

In such cases, if you think that you have a valid reason for bringing a lawsuit, you should approach a public interest law firm. The Bazelon Center is a national organization that primarily works with local advocacy groups and law firms. However, there are local resources in your state.

Each state has a Protection and Advocacy organization, which may be part of the state government or may be an independent organization. The federal Protection and
Advocacy for Mentally Ill Individuals (PAMII) Act mandates that each state maintain a “P&A.” Information about contacting your state’s P&A should be available in the blue pages of your local phone book, or you could also contact the National Association of Protection and Advocacy Systems (NAPAS), which is listed in Appendix B.

Other public interest groups doing work on behalf of consumers may exist in your community or state. For example, many law schools maintain public interest law firms that provide free services offered by faculty and students. Your state and local mental health organizations should be able to put you in contact with local public interest law firms.
A few final words: persistence

By now, you have much more information than you can digest. You can read a book about competitive bicycling, but you can’t get on a bike for the first time and use everything that you’ve learned. If you’ve taken the time to read this guide, then you are more politically involved than most Americans, so go out there and start advocating!

We’ll leave you with a few final words about persistence. Brian Coopper, NMHA Director of Consumer Advocacy, suggests one way to accomplish your advocacy goals is to use the “Chinese Water Torture.” Legend has it that by repeatedly dripping water drop by drop onto someone’s forehead, you can overcome the strongest resistance, even though a single drop of water creates only the slightest discomfort. What Coopper means by this analogy is that as an advocate, you should be persistent with the decision-makers and let them know that you’ll keep pushing for your issues until they agree with your requests.

Joseph Rogers, executive director of the Clearinghouse, has his own story about persistence. At a statewide meeting to discuss a $10 million initiative for the homeless, an official stated that two percent would be earmarked for homeless consumers. Rogers raised his hand and said, “the homeless mentally ill may make up as much as thirty to forty percent of the homeless people in our city.” Two percent changed to five percent, but Rogers shouted, “Five percent is not thirty percent!”

Eventually, the official increased the amount to thirty percent. “The amount was boosted because I kept raising my hand.” Persistence pays: if you don’t see results immediately, then you should continue trying. Consumer advocacy is an uphill battle, but it is one well worth fighting.
References


Appendix A

Federal Government Resources

White House

The President
The White House
Washington, DC 20500
http://www.whitehouse.gov

President’s Committee on
Employment of People with
Disabilities
1331 F Street NW, Suite 300
Washington, DC 20004
(202) 376-6200
(202) 376-6205 TDD
(202) 376-6219 FAX
http://www50.pcepd.gov

U.S. Congress—Senate

United States Senate
Washington, DC 20510
(202) 224-3121
http://www.senate.gov

Senate Committee on Appropriations
S-128 Capitol Building
Washington, DC 20510-6025
(202) 224-3471

Subcommittee on Labor, Health and
Human Services, Education, and
Related Agencies
Senate Committee on Appropriations
SD-186 Dirksen Senate Office Building
Washington, DC 20510-6034
(202) 224-7230

Senate Committee on Banking,
Housing, and Urban Affairs
SD-534 Dirksen Senate Office Building
Washington, DC 20510-6075
(202) 224-7391

Senate Committee on Finance
SD-219 Dirksen Office Building
Washington, DC 20510-6200
(202) 224-4515

Subcommittee on Health Care
Senate Committee on Finance
SD-219 Dirksen Office Building
Washington, DC 20510-6200
(202) 224-4515

Senate Committee on Health,
Education, Labor, and Pensions
SD-428 Dirksen Senate Office Building
Washington, DC 20510-6300
(202) 224-5375

Subcommittee on Children and
Families
Senate Committee on Health, Education,
Labor, and Pensions
SH-615 Hart Senate Office Building
Washington, DC 20510-6304
(202) 224-5800

Subcommittee on Aging
Senate Committee on Health, Education,
Labor, and Pensions
SD-428 Dirksen Senate Office Building
Washington, DC 20510-6300
(202) 224-5375

Subcommittee on Public Health
http://www.hhs.gov

National Council on Disability
1331 F Street, NW, Suite 1050
Washington, DC 20004-1107
(202) 272-2004
(202) 272-2022
(202) 272-2074 TTY
http://www.ncd.gov

Substance Abuse and Mental Health Services Administration
5600 Fishers Lane
Rockville, MD 20857
(301) 443-8956
http://samhsa.gov

Equal Employment Opportunity Commission
1801 L Street, NW

Washington, D.C. 20507
(800) 669-4000
(800) 669-6820 TDD
http://www.eeoc.gov

National Institute of Mental Health
National Institutes of Health
6001 Executive Boulevard, Rm. 8235, MSC 9669
Bethesda, MD 20892-9669
(301) 443-4513
http://www.nimh.nih.gov

Knowledge Exchange Network
Center for Mental Health Services
P.O. Box 42490
Washington, DC 20015
(800) 789-2647
(301) 443-9006 TDD
http://www.mentalhealth.org
Appendix B

National Mental Health Organizations

Advocacy/support organizations

National Mental Health Consumers’ Self-Help Clearinghouse
1211 Chestnut Street, Suite 1207
Philadelphia, PA 19107
(800) 553-4KEY (4539)
http://www.mhselfhelp.org

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314
(800) 969-NMHA
http://www.nmha.org

National Depressive and Manic-Depressive Association
730 N. Franklin Street, Suite 501
Chicago, IL 60610-3526
(800) 826-3632
(312) 642-7243 FAX
http://www.ndmda.org

National Association for Rights Protection and Advocacy
909 Echo Drive
Rapid City, SD 57702
(605) 399-9713
http://www.connix.com/~narpa/

Bazelon Center for Mental Health Law
1101 15th Street NW, Suite 1212
Washington, DC 20005
(202) 467-5730
http://www.bazelon.org

National Alliance for the Mentally Ill
200 N. Glebe Road, Suite 1015
Arlington, VA 22203-3754
(800) 950-NAMI
(703) 524 9094 FAX
(703) 516-7227 TDD
http://www.nami.org

Federation of Families for Children’s Mental Health
1021 Prince Street
Alexandria, VA 22314-2971
(703) 684-7710
http://www.ffcmh.org

National Association of Protection and Advocacy Systems, Inc.
900 Second Street, NE, Ste. 211
Washington, D.C. 20002
(202) 408-9514
http://www.protectionandadvocacy.com

American Self-Help Clearinghouse
St. Clare's Hospital
Denville, NJ 07834-2995
(973) 625-3037
http://mentalhelp.net/selfhelp

CONTAC (Consumer Organization & Networking Technical Assistance Center)
1036 Quarrier Street, Suite 208A
Charleston, WV 25301
(888) 825-8324
http://www.contac.org

National Resource Center on Homelessness and Mental Illness
262 Delaware Avenue
Delmar, NY 12054
National Empowerment Center
20 Ballard Road
Lawrence, MA 01843
(800) POWER 2 U
http://www.concentric.net/~Power2u

International Center for Clubhouse Development
425 West 47th Street
New York, NY 10036
(212) 582-0340
http://www.iccd.org

National Stigma Clearinghouse
275 7th Ave., 16th Floor
New York, NY 10001
(212) 255-4411

Provider groups

National Association of State Mental Health Program Directors
66 Canal Center Plaza, Suite 302
Alexandria, VA 22314
(703) 739-9333
http://www.nasmhpd.org

International Association of Psychosocial Rehabilitation Services
10025 Governor Warfield Parkway, Suite 301

Columbia, MD 21044
(410) 730-7190
http://www.iapsrs.org

National Association of Social Workers
750 First Street NE, Suite 700
Washington, DC 20002
(202) 408-8600
http://www.naswdc.org

American Medical Association
515 N. State Street
Chicago, IL 60610
(312) 464-5000
http://www.ama-assn.org

American Psychiatric Association
1400 K Street NW
Washington, DC 20005
(202) 682-6000
http://www.psych.org

American Psychological Association
750 First Street NE
Washington, DC 20002
(202) 336-5500
http://www.apa.org

American Nurses Association
600 Maryland Ave. SW, Suite 100-W
Washington, DC 20024
(800) 274-4ANA
http://www.ana.org
## Appendix C

**Advocacy Workbook**

1. **My United States Representative is:** ________________________________

   **Party affiliation:** __________________________ votes: pro-consumer anti-consumer neutral

   *Everyone in the United States has one Representative (or in territories, a non-voting delegate).*

<table>
<thead>
<tr>
<th>Washington office</th>
<th>Local office</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
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<tr>
<td>Phone:</td>
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<td>Fax:</td>
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<tr>
<td>E-mail:</td>
<td>E-mail:</td>
</tr>
<tr>
<td>Staffpersons’ names and titles:</td>
<td>Staffpersons’ names and titles:</td>
</tr>
</tbody>
</table>

2. **My first United States Senator is:** ________________________________

   **Party affiliation:** __________________________ votes: pro-consumer anti-consumer neutral

   *Two Senators represent each of the 50 states.*

<table>
<thead>
<tr>
<th>Washington office</th>
<th>Local office</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
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<tr>
<td>E-mail:</td>
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</tr>
<tr>
<td>Staffpersons’ names and titles:</td>
<td>Staffpersons’ names and titles:</td>
</tr>
</tbody>
</table>
3. My other United States Senator is: ________________________________

   Party affiliation: ______________________ votes: pro-consumer anti-consumer neutral

   **Washington office**
   Address: ____________________________
   Phone: ____________________________
   Fax: ______________________________
   E-mail: ____________________________
   Staffpersons’ names and titles: ________________________________

   **Local office**
   Address: ____________________________
   Phone: ____________________________
   Fax: ______________________________
   E-mail: ____________________________
   Staffpersons’ names and titles: ________________________________

4. The Governor of my state is: ________________________________

   Party affiliation: ______________________ votes: pro-consumer anti-consumer neutral

   **State capital office**
   Address: ____________________________
   Phone: ____________________________
   Fax: ______________________________
   E-mail: ____________________________
   Staffpersons’ names and titles: ________________________________

   **Local office**
   Address: ____________________________
   Phone: ____________________________
   Fax: ______________________________
   E-mail: ____________________________
   Staffpersons’ names and titles: ________________________________
5. My state Senator is: ___________________________________________________
   
   Party affiliation: ______________________ votes: pro-consumer  anti-consumer  neutral
   State capital office                        Local office
   Address:                                   Address:
   Phone:                                     Phone:
   Fax:                                       Fax:
   E-mail:                                    E-mail:
   Staffpersons' names and titles:            Staffpersons' names and titles:

6. My state Representative is: ____________________________________________
   
   Party affiliation: ______________________ votes: pro-consumer  anti-consumer  neutral
   State capital office                        Local office
   Address:                                   Address:
   Phone:                                     Phone:
   Fax:                                       Fax:
   E-mail:                                    E-mail:
   Staffpersons' names and titles:            Staffpersons' names and titles:
7. My mayor or commissioner is: ________________________________

Party affiliation: __________________________ votes: pro-consumer anti-consumer neutral

State capital office

Address: _________________________________

Phone: _________________________________

Fax: _________________________________

E-mail: _________________________________

Staffpersons’ names and titles: ______________________________________

Local office

Address: _________________________________

Phone: _________________________________

Fax: _________________________________

E-mail: _________________________________

Staffpersons’ names and titles: ______________________________________

8. My local representatives (e.g., city council) are:

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone number</th>
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</table>
9. State and local mental health authorities include:

I have checked:
- Local mental health authority
- State mental health planning council
10. Local advocacy resources include:

I have checked:
☐ State P&A
☐ Law schools
☐ Other groups