



National Mental Health Consumers' Self-Help Clearinghouse



“Knowledge is the key to open new doors”

Technical Assistance Guide

Advocacy and Recovery Using the Internet

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Introduction

The National Mental Health Consumers' Self-Help Clearinghouse has developed this Technical Assistance Guide for mental health consumers interested in using the Internet to help themselves and other consumers. We'll show how the Internet can be a powerful tool for recovery, advocacy, fighting stigma, and organizing self-help groups.

This Guide is not intended as an introduction to the Internet—thousands of such resources already exist, and we want to make this Guide as specific as possible. To get the most out of this Guide, you should be able to: (1) send and receive **e-mail**, (2) use a **web browser** like Netscape **Navigator** or Microsoft **Internet Explorer**, (3) follow **links** from web site to web site, and (4) use search engines such as **http://www.yahoo.com** and **http://www.hotbot.com**.

If you need assistance on Internet basics, call us at the Clearinghouse, (800) 553-4539, and we can put you in touch with some excellent resources. For example, the National Research and Training Center on Psychiatric Disability has produced an excellent booklet that covers all the Internet basics and also includes many mental health resources. (Call 312-422-8180.)

For those of you who know the basics, you also know that the Internet grows every second of every day, and that no matter how often we update this Guide, more resources will become available by the time you read this. Whenever we name specific resources, you should always keep in mind that you'll be able to find many others using search engines and links from other sites. The Internet is something that you learn by doing, so let's get going!

Managing Recovery

The many attractive features of the Internet make it a powerful recovery tool. The **worldwide web** has thousands of sites that provide information about diagnosis, treatment, traditional mental health providers, and alternative treatments. We consumers can use **newsgroups, message boards, chat rooms, and e-mail lists** to communicate with others who can share their experiences and offer us their support. We can also use the Internet to simplify tasks that we might find more difficult than others do, such as finding housing or looking for a job.

Every day we hear that the Internet is a revolutionary communications medium, but for us consumers, it is truly revolutionary. At the Clearinghouse, we know first-hand that mental illness can be an isolating experience at times. Our society has made it difficult for us to talk about our conditions even when we do feel like talking about them.

How does the Internet change this? First of all, we have anonymity. When it's tough for us to talk about our problems, we can look to the Internet as a way to communicate with others without having to reveal our identities. Second, it lets us quickly find others who understand what we're talking about. Finally, for a monthly fee, we can talk as much as we'd like to people around the world and look for all kinds of useful information.

Finding information on the worldwide web

Using the worldwide web to locate information has the advantages of being quick, fast, and inexpensive. Right from your desktop, you can search for information in thousands of newspapers and hundreds of medical journals, browse the Library of Congress catalog, and of course find information that is only available on the web.

Although the web is an excellent place to find information about diagnoses and treatments, you of course should use this information as a supplement, rather than a replacement, for professional and peer-run services. Fortunately, the web is also an excellent tool for locating these services.

If you are fortunate to have a choice of doctors or health plans, one way to look for a provider or health plan is to look for a compilation of ratings. For example, the magazine *U.S. News and World Reports* performs an in-depth study of health care providers each year and publishes its ratings at **<http://www.usnews.com>**. These ratings cover the best hospitals and HMOs, according to their studies. You can find information about a specific physician, e.g., training and prior disciplinary actions, through search services such as **<http://www.askmedi.com>**. Similar information may be available on your state medical board's web site. To find your state's medical board, go to **<http://www.docboard.org>**.

We at the Clearinghouse certainly recommend that you use the Internet to locate peer-run providers in your area. Thousands of consumer-run organizations serve communities in the United States. The easiest way to find one near you is to send us an e-mail at **info@mselfhelp.org** with your name, address, and phone number. To do your own search using the worldwide web, you might want to use a search engine (like **http://www.yahoo.com** or **http://www.hotbot.com**) or use the resources provided by the American Self-Help Clearinghouse at **http://mentalhelp.net/selfhelp**.

The American Self-Help Clearinghouse (which covers all types of self-help and is not affiliated with the publishers of this Guide) is part of a much larger and very valuable Internet resource, Mental Health Net, which is headquartered at **http://mentalhelp.net**. Mental Health Net is filled with descriptions of symptoms and treatments, and references to literature, but it is only one of many comprehensive mental health sites. Other comprehensive sites include iVillage's **http://www.onlinepsych.com**, the Center for Mental Health Services' **http://www.mentalhealth.org**, Dr. Philip Long's **http://www.mentalhealth.com**, and the former Surgeon General's **http://www.drkoop.com**.

When using the worldwide web for diagnosis and treatment information, you should look for as many sources as possible. Because the main cost of the Internet is buying the equipment and paying a monthly fee, cost should not limit the number of sites that you visit. Comprehensive web sites like Mental Health Net offer plenty of useful information, but any single web site can have an editorial bias. The best approach is to use search engines to look for different viewpoints and then decide for yourself what to believe and what not to believe.

You might also wish to do your own research rather than look at information that has been prepared for you. Our federal government has spent a lot of money creating Internet resources that allow the user to sift through a wide variety of information rather than reading a prepared presentation. For example, the Library of Congress allows you to search its catalog of several million books at **http://lcweb.loc.gov**. Using the National Library of Medicine's MEDLINE service, located at **http://www.nlm.nih.gov**, you can search several thousand biomedical journals and read the abstracts of articles for no charge.

If we continued to list resources for you, we'd never get to them all, and we'd take away another primary advantage to the worldwide web—that you can look from place to place until you find something that interests you. Start with the resources we've suggested, but discover new ones by using search engines and by following links from place to place.

The Internet as a mutual support tool

The Internet helps you to manage recovery in ways beyond using the worldwide web as a passive source of information. The Internet is a revolutionary support network because you can participate from home, can retain your anonymity, and talk to people throughout the world. Remember when you thought that you'd never meet another person who was like you and who understood you? You can get onto the Internet and immediately "meet" people who've been through many of the same struggles as you have. Not only can you benefit from their support, but you can also feel good that you are able to help others.

Some of the Internet tools that make such communication possible are newsgroups, message boards, chat rooms, and e-mail lists. Newsgroups, message boards, and chat rooms all are accessible through the worldwide web, and e-mail lists are available to anyone with e-mail.

We'll discuss how to use these four types of communication to your advantage as a recovery tool and show you how to access them using the worldwide web. No matter which type of discussion forum you choose to use, some basic rules should guide your conduct. First, never make any commercial advertisements. Second, making personal attacks (or **flaming**) is a part of the Internet, but we don't recommend that you participate because it defeats the purpose of mutual support. Third, send personal messages by individual e-mail, not in a public forum. There are other rules of "netiquette" that you can learn by trial and error, but following these three will make your life on the Internet much more productive.

Newsgroups

Of the various interactive methods of communicating over the Internet, the newsgroup is probably the most effective recovery tool. Newsgroups grew out of the **Usenet** section of the Internet, which is separate from the worldwide web, and your **Internet Service Provider (ISP)** might be able to provide you with **news reader** software that runs more quickly than your web browser does. If that last sentence confused you, ignore it and read on, because you can find the same newsgroups on the worldwide web.

Anyone with access to the worldwide web can go to one of two sources, **<http://www.deja.com>** or **<http://www.listz.com>**, and locate, read, and participate in many newsgroups relating to mental health topics—and just about every other topic under the sun. We could list some representative newsgroups for you, but you'd be better off going to one of the two sites mentioned and searching for the newsgroups that most interest you using the excellent search tools provided there.

News

groups are great both for asking questions and for sharing your own expertise. A newsgroup contains many **threads**, each of which is begun by a person **posting** a

question or comment. Anyone reading the newsgroup can post a response to any message in the thread. For example, suppose that you have been having a very difficult time relating to people at work because your depression has made interaction difficult. You could go to any of a number of depression newsgroups and ask how other people deal with co-workers. Supportive people who understand and relate to your situation are likely to respond.

Another area in which participating in a newsgroup can be helpful is discussing any medications that you are taking or are considering taking. Often when a doctor recommends taking a particular medication, the consumer is apprehensive about whether the medication will be effective and whether it will have any side effects. The newsgroup is the perfect forum to find out about others' experiences on a particular medication, as well as to share any positive or negative experiences that you've had. In fact, there are newsgroups dedicated specifically to medication, which you can find easily through deja.com or liszt.com.

Message boards

If you've been looking around on general mental health web sites already, you've probably seen links to message boards (also called "bulletin boards"). Message boards work similarly to newsgroups but don't seem to generate as much traffic; this is probably because newsgroups are older and are more accessible by people with slower computers. However, an advantage to a message board is that the person responsible for maintaining it can delete inappropriate postings such as commercial advertisements, off-subject comments, and personal attacks.

Almost every general mental health web site, regardless of who controls its editorial content, offers one or more message boards that allow consumers the opportunity to share their insights with each other. Mental Health Net has some active message boards at <http://forums.mentalhelp.net>, and other active message boards are located at <http://www.betterhealth.com/allhealth/boards> and <http://www.support-group.com/support.htm>.

Chat rooms

If you're looking for a type of discussion that is most like talking to other people in "real life," then you might want to try a chat room. In a chat room, you can talk to others about anything you'd like, but many people enjoy going to chat rooms dedicated to specific topics. Chat rooms dedicated to mental health do tend to be supportive, but remember that other types of chat rooms might be less friendly. As with newsgroups, you can access many chat rooms on the worldwide web, but your own ISP might have software that facilitates participating in chat rooms.

As you might imagine, a problem with chat rooms, as opposed to newsgroups and message boards, is that to get any information or support, someone must be participating in the chat at the exact time you are. This doesn't always work. As Ed Madara of the American Self-Help Clearinghouse puts it, "While newcomers usually romanticize about having real-time chat meetings, . . . much more mutual help is shared online through message boards than in real-time chat meetings." See <http://mentalhelp.net/selfhelp>.

You might find some excellent chat experiences, but don't get discouraged if people aren't available in chat rooms. One way to increase your chances of finding people with whom to chat is participating in the scheduled chats offered by sites such as <http://www.support-group.com>, <http://www.drkoop.com>, and <http://mentalhelp.net>. Scheduled chats are generally moderated by an individual and often have "special guests," similar to a call-in radio or television show.

As with any type of discussion group, you're better off finding a chat room that suits your needs and personality than just following our suggestions. If you'd like to look for additional chat rooms, go to a search engine like <http://www.yahoo.com> and type "mental health chat." You'll be surprised at how many hits you get, but remember that chats are only successful when enough people find them and are using them at the same time.

E-mail lists

If you have e-mail, you can "subscribe" to any of thousands of e-mail lists that automatically send messages to your e-mail inbox. Even if you rely on the library for Internet access, you can get a free e-mail address at <http://www.hotmail.com>. Lists vary in their accessibility: some restrict their membership; some only allow messages approved by the list manager; and some allow anyone to join and send messages to the group.

The advantage to joining mailing lists is that you receive messages automatically without having to look for them. However, this very feature can have a downside: as you join more mailing lists, your inbox might fill to capacity with messages that you don't have any time to read. Therefore, we suggest discretion in joining e-mail lists. Mailing lists are a much more powerful tool for advocacy (which we'll discuss later) than for recovery; however, you might want to browse the catalogs of mailing lists at <http://www.liszt.com> and <http://www.onelist.com>.

Using the Internet to make your life easier

Most of us know that the "little things in life" can put more of a burden on us when we're in recovery. If you are lucky enough to have Internet access, you probably already realize

that the Internet can make your life easier, giving you more time to concentrate on recovery.

Some of the little things for which the Internet is particularly useful include finding out information from your health insurer, getting tax forms, shopping from home, and others too numerous to mention. You can also have *fun* with the Internet and use it to follow sports teams, read poetry, learn about dinosaurs, and find out about almost anything you can imagine. On a more serious level, the Internet also simplifies two tasks that have traditionally been a barrier to recovery: finding a job and locating housing.

The Internet has made finding a job much easier and much less intimidating. Although we consumers still have many challenges to face as we seek employment, the Internet can simplify both looking for a job and getting hired.

Job-hunting is one of the most popular uses of the Internet, and web sites designed specifically for job seekers have sprung up everywhere. The biggest sites that list jobs nationwide are <http://www.careerbuilder.com>, <http://www.careermosaic.com>, <http://www.hotjobs.com>, and <http://www.careermart.com>. If you are looking for a job in a particular area, most big city newspapers have searchable job listings, and you can find just about any city's newspaper by going to <http://www.yahoo.com> (or another search engine) and typing in "newspaper" and the name of the city.

As a consumer, you might want to check out resources that list jobs that might be perfect for you. The Clearinghouse web site, <http://www.mhselfhelp.org>, has frequently-updated listings of job opportunities for consumers, and local nonprofits in your community might also have job listings on their web sites. The job hunting web sites are great, but you can expand your opportunities by exploring with a search engine.

Once you have an interview scheduled, you must be prepared for it, and the web is an excellent place to locate information about your prospective employer. Obviously, the first step is to look for the prospective employer's web site, if you don't already know its address. Either way, you should go to a search engine and do a search under the employer's name to see what type of interesting information pops up. You can also find information about an employer very easily if the local newspaper has a searchable index of past articles.

Another way to make your life easier is looking for housing using the Internet. Again, newspapers in most big cities have searchable housing ads, but as consumers, we often have more complicated housing needs than the general public. Conducting searches on the web is an excellent way to locate groups that assist people in finding housing. Another way to start is looking for assistance on your local United Way web site, which you can locate through <http://www.unitedway.org>.

Advocacy online

As a powerful research and communications tool, the Internet has already made an enormous impact on the mental health consumer movement. Advocates in the movement have been using the worldwide web to locate information about legislators and other decision-makers, as well as to locate information that supports their positions and keep tabs on their legislative adversaries. Consumers have also developed their own web sites to publicize and strengthen their advocacy efforts, and have begun to use e-mail lists as a powerful tool for linking advocates and announcing developments.

Locating government resources

Advocacy means influencing decision-makers, and the first step in becoming an advocate is to find out the identities of the parties making the decisions that affect you. Another Clearinghouse Technical Assistance Guide, *Systems Advocacy*, which is available at <http://www.mhselfhelp.org>, explains the various categories of decision-makers who impact consumers. That Guide also contains a workbook that allows you to record contact information for state mental health agencies, state legislators, federal legislators, and other decision-makers. Here, we'll show you how to gather contact information for elected and unelected officials, and you can do yourself an enormous favor by using the workbook as a convenient place to record information.

At the front line of the decision-making process are the providers who actually interact with consumers. Although providers act individually to a large extent, provider groups also can play a large role in shaping the way that professional providers interact with consumers. Many advocates therefore include provider groups as targets for their educational campaigns. You can locate your state medical board through <http://www.docboard.org>, and the American Medical Association (AMA) is located online at <http://www.ama-assn.org>. Other professional groups are easily located with search engines like <http://www.yahoo.com> and <http://www.hotbot.com>.

Consumer advocates should gain an understanding of the decision-making process in the public health system, which contains local, state, and federal components. The federal agency responsible for the Medicare program and partially responsible for state Medicaid programs is the Health Care Financing Administration (HCFA), <http://www.hcfa.gov>.

From state to state, the parties responsible for Medicaid decisions and other public mental health programs vary widely, but the confusing search for decision-makers can be simplified greatly by using the web. A good place to start looking for state mental health agencies is the National Association of State Mental Health Program Directors, <http://www.nasmhpd.org>. You can find contact information for a wider variety of

decision-makers in the State Resources Guides located at <http://www.mentalhealth.org/publications>.

State legislatures are also important, and most, if not all, states have developed web sites for their legislatures. You can find your state legislature’s web site most easily by searching for “state government” and your particular state at <http://www.yahoo.com>. State legislatures’ web sites generally allow you to find out the identity of your personal representatives in each house of the legislature.

Fortunately for advocates, the United States Congress has developed excellent web sites, <http://www.house.gov>, <http://www.senate.gov>, and <http://thomas.loc.gov>. The latter web site can be used to track any pending legislation in either house. Not only do the Congressional web sites offer you the opportunity to confirm the identity of your Representative and two Senators, but they also allow you to find out vital information such as committee membership.

Committee membership is an important concern for consumers interested in federal legislative advocacy: almost every bill must work its way through subcommittees and committees before it can become law. The web sites of some of the important committees and subcommittees are listed in Table 1.

Table 1. Important committees and subcommittees in the U.S. Congress	
Selected House committees	
Appropriations Committee, Subcommittee on Labor, Health and Human Services, and Education	http://www.house.gov/appropriations
Banking and Financial Services Committee, Subcommittee on Housing and Community Opportunity,	http://www.house.gov/banking
Committee on Commerce, Subcommittee on Health and Environment	http://www.house.gov/commerce
Committee on Ways and Means, Subcommittee on Health and Subcommittee on Social Security	http://www.house.gov/ways_means/

Selected Senate committees	
Finance Committee, Subcommittee on Health Care	http://www.senate.gov/~finance
Appropriations Committee, Subcommittee on Labor, Health and Human Services, and Education	http://www.senate.gov/~appropriations http://www.senate.gov/~appropriations/labor
Committee on Health, Education, Labor, and Pensions, Subcommittee on Children and Families, Subcommittee on Public Health, and Subcommittee on Aging	http://www.senate.gov/~labor
Committee on Banking, Housing, and Urban Affairs	http://www.senate.gov/~banking

Consumer advocates working on the federal level should not underestimate the policy work done by federal agencies. In addition to HCFA, which we've already discussed, some important federal agencies are listed in Table 2.

Table 2. Selected federal agencies' web sites	
Department of Housing and Urban Development	http://www.hud.gov
Department of Health and Human Services	http://www.hhs.gov
National Council on Disability	http://www.ncd.gov
Substance Abuse and Mental Health Services Administration	http://www.samhsa.gov
Equal Employment Opportunity Commission	http://www.eeoc.gov
National Institute of Mental Health	http://www.nimh.nih.gov
Center for Mental Health Services	http://www.mentalhealth.org

Don't forget the White House as an arena for federal advocacy. The White House maintains a web site at <http://www.whitehouse.gov>, and the President's Committee on Employment of People with Disabilities is located at <http://www50.pcep.gov>.

Advocacy groups on the Internet

As you know, you are not alone in the consumer movement, and you are not the only consumer interested in advocacy. Many advocacy groups have established web sites, which allow them to publicize their activities to the general public and to potential advocates, educate the general public and decision-makers about the issues, raise money through donations, and make contacts with others in the movement.

If you are interested in becoming involved with an advocacy group, and even if you are already involved but are curious about other groups, you can e-mail us at the Clearinghouse, info@mhselphelp.org, and we'll be happy to put you in touch with advocacy groups working in your area. The worldwide web is another excellent source of information about existing advocacy efforts. As always, we'll point you in the right direction but recommend that you do your own searching as well.

Advocacy groups on the worldwide web

Web sites of national organizations are an excellent source of advocacy information. This holds true even if you do not share the same beliefs as the national organization; you can visit their sites to learn about some of the issues coming up in the state and federal legislatures and draw your own conclusions. One national organization that has an excellent web site explaining current mental health advocacy issues is the Bazelon Center for Mental Health Law, <http://www.bazelon.org>. A great advocacy web site run by consumers, survivors, and ex-patients is <http://www.madnation.org>.

In addition to information about current issues, the web sites of national membership organizations can provide links to affiliates in your area. Some examples are the National Mental Health Association (NMHA), <http://www.nmha.org>; the National Alliance for the Mentally Ill (NAMI), <http://www.nami.org>; and the National Depressive and Manic-Depressive Association (NDMDA), <http://www.ndmda.org>.

You might also wish to locate your local protection and advocacy group, which each state maintains under federal law to protect the rights of mental health consumers. You can find your state affiliate through the National Association of Protection and Advocacy Systems (NAPAS), at <http://www.protectionandadvocacy.com>. Other local resources are found in the Center for Mental Health Services State Resources Guides at <http://www.mentalhealth.org/publications>.

Some advocacy organizations also make general advocacy resources available on their web sites. In addition to our Technical Assistance Guide, *Systems Advocacy*, available at <http://www.mhselphelp.org>, many other resources can be found on the web. For example, Independent Sector, which advocates for non-profit groups generally, has an excellent guide to federal advocacy, *The Nonprofit Lobbying Guide*, available at <http://www.independentsector.org>.

Action alerts and other e-mail lists

The web sites of many advocacy groups also offer possibly the most valuable advocacy resource on the Internet: action alerts. Advocacy groups often offer alerts about pending

legislation, court decisions, funding decisions, and other issues affecting consumers. These alerts also generally offer advice on how to contact decision-makers and how to persuade them about the issues.

Traditionally, organizations offered action alerts by fax or phone, and thus economic restraints limited the number of people contacted. With the creation of e-mail lists for advocacy topics, organizations can reach an unlimited number of people very inexpensively. As a consumer interested in advocacy, you would be wise to sign up for as many action alert e-mail lists as you think is manageable; even if you don't always agree with the positions put forward in the alerts, you'll increase your awareness of the issues. You can find action alerts on the web sites of the Bazelon Center, NMHA, NAMI, and NDMDA.

As an advocate, you can benefit from joining other types of advocacy e-mail lists. An action alert can be very useful, but it sums up an organization's position on a major issue. By joining other advocacy lists, you can read the opinions of other advocates, as well as learn about a wider variety of issues.

In some e-mail lists, only the list manager can send messages to subscribers. For example, the Clearinghouse has a mailing list (called "The Key") that we use to alert subscribers to important social issues. You can subscribe to this list at <http://www.mhselfhelp.org>, and you can find out about our other mailing lists by contacting us at info@mhselfhelp.org.

Other e-mail lists allow networks of consumer/survivor/ex-patient (CSX) advocates to communicate with each other. One example of a very busy activism e-mail list is "Act-Mad." You can join Act-Mad through the web site of the Madness Group, <http://www.peoplewho.net/Madness>, which also offers the opportunity to join other, more specialized mailing lists. (People Who Net, a CSX-run group, offers many other Internet resources in addition to the Madness Group.)

When you follow the Act-Mad link from the Madness Group's home page, you will also be offered the opportunity to join e-mail groups for advocates in individual states. By joining a list in your state, you can learn about the issues in your state's legislature, as well as network with other consumer advocates in order to form coalitions.

The Clearinghouse can't overstate the importance of these e-mail lists; we've helped to create electronic networks of consumer advocates nationwide. Even if you do not yet consider yourself an advocate, you can benefit from reading what others write, and you can then get involved at your own pace. The consumer movement needs your voice!

As you become more comfortable with your role as a consumer advocate, you will find that you are using these e-mail lists to provide information as much as you are to receive it. Other advocates will be grateful to hear about your involvement with state and local

issues: even though laws differ from place to place, the issues are often the same, and other advocates can use the work you've done to protect consumers where they live.

If you'd like to become even more involved in the consumer movement, you can start your own e-mail list. If you have an idea for a specialized or localized mailing list, you can propose a new list to People Who Net, at <http://www.peoplewho.net/add>. You can also start a mailing list for free, on any topic, at <http://www.onelist.com>.

Researching mental health issues

We've already discussed some of the ways to locate mental health information on the worldwide web, but it's worth reminding you that the web is also a great place to look for information for advocacy purposes. As a consumer advocate, you are fighting a noble battle, but decision-makers also want you to have facts to back up your advocacy. Many of the general mental health web sites that are excellent recovery resources also provide information that will be helpful to your advocacy efforts.

Mental health advocacy organizations often put information supporting advocacy efforts on their web sites. For example, several independent studies have concluded that insurance parity (equal coverage for mental health services) would not raise insurance costs significantly, and national organizations have posted these studies on their web sites.

You might be surprised at the type of information that you can find to assist your advocacy efforts. For example, a news story might cover a successful effort to train police officers in responding to mental health crises. You could use such a story to bolster your efforts to institute such a program in your community. Places to search for news stories include <http://www.cnn.com>, <http://www.nytimes.com>, and other big-city newspapers. You can also e-mail the Clearinghouse at info@mhelp.org to request materials from our consumer library.

If you don't think that you'll have time to surf the web looking for mental health issues (not an unreasonable thought), you might want to consider trying a "clipping" service, such as <http://www.handsnet.org>. Clipping services will search selected web sites and then e-mail you the results of their searches. Handsnet charges an annual fee, but does offer a 30-day free trial. You could try this service for a month as a way to familiarize yourself with the types of resources available on the web.

Fighting Stigma

The stigma that our society places on mental illness has always been a major struggle. Stigma has shaped the treatment of mental illnesses and has resulted in treatments more akin to incarceration than rehabilitation. It has made employment and fair housing far less accessible to consumers. It has made people less willing to seek treatment, and perhaps worst of all, it has given many consumers attitudes that defeat recovery.

The modern media too often reinforces stereotypes that consumers are violent and unable to recover to lead productive lives. News programs unfailingly point out a criminal suspect's psychiatric history whether or not it is related in any way to the crime.

For many years, consumers have organized initiatives to identify and respond to stigmatizing portrayals in the media. Access to the Internet can help you to join in this initiative; you can locate existing efforts, police the media, and contact other concerned people.

Stigma resources on the worldwide web

If you would like to help fight stigma, the consumer movement needs your help. The worldwide web is very useful for learning about stigma, as well as locating the factual information you can use to fight stigma.

Whether you are new to the consumer movement or are an experienced advocate, you can find useful background resources on the web. The Clearinghouse publication *Fighting Stigma* is available at <http://www.mhselfhelp.org>, and if you'd like additional resources, you can e-mail for technical assistance at info@mhselfhelp.org. The National Stigma Clearinghouse has a web site at <http://community.webtv.net/stigmanet>. Other web sites with many stigma resources include <http://mentalhelp.net>, <http://www.nmha.org>, and <http://www.mentalhealth.org>.

The web also provides you with the factual information you need to respond to stigmatizing portrayals. For example, whenever a news program or editorial portrays people with mental illnesses as violent, you can respond that statistics available from the MacArthur Foundation at <http://ness.sys.virginia.edu/macarthur/> show that:

The prevalence of violence among people who have been discharged from a hospital and who do not have symptoms of substance abuse is about the same as the prevalence of violence among other people living in their communities who do not have symptoms of substance abuse.

You can use the web to find other studies supporting your point about violence. You'll also be able to search for information to support other points you'd like to make to the media.

Policing the media

The worldwide web's "searchability" also makes it an excellent resource for locating stigmatizing incidents in the media. The same journalistic resources—like **<http://www.cnn.com>** and **<http://www.nytimes.com>**—that can provide great information for advocacy initiatives nonetheless should be monitored for unfair portrayals of mental illness.

Previously, stigmatizing incidents could be identified only if a concerned person happened to see or hear the portrayal, but whenever you are visiting a news site, you can spend a few moments searching for terms such as "crazy," "mental patient," "insane," and similar labels. You can also monitor entertainment sites such as **<http://www.etonline.com>** and **<http://entertainment.yahoo.com>**. Many advocacy groups report incidents of stigma on their web sites, including **<http://www.nmha.org>** and **<http://www.nami.org>**.

The Internet also helps you *after* you discover an example of stigma in the media, whether by web search or traditional methods. You can use e-mail networks to report the incident to other advocates, as well as anyone you know who might share your intolerance for stigma. You can also use e-mail to communicate incidents to national advocacy organizations such as the NMHA. National advocacy groups can use their advocacy expertise to contact the offending party, and can also widely disseminate reports of the incident.

Some people would argue that policing the media is akin to censorship, but that argument fails. Censorship is government suppression of free speech. What you are doing is exercising your right to free speech: when a media organization spreads misinformation about consumers, you are exercising your civil rights by responding and trying to educate the public about the truth.

Starting a Self-Help/Advocacy Group

For many years, the Clearinghouse has provided technical assistance to individual consumers interested in starting support and advocacy groups in their communities. The Internet has facilitated our technical assistance, which we routinely provide through our web site, <http://www.mhselfhelp.org> and by e-mail, info@mhselfhelp.org. More importantly, the Internet can greatly simplify and improve the process of starting a self-help group.

If you'd like to know a little more about the basics of starting a self-help group, you should look at our technical assistance publication, *How to Start a Self-Help/Advocacy Group*, at <http://www.mhselfhelp.org>. You might also wish to contact the Clearinghouse for a copy of our *Nuts and Bolts* Technical Assistance Guide, which provides even greater detail. Here, we'll discuss how the Internet simplifies the steps of creating a self-help/advocacy group in your community.

Background research

Before you begin work on starting your own self-help/advocacy group in your community, you should find out whether your community already has any such groups. You might be surprised at the answer: traditionally consumer-run groups have not had the resources to publicize their activities as much as they'd like.

The Internet can greatly simplify your search for self-help groups in your area. You can e-mail us at the Clearinghouse, info@mhselfhelp.org, for access to information about consumer-run groups and services nationwide. You can also use the web to locate groups in online databases maintained by the American Self-Help Clearinghouse, <http://mentalhelp.net/selfhelp>, and the Center for Mental Health Services, <http://www.mentalhealth.org/databases>.

If your background research locates existing self-help groups in the community, you should look into these groups. Do they represent your needs? Could you establish a program with their help? You should not let your motivation and enthusiasm be lowered by the existence of self-help groups; rather, you should use this as motivation to help establish more services, whether in conjunction with existing groups or on your own. You might wish to consult our Technical Assistance Guide, *Nuts and Bolts*, for further guidance on affiliating with existing organizations.

Existing self-help groups, even those not designed specifically for mental health consumers, can be an excellent source for answering some of the logistical questions involved in starting a self-help group. For example, when you're searching for a meeting place, you might ask the local Alcoholics Anonymous group where they meet. Other self-

help groups are usually helpful, but if you don't find this to be the case, you can use the web to locate community resources on your own.

Your web search for a meeting place will differ depending on the size of your community. In a large metropolitan area, your local government might maintain a list of community meeting places, and there might even be a web network of local nonprofit groups. In a smaller area, you can use the online yellow pages at <http://www.yahoo.com> to search for churches and community centers and contact them to find out whether they offer meeting space. You'll find these resources will continue to be helpful as your group grows and expands its activities.

Publicizing your meetings

The Internet should be viewed not as a way to publicize your meetings, but as a way to provide additional publicity. You should rely primarily on traditional methods such as placing notices in newspapers' community listings, and getting permission to post flyers in community mental health centers, doctors' offices, churches, unemployment offices, laundromats, etc. The Clearinghouse's other technical assistance guides provide more detailed publicity suggestions.

Obviously, the more people that you interest in your self-help group, the more successful it will be, and the Internet should be used as a tool to attract as many additional people as possible. If your local newspaper has a community bulletin board on its web site, make sure that it includes your meetings. If you participate in any online chats, newsgroups, or message boards that you think have a following in your local community, you should consider communicating about your project. You should explain why you think it's important for consumers to start self-help groups and end with an announcement of your meeting; that way the message will have general interest to those who don't live near you.

E-mail is an inexpensive way of publicizing your meetings, but of course this assumes that you have the e-mail addresses of people who might be interested in participating. You might consider using an e-mail list to publicize your meeting, but it is probably better to communicate with the list's manager before announcing a meeting. You can usually find out how to communicate with a list's manager on the same web site that explains how to subscribe to the list.

Consumer-run drop-in centers and other ongoing projects

As you become more involved in the consumer movement, you might be the type of person who organizes projects that are more involved than your basic support group. As your projects become more ambitious, the Internet will become even more helpful to you.

Perhaps the best example of an ongoing consumer-run project is a drop-in center, which provides a supportive environment for consumers and is especially valuable on evenings and weekends, when other community services might not be available. Drop-in centers offer a wide range of activities, from support meetings and fun get-togethers to job training and advocacy workshops. A more complete picture is provided in the Clearinghouse guide *Consumer-Run Drop-In Centers* at <http://www.mhselfhelp.org>. If you are serious about starting a drop-in center, it would be a good idea to contact the Clearinghouse personally at info@mhselfhelp.org for more in-depth technical assistance.

However, drop-in centers are only one of the many types of full-time organizations that consumers have been organizing in recent years. Another great example is the clubhouse, which operates on a membership model and provides employment and housing services to its members. (To find out more about clubhouses, contact the Clearinghouse or check out <http://www.iccd.org>.) There is no end to the types of consumer-run services that are possible, including crisis response programs, peer case management, and any of a wide variety of small businesses.

Here, we'll discuss how the Internet makes it easier for consumer groups to start and operate drop-in centers and other peer-run services. Operating such a program is a valuable and rewarding experience, but also a very complicated process. In addition to the considerations for starting a "part-time" self-help group, a group wishing to start a more ambitious project must think about securing ongoing funding, promoting activities, and dealing with business considerations.

Obtaining funding

Obtaining funding is a significant challenge for any group wishing to start a drop-in center or other ongoing consumer-run project. Traditionally, this could be subdivided into two challenges: first locating money that is available, and then successfully competing for that money.

The Internet greatly simplifies the first of the challenges by making it much easier for you to find sources of funding. It still requires a lot of hard work, but the search capabilities of the worldwide web, together with some great existing resources, make the job easier.

You might wish to start out by going to <http://www.fundsnetservices.com>. Using this web site, you can locate grantmakers operating in your state. You can then follow links to individual organizations. Other sites with links to funding sources include <http://www.granted.org>, <http://www.tgci.com>, <http://fdncenter.org>, and <http://www.findit.org>.

Using these index sites and traditional search engines, you should be able to find a great number of funding opportunities, but you still must face the second challenge of securing the funding that is available. The Clearinghouse offers a Technical Assistance Guide, *The Art and Science of Writing Grant Proposals That Win*, which you can request by contacting us. You can also locate general grant-writing information online at web sites such as <http://www.findit.org>, <http://fdncenter.org>, and by searching for “writing grant proposals” on search engines like <http://www.yahoo.com> or <http://www.hotbot.com>.

Publicizing activities

As with starting any consumer-run group, the Internet should be considered as an adjunct to other means of publicity. In addition to the methods we’ve already discussed, your ongoing organization might want to consider using e-mail lists and a web site to publicize its activities.

E-mail is an excellent way to publicize activities, but it relies on having access to the addresses of interested parties. From the beginnings of your organization, you should maintain a list of contacts in whatever means possible, and you should always collect e-mail addresses. E-mail may not be the *best* way to get people’s attention, but if you’re already on the Internet, then e-mail is the cheapest way to reach people.

If you’re just starting out and only have a few people interested in your organization, you can manually send e-mails to everyone, or create a group list within your e-mail program. As your organization grows, you might consider creating automated e-mail lists through a service such as <http://www.onelist.com>.

If you are going to use e-mails to publicize your activities, remember some general courtesy. People tend to receive a lot of e-mails, so you should try to keep your message brief and to the point. Also, provide as much contact information as possible, in case your recipients share the message with people not connected to the Internet.

As your organization grows, you might also consider establishing a web site to publicize your activities. Building a presence on the web involves three steps: (1) creating and maintaining your site, (2) finding a host for your site, and (3) publicizing the site itself.

Describing how to create your own web site is beyond the scope of this Guide, but there are many free resources available on the web. You can start with tutorials offered by the

Library of Congress, <http://lcweb.loc.gov/global/html.html>, or the Worldwide Web Consortium, <http://www.w3.org>. Also, searching for “web tutorial” on a search engine will produce hundreds of hits.

If you are planning to put up a simple web site, then you should have no problem locating a place that will host your site for free (probably in exchange for putting ads on your pages). In fact, you or another organization member might be able to obtain free server space for the web site from your personal ISP. Another option is to search for free web site services such as <http://www.fsn.net>.

Publicizing your site takes hard work, but the work will pay off as more people visit. Begin with the obvious: *everything* you send out should contain your web site’s address, including e-mail, posts to newsgroups, flyers, press releases, faxes, and so on. Another way to generate publicity is to participate in link exchanges. Go to other mental health web sites and follow the link allowing you to e-mail the site’s **webmaster**. Offer to establish a link to the other site and ask if your site’s address could be included in the other site. Contact as many sites listing mental health groups as possible.

Business considerations

Running a drop-in center or other ongoing “full-time” organization is in many ways like running a business. You’ll probably find that issues such as budgeting, staffing, insurance, and maintenance divert your attention from your primary purpose of helping consumers.

Fortunately, the Internet is an excellent way to find solutions to some of your everyday operational concerns. For example, you might be able to find volunteer or reduced-rate legal services through your local bar association, which you can locate through the American Bar Association (ABA), <http://www.abanet.org>. Similarly, you can visit the web site of the Public Interest section of the American Accounting Association (AAA) at <http://www.rutgers.edu/Accounting>.

General nonprofit service groups are another resource for locating advice and assistance for running your group. Some of these sites that we’ve already discussed include <http://fdncenter.org>, <http://www.findit.org>, <http://www.unitedway.org/websites>, and <http://www.independentsector.org>.

Useful resources

This Technical Assistance Guide has provided enough information for you to get started using the Internet to help yourself and advance the consumer movement, and we've certainly provided enough information to keep you busy for a while! All of the web sites we've discussed are contained in this directory of resources, and you can use these web sites to locate e-mail lists, newsgroups, message boards, and chat rooms. If you have any questions, please contact the Clearinghouse at info@mhelp.org for further technical assistance. Good luck!

Mental Health/General Health

Mental Health Net
<http://mentalhelp.net>

iVillage
<http://www.onlinepsych.com>

Internet Mental Health
<http://www.mentalhealth.com>

Dr. Koop
<http://www.drkoop.com>

Better Health
<http://www.betterhealth.com>

Support-Group.com
<http://www.support-group.com>

National Mental Health Organizations

National Mental Health Consumers' Self-Help Clearinghouse
<http://www.mhelp.org>

Bazelon Center for Mental Health Law
<http://www.bazelon.org>

Mad Nation

<http://www.madnation.org>

People Who Net

<http://www.peoplewho.net>

The Madness Group

<http://peoplewho.net/Madness>

National Stigma Clearinghouse

<http://community.webtv.net/stigmanet>

National Mental Health Association

<http://www.nmha.org>

National Alliance for the Mentally Ill

<http://www.nami.org>

National Depressive and Manic Depressive Association

<http://www.ndmda.org>

International Center for Clubhouse Development

<http://www.iccd.org>

MacArthur Research Network on Mental Health and the Law

<http://ness.sys.virginia.edu/macarthur>

National Association of State Mental Health Program Directors

<http://www.nasmhpd.org>

National Association of Protection and Advocacy Systems

<http://www.protectionandadvocacy.com>

Government Resources

Knowledge Exchange Network

(Center for Mental Health Services)

<http://www.mentalhealth.org>

Library of Congress

<http://lcweb.loc.gov>

MEDLINE
(National Library of Medicine)
<http://www.nlm.nih.gov>

Thomas: Legislative Information on the Internet
(Library of Congress)
<http://thomas.loc.gov>

The White House
<http://www.whitehouse.gov>

U.S. Senate
<http://www.senate.gov>

U.S. House of Representatives
<http://www.house.gov>

Health Care Financing Administration
<http://www.hcfa.gov>

President's Committee on Employment of People with Disabilities
<http://www50.pcepd.gov>

Other useful sources of information

Cable News Network
<http://www.cnn.com>

New York *Times*
<http://www.nytimes.com>

U.S. News and World Report
<http://www.usnews.com>

American Bar Association
<http://www.abanet.org>

Medi-Net
<http://www.askmedi.com>

Administrators in Medicine
<http://www.docboard.org>

American Medical Association
<http://www.ama-assn.org>

American Self-Help Clearinghouse
<http://mentalhelp.net/selfhelp>

United Way
<http://www.unitedway.org>

Independent Sector
<http://www.independentsector.org>

Funds Net
<http://www.fundsnetservices.com>

Community Resource Institute
<http://www.granted.org>

The Grantsmanship Center
<http://www.tgci.com>

The Foundation Center
<http://fdncenter.org>

FindIt.org
<http://www.findit.org>

Entertainment Tonight
<http://www.etonline.com>

Yahoo! Entertainment
<http://entertainment.yahoo.com>

Online tools

Deja
<http://www.deja.com>

Yahoo!
<http://www.yahoo.com>

CE-CREDIT.com
Your Continuing Education Resource

hotbot
<http://www.hotbot.com>

Liszt
<http://www.liszt.com>

ONElist
<http://www.onelist.com>

Hotmail
<http://www.hotmail.com>

Library of Congress Web Site Tutorial
<http://lcweb.loc.gov/global/html.html>

Worldwide Web Consortium
<http://www.w3.org>

Career Builder
<http://www.careerbuilder.com>

Career Mosaic
<http://www.careermosaic.com>

Hot Jobs
<http://www.hotjobs.com>

Career Mart
<http://www.careermart.com>

Hands Net
<http://www.handsnet.org>