



Psychiatric
Rehabilitation
Association

Advocating for Rehabilitation and Recovery

A Technical Assistance Manual for the Psychosocial Rehabilitation Advocate



Introduction

Today more than ever consumers and providers in psychosocial programs must be more aggressive about approaching key decision makers on mental health issues. The rule that “in politics all defeats and victories are temporary” has never been more true than today. We won the deinstitutionalization battles over 30 years ago, yet today we still hear some people questioning the value of that effort. We thought that the abuses in state and private psychiatric hospitals were a thing of the past, yet today our newspapers and news programs are telling us of new horrors. Ten or fifteen years ago few people understood the ramifications of managed care but today we are all affected by this new form of health care administration. Just because we believe that PSR programs should thrive does not mean that decision-makers will agree.

The goal of this Technical Assistance Manual on Advocacy is to help program personnel, consumers, and all interested parties become familiar with some of the basics of advocacy. We know that the range of advocacy expertise in our field varies widely and this made the task of preparing the Manual a difficult one. Yet we hope that even the most experienced advocate can find useful information in the Manual or use it in training for individuals just learning the ropes.



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Section One: Advocacy

Almost all community-based mental health services like psychosocial rehabilitation programs, Clubhouses, peer support programs, Lodge and ACT programs rely mostly if not entirely on public funding. If the people we serve every day are to benefit from our services, then you need to let your state and federal legislators know what it is you do, who it is you serve, how it gets paid for, and what might happen if it doesn't get paid for.

WHAT IS ADVOCACY?

Advocacy is the simple job of telling your story to the people who make the decisions on where and how the taxpayers' money is spent. There is a fairly predictable process at the federal level and at the state level to determine how taxpayers' dollars are allocated. Learn the process. At the federal level there are Appropriations Committees in the House and Senate that do the actual spending. But they are given instructions, or authorization, from the other committees. So for example, The House Appropriations Committee will allocate funding to the Substance Abuse Mental Health Services Administration (SAMHSA) based on the authorization instructions established by the House Commerce Committee that has authorizing jurisdiction over SAMHSA. Developing a good working relationship with the elected representatives and staff of the key committees is important to making sure your views and concerns are heard. This can be accomplished in number of ways: visits and meetings, letters, phone calls, or tours of your program.

Even though every state works a little differently, somewhere a committee of legislators is tasked with making decisions on programs that affect your agency and the people you serve. If you think you deserve a bigger slice of the pie then those are the people to talk to in your state capital.

BUT ISN'T THIS LOBBYING?

Advocacy is similar to lobbying in that you meet with legislators or their staff to discuss legislation and policy. Since most psychosocial programs are tax-exempt 501(c)(3) non-profit organizations, most of the concern revolves around what kind of activity is prohibited by the 501(c)(3) tax-exempt election. Tax-exempt 501(c)(3) organizations cannot endorse or oppose candidates for political office or make contributions to the campaigns of candidates for political office. However, individuals working for a 501(c)(3) can make contributions and can participate in campaigns as long as they do so on their own time. A clear firewall should be maintained between the political activities of the individual and the activities for the 501(c)(3) organization.

So what about lobbying? Whether you call it advocacy or lobbying they are basically the same. Certain limits on expenditures apply regarding how much funding a 501(c)(3) organization can devote to lobbying. If the IRS determines that your organization exceeded the limit during a given year, your organization loses tax-exempt status for that year, must pay taxes for that year and could face substantial penalties. The sections of the Internal Revenue Code that govern political activity by non-profits are Section 501(c)(3) and Section 4911. They are included in the Appendix.



WAYS TO ADVOCATE

Hiring Your Own Hired Gun

It's a myth that only well-heeled groups can afford a lobbyist, but it is unlikely that a single psychosocial program or clubhouse will have their own lobbyist. That decision is probably best made at the chapter level. The decision about whether to hire a lobbyist or keep the function internal will vary from chapter to chapter. If your chapter does decide to hire an outside lobbyist, remember that what you are paying for most of all is access and knowledge.

- Access: the lobbyist's ability to reach key decision-makers - legislators, the governor and key staff, department heads and staff.
- Knowledge: the lobbyist should know about your programs and the people served in those programs, the concerns and the issues and which committees and agencies have influence over those concerns and issues.

Most of all take your time and talk to other health care related groups about who might be the right lobbyist for your chapter. Although few PRA chapters have outside lobbyists, the New Jersey PRA Chapter has had a very positive experience with their lobbyist. Call the PRA office if you need the contact information for the PRA New Jersey Chapter. However, even if you decide to hire a lobbyist, you will still need to advocate in conjunction with their activity. The best strategy is a coordinated plan that combines the work of the lobbyist with the voices of consumers and others. If your chapter doesn't have a lobbyist then it is essential that a strong grassroots organization be in place. In any case an active grassroots organization is needed.

Building a Grassroots Organization

One of the strongest influences on a legislator is hearing from his or her constituents. This is true at all levels of government -- local, state, and federal. Letters and phone calls are the most common ways a grassroots movement is heard, but visits and even demonstrations are important ways of reaching your representative.

A key to effective grassroots campaigning is an organized public policy program. Being a player requires organization so here are some steps you can take to increase the effectiveness of your group's advocacy efforts:

Form a Public Policy Committee

- Recruit a Chair who is knowledgeable, enjoys public policy and is a good-promoter of your services. Having a co-chair can help lighten the load on the Chair;
- Make the Chair a leader, e.g. Chapter Vice-President, and consider making the committee a standing committee of your organization;
- Hold regularly scheduled Committee meetings;
- Take steps to publicize the committee's activities and successes through regular reports at Board meetings, action alerts, and newsletter articles.



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Set an Agenda

- Survey your members to get a sense of their priorities and build consensus on key issues;
- Hold a one day public policy retreat open to all;
- Focus on the concrete needs of your members rather than on sweeping “save the world” ideas;
- Keep the number of issues manageable -- probably no more than two or three issues should be considered priorities. Remember that legislative emergencies will always occur in the form of unexpected bills (both good and bad) so don't overwhelm your committee.

Do “I” have to advocate?

The demands on a legislator's time are severe. Meeting with constituents , fundraising, legislative business, not to mention family and work (if your legislature is part time like many state legislatures still are), all demand a legislator's attention. So if you're not advocating for your interests, you can bet no one is. Remember, the squeaky wheel gets the grease.

Build a Legislative Network

- The purpose is to expand your power-base and be the vehicle for rapid grassroots action;
- A simple phone-tree alert system is a good way to issue advocacy calls for action, but don't forget faxes and e-mails;
- Communicate with the legislative network --issue legislative summaries, regular updates on hot issues, action alerts, etc.

Implement Your Public Policy Program

Sell your agenda internally and externally by:

- printing and distributing it widely
- publicizing it in newsletters and mailings
- holding a visible, unifying public policy event such as a rally
- promote the agenda to allied mental health groups (consumer networks, AMIs, MHAs, professional groups, etc.)
Make sure someone (e.g. the Public Policy Chair) is responsible and accountable for putting events in motion and being the point person.

Grassroots Tactics

Communicating a strong, consistent message to the people making decisions often influences the outcome of a policy debate or discussion. The following tactics are common among all grass roots organizations and are the staple of a grassroots campaign. Consumer advocates are especially critical to a grassroots effort because they can describe firsthand the problems associated with a particular policy or policy proposal or can speak to the benefits of a policy as well.



Remember that facts matter. You should point out whenever possible those facts that make your case compelling. For example, arguments for improved community-based mental health care and psychosocial rehabilitation might include statistics demonstrating the economic soundness of offering PSR services and the superior outcomes of those services.

E-mail, Letter & Telephone Campaigns

Letters and phone calls are the most common form of grassroots action and now e-mail is rapidly becoming the fastest and cheapest form of communication. Regardless of how the message is delivered, remember that numbers count. Decision-makers, particularly legislators, will actually count the number of phone calls, letters, and e-mails they get in support of and in opposition to an issue.

Some helpful tips:

- If the call or letter is about a particular bill, use the bill number or title
- Be sure to state up front your support for or opposition to the bill
- Give detailed but concise reasons for your support or opposition
- Always, always, always be polite when communicating your message

Testimony at Hearings

Another way to ensure that legislators hear and understand your message is through direct testimony at legislative hearings. Most legislatures have committees that have jurisdiction over different agencies and programs. Be sure to find out which committees have jurisdiction over issues important to your agency and get to know the members and the staff. That way you have already developed a working relationship when an important issue comes before the committee. When a hearing is held on a specific topic, don't be bashful about asking to provide a witness. The staff will want to know who the witness would be and what that person is likely to say about the issue before the committee. The main point of hearings is to educate the members on a particular issue. Make sure your witness has something to say that sheds new light on an issue, emphasizes a key concern, or represents a viewpoint not often heard.

Most likely you will be asked to provide testimony in advance, and you might also be asked what questions you would like committee members to ask your witness. In your testimony use "people-first" examples – personalize the issue. Always try to use facts or data to support your testimony. For example, if the hearing is on funding you might want to talk about employment rates among consumers at your agency or how much your agency helps save the state taxpayers' dollars by reducing hospitalization rates. Be sure to avoid jargon or verbal shorthand since some committee members might not be familiar with the topic.



Meeting with Your Representative

The most common way to personally convey your message to your elected official is to meet with that person in his or her office. There are certain common courtesies you should follow when setting up a meeting. First, always schedule your meeting in advance with the office staff. Ask to speak with the person who handles the scheduling. Second, always inform the staff about who will be attending and what issue(s) will be the topic of the meeting. Remember, it is always an advantage if one or more of your group is a constituent of the representative you are meeting with. Before the meeting, if more than one person is attending, pick someone who can open the meeting with introductions. Although you will be asked in advance of the meeting, it can help to focus the discussion if you remind your representative why you are visiting. If the meeting is about a specific bill refer to the bill number and title and be sure someone in your group is familiar with the bill. State why you support or oppose the bill or a provision in the bill and make sure your arguments for or against are cogently and concisely communicated. If possible, try to gauge beforehand whether your representative agrees with your view. If you think they might disagree, try to anticipate what concerns they might have so you can address them in the meeting. And remember--always, always, always be polite.

When the meeting is over be sure to thank your representative for meeting with you and be sure to thank the staff for all their help in setting up the meeting. Staff remember such niceties, especially when communicated to their boss. Be sure to immediately follow up the meeting with a thank you note. If further information has been requested, be sure to provide it as soon as possible. Another way to influence your representative is to invite him or her to visit your agency. A visit to a psychosocial rehabilitation program will make a tremendous impact. A special occasion at the program is a wonderful time to have your representative visit, but any time the program is busy works just as well. Again, work with the representative's staff person who is responsible for scheduling to make arrangements. Be clear about the purpose of the visit and the arrangements. Alert the members of your program to the visit and the kinds of things their representative would like to know about. Invite board members and family to participate as well.

Allies

Forming coalitions with other mental health organizations will often prove useful. You are far more likely to be successful in achieving your goal with a broader coalition than if you go it alone. Many hands lighten a heavy load. Here are examples of the possible allies in any coalition:

- Consumers and/or consumer groups such as the local Alliance for the Mentally Ill
- Other psychosocial programs and their state chapters
- Clubhouses
- Community Mental Health Centers
- State and Local Mental Health Associations
- Associations for Ambulatory Behavioral Healthcare
- State psychiatric and psychological associations
- Organizations representing people with different disabilities



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- Protection & Advocacy groups

There might be other organizations that are significant in your community. When pushing for a major initiative, or opposing one, be sure to get as many groups and people as you can mobilized and focused on the goal.



Section Two: Legislation & Regulations

READING LEGISLATION

Reading legislation can be difficult and time consuming, but it doesn't need to be. Most people attempt to read a bill the way you read a novel or the newspaper -- expecting to read all or a large part of it at once. That's quite natural; after all it's how we were taught in school. Unfortunately, bills are not books or newspaper articles; they are intended to be law. You probably won't get through a bill all at once unless it is just a few pages long. Here are some helpful tips on reading and analyzing a piece of legislation.

- Read the Table of Contents first, if there is one
- Bills are written by Title and Sections. If there isn't a Table of Contents read through the Title and Section headings first.
- Focus on one section or subsection at a time.
- Within each section, focus on each sentence.
- Read carefully and pay attention to key words and phrases. In law, words are everything...words do matter. An "and" instead of an "or" can make all the difference in the world. Example: "The programs funded under this section are X, Y, and Z." "The program funded under this section is X, Y, or Z." The first example is inclusive of all the programs; the second means only one program gets funded.
- Take notes. Take notes or make notes in the margin of the bill if something is unclear, problematic, or important. Sometimes using a highlighter to mark key words in section or paragraph helps bring you back to an issue at a later time. When commenting on legislation, try to offer alternative wording to a section that concerns you. Legislators may not interpret your concerns the way you intended. By offering alternative wording for the legislation, you will ensure your message is communicated clearly and the legislator will have the work of drafting a change already started.

LEGISLATION & REGULATION: BOTH ARE LAW, BOTH ARE IMPORTANT

Just as important as influencing legislation is the task of influencing the regulations that executive branch agencies develop to implement the law. Legislators can and do leave issues unresolved when developing legislation. There are many reasons for this: because the issue is politically difficult to resolve, because the legislature does not want to or cannot draft the legislation as precisely as it needs and defers to the agency which can better develop the details, or simply because it is the desire of the legislature to leave the details to regulation. Leaving the details of an issue to regulation can sometimes be more advantageous to advocates. After all, if the law is improperly drafted, it takes the passage of new law to fix the problem, whereas a problem with a regulation can be dealt with at any time. Regulations are drafted by the agency responsible for implementing the law. These regulations have the force of law and their development is ignored at the peril of your program and the people you serve. The critical time to influence the regulatory process is either as the



regulation is being drafted or during the comment period after it is drafted. The comment period is that block of time (usually some number of months or days) for the public and interested parties to comment to an agency on the draft regulation. A comment period is usually set for a fixed period of time so be sure to get the comments in before the deadline or they may not be considered by the regulating agency.

Comments can be submitted by the groups that influence legislation -- individuals, programs, consumer groups, etc. In fact, agencies often rely on such comments because they represent the input from the experts in the field or the people for whom the legislation was drafted. Again it is important to offer alternative wording to regulations you feel need to be changed. You make the work of the agency staff much easier by doing so, and are more likely to get your changes into the regulations. Like the legislative process, the regulation writing process can be influenced by the writing of letters. Generally non-written forms of communication (phone calls) are not helpful and are usually ignored. However, meeting with the people writing the regulations can be extremely helpful. These meetings should be set up and conducted in the same way as a meeting with your representative, but because the people writing regulations are non-elected employees of the executive branch they are not obligated to meet with you. However, you should attempt to meet with those involved in the process so that you can make your views known.



Section Three: Media

RULES FOR DEALING WITH THE PRESS

The first rule when dealing with the press is to remember that no matter how long or how well you know a reporter, they are NOT your friend. So don't blame them if you say something controversial that ends up in print and gets you into trouble. While relationships are important and reporters value them because they need to cultivate sources of information, always be careful.

The second rule to remember is that ANYTHING you say is fair game. Expect that everything you say could end up in print before the entire world (and given the internet, that is a distinct possibility today). So be careful about what you say and how you say it. In addition, there is no such thing as going on "background." Don't think you can hide a really outrageous comment behind the "on background" screen. If it's juicy enough, the media will use it.

TALKING TO THE PRESS: THE "QUOTABLE QUOTE"

Now that you know the rules, how exactly do you get your message across in the most powerful way? The press can be tools for achieving your goal, but for the tool to work you have to know how to use it. One of the things reporters look for is the comment that "sums it all up" or gives them the bottom line in terms of the issue. They also want a statement or comment that grabs the reader. It's sometimes called the "quotable quote" or good copy. If you are a source of "good copy" you are more likely to get a call from the press when a mental health topic comes up. Here's an example: When discussing with a reporter about the excessive number of state psychiatric hospitals given the low total hospital population, the advocate in urging more closures said, "There aren't enough people in all the hospitals to fill even one." This comment ended up in print because it was succinct, to the point, and summarized the issue.

ACCURACY MATTERS

Want to ruin your relationship with a reporter? Give them bad information; they may never call you again. If you do not know or are not sure of the answer to a question, especially if numbers are involved (i.e. how many people are in the state hospitals in your state?) then just say you don't know, or say you'll get back to them (and then really do get back to them). Bad information is not a difference of opinion with an opposing party. That happens all the time. Bad information is when the facts you give are wrong. Reporters rely on you to give them the straight story. If you give out unreliable information, they will stop using you as a source.

THE BOTTOM LINE: GETTING YOUR MESSAGE OUT

The key to achieving your goal is getting your message out. Getting your message out first is critical. When important issues are being decided, decision makers can be influenced by the news stories on the subject. So, keep in mind the two rules, make sure you make it quotable, and remember that accuracy matters.



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PRESS RELEASES AND MEDIA ALERTS

A press release can be used to announce any item of importance to your program. It should tell the story in a concise way, running no more than two pages and answer the basic questions: who, what, when, where, and why. Be sure to include some quotes from key people -- your program's executive director, state chapter president, or the head of your consumer advocacy group. If the press release is being sent in conjunction with a specific event, it should be faxed or mailed so as to arrive the day before the event, and it should be available at the event. A sample press release is included in the Appendix.

Media alerts are a simple one-page announcement of any event that the media might be interested in attending. It contains only the pertinent information -- who, what, when, where, and why. It is always good to include a paragraph (no more) of teaser information. This information might be a short paragraph that will grab the attention of the reporter and provide some background. A sample media alert is in the Appendix.

MAKING A PRESS LIST

Developing a good relationship with the media means keeping in touch with them. Keep a list of the reporters you've talked to. Develop a press list that contains addresses, phone and fax numbers, and e-mail addresses so that you can contact them quickly. If possible put a little notation on the issues you've talked to the reporter about most recently. The demands on scarce public dollars are always high and the challenge is to convince legislators that your programs deserve some of those dollars. In order to do that it is important to set yourself apart from the crowd and tell legislators what it is that makes Psychosocial Rehabilitation different from any other services. The next section discusses some of the most powerful points to make.



Section Four: Selling PSR

OUTCOMES, OUTCOMES, OUTCOMES

Today the buyer of services whether an MCO, governmental agency, or private insurer, is looking for outcomes. Now outcomes can mean a lot of different things and the key is to stress the outcomes that are important to the buyer and those that make PSR so unique. The PRA Outcomes Toolkit is a good device for deciding which outcomes to track and also for tracking those outcomes. Basically you will want to stress that PSR programs focus on functional outcomes and not just clinical outcomes. PSR programs look at how the whole person is doing, not just from a medical situation, but also from the viewpoint of housing, employment, etc., because we know all these issues are important. By stressing the functional outcomes your program achieves you demonstrate the uniqueness of the services you provide. For more information about the Toolkit or to order one call HSRI at (617) 876-0426.

COST EFFECTIVENESS

Perhaps the biggest concern of most buyers today is cost. Cost explains the rapid growth of managed care. Cost explains the fight for lower taxes -- taxpayers are certain they are not getting their money's worth. The issue of cost is also the second strong point in favor of PSR programs. We know that community-based care is far less expensive than institutional care, and that psychosocial rehabilitation is among the most cost-effective community-based services. Make sure you can provide accurate information on the cost of your program.

THE POWER OF A VISIT TO YOUR PROGRAM

When you wrap the first two issues together -- outcomes and cost effectiveness -- psychosocial rehabilitation can compete with any service. However, if doubt remains the clincher in selling PSR is a visit to your program. Nothing is more powerful than having a consumer tell your representative that they didn't have a job or have a place to live until they came to your program. And the best place to have the consumer tell that story is right in your program.

EXPERTISE

As a PRA member you have the expertise in the field. Play to our organizational strengths by stressing the PRA Registry, Practice Guidelines, Code of Ethics, and any other relevant accreditation. In many states the majority of funding for psychosocial rehabilitation services continues to come from local and state funds. Knowing exactly what the funding streams are, who influences them and what the regulations governing them are is crucial to optimizing funding for your program. The state mental health authority, the state vocational rehabilitation department and the state Medicaid agency are all potential sources of funding for your program's services. You and your colleagues can shape the funding climate for each of these agencies through your advocacy efforts.



THE BUDGET

Influencing spending amounts and setting priorities is an essential component of human service advocacy. The budget process generally begins in the executive branch where agencies and departments develop spending plans for the coming fiscal year. It is critical that mental health advocates be involved in the development of the budgets for their state and the federal government and to make their voices heard. The development and approval of the budget is year-round ongoing process.

Typically, a budget request is drafted by the executive branch then submitted to the legislature for reviewing, revising, and approval. Legislative review is generally done by the Budget Committees of both the House and Senate. In some states, the Budget Committee might be further segmented into subcommittees. The members and staff of these committees play crucial roles in the budget process. Get to know these members and staff, especially those who have key positions of influence on mental health, Medicaid, VR and other areas important to psychosocial rehabilitation. It is essential that they know your priorities. Testifying at budget committee hearings is important so be sure to inquire about potential witnesses for these hearings. Also remember that much can be accomplished through meetings with legislators, both formal and informal, as well as through phone calls and letters.

Legislative power over the budget varies from state to state. In some states the legislature can only add money to the budget or move funds from one priority to another. In other states the legislature may only be able to cut funds. Make sure you know your state's budget process and shape your advocacy strategies accordingly. In addition to state funds, there are a number of federal or federal/state programs that can also provide funding. Here is a description of each.

HEALTHCARE

Medicaid

Medicaid is a means-tested medical entitlement program jointly funded by the federal government and the states. In all but a few states, Medicaid is automatically available to people on SSI, or Supplemental Security Income. Medicaid provides a broad array of services to persons with disabilities, including people with mental illness. However, many of these services are available only if the state chooses, or opts, to provide the service. This means you must advocate to convince your state legislature to adopt or modify a Medicaid option. This is usually a multi-year process but well worth the effort. An influx of Medicaid funding can dramatically enhance funding for rehabilitation services. Described below are three state options for people with mental illness.

Clinic Option

States can choose to provide many of the same services in a community setting that are available in a hospital outpatient setting, such as prescribing medication, but the clinic cannot be a part of the hospital.



Rehabilitation or Rehab. Option

Allows states to offer rehabilitative services that are “recommended by a physician or other licensed practitioner of the healing art within the scope of their practice under state law.” Those services must have as their goal “the maximum reduction of...mental disability and restoration of an individual to the best possible functional level.” The rehabilitation option has few restrictions and is more flexible than most Medicaid options.

Targeted Case Management

Medicaid law allows states to provide services “which will assist individuals in gaining access to needed medical, social, education, and other services. States may limit this option to persons with mental illness only, or people with HIV and/or AIDS. This is a waiver program, and unlike an option, can only be provided upon written approval of the Secretary of the US Department of Health and Human Services (HHS). It allows a state to waive certain requirements, such as the statewide provision of services and comparability of services across eligible populations -- thus the term “targeted” case management.

Medicaid Managed Care

What is Managed Care?

Managed care is a health care cost containment strategy that was developed in the early 1970s. The concept was that healthcare payers could both contain costs and ensure quality of care if recipients of care could be assigned to “networks” of providers. The federal law exempts such networks, called Health Maintenance Organizations (HMOs), from the anti-trust laws and allows the establishment of such networks, or exclusive groups of providers, whose members all agree to accept a certain fee for providing services to the enrolled recipients.

Why Medicaid Managed Care?

For most of the late 1970s and throughout the 1980s, healthcare costs in public sector programs like Medicaid grew at rates that most federal and state legislators felt were unsustainable. With state Medicaid budgets consuming as much as 50% of some state budgets, governors clamored for relief. The federal government responded by allowing states to experiment with different cost containment strategies. These cost containment strategies fall under two waivers known by their section numbers in federal Medicaid law – 1915(b) waivers and 1115 waivers. These waivers allow states to escape the myriad of Federal Medicaid requirements (thus the term waiver) and each has different rules. A state waiver must be approved, and renewed, by the federal government’s Health Care Financing Administration (HCFA). These waivers basically allow states to limit consumer freedom of choice in seeking care and permit states to limit consumers’ choice of services to those who belong to the network.

1915(b) Waivers

1915(b) Waivers allow a state to develop experimental mandatory managed care projects, primarily by allowing a state to “waive” Medicaid’s requirement of recipient freedom of choice in choosing a health care provider. These waivers are



approved for two-year periods and may be renewed at two-year intervals. The following states have 1915(b) waivers that include the provision of mental health services: Arkansas, California, Colorado, Connecticut, Florida, Iowa, Kentucky, Michigan, Missouri, Montana, Nebraska, New Mexico, North Carolina, Oregon, Pennsylvania, South Dakota, Texas, Utah, Washington, and Wisconsin.

1115 Waivers

1115 waivers are more extensive than 1915(b) waivers and, accordingly, the application process is more extensive as well. They permit states to do things not ordinarily allowed under Medicaid law. They allow states to enroll Medicaid beneficiaries into mandatory managed care and modify Medicaid eligibility standards. Under an 1115 waiver, states managed care plans cannot cost more than fee-for-service (budget neutrality) and they must ensure adequate access and quality of care. 1115 waivers can be granted for up to five years at a time. The following states have 1115 waivers that include mental health services: Alabama, Arizona, Colorado, Delaware, the District of Columbia, Hawaii, Kentucky, Maryland, Massachusetts, Minnesota, New Jersey, New York, Ohio, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont, and Wisconsin.

For more information about Medicaid and Medicaid managed care contact your state Medicaid agency or your state's managed care or behavioral managed care contractor.

Medicare

Medicare is a program funded entirely by the Federal government and therefore coverage is identical from state to state. Persons who receive Supplemental Security Disability Income (SSDI) may have Medicare instead of Medicaid. Medicare will pay for inpatient services, clinic visits and partial hospitalization services. Medicare does not currently cover psychosocial rehabilitation services.

Partial Hospitalization Services (PHS)

This service was included in Medicare in 1990 to provide acute care mental health services to individuals who would need full hospitalization if partial hospitalization were otherwise not available. Partial Hospitalization may be furnished only by hospitals to their outpatient populations or by a Community Mental Health Center (CMHC). Individuals eligible for PHS comprise two groups: individuals discharged from a psychiatric hospital for whom PHS is provided in lieu of continued inpatient treatment; and individuals who exhibit disabling psychiatric symptoms as a result of an acute exacerbation of a severe and persistent mental illness for whom PHS is provided in lieu of inpatient psychiatric hospitalization. Three requirements must be met to receive PHS: a physician must certify that the individual would need inpatient treatment in the absence of PHS; an individual written plan of care must be established and periodically reviewed by the physician; and the patient must be under the care of a physician. Services under PHS must be intensive active treatment including a combination of medical and nursing interventions, individual and group therapy, occupational therapy, family counseling, and various therapeutic activities that are not primarily recreational or diversionary in nature. Individuals must need six hours of programming for five days per week and frequency can be reduced as symptoms subside to four days and later



three days of attendance. Once it reaches this level, the need for PHS in lieu of inpatient care is considered not indicated and discharge is made to a lower level of outpatient care.

A new Prospective Payment System (PPS) has been instituted to hold down the growing costs of this PHS. PPS is a form of capitation on an individualized basis. Currently, the Medicare regulations have set the PPS at \$208.25 per day, of which \$46.78 is the beneficiary’s copayment. Partial Hospitalization Services are under a high level of scrutiny by the Health Care Financing Administration following an investigation that found high levels of fraud and abuse. Any agency that offers PHS must adhere to the regulations rigorously or risk losing the ability to be reimbursed for any Medicare services. Information about Medicare and Medicare services is available through your state Medicare Intermediary or regional Medicare office.

HOUSING

Housing is generally the largest single expense low-income households’ face. People with disabilities who may be receiving Supplemental Security Income (SSI) or who work in low wage jobs find it very difficult to find housing that is affordable. According to the federal government, housing is affordable to a low-income family as long as the cost of housing (rent or mortgage/tax payments plus basic utilities) does not exceed 30 percent of household income. Consistent with this standard, households earning \$11,000/year (minimum wage) cannot afford to pay more than \$275/month for rent and utilities.

Annual Income	Affordable Housing Cost
\$6,000 (SSI)	\$150
\$11,000 (minimum wage)	\$275
\$15,000	\$375
\$20,000	\$500

Department of Housing & Urban Development

Most of these low-income programs are funded by the U.S. Department of Housing and Urban Development (HUD). Though all of these programs are federally funded, some (as indicated) are administered and available through your state or city housing and community development offices. Information regarding housing funding is available through the Department of Housing and Urban Development at www.hud.gov or through your local Public Housing Authority (PHA). Information is also available through the Technical Assistance Collaborative at www.tacinc.org.

Public Housing Agencies and the PHA Plan

Public Housing Agencies (PHAs) were created by the Housing Act of 1937 to develop, own, and manage federal public housing under contract with HUD. PHAs are overseen by a Board of Commissioners that is either elected or appointed by the city or town. PHAs administer federal public housing units as well as Section 8 tenant-based certificates and vouchers. Historically, PHAs have been highly regulated by HUD. However, recent federal legislation has given greater flexibility to PHAs to decide how to use federal housing resources to meet housing needs in local communities. Beginning in 2000,



PHAs are required to prepare and submit to HUD a five year Public Housing Plan covering all aspects of a PHA's operations, including PHA income targeting and tenant selection preferences for federal public housing units and Section 8 rent subsidies. The PHA Plan must be developed in consultation with a Resident Advisory Board and be consistent with the housing needs and housing strategies described in the community's HUD mandated Consolidated Plan. (See Consolidated Plan below)

Federal Public Housing Units

Federal public housing is developed, owned, and operated by PHAs. HUD provides an operating subsidy for federal public housing developments to pay for the costs of operating and managing the housing not covered by tenant rents. Public housing tenants typically pay a limited percentage (usually 30 percent) of their income as rent to the PHA. Through the PHA Plan described above, PHAs may establish tenant selection preferences for their public housing units. PHAs may also designate studio and one-bedroom public housing units as “elderly only” housing – and reduce the supply of public housing units available to people with disabilities. However, PHAs may legally designate “elderly only” housing only if the PHA has a separate HUD-approved PHA Allocation Plan requesting the designation.

Since the 1970s HUD has funded very few new units of public housing. Many PHAs are now competing for HUD’s Hope VI Public Housing Revitalization Program, which provides funding for the demolition and redevelopment of older and deteriorated public housing. In an effort to revitalize the image of public housing, public housing units developed under the Hope VI program are frequently targeted to moderate income households rather than low-income households.

Section 8 Certificates and Vouchers

The Section 8 tenant-based certificate and vouchers programs were created by Congress as an alternative to public housing and privately owned subsidized housing developments to allow low income households more choice in housing and to reduce the concentration of low income households living in particular neighborhoods, especially in urban areas. The Section 8 program is administered by PHAs and provides tenant-based rental subsidies that can be used in privately owned rental housing chosen by the program participant that meets Section 8 guidelines. Since 1974, this program has become the major form of federal housing assistance available to very low-income households.

Under new public housing reform legislation, the Section 8 certificate and voucher programs will be merged into the new Housing Choice Voucher Program. The Housing Choice voucher provides a rent subsidy paid by the PHA on behalf of the program participant directly to the landlord. When new Section 8 participants receive a Housing Choice voucher, they may pay no more than 40 percent of their income in rent. The amount of the Section 8 rent subsidy is based on HUD Fair Market Rents for the area. Until 1995, PHAs were required to provide preference to very low-income families (income below 50% of median) who were homeless or at risk of homelessness. However, those requirements were eliminated by Congress. Under new federal laws, PHAs must target at least 75 percent of their Section 8 rent subsidies to households with incomes below 30 percent of median income. PHAs may also establish other tenant selection preference categories that are consistent with local housing needs. For example, PHAs may adopt a local preference for people with disabilities,



although there is no requirement that they must do so. There is usually a long waiting list for Section 8 certificates and vouchers, and many PHAs open their Section 8 waiting lists for new applicants for very limited periods of time.

The Section 8 Mainstream Program for People with Disabilities

In 1997, 1998, and 1999, Congress appropriated several set-asides of Section 8 rent subsidies targeted exclusively for people with disabilities. During this three year period, approximately 26,000 new Section 8 rent subsidies targeted to people with disabilities were made available by HUD to PHAs. Most of these rent subsidies were intended by Congress to replace the federal public and assisted housing units that are no longer available to people with disabilities because of the designation of “elderly only” housing. These Section 8 rent subsidies are usually referred to as the Section 8 Mainstream Program for People with Disabilities. Unfortunately, very few PHAs actually applied for Section 8 Mainstream funding. To address this lack of interest on the part of PHAs, in 1999 Congress directed HUD to modify the Section 8 Mainstream program and permit non-profit disability organizations as well as PHAs to apply and administer the program. Non-profit organizations are required to run the Section 8 program in the same manner as PHAs.

Privately Owned Federally Subsidized Rental Housing

Beginning in the early 1960s, Congress created a number of programs that encouraged the development of privately owned subsidized housing. During the 1970s, HUD stimulated the development of privately owned affordable housing through such programs as the Section 221(d)3 and Section 236 programs which combined long term mortgages with federal mortgage insurance. After Congress created the Section 8 program in the 1970’s, many of these properties also received Section 8 project based rental assistance for some or all of the units. Until 1992, the one bedroom Section 8 units in these developments were targeted by law to elderly households (age 62 and older) and people with disabilities under age 62. Since the mid-1990s, owners have had the discretion to restrict or exclude people with disabilities from moving into these properties under federal “elderly only” housing policies. In the 1970s and early 1980s, the Section 8 New Construction and Section 8 Substantial Rehabilitation Program was also used to encourage new subsidized housing development. As an incentive to expand private subsidized housing production / rehabilitation activities, HUD made a 15 year commitment of Section 8 rent subsidies to housing developers who were then required to provide the units to Section 8 eligible households, including people with disabilities. Developers used this Section 8 guarantee to obtain financing from other sources. Since 1992, these properties have also been permitted to adopt “elderly only” housing policies and limit the occupancy of units by people with disabilities under age 62.

The Washington D.C. based Consortium for Citizens with Disabilities Housing Task Force and the Technical Assistance Collaborative Inc. in Boston have estimated that by the year 2000, as many as 273,000 federally subsidized housing units may have been converted to “elderly only” housing – and no longer be available to people with disabilities under the age of 62. Most privately owned federally subsidized Section 8 developments in the United States are “at-risk” of conversion to market rate housing due to expiring HUD contracts and mortgage “pre-payment” options being exercised by the owners of these developments.



The Consolidated Plan (ConPlan)

The ConPlan is a HUD mandated application and strategic planning document prepared by all states and certain local government jurisdictions every year. The Consolidated Plan controls the use of 4 HUD programs administered by state and local housing officials and must be approved by HUD each year. These four HUD programs are: the HOME Program; the Community Development Block Grant Program; the Emergency Shelter Grant Program; and the Housing Opportunities for People with AIDS Program.

The ConPlan should not be treated as another bureaucratic requirement. It is intended to be a comprehensive, long range (5 year) planning document that describes housing needs and market conditions, housing strategies, and outlines an action plan for the future investment of federal housing funds. The ConPlan is important to the disability community because it controls how federal housing funds will be used to expand affordable housing opportunities, and who will benefit from these affordable housing activities. The housing needs and housing strategies adopted in the Consolidated Plan are also intended to influence the development of other HUD mandated strategic plans – specifically the new Public Housing Plan prepared by PHAs and the Continuum of Care Plan which guides the use of HUD McKinney Homeless Assistance Programs.

HOME Program

Congress created the HOME Investment Partnerships Program in 1990. The HOME program is a formula grant of federal housing funds to states and local jurisdictions. Local jurisdictions are larger cities and consortia of smaller communities (called “Participating Jurisdictions”). HOME funds can be used for the following uses:

- Rental housing production and rehabilitation loans and grants;
- First-time homebuyer assistance;
- Rehabilitation loans for homeowners;
- Tenant-based rental assistance (2 year renewable contracts).

All housing developed with HOME funds must serve low and very low income individuals and families. For rental housing, at least 90 percent of HOME funds must benefit families whose incomes are at or below 60 percent of area median income; the remaining 10 percent must benefit families with incomes at or below 80 percent of area median income. Fifteen percent of state or local HOME funds must be set-aside for use by community based non-profit organizations (called “CHDOs”). During 1999, Congress appropriated \$1.6 billion that was allocated by formula to approximately 500 communities and states.

Community Development Block Grant

The Community Development Block Grant (CDBG) program is a federal grant provided to CDBG “entitlement communities” (typically municipalities with populations of over 50,000 and urban counties with populations of over 200,000) and to all states. States may use CDBG funds only in non-entitlement communities, including rural areas. During 1999, Congress



appropriated \$4.75 billion for the CDBG program. At least 70 percent of CDBG funds must be used to benefit low and moderate-income people by providing decent housing and a suitable living environment, and by expanding economic opportunities. CDBG can be spent on any of the following activities:

- Housing rehabilitation (loans and grants to homeowners, landlords, non-profits, developers);
- New housing construction (only if completed by non-profit groups);
- Purchasing land and buildings;
- Construction of public facilities such as shelters for the homeless;
- Construction of neighborhood service centers or community buildings;
- Code enforcement, demolition, and relocation funds for people displaced because of CDBG projects;
- Making buildings accessible to the elderly and handicapped; and
- Public services (capped at 15 percent of a jurisdiction's CDBG funds) such as employment services and health and child care.

Emergency Shelter Grant (ESG)

HUD's ESG program provides grants to states and localities to address the needs of homeless individuals and families. Eligible activities for use of ESG include:

- Renovation, major rehabilitation, or conversion of buildings for use as emergency shelter;
- Up to 30% on essential services for the homeless;
- Up to 30% on homeless prevention efforts;
- Shelter operating costs, such as maintenance, insurance, utilities, rent, and furnishings (no more than 10% for operating staff costs).

Housing Opportunities for People with AIDS program (HOPWA)

The HOPWA is a HUD program that funds housing and services for people with AIDS. It is available as a block grant to states and larger metropolitan areas based on the incidence of AIDS in these areas. Approximately \$225 million was appropriated for HOPWA in FY '99. Eligible activities under the program include:

- Housing information and coordination services;
- Acquisition, rehabilitation and leasing of property;
- Project-based or tenant-based rental assistance;
- Homeless prevention activities;
- Supportive services;
- Housing operating costs;
- Technical assistance; and



- Administrative expenses.

Low Income Housing Tax Credit (LIHTC)

The federal government created the LIHTC program in 1986 to provide incentives for investment in low-income housing development by giving federal tax credits to investors in affordable low-income housing. Private investors (such as banks, corporations) buy the tax credits from the affordable housing developer. The affordable housing developer then uses these proceeds called equity (usually in combination with other financing) to construct or rehabilitate affordable housing. Because developers of affordable housing must often piece together various forms of financing, the LIHTC has become a critical piece of overall project financing. State Housing Finance Agencies develop plans, called Qualified Allocation Plans (QAP), describing how they will allocate LIHTC for new affordable housing projects. The federal government sets basic long-term affordability requirements on LIHTC projects. Under LIHTC, at least 20% of the units must be reserved for households earning less than 50% of the area median income or at least 40% of the units must be reserved for households earning up to 60% of area median income. LIHTC projects are required to by federal rules to accept applications from households with Section 8 certificates or vouchers, provided the household meets other tenant screening criteria.

McKinney Continuum of Care

Since the mid-1990s, HUD's homeless programs have been made available through the Continuum of Care approach – that is a local or state network or system designed to coordinate efforts to address homelessness. The Continuum of Care approach is intended to help communities develop the capacity to envision, organize and plan comprehensive and long-term solutions to addressing the problem of homelessness in their community. This comprehensive approach encourages communities to prioritize gaps in the housing and services available for homeless people and develop long term strategies and action plans to address these gaps using HUD McKinney as well as other housing and service resources. There are three HUD McKinney programs available through the McKinney Homeless Assistance national competition announced each year in HUD's Notice of Funding Availability (SuperNOFA).

The Supportive Housing Program (SHP)

The SHP program provides supportive housing and/or supportive services to homeless persons. SHP funding can be used to create transitional housing (temporary housing and services for up to 24 months); create permanent supportive housing for people with disabilities; or provide supportive services not in conjunction with SHP-funded housing. Eligible activities for use of SHP funds include:

- Acquisition of structures for supportive housing or to provide supportive services
- Rehabilitation of structures for supportive housing or to provide supportive services
- New construction of buildings for supportive housing where there is a lack of appropriate units that could be rehabilitated or the new construction costs substantially less than rehabilitation
- Leasing of structures for supportive housing or to provide supportive services



Psychiatric Rehabilitation Association

- Operating costs of supportive housing
- Supportive services

Shelter Plus Care

The Shelter Plus Care program provides rental assistance for permanent housing for homeless persons with disabilities (primarily those with mental illness, chronic problems with alcohol and/or drugs, and AIDS or related diseases). Only government agencies and PHAs are eligible to apply for S+C funds, which can be used for four types of rental assistance:

Tenant-based rental assistance (TRA)

Provides grant funding for a five year contract term. Participants reside in housing of their choice though grant recipients may require participants to live in a specific area in order to facilitate coordination of supportive services.

Sponsor-based rental assistance (SRA)

Provides grant funding for a term of five years through contracts between a grant recipient and a sponsor organization. Sponsors may be a non-profit organization or community mental health agency established as a public non-profit. Participants reside in housing owned or leased by the project sponsor.

Project-based rental assistance (PRA)

Provides grants for a term of either five or ten years through contracts between grant recipients and owners of existing structures with units that will be leased to participants. Rental assistance grants are for ten years if the owner agrees to complete rehabilitation on the units to be leased within 12 months of the grant agreement.

Single Room Occupancy Dwellings (SRO)

Provide grants for rental assistance for a contract term of ten years in connection with moderate rehabilitation of single room occupancy housing units.

Section 8 Moderate Rehabilitation Program for Single Room Occupancy (SRO) Dwellings for Homeless Individuals

The Section 8 SRO program provides public housing authorities and non-profit organizations rental assistance funds to assist in the development of Single Room Occupancy Dwellings (SROs) for homeless individuals. SRO projects are awarded Section 8 project-based rent subsidies for ten years – a long term commitment which helps the project sponsor obtain the other financing necessary to develop the project. SRO projects must select tenants who qualify as homeless under HUD rules. Other Section 8 tenant selection rules also apply to the Section 8 SRO program.

Section 811 Supportive Housing for Persons with Disabilities Program

The Section 811 Program (formerly the Section 202 program for people with disabilities) was authorized as a separate program for people with disabilities in the early 1990s. Section 811 provides capital grants and project rental assistance contracts to non-profit-sponsored housing developments for people with disabilities. Funds can be used to acquire, rehabilitate, or newly construct housing. Developers can use a variety of structure types, including multifamily housing complexes, condominiums, cooperatives, and group homes.



Each HUD region receives an allocation of Section 811 funds annually, which are made available to non-profit organizations through a national competition announced in a HUD Notice of Funding Availability. Because of extremely limited funding (\$194 million in FY '99), the Section 811 program is extremely competitive. Since 1995, 25 percent of Section 811 funds (\$48.5 million in FY '99) have been used to create Section 8 certificates and vouchers under the Section 8 Mainstream Program for People with Disabilities (see Section 8 above). In 1999, non-profit disability organizations as well as PHAs were eligible to apply for the Section 8 Mainstream program.

Department of Health & Human Services (HHS) Center for Mental Health Services

PATH (Projects for Assistance in Transition from Homelessness)

The PATH program is targeted to assist people with severe mental illnesses, who may also have a drug or alcohol addiction, and who are homeless or are at imminent risk of homelessness. The funding is available only to community non-profits and political subdivisions of the states (cities and counties). The funding is funneled through the state mental health authority from the federal government's Substance Abuse Mental Health Services Administration (SAMHSA) and is available on a grant basis. Information about the PATH program can be found at www.samhsa.gov/cmhs or at www.mentalhealth.org.

EMPLOYMENT

Social Security

Alternate Provider Program (AP Program)

Under current law, psychosocial rehabilitation providers can complete the Social Security Request for Proposal (RFP) to participate in the Alternate Provider program. This program allows providers of rehabilitation services to receive direct reimbursement from Social Security for every person they help find work and leave the Social Security cash benefit rolls. The provider does not payment until benefits to the individual have ceased. Prior to this program, any beneficiary on social security disability who SSA thought could work was referred only to the public VR system. Under the AP Program, State VR has a four month right of first refusal -- in other words, VR must first refuse service to the person before they could seek services directly from a private provider that SSA would reimburse under the AP Program.

Ticket-to-Work

- Several flaws were immediately apparent in the Alternate Provider Program:
- It strictly limited consumer choice through the state VR "right-of first refusal";
- It forced providers to assess outcomes prior to service delivery by end-loading all payments until the beneficiary was "off the rolls"; and
- It was overly burdensome for most smaller providers to complete the long and complicated RFP.



As result Congress is about to consider legislation that eliminates these barriers. First, the new law will create a “ticket-to-work” or voucher that any social security disability beneficiary can take to any rehabilitation provider, public or private. There will be no VR right of first refusal. Second, reimbursement under the Ticket-to-Work will be different. Milestone payments will be added so that providers don’t have to wait until the person is totally off the rolls before receiving any payment. Finally, payments are spread out over five years to make sure long-term job supports are provided.

The new payment system is simple -- it’s based on the savings to the Social Security Trust Fund over five years. Here’s how it works. Let’s say John is on SSDI and his check is \$700 per month. That means if John stays on benefits he’s eligible for \$8400 a year or \$42,000 over the next five years. Under the Ticket-to-Work, the provider can receive 40% of the total amount John would have received had he remained on benefits for five years—or \$16,800. Let’s say SSA decides to set “milestone” payments at the 3rd, 6th, and 9th month of the nine-month trial work period (TWP), and they set the total for the milestones payments at one-third of \$16,800 or \$5544. If the provider helps John get to the 3rd month of trial work, the provider gets \$1830. Another \$1830 will be paid when John reaches the 6th month of trial work, and another \$1830 when he reaches the 9th month of trial work. After the TWP, John is no longer eligible for cash benefits, and the remainder, \$11,256 (\$16,800 minus the \$5544 in milestone payments) is received by the provider in monthly payments for each month John is not receiving SSDI cash benefits (\$187.60/month). Now, if John has to go back onto cash benefits, the payments to the provider stops for each and every month John received benefits.

More information about the Social Security Administration’s policies affecting rehabilitation, work and income can be found at www.ssa.gov.

Vocational and Job Training

Department of Education Rehabilitation Services Administration (RSA) Title I Block Grant

Funds under Title I are allocated to the states from the federal government on a formula basis and the states match this funding. States must submit a plan for how the funding is to be allocated, and such services under the plan are to be available in every jurisdiction of the state (state wideness), unless the Commissioner waives state wideness to allow localities and non-governmental agencies and providers to receive funding. This can happen only in the event that doing so would assist in the rehabilitation of large number of individuals.

Title VI: Projects with Industry (PWI) and Supported Employment

Projects with Industry

The Projects with Industry program was established to foster greater partnerships with industry for the purpose of employing more people disabilities. Business advisory councils made up of representatives from the business community, individuals with disabilities, and the state VR agency, identify job and career availability with the community, identify the skills needed for those jobs, and prescribe training programs to develop the needed skills or job placement programs, for people with disabilities. The goal is to train individuals in the most realistic settings, help modify facilities or equipment,



and provide support services to maintain the employment of the individual. PWI funding is available on a grant basis for up to five years.

Supported Employment

Funding for Supported Employment (SE) is available as a distinct funding stream to the states for the purposes of providing SE services to individuals with the most severe disabilities. Determinations for eligibility are made on a case-by-case basis. Information on public vocational rehabilitation programs is available through your state VR agency or at www.ed.gov/offices/OSERS/RSA/.

Department of Labor Employment & Training (E&T)

Welfare-to-Work

Congress dramatically changed the nation's welfare programs in 1996. Congress ended the entitlement to benefits that existed under the Aid to Families with Dependent Children (AFDC) program and created a new program, Temporary Assistance for Needy Families (TANF). Under TANF, recipients are eligible for up to five years of TANF benefits over their lifetime. Simultaneously, Congress added a work/employment component to TANF. States are given incentives to move people from welfare to work, hence the name of the program Welfare-to-Work. Further, states that fail to meet the federal employment standards established under TANF risk losing part of their federal share of TANF benefits. The Welfare-to-Work law contains a provision specifically targeted to help "hard-to-employ" individuals. This category includes TANF recipients who have disabilities, including persons with a mental illness. States have two options regarding recipients who fall into this "hard-to-employ" category. States are allowed to exempt up to 20% of their TANF population from the work requirements. States can place these "hard-to-employ" individuals in this 20% set-aside. Or they can find them jobs.

That's where you come in. States are facing serious deadlines when it comes to meeting the employment requirements under the law. They will most likely use the 20% set-aside quickly in an attempt to meet the early federally mandated employment requirements. But once the 20% set-aside is filled, states MUST find employment for TANF recipients. Further, the employment requirement is graduated so that states must achieve higher employment rates for TANF recipients over time in order to draw down federal TANF funds. So, if a state fills its 20% set-aside to meet the first year's requirements, it will have to place in employment almost everyone else in later years to meet the increased demands later on. A significant number of the TANF population has some sort of psychiatric disability. Estimates vary widely, but undoubtedly most state welfare and employment offices will believe this population is difficult to employ. But if your program is successful at employment for people with psychiatric illnesses, states will see a real value in funding your efforts for two reasons:

1. Your program will help limit the number of "hard-to-employ" individuals who occupy space in the 20% set-aside, and



2. Your program can help move the “hard-to-employ” people in the 20% set-aside into employment as the employment requirements get tougher.

Do not underestimate the pressure a state will be under to employ TANF eligible individual. The requirements are tough; the penalties for missing the employment rate target are severe. And the clock is ticking -- now! The federal government’s Department of Labor is providing funding in the form of grants for agencies that provide employment services for persons who fall into the hard-to-employ category. Funding is announced through the DOL website at www.dol.gov and you can access the funding application through the website or through the federal register.

PRA organizational members receive regular special Bulletins with this information. Information on welfare-to-work and job training programs is available at www.doleta.gov or through your local DOL one-stop job-training center.

MENTAL HEALTH SERVICES

Community Mental Health Block Grant

This funding is directed to the states on a formula basis for the purposes of funding community mental health centers. In most cases, it comprises only a small portion of a state’s mental health budget but it is targeted by the federal government for the purposes of providing community mental health services. More information can be found at www.samhsa.gov/cmhs or at www.mentalhealth.org.

State Hospital Reinvestment

Spending on public hospitals ought to be a prime target for community-based providers of mental health providers. While the census in these institutions has declined dramatically over the last three decades, the amount of spending saved from census reduction has not followed people into the community. This has led to numerous problems, most notably gaps in service delivery that have the result of people being denied the services they need. This can have dire and often tragic consequences. PRA produced *Deinstitutionalize the Dollars*, a kit specifically designed to help advocates in states develop and pass legislation to move mental health dollars out of the institutions and into the community.

Substance Abuse Programs

The issues and problems of dual diagnosis, or co-occurring mental health/substance abuse disorders is nothing new to consumers or providers. PRA published the landmark book *Readings in Dual Diagnosis* that highlights the issues around the need for integrated services and treatment for people with co-occurring disorders. Yet, the fact remains that the funding streams for mental health and substance abuse services are very difficult to integrate. This can make it difficult to blend funds in the most efficient manner. PRA is working at the federal level to simplify the funding streams for substance abuse and mental health funds to make it easier for your program to provide critical integrated services. You can access the federal government’s Center for Substance Abuse Treatment at www.samhsa.gov/csac for more information.



PRIVATE FUNDING SOURCES

PRA is making progress on the effort to raise the awareness of private health and disability insurance carriers to the benefits of psychosocial rehabilitation services. As we move ahead, you should see more avenues of funding opening up from these sources.

Private Health Insurance

Because of the medical/clinical model nature of most health insurance plans, generally little is covered by such plans in terms of PSR services. Moreover, most mental health benefits are limited far more strictly than physical health benefits. This is prompting many states and Congress to enact Mental Health Parity laws that end the discrimination in these plans against people with mental illnesses. It is too early to determine the impact of Parity laws on the availability of PSR. Hopefully health plans will look to services like PSR as the ability to discriminate against mental health availability is ended and the private insurers search for the most cost efficient and treatment effective services.

Private Disability Insurance

Although most private disability insurers also limit the availability of coverage to people with mental illnesses, generally to two years, some companies like the UNUM Insurance Co. are looking aggressively at psychosocial rehabilitation. The latest trends in disability insurance are rehabilitation and return-to-work and for people with mental illnesses PSR services are key to reaching these goals. The experience of the public sector is transferring to the private sector to the degree that many partial disability plans aggressively pursue rehabilitation. In fact, it is now the government programs of SSI and SSDI that lag behind the private sector in terms of developing an emphasis on state-of-the-art rehabilitation. PRA is working with private disability insurance providers to spread the word about the effectiveness of PSR services.

Other Private Sources

While we are making progress with health and disability insurance carriers, they aren't the only non-governmental sources of funding. Many other fundraising avenues exist, such as foundation grants and fundraising, that could bring in support for your program.

Conclusion

Advocacy is essential in today's political environment. This Technical Assistance Manual on Advocacy will help the people in your program learn the basics of advocacy and begin the process of developing or complementing an ongoing advocacy component within your Program. While this Manual is far from comprehensive we will be updating and improving it in the coming months and years to provide more information and to adapt the manual to reflect changes in public policy. Please feel free to email PRA at info@psychrehabassociation.org with comments, suggestions, or questions. We welcome your input.



Appendix

SEC. 501(C)(3) NON-PROFIT LAW

501(c)(3) -- Expenditures by public charities to influence legislation

- (1)** General rule: In the case of an organization to which this subsection applies, exemption from taxation under subsection (a) shall be denied because a substantial part of the activities of such organization consists of carrying on propaganda, or otherwise attempting, to influence legislation, but only if such organization normally –
 - (A)** makes lobbying expenditures in excess of the lobbying ceiling amount for such organization for each taxable year, or
 - (B)** makes grass roots expenditures in excess of the grass roots ceiling amount for such organization for each taxable year.
- (2)** Definitions For purposes of this subsection –
 - (A)** Lobbying expenditures. The term "lobbying expenditures" means expenditures for the purpose of influencing legislation (as defined in section 4911(d)).
 - (B)** Lobbying ceiling amount The lobbying ceiling amount for any organization for any taxable year is 150 percent of the lobbying nontaxable amount for such organization for such taxable year, determined under section 4911.
 - (C)** Grass roots expenditures. The term "grass roots expenditures" means expenditures for the purpose of influencing legislation (as defined in section 4911(d) without regard to paragraph (1)(B) thereof).
 - (D)** Grass roots ceiling amount. The grass roots ceiling amount for any organization for any taxable year is 150 percent of the grass roots nontaxable amount for such organization for such taxable year, determined under section 4911.
- (3)** Organizations to which this subsection applies This subsection shall apply to any organization which has elected (in such manner and at such time as the Secretary may prescribe) to have the provisions of this subsection apply to such organization and which, for the taxable year which includes the date the election is made, is described in subsection (c)(3).

TITLE 26 - INTERNAL REVENUE CODE

26 USC Sec. 4911 Subtitle D - Miscellaneous Excise Taxes

CHAPTER 41 - PUBLIC CHARITIES

Sec. 4911. Tax on excess expenditures to influence legislation

- (a)** Tax imposed
 - (1)** In general: There is hereby imposed on the excess lobbying expenditures of any organization to which this section applies a tax equal to 25 percent of the amount of the excess lobbying expenditures for the taxable year.
 - (2)** Organizations to which this section applies
- (b)** This section applies to any organization with respect to which an election under section 501(h) (relating to lobbying expenditures by public charities) is in effect for the taxable year. Excess lobbying expenditures: For purposes of this section, the term "excess lobbying expenditures" means, for a taxable year, the greater of:



- (1) the amount by which the lobbying expenditures made by the organization during the taxable year exceed the lobbying nontaxable amount for such organization for such taxable year, or
 - (2) the amount by which the gross roots expenditures made by the organization during the taxable year exceed the gross roots nontaxable amount for such organization for such taxable year.
- (c) Definitions. For purposes of this section:
- (1) Lobbying expenditures. The term "lobbying expenditures" means expenditures for the purpose of influencing legislation (as defined in subsection (d)).
 - (2) Lobbying nontaxable amount. The lobbying nontaxable amount for any organization for any taxable year is the lesser of
 - (A) \$1,000,000 or
 - (B) the amount determined under the following table:

The lobbying nontaxable amount expenditures

Not over \$500,000:	20 percent of the exempt purpose expenditures.
Over \$500,000 but not over \$1,000,000:	\$100,000, plus 15 percent of the excess of the exempt purpose expenditures over \$500,000.
Over \$1,000,000 but not over \$1,500,000:	\$175,000 plus 10 percent of the excess of the exempt purpose expenditures over \$1,000,000.
Over \$1,500,000:	\$225,000 plus 5 percent of the excess of the exempt purpose expenditures over \$1,500,000.

- (3) Grass roots expenditures. The term "grass roots expenditures" means expenditures for the purpose of influencing legislation (as defined in subsection (d) without regard to paragraph (1)(B) thereof).
 - (4) Grass roots nontaxable amount. The grass roots nontaxable amount for any organization for any taxable year is 25 percent of the lobbying nontaxable amount (determined under paragraph (2)) for such organization for such taxable year.
- (d) Influencing legislation
- (1) General rule. Except as otherwise provided in paragraph (2), for purposes of this section, the term "influencing legislation" means:
 - (A) any attempt to influence any legislation through an attempt to affect the opinions of the general public or any segment thereof, and
 - (B) any attempt to influence any legislation through communication with any member or employee of a legislative body, or with any government official or employee who may participate in the formulation of the legislation.
 - (2) Exceptions. For purposes of this section, the term "influencing legislation", with respect to an organization, does not include:
 - (A) making available the results of nonpartisan analysis, study, or research;



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- (B) providing of technical advice or assistance (where such advice would otherwise constitute the influencing of legislation) to a governmental body or to a committee or other subdivision thereof in response to a written request y such body or subdivision, as the case may be;
 - (C) appearances before, or communications to, any legislative body with respect to a possible decision of such body which might affect the existence of the organization, its powers and duties, tax-exempt status, or the deduction of contributions to the organization;
 - (D) communications between the organization and its bona fide members with respect to legislation or proposed legislation of direct interest to the organization and such members, other than communications described in paragraph (3); and
 - (E) any communication with a governmental official or employee, other than -
 - (i) a communication with a member or employee of a legislative body (where such communication would otherwise constitute the influencing of legislation), or
 - (ii) a communication the principal purpose of which is to influence legislation.
 - (3) Communications with members
 - (A) A communication between an organization and any bona fide member of such organization to directly encourage such member to communicate as provided in paragraph (1)(B) shall be treated as a communication described in paragraph (1)(B).
 - (B) A communication between an organization and any bona fide member of such organization to directly encourage such member to urge persons other than members to communicate as provided in either subparagraph (A) or subparagraph (B) of paragraph (1) shall be treated as a communication described in paragraph (1)(A).
- (e) Other definitions and special rules. For purposes of this section -
- (1) Exempt purpose expenditures
 - (A) In general. The term "exempt purpose expenditures" means, with respect to any organization for any taxable year, the total of the amounts paid or incurred by such organization to accomplish purposes described in section 170(c)(2)(B) (relating to religious, charitable, educational, etc., purposes).
 - (B) Certain amounts included. The term "exempt purpose expenditures" includes:
 - (i) administrative expenses paid or incurred for purposes described in section 170(c)(2)(B), and
 - (ii) amounts paid or incurred for the purpose of influencing legislation (whether or not for purposes described in section 170(c)(2)(B)).
 - (C) Certain amounts excluded. The term "exempt purpose expenditures" does not include amounts paid or incurred to or for:
 - (i) a separate fundraising unit of such organization, or
 - (ii) one or more other organizations, if such amounts are paid or incurred primarily for fundraising.
 - (2) Legislation. The term "legislation" includes action with respect to Acts, bills, resolutions, or similar items by the Congress, any State legislature, any local council, or similar governing body, or by the public in a referendum, initiative, constitutional amendment, or similar procedure.
 - (3) Action. The term "action" is limited to the introduction, amendment, enactment, defeat, or repeal of Acts, bills, resolutions, or similar items.



Psychiatric Rehabilitation Association

- (4) Depreciation, etc., treated as expenditures. In computing expenditures paid or incurred for the purpose of influencing legislation (within the meaning of subsection (b)(1) or (b)(2)) or exempt purpose expenditures (as defined in paragraph (1)), amounts properly chargeable to capital account shall not be taken into account. There shall be taken into account a reasonable allowance for exhaustion, wear and tear, obsolescence, or amortization. Such allowance shall be computed only on the basis of the straight-line method of depreciation. For purposes of this section, a determination of whether an amount is properly chargeable to capital account shall be made on the basis of the principles that apply under subtitle A to amounts which are paid or incurred in a trade or business.
- (f) Affiliated organizations
- (1) In general. Except as otherwise provided in paragraph (4), if for a taxable year two or more organizations described in section 501(c)(3) are members of an affiliated group of organizations as defined in paragraph (2), and an election under section 501(h) is effective for at least one such organization for such year, then:
- (A) the determination as to whether excess lobbying expenditures have been made and the determination as to whether the expenditure limits of section 501(h)(1) have been exceeded shall be made as though such affiliated group is one organization,
 - (B) if such group has excess lobbying expenditures, each such organization as to which an election under section 501(h) is effective for such year shall be treated as an organization which has excess lobbying expenditures in an amount which equals such organization's proportionate share of such group's excess lobbying expenditures,
 - (C) if the expenditure limits of section 501(h)(1) are exceeded, each such organization as to which an election under section 501(h) is effective for such year shall be treated as an organization which is not described in section 501(c)(3) by reason of the application of 501(h), and
 - (D) subparagraphs (C) and (D) of subsection (d)(2), paragraph (3) or subsection (d), and clause (i) of subsection (e)(1)(C) shall be applied as if such affiliated group were one organization.
- (2) Definition of affiliation. For purposes of paragraph (1), two organizations are members of an affiliated group of organizations but only if:
- (A) the governing instrument of one such organization requires it to be bound by decisions of the other organization on legislative issues, or
 - (B) the governing board of one such organization includes persons who -
 - (i) are specifically designated representatives of another such organization or are members of the governing board, officers, or paid executive staff members of such other organization, and
 - (ii) by aggregating their votes, have sufficient voting power to cause or prevent action on legislative issues by the first such organization.
- (3) Different taxable years. If members of an affiliated group of organizations have different taxable years, their expenditures shall be computed for purposes of this section in a manner to be prescribed by regulations promulgated by the Secretary.
- (4) Limited control. If two or more organizations are members of an affiliated group of organizations (as defined in paragraph (2) without regard to subparagraph (B) thereof), no two members of such affiliated group are affiliated (as defined in paragraph (2) without regard to subparagraph (A) thereof), and the governing instrument of no such organization requires it to be bound by decisions of any of the other



such organizations on legislative issues other than as to action with respect to Acts, bills, resolutions, or similar items by the Congress, then -

- (A)** in the case of any organization whose decisions bind one or more members of such affiliated group, directly or indirectly, the determination as to whether such organization has paid or incurred excess lobbying expenditures and the determination as to whether such organization has exceeded the expenditure limits of section 501(h)(1) shall be made as though such organization has paid or incurred those amounts paid or incurred by such members of such affiliated group to influence legislation with respect to Acts, bills, resolutions, or similar items by the Congress, and
- (B)** in the case of any organization to which subparagraph (A) does not apply, but which is a member of such affiliated group, the determination as to whether such organization has paid or incurred excess lobbying expenditures and the determination as to whether such organization has exceeded the expenditure limits of section 501(h)(1) shall be made as though such organization is not a member of such affiliated group.



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FORMAT FOR PRESS RELEASE

FOR IMMEDIATE RELEASE CONTACT: **(Name)**

(Date) Phone: **(###-###-####)**

(TITLE OF PRESS EVENT)

(Location of event: City, ST) -- Remember, your press release should “tell the story” by answering the five key questions: who, what, when, where, and why. Keep your press release short, no more than two pages, and put key information first. Reporters don’t want to “dig” through your release to get the facts. If you need to present more details then do that in a fact sheet. Read and reread your release for typos, errors, etc. The ### sign is the way you indicate to reporters the end of the release.

SAMPLE PRESS RELEASE

FOR IMMEDIATE RELEASE CONTACT: Paul Seifert

December 14, 1995 (410) 730-7190

IAPSRs ANNOUNCES TOOLKIT PROJECT FOR MEASURING REHABILITATION OUTCOMES

Washington, D.C. -- The International Association of Psychosocial Rehabilitation Services (IAPSRs) announced its Outcomes Toolkit project for measuring psychosocial rehabilitation outcomes.

Ruth Hughes, Ph.D. of PRA, was joined by Paul Arns, Ph.D. who chaired the IAPSRs Toolkit Research Committee and Steve Leff, Ph.D. of the Evaluation Center at Human Services Research Institute (HSRI). HSRI produced the Toolkit for distribution. Also joining the panel was Bernard Arons, M.D., Director of the federal Center for Mental Health Services (CMHS). CMHS funded the Toolkit project. Also, IAPSRs) President-elect Scott Graham & Sandy Michalski, IAPSRs research consultant, were on hand.

People diagnosed with a serious mental illness are a high-risk and high-cost group in health care. Outcome research demonstrates the effectiveness of psychosocial rehabilitation in reducing risk and cost. Studies over 20 years report consistent findings of: reduced hospitalizations; increased levels of functioning and independent living, including increased rates of employment; and higher levels of client satisfaction than with other forms of treatment.

As a result, the mental health care system has been moving toward the development of psychosocial rehabilitation and community support services that address major deficits in functioning for persons with serious mental illnesses. However, the collection of functional outcome data has been sporadic and inconsistent. The Outcomes Toolkit will for the first time allow the ongoing measure of a comprehensive set of targeted outcomes on a nation-wide basis across a broad spectrum of mental health programs with various levels of sophistication. The Toolkit was designed to be comprehensive, simple for program administrators and consumers to use, easy for analysts to quickly compile and review the information sought,



and user-friendly for the general public and policymakers. The Toolkit will measure outcomes in several different areas: Hospitalization -- types and lengths of admissions before and during rehabilitation; Residential living -- measure according to type of accommodation, from independent arrangement to institutional and facility; Employment -- measure according to type of employment, from independent competitive to no employment at all; Education -- level achieved & current enrollment; Financial status -- income sources and amounts; Legal status -- levels of victimization and violations; Consumer satisfaction -- assess program participants' satisfaction with the program and with their own well-being. "The Outcomes Toolkit is an evolving document, but a logical and necessary step on the path to improving our nation's mental health system, and critical to implementing effective managed care for mental health services," Dr. Hughes said. "IAPSRS is already engaged in the next step of development, implementation of the toolkit evaluation system in agencies throughout the United States. We are also working with Canadian agencies to implement the evaluation system." As the Toolkit evolves it will become an essential element for establishing the standard of care for the nation's mental health system and for measuring the system's effectiveness in meeting that standard.

IAPSRS represents nonprofit community-based providers of rehabilitation services for people with serious mental illness. IAPSRS has over 1,600 organizational, individual and professional members across the United States, Canada, Europe and Australia.

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Psychiatric Rehabilitation Association

FORMAT FOR MEDIA ALERT

MEDIA ALERT

FOR IMMEDIATE RELEASE CONTACT: (Name)

(Date) Phone: (###-###-####)

(TITLE OF EVENT)

(Location of event: City, ST) -- Media Alerts tell the media where, when, & why some event is going to happen, what is going to happen and who is going to be there. The alert includes a VERY brief explanation of the event and CLEARLY indicates the essential facts. Media alerts are never more than one page. PLACE: Give location and address, and room if necessary. DATE: Month, Date, year. TIME: Hour, including am or pm. The ### sign indicates to reporters the end of the alert.

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SAMPLE MEDIA ALERT

MEDIA ALERT

FOR IMMEDIATE RELEASE CONTACT: Paul Seifert

December 5, 1995 (410) 730-7190

IAPSRS ANNOUNCES TOOLKIT PROJECT FOR MEASURING REHABILITATION OUTCOMES

Washington, D.C. -- On December 14th, the International Association of Psycho-social Rehabilitation Services will announce its Toolkit Project for measuring the outcomes of rehabilitation programs that serve people with severe mental illness. The Toolkit is the first comprehensive effort to measure the outcomes of rehabilitation programs for people with serious mental illness on a nationwide basis across a broad spectrum of programs with various levels of sophistication.

PLACE: National Press Club

Peter Lisagor Room

14th & F Streets N.W., Washington, D.C.

DATE: Thursday, December 14, 1995

TIME: 10:00 a.m. EST

Dr. Ruth Hughes of IAPSRS, will be joined by Dr. Paul Arns who chaired the IAPSRS Toolkit Research Committee and Dr. Steve Leff of HSRI. HSRI produced the Toolkit for distribution. IAPSRS President-elect Scott Graham will also join the panel. Completing the panel will be a representative from the Center for Mental Health Services. CMHS funded the Toolkit project.

The International Association of Psychosocial Rehabilitation Services represent non-profit community-based rehabilitation programs whose goal is to foster independence and self-reliance in people with severe mental disabilities.

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ENDNOTES

1. From *Organizing a Lobbying Campaign*, May 1994 PRA Conference, Herb Cromwell presenter.
2. *National Mental Health Association Advocacy Primer: A Toolkit for Promoting Positive Health Care Reform Through Education and Advocacy*, December 1998.
3. *ibid.*

Federal Housing Resource Guide, Technical Assistance Collaborative, Boston, MA, July 1999