

The Key



'Knowledge is the key to open new doors'

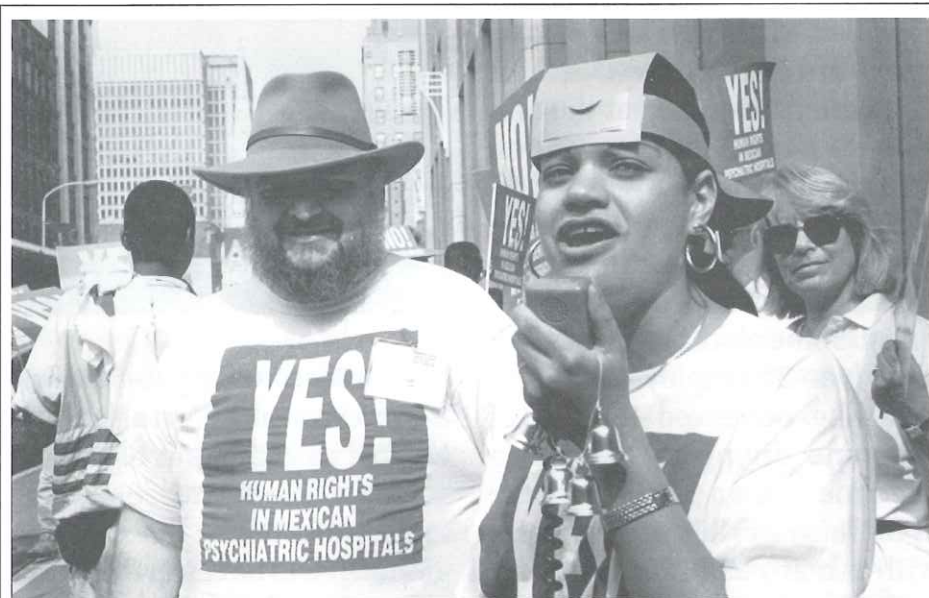
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NATIONAL MENTAL HEALTH CONSUMERS' SELF-HELP CLEARINGHOUSE NEWSLETTER

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Consumers seeking managed care reform face uphill struggle in state-level advocacy



Making our voices heard through demonstrations (American Psychiatric Association annual meeting, Philadelphia, 5/25/94). See story Page 5. — Photo by Harvey Finkle

By Violet Phillips

As managed care becomes a reality in more and more states, consumers, family members and advocates are facing their own hard reality — the difficulty in influencing systems that too often are over-complicated and unresponsive or may have been developed without their input. And with few federal laws protecting consumer interests, the process is just that much tougher.

"The consumer/family/advocate...
(See **BATTLE** on Page 14)

Collaborative leadership conference will be 'first major consumer event in nation's capital'

By Laura Smith

Plans are under way for "Coming Together in '98: United in Leadership," the Clifford W. Beers Annual Conference — the largest collaborative event between the National Mental Health Association (NMHA) and The

National Mental Health Consumers' Self-Help Clearinghouse. As this partnership grows, so do the advantages to everyone involved.

Location is one benefit. Scheduled for June 6-10, 1998, at the Hyatt Regency Crystal City in Arlington, Virginia, the confer-

ence is important for its proximity to the country's power base. "This is the first major consumer event to take place in the nation's capital," said Joseph Rogers, Clearinghouse executive director.

Innovation is another attraction. Attendees of this joint annual...
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The Key is funded by the Community Support Program of the federal Center for Mental Health Services.

Inside The Key:

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About non-violent direct action, and the importance of preparation. Page 6.

Anatomy of a press release — essential in advance of a demonstration. Page 9.

Learning the Ropes:

'When I got here, I saw what seemed to me a miracle . . .'

By Marie D. Verna

I'm happy to have the opportunity to introduce myself to all of you. Last May, I became the program manager of the National Mental Health Consumers' Self-Help Clearinghouse. I replaced Tom Leibfried, who has moved on to direct the new Office of Consumer Advocacy at the National Mental Health Association in Washington, D.C.

Previously, I spent 18 years in the private sector as a business writer, editor and training specialist. Some places I worked had as few as 25 employees — and there I experienced the fun of everyone diving in to meet a deadline or get a product out the door. I also worked at companies with as many as 40,000 people — such as my last employer, Merrill Lynch, where I learned the best practices of business.

Before I started working here, I had never thought about whether I was a consumer, a patient, a survivor . . . I was simply a person who had a mental illness, who needed to take care of myself, who needed medication and who would do anything to avoid a relapse, a breakdown or a hospitalization. I was also someone who couldn't tell anyone at work about my mental illness.

When I got here, I saw firsthand what seemed to me a



Marie D. Verna

. . . Clearinghouse program manager miracle: consumers reaching out to other consumers as equals and saying, "We share something. Let's walk down this road together. It will be easier that way."

I'm proud that the Clearinghouse is a leader in making this miracle happen. Each time someone calls here, our staff tries to provide sensitive, high-quality information and technical assistance. Some callers are just beginning to organize; others are operating sophisticated peer-run services; still others are first reaching out to their peers and may not know where to turn.

At the Clearinghouse, it's not "one-size-fits-all." No matter what the question or problem, our consumer staff members are

(Please see VERNA on Page 11)

What's new:

Clearinghouse plans initiatives to support growth of c/s/x movement across U.S.

By Joseph A. Rogers

Look for new initiatives from the National Mental Health Consumers' Self-Help Clearinghouse as we bring innovative methods and technologies to our job of providing technical assistance to the c/s/x (consumer/survivor/ex-patient) movement nationwide.

The movement is poised to complete its transition from a vision shared by a few far-flung leaders and groups to a popular movement that is a catalyst for systems change and social justice in thousands of communities across the U.S. To make this happen, local leaders, and c/s/x'ers who haven't yet thought of themselves as leaders, need only basic skills and techniques proven successful by their peers. That's where the Clearinghouse fits in.

The Clearinghouse has already provided technical assistance, information and support to several thousand individuals and groups over the past six years under a Center for Mental Health Services (CMHS) national technical assistance center grant, and an additional four years under previous federal grants.

Now our goal is to see that every community in the U.S. has at least one self-help group for every consumer who wants to

participate. Another goal is to see significant numbers of funded consumer-run services in every state as the consensus grows that self-help and consumer-run services are vital to the continuum of services needed by people with serious mental illness.

Meanwhile, the Clearinghouse recognizes that consumer-run programs need information that is far more sophisticated than a few "do's and don'ts" for starting a self-help group in a church basement. The Clearinghouse must provide information on topics as diverse as personnel issues,

such as employee health benefits; effective board membership; and obtaining funding from managed care organizations.

Here's how we plan to meet the movement's changing needs.

- Recognizing that many consumers need technical assistance but cannot afford in-person consultation, the Clearinghouse has started work on a project (supported by CMHS) to develop "toolkits," innovative materials for consumer groups across the country. The toolkits are reusable and portable and can serve

(Please see **ROGERS** on Page 10)

Clearinghouse workshops at Alternatives '98

Be sure to check out two workshops given by Clearinghouse staffers at Alternatives '98. If you're not attending, call us at 800-553-4539 to get copies of handouts.

- **Is Your Technical Assistance Technical Enough?**

Joseph Rogers, Executive Director / Marie Verna, Program Manager

This workshop will describe the technical assistance efforts of the National Mental Health Consumers' Self-Help Clearinghouse and help attendees understand the services available to them as they organize for change. As

the mental health care arena changes, consumers' needs for technical assistance become more sophisticated and, in fact, more technical.

- **Self-Help on the Internet**
Seth Margolies, Project Coordinator / Alex Morisey, Project Coordinator

In addition to face-to-face self-help groups, many are available via the Internet. These include newsgroups on various issues, mailing lists, bulletin boards and interactive chats. This workshop is designed for people who have little or no understanding of the Internet. — MDV

Fighting for social justice

NMHA, Clearinghouse forge partnership

By Michael M. Faenza

The National Mental Health Association's partnership with the National Mental Health Consumers' Self-Help Clearinghouse is important to the Association for both practical and moral reasons.

Mental Health Association advocates across the country have long noted that Clifford Beers, who suffered from bipolar disorder in the early 1900s, founded what later became the National Mental Health Association (NMHA). Throughout our history, this has had huge implications for the Mental Health Association movement.

All social movements are, at some level, bureaucracies that ebb and flow with changes in everything from setting strategic priorities to integrating fundamental values. The Key has asked me to give a personal view of NMHA's relationship with the Clearinghouse and with the larger, consumer-run Mental Health Association of Southeastern Pennsylvania (MHASP).

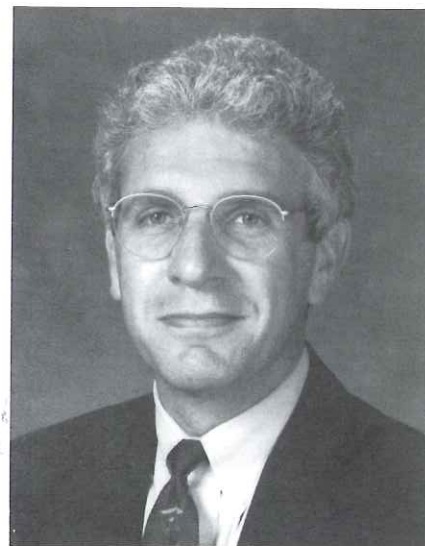
Our partnership has already been productive — first at the level of social justice and fairness, where it affects how we at NMHA use the resource that is the Mental

Health Association movement. Some of the most important work NMHA has done in years — through joint communications, planning and activities with the Clearinghouse — is the assistance we give our affiliates in fostering consumer empowerment and organizing.

Our partnership with the Clearinghouse is developing in an unprecedented and exciting way in "Coming Together in '98: United in Leadership," the Clifford W. Beers conference, planned for June 6-10, 1998. It reveals itself in our work together through the National Managed Care Consortium to build collaboration among national consumer and family organizations to protect consumer and family interests in state health care reform. It is active in Tom Leibfried's consumer advocacy at NMHA.

Placing Tom Leibfried, immediate past program manager of the Clearinghouse, as director of our new Office of Consumer Advocacy (in partnership with MHASP and the Clearinghouse) was NMHA's first concrete move toward integration with the consumer movement in many years.

Joseph Rogers and his colleagues at the Clearinghouse have long been leaders within the mental health movement



Michael M. Faenza

... NMHA president and CEO and, most specifically, within the consumer empowerment movement. The Clearinghouse and Joe Rogers' tenacity and strategic leadership are forces that are clearly impacting the NMHA movement.

I believe a consumer-centered and -driven effort within MHAs has the potential to significantly change how Americans see and respond to people with mental health needs. The idea that people with mental health disorders can shape and implement diverse initiatives that respond to public health concerns is very exciting.

Many of us believe the consumer movement has had a very difficult time in nationalizing and focusing itself as

(Please see FAENZA on Page 12)

Organize a demonstration to make your voice heard

By Susan Rogers

A versatile tool in any community organizer's toolkit is the demonstration. This means attracting as many people as possible — united in purpose and accompanied by flyers, picket signs, a bullhorn, and the media — to the same place at the same time.

"At the very least, collective actions boost participants' self-esteem and sense of community, and increase public awareness of the problems we face," said Clearinghouse executive director Joseph A. Rogers. "At best, they can turn the system upside down."

The ideal demonstration is thus designed to — and does — change the status quo. Other reasons to demonstrate are to publicize your demands, to call attention to injustice, to announce that there will be no "business as usual" until your voice is heard, and/or to show that you are an organized constituency that must be reckoned with. (As gay rights activists have chanted, "We're here; we're queer; get used to it!")

Said Rogers: "A lot of advocacy takes place in meeting rooms and over the phone. But when that breaks down, how else can you communicate to the powers-that-be that what they've done is not acceptable except by taking it to the streets?"

You can demonstrate and stay completely within the law, or you can perform non-violent direct action. (See box on Page 6).

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

Rogers said: "I've seen good campaigns start with a handful of people outside a supermarket [to support the lettuce boycott]. Each month we grew in size, until shoppers didn't want to enter the store," which was finally forced to close, he said.

Whatever your purpose, the steps in organizing a demonstration remain essentially the same.

1. Determine your goal.

"A goal can be as broad or specific as you choose," said Robert M. Smith, staff coordinator of the Brandywine Peace Community, a Swarthmore, Pennsylvania-based group that works for the economic conversion of weapons-producing corporations. "The most important thing is to determine the relationship of your goal to your target. It's

one thing to stand [on a street corner] and talk about human rights; it's another to do it in front of a weapons company."

2. Frame your goal in positive terms.

While this is not always possible, "it's always better to demonstrate *for* something than against it," said Rogers. "The press responds better." For example, a few years ago, when Philadelphia police shot and killed a man who was homeless and had mental illness after he had thrown a bottle at them, the Mental Health Association of Southeastern Pennsylvania (of which Rogers is also executive director) picketed the precinct involved, demanding that the mayor sign a bill, approved by City Council, establishing a civilian review board to monitor the Police Department. (The Mayor signed.)

3. Be ready to negotiate.

"Even when you're demonstrating against something, offer positive solutions," said Rogers.

(Please see ORGANIZE on Page 6)

*Publicize demands.
Call attention to
injustice. Change
the status quo.*

Think through advocacy strategy before planning a demonstration

(ORGANIZE from previous page)

"When the people [you are targeting] agree to meet with you, it's bad form not to be prepared."

Rogers recalled an early demonstration with the Mental Health Association, in May 1985: he and four others (including this reporter), supported by other demonstrators, chained themselves to the gates of Philadelphia's Public Housing Authority. The demand: that the Authority retract some proposed policies that would have discriminated against people with mental illness.

"We had been refused a meeting," Rogers said. "So we said, 'If you won't let us in, we won't let you out.' " The padlocks and chains created a "photo opportunity"; the press gave it great coverage. The Authority agreed to a meeting and rescinded the proposed policies. (The federal government later outlawed such discrimination.)

"The price of a successful attack is a constructive alternative," wrote community organizer Saul Alinsky in "Rules for Radicals." "You cannot risk being trapped by the enemy in his sudden agreement with your demand and saying, 'You're right — we don't know what to do about this issue. Now you tell us.'"

4. Think of a gimmick.

A "gimmick" will give your event color. "That kind of dra-

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About non-violent direct action

"Committing civil disobedience [also called non-violent direct action] means stepping over the line and breaking the law," said Joseph A. Rogers, executive director of the Clearinghouse. "For example, you might occupy a private space — move inside the lobby of an insurance company, where you're not legally allowed to demonstrate.

"There are risks and consequences when you do that," Rogers added. "You can be arrested, although in most areas you would just get a simple fine. Before you contemplate such an action, make sure you have legal help and support, and that your group is disciplined and non-violent. If people get into fights with the police, resist arrest or damage property, instead of a simple misdemeanor you can be charged with a felony."

In any demonstration, "people must understand what is acceptable behavior, and what is not," said Robert M. Smith, staff coordinator of the Brandywine Peace Community. "That is especially the case with civil disobedience."

Brandywine does not allow demonstrators to participate in civil disobedience unless

they attend a preparation meeting. The following is excerpted and adapted from Brandywine's guidelines, which conclude with a notice that the organization "has no funds available for bond and/or fines, nor can Brandywine be responsible for providing legal assistance and/or representation if desired in any court proceeding(s).

"We will observe with co-actors, police, [our target's] employees, and passersby the rules of human courtesy. We will exhibit no hostility (physical or verbal) toward anyone. . . . We will trust in the representation and facilitation of the designated coordinators."

For those doing non-violent civil disobedience:

"When asked to leave by [our target's] security or police, we will politely decline When we are placed under arrest, we will go peacefully, for we understand the legal jeopardy of our witness. Those of us who choose non-cooperation also understand that [this] does not mean resisting arrest; 'going limp' means to assume a posture of stillness. We will commit no acts that could endanger anyone. . . ." — SR

With flyers, phone calls and Web sites, get word out about your demonstration

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matic flair may interest the media," Rogers said. It may also make it more fun; as Alinsky wrote, "A good tactic is one that your people enjoy." That's why many such events include music.

The color may be guerrilla theater or costumes or what-have-you. At one in a series of demonstrations a few years ago at Philadelphia's City Hall to protest budget cutbacks, someone carried a nearly lifesize effigy of the City Council president. At another of the protests, near Halloween, people wore masks.

5. Choose a date, time and place for the demonstration.

This will be determined by what you are trying to accomplish. It may also be determined by the fact that a large number of your constituents are gathering — at a conference, for instance. If you provide a reason for people to rally and the people are already there, they will come.

6. Develop a flyer to alert your network about the event.

The flyer must include the time, date, place and reason for the event.

7. Disseminate the flyer.

Spread the flyer as broadly as possible by fax and mail (if you have time) and on the Web. If you don't have a Web site, ask sympathetic organizations to publicize it on theirs. What Woody Allen said about life — ninety percent of it is showing up — is

also true of demonstrations.

8. Follow up with phone calls.

If possible, call people to encourage them to join you. It is especially useful to call other organizations and coalitions who support your goals, so that they can turn around and urge their participants and members to attend the event.

9. Alert the media.

If a tree falls in the forest and no one is around to hear it, does it make a sound? No — and neither does a demonstration if there is no one to report it.

You can alert the media by issuing a press release. (See box on Page 9.)

Assemble several "press packets" — with background information about your group and the issues you're addressing. At least, bring copies of the press release.

Assign someone to watch out for press — easily identified by their TV cameras or other camera equipment, microphones or notebooks — and give them a press packet or release. The "press liaison" should offer to introduce the reporter to the leaders. Many reporters will also want to seek interviews from among the crowd without guidance.

Never tell the press how many people you expect; if you fall short, you'll lose credibility and the press may report the event a failure. (If you're asked in advance, say something like, "I hope there will be a good turnout so

that we will be able to communicate [your message]."

10. Find out if you need a permit.

"Luckily, we live in a country where we have the right to free speech, the right to assemble and express grievances, which is what a demonstration is," Rogers said.

"All demonstrations should be peaceful; most can be legal," he

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The Key

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From permits to picket signs, organizing a demonstration requires preparation

(ORGANIZE from previous page) continued. "In general, you have a right to demonstrate in any public place as long as you're not blocking access." Under some conditions, if there are problems in front of the building the target may ask you to move across the street, he said. And a loudspeaker may be allowed only during certain hours and not in a hospital zone. Different cities may have different rules about permits, he added; check in advance.

However, if your plan is to assemble a large crowd and march in the streets, you will need your route closed to traffic. You will thus need a permit and the help of the police.

11. Decide whether to notify the police.

"We notify the police when it is an openly announced action," said Smith of the Brandywine Peace Community. "Generally, he added, "non-pre-announced actions should be the exception." Publicity expands participation.

Big-city police departments may have Civil Affairs departments, whose job includes being present at demonstrations and, in effect, helping them run smoothly. In smaller towns or rural areas, this will probably not be the case. However, treat the police with respect at all times!

"Gandhi used to say that we need the energy of those who would oppose us," Smith said. However, he added, "one pitfall

is to almost turn the police into the enemy. The issue becomes people's conduct in regard to the police, rather than the injustice that people are decrying."

12. Write slogans and chants.

Chanting will communicate your message and unify your participants. One chant applicable to many situations is, "No justice, no peace!" However, you should also tailor some of the chants to your goals.

13. Make picket signs.

Use some of your slogans and chants for your signs. Again, your point is to communicate your message; be as specific and pithy as possible.

14. Develop a handout.

An informational handout is important for participants as well as passersby.

"Often people who participate in demonstrations have a sense

of why they're there, but they don't always have the background to understand why they're at that particular point [where a demonstration has been organized]," said Smith. "It's important to have the participants knowledgeable as to the goal and the particular focus."

You must also educate passersby, some of whom may be sympathetic and may take up the banner. One of your purposes is to expand public awareness of your cause and handing out flyers helps accomplish this.

15. Follow through.

Afterwards, follow up press calls and issue another press release if you achieved any results you want to announce. "Never anticipate your turnout," said Rogers, "but if you get a bigger crowd than you thought you

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Justin Dart, Jr., receives Medal of Freedom

Justin Dart, Jr., is among the 15 distinguished Americans who received the Presidential Medal of Freedom, the nation's highest civilian honor, from President Clinton on Jan. 15, 1998.

The White House issued the following statement: "Considered the father of the historic Americans with Disabilities Act, Justin Dart has worked from his wheelchair for more than 40 years to expand the rights of others.

From his days at the University of Houston organizing a civil rights initiative to his government service to his trailblazing work on behalf of people with disabilities, Dart has profoundly influenced the public policy of this nation."

Among other honorees are civil rights leaders James Farmer and Arnold Aronson, Cherokee Nation leader Wilma Mankiller, and philanthropist Brooke Astor.

Effective follow-through maintains demonstration's advocacy momentum

(ORGANIZE from previous page) would, crow about it. And if public officials made any promises, publicizing the promises may put pressure on the officials to follow through. You may also get some coverage from media that didn't cover the event itself."

Don't lose your momentum. "You may need to do multiple demonstrations at the same site — or long ones — to make your point," said Rogers.

Sometimes your actions achieve the hoped-for results.

Rogers described a "sleep-out" on the steps of the State Office Building in Philadelphia, in October 1987. The event was organized by Project SHARE [a Philadelphia-based consumer-run advocacy organization founded and led by Rogers] in coalition with two organizations of homeless activists.

"Our demands were simple: decent, affordable, permanent housing for homeless people with mental illness, who were not being adequately served in the existing system," Rogers said.

"We were prepared to stay all winter," he said, "but only 36 hours had passed before the Secretary of the Department of Public Welfare arrived from the state capital to meet with us, and promised [and later delivered] several million dollars to establish 'low-demand,' long-term residences for homeless people with mental illness."

Anatomy of a press release

An effective press release is like a short news article — no more than about 400 words, if possible. The release should be on your group's letterhead; under the letterhead, identify it as a Press Release. It should include a headline — e.g., "Rights group to rally at State Capitol to protest mental health budget cuts," and a dateline, including the town or city where your group is based or where the demonstration will take place. For example, if you are holding the event in your state capital but are based some distance away and are trying to attract the press that covers the capital, use the capital in the dateline.

At the top, above the headline, write "For immediate release." While you can issue a press release and ask that it be held for release later on, you have a better chance of interesting news organizations if you make the story seem more immediate.

The first few lines of the press release should answer the five W's: Who, What, Where, When and Why. For example: "A group of people who have mental illnesses and their supporters will rally at the State Capitol on Mon-

day, January 12, at 9 a.m. to demand that the Governor reinstate the funds cut from the budget for mental health services."

Include some background on the issues; you may also include quotes from organizers of the event. At the top or bottom, provide the name and phone or beeper number of one or two reliable contact persons who will be at their phones, carry their beepers or check their answering machines at least hourly.

Direct the press release to the assignment editors at the local media. If possible, follow up with phone calls. Ideally, your group will have developed a relationship with some reporters who cover your issues; contact them. (Don't address a press release to more than one person at any one news medium.)

When should you issue your release? To daily newspapers, radio and TV, roughly 24 hours in advance. Weeklies need more time (if you have it); find out their deadlines. Fax, e-mail or hand-deliver your release if possible. (For those who can afford their fees, there are also wire services, such as PR Newswire.) — SR

Executive Director discusses new plans for Clearinghouse initiatives

(ROGERS from Page 3)

as the basis of a training session by consumers with even a minimal understanding of the subject. Each comes complete with audio/video tapes of a training, a master set of handouts for reproduction, audio/visual materials such as overhead transparencies and slides (if applicable), and a short manual on how to conduct the training. The Clearinghouse is considering toolkits on establishing a drop-in center, peer support, spreading the word about your group, rights protection and advocacy, and developing consumer-run businesses.

- To support the increased sophistication of technical assistance needs, the Clearinghouse will completely rework its library of publications. All will undergo massive revision, using movement leaders as subject matter experts, who will also help the Clearinghouse select new topics.

- To disseminate this expanded information, the Clearinghouse is also redesigning its Web site so that its full set of programs, services and publications are more accessible.

- The Clearinghouse uses its Web site, e-mail, and our *listserv* ("TheKey") to communicate about technical assistance with Internet users. This list currently includes 350 subscribers and grows weekly. To stay in close touch with the Clearinghouse, you can subscribe through direc-

tions on the Clearinghouse Web site: <http://libertynet.org/~mha/cl_house.html>.

- Information services provided through the Clearinghouse's toll-free phone number will be enhanced by expanding the library of technical assistance materials.

- The Clearinghouse will continue to provide on-site consultations and trainings in cooperation with a nationwide network of diverse consultants, many of whom are veteran movement leaders. A typical consultation consists of a one- to three-day in-person training, focusing on needs identified by the group requesting the consultation; the consultant is selected based on his or her skills in that area. The toolkits (see above) are designed to meet many of the same needs when an on-site consultation is not practical.

- The Clearinghouse has provided timely information to movement leaders through periodic mailings for many years. We are now overhauling our database to better target these mailings and to improve the focus of referrals to c/s/x organizations. Our new database capabilities will expand our ability to track and communicate new movement efforts and better respond to the people we serve.

- Since its inception, the Clearinghouse has enhanced its technical assistance capabilities and

reached new constituencies by building coalitions. Our alliance with the National Mental Health Association (NMHA) will create valuable new links between consumers and local Mental Health Associations. The Coming Together in '98 conference is key to this effort. (See story on Page 1.)

- Work is also under way with Chilton Research Services on a CMHS-sponsored consumer self-help survey. Its purpose is to gain recognition for self-help in managed care programs and to address the issue in national mental health care reform policy.

Our goals and methods always reflect the fluid needs of the movement, so it's a sure bet that the Clearinghouse will roll out new initiatives in the years ahead. We are now in the third year of our second three-year contract with CMHS. The fact that CMHS is initiating another competitive grant process for technical assistance centers tells us we're doing a good job. We look forward to presenting a well-researched, well-thought-out proposal and, if awarded a third grant, will be happy to continue our work.

This progress could not have occurred without the support of our peers in the c/s/x movement, who communicated clearly through letters to CMHS that technical assistance centers are necessary. The Clearinghouse thanks all those who have supported our work.

Clearinghouse program manager reflects on mental health movement

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ready to help.

It's no accident that Clearinghouse staff members are good at their jobs. Part of my work here is to create positions for mental health consumers that match their skills, present opportunities for growth, and help them in their recovery. Everyone who works here, including myself, feels safe to learn, practice and make positive contributions. We feel free to acknowledge that we are mental health consumers with dreams of more than what the world has offered us so far, dreams we share with everyone else in the consumer/survivor movement.

Before I came here, I had never thought about a mental health "movement." I believed my mental health was entirely my responsibility; so what did it matter if consumers, families and advocates were organizing for change?

My single most difficult challenge since I came here has been to study and understand the movement—its past, present and goals for the future. The historical details are easy to learn; the philosophies, conflicts, motivations and personalities have been much more difficult to comprehend. In fact, the movement reminds me of a major historical event in my family of origin—the family portrait.

I come from a family of 11 children, so most projects we try

to accomplish, much like projects in the mental health movement, require tremendous negotiation and compromise. Of my family memories, the family portrait reminds me most of the movement efforts I've been involved in.

The most obvious comparison has been the time it can take to complete what might appear to be a simple task. My siblings and I needed 14 years and four attempts before we were able to present to my parents a half-decent formal photograph of all 11 of us. Because I had been the major organizer of the family portrait, I've often asked myself, "What took so long?" Just as in the movement, the answer has been, "An abundance of passionate, determined, vocal individuals, each working toward his or her own vision of what's right."

My youngest sister, for example, still berates me for scheduling the second attempt a week before she was to have braces removed. I suppose she couldn't visualize the portrait with silver across her teeth—even though the other 10 siblings were absolutely unable to schedule another time. And every in-law in the family still questions why they weren't included in the final shot.

Just as with movement efforts, I found myself asking then, "What's right if everybody's right? How can everyone be accommodated equally?" With the family portrait, my siblings and I had

the luxury of a defined end-product. We'd even heard our parents specifically ask for it. But what is the goal of the mental health movement? Is it even fair to say there's only one? Can we define it? Can we bring our visions of what's right into focus?

In 1969, my siblings and I started working on the family portrait; in 1983 we presented it to our parents. Looking back, it probably took too much time, too much energy, too many hurt feelings. But in the entire universe, no other proof exists that my parents created a beautiful family of 11 children who remain good friends.

And nowhere else in the universe is there evidence that anyone cares about the struggles of people who have mental illness aside from those active in the mental health movement: consumers, family members, advocates, providers and friends. For the sake of those who struggle in ways that only we know, let's bring together our visions of what's right. Let's look for the tangible end-products that give evidence that mental health consumers will reach their dreams. Let's unify and accomplish!

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Faenza discusses advocacy partnership between Clearinghouse and NMHA

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an identifiable force in public policy and services development. I believe that NMHA, when operating with independence and in a way that is true to its consumer-created legacy, is a vehicle that can bring consumer empowerment and influence more effectively into the larger "community mental health movement."

Consumer interests and empowerment will be increasingly central to NMHA's work as it

proceeds on its current road toward more assertive and focused advocacy motivated by a sense of social justice. Taking risks and making changes is important for the survival and strengthening of any organization; NMHA will grow and stumble and learn — and ultimately become a better force for social justice for people with mental illnesses.

My personal history is one of transitions and growth. I am a social worker, a community or-

ganizer and a clinician. I have a special interest and background in juvenile and criminal justice system issues and some clinical experience working with victims and perpetrators of sexual abuse. I also experienced significant emotional problems as a youngster and continue to suffer from clinical depression.

I have invested years in understanding and trying to change how juvenile justice systems respond to troubled children and into advocating and planning for resources to support outreach and responses to people who are homeless and suffer from mental and addictive disorders. A broad diversity of issues finds a comfortable home within NMHA, and my personal experiences and professional roles provide solid context for my work within the Mental Health Association movement.

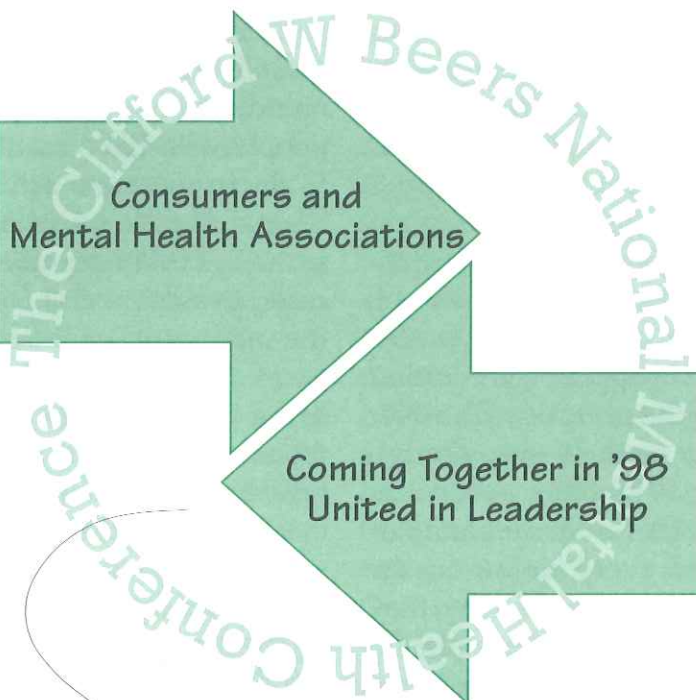
Perhaps the promise of the consumer movement in the U.S. will be increasingly realized through its integration and partnership with children's advocates (and professionals who have the hearts of advocates) and with family members and the range of citizens who care about individual and community well-being.

I don't see a vehicle out there better equipped conceptually or structurally than NMHA to realize this goal, and I don't see a more important partnership for NMHA than our collaboration with the Clearinghouse to fuel and help guide our movement.

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—Presented By—



A result of partnership with NMHA, conference will provide diverse training

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nual meeting will participate in the creation of a movement to combine consumer and Mental Health Association resources, with members of both organizations having the opportunity to draw on each others' knowledge and experience. "Consumers and Mental Health Associations share a great deal of common ground," said Michael M. Faenza, NMHA president and CEO. " 'Coming Together in '98' will be our first tangible opportunity to explore that ground together."

"I see this collaboration as a win-win situation," added Marie Verna, Clearinghouse program manager. "NMHA wins because the Clearinghouse brings a clear consumer voice to the table, and the Clearinghouse wins because NMHA brings a highly recognized, national organization."

The agenda for the conference is being designed around these mutual strengths. So far, 80 workshops are planned on such significant topics as consumer issues (such as the ADA, rights, managed health care); consumer-run programs; consumer/MHA partnerships; managing mental illness to prevent disability; agency/non-profit growth and development; advocacy training, and children's issues.

There will also be many opportunities for representatives from local communities to share their experiences with changes in health care. "Health care re-

form is happening on a local level," said Rogers. "This national training is important so we can learn from each other about the good things that are happening around the nation and also learn from the mistakes that have already been made."

The conference will kick off with a consumer leadership plenary. The session will feature consumer movement leaders discussing what has been done, what is being done and what needs to be done to improve consumers' lives. The plenary will include discussions on developing relationships with Mental Health Associations to enhance this important work.

A plenary on juvenile justice will be on the third day of the conference. The session will focus on the results of a national survey on mental health and juvenile justice issues. The proposed agenda starts with a breakfast to discuss the results of the survey, followed by training workshops on juvenile justice and a networking luncheon.

The fourth day of the conference features a public policy plenary planned to involve politicians from Washington who are working on policy issues. Here is an opportunity to find out what is being done by the government and how to be effective in educating policy-makers in order to effect systems change.

The highlight of the closing night dinner will be a speech by

Dr. Martha Manning. Author of "Undercurrents," Manning has struggled with debilitating depression, and her experiences both as a consumer and a psychologist give her a special perspective.

The last day of the conference is focused on government affairs, with featured speaker Gov. Howard Dean of Vermont. Vermont recently passed a broad-based insurance parity law that can be used as an example for other states. The law covers a wide range of mental health concerns for children and for adults, including substance abuse.

The government affairs sessions mark the conclusion of the conference. Afterward, attendees will have an opportunity to take part in Congressional visits and a rally at the Capitol. (More information on this special post-conference event is in the conference registration brochure.) The visits to legislators and the rally offer another opportunity for a show of strength.

"In more than 20 years of organizing, we have always worked to have our voice, the consumers' voice, heard on Capitol Hill," said Rogers.

"This is an opportunity to tell Washington: 'We're here and we aren't going away.' "

For more information on "Coming Together in '98: United in Leadership," please call 1-800-553-4539, ext. 297, or send an e-mail to <THE KEY@delphi.com>.

Facing uphill battle in the states, consumers seek managed care reform

(BATTLE from page 1)

cacy community was knocked off balance by this profound shift in the way health care is delivered," said Rob Gabriele, senior vice president of the National Mental Health Association. "We're used to working under the old social contract between the government and the citizens. We've had to scramble in the past few years."

Managed care, whether offered by a not-for-profit agency or a for-profit corporation, inserts another, even further removed level of control into already complex and aloof state-run health care delivery systems. That new level usually represents service contracts worth hundreds of millions of dollars. "Not only is it hard for consumers to have their voices heard, but purchase of this care is being done at a very high level of government," said Joseph Rogers, executive director of the National Mental Health Consumers' Self-Help Clearinghouse. "We're not in the driver's seat. This is about managed cash, not managed care."

Consumers and advocates have learned that they must become more sophisticated in how they approach managed care and what they can and should expect from the governments contracting for it. "States are talking the talk in terms of consumer involvement, but not yet walking the walk," said Gabriele. "What we're seeing is that consumers,

families and advocates still have to fight to be part of the early phase of decision-making — often the most important."

Advocates have also had to become increasingly aware of the flow of dollars and how it relates to services rendered. "There's definitely a feeling that state governments are giving up too much power, letting managed care companies have too much leeway in the guise of letting them save money," added Gabriele.

And although it is worthwhile when managed care organizations (MCOs) employ consumers and create consumer advisory boards, the commentary these consumers provide often begins too late in the process. Ideally, consumers, families and advocates should be involved in writing the request for proposal (RFP) that goes out to MCOs and in overseeing the final contract. These are the legally binding documents that will govern what kinds of services the MCO will offer and how they will be offered.

A contract that has been significantly influenced by advocates will include a consumer bill of rights, ombudsmen, clearly defined services — including non-medical services — and a definition of medical necessity that takes into account non-medical needs. The issue of "reinvestment," meaning the amount of money an MCO can take from the system as profit if savings

occur, also must be addressed.

"Ultimately it's a public system," said Rogers, "and we have to hold the states accountable."

But the advocacy community has to do this without significant legal protection. The only binding document is the 1997 Balanced Budget Act, which reauthorized Medicaid funding. Gabriele said that while advocates worked to get a whole menu of items included in the law, from ombudsmen programs to clear definitions of medical necessity, there still aren't enough significant protections written into it.

"States can still write plans without consumer involvement," said Gabriele. "States can decide to have managed care, can write and issue an RFP all without consumer involvement."

And while some beneficial changes were instituted — states over a certain population must offer at least one alternative provider, for example — the result is that consumers "must either depend on an enlightened state bureaucracy or push their way into involvement," said Gabriele.

This is hard in two ways: "States are reluctant to have outsiders in the process because it makes it slower and more difficult." On the other side, "it's hard for us because consumers don't know the business and language of contracting. We can't just go in and say we want more consumer

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Leaders: Input in contracts is key to successful managed care advocacy

(BATTLE from previous page) protections; we must say what kind of services and what rights should be enumerated."

The NMHA has conducted workshops to train groups of consumers, family members and advocates. The training program is twofold — an introduction to managed care and strategies for getting involved in the process. A third session, on rights, will be introduced this year. At the end of the training the groups strategize on what they want to accomplish in the next six to 12 months.

In some states, such as New York, these groups have been effective in influencing the contracting process or in helping to develop a managed care plan.

In other cases, such as Arizona, where ComCare declared bankruptcy last summer, advocates have gotten into the process on the second go-round. "It would have been nice to write it the first time," said Gabriele, "but at least they're involved now."

What the past few years have shown consumers, families and advocates is that they must step up to the plate. The stories from a few states — Arizona, Tennessee, Montana and New York — show the challenges involved.

In Arizona, consumers are getting more influence the second time around — though what this will mean is uncertain.

Last July ComCare, the MCO responsible for Maricopa County (where Phoenix is located), declared bankruptcy with a \$20 million debt. ComCare was developed in 1993 out of the state's system of five Regional Behavioral Health Authorities. It was, according to consumer advocate and service provider Gean Lloyd, "considered the least user-friendly in the state."

Early on, four consumers and four family members were on the board. But soon there were only two, Dr. Max Dine and JoAnn Hayden. "Whenever we tried to get information we were told we were micro-managing," said Dine. "We were...really kept out of knowing exactly what was going on.

"When ComCare started, there was a consumer subcommittee," Dine said. "When we lost that [within six months], we lost whatever real power we could yield."

ComCare was also criticized by consumer advocates for touting its consumer involvement when only a few actually worked there. Dine, on the board of several organizations, left the ComCare board a year and a half ago to join the Arizona Center For Disability Law. But Hayden stayed until last July, when "I resigned in protest of the bankruptcy. I believed they were using funds that should be used for services instead of legal costs."

ComCare is now run by the state, which Hayden termed "inevitable. When ComCare claimed bankruptcy, we just rushed this process by a couple of years."

In September, however, the Department of Health Services began to develop a completely new RFP for Maricopa County with outside input. Hayden was asked by the department to join the System Redesign Committee,

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Advocates: some Arizona lawmakers resent funding mental health care

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which recently completed its proposal. According to Hayden, some of the recommendations include getting consumers in all levels of employment in the next managed care entity.

The process is quite different from her previous experience with ComCare. Then, "I was not listened to as far as increasing funding or involving consumers at any administrative level. This time, not only have I been asked, but I've actually seen it in writing." In fact, increasing consumer involvement is one of their main objectives, she said.

The RFP is now being written "behind closed doors," said Hayden, who knew there was no guarantee that her work would be used. The final version is due within the first quarter of this year.

"There's been more interest in the department in the views of the outside than I've ever seen before," said Ron Page, contracts management specialist for the Arizona Department of Health Services.

Despite contrary perceptions, Page said the department has not decided whether it will recommend that for-profit or not-for-profit entities — or either — will be invited to submit proposals.

Though Hayden said, "I have a lot of doubts about managed care," she believes this crisis is "getting us to move in a positive

direction."

The issue that remains is with the legislature. The only reason Arizona has public mental health care at all is because of a 1981 class action lawsuit that resulted in a law forcing the state to offer care. "Our behavioral health system has been in a state of revolution since the lawsuit," said Hayden. She said there has been more funding than before, but that she has found "resentment" from legislators who are forced to come up with the funding.

Said Dine of Arizona's legislators, "We have very few who are sympathetic to mental health issues." Or as Gean Lloyd puts it, "What's wrong with the state of Arizona's mental health system is the state of Arizona."

Tennessee is "a study in how not to do it," said Gabriele. "They went too fast and didn't get enough consumer and advocacy involvement. Now they're backtracking."

TennCare Partners is the entity responsible for state mental health care in Tennessee; it was spun off from the strictly medical TennCare system. Since July 1996, the agency has been overseeing the for-profit behavioral health organizations (BHOs) charged with administering services (Tennessee Behavioral Health and Premier). But in January 1996, advocates created the TennCare Partners Monitoring Group to

oversee the workings of the system as it got under way. They're still meeting.

The group involves some 30 organizations representing consumers, family members and other advocates—including Tennessee Voices for Children, Tennessee Justice Center, the Tennessee Healthcare Campaign, the Tennessee Alliance for the Mentally Ill (TAMI) and the Nashville Mental Health Association (MHA). "We're a collection of people who don't think the state is doing what they should be doing," said monitoring group chair Wib Smith.

The principal issue, say group members, is accountability for services delivered, or not delivered. "The state has made it very clear to consumers that they don't contract with providers," said Paige Macdonald, program director of the TennCare Partners Advocacy Line out of the Nashville MHA. "The attitude is, 'We contract with the behavioral health organizations; they contract to providers.'"

Both BHOs have the same state contract. Neither, Macdonald added, "is good at giving great service. And there are tremendous data problems between the BHOs and the providers."

"The lack of data makes accountability very difficult—from every level of the system," said Charlotte Bryson, executive di-

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Facing uphill battle in the states, consumers seek managed care reform

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 rector of Tennessee Voices for Children. "We can't track simple things," such as how many children with serious emotional disturbances or people with serious mental illness are being served.

Other issues to be monitored include loss of case management services for children and adults, the virtual disappearance of inpatient drug and alcohol programs and the loss of treatment for individuals with dual diagnoses. The group has also noted complaints of slow BHO payments to providers and cuts in fees for services.

The monitoring group has responded with several actions. First, they have continued to meet regularly since 1996 to identify the weaknesses of the program and report them to the state's TennCare Legislative Oversight Committee, the Bureau of TennCare and the Mental Health Legislative Study Committee.

They have also held public hearings where consumers, providers and advocates told their stories about dealing with the system. These hearings attracted the press and legislators, and witnesses were later invited to testify before legislative subcommittees. They also initiated regular meetings between monitoring group representatives and TennCare Bureau assistant commissioner Theresa Clarke.

"Advocacy groups are heard

by the current administration with great reluctance," said Smith. "We only started getting the attention of the commissioner for health and Theresa Clarke when we started holding public hearings."

The meetings with Clarke have sometimes been helpful, said Macdonald: "She gives us information to try to appease our concerns; and some things have been addressed — delays in paperwork, for example."

But it has also been at those meetings, Macdonald added, that Clarke has made it clear that the state is paying the BHOs and they are the ones to be held accountable for the services provided.

"That's how the system has been conceptualized and implemented," confirms Ann Alderson, director of policy and intergovernmental affairs for the

TennCare Bureau. "We're not focusing on BHO-provider relationships; we're focusing on the service package being delivered to participants."

The state has more than 30 people in its Office of Quality Assurance; but Alderson acknowledges, "We're in the process of getting this system more fine-tuned. I can't tell you its perfect, because it's not."

The monitoring group continues to strategize. The group has been writing to the governor and the Health Care Financing Administration (HCFA) about the weaknesses in the system.

"We are also considering an ad campaign talking about how bad things really are," said Smith.

"We push the issues," said Bryson. "The providers say there's not enough money in the

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New book profiles Clearinghouse's Rogers

Joseph Rogers, executive director of the Clearinghouse, is among the 100 people and organizations to be profiled in "Stone Soup for the World: Life-Changing Stories of Kindness & Courageous Acts of Service."

The publisher, Conari Press of Berkeley, California, says that the book "... begins with what one person can do and proceeds in ever-widening circles to the simple efforts that can and have

impacted the global village."

"Stone Soup for the World" includes a resource guide "as well as a directory to link readers to a vast array of community-building organizations," the publisher adds.

To coincide with National Volunteer Week, Conari Press is putting together what it describes as "the World's Largest Booksigning" at bookstores around the U.S. on April 17, 1998.

In Montana, managed care brings absurdities, frustration, advocates say

(BATTLE from previous page)
system; the state says there is. The contract calls for case management... someone needs to monitor that.

"We just want accountability," she added. "We have been vocal from the very first day and we just plan to keep on."

Last April, Montana instituted its statewide mental health managed care plan. Its development involved a couple of years of debate, legislative action and an RFP process that resulted in the for-profit corporation CMG being awarded the \$400 million contract. "It's been a Fellini movie ever since," said Wesley Alcorn, Consumer Council president of the National Alliance for the Mentally Ill (NAMI) and board member of the Montana AMI.

Montana is an extreme example of the complications that can occur when the corporate sector meets the public sector. A few months after CMG took on the state contract, the company was sold to Merit, a larger BHO. In the last few months, Merit was bought by Magellan.

"There were tremendous upheavals in the system when Merit bought CMG and when Magellan bought Merit," said Alcorn, who is among the consumers advocating on the state and federal level.

The problems were largely

administrative. The information management systems have been inadequate; consumers had trouble getting into the system and providers were not being paid. "There was a real bottleneck at first," said Laurie Ekanger, director of the state Department of Health and Human Services. "It would have been problematic under the best of circumstances, but the company's system really staggered."

Alcorn blames the mess partly on the choice of company. Consumers and advocates did not want the state to go with CMG because it had never run a public contract before. Their choice was Vista, which had — and which had already invested in a substantial computer system. Though there was consumer representation on the selection committee and public hearings were held, Alcorn considers the process flawed. (So did Vista, which sued and got a \$1.2 million settlement.) Flawed or not, he said, the selection process did come up with CMG but the state still got Merit, a company that had bid "and was specifically rejected."

But Ekanger, who is open about her concerns with the system, does not consider this the central issue. "From our point of view, we have a contract. Whoever is the corporate parent is bound by the contract and held to the same performance standards," she said. "The bottom

line is, we don't care who holds the majority shares as long as they get the claims paid."

To Ekanger, the Merit purchase was beneficial because the company became much more involved in operations, which she said have improved. "Our confidence bottomed out in October," she said, noting that the state had withheld payments to CMG at times. "But we've seen a big improvement in getting providers paid. We're no longer despairing; you could say we're cautiously optimistic."

But this cautious optimism relates to an improvement in the most basic aspect of the system's structure: the administrative functions. Actual quality service to consumers is barely mentioned, and Ekanger is aware of the discrepancy. "Our own jury is still out on whether this company is going to get us to the vision we had of really innovative consumer services. Ask us again in six months."

Alcorn has been writing HCFA in his capacity as NAMI Consumer Council president. "The bigger issue is how much oversight is going to exist with these waivers," he said. "This first foray has hurt the least organized and the most disenfranchised."

"Instead of doing a pilot project, which the state now admits they should have, they did the whole state," he added.

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New York leaders hope for user-friendly mental health managed care system

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"These are just some of the things the federal government didn't take into consideration when granting these waivers."

There has been advocacy along the way: consumers and advocates were on the selection committee, they sit on the board of the Montana Community Partners (the non-profit corporation that oversees the corporate contract) and consumers work as advocates in the BHOs. But Alcorn does not think the effect of this input should be overstated.

"Consumers, families and advocates were either tokenized or marginalized out of the process," he said. "We need to say to the state politicians that fee-for-service was a failure, but turning this over to the private sector is foolish. We're the consumers. We're the advocates and the families. And we'll tell you what's money best spent."

New York state does not yet have a cohesive plan for managed care in mental health services. But a plan is now being developed for a new system and there are hopes that it will be consumer-friendly — due in degree to a managed care bill of rights passed into law two years ago, a strong grassroots advocacy community that continues to develop, and enlightened leadership at the state level.

The law was prompted by the

lack of choice and consumer protection in the managed care that had been developed for the state's health system. But its provisions are so written — particularly in holding managed care companies accountable for service — that they can directly apply to mental health care.

Advocates have come together in part because of trainings given by the state Mental Health Association and sponsored by the state Office of Mental Health. These trainings are similar to those sponsored by the NMHA. "We've had 15 teams over the past three years from all over the state and New York City," said Joseph Glazer, president and CEO of the Mental Health Association in New York State. The result is that not only do these coalition members return to their communities with training and advocacy plans, they are able to contribute their influence to statewide initiatives.

For the past two years, the Office of Mental Health in New York, with the Department of Health, has been writing a plan that will introduce mental health managed care to people who receive Medicaid. Glazer said the state will use a mechanism known as Special Needs Plans (SNPs), so-called because they are intended to offer services to those consumers who meet specific criteria. According to Glazer, the state plans to introduce SNPs in a

few demonstration projects within the next year.

"Our Office of Mental Health has shown a very good commitment to ensuring that managed care works for people," said Glazer. To that end, many advocacy groups have been involved in developing the system, including the children's advocacy group Families Together, the largely consumer Resource Center for Systems Advocacy and the New York Association for Psychiatric Rehabilitation Services.

Said Glazer: "We can literally point to changes in the SNP that have been made because of our influence" — changes such as the exclusion of prior authorization and drug formularies, an improved method for filing complaints against managed care companies, and the inclusion of consumers and families on advisory boards.

The extent of the advocates' influence is still unclear. "We're hoping for the best," said Glazer. "How much of our input is taken will be known when the RFPs go out, which should be sometime before April."

Whatever happens, Glazer is still a realist: "I'm not terribly optimistic about managed care in general," he said.

"A great deal of effort is being made to include our needs and our goals in the plan, but they're still making the best of what could be a very bad policy."

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