



# 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/SURVIVORS NEED A VOICE IN WASHINGTON

Inside the Beltway, there are many who speak for people who have psychiatric disabilities. But who hears *our* voices? Mental health is a huge industry in the United States, with billions of dollars (including tax dollars) spent on treatment and research. But, except for isolated incidents that are noteworthy because they are so rare, all of this happens without significant input from the people who are most directly

affected. In general, federal mental health policy is developed and implemented by Beltway bureaucrats who, even when well intentioned, are far removed from the impact of their policies.

Some of this is unavoidable: as long as the federal government can raise revenues in ways that local governments can't, it will continue to play a major role in mental health policy. This is not always bad; for example, civil rights issues always seem better handled at the national level. But it would be better if we could bridge the

gap between federal policymakers and the people who must live with the impact of their policies.

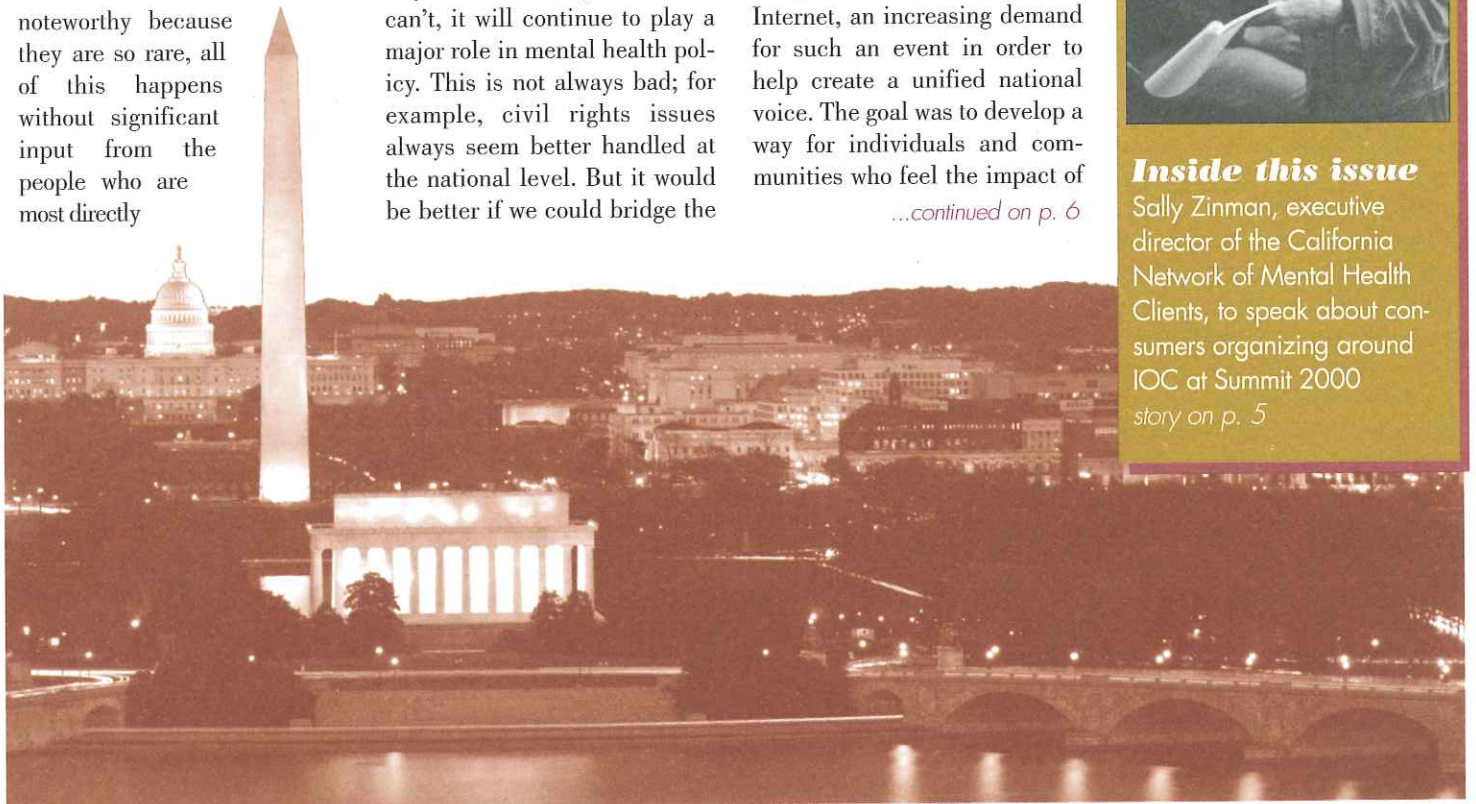
The National Summit of Mental Health Consumers and Survivors was organized in response to this need, with the participation of consumers/survivors across the United States. Many had expressed, via the Internet, an increasing demand for such an event in order to help create a unified national voice. The goal was to develop a way for individuals and communities who feel the impact of

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Sally Zinman, executive director of the California Network of Mental Health Clients, to speak about consumers organizing around IOC at Summit 2000  
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*Message from the Executive Director*

## TECHNOLOGY LEVELS THE PLAYING FIELD OF CONSUMER ORGANIZING

**W**ith more than 20 years of experience as an organizer, I have vivid memories of the days when organizing a statewide meeting could take weeks of work.

I remember sitting for hours at the kitchen table, pulling a list of addresses together from a dozen different sources and handwriting each one onto an envelope. I remember putting together a little flyer and going out to find someone with a mimeograph machine who would make copies that we could take back to the kitchen table and fold and hand stuff into each of the addressed envelopes. Then, all those envelopes had to be stamped and mailed.

So I relish the new technology that has given us so many exciting electronic tools to work with.

It has profoundly affected our ability to organize and, in fact, is a huge advantage to grassroots movements like ours which have no money, no national organization and are made up, essentially, of poor people who can't afford to pay dues.

This was on my mind recently as we did some organizing around Summit 2000. It still amazes me that you can write a notice on your word processor, spell check it, slap it into an e-mail message and send it out to literally thousands of people around the world, all within a matter of minutes.

Almost instantaneously, all those people can know what your meeting is about and even respond if they want. This interactive ability is important to me because it allows me to be accessible and receive feedback in

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**BY JOSEPH A. ROGERS**

a way I never could before.

The new technology almost puts us on a level playing field with larger, wealthier and better organized groups. The more sophisticated we get about using the new technology, the more level that playing field becomes.

The new technology gives organizers other important abilities. Often, rumors and

respond quickly with our own take on the issues.

I got a real sense of how important all this is when I was sent a draft of the Surgeon General's Report that contained some objectionable material on ECT. We wanted to take action, so we alerted people through the Internet. The e-mail response was so quick and so strong that people from the Surgeon General's office called and begged us to put the word out that they would make serious changes in the report to address our concerns.

So almost entirely by e-mail we were able to influence this major document in a way that made it much more balanced.

At the Clearinghouse, we're trying to make this new technology work for us and for the consumer movement. One way is through our two e-mail lists. The first, the Key, is a one-way list that allows us to get information out to people quickly. The second, our new Grassroots list, allows us to have a two-way exchange of information with subscribers.

In the past 20 years, our movement has gone from being a handful of small groups located in a few big states to many, many groups located in just about every state in the country. In some states, there are statewide groups that have networked together to get funding, provide programs and support

half- and full-time staff.

This is the foundation for what I believe can grow into a national movement that can speak in one voice and be heard all the way to Washington, D.C. And I believe the new technology will be a major factor in helping us get there. ●

# Join the Clearinghouse... Electronically!

See page 11

*These are very exciting  
times and we're happy  
to be a part of them!*

misunderstandings pop up because of things being said in the national press. In the past, it could take dozens of phone calls to straighten things out.

Now, though, with so much electronic media on-line, we can go to the Internet and check out what is being said and then



*Message from the Program Director*

# ACTIVISM VERSUS ACTIVITY

**W**hen I compare myself to people I've met in the consumer movement, I have to conclude that I'm not really an "activist" — at least according to the traditional definition.

I don't organize many protests or demonstrations; I don't storm government meetings; I don't yell much. I don't believe my contribution has to do with outward, obvious "activism."

On the other hand, I do make a lot of phone calls; I write a lot of letters and proposals; I spend hours writing budgets and project plans and meeting with staff to carve out project milestones and deadlines. I work long hours and I wake up every night at 3:00 am worrying about some task that still needs to be done or some complex problem that still needs to be solved - usually by some real deadline or with money that the Clearinghouse doesn't have.

I'm not generally described as a "passive" person, but I know I'm not an "activist" either.

I'm active. Is that good enough for the consumer movement?

BY MARIE VERNA

In the "profit" world, where I come from, I'd answer that question with more questions: Did I produce anything? If yes, was it worthwhile? Did it cost less to produce than I can make by selling it?

In the non-profit world, I gauge the Clearinghouse's success the same way, except I don't take home any financial profit. But the measure of our success still lies in the answers to those same questions.

In this issue of *The Key*, the best newsletter published about the consumer movement today, we reveal new products, new services, new ways to connect consumers, and new stories about active, powerful consumers all around the country. Just this newsletter alone is a major production—a worthwhile product that comes in on budget because Clearinghouse staff (and in-kind writers on the staff of the Mental Health Association of Southeastern Pennsylvania) are willing to work twice as hard as they get paid in the time before we go to press.

This issue highlights other Clearinghouse initiatives besides our newsletter: a new curriculum, new technology to answer the demand for including more consumers, new efforts to disseminate the information in our library to people who need it, a new forum for presenting consumer views to national policymakers. This issue describes tremendous activity at the Clearinghouse during the months since we successfully hosted the National Summit of Mental Health Consumers and Survivors in Portland, Oregon last August (talk about a major production!).

We're planning the Second National Summit, or Summit 2000, to be the next logical step: with the plank reports from Oregon in hand, let's now present our action steps to the major organizations in Washington, D.C., that affect national policy on a daily basis. Let's find out how many of our ideas can be incorporated into national policy, and ultimately formed into legislation. Let's leverage the work we've

already done to produce worthwhile results.

The Freedom Self-Advocacy curriculum is a collaborative effort with two powerful national organizations, which help consumers acquire, secure, and protect rights: the National Mental Health Association and the National Association of Protection and Advocacy Systems. The Clearinghouse used its close relationship with the Mental Health Association of Southeastern Pennsylvania to study what it sees as a serious lack of advocacy skills in consumers—a lack of attitude, skill, and knowledge when it comes to advocating for themselves. The result is an extensive curriculum made up of a comprehensive Teachers' Guide of educational techniques, methods, handouts, and samples combined with a matching Students' Guide that presents information in an easy, friendly style. The Freedom Self-Advocacy curriculum will go a long way toward improving fundamental skill sets among consumers and will become the foundation for recovery and leadership as we go forward.

The "webcast" of our pilot session for the Freedom Self-Advocacy curriculum is our own test of web broadcasting technology. With the help of business partners here in Philadelphia, we're using this session to learn how to broadcast Summit 2000 to consumers who can't get to Washington on June 6 because of financial, geographic, or emotional obstacles. Through our e-mail discussion lists— <thekey> and <grassroots>—and from activity on our website <www.mhselfhelp.org>, we know that consumers have the energy and enthusiasm to get involved. With technology, we plan to give them the tools to do that.

The Clearinghouse is a busy, active place and a healthy business by my standards. We're producing worthwhile products and inventing services that respond to consumers' needs. Profit analysts might wonder how, with limited funding. But I know that the answer isn't some complicated economics algorithm. The answer is hardworking, underpaid, energetic staff who demonstrate their commitment with *activity*. ●

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# SUMMIT 2000 TO BRING TOGETHER CONSUMERS AND MENTAL HEALTH POLICY LEADERS

Consumers and survivors from around the country will hear from national policymakers in Washington, D.C., in June as they continue the discussion on national issues that began last August at the National Summit of Mental Health Consumers and Survivors in Portland, Oregon.

Summit 2000: The Second National Summit of Mental Health Consumers and Survivors will take place on June 6 at the Loews L'Enfant Plaza Hotel. It will precede the annual Clifford Beers Mental Health Conference of the National Mental Health Association (NMHA), which will be held at the same hotel June 7-10.

The goal of both Summits is to help lay the groundwork for what could become a national organization of mental health consumers and survivors that would play a role in setting policy on mental health issues.

An important feature of Summit 2000 will be a dialogue between two panels, one made up of leaders of the consumer/survivor movement and the other made up of representatives of organizations involved in policy decisions on national issues affecting mental health.

In the morning, movement leaders will report on the consensus that was reached, and the action plans that resulted, on each of 12 different planks discussed in Portland. The planks, or issues, are Advocacy, Organizing, Force and Coercion, Financing, Alternative Services, Recovery, Stigma, Community Support Systems, Research, Forensic Issues, Multicultural Issues and Accountability.

Members of this panel will include many of the leaders who facilitated the discussions on these planks in Portland.

The second panel will be made up of representatives of national organizations that are involved in crafting policy decisions on mental health issues. They will respond to the reports from the first panel, after spending the morning listening to them with other attendees.

Members of the second panel are expected to include Robert Bernstein, executive director of the Judge David L. Bazelon Center for Mental Health Law; Bernard Arons, M.D., Director of the federal Center for Mental Health Services; Ruth Hughes, executive director of the International Association of Psychosocial Rehabilitation Services; E. Clark Ross, director of policy for NAMI; Curtis Decker, executive director of the National Association of Protection and Advocacy Systems; and Michael Faenza, who heads NMHA.


"In Washington there are many organizations that work for and in the interests of people with psychiatric diagnoses," said Joseph A. Rogers, executive director of the National Mental Health Consumers' Self-Help Clearinghouse. "At Summit 2000, leaders of the consumer/survivor movement will have an opportunity to meet with leaders of those organizations and hold them accountable by asking them what they are doing for us. We'll also be able to ask them to join with us in making the ideas that came out of the Portland Summit a reality by opening up the decision making process at the national level to include consumers and survivors."

In addition to the two panel discussions, a keynote address will be delivered by Sally Zinman, executive director of the California Network of Mental Health Clients. Zinman, who helped found the Network in 1983, will speak about how consumers have managed to keep the Network viable and successful.

At lunch, Chris Koyanagi, policy director for the David L. Bazelon Center for Mental Health Law, will talk on "Inside the Beltway: How Is Policy Determined in Washington, D.C., for Mental Health Consumers and Survivors?"

Marie Verna, program director for the Clearinghouse, said planners expect the Summit to attract as many as 200 people, including a number of consumers and survivors who were not able to attend the

Summit in Portland. Verna invites consumers and survivors to join the Clearinghouse "for what's sure to be the most important dialogue of the year between consumer/survivors and national organizations that have an impact on national policy." The one-day conference fee is \$75.



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# SALLY ZINMAN TO SPEAK AT SUMMIT 2000 ABOUT THE FIGHT AGAINST EXPANDING OUTPATIENT COMMITMENT LAWS

In the summer of 1998, a forum on expanding outpatient commitment laws was held in Los Angeles. Many of the people who spoke there, primarily family members, were in favor of expanding these laws, and the event got a lot of positive media coverage.

The forum caught consumers around the state by surprise. It also became something of a watershed event for the consumer movement in California.

"We didn't even know about it," said Sally Zinman, executive director of the California Network of Mental Health Clients. (Clients is the term used for consumers in California.) "But after that, we vowed that it would never happen again. We made a commitment to make sure that our people would be there to voice their opinions whenever and wherever this issue was brought to the table."

Since then, this commitment has become even more important. In January, bill AB 1800 was introduced in the California legislature. If passed, it would greatly expand the use of forced treatment and turn back the clock on hard-won civil rights protections for people diagnosed with mental illnesses.

Happily, the Network has been up to the challenge. The 1200-member, regionally based organization is in full gear on the issue, its work supported by surveys that consistently show that fighting the expansion of forced commitment is the top priority among consumers throughout California.

On June 6, Zinman will give the keynote speech at Summit 2000 in Washington, D.C., and will talk about the threat that she believes increasingly faces consumers throughout the country as states move to implement laws such as the one being proposed in California.

She said she believes this issue is the most important one facing the consumer movement today.

"This issue has unified the Network in an incredible way," she said. "The nationwide

BY CECE LENTINI

drive for more forced treatment threatens the gains made by the mental patient movement in the last 30 years. It threatens the life and liberty of all of us."

Zinman said that the Network is working against the expansion of forced treatment as well as for a system based on choice and freedom both inside and outside the system. "Every track we can be on, we're on," said Zinman.

The Network's effectiveness has been helped by a regional structure it adopted after a state-wide conference in 1996. Then, the Network divided the state into five different geographic regions, each with its own eight-hour-per-week regional Coordinator. This gives the Network the ability to stay on top of and respond quickly to developments throughout the state.

Ironically, the Network's effectiveness has also been enhanced because of gains made by consumers since the organization was founded in 1983.

"The Network is not this radical way-out organization," said Zinman. "Most of us are now used to working in the system. We all serve on committees and boards and commissions. Many people also hold jobs inside the system, or are links to the system because they serve in county liaison positions."

Inside the system, the Network has joined in a number of efforts.

For instance, the Network participated in an effort by five state organizations, including the state Office of Mental Health and the California Association of Local Mental Health Boards and Commissions, to look at the issue in three ways. The first was through research, the second was through forums held around the state and the third was through a consensus-building meeting involving 40 or 50 of the stakeholders in this issue.

The Network has also worked with the Little Hoover Commission, a respected non-partisan think tank that is developing policy recommendations on mental health issues.

In addition, the Network is involved with the legislature's Joint Committee on Mental Health Reform, which is studying the mental health system in order to develop policies about where state dollars should go.

In each case, Network members testify before committees, make presentations, serve on advisory boards and in general play any role that will make sure their voices are heard.

The Network also has been working effectively outside the system. For instance, working through its regional structure, it has brought hundreds of consumers throughout the state to Sacramento for two different demonstrations.

The Network has also formed its own coalition with three other organizations that oppose AB 1800. Called CARES (Coalition Advocating for Rights, Empowerment and Services), the coalition developed an alternative bill to AB 1800 that has been introduced into the state Senate. The CARES bill would promote the development of more community services, better discharge planning and the use of advance directives.

The Network, which does news alerts about the issue in traditional mailings to interested people, has also found e-mail to be a helpful organizing tool. The organization uses it to keep people informed and to do its own strategizing.

Whether working inside or outside the system, said Zinman, the Network remains committed to stopping the expansion of forced treatment in California and helping to build a truly voluntary community mental health system. "We've been honest all along that we don't want this fight," said Zinman. "But as long as our rights are being threatened, we have to fight back." ●



*A Voice in Washington...continued from p. 1*  
 federal mental health policy to be heard by policymakers, bureaucrats, and politicians at the highest levels. History teaches us that society only recognizes the rights of people when they stand up and speak in one voice.

We know from the Summit, the Alternatives conferences and the interactive electronic mailing lists that there is a dynamic grassroots consumer/survivor movement with emerging leadership. The question is how to focus that energy into a national organizing initiative that doesn't become just another bureaucracy.

One idea is to establish an independent, informal structure that would serve as "Organizing Central." This model, called the National Desk, is patterned on the European Desk, which helps people in the European Network of (ex-) Users and Survivors of Psychiatry to connect with each other and to make their voices heard.

Unlike a national organization, the "Desk" does not have its own identity, nor does it establish policies or operate programs. In Europe, for example, it helps the user movement connect with European legislatures, the World Health Organization, and other such entities. In the United States, it would connect the consumer/survivor movement to organiza-

tions such as the National Mental Health Association and the National Association of State Mental Health Program Directors and to various governmental bodies. The Desk would also act as a political clearinghouse, informing consumers/survivors and movement organizations around the country about federal policies as they are developed, reviewed, or revised. It would then facilitate movement involvement in the policymaking process. Run by a coordinator rather than a president or chair, it would help connect the consumer/survivor community to the Washington power structure.

The Clearinghouse operated on this principle when we widely disseminated the proposed language on electroconvulsive therapy in the draft of "Mental Health: A Report of the Surgeon General" as soon as we had it, so that groups and individuals could have an impact on the final product. We also set up a meeting with Dr. Richard Nakamura of the National Institute of Mental Health, who was one of the three government officials shepherding the Report to completion; and we invited Linda Andre, director of the Committee for Truth in Psychiatry, to join us at the meeting so that she could represent the interests of her constituency firsthand. The Clearinghouse provided the access, which would have been difficult for Linda Andre to obtain; she provided the expertise and personal experience.

The National Desk would facilitate ad hoc coalitions that would emerge as issues are identified. Depending on the need, these coalitions might be permanent or temporary, meeting a particular need and then disappearing as the goals are accomplished and the scenery changes.

The National Desk is consistent with the grassroots nature of our movement. It is also efficient: it can take months to get a decision from a large national organization that has a board and representatives. The National Desk would make no decisions; it would facilitate decision-making by others. People who want to act on an issue would be able to do so, as long as their actions were consistent with movement values, as have been established at large movement gatherings such as the National Summit of Mental Health Consumers and Survivors and the Alternatives conferences. (This would mean that "renegade" groups, such as, say, Skinheads for Ritalin, could not embarrass the movement.)

With a lot of volunteer effort and a part-time staff, the National Desk would be relatively low-maintenance and self-sustaining, and relatively independent of government money. The decision-making and value-setting would be piggybacked onto existing organizational initiatives, such as the Alternatives conferences and the Summit. It would not become identified with any one individual or group: leadership would emerge around an issue and, as new issues replace old, the leadership would change.

This model owes much to anarcho-syndicalism, which revolves around organizing all workers into one big union, keeping control in the hands of the rank and file, and opposing efforts to create a bureaucracy of full-time officials who are not accountable to the membership. The theory is that, without much structure or an entrenched leadership, the organization can stay honest and responsive to the grassroots.

The Clearinghouse is willing to help develop and underwrite a National Desk, but the ownership has to be in the hands of a larger group. That's what the Summit process is all about: convening people with an interest in national organizing and providing them with support.

Our next step is organizing Summit 2000. We hope that through these efforts at dialogue, a collective will emerge to work on this project. The Clearinghouse will be part of this collective, but the rest is up to all of you. ●

## New help with Self-help

What exactly is in the Clearinghouse library? Like most libraries, the Clearinghouse stores books and periodicals on shelves. But unlike other libraries, the Clearinghouse library includes an immense collection of active files about topics relevant to the mental health consumer movement.

These files contain hand-outs, pamphlets, and articles taken from newsletters, newspapers, journals, the Internet, training guides, and reports from mental health research and advocacy organizations from across the country.

We've selected the diverse topics in this collection for their relevance to self-help groups and mental health advocates as they encounter obstacles and seek to find solutions to the problems in the groups they organize.

Since our focus at the Clearinghouse is actually getting information quickly into the hands of those who need it, we're just starting the task of actually cataloging each item in the library. But we've put together a list of individual items for people interested in developing the peer counseling and leadership skills that help get a self-help group running smoothly. If a group can accomplish that much, it can focus on its members—not the problems with the dynamics within the group.

Call Karena Bayruns at the Clearinghouse at 1-800-553-4539, x256 if you'd like to hear more about the materials available from our library.



# IOC BATTLES RAGE ACROSS U.S.

**A**cross the country, movement activists are battling to prevent the passage of involuntary outpatient commitment (IOC) statutes, which, at this writing, are already a fact of life in 33 states and the District of Columbia.

Recently, IOC bills have been introduced in a number of states, including California, Maryland, Iowa and Washington; and advocates have marshaled their resources to defeat them. At minimum, such legislation would require someone with a psychiatric diagnosis who is living in the community to accept outpatient mental health treatment (usually involving medication). And, in many states, a person can be picked up and held for evaluation for commitment to a psychiatric hospital, according to Tammy Seltzer, a staff attorney at the Bazelon Center for Mental Health Law, in Washington, D.C.

"This may sound innocuous to some people, but it's not," said Seltzer. "In Michigan, for example, a gentleman who refused on three occasions to make himself available to the ACT [Assertive Community Treatment] team was subjected to police breaking into his apartment, spraying him with pepper spray, handcuffing him, and transporting him to the hospital, where he was forcibly injected with Haldol. The man was released within days because he did not meet the criteria for inpatient commitment; but the experience was traumatic."

The criteria used to determine whether someone can be committed on an outpatient basis are often much less stringent, and far less objective, than the inpatient commitment criteria (which usually involve deciding whether someone is an imminent danger to self or others). Therefore, far more people can be subjected to IOC.

The consumer/survivor advocacy community and citizen advocacy organizations are united in their opposition to outpatient commitment, which invades people's everyday lives, and only results in more coercion and in the draining of vital resources that could be much better spent on enhanced community-based services and supports, such as employment and housing programs.

On the other side of the debate are such

BY SUSAN ROGERS

organizations as NAMI and the NAMI-supported, Virginia-based Treatment Advocacy Center (TAC), of which Dr. E. Fuller Torrey is the chief spokesman. In the wake of a recent high-profile hostage case that ended in the deaths of four hostages and the perpetrator, Torrey co-authored a Baltimore Sun piece that claimed IOC would "help prevent such tragedies in the future and

Missouri, Montana, Nebraska, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, Utah, Vermont, Virginia, Washington, West Virginia, and Wyoming. (This list does not include states, such as Tennessee, that have Conditional Release statutes, "which require a person to meet inpatient commitment standards and be detained on an inpatient basis before a court can consider outpatient commitment," according to the

## The studies cited by IOC proponents to "prove" its effectiveness are flawed.

give every Marylander the chance to live a safe and productive life."

But the studies cited by IOC proponents to "prove" its effectiveness are flawed, advocates say. Bazelon has reported that a rigorous study at New York City's Bellevue Hospital — which provided enhanced, intensive services to two groups of people, with only one of the groups court-ordered to receive treatment — found no additional improvement resulting from the court order, nor any difference in the number of arrests or violent acts when the two groups were compared.

In addition, outpatient commitment statutes are not widely viewed as helpful in the public mental health system. Of the states that have such a statute, many rarely use it, according to a survey by the National Association of State Mental Health Program Directors.

IOC statutes are already on the books in Alabama, Delaware, District of Columbia, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Michigan, Minnesota, Mississippi,

Bazelon Center's chart.)

Bazelon is one of a number of organizations that oppose IOC; others include the International Association of Psychosocial Rehabilitation Services, the National Council on Disability and the National Mental Health Association. Bazelon has supported consumer/survivor advocacy on this issue by creating an ad hoc work group whose goal is to fight IOC via the media, as well as an electronic mailing list, <stop\_ioc>, on which movement activists share information.

### MARYLAND

In February, advocates were able to quash pending IOC legislation in exchange for updating advance directive legislation so that it would better apply to people with psychiatric disabilities, according to Laura Van Tosh, a leader in the effort to stop IOC in Maryland. However, hours before a final vote on the advance directive bill in late March, "advocates got word that members of the Maryland Psychiatric Society tried to sneak



in amendments allowing health care agents to involuntarily commit consumers to hospitals," Van Tosh reported to the <stop\_ioc> list. "Based on quick and effective advocacy, the entire bill (with these nasty amendments) was killed. Another state task force will be asked to further examine these issues and

NGRI or incompetency to stand trial.

"Both bills were put into a 'study,' which is usually the equivalent of legislative death," wrote Fleischner, staff director of the Massachusetts PAIMI (Protection and Advocacy for Individuals with Mental Illness). "However, due mostly to the efforts

words, the people whom this legislation misguidedly intends to help are unified in their opposition to it."

In a letter to the members of the Assembly Health Committee, movement activist Elaine R. Brooks, M.S.W., urged that, instead of AB 1800, the Assembly should fully fund another bill, AB 2034, sponsored by Assemblyman Darrell Steinberg. Last year, Steinberg introduced AB 34, intended to create voluntary holistic services. The bill passed, with \$10 million authorized to fund demonstration projects. AB 2034 is an attempt to add monies to these projects and create additional, similar services.

Brooks estimates that full funding in subsequent years for all California counties would require some \$350 million. The bill, supported by the advocacy community, provides funding for an array of services (including housing, psychosocial rehabilitation, and substance abuse services) that build on the integrative services model, which has been extremely successful in two counties (Los Angeles and Stanislaus) in which it has been piloted. In these two counties, which have expanded their community-based services, the incidence of

## "It is lousy public policy and deserves to be forced into legislative oblivion."

possibly make additional recommendations to the General Assembly," she wrote.

### IOWA

Although Iowa already has an outpatient commitment statute, an attempt was recently made to pass another. "The outpatient commitment that now exists is done only as part of the regular (inpatient) commitment process," said consumer activist Ellie Philips. "The new bill would make it very easy for anyone who has previously been committed to be returned to outpatient commitment." Philips reported to <stop\_ioc> that Ken Kress, a University of Iowa law professor who is also a consumer, had written the bill and had "made it his life's mission to get it passed." At a March 14 hearing, some two dozen consumers spoke against the bill; the professor and a sole supporter spoke in favor, Philips said.

The bill was defeated, but the war isn't over, Philips said. "Ken Kress got his 'platform' from AMI of Iowa," she said. "They didn't actively lobby for the bill this year, for some strange reason. I would guess we won't be that lucky again."

### MASSACHUSETTS

Two outpatient commitment bills were filed last year in Massachusetts, reported Bob Fleischner on <stop\_ioc>. One bill, supported and written by AMI members, would change the standards and procedures for civil commitment; a second, more limited bill, filed by the state mental health department, would create conditional discharge for people in mental hospitals after a finding of

of a former [Department of Mental Health] attorney whose son was murdered by a person who by some reports was not taking his prescribed psychiatric medication, the 'study' has come alive again."

On February 28, Fleischner testified at a hearing of the Joint Committee on Human Services and Elderly Affairs, with Dan Fisher and Judi Chamberlin of the National Empowerment Center. "Our testimony went very well," Chamberlin said. "We tried to focus on the fact that if there is a problem, this isn't attacking the problem."

### CALIFORNIA

California activists are fighting a bill that, if passed, would expand forced treatment and would erode the civil rights protections that they have struggled to achieve. The bill, AB 1800, was introduced in January by Assemblywoman Helen Thomson; it was a revised version of a similar bill she had introduced in the previous legislative session.

Opposition has been organized by the California Network of Mental Health Clients (see story on page 5). On February 28, the Network organized a demonstration in Sacramento; approximately 300 people participated. Network members have also testified at hearings on the bill held around the state. "For almost two years, clients throughout the state have made it their Number 1 priority to fight the expansion of forced treatment and outpatient commitment," said Sally Zinman, executive director of the Network. "In other

## Clients are unified in their opposition to this legislation.

forced treatment has dropped dramatically.

Brooks wrote: "AB 1800 would force inadequate, untested and unproven medical care onto people with any symptom of a mental illness . . . [and] would remove the legal protections that even the accused in criminal courts have not to be tried on their histories but only for the crime they are charged with. It is lousy public policy and it deserves to be forced into legislative oblivion." ●



# CLEARINGHOUSE COLLABORATES TO OFFER SELF-ADVOCACY TRAINING NATIONWIDE

**S**elf-advocacy skills allow consumers to assert personal preferences, protect legal rights, and obtain the best services possible. Through an ongoing initiative, the Clearinghouse, the National Mental Health Association (NMHA), and the National Association of Protection and Advocacy Systems (NAPAS) seek to help consumers throughout the country improve their self-advocacy skills.

"Traditionally, the mental health system has not taught us to advocate for ourselves," said Clearinghouse program director Marie Verna. "However," she said, "the Clearinghouse hopes to spread a message to other consumers that we are worth advocating for, and that we can—and must—advocate for ourselves."

To help fill the void left by the absence of self-advocacy training, the Clearinghouse has joined with local and national organizations to create the Freedom Self-Advocacy Curriculum. "We have created a nationwide, 'train-the-trainer' curriculum. We'll be training people throughout the country how to teach self-advocacy skills to consumers in their communities," Verna explained.

Beginning this fall, people who are interested in teaching self-advocacy can attend one of a number of national institutes, which the Clearinghouse will host throughout the country. "We are continuing to refine the format of these national institutes," said Verna, "based on feedback from a pilot train-the-trainer session that we held in April in Cherry Hill, New Jersey."

The Clearinghouse also used the pilot session to develop experience with "web-casting" technology. As Clearinghouse executive director Joseph Rogers explained, "We videotaped the pilot session, and people were able to watch it over the Internet via our web site, [www.mhselfhelp.org](http://www.mhselfhelp.org). We're very excited about this use of new technology to share information with the consumer movement."

Verna encourages interested people to watch the webcast as a preview of the upcoming national institutes. "The in-person institutes will be exciting events," she said. "Consumer leaders and other advocates will have many opportunities for discussion with the program designers, who have been researching self-advocacy strategies extensively. Attendees will also have a chance to learn in the presence of other leaders who face the same challenges when attempting to organize in their own states."

Clearinghouse educational specialist Alan Marzilli elaborated on the content of the national institutes, saying, "We'll explain how to teach a set of three self-advocacy workshops that the Clearinghouse designed in conjunction with advocates from the Mental Health Association of Southeastern Pennsylvania."

The nationwide scope of the Freedom curriculum makes it unique: although there have been some opportunities for consumers to learn self-advocacy at local events, this is the first truly national effort. In an attempt to identify issues of concern throughout the country, the Clearinghouse surveyed consumers nationwide. "We found that many of the issues were the same, no matter where the person was from," said Marzilli, "and we designed the curriculum around these crucial issues."

Another key to making the curriculum national in scope was collaboration with other national organizations, including the National Mental Health Association (NMHA) and the National Association of Protection and Advocacy Systems (NAPAS). "NMHA is proud of its ongoing partnership with the Clearinghouse," said Catherine Hyunh, director of NMHA's

National Consumer Supporter Technical Assistance Center. "The Freedom Self-Advocacy Curriculum is another vehicle to move us closer to our goal of social justice," she continued.

The federally mandated protection and advocacy (P & A) systems, which NAPAS represents, exist in every state to protect consumers' legal rights. Cheryl Bates-Harris, a disability advocacy specialist with NAPAS, explained, "The P & A systems already provide education and outreach to consumers, but with a central curriculum, more P & As will be able to teach self-advocacy."

Likewise, NMHA's participation in the curriculum will create many opportunities for consumers to learn self-advocacy skills. "We'll make every effort to promote this

worthwhile training through our 340 affiliates across the country," said Hyunh.

The Clearinghouse views the Freedom Self-Advocacy Curriculum as a powerful tool for strengthening the consumer movement nationwide. Said Rogers, "The reason we're teaching self-advocacy is not only to benefit individual consumers, but also to create a better-informed consumer constituency. If people can assert themselves and let it be known that the status quo is unacceptable, then we can work together to change the system."

Visit the Clearinghouse web site [www.mhselfhelp.org](http://www.mhselfhelp.org) and click on "Programs and Services" for a link to the self-advocacy section of the site. From there, you can learn more about the curriculum and find out about upcoming institutes. You'll also find instructions for joining an e-mail discussion list that will allow you to stay in touch with other advocates throughout the country teaching self-advocacy. ●

## *Freedom Self-Advocacy Curriculum*



# A ROUNDUP OF STATEWIDE ORGANIZING EFFORTS

Consumers working together to build a national organization can draw inspiration from the many statewide organizations already in existence (see related article about the fight against involuntary outpatient commitment). From state to state, consumer networks have taken a variety of forms.

One common model is an organization with member chapters throughout the state. In Texas and Maryland, for example, state consumer groups are gaining strength by increasing their numbers of chapters.

Texas Mental Health Consumers currently has 17 incorporated chapters and five more that are writing bylaws. Executive director Mike Halligan explained that the group uses its network of affiliates to do education and outreach programs around the state, and is "setting up a network of people talking to each other using e-mail." To further link consumers electronically, the group obtained a number of computers and is working with community mental health centers to provide Internet access to consumers.

On Our Own of Maryland actually began as a local group meeting in a church basement in 1981, according to executive director Mike Finkle, and that small group of dedicated people helped to start similar groups around the state. A federal grant helped a statewide organization incorporate and open an office in the early 1990s, and now On Our Own helps to create new consumer groups throughout the state.

"There's no mandate that they affiliate with us," said Finkle of the groups that they help to start. "Some have chosen not to join and

BY ALAN MARZILLI

pay dues, but some of those groups do come to our conferences and trainings." By holding an annual consumer conference, On Our Own creates consumer networking opportunities beyond its affiliate membership.

In other states, consumer groups do not have an affiliate network, but instead operate on a membership principle, with individual members or a combination of individual and organizational members. Two such states are Vermont and Pennsylvania.

Vermont Psychiatric Survivors charges optional yearly dues of one dollar for consumer/survivor members and focuses on providing recovery-based alternative services. Executive director Linda Corey reports that the group has enjoyed great success offering an educational program about recovery. The group also hosts support groups throughout the state and operates a toll-free warm line, among other services.

The Pennsylvania Mental Health Consumers' Association is active in both individual and legislative advocacy. Individual and organizational members set the association's agenda by voicing their opinions to the staff and by participating on the public policy committee. "As an association, we're responsible to the people we serve," said director of member services Wendy Wood.

Consumer-run technical assistance centers have been instrumental in organizing in some states. These centers have reached out to nur-

ture consumer groups and encourage individual consumers to become active in the movement.

In Oregon, The Office of Consumer Technical Assistance has two equally important objectives, said director Kevin Fitts. "Our first objective is to support the grassroots development of local peer-run projects, services and groups," he explained, "and our second objective is to engage consumers and survivors in public policy activities at all levels of system management and oversight."

Consumers in many states have taken a somewhat different approach, working within the state government to help foster state-wide consumer involvement. Currently, over half of the states have offices that represent consumer interests (including states that also have independent consumer networks). A good example of a state where a strong consumer affairs office has been able to make positive steps is Illinois.

Andrea Schmook hopes to organize consumers throughout Illinois from her position in the Office of Consumer Affairs in the state mental health department. Her role is to create opportunities for consumer involvement in the state mental health system. As she explained, "I'm not a spokesperson, I'm a catalyst."

Schmook has overseen the hiring of consumer specialists at each of the nine state hospitals in Illinois. She's also worked to get consumers involved in the advisory boards of the nine "networks" that correspond to these hospitals. "We've begun doing consumer conferences at the network level," said Schmook. Her hope is that out of these networks, consumers will be able to "get a statewide consortium off the ground." ●

## Get in touch!

### ■ Illinois Office of Consumer Affairs

Office of Mental Health  
160 N. La Salle, 10th Floor  
Chicago, IL 60601  
(312) 814-4823

### ■ On Our Own of Maryland

1521 S. Edgewood St., Suite C  
Baltimore, MD 21227-1139

(800) 704-0262  
onourown@frontier.net  
<http://www.onourownmd.org>

### ■ Oregon Office of Consumer Technical Assistance

1528 SE Holgate  
Portland, OR 97202  
(888) 790-9379  
<http://www.orocta.org>  
info@orocta.org

### ■ Pennsylvania Mental Health Consumers' Association

4105 Derry Street  
Harrisburg, PA 17111  
(800) 887-6422  
pmhca@epix.net

### ■ Texas Mental Health Consumers

7701 N. Lamar, Suite 500  
Austin, TX 78752

(800) 860-6057  
<http://www.tmhc.org>  
tmhc@tmhc.org

### ■ Vermont Psychiatric Survivors

1 Scale Ave., Suite 52  
Rutland, VT 05701  
(800) 564-2106  
vpsinc@together.net



# JOIN THE CLEARINGHOUSE ...ELECTRONICALLY!

In his column for this edition of The Key, Clearinghouse executive director Joseph Rogers discusses how electronic communication, especially in the form of e-mail lists, has helped the consumer movement make enormous strides in the past few years. Here's how you can join some important e-mail lists and use other technologies to join the Clearinghouse's efforts to network mental health consumers.

If you are interested in subscribing to the e-mail lists sponsored by the Clearinghouse, here's how to join:

✉ **The Key** (a one-way announcement list limited to upcoming events, funding opportunities, political issues, and other information important to the consumer movement)

Send the following e-mail to  
majordomo@dca.net:  
subscribe thekey  
end

✉ **Grassroots** (an unmoderated discussion list devoted to mental health issues)

Send the following e-mail to  
majordomo@dca.net:  
subscribe grassroots  
end

✉ **National Summit** (an unmoderated discussion list devoted to the National Summit of Mental Health Consumers and Survivors and other issues related to national organizing and consensus-building)

Visit the following web site and click subscribe:  
<http://www.onelist.com/group/nationalsummit>

✉ **Self-advocacy** (an unmoderated discussion list devoted to the topic of self-advocacy and the development of self-advocacy training methods)

Send the following e-mail to  
majordomo@dca.net:  
subscribe selfadvocacy  
end

In addition to the lists sponsored by the Clearinghouse, there are many other national and international e-mail lists devoted to mental health topics. Here are some examples:

✉ **NMHA Consumer** (an unmoderated discussion list for consumers, sponsored by the National Mental Health Association)

Send the following e-mail to  
majordomo@cfapress.org:  
subscribe nmha\_consumer  
end

✉ **Act-Mad** (an unmoderated discussion list devoted to mental health advocacy and social justice)

Send an e-mail to the following address:  
actmad-subscribe@listbot.com

✉ Consumers in many states have started e-mail lists devoted to discussion of mental health topics in those individual states. If you are interested in joining a list for your state, you can look for one by visiting the following web site:

<http://www.peoplewho.net>

✉ Consumers are continually starting new e-mail lists for discussion; if you are interested in starting your own e-mail list, you can do so using a number of free on-line services. Examples include:

<http://www.onelist.com>  
<http://www.topica.com>  
<http://www.egroups.com>

Keep in mind that the e-mail lists described here are only a snapshot of electronic networking. The Clearinghouse offers its web site, <[www.mhselfhelp.org](http://www.mhselfhelp.org)>, as a starting ground for consumers who want to become involved in national networking. Each day, people contact the Clearinghouse from the web site, looking for more information or wanting to get involved.

"We've used our web site as a way to build a constituency," said program director Marie Verna. "When people contact us and express their interest in getting

involved, we help them to learn about technologies and also put them in touch with existing consumer networks. The constituency we've built on-line allows us to put people together so that they can help each other," she continued.

The Clearinghouse is implementing even newer, more exciting technologies to further the consumer movement. In April, the Clearinghouse produced a "webcast" of a self-advocacy training session held in Cherry Hill, New Jersey (see related article). Using free software, people were able to watch an audiovisual presentation of the session on their own computers.

Looking toward the future, the Clearinghouse hopes to expand upon the webcast model to offer fully interactive on-line events. "We are coming up with strategies so that people who cannot travel in person to conferences or other events can still participate fully," said Rogers. ●

## ALTERNATIVES 2000 *A New Vision of Recovery*

### ALTERNATIVES 2000 CONFERENCE

The theme of the Alternatives 2000 Conference is "A New Vision of Recovery". The conference will offer a unique opportunity to inspire and empower mental health consumers/survivors and ex-patients. Through workshops and networking, the conference attendees will be given a chance to connect with peers who have been through similar experiences. The conference will offer many people their first hope that they can recover a meaningful role in society - that they can have full rights, housing, jobs, dreams and respect.

**Date of conference:** October 11-15, 2000

**Location:** Renaissance Nashville Hotel  
611 Commerce Street  
Nashville, Tennessee

**Group rate:** \$109 single, \$122 double, \$139 triple,  
\$149 quad occupancy

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