



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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National Summit organizers at the conference site in Portland, Oregon.

SUCCESSFUL NATIONAL SUMMIT LEADS TO ACTION PLANS

On August 26-29, the Clearinghouse sponsored the first-ever National Summit of Mental Health Consumers and Survivors in Portland, Oregon. This unique event, which was co-sponsored by consumer/survivor groups from throughout the country, sought to organize consumers and survivors into a strong national voice.

Clearinghouse executive director Joseph

Rogers said, “We planned the Summit as a place for consumers and survivors to come together and discuss the issues that are most important to us. Our goal was to identify the issues and identify areas of disagreement and areas where consensus could be reached. More importantly, participants would be able to develop action plans.

“The Summit was a preliminary

step in creating a unified national voice,” he continued. “It exceeded our expectations both in terms of attendance and what was accomplished. We’re really looking forward to continuing the great work that was done in Portland.”

Program director Marie Verna explained how the Summit was organized. “This Summit was very different from a ‘work-

...continued on p. 4

Message from the Executive Director

A CALL TO ACTION: DRAFT SURGEON GENERAL'S REPORT ENDORSES ECT DESPITE EVIDENCE OF DANGERS

In the spirit of the National Summit of Mental Health Consumers and Survivors — moving from discussion to action — we are issuing this call to action.

One of the major issues discussed in the Force and Coercion plank at the Summit was ECT (electroshock). Though the group did not come to complete consensus on the issue of totally banning shock (there was one dissent), there was agreement that forced shock should be banned and that close attention must be paid to issues such as informed consent.

Now comes the draft Surgeon General's Report on Mental Health, which goes far afield from this by misrepresenting ECT as "safe and effective." Since the Surgeon General's Office wields enormous influence, it's vital that we make our voices heard immediately, before the small window of opportunity closes.

The Surgeon General's Office needs to be urged to correct many false statements. For example, the Report asserts that "ECT has become a carefully regulated procedure" and refers to the "explicit written informed consent" that is supposedly required.

In reality, ECT is not carefully regulated. Despite repeated attempts by the American Psychiatric Association to get the Food and Drug Administration (FDA) to reclassify the ECT device as Class II, it remains in Class III. Class III means that the machine has not gone through the rigorous FDA testing required of medical devices, including safety testing and efficacy assessments. In other words, this is the FDA's highest risk category.

And there is no explicit written informed consent statement, since the standard forms completely misrepresent ECT's dangers. For instance, although the standard forms usually say that only one in 200 ECT recip-

BY JOSEPH A. ROGERS

ients experience memory loss, memory loss occurs in virtually all ECT recipients. (The American Psychiatric Association admits that the one-in-200 figure is "impressionistic.")

As for side effects, we are told that the most common is "confusion after each treatment, which generally clears within an hour. *Transient* [original emphasis] amnesia of varying degrees is also common, but it resolves within several months, except for some persistent loss of memory for the period immediately surrounding the treatment itself." (The Report refers to the "occasional [our emphasis] anecdotal evidence" of permanent memory loss but, in fairness, it does say that "permanent memory loss remains a legitimate topic for careful longitudinal study.")

The Report concludes by saying that "modern advances in treatment technique" have reduced the "adverse cognitive effects of ECT," and that, "[s]ince severe mood disorders also have pronounced effects on cognitive abilities, it is difficult to disentangle the effects of the illness from those of the treatment. Claims that ECT induces brain damage have been unsubstantiated by research (Greenberg, 1997; Weiner & Krystal, 1994).

Earlier, the Report had stated that "[t]he reasons for ECT's effectiveness are not known (Weiner & Krystal, 1994)." The Report does not mention the many studies that have shown that survivors of brain damage also experience a period of euphoria. It does not even state that, when ECT does cause some lifting of depression, this wears off pretty quickly.

The Report cites one main source — Weiner & Krystal, 1994 — six times; only

five other sources are cited. Clearly, the Surgeon General's Office simply did not do its homework, since there is a vast quantity of material that indicates that ECT is *not* safe. Nor is it effective, since all agree that any benefits — a lifting of depression — are merely temporary.

Linda Andre, head of the Committee for Truth in Psychiatry, the national organization of shock survivors, writes: "The 'Weiner' cited by the Surgeon General's Report is Richard Weiner, head of the American Psychiatric Association's task force on ECT, and also the head of the task force or committee which petitioned the FDA to reclassify the shock machine from Class III to Class II back in 1982, and [has] spearheaded that unsuccessful attempt up until the present.

"Doug Cameron's book names Weiner as the central figure in one of the greatest frauds perpetrated on the American public, 'The Great Electroshock Hoax' (title of book), in which machines were designed to be ever more powerful while the public was being told they used 'less electricity.'

"As a paid 'consultant' to shock machine companies, [Weiner] designs virtually all of the shock machines in the United States, and thus is responsible for upping the electricity on each new generation of shock machines. . . He admits getting \$\$\$ from shock machine companies but says it's deposited in his 'research' account. [He] won't say how much. Shock machine companies thank him in their instruction manuals. Krystal is simply his young protégé. . . ."

If you are outraged by this whitewash of an extremely dangerous and controversial procedure, write David Satcher, M.D., Ph.D., U.S. Surgeon General, 200 Independence Avenue, S.W., Washington, D.C. 20201, Phone: 202-690-7694, Fax: 202-690-6960; E-mail: <DSatcher@OSOPHS.DHHS.GOV>. ●

Message from the Program Director

WE WILL OVERCOME

For those of you who were able to stay in Portland for the Summit's closing session on Sunday morning, the memory of "the group shot" probably remains with you as a moving climax to an event that, by all counts, was a successful attempt to organize a national voice for mental health consumers and survivors.

The session had been an interactive, open dialogue between Summit attendees and plank facilitators, giving attendees an opportunity to voice to the whole group the concerns that had been discussed in many long,

BY MARIE VERNA

hard, smaller work sessions. All those at the closing session made concerted efforts to focus on the positive and to avoid issues that divide us, thanks in part to the facilitation of Hikmah Gardiner, long-time consumer advocate from the Mental Health Association of Southeastern Pennsylvania.

Most recalled that they discovered at the Summit that mental health consumers are more united on difficult issues than they are divided, that we actually agree more than we disagree.

For me, to hear consumers and survivors acknowledge that reality was a memory that, not only will stay with me forever, but one that helps me envision my deepest hope: One day in the foreseeable future, mental health consumers will receive, under both federal and state law, equal treatment, opportunity, and financial compensation as the rest of the American population. And as consumers and survivors recover, thrive, and contribute significantly to American life and its economy, we will gain the respect we lack today. The shame will go away.

This won't happen merely because we sang the chorus to a passionate song about social change. And it won't happen merely because the board of the Mental Health Association of Southeastern Pennsylvania voted to financially support the National Mental Health Consumers' Self-Help Clearinghouse's vision of a national gathering to reveal and document our unity. It won't even happen because the staff of the Clearinghouse worked tirelessly with that hope as its shared mission.

It will happen because consumers and survivors around the country will continue to work in their own states and in their own

forums to advocate for mental healthcare reform; to research safer treatments; to provide community supports and vocational opportunities; to change public policy; to testify before their legislatures about abuse and neglect; to document for the public record the situation for those with a mental health disability; to analyze the mental health issues for minority populations; to teach other consumers how to organize; to convince the public media that we have "a story" to tell; to organize and fund events like Alternatives, where mental health consumers and survivors can gain power and energy from each other; to exploit the power of the internet to pull us together; to raise funds, to help a newly diagnosed consumer understand and

Marie's Thank-You's

Hosting a national consumer event takes teamwork, cooperation, and a sense of a shared mission. It also takes hard work. For all that, let me say a heartfelt thanks to:

- The Oregon Office of Consumer Technical Assistance
- The MHA of Oregon
- All Volunteers
- The Working Participants in All Plank Sessions
- All Co-Sponsoring Organizations
- The Mental Health Association of Southeastern Pennsylvania (MHASP)

- Debby Boyd, Summit Coordinator, Clearinghouse
- Liz Knapp, Technical Assistance Coordinator, Clearinghouse
- Cece Lentini, Director of Communications, MHASP
- Alan Marzilli, Educational Specialist, Clearinghouse
- Joseph Rogers, Executive Director, MHASP & Clearinghouse
- Susan Rogers, Director of Special Projects, MHASP
- Sue Scotese, Administrative Assistant, Clearinghouse
- Bob Turri, Executive Assistant, Clearinghouse
- Bob Warden, Administrative Assistant, Clearinghouse



cope with his or her new reality; to continue the work that we've started.

It will happen because we're already working on it; the die has already been cast. From my viewpoint on the stage in Portland, I could see that consumers and survivors already plan to overcome the discrimination we've endured for so long. What happened at the Summit, as we gathered together around our banner, was merely our collective witness to our plan. We said outloud to one another, "Let us join our forces. Let us overcome."

The Clearinghouse, along with the Oregon Office of Technical Assistance and the MHA of Oregon, is honored to have provided the setting for such a significant and hopeful occurrence. We will overcome. ●

...National Summit continued from front cover shop' conference. Attendees took an active role in one or more of twelve planks on topics such as organizing, financing, force and coercion, and forensic issues." She added that although people were free to move around, most stayed with one plank. "The continuity allowed the planks to achieve results over a few days, but nobody was bound to a single plank."

On all counts, the Summit was an outstanding success. Kevin Fitts and Cecelia

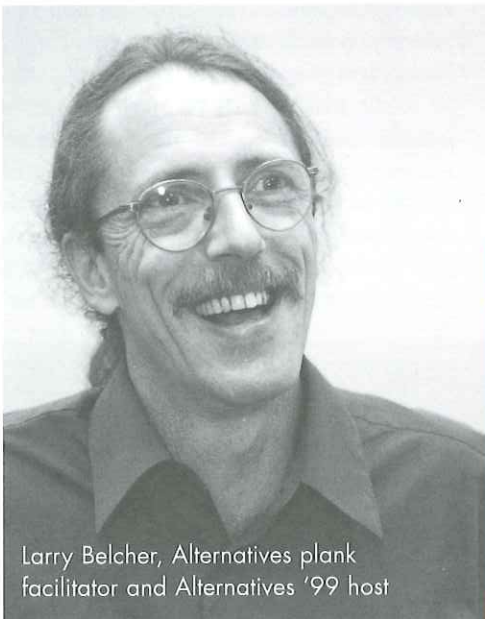
responsible and proactive in their lives and become more involved in the community."

Miriam Gershow served as the facilitator of the forensic issues plank and was excited that the Summit brought new voices to the forefront. "It was an inspiring experience," she said. "It was my first national consumer conference. Also, four of the five educational panelists, and at least half of

as facilitator of the alternatives plank. "The energy, knowledge and willingness of the people who worked in our group was outstanding, and political agendas and personality conflicts had no place in our work group."

Clifford Thurston of Washington State, who was an educational panelist in the financing plank, said that the consumer/survivor movement is making a

The Summit brought new voices to the forefront

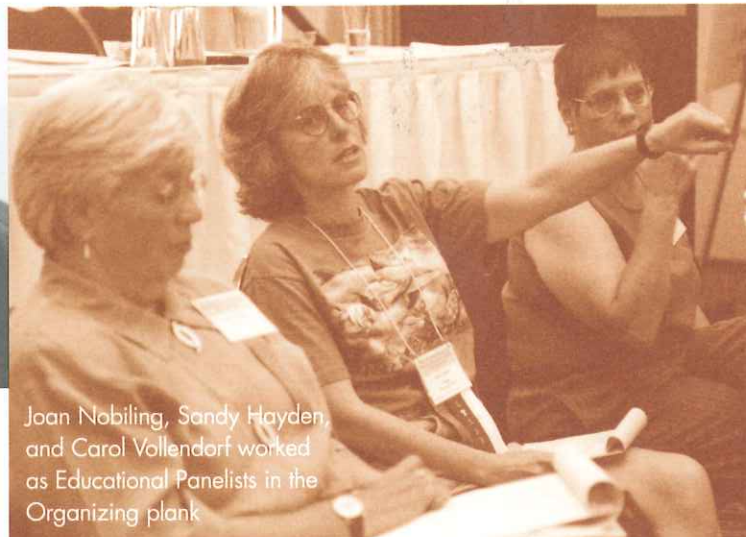


Larry Belcher, Alternatives plank facilitator and Alternatives '99 host

Vergaretti were excited to serve as local co-hosts of the Summit. "For years, I've been looking forward to having a national consumer/survivor event in Portland," said Fitts. "I'm very proud of the Summit because it was such a significant step in national organizing."

Vergaretti was especially impressed by how productive the discussions were. "It was amazing to have so many folks of different opinions come together. Any clashes that did occur were healthy."

The difference between the Summit and past conferences was that it allowed individual attendees to voice their opinions. Working participants (facilitators, co-facilitators, and educational panelists) guided the discussions. However, "the Summit gave everyone a voice," according to Mary Ellen Copeland, who traveled from Vermont to serve as an educational panelist. By speaking out, consumers "may be able to be more personally

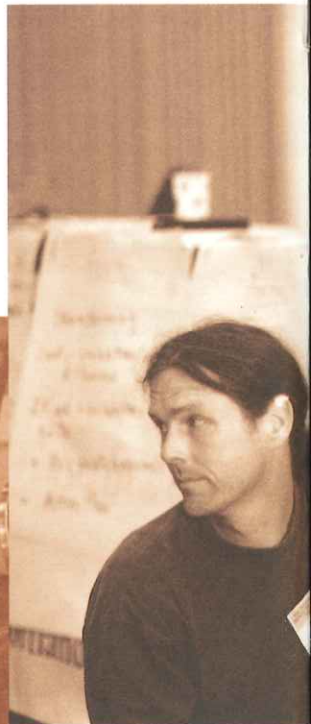


Joan Nobiling, Sandy Hayden, and Carol Vollendorf worked as Educational Panelists in the Organizing plank

the participants in the plank discussions were attending a national conference for the first time.

"It was an incredible process," Gershow continued, "and I was often awed by the knowledge, the wisdom, and the care with which a room full of strangers came together and created an action plan. We put an incredible amount of energy into creating a document for the rest of the consumer/survivor community to see and expand upon, to change and revise, as we all continue to do this work together."

Other working participants reported similar successes in their sessions. West Virginian Larry Belcher commented that he had "a wonderful experience" serving



difference but must continue to grow. "The Summit was a

huge success and we consumers/survivors now command a greater respect. Clearly the transformation of the public [mental health] system is well under way. We must now make best use of the vehicles we have at hand."

The co-sponsors and working participants were not the only people who felt that the Summit was a huge success: an even greater indicator was the overwhelmingly positive feedback from Summit attendees. Active participation was for many a new and exciting experience.

When asked what they enjoyed about the Summit, most of the attendees mentioned common themes: the "opportunity to contribute to a national platform," the "working

atmosphere,” being able to “produce tangible results,” and being “listened to and respected.” One attendee commented on “the brilliance of the disabled uniting to help one another,” and another on “the excitement, the hard work, and the freedom on people’s faces.”

After the Summit, some attendees even shared their feelings of accomplishment in public forums such as e-mail list serves.

ing with the working participants to create reports from each plank, Verna said. “As soon as each report is finalized, it will be posted on our web site. We’ll then send copies of the reports to everyone in our database, including all of the attendees. Our purpose is keep the discussions going.”

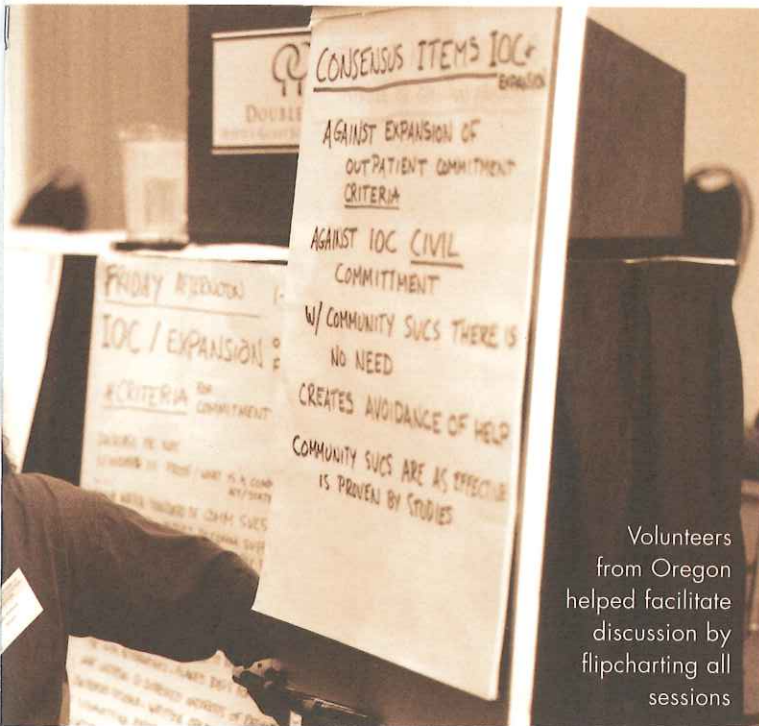
Perhaps Sandy Hayden, who served as an educational panelist on the organizing plank, said it best. “My impression, now that the National Summit has ended, is that it hasn’t. Attendees are fine-tuning each plank, a process that will continue well after the official compilation is distributed and read. I can’t recall any conference where so much activity will have taken place after people returned home.”

Belcher, who serves as director of CONTAC, another national techni-

Rogers echoed his colleague’s sentiment. “Cooperation between the technical assistance centers is vital to organizing a strong consumer/survivor voice. A big part of our mission here at the Clearinghouse is to promote networking among consumers and survivors throughout the country, and we will commit our resources to creating a strong national network.” While formal reports are still in the works, plans to continue the work of the Summit are already being implemented. Kevin Childs of New York, who set up the original e-mail discussion group for people to learn about and discuss the Summit, now has set up individual lists to serve as discussion forums for each of the Summit’s planks. (See page 7.)

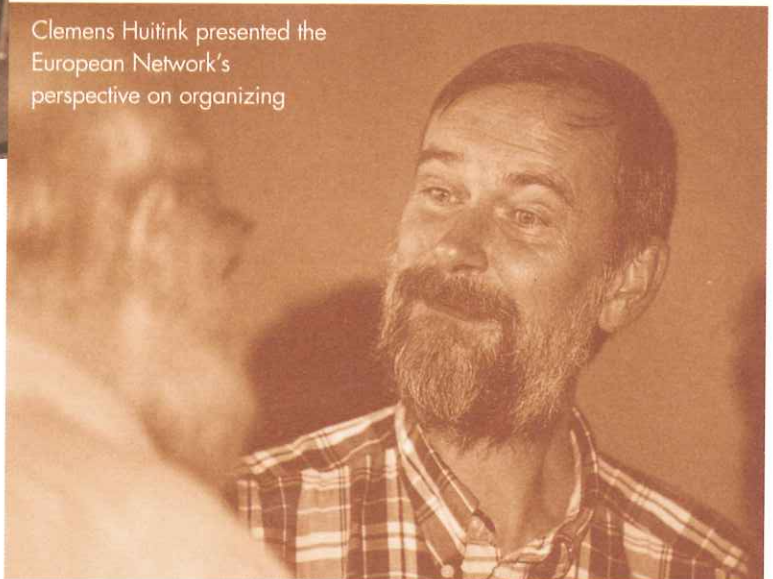
Californian Jay Mahler, who facilitated the recovery plank, is also making positive use of the information gathered at the conference. “I used a large part of the preliminary report in a presentation to the state mental health planning council. It was very well received.”

Rogers encourages everyone who was at the Summit “to use the Summit reports when they become available, but more importantly, use what you’ve learned at



Volunteers from Oregon helped facilitate discussion by flipcharting all sessions

Clemens Huitink presented the European Network’s perspective on organizing



Active participation was for many a new and exciting experience

Sherry Storms of Washington State called the Summit “without doubt, the most enjoyable gathering of consumers ever.” She attended the force and coercion plank, and called it “my first positive experience with consensus building in fifty years.”

Maxine Hayden traveled from California with her working dog, Skeeexix. She said that she met many people, and everyone with whom she spoke “confirmed how much they appreciated and enjoyed the National Summit.”

Clearinghouse staff are currently work-

cal assistance center funded by the Center for Mental

Health Services (CMHS), stressed the need for cooperation. He suggested “combining forces from all three technical assistance centers [the Clearinghouse, CONTAC, and the National Empowerment Center]; identifying as many consumer service providers as possible throughout the country; and soliciting their comments, concerns, and desired changes in the plank statements.”

the Summit to work for change where you live.” For those who did not come to the Summit, he said, “we welcome your input as we work on the ongoing action plans. We also hope that you’ll be able to attend future National Summits and other events at which consumers and survivors can build a national presence.” ●

— Alan Marzilli

CLEARINGHOUSE UNVEILS STATE-OF-THE-ART TECHNICAL ASSISTANCE GUIDES

This summer, the Clearinghouse announced a major upgrade to its collection of original technical assistance materials. Program director Marie Verna explained, "We're making our publications more informative and up-to-date and offering the entire curriculum as online, web-based, and readily accessible to consumers worldwide. The consumer movement is growing in strength and sophistication, and these new materials will help it continue to do so."

The Clearinghouse premiered its first set of new Technical Assistance Guides at the National Summit in Portland. The titles on display at the Summit were "Systems Advocacy," "The History of the Consumer Self-Help and Advocacy Movement," and "Advocacy and Recovery Using the Internet." Conference attendees expressed excitement over the new titles, many purchasing all three to take back to their home states and share with their agencies.

Technical assistance coordinator Elizabeth Knapp said that these topics were selected based on incoming technical assistance requests. "We created a list of priority publications based on the calls that we receive each week. Consumers are becoming more involved in advocacy efforts, and are using the internet more and more each day."

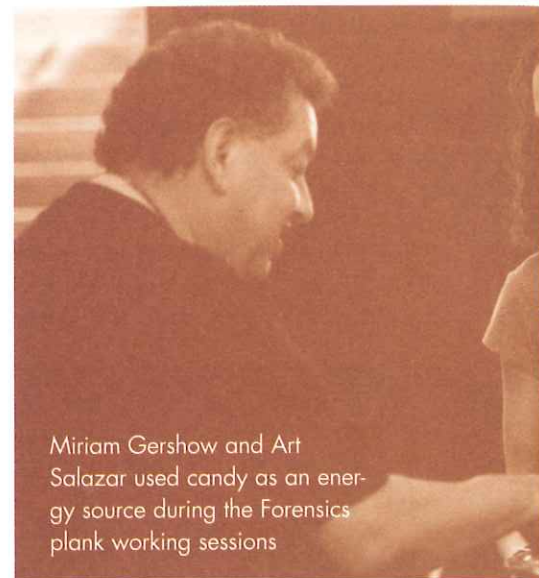
Additional titles are on the way. According to educational specialist Alan Marzilli, "Another major need of the consumer movement is developing business management skills. We're putting together an in-depth guide to consumer-run businesses and services. Another upcoming guide will show how to increase the consumer voice by serving on boards and committees."

Creating state-of-the-art materials is only part of the picture. All of the materials are available on the internet at the Clearinghouse web site, <http://www.mhselfhelp.org>. Executive director Joseph Rogers is proud of what he calls the "online inventory." Consumers anywhere in the world "can visit our web site and read our publications over the worldwide web. They can print out all or part of any Technical Assistance Guide free of charge."

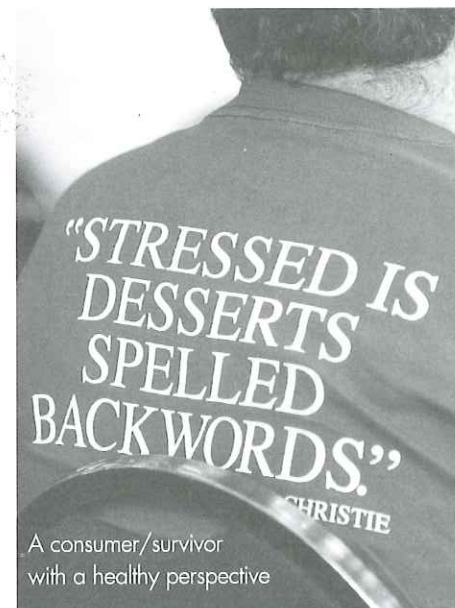
Marzilli explained that the new guides will be available in two formats. "The guides are available in traditional HTML format, which is the standard web format. They're also available in PDF format, which means that using free software, visitors can print professionally laid-out guides from their home computers."

Of course, the Technical Assistance Guides will continue to be available in print format. "When someone requests a publication by phone or mail," Verna said, "they'll receive a printed version of the PDF version currently posted on the web, packaged in a full-color cover, together with our latest brochure and information on Clearinghouse activities. The cost of the guides is free, but we ask for help with postage. Individuals who contact the Clearinghouse will also be placed in our database to receive future Clearinghouse mailings."

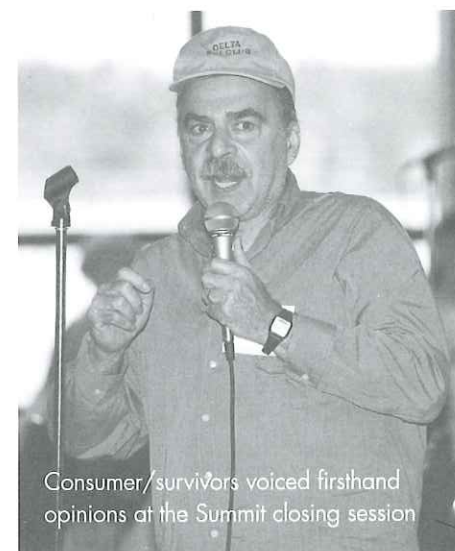
Please visit our web site to view our new Technical Assistance Guides. If you have any questions or would like an order form for the printed versions, please contact the Clearinghouse at 1-800-553-4539, ext. 256 or email us at info@mhselfhelp.org. ●



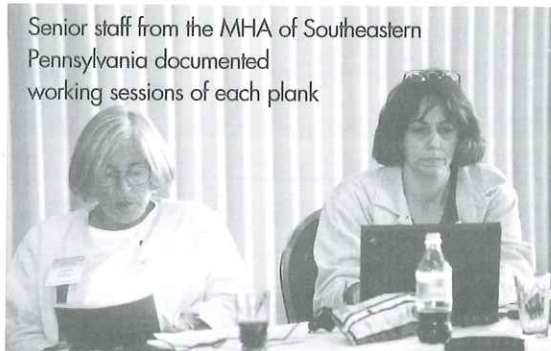
Miriam Gershow and Art Salazar used candy as an energy source during the Forensics plank working sessions



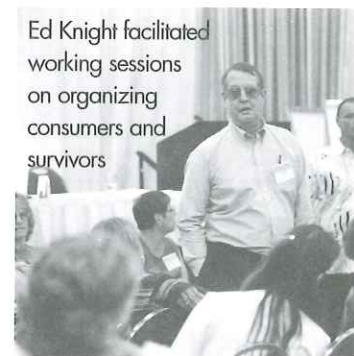
A consumer/survivor with a healthy perspective



Consumer/survivors voiced firsthand opinions at the Summit closing session



Senior staff from the MHA of Southeastern Pennsylvania documented working sessions of each plank



Ed Knight facilitated working sessions on organizing consumers and survivors

Keeping the Work of the Summit Alive

The Key

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We invite you to pass on and reprint any section of the newsletter without permission. Please cite *The Key* as the source of the article.

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Contributors: Alan Marzilli, Susan Rogers

Art Direction: Pamela Downes Lee

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We welcome your letters and suggestions. Write

The Key

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Now that the National Summit has ended, keeping the dialogues alive remains a major goal, and electronic communication will be vital to fulfilling that goal. Already, twelve e-mail listservs have been established for the individual planks of the Summit. By joining one or more of these lists, you can automatically send messages to everyone else on the list, as well as receive the messages that have been sent.

New Yorker Kevin Childs, who set up the listservs, said, "I envision the lists as a method of moving beyond the past into the future. The only way to do that is by working together today."

If you'd like to subscribe to a list, you may do so in one of two ways. You can send an e-mail to lyris@lyris.rainier-web.com. For example, if your name is Peter Jones and you'd like to subscribe to the advocacy list, the body of your e-mail should read:

subscribe advocacy Peter Jones

To subscribe on the worldwide web, visit the website <http://rainier-web.com/scripts/lyris.pl> and simply follow the instructions.

You can send messages only to those lists to which you have subscribed, but you can subscribe to as many of the lists as you'd like. Once you've subscribed, send messages to the following addresses:

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stigma@lyris.rainier-web.com

Clearinghouse program director Marie Verna encourages everyone to participate, not just those who attended the Summit. "Organizing a national consumer/survivor voice must be as inclusive as possible, and we encourage you to join us."

Electronic communication has been a big part of the Summit since the early planning stages. The Clearinghouse web site, <http://www.mhselfhelp.org>, has a National Summit page containing information about the Summit and how it was planned. Soon, the page will feature reports on individual planks.

The main National Summit listserv is also still quite active. It was established to allow advocates from across the country to help plan the Summit, and it continues to be a forum for discussing the work done at the Summit and a variety of other advocacy issues. To subscribe, visit <http://www.peoplewho.net>, follow the "people who" link, and then click on the graphic of the key.

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