Experts: Self-advocacy training is vital to consumer empowerment

CMHS asks NAPAS to work on the issue

By Susan Rogers

Consumer self-advocacy training changed Maureen Wood's life.

"Before I went into the program," she recalled, "I had been hospitalized constantly for major depression and post-traumatic stress disorder; I was extremely intimidated by the mental health system; I was not able to advocate for my own rights or play an active role in my own treatment plan." In fact, she said, she didn't even know what rights or options she had. "I was lost in the system, and the system was not helping me. I hadn't worked in probably three years."

Now, less than a year later, (Please see ADVOCACY on Page 8)

National leadership conference highlights, commentary inside

"Coming Together in '98: United in Leadership" — the largest collaborative event between the National Mental Health Association and the National Mental Health Consumers' Self-Help Clearinghouse - will take place June 6-10, 1998, at the Hyatt Regency Crystal City in Arlington, Virginia.

For more on the conference:
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• Toolbox

The Key is funded by the Community Support Program of the federal Center for Mental Health Services.
Message from the Executive Director

Making our presence felt in Washington

By Joseph A. Rogers

As I write this, I look forward to two exciting events in Washington, D.C. As you read this, one will be in the past, the other in the future. Both are major national efforts where consumers/survivors will play a significant role and the importance of our movement will be recognized.

The first is the “Walk the Walk (for lives touched by mental illness),” sponsored by the federal Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration. The second is “Coming Together in ’98: United in Leadership,” the largest collaborative event of the National Mental Health Association (NMHA) and the National Mental Health Consumers’ Self-Help Clearinghouse.

Walk the Walk, on May 2, 1998, was planned in cooperation with a steering committee representing 20 diverse organizations in the mental health area. These included, respectively, groups representing professionals, providers, and administrators; advocacy organizations of consumers/survivors, family members, parents, and concerned citizens; and government agencies.

The committee sought common ground and developed a statement of purpose that everyone could support: “to dispel misconceptions about mental illness, gain equal treatment for people with mental illness and celebrate mental health.” Whether or not the event draws the large crowd expected, the truly important thing about Walk the Walk is that we, consumers/survivors, will be marching in strength in the U.S. capital.

The second event is the joint NMHA/Clearinghouse conference (see pp. 1-2, 5-7 for details).

These two events will highlight, in Washington, the power of consumer/survivor organizing. And although our movement is not as united as it might be, the very fact that our numbers will be in the thousands at Walk the Walk and in the hundreds at “Coming Together in ’98” and on Capitol Hill following the conference will send a message that we are strong and organized, that our voices will be heard in the seats of power, and that administrators and policy-makers must heed our call.

Message from the Program Manager

Conference excitement builds

By Marie Verna

Here in Philadelphia, the pace has been accelerating steadily as we prepare for “Coming Together in ’98: Consumers and MHAs United in Leadership” in June. This is the largest national consumer leadership conference ever held in Washington D.C., and we expect the excitement to build in the upcoming weeks as we implement all the plans we’ve made with the National Mental Health Association.

At the Clearinghouse we think of “Coming Together in ’98” as a tremendous opportunity to bring consumers closer to Mental Health Associations around the country. We’ve spent the last nine months getting to know the needs and expectations of “the MHAs” from their representatives at National. We’ve had many, many fun and funny moments solving problems and working around obstacles — and we’ve become good friends.

But we’ve also had to accept that our enthusiasm for bringing strong, active consumers to the MHA movement hasn’t always been received with our level of optimism.

As we’ve talked about the conference, consumers here at the Clearinghouse have had to acknowledge that, in many ways, “Coming Together in ’98” represents a huge change to some of the 350 MHA affiliates around the country. And in some ways we’ve met with resistance to the idea of “consumers coming together with MHAs.” Their annual meetings typically followed a set program with expected events;

(Please see Verna on Page 11)
Alternative crisis intervention service

Under a CMHS-funded program, consumer-operated service is part of Philadelphia's crisis team. Services are offered late at night.

By Violet Phillips

A new crisis-intervention program getting under way in Philadelphia is putting a consumer-staffed and -focused service right in the middle of the city's mental health care system.

"It's not just this little thing consumers are doing on the side," said Chris Simiriglja, manager of ACCESS-West Philly, which runs the program. "We are actually part of the [city's] Crisis Response Center system." (ACCESS is an intensive outreach program and multi-service drop-in center serving homeless people with mental illness.)

The new program, Connections, is an After Hours Diversi- sion Center (AHDC), meaning it is a place for consumers who need help, but not psychiatric intervention, to get support and assistance — often late at night. The program, scheduled to kick off May 6, will be open Wednesdays through Saturdays, from 8 p.m. to 8 a.m., and will have on site both trained peer- and clinical-support staff. It will operate with the Mercy Hospital of Philadelphia Crisis Response Center (CRC), one of five CRCs replacing Philadelphia's old psychiatric emergency room system.

"Right now, two things happen when consumers go to the hospital in the middle of the night," explained Simiriglja. "Either they need intervention and they get admitted or, as is often the case, they don't need it — and they get kicked to the curb."

But just because a person in crisis doesn't need to be in the hospital "doesn't mean they don't need something," she continued. "They may need to be where people are at 3 a.m., and we want to offer them an alternative to the ER or the subway."

The AHDC concept came out of a directive from a committee of the West Philadelphia Task Force on Housing, Health and Human Services. Charged with examining unmet needs in the mental health continuum, the committee focused on the recurring issue of people in non-psychiatric crises having nowhere to go for help. Data indicated that high-volume psychiatric ER users included people experiencing drug and alcohol problems and various environmental emergencies. The AHDC program could replace high-cost hospital visits with responses that exactly fit these needs, said Simiriglja.

In the prototype, consumers without psychiatric needs who come to the Mercy Hospital CRC will be transported to the ACCESS center. There, she said, "our first mode of intervention would be peer support. Then, if the crisis is escalating, a clinical staff member can step in."

Because Connections is based at ACCESS, consumers can use the services available there, too, including meals, showers, clean clothes and a laundry. "Sometimes just helping a person get comfortable can help them deal better with the stress that caused the crisis," Simiriglja said. When necessary, staff members can do follow-up and time-limited case management to help consumers get needed referrals and services.

Connections is operating as a 20-month demonstration project, funded by the federal Center for Mental Health Services (CMHS) through savings from ACCESS. (Access to Community Care & Effective Services & Supports is one of about 20 such programs funded by CMHS.) But Simiriglja believes that the project will be so effective — both in terms of its cost and the well-being of the people served — that it will become a permanent part of the city's system, with programs created for all the CRCs.

"We've already heard from some of the other CRC hospitals saying they know they need a program like ours," said Simiriglja. "One thing we know for sure is that it works a whole lot better to do a peer-support intervention and get people back where they came from, than to send them out to the street."

Chris Simiriglja will run the Support Suite at the "Coming Together in '98" conference. (See p. 5.)
Early lessons on mental health
MHA initiative helps high school students tackle the issues, gain better perspective.

By Violet Phillips

Innovative student organizations in two North Carolina high schools are teaching students the importance of mental health.

The groups are Student Mental Health Associations located at two Davidson County senior high schools — Lexington in the town of Lexington and East Davidson in Thomasville. The students that join are getting to understand the importance of mental health and mental health issues at a young — and very important — age.

“When I was growing up, my Mom and Dad didn’t want to talk about what it meant to be mentally healthy,” said Brandi Gallimore, president of the student association at East Davidson, where she is a senior. “They thought that things would just work out for themselves.”

But high school is a stressful time, Gallimore acknowledged, and if we have our mental health, we can tolerate that better.

The student associations were developed by Kay Saintsing, the executive director of the Mental Health Association of Davidson County, who worked with the local board of education to get them going — four years ago at Lexington, two years ago at East Davidson. “We need to talk about mental health early to people,” she said. “Our students graduate with a much better perspective on themselves and others.”

The associations sponsor activities similar to those of most issue-oriented student groups — community service work, field trips and lectures. Field trips can mean visits to legislators in Washington, D.C.; service can mean working with an early childhood intervention program, and lectures can range from stress management to domestic violence to having a person with schizophrenia talk about the illness.

The students are not fazed by these issues, said East Davidson faculty advisor Suzan Quail. “They want to be involved.”

That’s a lesson that Saintsing learned from giving her own talks to students in the community. “If you address sensitive topics head on, they really appreciate it,” she said. “Frankly, they are feeling the pressure of mental and emotional stress, and I think they’re relieved to talk about it.”

Saintsing also believes that once young people are comfortable with mental health issues in their own lives, they can be better citizens of the world — becoming “more sympathetic to people with severe mental illness.”

Interestingly, the students seem generally unworried about the stigmas attached to mental health and illness. “The students who become members see no problem with it at all,” said Nancy White, faculty advisor at Lexington High School. “It probably does make them more open to talking about issues in their lives.”

That openness can have all kinds of effects. For one thing, it has enabled students to help one another. “I have invited some students to [particular] talks who I know were having problems and I thought the talk would be helpful,” said Gallimore, who has also been part of her school’s Peer Helping Program.

For another, it helps with personal growth. “Before I was a member, I would focus on small things all the time and blow them out of proportion,” Gallimore added. “Now, I have a much better outlook on my health.”

This kind of support and growth is exactly what Saintsing had in mind — and why, for example, she has student representation on her board of directors and why she believes mental health should be a greater part of the school curriculum.

“You don’t have to be 40 years old and have gone through a lot to know that mental health is important,” Saintsing said. “I want to share this concept of young people’s involvement.

“This is about adding life to mental health initiatives by bringing a group into our work that needs to be there.”

Not only do these students bring youthful energy to the cause, they also can add their own philosophical take on things. “I try to focus on the positive aspects of life,” said Gallimore. “One of my favorite quotes is, ‘Don’t look back in anger. Don’t look forward in fear. But look all around you in awareness.’”
Events and support services include Internet training, Clifford Beers award

Amidst all the workshops and speakers at the conference, there are other special events and services. Here are some highlights.

Events
- **Internet Cafe:** The Internet Cafe, with 10 computers, will be open on Sunday, Monday and Tuesday, whenever the exhibit hall is open. Sylvia Caras, creator of the MADNESS List on mental health issues, will be at this site five hours each day to offer information about using the Internet and to show different on-line mental health support sites. Come see the new Clearinghouse Web site! (See photo on p. 6.)
- **Coffeehouse:** Monday, 6-8 p.m., is a special time to socialize. An open microphone will be set up for anyone wishing to read poetry, sing a song, or tell a story. Refreshments will be served. Check the conference schedule for the site of this evening event.
- **Awards:** While many awards will be given at the conference, there are a few of particular importance to consumers. The Clifford W. Beers Award, presented to a consumer who has worked to improve conditions for and attitudes toward people with mental illness, will be given in a special awards dinner Sunday night. Awards will be presented for stellar work in the print and electronic media at a breakfast Tuesday morning. Among awards to be given at Tuesday's closing dinner will be the Tipper Gore "Remember the Children" Volunteer Award and the Ruth P. Brudney Social Work Award.

  - Opening Plenary — The Consumer Perspective: The first meeting, Sunday morning, will present a panel discussion on consumers working in coalition with Mental Health Associations. Clearinghouse program manager Marie Verna will moderate, with panel members Rob Gabriele, senior vice president at NMHA, consumer advocates Yvette Sangster of Connecticut and Sharon Yokote of Hawaii, and Clearinghouse executive director Joseph Rogers.

Services
- **Drop-in centers:** Two sites, one non-smoking and one for smokers, will be open 8 a.m. to midnight each day to provide comfortable places to relax. Coffee will be served.
- **ADA requirements:** The Hyatt Regency Crystal City offers ADA rooms, meaning the spaces, the furnishings, and the fixtures are intended to conform to ADA requirements. Conference representatives made additional recommendations, however, to ensure that these rooms were truly accommodating. They also recommended changes in some public bathrooms and other public spaces.
- **Support Suite:** Open and staffed 24 hours a day, the support suite will handle all kinds of emergencies — from emotional to medical. Someone will always be available to talk or help straighten out a problem here. This will be the place to come, for example, if it's late at night and you're feeling lonely and stressed out or if you've lost or forgotten your medications. Regular first aid will also be available here.

The suite will be run by Chris Simiriglia of ACCESS-West Philly (see p. 3).
Conference speakers will offer insight on many topics — from research to law

Three special guests will speak on important mental health and legal issues. The times and locations of these events will be posted at the conference.

Steve Hyman, M.D., will give the conference keynote address Sunday morning. Hyman directs the National Institute of Mental Health of the National Institutes of Health, where he oversees its mission of generating the knowledge to understand, treat and prevent mental disorders and to promote mental health.

Hyman has been actively involved in moving NIMH research into faster clinical application; he also continues to maintain his own research program at NIH.

Martha Manning, Ph.D., will speak at the closing dinner Tuesday. Manning is a clinical psychologist who has gone through her own debilitating depression, an experience she chronicles in the well-received book “Undercurrents.” Manning also appeared on an HBO special about depression, “Dead Blue.”

Gov. Howard Dean, M.D., of Vermont will speak on Wednesday at Government Affairs Day. In office since 1991, he has given priority to improving the lives of children and offering greater access to health care, particularly to people with low incomes.

In 1997 Vermont passed a broad-based insurance parity law covering mental health and substance abuse issues.

Come see the new Clearinghouse Web site, on display at the Internet Cafe. This new site is designed to make Clearinghouse services easier for consumers to access.

The Clearinghouse will unveil a prototype of our new Toolbox at a special caucus on Sunday, June 7, at 8 p.m. (location to be announced). We welcome your feedback.

The Toolbox is a kit designed to provide affordable technical assistance at a distance for consumers who want to start their own self-help groups.

The descriptive term Toolbox was chosen because each kit will contain the “tools” consumers need to get a self-help project going. The first tools are for planning a group, facilitating the group, and getting funding. Our designers are especially interested in hearing about the effectiveness, ease of use, and consumer recommendations about the cost of the Toolbox.

Once we gather feedback, we'll go back to the drawing board to create more tools.

In the meantime, consumers who have started self-help or advocacy groups are invited to share their expertise about the tools necessary to successfully organize mental health consumers into proactive, effective groups. Contact Liz Knapp at 1-800-553-4539, ext. 256, to contribute your knowledge.
Join us in Washington, DC at the Hyatt Regency Crystal City, VA

June 6-10, 1998

For more information call: 1 (800) 553-4539 X297

Just three miles from the White House, the U.S. Capitol, the monuments, the Smithsonian and one-half mile from Washington National Airport.

Conference topics on mental health issues will include:

- Consumer/Survivor Issues (ADA, rights, managed health care, etc.)
- Consumer-Run Programs
- Consumer/MHA Partnerships
- Managing Mental Illness to Prevent Disability
- Agency/Nonprofit Growth and Development
- Advocacy Training
- Children’s Issues

—Presented By—

National Mental Health Consumers' Self-Help Clearinghouse
Urged by leaders, CMHS backs study on P&A support for advocacy trainings

(ADVOCACY from Page 1)

Wood is employed full time as a respite worker in a residential program and is completely self-supporting. As required by the training program, she is also interning at a local mental health authority in Milford, Conn. There she tries to give other consumers the same information, skills, and motivation she was given. "I think I'd still be lost if it hadn't been for graduating from that program," she concluded.

Wood's training, provided by a consumer-run agency in Connecticut, is supported in part—both financially and through technical assistance—by the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program of the State of Connecticut Office of Protection and Advocacy for Persons with Disabilities, in Hartford. PAIMIs are one of several programs of Protection and Advocacy agencies, known as P&As. (There is one P&A in every state and territory, and they are federally mandated to protect and advocate for the rights of people with disabilities, including mental illnesses, developmental disabilities, and physical disabilities.) As one of their services, PAIMIs can support or provide consumer self-advocacy training, which can range from teaching consumers how to advocate for their rights in the mental health system to training them in the skills they need to effect systems change.

But while there is clear evidence of the effectiveness of such training programs as the one that graduated Maureen Wood, there is little information about how many other PAIMIs really do this work. And indications are that much more could be done.

Consumer self-advocacy training costs little and supports the PAIMI core mission, advocates say. But, until recently, neither the national association of P&As nor the federal agency that funds PAIMIs has engaged in a formal effort to encourage such initiatives. National leadership to foster creation of new self-advocacy programs at PAIMIs is needed, advocates say, and some federal officials are responding.

"P&As could do so much more than they are doing to empower consumers," said Joseph Rogers, executive director of the Mental Health Association of Southeastern Pennsylvania. "We have strongly urged that the Center for Mental Health Services [CMHS] and the National Association of Protection and Advocacy Systems [NAPAS] take a leadership role in encouraging, if not instructing, P&As to institute self-advocacy training initiatives, and that they work closely with consumer/survivor groups in their states to develop those initiatives."

Now, in response to such urging by consumer advocates and others, including the National Mental Health Association (NMHA), CMHS has asked NAPAS to study what P&As around the United States are doing to train consumers in self-advocacy skills.

Said CMHS director Bernard S. Arons, M.D.: "CMHS has requested that the technical assistance center for the PAIMI program begin work in the area of consumer self-advocacy. We have been assured that such activities will be done in collaboration with relevant organizations and parties, including the Mental Health Association of Southeastern Pennsylvania."

A NAPAS spokesperson described the project as "brand-new." "It is evolving as we speak," said Vicki Smith, deputy director of NAPAS and project director of its Advocacy Training and Technical Assistance Center (ATTAC), which is in charge of the initiative.

Smith added: "Apparently there were some letters back and forth between Joe Rogers and CMHS; and while we were aware that people within CMHS were very interested in doing more work around developing model procedures and such regarding consumer self-advocacy training, it was always just on the table as one of the many things they wanted us to do. And it was elevated to a 'to do' last week [in (Please see ADVOCACY on Page 9)
Advocates seek faster action on support for self-advocacy training

(ADVOCACY from Page 8)

mid-March].”

She said that ATTAC would gather information this year and, if NAPAS is awarded next year’s contract to provide technical assistance to the P&As, would review the materials and develop a model curriculum. She anticipates that the curriculum will be broad-based, because of the different needs of the various constituencies served by the P&As.

“Everything we do has to be inclusive of all different components of the P&A system client base...not just PAIML,” she said.

“There would be certain standards that would have to be involved with any consumer empowerment training program regardless of the disability; but we would let the experts within [each] specific [disability] community be the experts.”

Informed of Smith’s comments, Rogers responded: “My hope would be that NAPAS would move a little faster than seems to be planned, and I also hope that we don’t wait for consensus across all disability groups served by NAPAS.”

At the same time, the NMHA and MHASP are trying to get language inserted into the reauthorization legislation for the Substance Abuse and Mental Health Services Administration (which governs PAIMI) that would encourage P&As nationally to support consumer self-help activities, said NMHA’s vice president of government affairs, Al Guida.

Asked for his definition of consumer self-advocacy training, Guida answered: “At a bare minimum, we’re talking about attempting to empower consumers to speak out on their own behalf with respect to decisions that immediately touch their day-to-day lives. Almost invariably those are treatment decisions: a consumer ought to have a say in what type of psychotropic medication they receive, or whether they should receive any at all. That is the most basic rung of consumer empowerment.

“[It continues] to advocating on their own behalf in an internal appeals process run by a managed care organization, to the highest level, petitioning the government for adequate funding for the public mental health system. Consumer self-advocacy encompasses all of that,” Guida said.

Some P&As are already walking the talk. Connecticut PAIMI coordinator Susan Werboff strongly supports consumer advocacy training. “I would encourage all the P&As to do such training, and to support the consumer movement,” Werboff said. “It’s the best way to effect systems change.”

Connecticut’s P&A provides both funding and technical assistance to Advocacy Unlimited, Inc., in Wethersfield, Conn., which trained Maureen Wood. (A freestanding consumer advocacy educational program, until April 24 it was a division of the Connecticut Legal Rights Project, a non-profit law office serving individuals with mental illness in state facilities.) The program also receives funding from the Connecticut Department of Mental Health.

Yvette Sangster, who heads the four-year-old consumer-run program, said she has been doing consumer advocacy training informally for the last 15 years — including patients’ rights trainings on hospital wards for the last eight in order to help people take control of their treatment. “They’re working on what’s most important to them at the time. As they get stronger, they become advocates and go back and teach others,” she said.

“We’re really trying to build a grassroots movement that’s strong and knowledgeable.”

Her agency’s training, once a week for 14 weeks, is comprehensive, ranging from basic self-advocacy to complex systems advocacy skills and information. Topics covered include disability law (such as people’s right to be included in their own treatment planning and the laws covering medication and seclusion and restraint, as well as the Americans with Disabilities Act, the Fair Housing Act, and the Freedom of Information Act).

(See please ADVOCACY on Page 10)
Connecticut PAIMI teams with state to fund self-advocacy training

(ADVOCACY from Page 9)

The training covers such systems advocacy skills as “what services are in the community, how do you access them, what are the regulating councils around those services, and what councils and boards do you need to be on in order to make effective change within the system,” said Sangster.

“It also covers legislative advocacy, she said: “who are your legislators, how do you establish a relationship with them, how do you testify at a hearing, how do you find out the hearings are happening, how do you network, how do you build coalitions.”

“Then we [teach] other skills that advocates need, such as public speaking, dealing with the media, body language, time management, and a lot of other back-up skills, such as research skills,” Sangster said.

In short, she said, it’s “the basic knowledge of working to effect permanent, positive change in the mental health system and take control of your own life.”

So where does self-advocacy stop and systems advocacy begin? It’s a continuum.

Said Rogers: “You start with learning how to speak up for yourself. In that process, you learn skills to help others who may be getting the short end of the stick. Through fighting for your rights and others’ rights, you learn skills that can be used when you identify systemwide issues so that you can take collective action to truly change the system.”

He added, “Although not everyone is going to go on to become a systems advocate and many people will stop with learning to effect change for themselves, it’s extremely important that people can advocate for themselves—because, no matter how good a system of advocacy we create, it still comes down to an individual’s either having to accept a situation or raise their voice to change it.

“It all starts with the individual and can grow to where literally hundreds if not thousands are taking action to change the system,” Rogers said.

 Asked if this is all part of what P&As should be doing, Tom Leibfried of NMHA answered, “You bet.” Leibfried, a consumer who directs NMHA’s Office of Consumer Advocacy, explained, “Consumers have a lot to offer P&As in terms of extending their influence. It’s a sin of omission on the part of P&As not to use that resource.”

Iowa’s P&A also believes in the power of that resource. Through its Iowa Consumer Empowerment Project, it is training people with mental illness, family members and parents of children with emotional disorders. “The premise of the project is to empower consumers to be knowledgeable about the system and the issues, and to be able to use that knowledge and those skills to impact the mental health system in Iowa,” said project director Alfredo Alvarez, who is also the agency’s supervising staff attorney as well as the PAIMI and PAIR (Protection and Advocacy for Individual Rights) program coordinator. (Among those PAIR covers are people with mental illnesses who do not have developmental disabilities and do not live in institutions, he said.)

The training is in conjunction with the Alliance for the Mentally Ill of Iowa, which has a consumer component, Alvarez said. Topics include diagnosis and treatment of mental illness, effective meeting participation, the legislative process, managed care in Iowa, the Iowa mental health system, and fighting the stigma of mental illness.

The trainings will eventually be two sessions, each one-and-a-half to two-days long. “We’ve just finished our third Session I training,” he said. “We’ve modified things as a result of [participants’] input” to include more time for debriefing, dialoguing, and sharing new ideas. “Session II will include more specific tasks, such as using the civil rights complaint procedure, training on small claims, Fair Housing, and effective networking,” he said.

Participant Darline Brown, a

(See ADVOCACY on Page 11)
In Iowa, P&A trains constituents to make impact on mental health system

(ADVOCACY from Page 10)

longtime consumer movement activist, said she found the training informative. “You could tell from the questions people asked that some of them were just beginning to find out how they could have a voice. Then there were those of us who have been in the movement for many years.” Participants also included family members and staff of agencies, “a good mix,” she said.

Alvarez added that mentoring of participants by P&A staff is an important component of the project. “We’re also providing support after the project for six to nine months. If they get appointed to a committee, they can come back and we can be a sounding board for them.”

Yvette Sangster agreed. “Training is not a one-shot deal: you can’t just train people and then spit them out; you have to have a support system to guide them as their needs change. There’s no magic bullet here. If people are going to put time and money into a training, they’d better build in the supports.”

Also, she said, “the staff really have to believe in the strengths of people with mental disabilities. Folks that have been told they can’t do need a lot of time where they’re told they can do.”

As graduate Maureen Wood said, “Whenever I thought I couldn’t do something, Yvette believed I could.”

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Excitement builds as national leadership conference approaches

(VERNA from Page 2)

this year, the meeting will include many different programs and discuss many different themes.

As with any major change, the MHA affiliates will need to adjust to these differences, and if we want the conference to be successful, consumers should give them the space to do that.

In exchange, however, MHAers should make consumers feel invited and valued, since the conference is just as much about leading the consumer movement as it is about leading the MHA movement.

At “Coming Together in ’98” consumers want to feel welcomed for their firsthand experience as people with mental illness.

Clifford W. Beers, the founder of the National Mental Health Association, was horribly mistreated in both a private institution and a state asylum. He begins his autobiography, “A Mind That Found Itself,” by writing: “This story is derived from as human a document as ever existed; and, because of its uncommon nature, perhaps no one thing contributes so much to its value as its authenticity.”

It is our very authenticity as mental health consumers that motivates us to reform the systems that hurt us in the past or continue to hurt others. Because we’ve suffered the same torments as reformers such as Clifford Beers, we can say with absolute certainty that people with mental illness deserve better treatment. And because our experience, like Beers’, is also from our own human documents, we believe our authenticity gives us authority to assert what the issues should be in mental health care reform.

This very sense of authenticity is at the root of consumers’ enthusiasm and excitement over coming together in leadership with Mental Health Associations. We have much to learn from each other. Let’s use Washington as our setting; come there with open minds toward ideas, behaviors, and needs that seem new and different. In 1998, let’s make “Coming Together” more than a catch phrase for a conference. Let’s genuinely come together to learn from and laugh with each other — to become better friends.
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