



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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NEW FREEDOM COMMISSION SOLICITS INPUT FROM CONSUMERS/SURVIVORS

A new advisory group created by President George W. Bush to ensure “that the cracks are closed” in the mental health system and other systems serving people who have mental illnesses gives consumers/survivors and other mental health stakeholders a chance to provide information and advice to those who potentially have the President’s ear.

On April 29, 2002, Bush talked about closing the cracks in the system as he announced the creation of The President’s New Freedom Commission on Mental Health. Its goal is “to recommend improvements to enable adults with a serious mental illness and children with a serious emotional disturbance to live, work, learn, and participate fully in their communities.”

The Commission, chaired by Michael F. Hogan, Ph.D., director of the Ohio Department of Mental Health, includes mental health professionals, administrators, academics, researchers, and representatives drawn from the executive, legislative, and judicial branches of the federal and state governments. Among its members are Charles G. Curie, M.A., A.C.S.W., administrator of the Substance Abuse and Mental Health Services Administration (ex-officio); and Daniel Fisher, M.D., Ph.D., co-director of the National Empowerment Center, one of the

three consumer-run national technical assistance centers that support the consumer/survivor self-help movement.

At the New Freedom Commission’s first meeting, on June 18-19 at the Ritz Carlton Hotel in Pentagon City, Va., several people spoke about the importance of incorporating the points of view of those who have “been there.”

“IAPSRs deeply regrets that the Commission membership is not more representative of people who have experienced firsthand the failures, and the successes, of the public mental health system,” said Paul Seifert, director of government affairs for the International Association of Psychosocial Rehabilitation Services (IAPSRs). “The Commission can and should make up for this shortcoming by inviting consumer input and participation at every step.”

Toward this end, Fisher, the only commissioner who has identified himself as having been diagnosed with a mental illness, has been actively seeking input from a broad array of consumer/survivor activists. “I am making every effort to be as inclusive and informative as possible because I see ‘nothing about us without us’ as a central value of our movement,” he wrote in a recent e-mail.

In his opening remarks Fisher said, “I would like to see this commission recommend the transformation of the mental

health system to recovery-based services guided by hope, empowerment, and maximal involvement of consumers/survivors at the federal, state, and local levels in areas of policy, services, training, and research.”

Among the other movement activists who spoke was Lawrence Plumlee, M.D., representing Support Coalition International. Plumlee, formerly on the faculty of Johns Hopkins Medical School, noted the importance of informed consent. “Consumers should have full disclosure about the risks of proposed psychiatric treatments, and choice from a range of alternatives,” he said.

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Message from the Program Director

CONSUMER MOVEMENT CAN OVERCOME HARD TIMES

Everyone . . . is entitled to . . . the economic, social and cultural rights indispensable for his dignity and the free development of his personality." — *Article 22, Universal Declaration of Human Rights, adopted by the U.N. General Assembly in 1948 without dissent* <<http://www.un.org/Overview/rights.html>>

I first encountered the Universal Declaration of Human Rights during its 50th anniversary, when I was the National Mental Health Association's director of consumer advocacy. Seeing the aspirations of the consumer movement so clearly grounded as international aspirations for human rights inspired me.

The Declaration moved with me to graduate school in Michigan and then back to Washington, D.C. Over the past two years, as I lobbied for increased federal funding of mental health and addictions treatment services, the arid environment of statistics and legalese often made me think of my work as Clearinghouse program director from 1995 to '97. I missed the energy that comes from working in solidarity to ensure that consumers' voices are heard.

As I rejoin the Clearinghouse, the movement is at a critical juncture. After two decades of progress in which the value of consumer-run programs and the recovery concept have gained wider recognition, competition for resources and shifting federal priorities have left "alternative" consumer programs vulnerable. Ironically, the uncertain future of funding for consumer-run programs comes just as data pointing to their effectiveness and cost-effectiveness — through research funded by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (SAMHSA) — is being published.

Now, SAMHSA is shifting away from its role of identifying and researching

BY TOM LEIBFRIED



Tom Leibfried
Clearinghouse Program Director

promising practices. In an effort to comply with broader federal initiatives to "reduce redundancy," SAMHSA has proposed to shift its services research and development activities to the National Institute of Mental Health, which has not yet budgeted to pick up these activities. Innovative consumer-run programs are left in jeopardy.

When we consider the future of these programs, more than science is at stake; there is also principle.

Millions of Americans diagnosed with mental illnesses are routinely discriminated against: thousands are locked up in prisons and jails or languish in antiquated state hospitals; private mental health insurance coverage does not guarantee effective treatment; people with psychiatric disabilities are often unable to assert their right to reasonable accommodation in the workplace; and too many clinicians fail to understand that it is the consumer's ability to live a full life that is at stake.

Federal and state governments have implemented successful programs to help break down barriers to equal oppor-

tunity for disadvantaged minority groups such as African-Americans, Spanish-speaking people, and women. They should do the same for people who have psychiatric disabilities. The U.N. Declaration of Human Rights states that governments must recognize that "[e]veryone has the right to a standard of living adequate for the health and well-being of himself [or herself] and his [or her] family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, [or] old age . . ."

But making a statement of principles is not enough. Even Thomas Jefferson, the principal author of the Declaration of Independence, which articulated the inalienable rights of Americans to "life, liberty, and the pursuit of happiness," failed to liberate the slaves he owned. It took public pressure, mounted over the course of almost a century following the signing of the Declaration, to free enslaved Americans.

Every time minority groups have gained greater opportunities to participate in society, social movements have led the way. As the federal government threatens to abandon consumer-run programs, the people must lead so that the leaders will follow and recognize the human rights principle at stake.

The Clearinghouse and the other consumer/survivor-run national technical assistance centers stand ready to help the consumer movement as it works toward realizing its goals, which are directly related to our American ideal of equality. I look forward to helping promote the science and egalitarian principles of consumer-run programs, and feel confident that national networking and information-sharing efforts will be successful in helping these programs weather difficult times. ●

NEW RESOURCE CENTER TO ADDRESS DISCRIMINATION AND STIGMA OPENS

The Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration recently created a resource center to counteract the discrimination and stigma that accompany the experience of mental illness.

The CMHS Resource Center to Address Discrimination and Stigma (ADS Center) is operated by the Mental Health Association of Southeastern Pennsylvania through a contract with The Gallup Organization, with support from the Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services. The ADS Center was established to help mental health consumers, family members, advocates, managed care organizations, providers, local communities, and states design, implement and operate programs and campaigns to reduce stigma, and the discrimination and prejudice it engenders. The ultimate goal of the ADS Center is to enhance mental health consumer independence and community participation.

"The ADS Center provides specific resources and information for people or organizations interested in combating discrimination and stigma," said Susan Rogers, the new Center's project director. "The ADS Center also offers information about available publications, events, and issues of relevance." A Web site is currently under construction, and a semi-annual newsletter and a Speakers' Bureau are planned, she added.

"Mental Health: A Report of the Surgeon General" identified stigma as one of the major barriers that discourage adults with mental illnesses, and the families of children and adolescents with serious emotional disorders, from seeking treatment, Rogers noted. While approximately one in five Americans lives with a mental disorder in any given

year, estimates indicate that half of people with severe mental illnesses received no treatment in the past 12 months.

Aside from keeping people from seeking help, the consequences of discrimination and stigma for adults who have mental illnesses include lowered self-esteem; disrupted family relationships; and increased difficulty in building connections in the community, securing housing, and obtaining employment. Children who experience discrimination and stigma may be scarred for life.

A Wealth of Skills

Rogers said that, in developing the project, she is excited to be able to draw upon a wealth of skills and experience available through the ADS Center Steering Committee and consultants. "The ADS Center's distinguished Steering Committee consists of 10 people who represent a broad array of perspectives in the mental health arena," she continued. The Steering Committee members (alphabetically) are Laurie Ahern, co-director, National Empowerment Center; Larry Belcher, director, CONTAC; Richard Birkel, Ph.D., executive director, NAMI; Patrick Cody, until recently vice president of communications, National Mental Health Association, and now establishing an office of Freedom From Fear in the nation's capital; Patrick Corrigan, Ph.D., director, Chicago Consortium for Stigma Research, University of Chicago; Laurene Finley, Ph.D., Multicultural Training and Research Institute, Temple University; David Gonzalez, founder, www.seecinomania.com; Al Guida, mental health policy consultant; Carolyn Nava, senior family adviser, Technical Assistance Partnership, and staff, Federation of Families for Children's Mental Health; and James Radack, vice president of public education, National Mental Health Association.

"We are also thrilled to have the consult-

ing services of Dr. Otto Wahl, a prominent researcher and advocate," Rogers said. Dr. Wahl, a clinical psychologist and professor of psychology at George Mason University in Fairfax, Va., has published and lectured extensively on the subject of stigma. "In addition, Vanguard Communications, a Washington, D.C., consulting firm that develops and implements advocacy campaigns around such issues as the environment, public education, health care, and children and families, is providing its expertise in communications and materials development," she said.

Other CMHS Efforts

CMHS created the ADS Center as a next step following a number of CMHS activities aimed at eradicating discrimination and stigma.

In March 2001, CMHS sponsored the first National Mental Health Symposium to Address Discrimination and Stigma, bringing over 400 experts together to review research findings and best practices in this area. CMHS also published "Challenging Stereotypes: An Action Guide," which provides a step-by-step approach on how to respond to stigma in the media and elsewhere, including sample letters, resource listings, and strategies. An Anti-Stigma Kit consisting of a poster and other material is also available from the National Mental Health Information Center at 1-800-789-2647, or its Web site: www.mentalhealth.org/stigma.

In addition to Susan Rogers, the ADS Center is staffed by a bilingual (English/Spanish) information specialist, Samuel Rosario, who can be reached at 1-800-540-0320 Monday through Friday, 9 a.m. to 5 p.m. Eastern Time; its webmaster, Bill Krum, director of MHASP's Division of Peer Support and Community Education; and consultant Jennifer Bofinger, also consultant to Pennsylvania's anti-discrimination campaign www.openmindsopendoors.com. ●

GROWTH OF LGBT CONSUMER/SURVIVOR MOVEMENT SLOW BUT SURE

BY SUSAN ROGERS

A small number of determined advocates have been working for more than a decade to forge a movement within a movement. These are lesbian, gay, bisexual and transgendered (LGBT) consumer/survivor activists, who have not one but two closets to come out of.

The LGBT consumer/survivor movement is small, in part because of the risks of coming out, said one movement leader, Steve Holochuck of Massachusetts. "One of these identities" — homosexual or mentally ill — "is hard enough," he said. "When you have both of them, it's a particularly heavy load to carry. And then to be politically active and open about both of them — that's a big thing to take on."

Nevertheless, some intrepid leaders are taking it on. The initiative began in the '70s with gay and lesbian caucuses at the International Conferences on Human Rights and Against Psychiatric Oppression, which preceded the national Alternatives conferences. It continued at Alternatives '89 and '90. But it got a second wind at Alternatives '91 in Berkeley, Calif., Holochuck recalled. It was there that the Fruit and Nut Bar — a loosely organized national network of gay male, lesbian, bisexual and transgendered consumers and survivors — was founded.

The following year, at Alternatives '92 in Philadelphia, the Fruit and Nut Bar declared its mission: "to build mutual support among people who have this [LGBT] identity and make the mental health system more responsive to our needs and preferences." The statement continued: "We desire to build an acceptance and affirmation of people

with psychiatric labels in the sexual minority community and, likewise, of sexual minority people in the mental health consumer/survivor community."

There is general agreement that such acceptance and affirmation does not yet exist.



BGLT activist Mark Davis

Alicia Lucksted, Ph.D., of the University of Maryland Center for Mental Health Services Research, addressed this problem in a monograph entitled "Experiences of LGBT people with Serious Mental Illnesses: Raising Issues." In the monograph's summary, Lucksted, a lesbian and the recipient of the 1999 Early Career Research Award of the International Association of Psychosocial Rehabilitation Services (IAPRS), notes the homophobia and ignorance on the part of many mental health services staff.

Such a negative climate "certainly is there," said David Johnson, a gay psychiatrist in Lancaster, Pa. "My clients can go to a straight mental health practitioner and sometimes get very poor treatment," he said. "For example, a lot of gay people get diagnosed as being obsessive-compulsive because of their sex drive. They're treated as having paraphilia, an abnormal sex drive that might include pedophilia and fetishism. Especially in conservative areas, a lot of [professionals] still think same-sex desire is an illness."

This is in spite of the fact that, in 1973, the American Psychiatric Association declassified homosexuality as an illness — at least in part due to the courage of Philadelphia psychiatrist John Fryer. At the 1972 APA conference in Dallas, Fryer appeared in disguise on a panel to

announce, "I am a homosexual. I am a psychiatrist. I . . . am a member of the APA." Further, he said, "I could be any one of more than a hundred [gay] psychiatrists registered at this convention."

Unfortunately, Johnson said, many gay professionals contribute to the problems confronting their LGBT clients by staying in the closet. "While there are many gays and lesbians in influential clinical and administrative positions in community mental health, I suspect many don't feel secure enough in their positions to risk advocating for better services for their sexual minority community for fear of political consequences," he said.

The fact that homosexuality used to be a psychiatric diagnosis is at the root of some of the discrimination and prejudice that plague LGBT consumers, Holochuck noted. "It shows some of the arbitrariness of psychiatry that the APA takes a vote and then millions of American homosexuals are instantaneously cured. It shows the politics of pathologizing and labeling."

These politics are, in part, what the movement seeks to change. "The two halves of the struggle are the heterosexism in the consumer/survivor movement and the [mental health] system, and the oppression of people with psychiatric labels that exists in the [LGBT] community," Holochuck said.

"We've heard some heartrending stories," he continued. "One person who is a major leader in his state movement, and feels that he has to be in the closet, said that things are said in front of him in a movement environment and in program environments with consumers/survivors that are very heterosexist and homophobic. This is very painful to him." Holochuck said he has also "had people say things to me that have left me aghast."

That's why he makes no judgments about consumer/survivor movement leaders who choose not to make their



Steve Holochuck speaking at the Empowerment Center of Western Massachusetts, a peer-run agency

minority sexual status known. "People should do what they're comfortable with," he said. However, he added: "People who are out and visible, especially if they have leadership skills, would be making a contribution. And I certainly have been saddened by the failure of some people to come forward."

Another obstacle to LGBT consumer/survivor organizing is that the sexual and gender minority movements are not unified, according to Mark Davis of Philadelphia, a nationally known leader of the movement that he prefers to refer to alphabetically as BGLT. "Gay men and lesbians have different agendas and sometimes separate themselves from bisexual and transgendered people. Each culture — diverse within itself — has totally different health and psychosocial needs," he said. (See sidebar on Page 5.)

Davis believes it is a problem that "BGLT initiatives are being lumped together with overall cultural competence [efforts], which is a threat to the [other] minority groups that are umbrellaed under a cultural competence agenda. There seems to be no increase in resources, so the BGLT consumer/survivor movement is viewed as a financial threat because of having to share the pie with more people."

Yet another barrier is the intense homophobia that exists among some racial and ethnic minority groups. Cookie Gant of

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Transgendered Peers Face Additional Hardships

If lesbians, gay men and bisexuals suffer discrimination and prejudice, that's nothing to what transgendered consumers/survivors have to face, even from their peers.

"There is division among [LGBT] consumers/survivors," said Paula Lafferty, founder of Hearts & Ears, Inc., an LGBT consumer/survivor-run drop-in center in Baltimore. "I think it's primarily between GLB and transgendered people." This reflects the division among lesbians, gay men, bisexuals and transgendered people in the general population, she added.

As an example, she recounts the struggle to pass an anti-discrimination bill in Maryland that gives protection in the areas of housing and employment to gay men, lesbians and bisexuals but not to transgendered people.

"There are many gays, lesbians and bisexuals who strongly wanted to include transgendered folk on the bill," she recalled. "But the Legislature approached Free State Justice [FSJ], the political organization that was pushing the bill through, and said that the governor would not sign the bill if transgendered people were on it, and FSJ agreed to take them off the bill. In the words of [Maryland] transgendered activist Courtney Murphy, 'Now the Legislature thinks that they have addressed the issue and they won't think of transgendered civil rights for another eight or 10 years. Free State Justice should have worked to pass the bill with transgendered people included until it got through.' "

Since the bill's passage, however, FSJ has made amends with many of the politically active transgendered population, Lafferty said. They have formed and fund a committee called Marylanders Advocating Toward Transgender Equal Rights (MATTER), which Murphy co-chairs.

In spite of its denouement, the story illustrates the division between transgendered people and gay men, lesbians and bisexuals. But, clearly, this is not the sole source of difficulty for transgendered individuals.

"I think the issues that transgendered people have are so much more than the issues that GLB people have," Lafferty added. For example, she said, finding housing becomes more complicated.

"There is someone in our group who was homeless for more than five months and she stayed in abandoned housing because shelters don't know what to do with transgendered people," she recalled. "There is another [transgendered] person in the group — female to male — who is homeless, and is not staying in housing because they'll put him in with women, and that gives him the creeps. This person passes for male, does not talk like a woman, but his legal name is still the name given to him at birth. . . . So there are 10 times more problems [confronting transgendered people]."

A Hearts & Ears conference, to be held in October 2002, will include a panel focusing on the experiences and needs of transgendered people who receive services in the public mental health system, from both a consumer and provider perspective.

However, there are signs that the situation may be evolving. For example, a recent article on the Fox News Channel Web site quoted Paisley Currah, associate professor of political science at the City University of New York and a board member of the Transgender Law and Policy Institute: "[Transgender law is] totally exploding — in law, the amount of litigation, the laws passed, the law reviews written. Transgendered people have become more organized and [are] moving beyond merely a support system for each other to actually fighting for their rights." — Susan Rogers

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Michigan, an African-American woman and a lesbian who has been involved in the consumer/survivor movement since 1985, said that the prejudice against homosexuality in the African-American community is so bad that "given a choice of being gay or having a mental illness, [African-Americans] would choose having a mental illness."

Thus it is no surprise that the LGBT consumer/survivor movement has had what Bill Compton, a movement leader from Southern California, calls "a long incubation period." In fact, when asked about the LGBT consumer/survivor movement, Davis quipped, "What movement?" While praising various local organizing efforts, Davis explained: "I believe the BGLT movement in the context of the consumer/survivor movement is an abstract concept that is addressed sporadically. We get together in a caucus, at an annual conference, and we say we're going to do all these great things; but when we leave the conference, nothing happens."

However, he is hopeful: "I believe we're at a crossroads, where people are finally saying, 'Let's start organizing.'"

There have been some milestones.

Gant remembers organizing at Alternatives '89, in South Carolina. She recalled that a Center for Mental Health Services staff member, who is no longer there, "said there was money if we could organize." However, she said, "when we came out, we were personally attacked."

Davis concurred: "In South Carolina, there was great resistance to permitting BGLT folks a room for a caucus. I was still in the closet at that time. Well, sorta."

The next year, at the Bastille Day march at Alternatives '90, in Pittsburgh, "we marched together," Gant said.

But although nothing much was happening nationally, "Some of us did things on a local level," Holochuck said.

Among such local initiatives are the three Pink and Black Triangle Society self-help groups in Long Beach, Hollywood, and Palmdale, Calif., respectively. The groups were started by Bill Compton, director of Project Return Next Step, a network of 92 social self-help clubs. Compton, who received the National Mental Health Association's Clifford Beers Award in 2001, recently won the IAPSR

2002 Consumer Advocate award.

Although Compton is one of the select group of consumer/survivor leaders who are openly gay, he doesn't "get on a soapbox" about it, he said. In the three minutes he had to speak at the NMHA conference, he didn't mention he was gay, "because I thought it was more important to talk about outpatient commitment."

Another leader is Bert Coffman, who founded the Zappalorti Society in New York City in 1992, in memory of Jimmy Zappalorti, a gay Vietnam veteran with a mental disability who was murdered on January 23, 1990. The two perpetrators received life sentences, said Coffman. The group meets on Saturdays at the Gay Community Center of New York City.



Members of Hearts & Ears gather to march in the Baltimore Pride Parade in 2000

"The whole idea is for people not to feel alone and isolated, like they're the only homosexual on Earth," he said.

Another group, the Hearts & Ears, Inc., drop-in center in Baltimore <<http://www.heartsandears.org>>, which serves 70 to 80 people a month, is considered a movement milestone because it is fully funded by a grant from the Maryland Department of Health and Mental Hygiene, administered by the Baltimore mental health system.

Paula Lafferty, a leader of the LGBT consumer/survivor movement in Baltimore, said the center evolved from a support group she started at a psychosocial rehabilitation program she was attending. "Some of the staff were

derogatory about LGBTs and the sexuality of their clients in general," she said. "Key staff were lesbian, which helped a lot. There wasn't much homophobia directed specifically at us. However, almost all of the staff were derogatory toward consumers, which was painful, frustrating, and angering. More than anything, that was why we left," she said.

Saying that she is "going to try my hardest to connect people throughout the nation," Lafferty noted that Hearts & Ears is planning a conference in October 2002, which will include a panel of LGBT movement veterans from around the U.S.

One such movement veteran, Mark Davis, noted the importance of integrating the bisexual, gay, lesbian and trans-

gendered consumer/survivor movement into the larger gay pride movement. At the same time, Steve Holochuck is hopeful that the LGBT consumer movement will be able to create more "space" within the larger consumer/survivor movement. "I think that creating space is what all social movements are about," Holochuck said. "Before they can work on systems change, if they even want to do that, they need a space where they can feel free and supported. That would be the big achievement of this movement: we've started by creating space for ourselves."

For more information about the *Fruit and Nut Bar*, contact Mark Davis, mark.davis@phila.gov ■

CLEARINGHOUSE TO LAUNCH NEW PROJECT SERVING SOUTHEASTERN U.S.

The National Mental Health Consumers' Self-Help Clearinghouse is about to launch a regional branch office: the Southeast Consumer Clearinghouse (SECC), which will be based in the Raleigh-Durham, N.C., area. Funded by the Center for Mental Health Services (CMHS), SECC will primarily serve local and statewide consumer groups in Virginia, North and South Carolina, Georgia, Florida, Alabama, Mississippi, Louisiana, and Tennessee. Having grown up in Atlanta, I am looking forward to heading up the new project.

The timing is perfect: the consumer movement is really gaining momentum in the region. Statewide consumer groups are active in several of the states, and the numbers of local support groups and individual consumers involved in advocacy continue to grow. The new project will fuel this momentum by providing ongoing technical assistance to local and statewide consumer groups.

In the months leading up to its launch, SECC has been off to a running start. In my travels across the region so far, I have provided technical assistance to consumer groups that are just getting started and groups that are continuing to grow. Wherever I have gone, I have encountered enthusiasm and dedication.

In April, I met with the director and staff of Forest Park Drop-In Center, which is located in Broward County, Fla., on the grounds of a state hospital. This innovative program provides people who are separated from the community, and who may be isolated and alone, with a safe and welcoming environment for peer support and advocacy.

Later that month, in Columbia, S.C., I met with the leaders of CORE, a statewide consumer group sponsored by

BY ALAN MARZILLI

the Mental Health Association of South Carolina and dedicated to advocating for better services and protecting people's rights. The group is small but growing. During a two-day training in Columbia, I presented the Clearinghouse's Freedom Self-Advocacy Curriculum and a second day of specialized technical assistance on systems advocacy. CORE members will be taking advantage of this technical assistance by presenting the Freedom Self-Advocacy Workshops at the group's annual conference in November.

In May, I had the honor of giving the keynote address at the 10th Annual Alabama Recovery Conference, which was sponsored by the state's Department of Mental Health and Mental Retardation. The three days that I spent at the conference were enriching and inspiring.

In my new home state of North Carolina, we are currently experiencing a lot of changes. In November 2001, the state's Department of Health and Human Services proposed a new five-year plan that would drastically change the way that public mental health services are delivered, including privatizing some services. Members of the North Carolina Mental Health Consumers' Organization (NCMHCO) have raised concerns about how this plan would affect quality of services and the grievance and appeals process.

Since moving to North Carolina, I have had the opportunity to work with the Leadership and Advocacy Training Group that NCMHCO has formed as part of its Statewide Networking Grant from CMHS. Consumers from every region of the state have been communicating through meetings, teleconferences, and a new interactive Web site.

In June, I collaborated with Kathy Muscari of CONTAC to provide two days of training to this leadership group, and it was an energizing experience for everyone involved. The redesign of the state mental health system provides a window of opportunity for the creation of consumer-run services, which are few and far between in North Carolina. As Kathy and I presented information about the consumer-run services that exist throughout the nation, we could sense the commitment of the participants.

The end of the conference was exciting; everyone was bursting with ideas, and although group members were interested in various issues, they all agreed that they needed to take action. Each member of the group pledged to take certain steps before their next meeting, including bringing fellow consumers to county commission meetings, registering people to vote, and writing to their legislators. I look forward to continuing to work with the group as they endeavor to reach their goals.

With a growing number of dedicated consumer advocates, the Southeastern states are ready for change, and I am looking forward to working with groups throughout the region. Over the next year, SECC will conduct a number of training sessions with local and statewide consumer groups, based on the Clearinghouse's TEAM (Training/Education/Advocacy/Management) Tool Kit. These three-day training sessions will include one day of the Freedom Self-Advocacy Curriculum, a day focusing on the business aspects of consumer-run services, and a day dedicated to each group's individual needs. Give us a holler, y'all.

Contact: Southeast Consumer Clearinghouse, 265 W. Hwy. 54, Suite 125-PMB, Durham, NC 27713, seconsumer@earthlink.net ■

Message from the Executive Director

NEW FREEDOM COMMISSION SHOULD SUPPORT PEER-RUN SERVICES

The following is excerpted and adapted from testimony by Joseph A. Rogers to The President's New Freedom Commission on Mental Health, July 18, 2002.

The importance of consumer-operated services is recognized by no less an authority than the Office of the Surgeon General, whose 1999 report, "Mental Health: A Report of the Surgeon General," notes that consumer organizations "have invigorated the fields of research as well as treatment and service delivery design" (p. 14). . . .

Consumer-run services fill the gaps in the traditional mental health system. Their hours of operation include hours when traditional services are closed, and when such support is most needed to counteract people's isolation and loneliness. Consumer-run services also go into places often unserved by traditional programs, such as into the streets; they make extensive use of volunteers, are extremely cost-effective, and require little, if any, red tape. (It is red tape that often discourages people from using traditional services.)

One of the important things the federal government has done to promote the development of consumer-run services is to support national technical assistance efforts such as the Consumer Organization and Networking Technical

BY JOSEPH A. ROGERS

Assistance Center (CONTAC), the National Empowerment Center, and the National Mental Health Consumers' Self-Help Clearinghouse. We hope that support will continue.

Such technical assistance is vital to consumer-run programs, according to a monograph published by the federal government called "Consumer/Survivor Self-

There is almost no better university than experience ...

Help Programs: A Technical Report" http://www.mentalhealth.org/consumer_survivor/selfhelp/programs.asp. In this report, the authors noted that "[a]pproximately 70% of the [consumer-run program] sites indicated that more training and technical assistance would have contributed to increased successes. . . . Participants revealed that they felt hindered by this lack of knowledge and that coordinated, comprehensive approaches to meeting technical assistance needs

would have been of benefit" (p. 111).

This report also noted that "consumer/survivor-operated services are successful in increasing the overall quality of life, independence, employment, social supports, and education of consumer/survivors."

With training and education, people with significant firsthand involvement in the mental health system become service providers who are not only grounded in a knowledge base but who have the compassion and understanding natural for someone who has "been there." There is almost no better university than experience to teach someone what works and what doesn't.

The Mental Health Association of Southeastern Pennsylvania (MHASP), of which I am president and CEO, has 330 staff members, the majority of whom, including myself, are in recovery from mental illness and/or substance abuse, and/or have experienced homelessness. We provide nearly three dozen successful peer-operated services.

Johnathan Evans is one MHASP employee who started out as a service recipient and then became a key staff member. As an outreach advocate, Johnathan goes out on the streets to engage homeless people who have mental illnesses to ask them what they need

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Older Adult Group Opens D.C. Office

The Older Adult Consumer Mental Health Alliance (OACMHA), an advocacy organization dedicated to improving the quality of life of older adults affected by mental illness and their family caregivers, has opened an office in Washington, D.C. OACMHA seeks to promote through public education and advocacy the development of accessible, affordable and age-appropriate mental health services. Want to be a member or a state contact person? Contact Linda Powell, executive director, at OACMHA, c/o Bazelon Center, 1101 15th St. N.W., Suite 1200, Washington, DC 20005, 202-467-5730, ext. 140; e-mail: oacmha@aol.com; Web site: <http://amhserver.fmhi.usf.edu/oacmha/index.htm>.

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and what they want and to help them get those things.

Thirteen years ago, Johnathan himself was homeless, and one of our outreach advocates found him. Now he has a deeply felt commitment to helping others as he was helped.

Johnathan works for a program called ACCESS (Access to Community Care and Effective Services and Supports). ACCESS, which began with funding from the Center for Mental Health Services, offers "one-stop shopping" for homeless people who have mental illnesses. It includes everything from outreach to medical care to a place to take a shower

and get your mail. Through ACCESS, we have seen people who had been on the streets 10 to 15 years get into treatment, stabilize in housing, go through rehab and get jobs, with minimal supports. We have seen people reconnect with family members and get their children back. We have seen people get clean.

ACCESS, like all consumer-run services, promotes self-determination, the right of individuals to have full power over their own lives. "Self-determination in the mental health system refers to individuals' rights to direct their own services, to make the decisions concerning their health and well-being (with help from others of their choice, if desired), to be free from involuntary treatment, and to have meaningful leadership roles in the design, delivery, and evaluation of services and supports." I am quoting from a paper ("Self-Determination Framework for People with Psychiatric Disabilities") developed by a consumer workgroup organized by the National Research and Training Center on Psychiatric Disability at the University of Illinois at Chicago <<http://www.psych.uic.edu/UICNRTC/self-determination.htm>>.

Self-determination is the basis of all consumer-run programs. If people with mental illnesses are going to move toward recovery rather than languish in programs that are often little better than institutions, consumer-run services are an indispensable component of the continuum of care. This Commission should do all it can to support and promote such services, because they work.

Many distinguished researchers have noted the importance of peer support to the recovery process. One such researcher is Dr. Courtenay Harding, executive director of Boston University's Institute for the Study of Human Resilience, and an author of a landmark study of deinstitutionalized people with psychiatric disabilities in Vermont and Maine who had spent years warehoused in the back wards of mental institutions. Dr. Harding has said that as a result of the study, "We have very strong data showing that community integration, rehabilitation and self-sufficiency models — which was what the Vermonters had — are far superior to the Maine model of medica-

tion, entitlements, maintenance and stabilization."

While there has been research that supports the effectiveness of consumer-run programs, we need more. Dr. Jean Campbell, principal investigator of the Coordinating Center for the Consumer-Operated Services Project (COSP) Research Initiative <<http://www.cstprogram.org>>, which is studying consumer-run services in eight states, has said, "Knowledge about what consumer-run programs work, for whom, and at what cost is critical if these programs are to expand their funding as part of the continuum of care."

Many of us fear that a trend toward funding so-called evidence-based practices will unnecessarily restrict funding for innovative practices that are still gathering evidence, such as consumer-run services. Dr. Campbell, who is director of the Program in Consumer Studies and Training at the Missouri Institute of Mental Health, said, "Evidence-based research really supports the status quo because most evidence-based research looks at symptoms, recidivism, and treatment outcomes. It doesn't look at key consumer outcomes such as recovery and empowerment."

Dr. Campbell also happens to be a consumer. If we are going to move beyond the status quo toward true system reform, we must involve people who have "been there," such as Johnathan Evans and Dr. Jean Campbell, in every aspect of mental health policy, program, and research design, implementation, and evaluation.

As has been true for disenfranchised groups throughout history, true system reform has come about only when the people who are most affected stand up and speak in one voice. You don't see a civil rights movement made up of "others." You can get help from, be inspired by, and be funded by "others." But the only way a group's status in this society changes is when they get organized and make those changes part of an active effort. So if the New Freedom Commission truly wants to reform the system, it needs to acknowledge the self-help movement of people with psychiatric disabilities and heed the advice of that movement. ●



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The testimony by Joseph Rogers, executive director of the National Mental Health Consumers' Self-Help Clearinghouse, called upon the Commission "to reject coercive and involuntary treatments and to promote alternatives that are engaging and empowering." (See Page 8 for Rogers' testimony at the July 18 Commission meeting.)

The Commission expects to hold 10 to 12 public meetings during the next year, in various parts of the country. Dates and locations will be announced on its Web site.

Comments to the Commission may be made in three ways: via the Commission Web site <http://www.mentalhealthcommission.gov/contactus.html> or by e-mail to staff@mentalhealthcommission.gov; by mail to President's New Freedom Commission on Mental Health, 5600 Fishers Lane, Parklawn Building, Room 13C-26, Rockville, MD 20857; or by presenting comments to the Commission at its meetings. Guidelines governing the public comment period are provided on the Commission Web site. They include limiting comments to three minutes, calling 301-443-8956 two weeks in advance to get on the schedule, and bringing a written copy of remarks for the Commission's records.—Susan Rogers

NIMH studies seek volunteers

The Clinical Brain Disorders Branch is seeking volunteers with long-term schizophrenia for a six-month inpatient research study at the National Institutes of Mental Health (NIMH), in Bethesda, Md. The program is free, and involves extensive diagnostic evaluations, medication-free studies, neuroimaging, and psychological and neurological testing. Art therapy, educational groups, and occupational and recreational therapy will also be available. Participants must be between 18 and 55, be diagnosed with schizophrenia, and be free of significant medical/neurological illnesses and active substance abuse. For more information: Anne Riley, Ph.D., 301-594-0874 or, toll-free, 1-888-674-6464, or e-mail: anne.riley@nih.gov; or Web site: <http://cbdb.nimh.nih.gov/inpatient>.

NIMH is also seeking sibling pairs, at least one of whom has been diagnosed with schizophrenia, for a study on the genetics of schizophrenia. Outpatient testing procedures include clinical interviews, neuropsychological testing, a neurological exam, a blood draw, neuroimaging, and recordings of brain waves and eye movements. No change in medication is required. NIMH can assist with lodging and travel expenses to help families travel to Bethesda, Md. Siblings are compensated for their participation. Through the identification of the genes associated with schizophrenia, researchers believe that more effective treatments and methods of prevention will one day be possible for families at risk.

NIMH is also conducting shorter studies of outpatients with schizophrenia which may involve those with schizophrenia and their siblings or those with schizophrenia alone.

For information about eligibility requirements, please call Mary Weirich, M.S.W., at 1-888-674-6464, or e-mail weirichm@intra.nimh.nih.gov.

CLEARINGHOUSE GIVES PEER-SUPPORT PROPOSAL WRITERS A BOOST

Almost every week, the National Mental Health Consumers' Self-Help Clearinghouse assists groups working on grant proposals by helping them find literature that confirms the value of peer support, advocacy, and consumer-run services.

Even if your ideas about peer support and advocacy came from personal experience, citing scholarly evidence that backs up your ideas gives credibility to your proposal in the eyes of funders.

Some Clearinghouse clients are unfamiliar with supporting research and will seek our help with background reading before they begin work on a proposal. The Clearinghouse library cannot replace a college research library with a staff of professional librarians, but it can provide a head start.

The Clearinghouse can also function as a literature memory bank, which is helpful since most people do not keep a list of every article they have read — especially while browsing Web sites and reading e-mail. For example, many Clearinghouse clients have read at least parts of "Mental Health: A Report of the Surgeon General" or the Center for Mental Health Services publication "Consumer-Operated Services: A Technical Report," but the Clearinghouse provides reminders that these resources are excellent references to cite in a grant proposal.

We find out what concept a client is trying to substantiate; then we suggest studies that may be helpful. Copyright law prohibits our dissemination of many of the studies themselves, but we are able to direct people to useful research that is available online.

To obtain the actual studies only described in these online resources, take the descriptions to a local university library and ask a reference librarian for help locating them. Finally, for those of you approaching a deadline and adding citations to your grant proposal at the last minute, information from these abstracts

may be enough for your purposes without a trip to the library.

Call the Clearinghouse for more details about using these studies to enhance your grant proposals: 1-800-553-4539. For the cost of postage, we can also send you some additional supporting literature that we have in our library.

The following is a partial list of online information about the value and efficacy of peer support, self-help, and empowerment.

Citing evidence gives credibility to your proposal.

- "Mental Health: A Report of the Surgeon General" endorses peer support and consumer advocacy: <http://www.surgeongeneral.gov/library/mentalhealth/home.html>. The following section of the report is specifically on self-help and consumer advocacy: <http://www.surgeongeneral.gov/library/mentalhealth/chapter4/sec6.html#consumer>. The following section lists all the references for the studies cited by the Surgeon General:

<http://www.surgeongeneral.gov/library/mentalhealth/chapter4/ref4.html>

- Mark S. Salzer, Ph.D., of the University of Pennsylvania makes a case for consumer-operated services as an evidence-based practice: <http://www.bhrm.org/guidelines/salzer.pdf>. The context of the pdf document, for citation purposes, is: <http://www.bhrm.org/guidelines/mhguidelines.htm>

- The American Self-Help Clearinghouse compiled a summary of various peer support studies: <http://mentalhelp.net/selfhelp/selfhelp.php?id=864>

- Elaina M. Kyrouz and Keith Humphreys compiled a list of abstracts of articles describing the effectiveness of self help: http://www.mentalhelp.net/poc/view_doc.php?type/doc/id/993

- National Association for Rights Protection and Advocacy president Pat Risser's Web site lists some peer support studies: <http://home.att.net/~PatRisser/helpingclients/PeerSupportStudies.html>

- The following is a comprehensive, annotated bibliography on self-help and peer support published by the Missouri Institute of Mental Health Program in Consumer Studies and Training: <http://mimh200.mimh.edu/PieDb/01599.htm>

- The National Research and Training Center of the University of Illinois at Chicago convened a workgroup that developed the following bibliography, which has abstracts of articles and reports that support the value of self-determination and empowerment: <http://www.psych.uic.edu/UICNRTC/uicnrtc-sdbib.pdf>.

- The following paper gives information about and citations for the series of peer support/mutual aid studies conducted by Julian Rappaport and colleagues: <http://www.communitybuilders.nsw.gov.au/download/mutual.doc>.

- The following bibliography from St. Ambrose University has abstracts of scholarly articles that support the value of empowerment: <http://www.scs.unt.edu/classes/CSAG/4450/4450/ToolBox/empowerbib.htm>

- The National Resource Center on Homelessness and Mental Illness compiled a bibliography with abstracts on consumer involvement in service provision: <http://www.nrchmi.com/pdfs/bibliographies/ConsumerInvolve.pdf>.

- Information about the COSP study led by Jean Campbell, Ph.D., is available at <http://www.cstprogram.org/>. Keep checking the Web site for new developments in this important project. ●

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