Consumer input is sorely lacking in state plans to release people from institutions and help them integrate successfully into the community in compliance with the U.S. Supreme Court's 1999 decision in Olmstead v. L.C. This accounts for the generally lackluster quality of the plans, experts suggest.

According to the National Association of Protection and Advocacy Systems (NAPAS), the results of Olmstead planning around the country have been disappointing. At the same time, the need for such planning is increasingly clear. In its recently published assessment of Olmstead progress, NAPAS describes the movement of people with disabilities from institutions to the community, compared to the pre-Olmstead years, as "sluggish at best."

Advocates are urging consumers to get involved in Olmstead planning, and consumers who are involved to get more involved. "Even if you're satisfied with your state's plan, you have to be vigilant," advised Elizabeth Priaulx, community integration specialist at NAPAS. "The danger is that the states will say, 'We've got the credit we needed with the [disability] community; now we can cool our heels.' It's only as a result of consumer pressure that the recommendations will be implemented."

In Illinois, Olmstead planning seems to have suffered from the lack of significant consumer input. Barry Taylor, legal advocacy director of Equip for Mental Health, says that in Illinois, the state has been "lacking in vision, planning, and follow-through."

National TA Centers Threatened

President Bush's proposed Fiscal Year 2003 budget would terminate funding for the three mental health consumer-run national technical assistance centers (CONTAC, the National Empowerment Center, and the National Mental Health Consumers' Self-Help Clearinghouse). These centers, funded by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, provide information (including this newsletter) and technical assistance to support the consumer self-help movement. Also threatened are the two consumer-supporter technical assistance centers, operated by NAMI and the National Mental Health Association, respectively.

With the release of this proposed budget, the Bush administration is ignoring a growing body of evidence indicating the value of mental health consumer-run self-help services, which was recognized by the Surgeon General in the 1999 report Mental Health: A Report of the Surgeon General, and in a report published by the Center for Mental Health Services, entitled Consumer/Survivor-Operated Self-Help Programs: A Technical Report. See "Letter from a Grassroots Supporter," Page 7.
Message from the Program Director

A NEW FACE - A COMMON HOPE

It seems fitting that I write this, my first article for The Key, on the day that we celebrate the life of Martin Luther King, Jr. In thinking of Dr. King, I am reminded of the power of a single person to effect change — by “speaking up” at injustice and attracting others to a force more powerful than the self.

I am a lawyer with a long-standing interest in social justice issues. I practiced health law in a large firm for two years, which confirmed my suspicions that I’m not cut out for corporate America. So I left that life behind me and returned to graduate school for a master’s degree in bioethics, which I hope to receive this summer.

While back at school, I worked in managed care ethics and policy, an eye-opening education about priorities in health-care financing and delivery. Most recently, I coordinated a program at the Children’s Hospital of Philadelphia (CHOP) that teaches advocacy skills to pediatric residents. One of six such programs across the country, the initiative is part of a larger effort to change the way pediatricians are trained and to help them become more effective advocates for children in the community. I am hopeful that these efforts will return an element of humanism to a disease-oriented, technology-driven model.

I coordinated all facets of the CHOP program, including mentoring residents, creating a network of community supports and advocacy channels, acting as liaison with our community legal advocacy partners, and assisting in curriculum development and implementation.

My desire to bring my background in bioethics, health policy and community organizing to the Clearinghouse is not simply professional, but also relates to personal experiences with the mental health system.

I arrived on January 2 to find the Clearinghouse already well-established as a national consumer self-help technical assistance and information/referral source. Our latest effort is a newly expanded train-the-trainer curriculum, Freedom Grassroots Development. This new initiative builds on our Freedom Self-Advocacy curriculum, but adds information on creating and operating consumer-run businesses and services. We are currently piloting this curriculum at conferences across the country, and hope to visit a city near you.

Other new Clearinghouse initiatives include Olmstead advocacy training [see story Page 1] and cultural competency efforts. The training covers the basics of the U.S. Supreme Court decision; how to participate effectively in your state’s Olmstead planning process, including how to evaluate a state plan and how to enhance your negotiation, community organizing, and coalition building skills; and much more. As to cultural competency, exciting new linkages are being formed with individuals who wish to develop and invigorate a sister Hispanic consumer movement. In that spirit, we also plan to translate several of our technical assistance guides into Spanish.

Of ongoing concern are national organizing efforts. While we will continue to support and enhance self-advocacy, it is also time to concentrate on systems change. With Dr. King’s example as our guide, it is time to recognize the power of individual actions joined to shape a collective voice for change. Although the issues may vary and the consumer/survivor movement is diverse, it is imperative that we find common ground and advocate for systemic change that will elevate the status of mental health within our health system and the minds, and pockets, of our national, state, and local leaders.

I invite you to use our services to better advocate to improve your own life and the lives of others. Please keep us informed of your efforts, so that we might share ideas, information, and other materials with people across the country through our Web site, this newsletter, and our listserv.

Finally, I invite each of you to join this national organizing movement. It is in the power of each of us to better our own lives and, in joining with others, to create a better society within which to achieve individual dreams. Your voice is only as strong as it is used. As Dr. King wrote in “Letter from Birmingham Jail,” “We must use time creatively, in the knowledge that the time is always ripe to do right.”

I encourage mental health consumers to embrace the larger movement of which we are also a part: the struggle to secure civil rights so valiantly fought by African-Americans, women, and many other groups before us. And let us not forget Dr. King’s example: to “fight the good fight” through nonviolence and in the spirit of peace, in the hope that peace, and understanding, might spread, person by person, community by community.

I look forward to working with you. Until then, peace.
Equality, Illinois’ federally mandated protection and advocacy (P&A) agency, said that mental health consumers were conspicuously absent from a stakeholders’ meeting convened by the State of Illinois. “Overall, we have been very disappointed in the State’s actions since the meeting,” he continued. “The State has not moved forward in developing a ‘comprehensive effectively working plan’ as outlined in Olmstead, and there has not been any significant change in providing more community services to people with disabilities in Illinois.”

A consumer leader in Illinois acknowledged that representation had been affected by the lack of an organized statewide consumer group. However, she said, the State has recently made a great effort to include consumers in Olmstead planning, including hiring a consumer as the Olmstead facilitator at the Illinois Office of Mental Health (OMH).

In addition, according to a report by Advocates for Human Potential (AHP) of Delmar, N.Y., Illinois’ grant from the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration will be used to ensure that mental health stakeholders, and their interests, receive adequate representation in the final state Olmstead report. (CMHS has offered the states grants to promote community-based services. These grants complement the Real Choice Systems Change grants from the Center for Medicare and Medicaid Services [formerly the Health Care Financing Administration].)

“The grant from CMHS assures that mental health consumers will have a voice in the Olmstead planning and implementation process in Illinois,” said Nancy M. McVey, the newly appointed OMH Olmstead facilitator.

If you are satisfied with your state’s planning process, you are probably in the minority. Even the states that have developed plans would not meet the standards recommended by the U.S. Department of Health and Human Services, according to NAPAS, “because they do not include timelines or budgets,” which are critical to successful Olmstead implementation.

“The reports are awfully broad,” Priaulx said. “They will say things like, ‘We will try to identify individuals who have been in a state hospital three times in the past two years.’ They won’t say who’s in charge of doing that, the mechanism they’ll use, the timelines, who they will get to help with privacy issues — none of that is fleshed out.”

“Consumers have to be vigilant that the recommendations made in the plan are actually implemented,” she continued. “A big role for consumers would be to go through the report and get the Olmstead coordinators to give them timelines of the steps they will take to implement each recommendation.”

Maryland is one of the many states that fall short. “Our plan has no accountability and no timelines,” said Maryland consumer advocate Laura Van Tosh in a presentation on Olmstead planning at Alternatives 2001 last August. “They’ve made sure in our plan that no institutions will close.”

According to a response to the state’s plan by the Maryland Civil Rights Coalition for People with Disabilities, “the final draft . . . effectively dashed” the hopes of Marylanders with disabilities in state institutions and private nursing homes, numbering in the thousands, that they would soon be released into the community.

The Maryland plan contained “no timelines for bringing the State into compliance with federal law, no proposals for reallocation of resources to reverse the State’s history of institutional bias, nor even a commitment to actually spend the resources allocated for the current fiscal year,” the Coalition noted.

‘Even if you’re satisfied with your state’s plan, you have to be vigilant.’

(Like Maryland, most states have an institutional bias: According to a recent report from the U.S. Department of Health and Human Services [HHS], “institutional bias” can be traced to the way Medicaid was originally structured, nearly 40 years ago, when there was little besides institutions. “Today, despite the possibility of community alternatives, approximately 73 percent of Medicaid long-term care funding goes to pay for institutional care, while only 27 percent is directed toward home and community-based services,” noted the report, Delivering on the Promise: Preliminary Report of Federal Agencies’ Actions to Eliminate Barriers and Promote Community Integration. The report has been criticized by disabilities rights advocates for its lack of timelines, among other shortcomings. “If this is the federal definition of ‘action,’ heaven help us all,” said American Association of People with Disabilities national organizer Stephanie Thomas, quoted in a press release.)

The Maryland Coalition summarized its community-integration recommendations in six broad points: close state institutions, increase federal dollars to support community living, expand community capacity, increase consumer-directed outreach and support to people...

...continued on p. 4

We want to hear from you

We want to hear what you think of The Key. Does it include the kinds of articles you are interested in? What other stories would you like to see covered? Is there some national issue that needs to be highlighted? Please let us know by writing to us at The Key (see contact information on Page 5).

We would also love to hear how you like the help that the Clearinghouse provides. Please let us know if you have used our services, and how they have helped you or others.
...continued from p. 3

living in institutions, raise the income limit for Medicaid eligibility to 100 percent of the federal poverty level from its current limit of 49 percent, and implement the Medicaid Buy-In, which would allow people to work at jobs and still maintain their Medicaid coverage.

Maryland’s failure to develop an effective plan is not due to a lack of guidance from experts.

In October 1999, NAPAS issued a template of critical elements in developing a state Olmstead plan. These were (1) participation of key stakeholders; (2) a needs assessment process; (3) development of new community services and support infrastructure; (4) transition services; (5) individualized data collection; (6) outcomes measurement and target dates; (7) monitoring/quality assurance; (8) resource development; and (9) review, revision and updating of state plans every two years, or sooner if appropriate. However, according to the NAPAS report, advocates from only 11 of the 38 states who said that their state had or is working on a plan could get enough details so that they could rate their respective plans in these specific areas.

Consumers also need to monitor how their state is establishing its priorities: If people with developmental and physical disabilities are at the table and mental health consumers are not, mental health consumers are likely to draw the short straw. In an article in the November-December 2001 issue of the Journal of Poverty Law and Policy, Jennifer Mathis of the Bazelon Center for Mental Health Law wrote that, according to a recently published survey by the National Conference of State Legislatures (NCSL), when states have tried prioritizing various groups for short-term planning, “they have tended to plan for individuals with developmental and physical disabilities ahead of those with mental illness.”

Unfortunately, some states have been actively resistant to consumer input. Edward L. Knight, Ph.D., a consumer advocate living in Colorado who is vice president for recovery, rehabilitation and mutual support at ValueOptions, a major managed behavioral health care organization, said that it was difficult for him to find out when the Olmstead planning group in his state was meeting. “The guy didn’t want to tell me; I had to make him,” Knight said during the Alternatives 2001 presentation on Olmstead planning. Knight added that only three people with “standing” — i.e., consumers — turned up at the meeting. Although they had raised objections throughout the proceedings, the minutes reflected none. “We were listed as attending, and it said that three consumers were there and gave input,” Knight recalled — but no details were given.

The situation in some states is better. Alabama, for example, reported significa...

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**Plans Underway for Alternatives 2002**

By Alan Marzilli

It’s time to look forward to Alternatives 2002. This year, the Consumer Organization and Networking Technical Assistance Center (CONTAC) will host the annual national technical assistance conference, sponsored by the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration. The conference will take place September 19-22 at the Hyatt Regency Atlanta.

CONTAC director Larry Belcher and education consultant Kathy Muscari were impressed during CONTAC’s visit to Atlanta. Said Muscari, “There is a magic that takes place at this event, and I know there will be a great turnout. From all over the nation, there are lots of new programs and ideas to share. The consumer movement is alive and well, and Alternatives in Atlanta will provide a friendly and rich environment for learning, networking, recovery, and hope.”

Helping out locally were Delois Scott and Linda Buckner, of the Georgia Mental Health Consumers Network, and Larry Fricks, director of the state’s Office of Consumer Relations. Fricks promised attendees an “all-out welcome.” He suggested, “When you come, make a tour of the Martin Luther King, Jr., Historic Site a priority. It’s a place to replenish the souls of those weary from seeking justice and rights for all.”

As in past years, the conference’s host is seeking broad input from the consumer movement. CONTAC has formed a consumer advisory committee, and the two other national consumer-run technical assistance centers funded by CMHS — the Clearinghouse and the National Empowerment Center (NEC) — are also involved in the planning.

One exciting event will be a pre-conference technical assistance workshop for Statewide Network Grantees, which CMHS has funded to help build consumer coalitions in their respective states. The Clearinghouse hosted a similar meeting before the 1999 National Summit of Mental Health Consumers and Survivors, in Portland, Ore.

Joseph Rogers, Clearinghouse executive director, encouraged people to start seeking funding early. “CMHS usually offers a limited number of scholarships,” he said, “but many states send large groups of people. The best way to ensure that you can attend Alternatives is to seek funding at the state level.”

On the Net: CONTAC: http://www.contac.org
Atlanta Convention and Visitor’s Bureau: http://www.atlanta.com
Martin Luther King, Jr., Historic Site: http://www.nps.gov/malu/
CONTROVERSY SURROUNDS EVIDENCE-BASED PRACTICES

BY ALAN MARZILLI

In an era of decreased funding for mental health services, “funders have hooked onto the idea of evidence-based practices,” said Patricia Singer, M.D., of Dartmouth University. Singer’s project is helping generate momentum for evidence-based practices:

The Clearinghouse is funded by a grant from the Missouri Institute of Mental Health, said there is a danger that current government funding based on “knowledge development and application, which tends to support the identification, study, and dissemination of new and innovative programs” is shifting to an evidence-based approach. “This development potentially favors both ‘Big Science’ and a ‘top-down view of best practices’ in which both research and service dollars tend to flow into more traditional programs,” Campbell said.

“Taxpayers want evidence that what they’re paying for will lead to positive results,” said Dan Fisher, M.D., Ph.D., co-director of the National Empowerment Center in Lawrence, Mass. However, he cautioned, “If we only put money into areas that have been thoroughly researched, then nothing new would ever happen.”

Of particular concern is the possibility that funding for consumer-run programs will be cut in favor of evidence-based practices. “Evidence-based research really supports the status quo because most evidence-based research looks at symptoms, recidivism, and treatment outcomes,” said Campbell. “It doesn’t look at key consumer outcomes such as recovery and empowerment.”

While acknowledging that politics might lead to increased funding for evidence-based practices at the expense of other services, Singer said that the purpose of the project was not to affect a wide range of services, but to help community mental health centers operate more effectively. “There was a concern among [researchers] that what they were finding to be effective in their research is not being translated into services at mental health clinics,” she said.

Part of the problem for proponents of consumer-run services is that they have not been studied in controlled trials because of a lack of funding. Fisher feels that, in addition to funding evidence-based practices, it is important to fund “innovative practices that are gathering evidence.” He also believes that evidence-based practices should be constantly re-evaluated to see how they support consumers’ goals of independence and recovery.

Campbell is hoping that an ongoing multi-site study funded by CMHS will provide needed information on the effectiveness of consumer-run services when offered in conjunction with traditional mental health services. She is principal investigator of the Coordinating Center for the Consumer-Operated Services Project (COSP) Research Initiative, which is studying consumer-run services in eight states. “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,” she said.

From August 22 to 26, 2001, the Clearinghouse welcomed 900 consumers from around the nation to Philadelphia for the annual Alternatives conference.

Each year since 1985, Alternatives has given the consumer movement a national forum for sharing expertise. With funding from the federal Center for Mental Health Services (CMHS), the Clearinghouse takes turns hosting Alternatives with the National Empowerment Center and the Consumer Organization and Networking Technical Assistance Center (CONTAC).

"Alternatives allows the consumer movement to share information about the topics that really matter to us, like mutual support and advocacy," said Joseph Rogers, Clearinghouse executive director. "It is also a springboard for participants to organize at the national level."

New to Alternatives this year was a set of "dialogue sessions" on 12 topics, such as multicultural issues, force and coercion, and financing. These sessions originated at the National Summit of Mental Health Consumers and Survivors, held in Portland, Ore., in 1999. "The dialogue sessions are a vital step in national organizing because they allow consumers from around the country to identify key positions on which there is consensus, and to develop action plans to turn these ideas into reality," Rogers explained.

In the Community Support Systems dialogue sessions, facilitated by Joel Slack of Alabama, participants identified key supports necessary for consumers to live successfully in the community. One of the five key issues was the creation of legal advocacy and protections for consumers living in boarding homes. "While some states regulate varying aspects of the physical plant of a boarding home, they do not regulate human rights and recovery issues," said Slack, who called the issue a "national dilemma."

Participants in the forensic issues dialogue sessions, facilitated by Mary Jadwisiak of Washington and Tom Lane of Florida, identified two key action plans: the development of a national clearinghouse on consumer forensic issues, and a national training curriculum that would help consumers advocate more effectively for criminal justice reform.

The Alternative Services dialogue group crafted a statement of values, such as respect, growth, choice, and empowerment, which differentiate alternative services from traditional mental health services. "Everybody's viewpoint was included," said facilitator Larry Belcher.

As in previous years, Alternatives 2001 featured a full slate of workshops and half-day institutes on diverse topics such as peer counseling, leadership, and spirituality. One popular institute was "Recovery University," an introduction to four national programs: Vermont advocate Mary Ellen Copeland's Wellness Recovery Action Plan (WRAP), CONTAC's Leadership Academy, Advocacy Unlimited of Connecticut, and the New York-based BRIDGES curriculum.

Attendance at Alternatives 2001 far exceeded expectations, thanks in part to scholarships funded by CMHS and NEC, as well as numerous state organizations. At general sessions, the enthusiastic crowds spilled over into a second room with a live video feed. Rep. Jim Greenwood, R-Pa., drew cheers as he spoke about H.R. 2363, the Mental Illness Consumer-Run Services Support Act, which he introduced; the bill calls for funding 10 regional consumer-run technical assistance centers.

Conference participant Shirley Hollobaugh of Bakersfield, Calif., wrote that Alternatives was "an experience to be remembered." "I will never forget the feeling of all of us being there, sharing, caring, and learning from one another with pride and cooperation. No one was a stranger, just a friend we hadn't yet met."
...continued from p. 4

Marshall urges mental health consumers to do more cross-disability organizing: “We’ve got to start thinking in a broader way, start building up those numbers.” She also exhorts advocates to “form political liaisons. Get your legislators involved in the Olmstead process.”

Texas has had some success in this area, said Aaryce Hayes, PAIMI (Protection and Advocacy for Individuals with Mental Illness) coordinator at Advocacy, Inc., the Texas P&A. As there was a consensus that it was important to consider not only people in institutions but people at risk, she said, “we found out how many people had been hospitalized more than three times in six months. Then we used that information to educate legislators. The legislators then drafted language in S.B. 367 that said that individuals with mental illness being served by the public mental health system who had been hospitalized three or more times in 180 days should be considered at risk.” Although no dollars were attached to the bill, S.B. 367 was passed, she said; so were three other bills supporting Olmstead planning.

However, Mike Halligan, who heads Texas Mental Health Consumers (TMHC), the statewide consumer organization, believes that, so far, Olmstead planning efforts have not taken on the most significant challenges, such as establishing housing and services in the community. “What I see primarily is a lot of smoke and mirrors. I don’t want to knock the P&A, because I’m sure they’re doing all they can. A aryce does a great job. But I’m very cynical about our system.”

Hayes said that the Olmstead planning committee in Texas is trying to tackle these issues. “I don’t see how you can successfully implement Olmstead without having housing available as an alternative,” she said. In fact, the NCSL survey singles Texas out as one of only four states who are doing a good job of Olmstead planning because their plans “contain a clear vision for systems change, specific strategies and goals, agencies responsible for each strategy, timelines and budgets.” The others are Mississippi, Missouri, and Ohio.

The importance of community supports, including housing, in Olmstead planning is one of the subjects covered by an intensive training being provided to consumers around the country by the National Mental Health Consumers’ Self-Help Clearinghouse. Its goal is to help consumers become more effective Olmstead advocates. This training is funded by the Center for Mental Health Services as part of a more than $6 million initiative to promote community-based care, through a contract with the Princeton, N.J.-based Gallup Organization and AHP.

“Even if your state has finished your plan, it’s not too late,” said AHP’s Carol Bianco, project director of the CMHS Olmstead organizing contract with Gallup, during the Alternatives 2001 presentation. “It must be comprehensive and effective. If not, you can advocate for change.”

Letter from a Grassroots Supporter

I am a person who uses mental health services and someone who has greatly appreciated what the National Mental Health Consumers’ Self-Help Clearinghouse and CONTAC have done for me.

I worked from 1998 to 2002 at a clubhouse program, and one part of my job was to facilitate psychoeducational groups. Sometime in 1999, I located your Web site and found the Freedom Self-Advocacy Curriculum, which had just been developed by Alan Marzilli. I downloaded all the materials I needed to use this course to teach members of the clubhouse the skills they needed to advocate for themselves.

The class was a very big success, so big that there was not even enough room for all of the people who wanted to come. The teachers’ manual was especially helpful to me and I progressed greatly as a facilitator by using it. The information presented was very important and the people were hungry for it. Since that time, the momentum produced by these classes is so great that people have dedicated themselves [to] self-acceptance and learning about recovery. These people truly needed the training provided. They have been helped by the time, energy, and efforts of the National Mental Health Consumers’ Self-Help Clearinghouse.

Please let me tell you some other important ways your information clearinghouse has helped me. With the help of your literature on how to start and run self-help groups and the assistance of CONTAC’s Leadership Academy, several people in the Richmond, Virginia area have started an action-oriented group we call the Consumer Action Team of Greater Richmond. We are a consumer-run organization whose mission is to facilitate recovery, improve the quality of life, and inspire hope for people with mental illness through education, networking, and advocacy. We want to increase the educational opportunities in our area, and support the development of consumer-run programs. We recognize how important technical assistance is to our progress and we will need your help to continue successfully helping our brothers and sisters in the future.

Another huge reason why the Clearinghouse, CONTAC, and the National Empowerment Center are important to me is that you provide assistance to professionals and family members who need to know that mental health consumers can do so much more than they might have previously thought. We have been underestimated and you have raised the bar and we have responded. We must continue to keep the momentum going. Please forward this message to whomever you think will read it entirely and be encouraged by it.

Thank you sincerely,
Betsy Brown
Richmond, Va.
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