



The Key



“Knowledge is the key to open new doors”

Summer 2000 • Vol. 6, No. 2

NATIONAL MENTAL HEALTH CONSUMERS' SELF-HELP CLEARINGHOUSE NEWSLETTER

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SUMMIT 2000: JUSTIN DART ISSUES SOLEMN CALL TO ACTION

“ I love you. I love the human family. I love the human dream. We must unite to defend the dream, to make the dream real in our lives and in every life. America for all. Freedom for all. No forced treatment ever.

I congratulate each one of you here. You are expanding the horizons of humanity. . . . I do not represent a federal agency or any kind of an agency, and I speak to you simply as a passionate consumer advocate.

America stands at an historic crossroads. The decisions of 2000 and the first years of the 21st Century will determine the quality of the lives of people with and without psychiatric disabilities for decades to come.

America today has the knowledge, the money, the productivity and the technology to create a life of profound quality for all of our people. But there is still a great and growing gap between the haves and have-nots. Millions lack adequate rights, food, housing, education, health care and security for their senior years. In spite of the historic victories of our movement, people with disabilities — especially those labeled mentally ill — are still the oppressed of the oppressed. . . .

We can't empower all people with psychiatric disabilities until we enlighten and empower ALL Americans. You cannot have islands of authentic freedom and prosperity in an ocean polluted by prejudice and poverty.

The individualized empowerment of every person is the first and only legitimate responsibility of human culture. Now is the time to create that responsible culture. We must empower all to achieve their full potential to govern self and all, to create the best life for self and for all, and to enjoy the security of a life of dignity. . . .

We must create and enforce laws that abolish the persecution which we suffer every day in every aspect of life. We must abolish involuntary confinement, physical and psychological abuse, coercion, outpatient commitment, and forced treatment of any kind.

But rights are only the beginning. We must guarantee to each person — with and without a psychiatric disability — the tools to create the good life. I speak of the obvious: quality food, shelter, education, technology, and comprehensive health care, including full, consumer-controlled services for psychiatric disabilities. . . .

We must become government through elective and appointed office and voluntary action. We must create a politics in which government will be forced to empower. We must carry the fight to the media and to the people in every community. We must reframe the public dialogue. We must make the empowerment of all the first issue of American politics. The time has come to shout, “No more second-class citizens!” “America for all!” . . .

The community of people with psychiatric disabilities and of psychiatric survivors is by far the largest constituency among people with disabilities. There are tens of millions of us. We have members who are geniuses, who are millionaires, who are stars of sports and entertainment, who are leaders of government, business, science, academia and religion. We have the potential to be one of the most powerful forces in the culture. But it's not going to happen until we unite and until we organize. . . .

Let us rise above our differences. . . . Colleagues, the world is watching our movement. The world is watching America. The world will follow what we do. Failure is unthinkable. Get into politics as if your lives depended on it, because they do, and the lives of billions in the 21st century. Solidarity forever! Together, we shall overcome. I love you. Lead on. **”**



SUMMIT 2000:



Participate in the Summit process on-line!

Whether or not you were able to attend Summit 2000, we encourage you to participate in the Summit process on-line. At the Summit Web page, you can view a video webcast of Sally Zinman's keynote speech. Visit the Summit message board to read summaries of what occurred at Summit 2000, as well as to post your own reactions. And don't forget that all of the background papers and plank reports from the first Summit are also available on-line.

<www.mhselfhelp.org/summit.html>

Clearinghouse executive director Joseph A. Rogers opened Summit 2000 by congratulating the consumer/survivor movement for its many achievements. To continue growing, he said, the movement needs a national desk representing consumer/survivor interests.

Rogers explained that the first Summit, held last year in Portland, Oregon, was a step toward national organizing. "There are so many things that the movement agrees upon," he said, and the goal was to identify areas on which to "create collective action on a national basis." The resulting "plank reports" recorded consensus statements and action plans developed by the 450 Summit attendees.

Summit 2000 would be different, Rogers said. The group had come to Washington, D.C., to present the consumer/survivor viewpoints in the plank reports to "the people in Washington who are trying to represent our interests," he explained.

With a sense of urgency, keynote speaker Sally Zinman of California continued the theme of national organizing. The current political climate, she warned, "threatens the whole structure we've built of a mental health system that is consumer/survivor-driven."

Zinman discussed the battle in California against expanded commitment standards (see Spring 2000 *Key*). "But it's not just the story of California," she said. "It's a national battle for the heart and spirit of the men-

tal health system. We have to keep it consumer/survivor-driven, based on voluntary, holistic community services."

The key to effective organizing, Zinman suggested, is inclusiveness. "In California, we have been able to focus consumer/survivors from every walk of life... We're *unified and focused*, and that's what the movement nationally has to do."

Next, the people who had served as facilitators at the first Summit took turns presenting the plank reports that the attendees had developed.

Yvette Sangster of Connecticut, who had facilitated the Advocacy plank, reported the group's three major action steps: expanding education and support, improving fundraising, and breaking down stigma in society. "We have to be everywhere," she said.

Sangster attributed Connecticut consumers' successful battle to defeat an involuntary outpatient commitment (IOC) bill to inclusiveness and cooperation. "Start shaking hands with people you wouldn't normally shake hands with," she urged.

Brian Cooper of Virginia represented the Financing plank. "Managed care is here to stay," Cooper said, "and we need to deal with it." Community-based and consumer-run services are cost-effective, he said, but the challenge "is to educate managed care organizations (MCOs) about these types of programs. We need to get on their managing boards." Addressing insurance parity, the group concluded that legislation

THE PROCEEDINGS

must not be limited to specific diagnoses, stating, "If it's limited, it's not parity."

Larry Belcher of West Virginia facilitated the Alternative Services plank in Portland. The consensus was that services must have user involvement *at all levels* to be considered peer-run. The group concluded, "All peer-run programs shall be administered and managed by peers, and peers will have final authority over access, programming and management."

Housing and employment were two primary topics in the Community Support Services plank, according to facilitator Joel Slack of Alabama. However, he said, "there were also philosophical discussions. Two principles needed to be present in community support services: first, respect and dignity, and, second, consumer growth."

Jean Campbell, Ph.D., of Missouri is a consumer and a professional researcher who facilitated the Research plank. She reported, "A lack of research on consumer-run alternatives has limited our ability to get funding." She called for the development of research methods that are "appropriate for the needs and values of the consumer community."

The Multicultural Issues plank decided that 50 percent of scholarships for national conferences should go to culturally diverse groups, according to New Yorker Quincy Boykin. Drawing applause, Boykin noted that Rogers has committed to this standard for Alternatives 2001 scholarships, regardless of the amount granted by the Center for Mental Health Services (CMHS).

Also representing planks at the morning

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session were: Sally Zinman (Force and Coercion), Ed Knight, Ph.D. (Organizing), Jay Mahler (Recovery), Cathy Clemens (Stigma), Mary Jadwisiak (Forensic Issues), and Andrew Phelps (Social Accountability).

At lunch, Summit 2000 attendees heard from people actively involved in determining national policy and learned how consumers could become more involved in the process.

Mike Faenza, president and CEO of the

remarked, "I'm overwhelmed with this morning. I've definitely heard a different side of the story. On Capitol Hill, we tend to hear the professional side of the equation, and we don't hear the consumer side."

Chris Koyanagi, director of public policy for the Bazelon Center for Mental Health Law, gave further inspiration for consumer involvement in national policymaking. "There are two kinds of lobbying," she said. "One way is with money," and the other way



Consumer/survivors were there in mind,



National Mental Health Association (NMHA), urged consumers to become more involved with national policy development. He suggested that "making consumer empowerment and consumer issues central to our work" had helped NMHA grow. On a lighter note, he joked, "I don't see us taking over the consumer movement, but I think that the consumer movement might co-opt NMHA," and he also entertained the audience by singing and playing guitar.

Next, congressional staffer Mary Dietrich

is being "helpful, accurate, and *there*."

"I hope you intend to form an organization in Washington," she continued, explaining, "It's been far too long that we have not had a direct consumer voice on the inside, where policy decisions are made. There's no substitute for being available on a consistent basis."

In the afternoon, representatives from national organizations explained to the attendees how their organizations reflect the consumer/survivor viewpoint, as



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body, and spirit

expressed in the plank reports.

CMHS director Bernard Arons, M.D., responded to each plank, explaining how the agency’s programs reflect consumer concerns. Notable examples include supporting consumer technical assistance centers, funding research on consumer-operated services, developing anti-stigma toolkits, and supporting the Freedom Self-Advocacy Curriculum (see page 7).

Bob Bernstein, Ph.D., executive director of the Bazelon Center, expressed support for the Force and Coercion plank report; he discussed Bazelon’s activities to combat IOC laws and to limit the use of seclusion and restraints. Other issues important to the Bazelon Center include opposing the criminalization of mental illness and insuring funding for community-based services.

Curt Decker, executive director of the National Association of Protection and Advocacy Systems (NAPAS), called the collected plank reports a “terrific document” that “really ought to be a road map for all of us at the national level.” Decker addressed force and coercion issues at length, saying that NAPAS, as well as state protection and advocacy (P&A) systems, work to oppose IOC and the use of seclusion and restraints.

Building on his luncheon address, Mike Faenza reiterated NMHA’s support of consumers, expressing hope that NMHA and MHAs around the country would provide a

“place where consumers find a legitimate place to work and to lead.” He also spoke of the need for inclusiveness rather than an “us-and-them” attitude.

The International Association of Psychosocial Rehabilitation Services (IAPSRs), according to executive director Ruth Hughes, “represents mental health professionals who absolutely believe that every person with a mental illness can recover.” In this role, IAPSRs opposes IOC and any public portrayal of consumers as violent. In fact, the IAPSRs code of ethics requires members to fight stigma and discrimination in society. IAPSRs also supports consumer interests in its policy guidelines, which address equal pay for consumer staff. “Keep working with us; we’ll keep working with you,” Hughes urged.

E. Clarke Ross, NAMI’s deputy executive director for public policy, said many people associate NAMI with forced treatment, but he emphasized that the nine components of

ALTERNATIVES 2000 *A New Vision of Recovery*

ALTERNATIVES 2000 CONFERENCE

The theme of the Alternatives 2000 Conference is “A New Vision of Recovery”. The conference will offer a unique opportunity to inspire and empower mental health consumers/survivors and ex-patients. Through workshops and networking, the conference attendees will be given a chance to connect with peers who have been through similar experiences. The conference will offer many people their first hope that they can recover a meaningful role in society - that they can have full rights, housing, jobs, dreams and respect. Call or write Horizon Meetings: Alternatives 2000, P.O. Box 29570, Austin, TX, 78755, (877) 408-2401.

Date of conference: October 11-15, 2000

Location: Renaissance Nashville Hotel
611 Commerce Street
Nashville, Tennessee

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

Airline discounts available:

Southwest Airlines - Call 800-433-5368
ID Code: A3402
American Airlines - Call 800-433-1790
ID Code 92HOAJ



“We truly appreciate the hard work, dedication, and courage of the leaders here today, as well as everyone working at the grassroots level.”



NAMI's Omnibus Mental Illness Recovery Act (OMIRA) focus on systems reform. He characterized NAMI's Program of Assertive Community Treatment (PACT) "not as coercive, but as 24-hour-a-day assistance." Addressing the Financing plank's concerns about "partial parity," Ross said, "NAMI does prioritize the population that is the sick-

est, the most disabled population that is always the last to be served." "Ultimately," he continued, NAMI would support "full parity for everyone."

In the question-and-answer session, the representatives of the national organizations present were asked whether they would

offer financial support for a national consumer/survivor desk. Rogers, Hughes, and Decker offered their organizations' financial support. Faenza and Bernstein pledged in-kind support, while Ross pledged support if the desk appeared to be a viable voice for consumers. Arons, who heads a federal agency, said that CMHS support would depend on the national desk's activities because federal funds can't be used for lobbying.

Throughout the day, Clearinghouse program director Marie Verna presented each speaker with a plaque recognizing commitment to the national consumer/survivor movement. "The Clearinghouse sees its role at Summit 2000 as that of coordinator only," she said. "We truly appreciate the hard work, dedication, and courage of the leaders here today, as well as everyone working at the grassroots level." —Alan Marzilli

Announcing the Freedom Self-Advocacy Curriculum

If you'd like to teach consumers in your community how to become more effective self-advocates, then take advantage of the new Freedom Self-Advocacy Curriculum.

You can learn to teach three workshops covering the attitudes, skills, and knowledge necessary for effective self-advocacy. These workshops include role-plays and other activities, and they offer a variety of "advocacy modules" on topics such

as housing, employment, advance directives, and managed care.

Visit the Clearinghouse Web site today to print a complete set of training materials, including teachers' guide, students' guide, and handouts. If you do not have Internet access, please contact us; we can send the materials for the cost of printing and postage.

Additionally, the Clearinghouse offers train-the-trainer sessions at which we teach people how to offer

the workshops in their community. If your organization is interested in hosting a hands-on training session, please contact us for details.

The Clearinghouse has developed the Freedom Curriculum in conjunction with the National Mental Health Association (NMHA), the National Association of Protection and Advocacy Systems (NAPAS), and other organizations. www.mhselfhelp.org/freedom/
(800) 553-4539



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Write: **The Key**

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DO YOU SUPPORT A NATIONAL DESK?

At Summit 2000, people throughout the movement expressed the need for a "national desk" that could represent the movement's interests in Washington, D.C. What do you think? Please write to us or express your opinions on the Summit message board at www.mhselfhelp.org/summitboard/



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