

National Summit of Mental Health Consumers and Survivors

Portland, Oregon
August 26-29, 1999

Plank Reports—Executive Summary

The National Summit of Mental Health Consumers and Survivors, held in Portland, Oregon, from August 26 through 29, 1999, was organized by the National Mental Health Consumers' Self-Help Clearinghouse with the help of the Oregon Office of Consumer Technical Assistance, and co-sponsored by consumer/survivor groups from around the country. Its goal was to develop consensus around the issues of greatest concern to consumers and survivors and create action plans for future work. The unifying principle was the construction of a platform from which the movement can influence the national debate.

The Summit was organized in response to, and with the participation of, consumers/survivors across the United States. Many had expressed, via the Internet, an increasing demand for such an event in order to help create a unified national voice, and they helped hammer out the event's framework, including selecting the 12 "planks."

Four hundred fifty people from across the country attended, and many praised the working atmosphere, the successful consensus-building, and "the knowledge, the wisdom, and the care with which a room full of strangers came together and created an action plan," in the words of one plank facilitator. One participant called it "my first positive experience with consensus building in 50 years."

Attendees played an active part in developing one or more of the planks, on the topics of Advocacy, Organizing, Force and Coercion, Financing, Alternative Services, Recovery, Stigma, Community Support Systems, Research, Forensic Issues, Multicultural Issues, and Social Accountability.

Consensus

Consensus was reached on a range of issues.

In the Force and Coercion plank, everyone opposed the expansion of forced treatment, including involuntary outpatient commitment. Among other areas of agreement were a ban on forced ECT, and a "zero involuntary restraint and seclusion" policy within two years, to allow institutions time "to create a safe and therapeutic environment." ("Under a zero restraint policy, all incidents of restraint and seclusion must be demonstrated as medical emergencies," the report states.) The plank also reported out the following vision statement: "We will work toward a future where all the needs of a person with a psychiatric disability can be truly met in the community, gently, supportively, and holistically."

The Alternative Services plank developed several consensus statements. These included a definition of the function of alternative services: "to provide inspiration, hope, and personal experience to peers, provide education and training, and an array of consumer-run services in safe, coercion-free environments, as an integral part of a full system of resources." The plank participants also agreed that alternative services must encourage "active and ongoing user participation in all aspects of program decisions," and that "[p]rogram standards, staff certification and/or credentialing as well as program accreditation shall be designed by consumers for consumers based upon their unique experience and knowledge and consumer-generated

research.” The Community Support Systems plank agreed that “[a]ll services should be consumer-defined and consumer-selected.”

Saying that “research can be the voice of consumers,” the Research plank agreed that consumers must be organized, educated and empowered “to recognize the value of research on all levels.” Other basic principles included the “meaningful (not token) involvement of consumers” in research as well as research policy making, funding and publications, including “equal pay for equal work at all levels of research participation.” The group agreed that the measures of recovery developed by consumers should be linked to research in all spheres, including biomedical, pharmaceutical, policy and advocacy research, as well as the evaluation of traditional mental health services. Among the many other consensus statements was the overarching concern that “in no instance should the public good be placed before the civil rights and well being of an individual in research.”

The Forensic Issues plank reached consensus on the following benchmarks for defining a successful forensics system: “elimination of negative residues of treatments, providing for basic needs, elimination of recidivism, full re-integration into society, effective after-care programs, national consumer-run certification program on forensic issues for all providers, inte-

gration of non-system alternatives (voluntary diversion), sentencing equality, [and] adequate resources available for everyone needing release.” The plank reported out several common goals, including establishing national standards for pre-incarceration assessment for all people with possible mental health issues; developing and using alternatives to jail and hospital incarceration; and appropriate access to voluntary, peer-centered, community-based holistic treatment and services using best practices as defined by consumers. Training of police and correctional/hospital staff, ensuring quality treatment standards, and protecting inmates’/patients’ civil rights were also identified as goals.

The Multicultural Issues plank agreed on the importance of developing and increasing the number of mental health services and providers of diverse backgrounds that are available under managed care. Among the goals it reported were developing a “national anti-stigma campaign dealing with issues facing people of color who have mental illness” and “a central clearinghouse for diverse populations in order to make information and services accessible.”

The Social Accountability plank agreed that we should work “towards a society truly free of abuse, discrimination, hypocrisy and ignorance.”

Action Plans

Reviewing the detailed reports that came out of each plank, the reader can easily identify common themes in the action plans. Tied for first place were movement expansion/coalition-building and training and education.

Every action plan called for expanding the movement’s sphere of influence, by such means as developing statewide coalitions, both within the movement and with natural allies, such as other disability rights groups. Plans included suggestions to “develop support networks with outreach to communities and

families” (Multicultural Issues); “conduct community roundtables to solicit advocates,” and “develop within each state a coalition of all advocates to share ideas, discuss new issues, provide support” (Advocacy); “form partnerships with all players” (Financing); and “hav[e] a voice on a national level” (a Recovery plank participant, defining what “recovery” meant to her). The Stigma plank urged “develop[ing] alliances with other disability/disenfranchised groups who deal with stigma,” and the Research plank suggested “organiz[ing], educat[ing], and empower[ing]

consumers to recognize the value of research on all levels. Research can be the voice of consumers.”

Also singled out was the importance of training and education, both of movement activists and of others, including legislators, mental health professionals/providers, family members, the media, and the general public. Summit participants identified the need for activists to acquire expertise in a variety of areas that can be applied to self- and systems advocacy. These include public speaking, grant-writing, serving on mental health decision-making boards and committees, and legislative advocacy. Educating others – legislators and the media in particular – about mental health issues was also considered vital.

For example, the Force and Coercion plank reported the need to let people know that outpatient commitment does not work, and that what does make a difference is good community services. To achieve mental health insurance parity, the Financing plank exhorted people to “talk to everyone you know, [including legislators,] and urge them to support this effort!” The Stigma plank suggested “educating the public by using the media in ways that others can relate to” and “conducting outreach and education to other target groups,” especially to “counter the violence myth.” Additional advice from the Stigma plank was that, “to be effective, any educational initiative must focus on demonstrating that people who are diagnosed with mental illness are people first, with talents, skills and abilities . . .”

The necessity of ensuring broad representation on decision-making boards and committees and ad hoc task forces was also reported. “Bloom where you’re planted: get in there on the local level (county and state advisory boards),” urged the Financing plank. The Research plank insisted on the meaningful inclusion of consumers as representatives on Institutional Review Boards (IRBs), which review proposed research studies. Besides noting the importance of “ensur[ing]

consumer representation on boards, committees, etc., that oversee the regulation and provision of mental health services,” the Advocacy plank was also more specific: “Get consumers on transportation boards to push for adequate, affordable services,” and “ensure that every consumer sitting on a mandated consumer representation board or council receives transportation to meetings.” In fact, the need to advocate for improved transportation was noted by several planks.

The Summit did not overlook the usefulness of the Internet and other new technologies. The Financing plank recommended creating a web page to solicit donations and search for technical assistance for consumer-run services. Multicultural Issues suggested “develop[ing] a central clearinghouse for diverse populations, with Internet and e-mail capabilities, in order to make information and services accessible.” Getting more consumers onto the Internet, including making access and training available, was also recommended by the Recovery plank.

Besides a complex analysis of the values and principles, services and supports that are important to recovery, as well as personal and systemic barriers and a detailed action plan, the Recovery plank report also put a human face on the issue by quoting 30 session participants on what recovery means to them. Sheilah Hill’s response seemed to sum it up: “What does recovery mean to me? To have hope. To feel like a useful, needed person. To be able to utilize the abilities I have. To be able to help others and be a contributing member of society. To have a positive attitude. To be out of the victim mode and be able to transcend the experience I had. To feel connected to the Creator and other people. To take responsibility and take charge of my life. To lead a productive life. Inner healing. Enjoying living. Spiritual wholeness. Living effectively. It’s giving back, forgiveness. Helping other people. Believing in yourself. Overcoming obstacles in achieving my goals.”