## FINANCING DIALOGUE SESSIONS REPORT ALTERNATIVES 2001 PHILADELPHIA, PENNSYLVANIA

Facilitator: Brian Coopper, National Mental Health Association

Reporter: Jeanie Whitecraft, Mental Health Association of Southeastern Pennsylvania

**Goals/Objectives:** To review the financing plank report from the 1999 National Summit of Mental Health Consumers and Survivors and begin to put together a plan of action on the issues presented and any other issues that were not mentioned in the report that the group felt were important.

First Session: Thursday, August, 23, 2001

Attendance: Fifteen people.

The facilitator began by providing copies of the "Report from the Financing Plank" from the Summit in 1999, which were distributed to all participants. (Note: All the Summit plank reports are available online from <a href="https://www.mhselfhelp.org">www.mhselfhelp.org</a> or by calling the National Mental Health Consumers' Self-Help Clearinghouse toll-free at 800-553-4539.) Information was also provided pertaining to H.R. 2363, a bill entitled, "The Mental Illness Consumer-Run Services Support Act," introduced in Congress by Rep. Jim Greenwood (R-PA) and Marcy Kaptur (D-OH).

Participants were invited to introduce themselves and to briefly explain their interest in participating in the Financing Plank this year. Because none of the participants in 2001 were present for the Financing Plank discussions in 1999, the session began with the facilitator providing an overview of what the process had been in Portland two years earlier.

A dialogue ensued about how the people would like to proceed – should we merely validate the work that was done two years ago, or work towards consensus on other financing issues that needed discussion? With no objections raised as to the content of the 1999 plank report, the session continued with a very wide-ranging discussion about individual opinions on what they wanted to accomplish in this year's process, their interests in finding funding for local programs, and their personal feelings working within or interacting with existing mental health service systems.

The following issues and questions were raised by the various participants:

- What are the different sources of funding for consumer-run programs and funding for expansion?
- ValueOptions has standards that managed care companies should follow to partner with consumer programs. ValueOptions is in about 25 or 30 states.
- People are concerned about not being stakeholders in their own care.
- Insurance companies do not want to pay for mental health services for people who are self-employed.
- People who need longer-term care should not be seen as a social problem but rather as a health problem.

- SSDI and SSI are administered by a hostile bureaucracy that forces people to live in poverty in
  order to maintain health benefits. PASS (Program to Achieve Self Sufficiency) plans for people
  receiving Social Security benefits were discussed briefly. (Note: The facilitator highly
  recommended the "Do-It-Yourself PASS Plan Kit" by Barb Knowlen, available from
  www.mouthmag.com.)
- How do funders verify that a program is consumer-run? What is the definition of a "consumer," and what constitutes a "consumer-run" program?
- What are funders looking for in regard to program outcomes?
- Assessment/accountability for spending money is as important for consumer-run programs as it is for programs run by non-consumers.
- We need a combination of forces to legislate for more dollars.
- Life experience with mental illness and mental health services and supports offers unique insights into what helps in recovery and what doesn't.
- Consumer-run programs are less costly than traditional services because they employ consumers; but some professionals who may be threatened by competition may be biased toward consumerrun programs.
- How do we advocate for dollars for research to prove what we intuitively know about consumeroperated services, such as drop-in centers, warm lines, etc.?

It was felt that these issues and questions could be consolidated into some overarching guiding principles that should apply to the financing of mental health services and supports. The development of these principles was left for the second day.

Second session: Friday, August 24, 2001

Attendance: Six people.

After a review of the first day's session, the second session was spent trying to distill the input from Day One into a primary set of guiding principles that would be useful for advocates. With far fewer participants, the conversation proceeded productively. The following principles cover five major topic areas: Choice, Funding, Consumer Involvement, Parity, and Research.

## **Guiding Principles:**

- People must be able to choose from an array of traditional and non-traditional services and supports to meet their individual needs. (Choice)
- Consumers of mental health services and supports must be involved in a meaningful way (i.e., as employees and as members of decision-making bodies) in the planning, design, implementation and evaluation of any service delivery system. (Consumer Involvement)

- Due to the unique nature of these programs, priority must be given to programs that are run by consumers of mental health services. (Funding)
- Adjusted for inflation, the public financing of mental health services is approximately one-third less today than it was in the 1950s. This funding reduction must be recognized and restored. (Funding)
- Hospitalizations are inherently expensive, and any savings realized through downsizings and cost
  efficiencies must be used to expand and improve the array of available community-based
  services and supports. (Funding)
- Insurance coverage for the voluntary treatment of mental disorders must be equally comprehensive as that for physical illnesses. (Parity)
- Employees must receive equal pay for equal work. (Parity)
- Social Security, Medicare and Medicaid must become rational, responsive and user-friendly, with benefit levels that meet individual's needs. (Consumer Involvement, Funding)
- Funding must be increased for research on what constitutes successful and cost-effective outcomes from the consumer's prospective. (Research, Consumer Involvement)