

Report from Financing Plank
National Summit of Mental Health Consumers and Survivors
Portland, Oregon
August 26 - 29, 1999

Facilitator: Ken Liberto, Vermont Association for Mental Health
Co-Facilitator: Brian Cooper, National Mental Health Association
Panelists: Lena Klumper, Pamela H-Kraus and Clifford Thurston
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Session: First Session: Friday, August 27, 1999
Attendance: 20 - 25 throughout session

Goals / Objectives: To find common ground on several major issues regarding financing:

- **Managed care**
- **Health care reform: the issue of parity and how it affects mental health consumers and their treatment**
- **Consumer-run alternatives**

- The first session began with **individual participants** sharing their experiences, **which may or may not reflect the feelings of the group as a whole:**
- Two participants reported that some managed care companies are embracing the self-help concept, and consumers are being asked to come forward to work on the design and implementation of programs.
- Some agencies are having a problem knowing how to contract with managed care providers. Overall there seems to be a philosophy that even though consumers do a good job, they should be paid less.
- Problems exist in getting consumers to come forward and say what they need and want. Without this information, it makes it difficult to re-bid contracts.
- Managed care providers want involvement from both consumers and family members.
- Two of the educational panelists, who were from Colorado, reported that the managed care organizations they work for have Advisory Boards that include both consumers and family members. Within these boards, one consumer and one family member have voting seats on the Executive Board. Both consumers and family members are involved in quality improvement. The managed care providers also offer paid consumer and family member positions. Consumers help with Resource Coordination by meeting with groups of consumers to help them to obtain the services they need as well as find out what they can

do to help them improve the quality of their lives.

- One participant, stating that “we are the experts . . . we have the experiences,” brought up the idea of consumers working as consultants to managed care providers.
- It was agreed that self-help support groups are powerful, especially when combined with individual traditional treatment.
- Funding for consumer-run alternatives remains low; some receive only \$5,000 to \$10,000 per year.
- Participants raised concerns about where the money goes. One participant pointed out that if the state of Virginia were to earmark only 1 percent of its budget for consumer initiatives, that would result in the availability of \$7 million.
- One participant expressed interest in opening a consumer-run residence for dually diagnosed individuals, perhaps based on the Oxford House model. He would like more information on how to go about securing funding for such a project.
- How do we work/contract with managed care providers to secure funding for consumer-run alternatives?
- All were concerned that consumers be paid a fair salary.
- Many hope savings realized from managed care can be used to support consumer-run alternatives.
- There is a need to get consumers involved in their care.
- One participant spoke of looking to establish a consumer credit counseling service.
- It is important that we train consumers for “real” jobs (not hamburger-flipping or janitorial work).
- Some participants felt strongly that managed care had destroyed the mental health system in their community.

End of First Working Session

At the beginning of the second session, the Goals/Objectives of this group, as stated above, were reaffirmed.

Panel Overview:

- 1) Managed Care Organizations
- 2) Consumers paid for services.
- 3) Partners in planning
- 4) Consumer and family members vote
- 5) Training programs for peer counseling
- 6) Peer-support help line
- 7) Programs for consumers by consumers
- 8) Funding
- 9) Managed care

Topic Suggestions:

- 1) Consumer-run alternatives
- 2) Writing grants for funding
- 3) Creative financing
- 4) Networking for non-profits
- 5) Consumer involvement in care/treatment
- 6) Consumer credit counseling
- 7) Training for “real” jobs
- 8) Consumer-run drop-in centers
- 9) Parity within disorder discrimination
- 10) HealthChoices (Pennsylvania’s mandatory managed care plan for Medicaid recipients)
- 11) Consumer voice for control
- 12) Plans to use less money to do the same work

The Facilitator made the following statements, asking participants to agree or disagree with each:

Statement: Managed care was dreamed up by somebody from the Evil Empire.

Agree: 3

Disagree: 20

Statement: In no way, shape, or form do I want to have anything to do with managed care.

Agree: 1

Disagree: 20

Statement: There may be ways that consumers can leverage within existing managed care systems.

Agree: All

Disagree: None

Managed Care Negatives

- **Dreamed up by insurance companies**
- **Created “out of crisis”**
- **“Best bang for the buck”**

It is important to form partnerships with all players from the beginning.

We should learn from the past.

Go to local administrators who need our input.

Inpatient stays are expensive. What cost-effective services can replace these inpatient stays?

What new programs are being created? What does the population need?

Supply hard data to support your ideas. There is no need to reinvent the wheel; many times the data is available.

In some states, counties are not always equal. Counties need to pull together and support each other.

The following consensus statements emerged from the discussions:

Issue: Managed Care

- There is insufficient consumer involvement.
- Form partnerships; there is power in numbers.
- Communicate, including communicating to provider, to reach goals.
- Investigate possibility that managed care companies might support advocacy efforts.
- Investigate grant opportunities and foundations.
- Advisory Boards should assist in operations.
- Case management aides serve a vital function.

Action Plans:

- Create feedback loops: consumers and family members working in the field can bring back feedback/comments to managed care system (eyes and ears of the system).
- Bloom where you're planted: get in there on the local level (county and state advisory boards). Composition of these boards *must* include both consumers and family members. Secure funding from local sources to cover the cost of transportation/day-care for consumers to attend meetings.
- Agencies must make efforts to ensure that consumers feel ownership in these meetings.
- Get involved at the ground level. Some areas have not yet implemented managed care in their communities; get involved early in the process.

- Get educated and be prepared; involvement in the design and development of managed care contracts means getting educated and being prepared. A suggested start: “Partners In Planning,” a publication available through SAMHSA.
- Network and forge partnerships: know the players in your county/state. Include Health Care Financing Administration (HCFA), which defines what care will be provided. ITS plan IS renewed every couple of years. Consumers may be involved in this process.
- Persevere and be diligent: as consumers, we’re in there for life. Keep coming back; don’t take a back seat.

Before ending, participants reaffirmed the **importance** of consumers working with managed care, and that their work be **meaningful and compensated at fair market value**.

At the same time however, there is a need to be **Social Security-sensitive**. We need to be careful not to make a recommendation that someone remain on SSI/SSDI forever, leaving him or her trapped at an income cap to preserve entitlements. On the other hand, we must be careful to make sure that people’s health benefits are not hindered due to a switch between Medicaid and private insurance. This creates hard decisions, as many times consumers who are employed realize less money overall, due to their income’s being taxed and their loss of other benefits.

We concluded that the only answer is **CHOICE!** These are individual decisions. Consumers must be provided with options: there is a need for opportunities for consumers who want to volunteer or work part-time or full-time. Funders will need to be re-educated for consumers’ salaries to become fair and competitive.

Problems:

- 1) It is virtually impossible to support oneself on entitlement benefits.
- 2) It is difficult to get back on assistance once you’ve been on it, then left it and need to get back on.

Solution

Federal (Social Security) process needs a major policy overhaul.

END OF FIRST DAY’S SESSIONS

While the first day focused on the issue of managed care, the second day moved to the issues of health care reform and consumer-run alternatives.

Health care reform: the issue of parity and how it affects mental health consumers and their treatment

Fundamental Differences in Health Care

- Difference in lifetime limits
- Difference in co-payments for mental health treatment vs. physical health
- Difference in deductibles for mental health treatment vs. physical health

Three Specific Approaches to Parity

- 3) Limited Parity: Also referred to as SMI (Serious Mental Illness) Parity or SED (Serious Emotional Disturbance, when referring to children) Parity. This approach is supported by NAMI, and suggests limiting coverage to brain disorders or chemical imbalances.
- 4) Comprehensive Parity: all mental health conditions are covered.
- 5) Comprehensive Parity with the addition of substance abuse treatment. (This is the model that was adopted by the state of Vermont.)

Participant Comments:

- Almost all of the participants have been involved in working to pass parity legislation within their home states.
- Participants shared the comment that in addition to those who would benefit from parity legislation, they are concerned about those who may fall through the cracks — those who are working but are not covered by either Medicaid or private insurance. In addition, there is another group of individuals, who may have health coverage of some type but do not have a prescription drug plan. Many times, especially senior citizens or the “working poor” are forced to choose between paying their rent or purchasing necessary medication.
- There were concerns voiced about individuals who reach “cap limits,” forcing them into the public system.
- It was agreed that the present system is designed to keep people in poverty. Consumers are told to set goals and work to obtain these goals, which will move them back into the mainstream of society. At the same time, the government sets limits on personal assets you may have and still remain eligible for benefits. This leaves consumers in constant turmoil, coupled with the persistent battle of an illness that requires maintenance for the rest of their lives.

Upcoming Parity Legislation

Over the last 5-10 years, at least half the states in the country have adopted some type of parity legislation. The following bills are expected to reach the floor sometime this fall:

- **Senate Bill 796: Sponsored by Pete Domenici (R) and Paul Wellstone (D). Limited or SMI Parity.**

- **House Bill 1515: Sponsored by Marge Roukema (R), Bob Wise (D) and Peter DeFazio (D). This is a comprehensive bill — an approach that covers all mental health disorders and substance abuse.**

Almost all of the participants voiced their overwhelming support of House Bill 1515. However, when asked if they would support the Limited Bill, if faced with the reality that the Comprehensive Bill would not pass for several years, several participants said they would. These participants cited that **“although there is no justification for exclusion, something is better than nothing.”** They added that **“although this bill would exclude a lot of consumers [from coverage], it would still help a lot (perhaps providing coverage to up to 90% of the population).”** They agreed that **“the fight continues for the whole group . . . but if we lost the fight entirely because we wouldn’t compromise, we lose the fight for all.”**

The majority of participants, however, stood firm, stating that **“we must go for the whole pie . . . and perhaps, in the end, we would compromise a bit, but this is really an issue of equal rights for all.”** These participants also felt that they could not sell out part of the group by settling for some being excluded.

The participants reached consensus on the following points:

- **Limited parity is discriminatory.**
- **Limited parity would encourage mis-diagnosis, so that treatment would be covered.**
- **Treatment of a physical illness, such as cancer, is many times more expensive than the treatment of mental illness.**
- **If it’s limited, it’s not parity.**

What can consumers do (action steps)?

- ◆ One of the best anti-stigma campaigns you can get involved with is parity. Stigma keeps elected officials from understanding the nature of mental illness.

- ◆ [The] most effective advocates (lobbyists) are consumers. You don’t necessarily need to know the politics behind the issue. Consumers should testify at public hearings about their own personal situation, beginning by saying, “let me tell you what happens to me without adequate insurance.”

- ◆ Register to vote . . . and **VOTE!** Remember, politicians don't necessarily vote their conscience, they vote to keep themselves employed after the next election.
- ◆ Write and visit your elected officials.
- ◆ Get others in your community involved! Talk to everyone you know and urge them to support this effort!
- ◆ Participate on advisory boards; meet with stakeholders in your local community.
- ◆ Be persistent and persuasive. Realize that this fight may go on for 10+ years, before realizing our goal.

Consumer-run alternatives

What do we mean by this?

- Services which are run for consumers by consumers.
- All executive/management decisions made by consumers, including but not limited to all fiscal and program administration.
- Working 100% consumer (governing) board.
- May or may not be incorporated under 501(c)(3).
- May have an Advisory Board or advisors who are professionals, but this is optional.
- All decisions made exclusively by consumer users of service.
- Must be a place of hope and inspiration.
- Must be a safe place.
- Consumers must access these programs by choice, only.

Examples of Consumer-run Programs

- Consumer outreach efforts
- Consumer-run drop-in centers
- Respite programs
- Support/self-help groups
- Recovery house run by consumers
- Peer counseling centers
- Consumer advocacy programs
- Consumer case management programs
- Consumer-run vocational programs
- Consumer-run businesses
- Consumer telephone help lines
- Educational/Leadership Empowerment programs

Ideas for help in sustaining consumer-run alternatives

- Start out small; ask everyone you know to make a contribution: friends, relatives, neighbors.
- Incorporate under 501(c)(3).
- Solicit church donations.
- Local fund-raising efforts: bake sales, T-shirt sales, fairs, flea markets, car washes.
- Solicit in-kind gifts (especially office supplies and equipment).
- Go to local MH/MR/Behavioral Health discretionary funds for grass roots organizations.
- Inquire about end of the year money from counties.
- Apply for small grants from foundations, local companies, corporations.
- Apply to state for grant money.
- United Way for technical assistance, grant, in-kind donations from local businesses.
- Check the Internet; set up web page for donations; search for technical assistance.
- Get to know local providers.
- For every donation you receive, send an individually signed thank you note.
- Obtain support letters.
- Get on the mailing list of your State Representatives; he/she knows where money is.
- Remember, funders like collaborative work; work with others on shared efforts.
- Look to funders who specify that they support work in certain geographic areas.
- Check out Senior Volunteer Organizations who may volunteer to help you with items such as grant writing.

END OF SESSION