

CONSUMER
PARTICIPATION
MANUAL

WORLD HEALTH ORGANIZATION
BRITISH COLUMBIA PROJECT



A DOCUMENT TO FACILITATE
CONSUMER PARTICIPATION
IN THE MENTAL HEALTH SYSTEM

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SECTION I

WHY DO WE NEED CONSUMERS TO BE INVOLVED
IN MENTAL HEALTH PLANNING, SERVICE DELIVERY,
AND EVALUATION?

WHO ARE CONSUMERS?

CONSUMERS, FOR THE PURPOSE OF THIS DISCUSSION, are people with mental illness who are directly or indirectly receiving any type of mental health services or who are involved with any aspect of the mental health service delivery system.

- ❧ *On the pages that follow, we will identify two reasons why Consumers should be actively involved in the mental health care system.*

REASON 1

CONSUMERS HAVE A RIGHT TO BE INVOLVED.

CANADIAN SOCIETY IS BASED UPON CERTAIN ASSUMPTIONS
ABOUT THE RIGHTS OF INDIVIDUALS.

ONE OF THESE ASSUMPTIONS IS THAT PEOPLE SHOULD have direct and active participation in any process that affects their lives. This is an assumption that is basic to all democracies.

There are few instances in which people become as completely under the control of government and government funded services as is the case with the mentally ill. In many cases, virtually every aspect of a mentally ill person's life—from income, to housing, to medical treatment, to meals and entertainment—is directly regulated by government policy.

The policies and attendant programs that have such dramatic impact on the mentally ill are set by agencies that are empowered by society to control and care for the mentally ill. Despite being full-status members of society, consumers have been virtually excluded from any significant policy making role in these agencies. Even today, consumers have little, if any, direct control over either the decision or the consequent changes in practice that result from policy decisions.

❧ We believe and strongly maintain that consumers have a moral, and probably a legal, right to be directly involved in the policy and planning process for services that directly affect their lives.

REASON 2

CONSUMERS CAN HELP TO CREATE A BETTER MENTAL HEALTH CARE SYSTEM.

THE PAST 20 YEARS HAS SEEN SOME SIGNIFICANT CHANGES IN THE IDEAS THAT DOMINATE MENTAL HEALTH SERVICE PROGRAMS.

DEINSTITUTIONALIZATION, FOR EXAMPLE, HAS BECOME a cornerstone of mental health policy throughout the world. Similarly, recognition that mental illness is a bio-psychosocial phenomenon and that effective treatment requires coordination of a wide variety of people and professionals has been widely accepted. In the present climate of social experimentation, no one is quite sure which programs are most likely to succeed, or to carry us forward.

Consumers bring an important kind of knowledge to this situation—knowledge about what they need to survive in today's society, and knowledge about the dynamics of service delivery. Consumers, even more than trained mental health professionals, are in tune with the survival and health needs of consumers. And consumers feel more keenly than anyone the effects of shortcomings in policies and programs.

- ✎ *Recognizing this fundamental fact and using consumers in a meaningful way to provide checks and balances in the design, delivery and evaluation of services introduces a validity to the system that can be achieved in no other way.*

WHAT IS THE SITUATION TODAY?

WHILE THE IDEA OF CHANGING THE MENTAL HEALTH SYSTEM THROUGH THE INCLUSION OF INPUT FROM USERS IS CERTAINLY IN KEEPING WITH THE BEST LIBERAL HUMANITARIAN PRINCIPLES, THE REALIZATION OF THAT IDEAL IS DIFFICULT.

THE VISION OF EMPOWERING CONSUMERS THROUGH their inclusion in the power structure is not shared by all mental health service providers. Many bureaucrats and administrators are entirely comfortable with traditional committee decision making structures and are not enthused about the prospect of having to deal face to face with consumers. The Canadian Mental Health Association has discussed in detail some of these organizational and attitudinal barriers and showed how they prevent consumer participation from succeeding.

❧ *Experience has also shown that even the best intended plans to include consumers in the decision making process are hard to realize.*

The traditional government and private sector service systems are not designed to accommodate non-professionals in the planning and delivery process. Committee structures, funding mechanisms and information exchange systems are set up for the benefit of the professionals who run the system.

Consumers who enter the maze of committees, subcommittees, hidden agendas, and political processes are often assailed by the system's general insensitivity to their individual needs and, in consequence, often fail to have any significant impact.

SECTION II

SOME BASIC BARRIERS TO CONSUMER PARTICIPATION.

THERE IS DISCOMFORT AND DISSATISFACTION WITH THE WAY
IN WHICH CONSUMER ADVISORS ARE USED WITHIN THE
PROVINCIAL MENTAL HEALTH SYSTEM.

THE ISSUES THAT MUST BE RESOLVED BEFORE CONSUMERS can have a meaningful partnership role in the service planning and evaluation process crystallize around two specific concerns.

- ❧ *There is not a well developed rationale for the inclusion of consumers in the planning, delivery and evaluation process.*

In the absence of a well developed rationale stating the purpose of consumer involvement, and creating a position for consumers in the decision making structures and processes, the only role for consumers to play is to bring issues to the attention of the people who make the decisions. Since there is no obligation for those within the decision making elite to act on consumers' concerns, the consumer remains a minor and powerless participant in the system. In fact, it is common for consumers to present information to decision making bodies and receive no feedback on the value of their contribution, no acknowledgment that their input will help to establish policy, and no thanks for their efforts.

SOME BASIC BARRIERS (CONTINUED)

- ❧ *The structural and motivational factors that run the mental health service system favour the mental health professionals and disadvantage the consumers.*

Mental health professionals are trained in how health care systems work, understand the roles of the various professionals, have well-established communication networks, and are paid for their participation. In addition they often derive status and prestige from their participation in the service system.

Consumers, on the other hand, have none of these advantages. They are often less well-educated, tend to have a different understanding of the service system (the users' perspective), are not in well established communication networks, volunteer their time, and derive few benefits from their participation other than personal satisfaction. In short, it is very easy for paid mental health professionals to discharge their job duties by sitting on committees made up of their colleagues and peers. It is very hard for volunteer consumers to be effective participants on committees made up of people who are not only not well known to them but who have greatly different educational, economic and motivational backgrounds.

SPECIFIC PROBLEMS AND POSSIBLE SOLUTIONS.

WE HAVE IDENTIFIED A LIST OF SPECIFIC PROBLEMS THAT MUST BE ADDRESSED BEFORE CONSUMERS CAN BE EFFECTIVE PARTICIPANTS IN THE HEALTH CARE DELIVERY SYSTEM. THESE INCLUDE:

BARRIER 1: MONEY

Consumers are not able to afford to participate. Expenses that are typically incurred when consumers participate include: travel, meals, accommodations, incidentals, communications (telephone and mailing, and facsimiles if appropriate).

SOLUTION 1: UP-FRONT PAYMENT

(a) Sufficient moneys should be budgeted to cover the expenses incurred by consumer volunteers who participate in policy work. (b) Moneys should be provided to consumers in advance for such fundamental necessities as travel and accommodation.

BARRIER 2: LACK OF INFORMATION

Consumers are usually not familiar with how committees are structured and how they work. Information that is critical includes: terms of reference, background on committee members, rules of order, reporting structure of the committee, knowledge of who struck the committee, etc.

SOLUTION 2: PLANNED PREPARATION

(a) Consumer participants should, well in advance, be provided with background material on all aspects of the project or committee with which they will be involved. This could include background papers, policy statements, etc. (b) Consumers can benefit from brief pre-training courses that focus on the skills needed to effectively participate in committees.

PROBLEMS & SOLUTIONS (CONTINUED)

BARRIER 3: PROCESS

Consumers are often disadvantaged in terms of participating in the committee discussions. They often find it difficult to jump into unstructured debate, tend to focus on specific problems rather than global system problems, may not understand bureaucratic “bafflegab”, and are intimidated by “high-powered” committee members.

SOLUTION 3: USER FRIENDLY MEETINGS

Committees can adopt procedures that make it easier for consumers to participate. Formally “going around the table” using Delphic or similar procedures makes it more likely (a) that consumers will participate and (b) that participation will be more focused and relevant.

BARRIER 4: REPRESENTATION

A system does not exist for nominating consumers to committees. Consumers who have managed to become visible, for whatever reason, tend to participate while the majority are excluded. Consequently, there may be questions about representativeness that restrict the weight given to consumer opinion.

SOLUTION 4: RESOURCE POOLS

Consumers should be given support for developing a pool of available consumer participants, and service providers should use this pool to identify consumer representatives.



BARRIER 5: ROLE

There may not be a specific rationale for including consumers in the structure of the committee or other decision making body. The agency or group, in consequence, may not have a clear idea of the role that the consumer is to play. Consumers, by the same token, may be unsure of their role and unable to provide focused input.

SOLUTION 5: PROPER TERMS OF REFERENCE

The terms of reference for the committee or agency should explicitly identify and clarify the role of the consumer.

BARRIER 6: ISOLATION

Consumer participation in some situations consists of one consumer among a group of professional health care providers. This is a situation in which consumers are inherently disadvantaged and usually intimidated.

SOLUTION 6: EXPANDED PARTICIPATION

Assure that consumer participation be expanded to include at least two individuals, and provide means for these consumers to interact outside of the meeting place as well as at the meeting.