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CONSUMER INVOLVEMENT IN MENTAL HEALTH AND REHABILITATION SERVICES



**DIVISION OF MENTAL HEALTH
WORLD HEALTH ORGANIZATION
GENEVA**

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This document on consumer participation in mental health services outlines the rationale for such participation and presents a discussion of some of the issues involved in facilitating this at national and local levels.

"Consumerism" in mental health care is largely a development originating in Europe, North America, Australia and New Zealand. Thus many of the concepts presented here are ones which have come from developments in these regions, and not all of the ideas presented here may be transferable to other cultures. A further point is that this document is produced in English and it may be that terms such as "consumerism" and "consumer involvement" may be difficult to translate into other languages. The reader is referred to the discussion of terminology within the document for greater clarification of these terms. While generalization across cultures may not be easy, WHO encourages all countries to consider the fundamental notion that involving individuals in decisions about their own health care enhances the health care system and contributes to the development of Health for All by the Year 2000.

This document results from several consultations and meetings of WHO carried out within the framework of the WHO Mental Health Programme's Initiative of Support to People Disabled by Mental Illness. The principal activity was a WHO meeting on Consumer Involvement in Mental Health Services, held at the Central Institute for Mental Health, a WHO Collaborating Centre, Mannheim, Federal Republic of Germany, in November 1988. The meeting was financially supported by the Ministry of Health of the Federal Republic of Germany. WHO brought together this group of people* particularly concerned for the consumer position, in order to articulate the consumer viewpoint with regard to mental health services. It was considered important that these views be set out clearly, since they have not often been heard. Nevertheless, those involved in the development of mental health services need to consider this viewpoint and it is hoped that this document will go some way to allowing these opinions to be taken account of. The views expressed in this document, however, should be recognized as those of the participants at these meetings and do not necessarily reflect those of the World Health Organization.

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INTRODUCTION

Over the last few years there has been increasing recognition internationally that individuals should be able to take a more active role in decisions about health care practices which affect them. This can be seen from developments in the delivery of health services to those with physical illnesses. The WHO/UNICEF Declaration of Alma-Ata has affirmed this in Article 4 which states that "people have the right and duty to participate individually and collectively in the planning and implementation of their health care." (WHO, 1978, p.3). It has even been asserted that the right to autonomous decisions regarding one's own care is becoming a measure of life quality. This evolution has occurred because of the recognition that individuals have the right to information about their own health and the responsibility to participate actively in decisions which affect their well being.

Likewise, an individual's participation in community and national developments which have a collective impact is also an important right and responsibility. National and community self-reliance and social awareness are important factors

in human development. Community participation has been specifically encouraged by WHO "...representative community participation should be the rule in all official bodies that deal with...health", and more specifically, "Care should be taken to include representatives both from vulnerable groups and from groups that have shown particular interest and initiative in improving the health of communities" (WHO, 1985, p. 58). Thus individual and community participation should be encouraged by providing full information and assuring that the necessary institutional barriers to participation of individuals, families and communities are removed. In this way they can assume much greater responsibility for their own health and well being.

Recognition of the importance of individual and community responsibility for health has prompted WHO's inclusion of primary consumers and families in its Initiative of Support to People Disabled by Mental Illness. In this framework, it is hoped that increased responsibility and participation in the mental health service delivery system can be encouraged.

BASIC ISSUES AND CONCEPTS

There are several basic issues which must be considered when consumer involvement in mental health services is discussed. These issues frequently cause controversy among different groups concerned with mental health care and are presented here to encourage full and open discussion. They include:

- Terminology - what do words like "consumer" really mean
- Competence of consumers to participate in decision making
- Community participation - who should be involved, and what functions should they perform
- Rights of consumers
- Organization of consumer activities - at what level should consumers be involved
- Evaluation of mental health services by consumers

1. Terminology

At a time when ideas are changing rapidly, terminology tends to be confusing. The words patient, ex-patient, consumer, user, recipient and survivor are all seen and heard in different places. Some of this confusion arises because society has attached value and status to certain words such as "patient" and "doctor". It needs to be recognized that social values often influence the use of one term or another. Once these values are recognized, a fuller discussion of the appropriateness of these terms is more likely. For clarity, the use of the specific terms in this report are set out here.

The consumer

The term "consumer" has only recently entered health care discourse. The 1980s have seen an increasing emphasis on consumerism for political reasons in most developed countries. What might be termed "material consumerism" is the ability to make choices predicated on income to purchase from a range of options. In the material culture consumerism assumes the ability to pay and a range of goods to be chosen. The consumer does not expect to be involved in the manufacture of those goods and is required only to choose which of those goods he or she requires.

Health care consumerism goes beyond this. The health care consumer is more likely to wish to be involved in the planning, development, management and evaluation of services and to be involved with and consulted in the care, support and treatment programmes that he or she will receive. The health care consumer is thus desirous of being involved in the manufacture of the product, so to speak, unlike the material goods consumer.

But who are these "consumers"? Consumers of mental health services may be those who suffer mental health problems, or their family members, who also are frequently involved in the service system. All 'consume' the services pro-

vided in one way or another. The term consumer, however, may suggest a passive involvement with little participation. For this reason the phrase "user of mental health services" has developed. This was intended to describe only those with mental health problems themselves, or primary consumers. Unfortunately the term "user" has pejorative connotations with drug abuse which may undermine its helpfulness.

People who have been labelled as "mentally ill" and who have received inpatient treatment will often describe themselves as "survivors" or "recipients" of care. The term survivor suggests that the psychiatric or mental health care process was less than helpful and something to be survived rather than something which helped them to survive. The term recipient is again rather passive and suggests an acknowledgement of the "done-to" process of mental health care. The term "patient" is also unhelpful as many consumers will claim that it was unnecessary for them to become a patient and that they are certainly not one now; and the term "ex-patient" is similarly unacceptable because many consumers do not wish to be defined as an ex-patient, denying that they ever had something called "mental illness" in the first place.

There is thus no obvious term to use. The generic term which is probably best for this paper is consumer, but it must be recognized that this covers both those who personally suffer mental distress and their relatives or family members. For the purpose of this paper, therefore, the term "primary consumer" is used to represent those who have had direct experience of mental or emotional problems and the word "families" is used to mean those who have had some responsibility as relatives or family in caring for them.

Mental illness

The term "mental illness" is another phrase fraught with difficulty. Although it may be acceptable to society as a whole, many consumers deny that there is any such thing as mental illness while not denying the reality of mental distress. Those who are unhappy with the term illness are concerned that it has stigmatizing and pejorative connotations as it suggests a parallel with physical illness and thus conjures up the idea of a disease entity albeit with unknown aetiology.

Any group described in terms of "illness" cannot be expected to have a very positive image in its own eyes or in the eyes of society. The term "mental and emotional distress" is often preferred by such consumers.

Chronic mental disability

The phrase "chronic mental disability" is used frequently and needs clarification. WHO has defined the terms impairment, disability and handicap in its classification of such conditions. Thus according to WHO's definitions (WHO, 1980):

Impairment is "any loss or abnormality of psychological, physiological or anatomical structure or function" and "is characterized by losses or abnormalities that may be temporary or permanent ..."

Disability is "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" and is "characterized by excesses or deficiencies of customarily expected activity performance and behaviour, and these may be temporary or permanent ..." and "Disability is concerned with abilities, in the form of composite activities and behaviours, that are generally accepted as essential components of everyday life."

Handicap is "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal ... for that individual".

Within WHO's framework all three may result from mental illness but may only be applicable at certain times, for example during an acute illness episode. Thus labelling those who have had episodes of severe mental illness as impaired, disabled or handicapped may not always be accurate and further adds to the stigmatization of such people. In order to minimize this stigmatization as much as possible and to clarify the focus of its work, WHO has called its special work in this area the "Initiative of Support to People Disabled by Mental Illness".

2. Competence of Consumers to Participate in Decision Making

One of the most emotionally charged issues and one which stirs considerable debate is that of the competence of consumers, both those who receive direct services and family members, to participate in decisions regarding treatment, planning and administration, and evaluation. Many professionals and the lay public question the ability of primary consumers and family members to judge the appropriateness of care, and feel threatened by requests for participation in planning and evaluation activities. Primary consumers and family members, on the other hand, assert that no one knows better than they what services are most useful and when those services are most effective.

The issue of when a person is competent or has the capacity to make decisions on his/her own behalf is a crucial one and has implications for the whole notion that consumers have anything to contribute to mental health planning and evaluation. If consumers are categorically incompetent, then their advice is not worth seeking. On the other hand, it may be assumed that consumers of mental health services are not unlike consumers of other health services, that is, sometimes too ill or too close to the situation to be objective, but often able to offer rational opinions with the benefit of first hand experience. If this is the case it would follow that consumers, or the organizations that represent them, should have a voice in decisions about mental health care.

The role of professionals versus that of lay individuals is central to the discussion of competence. Well trained mental health professionals have a great deal of knowledge and experience, yet those who have had serious emotional disorders and their families assert that medical knowledge and skills are not what is needed. Consumers rather insist that what is needed most is social support and interventions designed to enhance their capability to live as independently and effectively as possible in the community. Some recent research also supports this (Avison & Speechley, 1987; Barter, Queirolo, & Ekstrom, 1984; Beiser, Shore, Peters & Katum, 1985; Test, 1981; Test & Stein, 1978). Assistance with

housing, education about symptoms and medication management, social skills training and vocational training has been shown to lead to the best community outcome for those with chronic mental illnesses.

In planning and evaluation, professionals and consumers should respect each other's expertise and experience, with a more balanced weight being given to the views of each. This implies a move away from the assumption that consumers have little insight into their own capabilities and limitations and a move toward recognition of the contribution that consumers can make. The negative attitudes and low expectations which professionals and the lay public sometimes have of the mentally ill should also change. Low performance expectations for consumers of mental health services are likely to doom them to low levels of performance.

3. Community Participation

In addition to participation by primary consumers and family members in decisions about mental health services, there has been a growing recognition of the need for other citizens to be involved in the planning and development of health services for the community (McCord, 1982). As community members' knowledge of their own needs increases, their investment in the services which are developed increases, as does the political and economic support which they can provide to the services (Zinober and Dinkel, 1981). By involving members of the community, motivation is developed to work together to solve problems and to develop adequate resources for health care. Community members thus achieve a feeling of shared responsibility for the services in their community and for other members of their society. Local citizens feel empowered in the development of health and social care and individuals are encouraged to take control over their own lives. This can lead to the development of a greater cohesion in society and can help to resist the pressures which cause fragmentation.

Community involvement should apply to the development of health care in such a way that the system becomes opened up to the influence of others besides health professionals and managers of the service. Within health care this other participation can be from a wide range of groups - both lay groups or health workers who might not normally have a voice in management. Since this document is concerned particularly with the involvement of primary consumers and families in mental health services this issue is not addressed in detail. Much of what is said however is applicable to the broader issue of community involvement in health and social care. For more detailed descriptions of these broader issues the reader is referred to other WHO publications (WHO/PAHO, 1984; Oakley, 1988).

Community participation or the participation of individuals and interest groups can range across a spectrum of activity. Such participation may include assessing the need of individuals for care and support, identifying of difficulties in meeting that need, reviewing available resources, assigning priorities to health and social care, giving a commitment to involvement in the provision of care; and providing overall direction and man-

agement of statutory and voluntary organizations in the delivery of such care. (National Institute of Mental Health, 1984)

In establishing a framework for community participation several points require discussion. These are:

Who should be involved?

Possible community involvement could come from:

- service users (people who may be currently patients in mental health care or may have been patients in the past)
- family groups
- community groups such as women's groups, groups representing ethnic minorities or groups representing others who are disadvantaged; churches and other religious groups
- representatives of local government and health care organizations
- representatives of trade unions or other professional groups within the health and social care delivery systems
- special community agencies
- self- and citizen-advocacy groups specifically set up to assist consumers of mental health services

What functions might they perform?

Any of the groups mentioned above may be involved in one or more of the following functions:

- provision of self help and mutual aid
- lobbying for changes in mental health care
- lobbying for increased resources for mental health care
- lobbying for policy change
- working to change attitudes, lessen stigma and to support consumer perspectives
- monitoring and evaluation of care
- educational activities for professionals and for the lay public

Typical areas of involvement in the existing mental health care services can include the planning, implementation, management and evaluation of care. This may include formal involvement in the planning process of local government and health care organizations, membership of governing bodies of such agencies,

direct support for service provision, management of associated services such as housing, leisure or employment services and financial reviews of the service system. Groups may also be involved in establishing alternative services, especially those under the control of consumers themselves, which may be complementary to the more traditional care offered by health professionals within the psychiatric services; or such alternative services may work in opposition to those provided by statutory agencies. Many voluntary agencies and user groups provide new services, plugging gaps in the provision made by statutory or insurance-funded private agents and often provide the services that consumers themselves feel are needed.

How might community involvement occur?

Community involvement can occur in a variety of ways. Some of these are implied in the previous two sections above. In more detail these might include:

1. Control over service systems. This may involve democratic accountability of services to community groups (which may be composed entirely of consumers) and may include the ownership of services.
2. Partnership in service management. This may include "forum" or "consortia" approaches to the involvement of consumers and community representatives in planning and management bodies but may go further and involve the users of services as equal partners in the care delivery. The use of people with direct experience of mental health problems in assisting health professionals in prescribing and treatment development has been described in many settings.
3. Consultation. Consultation does not usually guarantee that the advice of those consulted will be incorporated into the decision making process. Consultation is clearly important especially with those community groups which may not have direct involvement in a specific health care need. Consultation can, however, be a way of marginalising those who are being consulted if their suggestions and advice are simply discarded. Some of the better systems of consultation help to empower the user of services and their relatives by taking their input seriously and incorpo-

rating it into decisions about the way that services are delivered.

4. Self and citizen advocacy. Self advocacy involves providing the consumer with support and assistance to present his or her views either about personal treatment or about the wider service needs. Citizen advocacy is a term given to schemes for speaking on behalf of the consumer (or with them) either concerning the consumer's own treatment or the wider service needs.

The various kinds of citizen groups may have different goals and objectives. The objectives of one group may conflict with those of other groups even though they are all interested in achieving better mental health services. Citizen groups in general may not all concern themselves with the particular viewpoint of consumers and families, as some may wish to only consider such issues as the cost of services, development of physical facilities, fund raising, or other such topics.

A key element of involvement of any group in the decision-making process is determined by the amount of influence or power they have. Most citizens, including consumers and families, have traditionally had little power in the health care system and therefore they normally have had to align themselves with those who are in powerful positions. In doing so, they risk losing much of their influence. In order to avoid this, citizens can work toward gaining a voice in the system using formal mechanisms, thus becoming empowered to influence it.

Healthy communities result from citizen participation in health care and health promoting activities. Individual community members benefit from participation by developing an increased sense of self confidence. Individual competence is enhanced when participation is welcomed and seen as valuable. Recruiting representative citizens is, however, not always easy. Representatives of primary consumers and their relatives may be self-selecting and may not in fact adequately represent the broad opinion of the groups from which they are drawn. This can be avoided by obtaining as wide a representation as possible and by involving as many citizen or community groups as can be accommodated, thus enabling a democratic and accountable process to be established. (Issues related to the representation of primary consumers are dealt with in the section which follows.)

4. Rights Which Consumers Assert

As pointed out at the beginning of this document, consumers of health services generally are increasingly claiming their right to be involved in decisions which affect their health. Consumers of mental health services have also claimed this right but because mental illness has been so severely stigmatized, consumers have felt the need to call attention to several other basic points which can be seen as necessary prerequisites to a more equal dialogue and true consumer involvement in these decisions.

The right to be empowered

The two words which most clearly sum up the current debate are "advocacy" and "empowerment" (see Rose and Black, 1985). Those who have suffered mental distress are often viewed differently from other citizens. Users of the mental health service system are often viewed as deviant and the labels "illness" or "madness" are stigmatizing. Services may be paternalistic and a medical model of care can put great weight on the views of the doctor. Research has demonstrated that mental health problems, more than any other disability, are amenable to social care, psychological interventions, familial considerations as well as medical help. The paternalism of current services taken with the stigmatizing effects of a diagnosis of mental illness can produce a climate which reduces considerably the ability of individuals to control their own lives. Fundamentally this issue is about power. Many consumer organizations will argue that they are working towards empowering the primary consumers of services to be able to control their own lives once again and that such empowerment also requires control over service delivery and the planning, development and management of care. Empowerment can come in a variety of ways: simple respect for the individual reflected in the right to give or refuse informed consent is one aspect; another is control over resources; and a third is the ability to speak with and on behalf of other consumers openly and without fear of discrimination.

Principles Underlying Consumer Empowerment

Some underlying principles which spring from the aim of re-empowering primary consumers, and which can be used as a checklist for any service have been suggested (Survivors Speak Out, 1989):

1. A basic question to ask of any service (including advocacy projects) is "who is being empowered by this service?"
2. Services should recognize and seek to enhance people's abilities and not simply concentrate on difficulties.
3. Services need to recognize the existence of power relations and conflicts of interest between service providers and service users.
4. Services should be person centred not category centred.
5. Service users have a right to their own emotional response to their life situation and to the role of services within this situation.
6. Service users have a right to be their own advocate or have access to an independent 'advocate' who will support them in clarifying their own needs and wants and in pressing for these to be responded to.
7. Service users (and their advocates) have a right of access to all information and records relating to them and their case.
8. Service providers should be prepared to learn from service users and their experiences.
9. Services should question and re-evaluate any areas of compulsion which exist within their practice.
10. Service users have a right to discuss issues of concern to them in a user-only context should they so wish.
11. Service users should be involved in planning, developing and monitoring advocacy projects.
12. Services should be accessible and responsive to all users and potential users, whatever their disability, gender or ethnic background.

The right to representation

Patients admitted involuntarily to a psychiatric facility often lose many of their civil rights. They are generally not asked for their input about the kinds of treatment they will receive, including medication, and they often lose their rights to entitlement programmes such as pensions and social security benefits. Consumers feel that they

should have a representative of their own choosing who can speak on their behalf in these circumstances. In some countries laws have been passed which guarantee that a representative of the patient's own choosing will be consulted and will act on behalf of the patient.

An example of such a law is the United Kingdom's Disabled Persons Act (1986) which gives primary consumers the right to an advocate and to proper assessment for care, especially when leaving a hospital. Similar laws exist in other countries and in many cases have been used to protect the patient's right to appropriate treatment.

It should be kept in mind that those who are chosen to speak for primary consumers may not be consumers themselves, and may in fact not actually represent the views of consumers. Thus, both primary consumers and families should be entitled to representation of their own choosing. A separate issue is the question frequently raised by health professionals regarding the right or appropriateness of some consumer organizations to speak on behalf of all consumers. Primary consumers argue that if a truly representative view is desired, then resources must be provided by the funding authority which will allow for the kind of sampling procedures necessary to ensure full representation. In the meantime a less than perfect representation should be accepted rather than have no representation.

The right to access one's own medical records

In many cases, patients do not have the right to see their own medical records. But in some countries, the necessity of giving patients access to their medical records has been recognized and is guaranteed by law although this may be modified where serious harm to the patient may ensue. In such cases, the patient's representative could have access to the medical record. The reasoning for this is that if a person is being kept involuntarily in a hospital and wishes to appeal against this, it is only just that he or his legal representative should be aware of the grounds for this, and that there should not be "hidden" reasons or arguments in favour of such detention which the patient or his representative is not in a position to refute.

The right to be free of stigmatizing labels

Many consumers of services deny that the label "mental illness" is appropriate because it leads to visions of erratic and frightening behaviour. Once so labelled, they can be stigmatized and ostracized for life. Many admit that mental distress can be debilitating but wish to see an alternative approach taken to diagnosis and labelling. This approach would not necessarily deny that biological factors can play a part in causing mental distress, but would assert that the bulk of mental health problems are related to social, environmental and familial reasons. The proponents of this approach argue that diagnostic labels ascribe the problem to some deficit or personal wrong doing and imply that the person is responsible in some way. Diagnostic labels of mental illness tend to stick with a person for the rest of his life and may have profound negative consequences which follow the individual and often interfere with achievement of routine and normal activities such as applying for jobs, getting a driver's license, opening a bank account, securing a loan, purchasing property, etc. This issue is related to the discussion of competence and capacity to make decisions on one's own behalf. It is also related to the issue of privacy and an individual's right to be free from public scrutiny. Indeed, this issue is often at the core of difficult decisions about consumer involvement and is the keystone of consumers' criticism of psychiatry.

5. Organization of Consumer Activities in Mental Health Care

With the increasing recognition that consumers should be involved in decisions about their own health care, some consumer groups have taken an increasingly active role in establishing priorities and gaining individual control over treatment. However, questions arise about how deeply and at what levels consumers should be involved. Consumer participation can be envisaged at several levels:

- consumer involvement in their own treatment and care;
- consumer involvement in the design and management of local services;
- consumer advocacy work at the local and national level to influence policy decisions; and
- community education.

Each of these is considered separately below.

Involvement in treatment

There is a danger that patients may be considered merely as objects of treatment. In fact, consumers can in many cases, as dignified human beings, decide on matters concerning themselves. A large body of research has now been accumulated which demonstrates that persons who have serious mental disorders can, in fact, play a large and active role in the management of their own illness, and specifically in symptom management. Most of those directly affected by chronic mental disorders report active coping strategies to deal with and control the emergence of symptoms (Arieti, 1974; Breier & Strauss, 1983; Carr, 1988; Cohen & Berk, 1985; Falloon & Talbott, 1981; Leete, 1987; Lovejoy, 1984; Rolling, 1980).

The following suggestions have been put forward to increase consumer involvement at this level. Information should be provided to patients about the proposed forms of treatment so that an individual can give or withhold consent and so that he or she can choose among treatment alternatives. When a patient is too ill to do this, a substitute decision maker, rather than a doctor alone, could perform this function. Information about any detrimental consequences of treat-

ment should be provided and a second opinion should be available, if asked for. An adequate complaint procedure should be part of the service structure, and protection and advocacy services should be routine.

Consumers have attempted to become more involved in decisions at the treatment level in many countries. Thus, consumers have sought:

- the right to an informed consent
- the right to be involved in decisions about how medication will be given if it is accepted
- the right to take part in decisions about various forms of therapy and the involvement or non-involvement of the family or relatives in the therapeutic effort
- a greater say in what kinds of community care alternatives are needed including housing, vocational training, educational services, etc.

The level of hospital ward and organization

For hospitalized patients the ward is their daily environment. Yet the influence of patients on the rules in this environment remains small. Institutional rules and bureaucratic procedures often lead to situations in which the individual cannot develop and ultimately becomes alienated. Thus long term hospitalization has frequently been cited as the cause of disability in itself. In this case, the patient is expected to adapt to the needs of the institution rather than the other way round. One solution has been to develop representative patients' councils in hospitals, able to exert an influence on the daily living conditions of patients and on the input they have into the treatment process. Concrete aims at this level could include exerting an influence on:

- the spending of budgets;
- the recruitment of staff;
- treatment policy;
- procedures and routines;
- complaint procedures.

The level of policy and administration

The exclusion of consumers as competent actors in the process of decision making is also found at national policy and administration levels. In numerous governmental agencies, where the policy on matters of mental health care is decided, the voice of the consumer cannot be

heard. The composition of boards of mental hospitals is generally formed on the basis of power and instances in which consumers are appointed to these boards are very rare. The consequence of this is that such boards can lack the perspective of those who use the services. Both in governmental agencies and on hospital boards this may lead to a one-sided view when decisions are made. Consequently many consumers experience the decisions taken as unfriendly to them. Instead, patients' organizations have emphasized that they would like to be represented on administrative boards on equal terms with professionals.

The level of community education

Consumers have recently become actively concerned with educating the community and campaigning for social rights. These tasks are undertaken in an effort to change attitudes, reduce stigma, and increase awareness of the need for involvement at the other three levels described above. Thus, activities at this level can be seen as the supportive basis for inclusion of consumers in the first three levels.

Public education is usually aimed at two audiences, namely, the lay public, and health professionals.

1. Education for the general public can include:
 - a. The importance of putting forward positive images and of underlining the continuum between "normality" and "madness"/"mental illness".
 - b. The importance of promoting human understanding and placing a high value on personal experience and of taking this seriously.
 - c. Although the role of professionals in mental health services is important the public should be aware that consumer and family groups have important new perspectives and a vital role to play in this field.

2. Education for health workers can include:
 - a. The rationale for consumer involvement in the training of professional health workers,
 - b. The importance of challenging stereotyped relationships of care giver-receiver, competent-incompetent, etc.
 - c. The importance of giving credibility to information and experiences of consumers imparted during such training,
 - d. The importance of recognizing the life-long negative implication of labels and diagnoses.

6. Evaluation of Mental Health Services

Evaluation is an essential undertaking in monitoring mental health care delivery and ensuring that the service meets the needs of those for whom it is designed. Evaluation is however justified only if there is a willingness to modify the service delivery system as a result of evaluation (National Institute of Mental Health, 1984).

It is only in the last few years that monitoring and audit of mental health care has developed and only in some countries. Some examples include the Health Advisory Service in the United Kingdom; quality assurance projects in Australia; accreditation programmes in the USA and Canada. Demands for efficiency from a number of governments are putting an increasing premium on this activity and many organizations are now developing indices of performance and evaluative techniques.

Consumers are also concerned about the quality of mental health care but may approach this from a perspective different from professionals. A key index of quality of care for this group is the quality of life of those who receive services. Assessment of quality of life can be accomplished by asking consumers themselves how they feel about the services they received, as to whether or not they think the services were beneficial, and how they perceived the effect of the service on quality of life. Consumers can also be asked to describe the kinds of services which they think are needed, so that service delivery systems may be designed to better meet the needs of those who use them.

Developing evaluation tools which measure the dimensions in question can be a complex task. A number of service specific evaluative tools have been developed ranging from simple indices of performance to longitudinal surveys. One of the most detailed approaches is that provided by Programme Analysis of Service Systems (PASS). This work has produced a complex and powerful tool based on normalization criteria. However, several questions have been raised by consumers about the real value of this instrument. Most evaluation research instruments are based on policy interests, while very few instruments are developed to evaluate services from a consumer's perspective. There is a place for a valid evaluation technology tailored to the needs of

consumers which will enable them to participate in decisions about their own treatment. Systems of evaluation should be devised in consultation with consumer groups rather than seeking their approval and/or cooperation only in retrospect. It should be stressed, however, that in evaluation research - and in other research efforts as well - special attention should be given to guaranteeing a person's privacy and the privacy of their personal dossiers. An example of a consumer developed evaluation tool is the Camden Mental Health Consortium document: *Treated Well? A Code of Practice for Psychiatric Hospitals*, (Good Practices in Mental Health, 1988).

Burgeoning "consumerism" in many countries may foreshadow greater consumer involvement in evaluation. For example, there is now pressure for the Mental Health Act Commission in the UK to have primary consumers as members. Consumers may also be included in the visiting teams of health authorities and statutory bodies. Those who have had experience of inpatient treatment can provide a fresh perspective in assessing good or poor quality of care. In some cases however, a consumer may be reticent in expressing criticism during the evaluation if it is likely that he will use the service again, for fear of possible reprisals when next an inpatient. Consumers from districts outside their own may be the best solution. Consortium arrangements between consumers and professional staff, perhaps based on a mental health association, can also be helpful, as can the forum arrangements whereby statutory and voluntary agencies work together to promote the best possible care.

ORGANIZATIONAL ISSUES

In addition to the basic issues and concepts discussed in the previous sections, there are several organizational issues which need to be considered when serious thought is given to consumer involvement. These include:

- The various types of consumer organizations
- Development and organization of family groups as a specific form of consumer organization
- Some points which may facilitate the development of consumer groups
- Consumer involvement in diverse cultures

7. Types of Consumer Organizations

A wide variety of consumer organizations and mental health associations exist which strive for greater consumer input into the policy and planning process - for example MIND, Survivors Speak Out, and the National Schizophrenia Fellowship in the UK; Client Bond, the Patients' Councils, and Pandora in The Netherlands; the National Alliance for the Mentally Ill, the National Mental Health Consumers Association, and On Our Own in the United States, the Danish "Mad" groups, the Canadian Mental Health Association; and many in other countries throughout the world. It is important to distinguish the different kinds of organizations from one another although this is not always easy because there is frequently overlap in interests, functions and sometimes in membership. Moreover, some organizations which were originally begun with one purpose have expanded in recent years and now often have several divisions, some of which overlap with newer, single purpose organizations.

Mental Health Associations

Mental Health Associations (MHA) exist in many countries and were originally established as a non-professional or multidisciplinary voice advocating the development of mental health services. Now they are largely organized and run by professionals and they often make extensive use of volunteers. MHAs are not normally direct service organizations but lobby as political bodies and normally participate in consortia of mental health groups. MHAs rely heavily on professional staff and may or may not truly represent the consumer view. Some MHAs have now established consumer departments, sometimes staffed by former service users, which offer public education to the community and advocate greater consumer input into the service system. Such departments may also urge that more attention

be paid to consumer rights and some may even work with local and national governments to influence policy development.

Advocacy groups

Advocacy groups, such as the Organization of Patient Councils in The Netherlands, the National Alliance for the Mentally Ill and the National Mental Health Consumers' Association in the United States, and Survivors Speak Out in the United Kingdom, are usually involved in active lobbying efforts, with legislatures, professional groups, service facilities such as hospitals and sheltered housing units, for the purpose of achieving more consumer input into the design and evaluation of services, and a greater emphasis on the rights of the consumer and for more resources for mental health care.

Information groups

Information-providing groups also exist, such as Pandora in The Netherlands, which concentrate on trying to change the system by informing law makers, professionals, and the general public about mental illness and about the way that services should be designed from the consumer's view. These groups are not necessarily involved in lobbying or other political activities, although Pandora does in fact do so.

Alternative service groups

Alternative service groups, such as those which establish and run a service in opposition to and quite separate from the traditional professional mental health services are another form of organization. Some run a system which attempts to complement the existing services by providing "extras". Thus they may provide support through meetings and written material and offer some form of social club, consumer-run coffee houses or other activities through which consumers attempt to help themselves and one another. Professional input, usually minimal, may be used in any of the above and there are various models of work. The development of alternative services has become an important impetus for moving traditional services away from models which consumers feel are no longer useful. Thus, alternative services can meet unmet needs and point the way toward more relevant services.

Mental health workers organizations

In some locations, groups of mental health professionals who wish to advocate for changes in the system have formed organizations for this purpose. These groups usually do not include family members or primary consumers, although some may have a separate network or subdivision which accommodates consumers. This type of group most often works for better services within the traditional mental health service delivery system. An example is the National Schizophrenia Fellowship in the United Kingdom.

Inclusion of consumers in traditional services

Finally, mention can be made of professionally run services which try to include within the treatment programme a greater attention to family communication and other social interactions. Although strictly speaking this does not represent consumer participation, it is an attempt to understand the identified patient's situation in terms of his or her social position and encourage social helping processes for all those involved, rather than just view the patient as an isolated disordered individual who needs treatment.

8. Development and Organization of Families in Mental Health Services

The organization of families into advocacy groups is a relatively recent development. Such organizations were slow to develop in part owing to the influence of theoretical positions which blamed parents for causing mental illness in their children. Thus stigmatized, families were expected to be passive recipients of therapies or mere conveyors of information about their ill relatives. They felt unable to express their concerns as this might mean a loss of services. However, family dissatisfaction with mental health services has been great and, encouraged by the successes of other civil rights movements, and the emergence of the self-help movement, families decided to organize to achieve their goals (Hatfield 1986).

With continuing deinstitutionalization, those with mental illnesses have returned home, sometimes to families little prepared to provide the kind of care required. Surveys of relatives have shown that living with a person with a mental illness can be burdensome (Johnson, 1986). This emotional burden often arises from conflicts which result because family members feel overly responsible for their loved ones or because they worry about them.

Well developed family organizations carry out a range of functions such as advocacy for all persons with mental illness, including those too disabled to advocate for themselves. They also urge increased funding for research into the causes and treatment of mental illness, encouraging community participation in planning and policy activities related to mental health services, and they can be involved in the evaluation of these services.

The National Alliance for the Mentally Ill (NAMI) in the United States is an example of such an organization. NAMI originally developed as a family organization but also has primary consumers as members. Education for members about mental illness and affording members an opportunity to share similar experiences and exchange useful information are important functions. Some organizations such as NAMI use the varied professional expertise of their membership, thus having access to legal and other services by dedicated professionals with first hand knowledge of the problems.

A valuable contribution has been made by family members who have repeatedly pointed out to

professionals that even though they are often expected to provide home care for their ill relatives they have not been trained to do this. Recent research has demonstrated that mentally ill persons are especially vulnerable to stress and tend to suffer relapses when environmental stress levels are high. Recent research has shown that when all members of the household are provided with information about mental illness, trained in problem solving and other coping skills, and are instructed in ways of managing stress levels, relapse rates of family members with mental illnesses are markedly reduced (Falloon, Boyd, McGill, et al., 1981; Falloon, Boyd, McGill, et al., 1982; Falloon, Boyd, McGill et al., 1985; Hogarty, Anderson, Reiss, et al., 1986; Leff, Kuipers, Berkowitz, et al., 1982; Vaughn & Leff, 1976; Vaughn, Snyder, Jones, et al., 1982). Families and primary consumers have welcomed this form of assistance from professionals.

One caveat is that with the advent of family organizations, primary consumers have expressed concern that their wishes and needs will be subsumed under those of their more influential family members. The relation between primary consumer organizations and family organizations is often fragile and liable to conflict. In countries where both kinds of organizations have developed there is frequently alienation between the two groups and resistance on the part of primary consumer organizations to be involved in the decision making process with representatives of family organizations. This is not surprising since the interests of family members may not be compatible with the interests and needs of the primary consumers.

It has also been emphasized however, that family members and primary consumers have many points of common interest. For example, both groups have as a major objective the improvement of psychological well-being and quality of life of those with mental illness. They agree, too, that primary consumers have the right to live in the least restrictive environment and have a right to receive appropriate treatment. On the other hand there are differences in attitude and beliefs which are due to the differences in experience of mental illness. It is important that these differences and different perspectives be recognized and legitimized. Conflicts may arise over the civil commitment of persons with mental illnesses which can occur where relatives have powerful committal rights. This may increase the alienation of the individual from the family and sets the stage for continued stress when the person returns to the home.

9. Facilitating the Development of Consumer and Family Involvement

In some countries, consumer councils or organizations have been developed, facilitated by government encouragement and subsidies. Consumer councils or organizations can, like the other forms of organization described above, slant their interests towards the primary consumer's perspective (current and/or former) or towards the perspective of families. Development of such organizations is facilitated when funding levels are adequate to provide for paid staff. However, when paid staff are present there is a danger that they may be responsive to funders rather than to their constituent group. Additionally, national and regional offices are helpful in providing the essential infrastructure for the organization (e.g. local chapters with regional/national support). A valuable role which such organizations can play is that of representing consumers and families in planning and other meetings.

These organizations can also perform a valuable service by organizing participation of primary consumers in training programmes for mental health professionals. Representatives of such organizations can do much to change attitudes of mental health trainees and can also help to develop training materials for health professionals. Although not routine practice, this has begun to develop in several countries.

The two types of consumer involvement which have been discussed in this paper should be kept separate, namely, representation of consumer organizations and participation of individual consumers in decisions affecting their own care. Both of these should also be kept separate conceptually from the role of family organizations.

10. The Management of Consumer Issues

There are many ways in which consumers can articulate their views, individually and via non-government and government agencies. But what is the role of managers in the health care system when they are confronted by these views?

If it is assumed that the managers are in post to control resource allocation and service provision so that it serves the interests of the consumers and enables them to receive the best possible care, then managers should be interested in the views of the consumers and of those providing direct care, and be given every incentive to ensure that their needs are met within the constraints of limited resource availability.

To facilitate management responsiveness, a characteristic which should after all permeate the behaviour of public servants (clinicians and other professional workers alike), it is necessary to monitor the supply of consumer information to ensure that it is adequate, and to evaluate at regular intervals the ways in which managers respond to this information.

Thus for consumer and carer views about mental health services to affect the behaviour of service providers, this information must be made available to managers, who, in the interests of service development may wish to augment these views with their own surveys of patient and carer satisfaction with service provision. Additionally the performance of managers in reacting to these consumer needs must be monitored at regular intervals to ensure that the information gathered does influence service provision.

11. Cultural Differences in Developing Countries

The way in which patients' organizations have developed in Western Europe and North America should not necessarily be seen as a recipe for the development of such organizations elsewhere in the world. The emphasis on individuals and their right to organize themselves could elsewhere in the world be incompatible with the social and cultural conceptions existing there. It is not the intention to export or impose models. At stake is the restoration of the dignity of the person and the necessity of ensuring that rights which are guaranteed for healthy citizens are also guaranteed for those who are ill.

For example, in many developing countries the family is the most important unit of social survival. In most instances, whether located in rural or urban areas, individuals draw considerable support from their families. This is especially important in countries where social welfare benefits are nonexistent for persons with psychiatric disorders and where patients are completely dependent on the family for basic needs as well as for social and emotional support. Under these circumstances, it can be seen that family involvement in decisions which affect individuals with serious psychiatric disorders can be crucial. Furthermore, development of individual consumer advocacy groups comprised of patients would not only meet with disapproval and lack of success but would also leave patients without access to housing, food and shelter, and basic social contact and support (i.e. encouraging independence may be culturally and socially unacceptable).

A second issue is that in most developing countries the stigma attached to mental illness is very great and families proceed with extreme caution when deciding who will know about the mental illness of a family member. Thus, expecting and/or encouraging families in developing countries to take on an advocacy role may be unreasonable.

An alternative for advocacy in the developing world is to encourage nonprofessional, non-family consumer oriented action on the part of influential, public-minded citizens. While the limitations of such an approach can indeed be recognized, the alternatives, i.e. direct patient or family advocacy movements, may be extremely difficult to realize.

Brief guidelines concerning the formation of self-help/mutual support groups for the parents of mentally retarded people were developed at a workshop in Bangalore, India and are reproduced as an annex to a paper on the mentally retarded in developing countries (Sell 1984). Although of limited relevance to the subject of this document, it is an attempt to mobilize parents in a developing country.

THE SYSTEM OF CLIENT ORGANIZATIONS IN THE NETHERLANDS – AN EXAMPLE OF GOVERNMENT SUPPORT

In the Netherlands a well developed system of independent consumer organizations exists, financed by the Government. This system of organizations is designed to provide an opportunity for direct input from consumers and their representatives into the mental health services system. The aim of these organizations is to empower primary consumers who are utilizing services in the mental health system. The importance of the Dutch system is that the Government has recognized these organizations as having a legitimate voice in the system. Thus they are financed by the government, legislation is under discussion for mandating a patient representative on the governing board of each psychiatric hospital, and the organizations are operated by patient representatives.

It must be kept in mind that the policy of the Dutch Government is one which is rarely duplicated in other countries although some countries have taken steps in this direction and have supported the initiatives of consumers. For example, Canada has recently assisted consumers to voice their views and has funded a public education campaign through the Canadian Mental Health Association. Likewise, the United States Government, through its National Institute of Mental Health, has funded several initiatives including consumer run community service programmes, a national telecommunications conference network, and a series of national consumer conferences, all designed to encourage greater influence and action by consumers.

CONCLUSION

Research has taught us that those with chronic mental illness learn active coping strategies and develop techniques to master the symptoms of the illness. In this regard, those with chronic mental illness are not unlike patients who suffer from other illnesses, and who strive to find ways to minimize the effect of the illness on their lives. Consumers of mental health services have asserted their right to be involved in decisions about their own care, and in the planning and evaluation process.

WHO has encouraged participation by consumers and other members of the community in health care. This document has attempted to outline the issues involved and to present some mechanisms for including consumers in the planning, management and evaluation of mental health services.

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