
WHO INITIATIVE OF SUPPORT TO PEOPLE DISABLED BY MENTAL ILLNESS

PROPOSAL FOR A MULTISITE
RESEARCH AND ACTION
PROGRAMME ON CONSUMER
PARTICIPATION IN SERVICES



DIVISION OF MENTAL HEALTH
WORLD HEALTH ORGANIZATION
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**WHO INITIATIVE OF SUPPORT
TO PEOPLE DISABLED
BY MENTAL ILLNESS**

**PROPOSAL FOR A MULTISITE RESEARCH AND ACTION PROGRAMME ON
CONSUMER PARTICIPATION IN SERVICES**

This proposal for a multisite research and action programme on consumer participation in mental health services has been developed within the WHO Initiative of Support to People Disabled by Mental Illness. Early formulations of a proposal for such a programme were made at a series of WHO meetings and consultations held in 1987 and 1988. The underlying principles that should govern the conduct of such a programme were formulated at a WHO meeting held in Mannheim, Federal Republic of Germany, at the end of 1988, and this proposal was then formulated by a small working group convened in 1989. This proposal reiterates the underlying principles and specifies the target group of clients which it aims to help. Apart from setting out the need for a commitment for each participating centre to develop mechanisms for eliciting consumer views and allowing their involvement in service development and evaluation, the proposal does not attempt to specify exactly how this should be done in any centre.

Each centre, however, will follow the same protocol of evaluation whereby it can be judged if the centre has truly elicited the wishes of the consumers, has taken them into account in service development, and has involved the consumers in the management of the services. The ultimate aim will be to see in what way this involvement affects the consumers themselves and whether this can be judged as beneficial. This proposal however is focussed on an evaluation of the process of consumer involvement with much less emphasis at this stage on an evaluation of outcome.

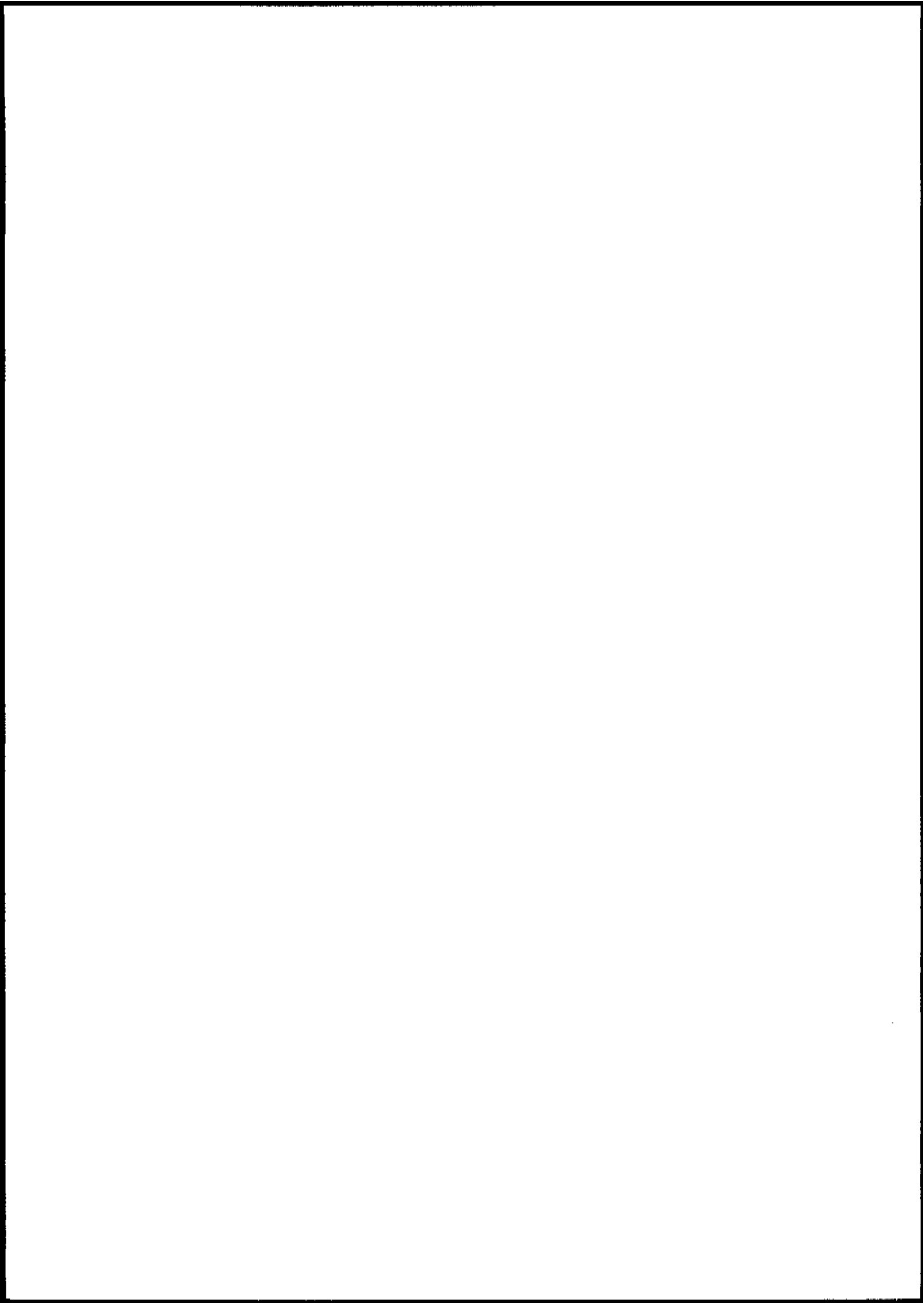
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1. RATIONALE FOR THE PROGRAMME

Recently consumers of mental health services have begun to assert their rights to participate actively in decisions about the services provided for them. The process of deinstitutionalisation which is underway in a large number of countries allows for the development local services which are tailored to the needs expressed by their consumers. This implies that consumers are able to choose from among a range of local services. Many countries planning the development of mental health services have expressed an interest in involving individual consumers, self-help projects and consumer organizations in this process. Until now, however, no systematic research and action and evaluation of the effects of consumer involvement in mental health services has taken place.

In the context of the WHO Initiative of Support to People Disabled by Mental Illness, the Multisite Research and Action Project will describe and evaluate the implementation of these methods of consumer participation.

The primary objective of the project is to encourage the expression of consumer views concerning the design, implementation and evaluation of local mental health services and to encourage mental health planners and care givers to incorporate these consumer views into the design of the mental health service delivery system. It is anticipated that services which are developed and evaluated with consumer input will more closely meet their needs and will reduce the proportion who lose contact with those services.

An additional benefit of this programme is that a network of such consumer oriented projects will be generated which will allow detailed discussion to take place about the methods, motives and difficulties of developing consumer participation in mental health settings. In this way more complex, wider issues will be addressed, including the relationship between the use of health and social services, the incentives and disincentives to using state benefits and services, and the nature of the care giver, patient and consumer roles. The knowledge gained from a comparison of projects in diverse locations will also contribute to our knowledge of mental health care across a variety of cultures and the factors which influence the success or failure of consumer involvement across these cultures.

2. THE MANNHEIM PRINCIPLES

The principles upon which the multisite programme is established are set out in the report of the WHO meeting on Consumer Involvement in Mental Health Services held in Mannheim in November 1988.

Although each of the sites will be characterized by many differences, several guiding principles should set the tone for their development.

1. Semantics: terminology which is used must not devalue or marginalize either the project itself, its users or its workers. Thus due regard must be given to consumers' views on the use of psychiatric terminology and unnecessary use of value laden terminology should be avoided.
2. Empowerment: users of the service must be clearly and visibly a part of the decision-making process at several levels, including:
 - (a) policy and planning;
 - (b) organization of the service; and
 - (c) administration and daily activity/routine.
3. Focus: the aim and focus of the service and the overall project should be on the enhancement of an individual's capabilities rather than on disability or deficits.
4. Nature of the project: the project must be socially-valued and must exist in as normal a setting as possible in order that there is no devaluing or marginalization of users, workers or the service itself. Thus, its location, name, physical makeup, etc., must be socially valued.
5. Quality of life: the primary goal of the project is to maximize all facets pertaining to the quality of life of consumers and also to ensure that the user is satisfied with this enhanced quality.
6. Choice: a major goal is to maximize all possible choices and opportunities available to users and to avoid limiting opportunities as far as is possible.
7. Transparency/openness: there must be guaranteed access for the consumer to all facets and processes of the project, including decision-making, access to one's own individual records, and to the evaluation processes.
8. Cooperation: a unique feature of the project should be that cooperation between users, workers, the community, and other interested organizations and individuals is stressed.
9. It is anticipated that although the projects will have some common elements, they will vary widely depending on needs and resources in each location. Further, a model which is developed in a given area may not work in collaboration with existing organizations to effect appropriate change or it may produce radically different and new organizations, either in cases where none previously existed or where the current organizations are clearly deficient with regard to meeting the needs of users.

10. It is possible that the project will start on a small scale, but it is absolutely essential that it be adequately and appropriately resourced in order to guard against its failure from inadequate or inappropriate resources. Secondly, it is possible that the project may employ consumers or previous consumers, always as paid employees at the same rate that others are paid. Pre-existing resources may be used, but these should not in any way adversely influence the development of the project. For example, while previously-trained staff may seem to be a valuable resource, frequently staff from pre-existing organizations come with negative attitudes and expectations which can adversely affect the development and outcome of the project. Thus one possibility is that users should be involved in the choice and evaluation of staff who will participate in the project.
11. Coordination and integration of the project with other community resources will be necessary. In order to ensure this, it may be that some form of case-management system will be needed. Whether a case-management is used or some other administrative mechanism is devised, it is essential that users of the services of this project have coordinated and integrated access to other needed and desired services.
12. An important function of the project will be to change community attitudes and reduce the stigma attached to chronic mental illness and disability. Therefore, a high priority should be placed on providing public and professional education by users themselves.

3. TARGET CONSUMER GROUP

The overall aim of the WHO Initiative is to reduce the disabling effects of long-term mental illness, and in particular highlight the contribution of social factors such as disadvantage and stigma to the level of disability experienced. The majority of people with severe social disabilities associated with mental illness will have a diagnosis of a functional psychosis (I.C.D. 9 295.x, 296.x, 297.x). There is evidence that this group is at risk of relative neglect by mental health services which are not specifically targeted towards their needs. The consumers included in the programme will however not be so severely disabled that they are unable to actively participate. The inclusion criteria for the target group, who have often been excluded from decision-making processes in the past, are as follows:

- 3.1. Age: between 18 and 65.
- 3.2. Disablement: people must exhibit a significant degree of disability in their and social and occupational functioning, as indicated by a score of 60 or less on the Global Assessment of Functioning Scale.
- 3.3. Duration of illness: minimum one year of duration of symptoms or contact with mental health services.

3.4. Residence: consumers may be living outside hospital or in hospitals which have a clear plan to discharge patients to community residential settings.

3.5. Exclusion criteria: a primary diagnosis of dementia, mental handicap, personality disorder, alcohol or drug abuse.

While it is accepted that participating sites may in practice provide services for consumers with a wide range of problems, the focus of the local projects and the data collection will be upon those consumers who fulfil the entry criteria.

4. SITE ENTRY REQUIREMENTS

The multisite project is one component of the WHO Initiative of Support to People Disabled by Mental Illness. Centres may thus wish to participate in the multisite programme, in other aspects of the Initiative or in both. Administratively, there may be a distinction between donor sites to the Initiative and participants in the multisite programme. Further discussions will clarify the extent to which sites contribute towards the costs of central co-ordination of the programme, and secondly how contributions may vary between sites in developing and developed countries. To qualify for admission to the programme a site must demonstrate that consumers of that specific site are actively involved in design, implementation and evaluation of the service. This means that there must be a real, ongoing and substantial commitment to involving consumers at every level of the local service. This also implies a willingness and ability to develop the service in line with feedback from consumers. The World Health Organization will be the final arbiter of whether a site shall be part of the Initiative, taking into account the requirements set out here and the Organization's more general priorities.

It is recognized that there will be wide cultural variations in the methods suitable for implementing consumer participation in different sites, and that these methods cannot be specified in advance. At the same time, a site wishing to participate must agree to follow a common core as set out in the guidelines within this protocol and to complete the regular, punctual and comprehensive data collection and reporting as set out in section 5 for at least the three year duration of the programme. Sites may well wish to add other activities to the common core according to the interests of that centre.

5. PROGRAMME DEVELOPMENT

The multisite programme envisages that each site will have as its primary focus the question of consultation with consumers and their participation in planning, providing and receiving services. The programme will contain a variety of different activities which may range from district planning exercises to single service delivery projects, all with high consumer participation. The target group is by its nature frequently

marginalized and in intermittent contact with services, and has considerable difficulty in articulating its needs and expectations to professionals and planners. The challenge of the multisite programme is to explore ways in which this articulation can be developed.

In view of the cultural and structural variations between sites, it is likely that the outcomes of the projects will differ according to local priorities. The common element, however, will reside in the common commitment to the process of developing an active consumer role in all aspects of services, and to developing new forms of consumer consultation. Further, the central core of any service at the local level is the quality of the face-to-face contact between the consumer and the service-provider, mediated through a relationship of trust.

It is anticipated that towards the beginning of each project the team will make a description of the existing local services for the long-term mentally ill, and the extent to which these services are actually used by the target group. In addition, each team may wish to make an estimate of the number of consumers falling within the target group within the local area, and to describe the life-styles, family and community support systems and service requirements of this group.

This initial exploration may yield considerable challenges to local teams. Many of the target group may, for example, be located within the Criminal Justice System, in facilities for homeless people, or receive inappropriate medical or social services. In some sites the tasks may be not to develop new services, but to better tailor existing services to the needs of the target group through the active involvement of consumers in service development. Some of these projects may come to bear little resemblance to what we currently understand to be mental health services. These implications may be among the most exciting challenges to the staff at the Multisite Research and Research and action projects. This approach may challenge usual conceptions of how mental health services should evolve, and, at the conceptual level, may provide new perspectives on common assumptions of what are the roles and needs of people with serious mental disorders.

In practical terms, each site will develop its own blend of methods to facilitate consumer participation. These may include a direct consumer role in consultation procedures, on planning and steering committees, in public mental health consortia, or their intermediaries such as advocates, representatives or partnerships. It is likely that this will not only be a top-down approach, but will encourage ideas and proposals to be generated among the target group and their families, for wide discussion and implementation.

6. PROGRAMME EVALUATION

Programme evaluation is to be understood as empirical research which examines how far the goals of innovative programs are met, and which identifies the factors which enhance the effectiveness of these services.

The results of this evaluation will be important both in relating interim results to the continuing development of the individual projects, and also in indicating the outcome of the programmes. Such evaluation should contain assessments at the beginning and end of the programmes, together with regular interim reports.

The dual research and action aspects of the programme will be evaluated within the overall methodology of comparative case studies.

6.1 The Aims of Programme Evaluation

The evaluation will aim to provide:

- 6.1.1 A project biography for each site that gives a systematic description and analysis of the dynamics of each project. These biographies will provide detailed descriptions of the process of project development that does justice to the richness and cultural specificity of each participating site, and to the experience of consumers taking part in the projects.
- 6.1.2 The comparison of goals, means and outcomes of individual projects.
- 6.1.3 Methods whereby the operation of individual projects can be monitored periodically and strategies adjusted where necessary.

6.2 Research Questions

Three main questions will be addressed in the Programme Evaluation. These focus on the degree of success in promoting consumer participation, on the social welfare outcomes of the projects at the levels of the individuals consumers and the local community.

- 6.2.1 Are the projects successful in promoting consumer participation in the design, implementation and evaluation of their work?
- 6.2.2. Does participation in these projects have beneficial consequences for the consumers involved, for examples in terms of an increase in self-esteem or in the development of new friendships?
- 6.2.3. Do the projects have beneficial consequences for the community in which they are situated? Are there now, for example, fewer people wandering the streets than previously. Evaluation will also consider the educative effect of the projects on their local communities.

6.3 Information Collection

A "common core" of information will be collected at each site, where feasible, and in addition WHO will encourage several sites to undertake sub-studies of specific aspects of the programme evaluation. Information will be gathered at the three levels: the district, the project and the individual levels. It is envisaged that the study design will permit comparison data at three points in time: before entry into the programme, at entry, and after entry (at one year follow-up intervals). The following are examples of information that may be relevant to local sites.

6.3.1 District Level

6.3.1.1 Core Information

- range of local mental health services available, their development, and future plans
- legislation with respect to rights of those with mental disorder (appeals, voting, complaints)
- housing policy for the seriously mentally ill

6.3.1.2 Additional data in a sub-group of sites

- employment rates locally
- ethnic composition of population
- types and levels of social security benefits
- health insurance provision

6.3.2 Project level

6.3.2.1 Core Information

- aims and processes by which these are established
- size of site project
- staff training and experience
- methods of implementing consumer participation
- functions and services offered/programme of project
- developmental stage/types of conflict and methods of mediation
- methods of staff participation
- links with other local services
- the follow-up of consumers who drop out of projects
- referral pathways
- drop out rate for target group
- diagnoses/case mix
- funding:sources and security

6.3.2.2 Additional data in a sub-group of sites

- impact on local services
- integration with local community
- staff turnover rate

6.3.3 Individual level

6.3.3.1 Core Information

- competence/social function/degree of disability
- narratives of individual careers
- diagnosis from case notes (with each consumer's permission)
- age and sex, marital status, housing type
- employment and psychiatric history
- history and current use of other supportive services
- medication use, reasons and consumers' reactions
- WHO Disability Assessment Schedule

6.3.3.2 Additional data in a sub-group of sites

- relationships between providers and consumers
- staff accounts
- family accounts of impact of project
- measure of consumers' satisfaction with services
- economic costs and benefits of participation in service
- ratings of degree of family burden
- rating of quality of life by consumers
- social network evaluation
- family involvement in mental health services

6.4 Research Variables

In order to obtain adequate answers to the research questions it will be helpful if, in the collection and analysis of the data, a distinction is made between three categories of variables: effect, process and control variables. The precise determination of these will be reached through discussion within and between sites.

- 6.4.1 Effect Variables: refer to the effects on the consumers that are achieved by the projects, as described above, including any unintended consequences.
- 6.4.2. Process Variables: refer to the means used by the programmes to achieve their objectives.
- 6.4.3 Control Variables: refer to the influence of the programmes on the wider community, for example on the government policies, local housing practices, and employment rates.

6.6 Collaboration between Consumers and Researchers

The nature of the relationship between consumers and researchers will both reflect the more active role for consumers promoted by this programme, and determine the information that will be available for the project descriptions and data analysis. The

Mannheim principles indicate a more collaborative relationship between consumers and researchers than is characteristic of more traditional research programmes. Further, the exchange of information on the development and evaluation aspects may be an important condition for the success of both. It is anticipated that consumers will be actively involved at each site in discussion on the research issues to be explored in depth. Similarly, access to case notes and discussions with third parties will be only with the permission of each consumer.

For a critical evaluation, however, a certain distance will need to be maintained between development and evaluation activities. It will be important to assign these responsibilities at each site to separate members of the project team.

7. TRAINING

Training will comprise two types of preparatory training and two forms of training with wider implications beyond the participating sites.

- 7.1 Training between sites for site coordinators to harmonise objectives
- 7.2 On-site training of co-ordinators and researchers to standardize data collection methods and aims
- 7.3 Training of selected consumers to enable them to play a part in , and where feasible conduct, training activities, for example in programmes to change attitudes of staff in hospital.
- 7.4 Using the experience that accrues from the sites to develop training modules for wider dissemination, which would be a component of the WHO Initiative of Support to People Disabled by Mental Illness

8. INTERNATIONAL STEERING GROUP AND COLLABORATIVE STRUCTURES

The World Health Organization will be responsible for the coordination and control of this project. An International Steering Group (ISG) for the project will be established whose function will be to advise WHO on the conduct of the Initiative in general and the Multisite Study in particular. This ISG will comprise of two people from each of the participating sites (one these a consumer) together with WHO staff, and a small number of observers. It is envisaged that the ISG will concern itself with, among others, the following functional areas, each of which may give rise to a sub-group where appropriate.

1. Programme Development
2. Communications: between sites
 external communications
 translation
3. Network training (modules)
4. Research: data coordination, analysis and interpretation

5. Finances
6. Preparatory training of research workers, site coordinators

It is expected that, independently of the work of the ISG and its sub-groups, there will also be continuing exchange of personnel and information between sites.

9. OUTPUTS

Throughout the course of the project several reports and other communications will be forthcoming. These will include annual reports, meeting reports and research related communications. In addition a regular newsletter between sites will be initiated if the need arises. It is anticipated that publications proposed for external dissemination will be issued. These will include a range of papers for professional and academic journals, conference presentations and reports and other means to publicize the programme.

Following completion of the project a summary report will be proposed. This may take the form of a manual or handbook which documents the process, outcomes of the programme, noting the practical methods and challenges in implementing such projects.

ANNEX 1

Examples of Site Projects

1. The development of consumer-based services for people with long-term mental illness on a large housing-estate (population approx. 30 000) in an area of multiple deprivation in Glasgow, Scotland. Statutory and non-statutory agencies are collaborating to develop local and accessible services, and to consult and discuss with people in the locality about the proposed developments. It is intended to generate a wide variety of projects within the housing estate that will embody the principles of consumer involvement. The Community Mental Health Team will also aim to: employ local people in the new mental health services; to foster the creation of self-help groups; and to establish the appointment of independently employed advocates for consumers of mental health services.
2. The development of an action research project in a Health Authority in the North of England. Previous research in the locality suggests that a large proportion of the target group are living in impoverished circumstances, distrustful of mental health professionals, and have minimal contact with services. Within the Health Authority there is broad commitment to developing forms of consumer participation, but also considerable uncertainty as to how to set about the task. The development team will endeavour to identify the needs and requirements of the target group, help to establish mechanisms of consumer consultation and participation, and foster new forms of service development. It is envisaged that these will include the creation of new forms of activity involving consumer participation and also changes to existing service structures.
3. A work project in Harlem, the Netherlands, which offers work placements to people with mental health problems who have been unemployed for long periods of time. In order to prevent the project from becoming an isolated entity, serving only the psychiatrically handicapped, use is made of local and regional public facilities to consumer participation at all levels: at the individual level of planning a working career, at the workshop level, and at project level in which consumers are members of the board.

ANNEX 2

Time Plan for the Programme

SCHEDULE FOR INITIATIVE AND MULTISITE PROGRAMME

	1988	1989	1990	1991	1992	1993
<u>Site Activity</u>						
Agreement of Site to Participate in Multi-site Project						
Agree Data Gathering Process and Instruments						
Train Site Researchers						
Creation of Multisite Steering Group						
On Site Programme Development Starts						
Annual Site Survey						
Annual Site Report						
Networking						
Newsletter						
Modular Training						
Regular Meetings of Steering Group						
Ongoing Evaluation						
<u>Initiative Activity</u>						
Mannheim Guidelines						
1st WHO Publication						
2nd WHO Publication						
WHO Coordination						
Call for Donors/ Sites						
Coordination of Initiative and Multisite Programme						
Annual Collation of Site Data						

ANNEX 3Site Programmes in the Wider Social Context

The "target group" (those with long-term mental disabilities living in the community) and their families and carers will as citizens have rights and entitlements to a range of mainstream social and health services as well as more specific access to specialist mental health services.

Many of the Initiative's target group have low levels of use of specialist services and are sometimes out of contact with a service from which they could benefit. They may also be disadvantaged in respect of other opportunities for example in finding work, in obtaining their income maintenance and in being appropriately represented in judicial proceedings and having their needs recognized within the criminal justice system.

The following "checklist" has been developed to assist in "Site Surveys" of the rights and entitlements of consumers within the sites, local and national, legal and welfare frameworks. The exchange and comparison of such surveys within the Initiative will assist sites to consider the comprehensiveness of their services to the target group and address issues of their citizen/clients rights and matters of assisted access to general services.

1. Access to the Labour Market
 2. Income Maintenance (Social Security)
 3. Health Insurance Disability Registration
 4. Housing
 5. Educational Services
 6. Transportation
 7. Legal Representation
 8. Ethnic Minorities
 9. Civil Commitment
 10. Access to Mental Health Services
 11. Information on Levels of Provision and the Implementation of Statute
 12. Basic Rights
1. Access to the Labour Market
 - 1.1 Is there a right to regular work for mentally ill people?
 - 1.2 Is there a right to sheltered work?
 - 1.3 Is there a law obligating employers to employ a certain percentage of (mentally disabled persons? Does this operate?)
 - 1.4 Is there a right to vocational training and other assistance to obtain (re)employment?
 - 1.5 Is there protection against dismissal for those with mental health problems?
 - 1.6 Are there programmes which are concerned with stress at work for employees?

- 1.7 Is a mental disorder caused by stress at work considered as an industrial injury/accident for which compensation may be claimed?
- 1.8 Is there an "equal opportunities" employment policy operating on gender, ethnic origin and health?

2. Income Maintenance (Social Security)

- 2.1 Do the consumers have access to advice and assistance to obtain the maximum entitlement to income maintenance?

3. Health Insurance Disability Registration

- 3.1 Does the consumer have access to health services free at the point of delivery and/or are they covered by a health insurance?
- 3.2 Do the target group benefit from special services, by being registered as disabled?

4. Housing

- 4.1 Is there a law protecting a mentally ill tenant from eviction by the landlord?
- 4.2 Is there a law promoting housing for mentally ill people?
- 4.3 Is there any form of "respite" housing as an alternative to hospitalisation?
- 4.4 Is there a right to assistance with housing problems (financial and social)?
- 4.5 Is there a balance between income for housing, other disposable income and care costs? What proportion of a mentally disordered person's income is taken up by housing costs?
- 4.6 Are there specific provisions available for homeless persons who suffer mental health problems?

5. Educational Services

- 5.1 Are there basic literacy and numeracy facilities of a remedial kind available to the target group?
- 5.2 Are there training programmes available to the target group?

6. Transportation

- 6.1 Do the target group benefit from free or subsidised travel; and on what basis of entitlement?
- 6.2 Do consumers and carers receive assistance in attending for treatment and visiting.

7. Legal Representation

- 7.1 Is there legal advice/legal aid for representation available to the target group?

8. Ethnic Minorities

- 8.1 Is the target group characterized by a particular ethnic group?
- 8.2 Is any particular ethnic minority in the site community over represented in the target group?

9. Civil Commitment

- 9.1 Does the mental health legislation provide for judicial process of civil commitment?
- 9.2 Are right of appeal and legal representation for appeals available?

10. Access to Mental Health Services

- 10.1 What legal basis exists for the target group's rights to mental health services and what are these?
- 10.2 What action can a member of the target group take to obtain or complain about mental health services?

11. Information on Levels of Provision and the Implementation of Statute

- 11.1 What "norms" or indicators of service provision exist for the target group and should ensure local service provision?

12. Basic Rights

- 12.1 Do members of the target group enjoy these basic rights: for example voting, freedom of access to public facilities, right to marry, have children, own property, inherit property, make a will.

The "Checklist" may be further developed and expanded to relate tot he variety of cultures within the multisite programme. The relationship which may emerge between access to Specialist and Generalist Welfare Services and dissemination (both positive and negative) and stigma will be of considerable interest for those participating in the multisite programme.

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