

WORLD ASSOCIATION OF PSYCHOSOCIAL REHABILITATION

International Practice in Psychosocial/Psychiatric Rehabilitation

Editor

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INTRODUCTION

In 1994, the World Association of Psychosocial Rehabilitation (WAPR), under the leadership of Dr. Benedetto Saraceno, invited the Center for Psychiatric Rehabilitation at Boston University, a member of WAPR, to create a WAPR Committee. The mandate of the Committee was to develop a list of psychosocial rehabilitation programs around the world that could represent examples of “best practice.” The Committee began its work in earnest in the fall of 1994 and worked through until the fall of 1997. The verification of information and publication of the directory was completed in early 1999.

The directory presents a list of selected programs, a brief overview of the state of psychosocial/psychiatric rehabilitation in each of the global regions used to organize the directory, as well as a description of minimum characteristics of “good practice.”

Establishing a Committee

Dr. Marianne Farkas, Co-Principal Investigator and Director of the World Health Organization (WHO) Collaborating Center for Research and Training Center in Mental Health at the Center for Psychiatric University, Boston University, USA, chaired the Committee. She invited people with well-established reputations in psychosocial/psychiatric rehabilitation to participate, while also attempting to ensure that all regions of the world were represented. There were many possible excellent candidates to choose from. In some regions of the world, many mental health researchers and administrators are involved in the development of psychiatric rehabilitation. In other areas, however, rehabilitation for persons with psychiatric disabilities is less well known and less easily accessible. As a result, committee members were chosen more for the areas of the world of which they were knowledgeable, rather than the region of the world that they represented. The Chair was also committed to including the perspective of persons with psychiatric disabilities on the committee and consequently, one member was a consumer-survivor/ex-patient, an internationally known advocate for the consumer movement. Eventually, the Committee was made up of 12 members from 10 countries. Full names and addresses of all contributors to this project, including Committee members are presented in Appendix A.

Establishing “Best Practice” Characteristics

Much of the Committee’s discussions were taken up with the problem of defining what “best practice” in psychosocial/psychiatric rehabilitation is. In some regions of the world, rehabilitation is a hospital-based practice. In other regions of the world, hospital based practices are considered to be an anathema to rehabilitation. In some regions, rehabilitation and resettlement are considered to be closely linked concepts. In others, the focus of rehabilitation is almost exclusively on the domain of work and employ-

ment. Bringing all these disparate views together to establish a list of unanimously agreed upon characteristics of “best” practice proved impossible. What is best practice and progressive in one area is considered to be regressive and irrelevant in another. Consequently, the Committee decided to develop *minimum characteristics* for good rehabilitation programs.

Minimum Characteristics for a “Good Rehabilitation Program”

Five characteristics survived the Committee’s discussion.

1. *The focus of the program is on persons with serious mental illness.*

The focus of the rehabilitation activities is the population of persons diagnosed with a major mental illness. The Committee agreed that, while there were many good rehabilitation programs for other populations, psychosocial/psychiatric rehabilitation programs had to have persons with serious mental illness as their priority population.

2. *The focus of the program is on improvement. Improvement is defined as helping people to increase their physical, emotional, intellectual functioning in the realm of housing, work or school, as is normative for their age, cultural expectations and personal interests.*

The Committee felt that good rehabilitation programs are not “holding facilities” but are ones that encourage growth. They help people to integrate into their communities as much as possible so that they can do what other citizens in their community do in daily life. A good rehabilitation program either provides, tries to have access to, or links with services in all domains (home, school, and work) and all types of functioning (physical, intellectual or emotional). The fact that programs *focus* on these areas does not mean that rehabilitation is the equivalent of *resettlement*. Some people want to improve their lives in their current situation. For others, a physical move is important. A good program responds to the particular wants and needs of the *individual*. The assessment of a person’s functional strengths and weaknesses with respect to a particular domain (home, work or school) must be done on an individualized basis in order to establish a responsive intervention plan, even if the program uses group activities as a primary modality for such an assessment.

3. *A program is designed to develop partnerships and to empower their constituencies.*

The program seeks to maximize natural supports. It seeks to help people experience themselves as members of the community and citizens of a society, rather than as “mental patient.” The design of the organization includes input from consumer-survivor/ex-patients and their families. Finally, information (e.g., treatment plans, medication, progress, etc.) is freely given to consumer-survivor/ex-patients and any family member or significant other whom the person wishes to receive the information.

4. *A program is integrated into a network of other services, resources and supports.*

A good rehabilitation program does not exist in isolation nor does it try to create its own closed society in order to provide services to persons with serious mental illness.

5. A program has easy access to clinical services.

In some parts of the world, practitioners deliver both rehabilitation and treatment in the same location. In other parts of the world, treatment services and rehabilitation services exist in totally different legislative systems. While everyone agrees that clinical treatment is an important part of overall recovery, there are large differences in opinions about how separate rehabilitation and treatment actually are. Some believe that medications are essential to recovery. Others do not. Some believe that treatment's focus on symptoms and illness precludes the possibility of dealing with functioning and "non illness"- related living. Some believe that the basic assumptions of the relationship of the person to the helper are so different across these services that they must be seen as different modalities. For example, the "patient-therapist" role of clinical treatment is vastly different from the "consumer-practitioner" role of rehabilitation in its expectations of compliance versus empowerment and self-determination.

To resolve the differences in perspective, the Committee chose to make clear that a good rehabilitation program has to have access to treatment. *How* the program achieves access to both services is not as important as the fact that easy access is available. These characteristics are summarized in Appendix D.

The Selection Process

A survey was developed at Boston University based on the agreed upon characteristics (see Appendix C). Committee members were asked to nominate programs that they felt fit the characteristics based on their experience or knowledge of the programs. This process of nominations resulted in a list of 120 programs. The list of programs was then sent to consumer-survivor organizations in those regions where there were such organizations to tap. The organizations or individual representatives were requested to review the list and to identify any that they felt clearly did not meet the characteristics. The organizations were also asked to nominate any programs that they felt did a better job of meeting the characteristics than the ones on the list.

When a program did not respond to the survey, Boston University contacted the program at least three times, by fax, telephone, or mail, before eliminating the program from consideration. The Chair of the Committee reviewed the returned surveys and eliminated those that did not clearly meet the characteristics. When there was sufficient evidence from the survey that the program met the minimum characteristics, the program was then further reviewed. The Committee had *no funds* to carry out site surveys of potential programs to verify whether or not the programs actually fulfilled the characteristics listed.

The limitations of this approach are clearly that the pool of programs selected to answer the survey depended upon the extensiveness of the Committee members' knowledge of programs in a particular region. There

may be programs that should have received surveys but did not because none of the Committee members or the informants that they tapped had heard of the program. Since the Committee was made up of people well known to their peers in the field and since they were involved in developing the criteria, this limitation was not a major barrier. The programs listed in the directory also depended upon the extent to which consumers in the region knew the program and were willing and able to review it against specific characteristics. Some of the consumer-survivor representatives did not know some of the programs on the list. Some felt that, in general, no professionally run programs that they knew of were “good rehabilitation programs” and, therefore, they did not feel able to review any programs with respect to the characteristics. Programs were rejected when the consumer-survivor/ex-patient representative specifically cited a program for not meeting a specific characteristic.

In summary, the programs listed in the directory are those:

- known to Committee members or their informants;
- who responded to the surveyed mailed to them;
- whose survey responses fulfilled the characteristics;
- and, in some instances, were also recommended by the consumer-survivor organizations.

Orientation to the Directory

The process of identifying Committee members, corresponding by mail and email to identify characteristics, developing the survey and obtaining responses took approximately three years. Reviewing the surveys and cross checking the programs with consumer-survivor/ex-patient organizations consumed another year. There were serious concerns about the accuracy of the information collected since many rehabilitation programs are funded and then closed over a three-year period; administrators often come and go, and mandates can easily change in three years. Consequently, another eight months were spent verifying the information collected. Programs that were included in the initial list but did not respond to repeated mailings during the verification process were not included. *The programs listed in the directory are, consequently, examples of psychosocial/psychiatric rehabilitation programs operating in December of 1998, targeted for persons with serious mental illness that appear to meet the Committee's characteristics.*

The directory itself is divided into six sections each representing a significant region of the world. Where possible, experts from each region have contributed a brief overview of the local development and current status of rehabilitation. In some regions, it was not possible to identify a specific person knowledgeable about rehabilitation in the entire region and willing to contribute an overview. Each regional overview is followed by an alphabetical list of the programs meeting the Committee's characteristics, with a profile of the program as reported in the survey.

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