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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The countries of the WHO African Region do not have national mental health policies. There is a shortage of specialized personnel, which is compounded by the brain drain. Widespread civil strife, the violence and its consequences are a common occurrence on the African continent.

The increasing poverty, natural disasters, wars, and other forms of violence and social disruption are major causes of growing psychosocial problems including alcohol and drug abuse, prostitution, street children, child abuse, and domestic violence. HIV infection has added considerably to the psychosocial problems experienced in many countries of the region, requiring extra support and counseling for those affected, and care for their surviving family, especially children.

The African Region of WHO is preparing a strategy to assist Member States in the development of national programs involving governments and other relevant partners. One of the main objectives of the strategy is to reduce the disability associated with neurological, mental, and psychosocial disorders through community based psychosocial rehabilitation.

Following are the guiding principles:

- Integration of mental health, prevention and control of substance abuse issues in the agenda of the national health sector reforms, particularly on organization, legislation and financing.

- Mental health promotion and provision of health care, targeting special vulnerable and risk groups.

- Prevention of substance abuse (tobacco, alcohol and other psychoactive substances) especially targeting young people.

- The priority interventions integrate: policy formulation and program development; capacity building, social mobilization and advocacy; information and education; research, partnership and collaboration, the balance of which will depend on availability of resources in different settings.

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As a whole, this vast and heavily populated region is marked by significant similarities in health policies, priorities, and the nature of hurdles faced by program administrators. The south East Asian region that includes the Asean Countries has a population of about 420 million people and stretches from Myanmar in the west to Irian Jaya in the east. In economic terms, the area has some of the richest and poorest countries in the world. However, the availability of health care except in cities and city-states is for the most part rudimentary.

The psychiatric services too suffer from a similar lack of trained manpower and good facilities. In the face of major problems such as infectious diseases, family welfare, women's health, and more recently AIDS, mental health is accorded low priority by planners. Even within the context of mental health, psychosocial rehabilitation takes a back seat with no clear policy guidelines, lack of trained personnel and training facilities, and very few takers at the level of program implementation.

Although there is some variation in the type of mental hospitals that exist in different countries in this region, most rely heavily on large government run institutions for the care of people with mental illness. Psychosocial rehabilitation of mental patients was largely practiced in large mental institutions until about 20 years ago. The number of psychiatric beds per 100,000 population is between 7 and 35 (WHO, 1994). The rehabilitation focussed mostly on work in the hospital's services or in the grounds that were turned to farms producing vegetables or livestock for the hospital. The advent of institutional care, introduced at the turn of the century in the more affluent countries, transferred the caregiver role of the family to the institution by removing the person with the disability from the support of his family. In exchange, especially since the 1950's, it offered the person more modern treatments. However the long term effects of institutional care and all its negative effects have spawned their own problems that need psychosocial rehabilitative measures for those in the institutional system of care today.

In the past 20 years a significant number of small community based mental wards in general hospitals have started to function in some countries and this has started to shift the emphasis to shorter stays in hospitals and more care in the community. The Mental Health Act has been set up in some countries in this decade and community based services have just begun. This has made a small dent in the type of rehabilitation of psychiatric rehabilitation practiced. Given all the hurdles that exist in this region, it is to the credit of a few that they have taken upon themselves the task of implementing rehabilitation models for the mentally disabled.
A number of rehabilitation units in the ASEAN countries are now concentrating on craftwork for sale. An even smaller number are doing industrial sub-contract work from the community. A further recent development has been the starting of day rehabilitation centres in the community. This is growing rapidly in the more affluent countries like Singapore and Malaysia but they exist also in Cambodia, Vietnam, Thailand and Philippines. Day rehabilitation centres promote community care and a greater degree of independence than was the case in the institutional setting where the work was usually limited in scope. The nearness of the day centre to the home of the patient has also involved the family in the process of rehabilitation, something that was not possible in the older institutional settings.

In India, psychosocial rehabilitation of persons with chronic mental disability has begun to assume importance in this region only during the last decade or so. At present, most of the agencies involved are in the south of the country. They are urban in location, institution based, and generally operating within the medical health framework. Almost all of them are closely linked with treatment centers, and maintenance medication still occupies a critical position. Many of these urban centers run a day care program, which provides respite for the family. The level of detail and sophistication of the programs vary. The emphasis is on work (sheltered workshops, vocational units, etc.), since the loss of jobs is very disabling in countries that do not have a social security system.

There is an increasing trend towards the use of community based techniques but these are still in isolation and need to be well integrated. There is also a need to work closely with agencies that treat other types of disabilities. The majority of the organizations that are taking responsibility for delivering psychosocial rehabilitation are non-governmental organizations (NGOs), that is they are not agencies that are run by nor directly paid for by local or national governments. While, their numbers and influence are increasing in this field, funding is almost non-existent. Many of these agencies, as a consequence, are preoccupied largely with fund-raising and resource mobilization. It is therefore extremely important to maximize the existing potential, namely that of the community, which for years has been handling and coping with mental disorders and disabilities. Rehabilitation services will therefore have to be offered at the level of the community itself.

The other critical resource, which exists naturally in this part of the world, is the family of the disabled individuals. Mental health care in Asia, has for centuries, been equivalent to care in the community by the families who seek help from traditional and religious healers. This practice continues to a large extent in the less affluent regions of this vast continent of over 3 billion people and therefore, for many more decades to come, the family will remain the cornerstone for the success of many health-related programs. The goals of rehabilitation are focused on strengthening the community and the family in order, therefore, to be more pragmatic and relevant.

Psychosocial rehabilitation programs in the East Asian regions, including China, Japan and perhaps to some extent Korea, seem to be characterized
into three types: The first is the "parachute" type, which is an isolated pro-
gram. These programs tend to develop in regions where neither medical
care nor other psychosocial systems have been set up. The second, "pilot"
type of program is characterized by support from university hospitals and
are of high quality. However, they are not integrated into a network of
other resources or supportive agencies. The third, "pioneering" type is char-
acterized by excellent programs that are integrated into other community
networks. These tend to develop in a "progressive area" under special local
conditions. Japan is a typical example of this type of development.
Psychosocial rehabilitation in Japan seems to be more oriented toward com-
unity based service because it has established a new "Mental Health and
Welfare Law" (1995). Many of the programs in Japan, however, are provided
by private mental hospitals. Because this hospital-centered system is so
tightly established, Japan's efforts to introduce change focus on the devel-
opment of the three types of programs. In contrast, psychosocial rehabilita-
tion in Taiwan has been able to move in the direction of developing a com-
prehensive community based system of service.

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Psychiatric Rehabilitation in Australia and New Zealand occurs mainly in community-based settings and in small agencies. The rehabilitation effort began in earnest in the 1980s, although people with long-term psychiatric disabilities began exiting institutions from 1960, with small amounts of funding from Federal, State and Territory Governments. The development of national organizations such as GROW, Schizophrenia Fellowship and Richmond Fellowship helped to establish the vision of hope for people with serious and long-term psychiatric disabilities, to improve their functioning and self esteem and to participate fully in the communities of their choice, including employment.

In Australia, under a Commonwealth-State Disability Agreement, which agrees on areas of responsibilities, psychiatric rehabilitation is the responsibility of State/Territories. The State of Victoria in Australia has been a leader in innovative developments in psychiatric rehabilitation and is still the only State with a consistent government approach to mental health reform with a specific budget for psychiatric disability support services. There are many inconsistencies across States and Territories but the trend is for more resources to be given to psychiatric rehabilitation service.

The consumer movement in Australia and New Zealand is extremely strong. Consumer involvement is now the norm. Criteria for government funding at local, State/Territory and Federal levels demand that consumers participate in planning and in the decision-making processes about all aspects of service provision. In Australia, consumers run the Australia Mental Health Consumers Network which has representation on the newly formed Mental Health Council of Australia, designed to bring together in partnership clinical, consumer, career and community-base organizations, Programs and services in both community-based and clinical settings are becoming more innovative and effective the area of psychiatric rehabilitation. Most programs and services are integrated into network of other generic services, resources, and supports.

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Progress in the development of rehabilitation services has been highly variable, both within and between countries, however some general trends are clear. Firstly, all countries are struggling to move away from an organization of services that depend on residential provisions sited in large, old psychiatric hospitals. This change is partly motivated by a belief now supported by considerable evidence that most people with serious and enduring mental health problems prefer to live and function better in various kinds of sheltered and supported settings in the community where they have access to the same range of activities and social supports that are available to every other citizen. This movement towards the community has proceeded at different rates in different countries and some (e.g., the Netherlands) have managed to maintain a very good standard of care in their hospitals, while at the same time vigorously developing community alternatives. Others, and here the UK is a good example, have had more difficulty in ensuring adequate access to good quality inpatient provision, as the overall number of long stay beds has been reduced.

Secondly, these changes have confirmed the warnings of scholars like Leona Bachrach. She reminded us more than twenty years ago that the traditional mental hospital was a complex organization, fulfilling a number of medical, psychological, and social needs and that if we had ambitions to manage without it, we would need to develop an equally complex range of services in the community. Some countries have made considerable progress in this respect, but all have had difficulties in ensuring that there is an adequate range of housing, occupational, social, psychological and medical support for all those who need it. With a few local exceptions, illustrated by some of the examples given here, no European country can claim to have a national coverage of comprehensive, community health services. Part of the reason for this is financial, but part is also related to the difficulties of interagency cooperation implied by such an agenda. To recreate comprehensive community services for the most severely psychiatrically disabled demands levels of cooperation between health and social services, housing agencies, work and occupational providers, primary care teams, which are unusual and sometimes impossible to achieve.

Thirdly, certain new groups of users (patients) have emerged as being particularly difficult to look after in community settings. They are often young, with treatment-resistant symptoms and a range of other problems (e.g., homelessness, alienation, violence, drug abuse, etc.). They may be reluctant to engage with traditional services and require a new style of provision (housing, work, etc.) which is more consistent with their image of themselves and more accepting of their need for services they choose, rather than those the professionals dictate. This means that rehabilitation services have had to move towards much more flexible models of service delivery,
based on specialized teams, providing a 7 day service with off hours coverage with perhaps a mix of trained and untrained staff in order to address the problem of non compliance. In the center of all these services remains the important issue of housing, work, and social support. These are invariably the most pressing priorities for patients, and professionals. Therefore, we have to struggle with the problem of how to reorient traditional services, which tend to put “treatment” and “professional interventions” at the top of the agenda. Some of the services in Italy (e.g., Trieste) provide perhaps the best examples of this kind of reorientation. However, wherever the voice of the consumer is allowed to have a real influence on the setting of priorities, one can always see the effects.

Fourthly, there are a number of technical developments, which are illustrated in these program examples. These include: developments in psychological interventions with psychotic symptoms at The Archer Center in Birmingham, England, family interventions to reduce negative expressed emotions at Roper in Germany, and new work initiatives in the form of social firms and cooperatives at Trieste and Berlin. These technical advances are welcome, particularly those that complement the advances in psychotropic medications and hold out the promise of significantly reducing subjective distress. However, recovery from serious mental illness and successful rehabilitation remain essentially psychological and social phenomena. What people choose to do and what their society allows them to do are thus still the crucial determinants of long term outcomes.

Finally, there is the question of money. Again, this issue is more important in some countries that in others. However, few places can be confident that all the money that was invested in the running of mental hospitals have found its way into financing community services. Often, it is not actually clear where the money has gone, but health budgets are expanding and it is clear that no government can afford to meet its citizen's expectations regarding health care. Hard rationing decisions therefore have to be made. In this context, the emphasis on research and evidence based good practice is extremely important. One of the major challenges for rehabilitation services in the next century will therefore be to supply information, regarding both the effectiveness and the efficiency of what they do.

Psychosocial rehabilitation therefore remains central to the mental health agenda and the problems of providing rehabilitation services, from a community base, in a humane and cost-effective manner, preoccupy all countries in Europe. Despite the obvious differences, there are also some very common themes. At the heart of these are the needs of people that rehabilitation services are meant to serve. These generally show much less variation from country to country and in my experience, there are approximately equal levels of dissatisfaction, almost irrespective of the service context. The problem is how to make sure that these voices are heard and how to genuinely involve them in decisions about policy and practice.

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The decade of the 1990s has been the decade in which psychiatric rehabilitation assumed its rightful place as one of the triumvirate of mental health initiatives, that is, prevention, treatment, and rehabilitation. In the 1990s, considerable agreement existed in the psychiatric rehabilitation field about the fundamental philosophy and values of psychiatric rehabilitation (e.g., supported housing, supported employment, consumer choice, self-determination); a variety of model service programs were demonstrated and disseminated (e.g., supported housing, supported employment, clubhouse, assertive community treatment), a significant body of research formed by the knowledge base of an empirically grounded field; preservice and inservice psychiatric rehabilitation training programs were available; and a technology to train practitioners in the skills of psychiatric rehabilitation (e.g., how to teach skills, how to set goals) had been invented. The intervention is now sufficiently described so that, if the results are promising, it can be replicated in service settings and clinical research programs. As would be expected, the psychiatric rehabilitation field in North America is becoming more empirically based with each passing decade.

As a result of these positive developments, the field of psychiatric rehabilitation has begun to influence the direction of the entire mental health field in several important ways. First of all, the psychiatric rehabilitation field’s emphasis on treating the consequences of mental illness, rather than just the illness per se, has helped bring to the mental health field a more complete understanding of the total impact of severe mental illness. As psychiatric rehabilitation increasingly becomes incorporated into the very fabric of mental health planning, public mental health organizations have begun to realize that they are responsible for delivering services that not only focus on relieving the symptoms of the illness but also emphasize improvements in functioning and role performance.

Secondly, psychiatric rehabilitation has helped the field of mental health understand that people with psychiatric disabilities, in contrast to historical myth, can recover from severe mental illness. This “paradigm shifting” fact about recovery from mental illness has helped give birth to the recovery vision. An overarching recovery vision is now an important component of the philosophy of psychiatric rehabilitation. Recovery is a vision that has emerged from the consumer literature. It is consumers who write and talk so eloquently and passionately about the promise of recovery. The recovery vision transcends the arguments about whether severe mental illness is caused by physical and/or psychosocial factors. People with severe spinal cord injuries can recover even though the spinal cord has not. Likewise, people with severe psychiatric disabilities can, recover even though some may still experience exacerbation of their symptoms, no matter what the cause is. Recovery, as we currently understand it, means growing beyond
the catastrophe of mental illness and developing new meaning and purpose in one's life. It means taking charge of one's life even if one cannot take complete charge of one's symptoms. Much of the chronicity that is thought to be a part of mental illness may be due to the way that the mental health system and society treat people with severe mental illness. Contributing to people's chronicity are factors such as stigma, lowered social status, restrictions on choice and self-determination, lack or partial lack of rehabilitation opportunities, and low staff expectations. Drastic system changes are needed if we wish to support people's recovery, rather than hinder people's recovery. Proponents of psychiatric rehabilitation are designing services to work towards the vision of recovery.

With the shift towards a recovery paradigm, the role of the consumer/expatient has increased exponentially. Professionals in every field have begun to come forward to acknowledge their psychiatric disability. Having new models for the career possibilities of persons with serious psychiatric disabilities has changed North American perspectives about what vocational rehabilitation should be about, about the role of workplace accommodations, and about the possibilities of having a real partnership among professionals with and without psychiatric disability. Consumer influence in system policy design, program delivery, research, and personnel development has emerged as a major element in the development of the field of mental health and rehabilitation.

Of course, many challenges to the psychiatric rehabilitation field remain. The mental health field’s renewed focus on cost containment and accountability (as reflected in the United States by the growth of behavioral managed care) is seen by many as both a threat and an opportunity for psychiatric rehabilitation. Past service re-designs (e.g., deinstitutionalization, the community mental health center movement) did not include psychiatric rehabilitation as a critical service ingredient. Fortunately, the popularity of psychiatric rehabilitation with consumer and family advocates, the psychiatric rehabilitation field’s relatively more well developed conceptual and knowledge base, and its unique focus on alleviating disability, make psychiatric rehabilitation a more relevant intervention in current and future system planning. There are already indications in the United States that the next round of managed care plans will include psychiatric rehabilitation as part of the required services.

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We might distinguish three stages in the development of the idea of a physical cure for the alienation that afflicts individuals. The first stage would be the Pinellian revolution with its postulate that there is always a vestige of reason in most individuals and consequently, there is always the possibility of recovery of a certain degree of reason in them. The second stage would be that of the asylum, the political moment of psychiatry, in which the idea of moral treatment is institutionally invested. In this stage, institutional and collective life, orderly and carefully supervised, will help the individual recover his or her reason. The third stage would be that of the apprehension of the basic impotence of the asylum community in the process of physical transformation and the use of this very same impotence as the main reason for the search of new models. The medicine of the soul, having experienced with the asylum community the impossibility and failure of transforming individuals through institutional power, abandons this illusion of potency, an illusion that still governs the social project.

In fact, all we see happening in the social area at present may be considered as a further development of the very same issue but with more serious connotations; both state and society came to the realization that in order to move towards progress, that is towards capital and economic riches, they will have to deal with the large number of disabled individuals who truly become and impediment to it. Having this in mind, we might say that the South American exclusion policies of the 80s and 90s would consist of a deliberate solution to this problem. The new social organizations would attempt at coping with all the issues that the welfare state was unable to deal with. In fact, it aimed at trying to propose a social solution to social problems. The welfare state always offers individualized solutions and consequently becomes unable to deal with the problems of the “have-nots”. It remains to be seen if society will opt for narrowing the gap between the “haves” and the “have-nots” or if it will abandon the latter to the final resource they can apply in order to be heard-violence.

In Brazil and in some other parts of South America, rehabilitation in the area of mental health has disengaged itself from the compulsive focus on work and taken up the construction of and restitution of human rights. It has taken up the task of teaching the “able” to live with the “disabled.” It has taken up the task of activating community resources, of encouraging social solidarity and preventing the formation of ghettos of destitute individuals. It has taken up the task of creating and enforcing legislation to promote justice and fair treatment of the mentally ill. It has directed human beings to realize that everything is deficient and that exactly because of this, there is hope that the human condition can improve.

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Appendix A: WAPR Committee Members and Text Contributors to International Practice in Psychosocial/Psychiatric Rehabilitation, 1994–1997

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Appendix B: Psychosocial Rehabilitation: World Health Organization
Consensus Statement*

Foreword

The main interest behind the production of this document was, on the one hand, to reach a degree of consensus on concepts and terminology and, on the other hand, to contribute to the improvement of living conditions of people with mental disorders, through the implementation of the principles described herein. Comments and suggestion on it, as well as information on its utilization and application, are welcome and should be addressed to the Editors. Those wishing to translate and/or adapt it into local languages are invited to do so, while keeping the Editors informed.

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BACKGROUND

Psychosocial rehabilitation (PSR), previously considered as tertiary prevention, has evolved into a concept, a body of knowledge on ways of organizing services and methods subject to empirical validation, and is concerned with the prevention and/or reduction of disability associated with mental and behavioral disorders.

Owing to the fact that it was initially practiced in the asylum-like old, large state mental hospital, most of its techniques and terminology are somehow associated with hospital-based care. Nevertheless, recent efforts and initiatives have demonstrated its power not only for people who have been associated with hospital-based care, but also—and particularly—for those in predominantly community-based care.

Its methods include modes of organizing services so as to maximize continuity of care, treatment and comprehensive interventions with the individuals' capacities being enhanced and excessive stress reduced in order to enable optimal economic and social participation and avoidance of relapse. It should be a joint enterprise in which professionals and users combine to transform the social roles of service recipients.

Because PSR aims to reduce stigma and handicap and promote equity and opportunity, its proponents engage in organizational, legislative, professional, quality of care and quality of life assurance, family organization and support, self help and participation, educational and promote efforts to strengthen services, expansion of services and research, and improvement of delivery systems. As such, PSR aims at helping individuals to fully enjoy all their rights, as expressed in international legal instruments and, when appropriate, by national laws.

As is the case with any developing field, PSR concepts and practice have not yet acquired full stability, hence the need for an authoritative consensus statement representing the views of those in a position to contribute to its formulation and advancement. This consensus statement, rather than being the final word on the subject, is intended to be a common ground that will facilitate further conceptual refinements and thus strengthen and improve services.

DEFINITION

Psychosocial rehabilitation is a process that facilitates the opportunity for individuals—who are impaired, disabled or handicapped by a mental disorder—to reach their optimal level of independent functioning in the community. It implies both improving individuals' competencies and introducing environmental changes in order to create a life of the best quality possible for people who have experienced a mental disorder, or who have an impairment of their mental capacity which produces a certain level of disability. PSR aims to provide the optimal level of functioning of individuals
and societies, and the minimization of disabilities and handicaps, stressing individuals’ choices on how to live successfully in the community.

PSR is complex and ambitious because it encompasses many different sectors and levels, from mental hospitals to homes and work settings. Hence, it encompasses society as a whole. Nonetheless, it is an essential and integral part of the total management of persons disabled by mental disorders. In consequence, the bodies involved in PSR are also varied, e.g. consumers, professionals, families, employers, managers and administrators of community agencies and the overall community itself. Given this complexity, the means to provide PSR vary, depending on the geographic, cultural, economic, political, social and organizational characteristics of the settings where PSR is provided.

OBJECTIVES

Intermediate objectives of the PSR process involve a series of steps which, while separate and valuable on their own, acquire their full meaning and force when closely coordinated. The steps include:

- reducing symptomatology through appropriate pharmacotherapy, psychological treatments and psychosocial interventions;
- reducing iatrogeny by diminishing and eliminating, whenever possible, the adverse physical and behavioral consequences of the above interventions, as well as - and in particular - of prolonged institutionalization;
- improving social competence by enhancing individuals’ social skills, psychological coping and occupational functioning;
- reducing discrimination and stigma;
- family support to those families with a member who has a mental disorder;
- social support by creating and maintaining a long term system of social support, covering at least basic needs related to housing, employment, social network and leisure;
- consumer empowerment by enhancing consumer’s and career’s autonomy, self-sufficiency and self-advocacy capabilities.

STRATEGIES

Experience has shown that PSR efficiency is highest when provided in the context of a community-based activity. The main components of PSR can be described at different levels of operation, of which the most relevant are the individual, the service, and the environment. PSR can be most effective when community-based, with the involvement of individuals, families and communities.
At Individual Level

Pharmacological treatment. Skillful use of psychotropic medication is often an essential component of PSR. Appropriate medication is useful in the reduction of symptoms and ensuing disturbances and in preventing relapses.

Independent living skills and social skills training. Independent living skills training concerns all those interventions related to basic daily living activities (e.g. feeding, bathing, dressing, grooming). Social skills training may be defined as those methods that use the specific principles of learning theory to promote the acquisition, generalization and durability of skills needed in social and interpersonal situations.

Both types of training have to take place in the context of real, everyday life experiences, not in closed, unrealistic settings. Social skills training is most useful when given as part of an overall rehabilitation package; several equally effective approaches are available.

Psychological support to patients and their families. Psychological support represents an important framework in which PSR has to be undertaken. Regardless of the specific techniques employed, intensive and continuing psychological support to patients and to their families, including education, is widely accepted as a key component of PSR programs. Self-help groups for relatives of long-term patients have also been proved to be an effective strategy.

The psychological support should also include information about consumers' and families' rights, and availability of psychosocial resources.

Housing. A serious effort to set up living alternatives to the mental hospital is an essential component of PSR. Different housing strategies can be adopted, depending on local resources and local cultural norms.

Ideally, normal housing (single, or shared if acceptable to client) with appropriate support from specialist staff should be provided. If sufficient resources are not available, group living alternatives may have to be considered.

The risks of maintaining large groups of disabled people together in institutional settings should not be overlooked. While alternatives are most desirable, the environment of many mental hospitals can and must be improved.

Vocational rehabilitation and employment. The importance of work and employment for people disabled by mental disorders cannot be overemphasized. Working and having a job increases the consumer's satisfaction and self-esteem and breaks the cycle of poverty and dependence. In addition, work gives an opportunity to socialize and communicate. Therefore, it is essential to set up vocational training activities that are related to real and concrete work experiences. Some individuals may also greatly benefit from.
specific pre-vocational training as well as from transitional employment programs.

Vocational training should start in hospital settings and later move outside to protected workshops in contact with the labor market. An effective solution to the sometimes variable health of people disabled by mental disorders could be the creation of self-sufficient enterprises which, whilst ensuring permanent jobs for those people are organized in a very flexible way as cooperatives—or social enterprises. Having an independent income is a powerful tool in enhancing consumer empowerment.

**Social support networks.** Social support networks are an enduring set of human relationships experienced by individuals in a positive light, that are likely to have a lasting impact on their life through the exchange of emotional, physical, economical and intellectual influence. They work mostly by strengthening the individual's coping ability.

Social support has a positive effect on mental health which may be direct (mental health is improved, irrespective of any stressors to which the individual may be exposed) or indirect (a “buffer” effect, which manifests itself only when the individual is exposed to stressors). They can also provide an integrated and comprehensive framework for all PSR services available.

**Leisure.** The ability to participate in and enjoy leisure activities of one's choice is also an important element of PSR. Access to appropriate leisure activities and freedom of choice is indispensable conditions for healthy leisure pursuits.

**At the Mental Health Services' and Human Resources' Level**

**Mental health service policy and fund allocation.** PSR must be considered as an essential component in every mental health service policy. When mental health policies are being formulated, it is important to avoid a split between services oriented to specific medical treatment—such as psychopharmacology—and services oriented to PSR. The integration of these components is essential and adequate funds have to be assured for PSR programs.

The community-based mental health service has to become a “case manager centre” able not only to provide treatment, but also to facilitate access to community resources, for the clients and their relatives. The integration of resources belonging to the health system with those of the community increases the mixing of knowledge and opportunities.

**Improvement of institutional and residential settings.** The improvement of human resources and material conditions of institutions where PSR clients are often living is an essential pre-condition for any PSR program. They must progress wherever the client is living; thus the psychiatric hospital has to be considered as a part of the overall PSR environment; there is an urgent need for guidelines on the minimum and/or optimum standards of care for those patients and clients.
Training for staff. Current training curricula for health workers are insufficiently oriented towards PSR. Therefore, specific PSR components should be introduced into the curricula of all relevant health qualification courses. Equally important is the inclusion of PSR-related content in continuing education programs for all relevant health workers irrespective of profession, experience and previous training.

Quality assurance. The question of quality of care is crucial. Health workers have striven to provide good quality care, from their own perspective. However, consumers insist on having not only good quality care, but also on having access to a range of different modalities of care. Thus what exactly constitutes “good quality” is still open to debate and a negotiated agreement needs to be arrived at in each case. However, there are several initiatives bringing together all those concerned in order to find a common definition of good quality mental health care.

A key issue related to the assessment of quality is the availability of written standards and indicators covering the whole range of services and facilities essential for psychosocial rehabilitation. These indicators and standards should be formulated so as to allow modification and adaptation into local guidelines and norms of care according to local needs and circumstances. Indicators are fundamental for both monitoring and evaluating PSR.

At Societal Level

Improvement of pertinent legislation. In most places, improvements in existing, or the formulation of new, legal provisions governing the organization of and access to the mental health care system are necessary in order to create the formal framework in which PSR programs can attain their maximum efficiency. Disabled persons should be entitled to the same rights and benefits, irrespective of the underlying cause (e.g. physical or mental) of their disability. The revised legislation should cover involuntary treatment and hospitalization, patients’ rights, and access to labor markets, housing, education and other social welfare benefits.

Consumer empowerment. Consumer empowerment constitutes both a component and a goal of PSR. Consumers should actively participate in planning, delivering and evaluating PSR programs. This empowerment is not simply a realization of the formal rights of patients but also promotes greater access to community resources for clients and their families.

Improvement of public opinion and attitudes related to mental disorders. The stigma attached to mental disorders touches not only people with mental disorders, but also their careers, both family members and health workers. Stigma and discrimination are based on negative attitudes and beliefs (usually erroneous ones) about mental disorders; such attitudes and beliefs are sometimes found even among mental health workers. While the modification of attitudes related to mental disorders may take a long time, interventions through legislation can produce much faster results.
RESEARCH

Given the many aspects involved in PSR it is felt that a great deal of research is necessary, covering all of the subjects and items mentioned previously. Universities, research institutes and professionals are therefore invited to examine the possibility of developing research activities in those areas, whereas governments and funding agencies are strongly urged to consider the establishment and strengthening of funds specifically allocated to activities related to PSR.

ACKNOWLEDGEMENTS

The production of this document would not have been made possible without the decisive support from the World Association for Psychosocial Rehabilitation (WAPR), and more particularly from its President, Dr Benedetto Saraceno, to whom we are deeply grateful.

Starting from a working draft prepared by Dr B. Saraceno and Dr J. M. Bertolote, comments and views of a broad range of experts were obtained and incorporated into successive versions until the final form was reached. We would like to express our gratitude to the following experts, who graciously dedicated their precious time, knowledge and expertise to the production of this statement.

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Appendix C: Program Survey

Descriptions of Programs Nominated by the International Committee

General Remarks: Thank you for agreeing to submit this application. The Committee appreciates the time that you are investing in letting us know about your program.

Please send your reply to:
Marianne Farkas, Boston University, Center for Psychiatric Rehabilitation, 930 Commonwealth Avenue, Boston, MA 02215 U.S.A.
Fax: (617) 353-7700; Phone: (617) 353-3549

I. We are asking you to fill out the following rather lengthy application form because you have been nominated as an organization which provides an example of good practice in psychosocial rehabilitation services. If you are included, your agency will be listed in a reference manual available for distribution internationally. Please feel free to send us any information other than what we have thought to ask about, if you think it pertinent.

If you have brochures or leaflets which describe your program please send it to the committee (if possible translate the relevant passages into English or French).

II. Language

There are many variations on common terms used around the world to discuss psychosocial rehabilitation. While not all the words are interchangeable, please use the one that has most meaning for you. The following is a list of the most common words that you will see in this application.

The person with the serious mental illness
consumer/survivor
client
patient
ex-patient

The difficulty being addresses
serious mental illness
serious psychiatric disability
psychiatric disability

The organization of activities that offer assistance
agency
organization
service
program
institution

The parents or relatives of a person with serious mental illness
family member
carer
III.

Name of agency/program ________________________________

Address ____________________________________________

Year agency/program began ______________________________

Phone ______________________________________________

Fax ________________________________________________

E-Mail ______________________________________________

Contact person ______________________________________

1. What is the mission or mandate of your program?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

2. What would you consider to be good outcomes for your program?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

3. "Serious mental illness" is defined as a diagnosis of psychosis, of at least 2 years duration in which there is difficulty in being a worker or a student or a homemaker/resident. Please describe your clients:

a) We serve _____ (number) clients per year.

b) Do you serve clients who do NOT have serious mental illnesses?

☐ Yes    ☐ No

If you do serve those who do NOT have serious mental illness, what percentage (%) of your total client population do they represent?

____% of our total client population.
c) The majority of our clients have the following primary diagnosis of major mental illness (please check only one):

- Schizophrenia
- Manic depressive illness
- Personality disorder
- Other (please identify the diagnosis)

---

d) The most frequent secondary diagnosis among our clients is (please check only one):

- Substance abuse
- Mental retardation/developmental disability
- Neurological impairment
- Other (please identify the diagnosis)

Physical disabilities

---

e) We do not accept clients who (please list any exclusionary criteria that you might have):

f) The average age of our clients is _____ (years old).

g) The range of our client population is between _____ (years) and _____ (years).

4. Please describe how your program or organization is staffed.

a) We have the following total number of staff ________.

b) Among our staff, we have the following number of (please complete as many as apply to your program):

_____ full-time staff
_____ part-time staff
_____ volunteers
_____ staff who are also consumers/persons with serious mental illness or psychiatric disabilities
c) We have the following number of staff in each of the disciplines listed (please complete as many as apply to your program):

___ Psychiatrists
___ Nursing Aides
___ Psychologists
___ Occupational Therapists
___ Social Workers
___ Rehabilitation Specialists
___ Registered Nurses
___ Non-professionals/paraprofessionals
___ Other (please identify)

5. Please describe your program/service.

a) We provide people help with (check as many as apply):

___ Housing
___ Personal Relationships
___ Work
___ Leisure/Recreational Life
___ Education

b) For the domains in which YOU do NOT provide assistance, do you link with other resources or agencies who do provide this assistance? (please check either Yes, No or N/A, which means that there are no resources or agencies in that domain in your area).

<table>
<thead>
<tr>
<th>Housing</th>
<th>☐ Yes</th>
<th>☐ No</th>
<th>☐ NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Relationships</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ NA</td>
</tr>
<tr>
<td>Education</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ NA</td>
</tr>
<tr>
<td>Leisure/Recreational Life</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td>☐ NA</td>
</tr>
<tr>
<td>Work</td>
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<td>☐ No</td>
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5. Please describe your program/service.

a) We provide people help with (check as many as apply):

___ Housing
___ Personal Relationships
___ Work
___ Leisure/Recreational Life
___ Education

b) For the domains in which YOU do NOT provide assistance, do you link with other resources or agencies who do provide this assistance? (please check either Yes, No or N/A, which means that there are no resources or agencies in that domain in your area).

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<tr>
<td>Work</td>
<td>☐ Yes</td>
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</table>

c) We provide our assistance by focusing on (check as many as apply):

___ The skills that people require to succeed in these areas.
___ The support/resources that people require to succeed in these areas.
___ The medications/clinical treatment that people require to succeed in these areas.
___ Other (please specify):
d) Are there other programs in your geographical area which provide the same or similar services?

☐ Yes  ☐ No

*If you checked "Yes," what sort of collaboration, if any, do you have with these other programs?*

---

e) Please check however many of the following statements are true for your program/service:

☐ We help our clients to increase their functioning over time.

☐ Whether or not they end up returning to hospital, we believe that clients with serious mental illness have the potential to grow and change.

☐ Our program considers a return to hospital to be a failure.

☐ We help our clients to integrate into the daily life of their community, rather than building protected or separate worlds for them.

☐ We use the community norms for non-disabled people and the clients' personal interests and strengths to decide what types of goals might be reasonable to aim for.

☐ We have easy access to clinical treatment services for our clients.

☐ We use the natural support system (rather than only professionals) as often as possible.

☐ We provide support for as long as the person wants and needs it.

☐ Our program is time limited. At the end of ____ (months, years) we either terminate services or refer the person elsewhere.

☐ Our program is not time limited.

☐ We have helped to develop other programs like ours in our region/country.
6. Please describe the programming that you have available for family members.

a) Does the agency offer any programs for family members?

☐ Yes  ☐ No

*If "No," please go to Section 7. If "Yes," please continue:*

b) Which of the following activities do you provide for family members? (please check as many as apply):

☐ Information about mental illness and medications in general.

☐ Information about the client’s treatment plans, progress or any other aspect of the client’s involvement in the service or program.

*(If you checked this activity, please check the procedure that applies:)*

☐ We provide such information upon request.

☐ We provide such information only if the client gives specific permission to do so.

☐ Surveying family members/involving family members in designing the program/service (such as location of service, hours of operation, types of activities needed, etc.).

☐ Psychoeducational classes for family members to learn how to cope with their disabled family member.

☐ Other (please specify)

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

c) Are there any associations for family members to help each other in your geographical region?

☐ Yes  ☐ No

*If "No," please go to Section 7. If "Yes," please continue:*

d) Does your agency work in co-operation with these associations?

☐ Yes  ☐ No

*If "No," please go to Section 7. If "Yes," please continue:*
e) What are some typical activities that your agency/program carries out with these associations?


7. Please describe the extent to which clients are involved in your program/service.

a) Do you provide clients with information about (please check as many as apply):

   ___ Mental illness
   ___ Their own progress
   ___ Medications
   ___ Any aspect of the program that the client requests
   ___ Their own treatment plans

b) Do you survey/involve clients in designing the program or service (e.g., Location of program, hours of operation, types of activities needed, etc.)

   □ Yes   □ No

If you checked "Yes," please describe this involvement:


c) Do you offer clients classes on how to improve or learn the skills that they need to succeed at home or at work or at school?

   □ Yes   □ No

(Please note: This activity is one in which skills are actually taught, rather than simply discussed or simply demonstrated. There are a variety of techniques used to teach skills. We are not asking about the specific technique, but rather about the general activity).

If you checked "Yes," please list some examples of skills you teach:


d) Are there any consumer associations in your geographical area? (e.g., Self-help groups; advocacy groups; consumer support groups not run by professionals).

☐ Yes  ☐ No

*If “No,” please go to Section 8. If “Yes,” please continue:*

e) Does your agency work in co-operation with these associations?

☐ Yes  ☐ No

*If “No,” please go to Section 8. If “Yes,” please continue:*

f) What are some typical activities that your agency/program carries out with these associations?

8. Is there anything else you feel that we should know about your program in order to understand whether or not it should be included in a reference manual on examples of good rehabilitation practice for persons with serious mental illness? (For example, is there an aspect of your program about which you feel particularly proud and which has not yet been mentioned?)
Appendix D: Summary of Minimum Characteristics of Good Rehabilitation Programs

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

2. The program is focused on improvement. Improvement is defined as helping persons 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.

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

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