Reaching the Unreached Persons with Mental Illness Through Community based Rehabilitation
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Through Community Based Rehabilitation

By

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Introduction

The global challenge posed by mental illness is very clear. Mental illness now accounts for about 12.3%\(^1\) of the global burden of disease. The figure will rise to 15%\(^2\) by the year 2020 when depression will disable more people than AIDS, heart disease, traffic accidents and wars combined.\(^3\)

The impact of mental illness on the lives of a huge number of individuals, related families and communities is enormous. However, the response to the problem is woefully inadequate. Mental illness weighs down particularly on the poor. The major reasons being low or no access to treatment facilities, affordability of the treatment, costs offered at the major institutions, levels of education and awareness regarding the diseases and recovery, so on and so forth.

It is widely acclaimed that community care is more effective as well as more humane than inpatient stays in mental hospitals.\(^4\) Though, there is a growing recognition for the need of community care especially in resource poor countries like India, very little is happening in reality. Despite the laudable intent, most programs fall short of the basic objectives, terminate prematurely or exist only on paper. Without a change in the current emphasis and direction, community care for mental illness in developing countries, especially in India would remain just a wish list of good things to be done. Dr. Jacob feels that “there is a need for innovative approaches that utilize the available resources in order to ensure that health care reaches the population”\(^5\)

The author fully agrees and explores further such possibilities. Based on the experiences of working in the field of health and disability, & more specifically, Community Based rehabilitation, she

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3 B. Wilkerson, President of Global Business & Economic Round Table on Addiction & Mental Health
4 Sunder Lal, B.M. Vashisht, Editorial- Moving away from mental institutions towards community mental health care, Indian Journal of community medicine, Vol. XXIX, No.1, Jan-Mar.2004
5 Dr. K.S. Jacob, Community Care for People with mental disorders in developing countries-problems & possible solutions, The British Journal of Psychiatry (2001) 178, 296-298
suggests a strong collaboration with existing CBR programs as one of the practical & feasible ways to reach the un reached people with mental illness and help them live with dignity.

**Experiences till date**

With the professional background of Medical & Psychiatric Social Work as well as Community Based Rehabilitation, the author has been working in the field of health & disability for last twenty years. The initial work focused on hospital based counseling of children (C.G.C.) as well as other inpatients, which later on shifted to initiation & implementation of outreach programs on various psychosocial issues. In the most recent years, the author has been working as a freelance consultant for social development issues with a major focus of work being the evaluation of Community Based Rehabilitation projects. Currently, in addition to her other work in social development field, the author is working as a consultant with CAPART,6 (GOI) and CBRF7(International Agency)

In almost all the projects evaluated by the author, (majority of them being rural programs), there was a striking absence of persons with mental illness in the target group. Mentally ill people are recognized as persons with disabilities as per the PDA, 19958 and yet they are NOT included in majority of the CBR programs meant for persons with disabilities! Yes, it is debated that the PDA act needs many more modifications in general and more so with regard to people with mental illness starting right from the definition! However, even within the given framework, a lot of things can happen if properly planned & implemented!

More people share their experiences in this regard. Anant Kumar, Rehabilitation Psychologist observes, “mental illness is a significant cause of disabilities in India, which has been largely ignored in health related development activities.”9

Another experience from Bangalore10 has observed that mental illness though included in PDA, 1995, is not included in CBR programs.

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6 Disability Division, Council for Peoples’ Action & Rural Technology, Govt. Of India.
7 Community Based Rehabilitation Forum, Bangalore
8 Persons with Disabilities (Equal Opportunities, protection of rights and full participation) Act, 1995, Govt. of India
9 Anant Kumar, Mental Health in a Public Health Perspective
Why is this non-inclusion of people with mental illness in CBR programs? What are the gaps? How can these be narrowed down so as to utilize the existing resources to ensure that health care is accessible to all those in need?

The paper will further explore possible directions for new collaborations based on various field experiences.

**Community based Rehabilitation**

Community based Rehabilitation or CBR as an approach to rehabilitation of persons with disabilities has been around now for last two decades. The concept of CBR dates back to many ancient cultures worldwide. History suggests that CBR existed in almost all ancient cultures in some way or the other. The concept of CBR, as we know today, came into late seventies when WHO report mentioned that despite the latest trends in treatment & rehabilitation techniques, majority persons with disabilities, especially from developing countries were not receiving the basic minimum rehabilitation services. This initiated the formalized beginning of Community Based Rehabilitation. CBR is defined as “a strategy within community development for rehabilitation, equalization of opportunities and social integration. CBR should be implemented through the involvement of disabled persons, their families and communities with support from appropriate health, education, vocational and social services.”

The initial WHO model was based on service delivery through PHC (Primary Health Centers) and WHO manual provided guidelines for implementation. Today, however, with NGOs (Non Govt. Organizations) & DPOs (Disabled Peoples’ Organizations) coming into the picture, there are many more models and thoughts.

Beginning as a cost effective way of reaching the rehabilitation services to the un reached persons with disabilities, especially in resource poor countries in Africa, Asia and to some extent Latin America; CBR has evolved gradually in concepts and process. From an alternative to service delivery to rural, marginalized, needy people, CBR today advocates human rights of persons with disabilities. It emphasizes that disability is no more a welfare issue but essentially a development issue. It has clearly shifted away from medical model of rehabilitation wherein the problem lies with the person with disability and emphasis is on making him normal; to a social model wherein the onus of change is on the society. There is also a gradual shift from the project mode to policy mode in a number of countries. CBR is also seen as a possible dimension to be included in poverty reduction strategies. Since poverty and disability are interconnected, CBR programs could be

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11 Joint position paper by WHO, ILO & UNESCO on Community Based Rehabilitation, 1994
scaled up and mainstreamed.\textsuperscript{12} Reduction of poverty requires awareness & education at all levels from primary schools to university and from job related training to employment. Therefore, it is important that all persons with disabilities become part of poverty reduction strategies and thus become contributing members of the society.

The indicators identified for the Millennium Development Goals\textsuperscript{13} include information about persons with disabilities. Hence, CBR programs should collaborate to monitor the activities for reaching these goals and while doing so; all persons with disabilities should be included in CBR programs.

The process of CBR differs from community to community, basically because the communities are different. Despite the unique & distinctive nature, there are some commonalities; major ones could be summed as follows-

- \textit{Awareness building}- CBR programs work towards awareness creation regarding the existence and problems of persons with disabilities
- \textit{Service Delivery }–CBR programs work as to reach the required diagnosis, treatment and rehabilitation services to persons with disabilities near their homes in their community.
- \textit{Training & Education- }CBR programs aim to educate the persons with disabilities, their families and communities around, on various disabilities related issues such as early detection & intervention modalities, education & vocational training & employment possibilities etc.
- \textit{Creation of Self Help Groups- }Almost all CBR programs try to create Self Help Groups of persons with disabilities and / or their family members as necessary. These groups can raise issues related to the rights of disabled; the problems faced by them and can seek answers as a group, leading to empowerment.
- \textit{Inclusion- }Almost all CBR programs aim for ultimate inclusion of Person with Disabilities in mainstream society. The aim is generally to assist the PwDs become productive members by helping them initiate & take benefit of equal opportunities, protecting their rights and helping them participate in mainstream society to their fullest potential.

\textsuperscript{12} International Consultation to Review Community Based Rehabilitation, Helsinki, 25-28 May 2003
During the recent International Consultation on Review of CBR\textsuperscript{14}, it was reaffirmed that CBR is a useful strategy to promote human rights, to provide services and to ensure equal opportunities for all people with disabilities. Highlights of the recommendations included the access to CBR programs for all people with disabilities. It further observed, “Within DPOs (Disabled Peoples’ Organizations) themselves there can be less attention paid to certain groups e.g. people with multiple disabilities, psychiatric conditions or intellectual impairments.”\textsuperscript{15} It is therefore, very crucial call for all concerned in the field of mental Health as well as Physical Disabilities to pay specific attention to include these groups into existing and future CBR programs. This should be prompting for people working in the field of Mental Health and Community Psychiatry to take appropriate actions urgently than awaiting move from others.

In brief, CBR strives to reach the un reached in a more equitable and sustainable manner than institutions, which are highly expensive, inappropriate in many cases and reaching very few lucky ones. The ultimate aim of CBR is the empowerment of the disabled individual and creation of family and community support, which is very similar to the aim of psychosocial rehabilitation of people with mental illness.

**Psychosocial Rehabilitation Services & Community Care for people with Mental Illness**

“Psychosocial Rehabilitation is a process that offers the opportunity for individual who are impaired, disabled or handicapped by a mental disorder to reach their optimal level of independent functioning in the community. It involves both improving individual competencies and introducing environmental changes.”\textsuperscript{16} Psychosocial Rehabilitation is a comprehensive process and not just a technique.

The strategies of psychosocial rehabilitation vary according to the needs of the person in need, his setting, the socio cultural aspects and conditions etc. Vocational rehabilitation. Employment and social support network are all aspects of psychosocial rehabilitation. The main objectives are consumers’ empowerment, reduction of discrimination & stigma, improvement of social competence and creation of long-term system of social support.

Community care means that the large majority of patients requiring mental health care should have the care available at community level. It should not only address the diagnosis, early intervention,
rational use of treatment techniques, continuity of care and such other services but should also enhance consumer involvement, partnership with families & local communities and integration into primary care. The specific ways of this integration would differ from country to country depending upon the status and functions of primary health care. In India, while advocating the integration of mental health services into general health care, it is of utmost importance that the PRI (Panchayati Raj Institutions) are sensitized & made aware of existence and extent of mental health problems, thereby encouraging them to demand such services.

*Community care is about the empowerment of people with mental & behavioral disorders* [17]. It is a global approach having inter-sectoral links. It is again a very important aspect in Indian scenario as the people with mental illness in India are torn between the Ministry of Health and Ministry of Social Justice and empowerment.

**CBR & Community Care for People with Mental Illness**

There have been sporadic experiments of specific CBR programs for people with mental Illness as well as integration of psychosocial rehabilitation services in CBR programs.

Chatterjee et al [18] conducted a study in a district of Madhya Pradesh in partnership with Asha Gram, an NGO working towards the rehabilitation of people affected by Leprosy. An attempt was made to adapt CBR model for use by people with chronic schizophrenia and the content was shaped by consultations with patients, families and the community. The objective of the study was to compare the effectiveness of CBR with that of outpatient care in the treatment of chronic schizophrenia. Altogether, 207 patients who entered the study, 127 in CBR group and 80 in OPC (Out Patient Care) group. Among the 117 fully compliant participants, the CBR model was found to be more effective in reducing disability. Within the CBR group, compliant participants had significantly better outcomes compared to partially compliant or non-compliant participants. Although the subjects in the CBR group were more socially disadvantaged, they had significantly better retention in treatment. The conclusion is that the CBR model, which has been generally widely used for people with physical disabilities in resource poor setting, is feasible for the care of chronic schizophrenia.

Bangalore experience [19] provides experiences of integration of psychosocial rehabilitation in an existing CBR program in a rural area of Kerala.

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Mr. Naidu\textsuperscript{20} from Basic Needs India observes that mental illness is indeed a developmental issue and needs to address issues of sustainable livelihoods, social integration and field research. He also remarks that community participation is the key issue. The same workshop also spells out the need for mental health network, which is also one of the recommendations of this paper.

The Raipur Rani\textsuperscript{21} training program\textsuperscript{1975}, initiated as part of WHO collaborative study, mentions the change in knowledge & attitudes of health workers about mental health disorders and beginning of psychiatric services where none existed before, due to extensive training undertaken in the program at community level.

Madurai experience\textsuperscript{22} concludes that CBR put into practice not only brings dignity in the lives of the mentally disabled and a sense of satisfaction of having contributed in the rehabilitation process, to the family and community involved but also brings forth a sensitization and awareness amidst the community regarding mental health dispelling the various myths & stigma attached to it.

**Discussion**

Based on the above observations, facts and experiences, the following points emerge.

- **Community Care for People with Mental Illness:**

  Community care is a better way of reaching persons with mental illness, especially in resource poor countries like India and definitely in rural India. The chapter on Mental Health Policy in the World Health Report 2001 mentions in clear terms that the ultimate goal is community based treatment & care. Since mental illness is prone to relapse, it becomes all the more important that appropriate community support is created so that community can help in early identification & control of symptoms, prevent or reduce relapse and optimize psycho-social performance of the individual helping him to get reintegrated in the society. Rural population by its very nature has greater community acceptance, have cohesive families that can offer support to mentally ill

\textsuperscript{19} Mathew Samuel, MurliK.P.Sivram Nair & Keshavan Nair, Integration of psychosocial rehabilitation into existing CBR programs: the Wyanand experience, Indian Journal of Psychiatry, poster presentation, Vol.42, April 2000
\textsuperscript{20} Mr. Naidu, Basic Needs India, in a workshop for Mental Health Stakeholders- Initiatives on Mental Health Policy in India, The British Council, New Delhi, 22 Jan, 2004
\textsuperscript{21} Mental Health in Developing Countries, WHO, 2001
\textsuperscript{22} Community Based Rehabilitation, www.msctrust.org/cbr.asp
patients. It is important, however, that family needs are understood & helped to cope with and appropriate skills are imparted and appropriate network is established at local levels.

- Community Based Rehabilitation as a feasible approach for care of Mentally Ill People with:

Though there are miles to go before one achieves the desired goals, CBR is emerging as a feasible and effective approach and is currently practiced with moderate success in the field of disability rehabilitation. CBR is not just alternative to reach the rehabilitation services to the un reached but also has a major rights based perspective, which would help the empowerment process of persons with disabilities. CBR has emerged as a feasible approach with its increasing emphasis on human rights of persons with disabilities and development perspective and can offer great scope in reaching the un reached people in need of services and other inputs and help their inclusion into mainstream society. This is particularly very relevant, keeping in mind the aim of empowerment of people with mental & behavioral disorders, spelt out in world Health Report, 2001.

- Non-Inclusion of People with Mental Illness in CBR programs:

However, in reality, majority of the existing CBR programs do not include persons with mental illness. Non-inclusion of persons with mental illness is due to various reasons, the major ones\(^\text{23}\) are as follows----

- I) There is an unseen but definite gap existing between the field of physical disabilities and mental illness. Some how, the people & professionals have been partitioned.
- II) As a result, there are very few opportunities for exchange between the two fields.
- III) As a repercussion, almost all CBR training centers provide negligible inputs to the trainees / professionals on mental illness as compared to other physical & sensory disabilities in terms of theory, practical exposure, written training material, case studies so on and so forth.
- The experience suggests that such negligible inputs regarding mental illness in turn make the trainees diffident to include people with mental illness in the CBR programs as they find it difficult to diagnose people with mental illness, provide appropriate interventions, referrals etc. Thus people with mental illness are left out of almost all CBR programs.
- There is also not much interest/ insistence by majority of the funding agencies on the inclusion / non inclusion of people with mental illness in the CBR programs, as most of

\(^{23}\) Based on the CAPART funded CBR projects evaluated by the author

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these agencies are familiar with and/or working in the field of physical/sensory disabilities.

- The experts in CBR field have begun taking notice of the non-inclusion of people with mental illness in CBR programs but unless there is strong move from mental health professionals, self-help and/or parents’ groups, the desired change would take much longer to come in.

- Human Resources Development & Sharing the Resources:
The main objectives of CBR & Community Care for persons with mental illness are similar and therefore, it is important that existing resources/programs are shared/utilized to its maximum potential for reaching the people in need. Dr. Chandra, WHO regional advisor, Health & Behavior has mentioned human resource development as one of the major steps to be taken by the countries. He insists, “general practitioners, nurses and other health professionals must be trained in identifying & managing patients.” On the same lines CBR professionals must be trained adequately regarding mental illness so that they can handle such patients confidently. e.g. Majority of the CBR professionals is not aware of IDEAS scale and/or how to include people with mental illness for disability benefits under various schemes etc. Adequate training material, appropriate networking & support become important backbones for human resource development for which existing resources can be modified for proper utilization.

- Bridging the Gap between the Ministries:
It is crucially important to bridge the gap between the Health Ministry and Ministry of Social Justice & Empowerment, if CBR programs are to include mental illness adequately & appropriately. The Ministry of Social Justice believes that mentally ill people are not their responsibility while the disability act, which the Ministry is duty bound to implement, includes mental illness with several other disabilities in its definition of disability. The disability act seeks rehabilitation schemes for the disabled, but the mentally ill do not figure in the ministry’s plans. For the Health Ministry on the other hand, mental illness is a state issue and Community Based Rehabilitation does not come under the purview of activities of the Health Ministry. As a result, the persons with mental illness are likely to be left out & continue to be neglected. One very good example of plight of persons with mental illness being left out in cold is the scheme of NPRPD.

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24 More UNIAJ MS HS 1920, 4 October 2001-Health-WHO-Mental Disorders
The NPRPD\textsuperscript{27} scheme is meant to provide training in comprehensive rehabilitation services to the persons with disabilities in rural area through respective state govt. at various levels. The syllabus approved for this program by RCI (Rehabilitation Council of India, GOI) does not include material on mental illness. There are a few concerned professionals/ people taking proactive steps but it seems to me that the efforts need to be manifold and the advocacy lobby needs to be more effective.

**Future Directions**

It is important therefore, for people working in the field of mental health & community Psychiatry to pay careful attention to the following---

- **Take initiative to break the unseen yet always existing barriers between people working in the field of mental illness & physical disabilities:**
  
  As seen by the experiences till date, there are barriers between the two fields of disabilities and mental illness. As a result the flow of exchange of thoughts, ideas, programs leave much to be desired so as to benefit from mutual field experiences. Initiatives should be taken to break these unseen barriers.

- **Create a common platform for experience / resource sharing on relevant issues related to people with all disabilities:**
  
  Once the barriers are broken down and a free flow of exchange begins, a common platform needs to be created where professionals as well as beneficiaries from both the sides can meet regularly. A regular information exchange on relevant issues such as awareness building, training and educational requirements etc. can be discussed so that the already existing structures/ programs are utilized to optimum potential.

- **Network with experts and agencies working in the field of physical & sensory disabilities, especially in the field of Community Based Rehabilitation:**
  
  Networking with experts & agencies in the field of CBR would provide a lot of opportunities to experiment and come up with replicable models of CBR to include persons with mental illness in the already existing as well as upcoming CBR programs, thus providing a more integrated approach as advocated in the Global mental Health Plan\textsuperscript{28} by WHO.

\textsuperscript{27} The National Program for Persons with Disabilities, Ministry of Social Justice & Empowerment, GOI

\textsuperscript{28} (MhGAP) WHO- Global Mental Health Plan, 2001
• **Advocate & provide better training for mental illness though existing CBR training centers:**

There are designated training centers for CBR training at various levels approved by various funding agencies. The information provided by these training centers on mental illness is very basic and field exposure to mental illness is almost negligible in current training programs on CBR. This is mainly due to lack of appropriate training material available at these centers, which are mostly organizations working in the field of various physical & sensory disabilities and therefore have a spontaneous and natural emphasis on those disabilities. It is important that efforts should be made to provide simple & easy to understand training material on early detection & intervention strategies, useful information on treatment & referrals etc. so that CBR programs find it easier to include & deal with the people with mental illness adequately. For this, professionals in the field of mental health need to not only to develop & circulate the up to date training material to appropriate training places but also to monitor how far these materials are utilized and how relevant these are to the practitioners in CBR field. Currently used training material for District Mental Health Program may be modified as & if required for this purpose.

• **Provide referral centers/support centers through a network of appropriate mental health professionals all over the country:**

For this, there may be a need to develop an association of mental health professionals interested in CBR or Community Care for people with mental illness. A list of such referral centers and / or networks could be made available to all CBR centers to passed on to the trainees so that appropriate referrals are made and person in need receive appropriate advice, treatment and rehabilitation services.

• **Ensure sensitization of PRIs regarding People with Mental Illness:**

As all of us know, that currently after the 73rd & 74th amendments, the PRIs or the Panchayati Raj Institutions play an important role in Indian democracy especially to reach the demands of people in remote areas. It is imperative, therefore, that these PRIs are sensitized on the issue of mental illness if we wish to see the services reaching to the needy in remote areas. In the wake of DMHP (District Mental Health Program) extending to more and more districts in coming years, it would be of great help that the demand for services for people with mental illness is raised from the PRIs. Therefore, it is crucially important to sensitize the people in PRI appropriately so that they are aware of the problems and the solutions and can help reach the appropriate services to the needy.
Ensure collaboration between Ministry of Health & Ministry of Social Justice & Empowerment:

Advocate to Ministry of Social Justice & Empowerment for the inclusion of persons with mental illness as their responsibility because the PDA, 1995 includes mental illness & the Ministry is duty bound to implement the act. It is important that training material on mental illness is included in the syllabus of NPRPD (National Program for Rehabilitation of Persons with Disabilities) before it is too late. Inter ministry meetings may be required on the issue otherwise both the ministries would keep passing the buck and persons with mental illness in remote rural area, in the bargain would loose out on another opportunity.

In a nutshell

The International Consultation to review CBR29 has recommended promoting access to CBR programs for all disabilities. With WHO’s slogan of ‘Close the gap, Dare to Care’ and the clear shift from “implementing stand alone mental health projects to more integrated approach for mental health at all levels,”30 CBR seems to be the most appropriate means to reach the un reached people with mental illness.

“It is important for all professionals to realize and accept that the rights of disabled people are not to be partitioned. The movement can go forward only together.”31 For those working with mentally ill people it is important to continue to be proactive and take appropriate steps to create more & more support; while for those working with other disabilities, it is important to include mentally ill as part of the disabled group. The stigmas, discrimination, lack of support are common to all and it is important to fight theses evils united.

If the abovementioned collaborations & efforts were undertaken urgently, then at least one way of reaching the unreached people with mental illness would open up efficiently. Persons with mental illness would be able to receive not only rehabilitation services in their communities, but also would be included in the mainstream society having equal opportunities, protection of rights and full participation. Together, let us take up the challenge and work towards this mission!

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30 (MhGAP) WHO- Global Mental Health Plan, 2001