

Issues and Challenges for Rehabilitation of Mentally ill persons in India

Harshit Sinha*

drharshitsinha@yahoo.com; vardaansinha@gmail.com; drharshitsinha@rediffmail.com

Abstract

The rehabilitation services in mental health are a mammoth task which involves wide spectrum of services and thus is a labour intensive and costly affairs. Though it is an eye-catching term, laudable slogan and widely pronounced jargon, but rarely does it find its real meaning in practice. Earlier the rehabilitation services were confined to hospital occupational unit and during those days sending a patient home from a mental hospital was itself rehabilitation. However, with the emergence of scientific methods (Psychiatric and Psychosocial rehabilitation process) and advancement in pharmacotherapy, today rehabilitation services in mental health sector has become utmost necessary element along with treatment. Though the rehabilitation services - both in the community and at institutions, are largely practiced in India but still it is at infancy stage. Lack of clarity for the clear definition of the “Rehabilitation” in mental health gave birth to many misconception and false practice in the name of rehabilitation of mental health. Absence of guiding principles of service delivery made the process of rehabilitation to be loosely bounded. Further lack of realization among the concerned authorities at various level leads to a greater confusion, mismanagement and made the subject of rehabilitation abandoned. So far there is no uniform framework that can be adopted in imparting rehabilitation services and there are great possibilities of missing links of ethical and legal issues; quality standards and quality of care without proper service deliver system. An attempt has been made to discuss status of existing rehabilitation services, address the concerned issues that could be strengthen by developing rehabilitation framework in mental health sector This will help to impart desired quality services which are in the reach of the patients such that the progress and performance of patients, as well service providers can be monitored simultaneously. This all could only possible is if a better coordination and understanding is being made between implementing agencies and ministries.

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*Freelance Consultants, Associated to Vardaan Philanthropic and Consultancy Services, Baroda, Gujarat, INDIA.

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Rehabilitation in mental health sector assumes that disabled persons need maintenance medication, social and independent living skills, healthy environment with desired resource and support to fulfill the demands of individual, their family and community as whole. Thus it is observed that rehabilitation is a complex and broad issue in mental health sector. The complexity starts in defining the word 'rehabilitation^a' in mental health. Though it is an eye-catching term, laudable slogan and widely pronounced jargon, but rarely does it find its real meaning in practice (Mohan, 2005). Tracing the history of India from colonial rule, quarantine or chaining was the only solution for the persons suffering from mental illness. During the decade of 60s and 70s, sending a patient home from a mental hospital was itself rehabilitation. Till mid eighties, there were limited drugs available for the cure of mental illness and allied disorders. The emergence of scientific approach – both psychiatric^b and psychosocial^c rehabilitation had open the avenue to a variety of settings (Day care centre, half way home, social club, long stay centre, vocational training centre, occupational therapy unit .. etc). However with the advancement of pharmacotherapy, the concept of rehabilitation begins to change from institution to community based and more inclined towards family care. On the contrary, the institutional based approach today has become a costly and labour intensive as it provide broad range of services in variety of setting. It is quite evident that the process involves multi-sector approach that includes total care and management of persons suffering mental disorder. In India, the extent and range of rehabilitation services vary remarkably because absence of uniform rehabilitation framework in mental health sector. This paper provides an overview of the rehabilitation services discusses the concerned issues and challenges yet to be resolved. It also provides a comprehensive understanding with various options such that the policy and programme manager working in the field of disability are largely benefited.

Background: Treatment and rehabilitation are interconnected seamlessly, as are the full range of bio-psychological services in continuous and comprehensive efforts to reduce impairment, disability, and handicap among the mentally disabled. Thus the interventions designed for the management of mental and behavioural disorders can be classified in three major categories viz., prevention^d, treatment^e, and rehabilitations^f. After prevention and treatment, an enormous population of mentally disabled persons needs psychiatric and psychosocial rehabilitation to improve their quality of life. For example India's National Mental Health Programme used the triad of diagnosis, disability, and duration to identify persons who suffer from persistent or recurrent organic, schizophrenic, mood, anxiety and other disorders that become chronic and erode or prevent the development of their functional capacities in relation

to three or more primary aspects of daily life. These functional areas of daily life include personal hygiene and self-care, self-directed, interpersonal relationship, social transaction, learning, recreation, and economic self-sufficiency.

However, inadequate resources and poor organization of service delivery for target population, which results in thousands of homeless, mentally ill persons in urban centers of our country, have amplified the challenge to both type of (psychiatric and psychosocial) rehabilitation services. The trans-institutional nature of the seriously mentally ill patients from civil hospital to jails, custodial board-and day-care home, and hospital of mental health located in urban centre is a condemnation of our society's human values. Our failure to provide high-quality, continuous psychiatric treatment is made more tragic by the availability of new rehabilitative technologies that, when systematically organized and delivered, have the potential to reduce morbidity, impairments^g, disability^h, and handicapsⁱ among serious and chronic mentally ill persons.

Today mental health systems and services in many parts of the world are undergoing significant reforms in structure and funding mechanisms that may lead to changes in approaches of the delivery of treatment and other support services. Best practices in rehabilitation for mental health are changing in response to new knowledge from research, clinical practice, consumer and care sources (NZMHC, 2000). The basic premise of giving importance to these reform activities is to ensure that rehabilitation services are delivered at the most appropriate level, in a timely fashion, and in the context of positive outcomes with associated norms and cultural values. This includes making appropriate distinction between clinical rehabilitation and disability support, and determining which services should be provided by professionals and non - professionals.

One of the important recommendations of World Health Organization (WHO, 2001) has been to develop community based mental healthcare programme. Developing community based rehabilitation programmes that are appropriate both from the point of view which includes parameters of human rights as well as not having a very big infrastructure for rehabilitation activities. In India, the National Human Rights Commission pointed out for the need for up growing management of the chronic population and stressed the demand for providing rehabilitation activity in all hospitals. It has now been realized that rehabilitation is an essential components of overall management of persons suffering from psychiatric disorders. In actual Rehabilitation in mental health has largely remained within the occupational therapy units of a few mental hospitals without any system and protocols. The Supreme Court has also directed to involve NGOs in the process of rehabilitation in the hospitals. Only, three NGOs are linked with occupational therapy unit in mental hospital at Bangalore, Chennai, and Thiruvanthapuram are working for long time. Recently the intervention made by an NGOs (Action AID) in mental health hospital located at Gwalior, Agar and Ranchi and in Baroda (Vardaan Foundation) faced many difficulties in execution of rehabilitation services from occupational therapy unit. This

is because there was no regulatory mechanism of coordination that resulted in conflict and confusion among NGOs volunteers and hospital authorities.

Current Status: The epidemiological evidence in mental health reveals that worldwide mental and behaviour disorders represented 11% of the total disease burden based on the disability adjusted life years (DALYs) and thus it is expected to increase to 15% by 2020. In the WDR 1993, four of the top ten course of disability were due to mental and neurological disorders; depression, which was rated fourth in 1993, is projected to be second in 2020 and will be number one among women. Globally around 24 million people worldwide suffer from Schizophrenia. In India, for population of approximately around 1 billion people, the psychiatrist disorder like schizophrenia are prevalent in about estimated 4 million people and 60 percent requires rehabilitation on their road to recovery (WHO, 2001).

This is only for schizophrenic patients but what about other disease, bipolar, other depressive, chronic anxiety disorders and in substance abuse. This missing data estimates does not portrays the ground realities of the requirement for the rehabilitation services in the mental health programme in India and also for the entire world. The data pertaining to right to rehabilitation at various levels (Global, National, regional and local) are only estimates and there is no exact data. Taking Thumb rule of TEN, it has been estimated that about 20% to 25% of severe ill mental disorder needs long term rehabilitation. Thus today a large proportion of persons with mental illness and mood disorders experience a poor quality of the life with long-term disability, persisting symptoms, or a relapsing course of illness has given birth to the field of psychiatric and psychosocial rehabilitations in India.

Since there is no national level survey for the exact number incidence and prevalence of the mental disorders, it was difficult to estimate the actual demand of the rehabilitation services. Not all but taking account of the most developed state of India, the impact of globalization could easily be seen in Gujarat. Owing to its multiple socio-political and economic complexities, mental health problems in Gujarat are on the rise (MH Mission Report, 2003). It is estimated that there are 2.8 million adults with common and severe mental disorders at any point in time. Each year about 11,000 new cases of schizophrenia are added to the mental disorders burden. The population burden of all severe mental disorders is more than four times the number of persons affected by schizophrenia. Co-morbidity with physical disorders is common. Events such as natural calamities and social and family disturbances in Gujarat have significantly contributed to the number of reported cases of depression, trauma and anxiety. The right of rehabilitation to the mental health patients becomes more acute because the proportion (20% to 25%) of treated persons requiring rehabilitation services are not accepted by their families and thus also in the society.

Service Delivery System: Besides, one of the important challenges in the process of rehabilitation is to move from the traditional medial model to psycho-social familial and community model. Demystifying the illness and supporting and strengthening the family and the immediate community to manage and help the

person is of crucial and critical important to both. Rehabilitation services in mental health can be divided into two phase. The first phase is the period of 25 years after independence, in which the rehabilitation activities are restricted to hospital setting largely confined in the government mental health hospital. The emphasis was, on keeping the long-stay patients occupied with some form of work or activity. This era was largely based on psychiatric rehabilitation that were based on track record of stages of the disorder, ranging from prodromal, to acute, to residual phase. While the second phase begins in the early seventies when real efforts were made for doing rehabilitation work in mental health sector, which was more emphasized on to reintegrate the patients with the family and in the community as whole. It gained momentum with the birth of psychosocial rehabilitation, which came into existence in mid eighties with the support of WHO in the formation new body 'World Association of Psychosocial Rehabilitation' (WAPR). This era witnessed both the psychiatric and psychological programmes were imparted jointly with interventions of several non governmental organizations (NGO) and social activist. It is in this phase that rehabilitation activities, in true sense were practiced and emerged as felt need. Apart from the psychiatric rehabilitation, a range of social, educational, occupational behaviour and cognitive intervention were applied Here multi sector approaches were involved that takes care of the total management of persons suffering from mental disorders. This is because here consumers, professionals, families, employers, managers and administrators at various levels are involved in the process of rehabilitation.

Institution: It was the Bhore committee report that had emphasized occupational therapy as a powerful therapeutic weapon for psychiatric patients in such away that it creates an atmosphere of industry throughout the hospital and to make occupation an activity that is approved by a patient. As a result, the occupational therapy of Central Institute of Psychiatry (CIP), in Ranchi came out as centre of excellence and had helped in setting up similar types of occupational therapy unit at Mysore and Chennai. However after fifty years, the evaluation done by the National Human Rights Commission (NHRC, 1999) portrays the grim situation of the 40 mental hospital in 18 states of country.

The major findings for psychiatric rehabilitation activities revealed that only 36 percent of Government mental hospital have a separate facility for vocational training. The rehabilitation activities were confined to the occupational unit (OT) in about 63 percent of hospital without much conceptual clarity, and are carried out by untrained professionals. About 19.44 percent of the hospital indicated to have day care services. Among these 41.66 percent reported regular production. Only 8.33 percent of Government psychiatric hospitals revealed to have rehabilitation ward. Further the execution of rehabilitation programme with real concept was found confined to three hospitals located in southern states of India (NIMHANS, Bangalore, The Karnataka Institution of Mental Health, Dharwad, The institution of Mental Health Chennai, and The Mental Health Centre, Thiruvanthapuram, Kerela) and is managed by NGOs. The

long stay facility was confined to 47.22 percent of the hospitals for chronic patients only.

The day care programme in the hospital was found effective in reducing the burden on the family and also gives them the much needed respite from patients care. However it was routinely working in less than 10% of the government mental health hospital. Though there are several reasons for not replicating the concept of rehabilitation as occupational therapy unit and day care centre, but the paucity of human resource (Psychiatrist, Clinical Psychologist, Occupational therapist and psychiatrist nurses), persisting stigma and wrong notion towards hospital are the major constraints in developing the concept of rehabilitation linked with the institutions (Mental Health Hospital). This has only given emphasis much to primary^d and secondary^e prevention there by making it more as medical model caring mostly for the long stay patients with little emphasis to attend the rehabilitation needs of the patients or concerns of their family (Sinha 2002).

Community: On the contrary, the birth of psychosocial rehabilitation gave momentum for the Community Based Rehabilitation (CBR) programme that is in existing due to untiring efforts of NGOs and like minded individuals. Though the pace of growth was slow, but their results were very encouraging. The CBR is very appropriate in the Indian cultural setting where social and community bonds are quite strong and deep –rooted. However their success largely depend upon the inter sector coordination. There are very few examples in India. One of the early (1970) examples is the first ‘Half Way Home’ Medico Pastoral Association (MPA), first day care center friends of NIMHANS, first unit later department of rehabilitation in NIMHANS. Thereafter, with the active involvement of mental health professional and collaborative efforts patients, family, and community there were many community based rehabilitation models in India. Apart from MPA and NIMHANS, the other established models in rehabilitation (both GO and NGO) running rehabilitation activities are Home for Homeless in CNK, Kerala (Radhakrishnan, 2005); Long Stay Home in CADBAM, and RFPG college, Bangalore (Kayansundaram, 2005); Family Day Care center (Raheja, 2005), Long Stay, Jyothi Niwas (Johnny, 2005); Bio-Psycho-social model, Pune (CMHCC 2005), Day care Service, Sarthak (Bhagat 2005); Sheltered workshop, Ashadeep, Guwahati (Mukul,2005), Self Help Group Chavakkad (Pfizer, 2005); Banyan tree community model, Chennai; Self Help Group like Margdarshika, ASHA at Chennai, Richmond Fellowship (India) in Banagalore, SCARF, Chennai, SHRISTI, Madurai, PRERNA, Mumbai; SAMARPAN, Indore, BPA, Ahmedabad; ASHADEEP, Junagadha, VARDAN Day care centre and self help group and many more. It is estimated that almost 60 - 70 such centre are spread across the country but are largely concentrated in Southern part of the country..

The other NGO like AMEND (Bangalore), are entirely run by, and focus on families of those affected by severe mental disorders. The family in India plays an active role in initiating treatment ensuring compliance with treatment and in providing the much needed emotional support. The family, rather than the patients, is acknowledges as the consumer of both psychiatric and psychosocial services and have received more

attention from mental health professionals. The activities of the BAPU trust (Pune) demonstrate how feminist theory can contribute to the discourse on the linkage between women's lives in a gender-based society and their mental health. Similarly, PARIPURNATHA, Kolkata, is unique example because it was primarily started to address the rehabilitation needs of women with mental illness in judicial custody. The MS Chellamuthu Trust, Maduari (Rajkumari, 2005) has set a unique example for better partnership between mental health professionals, NGO and the community at large there by able to provide low cost, effective care and comprehensive range of services (Ramasubramanian, 2005). Similarly there have been community initiatives for the mentally ill that have been less visible. Several individuals and families in Kerala have been involved in providing food, clothing, shelter, medicine and occupational therapy free of cost for the destitute mentally ill (Radhakrishnan, 2005).

Overall it has been noticed that the rehabilitation models have been developed in its own due course of time and reach to the current maturity. These models have their own philosophy and are imparting diversified services depending upon the available resources in various settings (Hospital, Community, Home, and family groups). However major concern is related with the standards adopted in imparting these diversified institutions in different settings. Overall it seems that though the rehabilitation are widely imparted, but the availability of resource, inclusion of the social dimensions, appropriate community/institutional cost effective intervention are yet to be tested and sustained with holistic approach. The emerging view is that CBR programmes for the mentally ill should be integrated with existing community development programmes, especially in the area of disability, so that there is no duplication and waste of resources.

Issues Concerned: Health without mental health and mental health without rehabilitation services is not complete in health, social and allied sector. However there are many complexities in mental health sector as also observed in the rehabilitation services. This is because the rehabilitation services are a mammoth task that involves broad spectrum of services, labour intensive and expensive. Reviewing the current scenario of our country, it was discovered that many organization have already taken up substantial efforts in running either institutional or community based rehabilitation programme. However there are many issues that are point of debate in execution of rehabilitation programme in context to disability in mental health sector.

Confusion over terminology: Psychiatric rehabilitation is the basic and utmost necessary for the rehabilitation programme. However in mid eighties with the advent of new terminology "Psychosocial", it becomes difficult to implement both rehabilitation processes in practice. Rehabilitation services are largely projected and propagated as psychiatric rehabilitation. The real essence of the rehabilitation services are never made understood to non professionals especially among NGOs. It has been observed that non professional got confused between the two terminology and have always raised their doubts viz., if the benefits of psychosocial rehabilitation are so overwhelming, than what is the need of psychiatric rehabilitation? Is there any difference or similarities? Which is more appropriate or superior? Are they

interconnected? In practice if both type of rehabilitation process are operated simultaneously there will be always a conflict between professionals and non professionals.

Usually the medical model is preferred most and the professionals believed in doing all the activities at own there by neglecting the role of non professionals. Ideally it should be propagated that both (psychiatric and psychosocial) approaches are interconnected to each other and have symbiotic relation. One must remember that psychiatric rehabilitation assessment is the first phase and it is inevitable process that is compulsory to be attended and later could be integrated as back up support while executing psychosocial rehabilitation programme.

Lack of Rehabilitation Framework: Psychiatric and Psychosocial rehabilitation is a grossly neglected area in India. Till recently, it has been poorly developed and under funded. Earlier rehabilitation largely remained within the occupational therapy units of few mental hospitals. However during last three decade there is sudden rise of rehabilitation services out side the institutions having NGO taking leading role. However owing to the demand it is felt that rehabilitation services in mental health sector are still in infancy stage. In the absence of exact number of person (suffering from mental disorders) requiring rehabilitation services, the question arises whether rehabilitation programmes for persons with psychiatric disorders are indeed needed in India? What type of mental disorders really needs rehabilitation services and how much and to what extent? Lack of clarity for the clear definition of the “Rehabilitation” in mental health gave birth to many misconception and false practice in the name of rehabilitation of mental health. Absence of guiding principles of service delivery made the process of rehabilitation to be loosely bounded. Besides, lack of realization among the concerned authorities at various level leads to a greater confusion, mismanagement and made the subject of rehabilitation abandoned. So far there is no uniform framework that can be adopted in imparting rehabilitation services and there are great possibilities of missing links of ethical and legal issues; quality standards and quality of care without proper service deliver system associated with it. However, attempts have been made by NIMHANS and some institutions like MSCTRF, (2005^{a&b}), and Vardaan Foundation – (Sinha 2006^a and Sinha 2005^b) on the guidelines for providing such rehabilitation services.

Recently, there has been a great interest by policy makers, consumer and care giver, and service providers, in learning which models or elements of models for rehabilitation for mental health are the most effective in delivering the desired outcomes (Vardaan 2006^a). This interest has grown since both institutional and community based rehabilitation services are now largely practiced in India. The need for policy development and a rethinking of existing practices has to be identified to develop the framework of rehabilitation in mental health sector. This could be a policy statement that is intended to guide policy and planning initiatives at the micro and macro level of health services to various organizations working in this field. It also seeks to minimize fragmentation of service delivery, and to link the various aspects of rehabilitation (consumer perspective, ethical and legal issues, safety norms,

networking, training aspects and other support mechanism ...etc) and support services to promote continuity of care.

Absence of Resource: The status of resource allocation shows that there is a quantum jump from the 9th to 10th five year plan by allocating Rs.1900 million. Of these, 33% is for improving 200 District Mental Health Programmes (DMHP) across the country; 18% for improving medical college and department of psychiatry, 40% for strengthening mental health services, 6% for IEC and 3% for research. The rehabilitation programme has been given least preference thereby making it as allied services with treatment imparted at institutional level. One can argue that rehabilitation is matter of social affairs and the health ministry is concerned delivering treatment services in mental health sector. The subject matter of rehabilitation much falls under the purview of social and other allied sector. In the absence of any criteria, the resources are largely unorganized in the social sector and usually rely on the national figures. As per the national census 2001, the total disable persons reported is around 21,906,769 of which 49% were visually disabled, 7% with speech, 6% with hearing, 28% with locomotors and only 10% reported with mental disorders. Here it seems that the burden of mental disorder are low, however the stigma as well as ignorance among the general population perpetuated this under – reported figures of disabilities with mental disorders.

The gap between the available resources and growing demand of rehabilitation services is a problems area and arises due to lack of coordination mechanism between government agencies. Looking the current demand, yet rehabilitation services remains one of the most neglected and least integrated streams in mental health sector compared to other disabilities. As earlier pointed out that both psychiatric and psychosocial rehabilitation have symbiotic relation, it becomes utmost necessary that all concerned government agencies adopt a common mechanism in allocating the resources for the rehabilitation services for mentally disabled persons. This could be implemented based on need-based allocation of resources thereby enabling adequate provision of both (Psychiatric and Psychosocial) type rehabilitation services and demarcating roles and responsibilities among professionals and non professionals.

Research and Training: Research in mental health sector are largely confined to few institutions (NIMHANS, HIBAS, RFSI and SCARF) and had developed sustainable material to train desired carder of the human resource involved both in treatment and rehabilitation services. Some interesting studies are also done at medical college and now NGO are also conducting research studies related to community based intervention for rehabilitation services. Apart from intervention, research is equally important to know the behaviour dynamism. Since the budget for research is very low, it should be emphasized to allocate substantial budget for research and include more number of institutions as well a technically sound NGOs for conducting community based research (which includes social, economic, service delivery, human rights aspect etc) in context to not only treatment but also for rehabilitation programmes.

Owing to the requirement of psychiatric and psychosocial rehabilitation services, it becomes essential to train a large number of human resource having varying roles and responsibilities in the process of rehabilitation. In India there is acute shortage of psychiatrist, clinical psychologist, occupational therapist, psychiatric nurses, and social workers. The major hurdle for providing the rehabilitation services is lack of trained professionals and the training is restricted to few institutions that are largely confined to the southern part of our country. In order to expand the rehabilitation services, training of professionals and non professionals will need to be taken up on war footing to bridge the gap between demand and supply. Thus more funds are required to be allocated for conducting training for both psychiatric and psychosocial rehabilitation programme uniformly all over India. Even, if the non professionals are having qualification of matriculation and higher secondary, having interest in working for mental health and are trained properly for psychiatric care, can yield satisfactory level results. The word psychiatric itself generates stigma among masses and intervening agencies. It is professionally correct to relate professionals like psychiatrist and psychologist directly to the field of psychiatry, where as associated professionals like psychiatric occupational therapist; psychiatric nurses; psychiatric social worker etc are in acute shortage. Associating the word “psychiatric”, the problems become acute and disturbing. Removing the word ‘psychiatric’ from these cadres of professionals can yield satisfactory results as pilot tested by an NGO Vardaan Foundation (Sinha 2006^a).

Consumer perspective: Since the advent of the psychosocial rehabilitation programme, the consumer perspective had gained momentum in the process of delivering services (both treatment and rehabilitation) in mental health sector. When saying consumer it is the individual sufferers and if taken unsound mind of the person than the first family members is considered as consumer. Looking cultural set up of our country, families are more tolerant of deviant behaviour and more willing to take care of the ill members. However with the increasing urbanization, life styles are undergoing rapid change. The nuclear family system and shrinking social values combined with the increasing financial strain, is making more difficult to care for an ill family ward/relatives (Sinha,2005^a). There are several studies, which suggest that distress and burden of caring for an ill relatively is very high and disruptive to daily routine work in the family. This is true for both urban and in rural setting. These are the reasons that still have given institutional based (hospital) services a grip and importance in the era of the ‘deinstitutionalization’.

When the patients or their family members are brought into centre of focus, their rights as consumers are largely related with the treatment, informed consent for doing surgical procedure, against all abuse, in providing certification, maintaining confidentiality of data, for restraint and seclusion, employment, housing, education etc. Overall keeping the perspective as consumer all, civil, legal and other rights are associated with it as defined in the United Nations charter (UN, 1997 & 2007, WHO 2005). Owing to the consumer perspective, the common value dilemma is balancing patient’s self –determination over provider’s expertise. In India, the mental health

sector at present depends primarily on medications for treatment, because there is no consumer movement in mental health and the government has provided little regulation in this regards. The area of medication for mental disorders is largely run and govern by psychiatrist and drug companies, leading to a number of undesirable effects for the clients (the patients), like over prescription of drugs, lack of rationality to drug prescriptions, shortage of essential drugs in the public sector and forced drug use. This all usually happened due to ignorance as well as lack of collective voice against such mal practices. There are countable institutions where the facilities of filing grievances are available.

As regards the advocacy groups, education and consumer protection have important roles to play in the mixed market economy. However in the government set up, the information and education over these issues till date have been low and least priorities. The status on these aspects has been different among the voluntary sector and NGOs. With the growing concern, the families have come together to provide emotional support to each other, address common concerns and fight for the rights of people with mental disabilities. Family self-help groups such as 'AASHA' in Chennai and 'AMEND' in Bangalore have been pioneer in this movement. This is mere a tip of iceberg against the large number of unresolved consumer problems in mental health sector. To address this, we need a large consumer movement that is widely spread through out our country not only by grassroot level organization but also with equal contribution of the clients-the sufferer, and their family members.

Social Justice and Issue of Human Right: Mental health and human rights are inextricably linked on a variety of levels. Treatment and rehabilitation centers, workplace, within the family etc, are the place where gross human rights violation are observed that are expressly designed to break down and eventually destroy individual and collective mental health in the target community.

In India, it was first NHRC report on quality assurance raised the issues pertaining to human right violation at mental health hospitals. The other organization like BAPU Trust, Sarthak, Human Right Law Network (HRLN), Vardaan Foundation (Sinha 2006^c), AMEND etc are found active for fighting the rights of mentally ill persons in the community as well at institutions. However, the issue of human rights gained momentum with public interest litigation (PIL) and Supreme Court directives. These judgments concerning persons with mental illness and disabilities are mostly in the form of PILs wherein eminent jurists and members of civil society have approached the apex court fighting the legal battle for the gross human right violation occurred at various type of institution and in domestic life of an individual suffering mental disorder. Thus today in essence, the human rights perspective on disability means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems, towards viewing them as holders of rights.

The disability rights debate is not so much about the enjoyment of specific rights as it is about ensuring the equal effective enjoyment of all human rights, without

discrimination, by people with disabilities. It is now quite evident for public health professional and human rights activities, that human right is the integral part of the mental health sector and the right of equity and equality are the bases of the good practice in mental health sector. Thus one cannot neglect the human right issues concerned with the treatment, rehabilitation, and other related welfare of individual suffering mental disorders. International human rights conventions, treaties, law etc creates broad range of obligations on governments with respect to people with mental disabilities. Thus today human right law requires protections against government intrusion upon individual freedom and autonomy, and it requires positive action to from guidelines for diversified groups and institutions setting. This will ensure some mechanism to control violation of human rights and ensure that the desired services are accessible and appropriate (MOHFW, 2007)

Ethical and legal issues: During pre independence the mental health hospital was governed by the Indian Lunacy Act of 1912. The revised version of this was drafted in 1958 and almost after three decade it was implemented as Mental Health Act in 1987. After five year in 1992, this Act was implemented almost all over India, as State Mental Act Authority (1992). However before the mental health act was implemented, the Rehabilitation Council of India (RCI) was established in 1986 by an act of parliament that was mainly aimed for the functioning related to licensing of rehabilitation professional, and monitoring and accreditation of training facilities and short and long term training course in rehabilitation. After the implementation of MH Act in 1987, it took almost 12 years to form the Person with Disability Act (PWD) in 1995, pertaining to prevention and early detection of disabilities, protection of rights, education, training, employment and rehabilitation of person with disabilities. Although mental illness was included as one of the disabilities, the definition of mental illness was not clear. It was because of this reason, mental illness was supposed to be removed from the PWD Act. However with the intervention of Indian Psychiatric Society (IPS) the mental illness remained intact in PWD act by introducing the Indian Disability Evaluation Assessment Schedule (IDEAS). However, still the IDEAS scale does not fit equally for temporary and permanent disability for mentally ill persons. Further, the findings of “unsoundness of mind” and moreover, the definition and scale of mental illness is linked to identification and measurement, and this whole model is based on expert power that largely varies among individual professionals as a problem of differential diagnosis.

Looking all the three legislation in context to human rights what actually we have gained? What is total output? The MHA deals with the treatment and the PWD Act deals with rehabilitation of the mentally ill. According to the MHA, all agencies that care for the mentally ill comes under the purview of the State Mental Health Authority. As per the PWD Act, the monitoring and control of rehabilitation facilities, both residential and non residential come under the purview of the Commissioner of Disabilities. While the government sector is exempted from all regulation, these two Acts have made it difficult for the various rehabilitation agencies in the voluntary and NGO sector to operate. In effect, there are parallel controls from two different

ministries. The RCI has become a third monitoring agency. This has only resulted in a lot of confusion, a sense of mistrust that the government is only interested in a 'Licensing Raj' with very little improvement in the actual development and delivery of services has been made (Murali, et al 2004).

Today in India what actually required, is that, all concerned authorities need to carefully consider the obligations under international law that are immediate and prioritize those domestic laws and practices that need prompt attention to realize the protections required by international law. An eminent legal expert (Danda, et al, 2004) pointed out that some points in the existing disabilities laws require modification (MHA, Section 6(2); 7, 8, 9, 10, 11, 12, 13, 14, 18, 40, 43, 81 and 91 SMHR 1990, Rule 20 and 22). Similarly owing to the need Prof. T. Murali clearly points out, to improve hospital-based services and ensure that the minimum standards outlined by the NHRC are implemented. Further he emphasized to develop practical norms and guidelines for the voluntary and NGO sector and actively encourage the setting of the CBR service model. Overall, it apparent to develop a single-window regulatory authority so that persons with disability and those working in the area with scarce resources are not confused and easily adopt the existing system. Thus it is imperative to have better coordination among these agencies/ministries.

Monitoring and Evaluation: With the growing demand and need for rehabilitation of mental disorders, it is inevitable that both psychiatric and psychosocial rehabilitation are accounted as they have symbiotic relation with each other. The World Health Organization (WHO-Atlas, 2001) has pointed out that the imbalance between "disease information" and "resource information" is a major impediment to planning mental health services. Thus it becomes essential to maintain a patient's history (both psychiatric and psychosocial) such that it portrays the real incidence, prevalence, course, diagnosis, classification, disability and burden of mental disorders.

Today, majority of mental health delivery institutions in India give emphasis and importance only to clinical data of mental illness. This is because in mental illness, the word "rehabilitation" commonly understood as psychiatric rehabilitation. However, with the growing influence of reducing the disabling effects of chronic mental illnesses and making patients reach their optimal level of independent functioning in the community, it becomes essential to trace every aspect of rehabilitation. This is a challenging task, as the process of rehabilitation in mental health care is complex and has broad spectrum of *inter* and *intra* sectorial dependency - as observed from the first day of the treatment to the last day of resettlement^j of the client (WHO, 2000).

The attempt made by Vardaan Foundation (Sinha 2006^b), is the best example to provide information for the management of mental health programme and services such that the system helps in monitoring the health situation, the performance of promotive, preventive, and curative health services, and availability and utilization of health resources. The information obtained through this system are not only useful for monitoring and evaluation of the progress and performance of persons

under going treatment and rehabilitation services but also in knowing prevalence and incidence of mental disorders. It also helped in keeping services record of service providers and in knowing various types of histories and performance data, and possible linkage and interrelationship of the variables used in various data tools which was found largely useful to categorize into the following interrelated and possibly overlapping subsystem:

Thus such data tools record keeping procedure and software should be made mandatory for all service delivery organizations dealing in mental health sector. Such databases would be helpful in giving information on the burden and needs, local expression of mental disorders, and pathways to care patterns. This will lead to developing appropriate intervention programmes from rehabilitation to finally resettlement in the community. Thus awareness of sensitivity to mental health at different levels of the policy structure will be better understood by developing such monitoring system that could further strengthen in shaping up policy, programme, and other research agendas. The information generated with such database has policy formulation and other implication that reflects the diverse realities and influence on the mental health sector for both treatment and rehabilitation services.

Conclusion: Rehabilitation services in mental health sector are having broad spectrum of services and thus are labour intensive and costly affairs. In India, both institutional and community based rehabilitation programme are largely practiced, but with the absence of the resources, man power and lack of rehabilitation frame work has made the process loosely bounded. Thus now it become essential for policy maker to rethinking and study existing practices so that the much awaited aspect of developing the rehabilitation framework could be initiated in mental health sector. It will not only help to cater the demand but also identifies roles and responsibility, the minimum criteria to delivery quality services, and feasible way of monitoring the progress and performance of the patients as well as of services providers.

Besides, comprehensive care of rehabilitation in mental health sector, it has to be made feasible and within the reach of individuals suffering mental illness. Thus it becomes essential to trained both professionals and non professionals for psychiatric and psychosocial rehabilitation programme. In order to address the issues related to stigma and understanding the needs of the patients and family members, it become apparent that the desired rehabilitation services should also and equally be linked with the community. With the growing economy and globalization, the consumer movement should provide thrust to address the issue particularly concerned to protect the rights of the mentally ill and provide value based and ethical care. Today it has been recognized that human right is the integral part of the mental health sector and the right of equity and equality are the bases of the good practice. Thus persons with psychiatric disability have a right to rehabilitation. To make the things happened in reality, it is imperative to have better coordination among these agencies and ministries.

Notes

- a. **Rehabilitation:** Various methods to enable mental health patients who are not totally improved, so as to improve their social vocational skills for independent living. (Adopted from Kaplan and Sadocks, 1999).
- b. **Psychiatric Rehabilitation:** It is defined as a set of targeted interventions that is intended to prevent further, or reduce disability that is associated with mental health problems (Barton, 1999) or it is to teach skills and provide community support so that individuals with mental disabilities can function in social, vocational, educational and family roles with the least amount of supervision from helping professionals. (Adopted from Kaplan and Sadocks, 1999).

Psychiatric rehabilitation assumes that disabled persons need maintenance medication, social and independent living skills, and environmental resource and support to fulfill the role demands of community life. One has to keep track of stage of the disorder, ranging from prodromal, to acute, to remission phase; that contains treatment and rehabilitation modalities, such as drug therapy, family and cognitive therapies, social skills training and vocational rehabilitation.

- c. **Psychosocial Rehabilitation:** It is the process that facilitates the opportunity for individuals – who are impaired, disabled or handicapped by mental disorders – to reach their optimal level of independent functioning in the community (WHO 1996). It aims to help in reducing the disabling effects of chronic mental illness and to highlight social and environmental barriers, which hinder treatment and rehabilitation efforts and which add to the stigma of chronic mental illness. In addition to this it also includes consumer empowerment and involvement with planning, delivery and evaluation of mental health services.

Overall the concept of psychosocial rehabilitation is focused to increase the ability of individual for independent functioning and making competitive enough to lead best possible quality of life by changing the surrounding environment of an individual experiencing any mental disorders. The term psychosocial rehabilitation and support is used herein to refer to a range of social, educational, occupational, behaviour and cognitive intervention designed to increase the individual's basic psychosocial capacities for role performance and manifestation of his or her potential (Adopted from PSR, 2000)

- d. **Prevention:** Primary prevention or specific protection comprises measures applicable to a particular disease or group of diseases in order to intercept their causes before they involve the individual; in other words, to avoid the occurrence of the condition (Adopted from WHO Report, 2001).
- e. **Treatment:** Secondary prevention refers to measures to arrest a disease process already initiated, in order to prevent further complications and sequelae; limit disability, and prevent death (Adopted from WHO Report, 2001).

- f. **Rehabilitation:** Tertiary prevention involves measures aimed at disabled individuals restoring their previous situation or maximum the use of their remaining capacities. It comprises both interventions at the level of the individual and modification of the environment (Adopted from WHO Report , 2001).
- g. **Impairments:** The characteristic positive and negative symptoms and associated cognitive and affective abnormalities of disorders such as schizophrenia; autistic disorder, and bipolar disorder (Adopted from Kaplam and Sadock, 1999).
- h. **Disability:** The restrictions and impairments imposed on such functional life domains are personal hygiene, medication self management, recreation for leisure, and family and social relationships (Adopted from Kaplam and Sadock, 1999).
- i. **Handicapped:** The disadvantage experienced by an individual with impairments and disabilities that limits or prevents the fulfillment of normal roles, such as workers, student, friend, citizen and family members.(Adopted from Kaplam and Sadock, 1999).
- j. **Resettlement:** The rehabilitation services is not completed till a person has resettlement or at economic front to learn his livelihood or settled a calm domestic life (Adopted from Bennett, 1983). One must remember that resettlement would constitute the end point of good rehabilitation. It is one of the difficult tasks and there are evident that many services providers had spend their entire life in the resettlement of a single persons. This is the most challenging part in the process of rehabilitation. Without rehabilitation, resettlement would not be possible, as an unprepared person with residual disability cannot be placed in either a familiar or alien environment. Rehabilitation, therefore should prepare the person for resettlement by addressing itself to various aspects of the individuals and the environment (Adopted from Singhal, 1999).

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