Human Rights and Stigma Reduction in the Process of Rehabilitation of the Mentally Ill

Prince C P
Asst Professor, School of Social Work
Mangalore
Email: cpprincepsw@gmail.com

Abstract: *Mentally ill persons are approached with stigma and families want to abandon them even in the wake of 21st century. It is a severe human right violation. However there are emerging models caring the destitute mentally ill with individual initiative and family collaboration who bring back the human right of the mentally ill person by removing stigma and caring them with dignity and worth. This paper is a case study of a rehabilitation centre at Kottayam in Kerala run by an ordinary person along with his family caring more than 300 mentally ill including children.*

The objective of the study is to find out how the stigma reduction through a grass root community assistant rehabilitation model and enhance human right of the mentally ill persons. A qualitative design with case study methodology is followed.

The result shows that factors like acceptance of the persons with mentally ill as a family member calling him/her son/daughter and treating them so, allowing them the freedom of expression and interaction, exploring their innate abilities and host of others make them to cross the barriers of stigma. It gives back the human rights lost when they were thrown into the streets. The founder of the centre visits schools colleges, temples, churches and other community centres to disseminate information on mental health. The participants of such interaction program visit the rehabilitation center and understand how mental illness is just like any other chronic illness and spread the message back home. The entire process of community involvement enables to recreate a pro human right perspective towards persons with mental illness. Their dignity is regained; care and love in the centre as if in a family pitch their rights back in position. The entire process removes stigma about mentally ill persons and place them in a high position and prepare the society to own the responsibility to care these persons with cognitive deficits. Thus the care of mentally ill ultimately leads to stigma reduction and prepare the families and communities to accept and

care the persons with mental illness. The entire process of stigma reduction contributes to the promotion of human rights of the mentally ill person and creates a model of right based care and rehabilitation of the persons with mental illness.

Key Words: *Care of the Mentally Ill Persons, Human Rights and Stigma Reduction, Acceptance as Family Member, Engagement of the Community*
Director, ASWAS Foundations, Mangalore, Karnataka, India.

Introduction

Unlike any other disorders mental illness is always stigmatizing even in the modern world. Apart from cultural factors, illiteracy, ignorance about mental illness, its symptoms and treatment lead many to consider the persons with mental illness as somebody unwanted in the society. Although considerable attempts are made by academicians and practitioners to help the public to change their perspectives towards mental illness it takes time for a transformation to fix its space.

Social exclusion is major problem in mental illness disability like any other disability or much more due to the stigma attached. Family exclusion and community exclusion expel the mentally ill to the street. The human right and dignity of the person is shattered and forced to lead a life in inhuman conditions. The rehabilitation mission under study is a family centered community based model in Kottayam, Kerala, India is meaningful in this context. The centre is similar to its counter parts across the nation. All such centers were started with individual initiatives driven by a social or spiritual motive to serve the humanity particularly the vulnerable. Hence they picked up the so called socially excluded mentally ill on the street sheltered and cared. The lost dignity is given back and human rights are ensured to the mentally ill in the whole process. It is based on the deprofessionalised or non professional approach of the rehabilitation process emerged and bloomed into success story for the past 20 or more years. The paper discusses the non formal strategies adopted by the individual visionaries in their march to protect and care the destitute mentally ill persons in stigma reduction and regaining the human rights of the persons with mental illness.

A brief review of literature would be helpful to position the problem of exclusion, recovery based rehabilitation and the methods of overcoming the barriers around it.

Community Based Rehabilitation in Mental Health Sector

Community based rehabilitation model began with community support systems in the west, In the mid-1970s, a series of meetings at the National Institute of Mental Health (NIMH) gave birth to the idea of a community support system (CSS), a concept of how services should be provided to help persons with long-term psychiatric disabilities (Turner and TenHoor, 1978). Recognizing that post deinstitutionalization services were unacceptable, the CSS described the array of services that the mental health system needed for persons with severe psychiatric disabilities (Stroul, 1989).

Nowadays there is a broad consensus on the need to shift from the model of care based on the traditional large psychiatric institutions to modern comprehensive community-based models of care, including acute patient units at general hospitals. The main reasons for this shift are the following:

Accessibility to mental health care of people with long term mental disorders is much better with community-based services than with the traditional psychiatric hospitals (Thornicroft and Tansella, 2003).

Community-based services are associated with greater user satisfaction and increased met needs. They also promote better continuity of care and more flexibility of services, making possible to identify and treat more often early relapses, and to increase adherence to treatment (Thornicroft and Tansella, 2003; Killaspy, 2007).

The community-based services better protect human rights of people with mental disorders and prevent stigmatisation of those people (Thornicroft and Tansella, 2003).

Studies comparing community-based services with other models of care consistently show significant better outcomes on adherence to treatment, clinical symptoms, quality of life, housing stability, and vocational rehabilitation (Braun P. et al., 1981; Conway M. et al., 1994; Bond et al, 2001).

Studies suggest that care in the community for acute psychoses is generally more cost effective than care in a hospital, although it is important to note that these results cannot be generalized to all patients requiring admission to psychiatric beds (Goldberg, 1991).

Studies also show that, for patients who require prolonged stays in the hospital, hostel wards provide a cost-effective alternative that is preferred by the patients themselves (Goldberg 1991). Other studies show that, when deinstitutionalisation is correctly developed, the majority of patients who moved to from hospital to the community have less negative symptoms, better social life and more satisfaction (Leff, 1993;1996).

The right to community-based services, expressly recognised in Article 19 of the United Nations Convention on the Rights of People with Disabilities (CRPD), has significant implications for the organisation of mental health services, since it implies that:

1. All persons with disabilities have the right to live in the community, choose their place of residence and have access to residential and domiciliary services as well as other community services;
2. States should facilitate the inclusion and full participation in the community of persons with disabilities;
3. Community services and facilities for the general population should also be available for people with disabilities.

WHO in its report on Psychiatric Rehabilitation consider rehabilitation to improve the skills of the clients and to strengthen the support system related to clients' goals. But should this rehabilitation model controlled by professionals? Studies show that non professional segments have better output in terms of recovery in the entire rehabilitation process.

The development of the concept of a comprehensive community support system, combined with the rehabilitation model's more comprehensive understanding of the impact of severe mental illness, has laid the conceptual groundwork for a new vision for the mental health service system of the 1990s.

1. Recovery can occur without professional intervention. Professionals do not hold the key to recovery; consumers do. The task of professionals is to facilitate recovery; the task of consumers is to recover. Recovery may be facilitated by the consumer's natural support system. After all, if recovery is a common human condition experienced by us all, then people who are in touch with their own recovery can help others through the process. Self-help groups, families, and friends are the best examples of this phenomenon.

It is important for mental health providers to recognize that what promotes recovery is not simply the array of mental health services. Also essential to recovery are non-mental health activities and organizations, e.g., sports, clubs, adult education, and churches. There are many paths to recovery, including choosing not to be involved in the mental health system.

2. A common denominator of recovery is the presence of people who believe in and stand by the person in need of recovery. Seemingly universal in the recovery concept is the notion that critical to one's recovery is a person or persons in whom one can trust to "be there" in times of need. People who are recovering talk about the people who believed in them when they did not even believe in themselves, who encouraged their recovery but did not force it, who tried to listen and understand when nothing seemed to be making sense. Recovery is a deeply human experience, facilitated by the deeply human responses of others. Recovery can be facilitated by any one person. Recovery can be everybody's business (Antony, 1991).

Barriers in Mental Health Rehabilitation

The community based rehabilitation is also not free from barriers. The barriers existing in the disability rehabilitation process also seems to be present in the rehabilitation of the mentally ill persons through community models. The experience in most countries is that the development of community services is a complex process that faces several important barriers. Some of these barriers exist at the policy level, and may occur when there is a lack of adequate mental health policies and legislation, budgets are insufficient or where there is procedural discrimination against persons with mental disorders, in terms of limited or lack of health insurance. Other barriers are found at the level of the health system and include: difficulties in releasing resources from the large institutions (which absorb the greater part of the available funding), resulting in under investment in community-based services; lack of integration of mental health services with the general health system; lack of integration between mental health and social care systems, including poor co-ordination with housing, welfare and employment services; lack of co-ordinated partnership working between statutory and non-statutory mental health services, including the voluntary and independent sectors; and inadequate training of staff across systems (WHO, 2001).

In addition to research showing that individuals with disabling mental disorders receive low levels of vocational services or none at all, a body of research beginning in the 1980s (Robin et al, 1990) has found that large proportions of this population receive no clinical services and that those who do fail to receive adequate care (Lehman et al, 1998, Wang et al, 2000).

Baldwin and Johnson (1998) studied disability-related employment discrimination by examining earning differentials and applying econometric techniques previously used to study race and sex discrimination. After they accounted for productivity differentials related to functional limitations and other productivity related individual characteristics, such as education, occupation, and part-time employment, large unexplained variance in wage differentials between people with and without disabilities remained.

In a qualitative research on barriers of disability they found out the factors responsible for the barriers. In summary the qualitative research suggests disabled people face notable barriers in relation to:

1. **Having Sufficient Choice and Control**
   For example; limits to choice of employment, or choice and independence of young disabled people.
2. **Access and Inclusivity**
   Including around the accessibility of places and spaces and the inclusiveness of mainstream education and the workplace.
3. **Having their Voice Heard**
   Despite being no less likely to want to get involved in improving society, disabled people consistently reported not being listened to.
4. **Stigma and Discrimination**
   Compounding the other challenges, many disabled people are treated unequally because of the stigma attached to their condition.
5. **Participation and Connectedness**
   The research suggests that reduced funding and other pressures are limiting the ability of disabled people to maintain social connections.

Research participants who took part in the qualitative research feel very strongly that there is an urgent need for a change in the attitudes and behaviour of health and social care professionals and staff, through training and education. More specifically, they feel that health and social care professionals need to make more time for disabled people.

They also feel that they need to have more empathy and sensitivity and a better understanding of the social impact of their conditions. Participants feel that disabled people themselves are best placed to deliver such training and awareness-raising effectively. However any organisation seeking to tackle this problem with attitudes need to be aware of the systemic and structural constraints acting on health and social care professionals in terms of many competing priorities for training and limited funding. Along with attitudinal changes a few more suggestion given in various studies are given below. According to Ali Jookhun (2012), some factors to consider in creating an inclusive and accessible society are:

1. Changing our daily attitudes towards disabled persons concerning education, employment, etc. A disabled person ought to get a job not because he/she is disabled, but because he/she deserves a job ; and for this, inclusive environments for enabling education within the society are important together with ensuring that proper equipment/tools for the work are made available.
2. **Creating Accessible Environments**

   Facilitate movement and independency of disabled persons. Supports to enable people with disabilities to flourish must be created. For example : Allow for public transport and schools with accessibility facilities, make ATM accessible to wheelchair users, toilets at work must be designed for disabled, etc. Free transport despite being "free" for all is not 'free' for disabled persons if they can access the facility.
3. **Introduce and Mend Laws to Create Enabling Legislations**

   Laws are meant to protect. Greater protection must be given to those less able to defend themselves. It is shocking to see presumed aggressors not being condemned due to lack of proof (a journalist wrote an interesting article where a presumed rapist was freed due to mental disturbances of a mentally disabled person).
4. **Revamp Existing Institutions for Disabled**

   The Disability Watch - what results has it produced after being launched since a year (launched in December 2011) ? How come with rampant atrocities perpetuated against disabled persons, the Disability Watch is dumb ? The CDU, the Disability Watch and other such institutions are not the toys of Ministries to be used for 'patchwork'. Revamp these institutions, revitalise them and give them controlled autonomy with time-based performance appraisals.

However the models discussed in this paper generates a paradigm shift in the very process of mental health rehabilitation. How people centered family based community model of rehabilitation can adapt an inclusive policy to break the barriers of disability is an experimented reality in such approaches over the past 20 or more years.

Methodology

The objective of the study is to find out how the disability barriers are overcome through a grass root community assistant rehabilitation model. A qualitative design with case study methodology is followed. The case study is based on a single unit but different dimensions in the removal of barriers in disability rehabilitation are discussed.

Case study

Luxurious greenery adorns the ambiance of the village on the outskirts of Kottayam, the first 100% literacy district in India. The villagers are engaged in agriculture and village bound business. A series of building complex could be seen as you travel through the state highway nearby. It accommodates 280 persons with mental illness. It was the great vision of Mr Tomy who brought the mentally ill persons from the street and gave shelter to them. He was compassionate to the poor and needy from childhood. When he was serving in Kottayam medical college he used to give food to the poor patients and later he picked up the persons with mental illness from the streets and gave shelter and care in his own house. Nothing could prevent his commitment and dedication for the cause to give a life different to the rejected and marginalised mentally ill people. His wife and children co-operated with the mission and it grew very fast.

Accepting them as brothers or sisters was the beginning. Non professional intervention began its curing voyage over those feelings of love and compassion. Jesus Christ, the God of inspiration helped him to swim through troubled waters. The roads were full of thorns but turned out to be bed of roses in the smiles of the hundreds given care. There were doctors, engineers and other people of great profile whose mental balance derailed and moved around like a little child. Tomy was ‘Dad’ for them and his wife Mercy became true resemblance of God’s mercy and today she is the ‘Mom’ of everyone over there. Accepting each as family member and live a life under one roof is not an easy task. Their road was one less travelled and the

community realised the sweat and blood behind the whole task. The primary element of breaking the barriers was this acceptance of the clients as family members. It created a wave of healing and majority of the clients are with minimum or no medication.

Tomy was working tirelessly for the past 25 years. He visits schools, colleges and other public institutions and disseminate information about persons with mental illness. He invited the school and college students to visit his home filled with persons having mental illness. They came in groups, boys and girls and witnessed the reality that the so called 'persons with mental illness' go around as 'normal' as anyone else. It opened their eyes and thousands of other people in the society who realised that the persons with mental illness are not a group to be scared but to be cared as one of the family members. They came in groups with cash and kind to support the mission. Several people stayed back to serve as volunteers. You call it 'a movement?' Or 'Innovation?', whatever you name it there is considerable amount of stigma reduction and you witness persons with mental illness live with dignity and worth. Is not the human right ensured to these brethren? Indeed it the process of family based care where you blend both professional and non professional service to get a taste of homely environment and rediscover the rejuvenation of human rights.

Secondly engaging the clients in day to day functioning of the agency was breaking the barriers of disability. It gave them dignity and self esteem. From housekeeping to kitchen and shaving the highly disabled enabled a sense of empowerment among the inmates. Everyone felt a sense of belonging. It helped them to set right their cognitive faculties. There are less incidents of aggressive behaviour among patients. The drug compliance is well maintained. It literally led to recovery process enhancing their human rights.

Third factor is the readiness of the clients to take up responsibilities. The conventional attitude is that the mentally ill person cannot care babies is proved untrue here. They look after babies with extra care. One who observes them get amazed why they are still kept under shelter? In several occasions such persons were rehabilitated back home the attitude of family members may not be conducive. It leads to poor care, inadequate and irregular medication and consequent relapse. Therefore the attitude of the care givers enables them to break the barriers of disability and make them function in socio-biological situations. Witnessing such care model helped many in the whole process of reducing the stigma of families and community.

Fourth factor is the cordial relationship between the inmates which creates a harmonious environment in the centre. Whatever activities undertaken in group there is good cohesion and mutual cooperation which is unlikely even some normal settlements. The readiness to sacrifice for the other, concern towards the needs of other and helping attitude make them more normal than the so called mainstream normal. It gave a new paradigm of facilitating human right to the persons with mental illness.

Finally the self help skills and communication skills they learn in the centre through day today activities make them cross all barriers of disability. The involvement of professionals is minimum whether the weekend Psychiatric consultation, monitoring of medication by nurses and intervention of social workers. Most of the Psychiatrist in the National Institute (NIMHANS, Bangalore) extend their helping hand this deprofessionalised model and support in training and development in the entire process of enhancing human rights to the persons with mental illness in this family care model.

Conclusion

Stigma is manmade. Disability may be natural outcome of an infirmity. However, one should find that the attitude change in the care taker may be the key factor in empowering the mentally ill, to cut across all barriers of stigma in disability care. The centre at the outskirts of Kottayam distinct out in giving an example of how the pro-patient attitude can really make a difference in the mentally ill. Although it is an established fact in such centers, the driving force behind the phenomena yet to be studied. It could be a live model for all professionals working with the rehabilitation of the mentally ill persons pan national.

References

Ali Jookhun (2012): Persons With Disabilities: "Removing Barriers to Create an Inclusive and Accessible society for All", *Le Mauricien,* 14:45.

Anthony, W. A. (1991). Recovery from Mental Illness: The New Vision of Services Researchers. *Innovations and Research,* 1(1), 13–14.

Anthony, W. A., and Blanch, A. K. (1989): Research on Community Support Services: What have We Learned? *Psychosocial Rehabilitation Journal,* 12(3), 55–81.

Anthony, W. A., Cohen, M. R., and Farkas, M. D. (1990). *Psychiatric Rehabilitation*. Boston: Boston University, Center for Psychiatric Rehabilitation.

Baldwin ML, Johnson WG (1998): *Dispelling the Myths about Work Disability, in New Approaches to Disability in the Workplace.* Edited by Thomason T, Burton JF, Hyatt DE. Madison, Wis, Industrial Relations Research Association.

Jose Miguel Caldas de Almeida and Helen Killaspy (2011): *Long-Term Mental Health Care For People With Severe Mental Disorders,* European Union.

Lehman AF, Steinwachs DM (1998): Patterns of Usual Care for Schizophrenia: Initial Results from the Schizophrenia Patient Outcomes Research Team Client Survey. *Schizophrenia Bulletin* 24:11–19.

Phillip Copestake (OPM), Sanah Sheikh (OPM), Sheonaidh Johnston (Ipsos MORI) and Alex Bollen (Ipsos MORI) (2014): *Removing Barriers, Raising Disabled People's living Standards.*

Robins LN, Regier DA (eds) (1990): *Psychiatric Disorders in America: the Epidemiologic Catchment Area Study.* New York, Free Press.

Stroul, B. (1989). Community Support Systems for Persons with Long-term Mental Illness: A Conceptual Framework. *Psychosocial Rehabilitation Journal,* 12, 9–26.

Turner, J. E., and TenHoor, W. J. (1978). The NIMH Community Support Program: Pilot approach to a Needed Social Reform. *Schizophrenia Bulletin,* 4, 319–348.

Wang PS, Berglund PA, Kessler RC (2000): Recent Care of Common Mental Disorders in the US: Prevalence and Conformance with Evidence-based Recommendation. *Journal of General Internal Medicine* 15:284–292.

William A. Anthony (1993): Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s, Reprinted from *Psychosocial Rehabilitation Journal,* 16(4), 11–23.

WHO. World Health Report 2001. *Mental Health: New Understanding, New Hope.* Geneva, World Health Organization, 2001.