Rehabilitation of long-stay patients in state mental hospitals: Role for social welfare sector

Thanapal Sivakumar, Jagadisha Thirthalli, Bangalore N. Gangadhar
Department of Psychiatry, National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka, India

ABSTRACT

Barriers to discharge long-stay patients with mental illness (PWMI) are complex and involve social factors. Recent legislations emphasize community living and creation of facilities by Government for PWMI without social support. The Honorable Supreme Court has dealt with the need for setting up rehabilitation homes for long-stay PWMI who do not require hospitalization. In such cases, nominated representative from social welfare sector needs to be involved in discharge planning. The social welfare sector needs to play a bigger role in the rehabilitation of long-stay PWMI.

Key words: Community living, long-stay patients with mental illness, social welfare sector, state mental hospitals, Supreme Court of India

INTRODUCTION

Thousands of patients with mental illness (PWMI) are hospitalized for several years to decades in mental hospitals across India.\(^1\)\(^2\) Thanks to modern treatments, most patients have recovered symptomatically to be fit for discharge. Only a small proportion of them require a long-term stay in hospitals due to suboptimal response to treatment, significant disability, and need for institutional support.\(^3\) A substantial proportion continues in the hospital in a state of “handicaptivity”: accepting the security of a hospital due to a lack of better available alternatives.\(^4\) The recent NIMHANS/National Commission for Women (NCW) 2016 report, while acknowledging that long-stay PWMI should be treated and returned to families or be in the least restrictive settings like community or half-way homes etc.,\(^5\) poses a scathing question. “…Where are these in India? The only alternative presently is the street….”\(^5\)

There have been reports from the National Human Rights Commission (NHRC),\(^2\)\(^3\)\(^4\) NCW,\(^5\) mainstream media, and nongovernmental organizations (NGOs)\(^6\) on the “sub-optimal” living conditions of the state mental hospitals in India due to multiple factors including overcrowding, inadequate human resources, poor infrastructure, custodial mindset, and lack of support for rehabilitation and reintegration. The last two aspects are critical in the successful discharge of long-stay PWMI. As of now, these are being largely addressed by mental health institutes, which function as part of the health sector. However, the role of health sector is minimal, and that of the social welfare sector is paramount in these aspects. In fact, programs pertaining to rehabilitation and reintegration of persons with disabilities (including those with disability due to mental
illness) with the mainstream society has been the mandate of the Ministry of Social Justice and Empowerment (MSJE) of the Government of India and its counterparts in the States and Union Territories.

Although the NHRC follow-up report in 2008 documented some progress in terms of reducing the number of long-stay PWMI by more than 50%, the prevailing situation is “unacceptable”.

BARRIERS TO DISCHARGE FOR LONG-STAY INPATIENTS IN STATE MENTAL HOSPITALS

The NHRC/NIMHANS report of 1999 stated that “Large institutions, inadequate psycho-social interventions, long distances, and unavailable families perpetuate chronicity” of patients in state mental hospitals. Barriers to the discharge of a long-stay PWMI is complex and includes factors mentioned below:

1. Families are unwilling to take the patients back. For relatives of “unwanted” mentally ill patients, the mental hospitals serve as “dumping grounds.” Some patients may not have any living family members to whom he/she may be discharged.
2. Patients are unable to communicate their address – Some might have left their homes years ago and might have forgotten their address; others may have limitations that preclude communication of their address (e.g., patients speaking a language that the hospital staff cannot comprehend, patients having serious communication difficulties like speech/hearing impairment).
3. Patients belong to different states or countries. In this case, there are additional logistical and bureaucratic barriers to discharge the patient.
4. When patients were admitted under reception order for the treatment of mental illness (under the Mental Health Act 1987), there are logistical difficulties in decertifying patients. In some cases, the wording of the “reception order” may also create barriers. For example, reception order may have stated that the patient needs to be treated and discharged to the family. When the family does not exist or cannot be traced or is unwilling to take the patient back, there are barriers to shifting to another institution.

Most long-stay patients, who have recovered symptomatically, aspire for a “normal life” like others. The hospital atmosphere is not suited to address their aspirations and emotional needs. Mental hospitals are not equipped to offer the supports required to progress in the road to recovery in the form of positive social role models, avenues to take up a career/studies, fulfillment of social milestones such as getting married and being financially independent. For this group of patients, continued stay in the mental hospital itself is a serious hindrance to recovery.

LITIGATIONS AND LAWS ABOUT LONG-STAY PATIENTS IN MENTAL HOSPITALS

The NHRC report (2008) cited Court judgments that it is the “statutory obligation of the State Government to bear the cost of mentally ill persons.” Recent legislations (viz., Rights of Persons with Disabilities [RPWD] Act [2016] and Mental Health Care Act [MHCA] [2017]) clarify the rights of persons with mental illness and the responsibilities of the Government.

Both legislations place an emphasis on community living and creation of facilities by Government for PWMI without social support.

The RPWD Act (2016) states the responsibility of the Government for formulating schemes and creating facilities for community living.

1. Clause 24 (1): The government should “formulate necessary schemes and programmes to safeguard and promote the right of persons with disabilities for adequate standard of living to enable them to live independently or in the community” and
2. Clause 24 (3c): Such schemes should provide for “facilities for persons including children with disabilities who have no family or have been abandoned, or are without shelter or livelihood.”

The MHCA (2017) makes it clear that a person with mental illness shall not stay back in the hospital as a default option for want of alternatives. The relevant clauses of MHCA (2017) are as follows:

1. Clause 18 (5c): “Long term care in a mental health establishment for treatment of mental illness shall be used only in exceptional circumstances, for as short a duration as possible, and only as a last resort when appropriate community based treatment has been tried and shown to have failed”
2. Clause 19 (1): “Every person with mental illness shall have a right to live in, be part of and not be segregated from society; and not continue to remain in a mental health establishment merely because he does not have a family or is not accepted by his family or is homeless or due to absence of community based facilities”
3. Clause 19 (2): “Where it is not possible for a mentally ill person to live with his family or relatives, or where a mentally ill person has been abandoned by his family or relatives, the appropriate Government shall provide support as appropriate including legal aid and to facilitate exercising his right to family home and living in the family home”
4. Clause 19 (3): “Establishment of less restrictive community-based establishments including half-way homes, group homes and the like for persons who no longer require treatment in more restrictive mental health establishments such as long stay mental hospitals.”
Over the past three decades, public interest litigations and judicial responses have, to some extent, shaken off the inertia in the reform of mental hospitals. The Honorable Supreme Court order dated July 10, 2017 (Gaurav Kumar Bansal vs. State of Uttar Pradesh) dealt with the need for setting up rehabilitation homes for persons

i. Living with mental illnesses who have been cured; who do not need further hospitalization

ii. Who are homeless and

iii. Who are not accepted by their families.

The Honorable Supreme Court (Gaurav Kumar Bansal vs. Mr. Dinesh Kumar and Ors) by its order dated February 25, 2019, and has asked for status reports to be filed on affidavit by all the State Governments and the Union Territories.

**IMPORTANCE OF THE ROLE OF SOCIAL WELFARE SECTOR**

Mental hospitals have worked on the reintegration of long-stay patients using their staff, support of other government departments (notably, the police) and partnership with NGOs. However, mental hospitals alone, or for that matter, health-care sector itself may not be able to address the challenges of providing better living conditions for all the long-stay PWMI, as the challenges are largely social. Clause 14 (4e) of MHCA (2017) specifies that when no relative/caregiver is available, the Mental Health Review Board “shall appoint the Director, Department of Social Welfare, or his designated representative, as the nominated representative of the person with mental illness.” As per MHCA (2017), the responsibility of care for long-stay patients (who are patients without “social support”) hence, lies with nominated representative from social welfare sector who is involved in discharge planning and rehabilitation.

In India, most PWMI are taken care by their families. The family takes care of most of the needs of the PWMI, including shelter, clothing, food, emotional, financial, medical, and rehabilitation. The family is involved in key decisions, including treatment-seeking, follow-up with mental health professionals, monitoring medication adherence, employment, and marriage. In the case of long-stay patients without family support, the role of family needs to be taken up by other agencies to facilitate rehabilitation and reintegrations. With the law mandating the representative of the social welfare sector to be the nominated representative, it becomes imperative that this sector has to cater to the needs of the PWMI in a comprehensive manner. It is important that the care provided by the social welfare sector should go beyond providing the PWMI with safe shelter and food. The sector has to take up the onus of assisting the needs of PWMI with respect to studies, employment, marriage, citizenship (e.g., by providing Aadhaar cards, voter ID cards, etc.), financial autonomy (e.g., by opening bank accounts, linking disability pension to the bank account, etc.), practice of religion, etc. Only when these needs are addressed is the reintegration would be complete and this goes a long way in making homeless PWMI live with dignity and autonomy, which they deserve as fellow human beings.

**GOVERNMENT OF INDIA INITIATIVES**

In this context, the Department of Empowerment of Persons with Disabilities (Divyangjan) under MSJE has come up with “Deendayal Disabled Rehabilitation Scheme” (introduced on April 01, 2018) which offers provisions for the facilitation of halfway homes for psychosocial rehabilitation of treated PWMI. Guidelines have also been framed regarding procedure and norms to followed while setting up of rehabilitation homes (half-way homes and long-stay homes) for PWMI “who have been cured,” do not need further hospitalization, are homeless or are not accepted by their families. Patients languishing in mental hospitals may benefit from such schemes.

**INITIATIVES FROM NONGOVERNMENTAL ORGANIZATIONS**

There are pioneering initiatives from the NGO sector in reintegration and community living options for patients. For instance, “Shraddha” has helped in the reintegration of >7000 PWMI back to their families across the country. “Shraddha” utilizes nuggets of information provided by PWMI to trace the family with help of groundwork involving community resources and facilitates reunion. The organization has been working with state mental hospitals to assist in the process of tracing the address and reintegrating patient back to families. Another NGO, “Banyan”, has demonstrated that it is feasible to accommodate the institutionalized PWMI in a range of supported-inclusive living options to encourage participation, independence, and social inclusion in rural and urban communities. In their “Home again” program, “personal assistants” – women volunteers drawn from the community, with no special qualifications, handhold PWMI 24 × 7 and offer necessary support to facilitate living in rented accommodations in the community. The cost of care is reported to be about Rs. 10,000/month per person – it is considerably more economical than the cost incurred by mental hospitals for a bed per month.

**ADDITIONAL INPUTS REQUIRED FROM SOCIAL WELFARE SECTOR IN INDIA**

The important role of social security benefits (including disability pension) to facilitate community living of long-stay institutionalized PWMI has been documented in other countries. Resources in the social welfare sector should be used for coordinated utilization of several existing schemes that would go a long way in comprehensive postdischarge care of long-stay patients and prevent rehospitalization.
1. As a first step, the Aadhaar card should be provided as proof of identity and address. This would pave way for several important services, including the opening of bank accounts, getting voter ID cards, securing a job, etc.[20]

2. Disability certificate (where applicable) along with access to welfare benefits entitled for a person with a disability including disability pension, travel, and other benefits for the patient and caregiver.[21] The amount of disability pension needs to be periodically revised according to inflation/cost of living

3. Supported education and employment need to be integrated across various discharge pathways, including discharge to families, half-way homes, and long-stay homes to facilitate social reintegration, reduce stigma, improve quality life, and functioning. Patients can be enrolled in skills training initiatives under government as well as NGOs and livelihood options including Mahatma Gandhi National Rural Employment Guarantee Act

4. The Government can also consider incentives in the form of specific schemes for families who accept the patient back to their families like offering loans at nominal interest to start self-employment and extra rations for the family taking care of the patient

5. Access to psychiatric care and psychotropic medications close to the home through a Government mental health facility is now possible, with the district mental health program being launched in all districts of the country. This will bring down out-of-pocket expenditure incurred by families for providing treatment to PWMI.[22]

**STEPS TO PREVENT “NEW” LONG STAY INPATIENTS**

As the MHCA (2017)[23] precludes long-term hospitalization, it is imperative that nominated representative from social welfare sector would be closely involved with mental hospitals right from the time of admission of a “homeless person with mental illness” and in discharge of patients with poor social support. The Department of Empowerment of Persons with Disabilities (Divyangjan) under MSJE needs to work with governmental and NGO’s to expand “Deendayal Disabled Rehabilitation Scheme” in creating less restrictive community-based establishments including half-way homes and long-stay homes in each district across the country. Another option for long-stay female PWMI who are capable of independent living is the “Swadhar Greh” scheme (promoted by the Ministry of Women and Child Development) for providing shelter, food, clothing, and health as well as economic and social security for women victims of difficult circumstances without social or economic support.[23]

**CAUTION ABOUT TRANS-INSTITUTIONALIZATION**

In Western countries, one of the unforeseen negative consequences of deinstitutionalization is transinstitutionalization. “Trans-institutionalization” is defined as the moving of patients from one institution, such as a mental hospital, to being dependent on another type of institution, such as a shelter, community hospital, jail, or nursing home facility.[24] In the USA, the state prison system has become the largest mental health institution in the country.[25] Reports state that there are 10 times as many persons with severe mental illness in prisons and jails than in mental hospitals.[25]

In India, there is a real possibility that a “custodial” mindset may be replicated in the “half way and long stay homes” proposed to be set-up to facilitate community living for long-stay PWMI with poor social support or high support needs. The staff-patient ratio and supervision in such facilities are likely to be lesser than in a mental hospital. The possibility of abuse or patients getting out of the facility and getting incarcerated cannot be ruled out.

In this context, it is necessary that challenges of deinstitutionalization in western countries are overcome in India. The rules and regulations for setting up community living facilities under RPWD Act (2016)[11] and MHCA (2017)[12] ensure minimum standard of care. This should be ensured with the provision of adequate funds, infrastructure, handholding of staff working in these facilities to create culture of facilitating “recovery,” liaison with all stakeholders and ongoing monitoring.

**NEED FOR INTER-MINISTERIAL COORDINATION**

Experts have observed that continuum of care for patients has been overshadowed by rigid boundaries of the administration by different ministries.[13] Under the Indian constitution, health falls under jurisdiction of the Ministry of Health and family welfare (MOHFW) while rehabilitation is under the jurisdiction of MSJE. There is a need for both ministries to work closely with each other.

The NHRC/NIMHANS report of 1999[3] documented a lack of cooperation between MSJE and MOHFW.[3] A mechanism of continuous intensive cooperation between the two ministries was recommended for rehabilitation aspects.[3] It was suggested that member from MSJE could be a member of the state mental health authority; and similarly, a member from MOHFW could be a member of the central coordination committee formed under Persons with disabilities act 1995.[3]

The recent MHCA (2017)[12] and RPWD Act (2016)[11] have specified that representatives of MOHFW and MSJE are present in central/state mental health authority and central/state advisory board on disability, respectively. This should facilitate closer collaboration between the ministries to take care of PWMI. Having a nominated representative
from social welfare sector for PWMI with poor social support will also aid in closer coordination.

While the long-stay patients with poor social support are expected to be taken care in “half way homes and long-stay homes” established by the Department of Empowerment of Persons with Disabilities (Divyangjan) under MSJE, the patients will require continued clinical care from mental health professionals. Unlike other disabilities, ongoing treatment with periodic consultations is necessary to ensure that symptoms are under control.

MHCA (2017)[12] has ensured that it is the right of PWMI to get free and accessible mental health services at government-run or funded establishments from the community health center and/or other services close to their residence. This has ensured that state governments take up the role of district mental health program seriously. The District Mental Health Program Teams are best suited to provide ongoing interventions in government-run or government-supported halfway homes and long stay homes.

CONCLUSION

The RPWD Act (2016)[11] and MHCA (2017)[12] have ensured the right to community living to PWMI. Long-term hospitalization in mental hospitals is not the default option. While the creation of “half-way homes, group homes” and long-stay homes’ can be criticized as “trans-institutionalization,” they are likely to provide better opportunities for community living, be less expensive for the government and also relieve precious hospital beds to treat many acutely symptomatic patients. It is necessary to create adequate social supports while embarking on the transition using family network as well. Health and social welfare sectors need to work in close liaison in the process.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Narasimhan L, Mehta S, Ram K, Gangadhar B, Thirthalli J, Thanapal S, et al. National Strategy for Inclusive and Community Based Living for Persons with Mental Health Issues. New Delhi: The Hans Foundation; 2019.

2. Nagaraja D, Murthy P, editors. Mental Health Care and Human Rights. 1st ed. New Delhi: National Human Rights Commission; 2006. p. 69-84.

3. Ministry of Law and Justice, Government of India. The Rights of Persons with Disabilities Act, 2016. Ministry of Law and Justice, Government of India; 2016. Available from: http://www.disabilityaffairs.gov.in/upload/uploadfiles/JPWD%20Act%202016.pdf [Last accessed on 2019 Apr 14].

4. Supreme Court of India. Supreme Court of India. Record of Proceedings Commit.pet.© no. 1653/2018 in w.p.© no. 412/2016. Gaurav Kumar Bansal vs. Dinesh Kumar & ORS (with/ANo. 122/2016) in Reporter to appear and argue in person) with MA 2352/2018 in W.P.No. 412/2016 (PIL-W); 2019. https://www.st.gov.in/supreme3court2018/32117/32117_2018_Order_25-Feb-2019.pdf. [Last accessed on 2019 Apr 19].

5. Seshadri K, Siva Thar T, Jagannathan A. The Family Support Movement and Schizophrenia in India. Curr Psychiatry Rep 2019;21:95.

6. Deendayal Disabled Rehabilitation Scheme (DDRS): Department of Empowerment of Persons with Disabilities. Available from: http:// disabilityaffairs.gov.in/content/page/ddrs-scheme.php. [Last accessed on 2019 Apr 21].

7. Shelar J. The Story of a Doctor who Reunites Lost Mentally-Ill Patients with their Families. The Hindu; 06, August, 2018. Available from: https://www.thelindia.com/sce-tech/health/in-conversation-with-ramon-magsaysay-award-winner-psychiatrist-bharat-vatwani/article24613279.ece. [Last accessed on 2019 Apr 30].

8. These Homes are Helping Women with Mental Illness Merge into Society. The Week. Available from: https://www.theweek.in/leisure/society/2019/01/09/these-homes-helping-women-mental-illness-merge-into-society. [Last accessed on 2019 Apr 30].

9. Pedersen PB, Kolstad A. De-institutionalisation and trans-institutionalisation – Changing trends of inpatient care in Norwegian mental health institutions 1950-2007. Int J Ment Health Syst 2009;3:28.

10. Sivakumar T, James JW. Facilitating aadhaar and voting for long-stay patients: Experience from a tertiary care center. Indian J Psychol Med 2019;41:472-5.

11. James JW, Basavarajappa C, Sivakumar T, Banerjee R, Thirthalli J. Swavlamban Health Insurance scheme for persons with disabilities: An experiential account. Indian J Psychiatry 2019;61:369-75.

12. Sivakumar T, James JW, Basavarajappa C, Parthasarathy R, Naveen Kumar C, Thirthalli J. Impact of community-based rehabilitation for mental illness on 'out of pocket' expenditure in rural South India. Asian J Psychiatr 2019;44:138-42.