



NATIONAL STRATEGY FOR
INCLUSIVE AND COMMUNITY
BASED LIVING FOR PERSONS
WITH MENTAL HEALTH ISSUES





NATIONAL STRATEGY
FOR INCLUSIVE AND
COMMUNITY BASED LIVING
FOR PERSONS WITH
MENTAL HEALTH ISSUES
— 2019 —

— PARTNERS —



Ministry of Health
and Family Welfare
Government of India



Ministry of Social Justice
and Empowerment
Government of India



THE NATIONAL TRUST



CREDITS

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Photos from Archives of various partner organisations representing a mix of staff, service users, carers and members from the general community. Verbal consent obtained from subjects.

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References

- Ministry of Health and Family Welfare, Government of India, Letter No. F.No. V.15016/143/2017-PH-I dated 25th Sept 2017. (copy attached)
- Ministry of Social Justice and Empowerment, Government of India, Dept of Empowerment of Persons with Disabilities,
Vide letter no. F.No. 22-40/2017 – DD – III dated 19th December 2017. (copy attached)
- Report of the Committee to formulate Schemes / Guidelines for “Rehabilitation of Persons who have been Cured of Mental Illness” by the
Dept of Empowerment of Persons with Disabilities reference Vide OM dated 28.12.2017. (copy attached)
- Guidelines for Discharge of “Mentally Cured” or ‘Fit for Discharge’ Patients from Mental Health Institutions – submitted by Ministry of Health and Family
Welfare, Government of India to Hon’ble Supreme Court of India, pursuant to the directions in W.P. (Civil) no. 412/2016 vide order-dated 22.02.2017.
(copy attached)

Background

1. Institutional medical approaches have dominated the treatment landscape for people with mental illness since the late 1800’s. At the time when people with mental illness were cast away in prisons, emergence of large provincial and State run mental hospitals were unarguably a desirable alternative, born out of the Moral Treatment movement. But before long, conditions in institutions were in grave decline. The beginning of the 1960’s saw a discernable shift in the thinking of more developed societies especially in the U.S. and Europe. These nations were gradually gravitating to the idea of community treatment rehabilitation approach. This approach evolved over a period owing to the disenchantment with the ill-equipped and ill-run state institutions. These institutions had largely turned into a form of custodial care with large amount of abuse and neglect.

2. While de-institutionalisation was gaining momentum in North America and parts of Europe, institutions were the mainstay for mentally ill in third world countries including India. In the last decade, India has seen some movement towards de-institutionalisation. But these are in small measures, mostly individual endeavors, made by a few non-governmental organizations. At national and state levels, some of the schemes have been started but these are far from the holistic approach it deserves, such as community treatment, psychological rehabilitation and case treatment. It is thus felt, that for all those individuals who have recovered or can be repatriated and still subjected to the harsh & inhumane living conditions of institutions, it is the right time to initiate effective community-based support services in its true spirit and form.

3. Any meaningful initiatives at the state or national level can succeed only with the government participation. It is a well-known fact that there are thousands of people with mental illness, though treated, are languishing in mental hospitals. People are most often stuck and left forgotten in these institutions for extended periods of time or even for a lifetime.

4. Two landmark pieces of legislation have been passed which potentially pave the way for next steps in developing an effective community system of mental health. The first is the Mental Healthcare Act of April 2017, which contains several important requirements that advance the possibility of de-institutionalization of long-stay patients in mental hospitals, as well as create advantageous conditions for preventing such institutionalization, where possible. The second is the Rights of Persons with Disabilities Act of 2016, which is designed to bring practice in line with the standards set forth by the UNCRPD, of which India is a party. The Supreme Court following a public interest litigation this year has stated “the Government cannot allow a person to be kept in a mental asylum or a nursing home after he or she is fully cured of the ailment. They have to be brought back to civil society” (Indian Express, 2017), adding yet more timeliness to the efforts to move forward towards deinstitutionalization.

Aim

5. The aim of this study is to evolve a comprehensive national strategy for inclusive and community based living for persons with mental health issues.

De-institutionalization in India

6. De-Institutionalisation can be defined as the replacement of long stay psychiatric hospitals with smaller, less isolated community based alternatives for the care of people with mental illness/psychosocial disability. De-institutionalisation as a process is not limited to the reduction of psychiatric hospitals patients. It is a complex process leading to provision of alternative services such as strengthening community based care and approaches.

7. India was amongst one of the first countries in developing world to formulate a National Mental Health Programme in 1982 and advocated integration of mental health into primary health. However, over the years, this initiative lost steam as well as credibility. There has been both appreciation and criticism of this programme. It has been successful in parts and has left a positive impact in terms of progressive thinking and aims. Consequently, the first National Health policy document for India was released in October 2014. The vision enunciated in the policy is to promote mental health, prevent mental illness, enable recovery from mental illness, to promote positive community-based support, and ensure socio-economic inclusion of persons affected by mental illness by providing affordable and quality health and social care to all persons through their entire life span.

8. There has been a lot of movement ever since this policy was formulated. The long pending ‘The Right of Persons with Disabilities’ bill was passed by the parliament in Dec 2016 which is yet another landmark achievement in the series of these events. The time is now ripe to go in for de-institutionalisation. Any efforts in isolation would be limited and the Government involvement is a must from long term sustainability point of view.

Task Force

9. Before ordering the study, the THF consulted the Ministry of Health & Family Welfare, Govt of India Ministry of Social Justice and Empowerment, Dept of Empowerment of Persons with Disabilities, Govt of India and National Trust, Ministry of Social Justice & Empowerment, Govt. of India for their participation in the study. Members were nominated by each Ministry (Ministry of Health and Ministry of Social Justice & Empowerment) and National Trust with the approval of the Competent Authority. The composition of the Task Force has been finalised with a deep and careful selection after taking prior consent from all members to be part of this task force. The composition is given as under:

Dr S. Parasuraman Director, Tata Institute of Social Sciences (TISS) Mumbai	Chairman
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Mr Mukesh Jain, IPS / Nominee Joint Secretary & CEO The National Trust, Ministry of Social Justice & Empowerment New Delhi	Co-Chair
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Dr Alok Mathur Addl. DDG, Dte.G.H.S. Ministry of Health & Family Welfare, Govt of India, New Delhi	Co-Chair
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Shri T. C. Siva Kumar, Director, DEPwD Ministry of Social Justice & Empowerment, Govt of India, New Delhi	Member
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Dr Nimesh G Desai, Director, IHBAS	Member
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Dr Narender Sharma Associate Director Keystone Institute India, New Delhi	Member
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Ms Ratnaboli Ray Director, Anjali, Kolkata	Member
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Mr Mukul Chandra Goswami, Padmashri Founder Secretary, Ashadeep, Guwahati	Member
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Dr G V Rao Executive Director, The Hans Foundation	Member
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Ministry of Women and Child Development, Govt of India

Consulting Adviser
Ms Elizabeth Neuville
Director, Keystone Institute India, New Delhi

Scope of Work

10. The scope of the study is enunciated below but not restricted by it.

- a) Develop a position paper on approaches for long stay institutionalized persons with mental health issues to be reintegrated back to their families or into appropriate inclusive living options.
- b) Study and analyse de-institutionalization/socially inclusive models, which would be most suitable in the Indian social context.
- c) Study work/Schemes initiated at State/National level by the respective Governments and other civil society initiatives, which show potential for replication/modification and adoption at a National/State level.
- d) Enumerate challenges in implementation of community-based models for persons with severe mental illnesses, who lack family support.

Service Delivery / Programme Implementation and creation of demonstration sites

- e) Identify States where conditions are favorable for implementation of pilot projects.
- f) Focus on prevention of long term institutionalization by ensuring adequate support networks.
- g) Identify existing Government Schemes/legislations which can be integrated and lend long-term sustainability to various initiatives.
- h) Identify potential organisations working in the same thematic areas for future collaborations.
- i) Budgeting aspects and Financial Implications.

Terms of Reference

11. Terms of reference for the task force are: -

- (a) Task force will complete study and submit a report by 30th July 2018.
- (b) All the expenditure incurred on the study will be borne by THF.

12. The task force has been set up with the aim of unifying efforts and to evolve a long-term sustainable strategy for de-institutionalisation at the State and National level. Such a strategy can only succeed with the active participation of Governments. It is time for all those hundreds of thousands mentally ill in India to come out of the vicious circle of systemic abuse and neglect and enter into the virtuous circle of new dawn where they live in equality and treated with dignity. The task force has an arduous and daunting journey ahead. However, the task ahead is so onerous and promising for the mankind that it will keep them on a steady compass to reach their destination.

Lt. Gen S M Mehta, (Retd) AVSM, SM, VSM and Bar
Chief Executive Officer
The Hans Foundation, New Delhi

Dated: 12th January 2018

No. T. 20013/41/2018-NCD
Government of India
Ministry of Health and Family Welfare

To.

Principal Secretaries (HFW) of all States/UTs

Subject: Study on de-institutionalization of persons with mental illnesses admitted in various mental health institutions of the country.

Sir,

I am directed to inform you that the Government has issued notifications for appointing 29th May, 2018 as the date on which the Mental Healthcare Act, 2017 shall come into force along with the Rules framed under the said Act.

2. As per the provisions of the Act, the State Governments are required to take action on various provision of the Act in a time bound manner so as to ensure effective and timely implementation of the provisions of the Act. The provisions of the Act also discourage long-term institutionalization of the mentally ill persons in mental health institutions.

3. Hans Foundation, a charitable trust and a not-for-profit organization in India, is carrying out a study on de-institutionalization of persons with mental illnesses admitted in the mental health institutions of the country. The study is expected to come out with recommendations with respect to discharge and further rehabilitation of long-stay patients in such institutions. In this regard, a Task Force has been constituted by the organization which has developed a study protocol to assess the condition of persons who have recovered from their mental illness, but are still languishing in these institutions for more than one year, Six institutions/organizations, namely NIMHANS (Bangalore), Hospital for Mental Health (Ahmedabad), IHBAS (Delhi), BALM (Chennai), Anjali (Kolkata) and Ashadeep (Guwahati) have been entrusted to carry out the study. The study has been given ethical clearance by TISS, Mumbai and the data collected would be kept confidential.

4. In the view of the above, it is requested that necessary directions be kindly issued to the concerned officials of the mental health institutions in your state to facilitate the visiting teams of the above six institutions/organizations.

Yours faithfully,



(Ajaya Kumar KP)

Under Secretary of the Govt. of India

Telefax: 011-23061342

F. No: - 22-40/2017-DD-III

Government of India

**Ministry of Social Justice and Empowerment
Department of Empowerment of Persons with Disabilities**

Antyodaya Bhawan, CGO Complex, New Delhi

Dated the 19/12/2017

To,

Lt. Gen S.M. Mehta
CEO - The Hans Foundation
E - 4, Asola Homes, Asola
(Near Sani Dham Mandir)
Mehrauli
New Delhi - 110074

Sub: Nomination of members from Department of Empowerment of Persons with Disabilities for the Study on Directive towards a sustainable National Strategy for De - Institutionalization of Persons with Mental Illness.

Sir,

I am directed to refer to you letter dated 16/11/2017 on the above cited subject and to say that Sh. T.C. Siva Kumar - Director of this Department has been nominated for the above study, is contact details are as under:-

Department of Empowerment of Persons with Disabilities
Room No 520, Pt. Deen Dayal Upadhaya Antyodaya Bhawan
CGO Complex, Lodhi Road
New Delhi - 110003
Ph. No: 011 24369025 / Mob: 9441229519
E.Mail: tc.sivakumar@gov.in

2. This issue with the approval of competent authority of the Department.

Yours faithfully,



(D.K. Panda)

Under Secretary to Government of India

Tel: 24369054

Copy To:

1. Sh. T.C. Siva Kumar - Director, kindly note that association with The Hans Foundation for the above study should not affect performance in the Department,
2. PSO to Secretary, DEPwD

F.No. V. 15016/143/2017-PH-I
Government of India
Ministry of Health and Family Welfare

Nirman Bhawan, New Delhi - 110011
Dated 25th September, 2017

To,
Shri G.V. Rao,
Executive Director,
The Hans Foundation,
C-303, 3rd Floor, Ansal Plaza,
Andrews Ganj, New Delhi - 110049

Subject: Nomination of a member to the Task Force to be set up by The Hans Foundation.

Sir,

I am directed to state that Dr. Alok Mathur, Addl. DDG, Dte.G.H.S. has been nominated as a representative of the Ministry of Health & Family Welfare in the Task Force to be set up by the The Hans Foundation to evolve a Strategy which serves as a vehicle for advocacy and adoption of de-institutionalization.

This issues with the approval of the Competent Authority.

Yours Faithfully,



(Ajaya Kumar KP)

Under Secretary to the Govt. of India
Telfax:011-23061342

Copy to:
Dr. Alok Mathur, Addl. DDG, Dte.G.H.S.

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Ms. Julie George

External Expert-Child Rights

Prof. Nilima Mehta

Community Representative

Mr. Bhaskar Kakad

Member Secretary

Prof. Surinder Jaswal

**Institutional Review Board
Ethics Clearance Report**

Serial No. of IRB Meeting	2018-19	01
Project Title	National Strategy for Inclusive and COmmunity Based Living for Persons with Mental Health Issues	

Name of Faculty In-charge/Project Coordinator/Principal Investigator:
Prof. S. Parasuraman

Date of Submission to the Committee	0	9	0	7	2	0	1	8
Date of Submission to other IRB's (if applicable)								
Date of First Review	1	1	0	7	2	0	1	8

The IRB appreciated the topic of the proposal. The IRB acknowledged that the study has the potential to be a pioneering study in the field of Mental Health. The IRB suggested the following suggestion regarding the ethical component of the study:

1. A component of the study could focus on the situation and the voices of the people with mental health issues who are not in institutionalized care settings as this is also a vulnerable group.

The IRB also observed the following scientific recommendation which may intertwine with the ethical components of the study:

1. The study could benefit from referring to the TISS study titled 'Status of Women in Mental Hospitals in Maharashtra' which was commissioned by the Maharashtra State Commission for Women in 2002-2003.

All suggested changes have been adequately addressed.

[Signature]

Signature of the Chairperson

[Signature]

Signature of Member Secretary

Date of issue: July 24, 2018



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மாநில மருத்துவ
சிகிச்சை

மாநில மருத்துவ சிகிச்சை



Acknowledgements

We express our gratitude to the study participants, long-stay service users across India's state mental hospitals, who offered us their data and stories that form the substance of this report, which aims to inform pathways to inclusive living options. A wide variety of stakeholders were involved in the conceptualisation and execution of the study. In particular, we wish to thank the Ministry of Health and Family Welfare, Government of India, the Departments of Health of various states and Superintendents and staff of state mental hospitals for their support that made the study possible.

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EXECUTIVE SUMMARY

Worldwide, a median of 18% of people living in psychiatric facilities have been there for a year or more.⁵

Mental health is increasingly acknowledged as a growing priority for public health and development, contributing to 13% of the global burden of disease¹ and 37% of healthy years lost due to ill health.² Despite this recognition and the availability of effective evidence-based interventions, people with mental illness in low- and medium-income countries do not receive necessary care.

Of the estimated 150 million Indian citizens with mental health concerns, 60% of people living with schizophrenia do not receive the care they need.³ According to the National Mental Health Survey 2016, the overall treatment gap in India is estimated to be as high as 83%.⁴

Further, people with mental illness are excluded from meaningful participation in work, family and community, and face widespread discrimination and

abuses of their human rights. Within this broader context of social exclusion, a profound and significant form of oppression facing people with mental illness is long-term institutionalisation in tertiary psychiatric facilities and rehabilitation homes.

Worldwide, a median of 18% of people living in psychiatric facilities have been there for a year or more.⁵ Modern psychiatric facilities, while varied in their quality of care and rights-based orientation, are remnants of the asylum model of mental health care, and some continue to be characterised by paternalism and restrictive practices. Irrespective of the quality of care at such hospitals, the institutionalisation of people with mental illness over extended periods perpetrates segregation and their exclusion, distancing them from socio-economic, cultural and political resources and the right to live with dignity.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) articulates in Article 19



the rights of disabled people, including those with psychosocial disability, to live independently and be included in the community. This includes the right to choose their residence and enjoy access to a range of home-based or other community support, including any necessary personal assistance to enable them to live and participate in the community, so that they are not segregated or excluded in any way.

Consistent with the UNCRPD, the Rights of Persons with Disabilities Act of 2016 (RPWD) and the Mental Healthcare Act of 2017 (MHCA) enshrine the right of people with psychosocial disabilities to live in the community and mandate government responses. In early 2017, The Supreme Court of India passed a directive, subsequent to a Public Interest Litigation (PIL) filed by Gaurav Kumar Bansal (Writ petition No 412/2016), for national and state governments to develop a strategy to address the issue of long-stay in mental hospitals.

About 32% of mental hospital beds in India are estimated to be occupied by long-stay service users, a higher proportion than the global median and the median estimate of 11% for the South East Asian region.⁶ In the last decade, India has seen some movement towards de-institutionalisation. But these are in small measures, mostly individual endeavours, and far from holistic community-based support services in true spirit and form.





In the last decade, India has seen some movement towards de-institutionalisation. But these are in small measures, mostly individual endeavours, and far from holistic community-based support services in true spirit and form.

A directive by the Hans Foundation was issued to undertake a study across 43 state psychiatric facilities across 24 states to develop a comprehensive national strategy for inclusive and community-based options for people with mental illness in India.



Currently, available options for long-term care outside psychiatric hospitals are mostly limited to institutional set-ups run by both state and non-state actors.

In this context, given the issue of long-stay in state mental hospitals in India and the need to initiate alternatives, The Hans Foundation set up a national-level multi-stakeholder Task Force, comprising state and non-state actors, to understand and articulate approaches that address the concerns of persons with severe mental illness with long-term care needs and offer sustainable, dignified, inclusive living options. A directive was issued to undertake a study across 43 state psychiatric facilities in 24 states to develop a comprehensive national strategy for inclusive living options for people with mental illness in India.

The study's primary objectives were to determine the population with one or more years of stay in state mental health hospitals in India, understand the nature and needs of this cohort and exit options to enable community living.

Ethical clearance for the study was obtained from the Institutional Review Board (IRB) of the Tata Institute of Social Sciences (TISS).

The study used a cross-sectional, mixed-methods design with semi-structured interviews with service users across state mental hospitals as well as focus group discussions (FGDs) and key informant interviews (KIIs) with stakeholders – hospital staff across cadre, representatives from Department of Health and service user-carer groups.



Task Force members surveyed hospitals across different states listed as follows:

- The Banyan Academy of Leadership in Mental Health (BALM) – Kerala, Maharashtra, Jammu and Kashmir, Andhra Pradesh and Telangana (11 hospitals)
- Institute of Human Behaviour and Allied Sciences (IHBAS) – Delhi, Punjab, Rajasthan, Haryana, Himachal Pradesh, Uttar Pradesh and Uttarakhand (9 hospitals)
- Hospital for Mental Health, Ahmedabad – Gujarat and Madhya Pradesh (6 hospitals)
- National Institute of Mental Health and Neurosciences (NIMHANS) – Tamil Nadu, Karnataka, Bihar, Goa, Jharkhand and Odisha (8 hospitals)
- Ashadeep – Assam, Meghalaya, Tripura and Nagaland (4 hospitals)
- Anjali – West Bengal (4 hospitals)

Data were gathered between August 2018 and February 2019 using the Parrot survey applicationⁱ on hand-held devices and analysed using SPSS v 22.0.

ⁱ Parrot Solutions Pte Ltd, Delhi designed a tablet accessible application that captured data during data collection across different sites and stored in a centralised cloud based database.



FINDINGS

1. Number and Background

Characteristics:

36.25% (4935) of residential service users at state psychiatric facilities have been living in these institutions for one year or more.

- a. There are more women than men (54.3% women, 45.7% men) in the long-stay population.
- b. Punjab (233), Tamil Nadu (612), West Bengal (971), Uttarakhand (19), Madhya Pradesh (206) have the highest proportion of long-stay service users (>60%).
- c. Assam (10), Bihar (9), Telangana (50), Andhra Pradesh (25), Karnataka (69), Kerala (168) had the lowest proportion of long-stay service users (<15%).
- d. The average age of long-stay cohort was 45 years with 25 participants less than 18 years and 781 participants over 60 years of age.
- e. About 33.1% of those who entered into long-term institutionalisation were brought by families, and 55.4% were referred by the police or magistrates, indicating possible history of homelessness.
- f. The median duration of stay is six years. Close to half (48.8%) had lived inside institutions for one to five years, and 11.4% had lived for over 25 years in hospitals.
- g. The majority (77.1%) were living in closed wards and 1% were in solitary confinementⁱⁱ often for years.

2. Disability and Clinical Status:

Service users in the long-stay cohort presented with a range of clinical needs with a median score of 6 on the Modified Colorado Symptom Index (mCSI),ⁱⁱⁱ with persistent symptoms in about 40%. The majority (77.4%) had only mild to moderate disability as rated on the Indian Disability Assessment Schedule (IDEAS).^{iv} Despite this:

- a. Only 15.1% were engaged in acquiring skills and only 0.7% were in paid work.
- b. Removal from wider society was evidenced with hyper-segregation of these facilities – 93.5% never stepped outside the hospital, 86.5% never received a visitor, and 94.8% never visited anyone outside the hospital.
- c. Tamil Nadu, Karnataka and Bihar have over 40% of service users in the long-stay cohort, requiring high support for their daily living.

3. Prospects for Community Placement:

None to moderate problems are anticipated with transition and placement in the community for the majority (78.6%) of the long-stay cohort.

- a. Among participants expressing preferences for return to community, 41.9% prefer to go back to their family, 13.2% prefer supported living, while 14.4% wish to remain at hospital and 30.5% did not express a clear preference.^v
- b. Family resistance is noted in 32.6% of the cohort and may prevent the most preferred option of returning to family from being realised.
- c. Based on disability, clinical status, preferences and support needs, three broad community placement options are assessed as potentially feasible and appropriate:
 - Family placements: Recommended for 24.8% of this cohort who may be reintegrated with their family and supported with after-care packages
 - Scatter-site Housing with Supportive Services: Rented accommodation in ordinary rural or urban neighbourhoods shared by a group of people with personalised and need-based on-site or off-site staff support recommended for 44.9% of the long-stay cohort. Locally developed models such as Home Again (The Banyan) and

Non-Congregate Group Homes (Swayamkrushi) may be considered for replication.

- Congregate Housing with Supportive Services: Group Homes shared by people with 24/7 on-site staff support recommended for 20.7% of the long-stay cohort.

Additionally, halfway homes on the hospital campus or within its vicinity with a similar or stepped-down degree of support as acute care units maybe considered for 9.6% of the long-stay cohort with extremely high support needs.

ⁱⁱ Refer to Glossary (Point 30)

ⁱⁱⁱ Refer to Glossary (Point 18)

^{iv} Refer to Glossary (Point 21)

^v Refers to people who did not answer the question or preferred not to state their preference.

4. Perceived reasons for long-stay among stakeholders:

- a. Inability to trace and reconnect with families of those with histories of homelessness either due to possible migration, lack of information or logistical barriers such as language.
 - Resource deficits in terms of necessary human resources and financing for undertaking reintegration (sociotherapy, travel, translation) leading to service users living well beyond the time necessary for recovery.
 - Policy deficits that place barriers on atypical discharges (such as self-discharge, into group homes, employment with a hostel), inter-country repatriation efforts and so on that often unfavourably affect people with histories of homelessness.
- b. Sedimented negative attitudes against people with mental illness based on previous episodes of illness challenging acceptance in the family and consequent adjustment in the family environment.
- c. Poverty and lack of effective continued care conflating demands placed on carers and leading to loss of social capital, especially in instances where clinical needs are high, resulting in institutionalisation.
- d. Pathways into long-term institutionalisation defined by gender-based disadvantage with disruptions in family and intimate partner relationships and consequent irreconcilable trauma.
- e. Limits of existing therapeutics in addressing symptoms contributing to a cohort with persistently high support needs.
- f. Choice among a section of service users to not return to past environments of trauma (such as sexual abuse, intimate partner violence) that are intertwined with their trajectories of ill-health and homelessness.





g. Non-conformity to expected social roles and occupational functioning (contributing to household chores, demonstrating specific social behaviours, earning an income etc.) causing families to disengage with service users.

h. Increasingly disintegrated families, such as single older carers, siblings or distant relatives who are unable or reluctant to offer care.

RECOMMENDATIONS AND ACTION PLAN

1 Frame values and protocols - non-negotiable drivers that must define the structures and processes of Community Placements for the long-stay cohort, to fully realise community living and prevent these alternatives from lapsing into micro-institutional facilities vested with similar power differentials. These include: person-centred plans, rather than facility-based plans, flexible range of supports and service including personal assistance for a range of disability levels, choice of variegated housing options and support for community participation.

2 Set up a **National Steering Committee** under the aegis of the Ministry of Health and Family Welfare to function as a leadership and stakeholder collective to pursue shared visions of moving from long-term institutionalisation to community-based alternatives. Set up **State Steering Committees** that will work on implementing and actioning the process of de-institutionalisation in each of the states in accordance with the RPWD 2016 and MHCA 2017.

3 Imagine and implement an expansive Community Care System that allies with the Social Care Sector to keep pace with supports needed when people move out of hospitals and decisively alter progressions and re-entry into homelessness and long-term institutionalisation.

4 Designate investments for defined pathways out of hospitals with accompanying legislative and policy support, particularly to support discharges into community living alternatives.

- a. Family placements: INR 60 lakhs (@ INR 5000 per person) for about 25% (n=1206) recommended to be reunited with their families with INR 60 lakhs further annually for aftercare services
- b. Scatter-site Housing with Supportive Services: INR 37 Cr (@ INR 14000 per person per month) annually for shared, rented accommodation in ordinary rural/urban neighbourhoods shared by a group of 4-5 people with personalised on-site or off-site staff support recommended for about 45% (n=2189) of long-stay cohort
- c. Congregate Housing with Supportive Services: INR 25 Cr annually (@ INR 20000 per person per month) for Group Homes shared by people with 24/7 on-site staff support recommended for about 21% (n=1009) of long-stay cohort

Note: Refer to Appendix 2 for detailed workings



5 Align efforts of community placements with key social entitlements linked to the Community Care System - disability allowance, voting rights, banking access, ration card - that can positively effect social inclusion and long-term sustainability of placements.

6 Overhaul the Institutional Care System to embrace effective, appropriate, high quality, rights-based emergency and acute care.

- Re-imagine care by separating it from 'control' and 'management' and enhance quality across domains from personal grooming and menstrual hygiene choices to access to diverse choice based work engagement options.
- Fix resource and policy deficits around discharge planning and continued care
- Enhance staff capacities (staff-client ratio and skills) so that they can embrace contemporary modes of care.
- Decentralise bed capacities from hyper-segregated, large facilities to localised services in District - and Taluk-level hospitals. Large institutions, structurally and in terms of management, are unsuitable for the personal attention necessary to offer flexible support that is critical for recovery. It is essential to rationalise the size of institutions to cap numbers and distribute acute care services across smaller, integrated set-ups.
- Introduce a Family Assistance Scheme or Cash Transfers to support Family Placements when households face socio-economic distress

7 Set up a national network online with a database management system to record, monitor, track, update status with a view to enable a robust after care system in place.





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It is imperative to recognise and urgently restore the right of people with psychosocial disabilities to live in the community, with flexible support that enables them to make choices about and exercise agency over their care and daily living, and engage in lived experiences with personal meaning. For this right to become a reality, governments need to increase financial investment defined by a policy and accompanying National Scheme for Personal Assistance and Housing Options to promote community living for people with long-term care needs. Such implementation of inclusive living options may be anchored by licensed providers and further supported by investment from other stakeholders, with quality assurance oversight offered by a National Steering Committee and State Steering Committees as co-ordinating leadership bodies.

Differences in the experience of de-institutionalisation across countries emphasise the need for investments in an expansive, balanced continuum of care that can not only support those discharged but also prevent progressions into long-term institutionalisation. Experiences of inclusive living options in India, and elsewhere in the world, demonstrate gains for people discharged from hospitals, favourable attitudes towards mental health in communities where people are placed, and cost savings and increased efficiencies in the institutional system.

A national-level movement for inclusive living options for people living for extended periods in state mental hospitals has the potential to contribute to social justice and human rights, alter stigmatising notions of mental ill-health and change the landscape of mental health care in the country.



BACKGROUND

The contradiction between the growing importance of mental health issues accompanied by sub-optimal resources and lack of translation of policy into action is echoed in the Indian context, where 10.6% of the population is estimated to be living with mental health issues, 13.7% having experienced mental illness at some point during their life.¹²

Mental health is increasingly acknowledged as a critical development issue and included in the Sustainable Development Goals (SDGs).⁷ SDG 3 focuses on ensuring healthy lives and promoting well-being for all at every age. Beyond the conception of 'No health without mental health', contemporary international discourse recognises the removal of barriers encountered due to mental ill-health as significant to achieving development gains.

Mental health conditions contribute to nearly 13% of the global disease burden according to one estimate⁸ and account for 37% of healthy years of life lost to non-communicable diseases.⁹ The share of mental illness in Disability-adjusted life years (DALYs) has increased by 41% between 1990-2010.¹⁰

Despite advances in evidence-based health and social care responses for better mental health, 50-90% of people in low- and middle- income countries, (LMICs) do not receive care.¹¹ Mental health continues to receive very little funding globally, with the existing marginal allocations being disproportionately applied to maintaining tertiary care in institutional facilities.

In LMICs, overburdened and under-resourced public health systems struggle to absorb and make the necessary interventions. Human resources across the spectrum from psychiatrists to social





workers and psychologists are often not available and even if they are, a curative approach predominates, resulting in little focus on the support necessary for meaningful social recovery, such as the return to work, participating in the household and claiming space and roles in social, economic, political and cultural spheres.

The contradiction between the growing importance of mental health issues accompanied by sub-optimal resources and lack of translation of policy into action is echoed in the Indian context, where 10.6% of the population is estimated to be living with mental health issues, 13.7% having experienced mental illness at some point during their life.¹² Consistent with global trends, those with low educational attainment (less than primary level schooling) and low-income households have higher rates of prevalence.¹³

Income disparities lead to stark biases in health including mental health - low-income households are estimated to have a 40% higher prevalence rate of mental disorders than households in the highest income quintile.¹⁴ From among the 150 million Indians in need of mental health services, fewer than one in ten with common disorders and only 40- 50% of those with serious mental disorders are receiving any form of care.¹⁵ There are only 0.8 mental health nurses, 0.06 social workers, 0.07 psychologists and 0.29 psychiatrists, per 100,000 people.¹⁶ The number of mental health hospital beds is around 2 per 100,000, well below the world average of 6.5 per 100,000.¹⁷ Only 1.3% of health expenditure in India is set aside for mental health, mainly concentrated in upgrading tertiary care, state mental hospitals into Centres of Excellence.¹⁸

The District Mental Health Programme (DMHP), the flagship community care initiative attempting to meet mental health needs alongside primary health care, has had to grapple with these limited resources and disparities in the readiness of the public health system across states. Despite its intentions, the DMHP has largely been confined to camp-style, medicalised service provision with negligible focus on social recovery.¹⁹

One of the most profound manifestations of social exclusion of people with mental illness is the phenomenon of long-stay, service users spending their entire lives within the confines of acute care settings or, in some countries, prisons.

These gaps in necessary support for people with psychosocial disabilities burden them disproportionately with liabilities, such as the risks for early mortality, poverty and homelessness. Moreover, failure of care creates social exclusion that is further accentuated by intersections with structural violence in the form of systemic, enduring disadvantages experienced by oppressed groups. The life expectancy of people with serious mental illness is 10-25 years below the average for the general population.²⁰ They largely remain out of work – about three-quarters or more of people diagnosed with schizophrenia are estimated to be unemployed by various studies in developed countries.²¹

Two studies from India found a greater labour participation among those living with schizophrenia compared to developed countries, although 40-50% do not re-enter employment.²² Barriers to civic and political participation persist due to use of the term ‘unsound mind’ in several laws,²³ which casts doubts on the decision-making capacities of people with psychosocial disabilities. Globally, the risk of losing or being excluded from disability benefits are manifold for psychosocial disabilities in comparison to other disabilities.²⁴

Development initiatives and state entitlements, including in India,²⁵ despite legislation, are out of reach for most people with mental illness.²⁶ In the Indian context, stigma is produced and reiterated when people are unable to meet social expectations and continue to struggle with the most obvious symptoms of their illness.²⁷

Social networks are diminished, and their engagement with care services are also affected as a result. Homeless people with mental illness are disenfranchised and left with the limited choice of incarceration in institutional facilities, including homes regulated by anti-beggary laws that criminalise poverty.

One of the most profound manifestations of social exclusion of people with mental illness is the phenomenon of long-stay, service users spending their entire lives within the confines of acute care settings or in some countries, prisons – segregated and removed from the outside world. Modern public psychiatric hospitals are often remnants of asylums set up in the 1700s and 1800s based on principles of ‘moral treatment’. To understand the contemporary reality of long-stay in institutions for people with mental illness, examining the history, of these facilities and the de-institutionalisation efforts to move long-term beds into community care, becomes relevant.



Asylums: Long stay & De-institutionalisation

Over time, asylums evolved into geographies of social control designed to dominate non-conforming individuals and groups and establish adherence to the majoritarian social order.

Moral treatment emerged as an alternate paradigm during the 1700s in response to the appalling conditions prevailing in ‘madhouses’ and ‘poor houses’ where people with mental health issues were cast away by society. This approach focused instead on freeing people from chains, humane environments, and large open grounds where people could heal and recover through engagement in work in family-like communities.

Rejecting the established methods of therapy for people with mental illness at that time (such as chaining, forced purging, blood-letting and so on), Tuke promoted the idea of a household where patients learned discipline and moral standards through the benevolent but strict oversight of the asylum director.²⁸ The York Retreat run by the Tukes was a relatively humane sanctuary that considered patients’ basic needs and emphasised work.²⁹ Conditional rewards and punishments were used to impose the ‘good patient’ archetype. In his essay *Memoir of Madness* Pinel advocated that mental illness is curable and that doctors must observe and engage with patients to understand the history of their illness, precipitating events and then arrive at a diagnosis and treatment plan.³⁰

By the 1800s, the benevolent, paternalistic outlook of moral treatment combined with medical treatment³¹ and several asylums based on these principles mushroomed across Europe and eventually in colonised countries.

Over time, these asylums – despite the emphasis on humanitarian conditions – evolved into geographies of social control designed to dominate non-conforming individuals and groups and establish adherence to the majoritarian social order. These segregated colonies of people with mental illness established across several countries became facilities that housed psychiatric hospitals where a majority of people with mental illness lived forever. By the 1950s and 1960s, the first antipsychotic drugs had been developed. With the end of colonialism and in the aftermath of World War II, social justice movements emphasising human rights emerged.

In parallel, a socio-political movement to replace long-stay beds in mental hospitals began, with increasing recognition of not only the unacceptable conditions in psychiatric hospitals but also the untenable reality of incarceration, which distances people with mental illness from their rightful claims to socio-economic and cultural resources.

Foucault criticised the ‘moral treatment’ paradigm of asylums, in his book *Madness and Civilization, A History of Insanity in the Age of Reason* (1965). He analysed the asylum as a damaging system that coerced the ‘insane’ to accept perceived moral transgressions and replace their different ways of being with values of their custodians – dialogue between ‘reason’ and ‘unreason’ had been replaced by the imposition of ‘reason’.³²







In 1961, Goffman published his seminal work *Asylums*, based on participant-based ethnographic research at St. Elizabeth's hospital, housing over 7,000 people in Washington DC, in which he examined the social situation of people with mental illness detained in psychiatric hospitals. He coined the term 'total institution' to describe these facilities, which he analysed as akin to prisons and concentration camps, where people with mental illness were far removed and detached from society and lived all aspects of their lives as anonymised individuals over an extensive period of time under the gaze, remit and rules of an oppressive regime.³³ His description of how people with mental illness were socialised within the confines of an authoritarian system into roles of the good patient – 'dull, harmless and inconspicuous' – unravelled the meaning of hospitalisation for patients with mental illnesses, and its deleterious effects on living within such regimes.

Several class-action suits against psychiatric institutionalisation in the United States quoted Goffman's work. The work of formerly hospitalised people, such as Judi Chamberlin's *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, propelled a user-survivor movement that questioned the hegemony of these institutions and their primary role in addressing needs of those diagnosed with disorders by modern psychiatry.³⁴

Rosenhan's experiment in 1973 recruited healthy participants to pose as psychiatric patients and gain admission in 12 hospitals across the United States (US) and demonstrated the lack of reliability in processes that are used to diagnose people with psychiatric disorders and confine them in hospitals.³⁵ The experiment published as *On Being Sane in Insane Places* strengthened the case for de-institutionalisation.

Although efforts to move people from psychiatric hospitals into the community began in the 1950s, these gained traction by the 1970s – a period that witnessed sizeable reductions of beds for tertiary-level care, which were in some countries replaced by community care.

With the emergence of the welfare state, budgetary considerations influenced policy decisions that sought to replace expensive beds in acute care settings³⁶ – in the United States this meant transferring costs to federal exchequers. Advances in antipsychotic drugs enhanced the likelihood of care in the community and accelerated the policy and process of de-institutionalisation.³⁷

Over the next few years, across several countries, long-stay service users were discharged into the community. Hospitals in the United States and United Kingdom discharged over half a million people.³⁸

In Italy, Basaglia pioneered a community-based model of mental health care to end the legacy of social exclusion imposed by mental hospitals,³⁹ which he believed were the principal reasons behind chronicity and symptoms demonstrated by many users of these institutions.⁴⁰ He advocated for Law 180, which abolished psychiatric institutions in Italy.

The experiences and results of the de-institutionalisation movement have been diverse, depending on health and welfare systems and social contexts in different countries. Pat Capponi writes about her time in a group boarding home as one among the many who were discharged from a hospital in Canada. In her book *Upstairs in the Crazy House*, she recalls days filled with despair and social indifference and draws a parallel to the similar apathetic conditions that existed in the hospital.⁴¹ Barbara Taylor's memoir, *The Last Asylum: A Memoir of Madness in Our Times*, points to the reality of de-institutionalised lives with limited participation and social integration in group homes or single housing units.⁴² She writes:

“It is pointed out to me that mental illness is often episodic; that many people are unwell only intermittently and what they really need is help in utilizing their capabilities during their well times instead of becoming “career mental patients” consigned to psychiatric ghettos. There is real force to this argument, and when I repeat it to a service-user activist he strongly endorses it. But it is also a convenient argument, legitimizing yet more swingeing cuts in mental health budgets, and one that leaves untouched the miserable isolation of many mentally ill people in the UK today, sitting alone in their flats with only a television to keep them company. One man who spends his days like this, sitting by himself in front of the TV, told an interviewer: ‘It’s just like being on a ward again, except there’s nobody else there’.”



Some studies have linked homelessness, unemployment, repeated admissions or ‘revolving door’, or worse incarceration in prisons,⁴³ to the reduction of beds,⁴⁴ while others, including a systematic review, refute these claims.⁴⁵ Since the 1990s, institutionalised care in some countries has risen. In most Western countries while typical psychiatric beds continue to decline there has been a significant increase in forensic psychiatric beds and places in supported housing⁴⁶ – a process variously described as trans- or re-institutionalisation.

Recently, 144 people with serious mental illness died of starvation and neglect after being shifted as part of a larger cohort of 2,000 people de-institutionalised in South Africa.⁴⁷ However, evidence from some countries demonstrates favourable outcomes among those discharged. In most instances, adequate creation of community support and diverse services across a continuum of care were an integral part of the de-institutionalisation process.⁴⁸





Mental Health Reform in India

As the British established their presence in India these facilities became vested with racial prejudice that differentiated between the ‘superior’ Western mind and the ‘native’ mind.⁴⁹

In India, while there were references to mental hospitals in the fifteenth century, the establishment of asylums was conceptualised and brought about during the time of the East India Company in the 1700s. The political and social climate of India during this period was fraught with war and turmoil with the fall of the Mughal empire, the rise of the Marathas and the Sikhs in the north and fights between the British and French in the south. This contributed to the need to have separate hospitals for people who were ‘insane’.

The asylums in Calcutta, Bombay and Madras established during this time coincided with the increasing presence of the British East India Company in these places. Initially, the asylums were created, mirroring ideologies and treatments that were prevalent in the West. As in England, many of the asylums in India were privately owned. They served British military forces and Indian sepoys working for the company.

The transfer of control from the East India Company to the British Crown was significant as it brought about the enactment of the first Lunacy Act in 1858, where public health, including care and treatment of Indian insane in the asylums, came under the control of provincial government. As a result, a number of asylums were built across the country based on guidelines proposed in the Lunacy Act for the establishment of and admission to them.





In 1912 a new Lunacy Act consolidated existing legislation. Mental hospitals came under the charge of civil surgeons with the appointment of specialists in psychiatry at each hospital. As in most places around the world, the asylums were constructed primarily to separate the 'mentally insane' from the general population. There remained, however, a significant disparity of services between the asylums in India and England. Further, while in the initial years, doctors' notes account for indigenous socio-medical explanations of presenting symptoms, as the British established their presence in India these facilities became vested with racial prejudice that differentiated between the 'superior' Western mind and the 'native' mind.⁴⁹ The standards of care and facilities provided varied on the basis of social class and nationality, with the Indian population exposed to poor and unhygienic conditions with minimally or untrained staff.⁵⁰

Reports by Mapother (1937–38) and Taylor (1946),⁵¹ ten years apart, emphasised the continuing conditions of custody and detention of people of mental illness in overcrowded and inhumane conditions in several psychiatric hospitals. The Bhore committee (1943–46)⁵² was similarly critical of the inadequate facilities and infrastructure. It mentioned the demoralisation of staff who struggled to digest the scale of the problem or to overcome lacklustre bureaucrats.

By the end of World War II, the administration lacked motivation and interest in furthering the development of health care. There was significant deficiency in professional training, with opportunities for medical education made available on an ad-hoc basis rather than on need. Preventive health care, in the form of improving living conditions, sanitation and hygiene and poverty-alleviation schemes, was severely lacking in the ethos of provincial medical professionals. In the post-independence years, psychiatric services and available health professionals were meagre and for the most part non-existent in many parts of the country.



The recommendations made by the Bhore Committee receded into the background with only a portion implemented. Most psychiatric hospitals continued to exist with sub-optimal conditions and long-term population. In *The Unwanted Patient* (1970), K. Bhaskaran⁵³ highlights the culture of neglect in these facilities – and proves that a large percentage of users living long-term at the hospitals were those without any psychiatric needs. He also writes about ‘familial resistance’ to provide post-discharge care, coupled with a ‘lack of other viable alternatives’ that led to users languishing in hospital wards for years with detrimental effects on their ability ‘to re-enter the world’.

A series of public interest litigations (PILs) in the 1980s in India shed light on the issue of long-term confinement of people with mental illness in institutional facilities.⁵⁴ *Sheela Barse vs Union of India* (1986) sought to review the deplorable conditions in which persons with mental illnesses (categorised as ‘non-criminal lunatics’) were languishing in

the gaols of West Bengal. The Supreme Court directed the need for relevant user-directed treatment and jurisprudence monitored by human rights reviews – especially for those in obscurity (homeless or deserted individuals). This also led to the founding of ‘Paripurnata’, the objectives of which were to demonstrate ways for people with mental illness to be re-integrated into society. Functioning as a halfway home, the organisation proved to be a working model on how to be effective, focusing on encouraging autonomy, choice and self-reliance.

In some states, people with mental illness were transferred from prisons to state mental health facilities in response to the judgement as also with transition to the Mental Health Act of 1987 that replaced the Indian Lunacy Act of 1912. Monitoring of state mental hospitals was entrusted in 1997 to the National Human Rights Commission (NHRC) by the Supreme Court in response to several PILs concerning the ‘inhumane’ treatment of inmates’ at Agra, Gwalior and



Ranchi (Writ petitions No 339/86, 901/93, 448/94 and 80/94). In the same year, the NHRC commissioned NIMHANS to assess the quality of care in hospitals across India. The Quality Assurance report of 1999⁵⁵ was subsequently disseminated to state health secretaries for relevant action. The report identified two types of mental hospitals in India – the first, which ‘do not deserve to be called ‘hospitals’ or mental health centres... but are ‘dumping grounds’ for families to abandon their mentally ill member’. And the second, which offer basic living amenities, food and shelter with ‘very little effort ... made to preserve or enhance their daily living skills’.

Highlighting a wide range of human rights violations across these facilities, the report stressed the need for better allocation of financial resources, and for the provision and enhancement of services within the mental hospitals such as rehabilitation services, community-based outpatient services, development of aftercare services, greater community participation and

inter-disciplinary collaboration. Follow-up reports of 2008⁵⁶ and 2012⁵⁷ by the NHRC note some changes across hospitals, primarily infrastructural. To address the lack of human resources highlighted by the NHRC reports, the 11th Five-Year Plan introduced a grant to develop select hospitals into Centres of Excellence with a one-time investment of INR 30 crores to be used for buildings and postgraduate programmes in mental health, eclipsing in the process the investments necessary to address human rights priorities.

However, reintegration efforts at some of the hospitals such as Lokopriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH) in Assam (repurposed as an autonomous institute based on orders of Guwahati HC), and Hospital for Mental Health (HMH) Ahmedabad, Institute of Mental Health and Hospital (IMHH) Agra in collaboration with ActionAid and so on, resulted in halving the median number of long-stay users between 1996 and 2008.





IHBAS in Delhi became perhaps the only state mental hospital with no long-stay users in 2017. The hospital had already instituted a successful programme of re-integration of homeless people with mental illness. In 2017, IHBAS established Saksham, a rehabilitation home for 42 people who had been living for a year or more in the hospital.

Some notable collaborations have been forged with the focus on improving services within the mental hospitals. Anjali, a non-profit organisation, collaborates with the Government of West Bengal and works across four state mental hospitals with people with psychosocial disabilities, offering comprehensive packages of 'personhood building and capacity enhancement' services that are aimed at securing full participation and agency over process of recovery, care and ultimately moving towards self-determination. The empowerment process facilitates long-stay residents to challenge the environment of violence and neglect, anti-resident norms and procedures within the institution and also advocate with the State machinery to bring about systemic changes ensuring their citizenship rights, including sexual rights – which remain mostly unspoken. The process continues beyond the mental health institution into the community after discharge and Anjali is present in their post-integration life journey.

The Quality Rights Project, a multi-stakeholder collaboration, between the Indian Law Society, Pune and HMM, Ahmedabad, works across six hospitals in Gujarat to build capacity and introduce systemic changes that can enhance the quality of care and end human rights violations in institutional facilities.

The Government of Kerala and The Banyan collaborate to address community-placement priorities, reintegration with the family or assisted housing in the community, of long-stay users in three state mental hospitals. A joint venture between Tata Trusts and the Government of Maharashtra, Project Udaan, aims to improve the quality of life of the people residing in the Regional Mental Hospital, Nagpur by addressing issues concerning infrastructure, staff training and capacity, care provision, treatment capabilities, rehabilitation opportunities and data management.

Another example of a multi-sectoral collaborative partnership is between the Regional Mental Hospital, Pune, the LGBRIMH, Tezpur and two NGOs, Parivartan and Sangath.

INCENSE, an integrated care programme, was developed and piloted with the aim of initiating reforms in mental hospitals, to benefit long-stay users (residing in hospital for more than 12 months), homeless people with mental illness in catchment areas around the hospitals and those living in the vicinity of the hospitals without access to care.

Despite such reforms and initiatives in India, a paternalistic worldview persists in how users are treated, with differentials in power, control and social distinctions being commonplace. Basu (2009), in her analysis of ethnographic observations at a large state mental hospital, highlights intractable structures and the politics behind exit pathways with particular concern.⁵⁸ She exemplifies that a user is very rarely declared free to leave – there is always an underlying possibility of being hurled back into the system, just because the family intermittently decides they need to be away from the person for reasons best known to them, with a spike noticed in the number of readmissions during festival or wedding seasons.

Ethnographic observations by Varma (2016) in one of the hospitals highlight the ‘monotony of life’ in the long-term wards, in contrast to the short-term wards.⁵⁹ She goes on to observe how neglect was practised and normalised in the closed wards, with residual implicit stigma and lack of hope practised by mental health professionals in these spaces.

In the two decades since the first NHRC report, while there have been several state and non-state initiatives, including the declaration of state mental hospitals as Centres of Excellence with grants for improvement, the situation remains unaltered in all but a few facilities. The NHRC echoes this in the 2016 report on mental hospitals, pointing to a large number of long-stay patients across 44 mental hospitals, the majority from Kerala, Tamil Nadu, West Bengal and Maharashtra.

Long-stay: Current Scenario and Need for Study

Globally, of persons with mental illness who are admitted to psychiatric hospitals for treatment, a median of 18% continue to stay there for more than one year.⁶⁰

Upper-middle- and high-income countries (UMICs and HICs) had the highest rates of incarcerated people with mental health issues in hospitals. Countries in the Western Pacific, African and American regions had over 20% of people living for longer than a year in psychiatric facilities. About 32% of mental hospital beds in India are estimated to be occupied by long-stay service users,⁶¹ a higher proportion than the global median and the median estimate of 11% for the South East Asian region.

The literature underlines the systemic effects of long-term institutionalisation and the need to construct housing that provides care across aspects of the clinical, the social and the area in between. A study in the Indian context on rehabilitation needs of women with mental illness who are hospitalised long-term due to poor family support concludes that ‘the hospital atmosphere may not be geared to cater to their complex aspirational/emotional needs’ and emphasises on the need for housing, education and employment.⁶² Long-term confinement can be a predictor of homelessness.



The consensus across stakeholders has long been the pressing need to make the transition from large institutional settings to community-based care. As discussed earlier, while there have been mixed experiences with de-institutionalisation, there is evidence from several countries that initiatives to enable the transition of people staying long in institutional spaces into community care can be positive if accompanied by adequate support and services across a continuum of care. These benefits include the greater likelihood of developing life skills, work, choice, and a higher quality of life.

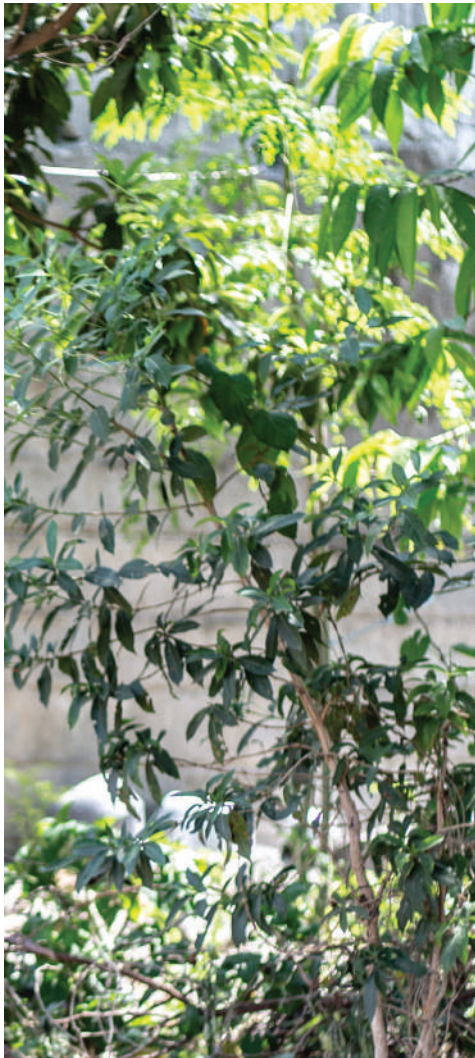
Legislation in India and international policy have called for appropriate and responsive provision of alternatives to long-term institutionalisation of people with mental illness. The United Nations Convention on Rights of Persons with Disabilities (UNCPRD) in Article 19 articulates the right to live independently and be included in the community.



Signatories to the Convention, including India, are obliged to recognise the ‘equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community’.

People with disabilities, including those with mental illness, are entitled to choose their place of residence and have access to a range of home-based or other community support, including personal assistance, that may be necessary for them to live and participate in the community, so that they are not segregated or excluded in any way.

The Mental Health Policy of 2014 articulates the need for mental health care that will represent the essential components of health services and development goals for the country. NIMHANS corroborates this view in the National Mental Health Survey 2015–2016. Murthy (2017), in his article on the survey, notes the state of major mental facilities and the ‘inadequacy and limited care accessibility’ of other potential service arms and stresses the need to move towards promoting interfaces that could provide ‘more than only care’ and aid in mental health promotion and community re-integration options.⁶³



The Rights of Persons with Disabilities Act of 2016 (RPWD) enshrines the right of people with psychosocial disabilities to live in the community and to not be obliged to live in any particular arrangement. It mandates government responses that enable ‘access to a range of in-house, residential and other community support services, including personal assistance necessary to support living with due regard to age and gender’. The RPWD 2016 goes a step further to emphasise these rights also for people with high support needs:

... ‘high support’ means an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities, to take independent and informed decision to access facilities and participating in all areas of life including education, employment, family and community life and treatment and therapy ...

The Mental Healthcare Act of 2017 emphasises the Right to Community Living (Article 19, Chapter V):

The appropriate Government shall, within a reasonable period, provide for or support the 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 ...

In early 2017, The Supreme Court of India passed a directive, following a PIL filed by Gaurav Kumar Bansal (Writ petition No 412/2016), for governments to develop a strategy to address the issue of long-stay population in mental hospitals.

In this context, given the long-stay issue in state mental hospitals in India and the consequent detrimental effects, there is an urgent need to articulate approaches that address the issue of people with severe mental illness with long term care needs and offer sustainable, dignified, inclusive living options that ensure their well-being.

In India and elsewhere, scattered and congregated housing options in natural and built communities have emerged in response to the need for long-term care across diverse constituencies. These include the Camphill Association that offers shared communities for adults with developmental disabilities, Housing First that places homeless people in individual state-subsidised rented units in diverse neighbourhoods, and Home Again in India that combines housing with personalised support services for people with mental illness, irrespective of disability levels.

In this context, The Hans Foundation constituted a national-level Task Force of central government representatives and civil society organisations (CSOs) to develop strategies to transition long-stay cohorts out of state mental health hospitals in India. The Task Force is led by Dr S Parasuraman (former Director of Tata Institute of Social Sciences) and includes members from the National Trust, Ministry of Health and Family Welfare (Government of India), Ministry of Social Justice and Empowerment (Government of India), the National Institute of Mental Health and Neurosciences (NIMHANS) and representatives from other leading mental health organisations.





As a first step, the Task Force undertook a national-level study of people residing for over 12 months with no discharge options across 43 state mental hospitals in India, scoped local stakeholders and developed innovations that may be replicated. The aims and objectives of the study were as follows:

Aim:

Evolve a comprehensive national strategy for Inclusive and Community-based options for people with mental health issues in India

Objectives:

1. Determine the population with one or more years of stay in state mental health hospitals in India
 2. Understand the nature and needs of the cohort with over one or more year of institutional stay in state mental health hospitals in India by assessing their socio-demographic characteristics, clinical and functional status, disability profile, personal preferences for re-integration and prospects and risks for community placement
 3. Understand existing government or civil society initiatives for re-integration, assisted/supportive/independent living to address long-term needs of people with mental illness, review existing data and evaluations of their costs and success, and assess their readiness for replication in other contexts in India
 4. Understand feasibility and readiness of contexts and stakeholders in various states for transitioning long-stay cohort out of hospitals and setting up demonstration pilots of inclusive living options
 5. Assess existing central and state government schemes and develop strategies for financing identified models over the long-term
 6. Determine human resources, infrastructure, services and associated financial investments that may be necessary to transition long-stay cohort across state mental health hospitals in India to community-based care
 7. Develop a position paper on inclusive and community-based approaches for transitioning people with mental illness living for one year or more in state mental health hospitals in India
- The narrative that follows details key quantitative findings alongside qualitative insights on the nature and extent of the problem. The most appropriate options for transition to the community for the diverse population are discussed in the broader context of well-being, dignity, citizenship, rights and inclusive living.

METHODS

The study employed a cross-sectional design combining quantitative and qualitative methods. Semi-structured interviews with long-stay population, key informant reports, focus group discussions (FGDs) and interviews with stakeholders and secondary sources were used to gather data.

The national-level Task Force of CSOs and central government representatives, facilitated by The Hans Foundation, conducted the study at 43 state tertiary mental health facilities in India. The members and hospitals are listed below:

- The Banyan Academy of Leadership in Mental Health (BALM) – Kerala, Maharashtra, Jammu and Kashmir, Andhra Pradesh and Telangana (11 hospitals)
- National Institute of Mental Health and Neurosciences (NIMHANS) – Tamil Nadu, Karnataka, Bihar, Goa, Jharkhand and Odisha (8 hospitals)
- Ashadeep – Assam, Meghalaya, Tripura and Nagaland (4 hospitals)
- Anjali – West Bengal (4 hospitals)
- Institute of Human Behaviour and Allied Sciences (IHBAS) – Delhi, Punjab, Rajasthan, Haryana, Himachal Pradesh, Uttar Pradesh and Uttarakhand (9 hospitals)
- Hospital for Mental Health, Ahmedabad – Gujarat and Madhya Pradesh (6 hospitals)





Sample

Participants were drawn from people residing at 43 state mental hospitals in India who had been diagnosed with a mental illness and had stayed for one or more years at the hospital. It was anticipated that between 3,500 and 8,000 people would need to be surveyed.

In addition to the participants, primary care staff at the hospital (nurses and health workers/ward assistants) and key members of the team treating each participant (psychiatrist, social worker, psychologist) were interviewed to elicit

data for clinician or staff-rated items and augment information.

Stakeholders for interviews and FGDs in each state were drawn from people living with mental illness, carers, leadership and functionaries of the health and social welfare departments, directors of the state mental health hospitals, CSOs working on homelessness, mental health or related sectors.



Measures

A semi-structured self-report survey schedule to assess existing occupancy and staffing details alongside indicators of their background characteristics was used to gather data from directors of various state mental hospitals to understand the extent of long-stay in mental hospitals.

A semi-structured interview schedule with the following domains and measures were used to gather data from the long-stay cohort at each hospital through face-to-face-interviews with participants, a review of their case records and interviews with the primary care, treating team and co-residents:

- Socio-demographic variables
- Qualitative history of illness and homelessness (if any)
- Details of admission, length of stay and critical incidents during stay
- Details of family, addresses and reintegration attempts

- Diagnosis and treatment including comorbid physical conditions
- Work and occupational status
- Current symptoms status – Modified Colorado Symptom Index (mCSI) (Conrad et al., 2001) Ref: Glossary 18
- Disability – WHODAS 12 (Staff rated version) (Üstün et al., 2010) and IDEAS (Thara, 2005) Ref: Glossary 19, 21
- Subjective well-being – Modified version of Cantril's Ladder (Cantril, 1965) Ref: Glossary 23
- Functioning, prospects and risks for community placement – Community Placement Questionnaire (CPQ) (Clifford et al., 1991) Ref: Glossary 20

The Modified Colorado Symptom Index (mCSI) is a self-reported measure of psychological symptoms in the last month on a five-point scale ranging from experiencing no symptoms at all to experiencing symptoms almost every day. WHO-DAS 2.0 12-item scale may be

self-reported or proxy rated, to assess the participants' level of disability from none to extreme or cannot do.

A qualitative guide with open-ended probing questions was used to conduct interviews and FGDs with stakeholders in each state to understand contextual enablers and barriers to reintegrating people from mental hospitals, implementing inclusive living options, existing strategies and approaches for reintegration and long-term care in mental health or other sectors that may be adapted.



Data Collection

Multi-lingual collectors gathered data with the help of tablets with preloaded forms, synchronised to a database stored on a cloud-based server. A detailed reference guide for the semi-structured interview schedule was prepared for use by data collectors to ensure uniform understanding of items and appropriate recording of data. Lead researchers from each implementing organisation met before data collection to finalise item-wise interpretation and the process for gathering data.

Lead researchers trained data collectors at the implementing organisation sites. Each implementing organisation gathered data over a period of two to four months depending on the number of long-stay population at each hospital. The team at each hospital had a dedicated senior researcher who conducted daily data audits by systematically checking responses for a portion of data gathered by repeating the interviews done on that day or by observing each data collector as they conducted the interviews. Data collectors wrote qualitative summary notes as part of the forms. Significant case studies were documented. Senior researchers led team debriefings to summarise progress and resolve any discrepancies or process errors at each hospital at the end of each day.

Face-to-face interviews and FGDs were conducted at the state level with various stakeholders by senior researchers from the implementing organisations. These were audio recorded or summarised as minutes. Audio recordings were transcribed into English for analysis. Data were maintained in a centralised cloud-based repository. A central team of Research Associates (RAs) carried out audits to check for missing and conflicting variables and duplicates and ensured that the data were cleaned and prepared for analysis. Secondary data from various states were examined and organised in a common assessment format prepared for the purpose of analysis.



Data Analysis

Data from participants across hospitals and states were combined and analysed at two levels. Data were analysed from each hospital and state and compared between them, as there may be diversity in the experience of long-stay. Quantitative data were analysed using SPSS (v.22). Initially, the data were examined using descriptive statistics. Parametric and non-parametric tests (Independent Sample t-test and Mann-Whitney U test) were used to examine gender differences within each state among long-stay populations in state mental health hospitals.

Funding and Ethics

The study was supported by The Hans Foundation, a philanthropic organisation which provides support to non-profit organisations to improve the quality of life of marginalised communities in India. The study was approved by the Institutional Review Board (IRB) of the Tata Institute of Social Science (TISS).

Consent forms were used to inform participants about the purpose of the study in addition to their rights as participants. These included the right to choose to participate, to refuse to answer any question, to leave interviews/FGDs/other workshops at any point and to decide to withdraw their information at a later point. A proportion of long-stay population with high clinical needs were not able to clearly express consent.

Considering the minimal risks to participants involved in a cross-sectional, non-interventional study, the interviews were audited by data-collection supervisors to ensure that no coercion, persuasion, suggestion or manipulation was used to elicit information. Participants of the study were kept anonymous, and no names were used during analysis or reporting. Access to the data during the research was governed by a multi-level permissions protocol that specifies roles and types of data access on a need-to-know principle.

Limitations

There were some limitations to the study. The study involved a large number of long-stay users residing in different hospitals across the country, interviewed by numerous data collectors from different organisations. Despite the initial groundwork and the monitoring measures that were designed to ensure uniformity in response, a few drawbacks were identified in data design, collection and analysis. Certain background characteristics were not included in the semi-structured survey of the long-stay users like marital status, education, family dynamics before hospitalisation and socio-economic indicators, which may have provided further insight into the participants' background.

Unforeseen challenges in the field emerged from a lack of shared priorities between the data collectors and hospital staff, with the latter unable to work around their daily schedule and data collectors having to work within the time constraints placed on them by the staff, thus overshooting the time allocated for data collection.

There were difficulties in gaining permission for male data collectors to interview women in the female wards. Some inconsistencies in data, in addition to missing data, were observed across the survey. Inconsistencies in recording of data in different parts of the survey and non-exhaustive files in some hospitals with poor socio-economic and clinical information recorded were noted. Possible biases in responses given by hospital staff, who were used as an alternate source of information when data could not be determined from the user. The study was limited to long-stay population in non-forensic wards of state-run psychiatric facilities and did not include people who maybe institutionalised in other settings such as rehabilitation homes, prisons and forensic wards.





KEY FINDINGS

Proportion of Long-stay in State Mental Hospitals

A total of 4,935 people were identified with one or more years of stay in 43 state mental hospitals across 24 states; 36.25% of the total number of people living in these facilities at the time of survey were residing for over a year or more.



FIG. 1.
Proportion of Long-stay in Residential Population at State Psychiatric Hospitals

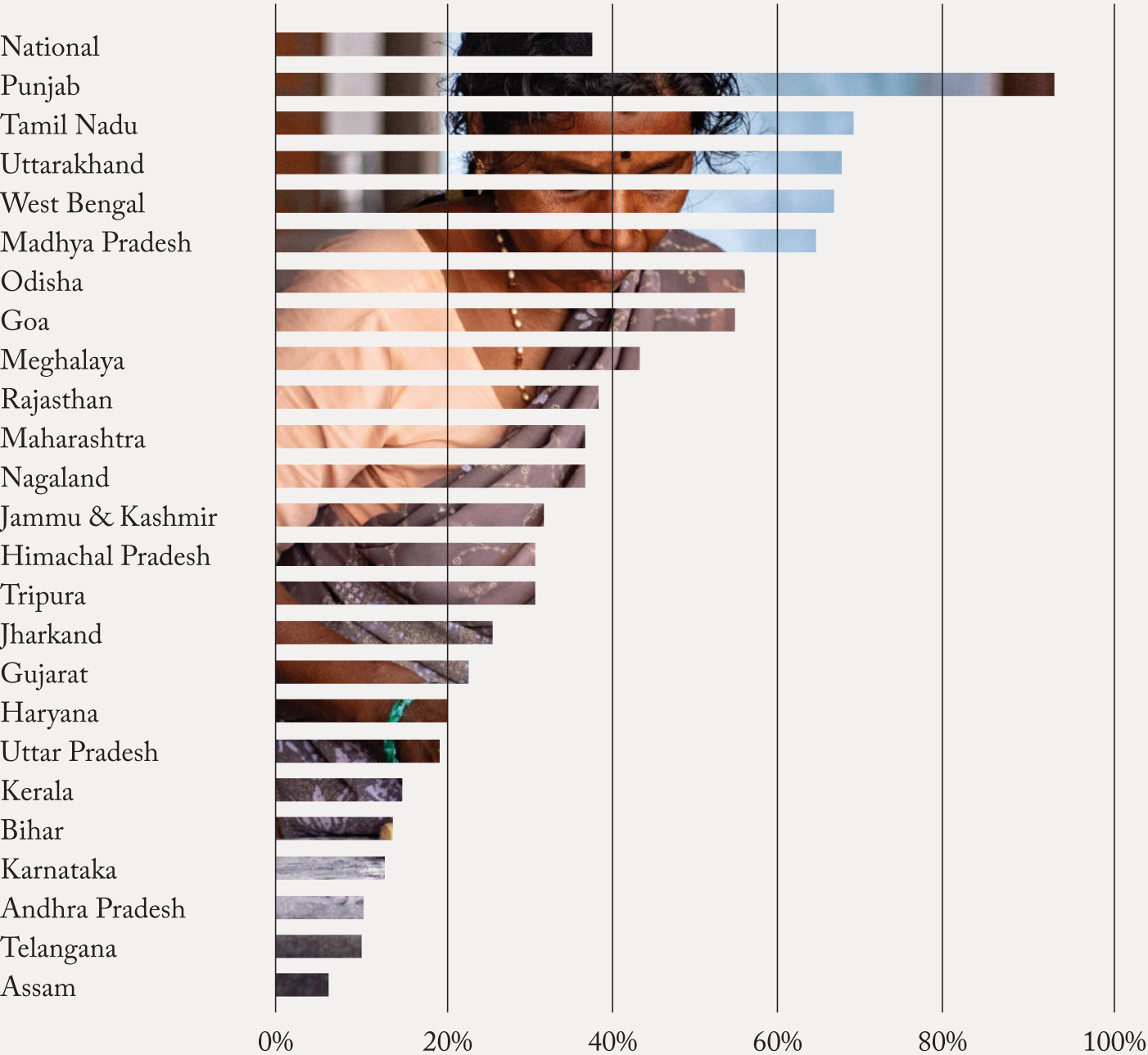


TABLE 1.
Long-stay Service Users in Psychiatric Hospitals across States in India

Number of people > 1 year of stay					
	Total Number of Inpatient clients	Men	Women	Total	% Long-stay
Andhra Pradesh	242	9	16	25	10.33
Assam	161	6	4	10	6.21
Bihar	68	8	1	9	13.24
Goa	201	62	46	108	53.73
Gujarat	673	74	75	149	22.14
Haryana	40	7	1	8	20.00
Himachal Pradesh	62	16	3	19	30.65
Jammu and Kashmir	58	11	7	18	31.03
Jharkhand	633	101	190	291	45.97
Karnataka	570	28	41	69	12.10
Kerala	1267	121	47	168	13.26
Madhya Pradesh	324	68	138	206	63.58
Maharashtra	3722	551	807	1358	36.49
Meghalaya	116	24	26	50	43.10
Nagaland	11	1	3	4	36.36
Odisha	84	19	28	47	55.95
Punjab	251	138	95	233	92.83
Rajasthan	349	72	60	132	37.82
Tamil Nadu	883	325	287	612	69.31
Telangana	500	25	25	50	10.00
Tripura	194	27	32	59	30.41
Uttar Pradesh	1703	95	225	320	18.79
Uttarakhand	28	6	13	19	67.86
West Bengal	1473	462	509	971	65.92
Total	13613	2256	2679	4935	36.25

Nationwide, more women (n=2,679, 54.26%) than men (n=2,256, 45.74%) have been confined in state mental hospitals. Women form a larger proportion of long-stay cohort in 14 of the 24 states surveyed.

Excluding Nagaland, where only four were identified as long-stay, these gender differences with women forming a significantly higher proportion of long-term users were most starkly observed in the state of Uttar Pradesh (70.31% women, 29.69% men).

A total of 44 users did not consent to the use of interview data for the purpose of research and were excluded from analysis. The final sample considered for analysis is 4,891.



FIG. 2.
Proportion of Men vs Women in Long-stay Service-Users at State Psychiatric Hospitals





Background Characteristics

The mean age of participants was 45.88 (SD=14.73) years. The youngest participant was 12 years, and 25 participants were under 18 years of age, while two were 99 years old.

Of the participants, 79.3% were Hindu in the majority of states except Jammu and Kashmir, while 6% expressed no religious affiliation. Religious affiliations reported by participants generally mirrored the religious demographics of the state. A large proportion of participants identified as Muslim in the states of Jammu and Kashmir (72.2%), Tripura (37.3%) and Bihar (33.3%). In Tripura, migration from Bangladesh was reported as one of the reasons for people being unable to go back to the community. While systematic data on the number of inter-country migrants among long-stay are not available, this was observed in the North East, Bihar and West Bengal.

Some of these users have been staying here for more than 10–15 years. Among these, there are more than 25 users who hail from Bangladesh and one from Nepal. Although we have tried liaising with the respective governments, it is often a very slow and cumbersome process, claims are always contested – till date, the Bangladesh Government has agreed to take back seven users. - FGD participant from Tripura

A majority of participants were conversant in Hindi (30.9%), followed by Bengali (18.9%). Within states, while the local language predominated, in most hospitals between a quarter to half of the long-stay service users spoke another language.

Participants were diagnosed predominantly with schizophrenia (50.4%) followed by psychosis NOS (not otherwise specified). Acute psychosis was the recorded diagnosis in 4.6%, and bipolar disorder was noted in 4.7% of participants; 3.5% of participants (n=132) had no current diagnosis; 22.5% experienced concurrent intellectual disability, the most prevalent disability in this cohort. This was followed by chronic neurological conditions (7.9%), speech and language disability (5.9%) and poor vision (3.9%). A total of 24.1% of participants experienced co-morbid physical illnesses, mainly non-communicable diseases (18.3%) such as asthma, diabetes and cardiovascular disorders.



FIG. 3.
Diagnosis of Long-stay Service Users at State Psychiatric Hospitals

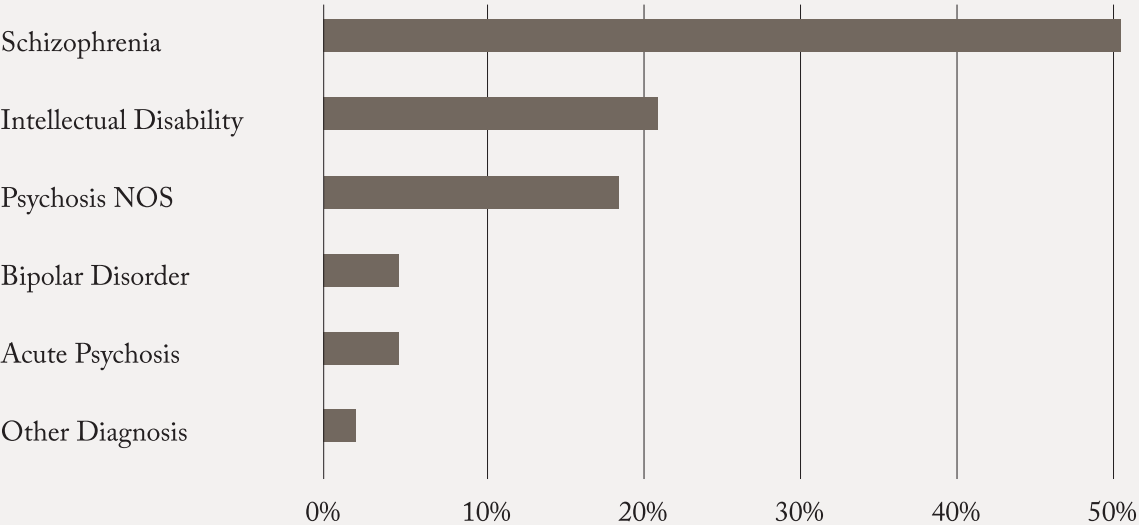
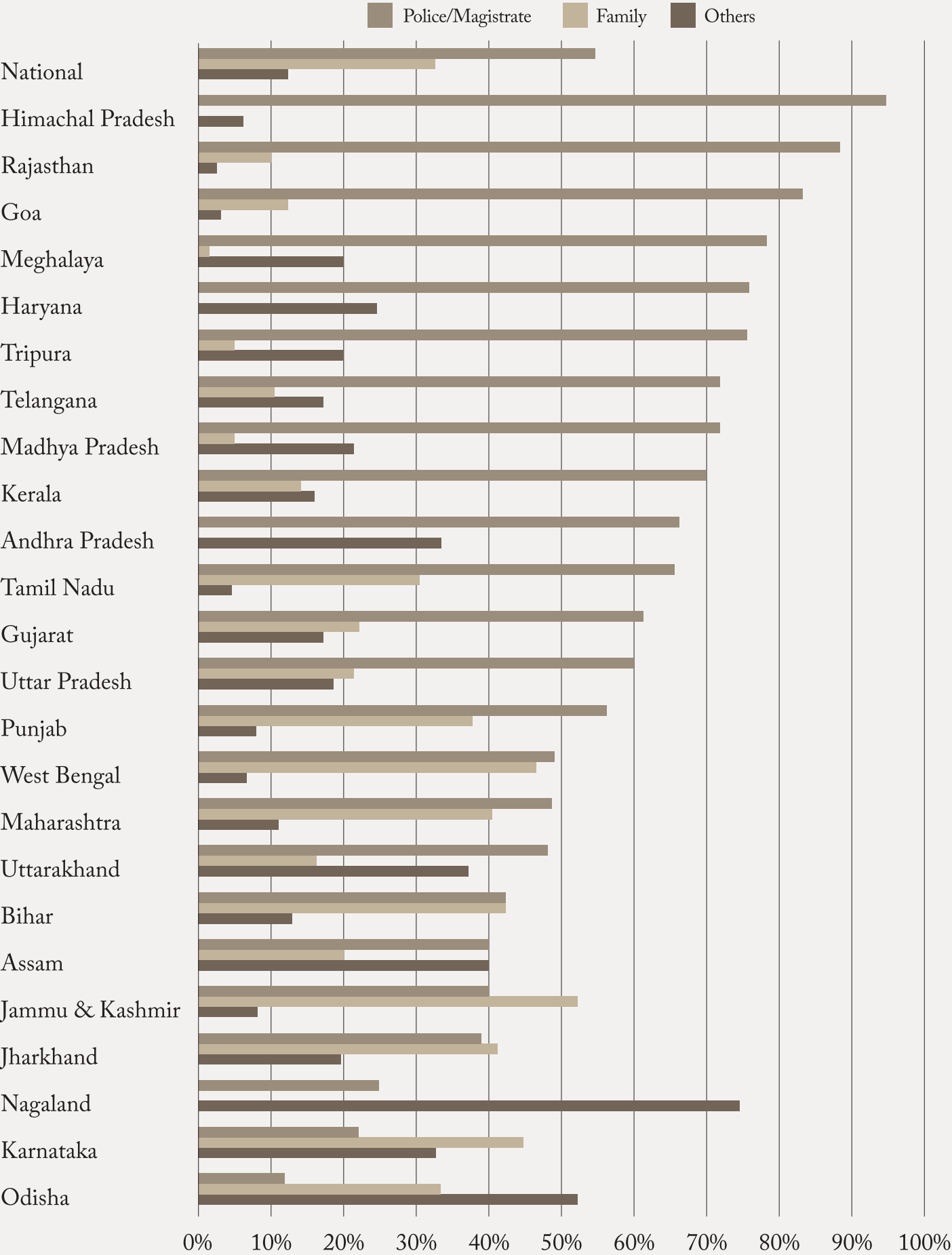


FIG. 4.
Persons who admitted Long-stay Service Users at State Psychiatric Hospitals



History of Stay in State Mental Hospitals

Of long-stay patients, 33.1% were brought to the hospitals by their families, and 55.4% were referred by the police or magistrates, indicating a history of homelessness.

In Karnataka, Jammu and Kashmir and Odisha, most long-stay users were admitted by their families; while family admissions and those with possible histories of homelessness were near equally split in states of Maharashtra and Bihar.

Median years of stay in hospitals was 6 (IQR=13) years, with the minimum duration as one year and the maximum 62 years; 48.4% of the participants had been living for between one and five years in these hospitals, accounting for the majority of users.

State-wise differences in duration of stay were observed with nine out of 24 states recording a higher than national median. Excluding Nagaland, which had a small sample, Karnataka (Mdn=14) and Tamil Nadu (Mdn=12) recorded a higher median duration of stay.



Among long-stay users, 11.4% had been there for over quarter of a century – in effect a better part of their lives had been spent within the confines of these facilities, 40 of them for 50 years or more. Gender differences in duration of stay were observed in Uttar Pradesh and Jharkhand, where men on an average remained longer than women. In Maharashtra, significant gender differences were observed with women being hospitalised for more years than men.

A total of 77.1% were living in closed wards,^{vi} 21.9% in open wards with designated hours to leave. Contrary to the national trend, participants in open wards^{vii} were predominant in Uttarakhand (100%), Himachal Pradesh (100%), Nagaland (100%), Jharkhand (85.6%), Uttar Pradesh (81.9%) and Punjab (60.5%). A total of 47 participants (1%) were living in solitary confinement^{viii} in Kerala (23), Maharashtra (11), Gujarat (11), Andhra Pradesh (1) and West Bengal (1).

Micro reasons for use of solitary confinement were varied but coalesced around the theme of risks – personal or interpersonal (including one instance of serious harm and another of the death of a staff member) – that presented difficulties in caring for the person.

Only 13.9% had been readmitted to the hospital, whereas only 12.2% had been discharged – some of those readmitted were never formally discharged. Rather they had walked out before either being brought back or returning on their own. The exceptions were Jammu and Kashmir (61.1%) and Karnataka (49.3%) where high rates of readmission and higher average number of readmissions were observed. Tamil Nadu (24.3%), Bihar (22.2%) and Gujarat (22.1%) similarly had rates of readmission higher than the national average among long-stay service users. Assam and Nagaland had very small samples; three out of 10 and one out of four had a history of admission to the same facilities in these states respectively. Long-stay service users at hospitals in Himachal Pradesh, Haryana, Uttarakhand and Meghalaya had no history of previous admission to these facilities. We found that 4.7% of people experienced serious physical illness requiring hospitalisation during their stay – 2.9% had sustained a serious physical injury while 1.1% had attempted to die by suicide during their stay.

Hema, a woman in her late 20s, has been in solitary confinement in one of the hospitals for seven years, almost the entire duration of her stay since she was brought to the hospital on account of homelessness. The only time during the day that Hema comes out of the small space she occupies is when she has to eat and take her medication. The reason she is kept confined as reported by staff is because she consumes ‘naala ka paani’ or water from an adjoining wastewater pathway. So, to protect her from consuming this water she is confined. From general observations on the surface, it appears staff are not supported in ways to find alternatives from such situations, and they use methods that are validated through a longitudinally persistent culture as ‘in best interests of the client’.

^{vi} Refer to Glossary (Point 30)

^{vii} Refer to Glossary (Point 32)

^{viii} Refer to Glossary (Point 33)

FIG. 5.
Duration of stay of Long-stay Service Users at State Psychiatric Hospitals

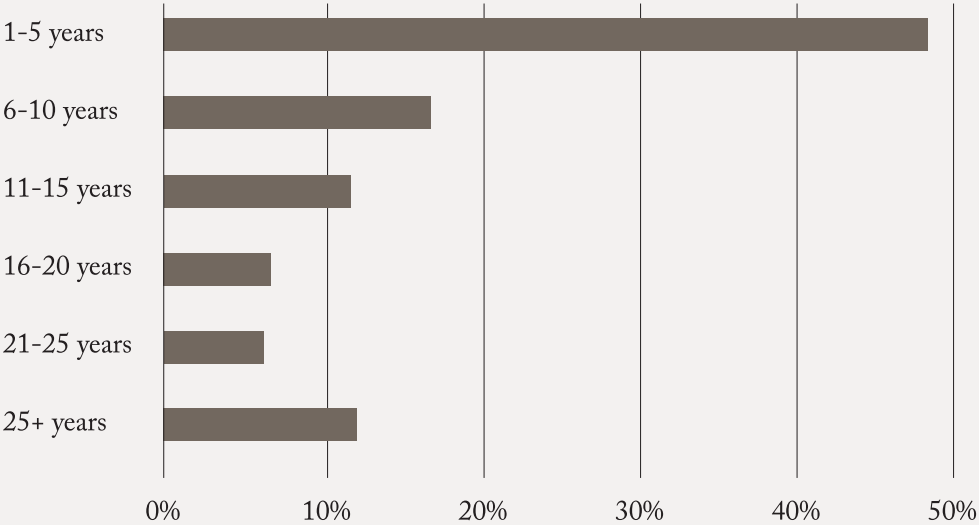


FIG. 6.
Type of Ward occupied by Long-stay Service Users at State Psychiatric Hospitals

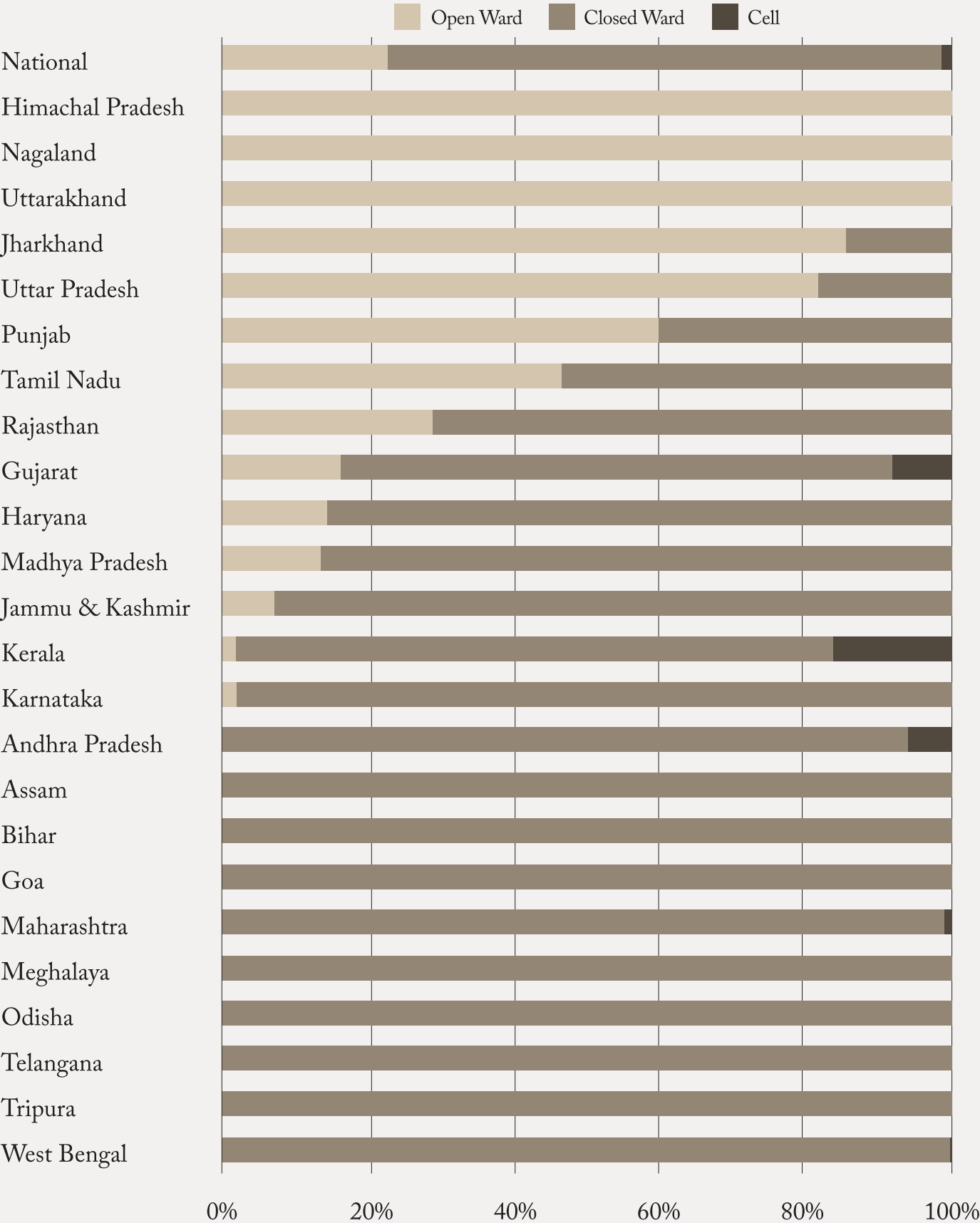
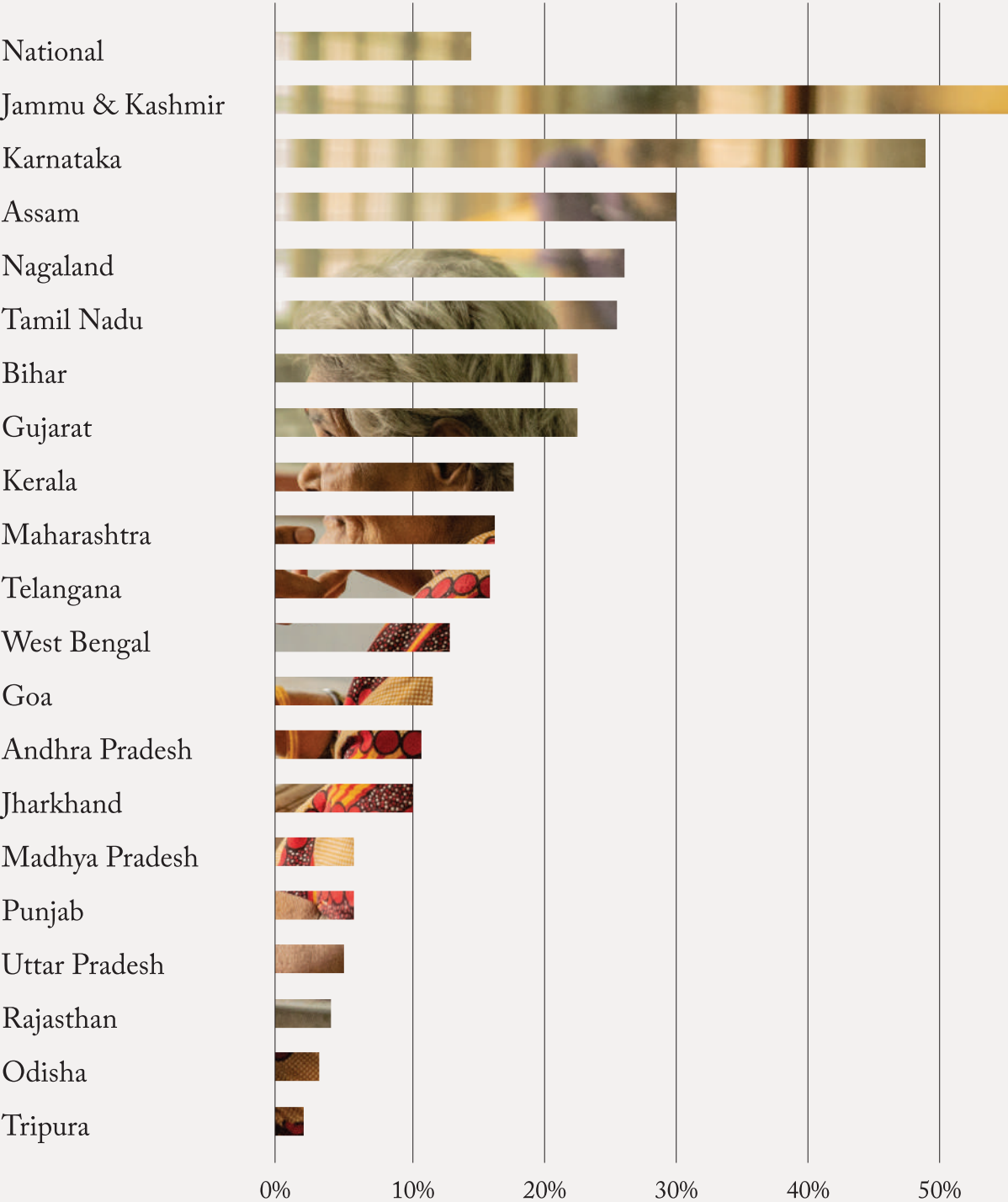


FIG. 7.
Prevalence of Readmissions (to same facility) among Long-stay Service Users at State Psychiatric Hospitals



Current Status

The modified Colorado Symptom Index (mCSI)^{ix} was used to measure current level of symptoms in the long-stay cohort. The median score on mCSI was 6 (IQR=12) indicating a diverse range of clinical needs from low to high.

Participants demonstrated no current symptoms with a score of 0, to being highly symptomatic with a score of 56. There is no generally accepted cut-off for mCSI.^x Assuming that scoring on at least half of the 14 items as the cut-off for continued symptomatology, 40% of people had scores indicating persistent symptoms.

Consistent with the mCSI, the rating on Community Placement Questionnaire (CPQ) section on difficulties due to symptoms observed that 64.4% of users had no to mild problems overall due to symptoms which do not significantly affect their participation in rehabilitation programmes or social activity.

The majority were on psychiatric medication, 10.9% on Clozapine;^{xi} 59.4% readily accepted medication from staff and 19.1% were responsible for independent administration of oral medication. However, 18.6% required additional support to take their medication and 2.9% preferred not to accept medication. Minimal side-effects were observed with 7.4% (356) showing moderate to very severe problems.

Disability was measured using Indian Disability Evaluation and Assessment Scales (IDEAS)^{xii} and WHO Disability Assessment Schedule 12 item (WHODAS 12).^{xiii} The median WHODAS 12 score was 13 (IQR=20) indicating varied levels of disability, which is about four times higher than the normative average score in the general population.

^{ix} Refer to Glossary (Point 18)

^x Refer to Glossary (Point 18)

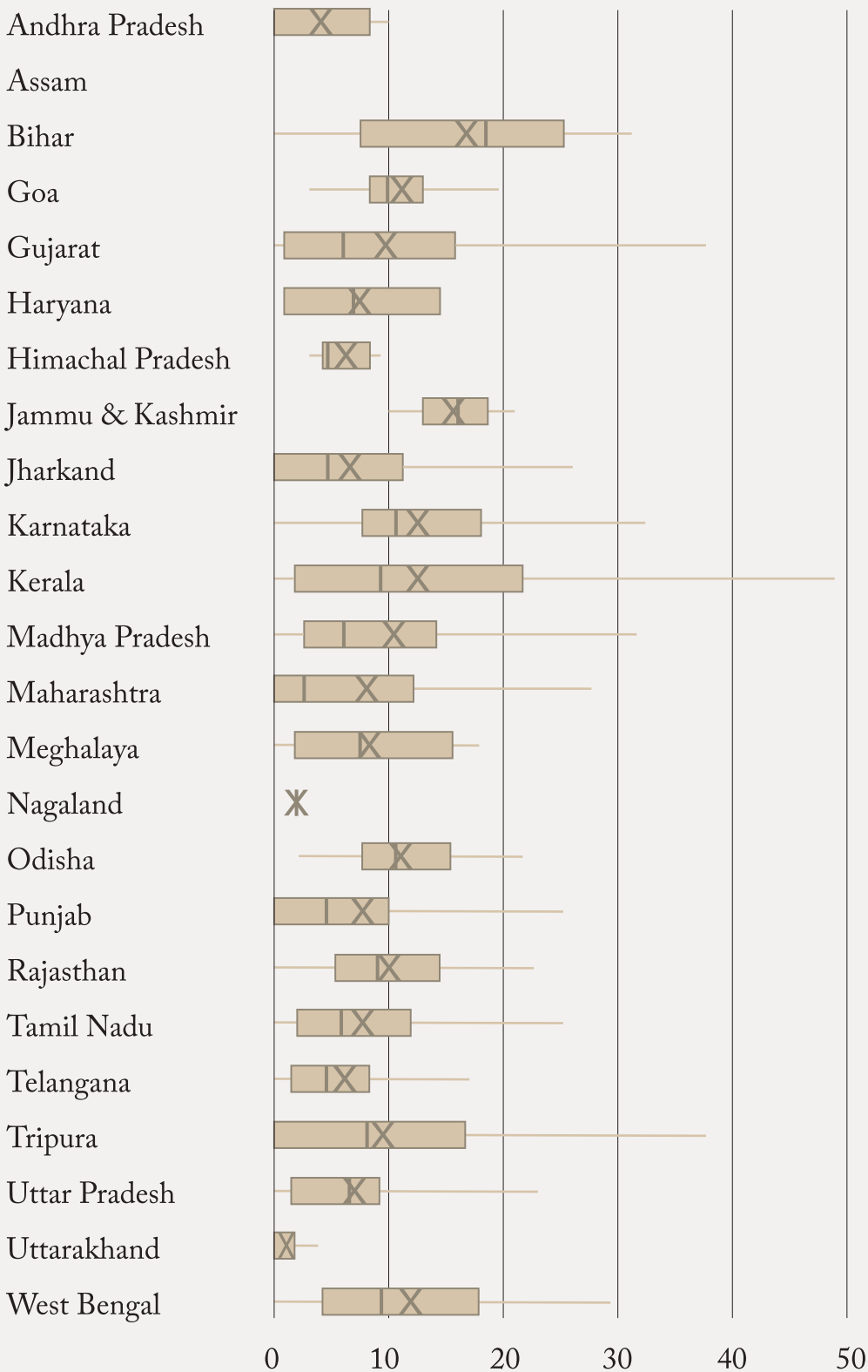
^{xi} Refer to Glossary (Point 31)

^{xii} Refer to Glossary (Point 21)

^{xiii} Refer to Glossary (Point 19)



FIG. 8.
Symptoms - mCSI scores of Long-stay Service Users at State Psychiatric Hospitals



WHODAS 12 ranged from no disability with 0 (n=473) to high disability with highest scores of 60 (n=113). In 14 out of 24 states the WHODAS 12 median scores were higher than the national median. The highest median scores on disability were observed in Tamil Nadu (Mdn=24, Range=48), Uttarakhand (Mdn=28, Range=60), Himachal Pradesh (Mdn=26, Range=31) and Karnataka (Mdn=26, Range=51). While West Bengal (Mdn=6, Range=60), Telangana (Mdn=7, Range=40) and Odisha (Mdn=8, Range=20) had lowest median scores.

Gender differences in disability were observed in Maharashtra (Male: Mdn=6, Range=48; Female: Mdn=17, Range=59), Punjab (Male: Mdn=8, Range=60; Female: Mdn=23, Range=60) and Uttar Pradesh (Male: Mdn=8.50, Range=49; Female: Mdn=17, Range=59) with disability scores higher for women than for men.

The median IDEAS score was 5 (IQR=7) with scores among participants ranging from 0 to 16. Global disability scores in IDEAS account for the duration of illness and disability associated with living with a chronic illness.

The majority of participants experienced Mild (35.7%) to Moderate (41.7%) disability. There were three states with more than 40% of long-stay users classified with Severe Disability – Tamil Nadu (46.1%), Karnataka (44.9%) and Bihar (44.4%). The states of West Bengal (1.6%), Tamil Nadu (2.6%) and

Maharashtra (0.8%) have 10 or more users with Profound Disability. On the other hand, the hospitals in Andhra Pradesh (55.6%), Madhya Pradesh (51.5%), Kerala (48.2%), Jharkhand (40.2%), Maharashtra (44.9%), Odisha (51.1%), and Uttarakhand (63.2%), all had the highest number of long-stay users with Mild Disability.

These assessments of overall disability among participants are reflected in the Daily living domain of the CPQ.

The majority of participants needed little to moderate support in getting up in the morning (87.3%) and experienced no to moderate neglect in keeping up their personal appearance (84.5%). However, there were certain tasks associated with daily living that had over a quarter of participants needing high support – 26.9% were unable to prepare simple items of food and drink, 26.6% were unable to use public transport or extremely reluctant to use it if they had the opportunity to, 28.9% rarely or never participated in structured activities, 29.9% engaged in little or no social interaction, 28% had minimal interactions with staff and 29% had minimal conversation with other users.



FIG. 9.
Impact of Psychological Issues on Functioning

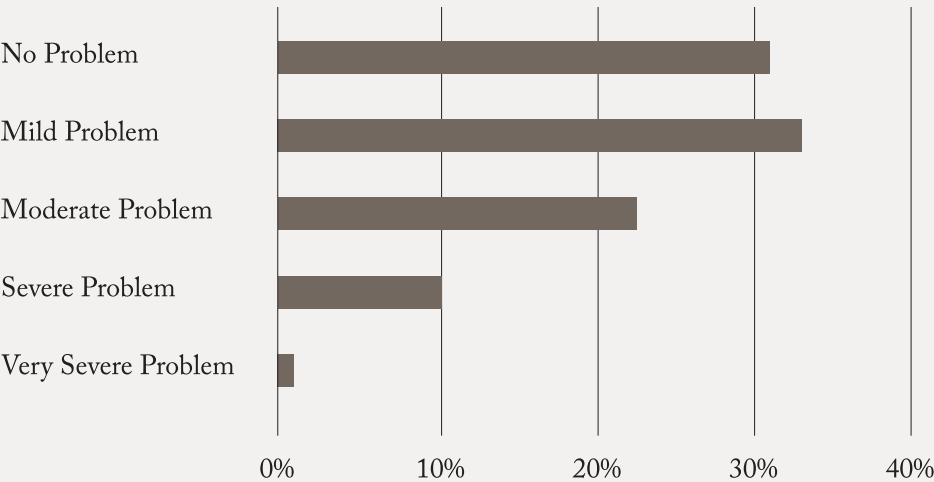


FIG. 10.
Disability - WHODAS Scores of Long-stay
Service Users at State Psychiatric Hospitals

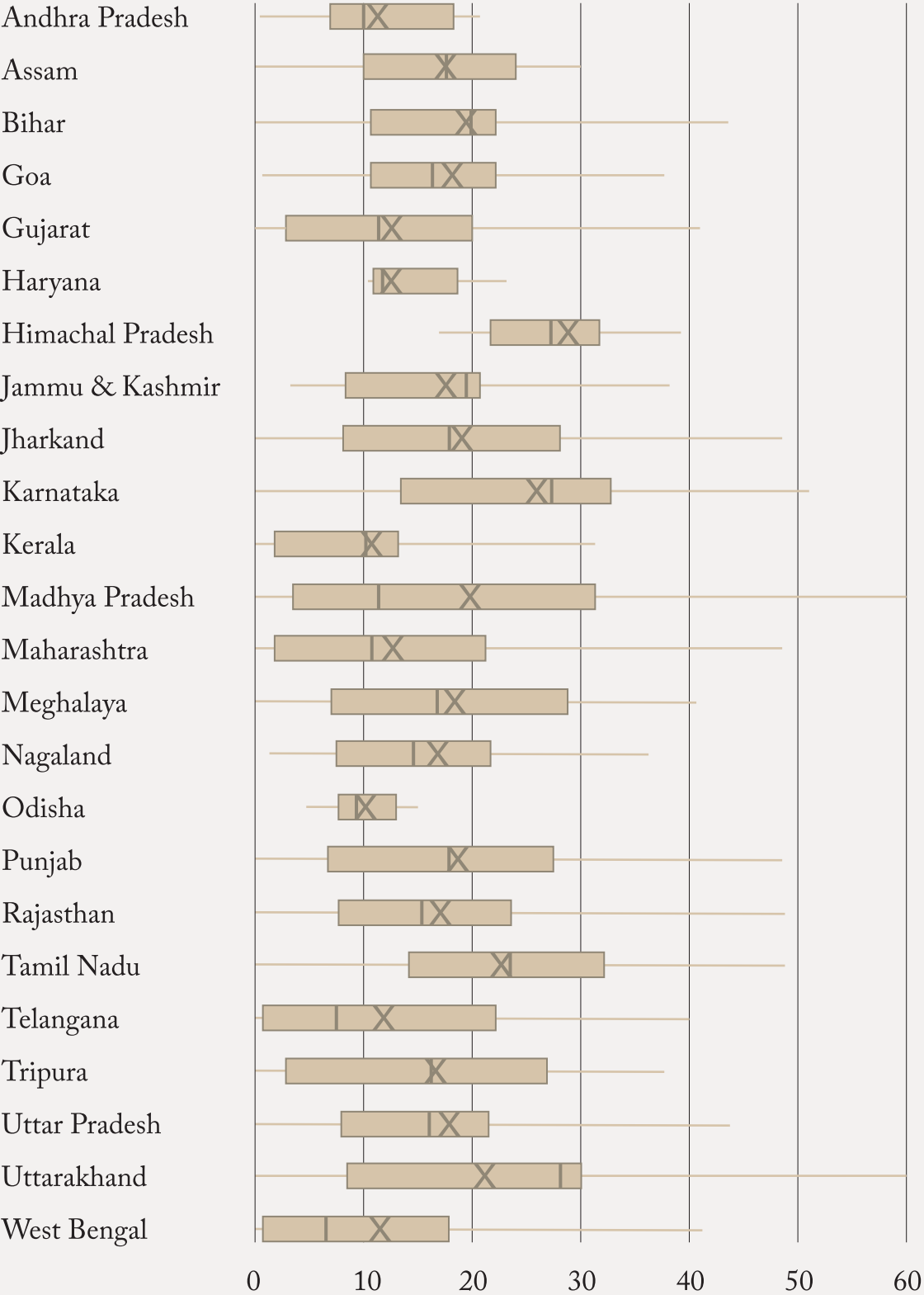


FIG. 11.
Global Disability Assessment (IDEAS) of Long-stay Service Users in State Psychiatric Hospitals

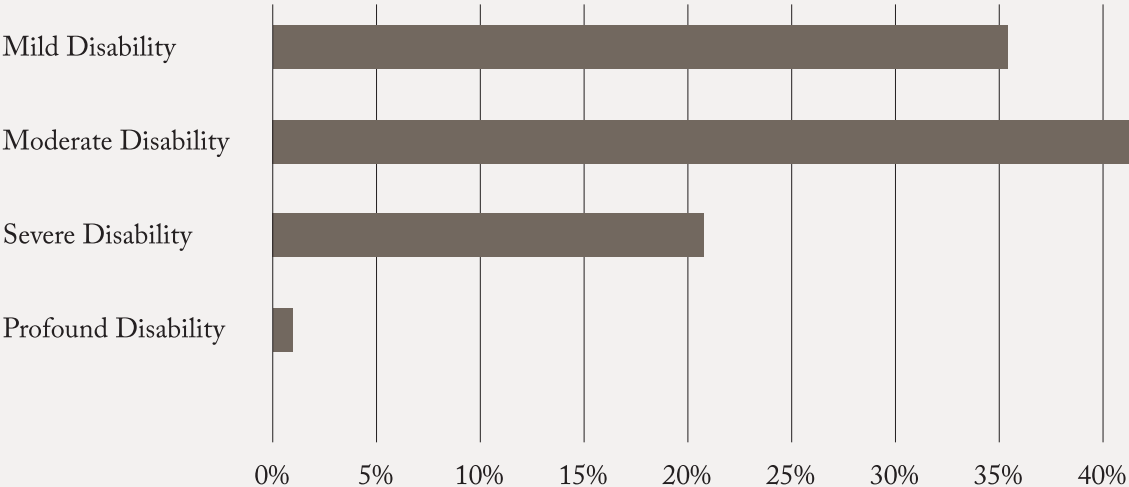
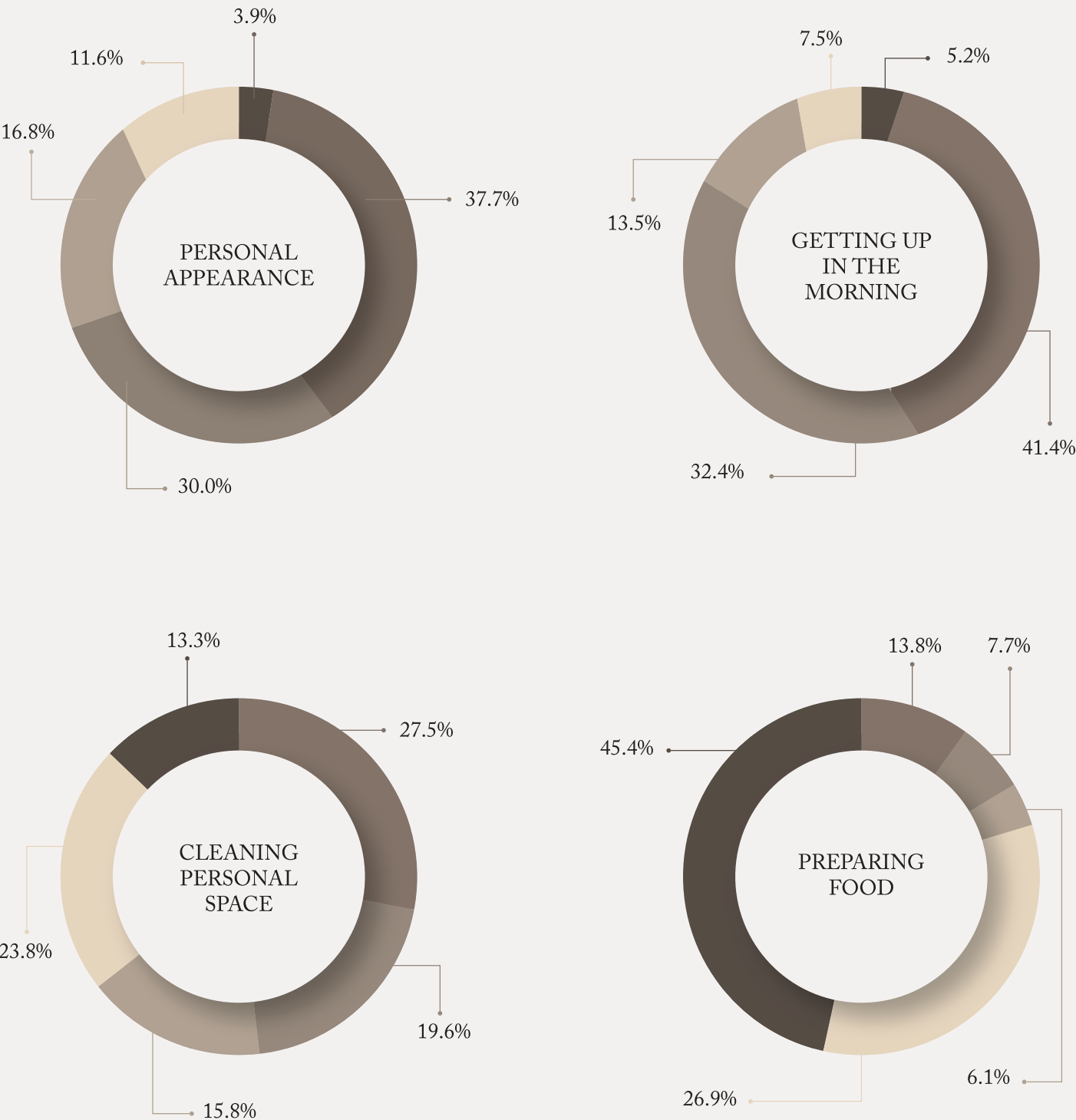
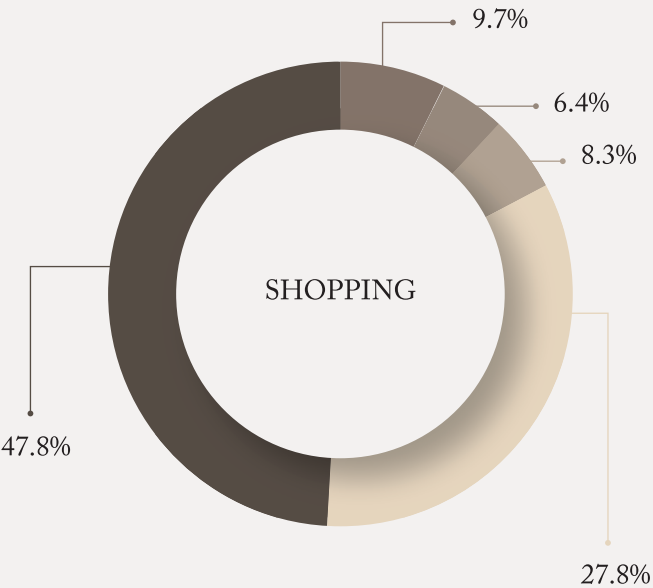
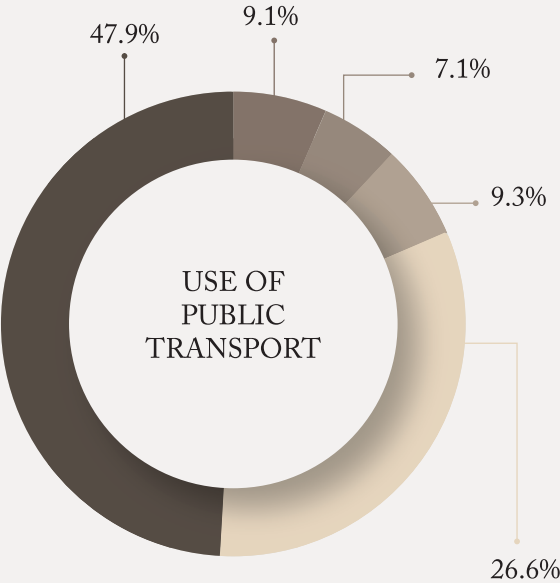
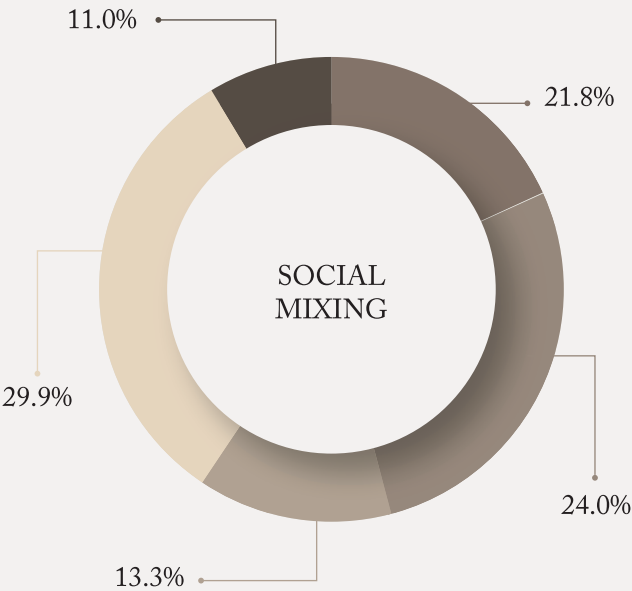
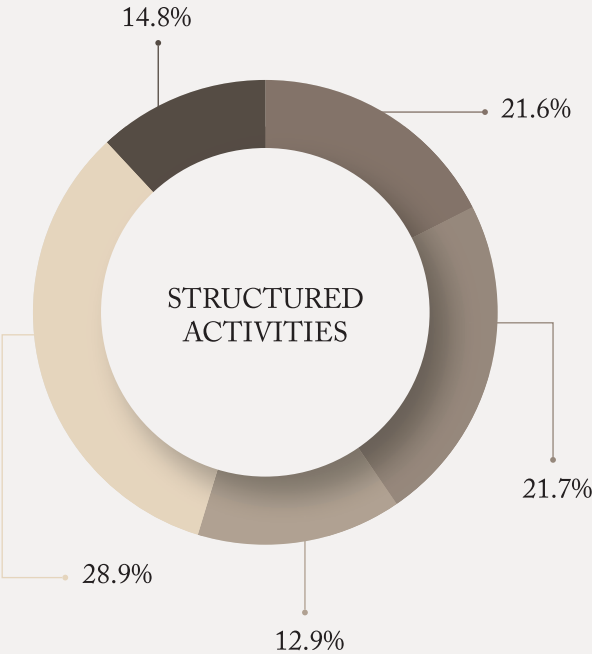


FIG. 12.
Support assessed based on level of Daily Functioning



No Support Low Support Moderate Support High Support Uncertain^{xiv}



^{xiv} Refers to when rater did not have an opportunity to observe or verify with staff/others as the user may have shifted recently or the staff may have been new, or hospital settings did not offer opportunities to engage in such activities.

More than abilities, the lack of opportunity to reconnect and engage in these tasks in structured institutional environments may contribute to these assessments. The level of support could not be determined for nearly half of the participants in domains of shopping, preparing items of food or drink and using public transport, as hospital settings did not offer opportunities to engage in such activities and participants' functioning could not be determined.

A total of 93.5% participants had never gone outside the hospital. Hospitals in the states of Gujarat (65.1%), Haryana (62.5%) and Jammu Kashmir (77.8%) had a relatively low number of long-stay service users who were confined to the premises and between a quarter to approximately 40% went out of the hospital, more so in Gujarat where 22.1% travelled outside at least once a month.

Over the last two years, 98% had never worked outside the hospital. Despite an assessment on CPQ that only 31.4% of long-stay users were unable or did not wish to work, 84.2% were currently not engaged in any kind of work or skill training; 13% stated that there were no opportunities for work, perhaps indicating a disconnect between the kind of work they preferred or were used to and what was on offer, or perhaps that some form of gatekeeping/intake capacity limitations exclude them from freely accessing work options.

Only 15.1% were engaged in skill or vocational training and 35 (0.7%) were currently employed with jobs ranging from working in the canteen, laundry and selling tea at the outpatient clinics. Most of those employed were from West Bengal and placed in social enterprise initiatives that Anjali, a non-profit organisation, had facilitated in these hospitals.

Social contact and relationships outside the care facilities were negligible – 86.5% had never received an external visitor and 94.8% had never visited anyone outside the hospital.

Subjective well-being on the CSS (Cantril's Self Anchoring and Striving Scale) was not rated by about 80% of the participants. Scores were assessed mainly in Maharashtra, Telangana, Andhra and Kerala. Participants evaluated their future more favourably ($M=6.58$, $SD=2.42$, $n=939$) compared to their current life ($M=4.74$, $SD=2.59$, $n=984$) and life before treatment ($M=4.40$, $SD=2.73$, $n=912$), which was mostly interpreted as life before being hospitalised. Participants expressed aspirations for return to their life as it was before – cultivating land, getting back to children, being at home, living among their social ties, whom they miss. Gender differences were observed in Kerala and Maharashtra, where on average men rated their present life at the hospital and their future life higher on the scale than did women in relation to their present and future life.



Perceived Reasons for Long-stay in State Mental Hospitals

Several reasons emerge for phenomenon of long-stay, which coalesce around histories of homelessness, high clinical needs and factors that drive social rejection, familial refusal and abandonment of people living with mental illness.

Several hospitals have taken initiatives to address the need for reintegration of long-stay service users. Despite budgetary constraints, there were several anecdotal instances of staff of hospitals pooling in personal resources to reunite a service user back to the family. Several facilities have collaborated with non-profit organisations, such as Shraddha Rehabilitation Foundation and Shanti Kutir, to trace families and assist service users in journeying back to their communities as also to offer other institutional living arrangements. However, despite these efforts a sizeable number of service users remain institutionalised long-term in these facilities.

In FGDs and interviews with stakeholders, several reasons emerge for phenomenon of long-stay, which coalesce around histories of homelessness, high clinical needs and factors that drive social rejection, familial refusal and abandonment of people living with mental illness.

1. Sedimented attitudes about people with mental illness based on previous episodes of illness were perceived to drive reluctance among families to accept relatives with mental illness even if they had recovered. Rather than being situated solely within the household, these attitudes are sometimes driven by neighbourhood prejudice and pressures. One carer articulates his predicament:

“

My son was working as a pipeline investigation officer – it was a decent job with reasonable pay and we were able to lead comfortable lives. Then he was diagnosed with mental illness and one by one in succession he lost everything – his job, his dignity and respect in the neighbourhood. Anything goes wrong in our society [group of flats], he is blamed for it. I even had to sign an undertaking to the flat management agreeing to the same.

Society is the problem. They do not let us live in peace. He has recovered now but they are refusing to give his old job back to him, people ridicule him all the time, this is miserable existence, it is.

”

Further, post-discharge continued non-supportive patterns of communication and dynamics derived from the baggage of past behaviour were perceived to contribute to a failure to sustain recovery.

PANDEY

Pandey has a wife, a son, a daughter and three sisters. Living in one of the hospitals since 1999, he has been able to reach the socially accepted cues that indicate recovery – he is not dependent on anyone, does not present any clinical symptoms and is socially adept. Yet, he continues to live in this hospital. It was October and Pandey remembers the day he left home for treatment, egged on by his wife and neighbours. But he was a sad man, who wallowed – quite understandably so because his family stopped all connections with him after that fateful day.

Close to ten years of living within has allowed Pandey the time to relearn his way around his illness and sort out his life's particulars. The hospital team had reached out to the family continually but were unable to succeed in making them overcome their combined steadfastness to not allow Pandey into their lives again. He tried speaking to them individually, but in vain.

Pandey was just learning to let go of hope when one day amidst all this, he came to know that his daughter's marriage was fixed to happen soon. His aspiration to be one with his family resumed and he all but beseeched them that he be allowed to partake in the happiness, but again was met with rejection through silence.

Pandey let go of these thoughts after this incident and has decided to live the rest of his life within the hospital, helping other service users. With time he has been able to shift his gaze and start seeing the place as home too.

GOWTHAM & SETHU

Gowtham, a male attender, who has spent decades in one of the hospitals, recalls an instance where he accompanied a user who had fully remitted clinically back to his home town in Kerala.

Despite the visible recovery made by Sethu, his wife and adult children refused to have anything to do him – their past experiences combined with prolonged absence made them resistant to the very thought of the user becoming a part of the family again. The same day Gowtham found an institutional facility for men, non-psychiatric, lest the user descend into homelessness again.



2. Lack of comprehensive continued care, that can assist users and families to navigate medication adherence, side-effects, relational disruptions, financial duress, sexuality and engage in meaningful roles including paid employment, was perceived as contributing to repeated admissions and in due course family rejection of people with mental illness.

Community-based support to sustain recovery is perceived to be low, offering families facing socio-economic distress few alternatives other than the tertiary facilities. This is further conflated by a treatment paradigm that offers care in circumstances that disrupts families rather than inclusive settings where they can stay nearby during care and learn and adapt positive roles that can help sustain recovery.

MUKESH

Mukesh is from a middle-class family running a grocery store. After a substantial period of stay in one of the state mental hospitals, his family was sought and counselled to allay their immediate hesitations, following which they agreed to his discharge. But with time they realised that providing care required more than just an inclination. There were complications – be it Mukesh's persistent suicidal ideations or the acculturated practices he had developed over during his stay at the hospital, which required greater amounts of care and frequent outpatient visits.

This the family was unable to provide – all members were engaged in some form of work. To address the disruptions, Mukesh was readmitted to the hospital. Although this was initially meant to be for a short duration, the period of stay extended before culminating in discharge and another readmission. This continued as a vicious loop – resulting in a total of three subsequent readmissions – and distress for the user and the family in the interim.

As the family grew increasingly wary and resistant over time, Mukesh was abandoned by them in the vicinity of the hospital to fend for himself. Mukesh now remains homeless right next to the hospital and ekes out a living by begging.

3. Choice among people living with mental illness to not return to past environments of trauma led to some living in the hospitals over the long term. Some participants recalled extremely difficult circumstances at home – trauma apart, daily struggles for food and other essential resources – in contrast the hospitals offered them a refuge, whatever the conditions. For a subset of users with a long period of stay in these hospitals a future life outside, especially in family environments that have been less than kind, is not considered.

SUDHA

In 2011, Sudha was admitted to a state mental hospital by her uncle. Although for many others in the facility, living at home was the unfulfilled wish, Sudha preferred life following her admission. This was because the life she left behind was immeasurably more difficult – sexually abused by her father, grappling with her mother’s untimely death and following social and economic deprivation, Sudha never received any support from the others around her. Then one day, her father remarried and sent Sudha away to the care of a distant relative (the uncle mentioned above), who got her a job and a living space in a hostel.

She worked as a receptionist, earned, life was going on. Until Sudha met with an accident that caused the temporary immobilisation of her leg. Their finances exhausted and unable to provide care, her uncle admitted her to the hospital simply because the facility would allow her stay for free and provide some care.

Although initially proposed as a temporary arrangement by her uncle, Sudha liked life at the hospital. Not being seriously ill (especially not having any diagnosis of mental illness at present) afforded her the opportunity to take on the role of a peer supporter, help the staff with their routine work and gain a sense of purpose as well. She does not want to leave the hospital – this has become her life and anything other than this would mean having to relearn how to be. Sudha is unwilling to relocate or consider a plea for discharge (although she was cleared as ‘fit’ by the internal VC committee that contemplates and decides discharges), as she considers the hospital and people, life within as home.

AYUSHI

When Ayushi danced, she felt close to happiness. Also, it reminded her of home. Home was a small town in Bangladesh, where she shared space with her parents and siblings. Leading a simple life, Ayushi managed to pursue what she liked – she attended classes at college in the day and took dance classes in the evening to supplement the family's income. Life went on its course until she fell in love with Jagdish. Love struck her with full force, with Ayushi becoming increasingly drawn to Jagdish. So did the opposition – for it ended with Jagdish rejecting her proposal after few years of courtship, as he wanted to renounce life and go down a spiritual path without attachments.

Ayushi lapsed into misery, the pain infiltrating her physical and mental health. Desolate, she tried to make peace with the present, but often ended up losing her sense of self. To make matters worse, her family decided that this was the right time for marriage and arranged for her to marry a person from the neighbouring area, despite her not consenting to the marriage. Ayushi descended into greater unhappiness for the next two years where she had to traverse a complicated relationship, replete with abuse.

The marriage ended in divorce, after which she had to subsist in a life without any dignity. A weary but visibly relieved Ayushi came home to her parents hoping for some basic support and understanding, only to be viewed with fear, disgust and shame. This adversely affected her already precarious mental health. She left home one day and spent some days on the streets of Patna, before being admitted at the state mental hospitals in Ranchi and later in Berhampore. Ayushi describes this shift was also against her wishes, the logic of the hospital staff being that she spoke Bengali and hence was a 'better fit' in the latter hospital.

A fierce Ayushi exploded in rage and resisted this change. She was exhausted with not being allowed to exercise any control in shaping her own narrative. However, in time, she was able to reach a personal sense of recovery and learned to adapt to living within the Berhampore hospital. Significantly, although the team was able to help her reconnect with her family in Bangladesh, Ayushi declared that she will not move out and was 'far happier here'. She says – 'Once in a mental hospital, you cannot get out it. So might as well love the place and be happy. Nobody takes home a mad person'.

4. Pathways into long-term confinement defined by gender-based disadvantage are reported among women, who form a larger proportion of this cohort. Qualitative notes accompanying narrations of abandonment by women in the sample reveal pathways that may be discerned through a gender-based disadvantage lens – with disruptions in family, marriage and with intimate partners and consequent irreconcilable trauma. In the words of a social worker at one of the state mental hospitals:

“ In our society, women are always at a disadvantage. There are more women who are long-stay than men. Why do you think that is? Because no one wants a woman who doesn't behave as expected – cook, clean, keep quiet – she is a burden. ”

KANTHA

Kantha was less than 10 years old when she was forced by her father to marry a much older adult man. In these two years she had seen violence, apathy, and suffered sexual abuse at the hands of her partner. Having wrenched herself away from the violent household, Kantha tried to seek shelter with her father – only to be shamed and scorned away for failing to live within remits of the relationship.

Two years later, she entered one of the state mental hospitals as a service user after spending the intervening years ill, homeless and desolate. Her earliest memory from this time is of spending time with another user who used to prepare the dead bodies of users for transport. She doesn't know why, but for some inexplicable reason, Kantha was expected to take on the role in time. She recalls a maushi telling her – 'you do this work well now, so that when you are dead, someone will do the same for you'. Kantha is now 30 years old – she still carries out this process every time a user is declared dead, without much hope, tired but used to it.

JASMEERA

Jasmeera did not have a happy marriage. Those were the days of long hours of work, where she had to toil both at home and outside, so that the family could stay afloat. It was not grinding poverty that was the factor here – the difficulties were far more. Her husband was perpetually dissatisfied – his expectations were never met, regardless of how hard she tried. With days she had to learn to be silent and not respond to his tirades – all in an attempt to calm the acrimony, more so for the sake of their two daughters.

But the problems loomed large, with constant arguments and abuse, sometimes even physical, defining their relationship. This was not the life she was acquainted with before marriage. Coming from a family in Jalandhar with enough means for survival (her father was in the army), Jasmeera was allowed her freedom and encouraged to do as she chose. But the change in her life after the marriage, resulted in Jasmeera's mental health taking a turn for the worse

She grew increasingly morose and had frequent outbursts, possibly as a result of years of pent-up emotions. A stand-alone episode where Jasmeera tried irrationally to hit her husband with a flower vase cemented the perception that she indeed was not doing well. She started to obtain inpatient treatment at one of the hospitals at the behest of her husband. Although improvements were slow, they appeared over time, culminating in her being ready to re-enter the community.

But in the interim, her husband with her extended family colluded to ensure that Jasmeera stayed at the hospital. The family, caught in their gruelling busy lives, especially after Jasmeera's father's death, grudgingly accepted this as her fate. And this is how Jasmeera has lived almost her entire life for many years in the hospital, despite being able to move on from those days of being chronically ill. Except for some visits by her older daughter (who is an adult now), Jasmeera has almost been forgotten by the people she knew as family.

However, her life is not entirely without meaning – although she has tough days where her symptoms resurface, happy days also appear, where on a whim, she breaks into a dance with the few friends she has identified and so the days slip by – ambiguous, without a large sense of purpose, but peaceful.

5. Non-conformity with expected roles was articulated in a cross section of opinions among stakeholders as another reason for families to abandon a member with a mental illness. People with mental health issues who do not take up the usual household tasks or remain out of consistent paid work are perceived to be at risk of being abandoned by their family if the results of treatment are not consistent with such roles. The added burden of a person perceived as non-contributing to the household was unwelcome and led to disengage with hospital residents.

RAVI

Ravi says no one is there to care for him. He says it is this gloomy, perennial thought that keeps him company while in the facility. And then he clarifies – ‘I have no one inside or outside this space. I am 40+ years now, have always been single, although I did yearn for a partner, it never happened. Then he pauses and continues – ‘Of course the loneliness did not make me feel good – I took to other habits that filled up the void to an extent’ – referring to the drugs he abused for a larger part of his life before getting admitted.

This resulted in mental illness induced in part by harmful substance use and in part by his surroundings. Cast aside by his family as a ‘failure’, Ravi has been a resident in the hospital for the past seven years. He vaguely mentions that there are some legal cases against him as well. When asked if he would like to return back to living outside, he looks up quizzically and repeats – ‘but I have no one to provide me care, what will I do outside?’

JAYANTH

J ayanth never felt loved. Although life afforded him opportunities to study – the combined hopelessness he felt because of always being viewed through the gaze of his illness, made him drop out. Eventually he got married, had a son, but the weight of expectations foisted on him weighed him down, causing troubles in his relationships and family as well his social life. He was unable to work beyond a point. He wanted to do something different that did not entail physical application, especially exacerbated because of being ‘expected’ to play the role of a son.

Exasperated with having to depend on others to lead his life, Jayanth’s father saw fit to come and drop him in the facility.

When he tried reasoning with his father saying he could not bear to live away from home and that he was trying his best to provide, his father did not pay any heed. Jayanth says his father was spurred on to do this by his second wife because she did not want to care for him. He then later reveals that it was one similar day some years back that Jayanth’s mother had also been admitted to the facility – the underlying silence implies that this was more because she was a hindrance rather than because of an inability to provide care.

6. Increasingly disintegrated families were articulated in the experience of several stakeholders. For some the long-stay cohort, the primary and invested carers had died or were single parents (mostly women) and other family members such as siblings were either not available or reluctant to care.

A M E E R

Ameer had finished his undergraduate degree in business applications and just started a job when his mother died. Even before he could give a dignified closure to his grief, Ameer's father remarried. Unable to accept this, Ameer spoke out against the union and lashed out in rage. However, his anger and indignation at having his mother's position replaced and so soon, without so much as a discussion with him, was misconstrued as 'his mind being disturbed'.

He says that the police colluded with his step-mother because of shared vested interests – and that their aim all along had been to somehow cut him off from his share of property. It has been 12 years since Ameer entered one of the state mental hospitals – the prime of his youth has been spent in within an institution, his family has outright refused to reconnect with him and Ameer will spend the next few decades within the hospital until other non-normative pathways for exit are identified.





7. Poverty was perceived as barrier to manage complex demands of care. Recovery demonstrated during the stay in the hospital was observed by stakeholders to disintegrate in less than optimal socio-economic circumstances, leading to readmission. The socio-economic characteristics of households of people in this sample were not systematically gathered, including for those brought in by families. Therefore, systemic barriers besides the immediate markers of family abandonment need further exploration. In the words of one carer:

It is not that I do not wish to keep her. She has been through three re-admissions – each time I had to bring her back for perfectly valid reasons. One time, she caused a fire at home. Then another time she locked all of us inside home without any reason. The next year she tried to die by suicide by jumping down a flight of stairs. What else can I do but lodge her here?

Drawing attention to the struggle for families living in poverty to remain engaged with limited, distant outpatient options, another carer says:

Can you tell me what illness my wife has? Why am I unable to access these medicines from a local dispensary? We are from Aurangabad and have to travel all the way here for a check-up. This is exhausting all our resources and will.

8. Inability to trace and reconnect with families of those with histories of homelessness either due to possible migration, lack of recall or logistical difficulties such as language barriers, lack of financial and human resources was reported as a reason for the persistence of long-stay in some of the hospitals.

RADHA

Radha arrives for the interview with a downcast expression – but her face brightens when she realises that the data collector can speak her language (Tamil). Lapsing into a monologue that is part Tamil and Telugu, Radha says that she comes from Salem. Some more prodding and she is able to give more details like a local landmark, the work her husband used to do and her children's names. She says 'all these years, I have tried explaining to them that I need to go back home, my husband needs me, he cannot be away from me for this long, but they never understood what I spoke and only hushed me away'.

Radha subsequently also reveals that her husband had married for a second time, that the second girl 'was also nice and used to take care of my children and me'. She left home one day after a fight, with the hope of returning home, but lost her way, took a train by mistake and ended up here.

The data collector further says that Radha clutched her hand and all but implored to be taken home, back to the lands which were familiar to her and that the food, people and language spoken here is too alien – 'although I have learnt to adjust with it, I even have some friends'.

MEHZABIN

Mehzabin is 50 years old and diagnosed with Bipolar Disorder. Originally from Pune, she yearns to return to her small house and reconnect back with her days as a domestic worker. Although she is doing well and has not seen a resurgence of symptoms for the last seven years, the hospital team has not found the means to trace her family.

Having stayed for so long, she fears she may have a relapse. By her own admission, her episode of mental illness and homelessness were triggered by persistent disruptions in her marriage combined with her husband's alcohol abuse.

A resilient woman coming from a Muslim community, Mehzabin believes she can face her family and has the means to support herself on her own by working. At the hospital, she wants the committee to approve her discharge fitness or let her go on her own.

9. Limits of existing therapeutic assistance in addressing symptoms were perceived to contribute to a cohort with persistently high support needs. Such residents were either unable to offer information about their families or if the families were known, they were unable to offer the necessary support.

The combined experience of intellectual disability and lack of necessary support was perceived to compound the issue of lack of meaningful outcomes.

NEELAM

Neelam's appearance does not betray her age. Although she is wearing the pale blue uniform like other users, there are certain markers in her dress which make her illness obvious.

The only words that she says when she realises that she is speaking to a social worker are – 'I want to go home. I have a daughter'. She says she is from Kerala and Kolkata sometimes. At other times she says, 'I come from Sabarmati Ashram in Gujarat. Did you meet my son?'

Any attempt to bring some coherence into the conversation is lost – with her pointing to different directions and landmarks when asked to explain the route to go back home. Neelam, however, is certain she can take us to her home if only we allow her to step outside, it is just that she 'is not very good with words and it is all very confusing'.

When probed on how such issues may be counteracted, opinions ranged from making accommodations in the form of free medication, travel support to providing immediate service during critical care situations. Carers felt the system is too mechanised, with individuals not having the time to provide solutions that allow for user to remain at home. While interventions such as group homes were looked at with interest by providers and some users, carers were sceptical.

Despite these systemic limitations and an inherited legacy of confinement, the desire for a changed scenario is perceptible in the FGDs. Civil society initiatives such as Anjali, Parivartan, ILS Pune, Schizophrenia Awareness Association (SAA), Sneha, Bapu Trust are engaged in collaborative and individual ventures in mental health – resources that can be leveraged in planning and implementing a strategy for offering services in the form of community support, finding responsible alternatives for long-stay and reducing the size of hospitals.

Intent must be met with investments and the leadership to drive through the necessary change across the continuum of mental health care.



Prospects for Transition to the Community

Overall, in response to an item at the beginning of the interview, the majority of participants (51.8%) preferred to return to their family, while 21.5% wanted to remain at the hospital. Only 3.3% wanted to attempt assisted housing or employment with an independent living option. Among them, there were more women (n=91) than men (n=70). More women (n=1330) wanted to return to families than men (n=1204). Women (n=583) formed a greater proportion of those who wanted to continue at the hospital than men (n=468), while 30% or more participants in the states of Jharkhand, Karnataka, Madhya Pradesh and Odisha preferred to stay at the hospital.

These choices are reflected in Tara's vignette. Tara came in as a 12-year-old girl to one of the hospitals, where she has lived for 62 years. Asked if she would consider discharge as an option, she resignedly asks – 'my youth, a whole lifetime has passed by, what difference do you think it will make whether or not I go back to the world now?'

By the end of the interview, in response to the item in the Community Placement Questionnaire (CPQ), some preferences appear to have changed– with 41.9% preferring their family of origin and 14.4% wanting to continue in the hospital.

Housing options in the community – Independent living, shared and assisted housing were preferred by about 13.2%, while 30.5% did not express any clear preference. The presentation of options other than those experienced may be necessary to enable informed choices.

In the overall team assessment, 78.6% of participants no to moderate problems were anticipated with placement in community. For 17.5% of participants, complex needs were assessed which may place high demands on staff while only 3.9% were assessed to have very high needs that may preclude a successful placement in the community. Risks to oneself and others because of community placements were not identified in a majority of participants assessed – 90.9% had no or mild problems with respect to danger to self or others, which can be managed by staff in a supportive setting, and 82.1% had no or mild problems with their behaviour having little to no impact on day-to-day activity.

Family objections to discharge were reported in 19.2% of people in this sample, more prevalent for men (24.2%) than women (15%). Refusal by family to have a client live at home with them was reported in 32.6% of participants.

FIG. 13.
Preferred Placement Expressed at End of Interview by Long-stay Service Users at State Psychiatric Hospitals

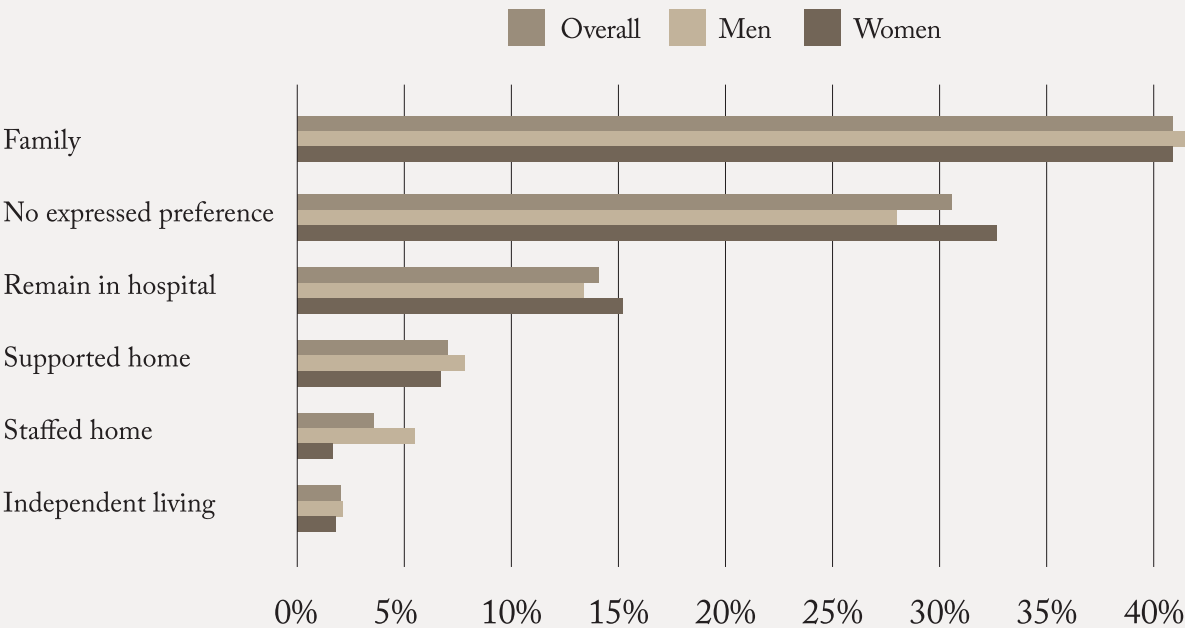
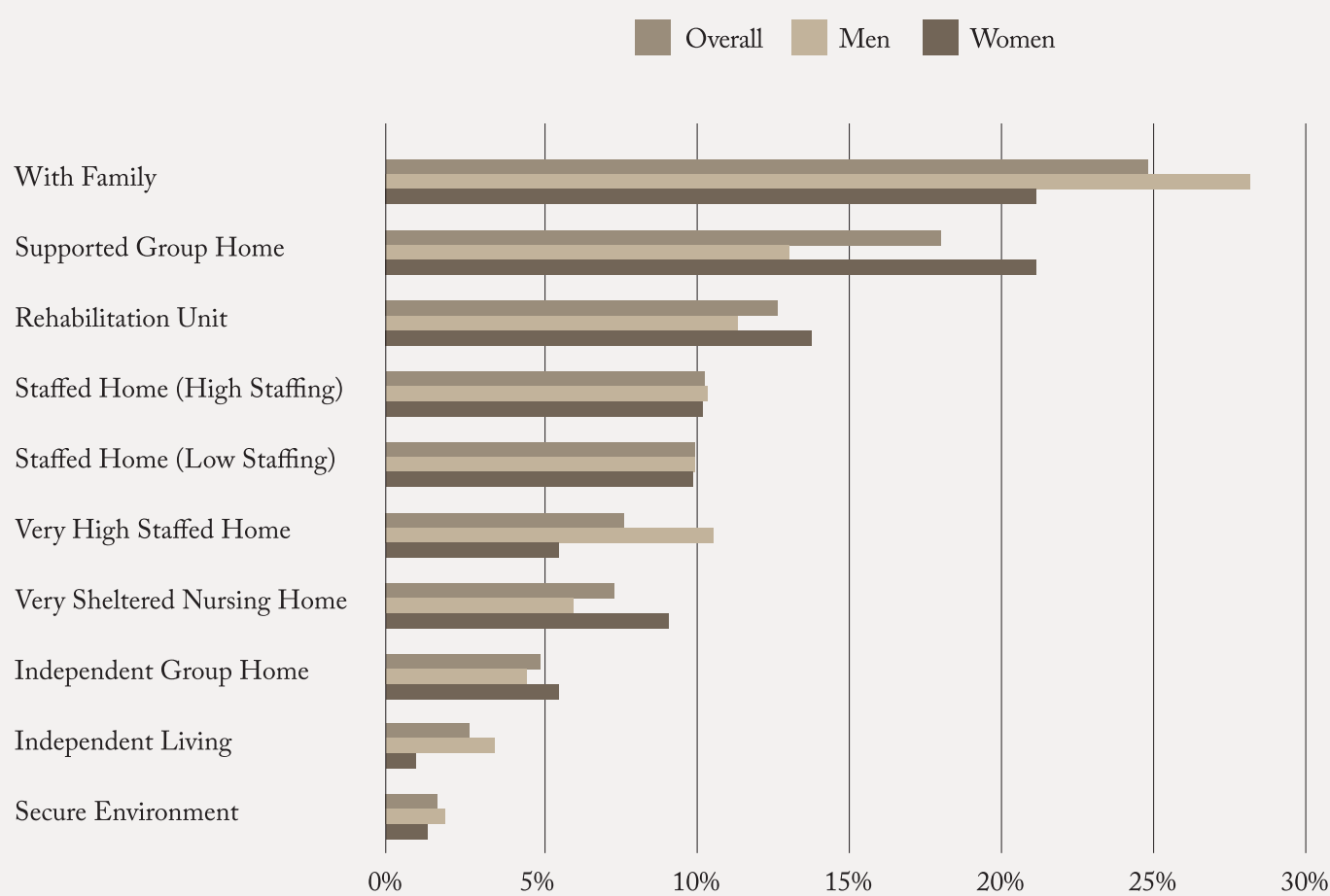


FIG. 14.
Best Possible Placement for Long-stay Service Users at State Psychiatric Hospitals



Family placements were recommended only for 24.8% of this cohort. The majority (53%) were recommended for housing placements with different levels of support in the community, with approximately 44.9% being able to be supported in scatter-site housing (homes scattered across ordinary neighbourhoods) and 8.1% with very high levels of support that may potentially be offered in congregated or clustered housing environments (homes in close proximity with shared facilities) and 12.6% were recommended potentially transitional or permanent rehabilitation homes, which may again be offered through clustered housing environments. About 9.6% were recommended environments with levels of support that are as high as an acute care or nursing home facility.

Perhaps reflecting the higher level of disability observed in Tamil Nadu, 18.5% were recommended continued placement in an acute care or nursing home facility and 30% were assessed to require a home with a high level of staffing, including night shifts. In Karnataka 18.8% and in West Bengal 16.6% were recommended for placements in nursing homes or to continue at the hospital.

These recommendations for placement also require the presence of necessary support – brief periods away from their placements (48.3%), work support in the form of adult day programmes or social co-operatives that offer accessible environments with necessary accommodations, information on local resources (84.3%) and problem-solving to assist access (8.9%) and personal financial support (92.6%).

In the overall assessment, the majority of long-stay clients demonstrated mild to moderate disability with little to moderate level of potential community support.

STRATEGY TO ADDRESS LONG-STAY IN STATE MENTAL HEALTH HOSPITALS IN INDIA

Globally, community-centred care approaches have been pursued to replace mental health services based on large-scale institutions in response to the issue of long-stay.

This assessment of long-stay participants across the 43 state mental hospitals in India demonstrably emphasises the imperative to develop alternatives to their continued incarceration and denial of access to social, economic and cultural resources.

Globally, community-centred care approaches have been pursued to replace mental health services based on large-scale institutions in response to the issue of long-stay and unacceptable conditions in institutional mental health facilities. De-institutionalisation has had mixed outcomes in different countries. Kunitoh (2013), in a systematic review, found that the vast majority of literature demonstrates positive outcomes in social functioning among those who were discharged from hospitals into the community.⁶⁴ Modest improvements in symptoms were observed less unequivocally, while mixed results were evidenced across studies on quality of life. The review considered 12 studies that evaluated outcomes of de-institutionalised populations in Australia, Canada, England, Germany, Ireland, Israel, Italy and Japan.

Although some scholars have linked de-institutionalisation to homelessness and increased incarceration of people with mental health issues, a systematic review of 23 studies that tracked these outcomes among discharged clients from mental hospitals across several countries found that the

majority did well in the community over the long term.⁶⁵ The review represents outcomes from populations of de-institutionalised patients from Albania, Australia, Austria, Canada, Finland, Ireland, Italy, Japan, the United Kingdom (UK) and the United States (US); 15 of the 23 studies found no homelessness among discharged clients, while the rest found rates of 0.9–2%; 11 of the studies found no discharged clients landing up in prison, while rest found between 0.3–4.6% of people entering the criminal justice system.

This may, however, not account for new cohorts of people with mental illness, who have, in the absence of institutional beds and adequate community alternatives, become homeless or are imprisoned. Across countries that underwent de-institutionalisation, the phenomenon of ‘new long-stay’, newer cohorts of people occupying either psychiatric beds or encountering the criminal justice system has emerged.

In the US in particular, 25% of people in the criminal justice system are estimated to have serious mental disorders.⁶⁶ Similar to deficits secondary to institutionalisation observed among those who spend lengths of time in psychiatric hospitals, a trajectory of progressing from acute to chronic needs is manifest. With growing demands of new cohorts of people with mental illness in European countries, a trend of re-institutionalisation with an increase in the number of long-stay beds in psychiatric hospitals and supported housing has emerged.⁶⁷







The experiences of de-institutionalisation across the world, albeit in different circumstances and contexts than contemporary India, offer lessons that need to be considered in devising a strategy for addressing long-stay in psychiatric hospitals in India.

In India, unlike the high-income countries where most of the experiences of de-institutionalisation took place, bed availability and occupancy remain lower than anticipated for the prevalence of mental illness observed.

Processes of enabling access to inclusive living options for long-stay clients may therefore not necessarily mirror the Western experience of cutting the number of beds. Instead, considerations of the size of institutions, decentralising services (including hospital beds) and improving the quality of living standards and care in institutional facilities, parallel to the creation of community alternatives, may perhaps be more appropriate.

Second, strategies must span beyond the creation of immediate discharge to structures such as group homes, rehabilitation units to encompass the commensurate expansion of community mental health services. It may be argued that the more successful de-institutionalisation efforts are where the de-centralisation of services was overlaid with transfer of care to the community. Progressive discharges of long-stay cohort must be met simultaneously with investment in community services and support.

Third, pervasive social disadvantage and the limits of known treatment options in schizophrenia-spectrum disorders (which are over-represented in long-stay cohorts) may contribute to a continuing trend of people requiring long-term care.

Social deprivation has been found to explain different rates of long-stay beds across districts in England following de-institutionalisation at Friern and Claybury psychiatric facilities.⁶⁸ Longitudinally, the expansion of long-stay services will continue to need investment until community-based mental health services combine with welfare sectors to adequately tackle the social disadvantages that influence access and outcomes among people with mental health issues.

Fourth, presence does not equal participation – moving people into the community may not necessarily translate into long-standing gains in terms of their quality of life and social inclusion. New structures in disparate settings may mirror the same patterns of control and inconsistent quality of care that became pervasive in many psychiatric facilities. Pattison and Armitage (1986)⁶⁹ argue that people with serious mental illness may be harmed by being placed in deprived communities that are ‘unreceptive, uncaring and resistant’.

Studies have found that social integration, such as developing relationships, re-entering work, and civic participation continue to remain low in de-institutionalised and assisted housing participants. Defining priority outcomes to be pursued as a consequence of addressing long-stay will determine models and strategies that will need to be adopted.

Examples of Models to support Community Living and De-institutionalisation

CLUBHOUSE MODEL

In the 1940s, six people with mental illness met at the Rockland State Hospital's clubroom, 'shared their stories, read, painted and participated in social functions'.⁷⁰ Following their discharge, they began meeting on the steps of the New York's Public Library, recreating supportive relationships and belonging that they had fostered in the hospital. In 1948, this group established the original clubhouse, Fountain House in New York, as a space for people with mental illness to find themselves and achieve their potential as valued members of a community.

The Clubhouse model is anchored in the belief that people have inherent strengths that help them recover from the effects of mental illness, and that work and consequent relationships are restorative. The model involves a peer-led working community across areas of running the clubhouse such as reception and membership, communications, horticulture, cooking, research and wellness. Through engagement across any of these areas, members share ownership, form relationships, find dignity and meaning as part of a welcoming, vibrant and supportive community. Members of the Clubhouse access Employment Placement Services, Housing options and College Re-entry Programmes

that help them return to the community and pursue their aspirations. A wide variety of choice is available across these services and tailored for members based on their preferences and needs. For example, members may choose transitional employment opportunities which are time-limited (six to nine months) part-time placements with employers with whom the Clubhouse has a formal relationship and offer support in the form of staff or other members covering for absence.

Alternatively, Supported Employment, where on- and off-site support is available in placements with an array of employers in mainstream jobs, or Independent Employment, which is facilitated placement without any on-site support may be accessed by members. Housing options can similarly range from residences in the Clubhouse to families/friends or independent rented apartments. The Fountain House model, through social franchising (replication by local partners accredited by Clubhouse International), serves over 100,000 people with mental illness, including those with histories of homelessness, in over 300 locations in 30 countries.



Clubhouse International is the oversight body to ensure adherence to quality standards across these franchises. Clubhouses are accredited following intensive training of staff of the franchises in the model and on-site review of implementation of standards. Among Fountain House members 42% are in employment compared to 15% in the general population of people with mental illness, only 10% of members are re-hospitalised compared to 50% in the general psychiatric population and 77% of members complete a university degree compared to 32% in the general population of people with mental illness.⁷¹

A systematic review of the Clubhouse model involving 52 published articles demonstrates support for superior employment outcomes, reduced hospitalisation and better quality of life in members of the Clubhouse; a result echoed in Randomised Controlled Trials (RCTs) that compared randomly assigned participants of the model with those in as usual care.⁷²

Quasi-experimental and Observational studies in the review offer support for improved education and social relationships outcomes. Estimated to cost one-third of Inpatient services and substantially lower than Assertive Community Treatment, the Clubhouse model's effects on re-hospitalisation rates and reducing involvement in the criminal justice system offer savings in averting the costs of institutionalisation.⁷³



HOME AGAIN

Home Again (HA), providing housing with supportive services, offers people living with mental illness the opportunity to live in rented, shared homes in the community with bespoke support provided by personal assistants for health, socialisation, economic transactions, work, leisure and pursuits that have personal meaning.

People come together to form affinity groups and live in homes in a community, creating a shared space of comfort, that is similar to a family environment. Along with housing, the intervention features support services including social care and facilitation (opportunities for a diverse range of work, facilitation of government welfare entitlements, problem solving, socialisation support, leisure and recreation), access to health care, case management (detailed bio-psychosocial assessments and personalised care plans) and onsite personal assistance.

HA is managed by a multidisciplinary team, most of whom are non-specialist personal assistants. A typical home has four or five women with one or two on-site personal assistants visiting or living with them based on need.

Sixty people living in such housing arrangements scattered across a 10–15 km radius will need to be served by a full-time 20–26 member team comprising a programme manager, a social worker,

a nurse and 18–24 personal assistants (based on the levels of support needed) who work on a shift basis. Access to community resources in a vibrant neighbourhood, such as varied work and recreation options, banks, and such utilities, are essential. Sixteen hours of psychiatrist's time a month on an outpatient basis will be needed for consultations, along with other health services (inpatient or outpatient) as appropriate. HA was initiated by The Banyan with research grants from the Grand Challenges Canada (GCC) and is supported currently by The Hans Foundation and The Paul Hamlyn Foundation.

The intervention has been implemented in neighbourhoods in Chennai, villages in Trichy and Kancheepuram districts of Tamil Nadu; Malappuram and Thrissur in Kerala; and Guwahati and Boko in Assam with a partner, Ashadeep. This includes a peer-led implementation in Trichy by two sisters, Amali and Jacqueline, who have experienced homelessness and mental illness.

As anchors of this programme in Kovandakurichi, Trichy, they are lending an intimate and in-depth perspective shaped by their own experiences and dynamically contributing to enhancing the intervention across sites. The HA implementation in Guwahati and Boko, Assam is led by Ashadeep, a carer-led non-profit, which was supported with capacity building over one year to transfer the intervention to the local context.

HA has demonstrated significant gains with increased community integration and reduced disability among service users.⁷⁴ Outcomes from the GCC-funded trials across these sites indicate:

- Transitions from hospital to community living are possible even for those with higher perceived clinical needs.
- Community integration of people in HA increases compared to a matched group of people who remain in institutional settings. Significant effect on community functioning is indicated by higher scores on the Community Integration Questionnaire (CIQ), with more participation in leisure, shopping, and in running a home.
- Disability of people in HA gradually decreases compared to a matched group of people who remain in institutional settings. Significant effect on disability over time is indicated by lower scores on the World Health Organization Disability Assessment Schedule 12 item (WHODAS 12).
- Social distance towards people with mental illness declines significantly in neighbourhoods where these homes are located.
- Ethnographic observations reveal an emphasis on a sense of family that offers social support and fosters hope. Perceptions of stigma and mental ill health and distress are observed to evolve as interactions with residents of the houses develop and become more frequent.
- Without deriving any causal inferences, improved re-integration rate and reduced average number of inpatient days were observed in the institutional facility in Tamil Nadu, coinciding with the transition of long-stay service users to Home Again.

Currently, 175 people live across 37 homes in Tamil Nadu, Kerala and Assam. HA presents an alternative to the continued incarceration of people with mental illness, including those with persistent and high levels of support needs, with demonstrated gains for community integration and disability. Through HA, those who are systematically marginalised on account of mental illness, poverty and homelessness are able to regain agency over their care and lives and claim space to participate socially, economically and culturally.

HOUSING FIRST

Developed to provide ‘permanent homes’ to homeless people, Housing First functions without placing any priority on treatment expectations.⁷⁵ Initially designed as an approach to house individuals considered as ‘absolutely homeless’ with mental illness or addiction issues (‘high and complex needs’) under the Pathways to Housing programme⁷⁶ in New York City, the model has been considered widely successful in realising housing stability.

The Permanent Supportive Housing (PSH) is preferred for individuals and families who have histories of mental illness, disabilities, and substance-abuse issues apart from chronic homelessness – consequently needing a degree of services (permanent housing and support needs). The second, the Rapid Rehousing (RRH) is aimed at people who need immediate housing and assistance for short periods.

Actively drawing housing as a primary right, the intervention operates by providing ‘an array of services’ and engagement to equip individuals with social capital.⁷⁷ Moreover, it does not preclude those who have prior histories of criminal incarceration and believes that user choice should dictate all support being extended, allowing for separation of treatment and housing, organic transactions and the pursuit of individual and collective well-being.

Housing First is offered unconditionally and users are not expected to pass through a series of supportive services or productive behaviours to access or retain it. Entirely non-coercive, the model is hailed for challenging assumptions about the choices and behaviours that cause homelessness.⁷⁸

In Housing First, if users refuse to comply with treatment or lapse back into harmful substance use, they are not penalised – if these result in eviction by the homeowner, the intervention actively works towards continuing to support the user starting with a house search, emphasising ‘flexible support as long as required’.

Historically, before the advent of Housing First, the ‘Staircase’ model was in practice, which also originated in North America. Here, permanent housing and all associated support was made available to those homeless people who successfully took the series of steps that effectively ‘trained’ them to ‘live independently’. Also called ‘treatment-led approaches’, this placed focus on the illness and retainment of the support in a linear fashion, while Housing First emphasises ‘housing’ being made available ‘first’ before anything else.

Housing First has demonstrated its effectiveness and reliability across various studies. Systematic reviews report that users are able to access housing faster and are more likely to remain stably housed.⁷⁹ From the point of view of the community, the model is efficient as it offsets the high costs of frequent hospitalisation and incarceration associated with long-term homelessness.⁸⁰

These results are evidenced in replications of Housing First in other countries such as the At Home/Chez Soi (Government of Canada)⁸¹ and Housing First Europe (supported by the European Commission).⁸² However, most of these studies focus on individuals without dependants or extended families, so the applicability of the approach in such contexts may need further investigation.



THE OXFORD HOUSE

The Oxford House model provides housing and rehabilitative services to enable individuals with issues of substance abuse to reach abstinence and recovery. Established under the aegis of the Oxford House World Services, the model adopts a range of shared and individual housing, using community support. Entirely user-directed, the model accords primacy to self-governance.⁸³ Significantly, this also extends to the point of admission to the programme – with users democratically deciding whether an applicant's request for support should be considered.

The organisation runs on an ad-hoc non-ownership of property basis, with users finding rented accommodation that can be pursued for affiliation to the model's charter. Typically, each house is shared by six residents, all equally liable for overall its management and the responsibilities it entails. This can include simple tasks like division of work, assimilation of life skills and successful reintegration into the community. Anchored by users, the model's residents choose their own treatment options, for instance they can access help offered by professionals (e.g. Alcoholics Anonymous, Narcotics Anonymous) or choose not to, with an emphasis on social support and guidance from fellow residents. Each house convenes for periodic self-run meetings where individuals have an equal voice, with advocacy and assistance from support workers available on request. Routine tasks like financial matters and resolving other key issues of daily living that may arise are discussed, leading to a culture of peer support and engagement.

Nealon-Woods et al. (1995) observed that it is possibly the 'predictability of everyday events' within the house that stabilises the 'turbulence of addiction' in the journey towards long-term recovery and sobriety, complemented by 'a positive dependence on recovering peers'.⁸⁴ Large-scale analyses of the model report consistently high rates of abstinence. For instance, a national endline survey of 900 respondents revealed a substantive reduction (13.5% reported substance use after 12 months of residence) on follow up.⁸⁵ Best et al. (2014) conclusively showed that almost half of the sample engaged in active employment.⁸⁶ A defining outcome highlighted is increased 'recovery capital' reported post-stay in an Oxford House, with direct impacts on domains such as social support, identification with roles and overall quality of life.⁸⁷









SWAYAMKRUSHI – GROUP HOMES

Swayamkrushi group homes were introduced to challenge the facility approach which has been the norm in residential services for people with an intellectual disability. Working in Hyderabad with a specific population (those with an intellectual disability and diverse histories of low prospects of family reunification), the model created a framework that allows people to live together and form living spaces that are self-directed and individualised with support being available when required.

A group of six users and one on-site carer share apartments situated in larger complexes – these are rented and designated as a place of accommodation. Realising the felt need to make interventions that enable people with disabilities to incrementally achieve well-being, Swayamkrushi emphasises facilitating users to set personal directives for care. Service users are encouraged to reframe their narratives and extend their living to beyond being within these spaces of care.

Users actively engage in order to consciously create neighbourhood networks, access communities' resources and optimise opportunities for work, leisure and social relationships such as friendships, based on individual interest. Dialogue is encouraged with users to find ways for them to participate substantially and perform routine daily tasks independently. This can be at home concerning everyday activities or outside in the larger social space. Sensitisation to encourage employers to hire persons with intellectual disability is another area of focus – accommodations that will need to be made are explained to both parties (reduced work hours, flexible timing options, etc.) to ensure retention.

Social entitlements are also concentrated on – since Swayamkrushi operates as a nodal agency for the National Trust, it subsequently facilitates various schemes such as the Niramaya Disability Health Insurance Scheme.

INTENTIONAL COMMUNITIES – L'ARCHE

In 1964 Jean Vanier made a faith-based decision and invited two intellectually disabled men (Philippe Seux and Raphaël Simi) to leave the institution in which they were living and live with him instead.

Calling the intervention 'L'Arche' – meaning 'The Ark', or 'Place of Refuge' – Vanier drew on the belief that sharing life and extending love and friendship to those who are systematically excluded will result in creating a 'true sense of community'.

His personal notes during the time he shared with the two men speak about how the process of living was one of 'mutuality of care' and that the experience helped him more by 'revealing his own inner pain' and easing 'his own personal path towards God'.⁸⁸





Drawing heavily on Christian traditions (of 'sharing, forgiveness, simplicity, prayer'), Vanier credits the L'Arche model with allowing them to engage in 'socially valued roles', increasing their self-worth.

This marked the beginning of many others who wanted to join as part of the movement and to cohabit and co-create a faith-centred community, resulting in similar offshoots beyond Trosly in France where this began. Recognising that a simple 'charitable' offer of living space cannot go beyond a certain point, the model started offering simple vocational opportunities that will enable the members to engage economically (through workshops).

Now spread across 30 countries and five continents, there are almost 100 houses or workshops offering the L'Arche way of living. The belief system is centred around three central tenets that influence its practice of 'intentional community setting'. It acknowledges the power of each person's value and maintains that transformation is possible only through a sense of reciprocity created through social ties. Thus, it maintains that relationships can play a part that is more than merely incidental to a better quality of life – for instance, the model rejects the staff–user differentiation. All residents regardless of their disability are identified as family or friends.⁸⁹ The model reinforces among its members that individual value extends beyond economics, transactions, functionality or efficiency resulting in a framework that challenges conventional notions of a person's value and worth.



CARE FARMS

In parts of Europe and specifically in the Netherlands, ‘Care Farms’ – also known as ‘Social Farming’ or ‘Farming for Health’ – refer to the practice of increasing well-being by increasing participation in agricultural or farm-related activities.

Care Farms are contemporary interventions that actively mix health and farming to result in what is technically conceptualised as ‘Green Care’.⁹⁰ Over the last decade, this has seen a major resurgence in the UK, where private farms are entering into collaboration with health and care agencies to offer people with mental health issues a way to pursue farming in an environment that is inherently supportive. Initially, farm owners enter into agreements whereby service users do unpaid work in a supervised setting that is committed to providing for their health, educational and social care needs.

Users are involved in a wide variety of activities that can range from checking livestock, providing water for grooming to farm maintenance. Prioritising inclusion, the model acts as ‘an alternate collective space’ or ‘social hub’ for people to spend time in a productive and self-directed fashion and by extension participate in society and everyday activities. Care farms thus function as an integrative care set-up which allows for ‘highly interdependent’ friendships to thrive

The collaborative nature of the work also fosters a space in which issues of power imbalance between users and staff are minimal.⁹¹ There are demonstrable improvements in the lives of such users, with a systematic literature review noting favourable effects on clinical status, with 'social and occupational' aspects of the farm-based intervention perceived as beneficial by those using it.⁹²

Apart from bringing in a sense of security and the therapeutic impacts, FGDs among users conducted by Rotheram et al. (2017) show that 'happiness' is a significant emotion that users associate with Care Farms.⁹³ The authors state that the farms can bypass the focus on 'individual attitudes, behaviours' and more 'traditional measures of health and wellbeing' and become 'enabling spaces'.

Thus, the model has been seen positively by users, who cite physical and other benefits such as reduced social barriers. Users describe how such spaces allow them to conceptualise life positively. Since all tasks in the farms are valued – a physically demanding task is seen as important as a strategic task – users across disabilities are able to exercise increased purpose and choice and move towards pathways of 'independence, mastery and autonomy'.



TRIESTE

Motivated by what were then isolated movements towards de-institutionalisation in Trieste and the cities of Arezzo and Perugia in Italy, the Italian parliament passed Law 180 that banned psychiatric hospitals. Trieste is largely credited with building a model of care by reworking the San Giovanni Mental Hospital, which moved away from a clinical response to an innovative, holistic, social response which emphasised transforming the mental health framework by dismantling existing mental hospitals, prohibiting the building of new hospitals and separating treatment from social control.⁹⁴

The core of the model lies in its Community Mental Health Centres (CMHCs), which function on a 24/7 basis and cater to catchment areas through an integrated set-up that covers a general inpatient setting for emergencies and short stays for less than 24 hours, assisted housing at different levels of supervision based on an informal agreements among (ex) users, the team, and caregivers, two day-care centres and social enterprises.

Emphasising a sense of responsibility towards the community, the approach ensures care through 'active negotiations or dialogues', 'supporting individual strengths' while combatting 'social conformation to the vestiges of institutional behaviours'.⁹⁵ Separating the Trieste model from traditional de-institutionalisation practices, Mezzina points that the paradigm is 'geared to the complexity of daily living in the community'.⁹⁶



Disseminating a whole-systems and recovery approach, the model is pivotal in synthesising cross-cultural principles such as ‘citizenship, distance, power, and language’ – rationalising the need for rehabilitation, recovery, and social inclusion services that are seamlessly built into service provision.⁹⁷

Shifting the focus from individual aspects of illness or infrastructure, the model operationalises social contexts to develop a narrative that focuses on the personhood of the users in communities of care. The approach’s ethos and value orientation emphasise enhancing the user’s capacities for self-help, enlisting the solidarity of like-minded organisations and non-professionals, educating the general public and complementing the families with local care resources.⁹⁸

A working paper by Dell et al. (2001) suggests that while reform through replication is welcome, there is a need to ensure that the intervention does not multiply into ‘mini asylums’.⁹⁹ Basaliga similarly observes that alternative pathways similar to that of Trieste aiming at community participation must move away from descriptions of ‘efficiency’ or ‘deviances’ central to illness and focus on ‘preserving the idea of the person (user) as whole’, to prevent a lapse into ‘new forms of reductive institutionalisation’.¹⁰⁰

Although the model began with the aim of reducing admissions to a psychiatric hospital, the effort has gradually moved towards efforts in rehabilitation and social integration, with the community mental health centres ‘epitomising the philosophy of the Basaglian de-institutionalisation through their design, locations, and services’.¹⁰¹



INSTITUTE OF HUMAN BEHAVIOUR AND ALLIED SCIENCES (IHBAS)

Following the National Human Rights Commission's push for reforms, across the three vertical pillars of 'facilitating discharge and placing patients back into the family', 'introducing teaching and research in mental hospitals' and a general 'accountability to civil rights', the Institute of Human Behaviour and Allied Sciences (IHBAS) placed priority on reforms that have changed the landscape of care provided at the hospital.

Collaborating with the Aashray Adhikar Abhiyan (AAA) and Delhi Legal Services Authority (DLSA), IHBAS put into effect a multidisciplinary intervention model through the Health Intervention for the Homeless (HIGH) project, aiming to provide social support and legal aid apart from medical care to people caught at the intersection of homelessness and mental health.

The model was initially piloted through a network of community volunteers in parts of Delhi (such as Nizamuddin, Connaught Place and Old Delhi Railway Station) that were known to have large populations of the homeless people with mental illness. A report that evaluates the pilot phase of the project details seven sequential steps to care that formed part of protocol – which started with identifying potential users through street engagement, before invoking treatment and other local care needed based on the willingness to participate.¹⁰² A 'Mobile Court' was also initiated for legal outreach, to ensure that care was offered in a manner that was both ethically sound and legally appropriate.

Qualitative vignettes detail practical barriers routinely faced by the team, especially at the beginning. MB's story – who was referred to clinic by a local 'paan walla' – a salesman of paan (we will call him R), is typical.

Suspicious of the intentions of the project at the outset, R had contemplated whether to refer a wary MB for care. The team's actions, however, gained their combined confidence over a period of time, owing to attention to detail, such as responding to his request of a woman volunteer for follow-up. A treatment care plan was drawn up collaboratively, with R agreeing to administer medicines to MB – who became better, pursued a vocation of her choice, independently sought outpatient care and moved towards personal recovery. Care across the continuum was encouraged but inpatient admission was not seen as a response unless needed and consented to.

Of 49 users with serious mental illness who were enrolled as part of the project in year 1, rehabilitation efforts were fully and partially achieved for 23% and 18% of the population respectively.¹⁰³ This service perspective has gone along with the hospital's internal decision to systematically reduce the term of stay across its inpatient users.

The average length of hospital stay is maintained at a maximum of three or four weeks for new admissions. Prospects for reintegration and community re-entry are identified and implemented along with local care resources such as proximal care settings.

In addition to family placements, people are offered the choice of shelter at the half-way home (called 'Saksham'), which functions in the hospital campus in a non-custodial setting, or are equipped with skills that make it possible for them to pursue optimal work options that ensure long-term sustenance. Future efforts will be made to replicate model to other districts of Delhi and significantly develop interlinkages, expand the community mental health programmes and maintain intersectoral collaborations.

GOVERNMENT OF KERALA– THE HANS FOUNDATION– THE BANYAN PARTNERSHIP

Encouraged by The Banyan's positive experience of reintegrating 76% of homeless people with mental illness with their families and positive results from Home Again, a partnership was forged in early 2018 between The Hans Foundation, the Government of Kerala and The Banyan to collaborate across the three state mental hospitals in Kerala and work on enabling exit pathways for the long-stay cohort.

The Hans Foundation is the primary investing partner with the Government of Kerala, progressively taking on necessary financing of the programme over three years. The Banyan, a CSO, shares human resources to work alongside the hospital teams for facilitating re-integration and implements the Home Again intervention.

Following the initial screening of 221 service users in the three government mental hospitals in Kerala (Kozhikode, Thrissur and Trivandrum), a reintegration and aftercare team from The Banyan was placed at each of the hospitals to collaborate with the hospital staff and effect a robust system of discharges to various exit pathways. An action intervention has been adopted by the Government of Kerala which seeks to re-conceptualise living arrangements – family placements for those for whom it is possible and long-term options like Home Again for the others, named 'Snehakoodu' – for the long-term care users mentioned above, keeping in mind choice and feasibility.

One hundred people have been discharged through this collaboration, 64 have returned their families, 16 have moved into homes served by Home Again, while the remaining have either returned to the hospital or been placed in other institutional settings. Priority populations have been defined and redefined allowing for less system stagnation and efficient, personalised rehabilitation plans. Pre-discharge preparatory sessions with a focus on assisting users to gain independence across domains of daily living, reconnecting with roles they once performed, manage their health needs and preferences including medication, and develop strategies to negotiate family and community dynamics.





Families are also engaged pre-discharge to help them identify with the support necessary to sustain recovery. Each discharge is accompanied by a care package that is based on a graded system of aftercare across five levels entailing home visits, phone-based follow-up, social care across housing/ education/work/safety and cash transfers. The pre- and post-discharge care forms an essential part of this partnership as complexities, histories, multidimensional household poverty and different expectations on the part of users and carers often interfere with recovery. For instance, unresolved trauma perpetuates the illness, causes recurrent homelessness and reduces recovery. Strategies such as assistance in the form of gender-based counselling for a service user in an emotionally exhaustive relationship have helped.

The partnership has also worked on exploring atypical living arrangements and eliciting participation of the larger communities while implementing the Home Again model – this has been relatively successful and helped the team to move forward in therapeutic relationships with former service users whose circumstances are fraught with multifactorial challenges. Shibu's transition back to his home with support from the hospital, The Banyan and members of the community exemplifies such individualised community placements.

SHIBU

Shibu's father died suddenly. Not having been prepared for his death or the travails that would follow them indiscriminately, Shibu and his mother (Anita) found themselves at the behest of relatives for their survival. This culminated in them being directed by the extended family to move to a different house, a smaller and cheaper one. The newness of the place stood out and reeked for Anita – who did not like the succession of changes that were being foisted upon her one bit.

A service user, her illness took a significant turn for the worse. Her anxieties and insecurities weighing heavily on her, and the exasperation of a life that was gloomy, mundane and without much purpose, she took to rejecting medication for she did not feel ill and despised being forced to ingest anything that did not make sense to her. Shibu, meanwhile, reveals that although he took steps to return to normality, enrol for college, attend classes, even take up a new job, these arrangements did not last long as his mother took to trailing him wherever he went, probably due to the extreme social distress and overriding health complications that had developed in the interim.

Shibu retreated and started spending more time with his mother, forcing himself into what had lapsed by then into a possibly toxic relationship. Moreover, they were met with repugnant hostility – relatives who cared earlier avoided them, lest the responsibility of having to provide care was imposed upon them by default. Compounded by the serious inadequacy of resources, Shibu also developed mental health issues with time. In a possibly unfair assessment of their ability to co-exist and access mutual care from the larger community, a few relatives colluded in having them admitted to the mental hospital in 2004.

Shibu was 20 years old then. The subsequent 15 years of Shibu's life flashed by within the institution – 'Family members were okay to visit us occasionally, but always refused to take us back home, we were always a burden. They did not even change their answer when my mother fell desperately ill due to certain difficulties and the terrible living conditions inside – she died here, within these walls, festered with indignity and never seeing the outside world.'

Realising that efforts to discharge and reunite Shibu with his family predicted failure given the pattern, the hospital social worker recommended Shibu to The Banyan's reintegration and aftercare team to collaboratively design an alternative exit pathway. Shibu eagerly participated in pre-discharge sessions that saw him express a defined want to return to his old house, where he had known life intimately. This wish was validated by reviewing other goals and expectations across several interacting domains within the broader mental health framework that would allow sustained recovery intertwined with autonomy and wellbeing. Shibu also consented to share the living space with another user – Narayan, a friend who was experiencing similar long-term needs.

A home visit was planned to familiarise the user and team as to what they might expect – a health worker who was personally inclined to help conducted it, given that Shibu had formed a bond with her over the years. The house was as expected derelict and required repairs – new pipelines, furnishings and a fresh coat of paint to name a few.

Significantly, here is where the community stepped in, challenged the norm and rallied around to contribute a compelling change in the narrative – while a neighbour offered drinking water from his well, the hospital offered to sponsor a water tank and pipelines. The local village panchayat went ahead and granted money for the purchase of required furnishings, the villagers pooled their money and time to help with the plumbing and paint work. After a brief period of stay in another shared home, to get a feel of the life set out for them, Shibu and Narayan moved into their home. The health worker accepted an offer to join as a personal assistant who would provide support as required.

Their arrival marked an occasion for the villagers – who arranged for a feast and celebrated the return with genuine happiness. With time, they were included as part of the community's larger familial structure, included in social gatherings, co-sharing resources and opportunities for work. Shibu and Narayan are presently engaged in self-directed pursuits, training hard in junior office roles, establishing their independent narrative, one step at a time.

Stakeholder Perceptions on Schemes to Support Community Placements of Long-stay

Focus group discussions and interviews with key stakeholders across state mental hospitals – staff across cadres, users, carers and bureaucrats – highlight four public schemes that may be leveraged to support community placements if barriers and challenges in accessing entitlements are circumvented.

Disability Allowance

A monthly disability allowance was perceived by stakeholders to assist with mitigating family poverty and as a potential source of financing for people living independently or in shared accommodation.

The Indira Gandhi National Disability Pension Scheme and State-level Disability Pension Schemes for people with mental illness were reported to be available in 14 states – Telangana, Bihar, Goa, Gujarat, Maharashtra, Madhya Pradesh, Kerala, Tripura, Assam, Rajasthan, Nagaland, Jharkhand, Odisha and Karnataka. Among these states that have monthly allowances ranging from INR 400–INR 3500 per month based on disability levels evaluated by IDEAS, stakeholders in Maharashtra, Goa and Karnataka report accessibility issues that are similar to states where disability pensions are not disbursed to those with psychosocial disabilities. Challenges expressed by stakeholders include:

- Disability certification for mental illness remains a challenge due to lack of awareness of its applicability to mental illness and associated processes at the grassroots operations level. Much confusion persists on mental illness being covered under these schemes.

- Misinterpretations regarding the nature of the disease such as mental illnesses are only episodic and completely ‘curable’ are often cited as reasons to turn away applicants.
- Notions of visible (physical) disability being more verifiable compare to invisible (mental) disability have meant that the people with mental illness are excluded and do not access these benefits.
- People with psychosocial disabilities from low-income households live in insurmountable distress and do not have the resources to engage in administrative follow-up.
- Exclusion of homeless people with mental illness on basis of the lack of proof of address.
- Lack of interface between the Health and Social Welfare Departments leading to poor translation of disability benefits for people with mental illness.



District Mental Health Programme (DMHP)

Linkages to the DMHP for continued care post-discharge as well as strengthening of community mental health to curb pathways into tertiary-level institutionalisation were articulated as important priorities by stakeholders across states. Stakeholders in Uttar Pradesh (where the DMHP teams reportedly visit Primary Health Centres (PHCs) three times a week) and Gujarat perceived the DMHP's functioning as effective, with the latter reporting better implementation in urban areas than in rural areas.

Main barriers reported by stakeholders to DMHP's functioning include:

- Low uptake of open positions, low availability and high staff turnover. Basic extension to cover all districts faces problems due to non-availability of workforce

- Poor to mediocre availability of essential services leading to poor visibility of community mental health services, reinforcing tertiary care dependence with outpatient services run by state mental hospitals continuing to be main access points for users-carers
- Lack of mental health support at the PHC level – Doctors, Asha workers and Anganwadi workers are sensitised through the DMHP, but training is perceived as insufficient
- Lack of linkages between DMHP teams and tertiary care to facilitate post-discharge services
- Bureaucratic hurdles with delayed release of funds for DMHPs
- Lack of availability of medication at PHCs
- Lack of availability of social care support
- Barriers to early identification of mental health issues and care





Public Distribution Scheme (PDS)

Only in a small number of states stakeholders discussed prospects of linking households in supported living to PDS. In the state of Rajasthan, reportedly households with at least two disabled members are subsumed under the below-poverty-line category and can obtain ration cards.

However, histories of homelessness, lack of sustained tenancy and exclusion of atypical household arrangements from scheme norms (such as a group of unrelated service users living together) are barriers to accessing benefits under the PDS.





Schemes for Housing and Rehabilitation/Half-way homes

Stakeholders in a small number of states discussed the potential for existing housing schemes to finance accommodations in the community for transitioning long-stay population from the state mental hospitals.

National and State-level housing schemes for those living in poverty are available across several states (including a scheme that grants land ownership for people from marginalised backgrounds in Karnataka). However, accessibility was reported as a significant challenge across states, as histories of homelessness among a substantial proportion of the long-stay cohort and the lack of documents to prove eligibility leads to exclusions, forcing trans-institutionalisation in existing government or civil society institutions.

Two state governments have reportedly earmarked funds, following the Supreme Court directive to take action on continued confinement, for long-stay/half-way homes.

These include the Rajasthan (INR 7 crores) and Jammu and Kashmir. In the absence of policy supports for supported housing options, trans-institutionalisation is perceived by stakeholders as the most pragmatic choice on hand, though they recognise the limits and value-dependencies of such placements in promoting social inclusion.

“

The Government will be building rehabilitation centres, and the chances are high that it will also be another form of the mental health institution. Even in the ‘halfway’, which is an alternative has a client-patron relationship.

If the residents cannot think of it as their home, then it is pointless. They would always think that their families have rejected them. At the same time, the community will call it an ‘asylum’ or some other name which bears the same stigma as the mental hospital. Social integration can happen only if the gap between the community and residents is mitigated, which is unlikely.

- Senior Health Official in one of the States

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“

We have been shifting users who are old and need long-term stay options to (name), it is a typical old age home, which houses older adults from the locality who need living space, care and support. They have all of these here and live in a mixed setup – i.e. alongside other residents who don’t have mental illness necessarily.

Maybe it is not home, but it is a community all the same and affords a life which is much better than living here (in the hospital).

- FGD Participant in one of the States

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Strategic Directions to Address the Long-stay Population in State Mental Hospitals in India

Frame values – non-negotiable drivers that will define the structures and processes of community re-entry for long-stay cohort. Enabling inclusive living options to redress long-term incarceration in psychiatric facilities entails adherence to values that are uncompromising in the pursuit of the right of people with mental health issues to live in the community. In the absence of value drivers that emphasise social inclusion, structures and processes of community placements may lapse into short-term measures that focus on removal from psychiatric facilities into other similarly oriented institutional settings without any tangible benefits to promoting participation in the community.

Social inclusion often used interchangeably with participation and integration in an ecological conceptualisation spanning the individual, interpersonal and community includes ‘being accepted as an individual beyond disability, significant and reciprocal relationships, appropriate living accommodations, employment, informal and formal supports, and community involvement’.¹⁰⁴

Community living involves adequate, accessible and appropriate accommodation options that are open and located alongside the homes of the general population, flexible choices for people, to the greatest extent possible, on where, with whom and how they live and personal supports that enable people to participate in the community.

The Rights of Persons with Disabilities of Act (RPWD) of 2016 in Chapter 2, article 5 mandates the following entitlements for community life of disabled people, including those living with psychosocial disability:

- (1) The persons with disabilities shall have the right to live in the community.*
- (2) The appropriate Government shall endeavour that the persons with disabilities are,—*
 - (a) not obliged to live in any particular living arrangement; and*
 - (b) given access to a range of in-house, residential and other community support services, including personal assistance necessary to support living with due regard to age and gender.*

The Act offers non-negotiables to drive the process of transition from institutional care to community living for people with psychosocial disability, mainly, the obligation to provide environments and supports that are personalised and adapt to individual needs rather than coercing disabled people to

live in specially designed structures to which they have to adjust. The articulation in RPWD 2016 offers fundamental value drivers for the process of creating options for community living:

1. Person-centred plans, rather than facility-based plans, for community placements
2. Flexible range of supports and services
3. Choice of varied housing options
4. Personal assistance for a range of disability levels
5. Support for community participation

Living in the community for people with mental illness, therefore, means access to choices and resources as any other citizen, with necessary support to live wherever they wish. Mixed experiences of group homes and rehabilitation facilities to comprehensively address social exclusion has led to the consensus that the emphasis in community living must be on support for the person and that plans cannot be facility based.

Rather, community placement plans need to be individualised to offer flexible services that help people to exert control over their homes and daily routines, exercise choices over how and with whom they want to live and establish interpersonal connections in the community, across social, economic, cultural and political domains.

Designate Investments for Defined Pathways out of Institutional Care

Investments must follow service users discharged from hospitals for their living, support and continued care. The Deen Dayal Rehabilitation Scheme presently offers a grant for CSOs to set up half-way homes for those with psychosocial disability under the Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment.

However, in its orientation (remaining restricted to a reductive 'treated and controlled' category) and budgeting (with no provisions for different housing options, personal assistants and low client welfare expenses) it is discordant with RPWD 2016 and consequent markers of community living. A comprehensive overhaul of this scheme or a completely new scheme needs to be formulated to support community placements of long-stay cohort from state mental hospitals in India.

In this assessment of people living for a year or more across state mental hospitals in India, based on the estimated proportion of people for various recommended placements, three broad options for discharge and placement based on assessments of possible placements in the CPQ emerge: Housing with Supportive Services for those who may be placed in Independent Living, Supported Group Homes, Staffed Home (low to high staffing), Intentional Communities –

Congregate/Clustered Group Homes for those who need Very High Staffed Homes and Rehabilitation Homes, and Family placements for those rated to be placed 'With family/familiar person'.

1 2,189 people (45%) may be placed in scatter-site Housing with Supportive Services (such as Home Again, Swayamkrushi's Group Homes) – rented accommodations in ordinary urban or rural neighbourhoods, with personal assistants as necessary supervised by a care team. The Banyan's implementation of Home Again currently costs INR 8750 per person per month. However, these costs do not account for the initial need for more personal assistants, non-recurrent costs and those associated with capacity building. Assuming a cost of INR 14000 per person per month, an outlay of INR 37 Crores will be required annually for offering housing options with necessary support across daily living, health, work and recreational needs.

2 1,009 people (21%) who require transitional/rehabilitation environments or higher levels of support may be facilitated discharges through Intentional Communities – Congregate/Clustered Group Homes. An estimated INR 25 Crores will be required annually





to support such arrangements based on estimated costs of INR 20,000 per person per month.

3 1,206 people (25%) may be facilitated Family Placements, returning to their families with continued care support through the DMHP and Disability Allowance through the Pension Scheme for Disabled people available under the Social Justice and Empowerment Ministry and State Disability Welfare Departments.

A one-time investment of INR 60 lakhs to facilitate pre-reintegration sessions and trips back to the family (or travel for families to receive their kin) is estimated with annually an investment of INR 60 lakhs for continued care.

For both 1 and 2, a **National Scheme of Assistance for Personal Assistance and Housing Options** to promote inclusive living for people with long-term care needs is needed to support scatter-site or congregated housing services with bespoke support offered by user-carer collectives or civil society organisations licensed as providers by the Government.

The Central Mental Health Authority (CMHA) and the State Mental Health Authorities (SMHA), constituted under the MHCA 2017 may be engaged in issuing necessary guidelines to ensure quality and minimum service compliance for inclusive living in both scatter-site and congregated formats.

Funding from the scheme should not be restricted to typical agency-mediated and managed options with supportive services. Flexibility may be needed for personal assistant services to be accessible to disabled people to purchase support directly so that services are not tied to facility-based plans or structured programmes. Disabled adults with a range of support needs who may want to live in their own houses or choose a home by themselves may receive necessary financing under the scheme so that they are able to determine and buy the support they need. For instance, in the UK disabled adults can buy the support they want under the Community Care (Direct Payment) Act 1996.

Further, the scheme may need to recognise and support contemporary work participation initiatives that are not tied to traditional trade skilling but adopt person-centred, social co-operative approaches such as Anjali's facilitation of the user-led 'Dhobi Ghat – a laundry unit' as an enterprise in the Pavlov psychiatric facility in West Bengal.

For 3, Family Placements, psychiatric hospitals' budgets will require to be expanded to include reintegration expenses and employing more social workers to support ratios essential to continually work on reintegration and aftercare work with families, especially for the people with histories of homelessness. To transition people living for over one year or more with quickly pooled resources, partnerships with CSOs such as the Government of Kerala- The Hans Foundation-The Banyan or Government of West Bengal-Anjali or the earlier partnership between Government of Uttar Pradesh-ActionAid may be considered.

The Indira Gandhi National Disability Pension Scheme and state government schemes of pension may be suitably applied to support aftercare cash transfers to people discharged from psychiatric facilities. Linkages to the DMHP for continued care post-discharge need to be established to prevent re-hospitalisation.

About 9% of service users in the long-stay cohort were assessed to require very high support either in psychiatric nursing homes or hospitals. Reintegration approaches for this cohort need to be developed.

Additionally, integration with social entitlements and enrolment alongside discharge may need to be adopted. These include: Voter's ID, Bank account, Disability certificate, Disability pension and so on. Some hospitals have facilitated these social entitlements along with employment options (both within and outside premises). For instance, NIMHANS has facilitated bank accounts and voter's ID for most of their service users. Policy support needs to be extended to remove barriers to accessing these entitlements such as the conflation of unsound mind and mental illness to deny bank accounts.



Recognise and Legitimise Service-User Advocacy

Service-user advocates, individuals and groups across the country must form an integral part of processes of planning and implementing directions that involve the placement of long-stay cohorts in the community.

A cohort of service users across a spectrum of hospitals surveyed for this study, despite barriers and challenges imposed by the systemic deficiencies, had seized opportunities to define their roles in the hospitals – from offering support to peers to navigate the system to mediating relationships between staff and other clients. Their roles must be recognised and enabled to offer feedback on the mental health system.

Instituting a formal paid position of ‘peer advocate’ and ‘peer managers’ may lend their existing participation legitimacy. It may help create a sense of validation, ownership and purpose in life, and contribute to subjective notions of recovery.

The adoption of peer-support workers and advocates as mandatory in services – including as auditors and experts to evaluate quality – may be a necessary step for people with mental illness to lead changes needed in the mental health services.

Peer managers and advocates with lived experience of mental illness who have negotiated and established for themselves social capital and valued roles can offer insights that can initiate similar trajectories for others.

Beyond tokenistic participation, support for federating and access to the political language and resource base that can enable them to negotiate at the table currently occupied by traditionally defined ‘experts’, will be necessary to ensure meaningful translations of inputs.



Imagine and Implement an Expansive Community Care System that Allies with the Social Care Sector

Community Care Systems must not only be able to provide continued clinical care for discharged service users but also ensure that socio-economic issues that mediate and moderate sustained recovery are adequately addressed; and that services drive outcomes with meaning such as return to work, participating in the household and belonging to a community.

Across models that support community living the essential nature of work-mediated income supports for a range of needs such that people value their life and reciprocal relationships emerge as essential facets of successful community placements. Therefore, the imperative of placing people with long-term care needs in the community also involves reimagining the DMHP, identifying and fixing gaps in existing community mental health services, through a plan that accounts for a pace that is commensurate with the rate at which people move out of hospitals.

Besides ensuring the availability of clinical care through the DMHP, the health system will need to ally with social welfare systems to enable the provision of affirmative disability support, housing, employment and other social care interventions including intensive support necessary for complex needs arising from age and clinical prognosis. Both integrated teams and inter-agency collaborations are effective ways to promote convergence between health and social welfare.

Identify and Tackle Pathways into Institutional Care Use

States and stakeholders in the mental health sector need to investigate factors engaged in the use of institutional services by people with mental illness and within this, predictors associated with pathways into long-term residence, including homelessness. Tackling progressions into a chronic course of mental health issues and long-term occupancy need to be addressed as experiences across countries demonstrate that new long-stay populations are left to the streets or end up in prison when community-based services are inadequate and psychiatric facilities close their doors on new admissions after de-institutionalisation.

Systematic socio-economic data of service users such as caste, household income and composition and so on were not captured as part of this study. Further, data were gathered only from those who progressed to long-term institutionalisation.



Therefore, predictors of long-stay may not be inferred from the available quantitative data of this study. However, the larger representation of those with possible history of homelessness and women in the cohort, and a near quarter proportion of people experiencing intellectual disability, offer directions that may be pursued to understand trajectories into long-term use of institutional facilities.

Qualitative vignettes gathered during the course of the study and stakeholder perceptions indicate the role of social disadvantage in long-term institutionalisation of people with mental illness. Caste, gender and the intersections within, define social disadvantage in the Indian context.

A case-control study conducted in the National Capital Region found a significant interaction effect of caste, gender, mental illness and stigma, with women from disadvantaged castes with a mental illness more likely to experience poverty as a consequence of stigma than male controls.¹⁰⁵

Similarly, a cross-sectional study of women with mental illness accessing outpatient services in Tamil Nadu found significant differences in caste among those who experienced homelessness and those who did not. Disproportionate number of women with mental illness who had a history of homelessness were from disadvantaged castes, and homelessness was predicted by relational

disruptions (largely those associated with gender-based violence) and low educational attainment.¹⁰⁶

From a community care perspective, investigating preventive strategies such as integrated service supports combining social and clinical care, that validate and engage in personalised biopsychosocial formulations of presenting distress, may be necessary.





Overhaul the Institutional Care System

Socio-economic and cultural factors interplay with the institutional mechanism of provision to produce the reality of long-stay and compromised recovery options and rights. Various care paradigms were observed across state mental hospitals – however, in particularly large institutions with a sizeable number of long-stay service users, an overhaul of the system becomes an important accompaniment to the process of community placements.

Radical restructuring of the Institutional Care System, instead of tokenistic methods of renaming or raising new buildings, to adopt a contemporary mode of care centred around service users' needs and preferences for recovery, will have far-ranging consequences for human resources and leadership quality in the mental health sector. Institutional rejection of the colonial vestiges of care and illness calls for a fundamental overhaul of the system.

Processes and practices from State mental hospitals identified by the National Human Rights Commission, in order to transcend issues associated with custodial care and quality, need to be diffused to facilities that continue to struggle with serious human rights violations. The Hospital for Mental Health, Ahmedabad and Centre for Mental Health Law and Policy, Indian Law Society, Pune are engaged in a Quality Rights Project that aims to improve quality of care in mental health facilities in Gujarat. Similar initiatives across States will be essential to complement the process of placing people back into the community.

- **Quality of Care:** To re-imagine care perspectives, there is a significant need for investment in the quality of care that users receive, beyond investments in buildings to house new courses for advanced training in Psychiatry and related disciplines. Options for personal grooming, dignified menstrual hygiene choices, access to adequate toilets – such needs go beyond simplistic notions of hygiene, sanitation and possible health implications, and intersect with users' privacy and dignity.
- **Discharge Planning and Continued Care:** A culture of ad-hoc discharge and confinement exists within the facilities – this has been a recurring theme in field observations and FGDs. A participant in one of the FGDs speaks of the problem of long-stay exemplified by the lack of reintegration/ aftercare policies and budgets:

There is no written policy for reintegration, but we follow some strategies that include coordinating with local police/law enforcement, collaborating with Metropolitan Magistrate, contacting local NGOs, panchayat bodies, establishing collaborations with the resident commissioner and utilising personal contacts. As we do not have funds for reintegration, voluntary donations from staff are used to meet expenses in reintegration.

Volitional withdrawal or exit from a home (connected responsibilities, roles) – has automatically been seen as divergent behaviour because of socio-cultural mores and hence they are incarcerated. For instance, in one hospital, user Madhu's discharge was facilitated with an unwilling family without complementary local care resources – resulting in three consequent readmissions, continual homelessness, a nomadic existence and distress. Not just Madhu, but other users live outside the hospital gates, eking a living by begging, without access to services, despite literally being on hospital premises.

- **Policy for Atypical, Non-Family-based discharges:** Recognising and encouraging non-normative discharges such as self-discharge to independent living as a single employed person or communal living with people unrelated by blood – should be another priority, irrespective of the person's gender. In one of the hospitals, an FGD participant says:

Qualitative notes show the existence of users in residence for more than 50 years. Some are treatment resistant; others have attained recovery. Used to ways of being within the hospital, many claim they will not be able to adapt to life outside easily. So, we have had to develop local solutions to the crowding we face – for instance, here we practise what is known as Lone Discharge – where users are allowed to travel back home on their own, once the treatment team is convinced of their ability to do so. Users are given medicines and money at the time of discharge.



- **Policy support to facilitate inter-country discharges (Bangladesh/Nepal):** Hospitals in Bihar, West Bengal and North-East face bureaucratic hurdles in reintegrating service users from neighbouring countries, particularly Bangladesh and Nepal. Policy support is necessary to address barriers and create a process that easily accessible and friendly for service users and hospital staff.
- **Work Participation initiatives beyond trade-based, traditional skills:** Investing in choice-based work pursuits may act as an active buffer that can ideally percolate down allowing for personal resource generation, independence and generally higher quality of life.
- **Family Wards:** The introduction of family wards or transitional wards – where users stay for a short period and access services in a supported environment of care, in the mandatory presence of a carer – may help reduce incidences of abandonment due to carer being unable to cope with misunderstood needs, foster recovery and increase rates of successful reintegration. This may address the perception in some hospitals' FGDs that gaining admission through a court order was relatively easy and that this contributed to the wilful abandonment of users.

- **Decentralising bed capacities:** States with large institutional capacities need to consider the question of bed capacities and whether there is person-centred legitimate need for these to be concentrated in hyper-segregated, large residential care options – rather than the creation of alternative pathways with access to local services.

Interlinking care to allow for effective use of DMHPs and setting up of non-segregated, integrated inpatient care in public health facilities are ideas that need implementing. The National Health Mission of Tamil Nadu, for instance, has introduced Emergency Care and Recovery Centres within District Hospitals that cater to the needs of homeless people with mental illness as well as supporting inpatient services for upstream referrals from the DMHP outpatient services.

- **Family Assistance Scheme or Cash Transfers to Support Family Placements when Households face socio-economic distress:** A scheme of family assistance, cash transfers to users and carers may mitigate long-stay owing to household social vulnerabilities that act as barriers to successful discharge. Active involvement in designing measures to decrease carer burnout as part of the DMHP should also be actioned.



- **Reintegration and Aftercare Networks:** Creation of local resource arms (civil society and other experts) across states will help in furthering the reintegration efforts of users who speak non-native languages. There have been accounts of users languishing for years within the institutions despite reintegration prospects because of language and geographies that staff are unfamiliar with (such as Adivasi dialects) are barriers to communication.

- **Shift in Language in Institutional Cultures:** Language-festering stigma such as the use of 'Unknown' for those with histories of homelessness need to change so that tacit forms of discrimination do not prevail. To illustrate further, one of the hospitals is located on the 'pagalkhana' road, which loosely translated means 'madhouse' road. This does not bode well – not for users who live in the institution, staff who work there or the larger community, for the pejorative term perpetuates antiquated notions of mental illness and does not represent the changes that have happened in the mental health sector over the years.

In the words of a participant in an FGD in one of the states:

Nobody knows that the word 'pagal' is pejorative, it is in practice because people do not know it is wrong and offensive to use the word. This must change, if we need reform, we must start at the basics.

- **Staff Capacity Building to embrace contemporary approaches to mental health and human rights:** Staff, especially the ancillary staff (ward attendants) who have remained in the hospital for decades, need to be supported and supervised by a team with contemporary perspectives on care. Removing the vestiges of outdated care methods will be a challenge. Newly appointed staff learn from what they see, hear and exists, which implies the need for systemic changes. Rotating personnel across sites and departments will significantly reduce the authority that comes with familiarity.

Quality Assurance in Inclusive Living Options – Legislative and Policy Support

Legislative and policy support accompanies the most successful de-institutionalisation efforts. There are risks of intended community living or inclusive living options descending into microcosms of facilities with poor quality of care and human rights violations in the absence of measures to assure compliance with minimum standards.

To successfully implement inclusive living options in various locations on a nationwide scale, policy recognition of such an approach may offer a standardised oversight system that ensures compliance with non-negotiables while allowing service providers the freedom to innovate in their contexts.

While the Mental Health Policy 2014, RPWD 2016 and MHCA 2017 offer a base, it is vital to articulate quality assurance guidelines for community living at a national and state level and to institute mechanisms to ensure that the standards will be monitored and rectified when not met.





Leadership and Stakeholder Collective to Move towards Shared Visions

The complexity of the de-institutionalisation process requires a leadership body that can operationalise the transformative imperatives of creating inclusive living options in parallel to reform of psychiatric hospitals and strengthening the care paradigm of DMHPs.

This leadership body will need to engage with a variety of stakeholders and enable vertical and horizontal coordination between the Health and Social Welfare ministries/departments at the national, state and district levels. The multiplicity of stakeholders with divergent perspectives and interests – psychiatric hospitals, government administrative units, carer groups, service users, professional groups such as those of psychiatrists – will need to be engaged in the process of shifting the care of people with long-term care needs to the community.

In this context, the leadership body may need to deal with a collective of various stakeholders and develop shared visions to take forward the necessary changes in the mental health system. It may be particularly relevant to understand the motivations of groups that are opposed to the idea of community living for people with mental illness across disability levels and engage with them to reformulate or deflect their influences.

ACTION PLAN

Information has been collected on long-term service users (those who have stayed for at least one year, often more) in 43 mental hospitals across 24 states over a period of seven months (August 2018 to February 2019). The assessment is to enable the process of developing alternatives that can replace present ways of living long-term in an institution. This plan has been conceived on the basis of quantitative and qualitative datasets. Since the information has been captured over a period of time, changes – if any – before implementation are likely to be incorporated subsequently. Given the broad scope, it is envisaged that revisions that occur during time of re-entry into the community will be documented remotely in real time using cloud-based technology.

At the time of compiling this report, there were approximately 13,124 service users living in the 43 state mental hospitals, of whom 4935 have long-term needs. Since 44 people did not consent to participate in this process for various reasons, the Task Force recorded and collated details of only 4891 individuals.

A recent directive of the Supreme Court and Guidelines issued via the Ministry of Health and Family Welfare make it mandatory that the period of stay in these institutions should not exceed six months. A substantive increase in the number of long-stay service users is foreseen if this is taken into consideration.





1. Findings

The findings of the Task Force on the preferences of long-stay service users, captured during the course of their interactions, are summarised below:

Community Placement Options	Preference of service users (n=4838, data missing for remaining)		Possible community placements (n=4871, data missing for remaining)	
	Number	Percentage	Number	Percentage
Prefer to return to family	2027	41.90%	1206	24.76%
Supported living	636	13.15%	2189	44.94%
Remain at Hospital	699	14.45%	467	9.59%
Did not express a clear preference	1476	30.51%		
Rehabilitation Homes or Very Highly Staffed Homes (may be offered in Congregate/Clustered Group Homes)			1009	20.71%
Total	4838	100%	4871	100%

Note: Preferences of service users were rated by the participants themselves. Based on disability, clinical status, family availability/acceptance and their preferences, the team assessed and rated possible community placements

2. National Steering Committee

A National Steering Committee needs to be set up under the aegis of the Ministry of Health – it is hoped that this will act as an apex body, enable effective coordination and be responsible for implementation.

The contemplated composition of the Committee is as follows:

Proposed Chairperson

- Secretary, Ministry of Health and Family Welfare

Proposed Members

- Joint Secretary, Ministry of Social Justice and Empowerment
- Joint Secretary, National Trust, Ministry of Social Justice and Empowerment
- The Attorney General or Retired High Court Judge as Legal Representative
- The Hans Foundation as National Coordinator
- A minimum of two users and carers with lived experiences of mental illnesses and preferably institutionalisation
- Two to three state or non-state organisations with track record of implementing community living and de-institutionalisation (Advisers and Technical Partner)
- International experts on community living and de-institutionalisation

Associate Members

- Principal Secretaries, Department of Social Welfare of all states
- Principal Secretaries, Department of Health of all states





3. Roles and Responsibilities of National Steering Committee for Inclusive Living

A. POLICY FORMULATION

- Develop a comprehensive policy for reintegration with families or other preferred carers and anchor inclusive living options for long-stay individuals in the community – this might be in formats such as Supported Living, Independent Living, among others.
- Emphasise the roles and responsibilities of all stakeholders, including the National Coordinator, Advisers, Technical Partner, Associate Members etc.
- Disseminate policy to stakeholders across states such as Ministry of Social Justice and Empowerment, Ministry of Women and Child Development, State Mental Hospitals and Implementation Agencies.

B. CONVERGENCE WITH GOVERNMENT SCHEMES

- Map the various existing Central Schemes which can be dovetailed into the inclusive living programme.
- Legislate uniform application of these Schemes across the country as far as possible.
- Review and recommend modifications in these Schemes, to enable state governments eventually to take over the programme.

C. PROGRAMME DOCUMENT

- Design a Programme Document with the help of the Technical Partner and Member Advisers.
- Develop a short-term (three years) and long-term (five to ten years) plan with budget components and cost overlays.
- Define the composition and role of State-Level Committees.

D. MONITORING AND EVALUATION

- Develop a detailed Monitoring and Evaluation (M&E) Framework.
- Hold quarterly or six-monthly meetings to assess the progress and obtain feedback from the states.

E. RESOURCE MOBILISATION

- Demonstrate a fundraising strategy to build up financial resources.
- Advise the government to allocate funds for the Community Placement Programme.
- Identify and invite Corporate Social Responsibility (CSR) partners to participate in the programme in the form of a Public–Private Partnership (PPP).

F. RESEARCH AND DATA MANAGEMENT

- Develop a comprehensive data-management system (National De-Institutionalisation Management Network) for tracking, live reporting, monitoring and generating reports and returns.

4. State Steering Committee

Each state should set up a State Steering Committee, which will be mainly responsible for planning, staffing, directing, coordinating and ensuring all actions for implementation of the community placement programmes. The proposed composition of the Committee is as follows:

Chairperson

- Chief Secretary

Members

- Principal Secretary, Social Welfare Department
- Principal Secretary, Health Department
- Principal Secretary, Women and Child Department
- Principal Secretary, Finance Department
- State Coordinators, Civil Society Members
- Implementation partners
- Superintendents of Mental Health Institutions
- Representatives of Service users–Carers

Legal Member

- To be nominated by each state

Every state has at least one or a maximum of four mental hospitals in major cities. The Home Again approach will entail setting up homes in these cities. At present, the estimated number for Home Again is approximately 2200 individuals with varying degrees of disability (plus an additional 1000 with more complex needs).

Placing four or five women or men per home implies setting up 400 to 600 community homes in the country in addition to another 200–250 homes for those needing greater care and support. The need for support will vary on the degree and type of disability. There are some models available in the country and, as mentioned in the report, these may serve as a guide to assess the overall requirement.

There is also a need to designate NGOs to coordinate at the National or State level – those with previous experience of working with the government may be given preference. These NGOs could be nominated or selected through a Request for Proposal (RFP) process. Similarly, there would be a need to select implementation partners for community living and reunification programmes.

5. Roles and Responsibilities of State Steering Committee

- a. Implement National Policy in coordination with state hospitals and other stakeholders.
- b. Select the NGOs, implementation partners and technical partners through the RFP process.
- c. Specify the roles and responsibilities of different government departments, including State Coordinator NGO, Implementation and Technical Partner NGOs and Hospital Superintendents.
- d. Ensure adequate training and coordination between various partners and stakeholders.
- e. Formulate short-term and long-term plans with budget allocations.
- f. Review the protocol for discharge of service users for community-based inclusive living.
- g. Develop a legal framework for discharge of service users
- h. Issue Guidelines and ensure dovetailing of State Schemes and allowances in the overall budget planning.
- i. Review and suggest modifications to existing schemes as programme needs arise.
- j. Task the Coordinator across States to develop programme documents for each hospital in consultation with Implementation Partners.
- k. Formulate Statement of Purposes (SOPs) for different processes.
- l. Develop Statement of Purposes (SOPs) for data entry, discharge etc. and enable coordination with other parties.
- m. Mobilise funds through the PPP route or through partnerships with funding agencies in the social sector.
- n. Set up a robust system of monitoring, reporting and local community-based aftercare.





6. National De-Institutionalisation Management Network

A. OBJECTIVE

To create a cloud-based platform to connect the 43 mental health hospitals, establish State and National nodes down to the District or PHC level with connectivity extended to service users and carers enabling monitoring and capturing of real-time information related to the individuals placed in community living.

B. OVERVIEW

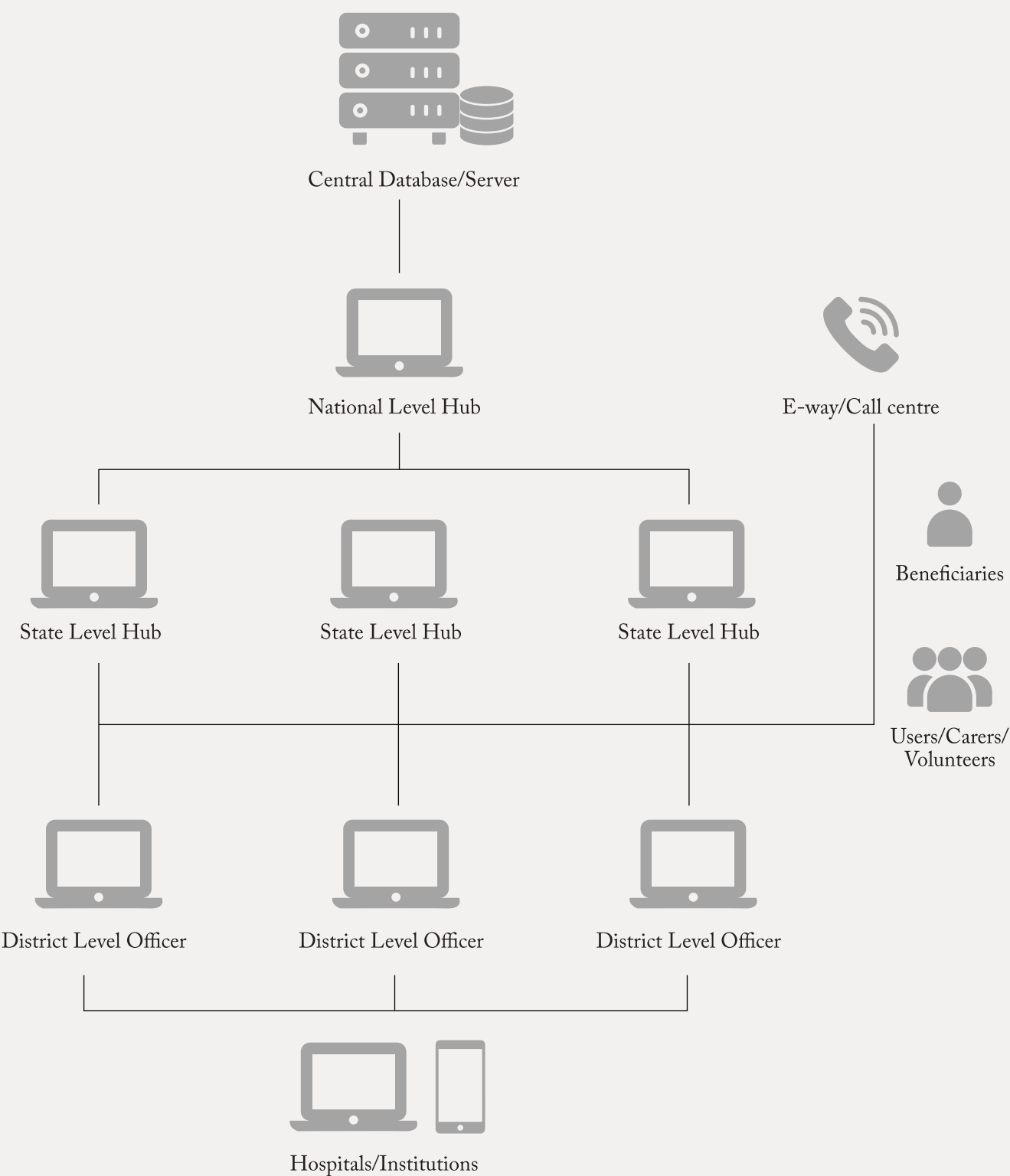
There is a need to record information on long-stay service users from all the 43 institutes on a centrally connected technology platform that will enable delivery of co-ordinated follow up services. Each time a long-stay service user is discharged to be reunited with their family or placed in a community set-up, the relevant information will be captured by the system and automatically stored on the central database. The system will be designed to ensure that these 43 institutes are able to share information and are able to monitor the progress of service users discharged to live in a community.

Biometric integration will help any of the institutes to identify and view information regarding these individuals. The network will have a National Node, States Nodes and an E-way. The proposed system will also be used to help understand the progress of such individuals and will also be designed to facilitate the sharing of information and knowledge. Access to the database will be on a need to know basis, with confidentiality built into it.

C. PROPOSED FEATURES

- Centralised Database for information pertaining to all long-stay service users registered at 43 mental health hospitals (existing and new service users)
- Cloud-based software with internet and mobile device versions for easy access
- Capture service users' history
- Capture of medication and follow-up plans
- Data collection for periodical feedback on individual progress
- Service users and Carers portal
- E-Way/Call Centre for beneficiaries/carers and volunteers to report or ask for information (initially to be a 12/7 and later a 24/7 facility)
- Auto Alerts to facilitate timely follow-up as per individualised care plans
- Security features and access mapping at National, State Hub and individual hospital levels
- Detailed reporting features for all teams
- Data analytics for all stakeholders and participating agencies
- Community broadcasts for knowledge sharing

D. PROPOSED BASIC ARCHITECTURE



7. Estimated Budget

The budget is an estimate for further planning by respective stakeholders. There are certain assumptions, based on the existing models in the country for inclusive community living and reintegration with families. The working budget is given below.

A. INCLUSIVE COMMUNITY LIVING (HOME AGAIN) ASSUMPTIONS

- Four or five individuals will live together in one home
The home will be rented in a residential neighbourhood, rural or urban
- Support staff will be allocated according to need, and may range from one to three members on a shift basis
- An individualised care plan will be developed for each resident, and opportunities for work, household and community participation will be facilitated based on interest

- Health-related support services, such as medication, psychosocial therapy, physiotherapy, and counselling will be made available
- Basic needs such as food, clothing, entertainment etc. will be offered, potentially supported by the states’ social welfare schemes
- In homes with low support needs, part of the expenditure may be contributed by residents through income earned from various occupations or livelihood options they may choose to pursue
- The house will be modified, renovated and equipped according to the needs and accommodations requested by residents

Based on existing models in different locations of the country, the monthly cost per resident, considering the above, works out between INR 12,000 to 14,000. For estimation purposes, a higher monthly average of INR 14,000/- per resident has been considered.

Cost Estimate for Inclusive Community Living Option	
Total residents estimated for inclusive community living	2189
Cost per resident per month @ INR 14,000 per person	INR 3.06 Cr
Annual expenditure for 2189 people	INR 36.77 Cr

i.e. approximately INR 37 Cr

Note: The annual cost will rise in accordance with inflation and the increasing number of individuals supported under the programme.



B. REINTEGRATION WITH FAMILIES
ASSUMPTIONS

- Dedicated staff will be appointed to verify the family details of persons willing to pursue reintegration
- Travel expenses for the person and the staff member is to be a one-time fixed cost
- Regular follow-up visits by the appointed caregiver or local NGO representative will need to be made
- Medical support will have to be offered
- Costs of repeated incidence of illness, exacerbation of stress, increase in disability levels and hospitalisations will have to be borne
- Considering all of above and based on existing efforts in the country, it is estimated that a one-time expenditure of INR 5000 per person is incurred on reintegration and INR 5000 for the recurrent costs
- In the case of families who live in extremely disadvantaged situations, unique social needs have to addressed with the means to enable access to disability allowance, PDS and livelihood support such as the Mahatma Gandhi National Rural Employment Guarantee Scheme (MNREGS) or other work placement. In the case of individuals with special needs, in extreme disadvantage due to poverty such as those who are homeless, or where various family members live with a disability, or a household headed solely by women or elderly people, or where the main caregiver is an adolescent or younger child, further support networks may have to be built as part of an aftercare or continued care framework – the lack of which is often responsible for recurrent descent into homelessness and hospitalisation.

Total residents estimated for reintegration with families	1206
One time cost of reunification for 1206 people @ INR 5,000 per person	INR 60,30,000
Recurrent continued care costs for 1206 people @ INR 5,000 per person per year	INR 60,30,000
Annual total INR 1,20,60,000	INR 1,20,60,000

i.e. approximately
INR 1.20 Cr

C. INTENTIONAL COMMUNITIES –
CONGREGATE/CLUSTERED
GROUP HOMES ASSUMPTIONS

- People who require greater degree of supports may be offered home- and community-like environments in housing units, congregated or clustered in a location.
- Rest of the assumptions for community living remain same.
- Based on existing models in the country, the monthly cost per person is INR 18,000 – 20,000. For the purpose of estimation, a monthly cost of INR 20000/- per person has been considered.

The proposed action plan is based on certain assumptions and will evolve further in consultation with the ministries and other stakeholders. The budget for the various models and services are tentative and may increase or decrease depending on government participation or contributions through various state schemes.

The organisation suggested will have its extension/expansion at the district or block levels. The National institutional network will cascade down to the block levels in phases starting with National and State Nodes and hospitals.

Total residents estimated for Congregate/Clustered Group Homes	1009
Cost per resident per month @ INR 20,000 per person	INR 2,01,80,000
Annual expenditure for 1009 people	INR 24,21,60,000

i.e. approximately
INR 25 Cr



8. Operationalising the Action Plan

Once the study is accepted and disseminated by the Ministry of Health, all efforts will be made to bring some of the major philanthropic/CSR organisations on board. Government of India, foundations and other interested organisations can join in creating platform to operationalise and fund the pilot projects with the participation of the respective state governments.

Technical and implementation partners such as The Banyan, BALM, Anjali, Ashadeep, Tarasha, TISS, NIMHANS, IHBAS and others that have been working in this field for decades and are nationally and internationally recognised for their outstanding efforts would join this platform. Some of these organisations have already started working on pilots in the states of Kerala, Maharashtra, Tamil Nadu, and Uttarakhand after signing a tripartite/ bipartite agreement with state governments and some of the funding agencies such as The Hans Foundation and Tata Trusts to name a few. The spirit of the Memorandum of Understanding (MOU) is guided by the fact that the state governments will gradually take over these programmes in three to four years, with technical expertise still being provided by the implementation partners.

Some governments will be signing the MOUs shortly to start de-institutionalisation work in their states, with a firm commitment to take over funding and running of these programmes in three to four years. These pilots can serve as examples for others to follow.

As such initiatives expand to other states it becomes imperative to create a robust monitoring and aftercare system. Technology can facilitate this. Therefore, a secure cloud-based National De-Institutionalisation Management Network may be needed, for which the The Hans Foundation has begun conceptual work.



CONCLUSIONS

Long-term hospitalisation or confinement of people with psychosocial disabilities represents a critical deficit in social justice – 36.25% of people living in state-run psychiatric facilities in India have been confined to them for over a year or more. The vast majority have no or mild to moderate disabilities requiring support that could feasibly be provided in community-based settings.

Complex, multi-factorial social disadvantage coupled with challenges in institutional care accompanies their long-term stay at these facilities – a significant proportion has experienced homelessness. Worldwide experiences of de-institutionalisation, including examples from India, entailing placements with the family and in community-based housing with supportive services and simultaneous enhancement of local-level mental health services, offer lessons and approaches that may be adapted to address the issue nationally.

The process must begin with recognising the right of people with psychosocial disabilities to live in the community as enshrined in the RPWD 2016 and MHCA 2017, with flexible support that enables them to make choices about their home, exert control over their care and daily living and engage in experiences that have personal meaning.

For this right to become a reality, governments need to assume financial investments defined by a policy and accompanying National Scheme of Assistance for Personal Assistance and Housing Options to promote community living for people with long-term care needs.





The implementation of inclusive living options might be anchored in licensed providers, with quality assurance oversight offered by a coordinating leadership body. Experiences of inclusive living options in India, and elsewhere, demonstrate gains for people discharged from hospitals, favourable attitudes towards mental health in communities where people are placed and cost savings and a more efficient institutional system.

Failures in community placements, regressive steps into jails and other institutional facilities for new cohort of long-stay, and adverse outcomes witnessed more recently in inadequately planned and monitored transitions must inform parallel initiatives that ensure adequate community resources to meet the complex and diverse needs of this population. Therefore, investments must also follow an overhaul of the tertiary care facilities and the DMHP, particularly in domains of social care, which can decisively alter the progression towards homelessness and long-term institutionalisation.

A national-level movement for inclusive living options for people living for extended periods in state mental hospitals has the potential to contribute to social justice and human rights, alter stigmatising notions of mental ill-health and change the landscape of mental health care in the country.

GLOSSARY OF TERMS

1 Sustainable Development Goals (SDGs)
The Sustainable Development Goals (SDGs), is a universal call to address specific thematic priorities such as poverty, climate change, innovation and effect action that works towards ensuring peace and justice for all.
Reference: The Sustainable Development Goals Report 2017

2 Disability-adjusted life years (DALYs)
Disability-adjusted life years (DALYs) is the summary aggregate of the years of life lost (YLLs) by a population due to premature death or 'less than optimal health' or years lived with disability (YLDs).
Reference: WHO methods and data sources for global burden of disease estimates 2000-2015

3 Low- and Medium- Income Countries (LMICs)
Based on the World Bank list of analytical income classification of economies, for the fiscal year of 2019, those countries with a GNI per capita between \$995 (INR 69,387.04) and \$3,895 (INR 2,70,638.23) in 2017, are defined as Low and Middle Income Countries respectively.
Reference: World Bank Group's classification on LMICs

4 The District Mental Health Programme (DMHP)
Launched in 1996, The District Mental Health Programme (DMHP) envisages to transition services from facilities to the community and integrate mental health with primary health care services.
Reference: Handbook on XIIth Plan District Mental Health Programme by Policy Group, Ministry of Health and Family Welfare (MoHFW)

5 National Human Rights Commission (NHRC)
Established in 1993, The National Human Rights Commission (NHRC) is governed by statutes of the Protection of Human Rights Act, 1993 and upholds

'rights relating to life, liberty, equality and dignity of the individual guaranteed by the Constitution or embodied in the International Covenants'.
Reference: NHRC Website

6 Public Interest Litigations (PILs)
'Public Interest Litigations' are used by individuals or communities to challenge the decisions of bureaucracy or public bodies or issues of public concern through the justice framework and thereby advance parameters of human rights and equality.
Reference: The PILS Project Website

7 National Institute of Mental Health and Neuro-Sciences (NIMHANS)
The National Institute of Mental Health and Neuro-Sciences (NIMHANS) functions as the 'apex center for mental health and neuroscience education in the country' and operates autonomously under the Ministry of Health and Family Welfare (MoHFW).
Reference: The NIMHANS Website

8 Lokopriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH)
Lokopriya Gopinath Bordoloi Regional Institute of Mental Health was established in 1876 in Tezpur, Assam and functions as a tertiary mental health care institute and also runs a post - graduate teaching and research centre to supplement human resource requirements in the field of mental health in the region.
Reference: The LGBRIMH Website

9 The Institute of Mental Health and Hospital (IMHH)
The Institute of Mental Health and Hospital in Agra, was established in 1859, and operates as an autonomous institution, to improve treatment and care of those with mental illness and provide education, training and research on mental health.
Reference: The IMHH Website

10 INCENSE

The INCENSE programme by SANGATH, is working towards 'developing a blueprint for action with an integrated community based approach' for mental hospitals to consider and implement in India.

Reference: The Sangath Website

11 Non-Governmental Organization (NGO)

A Non-Governmental Organization is any organised group without a said profit motive, driven towards a common civil interest - a variety of domains including service provision, advocacy, monitoring and evaluation, research is performed by these institutions.

Reference: United Nations, Civil Society Unit

12 United Nations Convention on the Rights of People with Disabilities (UNCRPD)

The Convention on the Rights of Persons with Disabilities is a 'comprehensive human rights treaty an explicit, social development dimension' to continue and bring forth international implications to 'change attitudes and approaches to persons with disabilities'.

Reference: United Nations, Department of Economic and Social Affairs

13 Mental Illness (MI)

Mental Illness is defined as 'a mental, behavioral, or emotional disorder'. It is treatable and a large majority of individuals with mental illness continue to function in their daily lives.

Reference: National Institute of Mental Health

14 Mental Healthcare Act of 2017 (MHCA 2017)

The Mental Healthcare Act of 2017 was brought about to strengthen the human rights of people with mental illness. It lays large emphasis on advance directives, nature of admissions etc - all to restore the rights of people with mental illness.

Reference: Ministry of Health and Family Welfare (MoHFW), Govt. Of India

15 The Tata Institute of Social Sciences (TISS)

Formulated in 1936, TISS has the credit of being Asia's 'oldest public funded institute for professional social studies education'. By placing a focus on field action, it has been instrumental in shaping public policy and anchoring multiple social welfare developmental initiatives.

Reference: The Tata Institute of Social Sciences Website

16 The Banyan Academy of Leadership in Mental Health (BALM)

Founded in 2007, The Banyan Academy of Leadership in Mental Health (BALM) is a teaching institution that emerged from multiple years of grassroots inquiry into mental health, poverty, scarcity and inequity through services offered at The Banyan.

Reference: The Banyan Academy of Leadership in Mental Health Website

17 Institute of Human Behaviour and Allied Sciences (IHBAS)

Established in 1993 to comply with the directives of the apex court in pursuance of a public interest litigation, IHBAS works in domains such as patient care, mental health / neuroscience research and teaching - to enhance 'user satisfaction levels'.

Reference: The IHBAS Website

18 Modified Colorado Symptom Index (mCSI)
The mCSI is a 14 item scale that is used to gauge the likelihood and extent of mental health problems. With its validity and reliability often acknowledged as a 'brief, self-report measure of psychological symptomatology', the mCSI is routinely used in studies which have population cohorts drawn with a history of homelessness and mental illness.
Reference: Conrad, K. J., Yagelka, J. R., Matters, M. D., Rich, A. R., Williams, V., & Buchanan, M. (2001). Reliability and validity of a modified Colorado Symptom Index in a national homeless sample. Mental health services research, 3(3), 141-153.

19 WHODAS 12
The WHODAS 12 also known as the WHODAS 2.0 is a generic tool developed by The World Health Organization (WHO) to cross-culturally capture 'social, occupational, physical, and role impairments associated with a health condition' among adult populations.
Reference: Üstün, T. B., Kostanjsek, N., Chatterji, S., & Rehm, J. (Eds.). (2010). Measuring health and disability: Manual for WHO disability assessment schedule WHODAS 2.0. World Health Organization.

20 Community Placement Questionnaire (CPQ)
The Community Placement Questionnaire (CPQ) is an assessment instrument administered to staff to record the needs of long stay users. The mean score calculated from the different domains help to arrive at an overall index, projecting user's readiness to shift score as hard-to-place or otherwise.
Reference: Clifford, P., Charman, A., Webb, Y., Craig, T. J. K., & Cowan, D. (1991). Planning for community care: the Community Placement Questionnaire. British Journal of Clinical Psychology, 30(3), 193-211.

21 Indian Disability Evaluation and Assessment Scale (IDEAS)
Developed in the year 2000 by the Rehabilitation Committee of Indian Psychiatric Society, the IDEAS serves as a scale that aids assessment of disability levels in the local Indian context. The scale's usage is recommended for certification of disability by the Government of India (GOI).
Reference: Thara, R. (2005). Measurement of psychiatric disability. Indian Journal of Medical Research, 121(6), 723.

22 The Rights of Persons with Disabilities (RPWD) Act, 2016.
Enacted in December 2016, this has mandates and timelines for establishments to ensure accessibility of infrastructure and services for the disabled population, across various aspects of life.
Reference: Diversity and Equal Opportunity Center, India

23 CSS (Cantril's Self Anchoring and Striving Scale)
Initially developed by Hadley Cantril, the Cantril Scale is used to assess wellbeing. It measures life satisfaction 'closer to the end of the continuum representing judgments of life or life evaluation'.
Reference: Cantril, H. (1965). Pattern of human concerns.

24 Grand Challenges Canada (GCC)
Grand Challenges Canada (GCC) refers to a Canadian nonprofit organization, funded by the Government of Canada that tackles issues and improve lives in low- and lower-middle-income countries - by presenting 'integrated innovation' and solutions through investments.
Reference: The Grand Challenges Canada Website

25 Community Integration Questionnaire (CIQ)

The Community Integration Questionnaire (CIQ) is a 15 item inventory used to assess community integration levels and is split into three sections namely: 'home integration (H), social integration (S) and productive activities (P)'.

Reference: Willer, B., Rosenthal, M., Kreutzer, J. S., Gordon, W. A., & Rempel, R. (1993).

Assessment of community integration following rehabilitation for traumatic brain injury. The Journal of head trauma rehabilitation, 8(2), 75-87.

26 Permanent Supportive Housing (PSH)

Permanent Supportive Housing (PSH) is a housing model that works to create access to housing and provide supportive services to people with a history of homelessness, deprivation and/or disabled. Under this, individualised supportive services that are 'voluntary, and available 24 hours a day/7 days a week' are offered - and they are not tied to offer of housing made.

Reference: National Alliance to End Homelessness

27 Rapid Rehousing (RRH)

The Rapid Re-Housing (RRH) is a model 'informed by the Housing First model' that acknowledges, with limited support some people or families-nearing homelessness, can regain housing stability. The National Alliance to End Homelessness identifies three core dimensions to RRH programs: 'Housing identification, financial rental and move-in assistance, and case management and services'.

Reference: National Alliance to End Homelessness

28 HPRP or Homeless Prevention and Rapid Re-Housing Program

The Homelessness Prevention and Rapid Re-housing Program (HPRP) is an assistance model that provides homelessness prevention assistance to beneficiaries who can 'demonstrate' the 'immediacy' in the need presented and is required to cooperate for consultations with social welfare officers.

Reference: National Alliance to End Homelessness Website

29 Service User

Service User refers to a person receiving mental health care. It is meant to point towards those people who commission, receive and use the services relating to health care - especially in a mental health setting.

Reference: McLaughlin, H. (2009). Whats in a name: 'client', 'patient', 'customer', 'consumer', 'expert by experience', 'service user' — what's next?. The British Journal of Social Work, 39(6), 1101-1117.

30 Closed Wards

Are inpatient wards, which are locked with entry and exit being controlled. Typically used to house users who are in chronic phases of serious mental disorders, to enable safe therapeutic treatment in the institution.

31 Clozapine

Clozapine is an atypical antipsychotic medication, used for refractory schizophrenia spectrum disorders.

Reference: National Alliance on Mental Illness

32 Open Wards

Wards that provide overnight care for service users in acute hospitals, with fixed timings of free movement outside the wards.

33 Cells

Placement of a user under the care, custody and control of a solitary confinement setting.

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APPENDIX

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Table 1. Long-stay Service Users in Psychiatric Hospitals across States in India

State	Total Number of Inpatient clients	Number of People > 1 year of stay			%Long Stay
		Male	Female	Total	
Andhra Pradesh	242	9	16	25	10.33
Assam	161	6	4	10	6.21
Bihar	68	8	1	9	13.24
Goa	201	62	46	108	53.73
Gujarat	673	74	75	149	22.14
Haryana	40	7	1	8	20.00
Himachal Pradesh	62	16	3	19	30.65
Jammu and Kashmir	58	11	7	18	31.03
Jharkhand	633	101	190	291	45.97
Karnataka	570	28	41	69	12.10
Kerala	1267	121	47	168	13.26
Madhya Pradesh	324	68	138	206	63.58
Maharashtra	3722	551	807	1358	36.49
Meghalaya	116	24	26	50	43.10
Nagaland	11	1	3	4	36.36
Odisha	84	19	28	47	55.95
Punjab	251	138	95	233	92.83
Rajasthan	349	72	60	132	37.82
Tamil Nadu	883	325	287	612	69.31
Telangana	500	25	25	50	10.00
Tripura	194	27	32	59	30.41
Uttar Pradesh	1703	95	225	320	18.79
Uttarakhand	28	6	13	19	67.86
West Bengal	1473	462	509	971	65.92
Total	13613	2256	2679	4935	36.25

Table 2.1. Average Age of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean(SD)	Median(IR)	Minimum	Maximum
Andhra Pradesh	42.22(12.173)	41(19)	28	68
Assam	41.50(12.250)	42(22)	20	56
Bihar	34.33(12.58)	28(22)	19	55
Goa	46.61(13.560)	45(19)	23	92
Gujarat	47.87(16.094)	46.50(20)	17	98
Haryana	41.88(12.159)	39.50(22)	23	56
Himachal Pradesh	39.53(13.753)	36(21)	23	71
Jammu and Kashmir	43.22(12.293)	44.50(20)	16	61
Jharkhand	47.97(16.986)	46(26)	19	91
Karnataka	52.57(16.151)	51(22)	22	95
Kerala	44.49(12.999)	44(19)	16	78
Madhya Pradesh	46.37(16.016)	43(20)	18	95
Maharashtra	47.27(14.710)	47(22)	15	99
Meghalaya	40.75(13.136)	38.50(18)	20	74
Nagaland	61.25(16.091)	58.50(30)	45	83
Odisha	39.94(12.015)	35(15)	22	75
Punjab	50.79(15.947)	48(21)	23	98
Rajasthan	45.17(13.872)	44(19)	19	81
Tamil Nadu	50.24(13.670)	49(17)	18	97
Telangana	41.70(10.467)	42(15)	20	65
Tripura	37.11(9.759)	37(12)	17	72
Uttar Pradesh	43.41(15.834)	40(25)	18	98
Uttarakhand	42(11)	40(14)	18	63
West Bengal	41.26(12.648)	40(18)	12	87
Total	45.88(14.734)	45(21)	12	99

Table 2.2. Duration of Stay of Long-stay Service Users in Psychiatric Hospitals across States in India

State	1-5	6-10	11-15	16-20	21-25	25+
Andhra Pradesh	77.8% (14)	22.2% (4)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Assam	100.0% (10)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Bihar	100.0% (9)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	49.1% (53)	24.1% (26)	10.2% (11)	3.7% (4)	4.6% (5)	8.3% (9)
Gujarat	72.5% (108)	10.7% (16)	6.0% (9)	2.7% (4)	0.7% (1)	7.4% (11)
Haryana	100.0% (8)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	63.2% (12)	36.8% (7)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Jammu and Kashmir	61.1% (11)	27.8% (5)	5.6% (1)	5.6% (1)	0.0% (0)	0.0% (0)
Jharkhand	38.8% (113)	22.3% (65)	5.2% (15)	4.8% (14)	6.5% (19)	22.2% (65)
Karnataka	27.5% (19)	15.9% (11)	11.6% (8)	8.7% (6)	14.5% (10)	21.6% (15)
Kerala	67.1% (106)	15.8% (25)	4.4% (7)	5.1% (8)	4.4% (7)	3.2% (5)
Madhya Pradesh	50.5% (104)	18.0% (37)	11.2% (23)	9.2% (19)	5.3% (11)	5.8% (12)
Maharashtra	45.1% (594)	13.0% (171)	8.0% (105)	7.4% (98)	8.3% (109)	18.2% (239)
Meghalaya	66.0% (33)	22.0% (11)	8.0% (4)	2.0% (1)	0.0% (0)	2.0% (1)
Nagaland	0.0% (0)	25.0% (1)	25.0% (1)	25.0% (1)	0.0% (0)	25.0% (1)
Odisha	97.9% (46)	0.0% (0)	0.0% (0)	0.0% (0)	2.1% (1)	0.0% (0)
Punjab	35.6% (83)	13.3% (31)	14.6% (34)	9.9% (23)	9.4% (22)	17.1% (40)
Rajasthan	43.9% (58)	25.0% (33)	10.6% (14)	7.6% (10)	6.1% (8)	6.9% (9)
Tamil Nadu	21.5% (131)	20.5% (125)	24.3% (148)	10.2% (62)	6.2% (38)	17.2% (105)
Telangana	80.4% (37)	13.0% (6)	2.2% (1)	2.2% (1)	2.2% (1)	0.0% (0)
Tripura	91.5% (54)	8.5% (5)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Uttar Pradesh	49.7% (159)	15.6% (50)	14.1% (45)	3.4% (11)	6.3% (20)	10.9% (35)
Uttarakhand	89.5% (17)	10.5% (2)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
West Bengal	59.3% (576)	18.2% (177)	11.3% (110)	6.5% (63)	3.8% (37)	0.8% (8)
Total	48.4% (2355)	16.6% (808)	11.0% (536)	6.7% (326)	5.9% (289)	11.4% (555)

Table 2.3. Diagnosis of Long-stay Service Users in Psychiatric Hospitals in India

Diagnosis	N	%
Schizophrenia	2466	50.4%
Acute Psychosis	227	4.6%
Delusional Disorder	10	0.2%
Bipolar Disorder	231	4.7%
Psychosis Nos	857	17.5%
Dementia	10	0.2%
Other organic psychosis	39	0.8%
Depression	32	0.7%
Obsessive Compulsive Disorder	11	0.2%
Anxiety	6	0.1%
Harmful Substance Use	42	0.9%
Alcohol dependence syndrome	7	0.1%
Personality Disorder	10	0.2%
Intellectual Disability	1057	21.6%

Table 2.4. Religious Affiliations of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Hindu	Muslim	Christian	No Religious Affiliation	Others
Andhra Pradesh	88.9% (16)	0.0% (0)	5.6% (1)	0.0% (0)	5.6% (1)
Assam	50.0% (5)	10.0% (1)	0.0% (0)	0.0% (0)	40.0% (4)
Bihar	66.7% (6)	33.3% (3)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	85.2% (92)	5.6% (6)	8.3% (9)	0.0% (0)	0.9% (1)
Gujarat	86.8% (118)	8.1% (11)	0.7% (1)	2.9% (4)	1.5% (2)
Haryana	75.0% (6)	25.0% (2)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	100.0% (3)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Jammu and Kashmir	16.7% (3)	72.2% (13)	0.0% (0)	0.0% (0)	11.1% (2)
Jharkhand	90.4% (263)	5.8% (17)	1.0% (3)	0.0% (0)	2.7% (8)
Karnataka	82.6% (57)	14.5% (10)	2.9% (2)	0.0% (0)	0.0% (0)
Kerala	69.3% (113)	7.4% (12)	11.7% (19)	8.0% (13)	3.7% (6)
Madhya Pradesh	81.3% (157)	8.3% (16)	0.5% (1)	9.3% (18)	0.5% (1)
Maharashtra	85.5% (1094)	8.0% (102)	1.1% (14)	4.5% (57)	1.0% (13)
Meghalaya	52.0% (26)	24.0% (12)	10.0% (5)	0.0% (0)	14.0% (7)
Nagaland	25.0% (1)	0.0% (0)	50.0% (2)	0.0% (0)	25.0% (1)
Odisha	100.0% (47)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Punjab	71.3% (149)	3.8% (8)	0.5% (1)	4.8% (10)	19.6% (41)
Rajasthan	92.1% (117)	7.9% (10)	0.0% (0)	0.0% (0)	0.0% (0)
Tamil Nadu	64.9% (397)	4.9% (30)	2.6% (16)	25.3% (155)	2.3% (14)
Telangana	87.2% (41)	10.6% (5)	0.0% (0)	0.0% (0)	2.1% (1)
Tripura	55.9% (33)	37.3% (22)	0.0% (0)	0.0% (0)	6.8% (4)
Uttar Pradesh	84.9% (265)	8.7% (27)	0.0% (0)	6.1% (19)	0.3% (1)
Uttarakhand	68.4% (13)	5.3% (1)	0.0% (0)	26.3% (5)	0.0% (0)
West Bengal	77.8% (755)	12.6% (122)	0.7% (7)	0.4% (4)	8.5% (83)
Total	79.3% (3777)	9.0% (430)	1.7% (81)	6.0% (285)	4.0% (190)

Table 2.5. Long-stay Service Users in Psychiatric Hospitals that Speak the State’s Language

State	Language	Other Languages	Uncertain
Andhra Pradesh	38.88% (7)	55.55% (10)	5.55% (1)
Assam	40% (4)	40% (4)	20% (2)
Bihar	44.44% (4)	55.55% (5)	0% (0)
Goa	33.33% (36)	56.48% (61)	10.2% (11)
Gujarat	65.8% (98)	25.5% (38)	8.7% (13)
Haryana	0% (0)	100% (8)	0% (0)
Himachal Pradesh	52.6% (10)	21.05% (4)	26.3% (5)
Jammu and Kashmir	66.7% (12)	22.22% (4)	11.1% (2)
Jharkhand	0% (0)	95.87% (279)	4.1% (12)
Karnataka	55.1% (38)	44.92% (31)	0% (0)
Kerala	55.2% (90)	36.19% (59)	8.6% (14)
Madhya Pradesh	93.2% (192)	2.42% (5)	4.4% (9)
Maharashtra	64.3% (853)	29.64% (394)	6.2% (82)
Meghalaya	58% (29)	36% (18)	6% (3)
Nagaland	25% (1)	75% (3)	0% (0)
Odisha	89.4% (42)	10.6% (5)	0% (0)
Punjab	50.2% (117)	48.49% (113)	0.9% (2)
Rajasthan	35.61% (47)	53.03% (70)	11.36% (15)
Tamil Nadu	70.66% (431)	22.62% (138)	6.72% (41)
Telangana	61.70% (29)	36.17% (17)	2.13% (1)
Tripura	84.75% (50)	10.17% (6)	5.08% (3)
Uttar Pradesh	88.13% (282)	8.44% (27)	3.44% (11)
Uttarakhand	89.47% (17)	10.53% (2)	0% (0)
West Bengal	78.17% (759)	18.85% (183)	2.99% (29)
Total	64.39% (3148)	30.35% (1484)	5.26% (256)

Table 3.1. Type of Admission of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Voluntary	Compulsory Detained
	44.4%	55.6%
Andhra Pradesh	(8)	(10)
	60.0%	40.0%
Assam	(6)	(4)
	77.8%	22.2%
Bihar	(7)	(2)
	97.3%	2.8%
Goa	(105)	(3)
	53.0%	47.0%
Gujarat	(79)	(70)
	37.5%	62.5%
Haryana	(3)	(5)
	94.7%	5.3%
Himachal Pradesh	(18)	(1)
	61.1%	38.9%
Jammu and Kashmir	(11)	(7)
	88.4%	11.7%
Jharkhand	(257)	(34)
	68.1%	31.9%
Karnataka	(47)	(22)
	47.7%	52.2%
Kerala	(77)	(84)
	28.6%	71.4%
Madhya Pradesh	(59)	(147)
	35.3%	64.7%
Maharashtra	(466)	(855)
	90.0%	10.0%
Meghalaya	(45)	(5)
	50.0%	50.0%
Nagaland	(2)	(2)
	44.6%	55.4%
Odisha	(21)	(26)
	69.1%	30.9%
Punjab	(161)	(72)
	97.0%	3.0%
Rajasthan	(128)	(4)
	46.9%	53.1%
Tamil Nadu	(287)	(325)
	19.2%	80.8%
Telangana	(9)	(38)
	78.0%	22.1%
Tripura	(46)	(13)
	79.7%	20.3%
Uttar Pradesh	(255)	(65)
	42.1%	57.9%
Uttarakhand	(8)	(11)
	93.6%	6.4%
West Bengal	(909)	(62)
	61.80%	38.3%
Total	(3014)	(1867)

Table 3.2. Persons/Institutions who Initiated Admission of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Family	Police	Magistrate	NGO	Another Hospital	Other
Andhra Pradesh	0.0% (0)	38.9% (7)	27.8% (5)	0.0% (0)	5.6% (1)	27.8% (5)
Assam	20.0% (2)	40.0% (4)	0.0% (0)	30.0% (3)	0.0% (0)	10.0% (1)
Bihar	42.9% (3)	28.6% (2)	14.3% (1)	0.0% (0)	0.0% (0)	14.3% (1)
Goa	13.0% (14)	84.3% (91)	0.0% (0)	0.9% (1)	0.0% (0)	1.9% (2)
Gujarat	22.6% (33)	37.0% (54)	24.0% (35)	2.7% (4)	1.4% (2)	12.3% (18)
Haryana	0.0% (0)	37.5% (3)	37.5% (3)	0.0% (0)	0.0% (0)	25.0% (2)
Himachal Pradesh	0.0% (0)	94.7% (18)	0.0% (0)	5.3% (1)	0.0% (0)	0.0% (0)
Jammu and Kashmir	53.3% (8)	20.0% (3)	20.0% (3)	0.0% (0)	6.7% (1)	0.0% (0)
Jharkhand	41.7% (113)	37.6% (102)	1.1% (3)	1.1% (3)	0.4% (1)	18.1% (49)
Karnataka	44.8% (30)	16.4% (11)	6.0% (4)	0.0% (0)	1.5% (1)	31.3% (21)
Kerala	14.1% (23)	36.8% (60)	33.1% (54)	5.5% (9)	0.0% (0)	10.4% (17)
Madhya Pradesh	5.9% (12)	26.3% (54)	45.9% (94)	5.9% (12)	0.0% (0)	16.1% (33)
Maharashtra	40.5% (535)	43.1% (570)	5.3% (70)	2.9% (38)	0.1% (1)	8.2% (108)
Meghalaya	2.0% (1)	76.0% (38)	2.0% (1)	2.0% (1)	0.0% (0)	18.0% (9)
Nagaland	0.0% (0)	25.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)	75.0% (3)
Odisha	34.0% (16)	10.6% (5)	2.1% (1)	6.4% (3)	8.5% (4)	38.3% (18)
Punjab	37.2% (86)	54.5% (126)	1.3% (3)	0.4% (1)	0.0% (0)	6.5% (15)
Rajasthan	9.8% (13)	87.9% (116)	0.0% (0)	0.0% (0)	0.0% (0)	2.3% (3)
Tamil Nadu	30.6% (186)	32.0% (194)	33.3% (202)	2.8% (17)	0.2% (1)	0.8% (5)
Telangana	10.6% (5)	34.0% (16)	38.3% (18)	12.8% (6)	0.2% (1)	4.3% (2)
Tripura	5.1% (3)	74.6% (44)	0.0% (0)	5.1% (3)	0.0% (0)	15.3% (9)
Uttar Pradesh	21.6% (69)	56.6% (181)	3.4% (11)	0.0% (0)	0.3% (1)	18.1% (58)
Uttarakhand	15.8% (3)	31.6% (6)	15.8% (3)	0.0% (0)	0.0% (0)	36.8% (7)
West Bengal	45.3% (437)	49.0% (473)	0.0% (0)	2.1% (20)	0.1% (1)	3.5% (34)
Total	33.1% (1579)	45.4% (2166)	10.0% (479)	2.6% (123)	0.3% (14)	8.6% (408)

Table 3.3. Type of Stay within the Facility of Long-stay Service Users in Psychiatric Hospitals across Stats in India

State	Open Ward	Close Ward	Cell
Andhra Pradesh	0.0% (0)	94.4% (17)	5.6% (1)
Assam	0.0% (0)	100.0% (10)	0.0% (0)
Bihar	0.0% (0)	100.0% (9)	0.0% (0)
Goa	0.0% (0)	100.0% (108)	0.0% (0)
Gujarat	14.8% (22)	77.9% (116)	7.4% (11)
Haryana	12.5% (1)	87.5% (7)	0.0% (0)
Himachal Pradesh	100.0% (19)	0.0% (0)	0.0% (0)
Jammu and Kashmir	5.6% (1)	94.4% (17)	0.0% (0)
Jharkhand	85.6% (249)	14.4% (42)	0.0% (0)
Karnataka	1.4% (1)	98.6% (68)	0.0% (0)
Kerala	1.8% (3)	84.0% (137)	14.1% (23)
Madhya Pradesh	11.7% (24)	88.3% (182)	0.0% (0)
Maharashtra	0.0% (0)	99.2% (1318)	0.8% (11)
Meghalaya	0.0% (0)	100.0% (50)	0.0% (0)
Nagaland	100.0% (4)	0.0% (0)	0.0% (0)
Odisha	0.0% (0)	100.0% (47)	0.0% (0)
Punjab	60.5% (141)	39.5% (92)	0.0% (0)
Rajasthan	28.8% (38)	71.2% (94)	0.0% (0)
Tamil Nadu	46.9% (287)	53.1% (325)	0.0% (0)
Telangana	0.0% (0)	100.0% (47)	0.0% (0)
Tripura	0.0% (0)	100.0% (59)	0.0% (0)
Uttar Pradesh	81.9% (262)	18.1% (58)	0.0% (0)
Uttarakhand	100.0% (19)	0.0% (0)	0.0% (0)
West Bengal	0.0% (0)	99.9% (970)	0.1% (1)
Total	21.9% (1071)	77.1% (3773)	1.0% (47)

Table 3.4. Average Number of Admissions of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Minimum	Maximum
Andhra Pradesh	0.11(0.323)	0	1
Assam	0.30(0.483)	0	1
Bihar	0.33(0.707)	0	2
Goa	0.44(1.682)	0	13
Gujarat	0.92(2.256)	0	8
Jammu and Kashmir	8.33(11.692)	0	36
Jharkhand	0.16(0.545)	0	4
Karnataka	1.44(1.875)	0	7
Kerala	0.69(2.282)	0	13
Madhya Pradesh	0.11(0.512)	0	4
Maharashtra	0.30(1.069)	0	17
Nagaland	0.25(0.500)	0	1
Odisha	0.02(0.146)	0	1
Punjab	0.15(0.736)	0	6
Rajasthan	0.05(0.377)	0	4
Tamil Nadu	0.56(1.384)	0	8
Telangana	0.21(0.657)	0	4
Tripura	0.02(0.130)	0	1
Uttar Pradesh	0.09(0.483)	0	4
West Bengal	0.16(0.539)	0	8
Total	0.33(1.376)	0	36

Table 3.5. Average Number of Discharges of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Minimum	Maximum
Andhra Pradesh	0.11(0.323)	0	1
Assam	0.30(0.483)	0	1
Bihar	0.33(0.707)	0	2
Goa	0.43(1.689)	0	13
Gujarat	0.82(2.197)	0	8
Jammu and Kashmir	8.28(11.726)	0	36
Jharkhand	0.13(0.460)	0	3
Karnataka	0.94(1.610)	0	7
Kerala	0.65(2.210)	0	13
Madhya Pradesh	0.09(0.455)	0	4
Maharashtra	0.28(1.032)	0	16
Nagaland	0.25(0.5)	0	1
Odisha	0.02(0.146)	0	1
Punjab	0.14(0.700)	0	6
Rajasthan	0.03(0.275)	0	3
Tamil Nadu	0.38(1.241)	0	8
Telangana	0.19(0.537)	0	3
Uttar Pradesh	0.08(0.477)	0	4
West Bengal	0.16(0.531)	0	8
Total	0.28(1.325)	0	36

Table 4.1. Physical Co-morbidities in Long-stay Service Users in Psychiatric Hospitals across States in India

State	Non- communicable	Infectious	Others
Andhra Pradesh	11.1% (2)	5.6% (1)	5.6% (1)
Assam	20.0% (2)	20.0% (2)	0.0% (0)
Bihar	11.1% (1)	0.0% (0)	0.0% (0)
Goa	35.2% (38)	0.0% (0)	0.0% (0)
Gujarat	21.5% (32)	2.7% (4)	1.3% (2)
Haryana	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	0.0% (0)	0.0% (0)	0.0% (0)
Jammu and Kashmir	27.8% (5)	0.0% (0)	0.0% (0)
Jharkhand	19.6% (57)	2.1% (6)	4.5% (13)
Karnataka	39.7% (27)	2.9% (2)	11.8% (8)
Kerala	16.6% (27)	7.4% (12)	1.2% (2)
Madhya Pradesh	9.7% (20)	1.9% (4)	1.9% (4)
Maharashtra	15.1% (185)	2.1% (26)	0.3% (4)
Meghalaya	8.0% (4)	0.0% (0)	2.0% (1)
Nagaland	0.0% (0)	0.0% (0)	0.0% (0)
Odisha	23.4% (11)	2.1% (1)	4.3% (2)
Punjab	3.4% (8)	2.1% (5)	0.4% (1)
Rajasthan	1.5% (2)	0.0% (0)	0.8% (1)
Tamil Nadu	63.4% (384)	7.9% (48)	19.6% (119)
Telangana	23.4% (11)	0.0% (0)	0.0% (0)
Tripura	1.7% (1)	0.0% (0)	1.7% (1)
Uttar Pradesh	2.8% (9)	0.0% (0)	0.9% (3)
Uttarakhand	0.0% (0)	0.0% (0)	0.0% (0)
West Bengal	4.8% (47)	0.5% (5)	0.2% (2)
Total	18.3% (873)	2.4% (116)	3.4% (164)

Table 4.2. Concurrent Disability in Long-stay Service Users in Psychiatric Hospitals in India

Concurrent Disability	N	Percentage
Blindness	45	1%
Low-vision	174	4%
Leprosy cured person	12	0%
Hearing Impairment	138	3%
Locomotor disability	133	3%
Dwarfism	8	0%
Autism Spectrum Disorder	10	0%
Intellectual Disability	1099	22%
Cerebral Palsy	13	0%
Muscular Dystrophy	9	0%
Chronic Neurological Conditions	357	7%
Specific Learning Disabilities	22	0%
Multiple Sclerosis	5	0%
Speech and Language disability	287	6%
Thalassemia	8	0%
Haemophilia	8	0%
Sickle cell disease	5	0%
Acid attack Victim	3	0%
Parkinson's Disease	19	0%

Table 4.3. Long-term or Life Threatening Illnesses among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Yes	No
Andhra Pradesh	0.0% (0)	100.0% (18)
Assam	20.0% (2)	80.0% (8)
Bihar	0.0% (0)	100.0% (9)
Goa	33.3% (36)	66.7% (72)
Gujarat	11.4% (17)	88.6% (132)
Haryana	0.0% (0)	100.0% (8)
Himachal Pradesh	0.0% (0)	100.0% (19)
Jammu and Kashmir	5.6% (1)	94.4% (17)
Jharkhand	23.0% (67)	77.0% (224)
Karnataka	31.9% (22)	68.1% (47)
Kerala	13.5% (22)	86.5% (141)
Madhya Pradesh	5.3% (11)	94.7% (195)
Maharashtra	9.3% (123)	90.7% (1206)
Meghalaya	0.0% (0)	100.0% (50)
Nagaland	0.0% (0)	100.0% (4)
Odisha	0.0% (0)	100.0% (47)
Punjab	2.6% (6)	97.4% (227)
Rajasthan	1.5% (2)	98.5% (130)
Tamil Nadu	31.1% (190)	68.9% (421)
Telangana	0.0% (0)	100.0% (47)
Tripura	0.0% (0)	100.0% (59)
Uttar Pradesh	5.6% (18)	94.4% (302)
Uttarakhand	0.0% (0)	100.0% (19)
West Bengal	5.4% (52)	94.6% (919)
Total	11.6% (569)	88.4% (4321)

Table 4.4. Issues in Mobility faced by Long-stay Service Users in Psychiatric Hospitals across States in India

State	No Problem	Mild Impairment	Moderate Impairment	Severe Impairment	Very Severe Impairment
Andhra Pradesh	72.2% (13)	16.7% (3)	11.1% (2)	0.0% (0)	0.0% (0)
Assam	80.0% (8)	10.0% (1)	0.0% (0)	0.0% (0)	10.0% (1)
Bihar	100.0% (9)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	90.7% (98)	7.4% (8)	0.0% (0)	1.9% (2)	0.0% (0)
Gujarat	53.0% (79)	32.2% (48)	10.7% (16)	2.0% (3)	2.0% (3)
Haryana	62.5% (5)	37.5% (3)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	26.3% (5)	57.9% (11)	15.8% (3)	0.0% (0)	0.0% (0)
Jammu and Kashmir	5.6% (1)	33.3% (6)	61.1% (11)	0.0% (0)	0.0% (0)
Jharkhand	50.2% (146)	37.5% (109)	5.8% (17)	4.1% (12)	2.4% (7)
Karnataka	66.7% (46)	23.2% (16)	5.8% (4)	4.3% (3)	0.0% (0)
Kerala	54.5% (84)	21.4% (33)	11.0% (17)	5.8% (9)	7.1% (11)
Madhya Pradesh	49.0% (101)	35.0% (72)	8.3% (17)	7.3% (15)	0.5% (1)
Maharashtra	54.8% (722)	28.5% (375)	8.6% (113)	7.0% (92)	1.2% (16)
Meghalaya	56.0% (28)	26.0% (13)	6.0% (3)	12.0% (6)	0.0% (0)
Nagaland	25.0% (1)	50.0% (2)	25.0% (1)	0.0% (0)	0.0% (0)
Odisha	61.7% (29)	29.8% (14)	8.5% (4)	0.0% (0)	0.0% (0)
Punjab	48.1% (112)	36.9% (86)	9.9% (23)	5.2% (12)	0.0% (0)
Rajasthan	43.2% (57)	33.3% (44)	13.6% (18)	9.8% (13)	0.0% (0)
Tamil Nadu	49.0% (299)	34.6% (211)	12.6% (77)	3.3% (20)	0.5% (3)
Telangana	61.7% (29)	25.5% (12)	6.4% (3)	4.3% (2)	2.1% (1)
Tripura	57.6% (34)	23.7% (14)	13.6% (8)	1.7% (1)	3.4% (2)
Uttar Pradesh	47.8% (153)	34.7% (111)	10.9% (35)	5.0% (16)	1.6% (5)
Uttarakhand	63.2% (12)	31.6% (6)	5.3% (1)	0.0% (0)	0.0% (0)
West Bengal	67.5% (655)	18.6% (181)	3.8% (37)	9.8% (95)	0.3% (3)
Total	56.0% (2726)	28.3% (1379)	8.4% (410)	6.2% (301)	1.1% (53)

Table 4.5. Daily Activities Requiring Support as a result of Physical Disability in Long-stay Service Users in Psychiatric Hospitals across States in India

State	Yes	No
Andhra Pradesh	11.1% (2)	88.9% (16)
Assam	20.0% (2)	80.0% (8)
Bihar	0.0% (0)	100.0% (9)
Goa	30.6% (33)	69.4% (75)
Gujarat	26.8% (40)	73.2% (109)
Haryana	25.0% (2)	75.0% (6)
Himachal Pradesh	21.1% (4)	78.9% (15)
Jammu and Kashmir	55.6% (10)	44.4% (8)
Jharkhand	48.1% (140)	51.9% (151)
Karnataka	55.1% (38)	44.9% (31)
Kerala	26.0% (38)	74.0% (108)
Madhya Pradesh	15.5% (32)	84.5% (174)
Maharashtra	18.9% (249)	81.1% (1068)
Meghalaya	28.0% (14)	72.0% (36)
Nagaland	75.0% (3)	25.0% (1)
Odisha	19.1% (9)	80.9% (38)
Punjab	20.6% (48)	79.4% (185)
Rajasthan	38.6% (51)	61.4% (81)
Tamil Nadu	47.6% (291)	52.4% (320)
Telangana	25.5% (12)	74.5% (35)
Tripura	22.0% (13)	78.0% (46)
Uttar Pradesh	26.0% (83)	74.0% (236)
Uttarakhand	26.3% (5)	73.7% (14)
West Bengal	20.2% (196)	79.8% (775)
Total	27.1% (1315)	72.9% (3545)

Table 4.6. Incontinence Issues faced by Long-stay Service Users in Psychiatric Hospitals across States in India

State	Rarely or never	Occasionally, but less than weekly	Weekly	Daily
Andhra Pradesh	94.4% (17)	0.0% (0)	0.0% (0)	5.6% (1)
Assam	80.0% (8)	20.0% (2)	0.0% (0)	0.0% (0)
Bihar	100.0% (9)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	96.3% (104)	3.7% (4)	0.0% (0)	0.0% (0)
Gujarat	81.9% (122)	11.4% (17)	3.4% (5)	3.4% (5)
Haryana	87.5% (7)	12.5% (1)	0.0% (0)	0.0% (0)
Himachal Pradesh	73.7% (14)	21.1% (4)	5.3% (1)	0.0% (0)
Jammu and Kashmir	55.6% (10)	16.7% (3)	16.7% (3)	11.1% (2)
Jharkhand	81.4% (237)	9.6% (28)	4.8% (14)	4.1% (12)
Karnataka	81.2% (56)	15.9% (11)	1.4% (1)	1.4% (1)
Kerala	81.8% (121)	8.8% (13)	3.4% (5)	6.1% (9)
Madhya Pradesh	83.0% (171)	11.2% (23)	2.4% (5)	3.4% (7)
Maharashtra	84.2% (1108)	8.1% (106)	4.0% (53)	3.7% (49)
Meghalaya	88.0% (44)	12.0% (6)	0.0% (0)	0.0% (0)
Nagaland	100.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)
Odisha	100.0% (47)	0.0% (0)	0.0% (0)	0.0% (0)
Punjab	80.7% (188)	12.0% (28)	3.9% (9)	3.4% (8)
Rajasthan	68.2% (90)	20.5% (27)	6.1% (8)	5.3% (7)
Tamil Nadu	77.6% (474)	19.3% (118)	2.3% (14)	0.8% (5)
Telangana	80.9% (38)	14.9% (7)	4.3% (2)	0.0% (0)
Tripura	84.7% (50)	13.6% (8)	0.0% (0)	1.7% (1)
Uttar Pradesh	83.1% (265)	11.3% (36)	3.1% (10)	2.5% (8)
Uttarakhand	84.2% (16)	10.5% (2)	5.3% (1)	0.0% (0)
West Bengal	85.1% (826)	12.4% (120)	1.0% (10)	1.5% (15)
Total	82.8% (4026)	11.6% (564)	2.9% (141)	2.7% (130)

Table 4.7. Impact of Physical Disability among Long-stay Service Users in Psychiatric Hospitals across States in India

State	No Disability	Mild Disability	Moderate Disability	Severe Disability	Very Severe Disability
Andhra Pradesh	61.1% (11)	33.3% (6)	5.6% (1)	0.0% (0)	0.0% (0)
Assam	40.0% (4)	40.0% (4)	0.0% (0)	10.0% (1)	10.0% (1)
Bihar	100.0% (9)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	89.8% (97)	7.4% (8)	0.9% (1)	1.9% (2)	0.0% (0)
Gujarat	80.5% (120)	12.1% (18)	5.4% (8)	2.0% (3)	0.0% (0)
Haryana	75.0% (6)	25.0% (2)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	68.4% (13)	26.3% (5)	0.0% (0)	5.3% (1)	0.0% (0)
Jammu and Kashmir	5.6% (1)	38.9% (7)	55.6% (10)	0.0% (0)	0.0% (0)
Jharkhand	50.9% (148)	27.5% (80)	13.1% (38)	4.5% (13)	4.1% (12)
Karnataka	62.3% (43)	15.9% (11)	11.6% (8)	8.7% (6)	1.4% (1)
Kerala	45.3% (67)	31.8% (47)	10.1% (15)	7.4% (11)	5.4% (8)
Madhya Pradesh	84.0% (173)	8.3% (17)	3.9% (8)	2.9% (6)	1.0% (2)
Maharashtra	61.3% (806)	24.7% (325)	7.5% (98)	5.4% (71)	1.1% (14)
Meghalaya	44.0% (22)	36.0% (18)	6.0% (3)	6.0% (3)	8.0% (4)
Nagaland	25.0% (1)	25.0% (1)	50.0% (2)	0.0% (0)	0.0% (0)
Odisha	46.8% (22)	29.8% (14)	21.3% (10)	2.1% (1)	0.0% (0)
Punjab	69.5% (162)	18.9% (44)	9.4% (22)	2.1% (5)	0.0% (0)
Rajasthan	47.7% (63)	25.0% (33)	21.2% (28)	5.3% (7)	0.8% (1)
Tamil Nadu	32.7% (200)	37.0% (226)	23.1% (141)	6.7% (41)	0.5% (3)
Telangana	42.6% (20)	34.0% (16)	14.9% (7)	8.5% (4)	0.0% (0)
Tripura	50.8% (30)	27.1% (16)	16.9% (10)	1.7% (1)	3.4% (2)
Uttar Pradesh	69.6% (222)	15.7% (50)	9.4% (30)	3.4% (11)	1.9% (6)
Uttarakhand	78.9% (15)	10.5% (2)	10.5% (2)	0.0% (0)	0.0% (0)
West Bengal	49.0% (476)	24.4% (237)	13.0% (126)	12.3% (119)	1.3% (13)
Total	56.2% (2731)	24.4% (1187)	11.7% (568)	6.3% (306)	1.4% (67)

Table 4.8.1 Symptoms and Disability (mCSI) of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Median (IR)	Minimum	Maximum
Andhra Pradesh	4.181(6.794)	0(8)	0	21
Bihar	16.111(10.694)	18(19)	0	31
Goa	11.232(5.633)	10(5)	0	36
Gujarat	9.784(10.184)	6(14)	0	38
Haryana	7.333(6.506)	7(6)	1	14
Himachal Pradesh	5.2(2.168)	4(4)	3	8
Jammu and Kashmir	14.89(4.404)	15(5)	2	21
Jharkhand	6.137(6.501)	4(11)	0	26
Karnataka	13.246(8.812)	11(10)	0	39
Kerala	13.239(12.804)	9(19)	0	55
Madhya Pradesh	10.411(10.828)	6(11)	0	47
Maharashtra	7.622(11.087)	3(11)	0	56
Meghalaya	7.684(5.888)	7(12)	0	17
Odisha	11.152(4.242)	11(7)	3	21
Punjab	7.083(8.374)	4(10)	0	39
Rajasthan	9.979(6.651)	9(7)	0	28
Tamil Nadu	7.02(7.430)	5(9)	0	53
Telangana	5.62(5.507)	4(6)	0	22
Tripura	9.297(9.240)	8(16)	0	37
Uttar Pradesh	7.455(7.341)	7(9)	0	48
Uttarakhand	0.8(1.788)	0(2)	0	4
West Bengal	10.641(9.119)	8(13)	0	56
Total	8.72(9.692)	6(12)	0	56

Table 4.8.2. Symptoms and Disability (WHO DAS 12) of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Median (IR)	Minimum	Maximum
Andhra Pradesh	11.20(7.254)	10(15)	1	21
Assam	16.60(10.058)	16.50(17)	0	30
Bihar	20(15.025)	21(26)	0	44
Goa	17.45(10.642)	15(13)	1	48
Gujarat	14.17(11.024)	12.50(15)	0	56
Haryana	13.75(7.126)	13(8)	0	24
Himachal Pradesh	28.26(7.709)	26(11)	17	48
Jammu and Kashmir	16.44(10.466)	19(16)	3	36
Jharkhand	18.87(13.180)	17(20)	0	48
Karnataka	24.14(12.248)	26(19)	0	51
Kerala	11.76(11.215)	11(13)	0	48
Madhya Pradesh	20.23(19.480)	12(26)	0	60
Maharashtra	13.68(12.274)	11(18)	0	48
Meghalaya	18.18(12.062)	16(22)	0	41
Nagaland	15.75(14.221)	13(27)	2	35
Odisha	9.15(3.783)	8(5)	3	23
Punjab	18.12(14.421)	17(20)	0	60
Rajasthan	17.42(12.283)	15(16)	0	60
Tamil Nadu	23.35(11.548)	24(16)	0	48
Telangana	12.18(12.414)	7(22)	0	40
Tripura	15.80(12.395)	15(23)	0	46
Uttar Pradesh	16.81(12.233)	15(15)	0	59
Uttarakhand	21.68(15.159)	28(24)	0	60
West Bengal	12.87(16.715)	6(16)	0	60
Total	16.25(14.148)	13(20)	0	60

Table 4.8.3. Symptoms and Disability (IDEAS) of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Median (IR)	Minimum	Maximum
Andhra Pradesh	5(3.581)	4.50(5)	0	13
Assam	4.50(3.240)	5.50(6)	0	9
Bihar	6.67(5.099)	6(11)	0	13
Goa	9.42(2.792)	10(3)	4	16
Gujarat	5.67(3.670)	5(6)	0	16
Haryana	4.50(3.117)	3.50(5)	0	9
Himachal Pradesh	9.42(2.755)	9(3)	5	16
Jammu and Kashmir	6.94(3.903)	7(8)	0	12
Jharkhand	7.37(4.494)	7(7)	0	16
Karnataka	8.74(4.578)	9(8)	0	16
Kerala	5.75(5.130)	4(8)	0	16
Madhya Pradesh	5.57(3.835)	5(5)	0	16
Maharashtra	4.98(4.130)	4(7)	0	16
Meghalaya	6.76(3.595)	7(7)	0	14
Nagaland	5(4.546)	4(9)	1	11
Odisha	5.89(1.821)	6(3)	4	10
Punjab	5.78(3.966)	6(6)	0	16
Rajasthan	5.96(4.039)	6(5)	0	16
Tamil Nadu	9.22(4.072)	10(5)	0	16
Telangana	4.91(3.764)	4(7)	0	12
Tripura	6.46(4.411)	6(5)	0	16
Uttar Pradesh	5.53(3.897)	5(5)	0	16
Uttarakhand	5.16(3.834)	4(6)	0	14
West Bengal	4.66(4.282)	4(8)	0	16
Total	5.98(4.401)	5(7)	0	16

Table 4.9. Global Disability Assessment of Long-stay Service Users in Psychiatric Hospitals across States in India

State	No Disability (0%)	Mild Disability (<40%)	Moderate Disability (40%-70%)	Severe Disability (71%-99%)	Profound Disability (100%)
Andhra Pradesh	0.0% (0)	55.6% (10)	44.4% (8)	0.0% (0)	0.0% (0)
Assam	0.0% (0)	30.0% (3)	60.0% (6)	10.0% (1)	0.0% (0)
Bihar	0.0% (0)	22.2% (2)	33.3% (3)	44.4% (4)	0.0% (0)
Goa	0.0% (0)	29.6% (32)	50.0% (54)	19.4% (21)	0.9% (1)
Gujarat	0.0% (0)	38.3% (57)	49.0% (73)	12.1% (18)	0.7% (1)
Haryana	0.0% (0)	37.5% (3)	25.0% (2)	37.5% (3)	0.0% (0)
Himachal Pradesh	0.0% (0)	36.8% (7)	47.4% (9)	15.8% (3)	0.0% (0)
Jammu and Kashmir	0.0% (0)	33.3% (6)	55.6% (10)	11.1% (2)	0.0% (0)
Jharkhand	0.0% (0)	40.2% (117)	38.8% (113)	19.9% (58)	1.0% (3)
Karnataka	0.0% (0)	10.1% (7)	43.5% (30)	44.9% (31)	1.4% (1)
Kerala	0.0% (0)	48.2% (68)	35.5% (50)	14.9% (21)	1.4% (2)
Madhya Pradesh	0.0% (0)	51.5% (106)	36.9% (76)	11.2% (23)	0.5% (1)
Maharashtra	0.0% (0)	44.9% (588)	39.4% (516)	14.9% (195)	0.8% (10)
Meghalaya	0.0% (0)	32.0% (16)	54.0% (27)	14.0% (7)	0.0% (0)
Nagaland	0.0% (0)	50.0% (2)	50.0% (2)	0.0% (0)	0.0% (0)
Odisha	0.0% (0)	51.1% (24)	40.4% (19)	8.5% (4)	0.0% (0)
Punjab	0.0% (0)	42.5% (99)	42.5% (99)	14.6% (34)	0.4% (1)
Rajasthan	0.0% (0)	42.4% (56)	47.7% (63)	9.8% (13)	0.0% (0)
Tamil Nadu	0.0% (0)	9.2% (56)	41.8% (256)	46.1% (282)	2.6% (18)
Telangana	0.0% (0)	40.4% (19)	44.7% (21)	14.9% (7)	0.0% (0)
Tripura	0.0% (0)	45.8% (27)	45.8% (27)	8.5% (5)	0.0% (0)
Uttar Pradesh	0.6% (2)	39.7% (127)	44.1% (141)	15.3% (49)	0.3% (1)
Uttarakhand	0.0% (0)	63.2% (12)	15.8% (3)	21.1% (4)	0.0% (0)
West Bengal	0.0% (0)	29.8% (287)	42.8% (413)	25.8% (249)	1.6% (15)
Total	0.0% (2)	35.7% (1731)	41.7% (2021)	21.4% (1034)	1.1% (54)

Table 5.1 Administration of Psychiatric Medication among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Administers independently or with minimal monitoring	Patient accepts medication readily from staff	Requires prompting/ supervision to ensure taking of medication	Major problems in administration
Andhra Pradesh	5.6% (1)	83.3% (15)	5.6% (1)	5.6% (1)
Assam	0.0% (0)	100.0% (10)	0.0% (0)	0.0% (0)
Bihar	0.0% (0)	0.0% (0)	88.9% (8)	11.1% (1)
Goa	0.0% (0)	77.8% (84)	22.2% (24)	0.0% (0)
Gujarat	1.3% (2)	91.3% (136)	6.7% (10)	0.7% (1)
Haryana	12.5% (1)	62.5% (5)	25.0% (2)	0.0% (0)
Himachal Pradesh	0.0% (0)	78.9% (15)	21.1% (4)	0.0% (0)
Jammu and Kashmir	0.0% (0)	66.7% (12)	22.2% (4)	11.1% (2)
Jharkhand	32.0% (93)	52.9% (154)	11.3% (33)	3.8% (11)
Karnataka	23.2% (16)	63.8% (44)	11.6% (8)	1.4% (1)
Kerala	12.9% (19)	55.8% (82)	27.9% (41)	3.4% (5)
Madhya Pradesh	3.4% (7)	84.9% (174)	10.2% (21)	1.5% (3)
Maharashtra	15.5% (206)	48.2% (641)	30.8% (409)	5.5% (73)
Meghalaya	2.0% (1)	86.0% (43)	12.0% (6)	0.0% (0)
Nagaland	0.0% (0)	75.0% (3)	25.0% (1)	0.0% (0)
Odisha	29.8% (14)	66.0% (31)	4.3% (2)	0.0% (0)
Punjab	25.8% (60)	65.2% (152)	9.0% (21)	0.0% (0)
Rajasthan	16.7% (22)	64.4% (85)	18.9% (25)	0.0% (0)
Tamil Nadu	24.3% (148)	54.9% (335)	15.6% (95)	5.2% (32)
Telangana	0.0% (0)	91.5% (43)	6.4% (3)	2.1% (1)
Tripura	0.0% (0)	89.8% (53)	10.2% (6)	0.0% (0)
Uttar Pradesh	17.2% (55)	68.4% (219)	14.1% (45)	0.3% (1)
Uttarakhand	0.0% (0)	89.5% (17)	10.5% (2)	0.0% (0)
West Bengal	29.6% (287)	55.5% (539)	13.8% (134)	1.1% (11)
Total	19.1% (932)	59.4% (2892)	18.6% (905)	2.9% (143)

Table 5.2 Side Effects from Prescribed Medication among Long-stay Service Users in Psychiatric Hospitals across States in India

State	No problems in this area	Mild problem	Moderate problem	Severe problem	Very severe problem
Andhra Pradesh	61.1% (11)	27.8% (5)	11.1% (2)	0.0% (0)	0.0% (0)
Assam	100.0% (10)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Bihar	100.0% (9)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	94.4% (102)	3.7% (4)	0.9% (1)	0.9% (1)	0.0% (0)
Gujarat	71.8% (107)	21.5% (32)	6.0% (9)	0.7% (1)	0.0% (0)
Haryana	62.5% (5)	37.5% (3)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	5.3% (1)	84.2% (16)	5.3% (1)	5.3% (1)	0.0% (0)
Jammu and Kashmir	50.0% (9)	38.9% (7)	11.1% (2)	0.0% (0)	0.0% (0)
Jharkhand	52.6% (153)	42.3% (123)	4.8% (14)	0.3% (1)	0.0% (0)
Karnataka	82.6% (57)	15.9% (11)	1.4% (1)	0.0% (0)	0.0% (0)
Kerala	65.2% (101)	20.0% (31)	5.8% (9)	2.6% (4)	6.5% (10)
Madhya Pradesh	81.6% (168)	12.1% (25)	5.8% (12)	0.5% (1)	0.0% (0)
Maharashtra	63.7% (838)	26.3% (346)	6.1% (80)	2.7% (36)	1.1% (15)
Meghalaya	94.0% (47)	6.0% (3)	0.0% (0)	0.0% (0)	0.0% (0)
Nagaland	100.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Odisha	91.5% (43)	8.5% (4)	0.0% (0)	0.0% (0)	0.0% (0)
Punjab	72.5% (169)	20.6% (48)	5.2% (12)	1.7% (4)	0.0% (0)
Rajasthan	75.8% (100)	22.0% (29)	1.5% (2)	0.8% (1)	0.0% (0)
Tamil Nadu	64.2% (392)	30.9% (189)	3.8% (23)	1.0% (6)	0.2% (1)
Telangana	68.1% (32)	21.3% (10)	6.4% (3)	4.3% (2)	0.0% (0)
Tripura	91.5% (54)	8.5% (5)	0.0% (0)	0.0% (0)	0.0% (0)
Uttar Pradesh	71.3% (228)	21.6% (69)	5.6% (18)	1.3% (4)	0.3% (1)
Uttarakhand	73.7% (14)	21.1% (4)	5.3% (1)	0.0% (0)	0.0% (0)
West Bengal	83.8% (814)	8.2% (80)	3.4% (33)	4.4% (43)	0.1% (1)
Total	71.2% (3468)	21.4% (1044)	4.6% (223)	2.2% (105)	0.6% (28)

Table 6.1. Status of Work Participation of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Employed	In Skills or Vocational Training	Not Engaged in Work	No Opportunities for employment or vocational training
Andhra Pradesh	0.0% (0)	27.8% (5)	22.2% (4)	50.0% (9)
Assam	0.0% (0)	0.0% (0)	100.0% (10)	0.0% (0)
Bihar	0.0% (0)	0.0% (0)	11.1% (1)	88.9% (8)
Goa	0.0% (0)	40.7% (44)	59.3% (64)	0.0% (0)
Gujarat	0.0% (0)	28.2% (42)	69.1% (103)	2.7% (4)
Haryana	0.0% (0)	37.5% (3)	62.5% (5)	0.0% (0)
Himachal Pradesh	0.0% (0)	0.0% (0)	100.0% (19)	0.0% (0)
Jammu and Kashmir	0.0% (0)	0.0% (0)	88.9% (16)	11.1% (2)
Jharkhand	0.0% (0)	25.8% (75)	73.5% (214)	0.7% (2)
Karnataka	1.4% (1)	33.3% (23)	63.8% (44)	1.4% (1)
Kerala	0.0% (0)	50.3% (82)	28.8% (47)	20.9% (34)
Madhya Pradesh	0.0% (0)	17.0% (35)	81.1% (167)	1.9% (4)
Maharashtra	0.2% (3)	10.3% (137)	62.5% (831)	26.9% (358)
Meghalaya	0.0% (0)	0.0% (0)	22.0% (11)	78.0% (39)
Nagaland	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (4)
Odisha	0.0% (0)	0.0% (0)	100.0% (47)	0.0% (0)
Punjab	0.0% (0)	1.3% (3)	87.6% (204)	11.2% (26)
Rajasthan	0.0% (0)	6.8% (9)	89.4% (118)	3.8% (5)
Tamil Nadu	0.2% (1)	16.0% (98)	82.7% (506)	1.1% (7)
Telangana	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (47)
Tripura	0.0% (0)	0.0% (0)	1.7% (1)	98.3% (58)
Uttar Pradesh	0.0% (0)	25.9% (83)	69.7% (223)	4.4% (14)
Uttarakhand	0.0% (0)	0.0% (0)	52.6% (10)	47.4% (9)
West Bengal	3.1% (30)	9.8% (95)	86.6% (841)	0.5% (5)
Total	0.7% (35)	15.0% (734)	71.3% (3486)	13.0% (636)

Table 6.2. Income/Incentives per month of Long-stay Service Users in Psychiatric Hospitals across States in India

State	0	1-1000 (INR)	1001-2000 (INR)	2001-3000 (INR)	3001-4000 (INR)
Andhra Pradesh	100.0% (18)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Assam	100.0% (10)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Bihar	100.0% (9)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	59.3% (64)	40.7% (44)	0.0% (0)	0.0% (0)	0.0% (0)
Gujarat	84.4% (124)	15.6% (23)	0.0% (0)	0.0% (0)	0.0% (0)
Haryana	100.0% (8)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	100.0% (19)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Jammu and Kashmir	100.0% (18)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Jharkhand	78.0% (227)	22.0% (64)	0.0% (0)	0.0% (0)	0.0% (0)
Karnataka	76.8% (53)	23.2% (16)	0.0% (0)	0.0% (0)	0.0% (0)
Kerala	92.6% (151)	7.4% (12)	0.0% (0)	0.0% (0)	0.0% (0)
Madhya Pradesh	91.7% (189)	8.3% (17)	0.0% (0)	0.0% (0)	0.0% (0)
Maharashtra	99.8% (1300)	0.2% (2)	0.0% (0)	0.1% (1)	0.0% (0)
Meghalaya	100.0% (50)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Nagaland	100.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Odisha	100.0% (47)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Punjab	100.0% (232)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Rajasthan	100.0% (132)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Tamil Nadu	95.8% (586)	4.1% (25)	0.2% (1)	0.0% (0)	0.0% (0)
Telangana	100.0% (47)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Tripura	100.0% (59)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Uttar Pradesh	100.0% (320)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Uttarakhand	100.0% (19)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
West Bengal	96.2% (934)	0.7% (7)	1.5% (15)	1.1% (11)	0.4% (4)
Total	95.0% (4620)	4.3% (210)	0.3% (16)	0.2% (12)	0.1% (4)

Table 7.1. Subjective Well-Being (Cantril's Present) of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Median(IR)	Minimum	Maximum
Andhra Pradesh	6.40(2.914)	5.50(5)	1	10
Jharkhand	6.51(2.283)	6(3)	2	10
Kerala	5.29(2.223)	5(3)	1	10
Maharashtra	4.20(2.519)	4(4)	0	10
Meghalaya	5.45(3.560)	4(7)	1	10
Telangana	4.97(1.382)	5(0)	2	8
Tripura	6.78(3.701)	7(7)	1	10
Total	4.74(2.597)	5(4)	0	10

Table 7.2. Subjective Well-Being (Cantril's Before Treatment) of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Median(IR)	Minimum	Maximum
Andhra Pradesh	7.33(3.391)	10(5)	1	10
Jharkhand	4.27(1.957)	4(2)	1	10
Kerala	5.08(2.666)	4(5)	1	10
Maharashtra	3.90(2.498)	3(4)	0	10
Meghalaya	6(3.162)	6(2)	1	10
Telangana	6.11(1.659)	7(2)	3	10
Tripura	6(3.571)	6(7)	1	10
Total	4.40(2.734)	4(4)	0	10

Table 7.3. Subjective Well-Being (Cantril's Future) of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mean (SD)	Median(IR)	Minimum	Maximum
Andhra Pradesh	7.70(3.324)	10(5)	1	10
Jharkhand	6.77(2.319)	7(3)	1	10
Kerala	7.89(2.550)	9(3)	2	10
Maharashtra	6.40(2.255)	6(3)	0	10
Meghalaya	5.10(3.843)	4(8)	1	10
Telangana	7.65(1.125)	8(1)	5	10
Tripura	5.50(3.251)	4(6)	1	10
Total	6.58(2.424)	7(3)	0	10

Table 8.1. Personal Appearance of Long-stay Service Users in Psychiatric Hospitals across States in India

State	No self-neglect. Maintains a neat appearance without help or prompting from staff	Mild self-neglect. Bathes and dresses but need some supervision	Moderate self-neglect. Bathes and dresses only with close supervision	Severe self-neglect. Refuses or is highly resistant to bathing, dressing OR is unable to attend to personal appearance	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	61.1% (11)	27.8% (5)	11.1% (2)	0.0% (0)	0.0% (0)
Assam	50.0% (5)	50.0% (5)	0.0% (0)	0.0% (0)	0.0% (0)
Assam	66.7% (6)	0.0% (0)	22.2% (2)	11.1% (1)	0.0% (0)
Goa	75.0% (81)	9.3% (10)	3.7% (4)	12.0% (13)	0.0% (0)
Gujarat	45.6% (68)	30.9% (46)	18.1% (27)	5.4% (8)	0.0% (0)
Haryana	25.0% (2)	62.5% (5)	12.5% (1)	0.0% (0)	0.0% (0)
Himachal Pradesh	0.0% (0)	21.1% (4)	47.4% (9)	31.6% (6)	0.0% (0)
Jammu and Kashmir	5.6% (1)	38.9% (7)	27.8% (5)	27.8% (5)	0.0% (0)
Jharkhand	29.9% (87)	36.1% (105)	19.6% (57)	14.4% (42)	0.0% (0)
Karnataka	37.7% (26)	15.9% (11)	13.0% (9)	33.3% (23)	0.0% (0)
Kerala	28.8% (47)	32.5% (53)	11.7% (19)	9.2% (15)	17.8% (29)
Madhya Pradesh	35.4% (73)	32.0% (66)	20.4% (42)	11.7% (24)	0.5% (1)
Maharashtra	35.4% (470)	32.2% (428)	12.5% (166)	14.4% (192)	5.5% (73)
Meghalaya	16.0% (8)	38.0% (19)	44.0% (22)	2.0% (1)	0.0% (0)
Nagaland	25.0% (1)	25.0% (1)	50.0% (2)	0.0% (0)	0.0% (0)
Odisha	72.3% (34)	17.0% (8)	6.4% (3)	4.3% (2)	0.0% (0)
Punjab	39.9% (93)	22.7% (53)	27.9% (65)	9.0% (21)	0.4% (1)
Rajasthan	30.3% (40)	27.3% (36)	31.8% (42)	10.6% (14)	0.0% (0)
Tamil Nadu	24.3% (148)	28.6% (174)	25.3% (154)	20.2% (123)	1.6% (10)
Telangana	42.6% (20)	36.2% (17)	12.8% (6)	6.4% (3)	2.1% (1)
Tripura	33.9% (20)	32.2% (19)	23.7% (14)	10.2% (6)	0.0% (0)
Uttar Pradesh	34.1% (109)	39.4% (126)	17.8% (57)	7.8% (25)	0.9% (3)
Uttarakhand	36.8% (7)	36.8% (7)	21.1% (4)	0.0% (0)	5.3% (1)
West Bengal	49.9% (485)	26.9% (261)	11.1% (108)	4.4% (43)	7.6% (74)
Total	37.7% (1842)	30.0% (1466)	16.8% (820)	11.6% (567)	3.9% (193)

Table 8.2. Levels of Difficulty in Getting Up in the Morning among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Little or no difficulty in rising. Rises most mornings with little or no prompting	Mild difficulty in rising. Sometimes rises without prompting, more often needs prompting	Moderate difficulty in rising. Needs regular and sometimes frequent prompting to rise	Severe difficulty in rising. Rises with difficulty only after regular prompting OR requires physical assistance	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	61.1% (11)	38.9% (7)	0.0% (0)	0.0% (0)	0.0% (0)
Assam	60.0% (6)	40.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)
Bihar	66.7% (6)	11.1% (1)	11.1% (1)	11.1% (1)	0.0% (0)
Goa	85.2% (92)	5.6% (6)	2.8% (3)	4.6% (5)	1.9% (2)
Gujarat	43.6% (65)	32.2% (48)	20.1% (30)	3.4% (5)	0.7% (1)
Haryana	50.0% (4)	37.5% (3)	12.5% (1)	0.0% (0)	0.0% (0)
Himachal Pradesh	0.0% (0)	31.6% (6)	42.1% (8)	26.3% (5)	0.0% (0)
Jammu and Kashmir	5.6% (1)	44.4% (8)	44.4% (8)	5.6% (1)	0.0% (0)
Jharkhand	44.7% (130)	35.4% (103)	11.3% (33)	8.6% (25)	0.0% (0)
Karnataka	62.3% (43)	23.2% (16)	7.2% (5)	7.2% (5)	0.0% (0)
Kerala	41.1% (67)	27.0% (44)	8.6% (14)	4.3% (7)	19.0% (31)
Madhya Pradesh	36.4% (75)	44.7% (92)	15.5% (32)	2.9% (6)	0.5% (1)
Maharashtra	32.5% (432)	39.7% (528)	11.4% (152)	10.2% (136)	6.1% (81)
Meghalaya	54.0% (27)	22.0% (11)	16.0% (8)	8.0% (4)	0.0% (0)
Nagaland	50.0% (2)	25.0% (1)	25.0% (1)	0.0% (0)	0.0% (0)
Odisha	61.7% (29)	27.7% (13)	6.4% (3)	4.3% (2)	0.0% (0)
Punjab	43.3% (101)	16.3% (38)	26.6% (62)	5.6% (13)	8.2% (19)
Rajasthan	40.9% (54)	36.4% (48)	18.2% (24)	4.5% (6)	0.0% (0)
Tamil Nadu	26.7% (163)	35.2% (215)	19.0% (116)	13.4% (82)	5.7% (35)
Telangana	40.4% (19)	31.9% (15)	21.3% (10)	4.3% (2)	2.1% (1)
Tripura	39.0% (23)	32.2% (19)	18.6% (11)	10.2% (6)	0.0% (0)
Uttar Pradesh	39.4% (126)	33.8% (108)	17.8% (57)	7.2% (23)	1.9% (6)
Uttarakhand	36.8% (7)	47.4% (9)	10.5% (2)	0.0% (0)	5.3% (1)
West Bengal	55.9% (543)	24.9% (242)	8.1% (79)	3.3% (32)	7.7% (75)
Total	41.4% (2026)	32.4% (1585)	13.5% (660)	7.5% (366)	5.2% (253)

Table 8.3. Maintenance of Personal Space among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Cleans room/bed area well and spontaneously e.g. keeps tidy, clean etc.	Cleans room/bed area with little or no prompting, but not well	Cleans room/bed area but needs prompting and/or supervision	Does not clean room/bed area OR unable to without physical assistance	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	55.6% (10)	11.1% (2)	5.6% (1)	27.8% (5)	0.0% (0)
Assam	10.0% (1)	20.0% (2)	30.0% (3)	40.0% (4)	0.0% (0)
Bihar	66.7% (6)	0.0% (0)	22.2% (2)	11.1% (1)	0.0% (0)
Goa	8.3% (9)	7.4% (8)	0.0% (0)	0.0% (0)	84.3% (91)
Gujarat	32.9% (49)	24.2% (36)	26.2% (39)	16.8% (25)	0.0% (0)
Haryana	37.5% (3)	37.5% (3)	12.5% (1)	0.0% (0)	12.5% (1)
Himachal Pradesh	0.0% (0)	15.8% (3)	57.9% (11)	26.3% (5)	0.0% (0)
Jammu and Kashmir	11.1% (2)	22.2% (4)	33.3% (6)	33.3% (6)	0.0% (0)
Jharkhand	17.5% (51)	18.2% (53)	25.8% (75)	38.1% (111)	0.3% (1)
Karnataka	14.5% (10)	7.2% (5)	8.7% (6)	7.2% (5)	62.3% (43)
Kerala	25.8% (42)	16.0% (26)	13.5% (22)	13.5% (22)	31.3% (51)
Madhya Pradesh	26.2% (54)	23.3% (48)	20.9% (43)	18.0% (37)	11.7% (24)
Maharashtra	24.2% (322)	19.7% (262)	15.3% (204)	33.0% (439)	7.7% (102)
Meghalaya	14.0% (7)	18.0% (9)	22.0% (11)	38.0% (19)	8.0% (4)
Nagaland	50.0% (2)	0.0% (0)	0.0% (0)	50.0% (2)	0.0% (0)
Odisha	25.5% (12)	10.6% (5)	8.5% (4)	51.1% (24)	4.3% (2)
Punjab	30.9% (72)	12.4% (29)	25.8% (60)	16.7% (39)	14.2% (33)
Rajasthan	28.0% (37)	32.6% (43)	24.2% (32)	12.9% (17)	2.3% (3)
Tamil Nadu	10.8% (66)	6.7% (41)	9.4% (57)	40.7% (248)	32.3% (197)
Telangana	34.0% (16)	14.9% (7)	10.6% (5)	19.1% (9)	21.3% (10)
Tripura	18.6% (11)	11.9% (7)	22.0% (13)	42.4% (25)	5.1% (3)
Uttar Pradesh	30.6% (98)	34.1% (109)	19.4% (62)	13.1% (42)	2.8% (9)
Uttarakhand	15.8% (3)	42.1% (8)	15.8% (3)	15.8% (3)	10.5% (2)
West Bengal	47.5% (461)	25.6% (249)	11.6% (113)	7.5% (73)	7.7% (75)
Total	27.5% (1344)	19.6% (959)	15.8% (773)	23.8% (1161)	13.3% (651)

Table 8.4. Preparation of Simple Items of Food and Drink among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Able to prepare a simple snack or drink. e.g. tea	Able to prepare a simple snack/drink with supervision	Able to prepare a snack with close supervision and/or help	Unable to prepare a simple snack/drink	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	38.9% (7)	22.2% (4)	0.0% (0)	16.7% (3)	22.2% (4)
Assam	0.0% (0)	0.0% (0)	0.0% (0)	10.0% (1)	90.0% (9)
Bihar	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (9)
Goa	1.9% (2)	0.0% (0)	0.0% (0)	0.0% (0)	98.1% (106)
Gujarat	10.7% (16)	20.8% (31)	14.8% (22)	36.9% (55)	16.8% (25)
Haryana	0.0% (0)	0.0% (0)	12.5% (1)	25.0% (2)	62.5% (5)
Himachal Pradesh	0.0% (0)	0.0% (0)	0.0% (0)	73.7% (14)	26.3% (5)
Jammu and Kashmir	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)
Jharkhand	5.8% (17)	0.0% (0)	0.7% (2)	30.6% (89)	62.9% (183)
Karnataka	8.7% (6)	1.4% (1)	4.3% (3)	21.7% (15)	63.8% (44)
Kerala	6.1% (10)	8.6% (14)	4.9% (8)	11.0% (18)	69.3% (113)
Madhya Pradesh	12.6% (26)	12.6% (26)	11.2% (23)	45.1% (93)	18.4% (38)
Maharashtra	9.5% (126)	4.8% (64)	5.7% (76)	19.9% (264)	60.1% (799)
Meghalaya	0.0% (0)	2.0% (1)	0.0% (0)	2.0% (1)	96.0% (48)
Nagaland	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (4)
Odisha	17.0% (8)	6.4% (3)	2.1% (1)	68.1% (32)	6.4% (3)
Punjab	14.6% (34)	4.7% (11)	2.6% (6)	27.5% (64)	50.6% (118)
Rajasthan	8.3% (11)	11.4% (15)	18.9% (25)	49.2% (65)	12.1% (16)
Tamil Nadu	3.0% (18)	1.6% (10)	1.0% (6)	43.8% (267)	50.7% (309)
Telangana	0.0% (0)	0.0% (0)	0.0% (0)	10.6% (5)	89.4% (42)
Tripura	0.0% (0)	0.0% (0)	1.7% (1)	1.7% (1)	96.6% (57)
Uttar Pradesh	7.2% (23)	5.9% (19)	5.0% (16)	30.3% (97)	51.6% (165)
Uttarakhand	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (19)
West Bengal	38.4% (373)	18.4% (179)	11.1% (108)	23.8% (231)	8.2% (80)
Total	13.8% (677)	7.7% (378)	6.1% (298)	26.9% (1317)	45.4% (2219)

Table 8.5. Shopping among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Able to purchase major items of clothing without help e.g. shirt, shoes etc	Able to purchase minor items from a shop without help	Able to purchase minor items with supervision	Unable to purchase items OR with not use shops	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	11.1% (2)	5.6% (1)	0.0% (0)	11.1% (2)	72.2% (13)
Assam	0.0% (0)	0.0% (0)	0.0% (0)	20.0% (2)	80.0% (8)
Bihar	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (9)
Goa	1.9% (2)	0.0% (0)	0.0% (0)	0.9% (1)	97.2% (105)
Gujarat	3.4% (5)	6.7% (10)	24.8% (37)	41.6% (62)	23.5% (35)
Haryana	0.0% (0)	0.0% (0)	12.5% (1)	37.5% (3)	50.0% (4)
Himachal Pradesh	0.0% (0)	0.0% (0)	0.0% (0)	57.9% (11)	42.1% (8)
Jammu and Kashmir	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)
Jharkhand	6.5% (19)	0.7% (2)	3.4% (10)	26.8% (78)	62.5% (182)
Karnataka	7.2% (5)	7.2% (5)	1.4% (1)	27.5% (19)	56.5% (39)
Kerala	5.5% (9)	5.5% (9)	6.7% (11)	15.3% (25)	66.9% (109)
Madhya Pradesh	6.3% (13)	8.3% (17)	19.9% (41)	43.2% (89)	22.3% (46)
Maharashtra	5.2% (69)	3.1% (41)	5.0% (67)	22.8% (303)	63.9% (849)
Meghalaya	0.0% (0)	2.0% (1)	0.0% (0)	0.0% (0)	98.0% (49)
Nagaland	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (4)
Odisha	27.7% (13)	4.3% (2)	4.3% (2)	63.8% (30)	0.0% (0)
Punjab	12.4% (29)	3.9% (9)	2.6% (6)	27.0% (63)	54.1% (126)
Rajasthan	3.8% (5)	3.0% (4)	14.4% (19)	58.3% (77)	20.5% (27)
Tamil Nadu	1.8% (11)	0.8% (5)	1.8% (11)	46.1% (281)	49.5% (302)
Telangana	0.0% (0)	0.0% (0)	0.0% (0)	12.8% (6)	87.2% (41)
Tripura	1.7% (1)	1.7% (1)	0.0% (0)	0.0% (0)	96.6% (57)
Uttar Pradesh	5.3% (17)	0.6% (2)	4.1% (13)	24.7% (79)	65.3% (209)
Uttarakhand	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (19)
West Bengal	28.2% (274)	21.0% (204)	19.1% (185)	23.5% (228)	8.2% (80)
Total	9.7% (474)	6.4% (313)	8.3% (404)	27.8% (1359)	47.8% (2339)

Table 8.6. Participation in Structured Activities among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Participates in structured activities regularly and with little or no prompting	Participates in structured activities fairly regularly but needs some prompting	Requires consistent prompting but even then, only participates irregularly in structured activities	Rarely or never participates in structured activities	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	11.1% (2)	38.9% (7)	0.0% (0)	16.7% (3)	33.3% (6)
Assam	30.0% (3)	20.0% (2)	10.0% (1)	40.0% (4)	0.0% (0)
Bihar	22.2% (2)	33.3% (3)	11.1% (1)	33.3% (3)	0.0% (0)
Goa	12.0% (13)	33.3% (36)	3.7% (4)	37.0% (40)	13.9% (15)
Gujarat	28.2% (42)	30.9% (46)	24.8% (37)	15.4% (23)	0.7% (1)
Haryana	12.5% (1)	50.0% (4)	25.0% (2)	12.5% (1)	0.0% (0)
Himachal Pradesh	0.0% (0)	15.8% (3)	10.5% (2)	42.1% (8)	31.6% (6)
Jammu and Kashmir	5.6% (1)	5.6% (1)	0.0% (0)	22.2% (4)	66.7% (12)
Jharkhand	17.5% (51)	16.8% (49)	13.7% (40)	36.1% (105)	15.8% (46)
Karnataka	15.9% (11)	11.6% (8)	14.5% (10)	52.2% (36)	5.8% (4)
Kerala	14.7% (24)	20.2% (33)	8.0% (13)	23.9% (39)	33.1% (54)
Madhya Pradesh	25.7% (53)	27.2% (56)	27.2% (56)	19.4% (40)	0.5% (1)
Maharashtra	25.5% (339)	22.0% (293)	9.1% (121)	28.1% (374)	15.2% (202)
Meghalaya	12.0% (6)	34.0% (17)	8.0% (4)	28.0% (14)	18.0% (9)
Nagaland	50.0% (2)	0.0% (0)	0.0% (0)	25.0% (1)	25.0% (1)
Odisha	19.1% (9)	36.2% (17)	4.3% (2)	38.3% (18)	2.1% (1)
Punjab	22.7% (53)	14.6% (34)	13.7% (32)	24.5% (57)	24.5% (57)
Rajasthan	13.6% (18)	25.8% (34)	19.7% (26)	34.1% (45)	6.8% (9)
Tamil Nadu	7.7% (47)	11.0% (67)	12.3% (75)	46.0% (281)	23.1% (141)
Telangana	12.8% (6)	36.2% (17)	10.6% (5)	21.3% (10)	19.1% (9)
Tripura	16.9% (10)	18.6% (11)	13.6% (8)	28.8% (17)	22.0% (13)
Uttar Pradesh	19.1% (61)	27.8% (89)	14.7% (47)	20.9% (67)	17.5% (56)
Uttarakhand	21.1% (4)	31.6% (6)	21.1% (4)	10.5% (2)	15.8% (3)
West Bengal	30.7% (298)	23.5% (228)	14.7% (143)	22.9% (222)	8.2% (80)
Total	21.6% (1056)	21.7% (1061)	12.9% (633)	28.9% (1414)	14.8% (726)

Table 8.7. Social Mixing among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Mixes with others and forms friendships or relationships with particular individuals	Mixes with others but does not seem to form particular friendships or relationships	Mixes little with others on the whole but enjoys participating in some social activities	Engages in little or no social interactions	Information not available and no opportunity to observe
Andhra Pradesh	16.7% (3)	27.8% (5)	5.6% (1)	22.2% (4)	27.8% (5)
Assam	40.0% (4)	20.0% (2)	10.0% (1)	20.0% (2)	10.0% (1)
Bihar	44.4% (4)	0.0% (0)	11.1% (1)	44.4% (4)	0.0% (0)
Goa	1.9% (2)	38.0% (41)	1.9% (2)	57.4% (62)	0.9% (1)
Gujarat	20.8% (31)	32.2% (48)	16.1% (24)	26.8% (40)	4.0% (6)
Haryana	12.5% (1)	37.5% (3)	12.5% (1)	37.5% (3)	0.0% (0)
Himachal Pradesh	0.0% (0)	5.3% (1)	36.8% (7)	52.6% (10)	5.3% (1)
Jammu and Kashmir	0.0% (0)	0.0% (0)	0.0% (0)	5.6% (1)	94.4% (17)
Jharkhand	16.8% (49)	22.3% (65)	19.9% (58)	38.8% (113)	2.1% (6)
Karnataka	10.1% (7)	20.3% (14)	14.5% (10)	52.2% (36)	2.9% (2)
Kerala	14.1% (23)	15.3% (25)	8.6% (14)	21.5% (35)	40.5% (66)
Madhya Pradesh	24.3% (50)	37.4% (77)	14.1% (29)	24.3% (50)	0.0% (0)
Maharashtra	23.3% (309)	20.8% (277)	10.9% (145)	31.0% (412)	14.0% (186)
Meghalaya	18.0% (9)	32.0% (16)	6.0% (3)	20.0% (10)	24.0% (12)
Nagaland	25.0% (1)	0.0% (0)	0.0% (0)	25.0% (1)	50.0% (2)
Odisha	21.3% (10)	44.7% (21)	6.4% (3)	25.5% (12)	2.1% (1)
Punjab	26.2% (61)	20.2% (47)	22.3% (52)	25.8% (60)	5.6% (13)
Rajasthan	16.7% (22)	29.5% (39)	14.4% (19)	39.4% (52)	0.0% (0)
Tamil Nadu	6.9% (42)	13.8% (84)	13.8% (84)	49.2% (300)	16.4% (100)
Telangana	10.6% (5)	25.5% (12)	4.3% (2)	14.9% (7)	44.7% (21)
Tripura	8.5% (5)	33.9% (20)	16.9% (10)	25.4% (15)	15.3% (9)
Uttar Pradesh	20.9% (67)	27.8% (89)	23.1% (74)	25.0% (80)	3.1% (10)
Uttarakhand	26.3% (5)	15.8% (3)	15.8% (3)	42.1% (8)	0.0% (0)
West Bengal	36.6% (355)	29.4% (285)	11.0% (107)	14.9% (145)	8.1% (79)
Total	21.8% (1065)	24.0% (1174)	13.3% (650)	29.9% (1462)	11.0% (538)

Table 8.8. Initiating Conversation with Staff among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Regularly initiates and sustains a conversation with members of staff	Occasionally initiates and sustains a conversation but rarely involved in more than a brief exchange	Rarely initiates but responds briefly to prompting e.g. requests, jokes	Minimal interactions, rarely more than single word prompted exchanges	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	11.1% (2)	44.4% (8)	16.7% (3)	22.2% (4)	5.6% (1)
Assam	40.0% (4)	10.0% (1)	0.0% (0)	50.0% (5)	0.0% (0)
Bihar	55.6% (5)	0.0% (0)	0.0% (0)	44.4% (4)	0.0% (0)
Goa	0.0% (0)	36.1% (39)	4.6% (5)	58.3% (63)	0.9% (1)
Gujarat	23.5% (35)	28.2% (42)	20.8% (31)	26.8% (40)	0.7% (1)
Haryana	37.5% (3)	12.5% (1)	0.0% (0)	50.0% (4)	0.0% (0)
Himachal Pradesh	0.0% (0)	15.8% (3)	21.1% (4)	63.2% (12)	0.0% (0)
Jammu and Kashmir	0.0% (0)	27.8% (5)	44.4% (8)	22.2% (4)	5.6% (1)
Jharkhand	22.7% (66)	24.7% (72)	21.0% (61)	29.6% (86)	2.1% (6)
Karnataka	14.5% (10)	20.3% (14)	14.5% (10)	47.8% (33)	2.9% (2)
Kerala	19.6% (32)	23.3% (38)	12.9% (21)	20.9% (34)	23.3% (38)
Madhya Pradesh	20.9% (43)	25.7% (53)	23.8% (49)	28.2% (58)	1.5% (3)
Maharashtra	24.2% (321)	20.4% (271)	16.9% (224)	30.5% (405)	8.1% (108)
Meghalaya	18.0% (9)	40.0% (20)	6.0% (3)	28.0% (14)	8.0% (4)
Nagaland	25.0% (1)	25.0% (1)	25.0% (1)	25.0% (1)	0.0% (0)
Odisha	27.7% (13)	38.3% (18)	12.8% (6)	21.3% (10)	0.0% (0)
Punjab	29.2% (68)	20.2% (47)	23.6% (55)	24.0% (56)	3.0% (7)
Rajasthan	14.4% (19)	31.1% (41)	15.2% (20)	39.4% (52)	0.0% (0)
Tamil Nadu	13.1% (80)	20.8% (127)	14.6% (89)	42.1% (257)	9.5% (58)
Telangana	25.5% (12)	19.1% (9)	21.3% (10)	21.3% (10)	12.8% (6)
Tripura	13.6% (8)	37.3% (22)	23.7% (14)	23.7% (14)	1.7% (1)
Uttar Pradesh	23.4% (75)	28.4% (91)	22.5% (72)	25.0% (80)	0.6% (2)
Uttarakhand	15.8% (3)	21.1% (4)	26.3% (5)	36.8% (7)	0.0% (0)
West Bengal	44.9% (436)	22.0% (214)	13.2% (128)	11.1% (108)	8.8% (85)
Total	25.5% (1245)	23.3% (1141)	16.7% (819)	27.8% (1361)	6.8% (324)

Table 8.9. Initiating Conversation with other Patients among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Regularly initiates and sustains a conversation with other patients	Occasionally initiates and sustains a conversation but rarely involved in more than brief exchange	Rarely initiates but responds briefly to prompting e.g. request, jokes	Minimal interactions, rarely more than single word prompted exchanges	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	16.7% (3)	27.8% (5)	38.9% (7)	16.7% (3)	0.0% (0)
Assam	50.0% (5)	0.0% (0)	0.0% (0)	50.0% (5)	0.0% (0)
Bihar	44.4% (4)	11.1% (1)	0.0% (0)	44.4% (4)	0.0% (0)
Goa	0.0% (0)	37.0% (40)	1.9% (2)	60.2% (65)	0.9% (1)
Gujarat	15.4% (23)	32.2% (48)	17.4% (26)	32.9% (49)	2.0% (3)
Haryana	37.5% (3)	0.0% (0)	0.0% (0)	62.5% (5)	0.0% (0)
Himachal Pradesh	0.0% (0)	15.8% (3)	21.1% (4)	63.2% (12)	0.0% (0)
Jammu and Kashmir	0.0% (0)	11.1% (2)	38.9% (7)	44.4% (8)	5.6% (1)
Jharkhand	20.6% (60)	23.0% (67)	25.4% (74)	29.6% (86)	1.4% (4)
Karnataka	10.1% (7)	23.2% (16)	14.5% (10)	47.8% (33)	4.3% (3)
Kerala	22.7% (37)	20.2% (33)	8.6% (14)	25.8% (42)	22.7% (37)
Madhya Pradesh	20.4% (42)	35.4% (73)	18.0% (37)	26.2% (54)	0.0% (0)
Maharashtra	23.4% (311)	22.7% (302)	16.2% (215)	29.9% (398)	7.8% (103)
Meghalaya	28.0% (14)	30.0% (15)	10.0% (5)	26.0% (13)	6.0% (3)
Nagaland	50.0% (2)	0.0% (0)	25.0% (1)	0.0% (0)	25.0% (1)
Odisha	25.5% (12)	36.2% (17)	4.3% (2)	34.0% (16)	0.0% (0)
Punjab	35.2% (82)	15.9% (37)	23.6% (55)	22.3% (52)	3.0% (7)
Rajasthan	17.4% (23)	34.1% (45)	15.2% (20)	33.3% (44)	0.0% (0)
Tamil Nadu	13.7% (84)	20.9% (128)	13.1% (80)	43.7% (267)	8.5% (52)
Telangana	25.5% (12)	21.3% (10)	21.3% (10)	25.5% (12)	6.4% (3)
Tripura	25.4% (15)	25.4% (15)	23.7% (14)	23.7% (14)	1.7% (1)
Uttar Pradesh	27.8% (89)	25.0% (80)	20.6% (66)	25.6% (82)	0.9% (3)
Uttarakhand	15.8% (3)	21.1% (4)	15.8% (3)	42.1% (8)	5.3% (1)
West Bengal	41.3% (401)	22.7% (220)	14.4% (140)	13.0% (126)	8.7% (84)
Total	25.2% (1232)	23.7% (1161)	16.2% (792)	28.6% (1398)	6.3% (307)

Table 8.10. Risk to Personal Safety among Long-stay Service Users in Psychiatric Hospitals across States in India

State	No risk. No evidence that person presents safety risk to self or others	Low risk. Mild concern about possible risk although no reported incidents	Medium risk. No reported incidents but behaviour strongly suggestive of potential risk.	High risk. Incidents suggest high to self or others	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	55.6% (10)	33.3% (6)	5.6% (1)	0.0% (0)	5.6% (1)
Assam	90.0% (9)	0.0% (0)	10.0% (1)	0.0% (0)	0.0% (0)
Bihar	88.9% (8)	0.0% (0)	0.0% (0)	0.0% (0)	11.1% (1)
Goa	87.0% (94)	7.4% (8)	2.8% (3)	2.8% (3)	0.0% (0)
Gujarat	54.4% (81)	22.8% (34)	16.1% (24)	6.7% (10)	0.0% (0)
Haryana	50.0% (4)	25.0% (2)	0.0% (0)	12.5% (1)	12.5% (1)
Himachal Pradesh	21.1% (4)	68.4% (13)	0.0% (0)	5.3% (1)	5.3% (1)
Jammu and Kashmir	38.9% (7)	44.4% (8)	5.6% (1)	5.6% (1)	5.6% (1)
Jharkhand	68.7% (200)	11.3% (33)	14.1% (41)	4.8% (14)	1.0% (3)
Karnataka	72.5% (50)	10.1% (7)	10.1% (7)	4.3% (3)	2.9% (2)
Kerala	48.5% (79)	17.2% (28)	5.5% (9)	3.7% (6)	25.2% (41)
Madhya Pradesh	43.7% (90)	37.4% (77)	11.7% (24)	6.3% (13)	1.0% (2)
Maharashtra	57.3% (761)	18.8% (250)	9.3% (124)	6.0% (80)	8.6% (114)
Meghalaya	74.0% (37)	12.0% (6)	4.0% (2)	4.0% (2)	6.0% (3)
Nagaland	100.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Odisha	78.7% (37)	14.9% (7)	6.4% (3)	0.0% (0)	0.0% (0)
Punjab	60.5% (141)	26.6% (62)	7.3% (17)	3.0% (7)	2.6% (6)
Rajasthan	49.2% (65)	32.6% (43)	11.4% (15)	6.1% (8)	0.8% (1)
Tamil Nadu	16.5% (101)	41.9% (256)	10.0% (61)	14.6% (89)	17.0% (104)
Telangana	57.4% (27)	21.3% (10)	12.8% (6)	6.4% (3)	2.1% (1)
Tripura	84.7% (50)	10.2% (6)	1.7% (1)	0.0% (0)	3.4% (2)
Uttar Pradesh	57.8% (185)	22.2% (71)	10.3% (33)	2.8% (9)	6.9% (22)
Uttarakhand	52.6% (10)	21.1% (4)	21.1% (4)	5.3% (1)	0.0% (0)
West Bengal	64.1% (622)	18.6% (181)	6.6% (64)	2.9% (28)	7.8% (76)
Total	54.7% (2676)	22.7% (1112)	9.0% (441)	5.7% (279)	7.8% (382)

Table 8.11. Use of Public Transportation among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Able to use public transport alone and without supervision	Able to use public transport with some prompting/ minimal supervision	Able to use public transport with close supervision by staff, relatives or friends	Unable to use public transport OR extremely reluctant to use	Not Known. Information not available and no opportunity to observe
Andhra Pradesh	5.6% (1)	11.1% (2)	16.7% (3)	11.1% (2)	55.6% (10)
Assam	0.0% (0)	0.0% (0)	0.0% (0)	10.0% (1)	90.0% (9)
Bihar	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (9)
Goa	0.9% (1)	0.0% (0)	0.0% (0)	0.0% (0)	99.1% (107)
Gujarat	4.0% (6)	10.1% (15)	18.8% (28)	45.0% (67)	22.1% (33)
Haryana	0.0% (0)	0.0% (0)	0.0% (0)	37.5% (3)	62.5% (5)
Himachal Pradesh	0.0% (0)	0.0% (0)	0.0% (0)	57.9% (11)	42.1% (8)
Jammu and Kashmir	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)
Jharkhand	1.0% (3)	0.7% (2)	2.7% (8)	26.1% (76)	69.4% (202)
Karnataka	10.1% (7)	7.2% (5)	2.9% (2)	27.5% (19)	52.2% (36)
Kerala	6.1% (10)	6.7% (11)	6.1% (10)	16.0% (26)	65.0% (106)
Madhya Pradesh	4.9% (10)	5.8% (12)	21.8% (45)	46.6% (96)	20.9% (43)
Maharashtra	5.7% (76)	4.2% (56)	5.0% (67)	21.9% (291)	63.1% (839)
Meghalaya	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (50)
Nagaland	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (4)
Odisha	25.5% (12)	14.9% (7)	4.3% (2)	55.3% (26)	0.0% (0)
Punjab	12.0% (28)	4.7% (11)	3.0% (7)	24.9% (58)	55.4% (129)
Rajasthan	3.8% (5)	9.1% (12)	14.4% (19)	58.3% (77)	14.4% (19)
Tamil Nadu	1.1% (7)	1.5% (9)	1.6% (10)	45.8% (280)	49.9% (305)
Telangana	0.0% (0)	0.0% (0)	2.1% (1)	10.6% (5)	87.2% (41)
Tripura	3.4% (2)	0.0% (0)	0.0% (0)	0.0% (0)	96.6% (57)
Uttar Pradesh	5.0% (16)	2.2% (7)	2.2% (7)	24.7% (79)	65.9% (211)
Uttarakhand	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (19)
West Bengal	27.0% (262)	20.5% (199)	25.4% (247)	18.7% (182)	8.3% (81)
Total	9.1% (446)	7.1% (348)	9.3% (456)	26.6% (1299)	47.9% (2341)

Table 9.1. Overall Impact of Psychological Difficulties on Engagement and Participation in Activities among Long-stay Service Users in Psychiatric Hospitals across States in India

State	No problems	Mild problem	Moderate problem	Severe problem	Very severe problems
Andhra Pradesh	11.1% (2)	66.7% (12)	11.1% (2)	5.6% (1)	5.6% (1)
Assam	0.0% (0)	60.0% (6)	30.0% (3)	10.0% (1)	0.0% (0)
Bihar	22.2% (2)	22.2% (2)	22.2% (2)	33.3% (3)	0.0% (0)
Goa	58.3% (63)	26.9% (29)	10.2% (11)	4.6% (5)	0.0% (0)
Gujarat	27.5% (41)	43.6% (65)	22.1% (33)	6.0% (9)	0.7% (1)
Haryana	12.5% (1)	25.0% (2)	50.0% (4)	12.5% (1)	0.0% (0)
Himachal Pradesh	5.3% (1)	21.1% (4)	36.8% (7)	31.6% (6)	5.3% (1)
Jammu and Kashmir	5.6% (1)	16.7% (3)	55.6% (10)	22.2% (4)	0.0% (0)
Jharkhand	14.1% (41)	34.5% (100)	40.7% (118)	10.0% (29)	0.7% (2)
Karnataka	34.8% (24)	14.5% (10)	27.5% (19)	18.8% (13)	4.3% (3)
Kerala	26.2% (37)	29.8% (42)	26.2% (37)	13.5% (19)	4.3% (6)
Madhya Pradesh	30.6% (63)	43.2% (89)	17.0% (35)	7.8% (16)	1.5% (3)
Maharashtra	51.7% (673)	28.5% (371)	11.9% (155)	6.5% (85)	1.4% (18)
Meghalaya	14.0% (7)	36.0% (18)	30.0% (15)	18.0% (9)	2.0% (1)
Nagaland	0.0% (0)	25.0% (1)	50.0% (2)	25.0% (1)	0.0% (0)
Odisha	2.1% (1)	23.4% (11)	44.7% (21)	29.8% (14)	0.0% (0)
Punjab	20.7% (48)	34.1% (79)	34.9% (81)	9.9% (23)	0.4% (1)
Rajasthan	20.5% (27)	42.4% (56)	28.0% (37)	8.3% (11)	0.8% (1)
Tamil Nadu	11.5% (70)	29.5% (180)	39.4% (241)	19.1% (117)	0.5% (3)
Telangana	40.4% (19)	38.3% (18)	8.5% (4)	6.4% (3)	6.4% (3)
Tripura	8.5% (5)	33.9% (20)	39.0% (23)	18.6% (11)	0.0% (0)
Uttar Pradesh	27.6% (88)	37.0% (118)	27.0% (86)	6.6% (21)	1.9% (6)
Uttarakhand	31.6% (6)	47.4% (9)	10.5% (2)	5.3% (1)	5.3% (1)
West Bengal	29.2% (284)	37.5% (364)	20.5% (199)	8.9% (86)	3.9% (38)
Total	31.1% (1504)	33.3% (1609)	23.7% (1147)	10.1% (489)	1.8% (89)

Table 10.1. Access to Personal Beds in Psychiatric Hospitals across States in India

State	Yes	No
Andhra Pradesh	83.3% (15)	16.7% (3)
Assam	100.0% (10)	0.0% (0)
Bihar	100.0% (9)	00% (0)
Goa	100.0% (108)	0.0% (0)
Gujarat	99.3% (148)	0.7% (1)
Haryana	100.0% (8)	0.0% (0)
Himachal Pradesh	100.0% (19)	0.0% (0)
Jammu and Kashmir	100.0% (18)	0.0% (0)
Jharkhand	99.0% (288)	1.0% (3)
Karnataka	100.0% (69)	0.0% (0)
Kerala	86.9% (139)	13.1% (21)
Madhya Pradesh	99.0% (204)	1.0% (2)
Maharashtra	37.8% (503)	62.2% (826)
Meghalaya	100.0% (50)	0.0% (0)
Nagaland	100.0% (4)	0.0% (0)
Odisha	0.0% (0)	100.0% (47)
Punjab	100.0% (233)	0.0% (0)
Rajasthan	95.5% (126)	4.5% (6)
Tamil Nadu	98.9% (605)	1.1% (7)
Telangana	87.2% (41)	12.8% (6)
Tripura	39.0% (23)	61.0% (36)
Uttar Pradesh	100.0% (320)	0.0% (0)
Uttarakhand	100.0% (19)	0.0% (0)
West Bengal	79.4% (771)	20.6% (200)
Total	76.3% (3730)	23.7% (1158)

Table 10.2. Access to Personal Cupboards in Psychiatric Hospitals across States in India

State	Yes	No
Andhra Pradesh	88.9% (16)	11.1% (2)
Assam	100.0% (10)	0.0% (0)
Bihar	11.1% (1)	88.9% (8)
Goa	100.0% (108)	0.0% (0)
Gujarat	67.8% (101)	32.2% (48)
Haryana	100.0% (8)	0.0% (0)
Himachal Pradesh	100.0% (19)	0.0% (0)
Jammu and Kashmir	0.0% (0)	100.0% (18)
Jharkhand	27.1% (79)	72.9% (212)
Karnataka	40.6% (28)	59.4% (41)
Kerala	7.2% (10)	92.8% (128)
Madhya Pradesh	22.3% (46)	77.7% (160)
Maharashtra	2.9% (39)	97.1% (1290)
Meghalaya	4.0% (2)	96.0% (48)
Nagaland	0.0% (0)	100.0% (4)
Odisha	0.0% (0)	100.0% (47)
Punjab	0.4% (1)	99.6% (232)
Rajasthan	38.6% (51)	61.4% (81)
Tamil Nadu	1.1% (7)	98.9% (605)
Telangana	10.6% (5)	89.4% (42)
Tripura	0.0% (0)	100.0% (59)
Uttar Pradesh	0.3% (1)	99.7% (318)
Uttarakhand	0.0% (0)	100.0% (19)
West Bengal	14.4% (140)	85.6% (831)
Total	13.8% (672)	86.2% (4193)

Table 10.3. Access to Preferred Food in Psychiatric Hospitals across States in India

State	Yes	No
Andhra Pradesh	0.0% (0)	100.0% (18)
Assam	0.0% (0)	100.0% (10)
Bihar	11.1% (1)	88.9% (8)
Goa	21.3% (23)	78.7% (85)
Gujarat	15.4% (23)	84.6% (126)
Haryana	12.5% (1)	87.5% (7)
Himachal Pradesh	0.0% (0)	100.0% (19)
Jammu and Kashmir	5.6% (1)	94.4% (17)
Jharkhand	14.1% (41)	85.9% (250)
Karnataka	34.8% (24)	65.2% (45)
Kerala	10.8% (17)	89.2% (140)
Madhya Pradesh	1.0% (2)	99.0% (204)
Maharashtra	8.8% (117)	91.2% (1212)
Meghalaya	42.0% (21)	58.0% (29)
Nagaland	0.0% (0)	100.0% (4)
Odisha	0.0% (0)	100.0% (47)
Punjab	0.0% (0)	100.0% (233)
Rajasthan	0.8% (1)	99.2% (131)
Tamil Nadu	23.7% (145)	76.3% (466)
Telangana	25.5% (12)	74.5% (35)
Tripura	0.0% (0)	100.0% (59)
Uttar Pradesh	0.0% (0)	100.0% (320)
Uttarakhand	5.3% (1)	94.7% (18)
West Bengal	13.1% (127)	86.9% (844)
Total	11.4% (557)	88.6% (4327)

Table 10.4. Access to Personal Hygiene Products in Psychiatric Hospitals across States in India

State	Yes	No
Andhra Pradesh	66.7% (12)	33.3% (6)
Assam	100.0% (10)	0.0% (0)
Bihar	100.0% (9)	0.0% (0)
Goa	100.0% (108)	0.0% (0)
Gujarat	71.8% (107)	28.2% (42)
Haryana	75.0% (6)	25.0% (2)
Himachal Pradesh	0.0% (0)	100.0% (19)
Jammu and Kashmir	0.0% (0)	100.0% (18)
Jharkhand	85.2% (248)	14.8% (43)
Karnataka	79.7% (55)	20.3% (14)
Kerala	43.5% (60)	56.5% (78)
Madhya Pradesh	58.7% (121)	41.3% (85)
Maharashtra	43.8% (582)	56.2% (747)
Meghalaya	68.0% (34)	32.0% (16)
Nagaland	100.0% (4)	0.0% (0)
Odisha	0.0% (0)	100.0% (47)
Punjab	47.2% (110)	52.8% (123)
Rajasthan	89.4% (118)	10.6% (14)
Tamil Nadu	47.9% (293)	52.1% (319)
Telangana	25.5% (12)	74.5% (35)
Tripura	47.5% (28)	52.5% (31)
Uttar Pradesh	60.3% (193)	39.7% (127)
Uttarakhand	47.4% (9)	52.6% (10)
West Bengal	87.2% (847)	12.8% (124)
Total	61.0% (2966)	39.0% (1900)

Table 10.5. Access to Leisure Activities in Psychiatric Hospitals across States in India

State	Yes	No
Andhra Pradesh	0.0% (0)	100.0% (18)
Assam	0.0% (0)	100.0% (10)
Bihar	0.0% (0)	100.0% (9)
Goa	38.0% (41)	62.0% (67)
Gujarat	69.8% (104)	30.2% (45)
Haryana	87.5% (7)	12.5% (1)
Himachal Pradesh	0.0% (0)	100.0% (19)
Jammu and Kashmir	0.0% (0)	100.0% (18)
Jharkhand	62.9% (183)	37.1% (108)
Karnataka	17.4% (12)	82.6% (57)
Kerala	23.9% (37)	76.1% (118)
Madhya Pradesh	1.5% (3)	98.5% (203)
Maharashtra	17.4% (231)	82.6% (1098)
Meghalaya	0.0% (0)	100.0% (50)
Nagaland	0.0% (0)	100.0% (4)
Odisha	0.0% (0)	100.0% (47)
Punjab	0.9% (2)	99.1% (231)
Rajasthan	0.8% (1)	99.2% (131)
Tamil Nadu	2.9% (18)	97.1% (593)
Telangana	0.0% (0)	100.0% (47)
Tripura	0.0% (0)	100.0% (59)
Uttar Pradesh	7.5% (24)	92.5% (296)
Uttarakhand	0.0% (0)	100.0% (19)
West Bengal	14.4% (140)	85.6% (831)
Total	16.4% (803)	83.6% (4079)

Table 11.1. Overall Potentiality of Danger Posed to Self or Others among Long-stay Service Users in Psychiatric Hospitals across States in India

State	No problems	Mild problem	Moderate problem	Severe problem	Very severe problems
Andhra Pradesh	83.3% (15)	5.6% (1)	11.1% (2)	0.0% (0)	00% (0)
Assam	100.0% (10)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)
Bihar	88.9% (8)	11.1% (1)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	97.2% (105)	1.9% (2)	0.9% (1)	0.0% (0)	0.0% (0)
Gujarat	79.2% (118)	14.8% (22)	5.4% (8)	0.7% (1)	0.0% (0)
Haryana	62.5% (5)	37.5% (3)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	47.4% (9)	42.1% (8)	10.5% (2)	0.0% (0)	0.0% (0)
Jammu and Kashmir	50.0% (9)	22.2% (4)	22.2% (4)	5.6% (1)	0.0% (0)
Jharkhand	87.6% (255)	10.3% (30)	2.1% (6)	0.0% (0)	0.0% (0)
Karnataka	76.8% (53)	15.9% (11)	4.3% (3)	2.9% (2)	0.0% (0)
Kerala	71.8% (117)	15.3% (25)	6.7% (11)	3.1% (5)	3.1% (5)
Madhya Pradesh	86.4% (178)	10.7% (22)	1.5% (3)	1.5% (3)	0.0% (0)
Maharashtra	79.5% (1056)	14.1% (187)	3.7% (49)	2.1% (28)	0.7% (9)
Meghalaya	68.0% (34)	20.0% (10)	12.0% (6)	0.0% (0)	0.0% (0)
Nagaland	50.0% (2)	25.0% (1)	25.0% (1)	0.0% (0)	0.0% (0)
Odisha	85.1% (40)	8.5% (4)	6.4% (3)	0.0% (0)	0.0% (0)
Punjab	69.8% (162)	20.7% (48)	5.6% (13)	2.6% (6)	1.3% (3)
Rajasthan	78.8% (104)	16.7% (22)	4.5% (6)	0.0% (0)	0.0% (0)
Tamil Nadu	55.0% (336)	33.7% (206)	9.3% (57)	2.0% (12)	0.0% (0)
Telangana	76.6% (36)	12.8% (6)	8.5% (4)	0.0% (0)	2.1% (1)
Tripura	79.7% (47)	18.6% (11)	0.0% (0)	0.0% (0)	1.7% (1)
Uttar Pradesh	71.2% (227)	19.4% (62)	7.2% (23)	1.9% (6)	0.3% (1)
Uttarakhand	57.9% (11)	31.6% (6)	5.3% (1)	5.3% (1)	0.0% (0)
West Bengal	67.3% (653)	17.0% (165)	7.8% (76)	7.4% (72)	0.5% (5)
Total	73.4% (3590)	17.5% (857)	5.7% (279)	2.8% (137)	0.5% (25)

Table 12.1. Overall Behavioural Difficulties observed among Long-stay Service Users in Psychiatric Hospitals across States in India

State	No problems Present	Mild problem	Moderate problem	Severe problem	Very severe problems
Andhra Pradesh	88.9% (16)	11.1% (2)	0.0% (0)	0.0% (0)	0.0% (0)
Assam	90.0% (9)	0.0% (0)	10.0% (1)	0.0% (0)	0.0% (0)
Bihar	77.8% (7)	0.0% (0)	22.2% (2)	0.0% (0)	0.0% (0)
Goa	87.9% (94)	8.3% (9)	1.9% (2)	1.9% (2)	0.0% (0)
Gujarat	55.0% (82)	32.2% (48)	11.4% (17)	1.3% (2)	0.0% (0)
Haryana	25.0% (2)	50.0% (4)	12.5% (1)	12.5% (1)	0.0% (0)
Himachal Pradesh	5.3% (1)	57.9% (11)	21.1% (4)	10.5% (2)	5.3% (1)
Jammu and Kashmir	5.6% (1)	38.9% (7)	38.9% (7)	16.7% (3)	0.0% (0)
Jharkhand	49.8% (144)	30.1% (87)	19.4% (56)	0.7% (2)	0.0% (0)
Karnataka	59.4% (41)	23.2% (16)	14.5% (10)	2.9% (2)	0.0% (0)
Kerala	48.6% (70)	29.2% (42)	10.4% (15)	4.9% (7)	6.9% (10)
Madhya Pradesh	66.2% (135)	25.5% (52)	5.9% (12)	1.5% (3)	1.0% (2)
Maharashtra	69.9% (910)	21.8% (284)	4.8% (63)	2.8% (37)	0.6% (8)
Meghalaya	50.0% (25)	38.0% (19)	2.0% (1)	6.0% (3)	4.0% (2)
Nagaland	0.0% (0)	100.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)
Odisha	36.2% (17)	36.2% (17)	21.3% (10)	6.4% (3)	0.0% (0)
Punjab	50.4% (117)	27.6% (64)	17.7% (41)	3.4% (8)	0.9% (2)
Rajasthan	57.6% (76)	34.8% (46)	7.6% (10)	0.0% (0)	0.0% (0)
Tamil Nadu	44.7% (273)	27.0% (165)	22.7% (139)	4.9% (30)	0.0% (0)
Telangana	74.5% (35)	10.6% (5)	6.4% (3)	2.1% (1)	6.4% (3)
Tripura	52.5% (31)	33.9% (20)	10.2% (6)	3.4% (2)	0.0% (0)
Uttar Pradesh	42.9% (137)	36.4% (116)	15.0% (48)	4.4% (14)	1.3% (4)
Uttarakhand	63.2% (12)	21.1% (4)	15.8% (3)	0.0% (0)	0.0% (0)
West Bengal	49.8% (483)	28.2% (274)	10.2% (99)	9.4% (91)	2.4% (23)
Total	55.6% (2718)	26.5% (1296)	11.2% (550)	4.4% (213)	1.2% (59)

Table 13.1. Preferred Placement noted at the beginning of the interview among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Family	Employment with hostel or home again	Continue at hospital	Other
Andhra Pradesh	50.0% (9)	11.1% (2)	16.7% (3)	22.2% (4)
Assam	50.0% (5)	0.0% (0)	10.0% (1)	40.0% (4)
Bihar	88.9% (8)	0.0% (0)	0.0% (0)	11.1% (1)
Goa	35.2% (38)	0.0% (0)	6.5% (7)	58.3% (63)
Gujarat	55.0% (82)	5.4% (8)	16.8% (25)	22.8% (34)
Haryana	75.0% (6)	0.0% (0)	12.5% (1)	12.5% (1)
Himachal Pradesh	63.2% (12)	0.0% (0)	0.0% (0)	36.8% (7)
Jammu and Kashmir	44.4% (8)	11.1% (2)	5.6% (1)	38.9% (7)
Jharkhand	39.5% (115)	0.3% (1)	30.6% (89)	29.6% (86)
Karnataka	20.3% (14)	5.8% (4)	31.9% (22)	42.0% (29)
Kerala	39.9% (65)	6.1% (10)	12.3% (20)	41.7% (68)
Madhya Pradesh	34.5% (71)	9.7% (20)	37.9% (78)	18.0% (37)
Maharashtra	48.0% (638)	4.9% (65)	26.9% (358)	20.2% (268)
Meghalaya	56.0% (28)	0.0% (0)	6.0% (3)	38.0% (19)
Nagaland	25.0% (1)	0.0% (0)	50.0% (2)	25.0% (1)
Odisha	46.8% (22)	8.5% (4)	44.7% (2)	0.0% (0)
Punjab	67.4% (157)	0.0% (0)	13.3% (31)	19.3% (45)
Rajasthan	59.8% (79)	0.0% (0)	20.5% (27)	19.7% (26)
Tamil Nadu	20.6% (126)	4.2% (26)	22.7% (139)	52.5% (321)
Telangana	57.4% (27)	6.4% (3)	21.3% (10)	14.9% (7)
Tripura	66.1% (39)	0.0% (0)	1.7% (1)	32.2% (19)
Uttar Pradesh	71.3% (228)	0.6% (2)	12.8% (41)	15.3% (49)
Uttarakhand	63.2% (12)	0.0% (0)	31.6% (6)	5.3% (1)
West Bengal	76.6% (744)	1.4% (14)	17.0% (165)	4.9% (48)
Total	51.8% (2534)	3.3% (161)	21.5% (1051)	23.4% (1145)

Table 13.2. Preferred Placement noted at end of interview among Long-stay Service Users in Psychiatric Hospitals across States in India

State	No expressed preference	Independent living	Back to family/area of origin	Supported home	Staffed Home	Remain in hospital
Andhra Pradesh	38.9% (7)	5.6% (1)	38.9% (7)	0.0% (0)	0.0% (0)	16.7% (3)
Assam	60.0% (6)	0.0% (0)	40.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)
Bihar	11.1% (1)	0.0% (0)	88.9% (8)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	50.5% (54)	0.0% (0)	32.7% (35)	11.2% (12)	0.0% (0)	5.6% (6)
Gujarat	34.7% (51)	2.7% (4)	24.5% (36)	14.3% (21)	6.8% (10)	17.0% (25)
Haryana	37.5% (3)	0.0% (0)	37.5% (3)	12.5% (1)	0.0% (0)	12.5% (1)
Himachal Pradesh	36.8% (7)	0.0% (0)	63.2% (12)	0.0% (0)	0.0% (0)	0.0% (0)
Jammu and Kashmir	55.6% (10)	0.0% (0)	44.4% (8)	0.0% (0)	0.0% (0)	0.0% (0)
Jharkhand	28.3% (82)	0.3% (1)	41.0% (119)	0.3% (1)	0.0% (0)	30.0% (87)
Karnataka	52.2% (35)	3.0% (2)	17.9% (12)	7.5% (5)	0.0% (0)	19.4% (13)
Kerala	36.8% (53)	4.9% (7)	41.0% (59)	4.2% (6)	4.9% (7)	8.3% (12)
Madhya Pradesh	30.6% (63)	2.9% (6)	22.3% (46)	15.5% (32)	3.4% (7)	25.2% (52)
Maharashtra	29.9% (391)	3.8% (49)	32.9% (430)	15.5% (203)	10.9% (143)	6.9% (90)
Meghalaya	38.0% (19)	0.0% (0)	58.0% (29)	0.0% (0)	0.0% (0)	4.0% (2)
Nagaland	50.0% (2)	0.0% (0)	0.0% (0)	0.0% (0)	0.0% (0)	50.0% (2)
Odisha	8.5% (4)	0.0% (0)	46.8% (22)	23.4% (11)	0.0% (0)	21.3% (10)
Punjab	31.5% (73)	1.3% (3)	57.3% (133)	0.9% (2)	0.0% (0)	9.1% (21)
Rajasthan	47.0% (62)	1.5% (2)	43.2% (57)	1.5% (2)	0.0% (0)	6.8% (9)
Tamil Nadu	54.2% (330)	1.3% (8)	15.4% (94)	3.9% (24)	0.3% (2)	24.8% (151)
Telangana	17.0% (8)	4.3% (2)	61.7% (29)	0.0% (0)	2.1% (1)	14.9% (7)
Tripura	32.2% (19)	1.7% (1)	66.1% (39)	0.0% (0)	0.0% (0)	0.0% (0)
Uttar Pradesh	26.6% (85)	1.3% (4)	63.3% (202)	0.3% (1)	0.3% (1)	8.2% (26)
Uttarakhand	31.6% (6)	0.0% (0)	42.1% (8)	0.0% (0)	0.0% (0)	26.3% (5)
West Bengal	10.8% (105)	2.3% (22)	65.4% (635)	3.2% (31)	0.1% (1)	18.2% (177)
Total	30.5% (1476)	2.3% (112)	41.9% (2027)	7.3% (352)	3.6% (172)	14.4% (699)

Table 13.4. Long-stay Service Users in Psychiatric Hospitals across States in India Assessed to Remain in Hospital rather than have Purpose-built Accommodation

State	Yes	No
Andhra Pradesh	0.0% (0)	100.0% (18)
Assam	0.0% (0)	100.0% (10)
Bihar	0.0% (0)	100.0% (9)
Goa	5.6% (6)	94.4% (102)
Gujarat	17.7% (26)	82.3% (121)
Haryana	87.5% (7)	12.5% (1)
Himachal Pradesh	10.5% (2)	89.5% (17)
Jammu and Kashmir	5.6% (1)	94.4% (17)
Jharkhand	25.2% (73)	74.8% (217)
Karnataka	53.6% (37)	46.4% (32)
Kerala	20.0% (31)	80.0% (124)
Madhya Pradesh	20.9% (43)	79.1% (163)
Maharashtra	0.2% (2)	99.8% (1327)
Meghalaya	6.0% (3)	94.0% (47)
Nagaland	0.0% (0)	100.0% (4)
Odisha	17.0% (8)	83.0% (39)
Punjab	13.8% (32)	86.2% (200)
Rajasthan	25.0% (33)	75.0% (99)
Tamil Nadu	34.0% (208)	66.0% (403)
Telangana	0.0% (0)	100.0% (47)
Tripura	1.7% (1)	98.3% (58)
Uttar Pradesh	20.4% (65)	79.6% (254)
Uttarakhand	5.3% (1)	94.7% (18)
West Bengal	31.6% (307)	68.4% (664)
Total	18.2% (886)	81.8% (3991)

Table 13.5. Long-stay Service Users in Psychiatric Hospitals across States in India Requiring Placement in Facilities for Persons with Learning Disabilities

State	Yes	No
	0.0%	100.0%
Andhra Pradesh	(0)	(18)
	0.0%	100.0%
Assam	(0)	(10)
	11.1%	88.9%
Bihar	(1)	(8)
	17.6%	82.4%
Goa	(19)	(89)
	4.1%	95.9%
Gujarat	(6)	(142)
	0.0%	100.0%
Haryana	(0)	(8)
	10.5%	89.5%
Himachal Pradesh	(2)	(17)
	44.4%	55.6%
Jammu and Kashmir	(8)	(10)
	9.0%	91.0%
Jharkhand	(26)	(264)
	11.6%	88.4%
Karnataka	(8)	(61)
	21.9%	78.1%
Kerala	(34)	(121)
	4.4%	95.6%
Madhya Pradesh	(9)	(197)
	38.9%	61.1%
Maharashtra	(507)	(795)
	10.0%	90.0%
Meghalaya	(5)	(45)
	25.0%	75.0%
Nagaland	(1)	(3)
	0.0%	100.0%
Odisha	(0)	(47)
	0.9%	99.1%
Punjab	(2)	(229)
	3.8%	96.2%
Rajasthan	(5)	(127)
	14.8%	85.2%
Tamil Nadu	(90)	(520)
	21.3%	78.7%
Telangana	(10)	(37)
	5.1%	94.9%
Tripura	(3)	(56)
	1.6%	98.4%
Uttar Pradesh	(5)	(314)
	0.0%	100.0%
Uttarakhand	(0)	(19)
	16.2%	83.8%
West Bengal	(157)	(814)
	18.5%	81.5%
Total	(898)	(3951)

Table 13.6. Long-stay Service Users in Psychiatric Hospitals across States in India Requiring Occasional Treatment away from the placement

State	Yes	No
	44.4%	55.6%
Andhra Pradesh	(8)	(10)
	40.0%	60.0%
Assam	(4)	(6)
	88.9%	11.1%
Bihar	(8)	(1)
	10.2%	89.8%
Goa	(11)	(97)
	41.2%	58.8%
Gujarat	(61)	(87)
	62.5%	37.5%
Haryana	(5)	(3)
	100.0%	0.0%
Himachal Pradesh	(19)	(0)
	94.4%	5.6%
Jammu and Kashmir	(17)	(1)
	9.7%	90.3%
Jharkhand	(28)	(262)
	29.0%	71.0%
Karnataka	(20)	(49)
	49.4%	50.6%
Kerala	(79)	(81)
	32.0%	68.0%
Madhya Pradesh	(66)	(140)
	48.8%	51.2%
Maharashtra	(637)	(669)
	40.0%	60.0%
Meghalaya	(20)	(30)
	25.0%	75.0%
Nagaland	(1)	(3)
	10.6%	89.4%
Odisha	(5)	(42)
	47.8%	52.2%
Punjab	(111)	(121)
	74.2%	25.8%
Rajasthan	(98)	(34)
	28.8%	71.2%
Tamil Nadu	(176)	(435)
	42.6%	57.4%
Telangana	(20)	(27)
	37.3%	62.7%
Tripura	(22)	(37)
	57.7%	42.3%
Uttar Pradesh	(184)	(135)
	31.6%	68.4%
Uttarakhand	(6)	(13)
	76.4%	23.6%
West Bengal	(742)	(229)
	48.3%	51.7%
Total	(2348)	(2512)

Table 13.7. Environment for Work and Adult Day Program for Long-stay Service Users in Psychiatric Hospitals across States in India

State	Drop-in centre	Day Centre (low key)	Day Centre (activity-orientated)	Sheltered work (low key)	Supported work (moderate-high ability)
Andhra Pradesh	0.0% (0)	27.8% (5)	61.1% (11)	11.1% (2)	0.0% (0)
Assam	0.0% (0)	40.0% (4)	30.0% (3)	20.0% (2)	10.0% (1)
Bihar	55.6% (5)	44.4% (4)	0.0% (0)	0.0% (0)	0.0% (0)
Goa	46.3% (50)	32.4% (35)	14.8% (16)	1.9% (2)	4.6% (5)
Gujarat	25.0% (37)	33.1% (49)	25.7% (38)	10.8% (16)	5.4% (8)
Haryana	12.5% (1)	12.5% (1)	50.0% (4)	25.0% (2)	0.0% (0)
Himachal Pradesh	10.5% (2)	52.6% (10)	36.8% (7)	0.0% (0)	0.0% (0)
Jammu and Kashmir	0.0% (0)	83.3% (15)	16.7% (3)	.0% (0)	0.0% (0)
Jharkhand	9.7% (28)	25.2% (73)	43.8% (127)	12.8% (37)	8.6% (25)
Karnataka	37.7% (26)	13.0% (9)	15.9% (11)	17.4% (12)	15.9% (11)
Kerala	14.3% (20)	22.9% (32)	27.1% (38)	16.4% (23)	19.3% (27)
Madhya Pradesh	16.5% (34)	38.8% (80)	32.0% (66)	7.8% (16)	4.9% (10)
Maharashtra	4.9% (64)	36.4% (474)	16.1% (210)	31.8% (414)	10.8% (140)
Meghalaya	6.0% (3)	36.0% (18)	32.0% (16)	10.0% (5)	16.0% (8)
Nagaland	0.0% (0)	75.0% (3)	0.0% (0)	0.0% (0)	25.0% (1)
Odisha	27.7% (13)	38.3% (18)	27.7% (13)	6.4% (3)	0.0% (0)
Punjab	10.3% (24)	22.0% (51)	59.5% (138)	7.3% (17)	0.9% (2)
Rajasthan	9.1% (12)	11.4% (15)	69.7% (92)	9.8% (13)	0.0% (0)
Tamil Nadu	10.0% (61)	41.1% (250)	27.4% (167)	13.0% (79)	8.5% (52)
Telangana	2.1% (1)	2.1% (1)	48.9% (23)	17.0% (8)	29.8% (14)
Tripura	0.0% (0)	44.1% (26)	23.7% (14)	8.5% (5)	23.7% (14)
Uttar Pradesh	20.1% (64)	33.9% (108)	37.6% (120)	5.3% (17)	3.1% (10)
Uttarakhand	15.8% (3)	36.8% (7)	47.4% (9)	0.0% (0)	0.0% (0)
West Bengal	14.7% (143)	20.3% (197)	21.7% (211)	20.3% (197)	23.0% (223)
Total	12.2% (591)	30.7% (1485)	27.7% (1337)	18.0% (870)	11.4% (551)

Table 13.8. Long-stay Service Users in Psychiatric Hospitals across India Requiring Services to Address Harmful Substance Use

State	Yes	No
Andhra Pradesh	0.0% (0)	100.0% (18)
Assam	20.0% (2)	80.0% (8)
Bihar	11.1% (1)	88.9% (8)
Goa	1.9% (2)	98.1% (106)
Gujarat	0.7% (1)	99.3% (146)
Haryana	12.5% (1)	87.5% (7)
Himachal Pradesh	0.0% (0)	100.0% (19)
Jammu and Kashmir	5.6% (1)	94.4% (17)
Jharkhand	14.5% (42)	85.5% (248)
Karnataka	10.1% (7)	89.9% (62)
Kerala	4.3% (7)	95.7% (156)
Madhya Pradesh	2.4% (5)	97.6% (201)
Maharashtra	8.9% (115)	91.1% (1182)
Meghalaya	38.0% (19)	62.0% (31)
Nagaland	100.0% (4)	0.0% (0)
Odisha	95.7% (45)	4.3% (2)
Punjab	0.9% (2)	99.1% (230)
Rajasthan	0.0% (0)	100.0% (132)
Tamil Nadu	1.3% (8)	98.7% (601)
Telangana	6.4% (3)	93.6% (44)
Tripura	28.8% (17)	71.2% (42)
Uttar Pradesh	1.6% (5)	98.4% (314)
Uttarakhand	0.0% (0)	100.0% (19)
West Bengal	5.7% (55)	94.3% (916)
Total	7.1% (342)	92.9% (4509)

Table 13.9. Awareness of Local Resources among Long-stay Service Users in Psychiatric Hospitals across States in India

State	Not aware	Aware but reluctant to use	Aware and would attempt to access
Andhra Pradesh	77.8% (14)	5.6% (1)	16.7% (3)
Assam	100.0% (10)	0.0% (0)	0.0% (0)
Bihar	77.8% (7)	0.0% (0)	22.2% (2)
Goa	95.4% (103)	0.0% (0)	4.6% (5)
Gujarat	51.7% (76)	35.4% (52)	12.9% (19)
Haryana	87.5% (7)	12.5% (1)	0.0% (0)
Himachal Pradesh	100.0% (19)	0.0% (0)	0.0% (0)
Jammu and Kashmir	88.9% (16)	0.0% (0)	11.1% (2)
Jharkhand	80.6% (232)	11.5% (33)	8.0% (23)
Karnataka	88.4% (61)	8.7% (6)	2.9% (2)
Kerala	87.1% (142)	6.1% (10)	6.7% (11)
Madhya Pradesh	69.9% (144)	24.3% (50)	5.8% (12)
Maharashtra	84.3% (1100)	10.3% (134)	5.4% (71)
Meghalaya	84.0% (42)	2.0% (1)	14.0% (7)
Nagaland	75.0% (3)	0.0% (0)	25.0% (1)
Odisha	87.2% (41)	8.5% (4)	4.3% (2)
Punjab	67.2% (156)	15.1% (35)	17.7% (41)
Rajasthan	68.9% (91)	15.2% (20)	15.9% (21)
Tamil Nadu	96.7% (589)	3.0% (18)	0.3% (2)
Telangana	78.7% (37)	8.5% (4)	12.8% (6)
Tripura	79.7% (47)	1.7% (1)	18.6% (11)
Uttar Pradesh	78.1% (249)	9.4% (30)	12.5% (40)
Uttarakhand	100.0% (19)	0.0% (0)	0.0% (0)
West Bengal	91.7% (890)	3.5% (34)	4.8% (47)
Total	84.3% (4095)	8.9% (434)	6.8% (328)

Table 13.10. Access to Financial Resources among Long-stay Service Users in Psychiatric Hospitals across States in India

State	None	Assistance from family	Welfare benefits	Pension/personal resources
Andhra Pradesh	100.0% (18)	0.0% (0)	0.0% (0)	0.0% (0)
Assam	100.0% (10)	0.0% (0)	0.0% (0)	0.0% (0)
Bihar	33.3% (3)	44.4% (4)	0.0% (0)	22.2% (2)
Goa	100.0% (108)	0.0% (0)	0.0% (0)	0.0% (0)
Gujarat	95.9% (141)	3.4% (5)	0.7% (1)	0.0% (0)
Haryana	100.0% (8)	0.0% (0)	0.0% (0)	0.0% (0)
Himachal Pradesh	100.0% (19)	0.0% (0)	0.0% (0)	0.0% (0)
Jammu and Kashmir	77.8% (14)	11.1% (2)	5.6% (1)	5.6% (1)
Jharkhand	99.0% (287)	1.0% (3)	0.0% (0)	0.0% (0)
Karnataka	85.5% (59)	8.7% (6)	4.3% (3)	1.4% (1)
Kerala	84.5% (120)	13.4% (19)	0.7% (1)	1.4% (2)
Madhya Pradesh	99.0% (204)	0.5% (1)	0.5% (1)	0.0% (0)
Maharashtra	92.6% (1210)	5.9% (77)	1.3% (17)	0.2% (3)
Meghalaya	100.0% (50)	0.0% (0)	0.0% (0)	0.0% (0)
Nagaland	100.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)
Odisha	91.5% (43)	8.5% (4)	0.0% (0)	0.0% (0)
Punjab	83.2% (193)	3.9% (9)	6.9% (16)	6.0% (14)
Rajasthan	97.7% (129)	2.3% (3)	0.0% (0)	0.0% (0)
Tamil Nadu	93.9% (572)	5.3% (32)	0.7% (4)	0.2% (1)
Telangana	97.9% (46)	2.1% (1)	0.0% (0)	0.0% (0)
Tripura	100.0% (59)	0.0% (0)	0.0% (0)	0.0% (0)
Uttar Pradesh	97.5% (311)	2.5% (8)	0.0% (0)	0.0% (0)
Uttarakhand	100.0% (19)	0.0% (0)	0.0% (0)	0.0% (0)
West Bengal	88.4% (857)	2.2% (21)	0.2% (2)	9.3% (90)
Total	92.6% (4484)	4.0% (195)	1.0% (46)	2.4% (116)

Table 13.11. Overall Level of Problems relating to Community Placement of Long-stay Service Users in Psychiatric Hospitals across States in India

State	Not at all serious	Moderate problems	Severe Problems	Very Severe Problem
Andhra Pradesh	0.0% (0)	66.7% (12)	33.3% (6)	0.0% (0)
Assam	20.0% (2)	50.0% (5)	30.0% (3)	0.0% (0)
Bihar	33.3% (3)	33.3% (3)	33.3% (3)	0.0% (0)
Goa	57.0% (61)	27.1% (29)	13.1% (14)	2.8% (3)
Gujarat	40.8% (60)	46.9% (69)	11.6% (17)	0.7% (1)
Haryana	12.5% (1)	75.0% (6)	12.5% (1)	0.0% (0)
Himachal Pradesh	0.0% (0)	57.9% (11)	31.6% (6)	10.5% (2)
Jammu and Kashmir	5.6% (1)	72.2% (13)	22.2% (4)	0.0% (0)
Jharkhand	26.2% (76)	56.2% (163)	14.8% (43)	2.8% (8)
Karnataka	29.0% (20)	36.2% (25)	17.4% (12)	17.4% (12)
Kerala	35.0% (57)	39.3% (64)	12.3% (20)	13.5% (22)
Madhya Pradesh	58.7% (121)	28.6% (59)	11.2% (23)	1.5% (3)
Maharashtra	48.9% (637)	36.3% (473)	12.9% (168)	1.8% (24)
Meghalaya	12.0% (6)	60.0% (30)	24.0% (12)	4.0% (2)
Nagaland	25.0% (1)	50.0% (2)	25.0% (1)	0.0% (0)
Odisha	12.8% (6)	68.1% (32)	19.1% (9)	0.0% (0)
Punjab	26.3% (61)	50.4% (117)	19.8% (46)	3.4% (8)
Rajasthan	19.7% (26)	65.2% (86)	12.9% (17)	2.3% (3)
Tamil Nadu	18.9% (115)	48.3% (294)	28.2% (172)	4.6% (28)
Telangana	38.3% (18)	46.8% (22)	10.6% (5)	4.3% (2)
Tripura	25.4% (15)	55.9% (33)	18.6% (11)	0.0% (0)
Uttar Pradesh	26.0% (83)	56.1% (179)	14.4% (46)	3.4% (11)
Uttarakhand	57.9% (11)	26.3% (5)	10.5% (2)	5.3% (1)
West Bengal	34.8% (338)	37.5% (364)	21.4% (208)	6.3% (61)
Total	35.4% (1719)	43.2% (2096)	17.5% (849)	3.9% (191)

Appendix 2: Budget

Budget Per Person Per Month for Inclusive Living Options

Housing with Supportive Services*

Line Item	Annual Costs for supporting 60 Service Users	Cost Per Person Per Month	Description
Food	₹1,800,000	₹2,500	Groceries, Meat, Vegetables, Milk, Eggs, Gas for Cooking, Drinking Water and Other food items
Health	₹432,000	₹1,000	Psychiatric Medication, General Medication, Hospital Visits, Hospitalisation and Routine Tests
Welfare	₹720,000	₹1,000	Clothes, Leisure and Recreation, Personal Grooming Items, Sanitary Items for Self and Household and Other Living Expenses
Allowances and Incentives	₹360,000	₹500	Allowances or Incentives paid for well being and work participation
Work Initiatives	₹108,000	₹150	Supported Employment, Social cooperatives, Small businesses run by service users and so on
Rent for Housing	₹1,728,000	₹2,000	Rented accomodations in rural or urban neighbourhoods
Utilities	₹144,000	₹200	Electricity and Water
Repairs and Maintenance	₹144,000	₹200	Household Repairs and Maintenance
Human Resources	₹3,360,000	₹4,667	For 60 clients 1 Program Coordinator @ INR 25000 per month, 1 Nurse @ INR 15000 per month and 24 Personal Assistants (24 @ INR 10000 per month on an average). Psychiatrists, General Physisicians and Specialists consulted on an oupatient basis at local DMHP or nearest Community Mental Health Programme. Positions may be drawn from people with lived experience.
Capacity Building and Training	₹360,000	₹500	Capacity Building and Ongoing training for Staff
Administration	₹216,000	₹300	Travel, Communication, Printing and Stationery
Household Furnishings	₹720,000	₹1,000	Furnishings and Utensils for Homes, reduces after first year
Total	₹10,092,000	₹14,017	

*based on implementations in Tamil Nadu, Kerala and Assam

Intentional Communities - Congregate/Clustered Group Homes*

Line Item	Annual Costs for supporting 60 Service Users	Cost Per Person Per Month	Description
Food	₹1,800,000	₹2,500	Groceries, Meat, Vegetables, Milk, Eggs, Gas for Cooking, Drinking Water and Other food items
Health	₹1,080,000	₹2,000	Psychiatric Medication, General Medication, Hospital Visits, Hospitalisation and Routine Tests
Welfare	₹720,000	₹1,000	Clothes, Leisure and Recreation, Personal Grooming Items, Sanitary Items for Self and Household and Other Living Expenses
Allowances and Incentives	₹360,000	₹500	Allowances or Incentives paid for well being and work participation
Work Initiatives	₹108,000	₹150	Supported Employment, Social cooperatives, Small businesses run by service users and so on
Utilities	₹360,000	₹500	Electricity and Water
Repairs and Maintenance	₹360,000	₹500	Repairs and Maintenance of Group Homes
Human Resources	₹5,520,000	₹7,667	For 60 clients 1 Program Coordinator @ INR 30000 per month, 1 Case Manager @ INR 20000 per month, 2 Nurses @ INR 15000 per month, 18 Personal Assistants @ INR 10000 per month on an average, 2 Cooks @ INR 15000 per month on an average, 2 Assistant Cooks @ INR 10000 per month, 4 Housekeeping @ INR 10000 per month, 3 Security @ INR 10000 per month, Visiting Consultants (Psychiatrist and General Physician) @ INR 40000 per month; Positions may be filled from participants of the community
Capacity Building and Training	₹360,000	₹500	Capacity Building and Ongoing training for Staff
Administration	₹720,000	₹1000	Travel, Communication, Printing, Stationery, Housekeeping and Sanitation
Asset Maintenance	₹720,000	₹1000	Maintenance of Building and Equipment
Household Furnishings	₹720,000	₹1,000	Furnishings and Utensils for Congregate Homes, reduces after first year
Total	₹12,828,000	₹18,317	

*based on implementations in Tamil Nadu, in addition one time investment in congregate housing units with common community spaces will be required

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