Integrated Community Care for the Needs of Vulnerable People with Severe Mental Disorders

– THE INCENSE PROGRAM –

INCENSE

Grant Completion Report (2011-2015)

The INCENSE program was conducted as a partnership between:

Sangath, Goa

Parivartan, Pune and Satara

Lokopriya Gopinath Bordoloi Regional Institute of Mental Health, Tezpur

Regional Mental Hospital, Yerwada, Pune

Parivartan

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Acknowledgements

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Acknowledgments

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Acknowledgments

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Executive Summary

The INCENSE program was conceived as a systemic response to the challenges involved in addressing the many unmet needs of highly vulnerable people with severe mental disorders (SMDs) like Schizophrenia living within mental hospitals, in their homes and without shelter on the streets.

The aim of the INCENSE program was to build on existing systems of care and gradually develop a systemic framework to support people with SMDs in vulnerable positions in a more humane and effective manner.

This program was to be implemented by developing a multi sectoral network of partners who could, by pooling their resources, collaboratively try and address the unmet clinical, social and humanitarian needs of persons with SMD in an integrated manner.

The Anticipated Outcomes of the Program were:

- The gradual restoration of the health and maximizing wellbeing of individuals with SMDs
- Providing opportunities for inclusion and restoration of their citizenship rights
- The development of enabling care pathways to promote and sustain the above

The INCENSE program has been implemented through a partnership between two non-governmental agencies (NGOs) - Sangath and Parivartan working in tandem with two of India's oldest and largest mental hospitals - the Regional Mental Hospital (RMH) at Pune and the Lokopriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH) at Tezpur. In the first phase of the program, the focus was on constructing the framework and essential structural aspects of a need based, integrated system of care

for specific groups of vulnerable people with SMDs that would facilitate their holistic recovery. In parallel to working with individuals,it was also necessary to address the key systemic gaps in developing such pathways at each of the sites. These included, for example, the lack of exit options from mental hospitals due to the paucity of supported housing facilities, the absence of community based services for continued care, the lack of employment opportunities and the formidable legal and logistic difficulties involved in making appropriate treatment available for homeless persons with SMDs.

Across both sites, the program was developed in a phased manner starting with an in depth situational analysis, the subsequent implementation of the various components of the intervention and the phase of the evaluation of the individual and systemic outcomes.

The overall goals were firstly, to understand whether it would be feasible to develop a collaborative, multi sectoral network and connect the various components of the intervention within it; secondly, whether such an arrangement would be acceptable to the key stakeholders; and thirdly what effect the intervention would have on the outcomes of individuals receiving the intervention.

While a similar approach was tried at both Pune and at Tezpur, the program evolved in somewhat different trajectories. This divergence was very much influenced by the situation of the two hospitals and the local social, economic and health system differences at the sites.

In broad terms, the bulk of the work at Pune was within the hospital system while at Tezpur, the majority of work was located in the community surrounding the hospital. The important commonality has been their continued engagement as key partners and their engagement with a broad spectrum of agencies.

Executive Summary

The INCENSE program has worked with a large number of vulnerable persons with SMDs to promote their inclusion and recovery, with the two hospitals to develop integrated care pathways, with community based organizations for providing access to a range of supported housing options, with institutions for technical expertise and with many other agencies and individuals in the local communities for enabling real life work options, social inclusion and citizenship.

PUNE

At Pune, there has been progress made in developing care pathways across the hospital and community for some long stay and homeless persons, in developing and operationalizing a Supported Community Home, in developing work options within the hospital, in restoring basic citizenship entitlements, in placing people with SMDs in individual jobs and in developing a dedicated recovery oriented ward and transit facility.

TEZPUR

At Tezpur, in addition to the work with long stay and homeless persons, there is a robust catchment area based service arrangement through the partnership with the LGBRIMH and the community based program delivered by the INCENSE program staff. There is also a vibrant network of local and regional partners who are aligned to the program. This collective initiative has enabled people with SMDs access employment opportunities of various kinds, allowed innovations in relation to financial planning and inclusion, enabled participation of patients and family caregivers and has generated a supportive social milieu for change.

Overall, it has been feasible to develop productive and acceptable partnerships to address the multidimensional needs of persons with SMDs

and that, for many individuals and their families, it has had a positive impact. On the other hand many of the complex systemic challenges like addressing the heterogeneous care needs of the large pool of long stay persons at the RMH, making entry and exit from hospitals and relocation back to homes easier for homeless persons with SMDs, developing financially sustainable housing and collective work options and continued community care provision will require additional work.

FUTURE FOCUS

Over the next 12 months, the focus of the INCENSE program will be on consolidating and strengthening of the care pathways developed thus far, in expanding certain components like community based care at both sites and in addressing the persisting challenges described earlier in a systematic manner. By now, a sound collaborative platform has been constructed on which additional, in depth initiatives can be layered realistically.

We look to the future optimistically in working towards the ultimate goal of developing a systematic and evidence based blueprint of action for responding to the health and humanitarian needs of highly vulnerable persons with SMDs that can be used and adapted in other settings.

Introduction to Project

Across the world, people with SMDs like schizophrenia and their families have difficulty in accessing appropriate, effective and affordable health services and social supports. In countries like India where access to mental health services are limited, these gaps between need and availability of services contribute to their experiencing high levels of disability, premature mortality and social exclusion that, in some cases, can lead to the denial of fundamental citizenship rights.

For many people with SMDs, this lack of appropriate and accessible health services and social supports condemns them to lives of silent despair, impoverishment and injustice. While people with SMDs who are homeless are the most visible face of this abandonment, there are equally many others in similar situations of extreme disempowerment, though out of sight within institutions and in their homes.

The INCENSE program was developed as a response to the unmet needs of highly vulnerable people with SMDs living within mental hospitals for long periods of time, at homes and on the streets. The aim was to develop an evidence based and systemic operational framework, by strengthening and addressing gaps in existing systems of care, that would support these vulnerable people better than current care arrangements.

Since the intent was to build on existing care systems and to work with highly vulnerable groups who were either living within mental hospitals or potentially needed access to care in these hospitals, the INCENSE program was implemented through a collaborative partnership between two mental hospitals and two non-governmental organizations (NGOs) at Pune and Tezpur.

At Pune, Parivaratan was the primary NGO partner linked with the Regional

Introduction to Project

Mental Hospital (RMH), while at Tezpur,Sangath was in a partnership with the Lokopriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH). Such an arrangement was felt to be the most pragmatic start up mechanism that would allow for the gradual development of the larger network.

The INCENSE program has been operational since March, 2011; during this time the focus has been on constructing the range of services and integrated recovery oriented pathways of care for long stay persons in hospitals, homeless persons with SMDs and people residing in their homes. This necessarily involved working with the RMH and LGBRIMH very closely as well as reaching out to a broad based alliance of partners locally, regionally and nationally.

The summary report provides a brief description of the evolution of the INCENSE program, the current situation and a brief outline of the immediate future plans. To help bring together the many parallel strands of the program, the report describes the principal thematic areas of work, their outcomes and the implications of the outcomes.

Chapter 1

Project Settings

Tezpur is a small town situated on the banks of the Brahmaputra in the river Sonitpur district of the Indian state of Assam, with a

rich historical and cultural legacy and is a centre for regional economic activity. The multiethnic town also has a large presence of the defense forces and merges into the predominantly rural setting surrounding it with mixed urban and rural habitats, economy (agriculture and trading) and a social milieu in rapid transition.

Established in 1873, the LGBRIMH at Tezpur is one of the oldest examples of mental asylums set up in India. This hospital has an interesting history and has made considerable progress in institutionalizing reforms related to clinical and administrative processes.

LGBRIMH is one of the three institutions in the country that are funded directly by the Government of India and is a designated centre of excellence with post graduate academic teaching courses in psychiatry, psychiatric social work, psychiatric nursing and clinical psychology. It is the only such tertiary care institution in the North Eastern region of India and provides a range of multi-disciplinary adult services to thousands of service users coming from a large catchment area and from diverse cultural backgrounds.

Chapter 1

Project Settings

At the time of the initiation of the INCENSE program, the Institute had 37 long stay persons living in well staffed and idyllic segregated wards with access to work and some recreation.

Rehabilitation Centre at Tezpur's LGBRIMH.

Pune, In contrast to Tezpur, is a large urban metro, in the state of Maharashtra, with a substantial manufacturing, trading and more recently, service based (IT, hospitality, etc.) economy and is a hub for educational institutions.

Project Settings

The RMH located at Yerwada in Pune, is also another historical milestone in the spread of mental hospitals in India and was established in the current grounds in 1915. This is one of the largest in the country spread over area of 133 acres with current bed occupancy of around 1800 persons.

The RMH is a tertiary care service delivery institution that is managed by the Ministry of Health and Family Welfare of the State Government of Maharashtra and does not have any current teaching or training functions associated with it.

Though some new facilities have been built in the campus over the last decade, the hospital continues to struggle with the very large number of long stay persons, the continued shadow of custodial care practices and systemic inertia for change. In this situation, for the RMH, the most pressing perceived need was to respond to the issue of a very large number of long stay persons living on wards across the hospital.

Front entrance to the Regional Mental Hospital in Pune.

Project Settings

Mental hospitals are a highly heterogeneous group of institutions each with their unique history, trajectory of evolution, resources and institutional cultures.

Therefore, attempts to develop a collaborative partnership between the hospitals and external agencies need to be mindful of their historical and cultural legacy, care practices, their particular social, economic and administrative circumstances, the people in positions of power and the larger social milieu.

To acknowledge and account for the inherent confounding effects of the site, a deliberate choice was made to engage with two different mental hospitals located in different social contexts. While the choice of the two sites was based on convenience and potential feasibility, the main intention was to understand the 'effect modifier' impact of the sites while attempting a similar intervention across them.

As we shall encounter in the rest of the report, the evolution of the INCENSE program was quite different across the two sites and was highly influenced by the situation and needs of the hospital and the local community.

Chapter 2

Situation Analysis

A systematic analysis was conducted across the two sites at the start of the program cycle to provide comprehensive information about the baseline status of vulnerable individuals and the existing care systems at both sites.

For individuals who were either staying for more than 12 months in the hospitals, those on the streets and for those living in their homes, the objectives were to detail their socio demographic and clinical profile, baseline levels of functioning, the profile of their perceived needs and, for long stay persons, their readiness to move into supported community housing.

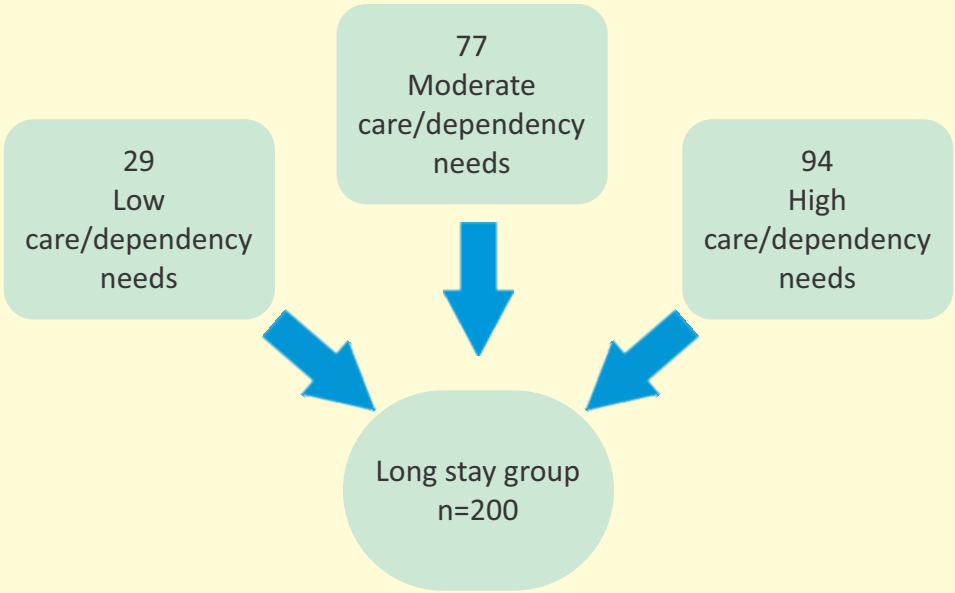
The systemic objective of the situation analysis was to understand the existing services for these groups and to identify the key challenges, including exit and entry barriers, for the development of integrated care pathways at each site.

2.1:Findings of the Situation Analysis

A total of 468 persons with SMD were engaged with in the situation analysis exercise across the sites; 237 of them were long stay residents of the two hospitals; 188 were living with their families and 43 were homeless.

2.1.1: The majority of the 237 long stay persons had a primary ICD-10 diagnosis of schizophrenia, a long duration of illness (median duration of 18 years) and had spent almost 12 years at Pune and more than 18 years at Tezpur in the hospital. This group of people had high levels of disability across multiple domains of personal, social and occupational functioning, more so in Pune than at Tezpur. Around half of the long stay persons at Pune were also rated by the nursing staff as having high care or dependency needs making it very unlikely that these could be met in low-moderately staffed community housing facilities.

Figure 1: Profile of care/dependency needs of long stay persons at the RMH, Pune



Across both sites, the lack of any meaningful activity was a highly prevalent unmet need. Social needs were completely unmet across the sites as was the complete absence of any proof of citizenship.

There were no worthwhile opportunities for any paid employment, hobby or recreational activities nor were there any efforts to address independent living skills like self-care. Discrimination from others was highly prevalent as was low self-esteem and shame in relation to negative discrimination.

Table 1: Needs of long stay persons across sites:

Domain	Pune (n=200)			Tezpur (n=37)		
	Unmet	Partially met	Met	Unmet	Partially met	Met
Symptom Management: Positive Symptoms	71 (35.5%)	25 (9%)	114 (57%)	3 (8.2%)	1 (2.7%)	33 (89.1%)
Engagement in any Meaningful activity	137 (69.5%)	62 (31%)	1 (.5%)	25 (67.6%)	6 (16.2%)	6 (16.2%)
Social Citizenship proof	198 (99%)	2 (1%)		37 (100%)		
Access to disability benefits	199 (99.5%)	1 (.5%)		37 (100%)		
Paid employment	199 (99.5%)	1 (.5%)		35 (94.5%)	2 (5.5%)	
Social Functioning	147 (73.5%)	50 (25%)	3 (1.5%)	32 (86.5%)	4 (10.8%)	1 (2.7%)
Friends	199 (99.5%)	1 (.5%)		36 (97.3%)		1 (2.7%)
Family						
Hobbies	176 (88%)	24 (12%)		36 (97.3%)		1 (2.7%)
Self Care Hygiene	25 (62.5%)	66 (33%)	9 (4.5%)	13 (35.1%)	15 (40.5%)	9 (24.3%)
Money Management	192 (96%)	6 (3%)	2 (1%)	35 (94.6%)		2 (5.4%)
Use of Transportation	199 (99.5%)	1 (.5%)		36 (97.3%)		1 (2.7%)
Personal Safety	133 (66.5%)	61 (30.5%)	6 (3%)	11 (29.7%)	11 (29.7%)	15 (40.6%)
Physical Health	116 (58%)		79 (39.5%)	14 (37.8%)		23 (62.2%)
Stopping tobacco						
Stigma	188 (94%)	12 (6%)		36 (97.3%)	1 (2.7%)	
Discrimination from others	186 (93%)	6 (3%)	8 (4%)	34 (91.9%)	1 (2.7%)	2 (5.4%)
Low Self Esteem/Shame						

2.1.2 Hospital care systems for the long stay patients

The two hospitals provided a contrast in relation to their care systems for long stay persons. While at Tezpur, the small number of long stay persons were living in small, well staffed, segregated wards in an idyllic setting and receiving multi-disciplinary care, the situation at RMH was quite different.

This was reflected in the much higher proportion of long stay persons currently resident in the hospital and a formidable set of challenges in relation to the physical infrastructure, the lack of individualized treatment provision, the continued legacy of custodial care, the difficulties in accessing general medical care and the absence of rehabilitation and discharge planning within the provisions of the Mental health Act of 1987.This difference reflected in the different outcomes seen for the long stay patients at these sites.

2.1.3 As can be imagined, homeless persons with SMDs from both sites were in a highly precarious situation with obvious unmet basic needs related to safety, shelter and treatment.

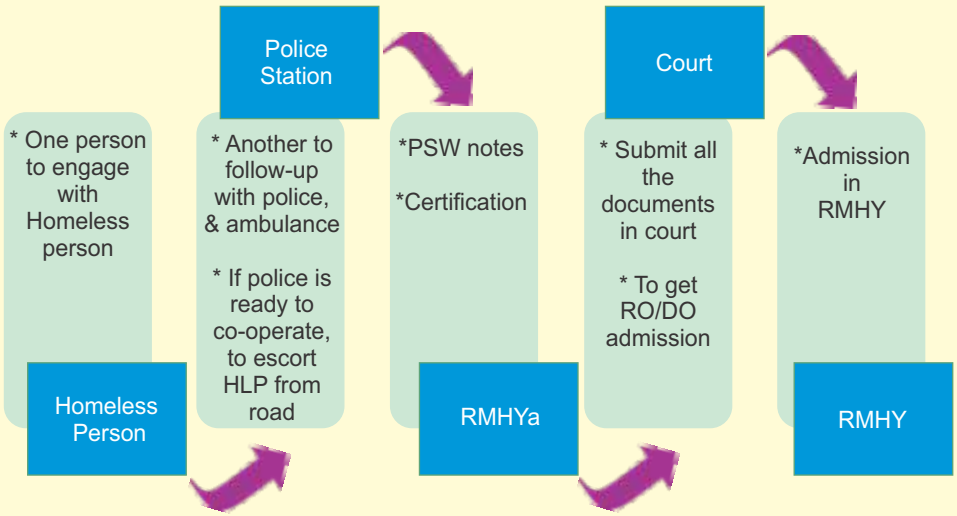
Table 2: Profile of persons with SMD on the streets at Pune and Tezpur.

Variable	Pune (n=24)	Tezpur (n=19)
Age in years (median with SD)	38 (11.3)	36 (9.1)
Sex (n and %)		
Male	6 (25%)	16 (84.2%)
Female	18 (75%)	3 (15.8%)
Have family in local area (n and %)?		
No	8 (33%)	10 (52.6%)
Yes	11 (45.8%)	9 (47.3%)
Don't know	5 (20.8%)	0 (0%)
Sleeping place:		
Home	0 (0%)	5 (26.3%)
Footpath/outside a shop/Bus stop	8 (33.3%)	10 (52.6%)
Shelter Home/Hospital		0 (0%)
Don't Know	16 (66.6%)	4 (21.1%)
Who provides food?		
Family	0	5 (26.3%)
Community (shopkeepers, hotel owners, temple, passer-by)	8 (33.3%)	11 (57.9%)
Shelter home/Hospital	16 (66.6%)	0 (0%)
Don't know	0	4 (21.1%)
Key Informant:		
Family		3 (15.8%)
Community Social Workers	0	8 (42.1%)
Staff at Shelter homes/hospital	16 (66.6%)	0
Community(shopkeepers /passersby/neighbours)	8 (33.3%)	8 (42.1%)
Physical Appearance:		
Poor/hygiene not maintained	7 (29.1%)	14 (73.6%)
Reasonable/Hygiene maintained	17 (70.9%)	5 (26.3%)
Any Immediate danger to self or others:		
No	19 (79.1%)	12 (63.2%)
Alcoholism/Substance Abuse	9 (37.5%)	4 (21.1%)
Violence/self harm	3 (12.5%)	3 (15.7%)
Any Physical health problem that requires immediate attention		
No	24 (100%)	14 (73.6%)
Yes	0	1 (5.2%)
Don't Know	0	6 (31.6%)

2.1.4 Systemic challenges for homeless persons with SMD

For homeless persons with SMDs, the systemic challenges were in relation to both their entry and exit from the hospitals. The most important entry barriers for homeless persons with SMD requiring acute hospital care were the procedural problems like the reluctance of police to get involved in the rescue of homeless mentally ill persons from the streets and the logistical difficulties in obtaining reception order for treatment by the court.

Figure 2: The process of admission of homeless persons to the RMH, Pune



HL/ HLP = Homeless Person; **PSW** = Psychiatric Social Worker; **RO** = Retention Order; **DO** = Detention Order; **RMHY** = Regional Mental Hospital, Yerwada

In addition, in the absence of clear exit options, homeless persons admitted to the hospitals for the treatment of acute problems were at high risk of becoming long stay patients of the hospital, especially at the RMH.

2.1.5: In comparison to homeless and long stay persons, people with SMDs living with their families had lower levels of disabilities and better functional levels. The most important unmet needs included difficulties in symptom control, erratic access to treatments, lack of meaningful activities to engage in, lack of paid employment, social difficulties like lack of access to disability benefits, poor social networks including the lack of friends and sometimes poor family support, the inability to use public transport or

money and importantly, the pervasive problems related to stigma, negative discrimination and poor self-esteem and shame.

2.1.6 Systemic problems for patients in the community with SMD

At Tezpur, the most prominent barriers for persons with SMD who were residing in the community in accessing care from the LGBRIMH were the high level of stigma attached to the hospital in the local community and the difficulty in accessing the hospital due to the lack of affordable and convenient public transport.

Finally, both hospitals existed in relative isolation, had no community based services to follow up with patients discharged from the hospital and had few links with partners in the local community who could be of benefit in addressing the many unmet needs and systemic barriers to the provision of integrated community based care.

2.2: Implications for the program

The main findings of the situation analysis highlighted the many unmet needs and the extremely serious disabilities and social disadvantages faced by vulnerable groups of people with SMDs.

In addition, the results clearly indicate that there are many systemic gaps and problems in the operation of the current care systems that hinder their recovery. These include the lack of suitable exit options for people with long duration of stay within hospitals who did not require ongoing inpatient care, the difficulties involved in accessing treatment for homeless persons with SMDs, the lack of social and vocational opportunities, pervasive discrimination and the absence of community based care to ensure continuity of services.

The findings also highlighted the complexity of the task involved in meeting the needs of such disadvantaged groups and in the creation of integrated care pathways within the specific context of the hospital and site. The ways in which these individual and systemic challenges were addressed is detailed in the next section of the report.

Chapter 3

Interventions with groups of Vulnerable persons

3.1 Goals of the INCENSE intervention

3.1.1 Long stay persons with SMD in hospital

For the existing pool of people with a primary diagnosis of SMD who had been staying in the hospitals for more than 12 months, the intent was provide an additional (to ongoing care in the hospitals) structured psychosocial intervention to improve their individual functioning and to construct a pathway for their exit to supported community living and work options.

3.1.2 Homeless persons with SMD

For homeless persons with an ongoing SMD, the intent was to develop a pathway for their identification, engagement, acute treatment in the hospitals and then relocation back to their families or to intermediate supported housing facilities in a structured and systematic manner. Linking all these aspects together into an integrated care pathway was to be the primary role of the INCENSE teams at each site.

3.1.3 Persons with SMD in the community

To address the unmet needs of persons with SMD living in their homes, a flexible, need based, multi component community intervention was to be provided in a defined catchment area at Tezpur and Pune by the program team working in collaboration with the LGBRIMH and the RMH and a number of local partners. In such communities, for persons with SMD who were experiencing frequent readmissions or were attending the out patient services with continued unmet needs, the intent was to provide integrated community based care to improve their overall functioning and reduce their repeated episodes of admission.

3.1.4 The INCENSE intervention

Across these groups, the INCENSE intervention consisted of three main domains:

1. Integrated clinical and social care for individuals and families
2. Access to livelihoods and
3. Multi-sectoral collaborations for addressing their social and citizenship needs.

Figure 3: The INCENSE program intervention domains

3.2. Addressing the problems of long stay persons in mental hospitals

In light of the situation at the RMH at Pune and at the LGBRIMH at Tezpur, a substantial effort was made to address both the individual unmet needs of patients with SMD and the systemic challenges in developing recovery oriented care pathways for long stay persons – defined as those having more than 12 months uninterrupted stay in the hospitals.

Since the milieu, number and care practices involving long stay persons varied between the hospitals, we will consider them separately in the sections below.

3.2.1: Intervention description at Pune

At the RMH, the first problem was the lack of a reliable census of the actual numbers of such long stay persons within the hospital. As an initial step, the program staff undertook a detailed cross sectional census of the files of inpatients to arrive at this number.

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669 such persons with SMD were identified from the total 1700 files scanned (39.3%) as having stayed in hospital for more than 12 continuous months. A purposive sample of 200 (30% of long stay patients identified) persons with a primary diagnosis of psychosis were identified and ultimately engaged as explained in **APPENDIX 1**

This group was then provided with a structured, need based psychosocial interventions (individually and in groups) to augment usually available care. The intervention package was designed to promote their health and well being, provide access to work, livelihood promoting opportunities,

A person with SMD watering an in-house vegetable garden at the RMH, Pune.

recreational opportunities and address unmet instrumental aspects of citizenship (like identity proof, equitable payment for work, access to and inclusion in the financial sector).

Persons with SMD picking up job skills of a tradeat the hospital.

Persons with SMD in an auditorium at the institution watching a film.

In parallel to the individual interventions, a concerted effort was made to address some of the key systemic barriers towards developing recovery oriented care pathways that would enable improved individual outcomes within the hospitals and also enable the gradual relocation of some long stay persons within RMH into supported community facilities with ongoing, needs based clinical and social support services in a phased and systematic manner.

3.2.2: Intervention delivery at Pune

The individual and group based psychosocial interventions focused on improving personal care, improving social skills and interactions, access to

recreational and work options. This was provided by trained and supervised recovery support workers (RSWs) within the existing wards facilities. While the RSWs took the lead in providing the intervention, all possible efforts were made to engage the ward and support staff in these activities as well as work closely within the social work department and the occupational therapy unit.

3.2.3: Summary findings and their implications at Pune

The difficulties involved in meeting the needs of the existing long stay persons within RMH proved to be a formidable challenge. At the time of entry in the program, most long stay persons had already been in the hospital for many years with an incremental increase of unmet needs, institutionalisation (loss of purpose, self esteem and agency), persistent impairments (like negative symptoms, cognitive impairments) and serious disabilities across multiple domains. In effect, they represented one of the most challenging clinical populations to work with high dependency or care needs.

The overall impact of the intervention, (as measured by the routine outcome measures) was quite modest across various domains of unmet needs, disabilities and functioning and only a small proportion of long stay persons experienced significant benefits. The most plausible reason for this might be that the systemic environment in which the intervention was located did not change. In other words, unless simultaneous measures are taken to refashion the environment (living conditions, basic infrastructure like sanitation and cleanliness), reconfigure the wards (segregated and smaller**)** and introduce contemporary care planning (to make it individualized, need based, multidisciplinary and geared towards planned discharge in a timely manner), the impact of additional psychosocial interventions will be dampened in the systemic noise.

One of the other key systemic objectives was to create a pathway for some long stay persons to relocate outside of the hospital and into supported housing facilities in the community. However, the number of people who actually did so was small. This statement must also be qualified by the fact

that the community housing support available in the program was only for women, minimally staffed and could, therefore, only accommodate those who were both capable and determined. It is possible that more long stay persons can be relocated in community housing facilities that have greater specialist staffing; however, in the short term, this option will continue to be difficult to access readily.

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Some of the long stay women who had made the transition to supported housing facilities opted to come back to the hospital as they found dealing with the demands of life difficult. One possible reason for the low rate of successful relocation was the absence of a transit facility where dedicated efforts could be made to gradually prepare selected long stay persons for future community living and for real life work.

Given this situation, it is clear that for the majority of the current long stay persons, exiting from the hospital is not an easy option, at least in the short term. However, the humane and ethical imperative to improve their situation while continuing to be in the hospital is also urgent. Thus, for the RMH and other hospitals with a large pool of long stay persons, there is an urgent need to find innovative ways of meeting these twin challenges- creating integrated pathways for some of the current long stay persons to relocate in the community while also developing living environments and care practices for those with greater care needs that cannot be realistically met in community settings.

In the short term, while well staffed and resourced community housing options in the community are unlikely, creating similar facilities within and with the active collaboration and ownership of the RMH staff, is the best way forward. This model has been actioned through the purpose built and staffed long stay and transit care facility within RMH called “Devrai Ward”.

3.2.4 The Devrai'' (sacred grove) facility at Pune

To address this gap in the care of long stay persons, a pilot initiative of creating such a recovery oriented ward and a transit facility within the hospital was jointly planned and implemented by the RMH and Parivartan.

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Through almost 12 months of negotiations and preparation, two structurally sound but abandoned buildings within the hospital were identified and refurbished to create these facilities.

The recovery oriented ward was to house a total of 40 long stay persons with dedicated hospital staff, collective work options, recreation and leisure options, ongoing, needs based psychosocial interventions woven within an overall therapeutic community orientation.

The recovery oriented ward and a transit facility within the RMH, Pune.

The transit facility is smaller (two-three bedded), independent and is envisaged to house those who are in a position to make the transition to the available supported community housing facility. As part of this process, employment in individual jobs can be realistically provided for some persons locally, while they reside in the transit facility. Finally, to enhance the therapeutic quality of the environment, the open spaces around these facilities have also been reclaimed and spruced up and made friendly for gardening and horticulture activities.

This arrangement and facilities ('Devrai'- sacred grove) will provide some answer to the question of whether such dedicated facilities are more effective than usual care practices in improving the quality of life of long stay persons. If this is so, it might provide an evidence based template for

hospitals to consider in the future, especially since fairly similar approaches have been shown to have worked in other LMIC hospitals as well.

The environmental ambience surrounding the 'Devraj' Facility in the RMH.

'Devrai' is also an example of the hospital, the government, an NGO, a committed funding agency and a range of individuals and agencies collaboratively responding to the needs of long stay persons. It demonstrates the value of multi sectoral collaborations as a method for innovative solutions to complex problems within these hospitals.

Finally, it seems obvious that prevention is the best systemic response is the prevention of new long stay for persons accessing the hospital as the continued influx of new long stay persons to the already large existing pool overwhelms the hospital system. This is also something about which progress can be made fairly quickly by initiating a number of key steps- strict compliance with the provisions of the MHA, 1987, having an IT system that supports this process by tracking the progress of the person with SMD and most importantly, by initiating individual and multi-disciplinary care planning, regular reviews and discharge procedures in consultation with the family, provision of continued treatment in the community and linkages with supporting agencies to address unmet social needs. This process has also been conducted by a number of hospitals

(including LGBRIMH) fairly effectively from which a ready template of actions is available.

3.2.5: The intervention with long stay persons at LGBRIMH

The work with long stay persons at Tezpur was qualitatively different in many ways. Firstly, by the time the program was initiated, there were only 37 long stay persons who were housed in dedicated and adequately staffed male and female wards in an idyllic environment. In this context, the additional intervention provided by the INCENSE team had a synergistic effect and was well accepted by the long stay persons, staff and the hospital system. The intervention could meet additional medical needs (like corrective devices for vision, hearing, dentures, etc.) and was able to create additional avenues for engagement, recreation, work opportunities inside and outside of the hospital and, in one instance, enabled the relocation back with their family.

Towards the middle of 2014, all the remaining 36 long stay persons at the LGBRIMH were shifted to long term residential facilities operated by non-government agencies (one for men and the other for women) as per the directives of the High Court of the state of Assam acting on a public interest litigation. While well intentioned, this development raises the question of choice and autonomy of long stay persons in determining their location of stay and about the adequacy of the care provided in these facilities where staffing is both much less intensive and not of comparable quality and oversight.

Residential facilities in the community with varying degrees of support are a necessary component of the service mix for some persons with SMDs within and outside of hospitals. While there are a few such existing facilities in the for-profit and not-for-profit sector, the gaps in the provision of supported housing in India, especially for the most socially disadvantaged populations like long stay persons, are huge. This gap has been identified in the current Mental Health Policy of the Government of India and there are recommendations to have such long stay facilities

operational in the districts. This represents a potential opportunity for hospitals like the RMH to develop adequate quality and in line with best practices.

Through the experiences of working with long stay persons within and outside of the hospital, the program can contribute to building the capacity of organizations and care providers to provide recovery oriented care to manage the needs of long stay persons in community facilities across their lifespan and in implementing standards of care that are compliant with the provisions of the new Mental Health Care Bill.

3.3 Community based care at Tezpur and Pune

As described earlier, one of the key objectives of the INCENSE program was the development of integrated services across the hospitals and community for vulnerable persons with SMDs. As an essential part of this integrated pathway, community based services were developed at both Pune and Tezpur to support homeless persons with SMDs and to provide ongoing support for long stay persons relocated to supported housing facilities.

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At Pune, community services were provided for a **selection of persons with SMDs**, those who were experiencing frequent re-admissions, as well as for some selected persons with SMDs who were attending the outpatient department at RMH.

At Tezpur, it was also possible to implement a collaborative community based intervention (with the LGBRIMH providing clinical, social and rehabilitation support and the INCENSE program providing the community staff) in a defined catchment area.

This intervention was designed to reach out to those persons with SMDs who, in spite of having a tertiary care facility close by, were not able to/did not have appropriate access to services.

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Other than service provision, community based services also represent an important opportunity for mental hospitals to address the issue of isolation from their local social milieu. Community services are a potential conduit for promoting dialogue and partnerships between the hospitals and outside agencies across various sectors.

Thus, community services represent an opportunity for new and innovative ideas to permeate within the hospitals in dealing with traditionally difficult problems. In the section below, we briefly describe the community intervention and the outcomes across the two sites and the implications it has for the future of the program.

3.3.1: The community intervention at Tezpur

The community based care intervention was implemented in the entire town of Tezpur (consisting of 19 smaller municipal units) and in six surrounding 'Gram Panchayats' for a total population of approximately 120,000 people (as per the latest, 2011 population census figures).

The first step involved was the agreement with the LGBRIMH about the methodology of developing a catchment area based community service and the clarification of the roles and responsibilities of the Institute and the INCENSE program.

In the second step, persons with SMDs in the catchment area were

identified through a three stage procedure- a key informant based survey, face to face screening by lay trained recovery support workers (RSWs) using a standardized tool and a diagnostic assessment by psychiatrists. A proportion of those who were diagnosed as having an SMD (most commonly, schizophrenia) consented to inclusion in the program; a total of 170 persons with SMDs and their families were enrolled in the program after obtaining their informed consent.

In the third step, a systematic attempt was made to understand their current overall situation across various domains : their socio - demographic status, overall functioning, needs and disability. This information laid the foundation for developing collaborative individual care plans and for the subsequent matched (to needs and priorities of persons with SMD and their families) intervention inputs. The community based intervention, delivered by trained and supervised RSWs, was largely in concordance with the best available evidence together with regular medical reviews and access to the multi-disciplinary services available at LGBRIMH.

Skill building session for persons with SMD at Tezpur site

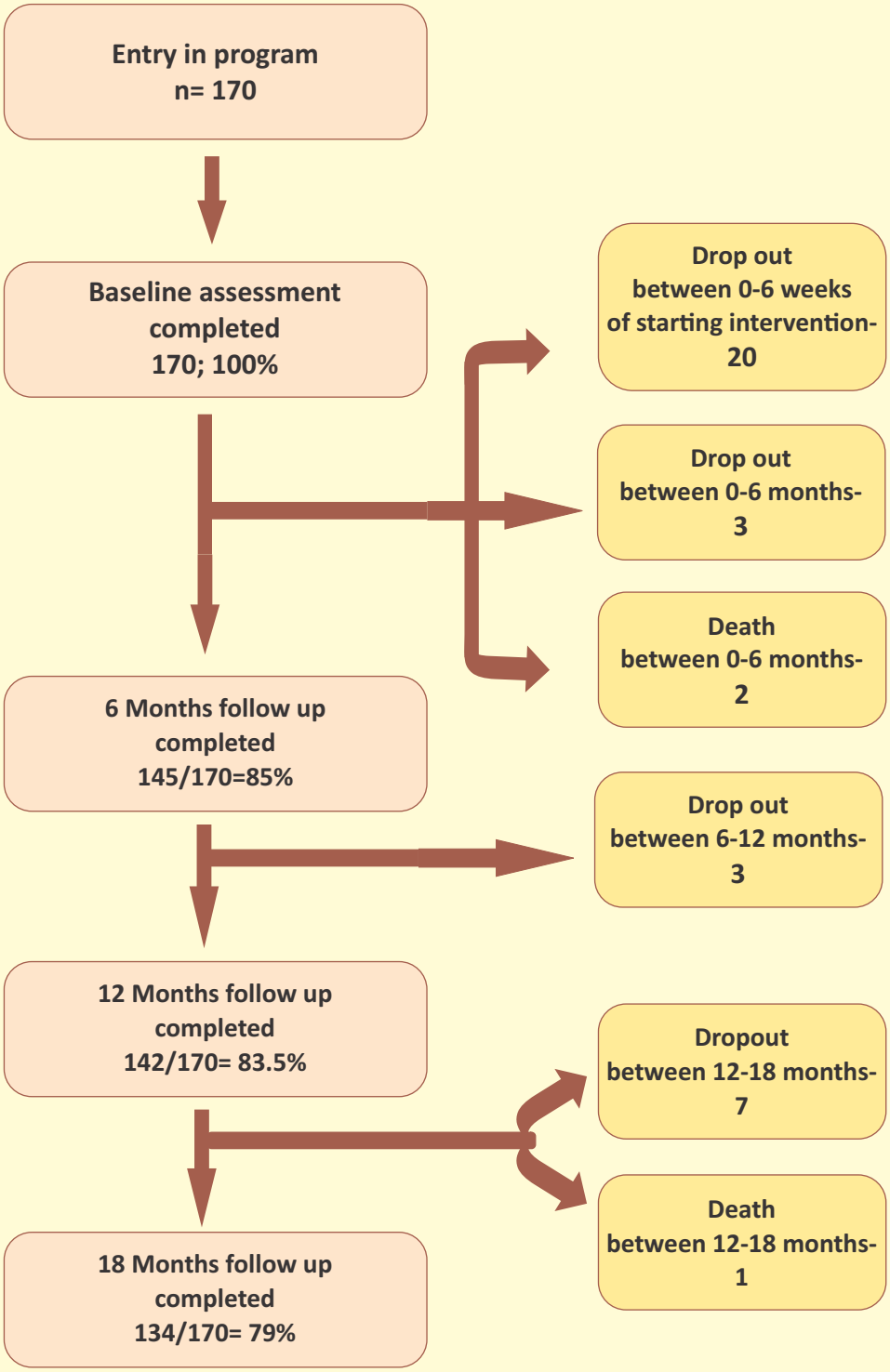
In addition, over the last 18 months of the intervention there has been a sustained attempt to respond to the unmet needs identified as being most problematic (like access to employment, financial difficulties, social exclusion) by persons with SMDs and their family members.

Through this process, the intervention package has been augmented by additional focus on access to employment options, engagement and networking with community agencies as well as financial inclusion, financial planning and investment strategies.

Outcomes of community intervention at Tezpur: The collaborative community based intervention at Tezpur has been able to improve access to integrated care for people with SMDs in the catchment area (thereby reduce the treatment gap) and has been acceptable to persons with SMDs and their caregivers (see Figure 3 below).

The intervention has improved individual outcomes (as measured by routine outcome measures), improved access to meaningful employment, helped persons with SMDs and their families access services more appropriately, and very importantly, has succeeded in developing a broad alliance comprising the Institute, the INCENSE program staff and a range of local and regional partners and individuals. The LGBRIMH today is much more connected to the local community and is open to a range of collaborations with credible partners.

Figure 3: Intervention flow chart of the community cohort at Tezpur



Another important outcome of the community intervention has been the inclusion of peers and caregivers within the program team and the initial success with efforts at getting people with SMDs and their caregivers collaborate on developing collective employment options.

***Rupali Sharma** is recovering from her illness and is part of the INCENSE team as a peer support person. She brings great empathy and energy in her work and has been instrumental in coordinating various home based and collective work options with great distinction.*

A recent focus of the program has been on engaging with the local community more directly through interactions with the local government and health departments and a range of interested local community members.

The initial results of this process has been encouraging with the development of local community volunteers who are engaging with people with SMDs in their neighborhood, encouraging them to seek appropriate services at LGBRIMH and supporting them in continuing their treatments (through a process of befriending) while consulting with the INCENSE team.

Finally, as described earlier, the community intervention has been available to homeless persons with SMD in the catchment and also for long stay persons; this included engaging with the family and providing ongoing care for the one long stay person who is now living with their family.

3.3.2: The community intervention at Pune

The community based services at Pune were developed initially to support homeless and long stay persons with SMD in their care pathway, including in supported community facilities. Since the high vulnerability and needs profile in these two groups are very different from that of a domiciliary cohort, the community based intervention had to suitably modified. For example, at every key point in the care pathway of homeless persons (identification, engagement, care planning, facilitating admission to the hospital, planning for discharge through relocation to family or to supported community housing), there were a variety of unique individual and systemic challenges that needed a suitable response.

Thus the community intervention had to respond to the unique needs of homeless persons with SMDs- safety, shelter, food and treatment as well as become acquainted with the process of relocating persons who had recovered, back with their families.

Finally, for those who were not in a position to go back home, the community services continued to provide individual support for promoting independence, access to employment and well informed management of their illness in the supported housing facilities. Over time, through implementing the intervention, there is now greater clarity on the nature of community based services that are required for making integrated care systems possible through mental hospitals for long stay and homeless persons with SMDs.

In addition, sustained efforts were made to identify and provide need based community services (as described above) for people with SMD experiencing frequent readmissions and for those accessing the OPD (outpatient department) at the RMH. The assumption was that provision of integrated care would reduce the need for further hospital admissions and also effectively respond to the unmet psychosocial needs of persons attending the OPD (like employment).

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However, while there were benefits for individual persons through these initiatives, there was little systemic uptake of the community based intervention. These modest outcomes are, by themselves, a reminder of the potent effect modifier impact of the systemic context of the hospital on the trajectory of development of integrated care systems. For both the readmission and the OPD groups involved, a number of systemic changes are necessary for the integrated intervention to work, unlike the situation at Tezpur where community services blended easily with the current system.

For example, with people who were experiencing frequent readmissions, there had to be a reliable system for their identification, for developing collaborative individual care plans to look at the reasons for readmissions, working with families and careful discharge planning with continued access to community based care.

Similarly, for the OPD based intervention to work, it needed a similar system of identification of persons with SMD who had unmet psychosocial needs, their referral to the INCENSE team and the delivery of a matched collaborative intervention that had the active involvement of the treating team at the hospital.

In spite of the lack of success in setting up viable community services, there were a number of people who did benefit from the community based intervention (that included facilitating access to employment opportunities) in a manner similar to that in Tezpur.

While we intend to continue making efforts for encouraging the hospital to adopt such integrated service provisions, there is also a need to unfasten a potentially effective intervention from the process of change in the hospital and test it out in other circumstances. While in an urban centre like Pune, access to medical treatment is relatively simpler, there is no corresponding agency for providing additional psychosocial care through community based services.

In the next few months, we intend to explore the feasibility of providing community services in urban settings through two main approaches- developing a catchment area based service in partnership with RMH and other tertiary care hospitals in the city (similar to the Tezpur team's efforts) and by creating mechanisms for families to approach the INCENSE team for such services directly (self-referral or referral from the treating psychiatrist).

3.4 Responding to the needs of homeless persons with SMDs

Responding to the situation of extreme abandonment that homeless persons with SMDs experience was an ethical imperative for the INCENSE program across both sites. It was also clear from the beginning that the task was formidable not least because there was little prior experience within the team around this domain of work.

In the last three years or so, through a process of learning by doing, the program team has made some headway in understanding the systemic challenges involved in responding to the needs of such individuals with varying degrees of success. As was the case with long stay persons, the site greatly influenced the nature of the care pathway and the overall outcomes of the INCENSE program work with homeless persons.

3.4.1. Intervention development and description at Pune

At Pune, the situation analysis clearly revealed that homeless persons with concurrent SMDs were faced with formidable entry and exit barriers in relation to RMH. Homeless persons with SMDs were faced with twin challenges – firstly, it was extremely hard for them to access required treatment due to a variety of systemic barriers involving their rescue and admission to RMH.

Secondly, it was often difficult for them to exit the hospital, especially when the family could not be contacted or did not come to take the person home. Homeless people who came into the hospital were thus, much more prone to experience long term institutionalisation.

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In this context, the program at Pune worked with a small cohort of homeless women who were currently experiencing one or the other (sometimes both) of these twin barriers. Thus, the cohort of women under the 'homeless' rubric were drawn from two ends :

A) those who were currently homeless and on the streets and
B) those who were homeless in the past but were currently admitted (and thus technically not homeless) in institutional facilities.

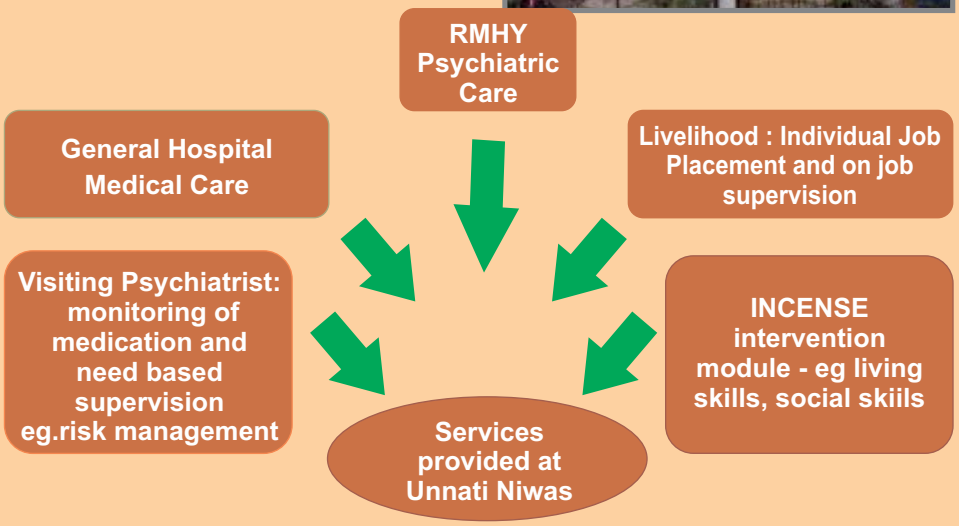
As an initial step towards creating an exit pathway for such institutional 'homeless' mentally ill persons, the INCENSE program developed a formal understanding between the program, RMH and 'Maher'- an NGO based in Pune that rescued, housed and treated homeless women in supported community residential facilities.

However, it soon became apparent that, even at Maher, where care was delivered in compassionate manner, a significant exit barrier for some persons staying there was the lack of supported housing options that facilitated more independent living. This block was leading to inappropriate long term institutional stay for some of the persons with SMDs at Maher who were well and wanted to move on to a life of more individual freedom and choice.

To address this gap, a series of consultations were held with Maher; these resulted in the setting up of a new supported community housing facility for women - 'Unnati Niwas' in September 2012.

Developing recovery oriented housing and work options for people recovering from SMDs

Unnati Niwas was developed as a low staff supported housing facility that would enable women with SMDs to live independently and access work through individual job placements or through collective efforts.



Unnati Niwas was meant to be a further milestone in their pathway to eventual autonomy and independent living while developing the necessary skills to negotiate life in the city. The facility was operated by Maher with the INCENSE program contributing to the recurring cost of the facility and staffing, by providing staff time in ongoing clinical and rehabilitation services, staff supervision at Maher and in efforts to provide employment through individual jobs or collective work options. This arrangement was also agreed upon with RMH to ensure that a coordinated pathway of care that promoted increasing degrees of autonomy (and that allowed for people to move between these structures according to their needs) was collaboratively agreed upon and implemented.

In tandem, there was a rigorous attempt made by the team to engage with purposively selected group of homeless persons with SMDs on the streets of Pune.

The process of identifying, engaging, assessing, admitting to RMH, providing continued services while in hospital and then coordinating their exit to their families (as the first preference) or to Maher and a couple of other such NGOs in the State (with whom networks were developed later) or Unnati Niwas if relocation back home was not possible. The challenges associated with these are detailed in **Appendix 2**.

3.4.2. Main outcomes at Pune

The individual and systemic outcomes of homeless persons with SMDs in the INCENSE program were mixed. There was a clear trend to suggest that, a significant proportion of homeless persons with SMDs currently living on the streets can be relocated back home. However, it is also clear that, there is a smaller proportion cannot be reunited with their families and will need continued residential support.

The outcomes of people who moved to Unnati Niwas from Maher or the RMH are equally mixed. While a small number of people could find and continue with individual jobs and reunite with their families, for most people making the next step to individual, independent living was not possible or considered desirable.

One of the most important reasons attributed by people who wanted to go back to Maher or to the RMH was that the amount earned through jobs did not translate into substantial changes in their perceived quality of life.

3.4.3. Implications at Pune

Before going any further it must be emphasized that, unlike for the long stay and the community intervention at Tezpur, the cohort of homeless persons in the program were relatively small and, in the case of Pune, overwhelmingly women and purposively chosen.

Thus any conclusions drawn from the outcomes are necessarily of limited generalizability. With these limitations in mind, the outcomes indicate that:

- care for homeless people with concurrent SMDs is a complex and highly resource intensive exercise with multiple challenges
- a coordinated response between mental hospitals and community agencies on addressing entry and exit barriers is modestly successful in developing an integrated care pathway
- a significant proportion of those who cannot be relocated back to their families will need longer term care in supported community housing facilities
- a small number of people will be able to make the transition to more independent living while successfully holding individual jobs
- prolonged stay and institutional care, whether in hospital or in long term care facilities in the community, is inversely correlated with successful negotiation of independent living and working.

For the INCENSE program at Pune, there are three main implications from the pilot phase of work with homeless women with SMDs. Firstly, the results suggest that the current work needs to be consolidated and that the systemic blocks in the care pathway need further exploration. For example, it is clear that the appropriateness of the exit facilities- Maher and Unnati Niwas need to be studied from the perspective of the women involved in greater depth to calibrate the intervention and help a greater proportion of women achieve good outcomes. Secondly, it is necessary to develop a similar interagency pathway for men, especially since Maher is now in a position to provide housing, rehabilitation and some work options in collaboration with the INCENSE team. Finally, the competencies of the program team will be better engaged in supporting the hospital and Maher and other agencies working with homeless persons through ongoing focused collaborations.

Towards this end, the program will work with RMH to identify people who have come in through involuntary treatment orders (and are currently unable to leave the hospital due to lack of exit options) to be shifted to 'Devrai' for dedicated preparations towards phased exit or a more pragmatic arrangement of living in and working outside of the facilities that many people seem to prefer possibly as the sense of dislocation is less acute.

Similarly at Maher and Unnati Niwas, the consultations with women (and men) in these facilities will help indicate what is more desirable and possible from their perspective. The program will also work towards a strategic engagement with other key stakeholders, especially the local municipal and state government in close partnership with the Tata Trust to develop a systemic and sustainable response for such persons at Pune.

3.4.4: INCENSE program with homeless persons with SMDs at Tezpur

In contrast to the intervention at Pune, the narrative of the engagement with homeless persons with SMDs at Tezpur was quite different due to some key differences with the situation at Pune; firstly, the entire cohort consisted of people with SMDs on the streets; secondly, that since this was a catchment area based program, it was possible to identify a representative cohort of homeless persons with SMDs and; finally, that the absence of any available community housing option like Maher at Tezpur necessitated a different approach to the issue of finding supported community housing options for people who could not be reunited with their family.

A similar process of intervention delivery across the street, hospital, family relocation and placement in supported community housing facilities was developed with the INCENSE team providing the link between the various components of the system. Through this intervention, the program was quite successful in promoting the reunion of homeless persons with SMDs with their families.

Another important aspect of the success of this approach in retaining people at home has been the effort to respond to the social determinants of homelessness - most frequently, lack of financial resources for caring for the person with SMD. Prior to the person going back home, there is a systematic engagement with the family especially around the likely challenges they might face in supporting their family member recover and the potential solutions to these.

For example, for those who are within a reasonable distance, there is an ongoing home based intervention as well as attempts to provide access to livelihood augmentation whenever feasible. This longer term engagement with the family unit is possibly critical in preventing a return to homelessness which is a distinct possibility if treatment, rehabilitation and financial needs of the family are left unaddressed. The LGBRIMH has played a key role in this process by providing continuing access to clinical needs, free medications and social work interventions

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While admission to the LGBRIMH for homeless persons was a difficult process, the more challenging aspect was the lack of any supported housing facilities for those who needed such support. In response to this, a concerted attempt was made to engage with a number of local and regional agencies who were currently providing some form of respite care or were willing to do so. This included the local branch of the Missionaries of Charity and a local temple Trust who are willing to provide accommodation and work in their 'goshala (cow shed)' for a small number of men who might need long term care.

For a couple of men, collaborations have been established between the team and key members of the local community to provide shelter, food, treatment and work in a stable manner. The point to stress is that the local social milieu at Tezpur allows for innovative and participatory solutions.

In a separate process, the State Government of Assam has, over the last two years, under the guidance and overview of the State High Court, initiated a pioneering social welfare initiative for persons with SMDs who

***Raghunath Poudel** is the priest at a local temple and also manages the serene farm and cowshed located on the banks of the Bramhaputra river at Tezpur. He was instrumental in engaging people with severe mental disorders in a highly inclusive manner within the activities of the farm with great success.*

need long term institutional care. At each district, a specific NGO has been officially mandated to take in such persons and provide for their care in the long term with the continued financial support of the Government.

The government has also specified a clear Standard Operating Procedure for the admission (including the roles of the police and judiciary) and appropriate and timely discharge from acute treatment facilities like LGBRIMH with the district Welfare Officer being the mandated nodal person for making appropriate arrangements on a case by case basis. Through this initiative, in the Sonitpur district where Tezpur (as the district headquarter) is located, an agency which provides long term stay facilities for people with a variety of disabilities has been notified as a designated long term residential care facility.

Over the course of time, in part due the increasing availability of a coordinated process of discharge to the family or to long term care options in the community, the engagement with LGBRIMH on the issues around

admission of homeless persons with SMDs has improved considerably. In addition, this has led to more dialogue between the various key stakeholders- the police, judiciary, legal aid services, community agencies and individuals at Tezpur which, in itself, is a welcome development.

A more recent heartening development is that the new NGO formed at Tezpur, 'Atmikha' has taken an executive decision to continue with efforts to ensure that homeless persons with SMDs are identified, treated in hospital as necessary and rehabilitated appropriately.

At this time, the INCENSE program will continue to provide and improve connectivity between the various stakeholders and agencies involved in the local network as well as address gaps in the system using locally available community resources. For example, one of the gaps in the current system is the absence of a short stay facility where people can stabilize and recover their social and work skills after discharge from hospital before going home.

Such a facility can also respond to the respite needs of persons with SMDs in the community and their caregivers and in the long term function as a peer driven crisis and respite centre which also provides work and support for livelihoods. Thus, overall, there is a favorable environment of developing a collaborative, multi sectoral, responsive, comprehensive and integrated pathway for homeless persons with SMDs at Tezpur.

Chapter 4

Employment for Promoting recovery

Lack of access to meaningful employment is one of the most commonly identified unmet needs of people with SMDs and their caregivers, one of the most important determinants of outcome and most importantly, is one determinant which can be realistically modified. Thus, from the very beginning of the program, there was a significant focus on the issue of employment and livelihoods for people with SMDs as an essential ingredient of the overall intervention. The other reason to focus on employment options was to open up dialogue with external agencies that had the expertise and opportunities for providing meaningful employment.

Again, through a process of learning by doing, the program now has accumulated a reasonable understanding of the individual, family and systemic challenges involved in enabling people with SMDs access work that is feasible, appropriate, meaningful and financially viable.

As is the case with all other domains of the intervention, the site had a powerful impact on the actual development of this area of work; this is not surprising given the great diversity in the social and economic milieus and the cohort of people the program largely engaged with.

4.1. Intervention development and description

The limited available literature from low and middle income country settings suggests that access to individual micro credit loans for small businesses, sheltered employment and inclusion in existing government employment initiatives are possible options for promoting livelihoods for people with SMD, especially in rural areas.

However, there is little evidence that such initiatives actually translate into financial empowerment in the medium term or that they enhance social inclusion or improve feelings of self-worth for the individual.

Thus, while there is little doubt that employment options should be more accessible to people with SMDs, there is limited evidence or conceptual

clarity on how this can be effectively achieved in India and other similar countries.

This is a key gap in current community services development and seriously limits the possibilities of independence, autonomy and the exercise of individual choice for people with SMD and their already burdened caregivers.

The **INCENSE employment related intervention was based on three essential criteria**: firstly, that it had to be **congruent with the aspirations of people** with SMD and their caregivers; secondly, that it would be **feasible to develop and implement within the local settings**; and finally, that it **needed to actively involve a large cross section of people in the community** working collaboratively with people with SMD and their caregivers.

In the course of the pilot phase of the INCENSE program, the three main types of employment options trialed were:

- Collective employment options
- Individual job placements
- Home based employment

4.1.1. Collective work options at Pune

The collective work options at Pune are now being tried at a number of institutional locations- at RMH, Maher, Unnati Niwas and a local inpatient psychiatric unit attached to a Medical College. Of these, the hospital based work options have been ongoing for the longest period and, after a few hits and misses, has stabilized around paper products and the production of clay beads for making decorative items. These activities have now been centralized at the 'Devrai' facilities and there are plans to diversify the product range in the near future

Employment for Promoting recovery

The **Kimaya** brand represents the efforts of persons with psychosocial disabilities at the Regional Mental Hospital in Pune, in working towards their economic empowerment.

The inmates create and produce a range of items from handmade paper bags and handmade diaries to jewelry items. Not only is it a source of earning a living but also a boost to their self-worth.

While there is a relatively small cohort of long stay persons who are engaged in this work, for those who are, the benefits are obvious across multiple domains- greater mental and physical well-being, improved self-esteem, less internalized stigma and a sense of purpose.

Enabling access to work options has also been accompanied by efforts to provide citizenship proof, access to bank accounts and some ability to use the money generated as profits for their individual needs. In addition, the many efforts made have opened a trilateral dialogue and partnerships with a number of community agencies in the NGO and the private sectors as well as with private social entrepreneurs.

While it is clear that these and other similar work options are feasible in institutional settings, there are still a number of key challenges that need further in depth exploration. Firstly, there is the issue of whether these initiatives can make the transformation from being rehabilitation options to sustainable employment methods in a highly urbanized and competitive environment. The critical link in making this happen is the establishment of an a priori secure and profitable market linkage for any product being planned.

Secondly, while competing in the open market, there are also some limiting factors inherent in the workforce in such institutional settings that place **a** restriction on productivity and consistency. This factor needs to be taken into account explicitly while planning for possible work options.

Thirdly, even if there are reasonable financial returns, it is not clear if this will translate into improvements in their quality of life in the absence of concurrent systemic changes that allow them to manage and use the money in personally meaningful ways within their institution of residence.

Finally, it is also unclear as to how far people with SMDs can become more active partners in managing the units with more limited external support in the longer term. Working with the NGO and private sector may offer opportunities to test whether these key challenges can be overcome. These are some themes we are keen to follow through in the next phase of the program.

4.1.2. Placement in individual jobs at Pune

The individual job placement stream at Pune were made available to persons with SMDs from the community cohort that also included previously homeless persons and long stay persons who had been relocated to supported housing facilities.

Over time, the team has acquired considerable experience in developing a structured process of supporting persons from highly vulnerable positions, access and continue with competitive, open market work. To do this, two

parallel strands needed to be brought together; firstly, ensuring the willingness and the ability of the person to work and; secondly, finding employment in an informed and supportive environment.

A substantial effort has been put in to find suitable job options mostly in the informal economy sector. A number of individuals, companies and other employment agencies have been approached and in many of them, there was willingness to employ persons recovering from their SMDs in their workforce. This led to the creation of a database of potential employers and details of available jobs.

This initial openness to the idea was supplemented by systematic orientation for the management about the particular strengths and limitations of people with SMDs at work and how they need to be supported without being patronizing or demanding. The individual with SMD was also assessed to understand their work background, current skills, preferences and ability/ willingness to undertake the necessary tasks for holding down a job (adequate grooming, travel, handling money, interpersonal skills, etc.)

Resident from Unnati Niwas working as a service staff in a local mall.

When the job and individual had been reasonably matched, there was an attempt made to further disaggregate the skills involved in doing the job and to modify them as per the convenience of the person as far as possible. After this preparatory work, the placement occurred in a graded manner with the continued support and supervision of the community team and the management.

The immediate few days after placement is a critical period in which the need for support is the greatest as the person comes to terms with the job requirements and negotiates the way of interacting with co-workers and in some cases, customers. Once this period is successfully negotiated, the chances of the person being able to hold on to the job increase sharply. During this time, direct support can be scaled down with continued efforts to involve and elicit the feedback of employers about the overall experience and areas where improvements could be made.

During the course of the pilot program, it was possible to organize a variety of such individual job placement for a reasonable cohort of persons with SMD and for some caregivers at Pune. The outcomes were mixed with about half of the cohort being able to hold on to work for a reasonable period of time.

4.1.3. Collective work options at Tezpur

At Tezpur, a number of collective work options were tried for people with SMDs and their caregivers; the key difference with Pune is that these were located in the community.

The choice of the particular work option was chosen on the basis of consultations with persons with SMDs and their caregivers, with local and regional partner agencies that had some expertise in livelihood promotion and on some analysis of the market access, uptake and potential for profits while considering skills that existed within the group (like weaving and working with bamboo).

As in Pune, there were serious problems in taking these collective work options to a point where they could be financially viable for reasons that are broadly similar to those outlined earlier. In addition, at Tezpur, as these units were set up in various locations, another significant barrier was the cost and difficulties involved for people to commute to the centers regularly.

To address such logistical challenges, more recently, a different approach is being tried. Instead of the program selecting the activity and the location, there is a concerted attempt to engage with a group of persons with SMDs and their caregivers living close to each other as the first step. This involves working with the group in thinking through potential options and then collectively selecting the activity (like the new tailoring unit) after understanding the logistics, local market conditions and the financial viability of the enterprise.

Sakhi, a ladies tailoring centre employing women recovering from SMDs.

Sewing machines at Sakhi in Tezpur

The whole exercise is being led by a peer worker with the technical skills to organize the tailoring activities; involving such peer workers and caregivers more centrally into the planning and management of such enterprises is an agenda we wish to explore further.

In the more rural parts of the catchment area, we are also using a similar process to develop collective work options that are more suited to the rural economy and context. For example, in consultation with the Fisheries department of the local government, there are plans to develop a self-help initiative of commercial fish ponds (by augmenting existing ponds) and also incorporation of modern agricultural practices in existing farmlands.

4.1.4. Placement in individual jobs at Tezpur

Another major focus of the employment related intervention at Tezpur was around securing work through Individual job placements for persons with SMDs who were interested and willing and for some caregivers as well. The process of finding potential employers in the local area, engaging with them, matching the job to the person, their graded placement and continued support from the team was fairly similar to the approach at Pune.

The outcomes of this exercise are very encouraging with a significant proportion of the community based cohort having both access to jobs and continued employment in these with varying levels of income and every possibility of more such persons with SMDs and their caregivers being able to access jobs.

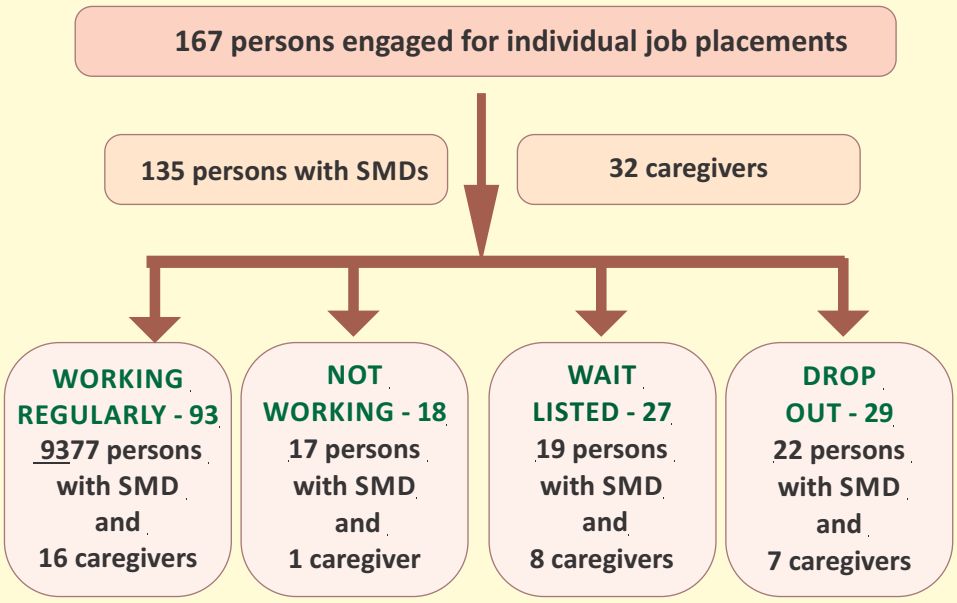
What was also very heartening was that workplaces, co-workers and especially the management of local businesses were extremely accommodating and went out of their way to include persons with SMDs or their caregivers in the workforce.

Another important illustration of the impact of the site was on the outcomes of individual job placement process. While no causal attributions are possible, there could be independent associations with the overall degree of vulnerability of the cohort across the sites, with the greater availability of acceptable jobs in the informal sector at Tezpur and the marked difference in the economic structure with Pune having a more competitive and formalized job market with much lesser room for accommodating the special needs of persons with SMDs. These and other

associations will need to be studied in depth to help improve the availability, acceptability and effectiveness of individual job placement process across the sites.

Jyoshmoy Paul *is the owner of a small hotel at Tezpur and has employed people with severe mental disorders in his establishment in an inclusive and equitable basis. He has gone a step further and also provides for the medicaton for his employees.*

Figure 5: Summary of individual job placement across the sites (combined numbers)



4.1.5: Home based livelihoods

The work around home based employment at Tezpur developed during the course of the individual job placement process described earlier and in specific response to some important reasons of dropping out like having to commute to a place of work (making it both time and financially unviable), the added difficulties of women not being allowed to go out regularly by some traditional families and the lack of flexibility in working time to suit other family needs like taking care of elderly parents or children at home.

A group of women involved in home based livelihood activities

4.1.5: Home based livelihoods

The biggest problem associated with home based work is the inherently limited commercial viability of the enterprise due to the lack of scale, uncertain quality standards and market access on favorable terms. This problem was addressed at Tezpur in two ways; firstly, by developing work clusters i.e. link together a group of persons with SMDs and their families from a small geographical area in producing similar goods and; secondly, by securing a priori market access.

One of the most interesting developments has been the linkage of these clusters with the rehabilitation unit of the LGBRIMH to create a viable hub and spoke model. The rehabilitation unit links the groups together by

providing access to materials for producing goods and by buying back the products manufactured at competitive rates which the unit then sells in the open market. This arrangement has been mutually satisfactory and there are plans to take this collaboration further. For example, the program has now established dialogue between the cluster members, the rehabilitation unit and a social enterprise that works with selling clothes, accessories and other unique regional handicrafts to a global audience through online transactions.

The specific plan is for the staff of the agency to provide the initial training and supervision for people with SMDs and their caregivers in developing a hand weaving unit at the rehabilitation section. This new unit will establish a similar arrangement with clusters of individuals who are used to weaving at home and organize for the equitable buyback of products. If these early experiments are successful, this opens the idea of the rehabilitation units of the mental hospitals become catalytic enabling hubs for incubating innovative social enterprises involving people with SMDs.

Chapter 5

Addressing Financial exclusion

Financial exclusion by the denial of opportunities for decent livelihoods and for accessing legitimate financial services is a highly disempowering method of social discrimination that many people with SMD routinely face.

Though suggesting that access to livelihood options is associated with better clinical outcomes for people with SMDs in India, the current literature does not answer the question of whether access to employment leads to longer term economic security or improved social inclusion.

In most high income and in some middle income countries, people with SMDs have access to health and social services that are wholly or partly financed by the Government. In addition, a number of social security services like disability pensions, supported housing and job placements are in place to provide a safety net and support persons with SMDs manage their lives reasonably independently in the long term.

In the absence of such publicly provided health care and social security in India, providing people with SMD and their caregivers the skills to plan and manage their finances for long term treatment costs and social security is a necessary follow through method to ensure that increased income translates into longer term security and dignity.

Addressing this issue is also very important from the perspective of caregivers- typically, ageing parents or spouses for whom the lack of effective future treatment related, social and financial security are serious concerns, especially when they are no longer around. In this context, including financial management and planning skills within the overall intervention can potentially add considerable value by:

- Enabling people with SMD access basic financial services like banking and insurance by addressing the various systemic barriers that limit their basic citizenship rights (of opening and operating bank accounts, for example)
- Providing persons with SMD and their caregivers the financial

literacy skills and support to make informed plans to manage their current and future financial situation and to address the longer term financial needs of the person with SMD

- Enable access to available financial protection for meeting the health care costs of persons with SMD in the future

Since there was no in house expertise available within the team in relation to financial management, a collaboration was developed with the IFMR Finance Foundation, Chennai who have a great deal of expertise on the issue of financial inclusion.

Through this collaboration, a couple of senior staff from Tezpur were provided with onsite training at Dehradun on the relevance of financial management, methods of conducting the financial assessment exercise (developed and used widely by IFMR in the other operations) and for the understanding of linkages to financial products like saving schemes, pension and insurance.

Following this, the exercise of introducing financial management and planning for people with SMDs and their caregivers has been piloted at Tezpur (as it had a larger community cohort where such an exercise was most relevant and feasible) with very interesting results.

This pilot exercise clearly demonstrates the relevance, feasibility and acceptability of the procedure and has led to families and individuals using some of the surplus money to open 'Jan Dhan' accounts in local banks, invest in post office and bank savings as well as invest in the National Pension Scheme (NPS).

Finally, some of these families who live below the officially designated poverty line have been linked to available government funded health insurance schemes like the Rashtriya Swasth Bima Yojana (RBSY) to facilitate treatment of physical health problems.

Thus, the early results of incorporating a financial planning and

management component in the overall INCENSE package of intervention are encouraging and seem to meet an important and unaddressed need.

We intend to expand on this work to understand, for example, the quantity of savings that would enable people at different age groups have access to a reasonable sum of money in their older years and develop an age and gender adjusted method for determining an effective social security quantum in India and whether the delivery of benefits could, in the future, be linked to their individual bank accounts.

Chapter 6

Engagement with hospitals - Process, outcomes and implications

6.1. Engagement with the RMH and LGBRIMH

As mentioned earlier, the key structural driver of the INCENSE program was the partnership between the hospitals and the NGOs - Parivartan and Sangath. A brief narrative of how this process unfolded across the RMH and the LGBRIMH merits some description.

6.1.1. Partnership between RMH and Parivartan

At the RMH at Pune, Parivartan had an ongoing voluntary presence within the hospital since 2008. Thus, for the INCENSE program, it was relatively easier to develop an effective working alliance with the hospital and, crucially, assure the continuity of key personnel who were familiar to hospital staff. The previous history of engagement also led to a quick consensus that the focus of the initial phase of the program needed to be on addressing some of the obvious unmet needs of a large number of long stay persons.

1) The first point of systemic engagement was a survey carried out with a proportion of staff across various categories to understand their attitudes towards care in community settings. This also provided a platform for the dissemination of information about the program to a large cross section of the hospital staff. The generally positive endorsement of the idea was fed back in a public dissemination meeting where the hospital staff was encouraged to provide continued suggestions for changes.

2) The second focus of systemic engagement was around the issue of providing work and recreation options for long stay persons living in various wards for men and women. A number of efforts were made to develop work options within the hospital starting with horticulture in the various pockets of land available and lying unused within the hospital. While this did work quite well initially, pilferage of the agricultural produce

was a serious problem which compromised the viability of this option and ultimately led to its abandonment. Extending the idea to include less pilferage prone options like sericulture and a nursery was also not sustainable due to the lack of clarity about what the financial incentives of participation would be and a consequent lack of uptake by long stay persons and the hospital.

Based on these experiences, a decision was made to shift to work options based on non-consumable products that had the potential to generate some quantum of income for individuals involved in their manufacture.

A number of options were tried with mixed results- while things like jewelry making with women's groups was not sustainable, others like paper related work and clay bead making with men's groups have continued successfully. More recently, paper bowl and paper plate manufacturing is being piloted in close collaborations with RMH, Maher, Unnati Niwas and a private inpatient setting at Pune.

3) Thirdly, the program staff also worked closely with the hospital administration to enable the provision of basic citizenship proof for long stay persons as the majority of them did not have any such valid document. After much effort, many of the long stay persons were formally included in the national population database and were provided with a unique national 'Aadhar' card and number.

The issue of Aadhar cards (the unique identifying proof of citizenship being rolled out in India) was a critical step that enabled a number of other downstream actions like the opening of individualized bank accounts as an essential part of social and financial inclusion.

The hospital has now committed itself to completing the process with all long stay persons in the hospital and is in talks with a local public sector bank for opening the new 'Jan Dhan' zero balance accounts being encouraged by the Government of India.

Patients with their Aadhar cards: Their gateway to identity and financial inclusion

4) Fourthly, to address the obvious pernicious effects of long term institutionalization, a concerted attempt was made to engage with a number of non-acute wards in an attempt to introduce activity structuring, work and recreational options and the principles of individual care planning, to the extent possible. From the beginning, all such initiatives were discussed with the existing staff and selected interventions were delivered in the many periods of everyday life with no scheduled activity. However, in spite of persisting for more than 12 months, there was very limited uptake of these efforts leading to the closure of this component of the program.

5) Fifthly, a concerted attempt was made to develop a dedicated transit facility within the RMH where long stay persons could live in and acquire the social, instrumental and vocational skills that would enable them to move into supported community housing facilities. After almost a year of consultations with the hospital (starting from December, 2011), a 'day care

transit' facility was agreed on and six persons were selected for thisinitiative. This experiment was also not successful - the two most important reasons were the lack of dedicated staff support from the hospital and the half measures inherent in the 'daytime transit facility'. In effect it became a daytime workplace shorn of the larger purpose of helping long stay persons acquire a range of skills to manage their lives more independently in the community in future. This led to the closure of the facility after 12 months of trying to make it work.

6) Sixthly, during discussions with the State government, Parivartan was asked to come up with a **prototype of a data management system** that would help in understanding some basic aspects of the system. This included the provision of a unique ID to every individual person accessing inpatient care in the hospital, recording the admissions and discharges that occurred on a daily basis and the transfer of inpatients within the various wards (acute care, observation, longer stay) of the hospital.

The outline of this basic data management system was developed in consultation with the hospital and then implemented for a period of six months. The system involved the collaboration of ward sisters in completing the information on a daily basis from registers that they already maintained for recording admission, discharge and movement of persons with SMDs between various wards. This arrangement started off well but tapered off rapidly making it incumbent on the program staff to prepare these reports. Since this was not sustainable, the initiative ended after about eight months of efforts.

In spite of these mixed outcomes, it was possible to work with the hospital and other partners to develop an initial pathway for the staged exit of both women and men who had been in hospital for long periods into supported housing facilities. In itself, this is a significant outcome as it signifies a readiness on the part of the hospital to develop collaborations with a range of partners for addressing long term and complex problems.

Chapter 6

Engagement with hospitals; Process, outcomes and implications

In conclusion, there were three main learning experiences for the program at Pune in terms of the engagement with a complex system like the RMH.

Firstly, it is clear that sustaining systemic changes in a hierarchical system like the RMH needs a clear mandate and continued leadership from the top - the Superintendent, the other senior psychiatrists and the State Government. This was not consistently available during most of the first three years of the program due to frequent changes in key personnel and it is not surprising that many of the initiatives tried in that period could not be continued.

Secondly, attempting concurrent changes in multiple parts of the system, like working in existing wards, trying to develop new ways of structuring the ward activities, developing work and livelihood options and a new information management system with an uncertain mandate may not have been the best strategy to manage systemic disruption and resistance.

In recognition of the fact that, in spite of making very substantial human resource investment, many initiatives did not yield lasting systemic changes, in the last 18 months, focused efforts were directed towards developing a limited number of in depth collaboration with the hospital. This strategy has proved to be more effective- a prime example of this is the Devrai facility.

Finally, for us, it has also been an opportunity to experience at close quarters the often unappreciated, stigmatized and difficult conditions in which staff in these hospitals have to work in. The process of demoralization and institutionalization is equally applicable to staff working in mental hospitals and, unless this is recognized and rectified through continued training and specific skill development, improvement in care practices is unlikely. In spite of this, there are many staff who are deeply empathic and have the desire to innovate and make things better in their own ways - fostering such local champions of good practice is an equally necessary component of planning changes.

6.1.2 Partnership between LGBRIMH and Sangath

At Tezpur, in the absence of an intermediary agency like Parivartan, the initial program and financial management arrangements were nested within the existing LGBRIMH structure. This arrangement led to a series of problems in the first 12 months due to the tensions inherently involved in the program management arrangements and unclear boundaries.

In response to this situation, two major changes were implemented; firstly, all aspects of program and financial management were vested clearly with Sangath thus defining the boundaries of the relationship in more unequivocal terms. Secondly, it was mutually decided that the focus of the program needed to shift from working inside the hospital to developing integrated services and linkages with the local community. These decisions have, in the last two and half years, helped the program team at Tezpur develop a distinct identity and equitable relationships with the Institute, for innovative and integrated community based services (together with the Institute) to be implemented and for new linkages with local and regional community agencies to be developed with mutual benefits.

A more recent and significant development in this regard has been the setting up of an NGO-'Atmikha' in Tezpur by the local program staff and a range of other individuals from the local community. This addresses two key longer term requirements of the program at Tezpur- the gradual ownership and operational management of the program by a sustainable local agency and the formal alliance it creates between program staff, key staff within the Institute and in the community.

At this time, the partnership between the LGBRIMH and the program has become more mature and effective and has the potential to further consolidate and expand on the theme of mental hospitals opening their doors to help develop integrated services in a collaborative and multi sectoral manner.

In conclusion, across the two sites, in terms of the partnership between large State and Central government run hospitals with NGOs in working

towards a common program, the most heartening feature was the enduring nature of the relationship over an extended period of four years. Given the often fraught pragmatic and ideological differences involved in managing such partnerships, the INCENSE program is a welcome development that demonstrates the feasibility and acceptability of developing such enduring and mutually collaborative initiatives.

Chapter 7

Supporting network of Community agencies

Across both sites, one of the most positive aspects of the program has been the gradual development and progressive strengthening of links of the hospitals with a number of local and regional community agencies. While certain examples of these have been highlighted in the previous sections of the report, there are many others who have contributed their time, ideas and resources towards building up a supportive network.

At this time, there are thriving partnerships with a number of credible partners from the government, community based organizations, academic institutions and the private sector- formal and informal.

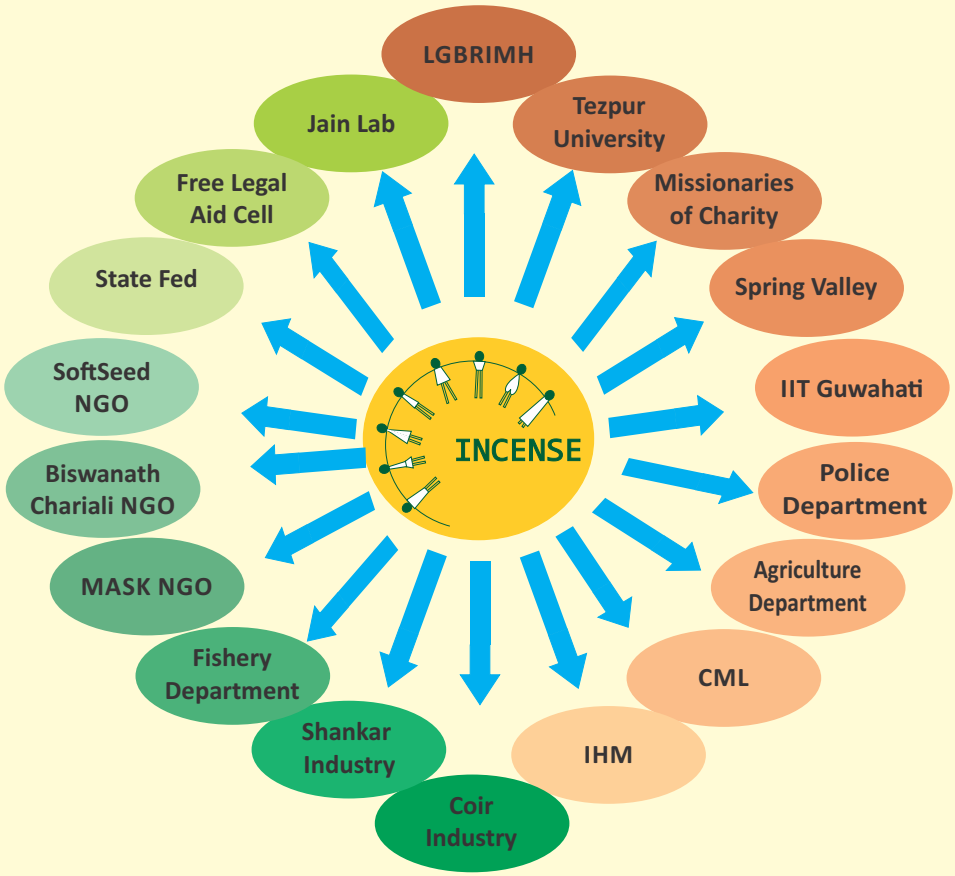
Much of the collaborative efforts have been related to promoting livelihoods, providing supported community housing options and around the financial inclusion aspects of the program.

In addition to these collaborations to enhance the recovery of individuals, the community engagement process has also been able to connect the hospitals, especially the LGBRIMH, to the local and regional community outside of their walls with tangible benefits.

Combined with community based services, this win- win strategy of engagement has gone some distance in addressing the isolation and stigmatization of the Institute in the local community and has opened up a shared space for collaborative and constructive dialogue.

Supporting network of Community agencies

Figure 6- The collaborative multi-sectoral network at Tezpur.



Chapter 8

Future Direction

The INCENSE program was an ambitious and complex exercise started with very little idea of how it would unfold. The last four years of the INCENSE program have been a roller coaster journey during which time a large and diverse stream of activities have unfolded with varying outcomes.

At this time, the program has been provided with an additional grant by the Tata Trust for a period of 12 months (from March'15- February'16). Given the rather hectic pace of developments within the program over the last four years, we feel there is a need to pause, reflect and then consolidate the most promising aspects of the program across the sites for larger scale systemic impact. Thus, over the next 12 months, we intend to focus on:

- consolidating, recording and the strategic dissemination of the findings
- continue to work with RMH to develop the 'Devrai' facility for long stay persons further
- expanding the community based interventions in Pune in a dedicated catchment area and through other locally feasible methods like linkages with other tertiary care institutions like local medical colleges, general hospitals providing psychiatric care, private psychiatrists, etc.
- systematically developing financially viable collective work options, improving on the process of individual job placements across both sites and on making the financial planning and management component more accessible
- systematically engaging with persons with SMDs and their family members for enabling their participation in the program as peer support providers and in other collective initiatives

Future Direction

- enabling families, caregivers and persons with SMDs (within and outside of the ambit of the program) access to supports of various kinds- information about managing the illness, care planning and matched community based rehabilitation, employment options and support groups
- strengthening close and direct engagement with the local communities at Tezpur to expand the reach of services through volunteers to another challenging geographical area of the district
- developing more robust partnerships and opportunities at both sites for employment, housing, social inclusion as well as develop a cadre of trained volunteers who could provide some time and expertise for the program in innovative ways

Conclusion

In the last four years, the INCENSE program has started from being a statement of purpose to a vibrant, innovative, robust and multi dimensional program. At both Pune and at Tezpur, a multi component intervention has been systematically developed and collaboratively implemented with multiple partner agencies for vulnerable groups of people with SMDs.

Given the complexities involved in developing and managing the program, the current robustness of the program, in itself, represents the value of the primary INCENSE idea - that collaborative and multi sectoral partnerships is a feasible and acceptable method of responding to the needs of highly vulnerable people with SMDs more efficiently and effectively.

In addition, the range of innovations developed during the course of the program through the multi sectoral partnerships like the catchment area based community care in conjunction with the LGBRIMH, the gradual development of care pathways that address persistent exit and entry barriers for vulnerable people with SMDs, the development of the Devrai facility at RMH, the experience with various kinds of employment

Future Direction

initiatives and efforts at financial inclusion merit further scientific evaluation as they have the potential to be applicable in other settings.

Finally, there is the important question of whether this intervention can be scaled up in other mental hospitals. The INCENSE program experience thus far clearly indicates that the internal characteristics of the mental hospitals and the external social context will shape the same intervention differently.

Thus, in a narrow sense, there is limited generalizability of the intervention in view of the evident impact modification by the setting. However, this linear understanding around scaling up (similar inputs will lead to a same set of outcomes in multiple settings) is inadequate when applied to the context of highly complex health system entities which, as the active recipients of the change process, will inevitably shape systemic interventions differently.

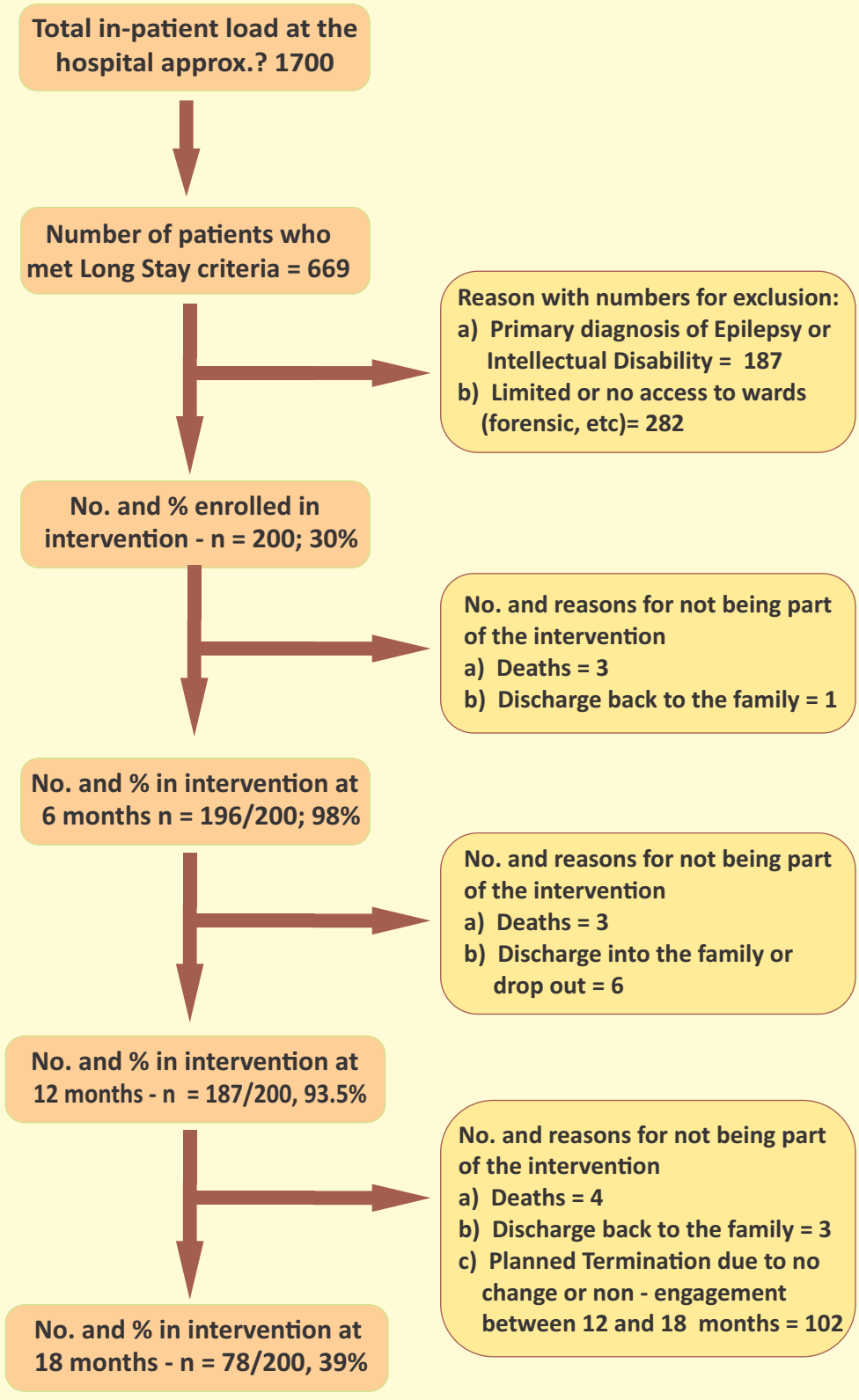
What is generalizable across settings however, are the idea of multi sectoral collaborations as a method of introducing changes, the methodology for change implementation - situation analysis, intervention development, implementation, evaluation and iterative strengthening, a strong focus on building responsive and recovery oriented care pathways by making the most of local resources and the need for continued engagement and leadership.

Through its share of successes and failures , the program has matured and is poised at a very exciting point on multiple fronts and we look forward to the future with optimism.

INCENSE

Appendix 1

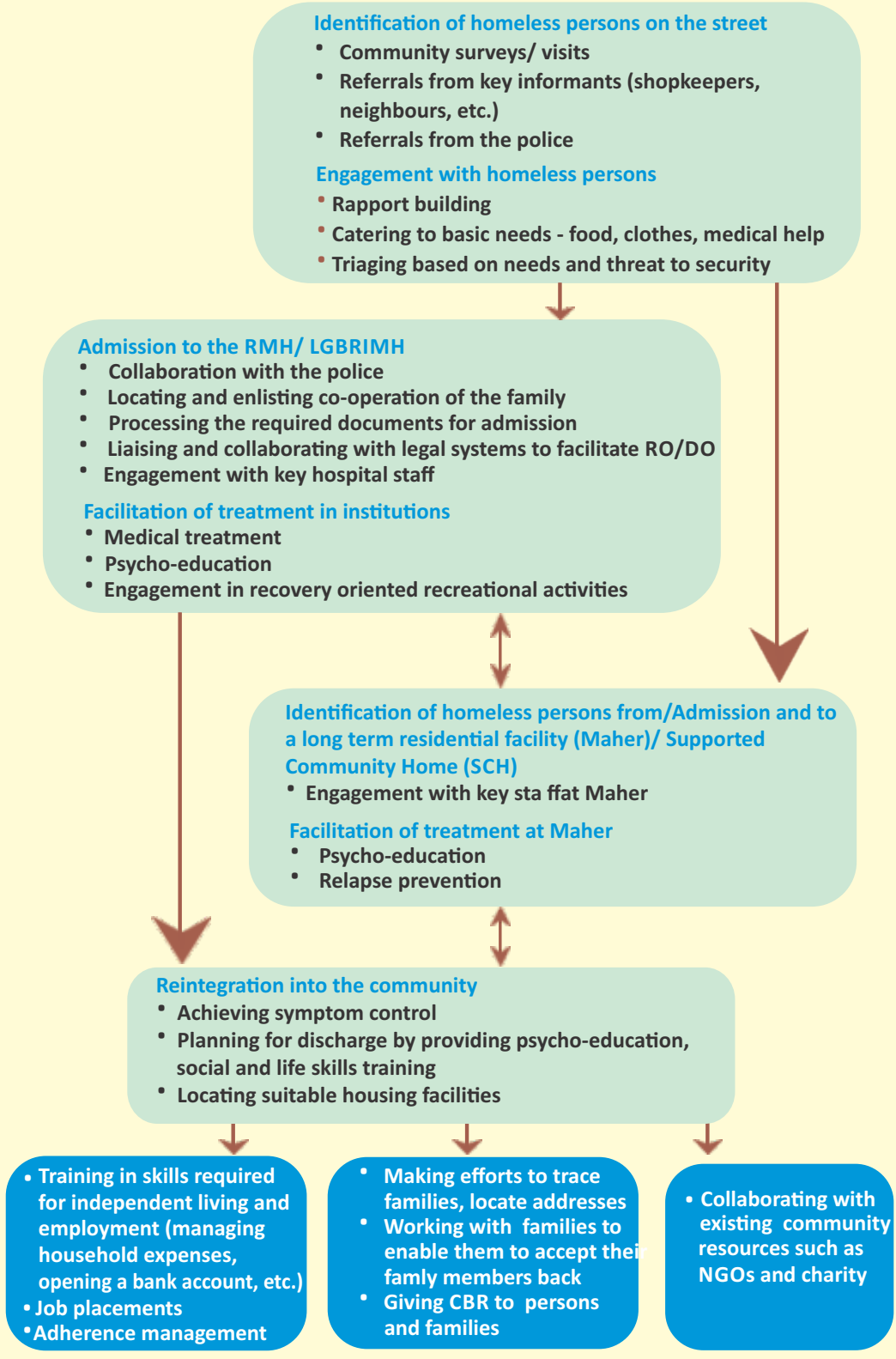
Flowchart of Long Stay (LS) Patients at Pune Site



INCENSE

Appendix 2

The INCENSE intervention for homeless persons with SMDs



KEY: • Components of the homeless program • Interventions to enable reintegration into the community

· Nbte: Maher and SCH are applicable to only Pune, and so far Alternative Community Living has taken place only at Tezpur

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