Pathways of Hope
Stories of Courage
A JOURNEY IN MENTAL HEALTH AND WELLNESS

Foreword by Ratan N. Tata

TATA TRUSTS
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CONTENTS

vii  Foreword by Ratan N. Tata
1    Mental health matters
8    These are the happiest days of my life

Section ONE
Innovative community-based pathways of care and recovery

14   No health without mental health
    Tata Trusts’ pioneering Jan Man Swasthya Programme

42   He may live on the pavement but he is not homeless anymore
    Iswar Sankalpa’s community-based caregivers’ programme

60   Care comes home on a bus
    SCARF’s use of technology to provide access to psychiatric services in remote areas
Section TWO
Rethinking institutional pathways of care and recovery

78  You can see that life is coming back to them
The Devrai pathway for a structured exit from the mental hospital

94  The architecture of care that creates a safe place for personal recovery
An exploration of the value framework of Adaikalám

114 The men were still on the streets, so we had to take care of them
Recovery and reintegration of homeless men at Udayan

130 Earning its place in the community
How the INCENSE team created a bridge between the mental hospital and the community

150 One step before independence
A Parivartan Trust-led collaboration to help homeless women get back to the mainstream of life

162 Make their valour count!
This book is important. Not because it documents the role that Tata Trusts has played in shaping the mental health sector but because its pictures and words make us see, hear and respect women and men who have been invisible at best and neglected, disenfranchised and abused at worst.

This book is about hope: hope that there is a way out of suffering and despair; that recovery is possible and people with mental illness can rebuild their lives, regain their identity and autonomy and renegotiate their place in the world. This requires that they put in the hard and heroic work needed for personal recovery; it also requires support from a variety of sources — family members, caregivers, co-workers, professionals, the private and public sector, as well as society at large.

This book is about immense possibilities: if a love of humankind is one of the definitions of philanthropy, then all of us are already endowed with the biggest resource needed to provide this support. It is my conviction that our collective will and compassion working in tandem with the right resources, innovation and knowledge can dramatically transform the highly underserved mental health sector. We can make it more humane, more efficient, and we can make it truly responsive to the needs of men and women with mental illness living in urban as well as remote rural areas.

Pathways of Hope, Stories of Courage is our tribute to these men and women who are on their journey to recovery. Their humanity, courage and resilience are honoured on every page, in every picture and in every sentence of the book.

Ratan N. Tata
Chairman, Tata Trusts
MENTAL HEALTH MATTERS

Mental health and mental illness

Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community.

Mental illness or ill-health is a recognized, medically diagnosable set of illnesses that results in the significant impairment of an individual's cognitive, affective or relational abilities. Mental disorders result from biological, developmental and/or psychosocial factors and can be managed using approaches comparable to those applied to physical disease (that is, prevention, diagnosis, treatment and rehabilitation).

Mental health and ill-health are a single continuum; they can be defined as parts of the same continuum, with wellness at one end and illness at the other. We are all somewhere on the continuum and are likely, at some point, to move along it in one direction or another.

There are, however, scientific systems that help make diagnoses related to mental ill-health. The predominantly used systems are the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorders.

Illnesses such as schizophrenia, bipolar disorder and psychoses not otherwise specified are considered to be Severe Mental Disorders, while other illnesses such as depression, anxiety and panic attacks are referred to as Common Mental Disorders.

The mental health crisis in India

Mental health is a critical, and sadly neglected, aspect of health in India. While mental illness occurs globally across all socio-economic groups, ethnicity and race, it is – like many other illnesses – closely linked to poverty. Mental illness impedes people's ability to earn a livelihood, thus making them poorer; at the same time, poverty increases the risk of developing mental illness. Adding to the burden is the stigma attached to mental illness and the discrimination that those who are ill have to face. The debilitation of the illness and the misery of discrimination combine to create a life situation that is full of difficulties and suffering for the person and the family.
According to the *Mental Health Atlas 2011* published by the World Health Organization, only 0.06 per cent of the total health budget in India is allocated to mental health. This is a clear indication that despite the large disease burden, mental health care is not a national priority and remains on the fringe of health care delivery. The shortage of public mental health care services further burdens the families who are compelled to utilize their scarce resources on care and treatment, thus pushing them even further into poverty.

Service delivery is particularly poor in rural areas where the services are most needed. What makes this inertia inexcusable is that most mental disorders have known treatments and the cost of treatment is not very high. There is evidence to show (as in the programmes of Tata Trusts) that comprehensive, high-quality services cost only about Rs. 1,500 per person per year.

The stigma of the illness and the lack of trained human resources, appropriate care and correct information combine to marginalize persons with mental illness to such an extent that they lose all power, all rights, all recognition as human beings. They become invisible. And invisible persons are easy to abandon. It is this cumulative injustice of mental illness that Tata Trusts seeks to address.

**Tata Trusts’ involvement in the mental health sector**

As one of the oldest non-sectarian philanthropic organizations in India, Tata Trusts has played a pioneering role in transforming traditional ideas of charity and introducing the concept of proactive philanthropy to make a real difference to communities across the country. In the mental health sector, as in several other areas, its involvement extends beyond providing financial support.

“Mental illness is like a black hole in the thinking of people. Our fundamental mission is to bring light, to take leadership in all aspects so that people with mental illness receive the right care and treatment and become productive and happy. This is very much in keeping with the vision of the founder, Jamsatji Tata. Many people may not know that the bedrock of his vision was compassion and the alleviation of suffering. We must not lose focus on this.”

*R. K. Krishna Kumar, Trustee, Tata Trusts*
Tata Trusts is actively involved in innovative programming in the area of mental health. It has, in fact, played a pivotal leadership role in shaping the work done in mental health in India. It has given critical momentum to mental health action in the country by directly implementing mental health programmes, bringing treatment and care to remote areas where they are urgently needed, supporting initiatives that are way ahead of their times, and also designing and implementing innovative pathways of care through its collaborations with government and non-government organizations.

**Tata Trusts’ key contributions to mental health care in India, 2009-15**

- More than 56 lakh people in nearly 4,000 villages covered by mental health programmes
- Comprehensive mental health care services provided directly to more than 30,000 people
- More than 1,500 people restored to functional employment
- More than 2,700 people (who had wandered away) reunited with their families
- More than 5,700 frontline workers trained to deliver mental health care services at community level

The vision of the Trusts, going forward, is to catalyze change: it is committed to improving access to quality mental health care services, raising awareness and knowledge regarding mental health issues, increasing the number of trained mental health service providers across new geographies, and facilitating enhanced financial investment in the mental health sector from varied stakeholders. The task is monumental, the need is urgent. Global and local knowledge has to be converted into real models and put into action. All this will require experimentation, adaptation and the backing of philanthropies like Tata Trusts.

> "While the global mental health dialogue emphasizes the development of community-based and primary care mental health services, it is silent on the long-term care of people with severe vulnerability – a large part of which is taken care of by the mental hospitals. Tata Trusts and its partnerships have sought to reshape the care pathways of mental hospitals through a process of systemic reform rather than close down these institutions and thus abandon hundreds of people who need these services the most."

*R. Venkataramanan, Managing Trustee, Tata Trusts*
Pathways of Hope, Stories of Courage explores some innovative pathways for the rescue, recovery, rehabilitation and social inclusion of men and women with mental illness. These pathways are in different settings and in different parts of India. They include urban and rural settings as well as community-based and institutional settings. Some of these pathways are public-private partnerships, others are innovations conceptualized and implemented by voluntary organizations. Tata Trusts has played a critical role in shaping and supporting these pathways of recovery for people with severe mental illnesses such as schizophrenia, bipolar disorders and epilepsy.

The pathways are illumined by narratives of the men and women – and their caregivers – who have journeyed on them. The stories illustrate how mental illness can happen to anyone, that for most of these illnesses there are known treatments that are fairly inexpensive, and that treatment leads to dramatic transformations that take place in relatively short periods of time. What is more, it is not only the person with mental illness who gets transformed; the family is also relieved of its many burdens. The narratives also affirm that it is possible even in resource-limited settings like India to create models that are indigenous, ingenious and relevant; models that build upon existing resources and infrastructure so as to serve even those who live in remote rural areas.
Pathways of Hope, Stories of Courage also attempts to redefine the notion of recovery. Recovery is not only about treating the disorder but also restoring maximum functionality. And that is why the mental health sector needs the involvement of a broad spectrum of stakeholders to address the multifold vulnerabilities experienced by people with mental illness. This involvement of various disciplines and professions is one of the aspects that the book advocates for.

Ultimately the book is about hope: hope that gaining an understanding about mental illness, and encountering men and women who are engaged in the heroic task of rebuilding themselves and their world, will bring about a change at a personal and human level. Change in how we perceive them, acknowledge them and interact with them. Change that will allow us to see these men and women in all their humanity, see the badge of courage that they wear, and honour it in any way we can.

Tata Trusts and the team that worked on this book salute the generosity of all those who shared their stories with us. Our heartfelt thanks go out to all of them, and also to their families, their caregivers and the organizations that led us to them. Each and every interaction has inspired us and made us more human.

Tasneem Raja
Lead – Mental Health, Tata Trusts
Mental illness prevalence in India is **65** per 1,000 population\(^1\).

India accounts for **15%** of the global burden of mental, neurological and substance abuse disorders\(^2\).

The age group of 15-34 years is most affected by mental disorders in India\(^2\).

Women are much more affected by anxiety and depression than men in India\(^2\).
There are 43 mental hospitals in India.

For every 1,000,000 people in India:

- 6,500 have mental illness
- 1,469 beds available in mental hospitals
- 14.52 are admitted to a mental hospital of whom 14% stay for more than 5 years
- 0.3 outpatient facilities available

About 1 in 10 people with mental disorders are thought to receive evidence-based intervention in India.

Only 0.06% of the Central Government’s health budget is allocated to mental health.

The burden of mental, neurological, and substance abuse disorders is estimated to increase by 23% between 2013 and 2025.

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1 Derived from a 2005 report quoted in Mental Health Care in India – Old Aspirations …… Renewal Hope – Report of the Technical Committee on Mental Health constituted by the National Human Rights Commission to evaluate mental health services in India, 2016, p.10
http://nhrc.nic.in/Documents/Mental_Health_report_vol_I_10_06_2016.pdf

2 Fiona J Charlson et al., The burden of mental, neurological, and substance use disorders in China and India: a systematic analysis of community representative epidemiological studies in The Lancet, Volume 388, Issue 10042, 376-389
http://www.thelancet.com/journals/lancet/article/PII/S0140-6736(15)30590-6/fulltext#sec1

3 Mental Health Atlas 2015, Department of Mental Health and Substance Abuse, World Health Organization
http://www.who.int/mental_health/evidence/atlas/profiles/ind_mhs_profile.pdf#ua=1
These are the happiest days of my life

Sangeeta Adhikari comes from a prominent, well-to-do family of Guwahati. With a Bachelor’s degree in Education, Sangeeta is the youngest of five siblings; she has three brothers and one sister. Sangeeta writes a page or so in her diary every day. She revisits those moments that shone with significance and records them in her own brave words. This is a daily declaration of faith – in herself and in her commitment to rediscovering meaning, purpose and joy.

In August 2003, Sangeeta was diagnosed with a severe mental illness known as bipolar disorder. She remembers being admitted to hospital ten times. But every time she got better, she stopped taking her medicines and relapsed. Her career as a schoolteacher got disrupted. But she loved teaching and always went back to it. Through the nine years of her struggle with the illness, she taught in four different schools. Her parents wanted her to be independent and supported her in every way possible. Then her mother passed away; within a few years she lost her father as well.

‘When my parents died there was no one to take care of me. I was almost on the streets. Not almost, I was on the streets for one night and two days.’ The police found her around midnight — out of control, in poor hygiene, quarrelling with taxi drivers in a market area. They brought her to Ashadeep’s Transit Care Centre.

With medication, counselling and psycho-education, there was a dramatic transformation in a month’s time. Soon Sangeeta was well enough to join her family, ‘... but they did not accept me. So I was brought back here. I came back to Ashadeep on 21 February 2012. Since then I have been here.’
Ashadeep is Sangeeta’s home now. She has put in the hard work of learning about herself and her illness. ‘For many years I had this illness because I used to stop taking the medicines. My state became so terrible, I was on the streets. But now I have become aware that without medicines nothing is possible for me. I have to take the medicines. In three-and-a-half years, I have not had any symptoms. I have only one problem now: I get tremors because of the medicines. My whole life I will be indebted to the people of Ashadeep for the care that they have taken of me; otherwise I would have been a beggar on the streets of Guwahati. When I see a beggar on the streets of Guwahati, I think to myself, this would have been my condition too.’

Speaking of the worst days of her life with grace and honesty is what makes Sangeeta so endearing. She knows that she will have to live with this illness for the rest of her life, that there will be good days and not-so-good days. But she has not let her illness or her abandonment define her.

There is no self-pity and no blame. There is warmth and sincerity, acceptance and gratitude. This makes her a kindred spirit, one that connects with all those who cherish these values. Those who have known grief and loss in their own lives find it moving to hear her say, ‘I often miss my parents, but one day everyone has to part from their dear ones . . . they will always remain in my heart.’

Sangeeta is now in the midst of a new chapter in her life. She has returned to her calling – she teaches special children at the Day Care Centre. ‘The children are so innocent; they need extra care and extra support. They give me so much confidence and strength. With them my mind becomes fresh and free from all the stigma. I don’t want to miss a single day of being with them. They give me so much joy. I think these are the happiest days of my life.’
For a majority of people in India, particularly those living in rural areas and in remote places, health care is often not accessible or affordable. When it comes to mental health, the problem becomes even more acute. Psychiatrists are insufficient in number. What is more, most of them are urban-based and in the private sector. Men and women in rural areas who need mental health care services therefore remain unserved, with thousands living in silent despair, impoverishment and injustice.

This section brings to life the experience of creating pathways of care as close as possible to people living with severe mental illness. What makes these stories special is that the community is the crucible in which these pathways have been created. Each of these stories highlights the possibilities and potential of reaching care to those who most need it, in circumstances that otherwise appear daunting.

As part of its leadership role in shaping the mental health sector, Tata Trusts has co-designed and put into action a community-based pathway for mental health care service delivery called Jan Man Swasthya Programme that can reach even those in remote rural areas. The innovative features of this pioneering pathway, involving several organizations in different parts of India, are elaborated in the first narrative of this section, titled *No health without mental health.*

*He may live on the pavement but he is not homeless anymore* is about ordinary people who have become the caregivers of homeless men and women with mental illness. These caregivers are the pillars of a unique initiative that provides psychiatric treatment and support to the homeless right where they live; they also demonstrate that kindness, generosity and humanity are well and alive in the streets of Kolkata.

*Care comes home on a bus* is about an innovative intervention that uses telecommunications technology to make available the scare resource of a psychiatrist to people living in remote villages of Pudukkottai district in Tamil Nadu. While technology plays a key role, the intervention is grassroots- and community-based. Trained community health workers identify people with mental illness, motivate them to access the service, and support them and their families all through their journey of recovery.
Innovative community-based pathways of care and recovery
Ashima Boro *(left)* with her mother, on the verandah of their home in Durapara village, Assam. After living with a severe mental illness for a decade, Ashima has made a dramatic recovery.
No health without mental health

Tata Trusts’ pioneering Jan Man Swasthya Programme

Ashima is at work in the pond behind her home. Her mother, Draupadi, is by her side, as she had been for the ten years during which Ashima had suffered from a severe mental illness. Those were years of darkness and bewilderment and sadness. Ashima would tear at her clothes, wander about and become so aggressive that she had to be chained at times.

Draupadi had looked after Ashima; she had taken her all the way to the government hospital in Tezpur as well as to a private psychiatrist in Guwahati. But she had not been able to continue with the treatment. The hospital had been too far away and the private doctor unaffordable. So, although Ashima had improved, she had relapsed once the medication stopped.

Then Draupadi had come to know about a mental health care programme that was to start in Boko block, right at her doorstep as it were. She would not have to spend money on travel or on medicines. All she had to do was to take Ashima to the local Primary Health Centre (PHC) where the psychiatric camp, that was part of the mental health care programme, would be held every month.

Ashima was diagnosed as having schizophrenia. The local team that ran the mental health care programme provided support in the form of counselling and psycho-education. They also worked out a personalized recovery plan for Ashima. Within twelve months, Ashima was in remission. She now needs only maintenance medicine.

The transformation in Ashima is dramatic; she is meticulous about her self-care; she helps her mother with the housework and reassures the local team who continue to visit her at home: ‘... I know how to take medicines and on time.’

Fishing in the pond every afternoon, mother and daughter have found life again.
It was the Jan Man Swasthyā Programme (J MSP), co-designed and put into action across multiple sites by Tata Trusts, that made available quality assured mental health care services to Ashima, and to hundreds of others like her.

Over the decades, Tata Trusts has established trusted relationships with several non-government organizations (NGOs) that run their own community health programmes. Tata Trusts has partnered with some of these NGOs and empowered them to implement J MSP in their area of operations. This is an ingenious way of nesting mental health care services within existing community health programmes.

**J MSP has a singular design that each partner organization implements to make available quality assured mental health care services for three priority conditions – psychoses, depression, and convulsive epilepsy.**

Parivartan Trust hosts the secretariat for this hub-and-spokes model; Foundation for Research in Community Health, the Ant, Ashadeep, Jan Chetna Manch and Ramakrishna Mission Home of Services are the other partner organizations.

Each partner organization creates its own local mental health care team that is a mix of specialist and non-specialist members. The psychiatrist is the only specialist member. In the front line are locally based community health workers who are trained and empowered. The local team conducts a mental health clinic (also called mental health camp), and educates the family about mental illness and the support that they can provide. The team also creates a care plan that evolves to meet the changing needs of the person as she journeys towards recovery.

The role and functions of each team member as well as all aspects pertaining to mental health care delivery, supervision, quality control and record keeping are spelt out in the protocols devised by Parivartan Trust in collaboration with Tata Trusts. The protocols ensure that the mental health care provided is of an assured quality and standardized across all J MSP sites.

Each partner organization simultaneously engages with the local community and advocates with the government.
Community engagement is about creating awareness, addressing stigma and involving community resources in the process of mental health care delivery.

It is also about educating the community to generate a demand for mental health care services to be available at the local level.

One of the partner organizations, the ant, conducts a mass awareness programme on market day in Birhamgaun village in the remote Chirang district of Assam. With the street play gathering a crowd and the one-on-one interactions addressing individual concerns, the ant has found an effective way to use the visibility of a well-attended public place to draw attention to the mental health clinic that it conducts in the state dispensary close to the villagers’ homes.
Parivartan Trust, another partner organization, also uses the medium of the street play. The main difference in its street plays, however, is that most of the performers are Accredited Social Health Activists (ASHAs).

Parivartan Trust has co-opted 15 ASHAs and made them part of the JMSP that it implements in three rural areas of Satara, in Maharashtra. The ASHAs are village-level government workers. They belong to the community and know it intimately. That is why they are ideally suited to identify persons with mental illness and support their journey to recovery.

Involving the ASHAs as performers in street plays is also an inspired strategy. An ASHA-performer speaks for all her colleagues when she says, ‘We have seen the suffering of the persons and their families; we feel all this and remember all this when we perform. If we had not done this work, the street plays would not have this kind of energy.’

While working with the partner organization, the ASHAs gain insights and understanding about mental illness and mental health care. This knowledge will remain with them and in turn be available to the community.

‘All this is very important from the sustainability point of view,’ explains Dr. Hamid Dabholkar, Trustee of Parivartan.

In Satara, three Gram Sabhas have passed a resolution that they want mental health care services to be initiated in their PHCs. Dr. Dabholkar elaborates: ‘we are educating them that if they think mental health is an important issue, then it is their democratic right to demand for mental health services close to their doorstep. This way, whether Parivartan remains or not, that process is in place.’
The partner organizations and their local JMSP teams also advocate with the government for making available some of their field-level resources, such as the PHC. The PHC is easily accessible. The villagers use its services for a variety of general illnesses. In such an environment, persons with mental illness and their families are likely to feel more comfortable and less stigmatized.

The local team of the Foundation for Research in Community Health (FRCH), for example, conducts a monthly mental health clinic at two PHCs in rural Maharashtra – Walha and Belsar.

This strategy of building its mental health care pathway around the PHC paves the way for the integration of mental health care services within the public health system. Such integration is the only way that mental health care services can reach urban as well as rural areas and become sustainable.
It is not only the use of the PHC premises that is being advocated for. Medical officers of some PHCs have received training in treating epilepsy. Persons with this illness will get treatment from the PHC itself. They will not have to wait for long hours in the district hospital which is also far away from their village.

Advocacy for making psychotropic medicines available at the PHC is ongoing. Some partner organizations have succeeded. Others ask the villagers to buy the medicines. With simple mathematical calculations about what the medicines cost and the daily wage earned by a family member, the local team demonstrates that a month’s supply of medicines costs no more than a family member’s wages for a half-day of work.

The partner organizations make sure that the local pharmacy stocks the medicines that they recommend. This care and concern is part of the support provided by partner organizations; only then can their services truly be called ‘quality assured’.
All mental health clinics conducted by partner organizations are in rural areas, but none are as remote as the mental health camps conducted by the ant, in the state dispensaries at Rowmari, Aamgudi, Subajar and Santipur in Chirang district.

Chirang district is in Bodoland Territorial Area, Assam. Till recently Chirang was a conflict-prone area with a long history of violence. It is also one of the remotest parts of India, very close to the India-Bhutan border.

The ant’s mental health camps draw large crowds. This could be the result of several years of conflict and violence. It could also be that Chirang is an unserved area where mental health care services are simply not available.

While the ant still struggles to get medicines from the government, it is doing everything that it can to bring down out-of-pocket expenditure by procuring the medicines from reliable and cost-efficient sources. The whole team is involved. They explain the medicine dosage to the person and the family member, make entries in the register, and save costs by giving the exact number of tablets that will be required for a month’s supply. The ant’s Executive Director, Jennifer Liang, elaborates: ‘... if a person has to be given, say, 22 tablets from a strip of 30 tablets, we will sit and cut out the 22 tablets so that we can save money.’

Salna Khatun (seen in picture on opposite page) who is under treatment for epilepsy, is a regular at the mental health camp in Rowmari. Each time she travels for three hours by train to reach the camp.
For most persons with severe mental illness, the road to recovery can be long and difficult. The local partners implementing the Jan Man Swasthya Programme ensure that sustained and individualized care is available to every single person who needs it. Mahendra Nikam’s story is a good example of the positive results that JMSP has achieved.

It began as a day like any other. Mahendra, a young man of 35, an electrician by profession, with a wife and two children, was running an errand on his motorbike when he met with an accident. This traumatic incident shut the door on Mahendra’s life as he knew it. He developed schizophrenia. He became aggressive, pelted people with stones, and on one occasion even thrashed a cat against a wall and killed it. The family plummeted into despair. They took a loan and institutionalized Mahendra. He improved, but relapsed when he came home. His wife left him, his parents felt powerless. This continued for eight years.

Then a community health worker from partner organization FRCH’s mental health care team visited his home. Mahendra greeted her with knife in hand. She left, but came back with her team a few days later. The family was not convinced that Mahendra could get better. But the team continued to visit and counsel the family. They created a mental health care pathway for Mahendra, one that included getting help at their mental health clinic that was conducted at the nearby Walha PHC. They provided psychosocial support to the family and also devised an individualized care plan for Mahendra to help his recovery.

The first step was symptom reduction. Next, the care plan concentrated on the psychosocial aspects of his recovery: it addressed his need for security, helped him restore his self-confidence and mend his relationships with his family.
The team helped his estranged wife to understand how critical her support was to Mahendra’s recovery. She returned home, and also undertook the responsibility of administering the medicines.

The team encouraged his brother to ask for Mahendra’s help in the fields. Working and earning money made Mahendra feel productive. As Mahendra journeyed further on the path of recovery, the care plan focused on increasing his mobility, building his confidence to ride his two-wheeler once again. Mahendra started venturing out on short trips. He started coming to the mental health clinic at the PHC on his bike, and even rode all the way to another district with his brother.

The months passed. Mahendra was more visible in the neighbourhood; the big break came when he was offered an electrical contract in the village. Things were looking up for Mahendra: he had mended his relations with his wife, parents and children; he had returned to his trade. He was regular with his medication and attended the mental health clinic at the PHC as per schedule.

The local team, especially the community health worker, kept up with the home visits. There came a time when they noticed signs of lethargy and were worried that Mahendra would relapse. The team equipped Mahendra and his family to recognize the signs of relapse and to seek help if they noticed these signs.

With the support of his wife and family, as well as the care and treatment he received, Mahendra made a dramatic recovery.

‘Now the children have got their father back,’ says his wife, Kalpana. ‘The parents have got their son back . . . and I have got my Mister back.’
Nesting mental health care within community health programmes; engaging the community and its resources; advocating for the use of government resources available at community level; paving the way for integration of mental health care within the public health system – this is the Jan Man Swasthya Programme.

It is a pathway that has demonstrated that quality assured mental health care services that are acceptable, accessible and affordable can be made available even in remote rural areas, and that men and women with mental illness can get well and become functional while living at home, within their family, village and community.

Tata Trusts’ Jan Man Swasthya Programme
• has a uniform design wherever implemented
• has protocols for every aspect of care
• is layered on primary health care
• is a non-specialist, frontline-worker-led model
• is India’s first multi-site-implementation effort to have a standard protocol-based programme that can be integrated in primary care and scaled up through the public health system.
Dino’s story

Dino Basumatary of Banduguri village, Assam, used to be a tractor driver. While on his way to a New Year’s day picnic, Dino met with an accident. He suffered a head injury and was hospitalized. Dino developed an anxiety disorder. His family consulted faith healers. That did not help. Then a person who was taking treatment from the ant’s mental health camp at Rowmari told the team about Dino.

The ant’s facilitator, Sonima Basumatary, visited Dino’s home and counselled the family. Dino’s wife agreed to bring him to the camp. Dino was regular in his treatment. It took eight months for Dino’s condition to improve.

Sonima convinced the family that even though it was not possible for Dino to resume his earlier job of driving a tractor, it was imperative for Dino’s recovery that they find an alternative source of livelihood for him.

On Christmas day the same year, Dino and his wife opened a tea stall.
Recovery from mental illness is a process and not an end in itself. Although the journey of recovery starts with addressing the symptoms of the illness, being symptom-free is not necessarily a prerequisite for recovery. The goal is to help the person build a new life, one that is satisfying and meaningful even with the limitations caused by the illness.
Khukudi is preparing her afternoon meal. No one knows how long she has lived in this Kolkata neighbourhood. What we do know, however, is that she is a different person today from what she was a few years ago, thanks to Gouridi, her caregiver.
He may live on the pavement but he is not homeless anymore

Iswar Sankalpa’s community-based caregivers’ programme

“One winter’s day, Dr. K. L. Narayanan and I were walking close to where the Missionaries of Charity have their home. Just opposite the home, we saw a man eating out of a huge garbage vat. I wondered why this man had to eat from the garbage bin, when the Missionaries of Charity distributed food every day.

Dr. Narayanan told me that in all likelihood the person was homeless and had a mental illness as well. Given his symptomatic condition, people would be afraid to approach him and he too would not allow anyone to come near him, let alone give him food.

I asked Dr. Narayanan what would happen to the man. He said that he would most probably not survive for more than four to five months. When he died, he would be an unnamed corpse, because nobody would know where he was from; he could have wandered into Kolkata from another city and even another state. His family would not know about his death, so it was likely that they would continue to wait and to hope that their lost family member would return home one day . . . All this hounded me.”

Sarbani Das Roy
Sarbani Das Roy and Dr. K. L. Narayanan co-founded Iswar Sankalpa. There was no master plan, just the force of will to do something for homeless people with mental illness. Their team, consisting of ten members, bought a map of Kolkata and divided its 41 wards amongst themselves. Each day, they walked through the streets and put a point on the map where they found a homeless person with a mental illness. What astounded them was that there was always someone, a man or a woman, who kept a lookout for the homeless person with mental illness. A worker at a tea shop, a vegetable vendor, a kirana shop owner – these people cared for and protected the homeless person even though he was not a family member, a relative or even from the community. They were the caregivers in the true sense of the word.

**It was on this foundation of the goodness and generosity of ordinary people that Iswar Sankalpa built its community-based caregivers’ pathway.**

This pathway offers the homeless with mental illness the choice to conduct their journey of recovery while continuing to live within the community. They do not have to be institutionalized. Instead the Iswar Sankalpa team reaches out to them wherever they are – the psychiatrist conducts his ‘clinic’ on the roadside; the social worker maintains daily contact, provides support, and when needed even looks after the person’s hygiene needs. The caregiver takes on the additional responsibility of dispensing medication under Iswar Sankalpa’s supervision. The caregivers assume full ownership of the person’s journey of recovery. They do not like the person they care for to be called ‘homeless’. As one of them said, ‘... he may live on the pavement, but is our person now; he cannot be called homeless anymore.’
Here is Khukudi again *(on the right, in picture on opposite page).*
She is with her caregiver, Gouridi. It is not known how long Khukudi was on the streets but when she wandered into Gouridi’s neighbourhood, she was aggressive, had poor hygiene, and her long hair piled high on her head was knotted up and had not been combed for a very long time.

Gouridi took her under her wing and soon earned the reputation of being Khukudi’s shield. She managed to persuade Khukudi to take the medicines; helped her with food in the early days. But within a few months Khukudi started cooking her own food. Gouridi could see Khukudi changing day by day. The progress was slow, but each milestone increased Gouridi’s pride in this woman who had silently borne so much suffering in her life.

An important milestone was Khukudi’s decision to have her hair cut. Another was her insistence that she could take the medicines on her own; she did not want Gouridi to supervise this activity. Yet another was when Khukudi began to supplement her earnings from rag-picking by preparing and selling snacks in the evening. And when she was offered a place in a shelter, Khukudi refused; she chose to be near Gouridi, she said she felt secure around her.

Khukudi’s journey of recovery has been informed to a large extent by the diminutive Gouridi’s large presence in her life. But the caregiver takes no credit. Instead she narrates an incident which shows how Khukudi has taken charge of her own life. ‘We are trying to get a voter identification card for Khukudi. This document will enable her to get a widow pension. So I was filling up the voter identification form and since Khukudi was not around, I put my own thumb impression on the form. When I told all this to Khukudi, she said . . . *Tear up the form; get me a new form.* *I will put my own thumb impression.* Khukudi set me straight. This is how much she has progressed.’

Like Gouridi there are 88 caregivers who make up the community-based caregivers’ pathway. They have no connection to the 150 homeless people with mental illness that they take care of, except the deepest and most fundamental one – that of sharing a common humanity.
Supporting the caregivers and ‘their people’ is the Iswar Sankalpa team. They invest not only their skills but all of themselves in caring for those who have so long known nothing but suffering and neglect. And the results are there for all to see.

Mukesh’s story is a typical example. He developed a mental illness, fell into bad company, did drugs, became severely malnourished and was close to losing his life.

These days, Mukesh (seen in picture on opposite page) is a responsible young man. He takes his medicines regularly, follows a strict daily routine of self-care, and has found himself a source of livelihood. Though Tapan Prodhan (currently in charge of reintegration at Iswar Sankalpa) came into his life as a social worker, Mukesh regards him as his friend, one who helped him – seven days a week for six years – to turn his life around.
This is Kaluprasad (extreme right) with caregiver Sanjay Das and social worker Swapan Halder (extreme left).

Kaluprasad is the field supervisor of the outreach programme. When Iswar Sankalpa receives a phone call regarding a homeless person in a vulnerable condition, it is Kaluprasad who finds him. He is the one who cleans the person, removes the maggots and administers first aid. Kaluprasad does not make a big deal about the depth of his contribution. But he is perhaps the bravest example of the values that the caregivers’ pathway is built upon – care, compassion and love.
The advantages of the community-based caregivers’ pathway are many: the community takes ownership of the homeless men and women; it is also resourceful enough to provide options for employment; this in turn helps the process of recovery and rehabilitation.

The caregivers have a 24x7 presence and are available at any time and even in emergency situations. What is more, the homeless are not displaced and institutionalized. Instead they recover right where they live, within the community. And so they are spared from going through the difficult phase of transition and readjustment.

This pathway also subverts the power dynamics between the mentally ill and their caregivers. It is the Iswar Sankalpa team that reaches out to the people. It is entirely up to them to decide whether they want the team’s services. The power lies totally with the people.
Madhusudan’s story

Every day, social worker Swapan used to visit Madhusudan at the bus stop where he lived. And Sanjay, who had a tea stall close by, brought him tea. But neither dared sit next to him, for Madhusudan had wordlessly communicated that he did not want any kind of help.

It took a year before Madhusudan was ready to receive care. He let the psychiatrist examine him, accepted some clothes from Sanjay and even agreed to let Swapan give him a bath every day.

What brought about the change? Laboni Roy, Assistant Director, Projects, provides an explanation: ‘Madhusudan must have gone through years of suffering and trauma, but nobody had cared. Then out of nowhere, Swapan appeared in his life, visiting him every day. Then Sanjay also showed up. Slowly, slowly Madhusudan must have realized that these people care for him, that they love him. And that made him accept the care.’

Sanjay has now become Madhusudan’s caregiver. He ensures that Madhusudan takes his medicines every day. Swapan still visits him every day. Madhusudan’s hygiene has improved. But there are days, especially cold ones, when he does not want Swapan to give him a bath. Laboni’s advice at such times is: ‘Give the person as much basic hygiene as he is comfortable with, and don’t worry about the rest. Don’t impose your will. Your touch should be of affection, not of force.’
What separates mental health from mental illness is a fine line; it is relative to time and place. What may be considered ‘normal’ in one culture may not be considered so in another culture. Also, a person may be ill for a period of time and then be well again.
Elamathy was Panchayat Councillor for five years. She gave up this position when she developed a severe mental illness which shattered the family. ‘At one point I even started having thoughts of killing her or killing myself,’ says her husband, Chinnaya. ‘But then, the bus arrived.’
Care comes home on a bus

SCARF’s use of technology to provide access to psychiatric services in remote areas

There is a bus that functions as a mobile clinic. But this mobile clinic is unique. It is outfitted with telecommunications technology – TV screen, computer with a high definition camera and high-speed internet. It is through this technology that the psychiatrist who is physically in Chennai city and people with mental illness and their families who are far away in the villages of Pudukkottai district, Tamil Nadu, get connected to each other.

This unique way of linking people in remote areas with a specialist resource has been initiated by the Schizophrenia Research Foundation (SCARF).

SCARF’s community-based intervention of mobile tele-psychiatry plays a critical role in bridging the treatment gap – a gap which is widest in rural areas, where men and women with mental illness live without treatment and care for five to ten years and sometimes even longer.

For four days of the week, the bus parks at a different fixed point in different villages in Pudukkottai district. The fixed point is close to a bus stop so that people from neighbouring villages can also access the mobile clinic. The route is so designed that the bus reaches every fixed point at least once a month.
Today the bus is parked at Thirumayam village. Some of those who have gathered are first-timers, others are regulars. SCARF’s local team interacts with them and carries out the necessary preparatory work.
The clinic is set up inside the bus. Technological devices are hooked up at both ends: in the bus and in the psychiatrist’s office in Chennai.

One person at a time, along with his or her family member, gets into the bus. The consultation with the psychiatrist begins. The psychiatrist as well as the person and the family member are able to see, talk and listen to one another through the television screen.

The clinical co-ordinator facilitates the interaction, and notes down the psychiatrist’s instructions regarding treatment and medication.
As far as possible, the people at each fixed point are treated by the same psychiatrist. This continuity of care is ensured by having a fixed roster and fixed timings for each psychiatrist. An efficient electronic recording system provides the psychiatrist with information regarding the person’s history and progress. The prescription is handed over to the pharmacist who has a small counter at the back end of the bus. Medicines are made available and the date for the follow-up is indicated.

By the end of the day, over twenty-five men and women at different stages in their treatment receive consultation and medicine as well as a lot of personal attention and care. They will come back next month and the month after that on the day the bus is scheduled to visit their fixed point.
While the mobile tele-psychiatric clinic is a critical part of this community-based intervention, it cannot function as a stand-alone entity. It needs a team of community level workers to provide on-the-ground and ongoing support. These community level workers are trained on the job to become the backbone of the intervention. They go from door to door to identify those who are mentally ill, and also to educate and motivate their family members to bring the person to the mobile clinic for treatment. They also provide support all through the journey of recovery and beyond.

Jyothi Amalan (on the right, in picture on opposite page) is one such community level worker, whose courage and determination have put many people – like Mani – on the road to recovery. For ten years, Mani had lived like a recluse in a hut at the edge of the forest. He believed that people were out to harm him and this made him violent at times. He looked ferocious, with his metre-long hair and beard. His family had cut off all ties with him. Everyone in the village was afraid of him.

Even so, community level worker Jyothi was determined to meet Mani. She persuaded two people from the village to accompany her. ‘He had a big knife in his hand and he shouted at us, but I kept talking. I told him that I meant him no harm,’ recalls Jyothi. She went back again and again in the hope that Mani would begin to trust her. The first breakthrough came when Mani agreed to have his hair cut.

With his hair cut, and beard shaved, Mani looked like a different man. This initiation into self-care was done with the consent of Mani and his family. Next, Jyothi wanted Mani to come to the mobile clinic. She visited him every few days. This went on for two months. One day, much to the team’s amazement, Mani showed up at the mobile clinic. He was ready to receive the help that he so desperately needed.

Another milestone on Mani’s journey of recovery was his expressed desire to go back to his family. Jyothi knew that Mani had wrecked all his relationships. But she took it as a challenge to bring about the reunion. It took two years of persistence and skilful engagement to convince the family that Mani was not a threat to them. Finally the family agreed. ‘Reuniting Mani with his family made me very happy. I wanted to jump with joy!’ exclaims Jyothi.

Mani is taking small but significant steps on his journey of recovery. He understands the importance of regular treatment. When a family member cannot accompany him, he makes the trip on his own, travelling by public transport and even changing three buses en route. The family members are still wary of Mani, but not so his niece who says, ‘I spent many years being afraid of my uncle; but all that has changed. My uncle is back with us. I am happy to have him home.’
The third critical piece in this community-based intervention is the community itself.

Dr. Thara, Director, SCARF is very happy with the way the community has supported this intervention. She says, ‘The local community is also involved in a big way; whether it is teachers, the panchayat or volunteers – people are thinking about and talking about mental illness.’

Sujit John, Assistant Director, adds, ‘... when we want to hold an awareness camp, there are people who will give us a kalyana mandapam for free. Somebody will say, I will sponsor the tea and snacks. We have autorickshaw drivers who put our messages in their autos; shop owners who are ready to display posters ...’

Sethu Arumugam (seen in picture on opposite page) volunteers a different kind of support. He came to the mobile tele-psychiatric clinic to get treatment. It was the quality of care he received and the counselling and education provided to his family that motivated Sethu to become a volunteer. He creates a huge impact when he shares his personal experience at awareness programmes.

Sethu also helps out with individual cases, explaining to the family about the need to be supportive, asking for co-operation from those who complain about ‘the nuisance’ created by a person with a mental illness.

The involvement of volunteers such as Sethu helps this intervention to widen and deepen its impact on the community.
SCARF’s mobile tele-psychiatric intervention harnesses a variety of local resources – community level workers and the community at large – to maximize the use of the specialist resource and bring mental health care and treatment to remote areas. This model is replicable, reasonably cost-effective and resource-effective. Its sustainability depends upon its linkage with the community on the one hand and the public health system on the other.
Mujibur Rehman’s story

Mujibur Rehman’s wife, Noorjaanu, is only too happy to talk about the bus.

‘Many years ago my husband was diagnosed with schizophrenia. We had gone to private as well as government hospitals, but we did not see much change.

‘But here, we could see the difference. We come every month. Now he is doing well. He manages our little shop that is just opposite a school; I think he is even considering expanding it, but for that we will have to get a loan.

‘I am happy about the care this team gives us. They come to our house, they meet him in the shop . . . having someone who asks how you are makes such a big difference, especially to a person with this illness. I thank God for sending this service here.’

Some years ago, after 15 years of marriage, Noorjaanu and Mujibur Rehman welcomed their first child – a baby daughter. Now, on the designated day of every month, it is a family of three that waits for the bus to arrive.
Mental health care in India has been limited, for the most part, to the care provided in its 43 mental hospitals. Shrouded in rights violations and inhuman practices, these institutions largely carry forward the legacy of the colonial era in which they were established.

Over the last few years, Tata Trusts and its partners have been collaborating with these institutions to bring about systemic and much-needed reform. A few of these efforts to reshape care pathways are described in this section.

The first narrative is about a critical aspect of reform within the Regional Mental Hospital, Pune. This reform attempts to create a structured pathway of exit for men whose illness has been treated but who have so far not been allowed to leave the institution. You can see that life is coming back to them describes how this intervention will allow the men who are rehabilitated to breathe the air of freedom and resume a life of productivity and dignity in the world outside.

The architecture of care that creates a safe place for personal recovery highlights a very different institutional pathway – a transit-care facility in Chennai for homeless women with severe mental illness. This pathway recognizes the rights of the women to freedom, choice, dignity, inclusion and livelihood, and shows how this promotes personal recovery.

The men were still on the streets, so we had to take care of them describes how, in a rehabilitation home for men in rural Assam, homeless men with severe mental illness worked their way to recovery and were reintegrated with their families.

Earning its place in the community is about a community-based, multi-component effort to bring the local community closer to the mental hospital in Tezpur. This intervention made the community comfortable about accessing the hospital’s services and also made it possible for the hospital to address the unmet needs of the people who lived in the town and in the nearby rural areas.

One step before independence focuses on two women who had been homeless and mentally ill but now live independently and earn a livelihood. It tells the story of how a pathway of care that was collectively created by three organizations, including a mental hospital, led to a dramatic transformation in their lives.
Section

Rethinking institutional pathways of care and recovery
Sachin Naidu has been living in the Regional Mental Hospital in Pune for the past three years. His family does not want him back and so the hospital cannot release him, even though his illness has been treated and he is doing well on his journey of recovery.
You can see that life is coming back to them

"The Devrai pathway for a structured exit from the mental hospital"

Established in 1915 in Pune, the Regional Mental Hospital (RMH) is one of the oldest and largest mental hospitals in India. It faces a formidable set of challenges, including the continued legacy of custodial care and the absence of rehabilitation and discharge planning under the provisions of the Mental Health Act of 1987.

Given the lack of exit options, people like Sachin Naidu have languished in the hospital for several years. They have no freedom, no rights. They are housed in the overcrowded wards designated for chronically ill ‘patients’. They are in poor physical health; their social and living skills are equally poor. They know only two certainties: that their condition will deteriorate further, and that there is no exit.

Changes are, however, underway at RMH. Thanks to an innovative new effort called Devrai, Sachin Naidu may well be one of the first persons to feel the winds of change and freedom. He has secured a job outside and now awaits permission from the hospital to take it up. Sachin’s story paves the way for systemic change, creating a path for people who are on their journey of recovery to leave the hospital and reclaim their lives in the world outside.

Devrai is a critical aspect of reform within the Regional Mental Hospital. Initiated as a collaboration between RMH, Parivartan Trust and Tata Trusts, Devrai is an innovative pathway that takes the form of a recovery-oriented ward and transit-care facility situated within the hospital premises. The goal is to work with a small group of RMH residents in order to prepare them for a phased exit from the hospital.
Two abandoned RMH structures were renovated, refurbished and dramatically transformed to create Devrai.

Each resident at Devrai has his own bed, and a locker where he keeps his clothes as well as his personal kit, that includes items such as comb, hair oil, table mirror and hand towel. When this kit was distributed, one of the residents peered into the mirror and said that that was the first time in more than a year that he had been able to look at his face.
Devrai is more than a physical space. It is an environment that is conducive to the rebuilding of lives, to restoring health and well-being by providing individualized psychosocial intervention, to making the men functional and capable of earning a livelihood outside the hospital.

The Devrai environment and all that it stands for has brought about profound changes in the quality of life of its twenty residents. These are men who were transferred from the main hospital. Changes in the quality of life began with self-care. The men got into the daily habit of taking a bath, brushing their teeth, changing clothes, and using the toilets which, unlike their earlier ward, were clean and even had running water.

Changes in the quality of life also came from having opportunities for relearning social and living skills as well as livelihood skills. Work, and that too work which afforded them a small income, gave the men a sense of purpose as well as a greater sense of physical and mental well-being. Many individuals and agencies came forward to set up livelihood-related facilities, like the nursery where some of the residents are engaged in growing and nurturing indoor saplings and plants.

Accustomed for so long to being invisible and voiceless, at Devrai the men are learning to assert themselves. An important breakthrough is being able to say ‘no’ when RMH employees try to foist their work of cleaning toilets on the residents. Dignity of labour is upheld at Devrai but so is fairness and justice.

Change in quality of life also came from treating each resident as an individual, as a citizen entitled to the same rights as others in the country.

All these years when the residents were in the mental hospital, they did not have any documentation that showed that they existed, even though a government institution housed and looked after them. Many of them had been registered at the hospital simply as ‘unknown male’. The Devrai team has worked hard to secure proof of citizenship for the residents. Many residents are now formally included in the national population database and have been provided with a unique national Aadhaar card and number. This document not only gives them an identity, it is also critical for social and financial inclusion.
The cumulative impact of so many changes has brought about an encouraging outcome. The Devrai pathway has fostered confidence and independence, encouraged supportive relations among its residents, helped restore dignity and addressed their rights as citizens.

Jai Adawadkar, Clinical Services Coordinator, Parivartan Trust, who has been instrumental in setting up Devrai, says, ‘Devrai has given the men hope. I see the change in their faces, in their body language and in the way they talk about their future. They now have a sense of being someone.’

Devrai’s significance also lies in being a sustainable pathway, built on the existing system of care available at RMH. It shows the way for other mental hospitals to also have similar recovery wards.

‘What is very important is that almost everything is from the Regional Mental Hospital,’ says Dr. Hamid Dabholkar, Trustee, Parivartan Trust. ‘The infrastructure, the staff and the residents are from the hospital. What we brought in is the idea, the passion and the knowledge. So there is a great chance that it will sustain.’

Efforts are also underway to operationalize the transit-care facility. Dr. Amit Nulkar, Lead Clinician, Parivartan Trust, highlights its potential as a critical piece in the process of reform: ‘... for those residents that cannot go home, why can’t they become productive members of a larger community, whilst making the hospital their de facto home? In many ways, it is their home, they have lived here for five years, ten years, with no way to go out ... That is the dream of the transit-care facility, where two or three persons can stay – a kind of men’s hostel; they dress up, take their tiffin box and go to work; they come back ‘home’. They are independent. Obviously there is some supervision. But with support, they can be functional and productive members of society.’
Devrai is an example of how the government, a non-government organization and Tata Trusts have come together to create an innovative pathway that offers hope – hope that recovery is possible and that there can be ways out of the mental hospital, out of mental illness and into meaningful lives.
Abhijeet’s story

Abhijeet Mane was found wandering on the streets of Satara. After much persuasion, his brother agreed to come forward and admit him to RMH. For a year and a half, Abhijeet remained in the ward for chronically ill patients. His symptoms of loss of bladder and bowel control did not improve in all this time.

The Devrai team made a concerted effort to get him into the recovery ward. At first he did things very slowly; it was difficult for him to get up in the morning; he wet his bed and could not take care of his personal hygiene. Gradually he regained control of his bodily functions; the medication helped.

Other residents of Devrai also helped him. For instance, every hour, one of them would remind him to go to the toilet. Abhijeet was asked to choose a different resident each day. This person would quietly and gently make sure that Abhijeet did his chores of cleaning his clothes, making his bed... All this helped in habit formation. He became functional enough to operate the coffee vending machine at the RMH Outpatients Department.

Then Abhijeet had a relapse. This was a setback but the supportive environment of Devrai has helped him to get back on the path of recovery once again.
Perhaps no other illness is accompanied by as much stigma and discrimination as mental illness. The stigma leaves a lifelong, inerasable mark on those who are ill; it spans generations; it extends to their families and also to grassroots workers and professionals who provide care. The stigma makes people with mental illness vulnerable to physical and sexual abuse; it snatches away their dignity and human rights, and denies them their rightful place in society. It also acts as a barrier to seeking treatment, and to finding gainful employment.
'When I came here I did not talk to anybody, I did not smile. I was lost in my world. Now I smile nicely, talk and move around here and there. Everybody tells me that I look nice when I smile,' says Saraswathy, who runs a small snack shop at Adaikalam.
The architecture of care that creates a safe place for personal recovery

An exploration of the value framework of Adaikalam

In her doctoral thesis on understanding the mental ill health-poverty-homelessness nexus in India, Vandana Gopikumar quotes a homeless woman named Sita: ‘... You have to live my life to understand what it means to climb trees in the night and save myself from violation of dignity and body, walk past many men and women in my dishevelled, almost naked state and yet go unnoticed, yearn for food and clean drinking water and not be in a position to access it...’

It is the recognition of the lived experience of women like Sita that informs the architecture of care at Adaikalam, a transit-care facility for homeless women with mental illness. Adaikalam is part of a non-government organization called The Banyan. According to Vandana Gopikumar, co-founder of The Banyan, this architecture of care creates ‘a safe place that promotes personal recovery.’

Adaikalam is a safe place where at any given time there are about 150 women, who have the freedom to be themselves. This pathway has rejected the notion that people with mental illness are violent and has replaced it with the notion that each person with mental illness is a unique individual – her lived experience is unique and how she makes sense of herself, her relationships and the world is also unique. And that is why her process of recovery, her journey to regain all that she has lost on account of the illness, is also unique and personal. It takes place at her own pace and in her own time; in fact the journey of recovery is driven by the woman herself.
Whatever her physical, mental or emotional condition may be, there is a health care worker who greets every newly arrived resident as if she is a guest. She is washed, bathed, attended to and given a welcome kit that has items such as soap, towel, hair oil, a packet of bindis and some clothes. The contents of the welcome kit may seem insignificant but for the welcomed woman it is the first offering of care, respect and comfort that she has received in many months or even years.

A multidisciplinary team comprising psychiatrist, psychologist, social worker and other health care workers provides what Dr Kishore, Director, The Banyan, calls ‘humanizing care’. But the agency lies with the woman; to a great extent even the power lies with her. She decides whether she wants to take the medicines, and she also decides whether she wants to stay at Adaikalam or leave. She has power and she has choice.

‘There are options,’ says Vandana, ‘if you want chapatti, you go and make your own chapatti; we have chapatti on some days of the week. About clothing, we offer different kinds of clothing; we offer different kinds of bindis.’

Offering bindis of different shapes and sizes may seem trivial but consider this: a woman from Bengal may have used a large-sized bindi to adorn her forehead; her illness has brought her to Adaikalam in Chennai. Food, clothing, even adornment help the person to reclaim her lost space, to reconstruct who she was; they bring her lost identity to the forefront, and help her develop a pride in being her own person. All these are critical aspects of personal recovery.

And the person has freedom. No room is locked. Not even the Acute Ward where some women go when they wish to be alone.
Not only have the locks gone, but so have the doors to the Acute Ward. This was at the suggestion of the women. And they were right. No doors, open spaces helped to reduce negative emotions.
Saraswathy, who runs a small snack shop at Adaikalam, was preparing muffin batter when Archana Padmakar, Assistant Director, Adaikalam, introduced her. She finished the preparation, put the muffin tray in the oven and then told us about herself, about how she had changed since coming to Adaikalam.

She then returned to the muffins after giving Archana permission to complete her story:

‘Till recently Saraswathy’s world was very small – her shop and her room, that’s all. She is quiet by nature. In the initial days, when her symptoms of schizophrenia were severe, she was even quieter. I wanted to take a picture of Saraswathy. She was doing puja and was looking very nice, with flowers in her hair, but she said that she did not look nice, and refused. That was the way she used to think – that she was not nice and that’s why she was driven away from her home.

‘Now her personality has changed so much. Now she is seen all over the campus. That itself speaks of her recovery. About a year ago, she started running the shop. She has also learnt baking. The courage she has shown, the progress she has made... she is remitted, she does not have symptoms, but nonetheless she has to take medication for the next two years.

‘Saraswathy is very particular regarding money matters. If I ask her, Can I give you the money later, she will say, No, I will come with you to your cabin, and she will make sure that she collects the money right away. She has bought a gold nose ring. She has a bank account where she saves the money that she has earned working in Adaikalam. She wants to save enough to buy a nice gold chain. She is aiming for that.

‘Right now I am not able to see her future outside of this place. We are like parents who feel separation anxiety when their children start school. But sooner or later, we have to let go...’
Meet some of the other women who have rebuilt their lives using the Adaikalam pathway. Some have returned to their homes and families, others live in groups with some supervision; there are also those who live independently.

Each one of them wears a badge of courage that you will see if you look at them closely enough.

In the courtyard of the Cluster Group Homes, Salma offers puja on the auspicious day of Vinayakar Chaturthi.
Sargunam (on the left in picture) and Priyavardhini have been friends for twenty-one years, ever since they met at Adaikalam. Though Priyavardhini continues to be delusional and also has physical ailments, she lives on her own, has her own routine and friends’ circle, and maintains good relations with the neighbours. Sargunam has been off medication for over a year. She lives with her nephew’s family, works as a housemaid and contributes to the household income. Even though she has to travel a long distance by bus, Sargunam visits her friend regularly.
Rajkumari (on the left in picture) lives with her sister Maheswari and her family. Maheswari talks about the many challenges of being a caregiver. ‘I have reached burnout point many times in the last twelve years since Rajkumari got better and came to live with us. I have even yelled at Rajkumari and told her to go back to The Banyan. But that has never come from my heart. She is my sister, I thank God I am in a position to take care of her.’
Shobana was reunited with her husband Karunanidhi ten years ago. She has not missed a single visit to The Banyan Outpatients Department – and her husband always accompanies her. As one of the psychiatric social workers at Adaikalam says, ‘Shobana does not have a complex that her husband is visually impaired and he does not have a complex that she has been mentally ill. They fit each other perfectly.’
The architecture of care that makes up the Adaikalam pathway is intense, particular, personal and intimate. It is built on a framework of values such as compassion, connectedness, negotiation, tough love, spontaneity, inspiring hope, building pride and promoting capabilities. It acknowledges the rights of homeless women to freedom, to choice, to dignity, to inclusion and to livelihood. It recognizes that each person is unique and that she will drive her journey of recovery in her own time and at her own pace.
Devi’s story

Devi lives with her daughter Preethi in Kovalam. She works at a resort in the housekeeping department. Before she leaves for work, Devi cooks and packs lunch for some of the neighbourhood children, to earn some additional income. Preethi will soon complete high school. Mother and daughter are settled in their own routines, they are a family of two who have had to get to know each other all over again.

Devi had left home with two-year-old Preethi when she could not take the beating from her husband anymore. For some time she stayed in a hut and worked as a daily wage labourer, but the landlord threw her out when she could not pay the rent. Living on the streets with no money and a child to look after and keep safe got too much for Devi. She was brought to Adaikalam. As she recovered, she started remembering the past and that she had a daughter. Meanwhile Preethi was returned to her father’s house. She was unwanted and ill-treated and taken to an orphanage. It took many years and much legal work to reunite Devi with her daughter.

At Adaikalam, Devi recovered, and learnt many skills which she put to use to earn money. When she was fully remitted she moved to Kovalam with Preethi. She lives independently along with two other former residents of Adaikalam.

Devi likes her job and is not afraid of falling ill again. ‘I fell ill because the situation was inescapable. Now my worries are routine, they are about Preethi settling down, but nothing I cannot manage.’

Preethi, who is usually shy and quiet, could not help showing her feelings when asked about her mother. ‘I am proud of her. I want to make life easier for her.’
The journey of recovery is often long and arduous, and also deeply personal. The individual has to rebuild her life step by step: she has to put in the hard work to recreate herself and her world; to change her attitudes, values, goals, expectations, skills and maybe even roles; to re-establish connectedness by repairing and recreating relationships that were damaged by the illness; and most importantly, to regain her autonomy and identity.
One day, while living on the streets, Ignatius Mundu went to a photo studio to take a picture of himself. Twelve months later, he was happy to have his picture taken once again. This time he was a resident of the Udayan Rehabilitation Home for Homeless Men.
The men were still on the streets, so we had to take care of them

Recovery and reintegration of homeless men at Udayan

Udayan Rehabilitation Home for Homeless Men in Bamnigaon, Kamrup district, Assam, is one of the many initiatives of Ashadeep, a Guwahati-based organization. In the past two years at Udayan, 48 men with mental illness have returned to functionality and been reunited with their families.

Udayan does not look or feel like an institution. It is sprawling, has open spaces, there is life and growth, and flowers and vegetables in the overflowing kitchen garden. And there is the effortless unfolding of the day. The activities are many, the purpose just one – to support the men to rebuild aspects of their selves that were destroyed by their illness and the time they spent on the streets.

Back home, the men have a routine, they work, earn, attend to their relationships and take part in social activities. These home-like rhythms are replicated at Udayan and care taken to be mindful of Assamese culture and traditions. Here, rice is part of all the meals, including breakfast, because that is what the men eat at home; the beds are wooden, not steel, and the cotton bed-sheets are the same as they are in Assamese households, bright with big prints . . .

Most residents of Udayan are in their twenties and thirties. Most of them are identified and brought into care during the early stages of their illness. These factors, combined with the home-like environment and care they receive at Udayan, enable most of them to recover within four to five months.
Working out in the open, tending to the garden, growing their own vegetables — some of the many life-affirming activities at Udayan.
WE HAD TO TAKE CARE OF THEM
A Standard Operating Procedure formulated and notified by the government of Assam has played an important role in bringing the homeless into care as quickly as possible.

This Standard Operating Procedure directs the police to pick up homeless persons from the streets and take them to the designated civil hospital, where they are examined. If they are found to have a mental illness, they are taken to one of the designated facilities such as Udayan for rehabilitation and then reunited with their families.

Assam is the only state to have this Standard Operating Procedure. Advocacy with the government by organizations such as Ashadeep has brought about this critical policy reform.
Once a resident of Udayan is rehabilitated, it is Joseph Sangma **(seen in picture on opposite page)** who is in charge of reintegrating him with his family. The challenges of reintegration are many, especially if the person’s home is located in a remote rural area. In most cases, it is not possible to contact the family beforehand. There is also the worry of acceptance and support from the family. But most times the homecoming is a joyous occasion.

Josephda speaks of the time when he and social worker Himangshu Nath had gone to Bihar, to an area near the Nepal border, to reintegrate two men with their respective families.

After they got off the train, Josephda set out with one of the men. They crossed endless paddy fields and were covered in mud by the time they reached the man’s house. His father was feeding the cattle. No sooner had he called out, ‘Dada!’ than the father threw down the bucket, and ran to his son. This happy occasion is still fresh in Josephda’s mind. ‘They were so full of gratitude; the father brought a bucket of water and started washing our faces. One of the cousins brought a goat. They insisted I stay for the feast but I kept telling them that I had to go, my colleague was waiting for me.’

In the meantime, Himangshu and his companion had got into an autorickshaw. Himangshu asked the driver about the family that he was looking for. Hearing the family’s name, an elderly woman, who was seated next to the driver, turned around and exclaimed in wonder and joy. She could not believe that she had not recognized her own nephew! Within half an hour, the whole village had gathered to celebrate the homecoming.

According to the team, nothing compares to the ‘high’ they experience every time they reunite a person with his family. ‘There was one person whose family I could not trace,’ said Josephda. ‘And that was my very first reintegration. So I told myself, the next one, hundred per cent, I will reach him home.’ This is a promise he has kept, not once but several dozen times.

Reaching the person home is not the end of the story. The team’s involvement with him continues – ensuring follow-up, staying in touch with the family to find out if any help is needed, even making sure that medicines reach in time by sending supplies by parcel post or delivering them in person.
'What was my vision for Udayan? I find it very difficult to answer this question. It was a very simple thing. We had worked with the women, so there were very few of them on the streets. But the men were still there. So we had to take care of them.'

Mukul Chandra Goswami
Founder, Ashadeep
Nilkamal’s story

Nilkamal Barman was rescued by the police from the National Highway and brought to Udayan. As he got better, Nilkamal shared his story – he had suffered a head injury and also had a history of epilepsy. When he lost his job, his brother would not let Nilkamal stay in the ancestral home. His parents-in-law gave refuge to his wife, young son and him.

At Udayan, Nilkamal recovered; he was anxious to go home, he missed his young son. Five months later, Josephda accompanied him home. Overjoyed and shocked, his wife fainted when she saw him. Her parents told Josephda how hard they had searched for Nilkamal; they had even filed a missing persons report. But they had not given up hope.

Nilkamal came for his first follow-up to Ashadeep’s Outpatients Department (OPD) in Guwahati. He did not turn up for the second, so the social worker followed up over phone and counselled the father-in-law about how critical it was for Nilkamal to continue with his medication. The family was also told about a psychiatric OPD that had started in a Primary Health Centre that was much closer to their village. Here too, the medicines would be available to them at no cost.

Then came the news that Nilkamal had had an epileptic episode. The family had not been able to afford the expense to travel to the Primary Health Centre. So Josephda made the trip from Guwahati to Nilkamal’s home with the medication.

The family has now resolved that they will somehow manage to make the trip to the OPD regularly, so that Nilkamal’s treatment can continue.
Recovery from mental illness requires support, and support can come from different sources – family, friends, co-workers, community caregivers and professionals. Medicines can treat only the biological aspect of a disorder. Other aspects, especially the psychosocial aspects, require a different kind of support. The main object of this support is to build the person's resilience, confidence and self-worth; to address his basic needs, including the need for security; to help in restoring relationships and finding meaningful employment; to find ways to include the person in all aspects of the mainstream of life.
One day Moon Baruah’s husband decided he did not want his young wife and baby daughter. Moon found her way back to her parents’ home in Tezpur, where she became severely depressed and developed a mental illness.
Earning its place in the community

How the INCENSE team created a bridge between the mental hospital and the community

The Lokpriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH), Tezpur is one of the oldest and largest mental hospitals in India. Although a centre of excellence, LGBRIMH was isolated from its local social milieu. The local community also kept its distance from the hospital because of the stigma of it being a ‘mental’ hospital. They accessed treatment erratically, mostly when the person’s symptoms became acute.

A bridge was needed to connect the hospital and the community, one that would make the community aware of and comfortable about accessing the hospital’s many services. The ‘connect’ would also allow the hospital to be truly responsive to the local community and help it address the many unmet needs of the men and women with mental illness who lived in Tezpur town and in the nearby rural areas. A collaborative, community-based, multi-component intervention became that bridge.

The collaboration was between LGBRIMH and INCENSE, a programme undertaken by Tata Trusts along with Sangath and Parivartan Trust. LGBRIMH provided clinical, social and rehabilitation support. A local team of INCENSE (Integrated Community Care related to the Needs of Vulnerable Persons with Severe Mental Disorders) became the hospital’s voice and presence in the community.

The INCENSE team built trust and established its credibility in the community. It created awareness about mental disorders: that they are illnesses that can be treated, and that quality assured treatment was available fairly close by at LGBRIMH.
The team reached out to persons with severe mental disorders who lived at home. It spent time understanding each person, especially in terms of his or her needs and disability, so that it could create individual care plans and devise ways of supporting and facilitating the process of recovery in tandem with LGBRIMH. During this process, the team also identified one of the major unmet needs of persons with severe mental disorders – finding meaningful work that could also become a source of livelihood.

Kabita Das used to be a handloom weaver. She stopped working on the loom when she developed a mental illness. She did go to LGBRIMH but was erratic in her treatment. The INCENSE team initiated a series of psycho-education sessions with her and her family. Kabita agreed to get treatment once again and be regular at it. She kept her word.

As she progressed on her journey of recovery, Kabita wanted to get back to her craft. But the family did not have the resources. The INCENSE team stepped in to provide the loom, the materials and also set up the shed. Within no time Kabita was earning enough to be able to conduct her enterprise on her own. Her speciality is weaving a traditional Assamese cloth called gamusa that is used for ceremontal functions in the village and in the community. Business savvy Kabita also caters to the tourist market. She knows the value of her skill and does not hesitate to price her products at a premium rate.

Returning to meaningful work and being able to earn from it – these aspects were fundamental to Kabita’s recovery. The dramatic change in her self-esteem was on full display when she addressed a gathering of 200 invitees and spoke about how the intervention had benefitted her. She even had a special word for those who were undergoing treatment, motivating them so that, like her, they too would get better.
The INCENSE team has also made attempts to secure work through individual job placements, not only for those persons who are on their journey of recovery but also for caregivers. The inclusion of caregivers is a unique feature of this intervention.

In addition, the team has developed work clusters among people who live close to each other. The group comprises those who are on their journey of recovery as well as their caregivers. The group selects an activity that its members are interested in, one that also has some income-generating potential.

Team member Rupali Sharma (second from the right, in picture on opposite page) leads the tailoring activity. She trains the group to produce embroidered and tailored products. The rehabilitation unit of LGBRIMH provides the materials and also buys back the finished products. The women earn a monthly income. But that is not all. Travelling to the unit fosters independence and confidence; spending many hours at the unit encourages interaction; news is exchanged and friendships are forged. In this way, many more unmet needs are answered. The linkage of the work clusters to the rehabilitation unit of LGBRIMH also helps reduce the isolation and stigmatization of the hospital.
As the INCENSE team gained more and more trust in the community, volunteers came forward to help with identifying those in their neighbourhood who needed help. That is how Recovery Support Worker (RSW) Kishore Baruah came to know about Moon Baruah. He visited the family. At first Moon’s father was very negative; he was convinced that Moon would never get better. Kishore was equally determined to persuade him to allow Moon to get treatment.

Finally her father agreed and treatment started. Within six months, even the father noticed the improvement in his daughter. Moon helped her mother with housework, took an interest in her daughter, and diligently attended the Outpatients Department at LGBRIMH.

As Moon began her journey of recovery, Kishore wanted Moon to join the tailoring unit that was close to her home. Moon was interested in tailoring but did not feel physically strong enough to travel. So another work option was worked out for her.

Moon’s home has a fishpond in its backyard. The local team saw its potential to generate a collective work option for Moon and two other persons, including a caregiver. With the help of the department of Fisheries, this work group will augment the pond so as to improve the quality and quantity of fish which, when harvested, will provide an income to the group.

While Moon’s father still worries about Moon, this group activity that takes place daily in his fishpond, the continued visits from Kishore, and the positive changes in Moon – all reassure him that even though Moon has been abandoned by her husband, she can move ahead on her journey of recovery with the help of others who are willing to reach out to her.
In addition to the department of Fisheries, the INCENSE team has other local and regional partners that have become a supportive network. For instance, talks are underway with the department of Agriculture for the setting up of kitchen gardens, and Pragati, the women’s group of Tezpur University exhibits and sells products made by men and women on the road to recovery.

Rukhsar (on the left, in picture on opposite page) is Rashida Khatun’s younger sister. She was in her final year of high school when Rashida developed a mental illness. It frightened her to see her sister become housebound, morose and even talk about ending her life. Everyone in the family felt helpless. They did not know how to help Rashida get better.

Intervention from the INCENSE team and regular treatment at LGBRIMH made the difference. Then the team and Rashida discussed work options. She said she liked embroidery and knitting. And that is how Rashida has become a regular at the rehabilitation unit of LGBRIMH, picking up materials from there, and taking back colourful products that earn her an income and give her the satisfaction of being useful as well as creative.

Now Rashida is full of demands. She wants a sewing machine and she wants to buy new clothes. And she is no longer afraid of going to LGBRIMH, either on her own or with some other women from the neighbourhood.

Rashida, like many others and their families, has revised her opinion about the hospital. It is no longer a place that evokes fear and shame. Now it is seen as a supportive place that has earned its place in the community. Rashida wants to attend training workshops in LGBRIMH’s rehabilitation unit to enhance her skills.

Her sister’s illness and recovery have redefined what Rukhsar wants to do with her own life. She is now a peer worker with the INCENSE team and also performs in their street plays. She has a minor role, but she is keen to observe and learn how the other team members use the medium of a street play to draw the attention of the audience to their words and actions.

Rukhsar is happy to be part of the performance. As she is to be part of the bridge that brings the community closer to the hospital and helps the hospital reach out to the community. ‘My family did not know anything about mental illness and the hospital till RSW Bishnu Das came and talked to us; now I should also do something, I don’t want others to suffer like my sister did.’
The young team of INCENSE has become a bridge between one of the oldest and largest mental institutions in the country and its surrounding community. The result: the hospital has been accepted as a positive and useful resource whose many and useful services are comfortably accessed by the community.

The team also uses its ingenuity to create livelihood options, not only for those with mental illness but also for their caregivers.
Hemanta’s story

Hemanta Borah dropped out of college when his family could not support his education. To make matters worse, the family lost their home; poverty took a toll on Hemanta’s physical and mental health. The bewildered family did not know how to help him. Hemanta remained mentally ill for eighteen years.

According to Hemanta’s mother, Recovery Support Worker Biswajyoti Borah was a godsend; it was he who changed their sorrow to joy. Biswajyoti was part of the INCENSE team. He took Hemanta to LGBRIMH for treatment. His constant attention and presence became a source of strength for Hemanta on his journey of recovery.

When Biswajyoti realized that Hemanta was skilled at cutting wood and bamboo, he encouraged him to work at crafting bamboo products. Hemanta liked the idea, especially because it could provide a source of income for his family. To begin with, he worked on small products such as fans.

‘At first his finishing was not very good,’ said Biswajyoti, ‘but now his products are good enough to be sold in exhibitions; they fetch him more than a thousand rupees each month.’

When tourists drop by his house to buy some of his work, his mother urges him to raise the price. But Hemanta stays firm. ‘What will they think of Assamese people if we overcharge!’ exclaims Hemanta.
The journey of recovery is driven by hope. Hope that recovery even from severe mental illness is possible. It is this hope that charges the person to seek treatment and continue with it, to empower herself and renegotiate her place in the world.
One step before independence

A Parivartan Trust-led collaboration
to help homeless women get back to the mainstream of life

It is evening. Indu and Sukanti are returning from work. On the way they will shop, maybe meet a friend and have a chat... just like thousands of women in Pune city.

Indu and Sukanti – ordinary women with extraordinary lives. There was a time when both women were homeless, mentally ill and admitted to the Regional Mental Hospital (RMH), Pune, where their illness was treated. Then they were discharged. But Indu and Sukanti did not have a home to go back to.

Indu’s husband had abandoned her, and her brother and his wife did not want her to live with them. That is how she had found herself on the streets where she had spent ten years of her life.

Sukanti is from Odisha. When her husband died, her mother-in-law threw her out of the home, keeping back Sukanti’s two small children. She was found in Mumbai and brought to Pune.

Not wanted at home and with no financial or other resources to find shelter, Indu Kshirsagar and Sukanti Nayak would have found themselves back on the streets. In all likelihood, they would have been taken advantage of, ill-treated, abused, and sooner or later they would have become severely mentally ill all over again.

This frightening scenario, however, did not take place.
Along with Tata Trusts, three organizations stepped forward to collectively create a pathway for the crucial interim period between discharge from the mental hospital and reintegration into the mainstream of life.

The pathway took the form of a supported community housing facility. It would be their temporary home; provide shelter, equip them with social skills and living skills; prepare them to earn a livelihood so that eventually they would be able to live independently and negotiate the many challenges of city life.

Maher provided temporary shelter as well as a caregiver. Parivartan Trust undertook the responsibility of providing psychosocial intervention, job placement and on-the-job supervision. RMH provided medicines and psychiatric care in its Outpatients Department.

This pathway became a lifeline for Indu and Sukanti and many other women who survived the streets, fought back the darkness of mental illness, and showed grit and courage to want to create a new life for themselves.

How long will Indu and Sukanti need this pathway? Caregiver Varsha Bhujbal (seen with Indu in picture on opposite page) says, ‘They have all journeyed step by step; with each step they have progressed. This pathway is getting them ready to become independent.’
Psychosocial intervention plays a critical role in helping create a new life. Shamika Bapat (seen with Indu in picture on opposite page), Clinical Services Coordinator, Parivartan Trust, talks about the nature and scope of Indu’s psychosocial intervention:

‘When you are mentally ill, money has no meaning. So Indutai, who had been on the streets for ten years, had to relearn how to handle money: even simple calculations such as . . . if you buy vegetables for three rupees and you give the shopkeeper five rupees, you have to get back two rupees . . . have to be relearnt.

‘Indutai had to relearn social skills – how to converse, how to make a request, how to apologize, how to communicate with the doctor at the mental hospital.

‘Every small aspect has to be relearnt, including personal hygiene – the need to keep body and hair clean; also how to dress, how to appear neat and presentable.

‘Indutai had never been inside a mall. When she got a job in housekeeping in a mall, she did not know how to use the lift or the escalator, or the western-style toilet. We used to accompany her to the mall and sit there all day long during the first few weeks.

‘Confidence building is a big part of psychosocial intervention. We had to work hard with Indutai to raise her self-esteem.

‘It is like teaching a child. Every small thing that we take for granted has to be relearnt. Old skills that have been forgotten and new ones as well; it is equipping the person with the skills and the confidence to interact with the community.’
ATM मध्ये प्रवेश करताना
कृपया हेलमेट, गौंगल,
कॉप, स्काफ घालून
येऊ नये, आश्विन
Today Indu and Sukanti are independent. They live in a women’s hostel. And work hard to earn a living.

Indu holds down two jobs; she works as a cleaning assistant in an office and also makes chapattis in the hostel. Sukanti works in housekeeping in a residential facility. Her employer is more than happy with her work. Her confidence is growing in leaps and bounds. She goes to the bank on her own; she wants to save as much money as she can, so that when she visits her children in Odisha she can give the money to her mother-in-law. Her only extravagance is her smart mobile phone.

Shamika completes Sukanti’s story: ‘Sukanti is not even 30 years old. Not a single thing has gone smoothly for her since she was born. Her parents rejected her, sent her off to live with her aunt who was not good to her. Her uncle did not behave well with her. She was forced to marry someone she did not care for. Her mother-in-law harassed her and when her husband died she was thrown out of the house. She went back to her mother who did not want her. She tried going back to her in-laws but was refused entry into the house. That is how she found herself on the streets. She has suffered so much. And still she is very stable, very positive; the way she has coped with the adversities in her life, that’s a learning for us also.’
Indu and Sukanti are proof positive that it is possible to reinvent and rebuild lives even after undergoing all manner of suffering. All they needed was a pathway that offered shelter, skills and support, so that they could equip themselves to return to the mainstream of life.
Mustafa spends most of his time in the market; he does petty jobs and earns enough to support himself. After finishing his work in the market, he goes to the INCENSE office almost every day and salutes the team — and what a salute it is!
Make their valour count!

Mental illness is closer to us than we realize. Let us take a close look around our own lives – our family, relatives, friends, colleagues, people who live in our neighbourhood . . . In the criss-cross of these networks we will find someone with a mental illness: an ageing relative, perhaps, who suffers from dementia; a neighbour’s son who is so afraid of crowds that he hardly leaves home; a colleague’s young daughter who committed suicide; a friend who has extreme mood swings; a co-worker’s grandmother who suffers from acute anxiety . . . And what about ourselves? Haven’t we at times felt so ‘low’, that doing even a simple and habitual task required a gigantic amount of effort?

All this brings home a fundamental truth: that mental illness affects us all, directly or indirectly. But despite the pervasiveness of mental illness there is a severe shortage of trained professionals to provide specialist care and treatment in our country. According to one estimate\(^1\) there is a 77 per cent deficit of psychiatrists in the country. The shortage of clinical psychologists is 97 per cent, and of psychiatric social workers 90 per cent. More and more professionals are therefore needed, who can provide clinical care.

While the need for specialized resources is undeniable, it is equally true that people with mental illness need much more than medicines and clinical care. This ‘much more’ comes from a variety of sources: from community workers, family members, medical officers at health centres, and just ‘ordinary’ men and women motivated by simple kindness and compassion.

A few of their stories are shared here.


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Community-based programmes are a significant way forward in addressing the mental health crisis in our country. And it is the frontline workers – the community health workers – who form the backbone of all such programmes. It is they who undertake the difficult task of providing the individualized, all-round, day-to-day care and support that is critical to recovery. Although these health workers are not highly educated, they go through a systematic training process that enables them to provide high quality care under supervision.

Community health workers play many roles – they are confidants, educators, all-round help providers; they create awareness about mental illness and treatment; they become actors in street plays, and much much more.

Parivartan Trust’s community health worker Sultana Riyaz Mulani is on her way to a street play venue. She will help set up the play and interact with the audience after the performance. If need be, she will also conduct a group discussion to reinforce the key content points of the play.
The work of the community health workers is tough and thankless. Many a time they are shunned and abused by families who are unwilling to accept that a family member has a mental illness. But they do not give up; they continue making home visits, find different ways to educate and motivate the families.

Their work is also physically, mentally and emotionally challenging. It is not uncommon for community health workers to find men and women kept in chains by families that are helpless and unable to cope. Discouraged they may be, but they soldier on; they do not give up hope; and when they finally make a breakthrough, when they are able to motivate a family to seek treatment, they get their reward: they earn the trust of the family and forge relationships that, in the words of Namrata Lavhale (seen on the right in picture above) ‘... are even greater than friendship.’

Here is an account of another friendship: between Sharada Khawale (seen on the left in picture on opposite page) and community health worker Rupali Bhate. Like Namrata, Rupali also belongs to the Jan Man Swasthya Programme team of the Foundation for Research in Community Health (FRCH).
Sharadatai’s illness had ruled her life for eight years. She remembers those years when she had suffered from a major depressive disorder. Then Rupali and the local FRCH team motivated her to come to the mental health clinic that they conducted at the Walha PHC. Rupali made constant home visits and became a regular feature in Sharadatai’s life. With counselling, psychosocial education, a regimen of exercises and clinical treatment, Sharadatai underwent a dramatic transformation within six months.

When asked to describe her contribution, Rupali acknowledges: ‘I think that Sharadatai found in me someone who understood her and her problems, and that also helped a lot.’ When asked why she chose to work as a community health worker, she says: ‘My work gives me the satisfaction that I can do something for others . . . My self-confidence increases; I feel that I will be able to face even more difficult situations and overcome whatever obstacles come my way.’

Like Rupali, most community workers agree that their work impacts and enriches their own life as well; that, in helping bring about a transformation in the person with mental illness, they too get transformed.
Mental illness takes a toll not only on the person who is ill but also on his or her family. Caring for a family member who is not responsible for her actions, undertaking the financial responsibility for treatment, dealing with the stigma, and above all, coping with the emotional trauma of seeing a loved one suffer – all this is part of the daily burden carried by families of people with mental illness. At the same time, the support, care, understanding and love of the family is critical to recovery.

Khursheeda Begum carries a passport size photo of her son Shams Tabrez Alam and shows it off to all and sundry. The mother gives praise and blessings to the Urban Mental Health Programme of the Kolkata Municipal Corporation for the transformation in her son.

‘My son is well now and is back to work, driving a big truck,’ says the mother. ‘But two-and-a-half years ago, my son was eating out of garbage, had not slept in six months and had become so violent that we had to tie his hands and feet.’
When his wife Mohanambal developed post-partum psychosis, Ramachandran left his job in Coimbatore to come back to the village to get her help and take care of her. His happiness at his wife's progress is writ large on his face. ‘I know she has mental illness; I am able to accept, adjust and also help her to be as functional as possible.’

Ramachandran has invested his savings in a small shop where Mohanambal works alongside him. He now wants to take a loan to expand the shop. ‘I want to put the shop in her name so that she has the satisfaction of owning the place. The bank account is also in her name.’
There are over 25,000 Primary Health Centres (PHCs) in our country. Imagine the impact our public health system would create if all the medical officers in all the PHCs were to extend their role – like the two doctors featured here – to include treating at least some of the mental illnesses.

Dr. Arun Pathole is the Medical Officer of Limb PHC, Satara, Maharashtra. The community looks up to him; his Outpatients Department is always overflowing. But he is willing to take on a larger workload and reach out to community members who have mental illness. And to do that, he has undergone training in treating epilepsy and would like to be trained in treating other severe mental illnesses as well.
Other medical officers like Dr. Ujjal Kumar Sarmah (seen in the centre in picture below), Senior Medical and Health Officer, Boko Block PHC, Assam have, in fact, begun the work of identifying those with mental illness among the patients who come to their PHCs for primary health care.
Like doctors, other health professionals too can make a difference – particularly in the rehabilitation of people who are on the road to recovery.

Jai Adawadkar (seen on the left in picture below) has a Master’s degree in Clinical Psychology. Shamika Bapat’s Master’s degree is in Counselling Psychology. As professionals, both these young women chose to work in the mental health sector and that too in interventions that are related to rehabilitation.

Jai has played a key role in setting up a recovery ward for men, called Devrai, within the Regional Mental Hospital, Pune. Shamika has helped create a pathway that offers shelter, skills and support to homeless women during the critical period of transition from the mental hospital to the mainstream of life.

Jai and Shamika represent many young, committed professionals who find their work with the mentally ill to be rewarding.
Dilip Gaonkar, Coordinator, INCENSE programme, Tezpur, says that working with the mentally ill, seeing them overcome obstacles, become independent and get their lives back, motivates him and his team to work with even more zeal. Such is the rapport that he and his young team have built with the homeless as well as with the families of people with mental illness that his office has become like a drop-in centre.

Mustafa is one of the regulars. He comes to the office almost every day and salutes everybody. What Mustafa is perhaps saluting is the acceptance that he gets from all the team members in that office. Perhaps he intuits their affection and understands that he matters to this young team.
Can the role of public officials include advocacy for service delivery in mental health programmes? Can it also include the use of public resources for the benefit of people with mental illness? The answer to both these questions is . . . YES!

Popular local leader and councillor Nizamuddin Shams has played a key role in bringing the Urban Mental Health Programme to his ward’s 80,000-strong, low-income population in Kolkata. This programme, initiated by a non-government organization called Iswar Sankalpa, is conducted in the Urban Health Unit, which is nested within the community. This makes the programme not only accessible but also acceptable: people can walk to it; women can go there on their own; but most importantly, since the Urban Health Unit is used by everyone for their primary health needs, those with mental illness and their family members do not feel stigmatized when they too go there. A caregivers’ support group that meets regularly in the Urban Health Unit is also part of the Urban Mental Health Programme. The hope is that the success of the programme will help in advocating for such a programme in every Urban Health Unit in every ward of the Kolkata Municipal Corporation.
Every day, police officers of Hastings Police Station in Kolkata come face to face with homeless men with mental illness. This is because there is a Day Care Centre for Homeless Men within the premises of the police station.

The location of the Day Care Centre inside the police station is an ingenious strategy. It provides law enforcement officials an opportunity to see the homeless with mental illness not as lawbreakers and nuisances but as people – as vulnerable people who need their help and protection.
Can an ‘ordinary’ person, one who is not a public official or a medical professional or a health worker, one who has no ties of family or friendship to any person with mental illness, make a difference?

YES, we can. Each one of us can make a difference. All it requires is some imagination, ingenuity, skills and sensitivity.

Pujari Raghunath Poudel, the priest in charge of a temple goshala (cow shed) in Tezpur, has offered to provide work to men who are on their journey of recovery. He feels that having a daily routine of tending to the cows, feeding and bathing them, will help the men gain confidence and even earn a small income.
What is it that we can do?

We can educate our families and friends; create livelihood opportunities; include mental health programmes in our philanthropy; address stigma; use technology to create solutions that can facilitate access to treatment.

We can offer our expertise in training; set up support groups for caregivers; use film, social media, print media, any media to tell inspiring stories. We can advocate for institutional reform, for policy change . . .

We can find ways to help strengthen existing pathways or create new ones. The potential for caring and kindness, for giving and receiving, is limitless.

Next time you see a homeless person with a mental illness, see his suffering and helplessness; when you encounter a person on her journey of recovery, see courage and resilience; and when you see a family member or friend or professional or anyone else making the effort to reach out to someone with mental illness, see grit and grace.

The journey of recovery from mental illness is a journey of hope and courage – both for the people with mental illness and for those who reach out to them.

Make their valour count!