CREATING SPACE FOR THE NOWHERE PEOPLE

NAYA DAUR

COMMUNITY-BASED TREATMENT AND SUPPORT FOR THE HOMELESS MENTALLY ILL

A REVIEW

ISWAR Sankalpa

Support for the mind

Review Study supported by the Navajbai Ratan Tata Trust

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ISWAR
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WHO ARE THE NOWHERE PEOPLE?

WHEN YOU ARE HOMELESS
AND CAN BARELY CLOTHE YOUR BODY,
YOU HAVE ONLY YOUR SENSE OF SELF TO
REMIND YOU THAT YOU ARE HUMAN.
YOU ARE VULNERABLE.
PSYCHOLOGICALLY, SOCIALLY,
ECONOMICALLY.

WHEN YOU ARE MENTALLY ILL,
YOU LOSE YOUR SENSE OF SELF, AND
OTHERS SHUN YOU.
YOU ARE VULNERABLE.
PSYCHOLOGICALLY, SOCIALLY,
ECONOMICALLY.

WHEN YOU ARE HOMELESS
AND MENTALLY ILL,
THE WORLD TURNS ITS BACK ON YOU.
YOU DON'T EXIST.
YOU BECOME THE NOWHERE MAN

PREFACE

Based in the city of Kolkata, West Bengal, Iswar Sankalpa is a non-profit organization that aims to ensure the dignity and holistic well-being of persons with mental health problems, particularly those from less privileged backgrounds.

Initiated in June 2007, Naya Daur, Iswar Sankalpa flagship programme, is a sustainable community based care and support programme for the homeless mentally ill, - a programme that weaves together state, private and community into a network of resources that not only cares for this forgotten population, but works actively towards making them productive members of families and community. As far as the organization is concerned, there can be no population more underprivileged and under-served than the homeless mentally ill, and the model of care has been designed with the following objectives:

- To bring together a range of agencies needed to take care of the needs of a homeless mentally ill person.
- To provide facilities and services to counter the abysmal lack of mental health in the public health system.
- To address discrimination in a class of people already marginalized by poverty.

The primary purpose of this document is to chronicle the experiences of Naya Daur from inception till date, (June 2007 – March 2011), a period of about four years. Although the project is supported by documents, including case reports, the organization's periodic reports to funders, and annual reports, it is necessary to collate the information in these in a comprehensive manner to record the evolution and processes of the community based model of care and support for the homeless mentally ill, document the learnings through this journey, and to understand its outcomes and impact for the purpose of informing further action.

Iswar Sankalpa feels that its community based model is innovative and cost-effective, and most importantly, addresses the discrimination faced by the mentally ill, whatever be their socio-economic status. The journey however, has not been without its challenges and failures, and the organization would like to share its learnings with other organizations and individuals who work in mental health and allied support services, both state and non-state. Iswar Sankalpa hopes that this document will be of particular interest to organizations that have adopted community based mental health mechanisms.

While the successes have been many, the untimely death of Dr. K. L. Narayanan, one of the founders and key visionaries of Iswar Sankalpa, just a year into the project, has been a body blow to the team. His loss however, has made us more determined to live up to his vision of a world where the mentally ill, whether homeless or otherwise, are treated with the respect and compassion that is their right.

This report is a tribute to his vision.

Sarbani Das Roy,
Secretary, Iswar Sankalpa

ACKNOWLEDGMENTS

CLUBS

Rotary Club
Behala young men's Association
Subhas Sangha, Kashi Mitra Ghat
New Sporting Club, Kankurgachi
Jhamapukur youth sporting Club
Pradeep Sangha, Shyambazar
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Jana Swasthya Committee
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Junior Boys Sporting Club, Khidderpore
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Gitanjali club, Chetla
66 Pally
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Putiyari Club
Minister club
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Dhakuria Rickshaw Union
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Shri Jawed Shamim (Jt. Commissioner HQ)
Shri Goutam Mohan Chakraborty D.G. Armed Force)
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Burtolla P.S.
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Jorabagan P.S.
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Medica super Speciality Hospital
Rotary Club
Jayprakash institute of Social studies
Amrapali
CDMU
New Life Nursing home
Salvation Army

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Department Of Health and Family Welfare
Department Of Women and Child Development and Social Welfare

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Alteus Biogenics Pvt Ltd
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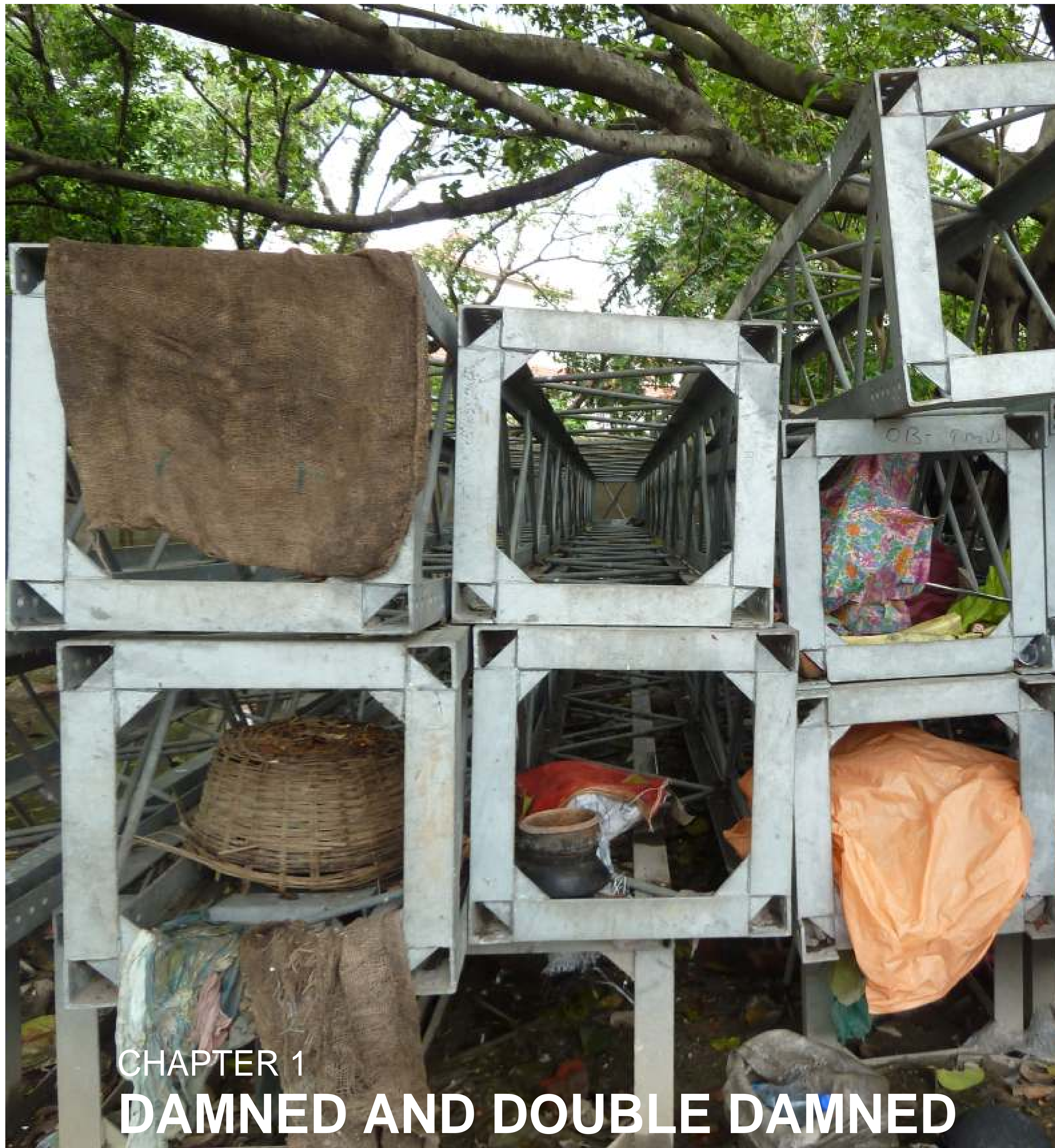


CHAPTER 1

DAMNED AND DOUBLE DAMNED

THE NOWHERE MAN

THE INDIGNITY OF URBAN HOMELESSNES

Harsh Mandar's “Living Rough, Surviving City Streets, a Study of Homeless Populations in Delhi, Chennai, Patna and Madurai” is one of the few insights available into what it means to be a homeless person in urban India. Being homeless means living a sub-human life – sleeping under a bridge or on a pavement, eating sub-standard, irregular meals, and performing daily ablutions in full view of others. Being homeless means bringing up a family without any privacy or protection, being vulnerable to the vagaries of nature, violence and abuse from street predators, or even sudden death at the hands of a careless drunken driver.

Being homeless means having little or no access to even the most basic of public services, and paying for everything that has to be used. At the Sulabh complexes for instance, every visit to the toilet, every bath, must be paid for, in cash, immediately. At road-side taps, being homeless means have to wait till slum-dwellers – citizens with more rights – collect their water. Even night shelters – if there are any - come at a price. Yet, being homeless means being a non-citizen – being denied public rations, a BPL card or even a voter's identity card.

While the urban middle class look down on the homeless as people with no right to be where they are and 'wish they would go back to wherever they have come from', the state has an openly hostile relationship with them. State authorities look on the urban homeless as parasitical, lazy, unhygienic and largely criminal. In periodic 'beautification' drives or ironically enough on Republic Day or Independence Day, the

police and municipal bodies evict the homeless from their spaces so that the 'dignitaries' who pass through the streets are not offended by their unseemly presence.

There are laws that criminalize the urban homeless, including laws which provide for arrest, incarceration and custodialization for sleeping or loitering on the streets, for merely having 'no ostensible means of livelihood' or even for simply being a child 'in need of care and protection'.

> "*The picture that emerges in the relationship with the State is of great official hostility to some of the most dispossessed residents of cities, homeless men and women, boys and girls. They survive without resistance their periodic onslaughts, as they feel profoundly powerless and have nowhere else to go. The State feels absolved of any responsibilities except against the urban poor. There is an unstated de facto hierarchy of citizenship. The legitimate citizens of the city who are deemed to deserve both protection and services from the State are those who live in homes and settled orderly colonies. Those who are too impoverished to afford these are lesser citizens, with a downward hierarchy of legitimacy, from residents of authorized slums, to those that are unauthorized, to those finally those who are at the bottom of the heap, the wretched mass of the cities' homeless. To them, the State owes nothing, except to drive them away from the city to which they are seen to have no rights whatsoever.*"

- Harsh Mandar, Living Rough, Surviving City Streets, a Study of Homeless Populations in Delhi, Chennai, Patna and Madurai

MENTAL ILLNESS - IGNORANCE AND DISCRIMINATION RULE OVER SCIENCE AND REASON

The care of people with mental and behavioural disorders has always reflected attitudes and values driven by prevailing social perceptions of mental illnesses. Although advances in neuroscience and behavioural medicine have shown that, like many physical illnesses, mental and behavioural disorders are the result of a complex interaction between biological, physiological and social factors, mentally ill persons are continually stigmatized and discriminated against in homes, communities, the workplace, and in healthcare settings. Mental illness is often seen as a personal failure or weakness of character; mentally ill persons face loss of shelter and work, neglect, abandonment and outright violence. Many are denied the right to vote, marry and have children.

Even when people with mental disorders are recognized as having a medical condition, the treatment they receive is often less than humane. In many countries, including India, people do not have access to mental health care at the primary level; the only available care is in psychiatric institutions, many of which have been associated with gross rights violations, including degrading treatment and inhuman living conditions.

The following excerpt from "Why mental health services in low and middle-income countries are under-resourced, under-performing: An Indian Perspective' by D. S. Goel, published in The National Medical Journal of India (Vol 24, No. 2, 2011), gives a historical background of mental health care in India:

> "*Though the history of state-funded public hospitals in India can be traced back to the times of Emperor Ashoka in the third century BC, there was no tradition of institutionalizing the mentally ill, who were invariably treated within the community. The first mental asylum came into existence at Calcutta (now Kolkata) in 1787, during the rule of the British East India Company, and catered mainly to 'insane' soldiers. Initially, English laws such as the Act for Regulating Madhouses, 1774 provided the legal framework for these asylums. Following the first war of independence of 1857, the first British Indian law on the subject, the India Lunacy Act, 1858 was enacted. This was followed by the Indian Lunacy Act, 1912, which was replaced 65 years later by the Mental Health Act, 1987. Despite several attempts at reform, conditions in most of these asylums, rechristened mental hospitals in 1920, remained abysmal.*

Forty years later, on the eve of India's Independence, and after a detailed survey of all mental hospitals in the country on behalf of the Bhore Committee, chaired by Sir Joseph Bhore, the then Superintendent of the European Mental Hospital, Ranchi and Honorary Consultant to the Eastern Army Command, Colonel Moore Taylor, said: 'Every mental hospital which I have visited in India is disgracefully understaffed. They have scarcely enough professional workers to give more than cursory attention to the patients, to say nothing of carrying a teaching burden… The policy of increasing bed capacity, which has incidentally led to gross overcrowding in most of the mental hospitals, rather than personnel has been stressed in the past, but the cure of mental patients and the prevention of mental diseases will not be accomplished by the use of bricks and mortar…. Finally, I would stress that the conditions in some of the mental hospitals in the country are disgraceful, and have the makings of a major public scandal…'

Over the next few decades, concerned citizens brought to the attention of the Supreme Court the terrible conditions prevailing in some of the mental hospitals through public interest litigation. The Supreme Court, shocked by the conditions and considering them a gross violation of the fundamental rights guaranteed under Article 21 of the Constitution of India, asked the National Human Rights Commission (NHRC) to survey all 37 government mental hospitals (combined bed strength of 18,918) in the country. The conclusions of the well-documented NHRC Report of 1996 are echoed in just one sentence: 'It was as if time had stood still.'

The dawn of the new millennium heralded a new era in the field of mental health in India. Perhaps for the first time in history, paucity of resources ceased to be the limiting factor in mental health planning at the national level. The Tenth Five-Year Plan (2002–07) saw quantum accretion to the National Mental Health Programme, fiscally and otherwise. The initial momentum could not, however, be sustained and there were significant areas of under-performance. Many of the past mistakes were repeated and contributed to these failures. Tragically, few lessons appear to have been learnt and many of the same, and more, mistakes are likely to be made in the Eleventh Plan. There is still time to heed a wake-up call.

THE HOMELESS MENTALLY ILL - DOUBLY DISADVANTAGED, DOUBLY STIGMATIZED

Marginalized by mental illness and disenfranchised by homelessness, homeless people suffering from psychiatric disorders are among the most stigmatized and vulnerable members of society in urban India. They are often found, in various states of mental distress and physical neglect, at railway stations, bus stands, pilgrim centres and on city pavements. No one cares to understand that these people are not 'crazy' – all they have is an incommunicable mental disorder – a medical condition that can be reversed with medication, care and a little support. They are the 'nowhere people' – separated from – or abandoned – by their families, ignored by welfare and health agencies, and pariahs to the rest of society.

Victims of the vicious link between poverty and mental illness, the homeless mentally ill are the least able to take care of themselves, and yet are subject to a hostile environment that can only worsen their condition. More than other homeless people who stick together in families and communities and survive by begging or working for minimal wages, the mentally ill are the most vulnerable because they are shunned even by other homeless people. Many have some form of psychosis, and paranoia causes them to distrust others. They lose their memories, and wander around in a constant state of hyper-vigilance and fear. Those who have depression and other mood disorders have no motivation to look after themselves, and with no social or familial support to protect them from the pain in their minds, remain lost in an inner world of torment and trauma. The mental illness leaves them incapable of even foraging for a meal, keeping themselves clean and protecting themselves from a hostile environment. Mentally disabled women and children on the streets are especially vulnerable to physical and sexual abuse. With the mental disease having taken away all physical and psychological coping mechanisms, they are totally defenceless against violence and rape.

Four out of five mentally ill homeless persons also have significant physical health problems. Unable to take care of themselves, they suffer from problems ranging from malnutrition, open lesions, rabies, untreated wounds, HIV/AIDS and are especially vulnerable to communicable diseases.

HOMELESS MENTALLY ILL PERSONS IN KOLKATA, WEST BENGAL

Soon after Iswar Sankalpa's inception in 2007, the organization conducted a baseline survey of homeless mentally ill persons within the 141 wards of Kolkata. The survey, conducted over a period of 8 months, identified over 466 persons in need of immediate medical treatment and psycho-social support.

The disease profile of persons identified in the baseline study is illustrated in the graphic below:

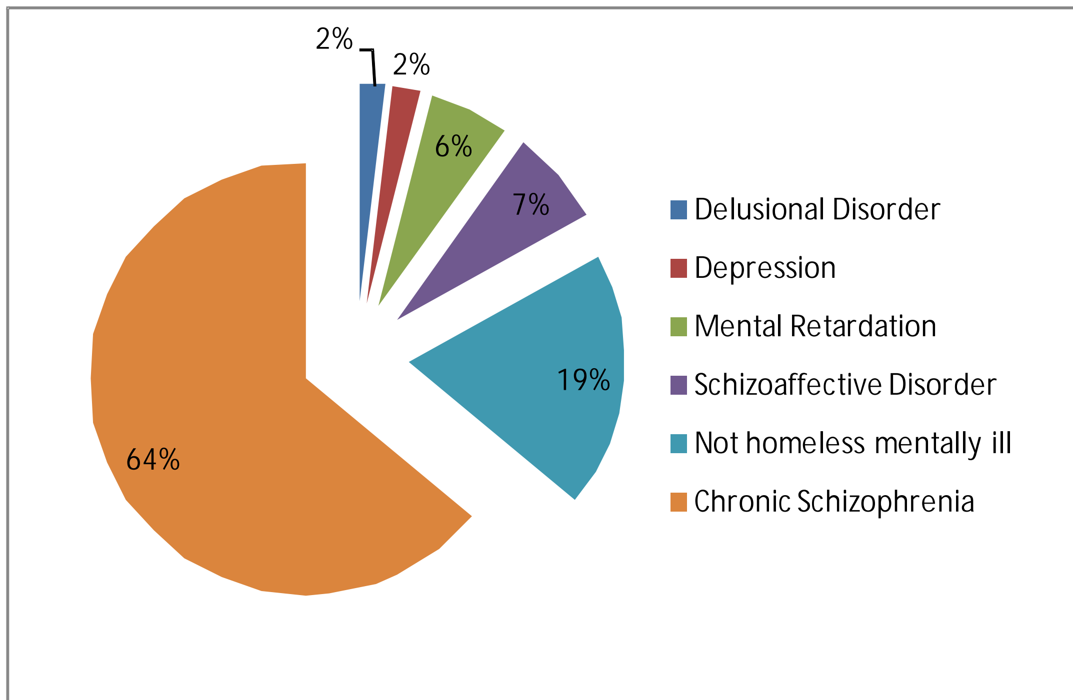


FIGURE 1: DISEASE PROFILE OF HOMELESS MENTALLY ILL PERSONS IN KOLKATA, BASELINE STUDY (2007)

Other findings include the following:

- The majority of the persons were between 18 to 35 years
- 20% of cases had major physical ailments
- 90% of the men had a physical injury
- While women were the most vulnerable to sexual abuse and harassment, men were also subjected to physical abuse.
- A large number, mainly men, were prone to substance addiction

HOW DOES ONE IDENTIFY A HOMELESS MENTALLY ILL PERSON?

Most homeless persons with severe psychiatric conditions are easy to identify by their outward appearance – an obvious lack of self-care and self-preservation is one of the indicators of mental distress. While the onset of most mental illnesses are marked largely by subjective symptoms – complex feelings and thoughts that cause mental distress to the sufferer - there are a number of externally manifested symptoms that become apparent without timely treatment. While apathy and motor retardation, usually indicative of depression, are relatively difficult to detect on the street, the restlessness and agitation of a person

suffering from mania or the extreme self-neglect and erratic behaviour of a person with psychosis become apparent to even the casual observer.

Apart from long, matted hair, uncut and dirty nails and grimy clothing, a significant number of them carry open sores, wounds oozing with pus and signs of various communicable diseases. Some have no belongings except the scraps of clothes they wear; others constantly clutch their motley possessions in an assortment of plastic bags and bundles. Behaviour such as talking to oneself, laughing or singing wildly, eating from garbage cans, masturbating or defecating in full view of other persons, running around erratically or extreme agitation are signs that social workers on the beat look for.

Such persons are mostly alone – paranoia, or ill-treatment makes them stay away from others, and for fear of violence or contagion, people on the street keep their distance, even crossing the street to avoid them.

Homeless no more

Perhaps the most significant finding , a finding that emerged as Iswar Sankalpa started the treatment process, is that a number of mentally ill persons are homeless because of cognitive dysfunction caused by the mental disorder - they simply cannot remember where they've come from.

With psychiatric treatment, they remember their names and addresses, and have no reason to be homeless anymore.

January 2008 - when Iswar Sankalpa first came across Manasi, she was a deranged terrified woman, lying semi-conscious near a garbage heap.

A few days later, she was persuaded to attend a medical camp being held by the organization in the neighbourhood. She had a wound on her right leg, and was diagnosed with schizophrenia. Taken first to Baul Mon Nursing Home, and then to Antara, she slowly responded to treatment, and remembered her address.

March 2008 - Manasi returns home to her husband and a fulfilling family life. Iswar Sankalpa's social workers visit her to top up her medication and check on her improvement.

CHAPTER 2

NAYA DAUR

A COMMUNITY-BASED CARE & SUPPORT PROGRAMME FOR THE HOMELESS

Based upon the findings of the baseline survey conducted in 2007, Iswar Sankalpa initiated community based mental health care and ongoing support for the target population, concentrating its activities mainly in the wards with the highest density of homeless mentally ill persons.

STREET OUTREACH, SUPPORTED BY COMMUNITY CAREGIVERS

Working with the homeless mentally ill is relatively virgin territory in India, and the organizations that do so follow an institution based model. Initiated in June 2007, Naya Daur, Iswar Sankalpa's flagship programme, is a sustainable community based care and support programme for the homeless mentally ill in the metropolitan areas of Kolkata - a programme that weaves together state, private and community into a network of resources that not only cares for this forgotten population, but works towards making them

productive members of families and community.

Community-based models per se are not a novel concept - globally, enlightened governments are restructuring mental health services to take cognizance of the holistic well-being of persons with psychiatric disorders, with community based services providing delivery of mental health services at the primary level. However, most community based models assume the presence of a family that initiates an enquiry into the mental state of one of its members, and secondly, assume the presence of a community that can be mobilized in support of the same. Unfortunately, most homeless mentally ill persons have the support of neither community nor family - Iswar Sankalpa therefore mobilizes all sections of civil society and the government to create a community that acknowledges their presence and takes responsibility for their treatment and reintegration back into society. Moreover, in the stark absence of even basic mental health services at the primary level, let alone integrated services, Iswar Sankalpa works as a nodal agency creating a referral network of appropriate support services, and making them accessible to the homeless mentally ill.

The Naya Daur team comprises psychiatrists, social workers, psychologists and activists who work with the community, hospitals, homes and shelters to bring acutely needed medical treatment those homeless people suffering from psychological disorders. Key activities include assessment of the mentally ill on the streets, treatment and rehabilitation (both on the streets and in institutions), and restoration and reintegration of recovering cases into family, if there is one, and in the community.

What is unique in this model, both from the point of view of homelessness and from the mental health perspective is the attempt by the organization to treat as many patients as possible on the street, supported by an ecosystem of caregivers drawn from the neighborhood community. While acute cases of mental and physical illnesses are treated in hospitals, quite a few patients do not need hospitalization - all they need is regular medication and some help in caring for themselves. In such cases, Iswar Sankalpa mobilizes people in the neighborhood to act as caregivers - to regularly give them their medicines, take them for a hair cut or a bath, and ensure that they are protected from abuse and other crimes as far as possible.

MENTALLY ILL

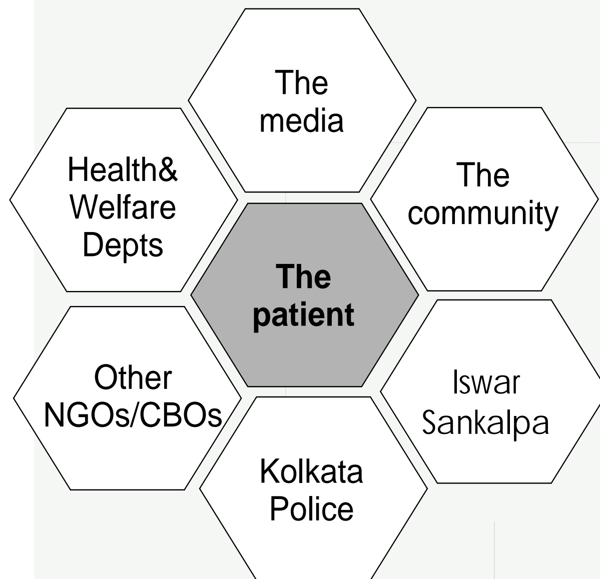
THE ROLE OF CIVIL SOCIETY

The baseline study (2007) not only identified the number of homeless psychiatric cases in each ward of Kolkata and their disease profile; it also identified and enumerated community resources such as medicine shops, NGOs and CBOs, pharmaceutical companies, other corporates and concerned individuals as potential players in the community based treatment and care model. Using these resources, a wider support network is formed by bringing together private individuals and organizations – both profit and non-profit - to create an integrated mental health service model – a model that reaches out to the patient, rather than in reverse.

THE ROLE OF STATE AGENCIES

Designed on the premise that each and every one of India's estimated 4,00,000 homeless mentally ill persons has a right – a right to care, a right to dignity, and a right to all the resources that other citizens of this country enjoy, Naya Daur's community based model also mobilizes state agencies in taking responsibility for a section of people whose absence is conspicuous in policy and planning, not just at state levels, but at national levels as well.

Key amongst the public agencies that support the network are the Kolkata Police, the state's social welfare department, the Kolkata Municipal Corporation and of course, the health department's psychiatric hospitals where Iswar Sankalpa takes acute psychiatric cases for treatment.



Naya Daur personnel

- Project Coordinator (1)
- Social workers (9)
- Counselor (1)
- Documentation (1)
- Part-time psychiatrists (2)
- Ambulance driver
- Accountant

BUILDING A NETWORK OF SUPPORT

through advocacy and coordination with agencies and Communities, and Mental Health camps

FIGURE 2: BIRD'S EYE VIEW OF NAYA DAUR - A COMMUNITY-BASED TREATMENT & SUPPORT PROGRAMME FOR THE HOMELESS MENTALLY ILL

COMMUNITY BASED MENTAL HEALTH TREATMENT AND SUPPORT ACTIVITIES

Case Finding and Engagement

Assessment

Intervention Planning

Treatment and Support

Rehabilitation

Reintegration into community / restoration to families

Follow up

NAYA DAUR IS DESIGNED TO:

- To bring together a range of agencies needed to take care of the needs of a homeless mentally ill person.
- To provide facilities and services to counter the abysmal lack of mental health in the public health system.
- To address discrimination in a class of people already marginalized by poverty.

CHAPTER 3

THE TREATMENT AND SUPPORT PROCESS

CASE FINDING AND ENGAGEMENT

Social workers on their daily rounds identify and assess cases of mentally ill persons on the street. Each social worker has a regular beat - the constancy of a social worker in a community is necessary so that he / she becomes a familiar face to the community, as well as a part of the physical and psychological space of the identified mentally ill person.

Making initial contact with a potential patient on the street is a delicate and pain-staking process, one that could take days, or even weeks, that is of course, if the person has not moved out of the social workers beat. Using eye-contact, initiating non-threatening conversation, offering food or a cup of tea, the social worker begins to build rapport and assess the mental state as well as the physical needs of the patient. The rapport building process also gives the social worker a chance to assess the potential patient's daily routine –

whether he or she is likely to remain in the same neighborhood and therefore remain in contact for the necessary period of treatment. Rapport building is sometimes an long and arduous process because of the lack of a common language - some persons are from other states and speak only in their own mother tongue.

Identification of caregivers

Simultaneously, the social worker tries to identify and build rapport with a potential caregiver – usually someone who is visible on the street all day. Some patients are already being given food by good samaritans on a regular basis – these persons are best posited as caregivers, as they already have some kind of daily interaction, however tenuous, with the mentally ill person. In some cases, caregivers have readily come forward, in many cases, social workers face an outright refusal.Others come forward when they see the social worker taking care of the person – sometimes out of curiosity, sometimes to offer help, and sometimes to demand that the person be taken away from the neighbourhood. Such interactions provide social workers with the opportunity to spread awareness - about mental illness, about the curability of the disease, and about the need to treat the homeless mentally ill with compassion and respect.

Negotiating with a caregiver involves addressing the caregiver's lack of knowledge about mental illness, dispelling the common myths about the threat of danger and violence, and outlining the supportive role of Iswar Sankalpa in the process.

All patients who are identified do not come under the coverage of treatment because

- Being shelter-less and itinerant, they are sometimes hard to locate after the first meeting
- Some refuse to engage with social workers, and allow no scope for negotiation.
- In many cases, even if persons are approachable and engage in discussion, they refuse to come for treatment

Just as Iswar Sankalpa believes that the 'right to care' is an inalienable right of all persons, it also believes that all persons with psychiatric disorders have the right to refuse medical treatment, the latter right only being over-ridden if the person is likely to cause harm to himself or others. Negotiation for treatment therefore an important step in the process, as the cooperation of the patient is essential for treatment over a long term. If the person's family has been identified, rapport is built with them and their consent is sought for medical treatment.

Other referrals

While case finding is a part of a social worker's daily outreach routine, periodic advocacy and mental health camps held in partnership with community organizations are also instrumental in identifying persons in need of help. Such camps, although focused on the homeless mentally ill, also encourage others in the community to reveal mental health problems, either in themselves or in their families, and such persons, are referred to other organizations – for medical and psycho-social help. Other outreach activities such as consultations with government officials, private organizations and individuals also result in a number of referrals.

A number of homeless mentally ill persons come to the notice of the police or concerned citizens because of the overt symptoms of psychiatric distress – they are highly agitated, behaving irrationally, often causing a disturbance in the neighbourhood - and if left without medical and psychological intervention, are a danger to themselves and others. In such cases, Iswar Sankalpa’s Emergency Response Unit works together with the Kolkata Police to deal with the immediate crisis, obtain custody of the patient from the court, and bring the person into the treatment and support process.

ASSESSMENT

Once the social worker feels that sufficient rapport has been built up with the potential patient, the organization's psychiatrist visits the patient on the street, conducts a mental and physical assessment, and prescribes medicines. Assessment comprises the following areas:

Health Assessment

- History-taking and mental state examination by the psychiatrist, with provisional diagnosis
- Risk assessment – including risk to self, to others, and lack of self-care, physical condition of patient
- Capacity assessment – the patient's 'insight' – i.e. awareness of his / her own mental state, and the ability to give consent to treatment.

Psycho-social Assessment

- Degree of hygiene and self-care
- Food habits
- Clothing
- Living skills – e.g. the ability to cook, shop, understand the concept of money
- Social skills
- Communication – through behaviour and inter-personal interaction
- Vocational / occupational ability
- Vulnerability – the degree of support the patient gets from the community, the chances of physical or sexual abuse, and of drug or alcohol addiction

INTERVENTION PLANNING

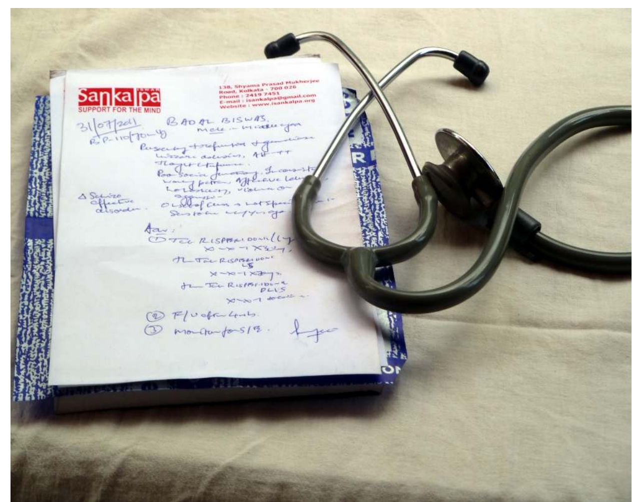
If the psychiatrist feels that the patient does not need hospitalization but needs only a daily dose of medication, the patient is treated in the community space which he/she is habituated to. In some cases, the psychiatrist may not even recommend pharmacotherapy immediately; such cases remain under the social workers caseload, being monitored for further deterioration / improvement. Intervention planning includes:

Health Intervention

- Planning how to provide medicines – either by the caregiver or the social worker

Psycho-social Intervention

- Fixing short-term and long-term goals of treatment with the patient
- Fixing day-care or drop-in-centre activities
- Institutional care / shelter for vulnerable patients



Medical Regimen

The type of medicine and its dosage is fixed depending on the patient's condition, the availability of a caregiver, and the likelihood of the patient continuing treatment (while some persons remain in a geographical area, some are highly itinerant and may become untraceable).

Medicines are usually kept to a minimum – usually a once-a-daily dose and side-effects are explained to the caregiver as well as to the patient, wherever possible.

TREATMENT AND SUPPORT

For patients with caregivers, social workers give each caregiver a week's supply of medication, which the caregiver gives to the patient once a day. If there is no caregiver available, or a caregiver drops out of the programme, then social workers give the medicine and food to the patient during their daily rounds.

Patients – are encouraged - and helped to have a bath – usually at the local Sulabh complex, to cut their nails, and are given a change of clothing when required. Those who don't receive regular food from others, or have no means to cook their own food, Iswar Sankalpa arranges a daily meal for them. Currently, food for patients in the Sealdah and Beniapukur areas is being sponsored by The Samaritan's Free Kitchen; in other cases, the social worker persuades a local food vendor or restaurant to provide a meal a day, either for free or at a cost which is borne by Iswar Sankalpa. More often than not, once people in the community overcome their inhibitions, they volunteer to provide regular food and clothes to the patients.

Initially there is a tendency on the part of the community to force the social worker remove the patient from the community or to take the full responsibility of the patient by institutionalizing him/her. At this point it is critical to explain to the community that the social worker is not the guardian of the patient, rather is the facilitator of a process of recovery and reintegration in which the community plays a significant role.

On the other hand, there have been instances when communities have shown their protective side and have stopped Iswar Sankalpa's social workers taking a patient away from the street – perhaps to a clinic or hospital – assuming that the social workers were traffickers or exploiters.

TREATMENT SPACES

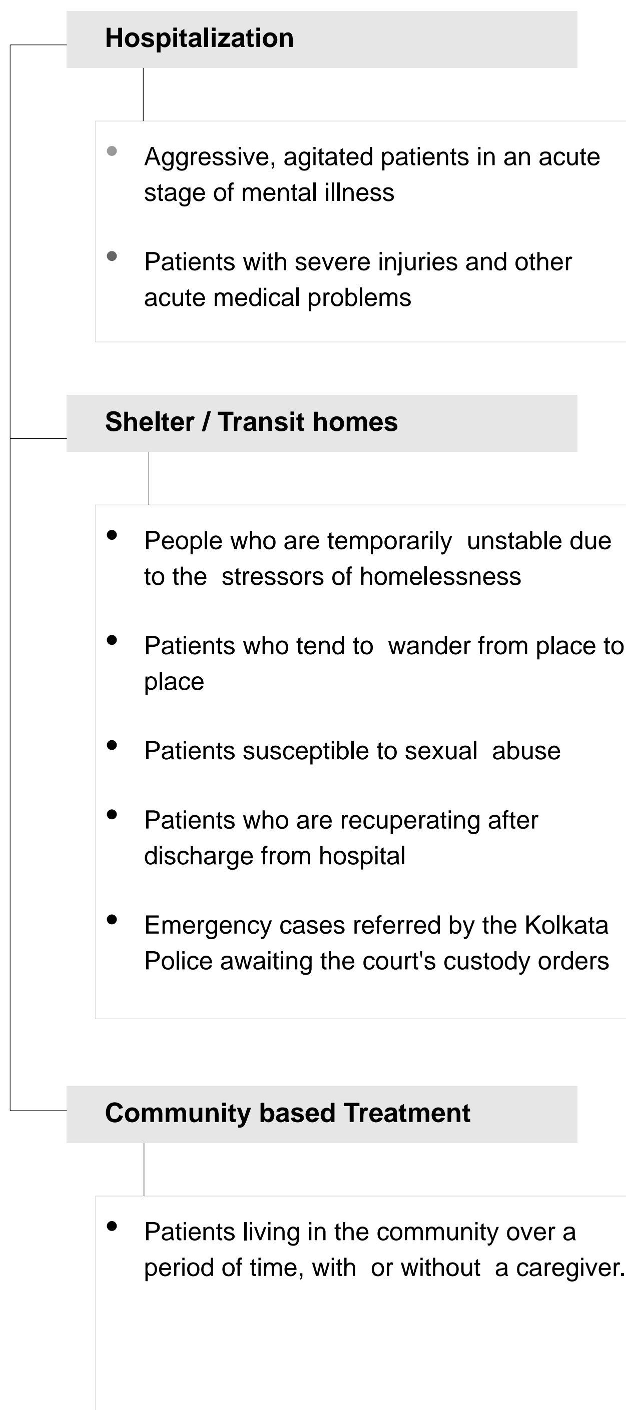


FIGURE 3: TREATMENT AND SUPPORT SPACES

MONITORING OF PATIENTS

Apart from the daily monitoring by social workers, patients are visited by the organization's psychologist once every two weeks and once a month by the psychiatrist.

Monitoring is essential to:

- Understand the progress / deterioration of the patient
- Understand the patient's needs and requirements.
- ·Plan new strategies and interventions for the patient
- ·Evaluate the social workers' effectiveness in dealing with patients and planning future action

A case file is maintained for each patient, with records being kept both on paper and in a database. Several documents are maintained – the social workers maintain daily worksheets, which are supplemented by records written-up by the psychologist and psychiatrists. Key monitoring indicators are as follows:

Functional Indicators – this refers to the capacity of performing tasks and activities that people find necessary or desirable to perform in their daily lives.

- Hygiene – brushing teeth, bathing regularly, personal cleanliness, healthy and hygienic food habits
- Communication – regular and normal verbal / gestural communication with social workers and others
- Functional daily activities – understanding the value of money; working (wage work or household chores), helping others, shopping, using public transport
- Recalling home address, and the desire to return home

Psychological indicators – including mood, sleep, anger, excitement, lethargy and obsessive behaviour.

Caregivers are also taught how to monitor progress in the patient: to observe changes– whether in speech, or in appearance or behaviour, and most importantly, to monitor treatment compliance. More involved caregivers – with other locals pitching in – take charge of improving the patient's personal hygiene, provide them with clean clothes, a sheltered space to sleep in, and step in to protect their care-recipients from abuse and violence.

REHABILITATION

Rehabilitation is often a slow and difficult process, during which the patient gradually re-learns self-care and social skills and begins to engage in the activities of daily living.

On 5th December, 2009, Sri Goutam Mohan Chakraborty, Commissioner of Police, inaugurated a Drop-in-Centre for the Homeless Mentally Ill at Hastings Police Station. Iswar Sankalpa uses the Drop-In-Centre as a rehabilitation space for recovering patients whose families are yet to be traced, or for those who have no families to go back to. Daily, a number of street-based patients from various localities are transported in the organization's ambulance, offered bathing facilities and food, and introduced to a steady routine through occupational therapy, art and drama therapy. Activities include gardening, paper bag making, and clay-modelling. Recovering patients, particularly males, often become victims of chemical addiction on the street, and the drop-in-centre has been especially useful in preventing them from falling prey to street drugs.

Similarly, at Sarbari, the organization's night-shelter-cum-rehabilitation-centre for homeless women at Chetla, female patients are exposed to drama, dance and art therapy, and participate in vocational activities which prepare them to return to a meaningful, self-reliant life.

Pratap Singh, a former patient, earns a daily wage washing utensils and doing odd jobs at a restaurant

Patients who have community caregivers are encouraged to engage themselves in some kind of occupation as soon as possible within the community itself. Sometimes they are engaged by the caregivers themselves, in their shops or restaurants. Rehabilitation and reintegration of the patient into a normal life then becomes a seamless part of the recovery process.

- On an average, in 3 -4 months the patient starts helping the caregiver in simple chores
- By the end of 18– 24 months the patient is capable of earning wages at par in service.
- Selling vegetables, cooking in roadside eateries, assisting in eateries, washing cars, tending animals in the farm, assisting shopkeepers in buying and selling merchandise are some of the different activities patients are involved in.

Sabbir picks up the skills of shoe making and earns a regular wage at his caregiver's business

REINTEGRATION INTO COMMUNITY AND RESTORATION TO FAMILIES

The goal of Iswar Sankalpa's intervention is the eventual integration of the patient into the community – and if there is one – the family. As mentioned earlier, many patients are on the street because of a decline in cognitive functioning caused by the mental illness, and a tendency to wander and get lost. As the treatment progresses, they recover their cognitive faculties, remember their names and their homes. With the help of the Kolkata Police, all attempts are made to locate their families.

If the families cannot be located, or refuse to take the patient back, or if the patient is unwilling to return to the family, Iswar Sankalpa makes other provisions for the relocation of such cases in safe spaces in the community, or in the case of the highly vulnerable, in institutions.

FOLLOW-UP

In 2010-2011, Iswar Sankalpa conducted a follow-up of patients who had been repatriated to their homes outside Kolkata. The results have been disappointing – while most patients are still with their families, many have discontinued medication, either because of a lack of availability of medicines or lack of initiative or ability on the part of the family to continue treatment. While a few have resumed normal lives, most have no skills or opportunities to contribute productively, and are engaged in little or no activity beyond a few domestic chores.

For future repatriations, the organization plans to conduct a deeper assessment of the family and the community resources, and a longer engagement with both to ensure that the patient returns to a family that is clearly aware of the patient's needs and abilities, and that a network of community resources drawn from neighbours, panchayats, self-help-groups, Anganwadi / Asha workers, primary health centres etc are mobilized into supporting the patient, as well as providing opportunities for productive activity.

THE NEED FOR PROTECTED SPACES - A THREAD RUNNING THROUGH THE PROCESS

One of the earliest challenges faced – and the most intractable – was, and to some extent still is, finding a transit space where the homeless mentally ill can be temporarily sheltered. The shelter could be for a couple of hours, overnight or for a number of days/months.

Recovery from mental illness is often a slow and fragile process, some cases having high chances of relapse. Some hospitalized patients recovering from acute phases of illness cannot be expected to return to the rigours of street living - or even living at home, assuming they have a family - until they are sufficiently mentally and physically resilient enough, yet, their condition does not justify them remaining in hospital. In such cases Iswar Sankalpa places such patients with other non-profit or community-based shelters and homes, and follows-up with psychiatric treatment and monitoring.

Mentally sick women are even more vulnerable than men – physical and sexual abuse and repeated pregnancies adds to the trauma of mental illness and homelessness. Even recovering women patients remain vulnerable - one of Iswar Sankalpa's patients, Tuku, was visibly upset when she was given a bath and fresh clothes – she said that her dirty body and filthy, matted hair kept men away - and that they had taken away her only protection. Just how vulnerable women can be was brought home to them when a female patient with schizophrenia - recovering after many months of treatment by a community caregiver on the street – was gang-raped and left for dead one night in a vacant building lot.

Iswar Sankalpa runs Sarbari, a 100-bedded night-shelter for homeless women, where 50% of the beds are reserved for mentally ill women. Sarbari, inaugurated on the 25th of April, 2010 is a joint venture with the Kolkata Municipal Corporation.

Often, emergency patients need to be kept in a sheltered place – often overnight - before the legal formalities necessary to take them into the organization's are completed.

However, Iswar Sankalpa found that no state agency was willing to take the responsibility of providing a transit space – the Social Welfare Department felt that since these were psychiatric patients, they were the responsibility of the Health Department, and the Health Department believed that since these were homeless people, they were in the Social Welfare Department's domain.

In the absence of a shelter of their own, Iswar Sankalpa would have to admit emergency cases in private nursing homes or shelters till they got a court order. Currently, while Sarbari, Iswar Sankalpa's night shelter, provides the necessary space for female emergency cases, men still need to be housed in private care.

It must be understood however, that institution based care is not an end in itself – it is only the means to an end – the end being integration of the person back into the community – and family, if there is one. Only in highly vulnerable cases – such as recovering women who have no means of support, the severely mentally ill with high chances of relapse and the elderly, does the organization consider long –term institutionalized care.

CHAPTER 4

NOWHERE NO MORE

IMPACT AT THE INDIVIDUAL LEVEL

Key figures for the period June 2007 to March 2011 show that the project has:

- Identified over 1114 homeless mentally ill persons
- Provided food to 1015 cases on a regular basis, clothing to 765, and hygiene care to 765.
- Has medically treated 615 cases of which 78 were emergency cases
- 69 cases have been restored to their families – they are homeless no more.
- Currently, 174 cases are under regular treatment, and 44 of the 69 restored cases have been followed-up, with the remaining underway.

Figures and fact-sheets do not however tell of the changes in quality of life of the persons being cared for. For all, life has changed in small, but significantly human ways.

For one, they are guaranteed the basics of life – some clean clothes and a daily meal.

They re-learn to look after themselves - bathe, use sanitary toilet facilities whenever possible, cut their nails and hair, wash their hands before eating – all of which not just maintains hygiene and reduces sickness, but also enhances their sense of self and dignity.

They receive a package of mental health services – diagnosis, psychiatric treatment and psycho-social support and rehabilitation. This includes providing treatment for co-morbid physical problems.

TO HELL AND BACK

In March 2008, Malleswari was found in Kalighat. She was a bizarre sight- a woman in her mid forties wearing a loincloth, her head smeared with vermilion, marigold garlands strung around her neck. She was thrashing the cars passing by with the branch of a tree. Suddenly a taxi driver stopped his vehicle and got down to beat her. Dr. Narayanan, who lived near witnessed the incident and intervened immediately. He brought the agitated Malleswari to his home and there she was given food, clothing and helped clean up.

She was very aggressive and muttered curses the whole day long. After informing the police, social workers took her to a nursing home, and then to Antara Psychiatric Centre for treatment. Later she was moved to Paripurnata- a rehabilitation centre. After about three months she began to recover, and the social workers discovered that she was from Hyderabad.

Through the Kolkata Police Missing Persons Squad Iswar Sankalpa located her husband and young son - who had not seen her ever since the day she had wandered away from home in a psychotic haze six years ago. On the 16th of January, 2009, a social worker from the organization escorted her home and reunited her with her family. Mother and son stared at each other incessantly - it seemed for ages - until they reached out and wordlessly embraced each other.

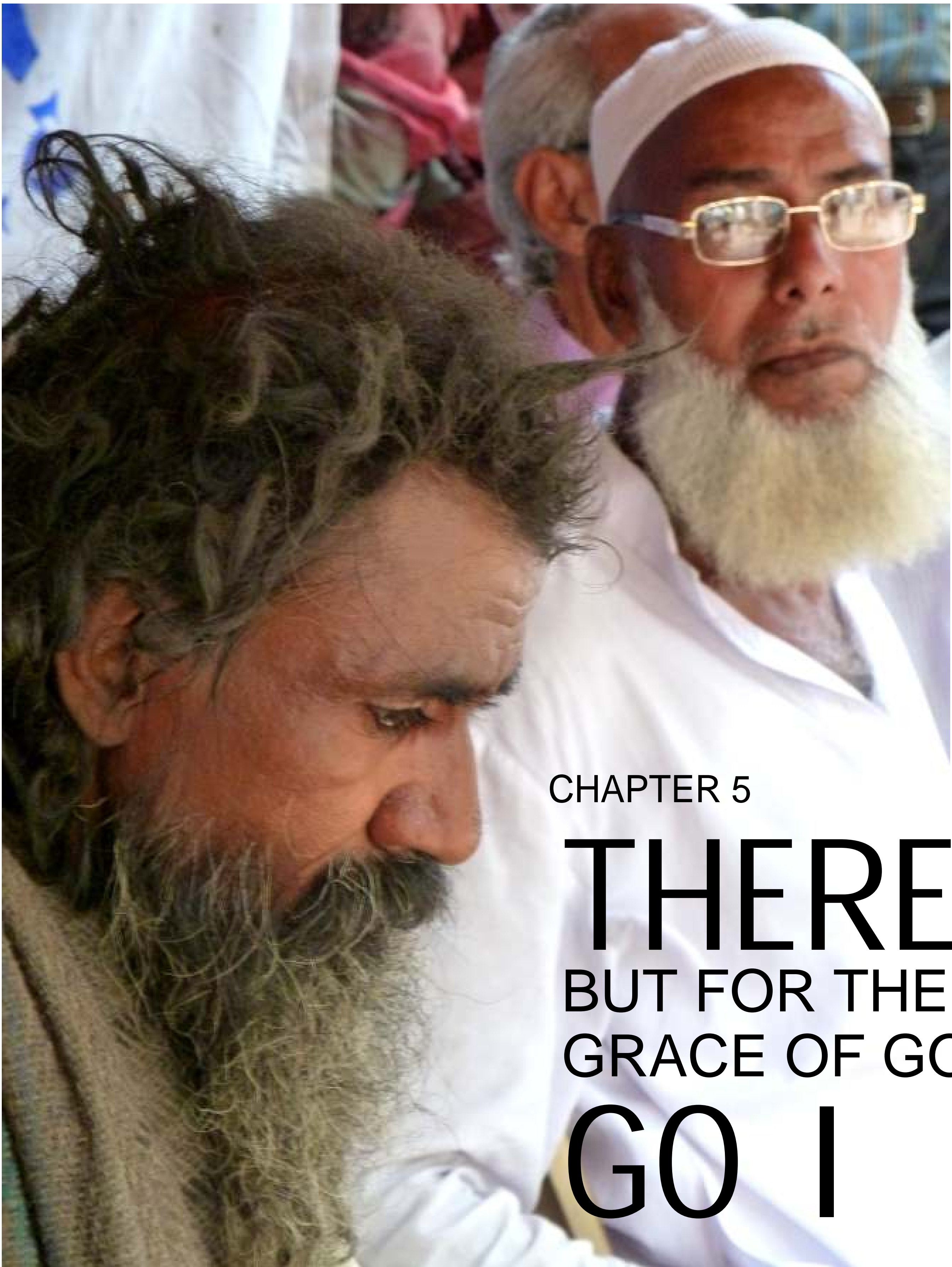
Women are protected to the extent possible by predators on the streets – those who are vulnerable are housed in Sarbari or with other shelters. All patients who are psychologically or physically vulnerable are sheltered to the extent possible.

As their mental state improves their ability to take care of themselves increases, as well as the ability to take decisions about their own lives. While the indignities of urban homelessness still envelope them, in the community spaces they inhabit, they are no longer invisible and untouchable. For those with families, there is a very real hope of being reunited with them; for those who do not, they are being supported in the process of creating social bonds with the urban community around them, or are provided space in shelters and long-stay homes.

FULWARI AND FRIENDS, BUILDING COMMUNITY

Sealdah station, home to the maximum number of homeless people in the city, is where an unlikely new community is being born. A group of our patients, all women, have come together of their own accord, and take care of each other. They cook together, bathe together, sleep together, and watch out for each other.

One among them, Fulwari, is the leader of the team. She keeps a motherly eye over her little community, and reports to us when someone is missing or not being cooperative. When they sit down to share their food, one of them divides it equally and then distributes it. Even though they do not communicate well with each other, they know that they are safe and secure - they have each other now.



CHAPTER 5

THERE BUT FOR THE GRACE OF GOD GO I

IMPACT AT THE COMMUNITY LEVEL

THE COMMUNITY OF CAREGIVERS

It goes without saying that the small army of caregivers – 45 in all – one of whom is homeless, has been one of the success stories of the programme.

So who makes a good caregiver in this programme? There are a few qualifiers – the caregiver needs to be visible to the patient every day, appear trustworthy to the patient, and must be willing to hand over the prescribed medication once a day. And as one person takes a step forward, others overcome their inhibitions and follow, and slowly a community of volunteers – each playing a small role – often forms around the patient. The other qualifier – the willingness to help a fellow human – is really the baseline requirement. There are those who can look away, and there are those who don't. The key is to tap those who don't. And often, when one person overcomes their fear and acts, others follow.

When one looks at the profile of the caregivers, what stands out is that most of them are people of very little means themselves. Some run small businesses, one is a school girl, and one is a homeless person himself. Many caregivers already play an informal caregiving role – if one were to call it that – in the community anyway. From giving alms and food to the poor, lobbying for services with local counselors, helping people get beds in hospitals, using donations from the local wealthy to run free clinics for the poor – there is no dearth of people who work quietly for a social cause.

This is my family now

A resident of Bishnupur in South 24 Parganas, Prabir Kumar Sardar worked as a labourer at a factory in Ballygunge. When he became mentally ill, his family shunned him, and one day he left home never to return. No one knew where he went, and his family made no attempt to find him, not even to lodge a missing persons diary at the police station. He used to roam naked and eat from garbage vats in the Kalighat Rashbehari area. The people used to make fun of him. Because of his flowing beard, long moustache and his habit of offering prayers, locals called him Ramakrishna. A local lad, Sivaprasad Roy, developed a fondness for him and brought Sardar's case to Iswar Sankalpa. Today, after a year of treatment, Sardar is a changed man, with little resemblance to the ill-kempt 'pagol' roaming the streets. He continues to live on the footpath, and takes a bath everyday at the Sulabh complex. The very locals who tormented him earlier, now take care of him.

Iswar Sankalpa contacted his family, who came to visit him and broke down on seeing Sardar. They wanted to take him home, but Sardar refused to leave the area. The closeness he has developed with the locals, and the neglect he suffered at the hands of his family members have forced him to stay back. Even the locals do not want to lose him. They are planning to help him open a tea stall very soon. Sardar said: " I have no home. I want to stay here. These people are my family members"

Caregiver at fourteen

Nasreen, a fourteen year-old schoolgirl in Rajabazar, comes from an impoverished but genteel family living in Rajabazar, one of the most congested areas of the city. Her father retired some years ago, and her elder sister dropped out of school to take care of the family as her mother's health deteriorated. Nasreen is Wahib's care-giver.

Wahib was a former neighbour - a young man whose family had moved away some years ago - but had returned only to dump Wahib back on the pavement of their old house because he was mentally ill. When the Iswar Sankalpa social worker was looking around for a caregiver - the spunky young Nasreen volunteered to give him his medicines. Not only does she give him his daily tablets, she scolds him if he doesn't bathe regularly, and makes sure he gets at least one square meal a day. If the neighbours demur at providing food, she gives him some from her own kitchen. This from a family that is always worried about where their next meal is going to come from. When asked why she and her family continue to support Wahib she simply shrugged her shoulders, grinned widely and said, "If I don't then who will?"

MAKING THE INVISIBLE VISIBLE

It must be understood that the community based model works at two levels. At one level it provides mental health treatment and support services to the homeless mentally ill. At another level – equally significant – it works for social change. The slow but obvious changes taking place in the person being treated on the street – the transformation of an incoherent derelict into a human being capable of coherent thought and action is a very public demonstration of mental health in action, - action, that as always, speaks louder than even the most evocative words spoken at any advocacy meeting or awareness camp.

The very visible act of treating someone on the street - that too someone who is on the outer fringes of untouchability - has created ripples of change in the minds of those who have been witness to it. There have been those who have come forward – the caregivers, the volunteers, people who have donated food, clothes, and medicines and so on. These are the visible ripples across the surface of a hitherto indifferent society. And for every passer-by who sees a caregiver – a paan-vendor perhaps, handing over medicine to a 'pagol', and asks why – a ripple is created. And for every person on the street who sees a doctor sitting at the edge of a pavement attending to bundle of stinking rags with a human being inside, and who turns away, whether in denial or in disgust – a ripple has been created. That what is considered human junk, is after all, human, and cannot be ignored.

The stigma and ignorance around mental health does not affect just the homeless - there is a shroud of silence over mental illness at all levels of society, and a high degree of ignorance of how to deal with a mentally ill person. Yet, the management of homeless psychiatric patients in public spaces has given those watching some food for thought, and at awareness and medical camps, a number of persons have ventured to asked about the availability of such care for people they know.

Javed, a caregiver in Rajabazar recalls that people would ask him why he was giving Darshan medicine. His family had been in the area for generations, and in his experience – many such hapless people would roam the area, and sometimes come and stand silently by the hotel. And they would be fed. When approached by Iswar Sankalpa he saw no harm in helping out – it didn't take up any time or energy – all he had to do was handover Darshan’s medicines with his food.

Although he had to take much flack from others – Javed's attitude was “if you don't want to help, then don't – just let me get on with what I'm doing'. The objections became weaker as people noticed visible changes in Darshan, both in his physical condition and demeanor, and most acknowledge that Javed had done the right thing.

And some of those who objected have come up to him later asking to be introduced to the 'pagalo ka daaktar' so that someone in their family could be treated.

Advocacy meetings, awareness gatherings and mental health camps are a core part of the support network creation process.

The following figures relate to 2007 - March 2011:

Mental health committees formed: 2 (25 people)

Awareness camps held : 87 (2425 people)

Advocacy meetings conducted : 12 (345 people)

MENTAL HEALTH CAMPS - A POWERFUL ADVOCACY TOOL

Objectives

To identify and bring the homeless mentally ill of a particular area under the umbrella of Naya Daur.

- To include these persons in the community space and encourage the community to take responsibility for their care
- Bring together a range of people – local clubs and associations, welfare organizations, pharmaceutical companies and interested individuals into the process
- Spread awareness of mental health and advocate for the rights of the homeless mentally ill

Pre-camp activities

- Identification of an area with a high number of homeless mentally ill persons
- Advocacy with local organization in the vicinity for hosting camp – usually a club or a welfare association
- Engagement and negotiation with homeless mentally ill to undergo treatment
- Identification and negotiation with potential caregivers in the locality
- Arrangements for toilet, bathing space, water, food, barber, clean clothes, medicine, chairs/tables etc
- Notify and invite local police station, ward councilor, medical representatives, media for coverage

At the camp

- Ambulance brings willing patients to the camp
- Patients given tea and biscuits, and history recorded by social worker. First aid provided if necessary
- Patients' mental state examination by psychologist
- Diagnosis and prescription by psychiatrist.
- Hygiene care (cutting of hair and nails, bath and change of clothes) and a hot meal given by social workers and community volunteers

Post-camp activities

- Willing patients and caregivers become a part of the daily treatment and care process
- The camp brings about a degree of change in the perceptions of the community about the mental health, the homeless mentally ill.

FIGURE 4: PROCESS MAP OF A MENTAL HEALTH CAMP

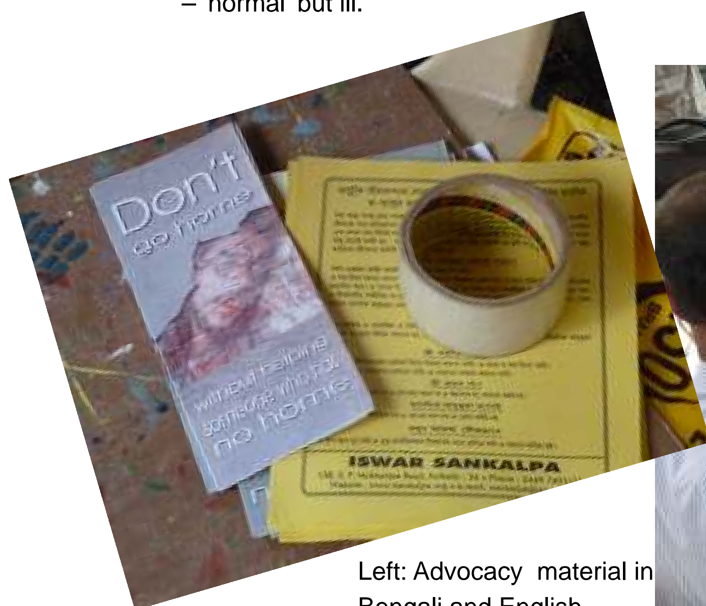
Some outcomes of a mental health camp

- Homeless mentally ill persons who come to the camp return clean and tidy, with a full stomach- at least for that day, have a new set of clothes and a towel, and are encouraged to stay in touch with social workers for their treatment.
- Patients who are maggot affected, have injuries and dog-bites, or serious health problems are given first-aid and taken to hospitals if necessary. Seriously mentally ill patients are referred to government hospitals.
- Patients willing to go back home, if they can recall their home address, are restored back to their homes.
- The club in which the camp is held is motivated to work with the organization.
- Care givers are appointed for patients who agree to come into treatment.
- Curiosity of the local people, club members and other onlookers turns into serious concern when they see social workers dealing with patients with compassion and lack of fear.
- Social workers, when they, touch, talk, converse, bathe, feed and engage with the 'roadside mad' persons leave the community people awestruck. Some go home touched and some become motivated to give the social workers a hand.
- The community witnesses the transformation of a hopeless bundle of rags into a human being, and begins to believe that they are just like all the others – 'normal' but ill.

Above: Patients being helped to alight from the ambulance

Right: A new patient tentatively sips water

Below: A general physician conducts a physical assessment of a new patient



Left: Advocacy material in Bengali and English

Above: Awareness material being distributed

Above: A member of the local club addresses the gathering

Below: Even those who are not homeless come by to consult doctors about their mental problems

Below: The social worker explains the camp's proceedings to curious children

CREATING AN INTEGRATED NETWORK OF PRIVATE ENTERPRISE

> *"Civil society can play an important role in supporting people with mental health conditions to access needed resources and to integrate fully into the community, through direct service provision and advocacy. Services provided by civil society can include health care, social services, education programmes, and livelihood (income generation) projects. In addition, civil society can advocate to government and funders for the need to recognize and support people with mental health conditions."*

World Health Organization, Mental Health and Development: Targeting people with mental health conditions as a vulnerable group

There are numerous CBOs, NGOs and other organizations dotting the city of Kolkata working for the betterment of the under-privileged and marginalized. Many however, work in small geographical areas, in a particular sector and in isolation to other services. Relatively few work for the homeless – those who do so, such as the Missionaries of Charity, mostly provide food and clothing, and provide shelter to the absolutely vulnerable. However, provision of medical treatment to the homeless mentally ill seems to have slipped through the cracks – perhaps because of the nature of the illness and the population.

Naya Daur has, therefore, attempted to tie these resources together to create an informal network of care. A number of NGOs who treat and shelter mentally ill persons and are part of our referral network – providing shelter, food, rehabilitation and other services to vulnerable patients who cannot be treated on the streets. Some NGOs provide food, some organizations – including pharmacists, provide free medicines and other supplies, yet others clothes and other supplies. Some pharmaceutical companies provide drugs at subsidized costs, the short-fall is made up by collecting medicines given as samples to psychiatrists.

THE ROLE OF THE MEDIA

Apart from giving the organization's successful efforts publicity and support, sensitive reporting by the media has been instrumental in raising awareness and in helping families locate their lost ones.

Jhuma, whose family saw her in a television coverage of one of our health camps. Jhuma had been missing for over 5 years

Babai's photograph in the Telegraph was recognized by a neighbour who alerted his family. Babai had been missing for over 2 years

MONDAY, NOVEMBER 10, 2008
Hindustan Times
KOLKATA • METRO • RS 2.00

Before: A MENTALLY ILL MAN WHO WAS BROUGHT TO THE CAMP

After: THE SAME MAN AFTER A SHOWER, HAIRCUT AND FOOD

The caring touch that heals

A medical camp was organised to examine mentally ill vagabonds

Sibendu Das
Kolkata, November 9

RONALDO IS quite a known figure among local residents at Taratala. And we are not talking about the Brazilian soccer star though this namesake too is a football enthusiast. He speaks excitedly about football whenever a match is on at the local club's television. But one day he earned the wrath of the police by slapping a traffic cop. He was on the verge of being arrested when locals came to his rescue, explaining that he was mentally ill.

Few mentally ill vagrants are as lucky since most people are not sympathetic towards them. "I once saw some youths throwing hot water at a mentally ill person. Even if we can educate people to stop them from harming such people, it would be a great success for us," said Chameli Saha, a social worker who is part of Naya Daur, the only project of its kind in eastern India to support mentally unstable vagabonds.

It is to sensitise people about the likes of Ronaldo that Iswar Sankalpa, a non-profit organisation, arranged a medical awareness camp at Chetla Agrani Club under the patronage of Borough-IX chairman Bobby Hakim on Sunday. The social workers surveyed the area and identified 12 homeless mentally ill, who were taken to the club for psychiatrists to examine them. All 12 were given a haircut, bath, shave, clothes andfood.

A few weeks prior to the camp, social workers identified caregivers —tea-stall owners, temple priest, streetside ironing man, dhobi — in the locality and motivated them to administer the prescribed medicines to the patients. "Near Hastings Bridge, we have come across a homeless physically handicapped person who voluntarily administers the medicines to two mentally deranged vagrants," said Iswar Sankalpa president Ranadip Ranjan Ghosh Roy.

The main aim behind the project is to end the stigma associated with mentally ill people in our society. "But it is easier said than done. Initially, many of us felt stigmatised when our acquaintances made fun of our profession. But slowly we got rid of the feeling," said Amrita Roy, project coordinator, Naya Daur.

Iswar Sankalpa secretary Sarbani Das Roy said: "We know one such patient who was a goldsmith and after our treatment he went back to his profession."

The NGO has come across at least 100 such patients. But it is suspected there are over 300 mentally ill vagabonds. Since they do not stick to one particular place, they had missed a lot of them during their survey. Recently a drop-in centre has been opened near Sealdah station. Its primary aim is to evolve a viable community care model to help the patients in their recovery. The success of the project prompted the Howrah station authorities to contact the NGO to run a similar programme, but Iswar Sankalpa had to refuse owing to lack of manpower.

Ideally, 2,500 working hands, including at least 40 psychiatrists, are needed to care for all the mentally ill vagrants in Kolkata alone. But that seems a distant dream. One way to counter this problem has been to set up a mental health committee comprising ward councillors, stakeholders such as local doctors, teachers and police.

Another obstacle is lack of funds. "At least Rs 30 lakh per annum is needed to carry out the project. But we manage to procure only Rs 12 lakh," Das Roy said. But there is still hope as the project is being appreciated by different quarters.

Mayor Bikash Ranjan Bhattacharyya has arranged for a mobile medical dispensary under Member of Parliament Local Area Development fund scheme. The Army Wives' Welfare Association has recently donated clothes and other needful to the organisation. Many corporate houses have also contributed.

letters@hindustantimes.com

"*It is in the treatment of vulnerable sections of society that we see the real test of governments' duty to protect, respect and fulfil the rights of the population. Development stakeholders have important obligations in this regard…. ………. development that only improves the lives of some people – while others remain as badly off or even worse off than before – is fundamentally deficient in nature. Improving the lives of the most vulnerable is in itself a core development objective.*

Through targeting by development programmes, people with mental health conditions can be empowered to reach their goals and participate fully in society. In order to achieve this they must have access to opportunities and services, be liberated from stigma and discrimination and be free to exercise their fundamental human rights."

World Health Organization, Mental Health and Development: Targeting people with mental health conditions as a vulnerable group

CHAPTER 6

IMPACT AT THE STATE LEVEL

The state government is constitutionally responsible for the delivery of health-care services to all citizens, and its resources, though inadequate, are still vastly larger than any other organization. Where the state government significantly fails is in the convergence of planning and service delivery, both to the homeless and to the mentally ill.

Much of the last four years has therefore been spent in intensively advocating with the state government and its diverse arms to bring psychiatric care and allied services to the target population. This advocacy has resulted in various liaisons - key amongst the government players partnering the programme are

- The Kolkata Police, who initiate emergency calls when they locate mentally ill persons on the street who appear to be either a danger to themselves or others, and play a significant role in ensuring that state hospitals admit emergency cases, as well as in locating the families of patients, many of whom are not from West Bengal. The Kolkata Police have also allocated a space at the Hastings Police Station which is used by Iswar Sankalpa as a Drop-in-Centre for recovering patients. Certain officials however, have expressed reservations about hosting such facilities at police stations – fearing public outcry if any mishap were to happen to a patient on their premises – a fear that really has no basis, as the patients who are brought to the drop-in-centre are those who are relatively stable and are on the road to recovery.

- The Kolkata Municipal Corporation, who have been a part of the project since its first activity, the baseline study of homeless mentally ill persons in the Kolkata Municipal areas. The erstwhile Mayor, Mr. Bikash Bhattacharjee has been a staunch supporter, and through his good offices, Iswar Sankalpa was gifted an ambulance by Dr. Arjun Sengupta, Member of Parliament. Since April 2010, the Corporation has provided a space to Iswar Sankalpa which is used as a night-shelter for women, where 50% of the beds are reserved for homeless mentally ill women who need shelter. As on date, the Corporation's primary health care centres have no provisions for psychiatric care, a fact that Mr. Arnob Ray, Commissioner, Kolkata Municipal Corporation puts down to a lack of 'push' from national health departments, and a lack of 'pull' for services from communities.

- The state's general and psychiatric hospitals, which come under the Health Department. State hospitals such as Bangur, NRS, R.G Kar, and S.S.K.M have admitted patients and helped in their recovery, although they lack the necessary resources and infrastructure to take care of patients who may be

- violent. Some of the patients have been rehabilitated in government homes. However there have also been instances when patients have been refused treatment, and the partnership with the Kolkata Police has helped in this respect.

- The Department of Women and Child Development and Social Welfare West Bengal regrettably has no services or solutions to offer in the community-based delivery model. Although mandated by the Supreme Court in 2010 to set up shelters for homeless people in all major cities of the country, the department has as late as August 2011, announced the scheme in West Bengal. The only other space that the department can offer is the Vagrant's Home in Murshidabad, as the Vagrants' Homes in Kolkata are out-of-bounds for psychiatric cases.

One of the early challenges faced by Iswar Sankalpa, a challenge that still raises its ugly head, is the outright refusal of state hospitals or out-patient clinics to treat such patients. For one, their outward appearance and lack of hygiene is a deterrence, and clinics refuse to entertain them on the pretext that they pose a risk to other patients. More irresponsible have been the games played by state hospitals – while psychiatric hospitals refuse to admit persons with co-morbid physical ailments as they claim they have no facilities to treat physical problems, general hospitals use the same excuse, refusing to treat their physical problems since that they have no means to handle psychiatric cases.

Citing shortage of beds is a ready defense – one that hospitals can easily hide behind given the widely publicized shortage of resources in the state health care system. This challenge has been met by admitting patients into private clinics and hospitals after persuading them to reduce their charges.

Experiences with the Railway Protection Force, Sealdah Station, Kolkata

Iswar Sankalpa's experiences with the Railway Protection Force – both positive and negative experiences – underline the short-lived gains of rapport-builiding with officials and the necessity of developing state level policies and procedures to ensure that treatment and support for the homeless mentally ill gets institutionalized within the government system.

In its attempts to enforce stricter security measures in 2007, the Railway Protection Force (RPF) was keen to clear the station area of vagrants, but later chalked out a humane plan to solve the problem in partnership with Iswar Sankalpa. They organized health camps for those living on and around the station premises, helped identify those in need of medical help, moved the courts on to allow Iswar Sankalpa to take care of these patients, and helped in repatriating them back to their homes.

Unfortunately with a change in officers, the understanding between the RPF and Iswar Sankalpa was lost; with the current officers being more concerned about the 'threat' posed by the homeless mentally ill to the security of the station, while they do not obstruct the organization's work, they are not co-operative either.

CASE STUDY: CONVERGENCE WITH THE KOLKATA POLICE

Background

A number of the homeless mentally ill come to the notice of the police or others because of the overt symptoms of psychiatric distress – they are highly agitated, behaving irrationally, often causing a disturbance in the neighbourhood - and if left without medical and psychological intervention, are a danger to themselves and others. Mandated to act under the Section 25 of the Mental Health Act, 1987, the Kolkata Police, with technical assistance provided by Iswar Sankalpa, bring the patient under the ambit of Naya Daur.

Under Section 25 of the Mental Health Act, 1987, the Officer-in-Charge of a police station is duty bound to take into protective custody any wandering mentally ill person who is not able to take care of himself or is dangerous because of such illness. The mentally ill person must be produced by the concerned police officer before the nearest magistrate within 24 hours for further orders.

Prior to Iswar Sankalpa's partnership with the Kolkata Police, the latter did not have the wherewithal to deal with aggressive or traumatised mentally disturbed people on the streets in need of emergency care. Periodically, they would, under the Vagrancy Act, 1943, round up homeless persons to be produced before a Magistrate. All such 'vagrants' – including severe psychiatric cases, would be detained indefinitely in the Vagrants Home until they were classified either as lepers, the insane or mentally deficient, suffering from communicable diseases or children. Persons declared by the Magistrate to be 'insane or mentally deficient' were then transferred to the Vagrants Home in Murshidabad, the only one in West Bengal earmarked for psychiatric cases, where they would languish practically unattended because of the dearth of state-employed psychiatrists.

Later, when Iswar Sankalpa began work in the field in 2007, an informal partnership grew between the two organizations. Each time social workers located a homeless mentally ill person who needed hospitalization, they reported the matter to the local police station as a matter of course before hospitalizing the patient. The collaboration grew through sustained advocacy on the part of Iswar Sankalpa and a high degree of receptiveness on the part of the Kolkata Police, and as an increasing number of police stations became aware of the existence of an organization that took care of a hitherto ignored population, some began regularly coordinating with Iswar Sankalpa as soon as they came across such persons. Through their extensive networks, the Police also worked to identify the homes and families of such rescued persons, many of who come from distant states. Their involvement further increased with the setting up of a Drop-In-Centre at the Hastings Police Station as a rehabilitation space for recovering patients.

In a order dated 22nd February 2010, Sri Bani Brata Basu, Special Commissioner of Police II, with the permission of the Commissioner of Police, Sri Goutam Mohan Chakraborty, issued instructions to all Divisional Deputy Commissioners reminding them of their duties towards the homeless mentally ill under the Mental Health Act, 1987 and advised them of the procedures and protocols to be followed towards such persons. As of March 2010, the Iswar Sankalpa team began formally providing technical assistance to police stations within the Kolkata metropolitan area.

The partnership process

The process begins when a police station contacts Iswar Sankalpa when the police come to know of a person who is creating a law-and-order problem on the streets and appears to be psychologically disturbed.

- Iswar Sankalpa sends an Emergency Response Unit consisting of a ambulance and a trained social worker to assess the case, and if the assessment confirms that the person does need psychiatric treatment, the team arranges for emergency care, assists the police in acquiring a doctor's certificate and often provides overnight hospitalization or shelter until the police can produce the person before a magistrate.

- Once the magistrate assigns the patient to Iswar Sankalpa's care, the organization takes complete responsibility for follow-up and support to the patient until release from hospital. Often the patient's physical condition needs to be treated first, and given the lack of space and facilities in public

- treatment, the team arranges for emergency care, assists the police in acquiring a doctor's certificate and often provides overnight hospitalization or shelter until the police can produce the person before a magistrate.

- After patients are released from hospital, Iswar Sankalpa takes care of them, either by placing them at shelters or homes, or back into the community, and provides them with rehabilitation services for as long as necessary.

- In cases where patients divulge their names and addresses, the Kolkata Police and Iswar Sankalpa work together to restore them to their families.

Significant outcomes

Increase in number of restorations

The longer a mental illness remains untreated; the worse is its effect on the mental abilities of a patient. Therefore the earlier a wandering homeless person is picked up by the police, the earlier and easier it is to restore the person to his or her family. With the deterioration of mental faculties, patients who have been missing from home for the last 4 – 7 yrs find it difficult to remember their exact address, moreover in many cases, the families have moved from their original addresses, husbands have remarried and therefore it becomes even more difficult to return them to their families.

With the Police Commissioner's order to all police stations to actively identify such cases, the prompt detection of a mentally ill person who has wandered away from home allows for earlier treatment and quicker recovery, as well as for speedier restoration of the person to his / her family.

- Ensuring the cooperation of other government stakeholders

The support of the Police Department and the issuance of court orders to hospitals to admit cases have been of great help to Iswar Sankalpa in getting patients admitted to state government hospitals. Apart from ensuring that state agencies - who often plead scarcity of resources as an excuse for not providing adequate services - admit our patients, the presence of state support for the individual who has lost his or her identity to an illness has given a humanitarian face to the state's service delivery mechanisms. People who were looked upon as 'security threats'/law breakers or simply human junk who needed to be removed during beautification drives in the city have now been offered a helping hand.

- Demonstration of convergence

Convergence is imperative between agencies – whether private or public - to provide services to persons who are marginalized and do not have the means to demand their rights. It has been Iswar Sankalpa's experience that neither the State Health Department nor the State Social Welfare Department are willing to take responsibility for the homeless mentally ill. While the State Social Welfare Department feels that since these are mentally-ill patients, they should come under the purview of the Health Department; the Health Department is of the view that since they are homeless, they are the Social Welfare Department's responsibility.

Yet, the partnership between Iswar Sankalpa and the Kolkata Police shows that convergence is an achievable strategy and can occur seamlessly if it is facilitated by proper planning and the application of appropriate technical and procedural inputs from multi-disciplinary perspectives.

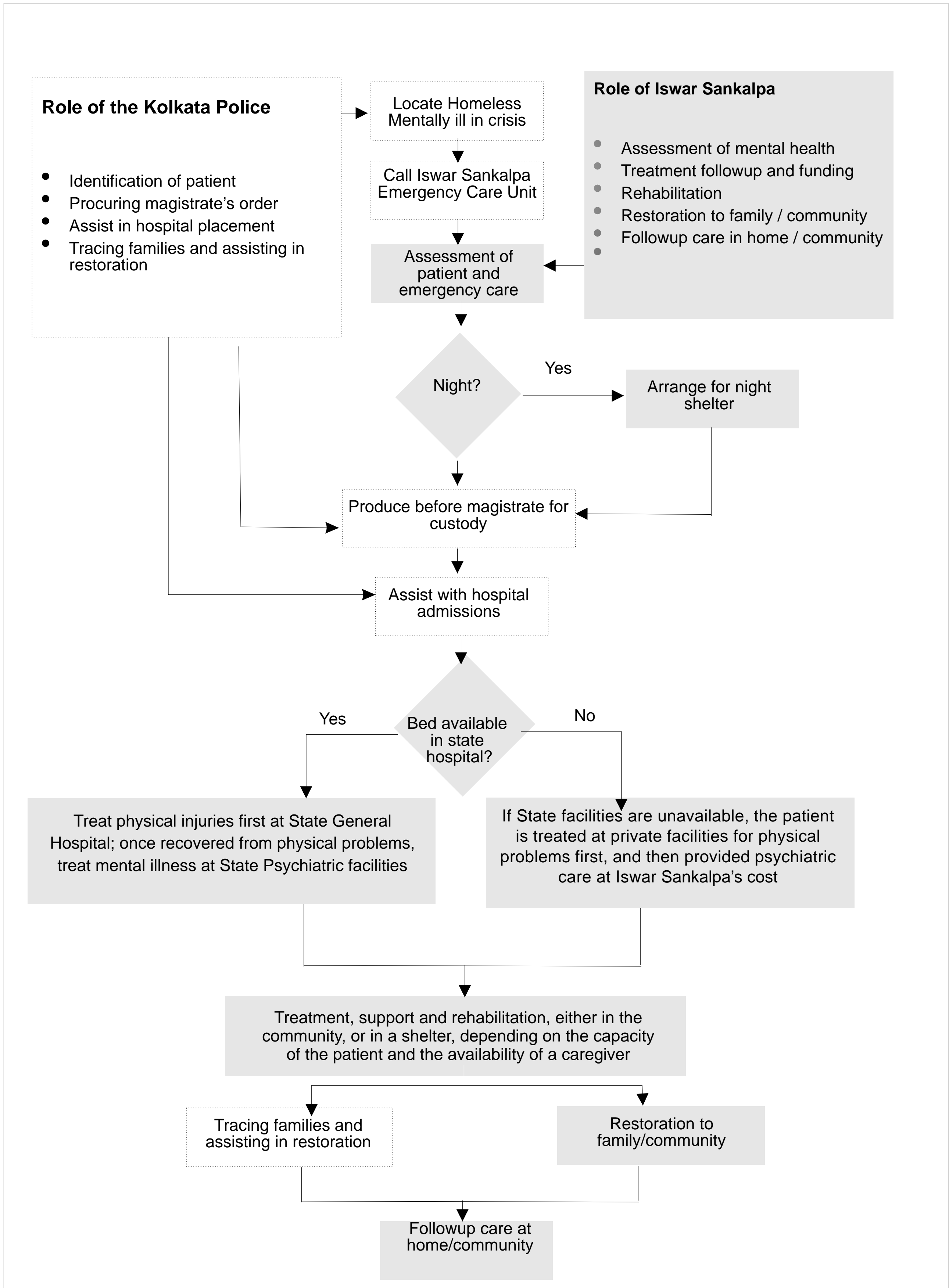


Figure 5: Process flow showing roles and Responsibilities of Kolkata Police and Iswar sankalpa

Case studies

Baranali Manna's case highlights the range of organizational resources that are needed to handle a particular case, and how, when the arms of the law, health department and the social sector come together, the human rights of citizens are protected and lives are saved.

Baranali, about 16 – 18 years old, was found on 15th March 2010 by the Kolkata Police near Central Avenue (under Jorasankho Police Station), creating a disturbance by trying to direct traffic. She was found to be mentally disturbed, though not violent, by Iswar Sankalpa's emergency response team, and taken to Amrapali Nursing Home for the night. The next day, she was produced in Court by the Kolkata Police, where the Magistrate officially put her into the care and custody of Iswar Sankalpa, and issued an order that she be admitted to Pavlov Mental Hospital, a state psychiatric facility.

While she underwent treatment, her family was traced by the Kolkata Police, and Iswar Sankalpa's social workers intervened to reunite her with her family. Today, she is home again, with Iswar Sankalpa conducting regular follow-up visits.

Namita Bal could not have been more appropriately 'found' –wandering aimlessly on the Kolkata Maidan on the 15th of April 2010, she stumbled into an IPS Officers cricket match being held there. She was muttering and chuckling to herself and wearing only a shawl.

When approached by the Emergency Response Unit, she was initially wary, but agreed to go to Amrapali Nursing Home with the social worker, and revealed her name and address.

Quick coordination between the Maidan Police Station and Sankrail Police station - where her home is - ensured that her family were immediately informed. They arrived to collect her the next day - It turns out that she has been suffering from psychiatric disorders for about 3 years, and is now being treated at SSKM hospital by her family.

Kalpana Mohanty, a girl in her early twenties, was referred to Iswar Sankalpa by South Port Police station. While her general appearance was more-or-less clean and she appeared physically healthy, she was constantly talking to herself, and when addressed, would reply very aggressively. Careful handling by the emergency response unit ensured that she agreed to go with them to Iswar Sankalpa's night shelter called Sarbari in Chetla, where she was diagnosed as displaying manic symptoms. She did not however, require hospitalization, and was domiciled in Sarbari.

After she began to trust her caregivers, she revealed her natal family's address in Cuttack (her husband had deserted her), and expressed a great deal of sadness whenever she thought about her three-year old daughter.

After an extensive search her family was located, and with the cooperation of the Kolkata Police, the Cuttack Police and the Panchayat Pradhan of her village, she was restored to them. She has recovered enough to understand the need for regular medical treatment and self-care and hopes to bring her life back towards a semblance of normalcy.

CHAPTER 7

CREATING A SPACE FOR THE NOWHERE PEOPLE

CHALLENGES FACED AND LESSONS LEARNED

The road from mental illness to mental health is rarely linear or predictable. For one, unlike the diagnosis of physical disorders which are supported by a battery of objective indicators that can be accurately measured by state-of-the-art instruments, the diagnosis of mental disorders depends largely on the diagnostic skills of psychiatrist, and his ability to elicit a comprehensible account of the patient's subjective thoughts and emotions which are usually chaotic, disturbing and erratic. Treatment adherence and the chances of effective recovery are increased by a trusting physician-patient relationship, the support of family and community, the availability of the multi-faceted services that psycho-social recovery and rehabilitation requires. Some disorders develop chronic courses, and require treatment and support throughout the patient's lifespan. Relapses are common – and the causes for relapse could be physiological, socio-economic, or a combination of various complex factors.

The variables in the Naya Daur programme are numerous – the incoherence of thought and emotional fragility of psychiatric patients is exacerbated by the instability of having a roof over one's head, the need to scrounge for food wherever one can get it, and the very itinerant nature of homelessness. Each street is different – some more hospitable to the homeless mentally ill and some less so. Each patient is different – his bonds to another in the community will be as tenuous or as trusting as his experiences in the community have been, as stable or as chaotic as his current mental state is.

- Trying to bring itinerant persons into a treatment regimen while respecting their autonomy in an unregulated space results in reduced drug compliance, dropouts from treatment, rehabilitation and supportive employment.

- The necessity to keep side-effects of medication to the minimum so that patients can go about their daily lives means administering a simplified drug routine over a longer period of time. Women patients particularly, resist taking drugs once they feel the sedative side-effects – it reduces their ability to stay awake and vigilant, especially from night predators.

- The vulnerability of the population ranges from daily neglect and hunger to physical, sexual and psychological vulnerability, especially for women, as well as substance abuse. The lack of government facilities and services at the primary level - in terms of medical care, food security, night shelters, rehabilitation services, employment support, amongst others forces the caregiving team to depend highly on voluntary donors, and if those are not available, pay for private services.

- The community care model falls short when it comes to cases of extreme vulnerability, or people suffering from schizoid or other forms of personality disorders, persons who are addicted to hard drugs or those with severe co-morbid physical illness such as tuberculosis or HIV / AIDS.

- The restoration of persons to families and the findings on follow-up a return to family is not necessarily an ideal solution. Most of the organization's patients come from poor socio-economic backgrounds, some from rural areas. Some families are not equipped – either psychologically or economically – to deal with a mentally ill person, and the quality of life for the returning person does not necessarily improve when back home. Some families give assurances of understanding – yet once home, either leave the person in a state of neglect, or ill treat them, at best they take them to local healers and quacks for a 'cure'. Others cannot afford to continue treatment, and even those who want to do, have no qualified medical services available in their area.

- The compartmentalization of government services – general hospitals for physical ailments and psychiatric hospitals for mental illnesses ignores the co-morbid nature of health problems, and leaves the homeless mentally ill in no-man's land. A similar compartmentalization results in both the state health department and the state social welfare department washing their hands of a population – the former department refusing to deal with them because they are homeless, and the latter because they are mentally ill. And in spite of intensive reworking of national mental health programmes over the last decade, such programmes will remain largely ineffective unless there is an increase of awareness of mental health issues and a corresponding rise in demand for services from communities.

- While sustained advocacy has led to awareness and supportive action by various government officials, the organization can only depend on their support while such officials are in office. Once they leave, or are transferred, the organization has to begin again from scratch. One such case is the Railway Police Force at Sealdah Station, which was highly supportive two years ago because of an enlightened leadership, but with a change in guard, now look on the homeless mentally ill from a 'threat to security in public spaces' lens.

- Kolkata is a city of 44,86,879 people – over 24,252 persons per square kilometer (Census 2011). On the positive side, this is a huge pool of potential caregivers. On the negative side, the homeless mentally ill are just a drop in the ocean of people struggling for space, services and survival in an over-burdened city. Making visible the cause of the homeless mentally ill, however vulnerable they may be, is an up-hill battle in a state that ranks at the bottom of a number of socio-economic indices.

- The nature of the treatment and support process, and the necessary advocacy that is a parallel part of the process, places heavy demands on the caregiving team – not just in terms of leg-work but in terms of personal investment in the process, innovation, adaptability, team-work and the conviction to continue in the face of the hostility and lack of understanding of communities, and the utter indifference and lack of facilities in the system.

WHY TAKE THE PATH LESS TRAVELLED?

"The mental health scene in India at the dawn of the twenty-first century is a bewildering mosaic of immense impoverishment, asymmetrical distribution of scarce resources, islands of relative prosperity intermixed with vast areas of deprivation, conflicting interests and the apparent apathy of governments and the governed alike. In the context of the huge and perhaps unsustainable levels of over-population, the problems appear to be insoluble. Yet a solution must be found if we are to survive. This calls for courage, vision and a vibrant spirit of innovation, unburdened with the obsolescent shibboleths of psychiatric mythology. We will have to get off the beaten track, and embark upon this journey without a road map to help us along. We will have to invent solutions. We have the technical skills required to achieve this goal. Do we have the wisdom to choose the right path?'"

"Why mental health services in low and middle-income countries are under-resourced, under-performing: An Indian Perspective' by D. S. Goel, published in The National Medical Journal of India (Vol 24, No. 2, 2011)

So why has Iswar Sankalpa chosen to work with the homeless mentally ill - a population so marginalized that they are only referred to as vagrants in laws drafted in the 19th century, and not considered in the current national developmental agenda – even on paper? And why choose a model that treats a patient in a social environment that is fraught with deprivation, uncertainty and unpredictability? For a health issue where progress is dependent on innumerable factors, difficult to measure objectively, and where one step forward could be accompanied by two steps backward. And as can be seen in outcomes of the last four years, a programme in which tangible results – in terms of 'cured patients' – are relatively disproportionate to the amount of resources – especially human resources– put in.

Dealing with the ultra-marginalized is not just ideological posturing from a human rights platform; it makes sound developmental sense. Mental illness and homelessness are two pervasive issues that societies need to urgently address, for both have a negative impact on the lives of individuals and communities. 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. In this positive sense, mental health is the foundation for individual well-being and the effective functioning of a community. While there is no causal link between poverty and mental illness, the two states can feed into each other – while poverty and its attendant stressors are a breeding ground for mental disorders, untreated psychiatric disorders can lead

individuals and families into unemployment, social alienation and poverty.

- The community-based treatment and care model the homeless mentally ill, based on an analysis of the considerable gaps in mental health service delivery in West Bengal, made more complex in the context of homelessness, has been designed to:
- Provide mental health facilities to counter the abysmal lack of mental health in the public health system
- Bring together a range of agencies needed to take care of the needs of a mentally ill person
- Address discrimination in a class of people already marginalized by poverty

Apart from being cost-effective (see Table 1 below), the model, by making institutional stakeholders, especially the government, take responsibility for the health and development of a vulnerable group of people, can become sustainable in the long term.

The Naya Daur model is based on the organization's aversion to the practice of uprooting and institutionalizing people in the name of medical service – a practice that is neither cost-effective nor dignified, and renders restitution and rehabilitation that much more difficult. Contrary to popular perception, people who are mentally ill do possess the ability and right to self-determination and autonomy, and even homeless people, though needy, possess self-dignity and a sense of belongingness - belongingness to their particular corner of the pavement, to the few tattered clothes and titbits that they possess, and to the people around them. While the organization offers alternate forms of living and treatment, it allows for individual choices, and adapts its support according to individual preferences and needs. The belief that intervention, medical or otherwise, should be kept at the minimum level, with minimum disruption of a person's life ensures that treatment and support is provided to the extent that is desired and accepted by the person concerned, while trying not to subsume his or her existential self under the rubric of modern psychiatric and developmental discourse. By including neighbours and local communities, the organization garners local resources as well as works towards reducing the stigma against mental illness and mentally ill persons.

	Street based care by social worker	**Street based care with active caregiver**	**Institution based treatment**
Food	15.00	-	
Barber	1.00	-	
Hygiene care	2.00	-	
Medicines	5.00	5.00	
Travel	4.00	2.00	
Salaries	24.00	12.00	
Telephone calls	5.00	5.00	
Doctor's fees	15.00	15.00	
Total	**71.00**	**39.00**	**150.00**

Table 1: Comparative Costs per Day (in Rs.) for community based treatment as against treatment in Institutions

Through its community based model, Iswar Sankalpa hopes to elicit and understand the meaning of 'madness' in local cultural contexts, and to bring them into its theorization and practice. The organization believes that a different concept of mind – its health, its pathology – born out of community experiences, perceptions and cognitions can help evolve a more viable and sensitive notion of community care in the field of mental health.

In the long run, the organization hopes to offer an alternative model of understanding of mental distress as well as care giving for the distressed – alternate to what is being taught and practiced in hospitals and extension clinics, the latter often contributing to pathologization and marginalization of human beings.

The successes of the Naya Daur programme have been modest, yet by offering at least a modicum of support and medical treatment, however imperfect, to the homeless mentally ill, Iswar Sankalpa believes that it has taken some critical steps towards a creation of a humane and respectful environment for those suffering from mental disorders.

METHODOLOGY

This study has been written after a desk research of all documents available with Iswar Sankalpa, and interviews with all major stakeholders, including patients, caregivers, state and city officials, the Iswar Sankalpa team and other persons who have participated in the programme.

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ABOUT ISWAR SANKALPA

Established in June 2007, Iswar Sankalpa is an organization that brings psychiatric care and allied services to the homeless mentally ill on the streets of Kolkata. The team comprises psychiatrists, social workers, psychologists and activists who work with hospitals, state and private agencies and communities to bring acutely needed medical treatment to homeless persons suffering from psychological disorders.

Governing body

Patron	Smt. Rotrout Roychowdhury
President	Dr. Ranadip Ranjan Ghosh Roy
Vice President	Dr. Prabir Paul
Secretary	Smt. Sarbani Das Roy
Asst. Secretary	Dr. Debashis Chatterjee
Treasurer	Dr. Srikumar Mukherjee
Member	Sri Surajit Ray
Member	Smt. Kalpana Basu Mazumder

Team

Banani Nath
Chameli Rani Saha
Kalu Prasad
Laboni Roy
Mrinmoyee Bose
Monorama Majumder
Poulami Dutta
Tanmay Roy
Tapan Prodhan
Rumpa Halder
Sabitri Mondal
Samata Biswas
Sankar Mouli
Subir Sen
Sukhdeb Sau
Supriyo Naskar
Suprokash Chakravorty

Supporting psychiatrists
Dr. Abir Mukherjee
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Sankalpa - the resolution to make a difference

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