Understanding the Mental ill Health – Poverty – Homelessness Nexus in India:

Strategies that promote distress alleviation and social inclusion

Athena Institute, VU University Amsterdam

Thesis Manuscript

Vandana Gopikumar

August, 2014

The Banyan, Chennai, India
Understanding the Mental ill Health – Poverty – Homelessness Nexus in India:

Strategies that promote distress alleviation and social inclusion

ACADEMISCH PROEFSCHRIFT

door

Vandana Gopikumar

The Banyan, Chennai, India
Promotor: Prof. Dr. J.F.G. Bunders-Aelen

Co-promotor: Prof. Dr. S. Parasuraman
About this thesis

This thesis enquires into the nature of distress experienced by persons with mental health concerns who live in conditions of poverty or homelessness. Having worked and lived with such persons for over two decades through The Banyan, an organization I co-founded, this inquiry is both poignant and significant. Driven by an agenda of understanding and communicating the nature of the complex problems experienced by such persons, this thesis aspires to contribute to a body of knowledge that will help alleviate the suffering of this vulnerable group. Without the users of The Banyan’s services, who shared their insights and experiences so trustingly and freely, this thesis and indeed, much of my learning and work, wouldn’t have been possible: they are my teachers, friends and inspiration.
# Table of Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page No.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Account</strong></td>
<td>8</td>
</tr>
<tr>
<td><strong>Chapter 1 – Introduction</strong></td>
<td>11</td>
</tr>
<tr>
<td><strong>Chapter 2 – Theoretical concepts</strong></td>
<td>20</td>
</tr>
<tr>
<td><strong>Chapter 3 – Research design</strong></td>
<td>42</td>
</tr>
<tr>
<td><strong>Part 1: Setting the scene: persistent and complex problems in the</strong></td>
<td>53</td>
</tr>
<tr>
<td>mental ill health – poverty – homelessness nexus</td>
<td></td>
</tr>
<tr>
<td>Chapter 4 – Persistent, complex and unresolved issues in the Indian discourse on mental ill health and homelessness</td>
<td>54</td>
</tr>
<tr>
<td>Chapter 5 - The chicken and egg situation: systemic deterrents to fixing persistent problems of homelessness and mental ill health in India</td>
<td>77</td>
</tr>
<tr>
<td><strong>Part 2: Responding to challenges through meaningful innovation and cultivation of values amongst human resources.</strong></td>
<td>98</td>
</tr>
<tr>
<td>Chapter 6 - Responsive mental health systems: a conceptual framework emerging from The Banyan’s experience in Tamil Nadu, India</td>
<td>99</td>
</tr>
<tr>
<td>Chapter 7 – Enabling access to mental health care: perspectives from The Banyan experience in India</td>
<td>114</td>
</tr>
<tr>
<td>Chapter 8 - The role of non-governmental organisations in community mental health care</td>
<td>123</td>
</tr>
<tr>
<td>Chapter 9 - Mimicking family as a therapeutic strategy in promoting recovery from mental illness and building human-resource capabilities</td>
<td>143</td>
</tr>
<tr>
<td><strong>Part 3: Understanding the diversity in human rights conceptualization with the mental health discourse: voices of the Indian mental health user</strong></td>
<td>163</td>
</tr>
<tr>
<td>Chapter 10 - Human rights in the context of mental health: perspectives from service users of The Banyan, India</td>
<td>164</td>
</tr>
<tr>
<td>Chapter 11 - Mental Illness, Care, and the Bill: A Simplistic Interpretation</td>
<td>181</td>
</tr>
<tr>
<td><strong>Part 4: Aligning strategies with diverse sectors and stakeholders: the role of policy, responsible business and education</strong></td>
<td>192</td>
</tr>
<tr>
<td>Chapter 12 - Comment on “The Mental Health Act 1987: Quo Vadimus?”</td>
<td>193</td>
</tr>
<tr>
<td>Chapter 13 - Challenges of teaching clinically applied anthropology and cultural psychiatry in India: an evolving partnership between a UK university</td>
<td>199</td>
</tr>
</tbody>
</table>
and an Indian NGO

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 14 - Making business sense of corporate social responsibility</td>
<td>217</td>
</tr>
<tr>
<td>Chapter 15 - Conclusions</td>
<td>230</td>
</tr>
</tbody>
</table>
**Account**

Chapters 1-3 introduce the main themes and theoretical concepts of this thesis. Part 1 of the thesis probes deeper into the problems of mental ill health, poverty and homeless in India, while Part 2 captures innovative responses to address the distress, as a result of this nexus. Part 3 attempts to interrogate the understanding of human rights within this context in Chapters 10 and 11. Part 4 discusses the need for alignment with external stakeholders in Chapters 12-14. Chapters 4-14 are based on eleven articles that have been published or submitted to peer reviewed journals.

Part 1: Setting the scene – Persistent and complex problems in the homelessness – mental ill health – poverty nexus

*Chapter 4*

Gopikumar V., Narasimhan L., Easwaran K., Bunders J., Parasuraman S. (under review) Persistent, complex and unresolved issues in the Indian discourse on mental ill health and homelessness

*Chapter 5*

Gopikumar V., Narasimhan L., Ravi M., Bunders J., (under review) The chicken and egg situation: systemic deterrents to fixing persistent problems of homelessness and mental ill health in India

Part 2: Responding to challenges through meaningful innovation and cultivation of values amongst human resources

*Chapter 6*

Gopikumar V., Narasimhan L., Regeer B., Jayakumar V., Bunders J., (under review) Responsive mental health systems: a conceptual framework emerging from The Banyan’s experience in Tamil Nadu, India

*Chapter 7*

Gopikumar V., Jayakumar V., Narasimhan L., (2013). Enabling access to mental health care:
perspectives from The Banyan experience in India. *Commonwealth Health Partnerships*

**Chapter 8**


**Chapter 9**


**Part 3: Understanding the diversity in human rights conceptualization with the mental health discourse: voices of the Indian mental health user**

**Chapter 10**

Narasimhan. L., Gopikumar. V., Sarin A., Regeer B., Bunders J., (under review) Human rights in the context of mental health: perspectives from service users of The Banyan, India

**Chapter 11**


**Part 4: Aligning strategies with diverse sectors and stakeholders: the role of policy, responsible business and education**

**Chapter 12**


**Chapter 13**

Challenges of teaching clinically applied anthropology and cultural psychiatry in India: an evolving partnership between a UK University and an Indian NGO. *Teaching Anthropology, 2*(2).

*Chapter 14*

Chapter 1  Introduction

Living with a mood disorder sometimes makes me vulnerable. But what raises deeper existential questions, exposing me to an altogether different level of marginality and pain, is the hardship encountered on account of poverty and homelessness. And yes, being a woman further builds distress. You have to live my life to understand what it means to climb trees in the night and save myself from violation of dignity and body, walk past many men and women in my dishevelled, almost naked state and yet go unnoticed, yearn for food and clean drinking water and not be in a position to access it. Look at you, your bag, your clothes, your diary with plans for the year scribbled – I don’t plan, I don’t hope, I live for the day. Not that I don’t want to, but I simply cannot afford to. I do not enjoy that and many other privileges that many of you take for granted.

Life is lived and experienced differently by different people. Although motivations, aspirations and goals vary, almost everyone seeks happiness. Many factors contribute to this state of contentment including the joy derived from relationships, pleasurable activities, work, success, and a sense of meaning. Similarly, health has been evidenced as being critical to both contributing to this state of well-being as well as in being an outcome of well-being.

Mental illness undermines many aspects of health, well-being and personal contentment. Mental ill health is distressing even when experienced independently. In combination with poverty and homelessness, its effects are devastating. The quote above from Sita, a client of a non-governmental organization in India, gives some indication of the alienating effect of mental illness in situations of homelessness and poverty.

Mental health on the global agenda

The World Health Organization (WHO) defines health as a ‘state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (WHO, 2001b: 1). Within this framework, mental health assumes enhanced prominence and significance in today’s world. Despite this growing acceptance of the crucial importance of mental health, the global prevalence of mental illness is increasing (Torrey and Miller, 2007). Over the years, causative factors for mental ill health have been studied extensively, originating in discussions centred around the brain and biochemistry, and increasingly expanding to include broader themes of ecological systems, social capital and adversity (De
Despite the raised awareness of poor mental health and its implications in all areas of life, mental disorders and conditions continue to account for 37% of non-communicable diseases (NCDs) in terms of healthy life years lost, and rank worldwide as the leading cause of disability adjusted life years (DALYs) (Bloom et al, 2011).

Globally, annual spending on mental health is less than USD2.00 per person per annum and less than USD0.25 per person in low-income countries (WHO, 2011). This low level of funding demonstrates the general lack of intent and urgency given to mental health. At the same time, the serious problems of poverty and inequity are also being addressed inadequately at policy and implementation levels. In this context, the 65th World Health Assembly in 2012 has called for convergence between the social and health sectors to address mental health issues in a more integrated manner (WHO 2012, Atun et al, 2013, Townsend, 2013). New research is needed to investigate mental ill health and to design effective health systems. Current studies are not drawing the attention they should, resulting in limited change. While newer trends and methods of alleviating the distress caused by mental ill health have emerged in the form of medications, science, neuroscience and therapeutic and development practices, outcomes have not improved significantly in many parts of the world, including in India.

**Mental health and poverty**

Individuals living in poverty are much more vulnerable to developing mental health problems, including both severe mental illness and common mental health disorders. Indeed, the highest incidence of the global burden of neuropsychiatric disorders is in low and middle-income countries (LMICs) (WHO, 2007). Furthermore, depression is 1.5 to 2 times more prevalent among low-income groups (Patel, 2001). Hunger, debt, overcrowding, poor or inadequate housing, poor education and unemployment correlate with higher estimated prevalence of common mental disorders (Patel et al, 1999, 2001). To illustrate this, the 2010 World Disability Report considers that the poorest worldwide are persons with disabilities, including persons with psychosocial disabilities (WHO and World Bank, 2011). While social causation explains how being poor can contribute to the onset of mental health problems, the social drift hypothesis considers that mental health problems contribute to a descent into poverty and poor socio-economic status (Lund et al, 2011). Similarly, the experience of scarcity can affect people in many different ways and recent research demonstrates its additional impact on cognition (Mani et al, 2013).

Poverty, coupled with inadequate and inaccessible health care and support systems, can render persons with mental ill health homeless and susceptible to rapid deterioration, placing them in an environment of conflict, distress and heightened vulnerability. Homeless
persons with mental illness are stripped of health, dignity and productivity, and often paralyzed into inaction. In many LMICs, this deterioration is facilitated by ineffective policy, planning and legislation; weak development intent; poor governance and leadership; implementation gaps; and a divided, apathetic society.

Responses to the pressing problems of homelessness and mental illness have ranged from alarm to inquiry and engagement. However, solutions to these problems have not been effective, possibly because of the pervasive nature of poverty and the complexity of the relationship between homelessness and mental illness. Poverty is a predictor of ill health at individual and population levels (Fiscella and Franks, 1997; Subramanian et al, 2002; WHO, 2000a), while health improvement is linked to poverty reduction and development. Despite widespread knowledge of these links and participation of many stakeholders at global and national levels, the spiralling downward phenomenon of homelessness and mental ill health has not been stalled, curtailed or reversed in over three decades, representing a form of double jeopardy.

How does one resolve this silent pandemic? How can this problem be understood in its entirety? Are lives of those affected by poverty, homelessness and mental ill health understood in the nuanced, layered, non-linear way in which they present themselves rather than in isolated clusters? Are most proposed solutions too simplistic, not taking cultural and social diversity and individuality into account? Should serious attempts be made to understand critical elements of the phenomena of poverty, homelessness and mental ill health and to provide more cohesive insights?

**Mental health and poverty in India**

Given that India is the second most populous country with an estimated 2014 population of 1.261 billion, it is probable that India is home to a proportionate level (17.5%) of the world’s mentally ill. Estimates of the number of people suffering from mental illness in India vary considerably from 650,000-700,000 (Ministry of Health and Family Welfare, 2005, Shields, 2013), to 55 million (Patel, 2009) and 65-70 million people (ICMR, 2007) and ranging from 5-20% of the Indian population. Estimates of the treatment gap in India, defined as the difference between those who require care and those who receive care (Kohn et al, 2004), is estimated to be up to 90% (Patel, 2009).

Provision of mental health care in India, as in many other LMICs, faces a number of serious challenges. A strong public health system is at the backbone of an effective mental health system but public health is making slow progress in India. Health systems and health
budgets are both inadequate as are human resources both in terms of quantity and quality. As a result, out of pocket spending on health is significant, driving people into further distress and poverty. As evidenced in the literature, poverty and social exclusion have direct impact on the extent of stress and the onset of mental disorders (Banerjee et al, 2011; Payne, 2006; Wagstaff, 2002).

The National Mental Health Programme (NMHP) launched in 1982, mandated delivery of mental health services to administrative units (villages, blocks, districts and towns) through the District Mental Health Programme (DMHP), which currently, more than 30 years since its initiation, only operates in 123 of the 640 districts. The DMHP has shown mixed results: some goals have been met in some regions, while many remote rural areas still remain under-serviced (van Ginnekin et al, 2014). Similarly, the goal of integrating mental health into public health has also not been accomplished (Khandelwal et al, 2004; Thara et al, 2004). Services provided under the DMHP are grossly inadequate to meet the needs of the majority of persons who live in poor circumstances and are unable to afford private, paid services, hindering processes of early identification, treatment, stigma reduction and recovery. In addition, The DMHP addresses mental illness from a disease perspective, ignoring the context of complex economic, emotional and social problems. This presents challenges given that mental illness is strongly linked to widespread poverty and homelessness: almost 70% of the Indian population continues to live on less than USD2.00 per day while some 1.94 million persons are homeless. Health system reforms to address the treatment gap often focus on increasing availability of services with financial and human resource investments. While such reforms may increase capacity of services at the grassroots, the health system remains unaltered. Given the complexity of the problems of mental illness and poverty, more fundamental change is needed at macro, meso and micro levels, especially in terms of implementation and human resources.

Mental health, human rights and personal recovery in India

In parallel to discussion of the barriers to mental health being constituted by poverty and the health system in India, increasing attention is being paid to violation of rights of persons with mental illness in communities and hospitals. This is part of a global trend in which increasing prominence is being given to the human rights-based approach to mental health, thanks to progressive legislation and frameworks such as the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which came into force in 2008. Despite this trend, many ground level realities remain unchanged and there is evidence of widespread abuses of human rights in India’s 43 mental hospitals (Murthy, 2011). Following the Erwadi incident where 28 people died chained to their beds in a mental hospital, the National Human Rights Commission carried out reviews in psychiatric hospitals. The results revealed numerous violations of rights occurring in facilities providing mental health care throughout the
Violations of human rights in mental hospitals diminish autonomy and agency, essential for facilitating recovery of individuals with mental health problems. However, a rights-based perspective should go beyond the unjust care mechanisms prevalent in mental hospitals to take the innumerable violations in the community into account, reflecting the multiple realities and deprivations experienced by the Indian populace. Violations of human rights in the community drain the potential of disadvantaged groups, enhancing their vulnerability and diminishing their capability. In fact, violations in the community are probably the most pressing issue, given that up to 90% of those with mental illness receive no treatment.

The missing link: leadership, values and human resources

*Human resources are the most valuable asset of a mental health service. A mental health service relies on the competence and motivation of its personnel to promote mental health, prevent disorders and provide care for people with mental disorders.*

(WHO, 2005: 1)

To bring about improvements in equity and mental health, system and policy level changes are required. One crucial element of this change which is often ignored comprises appropriate human resources, leadership and values. Appropriate human resources, leadership and values should be combined to direct the scenario for change and build creative strategies and responses to the complex problems discussed above. The paucity of good quality human resources is an enormous challenge in India. For every 100,000 persons, India has 0.4 psychiatrists, 0.02 psychologists and 0.02 social workers, most of whom are located in urban areas (WHO, 2001). More significantly, their competencies and motivations assume critical importance because working with persistent problems in under-resourced regions, over extended periods of time, can be arduous. Is too much attention being focused on select cadres, such as psychiatrists and psychologists, ignoring the needs of many others who require training and education? Are training and education programmes preparing professionals in a manner in which appropriate leadership and values are promoted?

This thesis attempts to link Sita’s distress and call for help to the current discourse in mental health. The need to respond to this crisis with individual and systemic arrangements represents the scope of this thesis, stimulated by an individual, institutional, and national journey to improve the lives of persons with mental illness. It is part of an individual journey because in 1993 I came across:
...a half-naked, mentally ill homeless woman in absolute distress on the road in front of her college. Nobody else seemed even to notice her... Mental health institutions and [non-governmental organizations] were reluctant to admit the woman in desperate need of medical and psychiatric attention.

As a direct response to this experience, I founded The Banyan, a mental health care and treatment centre in Chennai, Tamil Nadu, India, with a close friend, Vaishnavi Jayakumar. Since 1993, The Banyan has been offering a range of services, adapted to meet the complex needs of its client group of homeless and poor women, men and children with mental health problems. In addition, The Banyan subsequently has also become increasingly involved in national and regional advocacy. As part of efforts by a broad range of stakeholders to reform the mental health system, I am also a member of the Mental Health Policy Group, appointed by the Ministry of Health and Family Welfare, Government of India that prepared the first National Mental Health Policy and Plan. In addition to representing an individual, institutional and national journey, this thesis is part of a global journey to improve mental health care, given the proportion of the world’s mental illness in India and given India’s prominence in global efforts to improve mental health.

This thesis thus focuses on experiences of distress at the intersections of mental ill health, poverty and homelessness in India. Each of these conditions is complex even in isolation; when they merge, the impact is devastating. In LMICs, as is the case in India, the effect of poverty on mental ill health and of mental ill health on poverty is critical. This co-relation increases ill health and socio-economic vulnerabilities (Read, 2010; Murali et al, 2004). Further, when mental ill health and poverty interact, a descent into homelessness often takes place (Munoz et al, 1999). However this downward spiral has not yet been critically examined with the depth and urgency it requires. Such an examination needs to take individual and systemic processes into account. This is an important inquiry when mental health problems and inequity are on the rise, and the at risk population is rising. The downward drift into poverty and homelessness has a socio-economic impact at individual, community and national levels since mental ill health under these catastrophic situations can result not just in compromised health but social exclusion, loss of productivity, and loss of agency, choice, capabilities and life. The ripple effects of this co-occurrence across many domains plays out in intricate and complex ways. Thus, this thesis, while attempting to understand the nature of the larger problems of poverty and mental ill health in the Indian context, explores specifically the descent into homelessness. It then goes on to examine individual and institutional approaches that have reversed this spiral, facilitated recovery and catalysed positive change by improving the quality of life of persons who live on the margins using creative methods as strategies. It finally attempts to understand initiatives at
I hypothesise, that mental ill health cannot be addressed and resolved with the depth and integrity it requires unless the primary problem of poverty is tackled and dealt with firmly and with a sense of urgency. I also hypothesise that although the problem is extraordinarily large and complex, much can be learnt from individual narratives, organizations and initiatives that have brought about change in small ways, utilizing their insights to build a more robust, creative, integrated, co-ordinated and collaborative response that takes into account the dynamics of the real world. Based on these hypotheses, my main research question is:

*What are the complex problems experienced by persons living in poverty and homelessness with mental health concerns in India and what are the strategies that help address this distress?*

The next chapters describe the theoretical concepts and research design that guide the thesis.

**References**


24. World Health Organisation, 65th World Health Assembly Media Report
25. World Health Organisation, Mental Health Atlas
   http://whqlibdoc.who.int/publications/2011/9799241564359_eng.pdf?ua=1
26. World Health Organisation, Mental Health Gap Action Programme
   http://www.who.int/mental_health/mhgap_final_english.pdf
27. World Health Report, Mental Health : New Understanding, New Hope
Chapter 2  Theoretical concepts

Chapter 1 highlights the multi-dimensional characteristics of the mental ill health – poverty – homelessness nexus. Although this nexus has received much attention and been written about in the literature, the systemic, micro-level aspects of this nexus that present intractable problems have yet to be explored, particularly in the Indian context. This thesis attempts to go beyond a description of the current situation, aiming to find some innovative and strategic methods of approaching this nexus.

This chapter focuses on the theoretical concepts and frameworks that contribute to the mental ill health and poverty nexus. The first part considers persistent problems, including concepts of mental ill health and poverty; mental ill health and vulnerability; and the mental ill health – poverty – homelessness nexus. I define each of these problems in a way which takes their complexity into account, exploring reasons for their persistence. The second part of the chapter examines responses to these persistent problems and highlights the concepts of personal recovery, critical and reflexive thinking, capabilities and human rights, and coordinated health systems. These concepts facilitate integrated care, essential in building sustainable and robust responses. I define persistence in this thesis, illustrating it with examples primarily from The Banyan’s experience. In the context of this nexus, the multi-level model, encompassing the macro, meso and micro level, serves as an appropriate approach to understanding and addressing these problems. I describe its relevance in the final section. The chapter concludes by arguing that there should be a nuanced understanding of the dynamics and mechanisms shaping the interaction between homelessness, poverty and mental ill health, and examines the importance of multiple narratives at individual and organizational levels, continuously reinforcing the need for iteration between actors at the micro, meso and macro-levels to ensure real world representation and depth.

Definition of persistent problems

Persistent problems are complex and unstructured, and are present in every system (Loorbach, 2007), including societal systems. The intersection of mental ill health and poverty is one such persistent problem, perhaps more severe than each of these problems in isolation. Independently, they both qualify as persistent problems. Mental ill health and poverty also feature multiple other intersections, such as that between ill health and mental health, mental ill health and social exclusion. Problems are persistent when they are very difficult to solve or deal with, given our current way of thinking:
Firstly, they are complex: multiple causes and consequences exist – covering societal domains – and they are rooted in social structures and institutions. Furthermore, they are uncertain; no easy solution exists, reduction of uncertainty by more knowledge is not always possible, and every possible solution changes the perception of the problem. Thirdly, they are difficult to manage; a lot of different actors – representing different interests – are involved, and they all try to influence each other while remaining relatively autonomous. And lastly, they are difficult to grasp; structure and boundaries are unclear in relation to a strong system dynamic. (Rotman, 2005 cited in Dirven et al in Bunders and Broerse, 2010: 31)

Based on this definition, the mental ill health – poverty – homelessness nexus qualifies as a persistent problem. The nexus demonstrates multiple domains and causations with a high degree of uncertainty, owing to multiple variables that are both influences and consequences. In order to understand and subsequently generate creative strategies to address this persistent problem, a multi-faceted transdisciplinary approach is suggested that takes into consideration relevant actors and levels of influence.

In the next section, I explore the concepts of mental ill health and poverty, and the nexus between mental ill health and poverty given their persistence and complexity.

Exploring the concepts of mental ill health and poverty

Mental ill health

Mental ill health is a concept with a diversity of meanings, representing a spectrum of behaviour ranging from quirkiness and eccentricity to mental illness, often depending on the context and perspective of the individual or group. Normalcy and abnormality are relative concepts, subject to cultural, social, geographical and personal influences and understanding. At the far end of the spectrum, there are some mental states characterized by the sheer magnitude of the distress and dysfunction accompanying them. It is these states that are viewed as mental illnesses, including schizophrenia, mood disorders or depression. These conditions undermine the capacity of individuals.

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 (WHO, 2004). Mental health is also defined as more than the mere lack of mental disorders or disabilities (WHO, 2003). Mental disorders
comprise a broad range of problems such as depression, anxiety, schizophrenia, bipolar disorder, dementia, intellectual and learning disabilities, and disorders due to substance misuse (WHO, 2010). Given that mental illness is frequently viewed from the perspective of disability, disability also requires definition. Disability is an umbrella term for impairments, activity limitations and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors) (WHO, 2011).

In the past, the predominant global perspective to mental illness has been the medical view, which attributes the origin of mental illness to the brain and biochemistry. However, despite innovative technologies that enhance understanding of the brain, there is still inconclusive evidence about the causes and precise nature of mental illness. This lack of clarity, combined with rejection of the construct of mental illness itself by some commentators (Szasz, 1974) has led to uncertainty and ambiguity, culminating in the anti-psychiatry and deinstitutionalization movement. In this movement, many people opposed the admission of those with mental illness to hospitals because hospitals were often ill equipped to respond to people’s needs, owing to a rapid increase in numbers. However, instead of initiating reforms, many mental hospitals were closed:

> Once these institutions were closed, without comprehensive follow up and community mental health programmes, many people in need of care ended up on the streets, or in halfway homes or prisons, and were pushed to the margins, thereby leading to what can be described as trans institutionalization – from one impersonal place of care to another. (Torrey, 1997: 14)

At the same time, the medical system and society have sometimes provided an inadequate and an inhumane response to persons experiencing mental health problems.

It is currently generally accepted that the mind and behaviours cannot be entirely understood from the perspective of mental ill health (Jain and Jadhav, 2008). With the insights of Freud and Jung, which gained acceptance from the 1900s onwards, discussions around the conscious and the unconscious became predominant in consideration of the mind and behaviours. As medical care and the era of pharmacotherapy took off from the 1930s, protocols for care were developed and concepts of mental disorders were structured and defined from a psychiatric perspective by the Diagnostic and Statistical Manual of Mental Disorders (DSM) by the American Psychiatric Association, currently in its fifth and much critiqued edition (American Psychiatric Association, 2013), and by the International Classification of Disease Manual (WHO, 2010), now in its tenth edition with the eleventh already underway.
More recently, evidence of the role of societal and psychosocial factors in precipitating mental illness has dominated scientific and popular literature, establishing the linkages between poverty, stress, poor social health and mental ill health. Social health can include enjoying equality, domestic relationships, freedoms and capability, and resisting subjugation and oppression. These discussions broaden the mental health discourse. A recent study has estimated that the cumulative global impact of mental disorders in terms of lost economic output will be USD16,300,000 million between 2011 and 2030, demonstrating that development of accessible and appropriate services is not only a health and human rights priority, but also an economic imperative (Lund et al, 2011).

While the constructs of mental illness vary, there is general agreement that mental illness is a bio-psycho social construct that can be disabling (Bury, 1996). This can be illustrated with two models from the literature in Figures 1 and 2, one relating to the development of schizophrenia (Warner, 2004), a severe mental illness, and another considering pathways to the development of common mental disorders from the perspective of social capital (De Silva et al, 2007). Both are interactional models that take into account the impact of plurality, individual social contexts, influences, relationships, genetic predisposition and many more variables.

![Figure 1: Interactional model for factors possibly affecting the onset, course and outcome of schizophrenia (Source: Warner, 2004)]
These models illustrate the fact that mental illness is a bio-psycho social construct with complex, interactional pathways to development. Given this complexity, it is not surprising that there is considerable diversity in the experience of people suffering from mental illness, which cannot be ignored if health services are to meet individual needs:

*Psychosis is more terrifying, and those who experience it cannot return the glasses. The voices and images throb in their brains. Psychosis hurts, and, although now I have seen it at close range, I know it is beyond my capacity to understand it from the inside.* (Luhrmann, 2010: 144)

*In the car, everyone else was chatting merrily..... but I was completely silent. That was my way. When the fantasies took over, I could see only them. And while lost in them, I would exert as much of my ill as I could summon to keep anyone from knowing what was going on.* (Saks, 2007: 103)

Examining the personal experience of illness, Arthur Kleinman describes the illness narrative of several clients and scrutinizes their understanding of their experience:

*When I’m in a bad mood, I see myself as a failure. I have no close friends, a terrible job. I can hardly make it economically – I’m far away from family members – and when I get close I don’t fit in. I’m spiritually dissatisfied, too. But when I’m feeling*
better, I can see some strengths too: I’m close to my sisters. Surviving itself is a kind of success. I’m made some acts of kindness and generosity. I have a strong if corrosive intellect. (Kleinman, 1988: 83).

Kleinman refers to the personal exploratory model as self-reflective and contextually interpretative, demonstrating strong conceptual clarity.

Given the key importance of the experience of the individual in mental illness, I take individual narratives and perspectives into account while attempting to deconstruct the experience of mental illness. In this thesis, organizational and societal trends are juxtaposed with individual narratives, respecting the link between them. The distress caused by mental ill health originates in the minds and brains of individuals, and thus the individual perspective needs to be considered when undertaking inquiries at the micro level.

Poverty

There has been extensive work on the nexus between mental health and poverty (see, for example, Patel and Kleinman, 2003). Poverty can conceptualized in different ways, depending on the perspective taken and metrics used for assessment. Poverty is a broad construct which is often ideologically loaded and deeply political (Noble et al, 2004; de Toit, 2005; Bolweig et al, 2008). The aim of this thesis is not to generate a new conceptualization of poverty but, similar to the approach taken by Bolweig and colleagues (Bolweig et al, 2008), to adopt a pragmatic approach to the concept of poverty, subject to a number of meanings and concerns that animate both policy and popular rhetoric. A nuanced, in-depth understanding of poverty should include the subjective meanings and experiences of poverty from those with first-hand experience (see, for example, Narayan, 2000). Another way to look at poverty is to focus on its impact on levels of well-being and agency, going beyond monetary resources of individuals and families. This is known as the capabilities approach (Sen 1990, Sen 1992). Although there has been substantial debate as to what an adequate level of wellbeing or ‘achieved agency’ represents in different contexts (Bolweig et al, 2008), the capabilities approach nevertheless provides a framework to understand poverty in the Indian context.

The multivariate pathways into poverty include ill health, mental ill health and social exclusion (Lund et al, 2011). This is demonstrated in Figure 3 which captures the cyclic nature of the problem or the chicken and egg situation. Both social causation resulting in poverty and social drift, enhancing vulnerabilities and resulting in a downward spiral, are demonstrated.
Exploring conceptual issues in persistent problems: the mental ill health and poverty nexus

The linkages between mental ill health and poverty have often been observed (see, for example, WHO, 2007) and have long been understood as a vicious cycle (see Figure 3). This mental health and poverty cycle is based on the observation that those living in poverty do not often have the financial resources to maintain living and health standards, and are at risk of living in adverse environments (such as homelessness), all of which can augment the risk of developing mental health problems (WHO, 2007). Similarly, those already in a state of mental ill health may not have the financial resources to access care and may be unable to maintain employment, thereby increasing their poverty (WHO, 2007). Homelessness, one aspect of poverty, is a multi-factorial problem because it can be a consequence of mental illness and also restricts opportunities for income generation (Chamberlain 2007; Funk et al, 2012). Conversely, people living on the streets are also at risk of developing mental illness as they are subjected to harsh economic and social conditions (de Graft et al, 2007; Funk et al, 2012).

Double jeopardy

The double jeopardy hypothesis has often been used to consider the relationship between ill health and poverty. The cycle of one leading to the other – ill health to poverty and poverty to ill health – has been discussed in the literature. In his insightful paper, ‘Can
poverty drive you mad?’, John Reid argues that while social causation explains how poverty causes psychosis, social drift explains how poverty is involved in its maintenance (Read, 2010). Read goes on to speak of relative poverty and related inequity as strong predictors of mental health problems including schizophrenia. His paper presents a diverse range of evidence as a result of systematic synthesis of data, each pointing at the intertwined co-occurrence of psychosis and poverty. Similarly, an increased rate of illness and mortality is associated with a high rate of inequality between the richest and poorest in society (Warner, 2004). Illness and death rates, and the incidence of stressful life events, are higher among the working classes, contributing to increased prevalence of stress-related physical and mental illness, including schizophrenia (Warner, 2004). Psychological distress, social exclusion and isolation, and well-being are thus intricately linked to poverty.

Mental ill health – poverty – homelessness nexus

The causal dilemma between homelessness and mental illness has been discussed in some detail in the international literature as part of efforts to better address these phenomena. A study of 4,291 homeless persons in Australia found that 31% had a mental illness (Johnson and Chamberlain, 2008). Of these, 15% had mental health problems prior to becoming homeless, while 63% developed mental health issues while homeless. Research in Madrid, Spain, unequivocally links the prevalence of a mental illness, drug or alcohol use and stressful life events to homelessness (Vázquez and Muñoz, 2001). A study of the mental health problems among homeless people in Sweden (with focus on Stockholm) identified 3,000 homeless persons of whom 47% were affected with a mental health issue (Halldin et al, 2001). Similarly, 1% of the Belfast population was estimated as being homeless, of whom 41% was affected with schizophrenia (McAuley and McKenna, 2008). Research also suggests that the prevalence of depressive symptoms and disorders amongst homeless persons is higher than the approximate 10% prevalence in the general population. According to study of homeless persons in Tubingen, Germany, 26% were suffering from an anxiety disorder, 15% from an affective disorder, and 11% from a disorder of the schizophrenic spectrum (Langle et al, 2005). This was also the case for schizophrenia with studies suggesting that homeless persons report 6-13% prevalence, compared to an estimated 1% in adult populations (Langle et al, 2005).

A significant percentage of persons are homeless as a result of their severe mental disorder, particularly schizophrenia when it occurs in combination with housing instability (Caton and Goldstein, 1984; Link et al, 1994; Phelan and Link, 1999). Another study maintains that one quarter of the homeless population is affected by a mental health issue, with the onset of a mental illness, particularly schizophrenia, preceding the state of homelessness (Timms, 2005). Untreated severe mental illness, owing to lack of appropriate pathways to care, especially amongst the poor, can culminate in a state of homelessness. Homelessness and
mental ill health, both in isolation and when they co-occur, can deprive an individual of ontological security, represented often by a sense of constancy, control, daily routine and privacy (Tsembeirs et al, 2004).

Draine and colleagues (2002) examine the role of social disadvantage in crime, joblessness and homelessness among people with serious mental illnesses in US cities, probing the social context of such persons. They determine that ‘poverty moderates [facilitates] the relationship between severe mental illness and social problems’ (Draine et al 2002: 565). Furthermore, they explain this complex mix of poverty, ill health and homelessness ‘as not being amenable to simple explanations’ (Draine et al 2002: 565) and place poverty, not mental illness, at the root of homelessness. Although the link between homelessness and mental health is generally recognized, there is no conclusive evidence of a consistent, causal relationship.

**Mental ill health, vulnerability and distress**

As shown in Figure 1, there are many interlinkages and interactions between mental ill health, increased vulnerability, and reduced development opportunities, encompassing social capital and inequalities. Although this model shows the overall interactions between these concepts of mental ill health, development outcomes, and vulnerabilities, it does not provide an understanding of the intricacies of these interactions and the mechanisms which perpetuate this vicious cycle and halt progress in addressing this persistent problem.

The lack of a clear solution places large populations at risk, with higher probability of susceptibility to ill health, both physical and mental. This vulnerability can be defined as having:

...two sides: an external side of risks, shocks, and stress to which an individual is subject to; and an internal side which is defenceless, meaning a lack of means to cope without damaging loss. Loss can take many forms—becoming or being physically weaker, economically impoverished, socially dependent, humiliated or psychologically harmed. (Chambers, 1989: 1)

Annie Duflo defines vulnerability in the context of poverty as ‘a probability: the risk that a household will fall into poverty at least once in the next few years’ (Duflo, 2005: 7). The degree of vulnerability depends on the risks faced by households and their ability to respond to these risks (Siegel et al, 2002).
Poverty is one source of vulnerability; poor people are more likely to fall sick or to be affected by political or communal events, and repeated exposure to downturns reinforces poverty (Morduch, 1999). Many households, while not currently in poverty, recognise that they are vulnerable, and that events could easily push them into poverty; a bad harvest, lost job, an unexpected illness, or a lull in business (Prichett, 2000).

In the case of health, individuals and families are usually taken by surprise, making them far more vulnerable, while they are generally more prepared for other shocks, such as weather conditions and natural disasters. In order to prevent production shocks, households can choose non-risky activities but this is not possible with health shocks (Gruber-Gertler, 1997). Illness pushes households into poverty, through lost wages, high spending for catastrophic illnesses and repeated treatment for chronic illnesses (World Development Report, 2004). Somi and colleagues have found that health shocks and their associated costs have both short-term and long-term impacts on household welfare (Somi et al, 2009). In the short run, households that experience health shocks are forced to substitute the consumption and production expenses for health care. In the long-run, returns from investment in productive activities tend to reduce (Somi et al, 2009). The relationship between vulnerabilities, mental disorders and adverse development outcomes can be seen in Figure 4.

![Figure 4: Relationship between vulnerabilities, mental disorders and adverse development outcomes](source: WHO, 2010)
While vulnerabilities can result in distress, in the form of stress, anxiety, despair or grief, vulnerabilities themselves are usually caused by more extraneous factors and are often not entirely in the control of individuals. Distress, linked to mental ill health, has multi-dimensional implications for critical socio-economic domains, such as employability, income, functionality, pursuit of meaning and relationships, and for quality of life. The holistic focus on well-being as contributing to mental health has encouraged policy and service planners to focus on prevention and promotion as much as on intervention. Thus, a whole spectrum of domains, services and stages of life are open to a mental health interpretation, including infancy and childhood (maternal and child health, nutrition, parenting), adolescence and early adulthood (education, skills and life-skills development, capability and health), and adulthood and old age (employability, productivity, capability, health, family and community networks). Within this matrix, physical and social health share an interdependent and symbiotic relationship with both health and mental health.

I now attempt to understand how to respond to these persistent and complex challenges by promoting integrative, reflective practices.

Responses to persistent and complex challenges

While persistent problems are, of their nature, difficult to solve, many actors are perpetually and rightfully trying to solve them. The lessons from these experiments are critical and inform policy and planning. The common thread used throughout the thesis is that of weaving together individual and organizational narratives, facilitating a two-way conversation between these experiences. Figure 5 shows the two-way engagement between individual and organizational narratives, feeding into policy discussions.

![Figure 5: Two-way engagement between individual and organizational narratives, feeding into policy discussions](Source: Author)
I use the concept of the Dialogue Model in this thesis to consider the two-way engagement between individual and organizational narratives, and how they feed into policy discussions. This Dialogue Model is key to supporting user-centricity, a commonly recognized aspect of responsive health services.

**The Dialogue Model**

This is a suitable method to use, particularly in the case or service formulations driven by expressed needs that place the user at the centre. This allows for an emergent design in practice, develops processes in consultation with stakeholders, and encourages research supported by insights and contributions of clients. This model follows a six-phase plan that includes initiation and preparation, consultation, prioritization, integration, programming and implementation (Table 1).

<table>
<thead>
<tr>
<th>Table 1: Six key principles of the Dialogue Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <strong>Active engagement of clients</strong>: Extra attention is paid to the wishes and needs of clients and their inclusion in the various phases. Ideally, clients are involved as early as possible.</td>
</tr>
<tr>
<td>2. <strong>Good social conditions</strong>: A genuine dialogue between stakeholders requires the creation of conducive social conditions, including openness, trust and respect.</td>
</tr>
<tr>
<td>3. <strong>Respect for experiential knowledge</strong>: The research methods used to incorporate an understanding of the questions and concerns of clients into the process.</td>
</tr>
<tr>
<td>4. <strong>Dialogue</strong>: A genuine dialogue needs to ensure that participants listen to each other during the process and learn about their own and each other’s perspectives and experiences, which may eventually result in an adjustment of their opinions.</td>
</tr>
<tr>
<td>5. <strong>Emergent and flexible design</strong>: Since the issues of stakeholders cannot be known in advance, the design cannot be pre-ordained. The design emerges gradually in conversation with all parties, although the basic pattern and separate phases of the methodology are pre-set.</td>
</tr>
<tr>
<td>6. <strong>Process facilitation</strong>: Since the process should be fair, the collaboration between stakeholders is fostered by an independent process facilitator (with no stake in the content of the outcome) who creates the conditions for successful participation and dialogue.</td>
</tr>
</tbody>
</table>

The Banyan has conducted small niche experiments, attempting to innovate and find solutions to the persistent problems it has faced, ensuring that responses and approaches were integrated consciously, to ensure sustainability. In this context, the System Innovation theory is discussed as a concept.

**System Innovation Theory**

Central to this theory is the multi-level perspective, the multi-phase concept and transition management. The sub-concept most used in this thesis and by The Banyan is the multi-level perspective that incubated a typology of experiments in an attempt to develop the most appropriate responses to problems of increasing complexity (see Figure 6). More stakeholders and more aspects are involved as the inquiry delves deeper into multiple domains and variables, using diverse contexts, actors and influences. This process if referred to as **deepening**, a process that emphasizes substantial learning in a specific context so that new knowledge can help develop best practices, build evidence and understand the nature of the social innovation, including the culture, structure and practices. Transition theory posits that a system encompasses culture, structure and practices, referring to this cluster as a constellation. Culture in this context refers to the dominant value system, structure to the ‘physical, economic, legal, financial, organizational, and power structures that facilitate and/or constrain’ (Van Raak, 2010: 53, 55) and practices constitute the tasks that make the system work in a intended direction. This assumes both relevance and significance in the context of the mental ill health – poverty – homelessness nexus, The Banyan and this thesis.

Gains from niche level experiments that break the norms and pursue creative solutions, as well as the interaction between the niche, meso and micro are all demonstrated in the following chapters as some of the responses of The Banyan and the mental health system in India are examined. As can be seen in Figure 7, this research can be characterized as involving a large number of disciplines and high variety of stakeholders. It is thus transdisciplinary research in which the results are applicable and relevant to the real world. Multiple stakeholder interactions are a necessary part of interdisciplinary and transdisciplinary research. Such insights from many actors have the depth and capability to influence significant positive changes.
Figure 6: The multi-level model (adapted from Geels and Kemp 2000 in Bunders and Broerse 2010: 11)

Figure 7: Typology of experiments (Source: Bunders and Broerse, 2010: 15)
Clarifying persistent problems and reflective practice: The Banyan experience

The Banyan, a non-profit organization based in Chennai, Tamil Nadu, India, is an organization which, over the last 21 years, has focused on understanding the relationship between mental ill health, poverty and homelessness and the lived reality of men and women on their journeys from the margins to recovery. The Banyan has continuously modified its strategies, services and programmes to meet evolving client needs. This process has followed the action learning spiral, intrinsic to action research, depicted in Figure 8.

Action research

Action research is a research process which spans the processes of action to reflection. Action research typically is a cyclic process with continuous phases of action, execution, and reflection which shape outcomes and/or programmes. There are both technical and practical orientations within action research (Rearick & Feldman, 1995). A practical orientation within action research recognizes that human activities are ‘highly situated and steeped in the moral and ethical’ and interact with the broader environment/ecological system (Rearick & Feldman, 1995: 3). The Banyan experience with its clients and communities takes this approach because it links a detailed, locally nuanced understanding of the internal dynamics of poverty, mental ill health and homelessness and their interaction with the broader political economy and system in which they are situated in India. Applying an action research framework to The Banyan’s experience over the last 20 years enables reflection and elicits lessons and an in-depth understanding of strategies, particularly showing how The Banyan’s services have continuously evolved to fit client needs and demands. Reflective practice can involve reflection-in-action and reflection-on-action, both of which are relevant to this thesis. Reflection-in-action refers to reflecting on behaviours and decisions while carrying out the action; conversely, reflection-on-action is a post-hoc process where the researcher or organization reviews their actions and elicits new understandings retrospectively which can be applied to shape future outcomes (Greenwood, 1998).

Figure 8 shows the basic progression of reflective practice and learning and action cycles. This cycle represents The Banyan’s progression of learning and action to develop user-centric, integrated responses to issues of mental ill health, homelessness and poverty, both in Tamil Nadu and throughout India.
Figure 8: Reflective learning and action process (Bunders and Regeer, 2009)

While core problems of mental illness and homelessness are demonstrated at the societal, systemic, organizational and individual levels, there are also human rights concerns that need to be discussed. Persons with mental illness are often unable to work, experience stigma and discrimination. They ‘are not provided with education and vocational opportunities for “effective enjoyment” of the Universal Right to Life, on an equal basis with others - and indeed enjoyment of all human rights’, according to the UNCPRD. While these concerns can be addressed using the framework of human rights which pits institutional care or treatment against choice, I prefer to employ Sen and Nussbaum’s capabilities approach in this thesis because it summarizes comprehensively the many rights that an individual must enjoy to live a good life.

The capabilities approach

As outlined above, the capabilities approach developed by philosopher Martha Nussbaum and economist Amartya Sen, has recently emerged as a key theoretical framework on well-being, development and justice (Robeyns, 2011). The capabilities approach considers that assessments of individual well-being, equality, justice, and the development of a community or country should not primarily focus on resources or mental state, but on effective opportunities that people have to lead the lives they value and to pursue their own well-being (Robeyns, 2006). It can be used to empirically evaluate individual or group well-being, such as inequality or poverty. As a consequence, this approach has found its way into welfare economics, development discourse, political philosophy, public health, and gender studies.
Nussbaum’s central capabilities comprise life, bodily health, bodily integrity, senses, imagination and thought, emotions, practical reason, affiliation, other species, play, and control over one’s environment. These capabilities play a critical role in understanding the pathways to well-being among individuals and groups. Like poverty, disability can be represented as a deprivation of capabilities as it interferes with an individual’s ability to make valued choices and participate fully in society (Hopper, 2007). This thesis explores the applicability of Nussbaum’s capabilities approach to personal recovery among persons concurrently affected by homelessness and mental ill health. It also explores the pertinence of the capabilities approach within the currently uni-dimensional international discourse on human rights. A capabilities approach to recovery and the promotion of rights within the mental health discourse will provide for a robust and dynamic framework that encourages a re-think of existing service packages and approaches, placing much needed emphasis on the creation of conducive environments that make individuals thrive, and not simply survive (Hopper 2007).

Finally, I discuss the concept of personal recovery that promotes well-being. What do individuals perceive as recovery? What are the guiding values that drive this process?

**The framework of personal recovery**

Hope, self-identity, meaning in life, including life purpose and goals, and personal responsibility encourage people to be aspire to be well. In Figure 9, there is a representation of the attributes that best define a recovery approach in the context of the problems discussed earlier. This thesis is guided by this framework in understanding recovery.

In a qualitative study, Mancini (2007) found that ‘at the heart of the recovery process was the transformation from an illness-dominated identity to an identity of agency [and] competence’ (Mancini, 2007: 50). Using more of a relational ‘self in community’ focus, Nelson and colleagues explored how ‘increased control over daily life’ emerged within the context of ‘supportive and equitable relationships’ with peers, family and friends, and ‘participation in the community-at-large’ (Nelson et al, 2001: 131-138). Both perspectives may be important and, building on a consensus exercise involving survivor activists, Judi Chamberlin proposed a working definition of empowerment that combines ‘both an individual and a group dimension’ and involves ‘effecting change in one’s life and one’s community’ (Chamberlin, 1997: 43-44). Within this context, the notion of The Banyan’s approaches to care are examined, using personal narratives.
This thesis therefore focuses on presenting these insights and understandings from The Banyan's experience within the broader policy and development domains. It also attempts to contribute to a deeper understanding of the dynamics, intricacies and processes in the mental ill health – poverty – homelessness nexus which are often not studied or addressed, in order to generate creative solutions to breaking this cycle and impacting multiple dimensions of one’s life. The next chapter will delineate the research approach and associated design for this thesis, and present sub-questions and structure of the thesis.

References


Chapter 3  Research design

While there has been some global inquiry into the nature of challenges and distress faced at the intersections of mental ill health, poverty and homelessness, further research is needed to investigate how this relates to the Indian context. Indeed, further research is probably needed in LMICs and other South Asian countries with their distinct socio-economic fabric. The aim of this thesis is, therefore, to understand the challenges and complexities at the micro, meso and macro levels that shape the persistent character of mental ill health, poverty and homelessness, discussing appropriate tailor-made, client-centric approaches. In the light of the aims of this thesis, the main question that guides this research has two components:

*What are the complex problems experienced by persons living in poverty and homelessness with mental health concerns in India and what are the strategies that help address this distress?*

The primary objective of this research is to open up discussions of the unique nature of the mental ill health – poverty – homelessness nexus, examine the grave challenges that this nexus presents and draw serious attention to this complex problem, given that it is an essential part of the development and health discourse. An allied objective is to learn from innovative experiments and approaches to respond to elements of this complexity in creative, culturally sustainable ways.

The thesis is divided into four parts, reflecting the two objectives formulated above. Part 1 provides an in-depth analysis of the systemic challenges posed by the mental ill health – homelessness – poverty nexus. Part 2 considers appropriate responses to promoting access to mental health care in India, which are able to reach vulnerable populations and provide comprehensive care including long-term support and promotion of self-reliance. It also interrogates the nature and causation of distress, as assessed and understood by The Banyan’s clients, examining their narratives of the descent into homelessness and processes of personal recovery. It probes deeper into the nature of inputs at the human resource or organizational level that aided the process of recovery. Part 3 is concerned with the challenges in terms of human rights and associated dilemmas. An attempt to deconstruct human rights is initiated by listening to the voices and interests of the Indian clients of mental health services, primarily from resource poor and deprived backgrounds. The final
Part 1. Setting the scene: persistent and complex problems in the mental ill health – poverty – homelessness nexus

The first study in this thesis presents an overview of the mental ill health – poverty – homelessness nexus in India, and identifies the extent and source of vulnerability and distress from both macro and micro perspectives. All perspectives converge on the perceived need and expression of the client of the mental health service. Scientific inquiry into mental ill health and its social and physical determinants is discussed extensively. With mental illness on the rise (WHO, 2003; Torrey and Miller, 2007), global attention to alleviate distress seems critical. Evidence shows that mental ill health is more common amongst people who experience relative social disadvantage (Desjarlais et al, 1995). The impact of poverty on mental ill health and mental ill health on poverty has been well documented by researchers (see, for example, Patel, 2001, Lund, 2011). While suffering and pain are universal, and the needs of those affected with mental concerns are recognized as urgent, poverty is an additional challenge and adversity seems to magnify the nature and extent of vulnerability and distress. Those who are rendered homeless, as a result of the nexus, experience persistent and intractable suffering, often leading to hopelessness.

While debates over the primacy of mental ill health leading to homelessness continue, poverty, unplanned deinstitutionalization (Torrey, 1997), hopelessness, the unmanageable caregiver burden, stigmatizing community perceptions and attitudes, poor prognosis, chronic disability and complex ongoing needs continue to affect many lives. This state of affairs prevails, despite sophistication in mental health science and the increasing robustness of therapeutic frameworks. This study identifies critical issues that require deeper examination using the following sub-questions:

1. What are the complex, yet somewhat ignored strands of the mental ill health-poverty and mental ill health-homelessness discourse that need renewed focus and attention?

2. What are the specific problems emerging as a result of the mental ill health – poverty – homelessness nexus?
Part 2. Responding to challenges through innovations and cultivation of appropriate values among human resources

Part 1 of this thesis considers that poverty appears to accentuate the vulnerability and distress resulting from mental ill health, presenting barriers and challenges in terms of access to health services, poor social networks, compromised capability and capacity, and weak or non-existent social security nets that result in a downward spiral to the margins. Part 2 further explores the role of poverty in the mental ill health – poverty – homelessness nexus, as well as proposed responses and innovations to tackle this nexus and the challenges it presents in the Indian context.

While methods for attaining better mental health outcomes in practice are still needed, some innovations have engaged with complex spaces and service needs. These innovations have been able to respond to contextual changes through a process of reflection, fine-tuning, and learning. Lessons from these innovations need to be documented because they can inspire future developments and address some of the implementation gaps. The resulting sub-question is:

3. **What are the attributes and response systems of organizations which address the multi-dimensional needs of homeless and poor persons with mental health concerns?**

This part is also concerned with consolidating many of the key themes through personal stories and narratives of mental health clients within The Banyan’s mental health care system from the perspectives of distress and recovery. Through these narratives, themes of poverty, homelessness, mental ill health, ontological security, distress, hope and recovery are questioned and linked back to the conceptual discussions in the previous chapters. This section focuses on the development of key values amongst organizations and human resources that support processes of individual recovery. The resulting sub-question is:

4. **What precipitates the descent into homelessness? What are critical methods and values that promote recovery and appropriate human resource development?**
Part 3. Understanding diversity in the conceptualization of human rights within the mental health discourse: voices of the Indian mental health client

The UNCRPD advocates for many entitlements that people with disabilities have been unjustly denied. It represents a timely declaration and a step in the right direction in terms of promoting non-discrimination and barrier-free environments. However, the nuances facing this understanding and the nature and experience of rights from the perspective of the mental health service client have not always been well understood. Legal capacity, and voluntary and involuntary treatment continue to be central to this discourse. In an attempt to bridge the gap in understanding, this part of the thesis considers rights from a multi-stakeholder perspective, trying to represent the voices of the missing Global South, particularly from India. The balance between the right to life and the right to full legal capacity, even in times of bodily degradation and death, are also studied and reflected upon. The resulting sub-question is as follows:

5. How are rights understood from the perspective of Indian women who have experienced mental ill health, poverty and homelessness?

Part 4. Aligning strategies with other sectors and external stakeholders

Part 4 looks beyond the work of The Banyan to the macro level, stressing the need for alliances and collaboration with the mental health sector. These alliances need to be diverse and incorporate business and corporations, the educational sector, global advocacy movements and national and international policy makers. This part concludes with a commentary on the need for pro-poor health and welfare legislation, based on the Indian context and reality. This comment comes in the wake of the forthcoming Mental Health Care Bill that mandates access to health care as a right for all Indians, holding the Government responsible for the well-being of individuals and communities. The following sub-questions are addressed in Part 4 of this thesis:

6. Are the needs of the vulnerable groups reflected in the amendments to the Indian Mental Health Care Act, 1987?

7. How can academics and practitioners collaborate to develop skills and shape perspectives in the mental health sector?

8. How can the mechanism of corporate social responsibility (CSR) lend itself as a strategy to address complex societal problems?
Research approach

The research documented in this thesis has a global and local focus. The global focus considers the conceptual issues linked to the mental ill health – poverty – homelessness nexus, as well as the potential for collaborations and alliances nationally and internationally. The local, micro perspectives are addressed in the chapters focusing on the cases of clients and organizational learning experiences of The Banyan.

The chapters are clustered into four parts. The first cluster consists of challenges in the mental health care system in India; the second focuses on strategies and solutions to address these challenges; and the third part focuses on challenges and dilemmas in the human rights discourse; and the fourth part focuses on aligning solutions and strategies with external stakeholders, such as corporates, educational institutions and national policy bodies, to ensure that programmes and approaches are effective and sustainable.

Methodological approaches

The thesis provides an in-depth exploration of the complex, systemic problems of homelessness and poverty in mental health by examining the experience of an organization which has been trying to tackle these problems over a period of 20 years. For this reason, primarily qualitative approaches drawn from participatory action research (Freire, 1972), grounded theory (Glaser & Strauss, 1967), and phenomenology (Smith, 1996) are used.

Chapter 4 investigates the challenges that exist in the mental health care system for people living in homelessness and poverty in India. The paper in this chapter explores the concepts of mental ill health, homelessness, and poverty, and the mental ill health – poverty – homelessness nexus. It aims to capture the complexity and distress inflicted by the co-occurrence of poverty, mental ill-health and homelessness. By examining existing evidence through a narrative review, the chapter considers the implications of this nexus on health systems, human rights, and the social sector. It also sheds light on intricate factors perpetuating these challenges in the Indian mental health context.

Chapter 5 considers the chicken and egg situation, namely whether homelessness or mental illness comes first. It uses a participatory action research framework to examine homelessness in the mental health context against the backdrop of the authors’ experience with The Banyan. The paper supports this contextual analysis with cases, personal observations and selected quotes from the Banyan’s clients. These cases and quotes were selected based on their perceived fit to illustrate the factors described in the paper.
**Chapters 6 and 7** attempt to understand the nature of health service responses that may be able to address the complex problems of mental illness and homelessness by considering the organizational evolution of The Banyan since its inception in 1993. It enlists challenges at the meso and macro levels within the context of The Banyan experience, and describes some of the innovations at the niche level that provide user centric services. A timeline narrative of the organization is retrospectively constructed using archival documents, such as annual reports and evaluation studies and first person accounts based on personal participation. This narrative is then analysed using an action research framework (Kemmis and McTaggert, 1988) to identify transitions in strategy characterized by either incremental or radical learning. This analysis is used to identify attributes and values for constructing responsive mental health systems appropriate for addressing the mental ill health – poverty – homelessness nexus.

**Chapter 8** considers the role of not-for-profit organizations in mental health care against the backdrop of complex case studies that consolidate and illustrate all of the challenges in mental health. Qualitatively analysing reports from national-level seminars hosted by The Banyan Academy of Leadership in Mental Health (BALM) and first person accounts based on field visits across the country, the chapter discusses organizational responses, based on their strategic and constituency focus and the challenges they face.

**Chapter 9** is an inquiry into homelessness. It attempts to listen to the voices and perceptions of persons who have experienced mental illness and homelessness, focusing on the factors predicted their descent into homelessness and distress. Interpretative phenomenological analysis (IPA) (Smith, 1996) served as the primary qualitative approach for this paper. Focus group discussions (FGDs) conducted by two Masters-level researchers, using an open-ended guide, were the main method for data collection. Two FGDs were conducted: one with women who have been re-integrated back into their communities, one with women who reside at the residential facilities provided by The Banyan. In total, 23 clients participated in the FGDs to develop an in-depth understanding of their trajectories and experiences. The key emerging theme of the FGDs, namely the breakdown of family connections and consequent homelessness, is examined in the context of the author’s personal observations and interactions with clients.

**Chapters 10 and 11** consider the construct of rights, as perceived by clients of mental health services who have concurrent experiences of homelessness and poverty. This knowledge is considered and discussed in the context of larger reforms, policy, declarations and legislation to examine chances of matching, triangulation or corroboration, to develop a bottom up, expansive, collaborative and multi-dimensional understanding of rights. Chapter 10 explores the construct of rights in 15 qualitative interviews with clients of The Banyan, mainly women who have been homeless with a mental illness. An FGD for member checking
(Lincoln and Guba, 2000) followed the interviews. Thematic analysis was the preferred method of data analysis. Coded segments from the interviews were presented to participants to stimulate discussion and data interpretation.

**Chapter 12** is a commentary and opinion piece on the proposed Mental Health Care Bill (2013) introduced by the Ministry of Health, Government of India. It focuses on the concepts of mental illness and disability, and argues for the need for a pro-poor policy.

**Chapter 13** is a retrospective narrative of a teaching collaboration between a UK University and an Indian NGO. The article was written by the stakeholders in the collaboration and describes how teaching changed from a sole focus on theory to a mixed method of theory and practice, focusing on the local instead of the global through the lens of cultural psychiatry.

**Chapter 14** reviews CSR by considering two dimensions of socially relevant business. Qualitative reviews of published information on CSR in India, and personal impressions based on engagement with CSR, are analysed using the typology of CSR approaches that was developed.

**Chapter 15** revisits and consolidates all the themes in the main inquiry and discusses findings and conclusions.

**Research teams**

As all of the articles in this thesis fall under the scope of The Banyan’s work, and all of the research teams for each of the studies were in-house staff of The Banyan. This included social workers, psychologists, research associates, and case managers. The research staff conducting the interviews and FGDs in Chapters 6 and 8 consisted of three case managers with substantial experience within The Banyan. Three Masters-level researchers led the FGDs in Chapter 9. As the author of this thesis was not leading the FGDs in Chapters 6 and 9, this allowed for a more objective look at the data. With the exception of Chapters 12 and 13, where the researcher contributed to the papers, all other studies were conceptualized, executed and written by the researcher, sometimes collaboratively with co-researchers.

**Ethical considerations**

Ethical aspects were taken into account throughout the thesis. This thesis is part of a larger process of engagement with the constituency of people with mental health issues who experience homelessness and poverty. Ethical oversight mechanisms for the research are
the same as employed by The Banyan. Findings from this inquiry are part of the ongoing learning and adaptation of appropriate services. For case studies selected for Chapter 5, informed consent was obtained from women. Participants in Chapters 9 and 10 were briefed about the aim of the interviews and FGDs, and informed consent was obtained. Participants were offered the option to withdraw their consent at any point. For all the primary data collection in this thesis (Chapters 9 and 10), besides seeking informed consent, appropriate measures were taken to de-brief as well as follow up on needs and choices of participants since much of the inquiry involved revisiting their experience of distress. Names and identifying information were changed, depending on the request of participants.

**Ethical approval**

Chapters 4, 5, 6, and 7 comprise narrative reviews of The Banyan’s work, without any active participation of clients. Therefore, no ethical approval was required. For Chapters 6, 8 and 10, ethical approval was obtained from The Banyan Academy of Leadership in Mental Health’s External Ethics Committee. Chapters 11-14 comprise analytical reviews with no active client work, and hence there was no need for ethical approvals.

<table>
<thead>
<tr>
<th>S. No</th>
<th>Study</th>
<th>Location</th>
<th>Type of Study</th>
<th>Chapter</th>
<th>Part</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Persistent, complex and unresolved issues in the Indian discourse on mental ill health and homelessness</td>
<td>India</td>
<td>Narrative review</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>2.</td>
<td>The chicken and egg situation: systemic deterrents to fixing persistent problems of homelessness and mental ill health in India</td>
<td>India</td>
<td>Narrative review using participatory action research</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>3.</td>
<td>Responsive mental health systems: a conceptual framework emerging from The Banyan’s experience in Tamil Nadu, India</td>
<td>Tamil Nadu, India</td>
<td>Timeline narrative retrospectively constructed, analysed by action research framework</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>4.</td>
<td>Enabling access to mental health care: perspectives from The Banyan experience in India</td>
<td>Tamil Nadu, India</td>
<td>Descriptive review of The Banyan’s programmes and services</td>
<td>7</td>
<td>2</td>
</tr>
</tbody>
</table>
### Research validity

A number of approaches embedded in this thesis were used to validate the findings of the research. The conception of validity is dependent upon the paradigms of inquiry that are employed by the researcher (Creswell and Miller, 2000). This thesis is an inquiry of depth, grounded in a constructivist epistemology, anchored in the 20 years of direct, relevant field experience. The thesis draws from a niche dataset representing highly diverse client trajectories and organizational responses. The analysis and results are based on in-depth and rich descriptions of organizational and client experiences of homelessness, poverty, and
mental ill health, elicited through a variety of methods (timeline narratives, participant observation, interviews and FGDs).

Diverse research teams representing organizational staff with Masters-level training in varied disciplines were involved in data collection. Triangulation was ensured through corroboration of descriptive data from multiple sources, ranging from organizational memory, annual reports, and evaluation studies to staff feedback. Recursive processes were engaged in data collection, analysis and interpretation; all three operating as overlapping rather than discrete parts of the inquiry. Multiple investigators were involved in analysis and interpretation of results. Moderated discussions were used to resolve discordant perspectives on the data. Most importantly, to ensure that the data analysis authentically represented the perspective of participants, the author employed member checking (Lincoln and Guba, 2000). Data and findings were presented to participants for interpretation and assessment of the credibility of results. Ongoing analysis, and revisiting lines of inquiry with co-investigators, facilitated conceptual complexity and served as data audits to point out potential bias or distortion. All findings were discussed using rich descriptions of the context of this thesis and therefore may be applicable to other contexts and settings.

In an effort to increase validity of the findings presented in the various parts of this thesis, the author shared the draft manuscripts with other staff and peers outside the organization to provide criticism and contribute to the process of analysing and writing. Furthermore, the author employed reflexivity, specifically being aware of how her role as co-founder of The Banyan and how her personal perspective might shape the findings and interpretation of the results.

References
5. Lincoln, Y. S., & Guba, E. G. (2000). The only generalization is: There is no generalization. *Case study method, 27*-44.


Part 1

Setting the scene
Persistent and complex problems in the mental ill health – poverty – homelessness nexus
Chapter 4

Persistent, complex and unresolved issues in the Indian discourse on mental ill health and homelessness

Abstract

Challenges in the provision, accessibility and corresponding treatment gaps in mental health services in India and other low- and middle-income countries have been the subject of considerable discussion in recent times. Moving away from frequently acknowledged macro concerns, however, a few recurring and “wicked” or persistent problems remain insufficiently analysed. If not addressed, these could present large and significant crises – at human, economic and governance levels – hampering progress and resulting in the loss of human and social capital and potential. The article aims to capture the complexity and distress caused by the co-occurrence and interrelatedness of poverty, mental ill health and homelessness. It examines the ramifications of this nexus in domains including health systems and access to health care, productive living and full participation, social attitudes and responsiveness and the development of human resources and leadership in the social sector. It also discusses the failure to engage with these issues, which results in greater vulnerability, distress and social defeat among the affected populations.

Introduction

The global burden of disease study 2010 indicates that the health of a given population can improve only if the prevention and treatment of mental ill health and the prevention of substance abuse are a public health priority (World Bank/IHME, 2013). Epidemiological studies indicate a life-time prevalence of mental disorders among adults ranging from 12.2% to 48.6% (Kohn et al, 2014). There is, however, great variation among individuals and populations who are able obtain access to mental-health services, and rates of access are lower in low and middle-income countries (LMICs), including India, despite greater need. Multiple factors influence health outcomes, many of which have been well researched and discussed in scientific and grey literature, emerging from which are substantial policy recommendations, advocating for more public expenditure on health, the development and deployment of effective human resources, well integrated, cost-effective and accessible
treatment options, etc. These guidelines, while essential, have become increasingly rhetorical, since changes – at least in the Indian context – remain painfully slow.

Let us take a look at some of the intractable problems that slow down the system for responding to mental health. What makes the nexus between mental ill health and poverty so persistent? We employ the following definition of persistent problems:

*Firstly, they are complex: multiple causes and consequences exist—covering societal domains—and they are rooted in social structures and institutions. Furthermore, they are uncertain; no easy solution exists, reduction of uncertainty by mere knowledge is not always possible, and every possible solution changes the perception of the problem. Thirdly, they are difficult to manage; a lot of different actors—representing different interests—are involved, and they all try to influence each other while remaining relatively autonomous. And lastly, they are difficult to grasp; structure and boundaries are unclear in relation to a strong system dynamic.*

(Bundes and Broerse, 2010: 31)

We discuss the nexus between mental ill health, poverty and homelessness in the context of multiple causation and consequences, lack of clarity, influences of multiple stakeholders and the difficulty in grasping their structure and boundaries.

The contemporary understanding of mental health accepts the association between ‘ontological security’ (or a stable mental state), an acceptable quality of life and improved mental health. No longer is the discussion restricted to the realms of neuroscience and psychiatry and to dopamine and serotonin balances; it is also about the eco-system and its impact on the way people think, act and live in harmony with themselves and their surroundings. While poverty, mental ill health and homelessness are complex problems even when experienced in isolation, in combination they develop a persistent shape. Each of these phenomena is influenced by multiple factors (Loorbach and Rotman, 2006). The consequences are also detrimental and multi-dimensional, resulting in acute distress that affects many domains, especially health, quality of life and emotional strength. At the core of this distress is the poverty factor. This can often be the tipping point, pushing a person who is experiencing mental ill health into homelessness – or vice versa.

Let us begin by understanding the nature and extent of poverty and its impact on the other strands of this nexus.
**The poverty factor**

Seventy per cent of India’s population continues to live on less than USD2.00 a day, while 37% live on less than USD1.25 a day. This measure of poverty is defined in terms of the ability to purchase basic goods. However, many other impediments also affect the lives of the poor – for instance, people living in rural and remote areas in India either succumb to complex or chronic ailments like cancer and kidney problems, or are unable to seek treatment because of the lack of adequate facilities in low-resource settings. Despite the large spread of Primary Health Centres (PHCs) across India, many remain closed (Banerjee and Duflo, 2011) – and when they are open they are inadequately equipped to respond to needs in terms of attitudes, human resources and infrastructure. These inadequacies push people further into debt as a result of having to pay for private health care. The Business Standard Health Report 2010 states that nearly 25% of the poorest quintile in rural areas forgo treatment when they fall sick (Mahal et al, 2010). The National Sample Survey Organisation indicates a rise in out-of-pocket spending from 32% in 1995–96 to nearly 45% in 2004, resulting in a slide to below the poverty line (Mahal et al, 2010).

While there continue to be major deficits in health care, education is also failing to promote upwards mobility. Although it is a basic service, it is grossly inadequate and simply not preparing children for a healthy and competitive future. A survey conducted by Pratham, a large Indian NGO, which fed into the Annual State of Education Report (Pratham Annual Status of Education Report, 2005), tested 700,000 children across randomly chosen villages. It found that close to 35% of those aged between seven and 14 years were unable to read a simple paragraph (first-grade level) and almost 60% could not read a simple story (second-grade level). Only 30% could perform second-grade mathematics (Banerjee and Duflo, 2011).

Despite India’s industrial progress, which has created an affluent few, 200 million of the 600 million people who are without electricity have never been connected to power (Drèze and Sen 2013), symbolic of the darkness they experience on many counts. While India’s economy has grown rapidly in the past two decades or so, a basic requirement such as good nutrition – ‘children and adult women are more undernourished in India (and South Asia) than almost anywhere else in the world’ (Drèze and Sen, 2013) – has been neglected. Although India’s gross domestic product (GDP) per capita has increased dramatically compared to the South Asian region as a whole, its social indicators and commitment to equity have been gravely neglected.
A related symptom of India’s lack of governmental commitment to health care is that public expenditure on health accounts for less than one third of total health expenditure. Only a few countries (such as Afghanistan, Haiti, and Sierra Leone) have a lower ratio of public health expenditure to total health expenditure. (Dreze and Sen, 2013: 149)

This has also resulted in poorer sanitation with almost 50 million people defecating in the open, resulting in a significant rise in diarrhoeal infections (UNICEF/WHO, 2009). India has low literacy rates, poor nutritional status, and high infant and maternal mortality rates that are higher than most other countries in this region. Its long-standing neglect of children (the proportion of underweight children is twice that in Sub-Saharan Africa), women and other vulnerable groups has led to skewed, non-inclusive and disparate growth (Dreze and Sen 2013: 46-53).

Let us delve a little deeper into the dynamics of the ill health and poverty chain or nexus.

Figure 1: The Ill Health and Poverty Nexus (Source: Authors)

Figure 1 indicates the lack of exits from this vicious cycle that perpetuates poverty, ill health and compromised well-being. The fragmentation in India’s public health system has led to linear understandings of health and well-being, with their interconnectedness often ignored. There is little convergence between horizontal and vertical systems, resulting in
few or no deep linkages in implementation, health-related communication and training. This situation interplays with gender and other such cultural dimensions to further fragment the system rather than bringing it together in a cohesive whole. Neglecting the eco-system generates inequity, increasing the extent of multi-dimensional poverty.

The associations between health, inequality and income or social disadvantage have been explored by epidemiologists, social scientists, health researchers and economists. According to the economist Angus Deaton (2003), the richer and better educated are likely to live longer and healthier lives than the poorer and less educated, and also experience lower rates of mortality and morbidity. The psychiatrist Daniel Kahneman and Angus Deaton suggest that low income exacerbates emotional pain as a result of poor health. It results in a greater incidence of divorce, lack of care, loneliness etc. and has a negative impact on emotional well-being (Kahneman and Deaton, 2010). The Gallup data analysed by Angus Deaton in 2006 demonstrated the positive effect of wealth on life satisfaction (Deaton 2008).

Epidemiologists regard socio-economic status as the fundamental cause of health outcomes and classify income inequality as a health hazard. Research conducted on sugarcane farmers demonstrated the negative impact of scarcity on cognition (Mani et al, 2013). In addition, scarcity affects mindsets, influencing people to think and behave in ways that could negatively affect long-term gains (Mani et al, 2013). The focus is always on meeting the most immediate need so that investments in health and education are forgone or neglected.

The ill health and mental ill health and poverty nexus

Studying the epidemiology of common mental disorders in South Asia, Patel (1999) cited old age, poverty, female gender and low levels of education as risk factors for vulnerability to stress and to experiencing depression and/or anxiety (Patel et al, 1999). Further, close interactions have also been observed between socio-economic deprivation and mental disorders, with debt, poor housing, overcrowding and economically disparate societies emerging as risk factors that lead to greater susceptibility to schizophrenia (Patel, 2001). In 2010, the World Health Organization (WHO) and the World Bank found that people living with disabilities were among the poorest worldwide, with nearly 75% of mental disorders among people in low- and middle-income countries (WHO and World Bank, 2010). Besides the obvious manifestation of disorders, income inequality is negatively correlated with social cohesion and social capital, and could precipitate a state of chronic stress.
The diverse, transformational and evolving nature of mental illness and society – and thus the set of anomalies, ambiguities and inconsistencies that go with it – can make it stressful to work in this sector. Whatever the intervention, there can never be complete confidence that it will have a clear outcome, unlike the case of most physical ailments. The system of detection and treatment, while based on science and empiricism, is not always accurate since the spirit-level dynamics of the psyche cannot always be captured in absolute ways. The relationship between the body and the spirit exists in mental (ill) health more than in any other branch of medical care.

Figure 2: Pursuing well-being (Source: Authors)

Figure 2 represents the many facets that contribute to overall well-being over the course of a person’s life. The variables and influences include – but are not restricted to – demography, birth, parenting, kinship, socio-economic background, social, sociological and ecological health, working life and major life events. Besides biochemical changes and life disruptions or events, personality traits and stress endurance, coping mechanisms and resilience patterns also need to be factored in.
Hence a basket of interventions that combine the conventional evidence-based responses with the eclectic or psychodynamic – through a trial-and-error method – would constitute a care plan that typically would vary from one individual to another, with some basic protocols that most could regard as an optimum intervention plan. All these dimensions work in tandem to contribute to a person’s mental health, which makes the related discourse very complex. This lack of simplistic clarity in the science of mental health can be disconcerting.

**Homelessness and mental illness**

Often, the safety threshold is crossed when a person experiences extreme vulnerability, resulting in a downward spiral into homelessness. Those who are living on the street are just as likely to experience psychotic episodes as a person who has a mental disorder; and those who experience psychosis are just as likely to become homeless as a result of the illness. Tanya Luhrmann (2010) considers the risk.

*In 1998 the American Journal of Psychiatry published research that tracked patients after first hospitalization at ten out of twelve Long Island, New York hospitals. In this study, one in six patients with psychotic disorder either had been homeless or would become homeless in the following two years. In 2005 the journal published another study that analyzed the records of all patients treated in the public mental health system in San Diego over the course of one year. One in five patients diagnosed with schizophrenia was homeless at time of contact. Both studies – by the nature of their measurement and method – undoubtedly underestimate the risk of periodic homelessness for those with schizophrenia or some other psychotic disorder.*

(Luhrmann 2010: 146-147)

Very few conditions have as debilitating or devastating an effect as the co-occurrence of homelessness and mental illness. Evidence points both to periods of extended homelessness resulting in compromised mental health and to untreated or chronic mental illness rendering a person homeless. The latter tends to be more frequent in low-resource settings, especially among people who are living in poverty and/or who have poor access to health care. Homeless persons who also suffer a mental illness live a life of uncertainty, often depending on scavenging for food from garbage bins. Largely feared or ignored by society, they often are victims of crime and deprivation, and are vulnerable to other types of ill health. Women in particular are prone to exploitation and often live in fear. People’s mental ill health often robs them of most other basic survival and self-preservation skills; many are found wandering emaciated and with wounds that are sometimes infested with maggots. Homeless persons who have a mental illness are also far more likely to suffer from other problems including substance abuse, cognitive deficits and suicidal thoughts (Munoz et al, 1998).
Conceptually, homelessness refers to the absence of a safe, clean and permanent habitation or home. Those living in emergency shelters, on the streets (sleeping rough) or in insecure or inadequate arrangements can be classified as homeless (Tsemberis and Eisenberg, 2000).

While mental illness and substance abuse is one of the pathways to homelessness, other causal factors include urbanisation, industrialisation and the related loss of traditional jobs such as farming or weaving, migration, acute poverty, unemployment, social exclusion, the changing structure and culture of the family, and chronic health issues and related out-of-pocket spending (Johnson and Chamberlain 2008; National Resource and Training Centre on Homelessness and Mental Illness 2003). According to the 2011 Census of India there are 1.8 million homeless persons in India (Ministry of Home Affairs, Government of India, 2011). While developing nations seem to be struggling with this issue, similar trends are observed in high-income countries. It is estimated that 20-25% a nation’s homeless population suffers from some form of severe and persistent mental illness (National Resource and Training Centre on Homelessness and Mental Illness, 2003).

It seems reasonable to conclude that the absence of an appropriate and accessible public mental health system and strong poverty-alleviation mechanisms distances those who most need them from pathways to care (WHO, 2010). When this journey culminates in homelessness, the problem assumes grave dimensions that not only highlight a public health emergency but also a social catastrophe. Given the increase in mental ill health and inequity, this downward spiral is not to be ignored, placing those at the bottom of the socio-economic pyramid at high risk.

Having established the complexity and persistence of this nexus, we now use this framework to discuss the significant challenges that require urgent attention at multiple levels.

Disability and health promotion – a development agenda

Disability and health are somewhat marginalised in the development agenda, despite the fact that persons with living with disabilities have been found to among the poorest in the world (World Disability Report, 2010). While niche movements to promote rights of people with disabilities provide an impetus in the right direction, the United Nations Convention on the Rights of Persons with Disabilities rightly focuses on the need for greater cooperation to ensure that disability issues are integrated in the wider development discourse (UN General Assembly, 2006). Similarly, according to Amartya Sen, ‘health constitutes an important capability, in that it enables individuals to pursue things they may value’ (cited in Mahal et
In a nation such as India, where the health budget represents as little as 1.2% of GDP – compared to the military budget, which is among the top ten worldwide – the intent to allow health and productivity to take centre stage seems questionable. Mental ill health is affected as a result of lethargic action on both counts, sitting at the cusp of health and disability discourses.

Poverty alleviation: how serious is serious?

The endemic nature of Indian poverty has long been the reality, to the extent that most people are conditioned to this injustice. Multiple deprivations, inequities and disparities are growing, as is the divide between the affluent and the less privileged. While markets and the economy are essential to growth and progress, these cannot be achieved at the cost of inclusiveness and justice. Many policy-makers and reformers, including the polity, claim to have given this all-pervasive issue considerable thought and resources, but how serious are these stated intentions? If growth targets have been surpassed and a few luxuriate in high-quality health care, housing and other amenities, why are others still relegated to a life of penury and hopelessness?

Srinivasan and Mohanty (2004) observed that households belonging to the Scheduled Tribes (ST) and Scheduled Castes (SC) were living in ‘abject deprivation’ (49%) and ‘moderate deprivation’ (41%) respectively, and have limited access even to basic amenities. Reporting of ailments and the uptake of health services is lowest among these groups. Diversity is the norm and not the exception in India – not only do districts vary on many indicators, but even within a single village sources of discrimination range from caste and class bias to gender, in addition to rural and urban divides and disparity in political investment and resources etc.

The locations of PHCs are not always readily accessible, which is why 11% (14.4 million) of rural households do not get treated (NSSO, Government of India, 2006). Poor connectivity and inadequate road and transport services impede the use of PHC services. More importantly, potential users’ lack of faith in them, combined with fear of discrimination on account of deprivation and perceived low status, further distances people living in poverty from those who provide the services.

In a crowded, understaffed PHC, patients are hardly given the opportunity to express concerns or grief and enjoy private time. Das and Hammer refer to the prevalence of the 3-3-3 rule: ‘the median interaction lasts three minutes; the provider asks three questions and occasionally performs some examinations. The patient is then provided with three
medicines’ (Das et al. 2008 cited in Banerjee and Duflo 2011: 55). While this is the observation in the private sector, public health providers are said to spend negligible time with patients, with minimal communication and physical contact.

Among the many aspects that render a person vulnerable, gender and the geo-socio-political contexts in the Indian scenario are perhaps critical in determining health-seeking behaviour. India ranks 137 in the Human Development Index (2012) and 129 on the Gender Inequality Index (GII) (UNDP, 2012). The GII is based on three dimensions: women’s reproductive health, empowerment and participation in the labour force. The susceptibility to ill health, stress and marginalisation is pronounced at different stages of the life of girls and women.

Although there has been some progress in certain areas, there is as yet no determination to develop suitable strategies and responses to people’s crises.

Weak health systems: Health in India is politically and administratively divided between the central and State governments, with federal independence playing an important role in budget allocation, interpretation of policy and implementation. So what the central government mandates is not necessarily relevant or regarded as obligatory in any given State.

The National Mental Health Programme (NMHP) is integrated into the primary health care system in India, through its PHCs, the only accessible and affordable provision of health care across its uneven, diversely and differently resourced regions. The 1978 Alma Ata Declaration, identified primary health care as a critical pathway to achieve universalisation of healthcare. WHO describes, primary health care as involving the health sector, agriculture, animal husbandry, food, industry, education, housing, public works, communications and other related sectors and demands the coordinated efforts of all these sectors (WHO, 2005). As early as 1946, the Bhore Committee stipulated that ‘no individual should fail to secure adequate medical, curative or preventive care, because of the inability to pay for it’ (Bhore, 1946). It called for special focus on vulnerable groups, including those with a mental illness.

Despite this, health is hardly the equitable commodity envisaged in the Indian Constitution. It is on a shaky, unequal and under-resourced public health system that the NMHP piggybacks. The NMHP was initiated in 1982, with the aim of integrating mental health care and primary health care and reaching the previously unreached through the early identification, treatment and referral systems for common and severe mental disorders. The District Mental Health Programme (DMHP), however, covers only 123 of the country’s 640
Districts, 30 years after the NMHP was introduced. Even in these districts, the programme is not fully operational, facing problems akin to those faced by the PHCs – lack of human resources, training and medication etc., forcing those in need of health care to seek private services or simply to ignore the problem or live with it.

Health management includes effective vision, leadership, governance and implementation. In order to plan for a robust and systematic approach to health, the stage has to be set. In the current scenario, frequently exposed to inadequacies, crisis fighting becomes the norm, allowing only limited time and space for the adoption of finer values such as responsiveness, sustainability, impact measurement and enhancement. Battling very basic challenges such as poor sanitation and nutrition or housing, under-equipped clinics and demotivated or overburdened staff is more the norm than the exception. Exploration of financial and medical products, promoting community health and positively influencing help-seeking methods to build healthier and happier communities remains a distant goal, despite being reiterated frequently in policy documents and international treaties and mandates. Systemic changes and innovations, while urgently needed, may not thrive in a disempowered, poorly regulated, fragmented system, where coordination among departments responsible for health, social welfare, health education, and rural and urban development is far from healthy or cohesive. Usually only the symptom is treated, if at all, allowing for the barrage of reasons behind the external manifestation to fester, building a climate and attitude of poor accountability, apathy and inertia.

High rate of suicide: According to a study by Patel et al (2012), suicide rates in India are among the highest in the world. A significant number of those who take their own lives are aged between 15 and 29 years, primarily women. While distress related to socio-economic factors could well be the underlying cause of this trend, the high incidence is also a mental health concern and a public health priority.

Human resources: better quality and motivated or more in number?

Professionals and others working in the mental health sector include nurses, psychiatrists, social workers, psychologists, occupational therapists, primary care physicians, community workers, barefoot counsellors and health workers, among others. While some of these are part of mainstream health system, few are trained specifically to work with people who have mental health issues. A 2002–2003 World Bank study on absenteeism in Bangladesh, Ecuador, India, Indonesia, Peru and Uganda states that the average absentee rate of doctors and nurses across these countries was 35%, against India’s 43% (Chaudhury and Hammer 2004). But the challenge is not only the number crunching, but also the quality of training, interventions and services. While the response to many psychological problems is predominantly medical, the approach needs a rethink within the public health system,
keeping in mind the cultural and social contexts. If medication is the first line of treatment and primary care physicians are mainly responsible for identifying and treating mental illness, many of them feel under-equipped to do so given the brief training in psychiatry in the medical curriculum (Jacob 2010). Jacob questions the capacity of general practitioners to identify depression, anxiety or other common mental disorders if their only interface with psychiatry is an acute care centre or tertiary-level hospital where patients with severe mental disorders are generally treated. Besides pharmacotherapy, there are hardly any resources at this level to alleviate distress related to the patient’s psycho-social concerns.

On another note, motivation seems to be a significant challenge in this sector. To sacrifice more lucrative career paths in favour of working in a low-resource setting would essentially place the mental or general health practitioner in an environment facing the same complex problems as do those communities, ranging from poor infrastructure, sanitation, education systems to inadequate roads and connectivity and health services. All in all, the stress of living in a politically layered society facing such barriers would intimidate the most committed and passionate of health professionals. How can one expect services to be highly efficient when morale is low? While convergence is largely a broad policy goal, to date many of the District Mental Health Programmes do not recruit social workers or psychologists: how, then, does one encourage trans-disciplinary participation? Working with complex mental health issues can present its own set of difficulties for the mental health professional. Combatting both occupational hazards and also interdisciplinary rivalry and being undervalued is a further challenge faced by non-medical specialists.

Community participation and cross linkages that are considered mandatory in any public health programme are virtually absent in the NMHP, which is almost always driven by a specialist, usually a psychiatrist, despite the integration and convergence of approaches promoted by WHO.

Poor leadership development: Even in the training of mental health practitioners, strategic management and leadership development take a back seat. Implementation involves not simply the accumulation of knowledge to inform practice but also the development of an aptitude for creative problem-solving and critical, analytical and sometimes lateral thinking as well as an ability to innovate, keeping a clear view of the long-term vision and goals. In the social sciences in particular there is a need to examine and review current teaching methods in order to promote the development of real-life and real-time perspectives, strategy and character.
Where are the values? Among the many values that are universally critical to any individual, those that stand out as most relevant in the context of mental health include appreciation of diversity, affinity with a culture and ethos of responsiveness, ability to understand, live, confront and work with complex problems and most importantly to respect the inherent dignity and rights of the individual person.

Values are lost or deficient on many counts – in the mental hospitals, in the community, in civil society organisations (CSOs) and in society at large. Mental hospitals are in a sense the face of everything that represents healing and recovery from mental disorders. Owing to poor living conditions, and a non-conducive, discriminatory approach, mental hospitals are feared rather than sought. This raises the stigma levels rather than offering relief and encouraging caring partnerships between the patient and those providing health care. Even today, there have been only limited reforms to repair the damage and reform the system in a world that takes pride in its scientific progress and revolutions.

This apathy and inertia are possibly reflections of a society that has degenerated in a milieu of advancement to a point of accepting the loss of personhood and rights as the norm for a few. Those tucked away in mental hospitals or living in communities where they are subjected to distressing conditions are somewhat invisible people and causes. Homeless people are barely a part of our society – they exist and yet are expendable. Democracy based on simple majority rule seems to have led to the assertion of the primacy and rights of the dominant and powerful groups – collapsing all sense of empathy, kinship and culture in communities such that they can accept differences and enable equity.

Fragmentation of rights: Standards of rights and models of care are critical in this discourse. However, factoring in niches that are unique to geo-socio-political contexts is essential to the appropriateness of care. Macro planning has to be informed by micro contexts and particularities. In India, rights seem to be dictated by international habitats and sensibilities that are sometimes irrelevant to the context. Basic rights are critical to all and have to be set out clearly and also be made mandatory. In the context of disability and mental ill health, however, measures to promote human rights have to be understood in the language and culture of the persons affected, which is often at variance with global standards. These balances are delicate and sensitive and the sophistication of expression alone cannot be deemed a significant protector of rights. Deep engagement with socio-political contexts and distress arising from the denial of rights and voice is the only way to build trust and to empower groups and individuals experiencing issues related their mental health. Any sense of universality in what is inherent (dignity) and promoted (rights) runs counter to the ideology of being person- and context-centred, driven, dependent and determined.
Divided lobbies: Many landmark laws, empowering policies and welfare mechanisms aimed at improving peoples’ lives have worked thanks to persuasive advocacy driven by multiple stakeholders who set aside individual differences to ensure larger gains for those whom they serve. In the process, compromises are made – without departing from core principles – in order to accommodate other views. Despite the lack of total consensus, lobbies join together to ensure a balanced approach on vital issues. The mental health lobby that remains divided on issues of rights, institutionalisation and access to care has somehow been unable to reach a middle path that is acceptable to most stakeholders. Competitive goals and political persuasions sometimes cast advocacy in a particular light, which is not productive. The inability to grasp complexities and the obvious discomfort with responses that do not fall into prevalent and populist notions of rights or evidence is a cause for concern. On the other hand paternalistic approaches to mental health, inhumane practices in institutions and the community alike, ethical compromises driven by the pharmaceutical industry, watertight categorisation of mental disorders, criminalising legislation, violent ‘round ups’ of persons who are homeless and affected by mental health issues, power hierarchies and the overall exclusion of people with differences is equally distressing. However, advocacy is usually driven by urban, English-speaking representatives, who may not be entirely aware of the reality of fellow activists who come from and serve a different or less privileged background/population, and who experience different realities. A middle path is viable, but personal egos often get in the way, making this debate one of personal ideology and achieving success and less about alleviating distress and suffering. Negotiations and conversations rarely take place. Thus such movements, while positive in structure and approach, fail to recognise many local issues, generalise interventions and themes beyond acceptable limits and assume custody and leadership over large populations. While some of these interventions are meant to dismantle power structures and empower the invisible and voiceless, a top-down approach does just that – it reinforces power structures.

The urgency to scale up: Unless the ecosystem promotes a development-driven agenda, many of the complex issues discussed earlier become harder to address and somewhat redundant, despite the presence of a specific health policy. Health access and infrastructure must necessarily improve in order to facilitate any scaling up. Most models and protocols that are suggested as replicable have to be tested locally, taking into account context-generated inconsistencies and challenges. To scale up is essential and needs to be promoted. However, sustainable growth, progress and transformation will thrive only if the uncertainty arising from poverty and its consequences can be mitigated.
Heightened vulnerabilities within this nexus: While homeless persons who also suffer mental ill health experience extreme distress, equally vulnerable are children living with their homeless parents and also sleeping rough, or young and elderly caregivers in view of their frailty and inability to comprehend or cope with the situation. Chronic disability as a result of mental illness affects not just the patient but also the carer.

Co-morbidity: Many homeless persons who have mental health issues, men in particular, develop co-morbidity, substance abuse being one of the most chronic forms, with severe health and socio-economic repercussions as well as greater vulnerability to suicide (Shelton et al, 2009). The strategy and spaces to address this issue are currently either unavailable or inadequate. The risk of homeless and/or poor persons attempting or committing suicide is far more significant than among populations that are not homeless or living in poverty (Schutt et al, 1994).

Long-term care: People who have a mental illness often experience chronic disability and thus require ongoing support over extended periods of time. In the case of homeless persons with mental illness and elderly patients, or those being cared for by elderly parents, spouses, family or friends, their needs are gradually yet consistently becoming a cause for concern. Many of those with long-term needs are languishing in mental hospitals, jails or on the streets, barely existing, waiting to die. Based on a single-day census, mental hospitals in India recorded a 45% occupancy rate of in-patients with long-term needs. This compelling statistic reflects the nature and extent of the problem –approximately half of those currently being treated in Indian mental hospitals may never leave (Reddy, 2001). The abysmal state of most mental hospitals further complicates the situation, indicating the possibility of rights violations and thus the poor quality of life that many of these patients are likely to experience until their death. In addition many who currently live in their own home are perhaps at risk of a similar fate in the absence of safety nets and more humane living options other than mental hospitals or the streets.

The nature of mental ill health

While causal factors and phenomenology vary from genetics to social structures, the brain and the mind have always in a sense remained an enigma, despite advances in science and knowledge. There are not always simple solutions to addressing the needs of those who suffer mental ill health. While depression may have a scientific basis, pure sadness as a result of loss – loss of networks, property or identity – cannot be dismissed or ignored. The network of multi-dimensional circuits and paradigms further enhance the extent of complexity attributed to differences in behaviour and perception on account of a mental illness. The debate on how much personality and how much genes, how much social
systems and how much neurotransmitters and imbalances, continues to resonate with every mental health professional who takes a robust and engaged approach to dealing with each patient.

Discussing these challenges brings some issues, visible and invisible, complex and persistent, into our immediate collective consciousness. Based on these considerations, it is possible to make recommendations regarding research, implementation, policy and training that could determine and influence the future course of health and well-being and thus the incidence of mental ill health and homelessness, deprivation and marginality. The attempt is to address distress at all levels – individual, family, community and society – and respond to conditions that precipitate distress with a firm hand, prioritising goals on the basis of their critical nature.

Real-world dilemmas and the way forward: the ostrich syndrome

Since they are complex issues, many choose to view homelessness and mental illness in ways that do not challenge their intellect significantly. With limited risk-taking in thematic inquiry and implementation many of the grey areas that need to be scrutinised are not adequately researched or addressed, while the obvious are reiterated and studied. This also inhibits innovation. Tough questions are rarely asked – when a person with a mental illness who is also homeless can and cannot be admitted; why organisations fail; how one assesses the quality of life in institutions, keeping in mind social, economic and ethno-cultural considerations; why community care is sacred when often the a community member could be infringing the affected person’s rights just as much as an institution might; long-term needs, caring patterns etc. In order to achieve any positive movement, this status quo and superficial engagement has to be challenged and become a deeper, more meaningful commitment. This is a simple, yet essential, first step in a positive direction.

Lack of dialogue and the nature of competitive forces in the real world often get in the way of collaboration and meaningful inquiry. Personal aspirations, career paths and disciplinary rivalry often counter the very cause one aims to serve. In keeping with trans-disciplinary methods, recognising these barriers and yet cooperating to achieve a greater vision, is perhaps the only realistic and optimistic way to move forward. This is relevant in research, practice, teaching and implementation, where individuals and institutions from different schools of thought and with varied strategic visions and ideologies collaborate to address a large and pressing social problem.
Implications for policy and society: For reforms in the health and mental health or social sector to achieve an impact in the Indian context it is imperative to promote some sense of justice, balancing the rather skewed and pro-growth agenda with development and equitable progress for the majority. While good governance, effective planning, accountability and strategic feedback loops based on real-world dynamics will help to build stronger programmes, there is also a need for society as a whole to feel the urgency and need to pursue these goals more ardently. While the government and civil society organisations (CSOs) can uphold these values and missions as their mandate, other critical players such as the corporate world and society at large have to be urged to feel responsible for building empathy, unity, fair-mindedness and equity. Not only do safety nets have to be strengthened through proactive schemes including unconditional cash transfers, disability allowances, open shelters for the homeless, soup kitchens, but also access to basic services such as education and health care have to be non-negotiable and provided as set out in most national constitutions. In the absence of appropriate delivery mechanisms, the government has to be held accountable. This transition will undoubtedly take time to be seen to fruition. All forces and stakeholders, however, have to be encouraged to collaborate to see this process through effectively. In the meanwhile, efforts to foster community participation and constructive engagement with social problems have to be encouraged in creative ways.

Implications for research: In the real world, programme implementation faces many potential interruptions ranging from fragmentation, staff burnout and complex problems, to lack of solutions and resource crunches. In this context, Angus Deaton challenges the Random Control Trial (RCT) - driven approach to making the transition to scale up, and the over-reliance on this research method (Deaton, 2009). Yet, this trend rules with limited emphasis on practice based evidence. Is empiricism over valued with no grounding and valorization of knowledge in the real world? Is the scientific community lacking not in ideas or research, but in those who can implement these innovations effectively. Most programmes that have been scaled up stagnate at a particular point, since research is often driven by a single agenda of studying a problem, while implementation tends to be neglected.

Bunders and Broerse (2010) discuss this when they speak of an emerging scientific field – that of system transition innovation and transition theory. They say that the central notions in this theory include the ‘multi-level perspective, the multi-phase concept and transition management’ (Bunders and Broerse, 2010: 10). Extending this concept to research, they recommend greater inclusion of stakeholders and the application of ‘a typology of experiments of increasing complexity’ (Bunders and Broerse, 2010: 14).
The purpose of social research is to have a positive effect on human lives, driving the necessary innovation and pragmatism to address issues that are relevant to the most complex problems. This remains neglected in mental health, with limited engagement with critical issues – long-term or respite care, independent living options for persons with low, moderate and high needs, human resource training, performance gaps and burnout, voluntary or involuntary commitment and caring patterns – insufficiently researched. Grand Challenges Canada and WHO have come together to invite practitioners to engage in research and showcase bold ideas and practical interventions. While scientific efficacy is critical to this endeavour, equally important is the idea and the ability to implement it from transition to scale. There is a pressing need for similar funding direction and investment from local governments and industry.

A result of this argument is equally bold – the hypothesis that the root of mental ill health can be fixed faster and more effectively only if well-being indicators improve and poverty and its negative consequences are addressed more coherently and enthusiastically. No longer is the discussion only about interventions or clinics, it is also about what we eat, the jobs we seek and the life we lead. While we wait for this large-scale transition, an effective way to overcome the ‘chicken and egg’ situation is to address aspects or elements of the distress in part and yet thoroughly. Several government and civil-society initiatives such as The Banyan, Ashadeep, Karuna Trust, TRU, SCARF, Ashwini, Sangath, Koshish, Anjali and Bapu Trust have shown how this is possible.

**Implications for practice and education:** Bunders and Broerse (2010) examine transitions in health systems and speak of the merits of a trans-disciplinary approach to and engagement with multiple stakeholders to solve persistent problems, which are often of a complex nature. These insights are to be woven into existing practice codes so that a stronger system and structure of implementation emerges. Practitioners and issues related to human resource policy and management, including those related to strategic leadership and motivation, status and career paths, have to be discussed in greater detail to ensure continued and deeper participation. In view of the nature of the problems and responses, social work education seems critical for those engaged in mental health practice. How equipped and current is such knowledge in the Indian context? What aspects need further development or a rethink from a pedagogical perspective – is constructivist epistemology a line to pursue? These are crucial discussions that will aid in the development of context-specific training programmes. Education should move out of traditional classrooms into the field – complex experiments should be treated as training grounds, as they should be showcased as demonstrable approaches or responses to serious problems, constructing these in a dynamic and adaptive manner that meets the world’s many realities.
Implications for the rights movement: Some regard access to care and justice as a primary right, while others set greater store by personhood and legal capacity. Where does the call for constitutional and individual rights meet diverse perspectives and realities? The voices of the Global South have not been adequately represented in these debates, which this has had repercussions on the tone and direction of the discourse.

Fragmentation of rights versus collective voices in unison: There have been debates on rights ever since psychiatry has existed, and rightly so in the wake of the inhumane experiments and degrading treatment that were meted out to persons with mental ill health. In the process, however, some of the genuine benefits of treatment and safety have been misrepresented or under-represented because of the dominant tone of a non-medical, non-residential care ethos in the rights movement. The debate on admitting a homeless person into a care facility is often brought up as an essential part of the human rights discourse. Elyn Saks – a researcher, psychiatrist, lawyer and user of the mental health system user – says, in this context:

*If a person is unable to provide protection for himself from the bad elements and from malicious people and no less restrictive alternatives are available, we should be able to civilly commit that person until he can care better for himself, provided that he is impaired, transformed, and treatable. It seems correct, then, to say that the person is dangerous to himself and gravely disabled – he is exposing himself to more than usual, harm from being homeless, and he is doing so as a result of his mental illnesses.* (Saks 2002: 80)

Extremes on both sides occur when in the name of choice activists refuse to engage deeply with complexities and loss as a consequence of this approach – women are raped, men wounded, children lost and lives ruined. On the other hand, society is intolerant of differences and communities are often inclined to clear their immediate vicinity of any such “troublesome persons”, more out of the need for personal safety than because of a sense of empathy or justice. Both of these stances are simplistic interpretations of human rights that fail to engage with the varied dimensions of the problem and vicissitudes.

Conclusions

*The poverty–homelessness–mental illness nexus: the triple helix formulation*

Elements both in singularity and in this composition validate the theory of multiple causes, consequences and domain interactions discussed above. The binding and affinity between
these independently complex units draws multiple actors into the mix, all representing diverse dimensions – for example, human rights, caste, marginalisation and poverty; gender, poverty and mental illness; migration, homelessness, substance abuse, mental illness and suicidal thoughts or suicide. Each of these variables represents a large disciplinary system – be it the humanities or philosophy, society or sociology, social sciences or life sciences and health. While interacting with each other, these systems are also autonomous and have a timeline and direction of their own and are thus subject to and exert independent influences.

*Distress footprinting*

Given the relativity and reflexivity attributed to each of these concepts, the sequence of events is seldom clear. However, a distress timeline can usually be built over a person’s life span, based on the binding impact. Distress from a single source is usually less acute and chronic than distress from multiple sources. From this emerges a hypothesis that this composition has a catastrophic impact at multiple levels – individual and in kinship circles, and at the capabilities and social level.

This evidence points in the direction of one clear trend – that poverty does not only lead to ill health but also stands in the way of seeking health and well-being. Ignoring the so-called elephant in the room will not make the problem disappear. Unless poverty-related deprivation or inequity is tackled in a firm and decisive manner, little else can be expected to fall into place, irrespective of attempts, experiments or intentions. As the more persistent problem to address, planners and governments should acknowledge the truth that stares us in the face and respond to it a concerted manner. Equally important is the need to focus on other new and compelling challenges such as long-term care, carers’ needs, value-oriented responses, strategic leadership, and so on, before they become intractable, insoluble crises. At the root of these actions are other corresponding benefits.

**References**

Available at: http://www.who.int/mental health/policy/mhtargeting/development targeting mh summary. pdf.


21. Muñoz, Manuel, Carmelo Vázquez, Paul Koegel, Jesus Sanz, and M. Audrey Burnam (1998) "Differential patterns of mental disorders among the homeless in Madrid (Spain) and Los Angeles (USA)." Social psychiatry and psychiatric epidemiology 33, no. 10: 514-520.
Chapter 5

The chicken and egg situation: systemic deterents to fixing persistent problems of homelessness and mental ill health in India

Abstract
Mental illness and homelessness are systemic, interlinked problems in India. Up to 55 million people are estimated to be suffering from mental illness, while estimates for homelessness range from 1.8-78 million. Deeper understanding of the relationship between homelessness and mental illness is needed to support the strategies and actions to address them. This paper considers the chicken and egg situation – whether homelessness or mental illness comes first – against the background of the authors’ experience with The Banyan, a mental health care and treatment centre in Chennai, Tamil Nadu, India. It is part of personal, institutional and national journey to understand and address mental health and homelessness. It first reviews the extent of homelessness and mental ill health in India, with cases, personal observations and quotes from The Banyan’s service users. The complex relationship between poverty, ill health and inadequate health service access in India is examined. Finally, systemic responses to mental ill health and homelessness are presented, identifying innovations, steps in the right directions both globally and in India, and implications for policy, implementation and research.
Introduction

Homelessness and mental ill health are distressing, even when experienced independently. In combination, the effects are devastating. Mental illness and homelessness are widespread in India. Estimates of the number of people suffering from mental illness in India vary considerably from 650,000-700,000 (MoHFW 2005, Shields, 2013) to 55 million (Patel, 2009), and ranging from 5-20% of the Indian population (Patel, 2009, Minds Foundation, 2010). Estimates of the treatment gap, defined as the difference between those who require care and those who receive care (Saxena et al., 2004) is estimated to be up to 90%. (Patel, 2009). Homelessness is also a serious problem, although statistics of its extent also vary considerably. The 2011 census established that there were approximately 1.8 million (17.73 lakh)1 homeless people in India who ‘...live in the open or roadside, on pavements, in hume-pipes, under flyovers and staircases, or in places of worship, mandaps, railway platforms, etc’ (Census of India, 2011). However, this may represent an underestimation of the extent of the problem: in 2003, Action Aid estimated at that 78 million people were homeless in India (Action Aid, 2003).

Homeless people are vulnerable and distressed in many ways and often experience acute forms of deprivation and scarcity. As a consequence, they become increasingly vulnerable to mental, social and physical ill health. In the absence of basic amenities like food, water, clothing, access to sanitized toilets and healthy living conditions, combined with feelings of alienation, homeless people live on the margins of society. Ethnographic studies of adverse environments like the slums of Mumbai, India, have indicated that migration, displacement, homelessness and ethnic disharmony shape local experiences and the mental health of the individuals of that community, often resulting in feelings of hopelessness, demoralization, anger, addiction, depression, hostility and violence (Parkar et al., 2003).

Given the persistent, systemic nature of both mental illness and homelessness in India, a deeper understanding of the relationship between them is needed to support the strategies and actions to address them. This paper is focused on the chicken and egg situation, namely the causal dilemma with regard to the chronological sequence of these conditions – whether homelessness or mental illness comes first – against the background of the authors’ experience with The Banyan, a mental health care and treatment centre in Chennai, Tamilnadu, India. The Banyan has treated and supported some 1,700 and 40 homeless women and men with a mental illness, particularly psychosis and mood disorders. The Banyan was founded in 1993 by the first author with Vaishnavi Jayakumar after:

---

1 This confusion is probably the result of differences between the Indian and the Arabic numbering systems. In the Indian system, the lakh (100,000) and crore (10 million) are frequently used.
...[she] came across a half-naked, mentally ill homeless woman in absolute distress on the road in front of her college. Nobody else seemed even to notice her... Mental health institutions and [non-governmental organisations] were reluctant to admit the woman in desperate need of medical and psychiatric attention. Several more such encounters over the next few months left the idealistic duo disillusioned and the idea was born that they should do something about the problem themselves (Genesis of The Banyan, 2009).

The first author is also a member of the Mental Health Policy Group, appointed by the Ministry of Health and Family Welfare, Government of India, to prepare the first National Mental Health Policy and Plan (Mental Health Policy, 2012).

This paper is, thus, part of personal, institutional and national journey to understand and address mental health and homelessness in India. We start by reviewing the extent of homelessness and mental ill health in India, with cases of two families. In addition, we consider what it is like to be homeless, mentally ill and poor, based on the authors’ personal observations and quotes from The Banyan’s service users. We also review in detail the complex relationship between poverty, ill health and inadequate health service access in India. Finally, we present systemic responses to mental ill health and homelessness, identifying innovations, steps in the right directions both globally and in India, and implications for policy, implementation and research.

Although the paper is focused on India, it will be of interest to researchers and practitioners attempting to address mental health and homelessness in circumstances of inadequate health service access, generally characteristic of low and middle income countries (LMICs). More than 80% of people suffering from mental disorders are living in LMICs (WHO, 2009).

**Homelessness and mental ill health in India**

**Homelessness**

According to the 2011 Census, the homeless population has declined over the 2001-2011 period to approximately 1.8 million (17.73 lakh), although there has been a 20.5% increase in urban areas (Census of India, 2011). The National Advisory Council (NAC) estimates that 1% of urban population of India is homeless, and homelessness is an issue of growing social concern (National Advisory Council, 2012). Homelessness affects multiple domains or spheres and even generations and often has long-term negative and catastrophic effects that include degradation and loss of human life (National Advisory Council, 2012). With rapid urbanisation and extreme poverty and inequity on the one hand, and restricted and
scarce mental health services on the other, the extent of this problem in India can be seen as a social epidemic.

In India, pathways to homelessness are multifactorial. However, abject poverty, ill health, inadequate housing, poor social networks, social exclusion, unemployment and distress migration from rural to urban areas in search of better livelihoods and health care options, are some of the fundamental causes of migration-related homelessness. Many homeless persons sleep rough and suffer harsh climate changes, starvation, ill health, abuse, eviction and harassment. Amongst homeless families, men, women and children, the latter two groups are often victims of domestic violence, marital conflict and abuse, or are simply abandoned (Tipple et al., 2003, Speak et al., 2010). A large number of persons with mental illness wind up homeless because of illness-related confusion, disorientation and wandering tendencies. Such persons may also experience co-morbid symptoms as a result of their dependence on substances, compromising their health further. Unfortunately, the archaic Bombay Beggary Act of 1959, criminalizes such persons who can even be arrested and remanded into judicial custody in state-run beggar’s homes (EPW, 2010).

Homelessness in India is part of widespread and multi-dimensional poverty. India is home to 1270 million persons, of whom 32.7% live below the poverty line on USD 1.25 a day with 68.7% living on below USD 2.00 a day (World Bank, 2014). Access to the basic entitlements in keeping with the Constitution of India, such as food, education and health, have not improved significantly over time. State health spending remains exceptionally low at 1.2 % of Gross Domestic Product (GDP) (Dreze and Sen, 2013). Although India’s status in the Global Hunger Index has improved over the 1990-2013 period from 32.6-21.3, it is still one of 19 countries with ‘alarming’ or ‘extremely alarming’ levels of hunger in the year 2013 (Grebmer et al, 2011). With regard to literacy rates, India has been left behind by other South Asian countries, such as Bangladesh, Nepal and Sri Lanka, and by East Asian countries, such as China, Malaysia, and the Philippines. Infrastructure development, whether roads, power or service facilities is urban region biased, perpetuating the rural urban divide (Dreze and Sen, 2013: 113). Some 200 million people currently live without electricity and have never been connected to power (Dreze and Sen, 2013: 9). Social welfare schemes that attempt to draw people out of poverty are unevenly distributed and not sufficiently efficiently managed, often giving way to corruption. Infant mortality and under- 5 mortality rates remain high at 47 per 1000 and 61 per 1000 live births respectively (Dreze and Sen, 2013: 51). The proportion of children below five years who are undernourished and thus underweight and stunted is at 43% and 48% respectively (Dreze and Sen, 2013: 159-161).

Multi-dimensional poverty, the combined result of poor nutrition, housing, health, literacy and infrastructure and culture-based disempowerment, in the absence of safety nets, places a majority of the population in the grip of inequity and thus at risk. This is further exacerbated by dominant power equations and gender and caste bias. All this, while a
parallel India is poised to take off as an economic and socio-cultural hub, creating a dual faced reality: the exceptionally privileged and the deprived.

Case Study 1
Mr. and Mrs. J live together with their two children; a boy and girl aged 4 and 6, under a bridge with a group of other homeless persons. Approached for a scheduled evening conversation to encourage them to use the services of The Banyan, Mrs. J speaks of a house that she lived in prior to her marriage with eight other siblings, her mother and her then uncle and now husband, until a severe storm destroyed all that they had and rendered them homeless. Ever since, the streets of Puducherry and Chennai have been their homes. Their children were born in hospitals and then moved to their street home and have since known no other form of habitation. They are now used to the unreliability of daily wages, food and water. They wake up early to relieve themselves, particularly the woman, who has to safeguard her body from subtle glares and more direct attacks. The girl child suffers from an oozing wound to the head that seems to have become infected, resulting in a fever. While a natural disaster grabbed their home and life, a continued state of homelessness seems to have not just rendered them shelterless, but hopeless and perhaps depressed. They seemed to have reached a stage of inertia, experiencing apathy of an acute nature, where nothing matters anymore, not even the loss of a child. Attempts by The Banyan to engage with this family and reach a consensus on a plan that will require some effort and investment on both parts, and yet result in a more favourable future, is ignored.

Mental health and mental illness
In India, the National Mental Health Programme (NMHP) launched in 1982, mandated delivery of mental health services to administrative units (villages, blocks, districts and towns) through the District Mental Health Programme (DMHP) which currently, more than 30 years since its initiation, still operates only in 123 of the 640 Districts. Services provided under the DMHP are grossly inadequate to meet the needs of the vast majority of persons in rural areas who are unable to afford private, paid services, hindering processes of early identification, treatment, stigma reduction and recovery. Even in the districts where the DMHP is available, it is based on medical model with negligible linkages to social care and its related administrative departments. Thus, the family as a unit is not supported in difficult circumstances, even as the individual struggles to negotiate her/his recovery process.

---

2 The first author met the Js when she was on night rounds as part of the ongoing street engagement with homeless people of The Banyan.
Case Study 2
Muniamma, 70, haggard and emaciated, lives in a near roofless hut in a remote village in Tamilnadu. She is the primary care giver to a son, 35, affected by alcoholism and a daughter, 50, mildly intellectually disabled and experiencing psychosis. She survives on daily wages, selling odd goods including fish, and an old age pension. She seems tired, her eyes watering constantly, her only social contact with cats and dogs that she feeds. She has no social support, fears her son who could return home violent, and worries about her daughter’s future after she has passed on. None of the three individuals experience any semblance of what one would consider an optimal quality of life. On the verge of losing resilience, the thought of suicide has crossed her mind. Her needs range from shelter, nutrition, physical health to respite care support, while the children have their own set of needs that may find relevant responses through social prescribing. Long-term care planning and skill development to facilitate independent living are also essential to this composition. However, all these interventions are more likely to work in a context where despair and scarcity are not the primary emotions and experiences.

Social exclusion and alienation: being homeless and mentally ill
While case study 1 demonstrates how susceptible members of a homeless family are to stress and distress related depressive states, case study 2 exposes the vulnerability of a person living with a mental illness to homelessness, especially when ill health and poverty combine, producing somewhat paralyzing and irrevocable effects. In our experience of working with The Banyan’s service users, the personality of a homeless person with mental illness can at best be described as disconnected or disengaged from the rest of the world. While conformity with prevailing societal norms and standards is not a yardstick to measure health and well-being, homeless persons with mental illness are often invisible and function as non-persons. Their primary source of food is the garbage can. They are often susceptible to accidents and injury and live in poor health. Sexual abuse is unbridled on the streets, with homeless women experiencing the worst. For example, a study in France has demonstrated that 23% of homeless women with schizophrenia have been raped, with two thirds of them having been raped multiple times (Darves-Boronoz et al, 1995). To protect themselves from attack, homeless mentally ill women have been known to wear 10 pairs of panty hose at once and bundle up in layers of clothing (Cooper et al, 1998).

Homeless men and women are often also subjected to ridicule and violent physical attacks. They live in most inhabitable locations including pipelines, cardboard boxes and underpasses and bear the brunt of changing climatic conditions. Evidence also indicates that this group has a markedly elevated death rate as a result of accidents, poor health, crime,
abuse and suicide (Cheung et al., 2004, Babidge et al., 2001, Hwang et al., 2001). The sometimes disorganized and paranoid thoughts, withdrawn personalities, poor problem solving skills and almost non-existent help-seeking behaviour may steer them further away from a supportive and caring environment to live almost calamitous lives. These quotes from The Banyan’s service users illustrate these processes:

I didn’t know where I would get my next meal from. But some people were kind. Some were mean though and would shoo us away. Thank God I was too young to feel the pain and insecurity that my Mother probably experienced, caring for me on the streets. Also, it helped I was blind and didn’t fear what I didn’t see as much as my mother did what she saw. ’ (Ms. K, now 21 on spending a year with her mentally ill mother on the streets when she was 5.)

The nights were scary. I would climb a tree and attempt to sleep, holding on to a branch, waiting for dawn to break. (Ms. T)

To be woman, poor, homeless and mentally ill is the worst punishment one can suffer. It is three drubbings rolled into one, in a single lifetime. No God can be this blind and harsh! (Ms. M)

Homelessness took away my dignity, but more importantly, separated me from my child and made me hopeless. I now have a house, feel well, hold a job, but it somehow feels like I have lost my sanity and life forever. (Ms. R on losing her child in a train, when she was unwell, homeless and wandering)

Besides the visible losses that the individual suffers on account of their dual states of homelessness and mental ill health, there are also emotional losses that further compound the negative psychological impact, resulting in greater stress and poorer mental health outcomes. The consequences of this phenomenon affect multiple dimensions of life. Most suffering is perhaps on account of the loss of the feeling of connectedness: the streets are lonely and an unwell, paranoid mind is also lonely. This combination is emotionally fatal and destructive, resulting in long lasting negative effects including psychological scarring and loss of ontological security and psychological centrality, all critical in promoting well-being.

In order to understand simultaneous manifestation of homelessness and mental illness, it is important to study its underlying causes: poverty, ill health and inadequate health service access.
Complex causative processes of homelessness and mental illness

In the Indian context, the co-occurrence of homelessness and mental illness can be ascribed to poverty, ill health, and inaccessibility of health services. Indeed, the impact of poverty and ill health in the absence of a responsive health system may be central to perpetuating conditions of homelessness and ill mental health. Poverty, ill health and homelessness form a complex, social aggregate, making them far more persistent and difficult to address than they would be independently, while ill health and homelessness are in themselves complex, persistent phenomenon. Homelessness and mental illness exacerbate poverty, ill health and poor access to health services. There are three possible equations that emerge. First, ill health leads to stress and, in the absence of adequate health services, results in out of pocket spending. This, in turn, accentuates distress, deprivation and poverty levels, resulting in greater vulnerability to mental ill health and homelessness. Second, the poorer you are, the greater the likelihood of general health ailments and mental illness. The poorer you are, the less access to appropriate health care. The feeble and weaker the response systems, the worse the health, the greater the neglect, disability and disease burden, and the greater the distress, often resulting in mental ill health and likelihood of homelessness. Third, mental ill health and lack of access to adequate health care operate as triggers which, in a context of poverty, often render persons homeless. Like homelessness and mental illness, the link between poverty and ill health is also reciprocal and complex. It may be that crises of homelessness and mental illness are outcomes and, in some respects, extensions of other equally critical and persistent sets of problems: poverty, ill health and poor health access.

The chain of circumstances in this co-occurrence of homelessness and mental illness challenges the typical cause and effect paradigm. In the backdrop of poverty and ill health coupled with lack of access to adequate health care, mental ill health and homeless do not have one simple cause. Immediate triggers can be natural disasters (case study 1) or a combination of factors: alcoholism, unstable and inadequate housing, the burden of being an elderly caregiver, ill health and poverty (case study 2). This form of systemic or probabilistic causation usually finds its origin in a network of causes, both direct and indirect or less obvious.

Figure 1 divides Indian Society into the socio-economic criteria of very well resourced; persons living in poverty with poor health access; and homeless persons with mental illness, representing the collapse of numerous safety nets and the transition from a fragile to an unprotected stage of peril. The measures of vulnerability and social exclusion increase corresponding to the decrease in socio-economic status. However, the huge at risk population, the largest constituency in the Indian state, is not in a safe zone because of constant exposure to multiple health, social and economic shocks. Muniamma illustrates this clearly as she and her family sit on the brink of homelessness. Access to care assumes the need for more than medical relief. Symptom control can improve a single domain but
not deal with the collective distress of a household that is denied basic amenities and caught in multiple poverty traps.

To understand the lasting nature of these conditions, the nature of poverty and ill health in India, and the interlinkages between them, are described in more detail.

**Poverty, mental illness and homelessness: a vicious and destructive cycle**

Angus Deaton (Deaton, 2008) writes about the importance of health saying, ‘Without health, there is very little that people can do and, without income, health alone does little to enable people to lead a good life.’ As Kofi Annan, the former UN Secretary General remarked: ‘The biggest enemy of health in the developing world is poverty’ (WHO, 2001). Poverty leads to ill health and ill health leads to poverty.

While poverty, particularly rural poverty, has been proven to be a risk factor for homelessness, its impact in precipitating mental disorders has received increasing attention in the last two decades (Jiloha et al., 2013). Homelessness implies a lack of social ties, social exclusion and marginalization (Edgar et al., 1990). In The Banyan’s experience, homelessness has been primarily precipitated by mental illness. However, general trends comprise abysmal living conditions, poor infrastructure, loss of traditional livelihoods, ill health and poor health access. Fragility as a result of poverty influences the psyche in multiple ways, sometimes increasing endurance and resilience, and building preparedness. Sometimes it crushes a sense of self preservation, dignity, hope and agency, resulting in self-destructive behaviour such as substance use and crime. In a similar way, mental health outcomes are also influenced by a state of poverty.

Anandi Mani, Sendhil Mullainathan and colleagues recently investigated the impact of scarcity on peoples’ lives (Mani et al., 2013). Their results are consistent with what we observe in practice: **most people make wrong choices when experiencing neediness.** The strain of poverty seems to result in diminished cognitive functioning as well, often resulting in impaired or compromised decision making. The World Health Organization (WHO) has established a direct link between the poverty and mental illness: three fourths of the global burden of neuro-psychiatric disorders is borne by LMICs (WHO, 2010). The interplay between mental ill health and poverty is a complex and vicious cycle (WHO, 2009). Evidence from a twenty year period demonstrates that common mental disorders (CMD) are twice as prevalent among the poor. For example, depression is 1.5 to 2 times more prevalent amongst low income groups in a population (Lund et al, 2010). Hunger, debt, overcrowding, poor or inadequate housing, poor education, unemployment: these poverty traps correlate with higher estimated prevalence of CMDs (Patel et al., 1999, Patel et al., 2001), demonstrating a relationship between stress, poor quality of life, diminished capabilities
and life satisfaction, and greater suffering and distress. In the next section, we consider the role played by inadequate health services.

![Diagram](Image)

**Figure 1: Representation of the Indian at risk population (Source: Authors)**

**Inadequate health services, ill health and poverty**

In India, the proportion of people not seeking or receiving treatment amongst ‘the poorest 20% is nearly twice that of individuals in the richest 20% of the population. Nearly one quarter of the poorest 20% in India’s rural areas forego treatment when reporting sick (Mahal et al., 2010).’ One of the panchayat (local self governance) members corroborated this when asked by one of the authors about the incidence of kidney disease and cancer in the village of Kovalam: ‘If people are afflicted with a serious ailment and are poor, they often choose not to pursue treatment in the cities. The burden of travel to a city or town, loss of wages of the caregiver, the emotional distress that accompanies such a process and dishevels already complicated family life is simply too much for a person to take. They simply choose to die.’

In India, health services are part of both the State and Federal system and structure. Public health is organized to the village level through a network of clinics and hospitals that are brought under unified control at the administrative level of the District. Prevention, health
promotion and other health related programmes are implemented principally through Primary Health Centres (PHC). Most PHCs cover a population of 30,000 with a sub-centre being located closer to the village for a population of 5,000. The PHCs have cadres of medical doctors, nurses, auxiliary health workers and a large number of Accredited Social Health Activists (ASHAs) to work in the community. In addition, every District also has a District Hospital with specialist services and a teaching hospital; these are managed by different operational departments, resulting in fragmentation. The PHCs deal with minor medical needs, primarily focuses on reproductive health and institutional deliveries. According to a 2003 survey conducted by the International Institute for Population Sciences, Mumbai, only 69% of the PHCs had at least one bed, only 20% a telephone and only 12% enjoyed regular maintenance (Dreze and Sen, 2013: 149). When they were set up following the Bhore Committee in 1946, they were originally designed to respond to multiple medical needs. In addition, the sub-centres in many regions are not operational, remaining shut. Health facilities in urban areas are sometimes worse than in rural areas as a result of overcrowding, poor sanitation, and poor accessibility. Only 42% of slum children receive all recommended vaccinations and over half (56%) of childbirths take place at home (Yadav et al., 2011).

Given the under resourced, ill-managed public services, there is considerable reliance on private health care. This reliance is compounded by attitudinal barriers with medical staff often demonstrating social class supremacy in contact with the illiterate, poor, health seeker. The combination of poor services with negative attitudes leads many clients to opt for private care where they experience greater responsiveness and are treated with dignity. In this process, clients have to borrow to meet their health needs, often having to resort to informal, unstructured and high interest financing methods in the absence of insurance or social security nets. According to National Sample Survey (NSS) data, there is considerable loss of household income due to ill health, out of pocket spending is high and rising, especially for non-communicable diseases (NCDs) (Mahal et al., 2010). These health expenditures can have catastrophic effects on the 70% of the population who are at risk (see Figure 1). Garg and Karan (2004) estimate that out of pocket expenses for health services caused 3.3% of the Indian population to slide below the poverty line in 1999-2000. Furthermore, poor health can also weaken long-term cognition, education, employment and income.

In this challenging environment, medical staff are not performing well. Das and Hammer have established the 3-3-3 rule in private and public health care in India, although public health care appears to be much worse than private care, namely the median interaction lasts three minutes, the provider asks three questions and three medicines are usually dispensed by the doctor, with examinations, instructions, details on follow up and referrals being rare occurrences (Das et al., 2004). This is compounded by a high rate of absenteeism. A World Bank survey found that the average absentee rate of medical staff, doctors and
The chicken and egg cycles: double jeopardy or more?

The double jeopardy hypothesis has often been used to consider the relationship between ill health and poverty (Whitehead et al., 2006). The cycle of one leading to the other – ill health to poverty and poverty to ill health - has been discussed in the literature. John Read in his insightful paper, ‘Can poverty drive you mad?’ (Read, 2010) argues that while ‘social causation’ explains ‘how poverty causes psychosis’, ‘social drift’ explains how ‘poverty is involved in its maintenance.’ Read goes on to speak of relative poverty and related inequity as strong predictors of mental health problems including schizophrenia. His paper presents a diverse range of evidence as a result of systematic synthesis of data, each pointing at the intertwined co-occurrence of psychosis and poverty. Similarly, an increased rate of illness and mortality is associated with a high rate of inequality between the richest and poorest in society, according to Richard Warner in his book, ‘Recovery from schizophrenia.’ (Warner, 2004) Warner argues that illness and death rates and the incidence of stressful life events are higher among the working classes, contributing to increased prevalence of stress-related physical and mental illness. Attributes in the economic, social and sociological domains that impact psychological distress, social exclusion and isolation, and well-being are intricately linked to poverty or its absence.

Mental illness, homelessness, poverty and more general ill health are interlinked in complex patterns in the Indian context (see Figure 2). In these circumstances, mental illness and homelessness represent a double jeopardy, namely risk and disadvantage occurring from two sources simultaneously. Mental illness and homelessness are enmeshed in chicken and egg cycles in which they can each trigger further poverty and vulnerability (Figure 2). In India, there are enhanced losses because the shocks are severe, leading to ill health, debt (Richardson et al., 2010), poverty, social exclusion, lack of health access and stuckness (Young et al., 1999), almost as if the double jeopardy hypothesis is applied twice over. Given the complexity of the relationships between mental illness, homelessness, poverty and more general ill health, it might be more accurate to talk of multiple jeopardy in which risk and disadvantage occur from multiple sources.
Systemic responses to mental health and homelessness: current status, innovations and future development

In India, homelessness and mental illness influence each other but there is no clear causal pathway, neither is it clear which comes first. The foundations of both can, instead, be found in the widespread poor quality of life and poor health care experienced by a large proportion of the Indian population. Thus, poverty and an inadequate health systems have to be tackled strongly and urgently as complex problems. Against this background, the co-occurrence of homelessness and mental illness is only the visible tip of the iceberg: 70% of the Indian population is at risk. Deterioration occurs when ill health or poverty or the combination is experienced. In this complex picture, most health problems cannot be tackled by a disease approach which ignores the influence of deep-rooted social problems.

Typical systemic responses to homelessness and mental illness are legal, judicial, corrective, medical and social, comprising the opening of shelters, soup kitchens, linkages with mental hospitals, referrals to non-governmental organisations for continued care, admissions into beggars’ homes and sometimes arrests, leading to imprisonment. In recent times, a new
range of responses has emerged that attempt to address the complex and ongoing needs in more dynamic ways.

**Innovations in ending homelessness amongst people with mental ill health**

While larger environmental and economic transformations have to take place if improved outcomes are to be achieved in the Indian context, some innovative, intermediate solutions have been developed in India and in other countries which could be applied on a wider scale.

The Banyan has initiated an experiment to respond to the long-term needs of recovered women, previously rendered homeless on account of their mental illness, with an emphasis on independence and self-reliance. Having achieved their own notions of recovery and not able to return to their original habitats, some women have chosen to live in The Banyan’s shared housing, based in rural areas and free from overcrowding. Clients find jobs locally, assisted by social mobilisers. The arrangement is graded, with those who experience higher needs settling into a facility that is better supervised and more organization-driven while those with negligible needs run their homes almost independently. In some cases, children and mothers live together with the support of The Banyan’s social care and social prescribing programmes. When required, care or interventions are escalated to the next grade, possible because The Banyan hosts a spectrum of services at multiple levels, including emergency care. This innovation has resulted in much more significant mobility and capability, and could be scaled up as a long-term response for others in similar circumstances (Ravikanth et al., 2012).

The State of Kerala has established a successful health and mental health delivery system with care at the sub-centres, demonstrated by the case of Thiruvananthapuram District (WHO, 2008). The Kerala Panchayat Raj system, considered the best in India, also plays an important role in delivering services to its constituents. This bottom up approach of collaborative care seems to have achieved scale and impact (Nair, 2011).

The Housing First vs. The Treatment First approach has had favourable results amongst homeless persons with a mental illness in Canada (Hwang et al, 2012). This approach is based on the primary individual need for shelter or a safe space, and accordingly helps homeless persons access housing without conditions such as treatment of the mental disorder or withdrawal from substance abuse. In a parallel intervention, local support networks and referral pathways are built to assist the person in need. The approach is akin philosophically and ideologically to the capabilities approach taken by The Banyan.
Steps in the right direction

In addition to these innovations, there are also signs of positive developments, both internationally and in India itself, in relation to poverty eradication, mental health, and homelessness. Globally, much focus has been placed on the eradication of poverty and hunger by the Millennium Development Goals. According to NSS data, poverty seems to have decreased by 15% in India over the 2004/5-2011/12 period (The Hindu, 2013). For the first time, India has developed a Mental Health Policy (Patel, 2013) that recognises the multiple domains that contribute to mental health. In this policy, the focus has moved from medical responses to social prescriptions, keeping in mind that mental health is both a right and an entitlement, and that every health seeker should be assured of adequate medical attention and a diverse range of robust social services. Inter-sectorial coordination promoted by this policy, also resonates with the call for convergence mandated by the 66th World Health Assembly (WHO, 2013). Meanwhile, the most recent Mental Health Action Plan (2013-2020) initiated by the WHO also uses a similar lens to construct its priorities and objectives. A development framework for mental disorders and mental health that moves beyond a simplistic, reductionist, bio-psychosocial and genetic model is finally emerging.

On the homelessness front, the Supreme Court has mandated construction and opening of a shelter for every 100,000 population in all States (The Hindu, 2013), and reasonable progress has been achieved. Between this campaign and the National Urban Health Mission, the State aspires to care for its most vulnerable, namely the homeless and slum dwellers (Yadav, 2011). However, poverty reduction and improved access to health care are needed if any of these further changes are to be effective.

Implications for policy

The State’s social and health policies need to be reformed if they are to extricate persons from mental illness, homelessness and the downward spiral of poor health, compromised lifestyle, substance use, deprivation, marginalization, hopelessness, and often, even physical and sexual abuse, violence, suicide and death. The new policy framework has to take into account the interlinkages between poverty, mental ill health and homelessness and to approach promotion of mental health from a development and capabilities perspective. Such reforms have to be effective within the Indian reality of widespread poverty. Poor commitment to essential pro-development and pro-justice agendas may even defeat the current progressive steps towards developing a strong mental health policy.

A development agenda based on universal, basic entitlements, but open to eclectic mixing of strategies and steeped in the capabilities and inclusion philosophy, needs to be adopted. Although this is the long-term aim, there is an urgent short-term need to assist the groups most at risk of sliding into abject poverty. This can involve programmes for the hardcore poor, such as the one providing positive outcomes in Udaipur (Banerjee et al., 2011). It
is imperative that India becomes impatient with inequity and caters to the needs of marginalized and under-resourced groups that are increasingly at risk. An active social security and care programme is perhaps the only way to reach persons with mental illness and the homeless. However, they may be so peripheral that they resist any form of mobility, perhaps owing to psychological scarring, apathy, cynicism, scepticism and hopelessness. To address their needs, government and non-state actors will have to transition from a compartmentalized health and social system approach to an integrated one. This will require health services that move beyond the realm of medicine to include social care and holistic, client-driven services.

The notion and construct of health and access has to be redefined both from a policy and health services perspective to include a transitions approach with core values embedded in user-centric services. Health and mental health policies, besides fulfilling their own responsibilities, may need to influence poverty eradication, welfare and development policies. If the proportion of the at risk population can be reduced, health systems will become more operable and human resources more motivated. If perpetuation of poverty is not stalled virulently and access to health promoted diligently, societal well-being and thus the over-arching goal of India’s economic and social progress may be almost unattainable.

**Implications for Implementation**

**Public spending has to increase both on health (and related areas) and social security if capabilities are to be built.** Long-term gains of this approach will result in more equitable societies. In addition to financial resources, human resources may be considered the cornerstone or pivot of a successful programme. Development of human resources, capable of leading the new health and social services, is one of the priority areas requiring attention.

**A Transition Management(TM) approach needs to be adopted, taking into account the need for a suitable vision, a long-term perspective and diverse responses, all immersed in the culture of a complex adaptive systems theory (Raak, and Roen, 2010: 72-77).** Such an approach is typically distributed across three spheres, operational (focused on practices), tactical (focused on structures) and cultural (focused on the culture/ the abstract), and across a time period of 0-30 years, with the most critical transitions taking place within the 0-5 year period. During this period, leadership and intent has to be bold and entrepreneurial, with the ability to take risks, ‘address uncertainty’ in the absence of clear outcomes or predictors by ‘keeping options open (Raak, and Roen, 2010: 72-77).’ For visioning and planning, keeping options open implies that methods used should allow for multiple futures and multiple paths to these futures. In experimenting, keeping options open implies allowing many small scale experiments that start from different paradigms. Innovation is the need of the hour and this paradigm shift may facilitate it. The value with
which this effort is initiated is critical. Austerity, even during periods of economic downturn, does not lead to achievement of long-term goals, according to Stuckler and Basu (2013).

**Implications for research and epistemology**

While much focus currently rests on formulation of service packages and protocols that are evidence based, the lessons emerging from practice based evidence, often grounded in constructivist frameworks are not exploited sufficiently. Such approaches are dynamic in their learning and are built in the real world, ensuring authenticity of environment and distress and continuity. Like the innovations discussed above, many other approaches that promote good practices, address and respond to needs and fill gaps already exist, and need to be disseminated and shared.

Participatory Action Research which actively solicits the engagement of user groups in building knowledge is essential for effective and useful learning, especially since many of the issues flagged in this article are contextual. However, sample selection has to be diverse and representative of the Indian cultural, social and economic reality for accurate generalisations or trends to emerge. Policy and services influenced and guided by these perspectives have the scope to be appropriate and have a greater impact. A constructivist epistemology is also much needed, especially in the case of evolving and dynamic health and social conditions, such as homelessness and mental illness.

**References**

5. Chaudhury, Nazmul, Hammer, Jeffrey S, Kremer, Michael, Muralidharan, Karthik, Rogers, F. Halsey, Missing in action: teacher and health worker absence in developing


12. Dreze, Jean, Sen, Amartya, loc.cit, p. 113

13. Dreze, Jean, Sen, Amartya, loc.cit., p. 149


21. Ibid, p. 159-161

22. ibid, p. 51

23. ibid, p.9

24. Ibid.
28. Mahal, Ajay, Fan, Victoria, India Health Report 2010: The case for improving Health in India, p. 6-7
31. Mental Health and Development; Targeting people with mental health conditions as a vulnerable group. WHO Press, Geneva.  
http://www.who.int/mental_health/policy/development/eu/index.html and  
32. Mental Health Policy Group, Government of India http://mhpolicy.wordpress.com/  
(Accessed 10 July 2014)
37. Nair, C. Gouridasan, Kerala adjudged State with the best Panchayati Raj system in the country, The Hindu, 2 April 2011,  


43. Raak, Roel van, The transition (management) perspective on long-term change in health care, in Transitions in health systems: dealing with persistent problems, eds Broerse, Jacqueline E.W, Bunders, Joske GF, VU University Press, Amsterdam, p. 72-77


54. This figure is widely cited in publications but the source is usually not cited, although on occasion the methodology is discussed in detail. The clearest citation appears to be: Action Aid, Study of the Homeless. Report, 2003
Part 2

Responding to challenges through innovation and cultivation of values amongst human resources
Chapter 6

Responsive mental health systems: a conceptual framework emerging from The Banyan’s experience in Tamil Nadu, India

Abstract

Background
Mental health has gained prominence globally as a public health priority. However, many Low and Middle Income Countries (LMICs) have a substantial treatment gap because services are unable to meet user needs. India, probably home to 65-70 million people with mental disorders, faces serious problems in matching their needs.

Objective
This article seeks to understand what sort of health service responses might be able to address this treatment gap, based on the 1993-2014 experience of The Banyan, a non-governmental organisation (NGO) providing mental health care to people living in poverty and homelessness in Tamil Nadu, India.

Design
The authors retrospectively and qualitatively examine the evolution of The Banyan using a timeline narrative. Based on the action reflection learning theory, this narrative was recursively organised and analysed to identify the organisation's strategy and key elements underlying the conceptual framework for mental health system responses in the context of complex problems.

Results
On the basis of this analysis of The Banyan's transitions, 'user centred' and 'service integration' emerge as main dimensions of responsive health systems. Based on these two attributes, a typology of services is derived, indicating the responsiveness and appropriateness of mental health systems in addressing complex problems. The role of organisational culture and expressed values in this process of change is considered.

Conclusions
Responsive mental health systems can best be constructed with both a user centred and service integration focus.
Introduction

Mental health has gained prominence as a global public health priority in the recent years. The World Health Organisation (WHO) estimates that 7.5% of the global disease burden is caused by mental and behavioural disorders (Murray et al, 2010). A 2004 multi-country study found that 76.3- 85.4% of persons living with serious mental illness in Low and Middle Income Countries (LMICs) had received no treatment in the previous year (Demyttenaere et al, 2004).

India is the second most populous country with an estimated 2014 population of 1210 million, (Government of India, 2001) and home to some 65-70 million people with mental health disorders (ICMR, 2007). Provision of mental health care in India, as in many other LMICs, faces a number of serious challenges. Mental health services are grossly inadequate (Saxena et al, 2005) and tend to approach mental illness from a disease perspective, (Jain and Jadhav, 2009) ignoring the context of complex economic and social problems that contribute to wellbeing. Mental illness is strongly linked to widespread poverty (Lund et al., 2010) and homelessness (Fazel et al., 2008): almost 70% of the Indian population is living on less than USD2.00 per pay (World Bank, 2010) while some 1.8 million persons are homeless (Government of India, 2001).

Health system reforms to address the treatment gap often focus on increasing availability of services using financial and human resource investments. While such reforms may increase capacity of services at the grassroots, the health system remains unaltered. Given the complexity of the needs of the clients, more fundamental change is needed. The primary aim of this article is to understand the nature of mental health system responses that are appropriate for addressing the needs of people with mental illness living in poverty and homelessness. To do this, it analyses the experience of The Banyan, a non-governmental organisation (NGO) providing mental health care in Tamil Nadu, India. The secondary aim is to understand the organisational culture which promotes appropriate mental health system responses as a basis for scaling up such systems.
Present investigation

This article considers the evolution of The Banyan's mental health system as it has developed to meet the needs of its clients. The Banyan provides comprehensive mental health services in institutional and community settings for people experiencing poverty and homelessness. Starting in 1993 with a crisis intervention and rehabilitation centre for homeless women with mental illness in the city of Chennai, The Banyan has grown to provide wellbeing oriented mental health services, including emergency, open shelter and street based services, long term and alternative living options, and social care. In order to address deficits in strategy and human resources among various stakeholders, it has established a sister organisation for training, research and advocacy, The Banyan Academy of Leadership in Mental Health. Since 1993, The Banyan has supported 1691 homeless women with mental illness: 1065 have been reunited with their families or communities of origin; and 80 women access shared housing through a cottage-style open facility. Almost 2500 have been reached through community clinics and allied social care services (such as livelihood and welfare facilitation) in rural and urban areas.

Methods

The evolution of The Banyan has been described in several documents such as annual reports and evaluation studies. This was further examined retrospectively and qualitatively, covering organisational strategy, key elements and an emerging conceptual framework for mental health system responses in the context of complex problems. Two qualitative methods were used: a timeline narrative of the organisation and a reflexive action analysis. A timeline narrative was constructed based on data from key informants, annual reports and evaluation reports. One of the authors (VG) is co-founder of The Banyan and played a central role in this exercise. Next, the timeline narrative was coded and analysed using models of action reflection learning in which knowledge is co-created by various participants who act and reflect on real world issues (Kemmis and McTaggert, 1988). Interpreter triangulation was facilitated through a recursive process of organising data. The four domains in action reflection learning processes -- planning, action, observation, reflection (Kemmis and McTaggert, 1988) -- were used to construct an analysis matrix:

Planning: elements of narrative that constitute a strategic direction towards achieving organisational vision;
Action: elements of narrative that involve activities to execute the plan;
Observation: elements of narrative relating to what the organisation experienced following implementation of planning; and
Reflection: narrative elements that express learning as result of the execution experience and the measurement of progress in congruence with the organisational vision.

Given that learning, planning and reflection are continuous, the authors defined 'system
level evolution’ as the key criteria to distinguish the different lifecycles. In addition, the organisational culture of The Banyan has been analysed because organisational culture can provide useful insights into the working of development interventions (Lewis, 2003) and thus potential for upscaling. However, organisational culture is like an iceberg, only a small part of it is visible or manifest (Schein, 2005: 25-26). Expressed values represent the key aspect of manifest culture (Schein, 2005: 28-30) and, for that reason, represent the focus of this analysis of organisational culture.

Results

Lifecycles

Organisation of The Banyan’s narrative into the four domains of planning, action, observation and reflection revealed four distinct lifecycles, each one with a plan originating from the reflections of the previous lifecycle. The Banyan started as a shelter service for homeless women with mental illness. It was started after VG and VJ

... Came across a half-naked, mentally ill homeless woman in absolute distress on the road in front of her college. Nobody else seemed even to notice her... Mental health institutions and [NGOs] were reluctant to admit the woman in desperate need of medical and psychiatric attention. Several more such encounters over the next few months left the idealistic duo disillusioned and the idea was born that they should do something about the problem themselves. (The Banyan)

The shelter facility, started to provide space for this niche constituency of mentally ill, homeless women, transitioned into a transit recovery space. With recovery of users and their expressed needs of living with family, The Banyan began facilitating reunion with families as a form of reintegration (Lifecycle 1). The positive response of many families and communities in welcoming back these women altered the organisation’s understanding of what had led to homelessness. The organisation also recognised that the magnitude of issue was far greater than initially anticipated; and that continuity of care post reintegration with family or community was critical.

From 1996 onwards, The Banyan expanded capacity by constructing new premises and began to offer multiple after-care options for those who had left the shelter (Lifecycle 2). Reintegration became systematic and included options for self-discharge, employment, living in group homes and referrals to non-mental health institutions. As numbers continued to increase, The Banyan realised the importance of putting the needs of their niche constituency on the agendas of local and national bodies, part of a critical strategic effort to address scale and access issues. This involved an increasing emphasis on the role of the
state and rights of homeless persons. In the provision of after-care, The Banyan began to understand the difficulties of recovery in poor, vulnerable and distressed families. Local care, expressed as a need by users, was hypothesised by a third party evaluation (NIMHANS, 2003) as being important to maintaining a state of recovery. In addition to challenges in providing continuous care to maintain recovery, The Banyan experienced problems with institutional care: many people with long term needs were unable to exit the system because of the absence of local care; and large communal spaces were not providing quality care.

During 2004-2012, user demands for alternative living spaces for those who could not return to their families led The Banyan to develop shared housing and community living options (Lifecycle 3). The need for continuity of care led to piloting of social care in the community using socioeconomic instruments (disability allowances, employment, home visits). Through this engagement in social care, The Banyan began to develop a deeper understanding of micro-level issues and the perpetuating nature of inequities, including poverty, gender and old age. Local care did not always translate to benefits on the equity front, with poverty continually placing persons with mental illness at the risk of downward social drift and homelessness. The Banyan also learnt from user evaluations that positive outcomes are rooted in experiencing a better life. This led The Banyan to link treatment commitment and care to benefits in terms of distress mitigation and positive mobility. During this period, The Banyan also began to collaborate with other stakeholders, such as the state mental health facility and other NGOs, to replicate its recovery and reintegration model. The challenges of providing institutional care rooted in an ethos of user self-determination became more evident: while there needed to be protocols for minimum services and processes, the key challenge was privileging user needs and rights among human resources. This led to the identification of human resource deficits in the mental health sector, not just in terms of numbers but also in terms of lack of appropriate core values, leadership and multi-disciplinary intervention skills. Reflections on these developments led to dramatic changes in service integration during Lifecycle 4 from 2012 onwards, placing greater emphasis on recovery in the context of poverty. Greater understanding of the complex causal pathways to homelessness and of user expectations led to the adoption of a stronger development agenda within The Banyan, involving a comprehensive social care system of welfare entitlements and social interventions targeting well-being. The Banyan also investigated alternative service contact options for homeless persons with open shelters and street engagement. Quality systems were introduced within institutional care, focusing on privacy and dignity during bathing, and the availability of a minimum level of assets such as a toothbrush and fitted, coordinated clothes.
The organisation further integrated a well-being approach towards mental health into its community mental health programs by initiating the NALAM (Tamil for 'wellness') project with support from Grand Challenges Canada. The project utilises village level wellness mobilisers to deliver a range of interventions from counselling to social welfare facilitation to mitigate distress and promote outcomes in socio-economic spheres as a preventive and beneficial strategy towards better mental health. The Banyan also forayed into alternative service contact options for homeless persons with psychosocial disabilities through open shelter and street engagement in partnership with the Corporation of Chennai. Through this initiative the organisation has been able to offer flexible and user initiated access options for homeless persons. Based on the NALAM approach, an active engagement with the community in vicinity, Dooming Kuppam, through life skills, skills development and other social interventions aimed at psychosocial distress mitigation have been incorporated as a key component of this project.

In addition, driven by the success of independent living through shared housing in the villages and its consequent impact on quality of life of women who were once homeless, the organisation has sought to extend this approach towards addressing the needs of those who require higher levels of support and yet may be enabled to live in accommodations in the community with in house staff support. While on the one hand this involves the facilitation of housing with graded support, its focus is on facilitating socio-economic-political participation in village communities for service users. Through this approach, the organisation aims to sustainably and in a cost effective manner address the issue of long term care in mental health; and thereby provide exit pathways for people in institutional spaces, improve their quality of life, mental health outcomes, social inclusion, independence and rights. This will address the challenge of appropriate and humane care for those most marginalised on account of homelessness and mental disorders and will most meaningfully contribute if scaled up to address the issue of long stay in state mental hospitals.

To address human resource deficits, the Institute for Mental Health, Social Sciences and Transdisciplinary Research (IMHST) for graduate students was developed, a training ground that aims to cultivate critical perspectives and values by offering opportunities to learn by observing and doing in the real world. Grounded in constructivist pedagogy, human resources thus developed are expected to demonstrate the capacity for innovative, radical and reconstructive approaches to tackling both micro and macro level challenges in mental health in the context of marginalisation. Table 1 below provides a summary of system level transitions in The Banyan's mental health system.
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus</td>
<td>Humanistic response to homeless women with mental illness: crisis intervention, shelter, reintegration, after-care</td>
<td>Institutional development: strengthening capacity, content and quality of responses</td>
<td>Mental health services in the community and stakeholder expansion, research and advocacy</td>
<td>Development of reconstructive approaches in community and institutional care with focus on well-being: identity/personal growth/self-determination/fulfilment/meaning in life; Building capacities among human resources to integrate theory and field practice</td>
</tr>
<tr>
<td>Reasons for focus</td>
<td>Lack of adequate responses to address deprivation and violence faced by homeless women with mental illness</td>
<td>Scale of issue in quantity as well as complexity; Infrastructural development with strengthening of systems of care for efficiency perceived as solution</td>
<td>Lack of access to care and continuity in care hypothesised to stem from presence vs absence deficits in community mental health; Model formulation and dissemination of protocols as a means of scaling up</td>
<td>Micro and complex issues: non linearity in the relationship between poverty, mental health, access to care and outcomes; Need for development focus to mental health services integration; Ethos/Core values scaling as opposed to standard operating protocols given dynamic nature of issue</td>
</tr>
<tr>
<td>Description of constituenc y</td>
<td>Homeless women with mental illness</td>
<td>Homeless women with mental illness and their families and communities</td>
<td>Persons with mental illness and their families living in poverty and homelessness in urban and rural areas</td>
<td>Persons, families and communities with psychosocial concerns living in poverty and homelessness in low resource settings; Human resources in development and mental health sector</td>
</tr>
<tr>
<td>Description of</td>
<td>Hospitals, media, general public,</td>
<td>Other civil society</td>
<td>Government, Other civil society</td>
<td>Academic community, international institutions,</td>
</tr>
<tr>
<td>stakeholder system</td>
<td>philanthropists, social clubs</td>
<td>organisations, hospitals, media, corporates, general public, government</td>
<td>organisations, hospitals, media, corporates, general public, government</td>
<td></td>
</tr>
<tr>
<td>--------------------</td>
<td>-----------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>local governments, federated and non-federated community institutions, Governments, Other civil society organisations, Hospitals, Media, Corporates, General Public</td>
<td>local governments, federated and non-federated community institutions, Governments, Other civil society organisations, Hospitals, Media, Corporates, General Public</td>
<td></td>
</tr>
</tbody>
</table>
Over the 20 year period, The Banyan’s strategic focus has developed from crisis intervention for homeless women with mental illness to an integrated service approach, including a wide variety of responses to clients' psychological, financial, cultural and social well-being. During The Banyan's evolution, it became evident that focussing on one element of the problem was not enough: clients are caught in a multidimensional trap which needs to be approached in a tailor-made, user-centred way. To understand how these developments and organisational health systems can be scaled up, we consider the organisational culture driving this process of development.

Organisational culture and values

Although there have been considerable changes in The Banyan’s strategic focus since 1993, the expressed values have remained unchanged: commitment to the well-being of people, drive to understand the needs of clients, acceptance of the complexity of the reality of clients, and willingness to reconsider the identity of the organisation. These values have been built into the organisational culture through a number of processes:

- listening to the needs of clients during an on-going dialogue in which all staff members participate4;
- maintaining high staff morale under extremely difficult circumstance by articulating, sharing and celebrating achievements, large and small;
- achieving synergy between activities, ambitions, competences and dreams of all network partners and staff members;
- combining in-depth understanding of the problem with the bigger picture; and
- maintaining high aspirations and ambitions. For example, The Banyan is currently considering initiation of a South and South East Asia Consortium on Mental Health to facilitate widespread, regional access to quality mental health care.

These values appear to create an organisational culture which is anchored in action learning (Figure 1).

4 In addition individual or group therapeutic contact with users by various levels of mental health professionals and other ongoing spontaneous interactions, The Banyan conducts an annual service user audit of the organisation. There are dormitory meetings and an external human rights committee meetings monthly that serve to systematically elicit, record and incorporate the voice of users into service design and delivery.
Indeed, it is this action learning which appears to be at the foundation of a responsive mental health system. Two key attributes emerge from the analysis of The Banyan's responsive mental health system: ‘user centred’, placing the user at the centre in defining responses; and ‘service integration’, namely instituting appropriate, multiple responses at a systems level.

Both micro and system level transitions in The Banyan's mental health system have been based on increasing understanding of user demands and needs. Over the 20 year period, clients have evolved from service users to participants to owners. For example, homeless women with mental illness who once used The Banyan's shelter services now work as mental health 'change agents' in their communities. The first key dimension of being 'user
Initially prioritising user self-determination (Lifecycle 1), the organisation engaged in an ongoing dialogue with its service users to gauge their experiences, needs and outcome definitions. Service system inputs and ends being pursued are not rigidly predetermined or universal. Rather there is an active process to engage with users to understand problems from their perspectives, the gains they seek to achieve and the means they visualise towards the same. The service system through its ability to personalise responses seeks to support rather than constrain users into accepting what is available. While measures of success in mental health are often based on outcome evaluations through standardised instruments, The Banyan measured success by evaluating user experiences of an intervention and their challenges to recovery. According to the Banyan, services that respond to user input are more effective in ensuring positive outcomes and in motivating users to sustain recovery. Thus, the framework of recovery is user defined, with meanings and evaluations that are user specific rather than disease specific. This process of dialogue for co-creating knowledge serves as the basis for formulating systemic responses is the second key dimension of being ‘user centred.’

As a consequence of this user centred focus, The Banyan worked towards service integration in terms of quantitatively enhancing service diversity and levels, and qualitatively enhancing levels of integration within the delivery system. Responses to emerging user input, such as a trip to reunite with family (Lifecycle 1 to 2) and alleviating financial distress (Lifecycle 2 to 3), were institutionalised as systematic mechanisms, a process that increased comprehensiveness of both horizontal and vertical service offerings.

Scaling up
Based on the dimensions 'service integration' and 'user centred' emerging from The Banyan's mental health system, we use a typology of mental health system responses' (Figure 2) to compare with other types of mental health services.
The x axis represents the degree to which a health system is ‘user centred’. The y axis represents the degree to which a health system demonstrates ‘service integration’. Responses may be highly user centred, but may not converge in a systematic manner. An example is a response that involves food packet distribution on the streets. While on a case to case basis, other emerging needs such as health may be met, there is no process at a systems level, which may lead to limited scoping and outreach. On the other hand, one may also have highly integrated services, which are constructed without placing the user at the centre. In such an instance, despite sophistication, services may continue to not appropriately address user needs. Unidimensional, simple interventions that are again not changing with user input are another type of health system response. Such responses if fulfilling an aspect of user needs may potentially lead to impact that are restricted to shorter cycles, while failing to build these into long term gains. Based on this analysis, highly user centred and service integrated responses appear to be preferred.
However, learning from the constituency and developing programs, and evaluating them is a rhetorical concept in development. **How are these attributes of 'user centred' and 'service integration' different for a responsive mental health system?** For instance, the integration of psychotropic medication in general health settings may also be argued as service integration. Table 1 illustrates the significant service system transitions in The Banyan's journey from a shelter service to a system that integrated clinical care with social prescribing in a variety of community and institutional settings. **While these transitions suddenly come to the fore between one lifecycle to another, they were preceded by a process of co-developing these services at a micro level with service users. This dynamic nature of change driven by the constituency is a key distinctive feature, wherein responses are ongoing leading up to systems level change, rather than in discrete blocks of planning, acting and evaluating.**

Transitions in The Banyan's system of mental health delivery have been based on addressing user needs. From the systems innovation perspective, The Banyan has been engaged in a niche experiment, addressing a unique, complex problem in a new way and transitioning with emerging new goals (Schot and Geels, 2008). In the complex adaptive systems theory, various components have adaptive attributes that spontaneously interact and respond to emerging needs or conditions (Geli-Mann, 1994). The Banyan's strategic response to the problem of mental illness among the homeless and poor has undergone cyclical changes from shelter to reintegration and recovery. The evolution of the user centred response as the primary element of organisational strategy is characteristic of a complex adaptive system.

**Conclusions**

Based on this analysis of The Banyan, **user centred and service integration emerge as main dimensions of responsive health systems. The conceptualisation of mental health and its inbound and outbound influences in The Banyan's experience has undergone transitions in response to needs of the constituency, as well as the context of service delivery.** Mental health system formulations that are resonant with user systems, wherein services are personalised, organised and delivered around user characteristics and needs, may be more appropriate in reaching out to marginalised populations such as those living in homelessness and poverty. Such responsive systems also need to be integrated with a development agenda. The Banyan's experience advocates for a dynamic, responsive and system innovation approach.

Such strategy is not always amenable to result in prescriptive protocols for scale, but could
lead to dissemination of representations of core values and their applications in practice. Core values of such innovation that describe the mechanism of action are essential to building frameworks for scale; and they are likely indicators of why some interventions are successful. For instance, transformational leadership with competencies to direct and effect the large degree of change may be most essential to initiating reforms in hospital based mental health care. Understanding value drivers of interventions and systems may be necessary in order to address the need for scaling up towards promoting access to mental health. This will require better mechanisms in service delivery frameworks that can continually ascertain user perspectives and translate the same into mental health formulations for practice. Bottom up health systems are required, unique to the constituency they serve, with core value frameworks serving as the replicable components of such systems.

References


Chapter 7

Enabling access to mental health care: perspectives from The Banyan experience in India

Introduction

This article examines the issue of access to mental healthcare using The Banyan experience, of working with persons with mental illness living in homelessness and poverty, as a backdrop. In the recent years, mental health has gained prominence in the global discourse on health driven by the findings of the World Health Organisation (WHO) Global Burden of Disease project that estimates that 7.5% of disease burden is contributed by mental and behavioural disorders (Murray et al., 2013). Recent developments around the UN Convention on Rights of Persons with Disabilities (UNCRPD) are significant to this discussion in the context of enabling access rights. Major themes in current global dialogue on access to mental health care are (i) accessible, affordable and appropriate services; (ii) the integration of mental health within public health systems through evidence based collaborative or collocated care supported through capacity building; (iii) the need for linkages between housing, social services and mental health; (iv) rights based approach that focuses on community based services and user participation (Yamin and Rosenthal, 2005; Burns, 2010). The article examines these broad themes with reference to their grassroots applicability and implementation for promoting access to mental health care given key learnings and challenges that have emerged during the Banyan's twenty years of work.

The Banyan experience in enabling access to mental health

The Banyan began in the year 1993 with ‘Adaikalam’, meaning ‘place of safety’, a rescue, care and rehabilitation centre for homeless women with mental illness in Chennai, India. The initiative started as a compassionate response with space for healing and hope that enabled reunions of women with their families/communities of origin all over India. As The Banyan continued outreach work with most marginalised persons and families living with mental health issues, multiple service arms evolved to address the variegated needs of this unique and complex constituency. Over the years Adaikalam metamorphosed into a Transit Care Centre (TCC) that promotes a biopsychosocial approach to care enabling a range of interventions personalised to the needs of users. The necessity for fostering a therapeutic community, freedom and choice within the institutional set up lead to development of concepts such as self-discharge, social audits and reviews led by users,
options to leave the centre of care for period of time to visit temples, work, buy articles, go out on a walk etc, therapeutic affinity groups, human rights cells that welcomed external activists to review the grievances registered and several other such measures. **Support through continued care post discharge led to establishment of an after care unit.** In a bid to institute reform in the state mental health facility and enable a government response for homeless persons with mental illness, The Banyan operated for a period of four years a mental health helpline, a three way partnership between the Chennai City Police and Institute of Mental Health (IMH). Emerging needs of context and individual specific options for moving towards community and independent living led to options of employment, group homes, supported housing, working women’s hostels, community fostering and self-help groups (SHGs). **Community Living (CL), a cottage styled open centre emerged as a measure of continued long term care for a small percentage who face a disproportionate burden of adversity on account of age, chronic illness, poverty or social exclusion.** In 2003, parallel to a review of The Banyan’s work by the National Institute of Mental Health and Neuro Sciences (NIMHANS), prevention of homelessness and promotion of mental well-being emerged as a significant corollary to the crisis intervention work. The organisation today operates Rural and Urban Mental Health Programmes (RMHP and UMHP) with Mental Health Clinics (counselling, psychiatrist reviews, medication, case and group work combined with Community Outreach (home visits, telephonic follow up, awareness and training) and Social care (employment, disability allowance, state entitlements facilitation, vocational training and day care). In 2012, responding to psychosocial issues within the urban homeless population, The Banyan along with the Corporation of Chennai (the urban local governing body) works in an Open Shelter for homeless men with psychosocial issues that also provides street based services for homeless persons in the immediate community. This is part of a larger campaign- Kind People, Happy City (KPHC), that aspires to enthuse a cross section of civil society actors to work in partnership with the government and offer support to the most marginalised in open shelters and on the streets – to build a sense of diversity, acceptance and promote social engagement in society.

In 2007, The Banyan established The Banyan Academy of Leadership in Mental Health (BALM) to address needs of human resource, stakeholder expansion and social sciences research in the mental health sector. BALM has fostered Training and Education partnerships with academic institutions, significantly the University College, London (UCL) and Tata Institute of Social Sciences (TISS) for short courses and a master’s programme with a focus on social, economic, cultural and political dimensions related to mental health for various levels of practice from case work, group work and community organisation to research and policy. **Stakeholder engagement with not for profit organisations and governments has and continues to enable dissemination of The Banyan’s approaches resulting in direct service provision for the most marginalised.** BALM’s research work focuses largely on socioeconomic correlates of mental health and is supported through
dissemination and advocacy for policy level impact. In order to evolve evidence based approaches for micro and macro issues in mental health, within the ambit of Mental Health and Social Action Lab (MHSAL), The Banyan and BALM engage in action research.

**Key learnings and challenges: implications for policy**

*Defining access to mental health: multi level, multi modal, multiple services*

The 1970s witnessed a shift in the approach towards access to mental health care. Many western countries adopted a policy of de-institutionalisation, focusing on creation of services in the community. The WHO funded several initiatives worldwide that established the feasibility of integrating mental health into primary care of public health systems. Patient self-determination movements resulted in the creation of ‘living wills’ or advance directives, especially in the USA. After three decades of global policy commitment, the mental health sector continues to grapple with the idea of enabling access despite the fact that more effective treatments are known.

Policies and guidelines are inadequate if it does not improve lives of people. Evidence of effective interventions is redundant if we do not know how to get them to people for better mental health outcomes. Therefore, the third ‘a’ - appropriate, in the oft repeated access to mental healthcare phrasing, is the most critical in ensuring that people are able to command necessary resources for securing their mental health. In determining public health priorities in mental healthcare, one cannot be guided by single switch prospects that appear on the surface to close treatment gaps, with no long term sustainability, ignoring depth, complex needs and nuanced challenges. the whole experience of mental illness must be recognised and the life cycle of a person living with mental illness should drive the creation of treatment protocols, legislation and policy – minimally oriented services do not serve the purpose of well-being in the longer run and thus present a different set of problems at a different stage of ill health of the user. Recovery constitutes a feeling of well-being that includes an understanding and management of symptoms/ behaviour, treatment commitment, ability to care for self and perform activities of daily living, enjoy work and social life and feel independent and confident. Resilience, coping skills and a healthy ecosystem also plays a critical role in promoting this ideal.

Supply side drivers for access to mental health within this paradigm of recovery and well-being mandate the provision of mutli level, multi modal, diverse services – from primary to tertiary, in formal/informal community and institutional settings, offering a spectrum of services, both pharmacological and non-pharmacological, delivered by a multi-disciplinary team through a coordinated care approach. Financing cost of care and enabling
infrastructural support for closest access are two other important supply side considerations. On the demand side, it is important for to cultivate and showcase positive patterns of help seeking behaviour and influence perceptions of mental health through community linkages and user carers’ active participation in the system.

Social and economic determinants in mental healthcare: convergence challenges

Social and economic factors, such as poverty, caste, urban-rural divides and gender, determine both onset of mental illness and access to care. Anthologies of users who have been part of The Banyan experience display patterns in user-care giver association of onset of mental health issues, relapse and non-adherence with bereavement, desertion, hunger, poverty, appearance of disability/morbidity in family, violence, poor quality of partner relationships and reproductive health. Marginalisation of women's needs within patriarchal structures, the experience of violence, and greater but unacknowledged burden of economic and social contributions to household and lack of autonomy are linked with lack of access to care and lower health seeking behaviour.

Taking note of the socio-economic determinants in mental health, the 65th World Health Assembly calls for convergence of social policy with that of mental health in delivering a composite service mix, relevant to mental health gains at community, family and individual levels (World Health Assembly, 2012). Mental Health services need to include social benefits and entitlements that enable early access, promote recovery, mitigate burden of care and help in sustenance of well-being. The Banyan's experience of conditional cash transfers called the Disability Allowance (DA) has demonstrated the potential for socio economic entitlements to be applied as incentives for making progress towards and sustaining recovery (Ravikanth and Dijkxhoorn, 2009). A feasibility report on inclusion of persons with disabilities including those with mental illness in the Indian state's employment guarantee scheme points towards the possibility of quality of life (QOL) gains through such measures (BALM, 2012). Social services within access to mental health care in addition to state entitlements involves the organisation and application of social resources in the community – such as support groups for addressing gender divides, early childhood interventions, in kind education support such as tuitions, substance use prevention measures, companionship and inclusion in social activities, soup kitchens, day care or vocational training units etc.

The policy challenge is in ensuring communication linkages at different levels of governance – linear and cross sectional – that allows for such integrated delivery of services, in least possible time. This communication is often marred by variegated awareness and understanding of what services exist and don't. An approach that has worked in several
initiatives is the creation of a two way referral systems – wherein social care providers screen, educate and refer to healthcare and vice versa. Another approach is deeper integration as a scheme within the health system such as conditional cash transfers for women opting for institutional deliveries. Similar policy initiatives that qualify and target mental disability for social benefits need to be undertaken. Health systems capacity building in this light requires capacity building for collaborating with social sector partners in delivering mental healthcare.

Addressing barriers in primary care integration

The absence of precise diagnostics and clear service pathways is a large deterrent in penetration of mental health care delivery at the primary health care level. The design of mental health services that are to be integrated into existing public health systems needs to be necessarily accompanied by a clear expression and widespread stakeholder acceptance of treatment protocols akin to the DOTS regime for Tuberculosis. Protocols need to detail in addition referral pathways and guidelines for their application – from the primary health care centre to secondary or tertiary, from the first intensive phase of treatment to a rehabilitation and self-managed care phase AND so on. In developing and applying these referral pathways, the intent must be understood and accepted uniformly by all stakeholders. Without consensus among clinicians, users, families and administration on referral pathways, the concept of stepped care in public health policy becomes redundant. The adoption of such protocols that can greatly aid delivery at primary care levels has been staggered by lack of dissemination, consensus and advocacy, which made a difference to the penetration of the DOTS regime for Tuberculosis.

Overburdened public health infrastructure, low priority in healthcare budgeting, minimal mental health orientation in undergraduate medicine curriculum, case load burden, inadequate continuing training, staff transfers/turnover and administrative inconsistencies affecting recruitment of necessary staff, lack of well-being focus and poor social care integration, fund flow and drug procurement/distribution are some of the other barriers affecting integration of mental health within primary care in India. Even if protocols exist and are widely accepted, regional variations in quantity and quality of public healthcare, makes complete integration of mental health in the immediate future a near impossible task. Incorporating greater specialist support, from professionally non-qualified but trained core mental health staff, located at Primary care level either within the public health system or in the village, enabling effective case management is an approach that has been tried by various initiatives in chronic disease management and may be tested for feasibility and effectiveness in mental health given current scenario. Referred to as non-specialist workforce, community health workers, are known to act as significant drivers of help seeking behaviour. There is need to innovate for addressing financing and retention challenges that confront sustainability of large grass-roots workforce.
While there is much emphasis on scaling up evidence based practice in the current international discourse in the mental health sector, practice informs theory. Therefore, evidence gathering must look towards studying indigenous designs of mental health care delivery that have met needs of the sector in their own unique way. Research investments are necessary towards studying service protocols and indigenous approaches for addressing community mental health goals within or outside the public health system.

Transforming tertiary centres for mental healthcare

Often relegated to the background in access to mental healthcare discussions are changes necessary in tertiary service delivery. Given the abysmal conditions of mental health hospitals, and the horror stories that emerge from within, it is not surprising that they are seen as revolting, unnecessary blots for the movement towards community care. However, access to mental healthcare is contingent to the transformation of tertiary centres from crumbling remnants of the colonial era to partners in the public health system. Unless tertiary care centres start to show resemblance to hospitals and align themselves philosophically with community based mental health services, gains for access cannot be achieved. While state institutional care as it exists today is to be questioned, the relevance of quality hospital based care for sections of the population cannot be ignored. Equating de-institutionalisation with de-hospitalisation in countries across the world has impacted homelessness among persons with severe mental health issues. In addition, tertiary centres perform a vital role in motivating and training human resources for mental health care. The practice and ideology at these institutions must, therefore, be aligned with public health policy. Realigning service delivery towards a therapeutic alliance, providing a quality assurance in essential facilities such as housing, food, water, safety, privacy, sanitation, health, creating universal discharge options irrespective of nature of admission, eliminating human rights violations even in mere spirit – these will serve as steps towards de-stigmatising mental illness and inspiring people to take up occupations in the mental health sector. Hospital bed spaces in secondary and primary health centres at the lower administrative units are necessary to ensure that the burden of in-patient care is not disproportionately placed on tertiary centres which can be relieved from over-crowding and associated issues.

Token changes, such as renaming of these centres, flushing awash with funds, changing names of staff, capacity building measures alone, will not help. Systematic, continuous and detailed long term effort through strong leadership, effective training and monitoring is required in comprehensively developing policy and applying a transformational framework for mental health hospitals.
Homelessness, civil commitment and access to mental healthcare

Access to mental healthcare is concerned with equit y gains for those who are marginalised. For homeless persons with mental illness, justice in attaining these equity gains, lingers over thin ice. Much of the current, global interpretative commentary around rights as outlined in the United Nations Convention for Rights of Persons with Disabilities (UNCRPD) is concerned with the institutional settings in mental health, particularly treatment initiated by involuntary commitment being contrarian to the spirit of the Convention. The truth, as The Banyan has learnt, is that no one chooses to lose contact with reality and therefore live on the streets – a brief, responsible and acutely cautious period of taking a decision to provide access to care through civil commitment can change lives. Ratna made her journey back home on the day of her daughter’s marriage after two decades being away from family; Malar went back to live, work and support her son in a small tribal hamlet; Parimala found solace in employment in a beauty parlour while living in a rented home close to The Banyan; Janaki lives with a group of six women in a cottage as part of a community visiting working in the state’s employment guarantee scheme and maintaining occasional contact with relatives. These are vignettes of ordinary 'sane-insane' people attempting to enjoy civil liberties. Philosophical stances on freedom bear no meaning despite their paradoxical shallow depths if they fail to facilitate true liberty for those at the margins, exposed to the worst form of cruelty and torture on the streets. It is unfortunate that the debate on institutional care and access to mental health, specifically involuntary commitment, finds media attention with reports of horrific gun violence. Herein lies the problem with society’s capacity for responsible use of civil commitment. Few persons with mental illness are at risk of violence, even the ones who need the state to mandate a treatment order.

In defining access rights, policies must bear in mind the primacy of user choice but also be bold to step in with affirmative action in case the capacity to make that choice has been torn apart by illness. On the one hand policy must ensure checks and balances, while on the other the orientation cannot be to contain violence, but to enable recovery.

Alternative institutional spaces and housing: addressing homelessness and long term care

While The Banyan experience contends that ‘civil commitment’ can contribute to personhood and rights, in reality the palpable rigidity imposed by the term exists only on paper. Despite The Banyan’s experience with providing access to homeless persons being largely mandated through state orders for commitment, in several cases, these measures were necessitated by legal compliances than actual resistance by users to treatment or other services. Many users live at The Banyan’s centres voluntarily, of their own free will. Some take their medication when they choose to; while others stake claim over spaces for
their living arrangements. Relationships are formed, people look out for each other, and people fight; fun and conversations fill out the daily schedule. Institutional spaces, even those that are closed with limited restrictions, resemble community, with scope for social and occupational roles and full enjoyment of civil liberties, perhaps even more so in a largely poor, fragile, under resourced country like India. Open and quasi open shelters, community living arrangements, community fostering, group homes, supported housing, affinity groups contribute to hope, aspiration and happiness (Ravikanth et al, 2012). Long term dependency needs of users-carers who are elderly, chronically ill or highly economically distressed must be acknowledged.

Housing, the fulfilment of basic needs, as evidenced by anthologies of women who have journeyed with The Banyan, is a stepping stone towards recovery. In this context, institutional spaces and housing - transitory, supported, supervised or independent – are a critical pathway for access to mental healthcare. Policy measures must encourage the creation of living arrangements for persons with mental illness, as a means of recovery and/or as continued long term care.

Conclusions

Mental health is a comparatively new field, there not very much that is known and established. Part of the difficulty in formulating an approach towards access to mental healthcare lies in this. For now, as individuals, organisations and governments, invested in access to mental healthcare, one can reinforce commitment to enabling multi-level, multi modal and diverse services; user-carer participation; inter sectoral collaborations between public health and social services; and research for systematic evaluation of emerging innovations.

References


Chapter 8

The role of non-governmental organisations in community mental health care

Case study 1: Kamala washes vessels outside her house, a small hut in a village in the Thirupur block of the Kanchipuram district, a district with higher health and social indicators compared to many others in the state of Tamil Nadu. As one approaches her house enquiring after her, the neighbours comment on her ill health in the very way in which they receive her guests, ‘What is the point is asking for her? Ask for someone who will respond coherently.’ Such is the perception of a person with a mental health issue who shows poor prognosis and this, sadly, is the case of anyone with a major mental illness such as schizophrenia or bipolar disorder that predominantly goes untreated for an extended period of time, especially in rural and remote areas where the combination of poor awareness, limited access to health facilities, poverty and social ill health affect health-seeking patterns to a considerable extent. Her father, Karuppan, seated on a chair, himself affected by a stroke that took away many of his faculties seems oblivious to his surroundings. Flies hover and settle on his body and he tries to shake them off. Kamala’s sister-in-law, who lives close by, comes in and briefs us on Kamala’s health. She feels that Kamala’s self-talk has now lessened and that she is considerably engaged in the lives of her children. Kamala, however does not respond to the guests. She mumbles something occasionally and then turns away, restless and wanting to leave the room. She is the youngest of the three children that Karuppan (65) and Solaiammal (60) had. Her brothers, while kind and concerned, are preoccupied with the problems of their own families; all of them are married and live in the neighbourhood. Kamala’s primary caregivers are her elderly parents who have aged faster than many healthy adults their age would, owing to the multiple stresses they have had to shoulder as a result of Kamala’s ill health. Marriage was seen as a solution to her problems and ‘wayward ways’ and so a marriage was arranged with a man from a neighbouring village who himself suffered from alcohol addiction. Unable to face the hardships of life and his own health issues, he committed suicide after which Kamala and her two children returned to the care of her parents. Her sons are in classes 6 and 9. Her elder son has just received the news that he has not passed his exams. Both the children have limited external support and rely on their mother and grandparents for most of their needs, including education and private tutoring. The elder boy already speaks of
dropping out of school, to seek work and support his family and seems serious and withdrawn for a child his age. The average family income of this household is approximately Rs.4,000 per month which includes an old age pension and Solaiammal’s meagre amount as a daily wage labourer, which again, is dependent on the availability of work in the unorganised sector.

Such is the reality of an Indian household that lives below the poverty line in a village or in a remote area. To deal with just the mental health issue is only touching the surface of the problem. For a healthy family to experience an optimal quality of life, multiple interventions are called for, both medical and socio-economic. The presence of either a sound government policy or the effort of non-governmental workers with sound skills sets and knowledge, which equip them to address this issue from both a clinical and development perspective is imperative. Besides the immediate relief that the medical support may offer, children and their mental health and education should be considered a priority, if the family has to recover as a unit and get not sucked further into a downward spiral. The stigma levels are linked to the stereotypes projected vis-à-vis people with mental health issues; but these are largely drawn from real life examples. This leads to the question:

When is care complete?

If this issue is not addressed at its core, both stigma and health-seeking patterns cannot be dealt with effectively. The absence of psycho-social interventions is obvious as one meets several Kamalas. Day care centres, group therapy, counselling, family support groups, vocational training and assisted care in the community are all concepts that have been spoken of, but rarely integrated into the National Mental Health Programme (NMHP). In these deficiencies lie the pitfalls of the programme.

Mental health sector: an overview

Despite gaining prominence in recent years, mental health remains relatively low on the agenda of the NGO sector. Mental illness along with HIV/AIDS, cancer and cardiovascular disease are projected to emerge as the top four illnesses in the world. Though there is a high prevalence and incidence rate, little progress has been made towards addressing some complex issues within the mental health sector. Mental disorders constitute 15% of the global disease burden, making it one of the leading causes of death and disability (WHO, 2004). This fact was reiterated by the Union Minister for Health and Family Welfare, Government of India, during a recent conference where he indicated that mental disorders such as schizophrenia, mood disorders, substance abuse and dementia contribute more to the global disease burden than cancer or cardiovascular disease.  

1
India lives mostly in its villages and often the remote regions of most states remain under-served. The health systems that exist are often under-equipped to deal with even basic health emergencies. The rural burden of poverty continues till today. Health hazards, both physical and psychological further aggravate the situation leading to deterioration in the quality of life. The India Health Report 2010, a Business Standard publication reported that 'Out of pocket spending on health is one of the major causes for increase in poverty, the proportion of households below the poverty line increased by about 8 percentage points post any expenditure on health.' The report estimated that the impact is felt more acutely in rural areas where 35-40% of the households fall below the poverty line as a result of health related expenditure. Loss of productivity and the opportunity costs linked to disability have a huge impact in a low income country like India where 41.8% of its population lives in poverty (Tendulkar, 2009).

Public spending on health, and specifically mental health in India is one of the lowest in the world: about 1% of the GDP on health (Planning Commission, 2007) and 0.83% of the health budget is spent on mental health. While the government health system has tried to respond in most states as swiftly and effectively as possible through its network of Primary Health Centres (PHCs), Taluk hospitals and district hospitals in the rural areas and through the municipal corporation clinics and general hospitals in the urban areas, there is still a huge gap that the country faces in terms of its health care delivery systems. There are also a great deal of inter- and intra-regional differences in health care delivery systems. Health is a state subject in India, which in effect means that the individual state governments take on the onus of determining the health agenda. The federal or union government can take the lead in policy initiatives or disbursal of funds but the states are the implementing authority. The organisation of public health care in the country operates from the national level to village level through a health care system at national, state, district, community, PHC and sub-centre levels through a network of hospitals/clinics etc. States have organised their health services structures in order to bring all health care programmes in a district under unified control. At the district level there is a link between the state on one side and the sub-district level structures such as PHCs and sub-centres on the other side. At present there is one PHC covering a population of about 30,000 (20,000 in hilly, desert and difficult terrains) or more. In most places there is one sub-centre for a population of about 5,000 (3,000 in hilly, desert and difficult terrain).

The pattern remains the same with regard to mental health. However, only 125 of the 626 districts in the country are currently covered by the District Mental Health Programme (DMHP) the flagship programme of the Union Health Ministry to provide services for persons with mental health issues, conceived as early as in 1982. The DMHP was intended to
integrate mental health into the public health system through early detection and community based locally accessible treatment and thereby reduce the burden of travel, amongst other issues, for users of the system. It also incorporated training, awareness creation and rehabilitation as integral parts, with the aim of mitigating stigma and increasing acceptance and positive attitudes towards people living with mental health issues (Murthy, 2011).

Several administrative and programmatic factors resulted in poor implementation of the programme. These include a lack of appropriate training programmes of primary care physicians and para-medical staff and scattered and sporadic supervision patterns and limited accountability. The model seemed more clinical and focused primarily on pharmacological interventions; so much so that the social worker and psychologist posts in many of the teams were left vacant.

The approach seemed reasonably top down and hence did not contextualise the needs of the community and look at wellness as a theme (Jain & Jadhav, 2008). To truly integrate mental health in the primary care process would require not merely a programmatic change in approach, but a rethink of the basic tenets of primary care itself. Public health is often mistaken in our part of the world as provision of medicines or organising health camps. This misconception needs to be eradicated from the minds of planners and implementers. Public health is conceptually distinct from provision of medical services or dispensing medication. The key goal should not be to merely reduce the population’s exposure to disease, but minimise the negative impacts of the illness on the individual, family and the community as a whole through a system that interfaces directly with the population being served.

There is no doubt that the public health system in India is under-equipped and understaffed and unable to cope with the needs of a growing population with most of the services intended for the chronically ill being concentrated in urban centres and mostly the large metropolitan areas. In the field of mental health, where close to 60 to 70 million Indians may suffer from some diagnosable mental health issue, of whom 10 million are estimated to suffer from serious mental illness, the challenge is immense.

Mental health is a very complex, nuanced subject that requires individualised and multifaceted responses, while standardised, mostly medical responses are the norm. While the usage of psychotropic drugs for treatment of mental illness is essential, one cannot but emphasise the importance of therapy, counselling, vocational training, working with families, awareness, sensitisation etc. Persons living with mental illness require a whole
spectrum of services that recognises the divergent needs. It is expected and desired that the responses are multifarious and accessible. The needs range from emergency services to post-care facilities in the community that include programmes like rehabilitation, social support schemes, day care programmes, long term services and access to entitlements.

While the focus is on the service delivery, attention also needs to be paid to two other important areas: awareness creation and training to ensure that the system has the right number of trained people to cope with the demand for services. At present, the number of mental health professionals (psychiatrists, psychiatric social workers, psychologists and psychiatric nurses) is grossly inadequate. For example, India has only 0.2 psychiatrists, 0.03 psychologists, 0.03 psychiatric social workers and 0.05 psychiatric nurses per 100,000 population (WHO, 2005).

**NGO sector in India**

The non-governmental movement in India is significant and with an enormous spread, particularly in the health and development sector. Charity with its roots entrenched in religious beliefs and values were fairly widespread in pre-colonial India and can be traced to the philanthropic and religious obligation on individuals to help the needy. Voluntary effort has always been an integral part of Indian culture and social tradition - the concept of Dhaana or ‘giving’. The construction of the Dharamshalas for the wayfarer that exist till today in many pilgrim towns, was based on the traditional Indian belief that a guarantee for shelter, food and security were essential for all human beings especially in the absence of the security of home and family. Voluntary action has undergone several changes through different phases in this century, from services provision based on charity, Gandhian voluntarism to action based activities based on ideology and charisma and finally to the current phase of advocacy among professionals and organisations that work for integrated changes based on gaps in services and policies. Funding for the voluntary sector received an impetus during the industrial revolution in India, as corporate wealth and surplus profits began to be channelled towards welfare and development work, although many of these programmes were restricted to the workers and their families. The international donor funding brought with it a certain emphasis on professionalism in the voluntary sector.

Governments and bilateral funding partners also showed an increased willingness to accept NGOs as partners. Development organisations today encompass a wide-ranging field of activities, including designing and implementing innovative programs in various sectors of development. The sector has drawn significantly on the skills of the for-profit sector and integrated them into non-profit organisations. Use of planning techniques and strategy formulation has resulted in a more structured approach in various areas of service delivery,
especially in programme planning, implementation, research, reporting, documentation, monitoring and evaluation; along with an increased emphasis on training to support grassroots initiatives that used technical knowledge specific to the sector and incorporated technological changes to improve efficiency within organisations. NGOs have distinct advantages, especially to innovate and design programmes with flexibility in implementation as well as in setting up a close monitoring system that allows for mid-course correction where required, as compared to government agencies and can therefore be seen as building bridges across these two groups.

The close linkage between health issues and poverty being established, work in the mental health sector is today the mandate of several NGOs, in addition to Government and private services. This is a welcome change from times when there was just a minuscule engagement of civil society organisations in this sector. Presently, NGOs in the mental health sector have seen a new, yet, distinct evolution. Below are several examples of interventions by NGOs that work to address mental health issues in India. The list is by no means exhaustive, but aims to provide an overview of various strategies adopted by NGOs to bring about change in the lives of people with mental health issues.

**Working with divergent mental health and well-being needs of people from lower socio-economic and vulnerable groups**

NGOs that work with homeless persons with mental illness, such as The Banyan in Chennai, Karuna Trust in Mysore and Ashadeep in Guwahati offer care and treatment at transit care facilities with the ultimate aim of re-integrating clients with their families. This kind of response has been based on a transit care model which requires a period of institutional care and incorporates a core belief that institutions are not the ultimate solution for the care and treatment of people with mental illness.

Re-integration with the family is an important aspect of the work of these organisations, considering that family members in India are culturally the most preferred caregivers for a person with mental illness. When a person is re-integrated with the family, the social worker or another mental health professional who has accompanied the resident on the journey to his or her family, offers counselling to the family on the process of treatment and care that the resident has gone through at the organisation. It is often important to stress to the family that if a person had acted in a way that was harmful or hurtful towards family members, that these actions were usually a part of the illness and that this person will return to normal after treatment and on recovery. The social worker also tries to link the resident and the family to a locally available treatment facility. The importance of continued medication and family support is stressed. The opportunity to create support groups and
engage in awareness creation exercises in communities surrounding the client’s home and family, particularly in rural areas, is seized.

The Banyan

The Banyan was founded in 1993 as a response to the needs of homeless women with mental health issues, often prone to physical and sexual abuse, among many other forms of ill treatment. The philosophy grounding the care model was one of empowerment, independent living and care in the community, family or at home. Though the starting point was a tertiary care, institutionalised setting, the larger goals or vision dominated right through and the process of care within was developed as a culturally relevant psycho-social model with emphasis on lay counselling, initiation of a buddy system, occupational therapy, vocational training and more recently psychological counselling. Over the first 10 year period, more than 900 women were reintegrated with their families across India.

At the end of this period, while the option of expanding from a 200 to a 400 bed inpatient facility stared The Banyan in the face, larger issues of the mental health sector and of strategic growth ensured a different path. A review of The Banyan’s work by the National Institute for Mental Health and Neurosciences (NIMHANS) and an institutional partner/funder, the Sir Ratan Tata Trust, highlighted the reasons for users of the mental health or other traditional systems falling through the cracks of the health system and ending up homeless and without support. Amongst others, the lack of access to care, high disease incidence and hence family burden coupled with poverty and the lack of awareness scored as the largest stumbling blocks. The Banyan, in view of this reality, then decided to establish demonstrable models with standard operational protocols to implement a spectrum of services ranging from community mental health programmes (rural and urban) to acute care, rehabilitative and long-term services along with client and caregiver support services.

Today The Banyan’s Community Mental Health Programme (CMHP) in Kovalam village has reached out to the needs of people in the Thirupurur block (with a population of approximately 134,0005) of the Kanchipuram district in Tamil Nadu. The highlight of the model is the utilisation of community resources such as community workers, self-help group members and other political systems such as the Panchayati raj institution in the identification of mental health issues, social rehabilitation and awareness generation. The model aims to promote the concept of wellness vis-à-vis treatment of illness. The Urban Mental Health programme has reached out to more than 700 clients from various areas in and around Chennai. Home visits and work with the families and assistance in areas other than health, such as education, forming social networks, strengthening interpersonal
relationships and employment are key aspects of these community based programmes. An extension of the transit care facility is the long term care centre, following the group home model in an open community in Kovalam. Cottages are assigned to six members who live together and try to operate as a single unit to the extent possible. These are persons who have long-term needs and either have no families to return to or suffer from chronic forms of mental disorders. This growing need for assisted community living, though miniscule is still significant and not many solutions that are non-restrictive and community based are at hand. The concept of community fostering, though at its infancy stages through the Self Help group model, where clients opt to live in rented houses in the community, has shown reasonable success in limited terms (Sharan, unpublished). However, this concept works best with higher functional clients and the pairing off with participants with different capacities is still in the process of being studied. Experiments such as the one in Geel, Belgium (Goldstein, 2003), where families offer foster care in their homes for a person with mental illness, have not been attempted except in the Ashagram model, which though similar in some ways, has not been adopted by the Government as yet.

The most recent innovation of The Banyan is The Banyan Academy of Leadership in Mental Health (BALM), founded in 2007, that uses The Banyan experience to advocate and influence trends and policy. It realizes though that many models of The Banyan need internal fine-tuning and studies them in greater detail to throw up challenges and gaps. Research and training are the cornerstones of BALM and these have been successful in replicating some of the work of The Banyan amongst other stakeholders to encourage greater participation in the mental health sector. The training programmes of BALM, other than those with its institutional partners, are primarily with the Panchayat Academy in Kuttambakkam, Thiruvallur district, Tamil Nadu. The training programme sensitises elected Panchayat leaders on mental health to actively engage them in the process of identifying, referring and advocating for the rights of people with mental illness in their villages. To date, leaders from 30 villages have been engaged in these training programmes. A significant outcome has been the provision of psychiatric medication at a PHC through the active intervention of the Panchayat leader.

Case study 2: Arumugam from Kuttambakkam has an 18 year history of mental illness. He was diagnosed at a temporary clinic set up during Panchayat leaders training programme and sent for treatment to the CMHP project at Kovalam. The man was treated within 6 weeks and was discharged. Shuba, his carer was an SHG leader who attended the Panchayat leaders training programme. Shuba was extremely for the change brought into their lives. The follow-up was a difficulty for the family though, since medication was not available at the local PHC. Arumugham was asked to attend the Banyan O.P. at K.K Nagar in Chennai, the closest to his
place of residence, which was still nearly 25 km away. The alternate solution to Arumugham’s problem would be to purchase medication from the local pharmacy which he could not afford. Fortunately, in Arumugham’s case the Panchayat Leader, Mr. Elango Ramaswamy was a very enlightened and proactive leader. He ensured that psychiatric medication was made available at Kuttambakkam PHC within a short space of time, not only helping Arumugam, but also others in the area who mental health need care.

The Banyan model has been effective in garnering public support and in promoting non-traditional bottom up approaches to mental health care in many ways. Its strength lies in it’s openness to embrace a balanced view to mental health care while retaining it’s spirit and dynamism, seeking newness, critiquing it’s own models and constantly reviewing theory and practice to better the mental health system. All its programmes are driven by a search for development and well-being.

**Ashadeep**

Ashadeep was founded in 1996. After a brief visit to The Banyan, Ashadeep began a transit care facility along similar lines to provide shelter and treatment for homeless women with mental illness in a population in Assam and other North Eastern states that was in dire need of mental health services.

The situation in the north-eastern states of India, viz., Assam, Arunachal Pradesh, Nagaland, Meghalaya, Manipur, Mizoram and Tripura is unique. These states have a predominantly indigenous tribal population and culture which influences several aspects that are directly related to health. There are as many as 220 languages spoken in the north-eastern states. Several languages have no script and therefore have no literature (Miri, 2003). This influences the generation of communication material which is heavily dependent on the written language in remote regions.

The geographic position has also ensured that almost all the states in this region have borders with other countries. The border areas are inaccessible terrain and this makes the region prone to infiltration and strife along with the continued presence of the armed forces. As a result of the political unrest and the volatile situation, the emphasis on human rights is also strong among the civil society organisations. All the states have had to grapple with several health issues due to the nature of the tribal societies, the geographic position and regional disparities – some of the issues are endemic malaria, poor reach of the public health system and generally poor infrastructure. These issues are compounded by
inaccessibility and remoteness of the region and the poor roads which are mostly mountainous. For example, several parts of Arunachal Pradesh remain cut off for nearly six months in a year from the rest of the nation.

Considering the remote location of the north-eastern states, the need for mental health care is intense with little or limited access to mental health services. The north-eastern region with a population of 38.49 million (Census, 2001) in an area of more than 2.6 lakh square kilometres is served by 386 hospitals with a bed strength of 20620 (Ratio 1:1518, National 1:1412). The doctors to population ratio in North East is deficient (e.g. Meghalaya 1:4758, National 1:2083) which falls short of both health infrastructure and man-power. There are only four Medical Colleges in the region to produce the required medical graduates. The North-Eastern Indira Gandhi Regional Institute of Health and Medical sciences (NEIGHRIHMS) was created to make up the deficiency in Human Health Resources. Lokpriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH) is one of the oldest mental health care institutes in India established in the year 1876. The Mental Hospital at Tezpur, the only facility in the North Eastern States that caters to patients from the region, has only 318 beds.

There are only two prominent NGOs working exclusively in the Mental Health sector - Ashadeep in Guwahati, Assam and the Sanker Foundation in Shillong. Ashadeep has stepped into human resource development and capacity building by organising several training programmes for caregivers other than mental health professionals to provide mental health care in an attempt to bridge the gap. Through its 6 partner NGOs in 3 north-eastern states, they have provided outpatient services and raised awareness on mental health. In addition, Ashadeep runs a day-care centre in Guwahati. Ashadeep also is involved in advocacy initiatives at a national level on mental health and disability related issues.

Karuna Trust

Karuna Trust in Mysore, Karnataka on the other hand had a community based programme to begin with, but adopted the transit care model after recognising the need for this service over a period of time. The Karuna Trust was founded in 1986 and is affiliated to the Vivekananda Girijana Kendra (VGKK). Karuna Trust runs primary health care centres (PHC) in 10 states in India as a public private partnership (PPP) model with the Governments of the respective states. In the PPP model, the Government funds the salaries of staff and medicine cost, while the Karuna Trust recruits the staff and operates the daily activities of the PHC, including awareness programmes. The PHCs run by Karuna Trust have shown significant positive developments - a reduction was observed in the crude death rate, infant mortality rate, child mortality rate, under five mortality rate, still birth rate, perinatal mortality rate,
neo-natal mortality rate, post natal mortality rate and maternal mortality rate. Specific programmes such as mother and child care, family planning and immunisation have success rates comparable or higher than the district, state and national level. One of the key features of the PHCs run by the Karuna Trust is that the medical staff lives in the premises of the PHC, which ensures availability of a doctor or other medical staff at all times. This practice increases the frequency of visits by patients, who are ensured of the availability of a medical officer.

In several PHCs in Karnataka and Arunachal Pradesh, mental health and epilepsy care is offered alongside the other health facilities, based on the model of the District Mental Health Programme, where primary health care doctors are trained in treatment of mental illness. The PHC in Gumballi in Karnataka is an example of a PHC where the general practitioner after a brief period of training through NIMHANS in Bangalore is able to treat common mental illnesses, without having to refer a client to the district hospital. However, people with severe mental disorders are mostly referred to the district hospital and not treated at the PHC level. General health workers also receive training in early identification, treatment, follow-up, rehabilitation, and counselling.

The Karuna Trust was a pioneer in working with tribal communities and has integrated mental health care in their clinic in the BR Hills, Karnataka.

*Iswar Sankalp*

Iswar Sankalp works with homeless persons with mental illness in Kolkata. The belief of Iswar Sankalp is that an institution, in the form of a mental hospital or permanent shelter, is not necessarily the best place for a homeless person with mental illness. Iswar Sankalp’s philosophy is that people who are living on the streets can and should decide themselves whether they would prefer to continue on the streets or stay at the half-way home when they need to. Iswar Sankalp reaches out to people on the streets directly by providing counselling and medication in the community, as well as through an open shelter, started more recently. Iswar Sankalp encourages participation from community members. To look after a person with mental illness on the streets. The key community ‘carer’ both administers the medication, prescribed by the clinician and monitors progress. Iswar Sankalp also works to organise homeless persons into support groups, so they can provide security and peer support to one another at different locations such as railway stations where they consider themselves vulnerable. Iswar Sankalp organizes regular training programmes for police officers to sensitise them on homelessness and mental illness as they could at many points be the first point of contact.
Working with tribal communities

Ashwini runs a general hospital in Gudalur, a remote tribal area in the Nilgiri Hills in Tamil Nadu. When an alarm was raised over the large number of suicides, the need for mental health services was realised. Ashwini initiated a community mental health programme by training people from the local area to provide mental health services. Considering the remote location of Ashwini’s hospital, recruiting mental health professionals to provide all treatment and care would have been difficult, hence the doctors at the general hospital are trained in the treatment of mental illness, and community workers have received training in identification and referral of people with mental illness.

Trust for Reaching the Unreached (TRU) started as an NGO to provide general health services and awareness in tribal districts in Gujarat in 1987. Similar to the situation that prompted Ashwini to start mental health services, the project areas with a large tribal population, saw a high number of suicides. After consultation with the community on mental health needs, TRU initiated mental health services by training health care workers in identification and referral. TRU has a public-private partnership (PPP) with the State Government through the District Mental Health Programme (DMHP). Similar to the Karuna Trust’s PPP, TRU runs 3 outpatient psychiatric clinics, where treatment is provided free of charge. TRU also conducts awareness programmes and trains doctors and paramedic staff at PHCs and CHCs on mental health, with all these activities being funded by the DMHP. Around 50 traditional healers have also been included in training programmes on mental health.

ASHA workers (community level workers employed through the National Rural Health Mission) are involved in the programme and are given incentives to refer clients with a mental health issue to TRU. So far, TRU has reached out to more than 1,000 clients through the out-patient clinic and has organised awareness programmes for more than 3,000 people in two blocks. TRU also conducts follow-up home visits to assist families in taking care of a person with mental illness.

Working with self-help groups

Anjali was founded in 2001 and initially started work in government mental hospitals to introduce interventions beyond medical treatment, such as art, dance, music etc. In addition, Anjali has initiated a community mental health programme in an urban area in the vicinity of Kolkata. In all its work, whether it is working in mental hospitals or in the community, Anjali aims to work together with Government agencies, in order to make projects sustainable. The community mental health programme called ‘Janamanas’ aims to
build capacity at the local level to identify and refer people with mental illness to the appropriate clinics and hospitals. In addition, Janamanas aims to create a therapeutic environment for people with mental illness to live within their own community, in order to encourage families to take care of a person with mental illness as well as reduce stigma. Women from self-help groups are trained on mental illness and disability and receive an incentive for referring clients to the municipal clinics for treatment. Kiosks have been set up where information can be sought on mental illness, treatment related to mental illness and any applicable Government welfare schemes. These groups also advocate for the inclusion of people with mental illness in government programmes. More than 100 women from self-help groups have been trained.

Focus on a rights framework

Bapu Trust for Research on Mind and Discourse was founded in 2001 to create a more humane mental healthcare system through research and advocacy. In addition to research, which is a core activity, BAPU focuses on human rights and gender-related issues as well. It runs a resource and advocacy centre on mental health with a thrust on peer-driven programmes. Bapu Trust also works closely with communities in providing non-medical clinical services, such as psychological therapies and studies the role of diet, nutrition, traditional systems of healing and the likes as part of a well-being model. Bapu Trust works with the belief that mental health problems need to be constructed not only as medical or health problems, but as social problems that need individual solutions. Bapu Trust also works with other organisations on capacity-building programmes and is a pioneer in cross-disability work and advocacy.

Basic Needs India (BNI) came into existence as an independent trust in 2000 after being affiliated to Basic Needs UK. Their vision is “However poor or ill a person is, s/he has the ability to manage his/her life”. Basic Needs India Trust (BNI) grew out of the belief that the rights of people who experience mental illnesses, especially those who are poor, must be addressed not only at an individual level, but also in the context of a wider world. BNI engages people living with mental illnesses and their carers in processes that are mutually supportive. All people involved in care and rehabilitation work, learn, grow and are strengthened together. BNI addresses both people’s mental health concerns and situations of poverty to ensure sustainable recovery. The underlying conviction is that mental health issues must be seen not only in medical terms but, just as importantly, as human rights issues. Such efforts include linkages with a host of people – people affected by mental illnesses, family members and other carers, community members, medical professionals, policy makers, and government officials.
BNI is a resource organisation, as opposed to a service delivery organisation and partners with grassroots level organisations and their community workers on training and capacity building programmes in order to empower them to provide medical treatment and counselling to persons with mental illness. Another focus area of this organisation is to organise programmes that promote positive mental health and prevention of mental illness, including sensitisation of communities to the needs of people with mental illness. These programmes aim towards building positive mind-sets and empathy in the communities in which they work. The grassroots level organisations work either on general health issues and integrate mental health services, or work exclusively on mental health.

BNI believes that institutionalisation is not an ideal solution for persons with mental illness. Instead, treatment offered at the community level is preferred and stressed. Basic Needs India works in parts of 8 States and 45 districts. The organisation and their partners have reached out to around 17,000 persons with mental illness and their families.

**Caregiver and user driven programmes**

Action for Mental Illness (ACMI) was founded in 2003 as an advocacy initiative, to impact legislation, policies and programs such that it positively impacts the quality of care for and rights of Indian citizens suffering from schizophrenia, bi-polar disorder and other mental illnesses. ACMI focuses on four kinds of advocacy: social, political, legal and media. ACMI’s direct community involvement in urban and rural areas in Karnataka is focused on the role of families in mental health care.

Activities consist of education and empowerment of families who are providing care for their family members affected by chronic mental illness. The empowerment component known as Kshema aims at promoting a supportive family environment during one-to-one sessions with the client and his/ her family, discussing topics such as illness related information to treatment and side effects, deficits and special needs. This package empowers families to cope with grief or guilt as well. Verbal and written information is provided to caregivers about the benefits available to disabled persons under the Persons with Disability Act 1995. A special feature of the programme is the assistance provided to families from low socio-economic groups to successfully access social entitlements from the state (both welfare and disability driven), such as the disability allowance.

Schizophrenia Awareness Association (SAA) in Pune was started by caregivers and user survivors of mental illness, whose core strategy is to organise themselves into support/self-help groups. The support derived from other clients who are suffering from mental illness is
considered to be a healing process in itself, besides regular treatment that somebody might be availing. The self-help groups also act as support networks for the members in case of emergencies as well as in dealing with the daily problems one experiences when living with a mental illness. SAA strongly emphasises the importance of employment for people with mental illness and assists its members in becoming gainfully employed. SAA conducts awareness programmes for family members, general practitioners and the media on schizophrenia and other mental illnesses. Books and films on schizophrenia are published and produced by SAA for the general public and health professionals.

Aasha was set up in 1989 in Chennai by a group of caregivers. In addition to running a home for people with mental illness, Aasha has a strong focus on employment. Aasha assists clients in locating employment in various companies and helps clients retain their jobs by liaising actively with their employers. Aasha also runs various employment units itself, that include a general store, a phone booth and a paper cup making unit. The residents of the residential care facility work in these units during the day and earn a salary that they are at liberty to use in whichever way that they desire.

Whole Mind India Foundation (WMIF) was founded in 2009 by a user survivor to create a ‘rainbow coalition’ of users. WMIF’s goal is to become a link between users and caregivers on the one hand and the Government, non-profit institutions on the field, media and stakeholders on the other. WMIF’s vision is ‘to make a difference to the life and times of people affected with psychiatric illness through capacity building of all the stakeholders based on constructive engagement and purposeful action.’ WMIF now plays the role of an activist and information disseminator and gradually hopes to engage in service delivery as well.

**Focus on research**

Sangath an NGO based in Goa, was founded in 1996 and works on various implementation-cum-research projects on subjects related to child and community mental health, amongst other health subjects. Sangath’s mental health projects include integrating care for common mental disorders in primary care, community-based interventions for people with schizophrenia and delivery of mental health care by non-specialised health workers, amongst others. They strongly promote the concept of evidence based, empirically validated interventions.

Schizophrenia Research Foundation (SCARF) in Chennai was founded in 1984. SCARF has established itself as a centre of repute in rehabilitation and research in disorders of the
mind. SCARF is one of the very few NGOs in the world to be named as a collaborating centre of the World Health Organization (WHO) for Mental Health Research and Training. In addition to its wide range of activities that include community outreach clinics, SCARF initiated a unique programme - telemedicine projects in 5 sites in Tamil Nadu to facilitate sessions between a psychiatrist and a client at a distance. The psychiatrist is stationed in Chennai, who speaks to the client and, if applicable, to his/ her family members through video and phone technology and advises appropriate medication and/or psycho-social interventions. SCARF has collaborated with local organisations, which house the telemedicine facility and disburse medication, after being trained in mental health. More than 400 clients have accessed the telemedicine facilities.

Working with traditional systems of healing

The pathways to mental health care are many, but the one most frequently used in India is through faith-healing practices. The Altruist, an NGO in Ahmedabad has initiated a mental health programme called ‘Dava & Dua’ at a dargah, where the organisation works together with the dargah administration. The aim of the programme is to provide an additional method of treatment at the dargah, besides the religious treatment that people with mental illness seek through the blessings of the saint. The Altruist organises out-patient clinics inside the dargah and organises training for the clergy on the medical aspect of mental illness.

A large number of people in India access faith healing centres as the first points of contact for treatment of mental illness; The Altruist initiative offers the option to access traditional and mental health both forms of mental health treatment in the same place. The Dava and Dua project has provided mental health care for more than 5,000 clients.

Community fostering

Ashagram in Madhya Pradesh was initially started as a community for people affected with leprosy. It was set up by people with leprosy themselves and provided a non-restrictive open environment geared towards rehabilitation. Over the years, other vulnerable groups were also welcomed into the community, such as people with mental illness and other disabilities, as well as widows and orphans. The membership of Ashagram is unique where all residents participate in the maintenance of the community according to their individual ability and capacity. Independence and agency of residents is promoted.
Ashagram provides long-term care for persons with mental illness with a strong focus on the sense of community and the support that people derive from each other. This arrangement provides an environment of equality, ownership and well-being of one’s self and encourages bonds with other members of the community.

**Challenges faced by NGOs in the mental health sector**

Until recently, mental health was not viewed as a space that required or warranted NGO work; owing to both scarcity of funds and limited focus on the disability itself. While the participation of community-based grassroots organisations working on health and cross disability have helped bridge this gap and open up the sector to an extent, the medical model and related perceptions/dominations continue to persist.

Paucity of funds, access to resources and limited fund-raising capacities sometimes prove to be a deterrent for many NGOs to sustain their work or to enter the sector. The geo-political dimensions of allocation of a disproportionately large amount of funds to certain diseases could also influence and contribute to the unequal distribution of resources.

A sense of divisiveness in the mental health sector hugely contributes to the lack of cohesiveness and a single, strong lobby that influences implementation, and policy. NGOs are largely classified into research-based, community-based, rehabilitation-based or medical, with limited crossover taking place. Many are grounded in ideologies that are deeply entrenched in their systems with a non-negotiable policy often erupting into intra-organisational disagreement. Limited funding and unhealthy competitiveness besides divergent guiding philosophies could also contribute to this trend.

The fact that psychiatry has predominantly remained a medically dominated domain does not help. Many times the initiatives of those from a non-psychiatry background are underrated or ignored. This prohibits a healthy, multidimensional approach from emerging. The trend is slowly changing, though in a limited manner. Despite the United Nations Convention on the Rights of People with Disabilities (UNCRPD) and its mandate, the important role and scope of user-survivors and caregivers, and that of other mental health professionals such as psychologists and social workers and other health activists has been limited. This has been one of the reasons for the sector being dominated by a few and hence resulting in limited convergence.

The operations of many NGOs are still pre-set in the traditional mindset of charity and hence the treatment patterns, the funding approach and the scope of activism and advocacy are limited. The notion of charity has to transform into responsibility, accountability, rights and development for the movement to be strategic, scalable, influential and driven.

Leadership in the sector is minimal, perhaps influenced again by the domination of a few. Greater charisma, management skills, showcasing of models backed by empirical data and
evidence is called for. The gap between grassroots work that impacts the lives of many and research is huge and growing. This disconnection needs to be rectified with each sphere.

The idea of community mental health itself needs to be understood in greater depth, instead of viewing it through a stereotypical lens. Communities are defined in different ways by biologists, sociologists etc. with descriptions ranging from ‘a group of interacting organisms sharing a populated environment’ to ‘a group of interacting people living in a common location’ to ‘a group of individuals whose intent, belief, resources, preferences, needs, risks and a number of other conditions may be present and common, affecting the identity of the participants and their degree of cohesion’.10 In the context of community mental health, the traditional mindset however, continues to view “communities” as an urban slum or a rural pocket typically. However, by this definition, a rehabilitation home, centre or clinic and many such unorthodox spaces should also classify as communities. This revolutionary approach would help mitigate stigma, open up and help reform psychiatric hospitals, by making them centres that offer multiple services to the community; one amongst them being emergency or acute care. This change in approach, understanding and branding would help impact health seeking patterns as well and make such centres more transparent in their operations.

Community mental health should ideally encompass care of all sorts: not just medical, but nutritional, spiritual, recreational as well as well as psychological and social. This is the only approach that will ensure completeness in process and give the movement a development slant that not just NGOs require, but countries like India and other low and middle income countries (LMIC) in general need. The only way to truly integrate mental health into general health is to look at the family as a unit and the individual as a whole. Mental health in a sense weaves together many dimensions of health and wellbeing and to achieve this, the individual and his/ her needs have to be addressed as a whole - in context to her work, health, socio-economic grouping, com- munity, tradition, culture and life.

**Positive trends in community mental health care in the NGO space**

The collaboration between government agencies and civil society organisations to deliver mental health services, as observed in the case of Karuna Trust, has demonstrated positive impact in terms of the reach and quality of care and services. This PPP model with a clear focus, mission, strategy and direction should be replicated in other regions and involve other organisations as well. Periodic reviews of this model should be initiated to understand reasons for greater effectiveness in service delivery and implementation of programmes.

The budget allocation for mental health services as per the Eleventh Plan indicates a considerable portion demarcated for engagement with non-governmental organisations (Ministry of Health and Family Welfare, 2007). This provision may not have been utilised to the fullest. A clear and transparent process that welcomes NGO initiatives and
collaborations and participation, particularly in the delivery of mental health services in rural and urban communities will impact the sector and programme significantly.

The participation of NGOs in Government Mental Hospitals is a much needed move to inculcate values of transparency and good governance. Closed institutions are often considered to be spaces or communities open to human rights violations and the presence of a knowledgeable ‘outsider’ who plays the conscience keeper is a valued addition. Anjali within Pavlov and Lumbini Mental Hospitals in Kolkata, Saathi and The Altruist within the Ahmedabad Mental Hospital, Koshish and many others that work with Institute of Human Behaviour and Allied Sciences (IHBAS) in New Delhi are some of the effective partnerships that have created significant impact not just within the institution but in allied areas of providing outreach services as well.

Federations of NGOs have been formed by organisations working in similar areas grounded in a common ideology: National Alliance on Access to Justice for Persons living with a Mental Illness (NAAJMI), All India Federation for Mental Illness (AIFMI) and Amity are organisations that are primarily user survivor or caregiver led and draw the attention of policy makers and specialists to the real needs of communities affected by mental health issues. These NGOs primarily play the role of advocates of human rights friendly policies and benefits (including access to health care and social entitlements) that reflect the needs of the user and the system.

Leaders from the NGO sector have now been co-opted into national committees and bodies, including one that will determine a mental health policy for the nation and in larger debates concerning mental health services and contribute to the policy and planning discussions.

Endnotes

2. Taluk is a sub-district unit under the decentralized administrative structure in India in several other states variants of the same name are used such as tehsil or mandal.
4. For a more detailed analysis of the programme refer to http://www.nimhans.kar.nic.in/dmhp/default.htm, Murthy 2011 and Jain and Jadhav.; 2008
5. Census India 2001
6. Names changed for reasons of confidentiality
7. The K.K. Nagar OP is part of the Urban Mental Health Initiative of the Banyan located within a government-run programme, the State Resource and Training Centre (SRTC).
The SRTC helps in obtaining ID cards for the mentally ill along with other disabled populations. The Banyan operates a day care centre as well at the same location.

8. Elango Ramaswamy, is the founder of the Panchayat Academy and an Ashoka Fellow.


References


9. WHO Atlas Mental Health, 2005

10. WHO Global burden of disease, 2003
Chapter 9

Mimicking family as a therapeutic strategy in promoting recovery from mental illness and building human-resource capabilities

Abstract

Background
The convergence between mental ill health and homelessness is well documented, but critical events that precipitate the downward spiral into homelessness and promote recovery remain only partially explored in India. Professionals and others who currently deal with this problem are also lacking in terms of their competence and number.

Aims
To understand reasons why persons with mental health concerns become homeless, and to explore creative and innovative approaches to restore balance and promote recovery, using attributes that a family connotes both as a value and as a strategy to develop human resources.

Methods
The qualitative study included focus group discussions and participant observation. Researchers also relied on organizational memory and case files. The data were analysed using a constructivist and phenomenological approach. Finally, feedback was drawn from leaders of other organizations that promote value based care and was clustered thematically.

Results
The findings suggest that besides poverty and deprivation, family breakdown is critical in building distress and rendering persons with mental illness homeless. The value of social affiliations and kinship in aiding recovery was observed. Thus, in the absence of a family, mimicking its attributes seemed to ground institutions and staff in a culture that developed the competencies to deal with complex problems such as the co-occurrence of mental ill health and homelessness.

Conclusions
This study highlights the critical need to develop creative and simple approaches to address
the needs of homeless persons with mental health concerns through resource-efficient models that promote culture and equity and enable personal recovery.

**Introduction**

The co-occurrence of mental ill health and homelessness represents a persistent and complex social problem that leads people into a downward spiral, affecting many domains and eventually their quality of life. Such persons experience multiple deprivations and are susceptible to further vulnerabilities such as substance abuse, cognitive deficits, depression, physical ill health and the risk of committing suicide (Muñoz et al. 1998; Gelberg et al. 1996; Weinreb et al. 1998). The World Health Organization (WHO) describes this group as highly marginalized (WHO 2010).

Johnson and Chamberlain (2008) posit multivariate pathways into homelessness that include the loss of traditional livelihoods, poverty, unemployment, social exclusion, urbanization, changing social institutions (family dynamics), chronic ill health, poor access to health services and out-of-pocket expenditure. Among many critical aspects, family breakdown has been widely accepted as a key factor leading to an individual’s eventual descent into homelessness (Chamberlain et al. 2011).

A large-scale study was conducted in Spain among persons with mental health concerns, which sought to understand precipitating factors that led to homelessness. It found that the participants viewed their pathways into homelessness as multi-causal – financial instability, the breakdown of familial and social ties, and mental illness were cited as critical events (Muñoz et al. 1999). The study used a Stressful Life Event (SLE) framework in order to determine the relationship between each such event and homelessness. The study revealed that almost one out of every three had experienced the death of a first-grade relation (parent, child or intimate partner), and almost two thirds had experienced the death of a family member or a close friend. In examining the causal relationships of the SLEs to homelessness, economic instability followed by the death of family members and close friends feature as prominent and essential factors. Feelings of abandonment and rejection are also perceived as significant triggers.

If the family symbolizes well-being, we need to understand what it represents. Waldegrave (2005) defines a family as any primary intimate group, which through blood ties or intentional commitment identifies itself as such. The role of a family, as well as affecting breakdown, has been observed to influence many other trajectories. Building positive behaviour that ensures physical and emotional well-being as a result of mirroring positive values (Repetti et al. 2002) is cited as one such. By the same token, in families that exhibit dysfunctional behaviour such as increased aggression, incessant conflict, rejection and coldness, there is a greater risk of behavioural problems including aggression, anti-social

Given this, the loss of the family or caregiver can result in an irreconcilable sense of pain that needs to be adequately addressed, especially in the case of homeless persons. The most obvious response is, where possible, to facilitate the person’s reintegration into the family environment. While this may work in some cases, many individuals may not wish to return to their birth or marital family and yet seek a family-like environment, connectedness and emotions. The challenge lies in responding to such needs.

This inductive inquiry aims to understand one of the most critical elements in the discourse on mental health that both catalyses the descent into homelessness and enables recovery. It attempts to capture methods and strategies that address this loss, build human resources that embody values that promote recovery, and repackage rehabilitation, clinical and social interventions in ways that encourage capabilities and inclusiveness.

Methods and results

This section outlines the research methods adopted to engage effectively with the issues in question. It also provides details on the nature of the study, sampling methods and sample characteristics.

Methods

The research adopted a qualitative design to ensure that the critical moments in the journeys of persons who have concurrently experienced homelessness and mental ill health were explored in detail, in order to develop a more nuanced understanding of the issues. Qualitative studies are exploratory in nature and seek to understand the ‘how’ and the ‘what’ of phenomena and delve in-depth into meaning-making and the participants’ lived experiences (Morrow 2007). Qualitative data-collection techniques are participant-led and follow a bottom-up approach. This facilitates the creation of a platform to articulate participant-generated perspectives, meanings and values (Willig 2008).

The study draws on narrative, phenomenological and grounded-theory approaches. The narrative study approach helps in understanding stories and events through semi-structured probes, and in reconstructing critical events in a chronological order. Phenomenological methods add depth to the exploration, and elements from grounded theory were used to develop core theoretical concepts based on emergent themes rooted in participants’ feedback and observation (Mills et al. 2008).
This study was conducted among homeless persons with mental illness who were using the services of The Banyan, a non-governmental organization (NGO) based in Chennai and Kovalam in the Indian state of Tamil Nadu. It was established in 1993, when the founders were confronted with one such woman who was naked, in distress and visibly deluded, yet lonely and uncared for. Since then, the NGO has built diverse and robust response systems to address the needs of this marginalized group across its many programmes. Its range of services include emergency and long-term care, rehabilitation, day care, skills development and access to employment as well as clinical and social care services for men, women and children with mental health issues and who are living in poverty, in both urban (four clinics) and rural (population drawn from across 54 village panchayats) locations.

A sample group of persons living with mental health concerns and had become homeless, and who used The Banyan’s clinical and social care services and reintegrated with their families or found other ways of living full lives was identified, based on their contact with the institution’s after-care or supported-housing services. Two Focus Group Discussions (FGD) were conducted with two women’s groups (n=23). At the time of the FGD, the women resided in their own/family homes, at The Banyan’s shared housing/alternative living programmes or at their workplace. All sessions were recorded, transcribed and coded. The results were clustered thematically and later analysed to draw the most relevant responses in the context of this study. The FGDs were conducted by researchers with master’s degrees in Mental Health Services Research, Development Studies and Counselling Psychology respectively, and a volunteer. A list of critical questions and probes were identified and shared with the facilitators.

The researchers also conducted interviews with a few leaders and caregiving organisations from across the country (n=6). Additionally they also drew information from organizational memory, observation, clients’ files, interviews with case managers and previously gathered data.

**Results**

While poverty and deprivation have often led to the downward drift into homelessness, family breakdown was frequently cited as critical in building distress. Domestic violence, the death of the primary caregiver, parental intolerance of differences, and the caregiver’s inability to cope and so reneging on this responsibility was found to be an important pathway to homelessness and withdrawal from society. While these present the perspectives of those using The Banyan’s services, often the aggression and conflict they had provoked resulted in impulse-driven flight and decisions also seem to have contributed to leaving home or wandering. The primary link in both cases is the family or what it
represents. There was an observed need for kinship, for a bond that involves people who provide almost unconditional support and care, signifying a deep commitment. In the case of an enduring mental illness the timeframe is usually significant, sometimes spread over the entire life of the affected person and the caregiver.

Descent into homelessness

Among many scenarios, what seems to result in irreconcilable pain and trauma is the co-occurrence of violence (physical and sexual) and loss of the primary confidante or emotional anchor, almost simultaneously, at an early stage in one’s life.

My dad burnt my mother with kerosene. He used to come drunk and abuse me. He took me to a lodge and sold me off to men. I saw where he put the money. I took it and ran away from home. After that he threw boiling oil on my legs. With that wound I got on the train. I didn’t have food or anything. I came to the railway station and was sleeping on the road. There were men all around leering at me. – (Ms M)

This experience perhaps compounded the psychological scarring and underlying susceptibility to mental illness, besides rendering her homeless. She tried holding on, experienced unrelenting abuse and finally fled when the perpetrator also eliminated her only source of hope and security – her mother. This nature of violence and snowballing of distress is extreme and not widespread. However, where the notion of everything that a family stands for is destroyed, the damage usually is lasting:

I wake up in the middle of the night almost habitually to speak to my mother. I can see her or and hear her voice. I don’t ever want this relationship to end. Though it means I cry almost every night, recalling my past.

Distress as a result of domestic violence, property and interpersonal conflict and stigma also features prominently among the reasons for this downward spiral.

My husband used to torture me, he didn’t allow me to sleep and I had no peace at all. I couldn’t talk to my children or family or anyone. I attempted suicide several times because of my husband. One day, not being able to stand it, I just left my house and wandered off.
My husband said that they cheated him and married him off to a crazy woman. He used to beat me and I felt like it would be best for everyone if I died.

We all lived together before. We split after a family property conflict.

Whether it is money or greed that breaks relationships, or intolerance of differences and subsequent rejection by one’s own family, or worse still stereotypical and culturally embedded gender bias in Indian society that coerces men and women to conform to their roles in an absolute sense – or in many cases a cumulative loss on many of these counts, loneliness and feelings of loss as a result of non-belonging can foster withdrawal from society.

The fascination for the male exists at many levels – such as the mother who yearns for a son or the wife, who prepares herself for marriage to serve her husband etc. Girls are deprived of education, food and other resources so the male can prepare himself to become the family breadwinner. Even traditional rituals concerning death favour the male. A female with a disability is thus treated with scant respect and dignity. A house or shelter do not necessarily connote a home and family. While this is not the norm, such spurning and non-acceptance could also result in a person wandering away.

I was hit and abused and thrown out on the roads every day. They’ll never keep me at home. I didn’t know what to do and the only alternative was to just sleep on the road. I even did all the housework, but no one fed me. If I said anything, they only threw me out of the house. In the rain, I slept outside and they didn’t even feed me.

From the caregiver’s perspective, non-compliance with treatment and the family’s code of conduct, perpetuation of disharmony, aggression and disruptive, impulsive or ‘socially undesirable’ behaviour also are apparent and critical pointers that result in homelessness.

She would never stay at home. I tried many times. She’s kind and loving and when she’s here she helps us out. But then she begins to get restless. And picks up quarrels over issues that will not normally affect her. And takes it to an extreme, even abuses and hits me sometimes. I know that she misses her grandmother and runs first to the graveyard to mourn her loss. After that brief period of grieving and solitude, one can
find her amidst a crowd, in street corners, soliciting men and dancing to film music blaring from loudspeakers.

These are the words of a caregiver who tried her best but in vain to safeguard her daughter, Ms S, who was affected with mood disorders, from the perils of a life on the streets. While she would visit home from time to time, her primary identity was that of an eccentric, strong and feisty street dancer. No amount of pressure, conditioning or reasoning, or even firm love brought about the change that would provide a sense of stability in her erratic life. She was brought up by her grandmother, whose death in a sense spelled doom in her own life. It was almost as though something snapped within, upsetting the balance and causing her to live a nomadic life.

Some reasons for leaving the family were more frivolous.

I fought with my family members and left home on my own. I just boarded a train and didn’t know where I was going.

However, most frequently the death of a loved one seems to be a predictor for homelessness.

I was well, but my mother passed away. After her death, people took care of me at home, but there was no one to speak to me with love.

My mother passed away while giving birth to me, my father took care of me, then passed away during my childhood, I don’t have any siblings.

Ms D self-immolated beside her mother’s grave, unable to live a life without the love, concern, tenderness and intimacy that she had provided. This spelt a particularly tragic end to one person’s life in The Banyan timeline, in some ways emphasizing the importance of the family and all that it represented.
The process of personal recovery

While the breakdown of the family precipitates the downward drift, aspirations to form social connections and restore some semblance of a family seem to define a common path to recovery. This serves both as a motivation to stay well, alive and to persevere. Besides a sense of belonging and comfort, this also seems to enhance a person’s sense of identity and meaning in life.

My biggest strength is that in all these problems, I have never ever wanted to die. I feel like I should live. I know I have a disease and I’m taking medicines – I should live for everyone.

I want to see my children grow up and get married.

I want to make my children study and bring them up to be very successful.

I want to save money with my husband and build a house and a secure future.

Whenever I thought I couldn’t go on, I thought of my son, and knew that suicide wasn’t the answer – I had to live for him.

Recovery means different things to different people. To some, it signifies the return to ‘normality’ while for others it could mean living with a disability and yet enjoying many entitlements and thus a good quality of life. The need to marry, find love, be productive, find meaning, do good, have children, experience hope, dream dreams, enjoy one’s mother’s cooking, etc. often represent a new start and thus stands for recovery. Personal recovery is always value-centred, oriented towards choice, and awakens a person’s power and encourages personal responsibility. It is focused on the person, promotes strengths, hopes and dreams and fosters empowerment. Its goals are pro-health, choice, transformation and control (Slade 2009).

Let us next explore the methods The Banyan used to either reintegrate a person with her family or when that was impossible to use available resources and opportunities to build an alternative family and home and promote diverse notions of personal recovery and well-being.
Integration into the family environment

I want to live my life, back home with my family. But I know that I can always rely on my family.

The primary goal of recovery was for clients to resume a productive and functional life in their own homes that most of them missed deeply and desired to return to. The Banyan achieved significant success in this area, reintegrating close to 1500 persons across the country. This is indicative of the 'lack of access' theory – that these women had wandered away owing to poverty and inadequate responses from the health system, not because they had been abandoned. Figure 1 below shows the spread of clients who have been reintegrated after accessing The Banyan’s mental health care services.

Figure 1: Map showing reintegration of persons who had left The Banyan

![Map showing reintegration of persons who had left The Banyan](image)

A total of 1500 persons have been reintegrated, of whom 1120 are marked on the map. There are 214 whose addresses are unknown, and 166 whose status is unknown (files missing). There are also exceptions to the rule. A significant number of clients opted not to return for one reason or another – either that the family was the primary source of distress or that they had not recovered enough to live entirely without The Banyan’s support. Table 1
shows the total number of persons who have used The Banyan’s Transit Care Centre services as of 5 August 2014.

**Table 1: Individuals who have been attended by The Banyan’s Transit Care Centre (TCC) since its inception**

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of persons who have used the services at The Banyan’s TCC</td>
<td>1709</td>
</tr>
<tr>
<td>(up to 5 August 2014)</td>
<td></td>
</tr>
<tr>
<td>Total number reintegrated at TCC</td>
<td>1500</td>
</tr>
<tr>
<td>Total number of persons who have been reintegrated with current status unknown</td>
<td>166</td>
</tr>
<tr>
<td>Number of persons who passed away while living at TCC</td>
<td>60</td>
</tr>
<tr>
<td>Number of clients who left TCC on their own account</td>
<td>36</td>
</tr>
<tr>
<td>Current residents at TCC</td>
<td>113</td>
</tr>
</tbody>
</table>

Table 1 indicates that of 1709 persons who had stayed at The Banyan’s TCC, 1500 returned to their original home. However, for those who had long term-needs, based on nature of the enduring problem, abandonment or disinclination to return home, other options had to be developed.

Often the decision to return, live independently or with some support from The Banyan depended on many of the factors discussed above, including individual abilities. Often the contact with the organization and knowing that it was ‘looking out’ helped. Data from The Banyan’s department of Monitoring and Evaluation indicate that approximately 12% of persons who entered The Banyan’s system of care require additional support in supporting their long-term care needs.

**Alternative, inclusive living options for persons with long-term needs**

Using the family as the basic structure that most yearned for and its perceived attributes in this therapeutic context as elements that helped to foster trust, kinship and an enhanced quality of life, The Banyan devised different living options in terms of the physical and social structure for each of these groups. Ranging from small, community-based houses for a group pursuing independent living, to shared housing facilities for persons with graded levels of disability with a team leader (head of household) and a health/life coach to a clustered group home, somewhat on the lines of a clubhouse, where clients resided voluntarily and determined the direction of the space in collaboration with staff members. In each of these options, care was taken to encourage social mobility, socializing (with neighbours in the community), family outings (to the beach or the movies), family problem solving (money and
child-related issues, also matters concerning marriage and love), all in an attempt to build pride in and ownership of their new home.

**Integrative, user-centred approaches**

Today, Ms M (whose case was discussed earlier) works for a living and draws salaries from various sources. One is a government scheme, the Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGS), where she engages in physically strenuous activity such as digging and cleaning, and the other is as a house help in the community in which she lives.

*I had suffered great loss. Help came from the right source and in a way I could bear to move beyond my painful past and experience. I felt wanted. I felt accepted. I had a group of friends with whom I could celebrate small joys, enjoy an evening of fun at the movies etc. Isn’t that what a family does? I will not go home. I have found work, relationships that matter and a life here. I look forward to my birthday when we cut a cake and I get a gift. (She flashes a broad grin.) And every Christmas, when I’m Christmas Thatha (Santa Claus).*

Ms M lives in The Banyan’s Alternate and Inclusive Living Programme in a small house rented with a few friends, by the beach in Perur, a village in Kanchipuram District in the state of Tamil Nadu. Her day involves all the normal chores – cleaning, some cooking, bathing, preparing herself for work, music in the evenings, some television, maybe a walk to the beach and chat with friends. Her life is not perfect – she still experiences distress most nights. But she has learnt to cope well and enjoys her productivity and independence. She contributes to the economy of the local community through her personal, financial and social transactions; her social mobility is unaffected and she aspires to a life that she has charted out for herself.

Ms M is an example, like 80 other residents who have opted to live in the variations of this facility described above, that the downward spiral or trend can be stalled and reversed. Her confidence and grit to look forward to life are testimony to this. Over the years, she learnt to cope with her distress (when she relives her moments of hunger, abandonment and assault) and demonstrate determination and resilience, partly through because of her own personality and partly because of the ‘strength and family like environment that The Banyan has been able to provide her with.’
Ms T, on the other hand accessed multiple services at The Banyan, and found peace and a happy life in many of these facilities, but looking for deeper meaning and contentment she hoped to reunite with her son and define her identity as a mother, householder and counsellor. Ms T had experienced many forms of distress in her life, including being sexually abused by a family member, mental ill health, homelessness and the loss of her child while she was living on the street. After coming to The Banyan, she showed quick signs of recovery, and was soon working in the housekeeping department. When The Banyan’s first self-help group was formed at the TCC, she was elected leader, owing to her entrepreneurial spirit and natural leadership style. The group soon moved to the clustered group homes in a rural area (Kovalam) and subsequently to independent homes in the community. Although she was autonomous, she clearly felt the urge to reunite with her son and return to familiar surroundings and build a home for herself, and she soon went back to the Nilgiris District in Tamil Nadu. She continued to be in touch with The Banyan, both in periods of good health and when she faced setbacks. She was also awarded a BALM fellowship\(^1\) for her work at an NGO mental health outpatient clinic in the Nilgiris. She has counselled more than 150 people to date and follows up on their wellbeing through home visits and telephone calls, enjoying using her own story and insights in helping others to recover.

While her mother, brothers and members of The Banyan provide her with support that she values, her primary bond is that with her child – this helps her to maintain hope aspire, feel well and find her family and home.

These results, observations and discussions lead us to the most critical question in this context: what are the values and traits that individuals yearn for that are therapeutic and represent a family?

**What does a family symbolize?**

For many people a family symbolizes blood ties and consistent unconditional support and fosters a sense of belonging. It also connotes a sense of commitment and responsibility that results in continued engagement. Even when spurned, many users longed to return to what they thought and knew to be their only natural ally and constant in life:

*I love The Banyan and all of you, but you cannot be my family. Your kindness made me feel better, but I will be happy only when I’m home, even if my family doesn’t love me or rejects me.*

Deeper exploration of clients’ lives revealed a natural, known and familiar environment that was neither sterile nor clinical, loosely structured and easy in its flow of conversations, transactions and emotions, that allowed for differences – sometimes accepting them and
other times condemning them – that also balanced love with encouragement, motivation, cajoling, coercion and firmness for the greater good, promoted independence, stimulated and integrated many aspects of living – all built on a foundation of connectedness, responsibility and trust. If they could return to this state, they sought to do so. When this was not possible they scouted for other options – from leaving the organization, finding recovery, meaning and a life of their own outside The Banyan to availing themselves of other services that were more representative of a home – not too organized and open to real-world dynamics. Based on these guiding principles and expressed needs, The Banyan conceptualized a framework of values that its multi-disciplinary team observes (highlighted in figure 2 below).

**Mimicking the family**

Social networks are described as a nexus of interpersonal ties consisting of family, friends, or other individuals who provide some type of support that ‘leads one to believe that he or she is cared for, loved, valued, and belongs to a network with mutual obligations’ (Milardo 1988:13, in Pernice-Duca 2010: 13).

Having established the importance of the family and the notions of emotional security and commitment that it represents, we now seek to transfer this knowledge to the care of persons with mental illness. Since mental ill health and homelessness and associated long-term needs are growing and critical problems, how can organizations and therapists or care mobilizers, case managers and social workers learn from this expressed need and imbibe attributes of what the family signifies into care systems, processes and protocols. Using The Banyan’s value framework (Figure 2, above) in care, we examine critical values and strategies that represent family-like structures and emotions.

**Figure 2: Key values in the construct of the family as conceptualized by The Banyan**
Initially, the co-founders of The Banyan lived alongside the people that they cared for, striking a close and unique bond that moved beyond the technical and therapeutic realm of establishing a rapport of something more personal and intimate that represented oneness, and was critical in determining the future direction of value development that every mental health professional was to assimilate. Cooking the same food for everyone and eating together, decorating the house for functions, welcoming guests, celebrating festivals, mourning the loss of a departed member in culturally relevant and accepted ways, visiting the doctor and hospital and staying nights if a client was admitted to an external hospital all denoted commitment and concern, besides affection.

‘Periamma and Chinamma, (small and big mother) – they are my favourite people’ said Ms I, who was affected with intellectual disability, as she neared the end of her life owing to having contracted drug-resistant tuberculosis. Having lived at The Banyan for close to 15 years, she felt the need to be pampered as she would have been at home, which in her case was non-existent. The only home she experienced was The Banyan. She expected gifts on her birthday, expected the founders to give her away in marriage and also wished to have children.

The small premises that The Banyan began with resembled a house in a residential area. Owing to increased demand and the magnitude of the problem, it soon evolved into a larger institution with increased capacity. With this development of a new identity, from a home to a hospital, there was a need to restructure systems and modify processes, as well as management-related investments in maintaining quality, developing protocols etc. Also, unlike in the infancy stages, the organization now had to approach concerns in a more standardized manner. The home-like feel was compromised both on account of this transition and growing number of users, until the quality in terms of basic amenities such as hygiene and also affection deteriorated. In this learning phase, The Banyan developed the ability to balance the two, realizing the need to continue to mimic the family-based approach and values from the old, intimate house and life and yet to standardize processes such that the reach and impact could grow. A mix of effective systems and values were gradually developed which included fostering therapeutic alliances, building smaller non-institutional communities within the facility, ensuring checks and balances in terms of rights, basic care and legal compliance and yet as far as possible and manageable, retaining the informal, fun and deep connectedness between volunteers, the clinical team, the clients and the founders. A lot of effort is devoted to training new staff in this way of caring, using clients’ narratives and organizational memory as critical tools.

As the organization grew, the time with clients was compromised to respond to organizational challenges including resource mobilization. Building strong second-tier leadership and an organizational culture that draws from its core values and institutionalizes them to the extent possible in its staff guidelines and training programmes is the only way to
ensure that a large number of people respond in a uniform fashion as an organization grows. This transition has to be carefully handled and can often fail.

**Human resources – capability development**

Extending and implanting the discussion of values into the discourse on human resources, the researchers interviewed a cross-section of The Banyan’s team to understand the personal attributes that they found essential in the development and practice of high quality care protocols.

**Responsibility** – *Because I felt responsible, I felt committed. Not in a burdensome manner, but in a light, connected sort of way. It was the connectedness that drove the responsibility primarily, but it wouldn’t be wrong to say that the reverse may also have been true sometimes. Either way, this ensures deep engagement, constant discovery of creative methods to beat distress and stuckness and the development of innovative methods that addresses unique needs of both the person I serve and myself.* (Senior Leader/Psychiatric Social Worker)

**Unity** – *I don’t discriminate between clients, I give equal respect to everyone.* (Psychiatric Social Worker)

**Understanding, compromise** – *Whenever there are problems in the team or with clients, I try to compromise with them. You have to adjust and live in any family. With clients who say no to coming to the outpatient clinic, I don’t fight with them because losing out on care will be their loss. I don’t let that happen. I adjust.* (Community Mobilizer/Life Coach)

**Loving, understanding, helpfulness** – *I am very loving towards the residents. Whatever they need, I try to provide for them. In the family, the mother is the primary provider. I play that role at The Banyan.* (Health Care Worker)

**Unconditional acceptance** – *I accept clients and friends for who they are, I don’t do anything with expecting returns.* (Psychologist)

**Love, compromise** – *I was very friendly with residents, I never called them by their name, especially those who were older, I always addressed them as Amma or Akka. They were like my family. I never allowed anyone to verbally abuse or hit clients. I used to take care of all the primary needs of clients, especially bathing, cutting their hair, removing lice etc. and more than that, I did it with joy.* (former Senior Health Care Worker at The Banyan)

**Equality** – *I became a better Mental Health Professional when I stopped thinking of myself as a Psychologist and the person as a patient. We were two individuals interacting and I started looking at the Patient’s problems as something I could have or can go through. Isn’t that empathy?* (Mental Health Professional and Researcher)
Unequivocal concern, tolerance and accepting the individuals for who they are - Import these values into a therapeutic community. By following these value systems, help the individual feel wanted, understood. Bring in a sense of openness, respect a person's dignity. A homeless person has a lot of issues with trust, given the abuse and ill treatment they have faced while on the streets. They have faced a lot of individual, social and political disintegration. Practising the above values will bring them back, help them pick up the pieces, and aid in recovery. (Senior Leader/Psychiatrist)

Bi-directional learning, friendship – After just a few sessions with clients I realised how much I had learned, and my perspective not only on being a mental health professional but also life, had changed dramatically. I soon began to think of each interaction as a conversation and a discussion to learn and adapt from, and became eager to understand more, and I think this style, evoked a sense of friendship and camaraderie (Mental Health Professional and Researcher).

In order to draw from the experience of other leaders and caregiving organizations, the research team interviewed six prominent individuals working in the mental health sector from Assam, Delhi, Madhya Pradesh, Maharashtra, Punjab and Tamil Nadu. Three were caregivers and founders of large NGOs, three had represented the sector in policy discussions, and all had concerned themselves with the proposed Mental Health Care bill 2012. Table 2 sets out the themes that emerged as important in the development of technical skills and values, summarizes key outputs and compares them to existing practices at The Banyan.

While social work, psychology and other mental health and social science practices employ standards of care, values and ethics that drive their interventions and responses, personal interpretations are often based on the practitioner’s personality, background, experiences and resulting bias. These interpretations are critical in deriving meaning from an action, value or response. While informed by knowledge and science, they are best understood when practised. That being said, developing these personal spaces and understanding deeper meanings in theory and prescribed actions by using reflective and reflexive forms of critical thinking are an essential guide in education and science. While knowledge can be gained through indirect methods, these perspectives can be built only through direct engagement, experience and/or participation.

Training professionals in complex fields such as mental health should focus on building capacity in aspects that shape a person’s ability to be creative, determined, empathetic and responsible. Continued learning and alignment with the real world as well as caregivers’ and clients’ own responses and insights become extremely important in the discourse on recovery and values. These reflections should also gain critical relevance in pedagogy and research.
<table>
<thead>
<tr>
<th>Technical expertise</th>
<th>Values</th>
<th>Examples from The Banyan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Technical expertise</td>
<td>Compassion and care</td>
<td>The Banyan has adapted to the context internationally recognized best practices to suit individual needs. The model was reviewed and audited by the National Institute of Mental Health and Neuroscience (NIMHANS), Bangalore, and the WHO. In addition, The Banyan’s sister organisation The Banyan Academy of Leadership in Mental Health was conceived to evaluate and improve The Banyan’s services.</td>
</tr>
<tr>
<td>Collaborative care</td>
<td>Optimistic attitude</td>
<td>Over the last 20 years The Banyan has fostered partnerships with academic institutes, civil society organisations, think tanks, state and national government.</td>
</tr>
<tr>
<td>Integrated care</td>
<td>Empathy</td>
<td>Multi-disciplinary team of clinicians including general physician, psychiatrist, social worker, psychologist, occupational therapist, counsellor, development practitioner.</td>
</tr>
<tr>
<td>Individualized care plans</td>
<td>Gaining perspectives by living with clients (<em>including family values</em>)</td>
<td>Each client entering The Banyan’s mental health system is aided on their journey to recovery through a meticulous planning of interventions by the clinical and social care teams.</td>
</tr>
<tr>
<td>Scientific enquiry</td>
<td>Drive to learn, improve and innovate</td>
<td>The Banyan is involved in developing innovative and sustainable mental health systems, and seeks to articulate grassroots realities in policy discussions.</td>
</tr>
<tr>
<td>Fostering therapeutic alliances and spaces</td>
<td>Promoting inclusion of various communities</td>
<td>A group therapeutic community and spiritual therapeutic community are commonly used approaches at The Banyan. In addition, the larger community engages with the organization through youth clubs and social enterprise.</td>
</tr>
</tbody>
</table>
Occupational therapy and vocational training | Creating an environment of belonging | The robust occupational therapy and vocational training departments at The Banyan provide access to several different kinds of work, based on individual choice, including housekeeping, cooking and indigenous crafts.

Providing access to choice | Promotion of dignity, equity and justice | Residents are at the centre of The Banyan’s universe. They have access to human rights, legal aid and grievance cells, and also are significantly involved in improving service provision through a unique user-led audit.

Challenges

While what is promoted is a ‘cosy feeling of closeness’, it may not always be possible to find such pure emotions among those working in the mental health and social sectors. Complete dependence on just a few individuals to drive this value in a controlled, charity-driven approach may not always be sustainable and will limit growth and scalability. There is also the possibility of fatigue among key individuals that could result in organizational breakdown or stagnation. Moreover, both the nature of mental illness and human behaviour are complex, unpredictable and dependent on many real-world variables. The potential for clients and managers to misuse such loosely structured approaches and values needs to be borne in mind. It must also be taken into account that much of life takes place in its grey spaces. Relationships and family values can similarly present their own set of challenges. It is almost always more than simply mimicking the family structure and ethos that facilitates transformation and recovery in the lives of clients. Organizational systems and many other structured and dynamic variables also contribute to achieving this goal.

Finally, just as expressed emotions can impede recovery within the family, so organizations also face this challenge.

Conclusions

While mental ill health is on the rise and persistent and enduring forms of mental illnesses continue to plague and concern the mental health sector, it is important to develop approaches that can address the diverse concerns of those who require emergency or long-term care in hospital or community settings. An important strategy emerging from clients’ expressed needs and that can assist in personal recovery seems to be the presence of a sound family – in terms both of physical space and psychological and emotional support. Drawing on the values that this represents, perhaps mimicking a family or elements of what a family constitutes can be considered as an intervention that satisfies the clients’ needs and promotes recovery in a wide range of contexts. The limitations and challenges posed by whether this is a feasible approach have to be explored further. However, currently caught in the flux between de-institutionalisation, trans-institutionalisation and institutionalisation,
many people who seek psychiatric services could experience a better quality of life if attention were paid to these values. Perhaps this is also an approach to consider as part of the discourse on the reform of mental hospitals. It may be relevant to document these processes and understand their relevance in greater detail in order to share these methods with other stakeholders as well. This approach could also be further developed into protocols or values to be used in the education and training of those aiming to work in the sector.

Endnotes

1 The BALM fellowship is a leadership and mentoring programme with a stipend awarded by The Banyan Academy of Leadership in Mental Health (BALM) to persons affected by mental health issues, who desire to work within the mental health and development space.

References

Understanding the diversity in the human rights conceptualization within the mental health discourse: voices of the Indian mental health user
Chapter 10

Human rights in the context of mental health: perspectives from service users of The Banyan in India

Abstract

Rights are universal and inherent in all human beings. In the real world, however, circumstances lead to inequitable life experiences, depriving many of justice and freedom. The human rights discourse in the context of mental health may be divided into two lobbies: one that considers agency and legal capacity and another that focuses on the right to health. With this backdrop, in this paper, we consider the perspectives of service-users of a mental health organization who have experienced homelessness or poverty. The construct of human rights, emerging from consultations with service-users, emphasizes on attainment of fundamentals – adequate food, housing and work – that are essential for survival and pursuit of wellbeing. These perspectives further posit an instrumental relationship between attaining these fundamental needs and achieving more complex personal states of agency, affiliation and control over life. We conclude that the human rights discourse in mental health must look beyond binaries and focus on addressing deprivations that represent intractable barriers for people to move from distress to a happy place.

Introduction

Many national constitutions include a range of rights that apply to all citizens, in keeping with universal declarations and conventions to which the state in question is signatory. These include protective rights, such as property rights, and those that promote rights, such as right to health or education. Although formally approved, in practice many of these rights have been and continue to be disregarded. This means that many citizens, especially those who suffer severe social deprivation, experience a greatly compromised quality of life. In particular, mental health continues to be largely absent in the broader framework of international development despite contributing to 7.4% of the global burden of disease (Murray et al., 2010).

The incarceration, detention, torture and gross neglect of people who suffer mental illness are frequently highlighted in the media as well as in academic publications and international agency reports. Violations include the loss of decision-making power, maltreatment by
families and communities and being stripped of community and political participation. Paul Farmer (2006) highlights the role of ‘structural violence’ in the form of poverty, socio-economic inequality, discrimination and its negative influences on health. Poverty contributes to the prevalence of psycho-social disabilities and is involved in its maintenance (Read, 2010). In response to these continuing human rights violations, the nature and priorities for the movement for mental health are set out and debated by scholars and think tanks in various settings.

The discourses on human rights in the mental health sector, while highly diverse, may be divided into two lobbies – one that emphasizes rights linked to agency and another that focuses on rights linked to health and development. In what may be seen as a legacy of the disability versus health lobbies, those aligned with disability movements typically cast the discussion in terms of the maltreatment of those who are receiving psychiatric care in hospitals and other institutions. In particular, the erosion of civil and political rights such as legal capacity and the apparent lack of legitimacy of psychiatric diagnoses are invoked to argue for the urgent need to secure rights that empower patients to make their own choices, including the choice to reject treatment (Minkowitz, 2006). Advocates for the right to health, argue for better and more accessible access to appropriate packages of care, citing the large treatment gap particularly in low- and middle-income countries (LICs and MICs) and the rising global burden of disease owing to mental disorders (Lancet, 2007). While there are nuanced opinions on both sides, there remains the basic incompatibility between advocating for the right to health versus the right to autonomy. At the same time, however, both sets of proponents call more or less uniformly for urgent large-scale reforms in institutional care and for a move towards community-based care that integrates health services and social care. The emphasis on the gains to be achieved and pathways to be followed differ in part because of how particular sub-groups of these lobbies perceive mental health – whether as a genuine disease or as a hegemonic tool of oppression conjured up by the medical community.

The voices of people in LIC and MIC contexts who are living with mental illnesses and have concurrently experienced homelessness and/or poverty are seldom heard in this discussion. Drew et al. (2011) conducted a consultative survey of 51 service-users across such contexts, with a predominantly literate sample of who people who were also exposed to or were active in the global movement on human rights and disability.

Given the largely missing voice of an ordinary service-user who comes from a highly marginalized context, the present authors set out to understand how people at the margins perceive their own human rights, how they envisage achieving these rights, and how they
frame their rights in relation to the prevalent international rights discourse on mental health. To answer these questions, this paper focuses on women living with mental illness who have experienced either homelessness or poverty, or both. The primary aim is to present the construct of human rights as perceived by a population that is at the margins of society, including the human rights movement. The secondary aim is to present alternative views to the approach and design of human rights mechanisms that emerge from the discussions with such women.

Methods

The authors undertook consultations with service-users of The Banyan, a non-profit organization based in the Indian city of Chennai, in order to understand their perspectives on what constituted human rights. Qualitative interviews were conducted with women (n=15) who have used one or more of The Banyan’s institutional services. Interviews were conducted by a team of researchers, two with master’s level training in social work (n=7), one with a post-graduate degree in international development (n=7) and one with master’s level training in psychology (n=1). This was followed up by a focus group discussion (FGD) with participants in which coded segments from the interviews were presented for purpose of discussion, analysis and interpretation.

Study location and population

This study was undertaken at The Banyan, a mental health organization in the Indian state of Tamil Nadu. Founded in 1993, The Banyan offers comprehensive clinical and social care services in both institutional and community settings to people experiencing homelessness and/or poverty. Among the institutional services are a 150-bed transitory recovery space in a hospital for women and a 30-bed open shelter for men in the urban area; and a 60-bed long-term facility styled as clustered group homes for women and a 12-bed in-patient facility for men and women in a community health centre in the rural area.

Participants were drawn from women who have as a result of homelessness or poverty and mental illness needed to use one of three facilities offered by The Banyan. We aimed to select a diverse mix of people based on their current work and living arrangements and chose those within our immediate reach who fit this profile. For this reason, purposive sampling was the main method used. The 15 women interviewed comprised those earning incentives for work within The Banyan and living in institutional settings (n=4), earning incentives for work within the organization and living in shared housing (n=4), earning through the state rural guarantee employment scheme and living in institutional settings (n=3), earning through employment and living in shared housing (n=3) and earning
incentives for work within the organization and living with their family (n=1).

**Instrument and data collection**

All the researchers who conducted the interviews used a semi-structured interview guide. Most interviews were conducted in Tamil (n=13), and a few in English. The first set of interviews was conducted over two sittings (n=7) or in a single sitting (n=7), based on the convenience of the participants. Additional information based on identifying gaps or significant probe areas through listening to audio recordings and reading of transcripts was sought through further sessions with some of the participants (n=3).

**Analysis**

Audio recordings were transcribed verbatim in Tamil or English, depending on the language in which the interview was conducted. The Tamil transcriptions were subsequently translated into English and then back translated to ensure that words retained their original meaning. Analysis of transcripts was primarily conducted using principles of thematic analysis (Green, 2006). A researcher inductively coded the transcripts, and the emerging list of codes was examined for similarities and differences, collated and categorized into themes. Coded segments were presented to selected participants (n=10) in an analysis workshop and emerging interpretations were jointly considered. Further, in keeping with the principles of qualitative analysis, multiple researchers were involved in the discussion and interpretation of the final results.

**Consent**

Verbal consent to participate in the interview was obtained prior to interviews being recorded. Written consent was subsequently registered in a consent form with each participant indicating her giving her consent with her thumbprint or signature. Participants were offered the choice to leave, withdraw or retract their consent at any time during the interview.

**Results and Discussion**

**Material and non-material definitions of well-being**

Service-users expressed rights along a continuum of needs, wants and desires. Building on the various descriptions of rights, we characterize needs as what people must have in order to live, wants as entitlements that may compromise a sense of well-being in their absence
but not necessarily in living as such, and desires as an opportunity to pursue future projects and build on existing levels of well-being while not necessarily causing an immediate deficiency in their absence. In a majority of interviews, rights were discussed in interdependent, meshed ways, with housing being discussed in the same breath as philosophy:

*Good heart, good philosophy, good nature environment. Good wind, smells. House, courtyard, a place to pray, a flowering plant, a pot, water, good heart, good people, a good bride, a good groom, children, all this is needed.* (ID2)

Rights were expressed in distinct, connected and integrated ways. Service-users conceptualized rights as being essential to living but more than that as elements that are essential for living well and flourishing. The latter were expressed in both material and non-material terms. Food, medicines, housing, clothes, work and money were broadly emphasized under material rights. Adequate facilities and amenities for living, education and health were also stressed. A majority referred to the rights to agency, equity, freedom from oppression, competence and social connections, which are non-material in character. A minority also spoke of the opportunity for growth and the fulfillment of their aspirations.

*One can work every day and keep doing work all the time. For a human being, if there is eight hours of work, eight hours of sleep, in the remaining time for about two to three hours must do something, watching television, reading a book. [Why?] for leisure, can learn about many things, we are not the only ones in this world. We can learn more about what surrounds us, we can live according to the direction [of the world].* (ID1)

In discussing emergent categories inferred from the researchers’ analytical lens, it is tempting to explore these binaries as dichotomous, much as we discussed the dichotomies between disability and health in the discourse on human rights. In contrast, Sen (1990) conceives development as substantive freedoms, which are choices people exercise to achieve ‘functionings’ that they have a reason to value – which may range from ‘elementary ones’ such as adequate nourishment, to ‘complex activities and personal states’ such as self-respect, political participation and so on. This paper therefore explores the connections between the rights expressed by service-users, the balances they posit in the process of securing such rights and the integration of seemingly opposing philosophical constructs of what living well – and therefore what such rights – mean.
Rights as fundamental needs: housing, food and livelihoods

All of the women interviewed for the purpose of this study shared a common background in experiencing extreme distress caused by being homeless. In the context of such distress, there was much emphasis at the outset in a majority of interviews on the very basic rights to housing, food and work:

*Fundamental needs have to be met – a space to live, food, clothes.* (ID7)

*Right to basic amenities in life. Right to food, right to shelter, right to income, right to work.* (ID10)

Further such basic rights were described in micro-level detail. For instance, in describing housing as a right, service-users spoke of a house with a roof that does not leak, with soap, a compound or a drinking glass for water.

*Good accommodation means that the house should be in a proper condition to protect the dweller from rain, wind, and floods the house should be proper. There should be a drinking water facility. Nearby, there should be a school where children can study, employment opportunities, shops, be in the middle of all required amenities.* (ID1)

*A house with a compound, a sink in that house, water and bathroom facility, a job of our own – if there is a job then for a house that is our own we can buy amenities for it.* (ID5)

Similarly, in talking about food as a right, some service-users detailed this through lists of ingredients:

*Rice, lentils, garlic, food, tamarind, lentils, oil. We should not say there is no food (chokes). It is a right.* (ID6)

At one level, the realization of these rights is linked to fundamentals of survival and by extension the opportunity to pursue life to the full. At another level, the attributes of these
fundamentals are highlighted to qualify what may be perceived as a right and therefore an opportunity for life, and what may not be.

Agency: connecting fundamentals to complex ‘functionings’

Descriptions of human rights in relation to the tangible necessities of life, such as food, housing, health care, work and income inherently also refer to the benefits they bring in the exercise of agency – personal expression and choice. Service-users perceived the personalizing processes of making a tangible choice as essential attributes to the fulfilment of these rights.

Food is also a human right, I would make and eat tomato rice even at home. In all rice varieties I like tomato rice the most, other kinds of rice such as chicken and others I don’t like. Even at home I would have tomato rice. At one time, when I was at Adaikalam [name withheld] made us sit in the auditorium for a question–answer, who likes what kind of food, lot of people were made to sit, they were asked to stand up and tell, at that time I said tomato rice. Even now I like tomato rice. I will eat other kinds, but tomato rice is my only favourite. Isn’t this also a right? Even now when they cook tomato rice at the PC, I am reminded of [name withheld] and that day’. (ID3)

The possession of decent housing as a material right is again linked to personal identity. The ability to decorate a house, being able to cook by oneself and eat, and to have friends and family over for social events and other such independent and interdependent activities that are made possible by having a house emerged as a key element.

Preparing food by ourselves, we can call people with similar interests, for security some ladies can be with us. I have suffered a lot in life, I prefer peaceful healthy home. (ID11)

The ability to exercise choice, to do as one wishes, that such possessions confer perhaps enables people to perceive some meaning in their lives, whereby it is not just that they exist but that their lives are enhanced through the validation of their personhood – an opportunity for exercise of competence and consequent satisfaction.
Anthony Giddens (1991) refers to the concept of ontological security as a stable mental state derived from a sense of order and continuity in one’s life, which is predicted by people’s positive experiences and therefore the ability to find meaning in their lives. Material possessions that enable non-material benefits and vice versa – living in a home with group of friends, earning money to spend at nearby shops – stand out as a significant thread in a majority of service-users’ descriptions of human rights. Having possessions and exerting their choice in such things enables service-users to exert mastery or control over their environment and living. For instance, while emphasizing the importance of money, one service-user referred to the further material gains that money may afford, but her characterization is inherently tied to the autonomy and mastery over life’s circumstances that it enables.

*If we have a house, we can live, money...With money we can buy everything, now, if there is no house, with money we can buy a house. If we have money we can create facilities in the house, water facilities, we can make the house grand, lot of facilities, for children good facilities we can create, but first we need money.... Money is important.* (ID9)

Further, consistent with service-users connecting the two categories and perceiving their integration as leading to fulfilment, although housing is described in material or tangible terms it is also perceived as fulfilling when it is combined with the quality of social connections within and beyond the home. In both the interviews and the subsequent analysis workshop, service-users stressed the need for a conflict-free harmonious social environment:

*Fridge, washing machine, small toys, dolls, children, babies, unity between husband and wife, blessings of the elderly, fridge, sofa set, dining hall, everything should be there.* (ID2)

**Social connections: the right to affiliation**

The quality of social connections stood out in all the interviews. Living in a certain kind of culture, having friends, being valued by others, social participation, a friendly neighbourhood and a conflict-free interpersonal environment found significant space in their construct of rights.

*Wear a dress like this, don’t wear a dress like that, there shouldn’t be such things. Don’t marry outside of caste, all this shouldn’t be there. Family and society should be*
with good practices. Good practices meaning, to not have bad cultures in society. (ID1)

We need a house, house, that is independent with good water facilities, people nearby should be the type to accommodate. Neighbours must be adjusting, keep good communication with them, see how they pick up their children, studies, learn from their knowledge and improve ourselves. Socializing with neighbours, taking tablets properly. Going with neighbours to functions and other such things. Neighbours are of interest because we always share, we go to collect water together, community people at that time enquire, they keep a watch. [House] must be maintained. We need money to be shared to maintain. ... At times we should invite relatives, friends.

We need a name and appreciation of four people, we should be at a big level. We cannot live without respect in the community. All rights will be spoilt. (ID11)

Social connections, or the right to affiliation, were elaborated in several dimensions. Being able to live in relation to others is one aspect, but of equal importance was the ability to be compassionate to others. Engaging in various social transactions, living in a just society and being treated with dignity and respect are central to the right to affiliation.

When I was on the street, many people would cross me and I would be paranoid and afraid of everyone. I would say ‘India is my country, all Indians are brothers and sisters’ – people would warm up and come and give me a handshake. I felt respected. Because I called them a brother or sister, we built a bond and they were willing to interact with me. (ID7)

On the one hand, service-users expressed the right to choice, individual expression and identity – while on the other hand, they linked this with right to affiliation and harmony in the social environment. When we examined coded segments of the interviews related to choice in the FGD with service-users, a corollary emerged. At the outset, a few characterized these quotes as selfish or too individualistic and therefore felt that the right to choice was untenable, while others said it was important to be able to exert choice in one’s life. This was further probed, primarily by offering a counter, since the same service-users had repeatedly brought up choice of food or the lack of it at The Banyan at several meetings with an external Human Rights Committee. From the subsequent discussion, a more
sophisticated interpretation emerged.

Choice is important. But it cannot come at the cost of others. If I say I want only tomato rice and there are 60 others to feed and one can only get the same food for everyone, I cannot insist because it is not reasonable. We have to think of the organization, others in the environment and choose so everyone benefits and no one is harmed. (ID11)

The right to choice is important and significant to living well, but such choice needs to be exercised with regard to the context and to be reasonable. Perceiving the capacities and feelings of the context and balancing personal choice within reasonable boundaries that do not adversely impinge on others is a necessary balance that service-users suggested in the exercise of choice. The capacity for independent moral insight that is derived from empathy and consequent action was presented as a nuanced and balanced exercise of the right to choice. This right is exercised through practical reason, by introspection, reflecting and resolving alternatives and then deciding how to act. Self-determination that is compassionate in essence and deliberative in its basis formed the general consensus among participants in this study, in balancing between seemingly opposite individual and collective value frameworks in human rights, in particular in relation to the right to choice.

Treatment options, choice and non-voluntary care

In this context, the debate on choice and access to care becomes particularly critical, especially in relation to the needs of homeless persons with mental health concerns. Should non-voluntary treatment be an option in the case of homeless persons with mental illness who are unable to seek care for themselves? Or does this represent an infringement of their basic freedoms, denial of their personhood and decision-making capacity? At the core of the notion of autonomy in mental health is the acceptance of the concept of illness – that the mind can occasionally be ill and therefore not necessarily a true representation of a person’s consciousness. How much of the illness is the user’s self, how much does it influence the self, or is the self an impaired ‘other’ during a period of illness? These questions do not have clear answers – at times a part of self is defined by illness, or when there is denial of the self that was evident during a period of illness and yet there also are times when despite a directive to withdraw treatment when they are not ill, many people exercise their autonomy in choosing a treatment centre when they are ill. These complexities in treatment and choice are well reflected in the following examples of feedback from service-users on their experience of treatment at The Banyan:

I am well because I took treatment. If I had not taken treatment I would have been
able to be in my house to this date. I am also able to be with my child, my family because of treatment. If I had not taken treatment I would not been able to be with my child, my family, with my mother, father. I may or may not have been in some home, that is also not something one can say, I would have been on the streets, that too for how many days can a person with mental illness stay on the streets without medication. Without medication, maybe about six months, that is all. (ID1)

I did not know the effect of my treatment while I was on it. Only in the past three years did I know the effect of the treatment and how essential it was for me. It gave me a life. It is very important. It improved my personality and my status in society. (ID7)

Yes there has been a change because I was in the dormitory system and with medication, tablets which were not so good hmm? And three four times I almost died with the tablet intake and therefore I feel I am much better now because I do not take the tablets. I work well and keep going. I did tell the doctor, when I really need medication, I will come and tell but tablets being forced on to me is unacceptable. [Interviewer- This ability to make the choice to not take tablets, do you think everyone has the choice?] I don't know but I spoke to the doctor concerned and she was good enough to accept. (ID15)

This variation in the experience of non-voluntary care and the opportunity to make choices within such a regime is indicative of The Banyan’s key learning in practicing institutional care particularly in instances where consent is a grey area. Care in the absence of explicit consent may not always be a violation of human rights. Similarly, the living conditions during a period of being homeless or otherwise may not necessarily represent choices –normative as it seems, a body that is defiled by 'maggots' is brought into focus not because it is an affront to how 'normal' others live, but because it does not necessarily represent how that person wanted to live in the first place (Kumar and Mills, 2013). Over the last 20 years, The Banyan has found itself examining voluntary and non-voluntary treatment, the philosophical ramifications of each and the benefits they present to the user. Until 2003, The Banyan's standard practice did not require court-mandated treatment orders for the homeless people that it reached out to until a fire at a facility near a faith healing centre brought regulation of institutional spaces into focus (The Hindu, 2001). The use of legal instruments relating to non-voluntary care was therefore incidental rather than by design. The organization’s current philosophical framework for voluntary and non-voluntary treatment accepts the concept of mental illness while being cautious about assigning an absolute lack of ability to exercise autonomy when a person is under the influence of illness. In essence, the organization believes that persons with mental illness are capable of exercising their choices even when they are ill but that it may not always be the case. Further, given current limitations to how much we know about mental health it may not be possible to make judgements based on normative criteria about when someone possesses the ability to
exercise choice and when they do not. Rather, an underlying value-based practice of user-centered responses must drive us in all efforts. To quote Elyn Saks from Refusing Care:

*Most people with serious mental illnesses seriously suffer. They are in pain. Not only are they distressed and disabled but they lack the ability to change by their own efforts* (Saks, 2010: 42).

The colour of one's skin or the choice of sexuality do not impose any disadvantage by themselves void of the contextual social impositions. Mental health issues, however, represent challenges even when social contexts do not contribute to any disadvantage (Burns, 2009: 21-22). It is therefore important to evaluate the necessity for non-voluntary treatment based on circumstances that may warrant such an intervention for the preservation of the individual's agency.

Since the limitations of current diagnostic and evaluation techniques are contingent on the practitioner’s abilities and value systems, there is a risk of persons being unjustly labelled and denied their liberties. The use of legal instruments in mandating non-voluntary care has been criticized heavily in libertarian lobbies (Davar, 2012). The Banyan's experience of the interface with the legal system has on the contrary led to the belief that it is precisely what may be needed to protect patients’ rights and avoid the unfair and unwarranted consequences of non-voluntary treatment and the incidence of institutionalized violations. The organization's move towards open shelters, community-based shared housing options and street-based services is in line with the understanding that voluntary treatment must be offered first, non-voluntary treatment offered next if necessary, and must be properly monitored, and that legal instruments have the potential to be used as a means to ensure and protect rights.

**Institutional and community care: transformation to a human rights paradigm**

In the discourse on mental health, community-based services are often seen in rose-tinted shades; they are pragmatic from a health perspective, while irrevocably connected to people achieving their full potential from a disability angle. However, the psychiatric hospitals are an artefact of society. Hospitals and communities share similar paternalistic values, feeding off each other. This is also true of community-based services that seek to serve the best interests of those who need mental health care but forget to incorporate any of their actual needs (Jain and Jadhav, 2009). Thus, while human rights may be violated in hospitals and closed wards, this also occurs in communities (Minas and Diatri, 2008).

An institution may refer mechanisms of social order with mediating rules for governing community living or the application of purpose of such institution. The oppressive, authoritarian application of rules that exclude and congregate specific individuals on the
basis of their characteristics severely restrict their liberty, autonomy and social living, and have resulted in institutional care to be vilified because of instances of gross abuses of human rights. Arguably, a therapeutic alliance as the basis for service delivery, user audits of service, mechanisms for service-users’ participation, non-negotiables in quality care, and treating users as change agents may be central to the premise of any service in mental health, including institutional care. As the purpose of the institution shifts from being a space to segregate and house ‘lunatics’ to providing a means for achieving autonomy, the rules within such spaces become defined in line with the aim of fostering freedom and friendships, both within and with the outside world.

The legacy of discrimination and cruelty in mental hospitals and in the community should not be forgotten. These atrocities continue today. It is critical to embark on transformative reforms in mental hospitals, by setting standards, building values and demonstrating change. Advocates of civil liberties should be credited for questioning long-term institutionalization and violations in hospitals and similar institutions. This has resulted in shorter durations of stay, the development of social care programs, and a focus on non-medical aspects. But to entirely negate the positive purpose served by hospitals and medical care detracts from a more balanced approach that several of the participants advocate – counselling, medicines, housing, health care, dialogue in treatment, voice in policy, freedom, transport, similar rights as others.

The State and accountability for rights

In keeping with the United Nations construct of human rights, interviewees cast rights in the light of everything to which they are entitled.

Government has assigned 14 fundamental rights. Freedom of speech is a right. The freedom to express – by speech, by writing. These rights are there but every human is not attaining them. The right to speech is the most important. If I have a difficulty, only when I communicate can I get that across. (ID7)

Rights were projected as entitlements on the basis of what they considered to be inherent in human nature and living well and what is guaranteed by virtue of citizenship. Referring to democracy in India and their right to vote, service-users associated accountability for rights as being vested in the government. Their characterization of human rights in relation to statehood perceived it only as a mechanism of assurance, while rights as such inhered in being human. The right to expression was discussed in several interviews and in the FGD in relation to securing rights by expressing one’s needs, raising one’s voice against violations and in ensuring that the state could be held accountable. They recognized such assurance as being enforced through processes of citizen expression, participation and activism. In
addition to conceptualizing rights as entitlements that can be claimed, they also included within this construct the ability to question and raise their voices against the violation of such rights.

Human rights means asking for rights. Basically, if I had to say, asking for basic facilities as a matter of right. I ask my son as a matter of right, study. Like that in Tamil Nadu, my needs, I speak as matter of right, because I cast my vote in the democracy. There is right to vote. Ration is a right. If they don’t give ration, I will ask, if The Banyan doesn’t give I will not ask. Now, if they don’t give rice in ration shops, I will say, at that place itself I will say, why are you doing such things? I will give a complaint, one day we will go in a group of five, write a petition and give, that they are not giving properly, we go to work and the timings don’t suit us, these kinds of complaints, if they give kerosene or if government is giving saree/veshti, if they don’t inform. (ID9)

This ability to demand rights as well as to express dissatisfaction or dissent in the case of violations was perceived as inherent in the possession of citizenship although service-users did not perceive rights as such as being grounded in citizenship. This raises the question of those who are state-less or have no citizenship. While being vested with rights by virtue of being human, what mechanisms can be used to ensure accountability in this case? Further, in states that are not democratic, what does citizenship or its lack entail? One service-user recounts an instance of something that happened when she was leader of a user support group at The Banyan:

When I was at The Banyan we called a press meeting for the right to vote, we asked in that press meeting that we need the right to vote, many people from the press had come and they put the news that people with mental illness also have the right to vote, putting out this news was a way in which our rights were protected. (ID1)

Another service-user characterized the lack of franchise as a violation of rights:

Mentally ill people and all have no rights, they can’t vote. (ID13)

The experience of disenfranchisement on account of becoming homeless and having a mental health concern is perceived as a violation. At the same time the ability to use the
media to raise awareness of having and demanding such rights is perceived as an instance when rights are protected. This indicates that while democracy and citizenship are perceived as promoting and protecting rights, human rights as such are not seen as creations of action by the state and other socio-political institutions. Rather they are seen in the context of dialogue and conscientization or awareness-raising processes that play a role in ensuring rights.

**Perceived value of law and international instruments**

Further discussing this theme in the context of laws and international instruments, participants mostly agreed that such frameworks may usefully be applied in securing rights. Almost all felt the need for laws as these made them *feel safer*, but at the same time they advocated for *exceptions to every rule* and the right to *unique responses*. Several questioned the wisdom of standardizing approaches based on the understanding and intellectual input of only a few. In this context, they referred to the rules laid down in international human rights laws and conventions as not taking into account their interpretations and insights; attributing privileges in terms of socio-economic status, place of stay and language spoken as the underlying criterion for legislative frameworks and reforms. One participant expressed her disenchantment with larger policy formulation as, *they are rich, so they can*, while many others expressed the need for representation of voices from within because *people with mental illness here are different* and *rules should relate to our context*. Participants expressed the need for *opportunities* to enable them also to participate and contribute to the formulation of policies and laws at national and international levels.

**Conclusions**

Many of the service-users echoed the ten central capabilities that Nussbaum (1997) advocates for the right to life (worth living), bodily health, bodily integrity, senses, imagination and thought, emotions, practical reason, affiliation, and control over one’s environment (Nussbaum, 1997). Reflecting, perhaps, their own experiences of deep distress and struggle for survival, the participants expounded a construct of human rights that engages primarily with issues related to the right to adequate food, housing and work – all essential for a good life and the pursuit of well-being. Once this is achieved they seek deeper meaning and social affiliations, such that they may expand their capabilities.

Values underlying human rights cannot be perceived in binaries of disability versus health – casting some as occupying the moral high ground and depicting others as ethically shallow. Rather, an overarching sense of empathy and justice should be embedded in any dialogue on human rights. Society has to make progress in its sense of ethos by embracing differences and aspiring to be harmonious and kind. These values will determine how we
care for the most marginalized.

The primary means for the realization of rights is built around participatory, comprehensive, unique and context-sensitive responses on the part of the state and society at large, and that place the user at the centre. In this context, while useful, policies and laws should reflect diverse needs and there should be efforts to create awareness about these laws. Furthermore, laws and those who enact them – from governments to advocates in civil society – need to pay attention to the fact that non-discrimination has to be demonstrated in action, not by withdrawal, but by engagement, as one participant summarized. Drawing on the recommendations of the participants of this discussion, there is a need to pay more attention to creating teams that determine and develop human rights frameworks that accommodate representations of diverse backgrounds and constituencies. Second, merely developing progressive legislation will not change the reality – basic constitutional rights continue to be denied even today. In the absence of these essentials, the foundation on which further progress and finer values sit, very little seems possible. In the discourse on mental health, options and debates have to move beyond a dichotomy between treatment versus choice or disability versus health. Both have their place.

In conclusion, as the participants summarized, human rights in the context of mental health should take an affected person from distress to a happy place. Borrowing from Amartya Sen (1999), for this form of human rights to be universally acknowledged and felt, we have to rid our society of unfreedom that deprives millions of the basic right to survive (Sen, 1999).

References

15. Sen, (see note 8) p.3.
Chapter 11

Mental illness, care, and the Bill: a simplistic interpretation

A critique of Bhargavi V Davar’s ideas of “psychosocial disabilities”, discrimination, autonomy, and informed consent (“Legal Frameworks for and against People with Psychosocial Disabilities”, EPW, 29 December 2012), two comments interrogate the essential concepts of mental illness and disability, and access to care within the legal framework of the draft Mental Health Care Bill.

The vulnerable and marginalised are often those who are the most neglected, violated and discriminated against. However, suffering is universal and does not always affect only those traditionally perceived as weak, be it the poor, elderly, homeless, persons living with a disability or a mental disorder, etc. It must be noted though, that loss of social capital undoubtedly enhances the extent of distress, relegating those who experience pain and loss as a result of their context further to the periphery. As a society, it is our duty and obligation to uphold values of justice and equity, as we promote the rights of underserved persons, keeping in mind the need to protect lives, minds, liberty and aspirations.

Bhargavi Davar (2012), in her article “Legal Frameworks for and against People with Psychosocial Disabilities”, rightly raises important issues around loss of personhood, discrimination, autonomy, involuntary commitment and poor quality of institution-based services in the mental health sector in India. However, her arguments tend to be unidimensional, inaccurate and stereotypical, thereby positing definitive solutions, even while referring to mental illness as a “complex” phenomenon. Given the nature, spread and depth of the problem, the discourse on mental health should be articulated scientifically and responsibly, even as one approaches it from different ideological slants. Reflecting on Davar’s views, the authors attempt to interrogate essential concepts of mental illness and disability, justice, rights, treatment and the proposed Mental Health Care Bill (MHCB).

Many lives, many perspectives

From the time of Bedlam, the first public “madhouse” (Burns 2006; Torrey and Miller 2001), to now, when the needs of persons with mental health issues are being addressed much
more emphatically (Murthy 2011), both perceptions about mental illness and ways of addressing the issue – the crude swirling chair or cold water baths – have fundamentally transformed, giving way to more humane and evidence-based practice that began with the advent of modern medicine. Initial narrow visioning of mental illness as a disease of the brain with its origin in genetics and biochemistry, has now broadened to include psychological and social factors. The influence of the larger ecosystem on one’s well-being, resulting in positive mental health outcomes is now clearly established (Eaton 1999; Bland, Renouf and Tullgren 2009). This integrated approach to address both severe and common mental disorders has met with a fair amount of success across the globe, regardless of the geography, ethnicity or socio-economic background (Luhrmann 2012).

Having said that, believing that we have learnt all our lessons and perfected the art of healing minds would be unrealistic. Even in these times of innovation and empiricism, there are many unanswered questions and unexplored territories. The nebulous biopsychosocial model is yet to gain shape and definite identity. The tryst between first and third generation drugs has continued for aeons now; some of the side effects are truly disruptive and despite the stress on the culture of care, violations still do take place in psychiatric practice, some visible, others subtler (Whitaker 2010).

The importance of what may be perceived as “non-traditional” approaches to care, such as befriending, community fostering, recruitment into workforce, federation into self-help groups, providing access to housing, etc., is not always part of mainstream mental health practice. Ironically, childhood trauma, existential ideologies, gender, patriarchal and paternalistic underpinnings of health and society, benign lifestyles, identity and loss, and other social costs are hardly ever considered relevant in addressing issues of distress and psychological equilibrium. While the application of medical care is essential in many disorders, social, cultural and sociological awareness, evolution and metamorphosis lend robustness to the approach. However, one can usher in this era of interrogation, inquiry and action only if one accepts the conceptual reality of mental illness within not just a legal and social, but a biological framework as well. Awareness of this dilemma and its resolution are essential to remain objective in dealing with observations and recommendations. At the crux of all interventions that one plans, this question will recur, and one sees this dilemma play out at many points in Davar’s article.

In psychiatry, the ideologies of Kraepelin, Bleuler, Freud, Jung and others, and that of Szasz (1996) and Laing stood at opposite ends of the pendulum. Elyn Saks (2007) delves in depth into this subject, analysing critically the concept of mental illness and the outcomes of civil commitment, while preserving personhood and promoting rights. This analysis presents deep insights drawn from the scholarship of law, psychology, psychiatry and lived experience. Saks’ (2002: 42) perspective on mental illness, perhaps, presents the centre of the pendulum, the balanced mid-path:
I am persuaded that a concept of mental illness is useful and necessary because I have seen what is called mental illness at close range. Most people with serious mental illnesses seriously suffer. They are in pain. Not only are they distressed and disabled but they lack the ability to change by their own efforts. They need help – often medication – and receive help when they are treated. Having a concept of mental illness probably does more good in the world than abandoning the concept, notwithstanding that the concept is fuzzy at the edges, so that some people will be wrongly stigmatised and others wrongly limited in their freedoms.

Rights, justice and dignity

Once there is clarity on the construct of the illness, there is greater acceptance, that disability caused as a consequence of the impairment precipitated by the illness results in one’s probable loss of competency temporarily. In order to fix the impairment and promote full participation in society, treatment – voluntary or involuntary – becomes essential. Lack or denial of intervention(s) would lead to further deterioration of an individual’s health and expose her to harm. In a context where informed consent may not always be achievable, the judicious move in the best interest of the individual may be to temporarily suspend the right to self-determination and opt for care and recovery.

This model promotes the well-being of an individual by arresting further deterioration and enabling her to achieve her fullest potential – a clear pathway to reclaiming the right to self-determination. Rendering justice remains at the core of this understanding, and provides legitimacy to addressing conflicting notions of rights, and an openness to be respectful of multiple and diverse realities, and not seek absolutes.

Fonk, project leader of the Innovation Network, in the context of considering transdisciplinary approaches to complex societal issues, says,

My impression of the commitment of societal organisations is that participating in interactive processes is not their core business; their mission is to lobby for particular interests... They don’t want to commit themselves to considering the future, especially if it concerns possible developments whose effects are still unclear. (Regeer et al 2009: 60)

While this was in the context of knowledge co-creation and transdisciplinary research on environment, the story in the field of mental health is no different.
In the same vein, it is also important to understand that we are all born with an inherent sense of dignity that others cannot take away or restore – neither loved ones nor custodians of human rights – and can only be safeguarded and preserved. Life events sometimes erode, scar or shake that belief, and it is only in this milieu that rights enter the picture. Placing such conversations in a realm of negativity, harshness, mistrust and dualism of “I – You” or “Us – Them” could engulf all hopes for building consensus (Frantzi 2004: 1). We believe that Davar’s differentiation of users and “liberal thinkers” on the one hand, and professionals and caregivers on the other seems judgmental. John Dewey’s notion of intelligent sympathy that propounded “objectivity and impartiality of moral knowledge” as the pillars on which resolutions of conflict could take place in a peaceful and positive environment should be brought back into today’s context of rights and activism (ibid: 6).

For a person with a debilitating mental illness, justice can be secured by propelling or nudging her to gain access to lifesaving and dignity-securing support in order to enable her to overcome her vulnerability, so she can access and enjoy her rights. Rights perform binary functions – to promote justice and equity. Without one, the other cannot exist. The central theme around the essentiality of personhood and rights is a subtle, nuanced debate and any reflection has to be carefully studied and understood.

Let us use an example to understand this perspective. Rani\textsuperscript{1} is a person affected with schizophrenia who has wandered away from her place of stay, a tribal village in a southern district in rural India, with her child in hand as a result of her untreated illness. Not realising the consequences of her action, she attempts to trade her child for some food. She wears torn clothes, has wounds on her body – a sign of abuse and being subject to harsh circumstances. In this context, application of the concepts of personhood, autonomy and rights becomes somewhat redundant in the absence of care.

Citing violation of dignity as a severe form of degradation at par with loss of autonomy, Saks (2002: 55) advocates the following clauses that “justify differential treatment”: “serious impairment, transformation into ‘a different person’ (loss of characteristic state of mind) and, in certain circumstances, amenability to treatment”. Like in Rani’s case where, when well, she felt the choices that she had made (to be on the streets, in the nude, with her child) were like the actions of “another person”. Saks (ibid: 61) goes on to add that severe disability or distress would have to be “documented in measurable ways” and that there should “be a risk of further detrimental consequences, such as alienating colleagues, losing one’s job, spending much money, becoming homeless, or becoming chronically severely ill”. She does add that commitment should take place only if the person in distress does not have reliable family or friends who can care for her outside of a structured, closed institution or hospital.
Ideally if Rani’s well-being was the focus, then that of her child would assume greater significance. The child’s right to life would be as important as freedom, autonomy and choice for Rani. How, then, can one bifurcate rights and view Rani’s rights as devoid of any co-mingling with the child’s? Similar crossovers take place between the rights of elderly caregivers and users, and adolescent children and parents; how can one deem one as more important than the other?

Davar, in her article, quotes clean-ups in the city of Chennai that aimed to be “beggar free” and refers to social workers attempting to “catch” people with a mental illness to lock them up. As long as discriminatory laws that criminalise peoples’ lives and livelihoods exist, the tendency to custodialise the poor and needy and the attempts to cleanse cities of differences and unorthodoxies will exist. However, law, policy, advocacy and the citizen’s social consciousness should be used to sieve the good from the rest. It is here that advocates have to play a role and brace themselves for a tough and long battle. However, it is important not to attribute motives based on semantics, conditioning and quick judgments, but on analysis informed by domain knowledge, context and cultural understanding of the issues.

Institutions and care in the community

Symbolism and metaphors assume typical shapes in our lives. Somehow, institutions are vilified irrespective of their chequered pasts because of the difficult functions they were to perform, while the “community”, which often reeks of callousness, has been overestimated and deified. Maybe we begin to open up to the thought of hospitals as communities and of community itself as an institution? There is no taking away from the fact that people will need emergency care in hospitals and in rehabilitation centres at different points in time. One cannot estimate accurately the numbers that we may have to cater to, what with the increase of the elderly, dependent users and caregivers, an area of concern that we suspect will soon grow to be an issue of looming importance (MSJE 2011). Undoubtedly, existing mental hospitals, beggars’ homes or jails are inadequate and need a major overhaul, which with intent, skills and leadership has been shown to be possible in some state-run mental hospitals and civil society organisations.

Not just Rani, there are numerous others who have found their way into The Banyan² in wounded, maggot-infested, battered conditions. E Fuller Torrey, author of Surviving Schizophrenia (1983) and director of the Treatment Advocacy Centre, and a caregiver himself, refers to the devastating conditions of homeless women in the United States after the period of deinstitutionalisation and cites the predicament of women with schizophrenia who, according to a study, suffer much more dire consequences as a result of their impaired thinking and are victims of rape often: “To protect themselves from attack homeless women
have been known to wear 10 pairs of panty hose at once and bundle themselves in layers of clothing” (Torrey 1996: 21).

Pete Earley, a journalist and caregiver, writes about the fight for access to care for his son in his book *Crazy: A Father’s Search Through America’s Mental Health Madness*, and describes the shift of people from hospitals to jails through the activation of the criminal justice system – the only hope for psychiatric care and protection. Below is an extract from the book, where he comments on another user’s ill health.

...there was nothing Dr P could do legally but wait until G became so despondent from being locked in a cell all day that he hurled himself against its walls, attacked an officer, or miraculously agreed to begin taking his pills. (Earley 2007: 87)

**Outcomes of involuntary care**

Ruchita Shah and Debasish Basu (2010) review coercion in psychiatric care from a global and Indian perspective, and highlight the ethical principles that drive professional care: beneficence, non-maleficence, justice and respect for autonomy. Like Saks, they point out the conflict that these principles are in with each other, especially in a mental health context. Katsakou and Priebe (2006: 232) showcase positive outcomes and yet remain guarded on generalisations: “On average, involuntarily admitted patients show clinical improvement and, at follow ups, view their admission and treatment rather positively.” However, a substantial number retrospectively were dissatisfied and felt the admission was not beneficial or justified. This is reason enough to research the reasons more thoroughly.

A study by Balagopal and Abraham (2010) that mapped care practices of reintegrated homeless clients of The Banyan indicated encouraging outcomes in the context of decreased homelessness, improved social networks and absence of severe disability. Furthermore, a majority returned to access aftercare services from the same service provider, indicating satisfaction and trust. Another case study (Ravikanth 2012) of The Banyan-supported self-help groups (of homeless women with a psychosocial disability), in relation to group and individual functions and their implications, indicates the presence of hope, aspiration and happiness – all traits that point in the direction of a timely and purposeful intervention.

There are exceptions to this rule; voices of dissent and dissatisfaction are picked up through internal social audits and rapid surveys conducted to improve the quality of services at The Banyan. Living with strangers, stigma, the feeling of losing control and protocolisation of life are some of the themes that underlie the disillusionment. Institutionalisation, of course, builds dependence, and if not offered in the right manner and for the right period of time, could lead to a further loss of self-preservation skills and promote fragility.
The Mental Health Care Bill

In this context of need, diversity, rights and the Indian sociocultural context, the MHCB is sensitively nuanced and advocates a balanced approach in responding to real-world needs, focusing on alleviating suffering, solving problems and ensuring reforms and justice, even as the user is placed at the centre of the legislation. However, Davar doubts the impact of the MHCB, using the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) – indeed a progressive, welcome and essential thrust in the right direction – almost as a threat, without realising that the MHCB is, in every way, in conformity with the spirit of the UNCRPD.

The most redeeming feature of the bill is the accountability that it places on the state and the public health system to deliver a spectrum of services that it considers essential to well-being, including provision of medicines and rehabilitative services. As of now, the District Mental Health Programme is operational in only 123 of the 640 districts, leaving the other regions underserviced (WHO 2011). If this Act is tabled in Parliament, the government will be responsible for ensuring full coverage. In a country like India, where access to healthcare is poor and out-of-pocket spending is high, spiralling the person into further poverty, this comes as much-needed relief (Patel, Lund, Hatherill et al 2010; Mahal, Debroy and Bhandari 2010).

The World Report on Disability (WHO and WB 2011), making a correlation between poverty and disability, states that the poorest in the world are persons with disabilities. Decrease in poverty levels, owing to easier access, could thus mean a consequential decrease in social disability. Besides direct health benefits, these will also trigger a ripple effect of indirect social benefits, including an attitudinal shift in how a user will approach the public health system and how communities will view mental illness.

The key issue that plagues the mental health sector is poor implementation and delivery, and acute lack of professionals and caregivers. This bill makes it mandatory that the government prepare itself for this task by “planning, developing and implementing education and training programmes in collaboration with institutions of higher education and training” (MoHFW 2012: Chapter VI, Section 31(1)).

The bill also focuses on investment into stigma and suicide reduction. In fact, the insertion of the suicide clause – “Notwithstanding anything contained in the Indian Penal Code or the Code of Criminal Procedure 1973, any person who attempts to commit suicide shall ordinarily be presumed, unless proved otherwise, to have mental illness and not be subject to any investigation or prosecution” (ibid: Chapter XVI, Section 124(1)) – helps decriminalise
the act and encourage those in need of counselling and related support to access it without fear or shame.

The right to live in the community is promoted actively as the user is encouraged not to be “segregated from society; and not continue to remain in a mental health establishment merely because he does not have a family or is not accepted by his family or is homeless or due to absence of community based facilities” (ibid: Chapter V, Section 19). This challenges the system and will hopefully encourage creative thinking and development of user friendly options for the multiple needs experienced by users and caregivers.

Davar refers to the MHCB as having done away with any kind of judicial intervention on the constitutional question of admission and discharge, leaving it in the hands of non-state actors. This is incorrect. Besides the State Mental Health Authority (SMHA) and the Central Mental Health Authority (CMHA), the Mental Health Review Commission (MHRC) and district boards of the MHRC have been constituted for this purpose. These are headed by a district judge and are meant to function like a tribunal, with representation from users, caregivers and civil society. If a judgment passed by the MHRC is not found satisfactory, the user/affected party can appeal to the high court.

The user, for the first time, will have the right to advance directives (AD), a legal document drawn up when the user is well, on the treatment protocols that s/he would like followed, and to a nominated representative (NR) to facilitate him/her in supported decision-making during periods of ill health or crisis.

All involuntary commitments in an extra ordinary situation have to be requested by an NR. In the case of homeless persons, the state or a state-appointed party would serve as the NR. If this is not acceptable to the user, s/he has the right to appeal for discharge at any point of time.

Positive state involvement

The process of the drafting of the bill was one of the few positive experiences that we have had in interacting with the state as it rightly opened its doors and ears to a multitude of persons from diverse backgrounds. This was a pleasant change from the clannish, intellectual conversations that a select urban, English speaking elite or typical activists have on issues of national significance. The Ministry of Health and Family Welfare has also worked on a Mental Health Policy (MHP) that aspires to be pro-poor and pro-rights. The MHP aims to take stock of the complexity of the problem, consolidate findings, assess needs, fill gaps, develop programmes and sketch systemic responses, compassionately and strategically, to the many deficits in care that we face today. This is work in progress, and will again engage stakeholder participation before the final draft is submitted for approval.
If the MHP comes to fruition, many lives will be touched, but the most significant impact will be on the lives of the rural underserviced – the 68.84% who seek similar services and care, but are left with no option but to suffer in silence (Chandramouli 2011). While there is a huge gap between macro policies and micro realities, and an equally significant distance between intent, policy and implementation, we are at least beginning to look in the right direction. India’s mooting the call for convergence between the social and health sectors at the 65th World Health Assembly in Geneva is an indication of what the policy will suggest and entail.

**Conclusions**

While paternalism, power monopolies, rights negotiations, insensitivity and intolerance have to be fought, truth must also be told. Psychiatric care, in many cases, is all that people have to cling on to sanity, life and hope. As a society and people, we like to belong. We like normal. Depending on our orientation, circumstances, exposure and value systems, and our innate Darwinian attributes and genes, we are intimidating, hostile, apathetic or empathetic to people perceived as different.

Locating treatment in medicine and finding a label that classifies symptoms as a medical ailment offers much solace. However, a few consider the idea of being slapped with a clinical diagnosis for their sadness, exalted state or visions revolting. Many improve dramatically with treatment and care, and with every success story, stigma decreases, health pathways improve, lives are saved and dignity preserved. However, many mental hospitals still carry attitudes of the dark years, perpetuating a culture of cells, isolation and intolerance.

To get to a common page of understanding and not be fanatical and closed in our understanding or approaches will be essential to all future representation of the holistic rights of persons with mental illness. We live in the world on the premise that we are co-dependent on each other. If that is the sort of symbiotic connection that helps us build a sense of faith and oneness in humanity, why should it be any different as we set out on a common goal of caring for persons with psychosocial disabilities?

**Notes**

1. A client of The Banyan who wishes to share her story of travel from the centre to the margins, and back.
2. The Banyan’s work with invisible people helped it design special services and provide tools for a new life wherever possible. The philosophy driving The Banyan is to catalyse
users into finding their own path to fulfilment – understanding that everyone is unique and has individual needs, aspirations and capacities.

References

1. ‘Vizhudugal and Thulir’ in Relation to Group and Individual Functions – Their Implications”, The Banyan Academy of Leadership in Mental Health, unpublished, available at www.balm.in
2. (Berkeley: Barnes and Noble).
22. MSJE (2011): National Policy for Senior Citizens, Ministry of Social Justice and Empowerment,
35. WHO and World Bank (2011) World Report on Disability, World Health Organisation and World Bank,
Part 4

Aligning strategies with diverse sectors and stakeholders: the role of policy, responsible business and education
Comment on ‘The Mental Health Act 1987: Quo Vadimus?’

Pratima Murthy has given an accurate summary of discussions, over the past several decades, in the field of mental health legislation and public policy (Murthy, 2010). As she indicates, until recently, the mental health sector was marked by lethargy and lack of commitment. Following the initiation of the United Nations Convention on the Rights of Persons with Disabilities, which India has both signed and ratified, we are now speaking a rights-based language in the current process of amendments to the Mental Health Act (MHA), 1987. It is essential that these rights be suitably represented, to facilitate the provision of optimal mental health services in India.

Pro-poor legislation

Almost half of India’s population lives below the poverty line (Gupta, 2009), with development taking place in a skewed manner. Further there is a rural-urban divide in all services. In this situation, many people face major barriers in accessing mental healthcare. Not only is the absence of service a hindrance, but the absence of an informed consumer movement weakens the spirit of community activism that should hold the State accountable for the delivery of what is a constitutional right of every Indian - the right to health and healthcare. The very nature of mental illness further complicates the behaviour of clients, and caregivers, and often influences health-seeking patterns. In developed nations, people are entitled by law to healthcare, and insurance protects them from out-of-pocket expenditure. Such facilities do not exist in India’s healthcare system (Gupta, 2009). The draft amendments focus on this issue and attempt to bring policy and legislation to view mental healthcare as a basic right.

Mental health policy revamp

The process of drafting amendments should be based on an analysis of the national mental health scenario. The amendments should address the gaps in the existing system and also lay the ground for a policy, based on the lessons learned from the past. As is noted in the
commentary, the two activities address challenges that both the sector and people with mental health issues face. Given the high incidence and prevalence of mental illness and disability, this process needs no justification (Shah et al., 2005). The strengthened National Mental Health Programme, as part of the 11th Five Year Plan, not only allocated an increased budget of Rs 1,000 crore, but also aimed to “decentralise the Programme and synchronize with National Rural Health Mission” (Government of India, 2010). However, it is debatable whether this led to any change or had any impact at the grassroots level, resulting in overall improvement of the quality of life of clients and their caregivers. To date only 123 of 626 districts are covered by the District Mental Health Programme (DMHP) and the status of these 123 districts is not entirely satisfactory. It is against this background that we must examine previous legislation and policy and evaluate their effectiveness or competencies.

The relation between poverty and ill health, mental health included, has long been discussed. However, the limited impact of the DMHP as it exists today cannot be attributed to poverty alone. We need to address the need for community services and culturally relevant, inclusive forms of treatment and therapy (Jain and Jadhav, 2008). We need better planned and strategised forms of training that are not entirely medicalised, for both mental health professionals and other management and administrative professionals. We also need additional human resources so that community or health workers are not overburdened. And while many speak of a failed DMHP, states like Kerala seem to have something better to showcase (WHO, 2008) and we should learn from these success stories.

Emergency services and hospitalisation will remain an important part of mental healthcare. The question is not of shutting down mental healthcare institutions but of whether these archaic structures can be made more humane and liveable. The ill effects of the process of unplanned “deinstitutionalisation” in the United States have been captured by Pete Earley, a journalist and a caregiver himself, in his book Crazy: A father’s search through America’s mental health madness (Earley, 2006). Almost overnight, mental hospitals were shut down with negligible community resources to depend on. As a result, many people with severe mental disorders became homeless and would wander the streets, and many finally ended up in prisons. In fact, some of the jails during this period had specific floors assigned for those with mental health issues. Earley speaks of the difficulties of dealing with real world concerns around his son’s illness against this background. He speaks of times when he almost hoped that his son would get picked up by the police simply so he could initiate treatment which in his case would be lifesaving.

While the aim of universal access at the community level is admirable, we must ensure the basics are in place.
Human rights, mental health facilities, and involuntary commitment

The author has rightly stated that the move from being “objects of charity” and “dangerous” to being subjects with rights is a much needed change, one that took long in coming because of stigma, discrimination, and the burden of the legacy of mental illness from earlier years. The draft amendments have tried to shed the “Mental Hospital Act” feel and balance the need for emergency services and hospitalisation; while ensuring that mechanisms of checks and regulation are in place. Two provisions are particularly interesting: a client’s access to the Mental Health Review commission (MHRC) via telephone or mail, and the role of the MHRC, through which members are empowered to make unplanned visits to institutions to ensure that basic standards are maintained and the rights of its residents are safeguarded at all points (Pathare and Sagade, 2010).

Mental illness presents complex and unique scenarios. All precautions must be taken to balance the possible tensions between rights and care. The needs of clients must assume paramount importance; their care and wellbeing must be the core of the intervention. The suggestion, in Section 20 of the draft amendments, to decrease the “supported admission period” - the period for which a person can be committed to a mental health facility without his/her consent - from 90 to 30 days is welcome (Pathare and Sagade, 2010). This will work well even for homeless persons with mental health issues, who otherwise may be forgotten within the system. However, the more difficult issue of homeless people with long term care needs may have to be addressed in greater detail. Can open rehabilitation homes in the least restrictive community environment be set up for this purpose?

There is always the fear that these checks remain on paper as part of the Act. After all, not many regulatory bodies have been able to go beyond presenting reports and laying norms and guidelines to actually effect change. One way to encourage this system and create transparency is to go the public private partnership way and open one’s doors to civil society participants.

Women, children and mental health

While some attention has been paid to children with mental health issues, mental retardation has been left out of the scope of the law, as the author notes. This is a vulnerable group and often prone to abuse within custodial institutions. A detailed look may be warranted, at the environment of those referred to as minors in the draft amendments. Similarly, in the case of women, neuropsychiatric conditions are estimated to be the second highest cause of disease burden worldwide (Thara and Patel, 2001). A UNDP report indicates that 70 per cent of the poor are women (UNIFEM, 2010) and calls for special approaches to
women’s mental health. There is a need for an additional focus on women’s mental and social health.

**Convergence with other laws**

While the need for an MHA cannot be dismissed, there is also a need to engage and work in tandem with other processes, be it the Persons with Disabilities Act, the National Trust Act or the National Health Bill. As the author points out, especially in an Indian context, the family or caregiver is affected, almost as much as the person with mental illness. Benefits and welfare measures are needed, especially with the majority of people living in poor socio-economic conditions. Further, rehabilitation, while dependent on clinical and psychological interventions, also draws heavily from social processes such as inclusion in employment schemes and assistance in housing and hostel facilities.

**Conclusions**

Mental health issues have initiated extensive debate and continue to do so. Dr Murthy has rightly stated that one can neither over- nor under-medicalise mental illness. The draft amendments draw from this perspective in defining the role of mental health facilities and mental health professionals. Some out of the box thinking is needed to fine tune these definitions and lay down specific protocols, such that the roles of mental health professionals other than psychiatrists and medical practitioners are also specified.

The interests of individual groups should not override the general good, notes the author. There is a pressing need for the mental health lobby to capitalise on this process which has been much delayed and make the best of it, keeping in mind the needs of both clients and caregivers. It is the right time to engage in debate and discussion and contribute to changing the face of mental healthcare in our country.

At Banyan, we run a transit care service for homeless people with mental illness, two community mental health programmes, a long term care centre, and an independent living programme. We also have a large coalition of users/ survivors and caregivers under the fold of Amity, an activist movement, and the Banyan Academy of Leadership in Mental health, our training, research and advocacy wing.

As a service provider and a public health activist, I would like to see policy and legislation improve the lives of people at the grassroots. Access to care, the burden on the family, stigma, lack of emergency services, absence of welfare schemes and entitlements -- all these continue to plague the mental health sector, with the consequent impact on the lives of
people with mental health issues and their caregivers. A good healthcare system should be equipped to deal with the needs of the most marginalised as well, more so in the case of mental illness and related vulnerabilities.

We need to be looking at the system with fresher perspectives, not just from a human rights stand (which should be cross cutting), but from the economic and health perspective of a developing country. The concept of a mental health system is still hazily defined with options other than the typical community programmes and mental hospitals scarcely discussed. How then will rehabilitation, allied services and a recovery-based model gain momentum? Critical issues of long term care, both in the case of homeless persons and the elderly, haven’t been dealt with seriously.

This issue must receive the attention that it deserves before it turns into the next crisis. Already we have mental hospitals that house several residents for as long as 25 years. But merely emphasising the need to discharge is only solving one part of the problem. “Transinstitutionalisation” is another response which again is not a sustainable solution. There is little or no innovative thinking as a result of which there is a sense of jadedness within the system. Accountability and effectiveness haven’t been emphasised enough, and proper monitoring and evaluation is not built into the legislation or policy.

References


Chapter 13

Challenges of teaching clinically applied anthropology and cultural psychiatry in India: an evolving partnership between a UK university and an Indian NGO

Abstract
The current emphasis on Global Mental Health risks losing the focus on the local and the particular and rendering anthropological insight pertinent. A more critical examination of pedagogical methods and curricula, and of the challenges of establishing collaborative, balanced partnerships is required. Since 2006, a group of clinical anthropologists based at UCL and members of The Banyan, have been working together on an innovative series of short, annual courses on social science theory and methods applied to mental health in South Asia. A UCL/BALM3 research unit was also established in 2008 employing local researchers to conduct joint studies into mental health and its related stigma in the Indian context. Following a brief history and outline of the collaboration, this paper discusses specific challenges: institutional issues and local economics; history and power dynamics; teaching versus training; working within mixed disciplinary and “cultural” domains both in the UK and India; and the spatial and temporal challenges of supervising research across continents. The paper concludes by reflecting on the contribution this collaboration has made to knowledge flow, examining localised and culturally specific understandings of pedagogy. These insights offer potential for similar international organisations seeking to establish inclusive and effective partnerships between frequently disparate contexts.

Introduction

Teaching in a global setting provides a new focus for anthropologists within the continuing construction and development of education establishments and departments abroad (Costello and Zumla 2000; Caruana and Spurling 2006). There is no template to guide the practical negotiation of complex differences in teaching styles, pedagogical understandings and expectations, as well as working across large geographical distances. There are also historical resonances that are especially pertinent for former colonies such as India that have to be recognised and responded to, when developing new teaching projects (Ofori-Adjei and Gyapong 2006; Subedi and Daza 2008). Critiques of teaching in post-colonial
settings focus not only on the issue of language, but also the challenges of inhabiting multiple worlds and identities that require teachers, as well as learners to address what knowledge they acquire and how (Bahri 1997; Gorski 2008; Jadhav and Jain 2008; Nandy 1983; Sen 2006; Spivak 1993, 1994). In our collaboration this was a constant and ongoing process whereby structure and content were debated alongside use of terminology, its meaning and the exploration of our individual values and philosophies that arose from our varied cultural backgrounds and identities (explored below). Whilst this paper does not provide a detailed impact assessment, feedback from participants has been included to illuminate the subject matter where appropriate.

Terminology was examined not only to avoid misunderstanding, but also to define meaning within its specific context and there were occasions when “translation” was required; especially how linguistic meanings and concepts were used and understood in both settings - India and the UK. Whilst the term “psychosocial” is commonly used throughout India, “anthropology” still remains (at least outside academic institutions) associated with its historical roots as a theory-driven discipline without obvious application to local mental health problems. In India, an important component of learning and acquiring knowledge, including research, is that it has a clear practical application. This highlighted an initial disciplinary division between our two models; University College London’s (UCL) focus on a model that promotes teaching theory, and The Banyan’s need to advance the use of applied methods within a specific local context. This resulted, after acknowledgement of the needs of the setting, in a shift by UCL away from an exclusive focus on theory, to a more balanced mix of both theory and applied intervention.

The number of institutional establishments and campuses set up in the international market of education and research is expanding (Hellsten and Reid 2010). Anthropology is well situated to provide input into the development not only of academic curricula but also into the specifics of work in these new globalised academic/teaching environments. It offers a useful perspective in understanding the local challenges involved in teaching not only across disciplines but also within different cultural domains. With its emphasis on cultural specificity, this paper identifies the challenges faced in working across such cultural boundaries from the perspective of our joint collaboration

The partnership

Since 2006, UCL and The Banyan have been collaborating on the development of teaching courses in social science theory and methods, and research in relation to mental health in India. UCL as a high profile university based in London, and The Banyan with her sister organisation, BALM, an influential NGO that supports and advocates on behalf of the mentally ill, cannot necessarily be thought of as equal partners through obvious
discrepancies in size, economics and objectives. And yet, through discussions and negotiations held between individuals within each establishment, a partnership was formed that currently conducts regular teaching courses and research.

The initiative began following informal discussions between an Indian trained British based psychiatrist with a PhD in medical anthropology, and one of the co-founders of The Banyan. Both had shared a desire to bring an alternative and more inclusive engagement between the social sciences and the NGO sector in the development of improved psychiatric theory and practice in India, which still remains rooted in western rather than local texts. There was both a theoretical and clinical gap in how mental health professionals were being trained that was not fulfilled by either mainstream psychiatric training or, for that matter, cultural psychiatry (Littlewood 1990). These courses were aimed at testing how culture and mental health could be better incorporated into a more locally based, culturally sensitive curriculum, in India. These discussions led to a request to the Vice-Provost at UCL for support and funding. Seed funding was granted by the Office for International Affairs, as part of UCL’s “Grand Challenges” which called for an inter-disciplinary approach to “Global Health and Citizenship, Intercultural Interactions, and Health and Human Well Being.” Funding has also been obtained through BALM’s access to government funding, as well as supporters and philanthropists in India, including from the business, media sectors and regular fund-raising events. In 2007, a memorandum of understanding (MoU) was signed between UCL and BALM to continue both its teaching and research initiatives. The MoU was renewed for a further period of five years in 2011 with a view to develop joint post-graduate teaching and research programmes, and also involve a prominent Indian social science university.

For UCL, the opportunities to develop local links and to advance social theory and method within the field of mental health in India were inviting. The expectation was that students and researchers would conduct applied research, and also learn about the organisation and approach of this locally based NGO. More significantly, this activity was in keeping with UCL’s stated vision of global citizenship and the internationalisation of shared curricula.5

For BALM, founded in 2007 as a training, research and advocacy organisation, the aim was to increase stakeholder participation in the mental health sector through the recruitment, training and nurturing of workers who were trained in The Banyan’s specific model of care, as well as dissemination of the model both regionally and across India. Added to this was the desire to collaborate in this new endeavour to advance knowledge through an exchange of ideas, skills and experience. The unified aim was to develop and enhance this relationship, which would be mutually beneficial in terms of the aims and objectives that whilst unique were nonetheless also complementary.
As BALM was established with the specific aim of training practitioners in The Banyan’s model and to conduct research into various aspects of that model of mental health in the Indian context, the research unit subsequently brought a further collaboration between the two organisations, through funded opportunities from UCL’s Global Health Initiative. Two studies have so far been conducted to investigate mental health and stigma in India and involved local researchers who have had an opportunity to gain experience in ethnographic research methods.

Both the teaching and the research unit were established in response to a locally identified need for more grounded teaching in the social sciences and research methods that would address mental illness and marginality in India.

The themes covered by this collaborative activity include an inter-disciplinary approach to mental health dimensions of displacement, disconnection and homelessness, with a focus on the Indian sub-continent. As partners are responsible for delivery of the courses, the aim is also to generate more localised texts and culturally relevant models of practice for mental health practitioners in India – a field that continues to use western-based psychiatric models and texts to inform both theory and service delivery (Jain and Jadhav 2009).

The broad aims of the collaboration are as follows:

- To extend knowledge and build on existing theories that will generate a more inclusive approach to the study and treatment of mental illness in South Asia.
- To develop cross-continent, multidisciplinary collaborations in order to create a dynamic force for change that is inclusive, challenging and vital to the greater understanding of what constitutes “global mental health”: including ideas and experiences of suffering and well-being.
- To offer an integrated, intellectual space to address these issues through its research and teaching programme, aided by an experienced faculty that include a multi-disciplinary team of senior clinicians with social science training, and front line staff from the NGO sector.

The UCL team, comprising both mixed primary disciplines and mixed ethnicity and gender, are to some extent more familiar within the multi-cultural context of British academia and National Health Service employment. In total, there are six members of the team: four males and two females of South Asian, British and Nigerian ethnic origins. All academics have clinical qualifications: these are represented by three psychiatrists (all male, including one child psychiatrist); a male social worker; female occupational therapist; and a female intercultural psychotherapist. All of them are trained medical anthropologists/sociologists and each member has conducted either teaching and/or long-term anthropological fieldwork within the region.
The Banyan and BALM team comprises a more dynamic membership, but at its core are the co-founder of The Banyan who is also a psychiatric social worker; the director - who is a researcher and psychologist; all are female and of Indian origin, apart from a resident anthropologist of Dutch origin. There is also a large and changing group of local, trained NGO workers and there is less regular input from a sociologist, an economist, a medical doctor and a psychologist who have also been involved at various times. Also, there are closely involved members of the corporate and development sector who have been instrumental in supporting the grounding of The Banyan and continue to have a key role in its financial management and future development planning, all based in India.

Within this mixed membership (for example, in terms of ethnic background, gender and discipline), cultural, disciplinary, social and gender factors emerged and contributed to the ethos of both teams. For example, the UCL team director, from a Dalit caste background has raised contentious issues in relation to teaching caste as a topic on the courses; the mix of disciplinary backgrounds has sometimes lead to hierarchical positioning in terms of roles, both within and across both teams; the ongoing dominance of a bio-medical training has often gone unchallenged by either team; and to a lesser degree, race, gender and religion have all been raised and discussed. Open acknowledgement of these complex issues has been critical in building trust as part of the ongoing development of the partnership, (including designing subsequent teaching courses), if not necessarily their easy resolution. Tensions in relation to social, ethnic, gender and professional identities exist within and across each team, as in any institutional setting. Efforts are made to openly discuss these as a process, not only in generating more effective working relationships, but also because they are key themes within much of the course content.

What both teams share however, is their often marginal status within their own institutional and social settings. This has influenced the identification of themes and methods taught on the courses, which focus on marginality in mental health. For example, each course begins with an exercise that encourages the sharing of some more personal information by each member, led by the teaching team that relates to cultural, social, and health care interests linked to the theme of the course and how this relates to marginalisation, both within institutional settings and through personal life experiences. Participants reported that this approach helped break down barriers and encouraged more openness and was considered beneficial considering the short time scale of each course.

The partnership’s future lies in developing and refining the collaborative relationship in order to deliver informed, creative and ethically based, applied research that will generate texts and locally relevant service delivery models for the sub-continent.
Teaching: adapting pedagogical expectations

The aims of teaching short courses sited at The Banyan, was two-fold and depended on each partner’s overall objectives, namely from UCL’s point of view; to encourage a more anthropological or social science perspective on mental health in India (Mishra 2007). The Banyan’s objective was to both train (through BALM), and inform participants of their approach and model which could then be disseminated more broadly. They also aimed to provide an integrated approach to mental health care in India that is embedded within a development paradigm. As mentioned in the introduction, following initial recognition of differences in style and emphasis, overall the objectives were complementary. Initially, sessions were allotted in line with each partner’s specific aims – teaching versus training. UCL focused initially on teaching, including social science theories and The Banyan provided the applied component.

Therefore utilising the respective strengths of each team meant to some degree, dividing up roles and methods rather than a full “intermixing” as had initially been anticipated. BALM primarily trains workers in field-based methods and institutional health care practice as well as advocacy skills, whereas UCL, as stated, primarily teaches theory and encourages exploration through ideas rather than professional training. Bringing the two together required an acceptance of both our strengths and limitations, so that training and teaching became complementary and not divisive, and meant that “teaching” (seen as theory grounded), was generally lead by UCL and training (seen as practice grounded) was lead by BALM. Such “teaching” and “training” were complementary components and approaches whose combination was one of the core strengths of the courses and the collaboration as a whole.

Participant’s feedback made it clear that the application of learning was a key element that was wanted on the courses. This meant a shift away from a purely theory-based learning to an integration of theory and practice based learning through, for example, clinical case material. To avoid an overly classroom-based style, some adaptation was necessary. This meant not only using a lecture format but also, as stated previously, discussions, group work, showing films, and presentation of case studies was required on behalf of participants and teachers, as interactive sessions were introduced. Apart from this, feedback from participants also made it clear that in order to fulfil obligations to employers and funders who had supported their attendance on the course, a clear goal/practical oriented outcome was required that could be applied to their workplace setting. The training approach was a better “fit” for demonstrating this.

This has since become the mainstay of our approach but, as stated previously, it is also the case that some reformulation has taken place by both parties in the collaboration. For example, UCL now uses more applied teaching techniques and The Banyan shares its
research knowledge as part of the courses. There have also been sessions which have been jointly focused around shared interests: for example, a panel discussion involving a client of The Banyan and her family, a local healer, an NGO worker from The Banyan and cultural psychiatrists. During this session, both theoretical and applied issues were jointly raised and discussed.

The short courses

A series of short courses in the social sciences with a focus on mental health has been held yearly since 2006. The course runs for three days and is organised around specific topics, as follows:

• Basic Introduction to Cultural Psychiatry
• Mental Health and Marginality
• Encounters between Psychiatry and Medical Anthropology
• Recent Advances in Cultural Psychiatry for South Asia
• Re-thinking Psycho-social Interventions in South Asia
• Possession States in South Asia: Theoretical and Clinical Dimensions
• Distress and the Body: Anthropological and Clinical Dimensions

In terms of learning outcomes, the course objectives have included:

• gaining an overview of social science theory and method in South Asia;
• learning key concepts from medical anthropology;
• integrating social science theory with clinical practice;
• applying cultural psychiatry in practice; learning to critique through social science; methods existing theories and practices of western psychiatry;
• determining the relevance of the “folk” sector in South Asia;
• exploring of working with ‘healers’ and other non-traditional practitioners;
• examining local "idioms of distress;"
• theorizing and critiquing categories of race, caste, gender and its relationship to stigma;
• exploring issues concerning trauma and somatisation from a South Asian perspective.

These courses are aimed at students, researchers and clinicians working in South Asia, as well as external participants with an anthropological interest in the region. So far, there have been 170 participants over the six courses; mainly front-line clinicians from both the public and private sectors in India, and social science researchers including: local NGO workers, psychiatrists, psychologists, social workers, occupational therapists, ayurvedic and homeopathic practitioners, and medical anthropologists as well as teachers. Countries represented include: India, Sri Lanka, Pakistan, UK, the Netherlands, the US, Canada, Italy, Norway and Germany.
Planning the courses, with the separation of members across not only international but also national boundaries in the case of the UK, takes time. Planning for the course starts a year before it takes place and involves multiple emails, phone conversations and discussions negotiating the timetable and tasks, which increase as the course nears. As time has gone on, the majority of the work in planning has now been done in relation to formulating roles: who does what.

Prior to the start of the course, a brochure is prepared outlining course information, timetable of each day's content and sent out for each participant in attendance, including the extensive reading list. In addition, participants are sent a structured form for submitting case studies. The emphasis is on submitting cases that participants find either clinically challenging or instances where western texts are ineffective in addressing both conceptualisation and management of the presenting problems.

The reading list, selected and prepared by UCL who have better access to resources, incorporates readings from a wide range of literature from medical anthropology, social anthropology, clinical/psychological anthropology, and cultural psychiatry that is relevant to South Asia. Importantly, the UCL team make an attempt to balance the readings with local as well as western or international texts where possible. Finding suitable material that appeals to an audience that is diverse in terms of skills and experiences, is a challenge and therefore both basic and more advanced literature is included. When preparing reading lists, feedback has also been considered, which pointed to the reading list being overwhelming when first received but then it was seen as valuable for post-course reflection. It has also highlighted the lack of locally relevant texts and access issues, whereby articles are not easily available, especially in the topics under discussion on the courses, and for students on low incomes.

Therefore, creating the reading list has provided a useful resource for participants related to the themes of each course and for the partners, can assist with any potential publications in the future. In the student selection process for each course, one of the criteria states that participants must have some familiarity with the basic literature or at least have come prepared, having studied relevant readings; consequently the reading list is posted out as early as possible. Submission of local clinical cases are also requested, for discussion and reformulation through anthropological theory applied to an Indian context. Advertising begins at least six months in advance across the print and web media, and costing is according to local and international rates.
Teaching methods

The courses use a mixed methods approach, which utilises a variety of styles and is aimed at ensuring that participants are provided with varied learning experiences through techniques such as: lectures, seminars, case studies, group work, films, role play, field visits, debates and panel discussions. Peer learning is also encouraged and participants bring case studies to be worked on over the duration of the course, taken from their particular work settings. Participants reported finding the mix of theory, practical group exercises, case-based discussion, and film an effective method of learning.

Interactive teaching methods were key to the learning process and enabled misunderstandings to be clarified and discussed; this has evolved as it was realised that not only are learning styles predominantly “by rote” for many participants, but also time is limited. Considering the mixed nature of the group, early interaction encourages participants to settle quickly within a conducive atmosphere. Participants valued the ethos of reflective learning that also included group discussion and feedback sessions at the end of each days teaching. Additionally, a summary of each days teaching content was requested by participants and subsequently, and it has received favourable feedback.

The introduction session mentioned above, was not only as an ice-breaker, but also allowed a shift in pedagogical thinking and method – one that was commented on by some participants as contrasting with what was seen as the more “traditional” teaching methods in many institutions in India. Generally, our teaching has involved a mixed media approach; for example, sharing clinical case vignettes or fieldwork experiences has expanded the perspectives of both types of participant and provided effective learning opportunities that also reflect a desire to bring the two “worlds” closer together.

It has been important having a mixed audience where participants (and teachers) learn from each other not only subject matter, but also - approaches. Participants come from varied social science and clinical backgrounds, as well as different stages in their education and training. This necessitates a more imaginative use of teaching methods reflecting their different experiences and backgrounds. The approaches used are under constant review based on feedback at the end of each course, as well as the daily feedback.

Interestingly, these differences between a clinical and social science perspective has mirrored the differences in approach and attitudes more broadly within the fields of medicine and the social sciences in the country. Indeed, one of the key achievements of the courses has been the development of a dialogue between the language of social science and that of mental health in India - toward a cross-fertilisation of ideas, methods and skills. By ensuring that each session revolved around clinical case based discussions and the subsequent introduction of anthropological concepts and methods, the participants were
able to link the specialised languages of psychiatry and medical anthropology with more immediate practical dilemmas in the clinic setting. Several participants commented on the value of learning how to connect local, academic and clinical perspectives, within their own contexts.

Each course is followed by a structured post-course debrief meeting of the teaching faculty, where planning for the subsequent years’ course takes place. This also includes a re-examination of each other’s expectations in terms of the collaboration; feedback from course participants; and ways of improving and developing the collaboration more generally.

**Research**

The collaboration is concomitantly driven by a desire to extend research capacities for academics and their students locally and from UCL, through access to field sites and informants and to advance relevant research. This provides a unique opportunity not only to build local capacities but also to exchange programmes of training and education in the social sciences in relation to mental health. There are two main research objectives therefore: firstly, to enhance the capacity of local health researchers interested in the social sciences, through both training and joint research initiatives. This is aimed at developing and promoting a more culturally appropriate methodology. Secondly, to conduct new research that is of interest to both partners. Two pilot studies have been carried out so far that provided local investigators with supervised experience in conducting small research projects within the newly established research unit.

Supervision of local research assistants was an especially rewarding and important learning opportunity, for both new researchers and supervisors. To date, two collaborative studies have been undertaken within the UCL/BALM research unit: the first one, looking at stigma towards mental illness among the population in South India; and, the second one, a small ethnography of a community living project run by The Banyan (Derges et al. 2012). The latter study involved two stages and two different research assistants; both had had medical training and were interested in gaining experience of social science/anthropology methods of interviewing and ethnography, although neither had conducted similar research before. The first fieldworker-researcher was employed for a period of five months and supervised at a distance via phone and email, before a final meeting towards the end of her study. The second research assistant was introduced to the field site and some basic techniques of ethnographic participant-observation over a period of a week by one of the UCL members prior to the project beginning. Following on from this initial introduction, contact with the research site was maintained via Skype and email. There were key experiential differences between the research assistants and the supervisor: phone supervision alone was
understandably less beneficial for the first research assistant and although good data was obtained, there was less opportunity to discuss methods and issues that arose as they happened. Data obtained from the second study was qualitatively rich, mostly due to the ethnographic methods employed and it was easier to monitor progress having had this initial face-to-face introduction, which built trust. Regular Skype calls further helped develop the supervisor/researcher relationship. This interpersonal knowledge was especially important as part of the ethnography in a mental health community project. It was also highly demanding due to the complex nature of the setting, including the part-time residency among individuals suffering severe mental health problems. The supervisor stated that supervision at a distance was also a challenge in terms of technology, time limitations, distance, and lack of regular opportunities for on-site interaction.

The language of teaching

Throughout, clarification of terms was required time in order to arrive at shared understanding. Although this slowed things down, it was necessary in order to reach a similar understanding. The majority of UCL faculty have conducted fieldwork in India and are fluent in one of the several languages spoken in the country, which helped considerably in unpacking these issues. The Banyan members contributed and ensured more in depth knowledge and experience in this process.

For example, The Banyan and the UCL partners did not have shared meaning about the concept of “culture;” the UCL team had greater, although not complete, familiarity with the terms’ usage in anthropology – at least with regard to the debates about utility. Initially, there was a wrong assumption that the notion of “culture” and its relevance to teaching were equally understood by all members of the collaboration. The Banyan did not share this preoccupation with defining “culture” and teaching “about culture” unlike the UCL staff, for whom “culture” was the mainstay of teaching in anthropology. After much discussion, it was ultimately recognised that this different understanding of “culture” was about different interpretation in relation to the salience of “culture” rather than its definition. This reduced its problematic role as increasing the tension between teaching and training. The local Indian equivalent of the term “culture” was in fact reframed as “social” and encompassed more operational terms of “culture” such as poverty, rights of the mentally unwell, discrimination, and lack of access to health care.

The challenges

The partnership has gone through various stages of development and learning in relation to its different agendas:
• financing;
• the need to bring in participants for the courses;
• providing evidence of success for future funding;
• promoting an understanding of what is meant by “culture;”
• developing methodologies in “teaching” versus “training;”
• and, resolving the spatial-temporal challenges of supervision.

These key challenges have been addressed alongside progress made in planning and implementing the courses and research. In sum, the success of the courses hinged on understanding not only cross-disciplinary methods in teaching, but also cultural and geographical boundaries with their complex nuances of language and terms that had to be continuously negotiated, responded to and re-formulated by all partners. Understanding these issues proved to be an important learning opportunity for all and could not have been otherwise anticipated. For both sets of collaborators who are positioned at the margins of their respective fields, there have been challenges. For example, the position of cultural psychiatry in relation to the broader more dominant field of biological psychiatry, and the position of The Banyan with regard to the mental health sector in India that remains dominated by medicine, affects the progress of the collaboration. Planning and development are a constant source of debate in the course of seeking ongoing funding

The partnership dynamic

Historically, India as a former British colony has been influenced by a Raj-style pedagogy8. Despite a residual teaching style that remains close to its colonial roots (rote learning within a non-interactive classroom environment), progress has been made in attendance and literacy rates. Now, India competes internationally through its many world-class universities and educational/training institutes and colleges. Alongside this there is a newer influx of interested international academic institutions and researchers, eager to benefit from the “New India” and who, it is often feared will take knowledge away and use it to further their own academic careers, without benefit to local institutions (Costello and Zumla 2000). A more recent critique suggests that the “internationalisation” of education is nothing new (Pietsch 2012; Cousin 2011). Pietsch (2012) refers to the similarities between the current and the imperial system, where accreditation of degrees obtained externally was biased, as they were not universally accorded the same value as those obtained from British based universities. This meant that graduates with the same degrees obtained from universities outside Britain, faced difficulties having their qualifications recognised or accepted when applying for jobs in the UK. In the current climate of high fees and global campuses, there is an increasing risk of a widening the gap between those able to afford a western education, and the continuing domination of education systems that disseminate western theories, methodologies, nosologies and language.
International NGOs compete for presence in India today and this influences existing partnerships. For example, UCL is not the only university with which The Banyan has an MoU. It can be said that from the perspective of NGOs such as The Banyan, this kind of competition is important within a context of funding shortages. However, BALM’s primary aim is not income generation; it is to increase human resources in the mental health sector in India. The main input from these institutions therefore, is to provide greater academic rigour.

Producing and sharing new knowledge is an important aim for both partners and has been a point of negotiation in relation to ownership of data from both the short courses and the research outputs. New knowledge has been generated and shared through writing, planning new research, and developing courses. It has required trust, sensitivity and ongoing discussion of these points. For example, discussion and negotiation as to what happens to material generated through the courses or research studies, including who has access and for what purpose, has been an ongoing discussion. These issues emerged slowly through informal discussions in relation to professional experience, qualifications and possession of local knowledge. Local knowledge in particular, was understandably the most contested area – and the most prized; the belief being that The Banyan/BALM members held local knowledge and expertise, while the clinician academics held the theoretical knowledge current in the UK at present. Whilst this was partially true, it was mostly however, a “belief”, whereas in reality all partners had contributions to make in theorizing, and everyone contributed with their local expertise. Trust has been built gradually (distance being a constraining force) through both informal and formal means. Informal social gatherings during visits are an important way of getting to know each other better in a non-teaching context. More formally, it was critical to allow time for the development of the partnership, especially in understanding attitudes to ethical practice, and approaches to mental health practices. Each visit contains a scheduled, recorded meeting to discuss the collaboration and its future, which is then followed up over the ensuing year. Visits by both teams to their respective work locations have helped develop an understanding of each institution’s ethos, as well as advantages and constraints. The Banyan have been able to attend three meetings in person in London, and we maintained an ongoing contact through Skype, telephone, and email exchanges. This has facilitated the sharing of experience and expertise with regards to the courses and research. This is an area of ongoing cross-fertilisation, as ideas and understandings emerge that need to be understood and exchanged; particularly in relation to local terminologies (including defining “culture”), mental health theories, expertise and knowledge.

There is another dynamic that relates to different concepts of “time.” UCL operates within a system defined through academic structures, which divides time into portions. A Western post-capitalist economy and culture also predominantly perceive speed as equalling efficiency; therefore scheduling and operating to strict deadlines is more common. An NGO
has very different constraints based in part on economic factors ensuring its ongoing existence. This means, priorities relating to the attainment of funding have to be emphasized, including publicity and dissemination of the work, for example. There is also perhaps less emphasis on schedules and timescales in the fulfilment of objectives. It also has to be remembered that for both UCL and The Banyan/BALM, the partnership is only one aspect of their work; both teams also work clinically and in teaching and research in their respective organisations.

For Higher Education (HE) institutes in countries such as the UK, finding suitable placements for students with regards to finances and experience is a priority when considering options for studying abroad. However, there is nervousness in fully committing to teaching ventures, especially those outside an established academic institute. Due to potentially increased financial instability, NGOs may be considered high risk when it comes to investment by academic institutions.

**Economics and the challenges of funding**

Economics was perhaps the most complex and continuous area of negotiation that highlighted the differences between both institutions. On the surface, it would seem likely that a UK institution such as UCL would be able to fund the courses with relative ease. Constraints on institutional and higher education funding and fewer grant giving bodies has meant *ad hoc* and piecemeal financing of the courses. This is not due to dissatisfaction or to a lack of interest but mainly – to less money in the pot. Priority is given to evidence of the success. What are they bringing in terms of financial and academic rewards? Are Research Excellence Framework (REF) points going to result from this work, in relation to the assessment of its impact as a research output, rather than a teaching output? Initiating collaborations of this kind with international partners, especially where there are different and unequal financial constraints, takes time. In the early stages, economic risk is required without the necessary reward of an immediate research output, as collaboration needs time to fertilise and produce work that will produce a worthwhile financial benefit for the home institution.

Similarly, The Banyan and BALM also have considerable financial constraints and rely on the benevolence of philanthropists and supporters. There is now government backing through grants and The Banyan is now part of a government mental health policy group. However, in terms of a more radical creative re-thinking of mental health care in the country, NGOs such as The Banyan – let alone research and training departments like BALM, struggle to develop when there is little security in its future. UCL also finds it challenging year on year, to find financial backing to support the ongoing collaboration. The effect of this challenge has been to delay longer term planning and commitment to future research development and the courses themselves are under constant threat of being withdrawn. A further economic consequence of this relates to participant numbers. This means balancing the desire for as
many partners as possible to boost the financial remunerations, against weighing the need for courses to be small enough, so that everyone contributes and benefits. Local participants regularly struggle to obtain funding and international participants must find airfares and accommodation, which adds to the already higher fees – and many of these participants are students on limited budgets.

Conclusions

The collaboration between UCL and The Banyan began on the basis of shared teaching on short courses, aimed at a local NGO and health workers interested in the social sciences and in mental health practice development. The collaboration arose out of concerns that local pedagogies in India were still predominantly based on western texts and not inclusive of local culture. “Cultural psychiatry” is able to fill this gap with locally based theories and nosologies. Courses were also predicated on a desire to challenge recent notions of a Global Mental Health movement by providing a contextualised perspective on issues that were of more specific local relevance (McCoy et al. 2008). Later came the goal to develop a research unit that would support both local and UCL research initiatives. This has developed with an increasingly mixed audience and, whilst the original intention still remains, the courses have progressed to the point of a full programme module.

The process of connecting UCL academics with a grass roots organisation in a low-income country has meant acquiring a double consciousness or an intellectual diplopia. In doing so, these insights have been deployed within the university setting through internationalising the curricula and teaching. Recognising that cultural issues impact upon staff-student relationships and learning outcomes has led to UCL establishing a unique Cultural Consultation Service (CCS) for Staff and Students.

For The Banyan and BALM team, the collaboration has provided an alternative theoretical perspective that is more accommodating of the locally specific setting. The exchange of ideas, knowledge and experience has supported mental health care development in the country. This exploration is continuous and incomplete as yet, as the ideas and practices are being digested, expanded and incorporated. But the collaboration has indicated a path that is more inclusive of the very particular problems faced by sufferers of mental illness in India and it has only been beneficial to those involved in their care.

The current challenge is how to take the collaboration forward. Overall, there has been much re-thinking and adjustment in terms of identifying appropriate pedagogies, understanding of power dynamics, negotiations around financing and economics, and adjustment of expectations and attitudes. Lengthy discussions have taken place over the years that have developed not only teaching, but also research activities that involve
planning the future direction of the collaboration. There is still a long way to go, and the current challenges address mainly this future direction. There is a willingness to continue on the part of all collaborators, but there remain severe constraints that are mostly institutional and economic. Both involve certain risks. Some of the main risks pertain to the development of trust and others result from the uncertain funding – there is a point after which more sustainable financial support will be indispensable, and, in the current climate of cutbacks and institutional nervousness in relation to “riskier” ventures, such financial sustainability appears increasingly remote.

Endnotes

1 “Clinician Anthropologist” is defined here as anthropologists with clinical training in the field of medicine or health-related professions.
2 Mental Health Sciences Unit, University College London (UCL), and The Banyan, a Indian NGO in Chennai that supports individuals with mental health problems, including the homeless.
3 BALM: Banyan Academy of Leadership in Mental Health.
6 A full impact assessment is currently in progress.
7 Language is a topic that has been raised by participants on the short courses: the need to develop local terminologies that are inclusive of local nosologies (this refers to local indigenous classifications of illness, disorders and diseases)
8 A “raj-style pedagogy,” refers to the teacher student relationship in India, which is rooted in a skewed interpretation of pre-colonial Indian cultural pedagogy and re-enforced by alienated teachers (Gurus) of Indian psychiatry who in turn, have successfully internalised European psychiatric philosophy. As a consequence, local psychiatry including its theory and practice is culturally invalid. An oppressive and stagnant dynamic between contemporary Indian teachers and their students, further perpetuates the alienated connection between doctors and their patients; urban health planners and their rural recipients; and between public mental health service providers and users.

References


28. Cultural Consultation Service, University College London http://www.ucl.ac.uk/ccs (Retrieved 12 December 2012)
Chapter 14

Making business sense of corporate social responsibility

In recent times, corporate social responsibility (CSR) has taken centre stage as a key subject of discourse and debate amongst management practitioners and academics alike. The need for and the possibility of corporations playing an active role in tackling a plethora of issues—ranging from pollution control to tackling AIDS, from combating climate change to providing education and health care, and from poverty alleviation to gender equality—is being keenly discussed. Social reporting has become common practice, at least among large, global corporations. A few companies in India have started publishing sustainability reports in line with the Global Reporting Initiative guidelines. The term ‘the CSR movement’ has gained currency, imparting an almost missionary, reformist halo to the whole issue.

Now, therefore, may be an appropriate time to ponder over the state of CSR in India—where it is and where it should be. Such an assessment would not be very difficult had there been a single, widely-held conceptualisation of CSR, a standard set of criteria and measures based on this conceptualisation and international benchmarks for CSR in emerging economies such as India, again flowing from this conceptualisation. The issues then would mainly relate to data availability and analysis. The reality, however, is that there exist several interpretations of what the social responsibility of business is. Different assessors of firms’ social responsibility employ different evaluation yardsticks without stating the conceptual foundation from which these are derived. Often a set of criteria are subjectively chosen and firms are rated against them. What is often not seriously dealt with is the correlation between these scores and the level of social responsibility that businesses exhibit.

We propose in this paper to circumvent these problems by first developing a typology that can be used to categorise extant CSR approaches. Next, we argue the case for one of these approaches—what we call ‘Serving Society, Profitably’—as being the one consistent with the long-term interests of business as well as society. We then turn to the ground reality in India and, based on published information and our own impressions, qualitatively assess which ‘CSR types’ are prevalent in India and the extent to which the approach advocated by us is followed by Indian companies. We conclude with some reflections on the road ahead.
Social responsibility of business: a typology and critique

What is CSR? A management scholar once remarked that there are as many definitions of corporate strategy as there are writers on the subject and the same could be true in the case of CSR too. CSR has been defined, variously and at different points in time, as obeying laws and customs; as meeting societal expectations; as balancing the interests of stakeholders; as living up to the expectations of ‘society at large’; as paying heed to the ‘triple bottom line of profits, people and the planet’; and so on.

Further, it is often stressed that CSR should be an ‘integral’ part of a company’s strategy; that the question of CSR has to take in the role of business in society; and that with globalisation, the diminishing role of the state in economic activity and the increasing elimination of government subsidies, the responsibility of businesses should be extended to cover developmental issues as well. However, CSR surveys hardly touch upon the extent to which such exhortations are actually being followed by companies. To come to terms with this complex and often confusing situation, we base our analysis on what we think are the two key dimensions of social responsibility. The first relates to corporate purpose—what a firm stands for, the raison d’être of its existence. Purpose could be categorised as societal value creation or value appropriation. The second dimension has to do with the extent to which social goals are integrated into its strategy. It is measured in terms of the extent of prevalence of ‘stand-alone’ CSR activities.

Based on these two dimensions, it would be possible to place the CSR approaches of businesses into one of four quadrants as shown in Figure 1. Quadrants I and II correspond to a corporate purpose of value appropriation. While quadrant I represents an approach that includes engagement in stand-alone CSR activities, quadrant II represents an approach where a firm undertakes activities that provide some social benefits while also subserving the firm’s business goals. We have named these approaches as ‘Add-On’ and ‘Strategic Philanthropy’ respectively. Likewise, quadrants III and IV represent a corporate purpose of societal value creation. We have named the approach represented by quadrant III ‘Serving Society, Profitably’. With regard to quadrant IV, in addition to its purpose being attuned to serving society, the firm also engages in charitable activities. We call this approach ‘Icing on the Cake’, the addition of philanthropic activities to a corporate purpose which is already attuned to creating value for society.

Before we turn to the different CSR types, it should be mentioned here that our typology is based on a positive approach to social responsibility and therefore includes only what firms do in the name of CSR. It is also possible to view responsibility from the point of view of businesses desisting from certain acts. Such an approach is not uncommon and is followed by many ‘orthodox’ businesses. They focus on shareholders’ interests and operational efficiency and ‘play strictly according to the rules’. They stay away from influencing
governments, indulging in corrupt practices and violating the ethical norms of the community they operate in. The theoretical justification for such an approach to CSR has been articulated most effectively by the free economy advocate, Milton Friedman (1970). According to him, the role of business is to create goods and services that are then exchanged by mutual consent. The only responsibility of business toward society is to obey laws and ethical customs; as long as a company pays its bills, does not break the law or indulge in fraud and unethical practices, it does not ‘owe’ society anything.

Types of CSR

CSR as a separate activity
This approach treats social responsibility as something unrelated to and distinct from a firm’s purpose and strategy. The actual CSR practices can take many forms. Companies may donate to religious or charitable causes. They may provide matching donations to causes close to their employees’ hearts. They may contribute to community development by creating their own foundations or donating to other initiatives that directly support such development, notably in health, education and agriculture. They may contribute to the preservation and improvement of the physical environment. Whatever the case, when it comes to the question of the reason for a firm’s existence, it is recognised that the firm exists in order to maximise profits through value appropriation.

More often than not, value appropriators pursue CSR as an add-on because their ‘CEO’ or influential top managers subscribe to altruistic ideals in their individual capacity. They may, for instance, subscribe to the idea that ‘much is expected from those to whom much is given’. Further, shareholders of these companies may also back such spending. For instance, Goldman Sachs’ investors, on 31 March 2006, voted down a unique shareholder proposal that claimed that the Wall Street bank was misusing shareholder resources by pursuing an expensive pro-environmental agenda, with the proposal garnering less than 0.01 per cent shareholder support.

Companies pursuing CSR as an ‘add-on’ sometimes seek to justify their CSR activities in terms of a ‘business case’. The cited benefits could include social legitimacy (and therefore less governmental intervention), attraction and retention of better-qualified employees (more so when they can become involved through payroll giving, fund raising activities or community volunteering) and enhanced company and brand image.

Strategic philanthropy
This is an approach to CSR that shuns ‘pure philanthropy’ and is the one that Porter and Kramer favour. According to them, philanthropic activities can be justified only if they help improve the competitive position of a firm (2002). They cite Cisco Systems as an exemplar
this approach. This company, producing networking systems and routers, invested in an ambitious educational programme—the Cisco Networking Academy—to train computer network administrators. This improved customer experience as they now dealt with well-trained network administrators. Not only that, it also alleviated a potential constraint on its growth while providing attractive job opportunities to high school graduates.

If such interventions help improve the competitive context of whole industries, would not a firm’s competitors also benefit from such actions and negate a competitive advantage for the company? Porter and Kramer suggest five reasons why this is not likely:

1. Such actions are generally localised to a particular area and competitors are not likely to be located in the same area.
2. Competitors can be made to share the costs.
3. The company that takes the initiative is likely to be in a dominant position and reap the most benefit from such actions.
4. Free riders would not get the same image boost that the leader would get.
5. Changes to competitive context can be tailored in such a way as to bring disproportionately large benefits to the leader rather than the competitor.

Serving society, profitably
This approach corresponds to a corporate purpose of societal value creation and stand-alone CSR activities are conspicuous by their absence. This approach aligns business and social welfare. It is not as if such an approach has emerged only recently—there have always been firms pursuing such a mission implicitly. However, it is only recently that attempts have been made to explicitly state the management philosophy that guides such businesses and make this the basis of a new normative order with regard to businesses as institutions. For instance, Ghoshal, Bartlett and Moran (1999) have exhorted businesses to see themselves as value creators rather than value appropriators and to accord primacy to creating value for society, treating profits as but the means to sustaining this process of societal value creation.

To provide an example, one can cite the following excerpt from a speech by Patrick Cescau, Group Chief Executive, Unilever at the INSEAD Fontainebleau Campus, France on 25 May 2007:

...we have inherited two enduring principles which have guided our approach to doing business. The first is that the health and prosperity of our business is directly linked to the health and prosperity of the communities we serve. Lever gave substance to this belief by building a garden village for his workforce at Port Sunlight and by his determination to tackle the appalling standards of hygiene and sanitation
in late Victorian Britain. He did this by the simple mechanism of making available to millions of people good quality, low cost soap.

The second principle that has been handed down is the simple notion that a successful business is a responsible business. Or if you prefer ‘doing well and doing good’. Central to this is the idea that we can create social benefits through our brands and through the impact which our business activities have on society and, very importantly, still make a good return for our shareholders.

There is no single business model for societal value creation; many models could emerge from management practice. One such business model has been termed a strategy of value innovation or Blue Ocean Strategy (Kim and Mauborgne 2004), the key characteristics of which are as follows:

1. Value innovation strategy is customer centric (not competition centric).
2. Value innovators deal with competitors not by beating competition but by making competitors irrelevant.
3. They create ‘blue oceans’ of large uncontested market spaces by offering innovative goods/services at affordable prices.
4. Through such pricing, value innovators expand demand and reap huge sales volumes. They employ target costing to tailor costs and earn a fair margin.

By focusing on expanding demand by making goods and services available to the mass of people, value innovators serve society. By settling for a modest portion of a constantly enlarging pie, value innovators also ensure a good return for their shareholders in the long run.

Icing on the Cake
This approach corresponds to quadrant IV in the figure. Firms following this approach not only create fresh value for society through their products and services, but also engage in stand-alone CSR activities. The motive, as in the case of CSR as an add-on, is to be found in the altruistic inclinations of the CEO or influential members of the top management. From the point of view of society, this is the ‘icing on the cake’ and would be only too welcome. From the shareholders’ viewpoint, it may be seen as being superfluous. Moreover, given the fact that in making societal value creation its purpose, a firm is settling for a modest portion of the value pie. Its slack resources may not be large enough to justify such activities.
A critique

Of the four approaches that we have outlined, we think that what we have called ‘Serving Society, Profitably’ is the one that should be adopted by businesses. We say this not because it would be the ‘right thing’ to do, but because it makes immense business sense. Before expanding on this, an explanation of our rejection of the other three approaches would be in order. These approaches are not tenable for two reasons: CSR as an ‘add-on’ is unjustifiable and value appropriation is not sustainable.

Add-On’s are not Justifiable
In opposing CSR, Milton Friedman argued decades ago that if corporate donations are to be made, they had better be made by individuals donating their own money. The corporation, he wrote in his book *Capitalism and Freedom* (1962), is an instrument of the stockholders who own it. If the corporation makes a contribution, it prevents the individual stockholder from himself deciding how he should dispose of his funds.

The view that shareholders are not the owners of a company has been well contested. It has come to be recognised that the shareholders are only one of several stakeholders of a company and that a manager is responsible not only to the shareholders who had put their money into the company, but also to the employees who had put in their labour (and lives) and the customers who looked to the company for goods and services. Notwithstanding this, however, when CSR is practised as an ‘add-on’ unrelated to the main business activity, Friedman’s argument would hold true and it does indeed seem more appropriate that charitable decisions ought to be made by individual shareholders—or, for that matter, individual employees—donating their own money.

Besides, Friedman assumed that corporations, when they address social objectives, provide no greater benefit than is provided by individual donors. To prove Friedman wrong, therefore, would require corporations to contribute more than mere money and address social problems that they are uniquely equipped to handle. This is far from what obtains when corporations pursue CSR as an add-on and try to address social objectives they are least competent to handle.

In advancing the notion of strategic philanthropy, Porter and Kramer (2002) have observed:

*Often the connection [between CSR and business goals] is only semantic, enabling the company to rationalize its contributions in public reports and press releases. In fact, most corporate giving programs have nothing to do with a company’s strategy. They are primarily aimed at generating goodwill and positive publicity and boosting employee morale.*
By the same token, the notion of strategic philanthropy advanced by Porter and Kramer could be criticised on the grounds that the social case is weak and tenuous. When a company selects, from amongst a host of social issues, only that which would help enhance its competitive position and boost profits, the social impact would not be much. With Porter and Kramer suggesting ways in which CSR activity can be made more restrictive, thereby preventing free-riding competitors from reaping its fruits, the misgivings only become more pronounced.

Value appropriation is not sustainable

It has been argued, on moral grounds, that profits are the means to an end and should not be treated as an end in itself. For instance, Handy (2002) observed:

...to turn shareholders’ needs into a purpose is to be guilty of a logical confusion, to mistake a necessary condition for a sufficient one. We need to eat to live; food is a necessary condition of life. But if we lived mainly to eat, making food a sufficient or sole purpose of life, we would become gross. The purpose of a business, in other words, is not to make a profit, full stop. It is to make a profit so that the business can do something more or better. That something becomes the real justification for the business. Owners know this. Investors needn’t care.

*To many this will sound like quibbling with words. Not so. It is a moral issue. To mistake the means for the end is to be turned in on oneself, which Saint Augustine called one of the greatest sins.*

Moral considerations apart, value appropriation as a long-term goal is untenable because it is self-defeating. To see how this is so would require an examination of Porter’s theory of competitive advantage (1985) which dominated managerial thinking in the 1980s and the early 1990s.

At a time when industrial organisation economists were investigating market imperfections so that policy actions to remove restrictions on the play of free competition could be formulated in the interest of consumers, Porter’s framework sought to do the opposite by suggesting ways for moving an industry away from pure competition in the interest of shareholders. Having created value in the form of products and services, firms had to capture the largest part of this value in cut-throat competition with suppliers, customers, competitors and employees. The value pie was a fixed one and the size of the company’s share of the pie was indirectly proportional to what the company allowed its rivals to capture. By erecting barriers to entry and by actions directed at restricting the bargaining power of customers and suppliers’ firms, an industry could retain a big chunk of value within itself. They can then compete for individual share, taking care to see that this rivalry does not get to a point where others stand to gain. When firms are thus busy competing for their
portion of the pie, they contribute little to *enlarging* the size of the pie. Indeed, as firms try to grab as much value as possible from each other, their suppliers and customers, the pie shrinks. Demand falls and supply outstrips demand. Prahalad and Hamel (1990) developed their notion of core competence—long-term technology platforms that could provide potential access to a range of markets. A firm could reconfigure its resources around its core competence and, through new product development, diversify out of an overcrowded market into a new one where it would be the sole player. It could thus reap high margins till its product gets imitated. By repeating this process, it could earn a continuous stream of Schumpeterian rents, the innovator’s monopoly profits.

While the core competence framework ruled the roost in the 1990s, it left unchallenged the premise that the purpose of business is to earn rents. The fact is that a business’ purpose continues to be value appropriation; it impels a firm to set high skimming prices for the new products (made possible through its core competence) and restrict output. This in turn would invite imitators to rush in to satisfy the unmet demand at reduced prices. To the extent that the core capabilities of a company are not utilised in creating a leap in aggregate demand, they contribute little to a firm’s growth.

In short, the obsession with value appropriation can only lead to a definite shrinking of the pie, reaching a point when there is nothing left to appropriate. Value appropriation contains in it the seeds of its own destruction. Indeed, the more firms take to value appropriation as their purpose, the greater is the danger posed to the very survival of capitalism. As Handy (2002) has noted:

The markets will empty and share prices will collapse, as ordinary people find other places to put their money—into their houses, maybe, or under their beds. The great virtue of capitalism—that it provides a way for the savings of society to be used for the creation of wealth—will have been eroded. So we will be left to rely increasingly on governments for the creation of our wealth, something that they have always been conspicuously bad at doing.

*Societal value creation makes business sense*

When the strategies of firms subserve the purpose of value appropriation, it leads them to focus on narrow, elitist segments of society, with large disposable incomes. Products and services are offered to those who can afford them. Large sections of society that cannot, on the face of it, afford these products and services are ignored. Again, the value appropriating mindset leads firms to restrict output at high price levels contributing little by way of expanding demand. On the other hand, when firms are driven by the mission of creating value for larger sections of society, it forces them to focus on exploiting technological advances to develop innovative goods and services that can be afforded by the larger section by radically altering their cost structures. This and the readiness to settle for a
modest share of an expanding pie greatly enhance demand. This helps firms create huge uncontested market spaces—the so-called blue oceans alluded to earlier—renders competition irrelevant, creates huge economies of scale which help hold imitation at bay and provides a sound basis for firm growth in the long run.

Value appropriation leads firms to adopt the competition as the frame of reference. The focus is on outperforming the competition rather than on creating fresh value for the customer. As Kim and Mauborgne (1997) have noted, this leads to imitation rather than innovation. The mission of creating value for society, on the other hand, sets the stage for value innovation. It provides a challenging goal that organisational members can identify with and behind which their efforts can be aligned.

Finally, a corporate purpose of societal value creation helps align business interests with social welfare, rendering separate ‘CSR activities’ redundant. Business truly becomes a social institution in addition to being an economic one.

The state of CSR in India

In the absence of a strong conceptual foundation of what the social responsibility of business is, and benchmarks deriving therefrom, some proxy indicators have been used to evaluate the state of CSR in India. It has been reported, for instance, that India had only 879 ISO 14001 environment management adoption certificates in 2004 compared to China’s 5,000. However, 95 Indian companies have reportedly backed the UN Global compact, considerably more than in China (Kumar 2004).

Such proxy indicators apart, how do firms in India measure up against the typology presented here?

As elsewhere in the world, there is no dearth of firms for whom CSR is an ‘add-on’ unrelated to their strategy. There are instances of firms devoting a certain percentage of their profits to community development, as there are of others ‘adopting’ villages in the vicinity of their plants and establishing free dispensaries or centres where women of the village are provided access to sewing machines. Some companies have shown their concern for public health by launching HIV/AIDS programmes, while a few others are addressing gender equality by granting paternity leave to their employees. Numerous other instances are regularly published in newspapers, company reports and corporate websites.

There are also instances of companies making out a business case for their CSR activities. While some have reported an increase in profits as a result of their CSR activities, others have reported a reduction in costs as a result of their energy conservation activities. There
are also companies that believe that their CSR activities have enhanced brand value and employee morale. While there is no gainsaying how well these claims would measure up against the definition of ‘strategic philanthropy’, it is our impression that ‘strategic philanthropy’ of the type practised by Cisco Systems is prevalent among Indian IT companies as well. There are other, original examples of strategic philanthropy, such as facilitating self-employment for the rural poor by enlisting them into the dealer network; this serves business interests simultaneously.

What is of special interest to us, however, is the question, ‘Are there Indian companies pursuing a purpose of societal value creation?’ Our impression is that there are but, like elsewhere in the world, the number of such firms is small.

As an example one could mention the Indica car project of Telco, the strategy behind which appears to be typically ‘blue ocean’. Subsequent to the delicensing of the auto industry, at a time when other firms were intent on offering deluxe and mid-sized cars by assembling imported kits, Telco addressed the needs of the lower end of the car market by making it their goal to offer a car that would combine several new performance criteria: enough space for an average Indian family to travel in, fuel efficiency and low running cost. They priced it strategically at an affordable Rs 2.8 lakhs. Working backwards from the strategic price that had been set, they employed target costing techniques to innovatively alter their cost structure. For instance, a team of 15 members comprising research, costing and accounting personnel, undertook the exercise of working out the target cost of the numerous components that went into assembling the interior. Subsequently, it began work on the design of the components. The team would design a component, calculate the cost involved and in the case of a cost overrun, change the design or the manufacturing technique. For instance, when the team designed the door pads it decided to go in for injection moulded door pads instead of those manufactured by the conventional ‘woodstock method’ since the former was more cost effective.2

Another example is ITC’s e-Choupal effort that began as an effort to re-engineer the procurement process for their agri-business by placing computers with Internet access in villages. It has now resulted in an e-commerce platform from which farmers benefit—through more accurate weighing, faster processing time, prompt payment and from access to a wide range of information, including accurate market prices and market trends, which help them decide when, where and at what price to sell. Farmers selling directly to ITC through an e-Choupal typically receive about 2.5 per cent higher returns than they would through the mandi system. Meanwhile ITC benefits from net procurement costs that are about 2.5 per cent lower. Farmers can order quality agricultural inputs online. Virtual aggregation of such demand effectively reduces the cost of these inputs, enabling them to benefit from volume discounts.
The road ahead

Indian businesses have significant technological and managerial capabilities and have the potential to transform Indian society and contribute to social welfare. For this to come about, as we have argued, firms ought to direct their capabilities at societal value creation rather than value appropriation. A sustained change in worldview—from profit as the ultimate goal to profit as the means to serve society—is needed. And, herein lies the long-term sustainability of firms as well. To become socially responsible in the real and deepest sense of the term calls for a change in the basic management philosophy of Indian businesses.

The first step in this direction would be for firms to critically assess their core capabilities and restate their corporate mission in terms of a few social problems that they are uniquely placed to address. These problems would not be immediately apparent—and for this reason we term them ‘real problems’; it would be necessary to complement a firm’s market-sensing capabilities with those from outside the organisation and extensive research. Trend analysis and scenario planning techniques could be employed to identify, in broad terms, the boundaries within which value innovation could take place, with the firm’s core capabilities being taken into account in defining this boundary. To cite an instance, through extensive research that tapped into many sources, Unilever identified six ‘consumer drivers’. Research found that people all over the world want to—Achieve More, Give Children a Good Start, Look Better, Be Free from Health Problems, Feel Good Daily and Be Healthy for Longer. This, in conjunction with Unilever’s core capabilities, helped formulate the Unilever corporate purpose as follows:

Our mission is to add Vitality to life. We meet everyday needs for [sic] nutrition, hygiene and personal care with brands that help people look good, feel good and get more out of life.

This statement of purpose was meant to help Unilever identify value innovation opportunities right across their portfolio of products. Something similar is called for from Indian firms as a first step towards becoming socially responsible.

While restating corporate purpose helps define the firms’ domain of societal value creation in a broad way, much work is required by way of operationalising this purpose in terms that are more precise and arriving at product/service concepts and designs. This involves developing a new performance criteria to aim at and to offer these goods and services at a strategic, affordable price. Target costs would then have to be worked out and achieved. All this calls for innovation and this in turn means a radical change in the organisational culture. Without a culture that fosters innovation, teamwork and a spirit of voluntary cooperation, no innovation would be possible.
It hardly needs to be stated that the role of the top managers in bringing about such a shift is crucial. Treading this alternative path requires a firm commitment on their part and the ability to translate this commitment into a clearly defined corporate purpose that permeates the organisation as a whole and behind which the organisational members are aligned. This and the building of an organisational culture of cooperation are the two most important and immediate tasks that top managers would need to address. This they owe society.

Before concluding, we would like to demarcate our line of thinking from a strand of scholarly opinion which argues that we are faced with a collapse of time-honoured institutions, and that it is the duty of businesses as social and economic institutions to fill the void thus created. We feel that businesses ought to create value for society along with other institutions and organs of civil society. In particular, charitable, not-for-profit and non-governmental organisations would continue to play a crucial role, especially when it is a question of bettering the lot of the poor and marginalised who have little or no purchasing power or productive capability. Indeed, the path of value innovation may provide one way of addressing the problem of scalability that many not-for-profits face. By leveraging their core capabilities into innovative business activities that bring in revenue, they can subsidise and effectively scale up their not-for-profit operations. Perhaps an exemplar would be the Aravind Eye Hospital, Madurai, where the 30 per cent paying patients subsidized the 70 per cent non-paying patients (as of 1994). Attracted by Aravind’s reputation and the high quality of service at an affordable price, paying patients flocked to it and were provided slightly better service facilities. The hospital treated poor patients for free and yet managed to make a healthy gross margin. This margin was reinvested in equipment and research which helped scale up and sustain its charitable work.

Notes


2. For a detailed account of the Indica project, see Venugopal (2001).


4. For a descriptive account, see Rangan (1994).
References

3. Handy, C. 2002. ‘What’s a Business For?’, Harvard Business Review, December,
Chapter 15  Conclusions

The links between the concepts of poverty, equity, and human rights in relation to health are many and profound. Both equity and human rights principles dictate striving for equal opportunity for health for groups of people who have historically suffered discrimination or social marginalization. Achieving equal opportunity for health entails not only buffering the health-damaging effects of poverty and marginalization: it requires reducing disparities between populations in the underlying conditions — such as education, living standards, and environmental exposures necessary to be healthy. Thus, both human rights and equity perspectives require that health institutions deal with poverty and health not only by providing care to improve the health of the poor but also by helping to alter the conditions that create, exacerbate, and perpetuate poverty and marginalization.

(Philip and Rayhan, 2004: 8)

In this chapter, I present the conclusions of my thesis, drawing from the main findings, guided by the research question:

What are the complex problems experienced by persons living in poverty and homelessness with mental health concerns in India and what are the strategies that help address this distress?

The main research question was formulated, based on the objectives set in Chapter 3:

- The primary objective of this research is to open up discussions of the unique nature of the mental ill health – poverty – homelessness nexus, examine the grave challenges that this nexus presents and draw serious attention to this complex problem, given that it is an essential part of the development and health discourse.
- An allied objective is to learn from innovative experiments and approaches to respond to elements of this complexity in creative, culturally sustainable ways.

To answer the research question, I first explored the mental ill health – poverty – homelessness nexus with two in-depth narrative reviews that examine the macro and micro level concerns and complexities. In Part 1 of the thesis, I consider this nexus with examples
which highlight the nature of vulnerability and distress. Having set the stage and demonstrated the complexity and persistence of the problem, I present some positive examples in the last section of Part 1. In Part 2, I consider in more detail innovations and approaches that help address the complexities in a more coherent and effective manner. In this context, in Chapters 6 and 7 I retrospectively and qualitatively examine the evolution of The Banyan, using a timeline narrative and attempt to understand the sort of health services required to address the needs of people with mental health concerns, living in a circumstance of multiple deprivations. In Chapter 9, I endeavour to understand journeys in and out of ill health and homelessness, considering The Banyan’s organizational responses and strategies in the light of these experiences of distress and personal recovery. This chapter also stresses the importance of developing human resources with an appropriate value system that promotes capabilities and well-being. This interaction between the individual and the organizational, or in other words between the micro and the meso-level, is demonstrated throughout this thesis, reflecting the dynamics of the real world. In Chapter 3, I address the complex challenge of human rights in the mental health discourse, presenting different perspectives which are based on insights of Indian mental health users. In the same context, Chapter 10 considers concepts of disability, mental illness and accessible care within the legal framework of the new Mental Health Care Bill (2013), soon to become law. In the final section, Part 4, I look outwards at alliances with external stakeholders and at the impact policy, culturally-relevant education and responsible business could have on building equity and robust responses to complex problems. Research sub-questions are used to highlight relevant discussion points and advise future strategy and direction.

Sub-question 1: What are the complex, yet somewhat ignored aspects of the mental ill health-poverty and mental ill health-homelessness discourse that need renewed focus and attention?

A number of complex problems emerge from the narratives in this thesis, emphasizing the persistent nature of the mental ill health – poverty – homelessness nexus. The magnitude of the problem was considered, together with its impact on individual quality of life and on the downward spiral into homelessness. Up to 65-70 million people are estimated to be suffering from mental illnesses in India (ICMR, 2007). Meanwhile, nearly, 70% of India’s population lives on less than USD2.00 a day, while 37% live on less than USD1.25 a day (World Bank, 2010). The co-relation between poverty, social disadvantage, mental ill health and homelessness established in this thesis is consistent with evidence from other studies (Draine et al. 2002; Torrey Fuller 1997; Sullivan et al, 2000; Riley et al, 2007; Chamberlain et al, 2011). The literature also considers that poverty facilitates the relationship between mental illness and social problems (Saxena et al. 2007; Murali et. Al, 2013; Burns et al. 2012;
Lund et al, 2011; WHO, 2010), a relationship which has also been established in this thesis. While previous analyses have examined the impact of poverty on mental health outcomes, this thesis emphasizes the multi-factorial nature of poverty in India. Pathways to ill health start with birth into a poor family. Poor nutrition, sanitation, education, housing, health access and employment result in a bleak future that builds distress. While an individual’s health is compromised by poor education, inequity based on location, caste and gender bias and other such deprivations, poor health systems further perpetuate the descent into abject poverty and homelessness. In such a context, mental ill health leads to enhanced vulnerabilities and greater disability. The 2010 World Disability Report declared that persons with disabilities were amongst the poorest in the world (WHO and World Bank, 2011). In addition, 75% of all mental disorders are borne by people living in low and middle-income countries (LMICs) (WHO, 2007). Much of this evidence demonstrates that poverty not only facilitates but reinforces ill health and mental ill health (Read, 2011). Rotman’s conceptual theory defining a persistent problem best captures this phenomenon of co-occurrence: multiple domains, multiple actors and many interactions are evident; the system is afflicted with inconsistencies and ambiguities; and substantial parts of the linkages are difficult to grasp (Rotman, 2005 cited in Dirven et al in Bunders and Broerse, 2010: 31).

Despite a clear trend emerging, the Indian government’s spend on health remains abysmally low at 1.2% of the Gross Domestic Product (GDP). The poor level of allocation to the social sector allocation remains a parallel yet related concern. Fragmentation not just in health systems, but also at the planning and policymaking level plagues the Indian system. As a result, landscape-level changes do not influence the regime level of health and mental health systems. Risk is widespread when mental ill health and poverty co-occur in the context of poor health systems and paucity of services. A combination of factors, ranging from high caregiver burden and helplessness, poor societal and governmental attitudes, inappropriate services, high stigma and multiple barriers and forms of discrimination, paralyses the individual into inaction and resignation.

Given this background, the National Mental Health Programme (NMHP) that operates within a weak health system, is grossly inadequate and covers only 123 out of 640 districts in India. In Chapters 4 and 5, I focus on double jeopardy, also known as the ostrich syndrome or the elephant in the room, namely the double risk facing a significant portion of the Indian population as a result of the poor health system and inequity, and their impact on mental health. Despite recurrent discussions on the impact of poor health on poverty and vice versa, and their combined, vicious impact on mental health, not much progress in reversing these trends has been achieved in India or in most other LMICs.
At the intersections of mental ill health, poverty and homelessness, critical gaps are also experienced at the level of human resources. These gaps include a lack of leadership and an inadequate training for practitioners in the mental health and social sectors. Practitioners are thus not prepared for work in an environment of enduring problems, diversity, plurality and ambiguity. In particular, the values which underlie their work are not appropriate.

In summary, the core problems of poverty and inadequate health services are not receiving the attention they deserve, undermining opportunities for sustainable, effective and long-term changes. This situation can be compared to a bucket with a hole in it because no amount of water can fill the bucket until the leak is mended: poverty and other critical health system inadequacies here represent the hole, the Indian population is the bucket and policy reforms represent the running water. In addition to having management and policy level implications, this situation also has implications for training and human resource development. There needs to be a focus on the quality of training and human resources, and on building leadership in the sector.

Sub-question 2: What are the specific problems emerging as a result of the mental ill health – poverty – homelessness nexus?

In order to answer this sub-question, Chapters 4 and 5 examine the nexus in detail. Chapter 5 focuses on the issue of homelessness and its impact on mental ill health, while Chapter 4 is concerned with poverty. In addition to evidence from the literature, Chapter 5 draws substantially from The Banyan’s organizational memory and insights. It first explores the critical causes of homelessness, namely migration, poor social networks, unemployment, ill health, domestic violence, abuse and poverty. The Census of India indicates as increase in homelessness in urban areas by 20.5% over the 2001-2011 period, marking its relevance as an important and growing problem of concern (Government of India, 2011). Despite constitutional commitments to the provision of basic amenities, many people continue to live in squalor. Homelessness represents the collapse of multiple safety nets, such as housing, health and social support, in the Indian context. Social causation explains how poverty causes mental illness and psychosis, while social drift explains how poverty is involved in maintenance of mental illness and psychosis (Read, 2011; Funk et al, 2011). A co-occurring matrix is developed that establishes the pathways to homelessness as a complex, intricately developed journey dependent on multiple variables, critically linked to lack of access to health care and poverty. These pathways have also been observed by other studies in India (Tripathi, 2011).
Using case studies, I demonstrate the enhanced susceptibility of homeless persons to stress and distress-related depressive states. A state of homelessness can be ascribed to systemic or probabilistic causation, finding its origin in a network of causes. The homeless experience violation of many rights, suffer starvation and poor health, and often report both sexual and physical abuse. Alienation and exclusion takes them down a path of apathy and hopelessness (Goodman et al, 1991). Depression is 1.5 to 2 times more prevalent amongst low-income groups and poverty traps, such as inadequate housing, debt, and hunger, are usually magnified in these circumstances (Patel, 2001). In such a situation, individuals are vulnerable and prone to a descent into homelessness. Thus, I conclude that the 37% of the Indian population who live on less than USD1.25 per day is likely to succumb to this silent epidemic and spiral into abject poverty, distress and homelessness, while those who are a little better off also stand the likelihood of a similar downward drift, especially in the event of any negative, widespread changes. Thus, I estimate that 70% of the Indian population is at considerable risk.

Other persistent problems that emerge are co-morbidity (especially in the case of substance misuse and mental ill health) and the need for inclusive, long-term care options. While human rights violations plague many mental hospitals in India, individuals with long-term needs have no other place to stay, especially in the event of the death, aging or ill health of the primary care giver.

The chapter concludes with describing some innovative methods that can address some of these challenges. These include open and inclusive communities and housing systems for homeless persons with long-term mental health needs in Tamil Nadu; local governance driven collaborative mental health care in Kerala; and a housing-first approach from Canada. Experiments are needed to address these complexities, based on commitment to a development agenda that promotes capabilities. A transition management approach, focused on practices, culture and structures, needs to be adopted, taking into account long-term perspectives and diverse responses. Bold, entrepreneurial leadership is needed which is able to take risks, address uncertainty and keep options open. Although the challenges involved are considerable, more niche experiments are needed to develop new approaches and strategies.

I conclude that poverty and inequity are at the core of the mental ill health – poverty – homelessness nexus. Governments and societies are responsible for perpetuating this persistent problem, and also have the ability to reverse this pattern by fostering collaborations, developing effective human resources and addressing real world problems. This view is also corroborated by evidence from other studies (see, for example, Burt, 2001).
Sub-question 3: What are the attributes and response systems of organizations which address the multi-dimensional needs of homeless and poor persons with mental health concerns?

Part 2 of this thesis demonstrates and outlines organizational strategies and values that help build robust responses to complex problems faced by individuals at the intersections of mental ill health, poverty and homelessness. While Part 1 focused on the nature of the complexity, this part attempts to capture best practices and strategies to address the distress. Chapters 6, 7 and 8 focus on The Banyan and the non-governmental sector, examining guiding values, strategies and nature of innovations, while Chapter 9 also considers organizational responses.

Using a timeline narrative, the four dimensions of planning, action, observation and reflection were used to construct an analysis matrix of The Banyan’s lifecycles. System level evolution was used as the key criterion to distinguish between the different lifecycles. The Banyan’s understanding of the impact of the co-occurrence of homelessness and mental ill health developed through the lifecycles. Poverty and absence of accessible and appropriate care were identified as critical factors responsible for this downward descent. While access was a barrier, the more significant barrier was quality of care. The lifecycles also demonstrate The Banyan’s strategic focus on integrated and continued clinical and social care in the context of vulnerable groups to facilitate reversal of the downward spiral and inspire upward social mobility and inclusion. This is also seen as an essential part of recovery focussed interventions in other studies (Bauer, 2013).

The problem of long-term care, discussed in Chapter 1, was resolved using non-institutional, inclusive methods as an innovation. Even as micro level understandings were developed, meso and macro level interactions at the state and policy level were recognised and their potential exploited. This role of multiple stakeholders in impacting change is also highlighted by the WHO (WHO, 2011). Quality checks and service audits, both external to the organization and conducted by its constituency, emerged as critical to both strategy and values, reinforcing user-centric identity and ideology. The role of poverty in this discourse, led The Banyan to adopt a well-being paradigm, drawing from the strengths of village-level community mobilisers to enable client recovery and pursuit of capabilities the need for high-quality human resources, based in an appropriate value system, was identified as an additional gap. This gap was addressed in the most recent organizational cycle with the establishment of a training and education centre for development of leadership skills and training of high-quality practitioners. In addition to user centricity and service integration, organizational culture and values also emerge as a significant catalyst in achieving desired
results. These values include ongoing dialogue between clients and practitioners, and between practitioners at all levels of the organization, making it possible to articulate and reinforce a common vision, and to support staff morale under difficult circumstances be motivated. This leads me to the conclusion that the value of action learning seems to be at the foundation of a responsive health system. This is achieved by placing the user in the centre in defining responses, and instituting appropriate, multiple responses at a systems level. Co-creating knowledge serves as the basis for formulating such systemic approaches (Broerse et al, 2010). A typology of responses at the mental health systems-level indicate The Banyan’s ability to quantitatively enhance service diversity and qualitatively enhance levels of integration.

In conclusion, relevant to the theoretical concepts discussed in Chapter 2, The Banyan follows a systems innovation perspective. It is engaged in a niche experiment addressing unique and complex problems in innovative ways, transitioning with emerging new goals but built on the ongoing value of dialogue with the foundation of the co-creation of knowledge. The Banyan’s organizational strategy is characteristic of a complex adaptive system with learning driven responses and feedback loops leading to systems-level changes, rather than having discrete blocks of planning, acting and evaluating. This dynamic system is user-centric, rather than disease-centric.

Chapter 8 documents similar niche experiments across the non-governmental sector in India which focus on community needs and promote well-being (Jain and Jadhav, 2008). Many of the innovations were characterized by a design involving user feedback loops. However, some common challenges were also noted: lack of resources posing sustainability issues; lack of human resources resulting in leadership issues; and divisive ideological stone-walling restricting potential for dialogue and advocacy. Despite these challenges, some organizations had established models of partnerships with other stakeholders, including the government and the corporate sector. Partnership increases transparency, enhances accountability and results in higher impact.

Chapter 9 uses personal narratives to explore the nature of distress experienced at the mental ill health – poverty - homelessness nexus. It then attempts to capture individual and organizational responses that help beat distress and pursue recovery. In the light of the cross-cutting themes discussed in the first part of this chapter, attempts are made to construct an organizational value deck or framework which can then be used in effective capacity building for human resources at different levels.
Sub-question 4: What precipitates descent into homelessness? What are the critical methods and values that promote recovery and appropriate human resource development?

Using a qualitative study design drawing primarily from organizational memory and individual narratives analysed using phenomenological and grounded theory approaches, critical factors contributing to the descent into homelessness for persons affected by mental illness were explored in detail. In addition to poverty, abuse, social exclusion, and the death of the primary caregiver, the crucial determinant perpetuating the downward spiral into homelessness involves collapse of the family. Kinship, affiliation, social bonding and belongingness are evidently vital for individual well-being. The Banyan’s approach over two decades reflects the importance of a family-like environment for therapeutic care and personal recovery. This is consistent with findings of other studies (Tew et al, 2011).

In keeping with the notion of creating a family-like environment to foster recovery, The Banyan has developed a framework of key values that are equivalent to the familial bond. This framework includes values like compassion, connectedness, responsibility, negotiation, tough love, spontaneity, inspiring hope, building pride, and promoting capabilities. It aims to foster therapeutic alliances, human resource capabilities and overall organizational strategy in providing care for persons with mental health concerns. Similar values have also been promoted as crucial to recovery by other experts and organizations within the mental health sector in India.

The Banyan has attempted to promote these values to all professionals working within the organization through structured and unstructured mentoring, capacity building programmes, inclusion of soft skills in performance appraisals and demonstrative leadership. These values, practiced with clients, are also echoed across interactions between professional teams. However, exclusive attention to nurturing this environment is likely to be unsustainable. Instead, it is essential to maintain the balance between a family-like setting and protocol-based care systems and management to support effective service delivery, growth, scalability and adaptability of the organizational model.

In conclusion, mimicking the family, creating innovative mental health care systems and approaches rooted in values, and promoting humane, empathetic, responsive care that is user centric, can significantly improve reinventing mental health systems. This approach provides another dimension to the concept of personal recovery and a new perspective to the international human rights discourse.
Sub-question 5: How are rights understood from the perspective of Indian women who have experienced mental ill health, poverty and homelessness?

Human rights comprise a central theme frequently discussed in relation to mental ill health. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) has focused adequately on many aspects of this discourse, including guardianship and legal capacity. While preservation of rights is a mandatory obligation of state and society, violations compel the development of an external framework to safeguards the interests of the vulnerable. However, unlike other disabilities, mental illness presents itself in a unique manner and is subject to ambiguities. Chapters 10 and 11 in Part 3 consider whether a unidimensional voice or mandate to human rights and mental illness will suffice, given the context of users and the proposed Mental Health Care Bill (2013).

The construct of human rights, emerging from consultations with service users of The Banyan, emphasizes on attainment of fundamentals – adequate food, housing and work – that are essential to survival and pursuit of well-being. This construct posits an instrumental relationship between attaining these fundamental needs and achieving more complex personal states of agency, affiliation and mastery over life. This establishes an integrated definition of human rights that perceives connections as well as balances between the dichotomous philosophies underlying perception of rights by the disability and the health lobbies. Critically, the construct reconcile the apparent conflict between the right to health with right to choice, particularly in the context of care without explicit consent, by proposing a value framework that acknowledges diverse needs and contexts and which places the user at the centre. While the literature is divided depending on the whether a disability or a health perspective is taken, few researchers have succeeded in weaving together critical themes relevant to both perspectives by compromising agency and self-determination short-term in favour of long-term treatment, recovery and wellbeing (Saks, 2002). Policy and legal frameworks must be drawn from the voices and experiences of people at the margins if they are to be effective in achieving human rights gains. Agency and by extension decisional capacity is promoted long-term by interventions in mental health that take a person from ‘distress to a happy place’, whether located in a community or institution.

Having discussed the most critical challenges and complexity around the mental ill health – poverty - homelessness nexus in Chapters 4-10, I now propose to understand the impact of external stakeholders and other sectors in mental health promotion. In keeping with the discussions in Chapters 2, 4, 5, 6, 7, 8 and 9, Part 4 argues for sustainable development in
the mental health or health sectors by inspiring policy level co-operation, education level reforms and corporate sector level assessment. Although Chapters 12, 13 and 14 were written in the 2008-2012 period, they still resonate the views articulated in the more recent chapters in Parts 1-3.

Sub-question 6: Are the needs of the vulnerable groups reflected in the amendments to the Mental Health Care Act, 1987?

Chapter 12 reviews the 1987 Mental Health Act, discussing draft amendments to ensure congruence with the UNCRPD which were written prior to the decision to develop new legislation as the Mental Health Care Bill (2013). Amendments to the Act reflected a rights orientation, appropriate to the then existing scenario in India. They aimed to reform the quality standards of mental hospitals and to address the treatment gap by ensuring accessible care as a basic right. Specific reforms to hospital care included constitution of a Mental Health Review Commission (MHRC) to ensure grievances were appropriately addressed. Some commentators applauded the amendments as contributing to the global mental health discourse (Atkinson, et al, 2003), while others were critical of their relevance, complexities and pragmatism, particularly of the MHRC and the Advanced Directive (Kala, 2013; Sarin, 2010). The need for a new mental health policy, alongside the process of drafting amendments, was a strategic effort to improve implementation. In addition, a pro-poor mental health policy was needed to meet the needs of vulnerable groups, including women.

Sub-question 7: How can academics and practitioners collaborate to develop capacity in the mental health sector?

Human resources have been identified as a pivotal aspect of a good mental health system; newer and more relevant methods to build capacity, skills and perspective have to be explored. In Chapters 6 and 9, I argue that education of health practitioners should be embedded in a constructivist pedagogy to foster the attitudes, resilience and values needed to defy the persistent problems of the health system in India. This will require more contextual, relevant curricula. Innovative teaching methods have to be tested in practice by collaborations between organizations providing care, such as The Banyan, and academic institutions.
Chapter 13 retrospectively analyses the challenges and achievements of collaboration between The Banyan and a British university, University College London (UCL). A mixed methods approach was taken to co-developing the curriculum, drawing from theory and practice and relevant to the Indian context. The aim of this collaboration was to learn from local experiences of suffering and well-being and to integrate them with globally relevant approaches; to develop multidisciplinary collaborations; and to provide an inclusive space to address issues that concerned researchers and practitioners alike. Breaking down barriers resulted in openness and building of trust that helped foster a healthier relationship. While UCL wished to encourage a more anthropological or social science perspective to the understanding and treatment of mental health issues, the Banyan Academy of Leadership in Mental Health (BALM) wished to replicate its approach to care in different contexts by sharing protocols and dissemination of information, aiming to reduce the treatment gap. Participants reported that the combination of theory, practice group exercises, case based discussions and films was an effective method of learning. Ability to apply learning in practice was a key participant expectation that met with considerable success, using complementary training and teaching approaches. I conclude that social and health sector-based education should use integrative, mixed teaching methods and diverse staff to ensure robustness in methodology and applicability. In addition, attitude and value building can be encouraged by using critical reflection as a tool for analysis (Delany et al. 2009).

Financial sustainability was identified as a challenge to collaboration. Since these results were documented, the UCL-BALM collaboration has come to an end due to lack of financial resources. However, new collaborations to pursue similar goals in human resource development have been initiated with two other academic institutions, namely the Tata Institute of Social Sciences (TISS), Mumbai, India and the Athena Institute, VU University Amsterdam, Netherlands. These collaborations have been developed with long-term sustainability in mind, leading to the establishment of a research and teaching institute, the Institute of Mental Health Social, Sciences and Transdisciplinary Research (IMHST). From 2013, the IMHST is offering Masters’ programmes in social work and mental health, counselling and management, policy and entrepreneurship in health and life sciences, aiming to respond creatively to real world challenges. The campus reflects this spirit and is located within the alternate housing facility of The Banyan. This need to embed learning in constructivist approaches is reflected in the previous chapters of this thesis.
Sub-question 8: How can the mechanism of corporate social responsibility (CSR) lend itself as a strategy to address complex societal problems?

Sustainability can be achieved through the development of social enterprises, partnerships with foundations and the government, community resource pooling, corporate social responsibility (CSR) and other such methods. CSR has become increasingly relevant in India because the India Companies Act (2013) obliges companies to spend 2% of their profits on the public good.

Chapter 14 considers CSR from the Indian perspective. Amongst the many forms of CSR practiced in India, the ‘serving society, profitably’ approach is consistent with the long-term interests of business and society and seems to be the most sustainable way forward. A strategy adopted within this framework is that of value innovation or blue ocean strategy, namely building a large uncontested market space of innovative goods at affordable prices. This approach is illustrated using the example of Unilever. Unilever’s approach to social good is embedded in two value drivers: the health and prosperity of business is linked to that of the community; and a successful business is a responsible business. The typology has been based on two key dimensions of social responsibility: societal value creation and social value appropriation. The ‘icing on the cake’ approach combines innovations with altruism at a societal level. Although this approach is of particular interest to society, it may not appeal to business stakeholders or dynamics.

Given the current regulation of CSR allocations, an integrated combination of the ‘serving society, profitably’ and the ‘icing on the cake’ approaches might be the best way forward. In the social sector, niche experiments have been successfully conducted that respond to distress using social entrepreneurship (Hand in Hand - [www.hihindia.org](http://www.hihindia.org), Villigro - [www.villgro.org](http://www.villgro.org)). The Banyan and like institutions can learn from these examples, upholding commitment, responsiveness, values and sustainability while being embedded in real world and market dynamics.

Validity of the findings

This thesis highlights problems in the mental health and social sectors in India so that these problems can be addressed more effectively. It also aims to improve understanding of the distress experienced by the poor and homeless with mental health concerns. Many of the insights and discussions are the result of the researcher’s work in the mental health and social sectors over two decades. Aspects of action research, grounded theory and
phenomenological inquiry were used in data collection and narrative reviews. Most of the research was exploratory and inductive in nature.

**Internal validity**

Owing to close engagement with the work on which the studies are based, possible bias of the researcher was consciously addressed and a number of methods were used to augment validity of this thesis, including triangulation of information through multiple sources including organizational reports, external reviews, academic and grey literature; discussion of key arguments with critical audiences, both internal and external to The Banyan and from a range of disciplines; and regular reflection with peers, senior colleagues and the supervisors (promoter and co-promoter). When focus group discussions or structured interviews were used, the reliability of the data and faithfulness of interpretation was generally confirmed with the participants. Much of the information obtained was also both transcribed and audio recorded in individual case files. Wherever case studies were used as a method, thick descriptions were used to capture thoroughly the meaning of the experiences.

**External validity**

This thesis is exploratory in nature, seeking to understand the complex-persistent nature of the mental ill health – poverty - homelessness nexus and possible strategies emerging from the twenty years of grassroots efforts of a non-governmental organization in India, an LMIC. Given the fundamental nature of this enquiry, findings are in the domain of conceptual depth and clarity, and not based on causal inferences. Therefore, external validity is first considered in light of how applicable these concepts are to wider contexts. Second, extrapolation of findings are considered in terms of transferability rather than of generalization.

The enquiry is embedded within a real world field action context and is positioned against the backdrop of third party evaluations of The Banyan and existing scientific literature that supports several underlying assumptions of the research. Further, findings across all parts of the thesis are discussed in light of several existing theories drawn from contexts with shared and divergent attributes – social causation, social drift, capabilities and transition management - that support the emerging concepts. Both idiosyncratic and overarching data have been used for the purpose of drawing findings, illustrating consistency with extant theories as well as differences where relevant.

How applicable are these findings to a wider LMIC context, and particularly to the wider group of people who face a similar double jeopardy of mental health with poverty and
homelessness? The findings of this enquiry are in the domain of broad framework of underlying values, rather than detailed prescriptions or blueprints for action. Further, the nature of pedagogy in stimulating such values and therefore subsequent action are considered. Although drawn from experiences of a single organization working in a city of Chennai, South India, the organization and the author (as co-founder) have a vast experience with the niche constituency under study. In addition, clients of the organization originate from several geographies spread across the length and breadth of India, a highly diverse country. While varying in their socio-cultural backgrounds, the majority of clients are linked by their common experience of mental illness, homelessness and poverty. Summative knowledge and concepts emerging from such an experience benefit from this heterogeneity when being considered for adaptation and upscaling. The predominantly action research methodology used in this thesis was able to embed findings in the context of their environment. Further, the thesis captures the evolution of responses in a specific context from the start. Descriptions of the context of action and the underlying assumptions make it possible to study, consider and adapt these findings to other contexts which may have both concordant and discordant features.

Learning, insights and conclusions

This thesis provides an overview of the challenges and persistent problems that plague the Indian mental health sector today. While this co-occurrence remains an under-researched subject in India, an acknowledged rise in both the prevalence of mental disorders and in the number of homeless persons in urban areas in India requires greater commitment to alleviate their debilitating effects on individuals and the distress they cause. This thesis has examined micro-level concerns, constantly linking them to meso-level systemic changes and macro-level impact, with iterations between all levels to yield a holistic and robust view of the problems. It then examined niche approaches at the micro-level that incubated innovations with the potential to facilitate positive change.

Critical and complex problems, such as inadequate access to health care, violations of human rights, poor health systems and poor quality of life, are the result of the combined occurrence of homelessness and mental ill health. While these issues have been highlighted over the years, limited progress has been achieved on the ground towards their resolution. This thesis explores whether the fundamental, intractable problems described here can be approached in a more resilient, long-lasting manner at the level of the landscape. Double jeopardy, due to co-occurring conditions, is studied in-depth and the role of poverty in precipitating stress, building distress, enhancing vulnerability and negatively impacting
health, mental health and capabilities is described through organizational experiences and individual narratives. Thus I argue that sustainable change at the health systems and population level can only be achieved if poverty alleviation mechanisms are strengthened, fine-tuned and delivered with a sense of urgency. The complex interactions between inadequate sanitation, nutrition, health care and housing at the landscape-level prohibit comprehensive mental health planning and execution, resulting in fragmented responses that do not always help resolve contradictions, conflicts and barriers in the system. As a result, individuals struggle to achieve their full potential in a situation in which 70% of the population is in a situation of poverty and is at risk of homelessness and mental ill health.

The 66th World Health Assembly resolution mandates convergence between different sectors to promote mental health (WHO, 2013). Consistent with this trend, the Mental Health Care Bill (2013) and mental health policy in India actively promote the responsibility and accountability of the government, ruling access to mental health care as a basic entitlement, although these frameworks have not yet been adopted in the Constitution. Ensuring that mental health access becomes an entitlement for all will mitigate considerable distress, possibly preventing further downward drift for many. In addition, more integrative approaches that address multi-dimensional needs have to be designed and advocated. However, in the interim, in anticipation of a more lasting, long-term change at the macro level, some successful niche experiments at the micro-level have successfully reversed the downward spiral and descent into aggravated poverty or homelessness. These approaches can be adopted to reduce the distress and complexity experienced at the intersections of homelessness, mental ill health and poverty. The innovations emerging from these niche experiments can have an impact on the meso-level of health systems and also influence landscape-level policies and governance structures.

Evidence emerging from these innovative designs and experiments emphasize that access is both a barrier and response. My own inquiry into the nature of distress encourages me to place particular emphasis on service quality because merely increasing services will not ease the burden on individuals and communities. A user-centric approach, coupled with service integration and embedded in a value system that promotes recovery and well-being, is needed to address the diverse and unique needs of persons. This approach is needed to improve the quality of services. Thus, the following elements are critical to improving services: attitudes in service delivery, the quality of human resources, the levels of integration, and the ability to be adaptive and to learn from co-creation of knowledge with the constituencies being served. In the mental health context, this signifies a deeper response than simply expanding the District Mental Health Programme (DMHP) from its current coverage of 123 districts to the full number of 640 districts. It would require examining the many other dimensions of care required to respond comprehensively to the needs of those with mental health concerns, including long-term care and living options, employment facilitation, caregiver concerns, and social inclusion.
These approaches to designing innovations and initiating changes at the system level draw from the transition theory, relying on feedback loops to develop substantial responses to diverse needs based on real world delivery and implementation. Experiments are needed in multiple contexts and the insights from these experiments need to be integrated into a cumulative body of knowledge that informs practice and supports development of nuanced strategies. Thus, simultaneous implementation and research in practice can lead to responses that accept the complexities of the real world. In this context, researchers and practitioners should not be too eager to demonstrate quick solutions and results, despite approaching persistent problems with a sense of urgency. They have to take into account the real world dynamics of a chaotic, underdeveloped health and social system and thus be prepared to take risks, struggle with results and modify their approaches. A new cadre of human resources needs to be developed, able to act in such a way, if quality changes are to be made in the mental health sector.

Different niche experiments also highlight the importance of change agents who commit to stimulating change and building internal capabilities, engaging with persistent challenges in the long term (Essink, 2012; Loorbach, 2007). These change agents usually have the potential to collaborate with multiple stakeholders, especially their primary constituents whom they serve. This feedback loop with primary constituents is important as the consequences of engagement and non-engagement are most critical to the development of services, impact, outcomes and innovation. Such agents, in addition to being able to influence regime-level culture, practice and structures, should have the ability to interact and collaborate with landscape-level actors, such as policy makers. These change agents should use their ability to persevere with ethically relevant issues, such as human rights, in the context of homelessness and mental ill health. Rooted in practice, their realities and perspectives are possibly inadequately represented in the level of international dialogue and discourse. As is the case with service development discussed above, quality and attitudes are also crucial at the level of human resources, fundamental to building mature skill sets and perspectives.

The policy climate within the global mental health movement and within mental health systems in India is currently conducive to many of these integrative and inclusive strategies, formulations and frameworks. The mental health system could thrive in this landscape if structures, values and practices could adapt, based on the complexities, dynamism and experiences of the real world. Such transitions could facilitate progress at the regime level from the ‘take off’ to ‘acceleration’ phase, challenging the status quo apparent in the mental health, health and social sectors. These sectors are closely related and interactions between them are at the heart of most of the complex problems that the systems are
facing. Given that many variables are involved, a backlash or slowing down of innovations and experiments is a possible threat to change.

Persistent problems can be addressed by fostering collaboration with diverse stakeholders from identical and divergent contexts, and by retaining the learning spirit within organizations. Experience of The Banyan shows that organizational learning is at the root of the ability to consider experience and insights from a broad perspective, address niche problems and develop an array of responses, approaches and interventions. Two-way interaction and learning between users and services, leaders and managers, researchers and practitioners, mentors and students, practitioners, researchers and policy makers, non-governmental and governmental leaders, and social and business sectors can support maturity and cohesiveness in response, knowledge and strategy, breaking with notions of traditional top down and bottom up interactions and with exclusive research-centred or practice-oriented solutions. Persistent problems have to be addressed by integration between multiple actors. Reflexive and reflective thinking, both as values and methods, facilitate this process of three dimensional knowledge creation.