Enabling access to mental health care

Perspectives from the Banyan experience in India

Vandana Gopikumar, Vaishnavi Jayakumar and Lakshmi Narasimhan

Introduction

This article examines the issue of access to mental health care using the Banyan experience of working with persons with mental illness living in poverty. In recent years, mental health has gained prominence in the global discourse on health, driven by findings of the World Health Organization's (WHO) global burden of disease estimates that attribute 7.5 per cent of the disease burden to mental and behavioural disorders.[1] Recent developments around the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) are significant to this discussion in the context of enabling access rights and promoting barrier-free, healing environments. Major themes in the current dialogue stress the need for:

- accessible, affordable and appropriate services;
- the integration of mental health within public health systems through evidence-based collaborative or co-located care, supported through capacity-building;
- linkages between housing, social services and improved mental health outcomes; and
- a rights-based approach that promotes community based services and user participation.[2,3]

This article examines these broad themes with reference to their grassroots applicability in alleviating distress and suffering and improving living standards.

The Banyan experience in enabling access to mental health

The Banyan began in 1993 as 'Adaikalam' ('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 women to be reunited with their families/communities of origin all over India. As the Banyan continued outreach work with such marginalised persons and families, multiple service arms evolved to address the diverse needs of this unique and complex group.

Over the years, Adaikalam metamorphosed into a centre that promoted 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 institution led to the development of concepts such as self-discharge, social audits, user reviews, 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 the establishment of an after-care unit, an essential service valued both by users and caregivers. In a bid to institutionalise the response mechanism for homeless persons with mental illness, the Banyan set up a mental health helpline – in partnership with the Chennai city police, the Institute of Mental Health (IMH). Emerging needs of context of moving towards independent living led to the creation of an employment hub, group homes, supported housing options, a working women's hostel and self-help groups (SHGs). A cottage-style, community living centre was formed to meet the continued long-term needs of a small yet significant percentage who face a disproportionate burden on account of age, chronic illness, poverty or social exclusion. In 2003, in tandem with a review of the Banyan's work by the National Institute of Mental Health and Neuro Sciences (NIMHANS) and the Sir Ratan Tata Trust (SRTT),[4] prevention of homelessness as a result of mental ill health and the promotion of well-being emerged as a significant corollary to the crisis intervention work. Today, the Banyan operates rural and urban mental health programmes through the following:

- Mental health clinics, which provide counselling, psychiatric consultations, free medication and case and group work;
- Community outreach initiatives, which help with early identification, building social networks, home visits, telephonic follow-up, awareness and sensitisation; and
- Social care programmes, which help with employment, disability allowance and state entitlements facilitation, problem-solving, family support services, vocational training options and day care.

Key learning and challenges – implications for policy

Defining access to mental health – multi-level, multi-modal 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 within 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, particularly in low resource settings.

In determining public health priorities in mental health care, one cannot be guided by single switch prospects that appear on the

Picture: Abhijit Dey/Commonwealth Photographic Awards

'What pills and early detection are to an illness, social security is to well-being and recovery'

surface to close treatment gaps with no long-term sustainability, ignoring depth, complex needs and nuanced challenges. 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 health, ill health, symptoms and behaviour; as well as treatment commitment, ability to care for self and perform activities of daily living, enjoy work and social life, and feel independent and confident.

Supply-side drivers for access to mental health within this paradigm of recovery and well-being mandate the provision of multi-level, multi-modal services – from primary to tertiary, in formal/informal community and institutional settings. The spectrum of services, both pharmacological and non-pharmacological, should be delivered by a multi-disciplinary team through a co-ordinated 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 to cultivate and showcase positive patterns of help-seeking behaviour and influence perceptions of mental health through community linkages and active user-carer participation in the system, including holding the system and state accountable.

Social and economic determinants in mental health care – convergence challenges

Social and economic factors, such as poverty, caste, urban-rural divides and gender, determine both onset of mental illness and pathways to care. The many users who have been part of the Banyan display patterns in user-caregiver association of onset of mental health issues, relapse and non-adherence, due to 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 the unacknowledged burden of economic and social contributions to household are all linked with lack of access to care and inappropriate health-seeking behaviour.

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 known as Disability Allowance (DA) has demonstrated the potential for socio-economic entitlements to be applied as incentives for making progress towards and sustaining recovery.[5] 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.[6] Social services in addition to state entitlements involve the organisation and application of

social resources in the community – such as support groups for addressing gender divides, early childhood interventions, education support, legal aid, substance-use prevention measures, companionship and inclusion in social activities, counselling kiosks, safe houses, soup kitchens, day care or vocational training units, and employment hubs.

The policy challenge is in ensuring communication linkages at different levels of governance – linear and cross-sectional – that allow for such integrated delivery of services, in the least possible time. This communication is often marred by limited awareness and understanding of what services are or are not available across different departments, making coming together as a whole a difficult task. This is where the notion of health, and indeed mental health, has to expand and broaden in scope and form to include related areas; and this bundle of services can then be offered to a consumer in a clear, concise and convenient manner. What pills and early detection are to an illness, social security is to well-being and recovery, and the two cannot be de-linked, especially in low resource settings.

Addressing barriers in primary care integration

The absence of precise diagnostics and clear service pathways is a large deterrent in penetration of mental healthcare delivery at the primary healthcare level. The design of mental health services that are to be integrated into existing public health systems needs to be accompanied by a clear expression and widespread stakeholder acceptance of treatment protocols. In addition, protocols need to detail referral pathways and guidelines for their application – from the primary health centre to secondary or tertiary, and from the first intensive phase of treatment to the rehabilitation and self-managed care phase. Without consensus among clinicians, users, families and administration on referral pathways, the concept of stepped-up care in public health policy will not be as effective as it should be.

Some of the other barriers cited as affecting integration of mental health within primary care in India, and perhaps the world over, include:

- overburdened public health infrastructure;
- low priority in healthcare budgeting;
- minimal mental health orientation in undergraduate medicine curriculum;
- case-load burden;
- inadequate continuing training;
- administrative inconsistencies;
- poor leadership and management; and
- poor social care integration.

Even if protocols exist and are widely accepted, regional variations in the quantity and quality of public health care make complete integration of mental health in the immediate future a challenging and difficult task.

While expert and public health resources that exist in the mental health area are inadequate, a lot of dependence is now on those who are commonly referred to as the non-specialist workforce: the community health workers who act as significant drivers of help-seeking behaviour and who have shown their worth in the Banyan-run programme.

While there is much emphasis on scaling up evidence-based practice in current international discourse, practice also informs theory, particularly in the mental health sector where new directions, needs and challenges are continually merging. Therefore, evidence gathering must look towards studying indigenous designs of mental healthcare delivery that are meeting the needs of the sector in their own unique way.

Transforming tertiary centres for mental health care

Often relegated to the background in access to mental healthcare discussions are the changes necessary in tertiary service delivery. Given the abysmal conditions of mental health hospitals, it is not surprising that they are seen as appalling, unnecessary blots on the healthcare landscape. However, access to mental health care is contingent on 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 semblance to hospitals and align themselves philosophically with community-based mental health services, gains in access cannot be achieved.

While state institutional care as it exists today is to be challenged, the relevance of quality hospital-based critical care for sections of the population cannot be ignored. Equating de-institutionalisation with de-hospitalisation in countries across the world has impacted the rate of homelessness among persons with severe mental health issues. Sadly, many remain without care and treatment, and live lonely and sad lives –some even in prisons, owing to legislation that restricts emergency and involuntary medical and psychiatric support and care. Hospital bed spaces in secondary and primary health centres at the lower administrative units and in government and corporation hospitals are necessary to ensure that the access points are many and the environment open, transparent and integrative; and to ensure that the burden of in-patient care is not disproportionately placed on tertiary centres.[7]

Token changes alone, such as the renaming of these centres, increasing their funding, changing the names of staff positions, and capacity-building measures, will not help. Systematic, continuous and detailed long-term effort through strong leadership, and effective training and monitoring are required in comprehensively developing policy and applying a transformational framework for mental health hospitals.

Homelessness, civil commitment and access to mental health care

Access to mental health care is concerned with equity 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 UNCRPD is concerned with the institutional settings in mental health, particularly treatment initiated by involuntary commitment being contrary to the spirit of the Convention. The truth, as the Banyan has learned, 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. Below are vignettes of ordinary 'sane-insane' people attempting to enjoy civil liberties.

- 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, working in the state's employment guarantee scheme and maintaining occasional contact with relatives.

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 enforce a treatment order.

In defining access rights, policies must consider the primacy of user choice but also be bold enough to step in with affirmative action in case the capacity to make that choice has been lost through illness. On the one hand, policy must ensure checks and balances, while on the other, the orientation cannot be to contain media-constructed violence but to enable recovery.

Alternative institutional spaces and housing for the homeless

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 rather than actual resistance by users to treatment or other services. Many users live at the Banyan's centres voluntarily. Some take their medication when they choose to; others stake claim over spaces for their living arrangements. Relationships are formed, people look out for one another, they fight; fun and conversation fill the day, as does occasional disharmony, sorrow and frustration. Institutional spaces, even those with limited restrictions, could resemble a community: one with scope for social and occupational roles and full enjoyment of civil liberties.

Open and quasi open shelters, community living arrangements, community fostering, group homes, supported housing and affinity groups contribute to hope, aspiration and happiness.[8] Long-term dependency needs of user-carers who are elderly, chronically ill or highly economically distressed must be acknowledged. With a rapidly growing elderly population, this could well be the next big problem area in mental health if unaddressed in a timely manner.

Housing, as evidenced by the many 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 health care. 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.

The role of the state: new dawn, new hope

The 65th World Health Assembly (2012) recently called 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.[9] This motion was proposed by India, and is a testimony to the country's recent commitment to mental health.

This commitment has also been seen by the introduction of a fresh Mental Health Care Bill, which will for the first time mandate access to mental health care as a basic right and entitlement – a never-before-tried introduction. This approach may even change the delivery pattern of services, by making the consumer more aware, build demand and make the system more accountable. In addition, India has also decided to work on a Mental Health Policy, which, informed by larger trends and challenges in the sector and in tandem with the Bill, proposes a range of reforms and services that place the poor, average Indian user and caregiver at the centre. These attempts seem earnest when one observes the active engagement of diverse groups of people – users, caregivers, activists, professionals, academics, clinicians, strategists – to finally arrive at what one hopes will emerge as a dynamic, real and bold piece of work. A focus on mental health through this bill and policy may indeed improve lives and productivity.

Vandana Gopikumar has a Master's degree in Medical and Psychiatric Social Work from the Madras School of Social Work, Chennai. Vandana is currently engaged in the strategic expansion and direction of the Banyan and BALM, and is passionate about working with the most marginalised and vulnerable. She is also a member of the Mental Health Policy Group appointed by the Ministry of Health and Family Welfare, Government of India. She is currently enrolled in a PhD programme with the Tata Institute of Social Sciences (TISS) and Vrije Universiteit (VU), Amsterdam, and attempts to study conceptual and real world co-relations between social capital, social exclusion, rights, homelessness and mental illness.

Vaishnavi Jayakumar dropped out of a Management programme to co-found the Banyan (with Vandana Gopikumar) in 1993. She has a talent for numbers and shouldered the responsibilities of administration and finance at the Banyan as the trustee for Internal Services. She is also a talented designer who enjoys creating awareness material on mental health and disability. Vaishnavi participates in disability rights advocacy in the national arena, questioning and evolving current paradigms of social policy process. Using technology to promote access to information has been her forte for more than a decade. Recently, she set up an online group that is kept informed on disability and mental health issues.

Lakshmi Narasimhan holds a postgraduate degree in Social Work specialising in Social Welfare Administration from the Tata Institute of Social Sciences. She joined the Banyan in 2005 and has since been involved in various capacities in clinical work, stakeholder engagement, documentation and research. She currently heads the Mental Health and Social Action Lab (MHSAL), which works on enabling and testing solutions of relevance to the mental health sector.

Endnotes

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