Voluntary Initiatives in Low-Income Countries – The Potential for Partnerships

Anil Vartak, Gurudatt Kundapurkar, Mukhul Goswami, Radha Shankar.

Low-income countries are characterized by depressingly similar scenarios of mental health services. Mental health policies and clearly enunciated mental health programs are absent in many developing countries. The low priority given to mental health translates into limited resource allocation. Hence, the mental health infrastructure is grossly inadequate, both in facilities and trained personnel. However in some countries there are a few custodial institutions that cater to people who are seriously unwell, albeit for brief periods. Uneven economic development also means that the limited services are concentrated in urban areas, leaving rural areas to deal with both poverty and absence of health facilities. In the absence of a robust public mental health delivery infrastructure, services are delivered in a variety of settings including primary health care facilities, custodial and teaching hospitals, and clinics of private practitioners. The standards of both medical care as well as psychosocial interventions (if any) vary greatly in these different settings (Kulhara et al. 1999).

How does this bleak scenario impact the lives of people who have to deal with long-term mental illness? Many patients living in these countries do not have guaranteed and regular access to medical treatment, and often have to travel long distances to consult mental health specialists. To illustrate, it is estimated that in India only about 10% of persons with major mental illness receive modern medical treatment. Vocational and other forms of psychosocial rehabilitation that assist in the recovery process are available to an even smaller number of patients.

The overwhelming majority of patients in India live with family carers (Sharma,V., Murthy, S., et al. 1998), who in turn face one compelling reality: it is *they* who are required to provide sustained care and support in all phases of the illness, with or without medical interventions. Due to economic deprivation and lack of social welfare benefits, family caregivers also become responsible for providing food and shelter, paying for treatment, and trying to obtain employment for the person recovering from major mental illness. Invariably social norms dictate that caregivers also try to arrange marriages for their loved one. In summary, it is family carers who take on a wide variety of responsibilities that in the western world are more likely to be performed by specialists such as case manager, social worker, job coach, vocational counselor, community psychiatric nurse etc.

Even though the emotional, practical and financial demands on families are enormous, they receive little or no guidance from professionals. And such assistance is entirely at

the discretion of the individual mental health professional. As a result, to the vast majority of patients and their caregivers in low income countries, many of the advances of evidence-based medicine and optimal treatments remain in the realm of the unreachable.

In response to the challenges of caring for persons with long-term mental illness, the last twenty-five years have seen the emergence of family support groups in many parts of the world. In low income countries, the robust family involvement in the care of persons with mental illness has catalyzed these support alliances to meet critical gaps in services, especially in the areas of family education and vocational and employment support to patients. Family groups are also active in mental health advocacy. Using India as the prime example, this chapter describes initiatives pioneered by family groups that relate to services that are perceived as essential by family caregivers, but are only sporadically offered by the professional mental health system. We also hope that the experiences gleaned from these service models (which have evolved over 10 years in response to felt needs) will provide guidance to family alliances working in countries with meagre human and financial resources.

Mental Health Infrastructure in India

India is the prototype of a large, low income country, which faces several challenges in the delivery of mental health services. For a country with a population of over one billion, there are fewer than 4,000 psychiatrists (the city of New York has more). The number of allied mental health professionals (psychologists and social workers) is negligible.

Like most developing countries, India has a highly fragmented and heterogeneous health infrastructure (unlike national health services in Europe, Australia and Canada).

Health care providers include:

1. **State Run Hospitals and Teaching Hospitals**

   The public mental health infrastructure comprises about 35,000 beds in large custodial institutions. Teaching hospitals provide mental health services, but are concentrated in urban areas. Most state run treatment facilities are characterized by staggering caseloads, and used primarily by people who are from the economically weaker sections of society. It is estimated that on average, a patient with a long-term mental illness spends no more than three minutes with a mental health professional during a review of the medication status. The skewed ratio between health care providers and service seekers implies that services in most state run facilities are geared primarily to providing crisis care and some basic level of pharmacological support, and the psychoeducational inputs that have been described in this book are practically non-existent.

2. **Primary Health Centres in rural areas**

   Primary health centers are located in rural areas and are staffed by primary care practitioners with very limited exposure and training in mental illness. It is estimated that 60 % of people with health problems seek help from these practitioners.

3. **Private Practitioners**

As in all developing economies, market forces have catalyzed the growth of a private mental health delivery system and it is estimated that 60% of urban India seeks the help of private practitioners. They represent an alternative to the busy, crowded and impersonal state run facilities, but services are provided on a fee for service basis. This often imposes a heavy economic burden on patients and family caregivers, given both the absence of health insurance, and the long duration of treatment that is required in major mental illness. Psychoeducational inputs for the management of major mental illness are provided entirely at the discretion of the individual practitioner.

4. **Non-Governmental Organizations**

The country has seen slow and steady growth in this sector, although these organizations are primarily confined to urban areas. They offer tertiary care services like day care programs and vocational rehabilitation activities and run residential care facilities.

This large gap between need for the mental health services and the limitations of resources to meet the need has led to some interesting developments in the last two decades. The formulation of the National Mental Health Program (NMHP) (1983), which envisages delivery of mental health services thru the primary care health network, is an important initiative. The NMHP utilizes primary care doctors and non-specialized community health workers with a basic education to manage mental health problems. This ambitious initiative aims to deliver mental health services to India's vast rural hinterland through decentralized approaches. But it is important to recognize that it is premised primarily on delivering biomedical interventions *to patients who will continue to receive sustained care from family caregivers.*

Although the population served by the voluntary sector is currently small, the contribution of these organizations has had a defining impact for the following reasons; firstly, they have developed new models of service delivery, which have the potential to be replicated in larger state-run facilities; secondly, the steadily increasing visibility of these initiatives has drawn attention to the concept of partnerships between health sector services and non-government organizations (NGOs) in health delivery systems. Policy planners are therefore suggesting that in countries with limited resources and multiple developmental and economic challenges, both civil society and the non-governmental sector have a role in delivering services in partnership with government. Family carers are important stakeholders in the care of people with major mental illness in all parts of the world (see Chapter 8). Do they have a role in the delivery of services as mooted in the concept of NGO and Civil Society partnerships? This chapter examines the concept in greater detail by studying two models developed by family organizations in India.

The Schizophrenia Awareness Association – Ekalvaya: Initiative in Family Education
Pune, India

The SAA was set up in the Western Indian town of Pune, which is a mid size city located in the more developed and affluent western part of India. The vast majority of its members are urban, educated, belong to the middle economic strata of society and provide care for a person with long-term mental illness. Like most self-help groups in the field of mental health, SAA was set up in response to three felt needs:

1. The need for illness-related information and guidance since professionals were perceived as too few and too busy to provide this guidance, and the existing mental health infrastructure offered negligible psychosocial inputs.

2. The need for emotional support, which could help caregivers cope with the challenges of caregiving. This was necessary as there was no forum for families to vent, share, and come to terms with the changed circumstances of their lives.

3. The need to deal with stigma, which restricted caregivers from trying options that could facilitate better recovery.

Based on these needs, the SAA has developed two primary streams of activity - educational programs and mutual support programs.

Educational Programs for Families

Studies have shown that caregivers do not perceive professionals to be part of their "help network"(Thangarajan1994), and in the presence of a traditional hierarchical gap that exists between professional and family caregivers, the latter are generally diffident to seek guidance from the busy professionals.

The SAA model has defined its role as complementary to that of mental health professionals, and serves to facilitate dialogue and communication between busy professionals and families seeking guidance. The SAA provides a regular forum for caregivers to receive illness-related information and training in groups. This has been achieved by developing collaborative partnerships with professionals who support psychoeducational interventions on a voluntary basis. The education initiative is driven, organized and sustained by the family group, and clinicians are called in to provide the professional perspective. Every fourth Saturday of the month is allotted to interactive discussion with professionals on a topic that has been chosen by family members and which generally relates to management of the illness. The group format not only allows for easy dissemination of illness-related information, but also discussion of issues that are challenging in the Indian context, like arranging marriages for persons in recovery.

The SAA has been successfully conducting this educational initiative for over 10 years. Family caregivers contact the group in a variety of ways. Referral to the group by mental health professionals and general practitioners has been one important pathway, with supportive mental health professionals even displaying posters about the group in their

consultation rooms. This has been achieved over a period of time by building relationships with this group of stakeholders. All illness-related literature, pamphlets, materials for awareness and media campaigns are generally developed in close consultation with professionals. SAA collaborates with mental health professionals to organize orientation programs for family physicians–often the first point of contact for family members. This has not only earned goodwill, but also enhanced the credibility of the organization. Keeping in touch with media persons on a regular basis has also enhanced the visibility of the family support group resulting in caregivers approaching the group directly, even before a formal consultation with professionals has been initiated. Experiences of SAA also suggest that families will contact the group at different phases of the illness based on their perception of the problems and possible solutions. When families are in denial mode they will not even think they need help. Owing to the fear and pain of social stigma, hiding the illness itself comes in the way of seeking help. Once the family has approached a professional they may not initially feel the need for any other help. However, over a period of time when the family has experienced slow progress or even relapses, they are more amenable to look for help from other sources.

Guidelines for educational activities

- Define the activities that your group can take on and communicate this clearly so that members do not get disappointed or feel let down

- Involve caregivers in deciding the topics for discussion in educational sessions.

- Focus on topics that have practical relevance to daily life

- Handle with great care discussions on controversial issues, such a religion, politics, faith healing, etc.

- Encourage caregivers to ask questions

- Consider classroom-type, short-term courses, and talk shows using audio visual aids and feature films to discuss key issues.

- Educational sessions must include:

  o Effective communication
  o Sharing of responsibilities
  o Things that the person in recovery should avoid
  o Financial planning and self-reliance for the person in recovery

- The role of yoga as a tool for relaxation, and the pursuit of hobbies in the recovery process are also topics that SSA members find particularly helpful.

- Maintain and nurture collaborative links with professionals to serve as resource persons

Critical Appraisal of the SAA Educational Initiative

Although the SAA model is eclectic and non-structured, it includes many of the essential elements of family psycho-education and family education identified in the course of this guidebook. More importantly, in a country where 95 % of patients with long-tem mental illness live with their families (Dani & Thienhaus 1996), the SAA initiative effectively

harnesses the potential of families to be educators and synergize their experiential knowledge with professional teaching.

Mutual Support to Promote Self-Care

While professionally-led interventions focus primarily on optimizing the caregiving ability of families, the SAA also has programmes for promoting meaningful physical and emotional self-care for caregivers. (This is similar to Reason to Hope, the international educational program of the World Fellowship for Schizophrenia and Allied Disorders and other family programmes–see chapter 2). This is particularly necessary in a family-centred society like India, with close family ties and obligations, illness in one family member has the potential to disrupt the entire family. The SAA philosophy strongly values the importance of collective strength and problem-solving from a self-help perspective to achieve this objective.

The goal of promoting self-care is achieved through programs that that give primacy to the value of the "lived experience" and facilitate sharing of experience between family members. This helps to reduce the sense of isolation, loneliness and shame in a country where mental illness is deeply stigmatized and caricatured.

Self-help sessions are facilitated by experienced family caregivers and give opportunities for individuals involved in the caring process to speak and share their experiences without the fear of being judged. Caregivers are encouraged to develop an overall life perspective, which includes the challenges of caring for their relative, but also caring for self. Another major objective is to promote realistic acceptance and guide caregivers from being exploited by myths and superstitions, which are not only expensive, but could also cause physical trauma to patients. The SAA model of mutual support emphasizes the role of mature and empathetic family caregivers who can take the role of effective facilitators.

Engaging family caregivers in the group process

On most occasions, caregivers coming to group for the first time want to talk one-on-one instead of sharing their problems in the meeting. For this reason "first-timers" are introduced to a family caregiver volunteer who will be his/her mentor and be able to listen to the family story on a personal level.

The first and third Saturdays of the month are especially allotted for bringing new people into the group. The senior caregiver members of the group talk of their own experiences in a very reassuring and supportive way. The main objectives of the group and its activities are narrated. It is also important to clarify activities that are outside the scope of the organization These include non-availability of medication, on the spot consultation with a psychiatrist or counselor or arranging for residential facilities for persons in recovery.

For those with very pressing or immediate problems it may be necessary to talk with caregivers in person, usually in the privacy of the home setting. If the organization is able to meet the current needs of the caregivers (and it is recognized that all needs cannot be met) then families realize that they can trust the group, and participation becomes robust.

Guidelines for Facilitating Mutual Support

- Encourage caregivers to speak and share their opinions by creating a non judgmental atmosphere
- Diffuse differences between caregivers, by listening and redirecting attention to areas of common interest
- Handle with extreme care controversial topics like religion, faith healing and politics, which can estrange members.
- Facilitators must be disciplined and ensure maximum participation by all members by keeping rapport with caregivers individually
- Facilitators must delegate responsibilities and avoid one man shows.
- Facilitators must accept that needs of caregivers are varied and complex and it may not be possible to meet all the needs.
- Facilitators must never assume the role of a professional as the atmosphere of a peer group gets diluted.
- Facilitating a mutual support group is an on-going learning process and facilitators must be receptive to change and updating their knowledge

The Ashadeep Model: The Transition from a Family Caregiver to a Caregiver at the Community Level
North Eastern India

As is the case with many family mutual support groups, "Ashadeep" was started in 1996 in response to the challenges faced by a family who had to care for a loved one with schizophrenia. The initial focus was on emotional and educational support for family caregivers. However, in the last 10 years the organization has grown both in size and in the scope of its activities, and has evolved into a much broader service model that can be replicated. The distinctive features of this family alliance are:

1. It operates in the North Eastern region of India, which is remote, economically underdeveloped, geographically inaccessible, and has an absolute paucity of mental health resources.

2. It has phased in its activities, primarily in response to the evolving needs of its constituents. The program therefore extends beyond educational and emotional support, addressing multiple psychosocial needs of patients and caregivers in the community.

3. It is an example of an NGO/Civil Society Partnership, and exemplifies the advantages of planned strategic networking within and outside the field of mental health.

The service portfolio of the organization currently includes the following activities:

1. Education and support activities for caregivers, with a focus on dealing with both the negative symptoms of the illness and the consequences of stigma.

2. Specialized support for elderly caregivers.

3. Vocational skills development for patients in recovery, both in residential and non-residential settings.

4. Creating employment and wage earning opportunities for patients

5. Conducting mental health camps in areas which have no mental health facilities

6. Supporting homeless mentally ill women

The discussion in this chapter will be limited to vocational and income generation activities of the organization.

Vocational and Income Generation Activities: An NGO and Civil Society Partnership

The professional literature has extensively documented that vocational rehabilitation and gainful employment are among the most pressing and articulated needs for people recovering from major mental illness and their family caregivers. This is hardly surprising given the fact that people disabled on account of long-term mental illness do not receive any monetary social security benefits in India, and it is invariably family caregivers who have to manage the expenses related to treatment.

Therefore members, particularly those living in impoverished circumstances, have a need to develop and sustain income generating activities, an activity that presents many challenges to the organization. Nevertheless, vocational and wage earning activities are offered in both residential and day-care facilities.

The innovative model developed by Ashadeep is replicable and sustainable because the emphasis has been to avoid subsidies, and to produce goods and products that are easily marketable and have commercial value within the community. This not only assures long-term viability, but also ensures that recovering patients are paid a fair income instead of a token honorarium.

How Ashadeep has Achieved this:

- Extensive networking with government that comes under the Ministry of Labor, Textiles. Social Justice and Empowerment, has helped the organization not only to gain access to guidance about producing commercially-viable articles, but more importantly created an ongoing technical training resource.

- Liaison with large Mental Health facilities in the public domain has created a steady and captive market for some of the workshops products like pillows and bed linen.

- Since the philosophy of income generation is to ensure a fair wage to the patient and caregiver stakeholders, the organization has also adopted an

aggressive marketing approach capitalizing on all available opportunities for small enterprises.

- The organization has consciously attempted to achieve economies of scale by supporting smaller and satellite workshops outside urban areas. The mental health camps organized by Ashadeep in rural and semi-rural areas have been the catalysts for satellite workshops and these have been facilitated by networking with non mental health NGOs who are engaged in development activities.

The integrated model of care developed by Ashadeep where patients move seamlessly across care settings depending on their recovery has not only created a steady human resource base for production, but also, and more importantly, provided employment security for patients.

Guidelines for Setting up Vocational and Income Generation Activities

- Think beyond occupational therapy mindset. The aim is not to keep patients "occupied` but ensure a fair wage.
- Identify commercially viable activities and identify products that have a good market in the region.
- Network with governmental and non-governmental agencies, which provide training in production and marketing of goods.
- Liaise with mental health facilities in the public sector to ensure a regular off-take of products manufactured in the workshop.
- Constantly update the product range and the training activities.

Conclusion

Governments in many low-income countries are actively encouraging partnerships in educational, health and social welfare sectors, with the stated objective of offsetting resource limitations. The psychosocial initiatives undertaken by family support groups of people with long term mental illness, are examples of these. These service models have emerged in response to the pressing needs of family caregivers and patients, and the limited efforts of the formal mental health system to attend to these needs.

However, family members of persons with long-term mental illness are not only key stakeholders, but also putative recipients of many psychosocial interventions. Their role in initiating and remaining actively involved in the delivery of these interventions gives rise to many questions that require discussion.

Would initiatives driven and executed by families further strengthen the reluctance of the formal mental health system to assume primary responsibility for these important services?. Will the state continue to regard them as privileges and not entitlements, and expect them to be handled by the voluntary sector? What mechanisms need to be put into place to ensure sustainability? How will family stakeholders ensure they hold an equitable role in these partnerships? A related issue would be the potential conflict of interest when the service provider could also become a direct beneficiary of the service.

We would like to suggest that the contours of multi-sector partnerships in mental health, which involve family groups have to be defined. However, the pioneering service initiatives undertaken by family groups are important demonstration and model experiments, worthy of replication by the formal mental health system.

References

Kulhara, P, Chakraborty., Ramana, A.L. 1999. Management of Schizophrenia: Minimum standards of care– psychosocial treatment. *Indian Journal of Social Psychiatry, 14,1-4.*

Sharma, V., Murthy, S., Kumar, K Agarwal, M., Wilkinson, G. 1998. Comparison of People with Schizophrenia from Liver pool, England and Sakalwara, Bangalore. *International Journal of Social Psychiatry,* 44 (3):225-230.

INDIA. Ministry of Health and Family Welfare. Directorate General of Health Services. 1982. *National Mental Health Program* for *India*. New Delhi

Thangarajan, C.M. 1994. *Coping with Schizophrenia in the Family*. Unpublished Ph.D dissertation. Tata Institute of Social Sciences, Mumbai, India

Dani, M.M., Thienhaus, O.J. 1996. Characteristics of patients with schizophrenia in two cities in the US and India. *Psychiatric Services* 47: 300 –301