MENTAL HEALTH
BY THE
"PEOPLE"

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October 10, 2006.

October 10, 2006.
Published by:
PEOPLES ACTION FOR MENTAL HEALTH (PAMH), Bangalore.
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Peoples Action for Mental Health is a voluntary initiate to empower individuals, families and communities towards promotion of mental health, prevention of mental disorders and care of the mentally ill individuals.

An undertaking such as the present book is the result of the combined efforts of several people. I owe a deep sense of gratitude to all of the persons who shared my vision and willingly gave their best efforts to make this book a reality.

My grateful thanks are to:

- Each one of the contributors to the book chapters, for sharing their passion for mental health, commitment to care, innovative drive, and finding the space in their busy lives to share their experiences;

- Dr. Kishore Kumar, Department of Psychiatry, NIMHANS, Bangalore for his support in coordinating a number of the contributions and critical suggestions for the making of the book a reality;

- Radha Srinivasa Murthy, my partner for life and partner in this venture, for sharing the many late nights, weekends in office and most importantly the vision for the book and

- Many others who helped make this book a reality.

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Introduction

There is international focus of human resources for health care. The theme of the World Health Report 2006(WHR 2006) is **Working Together for Health**.

The WHR 2006, begins with the following observation:

In this decade of the 21st century, immense advances in human well-being coexist with extreme deprivation. In global health we are witnessing the benefits of new medicines and technologies. But there are unprecedented reversals. Life expectancies have collapsed in some of the poorest countries to half the level of the richest –attributable to the ravages of HIV/AIDS in parts of sub-Saharan Africa and to more than a dozen "failed states". These setbacks have been accompanied by growing fears, in rich and poor countries alike, of new infectious threats such as SARS and avian influenza and "hidden" behavioural conditions such as <u>mental disorders</u> (emphasis added) and domestic violence.(xv)

The Report defines health workers to be

"all people engaged in actions whose primary intent is to enhance health"(p.1).

Further, the Report notes

"the ultimate goal of health workforce strategies is a delivery system that can guarantee universal access to health care and social protection to all citizens in every country. <u>There is no global blueprint that describes how to get there- each nation must devise its own plan. Effective workforce strategies must be matched to a country's unique situation and based on social consensus"</u>(emphasis added)(p.119)

I have been part of the mental health care developments of the country for over 30 years. An early paper in my career, along with Prof. N. N. Wig, in 1983, published in the American Journal of Psychiatry was titled "A training approach to enhancing mental health manpower in a developing country". That paper essentially outlined the possibilities for integrating mental health with general health personnel, as a way to address the wide gap between the mental health needs and the limited resources for providing care. I was also deeply impressed by the landmark publication of WHO in 1975 by Kenneth Newell, Health By the People, as the book came out at the time of my completing the postgraduate training in psychiatry.

During the last two decades, there has been quantum change in the mental health scene in India (pages 13-20). It is in this context, the place of self-care and informal care in mental health care becomes important. These two have been described at the bottom of the pyramid of optimal mix of mental health services by W.H.O.(2003).

The current effort is to document the many initiatives in India addressing the mental health needs by "people". In this book, "people" refers to persons other than the traditionally recognised mental health professionals like psychiatrists, clinical psychologists, psychiatric social workers, psychiatric nurses and occupational therapists who are recognised as mental health care providers.

Each of the contributors was requested invited to write about their experiences on broad guidelines covering

1. **Background** to the organization and the reasons for the initiative;
2. The reasons for **choosing "people"** for mental health care;
3. **Training** approaches developed;
4. **Care provided by the "people"** (what is the level of care and limits of care);
5. **Support** for the care by the mental health professionals;
6. **Difficulties** encountered and the measures used to overcome the same;
7. **Lessons learn**t;
8. **Resources materials**, publications developed that can be used by other organizations;
9. **Future plans** for the initiative.

The experiences shared by the over 30 authors reflects the wide range of initiative by "people" in India to address a wide variety of mental health needs. It is interesting that not all of these initiatives are addressing the traditional mental disorders.

Each author, was given the freedom to develop their own style of presenting their experiences, to reflect the very individual nature of the innovative effort. This is both a strength in a book like this and from purely editorial point of view a limitation. I think the benefit of this flexibility is more valuable than the limitations of differing styles of the chapters. All the authors have given their full contact details to facilitate easy communication.

The range of experiences do not cover all of the initiatives in India. Both the time available to compile the book as well as the availability of contributors limited the book being a comprehensive account of all that is happening in India in this field. Notable absent contributions are the school counselor experience of Mumbai, the multiple suicide prevention programmes (only two of the over dozen experiences appear in the book), to name a few. I hope the current effort will stimulate a much bigger effort towards a comprehensive documentation of the initiatives in future.

The development of multiple approaches to address mental health is a continuous process. This book takes a cross-sectional snap shot of the current situation. I also hope that the availability of so many approaches will lead to greater efforts in this field, as well as better networking of innovators top share, collaborate and care.

R. Srinivasa Murthy
Bangalore.

Overview of mental health care in India*

During the last 60 years, the place if mental health as part of general health has significantly changed in India. From a situation of minimal organized mental health care at the time of independence, mental health issues are now public agenda in various forms. Some examples are:

-The formulation of the National Mental Health Programme (GOI, 1982);
-The integration of mental health with primary health care (PHC) at the district level (Government of India. 2000);
-The adoption of Mental Health Act in 1987 and Persons with Disabilities Act in 1995;
-The Supreme Court judgments about mental hospitals and attempted suicides;
-The increasing participation of voluntary agencies in the areas of family self-help groups, rehabilitation, drug dependence and suicide prevention;
-Media coverage of mental health issues (DATE on radio in 1992, Mindwatch on TV in 1997);
-The attention to mental health problems at local, regional and national levels following the Erwady tragedy in August 2001.

The overall effect has been an increased recognition of the importance of mental health as important to the community. The evolution of such a recognition and the implementation of plans and policies that ensued after Independence can be divided into three phases: (i) 1947-1975; (ii) 1975-2000 and (iii) 2000 – ongoing.

1947-1975: Defining mental health needs

One of the earliest references to the needs of the mentally ill is the report in the Indian *Medical Review* (1938). The report mentions 17 mental hospitals in British India which could accommodate 8,425 patients, but the number of patients actually confined to those hospitals in 1936 was 11,793. there was overcrowding in almost all the hospitals but the problem was acute in Madras, Bombay and the United Provinces.

The dominant force in the development of mental health in the first phase was the policies relating to primary health care. Beginning with the Bhore Committee Report (1946), mental health has been part of the general health planning in the country. The major recommendation of the Bhore Committee was setting up of infrastructure in rural areas with the primary health centers as the chief focus. The proposals for mental health care were : (i) creation of mental health organizations as part of the establishments under the Director General of Health Services at the Center and the Provincial Directors of Health Services; (ii) improvement of he existing 17 mental hospitals and establishing two new institutions in the first five years and five more during the next five years; (iii) provision of facilities for training in mental health for medical professionals in India and abroad and for ancillary personnel in India and (iv) establishment of a Department of Mental Health in the proposed All India Medical Institute.

The next committee set up to review the health situation in the country was the Mudaliar Committee in 1962. an important outcome of this Committee's recommendations was the setting up of a number of district psychiatric units in different parts of the country and the creation of a Mental Health Advisory group at the Ministry of Health.

The Srivastava Committee (1974) was the next major committee to review the progress of health and suggest plans for the future. The committee recommended the community health volunteer (CHV) scheme. The training of CHVs contained a small component of mental health. Out of the total training of 200 hours, one hour was for mental health. One chapter in the CHV manual was devoted to the regulation and management of mental health emergencies and problems.

Growth of mental health services in India

Mental Hospitals: by the middle of the 1970s, the growth and development of mental hospitals was the main approach for the provision of mental health services. Most of the mental hospitals have remained undeveloped and unsatisfactory in terms of the services provided and the facilities for care. A recently completed survey of the mental hospitals by the National Human Rights Commission (NHRC) presents a picture of neglect of and a minimal level of care to the mentally ill. A large part of the stigma regarding mental illness is due to the poor conditions of the mental hospitals. There is an urgent need for extensive changes in the situation of mental hospitals so that these become centers of care an treatment, from being just custodial institutions.

The growth and development of general hospital psychiatric units (GHPU) in India was an important mile stone in the development of Indian psychiatry. Wig (1978) refers to it as a slow and silent change. It was a major revolution in psychiatric treatment. GHPUs facilitated a greater acceptance of psychiatric services by people in general and in changing the mental health scene in terms of training of mental health professionals and the research that emerged.

The development of district psychiatric units recommended by many health committees, notably the Mudaliar Committee (1962), has been very slow and uneven. At present every district in Kerala and Tamil Nadu have these units. However, the situation in the northern and north –eastern states is unsatisfactory.

1975-2000: integration of mental health into primary health care

The second phase can be called the period of integration of mental health into primary health care. The reasons for this integration were: (i) the recognition of the large numbers requiring mental health services, both in the community and general medical clinics. This was specially true for those living in the rural areas; (ii) the limited number of psychiatrists and other mental health professionals providing care; (iii) the emerging integration of all health programs form the vertical program model to multipurpose model; (iv) the international development of primary health care as the approach to organized health services; (v) the awareness of the importance of early recognition and treatment to prevent chronicity; and (vi) the goal of continuity of care and integration of the mentally ill into the community.

This integration occurred at two levels, namely the training of general practitioners and primary health care personnel working in the rural health services.

Rural Psychiatric Services

The organization of essential mental health services as an integral part of primary health care has been a major development in India. Two centers, one each in Bangalore and Chandigarh, initiated the effort. Currently, the program covers over 25 districts, in 22 states providing services to about 40 million people. This program is expected to cover 100 districts in the next 5 years.

At Chandigarh, this program was initiated in 1985. this was because the psychiatric services of the hospitals were observed to be used by a very small population. This aim was to develop a model for rural psychiatric services. The World Health Organization (WHO) also supported this approach. The WHO project "Strategies for extending mental health care (1976-1981)" was a multicenter project carried out in seven countries (Brazil, Colombia, Egypt, India, Philippines, Senegal and Sudan). The basic approach adopted in this model was to integrate mental health with the general health services and provide basic mental health care as a part of primary health care. The results demonstrated that mental health could be integrated with the general health services by prioritizing and developing proper training programs.

The Community Psychiatry program at the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore was launched in 1976. The aim of this rural project was to develop suitable training programs for doctors and multipurpose workers (MPWs) from the various primary health centers in Karnataka so that they could provide basic mental health care such as detection and management of epilepsy and psychosis. The team initially studied the needs of the rural population in one primary health center (1975-1980). The team identified the mentally ill in their homes through key informants and those attending the general health facilities. This was followed by as pilot experiment (1980-1986) to integrate mental health with primary health care in one primary health center with a population of 100,000. this was followed by a model program covering a district with a population of 2 million.

National level initiatives for a Mental Health Program

The Directorate General of Health Services organized national-level workshop at New Delhi (July20-21, 1981) to consider a draft mental health plan. The essential aspect of the suggested plan was to stimulate services both in the periphery and at the center to integrate mental health care at the levels of the health services.

The objectives of the program were to ensure availability accessibility of minimum mental health care for all in the foreseeable future; to encourage application of mental health knowledge in general health care and social development; to promote community participation in the mental health services; and to stimulate effort towards self-help in the community.

The specific approaches suggested for the implementation of the National Mental Health Program (NMHP) were :

- ***Diffusion mental health skills to the periphery of the health service system;***
- ***Appropriate appointment of tasks in mental health care;***
- ***Equitable and balanced territorial distribution of resources;***
- ***Integration of basic mental health care the with general health services and linkage to community development.***

The NMHP document was presented to the Central Council of Health and Family Welfare (CCHFW) at the meeting during August 18-20, 1982. it recommended that mental health must form an integral part of the total health program and it should be included in all national policies and programs in the field of health education and social welfare. It also highlighted the importance of mental health in the course curricula for various levels of health professionals and suggested that action be taken in consultation with the appropriate authorities to strengthen the mental health component. Similar recommendations were made by the same body when it reviewed the progress of the NMHP in October 1995.

Following the development of the NMHP in the past two decades the following initiatives and activities have been undertaken : sanitization and involvement of the state level program officers; workshops for voluntary agencies ; workshops for mental health professionals, namely psychiatrists, clinical psychologists, psychotic social workers, and psychiatric nurses; training programs in public mental health for program managers; state –level workshops for health directorate personnel; development of models of integration of mental health into primary health care up to the level of the districts; preparation of support material such as manuals and health education; and training program for teachers of undergraduate psychiatry.

Of the many initiatives, the integration of mental health with primary health care at the districts level is the important development. The essentials of the District Mental Health Program (DMHP), as developed at the Bellary District of Karnataka and currently under implementation in 24 districts in the country with Central Government are:

- **A decentralized training program for the existing health personnel on essentials of mental health care the at the district level;**
- **Provision mental health care in all general health facilities;**
- **Involvement of all categories of health and welfare personnel in mental health care;**
- **Provision of essential psychiatric drugs at all health facilities;**
- **A simple record-keeping mechanism to monitor the work of primary health care personnel in the provision of mental health care the;**
- **a mental health team at the district level for training of personnel, referral support and supervision of the mental health program.**

The initial project at Bellary demonstrated the feasibility of providing basic mental health care along with primary health care.

The National Health Policy (NHP, 1983) was adopted by the parliament to provide a new direction for health planning in India. One of the main recommendations was the increased emphasis on community participation and empowerment of the community for health.
"Special well-coordinated programmes should be launched to mental health care as well as medical care and also the physical and social rehabilitation of those who are mentally retarded, deaf, dumb, blind, physically disabled, infirm and the aged."

Progress of NMHP (1982-2006)

During the past few years, the DMHP has been adopted for implementation at the national level. The DMHP was launched in 1996/97 in four districts, one each in Andhra Pradesh, Assam, Rajasthan and Tamil Nadu, with a grant assistance of Rs.2.25 million has been made during the Ninth Five-Year Plan period for the NMHP.During the next five years , the districts covered were extended to 27 districts. During the recent five years, the coverage for the district mental health programme has been extended to nearl;y 100 districts(nearly one sixth of the country).In addition, a number of states have taken up the mental health reform in a comprehensive and time bound manner(eg. Haryana, Gujarat, Karnataka). All of these developments predicts the possibility of the mental health care becoming universally applicable to the total population in the coming years.

A reflection of the changes is the manner in which the mental health issue is reflected in the revised National Health Policy (2002), as compared to the 1983 National Health Policy(1983).

The **National Heath Policy (NHP, 2002)** includes mental health as follows:

"NHP-2002 envisages a network of decentralized mental health services for ameliorating the more common categories of disorders. The program outline for such a disease would involve the diagnosis of common disorders, and the prescription of common therapeutic drugs by general duty medical staff. In regard to mental health institutions for indoor treatment of patients, the policy envisages upgrading of the physical infrastructure of such institutions at he Central Government expense so as to secure the human rights of this vulnerable segment of society".

Disaster and mental health programs

The National Heath Policy (NHP 2002) envisages :
"An adequately robust disaster management plan has to be in place to be in place to effectively cope with situations arising from natural and man-made calamities."

The overall development of mental health care with emphasis on decentralized mental health services, involvement of a wide variety of personnel for such care, utilizing strengths of the family and community, and strong emphasis on sharing of knowledge and skills with the general population (destigmatization) are in line with the disaster-care goals. The increasing recognition of the mental health aspects of disasters will enhance the value of mental health by the community.

Mental health manpower development

The recommendation of the Bhore committee led to the establishment of the All India Institute of Mental Health at Bangalore in 1954. a postgraduate diploma in psychological medicine was initiated in January 1955. since then a large number of training centers have come up and there are at present over 50 postgraduate training centers in psychiatry. However, the number of training centers for psychiatric nurses, clinical psychologists, and psychiatric social workers is inadequate. About 3,000 qualified psychiatrists are working in different centers in the country. The number of non-physician mental health professionals is estimated to be about 2,000.

Of the 140 medical colleges in India, about three-quarters have an academic department of psychiatry. In the remaining, a psychiatrist functions as part of the department of general medicine with no additional staff. The minimum training required by a psychiatrist according to the Medical Council of India is for two weeks only, which is grossly inadequate. Often this training occurs in a distant mental hospital. This lacuna in giving adequate exposure, competence and skills to diagnose and treat mental disorders needs urgent attention. The stagnation of undergraduate training in psychiatry contrasts with the improvements in postgraduate training programs.

Legislative Changes

During the past five decades, along with the changes in the care of the mental ill, there have been legislative changes in the programs for persons with drug dependence and mental retardation. The Mental Health Act, 1987 replaced the Indian Lunacy ACT, 1912.

The Persons with Disabilities Act,1995 included mental disorders as one of the disabilities. The development of services for the mentally retarded has shown a dramatic improvement. The National Institute of Mentally Handicapped established in 1984 at Secunderabad has provided leadership in training of personnel, preparation of support material for different functionaries, as well as for research. In the area of drug dependence, the Narcotics and Psychotropic Substances Act, 1985 has come into effect.

2000 and ongoing: people participation in mental health care

Family involvement

In India, the majority of the mentally ill live with their families. Families have been a part of the health care program for long period. In the past 60years, the measures taken to involve the families have included involvement in care during the period of hospitalization educational programs for family members; partnership between professionals and families and the formation of self-help groups of families; and support for families caring for the mentally ill. Two National level caregiver workshops have been organized in 2001 and 2003. (pages 116-176).

Community involvement

A innovative programs have been developed to utilize community resources in the mental health program. The camp approach for addressing the problem of drug dependence is one of them. Volunteers have been inducted into teams in Rajasthan (for opium addiction) and Tamil Nadu (alcohol dependence)(Pages 222-231). The other area in which volunteers have been used extensively is the suicide prevention program at different centers in the country(pages 232-245). Another program of importance is the school mental health program, which focuses on training teachers to provide essential mental health care, and to involve them in teaching life-skills education to students(pages 82-115).

Public mental health education

A notable feature of the Indian mental health experience is community education. Professionals have used the available media, especially newspapers, magazines, radio and television to address the problems of drugs, alcohol, and tobacco (DATE programme) and mental disorders (Mindwatch series on the national television). The media has also focused on issues of mental hospitals, women in institutions, inmates of jails and mental retardation. A recent addition to these activities is the television chat shows, which often relates to mental health issues.

Other developments

The area of rehabilitation is making beginnings in India. Day care centers, half-way homes, and long-stay facilities are coming up gradually. There is a master's program for training rehabilitation personnel at the Richmond Fellowship, Bangalore and Father Muller's Hospital, Mangalore.

The positive aspects of the Indian mental health programme the enhanced recognition of the mental health needs of the community and services that are available in both the public and private sectors. However, it must be emphasized that the programs and initiatives have still not reached the majority of the population. There are large gaps and regional variations in the scope of such programs. While the rest of the world is discovering the value of mental health in primary health care and focusing efforts in this area, India, which initiated the integration of mental health in primary health care nearly a quarter century ago, has not done enough.

Agenda for the future

1. Advances in the understanding of human behavior and mental disorders justify the optimism of developing meaningful and realistic mental health programs.
2. The nature of mental health requires that actions and interventions be multidimensional. They should involve various sectors, professionals and approaches. The wide variations across India demand that individualized plans are developed for each state and union territory, along with a national plan and program. There is a need for a mental health organization at the center
3. At the psychiatric care institutions should be upgraded in terms of trained personnel, treatment and rehabilitation facilities, living arrangements, and community outreach activities.
4. Medical colleges should have independent departments of psychiatry to ensure adequate undergraduate training in mental health. District mental health teams should be constituted as part of district hospitals and the district health office. Integration of mental health with primary health care should be achieved to facilitate early identification of patients, their reintegration into the community.
5. Mechanisms to monitor the mental health of populations at the level of districts and subunits of districts should become part of the development of all heath information systems.
6. Support should be provided by the government for the families of the mentally ill in terms of community –based services, financial support for care, and formation of self-help groups. There should be enhanced involvement and aid to voluntary agencies to take initiatives towards promotion of mental health, prevention of mental disorders and treatment of the mentally ill.
7. Planned mental health manpower development should be undertaken by increasing the centers of training and creating opportunities for employment. Programs for public education should be developed through all available traditional and modern media.
8. Research should be supported at national, regional and local levels to understand the prevalence, nature and course and treatment response of mental health. There is an urgent need to understand the impact of social changes and development policies on mental health.

Summary

This chapter gives a holistic overview of the development in the field of mental health in India since independence. The first phase emphasized the developments beyond mental hospitals. The second phase moved towards integration of mental health with primary health care. The current phase is characterized by emphasis on community resources such as family, and volunteers. The process of mental health for all is guided by the approach of mental health care by all.

*** Modified from Mental Health Care in India by N.N.Wig and R.Srinivasa Murthy in (Eds) Lakshminarayana, R., SrinivasaMurthy, R., and Diaz, J.O.P. in Disaster Mental Health in India, Indian Red Cross Society, 2004. Delhi.(pages 20-36).**

National Mental Health Programme (NMHP) 2005-2006.

The Cabinet Committee on Economic Affairs has since approved the launching of NMHP during the Tenth Five Year Plan , which will cover the above components at an approved outlay of Rs.190 crores, which has now been revised to Rs.139 crores.

A Steering Committee was set up under the chairmanship of Secretary (Health) for implementing and monitoring of the NMHP during the 10th Plan. As recommended by the Steering Committee, 67 new districts have been included into the District Mental Health Programme, which includes 10 new districts from North-eastern Region.

The Government of India has constituted Central Mental Health Authority to oversee the implementation of the Mental Health Act, 1987. The Mental Health Act 1987, provides safeguards for protecting patients suffering from mental illness from stigmatization and discrimination. It provides for creation of State Mental Health Authority also to carry out the said functions.

The National Human Rights Commission(NHRC) also monitors the conditions in the mental health hospitals along with the Government of India and the states are currently acting on the recommendations of the joint studies conducted to ensure quality in delivery of health care. Steps are being taken to improve the cure of long stay patients especially those below poverty line and destitute(s) in the state run mental hospitals.

Thrust areas identified for the Tenth Plan

1. District Mental Health Programme in an enlarged and more effective form is covering the entire country. At present 94 districts are being funded under the programme.

2. Streamlining/modernization of mental hospitals in order to modify their present largely custodial role. A sum of Rs.38.39 crores was released for this activity in during 2005-2006.

3. Upgrading departments of Psychiatry in medical colleges and enhancing the psychiatric content of the medical curriculum at the undergraduate as well as postgraduate level. Nine medical colleges were funded in the year 2005-06 for upgradation.

4. IEC, research and training in the field of mental health. At present 57 research proposals are in the pipeline for funding for research in the field of mental health.

(from Annual Report 2005-2006, Ministry of Health and Family Welfare, Govt. of India pages 132-135).

Framework for mental health care

During the last five years, the world attention to mental health care was drawn by the choice of the World Health Organisation, to choose the theme of mental health for the World Health Day(April 7, 2001) and the World Health Report 2001. In devoting the World Health Day 2001 and the World Health Report 2001 to Mental Health, the World Health Organization (WHO) made a statement that mental health – "neglected for far too long, is crucial to the overall well being of individuals, societies and countries and must be universally regarded in a new light." (World Health Report, 2001). It also made recommendations for formulating policies for effective prevention and treatment. The theme "New Understanding, New Hope" stresses how science and common sense can be combined to break barriers about mental disorders. (World Health Report, 2001).

As a follow up of the World Health report, the Department of Mental Health, W.H.O. Geneva has developed the **Mental Health Policy and Service Guidance Package.** This package, to-date, consists of the following modules:

- **The Mental Health Context**
- **Mental Health Policy, Plans and Programmes**
- **Mental Health Financing**
- **Mental Health Legislation and Human Rights**
- **Advocacy for Mental Health**
- **Organisation of Services for Mental Health**
- **Planning and budgeting to Deliver Services for Mental Health**
- **Quality Improvement for Mental Health**
- **Improving Access and Use of Psychotropic Medicines**
- **Child and Adolescent Mental health policies and Plans**
- **Human Resources and Training for Mental Health**
- **Mental Health Information Systems**

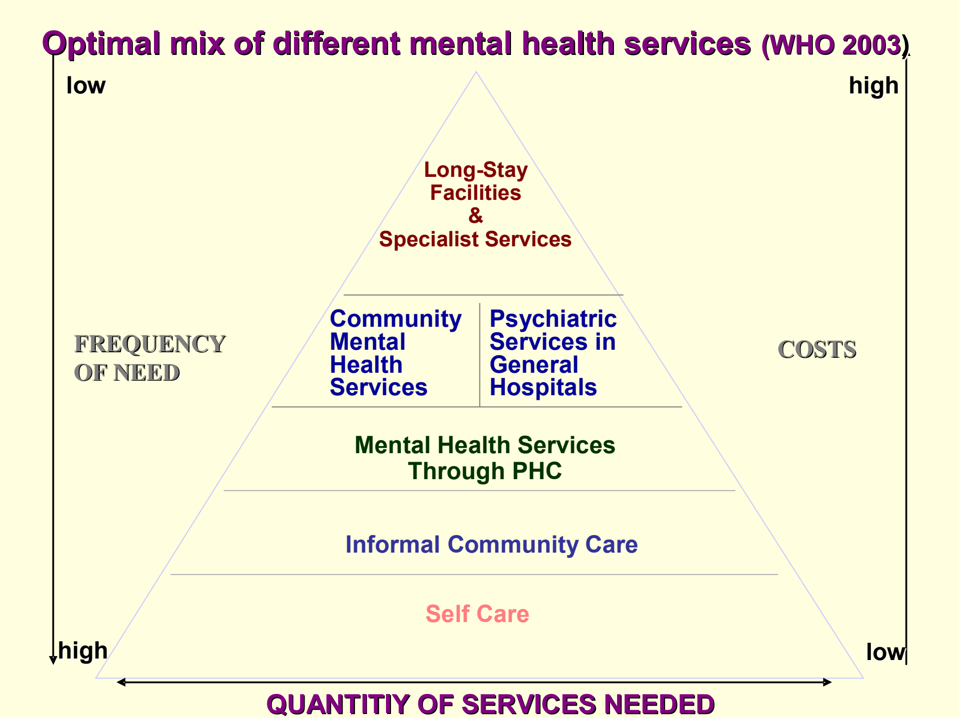
(All of these documents can be accessed from the WHO-Mental Health website.)

The following sections are from the above Policy package and covers the topics of establishment of an optimal mix of mental health services and the role of non-professionals(PEOPLE in the context of this book).

Establishment of optimal mix of services (*from Organisation of services for mental health- Mental Health Policy and Service Guidance Package, WHO, 2003,pages 33-34*)

The key issue for the service planners is to determine the optimal mix of services and the level of provision of particular service delivery channels. The absolute need for various services differs greatly between countries but the relative needs fore different services , i.e. the proportions of different services as parts of the total mental health service provision, are broadly the same in many countries. Services should be planned in a holistic fashion so as to create an optimal mix.

Figure shows the relationship between the different service components. It is clear that the most numerous services ought to be self-care management, informal community mental health services and community mental health services provided by the primary health care staff, followed by psychiatric services based in general hospitals and formal community mental health services, and lastly by specialist mental health services. The emphasis placed on delivering mental health treatment and care through services based in general hospitals or community mental health services should be determined by the strengths of the current mental health or general health system, as well as by cultural and socioeconomic variables.



Service functions and training requirements for an optimal mix of mental health services (from **Human Resources and Training in Mental Health**- Mental Health Policy and Service Guidance Package, WHO, 2005)

Informal Community mental health services.

Local community members who are not professionals in mental health or health care provide a variety of services. Examples of people working at this level of service provision include: lay volunteers, community workers, staff in advocacy organizations, coordinators of self-help/user groups, humanitarian aid workers, traditional health workers and other professionals such as teachers and police officers.

Many of these informal community-care providers have little or no formal mental health care training, but in many developing countries they are the main source of mental health provision. They are usually accessible and generally well accepted in local communities.

They can help with the integration of people with mental disorders into the community, and thus play an important supportive role to formal mental health services.

(i)Functions

It is important to pint out that informal community mental health service providers are unlikely to form the core of the mental health provision. Indeed, countries would be ill-advised to depend solely on their services. However, they can complement formal mental health services and form useful alliances.

Some of the important functions performed by informal services are:

Supportive care, including counseling and self-help. They can provide basic counseling for brief and acute mental health problems. This includes individual supportive counseling, family support, as well as group-based counseling for people with mental disorders and their families. They can play a useful role in catalyzing the setting up of self-help groups as well as support groups for individuals, carers and their families. They can also provide day-care services for people with mental disorders.

Help with activities of daily living and community reintegration. Many people with mental disorders have difficulty gaining access to the services necessary for living in the community. For example, a number of people with chronic and severe mental illnesses have enormous difficulties with activities such as shopping, traveling on public transport and obtaining benefit payments, to name a few. Informal services can play an important role in helping such individuals with these activities, thereby assisting them to reintegrate into the community.

Advocating the rights of people with mental disorders. Informal services can play an important role in advocacy. For example, they can educate individuals and their families about mental health issues and leadership, help individuals and their families to form their own organizations and contribute to the development, planning, evaluation, and monitoring of mental health services. They can also contribute to the development of mental health policies and legislation. Other advocacy actions include awareness raising, dissemination of information and education and training.

Preventive and Pronotive services. Examples of such services include teachers providing mental health services in schools, preventive programmes for alcohol and substance misuse, and interventions aimed at reducing domestic violence. In most countries community members, who are not necessarily mental health professionals provide these services, and in many instances these interventions are part of wider health and /or social interventions.

Practical support. In many communities, lay people provide basic, practical support, such as community –based housing for people with mental disorders, employment opportunities in sheltered workshops as well as in open employment, and shelters for women who are victims of abuse and domestic violence.

Crisis support. Informal services can play a useful role in crisis intervention, such as counseling in humanitarian emergencies, setting up and running telephone helplines, crisis support and help to families in distress, and counseling support to women who are victims of domestic violence.

Identification of mental health problems and referral to health services. When informal service providers are able to identify people with mental health problems but lack the competencies to address those problems, a key function is to refer those individuals to the relevant health services equipped to deal with such problems.

(ii) Competencies required

By definition, local community members involved in providing informal community care are not expected to have formal mental health training. Moreover, it is a heterogeneous group comprising lay people and family members, who may have no mental health training, traditional healers , who may be trained in indigenous systems of healing, and professionals from other fields, such as human rights activists, lawyers teachers and police personnel, who may be involved in many other functions described above. It is therefore not possible to prescribe minimum competency criteria for individuals involved in providing informal care. Instead, it is useful to think of some discrete competencies that may enable such individuals to become more effective in helping people in the community who suffer from mental disorders.

Useful competencies at the level of informal community mental health services include:

Basic understanding of mental disorders. This includes understanding the symptoms of mental disorders and how they affect the behaviour of individuals with those disorders. It also requires an understanding of the need for treatment, including medical and psychosocial interventions. In addition, it is useful to have an understanding of the needs of the people with mental disorders for ongoing treatment, the role of psychological and environmental factors in precipitating relapse, and the effect of mental disorders on individuals ability to deal with the activities of daily living, and to handle stigma and discrimination.

Basic counseling competencies. This includes listening and communication skills, especially empathic listening. Training should be provided in basic competencies, such as the need to maintain confidentiality, managing conflict of interests when dealing with individuals as well as their families, maintaining a neutral stance and dealing with disturbing emotions. The aim is to enable informal community caregivers to provide basic supportive counseling interventions. It is not expected that they will necessarily be trained in specific psychotherapy techniques, although in certain instances they may be under the supervision of trained professionals.

Advocacy. This is particularly useful because informal community caregivers are the best placed to advocate on behalf of people with mental disorders to professional service providers (including health and mental health care providers) as well as institutions. They may need to be informed about the legal framework and entitlements of people with mental disorders, as well as be trained in effective public communication and negotiating skills to help them in their advocacy work.(pages 67-69)

(*from* ***Human Resources and Training in Mental Health***- *Mental Health Policy and Service Guidance Package, WHO, 2005*)

Role of "PEOPLE" in mental health care

It is against this background of the development of policies for the organisation of mental health care in the international context and the Indian developments in mental health care, the current book addresses the place of "PEOPLE" in mental health care.

SECTION I-

Health and welfare personnel

Use of non-professionals for mental health care
During the 1960s and 1970s , a trend emerged of using non-professionals for delivering mental health care, known as deprofessionaltion . Non-professional workers often provide effective care because they have better knowledge of the community, language and customs. Often service users also more readily identify with them and form therapeutic alliances. It is important to ensure that non-professional workers are appropriately competent, and that professional staff can be drawn upon, when necessary, to deal with complex cases, provide supervision and consultation-liaison. If non-professional staff are to be trained and employed , consultation with professional staff is needed, to avoid the perception of that non-professional staff are undermining professional staff, lowering standards of care, and providing service managers with less costly workforce."(p.8)
(*from* ***Human Resources and Training in Mental Health****- Mental Health Policy and Service Guidance Package, WHO, 2005*)

Mental Health care by Health workers

Srinivasa Murthy, R.,
Bangalore.

Introduction

Mental health professionals in India have viewed community mental health as not only care in the community but care utilising the community resources, in other words care by the community. The review examines the role of general health workers in mental health care as part of the public health care system.

Need for Integration

There were many reasons for this integration of mental health services with general health services. Firstly, the recognition of the large numbers requiring mental health services, both in the community and in the general medical clinics, especially among those living in the rural areas . Secondly, the limited number of psychiatrists and other mental health professionals to provide care. Thirdly, the emerging integration of all health programmes from the vertical programme model to multipurpose model. Fourthly, the international development of primary health care as the approach to organise health services. Fifthly, the recognition of the importance of early recognition and treatment to prevent chronicity. Lastly, the goal of continuity of care and integration of the mentally ill into the community could be achieved by the integration of mental health with general health services.

There have been three factors that have emphasized the importance of health workers in mental health care.

First of this the problems of persons with mental disorders living in the rural community (SrinivasaMurthy, 1974, 1977,1978, Chandrasekar et al, 1981, Wig et al, 1981a, 1981b, Parthasarathy et al,1981, Naik et al, 1996) which emphasized the need for talking services to the community rather than expecting the patients to come to hospitals..

The second is the finding of a significant prevalence of mental health problems in primary health care (Srinivasa Murthy et al, 1976,Gautam et al, 1980, Harding et al, 1980, Sen et al,1987, Sriram et al, 1987, Seshadri et al, 1988, Bhattacharya et al, 1993, Channabasavanna et al, 1995, Amin et al, 1998). This necessitated that maost of the care should occur at the lkevel of primary health care, as patients with mental disorders were already reaching the health facilities.

The third finding is the demonstration of the feasibility of training of the health workers to undertake a limited amount of mental health tasks, as part of their routine health work (Menon et al, 1978, Issac et al, 1982,Srinivasa Murthy and Wig, 1983, Ignacio et all,1983, Gautam, 1985, Issac et al, 1987, Ignacio et al, 1989, Nagarajiah et al, 1994, Manickam et al, 1997, Pereira et al, 1998, Naik et al, 1994, Chisholm et al, 2000).

Historical aspects

One of the earliest efforts to develop mental health programme for the country was in the 1960 s. The Mental Health Advisory Committee constituted in 1962 met in 1963 , 1965 and 1966 to consider the various aspects of mental health needs in the country. The areas that received considerations were (i) the mental health bill , (ii) ambulatory treatment , (iii) training of mental health personnel, (iv) starting of epilepsy clinics , (v) improvement of mental hospitals, (iv) standardisation of forms and records for mental health services (vii) need for drugs (Ministry of Health,1964-66). The need for a comprehensive plan to organise nation wide services has been often expressed. The need for a clear plan led to the formation of a group of 3 psychiatrists to assist the President of IPS to prepare a blue print for national level of planning of Mental Health.

However, it was only during 1981 , the Directorate General of Health Services organised a National level workshop to consider a draft mental health plan his was held at AIIMS, New Delhi, in July 20-21, 1981 . The essential aspects of the suggested plan following the workshop is to stimulate services both in the periphery and the Center. This was planned to be achieved by suitably integrating mental health care at all levels of health services.

Efforts at Integration and Analysis of the Progress (1975-1982)

Chandigarh and Bangalore experiments in 70s: The organisation of essential mental health services as an integral part of primary health care has been a major development in the country. The efforts were started by two centres in the country, namely, Bangalore and Chandigarh. Currently, the programme is covering nearly 100 districts, in 22 states of the country providing services to over 100 million of the population.

The Chandigarh efforts were initiated in 1975. This efforts was the outcome of the observation of the limited utilisation of psychiatric services from the hospital (Khanna et al, 1974, Srinivasa Murthy et al, 1974, Srinivasa Murthy et al, 1977, Wig et al, 1979).The aim was to develop a model for rural psychiatric services. This effort was further supported by the WHO efforts in this area. WHO Project Strategies For Extending Mental Health Care (1976-1981) was a multicentered project carried out in 7 geographically defined areas in Brazil, Colombia, Egypt, India, Philippines, Senegal and Sudan and designed to develop and evaluate alternative and low cost methods of mental health care (including training methods) in developing countries (Sartorius and Harding, 1983). The basic approach adopted in this model is to integrate mental health with general health services and provide basic mental health care as part of primary health care.

At the Chandigarh Centre this project provided opportunities to understand the needs of the rural mentally ill and methods of proving care to them utilising the existing primary health workers and physicians (Srinivasa Murthy et al, 1978, Wig and Srinivasa Murthy, 1978, Wig et al, 1980, Wig and Srinivasa Murthy, 1980, Wig et al, 1981a, Wig et al 1981b, Srinivasa Murthy and Wig, 1983, Ignacio et al, 1983, 1989).

The programme of Community Psychiatry was launched in 1976 at the NIMHANS, Bangalore. The aim of the rural project was to develop suitable training programmes for the doctors and the multipurpose workers from the various primary health centres in the state of Karnataka, so that after their training PHC personnel could provide basic mental health care (detection and management of epilepsy and psychosis).The team initially studied the needs of the rural population in one primary health centre (1975-1980) (Chandrasekar et al, 1981, Parthasarathy et al, 1981). This was carried out by identifying the mentally ill persons in their homes through key informants and those attending the general health facilities (Kapur and Issac, 1978, Issac and Kapur, 1980).

These efforts of understanding the needs and methods of care in the community were followed by pilot experiment to integrate mental health with primary heath care in one PHC with a population of 100 000 (1980-86) (Issac et al, 1981, Issac et al, 1982). Following this a model programme covering a district with a population of 2 million (Issac et al, 1986, Naik et al, 1994, Naik et al, 1996).

Following these initial efforts at Chandigarh and Bangalore, a number of other centres took up the study of the feasibility of integration of mental health care with primary health care.Gautam (1985) completed a comparison of two different training programmes and its effectiveness.

Manuals of mental health were prepared at the different centres namely, Bangalore (Wig and Srinivasa Murthy, 1980, Wig and Parhee, 1984, Sharma, 1986, Srinivasa Murthy et al, 1987, Issac et al, 1988, Srinivasa Murthy et al, 1988, Sell et al, 1989, Sriram et al, 1990, Issac et al, 1994). Systamatic efforts were made to evaluate the effect of the training programmes utilising different methods (Sriram et al, 1989, Sriram et al, 1990a, Sriram et al, 1990b, Sriram et al, 1990 c) Bangalore centre has also prepared training video for use in the above training programmes along with a variety of evaluation tools.

Of the many initiatives, the integration of mental health with primary health care at the level of the district is the most important. This initiative has the community based and community intensive approach. (Issac et al, 1986, Naik et al, 1994, Naik et al, 1996, Srinivasa Murthy, 1992). The essentials of the District Mental Health Programme, as developed at the Bellary District and currently under implementation in nearly 100 districts in the country (with central government support) are:

- a decentralised training programme for the existing health personnel on essentials of mental health care at the district level;
- provision of mental health care in all general health facilities;
- involvement of all categories of health and welfare personnel in mental health care;
- provision of essential psychiatric drugs at all health facilities;
- a simple record keeping;
- mechanism to monitor the work of primary health care personnel in the provision of mental health care,
- a mental health team at the district level, for training of personnel, referral support and supervision of the mental health programme.

The initial project at Bellary demonstrated the feasibility of providing basic mental health care along with primary health care .

The current national level mental health programme envisages:

" a community based approach to the problem, which includes (i) training of the mental health team at the identified nodal institutes within the State;(ii) increase awareness in the care necessity about mental health problems; (iii) provide services for early detection and treatment of mental illness in the community itself with both OPD and indoor treatment and follow-up of discharged cases and (iv) provide valuable data and experience at the level of community in the state and Centre for future planning, improvement in service and research. The training of trainers at the State level is being provided regularly by the National Institute Of Mental Health and Neurosciences, Bangalore under the NMHP"(GOI,2000).

In the last 25 years of efforts of integrating mental health with general health services, the role of the health workers has been to (i) early identification of persons with different mental disorders; (ii) emergency first aid; (iii) public mental health education; (iv) referral to the health facilities;(v) guidance to families with mentally ill and mentally retarded persons and (v) follow-up of patients on long term care. As the most peripheral health functionaries in the primary health care systems health workers play an important role in the total service programme. However, it is to be noted that there are a number research and services issues that need to be answered to place the role of health workers firmly in the mental health programme (Srinivasa Murthy and Wig, 1993, Sartorius, 1997, Patel, 2000).

In the last few years, as part of the National Rural Health Mission, a new category of volunteer health worker, named, Accredited Social Health Activist (ASHA) has been introduced in the country. This new category of health functionaries can be expected to increase the reach of mental health care further by taking services close to the homes of the population.

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Anganwadi worker---role unlimited

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"Democracy is a government of the people, for the people and by the people" **-Abraham lincoln**

So why not, mental health also be of the people, for the people and by the people?

Introduction

Mental disorders figure among the leading causes of disease and disability the world over. Depressive disorders are already the fourth-leading cause of the global disease burden; they are expected to rank second by 2020, behind ischaemic heart disease (1,2). Meta-analysis studies indicated high prevalence rate of mental disorders in the community (58.2 per thousand) (3). Mental disorders affect one in four persons (1,2).

In the developing countries, trained mental health professionals are very scarce indeed-often. They number less than one per million of the population. Human resource crunch for mental health care has been duly acknowledged.(4) Clearly, if basic mental health care is to be brought within reach of the mass of the population, this will have to be done by nonspecialized health workers -at all levels, from the primary health worker, to the nurse or doctor-working in collaboration with, and supported by, more specialized personnel. This will require changes in the roles and training of both general health workers and mental health professionals. Minimum package of mental health services for all can be best delivered through primary health care system. Preventive and promotive programme along with awareness generation can be undertaken on sustainable basis through this infrastructure.(5)

Peripheral health workers have become important in the development of strategies to expand mental health care. First, since mental health services are geographically beyond the reach of most villagers, these primary health care personnel, who are the principal source of contact for any type of health service, are the only source of help in most instances for any kind of psychiatric problem. Since there is no likelihood of any dramatic increase in the number of mental health professionals, particularly in rural areas, the peripheral health personnel serve not only as the principal primary caregivers but also as the intermediaries between those health care specialists who do work in the rural areas and the population itself. The peripheral health worker, therefore, is the individual best placed to alter the attitudes and beliefs of the community's members so as to encourage use of more formal services (6).

Choice of "people"

Community mental-health care is becoming an accepted practice worldwide. National Mental Health Programme for India was started in 1982, the first such programme in a less-developed country (7). It is widely acclaimed that community care is more effective as well as more humane than in-patient stays in mental hospitals. It is, therefore, essential to develop mental health services in the community settings as an integral part of primary health care; to root out stigma, myths and misconceptions and discrimination against mental disorders. The World Mental Health report 2001 advocates community based mental health programmes and active involvement of families and consumers and community in the delivery of programme.(8)

People and the community are the biggest resources available in India. Many of the problems in the area of mental health can be effectively dealt with by the people and within resources available close to them. Large-scale dissemination of knowledge and simple skills to people and health volunteers should be addressed through primary health care. Capacity of family must be built and primary health care infrastructure should support the family to build their capacity to prevent and manage the mental health problems within the available means. What people do with their lives and those of their children affects their health far more than anything that government does. Building knowledge and awareness of families can make the real difference. Health guides, anganwadi workers and health workers as also Non-Governmental Organizations (NGOs) should raise the level of awareness of people on sound mind in sound body and attainment of positive mental health, through their own actions and practices as also utilization of available services.

Background

Through the District Mental Health Programme (DMHP) under NMHP, community outreach clinics, training of health personnel and IEC activities are being carried out by Institute of Human Behaviour and Allied Sciences (IHBAS), Delhi since the year 2000. IHBAS is a tertiary care neuropsychiatric mental health institute identified as nodal centre for execution of DMHP for the state of Delhi in India. During this period of running the Community clinic at Chattarpur village in southern district of Delhi, we have felt and strongly believe as of today that the people are the most important resource for the success of the community mental health programme. By people, I refer to the caregivers, health volunteers, school teachers, NGOs, panchayats and the anganwadi workers. School teachers and Anganwadi workers especially provide the ideal infrastructure for the identification and referral of disabilities and mental health problems. They can also be trained as facilitators to promote psychosocial development of the children under the system of Integrated Child Development Services (ICDS) which is poised for universal coverage has played a pivotal role for mother and child development in rural, urban and tribal areas. Non-formal education component and early childhood stimulation through play way activities have laid down firm physical, mental and psychological development foundation.

Care provided by the "people" (Anganwadi workers)

Anganwadi means courtyard. Under the Integrated Child Development Scheme, one anganwadi worker is allotted to a population of 1000. Anganwadi worker is trained in various aspects of health, nutrition and child development. The duties of anganwadi worker are -Regular health check-up, Immunisation, Health education, Non-formal pre-school education.The focal point for the delivery of ICDS services is an Anganwadi (a child-care center), located within the village or slum area itself. Each Anganwadi is run by an Anganwadi worker (AWW) and a Helper appointed from amongst the locality. In a way, the institution of anganwadis has been recognized as sheet anchor in personality development of young children. This is one of the finest examples of development of positive mind and mental health. International programme developed by WHO to stimulate mother-child interactions has much more chances for success if pursued actively in the family through ICDS system. This system involves families in total child development through integrated services of nutrition, health and education and relies on inter-sectoral co-ordination.

NIMHANS had rightly picked up ICDS system to involve them in National Mental Health Programme through District Mental Health Services. They are being imparted 5 days training programme at distict. level. Their training would be critical, as these workers will serve as link workers between community and the formal health services system. Since anganwadi workers are locally resident voluntary workers, deeply rooted in the community they can be most effective in dissemination of knowledge on mental health programme besides identification of clients at the earliest stage of morbidity, because of their continuous contact with families. Strengthening of this institution can be most rewarding and will have high payoff effects in the long run. National Population Policy envisages enlarging the sphere of ICDS to cover school going children up to the age of 9 years. Continuous on the job training of anganwadi workers through supervisory support can further enrich the non-formal education programme. The in-service training on mental health should be undertaken by supervisors or trained Child Development Programme Officers and it should focus on child development, personality development and learning by play way activities.(9)

DMHP Experience with Anganwadi workers

Under the District Mental Health programme, in the community outreach clinic at Chattarpur village, we were surprised to note that there were high drop out rates of patients from the follow-up, which was not understandable as the treatment was being provided literally at the doorstep. We then started making home visits to make enquiry into the reasons of dropout . During the same period we had organized a month long Mental health awareness camp in the village courtyard. This is when we had the fortunate meeting with the six Anganwadi workers of the locality. We found them eager to learn the mental health aspects, initially more for their own personal health and gathering knowledge for some of their distant relatives/ neighbors suffering from mental illness. We learnt that they had received very little training in mental disorders during their health training. Furthermore, their existing workload included relatively few efforts to address the needs of the mentally ill persons with whom they came in contact. Their knowledge of drugs used in the treatment of mental disorders was also extremely limited. Despite this relative dearth of knowledge, it was interesting to discover that almost all the workers expressed great willingness to take part in our DMHP activities including any basic training designed to enhance their ability to provide care to the mentally ill. Significant time constraints under which they operated left little time for new training in mental health. This was largely due to their ongoing responsibilities in maternal and child health care, and Polio eradication campaign, ,dengue fever treatment, and family planning.

Based on the Anganwadi workers existing knowledge of and attitude toward mental health problems, we felt the need to provide them some basic mental health skills in an orientation programme. They were imparted knowledge about the common mental disorders (CMDs) including depression and anxiety disorders, drug and alcohol abuse, mental retardation and Epilepsy. In addition they were provided the manual on mental health for primary health care workers developed by NIMHANS, Bangalore

To ensure support and supervision needed for the workers to carry out their work in the most effective way possible, they were provided with the phone numbers for contacting the DMHP staff team. This liaison was strengthened over the last few years. As they are well versed with the local geographical area, the mapping of the community became easier for carrying out our programme in an extensive manner.

Level of care and limits of care

In our experience the anganwadi workers have been useful in the following activities of mental health service delivery at the community level:

- Identification of cases (esp. CMDs and mental retardation)
- Prompt Referrals to the community clinics
- Helping in organization of awareness camps in the community
- Helping in tracing out the drop-out cases
- Helping to establish linkages with NGOs working in the community
- Helping to arrange Home Meetings with the specific population groups like house ladies and elderly
- Effective in promotion of Mental Health themes through street plays("Nukkad Naatak") and puppet shows

Lessons learnt and Future plans for the initiative

Our initial experience with the anganwadi workers has been encouraging .With minimal training/orientation their induction in mental health service delivery is possible. They are a motivated group and have high degree of acceptance in the communities. Our collaboration with them has been fruitful and has helped to strengthen the community mental health programme. We plan to extend our networking with the other anganwadi workers beyond our community field area,

as we have started 'Metaoutreach' clinics (outreach beyond outreach).

Conclusion

The people have to be taken along with, for the success of any community programme. The health care systems need to be appropriately modified and innovative in their approaches to involve the grass root people. They will form important chunks in the overall machinery of the government run community programmes. This is challenging task but at the same time rewarding too.

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Caring by Sharing: The Banyan Story

How Caring Can be a Shared Responsibility

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INTRODUCTION

Public health facilities across the country have grown manifold since the time India gained independence. The rural primary public health infrastructure consists of 1.45 lakh Sub-centres; 23,109 Primary Health Centres and 3,222 Community Health Centres (Annual Report 2005-06, Ministry of Health and Family Welfare, Government of India, p-1). "Despite the impressive public infrastructure, it is a cause for concern that only about 20 per cent services are being provided by the public sector while the private sector provides almost 80 per cent of the healthcare services," admits Prasanna Hota, Secretary (H & FW), Ministry of Health and Family Welfare, Government of India in the introduction to the Report. Also "non-communicable diseases such as cardio-vascular diseases, cancer, blindness, mental illness and tobacco use related illnesses have imposed the chronic disease burden on an already over-stretched healthcare system in the country."

Though the disease burden is increasing, the financing mechanism is not keeping pace. "The allocations for health have decreased from 1.3 per cent of the GDP in 1990 to 0.9 per cent in 1999," says the Report (page-1). Mr. Hota says that the Government is committed to raise the level of spending to two to three per cent of the GDP over the next five years (p-2).

On mental illness, the reach of the government and also the finance available are frustratingly thinly spread: The National Mental Health Programme, which was launched in 1982 "to mitigate the hardship of mentally-ill patients," now spreads over 94 districts, which roughly translates to less than a sixth of the country.

Funding for the programme has doubled from Rs.19.39 crore in 2004-05 (annual plan expenditure, page 34) to Rs. 40 crore (approved outlay for 2005-06). This is just one part of the story. The outlay is less than even the non-plan expenditure of JIPMER (Rs.40.52 crore in 2004-05) and only about half of what has been allotted to the other important national programmes such as the National Blindness Control Programme (Rs. 89 crore for 2005-06) and the National Cancer Control Programme including Tobacco Free Initiatives (Rs. 73.5 crore).

That is not all. "The Cabinet Committee on Economic Affairs has since approved the launch of the National Mental Health Programme during the tenth five year plan… at a cost of Rs. 190 crore, which has now been revised to Rs. 139 crore," says the Annual Report (p-133). Add to this the World Health Organization's observation: about 1 % of the population suffers from major mental illness and another 10-15 % suffers from minor mental illnesses.

Closer home, an evaluation report prepared on The Banyan by NIMHANS says that "mental disorders are more common than most people believe them to be. A number of epidemiological studies have been conducted in various parts of India to find out the prevalence of mental disorders. These studies have shown that different mental and behavioural disorders are present in about two to five per cent of the general adult population, the percentage varying from the range of conditions included under mental disorders… About one percent of the general population has serious forms of mental disorders requiring urgent care at any one point of time." (Making a Difference: Caring for Homeless Mentally-ill Women. The Banyan Experience. p-18).

The mentally-ill population is huge (see table) and growing (see appendix). It is very apparent that the systems that we have in place now are unable to cope and the people who are denied the benefit of that service are in no position to demand. Two facts are clear: one, there is a funding problem and two, the facilities are nowhere near meeting the demands.

It was into this void that The Banyan arrived on August 27, 1993. The founders were just out of college; not trained doctors. "There existed a very dire need and we, exposed to it in college, decided that we should do something," The founder-trustees, Vandana Gopikumar and Vaishnavi Jayakumar had said then. The Banyan cares for and rehabilitates homeless women with mental illness found in the streets of Chennai.

At its home, Adaikalam, The Banyan provides the women a safe shelter, care, medical attention, and a supportive environment to enable them to recover and to take responsibility for their lives again. The Banyan also supports the women's return to their families and communities and when there is no family to get back to, supports the women in setting up new lives for themselves. Over the past 12 years, The Banyan has reached out to more than 1,500 women and reunited around 850 women with their families throughout India.

The Banyan hopes to someday ensure that no mentally-ill homeless person is left uncared and unattended for in the streets. With this in mind, it has taken a strong role in lobbying for the rights of the homeless mentally-ill in order to facilitate localised access to mental health care. The Banyan draws its strength from its hundreds of volunteers and well-wishers, whose support is a driving force for making this world a more humane and caring place.

THE BANYAN MODEL

The goals of The Banyan are clear and give precise directions for its functioning. These are:

1. Quality
    - Improving and sustaining the quality of services that The Banyan provides
    - Taking steps towards setting standards in quality and models for quality service in the sector of mental health care for the homeless.

2. Access to Care
    - Improving access to care and other services within the realm of interventions that The Banyan is engaged in
    - Taking steps towards establishing standards and models for increasing access to care
    - Taking steps towards creating awareness and action at the Macro level with the government, NGOs and other stakeholders for improving access to care
3. Increase in Stakeholders
    - Precipitate an increase in stakeholders in the sector by getting more individuals, NGOs, clients, care givers, funding organizations, government, police, media and judiciary involved
4. Advocacy
    a. Work in partnership with the government (Tamil Nadu) to initiate interventions that change government's programmatic approach in both institutional and community based services
    b. Work within government systems and induce significant changes that can be replicated at an all India level for larger sectoral benefit

The Banyan handles the most difficult group of the mentally-ill – the destitute, abused women stripped of even their identities who lead an obscure and invisible existence on the fringes of society – and makes use of all the resources that were available – volunteers, health care workers, government, like minded NGOs, corporates, funding agencies, celebrities, IT professionals, bureaucrats, and many others.

While medication was strictly a psychiatrists' job, The Banyan believes that care giving should be undertaken by persons who have an inclination for caring, regardless of their educational or social background. The only factor is that they need to be trained on a few basic aspects of mental illness.

This is why The Banyan model is important. The message is that an organisation catering to the mentally-ill requires people who can give care and attention as much as they require medical practitioners whose prescriptions keep their illness under control. And, these care givers are required in much larger numbers than trained psychiatrists or clinical psychologists. Only with round-the-clock companionship (an act that will help monitor the patients as well) do patients develop trust with their care giver, and by extension, with the place where they stay – a vital factor for them to get well.

A typical admission to The Banyan happens like this: The police receive a call about a wandering, mentally-ill person through the recently established Mental Health Helpline, a collaborative initiative with The Institute of Mental Health, Chennai and a part of the Police Control Room manned by The Banyan's social worker. Sometimes, the organisation receives a call directly from a member of the public. The Banyan requests the caller to keep a watch on the person and sends two of its staff in its van. At the spot, even as a few people gather around the woman, the staff try to persuade the woman to get into the vehicle. Often, this is a difficult and long drawn process. The staff, including the driver, are not trained social workers; they are people with minimal education, who have been trained by The Banyan to handle situations like this. They would also have watched at least a dozen acts of picking up a mentally-ill woman from the street.

More often than not, talking alone does not help. That is where the police come in. Over the years, The Banyan staff and the police have established a rapport to the extent that they respond to these calls with sensitivity and with minimal time lag. Once the operation is complete, The Banyan staff distributes pamphlets to the onlookers that detail activities of The Banyan.

There are also legal procedures and processes to be handled. This involves filing a report with the police, creating photo documentation and also approaching a magistrate to obtain a reception order. All these are also handled by the same set of staff, who has, again been trained in these aspects. One point to be noted here is that since wandering persons with mental illness come into The Banyan only through this route, the rescue missions average one every second day. This could be at anytime of the day or night. This has meant that the body of people trained to handle a pick up needs to be substantial. Over the years, at least 50 people have been trained – and these include all the staff at The Banyan and select volunteers who come from different strata of society. The volunteers are an invaluable resource because they work elsewhere and hence, there is sometimes a chance that one of them could be near a spot where a patient has been spotted.

Once at The Banyan, a care giver – a woman with limited education but a trained Banyan hand – a qualified social worker and a doctor/paramedic conducts a through physical examination of the woman. Once this is done, the woman is washed and is treated for any external injuries. No psychiatric evaluation is done at this stage and the woman is in contact with only a couple of social workers and other patients who may have come in a around the same time.

The transformation of the care giver is one of the more interesting stories at The Banyan. Most care givers at The Banyan – there are about 40 of them – come from around the same cluster of villages near Uthiramerur (a village close to Chennai)and are usually school dropouts. The story began in 1993 itself, when the first care giver came into The Banyan. Ever since, there has been a steady flow and the women from this part of Tamil Nadu seem to have huge reservoirs of patience to deal with the mentally-ill. Of course, all of them go through a strict regiment of training and monitoring before they are in charge on their own.

It has to also be said that the care givers arrive at a time when they have been wondering about their own future. The agricultural economy has been decimated in the rain-starved parts of north Tamil Nadu leaving families in huge debts. Many have migrated to Chennai and its neighbourhood and have been working as housemaids. The Banyan has been able to offer these select few an alternative – being part of a movement that cares for the mentally-ill. With The Banyan being a popular name in and around Uthiramerur, naturally, the women are proud to tell people that they work for The Banyan. This also has a very positive spin-off. With people in these few villages aware of mental illness, the incidence of the disorder being treated as a 'curse' is practically non-existent in these villages. The Banyan runs an out-patient psychiatric department which caters to both men and women and this can be accessed by anyone. Residents of Uthiramerur also use the facility once a local doctor refers them for a psychiatric evaluation.

The care giver is the backbone of patient care at The Banyan. Hence, she has a list of duties to perform. The list is exhaustive and has been drawn up after wide-ranging consultations and a product of the experience gained in patient care over the years. The first and foremost duty of the care giver is to ensure that the resident (or residents) is/are within her periphery of vision always—through out her duty hours.

She is also in charge of the resident's hygiene and is hands on with regards to the primary care of residents (ADL). She has to ensure that residents who are part of her group (1: 20) are given holistic care and ensure that all residents receive their daily medicines. She has to give oral reports of residents during psychiatric and general health reviews with the respective doctors.

Besides, she has to ensure that the residents that she is in charge of are involved in pre-assigned productive activity. She is also the liaison person between the hospital and the banyan when a resident has to meet a doctor in a hospital. Once she returns from the hospital, the care giver has the job of updating her immediate superior of findings in the hospital.

The care giver projects needs when a resident is hospitalised and gets the required support from the Banyan. (These are subject to informal audits). She has to immediately report an abnormality that she observes in a patient and report to her immediate supervisors on emergencies and other findings.

The care giver is often called in to assist with picking up a mentally ill person from the street and also in the rehabilitation process.

Story of a health care worker

It was during that time that a Banyan team had come to my village to recruit healthcare workers. I was moved by the work that Banyan did. I was interested in the training that they promised to offer and also the salary.

Initially I was very apprehensive. Would I measure up? Will they send me back? I had heard stories in my village and in the media that people affected with mental illness could be very harmful to themselves and the society. I had heard people say that this was due to evil spirits. I came to The Banyan with such limited understanding. Gradually, I learnt that mental illness can be controlled and that it could happen to anyone at any point of time. My understanding of the issue grew slowly. It slowly dawned on me that this was a segment of population that was always misunderstood. Thus my training began. We were trained by the doctors and the social workers on what the problem at hand was and how it needs to be tackled.

Learning was a slow process. But with each passing day, with each small victory in reaching out to a resident, I became confident of handling even ‘tough’ residents. I was constantly aware that the resident was behaving in a particular manner because of her illness. I started liking my work because I was able to understand the amount of difference each one of us was able to make in the lives of so many women. There were also occasions that made me proud.

The most difficult task? Picking up a patient from the streets. In the streets they would often be in such a pitiful state, poorly clothed and eating from the garbage. Plus they distrust anyone who comes near them.

Back in The Banyan treatment would begin and slowly, we would see the same women improving and becoming what they earlier would have been.A new person, a fresh lease of life.

Many who have come to The Banyan, recover and go back home. Some die. Like Kamtha, whom we picked up from the streets. She was very young and beautiful. She had a very charming smile. When she came into our care she had grievous injuries on her body. She did not have clear speech. She spoke like a child but I could never understand what she was saying. She was also disturbed and could not tell us what or where her family was. I took care of her and slowly became very fond of her. But one day she fell ill. She was moved to hospital. Nothing helped. She died before my very eyes. I couldn’t understand death. I still do not. It affected me greatly. My words cannot explain how much trauma I underwent.

Another story that comes often to my mind is that of Rashmi*. She was picked up with very grievous injuries. Also the injuries had become infected and emitted bad odour. She spoke very good English but would not cooperate with us because of her poor mental health. We had to take her to the hospital for treating the injuries. I accompanied her to the hospital visits everyday. In the hospital many nurses and attenders who saw me with such a disturbed patient and her physical health would often ask me how I was able to work in the organization. They have commended me for my care and concern for the patients. It has always made me proud to be associated with the Banyan.

Once inside the walls of The Banyan, patients take varying lengths of time to open up. A social worker debriefs care givers after every shift to look for clues that will lead to the past and the social worker herself/himself spends considerable time with the newly arrived patient in a bid to enquire into the reasons behind the already-diagnosed illness.

Volunteers – the vital links

This part is a very simple story. Of ordinary and extraordinary people and how they cross the threshold of their immediate concerns and worries and look at issues beyond power failures, garbage accumulation and traffic snarls. Of how people get involved in mental health issues, why they should get involved, how to get them involved and at what levels they can be involved. In many ways, it is also one of the many ways to tell the story of The Banyan: through the eyes of a set of stake holders who volunteer cutting across all man-made and imagined barriers.

There is always this first question that people ask: Why should anyone, other than a psychiatrist, a clinical psychologist or a specially trained para-medic “deal” with a mentally-ill person?

Good question. We need to understand two basic facts here. One, there are not enough qualified people, especially in rural settings and peri-urban areas. Second, since The Banyan believes in reuniting the mentally-ill who have been separated from their families, there are a host of issues involved apart from the obvious psychiatric issues. And, this new strategy of getting the family involved also creates tremendous opportunities for ‘non-professionals’ to be involved in a whole gamut of the process of care and rehabilitation of the mentally-ill.

Let’s start from the beginning when a few things were clear: an organisation does not survive on love and fresh air and the founders did not have all the answers. Hence, the first volunteers were those from the neighbourhood, who had some of the answers. Food, for instance. Clothes, medicine, television, moped, etc. Once the neighbourhood was convinced that the people behind The Banyan were not the easily-giving-up types, a lot of issues were settled. They stood by the organization in times of need and any occasion to celebrate was not missed.

One of the first things that The Banyan did was to try and break the communication barrier with the immediate community. This meant spelling out needs and wants, explaining to people what kind of work went on and also making sure that the organization functioned in a transparent manner, always. It helped that a few celebrities endorsed the cause and the media highlighted these. Needless to say, when celebrities come back repeatedly and support an organization, people who come in contact with that event or who hear about that event, tend to attach credibility with the organization.

The Banyan seeks to ensure that each of those who want to help stay on and assume some responsibilities and have a degree of functional autonomy. A volunteer realizes one thing when he or she enters The Banyan: that he or she has set responsibilities and that he or she is in charge of doing that particular work within a fixed time frame. And The Banyan has drawn up a standard operating procedure to put a volunteer through the paces when he or she exhibits an interest in helping the organisation.

Volunteers go through an orientation-cum-training programme which acclimatizes them with the organization and also puts them in close contact with the persons who run The Banyan on a day-to-day basis. The Banyan routinely appeals to people in Chennai and else where to join in as volunteers through the media and its various outreach programmes and a few respond to this call. All those who volunteer are requested to visit the Banyan at their convenience and a staff member details them about the organisation. The volunteers are also requested to detail their area of expertise and also if they would be able to make available their skill-sets to The Banyan. Details of their availability, the amount of time they would be able to spare for the Banyan are all asked and noted. A quick tour is also organised across the facilities and an interaction with a few of the residents is also arranged.

At the end of this two-to-three hour experience, most of those who come in appear a little shaken by what they have seen and also with their interaction with the residents. The volunteers are asked nothing more at this point: they are merely told that when the need arises they would be requested to volunteer.

Now, there have been instances where volunteers have not come back after the first experience. The Banyan staff does make a few calls to find out if they would be available at a later date.

For those who accept to volunteer, The Banyan is in constant touch. They regularly receive e-mail and phone updates and also are invited to meetings and other functions of the Banyan and also of other like minded organisations.

Some of the volunteers, however, cannot spare too much time with the patients or at the organisation. Their skill sets vary – from IT professionals who help with the website to bureaucrats whose job keeps them at work for long hours.

They help from their own 'remote' locations – with advocacy, raising finances, trouble shooting and also advice. Being an organisation that is witnessing an explosive growth (unfortunately, may we add), the Banyan's need multiplies by the day. Some are needs that Banyan staff have not handled before and, on all these occasions, we turn to the large reservoir of people who want to help but have not known how to.

For instance, rehabilitation trips to north India is an instance where volunteers chip in. The Banyan seeks out volunteers who speak the language of the place where a rehab team is headed (and has been successful to a large extent). The volunteer travels with The Banyan rehab team and acts as the interpreter and translator. This is crucial because it is this person who speaks the local language, who speaks of the illness to the people of the neighbourhood: he or she is the person who has to first instil confidence in the local population and also convey the fact that mental illness is curable.

Basically, each of the volunteers could pick a need that they think they would be able to cater to. The list of needs is large: talking to patients in their language and dialect, writing letters to the patient's families, helping with maintaining accounts, drawing up a rehabilitation plan when a patient is ready to go back to her place, look at the possibilities of follow up, chalk out a sustainable strategy for fund raising, help in the efforts at raising funds, come up with new and innovative methods of reaching out and making people contribute, talk about the illness in various social and other fora to raise the awareness of the disorder, lobby with agencies for particular purposes, establish dialogues with the Executive, Legislature and the Judicial arms of the Government to enlist their support for the cause, or even merely help in the daily running of The Banyan.

While medical practitioners take care one aspect of the disease – the clinical part – the large body of volunteers form a tremendous 'hope' group. Their regular visits to The Banyan makes the recovering mentally-ill residents feel that they are not in some high security facility, makes them aware of the world around outside and that they too will be part of that world sooner rather than later.

Thus the person who walks in to volunteer has a range of tasks to choose from and handles only that part of operations – fund raising, advocacy, liaison, lobbying, media management, strategy development to achieve a variety of goals, trouble shooting both with respect to systems or external, man-made issues. For instance, there are volunteers who specialise in writing press releases of upcoming events; writing letters – in their mother tongue – to rehabilitated residents, or even handling phone calls on days when there is a staff shortage. Volunteers need to do things that they are comfortable with, and, and organisation with needs as diverse as The Banyan, finds it easy to find him/her a slot.

Once the name of a place is given, volunteers interested in map reading take over and locate the place on the map. A few others with intimate knowledge of travel conditions and possibilities draw up a schedule. Others link with government agencies/NGOs here to find out if any support structures would be available at the place where the rehabilitation team travels to. A few others look at financing – sometimes people or a group come forward to finance the trip, sometimes, The Banyan foots the bill.

Volunteer speaks

It's been more than a decade since I went on the first north Indian rehab trip of The Banyan, but the memory is still fresh. I remember the excitement and the apprehension as the discussions first began on the trip to rehabilitate 11 residents from north – spread across Orissa, Bihar, Uttar Pradesh, Delhi and Madhya Pradesh.

Excitement, because of the fact that we were being part of something unforgettable and apprehension, because of the fact that there were far too many things we did not know then.

Too many people helped and all the residents were back home. It was easily among the most amazing, fulfilling and exhilarating of experiences of my life. And I remember it for one woman who was reunited with her family: Ram Kumari.

What I am about to tell next, I myself would not believe if I was not part of it. There are times in life when the written word is inadequate to sufficiently convey an incident. As someone once said, a few events in life defy description. There are times when you attempt to repeat a story a hundred times over and each time you tell it, your voice breaks. There are times in life when you just barely realise what's happening around you. There are times in life when everyone is so irrationally happy and—are sobbing uncontrollably.

Well, I do not know how best to tell Ram Kumari's home coming. Here's the attempt: As she was leaving the Banyan, Ram Kumari had taken a few clothes for her children – tiny clothes that she had stitched herself. When she reached Pratapgarh, she seemed very unsure of where her house was – leading some of us to think that we had come to the wrong place. It was nearly afternoon on a hot, sultry day and we were on the verge of giving up. Just one more try, someone said: I think it was the taxi driver. We headed for the tracks near the railway station. As we reached the tracks, Ram Kumari's memory did the rest. She led us across the tracks into a crowd on the other side. The people seemed to be celebrating something and as they saw Ram Kumari, the whole crowd fell silent. Was this her? May be not, someone said. She was washed away in the floods so many years ago.

But as the normally reticent Ram Kumari began to speak, it dawned on people that it was the same woman. They could not believe. Ram Kumari told them the names of her children and showed them the tiny clothes she had stitched for them.

Again, silence. A few moments later, a girl ran out from inside of a hall behind the crowd, into Ram Kumari's arms. She was in her bridal wear.

Ram Kumari had landed up at Pratapgarh on the day of her daughter's wedding.

The daughter who she left behind as an infant, and for whom she had brought the tiny clothes, was already a woman!!

What happened next? Well, one need not know the dialect to understand tears. Everyone was crying, hugging, and distributing sweets…

Business approach

The basic Banyan approach to finding the resources to care for the mentally-ill has been businesslike. You could ask a donor for a certain amount of money citing a reason as vague as 'operations.' But make it more specific and cut it down to components and the donor base increases manifold.

Like for instance, the rehab bill that we discussed earlier. Or The Banyan's Special Occasion Scheme (SOS). The SOS brings meals for the residents. It is packaged in such a way as to enable people to gift food on a day that is considered auspicious for them (birth/death of their loved ones, anniversaries, etc.)

The Banyan's business approach makes it believe that fund raising entertainment events are just that – fun evenings and not a time for people to suffer a slipshod charity. Hence, professionalism is the watchword in everything that The Banyan does. The Banyan's blockbuster entertainment evening Netru Indru Naalai is a trendsetter in large format live entertainment in the country and the Basant Utsav, The Banyan's evening of live music under the stars in Dakshina Chitra is an event looked forward to by music lovers and the city's die-hard romantics.

In its initial days The Banyan also has resorted to the strategy of shocking society out of its indifference towards the mentally ill. The Banyan, supported by a finance firm, ran a series of eye-catching, screaming billboard campaign in the city of Chennai. The response was tremendous: The Banyan received 50 calls on an average each day. That meant at least five visits by people who have nothing to do with the illness each day. In the final analysis, it added at least one committed volunteer each week. A few of those people remain even today, more than a decade after the campaign

All of Banyan's strategies have grown from the multiplying needs of the residents. Whether it is the need for a dial 100 system, huge fund raisers, talking to NGOs in remote parts of the country – all have been necessitated by emerging needs. And The Banyan grows only because it responds to these needs tapping a variety of people from across various strata of society.

A few of the newer strategies are listed here:

Dual Strategy – The Banyan is now not just providing institutional services but is also working on a community based approach with three urban outreach clinics reaching out to 1000 clients in a year and rural outreach (both physical and mental health) in the Kovalam community. The Banyan is also working closely with families by providing economic support through a Disability Allowance and facilitating family support groups.

Advocacy with Government and Police through the Dial 100 Mental Health Helpline initiative. Through this unique partnership initiative the banyan have rescued 293 people from the streets of Chennai with the police help and admitted them for treatment at Institute of Mental Health. In a landmark MoU with Government of Tamil Nadu that lends success to the advocacy voice of deinstitutionalizing mental hospitals, the banyan sees itself as a catalyst in facilitating rehabilitation of people who have recovered at IMH.Close to 22 persons have been reunited with families. The use of a demonstrable model paradigm drives advocacy initiatives – including the replication of the Banyan model through national training partners for stakeholder increase and formation of lobby for the sector. Action based research studies to be undertaken in the forthcoming year will hopefully have a huge impact in pursuing this key goal.

Increase in stakeholders across the country through training partnerships with five NGOs who are/have replicated The Banyan like facilities. Ashadeep in Assam has been running the facility for a year, Karuna Trust in Karnataka have started in April 2006,Udavum Ullangal in tirupattur started in June 2006 and Akshaya Trust in Madurai and Chesta in Delhi are almost ready to take off.

Client Participation through the emergence of strong client led group who display insights into their issues and are all set to advocate for their own rights. Through all this and many more such initiatives, The Banyan focuses on improving the condition of persons with mental illness, especially those in the margins of society. Apart from the broad initiatives listed above there are also very many grassroots initiatives, at the level of the patient. These include the following for the recovered patients:

Distinct Identity: Movement into a premise distinct from The Banyan almost entirely run on a day to day basis by clients.

Effective functioning as a separate unit

Thrust on Employment: Facilitation of employment has received thrust through creating linkages with service based industries and skills training institutes. Close to 12 women from The Banyan work outside, and earn salaries and manage their money. About 40 women can be facilitated employment outside The Banyan. Also a training in a professional housekeeping course for a batch of 6 women at TVS Sri Chakra, Madurai has been facilitated. All are placed in households currently for the period of their internship

Theatre Therapy: Theatre therapy has contributed greatly to the personality as well as inter and intra personal relationships of clients in the group. It has promoted bonding amongst members of the group.

Steps towards Mother-Child Group Home: A process that is taking shape currently at The Banyan is the emergence of a support group of recovered women with no families to go back to. They have begun using the Banyan as a hostel facility and are engaged in productive and remunerative work outside of the banyan. The uniqueness of this group lies in the fact that all of these women were found with children while they were wandering, and after recovery have found the courage to visit their children in existing homes where they are accommodated. This group has also gone a step further by getting together and working towards establishing a group home which allows for them to live with their children.

Lessons learnt

People want to help. Most do not know how and where to start. Often, people help a cause/NGO because they know someone who is involved in that cause, or have a family member who is afflicted by a disease/disorder that a particular NGO addresses. We, who are involved in the business of making the lives of the marginalised better, need to reach out to as many people as possible. We need to talk to more people so that caring is not merely left to the Government and NGOs. It should be the business of the people and, 1.027 billion people can do more than any Government and any NGO. The challenge is to lure them into it, help them consolidate the information, appeal to their sensitivities that trigger a reaction in them. Which is why marketing, packaging and usage of simple, yet dynamic training methods are essential to any form of volunteer mobilisation. To provide a proactive, challenging, yet encouraging work environment that thrives on a transparent mode of functioning is the foundation of a win - win situation.

Conclusion

The Banyan's reach and range of activities for the mentally ill and the large body of people that it has involved at one level or the other, is reason enough to conclude that mental health is not merely the business of qualified psychiatrists or clinical psychologists. The need of the hour is out of the box thinking and this is best achieved when more and more people care for the cause. Bringing in fresh energy, newer thoughts and thereby a newer direction is as important as caring for the mentally ill.

Because, every helping hand counts.

APPENDIX 1

A WHO report in 2001, quoted by the BBC, said that 25 million people in India are in need of mental health services. Of these, at least a third need help to cope with disability resulting from various psychiatric disorders. Some experts have calculated that mental health problems contribute to an even greater reduction in the quality of life in India than tuberculosis or cancer. According to the website of the Central Bureau of Health Intelligence, India, the numbers of mentally-ill persons are 839,900 in rural areas and 261,100 in urban areas.

Estimated Number (in 00's) of Disabled Persons by Type of Disability and Sex 58th Round (July-December 2002) – All India

	Type of Disability	Rural			Urban		
		Male	Female	Total	Male	Female	Total
1	Any Disability	83,102	57,748	140,850	25,811	18,249	44,060
2	Mental Disability						
2.1	Mental Retardation	4,434	2,561	6,995	1,824	1,128	2,951
2.2	Mental Illness	5,022	3,377	8,399	1,623	988	2,611
3	Physical Disability						
3.1	Visual Disability						
3.1.1	Blindness	7,494	8,536	16,030	1,793	2,311	4,104
3.1.2	Low Vision	2,982	3,563	6,545	711	877	1,588
3.2	Hearing Disability	12,516	11,171	23,687	3,617	3,313	6,930
3.3	Speech Disability	9,495	6,532	16,027	3,416	2,102	5,518
3.4	Locomotor Disability	49,987	29,839	79,826	16,352	10,162	26,514
	Estimated Population	3,923,611	3,711,319	7,634,930	1,545,555	1,391,996	2,937,551

APPENDIX 2 - PUBLICATIONS AND READING MATERIAL

Out of Mind Out of Sight – Kendra (published 2002)

"Making a Difference – Caring for Homeless Mentally Ill Women, The Banyan Experience" – NIMHANS Review – An Evaluation Report Prepared by NIMHANS (first edition in 2003)

Annual Reports of The Banyan (from 2002 to 2006)

Transit Care Manual 2005 – Kenden and Lakshmi Narasimhan (not published)

"What About the Right to Care" – Article in The Hindu newspaper by Vandana Gopikumar (dated October 23, 2005)

Effectiveness of The Banyan Model of Care – Dr. Kishore (2006 WHO Final Report, not published)

A Review of The State Review Policy and Mechanisms for Care, Treatment and Rehabilitation in Tamil Nadu –Lakshmi Narasimhan and Dr. Elizabeth Negi (2006 WHO Final Report, not published)

Futures Search Conference: Methodology for Family and Community Based Management of Homeless Mentally Ill – Dr. Elizabeth Negi and Prof. Vasantha Kumaran (2006 WHO Final Report, not published)

Community Care and Rehabilitation

Kalyansundaram, S.
Bangalore.

Background

The Richmond Fellowship was founded in the year 1959 by Ms. Elly Jansen to provide residential care for those suffering from mental and emotional disturbances. Today, Richmond Fellowship organizations are established in more than 30 countries, providing effective rehabilitation services to people recovering from severe mental health problems. The Fellowship is the world's largest network of mental health service providers.

The Richmond Fellowship Society (India), located in Bangalore, India provides care and psychosocial rehabilitation for persons with mental health needs in India and also for those in the neighbouring countries. Since its inception in 1986 hundreds of individuals with chronic mental illness have benefited from the agency's professional expertise. It is one of the leading organizations in the mental health voluntary sector working with a community-based rehabilitation approach, and also has a strong presence in the development of human resources in this field in the country today. It is one of the founder members of the Richmond Fellowship **Asia Pacific Forum**, which comprises facilities in Australia, New Zealand, Hong Kong, India, Cook Islands, Macau, Nepal and Sri Lanka.

Headquartered in Bangalore, the Society has branches in Delhi (Greater Noida) and Lucknow. The Society's affairs are managed by the National Board, which is constituted by member representatives drawn from the various branches. Local Governing Councils oversee their respective branches.

The agency's work is shaped by the following objectives:

- To offer skilled help to those who are mentally and emotionally disturbed and to facilitate their rehabilitation and integration with family and society.
- To develop human resources in the area of psychosocial rehabilitation.
- To educate and create public awareness about mental illness, its treatment and to enhance peoples' understanding of the mentally disabled.
- To promote mental health in the community by providing courses in personality development and humanism.
- To network and collaborate with activities of similar organizations.

Major psychiatric illnesses are disabling as they affect multiple functions and are accompanied by social disadvantages. Severely ill individuals invariably face the possibility of rejection, humiliation, isolation, and denial of equal opportunities, and discrimination in various spheres of personal and public life. The stigma and negative consequences associated with such conditions envelop not only the individual, but also the family members.

A large number of people with mental illness are unable to access, and hence, deprived of any meaningful care. Care and recovery are hampered by ignorance, stigma, lack of information, and inadequate resources for care, among other factors. All of these prolong their distress and disability. Along with medical intervention, a vital component is psychosocial care offered at rehabilitation centres. Psychosocial care involves training and retraining ill persons in areas such as personal care, daily living, work habit, money management, social skills, vocational skills, and so on, to help them adjustment better and reintegrate meaningfully into their families and society.

The following rehabilitation / service facilities of the Fellowship and managed by trained professionals address these concerns:

1. **ASHA:** A halfway home functioning since January 1989, “Asha” offers care for individuals suffering from chronic schizophrenia or bipolar affective disorders. It offers a residential programme and can house 20 residents, both males and females. The duration of rehabilitation ranges from six months to one year. The home also offers respite care for shorter durations as per need.
2. **JYOTHI**: This group home caters to persons with chronic psychiatric illnesses who have been treated in therapeutic communities and need long-term support to function in society. This home can accommodate 6 male and 6 female residents.
3. **CHETNA:** This is a day care centre with vocational training facilities. Along with pre-vocational skills, vocational training is offered in tailoring, embroidery, printing, typing, basic computer skills, and plastic welding and moulding. The centre, designed to accommodate 45 clients, also functions as a sheltered workshop. Job placement efforts also form part of the rehabilitation inputs. Persons with schizophrenia, chronic epilepsy, affective disorders, and mild/moderate mental retardation with behavioral problems avail this facility.
4. **PRAGATHI:** This community-based multidisciplinary rural mental health project operates in Sidlaghatta taluk of Kolar district in Karnataka. This is an economically backward and consistently drought-prone area with a total population of 1,50,000 covering 100 villages. Among other services monthly camps are held, staffed by a multidisciplinary team, offering psychiatric assessment, medication and psychosocial interventions free of charge, for those suffering from severe mental illness and epilepsy.

Training programmes

Keeping in mind the paucity of trained personnel in the area of psychosocial rehabilitation, the Fellowship undertakes regular training and manpower development activities:

TRAINING: In 1989, the agency introduced a six-month training package in Psychosocial Rehabilitation, the first of its kind in the country. This was taken up to meet the urgent need for trained personnel in the field. As an ongoing activity, short-term programmes for students, professionals and volunteers are organized. These are recognized by a variety of academic and service-based institutions locally as well as internationally.

M. Sc. COURSE: The Richmond Fellowship Post Graduate College for Psychosocial Rehabilitation established by the Society offers a full-fledged two-year Master’s Degree course in Psychosocial Rehabilitation. It is supervised and run by an independent College

Management Committee. Affiliated to the Rajiv Gandhi University of Health Sciences, Bangalore, Karnataka, the course has received permanent recognition from the Rehabilitation Council of India (RCI). It is also recognized under Section 2(f) of the UGC Act, 1956 and is accredited with a five-star rating by the National Assessment and Accreditation Council (NAAC).

Reasons for the initiative to use "people" in care

- The existing mental health facilities, especially professionally trained manpower in the country are woefully inadequate to deal with the demand for such care. The agency's conscious use of "people" to support its activities has stemmed from this paucity of personnel.
- The involvement of individuals drawn from the community has helped in opening up the doors of mental health care institutions. The use of volunteers and other non-mental health persons builds bridges and helps eradicate the stigma and misconceptions that plague mental health care facilities.
- Such involvement of "people" in activities of care agencies has facilitated the therapeutic environment in the centres in terms of preventing it from degenerating into a closed institution.
- This has also made the term "community-based care/rehabilitation" more meaningful and achievable for the agency.
- There is greater accountability of the agency to civil society, as the agency is open and transparent in its activities. Efforts have been made to draw up support from as many representative groups as possible, be it students, professionals (retired or in-service), housewives, formal and informal leaders in the community and so on.
- This has resulted in greater community participation and ownership of the programme, as seen in our encouraging experience at Pragathi in Sidlaghatta.
- Over the decades, the agency's work has been diversified by the contributions of various such individuals. This can be seen tangibly in the variety of resources they bring in, be it physical help, financial assistance. In addition skills in areas like recreation, art, current information, and so on, are value added.

Using Community Resources

The Richmond Fellowship has moved from strength to strength over the years encouraged by the heartening trend of growing involvement of non-professionals and lay individuals who have no association with the field whatsoever, and yet help in the various activities of the agency.

The members of the Governing Council of the agency are drawn from different backgrounds have been a great source of strength. They have provided the agency with the necessary vision, support and guidance bringing with them their diverse expertise.

People from different strata of society have come forward to help and encourage the various activities of the fellowship and to join hands with us to provide the help and support that is needed in innumerable ways.

The rural experience

The agency has recently forayed into reaching out to mental health needs in the rural scenario, and out experiences over the last two years has been quite inspirational. The Pragathi centre in Sidlaghatta has seen people from all walks of life from the local community coming forward for the cause of improving mental health. The agency has been working towards demystifying mental illness by training volunteers and community members in creating public awareness about mental health and clarifying commonly held misconceptions and at the same tome trying to reduce the stigma associated with mental illnesses.

People from different walks of life help:

Various community groups that were mobilized for spreading awareness and orientation about early symptoms of mental health included:

- People working in the area with locomotor and other physical and sensory disabilities,

Secretaries to the village Panchayats

- Leaders in the village,
- Teachers from local schools,
- Sree Shakti Sanghas, self-help groups in the community,
- Anganwadi and Health workers at the Taluka level,
- Lay people who have certain health problems or carry some disabilities were also involved, and they formed self-help groups or local Sanghas to look into the needs and approach the concerning authorities for assistance.
- Primary Health Centre personnel
- Doctors and private general practitioners in the community.
- School teachers and students of higher classes (VIII-X standards).
- Coolie Sangha, i.e. people who work as daily wageworkers.

The urban experience

Since its inception, the agency has been receiving invaluable help at all its service facilities from people from varied educational and occupational backgrounds, professional as well as non-professional. Each has contributed to the growth of the Fellowship in his/her unique way by bringing in new ideas, knowledge, skills and talents to educate and improve the skill sets of the staff as well as clients.

Profile of volunteers

The organisation has had the fortune of working with students from different field like engineering, psychology, social work, sociology, science etc who have come to work as volunteers. There have also been individuals from different non-governmental organizations at the national as well as the international level. In addition housewives from different socioeconomic and educational backgrounds have helped us by giving their quality time.

These people have reached out to us by knowing about it by word-of-mouth from friends or other volunteers, mental health professionals, medical professionals, media (newspaper articles about the organization) and through our website.

The fellowship has a record of several such individuals who began as volunteers and later have joined as staff in administrative, financial, and clinical responsibilities.

Training approaches developed

The agency has a well-defined process of identifying suitable "people". The organization has a format for volunteers, which can be downloaded from the Internet or collected from the office and sent to the Secretary. The profile and the skill sets of the volunteer are discussed and the same is matched with the requirement of the organisation before re placing them in the different service centres.

The nature of work mandates that individuals be aware of psychiatric conditions, the disabilities that may result from such conditions and certain basic rules of working with disturbed individuals. Inculcating sensitivity to the needs of clients and families is one of the foremost tasks of orienting "people" to mental health care. There is an initial introduction about the organization, its emergence and growth, the various facilities that are run and their main functions and activities. They are taught various basic skills required working in the centre, including communication and counseling techniques. These help them to work and understand clients better.

Training programmes

Training programmes have evolved from short-term ones held as and when the need arose, to having a regular full-time professional postgraduate degree.

The Fellowship started its first training programme in Bangalore in 1989. Keeping in view the cultural needs, training modules were specially culled out to include issues related to family, society and mental illness. These initial programmes were of short duration and were not entirely sufficient to equip non-professionals with enough knowledge and skills and practical experience.

Hence, a full-fledged post-graduate programme was designed to create rehabilitation professionals to take care of the severe shortage of manpower in this particular area of mental health. Thus a full-time two-year programme offering a Master's degree in Psychosocial Rehabilitation was developed. These trained professionals are employed in psychiatric hospitals, psychiatric departments of medical colleges, and private nursing homes offering psychiatric treatment, and at rehabilitation centres such as halfway homes and day care centres where there is a pressing need for trained professionals to look after the needs of the mentally ill. The PG College of the Fellowship bridges this gap with its regular output of fully qualified Rehabilitation Professionals.

The training programme for volunteers and the community members of rural centre at Sidlaghatta was started in the year 2004 and was designed keeping in view their literacy level and their needs. This training in the rural centres has focused on creating awareness about mental health, myths and cultural beliefs and mobilizing the local manpower resources like village leaders, anganwadi and health workers, general medical practitioners (private and government sector), district medical officer and volunteers. The training is both educative and informative, while trying to bring about necessary attitudinal changes in the family members and the community as a whole. The training is essentially of a shorter duration, usually about half a day. These sessions are being conducted at various locations across the district. The training inputs are supplemented with providing pamphlets in the local language with information on mental health and the various treatment options facilities available, which are distributed after each such session.

Care provided by the "people"

Levels of care:

In the rural project of the agency, volunteers drawn from the various groups, youth as well as elderly, are assisting the centre's work in two main roles:

a) Spreading information about the centre's activities, notably the monthly camps, to the members of the community,

b) Providing the much-needed neighborhood support for recovering individuals and their families in the community

c) Identifying individuals in need of mental health care and directing them to the monthly clinics, and

d) Assisting the team of professionals in the smooth functioning of these clinics. All age groups, right from youth to the elders, actively participate in the activities of clinic.

At the urban centres, individuals assist in a variety of ways:

a) Assisting in the day-to-day activities of the facilities - such as conducting group recreation and leisure activities, basic literacy classes, teaching basic computer skills, house coverage in times of emergency, and so on

b) Indirect care by assisting in various financial and administrative needs at the centres and the fund-raising initiatives

Limits of care

The sensitive nature of personal as well as familial issues involved, and keeping in mind ethical issues such as confidentiality places limitations on the extent of therapeutic involvement and care that non-professionals can undertake.

Support for care by mental health professionals

Mental health professionals have a facilitatory role in the entire process of engaging volunteers and others who are not familiar with this area of care. They are also engaged in assessing the suitability of candidates, allotting work / roles in the centre based skills of the volunteers and level of comfort of the individual. Orienting and sensitising them to the area of work, guiding them in teaching new skills required for working with emotionally disturbed individuals, thereby channelising their skills and translating them into care components also form part of the training offered.

Difficulties

- While the agency gratefully acknowledges the services and participation by the volunteers, one does come across lack of consistency in their working due to fluctuating levels of motivation.
- Sustaining motivation levels over a period of time can be challenging in the rural areas, as per our experience. There have been instances of well-meaning individuals looking forward for some gain like monetary rewards and fame, which can work at crossroads with the work of the agency. This can be handled by acknowledging and giving credit where it is due, and through open appreciation at regular intervals, so as to sustain their interest and involvement and sense of belonging in the agency's activities.
- Individuals who are in a professional job elsewhere may find it difficult to juggle roles while handling a full-fledged career simultaneously with volunteering for some cause. Sometimes their services can be unavailable in the wake of their own personal commitments and preoccupations. Professionals stepping in to help them to realistically assess initially the kind of time and commitment they can offer will be helpful.
- The agency has to be alert to the possibility of the risk of burnout among this group, as they are not completely trained to undertake this task. This is particularly so in some aspects of work like dealing with some clients who have a more intense need for care, handling psychiatric emergencies, long hours of work, multiple roles especially when there is shortage of professionals. This can be addressed by a more stringent and comprehensive initial orientation, ongoing support from professionals in the agency, and by providing periodic breaks and offering guidance and support whenever needed.
- It has been difficult to involve youth in the community, especially in the rural areas. Motivating the neighbourhood also has been a significant challenge at times.

Lessons learnt

Dealing with these difficulties has given the agency enormous scope and opportunity for improving the quality of service offered. There are continuous challenges, some which the agency still is facing and attempting to resolve. Overall, during these two decades of growth, the organization has braved a lot of turbulent times and rough weather. The learning has been from all experiences, some pleasant and some sour. An important aspect has been that it is highly impossible to depend on skilled professionals alone to provide mental health care consistently due to the inadequate numbers and high staff turnover in the rehabilitation centres.

Future Plans

- Building a database of professionals and nonprofessionals willing to offer their time and services for supporting mental health care.
- Further channelising the resources of volunteers to suit to the needs of the clients and the agency.
- Improve the agency's presence and visibility in the community by strengthening its network with people from various sectors so as to
- Utilise volunteers to facilitate placement opportunities for clients in the community wherever suitable.
- Coordinating with small-scale entrepreneurs for assistance in marketing of products, and entrepreneurial skills training for clients
- Organising ongoing refresher training programmes to update skills and sustain motivation for them to perform better

Resource Materials

Often, existing resource materials developed by mental health professionals did not suit the requirements of the organization. There is a need to tailor-make and develop the agency's own resources to deliver better services to the clients. Some of the resource materials developed at the agency includes

- Structured programme for formal assessment of disability and continuous assessment.
- Assessment schedule for incentives to clients at day care centre.
- Psychosocial rehabilitation case history proforma.
- Symptoms checklist for rural centre (list of symptoms seen in mentally ill for laymen).
- Pamphlet with information on common mental illnesses in Kannada (local language) for rural centre.

Acknowledgements

I would like to express my thanks to Dr.G.N. Narayana Reddy, Founder Chairman of Richmond Fellowship Society (India), Dr.Dharitri Ramaprasad, Dr.Vijayalakshmi, Dr.Geeta Rau and Ms.Niveditha S for their help and support in the preparation of this chapter.

Mental Health in the Armed Forces: A Unique Consumer-Provider Partnership

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New Delhi.

Preamble

The Indian Armed Forces are unique in many ways. The second largest standing army in the world, next only to China's Red Army. The largest volunteer professional defence forces, with the widest recruitment base anywhere on the globe, representing every ethnic, religious and economic group in the vast Indian subcontinent. A virtual microcosm, reflecting the rich and varied socio-cultural mosaic of our ancient civilization, the Armed Forces are a vital unifying force in a polity which often appears vulnerable to centrifugal disintegration, particularly to western observers, like the well meaning John Kenneth Galbraith who described the Indian nation-state as a 'functioning anarchy'. One of the major contributors to the Armed Forces' credibility has been their scrupulously apolitical ethos. Alone among the developing 'third world' countries, in a neighbourhood beset with military dictatorships, they have remained truly professional and the possibility of a military coup is considered unimaginable in the Indian context even by the most cynical western commentators.

The Indian Army has another distinction, unique in the annals of military history. Few people realize that the army has been engaged in counter-insurgency operations continuously since 1948, when it was called out to deal with the Communist 'revolution,' including the establishment of a parallel 'government,' in the Telangana region of what is now Andhra Pradesh. Through Nagaland, Manipur, Mizoram, Assam, the Punjab and currently in Jammu & Kashmir, the army has lost more men in these operations than in the four wars with Pakistan. Added to these have been international peace-keeping duties under the aegis of the United Nations, from the disputed 38th parallel in Korea to battle zones in the Congo, middle east and elsewhere. This has meant significant reduction in rotation to 'peace' tenures, carefully time-framed to provide physical and psychological respite between stressful operational deployments, for most combat units. It is a tribute to the phenomenal tenacity of the *jawan* that, despite unimaginable levels of cumulative combat stress for over half a century, the Indian Army continues to maintain the highest levels of discipline, morale and battle-worthiness (1). This is in sharp contrast to the US Army which was devastated by problems of drug-addiction, desertions, indiscipline, *fragging* (killing of officers by their own men, using fragmentation grenades) and poor morale in the aftermath of the defeat in Vietnam. Both the US and British armed forces continue to be plagued by the problem of significant numbers of soldiers deserting their regiments in the ongoing operations in Iraq and Afganistan, and the Royal Air Force recently court-martialed a medical officer for refusing to serve in Iraq. The remarkable resilience of the Indian Army in the face of such overwhelming odds can be traced, among other factors, to strong leadership qualities in the officer corps, robust organizational structure and sound mental health promotion strategies, which are, perhaps, unique to this *subculture* and which have remained largely immune to the perceived decline in many critical civil society institutions. The mental healthcare system in the Armed Forces merits closer inquiry, for it involves a unique consumer-provider partnership model which could provide useful inputs for other mental health programmes.

Military Psychiatry in India

Before going on to the conceptual issues related to mental health in the Armed Forces, it might be worthwhile taking a quick look at the organisation and history of our military psychiatric services. For a total population of about 1.5 million serving officers and men, *plus* over 7 million dependents (families, parents), the provision of resources is as under:

Psychiatric centres	**30 (strategically distributed across nearly 130 miltary hospitals, from Kochi to Srinagar, from Jorhat to Jodhpur)**
Psychiatric beds	**1000(estimated ;exact figure 'unavailable')**
Psychiatrists	**56**
Psychiatric Nursing Officers (DPN)	**45**
Psychiatric Nursing Assistants (*PNAs*)^	**466 (Army 360, Navy 68, Air Force 38)**

Clinical Psychologists and Psychiatric Social Workers are posted at larger hospitals

(^selected from amongst general nursing assistants, *PNAs* undergo a rigorous 3-stage training programme in designated military psychiatric centres, with a curriculum equivalent to that for the Diploma in Psychiatric Nursing (DPN) course, and constitute the core psychiatric nursing component in the Armed Forces Medical Services)

The importance of psychiatric disorders came to the fore during the First World War, when the syndrome of *shell shock* was first described during the battle of the Somme, only to be forgotten during the intervening decades. The outbreak of World War II, found military medical services in India, almost totally unprepared to deal with psychiatric casualties. There were only 4 specialists in psychiatry on the authorized strength for the whole of India, stationed at the headquarters of Northern, Southern and Eastern Army Commands and the Western (Independent) Military District. Later the number was increased to 10 specialists, most of whom were allocated to the eastern theatre, where the 14th Army was preparing to drive the Japanese out of Burma, and a Consultant (Psychiatry) was appointed at General Headquarters India on 23 Apr 1942, the first incumbent being Brig EA Bennett, who, incidentally, introduced the first ECT machine in the country at the Military Hospital, Pune in 1943. The psychiatrists serving on the eastern front soon proved their mettle and were able to conserve manpower by treating most of the psychiatric casualties within the operational zone and returning them to duty. The official *History of the Indian Armed Forces during the Second World War* describes their contribution as being *"worth its weight in gold"*. Following this early success, 21 more psychiatrists, in addition to the existing 14, were sanctioned (Southern Command 15, Central Command 5, NW Command 4, Eastern Command 7 and Ceylon Command 7) on 7 Mar 1943.. The foundations of military psychiatry in India were thus firmly laid. Gradually, a pool of 70 Psychiatrists was authorized, which had swelled to 86 by the end of the war in 1945 and included stalwarts like the legendary Dr Vidyasagar and Col Kirpal Singh. Significantly, five of the nine founding members of the Indian Psychiatric Society who signed the original memorandum of association on 7 Jan 1947 in Delhi were serving or former military psychiatrists. In 1950, Maj GA Bhagwat prepared the first draft of the new mental health bill which, nearly four decades later, evolved into the Mental Health Act 1987, after being passed by the Parliament.

In the early years, most of the military psychiatrists were Englishmen, trained in Britain. Subsequently, during the war years, some were trained in India on an *ad hoc* basis and were later sent to the UK to study for DPM. Eventually, in 1959, the advance course in psychiatry was started at the Armed Forces Medical College, Pune and this was subsequently recognised for DPM as well as MD (Psychiatry). Military Psychiatry grew rapidly in the subsequent decades and was accorded subspecialty status by the Indian Psychiatric Society in Jan 1997. The first Military Psychiatry CME, organised by one of us (DS) at Military Hospital, Kirkee (Pune) in Sep 97, was a resounding success and this has since become an annual feature.

Mental health and the Men in Uniform

Mental health care for the men in uniform begins right from the point of entry, through stringent selection procedures, involving formal psychological assessment in the case of officer-cadets, coordinated by the Defence Institute of Psychological Research (DIPR), Delhi. During training at the National Defence Academy, Khadagvasla and the Indian Military Academy, Dehradun, professional psychologists monitor the cadets carefully with regard to the relevant parameters. There are, however, imperfects in the system and occasional cases of psychiatric breakdown or suicide/attempted suicide among the trainees highlight the need for sustained vigilance and ongoing upgradation of the screening instruments used at entry. The DIPR utilizes feedbacks from the training institutions, as well as from group testing officers in various recruitment centres, for the purpose.

Once the individual, on completion of training, is posted to the unit/regiment, the primary responsibility for monitoring the various mental health parameters passes on to the respective commanding officers, whose role as *pater familias* is somewhat akin to the head of a large joint family and who keep a careful eye on their flock through a well established chain of command, going down the line to the Non-Commissioned Officer (NCO) level. This includes the individual soldier's behaviour, reaction to situational stressors, alcohol use and any domestic/marital concerns, particularly on return from home-leave. Peer support and counseling from superior officers help most soldiers cope with routine stressors. If, however, the individual appears to be decompensating at any point of time, the commanding officer may seek psychiatric assessment/treatment by initiating a detailed report on a structured format , Armed Forces Medical Services Form-10 (AFMSF-10; the authors had been associated with the development of the present version, reproduced at the end of the chapter) to the regimental medical officer (RMO), who arranges a psychiatric consultation at the nearest military psychiatric centre. T

The scene now shifts to the military hospital where, subject to there being a mental health condition, the individual may be admitted for observation (as most often is the case) and treatment, or treated as an out-patient. After completion of treatment and a spell of sick-leave at home (where required), the patient is placed in the appropriate medical category (S-2 or S-3) for an initial period of six months(with varying degrees of restrictions on employability, depending on the diagnosis/clinical status) and discharged back to the parent unit. The responsibility for implementing the recovery plan now moves back to the commanding officer (CO), assisted by the regimental medical officer (RMO), who supervises follow-up and maintenance medication. At the end of the 6 month period, the individual returns to the psychiatrist for review, along with a progress report covering the duration, and is placed in the same/next higher medical category, depending on his condition, for a further period of six months. This process continues for two years, at the end of which the individual is either upgraded to medical category 'S-1' ((fit for all duties anywhere), or placed in medical category 'S-2' permanent (with specified limitations on employability), with provision for review every two years, or earlier if warranted by improvement/deterioration in the interim. Thus the entire process of recovery and appropriate employment, continuously titrated to the individual's condition and aimed at graduated return to full duties (2), is mentored by the commanding officer as head of the larger *joint family,* supported/punctuated by periodic reviews by the military psychiatrist. This unique consumer-provider partnership results in excellent outcomes even in serious mental disorders like schizophrenia and very few go on to chronicity/ invalidment from service on psychiatric grounds. Unfortunately, however, the same cannot be said with regard to alcohol/substance misuse disorders, which often remain refractory to treatment/prone to relapse, leading to eventual discharge for medical reasons. The following case-reports illustrate how the system works.

Case-report I: A 24 year old soldier, belonging to an elite mechanized infantry regiment, was observed to be withdrawn and behaving strangely on return from 2-month's annual leave which he had spent in his village in the Garhwal hills. Efforts of his buddies and the non-commissioned officer (NCO) failed to draw him out were unsuccessful and, in fact, he became rather hostile. He was eventually marched up to the Commanding Officer (CO), who was able to get the soldier to confide in him during a one-on-one interview. It appeared that the individual suspected that his young wife was having affairs with his brothers and even his father and was plotting with them to eliminate him. The CO assured him about his safety and sent him home on casual leave, along with two senior NCOs, to find out the facts. It emerged that the individual had been behaving strangely during his earlier leave at home and had made 'wild' allegations against various people, creating a very embarrassing situation for the family in the closely knit rural community. During the return journey to the unit, the soldier accused the NCOs escorting him of having seduced his wife too. He became hostile/agitated and had to be restrained en-route. On return to the regiment, he was again interviewed by the CO, who now initiated the AFMSF-10 report and asked the RMO to arrange a psychiatric consultation. At the military psychiatric centre the soldier was treated for his paranoid psychosis and made a satisfactory recovery. He was put on maintenance medication and returned to his regiment in medical category S3x6 months for further follow-up/rehabilitation. With ongoing organizational/community support he maintained satisfactory progress and was eventually upgraded to medical category S1 at the end of 4 years' observation. He went on to complete his normal tenure of service.

Case-report II: A 32 year old soldier having 13 years of service was referred for psychiatric examination while he was awaiting confirmation of life sentence for *desertion* , loss of Government property (weapon) and crossing over to enemy territory (Pakistan). The details recorded by the Presiding Officer of the Court Martial revealed that the individual, while returning from annual leave during Dec 1995, became convinced that the security personnel of the brigade where he was serving had been sent to follow him and that all his activities were being monitored on the radio sets concealed in their bodies. When he reached the Jammu Transit Camp (where the Armed Forces personnel report on posting/return from leave and are dispatched in secure transport to their respective field formations/regiments in the Northern Command operational zone), he believed that the same security personnel had reached there before him and he 'heard' them discussing among themselves as to how he should be disposed of. He did not sleep that night. He reached his unit location after two days of sleeplessness and fear of being killed. He reported the matter to his immediate superiors who did not, however, take him seriously. He was put on duty the next morning on a border post with arms and ammunition and a wireless set for communication. At the post he was given cooked food in which he found some 'yellow substance'. Convinced that his colleagues had poisoned the food, he threw it away without eating it. Apprehensive that he will be killed and buried in the snow, he ran away, became lost in the snow and wandered aimlessly till he was picked up by the Pakistani Rangers a day later.

He remained in the custody of the Pakistanis for nearly a year and was interrogated as suspected spy, before being pushed back into India. He was eventually apprehended up by the one of our border patrols on the Jammu border in a dishevelled state in Jan 1997. He was interrogated by the intelligence agencies, who did not believe his story, and was recommended for trial . The authorities were convinced that he was a malingerer and he was tried and convicted for treason by a court-martial.

While he was waiting for confirmation of the court's verdict by higher authorities, the Judge Advocate General observed that, despite his strange story, the soldier not been subjected to a detailed psychiatric examination before being sent up for trial. He was then referred for psychiatric evaluation , which revealed that he was suffering from paranoid schizophrenia. He was put on treatment and psychiatric opinion with regard to his mental state was forwarded to the authorities, who reconvened the court-martial, which now discharged him of all the charges and recommended admission to hospital for psychiatric treatment, as advised by the psychiatrist. The soldier recovered and remained in service, till retirement in medical category S2 permanent. The story thus had a happy ending and he went home with full pension, as well as disability benefits^^. The duration of his absence while in enemy territory was also regularized.

(^^A large number of our service persons who are discharged form service on medical grounds get disability benefits in addition to their pension. the disability is awarded by a board of officers for life at the time of discharge from service. If one is not satisfied by the award of a particular percent of disability, the individual is at liberty to appeal against the award, which is then re-assessed at the Armed Forces Medical College, Pune, or Army Hospital (Research & Referral), New Delhi by an *Appeal Medical Board,* headed by an officer of the rank of a Lt General.

A caveat needs to be entered here. No system is perfect and the Armed Forces are no exception. There are occasional systemic or human failures and the, fortunately, rare instances of abuse. The corrective mechanisms are, however, built into the system and are under constant review by, apart from the medical directorate, the consumers themselves, i.e., by senior supervisory officers who do not belong to the Army Medical Corps. A significant number of lapses can be traced back to communication failure, resulting from morbid reticence as often as from dereliction of duty. The recent suicide of a young woman officer, the first such tragedy amongst the growing number of women in the Armed Forces, probably illustrates the former. In order to investigate and address these macro-level man-management/public health issues, a large number of research projects, many funded by the Armed Forces Medical Research Council, have been carried out/are underway and these have provided significant inputs in higher planning/policy making (3, 4, 5, 6, 7)..

Public Health Perspectives

This rather detailed description of the military mental health model is intended to provide a template for generating pragmatic and replicable public health strategies. It offers a holistic and cost-effective mental healthcare delivery system, incorporated into the organization/community and optimising limited specialist resources, in partnership with the consumers, designed to yield improved outcomes. The active involvement of the consumer community acts as a *force multiplier* and assists in eliminating stigma and the consequent barriers in the pathway to care. It can be adapted to any public/private sector enterprise, or to a community-based concept like the *District Mental Health Programme,* substituting the military unit with local-self or civil society institutions such as village *panchayats* or *mohalla* committees and devolving to them the responsibility for monitoring/implementing the recovery plan. The philosophy underpinning this concept could have, arguably, implications transcending the boundaries of mental health.

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Referral for psychiatric evaluation:
Armed Forces Medical Services Form – 10.

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AFMSF-10

REPORT ON A CASE REQUIRING PSYCHIATRIC EXAMINATION/FOLLOW-UP

Note : This form will be completed by OC Unit/Ship in every case referred for psychiatric examination by either himself or by any MO attending the individual as out / in-patient. This report formalizes, in a structured format, the reasons, circumstances and other relevant background information suggesting the possibility of psychiatric illness / need for psychiatric examination in the opinion of the CO / Medical Officer concerned. It has no derogatory connotation or adverse administrative / legal implications, and cannot be made into a grievance / locus of a subsequent complaint, unless gross / obvious malafides is involved.

Report by OC

Number	Rank	Name	Age	Unit

Service : Army/Navy/Air Force Arms / Crops / Branch / Trade
Period of Service : Total Field/High altitude / Sea
Disciplinary Record / Entries Red-ink / Black-ink
Administrative Profile :
Punctual / Unpunctual, Disciplined / Indisciplined Dedicated / Casual

Alcohol/Drug Profile	Non Drinker / Drinker,
If Drinker	Social Frequent/Regular/Heavy/Uncontrolled – Gets drunk.
Alcohol/Drug Related	Misbehaviour/Absenteeism/Sick Report

The above individual has served under my command since……………………………………and I have regular/ occasional / rare personal interaction with him. The following is my considered report on him/her based on various inputs, personal observation / assessment of the individual's immediate superior / other sources.

1. Nature of duties.

(a) Nature of Present Duties	(b) Flying Hours
Trade	(only for Army Aviation Corps, Air Force and Naval Aviation)
Regimental	Total
Others	Operational

2. Competence and response to training.

(a) Professional	Above average/average/below average
(b) Regimental/others	Good / Satisfactory / Unsatisfactory
(c) Motivation	Above average / average / below average
(d) Performance under Stress	Good / satisfactory / Unsatisfactory

3. Psychosocial Profile.

(a) General Outlook	Cheerful / average / gloomy
(b) Social interaction	Active & outgoing / average / reclusive
(c) Abnormal traits*	Impulsive/Excitable, tends to overreact/ Suspicious/accusative/hostile towards authority.

*more than one can be ticked.

4. Behaviour:

(a) Prior to the onset of present illness / problem	Normal / abnormal (specify)
Since the onset of present illness / problem	Normal / abnormal (specify)
Since last psychiatric Hospitalisation / treatment (where applicable)	Improved to pre-illness level / partially improved / not improved/ worse (specify)

5. Follow-up data in respect of treated / low medical category cases.

(a) Compliance with treatment	Satisfactory / unsatisfactory
(b) Alcohol status	Abstinent / partly abstinent / not abstinent or worse
(c) Vocational performance	Satisfactory / equivocal / unsatisfactory (within employability restrictions)

6. Opinion as regards further retention in service

Option
(a) Retention recommended primarily in the interests of the organization.
(b) Retention recommended primarily in the interests of the individual to enable him to complete minimum pensionable service (________________years).
(c) Retention NOT RECOMMENDED as the individual has become an unacceptable liability to the organization.

(d) If retention in service is recommended, will you accept him under your own command? Yes / No
(e) If yes to option (d), will you be able to ensure that due corrective measures are taken in the unit so that the individual abides by the psychiatrist's advice / recommendations ? Yes / No

Note : Statements such as "As per medical opinion / psychiatric condition" will not be made.

7. Personal administrative data

(a) Date of posting in	(Specify if posted out)
(b) Date of leave	
(c) Pending disciplinary cases (if any)	
(d) Details of previous medical history.	

8. Any other relevant information (including unusual physical or mental stressors, domestic problems etc):

Date : Signature of Commanding Officer

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Care of elderly people with dementia by community volunteers- lessons from Kerala

Jacob Roy,
Kottayam.

Introduction

Care of the elderly is an important concern on the contemporary society due to the increasing population of elderly. India is currently entering a grey revolution; Kerala is the southern most state of India where the demographic transition towards aging is most marked. The demographic transition experienced by the state during 1961-1981 has led to drastic changes in age structure. The elderly population is growing at about two times faster than the total population of the state. The magnitude of the aged population has increased from 9 lakhs to 25 lakhs during 1961-91 and it reached 30 lakhs in 2001. It has been predicted that there will be an alarming increase in age related morbidity in the future to come. Dementia being an important age associated morbidity is emerging as an important public health problem in Kerala.

Prevalence of various dementing disorders has been well documented in developed countries. In India a few studies investigated the prevalence of various dementing disorders during the last decade. Two studies conducted in Kerala with the aim of assessing the magnitude of this disorder confirmed its presence. The study conducted in a rural community in 1996 estimated a prevalence of 4.4% in a population aged above 65.The urban study conducted in the city of cochin obtained a prevalence of 3.4% .

Dementia exerts a disproportionate and multifaceted impact on family and co-residents. Formal services catering for the needs of the patients with dementia are rare or non-existent in India. There is heavy reliance on formal and in particular family care for people with dementia. Any community based rehabilitation programmes for dementia necessitate effective and efficient utilization of resources with in the community.

Community Based Initiatives of ARDSI

Alzheimer’s and Related Disorders Society of India (ARDSI) is a registered, national, non-profit, voluntary organization dedicated to the care, support, training and research for people with dementia. ARDSI was formed by 1992 by affected family members, interested professionals and social workers. It aims to improve the quality of life of people with dementia as well as the care givers through support services, awareness campaigns and variety of other projects. ARDSI has 14 chapters spread across the country with its head quarters in Kerala. Through this network ARDSI implements a number of services like day care, home care, memory clinic, respite center, helpline and training of community geriatric care workers. One of its important objectives is to empower people in the community to cope up with the challenges caused by the illness. Its research activities are basically community oriented which include epidemiological investigations and psycho social interventions. 10/66 dementia research group (a network of researchers from mainly developing countries, It is committed to encourage more good quality research in those region where an estimated two third of all those with dementia live.) work in coordination with ARDSI centers at various places like Chennai, Vellore, Goa, Bangalore, Trissur, cochin and Hyderabad.

Community Geriatric Health Workers Training

The main objective of the training programme is to prepare personnel in community geriatric health, to educate care givers to take care of the elderly people in their homes to maintain a healthy and comfortable life at an optimum level. Community geriatric nursing blends three specialties with in the matrix of the nursing care of the older adult, geriatric, psychiatric, and community nursing and candidates with an aptitude in aged care work were selected from the community and the duration of the course was ten months. A multi-disciplinary team provides practical and theoretical training to the candidates. The eligibility for admission was an adult person with a pass in matriculation. Community geriatric health workers are instrumental in providing care for the aged in the community. They are entrusted with the following responsibilities.

- Identification of case
- Referral of patients
- Follow-up of patients in the community
- Act as a liaison between mental health professional and community.
- Providing nursing care to the geriatric patients in the community setting and in institutions
- To help the family members in care giving and provide them educational and emotional support.
- Transferring knowledge, skills and attitude for giving better care.
- Mental health education.
- Motivate the care givers to accept help from supporting agencies and self help groups.
- Act to ensure continuous, coordinated and comprehensive services for the elderly.

Home Care Project of Urban Community Dementia Services - Role of CGHWs

The health workers identify the cases through community survey. They are trained to administer simple screening tools to pick up potential cases of dementia. All the potential cases will be subjected to clinical evaluation by a psychiatrist in their homes to confirm the diagnosis. The team of experts from the center formulates an individualized care plan. The health workers do the liaison work between the family and dementia care center and they ensure continuity of care through periodic home visits.

A total 102 persons availed domiciliary care during the year 1996-99. the services provided include

- Educating the family members and creating awareness about aspects of the dementia and there by making a better understanding of the disease process and changing their attitude in a positive direction.
- Training the care givers to manage effectively the various behavioural and psychological problems associated with dementia.
- Severely disabled patients were helped to carry out their basic activities of daily living through nursing care, there by reduce the burden of care.

Evaluation study conducted after the completion of the project revealed that it was of great help to the majority of care givers (84%). 58% of care givers opinioned that they got training from the health workers to improve their care giving skills. The reasons for obtaining relief as reported in the evaluation study is given in Table 1

Table1
Reasons for the relief obtained through domiciliary care.

Reasons	**Frequency N=25**	**Percentage**
Gets information about to handle the patient	18	72%
Helps to remove the negative feelings towards the patients	5	20%
Right knowledge about dementia	1	4%
Get peace of mind for care givers as there is some one to talk to	3	12%
Get time to do other work	2	8%
Get some body to talk to the patients	2	8%
Get medicines	4	16%
No response	4	16%

The 10/66 Dementia Research Group Indian Network-Community based interventions

The 10/66 dementia research group conducted pioneering research programme pertaining to the psycho social problems faced by people with dementia and family care givers. The key findings can be summarized as follows:-

- *Dementia is a hidden problem:* Many people do not consider it as an illness, but as a part of normal aging, not requiring medical care. In India few people with dementia are seen by doctors (Patel &Prince 2001). The primary care doctors are not sensitive enough to detect the problems associated with dementia. There exist a therapeutic nihilism regarding the care of the demented.

- *Dementia is a stigmatized condition:* Dementia was often attributed by people to abuse, neglect, lack of love on the part of children towards the parent. Many a times, behavioural disturbances associated with dementia are considered as intentional and deliberate action from the part of the patient. These types of misinterpretations of symptoms are a source of family conflict or interpersonal problems. Psychiatric hospitals and old age homes selectively exclude patients with dementia, as their care is demanding and difficult.

- *Traditional care is under strain:* Indian culture is known for its reverence for the aged. The traditional joint family system was beneficial for the elderly. At present, there are evidences that the system of family care and support for older persons was less reliable than that has been claimed. Care for frail older people was almost entirely family based with little or no formal services. So it is apparent that there is need to raise awareness about dementia in the community and amongst health professionals and to improve access to appropriate health care for the elderly with mental illness.

Identification of cases by Anganwadi Workers

10/66 group developed and tested a model for community based rehabilitation of persons with dementia. Local community health workers were trained to deliver simple educational and training intervention for care givers. The Integrated Child Development Scheme (ICDS) is a national health programme established by the government of India. Local, educated women are recruited as health workers after formal training in community based maternal and child health care. As they run a daily pre-primary class room known as anganwadi, they are commonly known as anganwadi workers. Each anganwadi worker is assigned an area with a population about 1000. Anganwadi workers take part in a variety of community health programmes, not all of which are child focused. Home visits are part of their routine work. They keep detailed report about each households and update this in annual surveys. They have excellent rapport with local residents and tend to be aware of major health problems faced by families. The Trissur center (Kerala, India) of the 10/66 group developed an informant based strategy to identify community residing people with dementia (10/66 dementia research group 2000). The case identification method had been validated and proved to both useful and cost effective (Shaji K.S et.al)

Anganwadi Worker Training was done in two stages:

1. An introductory 90-minute training session. This covers topics like clinical features, common causes, course and outcome of people with dementia. Case vignettes of Alzheimer's disease and Vascular disease were used for this purpose. The anganwadi Workers were then given one month to prepare a list of all individuals, age 60and above in their localities. They were asked to classify them in to categories of definite cases of dementia, probable cases and non cases and this data was recorded.

2. One hour advanced training session. This cover clinical syndromes and disease concept in more detail, highlighting the particular characteristics of memory disturbances seen in dementia. Anganwadi Workers took an active part in this discussion, questions were encouraged, especially about specific cases they have encountered. Anganwadi Workers were asked to revise their initial list in the light of further training session preparing a final list containing names of those individuals who according to their judgment were suffering from dementia. This simple cost effective case finding method can be of practical use in the community based dementia care services in India and other developing countries with similar care systems.

Family and Community based Intervention by Multi-Purpose Health Workers

10/66 group developed a model for intervention to educate and train care givers to better manage people with dementia in the community. Any intervention needs to be consider the following facts –

- There should be some mechanism for the identification of cases in the community
- The intervention needs to be capable of being delivered in the home setting using existing resources
- In developing the intervention, consideration must be given to the resources available to deliver it. The content and level of intervention must be tailored to this, as well as to the cultural context.

The 10/66 interventions target not only the person with dementia and the main caregiver, but also include members of the immediate and extended family. The aim is to provide some basic education regarding dementia and Alzheimer's disease, and some more specific training regarding management of problem behaviour.

The Multi Purpose Health workers who will be responsible for delivering the intervention. They will first need to be given training to better identify cases of dementia in their locality. They will require some training in the protocol for the education and training intervention. It is important that these training sessions be kept as brief as possible. Multi Purpose Health workers' are busy health care staff with many responsibilities competing for their time. Training session lasted for two and a half days with periodic refresher course.

The Intervention

This consists three simple manualised modules; deliver over five half hour sessions at weekly intervals.

1. Assessment-one session
    - Dementia assessment
        1. confirm diagnosis
        2. cognitive and functional impairment
        3. behavioural symptoms
    - Care givers knowledge and understanding of dementia
    - Care givers arrangements
        4. Who are the family members?
        5. Who lives at home with the person with dementia?
        6. In what ways do they help out the principle care giver?
        7. What behavioural problems do the family members have to cope with?
        8. How burdened do they feel by caring for the person with dementia?

2. Basic education-Two sessions

- Dementia - a general introduction to the illness
- Dementia – what can I expect
- What causes dementia?
- Care and treatment for people with dementia

3. Specific training regarding problem behaviours-Two sessions

Up to eight problem behaviours identified in the initial assessment session are dealt with individually, as necessary.

- Personal hygiene
- Dressing
- Toileting and incontinence
- Repeated questioning
- Clinging
- Aggression
- Wandering
- Loss of interest in activities
-

Community care of demented by "Kudumbashree" volunteers

Kudumbashree is the name given to local women’s self help groups, consisting 20-40 members. They are of different age groups and educational backgrounds. However, in most instances, they are young women who have completed at least 10 years of schooling. With the help of District Coordinators of Kudumbashree a series of awareness classes are given.

Out of these volunteers those who have an attitude to provide care to elderly person with dementia are chosen to be in the group of community geriatric care workers. They are given further training on different aspects of dementia. Training is based on the care givers manual developed by ARDSI. These volunteers are then sent to the respective wards in the Cochin city. They conduct house to house survey for screening the elderly (over 65 years old) to identify dementia. They are trained to use a screening questionnaire and Malayalam adaptation of Mini Mental State Examination (MMSE). Those suspected to have dementia are further subjected to detailed examination to confirm the diagnosis. While these volunteers are doing the survey, the supervisors comprising the social workers and care manager identify, people with genuine interest,. These volunteers are given the option to join our “community geriatric care workers”. Once they accept the invitation they will have to under go further training in geriatric care. This will include theory and practical classes in the dementia care center. Type of care depends on the stage and needs of the patients and their families. The volunteers try to work with the family members. The time spent with each family varies, while they are in the homes, they make an assessment of the needs of the patient; provide information on management of difficult behaviour such as wandering, agitation, aggression, and incontinence. Specific instructions will be given to the family members as how to monitor the physical and psychological status of the patient and how to assist them in carrying out the activities of daily living. They will act as the connecting link between the Dementia care center and family. Family members are encouraged to participate in caregiver meetings (support Group) to alleviate their distress.

Merits and Limitations

These are some of the pioneering worth's in the community based rehabilitation of patient with dementia. The activities within these communities definitely helped to raise the awareness about dementia. It has been found that early identification and intervention is possible for dementia utilizing the existing resources with in the community. Knowledge and skills transferred to the family members empowered them to cope up with the challenges associated with dementia.

Care giving in dementia is a difficult and demanding task, which will leave the caregiver frustrated, angry and alone. Many of the caregivers are silent sufferers in the community. Their participation in the caregivers meeting helped them to reduce the impact of care burden. The important lesson is that it is possible to develop comprehensive, cost effective, culturally appropriate and family oriented interventions in the Indian community. The most important constraint is the low level of awareness about the dementia. At times, it was seen that people were reluctant to change the beliefs and attitudes regarding their relative's condition. Some people were reluctant to accept the services due to fear of stigmatization. A group of people in urban community was not receptive to the community-based services. They consider that their own arrangements for their relative were quite enough and some consider it as intrusion in their privacy. Though the trained community volunteer could identify the cases, their training was not adequate to satisfy some of the questions and queries raised by the family members.

Lessons learned

1. Choosing the community is important
2. Selection of volunteers to done meticulously
3. Ensure that no false promise is given regarding honorarium etc
4. Ensure that programme continue as a people's programme they should feel that it is their need.
5. However efforts are to be made to generate reasonable amount of money to be paid by the beneficiaries of the volunteers from the clients.
6. Importance to documentation should be given
7. Networking with the local government, NGOs, religious, cultural organizations is important.

Publications

1. Screening tools for dementia
    I. Mini Mental State Examination (MMSE) – Malayalam Adaptation

II. Cambridge Cognitive Examination of the Elderly (CAMCOG)-Malayalam Adaptation.
III. Behavioural and Psychological Symptoms in Alzheimer's disease (BEHAVE-AD)-Malayalam Adaptation.
IV. Functional Assessment Staging (FAST)- Malayalam Adaptation.
V. Manual of Care for Family Carers
VI. Alzheimer's disease (Malayalam). Kerala Literacy Mission Thiruvananthapuram .
VII. Dementia – Training manual for geriatric health workers.
VIII. Dementia News-News letter of ARDSI
IX. Fact Sheets About Alzheimer's disease and other dementia
X. Epidemiological studies –British Journal of Psychiatry 1996,2005.

Future plans

To extend the programme to near by areas

1. Bring people from other parts of the country, to explore the possibility of reflecting this care nodel.
2. Documentation as a film, particularly home care.
3. Improve the training of volunteers
4. Link the programme with teaching hospitals, colleges of nursing in the locality.

Acknowledgement

This study was conducted with the help of Dr. S. Shaji, Consultant Psychiatrist, Mr. Tonny Kurian, Project Officer, Manju Rejith, Care Manager, ARDSI Dementia Care Centre, Cochin.

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SECTION II

School/College teachers

Life skills education in schools – NIMHANS experience

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Introduction

Life skills are living skills or abilities for positive adaptive and positive behaviour that enables an individual to deal with demands and challenges of every day life effectively

(WHO 1997). Considering this definition, the current situation warrants urgent inputs to young people and adolescents in view of rapidly changing society, technological developments making information dissemination at an unimaginable speed, rapid urbanization and neuclearisation of families. All of the above factors have its clear impact of the value system in the community. These factors often confuse the adolescents and raise a storm in their mind about their competence. They often some how learn to survive in the race by doing things at their disposition. It is important to recognize life on earth should be lived by design rather than by chance to ensure a sense of well-being. The art of living by design cannot be learnt by merely reading the syllabus and from the guidance and support from the family and community. With each preoccupied with his own agenda to compete and achieve, nurturing adolescents to make them competent to face opportunities and challenges in their life needs systematic and ongoing inputs at a time when it is most needed. Nurturing is most important in adolescence, since it represents a transition from childhood to adulthood i.e., from being dependent on parents and carers to being independent and autonomous. This change in attitude can pose several problems in nurturing. While it is important to accept that the transition is a development phase in ones life, it is crucial to keep in place a process which helps the adolescent learn abilities to do the best he/she can with opportunity and challenge that comes his/her way. It is well recognized that mere education about the values/morals to be imbibed in one self; to behave in manner that is appropriate is not relevant to the development phase of adolescents. Changing values in the family and larger society will pose a major barrier for such an input at home. Therefore, an alternative method, which involves experiential learning, has been in practice to enable development of competencies for the last two decades.

Background for the initiative

National Institute of Mental Health and Neuro-Sciences (NIMHANS),Bangalore, India, is an autonomous institute funded by the Government of India. It was established in 1954 and the organization has contributed and provided leadership to every mental health initiative in the country. All the initiatives started in the Institute have been applied to other regions within the country as well as to other developing countries. With respect to health promotion in schools, NIMHANS initiatives started in the late eighties. These initiatives were called School enrichment programs and it was characterized by mental health professionals centered inputs in the schools. International developments in the nineties, largely that of the World Health Organization resulted in taking up life skills education in schools. The WHO published the literature on life skills education and general guidelines for developing life skills curriculum in the schools. They also offered training support for master trainers. It was in 1995 that a training program was organized by Prof R.Srinivasa Murthy former Head, Department of Psychiatry NIMHANS. The resource person for the training program was from World Health Organization. The training empowered few staff at NIMHANS and they started working on life skills education in schools. One school was identified in rural, urban and tribal locations respectively to implement life skills education in schools. It was found that life skills education was not possible in school without structured lesson plans. The WHO SEARO extended support to develop manuals for schools and this resulted in 52 activities(modules) for life skills education. These activities were divided into 20 activities for 8th standard, 20 activities for 9th standard and 12 activities for 10th standard. Teachers reviewed these manuals and correction in content and illustrations were made to ensure user friendliness and culture appropriateness.

Reasons for choosing teachers

Health promotion in schools using life skills approach needs trained manpower resources. Involvement of mental health professionals for implementation of life skills education is not a sustainable model. Further, the work load of mental health professionals does not allow for this kind of an input in the long run in school settings. Since it is not sustainable by mental health professionals to make life skills educational inputs in the school and specific lack of staff (school counsellors or social workers or psychologists), teachers become the most important resource for this activity. The choice of teacher as the life skills educator is justified for the following reasons. They are as follows- teachers have credibility and skills to handle children, use of available manpower resources in the school is sustainable in so far as life skills education is concerned and lastly, education system focuses on overall development rather than mere dissemination of knowledge. Teachers are concerned about the issues of adolescents like deliberate self-harm, substance use, poor academic performance, absenteeism, and school dropout and relationship problems. They always look for quick solutions to these problems. Most often their eagerness to sort these issues out results in frustration

Training approaches

Life skills education was institutionalized into the education system in four Districts of Karnataka. The approach used was a cascading model where master trainers were trained by mental health professionals for one week. The master trainers were expected to train teachers in their respective District Institute of education and training (DIET). The three days training program covered the following topics.

- Pre-assessment
- Behaviour and Health
- Issues in adolescents
- Need for life skills education.
- Life Skills Education- What, When, Why, Whom
- Differences between value and life skills education
- Peer Learning and Facilitation – (with discussion and brainstorming)
- Participatory Methods
- Facilitation skills
- Activity (demonstration)
- Going through 8th /9th and 10th Standard Module (demonstration one activity from the each of the module by teachers followed by discussion)
- Handling Sensitive Issues –Teacher's Role
- Starting the LSE program in the school
- Evaluation and Follow-up
- Future Program and Support
- Post Assessment

The training was participatory and activity oriented. Trainers were given hands on experience rather than in learning skills education teaching methodology rather than focusing on theoretical issues. Motivating teachers to highlight the importance of experiential learning methods occur constantly throughout the training session. The trainees are made to understand the four important steps in life education such as – Introducing an activity, group discussion on the activity, presentation by respective group leaders and ways of facilitating the responses and lastly linking strategies to life skills. The trainees are given an opportunity to understand issues like resistance in the class, handling children who are passive, techniques useful to maintain orderliness in class room, techniques useful to involve all the children in the activity and skills required to handle sensitive issues like sexuality, contraception, boy girl relationship and high risk behaviours. The training also highlights the need to develop patience, listening skills, encouraging children to participate and share their thoughts with out fear, learning to be neural during life skills class and facilitation skills.

Activities by teachers
(What did the teachers do after the training program and what was the response of the children)

Trained teachers went back to the school with a new message that life skills can be useful to promote psychosocial competence in adolescents. Some of the teachers were able to start the life skills class soon after their return. These teachers briefed their colleagues and head masters about the life skills education and its benefits to children. Though they did not receive a great degree of encouragement, they started the classes once a week. Soon the teachers realized that the space available in the classroom was not sufficient to engage the children in the life skills activity. Teachers decided to rake the children out to the open field to carry out life skills activity. Those who did have access to such a facility engaged children in the corridors of the school. It was disappointing for some teachers to learn that the school has become very noisy during such classes and complaints were made to the headmaster. The proportion of teachers who were able to take life skills to the class was about a third of the trained teachers. Teachers who conducted life skills class observed a significant change in their relationship with children. They observed- ‘children were hitherto tight lipped, but after the life skills class they have started taking very easily. They come to us with problems at home and studies. They are eager to seek our guidance, suggestion and help the moment problems confront them’.

Teachers also observed that their popularity had increased in the school in comparison to other teachers and this resulted in frequent conflicts between teachers. Teachers who were not involved in life skills education classes (only two teachers from one school were selected for training) started complaining to the head master that children have lost a sense of fear in the school and they were very noisy in the classroom. They seem threatened by the sense of ease children had after exposure to experiential learning methods.

Teachers who were actively involved in life skills education reported the following. “We have got transformed into better human beings after the life skills education training. We do not lose temper at home, our interaction with children and other family members gave improved to a great extent – so much so that there is peace and pleasantness at home". Attitudinal change was significant in younger female teachers with shorter duration of service. Science and language teachers also showed similar change compared to maths and social studies teachers.

A significant group of teachers did not start LSE classes in their for various reasons. Schools. They claimed that head masters were not cooperative, space was insufficient, and lack of funds to duplicate activity material as the key reasons for not starting the program. These teachers also had poor conviction about the value of life skills education. They felt that children would learn many unnecessary things as part of this class. They feared that they would start acting on the new ideas they get after the class. They also felt moral education, guidance and support is sufficient to mould children. They quoted their own life experience and justified saying that" we did not get any life skills exposure during our younger days and are we not successful in our life? ". They also reported that some topics couldn't be discussed in classroom because hidden information is brought to the public and children will become very curious – particularly issues concerning boy girl relationship, sexuality, and contraception. The most striking aspect of the working with teachers is that many teachers did not complete even one reading of the resource material even though it was in Kannada. Perhaps reading the lesson plans would have enlightened them about the activities and the power of experiential learning methods.

Some teachers reported that parents objected to teachers teaching any thing beyond the lessons. Parents have raised objections to taking about sexuality and contraception in the classroom. This was major source of de-motivation for some teachers. The teachers did not clarify further and stopped doing any activity in the school because of pressure from school management committee consisting of local leaders and the head master.

The above experiences clearly suggest that motivating teachers, baptizing them to accept and handling burnout is an important input that the trainers should give attention to in addition to training them to initiate health promotion using life skills.

What is the Impact of life skills education on children in schools?

Irrespective of culture and geographical locations, life skills education for adolescents has undisputed value. Implementation of life skills education in tribal locations in Karnataka resulted in decrease in absenteeism, improvement in academic performance and dramatic increase in pass percentage in secondary school leaning certificate results. Similarly, implementation of the LSE in four districts, revealed some positive developments as reported by teachers. Teachers reported a clear improvement in relationship between children and teachers. The attendance improved and there was a significant change in the degree of responsibility with respect to home and maintenance of orderliness in the classroom. They also observed that children spent a lot of time together to sort issues in studies and groups of children were engaged in group study activities Children also reported feeling good about coming to school and looked forward to the life skills .on Saturdays.

Teachers felt that life skills class is making children seek more of time from them to discuss issues in their home and school. Lack of time to do this has put lot of pressure on them observed some teachers.

Teachers have reported that parents have seen improvement in the behavior and level of responsibility in the children after life skills education in the schools. One parent said the "my daughter who was demanding all the time and she seems to have change suddenly lately ".

One parent observed that I am at peace now, me son manages his time well and does not spend so much time in front of the TV.

Levels and Limits in implementation of LSE in schools

Teachers form the important resource for implementation of LSE in schools. Teachers are trained for period of three days by the master trainers identified by the Department of education. The master trainers are lectures in District Institute of education and training (DIET). The mental health professionals supervised the training of the teachers by master trainers. The trained teachers were able to impart life skills education class for the respective classes. As mentioned above one in three teachers felt that life skills education is useful and they were able to conduct the class despite difficulties like space and time. The rest of the teachers were either paralyzed by the realities in the school or did not bother to take the initiative forward. Some teachers said the following which was encouraging to us – ' Life skills is a very novel non-threatening method to improve psychosocial competence; if teachers are not willing to set the agenda who will. There will no time when there are no problems in the school sector and therefore we should stop making excuses and start acting on the task of shaping people'. They were able to conduct life skills class based on the modules and problem of space was over come by conducting the class in the playground. They were happy that children enjoyed the LSE class and teachers felt good about the fact that the students have so much of hidden wisdom in them. While some teachers did the LSE classes in a way it should be done, an equal proportion of them said that they were able to integrate LSE classes while they were teaching other subjects like mathematics, biology and physics. Further, some teachers report using some other activity instead of what is mentioned in the teacher's manual. If teachers are able to use any other activity it is a welcome step provided they are able to meet the objectives of the session on hand and linking it to skills. The next group of teachers merely encouraged children to read the life skills manual play among themselves in their free time. There were another group of teachers who said that they are over worked and felt that either the art and craft teacher or the physical education teachers should be entrusted with the responsibility of LSE classes since they have lot of free time.

Their understanding about the sense of neutrality in life skills education class was not to the extent desired. Sense of neutrality of LSE class is an important skill that the teacher need, to help children learn from various experiences. The following example illiterates this- I am using the activity, understanding motivation in 8th standard activity manual. The case example is of a boy who discontinues school after death of his brother. The boy takes a decision to stop studying to earn money and support the family. Subsequently he repents his decision and he has developed alcohol Following group discussion by children many issues were brought by the children, teacher takes a moralistic view by saying that the boy should not have decided to discontinue school. She observed that the boy has no business to discontinue studies and he should have listen to his parents. Always remember children, listen to elderly and do as they say. If you do some thing against their wish you will suffer for rest of your life was the message at the end of the session. The above example suggests the lack of neutrality and judgmental attitude of the teacher.

More than one half of the teachers did not see facilitation as an important means of generating new strategies for development of competence. They conducted the life skills activity and did not use much of the information from group discussion and this is major limitation in so far as life skills education is concerned. Let us now examine an example to depict the above observation. In a module on time management, teachers was able to get the children to prioritize time and draw a pie chart to identify activities and allocation of time for each of the activities. Some children allocated a lot of time for play and TV viewing but others allocated less time for the same. Some of the bright students in the class were reflecting on allocation of time for studies every day from the beginning of the academic year. They also said that play activities. Recreation like music and helping parents at home was important very day. The teachers did not make use of the experience of bright students to make linkages but spoke on time management in her own way without giving much importance to the plan by the students. Perhaps facilitation as a concept and its importance not yet clear to the teachers despite three days of training. While it is recognized that teachers may not pick up required skills in three days of training, involvement of teachers as life skills education cannot be changed dramatically. This observation calls for specific initiatives to support teachers to understand their difficulties and constantly work to refine skills. This can be achieved by several local support mechanisms like life skills educators club, support groups on a monthly basis, review meetings with mental health professionals and lastly, refresher training programs at periodic intervals. The master trainer with the Block Education Officer should review the progress in Life Skills education class in their monthly meeting. They should ask every teacher for their experience in life skills class and find solution for technical problem (Such as facilitation skills, listening skills, communication skills and handling sensitive issues like sexuality and so on) and logistic difficulties like lack of funds, space for life skills activity, support to the teacher who is involved in life skills education class if she needs any. Teachers feel that giving suggestion and advice to children is far more useful compared to making sense out of the strategies discussed and tried by other students. This could be one major reason why they do not make an attempt to neutral and non–judgmental

Support required by teachers

It is untrue to claim that, three days of training guarantees adequate skills transfer to all teachers. Transfer of adequate skills depends upon many factors that include trainees and trainer variables. In general teachers consider life skills education an additional burden since they have to fulfill many responsibilities and also meet some targets specified by the department of education.

Teachers have both positive and negative responses to the concept of life skills education in school. Many teachers feel moral and value education is sufficient to mould children. They say, " We have enough and more people who have achieved in their life to inspire youngsters" therefore what is the need for life skills education" .

Some teachers observe "The single most positive and fulfilling experience in my life as a teacher is the possibility of teaching life skills education in my school. I did not realize that activities and games could have such a powerful impact of their minds. I strongly feel that life skills should be made compulsory in all schools".

" Teachers have become like doormats, why should we be involved in all the programs in the school. We are called for election duty, census duty and so on and on the top of it all if the school gets poor results were are issued memos".

"Teachers are over worked and underpaid, why are adding misery to our life. Please think of a separate teacher for life skills education" .

"Life skills education is a very positive thing in our school. We should get support from both the head master and the parents". All teachers should see life skills education in school is as important as science or maths. I am surprised that education for life gets less importance than others".

"I am a changed person today says a teacher. After the life skills education training program, there are lot of changes in me. I am able to understand my children and learnt to give them space. This has made a huge difference to me as a person and us as a family".

They are not recognized for their work and both of these factors de-motivate them. It is this group of teachers who are posted for life skills education training. Teachers need to be constantly motivated to take up life skills education as an important part of their job as teachers. Trained teachers require support to clarify their doubts about life skills concepts. experiential learning methods; skills to handle large number of children and skills to handle specific issues such as sexuality, contraception and reproductive health.

An example

Support from the head master and other teachers are considered vital to boost the morale of the average teacher and this aspect should be strengthened by better involvement of the school authorities. This is illustrated in the following example.

“Life skills education has been implemented in one of the schools. The most interesting aspect of this school is that head master also attends the life skills class and says that children are so excited and participate well. The teacher gets support from the head master for duplicating material. He talks about the value of life skills education in the school meetings” .

Even though need for support is recognized, it has not been possible to set up such a support system despite all efforts to do so. This is related to problems in coordination between the administrative wing (BEO) executive wing the (Headmasters) and the support systems to teachers the diet lecturers. Wherever there is sincerity and honesty in implementation of LSE by all concerned life skills education is successful. Further, the program should be reviewed by the elected representatives,like the member of legislative assembly, and the district level officer like the deputy director of education at least every month to start with. In a country like ours power is very important. Teachers value the power behind you rather the benefits of the program.

Parents should demand for life skills education in the schools. They should be willing to pay for this kind of service and very LSE teacher should specifically recognize for her contribution towards building the nation.

Further, interpersonal problems between DIET lectures (master trainers), their principals and schools teachers and their head masters become a major barrier in achieving it. It should be mentioned that support to teachers is an integral part of this program; support of the nature required wads not available to them because to host of factors like motivation, lack of conviction amongst master trainers about the need for life skills education, lack of support from the headmaster and lastly, lack of administrative support from the education system.

Difficulties encountered

Implementation of life skills education in schools has been done through teachers who were trained by the master trainers. Most of the trained teachers observed that life skills education is an additional responsibility. They often felt the need for a separate teacher to shoulder this responsibility. Lack of support from other teachers and head master was a de-motivating factor report by most teachers. Most schools did not have enough space in the class room to conduct the activity as required in the module and therefore many teachers just conducted didactic sessions on life skills education which seemed more like the value education or moral science class. However, some teachers were able to take the children out into the playground to conduct the life skills education. Teachers did have the funds to duplicate the activity material and this was a major source of tress. It was very interesting to note that teachers did not feel excited about the value of life skills education and the potential it has to improve psychosocial competence in children. Head masters did not cooperate with the teachers to identify a specific time to conduct LSE classes in the school. They often thought that allocating time for regular classes is more useful than life skills education class because teachers could compete the entire syllabus in time. Multiple tasks expected of the teacher were one factor responsible to set aside the life skills class. The facilitation skills of teachers need to be strengthened and most teachers find it difficult to learn this skill. .

Lessons learnt

Life skills training can be conducted for teachers and there is a significant gain in knowledge about issues that concern adolescents and the outcome of limitation in psychosocial competence. Change in attitude to life skills education does not last for a long time in teachers. They need constant support, motivation to make them see the importance of developing psychosocial competence in children within the context of school. Facilitation as a skill is difficult for them to learn in a short period of time. Most teachers need constant pressure by the authorities to make life skills education a priority in the school. The following are the highlights

- Master trainers can impart training but they some degree of supervision ad support from the mental health professionals. Availability of video module for life skills education can improve consistency in training.
- Uniform change in teachers opinion about the need for life skills education
- Very significant change in knowledge about life skills in teachers
- Teachers were satisfied by the training skills of the master trainers
- Teachers also reported changes in their own attitude and behavior after training in LSE both at home and the school.
- Lack of funds for duplicating activity material was a major problem
- Head masters have not identified a specified time for life skills class as part of school curriculum because of their preoccupation with target oriented system. Teachers and head masters are punished if they do not produce the desired results in the school.
- Some of the teachers are using free time to teach life skills education.
- Some teachers report that they talk about life skills education as part of other subjects like math's, social studies and geography
- Most teachers are engaging children in life skills education class at least once a week
- All the 299 schools have started LSE classes
- Lack of space in the classroom for activity was a major problem reported by the teachers.
- Lack of funds to duplicate activity material
- Funds for local support group meetings
- Uncooperative head masters
- Inability to complete the activity in 45 mts
- Lack of consensus about LSE being part of school curriculum
- Lack of video material
-

Resource material

Dissemination of life skills in schools using the available resources like teachers is the one of realistic alternatives to implement health promotion using life skills approach in schools. We started developing modules for the teachers in a systematic manner. Focus groups of school children from rural, tribal and urban areas were conducted to understand the needs and issues of children. Similarly focus groups were conducted for teachers, parents, policy makers and mental health professionals. Based on this 52 key areas were identified and lesson plans for each of the topic was developed. The modules can be divided into three broad heading.

PHYSICAL	PSYCHOLOGICAL	SOCIAL
Nutrition	Responsibility	Gender issues
Hygiene	Drug abuse	Dowry issues
Safety	Stress Management	Violence
Reproductive Health	Time Management.	Environmental pollution
Menstrual issues	Facing failure-love, exams etc.	Respect for elders
Teenage pregnancy	Facing Peer pressure	Social values
First Aid	Suicide	
HV/AIDS	Boy and girl relationship	
	Motivation, Improving self-esteem,	
	Memory, interpersonal relationship etc.	
	Controlling Anger, handling Criticism	
	Handling frustration	

Each of the module or lesson plan had the following key headings. Consisting of fact sheet, name of the activity, objective of the activity, life skills promoted, materials for the activity, facilitative questions and summary. The 52 activities were divided into 20 activities for 8th standard, 20 activities for 9th standard and 12 activities for 10th standard. This distribution was done based on the discussion with teachers and education policy makers to ensure that the lessons plans for respective classes are completed for the specified class in one year. Care was taken to see that the activity material developed in culture specific and user friendly, activity manual for health promotion using life skills for 8th, 9th and 10 standards. Current status of life skills education in Karnataka-

- Life skills education is implemented in all the Government schools in four districts
- Bangalore south district = 57 schools
- Bangalore Rural district = 107 schools
- Haveri district = 65 schools
- Udupi district = 70 schools
- Total number of schools = 299
- Total number of teachers involved =1095
- Total number of children benefited= 55,000
- Schools considered are only GOVT schools

Future Initiatives

Life skills education for adolescents has been recognized as a vital input in the context of school for enhancing development and psychosocial competence. Teachers who are burdened with several tasks in the school are the only resource at the present time. Implementation of Life Skills Education using this group of people needs a lot of support both from within the school and its administration. In view of these problems, it is worth considering volunteers to take up the responsibility of imparting life skills education program, or parents them selves becoming part of this initiative in the school. Development of video modules for LSE class in the schools school ease the work of teachers and this is been taken up in NIMHANS. It is also worth considering peer education as an approach to implement life skills and health promotion in schools. Peer education using students themselves seems a promising approach in view of several difficulties encountered during implementation. Lastly, the Government and the administration should commit themselves to promote health of children rather than just a lip sympathy for the program at present. Lastly, professionals should carry out research in life skills education with much more vigour so that corrections can be made with respect to what works and what does not. Advocacy by parents demanding for y

Conclusion

The mental health professionals working in the Department of psychiatry have trained large number of teachers; master trainers, parents and volunteers promote health of adolescents in the school. The most important aspect of work with respect to health promotion using life skills approach was the implementation of LSE in four districts. Lack of coordination and funding support from the education department has delayed evaluation of the impact of LSE in schools. Evaluation will be carried out randomly in schools of the four Districts in Karnataka (Haveri, Udupi, Bangalore Rural and Bangalore Urban) This is schedule to be done in September/October 2006. The Life skills education group has recently completed training of master trainers from Navodaya Vidhyalas in Hyderabad region and they will in turn training teachers within their clusters. This program will evaluated in April 2007 to understand the impact of life skills education. The Government of India has passed an order to make life skills education mandatory n schools but clarity is lacking as to which resource material should be used for life skills education since they have allocated only 18 hours for the same.

Appendix

Program schedule for master trainers

Day 1:	Detail	Resource Person
9.00 am to 9.30 am	Registration	
9.30 am to 10.30 am	Inauguration	
10.30 am to 11.00 am	Coffee/Tea	
11.00 am to 12.00 am	Pre assessment	

12.00 am to 1.00 pm	Introduction – Concept and Scope of Life Skills Education in Schools	
1.00 pm to 2.00 pm	Lunch	
2.00 pm to 3. 30 pm	Sharing of experiences – Teaching Teachers	
3.30 pm to 3.45 pm	Coffee/Tea	
3.45 pm to 4.40 pm	Health & Life Skills – What, Why, When and Who	
Day 2:		
9.00am to 10.00 am	LSE initiatives NIMHANS experience -I	
10.00 am to 11.00 am	LSE initiatives NIMHANS experience –II	
11. 00 am to 11.15 am	Coffee/Tea	
11.15 am to 1.00 pm	Participatory Methods	
1.00 pm to 2.00 pm	Lunch	
2.00 pm to 3.30 pm	Going through modules – 8th standard	
3.30 pm to 3.45 pm	Coffee / Tea	
3.45 pm to 4 .30 pm	Demo session –	
Day 3:		
9.00 am to 11.30 am	Peer Learning and Facilitation	
11.30 am to 11.45 am	Coffee/Tea	
11.45 am to 1.00 pm	How to handle the sensitive issues – Teacher's Role	
1.00 pm to 2.00 pm	Lunch	
2.00 pm to 3.30 pm	Going through modules – 8th standard	
3.30 pm to 3.45 pm	Coffee / Tea	
3.45 pm to 4.30 pm	Demo session – by the Group	

Day 4:		
9.00 am to 11.30 am	Building Motivation & Handling Difficulties and in teachers	
11.30 am to 11.45 am	Coffee/Tea	
11.45 am to 1.00 am	DSERT and Life Skills Initiatives	
1.00 am to 2.00 pm	Lunch	
2.00 pm to 3.30 pm	Going through module – 9th standard	
3.30 pm to 3.45 pm	Coffee/Tea	

3.45 to 4. 30 pm	Demo session and discussion	
Day 5:		
9.00 am to 11.30 am	Project to Program – How to plan for Workshops	
11.30 am to 11.45 am	Coffee/Tea	
11.45 am to 1.00 pm	Evluation of the LSE Program – role of MTs and Teachers How to record the class room level indicators	
1.00 pm to 2.00 pm	Lunch	
2.00 pm to 3.30 pm	Going through module – 10th standard and Demo session by group	
3.30 pm to 3.45 pm	Coffee/Tea	
3.45 pm to 4.30 pm	Follow up and Support	
Day 6:		
9.30 am to 10.30 am	Valedictory Function and Photo Session	
10.45 am to 12.00 am	How to Evaluate the LSE Program – Methods, role of MT's and Teachers	
12.30 am to 1.00 pm	Handling Difficulties	
1.00 pm to 2.00 pm	Lunch	
2.00 to 3 .00 pm	Sharing of participants experience and Clarifying doubts	
3.00 am to 4.30 pm	Post assessment	

Appendix - 2

3 Days Program Schedule for the teachers training .

Day – 1	
9.30 am to 1.00 pm	Inauguration (Invite Block Educational Officer/DDOI/ Local Head) Pre Assessment Behavior and Health, Life Skills Education- What, When, Why, Whom

2.00 pm to 4.30 pm	Differences between value and life skills education Peer Learning and Facilitation – (with discussion and brainstorming)
Day – 2 9.30 am to 1.00 pm 2.00 pm to 4.30 pm	 Participatory Methods Activity (demonstration) Going through 8th Standard Module (ask teachers to demonstrate one activity from the module)
Day –3 9.30 am to 1.00 pm 1.00 pm to 4.30 pm	 Handling Sensitive Issues –Teacher's Role Starting the LSE program in the school Evaluation and Follow-up Future Program and Support Post Assessment

School mental health – Delhi experience

Mehta, M.
New Delhi.

Introduction

There has been a growing concern all over the world, as an increasing number of children and adolescents are having difficulty in managing challenges of development. It has been estimated that one in five children and adolescents may have a mental health problem. WHO (2001) report on mental health estimates a global burden of serious Emotional Disturbances in children and adolescents to about 15%. At least one in ten, or as many as six million young people, may have serious emotional disturbance. And an estimated two-third of all young people with mental health problems are not getting the help that they need. In India alone, children and adolescent constitute 40-44% of over 1000 million population, and about 10-12% of them suffer from disorders in behavioral, learning and development. With so many young people in need of special care, it's important to identify students with mental health problems and take appropriate actions.

Prevalence

School based mental health programs are being considered as the need of the hour in various schools of Indian. The major reason for this, have been various school based studies which have reported increasing rates of mental health problems among school children over the past few decades. Rao (1978) found that 19.62% urban adolescents had identifiable mental health problems. Jiloha and Murthy (1981) found 20.7% school children to have identifiable mental disorders, similarly John (1980) found 21.4% prevalence among school children. Deivasigamani (1990) reported a prevalence rate of psychiatric disorders among school going children to be around 33.7%. Various Indian studies also report of observable sex difference in childhood mental disorders. Boys more than girls seem to be more prone to have identifiable mental health disorders like mental retardation, speech problems, problems related to anger and aggression, hyperactivity, and enuresis. Also, boys are more likely to demonstrate externalizing problems, whereas girls more of internalizing problems. Rutter (1970, 1982) also found that boys more than girls were more vulnerable in terms of developing childhood mental health disorder. In India, socio-economic strata of students were also related to the kinds of problems observed. Children from higher social strata were over protected and subjected to strict discipline, leading to neurotic problems, whereas children from middle and low social strata were ridiculed, rejected and subjected to harsh treatment suggesting the high possibility of developing anti social behavior. The symptoms observed among children varied according to the kinds of schools such as slum, rural, government or public.

Mehta (1989) conducted a study on 2055 Indian school children from rural areas around Delhi to identify the prevalence of mental health disorders in children. It was found that 13.28% children had identifiable mental health disorder. According to the broad diagnostic categories, maximum children were identified having behavioral and emotional problems such as oppositional defiant disorder, avoidant disorder, and overanxious disorder, followed by physical, intellectual and developmental disorders including mental sub normality, enuresis, and attention deficit disorder. 12.6% children were also identified as being "at risk" of developing identifiable mental health disorder.

In a study by Mehta (2000) on prevalence of stress in public and government school children of Delhi, it was found that 27% of public school children and 25.5% of govt. school children had mild stress. 10.2% of public and 6.7% of govt. school children had moderate to severe stress. These children demonstrated their stress through various physical and psychological symptoms such as headache, stomachache, blurring of vision, loosing temper, forgetfulness and also had presence of several daily hassles and stressful life events in their life. Presence of stress has been directly linked to the increased chances of development of serious mental disorders. Thereby, indicating the need to develop programs to prevent these children from developing serious problems later in life.

Mental health and schools

Schools play a significant and formative role in the cognitive, language, social, emotional and moral development of children. The relationship between school and child's mental health has come to hold a lot of importance in the past few decades, because of the tremendous amount of stress that students are facing to prove their worth in academic as well as non-academic pursuits. Schools have become a crucial learning ground, for learning not only academic related skills, but also for learning crucial life skills to handle psychological stressors and develop a healthy and well-balanced personality. Children spend a majority of their time in schools, and learn significant lessons of their life in schools. Schools can provide children with necessary skills, to help them cope with challenges of development.

Schools, therefore, have become the best place to develop mental health programs for children because:

- Almost all children do attend school sometime during their life
- Schools are the strongest social and educational institutions available for intervention
- Schools also have a profound influence on the community at large, by influencing the child and his family
- Children's ability to stay in school, learn, and utilize what they have learnt is greatly influenced by their mental well-being
- Schools can protect children from the hazards, which affect their learning, development and psychological well being
- Schools also play a crucial role in building self-esteem and sense of competence in the child
- School mental health programs are effective in improving learning and well being, and in treating psychological disorders
- A major contributor to the rising levels of stress among children is school related problems such as academic achievement and peer acceptance. Therefore, schools based programs can provide a preventive approach for the children

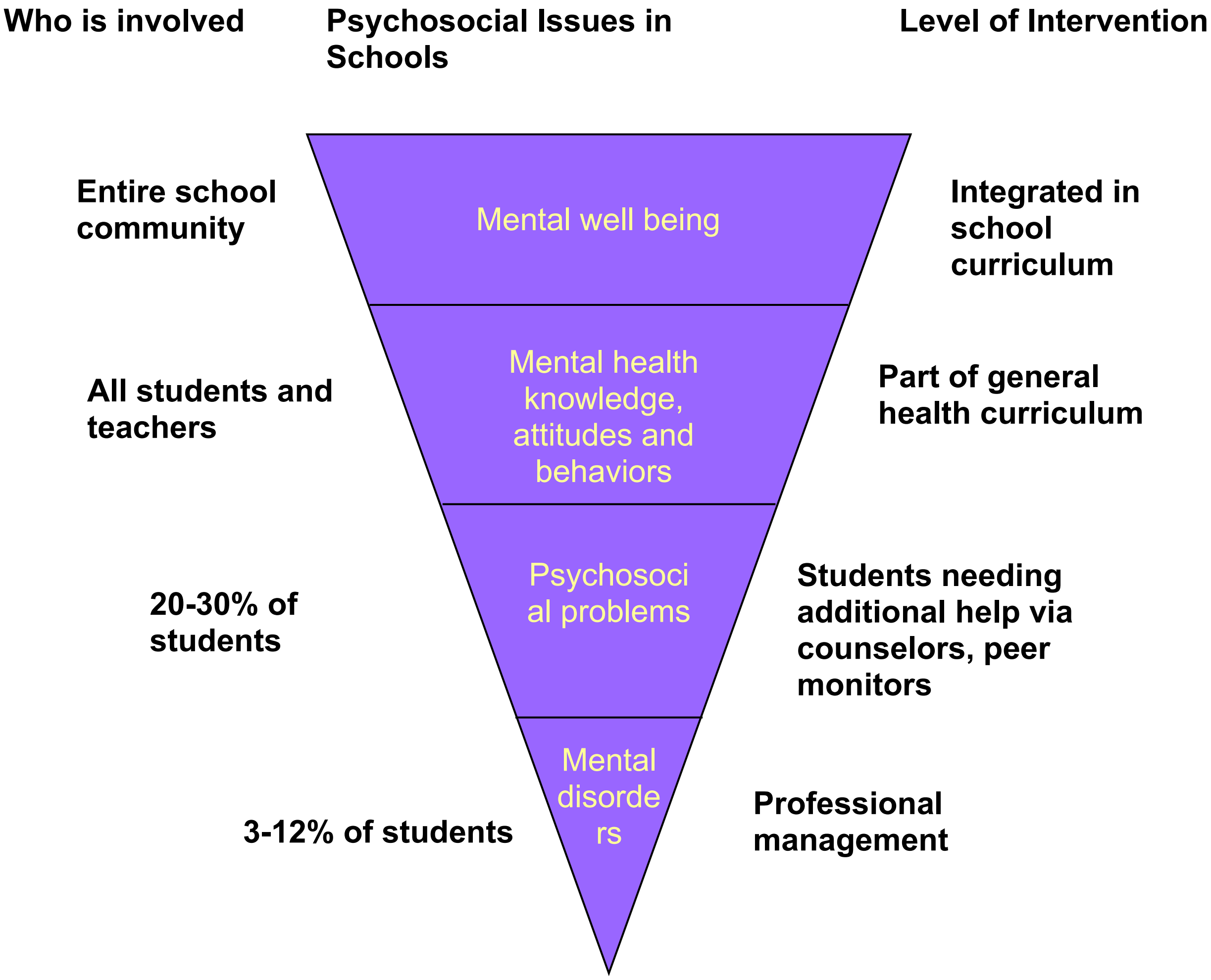
The aim of school based mental health program is to provide experience that would strengthen children's coping abilities to counter the environmental stresses and disadvantages encountered in their growing years. A comprehensive school mental health program views health holistically, utilizes all opportunities for health and behavior and empowers children and youth to act responsibly. Mental health and Life skills education has been demonstrated to reduce drug abuse, alcohol consumption, and cigarette smoking in children and adolescent. Issues related to well being and psychosocial competence of children affect the entire school community including students, teachers and school administrators. Therefore, a model framework (as presented in figure I) has been proposed for the school mental health program, which gives a detailed account of the individuals involved, the various psychosocial issues and the level of intervention at various stages in the successful implementation of school mental health program.

Mental health knowledge, attitudes, and behaviors affect all students and teachers. Educational interventions can make an important impact on the identification and handling of psychosocial and mental health problems. It is also important to identify children with problems early and target them for intervention. These early problems in school frequently endure and predict later, more serious problems such as school failure, school dropout, too early pregnancy, drug and alcohol abuse, delinquency and low levels of adult learning.

Thus, cost of these problems to individuals, families, and to a country is extremely high. Good school programs can counteract some of these risks and decrease the cost. A few children develop serious mental disorders based on specific biological vulnerabilities just as some children will develop other medical disorders such as asthma, diabetes and cancer.

Treatment by mental health professionals is as important as a receptive and supportive school environment. In the diagrammatic presentation below, it can be seen that levels I and II are primary prevention and health promotion and target the causes of healthy and unhealthy conditions with interventions to promote healthy living and prevent disorder from developing. Level III is secondary prevention and targets a more selected population of high-risk people to protect against the onset of disorder. Tertiary prevention (level IV) targets children who have already developed the disorder, with the intent of treating the disorder, reducing the impairment from disorder and /or preventing relapse.

School based mental health programs may be child or environment centered. The *environment-centered* approaches aim at improving the educational climate and providing opportunity for the children to interact within a healthy school program. It may also enhance the ability of teachers and administrators to deal with specific kinds of behaviors and make appropriate referrals wherever necessary. *Child centered* approaches include individual mental health problems, and focus on interventions as well as general classroom programs for improving the overall coping skills among children. In Delhi alone, there are estimated to be approximately around 2000 schools, out of which only 10% have in-house counselors, with no clearly defined roles and responsibilities.



Early identification in schools and role of teachers

School going children have a high probability of developing mental health problems, after stressful life events. It is also a well-recognized fact that schools are the major settings for the potential recognition of mental health disorders in children and adolescents. Many psychological problems are associated with under achievement in school performance, and teachers are able to make a notice of this, much before anyone else does. School students who may be at a high risk, may present high-risk behaviors such as poor attendance, delinquency, gang related activities, conduct and behavioral problems. Some early warning signs in school going children, at risk include:

Indicators of Mental Health Problems in Children & Adolescents

Indicators in younger children

1. Changes in school performance
2. Poor grades despite strong efforts
3. Excessive worry and anxiety or phobia (like school phobia)
4. Hyperactivity
5. Persistent nightmares
6. Persistent disobedience or aggression
7. Frequent temper tantrums
8. Developmental variations
9. Decline in constructive activities
10. Absenteeism

Indicators in pre-adolescents and adolescents

1. Substance abuse
2. Inability to cope with daily activities and problems
3. Changes in sleeping and/or eating habits
4. Excessive complaints or physical ailments
5. Defiance of authority, truancy, theft or vandalism
6. Intense fear of weight gain
7. Prolonged negative or sad mood accompanied by poor appetite or/and thoughts of death
8. Hurting other people or animals, or damaging property
9. Frequent outburst of anger
10. Avoiding people and wanting to be alone all the time
11. Difficulty in sustaining friendship
12. Inability to sit still, concentrate, or focus attention
13. Loss of interest in things usually enjoyed
14. Avoiding people and wanting to be alone all the time
15. Sudden Marked decline in academic performance
16. Numerous unexplained physical ailments
17. Extreme anxiety
18. Dropping out

Family factors which may predispose children to risk

1. Parental substance abuse
2. Mental illness
3. Chronic physical illness
4. Domestic violence
5. Cognitive deficiencies
6. Constitutional inadequacies
7. Social isolation, significant for lack of family and community support
8. Parental separation/ Divorce

Any of the behaviors can be a distinct sign that a student needs help, and a combination of warning signs should be a cause for consultation.

A school mental health program "Expressions" in Delhi (2000-2005), presented the following data regarding the most common behavioral and academic problems among school children, as observed by the teachers

Common Behavioral Problems as observed by the teachers	In %
1. Inattention	35%
2. Hyperactivity and restlessness	26%
3. Disobedience	16%
4. Aggression	11%
5. Emotional difficulty	9%

Common Academic Problems as observed by the teachers	In %
1. Lack of interest	30%
2. Slow learning	26%
3. Lack of Concentration	11%
4. Language difficulty	11%
5. Homework related issues	9%
6. Poor handwriting	7%
7. Lack of confidence	4%

Teachers as Mental Health Resource person

Teachers need a great degree of support to handle the needs of children with mental health problems. Yet, they rarely have training in identifying the first signs of emotional and behavioral problems among children. This further leads to lack of skills in managing the needs of children with mental health problems. A study by Chowdhary et al (1994) of the perception among 75 primary school teachers in Delhi of childhood psychiatric problems was conducted. Case vignettes of four disorders were used, i.e. hyperkinetic syndrome, over anxiety, somatoform and learning disorder. Teachers were able to identify hyperkinetic disorder, but not the others. It was also observed that they had a poor knowledge about their role in dealing with the problem. Therefore, it was found necessary to enhance their ability to identify mental health problems and facilitate early intervention.

Teachers can act as a mental health resource persons by performing the following roles:
- Understanding mental health and related problems
- Early detection
- Liaisons between parents and professionals
- Observation feedback

- Maintaining therapy plan
- Support person

Training teachers on mental health issues helps them in understanding the various problems that they are likely to come across in their students, which may require specialized help. The knowledge about problems also makes them more sensitive towards children, and helps them acquire skills to handle the students requiring special attention. This also assists in early detection of problems before they become completely debilitating for the child. Teachers also act as an important link between parents and mental health professionals. They are able to provide significant details regarding the child's behavior as observed in the classroom, which may or may not collaborate with the information provided by the parents. Also, they may be able to provide significant observations made during parent-teacher meeting to aid the professionals in understanding the child as well as his family dynamics. Teachers also play a significant role in the implementation of therapy, with children having special needs. They are able to monitor and observe the child's behavior in the classroom, provide feedback regarding the same, and assist in maintaining therapy as planned by the professional. Therefore, teachers act as a crucial support person in the planning and implementation of mental health programs.

It has been observed that the expectation of teachers from students, their teaching experience, and education status has direct influence on the teachers ability to successfully identify mental health concerns in school going children (Mehta, 1990) Teachers can not only play an important role in identifying students that may require intervention, but they can also play a proactive role in the efforts to reduce the effects of mental illness in other ways. Though teachers cannot directly prevent the students from having mental illness, but it is important to teach students coping skills and emotional understanding of their own feelings and that of others. Students who are taught about mental health, and learn tolerance and coping skills, enhance their ability to deal with emotional problems.

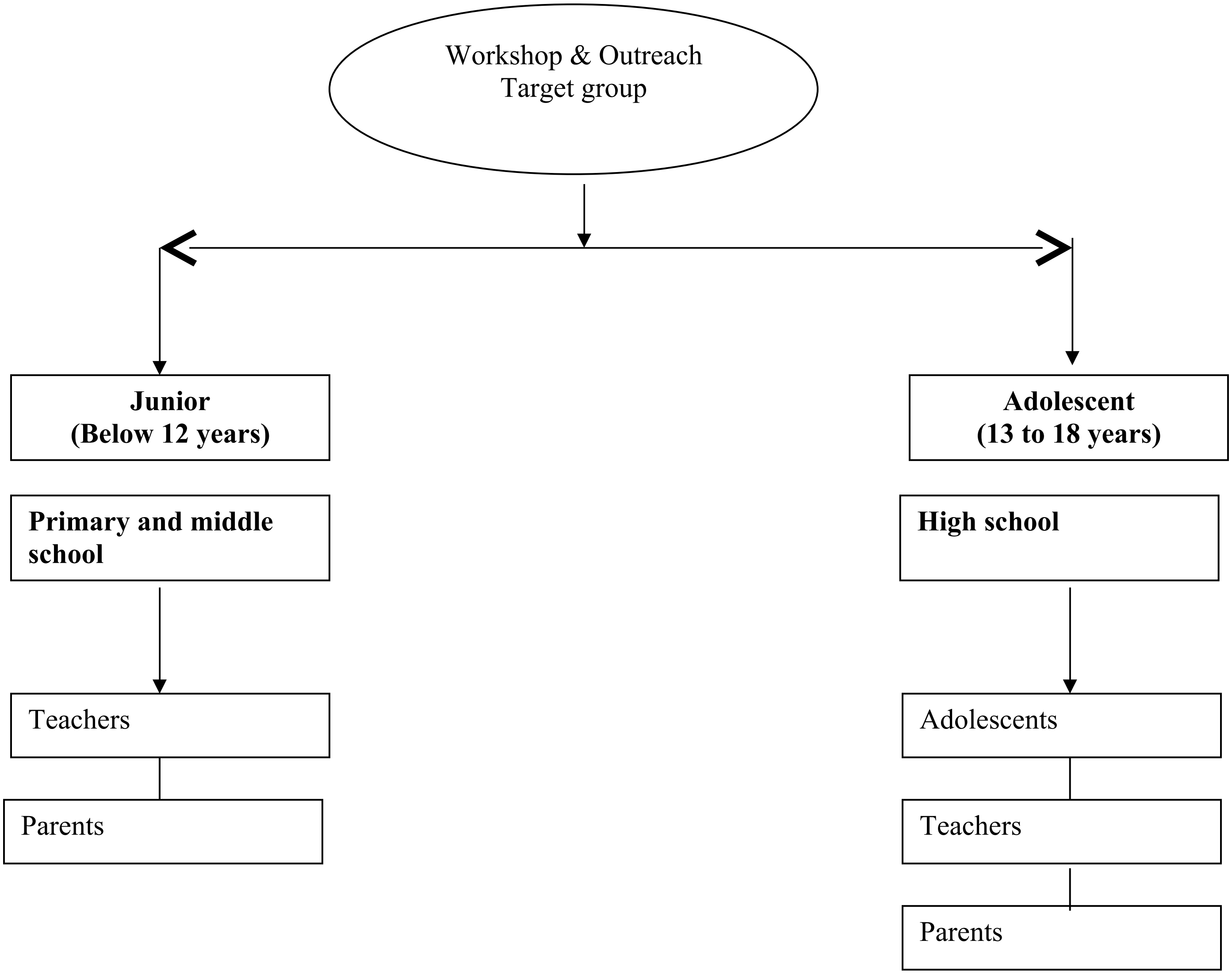
Delhi Experience

A school mental health program "Expressions" is being successfully run in Delhi schools since past six years. A team from Child Development and adolescent Health Centre, VIMHANS, New Delhi started this program. They have already conducted over 200 workshops in NCT region of Delhi schools and in a few satellite towns of Northern India (Amritsar, Ludhiana, Agra, Jodhpur, Banaras, Sikkim) for children and adolescents. The program consists of a three-part module on comprehensive school mental health, and is entirely experiential in nature. The modules by Expressions are:

Part 1: School mental health programs in India- Introduction and Rationale

Part 2: Common developmental, behavioral and learning problems in children- teachers & counselors' manual for pre-primary, primary and middle school children

Part 3: Life skills education in schools for adolescents- workshop manual for peer trainers, teachers and counselors.



The program also evaluated teacher's own mental well-being and stress levels, which can influence their professional output. It was found that 60% of teachers felt that a trained counselor would be of a great help for managing these children. Teachers also suggested that workshops with mental health professionals would help them further in supporting children with difficulties. 58% teachers also realized that a change in teacher's attitude herself was required to help difficult children in class. Child focused strategies were believed to be most important by 23% of the teachers.

Methodology adopted by the program:

For juniors, that are children below 12 years, workshops, seminars and camps are organized for teachers, parents and counselors in the primary and middle school sections. They are oriented towards understanding of common childhood developmental, emotional and behavioral problems via lecture, case vignette and interactive discussion. The problems covered include ADD/ADHD, problems of conduct and discipline, anxiety, depression, enuresis, school phobia, mental retardation; learning disability etc. Emphasis is laid on understanding classroom management strategies for these problems, so that these children can continue with mainstream schooling.

For adolescents (13 to 18 years) a cascade strategy for dissemination Life skills education is used in the adolescent population.
Step 1: Training workshops with school counselors/interested teachers is conducted to orient them to the rationale for Life skills education and its methodology, relevance in school set up, anticipated difficulties in cooperation of school administration, resource availability, continuity of program
Step 2: These counselors/teachers identify "Peer trainers" who have the qualities of leadership, motivation, psychological orientation, peer acceptance and consistent school record
Step 3: Training of Peer trainer. Four students' representatives per school attend one session per month with the core team of "Expressions" on:
Group building and empathy
Family communication patterns
Heterosexual relationships
Handling emotions-anger, loss
Stress and coping
Substance abuse and high-risk behavior
Growing with adolescent sexuality, HIV/AIDS and making healthy choices
Step 4: The peer trainer along with their counselor/ teacher then go on to train other students in their school using the same or a similar training schedule
Step 5: Feedback sessions with professional resource team includes:

- Summary presentation of each workshop conducted at respective school
- Quality control visit by the core team
- Discussion of common difficulties encountered

Preventive Program

Secondary prevention program entitled "Building coping skills among adolescents" has been planned and is being delivered by research team from AIIMS in schools of Delhi. This skill-building module is being pilot tested in a few schools of Delhi among children ranging from 14-17 years of age at present. This preventive module is oriented towards identifying adolescents at "risk", and helping them build crucial coping skills, to deal with their daily stressors in an effective manner. The major component of this module cover training in the areas of anxiety management skills, problem solving skills, skills related to anger management and social skills. The students are delivered this module in small groups of 10-12, to also help focus on individualized problems faced by the adolescents. Various techniques that have been adopted in the delivery of module comprise of presentations using flip chart, modeling, role-playing, discussions, team games etc. The module would help students attain and make use of positive coping skills, in face of various stressors to prevent them from developing serious mental disorders.

Planning for identification and management

TEACHERS TRAINING

As it has been discussed in the previous sections, that teachers play an important role as mental health resource persons, therefore, it becomes essential to train teachers on issues related to mental health among school children. **Several Approaches** have been adopted in training teachers for identifying mental health problems. A few of these approaches that have been used in various schools of Delhi consists of:

Approach I

Setting mental health team with professionals already working in the area

- Team provides lectures to parents and teachers in regional language
- Use of audio visual aids
- Children needing long term therapy were referred from school to mental health professionals
- Conducting time-bound enrichment programs using activities, projects, discussions, stimulation workshops and creativity camps
- In student enrichment programs using classroom and group orientation, teachers trained on the following aspects:
- In student enrichment programs using classroom and group orientation, teachers trained on the following aspects:
    - How to study effectively
    - Causes of and remedies for failure in examination
    - Characteristics of efficient students
    - Preparing for examinations
    - Prevention of health problems
    - Knowing about self and others
    - Causes of interpersonal difficulties
    - Orientation to future
    - Pupil-teacher expectations
    - Principles of mental health

Approach II

- Planning orientation program for teachers on child mental health
- Evaluation of knowledge and attitude of participants before and after the course through questionnaire
- Evaluation of techniques (lectures, handouts, case discussions, general discussion and role play) adopted in program by teachers
- Giving teachers case vignettes and asking them their opinion on dealing with the problems presented in case vignettes

- Examining counselor potential in teachers through the responses on case vignettes
- Planning and imparting techniques of counseling
- Evaluation
- Dealing with teacher resistance

Approach III

Teachers orientation program:

- Group orientation (20-30 teachers) in five weekly sessions of 1 ½ hours
- Content of orientation:
  - *Nature and causes of various psychiatric problems seen in children and adolescents*
  - *Recognition of these disorders*
  - *Disorders of emotions such as being shy, withdrawn, depressed*
  - *Disorders of conduct such as lying, stealing*
  - *Specific problems such as school refusal, adjustment problems*
  - *Poor school performance*
  - *Psychosomatic problems such as asthma, obesity*

- Training teachers interested in independent managing of problem cases in 20 or more weekly sessions of 1 ½ hours each for small groups of 8-10 teachers

Management strategies

- Training Teachers in counseling skills
- Training of Trainers
- Teaching simple cognitive behavioral strategies
- Training when to refer to a professional

Teachers can make use of a number of strategies to improve the understanding of mental illness and prevent its occurrence in school children, such as:

- Asking mental health professionals from school or outside to conduct special programs to teach social skill lessons in areas such as managing disagreement, assertiveness, empathy taking, accepting failure and self control, making and sustaining friends, making requests, working with others, etc
- Teaching student coping skills such as anger management, problem-solving skills, negotiating peer relationship, anxiety management, accepting failures, making choices (decision making)
- Allowing students to discuss events that are a cause of trouble for them in the school or house or community at large
- Encouraging students to verbally describe their emotions

Schoolteachers can also assure that students who might need assistance are referred to school mental health professionals for further assessment.

Therefore, training teachers on identifying mental health problems is imperative, to ensure that they are aware of possible consequences of stressors in children's life, and are in a position to take necessary remedial action as soon as possible. Also, addressing the needs of emotionally and mentally disturbed students within the classroom by the teachers is critical for learning to take place.

To reduce the effects of childhood mental illness, interventions need to begin earlier. This points out towards the increasing need to provide preventive measures prior to the development of significant symptomology.

Conclusion

In order to reduce the levels of childhood mental illness, interventions need to begin earlier, or ideally, preventive interventions need to be provided prior to the development of significant symptomology. In addition, efforts need to be increased to reach the many children who do not have access to the treatment. Many school going children with clinical level of problems never receive appropriate mental health services or receive inappropriate services. Therefore, teachers training programs, education of students, and school support from mental health professionals are the key ingredients in prevention, de-stigmatization, and intervention for students with mental health problems.

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Mental health care in colleges by teachers.

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Introduction

College students are the cream of adolescent and young adult population. They are under tremendous pressure as they are expected not only to succeed but also become toppers in their classes and courses. At the pre-university level, there is a crazy rush to enter professional courses like MBBS or BE. Courses like B.A., B.Sc., B.Com., attract a few students only. Students who fail to get into the courses of their or parents' choice, get frustrated. Though they join Arts or Science or Commerce courses their morale is very low. They start complaining about the parents, teachers and the society. They are less motivated to learn and complete the course. They may drop out of the course. The deteriorating value system in the society, failure of the political and administrative systems to provide them job opportunities, print and electronic media which on one hand put an unrealistic glamorous life style and on the other hand glorify sex, crime and violence, influence the college students in a negative manner. Families are becoming smaller and smaller and are unable to provide the needed support and guidance. Ambivalence, confusion, helplessness prevail in the student community. There are a few epidemiological studies which quote 15 to 20% of the students having recognizable mental disorders in the form of depression, anxiety, somatoform disorders, adjustment disorders, personality disorders and alcohol and drug abuse. Many more students may be suffering from sub-clinical symptoms, and emotional disturbances. These contribute to the observable behavioral abnormalities in them in the form of

i) Irritability, anger outbursts, aggression including ragging, being hostile to others
ii) Boredom, sadness, lack of interest, hopelessness and helplessness, being dull, withdrawn, express negative thinking
iii) Apprehensions, fears, feelings of inferiority, severe examination fear
iv) Conduct - problems like lying, stealing, running away from home, criminal activity, sexual promiscuity and immoral sexual activities
v) Alcohol and substance abuse and addictions
vi) Absenteeism, irregular to attend the class, dropping out from the course, poor performance or failure in the examination.
vii) Having medically unexplained somatic symptoms, often getting sick, accident proneness
viii) Suicidal attempts

Thus, students who have these problems have to be identified and helped.

Except a few private colleges, in all most all the colleges, counselling services are not available in India. Similarly trained counsellors and counselling services are very few in the community. Students with psycho-social problems and mental morbidity do not seek psychiatric treatment because (1) psychiatric services are not available in an affordable and approachable manner (2) Severe stigma is attached to mental disorders and psychiatric consultations, (3) Lack of awareness. Thus majority of the students who need help, remain unattended and uncared.

NIMHANS has developed many community based preventive and promotive programmes to reduce mental morbidity and to improve mental well-being of people. NIMHANS has designed and developed many innovative programmes to involve non-mental health experts, professionals and lay volunteers in organizing primary secondary and tertiary preventional activities in the society. College students being a high risk group to develop mental disorders. NIMHANS worked out a programme to involve college teachers in counselling and act as referral and support giving agents for those students who are having psychosocial problems and mental morbidity.

In 1986, one week seminar was held at NIMHANS to discuss the causes and remedies of problems of college students. Mr. R. Raghupathy, then Hon'ble Minister for Education announced that students counselling services would be organized in all the colleges of state of Karnataka.

In 1995, Department of Collegiate Education of Govt. of Karnataka and NIMHANS, Bangalore decided to organize short term training course in students counselling for volunteer teachers. These trained teachers would offer counselling services to the needy students as part of their job responsibility without any additional monetary benefits. They would do this work voluntarily. The principal, other teachers and administration would provide the needed facilities and support. NIMHANS agreed to provide the training and experts' assistance free of cost. Department of Collegiate Education appointed an officer at the level of Joint Director to co-ordinate the training programme, select the teachers and send them for training. Inauguration of the training course for the first batch of 23 teachers was done by Sri. D. Manjunath, then Hon'ble Minister for Higher Education, Govt. of Karnataka on 17.7.1995.

Objectives

1. To sensitize the college teachers - about:
    a) Modern - scientific understanding of human behaviour
    b) Biological, psycho-socio-cultural development of adolescence and the needs of adolescent boys and girls.
    c) Common psychosocial problems, minor and major mental disorders seen in the late adolescent period (16 to 21 years).
    d) Specific needs and problems of college students in their family and college life.
    e) Changing family and social life and its impact on students
    f) Role of parents, family, teachers, educational institutions and society in the care of students
    g) Impact of stress on health and intellectual functioning of an individual stress management and positive health.
2. To impact knowledge and skills to teachers in the following areas:
    a) Interviewing skills
    b) Psychosocial management of student's emotional problems
    c) Techniques and practice of counselling: Individual and group counselling
    d) Identify moderate to severe mental health problems in students and make timely referral to the experts
    e) Follow up the student for the required period
    f) Conduct educational activities to improve the health & functioning of the students

The training was given for 2 weeks. Faculty members from 4 departments - psychiatry, clinical psychology, psychiatric social work and psychiatric nursing were the resource persons. Lecture cum discussions, group discussions, role-plays, live interviews were some of the techniques used to impart the knowledge and skills. The trained teachers were expected to do the following activities in their respective colleges.

1) Provide individual counselling to the students who are having psychosocial problems.
2) Refer those students who have mental morbidity to near by psychiatrist / psychiatric department for treatment.
3) Conduct group educational activities on topics like
   a) How to improve learning and memory
   b) How to improve self esteem
   c) How to minimize or remove examination fear
   d) Positive mental health

4. Sensitize other teachers and staff of the college regarding students' psychosocial problems and their management. Get the support of all of them in conducting counselling services.

5. Give feedback to department of Collegiate Education, Govt. of Karnataka and NIMHANS about what they could do and what they could not do.

During 1995 to 2006, 26 batches of teachers from all over the State of Karnataka underwent the training. A total of 661 teachers got trained. Initially the duration of training was 2 weeks. Later it became 3 weeks as University Grant Commission of India (UGC) approved this training programme as equivalent to in-service training for teachers from departments of Psychology, Education and Human Resource Development. After 3 batches UGC withdraw this recognition because of administrative and technical reasons. Still later, the programme is conducted for 6 working days. The time tables for 2 weeks and 1 week are given in the appendix-1. The manual was designed, revised and got printed. It was sent to all the colleges in the state and was given to every trainee. Pre training assessment was made using (i) 6 common issues like how to manage a student with severe feelings of inferiority or examination fear or failed in examination etc. (ii) David Goldberg's General Health Questionnaire - 28 item, version .

Post training assessment was done by using another questionnaire consisting of 6 psycho social problems. Feedback regarding their satisfaction about the sessions conducted was obtained in a structured format .

Care provided by the teachers, problems encountered and the outcome

In general, all the teachers appreciated the training given to them. They wanted to increase the duration of training and conduct refresh courses periodically.

The following are the feelings expressed by the teachers:

"*This training has changed my attitude. I used to get upset and angry when I saw some students or relatives misbehaving. Now I would like to find out reasons for it and help them to change*".

"I have understood my own weaknesses. I will be a better person in the college and at home".

"I thought that human behaviour is difficult to understand. I believed that wrong behaviour should be severely punished. After undergoing training, I have learnt that one can understand human behaviour and punishment is not the only method to change it".

"I did not know that negative emotions could lead to diseases like diabetes, peptic ulcer. I will be a better husband to my wife and better father to my children."

"I thought low IQ was the main reason for poor memory. Now I understand how to advice my students to improve their memory."

Case Vignettes

Ms. M. aged 17 years told in tears that she has to discontinue her studies. Her father wanted her to work as a house maid to supplement the income of the family. She told that her father was very strict and did not allow anybody to change his mind. The teacher contacted the mother and found out that the real intension of the father was to collect big money by selling his daughter to a rich family. He was an alcoholic and many sexual relationships. The teacher approached the principal and with collective effort, the girl was placed in the hostel. Father was warned not to interfere with daughter's education. Mr. M. continued her studies and did well in the examination.

Mr. B. was considered to be a rowdy (antisocial) in the college. All students and teaches were afraid to take disciplinary action again him. He was irregular to the class and used to disturb everybody., The trained teacher with a positive approach, talked to Mr. B and enquired about is feelings. Mr. B. talked about his painful hardships he underwent because of poverty and irresponsible parents. He has to live with hostile uncle and aunt who used to insult him almost every day. He had learnt to make money by supporting a local political leader. The teacher convinced the principal and others to give the responsibility for organizing 'college day function' to Mr. B. Mr. B became very happy and organized the function well. The teacher took this opportunity to convince the boy to give up his anti-social activities. Mr. B. agreed to be a 'good student' in the college.

Ms. L. started coming late to the classes. She would miss one or two periods almost every day. On enquiry she would stay mute and would not give any reason for her behaviour. The teachers took the issue to the principal. The principal asked one trained teacher to make a home visit. The teacher found that the girl's mother had diabetic gangrene of the foot and was bed ridden. She could not afford surgical treatment. Girl's father was old. The girl had to do all the household chores and nurse the mother. She did not want to narrate this and get concession from attending classes. The college administration provided necessary financial help to the mother and appreciated the girls efforts in managing a very painful, difficult condition.

Mr. K. used to come to the college regularly but would spent her time either in the canteen or setting under a tree. She hardly attended the classes. Teachers opined that she was not interested in her studies and thus a bad student. Mrs. D. a trained teacher approached the girl and enquired about her behaviour. Ms. K. burst into tears and said that she would become an orphan. On further enquiry, the teacher learnt that Ms. K's parents were threatening each other for applying for divorce. They had severe marital discord. Father would take the son and mother would take the youngest daughter and Ms.

K. felt that neither the father, nor the mother would care for her. She did not want her parents to get divorced. Mrs. D. called the parents and suggested them to go for marriage counselling. She explained to them regarding their daughter's plight. Parents agreed to do so. Ms. K. started attending the classes.

Mr. S. who was prevented from entering the principal's office by the attender, but the attender with his shoes. All teachers and students demanded for dismissal of Mr. S. from the college., The principal asked Mr. V. a trained teacher to look into the matter and help him to take further action. Mr. V. found out that Mr. S. was very angry with the father, who was living in Dubai and had neglected Mr. S and the family. Mr. S's mother did not want to assert herself and take legal action against her husband who was living in Dubai with another wife. Mr. S. was depressed and was not attending the classes regularly. That day, the class teacher had asked him to meet the principal. And get his permission to continue the course. When he tried to enter the principal, he was stopped rudely by the attender which made him to lose temper and assault the attender. Instead of punishing him for this behaviour, the principal and Mr. V called the mother and the student and counselled them. Mr. S. was suggested to ignore the father's negligence and concentrate on studies. Necessary financial help was provided by students welfare fund.

A monthly review meeting has been arranged in one of the college located centrally in the city of Bangalore. Official permission is given to the teachers to attend these meetings. One faculty member from NIMHANS also attends.

Common problems identified by the teachers and managed

i) Emotional problems arising out of family, finance, interpersonal relationships, difficulties in learning, poor performance in examination, failed love affairs.
ii) Academic difficulties
iii) Financial difficulties
iv) Marital discord among parents and ill treatment of the students by parents / guardians.
v) Psychiatric disorders like depression, psychosis, hysterical dissociation states, attempted suicides
vi) Disciplinary issues in the college like irregular attendance, misbehaviour, disobedience, breaking the college norms, aggression, antisocial activities etc.

Teachers did refer students with psychiatric disorders to NIMHANS and other psychiatric centres for treatment.

Cases which were referred to Mental Health professionals

1. Students who are having high suicidal ideas/ have made an attempt.
2. Students who are irritable / aggressive
3. Students who are not communicating, refuse to talk about their problems.
4. Students who develop severe examination fear and refuse to appear for the examination.
5. Students who have mental disorders like OCD, Major depression, Schizophrenia or severe adjustment reactions.

6. Students with history of sexual abuse in the past.
7. Students with severe guilt/fear about masturbation.
8. Students who have psychogenic pain, unconscious spells, spirit / God possession or any psychosomatic symptoms.
9. Students who keep calling or meeting the teacher for suggestion unnecessarily and show features of Dependency on the counsellor.

Skills frequently used by the teachers.

1. Problem solving
2. Helping to take the appropriate discussions
3. Reassurance
4. Encourage and increase the 'self confidence' and self esteem.
5. Emotional support
6. Act as a vehicle of communication between the student and the parents and other teachers / principal.
7. Give correct information
8. Change negative thinking to positive thinking.
9. Helping to set realistic goals
10. Organizing financial support

Qualities of teachers that facilitate

1. Age, sex, experience do not count.
2. Teachers who read literature or have artistic talents
3. Teachers by nature are friendly, enjoy interacting with students.
4. Teachers who have come up in life ' working hard '.
5. Teachers who are not very much interested in earning more through private tuitions

Impact on the colleges

1. Some colleges took pride in the programme. It was included in the college magazine on brochure.
2. Some colleges organized 'stress management and positive mental health' talks for all teaching and non-teaching staff.
4. Many colleges bought books on Mental Health to their libraries.
5. Many colleges invited mental health professionals to address the parents.
6. In some colleges, the principal used the trained teachers to sort out inter-personal problem between the staff.
7. A few colleges conducted 'surveys' to identify family, financial other kinds of problems in their student population.
8. Some colleges became more 'students friendly' and addressed to the needs of the students. They took remedial measure to reduce dissatisfaction among staff and students.
9. One college (V.V. Sangha I Grade Women's College, Bangalore) published a book on 'Adolescent Mind' (Kishorachitta) written by Dr. C.R. Chandrashekar.
10. Many colleges included articles on 'Mental Health' in their souvenirs or magazines.

Difficulties encountered

The following difficulties were reported by teachers as well as identified by NIMHANS team.

- Non-cooperation of the principals and other teaching staff in some colleges
- No publicity was given for the services offered
- Many colleges could not give basic infrastructure facilities like a room, furniture, permission for the teacher to do counselling during working hours.
- Hesitation on the part of students to approach for counselling because of stigma, lack of confidentiality and privacy, fear of problem issue getting known to other teachers, parents and classmates.
- Lack of time to conduct counselling sessions
- Students refusing to consult mental health professionals
- Unrealistic/high expectations of the student from the counsellor
- Infrequent and no official directions or pressure from the authorities of department of collegiate education on the principals and teachers to organize counselling services. No incentives/rewards/appreciation for the work done by the teachers.
- No recording / reporting of the work done because of individual / administrative reasons
- Frequent transfers of some teachers to different places.

Lessons learnt

1. Though it is inadequate, one week's training course is practicable and acceptable.
2. There is need to conduct refresh courses within one year of about . 3 to 4 days duration to get feedback and offer refresher training.
3. The co-coordinating officer (at present, an officer at the level of Joint Director is designated) with an office should actively function to supervise the programme in the Dept. of Collegiate Education. Review and monitoring has to be done periodically. A separate budget head should be earmarked for this programme.
4. More than one third of the teachers of a given institution should be trained.
5. At least one full time professional counsellor should be appointed on the long run for each college who can locally supervise the services and act as a liaison officer between the counsellors and mental health professional, in that district.
6. Public education regarding students problems and need for counselling services should be undertaken round the year using all the available media and platforms.

Resource materials available

1. Manual on 'Students Counselling for college teachers' Pub: Department of Collegiate Education & NIMHANS, Bangalore
2. Improve learning and Memory - a booklet written by Dr. C.R. Chandrashekar. Pub: Navakarnataka Publications, Bangalore.
3. Adolescent Mind: Problems and their prevention written by Dr. C.R.Chandrashekar, Pub: by Navakarnataka Publications, Bangalore.

SECTION IV

FAMILIES of
Persons with Mental IllNESS

"Sihaya Samooh"-a mental health self-help support group in Pune (1992-99)

Mira Sadgopal
Pune.

Who were we and how did we come together?

In the spring of 1992 in Pune, three of us – Mira, Sudhir and Uday – found the seed of a 'community' amongst ourselves. We 'starters' hovered around the age of 50, being 'survivors' familiar with depression, mood-swing ('bipolar disorder'), oddities of thought and perception and behaviour ('schizophrenia'). We knew about fear, too. We were each taking medications, which the two men were apt to mix liberally with alcohol. Each of us had circles of friends gathered over years, but to cope with our ups and downs we decided we needed each other and to reach out, too, so other survivors could find us. We started meeting weekly and by-and-by others joined by word-of-mouth – Anu, Rohini, Sudhir (II), Ramesh, Manisha, Nitin, Padmakar, Shubhangi, Yashodhara, Charu, Anjali, Sushil, Anil, Pravin... and at least that many others. We grew into a sizeable group of persons who experienced various forms of emotional and mental distress, but not all of us were "diagnosed" with a mental illness.

Where did we meet?

After our decision at Sudhir's place, we moved out to a nearby public space – on the lawn next to the aeroplane in a corner of Kamala Nehru Park. Then the rains came, and we moved to the next corner – a tea-shop called "Four Seasons". After some months, the tea-shop flopped, and we moved to the third corner – a garden-restaurant called "Unique". We saw symbolic significance in each of the places and their names. In another sense, we were the 'wandering distressed' finding solace in mutual support.

Why the name "Sihaya Samooh"?

The name "Sihaya" was contributed by Uday – it is from the science fiction novel *Dune* by Frank Hubbard. It is the name of a female character, but it also meant 'spring-time in the desert' of a particular planet (that was not Earth)... and "Samooh" because we came together and recognized ourselves in each other.

What was the size of the group?

From the original three of us, we grew to our largest attendance of around 25 persons. That was one day at Unique, perhaps in 1995, and we could see it was unmanageable. We decided to spit into two groups. One met in the RCC Canteen on the fringe of the Symbiosis Institute campus on Senapati Bapat Road. The other sub-group – on the other side of the Mula-Mutha River – found a niche in a tinier garden-restaurant (sporting a couple of potted shrubs) on Kumthekar Road in Sadashiv Peth. After some time, it also wound up and through parents of a member we got a regular space (two small rooms) for a couple of hours once a week at 'Gita Bhavan'.

However, after the move from Unique we faced various problems. Neither of the two groups had more than a dozen to fifteen people attending at any one time. In fact, the RCC Canteen group broke up after a number of months.

What problems did the group face?

We faced various kinds of difficulties relating to spaces, perspective, leadership, methodology, our own diversity – I'll talk about each in a while, one by one.

What was the special outlook of the Sihaya Samooh?

We formed in a spirit of mutual aid with a special concept of 'self-help'. In this our position was not individualist but social – and even political, I would say – at the root. We understood that one could (and several of us did) take the position of "ex-patient". This meant we rejected the inherent power imbalance in the doctor-patient relationship. Rather than being "patients" we chose to see ourselves as "persons". In fact, we still might seek and take help from a trustworthy doctor and agree to use effective medicines, but we saw our intrinsic worth as a person was equal to any doctor.

Among ourselves, we adopted a set of values. Essentially, they were:

- non-competition
- strength in diversity, and

- creating space. Incidentally, these values had been serving as cornerstones of feminist organization in many parts of the world since the 'seventies.

How did these fundamental values reflect in Sihaya Samooh?

We saw Sihaya as a ‘space’ apart from so-called ‘normal’ society – a space we kept on ‘creating’. In this space we rejected the usual competitive relations of outside society – questions like, *Who is taller? Who is stronger? Whose complexion is lighter? Who earns more money? Who has more prestige?* Instead, we tried to understand and appreciate our differences, listen to each other carefully, identify and affirm the small-small strengths in each of us that we could join together, making our diversities into a strength.

How did ‘diversity’ play a role in mental health self-help support?

We were a motley group consisting of persons who experienced depression (sometimes with uncanny highs), fears of all kinds, delusions and paranoia, obsessive-compulsive patterns, hallucinations – and all the accompanying insecurity and distress. There were also several in our group who experienced varieties of epileptic episodes and seizures, and one who struggled with advanced Parkinson's (in this case, *not* due to side-effects of anti-psychotic medication) who came to us together with his anxious wife taking treatment for ‘schizophrenia’. Yet personally all of us knew the meaning of severe human mental and emotional distress. We even had one remarkable member of our group who was never really mentally ‘ill” – it was his brother who could never join our group who was home-bound with severe chronic schizophrenia.

As an example of how our diversity played its part, take the issue of stability in the group. Some of us, rather most, by nature of our disabilities, were unstable – myself included. Others, particularly individuals among those with epilepsy and Parkinsonism, showed a stability that was personally characteristic. This indeed helped to bind the group - whether it was by the regularity of their presence, by their paying quiet attention to routine matters, or by always remembering birthdays beforehand, and seeing that a card was made or brought, signed and given to that person.

However, sometimes the diversity could constitute a stress. A depressed person could not bear someone who was over-active, and some of us couldn’t deal with the suspicions some others had, or rather, some of us felt bound by our perceptions to mistrust. I know that the group with forms of epilepsy did not find their specific needs addressed. Likewise, two of our members were alcoholic, and that was enough for them to opt out of group solidarity, at least periodically!

What were the benefits to Sihaya group members?

A number of us, myself included, gained support to cope with and tide over our distressing phases or episodes. It helped our self-esteem to be accepted, listened to, respected and able to help others. A couple of our members later took up care-giving vocations because of the liberating experience and encouragement they received in the Sihaya Samooh.

What were the short-comings and limitations of Sihaya?

- We lacked a consistent self-help methodology, instead depending upon our mutual common sense and varied personal experience. We groped where we didn't know enough, and perhaps believed too much in mere listening to and exchanging with each other.
- Within our diversity there were some problems we couldn't deal with, as I mentioned, like delusions (true?) of mistrust about members, like epilepsy, and like alcoholism.
- Instability and inconsistency became a problem, especially in one of the sub-groups after we split into two.
- Many came with high hopes but were not able to get from us the help that they needed, or they were not able to continue to come for various reasons.
- Women found it harder to come to the group, in comparison to men who are physically and socially more mobile. This was despite the kernel of feminist ethics in the group!
- There were severe limitations in outreach in proportion to the great need for mental health support for sufferers in communities.

How did the Sihaya Samooh gatherings come to an end?

Generally, two things happened. Several of the people who held the group together had to move on to other places, geographic or vocational. At the same time one of the members – Anil – who joined around the end of 1995, moved on to launch a larger mental health self-help support initiative that today is represented by SAA (Schizophrenia Awareness Association) in Pune. After the Eklavya group began, and SAA got registered around 1997, we kept meeting for a couple more years. We lost a couple of main (and dear) members, like Sudhir (II) and Anu, due to their suspicions or disillusions. Our most stable Manisha found and married a man of her choice, and moved to Nashik. I (Mira) turned to focus my energies on the WAH! (Women and Health) Training Programme in Maharashtra. Rohini began her long battle with cancer, and needed to conserve her energy. For some time Anil and until the end (in 1999) Pravin were the mainstays of the weekly meetings.

Today a number of us in the old Sihaya group keep meeting me personally, including Nitin and Sushil, or get in touch by phone, like Yashodhara and Manisha. Some of us are 'recovered', others still 'surviving'... Some like Sudhir (I) and Rohini have passed away. We miss the sensitive protected space that we made, however, and we hope some day it will be created again – not just for us and in a single place, but with various names for many, many other survivors who need it, virtually in every human settlement and especially in urban habitats.

What is the significance of the Sihaya Samooh experience of seven years?

- ✓ It was the first organized 'mental health self-help support' group in Pune (as far as we know) and a pioneer in India.

- ✓ It demonstrated the ‘creation’ of a safe social space that could keep at bay the oppressions of so-called ‘normal’ society for some time.
- ✓ It harboured a vision of creating many such spaces in the future that with greater mass could even play a role in building a better society.

Rehabilitation by People - the AASHA Experience

Ratna Chibber
Chennai.

Background

I met Padma Bhushan Dr. Sarada Menon at SCARF for the first time way back in 1989 when I felt the world was collapsing around me on account of my brother who was mentally ill. Dr. Menon was a boon to families with a mentally ill person at home. What makes her different is that she is first a compassionate human being and only after that she is an excellent psychiatrist. She provided us families with the impetus to form an organization promoted and run by families for the betterment of our near and dear ones who had become victims of mental illness. It was she who repeatedly told us that families and families alone could take on the onerous task of rehabilitating our family members who were mentally ill.

Focus on Family/Care Givers

On hindsight, I can only say that Dr. Menon’s foresight was infallible. It has now been established beyond doubt that whilst early diagnosis and medication are important in the recovery process, there other are equally important aspects without which recovery can at best be a distant dream. These not-so-obvious aspects are:

- Care and compassionate
- Administering regular and timely doses of prescribed medicines
- Supervision and implementation of suitable hygiene standards and,
- A full-day time table for the patient.

The illness and medicines on the one hand tend to make the patient lethargic. The rehabilitation process, on the other hand, requires him/her to have some form of physical activity for a few hours during the day. This is easier said than done because many of them escape into their own secret world of make-believe. It is only the family or the care giver who can attempt to coax them out of their secret world and gently bring them in touch with reality. In my experience, I have also found in Pune, Kerala and even at AASHA that non-family persons, not being burdened with emotional factors with the patient, have done wonders with persons under rehabilitation. This I have seen to be particularly applicable in areas where the patients are being "trained" in specialist skills. Families have a handful when they try to cope up with their mentally ill relative and fight social stigma. Seeing their struggle, many non-carers who want to be of service to society have got drawn into the fray. Many if not most of them have provided patients and families with invaluable "shramdaan" (personal service) and novel ideas to speed up the journey of patients towards near-normalcy.

Training

Thanks to the efforts of Dr. Radha Shankar, AASHA received a sum of Rs.2.00 lakhs from Abilis Foundation, Finland. Using this money, AASHA ventured into unknown territory by opening up a retail sales counter for stationery. The unique feature of the shop was that all its employees are patients under rehabilitation either from AASHA Rehabilitation Home or SCARF. Every employee of the shop is paid a stipend, which in the early days came from well-wishers and donors.

A care giver who happened to be a retired government employee was placed in the shop as a Supervisor. Within a short span of time we learnt that residents who worked in the shop wanted to spend more time in the shop than in the Home. Also, persons employed in the shop showed remarkable signs of progress towards recovery.

One of the foremost features that yielded paid AASHA rich benefits in speeding up recovery was a "zero pressure environment". AASHA started a retail sales shop selling stationery items, chocolates and biscuits 4 years ago. The plan was to employ residents of AASHA Home (who were in the process of recovery and rehabilitation) and pay them a stipend not so much to pay for their needs as much as to help them regain their shattered self-esteem. Also by facing real-life situations in the shop, our plan was to gradually reintegrate them with mainstream society.

A few family members got together and decided who would perform what task, who would train and supervise the employees and what kind of training we would give them. None of us has ever run a shop and none possessed the attitude to run one successfully. But profit was never our goal. So, armed courage and missionary zeal, we went about our agreed tasks. We handpicked the first batch of employees from among the residents. As expected, they turned out to be quick learners and in time were able to manage the shop on their own. At AASHA we have broken down the principles we adhered to in simple Do's and Don'ts:

1. Treat them like adults, NOT school children.
2. Treat them as equals. DO NOT look down at them.
3. Tell the CLEARLY as to what decisions they can take and what they must refer to the supervisor.
4. DO NOT force them to do what they don't wish to.
5. Treat them professionally – be firm when firmness is required, reward them when they do well.
6. If they were accountants before being stricken by the illness, they may want to do accounting work only. ENCOURAGE this trend.
7. Train them in pre-determined modules – little each day.
8. DO NOT look over their shoulders when they are working.
9. Give them a feeling you trust them and rely on them.

It may not be possible for a family care giver to do all this objectively. Therefore, I believe a non-family person would be better suited for this function of Training.

Level and limits of Care

One of the most encountered hurdles in caring for a family member is "the other family members". Parents rarely abandon their own mentally ill offspring. But if they themselves are in need of help due to poor health or for economic reasons, they are left with no choice but to entrust their wards in the hands of Halfway or Life Care Homes for mentally ill persons. People who send their wards to such halfway homes should make it a point to visit their wards at least once a month and take their wards home once a month. If that is not done, the staff and care givers at the home often find it difficult to manage and contain wards who have pent up desire to see their parents or near relations. Lucky are the patients whose Families rehabilitate them in their own homes. It is however important that Families understand and accept that medication by itself is not enough to facilitate the process of recovery. Occupational Therapy or some kind of physical activity to keep them engaged is a must. Families rehabilitating patients in their own homes find themselves battling with their own emotions when some of them refuse to adhere to set time tables of work, eat, and sleep routines. A more common limitation felt by Families rehabilitating patients in their own homes is that they may not have the equipment and supplies for Occupational Therapy.

Support from mental health professionals

Like in most illnesses, the earlier the patient is diagnosed for mental illness, the better. It is not Mental Health professionals that are a hurdle to early diagnosis and medication – more often than not it is the patient's Family that presents a hurdle. They want to first exhaust all possibilities, including the supernatural. Exorcism rites are not uncommon even in highly literate and cultured Families. A lot of time is wasted on these worthless pursuits. This is where a self help group can contribute by way of awareness programs.

Mental Health professionals are ever willing to be of assistance to Families but they are hopelessly outnumbered. It is believed that India has just 3500 Psychiatrists who have to cater to over 20 million diagnosed cases of mentally ill persons. The task is mind boggling if not impossible. The number of cases of mental illness is growing at an alarming rate and in recent times drugs and alcohol induced mental illness has made matters worse. Incidentally the key word is diagnosed cases. We can't even start making a guess as to how many cases are out there walking the streets when they should be in high security psychiatric wards. Therefore the responsibilities on the shoulders of Mental Health professionals are onerous and can never be overemphasized.

Difficulties and possible solutions

There is no denying that even a minor fracture in a member of one's family evokes far more sympathy and concern in the rest of the family than if it were mental illness. On the contrary, the person with mental illness would be the subject of ridicule. He/she would be accused of laziness, poor hygiene or simply being "crazy" – all classic symptoms of mental illness. And if such thoughts originate from the breadwinner (be he a brother or brother-in-law or uncle) the care giver (who would most likely be the mother or sister) will be compelled to watch the atrocities showered upon the patient on a daily basis in silence.

Therefore the first major difficulty is for parents/families to come to terms and accept that their son/ward is suffering from mental illness. Social stigma and fear of its impact on marriage and job prospect of siblings is another problem that families have to face because of which they try to conceal the patient from society. But sweeping it under the carpet is never a solution because it will be at the expense of the patient who will only deteriorate. The solution lies more on self help groups and Psychiatrists' Associations help shattering myths and bringing awareness.

In all such cases, the Halfway Home appears to be the only solution. However here too one has to be very selective. There are all kinds of Homes run by all kinds of people, including fly-by-night operators. Not all of them understand the illness. The only way to treat patients, according to attendants in certain Homes, is to put them in solitary or threaten them, if not flog them.

Mental Health professionals and care givers in Halfway Homes find it frustrating when parents do not visit their wards or take them home on special occasions like festivals, birthdays etc. None of the difficulties are insurmountable once families come to terms with the illness.

Lessons learnt

In running the Home and Shops has driven home a few important lessons in the rehabilitation and recovery of mentally ill persons. The most important ones are:

a) Active Family participation is a key factor.

b) Stigma lies in our (Family's) minds. Families must first eliminate the stigma from their own minds and only after that try to eradicate it from society.

c) The most effective Occupational Therapy is sheltered/supported employment where they can interact with mainstream society on a daily basis.
d) Even chronically ill patients can be placed in non-critical jobs where they can have day-to-day interaction with 'normal' people.

Future plans

a) Rehabilitation Home for women at Tambaram.
b) Retail Sales Counter for Women at Tambaram Rehabilitation Home.
c) Bus for transporting Home residents everyday from the Home to their place of work and back.
d) Increasing member list both carers and non-carers to serve the cause of or mental illness.
e) Day Care Centres at both Homes for residents as well as non-residents.
f) Enlisting support from friends and well-wishers to open up avenues for employment for in sheltered/supported environs.

Mental Health 'of the people, by the people and for the people'

Ishita Sanyal
Kolkata

Introduction

India is a civilization united by its diversity. Different forms of religion; customs are followed here with a feeling of uniformity amongst all of them. Mental health in India too has witnessed diversity in approach, theory and practice, which probably were developed according to the needs of the society, the culture of the community and the socioeconomic factors.

Background of Turning Point

In India bondage of love and affection is the common thread, which keeps all the family members together. This probably is imbibed in our culture and is the greatest strength of our country. The people of India are family oriented. They not only care for their own family-but in place of work too they love all colleagues like members of a family who work together to achieve a common goal. In the community- family members living together develop bondage of love and affection and take care of each other like an extended family. With almost the same pride we talk about ‘our family’, ‘our school’, ‘our workplace’, ‘our community’. The interdependence on one another during the time of crisis is an integral part of our country. Till now individualistic approach is rejected and hated by people at large.

As a psychologist I was interested to explore human beings, their psyche and had empathy and understanding towards them. But when one of my own family member started suffering from schizophrenia-I realized how useless all my knowledge was and how unfruitful my education had been. Not being able to manage the whole situation effectively used to torment me every moment. I realized the pain and agony of the person concerned is totally different from the fear, anxiety and pain of the family members-adapt the role of a psychologist & see the problem objectively but I rather became emotionally involved in the whole situation. I had seen the desperate need of family members in search of ‘hope’ for the affected member. I had experienced the effects of High EE (Expressed Emotions) and how and why it forms. The management of home appeared to me as of utmost importance if the affected member has to stay in the family during his treatment. To me, it appeared that it is the ‘human right’ of the person concerned to stay and continue his treatments within the family as all of us want to be with our family members during the time of crisis or during illness.

I started thinking the possible way-outs for improving the quality of life of these unfortunate victims of mental illness. At that time I too was very much emotionally involved and whoever used to come to me for counseling appeared to me as my own sister or brother and their parents as my own parents. I was truly able to empathize and identify their pains-their agonies from two different angles.

At that time there was no rehabilitation centres in Kolkata who used to offer vocational trainings to the sufferers. Few vocational trainings that were imparted to the inmates of hospitals or NGOs were bookbinding or making pickles, which probably failed to motivate them to do the work

We have seen in our rehabilitation programmes that Medicines can help these persons up to a certain extent; counseling can improve their self control strategies and behavioral modifications-but what they needed most is the formation of a habit, a discipline in their life, a work to keep themselves engaged & also a source of earning. This they often fail to do alone in their home. The vocational trainings that are imparted to the person must be according to their aptitude & intelligence – otherwise it fails to motivate them for the work. Moreover, rewards, praises & remunerations for their work proved to be most effective to keep their motivation & make them continue to come to the rehabilitation centre on their own will. "Responsibility, Reward and Rehabilitation" are the three R’s, which often proved to be the essential key to success.

As the number of professionals in India is far less compared to the magnitude of the problem and also due to scarcity of funds, I tried to utilize the human resource of the family and the human resource of the person concerned for the upliftment of the Mental Health of persons suffering from schizophrenia. On the long run it proved to be highly effective as the person affected by mental illness often lose the self-confidence & do not expect anything positive from themselves & their life. Given them some responsibility & successful completion of it provided them the courage, the motivation, the confidence to try more & in the process they slowly develop faith & trust in themselves. Helping others & taking care of family members is often an activity, which they like to do once they gain back their lost confidence.(contrary to the popular belief that they are irresponsible & less empathic to others)

On my way to Madrid & Netherlands to attend the conferences, I was denied the boarding pass, as I didn't have the multiple entry visas for UK. I was upset- but one of my patient (A. Bhadra) who assist me in my official works showed me his interest to assist me in my effort to get the visa & make arrangement for the fresh ticket. He was with me for the whole day where we failed to change my ticket. I took the decision that I should leave the idea to attend the conference-as it appeared too stressful to me. He reminded me" Ishitadi, you always motivate us & tell us not to lose hope & try till end. So why today you are losing your hopes? Please try till the end." His words really motivated me to try further at least to keep my self-image to him & finally we got the tickets & visa. So given a chance they too can act as a motivator, a person who cares for others, and a person who can take household & outside responsibilities.

I started my efforts 8 years back without any fund or place to run the centre. I only had the determination, the will to do something for them. In India where there is no provision for any start up money to start a centre- keeping professionals in the centre could only proved to be an unrealistic dream. So without any economic resource I tried to utilize the available human resource to run the centre.

1st year- At the beginning I tried to convince people about my plans & the need of running such a centre at Kolkata. A few friends & relatives of affected individuals showed some positive response. One of my friends who have a retarded child offered us rooms in their centre for once a week. So, initially it was started once a week. The aim was to improve their quality of life through interaction, communication, group therapy & group games. At that time we used to provide the service completely free of charge. We only used to collect money through organizing cultural programmes staged by the beneficiaries.

At that time we had lots of hopes & dreams & expected support/funding from government & other agencies.

In the second year as we experienced that the beneficiaries were showing good improvements we started some vocational trainings like handicrafts and computer & increased the number of days to 4 days a week. As we had to rent the house for this purpose we used to take a token amount from the caregivers & also made them part of our team to raise funds for the purpose. As the caregivers were able to see the positive changes and improvements in the life of their child they started cooperating us in our activities. We started the first parents group in Kolkata organized the first workshop ‘caring for the caregivers”

The parents who cooperated with us, who were with us as resource person in all our endeavours like exhibitions (to sell the handicrafts made by them), sports, picnics & all the yearly celebrations were surprisingly able to understand their children & their problem in a better way than the parents who preferred to remain aloof in the whole process. Probably the exposure of the family members to other beneficiaries helped them to understand the symptoms & management in a better way & practice them safely in our centre with other affected individuals apart from their own child. This helped them to explore & understand whatever training & psycho education that we have imparted to them on others without getting emotionally involved in the process. As one of the mother has pointed out-‘ I used to feel helpless & hopeless when my son used to become aggressive as he remembered some of his negative childhood memories. I failed to console him at that time. I often used to get angry on him and myself as he was not able to understand my viewpoints & I failed to provide him any relief. Exposure to other children enabled me to understand their difficulties & helped me to handle my son’s problem more objectively with less emotional involvement. It helped me to improve our relationship”

The centre acted like a big extended family where if any parents fell ill others were present beside him or her to help them out. In any social occasions like marriage or birthday they used to call everyone & a good network between all members developed.

After the third year we started applying for funds & received it from Science & technology Department. Though they continued to grant the fund in the successive years also but they failed to provide it afterwards as the state Govt. run short of funds.

We got the help from few corporate houses who donated us the computer but the main help came from the parents & the parent’s organisation that we developed.
As the whole process of collecting funds, submitting proposals & projects are very time consuming without hardly any positive result we lost our hopes& tried to make ourself economically independent by reducing the cost of running centers by utilizing the available human resources. The recovered persons from our centre proved to be very successful as a trainer in computer, handicrafts & even official works. They gained courage & confidence in the process & became the living example for the beginners who used to join our centre.

From the fifth year onwards we focused more on activities of our centre & increased the number of Vocational trainings & tried to market the products developed from trainings. We have also received invitation from a shop at city center from where we sell the product all over the year. Apart from it we held few exhibitions also. Computer typing also helped them to earn them their pocket money.

Failures and Successes

As far as economic gain is concerned, my endeavors & Turning Point may be considered as a failure. The official problems of getting FCRA & renewal of 80 G often makes us depressed & we lose hope for any future. So we consider the center as our family & the beneficiaries as our family members. But for running a big family like this apart from Human resource we still need some economic resource too for smooth sailing of the activities.

If we study the prognosis & development of the affected individuals- their Functional level, their quality of life, their independence, their concentration level, their confidence, their management of delusions & hallucinations, their economic gains in the form of earning their pocket money- I would rather say that the success is more than we expected.

The negative symptoms of Schizophrenia like apathy, lack of drive reduced a lot. After the end of 8 year we have problems to close our centre even after the scheduled time as the beneficiaries now demand more & more work from the teachers & never get tired to complete their work. We have to remind them continuously that it’s time to close the centre for the day. The handicrafts teacher gets worried to arrange for the home works that they demand from her before going back to home.

People for Mental Health

People whom I have utilized are (i) family members (ii) close friends and relatives of affected members (iii) few persons of the community and (iv) the affected individuals themselves.

In fact in our organisation, the lion’s share of the work is now done by the affected individuals once they recover from illness. The illness almost completely breaks a person into pieces; forms a complete negative image of himself with insecurity and feeling of inferiority on the rise. They become fed up with their lives, their emotions, their families and feel clumsy and inadequate to communicate and interact with the society at large. Withdrawn from the society for a long time makes them feel insecure in front of outsiders. They start believing that “I am capable of nothing”.

In this background it appeared to me that it is very important to reestablish their self-confidence and regain a positive image of themselves. But it is not possible if they themselves do not gain confidence on them. So graded responsibility and rewards in the form of appreciation and economic rewards made them feel important and gain confidence and motivation to do more work. They started to do the works of the centre themselves.

Parents, on the other hand, given the responsibility get a chance to interact with other members suffering from illness. This helps them to understand the true nature of illness, its symptoms and its management without being emotionally involved with the person concerned. This in long run helps them to manage their affected family members more effectively.

Training Approaches Developed

Integrated trainings are essential for people suffering for years together. They not only need to learn vocational trainings (as they have lost the productive years of life when they started or in the process of education) according to their aptitude but also are required to learn proper communication and interaction strategies, training to build confidence and learn current affairs so that they feel free to communicate with others.

The trainings developed by me for the whole day programme are as follows:

1. Physical Exercise: - To recover from the usual lack of drive apathy, laziness and depression exercise forms an integral part of the training programme .Due to the side effects of medicine & also because of developing a sedentary lifestyle they generally gain weight. These problems can be effectively controlled by regular physical exercises. It also reduces joint pain, arthritis & other problems.

2. News Session: Newspaper reading and news discussion is organized with a sense of sharing of each other's feelings and views on day to day events. In this way a secluded person can be revived & the General knowledge makes him again feel that he is a part of the society. They can recover from inferiority feeling, seclusion once they again start gaining knowledge about current affairs. It helps them to communicate with people outside with confidence & courage. They feel that they no longer would play the role of a listener only in any communication process but can actively participate in any discussion.

3. Music: To help venture oneself, each individual is encouraged to sing out in harmony or solo and traditional or occidental musical games are organized as competitors to brew a challenge of each person's flair of music. Turning Point even reaches out to provide them exposure in television and radio. Regular cultural programmes help them to gain confidence once they successfully complete a programme.

4. Group Games to increase concentration and attention or Sessions on Communication through Role Modelling/Debates/Extempores/Trainings on how to face interviews

5. Debates-To actuate and give dimensions to the once curbed communication of the patients, debates help to provoke the spirit to convince one another of their standpoints and simultaneously develop a positive attitude for external social intermingling.

6. Activities: Skills and agility are best developed by innovative games and activities, which involve action to reduce the effects of inhibitions and withdrawals. Turning Point cranes its neck out for newer and newer games and activities that would not only act as a part of Behavioral Therapy but

also stimulate and expedite observation and motor skills, wits, , effort of acquiring prominence in public, freedom, initiative, positive drive, clarity and locomotion. Actions the spirit of preoccupation and ability of self-expression bears a clinical value because the impact of diversion helps to minimize the trauma of mental illness and brings a sense of self-esteem and fortitude and to the lethargic willingness to work easily results.

7. Group Therapy: Beyond counseling, group therapy by various therapeutic options allow patients to solve, share, recollect or conceptualize aspects that would, on one hand, bring out the inner feelings and viewpoints as also create an effect of empathy and correspondence with one another's situation.

8. Role Modeling: Role Modeling not only eliminates age-inappropriate attitudes of regression and clumsiness, but for those beneficiaries who have never forgone dire situations of practicality or emergency now get scoop to imagine he is as well answerable to society, that expectations are mutual in society, work and responsibility can itself be the reward. This increase s his self-esteem. Despite years of seclusion, now he develops a drive to work and find meaning in life.

9. Vocational Trainings- Turning Point is ever highlighting the magnificent hidden talents among its' beneficiaries So far, with meticulous efforts, the patients are readily producing quality paintings, collages and origami, handicraft items like consumer accessories, decorated pottery, children's items, various household utilities and office utilities that are made and sold by the organization. The money yielded is paid to the respective beneficiaries as a measure of their motivation, inspiration and their self-esteem

10. Creative Writing: Those gifted with creative writing talents are further encouraged and offered avenues for publication or jobs in news agencies or even trained to learn mass communication courses.

11. Recitation, Elocution and Extempore: Recitation, elocution and extempore on different fields of knowledge, people, experiences, places and ideologies provide diverse advantages starting from comprehension of mood, pronunciation, creativity to the extent of one's scope of conceptualizing and performing onstage or finding scope in avenues of broadcast.

12. Computer Training: Turning point took the courage to believe that the mentally ill were not incapable of computer education that becomes a necessary in modern jobs. And today, not only is Turning Point the pioneer in this ingenuous idea but as a matter of achievement, most of the patients have acquired the professional basic computer course certificate

from Turning Point, opting for computer programs in professional institutes, and now also practicing advanced computer programs in Turning Point. Enthusiasm as well as the prospect of attractive jobs availabilities involving computer applications led them to insist us for advanced computer courses and with much pleasure the organization has in meeting their demands eclipsing all troubles.

13. Cooking-_To make the beneficiaries Self -dependant is the main mission of the centre. One need to learn almost all the household works to be independent. This includes not only cleaning but also cooking, taking care of clothings and some outside work like marketing, banking etc.

14. Relaxation Therapy: Relaxation therapy techniques are demonstrated and the faculties invigilate the performances and finally the after effects and the experience is shared amongst them

Care provided by the people

While providing care special attention is to be taken so that the care makes the affected individual stand on their own feet once again, enables them to gain back lost confidence. The care should not make them feel that they are inadequate and need lifelong assistance and support.

Special attention is taken to improve their daily functioning level. The need assessment is most important for this. It is essential to communicate with the family members and find out the daily functioning methods of the family and how the affected individual can contribute something positive in his day-to-day activities. Graded responsibilities at home along with decision making when required helps them to gain the courage, confidence and control on themselves & their lives

FEW CASE PRESENTATIONS

The level and limits of care can be best provided by a case study of a girl at Turning Point.

Kakoli Bera aged 32 joined our organisation 8 years back. At that time she was an inmate of another NGO-but her mother used to bring her for joining our activity sessions and counseling.

She was expressionless, would hardly talk with anyone. In the counseling session she would only refer to her communications with famous movie stars. She was so obsessed by her delusions and hallucinations that it was really difficult to make an effort for effective counseling. I even suggested her mother to discontinue counseling at that time. But her mother, however, had full trust on me and requested me to continue her sessions. During the group games, her memory, her communication ability, her intelligence to apprehend the games were low and she could hardly enjoy taking part in it. But the perseverance of her mother along with the resource persons of Turning Point made changes over years of practice. It appeared difficult for her to pass thread through the eye of needle due to continuous trembling hands resulting from the side effects of medicine. Continuous effort to motivate her to learn the vocational trainings probably had made her to try each of them with full effort. She soon started trying some easy stitches of kantha and our appreciation made her feel important. She soon started participating in other vocational training programmes like drawing, collage and computer.

Within a year her memory increased, her communication was adequate and she showed signs of intelligence in almost all the games she played. She started to be a winner in the games. Her daily living skills also started increasing and she started doing all her works alone at the centre and even at home. In our training schedule, we lay special emphasis to make them realize that they are productive members of the family and it is their responsibility to take care of other family members.

She started going to the market, to the bank and assisted her mother in household chores too. Educating her to fight for her 'human rights' often made her argue with the handicrafts teacher about her due payment. But it was really a bolt from the blue when her mother suddenly fell seriously ill and was transferred to a hospital. She used to live alone with her widowed mother. We tried to provide her constant support by visiting her mother at hospital and regular phone calls at night. When she used to stay alone at her home, she would gleefully add-"I am well, don't worry about me". The parents' association of Turning Point was also active during this period and tried to provide help and support when required.

But Kakoli stayed alone, came to Turning Point alone without any assistance, took care of day-to-day activities alone and also was beside her mother throughout the treatment process.

The excitement of first earning-All of the beneficiaries feel always excited when they get remuneration for their work. But Priya was anxiously waiting for her earning. Her father often asked her to discontinue her trainings in the centre as it is difficult for them to provide the conveyance fare for her. So Priya made it a point to give her earnings for the journey from home to the centre.

According to Sujata it was REALLY SURPRISING for her when she received her first payment for handicrafts. She stays with her father & is now capable of doing all the household works alone .Now, she can also understand the difficulties of her father who have a Psychological problem. She now can even guide her father when he feels depressed.

Her aim is to become a teacher in the center to help others who are in need.She thinks that because she had a problem , she is able to understand people who have problems & have true empathy & identification for them.

The first journey abroad- Arunabha is intelligent, have great potentialities & had a childhood dream to visit England from his early childhood. He lost all his hopes, as he became a victim of mental illness. The continuous motivation to involve them in international conferences made him motivated enough to present his own case history & development by himself. When his abstract was accepted, he was excited, When he reached England tears rolled down his eyes " I never thought it would be possible to really come to England after my illness. Its like a dream comes true"

Helping other members-In our Annual excursions every year we have noticed a remarkable change in their behaviors during those days. Indra and Prakash were never good friends. But once they reached Chandipore, Prakash started helping Indranil to take his bath in the ocean & always used to keep a close watch on him. " Indra, Think me as your elder brother" he used to say. After the excursion when Indra's granmother died, Indra was very shocked, as he cannot accept death of loved ones. He always wants his parents & his caregivers to remain young & in good health. " We are all your family members. Don't you worry. We will all remain together & look after each other" Prakash & Kohinur was always beside Indra during his crisis & helped him to get out of it.

The benefit of sharing

Sharing food & visiting families at the time of need & on special occasion helps to develop a feeling of Bondage & love towards each other. All the families develop a feeling of togetherness like being a member of extended family.

According to Atasi Sengupta an active member of parent's group " The support group of parents has helped me to accept Indranil as he is today. My involvement with other sufferers helped me to identify their difficulties & hence appreciate all the endeavors of Indranil, which previously I failed to recognize. I have also now learnt to accept some of his failures & even learnt to BE with him, provide him needed support & show positive rational expectations from him."

" My son Indranil used to stay alone without any friends. Now he has many friends with whom he can share, go for a movie like all other boys of his age. His friend Kohinur was beside him as long as I was admitted to hospital during my eye operation. I really appreciated his sense of responsibility. He himself realized that Indranil may feel depressed & so he himself made plans to be with him all the time. What more I can expect from them?

It has been observed that parents who are active members of parents group develop a positive feeling & optimistic attitude, which help their children.
On the Contrary, Ratan's mother who used to tell that Ratan would never improve & had very low expectations from him remained in low functional level throughout three years.

Muktidi- one of our Handicrafts teacher- No one knows that Muktidi joined Turning Point as beneficiary & not as a teacher. To keep her occupied I suggested her to join the center, which proved to be a boon to her, & she has been able to recover from her illness.

“ When I joined the center I realized that here the other beneficiaries are doing so many works even after having more problems that me. It inspired me to take it as a challenge & overcome the problem. I also had my son & daughter who was dependant on me. This too was an added necessity to overcome the illness.
I had diploma in cutting & stitching but never I was able to teach it to others. Here, I got an opportunity to teach whatever I know to other beneficiaries here.
I like the place; I like the homely environment here. I like to interact with other beneficiaries with problem. Though some of them are aged they behave like a small child. I like to interact with them.
Surprisingly when I teach them & they want me to repeat it again & again- I do not get angry. But previously I used to get irritated when I had to repeat anything to my children. But interacting with them had increased my patience & I think I too am benefited from it in my personal life”-Mukti Acharya

Rita also repeated more or less the same story who joined the center at 40+ She gets satisfaction when she can help other members. She even has presented a scissor & a needle to a needy girl.

Human Rights

The Human Rights workshop helped the beneficiaries at Turning Point as they learnt to keep records of the handicrafts items prepared by them & ask & often fight for their remunerations in an assertive way. Sometimes their consciousness even causes tension to the Handicrafts teacher.

The need for self help groups

Rina, 43 was admitted to Railway hospital not for receiving any psychiatric treatment-but because a part of her scalp was eaten up by lice. She was accompanied by two nurses who held her firmly and were not willing to leave the room when I asked them to do so. “ She is violent and even in your counseling session we must be beside her.” They left the room reluctantly after I partly succeeded in convincing them that I am capable of handling her alone.

Rina was suffering from chronic schizophrenia since her childhood. Her father also was a sufferer of the same disease; her eldest sister committed suicide when she was in her teens and her mother suffered from depression. Only the youngest sister, who was then married and staying separately was fortunate enough of not being the sufferer of the disease. In their home there was not a single person to take care of others, give them the medicine or take care of their personal hygiene. After the counseling session (where Rina appeared calm and friendly) Rina told me, “ It is after so many years that a person behaved with me, talked to me as a human being-not as a lunatic. Generally people used to be harsh and rough towards me both mentally and physically. You appeared to me as my own sister. I want to cook some food for you.”

I felt very bad. Even after suffering from such a long time-she had the politeness, the human nature to think me as her sister (though scientifically we would say transference) and offer me food cooked by her. But the normal individuals with so many resources fail to show even a little concern for those suffering from mental illness. I had a deep regret at that time as I had no human resource to help them-no one to take care of their whole family. This made me realize the dire need to create self-help groups to help people who do not have anyone to look after them.

Effect of stigma

Debashish had borderline personality pattern with borderline intelligence. He was also non responsive to drugs. Once while returning back from office after the puja's his father saw that few local boys of his age asked him to dance over the stage that they made during the festival. Debashish was excited to find so many spectators of his creativity. The boys also started enjoying his dance. They clapped & a throwed stone towards him in their way of appreciation & poor Debashish was unable to understand it.

The desperate father-Raju's father came to me. Raju's mother died few3 years back. Raju was a slow learner. But after his mothers death he developed few Psychological problems. Raju's father had no other option but to keep him with some relatives during his absence. He was suffering from regression. He used to sometimes shout at the centre. At that time Turning Point was a new born institute where we have not been able to provide vocational trainings to all the parents & care givers.
The parents who used to come from far away places used to sit in one of the rooms of Turning Point. They used to sometimes hear him shouting & started revolting & asking the management that why we have kept a mentally ill person? At that time they all forgot that their children are also mentally ill & can become violent at any time. It was really difficult for us to make them develop a true understanding & empathy for Raja. His father would often visit the centre & request the mother's to be a little patient towards his son.

The unknown girl- I shall never forget her, as I felt hopeless not being able to help. I don't even know her name. She was trying to chew the live wires of electric post. She had no one in her family to take care of her & people were laughing at her to see her activities as "insane behaviors" which could only evoke laugh of the passerby. These are the times when we feel the necessity of having a house & in patient facility for the needed person.

Support

In our centre, we do not have psychiatrists who visit regularly-though we have psychiatrists in our executive committee. A person affected by mental illness can come to the centre for training and counseling but has the full freedom to continue his/her treatment under any psychiatrist they desire. We have a list of psychiatrists for referral. Mental health professionals support us during our conferences, workshops, seminars and awareness programmes.

Some beneficiaries who have recovered from the illness, some parents, some students who are willing to work as volunteers and some elderly persons of the community are provided adequate training in mental health programme so that they can act as a support to the affected individuals. (In this way we help the elderly to overcome frustration & depression). The recovered beneficiaries after training often proved to be more effective

in handling affected individuals and providing them support. Their own stories of recovery and the steps they had taken for it often become an example which others want to follow for their process of recovery. Affected parents provide support to other parents and can guide them during their time of crisis. Still now I remember the incident by a mother at Chennai in WFSAD conference-"When my son left our house, I was completely confused. My husband was aloof as always. Almost 48 hours till we got our son back, the members of the self-help parents group were with me, providing me emotional support, taking every necessary steps to inform police and hospital".
This is only a typical example of the support that the self-help groups of the parents and also the consumers can provide. Being the Director of Eastern Region of NAMI, India-I have seen that the success stories of other beneficiaries often act as a more fruitful and motivating tool for the affected individuals.

Difficulties Encountered

1. Apathy, lack of drive
2. Trembling hands, resulting from the side effects of medicines.
3. Lack of information
4. Stigma
5. Funding
6. Marketing the products
7. Marketing the centre
8. Difficulty to get volunteers
9. Craving for name and attention
10. Designing cost-effective projects.

1) Apathy, lack of drive is the two most common difficulties that are faced in a rehabilitation programme. A person suffering from mental illness prefers to stay back, withdraw himself from the vocational training sessions. Supportive atmosphere, encouragement, motivation and narration of success stories by the beneficiaries themselves once they recover-help them to gain enough confidence to explore the training sessions that are imparted.
2) Side Effects of Medicine- The most common side effects of medicine are trembling hands, which act as a nuisance in the process of vocational trainings. To avoid this at first they are given some graded tasks (both in handicrafts and computer training programme), which decrease the difficulty. Once they learn to gain control over it-they are given more training. In adverse cases they are referred to the concerned psychiatrists.
3) Lack of information and mental health literacy often leads to confusion in treatment. Parents, family members and the affected individuals often prefer to avoid treatment or do not opt for psychiatric treatment. Even when they go to a professional consultant, they hope for magical quick recovery from the illness. Family therapy, psycho education and awareness programmes both for the parents and affected individuals help to solve the problem.
4) Stigma – Stigma often acts as a stumbling block in the process of recovery from mental illness. The stigma often creates a major problem when it becomes

difficult to hire a house for running a rehabilitation programme. The people living in the community often protests to run a centre in their locality because of apprehensive fear about the illness. It requires awareness programmes in the community, cultural programmes by the beneficiaries, Mental Health Quiz to aware the community about Mental Health.

5) Funding – There isn't any funds allocated for Mental Health in West Bengal. As a result it becomes really difficult to carry on the day-day activities of the centre. Parents who have been benefited often try to raise funds for the centre.
6) Marketing the Handicrafts Products – A variety of vocational trainings are provided. The handicrafts products range from simple handkerchiefs to table cloths, table mats, decorative towels, cushion covers, bed covers, salwar suits, saris, ladies tops, ornaments made of beads, files, glass paintings, fabric works, decorative potteries, Bandhni works, decorative notebooks, mobile covers, jute flowers, jute bags, purses, belts, etc.

   As the motivation of the beneficiaries increased, the rate of production increased enormously making the marketing of the products a constant headache.

   We held few exhibitions to market our products apart from the regular outlets through few renowned shops.

7) Marketing the Centre – The works were done on purely voluntary basis and so never proper steps were taken to advertise the works that we are doing here.
8) Difficulty to get volunteers – Though we have got students, community persons as volunteers in our centre but they fail to sustain their motivation for long period and become irregular after a certain interval of time. Craving for name and money was another problem for these volunteers who started avoiding the works after a brief interval of time. The family members, the mothers and the affected individuals after recovery were a good replacement in their place who are regular, sincere and punctual too.
9) Designing Cost-Effective Programmes is needed for effective rehabilitation programme. Each individual has different needs and aptitudes. A programme, which will satisfy the needs of few of them and also being cost-effective, is needed.
10) Love and Marriage – Attraction towards opposite sex is natural. But if they fall in love with other beneficiaries and not being reciprocated-brings a relapse in them.

    We tried to induce a feeling that Turning Point is not the name of a centre-but of a family and here all the beneficiaries are brothers and sisters working together to reach common goals and objectives. After proper economic rehabilitation, they would be able to decide about their partner after consultation from professionals.

Lessons Learnt

Psycho education, awareness programmes, self-help groups and utilization of human resources that are readily available can make the programme viable.

Resource Materials

A book “Abujh Mon” was published few years back. It was written to make one aware how Mental Health affects from three different angles. The first-hand description of the sufferers and their feelings and experiences were written by them. The experiences of the parents, the breaking down of the family when only one member starts suffering are portrayed in that book.The pain a spouse faces due to Mental Illness is also depicted over there. In the end were the experiences and feelings of a psychologist. All of them are given in the form of short stories. It would be beneficial for both the layman and the professional to experience and identify the true-life feelings if it could be translated into English and then published. Every year we publish a magazine “Amader Katha” written by the beneficiaries, their parents & experiences of volunteers or teachers.

Future Plans

It’s a dream to make a theme park based on different cultures of India-like Bengali rural village, Rajasthani, Punjabi, etc. The beneficiaries along with some normal individuals would do all the major programmes of this park.Handicrafts section in it would depict the traditional embroideries and the beneficiaries can work there peacefully. The cultural and cuisine section can also comprise of both normal and affected individuals. Few small apartments where they can stay with their family at the end of the day would help them to work and stay in a sheltered community. In the reality where we lack funds it is a real luxury to dream about a smooth rosy future. It’s not worthwhile too to put the blame on the Government. Our goal is not to put the blame or responsibility on others but to make a path to achieve our goals; goals to change India from a bitter place to a better place for persons suffering from mental illness. For this the self-support groups must join hands together & work whole-heartedly for the better future. They must change the attitude of citizens of India & the policy makers to realize that the future of mental health scenario would not only be for the Mentally Ill alone but also would be by and of the mentally ill person. The Government, The Psychiatrist must treat the persons with illness & their family members as equal partners for care with the professionals after they receive enough psycho education once they recover from illness.

Conclusion

In a developing country like India where there is scarcity of funds for Mental Health-the utilization of available human resource can only be a beneficial solution to the challenge. Family plays a vital and central role in the life of Indians. So treatment of the affected individuals while keeping them in the family and also utilizing the tremendous human resources of both the family and recovered individuals could be an added solution. Mental Health issues in India can be ideally solved when it will not only be ‘for the people’ but also ‘by the people’ and ‘of the people’.

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Together we rise-KSHEMA Family Power

Nirmala Srinivasan
Bangalore.

KSHEMA is an acronym in Kannada[1] for Manasika (Rogigala) Kutumbhada Swa Sahaya or Self help by Families of persons with mental illness(MI). It is conceived and

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[1] Kannada is the name of the local language of the State of Karnataka in Indain Union.

implemented under the social advocacy projects of 'Action For Mental Illness' (ACMI) ; the project is executed by the family volunteers of AMEND (Association for Mentally Disabled)[2] self help group. *KSHEMA* is symbolic of 'people potential' and family power[3] in India. In this write up, we shall trace the history, features, merits and demerits of this unique "people" entrepreneurship.. *KSHEMA's* history begins with that of ACMI.

ACMI is an advocacy initiative that was started in 2003 for the cause of persons with MI[4] By its very nature, advocacy initiatives are not projects but movements that influence political climate, public perceptions and attitudes, power equations , policy decisions and budget allocations impacting the entire target population The definition of advocacy inheres the challenges in building the four dimensional strategy adopted by ACMI. These are social, political, legal and media advocacy. Social advocacy involves direct community based work with the families and in some cases with client patients too. Political advocacy is characterized by interventions in policy decisions , programs and budget allocations , actively done in the State of Karnataka in the Union of India. Affidavits and interventions in the Supreme Court of India and in the local High Court of Karnataka constitutes legal activism. In political and in legal activism, ACMI's contributions are marked by perspectives from patients and their care givers. Probably, for the first time, The Courts are sensitized to presentation of the Cause form the point of view of the Consumers and users of Psychiatric services. Finally, through media advocacy, ACMI seeks to debunk popular myths about the illness , the affected persons and legal drawbacks . *KSHEMA* falls under the social segment in the advocacy map of ACMI. It is also a logical extension of the political and legal initiatives. .

Many factors spawned the development of this unique product called *KSHEMA* Firstly, family experiences of shock, shame, grief, guilt and despair has adverse impact on the quality of life for the patient. Research shows that in addition to clinical interventions, family support is a significant input for the well being of the affected individuals. Unfortunately, starting with the onset of the illness right thru the lifecycle of the illness, most families lack the ware withal to provide a conducive environment. A patient friendly family environment is promoted with a family that is exposed to clinical and non clinical inputs on the course of the illness, communication skills, crisis management, rehabilitation methods etc. 'Chronic' care givers (like the members of AMEND) need constant reassurance in the form of emotional support , information inputs and coping skills as well. However, most families are unable to access such support because it is not available ; or available but not affordable ; and finally, even if available and affordable it is not experientially meaningful. Under such circumstances, "Experience" matters as much as "Expertise" for handling the diverse and complex responsibilities of care within the family framework. Another critical factor for choice of family agency is the dearth of mental health manpower for working with families.

The upshot of the above circumstances justified the rationale of choosing families as resources ; this is succinctly summed up by the Family- to- family Program of NAMI : "

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[2] AMEND is a Family and patient support group at Bangalore.

[3] In this essay, the word ' Family' means the family members who are carers or care givers of persons with MI or mental illness.

[4] For more information on ACMI, visit www.acmiindia. org

We are families who have bonded together because by sharing what we know and what we can do , we can best help our mentally loved ones AND survive the devastating experience ourselves" [5]. The logical choice fell upon the family members in AMEND.

The Product, Process and People of KSHEMA

There was no ambiguity about the nature of the core **Product** of KSHEMA, i.e. Family education and empowerment. However, the critical question was on the quantum of knowledge to be delivered under each . For instance, is it enough to talk about Schizophrenia as a single illness or as a group of illnesses ? Similarly, on the question of side effects of medication , do we talk about temporary impairment of sexual functions as a possible side effect or will it scare the families like the initial reaction of some in AMEND? Above all, subjecting the care givers from AMEND who have volunteered for *KSHEMA* to heavy reading (on a topic which we wish we could forget) was not practical nor desirable. So as an initial step in product management of *KSHEMA* , it was decided to identify simple and non threatening themes for family education which were as follows.

1. Illness related issues just enough for day to day family care.
2. Medication and Side Effects
3. Patient care and Management at home.
4. Rehabilitation Issues
5. Long term Care concerns
6. Care giver wellness
7. Benefits under the Law and other information.

Subsequently, the topics identified as above were given to a team of three professionals - a psychiatrist, a clinical psychologist and a lay counselor and a four family care givers outside AMEND. They were asked to critique the contents and narrow down the scope for negative reactions by the beneficiaries. This exercise proved to be of immense help to generate a basic framework for product design.. The stage was now set for brainstorming sessions for the first batch of *KSHEMA* volunteers selected from AMEND. .

Training Phase

The volunteers for *KSHEMA* were identified in one of the monthly meetings of AMEND. Two day brainstorming program was organized on 15th and 16th Nov 2003, for the selected volunteers form AMEND. The core areas identified by experts and care givers were not disclosed to the group ; on the contrary, they were asked to come out with a list of topics which in their view are important for home care and management- these are topics for which they had no access . It was amazing to see the variety of responses generated and the inevitable outburst of emotions in the group. Our efforts to look for a

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[5] p.2/2001 NAMI Califorinia Newsletter .

brand name for product of the Family to family service resulted in the *Eureka* of *KSHEMA* !

Skills Workshop was launched on Dec 4th and Dec 5th 2003. Using lectures, quizzes, and role playing techniques, the participants were made to experience the difference between the ventilation session in AMEND and the proposed *KSHEMA* 'sessions'. The role plays were particularly effective tools for internalization of their new roles as co-counselors [6]. Special importance was give to communication skills. Few volunteers found these sessions to be effective stress buster and also provide them with new insights. Knowledge package designed as a two day program , constituted the core of the Lecture sessions; participants had sufficient information on the nature of MI, side effects of medicines etc. Care was taken to avoid *excess* information (in-depth) about various types of MI as in the case of the NAMI program [7]. This rendered the quintessential flavor to the Indianness of the family intervention. In fact, the volunteers were even asked to avoid probing questions about the illness and diagnosis; "remain an authentic care giver" by ensuring basic eligibility criteria of the client family as family guardians of persons with mental disorders. "Let us not have any pretensions of even being counselors let alone mental health professionals' was the constant refrain in the training session. "After all , let us earn some *punya* and reduce our *paapa* by helping others *like us*" [8] was the worldview that made the service meaningful.

Final training session were conducted in Jan.2004, to finalize the list of critical information package – the core of *KSHEMA* to be imparted in the course of each encounter with the client family. These were classified into informational inputs, emotional needs, attitudinal changes (on issues like stigma) techniques of home based management and questions related to future concerns. The topics included the following.

- Information package was divided into FAQs on Illness, FAQs on Rehabilitation; FAQs on Problem Situations and Emergencies etc.etc.
- Care giver wellness
- Benefits and rights under the Persons with Disabilities Act 1995;
- Formation of Trust
- IT benefits
- Information on BPL (Below Poverty Line Card)
- Disability certificates and ID cards
- Special attention was given to Dos and Don'ts (See Box- 1)
- Opening and Closing each Session.
- Schedule of Visits to NIMHANS
- Protocols to be followed in NIMHANS
- Conveyance Reimbursement claims.

DOS AND DON'TS FOR KSHEMA GUIDES

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[6] Co-counselors or Peer Counselors.

[7] For example, NAMI goes into minute details of the various types of MI and the Program running into probably a total of 10 Sessions gives voluminous handouts with home work !. Apart from replicating the concept, the *nitti gritti* of the course outline besides skills and knowledge etc. had to be culturally adapted.

[8] The worldview mentioned here is part of the core tenets of Hinduism that believes in the principles of re-birth and the cumulative balance between good deeds (punya) and bad deeds (paapa) in the complete cycle of seven births that helps an individual to mitigate the adverse effects of fate or Karma. . To be a care giver of a chronic mental patient is perceived as negative karma.

- Introduce yourself as an AMEND member and a care giver; not counselor.
- As a care giver, it is not binding on you to disclose the exact relationship of the person under treatment in your family.
- Avoid sessions with patients; we are not trained for it.
- Avoid taking a stand on any religion ; if a client family asks you about astrology or any alternate therapy, share your experience if you have any ; but better ask them to consult the doctor.
- Avoid probing too much into family issues.
- If you are under stress yourself or if you are taking anti-depressants etc. better take a break from KSHEMA.
- Do not recommend second opinion or suggest any new doctors unless the client family insists upon it. Even if you do, follow the manual for change of consultants to advice the family.
- It is entirely your choice to help the client families informally so long as you do not take any responsibility on behalf of AMEND and ACMI.
- Avoid recording the feedback data sheet in front of the families. Give full attention to their problems and your suggestions.
- Remember to distribute health pamphlets / Other information sheets to families.
- Campaign for joing AMEND to local members.

We logged in a total of 10 working days spread over 4 months for the first batch of *KSHEMA* guides. At this stage it became imperative to ensure the standardization of the product (*KSHEMA)* delivery by the volunteers to guarantee quality and uniformity was required. For example, a single question on the methods to improve drug compliance among patients generated six to seven solutions; it was necessary that all the solutions were shared with the client families so that the service is complete in all respects. This called for uniform exposure to the delivery of the product which inevitably resulted in writing the *KSHEMA* manual of operations.[9] The manual helped the participants to keep it as a ready reckoner and added a professional touch to the venture.
Finally, the group had to face the question of evaluation and feedback on session interaction. It was rather premature at this stage to examine the scope of the program to external and internal reviews. It was decided therefore to introduce a structured feedback form which could serve the dual purpose of an interview schedule and an evaluation tool as well. Significant feature of this Volunteer Evaluation and Feedback form was that it has two columns for evaluation – one by self and the other by the peer family.

It was agreed that each volunteer would visit the in-patient Psychiatry wards at NIMHANS , the premier national institute in the country for mental health located here at Bangalore. The frequency of visits was decided as twice a month per volunteer [10]and duration about 2.30 to 3 hours of interaction with the affected families. The program at NIMHANS was launched on July 12th, 2004.[11]

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[9] Currently under review for publication . .

[10] It was ensured that at least three volunteers visited per week.

[11] We wish to thank the VC and Director of NIMHANS, Prof.Dr.Nagaraj for granting official permission to carry out this work.; the then HOD Psychiatry, Dr.C.R.Chandrasekar, ,Dr.Parthasarathy for their support and recommendations; and all

Subsequently, review workshops were held every quarter for obtaining volunteers feedback; and this practice continues till date. The Review workshops are also used for induction training of new volunteers. An excerpt from one such Workshop is mentioned below.

"*On April 23, KSHEMA volunteers Review workshop was held. The volunteers came out with the concrete problems such as the size of the Report format, problems of self evaluation, self doubts in advocacy, resolving the issue of care givers wellness, time management and communication skills etc. The volunteers concurred that it was difficult to convince the family members about their own state of wellness. So the subsequent skills training focused on Immersion and Probing Skills.*[12] *The participant uptake was much faster than what was expected since "all of us are sailing in the same boat" was the cornerstone of the bond between the families. . In the next session feed back on the method of filling up the Evaluation format was handled. It was decided to redesign the format so that more space was available for data entry".*

Two significant changes were made to *KSHEMA* in the last Review workshop. Firstly, the volunteers were asked to suggest to the peer families about keeping an emergency kit ready in case of sudden hospitalization. ; the kit differed with the economic background of the family. Rural kits were different to the ones suggested for educated urbanites. Another change made in the most recent Review held in May 2006 once again touched upon emotional bonding between families. The Volunteer feedback form

that was handed over to the ACMI staff once a month by the volunteers. Critical study of the forms showed that not much data was available on Stigma ; in fact in some data sheets, there was no entry at all ! When asked, the volunteers confided that sheer exhaustion that comes in the way of starting a fresh question on stigma. So it was decided to begin the session by introducing oneself , AMEND identity and dovetailing one's experience with stigma as an entry point. Verbal reports so far seems to be reassuring on the new approach. .

A special mention needs to be made on the care provided by mental health professionals. Dr.Kalyana Sunadaram , CEO , Richmond Fellowship at Bangalore. He was approached initially for ratifying the FAQs of family care givers. The Question bank proved to be a major guideline for the brainstorming sessions. Dr.Ahalya Raghuraman , Associate Professor of Clinical Psychology, NIMHANS has been a marvelous *guru*[13]. Rather than imposing expert wisdom on us, she would make us *think, debate and act.* The nursing staff of the Psychiatry departments at NIMHANS and St.Johns hospital , Bangalore (where the program has been introduced on a small scale from March 2006) facilitate the program by identifying families that need such help. Their enthusiastic support provides a strong inspiration to the volunteers. Dr.Ali Khwaja was in charge of the Skills training workshop; the role playing and self- reflection workshops conducted by him had reinforced the new roles of *KSHEMA* volunteers.

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the nursing staff for the enthusiastic welcome extended to our volunteers.

[12] Training in immersion skills was handled by the author of this contribution based on her research experience on field techniques in Phenomenology.

[13] *Guru* in the Indian languages of Sanskrit and Hindi means 'teacher and mentor' rolled into one.

Fact file on *KSHEMA* :

Once the Program began, the feedback forms became regular monthly features. Hence a documentation became inevitable and as on date the *KSHEMA* database since its inception shows 458 families till date. Since March 2006, the project is funded by a leading international NGO.[14] Of these, more than 60% of the families belong to BPL [15] category. The average patient age is approximately 20 but difficult to estimate it correctly because some families were unable to state the age correctly. Other biographic data such as literacy levels etc. were not collected.

The voluntary spirit of AMEND has drawn attention of the United Nations Volunteers Program. Last but not least, AMEND won the Distinguished Service Award for 2005 from Indian Psychiatry Society for the *KSHEMA* service. So far 23 members from AMEND have been trained by ACMI; of which, six have dropped out ; two have left Bangalore. One of the biggest problems is absenteeism and irregularity by volunteers. This is an inevitable aspect of the challenge because all the volunteers being active care givers, relapse and low phase among their own wards results in their inability to be regular with clockwork precision. Yet another practical problem is identifying new volunteers as old ones drop out. It is not possible to induct new members of AMEND and the old ones are getting fewer by the year. ACMI has initiated training non care givers but with exposure to MI either in professional capacity or in social / familial networks. Currently two volunteers are working in NIMHANS and in St.Johns while a professionally qualified staff is handling *KSHEMA* through telemedicine for rural families in four districts in the State of Karnataka.[16] Though devoid of the Family -to-family flavor, their role-taking as 'care givers" appears to be fairly successful given their immense empathy and commitment.

Voice of *KSHEMA (by* the Volunteers) :

- *Most families did not have information about the nature of mental illness and its impact on a person's functionality.*
- *Family history / heredity, stresses of modern life , bad marriage, cruel in-laws, religious dogmas. Traditional beliefs about the illness was prevalent even among educated urban , professional caregivers. So much so, most families have experimented with traditional recipes for cure in some form or the other.*

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[14] As far as funding goes, it is confined only so far as meeting conveyance expenses of the volunteers is concerned. The work is carried out on a voluntary basis and the volunteers refuse to accept monetary remuneration for their service!

[15] BPL means Below Poverty Line

[16] Telemedicine is done from the centre at Narayana Hrudayala. Besides, ACMI has partnered with the Community Outreach Program of NIMAHNS and visits these centres along with the NIMAHNS team for family education , and separate session for the consumers or patients.

- *This project has helped me to understand the issues faced in every situation. I think I benefited as much as my peer.*
- *The family perception of the illness especially for those who are seeking treatment for the first time, is one of linear progression and so it becomes very difficult to make them understand the "ups and downs" concept advocated by professionals.*
- *Families were aware of the side effects of medication. Attitude to medication was positive and had faith in the medication and in the professionals.*
- *Relapse rates were surprisingly high due to drug non- compliance. Stopping medicines seemed a universal phenomenon cutting across all social groups. Accessibility and affordability were external factors responsible for discontinuing medication even if patient was co-operative. Battling poverty with MI is an experience that challenged many volunteers.*[17]
- *Relapse after marriage appears to be quite common for patients from rural areas.*
- *The care giver in most cases attending on the patient is the mother.*
- *By and large most family members could not respond to questions about their wellness and care. Even KSHEMA volunteers themselves have to be repeatedly reminded about this.*
- *Stigma does not seem to be an issue probably because of the institutional setting*[18]*; on the contrary, the biggest anxiety is future care. However, middle class and above seemed more sensitive to it than the poor families.*
- *Almost all care givers, irrespective of socio economic background , were concerned by the bleak prospects of future care .*
- *Most families expressed concerns about patients' ability to become functional status quo ante as it was before the illness.*
- *Information related to benefits under the Persons with Disabilities Act 1995 , Disability Certificate, Forming a Trust, Self Employment loans, Income Tax rebates etc. etc. elicited tremendous response from families . They expressed their gratitude for providing such information.*[19]
- *" Spoke about the nature of mental illness, They felt happy that at least somebody comes and talks to them and gives them information about the illness and about some side effects of the medicine and to ask the doctor of details etc. Told him to take the disability certificate before leaving the hospital and to take the (ID) for getting the bus and railway concessions."*
- *"I was shocked when I entered the general ward to meet the families. A few mothers had got together and were cursing their daughter who were admitted for bringing ill luck to the family. They were using all sorts of abusive language and one mother even threw the lunch away. So I got them out of the ward and made them sit down and listen to my story".*

Voice of The Subject (care givers) :

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[17] ACMI case in KA High Court

[18] There was no direct mention of stigma related issues except in case of a dozen or so families. However, in the recent Review Workshop, the volunteers are asked to approach the interview with sharing experiences on Stigma.

[19] AMEND has printed pamphlets in English and in local language . These are distributed to the families during the *KSHEMA* session.

- *“We got more knowledge about MI, what we can do and how we can manage. We got other useful information from them”*
- *“I am happy when you come". "My brain becomes fresh". "You told us about illness. That’s useful". Your visit is useful because we all talk to each other. Otherwise we do not talk because of language barrier".*
- *“We feel happy to talk to someone like us and they are able to understand our practical difficulties”.*
- *“I did not know anything about the legislations and also about all the benefits until I met you”.*
- *“What is the benefit of your visit? You have not given any solution to cure my daughter so that her husband will accept her”.*
- *“We don’t get medicines in the government hospital in our town. So when the medicine stops and by the time we come here he becomes worse. Why don’t you tell the doctors to keep medicines instead of telling me to give medicines?”.*
- *“ I am glad that the information about forming Trust is given . I shall try to do something”*

From Symbol to Institution

KSHEMA is a symbol of hope , of care , of family power. It is an excellent illustration of using cost effective techniques for optimizing local resources. Another interesting aspect of the program are care givers worldviews. The personal and the emotional appeals are the cornerstones to success of this program. Scope for strengthening the evaluation process through formal techniques is very much there. Formal techniques have been built into it, to the extent that is possible and desirable. Particularly in the context of these family sessions, the value addition is the phenomenology of experience. As a simple, cost effective and sustainable model , its scope for replication is immense. In India, where family resource is available in plenty, the implementation can be a supplement manpower shortage .Above all, it shows partnership with families in action resulting in . family power becoming a viable institution of change..[20]

From a Family Care-Giver to a Care-Giver at the Community level – “Ashadeep Model”

Mukul Goswami,
Guwahati

Family Care-Giving experience

The year 1981 was a landmark one in my life because of two events. In April I married Anjana – my partner for a life-time. In December my sister was affected with schizophrenia. This second event changed the course of our life; our partnership at home in taking care of my sister carried over into a partnership at the workplace, in taking care

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[20] ACMI offers consultancy for training and delivery of KSHEMA . Contact acmiindia@yahoo.co.in. ; sushri2@gmail.com

of other persons with mental illness and their families in the community through 'Ashadeep'.

At that point of time, Psychiatric care was available at least in the major towns of the seven States of North East India. But there was nothing beyond that to take care of the Psychosocial rehabilitation needs of my sister, whose onset of the illness was at the age of 14 years when skill development for future occupation was not yet instilled. Our 'will' to access rehabilitation facilities, usually present in most Indian families and our economic capacity to travel 4000 kilometers to NIMHANS, Bangalore, which is not possible for most families in our country did result in a positive outcome. Twelve years after the onset of her illness, we realized that Nilakshi was as functional as any of us.

Intervening needs felt at the individual family level

Our experience starting from the denial phase and dis-continuation of treatment through the process of countering stigma to skill development, made us realize that the availability of the following interventions, would have led to a faster, qualitative and less traumatic recovery of my sister :

1. Awareness on the nature and outcome of mental illnesses in the community.
2. Primary Psychiatric and other professional treatment.
3. Psychosocial rehabilitation
    a) developing coping skills of care-givers for different situations including the negative symptoms and countering stigma.
    b) Counseling and social skills development
    c) Vocational skills development
    d) employment/ occupation.

At the community level, the interventions required to achieve a better outcome of major mental illnesses, would not be any different.

Mental Health services available in the state of Assam

To address the needs of persons with mental disorders, a community must be equipped with manpower in the form of Psychiatrists, Psychologists, Psychiatric Social workers, Nurses; Outdoor and indoor treatment facilities ; rehabilitation facilities such as Day Care centres, Half way Homes, Vocational training centres and many other inputs and resources.

The inadequate facilities available in the state of Assam, in the above context can be gauged from the following Mental health resource map formulated by the 'National Survey of Mental Health Resources' carried out by the Director General of Health Services, Government of India during May and July 2002.

MENTAL HEALTH RESOURCE MAP OF ASSAM

Sl.No.	Parameters	
1	Population	26638407
2	Estimated case load of Major Mental disorders	266384
3	Estimated case load of Minor Mental disorders	1331720
4	Existing facilities – Hospital beds in Govt. Sector	500
5	Existing facilities – Hospital beds in Pvt. Sector	Nil
6	Manpower Resources	
	i) Psychiatrists	
	Available	29
	Required	266
	Deficit	237
	ii) Clinical Psychologists	
	Available	5
	Required	450
	Deficit	445
	iii) Psychiatric Social Worker	
	Available	1
	Required	564
	Deficit	563
	iv) Psychiatric Nurses	
	Available	1
	Required	50
	Deficit	49

From the above data it is seen that Psychiatric care facilities for the mentally ill were very much limited in both indoor and outdoor settings in relation to the need. The pressure on the 500 beds available is further compounded by the fact that the 360 beds of the LGB Regional Institute also cater to the other 6 states of the North East Region.

The data also shows that Rehabilitation facilities and manpower was nearly non-existent in Assam.

Formation of 'Ashadeep'– the first NGO in the field of Mental Health in the NE Region.

To help other families with similar needs, we as a family with a first hand positive experience of managing a person with major mental illness, felt that instead of waiting for the Government or others to build up these services, it was our moral duty to intervene, leading to the birth of 'Ashadeep' at Guwahati in the year 1996.

Based on the needs evolving as an individual care-giver, we felt that the priority was to bmeet the Psychosocial rehabilitation needs of the patient and the family, with focus on vocational training and employment. The first initiative of this family based organization was a Day Care centre.

Ashadeep's Day Care & Rehabilitation Centre for the Mentally Disabled at Guwahati.

A Day Care Centre at Guwahati with stress on vocational activity was the first rehabilitation facility initiated by Ashadeep.

This first initiative, commencing activities in the year 1996, has two separate divisions - one for those impaired or disabled through mental illness, where in addition to psychological treatments and interventions an attempt is made to improve the individual's social skills, psychological coping and occupational functioning. A number of clients of this group were affected by a mental disorder at a prime functioning level of their lives, so the efforts are always to take them up to their optimal level of functioning so that they can rejoin their earlier positions in life. But in other cases where the illness is more deep rooted and the disability is more severe or chronic the 'Sheltered Workshop' of Ashadeep becomes their workplace for perhaps their whole life. The education of the families on the nature and outcome of mental illness and also on the various coping skills in dealing with such a person is a very important component in the rehabilitation process of the mentally ill at Ashadeep. The Family support group meetings are of strategic importance in this aspect.

The other division of the Day Care Centre deals with Mental Retardation and other allied disorders such as Autism. Here in addition to special education, living & social skills training, training in arts, singing, dancing etc is imparted and finally vocational training compatible to the aptitude of the client is provided. The ultimate aim in the rehabilitation process of the mentally retarded is to make them function at their utmost mental capacity.

Ashadeep's Sheltered Workshop

Ashadeep's Sheltered Workshop is the workplace for the recovering members of all the rehabilitation facilities both day care and residential. At this workshop they produce various commercially viable articles. The products include tailored clothing, block printed clothing, file covers, pillows, candles, jute carpets and handicrafts, greeting cards and gift items. Each person recovering from mental illness, engaged in such meaningful vocational activity is given a stipend or a salary like any other work place.

Last year, the sales of products produced at the Ashadeep Sheltered Workshop received a big boost with the patronage received from NEDFi (North East Development Finance Corpn.) and the LGB Regional Institute for Mental Health, Tezpur.

The LGB Regional Institute for Mental Health, by purchasing their requirement of bed linen and clothing from 'Ashadeep's Sheltered Workshop', has perhaps created a new dimension in collaboration between Government Institutions and community based non-governmental organizations in addressing a common issue.

With our foray into the field of rehabilitation of the homeless mentally ill, the Sheltered Workshop has become more relevant.

Human Resources for these initial initiatives

Anjana with a Post Graduate degree in Sociology, the experience of taking care of her sister-in –law with schizophrenia and a lot of ideas on pre-vocational and vocational processes and innovations was the fulcrum of all activity at Ashadeep. The Psychiatrists of Guwahati, though not directly involved with the day to day activity , were always forthcoming in advise and guidance. They were also the primary source of referrals to the rehab facilities. The involvement of Dr. Dipesh Bhagabati initially and the very in depth involvement of Dr. Pradip Thakuria in all processes and facilities of Ashadeep till today , must be acknowledged. The 'Mental health Resource map' clearly indicates the nearly non-existent availability of other Mental Health Professionals in the State. Under these circumstances, a part –time Psychologist was the only true Professional involved. The mentally retarded were more fortunate, as trained 'Special Educators' were available.

The other support staff were just 'good people' with the right attitude towards the issue of mental disorders. Family members and consumers were always given priority in recruitment. The Orientation/ training of these staff members was achieved through sessions by the Psychiatrist/ Psychologist , exposure visits/ short training programmes at Guwahati Medical College ; LGB Regional Institute of Mental Health, Tezpur; NIMHANS; The Banyan, Chennai; Vocational Rehabilitation Centre, Ministry of Labour ; Weaving Service & Jute Service centres, Ministry of Textiles and a few more Governmental and Non- Governmental Resource centres.

Financial Resources for these early initiatives

The financial resources for the first four years was mainly generated from small donations from the community and income generated from the sale of products of the Sheltered Workshop. The 'Ashadeep' stall had become a regular feature at 'melas' and trade fairs. The 'Ashadeep Pillow' with fibre stuffing which was supplied to hospitals and nursing homes too was a 'star' revenue earner. In summer , the Ashadeep the 'black bordered' sarree was very popular amongst the women lawyers. Structured funding for the Day Care centre came through in the year 2000 only.

Outreach Programmes from the year 1999

The reach of the 'Day Care Centre' at Guwahati was obviously limited to the city only. To work towards the realization of the vision of Ashadeep to cater to the rehabilitation needs of persons with mental illness and their families in the North east region it was necessary to start Outreach programmes leading to the creation of more facilities. But obviously, it would be impossible for one organization to do so throughout the region. To overcome this dilemma, a two pronged strategy was developed.

On its own 'Ashadeep' developed a programme, where through the help of local family volunteers of an outlying area, regular monthly mental health camps were organized. The expenses of Doctors and other Professionals , medications were borne by Ashadeep, and the lunch was provided by the local population.

Through this process, after nine monthly camps, the first branch of Ashadeep started functioning at Khetri (40Kms) away , from the Gaon Panchayat Office. The two 'family volunteers ' who initially helped in making surveys and organizing the patients, were trained at the Guwahati Day centre to run the local centre.

Later, in the year 2003, a similar exercise led to the initiation of a rehabilitation centre at Morigaon (90Kms from Guwahati).

The second route was to encourage and provide all technical support to established NGOs working in other Geographical areas to enable them to create services in he field of mental health in those locations. The efforts with 'Deshabandhu Club – a renowned organization working in the field of economic development in southern Assam led to the opening of three Day centres in the Barak Valley of south Assam. Initial meetings have been held at Imphal (Manipur) also. Dr. T. Murali, HOD , Psychiatric & Neurological Rehabilitation , NIMHANS, Bangalore has been very much involved in this outreach process.

'Roshmi'-Half Way Home for women with mental illness

Perhaps going back to the role model of my sister and the needs we felt at the individual family level, a half way home for women coming from all corners of the region, was next on the agenda. 'Roshmi' , set up in the year 2003 was Ashadeep's first foray into the area of residential rehabilitation services.

Here again, it was possible to establish this home , because of a rare contribution of a family-caregiver Mr. Ajit Narayan Deb Kachari , who wanted to help others in the community who have suffered like his sister , who was affected with schizophrenia at the tender age of 15 years. He donated his house to Ashadeep to start the Half Way home. The property is currently valued at Rs 10 million.

'Roshmi' fitted into the 'Ashadeep' canvas both as a referral destination and also as a back-up service provision for the clients of our Outreach and Day Care programmes. Later, it also became a work-place and also group home for the recovering women with mental illness rescued from the streets of Guwahati.(Navachetana project). 'Sinotee' and 'Jonalee' used to household work, but rejected by their husbands because of their illness, are today eking out a livelihood as attendants at Roshmi, a situation much better than wandering on the streets. 'Reena', had recovered sufficiently to become the key employee at the 'Sheltered Workshop', today she is the Vocational Trainer at Roshmi.

'Prashantiloy'-Day Care and Recreational Centre for the Elderly

Apparently a misfit in the Ashadeep canvas, this centre is a vital support structure for a very vulnerable group amongst the elders – the family care-givers of mentally ill persons, whose levels of burden and trauma is un-imaginable. Also the changing pattern of lifestyles of families in urban areas, has led to the increased isolation of elderly people in the sphere of day to day living. Depression in this vulnerable group of people was becoming more and more common. 'Prashantiloy' in this case plays the role of a preventive measure.

With the above objective in mind, 'Prashantiloy' was set up to provide care, recreation, supportive therapy and vocational activity to members of the population who were above the age of 60 years.

Types of Care and Services provided in the Day Care Centre:Counseling and Group Therapy to improve the family and social relations of the aged people. This helps to overcome the feeling of loneliness and frustration which are very common amongst aged people.

(1) Health care both physical and psychological.
(2) Yoga and other physical activities, which will keep the members physically fit.
(3) Sharing and Learning new skills amongst the members.
(4) Recreation viz. Television, Music System, Library, Indoor games etc.
(5) Outing / visits to religious and other places.(The Ashadeep bus is used)
(6) Provision of Lunch, taking care of the nutrition factor.

The beauty of this centre is that all programmes are devised and administered by the elders themselves. Two young men and one lady, who have been clients of our Day Care centre are the support staff of this facility. Our team of Psychiatrist, General Practitioner and Psychologist provide the periodical clinical health care support. The elders themselves are a major support for the residents of our Day centre, Roshmi and Navachetana.

'Navachetana'–A Project for Rehabilitation of Homeless Women with Mental Illness initiated in March'2005

So far, all rehabilitation initiatives of Ashadeep, both in day-care and residential settings was for people with mental disorders who were accompanied by family members. All interventions were made in collaboration with the family. But our sights were always on those persons with mental disorders living on the streets. Like any other citizen, this marginalized and very vulnerable group of people became 'invisible', making our commitment towards the issue of mental illness seem very hollow. An exposure to the work of the Banyan, perhaps gave us the courage to make an attempt to rehabilitate this most marginalized section of our population. As 'family activists', we were always firm in our belief, that in most 'normal' circumstances the loved ones who had wandered away from home would be readily accepted back , and more so if the right interventions are made with the patient and the family. Our experience so far has not changed this view point very much.

The vulnerability of a mentally ill woman on the street is much more than a man, and so in the first phase, the rehabilitation activity of 'Navachetana' has been limited to women only.

The current objectives of the project are:

1. To rehabilitate the homeless mentally ill women of Guwahati through a process of care and rehabilitation interventions, so as to re-integrate them with their families.
2. To equip those who cannot be re-integrated with their families with necessary skills and generate employment for them in the community or at the Sheltered Workshop.

3. To gradually address the needs of the lower end families, so as to prevent homelessness due to mental illness.

In the first phase of the programme, the homeless mentally ill women rescued from the streets of Guwahati, were provided with residential care and rehabilitation from the 'Navachetana Rehabilitation Home'. And with recovery, they were re-integrated with their family whenever possible. Continued follow-up with medicine supply is attempted to be maintained in all re-integrated cases. Those who became functional , but could not be placed back with their families, employment was provided , either in the various facilities of Ashadeep or at the Sheltered Workshop. For the very old or the severely disabled who could not be taken home, attempts are made to place them at other Support Shelters such as elderly homes etc.

In the first year of operation, working with a capacity to accommodate 20 women at a time, 43 mentally ill women have been rescued from the streets, out of which, 24 of them have been re-integrated with their families.

The statistical details given below will give an insight into the involvement of the different people involved in the process of rehabilitation at 'Navachetana'.

DETAILS OF RESIDENTS AT NAVACHETANA

1. ***Information from*** : Public – 13, Police / Child Line – 15, Ashadeep's staff & Volunteers – 15
2. ***Rescue*** : AD Staff & Volunteers – 22, With Police help – 5, Directly admitted by police – 12, Child Line – 4
3. ***Geographical area of homes of Residents*** : Assam – 34, Bihar – 2, West Bengal – 2, Arunachal Pradesh – 1, Delhi / Haryana – 3, Karnataka – 1
4. ***Diagnosis*** : Schizophrenia – 33, MR – 4, Bi-Polar Disorder – 4, Behavioral Problems – 2
5. ***Medical Treatment received earlier*** : 13, 5 at LGB Institute
6. ***Age*** : Below 30 years – 15, Above 30 years – 28
7. ***Economical Status*** : Lower strata – 35, Middle class – 6
8. ***Vocational Skills*** : Earlier skills present – 14, skills could have been developed / could be developed – 17, very little chance of developing vocational skills – 10
9. ***No. of women rescued and subsequent pattern*** : Rescued – 43, Re-allocated with family – 24, Absconded – 3, Currently at Navachetana – 19, Re-admissions – 4
10. ***Follow up action / contact with ex-residents*** :

No contact – 4, Back on ~~street~~ – 2 Follow up maintained – 18
Productive occupational activity at home- 7
Reasonably progressing at home – 7
Passed away (over 70 yrs.) – 1
Relapses –3

VITAL NETWORKS DEVELOPED :

1. The Police Department – Circulars have been sent to all Districts , regarding the services of Navachetana, and as a result there have been enquiries from the various districts. At Guwahati the 'Women's Thana' had been providing us with security support for rescue whenever required. Gradually most of the Police stations of Greater Guwahati are bringing the homeless mentally ill women to Navachetana.

The addl. Director General of Police (CID) has sent a communication to us on the need to sensitise the Police personnel on the issue of Mentally Ill on the streets.

2. The LGB Regional Institute for Mental Health, Tezpur – One of the oldest Mental hospitals in the country has today become the premier Institute in the field of mental health in the North eastern region.

A strategic networking has been developed with this Institute in the following areas :

- Providing back up indoor treatment to any HMI person referred from 'Navacheatana'.
- To meet their requirements for bed linen , pillows etc. from the production of Ashadeep's Sheltered Workshops.
- The Institute has submitted a proposal under the WHO Biennium programme for 2006-07 for developing a model for mental health care and treatment of Homeless Mentally ill in collaboration with Ashadeep. In this model the rescue and rehabilitation components will be taken care of by Ashadeep, and the LGB Institute will take care of the treatment and medications.

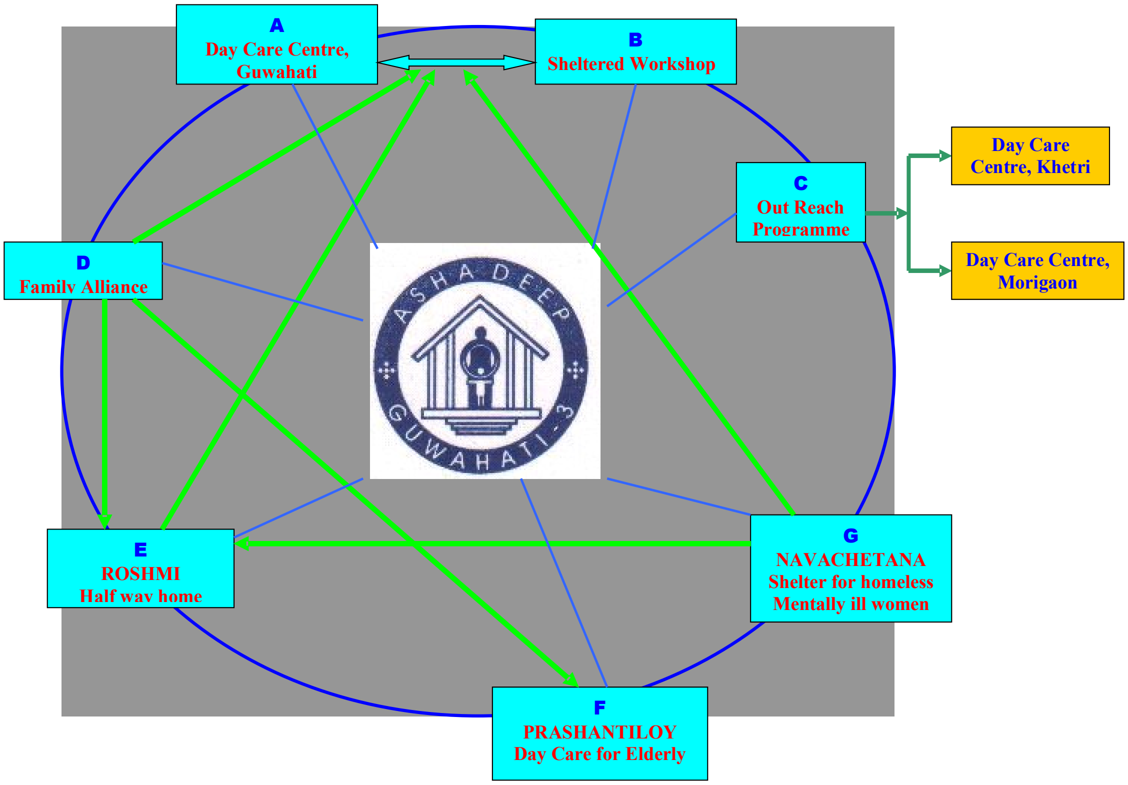
2. **The Banyan, Chennai -** The initial model for care of the HMI of Navachetana was formulated after a study of the Banyan model, and the National workshop organized by 'The Banyan' was one of the major inputs. This relation with the Banyan has been further strengthened with an in depth study of the activities of 'Ashadeep' by a team from that organization. Two more visits by Banyan staff have been made to Ashadeep, one – for guidance on organizational restructuring and the other – on hand training on Care and Rehabilitation Processes at Navachetana. Orientation of the staff of Ashadeep with the various areas of activities of the Banyan has been initiated.

Human Resources-the situation at Ashadeep today

It is obvious from the above, that the present level of activity of Ashadeep cannot be maintained with grass root level workers only. To create quality in the services, a team of professionals have been pooled , to guide all rehabilitation and administrative activity of the organization. The Psychiatrist, General Doctor, Social Workers, Administrators, Vocational trainers, trained nurses are part of this team, which facilitates all the components of Ashadeep. Financial support from Sir Ratan Tata Trust , Mumbai has made it possible to form this team of 'pooled human resource'.There has not been much change in the pattern of the grass root level workers.

The village is definitely remote, but the traditional bonding of an Indian family is very apparent in the warm welcome accorded to ‘Promilla’(blue saree &green blouse) who had wandered away from home and was rescued and rehabilitated back into the family through ‘Navachetana’. Shristi, our social worker had to walk a long way to reach Promilla’s home near the foothills of Bhutan.

The Ashadeep Structure as it stands today



Each of the programs run by Ashadeep is distinct and has been designed for specific user groups. A structure like this allows each centre to partake of the other’s services, while keeping its distinctive nature intact. For example, those who come to the day care centre often help out in the day to day affairs of the special school as teachers. “Patients” are transferred from one centre to another and also contribute to the functioning of the organization. If someone is recovering fast enough in *Roshmi* or *Navachetana* and do not need to be totally institutionalized, they can attend the day care centre and help out in the various income generating activities run by the organization. The existence of centres like the old age recreation home creates informal networks of disseminating information about mental illness even if it is done unconsciously. The staff services and the administrative functions of the various programmes are shared. Ashadeep has also been trying to organize a pool of volunteers across the state of Assam. Even though they do not work officially for *Ashadeep*, being associated with the organization at any level provides them with the scope to know of mental illness beyond commonsensical perceptions.

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Different paths, common goal: research advocacy support and help for the mentally ill (RASHMI)

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Background

What is health? It is said to be a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (World health Organization 2001a, p.1). Many factors contribute to mental well being- socio-economic conditions, religiosity, good physical health and longevity among others. The absence of a diagnosable mental disorder is not necessarily an indicator of positive mental health. One way to think about mental health is by looking at how effectively and successfully a person functions. Feeling capable and competent; being able to handle normal levels of stress, maintain satisfying relationships, lead an independent life; and being able to bounce back or recover from difficult situations, are all signs of mental health. In an ideal world everyone would be mentally and physically healthy. (www.**wikipedia**.org).

Yet we live in not ideal but a real world- where loved ones fall ill, and due to social taboos and stigma we cannot even seek information or help. The silence is so enveloping that we do not talk about this illness to the person sitting next even in the hospital setting. Indian research shows that stigma and discrimination is worse for women, especially housewives who feel even more guilty and stigmatized and moreover have no one to share feelings with. Those who felt stigmatized, also felt more burdened by the illness of their close relative. (Final Report; Development of Rehabilitation and Management Skills in Families of the Mentally Ill and Family Mental Health Education. Department of Psychiatry, Dr. Ram Manohar Lohia Hospital , New Delhi, India, Funded by the World Health Organization, March 2005).

In 1995, Prof. Dr. V. L. Nimgaonkar of the Western Psychiatric Institute and Clinic, Pittsburgh , U.S.A, and I began planning a study to conduct genetic research in Schizophrenia. While the ultimate aim was to find out the genetic causes of this serious disease, we also wanted to map the risk of falling ill with Schizophrenia in the Indian population, clinical characteristics of this illness in India etc. This was wok which had never been carried out in a detailed systematic way in India before. We initiated the Indo-US Collaborative Study of Schizophrenia Genetics at the Dr. R. M. L. Hospital, New Delhi funded by the Office of International Health, Dept. of Health and Human Services, USA. It involved long clinical interviews with the sufferers as well as family members. One of the distinguishing features of this project was that our Senior Research Officer, Dr. Triptish Bhatia, did not work in hospital only. If they could not come to hospital, she would visit clients at home to conduct her interviews. Home visits meant long informal chats in addition to the scientific work. And so, slowly families began breaking the conspiracy of silence by asking- “Are there other families like us?” There were several families where more than one child was ill with the same illness and they were in special need of psychological support from people like themselves.

Their need touched us. We had long been aware of lack of social support for mentally ill and their families in Delhi. Dr. V. L. Nimgaonkar had been in touch with several charters of the National Alliance on Mental Illness (NAMI) in the U.S.A. Looking at the effectiveness of NAMI to campaign for issues concerning mental illness- they could even move Senators- we became aware of the sort of power sufferers and their families were capable of in combating the social aspects of this illness.

Beginings

In Delhi, we sought help from one of the pioneers of mental illness legal activism in India- Dr. Amita Dhanda- then at the Indian Law Institute, New Delhi. Amita had written the book on mental laws in India, and had been involved, along with Dr. R. Srinivasa

Murthy of NIMHANS, Bangalore, in reviewing mental hospitals in West Bengal on behalf of the Supreme Court of India. We had long discussions- Triptish, Amita and I. There was little communication across groups and therefore even less advocacy of mental illness in our country. What could we do? Slowly "our' families joined us in discussion, and the conspiracy of silence was broken at last. (Final Report, Indo-US Collaborative Study of Schizophrenia Genetics, Office of International health, Dept. of Health and Human Services, Parklawn Building, Rockville, Md. 20857, USA).

We decide to get together to form a group which could discuss ways of caring for mentally ill members in the family, and gain knowledge about nuances of medical treatment. We first met in February 1998 as an informal support group for the sufferers and caregivers of the mentally ill. We met once a month on Saturday in Amita's chamber at the Indian Law Institute, to discuss questions-

- What was the cause of mental illness?
- What and how effective were its treatments?
- What did a parent do when the sick son or daughter behaved in odd or unacceptable ways?
- What were the laws, insurance policies in our country for such people?

Primary aims and objects of our group were to reduce the hostility and rejection faced by the mentally ill and their families, work for acceptance of such patients in larger society and removal of stigma, make medical treatment more accessible to such people, and to fight for their legal rights. Day to day problems being faced by such families were often resolved by discussions within the group during meetings.

Our group continued to meet monthly to exchange knowledge as well as informal care giving notes on dear ill ones. Slowly we began to feel the need for a more formal structure, especially as we had started organizing public meetings on various topics related to mental health. In the last meeting of the year (1998) a decision was taken to form a non- profit Society of the mentally ill and their families and register it with the Indian Registrar of Societies. It was decided to make this a fully elected Society rather than a Trust, to have different categories of membership etc. Members used to be deeply exercised over each matter under discussion and some issues took several meetings to resolve.

What would this Society do? What would its focus be? Obviously support and activism were primary, but a group was also needed to focus on the lack of research in mental health in India. Finally a very bright patient gave us the answer- and RASHMI was born. RASHMI (Research Advocacy Support and Help for the Mentally Ill) was registered under the Indian Societies Act xxi, of 1860 vide registration number 36308 of 1999. This was a momentous day in the life of this organization and was celebrated by all members in the meeting held on January 2000.

In 1999, Amita was designated the Chair of a group constituted by the Ministry of Social Justice and Empowerment, Government of India to look into the lacunae of the Persons with Disability Act,1995,(equal opportunities, protection of rights and full Participation) and was enjoined to suggest improvements to it. The Act had been passed by the Parliament following lobbying by many groups of disabled people. There were few if any consumer groups concerned with mental illness in this lobbying. But mental illness is included in the Act due to efforts by individual psychiatrists, professional groups such as the Indian Psychiatric Society and Institutions like NIMHANS who had lobbied for mentally ill adults and children with intellectual disability, learning disorders, and autism.

Our group was exercised over the vague definitions of mental illness provided in the Act. We decided to present our petition to the Committee. RASHMI was the only group from entire North India to petition for rights of the mentally ill before this committee on January 30, 1999. Our suggestions found a mention of the Final Report of this committee.

Making progress

We began then to meet in a more public place, where caregivers could find us more easily- the Department of Psychiatry, Dr. Ram Manohar Lohia Hospital. The advantages were that we became more visible to people who needed us, but the disadvantage – as Amita put it- was the "medicalization" of mental illness. We know that course, outcome and sometimes even symptoms of mental illness are determined by social and environmental factors too.

An important event during year 2000 was the joining together of the group " Shri Sai Manavotthan Sansthan" (SSMS) an NGO working primarily for the homeless mentally ill as a Corporate Member of RASHMI. SSMS had an agenda which RASHMI helped fulfill- adoption of several families for taking care of all their requirements for psychiatric medicines. SSMS would supply all medicines pertaining to mental illness at their homes free of cost every month. This program has continued till today- 2006.

In 2001, Shri K. D. Prabhakar, Secretary RASHMI, participated on invitation in the First National Conference of the Caregivers of Major Mental illnesses organized by World Fellowship for Schizophrenia and Allied Disorders held at Chennai on May 25-26, 2001. The conference discussed issues related to volunteer work, problems faced by family groups etc. The meeting felt that "Self Help Groups" and ill persons required greater recognition and support from the professionals and policy makers. Accordingly it was decided to work for a national level organization for the causes of the mentally ill. Shri Prabhakar's commitment and sincerity to the cause of the mentally ill, as well as his practical observations about the difficulties in the care of the mentally ill were much appreciated by organizers and participants alike. In recognition of his efforts, he was requested to take up the post of Convener, National Federation of the Mentally Ill- Apex Organizations.

Activities

The special interest of RASHMI has been to hold public meetings to make people aware of problems and advances related to metal illness. Topics have ranged from "Informed Consent, Confidentiality and Related Issues" (presided over by a Justice of a High Court, held on November 7, 1998), a book release : Legal Order and Mental Disorder (a comprehensive review of Indian laws relating to mental illness) by Prof. Amita Dhanda, NALSAR Legal University, Hyderabad on March 5, 2000, and on July 28, 2000 on "Update on Genetics of Schizophrenia". On 12th October 2002 RASHMI in collaboration with Department of Psychiatry, Dr. Ram Manohar Lohia Hospital held a public meeting "Basic Needs of the Mentally Ill from Care Givers' Perspective". Dr. S.P. Aggarwal, Director General of Health Services was the Chief Guest. Dr. Vijay Chandra, Regional Advisor, Health and Behaviour, World Health Organization and Dr. C.P. Singh, Medical Superintendent, Dr. Ram Manohar Lohia Hospital, New Delhi were the Guests of Honour. The families of the carers attended the meeting to discuss the problems faced by them and their needs in looking after the patients. The WHO project mentioned above, was launched during this meeting at the Deptt. of Psychiatry Dr.RML Hospital.

On October 13, 2001 a national level meeting of all registered social work organizations (NGOs) working for the mentally ill was organized by RASHMI at the Seminar Hall, OPD Block, Dr. Ram Manohar Lohia Hospital. Problems of exclusion and stigma of mental illness compelled over 20 organizations active in the field to come together. It was hoped that this National Federation would be give us a united voice to lobby with the government for the betterment of the mentally ill. Separately, these organizations had not been able to make much headway. For instance, guidelines for the inclusion of mental disability into the Disability Act had not yet been formulated in spite of repeated pleas. A National Trust had already been created for intellectual disabilities such as mental retardation and cerebral palsy, but none for mental illness that may last lifelong in some cases. To a very large extent, RASHMI was instrumental in the formation of National Federation for Mental Illness.

Two more meetings for this National level organization have been held at Delhi under the aegis of RASHMI- the last, in April 2003 was presided by the then Minister of Health, Government of India and one of the Honored Guests was Dr. Shekhar Saxena from World Health Organization, Geneva.

All along RASHMI and professionals concerned with mental health in one way or another- law, psychiatry, clinical psychology- have worked together. Both have supported each other. At present RASHMI is participating in the JAGRITI program at the Dept. of Psychiatry, Dr. Ram Manohar Lohia Hospital, where we get together two Saturdays a month to answer questions of patients and caregivers and give them "Informed Support". While its constitution did not encourage professionals to become office bearers, active members of RASHMI have collaborated with research and other professional programs in every way. This is truly a consumer professional partnership.

RASHMI has also been petitioning various governmental and other agencies to highlight the problems faced by mentally ill persons and their families.

Difficulties

It has been a difficult journey and the most difficult part is to overcome the negative perceptions in the sufferers and families themselves. It is very easy to just give in or accept stoically the fate that is in store for us. It is much more difficult to fight on and perhaps face negative reactions from society.

Many caregivers become so burdened just looking after the ill member and taking over his responsibilities, that there is no time for them to come together to lobby or discuss. Moreover any advances made in issues like advocacy and research are so slow, and require so much sustained effort that it is often beyond the capacity of one individual or family.

Lessons learnt

It is important however not to lose hope and to keep trying collectively. Whatever advances were made, have been made when people came out in the open and fought stigma together. When hidden hurts are discussed novel solutions often come up. It is most important to be together.

RASHMI has been a path breaking initiative. But its founders are now tired, or ill, or otherwise preoccupied. In any case very organization needs new members, new approaches and new infusion of ideas. Perhaps this is the interregnum after which RASHMI will recoup, regroup and go forward with renewed vigor.

Objects for which RASHMI was formed are:-

- To support research on causes, treatment and management of mental illness;
- To work for the accessibility of medical treatment and other support services and for promotion of social welfare;
- To device strategies for the removal of stigma attached to mental illness in our society;
- To be a solidarity group where problems and concerns around mental illness can be voiced and shared;
- To advocate and agitate for the basic human rights of persons with mental illness;
- To facilitate communication between professionals, patients, families, friends, colleagues and other members of the society;
- To inter-act with Government and its agencies and other similar national and international bodies for voicing our concerns over discriminatory legal provisions and practices in legislation’s executive orders and judicial decisions;
- To seek such amendments in existing rules and statutes which further the basic rights of persons with mental illness;
- To Express opinion on proposed legislation on and in respect of laws pertaining to above, and connected matters and to make representations in respect thereof;
- To purchase or acquire movable or immovable property; to sell, improve or dispose of any such property, collect subscriptions, donations, or disburse funds for all or any of objectives of the society;

- To take such steps as may be expedient and necessary for maintaining the prestige of the Society and also for the procuring for its beneficiaries all due privileges from the Ministry of Finance, Ministry of Law, Ministry of Health, Ministry of Social Justice and Empowerment, Labour, Central Board of Direct Taxes, Central Board of Indirect Taxes and other concerned authorities or departments.
- To institute, create, establish Funds such as ‘Reserve Fund’, ‘Empowerment Fund’, ‘Members Mutual Benefit Fund’ or any other Fund or Funds that may be considered necessary as corpus fund of the Society and in the interest of the members of the Society, to make Rules and Regulations for such funds and to amend or abolish such funds.
- To do all such things and acts as are or may be incidental or conducive to the attainments of the above objectives.
- All the income earnings, moveable immovable properties of the Societies shall be solely utilised and applied towards the promotion of its aims and objects only set forth in the memorandum of Association and no profit on thereof shall be paid or transferred directly or indirectly by way of dividends bonus profits or in any manner whatsoever to the present or past members of the Society or to any persons claiming through any or more of the present or past members. No member of society shall have any personal claim on any moveable or immovable properties of the Society by virtue of his membership.

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Lay Persons As partners in mental health management -SAA-Pune's Experience

Anil Vartak and
Gurudatt Kundapurkar
Pune.

Mental Health Scenario - Pune 1996

From ages there is carryover of deep-rooted stigma about mental illness. Numerous myths & misconceptions have been inherited from generations in respect of persons diagnosed of mental disorders. Want of medical services and related infrastructure adds to the misery of the affected families. To make even a minor impact it is beyond the power and resources of government agencies and the professionals. Change of heart, change in the attitude of the community is a must. That is possible only with involvement of individuals of the society, the *'aam aadmis.'* So is the relevance, importance and urgency of ‘people-oriented’ or ‘lay-person-inclusive’ activities in achieving the goal of relief, rehabilitation and reintegration of affected families.

Till 1996 in Pune professional intervention was the only treatment available for persons with mental illness. There were clinics of a few psychiatrists, very few hospitals for admitting severely mentally ill persons and the Regional Mental Hospital at Yerawda. However, there was hardly any complementary activity at the community level. News and articles used to appear in the newspapers and magazines to report specific programs or to observe the World Mental Health Day etc. Self-help groups, awareness meetings, or socialization for shubharthis were almost non-existent. Two important events in mental health field that occurred in 1996 were : one was formation of Schizophrenia Awareness Association for rehabilitation of shubharthis and the other was formation of Ekalavya self-help support groups, one each for shubharthis and shubhankars.

Dr. Jagannath Wani, founder of SAA, hails from Dhule, Maharashtra, but is settled in Canada for the last 45 years. In the western countries MH NGOs/caregivers organizations emerged in the 80’s for spreading awareness, reducing stigma, imparting skills for coping and for advocacy of related issues. Dr. Wani himself had founded Schizophrenia Society of Alberta and had exposure to organizations devoted to schizophrenia and other mental illnesses in Canada**.** He initiated formation of SAA in 1996 with the help of some well-intentioned doctors and social workers from Pune to work for awareness, self-help and rehabilitation of shubharthis and shubhankars.

Another important event was formation of one of the earliest MH self-help support groups in Pune called Sihaya (pages 117-120). Dr.Mira Sadgopal, along with two others, was the founder of this group. Anil Vartak, who had joined it found the group extremely useful and was therefore eager to pass on this benefit to other affected persons in the community. But majority members of this group were reluctant to go public. Sihaya gave them safe place to share, to ventilate, to socialize and to develop fellowship. For them this Safe place was free of the stigma and competitive pressures of ordinary society. Some of them expressed fear of losing their privacy and confidentiality. Hence Anil Vartak decided to collaborate with Dr.Luktuke to form another group under the banner of Vasudha Manovikas Pratisthan, an NGO based in Pune. Dr.Ullhas Luktuke a leading local psychiatrist led this activity. Thus Anil Vartak was assisting Dr.Luktuke since it’s inception.

The initial response was very good but it reduced after some time. Later it was realized that the number of persons with schizophrenia is large, their needs are different and they become a drag on the progress of other patients. Hence a decision was taken to form a separate support group for persons with schizophrenia. So Anil Vartak is one of the founder members of this group, which was named Ekalavya. In 1998 Ekalavya and SAA decided to work together. Ekalavya and SAA now work for persons with any mental or nervous disorders.

Reasons for ‘people’ orientation

For the success of any program it needs direct involvement of stakeholder lay persons so as to ensure it has truly ‘people’s participation’. This becomes all the more important in the management of mental health issues. Involvement can be taken right from conceptualization of a program to it’s implementation. In India such involvement is very crucial for several reasons. Firstly, in India the number of professionals is very meager compared to the demand. Secondly, rehabilitation facilities either by government or private sector are extremely inadequate. Hence if **people** come together and form a group it is most beneficial. This group will exchange information about illness, provide mutual moral support and instil hope of recovery. The group provides a forum to the professionals also so that they can share their expertise. This kind of ***‘forum of the people, by the people and for the people’*** is not otherwise available.

Another reason for choosing people is the quality of help that shubharthis and shubhankars can give to each other is really something which cannot be compared to what others can offer. People with first-hand experience –either shubharthis or shubhankars - can genuinely understand each others’ problems, have empathy and provide support in times of crises.

Usually the stakeholders, their friends and relatives have genuine interest in providing meaningful life to shubharthis. Non-stakeholder but committed volunteers too are an asset to support group activities. They are ready to devote time, ideas, raise resources and take up new initiatives for providing meaningful life to shubharthis. Picnics, musical programs, informal cultural events etc. are possible with their own initiative.

Since these people work on voluntary basis their services are cost- effective. The services of self-help group meetings can be availed of by the families without much expense.

Converting lay into resource persons

Support groups for shubharthis and shubhankars are the platforms SAA has provided since the very beginning.
(a) Shubharthis’ group:
In the beginning this group did not have any formal structure like SAA had from the beginning. Shubharthis used to share freely their experiences of illness. They were able to ventilate their pent up feelings and also realize that they were not alone. This initially did provide some solace to them but later on other issues in the minds of shubharthis became more prominent. Ventilating anger, unpleasant incidences and complaints became the norm, rather than exception, of the group. The group gradually started turning into a non-productive ‘complaints group.’
We realized our group needed a method which will motivate them to share experience of their own efforts for regaining mental health. When we came across the Recovery Method developed by Dr.Abraham Low, we immediately said this method is going to be helpful to our shubharthis. We found this method simple to understand, shubharthi-friendly, close to our own culture and one that helps to control one’s symptoms irrespective of the nature of illness. Some of us underwent training of this Method and we started using it in our group since 2001.

Shubhankars' group:

In the beginning coming together, ventilating pent up feelings, sharing, obtaining advice were essential for this group. We found the group acknowledged even these simple gains. But as the group matured we realized that the activity was getting monotonous and stagnant. On the other hand expectations of the members grew higher. We therefore decided to change the structure of the proceedings. We opted to organize lectures of the professionals on predetermined topics or discuss among the shubhankars themselves predetermined topics useful in their daily life. This change ensured that needs of the shubhankars are served better and thereby their interest is sustained in the group meetings. The shubhankars' support group meetings are organized every 2nd and 4th Saturday of the month.

It became obvious that shubhankars and SAA this (lay volunteers) need proper knowledge about illness and related issues to effectively play their roles. So we conducted two programs one for the shubhankars and another for SAAthis. In order to develop SAAthis we designed another training, Support Group Facilitator's Program with focus on group dynamics & plenty of practical tips.

People-provided care

Involving stakeholders, that is, shubharthis, shubhankars and SAAthis in the management of mental health is the basic philosophy of SAA. SAA's apex decision-making body is made up of persons from this segment. Services of mental health professionals are availed of by SAA as advisers rather than their involvement in day-to-day organizational matters. Invariably we ensure stakeholders are involved right from conception of a new project to its implementation. Obviously there are advantages as well as limitations of this system.

Inherent limitations of lay groups

The basic aim of SHG is to create conditions or environment, which will motivate individual members to take initiative for self-improvement.

* Individual attention is possible only to a limited extent unlike the service provided by the professionals. Services, requiring a lot of time for an individual, needing tailored-made approach, however, are more of an exception when it comes to people-based organizations like ours.

* We do not provide any therapy which lies exclusively in the jurisdiction of the professionals. Hence for any professional treatment or counseling the families independently seek resources outside SAA.

* Unlike in a commercial for-profit organization, there is greater freedom and flexibility, of course within the limits of proclaimed objectives, in the matter of hierarchy, decision-making, delegation, taking responsibilities, etc. Consequently, some delays,

minor errors in judgement, hasty decisions are noted more leniently as a learning process, provided of course the intentions were bonafide.

* Volunteers are usually not professionally trained in financial, secretarial, managerial or mental health issues. This, we are aware, puts a limit on their performance but genuine feedback for better performance is provided in a dignified way.

* Sometimes the growth and direction of the organization tends to be swayed by the enthusiasm of the new volunteers who are yet to get familiar with the organizational philosophy, aims & objectives.

* We encourage shubharthis, shubhankars and SAAthis to attend conferences/workshops and training which will update their knowledge and develop skills for developing them as resource persons.

Mental health professionals' support

As mentioned earlier, Dr. Luktuke, a professional himself, had mooted the basic idea of a support group for shubharthis. In the beginning progress of our activity was slow. Some professionals even raised apprehensions like: "In what way will these lay persons, leading the group, be of any help?" "Will our patients be snatched away by other doctors if they join the group," "Medication can be the only treatment for persons with mental illness, especially for schizophrenia". As a result very few patients came through referrals of the professionals. New members were attracted basically through coverage by the media or through word-of-mouth publicity. Moreover, professionals who have their own rehabilitation center hardly referred their patients to our support groups.

Things have, however, changed over the last two to three years. More patients come to our groups based on recommendation of their doctors. We also have had couple of orientation programs for family physicians with the help of Pune Psychiatric Association. SAA invites many professionals for their talks in public or in our groups or for their being on SAA's experts' panel.

Mostly senior well-established doctors understand importance of the role of SAA activities and are ready to help without expecting publicity. While some junior doctors, who are yet to establish, obviously may be interested in publicity and in attracting patients through SAA's platform.

In general, the stages of changes in the professionals' approach towards NGOs can be summed up as – suspicion / indifference / curiosity / awareness / acceptance of group's complementary role & referral / readiness to collaborate / acceptance of support group as a part of mental health system. SAA may be at the fourth or fifth stage of attitudinal transition.

Difficulties and Solutions

As in the case of individuals, organizations too keep moving on the path of progress by finding solutions to unforeseen problems as they arise.

Here below are some of the difficulties & corrective measures taken by SAA:

D –Fall in attendance at the regular meetings.

S- Organizing meetings in a structured way, providing support, ensuring appropriate information is provided, inviting professionals for talks, starting support groups at locations nearer homes of families and having separate groups for non-Marathi speaking families etc.
D- Shubharthis group-fall in number.
S-Structured format, encourage use of Recovery Method in day-to-day life, preparing a booklet of meeting guidelines, staying in touch with members who have abstained for sometime etc.
D- Shortage of funds for regular meetings and for rehabilitation facilities.
M-Collection of voluntary donation from members at every meeting and financial support from outside funding agencies.

Lessons learnt

- There is no substitute for one's own initiative although outside help and expertise are needed. So the philosophy is : *We don't wait to get well to do things; we do things to get well and grow.*
- Just as there are moments of deep satisfaction being able to reach out, there are also those unavoidable frustrating moments when we need to have tremendous patience and faith. It will help one to remember: *Greatness lies not in never falling but in rising every time one falls.*
- Pangs of growth of an organization can be minimized by having well-thought-out and periodically-reviewed goals, continuously motivated & trained volunteers, delegation & decentralization in decision-making, especially using management techniques.
- Funds are necessary for the sustenance and growth of charitable organizations. Though fund-raising itself is a specialized skill, response to one's efforts will depend much on the proof of one's work and faithful exposure it gets in the community through media persons with whom we need to build rapport.
- Staying focused on and conserving resources for one's chosen objectives is not easy, especially with the risk of being tempted to compete with others, using short-term gimmicks.
- Collaborate with and involve as many segments of the society as possible, e.g. govt.agencies, professionals, media-persons, teachers, students, corporates, for credibility and long-term gains.

Resource materials developed by SAA

To inform, educate and motivate the resource persons SAA has had to develop reference and training material in various forms.

SAA publishes in Marathi & English, a quarterly newsletter entitled Ekalavya which gives information about developments in mental health field, useful tips for shubhankars and shubharthis and a review of SAA's recent & forthcoming activities. The newsletter serves as mouthpiece of SAA, a forum for stakeholders for sharing MH concerns of day-to-day life and an important resource material for our members. As organizations start growing, needs of shubharthis and shubhankars become apparent. It was noticed very early that one of the reasons for rampant myths and misunderstanding among shubhankars and people in general was lack of any literature in layman's language. So we published books that provide basic information about of mental illnesses - types and symptoms, do's and don'ts in day-to-day life and in crises , ways of promoting recovery and planning for the future. When SAA took this project fortunately it found a sympathizer in Ms.Kalyani Gadgil. Ms.Gadgil decided to translate the original English book 'Living and working with schizophrenia' into Marathi. This book was titled 'Schizophrenia- Ek Navi Janiv'. SAA decided to publish the book on its own in 2003 even without any experience in publishing. In spite of having limited contacts with the booksellers and distributors the book received very encouraging response from the readers. Third print edition of this book is currently available for sale.

- Pune is a cosmopolitan city and SAA has plans to spread its work in different parts of Maharashtra. Enthusiastic response to our first book in Marathi prompted us to translate it into Hindi too. That is how 'Schizophrenia-Ek Naya Ehsas' was published in 2003.
- 'Schizophrenia-A New Perspective' in English has also been released in July 2006.
- Activities of SAA gradually increased. On the one hand it was realized that general practitioners are the first point of contact for most of the affected families, on the other hand the GPs were keen to gain a better understanding of mental illnesses, their symptoms, diagnosis and recent treatment options. Hence SAA organized, with the help of PPA, an orientation programme for the GPs and also publish a book which with several articles on different issues of mental illness, diagnosis, complementary and alternative treatments. The book, 'Divided Mind' was the outcome.
- "A Beautiful Mind" movie was screened in Pune in 2003 by SAA, followed by discussion with the experts. The movie is based on the life of Prof.John Nash, a Nobel prize recipient, who suffered from schizophrenia in his early life. The movie depicts his personal and his family's struggle towards leading a meaningful life. SAA also conceived of the idea of a Marathi abridged version of the original book on Prof. Nash for giving a message of hope to affected families. "Sundar Te Man" was the Marathi version by Prof. Kamalini Phadke.
- Self-help group for shubharthis and shubhankars is one of the most important activities of SAA. As we started coming in contact with increasing number of persons who were seeking help from us, formation of new groups in Pune and even outside became necessary. Volunteers who were working with self-help groups were either trained or had experience of support group for years. This enabled them to grasp basic principles of self-help group and keep the working of the group focused. Important things about self-help group are confidentiality

about one’s sharing in the group, feeling of fellowship and non-judgmental attitude. Even though support group meetings are structured technical jargon is avoided and interactions are held in layman’s language. It was thought that if we want to start more groups we need some guidelines, which can be followed by all new groups. This will retain the basic spirit of self-help and will help facilitators to keep interactions focused. We therefore published MENTAL HEALTH SUPPORT GROUP GUIDELINES, a manual on self help support group for shubhankars, shubharthis and volunteers.

- We have brought out a book of poems entitled ‘Hope Floats’. The book shares frustrations, hope and aspirations of shubharthis, shubhankars and SAAthis. ‘Let us try and see..’ is another book about personal mental health strategies of Mr.Anil Vartak. We have also prepared draft resource material for training program for shubhankars, which is yet to be published.

Continuing to dream

Dreaming and exploring new avenues does not cease at SAA. Here is just a peep into what is yet to come**.**

Activity center

SAA is proud to have its own center at Dhayari which is about eight kilometers from Pune. This center inaugurated recently is built with funding from Canada and K.S. Wani Memorial Trust, Dhule. It has capacity of servicing around 50 shubharthis. To make this center fully functional will be our top priority. This center requires additional financial support. Identification and training of staff is now in progress. This center will provide facilities, which will not only keep shubharthis occupied but will provide them confidence and skills to live a meaningful life in the society. This is a new venture for all of us at SAA and we are learning from experiences of other similar institutions.

Support groups at Maharashtra’s district places

After gaining experience of around eight years we at SAA have understood the importance of self-help group as a Mental Health Recovery & Rehabilitation Hub for the surrounding areas. Such a hub can not only provide facility for meeting & sharing by shubharthis and shubhankars but also as a place around which shubhankars and volunteers come together and plan for more activities which help reduce stigma, develop awareness or rehabilitate shubharthis. Members of such activity can formally register their group. If they want they can raise funds from the public, besides contributing their mite, which gives them a sense of ownership & pride. Hence formation of a group devoted to the cause of the mental health is of great importance. That is why SAA proposes to start at least one such group at each district place in Maharashtra. SAA has already initiated such groups at few places like Nashik, Ahmednagar, Aurangabad & Dhule, besides Pune, in Maharashtra.

Local volunteers training

Organizing public meetings, ensuring large audience at a new place is relatively easy. What is more important and not easy is ensuring continuity of the group activities by local volunteers in a sustained manner. Periodic training and motivation for the local stakeholders are necessary.

Revised manual for support group facilitators

A more compact user-friendly manual for support group facilitators, both in Marathi and English, is need of the hour. SAA has taken up this assignment and the publications should be available in the next couple of months.

Collaboration/networking with other institutions

Organisational perspective and growth are bound to improve by it's networking and collaboration with other organizations & individuals engaged in mental health care and management. So SAA has been a founder member of the All India Federation For Mental Illness, apex body of shubhankars of shubharthis in our country. AIFMI, in turn, has chosen SAA-Pune and IPH-Thane as their official Resource Centres. SAA has been contributing to efforts of the World Federation Of Schizophrenia & Allied Disorders, the international body of mental health caregivers headquartered at Toronto, Canada. Other institutions with whom we had the privilege of networking are: Bapu Trust, Chaitanya Mental Health Centre, Nityanand Mental Health Institute, PMC's Kamala Nehru Hospital, Rotary Clubs, etc., all of Pune, Maitri Self Help Group-Mumbai, IPH-Thane, KSWani Pragat Adhyayan Sanstha-Dhule, Ekalavya Self Help Group-Nashik, Abhyas Mandal-Indore etc. Paper presentations by SAA representatives at WFSAD's conventions at Chennai & Kyoto-Japan and Recovery Inc.'s convention at Chicago and interactions at such forums also has enriched SAA's experience.

Nurturing fellowship

Reintegration of the affected families into the mainstream is the ultimate goal, next only to relief & rehabilitation through group support and vocational training. We found the following ways and means to facilitate this re-integration:
< Staying in touch with the families through phone calls and occasional home visits, including reaching out in times of crises.
< Observing fellowship-generating social functions like *rakhi bandhan, til-gool, haldi-kunku,* periodic family picnics, shubhankars' felicitation by shubharthis, Antarnad-a variety entertainment programme by shubharthis, mental health poster competition, art and craft exhibition-cum-sale, gymkhana activity etc. Encouraging shubhankars and shubharthis to participate in public awareness programmes, thus enhancing their self-esteem by working for a social cause.
SAA is a community-based organization, which is run by the PEOPLE. Following are the fundamental principles of SAA's working: --

- All the office-bearers are non-mental health-professionals.
- We don't provide any therapy.
- We believe in collaborating with the professionals.

- We believe that our way of working reduces relapses for persons with severe symptoms and promotes recovery for others.
- Even though we have specific way of working we believe that individuals needs may differ. We respect individual's freedom to choose what suits him.
- We believe that stakeholders and SAAthis are an important resource for the process of reintegration of shubharthis. Unfortunately as this resource is ignored in our society SAA and other similar NGOs have the responsibility to focus on this.
- We agree that mental disorders may be painful and even catastrophic. But we also believe that the same pain creates an equally strong desire in the stakeholders to reach out to others.

Summing up

In conclusion, we at SAA are more than convinced that there is incomparable strength to be derived by mobilizing people-oriented self-help activities, especially in a family-centric social setup prevalent in India. Burden on the over-worked and scarce professionals also is lightened by such initiatives. For the families too this system makes much economic sense. Besides these activities being more empathetic and more easily accessible aren't they worth popularising to every nook and corner of our vast and diverse country?

Multiple initiatives for mental health

Meena, M
Mumbai

Whilst the world has been quick to respond to the growing threats to the human body, little has been done especially in India, in response to the afflictions of the human mind. The mentally ill, the emotionally disturbed and those with severe personality disorders bear not only the anguish of their suffering but also the additional burden of society's indifference and ignorance. In spite of falling victim to false beliefs and deeply rooted misconceptions, the issue of mental health features very low on our government's agenda, and almost not at all on society's list of priorities.

The isolation of the mentally ill, the emotionally disturbed, and of the issue at large has only further perpetuated the callous indifference that exists within society. Integrating rehabilitation into community treatment is a necessity that cannot be further ignored.

Genesis

Meena Mutha the founding trustee of MANAV, started her role in this project as the caregiver of a daughter with learning disability who went on to develop a severe mental illness, diagnosed as Schizophrenia. The hopes that her daughter, now twenty, would move on from a special school out into the world of 'normal' children was shattered when the treating Psychiatrist, Dr Y Matcheswala made Meena aware of the severity of her child's mental health. The struggle of caring for an individual with vivid hallucinations, debilitating delusions, disordered thinking, confusion, mood disturbances and so on, all left the family distressed, confused, and very frustrated. Meena was new to the process of treatment, the long waits and visits to the psychiatrist, the agonizing process of administering the crucially important medication, repeated hospitalizations, spiralling treatment costs, dealing with curious enquiries from relatives, neighbours and friends made Meena increasingly sensitive to the agony that other families with less resources at their disposal would be burdened with.

After her daughter stabilized on the medications, Dr Matcheswala emphasized the patient needed psychosocial rehabilitation, since this illness had caused a process of unlearning basic personal, emotional, and social skills. The patient needed a multifaceted rehabilitation program before she could be reintegrated back into her previous 'normal' routine.

And, so a long, excruciating search began, in Mumbai, Pune, Satara, and many other places in Maharashtra, to look for an appropriate place to send her daughter. The severe dearth of rehabilitation services left Meena shocked and helpless. Accepting the suggestion of Dr Matcheswala, she chose at this turning point, to use her experience as an inspiration to make available to the city of Mumbai, a quality rehabilitation service to help people with mental/emotional disturbances.

All through her struggle of discovering her daughter's mental illness, its treatment, and lack of rehabilitation services a close family friend Mr. Suresh Gandhi stood by her, helping her to cope in every way possible. Meena suggested to him the idea of a rehabilitation centre and they both formed the MANAV Foundation trust, registered with the Charity Commission in May 2004, for this project. Masina Hospital was approached for space to start such a centre. A consultant psychiatric social worker was hired to help with the technical know-how to get the project started.

The process of setting up the centre began, from renovations, to furniture, recreation room, kitchen was all installed, and the centre was inaugurated on World Mental Health day, 10th of October 2003, and opened its doors to clients from February 2004.

Progress

- The MANAV Foundation's initial and foremost foray into the field of mental health met with success in its initial three month period, despite the trials and errors experienced.
- The rehabilitation centre opened its doors first on February 7th 2005, and has since worked steadily with an increasing number of clients from various backgrounds and with diverse case histories.
- Taking our lead form the very unfortunate "marine drive rape" incident, we organized "Refuse to be a victim", a workshop for women that focused on the physical and intellectual aspects of mental health. This self defence workshop held on 13th May 05 was attended by approximately 70-75 individuals and also included a panel discussion. Participating in this discussion were prominent members of the Mumbai Police and representative members of different organizations working for gender-related issues. Also involved in this discussion was the audience which largely comprised of concerned members and affected members of society.
- On 14th July 2005, putting into practice one of our most fundamental beliefs that steers the rehabilitation of our clients, we organized a day dedicated to the issues related to hygiene and physical presentation. A professional beautician facilitated this process, helping the clients to learn the basic skills related to presentation and hygiene.
- Purely for recreational purposes, a movie day was planned on 15th July 05 for the clients of MRC. The idea was thought of and executed completely by the clients, supported and encouraged by the organization which helps inculcate confidence and independence in them.
- On 11th September the first caregiver supportive training program was organized and successfully conducted by the Manav staff. It was attended by about 50 caregivers of our clients. It was a full day workshop which began with the screening of a Marathi film "devrai," which depicts the struggle of a sister coping with her younger siblings' mental illness and her discovery of the shades and challenges presented while dealing with a person with mental illness.
- Clients were treated to an Onam lunch, a Keralite festival for Harvest on 16th September. This gave them an opportunity to learn about a new festival and also taste new kind of food.
- A Marathi film on Schizophrenia produced by a mental health organization in Pune was to hold a premier show in Mumbai, Manav associated with them in organizing a press release on 16th September and the final screening on the 24th and 25th September '05. The film screening was a grand success with a very good turn out of audience consisting of people from all walks of life. As a keen participant in networking our team attended a NGO's meet organized by Karmayog, and we also participated in a talent show.

- The greatest achievement for the Manav clients was “Flow, the stream of energies,” held on 18th November, an opportunity for clients from all organization from Mumbai to come together a present a group dance, a fashion show and a rangoli competition. This show was a great boost for their sense of identity, and self-confidence.
- Manav team has been regularly networking with medical associations like the Bombay Psychiatric Society, to keep in constant touch and share our opinions and mission with the medical fraternity.
- On the 8th of January 2006, our second caregiver supportive training program was held, the topic was communication skills, which helped caregivers gain a lot of understanding of their communication habits and patterns and how body language helps the communication process tremendously.
- “The way we live” a series of documentaries on disabilities was co-organized by Manav, Astha, and Max Muller Bhavan, on 18th and 19th of January and Y B Chavan centre, Mumbai. This questioned the lay persons’ attitude and prejudiced beliefs towards persons with all kinds of disabilities.
- Manav celebrated its first birthday on the 14th of February 2006. The Rotaract club of Bombay Hill South, played games, got food and gifts for the clients of the centre, it was a fun filled party and celebration.
- On the 16th of February 2006, our organization participated in a NGO fair, held at Sophia college
- As a part of a recreational activity the client of Manav were taken to Tikujiniwadi for a daylong picnic and rides with a lunch
- The clients managed a stall at the fun-fair held at the Children’s Orthopedic Hospital on the 23rd of February 2006, Hajiali

Basic approaches

Manav functions under the umbrella of four broad mandates which are;

Networking

Networking with NGO’s, organizations, service clubs like Lions, Rotary and Giants, inner wheel with the aim of associating with these bodies for public awareness programs, fund raising and creating mental health awareness at a community level.

Intervention

Under this mandate MANAV provides counselling for persons with mental illness, personality disorders, and emotional disturbances. Counselling and support for the caregivers or families of persons with mental illness. MANAV Rehabilitation Centre, the focal point of MANAV’s efforts in mental health services is a day-care centre, where people with mental or emotional disturbances spend the day under supervision of mental health professionals. A fixed schedule is followed, with activities like daily living skills, kitchen skills, self-defence, yoga, physical exercises, group therapy sessions, drama therapy etc. Lately, a incentive driven activity of making paper bags, obtaining orders, and delivering the same to various shops to help clients gain independence and responsibility has been undertaken. The provision of a “safety net” for clients ready to leave the protected environment of the centre and embark on their individual journeys is essential as it lends support and eases the pressures of the outside world. This process will help the client gain independence, strength and much needed confidence, preventing relapses.

Training

Under this mandate of training, MANAV provides supportive training programs for families of persons with mental illness. To help them cope, manage and effectively handle their relatives. The emphasis of these training is to teach the caregiver self-care and stress management skills to ensure their physical and mental health to empower them to take care of their loved ones. Under training MANAV also offers and conducts workshops and training for various special groups like women, children, working women, and medical fraternity on subjects related to mental health.

Publicity and outreach

Preparing and publishing literature related to mental health is an activity undertaken as a part of this mandate. Writing articles on these issues for newspapers, magazines, doing talk shows on radio/television with the objective of promoting mental health, and importance of rehabilitation services is part of our outreach.

Aims and objectives of the the MANAV Rehabilitation Centre:

- To offer treatment, support and care to persons affected with a mental illness or a personality disorder or any emotional and/or mental condition that has rendered them unable to function.
- To provide after care and support to clients of the centre to ensure complete integration within society.
- To offer care and support to the caregivers of such persons
- Involving families, rendering therapy and support through the establishment of support groups for caregivers
- To offer counselling to disturbed and distressed adults with emotional problems and to individuals facing coping difficulties
- To encourage the involvement of the community in the cause of mental health by creating awareness and organizing sensitisation programmes in the endeavour to generate and facilitate the use of local employment facilities and resources
- To empower and facilitate the use of already existing resources and services within the professional community by networking and organising publicity for the purpose of sensitisation as well as skill-enhancing workshops, seminars and training programmes.

Our vision

Keeping in perspective the aims and objectives of MANAV Foundation, our vision could be stated as *"widening the horizons of mental health to ensure its recognition, importance and acceptance as a necessary component of society"*

Our mission, thus, is to enable individuals with mental illnesses and emotional disorders, to optimize their potential by providing and facilitating various opportunities that are currently denied them.

The following activities form an integral part of each day, structured specifically for the overall and successful development of each individual client.
This approach includes the following:

Yoga, meditation and physical exercise

The physical exercise sessions are specifically designed for the reduction of physical lethargy, which is a common symptom of mental illness. Exercising the body also induces smoother blood circulation especially to the areas of the brain, causing stimulation and cognitive activity. Appropriate physical exercise also improves physical stamina and health, whereas yoga strengthens the muscles, makes the body more flexible, and strengthens the mind. All focused physical activity facilitates coordination between the brain and the body. Yoga and Meditation plays a very important role in improving concentration and mental stability. Through meditation clients will also become more aware of their emotions and will develop the capacity to express them appropriately.

Daily living skills

The focus of this therapy is on developing skills and awareness needed to maintain personal hygiene, and environmental cleanliness. Other related skills are also inculcated in the clients. A daily living skill involves self-hygiene and cleanliness related to the client's immediate environment. Other skills related to daily living involve tasks such as basic kitchen activities, housekeeping skills, daily financial interactions and other household activities. This attempt goes a long way towards attaining independence and a sense of responsibility and confidence.

Counseling and professional services

Individual counselling

In keeping with the tenants of a holistic approach, clients receive one on one counselling on a continuous basis through out the course of his/her treatment at the centre. Counselling continues as a supportive component of after care once the client's reintegration into society is initiated. Higher levels of acceptance and understanding within the individual for his/her need for help are achieved through counselling, facilitating the client to determine his or her own course of action based on informed choices and with support. Importantly, the process plays a substantial role in behaviour modification by helping the client to identify destructive patterns of behaviour, and choose more appropriate patterns of behaviour.

Family counselling

Consistency in care is essential to the treatment of a mentally ill or disturbed person. Whilst under going treatment it is important for the caregivers to be supported and if necessary, learn new ways of handling the individual within his/her primary environment. Additionally, given the fundamental premise of this model, the client's reintegration into mainstream society begins with the client's immediate or primary environment. Within the Indian context, this primary environment in almost all cases is the family. Given the above, family counselling understandably becomes imperative in order to pave the way for optimum recovery.

Group therapy

These sessions are conducted by a trained social worker. The sessions are predominantly divided into community meetings, therapeutic discussions, and recreational activities. These sessions aim at improving social skills, communication skills, and inculcate recognition and acceptance of emotions, feelings, within the individual and in others. The group therapy also facilitates appropriate ways of dealing with different emotions and difficult situations. These sessions also provide an opportunity for our clients to interact independently with one another thus allowing healthy relationships to develop. . In Group therapy we also conduct the following activities namely Drama Therapy, Dance Sessions, Music Therapy, Art & Craft and kitchen Activities.

Occupational therapy

Occupational therapy involves the client in the production of articles and facilitates learning, concentration and focus. Occupational activities also initiate interest in art, craft, needle-work, etc.. The variety offered to the clients ensures that patterns of mechanized behaviour, daydreaming and inertia are replaced by stimulation, initiative and activity. Moreover, common symptoms of mental illness like imagined sights & sounds, and suspiciousness gradually decrease and facilitate recovery. Although the main focus of any and all occupational activities is therapeutic, occupational therapy also aims to the vocational rehabilitation of clients. All the products made by the clients, will be sold at exhibitions that are held at regular intervals for NGOs, and the money earned distributed amongst the participating clients

Swayam

Vocational Training programmes plays an active leadership role in advocating for the rights of individuals with disabilities, removing the physical and attitudinal barriers which often confront them, and publicizing their abilities and accomplishments to society at large. Vocational Training increases self-confidence and encourages towards a positive self-image. These training programmes are aimed to help our clients enter or return to employment.

Medication and other psychiatric treatment

Medical care will be provided to all clients depending on their needs. The team at the centre will include a social psychiatrist who not only understands and acknowledges the holistic approach but who also encourages and supports the said model. We aim that medication will be a part of each individual's therapy as and how necessary and will facilitate and complement the process of rehabilitation.

Future plans

An imperative aspect to making a difference in the mental health arena is the widening of scope and the broadening of one's reach. A part of The MANAV Foundation's plans is to expand and broaden it's horizons, foraying into territory that is intrinsically linked to an adult's mental health. Child mental health is fundamental to the community's well being at large. Personality disorders, behavioural problems, emotional instability, and coping capacities are all aspects of human development that find their roots in childhood. When ignored or neglected at an early age, many such issues related to mental health remain unresolved into adulthood, often causing the requirement for professional intervention.
The early detection of such signs, and the appropriate intervention at an early stage can prevent all round poor mental health.

The MANAV Foundation Rehabilitation Project plans to open its doors to children in difficult situations. Plans for this development are currently in the stage of finalization.
Given the dual disadvantage of women with mental health issues, The MANAV Foundation also plans to establish a cell that will provide a range of services to women with special emotional and mental health needs. Activities will include community outreach with a focus on advocacy and awareness. Fulfilling the therapeutic and legal needs of the women clientele will also be predominant objectives of this project.

Child/adolescent mental health care

As a future plan Manav would like to set up a mobile crisis intervention cell
This cell would cater to mental health crises outside the premises, by physically being present at various locations. This kind of cell is crucial at times of natural disasters
Life threatening illnesses like HIV/AIDS, are extremely stressful. Complications are caused and are also a result of these illnesses, for example, depression, anxiety, fear about the future and so on. HIV/AIDS counselling needs are extremely necessary when dealing with persons with these life threatening illnesses

Broader Mental health perspectives, Manav has professional and technical expertise in the field of broad mental health field like personality development, time management, stress management, communication and so on. We look forward to providing training and intervention to various target groups in order to train them in several broad mental health fields. Currently, we at Manav train various students in mental health from many esteemed institutes like Tata Institute of Social Sciences, Nirmala Niketan, Sophia College, SNDT College. Many more students training will be undertaken in the current year.

Conclusion

We at Manav believe that every individual has a right to opportunity, an opportunity for a better life, for a better tomorrow, and to live life to the fullest – no matter what the odds are. Manav aims to provide this opportunity to our clients. We believe that this is a step forward towards rehabilitation and the reintegration of our clients into society. We hope you extend your efforts towards our cause and help us in our march towards mental health.

SECTION-IV
FAMILY MEMBERS OF persons with Mental Retardation

Mental retardation – Role of parents

Venkatesh,K.R.
Bangalore

Introduction

Karnataka Parents' Association for Mentally Retarded Citizens [KPAMRC] is 26 years old now. The initiative to start this organization was many fold. The founder parents believed that the strength of the organization lies in several parents coming together for interacting, exchanging views and putting up a common front for achieving the desired goal, namely rehabilitation of their wards and enabling them to join the mainstream of life, like all others. The ways and means were many. The parents jointly made earnest efforts to move forward in as many ways as possible for achieving this goal.

The main focus of the parent is his ward, a special person who is also part of the community. Therefore, the Association took the first and probably the most important step to sensitize the people, the community and the society at large about mental retardation and other developmental disabilities.

Awareness campaigns, conferences, seminars and workshops, group and individual counseling and interpersonal communication were the tools which were effectively deployed to achieve this objective. Today, with certain amount of confidence one could say that this objective is achieved more in cities and urban areas. Efforts continue to spread it to the rural community and sensitize them about this major issue.

Interaction among the parents was encouraged to dispel the myth of destiny, karma, and the possibility of cure for this condition by medicine.

Manpower Development:

At the time the Association was formed there was hardly an institution giving training to special persons. The Rehabilitation Council was to come into existence much later. Training facility for the teacher was non-existent. The Association took upon itself to design the Teacher Training Programme, train teachers to be part of the special schools. NIMHANS was the first to come forward with its entire faculty to draw up the curriculum. Fine tuning was done later in consultation with experts of the Karnataka Government which readily recognized the six months certificate course which was formulated by the experts. Thus began a journey of manpower development in the year 1979. This was a pioneering effort on the part of the parents to find a way to facilitate the education of their special children. The Six month course was open and the focus of the training was skills. Over the years this certificate course became a one-year full fledged diploma course and now two year diploma course with the recognition of the Rehabilitation Council. Over the years two more courses, one in Autism and the other in Specific Learning Disabilities and Integrated Education were added with appropriate recognition by the National Council for Teacher Education. These two courses are one year duration and have the status of a diploma. The Association encourages parents to take these courses and today host of the parents are not only taking care of their wards at home but also working in special schools supporting the community at large. The Association is justifiably proud that over 1000 special educators are working in various schools in different parts of the state and even outside to help, develop the potential of the special person fully and become part of the mainstream.

Eligibility: Qualified teachers from regular schools, graduates / post graduates with teaching, degree qualified teachers in special education and currently employed as a teacher or parents of children with learning disabilities.

Focus of training; To provide trainees with the understanding of Specific Learning Disabilities as a major problem; to equip them with the knowledge and skills to help students teachers, parents, and administrators to cope with the problem and to enable trainees to implement the strategies involved in the process of Integrated Education of those with specific learning disabilities.

Skills expected;: They should be currently employed as a teacher or be a parent of a child with Learning Disabilities. To have basic knowledge of the condition of a persons with these disability.
Suitability of the trained persons to different settings: The trained persons can fit in both to the home environment and to the school environment. Parents who undertake this course will be able to assist and help their wards in the areas of disabilities of learning and also take care of persons with this disability in the neighbourhood. Trained teachers work in schools, both general and special to ensure that students with L.D. are trained adequately to join the mainstream which ultimately will be the objective of inclusive education
Trainers

The Association has also devised a four month programme exclusively for parents in Autism.

Details for One year Diploma Course

Eligibility for joining the course; Graduates / qualified teachers from special school / in special education or parents of children with autism
Focus of training: To provide trainees with the understanding of autism as a major problem that has recently been recognized as such. To equip them with the knowledge and skills to help students, teachers, parents and administrators of special / regular schools to cope with the problem. To enable trainees to implement the strategies involved in the process, in order that these children could be included into the mainstream of special / regular education.

Skills expected; should be teachers in special schools or have undergone special education course. Parents of children with autism are also eligible to take this course.
Suitability of the trained persons to in settings: Persons trained in this course can work in special schools meant for persons with autism spectrum disorder and multiple disabilities where autism is one of the conditions.

Trainers
Number of parents have taken this programme.

4 MONTHS PARENTS CERTIFICATE COURSE

KPAMRC organizes a 4 month certificate course for parents.
Eligibility: Any parent whose child is diagnosed with autism and who is willing to put in 4 hours of practical work with two children in an assigned institution and attend all theory classes once a week. The parents will be evaluated based on the set criteria.
Focus: To empower the parents with adequate knowledge about the disorder, its characteristics and symptoms. Also, to provide the parents with enough information on the management of the child's everyday problems. The parents will be equipped to conduct an informal assessment of their children to understand the child's difficulties and strengths. This will enable them to plan and carry out an appropriate educational program.

Skills: As mentioned above, parents will be equipped to evaluate their child's performance in all areas of development, viz., language and communication, motor, cognition, play and social skills, self care and behaviour management. Based on this evaluation, they are then taught to plan an educational program that will be implemented consistently. This will reduce the burden on the parent in terms of understanding what to do so that the progress of the child is unhampered. Parents also learn about positive behaviour management which is very essential as persons with autism can exhibit very challenging behaviours. Suitability of trained persons: Parents training course equips the parents to handle their own children only but does not equip them to work as special educators in schools. Trainers: Same as the regular course

Group Insurance:

Another initiative taken by the Association as early as 1980 was to sign a memorandum of understanding with Life Insurance Corporation of India to develop Group Insurance Trusteeship Scheme [LITs] for the parents of the Association. This scheme was available at two levels. At the first level parents were to make a one time payment towards the scheme. The interest on this amount was paid towards the premium of the scheme and passing away of the parent, the amount insured, i.e. Rs. 20,000/- was given to the Association. The Association acting as Trust and guardians of the special persons, gives a monthly maintenance allowance of Rs. 200/- for the maintenance of the child. Parents were entitled to become members of this scheme till they attain the age of 60. At level two the amount was reduced to Rs. 500/- per parent and proportionately the maintenance was also reduced to Rs. 100/-.

The Karnataka Government showed interest in this scheme and signed an MoU with KPAMRC to jointly put this scheme into operation. The Karnataka Government paid the initial amount for insurance to the LIC and the other formalities was taken care of by KPAMRC.

A major problem faced by the Association today is to fulfill its commitment to pay the maintenance allowance. While rate of interest on deposit coming down drastically, paying Rs. 200/- and Rs. 100/- monthly has become a problem. KPAMRC is fulfilling its commitment by diverting money from its own resources. Most probably a re-look about the scheme is warranted at this stage.

Parent Self-help group

Another area of interest is the parent self-help group initiated by the members of the Association to help out parents of persons with mental retardation and other developmental disabilities, in the neighbourhood. To begin with a parent member identifies a place where parents can assemble interact, exchange their experiences and views and deliberate on an action plan to find a solution to the problems of their wards. The purpose of the meeting is explained and volunteers among them invitee parents to be available on each day during specified time. At that time parents can leave their wards in the identified place where the KPAMRC member parent organizes training in different vocations of interest to special persons over a period of time. Efforts are also made to market the products produced by these special persons and offer an honorarium.

Periodically, the self-help group arranges a picnic, excursions and visit along with the wards. Occasionally, experts and parents of the other self-help groups are invited for interactive sessions. This effort has helped the parents of these groups to come out of despondency, regain mental strength to move forward. This has also helped special persons to learn and earn depending on their ability.

AKSHARA Vocational centre – an initiative of one of the parents of our Association, Mrs. Jaivanthi Hiriyur, was started on 19-10-1992 at Malleswaram, Bangalore. This centre is self-help group activity led by Mrs. Hiriyur to help and assist persons with mental retardation and other developmental disabilities of neighbourhood. This centre admits persons aged above 16 years after properly assessing the abilities of special person. Depending on their ability training in vocational skills are imparted be it drawing, painting, and stitching, envelope making, and mats etc., along with some academic skills and special occasions the centre offers incentives to its wards depending upon the products sold. However, everyone in the centre irrespective of his ability to produce goods is given a minimum incentive to encourage them and ensure non-discrimination.

Custom design bhajans, excursion, sports and games are other co-curricular activities which keeps the special youngster motivated and members of the self-help group a recharged lot.
IF possible could you describe one such group And its activities

Caregiver Programme:

KPAMRC, was most probably the first Association to think in terms of organizing a training programme to train persons who could act as caregivers and work with families in their houses and relieve the parents to have a respite.
The first programme was organized jointly with Spastics Society of Karnataka.
Eligibility; Adults with working knowledge of the regional language in reading writing and conversation.
Focus of training; Familiarization of disabilities, namely: mental retardation, cerebral palsy, autism, polio militias, basic principles of managing persons with these disabilities.
Skills expected; Familiarity in handling and managing children in home and institutional environment.

Suitability of the trained persons to different settings: Persons trained in this course are to assist the families having persons with intellectual disabilities as caregivers, depending on the requirement of the families, they could help the family by taking care of these special persons for a few hours every day or for a few days or on a regular basis. These caregivers were also available to the institutions to provide the required support in managing the special persons.
Trainers : Professionals working in the field on intellectual disability

Today, this programme after refinement is being implemented by the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and Rehabilitation Council of India. The programme is of six months duration and any NGO registered with the National Trust is eligible to organize this programme. KPAMRC is one of the pioneers in the country to have organized this National Trust programme which has helped to create a core of caregivers.

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities under the Ministry of Social Justice and Empowerment launched in a big way to develop a band of caregivers to help and assist parents at their homes and work in institutions meant for persons with mental retardation and other developmental disabilities. Master trainers who would in turn give training to grassroots level. Caregivers were initially given training at the premier National Institute for Mentally Handicapped [NIMH]. These Master Trainers coming from all parts of the country have trained the grassroots-level caregivers and till the end of March 2004 nearly 2000 trained caregivers were working in various parts of the country. Among them over 50% were home based caregivers. This programme was temporarily discontinued from the middle of 2004 as it was felt that caregivers are also to be given registration under the Rehabilitation Council of India. Now the National Trust has reintroduced caregivers programme with the desired modification.

PARIVAAR -- National Federation of Parents' Association

Most probably one of the initiatives of the Association which made a great impact at the National level was the initiative taken by the KPAMRC at the World Congress organized by the ILSMH in 1994 in New Delhi. There were representatives from various parts of the country attending the Congress and on the initiative of KPAMRC they discussed the formation of a National Federation of Parents Associations. This idea was accepted in its totality and the President of KPAMRC was elected to head an adhoc committee with a mandate to work out the modalities and the constitution to form a National Federation called PARIVAAR. This committee held a few meetings and finalized the constitution with a provision to have two levels of membership, the first one full fledged members eligibility being only parents association working in the field of mental retardation, autism, cerebral palsy and multiple disabilities, the other was affiliate membership to Associations of professionals and NGO working in these four disability areas. The Association was registered in the year 1996 and during the last 10 years it has grown from strength to strength.

The Federation which had initially only 22 parents' associations as its members at the time of formation, today has nearly 150 members. It has become a strong force at the national level being in the forefront of advocacy for persons with mental retardation, autism, cerebral palsy and multiple disabilities. It has also made an impact at the International level and is a member of Inclusion International. The Federation and Inclusion International have signed a MoU to mobilize and strengthen parents movement in India. This activity is going on for the last six years and the movement has spread even to rural areas in North-East and North West.

Parivaar is actively involved in providing different skills to its members to manage and implement various rehabilitation programmes meant for their wards effectively. As a part of this, Parivaar has organized workshops to impart managerial skill and skills on effective communication. Workshops have also been conducted to build leadership quality among its members. Parivaar is constantly interacting with Government of India and other national, international bodies working for the disability sector to develop an effective network.

The Honorary Secretary of KPAMRC is heading the organization as President of Parivaar and overseeing these activities.

Group Home:

All these 26 years KPAMRC firmly believed in the philosophy of just being a catalyst in promoting various rehabilitation activities for its wards through other interested NGOs. At times it acted as a trouble shooter with the completion of the Silver Jubilee. The Association decided to undertake projects with a role model for replication by parents association elsewhere. The foremost among them was to develop a group home complex where facilities for long-term residential care and rehabilitation will be available to persons with mental retardation and other developmental disabilities. Side by side it also agreed to provide facilities in the complex for senior parent couples to stay there. Undoubtedly, facilities are available for long-term residential care of special persons all over the country but these places have no arrangements to provide the much needed love and affection to these special persons which can be given only by parents. That is the reason why in the Group Home complex it was decided to make arrangements for senior parent couple to stay there. These parents who oversee the activities of the complex will also provide the much needed love and care to the residents. The complex will also have facilities for vocational training and sheltered workshop. A day-care centre will function which will be utilized both by the residents and the neighourhood.

The complex has been planned about 25 kms away from Bangalore in a rural setting. Hopefully this complex will become the forerunner for the establishment of many more such complexes all over the country. The establishment of this complex in a way answers the haunting question of a parent 'After us what?' by providing a home away from home.

Books and Publications:

KPAMRC always believed that interaction among the members and other like minded people was a vital input such growth it started with a quarterly newsletter just after a few years of its formation. The newsletter contains information about policies and programmes initiated by the Government, various activities undertaken by NGOs working in the field and of course major activities of the Association. Even today the newsletter continues to be the major link among the members of KPAMRC knowing the importance of knowledge dissemination among its members and other organizations. The Association also began publishing books and manuals on issues connected with mental retardation and other developmental disabilities, management of special persons, guidance to parents in managing their wards and training manuals to the teacher trainees. The first publication came out in early 90's and so far the Association has published 12 publication on different topics.

In addition special issues and souvenirs were brought out on major occasions like National Parents meet, national seminars and workshops.

Professionals Support:

KPAMRC has been getting spontaneous, unhindered support from professionals and experts. Thanks to its location in Bangalore. The Association from day one started interacting with professionals and experts of NIMHANS. The response has been overwhelming. Doctors in NIMHANS guided the Association in developing the curriculum for all the three diploma courses namely mental retardation, autism and specific learning disabilities and integrated education.

These experts and professionals were available to constantly review and update the curriculums. They and professionals working in other major institutions in Bangalore have been teaching these students of all the three diploma courses as guest faculty. The professionals are also on the Technical Advisory Board of KPAMRC to guide and steer professional activities of the Association. Parent counseling and guidance has been a continuing activity over the years. Parents and professionals have developed respect and regard for each other over the years with constant interaction with each other.

Barriers

It has generally been a smooth sail for KPAMRC despite facing road blocks now and then. All in all it has been a very positive growth.

It has been one of the aims of KPAMRC to work with other disability organizations for the common cause of welfare and rehabilitation of persons with disabilities. While working of and interacting with other NGOs there were in ego clashes. Discussions at length and appreciation of each others point of view has helped to resolve the issues.

Most important among the handicaps in the growth of the Association is the lack of involvement of younger parents. Efforts in this area have not yielded much result. Once in a way a parents shows interest but it is short lived. The Association fully appreciates, the commitment of the younger parents towards their families. It also understands that they being the bread earners of their responsibilities towards the family are very important.

The Association also appreciates that being young one has the attitude of concurring the world. Unfortunately, the efforts of the Association to dispel this myth has not proved successful. May be this issue is not confined only KPAMRC by the entire universe. It is here networking at a higher level to workout modalities and techniques to overcome this major hurdle is required.

Finance is another area which retards the growth of the Association. Occasionally, frustration creeps in. Interaction amongst parents and like minded people along with the reworking of the programme gives way once again to buoyancy and optimism.

Future Plans:

The Association has drawn up ambitious plans for further growth. Among them the enrolment of the more members. It has planned to increase the membership by at least 10 fold during the next five years. Supporting parents to start parent associations both at district and taluk level is another activity. Networking of association working for the same disability and networking with other disabilities at three levels taluk, district and state is also an important point in the plan of action.

One of the major future plans of KPAMRC is to have its own facility which will house the teacher training programme, library and a big auditorium, counseling and guidance centre, day care centre, vocational training and sheltered workshop, respite care, and facilities for research all under one roof in Bangalore.

Empowered, Enabled, Effective-Caring for the mentally handicapped

Pramila Balasundaram,
New Delhi.

Introduction

Mental handicap is not a health issue in the usual sense of the term .It is a complex blend of many factors not the least being the impact poverty makes on the presenting disability. When Samadhan began in Dakshinpuri ,the lack of established support systems and health infrastructure were evident. Given the characteristics of a resettlement colony the most urgent need seemed to be to dispel the superstitions and myths, which surrounded the fact of mental handicap. Puppet theatre, which translated our message into lively dialogue and action, was our preferred way of reaching out to an uneducated community and was an excellent source of entertainment and information .The impact was far reaching. .

Begininings

Our first service seekers, motivated by our puppet show were of course the mothers of children with mental handicap. Just being available and listening patiently brought us a rich harvest of enthusiastic and willing women. In these women I had a strong and motivated support group. Their skills and talents though unutilized were critical resources already present in the community. These women had the time for child rearing. There was a strong sense of family kinship. They had the potential to contribute financially towards their families but had never had the opportunities to develop this. I was also gradually realizing that a heavy dependence on highly qualified professionals was unrealistic. We had to devise ways to survive but with the necessary professional and technical inputs incorporated into our services. This resulted in the establishing of a Rehabilitation Clinic and professional consultancy was made available of fixed days and times. But for the services to be established it was the community women who formed the core group and the backbone of our service delivery. Interacting with these poor uneducated women and mothers from the target communities made it clear that it was *these women who should eventually own the whole initiative and investing maximum time and energy in their training become priority.*

Understanding the needs

Before any formal training could begin however there was need for some statistics on the prevalence of mental handicap in the community. Although no formal research was conducted, daily interaction with the women gave us valuable insight into many aspects of their life as mothers of children with mental handicap. We found that mothers of children with mental handicap living in such areas of poverty were largely left untouched by the various programs of the government and had no knowledge of the many good policies they could access. Even if they were aware there was a general malaise. They were not interested since they knew that whatever benefits there may be, may never come their way. Mostly governmental policies and plans targeted women in general but did not cater specifically to women who were mothers of children with disability and /or with mental handicap. What was established strongly was their disinclination to actively seek services for their mentally handicapped children, if their more immediate needs for the basic necessities of life were not met.

This very basic exercise of compiling information helped us design training modules, which would provide different levels and types of training. Amrtya Sen, the Nobel Prize winner titles his famous book " Development as Freedom" and makes an effective case for a paradigm shift in our stereotyped perception of "development". He sees all efforts for development as a step towards " freedom ". Traditionally in India, and in many Asian countries the girl child is expected to obey her father when small and obey her husband and mother in law when she is married. So " freedom " to develop latent skills for the poor uneducated woman is far from reality .The women we identified had all been deprived of the right to education, to employment and lacked self confidence and a sense of self worth. So the first crucial issue was to give these women an opportunity to broaden their perspectives so that this freedom would be reflected in the way they lived and generally conducts themselves both within and outside their families. To provide these women with a basic level of economic and social security it was necessary to make them generators of income and prompted their training for income generation.

Empowering women

The operational strategy of Samadhan was based on the concept of the Self Help Group but with this difference. Our goals were to make our production of handicraft papier mache items a profitable venture such that each member of the Self Help Group, whether mothers, women from the community or persons with mental handicap or other disabilities would take home income of at least a thousand rupees each month. In realty the results far exceeded our expectations. While the tangible results were income gained, the intangible results discernable in both the women as well as the mentally handicapped were an increased self worth, more self-confidence, and a new strength to take decisions in their families. Becoming contributors towards the income of the family has given them a newfound ability to make their opinions and suggestions heard. The most impact was seen in the changed perceptions of members of the community towards the mothers and the women. The women we had trained to function as community workers and home intervention workers are now a respected group of people. They are respected for their new knowledge of helping families with mentally handicapped children, for their abilities to initiate social change. Hitherto these women had been seen as fit only for work inside the home and as bearers of children. The persons with mental handicap have also achieved a paradigm shift in their place in the community, since now they are perceived as contributors of income.

Training in income generating skills with the achievable goal of an assured income, adult education, capacity building, regular orientation and motivational programs as well as medical, rehabilitative and clinical services were under girded by supportive services to their mentally handicapped children and thus addressed the needs of both groups. Inducting adult persons with mental handicap into the SHG resulted in quantifiable benefits of this combined workforce making for better quality of products, faster production, inculcating punctuality, keeping to deadlines and training in a very basic administrative and finance management skills. It effectively utilized the potential of women to enhance that of the disabled and in the process empowered both groups in a resourceful and creative way.

Training was geared to suit mothers with minimal time at their disposal and women in general who were motivated to work with us. Mundane issues like the time the MCD provides water had to be kept in mind. Husbands had to be informed and mothers in law convinced of the bona fides of their daughters in law's time spent with us. Mothers, who were members of the Self Help Groups, were trained over many sessions to produce beautiful papier mache handicraft items. Income from sale goes back to them. The women in general were trained to conduct surveys for identification of disability, document results, undertake home intervention and became, without realizing ,it strong agents for a change in perceptions of the community about persons with mental handicap and of course of women. I narrate briefly the experiences of two women and an adult with mental handicap to highlight the results of our strategy.

An example

Kheema is forty years old and the mother of three children, two of who are severely mentally handicapped. She has beautiful memories of her childhood in her village at the foothills of the Himalayas. All this changed when she was eight years old and was married off to a boy ten years her senior. At eighteen, her husband was generally held to have been successful in life since he had a regular job in Delhi. Ganesh was born when she was eighteen years old, followed by Laxmi two years later. Both children were severely mentally handicapped. Kheema remembers being bewildered and unable to understand what was ailing her children and finally put it down to being cursed. Her husband on hearing of the abnormality of his children stopped sending her money until a third daughter who was normal finally motivated him to take her back to live with him in Delhi. The needs of her children Ganesh and Laxmi brought Kheema to the Rehabilitation Clinic of Samadhan. When her husband lost his job after an accident Kheema joined the Self Help Group since she had heard that even the illiterate and the poor were helped to learn a skill and earn an income .In Samadhan , Ganesh gets professional help from highly trained and experienced specialists. Kheema works along with Ganesh making paapier mache handicrafts The home intervention worker visits both Khemma and Ganesh in their home to guide and lend a listening ear .Today Kheema and Ganesh earn approximately Rs 1000 each and are able to run the house with their income .The father unemployed and physically disabled after his accident is increasingly turning to alcohol for solace. It is the uneducated woman and the mentally handicapped boy who are the heroes of this little story.

Kheema has learnt to read and write and is thinking of opening an account in the local bank .We plan to help her join a micro credit scheme we are exploring. Her daughter Laxmi is also working after being trained and her one non disabled daughter is happily married. Both Ganesh and Kheema are happy and have achieved what many thought they were incapable of doing. Kheema todayrealizes that it was lack of opportunities that were the real curse in her life and today she knows she is no longer cursed.

Another example

Usha and Payal are another mother daughter success story. Usha is herself a mentally handicapped woman. Payal, also mentally handicapped was discovered by the survey worker during a routine identification survey in the target community of Dakshinpuri It took the survey worker many days and months of effort to convince Usha that both her daughter as well as herself can benefit by coming to Samadhan .She had to visit Usha's home almost ever day for over a month. Usha has only the vaguest of memories of her husband but is more aware of the unfortunate repercussion of his passing away. Samadhan had to intervene on her behalf and negotiate with hostile relations who envied the house her husband had left her.

Payal , means dancing bells. When the survey worker first identified her she was almost four years old. She was fearful, unsocial, crying easily, with her speech restricted to a few single words and a clumsy walk .She climbed the stairs to her house on all fours. Usha lavished all her love and care as best she could but Payal needed more support from professionally qualified people. Usha as well as her mother in law were unaware of Paya'ls disability. They survived because kindly neighbors looked in to see to their welfare. One-day Usha's mother in-law decided to explore what Samdhan was all about. That was the beginning of an exciting adventure for both Usha and Payal.

Payal was diagnosed as mentally handicapped due to genetic causes .The Home Intervention worker visited once a week and because of Usha's mental handicap she took the help of the neighborhood children and formed a play and activity group using techniques of drama therapy. Payal, now four years old blossomed and took active part in the dancing, singing and painting the worker introduced. Payal has learnt to read, count, and dance. Her speech has improved and her social behavior has undergone a remarkable change.

When her husband passed away, Usha was confused and distraught by the harassment she suffered from the other members of the family. Samadhan workers intervened and confronted those who were trying to cheat Usha out of her home and brought her to Samdhan. . A month long training has made her into a confident worker and today she is the only one in the Self Help Group who makes and supplies the little marble sized balls which decorate so many of the handicrafts they make.(SLIDE 16). Another happy ending. Payal and Usha .The house is run by the income Usha earns making the papier mache balls and Payal has benefited by her years in Samadhan and has been placed in a mainstream school in class I where she is progressing well, is happy, accepted by both her peers and teachers and is a totally changed person.

Another example

Lal Singh is a young man who is hydrocephalic. He is 23 years old and came to us when he was seven years. His mother concerned that his speech was unclear and the large size of his head brought him to the clinic. The assessment and screening showed him to be hydrocephalic with mild borderline mental handicap and spasticity on the right side of his body. Admitted into the Special education Unit he learnt self-help and cognitive skills. Once he had become proficient at writing and counting he was sent to the vocational training unit .He is now an important and valued member of the Self helps Group. He earns about Rs 1000 a month and is the star decorator and painter of the papier mache handicrafts which the others make. He is the sole breadwinner in his family .His mother is uneducated and a housewife .His father in unemployed. From being seen as a mentally handicapped person and used to jibes of the community members about the large size of his head, he has achieved a paradigm shift and is today a respected member of the community since he is now a contributor of income. He is the unofficial management person of the Self help Group. We have also admitted persons with physical disabilities as part of our Self Help Group.

Lessons learnt

So the Self Help Group is an inclusive unit composed of persons who are intellectually and handicapped persons, those who are normal, the mothers of the disabled and women from the target community. This has become possible because we were able to provide services at multiple levels, to suit a variety of needs both for the women, the mothers of the disabled and persons with mental and other disabilities. This model of service delivery is now replicated in our other areas of work. We have found that using locally available resources of woman power to provide services for the disabled and training persons with mental handicap who are part of their families and community is the most effective, the most cost effective and the most easily replicable.

Conclusion

I quote Richard Bach, author of Jonathan Livingston Seagull .He says "There is no problem which does not come without a gift in its hands. It is for us to find those gifts" The women from our target communities who are now actively involved in our work, uneducated, poor and deprived in many ways and the adult mentally handicapped who form part of our work force are the gifts we have discovered in Samadhan.

End Notes

In this context of adopting development as a goal for empowerment of women it is estimated that women account for 497.74 million and represent 48.3 % of India’s total population. The Constitution of India confers equal rights and opportunities on men and women in the political, economic and social spheres. Many policies and programs have been put into action from time to time besides enacting and enforcing special legislations in favor of women. In fact, right from the very first plan initiated in 1951-56, the development of women has been receiving attention of the government but only in the sixth plan there was a shift in policy from welfare to development. However, while the impact of these various developmental policies, programs and plans have brought a perceptible improvement in the socio economic status of women, problems like illiteracy , ignorance , discrimination and violence continue to persist even today and this attitude towards women is particularly evident in our low socio economic communities.

Parent cooperatives in the care of persons with Mental retardation

Govinda Rao
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Beginning

Krishna Kumar an employee of a public sector undertaking, has become an enterprising person with lot of drive and initiative and is considered a leader by many a parent of children with mental retardation in Karimnagar District of Andhra Pradesh. People have seen change in him over a period which was due to his daughter who is having mental retardation. Eighteen years back, guided by National Institute for the Mentally Handicapped (NIMH), he started a vocational training center for the persons with mental retardation in a remote coal mining area. Others have supported the initiative. All of them are parents of children with mental retardation who received the rehabilitation services from the NIMH and who had the benefit of the unique service model of parent cooperatives, a self-help concept, just developed in 1980s.

These parents and many others before visiting to NIMH had fatigue, a fatigue that made them to be pessimistic, and resigned to fate as their efforts for treatment of their child did not provide a ray of hope of development. Every one ~~attributed the mental retardation of their child to `karma' as they find~~ delayed developmental milestones in their child who is not able to attend to the activities of daily living (ADL). It is a shock for them to know that their child has mental retardation and it is a condition of arrested or incomplete development of mind that is specially characterized by sub-normality of intelligence, thus restricting or causing lack of ability in performing certain activities in their life. This is owing to impairment in cognitive, emotional or behavioural endowment. One of the key abilities for human beings to lead an independent life is to take decisions independently which they unfortunately are not endowed with. These children do face difficulties in attending to instrumental activities of daily living (IADL). They also have difficulties in reading, writing and calculating as well as in co-curricular activities.

Krishna Kumar and his colleague parents are, now, satisfied as presently each adult is reasonably earning a livelihood by engaging in productive life. They manufacture stationery and printing items for supply to the Singareni Collieries Company Ltd. a public sector undertaking that is also a patron of the vocational training center. A total of 78 persons with mental retardation are engaged in this set up who also produce food items, vegetables, flowers, carpentry items and the like that are easily marketable. They have recently added a waste paper recycling unit to produce hand made paper. Krishna Kumar and 120 other parents guide many parents in that region.

Gadkari, Ramjogarao, Mustaq Ali, Pant, Sen, Murty, Prakash Raju, Sankar Raman, are few among hundreds of parent leaders, who organized parent associations under the guidance and training from NIMH. Currently there are nearly 200 parent associations in the country with a membership of over 40,000 parents. National Federation called PARIVAAR functions as a central organ for all the parent associations that provide constant and regular support to the families, which include emotional support, providing information about the condition and referral resources, information about government schemes, organizing conferences for parents to elicit the needs and difficulties to be placed before the government. They also create public awareness, undertake programmes for community support and contribute to public policies.

NIMH, established in the year 1984 as an autonomous organization of the Government of India, has the mandate of developing state of the art service models, developing human resources and undertaking research and development in the area of intellectual disability in the country. It has realized that not only their families need support in the process of developing their children but they too have to become the partners of the service provision and other related issues. They have to be empowered to take care of their needs due to the presence of a child with mental retardation.

The families of the persons with mental retardation, particularly the parents and siblings do have needs different from others, which cannot be segregated from the special needs of the children with mental retardation, if the intention is to extend proper rehabilitation services. Some of the important family needs are information about the condition of the child, management of the child, services available, vocational rehabilitation, marriage issue of the child, emotional needs, social acceptance of the child, government benefits and legislation, etc. The needs of the families having a child with mental retardation have a bearing on the rehabilitation services of the persons with mental retardation.

Parents with varied backgrounds have their own strengths to build social capital of a self-help group, which is always greater than the sum total of the individual members. Parents know their children better than anybody else and they need to continuously do the exercises, therapies and other inputs at home beyond the school hours. Therefore they need to be given training for the follow up of the interventions at home situations. The families are therefore given appropriate training to take care of the specific needs of their children at home. They are also provided orientation about various aspects concerning the financial and physical support available through government schemes. Such training programmes are conducted for a group of parents in which the parents are able to develop close affinities with each other, strengthen their capabilities to cope with emotional feelings, learn from each others' experiences and ideas and work towards capacity building.

Using the matrix model NIMH developed and organized group parent training programmes on the basis of child characteristics and parent demographic features, which helped in enhancing the confidence of the parents and siblings of the persons with mental retardation. NIMH trained about 35,000 parents since its inception. Focusing on the needs of the information about the child's condition, emotional aspects, health related issues, referral information, future of the child, the training module aimed at building capabilities of the parents in becoming an active partner in the development process of the child. The ultimate goal of the rehabilitation services for the persons with mental retardation is to ensure independent living in the community on the basis of equal opportunity, protection of rights and full participation for which the Government of India is committed through legislation called the Persons with Disabilities (equal opportunity, protection of rights and full participation) Act. This was followed by a strategic approach of organizing self-help groups on the principles of common linking factors e.g. work place, location, age of the person with mental retardation, etc.

Reaching the training to the families in the rural areas is a gigantic task for few select centers. Waterfall effect can take place when master trainers are available in the field. Therefore a training package for master trainers has been designed and developed and it is expected that the parents in the unreached areas can have the benefit of the necessary training through hundreds of master trainers.

Some of the parent associations have also assumed the responsibilities of training the families, apart from organizing special schools, vocational training and many other programmes for the empowerment of the persons with mental retardation. There are some innovative parents having become special teachers, psychologists and therapists and some have taken up social work as their profession to extend support to other families. Training also takes care the need for informed choice of the parents in the matters of services to their children and they become quality conscious. After the training the family members are able to actively participate in teacher-parent meetings. Another method of training the parents is through the community programmes in which the anganwadi workers are oriented about the mental retardation. NIMH has organized training programmes covering several thousands of anganwadi workers at grassroot level in the villages. Demand for such community workers training is increasing due to public awareness.

Families who have organizational support like parent association, a special school or a vocational training center are able to plan, develop programmes and implement the same for the overall development of the children. These activities are done in consultation with professionals engaged in such organizations. Parents without the back up of organizations are able to continue the home-based training of their children under the supervision of the professionals. Parents who receive referral information from anganwadi workers (GRWs) at the community level are able to access the required services at the designated places.

In addition, package programmes have been developed for the siblings and other family members, as research evidence indicates that siblings and other family members play an equally important role in the life of a person with mental retardation. The outcome of the efforts of the master trainers, the trainers and empowerment of the siblings and family members are aimed at enhancing the quality of life of children with mental retardation. This has, in turn, a direct impact on the quality of life of the parent and the other concerned persons. In the case of children having mental retardation, it is the parents, siblings or the guardians who are their advocates to ensure equal opportunity, protection of rights and full participation.

The parents, having realized the need for a common platform to prioritize their needs, through the Parivaar, represent to the appropriate Government and other agencies for consideration of various programmes and schemes, which will benefit the empowerment of the persons with mental retardation. The result of their endeavours is encouraging as they have found place in various decision making bodies. The biggest need of a parent, which is yet to be answered practically, is “What will happen to our child after us?” This is the ultimate challenge in the area of mental retardation. NIMH facilitated to bring out the legislation for the care of the persons with mental retardation through the National Trust for the welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999. The parent associations have played a significant role in garnering the required support for the National Trust to become a reality.

They have representation on the Board of National Trust, which is primarily meant for supporting the persons with mental retardation and other disabled, through several programmes and schemes. One of the key objectives of the National Trust is to provide guardianship and also extend support for care of the persons with mental retardation even after the death of the parents. Despite much progress is desired in this aspect, a beginning in this direction itself is a welcoming feature. Hopefully, in due course, the programmes of National Trust may become very effective with the active participation of the parent associations. National Handicapped Finance Development Corporation Limited (NHFDC), a Government of India enterprise, has viewed the parents as the extended clients for financial assistance at subsidized rate of interest in employment generation ventures. In the formulation of National Policy the active participation of parent associations is noteworthy. Through this process, the parents have been empowered and they have become the advocates and activists for their children, not for their individual benefit but for the common cause.

NIMH supports PARIVAAR in organizing national parent meets since 1993 and till now 13 such national parent meets have been organized at different locations in the country in which more than 200 parent representatives annually meet to take stock of the programmes and schemes operating in the country and discuss not only policy issues but also the process of delivering the services. Some of the themes covered in these annual meets are social security, human rights, vocational training and employment, role of parents in the care, problems faced by parents and expectations of parents from professionals, strengthening their families, National Trust and NHFDC functioning, promoting parent groups, etc. An important outcome of these national parent meets is the proliferation and strengthening of the parent associations and better understanding between the parents and professionals.

The families have taken keen interest in showcasing the vocational skills by their children in the national special employees meets annually organized by NIMH since 1995. Participation in these programmes has been very encouraging. More than 200 special employees participate in these meets and till date 170 different trades have been demonstrated. Similarly in sports and games the parents take considerable interest by making their wards participate in special olympics and sivus games. They also encourage their wards to participate in abilympics. In a novel initiative undertaken by NIMH the performance of the persons with mental retardation in the national festival of music and dance for persons with mental retardation in 1999 has been very splendid and spectacular.

A team approach of the professionals has been instrumental in the development process of the persons with mental retardation. These professionals are from medical, rehabilitation psychology, special education, physical therapies, speech therapy, community rehabilitation and project management, who continuously strive to provide state of the art rehabilitation services. They undertake research and development activities to improve the delivery of services by making the process child centered and providing teaching and learning materials. Preparation of training materials for parents and making it available is a constant endeavour of most of the professionals. Parents are encouraged to participate in the case discussions in order to bring in improvement in the rehabilitation programmes of individuals. It is the support of professionals, which enable the parents to create public awareness, enlist the community support and bring convergence of various governmental activities towards the empowerment of the children with mental retardation. Professionals help the parents in setting up educational, vocational and placement programmes for their wards. Professionals have organized capability enhancement programmes in care giving through National Trust and NIMH. The relationship of parents and professionals has blended in a congenial atmosphere for the amelioration of the condition of their wards.

Rehabilitation Council of India (RCI) a statutory authority of Government of India, designed to standardize the human resource development programmes has in a great way promoted the training centers in the country with the help of NIMH. Currently more than 12,000 professionals in the area of mental retardation are on the live register of RCI. A plan is on the anvil of RCI to launch online training programme for the parents on a modular basis, which expectedly will cover larger number of parents through out the country. Since inception NIMH trained about 95,000 professionals under continuous rehabilitation education programme, which also focus on client delight particularly the parents and their wards. As a result of various research programmes NIMH has produced manuals, teaching and learning materials, books for professionals, public awareness materials. The books on self-help skills, social skills, vocational training, employment, guide for parents, material for early detection and intervention, home instructions on physiotherapy and on communication and language development are very useful for parents and families. Training materials flip charts, posters, manuals of village level social workers, teachers are useful for the grassroot level workers. Various topical issues and themes become the agenda of national and international conferences organized by NIMH.

Families usually are burdened with financial and physical stringencies which create problems in their campaign activities to promote self-help groups. Constant training of the members of parent associations is not feasible due to costs involved. Net working and collaborative strategies often become victims in positioning of parent organizations. They also face inadequacy in the professional support at their place of stay. The main concern of inclusion has yet to take its roots into the society, lack of which often causes constraints in the process of self-help capability building. Although reaching the unreached is given a thrust by the Government of India, community based rehabilitation programmes need to be intensified. Continuous training of the parent associations on capacity building and creating public awareness on campaign mode will help empower the families of persons with mental retardation. Parent associations some times face difficulties with the local NGOs who perceive them as a threat. Professionals have a great role in removing these roadblocks.

It is no doubt that self-help groups have a larger role in the empowerment of the persons with mental retardation. Strategic plans need to be at place to promote parent associations as per the objectives of Biwako Millennium Frame Work for Action towards an inclusive, barrier free and rights based society for persons with disabilities in Asia and Pacific and as per the National Policy of Government of India. There is a need for register of families and the persons with mental retardation at all levels viz., village, block, district, state and national level. Parent associations can facilitate in creating such registers which will help in better policy formulation for improvements in the future programmes.

Conclusion

Opportunity to every member of parent associations for articulating their views and needs can be made available if the spread of parent meets cascades down to the district level and for this, programmes need to be developed such that every parent's voice is heard through conferences and seminars to be organized at various levels before the national parents meet is organized. Every parent association needs to be provided training on capacity building. Schemes on social security if developed will strengthen the families. National Trust is making efforts to improve upon the existing programmes and develop new programmes based on their experience and feedback from the parents and professionals. Similarly, NHFDC may, after review of the effectiveness of the present financial assistance drawn by the parents for income generation by the persons with mental retardation, improve upon the existing schemes. Impact studies of the existing programmes related to families will have to be undertaken. Evaluation of the functioning of the parent associations will help in the improvement of their future performance.

SECTION-V

FAMILY MEMBERS OF CHILDREN WITH LEARNING DIFFICULTIES

Parents as change agents for children with learning disabilities- the ALDI, Kerala experience

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Thrissur.

Background

Kerala is the southernmost state in India, with a population that is largely middle class, and largely well educated. Women comprise 51.42% of the population. The state achieved 100% literacy in 1990, and the ratio of male to female literacy in the state in 2001 was 98.4% for males and 87.72% for females. The state has a good network of schools and health care facilities. The mortality statistics are good, and health indices compare well with those of developed countries.

Parents in Kerala place great emphasis on education, and there is a high demand for professional and technical degrees and diplomas. These are seen as a gateway to employment and the path to social and economic upliftment. A child who performs poorly in school is a source of distress to his parents. Such children are sent to expensive tuition classes, and this compounds the problem they face without touching its root cause.

The often quoted, and as often disputed, "health paradox" in Kerala reflects high levels of morbidity in contrast with low levels of mortality. With the availability of good obstetric care, the infant survival rates are good, while the "soft spectrum "of developmental disabilities is on the rise. There is some evidence to justify this observation. The data from the Child and Adolescent Psychiatry clinic at the Thrissur Medical College (Kishore et al 1998) had shown that of the total children presenting to the clinic, half had some form of developmental disability and of them 56% had Specific Developmental Disorders of Scholastic Skills, commonly termed Learning Disability (not to be confused with the use of this term in the UK where it refers to Mental Retardation). A recent survey has put the rates of Learning disability at 9.7% for children between the ages of 5 to 16. (ICCONS, Kerala) Children who have a Learning Disability fall into the "soft" disability category, which essentially means that they have problems with their learning, not obvious at birth, manifesting as they start school or sometime later. The difficulties they have are with reading, writing and /or arithmetic, with reading difficulty (dyslexia) being by far the commonest.

Children with mental health problems access the health care facilities at various points, often through Paediatricians or directed by their teachers and, rarely, directly to the Mental health department. Kerala did not have many Child Mental Health care facilities. In 1990 there were only three such centres in the state, two being in the private sector. These centres could cater to the more difficult and enduring mental health problems, but facilities for management of learning problems were scarce. A single Psychiatrist, at times assisted by a Clinical Psychologist, and occasionally by a Social work professional, often ran the centres and other support services were nonexistent. As a result, children with learning problems could not be offered services beyond simple diagnosis, receiving scant help from their teachers, and often little help from overworked professionals.

The rest of this chapter is broken up into phases to help the reader understand and put into the right perspective

Phase 1:

It is in the context described above that the voluntary organization called the Association for Learning Disabilities, India, (ALDI for short), was formed at Thrissur in Kerala. It started with two parents searching for help for their child with a Learning Disability - this resulted in the coming together of a few professionals (two Psychiatrists, and a Clinical Psychologist), teachers and parents who had an interest in starting such services. The first few years were spent in conducting awareness programmes within schools and among the general public, the process helping the members of the association learn and understand more about the problem. Two among the group, teachers with a basic interest in innovative teaching, volunteered to get themselves trained in Remediation techniques which were the backbone for the management of these learning disabilities. There were only two centres in the country at the time offering very basic level training in remediation. The Madras Dyslexia Association at Chennai and the Alpha to Omega centre at Chennai held courses that ran for two weeks and taught the basics of Remediation. Learning Disabilities involve Language skills, and this training was limited to those disabilities in English. After the two teachers were trained the Association set up a centre at Thrissur offering remediation for children with Learning Disabilities. The Child and Adolescent Psychiatry clinic functioning at the Thrissur Medical College served as a referral centre for these children. There was good liaison between the two.

The process received a shot in the arm when the Association was requested to assist the District authorities in the Total Literacy programme, in an effort to get school dropouts back to school. A report prepared by the Kerala Government's General Education Department in 2004, titled *Educational Statistics since Independence* indicates that the dropout rate in the 12,271 schools in the state, where over 48 lakh children study, was just 1.5 percent (compared to a national rate of 48%). According to the document, in lower primary schools (classes I to IV), there is one teacher for every 30 students, while in upper primary (classes V to VII); there is a teacher for every 29 students. The Total Literacy Programme, largely successful, did help rehabilitate a significant number of children and gave us certain valuable insights into the situation.

Among the Dropouts assessed by the team from ALDI, few had mental health problems, the major disability being Mental Retardation. Surprisingly, none had a Learning disability. The fairly obvious conclusion was that of the 10% of school going children who could be having a Learning disability, few drop out of school, while the large majority stayed within the system receiving little help. If these children were to be helped, programmes would have to be focused within schools, facilitated by the teachers. The Total Literacy programme, a series of awareness seminars, write-ups in the local newspapers (that are read by thousands), and a few radio and TV talks served to initiate a discourse within local society, the result of which was an unprecedented increase in the rate of referrals to the ALDI centre and to the Child and Adolescent clinic at the Thrissur Medical College. There was an urgent need to increase availability of services. The provision of services would have to change from being centre based to one available in the community, preferably teacher-focused within schools, if a large number of children were to benefit.

Phase 2:

By 1994, the membership of the Association had grown to 25, the majority being parents, with four Mental Health Professionals and a few teachers. The structure of the Association was made more formal. It was registered as a voluntary organization under the Kerala Scientific and Literary Charities act. The parents within the organization used their resources in helping set up and conduct awareness programmes in schools. They also assisted in the day-to-day running of the Centre. Trained Remediators and Professionals ran the clinic within the centre, and their liaison with the Child and Adolescent Psychiatry Clinic at the Thrissur Medical College was good. Through a process of evaluation, refinement and application we were able to develop a comprehensive programme in Malayalam for Remediation.

THE MODELS

In 1994, the Kerala Panchayath Raj- Municipal Act came into place, opening up a great opportunity for people to participate directly in the process of governance at the local self-government level. The first elections to the three tiers Panchayathi Raj set up were held in September 1995 and the Panchayaths came into being on the 2nd of October. A comprehensive government order in September 1995 transferred various institutions and staff to the three tier Panchayathi Raj Institutions. The budget of 1996, detailed the grants-in-aid, and the schemes transferred to the local bodies. Thus the allocation for the local bodies was seen as an independent subset of the State Budget giving it the stamp of legislative approval and protecting it from the vagaries of executive decision-making.

There was a change of Government in May 1996 and the Left Democratic Front Government embarked on a policy of massive decentralisation. Two landmark events helped in enlarging and deepening the process of decentralisation. First was the launching of the People's Planning Campaign on 17th of August 1996. This was spearheaded by the State Planning Board in partnership with the Department of Local Administration, with the full association of political parties, non-government organisations, professionals and elected members. It went beyond a government-sponsored programme and soon assumed the nature of a movement. It succeeded in harnessing public action for participatory planning at the grass roots level and created not only a favourable environment for genuine decentralisation but also built up a powerful demand for radical reform. The result was a paradigm shift to a people-centred, bottom-up approach to planning and development giving a direct and continuing role to the people. The People’s Plan Movement was aimed at empowering people by allowing them the freedom of choice in the selection and formation of development projects in accordance with their local situations. Thus a number of panchayaths had money and the freedom to decide how they were to develop the area and what sort of service they required.

The Idukki district of Kerala (with a total population of 1,129,221 of whom 8, 82,458 were literate) is formed of hilly tracts within the Sahya Mountains and boasts of having the largest area under forest in the state (2, 60,907 hectares). Kamakshi is a rural, agrarian based village in Idukki district. The Kamakshi Grama Panchayat proposed a scheme to look into the causes of scholastic backwardness among the children in the panchayath.

ALDI was chosen to set up a programme to achieve this task. We proposed a 2 year project whereby the Association would train a group of local school teachers in identifying causes for scholastic backwardness in children, undertake a brief assessment and start remediation techniques. A training Module was developed, and 12 teachers opted to be trained. The programme involved 2 days or 18 hours of training, once a month, the trainees being given tasks to be achieved in between sessions. The Professionals and the trained Remediators in the Association did training at Kamakshi. A public meeting was held to explain the process to the people, and separate meetings were held with teachers and parents within schools. The programme created an immediate impact. Teachers and students participated actively, and there was a perceptible change in teachers' attitudes to scholastic backwardness in children. At the end of two years when the project came to an end, we came away with a few new insights.

1. A subtle shift of paradigms from Learning disabilities to Scholastic backwardness was required. The larger issue of scholastic backwardness, better understood, more appealing to teachers and administrators, was made the focus. We designed a flowchart for analysis of causes leading to poor scholastic performance.
2. In Kamakshi Panchayath a large number of children were unable to read and write in class 6, 7 and upward since they had not acquired the "Basic Skills" or "Readiness Skills", often termed the building blocks for later learning. This was a major cause for poor scholastic performance among children in that panchayath. We designed a remediation format for these children and this was applied there.
3. The teachers we trained were well motivated, and worked hard to acquire the necessary skills. All teachers, in training or otherwise, easily understood the concepts of scholastic backwardness, and this understanding would be useful in screening children. Yet these teachers were hesitant to apply their skills unless supervised. Idukki District did not have Mental Health professionals trained in Child and Adolescent issues, and therefore supervision was difficult and hence after the project wound up, services deteriorated rapidly. The teachers in training were interested in becoming counsellors for minor mental health problems, and they often requested help for their own personal problems.
4. Stepping out of the protective confines of the clinic was anxiety inducing for the professionals involved, to say the least, but the bigger issue was the ability to demystify technical jargon and speak a language teachers understood.

Phase 3:

The insights gained from this project were applied in the next. In 2000, ALDI was invited to provide technical expertise in a project in Vilwattom Panchayath within Thrissur District, (population of 2,975,440 of whom 1,422,047 were males and 1,533,393 were females) set up jointly by CRY (Child Relief and You – a Mumbai-based NGO) and the Department of Social Work, Vimala College (a local womens' college in Thrissur). The primary aim was to train teachers in screening children with scholastic backwardness, and to increase their awareness of the causative factors. The teachers used a screening tool, which combined the Rutters' Proforma (a screening tool used the world over to

identify mental health problems in children) and ALDISS (Association for Learning Disabilities India Survey Schedule), a screening tool developed by the Association, in Malayalam, the local language, containing items specific to Learning Disabilities in Malayalam. Children who were screened by the teachers were further assessed by a trained team of "Special Educators", trained by ALDI to assess and undertake remediation in these children. In addition, each child was seen and assessed, and a diagnosis assigned, by a Mental Health professional. The programme ran well, with many children being screened and receiving fairly good quality of care, and the parents were satisfied at the levels of care achieved as also the care that was taken to ensure that no stigma was attached to these children. The Special Educators had ongoing support from the Association, developing surprisingly high-level skills in remediation, surprising since none had been teachers or educators earlier. To their credit, even after the Project was disbanded, many still retained their interest in Learning disabilities and maintained contact with the Association. The Panchayath had suggested a possibility of these Special Educators being absorbed into the schools, but that was an idea that sadly did not take off. The programme came to an end in 2 years but unlike the previous one, children identified and undergoing remediation were absorbed into the caseload of the Association, proximity of the Panchayath to the ALDI centre being the main factor.
The insights gained from this project increased our confidence in the "trainability" of people with no background in education in undertaking basic remediation of children with learning problems. This, we realised, was being applied in the Association's training programmes over the past few years. We also realized that "Special Educators" would have to be appointed by the Government in order to sustain their efforts (which did eventually happen). A third, and perhaps most important, insight was that continued support is required by those involved in remediation, both in training and for personal issues.

Phase 4:

The third and current "Model" draws heavily from the insights gained from the previous two. ALDI had been training a few parents in helping their children, a form of carer support necessitated by the paucity of trained Remediators. Those parents who expressed a desire to be trained in remediation were taught simple techniques to support their child's learning. The "training" was supplemented from time to time by insights gained from the projects, often modified to suit the needs of the trainees. It became clear that a group format worked best. In groups discussions and ventilation, helped in building group processes. These processes were interesting to observe and now form the main feature of our training. The resultant strong bond between the trainees contributed to the strength of the Association. In 1998, there were about 4 groups in training, mostly parents or other carers, and a few motivated teachers. The demand for such groups began to increase in subsequent years, necessitating introduction of modules, format and structure to the training. We discovered that most parents needed a simple psychological model to understand behaviour, the child's and their own. The first few groups consisted of people who had some form of training in Transactional Analysis, a psychological theory popular among the lay public in Kerala. The facilitator of the group was an individual trained extensively in this scheme. Hence almost by default Transactional Analysis became the basic format for group processes, being modified as and when needed, the essentials being retained.

In 2002 there were 20 groups in training in various parts of the state, the modules being similar. All trainees underwent training through the group format on 2 days once a month for a period of 20 months, the total hours often amounting to 350. Part of the time was spent in actual hands-on remediation of learning problems in their own child, supported by trained remediator's. The syllabus included a brief outline of the various theories of Learning the focus being on understanding learning problems their own child had, in relation to these theories. Trainees were taught to analyse learning problems and this was done using a simple algorithm given below. Learning problems were understood in the context of family dynamics, problems within the child and issues at school. We had developed a simple assessment format that looked at the child's learning problems from different perspectives, evaluating strengths, weaknesses, and looking at opportunities in learning. This format assessed memory, learning styles and evaluated errors made in learning. The parents (trainees) assessed their own attitudes to the child's learning problems. The trainee, in assessing other children later, used this assessment format. Training included a review of the assessment tool, the main aim being to look at its usefulness and whether it needed modification. Following assessment each child was given an Individual Educational Programme, which included a package for remediation and outlined short term, intermediate and long term targets. The parents (trainees), the child and the Special Educator (the facilitator of the group) and the mental health professional would discuss a time frame to achieve these targets. Training in Remediation techniques formed the main hub around which management revolved. The Association had formulated a remediation programme (called the ALDI remediation schedule), these are techniques used in remediation, some of which had been designed by the team. The trainees used the remediation package in helping their own child and a total of 20 children. The details of each child were discussed within the group. Towards the end of training the trainees were asked to make a presentation to a lay audience, and write a brief article on one area of learning in any magazine. The training was done in groups of 10 to 15 people. The first few sessions were devoted to understanding the basics of learning and also discussions about their own children. These discussions were in the form of sharing of distress and led to bonding and a feeling of belonging. This was the major strength of the group format. We did use formal learning techniques such as lectures, but the group processes were often preferred over the others. The same person, an individual trained in remediation initially, who had been with the organization since its inception, and was a teacher, led the groups. The syllabus was discussed within the group and modifications allowed to suit the group. This "open format" style is still followed. As the sessions progressed there was enormous sharing of information, support for emotional issues, and surprisingly little competition or within-group rivalry, the bonding, as said earlier, contributing to the growth of the group. The groups in their turn contributed to the growth of the Association.

One of the issues frequently debated was whether the trained Special Educators or the trainees were competent to make a “diagnosis” of Learning Disability. The Professionals within the group often faced considerable flak from their colleagues outside about allowing a dilution of standards by training lay people and allowing them to diagnose complex problems. Here it is necessary to elucidate the thinking of the group. Diagnosis or labelling of the problem was not something the trainee or the Special Educator did, they were well aware of the limits of their expertise. The child who is referred to the centre was seen by a Mental Health professional at some point of time and evaluated (please see the algorithm given at the end) and formal diagnosis was assigned. The Association believes that waiting for this formal diagnostic label would often mean that the child did not get help. Hence all children are first seen by the Special Educator and evaluated. This includes an evaluation of educational problems and behavioural problems. A detailed description of these is made and an evaluation of the child’s strengths and weaknesses. An Individual Education Programme (IEP) is then formulated and includes immediate, short term, intermediate and long term goals. Time frames to achieve these are defined and an action plan put in place after discussion with the parents. Remediation is begun as soon as an IEP was formulated. If the child needed a certificate in order to receive concessions in examination then a competent Professional did this. Most of our trainees were parents of affected children and hence did not need to be told that their child had not received a formal diagnosis. This is one area, of many, where the partnership between the professional and people helped arrive at decisions that were in the best interest of affected children.

The trained “Remediators” (these are the parents who had completed their training) were also capable of to help children with minor secondary behavioural problems. The combination of severe learning and behavioural issues in the same child was a reason to seek professional assistance. This delicate balance of when to refer was a frequent point of discussion at common “case conferences” during training, the decision being to refer when in doubt. All children assessed by the Remediators were seen by Mental Health Professionals, and the waiting lists were often long. Having a “provisional description” of

Case Vignette:

AB was a 10-year-old boy who was brought to our attention because of his behaviour. He would throw tantrums and refuse to comply with simple tasks. His parents were extremely distressed. He was brought to the Child and Adolescent Psychiatry Clinic at the Medical College where it was noticed that most of this behaviour centred around the times when he had to study or when he had to go to school. Examination time was often a nightmare; one parent took a month leave to ensure that the child prepared adequately. Supplementary analysis showed that he had a Specific Learning Disability. The child was referred to the ALDI clinic. At the ALDI clinic the parents were made aware of this link between his problems in studies and his behaviour. They were made to observe this for themselves by maintaining a diary of the child’s behaviour and their responses.

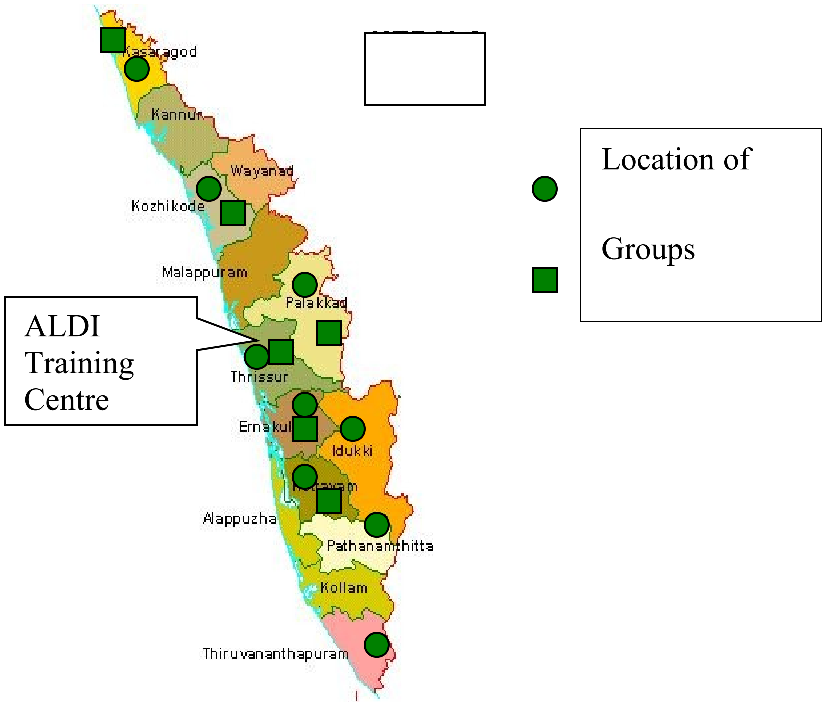
Using the ABC (Antecedents-Behaviours-Consequences) paradigm, a programme was chalked out by the Professionals, the Special Educator and the Parents about how to deal with this problem. Once an agreement was reached as to how the parents could change their responses, a series of desired consequences were written up. The child was involved at this stage. The parents met regularly with the special educator to monitor progress and to modify and correct responses. The special educator discussed the issues with the professional who in effect indirectly supervised the process. The child’s learning problems were assessed and an IEP was formulated.

The costs of training were deliberately kept down, and often a few deserving parents were supported with fee waivers. An average course of 20 months cost Rs 4000, including course material. In 2005 we had 32 groups running, the cost of remediation for an individual child being calculated at Rs 1200 a year (Kishore et al 2005).
This model has sustained over time, being surprisingly simple, cost effective and including carer support. In 2005, two professional organisations in Kerala, the Indian Association of Pediatrics and the Indian Psychiatric Society, Kerala State branch expressed an interest in emulating this model statewide. This project was stimulated out of the interest shown by some of the Office bearers of the two Associations who had an interest in Learning Disability. In areas where ALDI did not have groups running, the two Associations agreed to gather together interested parents and stimulate the formation of a group. The Associations agreed to bear the expenses and provide space to run the group. The training would be by the trainers from ALDI. The project took off well in a few centres and a couple are still running. The process is currently under review.

Professional- People partnerships

In 2002 the Association had about 200 members, most of them carers and mostly women. Involvement of professionals within the organization has been direct, some from its inception, others offering services when required. Most have been from the field of mental health, Psychiatrists, Clinical Psychologists, a few Speech therapists, and occupational therapists at times. The Association has always had non-professional leadership, individuals with a strong commitment to the cause and guiding its philosophy. As years progressed, the involvement of professionals has lessened, their involvement being at the policy levels and in designing courses and conducting evaluations. For the Professional in the Association this blurring of boundaries came gradually over years of working together. It involved a gradual development of trusts and respect in the competencies of the people in the organisation. When the Association was formed in 1990, the professionals within the group knew little about remediation or management of Learning Disabilities, their knowledge and skills lay in diagnosis and evaluation of Learning and behavioural problems. Hence in many areas the two, the professional and the non professional learnt together, sharing information and learning from each other. This process of learning together contributed to the development of respect and confidence. People trained by the Association and its members conduct the day-to-day running, training, group activities, and awareness programmes. Professionals help lend “visibility” and “legitimacy” to the organization. Psychiatrists have been with the Association as founding members. They have contributed significantly to its growth by providing guidance, designing and conducting courses, evaluation, research and often wearing multiple hats when the need arose. Clinical Psychologists were the benchmark against which the assessment of a Special Educator was compared. The assistance of Speech Therapists was helpful when the odd situation arose where Language and Learning disabilities were indistinguishable in a given child.

The people within the Association come from all walks of life, teachers, doctors (from all disciplines), housewives, engineers, farmers, all being carers of children with Learning Problems. Their level of involvement depended on motivation, their ability to spare time, and the level of skills acquired. Some people work full time as Remediators involved in remediation of children who came to the centre at Thrissur in Kerala. Others have had something to contribute to the growth of the Association. All of them have undergone the basic training in assessment and remediation. A few of them have expressed a desire to take up training, and the Association designed a higher course to accommodate this wish. These Remediators who have in a sense become “Master Trainers” or Special Educators have gone on to start ALDI centres in their own districts.



The time put in was voluntary, and there were no salaries paid. The spirit of voluntarism has been sustained, helping to keep costs to the bare minimum. The relationship between the professionals and the others within the Association has been mutually satisfying, the process of learning together has fostered mutual respect for the others skills and knowledge.

As more people came to know about the groups, demands came from different parts of the state for training. The Association has adopted a policy of taking training out to the people, which continues to be followed. When a sufficient number were registered (each group was around 15 to 20 people) the trainers would go to the area and begin training. We have found that this keeps the costs down and improves attendance. The rate of dropouts from training is about 15-20%.

Here it is necessary to address the gender issue in training. A large number of the trainees are women – about 65% at the last count. In comparison with many other states, women in Kerala are highly literate and educated. According to the 2001 census, they outnumber the male population 1058 to 1000. The economic marginalisation of women in Kerala has drawn considerable attention as a process providing an impediment to improving the status of women (Kumar, 1994; Arun and Arun, 2001). For example, while the female work participation rate in India increased from 19.7% to 22.7% between 1981 and 1991, in Kerala the ratio declined from 16.6% to 15.9% (GOK, 2003). However, it is interesting for a keen observer of the Kerala scenario to notice the radical shift now taking place in the socio-economic and political status of women by the formation of women's' self-help groups. It is no exaggeration to state that it is a silent revolution in the making. The women's' self-help groups have provided them a new sense of self-respect, put in place a voluntary but efficient organizational system and infused new strength in them. The new found economic freedom, organizational strength and exposure to an outside world other than their traditional domain, is slowly leading them to micro enterprises that are helping them in caring for the family and in a wider sense, society. The trainees in ALDI, a number of them women, educated housewives, keen to help their children and keen to contribute to the support of others, have been our major strength.

Influencing Policy

Phase 5:

This was never easy and initially no attempts were made to contact officials within the educational department. When the Department of Education was in the process of appointing Remediators to a few Government schools in 2000, the Association was asked to design a programme to train the Master trainers in Block educational panchayaths, who would then go on to train Remediators for appointment in schools. A 6-day training programme was designed and conducted at Thrissur, which began a long standing link between us and the Government. The Association was also involved in further training programmes conducted by the Department of Education from time to time.

The opportunity to influence policy came through persistent efforts made by individuals and their political connections. Initially the Educational department was averse to the idea of concessions for disabled children, and when the Integrated Education of the Disabled Child (IEDC) was formed, averse to extending these concessions to children with Learning Disabilities. However persistent efforts and letters from parents of affected children had its desired effect. The Association was invited to chair a session where the rules were formulated to include children with Learning Disabilities in the IEDC curriculum and offer them concessions in the Public exam.

Advocacy-Phase 6

At training sessions parents often complained about how their child was discriminated against in the 8th class, where the "filter " for the 10th class exam began. A child's poor performance in the 7th class was often a reason for parent administrator arguments and being issued a Transfer Certificate, in other words being asked to take their children elsewhere. There were instances of children being disallowed concessions given to the Learning Disabled, or not being told about them, at times due to the ignorance of school administration. These were initially dealt with on an individual basis, essentially negotiating with a difficult management, who to their credit often saw reason. The Association set up Justice Forums in 6 districts within the state where active ALDI groups were in place. These Justice Forums were monthly meetings of parents of affected children. The meetings were organized by the ALDI group, where a brief talk on some aspect of Learning would be given by an expert in the field, followed by a discussion of issues faced by parents. These issues were then taken up by the group who would arrange meetings with the school administration and, if necessary, officials from the educational department (who were often invited to these meetings). The discussions were often fruitful and a number of issues have been resolved. Many parents have seen this activity as a major need and continue to contribute to it.

School Adoption

This idea came from our earlier experience with schools in Idukki, understaffed and unlikely to receive the benefit of a Special Educator. We also began to realize the benefits of including certain teaching techniques used for Children with Learning Disabilities in the general teaching of all children. During our projects at Idukki and later at Vilwattom and during discussions at team meetings, we often debated how all teachers could become involved in helping children with learning problems. We had observed that most teachers were easily able to understand the concept of Learning Disabilities however only a few were interested in taking up further training as remediators. We also realised that not all children with learning disability need remediation. There were some who had perhaps mild learning disabilities and had learnt to cope with their problems through unique methods. The Association had a list of such effective coping techniques. A second observation made by parents of affected children was that learning techniques used to help their child who had a Learning Disability often helped the "normal" sibling to enhance his learning. These techniques facilitated easy learning in all children. The parents and teachers change in attitude to children's learning often removed pressure from the “normal” child to perform. These insights were fed back to all teachers who used them in general teaching. Some of the teachers who used these techniques reported exciting changes in pupils’ attitudes to learning. These insights were used in designing the preschool curriculum described below.

Schools for “adoption” by the ALDI groups are identified by their proximity, need, and the response of the Administration. A series of discussions were held between the ALDI centres and the school management about the levels and limits of the service that could be offered. The services offered were training teachers in identifying and understanding causes of scholastic backwardness, screening of children identified, remediation services to those who needed them, parental support through group processes. The services were voluntary; the school would offer support and the use of space. The process was reviewed yearly and targets set for each year. There are 2 schools in this scheme since 2005. These services were designed by the members and are being run by them, supervision and evaluation being done by professionals.

Pre-School Curriculum

In Idukki we found that a large number of children lacked “Readiness Skills” or Basic skills and this affected their future learning. The teachers in our group were keen to design a curriculum for pre-school children that would make learning simple and enjoyable and ensure that all children acquired Readiness skills. This was taken forward to the training groups as a task included in their syllabus during training and resulted in the formation of a pre-school syllabus. The core features of this syllabus are that it is redesigned every year by the teachers, includes a series of song, action and play by which children learn the basic skills and involves them in the process of learning. This syllabus has caught the interest of several schools and is being applied in 20 schools throughout the state.

With the growth of the Association, networking has become important. This is achieved through yearly refresher courses and the publication of the ALDI bulletin once in 2 months. ALDI is a voluntary organization, which was started by a few individuals. The journey through these years has been long and arduous, fellow travellers being many. **The major pillars on which it stands is the parents, people involved and motivated by the need to care for their children.** The experience of beginning this organisation, helping it to grow and expand has been invigorating to say the least. We began with the hope of helping children with Learning disabilities and have shifted goalposts to try and help all children with learning problems. The first aim was to train a few people in becoming Special Educators; we have landed up training parents to help their own children and other children too. These decisions were taken because of the experiences we had in the course of the years. These decisions were taken gradually and after a lot of deliberation and discussion. The process of sharing roles and responsibilities within the Association has been gradual. The professionals responded to needs, developing methods for transfer of knowledge, skills and responsiblity. There was a gradual evolution of roles within the organisation. The transition from a professional led organisation to a partnership and then to an organisation where the non-professionals take the lead has been gradual, exciting and a truly learning experience.

We understand that for the Professional (Mental Health, Child Health) Learning Disabilities are not a priority area. They are often at a loss when confronted with the complex issues faced by parents of children with learning problems. Administrators have not understood the need for concessions or the need to train Special Educators. Learning Disabilities do not form a part of the syllabus in Educational Courses or Medical Courses. We hope that sharing our experience will stimulate similar and even better experiments throughout the country. We understand that there are similar organisations working with children who have learning problems, we believe that it is important to network and share experiences. There are many more battles to be fought on many fronts. We believe the battle for the child with Learning disabilities has just begun.

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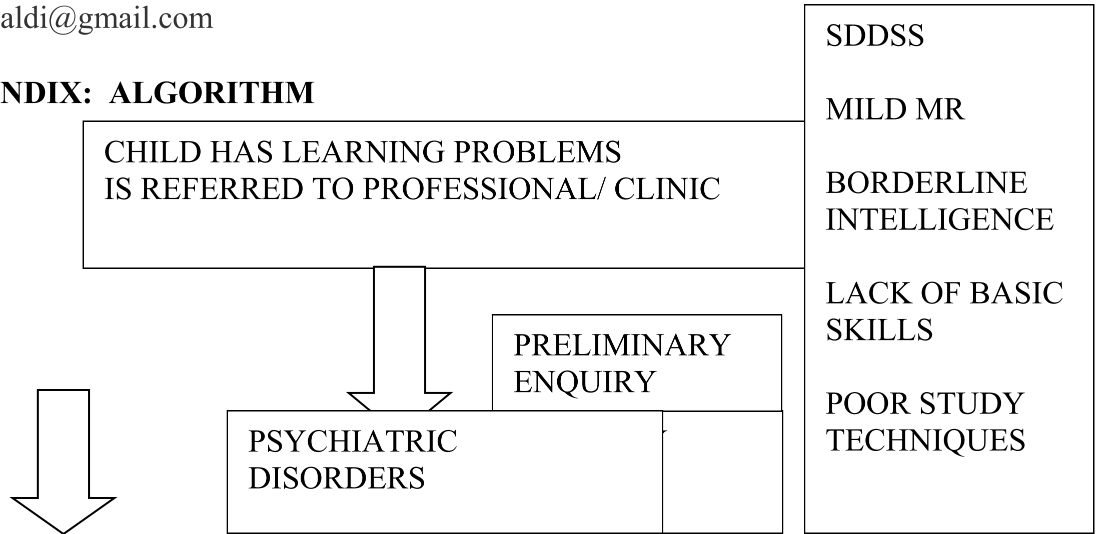
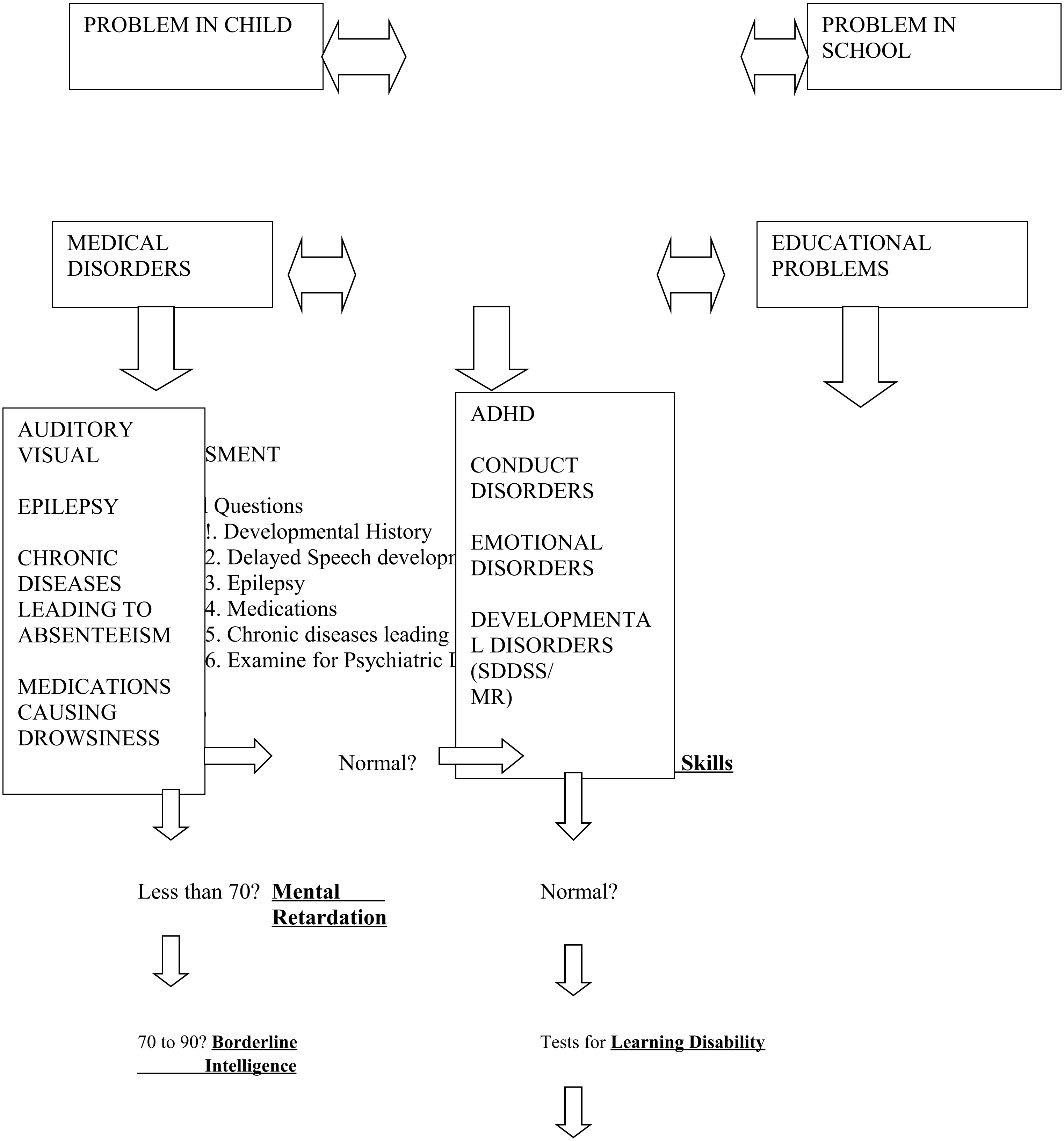
APPENDIX: ALGORITHM




PROBLEM IN CHILD
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3. Epilepsy
4. Medications
5. Chronic diseases leading
6. Examine for Psychiatric I
ADHD
CONDUCT DISORDERS
EMOTIONAL DISORDERS
DEVELOPMENTAL DISORDERS (SDDSS/ MR)
Normal?
Skills
Less than 70? Mental Retardation
Normal?
70 to 90? Borderline Intelligence
Tests for Learning Disability

Normal?

⇩

Check **Study Skills**

All these categories (children with Mild Mental Retardation, Borderline Intelligence, Poor Basic Skills, Learning Disability, Poor Study Skills) can be taken up for remediation.

SECTION VI

Community and Volunteers

Providing treatment for alcoholism through rural camps – a paradigm shift in the treatment approach

Shanthi Ranganathan,
Chennai.

T. T. Ranganathan Clinical Research Foundation – TTK Hospital is working in the field of addiction for the past 26 years. The organization has a 70 bed primary care center at Chennai which provides detoxification and psychological therapy for patients addicted to alcohol and drugs for a period of one month. An exclusive 15 day family programme is offered to provide care and support to families of alcoholics. Understanding the need for extended care for drug dependents and relapsed clients, an After Care Centre has been established to provide treatment for 3 months. The center initiated a Vocational Training Centre to provide training in computer education for clients and tailoring for family members to make them employable. Besides sharing our valuable experience with the NGOs through training, we have also developed a number of manuals, books and booklets for specific target groups like the professionals, para professionals, patients and their families.

Our first rural camp

It was the year 1989. A deeply distressed teacher from a school in Manjakuddi, a village in Tamil Nadu, expressed his anguish: "The fathers of our students drink excessively. As a result, many students are dropping out of school. Sometimes the children leave their homes in the dead of night for fear of facing their violent fathers. The problem is going out of our hands. Can you do something about this?"

The intense emotion and deep anguish behind the concern voiced by this teacher made us think. We recognized that alcoholism was rampant in villages and the villagers cannot access treatment. We had to do something…... There came a paradigm shift in our approach. We designed a cost effective community programme specially for the villagers making treatment available at their doorsteps. And the idea of conducting the first rural camp involving the community as an active change-agent was born.

We started off with our first camp in Manjakkudi .The results were so encouraging that we replicated the model in many other villages. Rural camps have now become an integral part of our mission. We conduct six camps every year making effective use of the resources available in the community.

Our Manjakkudi experience- a real life story

Kanniayappan, a weaver who lives in Kodavasal, another village near Manjakkudi, had been drinking heavily for the past 10 years. As his alcoholism progressed, he was unable to work and earn, and the family had to go without food for many days. His wife, Sarala approached his neighbour, Selvam who had been sober for the past one year after attending the camp. She requested him to motivate her husband for treatmen .
Did K attend the camp?
Did he benefit from it?
His story forms the thread of this document on treatment approach!

Critical components in organising camp programmes

- Working in partnership with the community / host organisation – prior to, during and after the camp. Identifying alcoholics living in one specific area through multiple entry points.
- Motivating the client and providing home detoxification
- Developing a comprehensive treatment programme and providing it in the community itself .
- Creating support in the community and maintaining the momentum

Partnership with the host organization

A camp cannot be conducted effectively by any treatment facility, unless the existing community is also involved in the process.

The community set up with which the treatment facility works in close coordination is called the host organization. Any local establishment which enjoys the trust and respect of the community and is willing to provide the basic infrastructure to run the camp and provide support to the patients during follow-up, can become the host organisation.

A few examples of host organisations are schools, rural upliftment societies, self-help groups, churches which are mainly non-governmental agencies. Since they work closely in the community, the local population can identify themselves with them.

Activities prior to the camp

A few months prior to the commencement of the camp, wide publicity is given in the village through distribution of pamphlets, projection of slides in cinema halls and announcement in local churches, schools, self-help groups (micro credit groups) etc. The clients are identified through multiple entry points –Teachers, doctors, health workers, clergymen, relatives, 'surpunch', informal community leaders. Recovering alcoholics from the earlier camps are the best source for referral.

Providing motivation and home detoxification

Since the host organisation is part of the existing network of the village, it already enjoys close association with community members. So this organisation will be aware of the drinking problem of people living in that village. The alcoholic himself might have sought help from them for his physical problems or his wife might have approached them for financial or other help which would have brought to their notice the underlying problem of alcoholism. They motivate the alcoholic to take help and they are more effective than any external agency offering treatment.

The host organization at Manjakkudi was a school and the teachers were actively involved in conducting the camp. Selvam went twice or thrice along with the teacher and spoke to K. Selvam shared about the problems he faced while drinking and the benefits he had derived from giving up alcohol. Since the teacher was well known and respected in the village, K felt touched by the interest he showed in the welfare of K. He kept telling Sarala that at least for the sake of the teacher, he should attend the camp

Prior to the camp, the client and family members are met at least thrice by the staff of the host organization. In the first meeting, the client is assessed and information about the camp is provided.

K had many queries regarding the camp. His biggest anxiety was " Will I be able to sleep without alcohol? I also have severe tingling pain in my feet and hands. Will I become alright?" The teacher in charge of the programme who had undergone training at the TTK Hospital, provided him appropriate information and assured him all support.

In the second meeting, medical check up is conducted by the local physician to make sure he complies with the selection criteria set forth for camps – less than 55 years of age, no major medical or psychiatric problem, lives in the vicinity of the community, has family support and not involved in selling of alcohol. .

K came with his wife Sarala for the medical check up. The local doctor who was already familiar with K, gave medicines for his neuritis and also to improve his appetite.

In the third meeting which is 7 – 10 days prior to the camp, chlordiazepoxide is given (without the label to prevent misuse) to deal with withdrawal symptoms as well as problems related to sleep. B complex and liver supplements are provided to improve their appetite. In case of any withdrawal problems, the clients are directed to meet the local physician who is familiar with the detoxification procedure. Giving up alcohol prior to treatment, helps in instilling confidence in the client, since he sees that it is possible for him to lead an alcohol free life. This step also helps the treatment facility to have clients who are well motivated.

To help them in their attempt to give up alcohol, a few tips are given - avoid being on an empty stomach; have regular meals; take lot of fluids and avoid the company of drinking friends instead spend time with the family. Giving up alcohol on a 'one day at a time' basis is also taught to them.

Clients who come without taking alcohol are given priority for admission

Sarala personally gave K the medicines all the ten days, made him stay at home and never allowed him to go out at all. Sarala made sure that she gave him lot of liquids in the form of butter milk, tender coconut water and never kept his stomach empty. As evenings are difficult times , Selvam made it a point to visit him in the evening and spent time with him sharing about his experience in the camp. The teacher also visited once to ensure that he had no withdrawal problems. On the day of admission, the tingling pain had reduced considerably and his appetite improved.

Conducting the rural camp

The host organisation arranges accommodation for the camp which is generally in a school, wedding hall or in a community center which is provided free of charge by the community. During the Camp, the host organization ensures smooth running of the camp. It also organises awareness programmes for the community from which patients are taken for treatment.

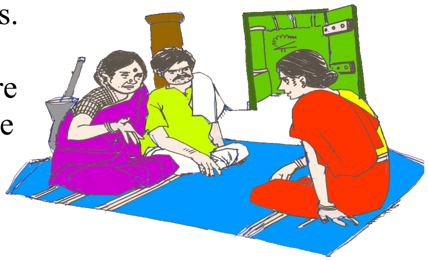
The teachers of Manjakkudi school were involved in many activities – serving food, organizing provision, vegetables for cooking, conducting entertainment programme in the evening with the help of students and also contacting the support persons in the community.

A comprehensive treatment programme

Treatment is provided by a small team of 2 counsellors and one recovering person who is trained as a counselor, a nurse and a ward boy from the treatment facility.

The treatment is an in-patient programme for patients for 15 days and the family members attend half-a-day programme on an out patient basis for 10 days. The components of treatment are

- Detoxification and treating physical problems associated with alcoholism (Medical support)
- Strengthening belief in a higher power (Morning & evening Prayer initiated by clients themselves)
- Thought for the day through a story and reflection on the story
- Providing basic information about alcoholism and issues related to recovery (re-educative lectures) and activities to assimilate input sessions
- Helping them to share the damage caused (Group Therapy)
- Guiding them to develop short-term, long-term goals (Counselling)
- Strengthening motivation by providing tips to stay sober (Sharing by recovering alcoholics)
- Opportunities to have fun through games in the evenings.



Since a large number of the clients and family members are illiterate, stories are used to teach them concepts. All the programmes are participatory in nature. Sharing by recovering alcoholics from the previous camps is considered the most meaningful component of treatment.

K told Sarala, ' When the counselor talked about the symptoms, it looked as if she was narrating my own life'. In the group therapy, K openly talked about the pain he had inflicted on his wife and children and broke down. During the session the other members were supportive and helped him deal with his feelings . He appreciated the fellowship.

When two or three recovering alcoholics shared their experiences, K repeatedly asked them – 'What did you do when you had the craving?' . They explained some of the time tested methods which had worked in their case – ate something to fill the stomach, shared their feelings with another recovering person, prayed to God to give strength or diverted their attention to other activities.

The family programme

The family programme helps the family members to express their feelings of shame, guilt, anger and hurt, teaches them methods to support client in recovery. They also learn to understand the importance of improving the quality of their lives. It is pertinent to note that rural women display tremendous forbearance and are willing to let go of their past and support their husbands in recovery.

After attending the sessions, Sarala felt relieved. She realized that she was not responsible for his alcoholism as accused by his relatives. For the first time, she realised that she had to take care of herself and her children. Sharing with other family members and spouses of previous camp patients was of great help to her.

Creating support in the community and maintaining the momentum

Making use of relatives and friends to support the patients in recovery, a two hour programme is conducted for support persons (brothers, sisters, uncles, aunts, friends, neighbours, clergymen, priests, teachers or recovering clients of previous camps). For each client, two persons are identified. The role of support persons is to provide encouragement and support to patient to continue with his sobriety. They also ensure regular attendance to follow-up programmes and in case of a relapse or disulfiram emergency, they intervene and get him back to alcohol free life. They also give additional help and support during recovery - recommending him for a job, or intervening in case of reconciliation with the wife.

Besides Selvam, Sarala's father attended the support programme. He was living in the same village. After K's discharge from the camp, he provided rice and other provisions for the entire month. Whenever there was a wedding to attend, K felt safe to go with his father-in-law. For the whole year, every Sunday he would visit K and make sure everything was ok.

Support persons are given an orientation on addiction being a disease, total abstinence the only solution to the problem, need for positive changes in one's life, importance of follow-up and relapse symptoms and what has to be done in case of a relapse.

After the camp

To consolidate the changes made by the patient during treatment, to strengthen his motivation to lead an alcohol free life and to help him make improvements in his quality of life, monthly follow-up programmes are arranged in the community itself for one year. During the follow-up meeting, disulfiram is provided and counseling is given. Home visits are also made by the staff of the host organization on a regular basis and especially during festival days like Deepavali or Pongal, to prevent relapses.

A staff from the host organization who has been trained by the treatment facility, provides follow-up support. He provides emotional support and encouragement to the patients when they feel low or depressed. When the family members approach him for help in case of relapse, he intervenes and arranges for necessary help. He also updates the treatment staff about the patient's progress during recovery.

One month after the camp, Sarala brought K to see the teacher in the school. K was anxious about paying back debts and was also depressed. The teacher spent an hour with him and gave him moral support . The same teacher visited him 2-3 times in the next one month. He also guided him on how to budget his income and repay debts .
Four months after the camp, the festival of 'Pongal' was celebrated. K 's second son met the teacher and shared his happiness - "For the first time after many years, we all ate together".

At the end of one year, patients who have completed one year of sobriety, are invited along with their family to a function to recognize their achievements and enable them to share their experiences with new patients. A medal is given as a token of appreciation.

K successfully completed one year without touching alcohol. His son who had earlier dropped out from school to earn for the family started going to school. K was regular for his work and was able to repay a part of his debts.At the end of one year, when K was given a medal in a function, which his father-in-law, spouse, his children and Selvam attended. This was a proud moment not only for K, but also for Selvam and K's father-in-law.

Empowering the community through training

From the community, the members of the host organizations are given two day training and also an opportunity is provided to observe a treatment camp conducted in another location for 15 days. The training programme provides information about symptoms of alcoholism, identification and motivation techniques, treatment methodology, relapse symptoms, methods to intervene and the importance of follow-up counseling. The medical doctor from the community is given a half-a-day orientation about home detoxification, medical and psychiatric problems commonly encountered, etc.

Organizing camps – Possible hurdles and methods to deal with them

Inadequate involvement of the host organization

Alcoholism management may not be a priority for the host organisation. They may see it as the sole job of a specialist, as a result of which they may not actively participate in the programme.

If this is the case, the host organisation should be motivated to include issues related to alcoholism as one of their goals.

`Thirumalai Charities' was working with several villages in and around Ranipet in the areas of immunization, establishment of women cooperative societies and health promotion. When they took up alcoholism camp , a few of their staff were trained in the area of alcoholism and in their health promotion work, awareness on the impact of use and abuse of alcohol was included.

Lack of experience in mobilising community support

The host organisation may not have worked in close cooperation with the community. They may at best be involved with activities like organizing religious discourses, distribution of sarees during festivals, etc. Some villagers are used to receiving monitory benefits from outside sources. They would be complacent and not prepared to take initiative to improve their life style.The host organization has to be guided to mobilize the community to get involved in the camp process.

In most of the camp sites, the patients of previous camps are encouraged to join together and sponsor a meal for the new clients. Some of the community members contribute their home products, for instance, vegetables, groundnuts and plantain leaves etc.

Lack of Leadership

To sustain the positive outcome of the camp, leadership is essential. The project will fail if guidance is not provided at every stage.

Therefore, when leadership qualities are found in a particular person, the treatment team should empower him with responsibilities.

In Manjakkudi, the Asst. Headmaster took the initiative and exhibited leadership qualities. The treatment team requested him to arrange a get together prior to Deepawal and organize awareness programmes in neighbouring villages.

Lack of foresight

The host organisation may have failed to do a thorough ground work. They may have failed to take into account, the local phenomena like monsoon, harvest time or important festivals. As a result, the community members may not take an active part in the programme. For example, if a camp is conducted immediately after a cyclone, people will be busy tackling the problem caused by the cyclone rather than attend the treatment programme. The treatment team has to ensure that the priorities of the community are given due weightage and not dismissed.

Inadequate back up medical support

If there is no back up medical support, in case of emergencies, prompt action cannot be taken. This may even result in loss of lives. Resentment, distrust and anger will follow and the programme will fail.

During assessment of the community, with the help of the host organisation, back up medical support has to be identified and ensured. During the course of treatment, an ambulance with a driver has to be made available for any emergency round the clock.

Community approach of treatment – our experience

We have conducted more than 96 camps in the last 18 years. What stands out is the extremely touching response of the people - openness and unquestioning trust of the clients and the total commitment of the host organization in incorporating camps as one of their prime activities. Our experience reveals that

- With minimal infrastructure, quality care can be provided at low cost
- Help is available at their doorsteps, hence people are accepting help
- Therapy and treatment procedures are made relevant even to the illiterate villagers, hence appealing

- As the entire community gets involved in the process, the incidence of alcoholism reduces over a period of time

Visible gains

The clients treated in camps make positive changes in their life functioning over a period of one or two years. Some of the improvements seen are

- Health condition improves tremendously
- Regularity in work, in turn, contributing for the family
- Paying back debts
- Getting the children into school (earlier they would have dropped out)
- Getting their daughters married
- Involvement in family activities – taking up household responsibilities
- Absolutely no violence
- Getting electricity for the house and repairing the house
- Respect in the community

Camp approach - 'doing with' rather than 'doing for'

In short, the camp approach of treatment is an indicator of how an empowered community can unleash infinite power to reform itself - a power which no external agency can ever match!

The treatment team

- Prepares the alcoholics to work towards total abstinence and lays the foundation to improve the quality of their lives.
- Empowers the host organization to take the necessary steps to sustain the recovery of treated clients.

The host organisation

- Provides ongoing support to consolidate the gains made by the clients.

The recovering alcoholics in the community

- Act as role models, providing empathetic support and caring encouragement

Future plan

Our experience in conducting rural camps for alcoholics, their effective implementation and the successful outcome, have made us think again – "Why not apply the same concepts to address the serious concerns of today - IV drug use and HIV?"

On an experimental basis, we have conducted two camps for IV drug users under the sponsorship of UNODC. Two training programmes were also organized for functionaries of NGOs in an attempt to provide an exposure to issues related to camp approach for IV drug users.

The task is not merely unfinished, a significant portion of it is yet to emerge. What we have taken, is only a small step; but its success will be yet another milestone in our treatment agenda!

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APPENDIX:

The story of five fingers will make us understand the importance of improving the quality in every aspect of our life.

The five fingers kept arguing as to who was the greatest and most important .amongst them

The little finger said "I am the greatest of all, because while worshipping God ."or wishing an elderly person, I stand out first

The ring finger said, "I am the most important as people wear their ring - whether it is silver, gold or diamond only on me and no marriage can be ".solemnised without me

The middle finger said, "No! I am the greatest as I am the tallest of all fingers ."and I have bodyguards on both sides of mine

The index finger or the pointer proudly said, "I can point out who is good and ."who is bad. I maintain discipline in the world. Therefore I am the greatest

Finally the thumb stood up and said, "Nothing doing. I am the most important and the greatest, for, with just one impression of mine, the whole world can be ".bought. I'm the legal entity

So all the fingers asked God to judge which was the most important. God asked each finger to execute a task all alone without help from any other finger. They tried and failed. They went back to God and accepted defeat. Then God made them understand that all of them were equally important and would be useful .only when working with the others and not just alone

In our lives too, merely giving up drinking is not recovery. We need to give up alcohol, improve relationship with family members, get involved in work, pursue healthy recreational activities and develop trust in a Higher Power. Recovery means learning to manage life better; it means learning to lead a .qualitative life

Lay volunteers – Can they prevent suicide?

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Over 100,000 people commit suicide in India every year. In the last two decades the suicide rate has increased by 64% from 6.4 in 1982 to 10.5 in 2002. The suicide rate of men has increased by 70% from 7.3 to 12.8 and the rate of women by 52% from 5.4 to 8.2.(1)

There is a wide variation in the suicide rate within the country. Kerala, Karnataka, Tamil Nadu and Andhra Pradesh which are the Southern States in India have a suicide rate of more than 15 / 100,000. In the Northern states of Bihar, Madhya Pradesh, Uttar Pradesh and Rajasthan the suicide rate is less than 5 / 100,000. This variable pattern has been persistent in the last twenty years. The suicide rate of women is lower than that of men, but by a small margin when compared to global sex ratio for suicide. The male, female ratio has been consistently low at 1.5 : 1. The fact that 72% of suicide in India are committed by persons below the age of 44 years impose a huge social, emotional and economic burden on the society.

The mental health services are inadequate for the needs of the country. For a population of over a billion, there are only about 3,500 psychiatrists. Rapid urbanization, industrialization and emerging family systems are resulting in social upheaval and distress. Diminishing traditional support systems leave people vulnerable. Hence, there is an emerging need for external emotional support. The enormity of the problem combined with the paucity of mental health service led to the emergence of Sneha in the field of suicide prevention.

It all started with a chance meeting this writer had with Ms. Vanda Scott, the then President of Befrienders International, during the IASP conference in Vienna, which led to a visit to the Samaritans branch at Manchester and the Central London Office. That lay people could play such a tremendous role in supporting the suicidal, inspired me to attempt such a model in conservative Chennai, where visits to psychiatrist were stigmatising.. Suicide was not talked about openly and attempts and completed acts were very often hushed up as it stigmatized the family and could turn into legal problems. Skepticism and apprehension expressed by people to whom the idea of just emotional support did not make sense, did not prove to be a hurdle to the birth of SNEHA on the 13th of April 1986. A chosen band of volunteers were trained to run the centre.

To understand the role of lay people in suicide prevention, one must first understand the concept of "Befriending". Befriending is offering unconditional and uncritical acceptance and respect to someone who seeks help in a crisis and who needs support in his / her efforts to deal with a life he / she finds less acceptable than extinction. It is a kind of listening therapy in a non-threatening atmosphere, which may not be possible in a clinical setting. Offered by trained lay people, it is directed more towards addressing the feelings experienced (anger, fear, disappointment, hopelessness, etc.) rather than offering suggestions and advice, in attempting to solve their problems. The key to befriending is allowing the persons the time and space to unburden themselves, and to be able to view their predicament from a different perspective in a calmer state of mind. This, more often than not, helps the person to work on the solution. The assurance of confidentiality and the option to remain anonymous, goes a long way in helping the distressed person to unburden. To an individual, whose self-esteem is at a low, this process facilitates healing and an emotionally stable person is more able to cope with stressors.

The basic quality of being a warm and caring person is an important attributes for effectively supporting a suicidal person. Volunteers are chosen on the basis of their capacity to listen attentively and to be accepting of someone going through a personal crisis. The Volunteers come from all walks of life as can be seen in Table 1. Training helps them to understand the thought processes of a person contemplating suicide and their role in preventing it. The module of training is given in Table 2. Apart from the training for the entire group of new volunteers, smaller groups (2-3) are formed and there are five sessions of 2 ½ hours with intensive role playing before they are enrolled as volunteers. The module of training is given in Table 2. Apart from the training for the entire group of new volunteers, smaller groups (2-3) are formed and there are five sessions of 2 ½ hours with intensive role playing before they are enrolled as volunteers. During the process of training, the consensus opinion of the trainers are taken and if the trainer or volunteers feel that volunteering in Sneha may not be suitable for the new volunteer, then it is mutually agreed that they will not become a volunteer in Sneha. Training also helps them identify individuals, who may require professional or psychiatric care beyond what a lay person can offer. The lay people are also aware of the fact that they are not professionals and steer clear of offering any kind of medical or psychiatric help. In fact, they encourage the distressed to seek professional help at the earliest, but always remaining available to offer care, warmth and understanding. On-going training of lay people is also a feature of suicide prevention centers like Sneha and it focuses on specific issues. Table 3 describes the different types of calls received in Sneha. Around 40% of the calls received have definite suicidal thoughts. They also offer suicide prevention training to other groups, who work closely with the community-like school teachers, NGOs, community health care workers, who in the course of their work, may come across people, who may be suicidal.

The question that would then arise is – How can lay people help the suicidal? Research reveal that a person, who is suicidal, is in a state of deep emotional pain and in a state of constriction of thought, affect and action. That is, they fail to see other options as a solution to their problem and suicide is seen as the only way out. At that juncture, if the person is shown warmth and caring, pain is eased. When listened to with respect, he / she feels acknowledged as a person. Empathy from another human being eases loneliness. And in due course, 'constriction of thought' opens up, when he / she is able to see other ways out of the situation, and suicide is no longer considered an option. There is a need in every human being to feel cared for and for those who are suicidal, the overwhelming feeling is that of being uncared for. The causes of suicide are many and varied, interpersonal problems, financial difficulties, health problems, failure in exams, loneliness, etc. What is that drives a person to take his own life? The question has been discussed, debated and analysed for centuries and we are nowhere near finding an answer. Suicide continues to remain an enigma. What is now known is ,that a large percentage of the distressed and suicidal need psychiatric or professional help. All of them need empathy and emotional support from a fellow human being. Something as simple as that, can save a human life. The endeavour of lay people is to work in tandem with the professionals at all times, as preventing a person from taking his or her life, is a major concern of both groups.

Since its inception, Sneha has received over 150,000 calls of the distress. Sneha has actively supported, trained and helped start centres at Hyderabad, New Delhi, Pondicherry, Thrissur, Cochin, Kolkatta, Ahmedabad and Mumbai. All of them have come together to form "Befrienders India" the National Body. These centres are affiliated to Samaritans Worldwide. The primary aim of these NGO's is to provide emotional support to suicidal individuals through befriending. Often these centres function as an entry point for those needing professional services.

Nested Suicide Prevention Programme

The concept of a nested suicide prevention programme was evolved where successful, relevant programmes are identified and the component of suicide prevention incorporated.

Reducing the availability of the means to commit suicide is an important suicide prevention strategy. Majority of suicides in India are committed by poisoning mainly by ingestion of organo-phosphorous compounds (pesticides). Forming an alliance with an environment activist group, bio-fertilizers were promoted. A study to assess the relationship between suicide rate and consumption of pesticides in India was conducted.

A theatre group was approached to perform street plays in the various tenements of the city. These urban slums can be best described as overcrowded, unhygienic and most of whose inhabitants are illiterate and work for daily wages. Street plays have had a long tradition in India. They are usually performed after 7 pm in an open place or street corner. The street plays focused on the themes of emotional distress, suicidal thoughts, need to seek help and the possible support systems. Visits to these settlements were subsequently made to assess the impact of those street plays. [2]

In India 2.1% of suicides (n – 2279) are committed by students following failure in exams. As the marks obtained determine the course the students can enroll in, a majority of them occur in May / June when the results of the Board exams are announced. Enormous competition to get into colleges, the media hype associated with the announcement of the top rankers and the shame associated with failure pushed the distressed student to suicide. With the help of media an awareness campaign was initiated in the year 2001. Public debates, media interviews press releases and guidelines to the media were issued. Parent associations were addressed and Sneha was open for 24 hours for that fortnight. It was also found that students who took their lives fell into two categories, those who expected a higher percentage and those who failed in only one subject. These factors were highlighted and appropriate method of handling the students were reported in both print and television media. The proactive stance taken by Sneha and the enormous media support created tremendous public response. A responsive government has introduced a new scheme in 2002 wherein students who have failed in one to three subjects can rewrite their examination within a month and can pursue their higher studies without losing an academic year.

The XXI Congress of the International Association for Suicide Prevention was conducted in Chennai in 2001. It was the first one to be held in a developing country in Asia and to be organized by an NGO (Sneha). Former President of India His Excellency Sri R. Venkataraman inaugurated the conference. One of the major goals in conducting the congress in Chennai, India was to raise awareness about suicide and suicide prevention among the public, professionals and policymakers.

Sneha's work can be best understood by the experiences and feelings of the volunteers of Sneha.

Volunteer 1

"I first heard about Sneha from a "caller" who said talking to them helped her a lot and that she had found most of the volunteers good. Then I went through the process of selection and preparation to be a volunteer here. When I first applied this caller was the typical caller in my mind, in the sense that I expected the clientele to be largely from middle class and educated backgrounds. This was on the premise that these are the sections of society who are more open to seeking professional help on issues of mental health and emotional stability. As the preparation proceeded I realized that a volunteer's challenges are far more than what I had imaged.

The preparation process was both scary and exciting. Each day we came away questioning our ability to handle such diverse range of issues and people. But the reassuring factor was the faith the long term volunteers showed in us. I was struck by the atmosphere of warm caring and good humored banter that flowed through their interactions with us and amongst themselves. There was also this sense of energy and strong commitment to the cause of suicide prevention which was inspiring enough to wash away my fears and doubts. I also felt that here was a group of people who are truly non-judgmental.

The idea of Befriending was new to me. I was prepared for a proactive counselor's role and it took me a while to accept that befriending, just being there and offering emotional support could be so powerful. As the role plays, that were a major part of the preparation, unfolded, I became aware that being a volunteer would mean being acutely conscious of my own emotional baggage and learning to hold back from pre-judging on the basis of this. It seems that volunteering with Sneha is not just an opportunity to contribute to society but also to embark on a journey of self-development. (GITA)

Prema has this to stay :

Until I joined Sneha as a volunteer, I had this opinion of myself. I was a friendly, broadminded, non-judgmental and compassionate human being, with love for all fellow beings. This is broadly true. But what I had not bargained for the kind of real life situations, where the above mentioned qualities are put to test by fire.

In our 'sequestered value of life' we hardly meet people whose value system are diametrically opposite to ours. A person who is engaged in an act, which your personal values cry out against, seldom sits across at home and chitchats with you. You are far removed from the situation, when you read about such an act in the newspaper. Not so in Sneha!

You are befriending this person pushing aside your personal values, listening to him as if his (sometimes) abhorrent tale is an every day occurrence for you. You are lending him support, guiding him away from suicide, making him feel better against your truer nature. It is then that you realize how rigid, bigoted and judgmental you actually are and how difficult it is to push aside the values you have grown up with, accept the person as a fellow human being, not condemn him on account of his behaviour.

This dimension to our personality must be accepted. This, I feel, is best done by unburdening ourselves to a co-volunteer. We don't have to be ashamed of our feelings, but accept them and remember to overcome them while befriending. Then it becomes our second nature. By virtue of not being exposed to such real life situations, many a person goes under the banner of compassionate and non-judgmental. Put them to the

Sneha touch stone and their true colours will show. With continued befriending, however, they will truly become better human beings."

Volunteer 2 (Shanthi)

"What brought me to Sneha? The suicide of a 16 year old neighbour devastated me, as we had been quite close and I couldn't get over the fact that she had not tried to talk to me. Or had she and I hadn't listened hard enough? These thoughts haunted me and soon after, hearing about Sneha, I scurried over to join up.

What kept me in Sneha? On the one hand it was the commitment of the volunteers around me, the camaraderie, the transparency of the working, the feeling of oneness and the fact that whether you were 20 or 65 you were treated the same by your co volunteers, and on the other, that fleeting look of relief, the slight lift of the shoulders, the flickering smile of a "caller" who had unburdened themselves and maybe felt like a boulder had rolled off their shoulders.

It always amazed me that an organisation could want me because I was "ordinary enough to be a volunteer" and that I did not need a line of degrees behind my name to help my fellow human beings. An organization, that asked only for 4 hours of my time in a week and yet treated me as if I had dedicated my whole life to them.

In all honesty, I have to accept that I have received as much, if not more, from Sneha than I put in. The contact with "callers" has made me appreciate what I have, taught me to roll with the punches life handed out, kept me from putting pressure on my kids when they were studying - the list could go on and on.

Sneha's outreach programme of Psychosocial support to the Tsunami affected village of Srinivasapuram was one of the most heartwarming experiences in my life. A village that was shunned my most people on the grounds that it was a den of thieves, drunks etc, gave us a tentative welcome that over the months turned into an amazing closeness, especially the children who would come running at our approach, hold our hands and talk to us their problems and worries, their anxieties and fears, was a humbling experience.

There a lot of good things that have happened in my life and a lot of not so good, many of these I would not mind if they had never happened. But my 19 years with Sneha I would never want to change even a minute of. "

Volunteer 3

"What is the most difficult aspect of being a volunteer, involved in suicide prevention? Before going on to the superlative, lets take a look at lesser difficulties. And even before that, let me tell you how I got myself into all this. Two people I know – one less than a friend and the other more than an acquaintance – committed suicide. They hardly looked the kind, who would kill themselves, but then, is there something like that. It opened my eyes to facts about suicide which, till hitherto, existed as myths in my mind. Determined to do my bit, I subjected myself to the exacting process of getting selected as a volunteer. I hadn't bargained for what came later. Volunteering opened up a world of pain , sorrow, depression, guilt and feelings of suicide of people going through crisis in their lives. Listening to them exposed me to their fears, rage, frustrations, and thereby evoked in me similar feelings. To understand the feelings of other because of their problems is a problem by itself – one that needs to be examined, analysed and solved. I have attempted to tackle the first two, and am still working on the last. The difficulty level of callers trying to solve their problems and volunteers trying to understand their feelings is the same.

Often times, after an exhausting session with a troubled person I have wondered if I had done "enough". The caller who came in with a distressed look on his face, had gone back satisfied with the encounter. Doubts plague me. The flip side to this is when someone going through a crisis walks in, unburdens but leaves in almost the same state of mind he was when he came in. What a let-down it is!

Being a volunteer, sometimes means taking on other responsibilities. I use the word "often" to highlight the fact that being a volunteer is a big responsibility. One day, you find yourself a leader or co-ordinator. Your co-volunteers look up to you for spilling out answers to their questions. Problems usually arise when there is a pecking order, but the difficulties are more in the absence of one. Interpersonal problems between the co-ordinator and volunteers arise. Being a deputy to the director is a different ball game altogether. Before you even realize it, the responsibility and the problems associated with the job, are thrust on you. This is one job in which you are constantly fielding questions – from the volunteers, the co-ordnators, the director and sometimes, even from the press, on the odd occasion you are asked to talk to a scribe.

Having wandered off to lesser difficulties let me come back to the "superlative" that I started off with. Being a volunteer is the most difficult job till you learn to empathize – and this does not come easily. Empathy comes only when you are able to transcend the boundaries of your beliefs, principles, convictions, cross the divide and enter into another's world. Empathy is the essence of being a volunteer."

Volunteer 4

"When he walks in, I have no inkling of what is to come. He has visited us on and off over the past few months. With a rough family situation and financial troubles, he has no one who is supportive. So we serve that purpose for him. He also counsels with a professional and is under medication for depression.

When he starts talking, I suddenly get the feeling that there is something different today. I feel a sense of purpose, a sense of resolve – and a strange cocky look in his eyes.

My mind struggles to understand the meaning behind it. Then I pull myself up and still myself to listen to the said and try to listen to the unsaid.

His voice feels hollow, hopeless, resigned…. He recounts his home situation and what has happened over the past week. It is tough. He feels powerless and swallowed up by it all and his pain is unbearable. There is no other way out you see, he says.

He has it all figured out. Strangely he feels at peace he tells me. He now knows what to do. And finally, he feels in control. He smiles exultantly. Everything else is beyond him like water rising up and going over his head. But this – he is in control of.

He takes out a small packet of white powder. This will do it for him. In one stroke it will wipe out the pain, he tells me.

I stare at the little packet. My mind goes blank with horror I feel helpless now, and hopeless, I grope around in frenzy for worlds to respond with.

In his eyes, I see a challenge. You tell me what I can do, he says.

Truly, honestly, all I can do at that moment is mirror his helplessness as I look back at him.

Then the moment breaks and his voice is different now. It sounds desperate, not resolute.

You tell me what I can do, he says as he recounts his situation. It is like going round in a circle over the whole thing and coming back to the same point, as death as the only way out.

But there is a subtle difference now. There is no longer the hard look of challenge in his eyes. Could there be a way out, he seems to ask. Could there be a way out.

And again as I look back at him, all I feel is helpless. I truly don't know, I tell him. But may be there is. May be we can't see it now, but we will… if we give ourselves some time?

He pauses, silent. Still. Suddenly tears come and roll down his cheeks. He makes no attempt to wipe them away or stop them. As I wait, my eyes on his bent ahead, I feel a surge of deep respect. For this human being – so frail and yet so strong for having been through all the pain that he has.

And I feel a tiny flicker of hope. Is that resolve melting a little? Have we bought ourselves some time. I wait, not daring to say a word. He is not here. His mind is away, going over past events, and do I dare to believe – may be future possibilities.

A long pause, then suddenly there is a flash of anger. He has been so sure before he came here, he tells me. Clear and sure. Now he was confused again. Confused and miserable.

I'm sorry I tell him and I wait.

He is lost in thought. There is nothing much to be said.

So what does he do now, he demands looking up suddenly.

Can we at least wait till the confusion clears, I ask. Can right decisions be made when we are confused? More so if the decision is irreversible.

He glares at me, angry, tortured and confused all at once.

Whatever happens we are here for you, I say with complete sincerity. In fact, that is the only thing I feel sure of at this point. That we will be there to share his pain. That we will always be available to talk things over if he wanted to.

He is silent for a long time. Then put this away he says, pushing the packet away from him. He can always get more if he wants to anyway, he says. There is a long pause again. I see signs of him wanting to leave.

Can I ask you something – I dare to ask.

What – he asks guardedly.

Next time you feel this way, can you talk things over with us before you take any step, I ask.

No answer. Why should I – he seems to be thinking. What right do you have over me.

What right indeed, I think.

We cannot stop you from doing it, if you do make up your mind to, I say.

He nods. Yes of course.

Whatever you decide to do, you don't need to be alone, I say. We are here if you want us.

He nods.

In a while he gets up to leave.

The powder I empty into the sink and turn the tap on. It washes away. That moment has passed, I think. That moment when he had been so clear and sure and could have taken his life.

As moments come and go, feelings come and pass on, I think. We feel and live from moment to moment, don't we?"

Lessons learnt

- Suicide is a growing public health problems in all of India
- There is growing evidence of linkage to socio-economic factors
- Volunteers can respond to suicidal persons
    - The spread of the crisis centres has been slow
- The success of centres seems to be linked to the availability of leadership and commitment at each centre
- There is need for greater support for the suicide prevention movement in India.

Conclusion

Apart from training the entire group of new volunteers, smaller groups (2 – 3) are formed and there are five sessions of 2 1/2 hours with intensive role playing before they are enrolled as volunteers. During the process of training, the consensus opinion of the trainers are taken and if the trainer or volunteers feel the volunteering in Sneha may not be suitable for the new volunteer, then it is mutually agreed that they will not become a volunteer in Sneha.

Suicide prevention is a major public health problem in India. There is an urgent need to develop a national suicide prevention strategy which is culturally appropriate and cost effective. Where there are multiple reasons for suicidal behaviour, effective care may also need to be multifaceted. This requires cooperation, collaboration and commitment.[3] Until now volunteer action toward suicide prevention was based on the needs of the client and what the volunteer could offer within the domain of their functioning. The need of the moment is to structure programmes undertaken by volunteers in the area of suicide prevention on scientific principles, constantly evaluate and study the efficacy of such programmes, and incorporate necessary changes, Sneha has started one such project in Srinivasapuram.

Suicide prevention in India is not merely a traditional exercise in health sector but a social objective and this objective can be achieved only when the society is involved in the preventive strategy.

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1. Accidental Deaths and Suicide in India. National Crime Research Bureau., Government of India. (2002).

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TABLE – 1

Volunteers details		
Sex	Male	39%
	Female	61%
Age	20 – 29	14%
	30- 39	20%
	40-49	25%
	50+	41%
Marital Status	Single	18%
	Married	71%
	Widowed	9%
	Divorced	2%
Educational Qualifications	Under grad	1%
	Graduate	62%
	Postgrad	33%
	Doctorate	4%

TABLE – 2

Training		
15 minutes	ice broken	This session helps not only as an icebreaker but also as to ascertain the individuals listening skills. The group is broken up into pairs and asked to speak to each other for 3 minutes. After which they have to introduce each other to the rest of the group.
15 minutes	Introduction	Short talk on Sneha and Befrienders India and Befrienders worldwide
15 minutes	The Principles and Practices under which Sneha functions	Reading and discussion of the P & P
105 minutes	Communication skills	
105 minutes	Grief	A talk on Grief
90 minutes	Suicide	A talk on Suicide
30 minutes	Asking the suicide question	How, when, where and why
150 minutes	Family situations -	role plays to highlight how a problem is perceived in different way by each member of the family. Learning to handle them without worrying about the problem

45 minutes	Sexual problems	The different kind of sexual problems that can be encountered when befriending
45 minutes	Sexual Demanding callers	Consistent handling of manipulative callers
30 minutes	Silent calls	What to do when there is silence on the other end of the line
30 minutes	Third party calls	Handling a person calling on behalf of someone else
30 minutes	letter callers/e-mail callers	
30 minutes	Ending the call	How to wind up a call
120 minutes	Mental illness	The different kinds of mental illness that can be encountered while befriending

TABLE 3

Family problems	30%
Marital problems	17%
Depression	13%
Third party calls	13%
Economic problems	6%
Physical and sexual abuse	5%
Physical illness	4.5%
Mental illness	2.5%
Educational problems	3%
Love failure	3%
Thank you	1.5%
Miscellaneous	2.5%

BEFRIENDERS' MEMBER HELPLINES (Befrienders Website)

National Associations

Befrienders India - National Association
c/o Sneha
No. 7 Besant Road
Royapettah
600 014
CHENNAI
Helpline 1: +91-44-2835 1232
Helpline 2: +91 44 2835 2345
Website: www.befriendersindia.org

Centres

Saath
B12 Nilamber Complex
H.L. Commerce College Road
Navrangpura
380 006
AHMEDABAD
Helpline 1: +91 79 2630 5544

SNEHA
No. 7 Besant Road
Royapettah
600 014
CHENNAI
Contact by: Face to Face ✓- Phone ✓- Letter: ✓
Helpline 1: +91-44-2835 1232
Helpline 2: +91 44 2835 2345
Website: www.snehaindia.org
Email Helpline: sneha_ft@vsnl.net

Lifeline Foundation
17/1A Alipore Road
Sarat Bose Road
700 027
KOLKATA
Helpline 1: +91 33 2474 4704
Helpline 2: +91 33 2474 5886
Helpline 3: 2474 5255
Website: www.education.vsnl.com/n4h/

AASRA
A-4, Tanwar View, CHS,
Plot NO - 43, Sector 7
Koparkhairane
400 701
NAVI MUMBAI
Contact by: Face to Face ✓- Phone ✓- Letter: ✓
Helpline 1: +91 22 2754 6669

Sumaitri Befrienders India
NDMC Complex 1st floor
48 Babar Road
Nr. Bengali Market
110 001
NEW DELHI
Contact by: Face to Face ✓- Phone ✓- Letter: ✓
Helpline 1: +91-11-3710763
Website: www.sumaitri.org

MAITREYI
255 Thyagumudali Street
605001
PONDICHERRY
Contact by: Face to Face ✓- Phone ✓- Letter: ✓
Helpline 1: +91-413-339999

ROSHNI
1-8-303/48/21 Kalavathy Nivas,
Sindhi Colony

S.P. Road
500003 A.P.
SECUNDERABAD
Contact by: Face to Face ☑- Phone ☑- Letter: ☑
Helpline 1: +91 40 7904646
Email Helpline: help@roshnihyd.org

The Samaritans Sahara
Sir J-J. Road
Byculla Bridge
400 008
MUMBAI
Contact by: Face to Face ☑- Phone ☑- Letter: ☑- Email: ☑
Helpline 1: +91-22-2307 3451
Website: www.mumbainet.com/health/samarita.htm

MAITHRI - Cochin
Ashirbhavan Road
Kacheripady
Ernakulam Kochi
682 018
Kochi
KERALA
Contact by: Face to Face ☑- Phone ☑- Letter: ☑
Helpline 1: +91 239 6272
Website: www.maithrikochi.org
Email Helpline: maithrikochi@yahoo.co.in

Listening with the Heart

Ali Khwaja
Bangalore.

Beginings

A quarter century ago, a quiet, unassuming and introvert housewife, Mrs. Alice Saldanha, was preparing for the retirement of her husband. Having spent decades in different far flung countries due to the nature of his work, she and her husband were now returning to Bangalore in India, their home town. The children had settled down, and Alice felt that there will be little for her to do. There was a yearning in her, a desire to give back to society and to human beings what God had generously given her in terms of wealth, family, health and peace of mind.

It was when Alice was visiting her eldest daughter in England that she came to know of the Good Samaritans movement, also known as Befrienders International. She went and visited them, and was amazed to know that just providing a listening ear to people in distress can be so effective in providing relief and solace. Looking back at her city of Bangalore, which had grown from a Pensioners' Paradise, to a bustling metropolitan, she realized that there are thousands of people who are caught in the rat race, and have no one who would listen to their story.

Alice came back and started in 1983 a small organization called "Helping Hand". She gathered a dozen of her most sincere and committed friends, and requested an expert in the field of mental health to provide these volunteers with training on how to listen, accept and empathize with people who need emotional support.

What started as a tiny setup in Alice's garage has today grown into a people's movement, with almost four hundred active, passive and past volunteers, all dedicated to the cause of giving their time and their hearts, expecting nothing in return, and giving the message to the lonely, distressed or suicidal that "we are there for you."

The First Step of the Thousand Mile Journey

This initiative taken by Alice did not create many ripples. Helping Hand, operating from a garage converted into a counselling center, offered free, confidential and unbiased emotional support to anyone who wished to visit, phone or write. Every morning and evening, there would be one or two volunteers on rotation manning the centre and welcoming anyone with any kind of emotional distress, relationship problem, or confusion in life. They were trained to just listen unconditionally, give total acceptance to the caller, refrain from being judgmental in any way, and try to empathize as much as possible. No advice or suggestions would be given. The principle was that when a person finds someone who gives him unconditional acceptance and supportive listening, he feels lighter with the catharsis, and eventually feels empowered to take his own decisions, or to cope with issues that have no solution.

The concept was new to traditional Indian society, which for centuries has believed in sharing only within the family, looking to God for support, or reaching out to religious teachers for guidance. Initially, there were not many callers. At times two or three days would go by without a single person walking in. Advertising through the media was expensive, and Helping Hand had no funds. Dedicated and sincere volunteers would come and sit for hours, talking amongst themselves or with Alice, and going back. But they did not feel disappointed, because they knew that manning the centre they were sending out the message of their availability on all days, if and when someone chose to reach out.

In contrast there were days when someone in serious distress would walk in, maybe a suicidal person, or one who felt that he could not go ahead as there were no alternatives – and would go back feeling lighter, with a feeling that there is someone who cares unconditionally, and many a time that itself would empower the person to make renewed efforts with a positive mind frame.

One particularly rainy evening, I was sitting alone in the centre watching the clock. Half an hour to go for closing time, and a continuous drizzle meant that no caller was likely to come. Sorely tempted to close down the centre and go home, by instinct I just sat on. Ten minutes before closing time I saw a shadowy figure walking in. I was shocked to see a young lady with a small baby in her arms.

Before I could say anything she blurted out, "I have left home with my baby and was on the way to killing myself when I remembered about Helping Hand and have come here." For more than an hour she cried, spoke, sobbed and poured out her woes. I sat dumbstruck just listening to her. At the end of an hour, she looked down at the little one and said, "you know something, I can't end my life till my baby is around. I think I will go back home and face whatever comes my way." She took an assurance from me that I will be available whenever she wants to come and talk, and quietly walked off into the wet night …...

As age caught up with Alice, a younger person who had recently migrated to the city and who had experience of running a similar centre in another city, slowly took over the reins. His name is Dr. Ali Khwaja, an engineer turned counsellor, a person who deeply understood the relevance and significance of extending emotional support and improving mental health at the grassroots. The team grew, and even when the initial volunteers had to drop out with increasing age, there were more and more people willing to extend their hands. Periodic orientation and training was provided to new batches of volunteers, refresher programs were held for the seniors, and the spirit of volunteering is not only kept alive, but growing stronger by the year.

Extending to Hospitals

As the word spread, more and more altruistic people wanted to become volunteers of Helping Hand. Work at the centre was limited. It was then that an opportunity arose in the form of a nearby hospital wanting volunteers to come and talk to patients. Some of the volunteers were given fresh training to understand the feelings that patients and their care-givers go through, and they started visiting the hospital on rotation every day for three hours. They guide new patients, give solace in emergencies, talk to family members when someone is in surgery or intensive care, and sit by the bedside of those who have no one to listen to them.

Work in hospitals is allotted based on the interest, capability and inclination of individual volunteers. In one major hospital's Emergency Medicine Department, our volunteers keep an eye for trauma cases, rush the patient in, sit with the attendant if he or she is breaking down, at times run around to locate the right doctor or get the blood grouping done, and even make arrangements if the patient has to be shifted to another hospital for any reason.

In contrast there are many senior citizens, including some octogenarians, who regularly man the Help Desk, sitting with a smile to receive illiterate patients, many from far off villages. They fill up their forms painstakingly, guide them to the right counters, give them solace and reassurance, and listen to their anxieties or their non-medical troubles with empathy.

Some trained volunteers work in cancer hospitals, particularly the palliative care wards, sharing the agony of the terminal cases, the distress of their loved ones. They pass on instructions of the medical staff, and clarify the patients' doubts by consulting the doctors. They listen patiently to the cry of the helpless, and hold hands to assure them that they are not alone.

This concept was so well appreciated that requests started coming in from all the other major hospitals of the city. Today Helping Hand volunteers are regularly present in eleven more important hospitals including National Institute of Mental Health and Neuro

Sciences, cancer hospital, the largest public hospitals run by the government, corporate hospitals, and those run by trusts and missionaries.

As far as possible, volunteers are given a hospital of their choice, and work of their aptitude. Senior citizens sit on “May I Help You?” desks, fill forms for the illiterate, guide patients to the right counters or departments; younger volunteers run around in Emergency, help in getting blood reports, arrange ambulances and push stretchers. Trained volunteers counsel people going through intense grief, bereavement or anxiety. While Helping Hand requires volunteers to give three hours of their time once a week, many of them happily visit hospital twice, thrice or even five times a week.

Counselling Centres

Simultaneously Helping Hand has spread itself to the four geographical zones of the city, and has a counselling centre in each area. This has particularly been done since Bangalore city has grown large and commuting distance and costs have risen considerably in the past few years. Two centres, in the North and South of the city (RT Nagar and Basavanagudi), are open full day Monday to Saturday, while two others function in the premises of a hospital and a polyclinic for two hours a day. The major two centres have more than twenty voluntary counsellors each, while the part-time ones average about 6 to 10 persons giving their free services on rotation once a week. In these centres many serious cases are taken up, including different members of a family when required, and some counselling extends to number of sessions lasting from 30 to 75 minutes spread over many weeks, till the person feels confident enough to move on in life.

These centres are premises of other philanthropic institutions, where a room or two is given to the volunteers on fixed hours to sit and talk with privacy.

The volunteers manning these centres are mostly people who have undergone a one year training in basic counselling skills, and have been found competent to deal with day-to-day issues faced by the common man, mostly in areas of relationships, goal setting, emotional distress, family and parenting.

The one year course, named “Diploma in Counselling Skills”, is open to all without any minimum qualifications, and requires a commitment of four hours of contact classes and three hours of practical work every week. It has no theory and no text books. Experiential learning begins with understanding oneself, identifying and managing feelings, and going on to understanding others. The group sits in a circle, and everyone’s opinion and experiences are taken into account.

Over the years these centres have seen a steady growth of callers, and now they are buzzing with activity on most of the days. People with any type of issues are encouraged to come and talk. Even if the problem apparently may be psychiatric, financial, legal etc., the volunteer gives a patient listening. This is done under the belief that when a person is facing a difficult or distress situation, just pouring out his thoughts and feelings help him lighten the burden. Since the volunteer does not offer advice or solutions, it helps the caller narrate everything, often in a flood of emotions that were choked up for a long time.

Only after the entire catharsis is over, comes the question of resolving the issue. It has been the experience of many volunteers that a majority of the callers just want to let out steam, or share with someone who is non-judgmental. Once that happens, they feel lighter, and go away never to return. They have developed the confidence to face their own issues, and either resolve them or learn to cope with them. The volunteers never intrude into the privacy of callers, and respect their wish of not coming back to give a report of progress.

Networking

As more and more people reached out to Helping Hand, volunteers would at times be confronted with cases which they were incapable of dealing with. Family members of people suffering from mental illness, victims of domestic abuse, parents of children with developmental disorders – many such callers would come with great hope. Their eyes would beseech the volunteer for help, yet the volunteer was trained to understand her limitations and not to transgress them. Thus began the process of developing a network of experts and professionals who such people could be referred to.

Over a period of time Helping Hand now has a data bank of over two hundred government, public and private institutions and individuals who could be helpful in some case or the other. Meticulously their specialization, costs, areas of operation and availability are noted down, and callers are encouraged to seek such professional help. At the same time the volunteer assures the caller that she is there as his friend and confidante, and he can come back to talk and give feedback on progress whenever he wishes to do so.

Over the years, professionals and institutions have also developed a warm regard for Helping Hand and its selfless services. Thus it is often found that a person referred from Helping Hand gets a little extra sympathetic and personal attention. In fact, many professionals themselves refer clients to Helping Hand for emotional support, knowing that the volunteer will give the extra time and attention that the professional may not be able to do. In all such cases there is a very clear dividing line of the role played by the volunteer and the professional.

Expertise of Volunteers:

Helping Hand does not follow a rigid selection procedure for volunteers. Almost anyone who comes forward is welcomed. Volunteers range from 18 to 80 years of age. They hail from very varied backgrounds. While a few are themselves medical professionals or psychologists, the vast majority are lay people from unconnected fields. There are many retired persons, a number of housewives, and also many busy professionals who desire to spend a few hours in the week giving back to society.

While all volunteers are initially trained in the basic skills of non-judgmentalism, listening and empathizing, there are many who have a special interest in learning how to deal with particular types of people. They are encouraged to get training and exposure in their area of interest. There are volunteers who work with alcoholism, others who assist families of mentally ill, some who spend time with terminally ill cancer patients. Some of the volunteers befriend disabled children, while others work with battered women. In a multi-cultural country like India, volunteers speaking different regional languages are put in touch with specific callers so that they can be attended to in their mother-tongue.

Most of the training is provided on-the-job. Since the work primarily requires people-interaction, volunteers learn best when they see their seniors dealing with different types of situations. Before sending them to the hospital, volunteers are given an orientation not only on the soft skills required to communicate, listen and empathize, but also on their limitations, and what they should NOT attempt to do. Assurance is given that back-up will be available for any issues that they may face. Volunteers are also encouraged to keep in touch with the centre and share their experiences, at least in the initial few months of their work. Care is taken to identify what the strengths of each volunteer are, and what type of work can be handled by him or her. Newcomers are attached to senior volunteers who have been working for a number of years, and as they develop confidence and capability, are given independent work.

Difficulties and Future Plans

Since Helping Hand has no direct or indirect source of funding, it does not maintain any staff or establishment. It operates from the office of a training institute, Banjara Academy, whose infrastructure is used free of cost. The persons currently heading the organization, Dr. Ali Khwaja and Mr. Raja Reddy, give their services entirely free of cost.

Due to lack of staff and logistics, at times it is difficult to keep in constant touch with the volunteers working in four different counselling centres and eleven hospitals spread over the entire length and breadth of the city. This at times leads to some volunteers feeling left out and uncared for. There is a constant attrition of people who lose their motivation within the first few months as they feel that they are only doing mundane and routine work which should be done by paid personnel.

About a third of the volunteers have stuck through thick and thin, many of them having completed a decade of service. It has been found that senior citizens constitute the bulk of those who stay on for long periods of time. There has been almost an equal number among men and women who have stayed on, although initial recruitment of volunteers shows more women joining than men. Many sincere women volunteers have to forcibly drop out due to their family commitments, transfers, attention required by children, etc. Some of these do come back if the situation changes and they can again give their time.
Among the dropouts there are many students who have to leave when they finish their respective courses and move on to other fields, and also many young people who are in

transferable jobs. We also do not deny that a small number (less than 10%) do drop out within the first few weeks due to dissatisfaction of the work they are doing. They at times are a good inspiration to the newcomers, and they try to motivate them to the best level possible. Despite this, dropouts are a regular feature, and the organization has to constantly keep looking for more volunteers from time to time. Since advertising is expensive, such volunteers have to be sourced through word of mouth and personal contacts, thus creating a limitation on numbers.

There is no hierarchy in Helping Hand. Other than the two persons mentioned above who act more as Mentors and Guides, all the other volunteers are treated equally. There are no financial rewards. Recognition is given only for consistency and number of years of service, and no comparison of quality of work is done. This has both advantages and disadvantages. There is a constant exploration and introspection going on to see whether the system can be improved upon. For the past few years, in each hospital one volunteer is appointed to coordinate for a period of three months, and the coordination continuous in rotation among all the volunteers who are interested to do so. This has been found to be a positive step forward.

There are no grandiose future plans or targets for this tiny organization. It is primarily people oriented, and relies on the goodness of human beings who give their services absolutely free of cost. Even their transport or a cup of coffee is paid for by the volunteers themselves. Resisting the temptation to involve in any activity that requires funds, Helping Hand has kept a clean track record for the past 24 years, and each volunteer feels proud to be associated with it. This includes dozens of previous volunteers who may not be able to give their regular services, but continue to be friends and well-wishers, and a source of moral support.

It is primarily a people's movement, and the persons currently heading it hope that the mantle will pass on from generation to generation, doing exemplary work in preventive mental health by providing an ever-ready friend who is willing to listen from the heart.

It is definitely suggested that this movement can and should be spread over all the cities throughout India, and eventually to the smaller towns. Helping Hand itself has been instrumental in promoting similar groups in cities like Mysore, Calicut and Chennai, primarily by sharing its experiences, giving guidance of the methodology and pitfalls, and also in training up their volunteers. Unfortunately some of these have not sustained, primarily because of lack of committed leadership. Groups that worked democratically by rotating responsibility were found to fizzle off when the initial promoters moved on. Such a movement requires a strong anchor by one of two permanent leaders who provide the continuity. We are ready to help any group, particularly in South India (due to logistic reasons we may not be able to extend to far away places), by providing inputs and encouragement if they wish to take up such activities. We are confident that every city has many concerned citizens who will come forward to contribute their time and their inputs if someone takes the lead to organize the group. Please do not worry about the length of the article.

Dr. Ali Khwaja, B Tech, MIE, PhD, honorary Director of Helping Hand, and a person who loves human beings.

Helping Hand's training wing

Banjara Academy has produced many small, practical and economical books dealing with related subjects, most of them written by the author of this paper. These books include:

1. You too can reach out – a Handbook for Lay Counsellors
2. Prevention of Youth Suicide and Distress
3. Young Ladies – Stress and Alcoholism
4. Understanding Today's Child
5. Life Begins at Sixty – Handbook for Senior Citizens
6. Help Yourself – what is Counselling
7. Mental Health
8. Child Abuse – prevention and treatment
9. Understanding Teenagers
10. Learning Difficulties (with resource directory)

Counseling training for Lay Volunteers in Bangalore City- Experiences of Prasanna Counseling centre

M.C. Pankaja and Guru Duttt
Bangalore.

Background

Prasanna counseling center was founded by Mr.Ajit Kumar, a engineer by profession. He took up social work as his lifetime job. Ajitji was the very epitome of social service, or 'seva' as we call it, and his unbounded missionary zeal took him to the doors of thousands of homes and families, social & educational institutions, community & rehabilitation centers all over India. Ajitji was greatly inspired by our traditional values & norms and, throughout his short life; he worked for the preservation of the time-honored way of life. And yet he was, so to speak, a pragmatist and a shrewd / perceptive observer of the inexorable changes that had been taking place in our social & family life.

Sri Ajit kumar noted the ' increasing industrialization' and the 'unceasing trend towards urbanization', and these, he rightly surmised, led to what he called 'the complexities of life and multiplied the varieties of problems'. He also lamented the self-defeating nature of this kind of social development: 'The accelerated pace of change in life and situations, the range of novel situations available and the wide and diverse options developed with the aim of bringing greater happiness to human beings have ultimately snatched (away) the very sheet anchor of contentment and happy living conditions to a very great extent….'

Although a conserver of the classical code ethics, Ajitji was at the same time liberal and practical-minded enough to concede that the 'Naturally evolved counselors… find themselves no longer technically adequate to tackle the problems of the present age'. (Emphasis added). When he spoke the of the 'naturally evolved counselor', he probably had in mind the old style patriarch or the authoritarian head of the extended family (of the pre-industrial era) with his fund of conventional wisdom and advice.

If this paternalistic ‘wise man’ had become out dated, indeed irrelevant, who then, could take his place in the new, changing social arrangement?

Ajitji felt that an experienced person with an open mind and modern education, could play the role of a lay counselor / mental health worker in the community – if he/ she is trained by mental health professionals in counseling skills.

It was by ‘sheer coincidence’, as Ajitji put it, that the Smt.Pankaja, - a school teacher, social worker and counselor by training – willing volunteer who could take on the task of building an institution of lay mental health workers; counselors who would work at centre as well as the community at large. This approach was driven by the need of large number of distressed individuals who were often ambivalent whether to consult a psychiatrist in the mental hospital or any other professionals for help. The former was stigmatizing and therefore many people did not seek any help from psychiatric institutions.

There were other considerations, too, that resulted in establishment of prasanna counseling and training center in 1980.

Reasons for choosing ‘people’

With rapid industrialization, urbanization, migration and nuclearisation of families, traditional support for the individuals and families are gradually disappearing. With increasing stress levels in urban life and lack of conventional buffers and supports, individuals are increasingly susceptible to stress and as a result manifest deliberate self harm, high behaviors, substance abuse problems, marital disharmony and increase in marital separation. All of the above mental health problems need care in a structured manner.

The need to develop lay counselor in the city came up due to two important reasons. Firstly, support with persons who have attempted suicide revealed that these people required support after being discharged from the hospital. Volunteers (Smt Pankaja and her team) felt that the time available was too short for them to sort out complex issues that drove people to deliberate self-harm. Follow up support for the discharged person can be organized of there were a set of dedicated volunteers who can maintain contact, talk to such persons at periodic intervals and provide them emotional support to live in the family and look at life beyond the episode of deliberate self harm. It is note worthy that such a work force did not exist in the city. It was on this background that Mr Ajit Kumar and Ms pankaja thought of lay volunteers as an alternative to support such persons and their families. More than 600 hundred lay volunteers have been trained over the past 26 years of prasanna counseling centers work in Bangalore city. The training is for four hours a week spread over a period of 26 weeks. The lay volunteer come from different walks of life and they consist of housewives, professionals, bankers, lecturers, schoolteachers, young graduates and retired individuals. The lay volunteers merely bear the cost of the training material which is about Rs 50/= (Rupees fifty only) for a period of one month and the total cost incurred by trainee is about Rs 300/= (Three hundred only) for the entire course.

Training approaches

The prasanna counseling informs people about the starting of the course by placing advertisements in the local newspapers every half yearly. About 60 volunteers are registered to under go six months of training in the premises of the counseling center. As mentioned early, the total number of training hours is 104 hours

Training of lay counselors is done by conducting, short-term courses (over 6 months) two days a week for two hours each schedule. Training is done by didactic lectures, sharing personal experiences, group discussion, role-plays, demonstration of clinical problems, interaction with people who seek help for psychological distress.

The training provides an opportunity to learn the following topics.

- Brain and behavior
- Emotional disorders,
- Major mental disorders,
- Substance abuse disorders,
- Management of psychiatric disorders in the community
- Counseling and scope of counseling
- Process involved in counseling.
- Handling resistance in counseling situation
- Childhood mental health problems.
- Visit to psychiatric institution
- Counseling session- Observation.

The training also involves regular interaction between the faculty and the trainees to discuss persons who present with psychological distress. The trainees are given an opportunity to work with clients as part of their internship for few weeks before they complete their training.

- Public lectures and seminars (workshops / Manual
- Media interviews / panel discussions / articles / self-help books. Brief courses (1-2 days) at outstation centers.

Care Provided by lay volunteers

The lay counselors are encouraged to work as voluntary counselors in prasanna counseling center after their training. . They are given the choice of the day, duration of voluntary work and time of the day to work as volunteers for them to decide. Out of the 600 volunteers trained so far, about 10% volunteers are currently doing voluntary work as counselors. Men and women are equally represented in the volunteers group. Some of the volunteers can provide counseling to distressed men, women, children and the elderly on a regular basis. All the lay counselors work under supervision to start with and depending on their ability to take up individual cases, they are assigned specific task of the assessing the distressed individual, formulation of a counseling plan. Lay volunteers are very excited to work as counselors. They say' It is great to work as a counselors. Being available to a distressed person, listen to him, support him make us feel very good". Most of the trained volunteers can listen to clients, support them, and maintain engagement with out many problems.

Volunteers can provide certain level care in their work as counselors. This is depicted by an example. "A 23-year-old lady presented to the counseling center with history of disturbed sleep and involuntary movements of the hand and neck. The counselor was able to obtain further information about the problems in her life. The client reported that she was married 8 months ago but does not live with her husband. She claimed that her husband did not like her because she was unable to speak English. The counselor was unable to understand the reason for involuntary movements though psychological distress secondary to marital problems were acknowledged. Medical evaluation revealed that she had rheumatic chorea for which she was appropriately treated. The counselors educated the patient about the treatable nature of her medical condition and encouraged her to bring her husband and in-laws for conjoint session. Client and her parents returned to the counselor with a bad news that husband has met with an accident resulting in paralysis of both lower limbs. Though the client was willing to stay with him and care for him, he rejected the offer. Parents and the client were educated about their rights and possible consideration of lawsuit for alimony. The client did not want to explore any such possibility and wanted to spend time in an ashram".

A 23-year-old lady was brought to the clinic with history being dull, noncomunicative, irritable at times and not taking care of her child. The counselor during in his interaction found the relationship between is strained. She found out that they disagree with several issues at home and that peace is seriously hampered. They reported that they moved to the city recently. The counselors were able to relate to the couple that their age difference could a matter of concern, which is causing a lot of problems between them. Husband seems to agree with that observation and said" She seems to disagree with what ever I say. It seems like daughter and father disagreeing over many issues in their relationship". The counselor was able to educate the couple about the age difference and experience. He leanrt to change his ways of relating to her, help her at home when ever he can and also encourage her to take up studies so that she can be occupied during her free time. With this intervention the couples are well adjusted and live happily. The wife observed that… " I was scared to come to counseling centre. I thought that my husband was trying to label me as mad and prescribe medicines. Soon I realized that counseling means talking and helping us understand problems in our own life and helping us to sort it out on our own".

Trained people can play the role of good empathizers

- They can be used for 'befriending' interventions to help people who are experiencing loneliness and suicidal ideation etc
- Lay counselors can give clarifications with regard to clients' goals, priorities etc, and assist the latter in the decision-making process

- They can provide moral support to caregivers whose morale is low.
- They can give information regarding related services such as legal aid / consultation, medical centers, disability benefits, vocational training centers, special schools for slow learners, charity institutions (for the aged)etc.
- Date / observations given by informants / trained 'people' are helpful in making an assessment of the patient's condition by the professional mental health worker
- Trained volunteers ('people') may readily differentiate abnormal and normal behavior and recognize disturbances at an early stage….
- They may explain to the caregivers and local people that … are not caused by 'evil eye', 'inauspicious' birth star of the patient, 'possession by the devil' etc
- Trained 'people' are familiar figures in their respective localities / communities, by virtue of which they are in a better position to persuade / motive substance abusers to go to dead diction center. .
- Volunteers, especially teachers, are in a vantage position to recognize emotional problems in children and adolescents.
- They can effectively spread mental health literacy among families, communities, and in workplaces and educational institutions..
- They can liaison between the professional worker and the patient with regard to follow-up treatment.
- They can counter stigma of prejudice attached to mental illness.

Limits

Volunteers may not be able to recognise mental treatment and behavioral abnormalities arising out of organic probably the edition wants to know at what prints in their day-to-day practice the lay counselors hit/reach their limits)

A 50 Year lady came to the counseling center on her own. She claimed that she was working as a cook in a rich mans house. She indicated that the landlord was in love with her. She further elaborated that he was too concerned about her often gave an encouraging pat on her head. She claimed that she was thrown out of the house because his children thought that she was getting too preoccupied about their father. It is after this incident that the client started writing letters to her landlord. The content of the letter was mainly about his love for her and she questioned him as to why he did not protect her inspite of being in love with her. The counselor thought that the version of the client was true and she was very supportive. Soon the counselor realized that the problem on hand was one of psychosis rather than betrayal by the lover.

- Sometimes the lay counselors are inclined to take a moralistic view of subnormal behaviour such as lack of will / motivation, lack of self-care, social withdrawal, slow learning etc, which may actually be … of underlying mental illness / illnesses.
- Similarly, they tend to think in terms of who is 'right' and who is 'wrong' when they are considering cases of interpersonal difficulties.

- Some of them believe that culturally derived and time hallowed practices such as meditation (dhyana) & yoga offer all-embracing ‘cure’ for every kind of illness under the sun.
- Conditions i.e, (eg: slow thinking in hypothyroidism) may be mistaken for depression .
- They may think that well-formed primary delusions are amenable to argument and reasoning.
- They are not always aware of the natural course / recurrence of mental illnesses.
- There is much confusion (even among the professionals!) as to where exactly we should draw the line, between the normal and the abnormal (eg: Normal ‘outbursts of temper’, dysphoria vs mood fluctuations); fear and phobia etc)
- Volunteers are reluctant to work with destitutes and very low-income groups.

Support to the care by mental health professionals

The trained volunteers need support and supervision on a regular basis. Mental health professionals initially see all clients. Depending on the nature of the clients problem, they are assigned to the counselors. The counselors is encouraged to collect all the information about the client, her family, problems he/she is concerned about using structured proformas. The counselors take on the client independently after this. He /She is provided support and clarification periodically. They are often encouraged to be observers in counseling sessions. Such sessions are taken up to handle difficult situations so that the lay counselors get a practical exposure to the nuances of counseling process.

“A young man reported at the counseling centre with his mother asking for help. He reported that he was married for the last eight months and that his relationship with wife has gone beyond repair because she is “MAD”. He alleged that she was very rude, aggressive, manipulative and so inhibited .He had decided to end the marriage because he finds it very difficult to understand her. The counselor was very sympathetic towards him. But she could not proceed further. A conjoint session was planned to understand the concerns of both the parties. This session was initially chaotic because both the parties started accusing each other. The supervisor laid the ground rules for both the parities to narrate their version of the story. This helped the counselor understand the way forward rather than feel helpless. Exploration also revealed several difficulties between the couple, mother in law and other relatives. Both the parties were educated about the nature of the problem, cause of their difficulties and ways and means of working through their difficulties. The mother and mother in law were also educated about their role in contributing to the problem. The family as a whole was taught skills to handle about a difficult issue openly rather than shouting and screaming at each other”.

A 12-year-old boy was brought to the centre with history of being very dull, in studies. Parents reported that he was being frequently accused of destructive and aggressive acts in the school. They said that he was given the last warning and in case he repeats the same. He will be expelled from the school. Parents were deeply distressed about it. The counselors squarely blamed the parents for not giving enough time to boy. She observed that … " If you allow the child to watch TV for long times… this is what is going to happen. Professionals intervened at this time and found that the child has Specific reading and writing difficulty. Further, both of his parents work long hours on weekdays and they are able to spend time only over the week's ends. Grand parents are the primary carers in the absence of parents. They try to do every thing they can to the child just to ensure that his mother is not forced to quit her job. The counselor was helped to recognize that specific reading writing difficulty, inconsistent parenting and lack of appropriate discipline was the cause for the Childs problem. They were encouraged to make alterations in their work schedule so that they can spend time with the child. With above inputs, the counselor could develop insight into her way of understanding the Childs problem and she also recognized that it is unfair to blame the parents for being inattentive and negligent of the child's needs.

Difficulties encountered

Volunteers are a useful manpower resource in the community. They can be trained and encouraged to work with distressed individuals under the supervision of mental health professionals or senior counselors. More than 600 volunteers were trained over the last twenty-five years in Prasanna counseling centre. However, only ten percent continue to provide voluntary time for the distressed people. They are initially very enthusiastic about playing the role of counselor but this does not last for a long time. Many of the counselors come for the training program to understand their selves, their problems and ways and means of coping with their problems. Some of the counselors also find the training and counselors role as a means of distraction from their own problems. They tend to give up this role soon after they have understood that many people have similar problems in the community. They seem to cope well and I should also do the same is their opinion.

- About 2/3 of the clients who are not in need of medication drop out of the (lay) counseling process / lose touch with the volunteers after 1-2 sessions.
- Volunteers have no power to issue "summons" to the other person/s in cases of interpersonal difficulties / disputes…
- Volunteers may not be able to give as much time as their clients wish / demand.
- Language barrier
- Sometimes the clients / patients are so poor and resourceless that the volunteers feel helpless to help them out….
- Lay volunteers sometimes tend to take sides in cases of interpersonal difficulties; they cannot remain neutral.
- They bring in their own baggage of norms, moral standards, and belief systems into the counseling process.
- Temptation to play the role of a preacher is hard to resist.
- It is difficult to show due regard to clients who have committed a series of blunders in their personal life.

Remedial Measures

Training of volunteers should be made more rigorous with more practical exposure rather than a lot of theoretical inputs. All the counselors are encouraged to present one difficult problem they have encountered in the last fortnight. This has helped them to understand the process of counseling better and they have been able to gain greater familiarity with techniques used in counseling. They are encouraged to observe the counseling sessions conducted by senior counselors and other mental health professionals who visit the centers. It would be useful to consider video recording of counseling process and various techniques used in counseling so that they can review the tapes periodically and master the techniques. The Prasanna counseling center is working on such a video module and hopes to complete the learning material in couples of months time if funds are generated for the same.

Lessons learnt

The experience of training volunteers has been a very fruitful and meaningful experience for the last two and a half decades. While many come forward to work as volunteers, their sense volunteerism does not last for a long time. Many volunteers come forward for the training to understand their own problems better. About 10% of volunteers are interested in providing their free time to help distressed individuals. Females are more committed than male counter parts. Female like to work with children more often than adults. Is their trying to understand issues of their own children while they with other children and families is some thing we have to examine. Volunteers are able to provide certain level of care. Encouraging increase their ability along with support and supervision in the form of case discussion, presentation and providing opportunities for observer's role from time to time. These inputs have clearly increased their ability to understand emotional problems in the client and support them to overcome difficulties.

- Volunteer should not breach confidentiality. They should not trivialize clients' concerns.

- They should spend more time <u>listening</u> to the clients and understand the nature of their problem from their point of view / perspective. They should <u>highlight</u> the achievements – however small they be – of the clients.

- They should not get involved in the personal life of the client (even as they feel concerned about the clients' predicament)

- Our experience shows that mental health professionals (i.e.those who are inspired by non-profit ideals) can extend their (scope of) work and aim at wider targets in the community if they harness / rope in trained volunteers.

- Trained 'people', working in tandem with the professionals can significantly ameliorate mental distress and in the general population. However, they are more successful when they are working with those sections of people who already have some resources at their command….

- A manual with contributions from senior psychiatrist, clinical psychologists, social psychiatric workers etc has been published for the trainees (4th edition).

- Provision of a small library for the use of counselors & trainees has increased their interest in reading about issues in counseling. .

- We have already set up a child guidance centre at our premises and another counseling centre in the northern part of the city with the help of counselors trained at our centre. We intend to open a few more counseling centers depending upon the infrastructure facilities available.
- The table below shows the number of people and the categorization of the problems based on the presenting complaints. It is interesting to note that availability of counseling services makes distressed people seek such services and the number of people using these services is actually increasing from the time of inception of the counseling program.

Nature of the problems	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	00	01	02	03
Physical	-	-	1	1	2	6	4	1	2	1	1	-	7	20	7	8	19	82	9	15	15	57
Mental	27	70	49	50	48	72	50	48	33	41	58	38	70	90	110	124	126	185	158	197	244	347
Marital	12	22	23	17	13	27	18	22	10	10	9	18	16	18	15	23	24	23	22	11	23	35
DSH	-	-	1	-	-	1	-	-	-	1	-	1	2	-	1	3	--	-	-	-	-	-
Alcohol	5	8	5	3	1	2	2	5	2	3	4	2	-	1	1	8	4	6	2	-	10	15
Domestic	12	28	15	10	9	25	7	15	12	14	13	6	8	10	15	4	14	15	13	18	24	46
Educational	-	-	-	-	-	-	-	-	1	4	12	3	1	8	11	9	26	53	80	81	137	96
Rehabilitation	-	-	-	6	10	17	11	1	2	17	12	10	6	1	2	5	1	-	-	--	7	1
Total	56	128	94	87	83	150	92	93	65	99	102	96	117	151	160	201	241	318	291	378	461	622

Resources materials

Prasanna counseling center has developed a manual "titled counseling manual for lay counselors and it is priced Rs.50/=

Future plans:

Prasanna counseling center plans to extend counseling activities to other locations in the city. Some of the lay counselors have started counseling facilities similar to prasanna counseling centers. They are able to enroll 50- 60 volunteers to undergo training in counseling PCC is also actively associated with volunteers else where in the country to establish counseling centers in their local area. There is a urgent need to carry out research with respect to work of PCC.The number of individuals who have availed services, outcome of the kind of help they were able to get and their current situation and the reasons for dropping out of counseling could be of help. The most important aspect of PCC is that with lay volunteers. Explorative studies to understand why some individuals chose to work as counselors, reasons for attrition in those who have dropped out, change in lives of people who have undergone counseling course and lastly, how they are using the skills acquired in the counseling course to help people in distress.

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Community mental health and development model evolved through consulting people with mental illness

Janardhan
Bangalore.

"Since eleven years he is suffering from mental illness but in these years he never got any other physical illness. It is really surprising…not even fever for that matter… Why does he live…? Why doesn't he die soon due to some other dreadful illness…? This is how we often feel about him" – **father of a person with mental illness**

Introduction

Mental, behavioral and social health problems are an increasing part of health problems in the world and in India too. Though the burden of illness resulting from psychiatric and behavioral disorders is enormous; it is grossly under represented by conventional public health statistics, which lead to focus on mortality rather than morbidity and dysfunctional. The number of people with mental illness will increase substantially in the coming decades for following reasons. First the number of people living in the age groups of risk for certain illness is increasing because of the changes in the demographic features. Thus there has been increase in the number of person with mental illness in the age group of 15- 45 years. Secondly, there has been substantial increase in the geriatric population having mental health problems, as the life expectancy is increasing. Thirdly, overall increase in the rate of depression seen in all age groups as an effect of changing socio-cultural-economic and political situation of the modern world.

Mental and behavioral disorders account for 12% of the global burden of disease. It is estimated that nearly 450 million people suffer from a mental or behavioral disorders in the world. Nearly 10 % of disability adjusted life years (DALYs) across all age groups are due to depressive disorders, suicides and alcohol related problems. Depression ranks third among men and second among women, yet mental health budgets of most of the countries are less than 1% of the total health expenditure.

Reasons for choosing people for mental health care:

India is a country with an approximate area of 3287 thousand square kilometer (UNO, 2001). Its population is 1.081 billion and the sex ratio (men per hundred women) is 106 (UNO 2004). The literacy rate is 68.4 % for men and 45.4% for women. The proportion of population under the age of 15 years is 32 % and the proportion of population above the age of 60 years is 8%. The life expectancy at birth is 60.1 years for males and 62 years for females. The healthy life expectancy at birth is 53 years for males and 54 years for females. Basic Needs India works with the NGOs and CBOs which are working with the marginalized section of population and also backward areas.

Need

In one of the meeting with the partner organizations, Thippana, Head of the organization from SACRED, Ananthpur once said that ‘’when they started the programme there were only 20 people identified in their project areas where as know after 4 years they have identified more than 200 people in the same area”. It is also to worth noted that one of the mental health coordinator expressed that “*When I joined I thought the CMH programme is very small. But after working with the people I realised that it is huge. It is like entering through the narrow end of a funnel and then it grows bigger and bigger and bigger.”*

A majority of the classical psychiatric epidemiological studies in the last four decades have been population based, focusing on general psychiatric morbidity in a small to medium population. A conclusion arrived at from these house-to-house surveys:

- It is estimated that 1 percent of the population suffers from severe mental disorders
- Ten percent of the population is reported to have common mental disorders.
- The reports also reveals that 15 – 20 % (in some studies it is 40 %) of the people approaching primary health care centers, general hospitals or private clinics for general health problems requires psychiatric assessment and evaluation. But most of them are not aware of it. They think and believe that they have some physical illness, and take various methods of treatment for relief, often in vain.

If we project this figure in our country, there would be little more than 10 million population suffering from severe mental illness, and the figures for common mental disorders will be 10 times to that of severe mental illness.

Mental Health Care

Mental health care has always been influenced and determined by contemporary beliefs, and India is no different. Traditionally, mentally ill people were often cared in temples and religious institutions, based on the principles that mental illness is a form of spiritual affliction and could thus be cured by religion. Superstition with inadequate mental health services in the community makes people with mental illness to subject to various harmful treatments, they are subjected to black-magicians, village quacks and witches and physical abuse in the name of treatment. They are kept outside the margin of the community meaning chained, locked in the rooms, wandering in the streets, staying for ever in closed wards of asylums, hospitals, etc.

Stigma and Discrimination

The case illustrated below would describe about mental illness and stigma on the family, which resulted in human rights issue. Family in desperation would chain their mentally ill family member.

Mr M

Mr M, a brilliant student since his young days, suddenly failed in his 2nd pre university course. Since then, he started wandering in the forests and became so violent that his own siblings were scared of him. Because of his behavior, the community even suggested his parents to throw him out of the house on to the streets. His parents always required the help of others to control him. Therefore they decided locked him up in a room with manacles for legs and hands. Mr M was left to doing every thing (eating, shitting, sleeping) in the room. His father used to carry the shit with his hands. Consequently, his whole family was stigmatized. Nobody showed interest in fixing up alliance with this family. Their home was called as mad person home, no one use to visit them as they were scared of Mr M. This resulted the family to chain him. There was problem in finding an alliance for Mr M siblings. The engagement was broken because of Mr M's illness. His parents lost lot of money in the process of his treatment etc. The local partner organization pleaded with the family to remove the manacles. This really had an effect on the family who then freed Mr M, the local organization facilitated treatment. Once the person became stabilized, people came forward to marry in their family, the engagement, which was broken was also reconsidered, they are married and living happily along with Mr M . He helps them in agriculture and grazes buffalos. He is no longer burden to the family, he is contributing to the family income.

The above-described story is not in isolation it is the fate of all people with mental illness in all over the world. A large section of people with mental illness are still inside their houses without any treatment, because their family members don't recognize the illness or they find it embarrassing to be recognized as family member of mentally ill, who are commonly called as 'mad'. The very thought of some one in the family getting mentally ill is a big shock and they do not want to believe it. Hence they first go to temples, black magicians, witches and faith healers and waste whole lot of financial and other resources. There is a fear that they would be victims of disgrace and indignity and thereby they loose the status or acceptance they enjoy in the community. The stigma is so tremendous, people feel ashamed and deny the illness. Therefore, the first and foremost element that shrouds the realm of mental illness is stigma attached to it. The very thought of some one in the family getting mental illness is a big shock and they do not want to believe it.

Due to stigma attached to the families, people with mental illness become the victims of discrimination and human rights abuse. The discrimination is seen from the family members and goes right up to the policy makers and state authorities. The attitude of the public is that, who care what we do for people with mental illness. People with mental illness have been treated as second-class citizens with no adequate facilities given either the state or the central government. As a result they face chronic ill health, and are an economic & social burden to the community leading to social destitution. Soon families loose hope and are left to the mercy of others.

Existing Laws

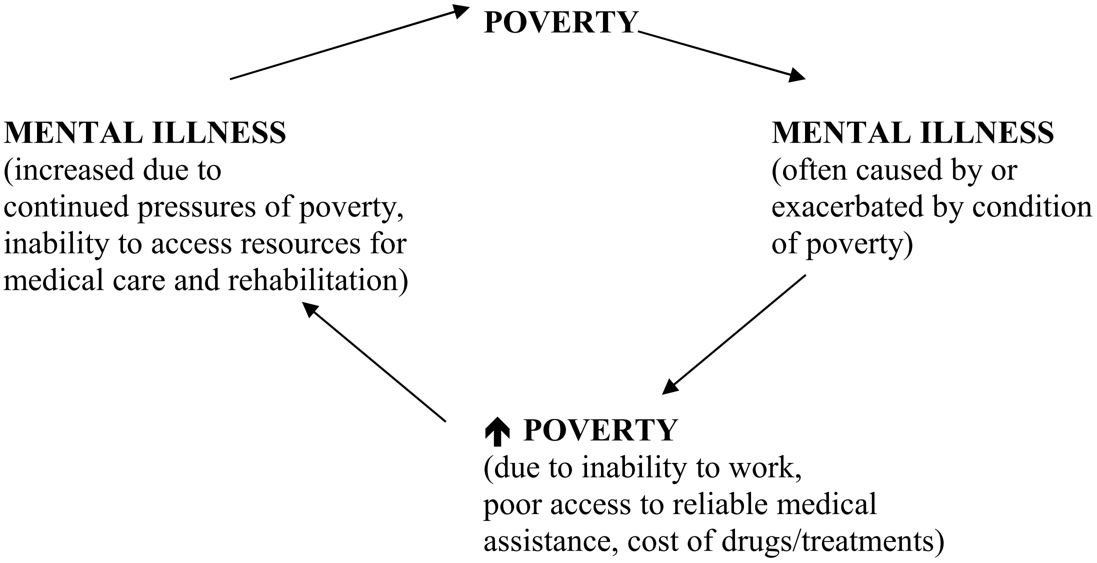
As per the law, a person with mental illness cannot sign any documents of sale, purchase, lease or any contract. The act is silent on these issues during the lucid moments/stabilized stage. Family members, mostly brothers, take undue advantage of this clause to deny the property rights to the person with mental illness; end up with ensuring the chronic mental illness, so that the so-called sane siblings enjoy the property.

Marriage and Divorce Act also permits legal separation of life partners if one of them is found to be mentally ill (certified by a psychiatrist). Generally in rural communities men are permitted to marry for the second time if his first wife is suffering from any disease like mental illness, epilepsy and etc. On the other hand if a married man becomes mentally ill, community insists wife to be caregiver and undergo all the problems. If a family has person with mental illness, eligible boys and girls getting life partner/married is almost next to impossible because of the stigma and is seen as a family illness. There are occasions where they hide the information and after marriage, problems erupt. It is also common where a close relative is pressurized to marry such a person.

Poverty and mental illness

Poor people with mental illness are not only vulnerable due to their condition, but also the vulnerability brought about by poverty, which is a consequence and to some extent cause of their condition. One of the main reasons that people find it hard to accept people with mental illness as equal members of their communities is that they do not see them as capable of contributing to the household or the community. For decades, researchers have shown that poverty and mental illness are correlated; the lower a person's socioeconomic status, the greater his or her chances are of having some sort of mental disorder. Poverty exacerbates mental illness

It is this cycle, which Basic Needs aims to address through its sustainable livelihoods interventions.



POVERTY

MENTAL ILLNESS
(increased due to
continued pressures of poverty,
inability to access resources for
medical care and rehabilitation)

MENTAL ILLNESS
(often caused by or
exacerbated by condition
of poverty)

↑ POVERTY
(due to inability to work,
poor access to reliable medical
assistance, cost of drugs/treatments)

This is the reality of the debt trap in the specific context of the family unit affected by mental illness.

Case illustration of Mrs SB from Dodabalapura would provide more details of how poverty led person to get mental illness.

Mrs S

Mrs SB is a living example for how a person can be affected by just having a mentally ill member in the family. She was married to a pretty well off family but her husband's siblings cheated them and they were left with very little property for their livelihood. Her husband met with an accident, resulting to injury on his head, resulted in epilepsy. She tried various places to get him treated, but in vain. Added to this, she also met with an unfortunate accident while at work in a generator factory and its one wing cut 4 veins on her neck. She was hospitalized only for 10 days and her employers cunningly made her sign a document, which she later got to know that it effectively sealed her chance of re-employment in the same company. As she had lost the job she did not have any other source of income for their livelihood which pushed them in debt trap. The relatives picked up fight with her husband, this ended up in an assault resulting head injury. She had to spend lot of money, sell their little land in getting him treated. All this life stresses contributed to her illness. Local partner organization identified this family, facilitated discussion for treatment and rehabilitation for the entire family. Now she earns a very meager amount of money by rolling beedis. She is happy that there are understanding people around her who support her both financially and emotionally.

In poor rural communities the ‘value’ attached to an ability to earn income is great and often is the defining factor for a person’s stand within the family (Underhill and Naidu, 2002) Mental illness causes severe stigma for the whole family and carers are also severely neglected due to their association with a mentally ill person. Bringing financial stability to the family unit and providing a productive role for mentally ill people is critical and core area of intervention of Basic Needs India so that they are able to take care of their basic needs for food, nutrition, health, and education.

Basic Needs India

Basic Needs India was conceived in 1999. Groundwork began in 2000 and the organization was registered as a trust in 2001. As part of ground work series of consultations were held with Mental health professionals, people with mental illness and their families, community members, community based organizations, and the NGOs. The work started with visiting various places involved in mental health work in Delhi and Punjab. The places include hospitals, centres run by charities, asylums, day care centres, private nursing homes, mental health professionals, etc. A mentally ill person during one of the consultation said that ‘never has anybody asked my opinion before, it is only here that I had chance to talk to you and express what I need’.

This meeting resulted us to consult people affected by mental illness so that we can understand their needs, which would govern the organization. This consultations has helped us to evolve a model for integrating mental health in any development programme. The consultation with the various stake holders has led us to evolve a list of needs of people with mental illness which are grouped as treatment needs, need for enhanced income and social integration.

Consultation

BasicNeeds India since its inception believes that nothing about people with mental illness with out consulting them. This resulted us to conduct series of consultations with people with mental illness, careers and their family members. The below given needs are the needs expressed by the people in one of the consultations held in Narendra foundation in Pavagada taluk, Karanataka. 13 people with mental illness and their caregivers participated in the consultation (7 men and 6 women with mental illness) They were divided in to two separate groups of people affected and their caregivers and the organization staff formed another group. The groups were given three topics to discuss among themselves and same to be reported back in the larger circle. The group was asked to discuss on: “My world” (for people with mental illness), “The needs”, and “what next”. People with mental illness were able to discuss their issues concerning them they were more specific in describing what they want. It was shock for the caregivers and staff when they listen to the discussion on the above given topics. People with mental illness expressed more about social integration and the need for treatment, where as caregivers and staff were vague and idealistic. They were preoccupied with their problems and they desired to get more support in terms of money and livelihood opportunities.

Treatment needs

- Want the help of a doctor
- Want medicines
- Want a cure for the illness
- Physical health

Need for enhanced income

- Want Financial help
- Want money for livelihood
- Want support to earn income
- Want loans
- Financial assistance to care for the person with MI
- Economic development programmes
- Vocational training
- Needs employment opportunities

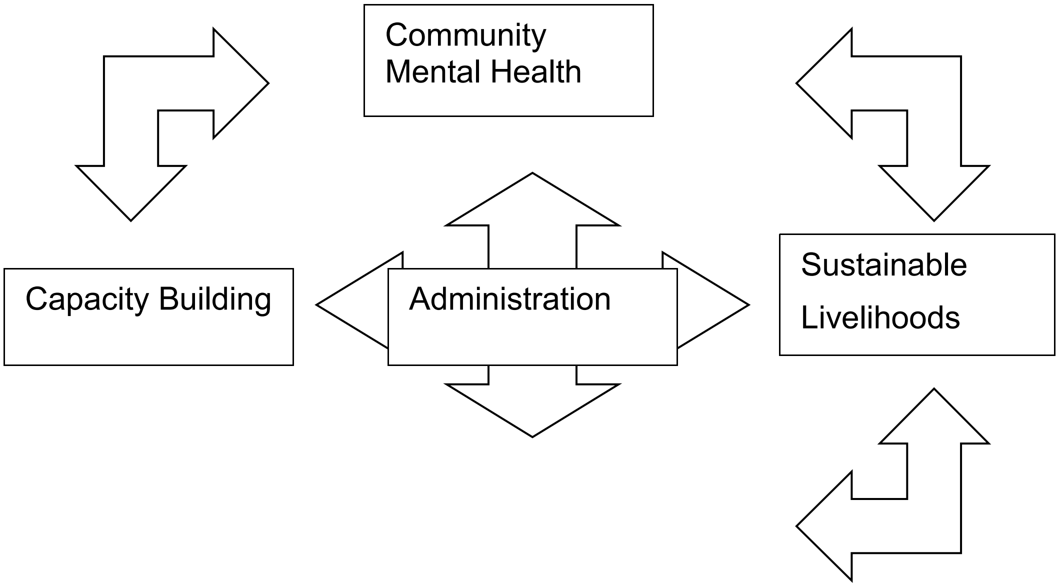
Need for social integration

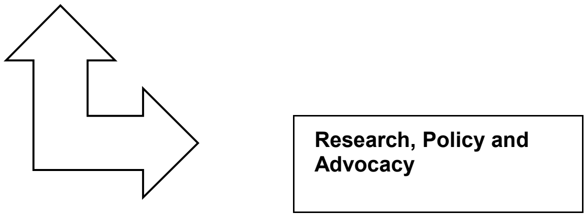
- Further education and continue education.
- Involvement in spiritual activities
- Opportunities to meet and share
- Self help Groups
- Support for access to treatment (transport)
- I need to be consulted for any family discussions/decisions
- Public retaliates badly, not want to be called ‘mad’
- I want to marry/ get them married
- I want my children/wife to stay with me
- I want to attend marriages
- I need to get recognition
- I need to get my share of land
- I want my children to go to school
- Low status due to illness

Especially the needs expressed by them and ‘what next’ guided the programme and from the perspective the ‘programme initiative’ is a result of people interested in the lives of people with mental illness and disadvantaged groups and their family members discussing on a common platform. This was followed by another consultation with two partners where the model emerged. Access to treatment, economic independence, social integration, and advocacy surfaced very clearly as basic needs and the vehicle to meet these needs is exercising rights. This has led us to evolve a model for community mental health addressing the needs expressed by people with mental illness. The model has five modules which are :

1. Community Mental health
2. Capacity building
3. Sustainable Livelihoods
4. Research and Advocacy
5. Administration and Management.

THE MENTAL HEALTH AND DEVELOPMENT MODEL





These consultations led to belief that mental health is not a medical issue alone; it is more of a development issue. The trust grew out of the belief that however poor or ill the person is has the capacity to manage his or her own life. BasicNeeds India's main role is that of creating a caring, accommodating and understanding environment to ensure fair treatment of people with mental illnesses. Such an effort involves liaising with and including a host of people—people affected by mental illnesses, family members and other carers, community members, medical professionals, policy makers and government officials. BasicNeeds India addresses both people's mental health concerns and situations of poverty to ensure sustainable recovery. The approach to health care is one that includes people with mental illnesses in immediate and larger development processes, with active participation of community members. BasicNeeds India hopes to generate sensitivity and influence public opinion around mental health issues.

Few case illustrations given below would summarise the how the model operates at the field level.

A tale of market and trade analysis

Mr. S a beneficiary of the mental health programme implemented by our partner in Tamilnadu shares his experience. Sethu has suffered from mental illness but has now recovered sufficiently to be able to run a small enterprise selling cooking ingredients from his bicycle. He rides around 35 kilometres per day on a regular set of routes and has built up a network of established customers. At the outset, he spent a good deal of time working out the various ingredients that were likely to be in greatest demand, such as pepper and coriander, and the quantities required.

He sells small packets tailored exactly to the needs of low-income customers who purchase their requirements daily and at prices that he knows to be competitive. Although he already had a bicycle, Sethu took up an offer of Rs.2,000 from one of the partner NGOs in order to get started. In response to our wishes and hope he would soon be able to afford a motorcycle and therefore cover a bigger area, he replied that this would push up prices for his customers and could actually damage his business.

A new livelihood for Mr V

Before he became mentally ill, he worked for thirty years in the weaving industry. He gave it up and concentrated in overcoming his illness with the support of his family. Following treatment and ongoing assistance from GASS, he decided to set up a small business supplying snacks to travellers using the bus shelter in his village. He starts preparing the food at 4.00am and sells from 8.00am until noon. Trade has been good and he turns over about Rs.300 each day, a modest sum but comparable to incomes for many people in the area.

Most importantly, pictured on the right with his daughters, describes himself as having a completely new beginning. He is confident and contented, enjoying the relative freedom of the work that he does now. Notably, the local *panchayat* has been instrumental in allowing to use the bus shelter, which is a favourable situation for his business.

Mrs S

Mrs S remembers the time when she got her illness around the time of December 2002. She used to hear certain voices that were disturbing. She used to keep silent, at times screaming, picking up fights, beating, etc. Children in the village were throwing stones at her. She expresses that her parents took her to various religious places and faith healers, they did not understand what I want. They spent 4-5 thousand rupees on this, which did not help her. During these desperation, they got in to contact with the local partner through other beneficiaries. The information about the programme was shared, she got benefited from the programme. Now Mrs S is stabilized and able to take care of herself and the family. She has even started a vegetable vending business with her father and makes around Rs. 100 per day and she feels confident of making her life with out depending on any one. She says, “20-25 people like me meet every month to share our experiences. As a group they worked towards getting medicines at Pavagada health center. The group actively participate in all the issue concerning their community. She told as I am vocal and share my experience, I like to spread message to more number of people, so that they can also benefit from such programmes and get cured from the illness.

BasicNeeds India through partnership with the community based organizations and non Governmental organizations has been working in parts of the 38 districts in Tamilnadu, Kerala, Karnataka, Andrapradesh, Bihar and Jharkhand.

BasicNeeds India is been working with ten partners directly and two partners are in turn working with the local groups/CBOs and implementing the programme. The table below would give more information about our partners and the districts where they are placed.

Organizations	**Districts covered**	**In few blocks of the District**
Grammena Abuyadaya Seva Samantha	Dodabalpura, Bangalore rural district	1
SACRED	Ananthpur rural mandal in Ananthpur district Papuly in Kurnool district	2
Narendara Foundation	Pavagada in Tumkur district	1
Urban programme- Bangalore slums	Association of people with disabilities Paraspara Trust APSA	1
Samuha	Raichur, Koppal and Karwara in north Karnataka	3

ADD India in Tamilnadu	Tiruvallur,Tangore, Podukotai, Tirchy, Teni and Dindigal, Kanyakumari, Nilgiris	8
ADD India in Kerala	Kumily, Kannanur	2
Vidyasagar in Tamilnadu	Vellore, Tiravurur, Erode, Tirunelveli	4
Nava Bharatha Jhakruthi Kendra in Bihar and Jharkhand	Hajirbagh,Saraikela Kharsawan, Ranchi,Daga, Palmu, Garhwa, Dumka, Nawad, Gaya, Patna, Musafarpur, Nalanda and Chakai	15

Basic Needs India

Basic Needs India is working with ten partner organizations in blocks of 38 districts. The situation as of today is

- Working in parts of the 38 districts in North and South India.
- Identified 8297 people with mental illness in the project area
- Treatment access for 5446 people and 4498 are stabilized.
- Gainfully occupied 3311 people with mental illness
- DMHP strengthened in three districts
- Inclusion and mainstreaming of people with mental illness
- Caregivers forums and associations have been formed
- Stabilized person with mental illness are actively advocating for their rights.
- Been able to succeed in making treatment available locally through government in at least 15 districts
- Accessing government schemes

Training approaches:

BasicNeeds India believes in consultation with all the stakeholders. BNI starts its work with consulting the field workers, supports them and builds their capacity so that they can identify and work with people with mental illness in their communities. Training needs of field staff of partner organizations have been identified, various workshops have been conducted in the areas of community mental health, sustainable livelihoods, capacity building, and research. The methodology adopted always will be participatory and using animation techniques. Field staffs are also been trained on other development issues like community participation and mobilization, communications, leadership skills and etc. This trainings has capacitated field staff to deal with the problems of families with mental ill persons. Inclusion of people with mental illness in the development programme is our charter, this would guide us in all the training programmes. BasicNeeds India believes that mental health a development issue rather than medical issue alone.

Care provided by the people

A different and better world for people with mental illness can be created through the community's understanding of issues related to mental health and a resultant positive response to the issues concerned. In this scenario the families of the mentally ill are vitally involved in such understanding. Through these an environment of mutual understanding can be built, where in people with mental illness enjoy their rights. The care for people with mental illness is seen in different level:

- Family members providing care to people with mental illness starts from baring all the violent behaviour, to accompanying them for treatment, than administering medicines, helping to engage in gainful productive work.
- Community providing support for the well-being of person with mental illness. This is seen in the form of not calling them as mad people, giving opportunities and advocating for the ensuring measures to meet the needs of people with mental illness
- Filed workers providing care for the people with mental illness and their families. This starts with identification, assessment, follow up, home based support and linking them to existing groups and mainstreaming
- Organization providing support to deal with other associated problems of people with mental illness and their caregivers. This is seen in the form of conducting camps, integrating them in to their existing programmes.
- Mental health professionals providing assessment, diagnosis and follow up support for people with mental illness. This is seen at various levels, conducting camps, providing services at the district hospitals, private practitioners involving in care and treatment, Home based support, and in district mental health programmes.

The caregivers do not recognize their role in the recovery process of their mentally ill person and often feels it is their responsibility to care for them. They often give credit to medicines, field workers and the mental health professionals. This led us to exploring of care giving roles of the people providing care for their mentally ill family member. The various roles of the caregivers, which are grouped as physical care, medical care, psychological care and social care has been listed down.

The innovative features of BasicNeeds India partnership with the local organizations is inclusion of people with mental illness in the development activities of the organizations. The programme is not seen as a separate entity. People with mental illness have been integrated in to the existing self help groups of the organizations or groups in the community. This groups act as an advocating agent in meeting the needs of people with mental illness.

Some illustrations:

Story of MS A

Ms A, 20 Year old from Tamilnadu hails from poor socio economic status. Prior to her illness she was working as housemaid, where in she had some precipitating event, which triggered her to get mental illness. As she was not productive, she was sent back home with out giving adequate attention. Due to the cultural belief system, family subjected her to black magician/village quacks treatment; this did not bring any change in her behaviour. The mental illness in her mother also became severe as a result she neglected family. Father was unable to cope with the situation, two of the elder siblings also left home as they were married. This resulted in the breakdown of the family, no one to care the ill people in the family. Relatives took the responsibility of supporting three younger siblings. As she was not cared, she ended up wandering in and around their village, at times she was found walking without cloths, sleeping in strange places. People were abusing her for odd behaviours; she was beaten up for entering their premises. The partner organization identified and facilitated discussion with the relatives and community members; as a result she was brought to treatment. Now after 2 years of treatment, her life has changes. Family is reunited. She has become a change agent in the village; she shares her experience and motivates mother to take treatment. She earns her daily wages along with the mother. She takes care of her younger siblings. She actively participates in the SHG Meetings and save money regularly. Ms A has become a change agent resulting change in the attitude of the family, relatives, neighbourhood and the community. She was treated in the community with the support of the relatives and the neighbourhood. It proves that community based intervention has less stigma and more scope for reintegration back in to the community life.

Volunteers:

The partner organizations are in constant search of volunteers, Few stabilized people with mental illness have become volunteers, who would help the field workers with identification, referral and follow-up, including integration into existing groups and action plans with families.. Some are members of the disabled federation and were clearly motivated to show that a disabled person can be ‘useful’. Volunteers also express that working with people with mental illness is easy and they could see changes immediately with the treatment, this would give recognition for them in their village which would give satisfaction, act as a motivator for their future endeavors.

Self help groups - Women

Self-help groups are a common feature of development work. In the work of BasicNeeds, they play an important role in the integrating people with mental illness in the mainstream, this would mutual support people in crisis

The self help groups runs with the motive of saving, this will be backed with the financial support from the institutions which would be circulated among the members. The members would design a livelihood option like cow rearing, weaving, petty shop, ram lambs and etc which would suits them. This would then be a source of regular income.

People with mental illness are active members of such groups, the groups have often taken the issues of mentally ill people and advocated for their entitlements in the panchyath. The groups also provide link for field workers of the local organizations and people with mental illness. The groups take the responsibility of following such people on a regaular basis assisting them in the livelihood programmes. The point to be noted her is that person will be not denied of membership because of the mental illness.

Caregivers Associations

Another important feature of BasicNeeds India is encouraging people with mental illness and their caregivers to form an association of their own. This provides platform for them to discuss various issues related to them and find solution to their problems.

To give an example, case of Mr B, whose family experiences unwelcome reactions of neighbours to their son? Mr B was wandering regularly in the streets, parents had to be found and brought back. The family attributes to the caregivers’ association in the village, which has helped them to over come stigma, the Association took the responsibility to explain the illness to others and enabled them to meet with other families in a similar situation. Mr B has now returned to work as a labourer and is maintaining full-time employment.

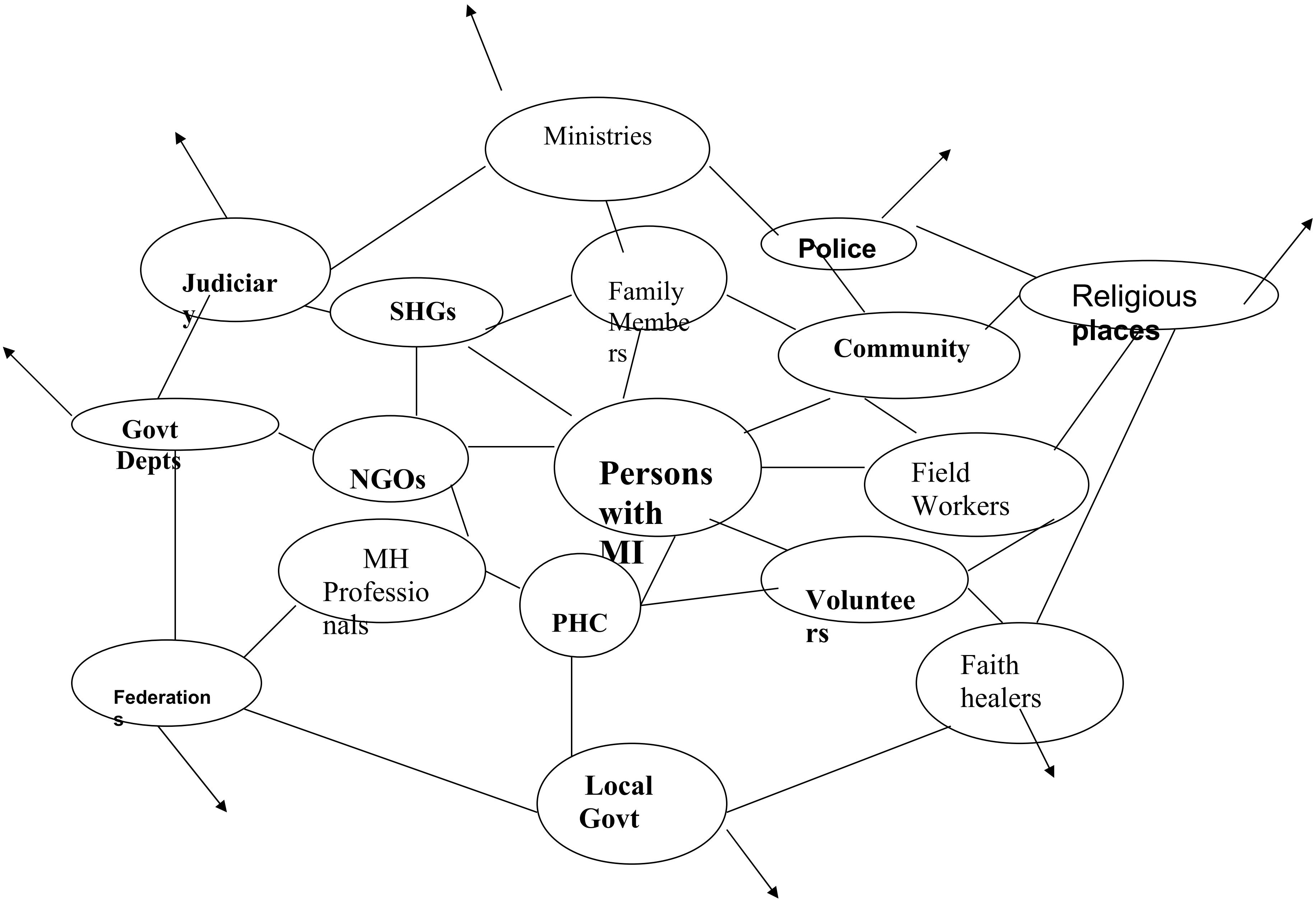
The caregivers association in one of the project area, took the decision to advocate for their right to treatment. As a result the association members met the district authorities, explained them the need for treatment to be made available at their block level. People with mental illness and their families decided to voice their needs rather than depending on the local organizations. This resulted in deputing psychiatrist to conduct mental health camps in the PHCs on a monthly basis, medicines also been distributed during camps from the government.

Awareness is generated through street theaters

Street theatre

Street theatres plays major role in generating awareness in the community. Street theatres are carried out regularly by the partner organizations. Some organizations also have formed troop for puppet shows. The local dialect and local experiences would guide them in performing the street theatre. The 'stage' would be simple, using all locally available resources. Banner also would be displayed which would summarise; causes, treatments and symptoms of mental illness, the purpose being to demystify the subject and to raise the awareness of the public of mental health issues. The street theatres would also through light on need for good care from the families and the community, which would go long way in rehabilitating people with mental illness. The message is also spread that people with mental illness can be treated at home as they do not require in patient care in the mental hospitals. The street theatre would be followed by question and answer session, where few people would come back with specific question, which would be addressed.

Several partners work together building an alliance among the mentally ill and their various supporters, to strengthen the community so as to be strong enough to address mental health issues currently prevalent and those that may occur in the future. The alliance building process took off in a big way in 2004 where all the partners and teams got together to form an alliance in south India in the process of the implementation of the community mental health programme. A chart was prepared to understand the community of the people with mental illness, which is like a web. This web chart is never complete in the sense that other relevant groups could be added as the process goes on expanding. Gradually larger structures are making an effort to support people with mental illness.


Ministries
Judiciary
Police
Family Members
SHGs
Religious places
Community
Govt Depts
NGOs
Persons with MI
Field Workers
MH Professionals
PHC
Volunteers
Faith healers
Federations
Local Govt

The illustration given below would explain the Advocacy efforts made by our partner organization and also bringing like minded people/ actors of mental health in a platform, they would advocate at the district, state and national level.

Towards Building an alliance of likeminded people

1. Awareness been created in the community with regard to illness, acts and the entitlements of people with mental illness. This has resulted in generating awareness among people, families panchyath members and etc. this resulted in creating an environment where people with mental illness started availing benefits of national prorgammes on poverty alleviation. People with mental illness who are stabilized have availed benefits of national employment guarantee scheme.

2. The district hospitals and the medical college of Ananthpur district did not had psychiatrist to treat 180 people with mental illness, been identified by our local partner. As a design people with mental illness have been included in to the self help groups of disabilities, they have become integral part of all disabilities groups. The federation took serious note of non availability of professional and the medicines in the district hospital. Conducted rallies, invited authorities for the world mental health day celebrations, press coverage, repeated representation to the district collector as resulted in the appointment of the psychiatrist in the medical college and the district hospital. This has also resulted in allotting separate ward for the psychiatrist patients in the district hospital.

3. When we initiated our work in Koppal district Mentally ill people were travelling for 10 hours to reach KIMH, Dharwad for treatment. The Organization of people with disabilities took serious note and advocated for the availability of medicines in the district head quarters. People availing treatment for their mental illness was registered in the District Hospitals, and the PHCs, this was supplied to the district collector asking him to take necessary action for making treatment made available locally. The district collector deputed psychiatrist from the neighbouring district to provide the services at the district hospital on one day in a week. The system did not continue for long as the psychiatrist resigned from the services. As per the directions of the high court, Government of Karnataka had trained medical officers on mental health for three months, who were designated as district mental health officers to implement the DMHP programme in the state. The state government did not allot funds for this programme, and the medical officers were assigned with other work. The local partner organizations, private psychiatrist and the district mental health officer combined together started working towards implementing mental health programmes in the Koppal district. Necessary steps have been made for the supply of medicines in the block and the district hospitals. The mental health camps have been regularised on monthly basis in 4 blocks. It is worth to be noted that the mental health programme has been implemented in the district with out budgetary allocation from the sate government. We also conducted training for the medical officers of the Koppal district who also actively participate in the monthly camps in providing services locally for people with mental illness.

4. In Jharkhand when we started our programme, people with mental illness and their caregivers were travelling from far of places to RINPAS for treatment. The hospital authorities were not prepared to conduct monthly camps in the few districts so that

people can avail services locally. This made our partner to write a petition to Human Rights Commission explaining the issues of people with mental illness in the state. As a result Human Rights commission invited our partner during their visit to RINPAS, It was decided in the meetings that RINPAS would conduct camps in two district head quarters, The partner organization has agreed to facilitate camps. This resulted in monthly camps in Hazirbagh and Sarikala.

BasicNeeds India in their network meeting with the donor organizations has been able to influence donors to include people with mental illness in their disability target groups. The donor organizations like CBM, CBR forum, ABILIS as a matter of policy have included people with mental illness in their disability programmes.

Lessons learnt:

A positive response from the community is at the core of BasicNeeds India programme. It is the community's understanding of mental illness and their favorable response that contributes to the healing and well being of vulnerable groups. When mentally ill people are included as members of the self help groups that access government schemes and when associations of carers are formed to address issues of mental health at local level, the evidence of community response is seen in the quote, a mentally ill person said ‘’ half of my family members and relatives know now that my mental illness can be treated and that people like me can be cured”. Such statements shows us the efforts of the field staff in demystifying mental illness and creating awareness among the community members.

- We are able to transfer basic skills to field workers and gain active involvement of people with mental illness and their caregivers in the treatment process
- Community mental health promotes high degree of collaboration and better social integration and mainstreaming
- Visible positive changes in people with mental illness, helps to generate awareness, motivation and improved follow up, family and community support resulting in mainstreaming
- Poverty exacerbates mental illness and reduces options for recovery. The consequences of poverty is the economic burden on the family leading to debt traps and in access to treatment
- When services are located locally it has more reach to meet the needs of vast majority located in the community and wider coverage with in existing system
- Mental illness can be treated with simple, relatively in expensive medication at the community level, only small percentage of them require institutional care. Early diagnosis prevents unnecessary investigations and promotes early recovery
- Staff and organizations gaining recognition in the communities on account of community mental health work

ON THE OTHER HAND

- Lack of social recognition and acceptance make them vulnerable to physical harassment, exploitation, and human rights violation
- High level of ignorance among all stakeholders on legal and policy resources

- Stigma and superstition attached to illness combined with lack of services lead to seeking treatment from faith healers that has ample adverse consequences
- Families have unrealistic expectations from people with mental illness (stabilized or not) and from the organizations.

Support for the care by mental health professionals

The mental health professionals play an important role in the process of recovery. They perform various roles like: Assessment of the illness, Dissemination of mental health skills for field staff

1. Field support to field staff in handling/helping people with severe and violent illness.
2. Diagnosis and treatment
3. Follow up services
4. Psycho education
5. Counseling to family members
6. Home based support for people with mental illness.

MAJOR CHALLENGES

- **Non availability of mental health professionals** and medicines in the project areas. BasicNeeds India have been collaborating with the private practitioner, which has lead to extending their services in the camps to reach vast numbers. There has been success in coordinating with the district teams for conducting training for the medical officers so that they identify people with common mental disorders in their day-to-day practice and refer them to camps for psychiatric intervention. Networking with the district authorities for the implementation of the district mental health programmes and for availability of psychiatric medicines in the district hospitals and in the camps has also been happening successfully.

- **Stigma and attitudinal difficulties**

Partner organizations are conducting series of awareness programmes through street theatres and small community group meetings. Stabilised people are involved in gainful occupation. This has resulted in generating awareness in the community about mental illness and in steady increase in self- identification of people with mental health problems. People with mental illness are encouraged to integrate in to the existing self help groups.

- **Inadequate attention given to the physical health of PWMI including food security, nutrition and the impact of low family income.**

Field staffs are making conscious efforts to ensure that people with mental illness and their families are involved in economic development activities to enhance family income. Increased family income would enable them to meet their other needs such as food security and nutrition. Efforts are also made to attend to the physical health needs both by the psychiatrists and general physicians.

- **Field staffs sometimes do not have adequate skills to work with people with common mental disorders.**

Training and retraining for the field staff are organised at all the project areas. Their counseling skills have been upgraded so that they can provide support to people with common mental disorders. Now the field staff are confident in identifying people with minor mental illness, referring for treatment and providing follow up services. In an attempt to promoted better helping skills we a promoting series of trainings for the field staff.

- **Difficulty in accessing disability certificates in all the districts.**

BasicNeeds India along with the partner organizations in the regional and network meetings has raised the issue on assessment camps for disability certificates. We have been successful in a few places, this need to be taken at large scale. Medical boards have been set up in all the districts. Some of the technical issues are coming in the way of issuing disability certificates.

- **High expectation from families irrespective of whether the person with mental illness is stabilised or not.**

Strategies need to be evolved, in order to tackle the expectations of the carers.

Conclusion

The rate of mental illness is increasing cutting across rich/poor, urban/rural. Though it seems like the states are taking notice of the gravity of the issue and attempts to address the needs of people with mental illness, let us be clear that, this lukewarm response is because of the pressure from the judiciary. Health including mental health is a fundamental right. Millions in India perhaps, don’t know that it is their right to avail treatment. People with mental illness are crying ‘ ’*My name is today*’ ’ Do we hear his/her voice?

Using community resources for psychosocial care in disasters

HarshMander,
New Delhi. and
R.Srinivasa Murthy
Bangalore.

Mental health is becoming a central issue for public health complex emergencies (WHO, 1992, 2001, 2003, Lakshminarayana et al, 2003, Mollica et al, 2004, Ghosh et al, 2004, SrinivasaMurthy and Lashminarayana, 2006). The article covers the current understanding about the use of community resources for psychosocial care The coverage is based on the experience of the authors with the Orissa Supercyclone .

The Need

In any natural disaster, large populations of women and men, boys and girls are suddenly exposed to intense, profound and multiple trauma and loss. In the space of a few minutes an hours, they frequently undergo more suffering than many people experience is an entire lifetime. Loved ones, homes, livelihoods, lifetime savings, dreams, hopes, ways of life, all may be ravaged forever. There may be grave uncertainty and despair about the future

> *We are on a wasteland – there's no other word for this vast soulless nightmare-scape of rotting slush, debris, mud, nets and dog and cat and human carcasses – in Akkarapettai, outside Nagapattinam. It has taken us over an hour to negotiate the slime and stench to where Dr Lakshmi Narasimhan – a tall, gently-spoken Salem doctor – greets the dusk with his team in the only way that makes sense in this post-tsunami miasma. They pick up andburnthebodies. This is only 500 metres from Akkarapettai – 500 hard-earned metres, yes, but a small distance really. But apart from this team – from the Democratic Youth Federation of India (DYFI), a CPM-affiliated organisation – nobody is out this far to do this work. Nobody. From what they tell us, there are dead bodies strewn all the way to where the sun finally sets; well, five kilometres in that direction, anyway. Nobody is interested in coming out even 500 metres; what will happen to those other bodies?*
> *Just getting here, we've seen at least three bodies on smoking pyres, at least five others just lying around. One's a little form, sex, age and even humanity wiped away, lying in a carton. Sprawled in the muck nearby is another. Brother? Mother? Who? In front of us is a collapsed hut; one body lies on it as if asleep. Two men lift the collapsed thatch roof; there are bodies below. They pull one out – a boy? – and put him on top with the other one. The others are too difficult to extract. Then they set fire to the roof.As we stand in the dusk, slime and stench, Veerappan, his wife Parvati, their daughter Pasupati, their sons Ganesh, Dinesh and Abhi – the names listed in a sodden exercise book at our feet – go up in flames. Dr Narasimhan and his comrades are done for today. They are already planning where in the muck they will go, first thing tomorrow morning.*
>
> *The day after (Tsunami Testominies, Jan 2005, by Dilip D'Souza*

Historically, post- disaster response both by state and non-state actors have tended to lay overwhelmingly greater stress on physical and material reconstruction is the wake of disasters than on mitigating and healing the emotional suffering, and the devastating and disabling psychosocial impacts of the rage of nature.

The neglect of the psychological impacts of disaster is greatest when affected populations are impoverished and socially and culturally distinct. There tends to be greater empathy when the survivors are ‘people like us’, the policy makers who allocate resources and priorities is disaster response. In India, as also in many countries of the world, there has been a growing awareness of the psychosocial consequences of disaster during the last two decades (WHO, 1992). The understanding of ways to actually intervene effectively in order to extend psychosocial support to survivors of disasters is relatively nascent.

The current account will attempt to outline the major psychosocial impacts of disasters, and some principles derived from recent experiences for ways to address these in the Orissa Super Cyclone 1998, by Action Aid India in collaboration with NIMHANS, Bangalore. The empirical data is derived principally form an Evaluations Report of Psychosocial Interventions with Super Cyclone Survivors in Orissa undertaken in 2002 by an independent team of Psychiatrists and social workers led by one of the authors of this paper, Dr. R. Srinivasa Murthy, Professor of Psychiatry, NIMHANS, Bangalore. The chapter will also draw upon the manual for Psychosocial care in disaster developed by NIMHANS and Action Aid India (2000) and by WHO (2005).

No one who experiences or witnesses a disaster can be psychologically untouched by it. The most commons immediate reactions are of anxiety tension and irrational panic. Some are shocked or numbed, unable or unwilling to accept the reality of their monumental loss. Some become euphoric because of their survival, others are racked by guilt. They believe that they are somehow responsible for the loss their loved ones, and are culpable because they saved their own lives.

Some people respond to a disaster by an extreme sense of disorientation, and talk and wander aimlessly, others become extremely withdrawn. Many are unable to sleep, become tense and hyper- vigilant always, interpreting every stirring of nature as the signs of a recurring disaster. Some experience ‘flashbacks’, reliving the trauma and terror of the disaster.

These responses are normal, and in some form or the other, occur even during individual tragedies in normal times. However, at such times, human social and cultural practices ensures almost universally that family members and friends typically rally around the person who has suffered the loss. There is solace and healing in rituals, religious and cultural practices.

In any major disaster, everyone- family, friends, community leaders, would have suffered; therefore there is mostly no one to extend a helping hand, or offer a shoulder to weep on. There is often no dignity in the disposal of corpses, no rituals, no opportunities and space for individual catharsis. The family as a unit may no longer exist. The unbearable psychological burdens are further compounded by the struggles for food and shelter, particularly if the distribution of relief is delayed, disorganized, inadequate and insensitive.

As the months pass, many survivors are unable to pull themselves out of their grief, losing interest in life, unable to rest to concentrate or summon energy; others seek solace in substance abuse or sex. There are some who become irritable and abusive. The NIMHANS study of Orissa found many victims especially widows and mothers were voices of their dead relatives (especially of husband or children). Some reported their presence around them and even felt their touch[21].

Predictably, the severest impact is on children. They may cry excessively, cling, have nightmares, wet their beds, or withdraw from study, play or friendships. The Orissa study reports that children were mostly crying for mothers, fathers (perhaps parents?) and for food. Some were almost always crying . Most were having nightmares and a few had somnambulism. Some children had almost become mute, they were not talking or eating and had socially withdrawal[22].

The NIMHANS Orissa study conducted two and a half years after the disaster found that the psychological needs in the survivor community is much greater than is any normal population. This is in broad conformity with meta-analysis globally, that shows that disasters increase the prevalence of psychopathology by approximately 17-20 percent on an average.[23]

Therefore, it is imperative for any disaster response plan to significantly address the enormous mental health needs of survivor populations. The response will contain social elements that have secondary psychological impacts, and psychological elements that have social impacts. These elements are so closely intertwined, that they are referred to as systems of psychosocial support.

To sum up, following disasters, it is well established that there is widespread need for psychosocial interventions among the survivors (WHO, 2003). The needs for psychosocial care among survivors of disasters is summarized (Table I)

TABLE I: Psychological problems among survivors of disasters (WHO,2003)

1. People with mild psychological distress that resolves within a few days or weeks
A very rough estimate would be that perhaps 60-80% of the quake -affected population falls in this group. These people need psychological first aid.
2. People either with moderate or severe psychological distress that that may resolve with time or with mild distress that is chronic
This group is estimated to be 30-50% of the earth quake effected population. This group would benefit from a range of social and basic psychological interventions that are considered helpful to reduce distress.
3. People with mental disorders: Mild and moderate mental disorder. This rate is likely to be – possibly up to 20% - after exposure to severe trauma and resource loss. Over a number of years, through natural recovery, rates may go down and settle at a lower rate, possibly at 15% in severely affected areas. Severe mental disorders. Rates for Severe mental disorder that tends to severely disable daily functioning (psychosis, severe depression, severely disabling anxiety, severe substance abuse, etc.) is 3-4%) after exposure to severe trauma and loss. Trauma and loss (a) may exacerbate previous mental illness (e.g., it may turn moderate depression into

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[21] *Evaluation report on Psychosocial Care of Survivors of Super Cyclone in Orissa. Sneha Abhiyan, Action Aid Bhubaneswar, NIMHANS. 2003. Mimeo)*

[22] *ibid*

[23] ibid

severe depression), and (b) may cause a severe form of trauma-induced common mental disorder in some people.

In most developing countries with limited pre-existing mental health services (WHO, 2005), organizing psychosocial care for the survivors of disasters is a challenge.

The Challenge

There is widespread recognition of the need for mental health interventions following disasters, whether it is the Tsunami of December 2004, the London bombings of June 2005, or the Katrina of August 2005, or the Kashmir earthquake of October 2005, people living in countries in conflict. The challenge posed in meeting the psychosocial needs of the survivors are manifold. Firstly, the numbers needing care are so large that even the economically rich country can not meet the need fully using only the mental health professionals as care providers and the treatment gap(what is needed and what is provided) is still greater in developing countries; secondly, majority of the population needing the care do not see mental health care as a priority; thirdly, due to the stigma of the label of mental illness , people who need care do not seek care even in well established systems of care like the war veterans; fourthly, the psychosocial care is not a one time need but a long term need, often over a few years, and for some people a continuous need; fifthly, the care, to be accepted by the survivors, has to be provided in the context of the culture, local traditions and community values; sixthly, the suggested/offered interventions have to be acceptable to the population and ideally should lead to self-help and empowerment and seventhly, the carers have to speak the same language as that of the survivors, which becomes difficult if the carers are from outside the area of the general population.

A recent report, a meta-analysis to establish the extent of compromised mental health among internally displaced persons, asylum seekers, and stateless persons based on 59 independent comparisons, showed that refugees had moderately poorer mental health outcomes. Interestingly, post displacement conditions moderated mental health outcomes. Worse outcomes were observed for refugees living in institutional accommodation, experiencing restricted opportunities, displaced within their own country, repatriated to a country they had previously fled, or whose initiating conflict was unresolved. Refugees who were older, more educated, and female and who had higher predisplacement socioeconomic status, and rural residence also had worse outcomes. In conclusion, the sociopolitical context of the refugee experience is associated with refugee mental health. Humanitarian efforts that improve these conditions are likely to have positive impacts(Porter and Haslam, 2005)

The Opportunity

During the last two decades, the above challenges have been addressed in an innovative manner by mental health professionals, especially by those working in developing countries, where the need is the greatest, by organising services using community resources.

There are two parallel developments of importance in this field. Firstly, a number of interventions have been developed that are non-pharmacological and utilses the culturally acceptable forms of interventions. Examples of this are, the "focusing therapy" in Afghanistan (Omidian, 2003)), use of "narrative therapy" with Sudanese refugees (Neuner et al, 2004) , the use of " writing down" the experiences; "9 step model" (Eisenbach et al, 2004) to mention a few examples.

The second equally important innovation is the use of the community resources for providing psychosocial care. The basic approach is to identify the crucial components of care and share these with a wide variety of persons in the community so that each group provides care within the limits of their competence. All of these community resources are supported and supervised by the professionals. Some of the skills shared with health workers, teachers and volunteers are: listening to the survivors, supporting members of the family, returning to routines of life, relaxation, externalisation of interests, games and play activities to desensitize children in the school setting and use of spiritual values.

A good example of the utilization of the community resources is the case study of the Supercyclone in Orissa in Eastern India.

The Supercyclone of Orissa

The Supercyclone hit Orissa on October 29, 1999, perhaps the most destructive natural calamity in India in the last century, with a wind speed of nearly 300kms. The incessant rains lasted for about 48 hours with a total downpour between 447 mm and 995 mm. The tidal waves from the sea reaching to 10 meters, struck the Orissa coast coming almost 15kms inland. There was massive damage to houses, vegetation, livelihood and the environment. Over 15 million people in the 12 districts were affected. Almost 20,000 persons were killed. There were 9885 deaths, with 8386 people died in one district (Jagatsinghpur district alone) of which 8119 deaths was reported in Erasama Block. About 1650086 houses were damaged because of cyclone as well as the ensuing flood. Almost 14901 primary school, 3425 high school buildings and 66 colleges were damaged.12000 km roads, 1447 bridges were damaged. Electricity supply to most villages was disrupted. With regard to the loss of standing crop, 1300000 hectare of paddy, 176000 hectare of vegetable crops and 257000 hectare of other crops were lost. 2 million trees were uprooted. There was extensive saline incursion in agricultural fields. In response to the super cyclone, the Government and Non-government agencies came forward for provide rescue, relief and rehabilitation of the affected in a concerted way.

Sneha Abhiyan or Campaign of Love

To meet the psychosocial needs of about 15 million population, there were only about 30 mental health professionals for over 20 million population of the State. Even these professionals were working in the cities, and in the most affected areas with nearly 90% of the deaths, there were no professional resources for psychosocial care. The rehabilitation attempts in the early days made one voluntary organisation, Action Aid (India) to realise the dangers of inadequate importance given to the psychosocial care following the disaster. The organisation made psychosocial care one of its priority. This resulted in the concept of Sneha Abhiyan “a campaign of love”. The overall goal of Action Aid (India) was to ensure total rehabilitation of the most vulnerable among the survivors of the Orissa super cyclone - children, women and old people who are left without the care of families and people who were under severe psychological shock and depression(SrinivasaMurthy et al, 2003) (Table II).

Table II: Main objectives of Sneha Abhiyaan:

- **Protection of the rights of the most vulnerable survivors of the Orissa super cyclone – children, women, old people and differently able who are left without the care of families.**
- **Ensuring the best possible psychosocial care and rehabilitation for these people.**
- **Strengthening caring responsibilities in the community and;**
- **Influencing the state policy with regard to these groups, particularly in the context of disaster.**

Sneha Abhiyan: Principles of psychosocial intervention

In attempting to address the profound mental health and emotional needs of disaster survivor communities, it may be assumed that the only major resource that is required is of mental health professionals especially psychiatrists, psychologists and psychiatric social workers. Since their numbers in a country like India are chronically short of the needs of the population even is normal times, their availability to directly address the psychological needs of hundreds of thousands of disaster survivors would appear impossible. In this perspective, although psychological burdens of survivors may even be acknowledged, the country currently lacks the technical resources to be able to address these.

What this view neglects, according to the design of Sneha Abhiyan, is that the greatest resource for healing and restoring the mental health of people affected by disasters of the survivors themselves, and the communities within which they are located. In the end, it is the extraordinary resilience of the human spirit itself that has enabled the human species to endure and overcome the severest of calamities - of war, famine and natural disasters through the centuries.

The fulcrum of our proposed strategies for psychosocial support to disaster survivors is therefore the community psychosocial workers (CPSW), who are lay volunteers drawn from survivor communities themselves. In a situation in which large numbers of mental health professionals are simply unavailable, there is no option except for the primary reliance on such CPSWs. However, it is possible to argue that even if sufficient numbers of mental health professionals were indeed available for direct interventions for all survivors even then for many interventions, CPSWs would be better suited and more effective.

The reasons for this is that the advice and support extended by the CPSWs would be generally culturally more appropriate and acceptable, and would also help rebuild the damaged social fabric.

The effectiveness of CPSWs in reducing the mental health burdens of survivor communities was confirmed - by the NIMHANS evaluation of the impact of their work in Orissa in the aftermaths of the super-cyclone of 1999.The study drew samples from both intervention and control villages and developed standardized tests of psychological morbidity among the respective populations. They found that the severity of symptoms was higher in the control population than in the interventions area. They confirmed also that there is a significant reduction in the symptoms reported in the intervention area, as compared to the control area where no such interventions were undertaken.(---[24]

However, it would be a grave error to assumed that CPSWs can achieve these results without the active enduring support of mental health professionals. Their support is indispensable in two important ways firstly in the identification and training of CPSWs and secondly, in providing an effective and reliable referral system for severe and persisting psychiatric disorders.

In summary, Sneha Abhiyan attempts to channelise the potential exists in survivor communities to themselves address, prevent, mitigate and heal the grave psychosocial impacts of disasters. However it believes that they can best achieve this in a sensitive and supportive partnership with trained and dedicated mental health professionals.

Sneha Abhiyan :Features of psychosocial intervention strategies

Selection and Qualification of CPSWs

The strategy required the selection of appropriate CPSWs. The qualification should be people who are observed to have naturally assumed community leadership in the aftermath of the disaster.

a) their willingness to work despite their own loss
b) their cultural acceptability, especially with vulnerable groups like single women, dalits and minorities,
c) natural counseling skills
d) an assessment of their own psychological resilience.

There should be a preference for women, dalits, minorities and persons with disabilities among the CPSWs.

In post-disaster Orissa and Gujarat, encouraging results were achieved with young CPSWs, both men and women around the ages of 18 to 35 years, mostly educated up to secondary schools. It was found that these young people displayed extraordinary sensitivity, psychological strength and dedication, and many came to be deeply valued by the communities in which they worked. However we should not generalize from this experience, and other models such as of middle aged non-literate women can be no less effective.

Training of CPSWs

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[24] ibid

The effectiveness of the CPSW depends significantly on the quality of her training. The training would need to be reflective, interactive and supportive, combining the transfer of counseling skills and technical inputs with social analysis.

The evaluations report of the Psychosocial interventions with the super-cyclone survivors in Orissa by the NIMHANS team summarises the process of training CPSWs (or S*neh-Karmis*- workers in the campaign of love) as follows:

The mental health team consisting of a Psychiatrist and a Psychiatric Social Worker trained a group of twenty trainers of trainees for a period of seven days in December 1999. The group was first allowed to ventilate their own traumatic experiences with the disaster. This was followed by the understanding of the impact of the super cyclone disaster in terms of the physical, psychological and socio-economic. Subsequently the types of emotional reactions to disasters at different points of time were enumerated. The practical guidelines for psychosocial interventions was given a major thrust through a variety of activities like role play, games and enacting a sequence of occurrence and looking at the psychosocial reactions and help by themselves. This was followed by demonstration of application of skills in the affected community for two days. The practical demonstration at the field level made the trainees to feel empowered/ confident that they can do it. The last session concentrated on debriefing and self care of the volunteer and outlined their specific tasks and roles. The tasks and roles were not specifically to take up psychosocial care independently but as a part and parcel of overall relief; rehabilitation and rebuilding activities.

The base training was followed by specific interventions for the children. A child counsellor trained the group on psychosocial counselling and play therapy for a period of one month. The children-training module consisted of understanding how creative means can be used with children and to develop some relevant material for use in play therapy. The methodology consisted of experiential exercises, examples and presentations of actual use with a child. The process of the training focussed on practical use of various mediums and presentations through charts. Similarly to work with women who lost their spouses a lady psychiatrist trained the volunteers for a period of two days. The training focussed on women and widowhood issues, the need to be acutely sensitive to issues of participation and empowerment, respecting their space, and avoiding blame. The training should not be a onetime event, but should be reinforced during monthly reviews and with longer inputs, possibly every quarter.

Intervention by CPSWs

Voices of CPSWs:

"Now after the psychosocial training, when I started talking to the people, I found I am able to talk lot more rather than just how is she. I asked many thing like about her sleep, about her health, her husband's behavior, about the future of her children, all of them responded and they felt very good to talk about their concern".

"It is not just giving away things or programme for the community, rather psychosocial work is for making the community to think about the programme about themselves and about their community. We talk a lot about all their concern."

"Psychosocial training is extremely helpful in the work. We have used the knowledge in

any interaction. Particularly this has made remarkable impact in the development of the motivation of the women to work and take up challenges after the riot with confidence. This also helped a lot to bring the community together and for binding the bonds of harmony."

NIMHANS/CARE India, Gujarat Harmony Project

Detailed manuals have been developed for CPSWs by WHO (2005) and NIMHANS in collaborations with Action Aid India (2000),.These spell out with detail and sensitivity the duties of CPSWs, and this handbook will not attempt to reproduce these here. However, some suggested interventions will be outlined, by way of illustration.

It is precisely because in a disaster, normal family, friends, social and cultural resources may not be available to help survivors deal with their loss and trauma that makes the intervention of external agencies essential. The CPSW becomes a source of individual strength support and healing, as well as a bridge between mental health professionals, government and aid workers.

The nature of support must be that restores the individual's own and family and communities coping mechanisms, rather than build lasting dependencies. The efforts should catalyze the building or revival of a 'caring community' in which each individual is supportive and involved in the well-being of others.

The first task of a trained CPSW would be to visit individual survivors, as well as organize groups meetings. The challenge would be of empathetic listening encouraging people to share their trauma, fears and aspirations. They would assure the survivors that their psychological trauma is normal, and would encourage them to grieve, but also to gradually commence normal activities of routine daily living and to find healthy ways of relaxation and recreation.

The CPSW needs to also work with the family and the local community as units. Apart from collective sharing and grieving it is therapeutic if several members of community take up a task together, such as of reconstructing a fallen school, teaching children, or taking care of single women and old people.

Voices of Survivors:

"In the group she talks to us all about family, daily life and the worries or about concern. It is not every thing solved, but I feel every one has problem so by talking many other ways of solution comes to me."

"After I started coming to the group meeting many of my family problems I started handling. As by various exercise, I understood I was just worried and dependent for every thing."

"Earlier I was just confused, not able to understand what will happen, always the fear and fear, tomorrow what will happen. I use to cry for half of the day, looking at the empty house. After she started coming to me, I started working. My house is not full but I feel satisfied and confident that I can take care of my children, nothing will happen."

Referrals

The success of the work of the CPSW would be contingent critically also on the strength and reliability of the referral systems. Referrals may be for more tangible material needs such as of shelter, livelihoods, schooling clean, drinking water, sanitation, health cares and legal entitlements.

At the same time, these may be for emotional and psychological problems that require professional interventions.

The CPSW would be trained to identify psychological problems at an early stage, and to intervene more intensively with such individuals and families. She would also be trained to recognize which persons need to be referred for professional care, and at what stage.

The first referral should be at the level of the primary health centre (PHC). It is highly unlikely that the medical personal in the PHC would have psychiatric training. In the aftermath of a disaster, it is urgent therefore, for a week-long capsule in service training in psychiatry for the doctors in all PHCs in the catchments area of which there has been the impact of the disaster. They also need to be equipped with sufficient psychiatric drugs.

Similar interventions would also probably be needed at the secondary level at the district hospital. Even the tertiary facilities in the medical college would probably require strengthening.

Caring of Carers

Too often do relief workers, especially those involved is psychosocial care take inadequate care of their own psychological needs. It is the paramount responsibility of aid officials at supervisory levels to ensure that this is done, that especially the front-line workers are emotionally protected, renewed and nurtured, to be able to cope in healthy ways with the enormous emotional burdens of their work.

The CPSW would encounter intense human suffering daily as part of her regular duties. The psychological burdens would be far too heavy for anyone but even more so for a CPSW who has also witnessed or been personally affected by the disaster. If adequate care is not taken, they may find themselves' burning out'. Early signs of this are an unwillingness to take a break from one's work even briefly, guilt if one indulges in recreation, disturbed sleep, irritability, crying easily, and depression. Unaddressed, these psychological problems can be compounded.

The solution is not clinical detachment on the part of the CPSW, because it is only the genuine empathy of the CPSW that will reach out and heal. However, care must be taken to ensure that a CPSW takes off at least one day a week for recreation and rest, daily finds time for exercise, books, music, friends, television or anything else she enjoys and shares with colleagues, family and friends.

Experience of Sneha Abhiyan:

Recognising the need for psychosocial care, a mental health team consisting of a Psychiatrist and a Psychiatric Social Worker trained a group of twenty trainers, all of them from the affected community, for a period of seven days in December 1999 (one month after the disaster). The group was first encouraged to ventilate their own traumatic experiences from the disaster. This was followed by the understanding of the impact of the supercyclone disaster in terms of the physical, psychological and socio-economic dimensions. Subsequently the types of emotional reactions to disasters at different points of time were discussed. The practical guidelines for psychosocial interventions formed the foundation of the training, using a variety of activities like role play, games and enacting an event and looking at the psychosocial reactions and help needed by the survivors. This was followed by demonstration for two days, of skills to use in the affected community. A practical demonstration at the field level made the trainees to feel confident that they can take up the care. The last session concentrated on debriefing and self-care of the volunteers and outlined their specific tasks and roles. The tasks and roles were not specifically to take up psychosocial care independently but as a part and parcel of overall relief; rehabilitation and rebuilding activities.

The community level intervention was carried out by 52 community level workers (Snehakarmis), all of them survivors of the disaster from the same survivor communities. These workers were trained by trainers, at the field levels in small groups with emphasis on practical work with the community. The topics covered were similar to those use4d in the training of trainers described earlier. These trained volunteers were then placed in the 35 intervention villages seriously affected by the Supercyclone. Initially these workers stayed with the single survivor residents in sheltered tents. Staying with the victims for 24 hours provided them with the opportunity to understand the psychological distress of the people, and helped them to formulate locally relevant psychosocial interventions. A group of mental health professionals from the National Institute of Mental Health and Neurosciences, Bangalore, India, (NIMHANS) developed manuals for the “Community Level Helpers” and the “ the general public”. The latter information brochure focussed on self-care among the survivors. (Kishore et al, 2000, Srikala et al, 2000)

The information booklets are unique in the sense that it addressed the psychosocial issues in a user friendly manner and was made available soon after the disaster. These were developed by a collaborative effort of professionals, voluntary organisations and the survivors and was based on their experiences. The manuals addressed the difficulties, reactions and issues in the aftermath of the cyclone. Further it provided information on how to reorganise and rebuild their own life and that of their families. The manual for the community level helpers addressed the lay volunteers, basic health workers, anganwadi workers, gramsevakas, national social service volunteers, civil defence personnel and other groups working with the survivors. These persons were a vital link between the affected population and the helping agencies arriving from outside the community. They knew the community well and had close ties with people in the locality. They were provided information on the principles of emotional support, understanding the impact of the supercyclone, types of emotional reactions to disaster, phases of the disaster responses, emotional support in terms of practical guidelines for psychosocial interventions with the general community and the special groups like women, children, specially abled and the uncared aged.

During the initial 3 months, the main activity undertaken by the community level workers was psychological support to survivors using different techniques. The workers listened to the victims giving time, understanding the victims losses and the reality of their life situation. Emotional support was provided by living with them in protected tents or frequently meeting them in community. They shared stories of bravery and fortitude from mythology and history. Sometime sharing the sorrow and crying with them, as a spontaneous reaction to the victims problems helped ventilation. They shared examples of others who were coping well. Sharing that the worker himself/herself had suffered similar trauma, and was being there to help, to share, to listen, to work for them helped immensely to build a rapport. Encouragement and engagement in daily activities helped the survivors towards recovery. Ladies were given some work and responsibility in the shelters. Distraction method was used frequently. Victims were encouraged to be self-dependent. They were given hope and assurance that the situations will change for better and that help was available. It was tried hard to prevent suicide attempt by remaining close to them explaining the futility of the act, the religious obstacles, children etc. as it was deemed appropriate. Religious activities (*bhajans, 'Asta Praharis', 'Saraswati puja', 'Gayatri japa*'- different typres of culturally accepted rituals associated with loss of life) were encouraged, which gave hope that God will take care of them. Many felt that if God had been responsible for their situation, then God would also take care of them, and give them the support to face it. Music cassettes containing songs describing the cyclone and its meaning helped people to cry. As a spontaneous response of the community thousands of copies of music cassettes were produced and marketed. "Mass Shraddanjali" or community participation in mourning rituals for all those who died in a particular village were conducted. There were community feasts on various occasions. During the 3-12 months, education and information about the living situation, rights, duties were stressed. Guidance on how to make best use of what resources were still with them, child care, education of children were offered by the workers. Assertiveness was taught and modelled. This was specially relevant to single women. Victims were helped with their livelihood activities. They were encouraged to continue the activities of daily living. Examples of local persons who have shown resilience and leading "normal" lives were used to model their own efforts. Individuals who had almost lost everybody in the family were grouped together to construct small units resembling families. They were encouraged to live like a family. "Sneha Committees" were formed which tried to understand and cater to the need of the community. Frequent community meetings were organized to discuss the problems faced by those without families and support and the developmental programmes available. In a few instances marriages of widows were arranged through the help of the villagers. Self Help groups were formed which helped each other on rehabilitation, economic matters, problem solving, giving mutual confidence etc. Meeting with lawyers were arranged for legal advice. They were also helped in banking. "School chalo" rally was organized to take children back to school. Plays (like street plays) often with mythological content were enacted to convey mental health messages. Role plays were conducted to teach various techniques of assertiveness, coping, ventilating etc.

There were a number of issues that emerged in the provision of psychosocial care by the workers. At the level of Snehakarmis, most of them felt inadequate in the amount of knowledge and skills they had to care for the community; they felt inadequate in group-counselling; there were periods of self doubt / guilty feelings. At times, shifting of the place of work hampered continuity of care. In some there was gradual decrease in motivation because of lack of guidance. Some workers experienced gender, age related difficulties in communication with older population. Since most of the community workers were young females, gossip and suspicion in the society about different motives (sexual, etc.) of the worker interfered with the work. Workers experienced the burden of distribution of relief materials with associated lack of adequate time for psychosocial interventions as part of their overall responsibility. Sometimes, over identification with community like considering the victims as family members interfered with objectivity. At the level of recipients, at the initial stages, most of the ladies were shy, some were crying inconsolably; a few were mute and difficult to communicate. There was social inhibition in talking to the workers, as outside the family and community. Taboo against taking psychological help was another barrier. Some survivors were very argumentative, quarrelsome suspecting the motives of counselors. There was un-cooperativeness when financial expectations of compensation, help to rebuild their homes were not met. Some survivors showed lack of enthusiasm, as improvement was not so quick and some survivors were not able to see the value of psychosocial support. At the level of community, discrimination against women workers and discomfort with women empowerment, expression of negative discouraging comments, threats for the workers and their work, challenges from political and power groups, were seen. Some men complained that the workers were giving more confidence to the ladies than what is acceptable to the community(some persons commented "you have made the ladies defiant"). There was unnecessary interference from relatives when money matters were involved. Talking to victims of opposite gender were not accepted properly in the society. There was taboo against psychiatric illnesses and people with obvious emotional problems were being commented as "pagal" (mad). Some people in the community felt that these are girls from the same village, 'what really can they do' and some family members often hesitated, prevented the survivors to attend the meetings or take help.

It was interesting to see the preexisting community problems and practices assume special importance during the rehabilitation phase. Some of these were: attitude of the general public towards women was often cited by most of the workers as a barrier to psychosocial care; food for work was not uniform in different areas, which was bringing in discretionary treatment to victims and interefered establishing rapport with some survivors; physical problems in reaching people in remote areas; the approach of other NGOs' in disaster work was different and did not include psychosocial care and emphasized only on physical support; high expectation from people on material gains from the volunteers; management of too much of money when family members expected a share of the victims' benefit.

The worker level facilitating factors were interest to serve others, altruism, patience, good communication skills, ability to accept a person uncritically, good social behaviour, ability to empathise and sympathise by the workers; positive feedback and encouragement from the beneficiary helped most. At the level of community, encouragement, acceptability of interventions, cooperation, support, suggestions from village elders, support from self-help groups were very helpful.

The impact of psychosocial care was quite visible. Most of the victims were rehabilitated in the community. There was a change from feelings of 'hopelessness' to motivation to live a better life. People had understood the value of psychosocial care. The attitude of desire to survive, self sufficiency and looking to the future optimistically was noted. Community as a whole was feeling more secure. There was more understanding and cooperation and less jealousy and quarrels among the community members. Victims were confident that they could survive the new life situation against all odds. They were able to see meaning in life and had 'reasons to live'. Some said that they were alive because of the timely psychological help they received. Acceptance of the emotionally disturbed persons had perceptibly increased in the community. Emotionally disturbed persons were no more being called as "mad". There was increased awareness of women rights, children's' rights and an increased ability to fight injustice. Assertiveness of the women had increased. Standard of care of children and women in the community had increased. Psychosocial care had improved the utilization of various developmental programmes. From a very inactive amotivated state, survivors improved to a state where they started asking for what they deserve, took relief, decided for themselves on what needed to be done. They sought for livelihood measures and started working on them.

One strong observation from the work was the important role of the professional support for the workers. Though the initial psychological reactions of most persons, came down with the support and help available locally, there were few individuals who had extreme degree of reactions immediately after the trauma, for whom it was felt that professional help was needed. The groups who needed professional care were those who had lost family members, who were mute, or crying always, neglecting personal care, had insomnia, were suicidal and those who had other extreme degree of reactions. The ones with more protracted and more severe form of reaction to stress needed psychiatric help. The need for professional help became more evident as the days passed by and the reactions of most persons came down; when the more difficult to manage cases, became clearly evident. The problems were suicidality, dissociative disorders especially convulsions and unresponsiveness, nightmares, odd behaviours (possibly psychosis), sleep disturbances, sexual problems, etc. Workers needed help in dealing with persons who according to them were suffering from 'hysteria' and 'craving for sex'. The need for professionals was also felt when guidance on the difficult cases seen in community was required. There was need for medicinal treatment and psychotherapy. However a few workers also felt that there was no need for medication for these patients as their reactions were understandable considering the magnitude of the trauma. This suggests the need for further training. Periodic follow up of the patients was also needed. To bring about changes of attitude of the community and for motivation for life style changes professional help was required. Social problems like begging, abuse of elderly and children, indiscriminate sexual activity by many were other problems which required help from professionals. Workers themselves needed professional attention. Often the workers were getting frustrated and felt helpless during their work. It was felt that the help from the professional should be timely, easily accessed during times of need. Technical jargons used by many professionals were not properly understood by the community and even workers.

Similar experiences of working with various community resources are available from India (Lakshminarayana et al, 2003,) like following the Gujarat earthquake in 2001, school teachers took up psychosocial interventions; earlier following the Bhopal disaster, for want of psychiatrists, general medical officers were trained in mental health care(Srinivasa Murthy et al, 1987),the communal riot survivors work(Kishore et al, 2000, Srikala et al,2000), post-tsunami psychosocial care(WHO-SEARO,2006) .
There are similar examples of the use of community resources in other developing countries like Afghanistan, Iran, Lebanon, Palestine, Phillippines, SriLanka (Prewitt et al, 2006).

What are the supports needed for the community level personnel to provide psychosocial care?

The experience of Sneha Abhiyan confirms that important factors are the selection of the people to provide psychosocial care, the initial training and most importantly the need for long-term continuous support is the theme that emerges from the many experiences. The workers dealing with a wide variety of needs of survivors need to meet periodically with professionals to get guidance and support. From my own two decades of experience, this can be about once a week for about one hour either in a one to one situation and still better in small groups of 6-8 workers with one professional. These sessions also can become supervisory sessions. Bereft of such support, programmes tend to loose focus or there will be “burn out” among the workers.

Conclusion

There are many advantages to the use of community resources for psychosocial care following disasters and in conflict situations. Firstly, the community resources are always available, even after the worst disasters; Secondly, these people are culturally sensitive to the needs of the population, speak the same language and are accepted by the population; thirdly, there is no stigma attached by the survivors to psychosocial care ; fourthly, it is possible to reach all of the population by this measure and lastly, in a number of situations the sensitization of the population and planners to the psychosocial needs in disaster survivors has led to reorganization and rebuilding of the mental health services.

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Addressing mental health and related social issues: the Roshni initiatives

Ravinder Kala,
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Ludhiana.

'Far away there in the sunshine are our highest aspirations.We may not reach them, but we can look up and see their beauty, believe in them and try to follow where they lead'.

The challenge

Mrs. A was married at the age of 17 years to a 40-yr-old man 12yrs back. She has three children – a 10-yr-old daughter, and two sons aged 6 and 4 years. Her husband was drinking regularly. During the last 3 yrs, he started drinking excessively, became more violent and used to accuse her of talking to some man on mobile phone, which was not true according to the other family members. He stopped giving her money for household expenditure and she felt that her children were being deprived of the basic needs. Their conflicts increased and she sought intervention from his brothers who tried to talk to him but these interventions did not help. Whenever he would beat her, the family members would come and talk to both of them to sort out the problems but the problems continued. Their conflicts increased and one night he came back at 11 P.M. completely drunk and started shouting at her repeating all past conflicts. He threw the food when she offered it to him. Then he started beating her violently to the extent that her forehead started bleeding. He kicked her, dragged her out on the street and picked up the sleeping children and threw them out as well. The neighbours stood as passive spectators but no one could intervene or stop him because he started abusing them and told them to keep off his family matter. She was lying there on the street injured and bleeding in body and soul along with her three children crying desperately but no one dared to help her. Finally, he went inside and someone rang up her parents who lived 5 km away and they came and took her and the children. After a few months, *Mrs. A* and her parents approached *ROSHNI* (a registered NGO in Punjab dealing with the protection and care of women, children, elderly and people with mental illness) to assist them in getting some financial support from the husband so that she could bring up her children while staying with her parents. She had now decided that she will never go back to him and to the life of torture and humiliation that she had suffered for so many years. Her daughter became quiet and withdrawn and was afraid of everyone because of the trauma of that violent episode.

The work done by the Roshni team included helping *Mrs. A* through psychological counseling in handling her emotional trauma. The counseling process also focused on helping the children deal with the emotional repercussions of the incident, particularly the daughter who had stopped going to school and was afraid of everyone. Problem solving processes were initiated to help her get financial assistance from the husband. The husband also came for counseling and wanted to take her back but did not agree to stop drinking or undergo de-addiction process because he felt he had a right to drink. He also did not guarantee that he won't beat her justifying that he had a bad temper which was beyond his control. After a few sessions, assessment of the marriage was made and it was felt that this was not a safe marriage for the woman and her children because the husband was an alcoholic and was a short tempered person with a tendency for suspiciousness after drinking. His brothers refused to take any responsibility. However, he was willing to give some money for the care of the children if she allowed him to meet the children regularly which she simply denied. Finally, after a few counseling sessions, a compromise was achieved where he could meet the children once a month and he agreed to pay the maintenance for her and the children. She said that she was afraid of him and didn't want to go back. After assessment of the marriage, she and her family decided that she would continue to live with her parents and take care of the children. Roshni helped her in getting trained in stitching work and got her a sewing machine so that she could earn additional money through productive work. This training empowered her to be self-employed and she was able to support herself and the children in the safe environment of her parent's house. For one year, she underwent regular counseling with Roshni team which further helped strengthen her coping skills.

Helping Proceses

We would like to emphasize here that most of the times, efforts of Roshni are to save the marriages. This objective is achieved by offering follow-up marital counseling services to strengthen the relationship and also taking care of the emotional problems experienced by the children due to marital conflicts. We also provide psychiatric treatments and counseling for those families where the marital problems were associated with mental illness or drug/alcohol abuse in either partner. Only in some situations where the assessment of marriage shows that the woman or children are unsafe, there is no financial security (e.g. the husband has mental illness, abuses drugs and refuses treatment and there is no responsible relative to assure support) or if there are serious differences among the couple and they decide to separate, then we help them achieve amicable separation.

Organisation

ROSHNI (meaning *'light'*) formally came into existence on 13th September, 2003 at Ludhiana in Punjab. The initial work started in May 2001, when a group of like minded people decided to work together to make a difference in the lives of people who were experiencing psycho-social problems leading to the deterioration of their mental health. Dr. D.J.Singh, *Ph.D,* psychologist and Deputy Director with Punjab Police Academy is the President of Roshni. Dr. A.K. Kala, *M.D.*, former Professor of Psychiatry at CMC, Ludhiana and a senior practising Psychiatrist is the Vice-President, and Dr. (Mrs.)

Ravinder Kala, *Ph.D,* a counseling professional with 30yrs of experience is the Secretary General of this organization. Along with a group of dedicated volunteers, we all are trying to make a small contribution in helping people experiencing life problems.

Domestic Violence

We initiated our work with the victims of domestic violence. started this work by setting up a 'Crimes Against Women' Police Counseling Cell at Ludhiana in Sept 2001. During our experiences, we found that a lot of domestic violence and crimes against women were associated with alcohol/drug abuse by the men in their lives (husband, father or brother). Counseling process and police protection together helped in alleviating the emotional problems experienced by women and their children.

From September 2001 till June 2006, 5538 cases were referred to the police counseling cell for marital disputes. Out of these, 35.4% applications were filed because they either sorted out their problems themselves and withdrew their complaints or these were not related to marital issues but other conflicts like property disputes. 40.4% marriages were saved through counseling process at the Police Counseling Cell. Training programmes for the volunteers from the public and non gazetted police officers who were posted in the police counseling cell were carried out.The training process focused on the basic counseling process and the ethics of counseling. A panel consisting of two volunteers and one non gazetted police officer counseled the couples. Each panel had at least one woman. Prpfessionals worked in a panel once a week and provided supervision for difficult cases during the meetings held once in a month. During these counseling sessions, During these counseling sessions, issues related to domestic violence, financial problems, extra marital involvements, marital problems associated with mental illness, alcohol/drug abuse in either partner and adjustment problems among the couple and the families were worked on. Another 17.6% people had irrevocable adjustment problems and they decided to go in for mutual consent divorce. Amongst 4.1% of the clients, where there were serious dowry demands and women experienced physical and mental torture, a police action was ordered against the husband and his family. However, 2.6% are still pending and the counseling process is going on.

If we exclude the filed cases, we find that 65% marriages were saved, 29% were divorced and only 7% police FIRs were registered against the husband. All the applications sent to the police were for FIR registration. The counseling cell played a significant role in handling the marital problems efficiently.

During the work at the police counseling cell, it also came to light that a large number of people were reluctant to seek police help for their personal and family problems because of the stigma attached to it. In other cases, although the husband and his parents appreciated the counseling process for resolving the marital problems, still they felt that their daughter-in-law had insulted them by approaching the police. Hence the need was felt for starting an NGO to offer help to a large number of people experiencing a multitude of life problems.

Roshni evolved with a broader aim of reaching out to the people in their community and work through their problems. Roshni members and volunteers started their work by developing awareness programs. We carried out awareness programs for victims of domestic violence. We have also had awareness campaigns for Human Rights with a special focus on rights of mentally ill, rights of women and child rights.

Awareness Programs of Roshni

The mental health professionals associated with Roshni visit schools and colleges and interact with students with the objective of bringing to surface the emotional problems experienced by them. We conduct "Family Life Skills Training Programs" for college students to help them strengthen their internal resources and to equip them with psychologically adaptive coping skills for dealing with problems of life more effectively. These programs also focus on handling the problems experienced by youth regarding their future plans and relationship problems with their friends as well as their parents. A large number of students have questions about life problems but they do not have a forum where they can discuss these and seek help. We feel that such programs play a major role in educating the youth about life.

Adopting a Village

Roshni has adopted village *Jassian* with a population of 5000 on the outskirts of Ludhiana City. Here, Roshni members work along with the panchayat and some dedicated people from the village who help in coordinating the activities in the village from time to time. One of the first steps undertaken by Roshni was to involve people with initiative and willingness to work for the development of *Jassian*.

Making Village People Members of Roshni VolunteerTeam

During our initial visits to the village, a lot of work was done in developing rapport, selecting active and interested village people who would coordinate the work with Roshni members. The village team included the Sarpanch Mr. Major Singh, an active ex-Sarpanch, Mr. Baljit Singh, Dr Ashwani Kumar, the village Dispensary Doctor, three educated farmers and three educated housewives. Mr. Davinder Singh and his wife Mrs. Sarabjit Kaur who had come back to their village after living a few years in Canada have also been actively involved in the work of Roshni as an integral part of the village team of volunteers. These volunteers help us by presenting a broader picture of the problems being experienced by the villagers and their expectations from Roshni. These volunteers are invited to participate in all the Roshni functions.

The Village Survey

Besides the information given by the village Roshni volunteer team, a general survey of the village was done to assess the extent of alcohol/drug abuse, domestic violence, school dropouts and unemployed youth. During this survey, it was found that 1.4% of the population had serious mental illness, 1.1% had mental retardation and 0.7% had serious drug addictions. About 10-12% of the families surveyed reported domestic violence. During this survey, it was also found that many young boys whose fathers were farmers were not interested in farming as a profession. They were not much educated and were not trained in any skills, so they couldn't get jobs. These young boys just whiled away their time, experimented with drugs and sometimes got into street fights. The economic problems of the villagers led to a number of family conflicts and frustrations. The village school is upto X class and most girls had to stop studies after X because the village didn't allow their daughters to go outside for higher studies.

Counseling the Victims of Domestic Violence

After these assessments, we started having regular interactive sessions with the women and youth of the village in order to understand their problems. Roshni members which incuded educated housewives, businessmen and some working women along with the village volunteers which included educated housewives and two farmers and the village doctor were trained in counseling & case assessment Counseling the victims of domestic violence and their families was the first step to help the women. The counseling process helped them in resolving the emotional conflicts and repercussions associated with the trauma of domestic violence and many other life-problems.

Camps for Treatment of Alcohol/Drug Abuse and Mental Illness

The team of mental health professionals,along with some Roshni members trained village volunteers and the village doctor started visiting the village once a week for screening and treatment of mental illness, alcohol and drug abuse. The village dispensary doctor, Dr Ashwani Kumar also co-coordinated with us and motivated the psychiatry patients to visit the dispensary on the day of our visit so that we could treat these patients adequately. These weekly visits by Roshni experts took care of a number of acute psychiatric problems of the village.

De-addiction camps were organized along with the help of the village doctor. During these camps, mild to moderate cases of addiction and those with irregular drug and alcohol abuse were treated. Regular follow-up counseling of these addicts and their families continued during the visits of Roshni mental health professionals. Those with serious mental illness and those with serious alcohol and drug dependence were treated by admitting them free of cost at the Psychiatric Hospital. But the outcome in case of irregular drug users was not good because they were unemployed and continued to experiment with drugs out of frustration and this caused a lot of anguish to their families.

Rural Employment - An Innovative Scheme

It was decided to develop employment opportunities for the youth of village *Jassian.* Committed Roshni members, Mr. Kewal Budhiraja and Mr. Rakesh Jain run hosiery businesses in Ludhiana and Mr. S.B. Singh works as a manager in an industrial unit. These people often come across situations where unskilled and semi-skilled labour is needed for the industry. As the first concrete step towards this direction, an interview camp for employment was organized in the village where a large number of youth and middle-aged men and women came and got them registered for employment. Out of 670 people registered, 50 were found to be appropriate for jobs and were employed within one week. The process of identification of suitability of candidates and the availability of jobs is steadily going on and more and more youth are getting employed. Some of them are recovered drug addicts who got saved from the negative cycle of economic problems and frustrations that take them back into addiction. Instead, they are being perceived as capable, earning family members.

Arranging Soft Loans for Poor Farmers

When there were crop failures, the villagers had to take loans at high interest and got into debt traps. Hence it was decided to help the poor farmers through bank loans. A cooperative bank manger was invited to interact with the villagers to help them in getting soft loans for farming and for starting self-employment.

Thus, Roshni members are taking small but significant steps in highlighting the problems experienced by the people in village *Jassian*. We have a good working relationship with the people. They are enthusiastic to work in collaboration with Roshni for the development of the village. We have plans to start vocational training center for the youth so that the economic development of the village keeps growing. An enthusiastic village couple, Mrs. Baljit Kaur and her husband have offered a room in their house to Roshni for starting the proposed vocational center for the youth of *Jassian* village. We also hope to adopt more villages and start similar programs, thereby developing a networking among the villages for mutually sharing their experiences and learning problem solving strategies from each other. Roshni also has on its agenda, a day-care center for the adult mentally retarded children to help them learn some vocational skills leading to rehabilitation and bringing them back into the mainstream.

One other activity undertaken is to address the gender bias against girl child.

CONCLUSION

Roshni initiatives show how a small group of professionals and some dedicated volunteers along with the active involvement of the community have collaborated their efforts in making a significant difference towards handling mental health and social issues at the local level.

We would like to close this chapter with an optimistically positive comment for Roshni members from Mrs. Baljit Kaur, a housewife from village *Jassian*. She remarked, "If you people have the determination to reach us and spare your valuable time and money for us, then why should we not cooperate with you in your endeavors which are for our benefit."

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SECTION VII

CONSUMERS

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Mumbai.

I stumbled upon the realty of how much a peer can do to a distressed individual when one day at my office an inconsolable Lakshmi, now grandmother, 72 years, suddenly started being attentive and listening to a member of Dignity Foundation, who happened to sit beside her in my office in Dadar, Mumbai some eleven years ago.

This is what happened

Grandma Lakshmi : “I cannot understand why my grandson, now 34 years will not spend time with me anymore. He does not talk to me at night when he comes home from work. He goes out on Sundays also from morning to night. My loneliness is not something he understands. For thirteen years I have been putting up with this treatment and I have nowhere to go.” So saying she started crying with heavy breathing and body shaking vehemently.

Mary Fernandez who also came to see me for some other problem looked at Lakshmi and said: “Do you know my daughter also behaves the same way. She even denied visitors coming to see me”. For the first time Lakshmi stopped crying and started listening to what Mary had to relate to her. In another one and a half hours Lakshmi and Mary went away together, arm in arm, and to this day they work together in our project called Dignity Companionship.

It was born out of my realization, sans any professional knowledge, that people can console and help each other and in so doing each one acquires a certain power over themselves and the difficult situation. As Social Worker trying to attempt to find solutions to problems of older persons, it occurred to me that I can utilize the entire subscriber base of my magazine Dignity Dialogue, the magazine for Productive Ageing, to counsel and support others in difficult circumstances. When 128 people out of 2000 responded to my call to come over for a meeting on loneliness mitigation in September 1995, the first service ‘Dignity Companionship’ was born. This was to be a precursor to another 20 services all of which came to rely on the same backbone – seniors as volunteers.

Productive Ageing

I set up Dignity Foundation as a charity to promote “productive ageing”, premised on scientific evidence that ageing is keyed to the level of vigour of the body and continuous interaction between levels of body activity and levels of mental activity. In fact age-related deterioration in most mental functions can actually be reversed. Research in gerontology and neuropsychology shows that mental activity makes neurons sprout new dendrites with which to establish connections with other neurons. The dendrites shrink when the mind is idle. To put it simply, a person who stops solving problems arrives at a point where he cannot solve problems. Lesson: Keep active.

To hail academic theories that actually help improve the quality of longer lives we are living today is not a bad proposition. In fact such knowledge can actually pepper daily life, and senior citizens can be self-goaded into adopting such "productive" postures. Knowledge is the most basic intervention that serves to dispel "ageism" – the falsely held stereotypes and myths about older people.

But what does one actually "do" in a society where such negative imagery of old people and discrimination is at its rampant worst. Witness, for instance, the plight of Dignitarian E A Abraham (81), Mumbai, who wanted to enrol for a course in a local college to learn Sanskrit. He was denied admission everywhere on account of his age. He therefore took to working for a Ph.D degree in Bombay University because that was the only possibility that did not have age bar. He successfully obtained a degree in Sanskrit when he was 75. Instances of denial of opportunity for productive ageing run into tomes of gerontological literature documented in ***Dignity Dialogue**,* the monthly magazine for productive ageing, where subscribers give vent to their agony, disappointment, disillusionment, and even betrayal.

Provision of structural opportunities to facilitate older people is then the challenge we face in India today, as the country's age profile assumes similar trends as in the greying Europe and silvering Japan. As sociologist Dr Parthonath Mukherjea, former Director of Tata Institute of Social Sciences, said in July 1996 while presiding over our first "convocation" of senior citizens who successfully learnt computer skills in our classes open only to old people, "individual NGO initiatives in providing such top end opportunities are extremely significant in the face of India's demographic trends. More than the government, it is the NGO sector that seems to come up with innovative ideas."

As social worker and a student of sociology, running services for senior citizens' life enrichment, it is my experiential finding based on our eleven years of everyday contact with seniors, that in India, the middle class, educated seniors are very quick to take to the need to practice 'productive ageing' activities. However, one crucial finding arising from our experience of providing second career prospects is the fact that in sharp contrast to western societies' emphasis on post-retirement leisure, holidays, good food, fun and frolic, Indian seniors are eager to embrace opportunities for social work. He/she places a higher evaluation of work ethic involved in social work rather in pastime leisure and fun.

The proof of the above statement is seen in Mumbai where 663 Dignitarians, in a unique collaboration with the Bombay Municipal Corporation (BMC), have got into the project of ***Cleaning Mumbai with Dignity***. Their morning walks have got converted into talks with BMC sweepers on the streets; their weekly social has turned into a meeting time for sharing of civic problems and redressal methods through the municipal ward officers; and the celebration of Independence Day has got clubbed with what they have titled as 'Freedom from Garbage Andolan'! Senior citizens have now created opportunities to act as community leaders whereby they help citizens not to throw garbage on the streets, and their own 150 "Model Streets" are offered as show cases to other citizens to follow suit. Sorting of garbage and composting within the compound is the training they are presently undergoing. A tremendous enthusiasm for the environment guides their need to keep active and socially integrated. They stand testimony to the dictum that social participation is senior citizens' best antidote to decline that is normally associated with age.

Or take their Helpline , for instance, where nearly 200 senior volunteers are working on providing companionship services to lonely seniors. "Sometimes elder-callers talk for over 40 minutes too, as they relate their life stories" said Shashi Patni (61), working for the fifth consecutive year on this project. The volunteers, all over 50 years, have been able to reach out to abused elders, where children or relatives have harassed them on matters relating to property. "By being there for older people in need of social support, we ourselves are relieved of the boredom and depression that used to bother me so much", says Metrani (85).

Launching of Dignity Walking Patrol, a vigilance project for Mahanagar Gas Ltd. in 2003 is another example of how senior citizens become the conduits for keeping other senior citizens and the community free from damages from gas pipe bursts. About 320 Dignitarians are utilized by Mahanagar Gas Ltd. whereby during their morning walks they also undertake to observe how many roads are dug in the vicinity and report the same in a systematic manner every day. In the bargain they also earn a honorarium for the social service rendered.

Productive ageing should not be restricted to the narrow limits of gainful work. Second career or post-retirement pursuit should be ideally defined as combining the best of work and leisure. When productivity is broadened to include work beyond participation in the labour force, to embrace activities undertaken with passion,(something you have always wanted to do, but could not in your first career), it assumes sociological significance. First, it is useful in arguments of the politics of intergenerational equity. Showing that late adulthood is still productive helps to refute the notion that the elderly are only a drain on family/societal resources. Second, the definite psychological benefits of productivity for the elderly themselves – such as better health, motivation, cognitive functioning, life satisfaction or self actualisation etc. Third the sociological relevance of productivity for social integration and participation. To the extent that urban India is very much a 'work society' productive work is a major link between society and individuals.

The crowning expression of productivity among senior citizens is self esteem – dignity. What the senior citizen in India wants is not fame, name, money, or fortune, but dignity. To be not only conscious of it, but also to be seen to be productive has an enormous amount of value addition to his sense of self importance. When the grandchild sees his grandfather organising his life with meaning and purpose, the former entertains not only a certain pride in owning up the latter, but actively indulges in even exaggerating grandpapa's busy schedules. The younger generation is happy to be proud children of productive parents and grandparents, who have in a manner of speaking learnt to look after themselves, and keep themselves busy and engaged in meaningful pursuits. This is our actual finding borne out of personal meetings, correspondence, articles and interviews that Dignity Foundation has had. He/she wants to live the rest of his/her life with self respect.

Ancient and medieval visions of ageing as the renouncing-focused end part of life is fast changing, making way for the secular, scientific, and individualistic outlook of modernity. This is true of at least the post-independence generation of India which has benefited the first wave of liberal education and who are all over 50 now. The corollary of recognising older people as potential contributors to the productive capacity of the society is the equally important recognition that they constitute an important market. Not for nothing did *Wall Street Journal* declare that "there is a lot of gold in geriatrics"—a potential that remains largely unexplored in India by business entrepreneurs. Insurance, housing, health, holidays and culturally oriented care services need to be tailor-made for the seniors. Till that time NGOs will have to nurture and deliver precious services for leading the seniors into productive ageing possibilities.

The objectives for which Dignity Foundation was established :

- Information Dissemination - To provide information to seniors through publishing, holding seminars and discussions.
- Productive Ageing - Undertake various services for their support and welfare and enable them to live productive, meaningful and interesting lives, drawing upon their knowledge, skills and experience.
- Construct a database to determine needs of senior citizens in India and devise ways to meet them.
- Awareness Building - To build awareness by dissemination of data collected from various sources.
- Services - To offer services which cater to the needs of the Senior Citizens
- A new Identity- To mobilize Senior Citizens to form a new identity group.
- Advocacy - To undertake advocacy with government and public welfare bodies with respect to the issues affecting the older persons at large.

A summary of various services offered to the Senior Citizens are listed underneath and in each service delivery , another senior citizen plays a vital role:

- **Dignity Dialogue**: The monthly magazine for productive ageing edited by a professional group of journalists and social scientists. But senior citizens are authors for some 16 pages in the magazine and they relish the creation of an exclusive space for them to voice their joys and sorrows, prose and poetry keenly shared with and appreciated by their peers.
- **Senior Citizens ID Card**: Issued on behalf of the Government of Maharashtra. It recognizes the Senior Citizens as a homogenous group and enables them to avail privileges. In 100 centres in Maharashtra, senior citizen volunteers occupy the counter to process application forms and issue cards. Four lakh senior citizens have been issued such identity cards.
- **Dignity Help line**: A social support system for older persons who are being abused. Help is extended through Peer Counseling, Police Help, Legal Help and other problem solving techniques. In four cities senior citizens volunteers receive training in social counseling and play a critical role in fact finding and conflict resolution.

- **Dignity Dementia Care**: Provides Day Care to the patients bringing respite to the caregiver and helping the Dementia patient cope with the disease, through a variety of activities. Awareness building exercises through, discussions and seminars are also undertaken. Senior citizen volunteers take turns to sit at the centre and conduct activities for members.
- **Dignity Companionship**: Volunteers from the Foundation visit Senior Citizens to give them company, enhancing their day-to-day lives.
- **Dignity Discovery**: To mitigate loneliness – the most prevalent of the problems that afflict older persons, a fortnightly trip is organised to scenic sites near Mumbai for Senior Citizens. The trip encourages people to come together and forge new friendships. Senior volunteers take the lead in organising such trips.
- **Dignity Senior Citizens Enrichment Centre**: A variety of programs are organised daily for the older persons combining entertainment and learning. The coordinator from amongst the members helps organize programmes.
- **Dignity Senior Citizens Counseling Centre**: Senior Citizens seeking counseling regarding, investment, legal issues, property matters etc. are given the opinion through a panel of professionals respectively. Senior volunteers are at the telephone fixing appointments with professionals.
- **Dignity Lifestyle**: A township of independent cottages for 500 Senior Citizens in Neral, near Mumbai. Residents have adopted village Mangaon, some 2 km away to help augment community resources. The Social Worker is the head of the village project.
- **Dignity Second Careers**: Retirees interested in continuing work are given job counseling and placed in the social sectors or industry willing to employ them. A retired manager from an electronics industry is the head of this division. A new link up with UTI Bank has delivered 20 senior citizens with an official recognition as Special Desk Officers helping other senior citizen customers to the Bank.
- **Dignity Computer Skills**: Basic computer literacy is given to Senior Citizens to enable them to communicate better and utilize their free time.
- **Security with Dignity**: A network of protection with Police assistance for Older Persons living alone. Senior citizen members of the Foundation help 83 police stations by meeting other senior citizens in problem situations. The Police Inspector sends word for these registered volunteers with shoe help older people living alone are contacted by the Police. Dignity Companion to the Traffic Police is an extension of the same principle.
- **Dignity Civic Service**: In collaboration with the Municipal Corporation, the members are engaged in locality management, improving its cleanliness. They actively promote awareness on segregating dry and wet garbage and insitu composting.
- **Dignity Walking Patrol Vigilance**: 350 Dignitarians keep a vigil over the Mahanagar gas pipeline of 600 km, running the length of Mumbai City.

They regularly educate the residents residing near the pipelines, on the need to prevent accidents and leaks to the pipelines.

- **Newly launched Voice of Dignity**: A Forum has been created on the Tenth Anniversary of Dignity Foundation in 2005 under this banner with decentralized facilities for hearing the voice of senior citizens across the country. A Secretariat facilitates spread of rights awareness and information through use of mass media for purposes of lobbying.
- **Suraksha Bhandan** : An annual event reaching out to 5 lakhs of school children where elder members of the Foundation distribute wrist bands on which is inscribed: " I protect your security with dignity". The idea is to instill in children a sense of respect for elders.

Thus Dignity Foundation is serviced by a band of 2500 senior citizen volunteer members in 5 cities, who take the services to the door step of other senior citizens.

Conclusion

The experience of over ac decade of work illustrates a number points. Firstly, the needs of the elderly population group is different in different cultures and in different social groups. Secondly, the services and approaches to care has to tailor made to suit the differing needs. Thirdly, there is an enormous pool of experiences, skills and resources in every community that can be harnessed to meet majority of the needs. Fourthly, the total care requires rebuilding of the caring community , starting from the family to the community and a supportive environment created and nurtured by the Government and civil societies. Fifthly, the development of innovative approaches is a continuous process, more of a marathon rather than a sprint.

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"To give them an hour of dignity" - mental health of elderly

Veena Wig,
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Background

When ever there is a talk about the so called groups, clubs or activities for the elderly, the focus is always on the urban middle class or elite class or elite seniors but never of the under privileges section of the society as the care takers being to the privileges class only.

This is first of its kind the first genuine attention towards the needy old women of the slum areas. the club "Gangadevi Club" is first of its kind the pioneering work for most deprived section of the slum, women population. This club is started by Dr.Veena Wig, under the project, "ATAM VISHVAS" as one of the activities of the N.GO. group at the centre at Mauli Jagran, at the outskirts of Chandigarh, U.T.

It is comparatively young club, as it started on Nov. 11 2004 under the tin shed pf the society. There are about 40 members at present, as an experimental number. We already have met more than 30 times. These meetings are held on every month on the 11th at 11am and last date of the month at the same time. It is easy for members to remember the dates and time, as most them are illiterate, the dates are only shifted if it happens to be a holiday or so. All these meetings and gatherings are very successful so far. The achievements are already making a dent in the slum population. The name of the club stands for the lady, Mrs.Gnaga Devi, not at all a leader or a politician, but the most abandoned, old sick, needy and neglected woman of the area, who virtually live on a "REHRI" (The pulling cart) under the tree in front of our tin shed society. The large family does not want her inside their small and already over crowded 'katcha' room. She is most irritable with her plight age problems and situation so virtually she is more out side on her Rehri. Thus name of the club is on her name., who is symbol of the under privileged women of the slums. Almost similar is the plight of the rest of the members.

Purpose of the club is to give this group" an hour of dignity" , a place to sit together, sharing the good and bad aspects of life, some bondage to each other, and providing them the umbrella of the name of Y.T.T.S., that they belong to a certain grouping in an organized way, along with providing them with some nutrition, some personal care items etc as well.

The idea and concept of the Club (*samuh*) was not easy to comprehend for these women. They never had the exposure of this kind of meetings and sitting together in a group, where the vocation or the family is not involved. The tradition with daily wager or working class is to sit together, at good or not so good happenings of the neighbourhood, in an unorganized and erratic manner. It took them quite sometime and many sittings together to appreciate the need of these meetings in an organized way and in a regular and regulated manner.

Challenge

How to start this kind of group and how to reach their wave length was a challenge of its own kind. It was not an easy task at all. There had to be an idea which should click and bind them together in some kind of a relationship. So, the gatherings of the group were started in an unique and unusual manner by providing them with hair oil and combs, telling to comb each others most unkempt hair. This was an idea with personal care of touch. We started the beginnings of our group activity like this. This method worked like a magic. It was a str5ange kind of a personal care to the neglected persons. The bondage with each other was established fast. Some of the initial responses were as follows;

> *"I do not remember when I put oil to my hair "*
> *"No body in my family has ever cared to oil or comb my hair"*
> *"How can I put oil in my hair, I am a widow"*
> *"How can use a colourful comb to my hair, my husband is no more"*
> *"My family never has money to buy oil for my hair"*

With the oiled and combed hair, there was a new kind of look and shade of dignity on their faces .families looked at them and received them at a certain unsaid grace, as they belong to a "group". This activity and the idea gave a quick and wonder like bondage to each other of touch and care within the group.

Meetings

On a typical meeting day, a cup of tea with some biscuits or snacks are served. Sometimes donations for extra fruit and other eatables were also provided. For closer interactions and some moments of joy, the singing, dancing is frequently organized. The all participate very happily. The different festivals are celebrated with great fervor. Many group activities that they have never done all their lives, games like passing the parcel, musical chairs, drawing with crayons, which they had never held in their hands, are very touching experiences for them. Doing any activity "just for enjoyment" had never happened in their daily routines.

Along with these activities, an eye camp was held and 23 spectacles were distributed. Medical checkups, gynaecological check ups were also arranged, though the follow-ups were not easy, as family members were not much cooperative , as they were mostly daily wagers.

Apart from these activities, the main aim is to spend quality time with them, to bring a smile to their faces and lives, a thing that they had long forgotten. Perhaps they can not even show a smile, as care takers may not take them as contented dependents. Personal care items according to the weather are distributed like pairs of socks, chappals, clothes, shawls, quilts, washing soaps, bath soaps, reels of thread, to make them somewhat self-sufficient. Touching instances were experienced when pairs of socks were distributed. One of the members of the group started talking them off saying " I cannot keep wearing to go home as I do not have a pair of chappals". Of course it was arranged.

There is never any budget in the family of the daily wager for the old, sick, dependent mother. One or two minor meals are more than their share. Sitting every time with them and sharing their feelings and thoughts is an experience of its own kind and provides insight into their daily routines.

Slowly the group became cohesive. Participants were asked to share among themselves,

" one happy moment and one not so happy moment of their lives"
"one good quality and one not so good quality in them"

Some examples of the responses to these questions were as follows:

"Good quality in me is that I eat what my family gives me and I make no fuss"
" I never demand items for personal care"
"I was happy once in my life when my son was born(he is keeping me now *most unwillingly)"*
"I do not remember when I laughed last"
"I want to see mountains and climb them"

Progress

The "Ganga Devi Club" has already celebrated one year of activities. The club has achieved a lot in one year. The members attend they meetings regularly and they look forward to the same. They have an identity now, a place to go where they are treated with dignity, and a feeling of belonging to a group. It has already made an impact on the neighbourhood. These old women are now seen approaching the club with a special envious look, ads they approach the place, where the feeling of being wanted and an hour of dignity is waiting for them. The Club has become a role model for the area and it is the first of its kind and functioning regularly. The senior Citizens Association of Chandigarh, Union Territory, has formally adopted the club on feb 25,2005, and they give support.

Impact

As the club is becoming popular in the area, aged men also want to become members, but women do not feel comfortabl;e in the company of other men during the singing , dancing and other activities. There is a need for a separate such club for men living in slums. During the last six months, a "self-help" group has been formed with the contribution of Rs. one .All the money is pooled , Rs.50/ is given right away on the spot to the needy, with the consent of the group. This is working like another bondage. Now the value of one rupee is realised.

Mrs. Ganga Devi breathed her last on November 24, 2005. Financial help was provided for the for her last rites. Her last journey was completed with great dignity and grace, which she probably did not get during her life time. Two minutes silence was also observed in her memory.

The care of the aged women goes on.

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SECTION VIII

General Public

Changing people’s attitudes to mental illness-Contribution of Rationalist Movement to Psychiatric Care in Punjab

Sandeep Kumar
Barnala.

Introduction

Stigma and discrimination of persons suffering from mental disorders is an important component of the barriers to providing effective mental health care in all parts of the world. People living in Punjab have their own share of misconceptions about psychiatric disorders. The situation was much worse 20 years ago. Many cases of abnormal behaviour were attributed to spirits. The patients suffering from dissociative symptoms or conversion disorder were taken to faith healers and saints or to religious places. There, these patients would shake their heads or gyrate the whole bodies along with scores of others. Often they would speak as if some one else is speaking through them. That was the period when psychiatrists were concentrated in big towns like Chandigarh, Amritsar, Ludhiana, and Patiala. In those days most of the people would consider only serious psychiatric diseases as mental health problems. The patient used to be taken to a psychiatrist only when he showed gross psychiatric symptoms like stone pelting or other violent and aggressive behaviour. People worried more about physical symptoms. Psychological symptoms either they would ignore or would seek the help of quacks, saints, or *maulvies*. Hundreds of patients would visit a Dargah (religious place) in Malerkotla, district Sangrur every Thursday. Thousands of rural people would throng Dera Baba Vadbhag Singh, another religious place near Hoshiarpur, every full moon day. They would take bath in a stream of water near the centre with the hope of getting a cure.

In those days, often one would read stories of abnormal happenings in households or in entire neighbourhoods. Almost every week you could find news about clothes getting cut, cattle dying, stones falling, or bloodstains appearing from nowhere in a particular house or in entire neighbourhood. In addition to misconceptions about psychiatric problems, the people believed in many unnatural phenomena. Often the stove would be worshiped as a god and people would approach it to know about their future. At times masses would rush to Sikh shrines to pay their respects to a hawk, believing that it was the one belonging to the tenth Sikh Guru, Guru Gobind Singh.

Background

Under such circumstances, a group of people joined hands to form an organization named *Taraksheel* Society (The Rationalist Society Punjab), with the primary aim of developing scientific temperament among the people. Started in the year 1984, the Society realized that most of the wrong beliefs in minds of the people concerned psychiatric diseases. So, they have been working on these diseases in addition to their other activities. It appears that the Society has done a yeoman's service in changing the attitudes of people about psychiatric disorders as well as sorting out many of their problems.

The Society has its origin in a book, "Begone Godman' by a rationalist from Sri Lanka, Dr. Abrahm T. Kavoor. (1) The book is about misconceptions and unscientific beliefs in the Tamilian Society of early 20th Century. Dr. Kavoor had worked among the rural masses of Sri Lanka as well as Tamilians of India. He had succeeded in dispelling many of these misconceptions and beliefs. Megh Raj Mitter, a science teacher in rural Punjab, India read the book and realized that the people in his state also suffered from similar notions and beliefs. He recommended the book to a colleague. The latter was so impressed with the book that he demanded a Punjabi Translation so that his wife could also read and benefit form it. The problem of this colleague was that his wife was under the influence of an astrologer who had already duped the lady of rupees 3,000 and had recommended additional rituals that would cost the family around 2,000 rupees more. (2) The colleague even offered an award of Rs 500, calculating that he would save Rs. 1,500 in the whole bargain. Mr. Mitter, with the help of his friends translated as well as published the book under the title, "…*Te Dev Purash Haar Gaye*'. They formed a society in April 1984 to publish the Punjabi translation and named the organization, Rationalist Society Punjab. In Punjabi, it was called Taraksheel Society Punjab. The Punjabi translation got an excellent response from the readers. The people liked the book so much that they started approaching the translators for solutions to similar problems. The latter had no readymade solutions in their hands. They read books on psychiatry, psychology, magic, and scientific basis of uncommon happenings; devised their own methods of solving people's problems and started applying these methods.

Why we chose the People?

At present the Society has about 3,000 members in about 100 Units spread throughout Punjab. The founders of the Rationalist Society took up common people as members of the Society because mental health was just one of their activities. Moreover, mental health care professionals were few in numbers, and even those available preferred to stay and work in big cities. The Psychiatrists could not give enough time even in their clinics, so the question of calling them to family homes didn't arise. There were hardly any clinical psychologists and psychiatric social workers. One more reason that the public shied away from the professionals was that the professional care was considered expensive and beyond their means. In a personal interview with the writer, Balwinder Barnala, a senior functionary of the Rationalist Society cited other reasons also for choosing ordinary people as volunteers. According to him, educated young men and women were ready to work without any remuneration because for them it was a part time activity while they had some other regular source of income. Also, these workers hailed from the society and knew the culture, the values, and the persons involved very well. More than twenty years into its existence, the Society continues to provide free service to the people, charging only travel expenses from the families.

Training the Volunteers

While selecting someone as a member the leaders ensure that the person has a scientific bent of mind and he is educated enough to read books written in Punjabi. After initial selection, the potential member is usually asked to read around 20 books, most of these published by the Rationalist Society. The books have articles with scientific explanation about abnormal behaviour and happenings. Many of these books pertain to psychiatric disorders . Some books describe the basis of hysteria and possession syndromes. Some other explain the psychological problem of youth and woman. The books dispel the misconceptions about nightfalls and size of the organ etc. A book *Manorog: Kaaran Te Ilaz* (Psychiatric Problems: Reasons and Treatment) describes in detail diseases like schizophrenia , depression, and anxiety disorders . The book describes etiology, symptomatology as well as the treatment options. A pediatrician has written a book on psychological problems of children. A Psychiatrist has written one on Depression and another on Epilepsy. There are books describing the impact of environment on mind. The rationalists, after in depth studies, have written books on hypnotism as well. A very interesting part is that they have translated at least 5-works of Sigmund Freud. These include psychoanalysis, and Literature and psychoanalysis. Books are available even on intimacy and love. Roshni and Tarkbani describe how the rationalists solved various cases. These also carry articles about the tricks played by the *sadhus* and Gurus (religious leaders) on the gullible. New members are also required to attend seminars and workshops where senior functionaries, and at times Psychiatrists, speak about various problems and their solutions. During case solving sessions, the junior members accompany the seniors as trainees. They observe how the cases are solved. With the passage of time they get trained and start working themselves. The leadership ensures that the juniors start working independently after sufficient exposure only.

By and large, the Society doesn't have a formalized training programme. However, recently a magazine has started a 2-year distance-learning course about Rationalism. The course is spread into 8-trimesters during which 8-books are sent every trimester to a student. At the end of the course, the students and their families get all their misconceptions removed, claims the prospectus.

A volunteer of the Society, Surinder Singh Jasdhol, shares his experience of the Society with the author. About 18-years ago, Surinder a young lad in his twenties was member of a sports club. In the club he had company of some Rationalists who often talked about exploitation of public because of irrational and unscientific thinking. Surinder got impressed with the talks and started reading books by the Rationalists. Finally he joined the Society about a year later. Association with the Rationalist Society has been a very fulfilling experience for him. From a small cycle shop he has built a big wheel-balancing workshop in a span of 20-years. He attributes his success to his rational thinking. He does not observe any religious rituals. He keeps his workshop open even on the Birthday of Baba Vishavkarma, a day that all artisans in Northern India observe as a complete close day. With this gesture alone he has helped many patients and other travelers whose vehicles broke down in nearby areas without any help available.

Surinder also narrates how he once persuaded his in-laws for scientific treatment of a relative with psychiatric problems. About 5-years ago he had gone to his in-laws house. There he found a faith healer had lit a big fire in the courtyard. Every body was bowing to him. Then they brought out a young girl who had not been working and sleeping well. The girl had been also complaining of sadness. At times she would cry loudly. The faith healer in order to control the spirit in the girl started beating her. On seeing all this Surinder took the senior family members to a side and explained them the futility of such thrashing. He also convinced them about the relevance of proper psychiatric treatment.

The ritual was stopped and the girl taken to a psychiatrist next day. She responded very well to treatment. And got married after some time. The family continues to be much obliged to Surinder who even now has a feeling of satisfaction for saving the life of the girl.

Services provided by the Rationalist Society

Services of the *Taraksheel* Society include awareness creation, solving cases, treating patients, and guiding patients for psychiatric care.

Awareness creation:
The Society applies a multi pronged approach to create awareness among the masses. Often people approach them with different personal problems. Through one to oneinteraction the members explain the scientific basis of the problem and try to dispel the misconceptions in the minds of patient and his family. The Society is publishing 2 magazines *Vigyan Jyot,* and *Taraksheel*. In these magazines, often articles about psychiatric diseases are published. The society has also published many books about psychiatric problems. Some of these are by psychiatrists and other doctors. . In Punjab, they have succeeded in convincing many a young men about the naturalness of masturbation and night-falls. They organize melas, Conferences, and Seminars where Society members as well as specialist doctors are called to speak about mental diseases. They also use magic tricks and drama for delivering the message. During crucial periods, they issue pamphlets and press releases explaining scientific rationale behind a phenomenon. About 10-years ago people in Punjab and neighbouring states queued up in front of Hindu temples to watch '*Ganesha*, a Hindu deity drinking milk form the pots'. The Rationalist Society explained that it was bases on capillary action only.

Case solving:
This is one of their main activities. They have solved 500 cases in 20 years. There occur abnormal happenings in one house, a group of houses, or in the entire village. At times the cattle start dying, or electronic parts start appearing in the vomit of a girl, there are sudden fires, or blood spots or stones littered at a particular place. The affected people contact the Taraksheel Society for help. The Society has devised a method. They interview each and every member of the household and try to pin point the person who is actually doing all this. In most of the cases the culprit is found to be actually a victim of the circumstances. They get a confession from the culprit and a commitment not to repeat such things in the future. At times they win the sympathy of family for the culprit/victim by explaining them the whole sequence of events. At others they warn the culprit about exposure and the incidents stop completely. In one such case the clothes would suddenly get torn. At times big pieces of fabric would be shorn out from the garments. Gradually money started disappearing from the house. The worst was when they lost a pair of earrings. Most of the articles belonged to the lady of the house, Sita. The family approached faith healers who advised them to serve food to the dogs or to carry other similar activities. Finally, after losing about rupees 13,000, the family contacted the Rationalists. They visited the family and interviewed each member. They could pinpoint that actually *Sita* was doing all this. So, they sought a commitment from her that such

things will not be repeated in future. In return, they assured her of complete secrecy. After a lull of about one month, the problems reappeared. This time the husband and *Sita* reached the Rationalist. During one to one interaction, a rationalist warned *Sita* of exposure to her husband about her activities. *Sita* confided to the Society member that she was afraid because her husband had bought a gun last year and told her that it would be used to kill someone. The Rationalists convinced the gentleman to sell off the gun and the problem was solved forever. (4)

Mr. Mitter narrates another story how they could save a whole village from reactive depression to which they were about to go after their religious articles were bunt. The society member got a message from a village in district Patiala that spontaneous fires were occurring in the village. Mr. Mitter with a colleague reached the village one morning to find the whole village in an eerie silence. On enquiry they were told that the men folk had gone to the local Gurdwara (the place of worship) because the previous night the religious articles had been burnt by unknown forces. The team went to the Gurdwara. Every body was in a state of disbelief, shock, and gloom there. The villagers told that their religious books (*Birs of Sri Guru Granth Sahib*), covering clothes of the holy book (*Rumalas*) and some other articles had been bunt. They considered it to he the worst omen. Their belief was that nothing could save the village from destruction if they had lost the articles of faith through some natural forces. The Rationalists assured the villagers of help. They interviewed many persons and found that one boy was present on every such occasion in the past. They took him in to confidence and heard his side of story. The boy told about his frustration. His father was a popular tailor in the village. With passage of time he had lost his vision and was no longer able to earn the livelihood. While the whole village prospered this family could not get two square meals in a day. Frustrated, the boy started igniting fires in the village. The agony of the sufferers would make him happy. The team succeeded in getting a promise from the boy by explaining him the virtues of hard work and warning him of exposure to villagers and thus dire consequences. After that a fire never recurred in the village.

Patient treatment:

Often patients reach them for treatment. The society has set up about a dozen treatment centers for such patients. Many of these patients are revolving their heads or dancing or gyrating frantically. It is generally believed by the family that they are suffering from '*operi shai dee kasari' i.e.*possessed by spirit of a deceased person. Every month the Society treats about 200-300 such patients. By a rough estimate they have treated more than 30,000 patients in 20 years. Their primary mode of treatment is talk therapy. Through this, the Rationalists try to convince a person that spirits or ghosts do not exist. The Rationalists explain to the family how all this evolves, like it's origin with a minor physical or mental problem, then some neighbours planting the idea that it is the spirit of a dead neighbour that is now inside, the patient starts believing it and the chain starts. They break this chain by clarifying that no spirit actually exists. In one such case, a girl from district Jullunder suffered from recurrent vomiting with the vomit containing radio parts. The Rationalist Society members assessed that the radio parts could not appear so frequently in the vomit if the person had ingested these. So, they concluded that the girl herself must have been mixing the parts in her vomitus. Through minute observation, they could see that at the time of vomiting the girl would put a hand near her ear. That hand concealed the radio parts, which would be released at the time of vomiting. The Rationalists confronted the girl in private. She told that her parents were not supporting her education though she was an intelligent girl. On the other hand, her parents had been doing a lot of effort for the study of her 2 brothers who were not studying at all. This irritated the girl much and she decided to teach a lesson to the family. Through gentle persuasion the Rationalists solved the problem. The parents assured of supporting the girl and the girl promised not to repeat such acts in future.

Young boys and girls approach them with confusion about sexual behaviour. While the media projects a very open society the families put a lot of restrictions on the youth. The Society members succeed in resolving these conflicts in the minds of youngsters.

They also tell the family that many people who behave as if they are possessed by a goddess are actually exploiters of the society. These exploiters masquerade as gods/goddesses so that the gullible bow to them and make huge offerings of money and materials. This helps many of the patients, especially those suffering from possession syndrome.

Some of the Rationalists practice what they call hypnotism, which we can understand as ‘strong suggestions’. Patient is taken to a ‘trance’, asked questions about abnormal behaviour and given strong suggestions for better behaviour in future. As for as medicines are concerned, these are not used at all. All the society members have been strictly instructed not to use or prescribe any medicine.

Guiding psychiatric Patients:

Patients with all sorts of psychiatric disorders be it schizophrenia, mania, depression, OCD, reach them for treatment. Almost always, they guide these patients to seek specialist care for their ailments.

Fighting corrupt faith healers:

Corrupt faith healers are known to exploit gullible psychiatric patients. Whenever a complaint reaches the *Taraksheel* Society its members investigate the matter and try to expose the design of such a faith healer. They have even instituted financial rewards for any saint or godman who can demonstrate super natural powers.

Support from the Mental Health Professionals

By and large, the Rationalists have received good support from the mental health professionals who have been delivering talks at their conference and seminars and also writing books and articles for the Society. In their Seminars they ask differences between hysteria and epilepsy. They are interested in differentiating between cases where only talk therapy would be enough versus cases that require medicine. Some of them wonder about the need for prolonged, or life long, treatment in chronic problems. They have been regularly referring patients who need psychiatric care. I am in regular contact with the Rationalist Society for more than 10-years. I attend their seminars, workshops, and conferences, get referrals from them, write articles in their magazine, and seek their help in exploring the family dynamics. The workshops and seminars are attended by members of the Society while the conference are meant for general public. I have found that these people are working selflessly for the society with a very scientific approach. Considering that they are non-professionals, their knowledge about psychiatric disorders is of good quality. They also have the will and the capacity to spend a lot of time with the patients, something that we psychiatrists do not have. This becomes very relevant for developing societies that do not have sufficient psychiatric social workers. Social workers, even where posted, are too few to visit patient homes regularly. With the dearth of trained mental health professionals, the services of such a society can be utilized. I suggest that psychiatrists can associate with such societies if they exist in their area or they can establish such organizations. We can definitely learn a few things from them. One is how to train non-professionals for family therapy or sorting out interpersonal problems. The other is how to penetrate into the society. Their experience of explaining scientific knowledge in simple, people friendly language for creating awareness also can be emulated

The Rationalists do not have much of interaction with Clinical Psychologists and almost no contact with Psychiatric Social Workers. In Punjab the former are too few and the latter almost non-existent.

Difficulties encountered and the measures used to overcome the same

The Society had to face a lot of resistance from the faith-healers and religious fanatics who believed that the Rationalists were hampering their businesses. Just last year the Society members had to face physical assault in a small town Tapa, District Sangrur. In a fair they were telling scientific reasons behind eternal fire at *Jawalaji*, a sacred Hindu temple. Some of the audiences took a strong objection to it. Their supporters joined hands and a scuffle ensued (5). The matters could be pacified only with the intervention of district administration after many days.

In the beginning, the Society faced hostility from some family members as well as the patients from whom they tried to get confessions. At times the families whose belief system they tried to break would become resentful to them. So, they have decided not to go uninvited. Usually they ask for a written invitation from the Family Head or the village Head (Sarpanch). At times the wrong selection of cases leads to violent outcomes. In my personal experience some of them have tried talk therapy or hypnotism on manic or psychotic patients. When the patient turns violent they have no training or means to handle the situation.

Some times immature or unknowledgeable people joined the society in search of glamour and glory. They would handle cases without sufficient training, would complicate the case and bring disrepute to the organization. The leadership always remains vigilant about the novices and also about the quacks that would join the society just to get patients. Once a patient reached such a quack he would apply quackery rather than the Rationalists' approach. Only "authorized" senior members are allowed to treat the patients. Bye and large the leadership insists that the treatment/counseling is given either at the treatment centers or at patient homes.The politicians of the area would also interfere in their work because their main concern was votes.

Lessons Learnt

The Rationalists, after about 20 years of work, realize more intensely the significance of services of mental health professionals. For such new societies the leadership underlines the need for associating with psychiatrists and psychologists from the very inception. Another lesson that they have learnt is the importance of gentle persuasion, instead of aggressive approach, in changing the mind-set of the society. They are convinced that beliefs can be changed. However, penetrating into the society is a mild, slow, and tedious process. Now they know the importance of suppressing one's own thoughts and allowing the others to express theirs. With this approach the Rationalists learnt the 'traditional' point of view and became better equipped to counter. They have also realized that direct confrontation with the families or culprits should be avoided.

Resource Materials

The Society has published around 100 books for development of rational scientific thinking. Around 30 of their books are on topics related to mental health. Some of these have been authored by doctors or even Psychiatrists. Some titles are: *'Aurtan Ate Mansik Rog'* (Women and Mental Disorders)*, 'Naujwanan De Maansik Rog'* (Mental Problems of Youth), *'Bachian Dean Manovigianik Samasiwan'* (Psychological Problems of Children), *'Udasi Rog'* (Depression), and *'Mirgi Rog'* (Epilepsy). Most of their books are in Punjabi while around 10 have been translated into Hindi. Their two magazines *Vigyan Jyot,* and *Taraksheel* often carry articles about psychiatric diseases. Taraksheel sells about 2,000 copies in Hindi and 15,000 copies in Punjabi. They have also developed a few audio and video CDs, and a website, www.tarksheel.com to spread the message of rational thinking.

Future Plans

The Rationalist Society is committed to make people's thinking scientific and to change the way of life of rural masses. The Society started its work in Punjab and gradually spread to nearby states. Now they are establishing their units in all parts of the country and even foreign countries where Punjabis are settled.

The Rationalist Society Punjab is a member of umbrella organization of 65 such societies in India, named The Federation of Indian Rationalist Societies (FIRA).

Conclusion

It appears that in the 22 years of its existence the Rationalist Society Punjab has mitigated the sufferings of many and has also successfully brought about a change in the society's attitude towards mental health problems.

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Appendix-1

List of Books

1.*'Aurtan Ate Mansik Rog'* (Women and Mental Disorders)
2. 'Naujwanan De Maansik Rog' (Mental Problems of Youth),
3.'Bachian Dean Manovigianik Samasiwan' (Psychological Problems of Children),
4. 'Udasi Rog' (Depression)
5.'Mirgi Rog' (Epilepsy).
6.'*Tusan Puchia'* (You asked)
7.'*....Te Dev Purush Haar Gaye'* (Begone Godmen)
8. *'Dev, Daint, Te Roohan'*
9. *'Manorog: Kaaran Te Ilaz'* (Mental disorders: Reasons and Treatment)
10. *'Te Phir Aag Lagnon Band Ho Gayee'* (And Then the fires Stopped)
11. *'Man, Mahol, Manorog'* (Mind, surroundings and Mental Disorders)
12. *'Tarak Ki Kasauti Par'* (Hindi) (Tested through Rationalism)
13. *'Samohan Neend: Kee, Kyon , Kiwen'* (Hypnotic Trance: What, Why, and How)
14. *'Baal Mano Vigyan'* (Child Psychology)
15. *'Roshni'* (The Light)
16. *'Tarkbaani'* (The Rationalist Voice)
17. *'Tarakjoti'* (The Rationalist Light)
18. *'Hypnotism: Kee , Kyon , Te Kiwen'* (Hypnotism: What, why, and How)
19. *'Chithian Likh Tarksheelan Nun Paian'* (Letters to the Rationalists)
20. *'Cheenian Bhoot Inj Bhajae'* (How the Chinese Defeated The Ghosts)
21. *'Chamatkaran Pichhe Vigyan'* (Science behind the Supernatural)

22. *'Tarkvad Kee Hai ?'* (What is Rationalism)
23. *'Maansik Rog Te Saada Smaj'* (Mental Disorders and Our Society)
24. *'Taraksheel Vaarta'* (The Rationalist Prose)
25. '*Kasran Kyon Hundian Ne'* (Why do possessions Occur)
26. *'Manovishleshan'* (Psychoanalysis)
27. *'Parmatma Dee Utpati , Is Bharam Daa Bhawikh'* (Origin of God: Future of this Misconception)
28. *'Pagambar Moosa Te Ik Ishwarvad'*
29. *'Sabhyata : Var Ke Srap'* (Culture: Boon or Bane)
30. *'Rachnatmak Sahit Te Manovishleshan'* (Literature and Psychoanaysis)
31. '*Sukhaven Pyar Sabandh'* (Comfortable Love Relations)

Many of these books have been translated into Hindi as well. Some of these books have been published by the Rationalist Society Punjab while some others are publication of Tarksheel Parkashan. There respective addresses are:

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SECTION IX

CONCLUSIONS

CONCLUSIONS

The wide gap between the need for mental health services and the available specialist and infrastructural facilities to reach the care has been the subject of international attention (World Health Report 2001-Mental Health: New Understanding, New Hope). However, even in the first 5 years after the release of the World Health Report, 2001 and observance of the World Health day 2001 with the theme of mental health (Stop Exclusion, Dare to Care), the situation appears to have not changed (World Mental Health Atlas,2005).

There is need for serious rethink about the approaches to be adopted to address the mental health needs of the total population.

The World Health Report, 2006, defined

"Health workers to be all people engaged in actions whose primary intent is to enhance health".(p.2)

This broader approach to think of everyone as change agents for health is an important paradigm shift. In the coming years, there is more focus on this shift and efforts to make health a priority area for action by one and all.

The more than two dozen experiences, brought together in this book, illustrates the scope and feasibility of focusing on the "power of the people".

Reading through the reports of the initiatives, a few issues can be addressed.

Firstly, the enormous need for mental health initiatives that exists in the community. It is salient to note that the initiatives have not limited to caring for the traditional mental disorders but gone beyond these to include the mental health wellbeing of people. This need exists, even in the state of Kerala (page 206) (which has the highest number of psychiatrists for its population, nearly ten times the national average) shows how limited can be when it is limited to mental health professionals. It is a daunting task to think of meeting the variety of mental health needs identified by the narratives, if they have to cover the over one billion population of India.

Secondly, the initiatives clearly demonstrate the feasibility of thinking of "people" as the source of change agents for health. Whether it is the general population(page3160, the consumers themselves(pages 306-314), or the families of the mentally ill (pages 117-183) or the families of the mentally retarded(pages 185-220) or the people who are providing other services like general health care (Pages 28-35), welfare (pages 36-40) or teachers (pages 82-107) and college teachers (pages 108-115) or lay volunteers(pages 41- 55, 221-304) , it is seen that they all have a role in mental health activities. It is equally important to note that , these non-professionals are providing care not only in the community , but in institutional settings like the half way homes(pages 41-54), and even in the Armed Services of the country. Of the many initiatives, the growing role of the families as change agents , in my mind., the most significant one. We are going to read more of this change in the coming years.

Thirdly, the question about how "effective" is this new initiatives can not be answered satisfactorily at this point of time. The initiatives are at the most about 3 decades old and in some cases as recent as one year. It will require time to assess the impact and the place it will take in the overall development of mental health in the country. What is striking is the high acceptance of the multiple approaches by the users. Thus it has a face validity. However, it is equally striking to note that majority of the initiatives are local and have not taken on the national level spread. For example, it was 30 years back, Sanjivini, in New Delhi initiated the suicide prevention by volunteers. Three decades on the number of formal suicide centres in the country is counted in less than a dozen (page 232) when it should be in hundreds , if not in thousands all over the country. This "local" nature of the efforts is a matter for serious consideration. What is it that is preventing the successful programmes to spread and take on a national character? Is it the lack of charismatic leaders, the lack of support from the government, the cultural and social difference across the country, are all relevant. There is need for greater understanding of this aspect in future, by in depth studies of these activities.

Fourthly, currently, almost all of the roles by the "people" have not been evaluated systematically., The group that has been studied closest to evaluation is the role of health workers. In a situation of competing models for care, at some stage both individually and collectively there is need for evaluation to under the level of care and limits of care that is achievable by each of these measures.

Lastly, what would be the place of all of these initiatives in the developing mental health care in the country? The future of this movement would depend on three "Ss ", namely, Spread, Synthesis and Support. There is no doubt that each of these beginning activities should spread to cover every part of the country. Mechanisms to achieve this has to be found, somewhat similar to the current extension of the Bellary model of integrating mental health care with general health service(pages 21). For such a spread to occur there is need for Synthesis of the experiences into lessons learnt, core educational materials and support systems for the "people" to function effectively. The third requirement is the Support of two kinds- professionals and government. The initiatives described by the authors have all recognized the important observation made by the WHR 2006,

"Supervision that is supportive and helps to solve specific problems can improve performance, job satisfaction and motivation"

A number of mental health professionals have gone beyond the traditional roles and supported the described initiatives. There is greater need for this to happen. We mental health professionals should consider these initiatives as complimentary and not contradictory to what we are doing.

The other support is the financial support by the Government. In the welfare scheme of India, funding for voluntary organizations working in the mental health field is still low in priority. There is an urgent need for the government to develop specific funding mechanisms to stimulate the spread of these innovative approaches to mental health care.

In India, documentation is a problem. Too often excellent programmes do not get the wider publicity and recognition that they deserve. It is important that efforts are directed to document the efforts in an ongoing and systematic manner so that others starting their work can benefit from the past experiences. This book is an effort in that direction.

On the occasion of the World Mental Health Day, 2006, let us join hands to make mental health for all a reality through efforts to make mental health by all.

There is growing awareness of the importance of mental health in the country. The focus has not only been on the care of the mentally ill persons, but includes the prevention of mental disorders and promotion of mental health. Organisation of mental health services has received a big boost in the country by the implementation of the National Mental Health Programme. However, the coverage is still limited top less than one sixth of the country. There are a number of initiatives by families of the mentally ill, the

voluntary organizations, professionals to utilize the important community resource of "people" for mental health.

The book brings together over 30 such experiences from different parts of the country and addressing a wide variety of mental health needs in the community.

On the occasion of the World Mental Health Day, 2006, it is hoped that the "people" power for mental health will become an important part of the mental health movement in India.