Voices Uniting for Change

Advocating for the rights of people with mental illness

Basic Needs India

promoting mental health
and development

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...promoting mental health and development

Basic Needs India grew out of the belief that the rights of people who experience mental illness, especially the poor and the marginalized, must be addressed not only at the individual level but also in the context of the wider dynamics in the community and society. Major resources available in the mental health sector are institution based rehabilitation or hospital based services, both of which are seen to be limited and impractical for the needs of poor persons with mental illness, especially for those living in the rural areas.

Vision

Basic Needs India seeks to satisfy the essential needs of all people with mental illness in India and to ensure that their basic rights are respected and fulfilled.

Mission

To initiate programmes in India, which actively involve people with mental illness and their carers that enable them to meet their basic needs and their basic rights are respected. In so doing, stimulate supporting activities by other organizations and influence public opinion.

BNI was registered as a Trust in 2001 with a specific mandate to address the issues related to community mental health in India.

Basic Needs India (BNI) initiated **a developmental and rights based model of mental health promotion,** building on the existing experiences of Community Based Rehabilitation, as opposed to the prevalent medical model. Since then it has been working with partner organizations in rural areas in parts of 46 districts in the States of Karnataka, Andhra Pradesh, Tamil Nadu, Kerala, Jharkand, Bihar, Qrissa, Maharashtra and in Bangalore-Urban areas.

The work of BNI has impacted the lives of approx. 19,000 families in many ways including providing access to treatment options, livelihood opportunities and formation of association and groups to advocate for their rights. Its experience so far with active involvement of all stakeholders has been a very positive, which can be phrased as stakeholders' model.

Photo on the cover.....

The members of Manasika Aswastharu Mathu Poshakara Kriya Vedhike demanding better services & care from the Directorate of Health & Family welfare in Bangalore.

Foreword

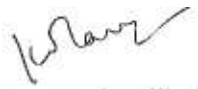
The issues of mental illness and mental health has not received the focused attention other chronic diseases have received. Internationally it is now recognized that there is immense neglect of this area and hence the reality of serious 'Mental Health Services Gap' as identified by WHO. However what services and support systems are required and relevant continues to be an area of enquiry. Beyond the role of service providers, the role of the family carers, the local community and host of other stake holders is also emerging.

It is in this context that the Basic Needs India's (BNI) decade long interventions on community mental health and development (CMHD) assume importance. In an effort to understand and intervene in mental illness and mental health from a social development and rights paradigm, BNI developed the CMHD approach. After the initial experiences among the rural poor communities, revealing insights have also emerged from the interventions made with the Bangalore urban poor.

This program experiences brought to light the healing influences of family carers, local supporters, protected livelihood initiatives, and the strong solidarity emerging among the organizations of the affected. Complimenting these community developmental initiatives have been the access pathways created for publicly provided care and entitlements.

The program has sustained in its core areas in spite of fluctuations in funding resources. The work has also opened up several community level needs and dynamics yet to be engaged with. These include the wide spread issues of substance abuse, vulnerable occupations of the urban poor such as garment workers, construction workers, domestic workers etc. leading to severe emotional distress and the gap of psychological support in the family and community environment.

This is work in progress, requiring attention from socially committed and adventurous individuals from governance, civil society, solidarity groups and health professionals. This report highlights the learning from the various community based interventions that BNI had undertaken and continues to be engaged in through its Community Mental Health Program in Bangalore urban slums, especially with the poor. It is hoped that these efforts would lead to an improved environment for these people to live with dignity.



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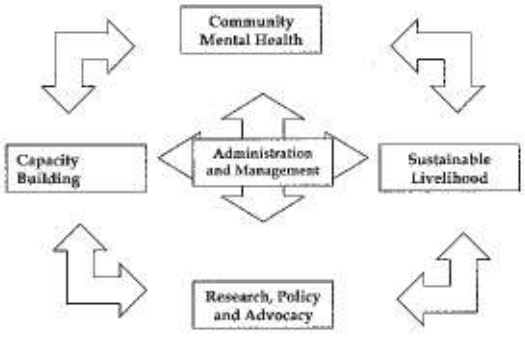
Director - Special Programs
Basic Needs India

Voices uniting for Change

(Advocating for the rights of people with mental illness)

Basic Needs India's Community Mental health and development model has been evolved through a series of consultations with affected persons, family members and partner NGOs. The model consists of five modules based on the needs and expectations expressed by different stakeholders.



How it all began.....

BNI focused initially on working with people with mental illness in rural areas. There was an assumption that health care services in urban areas are easily accessible to those in need as hospitals are located close by and professionals are also readily available. However, a consultation meeting with Bangalore based non-governmental organizations (NGOs) in 2002 revealed the situation to be quite different. Persons affected with mental illness in slum communities faced problems in accessing mentai health care services. Reasons for this were due to low income, marginalization, stigma, lack of knowledge on the illness and on the ways to access mental health care services.

A programme was initiated in 2003 to bridge this gap by BNI identifying three NGOs with a strong presence in several slums in Bangalore - Association of people with disabilities (APD), Paraspara Trust and Association for Promoting Social Action (APSA) as partners, who showed interest in mental health care. The programme started initially in 30 slums across the city, and expanded later to 100 slums.

BNI's rural experience was of immense value for planning the activities in Bangalore city slums. Some of the learning from past experience like the ones stated below were taken into consideration in designing the programme.

- Identification of needs through consultations with affected persons and their families;
- Inclusion of stabilized persons with mental illness in livelihood activities and other self-help groups goes a long way in mobilizing community support and in raising awareness on mental health;
- The need to collaborate and network with other mass organizations to strengthen the mental health movement.

Since 2004, BNI working in partnership with three NGOs has been reaching out to the poor in 100 slums (about one hundred thousand population) in Bangalore city. With active involvement of various implementing and resource partners, BNI is impacting on the lives of approximately 1,400 families living in these slums.

Team Structure

URBAN MENTAL HEALTH TEAM

BNI Urban Program Coordinator (1)

↑

Mental Health Coordinators at partner level (3)

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Field Staff (8) and Community Volunteers (8) at field level

Orientation to field staff

BNI organized an induction during the initial phase of the program for the staff of partners working in the field. The topics were on mental illness, types of illnesses, symptoms, misconceptions, and the difference between mental illness and mental retardation. This input helped them to identify the affected persons done initially through door to door survey and referrals from other programs of partner NGOs.

After identification the field staff during the visit to families, faced resistance and non-cooperation from affected persons and their families. They expressed their discomfort and fears about interacting with people on these issues. BNI facilitated a series of interactions with affected persons and their family members, understanding family dynamics and mobilizing community support. Family visits, being a key intervention, helped the team to develop confidence in their day to day work and laid the foundation to build relationship with the stakeholders. Many consultation meetings with affected persons and their family members helped in getting better insights to work with these people.

An urgent need to educate caregivers and community on mental illnesses was felt by all those working at the ground level to address the issues of stigma and discrimination. Different strategies were adopted and they were designed to be cost effective, promoting community participation and utilizing the existing skills within the group, for e.g. making use of the well trained street theatre teams of the partners.

- **Poster campaigns -** Distribution of posters on mental health issues in the community and putting them up in schools, hospitals, local government departments and public spaces in the urban slum communities.
- **Street plays -** For four years from 2004-08, performances were held regularly in slum communities. Socially relevant themes were selected to convey messages on misconceptions, beliefs and fears on mental illness and on their management. Stories in Kannada were scripted and the team consisted of field staff, colleagues from other projects and children (from the streets,

Cultural team performing a street play

homeless and orphans) from APSA and Paraspara Trust. Costumes, props and musical instruments were used to add some entertainment value. On the morning of the event, the team performing a street play would make announcements throughout the slum and performances were usually held in the afternoon. A central place within the slum or street junctions became the venue for these events which lasted about an hour. Contact details of the team were given if people needed any further information and clarifications. Street theatre, thus served not only to disseminate the issues of mental health, but it also built rapport for the organization with the community.

- **Wall-writings-** The team, along with affected persons and families, sketched messages in Kannada on mental health issues on the walls of public utility buildings in the slums. The themes changed over

Community leaders participating in wall writing

time, based on new learning and needs of the community. To start with, the team painted sketches and messages on symptoms, possible causes and treatment. In the second phase, the role of community in addressing the issues was highlighted. More recently, the rights of persons with

Orienting women self help groups on mental health issues

mental illness and their families, about the Mental Health Act and social security schemes available under the government were displayed.

- Groups like women SHGs, youth, CBOs, Anganwadi workers, school teachers and children where oriented on mental health issues through talks, display of posters, pamphlets and video shows.

Initially, sessions were conducted as part of the awareness drive, but recently few groups have approached the team requesting inputs to further their understanding on mental health issues. In a year about 40 such sessions in Kannada and Tamil are held.

Presentations focused on signs and symptoms of mental illness, causes, other options for treatment, misconceptions, the role of community in prevention of mental illness and on various entitlements available from the government for the affected persons.

An immediate impact of such awareness activities was an unprecedented increase in the number of phone calls to the NGOs seeking information and assistance. Further, voluntary disclosures also

Orienting volunteers on mental health issues

increased as families and affected persons themselves came forward to express their difficulties. Community participation and ownership of these awareness activities improved over a period of time. Many cases of human rights violations like physical abuse of affected persons were brought to notice and the team worked to reduce such incidents.

Care-givers groups evolve

Deep rooted social fears, stigma and marginalization have pushed many affected persons into isolation and have kept them in that situation. Visit to families helped many of them to talk about their problems and helped to convince community members to question their assumptions and misconceptions about mental illness.

The team facilitated residential camps, consultations and workshops for caregivers. The objectives were to educate individuals and family members on mental illness, misconceptions and cultural beliefs, anxieties related to treatment, marriage and livelihoods. When care-givers started interacting with one another during these camps they were able to empathize and relate to each others problems. Thus it was easier to form a peer group.

Care-givers met every three months with support from the field staff. They discussed treatment options, recovery and altitudinal barriers within the family and community. The team later suggested that the care givers meet at the community center to save time and money. The frequency of these meetings became monthly when the members could access the venue easily. New identifications were also possible with their presence. At present, there are seventeen care-givers groups and more than 230 care-givers participate actively in the program.

Meeting with caregivers

Advocacy - Need of the hour

Following many awareness programs, affected persons and care-givers started to approach Victoria hospital and NIMHANS (National Institute of Mental Health and Neuro sciences) in Bangalore City for services. As people faced difficulties in accessing treatment facilities, they started to express the need for better access to doctors and medicines and information on other treatment options. The first difficulty they faced was when the hospital authorities asked for BPL (Below poverty line) cards from those who wanted to avail free treatment. Many did not possess this card due lack of awareness on the need of such a document.

The needs were prioritized. The first priority was treatment but many families could not afford the travel expense and to buy medicines. The team assisted by giving them the travel costs. Some others were supported through small income-generation activities to supplement their income and to increase their self confidence.

Cognizant of the situation, the team started giving information to affected persons and their family members on their rights. This triggered the caregivers thought process and they realized that some of their basic needs were actually their right and that the government was obliged to fulfill them.

The first advocacy initiative took shape in October 2006. It was directed towards reorienting the current system into being more people-friendly. It was also realized that the advocacy efforts would impact not just Bangalore city alone but the entire state of Karnataka. With these objectives, the team along with affected persons, caregivers, representatives from women self help groups, youth and CBOs organized a rally and a press conference on World Mental health day to raise awareness on mental health issues.

Press meeting by Federation Members

Advocacy rally with Health Minister participating

The team and care givers groups presented a memorandum to the Health Minister Mr. R. Ashok which included a list of demands like appointment of additional resources for mental health; availability of medicines at Primary Health Centers (PHCs) and in all district hospitals; rehabilitation of destitute mentally ill persons and sensitising police personnel and judicial authorities on mental health issues.

After the presentation, the Health Minister invited the team and associated groups for further discussion, but subsequent efforts to meet with him were not successful. Disappointed, but still enthused, all those involved in advocacy efforts were determined to forge ahead and strategize their moves. The rally proved the importance of hearing people's voices.

Often the NGOs acting as mediators in advocacy are perceived to be soft in their approach with government officials. The importance of aligning and interacting with top bureaucrats in the government and not only with the politicians was realized, and it was accepted that confrontation with them on certain issues at times is unavoidable in the advocacy process.

The govt. officials too realized that the end users were not mere passive receivers, as the people were demanding that the health system be more

accountable and responsive to their needs. With these factors in mind, the team held discussions with the care givers groups, affected persons and the community groups on the next possible moves to reach their goal.

Manasika Aswastharu Mathu Poshakara Kriya Vedhike-

A federation is born

All stakeholders - the team, affected persons, caregivers and community groups felt the need to form a *Sangha* (an association of people with a common purpose) to raise their voice and to make effort to bring a systemic change. They believed that all the players/departments within the health sector coordinating and working for improvement would lead to a sustainable policy-level change that will benefit all users of health services in the long run. Networking with other disability groups to strengthen such an action was also recognized.

The team, after a brief review, felt that it would be good to bring together persons who have recovered from illness, care-givers, self-help groups of women, others from community based organizations, youth and cross disability groups. This process took almost a year to build, during when input on effective leadership and on requirements of effective functioning as a group were given to these people. Exposure visits to other federations were organized to help them conceptualize the idea of a federation.

Meanwhile, persons with mental illness and their supporters expressed the need to come together more often to share their experiences. About sixty members met every quarter and they gradually realized the need of an organizational structure to move forward. In February 2009 Manasika Aswastharu Mathu Poshakara Kriya Vedhike (Federation of persons with mental illness and their carers) was formed and elected its representatives. The office bearers included affected persons, caregivers and members from the community. Presently, they are involved in advocacy activities and support in new identifications, referrals, follow up, guiding persons on the procedures to obtain disability ID cards and other benefits from the government.

The members linked themselves with Kamataka Angavikalra Rajya Okkuta, (KARO, a federation of organizations working with persons with disability in Karnataka) and together with them they approached the government to address their issues. Letters were sent to the State Health Directorate and the Department of Disability Welfare asking them to organize a meeting to discuss issues related to treatment and rights of persons affected by mental illness, but unfortunately the response was not positive.

Subsequently, the Federation members applied to the Directorate of Health and Family Welfare under the Right to Information (RTI) Act. The response received showed an overall neglect of the mental health sector in the state. Many mental health personnel posts were yet to be filled, basic psychiatric services were unavailable even in district hospitals, and there was lack of counseling services and unavailability of Informative, Educational and Communication (IEC) materials in the Directorate. The Federation, KARO and the team demanded explanation from the Health Directorate through letters, but once again the response was not forth coming.

Federation members meeting to discuss their concerns and issues.

The Federation then decided to stage a protest on November 23rd 2007, coinciding with the commemoration of World Mental Health Day, in front of the Directorate of Health and Family Welfare. About 700 people including affected persons, caregivers, members from women self help groups, CBOs, youth and members of KARO and the Team participated in the protest *(see photo on the cover).* This caught the attention of Dr. Prema, Director of the Directorate. She listened to the needs put forward by the protestors and assured that their demands would be looked into and she would call for a meeting later with the Federation. However, the tall promises made by the Director never translated into action.

To keep the momentum going, the Federation members vigorously followed up with the Health authorities and met them in February 2008. This meeting was very productive as the Directorate ensured that all the action points discussed were implemented. As a gesture of commitment to their promises, they even released the minutes of the meeting!

There is a clause in the 11" Five Year Plan which states that District Mental Health Programme (DMHP) would be implemented in all the districts of the country. The federation and the Team realized that this was an opportunity to lobby with the Directorate of Health and State Mental Health Authority (SMHA) on this issue. After a series of meetings, the Directorate organized a day-long meeting with the Federation on 23rd October 2008 to discuss ways to accommodate the needs and demands of affected persons under the DMHP.

The SMHA appointed Dr. Srinivasa Murthy, a retired Professor from Dept. of Psychiatry (NIMHANS), as a consultant. He was asked to prepare a report on the current status of mental health services in Karnataka State and to suggest a plan of action to improve the situation.

One of the direct outcomes of such persistent advocacy efforts is the introduction of a special ambulance service exclusively for persons with mental illness. Further, the Directorate of Health and Family Welfare has started an orientation session on mental health to all the doctors in Karnataka at primary level care. Most PHCs in Bangalore have been covered and other districts are being covered stage wise. The Directorate has also prepared awareness materials in Kannada for dissemination through PHCs and district hospitals. Further, a proposal has been sent to the Central government requesting funds to launch DMHP in ten more districts, as at present only four out of 30 districts in Karnataka have this program.

"Strength does not come from physical capacity.

It comes from an indomitable will" - Mahatma Gandhi

The way ahead....

The members of Manasika Aswastharu Mathu Poshakara Kriya Vedhike (Federation of persons with mental illness and their carers) registered in 2009 are now motivating those persons with mental illness and their family members who are not yet registered as members to join the federation. They believe that an increased number would strengthen them further. A membership fee of 25 rupees is charged annually, which is renewable every year. The members get an identity card, and around 150 members have already received this card.

The elected representatives and active members of the federation with the support of partner team members have developed the vision and mission for the federation. They have also drafted the by-laws as they are planning to register the federation under the Societies Act.

Vision

Community based rehabilitation for people with mental illness, where their rights are protected, where they get equal opportunities to exercise their rights and to live with their families with dignity.

Mission

- Initiating community based rehabilitation program in Bangalore urban slums
- Organizing peopie with mental illness and family members at ward level
- Building alliance with other district and state level groups and federations
- Mobilizing local and other financial resources to initiate and strengthen the program and the alliance
- Provide livelihood opportunities for persons with mental illness and family members
- Advocate for the rights of persons with mental illness
- Accessing and effective utilization of government schemes
- Network with Government Departments
- Training on mental health issues for different cadres
- Raise awareness in community on mental health issues
- Participate in other community development activities

The Bangalore Urban program has been a tremendous learning experience for all those involved. The movement has spawned from individual and family to community level and is gaining strength. The advantage of collective strength in advocacy has come to the forefront. Networking with like-minded groups and alliance building has also become important for the federation and the team.

It would be useful to look at the strengths and challenges in this programme, so that actions can be taken to build on the strengths and to face the challenges.

Strengths:

- Active involvement of primary stakeholders - persons with mental illness, caregivers and family members.
- Partners interest in inclusion of mental health issues in their organization agenda and inclusion of persons with mental illness in their programmes.
- Networking with partners and other organizations like KARO and Jana Arogya Andolana.
- Psychotherapy and counseling as emerging strengths.
- Active participation of persons with mental illness in work therapy.

Challenges:

- Child mental health and illness due to substance abuse need to be attended.
- Sensitizing govt. officials on mental health issues.
- Livelihood module and linkage to community groups is inadequately implemented .
- Under utilization of govt. resources due to lack of knowledge on schemes.

Besides, few other issues that need to be taken up further are :

1. Psychiatric services should be made available and decentralized in the Rural and Urban Public Health System - Taluk Sub-divisional hospitals, District hospitals, urban health centers, secondary and tertiary hospitals.

2. Free psychiatric medicines should be provided in the above centers as per WHO norms and Drug Logistic Society Bangalore. (According to the Health Directorate there are supposedly 17 types of medicines available, but only 6 to 7 types of medicines are actually supplied.)
3. All medical officers should be trained on mental health / illness and inpatient services should be made available at all district hospitals.
4. Equip all district hospitals with psychiatrists and psychiatric social workers. According to information from the Health Directorate, only 16 district hospitals in the State have psychiatrists, 14 hospitals do not have them.
5. Effective use should be made of the 674 medical officers of primary health centers who are trained by the Health Directorate.
6. Patient-friendly environment needed at the hospitals.
7. Destitute homes should be established for the mentally ill in all the districts.
8. Disability certificates should be provided for all eligible mentally ill and he/she should get an acknowledgement whenever an application is made.
9. Community mental health workers should be appointed, based on the population of the area.
10. Awareness materials on mental health should be developed and made available at the Health Directorate; and awareness programmes on mental health / illness should be conducted at community level.
11. Police and judicial officials should be given orientation on mental health issues, services and related Acts.
12. Provide job opportunities for the recovered mentally ill persons.
13. Recovered people with mental illness and their caregivers should be consulted by at least few members of the Annual Planning Committee of the Health Directorate to plan related services.

The team is happy with the achievements thus far, but is aware that there are miles to go before the health system responds to the mental health needs of every citizen and empowers them to access these services. With that goal in mind, the federations and the team are working together for bigger steps ahead.

Current role of the federation in supporting persons with mental illness and family include,

- Identifying people with mental illness
- Educating people with mental illness and their families on illness and treatment
- Referring them for treatment and providing follow up care
- Enabling eligible people with severe mental illness to access disability ID cards
- Enabling eligible people to access schemes like disability pension, BPL cards, bus & train pass, housing under BBMP schemes and for self employment.
- Initiating information centers on mental illness and its management in the communities

- Organizing caregivers into groups
- Contact the local leaders to identify a place for an office and to hold meetings.
- Initiate efforts for local resource mobilization
- Meeting the BBMP ward leaders to address water and sanitation problems in the slum communities
- Admitting the destitute, neglected and poor children in Government hostels
- Supporting the families during emergencies like epidemics and other general health problems including pregnancies/deliveries
- Promoting awareness in the community on mental illness

BNI hopes that this account of the urban mental health initiative will pave the way for more of such efforts in other cities.

BNI expresses its thanks and gratitude to the three partner organizations - APSA, APD and Paraspara Trust for their co-operation; and to the Government and BBMP officials for their sympathetic hearing of the issues.

Thanks also to persons with mental illness and their families for their initiative and involvement.

Vedike Members listing their demands to the Govt. officials

Brief background about the three partners involved in this urban project.

Paraspara Trust

"Paraspara" means mutual. A small group of social activists started the Paraspara Trust in 1995 to enable children to enjoy a better quality of life. It worked in the slums in and around Yeswantpur railway station in Bangalore.

The initial focus of work was literacy: non-formal education and pre-primary education. Over the years their work evolved into a cadre building and community empowering process. Currently the project area covers a population of 60,000 people from 40 slums. Some of the ongoing projects are,

- **Child Right Action Forum** focusing on working with child labourers.
- **Balya:** efforts are to declare slums free of child labour
- **Kalike:** focuses on literacy and skills training for women.
- **Navabalya:** prevention of child labour and safeguarding their rights.
- **Arambha:** pre primary education through part time and full time crèches.
- **Punarchetna:** focuses on referral and counseling of persons suffering from mental illness in the slums through volunteers and resource persons from BasicNeeds India.

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Association for Promoting Social Action

APSA is a child-centered community development organisation. It believes that development is incomplete without the participation of the deprived communities. While the micro level work at the grassroots focuses on empowering the urban communities, the macro level work focuses on policy, advocacy and planning. The programmes of APSA are,

Nammane: a home for children under acute distress.

Navajeevana nilaya: Girls, who have graduated from Nammane and are working, trained in this shelter home in independent living skills.

Educational programme: in the slums using appropriate technology to meet the needs of children.

Kaushalya: This is a skill training project to provide quality skills to children in desk top publishing, tailoring, electronics, screen printing and stationery making.

Child labour project for children involved in hazardous jobs.

Slums outreach programme focuses on community organisation in over 135 slums in Bangalore and Hyderabad, to enable then to get basic amenities and legal aid.

Disability project: a comprehensive approach to provide a supportive environment to children both, at school and in their homes. They also have a 24 hours helpline for children in distress.

Community mental health programme: in 18 slums spread across the city, covering nearly 165 persons, suffering from various types of common and severe mental distress.

Association of People with Disability

APD started initially as a vocational training unit for persons with disabilities. Gradually over the last 50 years, the organisation grew to develop various need based programmes, as given below.

Shradhanjali integrated school for about 180 disabled and non-disabled children from disadvantaged backgrounds.

Appliance centre provides affordable and innovative aids such as crutches, calipers, body-braces and surgical shoes. It has a physiotherapy unit for therapy and awareness on managing loco motor disabilities, and trains aides in physiotherapy enhancing the functional ability and independent mobility of people with disability.

Outreach programme in 19 slums in Bangalore city with formal and non-formal integrated education, home based training for children, medical and surgical intervention, and vocational training. It also has a rural community

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