

BAPU TRUST FOR RESEARCH  
ON MIND & DISCOURSE

**BAPU TRUST FOR  
RESEARCH ON  
MIND AND  
DISCOURSE**

MENTAL HEALTH AND DEVELOPMENT: MODELLING  
COMMUNITY MENTAL HEALTH PROGRAM  
TO INFLUENCE NATIONAL POLICY

# EVALUATION REPORT

By:  
U. Vindhya, Kishore Kumar & Sadhana Natu



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**Editing:** Richa Sharma Dhamorikar and Bhargavi V Davar

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## **ABBREVIATIONS**

AIDS : Acquired Immunodeficiency Syndrome  
BPAD : Bipolar Affective Disorder  
BPRS : Brief Psychiatric Rating Scale  
BT : Bapu Trust  
CMD : Common Mental Disorders  
DMHP : District Mental Health Programme  
EPSRS : Extra-Pyramidal Symptom Rating Scale  
FBS : Family Burden Scale  
HIV : Human Immunodeficiency Virus  
ICMR : Indian Council of Medical Research.  
IDEAS : Indian Disability Evaluation Assessment Scale  
Kms. : Kilometres  
MANAS : Manashanti Sudhar Shodh  
MH : Mental Health  
MI : Mental Illness  
MR : Mental Retardation  
NIMHANS : National Institute of Mental Health and Neuro-Sciences  
NMHP : National Mental Health Programme  
NRTT : Navajbhai Ratan Tata Trust  
OCD : Obsessive Compulsive Disorder  
OPD : Outpatient Department  
PSLES : Presumptive Stressful Life Events Scale  
PTSD : Post Traumatic Stress Disorder  
PWD : Persons with Disability  
QOL : Quality of Life  
RCV : Resident Community Volunteer  
Rs. : Indian Rupees  
SC : Scheduled Caste  
ST : Scheduled Tribe  
SMD : Severe Mental Disorders  
SRQ-20 : Self Reporting Questionnaire - 20  
ST : Scheduled Tribe  
TOR : Terms of Reference  
UCD : Urban Community Development  
WHO : World Health Organization

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# 1. INTRODUCTION

## 1.1. About this report

Bapu Trust (BT) has been engaged in a project called *Mental Health and Development: Modelling Community Mental Health Program to Influence National Policy* in Pune city since May 2010. Conceived as an initiative in urban mental health, the project, designed to integrate mental health services in ongoing development programmes (including health, education, basic services, livelihoods, food security, housing and so on) is anchored within a vision of ‘mental health empowerment’ and of a paradigm shift towards developing strategies for enhancing the well-being of communities, rather than following a predominantly curative, bio-medical and institution-based model of health care (Davar, undated).

Specifically, the key objectives of this community outreach project are to:

1. To provide psychosocial counselling and referral services in urban slums of Pune (in the two localities of Lohiyanagar and Kashewadi in particular).
2. To increase knowledge and awareness about mental health through community friendly literature.
3. To study prevalence of mental health problems in the target community and analyse efficacy of the intervention carried out.

Earlier reviews of BT have focused on some aspects of this project on *Mental health and development* (Juvva, undated) and on the research programme (Kishore Kumar, undated). In April 2013, the principal investigator of the evaluation study was approached by the funders of the BT project, Navajbhai Ratan Tata Trust (NRTT) to conduct an evaluation of the effectiveness of the project. Initially, the scope of work outlined in the TOR included a field visit to BT; documents review (Proposal, Narrative Reports, Baseline Report and previous review reports); interactions with some of the users of BT’s services; and discussion with BT staff on psychosocial interventions provided by them; and developing a framework for an evaluation study. The present report includes observations and review of all of the above as well as the findings of an empirical study, conceptualized and designed with the collaboration of representatives of BT, NRTT and the evaluation study team.

The objectives of the present evaluation study were the following:

1. To obtain a profile of the current mental health status of the users of the services of BT in the two slums of Lohiyanagar and Kashewadi.

2. To conduct an effect evaluation of:
  - a. Levels of awareness in the residents of these two localities about mental health including stigma related to mental illness, and mental health-seeking behaviour.
  - b. Satisfaction with the type of services and quality of care provided by BT.
3. To understand the perspectives and perceptions of some key people associated with the project.

This report is therefore based on the initial field visit of the evaluation team (April 2013) as well as the findings of the research study done by the team (June 2013).

## **1.2. Structure of this report**

The first chapter of the report will describe the larger context of mental health care, and the overarching philosophy, vision, and objectives of this project of BT and its location in this larger context. Chapter two will detail the methodology of the research study carried for purposes of the evaluation and Chapter three will present and examine the findings in each of the three components of the evaluation: a) current mental health status of users; b) nature of awareness and attitudes about mental health and mental health-seeking behaviour of the users; and c) satisfaction expressed about the type and nature of services provided by BT. Chapter four will pull together lessons learned about what constitutes the BT model of urban mental health care and present recommendations of the evaluation team based on the data gathered, interactions with personnel and the documents perused.

## **1.3. The context of mental health in India**

### **1.3.1. The imbroglio of mental health: The present situation, challenges and need for advocacy of community mental health**

More than 10% of the population in India have mental health problems, indicating an epidemiological and demographic transition wherein non-communicable diseases are set to emerge as a major public health problem (Funk et. al. , 2010; Shidhaye and Patel, 2012), a problem that is projected to increase further in the next 25 years (Patel et. al. , 2011). Various studies in India have reported varying prevalence rates of mental disorders ranging from 9.54 to 370 per 1000 population with the disadvantaged and lower socio-economic strata being particularly at risk (Gururaj & Isaac, 2004).

Recent literature on mental health in low and middle income countries and those undergoing rapid socio-economic change broadly covers three major themes: a) the significant vulnerabilities that mental ill health involves, and the role of cultural, psychosocial and socio-economic factors that trigger, sustain or increase these vulnerabilities; b) the largely unmet mental health needs of affected



populations; and c) the inability of traditional psychological and psychiatric models to provide the quantity and quality of mental health services required.

***The vulnerability of mental ill health and its psycho-socio-economic and cultural correlates:***

People with mental health conditions, as identified by an analysis of major development stakeholders' projects and publications, form a group at risk, exemplifying all major criteria for vulnerability (Funk et al, 2010). The psychosocial, socio-economic and socio-cultural correlates of vulnerability include both predisposing factors to mental ill health as also the demographic, psychosocial, socio-economic and socio-cultural consequences of mental ill health that serve to sustain and increase the ill health conditions. Patterns of association between demographic and socio-economic characteristics are seen across countries - with women, widowed and older individuals, those reporting poor physical health, and those living with persons having poor mental health, reporting significantly worse mental health (Das, Do, Friedman & McKenzie, 2008). Physical health concerns especially those of great importance in developing countries such as HIV, were found to be significant risk factors for mental disorders such as dementia and depression. Other socio-economic and socio-cultural risk factors for mental ill health include social disadvantage (Funk et. al., 2010), poverty and debt (as seen in the alcohol-related deaths of men in Eastern Europe, the suicides of farmers and weavers in India and the suicides of young indigenous peoples in southern America) (Patel & Kleinman, 2003; Patel, 2007), gender disadvantage (WHO, 2000), low education, conflict, social exclusion, loss, trauma and displacement due to war, disasters and civil violence, with vulnerable groups reporting high rates of mental health conditions (Funk et. al., 2010; Lund, Breen, Flisher, et. al., 2010; Saxena, Thornicroft, Knapp, & Whiteford, 2007; Patel, 2007). Some studies propose a greater impact of multidimensional shocks such as illness or crisis (financial or otherwise) as compared to the overall levels of poverty (Das et. al., 2008).

Similar experiences have been reported in countries with rapid socio-economic change such as India wherein increasing urbanization, disparities between expectations and reality, and accompanying social upheaval in terms of eroding family support systems and new forms of external emotional support few and scattered, resulting in increasing psychological distress especially in the face of financial crisis (Chatterjee, 2009). Together with the impact of social upheaval in our country, is the huge burden of poverty whose relationship with mental health is complex and multidimensional.

***Poverty and mental health:*** Poverty and associated conditions such as unemployment, low education, deprivation and homelessness, is known to be a significant problem across several states of the country. The poor and the deprived have a higher prevalence of mental and behavioral disorders, including substance use disorders. This higher prevalence may be explained both by higher causation

of disorders among the poor and by the drift of the mentally ill into poverty because of lack of access to care, persistent disability, increasing family burden and lastly, stigma and discrimination. Though there has been controversy about which of these two mechanisms accounts for the higher prevalence among the poor, the available evidence suggests that both are relevant (Funk et. al., 2010).

The many consequences of mental ill health involve high rates of stigma, marginalization, discrimination, physical and sexual victimization, restrictions in the exercise of political, cultural, economic, social and civil rights, as also barriers to education and employment opportunities. Poor mental health is associated with lowered labour force participation (especially for women) and higher frequency visits to health centres, suggesting significant economic consequences of poor mental health for households and the health system. The cumulative effects can directly and indirectly serve to sustain and increase mental ill health, related disability and premature death in affected populations, in terms of restricting the ability to access essential health care especially when health care involves high costs, restricting access to social care, and generating poor self-esteem, low self-confidence, reduced motivation, and less hope for the future (Funk et. al., 2010; Das et. al., 2008; Patel, 2007). Further, the consequences of mental ill health have been found to have a direct impact on physical health correlates, in low and middle income countries in particular. For instance, maternal mental ill health was found to directly contribute to the burden of child mortality, a major concern of the Millennium Development Goals, with maternal ill health showing significant relationships with child physical health problems, low birth weight, growth failure and incomplete immunization (Patel & Prince, 2006; Miranda & Patel, 2005; Sachs & McArthur, 2005; Patel, Rahman, Jacob, & Hughes, 2004; Rahman, Iqbal, Bunn, Lovel & Harrington, 2004). Similarly, mental health disorders and consequences such as substance abuse were found to be risk factors for HIV/ AIDS (Collins, Holman, Freeman & Patel, 2006; Freeman, Patel, Collins & Bertolote, 2005).

On the other hand, these high prevalence figures and the consequent calls made to address the grave “emergency-like situation” with regard to the services and treatment gaps in mental health care (e.g., the WHO’s Mental Health Gap Action Programme, mhGAP, 2008) are also seen as part of the push towards “understanding mental health problems within a bio-psychiatric register” (p. 566, Kumar & Mills, 2013). Further, the interventions to raise mental health literacy as attempts to present “as definitive the contemporary western way of being a person” (p. 992, Summerfield, 2008, cited in Kumar & Mills, 2013, p. 561) are critically read as part of “the globalization of (arguably Western) bio-psychiatric systems of knowledge” (p. 550, Kumar & Mills, 2013). It is however not within the ambit of the present brief review of literature to dwell at length on this contested nature of mental

health care; the reference is being made here only to indicate the problematic nature of viewing mental health care in an uncritical manner.

***The unmet burden of mental health:*** It is by now well-established that the burden of mental health problems is enormous and forms an increasing component of health problems. However, mental health problems remain grossly under represented by conventional public health statistics, which primarily focus on mortality rather than the morbidity or dysfunction (Ganguly, 2005). Among low-income countries, the relatively few existing estimates of mental ill health suggest that prevalence levels are not significantly lower than those found in wealthier countries (Bijl, de Graaf, Hiripi, Kessler, Kohn, Offord, et. al., 2003; Patel, Araya, de Lima, Ludermir, & Todd, 1999) . Resources and services for mental disorders are however, disproportionately low compared to the burden caused by these disorders and large proportions of severely mentally ill populations in the developing world receive no treatment for their disorders, suggesting widespread under-utilization, poor access and hence unmet mental health needs (Das et al, 2008; Funk et. al., 2010) . Between 75% and 90% of people with mental disorders are said not to receive medical treatment in these countries (Saxena et. al. , 2007; Patel, Boyce, Collins, Saxena, & Horton, 2011). In most developing countries, care programmes for the individuals with mental health problems have a low priority. For instance, in low-income countries, depression represents almost as large a problem as does malaria (3.2% versus 4.0% of the total disease burden), but the funds apportioned for battling depression are only a tiny fraction of the latter (Mathers & Loncar, 2006). Provision of care is limited to a small number of institutions which are usually overcrowded and under staffed (Shah, 2005). Despite their vulnerability and the high prevalence, people with mental health conditions have been largely overlooked as a target of development work, even while other vulnerable groups like women and children and other health problems receive some focus (Funk et. al., 2010) .

***The need for a community mental health approach:*** Researchers contend that India's "mental healthcare system inherently marginalizes the very people it is meant to serve through its myopic methods" (Gaitonde, 2008). Those supporting the community mental health approach underscore the view that the huge burden of unmet mental health needs cannot be addressed by a mere extension of the existing traditional psychological and psychiatric services (Campbell & Burgess, 2012). They are critical of the tendency to medicalise peoples' responses to life problems such as unemployment or social displacement and other adverse social circumstances which serves to cloak the health-damaging effects of social and economic inequities and the ensuing stress. As a result, instead of focusing on the need to bring about radical social and economic change, a heavy emphasis on medicalization tends to depict mental ill health as an outcome of individual deficit rather than the

social setting. This, according to the advocates of the community mental health approach lessens the likelihood of affected people coming together to address and tackle adverse social circumstances (Campbell & Burgess, 2012).

Proponents of this approach are also critical of the prescriptive and top-down nature of the global funding architecture (Kelly & Birdsall, 2010), the imposition of ill-suited international models of behaviour change and service provision on local experiences of health (Vaughan, 2010), the positioning of communities as passive recipients of services rather than agents of their own health (Aveling, 2012). In contrast, the community mental health approach views communities as experts in their own right, as crucial partners in dialogue with biomedicine, as well as agents promoting “community mental health competence”, rather than being simply seen as helping to implement an imported and imposed biomedical agenda. It is argued that such an approach would ensure greater attention to the impacts of context, culture and local survival strategies on peoples’ responses to adversity and illness, greater acknowledgement of the agency and resilience of vulnerable communities and increased attention to the way in which power imbalances and social iniquities frame peoples’ opportunities for mental health (Campbell & Burgess, 2012).

The psychosocial, socio-economic and cultural correlates of mental health and its significant impact in low and middle income countries, the large mental health burden and its vastly unmet status, and the poor resource availability build therefore, a strong case for the adoption of a community mental health approach. Advocates of this approach argue that engaging with lay volunteers and low-level paid health workers would be more in line with the local socio-cultural framework, would deliver expanded services in resource-poor contexts with few trained personnel, increase the reach of these services through community participation, enhance the possibility of effective prevention, care, treatment and local advocacy, provide better access to practical, emotional and material support for the ill and the confidence to cope with or challenge social stigma, thereby leading to empowerment (e.g., increased income generation opportunities, enhanced social recognition, opportunities for community activism), and increasing opportunities for health, both at the individual and the collective levels (Campbell & Burgess, 2012).

***The community mental health programme in India:*** The District Mental Health Programme (DMHP) set up under the aegis of the National Mental Health Programme (NMHP), envisaged a decentralized community based approach that aimed at developing effective partnerships and active collaborations between the district mental health team, and various stakeholders such as the primary health care teams, community based organizations, non-governmental organizations, users, family

groups and various government departments to deliver a comprehensive and sustainable mental health care service that ensured accountability and focused on the local needs, and aspirations of the people with regard to mental health (Salhan & Thara, 2007; Murthy, 2011).

However, despite the ambitious initiatives of the central government in the form of the DMHP and increased resource allocation as also other initiatives towards enhancing the accessibility and quality of mental health services, researchers argue that the community mental health programme in India is far from satisfactory in its present state of functioning. Literature shows that India and south eastern Asia lag behind the rest of the world in community care for mental health (WHO's Mental Health Atlas, 2005). Only 10 per cent of those with mental health disorders are said to receive evidence based treatments (Murthy, 2004) and a vast majority of the population are outside the model programmes and lack the basic facilities suggested in the national plans (Jacob, 2001). A vast imbalance in access persists with most specialist centres concentrated in urban areas (Murthy, 2004) and several instance of human rights violation of the mentally ill being reported (Shidhaye & Patel, 2012). Published literature and independent evaluation of the DMHP indicates that the programme is to a large extent dysfunctional and ineffective in practice (Murthy, 2011), with its implementation in only 125 of 625 districts in India and its lack of fine tuning (Shidhaye & Patel, 2012; Chatterjee, 2009) and inadequate utilization of funding allocated (Shidhaye & Patel, 2012).

Reasons for the disappointing performance of the DMHP have been stated to be a 'top-down', 'one size fits all approach' to service delivery, inability to include diverse realities, poor governance, lack of a robust mentoring framework (Shidhaye & Patel, 2012); ill-paid and overburdened primary health care personnel (Goel, 2011); the lack of a policy document clearly stating goals, objectives, strategies and tasks with the result that the programme is variously interpreted and implemented at the district level (Ministry of Health and Family Welfare, 2008); and disproportionate reliance on psychiatric and psychopharmacological management with minimal engagement with community health workers (Goel, 2011; Ministry of Health and Family Welfare, 2008).

Other critical evaluations of the community mental health programme in India focus on the lack of integration into the primary health care systems (Jacob, 2010); the ineffectiveness of vertical programmes (Jacob, 2011); lack of program suitability to local needs (Jacob, 2010); paucity of well documented studies to determine the prevalence and pattern of mental disorders (Kumari, Mishra, Chaudhury, Singh, Verma & Kumari, 2009; Basic Needs, 2009); lack of human resource power in delivery of mental health care (Chatterjee, 2009); dearth of leadership in the mental health sector (Sinha & Jagdish, 2011); stigma and poor awareness, combined with reduced accessibility leading to

a lower demand for the utilization of the scarcely available services (Chatterjee, 2009); underutilization of funds allocated for raising community awareness and addressing stigma and discrimination associated with mental health disorders (Ministry of Health and Family Welfare, 2008).

***Uneven distribution of mental health services between urban and rural areas*** : The WHO-ICMR Pilot Project on Urban Mental Health revealed an uneven availability of mental health services, human resource deficit especially for non-medical mental health professionals and mental health service gap (82 per cent to 96 per cent) in the urban sector in particular (Desai et. al, 2004) thereby indicating the lack of accessibility to modern psychiatric services among the urban population (Desai, 2001). The existing mental health services are said to be disproportionately available in metro cities to the affluent classes and disproportionately unavailable to the lower socio-economic strata. Researchers also show that the DMHP model has remained largely confined to rural areas, and has been implemented in urban areas in very few places (Desai et. al, 2004). The strong pro-rural bias in the implementation of mental health programmes could have been possibly due to the fact that larger proportion of Indian population then resided in rural areas and these areas faced a lack of adequate services. However, this has also led to the situation of the urban mental health services being overlooked in policy and programme formulation at national and state level, which is a significant concern especially considering the changing global and Indian demographic profiles (Desai et. al, 2004). Further, there is also a paucity of information on the mental health service needs, availability, and utilization in urban areas. It is pointed out that a public health approach to mental health requires that these service needs be identified and strategies, and be developed through an inclusion of different sectors of health care service delivery, the government, private, non-governmental and the non-formal sectors in the assessment of the needs and the planning of the future services (Desai & Shah, 2002).

Researchers in the field underscore the point that delivering mental health care in India will require task-shifting to community and non-physician health workers who are trained and supervised (Patel, 2009, Chisholm, Flisher, Lund, Patel, Saxena, Thornicroft, & Tomlinson, 2007). Empirical evidence for such a perspective and efficacy of such a practice is to be found in programmes such as MANAS (Patel, et al, 2010), community based rehabilitation of schizophrenia in rural Madhya Pradesh (Chatterjee, Patel, Chatterjee, & Weiss, 2003; Chatterjee, Pillai, Jain, Cohen, & Patel, 2009) and the Home Care programme in Goa, to name a few.

The rationale and philosophy of BT and its interventions need to be viewed against this background of the dismal functioning of the DMHP, the ongoing community mental health initiatives of non-state actors such as non-governmental organizations and the imperative for a comprehensive mental health programme. Viewed against such a backdrop, the significance of a programme and model of mental health care such as BT's embedded in a vision of dovetailing mental health with development, social justice, and empowerment cannot be underscored more. The next section will outline the core philosophy and objectives of BT's programme, as understood and interpreted by us from the documents and the presentations made, and the interactions with BT staff.

#### **1.4. Vision, philosophy, and goals of the project**

In marked departure from the 'treatment and cure' paradigm of mental health care, BT's project is anchored within the 'social' model of understanding mental health, underscoring the linkages of mental health with development, social justice, human rights and of enhancing well-being, through interventions that build on capacities, resilience and support structures of communities rather than "merely provide a pathway for medicines to reach the mentally ill in the community" (p. 17, Davar, undated). Underpinning this project is the assumption that the continuum of mental health problems and psychological distress can be understood and addressed when there is concurrent attention to the biological, psychological and social dimensions of illness, and that illness and distress are embedded in and determined by combinations of biological factors, social and environmental contexts and the subjective experience of the individual. Following this assumption the project entails providing a network of intertwining and wide ranging services such as physical health care, social services, psychosocial counselling and nonformal support systems as well as promoting a primary prevention approach through generating awareness in the community about mental health, seeking help for mental health problems, and reducing stigma associated with mental health issues.

The project's commitment to the psychosocial and justice perspective is reflected in its emphasis on addressing the needs of underserved populations such as underprivileged and economically disadvantaged communities; and to whom a range of psychosocial services can be provided in a manner that is accessible and acceptable. The overall objective therefore is to address and alleviate the psychological consequences of adverse circumstances characterized by socio economic disadvantage in the context of an urban slum locale. In order to do this, two aspects of this *psychosocial programme* are distinguished :

- A '*psychological*' component involving identification of vulnerable individuals and providing support in order to facilitate the reconnection of the affected individual to his or

her environment and community. The psychological elements of this programme are therefore :

- *identification of people with mental health problems* (both severe and common mental disorders, as well as of the sub-threshold type)
- *making referrals* to existing medical or psychiatric services
- *providing arts based therapies and counselling services* and offering emotional support to individuals and small groups, and improving people's coping mechanisms.
- A 'social' component aiming to create an environment that facilitates the individual or groups of individuals to re-integrate through services such as :
  - *Community education* aimed to break down taboos about mental health and psychosocial problems, to increase awareness about counselling services and increasing capacity of community to provide emotional support and care.
  - *Networking* that is essential for understanding and addressing the needs of local people; for involving establishing and maintaining relations of trust with them; ensuring proximity to them through demonstration of sensitivity, empathy and compassion in order to enable addressing clients' needs through provision of quality care; and negotiating the service delivery within the community.

The range of services provided by BT therefore seeks to demonstrate its underlying commitment to an innovative paradigm of a comprehensive mental health care project that would in addition to making available necessary bio-medical attention, aims to offer humanized care and restore empowerment to the client.

## **2. METHODOLOGY OF THE EVALUATION**

### **2.1. Key sources and procedure**

The evaluation is based on :

1. Data gathered on the current mental health status profile of the users of BT's services and in particular those diagnosed as affected by severe mental disorders (SMD) and common mental disorders (CMD) in the two localities of Lohyanagar and Kashewadi of Pune city. Together these two localities have a population of around 50,000 individuals.
2. Data gathered on awareness in the general community about mental health issues and mental health-seeking behaviour.



3. Data collected on satisfaction expressed with regard to the type and quality of services and care provided by BT; perceived impact of the services on psychosocial coping mechanisms and perceived improvement in functionality and reduction of psychological distress from the perspective of the user.
4. Interviews with key informants such as hospital staff and community health workers involved with the project and to whom BT makes referrals; the Urban Community Development workers of Pune Municipal Corporation, and youth club representatives.
5. Key documents about the project: The following materials were provided to us for the evaluation :
  - i. Davar, B.V. (undated). Gender and (urban) community mental health: Sharing experiences from our service program.
  - ii. Kishore Kumar (undated). Review of Bapu Trust.
  - iii. Juvva, S. (undated). Review Report of Bapu Trust.
  - iv. Baseline data on mapping of the services in the project site (health, educational, recreational etc); household numbering and listing [undated] .
  - v. Narrative report on the outreach activities conducted between May and November 2011.
  - vi. Narrative report *Mental Health and Development: Knowledge capture and modeling services*, November 2011-April 2012.
  - vii. Bapu Trust (2012). What interventions have we found useful in our Urban Mental Health (UMH) work, which is non-medical ?
  - viii. Urban Mental Health Program, Bapu Trust (undated). Mental health and Development: Knowledge capture, Creating Resource Groups, and Modelling services: (2013-2016).
  - ix. Nair, K. (2011). Sakshi, Arts based therapy with single women.
  - x. Bapu Trust (undated). Seher, urban mental health program: Some case studies.
  - xi. Summary of intital proposal (undated).
6. Two visits to the project site (in the last week of April and first week of June 2013), meetings at BT office (in April 2013) with key personnel and functionaries associated with the project; notes made on the basis of seeing and listening to presentations (power point, oral and visual

in the form of a documentary film) made by BT staff; one focus group discussion in the project site with select users of services provided by BT; visits to homes and conversations with a small number of users.

7. Visits and meetings included the following sites and took place in April and June 2013:
  - a. Sonawane Hospital.
  - b. Community hall.
  - c. Homes of residents of the two localities.
  - d. Office of the Urban Community Development worker.

The visits and meetings were facilitated by BT staff. Notes were taken during the observations. The interviews and meetings were taped with the permission of the respondents. Review of the documents provided was carried out. In June 2013 the research study (with its three components of a) assessing the mental health status of clients with SMD and CMD; b) assessing a select sample on the dimensions of awareness about mental health and of satisfaction with the services provided by BT and c) gaining insight into the perspectives of key people associated with the project) was conducted by a team, led by the principal investigator and the lead consultant, Dr. Kishore Kumar<sup>1</sup>. This report draws on all these sources. Informed consent was taken from all the study participants, and other ethical guidelines such as maintaining participants' anonymity and confidentiality were followed.

Considering the volume of work that has been carried out over the past several years by a team of dedicated personnel, we cannot claim to have captured all its dimensions and depth within the brief period during which we got to know about the project. The data collected as part of the research study was meant only to quantify some aspects for purposes of evaluation of the effectiveness of BT's services. Even then, we do not assert to have captured all the ingredients that have gone into conceptualization and implementation of this project in a brief report such as this. This report is only a modest attempt to provide a broad overview of BT's work on the psychosocial services rendered by it in the economically disadvantaged locales of Pune, and to ascertain their effectiveness in terms of current mental health profile of the users, awareness and attitudes about mental health among the residents, and satisfaction of users with the services provided by BT.

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<sup>1</sup>Dr. Kishore Kumar conducted the mental health evaluation on the entire sample of users affected by SMD and CMD. The three field investigators, Pranjali Kulkarni, Sheetal Nimbalkar, and Laxmi Jambulkhar collected data on awareness about mental health and mental health-seeking behaviour; Dr. Sadhana Natu gathered data on satisfaction with BT's services and conducted the five key informant interviews.

## 2.2. Sample

The following table shows the total number of clients who have accessed and been supported by the outreach services of BT from the commencement of this project in 2010 till date.

**Table 1 : Outreach of BT : September 2010 - March 2013**

<b>Output of services</b>		<b>Output</b>
1	Number of CMD clients	84
2	Number of SMD clients	80
3	Number of group counselling clients	68
4	Support counselling clients	337
5	<b>No. of Corner meetings:</b>	887
6	No. of participants in corner meetings	4873
7	<b>No. of Awareness Meetings</b>	101
8	No. of participants in Awareness meetings	2671
9	<b>No. of Poster Exhibitions</b>	13
10	No. of participants in Poster Exhibitions meetings	881
11	Home visits	3734
12	Social referral clients (linking with other Urban Community Development programs with Municipal Corporation)	385
13	<b>Disability Certificate</b>	64
14	Total clients with psychological distress or disability	<b>633</b>

The samples constituted for the different components of the present study were as follows :

1. The sample for assessing the current mental health status of the users included all those who had accessed BT's services and who had been diagnosed with SMD and CMD.
2. The sample for assessment of awareness about mental health was constructed using a random sampling method (choosing every 10<sup>th</sup> person from a household from the mapping of households provided by BT). This however could not be strictly adhered to as it was found that the selected person was often not available on grounds of either migration, or could not be traced otherwise, or had died. In such cases, the person from the next household was taken for the sample. The 'person'

here referred to not necessarily someone who was the head of the household but any adult who was available at home at the time of data collection.

3. The sample for assessment of satisfaction with services by users was similarly constructed using the random sampling method of choosing every 6<sup>th</sup> person from the database of users provided by BT. Similar limitations in adhering to this criterion were encountered in that the next person was taken in cases of non-availability of the selected target participant. While 42 users were from Lohiyanagar, 43 were from Kashewadi, and 5 from adjacent localities.
4. Through the methods described above, the sample for the evaluation study was constructed as follows.

**Table 2: Sample of the evaluation study**

	<b>Dimension</b>	<b>Targeted sample size</b>	<b>Actual sample size</b>
1.	Evaluation of current mental health status  Users diagnosed with SMD  Users diagnosed with CMD	  84  80	    112
2.	Awareness about mental health and mental health-seeking behavior among residents of the two localities of Lohiyanagar and Keshiawadi who have participated in the awareness and corner meetings organized by BT	500	500
3.	Satisfaction expressed by users with type and nature of services provided by BT	100	90
4.	Key informant interviews	5	5

### 2.3. Tools

1. Evaluation of current mental health status of those who have accessed the services of BT and who have been diagnosed with SMD and CMD, was done with the following tools<sup>2</sup> .
  - i. Brief Psychiatric Rating Scale (BPRS)
  - ii. WHO Quality of Life Scale (QOL, Brief version)
  - iii. IDEAS
  - iv. Family Burden Scale (FBS, Pai & Kapur)
  - v. Extra-Pyramidal Symptom Rating Scale (EPSRS)

<sup>2</sup>The mental health evaluation was done by Dr. Kishore Kumar.

- vi. Self-Reporting Questionnaire (SRQ-20)
- vii. Brief Disability Questionnaire
- viii. Presumptive Stressful Life Events Scale (PSLES)

2. Assessment of levels of mental health awareness done on residents of the two slum localities who have participated in the awareness and corner meetings conducted by BT was done with a questionnaire adapted and developed from the *Knowledge, Attitude and Practice Questionnaire for Health Workers (Department of Psychiatry, NIMHANS, Bangalore; the ICMR evaluation study of DMHP; and from documents provided by BT on their activities and programmes, Appendix 1)*.
3. Assessment of levels of satisfaction of users with type and quality of services, and perceived improvement in functionality and alleviation of psychological distress was done with the help of a questionnaire developed for the purpose [Appendix 2].
4. Perspectives of important stakeholders about the nature of services provided and the observed qualitative changes were elicited from 5 key informant interviews.

### 3. FINDINGS OF THE EVALUATION

#### 3.1. Current mental health status of users<sup>3</sup>

The following table gives details of the sample size for the mental health status evaluation of SMD and CMD clients.

**Table 3: Sample for mental health evaluation of SMD and CMD clients**

	Status of SMD & CMD	Number of forms
1	Completed	112
2	Refused	3
3	Dead	4
4	Migrated	5
5	Out side the catchment area	31
6	Identified	4
7	MR	2
8	Not available	5
9	New cases	20
10	Total	186

<sup>3</sup>This section is based on the data collected by Dr. Kishore Kumar and on his write-up.

***Tools and procedure :*** Persons with SMD were assessed using BPRS, WHO QOL Brief version, IDEAS, Family Burden scale (FBS) and Extra-pyramidal symptom rating scale (EPSRS). For persons with non psychotic psychiatric morbidity (CMD), Self-Reporting Questionnaire (SRQ-20), Brief disability questionnaire, Presumptive Stressful Life Events Scale (PSLES) were used for evaluation. The raw data was handed over to the BT team. A data entry person was appointed for entry. After cleansing, the data was sent to the consultant specifically appointed for this purpose for analysis. All clients who had to be evaluated in detail were asked to come to BT office after being informed well in advance. The BT team had generated a list of prospective clients to be evaluated and a target of 15- 18 clients were to be evaluated every day. About one half of the interviews were done in the office while the rest was completed in the community. All clients to be interviewed informed about the need for evaluation and all of them except three clients refused to be interviewed.

***Results of SMD evaluation: Socio-demographic and clinical profile :*** Detailed evaluation using BPRS, WHO QOL, IDEAS, FBS and EPSRS was done for 67 people, 32 men and 35 women with SMD. The average age of the sample was 34 years. Nearly one half of the samples were illiterates, while one fifth has primary, and the rest had high school and pre-university education. About 32% of the samples were married and the rest were single by virtue of being separated, widowed, and divorced or never being married. Past employment suggested that majority of the sample were employed in the past -- before the onset of illness which also included young people perusing studies. Employment status at the time of evaluation suggested that nearly 40% were engaged in some kind of productive work while the rest were unemployed. 7 out of 10 people who were evaluated were Hindus while the rest were Christians, or Muslims or Buddhists. Majority of the sample belonged to Scheduled Castes and Scheduled Tribes and 22% belonged to upper castes. Nearly a third of the sample belonged to joint family while the majority belonged to nuclear family. It was interesting to note that none was living alone at the time of evaluation. The average family income per month was about Rs 6000 with a small sample having income of more than Rs 20,000 per month. The mean family size was about 5 and it was interesting to note that more than one member was affected with mental health problems in nearly one third of the families. One fourth of the sample had one or more physical health problems like anemia, dental caries, diabetes, hypertension and neurological disorders.

Nearly 55% of the sample did not seek any psychiatric intervention before they were referred for psychiatric intervention by BT. It was interesting to note that 45% of individuals had sought treatment from nearby psychiatric facilities, the most common facility being the Yerwada mental hospital.

Diagnosis showed the following profile – schizophrenia (56%), mental retardation (23.8%), acute psychosis (2.9%), BPAD(5.8%) and the rest were OCD and depressive disorders. Alcoholism constituted an important co-morbidity in addition to an identifiable mental health problem. Duration of illness revealed that one fourth of clients had an illness less than two years duration while the rest had longer duration of illness. Course of illness suggested that majority of the patients had continuous illness while 10 of the users had episodic illness. Disability due to psychiatry illness revealed that 9 out of 10 patients family members report mild to severe disability at the time of evaluation. Of the disabled individuals, more than one half had moderate to severe disability at the time of evaluation. With regards to current treatment, data suggested that 4 out of every 10 patients evaluated were on treatment while the rest had stopped or discontinued treatment for various reasons. The most common antipsychotic drugs prescribed is olanzepine and poly pharmacy was frequently seen amongst users of the services. Compliance with medication revealed that one third of patients were on regular treatment, 15% of patients were irregular and the rest had discontinued or stopped treatment altogether. Outcome of intervention at the time of evaluation suggested that only 10% of patients had complete remission of symptoms, about 30% improved symptomatically and the rest had not shown any improvement despite interventions. Follow-up care with mental health services revealed that about one third were using the services regularly, 16% were irregular and the rest had dropped out from treatment.

Barriers to use services revealed the following: Long distance from the health care facility as a barrier was reported by one fourth of patients who were evaluated. On the other hand, nearly a third of patients reported lack of relative to accompany the person, non availability of medication, non improvement in symptoms and lastly stigma and discrimination as the barriers for care. It was interesting to note that more that four fifths-three fourths did not perceive any barriers in utilizing services. This implies that about a third of patients in the community will require care at home because of the practical problems they encounter while continuing care in the long run (*Table 4*).

**Table 4: Problems in utilizing services**

Perceived barrier	Frequency	Percentage
Long distance	18	26.9
Lack of family member to accompany the patient	22	32.8
Non availability of free drugs	21	31.3
Non improvement in symptoms	21	31.3
Side effects due to medication	5	7.5
Stigma and discrimination	21	31.3

**Symptom profile based on BPRS:** The BPRS was administered to persons with SMD identified in the community. The most common symptoms seen in the sample was suspiciousness and somatic concern (Table5). About one third of the sample studied reported symptoms that they are being harmed by others and that they are convinced about it and had no insight into that symptom. Similarly about a third of the patients had bodily concerns such as reporting that parts of their body were not functioning or that their bodies had changed in some way. Emotional withdrawal was seen in about one third of the patients. Similarly, motor retardation, uncooperativeness and unusual thought content was seen in about one fifth to one quarter of the patients. Blunting of affect was seen in one fifth of the patients. However, excitement, posturing, mannerisms was seen in a very small proportion of patients. It was interesting to note that about a third of the patients were symptomatic – both positive and negative symptoms at the end of treatment for a long period of time. It was further interesting to note that the number of patients who had arousal features were very few in number.

**Table 5 : Frequency of symptoms on BPRS**

SL NO	Symptom	Frequency	Percentage
1	Somatic concern	22	32.8
2	Anxiety	5	7.5
3	Emotional withdrawal	21	31.3
4	Conceptual disorganization	9	13.4
5	Guilt feelings	1	1.4
6	Tension	6	8.9
7	Mannerisms and posturing	0	0.0
8	Grandiosity	1	1.4
9	Depressed mood	12	17.9
10	Hostility	10	14.9
11	Suspiciousness	22	32.8
12	Hallucinatory behavior	18	26.8
13	Motor retardation	20	29.8
14	Uncooperativeness	15	22.3
15	Unusual thought content	17	25.3
16	Blunt affect	14	20.8



17	Excitement	5	7.5
18	Disorientation	1	1.4

**Disability profile based on IDEAS:** Disability profile using the Indian Disability Evaluation Assessment Scale (Government of India) revealed the following results (*Table 6*). Two thirds of the patient's evaluation using IDEAS had disability on evaluation. One in 10 patients evaluated had severe to profound disability in the domain of self care. About one third of patients evaluated did not have any disability in self care at the time of evaluation. On the domain of interpersonal activities, it was found that 16% had no disability on objective evaluation. About 10% patients had mild disability while nearly one half of the patients had moderate to profound disability. Communication and understanding revealed a profile similar to the disability in interpersonal activity. About 15% of patients did not have any disability while the rest had disability - 10% mild, 14% moderate and more than a third of the patients had severe to profound disability. In so far as work was concerned, it was found that 15% of patients had no disability in the area of work, while the rest of 85% of patients had disability ranging from mild to profound. It was interesting to note that disability was present across all the four domains at the time of evaluation. However, the least disability was seen in the area of self care. This was followed by interpersonal activity, communication and understanding and work.

**Table 6 : Disability profile**

Domain	No disability	Mild	Moderate	Severe	Profound
Self care	19 28.3%	12 17.9%	14 20.8%	3 4.4%	4 5.9%
Interpersonal activities	11 16.4%	4 5.9%	13 19.4%	17 25.3%	7 10.4
Communication and understanding	10 14.9%	7 10.4%	10 14.9%	19 28.3%	6 8.9%
Work	10 14.9%	11 16.4%	8 11.9%	7 10.4%	15 22.3%

**Profile Summary of EPSRS :** Extra pyramidal symptoms are encountered commonly in patients who are prescribed antipsychotic drugs. Evaluation of the study sample suggested that about 34% of the patients who were prescribed anti-psychotics reported to have developed drug related side effects and the same was confirmed on clinical examination by the interviewer. The side effects reported were mild extra-pyramidal symptoms. Interestingly none of them had acute side effects like dystonia. About 16% of patients has involuntary movements (tardive dyskinesia). About one fourth of the patients had extra-pyramidal symptoms.

**Table 7: Profile based on EPSRS**

	Percentage	Frequency
1. Parkinsonism, dystonia, dyskinesia Questionnaire and behavioral scale (Sum 1.1 through 1.12)	23	34.3
2. Dystonia – physical examination Sum	3.1- 3.2 21	31.3
3. Dystonia : Physician's examination (Sum 3.1 through 3.2)	0	0
4. Dyskinetic movements: Physicians examination (Sum 4.1 through 4.7)	11	16.4
5. Clinical global impression of severity of dyskinesia (Score obtained on group 5)	11	16.4
6. Clinical global impression of severity of parkinsonism (Score obtained on group 6)	18	26.8

**Profile Summary of FBS:** The most common burden reported was financial, disruption of family routine and psychological distress consequent to the mental health problems in their kith and kin (Table 8). The least burden reported was in the domain of family interaction while about 60% of the burden was in the domain of family leisure and effect on the physical health of the carer. Most of the families reported burden in one or the other domain and perceived burden was reported to the tune of 94% by the study sample.

**Table 8 : Profile based on FBS**

Domain	Frequency	Percentage
Financial burden	51	76.1
Disruption of routine family activities	49	73.1
Disruption of family leisure	42	62.6
Disruption of family interaction	36	53.7
Effect on physical health of others	42	62.6
Effect on mental health of others	51	76.1
Any other burden	31	46.2
Subjective burden	59	88.0
Overall burden	63	94.0

**Profile summary of WHO QOL:** Majority of the individuals evaluated needed assistance to complete the QOL schedule. The data suggested that the mean score for physical domain was 12.77,

psychological domain was 11.57, social relationships was 10.0 and environmental domain was 9.66. The quality of life was poorest in the environmental domain, followed by the social relationships, psychological and physical. The values obtained for this sample when compared to the community norms published by the WHO are seen in the following table.

**Table 9 : Scores on WHO QOL**

<b>Physical N %</b>	<b>Psychological N %</b>	<b>Social relationships N %</b>	<b>Environmental N %</b>
7.00 3 (4.5%)	5.00 1 (1.5%)	4.00 7 (10.4%)	4.00 1 (1.5%)
10.00 8 (11.9%)	6.00 2 (3.0%)	5.00 2 (3.0%)	5.00 2 (3.0%)
11.00 5 (7.5%)	7.00 7 (10.4%)	7.00 2 (3.0%)	6.00 1 (1.5%)
12.00 5 (7.5%)	8.00 4 (6.0%)	8.00 10 (14.9%)	7.00 2 (3.0%)
13.00 5 (7.5%)	9.00 7 (10.4%)	9.00 2 (3.0%)	8.00 6 (9.0%)
14.00 14 (20.9%)	10.00 6 (9.0%)	11.0 2 (3.0%)	9.00 4 (6.0%)
15.00 2 (3.0%)	11.00 7 (10.4%)	12.0 19 (28.4%)	10.00 9 (13.4%)
16.00 2 (3.0%)	12.00 6 (9.0%)	13.0 1 (1.5%)	11.00 5 (7.5%)
17.00 2 (3.0%)	13.00 3 (4.5%)	15.0 1 (1.5%)	12.00 13( 19.4%)
<b>12.77</b>	14.00 2 3.0%	16.0 6 (9.0%)	13.00 2 (3.0%)
<b>18.2 NORM</b>	15.00 2 3.0%	<b>10.0</b>	15.00 1 (1.5%)
	16.00 3 4.5%	<b>18.2 NORM</b>	16.00 6 (9.0%)
	17.00 1 1.5%		<b>9.66</b>
	19.00 1 1.5%		<b>13.0 NORM</b>
	<b>11.57</b> <b>14.0 NORM</b>		

**CMD: socio-demographic and clinical characteristics:** Eighty seven clients who were provided psychological, and other forms of non drug therapeutic interventions were evaluated in detail using SRQ 20 to quantify symptoms, Brief Disability Questionnaire to capture disability, presumptive stressful life events scale to understand the nature and extent of life events. The sample consisted of 65 females and 22 males. Majority of the study sample belonged to the younger age group nearly (65%). About a one quarter of the sample consisted of middle aged individuals and 5% sample were elderly. About one third of the sample were illiterates while the rest had formal education. More than one half of sample had primary and high school education. One in four people who were evaluated were married while the rest were single by virtue of the being never married, separated, divorced or widowed. About one half of the sample were home makers and the rest were either skilled workers, street vendors, unskilled workers, or they were involved in either agriculture/horticulture related activities. One tenth of the sample studied were pursuing education and the number of individuals who were unemployed was about 2% only when their past employment was considered. However, when the current employment was considered, it was interesting to note that nearly one third of the sample studied were unemployed. Majority of the sample were Hindus and belonged to SCs/STs. The family income per month revealed that 60% of the sample reported a monthly income ranging from

Rs 2500 to Rs 7000. About 40% of the study sample reported a monthly income more than Rs 7000 per month. A large majority of the study sample lived within 3 kms distance from the health care facility; more than one half of the families were nuclear. It was encouraging to find that joint families existed in the study sample and they constituted nearly 40% of the families. The number of individuals living alone was negligible. More than one half of the families has 2-5 members in their family, the proportion of families with more than 6 members constituted nearly 40% of the families.

Four out of every ten people studied had one or more physical health problems and the most common being anemia, hypertension, diabetes, respiratory, neurological and dental problems. Eight out of every 10 people studied did not use mental health services despite proximity to such services prior to BT's intervention or facilitation. The most common mental health problems diagnosed is Dysthymia, (mild chronic depression), followed by anxiety disorder. A small proportion of patients studied had post traumatic stress disorder, adjustment, conduct and personality difficulties. Most of these individuals reported co-morbid nicotine use and significant number of families reported alcohol use in one or more family members. Ninety five percent of the studied sample were diagnosed with one or more mental health problems and the proportion of false positive cases were less than 5%. More than three fourths of the sample studied had mild to severe disability due to the mental health problems. The proportion of individuals who did not have disability was about one fifth of the sample. About 67% of the sample were on treatment. The treatment consisted of drug as well as psychological interventions. One third of the clients were not on any treatment at the time of evaluation. Of the individuals who are on treatment, 56% were regular, 22% were irregular and the rest had dropped out of the treatment. Data on outcome of intervention suggested that 8% of the patients had remitted completely, 58% had improved symptomatically and the rest continued to have psychological distress despite intervention. Majority of the clients did not report barriers in seeking interventions. One fifth of the clients reported that non availability of free drugs and lack of family members to accompany the persons to the psychiatric facility as an important barrier. About one tenth of the clients reported, distance, stigma, non improvement and side effects as barriers to continuity in care. However, it was interesting to note that a large majority of the users did not report any difficulty in using the services.

**Table 10 : Socio-demographic and clinical variables of persons with CMD**

<b>Variable</b>	<b>Value</b>	<b>Frequency</b>	<b>Percentage</b>
Gender	Male	22	25.2
	Female	65	74.8
Age	10-20 years	18	20.6

	21-30 years	20	22.9
	31-40 years	19	21.8
	41-50 years	17	19.5
	51-60 years	07	08.0
	>61 years	05	05.7
Education	Illiterates	31	35.6
	Primary	20	22.9
	Secondary	27	31.0
	Pre-university	06	06.5
Marital status	Never married	25	28.7
	Married	35	40.0
	Separated	5	05.7
	Divorced	3	03.4
	Widowed	13	14.9
Past employment	Agricultural labourer	2	02.2
	Self employed farmer	2	02.2
	Unskilled worker	8	09.1
	Street vendor	6	06.6
	Housewife	42	48.2
	Skilled worker	11	12.6
	Student	10	11.4
	Retired	2	02.2
	Unemployed	2	02.2
Current employment	Employed	60	68.9
	Unemployed	25	28.7
Religion	Hindu	64	73.6
	Muslims	19	21.8
	Christians'	02	02.3
	Others	02	02.3
Caste	Schedule caste	60	68.9
	Schedule tribe	3	03.4
	Others	24	27.7
Income per month	Upto Rs 2500	15	17.2
	Rs 2501- Rs 5000	25	28.7
	Rs 5000- Rs 7000	09	10.3
	Rs>Rs 7000	36	41.3
Distance	Up to 3 Kms	84	96.5
	More than 3 Kms	03	03.5
Family type	Living alone	3	03.4
	Nuclear	48	55.1
	Joint	34	39.0
Family size	1	3	03.4
	2-5	48	55.1
	> 6	34	39.0
Number of family members affected by mental health problems	1 member	68	78.1
	More than 1 member	16	21.9
Physical health	Normal	52	59.7
	Abnormal	35	40.3

Past psychiatric treatment	Used services	18	20.6
	Did not use services	69	79.4
Duration of illness	Upto 6 months	5	05.7
	7- 24 months	22	25.2
	More than 25 months	60	68.9
Coarse of illness	Episodic	11	12.6
	Continuous	74	85.0
	Difficult to ascertain	02	02.4
Diagnosis	Mixed Anxiety depression	03	03.4
	Gen Anxiety Disorders	24	27.5
	Dysthymia	44	50.5
	Emotional problems	04	04.6
	Adjustment disorder	02	02.3
	Alcohol Dependence syndrome	02	02.3
	Multiple substance	01	01.1
	Conduct disorder	01	01.1
	Personality disorder	01	01.1
	PTSD	04	04.6
	Panic disorder		
Outcome of evaluation at first contact	No physical or mental health problems	02	02.3
	Mental health problem	61	70.1
	Physical health problems	02	02.3
	Both physical and mental health problems	21	24.1
Disability due to psychiatric condition	No disability	20	22.9
	Mild Disability	41	47.1
	Moderate	13	14.9
	Severe	13	14.9
Current treatment	On treatment	59	67.8
	Not on treatment	12	13.7
	Not known	14	16.5
Compliance with intervention	Regular	49	56.3
	Irregular	20	22.9
	Drop out	18	20.6
Outcome of intervention	Recovered/remitted	07	08.0
	Improved	50	57.4
	No change	15	17.2
	Not known	15	17.2
Follow up with mental health services	Regular	43	49.4
	Irregular	20	22.9
	Treatment terminated	09	10.3
	Drop out	07	08.0
	Not known	08	09.1
Barriers to care	Long distance	13	14.9
	Lack of family members to accompany	17	19.5
	Non-availability of free drugs	19	21.8

Non improvement with treatment	13	14.9
Side effects of medication	5	05.7
Stigma and discrimination	11	12.6

**Relationship to SRQ, BDQ and PSLES:** The SRQ data showed interesting results. It was found that individuals who were separated and widowed had high SRQ score in comparison to those who were married and single. The mean score of SRQ for separated and widowed group was 16 and 13.31 respectively. Similarly, the brief disability scores was higher in the separated group and widowed group. The data suggests that psychological distress was higher in this group indicating the need for support both emotional and material. The presumptive stressful life events scale suggested that the number of life events reported was much higher in separated group in comparison to others. Co-relation of the SRQ score with occupation revealed higher SRQ scores was seen in unemployed, retired and unskilled workers. In comparison to other occupation the scores in unemployed and retired group was high but all the groups had higher mean score -- more than 10 -- meaning that all the groups had significant psychological distress. The least distress was seen in students. The SRQ scores with respect to caste revealed that the mean SRQ score and the number of life events was much higher in the SC castes in comparison to other castes. However, the mean disability on BDQ was comparable. This indicated that the personal adversities were much higher in the SCs in comparison to other castes. Family type and relationship to psychological distress and disability did not reveal uniform correlations. Persons who were living alone showed higher SRQ scores in comparison to nuclear and joint families. Interestingly, person living in joint families showed higher disability score in comparison to other. The highest numbers of life events were reported by people who were living alone. This indicated that person who were living alone needed constant engagement and on going support in the community.

With respect to diagnosis, some interesting findings emerged. Person who had both physical and mental health problems had higher psychological distress and disability in comparison to people with only physical or only mental health problems. However, the number of life events reported by person with no diagnosable mental or physical health problem indicating better coping strategies in that population. Current level of disability and its co-relationship with psychological distress revealed consistency in the findings. Disability was positively correlated to psychological distress and life events.

The variable current treatment revealed that persons who were not on treatment had higher psychological distress and disability in comparison to people who were taking treatment. This indicates the value of intervention in reducing distress and disability. Compliance with medication also revealed that people who were irregular continued to have psychological distress and they were disabled secondary to distress. They also reported higher number of life events in comparison to those who were taking regular treatment. This is a clear indication that people who drop out or become irregular should be contacted and initiated on intervention once again rather than assume a passive posture by the health care system. The data is therefore throwing light that under utilisers are continuing to be ill rather than presuming that they are well. Hence follow up of the clients is the only way to understand this dimension on a regular basis.

Outcome of intervention suggested that there was significant reduction in psychological distress in those who had recovered, or those who had improved in comparison to those who did not show much change in their level of symptoms. It was further interesting to note that the number of life events in people who responded poorly to intervention was much higher. This indicates that re-exploration of life difficulties is vital with respect to people who are showing change with intervention. Perhaps intensification of intervention and making the intervention more comprehensive may be very beneficial to such clients.

### **3.2. Awareness and attitudes about mental health and mental health-seeking behavior**

The following section presents the findings on the awareness and attitudes towards mental health and illness in a random sample of residents of Lohiyannagar and Kashewadi. The sample constructed for this purpose indicated the following profile of respondents (obtained from a chi-square analysis).

**Table 11 : Profile of respondents to Awareness about Mental Health Survey**

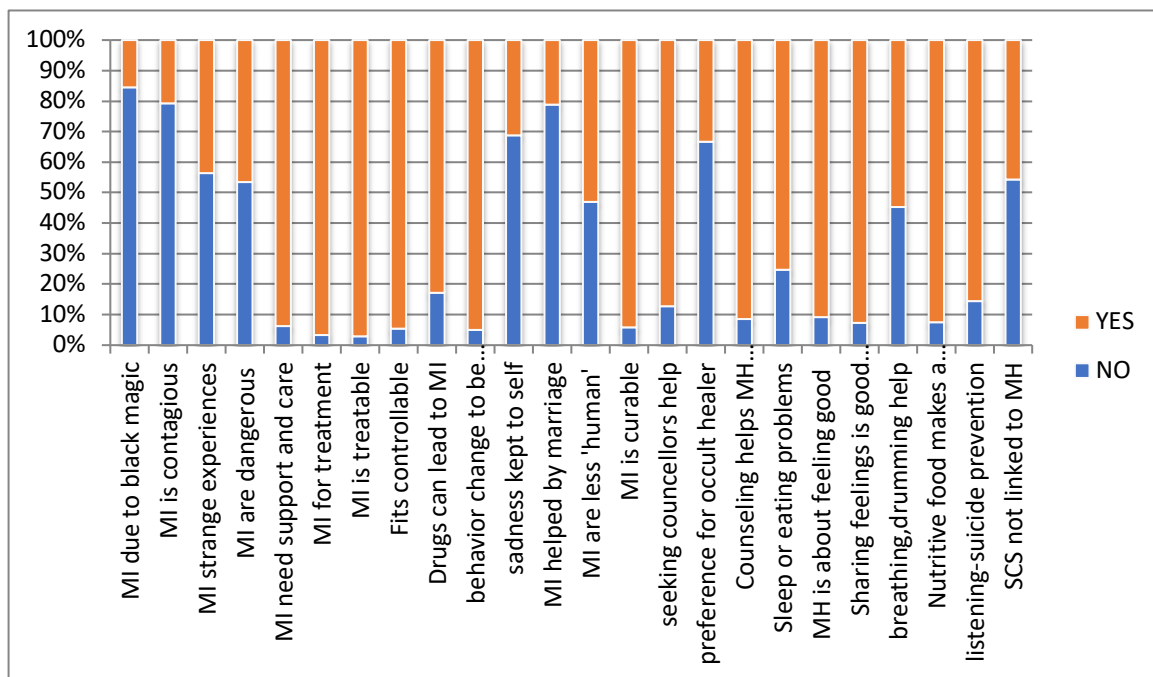
<b>Demographic</b>	<b>Most represented group</b>
Age	18-30 years
Sex	Women
Religion	Hindu
Education	5-10 years of formal schooling
Employment	Currently not employed
Type of family	Nuclear
Marital status	Currently married
Dependent status in family	Single earning member in family



	With three dependents
<b>Basic services</b>	
Type of dwelling	Pukka houses
Toilet facilities	Public toilet facility
Drinking water	Private sources of drinking water
Drainage	Closed drainage

The findings from the responses elicited from the awareness questionnaire (24 items on attitudes and 6 items on mental health-seeking behaviour) can be summed up as follows, and are presented graphically below.

**Figure 1 : Awareness about mental health among residents of Lohiyanagar and Kashewadi**



The significant results emerging from the analysis above are the following. Those who believe that:

- mental illness is not due to black magic, spirits or gods are significantly represented across the sample.
- mental illness is not contagious are significantly represented across the sample.
- the mentally ill do not have strange experiences are significantly represented across the sample.
- the mentally ill need care and support are significantly represented across the sample.

- the mentally ill need to be taken to the health centre for treatment are significantly represented across the sample.
- mental illness can be treated by effective and safe drugs are significantly represented across the sample.
- epileptic fits can be controlled by regular medication are significantly represented across the sample.
- excessive dependence on alcohol/drugs can cause mental illness are significantly represented across the sample.
- change in behavior of people is to be discussed with doctors/health workers are significantly represented across the sample.
- sadness and depression are not to be kept to oneself are significantly represented across the sample.
- the mentally ill cannot be helped best by getting them married are significantly represented across the sample.
- mental illness is curable are significantly represented across the sample.
- in case of excessive anxiety and sadness they would approach counselors are significantly represented across the sample.
- they would not prefer to approach occult practitioner about strange experiences are significantly represented across the sample.
- mental health problems can be resolved by talking to a counselor are significantly represented across the sample.
- sleeplessness and a lack of appetite can indicate mental health problems are significantly represented across the sample.
- mental health is about how good one feels with oneself, comfort in social interactions and handling demands of life are significantly represented across the sample.
- sharing feelings is good for mental health are significantly represented across the sample.
- deep breathing and drumming can help manage anger/negative emotions are significantly represented across the sample.
- nutritive food makes a difference to mental health are significantly represented across the sample.
- someone who understands feelings of people with suicidal tendencies can prevent suicide are significantly represented across the sample.

As mentioned earlier, the various activities organized by BT such as the awareness meetings, corner meetings and poster exhibitions together form the cornerstone of BT's preventive and promotive approach towards mental health. From what we gathered during the course of our interactions with BT staff as well as from the presentations made by them was that the field workers who form the bulwark of the delivery of the programme use these meetings to bust several myths about mental illness – for example, that the mentally ill are violent, dangerous, and that they cannot be cared for by the community – and offer psychoeducation on a range of topics related to fostering and promoting well-being, both physical and mental. These topics include mental disorders, substance use problems, mental retardation, deliberate self harm, and the interface of mental health with issues of gender such as domestic violence. Information is also provided about psychiatric services in Sonawane and Kamala Nehru hospitals, and counselling services offered by BT. These meetings, organized within the community itself, therefore form one of the critical components of the programme, in that they serve to dispel misconceptions about mental illness, identify those who may be at 'high risk', provide what has been termed by BT as 'neighbourhood care/alert' wherein neighbours are encouraged to enlist themselves to support and care for people who are isolated or stigmatized on account of psychosocial disability, and to provide help in crisis situations. It is through forming of such neighbourhood resource groups to act as social pressure groups that BT aims to reach out to individuals in psychological distress.

In addition to providing information about mental health problems, it is during such meetings led for the most part by the field workers that the vision and goals of BT's non-formal care are envisaged to be realized. These meetings are used by the BT field staff to initiate the therapeutic encounter in the sense that they mobilize the community around mental well-being, provide space and the opportunity for reaching out to people in psychological distress and deliver emotional first aid to those in need.

Another key element in building and fostering this kind of supportive systems of care (or what has been termed by BT as 'circles of care') is social networking wherein the individual with a mental health problem and who is at risk of isolation is helped by creating linkages with social support systems such as local support groups, recreational/learning groups, or by engaging the person in the corner meetings.

It appears from the findings reported above, that the periodic awareness and corner meetings conducted by BT had the desired impact. Respondents were presented with 24 statements about mental health and illness that can be grouped into categories such as :

- causes of mental illness.
- fear and exclusion of people with mental illness and integrating people with mental illness into the community.
- understanding and tolerance of people with mental health problems.
- attitudes and services for people with mental health problems.
- perception of positive mental health and well-being.

The respondents due to their exposure to these meetings and the interactions with the BT staff, demonstrated levels of awareness and attitudes about mental health that can be characterized as voicing tolerance and understanding of people with mental health problems; understanding the need to provide support and care to them; and perception of mental health and well-being as synonymous with the concept of feeling good about themselves, about their interactions with others and handling demands of everyday life.

It is only on the statement, “Mentally ill people are less human than “normal” people and hence do not deserve equal rights and equal respect” that mixed responses were received. 53 per cent people gave an answer in the affirmative to this statement while 47 per cent responded in the negative. ***Such a mixed response does indicate the need for more work to be done on stigma and exclusion of those with mental health problems and the need to integrate people with such problems into the community.***

Nevertheless, what is heartening to know from the responses to these statements is the belief in an overwhelming majority that professional help and services can be sought for mental health problems; that psychosocial services such as counselling, sharing and ventilation, supportive care can alleviate psychological distress and mental health problems. This belief in efficacy of psychosocial care for mental health is presumably not a blind belief, but must have been most likely fostered and demonstrated through concrete activities and nature of assistance provided by BT staff. To give just one example, the husband of a client who also enthusiastically attended the Group session based on Arts based therapy said “I was wondering about what exactly are these Bapu Trust people teaching my wife. So, I too attended one session and realized that they (BT) had created a family feeling among the women, there was no top-down approach. There was much to learn from that session”.

Publicising the need for seeking help seems to have been a primary function of BT activities such as awareness meetings, corner meetings, holding poster exhibitions and conducting commemorative events to mark mental health-related days of significance.

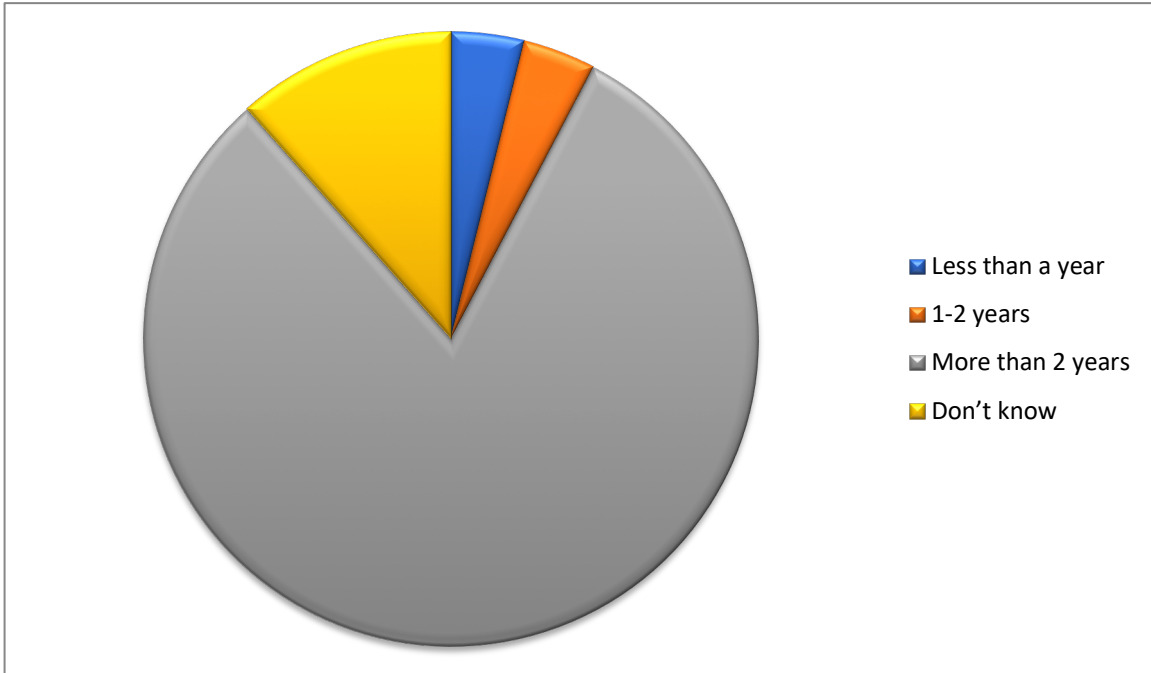
Another corroborative source is the case studies documented by BT (Bapu Trust (undated), Seher, urban mental health program) wherein all the four stories presented refer to the individual or his/her family member having heard of the nature of mental health problems and the organization's activities of providing help in this regard from the awareness/corner meetings held by BT.

### **3.2.1. Mental health-seeking behaviour**

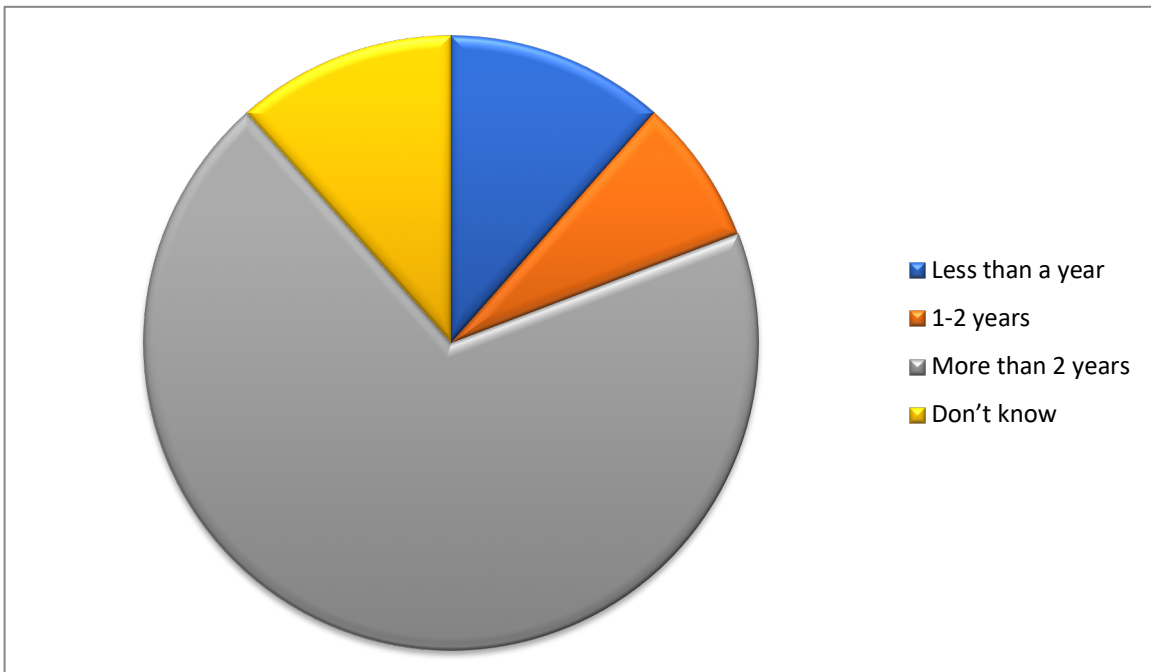
The awareness questionnaire also had six questions about mental health-seeking behaviour of the respondents starting with whether they had a person with mental illness in their family to what was the source/nature of treatment being provided. The findings are as follows.

Of the total sample, those respondents who did not have a family member with mental illness are significantly distributed. Only 27 respondents reported a family member with mental illness. Therefore, further analysis was carried out on the responses of these 27 respondents only. The following graphs indicate responses on questions such as commencement and duration of illness (of the family member), and the source from which the person is receiving treatment. As the graphs show, respondents whose family member had an onset of illness more than two years ago and those with the duration of illness of more than two years are significantly represented in the sample. Regarding sources of treatment, those respondents who have not sought treatment from faith healer are significantly represented. Those respondents who are not seeking treatment from other than faith healers, government and/or private hospitals are significantly represented, thereby implying that most of the users are taking recourse to either private or government hospitals for treatment. As for the type of problem reported, the largest category was *strange behaviour* including talking and laughing to oneself and hearing voices followed by *agitation and anger*. The main reason for discontinuing treatment reported was worsening of condition.

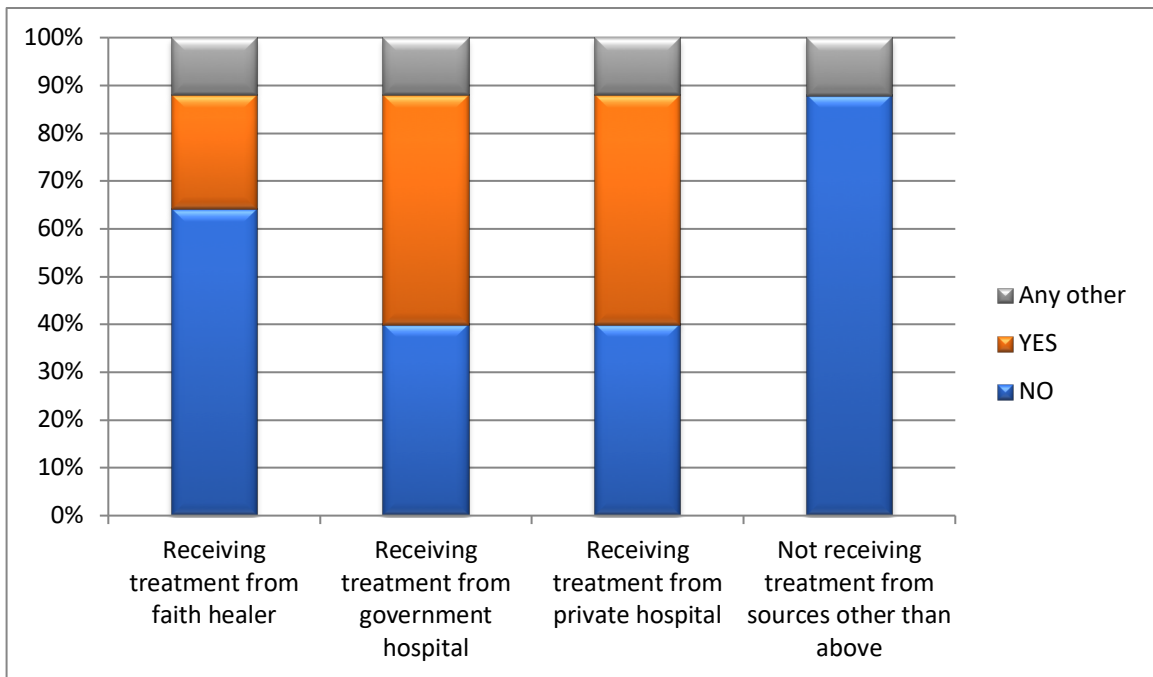
**Figure 2 : Commencement of illness**



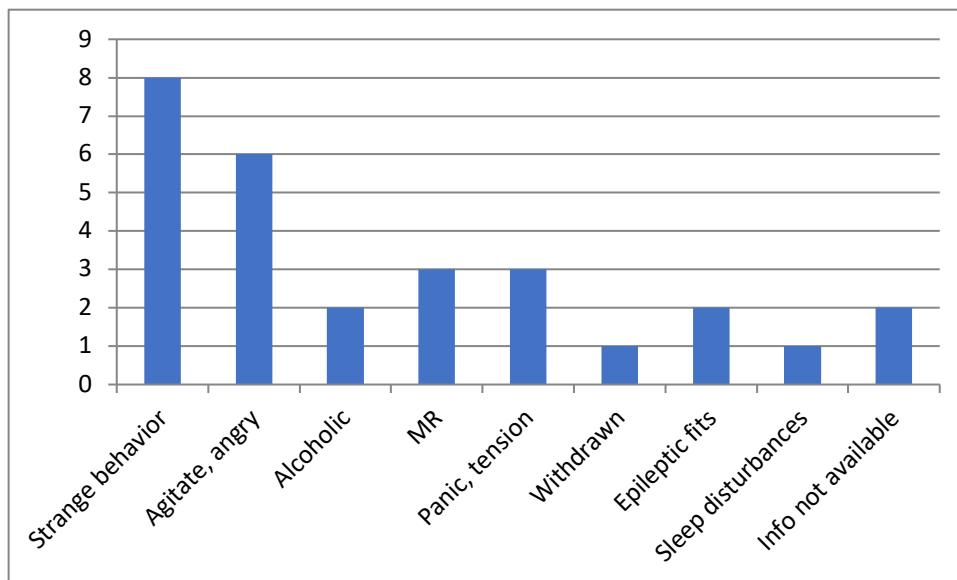
**Figure 3 : Duration of illness**



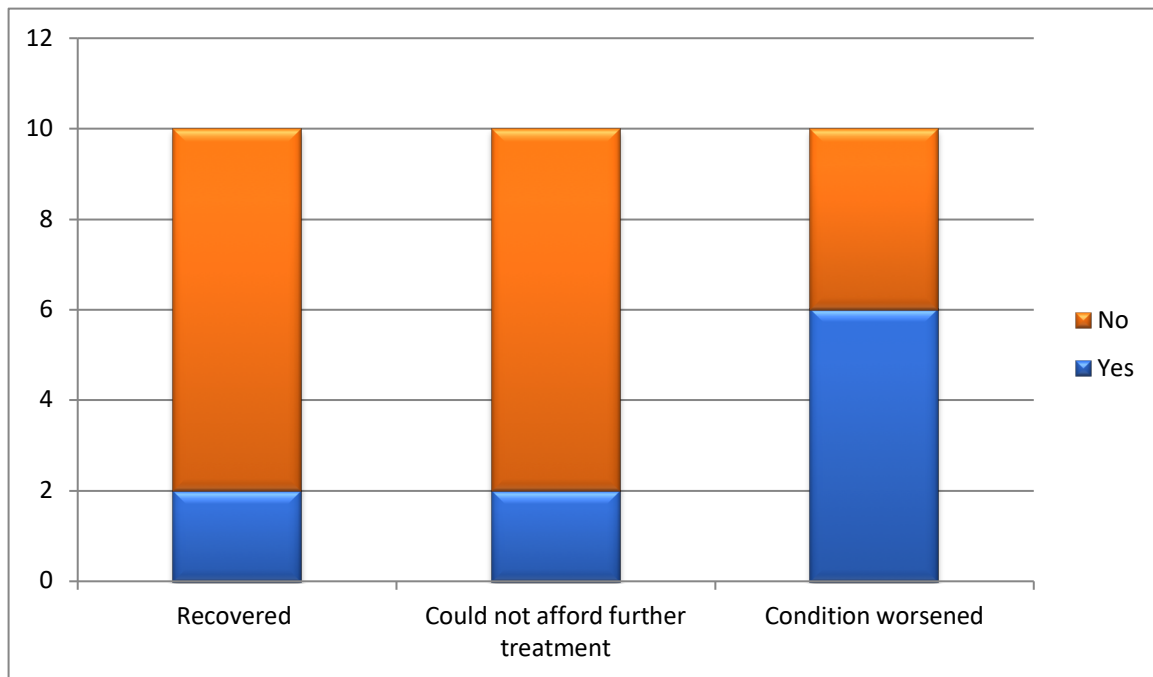
**Figure 4 : Sources of treatment**



**Figure 5 : Type of problem**



**Figure 6 : Reasons for discontinuing treatment**



Overall, the findings from this section on mental health-seeking behaviour show that the respondents who had a person with mental illness in their family were taking recourse either to a government or private hospital routed (presumably) through referrals made by BT. The major type of problem reported was “strange behaviour” followed by agitation and anger, and the reasons for discontinuing treatment was because of the perception that the condition had worsened. However, the sample size of those reporting mental illness in their family being small, these findings remain rather limited in their significance.

An aspect of BT’s work that did not emerge from the questionnaire above, but is reflected in other documents shared by them, is the work they have done on understanding ‘local’ concepts and expressions of mental health and well-being and related health-care seeking behaviour. For instance, in the paper *Gender and (urban) Community Mental Health* (Davar, undated) reference is made to such work with ‘high risk’ groups among women, particularly single women who have lost their husbands to alcohol or HIV, or deserted women; wives of alcoholic men; or adolescent girls. Examining popular nosologies of mental health problems not only help health workers to better understand people affected by these problems, it can also prevent imposition of categories that are of little relevance to the individual and his/her environment. Where existing resources are not sufficient, both in terms of human resources as well as in terms of coverage of formalized mental health care, understanding of ‘local concepts of mental health and definitions of mental health problems’ may



help in planning of mental health interventions in resource-poor settings. Use of ethnographic methods to understand cultural idioms of psychological distress, and to identify those at risk, and to plan for strategies of reaching care to them has been attempted by BT and outlined in the paper referred to above (Davar, undated). For instance, for these ‘high risk’ women suffering from ‘local syndromes’ of psychological distress (or *traas*, as it is referred to) characterized by tension, loss, fear, or anger, a primary aim of mental health interventions would be to provide not only talk based counselling and various other methods such as arts based therapies and relaxation techniques, but to emphasize group support. Such interventions are aimed at empowering existing social support systems, and to strengthen social cohesion and self-help within communities, thereby underscoring the *preventive* dimension of mental health care that BT is engaged in.

### 3.3. Satisfaction of users with BT’s services

This section presents the results of the Satisfaction survey conducted to elicit users’ satisfaction with the type of services provided by BT, competencies and attitudes of the staff, and perceived impact of these services on their functionality and well-being.

The profile of the respondents to the satisfaction survey obtained through chi-square analysis was as follows.

**Table 12 : Profile of users who responded to the Satisfaction Survey**

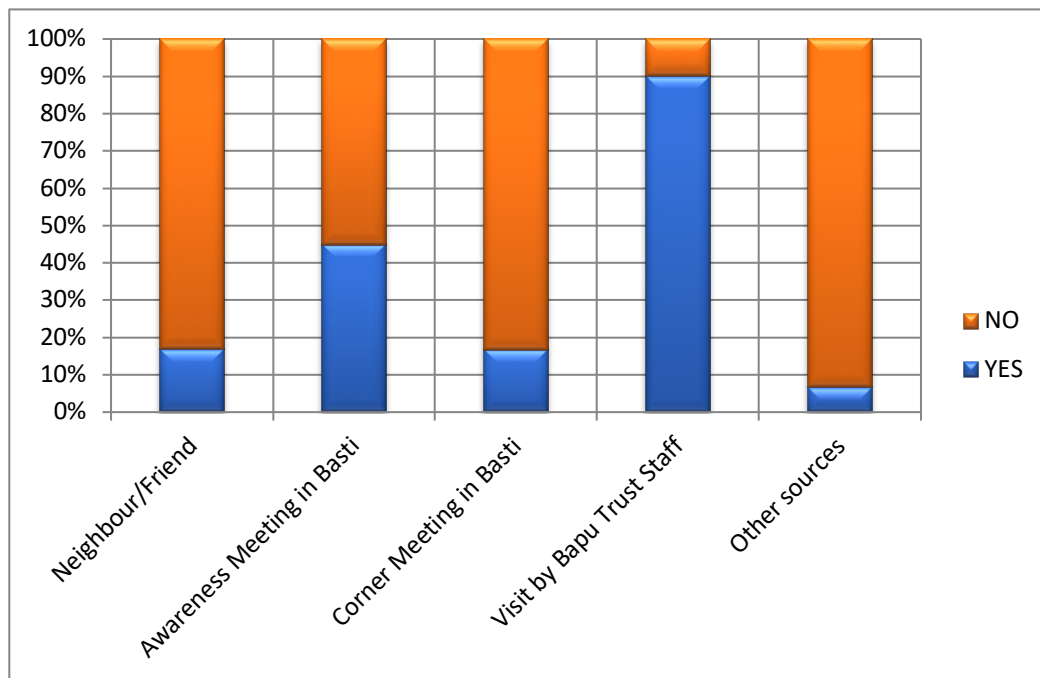
Demographic variable	Most represented
Age	18-30 years
Education	High-school education (7-12 years)
Employment status	Currently employed
Marital status	Married
Religion	Hindu
Caste	Scheduled Castes ( <i>Matang</i> and <i>Mahar</i> )
Type of family	Joint family

The users were sampled from the list provided by BT of individuals diagnosed as CMD, SMD cases as well as those from specific groups such as single women groups who were helped through Support Work, Peer Counselling and Group activities (Drum therapy, Art based therapy)

### 3.3.1. Source of knowledge

As the figure below shows, the principal source of knowledge about BT and its activities for the users was through the home visits and interactions with BT staff and its field workers in particular.

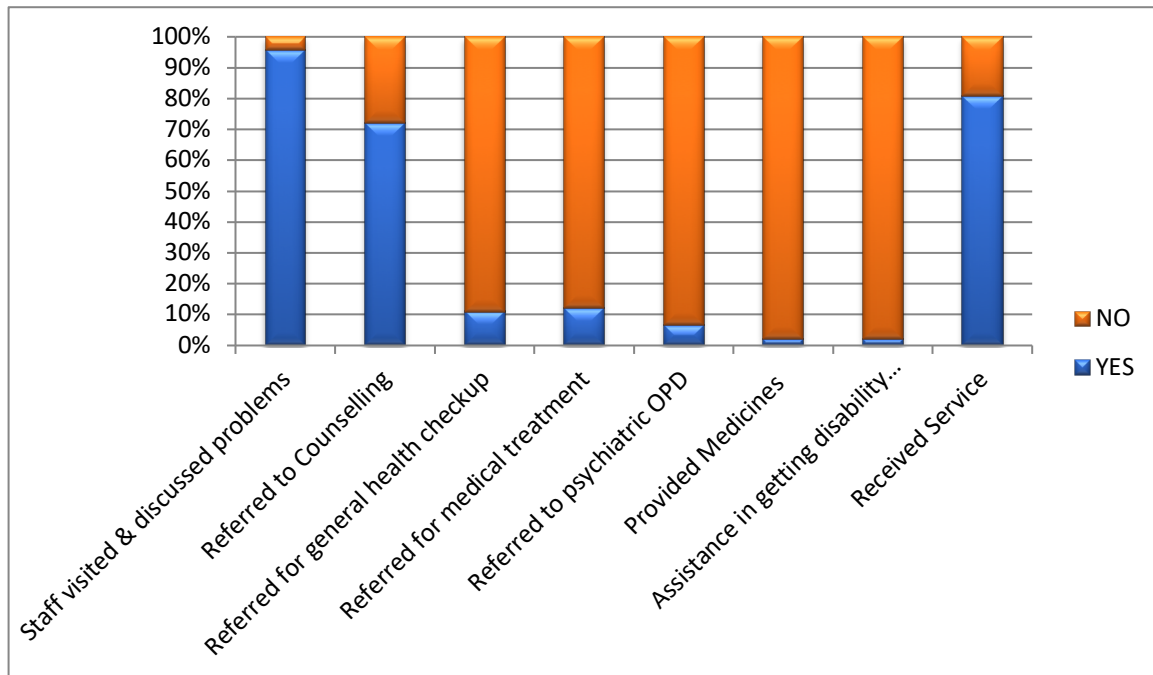
**Figure 7 : Sources of knowledge about BT services**



### 3.3.2. Type of services

Not only was the predominant source of knowledge about the services offered by BT through the visits by BT staff, those who have received services from BT are significantly represented across the sample, as the figure below shows. The types of services most frequently received were home visits of the BT staff and the referrals made for counselling by them, indicating that a majority of the respondents received the opportunity to discuss and share their concerns and referred to for counselling, based on their need. In contrast, those who received services such as referrals for general health check-up, or medical treatment, or psychiatric treatment were not significantly represented in the sample of users. Similarly, those who received services such as medicines, food, assistance with getting disability certificates of pension, or any economic assistance were not a significantly large number.

**Figure 8 : Type(s) of service received from BT**

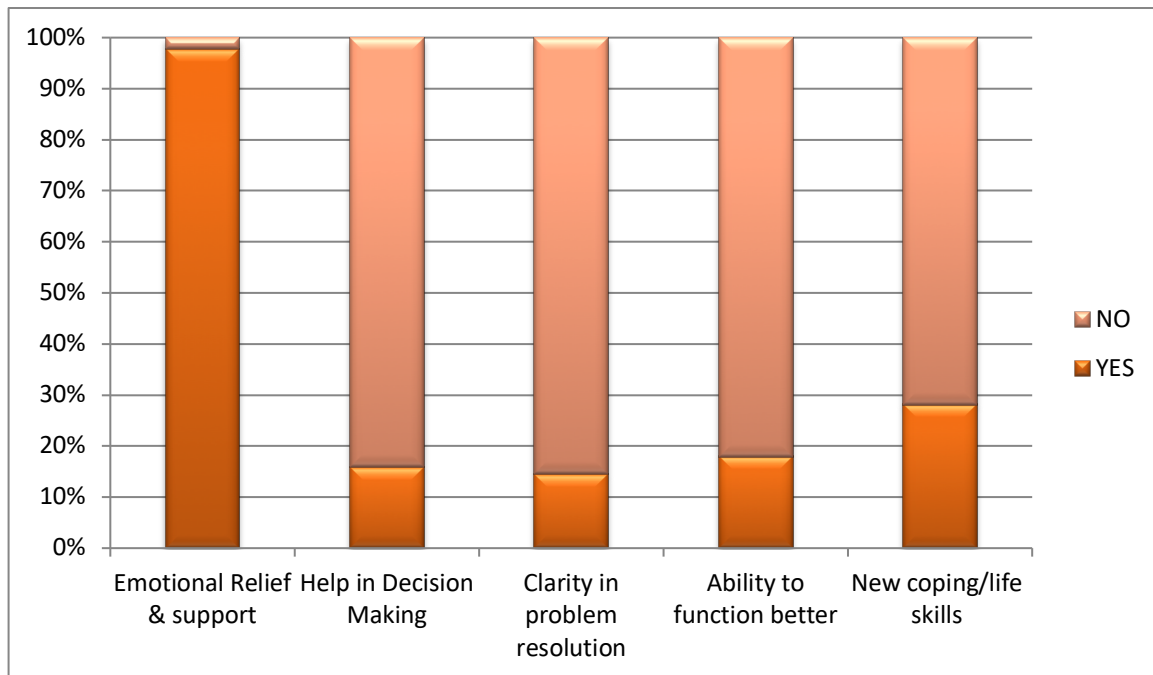


### 3.3.3. Perception of benefit of services

As the figure below indicates, emotional relief was the predominantly perceived benefit of services offered by BT by majority of the sample. Providing of space for ventilation, befriending, active listening, non-judgemental communication, and building of trust are envisaged as key processes that would cater to mental health needs of people. It is this kind of assistance that forms the foundation of the non formal care giver system, that is a distinctive facet of BT's model of urban mental health care.

*While the fact that the respondents rated emotional relief and support as highly satisfying is favourable, the relatively lower ratings on the other dimensions does indicate the need for BT to have a sharper focus on the nature of counselling services rendered by it and clarity on the expected outcomes of counselling.*

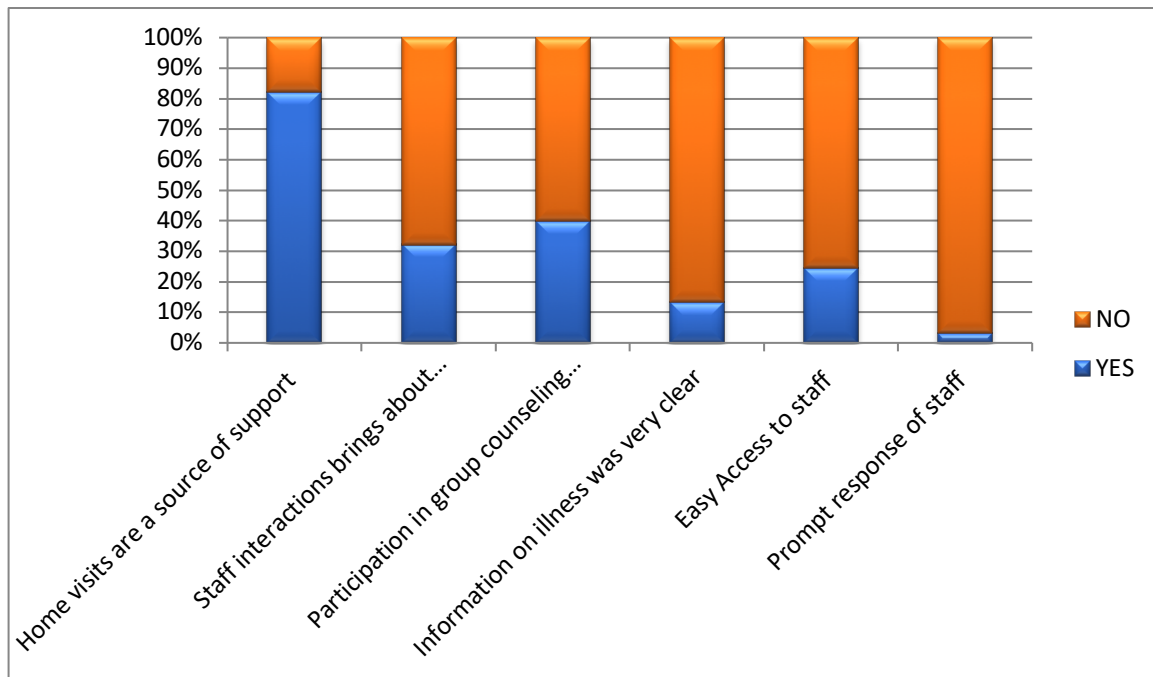
**Figure 9 : Perception of benefit of services**



### **3.3.4. Desirable aspects of service provision**

A desirable aspect of service provision by BT was the home visits that the users perceived as providing a significant source of emotional support. This was the most highly rated dimension by the respondents in comparison to others such as perception of comfort brought about by interaction with staff, greater understanding of problems consequent to counseling, clarity on information related to illness, and ease of access to staff and promptness of response of staff. Although this finding too, as the one above points to the need for a more sharply delineated model of psychosocial care and its expected outcomes, it should be emphasized that both these findings need to be interpreted with a degree of caution because of a) the limitation in randomization of the sample, mentioned earlier and b) the nature of BT's clientele itself. The sample of users consisted of both SMD and CMD clients, and those with sub-threshold psychosocial distress. Indeed, while only one-third of BT's clients were SMD/CMD clients, the latter formed the bulk of its clientele. Given the nature of the mental health problems of the clientele, it is possible therefore that it was predominantly emotional support they were seeking and it was such support that they received as services from BT rather than any other like for example, referral for medical services.

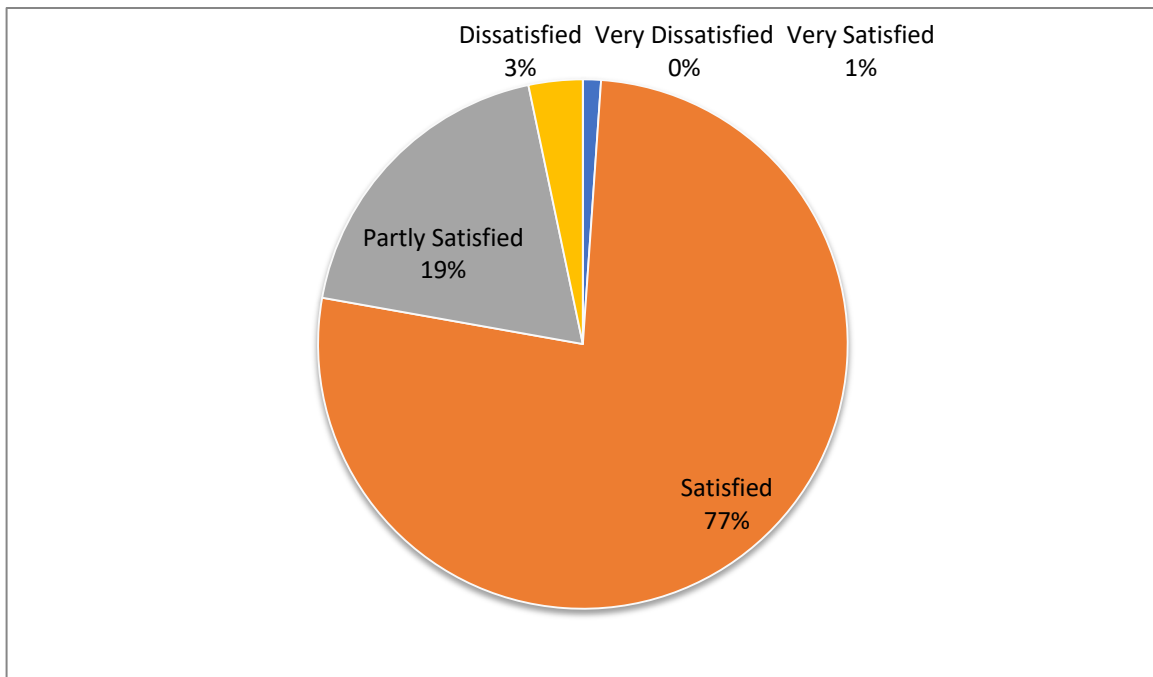
**Figure 10 : Desirable aspects of service provision**



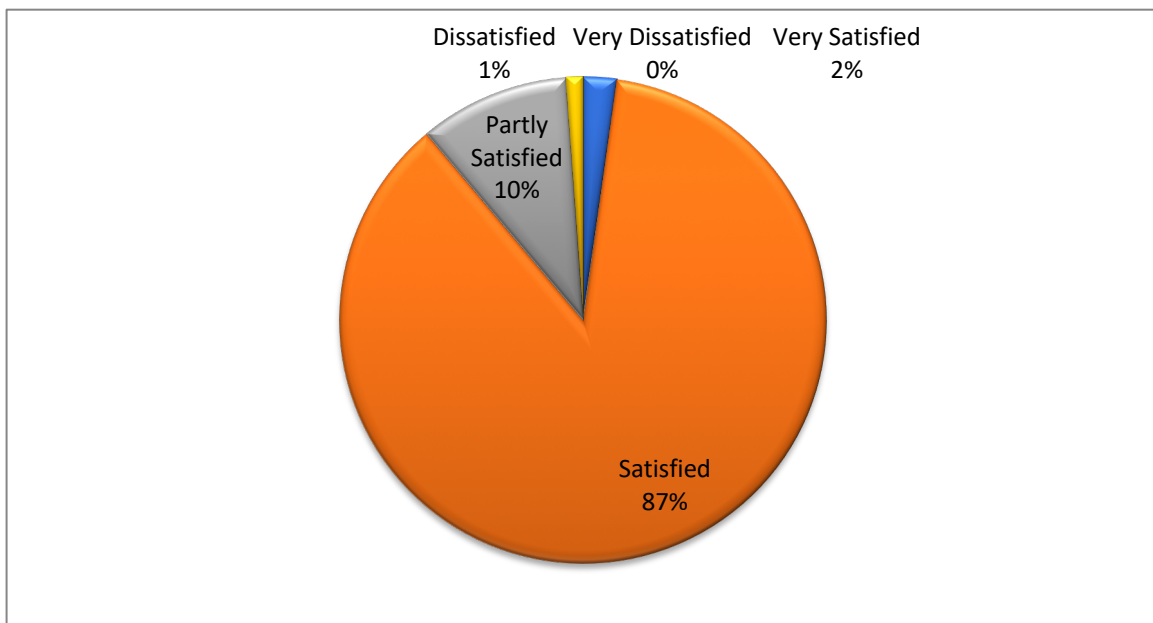
**3.3.5. Overall satisfaction with services of BT and with specific components of its services**

Those who feel satisfied with overall service provision of services by Bapu Trust are significantly distributed across the sample. Those who feel satisfied with the ability of the counselor/health worker to listen to and understand concerns are significantly distributed across the sample. Those who feel satisfied with the attitude of the counselor are significantly distributed across the sample. Those who feel satisfied with the information provided about counseling centre and other programmes of BT are significantly distributed across the sample. A significant number of respondents reported that they would consider approaching BT when needed. A significant number of respondents reported that they are willing to tell others about approaching BT when needed. These findings are graphically represented below.

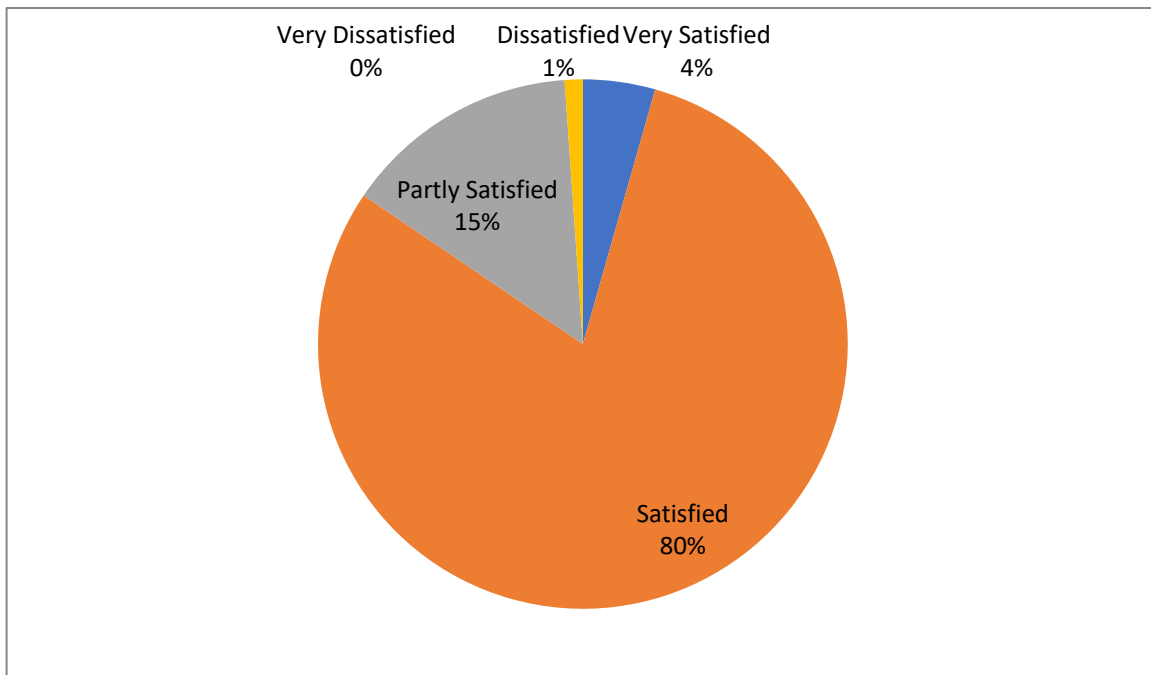
**Figure 11 : Satisfaction with overall services**



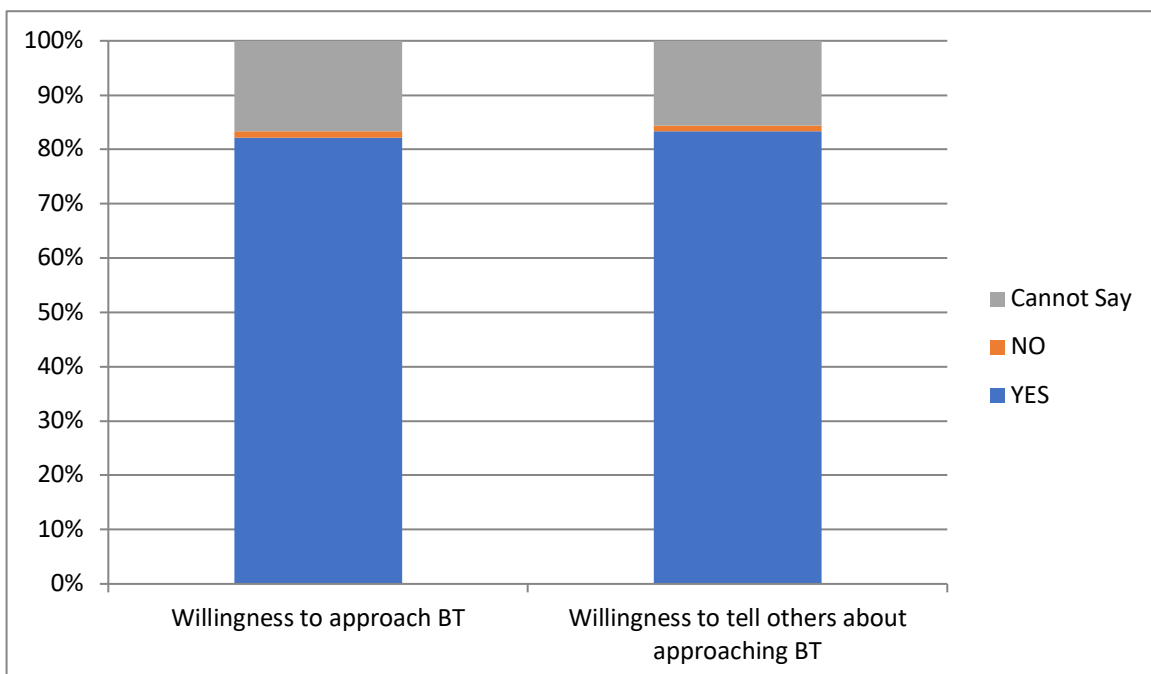
**Figure 12 : Satisfaction with ability of counselor to listen and to understand concerns**



**Figure 13 : Satisfaction with attitude of counsellor**



**Figure 14 : Willingness to approach BT**



From the findings presented above, and the interviews and observations made during our visit, it appears that the BT staff, and the field staff in particular have been *effective* in creating a space where people, and those from disempowered sections specifically can be heard with respect, sensitivity, genuineness and concern. The findings do indeed point to the overwhelmingly positive feedback that the service received for providing emotional relief and support in a non-threatening atmosphere

through regular home visits, followed by facilitating of problem resolution through making referrals to counselling/medical services.

Indeed, the core strength of BT's intervention seems to be precisely this feature – maintaining connectedness with communities, fostering close ties with families and creation of a space where individuals and families receive emotional relief and support for the issues of concern to them. It may be pertinent here to point out that the respondents/users perceived *emotional relief* as the single most important factor in BT's services that gave them satisfaction, and not clarity in problem resolution, decision making or ability to function better or giving them new coping/life skills. While this may reflect on the competencies of the field staff, it underscores the need for BT to engage more clearly, and more directly with the *relationship between mental health and development*, the primary objective of the project in the first place. This finding is a pointer to the need to flesh out with greater cogency the extent to which psychosocial services can address and alleviate problems of economic and social adversities that seem to engulf the lives of people in the slums. While the field staff, who are from within the same populace who inhabit the slums, and therefore share similar concerns, are indisputably, the central pillars on whom the functioning and effectiveness of the project rest, the operationalization of the principle -- mental health as empowerment -- needs to be charted with greater clarity. What is the exact nature of psychosocial care that can be provided to communities, who are beset with economic adversities, have poor access to basic services, limited resources of educational and employment opportunities, and who witness wide disparities in social status and economic standards of living all around them still remains rather uncertain and questionable.

### **3.4. Perceptions and perspectives of key informants<sup>4</sup>**

This section is based on five key informant interviews that were done with individuals who were closely associated with the project at various points of time and from whom we wished to know their perceptions of BT services – their reach, significance to the community, and limitations and challenges of the programme.

The interviewees were:

- Staff nurse at Sonawane Municipal Hospital.
- Urban Community Development (UCD) Group Coordinator.
- Resident Community Volunteer.

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<sup>4</sup>These interviews were conducted by Dr. Sadhana Natu, and the account here is based on her notes, observations and comments.



- President of Kashewadi Cricket Club and Tarun Mandal (Youth Club).
- Head of the Department, Dept. of Psychiatry, Kamala Nehru Municipal Hospital

All the interviewees, with the exception of the psychiatrist, had heard of BT through the field workers, thereby underscoring once again, the networks established by the field staff and the manner in which they have attempted to reach out to people and institutions whom they regard as crucial in delivery of mental health services to the community.

The nature of association of the field workers with the interviewees also reflects the essential ingredients of the programme – investment of energies and strategies into building bridges between community and key referral agencies, and within the community. For instance, for the staff nurse at Sonawane Hospital, who said that she shares a reciprocal relationship with BT, women from the community are brought to her by BT field workers for antenatal care and follow ups, and she in turn liaisons to refer specific cases identified by BT to the psychiatrist at the hospital every Wednesday. It is through these weekly referrals of individuals with mental health problems that she feels her involvement with BT's programmes has grown. Once again, she reiterates the perception that emerged from the satisfaction survey -- of the usefulness of BT's work – when she says that what she gets to hear from the *basti* people is that the [field workers] “pay attention to our problems and take personal interest to solve our problems”. She feels that there has been an increase in the number of women coming for antenatal care to the hospital due to the interventions of BT staff and that this will have a positive impact on the women's general health. This role of the field workers – of identifying those with mental/physical health problems, and of making the appropriate referrals was repeatedly mentioned by others as well. The UCD coordinator for instance, spoke of how the field staff motivate the people from the community to seek treatment from the hospital and adhere to medication as well. A group that was singled out for attention was that of single women in both Lohiyanagar and Kashewadi who were reported to have benefited from the Support Work and the group sessions. Furthermore, the liasoning role of functionaries such as the UCD coordinator was emphasized when she drew attention to her networking efforts with the departmental head of the UCD in order to facilitate BT's involvement in UCD work at the community level. Through such efforts, ward meetings with women in Lohiyanagar were organized so that BT field staff could disseminate information about the nature of their work to them. In the words of the UCD coordinator, “Even though many organizations are working in the bastis, BT has made a mark and created its own identity”. Similarly, the psychiatrist drew attention to the preventive aspects of work in BT's engagement with the psycho social domain of mental health that he finds laudable.

In addition to the intervention of such functionaries, the involvement of key individuals in the community who can play a significant role in spreading word about BT's programmes is seen as in the efforts of a youth club representative. He has been involved in BT activities through his help in mobilizing women and youth in particular as participants during programmes such as the awareness and corner meetings, and taking up several sundry responsibilities such as making arrangements for microphones, speakers, etc. for the conduct of these meetings.

A key person who has played a central role in the referrals that BT makes for psychiatric consultations is the psychiatrist working in both the hospitals – Sonawane and Kamala Nehru – that cater to the catchment area of Lohianagar and Kashewadi. Not only is he familiar with the work of BT right from its inception in 1998, but has been associated with this particular project, through the referrals made to him on Wednesdays at Sonawane hospital and also regularly at Kamala Nehru hospital.

It was his view that against the backdrop of neglect of mental health needs by the state in general, the work of BT deserved special mention because of the manner in which the field workers and the counsellors were able to develop good rapport with the community, and effectively address their mental health needs, both through their own work and the timely referrals made to him. The recovery rate of people affected by mental illness, and referred to the psychiatrist, has had a positive impact on the community's perception of the value and significance of the referrals made by BT. He mentioned in particular the fact that Lohianagar and Kashewadi have a large population of Muslims, among whom the practice of consanguineous marriages is likely to lead to Mental Retardation among the progeny. Information dissemination by Bapu on such issues has helped in creating awareness, he said.

The advantage that some of the interviewees saw BT had, was that it was the first organization to be working on issues of mental health in the community. Despite the initial apprehension and suspicion about its motives that people in general had, the strength of the programme, as many of the interviewees perceived it, is the confidence of the community that the staff had secured, the access they provide, the responsiveness with which they handle the community's concerns, and the referrals they make wherever appropriate. "The work of BT in urban slums is very important and necessary, since the plight of the 15 lakh urban poor in Pune is much worse than their rural counterparts" is how the psychiatrist put it.

All the interviewees repeatedly referred to the need for upscaling and replication of the work of BT in other parts of the city as well. As the youth club representative put it, this work definitely needs to be replicated elsewhere and in regions populated by the economically disadvantaged in particular

“since depression, unemployment, alcoholism, lack of education and crime” are issues that are germane to all the slums. Some of them drew attention to the need for BT to focus more directly on certain areas such as domestic violence and substance abuse, perceived by them as ‘high risk’ for mental health problems. The RC volunteer emphasized that the interventions of BT staff even in issues such as domestic conflicts have reduced stress levels in families.

Strengthening the networking with other social organizations, greater participation of men in corner meetings and forming strategic alliances with them, undertaking mental health camps wherein information about Government schemes related to physical and mental health can be provided, taking a nominal annual fee from the poor so that free treatment can be given to the families, expansion of service delivery of mental health in partnership with Pune Municipal Corporation in the future, and arranging for free medicines were some of the suggestions put forth by these people who have been closely associated with BT. The major challenge that many of them saw in BT’s work applies to many non-governmental organizations – insufficient funding and human resources to cater more adequately to the mental health needs of the communities .

## **4. LESSONS LEARNED AND RECOMMENDATIONS FOR WAY FORWARD<sup>5</sup>**

### **4.1. Lessons and limitations**

Findings of the empirical study provide substantial evidence of BT’s commendable work in the most difficult circumstances in the urban slums in the city of Pune. The urban mental health program implemented by BT fulfills an important need due to dearth of mental health services for the urban poor. The approach to psychosocial care is based on principles and perspectives of public health, and of community development, and rooted in the philosophy and larger vision of “facilitating transformational processes in the community” (BT, 2012). The manner in which the field staff have been able to build this ‘sense of the community’ from the grassroots and reaching psychosocial services to those in need is indeed highly appreciable and provides a template for delivery of such services to vulnerable populations. Further, the ability of BT to make effective use of the community resources such as *Anganwadis*, *Balwadis*, community halls, and schools for mental health work is excellent.

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<sup>555</sup>This section is based on Dr. Kishore Kumar’s write-up and U Vindhya’s observations.

Despite such highly laudable goals, some limitations in realizing them need to be pointed out. It appears that the resources required to address the psychosocial needs of the community have not been thought through adequately.

**Treatment gap:** It appears from the results that we have obtained that BT's ability to deliver psychosocial care to the community is much more robust than the care for people with SMD problems. A significant part of care for people with SMD is pharmacological and most of the care depended on other mental health services and networking ability rather than the BT staff's own skills. The number of people who have received care amongst the 50,000 catchment area is undoubtedly less in comparison to the actual prevalence. It is surprising that the number of people who should have been covered over a period of 36 months is much less. The table given below shows the treatment gap that exists in the project.

**Table 13 : Treatment gap**

	<b>Brain disorder</b>	<b>Rate per 1000 population</b>	<b>Number of people who should have received care in a population of 50,000</b>
1	Schizophrenia	2/1000	100
2	Mood Disorders	2/1000	100
3	Epilepsy	10/1000	'500 not expected to cover
4	Other psychotic disorders	4-6 /1000	200
5	Mental retardation	10/1000	500
6	Acute psychosis	3/10,000	15 new cases per year * 3 years = 45 new cases
7	Neurotic and stress related disorders	200/1000	1000
8	Substance use disorders	30/1000	1500
9	Child mental health problems	50/1000	2500

The above table clearly shows that wide treatment gap that exists with respect to coverage even though the project implementation period was three years. The urban mental health program implemented by BT clearly addresses the unmet treatment needs of the urban population as evidenced by the fact that 73% of the study population with SMD did not receive any treatment from the

psychiatric facilities in the local area even though the distance from the facility was less than 3 kms. With regards to current treatment, data suggested that 4 out of every 10 patients evaluated were on treatment while the rest had stopped or discontinued treatment for various reasons. The most common antipsychotic drugs prescribed is olanzepine and poly pharmacy was frequently seen amongst users of the services. Compliance with medication revealed that one third of patients were on regular treatment, 15% of patients were irregular and the rest had discontinued or stopped treatment altogether. Outcome of intervention at the time of evaluation suggested that only 10% of patients had complete remission of symptoms, about 30% improved symptomatically and the rest had not shown any improvement despite interventions. Follow-up care with mental health services revealed that about one third were using the services regularly, 16% were irregular and the rest had dropped out from treatment. Barriers to use services revealed the following : Data suggests that more than 50% had discontinued treatment despite regular support to the families, education about the nature of the illness and linking families to other welfare measures. Attempts to bring back patients on to treatment or facilitate admission for those patients who did not improve despite treatment have not worked out well. In fact one of the strengths of the community care rest on maintaining continuity with care for people who are on treatment. The required liaison with families and treating team should have been much better which is not the case in the present context. The number of people covered with disability benefits from the study population is very negligible. BT should launch a major advocacy campaign to ensure that all people with more than 40% disability as per the PWD act should have access to disability welfare benefits.

With respect to CMD, the study population has received a wide range of non drug intervention like supportive psychotherapy, individual therapy, behavior therapy, art therapy, cognitive behavior therapy and crisis intervention for the study population. The numbers covered seems very less compared to the actual prevalence. It is very surprising to note that the population covered is much less than 10% of the expected population based on the expected prevalence data. The outcome of intervention suggests that people who are on treatment have significant reduction in disability compared to those who are not on treatment. It was interesting to note that those who discontinued treatment for common mental disorders had higher number of life events, higher psychological distress score as measured on SRQ and higher disability. This observation clearly points out that the people who have dropped out of services have higher unmet needs which should be addressed proactively rather than thinking that they are a group of people who care less for the services. Specifically, we would like to draw attention to the following concerns :

1. The proportion of beneficiaries covered in the urban mental health program is far too less compared to the actual prevalence.
2. The impact of the awareness campaigns such as corner meetings, informal groups in the community, bringing in convergence of the available welfare measures has been good. However, the coverage should have been much higher than the present figures.
3. The psychosocial interventions carried out in the project are of high quality. Perhaps presence of a medical doctor/ psychiatrist could have increased the effectiveness of care further. For example more than 50% of patients with SMD have discontinued treatment and they were not put back on treatment for various reasons. The presence of psychiatrist/ proactively linking services with the families could have resulted in higher levels of care.
4. The number of people covered by the disability welfare benefit is virtually nil. This aspect requires higher degree of advocacy with the Government. Though BT has made substantial progress with respect to advocacy with the local Government departments, there is a need to step up advocacy activities to higher level so that effective implementation of the PWD act becomes a reality.
5. Including informal carers/community level workers in the service delivery of mental health program is a very positive development in so far as BT is concerned. However, BT should have paid attention to recruit higher number of community level workers compared to what it is now.
6. Supervision and impact of counselling -- From the documents provided to us, we could not gather whether systematic supervision of the counselling work is being done and whether it is being documented. Further, feedback from the clients can be elicited through brief exit interviews that can provide in-house evaluation of the impact of the counselling services.

## **4.2. Recommendations**

Based on the results of the empirical study and our observations we recommend the following:

1. The work of BT in urban slums in Pune city should have served as a model for urban mental health care. When the experience is considered in totality like the staff strength, coverage for the morbidity, linkages to welfare measures and outcome of intervention is far from satisfactory. Hence BT should increase the number of field workers from the present numbers. Given the situation there should be one worker for every 50 families.

2. BT needs to use all the corporation resources such as link workers, health functionaries like nurses, sanitary inspectors, and medical officers to integrate mental health into general health services.
3. BT can appoint a full time psychiatrist as part of their team for effective evaluation of the identified clinical problems as well as proactive service delivery. A significant number of families will require a range of services and implementation of such service would depend upon frequent case reviews by the medical team.
4. Involvement of the local General practitioners, faith healers and practitioners of alternative medicine in service delivery seem essential. The coverage for mental health problems can be increased only by bringing in more partners rather than confining to a set number of community level workers.
5. The urban mental health program should have a special teacher as part of the team to respond to the needs of the families caring for the intellectually disabled. At the present time, the coverage for this population is not only poor but also grossly inadequate.
6. Working with schools to promote health using life skills approach should become an integral part of the urban mental health program.
7. Focus on other special populations such as street children, prison population, homelessness and homeless mentally should receive attention in the next phase since all of them form an integral part of urban mental health program.
8. Conducting training for the staff of the corporation dispensaries and the general practitioners should be initiated so that the locus of care for mental health problems is in such facilities.
9. Training for the elected representatives and ward counselors should be done periodically to ensure better community participation and to increase advocacy for benefits.
10. Conducting outreach services on a periodic basis for one year should increase the case load.
11. Annual key informant interviews to detect new cases should be organized so that the number of cases can be increased.

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## APPENDICES

### Appendix 1: Questionnaire for assessment of awareness about mental health and mental health-seeking behaviour

1.	Mental illness is due to evil spirits, black magic, or wrath of gods	Yes/No
2.	Mental illness is contagious	
3.	Mentally ill individuals can have strange experiences like hearing voices and false firm beliefs	
4.	Mentally ill people are dangerous and should be avoided as they might cause harm	
5.	Mentally ill people need support and care from the family and the community	
6.	Mentally ill individuals should be taken to the nearest health centre for treatment	
7.	Mental illness can be treated by effective and safe drugs	
8.	Epileptic fits can be controlled by taking medicine regularly	
9.	Excess dependence on abusive drugs or alcohol may cause mental illness	
10.	Family and/or members of the community should recognize any change in behavior of people and discuss it with their doctors/health workers	
11.	If I am feeling very sad and depressed, it is better to keep it to myself	
12.	Mentally ill persons can be best helped by getting them married	
13.	Mentally ill people are less human than “normal” people and hence do not deserve equal rights and equal respect	
14.	Mental illness is curable	
15.	If I feel excessively anxious or sad, I ask the health worker/counselor for help	
16.	I prefer to go to the occult practitioner if I or any member of my family feel over excited and moody, or has experiences like hearing voices	
17.	Mental health problems can be resolved by talking to a counselor	
18.	Not getting sleep or not eating properly can indicate some mental health problem	
19.	Mental health is about how good people feel about themselves, how comfortable they are with others, and how they are able to handle demands of everyday life	
20.	Expressing and sharing with someone about my feelings and concerns is good for mental health	
21.	Deep breathing and drumming can help for managing anger and other negative emotions	
22.	Nutritive food makes a difference to mental health	
23.	Someone who can listen with understanding to a person who has suicidal thoughts can prevent suicide	
24.	Adequate housing, employment and education opportunities have nothing to do with mental health	
<b>MI in family and health seeking behavior</b>		
25.	Is there any person with mental illness in your family?	
If answer is yes, please answer the following questions		
26.	What is the type of problem? Can you please tell us the symptoms	
	a.	
	b.	
	c.	
	d.	

e.	
27. When did the illness start?	
28. How long has this person been suffering from this problem?	
29. From which source is the person receiving treatment a. Faith healer b. Govt. hospital c. Private hospital d. Any other (please specify)	
30. Is the person currently on treatment? If not, reasons for discontinuation a. Recovered b. Could not afford any further treatment c. Condition worsened and did not see any reason to continue treatment d. Any other reason (please specify)	

*Adapted from Knowledge, Attitude and Practice Questionnaire for Health workers (National Institute of Mental Health and Neuro-Sciences, Department of Psychiatry, Bangalore; ICMR evaluation study of DMHP, and from documents provided by Bapu Trust on their activities and programmes)*

## Appendix 2: Questionnaire to assess satisfaction of clients with care services of Bapu Trust

1. How did you come to know about Bapu Trust services?
  - a. From neighbour/friend
  - b. From awareness meeting organized in the basti
  - c. From corner meeting organized in the basti
  - d. From home visit by Bapu Trust staff
  - e. Any other (please specify)
  
2. Have you received any kind of service from Bapu Trust? Yes/No
  
3. If yes, what kind of help did Bapu Trust provide? *[can tick more than one]*
  - a. Bapu Trust staff visited me and spoke to me about my problems
  - b. Referred to Bapu Trust office for counseling
  - c. Referred to hospital for general health checkup
  - d. Referred to hospital for medical treatment
  - e. Referred to psychiatric OPD in hospital
  - f. Provided medicines
  - g. Provided food
  - h. Assisted in getting disability certificate
  - i. Assisted in getting disability pension
  - j. Any economic assistance
  - k. Any other (specify)
  
4. If availed any of the services above, what did you feel thereafter? *[can tick more than one]*
  - a. Emotional relief and support
  - b. Help in decision-making
  - c. Clarity in problem resolution/solving
  - d. Ability to function better
  - e. New coping/life skills
  - f. Any other
  
5. How satisfied are you overall with the services and care provided?
  - a. Very satisfied
  - b. Satisfied
  - c. Partly satisfied
  - d. Dissatisfied
  - e. Very dissatisfied
  
6. What do you like about the services provided by Bapu Trust?*[can tick more than one]*
  - a. Regular home visits by their staff is a great support
  - b. The way the staff interact with me makes me feel comforted
  - c. My participation in group counselling made me understand my problems in a different light
  - d. The information I was given about the nature of my problem/illness was very clear

- e. Access to their staff is easy
  - f. Response of the staff is quick and prompt
7. How satisfied are you with the ability of Bapu Trust counsellor/health worker to listen and to understand your concern/problem correctly
- a. Very satisfied
  - b. Satisfied
  - c. Partly satisfied
  - d. Dissatisfied
  - e. Very dissatisfied
8. How satisfied are you with the attitude of the counsellor towards you?
- a. Very satisfied
  - b. Satisfied
  - c. Partly satisfied
  - d. Dissatisfied
  - e. Very dissatisfied
9. How satisfied are you with the information you were provided about the counselling centre and other programmes and activities of Bapu Trust?
- a. Very satisfied
  - b. Satisfied
  - c. Partly satisfied
  - d. Dissatisfied
  - e. Very dissatisfied
10. Would you consider approaching Bapu Trust again if needed? Yes/No/Cannot say
11. Would you tell others about approaching Bapu Trust if needed? Yes/No/Cannot say

Bapu Trust has been actively implementing a project titled ‘Mental Health and Development: Modelling Community Mental Health Program to Influence National Policy’ in Pune since May 2010. This project was developed with the aim of promoting mental health empowerment, focusing on well-being of communities and integrating mental health services within development programs. This project was supported by Navajbhai Ratan Tata Trust (NRTT). An evaluation study was then conducted by a team of external evaluators for the funding agency to assess the effectiveness of the said project. The current report presents the methodologies adopted for the study, discusses the results thus obtained and furnishes recommendations for the programme.

**Contact details:**

U Vindhya: [u.vindhya@gmail.com](mailto:u.vindhya@gmail.com)  
Kishore Kumar: [kishore.shantha@gmail.com](mailto:kishore.shantha@gmail.com)  
Sadhana Natu: [sana.psychologist@gmail.com](mailto:sana.psychologist@gmail.com)

Bhargavi V Davar  
Bapu Trust for Research on Mind & Discourse  
SR.No.1/2, Flat No.202 & 302,  
GPG Green Valley,  
Handewadi, Pune - 412308,  
Maharashtra, India.  
[bt.admfin09@gmail.com](mailto:bt.admfin09@gmail.com)  
+02026441989



**Bapu Trust**