SATISFACTION -EXPECTATION RAPID SURVEY (SERAS)

DMHP PROJECT REPORT *Prepared by*

THE ALTRUIST, Ahmedabad (www.thealtruist.org) And Action For Mental Illness, Bangalore (www.acmindia.org)



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| Nirmala Srinivasan | Milesh Hamlai |
|------------------------------|------------------------------|
| 15 th August 2011 | 15 th August 2011 |
| Bangalore, INDIA | Ahmedabad, INDIA |
| (+ 91 9886031659) | (+ 91 9825070090) |

The Project and Field team includes

Dr. Nirmala Srinivasan, Managing Trustee (ACMI) Milesh Hamlai – Managing Trustee (Altruist) Dr. Chandrakant Parmar – Psychologist (Altruist) Aavruti Gusai – Forensic Psychologist (Altruist) Prakash Patel – Psychologist (Altruist) Kalpesh Patel – Social Worker (Altruist)

SERAS (SATISFACTION - EXPECTATION RAPID SURVEY)

Introduction

Project SERAS was launched in June 2011. It is a joint collaboration between the Altruist in Ahmedabad and ACMI in Bangalore SERAS has a brief but interesting history. It goes like this.

The poor performance of DMHP is a well-documented fact even in official records. The Reports reflect a lifeless story of numbers, but not the devastating impact on human lives condemned to seclusion and shame, best described in Pill that Swallows the Policy.¹ They are lifeless because the records do not have any documentation on patient outcomes and follow up care.² At present, there are only 123 districts covered by DMHP; and the underutilization of funds is an indicator of the poor absorption capacity of the Districts. In no way, it is a reflection of the people's low capacity (those in need of it) to utilize mental health services. To the best of our information, the ICMR REPORT³ is perhaps the only evidence based Client Evaluation of DMHP

¹ Sumeet Jain and Shushrut Yadav, "Pill swallows the Policy" from "Transcultural Psychiatry"

^{2009,}www.sagepub.com/cgi/content/abstract/46

² This has been verified with reliable sources.

³ Evaluation of District Mental Health Program Final Report Submitted to Ministry of Health and Family Welfare by Indian Council of Market Research, 2008.

indicating positive people's attitudes despite inherent flaws in the Program. The DMHP districts scored higher than the Non-DMHP districts in terms of knowledge of mental disorders as illness, treatment benefits, attitude to patients, acceptance of medicines as preferred to "miracles", community awareness and finally, respectful staff attitude towards clients and their families. Hence there is already evidence of DMHP as a preferred choice of treatment among the illiterate, poor villagers, despite their economic backwardness dispelling the popular notions of disbelief in Psychiatry.

The XII Plan is due for launch in 2012 and with incredible optimism and dedication; the MoH has proposed to scale up DMHP to all the 642 districts in the country during the next five year, giving mental health a new lease of official life. Needless to add, unlike the Government, for the 3% of Indians with SMDs⁴ and 10% with CMDs⁵, they need timely help more than a timely five year plan. This is the lived-in experience of the carers and users, the folk tales of DMHP that we don't get to see in any of the Evaluation Reports. The innumerable DMHP Evaluation Reports by district nodal officers and Government Psychiatrists and health officials has a major lacuna by not attempting to elicit people's views. At the same time, the data on 'Acceptability' of the Program meant for the people is critical for developing a sense of ownership among the people for long term sustainability and growth. SERAS is a modest attempt to overcome the lacuna.

ACMI and The Altruist are MH NGOs set up by individuals whose family members are under treatment for mental disorders resulted in a sense of common concern and curiosity about the fate of similar families, especially among the 'wretched of the earth⁶". Personal experiences as carers prompted expanding our boundaries of Care to the public space of working for the Cause itself. The Cause here was to examine the response of the DMHP clients as carers and users from the economically backward classes in rural Gujarat. From the micro-emotional world of carers to the macro-economic world of five year plans is literally a 'leap' for the partners in this research project which we undertook primarily to expose the worldviews of people other than officials. So our focus shifted to our peers, the Care givers and their

⁴ SMD or Severe Mental disorders are like Schizophrenia, Bi-Polar, Manic Disorders

⁵ CMD or Common Mental disorders like anxiety, depressive disorder.

⁶ Frantz Fanon, a psychiatrist who explored the psychological effect of colonization on the psyche of a nation as well as its broader implications in his classic "Wretched of the Earth" Grover Press, 1961.

wards. It is for the same reason that we have captioned it as DMHP Bottom Up or Upside down to unearth the views from below.

Why Gujarat?

The State of Gujarat has occupied a place of pride among the Indian States in the areas of Mental Health Policy, Plan and Program. It is the first State in the country to formulate a mental health policy and opt for accreditation of public health facilities. The Mental Health Cell and the State Mental Health Authority manage and monitor MH Activities. Other progressive achievements are NABH Accreditation of Government Mental hospitals ⁷ and the effort to organize mental health information systems under the HMIS of the Dept. of Health in the Government of Gujarat (GoG) WHO-AIMS report on Gujarat describes details of the Mental Health services available in the State⁸.

Altruist has been involved in the field of mental health since 2007 in Gujarat and has worked on various projects with the GoG, one of them being the compilation of WHO-AIMS Gujarat. More importantly, Altruist have also worked with the DMHP projects in Bhabhar Taluka, Deodar Taluka, Palanpur Taluka and Vadgam Taluka of Banaskantha district to create awareness in the field of mental health through various IEC activities and facilitation of trainings of Medical officers, Para medical staff, village leaders, social workers and other relevant people of the society. Yet another decisive factor for collaborating with Altruist is the innovative "Dava-Dua" project that provides spot psychiatric treatment for those who visit a Dargah in search of cure and solace. Altruist was thus familiar with the local ecology and enjoyed accessibility to the target population. Altruist has also started a Pilot helpline program in the city of Ahmedabad 'Aadhaar' to rescue wandering PwMI under PPP with the GoG and the local Commissioner of Police. Although the objective of this helpline is to receive public calls regarding the homeless wandering PwMI, calls are also received for Emergency and Crisis Help for which ambulatory services are provided by Altruist⁹. Under the same project, Altruist facilitates family education

⁷ http://www.gujhealth.gov.in/mc-mental-health.htm

⁸ http://www.who.int/mental_health/gujarat_who_aims_report.pdf

⁹ A similar service has been facilitated at Bangalore by ACMI but this is monitored and maintained by the KSMHA

and Disability certification for their wards drawing close parallels to ACMI's Uthama Sahaya Project in KA¹⁰.

ACMI was a keen partner in its endeavor to explore Gujarat's claims to credits in mental health services as compared to other States in India. Hence the collaborative effort took the shape of SERAS in Gujarat.

Project Environment:

Our final choice was the District Banaskantha in the Talukas of Deodar and Vadgam, located in the north of Gujarat with a population of 352,385¹¹, Banaskantha has a population of 2,504,244 of which 11.00% were urban as of 2001. It covers an area of 10,751 kms and is the third largest district in the state. Banaskantha shares its borders with Rajasthan in the North, Sabarkantha district in East, Kutch district in West and Patan district and Mehsana district in the South. The economy of the district is based on agro & food Processing, tourism, textile and mineral based industries (ceramics). The food Processing industry in the district has attracted 57% of the total investment in the district over the last two decades the district ranks first in the state in the production of vegetables contributing 17.67% to the total vegetable production of Gujarat. It is the largest producer of potatoes in the state. Bajra, Maize, Tobacco, Castor oil, Jowar, Psyllium are the other major crops of the district. It is also the third largest producer of oil seeds in the state after Junagadh and Jamnagar districts. The literacy figures are 51% for the District as a whole!

The district has rich mineral reserves including limestone, marble, granite, building stone and china clay. It accounts for almost the entire marble reserves (99.3%) of Gujarat and contributes about 15% to the total production of limestone in the State. Banas dairy is the dairy Cooperative under the umbrella of most popular brand name "AMUL - THE TASTE OF INDIA". Banaskantha District Central Co-operative Bank is an outstanding example of community run business ventures. It has got prestigious State Agricultural University, Sardarkrushinagar Dantiwada Agricultural University, Sardar krushinagar¹². The proposed Palanpur-Mahesana Investment Region along the Delhi-Mumbai Industrial Corridor (DMIC) is expected to drive the

¹⁰Launched between 2006-09, ACMI organized Disability certification for in-patients of private hospitals in BLR; and at Siddalaghatta and Doddaballapura rural clinics as well. The Program ensured payment of monthly maintenance allowance to the PwMI based on the DC for BPL users.

¹¹Census 2001

¹²<u>http://en.wikipedia.org/wiki/Banaskantha</u> district

economic growth of the district. (See Annexure 1 for Map and Fact File of District Banaskantha)

Health system in Banaskantha¹³

- The district of Banaskantha has 12 CHCs, 64 PHCs, and 422 sub-centers
- It has a 979 well-knit network of private medical care institutions and trust hospitals
- Of the 2 Government hospitals, one is at Vadgam which is 20 bedded but no psychiatry services.
- A mobile ayurvedic dispensary has also been sanctioned in Banaskantha district under Special Component Plan
- Pulse, a multi-specialty women's hospital, has entered into franchisee agreements with hospitals in Idar in Banaskantha to facilitate infertility treatment in the district

Given the population of Banaskantha 2,504,244, it is expected roughly that 3% or (75,127) would be suffering from SMD and 10% or (250,424) would be suffering from CMD. The immediate question is on the coverage of DMHP in the district. Both Deodar and Vadgam, the field areas for Project SERAS have diverse models of mental health care. Deodar has a Psychiatrist who visits from Hospital for Mental Health, Bhuj once a month; in Vadgam, the replacement for the psychiatrist who resigned a few months back (Palanpur District Hospital) is yet to be filled up. Each district has its unique characteristics that are described below.

The project made a minor detour to meet the carers and users under the on-going Dava and Dua Program of Altruist.

Deodar

Deodar is the main town of Deodar Taluka in Banaskantha District. It is approximately 100 km distance from the district headquarters at Palanpur. The taluka consists of 72 villages with a population of 146,393 as per census 2001 which means roughly as per WHO estimate, 3% or (4,392) SMDs and 10% or (14,640) CMD cases are to be found. <u>Under Deodar taluka there are 2 CHCs, 9 PHCs and 33 sub centres providing general health care to the Population</u>. The villages covered by SERAS in Deodar Taluka are Delwada, Dhanakwada, Khimana and Raiya situated

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¹³Census 2001

approximately at a distance of 15 kms from main city of Deodar. The population of Delwada is 800, Dhanakwada is 3,000, Khimana is 10,000 and Raiya is 1,000. Major economic activity of these areas is farming.

Psychiatry OPD is run at Deodar CHC on the first Friday of every month by doctors visiting from HMH Bhuj. Apart from that there are 2 private psychiatrists in Deesa and 5 private psychiatrists in Palanpur. The nearest private psychiatric services are available at a distance of 40 kms. The private psychiatrists charge anywhere between Rs 150 Rs. 200 for new cases and less for follow up cases. Additional expenses are incurred for other investigations and medicines if any.

Vadgam

Vadgam is the main town of Vadgam Taluka in Banaskantha District situated at a distance of 30 kms from the main city of Palanpur. The taluka consists of villages with a population of 205,992 as per census 2001. As per WHO estimate, SMD cases would be 3% of the population or approximately (6,180) and 10% of the population or (20,599) would be affected by CMD. <u>There are 2 CHCs, 7 PHCs and 37 Sub</u> <u>Centres under Vadgam Taluka.</u> These medical officers are not trained to treat mental illness and disorders. There are no private psychiatrists available in the entire Vadgam Taluka; the nearest mental health services is available at Palanpur and Patan, situated approximately at 30-60 kms; and also at Mahesana situated at 50 kms. Needless to add the farther one goes, more remote is the accessibility to any form of psychiatric care is available. SERAS villages in Vadgam taluka are Chhapi-7,592, Kotadi-1,143 and Pirojpura-2,972 and describe these villages. One PHC is there in Chhapi; and main economic activity in Kotadi and Pirojpura is farming and in Chhapi, it is business and farming.

Both Deodar and Vadgam are situated in opposite direction of the District Banaskantha. Deodar and nearby villages access OPD conducted at Deodar but only from Jan 2007. Vadgam and nearby villages and Talukas are under the care of the private mental health services. For all the 12 Talukas of Banaskantha District Govt. in-patient facilities are situated at Ahmedabad and Bhuj which are approximately 250kms apart from each other. Involuntary admission cases requiring Reception Order under the Mental Health Act 1987 go to Bhuj. The question of accessing emergency admission and care does not arise at all because such services are not available at Palanpur District hospital.

Unava (Project extension to cover Dava-Dua¹⁴ Program)

This is a unique concept of providing psychiatric services parallel to traditional faith healing under one roof of Hazrat Saiyed Ali Mira Datar Dargah. Situated at Unava a village in Unjha Taluka of Mahesana district of Gujarat people from diverse faiths congregates here to seek the Grace of the presiding saint, Hazrat Saiyed Ali Mira Datar. Families bring their ailing members including those with mental illness with a hope of cure and not just control. This concept of "Dava-Dua" was initiated by Altruist in the year 2008 funded by the Government of Gujarat. Unava is a village situated 5 kms from main Unjha Taluka city Unjha. There is a cottage hospital but there are no provisions for psychiatric services. The nearest place where people of Unjha city and Unjha taluka can receive psychiatric services is at Dava - Dua, Unava. Apart from Dava - Dua program the people have to travel 25 kms to Mahesana where the civil hospital does have psychiatric OP but no medicines available therefore they are prescribed from outside¹⁵. Neither in-patient nor referral services of any kind is available here.

There are 3 private psychiatrists practicing in Mahesana town of the District; other than that there are no public mental health services and care in this district. It is in this location that Psychiatric OP clinic is conducted from Monday to Saturday at the Dargah Trust office within the Dargah premises. The psychiatrist visits from Mahesana and Palanpur located between 20 to 60 kms from this village. On an average 15-18 patients visit daily during OP for treatment and cure. To date, the total numbers of patients are 9,616 of which new cases are (2,370) and follow-ups are (7,246).

Methodology

SERAS is described as Rapid "Survey"¹⁶ project for two reasons viz., lack of funding did not give us the luxury of leisurely field work; we were also keen to see if this project can feed into the 12th Plan Proposal with imminent deadlines. The sample

¹⁴Dava is Hindi word for "Medicines" (in this context it means psychotropic drugs). Dua is Urdu word for Prayers. So the help seeking pattern in this project lies in the two conflicting worlds of medicines and prayer. This is so because of its location in the Dargah.

¹⁵At times, the medicines meant for DAVA-DUA has been diverted to those who do not get medicines in the District hospital and cannot afford to buy from outside!

¹⁶It is more of a snap poll, type of assessment than a Survey and hence the latter is used within quotes.

population consisted of family carers and users, who were readily accessible and were also keen to participate in the Program. The only condition laid down for rigid screening was the age of the illness; that is, the users in the study should have been ill/under treatment for mental illness (MI) and disorders for not less than two years. District hospital records provided some information required to identify and locate the affected families and their members. The biggest drawback of DMHP is the lack of documentation and Mapping of the local communities.

In fact, the Sarpanch at Vadgam even refused to cooperate in helping the team to locate the "families where there are mad people". Due to awareness activities done by Altruist in Deodar taluka since 2007, people have realized the importance of mental health services but still there are apprehensions about talking on mental illness openly with the fear of stigma by carers and users. Vadgam is a recent taluka added to the fold of Altruist's IEC activities for creating awareness under DMHP. There is a lot of reluctance to accept the clinical aspects of mental illness and disorders among the affected people and even in the wider community. User participation was not possible due to symptomatic phase of the illness. The families interviewed during SERAS were by and large the from BPL category; but for a few with middle school education, the rest are illiterate and mainly with farming as the main occupation; some engaged in daily wage labor. The economic backwardness also accounted for their low status in the political leadership in the local community.

Finally, a total of 20 carers and 16 users were selected for the study with the help of local network by word of mouth and hence sampling bias is inevitable. They were interviewed using the open ended questionnaire. So it was a combo pack of open ended, semi-structured interviews supplemented by some observations from the field notes of the field staff.

On entry into the field, the team members introduced themselves and the purpose of their visit. They explained the importance of DMHP and also told them that this survey was being conducted to know about their satisfaction and expectation of services they were receiving under DMHP, also sought their suggestions for improvement. The people were receptive and co-operated with the requirements of the interview session.

Diagnostic and demographic details are in TABLE-2 below¹⁷. The total time taken for the entire Project was approximately a week.

| Names of Talukas | No of carers | Users males | Users- females | User age group | Diagnosis | Regular Medication | Non- Medical Inputs |
|---------------------|-----------------|----------------|-------------------|-------------------|--|-----------------------|---------------------------|
| DEODAR | 11 | 6 | 4 | 21-60 | Psychosis, Depression, Schizophrenia, Bipolar Mood Disorder, Paranoid Schizophrenia, Epilepsy. | Yes | Nil |
| VADGAM | 3 | NIL | NIL | NIL | N/A | N/A | N/A |
| UNAVA | 6 | 4 | 2 | 22-80 | Schizophrenia, Epilepsy, Depression | YES | NIL |

TABLE -2SERAS User Profile

The Interview tool (Annexure 2) was designed by identifying a set of questions under the six Objectives of DMHP mentioned in Box 2 below.

BOX 2- DMHP Objectives

- 1. Early identification and treatment of persons with mental disorders in the community
- 2. To see that the patient and their relatives do not have to travel long distances to go to the hospitals or nursing homes in the cities
- 3. To take pressure off the mental hospitals
- 4. To reduce the stigma attached towards mental illness through change of attitude and public education
- 5. To treat and rehabilitate mental patients discharged from the mental hospital within the community
- 6. To develop mental health promotion in the community
- 7. Reponses to Human rights and decision making capacity of the users.

Item no. 7 (in Box-1 below) was added to the set of DMHP Objectives so as to elicit the views of the clients to certain mental health issues that had the significance of

¹⁷Users, names/address etc. have been detained for purposes of privacy.

value addition from the point of view of the proposed MHC Bill 2011 replacing MHA 1987¹⁸. As you can see, users' capacity for decision making was used as a criterion to assess carers' views about their attitude towards Users' rights and legislations that advocate the same.

Questions under Q7on Human Rights

- 1. Who can decide about the patient's treatment or marriage or work or even living arrangements? Whom do you think can do this in your family?
- 2. Do you think the patient can do it?
- 3. If not why not? Do you believe that they are capable of taking decisions?
- 4. If so how much? Somewhat sometimes? Or all decisions always?
- 5. Are you aware of the new laws empowering patients to decide?

The process of constructing the questionnaire as an interview tool was done by formulating a set of open ended questions under each DMHP objective. The numbers of questions not only varied from one to the other, but were also repetitive at times to be used as an in-built mechanism to overcome respondent bias. There were almost 40 to 45 questions in all divided among the seven themes (see in BOX-1 above) including six DMHP objectives. These were administered in the course of semi structured interviews that lasted for about 30 minutes per person. In order to make the analysis more meaningful within the Satisfaction-Expectation axis, it was decided to frame questions that were relevant to these two set of experiences in the community. Annexure-2 shows the analytical framework of the tool.

We acknowledge the limitations of our methodology spawned by the modification of the questionnaire tool for Dava Dua setting at Unava. Since this entire area is already a controlled situation under the regular care and monitoring of Altruist, it was absurd to elicit views on DMHP objectives. Instead we decided to focus on the uniqueness of the combined experience of religion and mental illness into a single amalgam of life. Hence it was decided to use a brief questionnaire of only four contextualized questions (Annexure 2.1) that brought out the significance of the intervention by Altruist.

¹⁸The MHC Bill 2011 is a new Bill in place of Mental Health Act 1987. It gives Full Legal Capacity (FLC) rights to the users; provision is made for using Advance Directives as an enabler to exercise FLC.

Finally, the "rapid" responses were analyzed by segregating the ones on Satisfaction from those on Expectation for each of the 6 DMHP Objectives by carers and users separately. Client feedback for Q7 was on awareness of mental health legislations; and attitude towards User rights and capacity for decision making. The next step was the major challenge of translating the local language into English without missing out the nuances of emotions and meanings expressed by the respondents. We spent more time on translation than on field work; at times resulting in revisits and reviews! (Annexure 3 on Field Photos) The process of de-construction of responses to arrive at data analysis became another major challenge because the techniques were not based on any rigid tools of qualitative data analysis methods.

After careful scrutiny of the responses, the same were subjected to what we call as a DMHP Bottom Up exercise by interpolating the responses and interpreting the same within the framework of the clichéd Accessibility, Affordability, Availability and Sustainability. It is called a Bottom-Up assessment because SERAS is perhaps the pioneering study wherein the target population is used as Subjects and as Objects of the study.

Findings of the study

Being a qualitative study, we have made a sincere effort to present the cases as respondents' verbalization of their experiences with mental health services in their respective villages.

We arrived at the findings by analyzing the responses of the carers and users of Deodar, Vadgam and Unava within the Satisfaction-Expectation framework using the DMHP six dimensional objectives with our additional one on the subject of Human Rights. We have made a special effort to highlight carers responses from those of the users. In spite of the local structures of authority influencing people's choices and views, the project managed to get a good feedback from the Users. The responses are presented below for both the Talukas together. The Dava-Dua findings are mentioned separately.

1) Early identification and treatment of persons with mental disorders in the community

Early identification translated into the experiences of carers meant the realization that "things are not okay" with the member of the family. This was based on the changes

in the behavior followed by other changes like sleep etc. However, the early observation does not imply early intervention and treatment vide the understanding of the policy makers! Average time taken to access treatment has been not less than 2 years though the illness has been persisting for nearly four to five years. "We came to know that this is mental illness only when we met the doctor at Patan on the advice given by the villagers and other relatives." said a male carer aged 63 years. Ever since Psychiatric OPD was commenced at Deodar CHC (2007), these carers have switched over from the private facilities. They are happy that the doctors at psychiatric listen to them and seeks them their observations and views about the patients.

They added that they believe in the medical treatment but are not sufficiently informed about the side effects of the medicines. A carer broke his silence with the request that "The doctor must be able to tell us why it happens like this". Another 40 year old user captures the anguish and agony of the illness by pleading "I went twice to Deodar Hospital but could not meet the doctor, please tell the doctor to come regularly". Deodar OP loses its value addition to the Users if the specialist is not there. "First we were taken to religious place and then we were taken to a doctor" was one of the user's cryptic observations.

2) To see that the patient and their relatives do not have to travel long distances to go to the hospitals or nursing homes in the cities.

For the villagers in the vicinity of Deodar, the average time taken to reach CHC Deodar is about an hour to and fro; and the total bus fare for two including the attendant or carer who travels is Rs 80 per one visit. Waiting time is long because there is only one OPD for the entire month. They have to forgo their wages for the day because the whole day is wasted in accessing treatment. If they miss OP they have to wait for an entire month. While they are happy about the CHC facilities because of affordability and proximity, the waiting time is a drag on their resources. "My entire day of masonry work gets wasted but what can I do sir, I have to take him as he is my father" complains a 32 year old son.

In many respects Vadgam offers a striking contrast to Deodar taluka. Altruist team visited the three villages of Vadgam Taluka for interviews of carers and users for SERAS. The condition of the users whom they found in these 3 villages was not good because the users were not able to communicate with the field workers. When

the team interacted with a family in Chhapi who had a patient in their family, they refused to discuss anything about mental illness and also did not agree for the interview. The field team had difficulties in locating the user population in this Taluka because there are no mental health services and hence no records! Finally, with the help of village leaders they were able to find three carers in three different villages who allowed us to interview them but not the users. In the absence of local mental health care services, the condition of a few users was symptomatic!

There is no psychiatric OP at Vadgam Taluka nor are any private psychiatrists practicing in Vadgam Taluka; the nearest psychiatrists are in Palanpur 30 kms away and Patan 50 kms away. There was psychiatric OP running at Palanpur Civil hospital which is closed since January 2011.

Hence the question about satisfactory services was received with silence. The carers expressed tremendous satisfaction about the relief obtained with medication even though they are spending money by consulting a private psychiatrist. Obviously, a young male carer requested the field staff "to start psychiatric services in the area by the Government".

While Deodar villagers expect frequent OPDs to reduce pressure on one single day, those in Vadgam are keen to access free mental health care. Some asked for a vehicle to be provided to take their family members for treatment with some ease and comfort. They also expect that follow up treatment must be provided at their door step. "Full day gets wasted but what to do, it is our duty and our responsibility towards our family member". A few users expressed the desire to have a vehicle for medical runs so that the services of the family members who escort as attendants is spared for their daily work. They are not keen to travel alone in public transportation. In their view, the loss of a wage day can be avoided if there is a vehicle. A fifty year old female user wanted public conveyance facility to escort her to the hospital. However, a 66 year male user was satisfied with the support from his family; "they have been helpful during this problem of mine." The probability of a gender bias cannot be overlooked in the divergent views of the two elderly users – the male user perhaps enjoys better care than his female counterpart.

Other field notes / excerpts from the diary of the field staff is cited below.

- Reading between the lines, one wonders if the burden of care is emotional among the upper classes and economic among the poor when you listen to the 28 year old male carer saying "Though the distance to Deodar CHC is 2 kms and costs us 50 Rs. we spoil our whole day, our work is wasted and we get tired".
- "I have a goldsmith shop earlier when I had to travel to Ahmedabad for services I had to close my shop for 5-6 days, now for availing service at Deodar I have to keep my shop shut for half a day"
- "My salary is cut whenever I travel to the Deodar clinic; lot of time is wasted and I get harassed due to my patient" is the helpless statement 63 year old male carer.
- "Oh, we are happy to have psychiatric services at Deodar CHC". (female 22 years, carer, Deodar)

It is worth recalling that these carer families have to forgo their wages because absence from work is not considered medical leave. In spite of loss of livelihood, they display an amazing sense of responsibility and family bonding by regular visits to the OP clinic. This is seen in the observations of the two carers below which almost make us question our assumptions of poverty enforcing indifference and leading to street care. As compared with the urban care givers, these poor families neither have the resources nor the facilities to "dump" their wards in care homes. Hence put up with a hard struggle to cope up with it as long as they can and then... well we know the plight of HPwMI! (*Homeless persons with mental illness*)

- "My entire day of masonry work gets wasted but what can I do sir, I have to take him as he is my father complains a 32 year old male carer"
- "Our day gets wasted, money gets wasted but this much needs to be done by us as she is our family so it is our duty and responsibility" observes a 45 year old male carer.

3) To take the pressure off the Mental Hospitals

"This hospital is nearer!" is the spontaneous chorus from a group of users, high school or illiterate, males and females in the age group of 21-50. Does it mean for the Users, the official concern with excessive demand on a centralized facility is not the same as the users perspective of proximity? The location of Deodar CHC at a distance of about 2 to 3 kms is viewed by the carers as a big boon and the DMHP

objective is accordingly defined in terms of proximity of the treatment center rather than the demands made on inadequate infrastructure of District hospital.

For the Vadgam respondents, questions under this are almost redundant because they do not have the experience of a government facility for psychiatry. "Pressure is more of a subjective experience of affordability in terms of time or money" as noted by a field worker; hence no records of any response to this question in Vadgam.

4) To reduce stigma attached towards mental illness through change of attitude and public education

Overall the community in Deodar understands that it is an illness and they are supportive in their attitude towards and behavior with the patients and their families; therefore the families and patients do not have any stigma related to mental illness. The CHC has played a major role in developing a robust attitude towards mental illness in the community. "I do not believe in religious vows or sacred threads or faith healers; I am not at all interested in all such things" declared a 22 year old female carer.

Apparently, after seeing the effect of the psychotropic drugs on their wards, the carers do not believe in faith healing or any other rituals. They believe that there is no stigma in seeking treatment for an illness from the hospital because it is like any other illness! For a 63 year old male carer, the origin of stigma is in the behavior of the patient! "I have taken medicines from here and currently he is 'cured' so the question of stigma does not arise, on the contrary it is good". Are they blaming the users for the illness resulting in social stigma? Not known.

They decline seeking help from religious shrines for treatment for mental illness in their families. The carers and patients have agreed to participate in advocacy and awareness programs related to mental health.

"Yes I would join awareness programs if I am cured of my illness is the categorical statement of hope by the 60 year old male user in Deodar. Probably in Deodar, the CHC psychiatry OP is a catalyst for de-stigmatization. This is the message that one gets when one sees the striking contrast in the Vadgam about prevalence of stigma in the community. "Other people believe her to be mad!" regrets a forty year old husband who is a carer for his wife accessing services of a private psychiatrist at Patan and now at Palanpur. There is an undertone of a male ego hurt by the

community that is perhaps mocking at him for marrying an "insane" woman. The social reality of mental illness and its ramifications have not been adequately captured in the imagination of the Stigma busting IEC programs of DMHP.

Given the low visibility of the medical intervention in the local community, the rest of the community is not supportive enough to share the grief and shame of the family. "We believed in religious wows and sacred threads and faith healers at the onset of illness" admits almost all cares in Vadgam. These carer's want other people to understand them and support their patients because they are suffering from mental illness. They also want awareness related programs to be conducted in their area related to mental health so that the community becomes aware about this illness and they start becoming supportive to the patients. The carers are ready to participate in such programs. "If getting cured I do not have any problem in participating in such awareness program" believes the 60 year old user suffering from chronic Schizophrenia.

5) To treat and rehabilitate mentally ill patients discharged from the mental hospital within the community

The questions under this topic were focused mainly on patient management in the family as part of the community care concept. The familiar complaint of most care giving families is non-drug compliance on part of the patients resulting in relapse and even involuntary admissions. However, this does not seem to be the case at least in Deodar villages¹⁹! The patients are taking their medicines regularly on their own; neither the patients nor the carers require any external help for giving medicines. "We do not have any problem while giving medicines" claims a fifty five year old wife much to the disbelief of most MH professionals. More than the illness, she is embarrassed by the fact that her 60 year old user husband stays and works at home the whole day unlike the males in other households. The rigid social norms are so compelling that she does not mind sending him to a rehab center if the Government starts one.

The carers are sadly ignorant of the long term disabilities related to mental illness and disorders like most carers, even highly educated ones. They are willing to send their

¹⁹Srinivasan N. "Family Power" in *Mental Health by the people*. Published by Peoples Action for Mental Health, Bangalore. 2006 142-149.

patients to rehab centres, provided it is locally available. Significantly, their long term expectation seems to be one of good health, functionality and happiness rather than a protracted struggle of life long illness and dependence. One father hopes for a 'cure' for his 35 year old son!

Carers want to know about long disabilities of mental illness. They have not been told by the doctor. They want rehab centres to be started which would help to divert users attention and so that they can resume work. "Just want that he does his work and eats" says a fifty year old carer from Deodar. Unfortunately, treatment had to be discontinued for a family member because of inability to afford it! No wonder, the 35 year old sibling carer exclaims out of despair "He goes out of the house abuses others and harasses me". All users are doing some kind of small work such as going to fields, filling water and females are doing household work and stitching. "My family members are helping me to do small jobs since I am not well" remarks a 26 year old male user from Deodar. So FBR is already in progress under family care.

"Yes. He will definitely attend rehab center because I believe that if mind gets diverted in work this illness will go". We are not sure if these are insights or observations triggered off by social norms. In any case, it is amazing for its clarity, and sense of responsibility lingering with hopes amidst the misery of poverty. Is it not appropriate for DMHP to invite their folk wisdom on board for local mental health care services? Contrary to the popular belief, we found no EE especially the notion of the patient being a burden; on the contrary, the remarks about the absence of rehab opportunities have been made even without knowing what the long term disabilities can be!

6) To develop mental health promotion in the community

As we have seen in the comparative Deodar –Vadgam responses, under the other five objectives elaborated above, the responses to this sixth one is also marked by robust optimism in spite of poverty and lack of support. The Deodar villagers were familiar with awareness and MH promotion programs. We learn that some NGO conducted an awareness program but lately there have been not programs conducted. But generally it was felt that the patients who have recovered provide the best example for promotion. In both the Talukas, there was consensus among users and carers about the utility of these programs for understanding the course of treatment etc. These programs can help create awareness on mental health amongst the community.

They have also readily agreed to work on creating awareness on mental health if they are paid for it. According to them, the Panchayat's work is average; they are not sure whether the Panchayat can take up responsibility of supervising mental health programs because half the time Sarpanch and Talati are not present in the Panchayat office. Medicines are taken regularly because people believe in its capacity to cure. They are not happy about the Panchayat's role in monitoring the facility. They only want 'Sarkar' (Government) to do it! It means local institutional ownership model may not necessarily work out in all cases.

Responses on Human Rights in Deodar and Vadgam

Village India has many similarities across the country; the one important area being the decision making styles and structure in the family. It is still a very common experience for the male head of the family to assume the responsibility for decisions affecting the family in general, especially women, youth and disabled persons and children. Although new sociological developments are noticeable, by and large, the pattern continues everywhere including in Deodar and Vadgam. They said that the decisions related to the person under treatment for mental disorders such as marriage, treatment, work and residence is taken by the elders of the family. The carers and users were in complete agreement with the prevailing decision making process in their respective families. Hence it is not a question of Rights or violation of the same but simply a tradition backed up practice or shall we say "Best Practice" in their local idiom? However, when probed further, we realized that this universal practice assumes a skewed response in the case of PwMI. Some carers associated users' capacity for making decisions getting eroded by the illness.

"He is ill and he has lost his mind so he cannot take decisions". While this is also supported by research on Cognitive deficits associated with schizophrenia, there were others who dismissed the PwMI as an imbecile. "She does have any sense therefore she is not able to take any decision". Hence the question here is not one of culture but conviction that the illness erodes mental capacity. Once again we see close parallels between the Vadgam carers and those across the country hailing from the urban middle class background. Equally interesting is the lack of awareness about the existing legislation (no different to several families across the country). Some carers and users were keen to know more and were willing to get educated on the same. The overall response of the users and carers in both the Talukas was one of positive attitude and faith in the psychiatric treatment provided to the patients. The medical mind set of the carers and users is not surprising in the context wherein medical intervention is the only available service. In fact for the users who are under remission and for carers hoping for a cure, it was explicitly stated that treatment advocacy is a pathway to rights advocacy!

Dava-Dua Findings: (See Annexure 2.1 for the Questionnaire)

Dava & Dua program was implemented in the year 2005 and lasted for 9 months and discontinued due to lack of funds. In the year 2008 it was started again under PPP module with Altruist and it has sustained since then. We have interviewed six carers and six users in Dava & Dua program at Unava for SERAS. Details are recorded below.

1) How was the patient before year 2008?

Before 2008, the families used to seek help from traditional healers. But it did not help; and they were highly burdened with huge expenses by doing such rituals. Additionally, their health status worsened. The following excerpts from field diary provide evidence of their pre-2008 state of helplessness.

- Everybody in the house used to believe that I have gone mad (age25-female user)
- We felt that someone has come in the body and it is exorcism (age32-male carer)
- This problem has ruined my life; I am unable to do any work (age22-male user)
- He being the head of the family suffering from this problem I feel very sad and I take utmost care of him (age57-female)

2) What made them seek medical help from the psychiatric OP in the Dargah?

They found that DUA alone was not helping. So sought help from private Psychiatrists at Mahesana, Patan and Ahmedabad. Apart from the distance and cost, they felt some patients were not improving!! So in some cases treatment was discontinued. Finally, when Altruist started the project, they were convinced of its support and medical interventions. Excerpts from field notes are cited below.

• Sharing her early experience, a 22 year old female carer declared "After futile efforts from all such religious rituals and practices when we approached the local

doctors they told us that this was mental illness and medicines would be required for a lifetime".

- For a 25 year old user, "Medication was given until the expenses mounted and then we stopped. But now I am getting again from this Dargah."
- In praise of the service at Dava –Dua, an aged mother said "Whenever we went to the private psychiatrist at the town, our family members could not work and the entire day used to get spoilt. But not now."

3) What is the experience after Dava & Dua program came?

The families learnt of Dava and Dua program through posters, pamphlets, Mujavars of Mira Datar Dargah, local village Doctors, village leaders, Sarpanch of the village and Dava-Dua Staff. Treatment which was discontinued from private was immediately started within this program resulting in remarkable improvement. This led to faith in medicines and in the treatment provided by the visiting Psychiatrist.

Jottings from the Field diary show the following.

- "By availing treatment from here improvement is 80% and we are hopeful for 100% cure" is the fond hope of a female user aged 25 years.
- "After receiving treatment, we see the difference. We now believe that the cure for this is only with medicines, religious rituals and superstition is just a delusion" in the view of 30 year old female carer.
- A 58 year old male user believes "Since 2 years we have been taking treatment from Dava-Dua and medicines are always available." (Perhaps the medical model is embedded in the clients mind too).
- "This service has saved us our travel time, our work does not suffer, and this services being free of cost we save a lot of money" said two carers overjoyed with the support.
- Complementing the team, few clients said that "The team is so good that when we are about to finish our medicines they call us remind us for follow-up." This is the sigh of relief that can act as promos for DMHP!
- "The team also visits us at home and explains us about the illness and its long term disabilities, side effects of medicines and benefits of continuation of treatment" is how a thirty year old user put it.

4) If medicines would not have been available what would have happened to the patients?

A sensitive and hypothetical question such as this evoked intense responses of the carers and users in Unava. It appears from the field notes reproduced below that the family members felt that there prayers at the Dargah were really answered because of the psychiatry treatment and medication given at the spot.

- For the 25 year old carer "Our patient would have died or would have committed suicide but would never have become like the way he was before"
- A group of carers shouted "Our patient would have died"
- "People would have addressed me as mad! Now I am much better" said a (25 year old female user)
- "I would have become mad and my family would have had to suffer a lot" was the joint opinion of two middle aged users, male and female, respectively.
- "Medicines were necessary but if not affordable, we would not have been able to provide!"(female user 32 years old)
- "Future would have been spoilt, problems would have increased, would have to suffer more and felt it would have been better to commit suicide because I would become dependent on others!" was the sad remark of a 53 year old carer who is now able to manage his son under medication
- "Expressing her gratitude to the treatment", "My husband is the only earning member so would have come on roads and future of my children would have spoilt" admitted a 40 year old wife.
- "If **we** would not have taken medicines we would still have been doing religious rituals and my daughter would have been finished" adds a mother to show the relief obtained from medication²⁰.

Conclusions: Is it DMHP Bottom Up?

"AMUL - THE TASTE OF INDIA" is the pride of District Banaskantha. Today the Banas dairy is having most modern State-of-the-art and has also merited one more Award by QCI - Quality Council of India: DL. Obsessions with Standards and Quality, besides large production capacity are seen in the Milk Production of the District. Unfortunately from milk production to mental health services, the pride and glory of the District is seen nowhere. The District that cares for animals and animal

²⁰Altruist is proposing to start a rehab center in the area.

rights, the provisions for the mental health care is not even bare minimum resulting in a huge treatment gap of almost 70% or more. This is the condition in Gujarat, recognized as "leader" in mental health. SERAS Bottom Up analysis reveals the satisfaction-expectation responses within the framework of DMHP clichés of Accessibility, Affordability, Availability and Sustainability.

Before Deodar set up psychiatric treatment facilities, the affected person sand their families used to visit Patan, (which is another District of Gujarat 50 kms away from Deodar), having 2 private psychiatrists, Deesa 40 kms away with 2 psychiatrists and finally Palanpur 100 kms away with 5 private psychiatrists. In other words, all mental health services available in the District were private. In certain villages of Deodar, Vav, Tharad and Bhabhar Talukas, the frequency of public transportation is almost nil. There is one solitary bus that does the rounds from dawn till dusk. This created a lot of difficulties for the people to travel and avail mental health services. Since DMHP has started at Deodar patients and carers have sighed relief as travel time has reduced, medicines are available and timely treatment is met. Hence in people's view, accessibility is not just physical but is also the availability of treatment, doctor and frequent transportation. It is all the more for the people of Vadgam who had to discontinue treatment for their wards ever since the government psychiatrist resigned in Jan 2011 from Palanpur hospital. Hence what counts for the clients is not the mere location but the presence of a psychiatrist who can dispense medication.

We also see from the responses that 'Affordability' is not merely a monetary question of consultation fee in private. Affordability is interpreted as loss of family income due to commuting delays or waiting in the hospital, which is not taken care of, even when the treatment is physically accessible. There is more to the packaging than what we can ever imagine. Besides loss of a wage day or a business sales and deals, it is also the time taken for the delivery of service; waiting is inevitable because of the fact that there is only one District hospital covering an area of 146,393 for an estimated affected population of 19,022.

Drug compliance is unbelievable in-spite of low levels of literacy and poor awareness of mental disorders. One wonders if the rural scenario is more a case of irregular drug supplies driving the families to seek help from private psychiatrists. Continuity of treatment with a private Psychiatrist depends on cash flows in the family. Hence relapse occurs probably due to non-availability of either the medicine or the doctor. Care pathways are minimal if not nil. Emergencies are handled by restraining the patients using force and transporting to Deodar by private taxis! Such practices are enforced by the deficiencies in the system and not by carers' choice or intentions to ill-treat the PwMI.

Would the situation have been better, had the PHCs of these villages had a medical officer to treat them? Yes and No. YES because of the proximity factoring into the affordability aspects; NO because if the word goes around that a "Mental Doctor" (Psychiatrist) is available in the District hospital who is a Specialist, chances of seeking help at the District may be perhaps more than in the PHC. So strategies have to be worked out to make the local services immensely effective showcasing success stories because many carers and some users expressed full faith in the psychiatrist who attends on them at the Dava Dua project.

Unfortunately in none of the project areas are the people able to go beyond a medical paradigm of "our patients", cure, wellness, hope etc. except in a few cases where absence of rehab opportunities were mentioned, there was no demand for services other than free medicines, side effects, vehicle to commute to the hospital etc. The QOL concerns were totally absent, probably due to the overall existence in poverty and chronic misery. The fact that poverty has not crushed their hopes nor their dreams is indeed amazing. So they have expressed keenness to join Stigma Bursting Programs and Awareness campaigns provided they are paid for and trained a swell.

Another interesting fact is social stigma does not inhibit help seeking efforts. In other words, acceptance of treatment is not a covert operation as it happens in most middle class urban families! However, the traces of stigma in Vadgam are probably on account of the "anti-social behavior" of the symptomatic clients – who cannot be treated in the absence of a Psychiatrist. Therefore, Stigma is not "out there as a reality" embedded in people's minds but is probably related to the clinical intervention and medical advocacy to begin with.

The negative responses to Human Rights and Decision making capacity of users are not a surprise. However what is reassuring is their eagerness to learn about the legislations even if it has nothing to do with accessibility, availability or affordability. Similarly, enthusiastic responses to participation in advocacy, awareness and stigma campaigns, seeking rehab support services cannot be construed as indicating a sense of ownership. The social distance between them as clients and the DMHP or other treatment centres as service providers is deeply entrenched in their expectations for door step delivery of help in follow up care, hospital runs, etc. In this manner, the DMHP Bottom-Up has exercise has exposed the dominance of the medical model influencing social discourse of the carers and users. It shows the huge gap in the existential reality of mental illness where Rights along with other social aspects of PwMI's lives exist on parallel tracks of society. There needs to be more about what specific issue within the rights based approach should DMHP then focus on, based on these interviews? In fact, it seems a mission impossible to train these users and carers in the vocabulary of Rights. However, they made it abundantly clear that the medical and non-medical are two different realities and that mental illness is a medical reality with social consequences. There was hardly any concern on behalf of the users absence from decision making roles. There was no indication of accepting User rights as a part of coping skills; nor do they seem to see its relevance for the self-worth, recovery and wellness of the users in the same manner as they value

There was a divided opinion about sustainability of the Program by local institutions like Panchayats. Not many were keen takers to the Panchayats in Vadgam. We do understand the limitations of SERAS and its small sample size to draw generalizations for the country as a whole. We do need more qualitative analysis and certainly more DMHP Bottom-Up! Yet, it is clear that if 12th Plan should aim at integrating rights with mental health care as part of transiting to a rights based mental health care delivery, then we must plan for training packages for all the stakeholders including MH professionals, carers and users to view mental illness within the space of Rights advocacy.

Post Script: A Dialogue with XII Plan

medication.

"DMHP is a program for the people. Psychiatric OP is just a part of the program and not the program. By setting up OP facilities, 'patients' will get relief. However, to build a gamut of services through IEC, people should be made aware of the mental health as a whole. Training of social workers, para medics of the area, Medical doctors, village leaders and community elders of the taluka should be undertaken.

The people of the community need to be sensitized and empowered for mental health. Doctors are essential component of the program or any other health service but this program has multifaceted interventions such after care of the patients, counseling of families and patients, their rehabilitation services and moreover rehabilitating them with occupation. Role of a doctor gets limited when it comes to services beyond medication, they are an excellent guide on advising how and what to do, but after that their role ceases, we require people from different strata for continuation of work and its success. DMHP has various intersections while treating a patient, and equally are the roles of the local community for the acceptance and rehabs of them within the community. All aspects of DMHP such as OP, medication, and structured data collection, IEC, follow-up and monitoring have to be started simultaneously, followed by counseling and rehab. Only then will this program achieve its core objectives successfully.

If the Government alone takes up these responsibilities, again DMHP will slump as XI plan, therefore participation of public is inevitable for implementing all these services; and therefore Public private partnership becomes a must."

-Milesh Hamlai, Director, Altruist

Post Script: A Dialogue with XII Plan

"Let us not forget that the XII Plan has an ambitious target of 642 Vadgams and Deodars India to be brought under the DMHP Program. Following the 11th Plan DMHP review, the revised guidelines has proposed Life skills education in schools and colleges, suicide prevention programs, college counseling services, work place stress management, etc. These are additional inputs to the existing components of clinical services, IEC activities etc. It is unfortunate that the emphasis on IEC components and training has ignored the operationalization of the IEC components such as knowledge and skills empowerment of carers and users as much as attitude changes of DMHP personnel towards the patients. NIMHANS has published an OPS Manual called IEC for patients in 2008. It is an excellent source of basic information for the medical, para medical staff and the community. It is only Information, Education manual but not a communication manual because it does not spell out the procedures for transformation of knowledge and skills. Expertise in writing manuals does not necessarily imply expertise in training as well. Under IEC literature, distinction must be made between manuals on Information from those meant for training and communication. Training is a specialized skill and has nothing to do with medical expertise alone.

The focus of DMHP is on mental illness and disorders. Hence it is obvious for the program to be driven by psychiatrists along with other mental health professionals and medical officers. SERAS reveals the people's unflinching faith and hope in the medication therapy. However DMHP's utilitarian approach to the knowledge power of the medics and specialists fails to inculcate a sense of ownership and motivation among them. Internal ownership is the critical input for sustained service deliveries. Ownership of the program by the community is equally important but does not replace internal ownership. A simple way of developing internal ownership is to make DMHP a Brand product in the country. Perhaps with the introduction of few workplace hygiene factors for these DMHP ambassadors such as uniforms, bright and comfortable physical space of work, competitive salaries and above all comprehensive training for the task on hand - these can increase their sense of commitment to the Clinic. These HR interventions can be explored with the active participation of the private sector and the NGO sector under the PPP model.

Lastly, during the XII Plan period from 2013-2018, mental health care is likely to be brought under the legal framework of the present MHC bill, provided it becomes a Law by then. This may call for a makeover of the DMHP from its current service model to an advocacy model. It is expected to introduce radical changes by shifting the paradigm of healthcare from one of welfare to that of rights. If DMHP has to become a rights based service, then User rights must constitute the epicenter of clinical and non-clinical deliveries of mental health care.

In view of the suggestions made above, the approach to DMHP henceforth must be designed to mark a watershed in the history of mental health in India.

---- Nirmala Srinivasan, Director, ACMI

<u>Summary of Findings – Highlights of DMHP Bottom-Up</u>

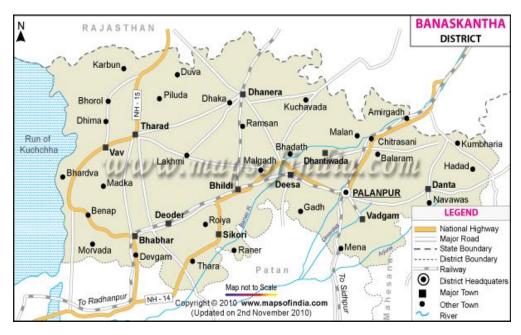
Of the two DMHP districts chosen, Deodar had a visiting psychiatrist; Vadgam had none and was serviced by a Private psychiatrist. Besides, there were no other activities in the DMHP package; neither IEC activities, nor NGO involvement, let alone delivery of basic mental health care.

The following findings have to be viewed against the backdrop of the two scenarios described.

- The size of the sample is not significant. What is important is its relevance in terms of models of mental health delivery. For instance the Deodar population has a visiting psychiatrist; yet it is not helping coz of a single visit per month.
 <u>Should DMHP empanel private psychiatrists in the vicinity as certified DMHP practitioners and pay them directly for the cases handled by them?</u>
 <u>Similarly for other MH professionals as well? This is done by several Centre/State/ Municipal Health programs in the country. As an extension to this, reimbursement of prescriptions can also be organized.</u>
- 2. The fact that the Government of Gujarat has a Mental Health Policy and accredited health facilities have not influenced the implementation of DMHP in the various districts.
- 3. There is absolute faith in Psychiatric treatment especially in medication. This is an independent variable by itself and is delinked from religious and ritualistic faith.
- 4. However, faith in psychiatry cannot be delinked from the economic reality of poverty for the simple reason that when there is no money, there is no medicine.
- 5. DMHP cannot be driven by a medical model alone though it is the basis on which the program needs to be planned.
- 6. There is awareness among the people about the difference between MOs and specialist Psychiatrists.
- 7. The demand for medication and treatment is not influenced by age, gender or religious beliefs.
- 8. Expectation of cure as an expressed wish goes as part of the demand for medical care.

- 9. There is divided opinion on the commitment and competence of Panchayats to run the Program.
- 10. The DMHP principles of accountability, affordability, accessibility and sustainability were interpreted by the users and carers in terms of their lived-in experience. This needs to be looked into for policy implications.
- 11. The interpretation of stigma in the project areas (rural areas) was more in terms of perceived social norms of behavior rather than norms of achievement. Stigma also does not influence help seeking behavior.
- 12. Care pathways have been devised by people's own initiative through the social network of village community.
- 13. Contrary to what was expected, the consumers expressed willingness to participate in promotional activities of DMHP on payment.
- 14. The recovered patient is the best ambassador for DMHP campaigns.
- 15. Sharp difference in day to day concerns noticeable between rural and urban care givers. The SERAS respondents were not unduly worried about "who after me?" A question that bothers the urban carers.
- 16. Complete lack of faith in the mental capacity of patients to make choices and decisions; partly because of cultural reasons but more so because of what they believed to be an illness that erodes thinking capacity. Are they wrong?
- 17. Complete ignorance of the Mental health Act and PwD Act does not come a as a surprise. However, it sends a clear message that if the government expects the program to be people driven, it is essential not only to empower but also enable them. Make the users aware about their right to full legal capacity and advance directives through DMHP by complementing medical model with rights perspectives.

ANNEXURE - I



Fact File

Geographical Location:

| Longitude: | 71.03° to 73.02° East |
|------------------------|---|
| Latitude: | 23.33°to 24.25° North |
| Temperature: | 45° Centigrade (Maximum) 50° Centigrade (Minimum) |
| Average Rainfall: | 1,550 mm |
| Rivers: | Banas, Saraswati & Sepu |
| Area: | 10,400.16 Sq. Km |
| District Headquarters: | Palanpur |
| Talukas: | 12 |
| Population: | 2,504,244 (As per Census 2001) |
| Population Density: | 233 Persons per sq. km |
| Sex Ratio: | 930 Females per 1000 Males |
| Languages: | Gujarati, Hindi and English |
| Literacy Rate: | 51% |
| Seismic Zone: | Zone IV |
| Source: | Banaskantha District Profile Booklet 2006-2007 |

ANNEXURE-2 SERAS DATA ANALYSIS FRAMEWORK

| DMHP Objectives | Questions | Satisfaction Carers | Satisfaction Users | Expectation Carers | Expectation Users |
|--------------------------------|-----------|------------------------|-----------------------|-----------------------|----------------------|
| Early Detection | 15 | | | | |
| Close Location | 10 | | | | |
| Pressure of MH Hospitals | 1 | | | | |
| Reduce Stigma | 7 | | | | |
| Rehab in Community | 7 | | | | |
| Promote MH | 10 | | | | |
| Human Rights (Users) | 6 | | | | |

ANNEXURE 2.1

SERAS - Dava & Dua Questionnaire

- 1. Before 2008 how was the patient?
- 2. Why did they take to Dava?
- 3. What is the experience after the Dava came?
- 4. If the Project had not been there, what do they think would have happened to their patient?

ANNEXURE - 3 – FIELD PHOTOS







