BASIC NEEDS INDIA

Promoting Mental Health and Development

COMMUNITY MENTAL HEALTH AND DEVELOPMENT PROGRAM IN SOUTH INDIA

2008-2011

A Report

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Dedicated to Late Mr. D.M Naidu

Our Mentor and Inspiring Spirit behind Community Mental Health and Development Program

In Remembrance of Mr. D.M. Naidu

Mr. D.M.Naidu the founder director of BNI passed away after a brief period of hospitalization on 15th March, 2011 at Bangalore. A memorial service is planned by his family on 27th March, 2011 at Association of the Persons with Disabilities (APD). The outpourings of condolences and expressions of grief and loss from several quarters and groups across the country and some foreign countries has been a testimony to the contributions and endearing qualities of this simple person.

Naiduji (as he is referred to) after spending over two and a half decades at APD, (much of it in senior leadership role) had a short term with CAPART, heading its Disability Wing. He teamed up with Mr. Chris Underhill subsequently, to co-found BNI a decade ago, recognizing the urgency and the low priority given to mental health by the concerned governance group. At a time when mental health was synonymous with psychiatrists and mental hospitals, psychiatric drugs and the pervasive stigma, BNI was a philosophy and an approach that was ahead of its times. The inspiration and ground level strategies came from the empowerment approach of community development, which was tested on the ground through pilot programs ably by Naiduji. Central to this unfolding pilot was a deep respect for the mentally ill person, put into operation right from the beginning, through 'consultation' with Persons with Mental Illness (PWMI) in developing the program. The community mental health and development (CMH&D) approach demonstrated an alternative, person friendly, participatory, demystified and replicable way for mental health promotion. Very quickly, Mr. Naidu and his small team undertook expansion of the work through partnership into several states to demonstrate its replicability in different situations.

Sustaining these rapid developments was Naiduji's resourcefulness and the able guidance of the strong trustees group that was put together. Naiduji's strengths were his deep sensitivity for the most marginalized, along with his managerial competence, wide network linkages and the respect he attracted through his simplicity and directness. Under Naiduji's directorship and with the steadfast support and guidance of the Trustees, the pilot initiative grew to partnership presence in several states. BNI successfully transitioned to a purely Indian identity and saw its growth into a nationally recognized resource group (and put in place a team to take it forward) all in the short span of ten years. The CMH&D approach also expanded to several countries, wherein the initiators came to him to learn their basic lessons.

As the community based and development oriented mental health work unfolded in several states, the need for national level advocacy became an urgent concern with Naiduji. He was motivated by factors such as, the magnitude of the (un-responded) needs of the affected persons in the country, the nascent stage of the development of CMH&D and hence, the non representation of the 'voices' of the poor marginalized PWMI in decision making at the governance level. He has been quite central to the evolving advocacy processes on behalf of the poor mentally ill persons at the national level. It has been stated by his friends from the national alliance that he has been a binding force, in the contextual reality of differing interest groups, individual egos and contradicting positions. He passionately championed the cause of his constituency and yet retained the relationship and respect of persons of other interest groups and professional groups. His enduring strengths have been, his simple lifestyle, transparent actions, willingness to be sensitive to another and differing view point and a sharp earthy wit.

Mr. Naidu was himself a *'wounded healer'*, stricken with polio at age of one year and several other lifelong afflictions and conditions. He is reported to have confided that the greatest challenge he had overcome was the emotional trauma around his physical disability as a child and that he felt equipped to

face all other challenges that came his way subsequently. He struggled and sought on an everyday basis to maintain a balanced judgment, in the face of the emotional conditions that was part of his make-up. Accepting that his end had come, his last days he used for positive affirmation of his numerous friends and younger associates and communicating that he was a contented person as he departs.

We at BNI will miss him and also hope to move to celebrating our journey together, while we continue on our larger journey ahead.

Mani Kalliath

For the BNI team

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ABBREVIATIONS

ADD DIP	Action on Disability and Development Direct Intervention Program
ADD India	Action on Disability and Development
ADS	Alcohol Dependence Syndrome
AIDS	Acquired Immuno Deficiency Syndrome
AP	Andhra Pradesh
ASSA	Amar Seva Sangam Aykudi
AVHV	Anantha Vikallangula Hakkula Vedhika
BNI	Basic Needs India
BPAD	Bipolar Affective Disorder
BPL	Below Poverty Line
CAPART	Counsel for Advancement of Peoples Action and Rural Technology
CBO	Community Based Organization
CBR	Community Based Rehabilitation
CMD	Common Mental Disorder
CMH&D	Community Mental Health and Development
CPMR & MI	Cerebral Palsy Mental Retardation and Mental Illness
CPZ	Chlorpromazine
DMHP	District Mental Health program
ESAI	Education Social Action Initiatives
GASS	Grameena Abyudaya Seva Samsthe
GIVAM	Grameena Ikyatha Vikalangula Abhivridhi Mandali
GTCS	Generalized Tonic- Clonic Seizure
HIV	Human Immuno Virus
ID	Identity
IGP	Income Generation Program
IKP	Indira Kranthi Patham
IRCDS	Integrated Rural Community Development Society
MBC	Most Backward Caste/Communities

MGNREGA	Mahatma Gandhi National Rural Employment Guarantee Act
MR	Mental Retardation
NBJK	Nav Bharat Jagriti Kendra
NF	Narendra Foundation
NGO	Non-Governmental Organisation
NIMHANS	National Institute of Mental Health And Neuro Science
NMHP	National Mental Health Program
NREGA	National Rural Employment Guarantee Act
NREGS	National Rural Employment Guarantee Scheme
OBC	Other Backward Caste/Communities
OCD	Obsessive Compulsive Disorder
PHC	Primary Health Centre
PSW	Psychiatric Social Work
PUC	Pre University Course
PWD	Person with Disability
PWMI	Person with Mental Illness
RDT	Rural Development Trust
SACRED	Social Action for Child Rehabilitation Emancipation and Development
SC	Scheduled Caste
SCORD	Society for Community Organization and Rural Development
SDTT	Sir Darobji Tata Trust
SHG	Self Help Group
SIP	South India Program
SJDT	St Joseph Development Trust
SMD	Severe Mental Disorder
SOCHARA	Society for Community Health Awareness, Research and Action
ST	Scheduled Tribe
Std	Standard
TCT	Thirumalai Charity Trust
TIA	Transient Ischemic Attack
TN	Tamil Nadu

TRED	Trust for Rural Education and Development
TSSS	Talessery Social Service Society
UK	United Kingdom
VO	Voluntary Organization
VOSARD	Voluntary Organization for Social Action and Rural Development
WHO	World Health Organization
WORD	Women's Organization for Rural Development

Preface

Mental health refers to our cognitive and emotional wellbeing - it is about how we think, feel and behave. Mental health includes a person's ability to enjoy life - to attain a balance between life activities and efforts to achieve psychological resilience.

Today, over a billion people in the world live with some form of disability. In the years ahead, mental illness is going to be of concern as the prevalence of illness will rise due to several factors including the vast ageing populations, higher risk of illness in older people, increase in chronic health conditions, neo-liberalization policies that affect the poor, inequitable development. This disability (mental illness) has a direct impact on mental health that disables an individual from dealing with everyday life.

The need to empower people living with mental health problems is the need of the hour and a collective effort must be made to remove the barriers, which prevent people with mental health problems from participating in activities of their communities, getting equal access to health care, education and employment.

As a result, BNI through its work has tirelessly engaged with communities, partner organizations and policy makers, to empower communities in dealing with mental health issues and disability rights and livelihood. The present study on the *Community Mental Health and Development Program in South India* endeavors to understand the South India program in its entirety – status of PWMI in order to have an understanding of issues involved in improving the lives of PWMI with the hope that it will influence policy makers, which in turn improve the lives of people with mental health problems.

Community Mental Health and Development Program in South India is a consolidated report of the Community Mental Health and Development program in South India implemented by BNI.

Community Mental Health and Development Program in South India delves closely into the lives of people with mental health problems, delving into a key strategy that CBR are an important way to respond to the needs of PWMI. PWMI have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty.

The study examines the multiple social barriers in accessing services that include fundamental rights, which includes right to life, health, education, employment and access to information. These difficulties, this study shows, are further exacerbated for the less advantaged communities, children, the elderly and the vulnerable.

Community Mental Health And Development Program In South India makes suggestions to all stakeholders – BNI and its partners, communities, including academicians, students studying the issues of mental health in India, government bodies, civil society organizations, including mental health and disabled people's organizations and medical practitioners seeking to look at the community interventions of mental health in the pursuit that an enabling environment will be created.

PWMI often do not have a voice. They should be central to our endeavors. BNI hopes and continues to work in bringing the voice of the voiceless to the fore with the hope of an egalitarian world.

Cibin Jacob V

C E Gururaghavendra

Muniraja T

Acknowledgements

BNI dedicates this study to late Mr. D.M. Naidu who was the visionary and guide to initiate this South India study. Throughout the study, we constantly fell back on his insights on communities and his messages remain with us.

We would like to thank the contributors, partner organizations, field support staff, staff members of organizations, the participants of the study and peer reviewers, editors of this Report. Acknowledgement is also due to the report advisors of BNI, all BNI staff for offering their support and guidance. Without their dedication, support and expertise this study would not be possible.

The Report also benefited from the efforts of many other people, in particular, individuals from all partner organizations for their assistance and support in the data collection: Mr. Thippana Director, SACRED, Ananthapur; Ms. Lakshmi Prasanna, Mental Health Coordinator; Ms. Deepika – Accounts and Administration; Ms. Amali, Director, GASS Doddaballapura; Mr. Ravi Kumar, Mental Health

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Thanks are due to ADD India, in particular: Ms. Nisha Printer – Director; Mr. Neel Kumar, Program Coordinator; Ms. Benita – Program Coordinator; and Ms. Bhuvaneshwari - Program Coordinator.

Thanks are due to Ms. Rajul Padmanabhan, Director Vidya Sagar and Mr. Nazir Jahangir, Coordinator Vidya Sagar.

The Report benefited from the efforts of all the Directors and Coordinators of secondary partners in Tamil Nadu and Kerala.

We like to express our deep appreciation to the individuals with mental illness, caregivers, who participated in this study.

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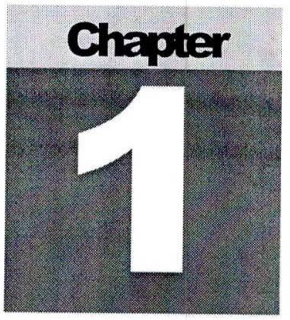
We would like to thank Ms. Lavanya Devdas, Communication and Advocacy Specialist, Society for Community Health Awareness, Research and Action (SOCHARA) for documentation, editing, and designing the book to provide a structural order to the Report. She has rendered critical insights to the report. Her help in providing pictorial representation of the mammoth amount of data collected, with help in analysis and interpretation of the data has benefited the report greatly.

BNI immensely thanks Dr. Saraswathi for guiding the South India Program team in reorganizing chapters and in finalizing the report in terms of interpreting the data presented, summarizing and highlighting the findings and their implications and in making recommendations. Her insights in to the several different aspects of the study have helped in making the presentation more meaningful.

BNI also wish to thank Ms Valli Seshan, and all the trustees of BNI: Dr Thelma Narayan, Mr. Ram Mohan, Dr. Rajaram, Ms. Malika Rama Rao, Mr. Ramachandran, Mr. Thyagaraju, Ms. Vandana

Bedi, Dr. Mani Kalliath for their encouragement and valuable inputs throughout the yearlong study of the report.

We hope that the encouragement will help in building on this study to further the cause of mental health interventions in India.



BNI'S COMMUNITY MENTAL HEALTH AND DEVELOPMENT PROGRAM

This chapter introduces you to the philosophy of BNI and BNI's Community Mental Health and Development programs in South- India 2008 through 2011.

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

BNI initiated a developmental and rights based model of mental health promotion, building on the existing experiences of Community Based Rehabilitation (CBR), as opposed to the prevalent medical model. Its experience so far with active involvement of all stakeholders has been very positive, which can be phrased as stakeholders' model.

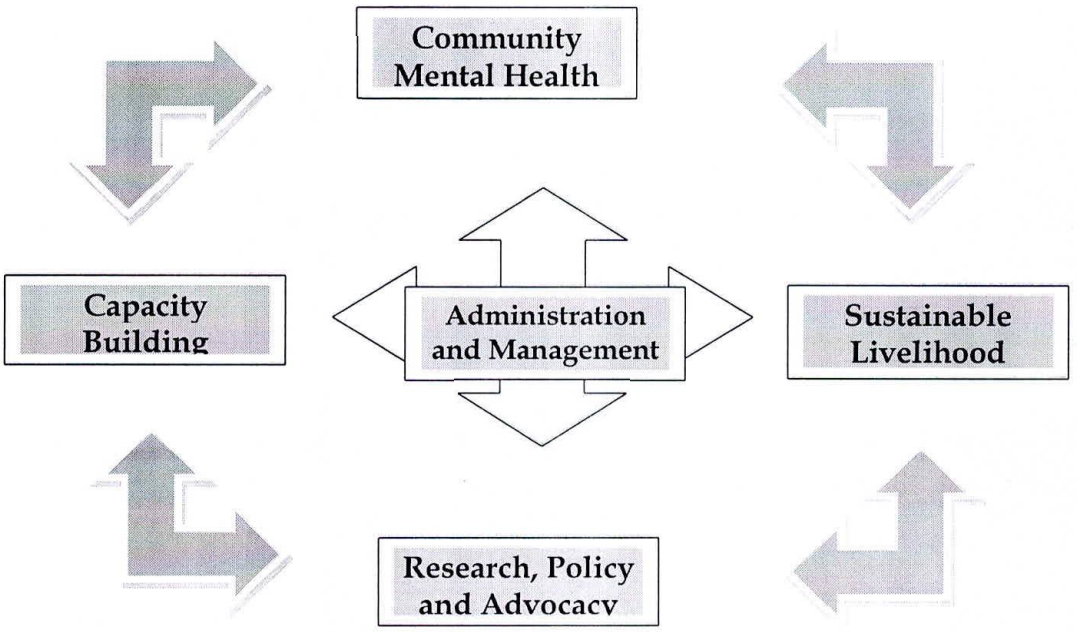
The purpose of BNI is to initiate programs that actively involve PWMI and their care givers to enable them to meet their basic needs and to ensure that their basic rights are respected and fulfilled. In so doing, to stimulate and support activities in other organizations that promotes the cause and influence public opinion and public policy on mental health issues'.

KEYPOINTS

- Development and Rights Based Model
- Program that involved PWMI
- Collaboration – to infuse public opinion and public policy

BNI's Community Mental Health and Development Model

BNI's Community Mental Health and Development (CMH&D) model has evolved through a series of consultations with affected persons, family members and partner NGOs. The model consists of five modules based on the needs and expectations expressed by different stakeholders.



Organization Partnership with BNI

Reaching out to partners in over eight states of India (Karnataka, Andhra Pradesh, Tamil Nadu, Kerala, Bihar, Jharkand, Maharashtra and Orissa) has been one of the great strengths of BNI. This partnership continues to strengthen CBR for people with mental health and endeavors to touch many lives.

In order to satisfy the essential needs of PWMI and to ensure their basic rights BNI decided to be a resource organization and the strategy or approach opted was working through partnership rather intervene directly at the ground. With the strategic approach of partnership BNI registered as a Trust in 2001, and since then it has been working with partner organizations in rural areas in parts of 46 districts in the States of **Karnataka, Andhra Pradesh, Tamil Nadu, Kerala, Jharkhand, Bihar, Orissa, Maharashtra** and in **Bangalore-Urban** areas.

MENTAL HEALTH IN BANGALORE URBAN

Over 1400 families are supported in the Bangalore urban. A lot has to be achieved to bring urban mental health in the public domain of advocacy.

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

To initiate and implement mental health program BNI evolved CMH&D model through a series of consultations with affected persons, family members and partner NGOs. The model consists of five modules based on the needs and expectations expressed by different stakeholders (community mental health, capacity building, sustainable livelihoods, research policy and advocacy and administration and management).

Types and Criteria of Partnership

Over the years, BNI has built the strength of partnership. In 2002 and 2003, BNI developed its partnership network to four organizations across India: Samuha Samarthya in Karnataka, ADD India and Vidya Sagar in Chennai in Tamil Nadu and Navbharath Jagruthi Kendra in Bihar and Jharkand.

Primary Partners and Involvement Criteria

In 2001, BNI collaborated with the primary partners meeting the core philosophy of BNI:

- Organizations involved in CBR for people with disabilities (PWD) were considered imperative, as mental health/illness could be included in such organizations. Bringing in the cross-disability sector was seen as important as mental illness is considered a disability.
- Realizing that the learning's of smaller organizations will be concrete and easily manageable.
- Organizations evolved from the same geographical area where they are working, (CBO's) where the culture and the needs of the local people are thoroughly understood and well-established relationship with the local communities.
- Small organizations are open to learn and at the same time these partners will be the laboratories, which enable BNI to experience, learn and to expand.
- Direct partnership with the partners.

Secondary Partners and Involvement Criteria

In 2003, BNI expanded its reach including the secondary partners to enable a greater outreach to its programs. The philosophy behind this involvement was in terms of:

- Involvement of organizations that are rooted in CBR for PWD were considered imperative, as the issues of mental health/illness could be introduced in such organizations.
- Large organizations had the adequate human resource and infrastructure to implement the program.

- Resource organizations are in disability sector.
- Resource organizations in turn were working with their own partners reaching larger population and could support the partners financially.

KEYPOINTS

- A transition from an individual, medical perspective to a structural, social perspective is the key to CBR. The shift from a "medical model" to a "Social model" is imperative to community participation
- Collaboration – to infuse public opinion and public policy.

With this, BNI saw the coming together of like-minded, community oriented organizations. Samuha Samarthya implemented the BNI model directly, and ADD India and Vidya Sagar implemented the project through their partners, hence were termed as secondary partners (Vidya Sagar works with four partners in Tamil Nadu and ADD India works with five partners in Tamil Nadu and two partners in Kerala).

Working Areas of Partners

Karnataka

Table 1.1 Partners in Karnataka

Name of NGO partner	District	Blocks	Number of Gram Panchayats	Number of Revenue Villages	Population
SAMUHA	Koppal	Koppal taluk	31	67	686184
		Gangavathi	16	25	
	Raichur	Deodurga	33	74	
	Karwar	Haliyala			
Grameena Abyudaya Seva Samsthe (GASS)	Bangalore Rural	Doddaballapura	23	298	268332
Narendra Foundation	Tumkur	Pavagada	33	112	184139

Andhra Pradesh

Table 1.2 Partners in Andhra Pradesh

Name of NGO partner	District	Blocks	Number of Gram Panchayats	Number of Revenue Villages	Population
SACRED	Anantapur	Anantapur Rural Mandal	25	45	364830
	Kurnool	Peapully	26	51	
		Thuggali	19	50	
		Pathikonda	15	26	

Tamil Nadu

Table 1.3 Partners in Tamil Nadu

Partners of ADD India	District	Number of Blocks	Number of Gram Panchayats	Number of Revenue Villages	Population
SCORD	Thiruvarur	1	16	34	49247
ESAI Trust	Nilgiris	1	10	123	69728
SJDT	Theni	1		31	118251
SJDT	Dindigul	1		30	35488
Resource Center	Kanyakumari	1	16	26	200000
WORD	Pudukottai	2	43	292	203592
Partners of Vidya Sagar					
ASSA	Thirunelveli	2	60	145	272821
IRCDS	Thiruvallur	3	51	197	
Nazrath Illam	Erode	1	10	104	74653
TCT	Vellore	2	40	250	

Kerala

Table 1.4 Partners in Kerala

Partners of ADD India	District	Number of Blocks	Number of Gram Panchayats	Number of Revenue Villages	Population
TSSS	Kannur	1	4	42	32550
VOSARD	Idikki	2	2	29	10208

Note

The data shown in the tables for the states is based on organization inputs.

Introduction to Partner Organizations

Social Action for Child Rehabilitation Emancipation and Development (SACRED) in Andhra Pradesh

SACRED is a non-profit, social, secular voluntary organization, which is committed for the most deprived and under privileged sections of the society. The main aim of SACRED is to equalize the disabled people to able bodied and make their active participation for their own development.

SACRED started work in 1997 with two villages and later expanded to 40 villages of Ananthapur district and 56 villages in Kurnool district. Action for Disabilities, UK and CAPART, New Delhi funds the organization.

SACRED has promoted Block level cross disability organization called GIVAM at Ananthapur Rural Block and federation is owning and implementing the CBR program. SACRED, with the support of other three network partners IKP, RDT and Timbuktu has promoted district level federation of the disabled called Anantha Vikallangula Hakkula Vedhika (AVHV).

Narendra Foundation in Karnataka

Narendra Foundation is a rural development project, registered on 2nd December 1997 with a Community-Based approach to disability and development. It covers the entire Pavagada taluk, which is one of the backward taluks in Tumkur district. Action Aid India has collaborated with Narendra Foundation (NF) in promoting disability intervention.

The vision and mission of NF constitute - ensuring dignity of life and empowerment of Persons with Disabilities (PWD) and community participation. In order to meet the overall aims of the organization, the work of the project is carried out through the following sectors like community organization, education, health and vocational training and income generation. NF also works to set up women's self-help groups and networks with organizations for community development activities.

NF has promoted taluk level federation called Swami Vivekananda Federation. Currently the federation is advocating for the rights of PWD including PWMI.

Gramina Abyudaya Seva Samsthe (GASS) in Karnataka

GASS is a registered voluntary organization established in 1996 works for the empowerment of PWD and other under privileged persons in the community. The association commenced its services in Doddaballapura town with initially 75 and later 150 villages from 1996 onwards.

GASS has involved in many activities like medical intervention to the disabled through general health camps, integrated education for disabled, self employment program, community development activities and so on. As a part of its activity, a mental health centre was established to provide ongoing assessment,

treatment and medical support for the people who are suffering from mental illness with the support of Community Psychiatry Unit of NIMHANS, Bangalore.

GASS advocated with Health and Family welfare Department and merged the medical camp and all the documents including case files are included in to primary health care.

Note

SACRED, Narendra Foundation and GASS are associated with BNI since 2000-01.

SAMUHA in Karnataka

SAMUHA is a voluntary organization established in 1987, based in Northern Karnataka, SAMUHA has undertaken community development programs with a special focus on vulnerable people, including People with HIV/AIDS and Disability. 'SAMARTHYA,' the disability unit of SAMUHA has been working through self-help groups and community-based organizations of people with disabilities at the taluk, district and state levels.

Samarthya also acts as a resource group for other programs on disability issues through training, exposure visits and guidance. Samarthya works in three districts – Raichur, Koppal and Karwar.

Note

BNI is working with SAMUHA since 2002.

As the organization shows interest to work with mentally ill, BNI arranged an initial meeting with the staff who expressed their interest to work in area of mental health. The scope of the organization is to reach

large number of people and the strength is well-defined in the organizational systems and funding strategies.

Action on Disability and Development India (ADD India) in Tamil Nadu and Kerala

ADD India is a resource organization in the disability sector registered in the year 1987 ADD India works with persons with disability through advocacy, using a rights-based approach. While ADD India works directly in three districts of Tamil Nadu, Andhra Pradesh and Karnataka. They also network with other disability organizations working in rural areas and provide training on the rights-based approach.

Note

ADD India has 32 partners in South India, of which 10 partners are associated with BNI since 2003.

Vidya Sagar in Tamil Nadu

Vidya Sagar is a resource organization registered in the year 1985. The focus of Vidya Sagar's work is on persons with cerebral palsy and other disabilities through a CBR approach. Vidya Sagar coordinates the activities of NGOs involved in CBR work and facilitates the identification of persons with disability, including children. It runs institutional programs through a school for children with disability, vocational training and human resource development, a post graduate course in special education for children with cerebral palsy, training of parents, staff and volunteers.

Note

BNI is working with four partners of Vidya Sagar since 2003.

Nav Bharat Jagriti Kendra (NBJK) in Bihar and Jharkhand

NBJK has been working in the field of socio-economic development of rural areas since 1971 and on various issues. The operational areas always have been Bihar and Jharkhand. It is working with as many as 2.1 million people and is supported by many partners and voluntary organizations. NBJK is working with issues like gender disparity, education, health, small group support and rural entrepreneurship to name a few. It has several financial and intellectual partners who are in constant support. As the states Bihar and Jharkhand are among the poorest states there are lots of challenges in front of NBJK to implement programs in favor of poor people.

This community mental health and convergence of services program started in the year 2002, is being implemented by NBJK through 25 partners across Bihar and Jharkhand. These 25 voluntary organizations are spread over 32 blocks of 15 districts. Bihar and Jharkhand were one state till 15th November 2000 when southern part of Bihar state was declared a separate state as Jharkhand. Now, under this mental health program there are 14 VOs working in Bihar and 11 VOs are in Jharkhand. This CMH&D program is implemented through NBJK with 25 partner VOs in Bihar and Jharkhand.

Note

BNI is working with NBJK since 2002.

Chapter 2

PROCESS OF THE STUDY

This chapter delves into the study process and methodology used in the CMH& D program.

In the year 2001, BNI entered into partnership with six organizations in south India to implement a project on mental health under the CMH&D model.

Background of the Study

The partners **Grameena Abhyudhaya Seva Samsthe** (GASS), **Narendra Foundation** and **SAMUHA** in Karnataka and **SACRED** in Andhra Pradesh implemented the project directly, hence were called the primary partners. Whereas, **ADD India** and **Vidyasagar** implemented the project through their partners, hence were termed as secondary partners. All the partners together implemented this model initially for seven years 2001 to 2008) with financial and technical support from BNI and the last three years (2008 to 2011) with only technical support (working Panchayats/Taluks/Blocks of partners of 20 districts in South India).

COLLABORATION THROUGH THE STUDY

Several organizations have come together in 20 districts in four states to engage in the assessment of mental health interventions.

Karnataka

Grameena Abhyudhaya Seva Samsthe

Narendra Foundation

Samuha

The **first phase** of this project was completed in March 2008. The main activities carried out in this phase under this model were identification of PWMI and linking them to treatment facilities, livelihood support and linkages, building community support groups and inclusion of PWMI and family members in those groups and activating the systems related to treatment at PHCs and district hospitals through advocacy.

Andhra Pradesh

SACRED

To continue on the learning from first phase, BNI renewed the partnership with its partners for three more years from April 2008-March 2011. Under this it was agreed that BNI will provide technical support to the partners, and they in turn will continue and sustain the process by strengthening the caregivers associations, the federations and the state level alliance of partners.

Further, the primary stakeholders were enabled to access their entitlements from the government. The processes agreed with the partners are:

- Documentation of the work outcomes and the gaps perceived.
- Influencing public opinion through advocacy on aspects of CMH&D model.
- Public awareness promotion through appropriate media towards stigma reduction and inclusion of PWMI in family and society.
- Focus on implementation of the National Mental Health Program (NMHP) with greater emphasis on involvement with the community.
- Promoting organizations of poor mentally ill persons, caregivers and supporters.
- Demanding greater allocation of resources towards the broader needs of poor mentally ill persons and their carers.
- Strengthening the South India Alliance for Mental Health to be effective towards governmental provisioning of mandated services.

- Network with other activist groups to advocate for PWMI to excise their rights and to access their entitlements.

Aims

The overall aims of the *Community Mental health and Development Program in South India* – are:

- To provide a deeper understanding on the functioning of CBR that serves as a strategy for mental health interventions.
- To provide information on mental health of vulnerable communities in South Indian states of Karnataka, Tamil Nadu, Andhra Pradesh and Kerala.
- To provide governments and civil society with a comprehensive view of mental health and the crosscutting problems, through providing analysis of the responses obtained from the NGO partners regarding the PWMI.
- To provide a foundation for additional research based on the analysis of the findings in the four states of South India. This will help BNI and its partner organizations in their intervention programs.
- To make recommendations for action at state, national and international levels.

Rationale for the Study

With this background the *CMH&D Program in South India* study was undertaken to examine the state of mental health – the cross cutting rights, issues and factors in South India program of BNI, namely CMH&D, from a community health, public health perspective, looking at recognizing the socio-cultural factors in mental health along with the support of care-givers with promotive aspects of interventions of mental health.

Planning the Study

Through the process of intense discussion, deliberation and the common collective knowledge in each member of BNI, because of many years of working in the area, proved insightful in drawing out the plan for the study.

The BNI team had discussions at multiple levels, from stakeholders, organizations, communities, caregivers, and people with mental illness, to enable a deeper understanding of the impact that programs have had in communities. In addition, the team looked at the letter of understanding with the partners (April 2008-March 2011).

Recommendations were sought from Sir Darobji Tata Trust (SDTT) and drawing the objectives for the consolidation. A brief assessment of the status of the partners in relation to program, data and relationship with BNI based on the previous field visits by the South India program (SIP) team was discussed vividly.

Drawing out the Objectives

- To know the status of PWMI and their families.
- To understand how the partners involving stakeholders are sustaining the program.
- To consolidate the learning of the program and replicate the same in future newer programs.
- To derive potentials for future directions.

Developing Proposal Based on the Objectives

Based on the objectives a small proposal on consolidation study of South India Program was developed and sent to SDTT.

The proposal included:

- Honorarium for persons at partners to collect required data.
- Honorarium for one associate at BNI.
- Travel for data managers and associate.

Mr. Gururaghavendra. C.E, the Program Officer- South India Program, was to lead the study process with the support of South India Program team members under the guidance of Mr. D.M Naidu.

Specifying the Objectives of the Study

This study aims at assessing the effectiveness of the outcomes agreed upon by BNI and its partners as mentioned above and the objectives are:

- **To enable BNI to understand how the program is sustained** by the partners and the involvement of other stakeholders in sustaining the program.
- To gain further **insights into the socio–economic aspects of the communities,** delving into the status of PWMI and their families and the benefits harnessed through various networks.
- To help the audience of this report – organizations working in the development sector, policy makers, communities, researchers and anyone interested in community mental health and to consolidate our experiences in **creating a discussion to enable further strengthening and refining the model of intervention** to allow mental health interventions in the country.
- To examine the South India program, its success, learning's in the light of the funding of the program for seven years and without funding for three years.
- To help BNI to plan for the next three years and to guide the newer programs on the basis of lessons learnt.

Other Considerations

- Identifying a person for each partner to work on this consolidation of information implied in the stated objectives and BNI to offer the required training to do this work.
- Collecting and consolidating quantitative data in the agreed format and parameters.
- Collecting qualitative data like impact of awareness programs in the community, orientation and training to community groups, inclusion of PWMI and their family members in to community groups, impact of advocacy efforts on availability of treatment facilities at the PHC and district level.
- Collecting information on strategies adopted, partner wise, to strengthen and sustain the program and how the data is used by them at different levels.
- Focusing on especially on persons with severe mental disorder and not merely on the quantitative figures comprising mostly of common mental disorders (CMD).
- Enquiring on the partners' entry and exit plans to be followed during the three years of non-funding support.
- Identifying issues and concerns of PWMI to be taken up with the government by the care givers associations and federations.

Population and Sample

The population of the study consisted of all the PWMI in the CMH&D program in South India. The sample consisted of the number of PWMI who participated in the study. The following tables present the figures.

Note: Limitation of the Study

The study includes only the socio-demographic profile of identified persons with PWMI and it does not take into account the socio-demographic profile of the general population of the working areas of BNI partners.

District-wise and Partner-Organization-wise Distribution of PWMI in the CMH&D Program of South India (2008-2011) and Participants in the Consolidation Study (2011) of BNI

TAMIL NADU

Table 2.1 District-wise and Partner-Organization-wise Distribution of PWMI in the CMH&D Program of South India

Name of the Organization	Data according to three years reports (2008-11) (population of PWMI)			Data according to the updated database – consolidation study		
	Male	Female	Total	Male	Female	Total
ESAI Trust	115	97	212	102	99	201
SCORD-Thiruvarur	130	119	249	100	113	213
SCORD-Tanjore	68	44	112	19	32	51
SJDT-Dindigul	104	97	201	97	102	199
SJDT-Theni	186	140	326	111	159	270
Resource Center	201	233	434	252	218	470
Vizhuthugal	52	44	96	0	0	0
ADD DIP	102	78	180	82	78	160
WORD	197	205	402	210	184	394
Voice Trust	149	90	239	0	0	0
ASSA	156	91	247	87	168	255
IRCDS	48	59	107	76	49	125
TCT	143	199	342	133	97	230
TRED	117	89	206	0	0	0
Total	**1768**	**1585**	**3353**	**1269**	**1299**	**2568**

KERALA

Table 2.2 Partner Organizations and Distribution of PWMI in the CMH&D Program in Kerala

Name of the Organization	Data according to three years reports (2008-11) (population of PWMI)			Data according to the updated database – consolidation study		
	Male	Female	Total	Male	Female	Total
TSSS	75	94	169	0	0	0
VOSARD	80	86	166	88	81	169
Total	**155**	**180**	**335**	**88**	**81**	**169**

KARNATAKA

Table 2.3 Partner Organizations and Distribution of PWMI in the CMH&D Program in Karnataka

Name of the Organization	Data according to three years reports (2008-11) (population of PWMI)			Data according to the updated data base – consolidation study		
	Male	Female	Total	Male	Female	Total
GASS	349	539	888	276	459	735
Narendra Foundation	233	215	448	174	145	319
SAMUHA	770	921	1691	230	260	490
Total	**1352**	**1675**	**3027**	**680**	**864**	**1544**

ANDHRA PRADESH

Table 2.4 Partner Organizations and Distribution of PWMI in the CMH&D Program in Andhra Pradesh

Name of the organization	Data according to three years reports (2008-11) (population of PWMI)			Data according to the updated database – consolidation study		
	Male	Female	Total	Male	Female	Total
SACRED	426	317	743	267	218	485
Total (South India Program)	**3701**	**3757**	**7458**	**2304**	**2462**	**4766**

The variation between the figures of PWMI as obtained from the three year reports of the partner-organizations and the figure obtained from the up-dated database during the consolidation study were due to:

- Rigorous advocacy efforts of the partner organization resulting in provision of psychiatric services in the taluk and district hospitals by the health department and the PWMI from the CMH&D program availing such facilities – resulting in withdrawal of CMH&D program from Karwar and Raichur districts of Karnataka (GASS and SAMUHA) and hence data-base could not be updated.
- Exclusion of those with epilepsy and mental retardation and also those PWMI who were regular in attending camp but were from outside the program area (NF and SACRED).
- Non provision of the required information (Vizhuthugal and Voice trust).
- Not being in partnership for 2008-2011 (TRED and TISS).

Out of a total of 7458 PWMI in the CMH&D South India program of BNI 4766 PWMI were in the consolidation study (about 64%). The female PWMI were higher in number than the male PWMI though the variation is negligible. In other words, consolidation study included almost equal number of male and female PWMI. There were variations among the four states in male-

female PWMI figures – Tamil Nadu and Karnataka had higher number of females, Andhra Pradesh and Kerala had greater number of males. The figures show variations among the partner organizations with reference to male/female figures.

Methods of Data Collection

Observation

Observation technique was followed throughout the study from the services point of view to see the services rendered by the partner organizations, keeping in background the mental health guidelines, local needs and infrastructure availability. For the case studies, details regarding living conditions, demographic and socio cultural factors of the patients were collected.

Case Study

This study is mainly based on the qualitative data and case studies on PWMI. Within the case studies, quantitative information was gathered, looking at the finer nuances of the social and family dynamics based on caste, occupation, monthly income and others.

In the case studies, emphasis was placed on personal information and demographic information of the families, substance abuse, stigma, human rights violation and the patients' perception of the problem. Emphasis was also given on the perception of the problem and occurrence of illness of PWMI, family members and caregivers, the place of living, issues of migration, major stress factors that impact the well being of the individual, information about the community outreach program, details of any previous medical interventions (in the context of type of practitioners, cost and satisfaction), need for mental health services, suggestions to improve the existing facilities, problem with present facilities and the people and family members perception of services, mental health, stigma and illnesses.

Interviews

Informal interviews were conducted with the PWMI and their family members when the field staff visited the families. Through the interviews with families, enquiries were made to understand the accessibility to information regarding government entitlements, services available in the districts and individual perception of mental health and the needs expressed by persons.

Interviews with community members on the improvement of the PWMI, their own perception of the illness, the changes in the perception of the illness through the years, the community support in providing livelihood opportunities, inclusion of PWMI into the support groups or self help groups in the community and support in accessing social entitlements were also taken into account.

Both the case studies and the informal interviews with the PWMI and their family members gave valuable insights about the perception of participants regarding mental health conditions and the services available, whether the treatment has been successful or not, reasons for the relapse of symptoms, the discontinuation of treatment, or moving to alternative modes of support like faith healers and quacks. The informal interviews helped in exploring processes, relationships and its consequences in detail.

Tools for Data Collection

Structured and unstructured interview schedule were used mainly to collect the information for the study. Apart from this, secondary data from various sources and in some cases informal unstructured interviews were carried out. A copy of the interview questionnaire is found in *Appendix 3, Interviewer's Journal.*

Consultation Meetings on the Study with the Partners

The consultations meeting with partners were carried out to help:

- Discuss the concept and importance of the study.
- Strengthen the relationship with partners.
- Draw mutual consent and agreement to initiate and accomplish the study.

Capacitating the Partners for the Study

For the data collection and collation capacity building in several areas was essential:

- Interview schedule was prepared based on the outcome parameters/indicators
  The same interview schedule was discussed with few selected partners to test whether the required data could be collected
- Translating the questionnaire in to regional languages.
- Orienting the partners on individual interview schedule (BNI team oriented Karnataka and Andhra Pradesh partners directly, in Tamil Nadu and Kerala BNI oriented the nodal partners ADD India and Vidya Sagar. Nodal partners oriented the secondary partners).

Field Testing the Interview Schedule

- Partners were asked to monitor five interview schedules each.
- The interview schedules were collated at BNI level and the gaps in the data were identified.
- The BNI team reoriented the partner teams to monitor the data collection process, examining the gaps in the pilot test of the interview. The gaps were built to fix the interpretation and responses of the feedback received in the interviews.

Developing the Formats for Collating Data

BNI developed the formats to help the collation of data. Several of the following methods were taken into account:

- Upgrading, editing and modifying the existing excel database. There was an attempt to add additional fields of social demographics in the database.
- Consolidated data format based on the parameter indicators was developed.
- Developed a qualitative interview schedule to collect qualitative data from the project directors and the coordinators.
- Partners were trained on the above formats.
- Monitoring visits were made by the BNI team regularly.

Collecting Data from Partner Organizations

The process of collecting data at the partner organizations considered the following technical details:

- Monitoring individual interview schedules by the partners by visiting each individual families and collecting data.
- Updating the case files based on the current status.
- Updating the excel data base partner wise.
- Transferring the data in to the consolidated format.

Collating Data at BNI

BNI collated the data partner wise, both excel data and the consolidated data. At the same time identified gaps in the data were listed discussed with the partners and sent back to the partners for further clarifications on the same. Based on the responses from the partners the same gaps were filled and data were edited.

Analyzing the Data and Development of the Final Report

Wading through the mammoth data was a formidable task. The several aspects of field information that looked at the personal, socio-cultural-economic aspects had to be collated. This meant long hours of re-working on chunking the information on the findings. For example, information on the gender differences with mental health, concerns of employment based on employment, age, religion, caste and other factors were taken into consideration.

Moving Forward

CMH&D Program in South India – charts out the ground reality of the status of mental health of the underprivileged sections in our society. This aspiration of the report is to work ahead, through partnerships and collaboration to encourage further participation and inclusion of PWMI. The fact that many people have been involved at different levels to address community mental health interventions, the aspiration of all is that this report contributes to concrete actions at all levels and across all sectors, to work towards one goal - to help promote social and economic development and the achievement of the human rights of PWMI across India.

Note

The data from the partners reached BNI in the month of March 2011.

Chapter 3

SOCIO-DEMOGRAPHIC PROFILE OF PWMI IN CMH&D PROGRAM

This chapter describes the PWMI identified in the CMH& D program of South India. This examines the distribution of PWMI with severe and common mental disorders according to their sex, marital status and age.

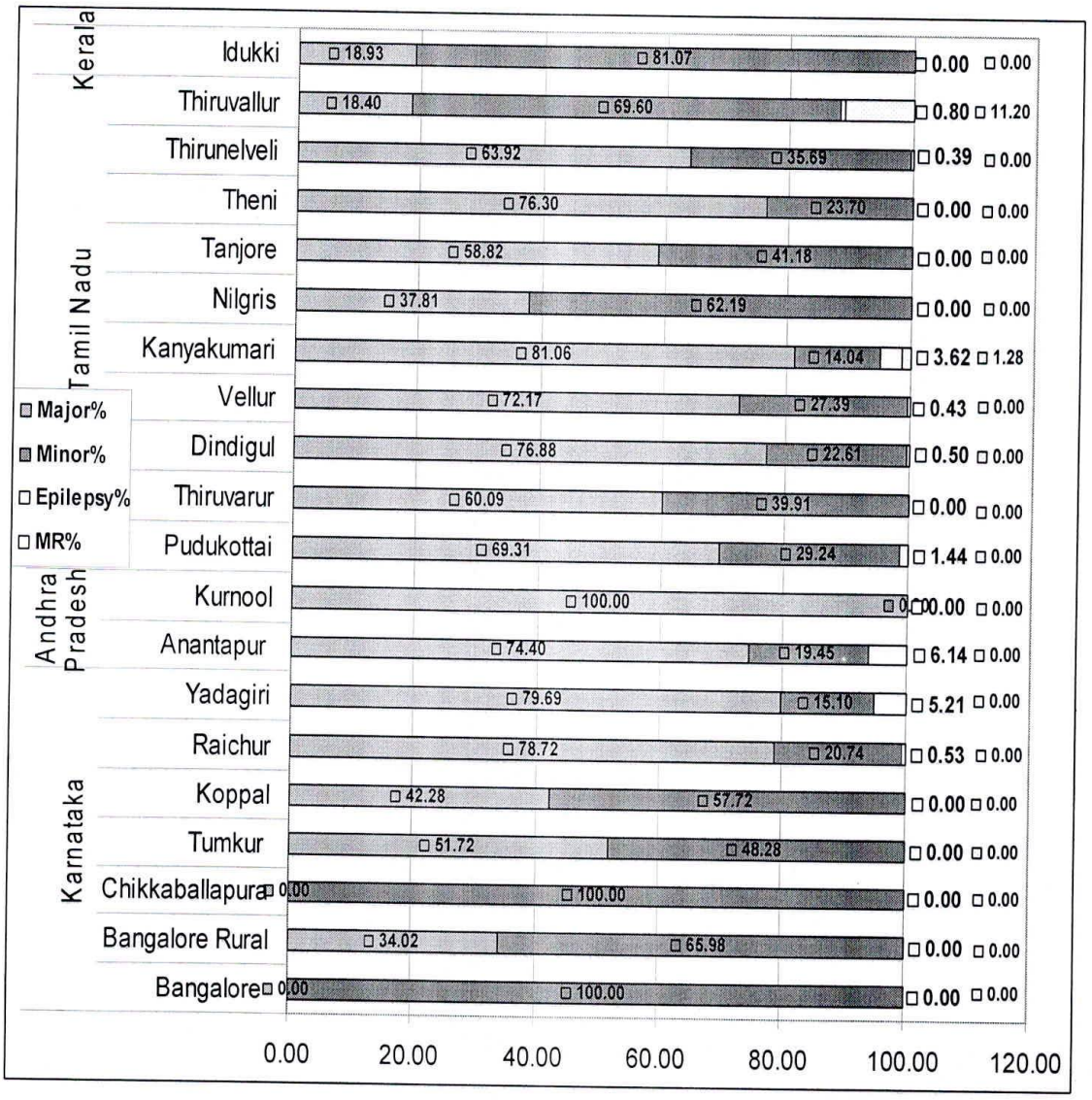
Section 1: Basic Demographic Data of PWMI in CMH&D Program

MENTAL HEALTH DEMOGRAPHICS IN INIDA

India is a country with an approximate area of 3287 thousand square kilometer (UNO, 2001). Its population is 1.081 billion and the sex ratio (Men per hundred Women) is 106 (UNO 2004). The literacy rate us 68.4 % for men and 45.4% for women. The proportion of population under the age of 15 years is 32 % and the proportion of population above the age of 60 years is 8%. The life expectancy at birth is 60.1 years for males and 62 years for females. The healthy life expectancy at birth is 53 years for males and 54 years for females.

Figure 3.1 Distribution of Identified PWMI in CMH&D Program based on Categories of Mental Illnesses depicts the distribution of PWMI identified in CMH&D program in terms of the types of illnesses.

Figure 3.1 Distribution of Identified PWMI Based On Categories of Mental Illnesses



The distribution of PWMI according to the categories of Mental Illness shows:

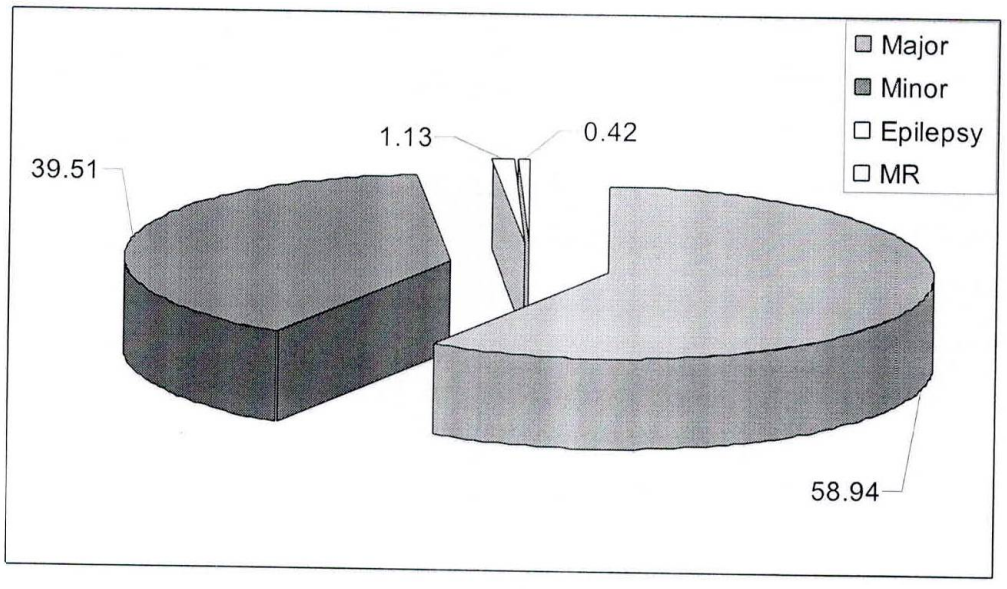
- In general, majority (2805 PWMI out of 4766) suffered severe mental illness (58.85%) and fairly good number (that is 1883 out of 4766, 39.51%) were going through common mental illnesses. Very small percentages of those identified were reported to have epilepsy (1.22%) and mental

retardation (0.42%) which are not really within the scope of the program. This is an evidence of the program achieving its objective of taking in a large number of PWMI, severe and common.

- Here again there are variations in number of PWMI with severe and common mental illnesses among districts within a state and among different states. Karnataka state had more of PWMI with major mental illness with two districts of Bangalore rural and Koppal contributing to this picture. In both the districts of Andhra Pradesh, majority were with major mental illness. The figures presented for one district in Kerala shows majority were in the category of minor mental illnesses. In Tamil Nadu, out of the ten districts, in eight districts majority were with major mental illness. And in two districts of Nilgiris and Thiruvallur, more members were with minor mental illness.

- It is interesting to note that the village communities in the study, not only sought help for major mental illnesses, but also for minor mental illnesses. This could be seen as people becoming more conscious of treating mental health problem that are not only severe but also the minor ones. The CMH&D program implemented seemed to have brought in this awareness in the rural south India. It may be due to changing beliefs related to mental illnesses and their treatments, from the religious rituals and other traditional practice to the medical, physical, psychological and social care with the creation of community awareness in support of PWMI.

Figure 3.2 Percentage Distribution of PWMI Based on the Categories of Illnesses

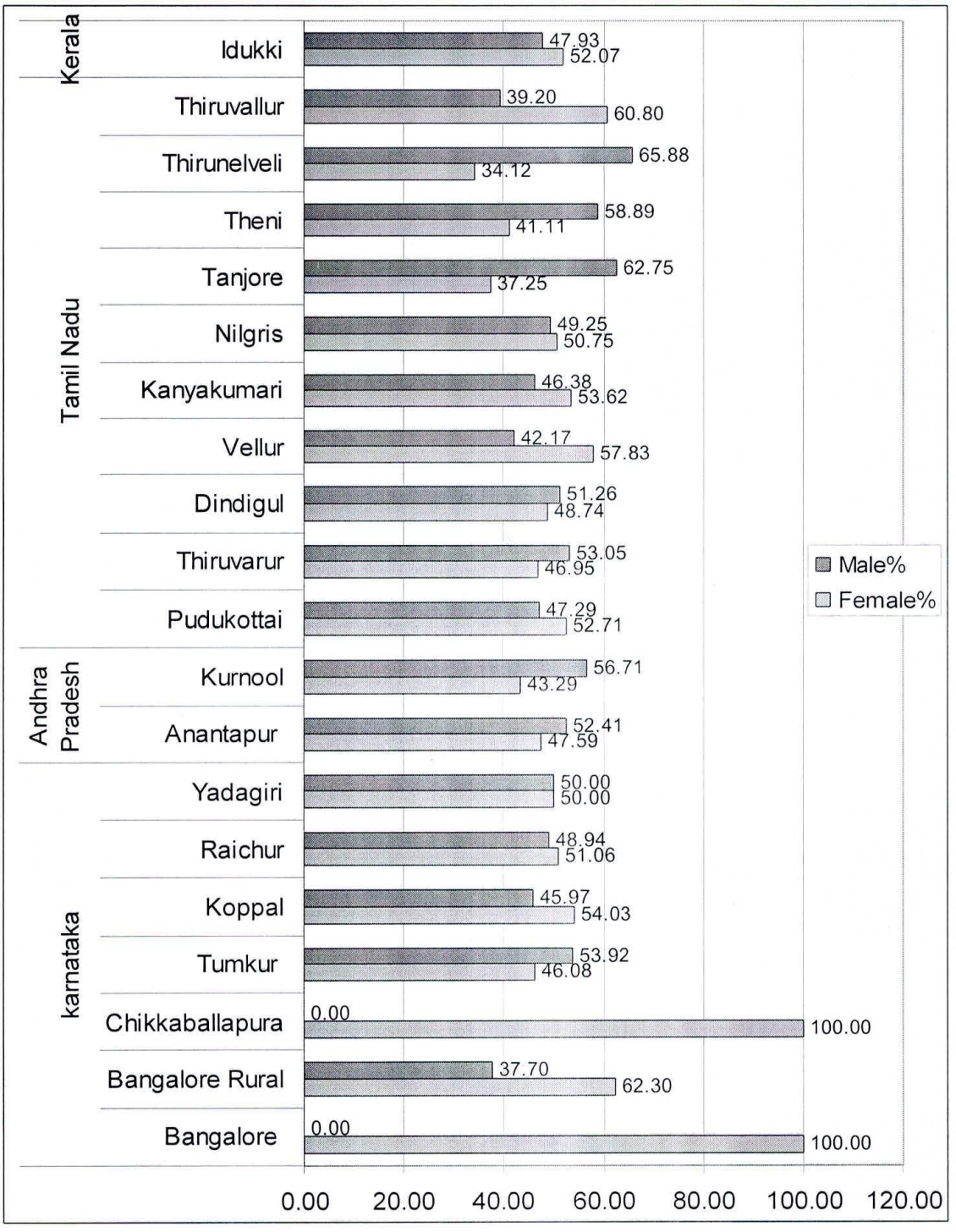


The diagram showing **distribution of PWMI based on the categories of illness** Majority (58.94 %) suffered severe mental illness, 39.51% suffered common mental disorder and less than 2% had epilepsy and mental retardation. As the majority were in the category of major mental illness, the focus of SIP was definitely on this category.

These figures indicate that CMH&D program focused not only on cases of severe mental illnesses but also on common mental disorder and thus on total mental health care. This also seems to indicate that village communities sought help for severe as well as common mental disorders pointing to the awareness created and the involvement of people in the mental health program.

Social hierarchy exists in society in terms of sex of individuals. An analysis of data regarding the distribution of PWMI according to sex was made. The results are presented in **Figure 3.3 Sex- wise Distribution of PWMI Identified in CMH&D Program:**

Figure 3.3 Sex- wise Distribution of PWMI Identified in CMH&D Program

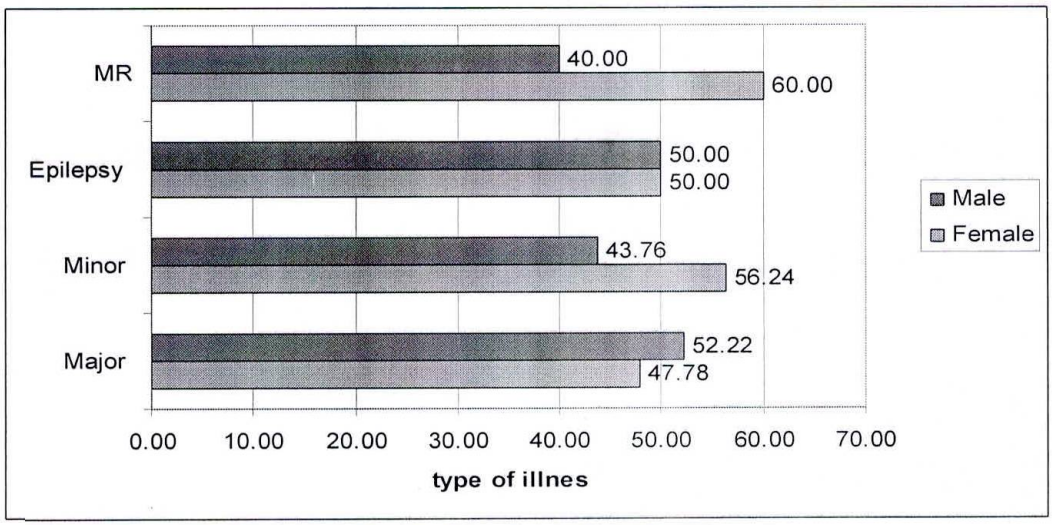


SOCIO-DEMOGRAPHIC PROFILE OF PERSONS WITH MENTAL ILLNESS IN CMH&D PROGRAM

In the CMH&D program of BNI in partnership with organizations in four states in South India, the data on the identified PWMI, as presented in **Figure 3.3 Sex- wise Distribution of PWMI Identified in CMH&D Program** show:

- The women and men PWMI identified were almost equal. Of the 4766 PWMI 2440 (51.20%) females and 2326 (48.80%) were males, with a slightly higher number of females than males.
- There is variation seen among the states and the districts with reference to the difference in the number of men and women PWMI. States of Andhra and Tamil Nadu show more males then females. Whereas in states of Karnataka and Kerala there were more females than males.
- In Tamil Nadu, of the 10 districts, five districts had more males than females and the other five districts had identified more females than males. In the two districts of Andhra the variation is quite wide. In Karnataka, the district of Tumkur showed wide differences. The variations in numbers of men and women PWMI are wider in certain districts than certain other districts.
- These variations could be real or may be due to the total duration of the program, the sex of the field staff, the nature of the community in terms of their beliefs and attitudes towards mental illness of men and women, the stigma attached to this, awareness and cooperation of the community and so on. This point out the need to understand the reality, and or the reasons for variation in number of men and women PWMI in the program so that efforts are made to help all PWMI in the community to participate in the program. The implementation can be effective with district wise planning as the variations seen could be taken in to account.

Figure 3.4 Sex-wise Distribution of PWMI Based on the Category of Illness



The above graph presents the frequency of **persons reporting mental illness by sex** with reference to major, minor, epilepsy and mental retardation categories of illness. Severe mental disorder in male was high compared to female (52.22 % to 47.78 %). Whereas under the category on common mental disorder women showed high level of prevalence of mental illness (56.24%:43.76%).

Sex-wise depiction of PWMI in the above graph shows that both men and women with major and minor mental illnesses were identified in CMH&D program of South India, though there is some variation in the number and percentage – more men with major mental illnesses and more women with minor mental illnesses. Almost equal number of men and women in the program indicates that the program seemed to have focused on both men and women, with an edge over women than men. When the figures for both major and minor illnesses are considered together, women were larger in number than men.

The reason for the women in larger number compared to men may be because of the triple role played by women and the responsibilities they tend to carry with a secondary status they are pushed into.

It is evident that the CMH&D program is gender-aware, meaning women are development actors as well as men.

'Marital status' of an individual is socially important, especially for women. The two graphs (**Figures 3.5, PWMI Based on Marital Status** and **3.7, PWMI Based on Marital Status and Sex**) and the **Figure 3.6 PWMI Based on Marital Status** brings to focus the prevalence of mental illness with reference to marital status and also with reference to sex.

Figure 3.5 PWMI Based on Marital Status

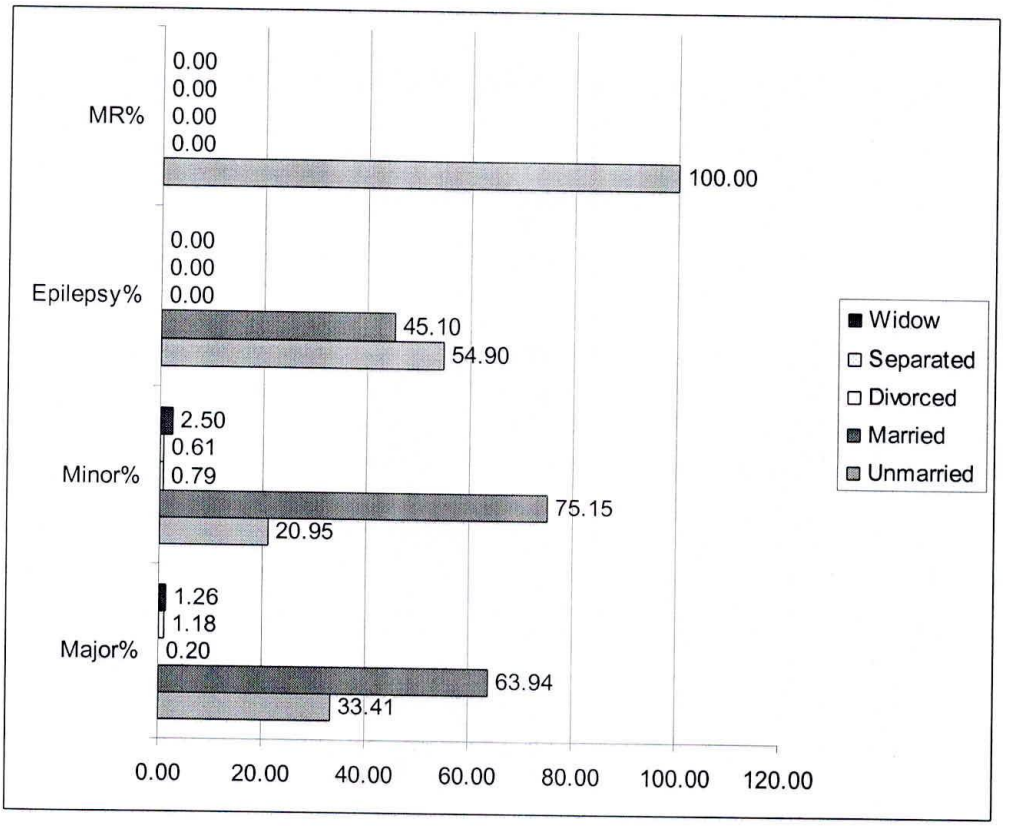


Figure 3.6 PWMI Based on Marital Status

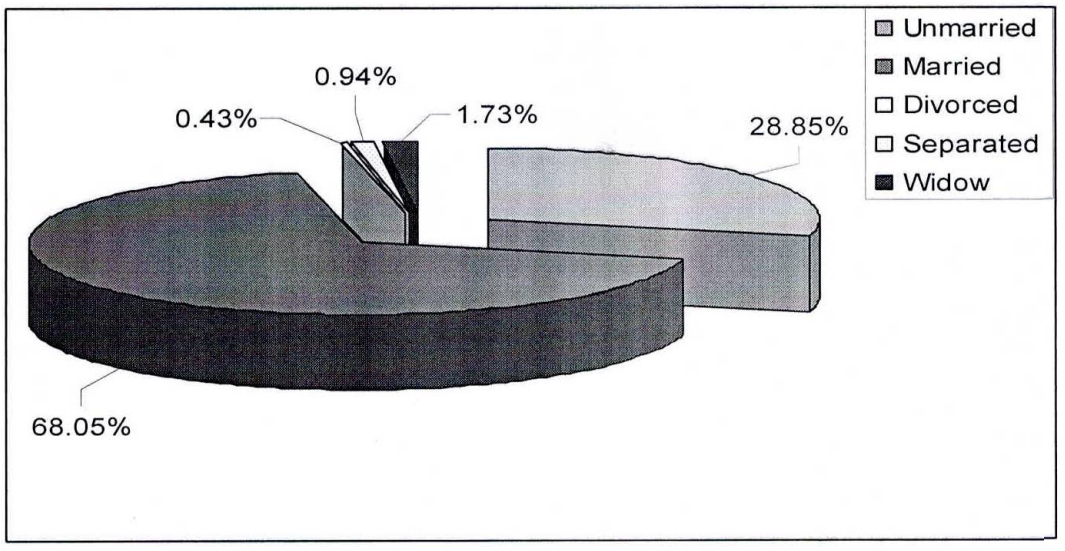


Figure 3.6 shows **PWMI based on marital status** in the identified PWMI's majority (68.05%) were married and 28.85% were unmarried, divorced and separated were 0.43% and 0.94 % respectively. Out of the identified PWMI 1.73% had lost their spouses.

Figure 3.7 PWMI Based on Marital Status and Sex

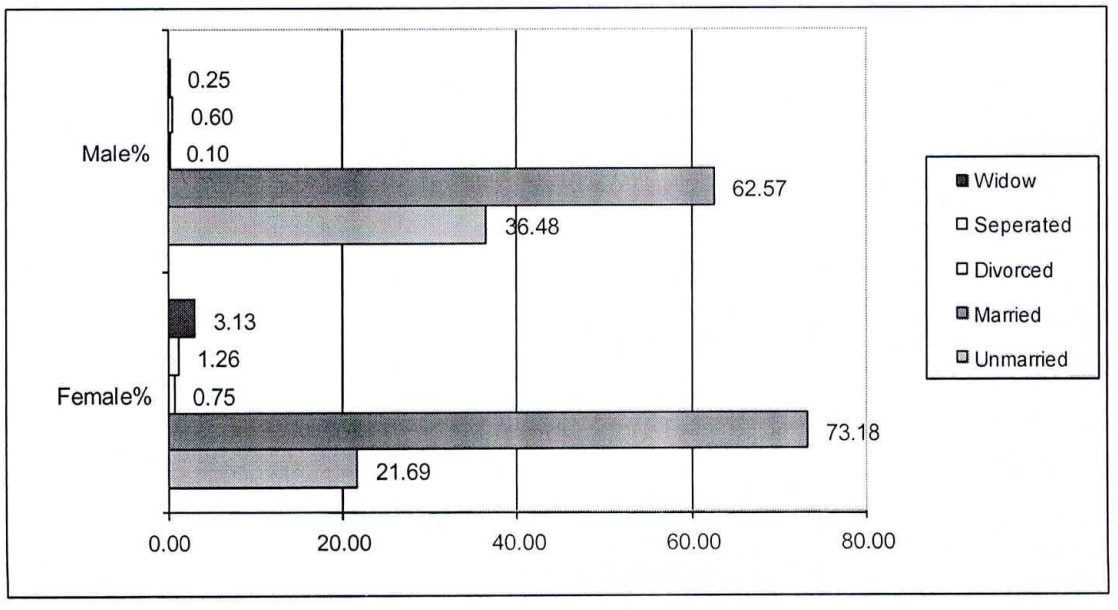


Figure 3.5 shows the percentage distribution of identified PWMI based on their marital status according to the types of mental illness. The prevalence of both severe and common mental illnesses was high with persons who are married (63.94% and 75.15% respectively) than those who are unmarried. The reason could be due to the stresses the family responsibilities and issues bring to the married persons. The data for the unmarried indicate nearly 33.4% with severe mental disorders and nearly 21% with common mental disorders. This could be due to the social issues – delays in getting married due to not finding suitable match, custom of divorcé, love failures, failures in education and employment.

This appears to be a matter of concern. A further probe into the reasons may show pointers in helping these young persons.

The persons divorced and separated and widowed though smaller in number and percentage, a total of 65 persons (2.6%) suffered severe mental illnesses; and 64 persons (3.9%) were with common mental disorders.

This could be due to the inferior social ranking and subordination of these categories of persons resulting in low self – esteem. Further information on the status of these groups could be of value in improving their condition of mental health.

The sex-wise distribution of **PWMI based on marital status** (**Figure 3.7**) shows that married women have a higher prevalence of mental illness (73.18) as compared to the men with mental illness who are married (62.57).

The study shows that a higher percentage of unmarried or single men suffer mental illness (36.48%) in comparison with single or unmarried women (21.69%).

The data on PWMI according to sex and marital status show that a higher percentage of married women were with mental illness, it is not merely the stresses of family responsibilities that marriage brings to women but in addition they are placed in subordinate position with little or no power to make decisions regarding their own health and exercising their reproductive rights.

The 'stages of life' brings with them stage specific issues in life. The importance of looking at the prevalence of mental illness according to age groups is recognized. The following graph brings out the results of analyzing the distribution of PWMI according to their age groups, as shown in **Figure 3.8.**

Figure 3.8 Prevalence of Mental Illness in Children, Young and Older Persons

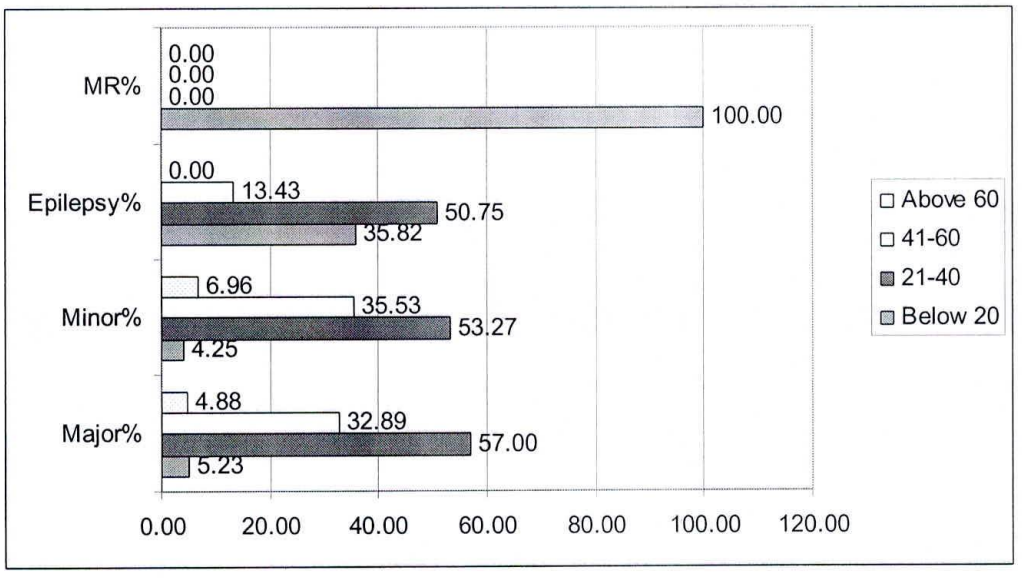
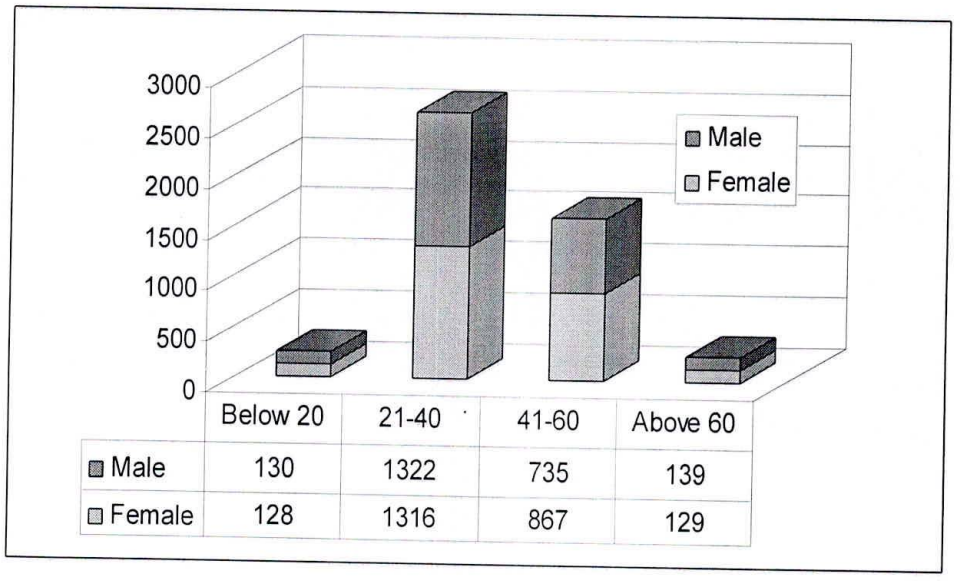


Figure 3.8 Prevalence of Mental Illness in Children, Young and Older Persons shows that under the categories of major, minor and epilepsy, a majority of the identified PWMI belong to the

age group of 21-40 (major mental illness being 57%, minor mental illness being 53.27% and epilepsy being 50.75%). The prevalence of epilepsy in adolescents and persons below 20 years is 35.82%.

Figure 3.9 PWMI Based on Age and Sex



	Below 20	21-40	41-60	Above 60
Male	130	1322	735	139
Female	128	1316	867	129

The representation of **mental illness based on age and sex** shows that there is more or less equal representation of male and female in all the age groups. Out of the identified majority of the people in both male and female belong the to the age group of 21 -40.

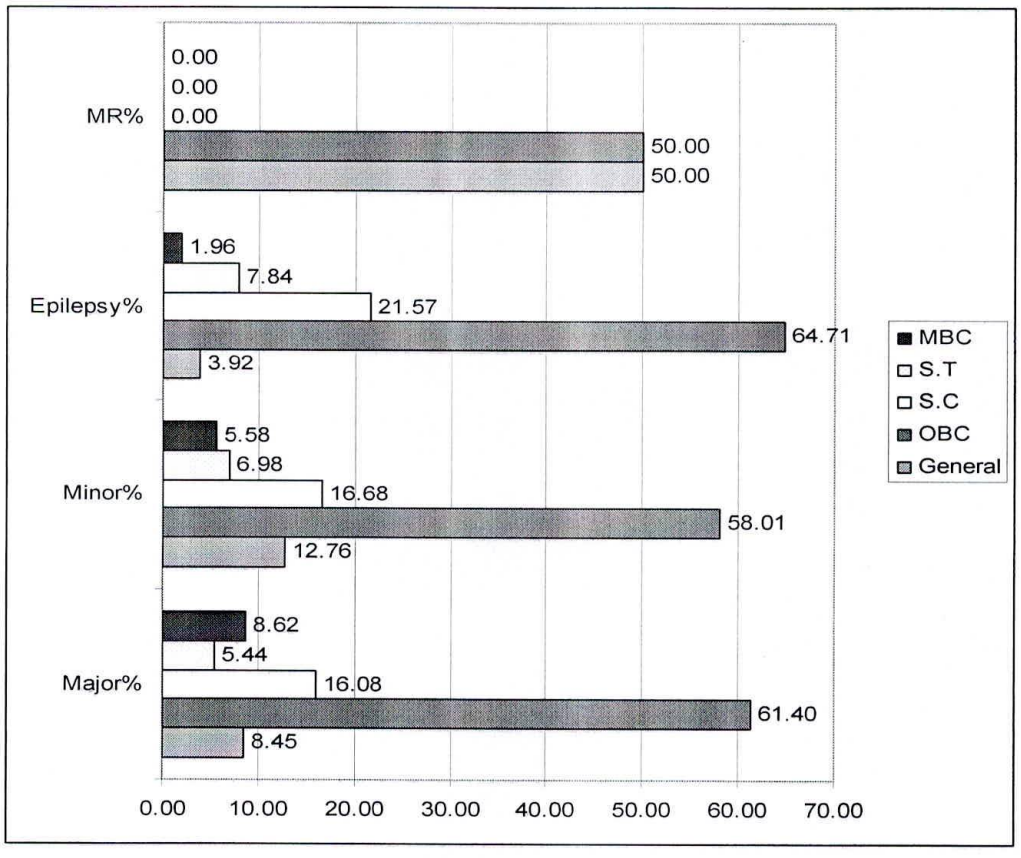
The prevalence of mental illness in the program area seem to be quite high during the most productive years of life, i.e, between 21 to 40 years. The CMH&D program brought to focus the age-group which required all attention to help them improve the quality of their lives.

Section 2: Socio-Demographic Data of PWMI in CMH&D Program

Mental illness is increasing cutting across several groups in society. This becomes severe with vulnerable groups. The gravity of the issue for the poor, the dalits, and persons with disability often need far greater support to help them through the conditions. Health including mental health is a fundamental right. Availing treatment is a right and today the situation is most critical.

Caste seems to be crucial in any development work. A study of the PWMI in CMH&D program according to their caste groups brings out the inclusion/exclusion of those who are in the lower rungs of the social ladder. Figure below depicts caste- wise distribution of PWMI in the program.

Figure 3.10 PWMI Based on Caste



The graph on distribution of PWMI based on caste and the types of illness shows that except with MR, a majority of the identified PWMI belong to other backward communities (OBC).

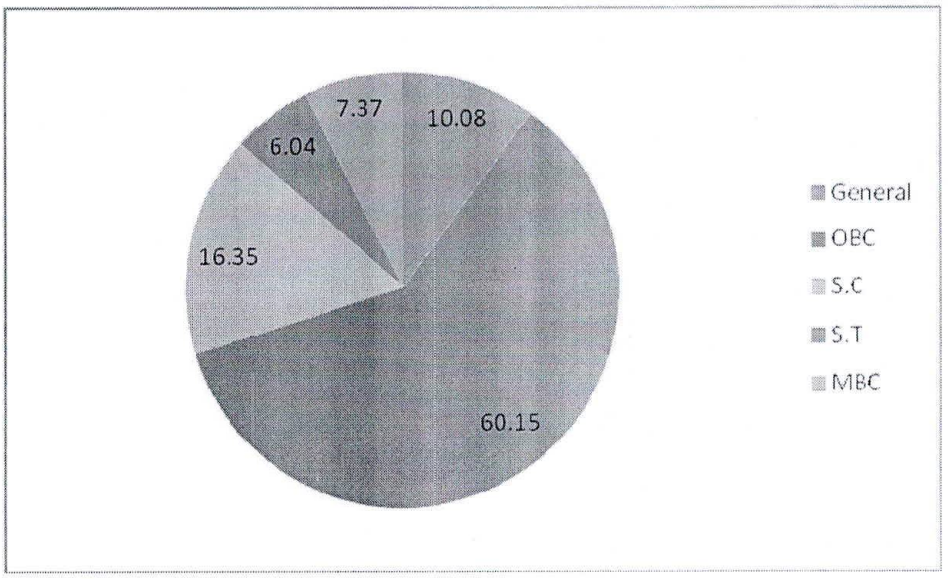
Among the identified PWMI, majority were from OBC in all the three categories of mental illness namely severe, common and epilepsy

- **Severe mental illness:** 61.40 %
- **Common mental illness:** 58.10%
- **Epilepsy:** 67.71%

Among those belonging to Scheduled Caste (SC) and Schedule Tribe (ST), high percentage of SCs suffered both severe mental illness (16.08%) and minor mental illness (16.68 %) and in epilepsy (21.57%).

People belonging to ST had severe mental illness (5.44%) common mental illness (6.98 %) and epilepsy (7.84 %). In caste groups other than the OBC, SC, ST and MBC representation in all the types of illness other than MR is about 4% to 10%.

Figure 3.11 Identified PWMI Based on Caste



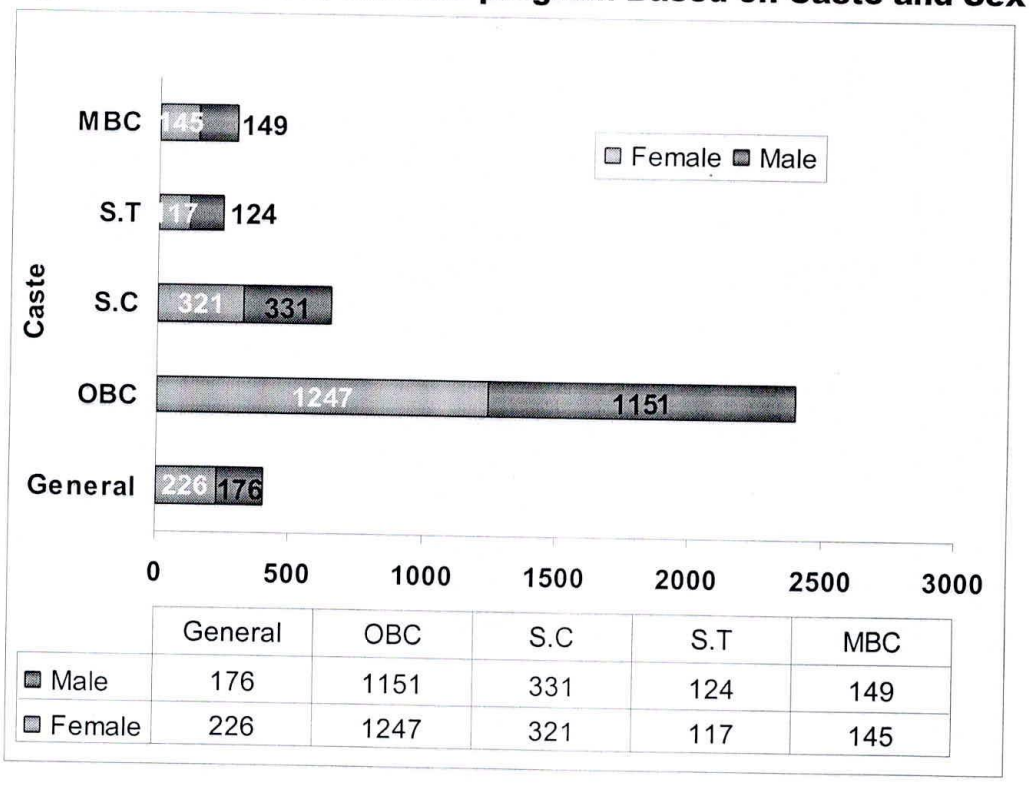
Sixty percent of the PWMI identified were OBC whereas SC's were 16%, ST's were 6%, MBC's were 7%. This pattern of representation of caste groups is reflected in the categories of illness specified. In general, almost 90% of PWMI belonged to the low socio-economic groups and hence from vulnerable sections of the village communities.

Caste wise analysis show that about 61% suffered major mental illness, approximately 38% had minor mental illness. In every caste group, persons with severe mental illness were more in number than persons with common mental disorders.

CMH&D program catered to the vulnerable sections of the communities the population un- reached by the health programs of the government.

Besides caste- discrimination, sex- discrimination is yet another social issue. The inclusion of PWMI not only from the lower castes that is important but within those castes, inclusion of women becomes essential. **Figure 3.9** shows the distribution of PWMI with reference to caste and sex.

Figure 3.12 PWMI in CMH&D program Based on Caste and Sex



	General	OBC	S.C	S.T	MBC
Male	176	1151	331	124	149
Female	226	1247	321	117	145

Figure 3.12 on the **PWMI based on Caste and Sex** shows in general that among OBC and Scheduled Caste the female representation was higher than male representation. In MBC and ST male representation of persons with mental health problems was higher than women with mental health problems.

Women in any society and in Indian rural society in particular occupy a secondary status and since they have a place next to men in accessing and availing any services such as skill development and economic improvement, maintenance of good health or meaningful education. In CMH&D program the identified

PWMI show women in quite large number as compared to men. This brings out clearly the focus of CMH&D on vulnerable groups caste or sex or literacy levels.

Educational level of individuals seems to play a role in individual's status in society. The graph here depicts the educational level of PWMI according to the types of illnesses.

Figure 3.13 Identified PWMI Based on Categories of Mental Illness and Education

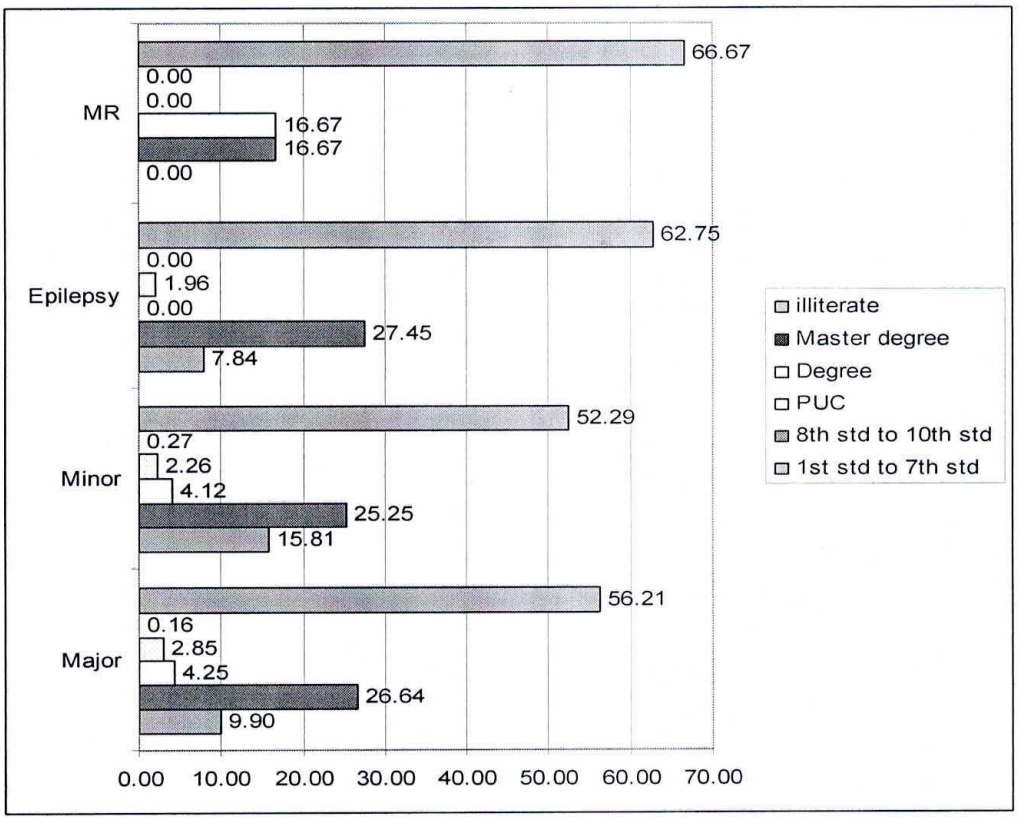


Figure 3.13 on PWMI based on categories of illness and education shows that the majority of identified PWMI (in all the types of illness) were illiterate. In all the types of illness other than mental retardation, at least 25% of the identified had basic education (8th to 10thStd education). Identified PWMI with higher education were in small percentage. Here again the focus is on the vulnerable section of the people with little or no education.

CHILDREN WITH MENTAL RETADATION

Children with mental retardation are more vulnerable to mental illness. Children with mild mental retardation may become very aware of their limited abilities compared with other children and may show emotional and behavioral problems in the classroom (such as hyperactivity). As they grow older, their difficulty in making friends may make them depressed and angry. Sexual problems may arise. Children with more severe mental retardation often have brain damage, which can make them more vulnerable to psychoses. If a child with mental retardation shows a change in behavior, you should suspect a mental illness.

'Gender' is a social issue as it has been already stated. Here again an analysis is made with educational level and sex of PWMI.

Figure 3.14 Identified PWMI Based on Education and Sex

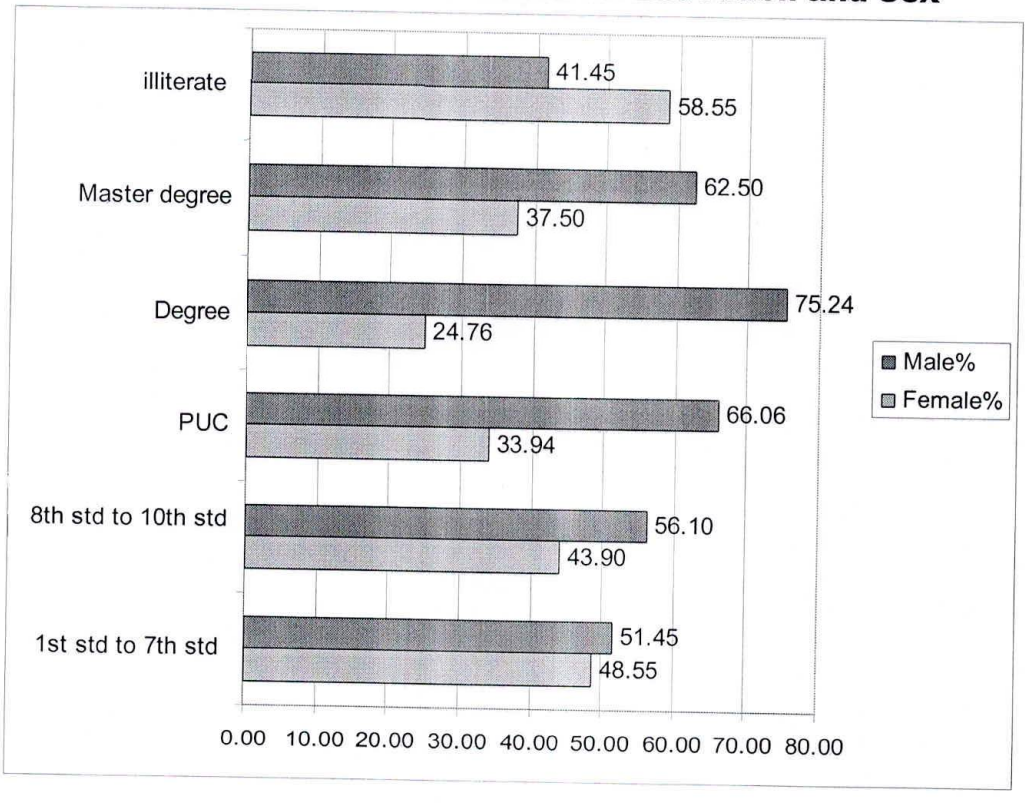


Figure 3.14 shows **PWMI based on education and sex.** It indicates that among the non-literate, the prevalence of mental illness among women is higher (58.55% in women to 41.45% in men).

There is a pattern visible in the data presented shows that women's literacy is lower than that of men as is evident in the national Census. The picture that emerges is that, illiterate and semi-illiterate men and women form a substantial proportion. Whereas persons with different levels of literacy, more men were identified than women. It could be just that men are in larger number in all these groups of educated persons. It may be the status they occupy as men and men with low to high education, it was the privilege given to them by the family and community.

CMH&D's focus on non-literate persons, the most vulnerable, is evident. With improving educational level, men more privileged, seem to have an edge over women. This could be seen as a result of the secondary status occupied by women. The family may get more concerned about men's mental illness. The men with education, the bread winner could gain priority in getting treated more than women with low or high education, as women with or without education have a subordinate position.

It is clear that mental illness was seen in all categories of persons with or without formal education. CMH&D's focus on non-literates stands out.

The number of men and women with mental illness was almost equal for persons who had completed primary education (class one to class seven). It is 51.45 for men and 48.55 for women.

The prevalence of mental illness in men was greater in persons with secondary education (class eighth to class ten) with 56.10% men and 43.90% women.

The critical age of adolescent young persons in the age group of 18 to 20 years where young persons have either completed or dropped out at pre-university level, show that the prevalence of mental illness was far greater among men – 66.06% in comparison to their female counterpart – 33.94%.

Through the interviews it was found that this age was often critical, as childhood experiences and challenges of adolescent development are often complex. Children in this age are given to heightened curiosity, sexual exploration and substance abuse being some reasons.

The prevalence of mental illness among men was greater with Master's Degree (62.50% men and 37.50% women).

Out of the identified population among persons holding a Bachelors Degree, 75.24% men were suffering from mental illness.

Inequality in education is an indicator to show that the lesser the education, the opportunities for upward mobility in employment, better lifestyle are compounding problems. Often the social inequity undermines education opportunities for children and women leading to greater stress in livelihood opportunities hampering growth and development. Among men with more and more education unemployment resulting in non-earning may cause problems related to mental health.

Note

Barring persons who are non-literate, the prevalence of mental illness is high among men in all the education segments/levels.

Section 3: Economic Status Data of PWMI in CMH&D Program

Economic well-being is one of the key elements to dignified living. This section looks at the finer indicators of livelihood opportunities, income, employment that directly influences the wellbeing of persons.

Economic wellbeing is one of the key elements to any individual realizing his/her full potential. It becomes critical for a person with disability, mental illness or for any individual born into poverty. This often impedes the potential for growing to ones full potential. A few indicators for the economic well-being of an individual are employment, income, wealth, occupation, along with the access to social security.

Note

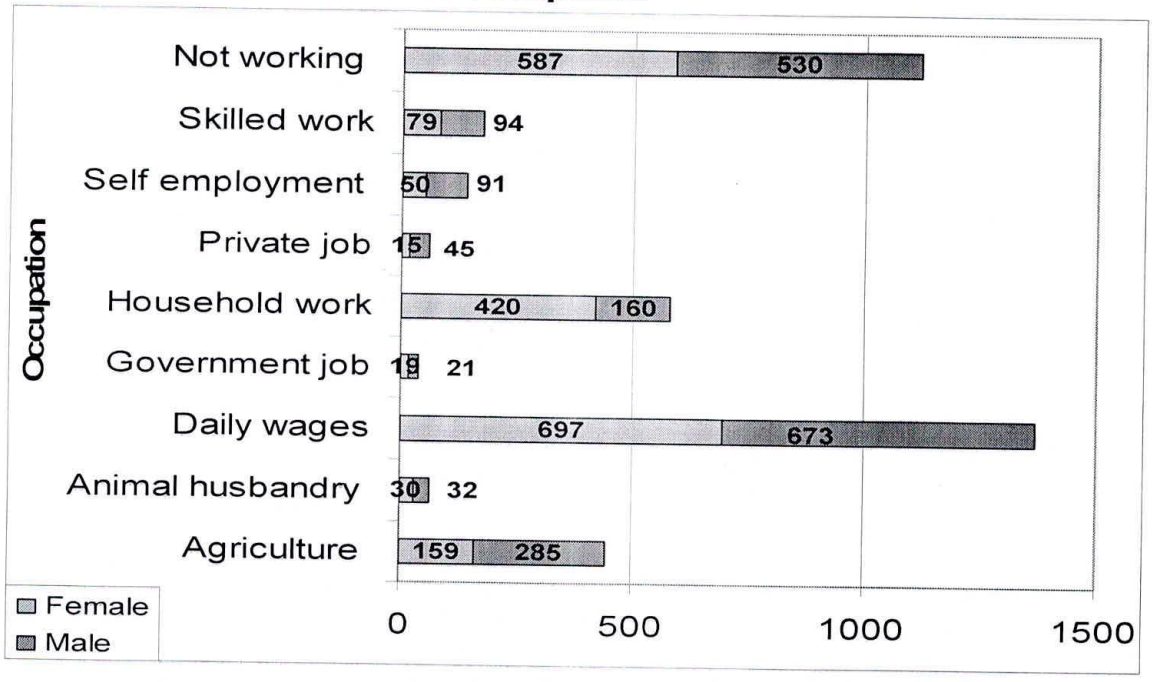
BNI looks at the wellbeing of a PWMI in its all-compassing forms. The involvement of an individual with mental illness in any form of productive work is therapeutic to the well-being of the individual. This directly has an impact on the social status of the family as it improves the economic security of the family. PWMI, their caregivers, the family and community have expressed this aspect.

Poverty and Mental Illness

Poor PWMI are not only vulnerable due to their condition, but also the vulnerability brought about by poverty, which is a consequence and to some extent cause of their condition. One of the main reasons that people find it hard to accept PWMI as equal, is that they do not see them as capable of contributing to the household or the community. For decades, researchers have shown that poverty and mental illness

are correlated; the lower a person's socioeconomic status, the greater are his or her chances of having some sort of mental disorder. Poverty exacerbates mental illness.

Figure 3.15 PWMI Based on Occupation



The **PWMI identified in the CMH&D Program based on occupation** shows the varied nature of occupation of PWMI (**Figure 3.15**). They were involved in agriculture, animal husbandry, daily wage earning, household work, and others.

Majority of PWMI identified were daily wage earners, with 697 being women and 673 being men (1370 persons). The daily wage earners also partake in agricultural activates.

Note

Total number of people involved in varied occupation as indicated in the table is 3987. For additional information, see tables listed in *Appendix 2, List of Statistical Tables Corresponding to Figures Presented in the Report.*

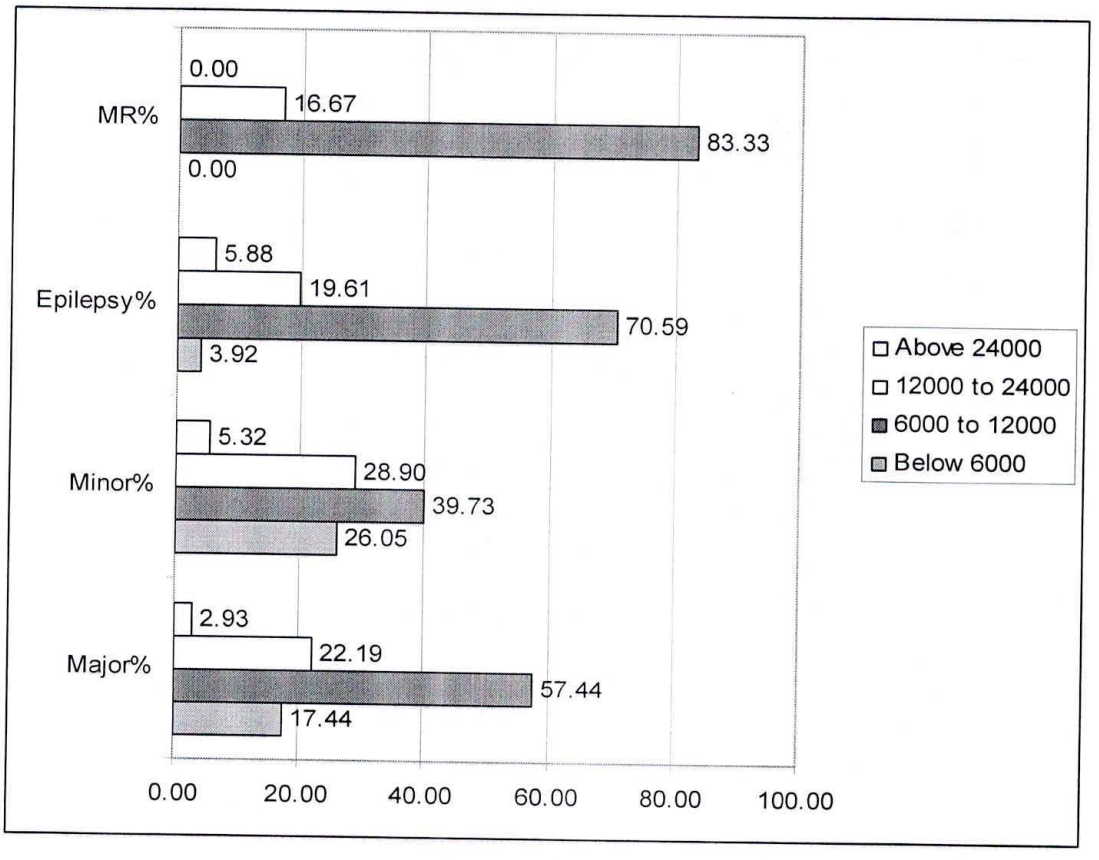
Daily wage earners work in agricultural fields, construction work, carpentry, weaving and NREGA.

The study shows that a total of 1117 persons (587 women and 530 men) are not involved in any productive work. It was observed that the PWMI who were in the symptomatic state, had poor family support, little or no enthusiasm of the community to integrate the individual, stigma and hence were unemployed.

Note

In Andhra Pradesh, the NREGA program has provided opportunities for people with disabilities including PWMI to seek 100 days of employment. Tamil Nadu, Kerala and Karnataka do not recognize the importance and need for integrating disabled persons and mentally ill within the NREGA program.

Figure 3.16 Identified PWMI Based on Types of Illnesses and Annual Income



The income level has a direct impact on the quality of life of an individual. There is an urgent need to improve the situation of PWMI in low-income families and communities.

Income of 6000 to 12000 Rupees

57.44% of people suffering from severe mental illness fall under the annual income bracket of 6000 to 12000 rupees. 39.73% of persons having common mental illness fall under this income bracket.

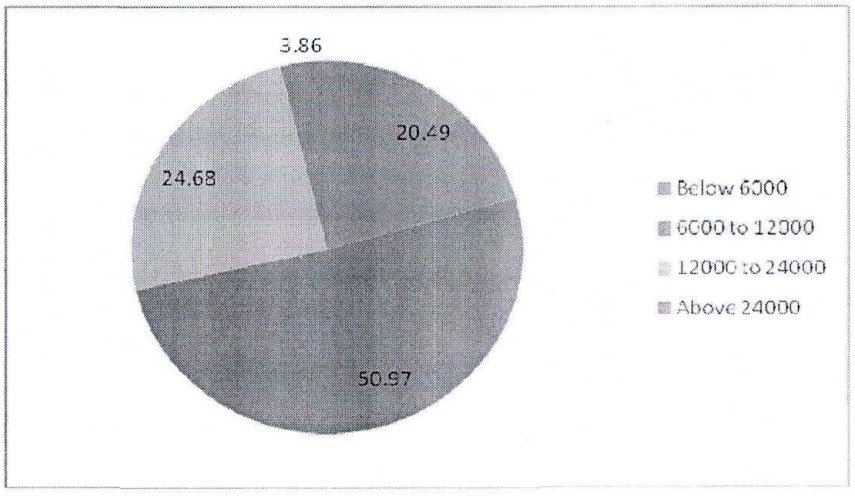
Looking at the data presented it is clear almost all the persons identified with mental illnesses in the CMH&D Program were in poverty. The World Bank figures show that five out of 10 Indians live on less than Rs.11.25 per head per day, which is considered the poverty line. This is approximately Rs.20, 000/-

per annum. Taking this as a base, it could be said the CMH&D program's focus was very much on persons living in poverty.

Annual Income below 6000 Rupees

17. 44% of persons with severe mental illness, 26% of persons with common mental illness come under the annual income of below 6000 rupees (**Figure 3.17**).

Figure 3.17 PWMI Based on Levels of Income



Over 50.97 % of the PWMI in the sample study were in the income group of Rs.6000-12000 per annum, 24.68% of PWMI were in the income group of 12000 to 24000.

From the above findings, it is clear that the CBR approach of the CMH&D Program of BNI was "*inclusive*", meaning, brought within the program all those who were not reached by even government health programs-the focus was clearly on the economically poor and socially excluded groups. The very 'inclusion' promises that this model is a viable and meaningful one as a developmental approach to community mental health.

Summary of the findings on the socio-semographic profile of PWMI in the CMH&D program of BNI in South India brings out that the program was developmental with:

- Inclusion of men and women in equal numbers; both married and unmarried men and women and belonging to all age groups young, middle-aged and old majority in 21-40 age groups.
- Inclusion of vulnerable sections of the communities, the population not reached generally by the government health program-meaning:
  - Majority belonging to OBC, SC and ST.
  - Large number of women than men.
  - Majority non-literates.
  - Majority in poverty with an annual income of less than Rs.12, 000/-per annum.
  - Majority on daily wage labor or unemployed.

Chapter 4

DIAGNOSIS, TREATMENT AND ACCESS TO TREATMENT

This chapter examines the diagnosis, impact of treatment and access to health care services for PWMI.

BNI has looked at the social model for mental health interventions. PWMI often have to brave considerable stigma that is attached with mental disorders. Furthermore, lack of information about mental illness and available help for and treatment make it difficult for PWMI to avail the services.

Mental health care has always been influenced and determined by contemporary beliefs and India is no different. Traditionally, PWMI were often cared in temples and religious institutions, based on the principles that mental illness is a form of spiritual affliction and could thus be cured by religion. Superstition with inadequate mental health services in the community make PWMI subject to various harmful treatments. They are subjected to black-magicians, village quacks - witches and physical abuse in the name of treatment. They are kept outside the margin of the community meaning chained, locked in the rooms, wandering in the streets, staying forever in closed wards of asylums, hospitals, etc.

Stigma and Discrimination

A large section of PWMI are still inside their houses without any treatment, because their family members do not recognize the illness or they find it embarrassing to own a family member who is mentally ill, commonly called 'mad'. There is a fear that they would be victims of disgrace and indignity and thereby they lose the status or acceptance they enjoy in the community. The stigma is so tremendous, that people feel ashamed and deny the illness. Therefore, the first and foremost element that shrouds the realm of mental illness is stigma attached to it. The very thought of someone in the family getting mental illness is a big shock and they do not want to believe it.

Due to stigma attached to the families, PWMI become the victims of discrimination and human rights abuse. The discrimination is seen from the family members and goes right up to the policy makers and state authorities. The attitude of the public is that, who care what we do for PWMI. PWMI are treated as second-class citizens with no adequate facilities given by either the state or the central government. As a result, they face chronic ill health, and are an economic and social burden to the community leading to social destitution. Soon families lose hope and are left to the mercy of others.

CMH&D Program in South India offers insights into some of these aspects, highlighting the changes that were visible at the grassroots level through the training programs for PWMI and their caregivers and the community. Strengthening of partner organizations have made a sea changing impact in the way mental illness is seen in the areas where the program is implemented.

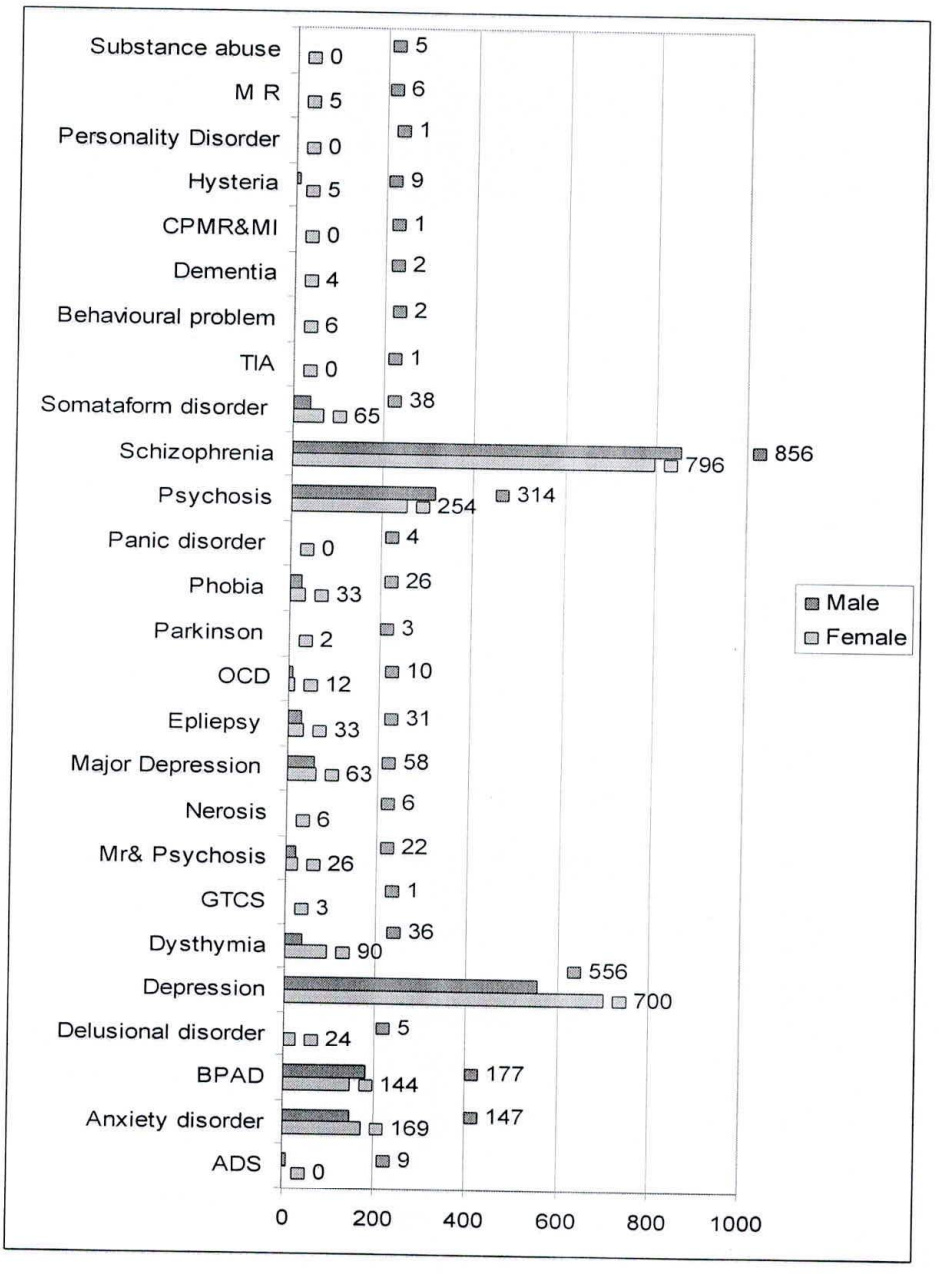
MENTAL HEALTH FACILITIES IN THE COUNTRY/PROGRAM AREA

🕮 Most of the district hospitals are not fully equipped and supplied with psychiatric medicines to treat PWMI; most often they are referred to multi specialty centers in the capitals/big towns. The medical professionals view mental health as an alien subject and do not give importance to either learn or practice in their day-to-day practice. There are 42 mental hospitals in the country with the bed availability of 20,893 in the government sector and another 5096 in the private sector hospital settings to take care of an estimated 1,02,70,165 people with severe mental illness and 5,12,51,625 people with common mental disorders needing immediate attention. The psychiatric medicines are supplied only in few primary health centers, community centers and the district hospitals. Medicines such as Amitriptyline, Lithium, Chlorpromazine (CPZ), Phenobarbital, Phenytoin sodium, Haloperidol, Carbamazepine, Imipramine and Resperidone are made available in few district hospitals. The rates of Resperidone (better drug than CPZ in terms of side effects) are cheaper than CPZ. Drugs like CPZ are purchased in surplus, which has lesser utility (For example, in Karnataka). Adequate laboratories facilities are lacking in the district hospitals to find out the serum level for lithium administration. In the primary health centers, except in some districts, where District Mental Health Program is operational, the government distributes none of these drugs regularly.

Diagnosis and Categorization of Mental Illnesses

In the CMH&D Program in South India, PWMI were examined by qualified psychiatrists and the diagnosis regarding the kind of mental illness of individual cases was made and recorded in individual files. There were compiled and categorized and presented in **Figure 4.1.**

Figure 4.1 Distribution of PWMI Based on Sex and Diagnosis of Illness



Severe Mental Illness *

- PWMI based on diagnosis, show that under severe mental illness, the prevalence of schizophrenia was high, where 856 men and 796 women were diagnosed with schizophrenia.

- Psychosis was the second most prevalent illness in 254 women and 314 men.
- Bipolar affective disorder was the third most prevalent illness seen in 144 women and 177 men.
- In general, the diagnosis showed that a large number of both men and women had schizophrenia, psychosis and bipolar affective disorder. Slightly higher number of men than women had severe mental illnesses. This could be because men are given medical attention earlier than women.

Common Mental Illness*

- Under common mental illness, 700 women and 556 men were diagnosed with depression.
- Anxiety was the second most prevalent illness

Majority of those who were diagnosed with common mental illnesses had depression and anxiety.

Note

A detailed description of symptoms of mental illnesses is presented in *Appendix 1 Symptoms of Mental Illness.*

** A detailed description of Symptoms of Mental Illnesses is presented in Appendix 1.*

Diagnosis of the types of mental illness, with reference to sex, showed higher number of men in the category of severe mental illness, as compared to women. The variation between men and women with schizophrenia was four percent and in psychosis and bi-polar affective disorder the variation is much wider, about 10 percent men were higher in number than women. In the category of minor or common mental disorders, women were higher in number than men, showing a 10% variation.

Regularity in Undergoing Treatment and Stabilization

Figures 4.2 and 4.3 depict the PWMI going through treatment process consistently and their stabilization (Becoming free from symptoms of illness).

Data on illnesses were further analyzed for regularity of PWMI in going through their treatment, with reference to the types of illnesses. **Figure 4.2 PWMI Based on Status of Treatment** presents the results of this analysis.

Figure 4.2 PWMI Based on Status of Treatment

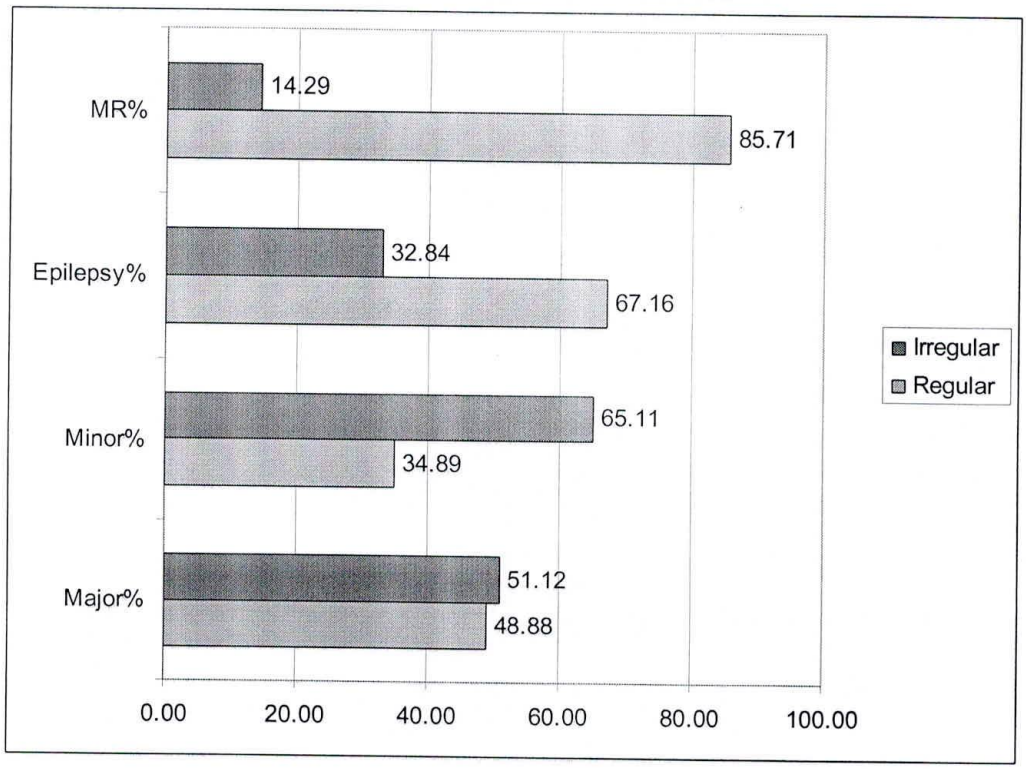


Figure 4.2 PWMI Based on Status of Treatment, shows that persons with common mental illness were often irregular with their treatment, (over 65.11%).

PWMI were far more regular in treatment. (48.88%) as compared to persons with common mental illness (34.89%).

Through the interviews, it was found that persons with common mental illness were often irregular because the symptoms thin out with treatment and the individual feels that she/he is cured of the illness; common mental illness sometimes can also be treated with alternative treatment such as counseling. The fear of stigma often inhibits the PWMI to continue treatment.

Stabilization or becoming free from symptoms of mental illness is most important, as it is an expectation that is crucial to CMH&D program. **Figure 4.3** shows the proportion of men and women stabilized.

Figure 4.3 PWMI Stabilized after Treatment Based on Sex

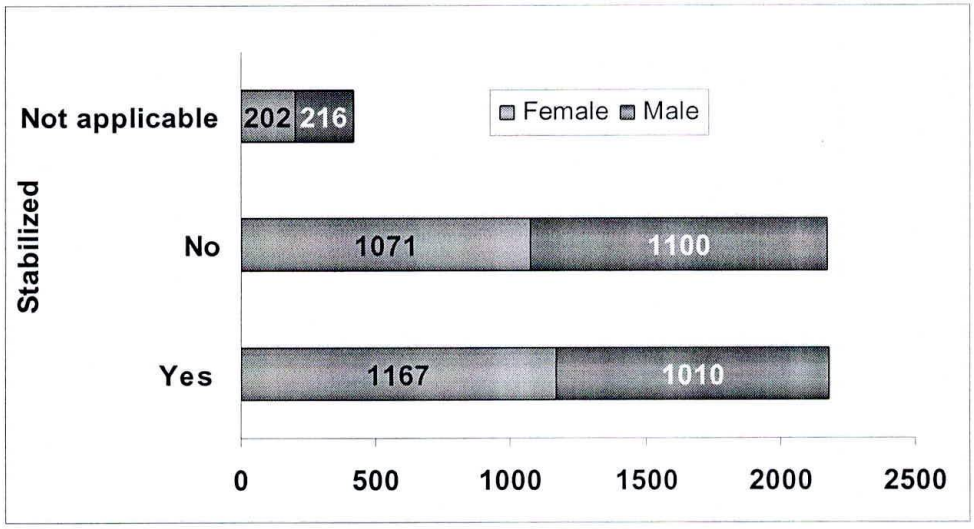


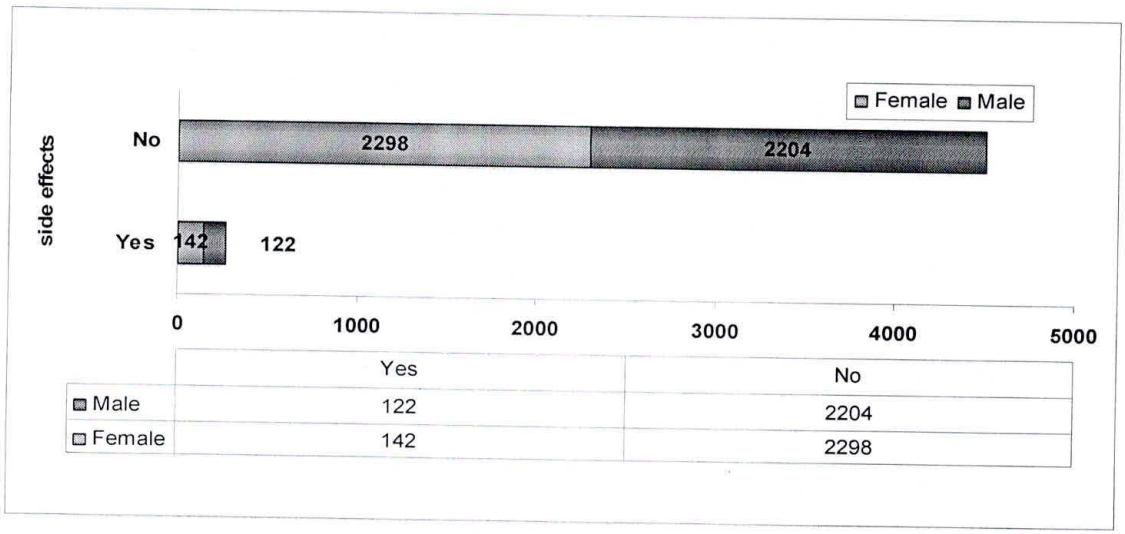
Figure 4.3 shows that of the total identified 4766 PWMI, 2177 were stabilized (45.68%). The reasons for PWMI who were not stabilized are mainly side effects and relapse of symptoms.

Nearly half of those with severe mental illness were regular, which seem to be a good percentage. The percent of PWMI stabilized was about 46% which is less than half. Considering the number still under treatment (*See* **Figure 4.8**) at the time of the study, the percent stabilized seems to be quite impressive.

Side Effects and Relapse

Data were further analyzed for those reporting side effects and relapse. The results of such analysis are presented in the Figures 4.4 through 4.7.

Figure 4.4 PWMI Reporting Side Effects Based on Sex

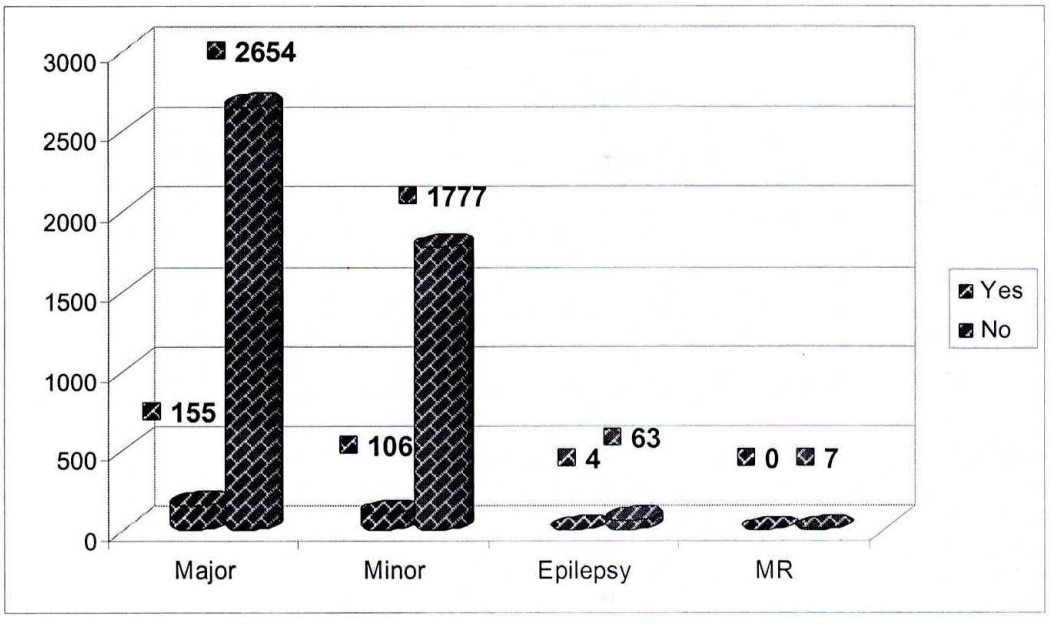


	Yes	No
Male	122	2204
Female	142	2298

Majority of persons reported no side effects to the medicines for both severe and common mental illness. Only 142 women and 122 men reported that they had side effects to the medicines that they were taking.

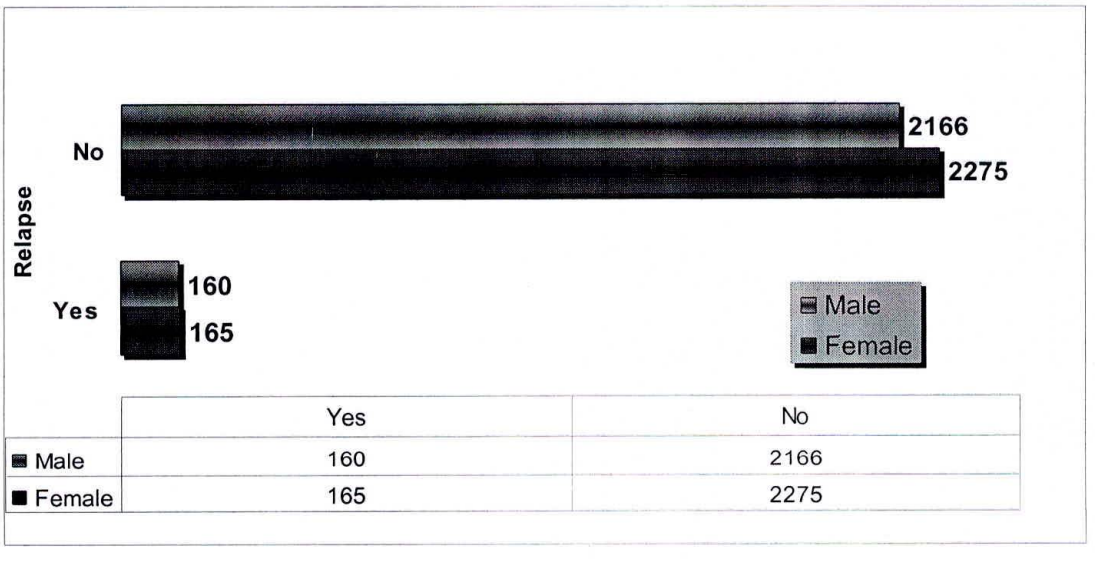
The community based rehabilitation and training to the family members did have a positive impact in identifying and addressing the problems of side effects in treatment and drugs. For example, the field staff and caregivers were trained to understand the kinds of side effects of psychiatric drugs. On the identification of these side effects, measures to tackle these were suggested: for example, consultations with the psychiatrist to understand the dosage or monitoring the frequency of taking the prescribed drugs were effective.

Figure 4.5 PWMI Reporting Side Effects Based on Types of Illness



Only 155 persons with severe mental illness reported side effects and 106 people with common mental illness reported side effects.

Figure 4.6 PWMI Reporting Relapse of Symptoms Based on Sex



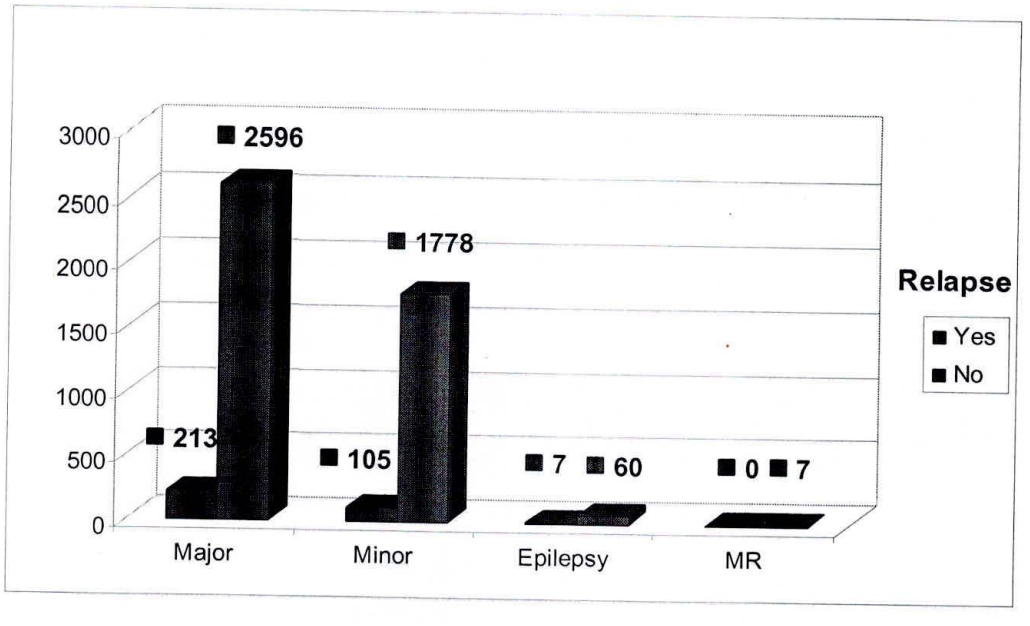
	Yes	No
Male	160	2166
Female	165	2275

Vast number of people reported that they had no relapse of symptoms (male: 2166 and Female: 2275). 160 men and 165 women confirmed that symptoms had relapsed.

The field staff and caregivers were trained to identify the indicators of relapse. The inclusion of PWMI who were stabilized was included in the self-help groups and this helped the community groups to monitor the treatment and interventions.

The **interventions in providing livelihood opportunities** and access to social entitlements supported the persons and their families in terms of treatment, travel and assisting in other basic needs.

Figure 4.7 PWMI Reporting Relapse of Symptoms Based on Types of Illnesses



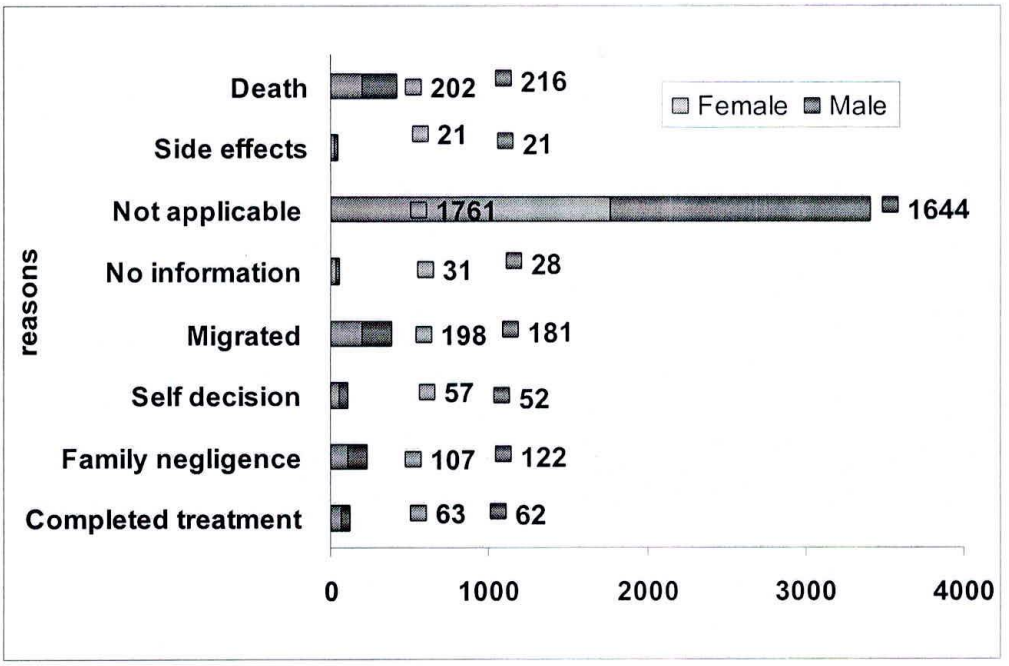
The persons who reported no relapse of symptoms on severe and common mental illness were 2596 (for severe mental illness) and 1778 (for common mental illnesses).

Figures 4.4 through 4.7 indicate that the number reporting side effects and relapse of symptoms was quite low showing the effective monitoring by the community in the CMH&D program. The variations between men and women with reference to the two variables showed slightly higher number of women than men. With the women forming 51%in the CMH&D program this variation is almost nil or negligible.

Dropout from Treatment

Figures 4.8 and 4.9 shows the PWMI dropping out of treatment in CMH&D program.

Figure 4.8 Dropout from Treatment Based on Sex



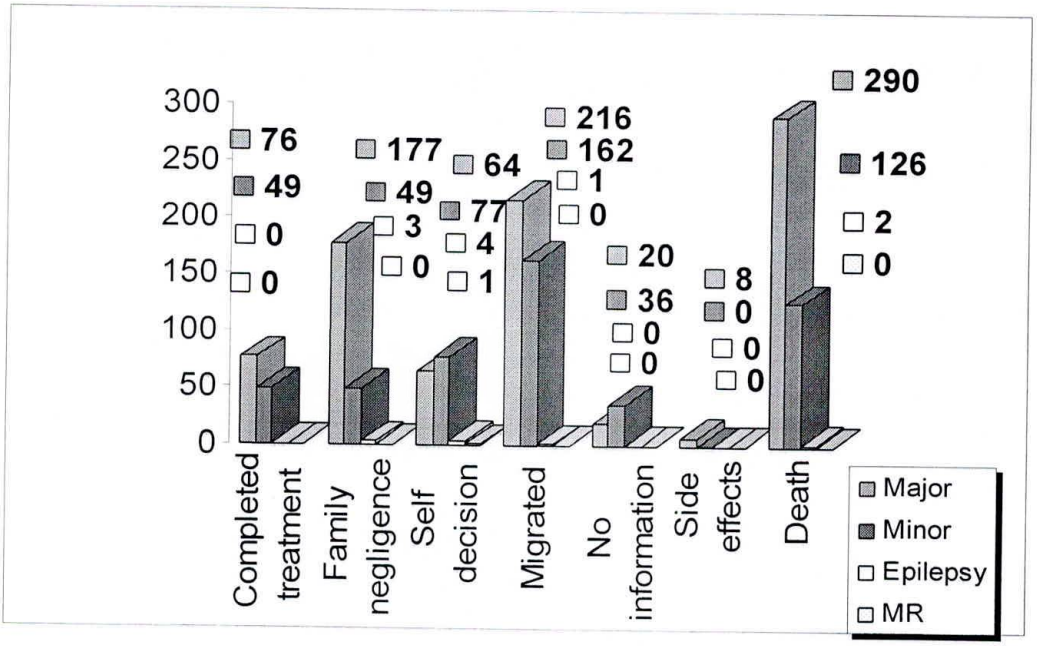
Note

The field that indicates **Not Applicable**, persons are on treatment. The numbers of persons in treatment were 1761 women and 1644 men out of a total of 3405 people interviewed in the sample study.

At the time of study, 3405 persons were part of the mental health program in their respective districts. The rest of the persons 1361 (28.6%) had dropped out for reasons ranging from, family negligence, migration and self-decision to discontinue treatment due to reasons of side effects and others.

The variation between men and women was quite meager. The reasons for dropping out were mainly death (nearly 9%) migration (about 8%), family negligence (5%) and self-decision (3%).

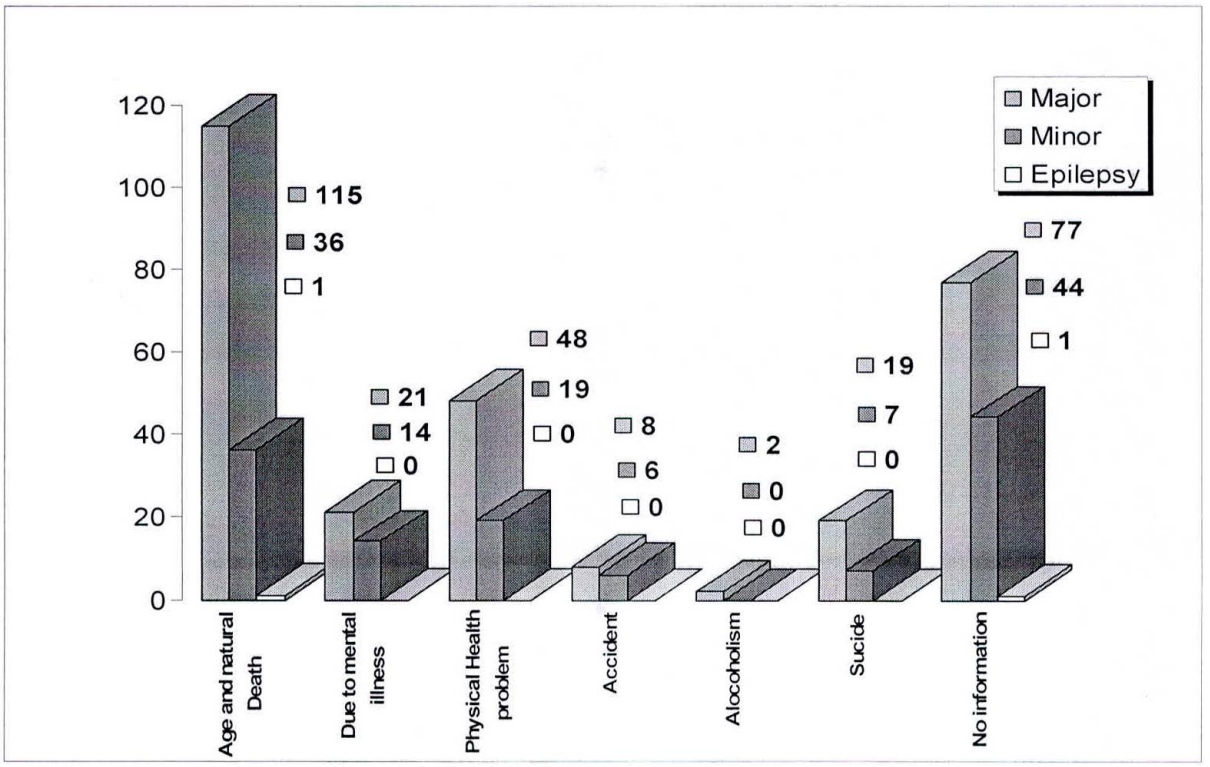
Figure 4.9 Reasons for PWMI Dropout from the CMH&D Program Based on Illness



Under severe mental illness, the significant reason for dropout was death (290). Other important reasons were the families and family negligence. Under common mental illness, death and migration of families were important factors for the dropout rate.

Further probe into the causes of death was made. **Figure 4.10** presents the findings in terms of the categories of illnesses.

Figure 4.10 Reasons for Death of PWMI According to Illness



Out of the reported 418 deaths, a large number of persons were with severe mental illness (**Figure 4.10**). Out of the total 418, 115 people died due to age and natural death, 48 due to physical health problems and there was no information on 77 deaths.

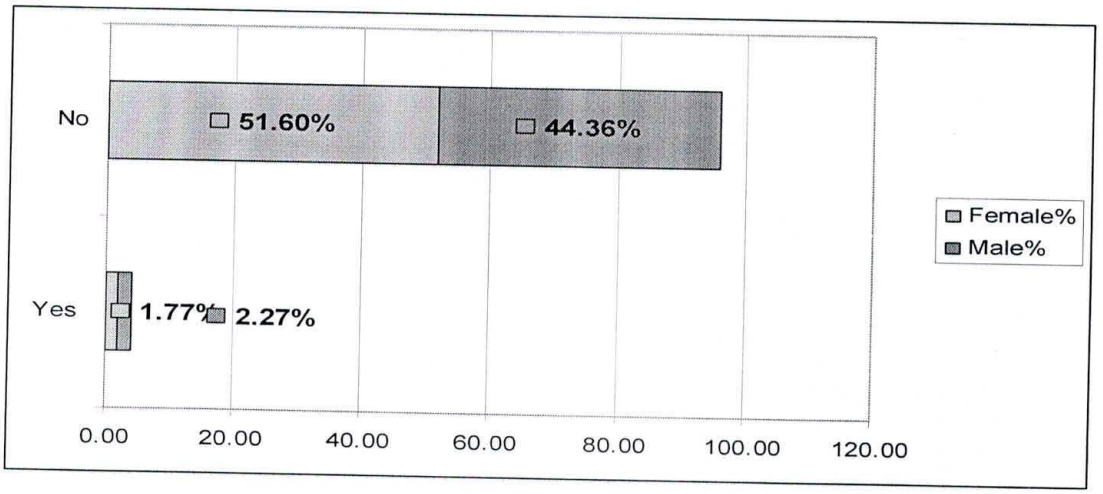
In the **severe mental illness category**, death due to mental illness was 21 and 19 committed Suicide.

In the **common mental illness category,** 36 people died due to age and natural death, 19 due to physical health problems and there was no information on 44 deaths.

Success Indicator

The discontinuance of traditional practice of consulting quacks for the solution to the Mental Illness was considered as an indicator of the success of CMH&D Program. Also, *see* Figure 4.11.

Figure 4.11 PWMI consulting Village Quacks



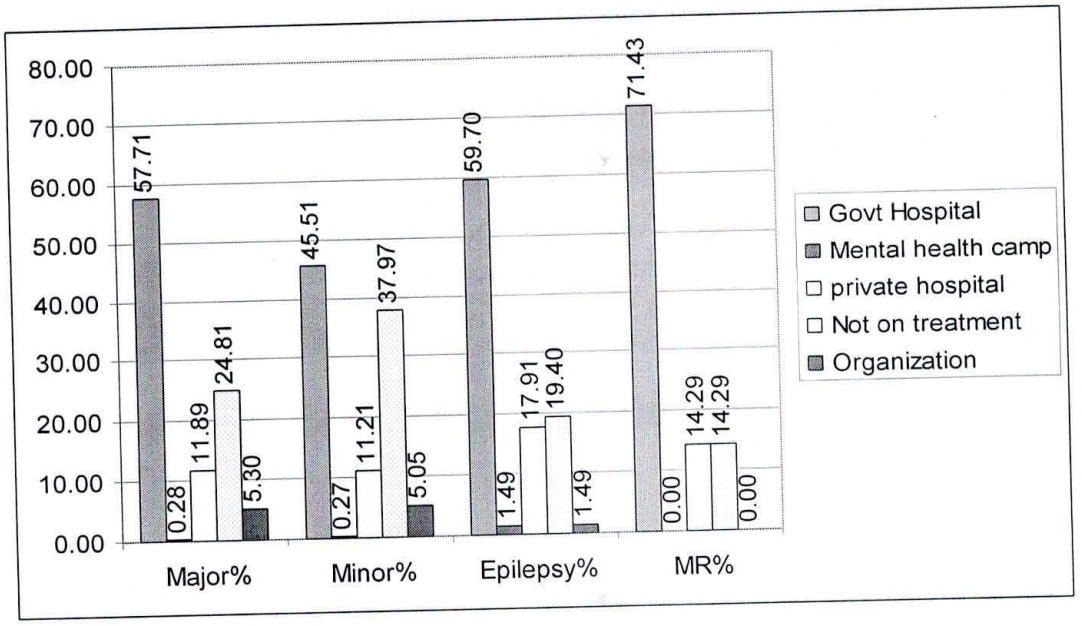
A high percentage of identified PWMI (both men and women) reported that they did not consult faith healers/village quacks. The results of training individuals, family members and community had gone a long way in addressing practices prevalent in the absence of medical services. In addition, there were noticeably immediate positive changes with medical intervention.

The CMH&D program, through its awareness program among the village communities seemed to have reached the people to seek the medical-psycho-social model of the program over the traditional faith healing approaches.

Success Indicator

Accessing treatment required by PWMI in government health care system is another important indicator of the success of the CMH&D Program. Figure 4.12 shows a positive relation to the access to treatment.

Figure 4.12 PWMI's Access of Treatment from Different Sources Based on Types of Illness



57. 71 % of persons with severe mental illness and 45.51 % persons with common mental illness had access to treatment in government hospitals (including epilepsy (59.70) and MR (71.43).

Note

The significance of **Figure 4.12** is that it shows that majority of the people are dependent on access to treatment from government health systems. It also indicates that in all the 20 districts, at least at the district level, treatment facilities are made available. This is the result of tireless engagement with the government by the primary stakeholders, community and the partner organizations.

Summary of Findings

The data presented in the figures show

- The diagnosis of mental illnesses of the identified PWMI in CMH&D Program showed that majority (2805) of both men and women were suffering with severe mental illnesses such as schizophrenia, psychosis and bipolar affective disorder.

This shows that the CMH&D program focused mainly on PWMI with major mental illnesses. Quite a good number (1883) were found with minor mental illnesses such as depression and anxiety. When analyzed, the findings according to sex showed a higher number of women in the category of common mental disorders. The variations between men and women in both the categories were in the range of four to ten percent. This implies that the program was gender sensitive. Taking care of common mental disorder as a measure of prevention of getting to the state of severe illnesses can be seen as a positive step.

- Persons with severe mental illnesses were more regular with treatment as compared to persons with common mental disorders. This was due to the symptoms thinning out with treatment quicker in common mental illnesses and also due to their seeking alternate treatment such as counseling.
- Regarding "stabilization" or becoming free from symptoms of mental illness, the data showed that 46% of those treated were stabilized. Considering the number still under treatment at the time of the study, stabilization of 46% is quite a good percentage.
- The number and percent of PWMI reporting Side effects was quite low (only 264) showing a positive impact of the program in identifying and addressing the problems of side effects.

Summary of Findings

- The "*relapse of symptoms*" of mental illness was reported in a small number of cases (only 325). This can be definitely attributed to the program inputs of the training of caregivers and community groups to identify symptoms of relapse and monitor the treatment and interventions such as livelihood opportunities and access to social entitlements supporting treatment, travel and basic needs.
- The data regarding the 'drop-out' of PWMI from the program showed 28.6% (1361 out of 4766). The reasons for dropping out were death (9%), migration (8%), family negligence (5%) and self-decision (3%).

Further probing into the reasons for death, it was found that ageing and natural death was the main reason in 152 cases (36%). The other reasons were reported to be physical health problem in 67cases (16%), mental health problems in only 35 cases (8%) and accidents and alcoholism in 16(4%). Reasons for about one third of deaths could not be identified.

Another important outcome is the reduced consultation with quacks and increased utilization of government health care systems. All these could become a reality because of the various inputs of the program, training of caregivers and community groups, livelihood opportunities and access to social entitlements, advocacy and moving the government system for providing the needed services.

Area of Focus for Future Programs

- Although one sees an important outcome in the reduced consultation with quacks and a systematic increase in the utilisation of government health care systems, one sees a slightly disturbing finding on the 'drop-out' of PWMI from the program.

  There is an urgent need to strengthen communities and add greater foucs in the commuinity rehabilitation and the related area of work. This must be considered seriously in future program.

Chapter 5

SOCIAL INCLUSION: COMMUNITY AND SOCIAL PARTICIPATION

This chapter delves into the support systems that are imperative for a PWMI, the caregivers and family. Stigma of the illness cripples the individual further, shunning the PWMI to a corner. There is a need for inclusive development for people with mental illness in the community, mainstream health, education, social and employment sectors. These safety nets go a long way in the well-being of the individual.

Community based rehabilitation programs lead to positive changes, often challenging negative attitudes in communities, leading to greater visibility and participation by people with mental illness. Community participation is a systematic way to remove barriers and enhance social development. It is about putting PWMI first. Through the study of mental health interventions in South India, important changes were seen when attempts were made to promote the need for inclusive development for people with disabilities in terms of education, access to employment and information.

A sharing of cultural spaces and belongingness go a long way in healing and rehabilitation. Community and social participation emphasizes the need to promote the empowerment of people with mental illness. This seeks:

- ✓ Participation in family decision-making
- ✓ Contribution to family income
- ✓ Involvement in productive work
- ✓ Involvement in community and social activities
- ✓ Inclusion in community groups
- ✓ Inclusion of care-givers in community groups

Note

The social inclusion of PWMI was studied keeping the total number of 2029 responses of PWMI. The percentages derived in the figures are based on the responses of 2029 PWMI.

Family Decision Making by PWMI

Figures 5.1 and **5.2** present the distribution of PWMI with reference to their participation in family decision-making according to the categories of mental illness and according to sex.

Figure 5.1 PWMI Involved in Decision Making According to Categories of Mental Illness

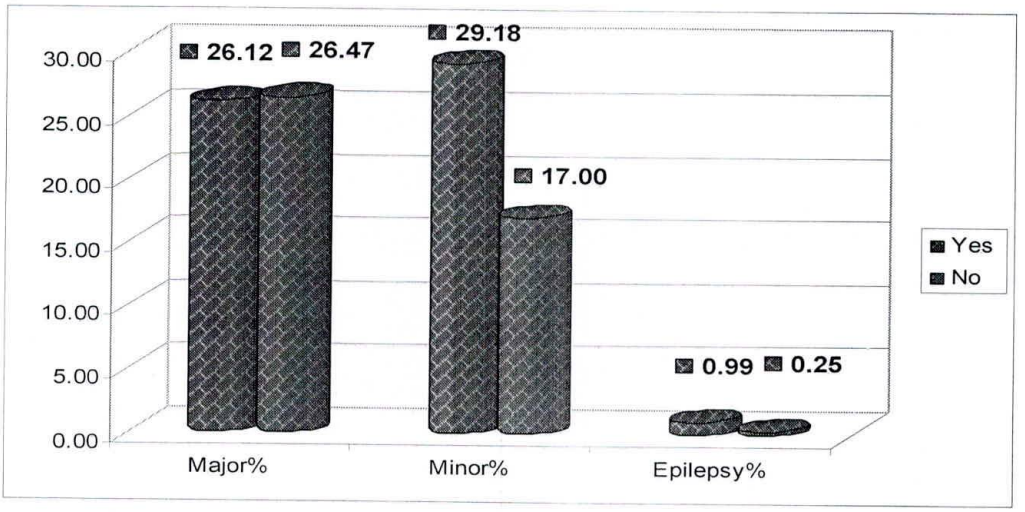
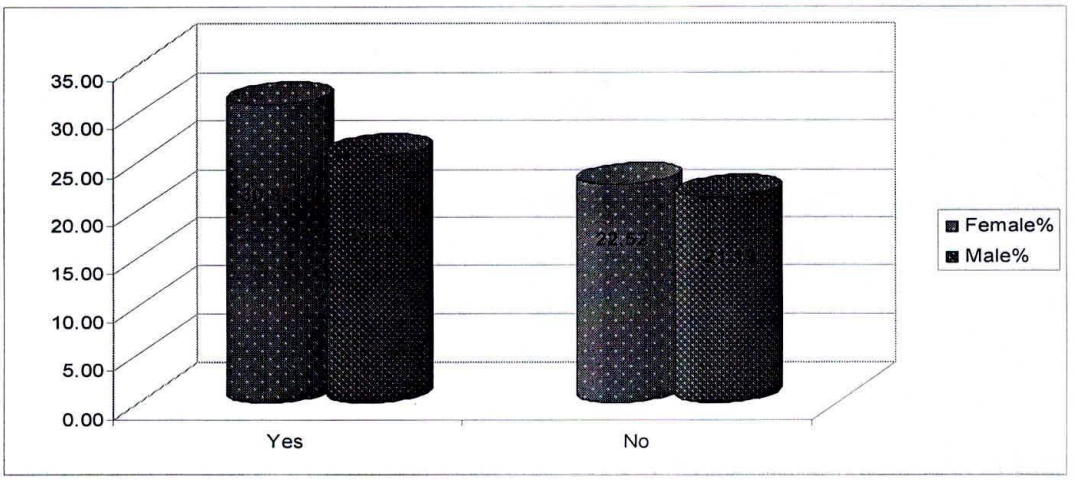


Figure 5.1 PWMI Involved in Decision Making shows that 56.28% of the PWMI were involved in decision making; whereas the other 43.72% were not involved in decision-making.

Persons with common mental illness were involved in decision making, in larger percentage than persons with severe mental illness.

Based on the individual and family interviews it was evident that, earlier, persons were not part of decision-making. After the recovery from the illness and with the ability of the individual to contribute to the status of the family, the families involved them in decisions like marriage, education of children, property related issues and others.

Figure 5.2 PWMI in CMH&D Program Involved in Decision Making Based on Sex

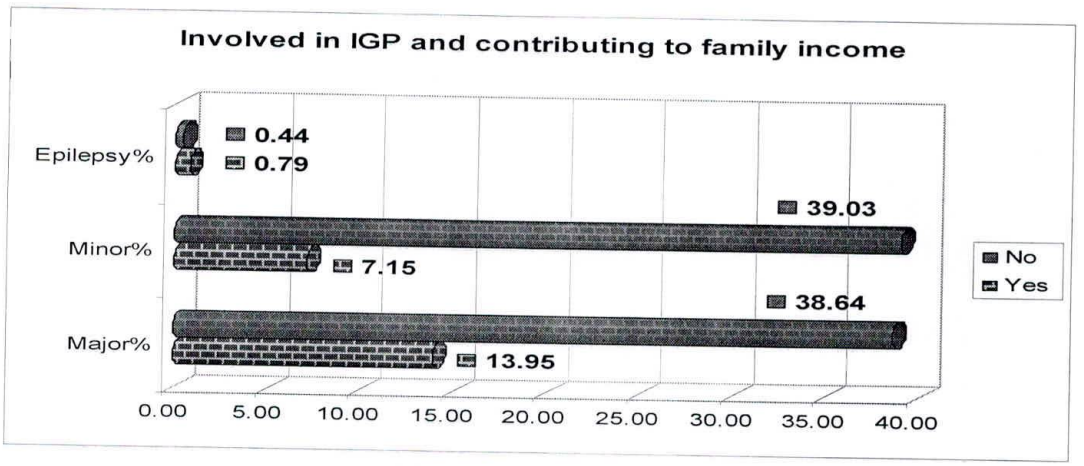


PWMI involved in decision-making were greater for women (30.85%) than for men (25.43). It is understandable taking the number with severe mental illness was more among men than women.

Contribution of PWMI to the Income of the Family

Figures 5.3 and **5.4** depict the distribution of PWMI reported to be contributing to the income of the family

Figure 5.3 PWMI Contributing to the Income of the Family



Only 13.95% of PWMI with severe mental illness and 7.15% of PWMI with minor mental illness reported that they contributed to family income.

Figure 5.4 PWMI Contributing to the Income of the Family Based on Sex

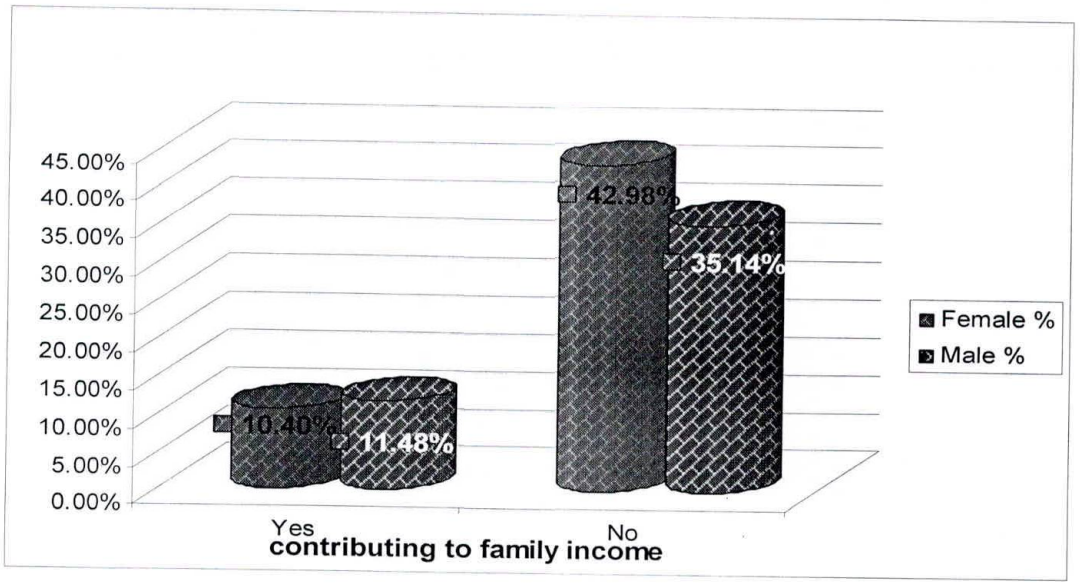


Figure 5.4 PWMI Contributing to the Income of the Family Based on Sex shows, out of the identified PWMI 21.88% are contributing to the financial status of the family. Out of the total 21.88% female contributes 10.40% and male 11.48%.

Therefore there is a need to strengthen individual skills to carry out occupation, family encouragement to involve PWMI, and community involvement to create opportunities for greater involvement of PWMI in such activities.

PWMI Involved in Productive Work

Figures 5.5 and **5.6** depict the involvement of PWMI based on categories of mental illness.

Figure 5.5 PWMI Involved in Productive Work Based on Illness

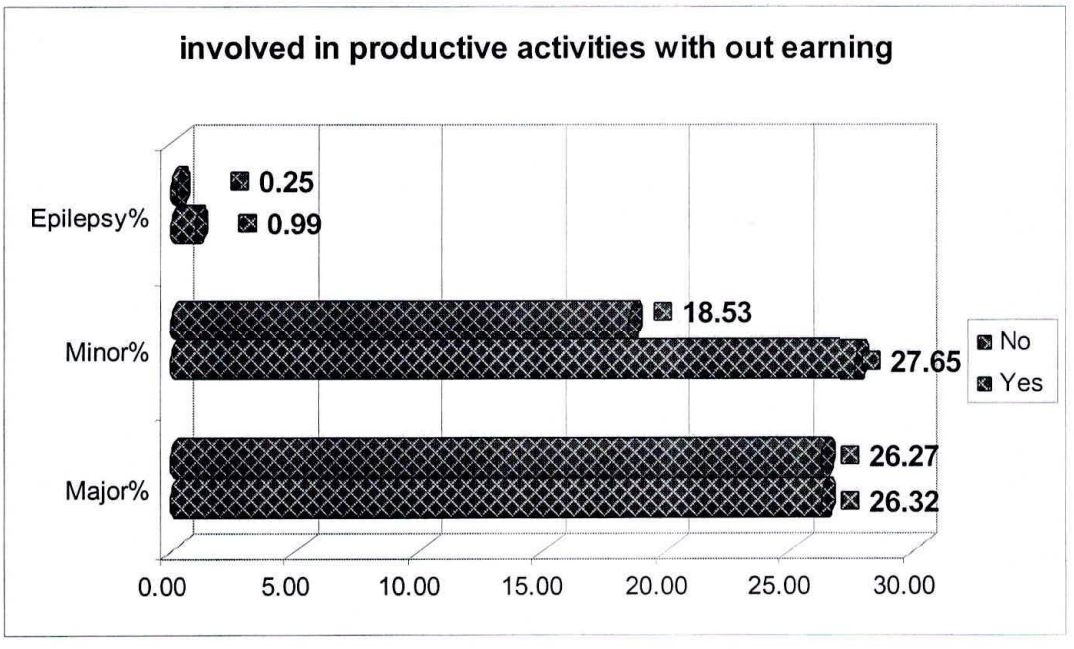


Figure 5.5 PWMI Involved in Productive Work Based on Illness shows that out of the total 54.95% of the PWMI were involved in productive activities without earning, in that 26.32% were people with severe mental illness, 27.65% are people with common mental illness and 0 .99% are people with epilepsy.

Figure 5.6 PWMI Involved in Productive Work Based on Sex

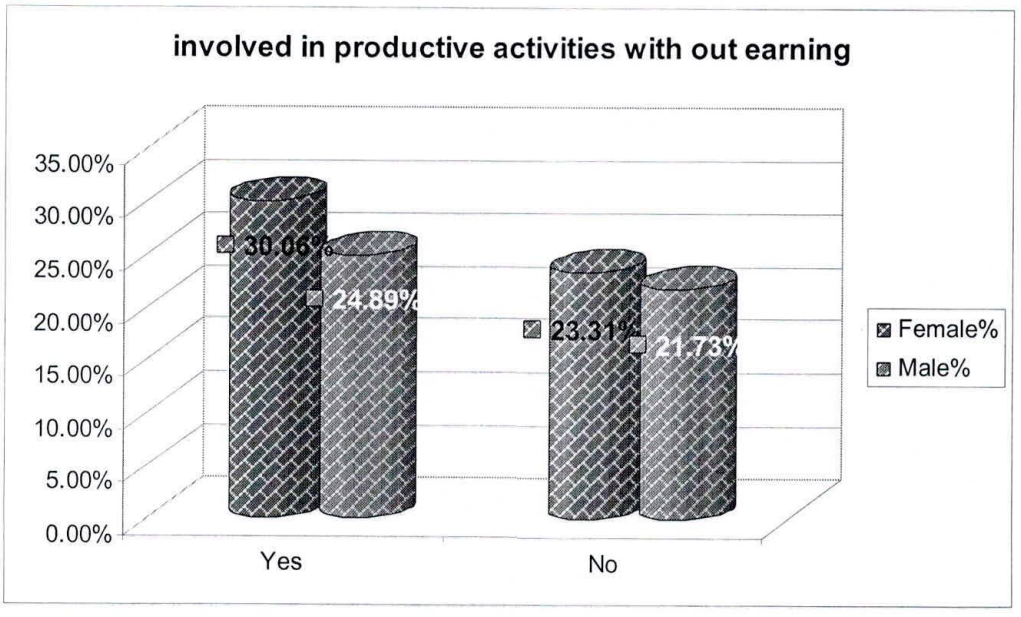


Figure 5.6 PWMI Involved in Productive Work Based on Sex shows that out of the identified 54.95% of PWMI who were productive, 30.06% were females and 24.89% were males.

Some of the common productive activities people involved were agricultural activities like sheep and goat raring, dairy farming, working in the agricultural land and taking care of household activities. It is evident that PWMI from rural background have more opportunities to involve themselves in productive activities because of rural culture and environment. During the study, many caregivers expressed that they were relieved from stress and were able to go out and earn their livelihood.

PWMI Involved in Community and Social Activity

Figures 5.7 and 5.8 bring out the extent of involvement of PWMI in terms of their percentage in community and social activity.

Figure 5.7 PWMI Involved in Community and Social Activity Based on Illness

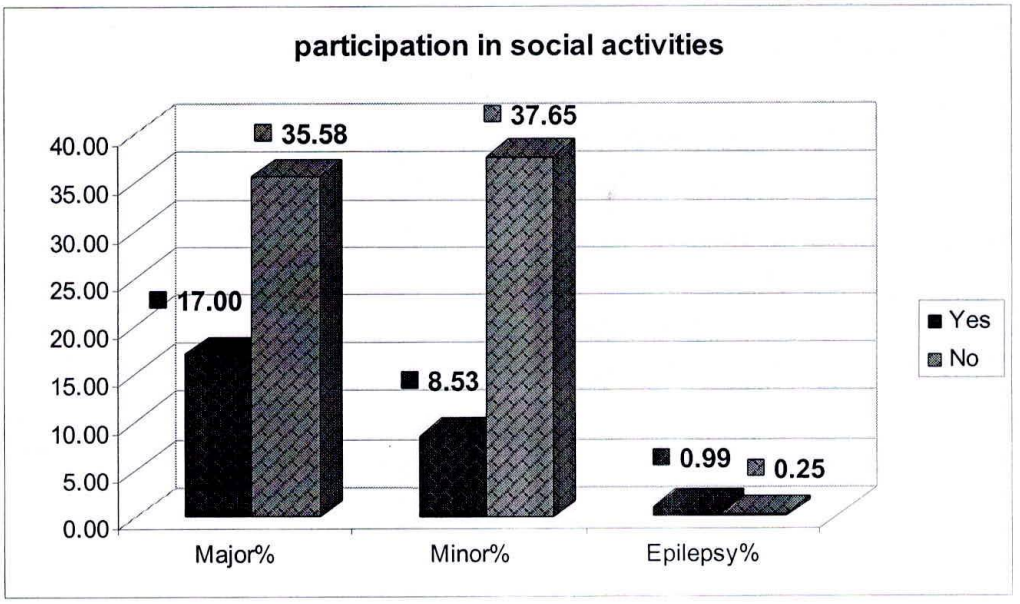


Figure 5.7 PWMI Involved in Community and Social Activity Based on Illness, shows that out of the total 26.52% of people with mental illness who participated in community and social activities, 17% were are people with severe mental illness, 8.53% were people with common mental illness and 0.99% were people with epilepsy.

Figure 5.8 PWMI Involved in Community and Social Activity Based on Sex

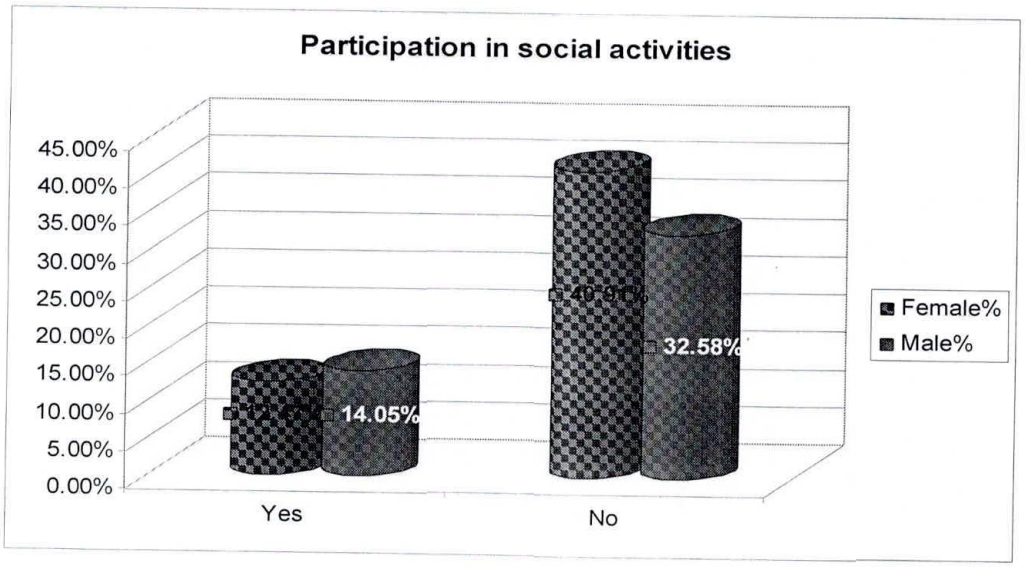


Figure 5.8 shows that out of the total identified 26.52% of PWMI, who were participating in community and social activities, 12.47% were female and 14.05% were male.

The study shows that the participaton of people with mental illness in community and social activities was comparably less because, of various factors like stigma, inadequate awareness, lack of family and community support.

Inclusion of PWMI in to Community Groups

Figures 5.9 and 5.10 bring out a *'Realistic'* picture of the numbers of PWMI who were members of the community groups such as self-help groups, womens groups and co-operative banks.

Figure 5.9 Inclusion of PWMI into Community Groups Based on Sex

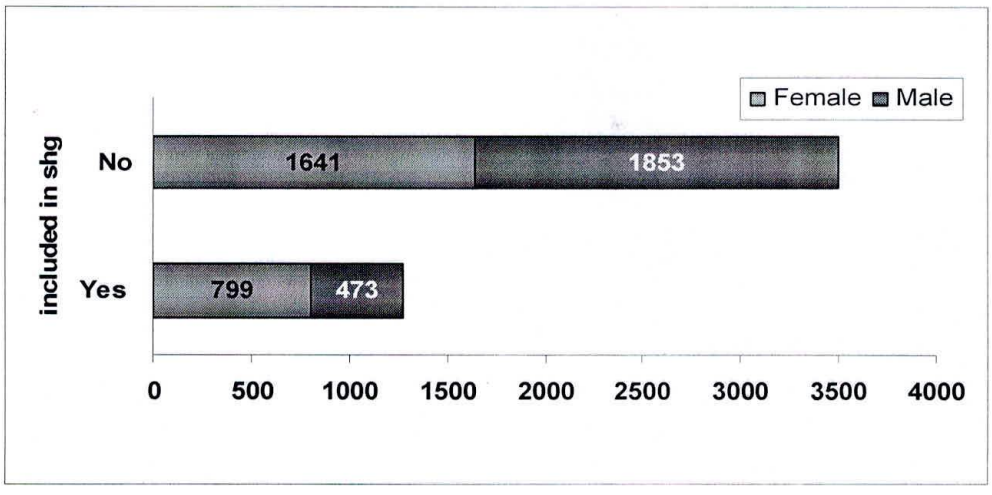
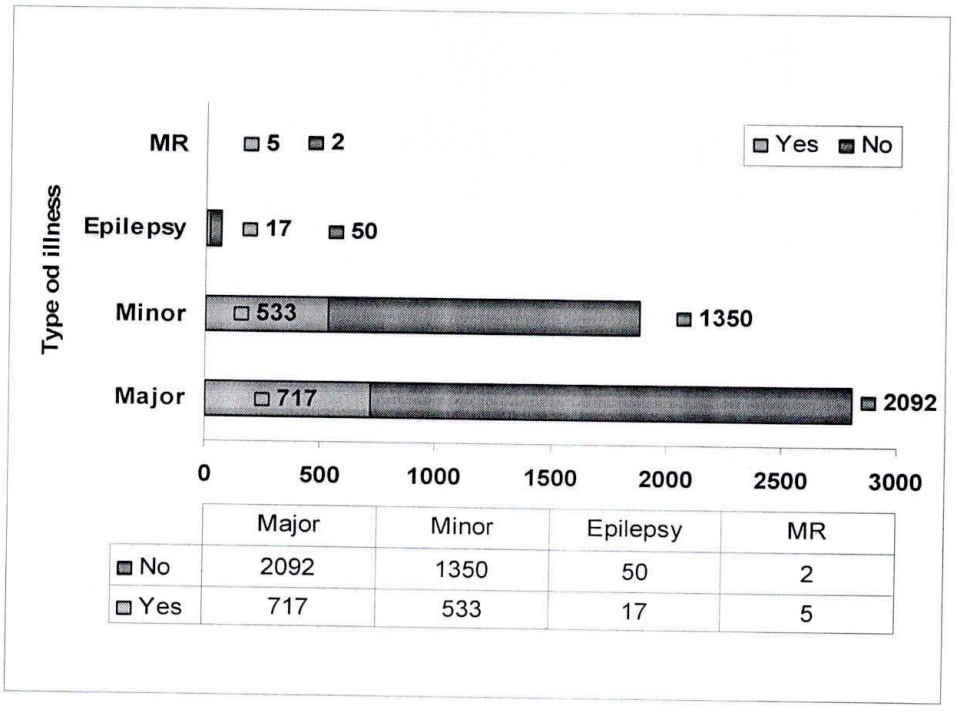


Figure 5.9 Inclusion of PWMI into Community Groups Based on Sex, shows that a total 1272 people were included in to community groups, out of whom 799 were female with mental illness and 473 were male with mental illness.

Figure 5.10 Inclusion of PWMI into Community Groups Based on Illness



	Major	Minor	Epilepsy	MR
No	2092	1350	50	2
Yes	717	533	17	5

Figure 5.10 Inclusion of PWMI into Community Groups Based on Illness, shows that out of the total of 4766, 1272 PWMI were included in to community groups in which 717 were people with severe mental illness, 533 were people with common mental illness, 17 were people with epilepsy and 5 were mentally retarded.

Stabilized people with mental illness were included in to community groups such as self help groups of people with disabilities, self-help groups of women and co-operative banks of women. people with severe mental illness were included more in to self help groups of disabled and this indicate the level of awareness and acceptance that mental illness is one of the disability. This social inclusion is supportive in getting loans for livelihoods and to advocate for the rights of PWMI.

Figure 5.11 Inclusion of Caregivers of PWMI into Community Groups Based on Sex

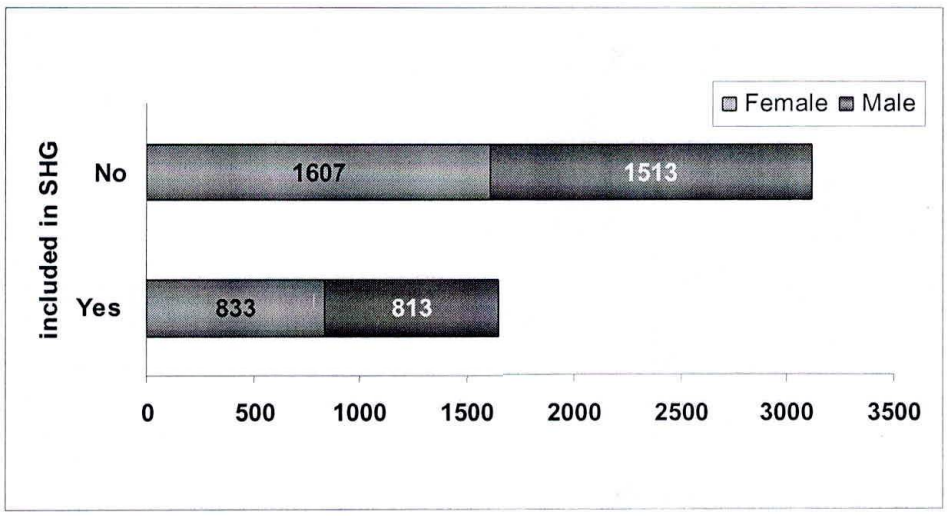


Figure 5.11 Inclusion of Caregivers of PWMI into Community Groups Based on Sex shows that 1646 caregivers of PWMI were included in to community groups, in which 833 were female and 813 were male.

The caregivers of PWMI were included in to community groups such as self help groups of PWD (few caregivers of severly/chronically mentally ill were represented) self help groups of women and co-operative banks of women. This indicate the level of awareness and acceptance of PWMI in the community and community mobilization. This social inclusion support getting loans for livelihoods in advocateing for the rights of PWMI. It is also enabling the community to understand the issues and needs of caregivers of PWMI.

Summary of the Findings

The data presented in **Chapter 5: Social Inclusion: Community and Social Participation**, shows:

- About 56% of PWMI with severe mental illness participated in family decision-making. More women participated (55%) in family decision-making than men (45%). It may be because that a greater number of women were in the category of minor mental illness and more men were in the category of major mental illness.
- About 22% contributed to family income out of which less than half (10%) were women and about 12% were men. Majority (78%) did not contribute to family income which point to the need for strengthening their skills in income generation. Lesser number of women PWMI were contributing to family income as compared to men, 14% with severe mental illness and 7% with common mental illness were contributing to family income.
- Involvement in productive work without earning by PWMI showed that about 55% were involved in productive work, out of which 30% were women and 25% men.
- A total of 26%of PWMI was involved in community and social activity. Out of this 17% were with severe mental illness and 9% with common mental disorders. Out of the total 27%, 13% were women and about 14% were men.
- A total of about 27% were in the SHGs. Out of this 15% were PWMI with severe mental illness and 11% were with common mental disorders. Out of the total about 17% were women and 10% were men.
- Inclusion of caregivers in SHGs was considered important as their life is intertwined with that of PWMI. A total of about 35% of caregivers were included in SHGs. Out of this 17% were the caregivers of PWMI with severe mental illness and about 15% were those care-givers taking care of persons suffering with common mental illness.

Looking at all of the above:

- ✓ One can see that over 50% of PWMI participated in family decision-making and also in Productive work without earning money. In these, there were more women than men.
- ✓ Only 22 to 26% of PWMI were involved in contributing to family income, in community and social activity. There were more men than women though the variation between them were only one to two percent.
- ✓ Higher percent of women were in SHGs than men. As women self-help groups were more common, this was quite possible for women.

Success Indicator

CMH&D program is making its way into the area of 'social inclusion' for PWMI. Starting within the family, over 50% PWMI involved in decision-making and productive work without earning, is the first step in social inclusion. Getting into wider community seemed to have come in to some extent. With efforts that are more intensive this should be possible.

Chapter 6

ACCESSING ENTITLEMENTS AND SOCIAL SECURITY SCHEMES

People with mental illness require a range of support and services to help them through their everyday needs. This section deals with entitlements and social security schemes that are supportive to PWMI and the extent of their getting them.

Persons with mental illness need support and services to help them through everyday challenges of life. Several factors come in the way of realizing their right to dignified living. The factors of age, sex, critical stages of life, employment, fast changing socio-economic situations, greater exposure to environmental risks, socio-economic status of the family, culture and availability of resources, that often varied remarkably across states and regions, often impact the condition of the person with mental health.

Entitlements and social security schemes of the government are important in exercising the rights of PWMI. The study listed the following schemes of the government that could be availed by PWMI:

- Poverty alleviation scheme
- Travel concession pass
- Below poverty line card (BPL)

- Disability pension
- Disability card

The BPL card and disability card are basic identity cards with which the rights of disability pension, travel concession and participation in various poverty alleviation schemes could be realized. The present study collected information from PWMI in CMH&D program, on their availing the schemes listed. The collected data were analyzed and presented in figures in the following pages.

Figure 6.1 Accessing Entitlements and Social Security Schemes by PWMI Based on Sex shows the number of PWMI availing each of the schemes according to sex.

Figure 6.1 Accessing Entitlements and Social Security Schemes by PWMI Based on Sex

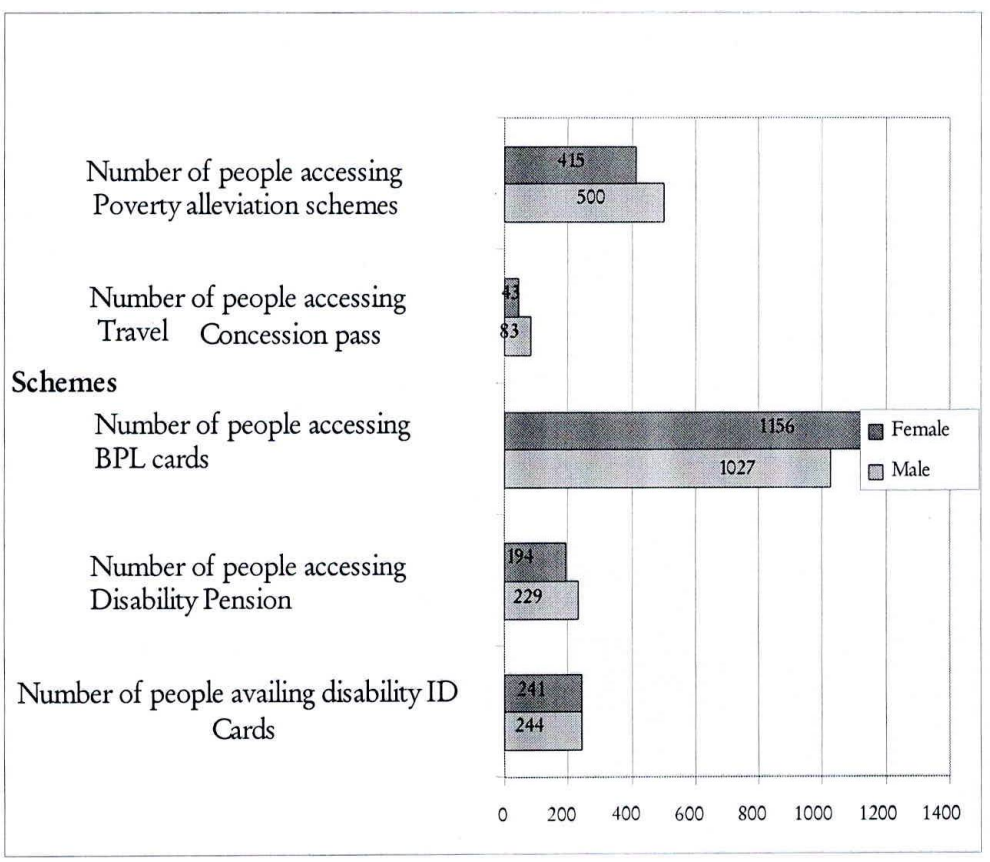


Figure 6.1 shows the male- female ratio of accessing social entitlements. The study shows number of persons who accessed BPL cards was 2183 (1156 female and 1027 male).

915 PWMI (415 female and 500 male) had accessed poverty alleviation schemes like housing, loans and beneficiaries of 3% allocation of resources under Panchayth Raj institutions.

485 persons with severe mental illness (241 female and 244 male) had accessed disability identity cards.

423 persons with severe mental illness were (194 female and 229 male) accessing disability pension. 126 PWMI had accessed concession travel pass in bus and train. The study shows male female representations in accessing social entitlements were almost equal.

Figure 6.2 depicts the percent of PWMI in CMH&D program that did/did not access disability cards.

Figure 6.2 Accessing of Disability Identity Cards by PWMI

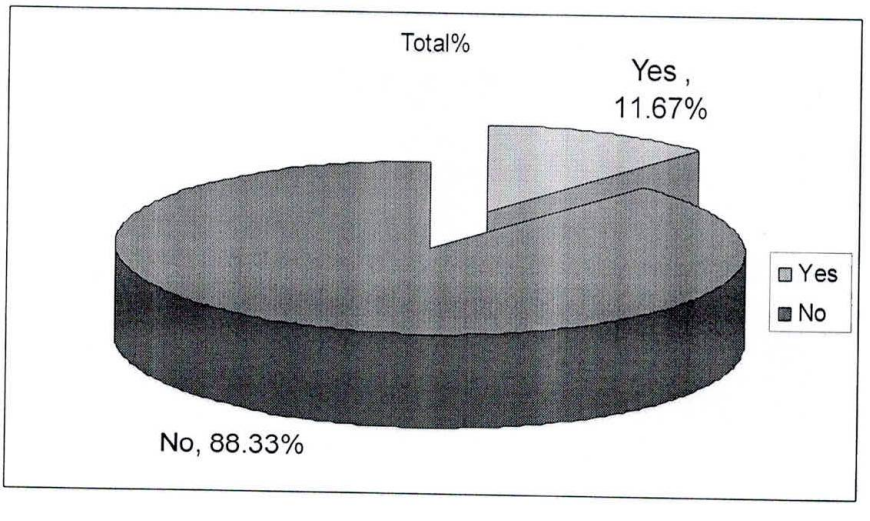
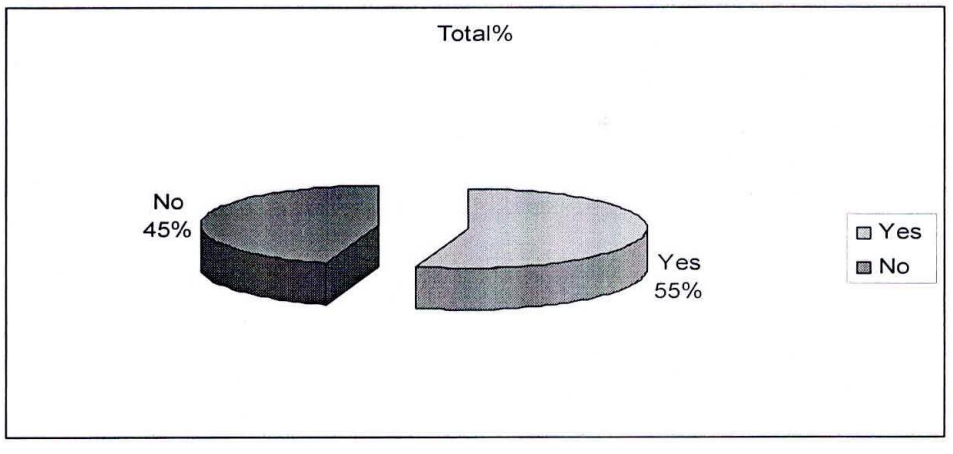


Figure 6.2 Accessing of Disability Identity Cards by PWMI shows 11.67% of the total identified PWMI had accessed disability identity cards.

The number of PWMI accessing disability identity cards were comparatively less reasons being only severe and chronic PWMI are eligible, secondly the PWMI are unable to produce the continuous treatment records for minimum period of two years and lack of implementation of uniform policy in relation to issue of disability identity cards in southern states.

Figure 6.3 and Figure 6.4 brings out the percent of PWMI in CMH&D program, who accessed/did not accessed BPL cards.

Figure 6.3 PWMI Accessing BPL Cards



Out of the total identified PWMI 55% of the families had accessed below poverty line cards (**Figure 6.3**). This study shows that majority of the families with whom BNI was working belonged to below poverty line.

Figure 6.4 Distribution of People Accessing BPL Cards According to Illness

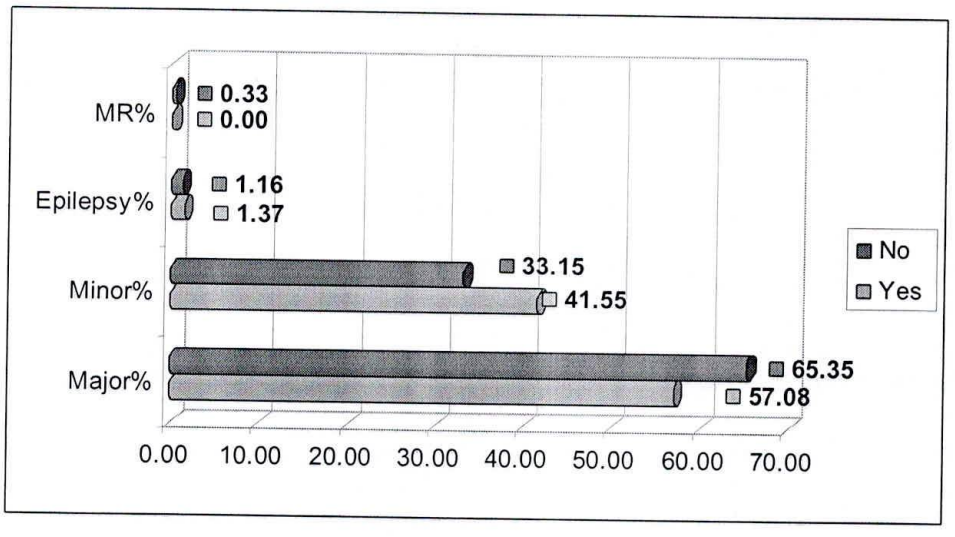


Figure 6.4 Distribution of People Accessing BPL Cards According to Illness, shows that out of the total persons accessing below poverty line cards majority (57.08%) were people with severe mental illness.

Figure 6.5 through Figure 6.7 show the percent of PWMI participating in NREGA according to sex and according to categories of mental illness.

Figure 6. 5 PWMI under NREGA

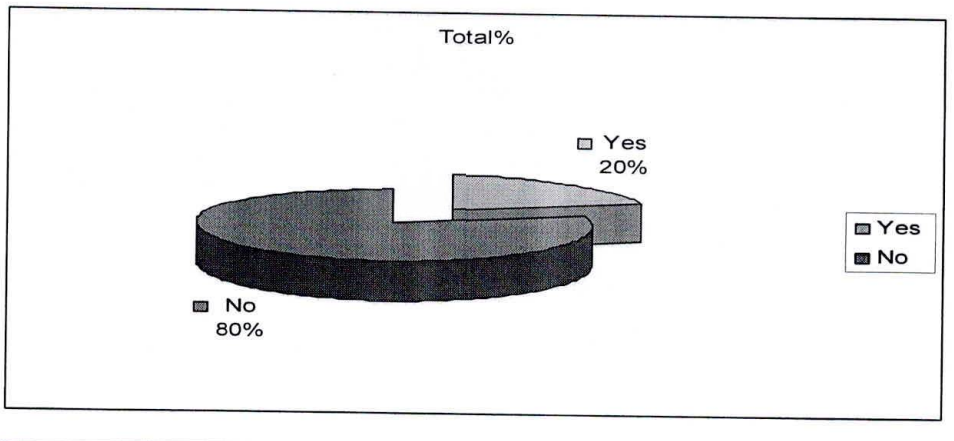


Figure 6.5 PWMI under NREGA, shows 20% of the total identified PWMI were involved and benefitting under NREGA.

Figure 6.6 PWMI under NREGA Based on Sex

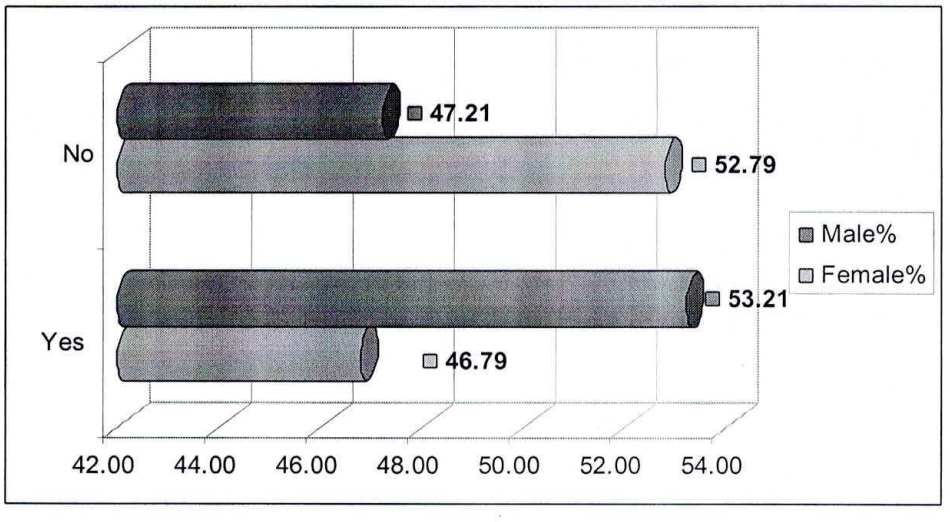


Figure 6.6 PWMI under NREGA Based on Sex shows that male female percentage of PWMI involved in NREGA program. Out of the total people involved, 53.21% were male and 46.79% were female. The study shows active involvement and representation of male-female beneficiaries under the program.

Figure 6.7 Distribution of PWMI under NREGA According to Illness

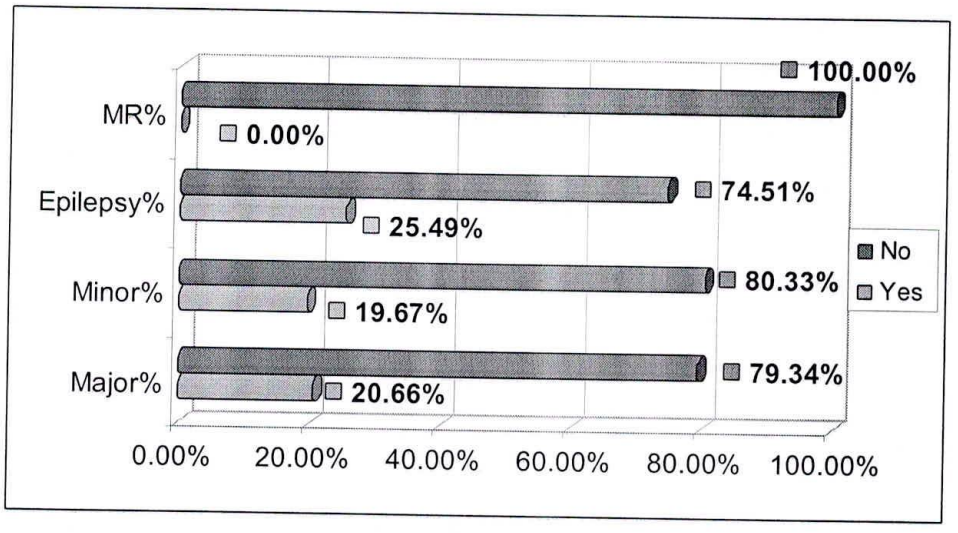


Figure 6.7 Distribution of PWMI under NREGA according to Illness shows out of the total identified, PWMI (20.66%), persons with common mental illness (19.67%) and persons with epilepsy (25.49%) were benefiting from NREGA program. The study shows equal representation of persons with severe and common mental illness under NREGA program. Participation in poverty alleviation schemes was only 19% accessing disability cards and pension. Probably acceptance of mental illness as a disability by the government took quite long and hence the percentage availing was small. Travel concessions may be the most recent entitlement, as it had been availed by only a few.

Note

NREGA is a national scheme guaranteeing 100 days of work for everyone below the poverty line. NREGA was recently renamed as Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGA).

Summary of the Findings

From the data presented in *Chapter 6, Accessing Entitlements and Social Security Schemes*, it is found that BPL card and disability cards are basic identity cards with which the rights of disability pension, travel concession and participation in various poverty alleviation schemes could be realized. The data as shown in graphs presented in this chapter indicate:

- The most accessed by PWMI was the BPL card even here, out of the total of 4766 PWMI, only 2183 (about 40%) accessed BPL cards; this included 24% women and 22% men.
- Disability cards were accessed by a very small number 485 out of 4766, (10%). The variation between men and women was meager, 244 men (5%), 241 women (5%).
- Disability pension was obtained by a total of 423(about 9%) out of which men were 229(about 5%) and women were 194(4%).
- Poverty alleviation schemes were availed by a total of 915(19%). Number of men availing the scheme were 500(about10.5%) and women were 415(8.5%).
- Travel concession passes given to disabled were availed by very few people: a total of 126 PWMI (2.6%) more men (1.7%) than women (0.9%).

Area of Focus for Future Programs: Accessing entitlements and social security schemes

It appears that a majority of the PWMI in the CMH&D program have not accessed Entitlements and Social security schemes. A beginning had been made with nearly half the persons accessing BPL cards.

Area of Focus for Future Programs: Ensuring NREGA is utilized optimally

Accesses to information, entitlements, bureaucratic challenges in accessing entitlements and utilization of government schemes are crucial in realizing the rights of persons with mental health problems.

Only 20% of PWMI in the CMH&D program had availed this scheme. More men (53%) availed the scheme than women (about 47%). Around 20% each of PWMI with major and minor mental illnesses availed the scheme. Availing the rights of PWMI in terms of the government schemes seemed a challenging task. CMH&D program needs to focus intensely on advocacy programs by the stakeholders groups and federation.

Chapter 7

MOVING FORWARD: MAJOR FINDINGS AND RECOMMENDATIONS

This chapter summarizes the report's findings about what is known about mental health and makes final recommendations to assist stakeholders in overcoming the barriers that are experienced by PWMI.

CMH&D in South India implemented by BNI had an in-built component of maintaining a data base of all the PWMI identified. This was the responsibility of the partner organizations who implemented the program. BNI introduced the tools for the purpose and guided them. The information from the data-base was summarized periodically in the form of quarterly reports.

Maintaining a database of the magnitude of 7458 PWMI, with all the information about the PWMI – tracking them over the years and all the inputs of the program and their responses to these inputs was not an easy task in an essentially oral culture, in which writing is not a part of life and living. In spite of this genuine difficulty, the database was maintained to a large extent. Evaluation of CMH&D South India Program by Sir Dorabji Tata Trust raised certain questions of importance regarding PWMI in the program over the years. The present study made further efforts to update the information about PWMI

as there were gaps to be filled, for which BNI requested the partner organizations to re-visit the PWMI , their families and village communities and gather the information required and organize them for analysis and consolidation.

The consolidation of the data was in terms of:

- Socio-demographic profile of PWMI
- Diagnosis, treatment and access to treatment
- Social Inclusion: community and social participation
- Accessing entitlements and social security schemes

Highlights of the study findings

I General

The program implementation is a collective effort of BNI, partner organizations (primary and secondary), the field personnel, the PWMI; the families of PWMI, the village community, the village level community organizations. Tracking of PWMI over the years is dependent on every one of these players. This is just to bring home the complexity of the process of keeping track of every individual PWMI.

II Socio-demographic profile of PWMI

1. Data on PWMI is quite huge with a total of 4766 with 2304 men and 2462 women; 2805 with severe mental illness and 1883 with minor mental disorders; besides 58 cases of epilepsy and 20 cases of mental retardation. The findings of database of such magnitude are valuable.
2. The program approach is developmental in that it focused on mentally ill persons who were economically poor, living in poverty and most vulnerable sections of society, mostly belonging to backward communities, scheduled castes and scheduled tribes and non-literates.

3. The program is gender-sensitive in that it included almost equal number of men and women. In almost all the aspects studied, men and women were found, with some variations. The variations were not very wide.
4. Looking in depth at the profile of the PWMI especially with reference to the program areas, brought out variations among districts within a state and among different states.

III Diagnosis, Treatment and Access to Treatment

1. The program focused on PWMI with severe mental illnesses much more than persons with minor mental disorders.
2. The inclusion of a fairly large number of persons with minor mental disorders could well be taken as a positive move by the villagers paying attention to minor mental illnesses early and could also be a measure of prevention of occurrence of severe mental illnesses.
3. Tracking revealed that course of treatment was fairly regular in the case of PWMI with severe mental illnesses and not so regular in the case of those with minor mental illnesses for reasons that they felt cured or they sought alternative treatment such as counseling
4. The results showed that the program had done remarkably well in monitoring 'side effects' of medicines given to PWMI and 'relapse of symptoms' in PWMI with about 6% reporting 'Side effects' and 7% with 'relapse of symptoms'. These results could be attributed to training or capacity building of care-givers, partner organizations and community groups in identifying symptoms of side-effects and relapse and also taking action.
5. **Stabilized** (free from symptoms) PWMI constituted 46%, fairly a good percentage, considering the number of PWMI still under treatment at the time of the study.
6. **Drop-out** of PWMI from the program could be considered a bit high, 28.6% - a third of this number died, another third migrated leaving about 5 % of PWMI dropping out due to family negligence and 3% deciding on their own. When deaths were probed further, ageing and natural deaths and physical health problems were major causes in more than half of the total deaths. Only about one eighth of deaths were due to mental health problems, alcoholism and accidents. The causes of about a third of PWMI deaths could not be identified

7. The other signs of progress were studied in terms of proportion of families of PWMI coming out of the traditional belief system of faith healing and proportion accessing government health system for further treatment. The results revealed a clear trend of consultation with faith healers (only 4% reporting such consultation) and a large number (60 %) accessing government health programs treatment facilities for mental illness for the district level hospitals were made available mainly due to the 'advocacy' efforts of the CMH&D program through tireless engagement with the government by the primary stake holders and partner organizations.

IV Social Inclusion: Community and Social Participation

1. It was not only "stabilization" of mentally ill persons that was aimed at by the CMH&D program. It was also working towards *'nurturing stabilization'* through confidence building process of social inclusion. This was studied in terms of:
    a. Participation of PWMI in family decision-making which showed involvement of 55% women and 45% men.
    b. PWMI's contribution to family income 10% women and 12% men.
    c. Involvement in productive work without earning 30% women and 25% men.
    d. Involvement in social and community activities 17% women and 10% men. Membership in SHGs 17% women and 10% men; care-givers membership in SHGs (35%).

In every one of the above, the participation proportion of PWMI with severe mental illness and with common mental disorders also showed the percentage in proportion to their respective numbers in the program, meaning more of PWMI with severe mental illness as compared to PWMI with common mental disorders.

V Accessing Entitlements and Social Security Schemes

Giving support to the economically poor and socially vulnerable PWMI through their **'Rights'** of accessing entitlements and social security schemes were facilitated by the CMH&D program. This was visualized as facilitation obtaining basic identity cards, namely, BPL card and disability card,

which are necessary requirement for exercising the rights of the disabled persons, travel concessions and poverty alleviation schemes.

The study findings showed a total of 40% (24%women and 22%men) had accessed BPL card and only 10% (5% women and 5% men) had accessed disability card; About 9% (5%women and 4% men) had received disability pension; about 19% (8.5%women and 10.5% men) availed poverty alleviation schemes; only 2.6% availed travel concession passes (0.9% women and 1.7% men; about 20% of PWMI had participated in NREGA – slightly less than 10% women and more than 10 % men.

Recommendations

The above findings of the CMH&D of South India program clearly brings out that this model is **Functional** and hence **Valuable** in reaching the rural and urban socio-economic groups of PWMI with considerable success. This is a pointer to take this **Tested functional model** to areas other than those already covered.

In the process of implementation and from the findings of the study consolidating the data it was found that certain program areas are strong and certain other areas need further strengthening. Based on these strengths and needs the following recommendations are made:

1. Working intensely with partner organizations has been a valuable experience. In this specific experience so far, it was mainly working with Community Based Organizations (CBO) with CBR focus for cross-disability. It is recommended that organizations in the fields of disability, health and development interested in including mental health component in their existing programs could become partners of BNI. A set of criteria for partnership could be developed.

   A preliminary meeting of the project holder and staff of the CBO expressing their willingness could be organized by BNI and facilitate them to meet PWMI, record and understand problems and issues, share their perceptions, discuss and explore the possibility of inclusion of a mental health program as

part of their development work. This could be followed by a due process of assessing the profile of the organization and joint program planning for the CMH&D program and nurture the partnerships with inputs needed based on a Memorandum of Understanding (MOU).

2. The CMH&D program study findings show that the approach is developmental and that the program is also gender-sensitive. These are basic strengths of the program and it should be ensured that these strengths are kept alive in future programs as well.

3. As it was found that there were variations in the profiles of the PWMI among the districts within a state and among states, it is recommended that planning for programs with partner organizations be area-specific.

   In this context, it is also recommended that the concept of District Level Initiatives (DLI) approach be introduced as the current partnership pattern of one partner in one district has limitations. With the DLI approach, it is visualized that selecting four or five partners in one district will help strengthen district level approach as well as coverage.

4. It was found that program included both persons with severe mental illnesses (such as schizophrenia, psychosis and bi-polar affective disorder) and also persons with minor mental disorders (such as anxiety and depression). Creation of a program environment that brings in all those who need the services within their own familiar area of living is crucial for the success of the program. This is again a basic tenet of the program that was in focus and this needs attention in all the future programs as well.

5. Regularity in undergoing treatment on the part of the PWMI with severe mental illness leading to stabilization, monitoring side-effects of medicines, relapse of symptoms, following-up with necessary action to keep these adverse effects minimal were considered the effects of a strong capacity building input in CMH&D program especially for care-givers, field personnel and the community groups. It is recommended that a resource team in training stake holders and partner organizations should form the core of BNI as training at different levels visualized and implemented in the current program have contributed to the success of the program.

It is also recommended that training materials be developed on the basis of the rich program experiences, in the form of Handbooks or Manuals for use with Senior Development Practitioners, field staff or grass root level workers.

6. The findings point to a need for keeping a watch on PWMI dropping out of the program. Though reasons such as ageing and natural death and migration are not within the reach of the program activities, careful identification of the reasons for dropping out and also deaths is a program area that requires strengthening. It is recommended that necessary steps be taken to include this kind of information in the tools used for collection of basic data; and also strengthen the skills of the staff of partner organizations in continued monitoring of PWMI for at least specified period of time and also strengthen the documentation skills of the personnel within the project or making it mandatory to have a person with skill in documentation on the staff of partner organizations. It is also recommended that for enabling development of the required skill in documentation the following tools incorporating the best practices are developed and used in training programs of the field-staff:

    - Check-lists for side-effects and management
    - Check-list for relapse and management
    - Check-list for drop-out and management
    - Check-list for the causes of drop-out and deaths
    - Check-list for 'individual rehabilitation plan'

7. Documentation of important information requires special attention especially in an oral culture, where written word has little or no relevance. The module on capacity building/training though included documentation as a unit, which helped in collection of information to some extent, strengthening this considering the limitations of availability of skills required, should become an area of focus in planning and implementation of CMH&D. It is recommended that special means to record the spoken word of the participants be searched and experiences of other development programs could be gathered to arrive at an understanding of recording of oral communication in the program area.

8. The findings that the communities seeking the faith healers were minimal and seeking government health facilities at the district level were becoming the norm point to the 'advocacy' efforts of the

CMH&D program through tireless engagement with the Government officials by the primary stake holders and partner organizations. It is recommended that the 'advocacy' component be further strengthened through building in strategies for advocacy with up-dated relevant information such as relevant legislations (Acts), UNCRPD and allocation of Government resources and orienting the partner organizations and primary stakeholders. It is also recommended to orient and network with departments like NRHM, DMHP, disability, revenue and judiciary.

9. It is recommended to explore the possibilities of negotiating with universities for including mental health components in school and college curriculum and also of introducing PG Diploma on CBR approach to mental health in the universities. This is an urgent requirement for enabling programs to have the personnel at the field level and at the organizational level.

10. The findings on participation of PWMI in family decision-making, in productive work with or without earning an income and in community groups such as self-help groups, disabled groups showed that a good beginning has been made in taking the PWMI through a difficult but essential process of social inclusion. The central focuses of these efforts were on involving them in social and 'livelihood' activities. It is recommended that this component of 'livelihood' activities especially through developing occupational skills and becoming active members of SHGs be strengthened through analysis of already existing information from the program experience, gaining insights and putting these insights into the program planning.

11. Findings on providing support to PWMI through facilitating them to exercise their 'rights' of accessing entitlements and social security schemes show clearly that it is a challenging task. It implies, on the one hand advocacy with government departments of health, education, social and employment sectors to reach every one without discrimination and on the other hand to empower people with mental illness to exercise their rights it is recommended that program plans to pay attention to these two important issues.

12. In this context, it is recommended that concerted efforts be made in building and strengthening primary stake holders, namely, PWMI, care-givers and cross-disability federations especially in terms of providing follow-up care, accessing social entitlements, advocate for their rights and linking them

to relevant mass movements such as mass disability groups, health movements, dalit and women's movements and concerned district and state level government departments and officials.

13. It is recommended that BNI to take measures to inform funding agencies about CMH&D program experiences and underline the urgent need to include 'mental health' as one of the priority areas of funding.

Appendix 1

SYMPTOMS OF MENTAL ILLNESS

This Appendix lists the common forms of mental illness ranging from severe mental illness, common mental illness and other forms of mental illness are reflected in this study. The symptoms of mental illness and its prevalence is seen through the findings in this report are referred and defined here.

Mental health is the psychological state of an individual who is functioning at a satisfactory level of emotional and behavioral adjustment. The Med lexicon's medical dictionary defines mental health as an "emotional, behavioral and social maturity or normality, the absence of mental or behavioral disorder; a state of psychological well-being in which one has achieved a satisfactory integration of one's instinctual drives acceptable to both oneself and one's social milieu, an appropriate balance of love, work and leisure pursuits."

MENTAL ILLNESS DISORDER

Mental illness disorders are widespread in the population with an estimated 1 % of the population having severe Mental illnesses and 5-15% having common Mental illnesses.

Categories of Mental Illnesses

There are seven broad categories of mental illnesses:

- Common mental disorders (depression and anxiety)

- Panic disorder, phobia, obsessive compulsive disorder, post traumatic stress
- 'Bad habits' such as alcohol dependence or drug misuse
- Severe mental disorders (psychoses)
- Mental retardation
- Mental health problems in the elderly
- Mental health problems in children

Severe Mental Illness

In the severe type of mental disorders, patients talk and behave very noticeably abnormally. The functions of the body and mind are severely disturbed, affecting the person's entire functioning and activities.

This group of mental disorders consists of three main types of illnesses: acute (brief) psychoses, schizophrenia, manic-depressive disorder (also called bipolar disorder). These illnesses are rare. However, marked behavioral problems and strange and unusual thinking characterize them. These are the disorders most typically associated with mental illness. The majority of patients in psychiatric hospitals suffer from these psychoses.

Some common features of severe mental illness are:

- Major mental disorders begin in young adulthood.
- They tend to be chronic and seriously disabling.
- Around one per cent of our population is affected by severe mental illness.
- They have high risk of becoming homeless.
- They are a heavy emotional and financial burden for the caregivers.
- They remain largely untreated.
- The illness affects their social and working life.

Schizophrenia

The key features of schizophrenia are:

A person with schizophrenia will experience some of the following symptoms:

PHYSICAL

- Strange complaints, such as the sensation that an animal or unusual objects are inside his/her body.

FEELING

- Depression
- A loss of interest and motivation in daily activities
- Feeling scared of being harmed

THINKING

- Difficulty in thinking clearly
- Strange thoughts, such as believing that others are trying to harm him/her or that his/her mind is being controlled by external forces (such thoughts are also called 'delusions')

BEHAVING

- Withdrawal from usual activities
- Restlessness, pacing about
- Aggressive behavior
- Bizarre behavior such as hoarding rubbish
- Poor self-care and hygiene
- Answering questions with irrelevant answers

IMAGINING

- Hearing voices that talk about him, particularly nasty voices (hallucinations)
- Seeing things that others cannot (hallucinations)

Mania

A person with Mania will experience some of the following symptoms:

FEELING

- Feeling on top of the world
- Feeling happy without any reason

- Irritability

THINKING

- Believing that she has special powers or is a special person
- Believing that others are trying to harm her
- Denying that there is any illness at all

BEHAVING

- Rapid speech
- Being socially irresponsible, such as being sexually inappropriate
- Being unable to relax or sit still
- Sleeping less
- Trying to do many things but not managing to complete anything
- Refusing treatment

IMAGINING

- Hearing voices that others cannot (often, these voices tell him/her that he/she is an important person who can do great things).

Acute or Brief Psychoses

The symptoms are similar to those of schizophrenia and mania. The key is that the symptoms begin suddenly and last less than a month. The typical symptoms seen are:

- Severe behavioral disturbance such as restlessness and aggression
- Hearing voices or seeing things others cannot
- Bizarre beliefs
- Talking nonsense
- Fearful emotional state or rapidly changing emotions (from tears to laughter)

Common Mental Disorders

Common mental illnesses (also called neuroses) cannot be easily defined. Unlike in severe mental illness or psychoses, in common mental illness, the persons do not lose touch with reality and they are able to meet the ordinary demands of everyday living. For all purposes, they appear normal and carry on with their work and

life. They generally have a good understanding of their problems. While they may not always cause much distress to others in the family and they do cause a lot of distress to themselves. Though disturbed to varying degrees, the person usually is not disabled completely and is able to carry on with his/her work and social life.

The basic features of common mental illness are excessive mental tension and worry. All of us get tense or worried from time to time, especially when faced with difficult problems. However, we are able to cope with the situations and overcome these tensions or worry with passage of time. If the tension or worry is too intense or prolonged, they tend to interfere with our sense of well being and disturb our normal functioning.

Many persons with common mental illness have feelings of inadequacy and inferiority – they lack self-confidence. (Many a time, the feeling of 'inferiority' may be turned opposite into egotistic behavior). This leads them to perceive common, every day problems as difficult and threatening. This constantly produces tension and worry and these individuals prefer to avoid facing these problems, ultimately resulting in physical or psychological complaints.

Many persons with common mental illness may have problems such as a difficult relationship, a family conflict and an unhappy marriage, difficulty at work place, persistent financial problems, serious and chronic physical illness in the family or a death of a close relative or friend.

Everyone experiences mental tension or unhappiness when faced difficult problems in life. However, in the case of persons with common mental illness, these tensions, worries and unhappiness become part of their life style, leading to constant feelings of insecurity and a need for support from others.

The exact symptoms of common mental illness can vary markedly from one person to another. Patients show either excessive or exaggerated emotional reaction to a stress or unhappy situation. They have symptoms like anxiety, fear, sadness, vague aches and pains and other bodily symptoms. They are aware of their problems and seek help (but more often, for the physical symptoms).

Depression

Depression means feeling low, sad, fed up or miserable. Almost everyone suffers similar emotion sometimes in life. To some extent, it can even be called 'normal'. For example, following the death of a close friend or relative, one could be overtaken by grief and depression. But, there are times when depression starts to interfere with everyday living. Then it becomes a problem. For example, everyone gets spells of feeling sad but most people manage to carry on with life and the feeling of depression fades off. Sometimes, the depression lasts for long periods, even longer than a month. It may be accompanied with symptoms such as tiredness and difficulty in concentrating. These feelings make it difficult for the person to work or look after children at home. The person may attempt suicide or talk of it. If depression begins to interfere with life and lasts for a long period of time, then we can assume that the person is suffering from an illness.

MENTAL ILLNESS DISORDER

📖 Mental illnesses can affect persons of any age, caste or religion. They can be poor or rich, rural or urban. Mental illnesses are not the result of personal weakness, lack of character, or poor upbringing. Mental illnesses are treatable.

If detected early and given appropriate care, medication or counseling and psychotherapy, the person can become completely normal. A person with depression problem may have a tendency to get it again, when faced with a crisis and would require the necessary help again. In general, depression is higher in women than men. About 18 to 23% of all women and 8 to 11% of all men have 'depression episodes' at some time or the other in their lives. Of these, six per cent of the women and three per cent of the men may require hospitalization at some time.

The Key Features of Depression

A person with depression will experience some of the following symptoms:

PHYSICAL

- Tiredness and a feeling of fatigue and weakness generally.
- Vague aches and pains all over the body

FEELING

- Feeling sad and miserable
- A loss of interest in life, social interactions, work, etc.
- Guilty feelings

THINKING

- Hopelessness about the future
- Difficulty in making decisions
- Thoughts that he/she is not as good as others (low self-esteem).
- Thoughts that it would be better if he/she were not alive
- Suicidal ideas and plans
- Difficulty in concentrating

BEHAVING

- Disturbed sleep (usually reduced sleep, but occasionally too much sleep)
- Poor appetite (sometimes increased appetite)
- Reduced sex drive

Anxiety

Anxiety is a sensation of feeling afraid and nervous. Like depression, this is normal in certain situations. For example, a person going to give a speech or going for a job interview or a student going for an examination will

feel nervous, anxious and tense. Some people seem to be always anxious but yet seem to cope. Like depression, anxiety becomes an illness if it lasts long (generally more than two weeks) and interferes with the person's daily life.

Anxiety and depression affect a large number of people. Generalized anxiety disorder is a condition that is commonly seen in people. According to a rough estimate more than 30% of patients attending medical or surgical problems have one or more symptoms of anxiety or depression. However, it is often unrecognized and not addressed because the attention is on the physical illnesses only. The characteristic feature of anxiety disorder is excessive fear and worry. They fear that the worst might happen whether it is relationships, work, school, finances or health. The person suffering from anxiety disorder finds it difficult to control the worry and fear and carry on with normal activities.

Most people with a common mental disorder have a mixture of symptoms of depression and anxiety. Most never complain of the feeling and thinking problems but instead experience physical and behavioral symptoms. This could be for many reasons they may feel talking of their psychological symptoms will lead to them being labeled as a 'mentally ill'.

The Key Features of Anxiety

A person with Anxiety will experience some of the following symptoms:

PHYSICAL

- Feeling his/her heart is beating fast (palpitations)
- A feeling of Suffocation
- Dizziness
- Trembling, shaking all over

- Headaches
- Pins and needles (or sensation like ants crawling) on his/her limbs or face

FEELING

- Feeling as if something terrible is going to happen to him/her
- Feeling scared

THINKING

- Worrying too much about his/her problems or his/her health
- Thoughts that she is going to die lose control or go mad (These thoughts are often associated with severe physical symptoms and extreme fear).
- Repeatedly thinking the same distressing thought again and again despite efforts to stop thinking them.

BEHAVING

- Avoiding situations that he/she is scared of, such as market places or public transport.
- Poor sleep

In addition to depression and anxiety, the following three varieties of common mental disorders may be seen commonly with specific or unusual complaints:

Panic Disorder

Panic is when anxiety occurs in severe attacks, usually lasting only a few minutes. The characteristic of panic disorder is the suddenness of fear that comes and takes over the person. They are associated with severe physical symptoms of anxiety and make the sufferers feel terrified that something terrible is going to happen.

A person may complain of having a heart attack. But when investigated, no abnormalities are found. Panic disorder is a chronic but treatable problem. But the person's social and work abilities may be affected seriously. He/she may have a poor quality of life and frequent relapses. Often unrecognized, this problem is often treated with excessive use of medicines. People under panic attacks are seen to breathe much faster than usual. This

leads to changes in the blood chemistry which cause physical symptoms. (Conscious and slow breathing can help in undoing the effect of the panic attack.)

Phobic Disorders

Phobia is as an irrational fear where the person tries to avoid the feared object, activity or situation. The fear could be in relation to something like animal (cat or cockroach) or water or heights. The presence or thought of the feared object or animal causes distress in the person who also usually, recognizes that his fear reaction is excessive. It disrupts his ability to function normally. Even if he/she knows his fear is silly and there is no reason for it, he/she still wants to avoid the object or situation.

Common situations that cause phobia or even a panic attack are crowded places such as markets and buses, closed spaces like small rooms or lifts and in social situations such as meeting people. In severe cases, the person may even stop going out of the house altogether.

Obsessive-Compulsive Disorder (OCD)

Many of us have habits and routines, which help to organize daily lives. But if a person develops a pattern of behavior which takes too much time and interferes with his/her daily life, then he/she is said to have OCD. OCD is an intriguing and often disabling syndrome characterized by two distinct phenomenon Obsessions and Compulsions. Obsessions are unwanted and persistent ideas, images and impulses that run through the person's mind repeatedly. Sometimes, these thoughts come only occasionally and are only mildly annoying. However, at other times, the thoughts come constantly and cause noticeable distress. A Compulsion is a behavior that is performed in response to the obsessions. The individual puts his thoughts into actions as per the rules he/she has made for him/herself, even though the person knows these are unnecessary or stupid, in an attempt to control the distress caused by the obsession. The obsessions and compulsions can become so frequent that they affect the person's concentration and lead to depression people with OCD hide their

problem to avoid embarrassment. Often these people are labeled as perfectionist/hygienic person. Studies have established that it is a fairly common syndrome with a prevalence of over 2%.

Post Traumatic Stress Disorder (PTSD)

These symptoms appear in a person after an exposure to a traumatic, life threatening accident or a natural disaster like earthquake or floods or man-made disaster like a bomb blast and riots. Some people involved in or witnessing it develops a group of symptoms termed '**Acute Stress Reaction**'. These symptoms may go away gradually over a period of a month or so in most people. But in some susceptible individuals, these symptoms persist and cause severe distress and inability to function.

Others

Alcohol and Substance Dependence

This is among the most common of mental illnesses although people may call them 'bad habits' and not illness. These are generally divided according to the substance involved - alcohol, opium, marijuana, cocaine etc. They are also classified according to the clinical state in which the person is: addiction state, complications of use/abuse and withdrawal symptoms.

A person with alcohol and substance dependence will experience some of the following symptoms:

PHYSICAL

- Stomach problems, such as gastritis and ulcers
- Liver disease and jaundice
- Vomiting blood
- Vomiting or sickness in the mornings
- Tremors , especially in the mornings
- Accidents and injuries

- Withdrawal reactions, such as seizures (fits), sweating, confusion

FEELING

- Feeling Helpless and Out of Control
- Feeling Guilty about his Drinking Behavior

THINKING

- A strong desire for alcohol.
- Continuous thoughts about the next drink.
- Thoughts of suicide.

BEHAVING

- Sleep difficulties
- The need to have a drink in the day-time.
- The need to have a drink early in the morning, to relieve physical discomfort.

Drug – Substance Abuse

A person who misuses drugs will experience some of the following symptoms:

PHYSICAL

- Breathing problems, such as asthma.
- Skin infections and ulcers if he/she injects drugs.
- Withdrawal reactions if the drug is not taken, such as nausea, anxiety, tremors, diarrhea, stomach cramps, sweating.

FEELING

- Feeling helpless and out of control.
- Feeling guilty about taking drugs.
- Feeling sad and depressed.

THINKING

- A strong desire to take the drug.
- Continuous thoughts about the next occasion of drug use.
- Thoughts of suicide.

BEHAVING

- Sleep difficulties.
- Irritability, such as becoming short-tempered.
- Stealing money to buy drugs; getting in trouble with the police.

Childhood Behavior Problems

These are mostly disturbances of behavior and conduct occurring in stressful family situations or as part of the child's development. The behavior is not appropriate to the age or circumstances of the child.

Psychosexual Disorders

Psychosexual disorders are of two types: sexual dysfunction and sexual deviation. In sexual dysfunction, there is lack of normal sexual interest or response. In sexual deviation, the behavior is unusual and violates the social norms of the society.

Organic Mental Disorders

These disorders are caused directly by damage to the structures of brain. The underlying disease may be in the brain itself or may be in other parts of the body. The important symptoms and signs of the disorders are: disorientation to time, place and people, poor understanding and calculation, memory problems, emotional instability, self neglect and absence of awareness of the same.

Mental Retardation (MR)

MENTAL RETADATION

📖 Mental retardation is not an illness, but a condition present from an early stage of life (usually from birth) which lasts for the rest of the person's life. There is no cure or treatment for MR.

Mental retardation means that mental functions are not as well developed as expected for the age of the child. Children with MR have difficulty with learning new things. The disability may affect all aspects of a child's development, from learning how to sit and walk to learning how to eat and talk. Much can be done to improve the quality of life for the child and family. MR can be mild, moderate or severe. The vast majority of children with MR have the Mild variety. You can identify the degree of MR from a careful history of the child's development.

Note

Many times, persons with MR may also have mental illness of some kind because of other problems along with MR or because of the way the family and community treat them, without understanding their condition. In such cases, the community worker has to find out the symptoms of the mental illness and have him treated for it.

People with MR can also experience different types of mental illnesses, such as, hallucinations, severe depression, and phobias. In such a case, the illness can be treated.

Appendix 2

LIST OF STATISTICAL TABLES CORRESPONDING TO FIGURES PRESENTED IN THE REPORT

The Appendix list out the Statistical Tables that corresponds to the figures represented in the CMH& D Program in South India report.

Chapter 3 Socio-Demographic Profile of PWMI in CMH&D Program

Table 3.1 Distribution of Identified PWMI in CMH&D Program Based on Categories of Mental Illness

District	Major	Minor	Epilepsy	MR	Total
Bangalore	0	2	0		2
Bangalore Rural	249	483	0		732
Chikkaballapura	0	1	0		1
Tumkur	165	154	0		319
Koppal	126	172	0		298
Raichur	148	39	1		188
Yadagiri	153	29	10		192
Anantapur	218	57	18		293

District	Major	Minor	Epilepsy	MR	Total
Kurnool	4	0	0		4
Pudukottai	384	162	8	0	554
Thiruvarur	128	85	0	0	213
Dindigul	153	45	1	0	199
Kanyakumari	381	66	17	6	470
Nilgris	76	125	0	0	201
Tanjore	30	21	0	0	51
Theni	206	64	0	0	270
Thirunelveli	163	91	1	0	255
Thiruvallur	23	87	1	14	125
Vellur	166	63	1	0	230
Idukki	32	137	0	0	169
Total	**2805**	**1883**	**58**	**20**	**4766**

Table 3.3 Sex-wise Distribution of PWMI Identified in CMH&D Program

District	Female	Male	Total	Total%	Female%	Male%
Bangalore	2	0	2	0.04	100.00	0.00
Bangalore Rural	456	276	732	15.36	62.30	37.70
Chikkaballapura	1	0	1	0.02	100.00	0.00
Tumkur	147	172	319	6.69	46.08	53.92
Koppal	161	137	298	6.25	54.03	45.97
Raichur	96	92	188	3.94	51.06	48.94
Yadagiri	2	2	4	0.08	50.00	50.00
Anantapur	89	98	187	3.92	47.59	52.41
Kurnool	129	169	298	6.25	43.29	56.71
Pudukottai	292	262	554	11.62	52.71	47.29
Thiruvarur	100	113	213	4.47	46.95	53.05
Dindigul	97	102	199	4.18	48.74	51.26
Kanyakumari	252	218	470	9.86	53.62	46.38
Nilgris	102	99	201	4.22	50.75	49.25

Tanjore	19	32	51	1.07	37.25	62.75
Theni	111	159	270	5.67	41.11	58.89
Thirunelveli	87	168	255	5.35	34.12	65.88
Thiruvallur	76	49	125	2.62	60.80	39.20
Vellur	133	97	230	4.83	57.83	42.17
Idukki	88	81	169	3.55	52.07	47.93
Total	**2440**	**2326**	**4766**	**100.00**	**51.20**	**48.80**

Table 3.4 Sex- wise Distribution of PWMI in CMH&D Program on the Basis of Categories of Illness

Type of Illness	Female	Male	Total	Total%	Female%	Male%
Major	1342	1467	2809	58.94	47.78	52.22
Minor	1059	824	1883	39.51	56.24	43.76
Epilepsy	27	27	54	1.13	50.00	50.00
MR	12	8	20	0.42	60.00	40.00
Total	**2440**	**2326**	**4766**	**100.00**	**51.20**	**48.80**

Table 3.5 PWMI Based on Marital Status

Marital Status	Major	Minor	Epilepsy	MR	Total	Total %
Unmarried	821	344	28	6	1199	28.85
Married	1571	1234	23	0	2828	68.05
Divorced	5	13	0	0	18	0.43
Separated	29	10	0	0	39	0.94
Widow	31	41	0	0	72	1.73
Total	**2457**	**1642**	**51**	**6**	**4156**	**100.00**

Table 3.7 PWMI Based on Marital Status and Sex

Marital Status	Female	Male	Total	Total%	Female%	Male%
Unmarried	465	734	1199	28.85	38.78	61.22
Married	1569	1259	2828	68.05	55.48	44.52
Divorced	16	2	18	0.43	88.89	11.11
Separated	27	12	39	0.94	69.23	30.77
Widow	67	5	72	1.73	93.06	6.94
Total	**2144**	**2012**	**4156**	**100.00**	**51.59**	**48.41**

Table 3.8 Prevalence of Mental Illness in Children, Young and Older Persons in CMH&D Program

Age groups	Major	Minor	Epilepsy	MR	Total	Total %
Below 20	147	80	24	7	258	5.41
21-40	1601	1003	34	0	2638	55.35
41-60	924	669	9	0	1602	33.61
Above 60	137	131	0	0	268	5.62
Total	**2809**	**1883**	**67**	**7**	**4766**	**100.00**

Table 3.9 PWMI in CMH&D Program Based on Age and Sex

Age groups	Female	Male	Total	Total%	Female%	Male%
Below 20	128	130	258	5.41	49.61	50.39
21-40	1316	1322	2638	55.35	49.89	50.11
41-60	867	735	1602	33.61	54.12	45.88
Above 60	129	139	268	5.62	48.13	51.87
Total	**2440**	**2326**	**4766**	**100.00**	**51.20**	**48.80**

Table 3.10 PWMI in CMH&D Program Based on Caste

Caste	Major	Minor	Epilepsy	MR	Total	Total %
General	205	192	2	3	402	10.08
OBC	1489	873	33	3	2398	60.15
S.C	390	251	11	0	652	16.35
S.T	132	105	4	0	241	6.04
MBC	209	84	1		294	7.37
Total	**2425**	**1505**	**51**	**6**	**3987**	**100.00**

Table 3.12 PWMI in CMH&D Program Based on Caste and Sex

Caste	Female	Male	Total	Total%	Female%	Male%
General	226	176	402	10.08	56.22	43.78
OBC	1247	1151	2398	60.15	52.00	48.00
S.C	321	331	652	16.35	49.23	50.77
S.T	117	124	241	6.04	48.55	51.45
MBC	145	149	294	7.37	49.32	50.68
Total	**2056**	**1931**	**3987**	**100.00**	**51.57**	**48.43**

Table 3.13 Identified PWMI in CMH&D Program Based on Categories of Mental Illness and Education

Education/ Qualification	Major	Minor	Epilepsy	MR	Total	Total %
1st std to 7th std	240	238	4	0	482	12.09
8th std to 10th std	646	380	14	1	1041	26.11
PUC	103	62	0	1	166	4.16
Degree	69	34	1	0	104	2.61
Master degree	4	4	0	0	8	0.20
illiterate	1363	787	32	4	2186	54.83
Total	**2425**	**1505**	**51**	**6**	**3987**	**100.00**

Table 3.14 Identified PWMI in CMH&D Program Based on Education and Sex

Education/ Qualification	Female	Male	Total	Total%	Female%	Male%
1st std to 7th std	234	248	482	12.09	48.55	51.45
8th std to 10th std	457	584	1041	26.11	43.90	56.10
PUC	56	109	165	4.14	33.94	66.06
Degree	26	79	105	2.63	24.76	75.24
Master Degree	3	5	8	0.20	37.50	62.50
Illiterate	1280	906	2186	54.83	58.55	41.45
Total	**2056**	**1931**	**3987**	**100.00**	**51.57**	**48.43**

Table 3.15 PWMI in CMH&D Program Based on Occupation

Occupation	Female	Male	Total	Total%	Female%	Male%
Agriculture	159	285	444	11.14	35.81	64.19
Animal Husbandry	30	32	62	1.56	48.39	51.61
Daily wages	697	673	1370	34.36	50.88	49.12
Government Job	19	21	40	1.00	47.50	52.50
Household work	420	160	580	14.55	72.41	27.59
Private Job	15	45	60	1.50	25.00	75.00
Self Employment	50	91	141	3.54	35.46	64.54
Skilled work	79	94	173	4.34	45.66	54.34
Not working	587	530	1117	28.02	52.55	47.45
Total	**2056**	**1931**	**3987**	**100.00**	**51.57**	**48.43**

Table 3.16 Identified PWMI Based on Types of Illness and Annual Income

Annual Family Income	Major	Minor	Epilepsy	MR	Total	Total %
Below 6000	423	392	2		817	20.49
6000 to 12000	1393	598	36	5	2032	50.97
12000 to 24000	538	435	10	1	984	24.68
Above 24000	71	80	3	0	154	3.86
Total	2425	1505	51	6	3987	100.00

Chapter 4 DIAGNOSIS, TREATMENT AND ACCESS TO TREATMENT

Table 4.1 Distribution of PWMI Based on Sex and Diagnosis

Diagnosis	Female	Male	Total	Total%	Female%	Male%
ADS	0	9	9	0.19	0.00	100.00
Anxiety Disorder	169	147	316	6.63	53.48	46.52
BPAD	144	177	321	6.74	44.86	55.14
Delusional Disorder	24	5	29	0.61	82.76	17.24
Depression	700	556	1256	26.35	55.73	44.27
Dysthymia	90	36	126	2.64	71.43	28.57
GTCS	3	1	4	0.08	75.00	25.00
Mr & Psychosis	26	22	48	1.01	54.17	45.83
Neurosis	6	6	12	0.25	50.00	50.00
Major Depression	63	58	121	2.54	52.07	47.93
Epilepsy	33	31	64	1.34	51.56	48.44
OCD	12	10	22	0.46	54.55	45.45
Parkinson	2	3	5	0.10	40.00	60.00
Phobia	33	26	59	1.24	55.93	44.07
Panic Disorder	0	4	4	0.08	0.00	100.00
Psychosis	254	314	568	11.92	44.72	55.28

Diagnosis	Female	Male	Total	Total%	Female%	Male%
Schizophrenia	796	856	1652	34.66	48.18	51.82
Somatoform Disorder	65	38	103	2.16	63.11	36.89
TIA	0	1	1	0.02	0.00	100.00
Behavioral problem	6	2	8	0.17	75.00	25.00
Dementia	4	2	6	0.13	66.67	33.33
CPMR & MI	0	1	1	0.02	0.00	100.00
Hysteria	5	9	14	0.29	35.71	64.29
Personality Disorder	0	1	1	0.02	0.00	100.00
M R	5	6	11	0.23	45.45	54.55
Substance Abuse	0	5	5	0.10	0.00	100.00
Total	**2440**	**2326**	**4766**	**100.00**	**51.20**	**48.80**

Table 4.2 PWMI in CMH&D Program Based on Status of Treatment

Person on Treatment	Major	Minor	Epilepsy	MR	Total	Total %
Regular	1373	657	45	6	2081	43.66
Irregular	1436	1226	22	1	2685	56.34
Total	**2809**	**1883**	**67**	**7**	**4766**	**100.00**

Table 4.3 PWMI Stabilized after Treatment Based on Sex

Stabilization	Female	Male	Total	Total%	Female%	Male%	Total
Yes	1167	1010	2177	45.68	53.61	46.39	100.00
No	1071	1100	2171	45.55	49.33	50.67	100.00
Not applicable	202	216	418	8.77	48.33	51.67	100.00
Total	**2440**	**2326**	**4766**	**100.00**	**51.20**	**48.80**	**100.00**

Table 4.4 PWMI Reporting Side Effects Based on Sex

Side Effects	Female	Male	Total	Total%	Female%	Male%	Total
Yes	142	122	264	5.54	53.79	46.21	100.00
No	2298	2204	4502	94.46	51.04	48.96	100.00
Total	2440	2326	4766	100.00	51.20	48.80	100.00

Table 4.5 PWMI Reporting Side Effects Based on Types of Illness

Side effects	Major	Minor	Epilepsy	MR	Total	Total %
Yes	155	106	4	0	265	5.56
No	2654	1777	63	7	4501	94.44
Total	2809	1883	67	7	4766	100.00

Table 4.6 PWMI Reporting Relapse of Symptoms Based on Sex

Relapse	Female	Male	Total	Total%	Female%	Male%
Yes	165	160	325	6.82	50.77	49.23
No	2275	2166	4441	93.18	51.23	48.77
Total	2440	2326	4766	100.00	51.20	48.80

Table 4.7 PWMI Reporting Relapse of Symptoms Based on Types of Illness

Relapse	Major	Minor	Epilepsy	MR	Total	Total %
Yes	213	105	7	0	325	6.82
No	2596	1778	60	7	4441	93.18
Total	2809	1883	67	7	4766	100.00

Table 4.8 PWMI Drop-out from Treatment Based on Sex

Reasons for drop outs	Female	Male	Total	Total%	Female%	Male%
Completed Treatment	63	62	125	2.62	50.40	49.60
Family Negligence	107	122	229	4.80	46.72	53.28
Self Decision	57	52	109	2.29	52.29	47.71
Migrated	198	181	379	7.95	52.24	47.76
No Information	31	28	59	1.24	52.54	47.46
Not Applicable	1761	1644	3405	71.44	51.72	48.28
Side Effects	21	21	42	0.88	50.00	50.00
Death	202	216	418	8.77	48.33	51.67
Total	**2440**	**2326**	**4766**	**100.00**	**51.20**	**48.80**

Table 4.9 Reason for PWMI Drop-out from the Program Based on Illness

Reasons for Dropouts	Major	Minor	Epilepsy	MR	Total	Total %
Completed Treatment	76	49	0	0	125	2.62
Family Negligence	177	49	3	0	229	4.80
Self Decision	64	77	4	1	146	3.06
Migrated	216	162	1	0	379	7.95
No Information	20	36	0	0	56	1.17
Side Effects	8	0	0	0	8	0.17
Death	290	126	2	0	418	8.77
Not Applicable	1958	1384	57	6	3405	71.44
Total	**2809**	**1883**	**67**	**7**	**4766**	**100.00**

Table 4.10 Reasons for Death of PWMI According to Illness

Reason for Death	Major	Minor	Epilepsy	MR	Total	Total %
Age and Natural Death	115	36	1	0	152	3.19
Due to Mental Illness	21	14	0	0	35	0.73
Physical Health problem	48	19	0	0	67	1.41
Accident	8	6	0	0	14	0.29
Alcoholism	2	0	0	0	2	0.04
Suicide	19	7	0	0	26	0.55
No Information	77	44	1	0	122	2.56
Not Applicable	2519	1757	65	7	4348	91.23
Total	2809	1883	67	7	4766	100.00

Table 4.11 PWMI Consulting Village Quacks

Consulting any village Quacks/Magicians	Female	Male	Total	Total%	Female%	Male%
Yes	36	46	82	4.04	43.90	56.10
No	1047	900	1947	95.96	53.78	46.22
Total	1083	946	2029	100.00	53.38	46.62

Table 4.12 PWMI Accessing Treatment from Different Sources Based on Types of Illness

Source of Treatment	Major	Minor	Epilepsy	MR	Total	Total %
Govt. Hospital	1621	857	40	5	2523	52.94
Mental health Camp	8	5	1	0	14	0.29
Private Hospital	334	211	12	1	558	11.71
Not on Treatment	697	715	13	1	1426	29.92
Organization	149	95	1	0	245	5.14
Total	2809	1883	67	7	4766	100.00

Chapter 5 Social Inclusion: Community and Social Participation

Table 5.1 PWMI Involved in Decision-Making According to Categories of Mental Illness

Participation in Family Decisions	Major	Minor	Epilepsy	MR	Total	Total %
Yes	530	592	20	0	1142	56.28
No	537	345	5	0	887	43.72
Total	1067	937	25	0	2029	100.00

Table 5.2 PWMI Involved in Decision-Making Based on Sex

Participation in Family Decisions	Female	Male	Total	Total%	Female%	Male%
Yes	626	516	1142	56.28	54.82	45.18
No	457	430	887	43.72	51.52	48.48
Total	1083	946	2029	100.00	53.38	46.62

Table 5.3: PWMI Contributing to the Income of the Family

Involved in IGP and contributing towards Family Income	Major	Minor	Epilepsy	Total	Major%	Minor%	Epilepsy%	Total%
Yes	283	145	16	444	13.95	7.15	0.79	21.88
No	784	792	9	1585	38.64	39.03	0.44	78.12
Total	1067	937	25	2029	52.59	46.18	1.23	100.00

Table 5.4 PWMI Contributing to the Income of the Family Based on Sex

Involved in IGP and contributing towards Family Income	Female	Male	Total	Total%	Female%	Male%
Yes	211	233	444	21.88	47.52	52.48
No	872	713	1585	78.12	55.02	44.98
Total	1083	946	2029	100.00	53.38	46.62

Table 5.5 PWMI Involved in Productive Work Based on Illness

Involved in any productive activities without earning	Major	Minor	Epilepsy	MR	Total	Total %
Yes	534	561	20	0	1115	54.95
No	533	376	5	0	914	45.05
Total	1067	937	25	0	2029	100.00

Table 5.6 PWMI Involved in Productive Activity Based on Sex

Involved in any productive activities without earning	Female	Male	Total	Total%	Female%	Male%
Yes	610	505	1115	54.95	54.71	45.29
No	473	441	914	45.05	51.75	48.25
Total	1083	946	2029	100.00	53.38	46.62

Table 5.7 PWMI Involved in Community and Social Activity Based on Illness

Participation in any Social Activities	Major	Minor	Epilepsy	MR	Total	Total %
Yes	345	173	20	0	538	26.52
No	722	764	5	0	1491	73.48
Total	1067	937	25	0	2029	100.00

Table 5.8 PWMI Involved in Community and Social Activity Based on Sex

Participation in any Social Activities	Female	Male	Total	Total%	Female%	Male%
Yes	253	285	538	26.52	47.03	52.97
No	830	661	1491	73.48	55.67	44.33
Total	1083	946	2029	100.00	53.38	46.62

Table 5.9 Inclusion of PWMI into Community Groups Based on Sex

PWMI Included in to the SHG	Female	Male	Total	Total%	Female%	Male%
Yes	799	473	1272	26.69	62.81	37.19
No	1641	1853	3494	73.31	46.97	53.03
Total	2440	2326	4766	100.00	51.20	48.80

Table 5.10 Inclusion of PWMI into Community Groups Based on Illness

PWMI Included in to the SHG	Major	Minor	Epilepsy	MR	Total	Total %
Yes	717	533	17	5	1272	26.69
No	2092	1350	50	2	3494	73.31
Total	2809	1883	67	7	4766	100.00

Table 5.11: Inclusion of Caregivers of PWMI into Community Groups Based on Sex

Caregivers included in the SHG's	Female	Male	Total	Total%	Female%	Male%
Yes	833	813	1646	34.54	50.61	49.39
No	1607	1513	3120	65.46	51.51	48.49
Total	2440	2326	4766	100.00	51.20	48.80

Chapter 6 Accessing Entitlements and Social Security Schemes

Table 6.1 Accessing Entitlements and Social Security Schemes by PWMI Based on Sex

Schemes	Male	Female	Total
Number of people availing Disability Certificate.	244	241	485
Number of people accessing Disability Pension	229	194	423
Number people accessing BPL cards	1027	1156	2183
Number of people accessing Travel Concession Pass	83	43	126
Number of people accessing Poverty Alleviation Schemes	500	415	915

Table 6.2: Accessing of Disability Identity Cards by PWMI

Disability Identity card	Female	Male	Total	Total%	Female%	Male%
Yes	241	244	485	11.67	49.69	50.31
No	1903	1768	3671	88.33	51.84	48.16
Total	2144	2012	4156	100.00	51.59	48.41

Table6. 3: PWMI Accessing BPL Cards

BPL Card Holder	Female	Male	Total	Total%	Female%	Male%
Yes	1156	1027	2183	54.75	52.95	47.05
No	900	904	1804	45.25	49.89	50.11
Total	2056	1931	3987	100.00	51.57	48.43

Table 6.4 Distribution of Persons Accessing BPL Cards according to Illness

BPLCard Holder	Major	Minor	Epilepsy	MR	Total	Major%	Minor%	Epilepsy%	MR%
Yes	1246	907	30	0	2183	57.08	41.55	1.37	0.00
No	1179	598	21	6	1804	65.35	33.15	1.16	0.33

BPLCard Holder	Major	Minor	Epilepsy	MR	Total	Major%	Minor%	Epilepsy%	MR%
Total	2425	1505	51	6	3987	60.82	37.75	1.28	0.15

Table 6.5 PWMI under MNREGA Program Based on Sex

Member in MNREGA	Female	Male	Total	Total%	Female%	Male%
Yes	379	431	810	20.32	46.79	53.21
No	1677	1500	3177	79.68	52.79	47.21
Total	2056	1931	3987	100.00	51.57	48.43

Table 6.7: Distribution of PWMI under MNREGA Program According to Illness

Member in MNREGA	Major	Minor	Epilepsy	MR	Total	Major%	Minor%	Epilepsy%	MR%
Yes	501	296	13	0	810	61.85	36.54	1.60	0.00
No	1924	1209	38	6	3177	60.56	38.05	1.20	0.19
Total	2425	1505	51	6	3987	60.82	37.75	1.28	0.15

Appendix 3

INTERVIEWER'S JOURNAL

The Interviewer's Journal describes the interviewing techniques, the questionnaire, procedure for filling the questionnaire and discussion on each question of all the questionnaires. This chapter also provides the details of all fieldwork procedures.

Community Mental Health and Development Program - Consolidation Study
2010 2011
Interview Schedule

Name of the Organization:
Personal Information

1. File Number :
2. Name: Father/ Husband's Name:
3. Address :
   - Village :
   - Panchayath /Ward :
   - Taluk / Block :
   - District :
   - Phone Number :
4. Age/ Date of Birth :
5. Sex : MALE | FEMALE
6. Religion :
7. Caste :

8. Belongs to SC/ST/OBC. If Yes, specify: _____

9. Educational level _____ : _____

10. Other skills/ trainings _____ : _____

11. Occupation _____ : _____

12. Marital status: Single/Married/ Widow/ Separated/ Divorced

13. Onset (beginning) of illness was before or after marriage :

A. If the onset of illness was before marriage, whether the person got married after treatment and stabilization
B. Annual income of the individual_____

History of Mental Illness

14. Onset of illness and causes:

15. Treatment taken and duration:

16. Mode of identification: PWMI/ Self / SHG / Fed / Staff / Volunteers / Others_____

17. Other information's (if any)_____

Family Details:

SL No	Name	Age	Relationship with the Client	Level of Education	Occupation skills	Annual Income	Remarks if any
1							
2							
3							
4							
5							
6							

17. Total income of the family: Up to rupees` 6000/-year, `6000-`12000, `12000-`24000, and above ` 24000/-

Current Status:

18. Diagnosis: _____

Common	Severe

19. Is person on treatment?(Yes /No) if No, give the details:

_____

If Yes, status of the treatment:_____

Regular	Irregular

20. Present treatment from

A. Government hospital (PHC, CHC, TQH, DH, MC, CAMPS, OTHERS).
B. Private practitioners/ hospitals
C. Non Pharmacological treatment (Ayurveda, Meditation, Counseling, Yoga, Homeopathy, Others)
D. Partner organization

21. Present medicines from

A. Government hospital (PHC, CHC, TQH, DH, MC, CAMPS, OTHERS)
B. Private practitioners (hospital)
C. Non Pharmacological treatment (Ayurveda, Meditation, Counseling, Yoga, Homeopathy, Others)
D. Partner organization:
E. Partial from Govt:_____

22. Support for Treatment

A. Earning and Contributing (Self finance):
B. Family contribution:
C. Community support:
D. Others:_____

23. Side effects? (Yes/No) (If Yes. mention the side effects and how you are managing?_____

24. Completed treatment and gone back to the pre-morbid level of functioning:

25. Stabilized? _____

26. Relapse? (Yes /No) if Yes, give reason_____

27. Drop-Out? (Yes/No) if Yes, give reason:_____

28. If the family is permanently migrated? Give details:_____

29. Death ?(Yes/No) if Yes, give details: _____

30. Any other health problems?(Yes/No) if Yes, mention the problem and causes: _____

31. Are you taking treatment (Yes/No) if Yes, give details _____

32. Participation in family decisions? (Yes/No)_____

33. Primary care within the family (details): _____

34. Community support(details): _____

35. Attitude of community towards PWMI? (details) _____

36. Participation in Social / community life? (Details) _____

37. Membership in any Community groups? (Yes/No) if Yes, mention the name of the group

38. Participation in the Community group meeting?

Regular	Irregular

39. If irregular, mention the reasons:

40. What information you are getting from the meetings and how is it benefiting you?

41. Undergone any training through the groups? if Yes, give details_____

42. Even now are you approaching village quacks and black magicians?_____

43. Participation in awareness programs :_____

44. Participation in advocacy programs: _____

45. Have you experienced being in shackles/ solitary confinements recently?_____

46. Relationship with spouse (husband/wife) and family members:_____

47. Are you aware of disability/ mental health acts?_____

48. Person's activities at home:_____

49. Activities outside the home:_____

50. Engaging in income generation activity:_____

51. Sources of income generation activities (Self, Family, SHG, Panchayaths, Bank, Corporation, Org, Any other:_____

52. To previous Job:_____

53. Undergone vocational or any other trainings?_____

54. Loans availed and state of repayment:_____

55. Are you getting equal opportunity in job? equal wages and equal respect in the community? ___

56. Are you having (owning) any assets? (details) _____

57. Are you making savings?_____

58. BPL card holder:_____

59. Economic status of the family:_____

60. Member in MNREGA (Self / family member)?_____

61. Accessing any welfare schemes or poverty alleviation schemes?

A. Disability ID cards:
B. Bus pass:
C. Train pass:
D. Pensions (details)
E. Loans (details)
F. Housing / Plot (details)
G. Utilization of 3% allocation of resources and from which department?
H. Training and employment (details) : _____

62. Any other schemes (Yes /No) If Yes, give details:_____

63. Any other information you would like to share?_____

64. Present needs of person:_____

65. Source of Information: self/parent/sibling/son or daughter/relative/others

66. Field staff's Note: _____

Date: **Coordinator's signature**

Name of the field staff/volunteer: **Signature:**