

# INDIAN PSYCHIATRIC UPDATE

---

**Rehabilitation Psychiatry**

Editor

**Anil Kakunje**



**Indian Psychiatric Society  
South Zonal Branch**

2022 VOLUME - 5

ISBN : 978-93-5680-270-4



**Pari**  $\frac{10}{20}$   
 $\frac{30}$

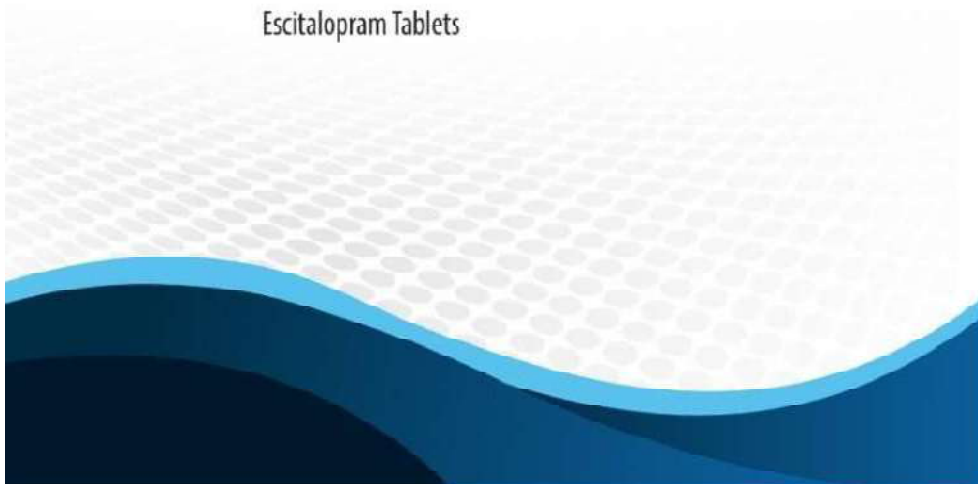
Paroxetine Tablets

**Inspiral**  $\frac{5}{10}$   
 $\frac{20}$

Methylphenidate Immediate Release Tablets

**Recita**  $\frac{5}{10}$   
 $\frac{20}$

Escitalopram Tablets







# **INDIAN PSYCHIATRIC UPDATE**

## **Rehabilitation Psychiatry**

Editor

**Anil Kakunje**

2022

**INDIAN PSYCHYSTRIC UPDATE****Title : REHABILITATION PSYCHIATRY**

Headquarters : Athma Hospitals ,12 –B,10<sup>th</sup> Cross (East),  
Thillai Nagar, Trichy - 620 018

E-mail : indpsyupdate@gmail

Web. : ipsszb.org

Official Publication of Indian Society South Zonal Branch

Copyright@2022 by Indian Society South Zonal Branch

**ISBN : 978-93-5680-270-4**

All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopy, recording ,or any information retrieval system, without written permission from publisher.

No responsibility is assumed by Indian Psychiatric Society South Zonal Branch for any injury and/damage to person or property as a matter of products liability, negligence or otherwise, or from any use or operation of any methods, Products, Instruction, or ideas contained in the material herein. Because of repaid advance in the medical sciences, in particular, independents verification of diagnoses and drug dosages should be made.

Although all advertising material is expected to conform to ethical (medical) standards, inclusion in this publication does not constitute a guarantee or endorsement of the quality or value of such product or of the claims made of it by its manufacturer.

Although all possible efforts have been made to ensure that no content in this book violates copyright laws, the responsibility of ensuring this lies with the respective chapter author(s). The editor, committee, and society are not responsible for any infringement of copyright.

Printed and Bound at Rajkumar Printers, Trichy.

Not for Sale.

Dedicated To

*All who care for persons  
with chronic mental illness*





**PREFACE**

It was a pleasant surprise when I was initially selected as a publication committee member for the IPS - South zone. Few years back I never thought I would be into writing books! Indian Psychiatric Update under the guidance of Dr. K. Ramakrishnan immediate past IPS-SZ President started on a strong note. I am thankful to Dr. Ramanan Earat for continuing with the same team and keeping the faith in us. Chairman Dr. Rajshekhar Bipeta is very systematic and co-ordinated the issues of Indian Psychiatric Update well. I chose Culture Bound Syndromes as the title for my first issue as section editor. This edition, my second one as section editor; is on Rehabilitation Psychiatry. I selected them as these topics need research from our region and written materials are less even in standard textbooks. I am delighted to pen this preface for such a book; which certainly is a dream come true.

I thank the entire South Zone executive committee, publication committee members and authors for their support and cooperation. I bow to all my teachers for their efforts in training me. Last but not the least such a work is not possible without the support from family members.

Happy Reading

Feedback is welcome

Dr Anil Kakunje, DPM, MD  
Editor - Rehabilitation Psychiatry  
anilpsychiatry@yahoo.co.in  
ORCID ID: 0000-0003-1038-8144



**MESSAGE**

I'm indeed privileged to write this message for "REHABILITATION PSYCHIATRY", as part of "Indian Psychiatric Update" from the Publication Committee of Indian Psychiatric Society South Zonal Branch.

The authors are of both Indian and International repute. These are the real time works by eminent authors like Dr. Bharath Vatwani, the Magsaysay Award Winner, Dr. Swaminath, Dr. Shaji, Dr. Murali Thyloth and others. The topics have been updated to match any standard book on Rehabilitation.

This book shows the amount of work done in India and this will be of great help for those who would like to take up Rehabilitation in a big way.

Let me congratulate each author, and especially Dr. Anil Kakunje who has put in great effort as an Editor to bring out this edition.

I wish this venture all the very best.

Best Wishes.

With Regards

Dr. Ramanan Earat  
President-IPS SZB  
drearat@gmail.com  
1/10/2022



## INDIAN PSYCHIATRIC SOCIETY SOUTH ZONAL BRANCH

Reg. No. KNR/CA/351/2017 email: ipsszboffice@gmail.com Website: www.ipsszb.org

### OFFICE BEARERS (2021-22)

President <b>Dr. Ramanan Earat</b>	Vice President <b>Dr. Kadiveti Uday Kumar</b>
Hony. Gen. Secretary <b>Dr. Suresh Kumar Gunapalli</b>	Hon. Treasurer <b>Dr. Gangaram K</b>
Hon. Editor <b>Dr. Shahul Ameen</b>	IPS SZ Representative <b>Dr. Naresh Vadlamani L</b>
Immediate Past President <b>Dr. Ramakrishnan K</b>	Immediate Past Secretary <b>Dr. Abhay Matkar</b>
Asst. Secretary <b>Dr. Arumkumar N</b>	

### STATE REPRESENTATIVES

Andhra Pradesh	: <b>Dr. Murthy GVS</b> (Secretary)	Dr. Srinivasa Teja P
Karnataka	: Dr. Somashekhar Bijjal (Secretary)	Dr. Raveesh B N
Kerala	: Dr. Anoop Vincen (Secretary)	Dr. Mohan Roy G
Tamilnadu	: Dr. Siva Ilango T (Secretary)	Dr. Panneer Selvam C
Telangana	: Dr. Pavan Kumar (Secretary)	Dr. Umashankar M

### PUBLICATION COMMITTEE

#### CHAIRMAN

**Dr. Rajshekhar Bipeta** MBBS,DPM, DNA

Professor of Psychiatry & Deputy Superintendent, Institute of Mental Health,  
Osmania Medical College, Hyderabad, Telangana, India. Email : braj111@yahoo.co.in

#### CO-CHAIRMAN

**Dr. Vikas Menon** MD, DNB

Additional Professor of Psychiatry, JIPMER, Puducherry, India. Email:drvmenon@gmail.com

#### MEMBERS

**Dr. Adishesamma Tiruvaipati** MD, DCH

Associate Professor of Psychiatry, Guntur Medical College, Guntur, Andhra Pradesh, India.  
Email: tadesesamma@gmail.com

**Dr. Anil Kakunje** DPM,MD

Professor & Head, Department of Psychiatry, Yenepoya Medical College, Mangalore,  
Karnataka, India. Email : nilpsychiatry@yahoo.co.in

**Dr. Vidhukumar K.** MD, MPil (Clinical Epidemiology)

Professor & Head, Department of Psychiatry, Government TD Medical College,  
Ernakulam, Kerala, India. Email: kumarv68@gmail.com



**CONTRIBUTORS IN ALPHABETICAL ORDER****Aditya Kashyap, MD**

Senior Resident of Psychiatry, Department of Psychiatry, Government Medical College Siddipet, Telangana

**Amritha Roy, PhD (Mental Health Rehabilitation)**

Assistant Professor, Jindal Institute of Behavioural Sciences, O.P. Jindal Global University, Sonapat, Haryana.

**Anil Kakunje, DPM, MD**

Professor & Head, Dept of Psychiatry, Yenepoya Medical College, Yenepoya deemed to be University, Mangalore E.mail : anilpsychiatry@yahoo.co.in

**Ashok Mysore**

Professor of Psychiatry, Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CAREADD), St. John's Medical College Hospital, Bangalore, India.  
E.mail : ashok.careadd@stjohns.in

**Athira N.D**

Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CAREADD), St. John's Medical College Hospital, Bangalore, India.

**Arudhra Gopalakrishnan**

Consultant Psychiatrist & Executive Director, Sowmanasya Hospital & Institute of Psychiatry, Trichy

**Arunkumar N**

Consultant Psychiatrist, TRUST - Shanthivanam, Director- Athma Hospitals & Research Pvt. Ltd., Tiruchirappalli - 620018, Tamilnadu.

**Aynkaran J R**

Community coordinator, Schizophrenia Research Foundation, R/7A North Main Road, Anna Nagar, West, Chennai-600101

**Bharat Vatwani, M.D. Psychiatry**

Ramon Magsaysay Awardee, Founder Trustee, Shraddha Rehabilitation Foundation, Mumbai.  
E.mail : vatwanibharat@gmail.com

**Bhaswati Kalita**

Psychiatric Social Worker, Assam Medical College and Hospital, Dibrugarh - 786002

**Ganesan Gopalakrishnan**

CEO and Senior Psychiatrist, Sowmanasya Hospital & Institute of Psychiatry, Trichy  
E.mail : sowmanasya@gmail.com

**Kotteeswara Rao**

Assistant Director, Schizophrenia Research Foundation, R/7A North Main Road, Anna Nagar, West Chennai - 600101

**Madhur M Rathi**

Senior Resident of Psychiatry, Institute of Mental Health, Osmania Medical College, Hyderabad, Telangana

**Mathew Varghese**

Senior Professor of Psychiatry, NIMHANS (Retd.), Adjunct Professor, St John's Medical College, Bangalore. E.mail : mat.varg@yahoo.com

**Mahesh R Gowda, DPM, DNB**

Consultant Psychiatrist and Director, Spandana Health Care, Bengaluru, Karnataka.  
E.mail :maheshrgowda@yahoo.com

**Murali Thyloth**

Senior Professor, Department of Psychiatry, Ramaiah Medical College, Bangalore  
E.mail : muralithyloth@gmail.com

**Nimmi Chandran**

Assistant Professor, Dept. of Psychiatry, Government Medical College, Palakkad, Kerala

**Nirupama Srikanth**

Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CAREADD),  
St. John's Medical College Hospital, Bangalore, India.

**Padmavati R MD, DPM**

Director, Schizophrenia Research Foundation (India), R/7A, North Main Road, Anna Nagar West Extn.  
Chennai - 600101, Tamilnadu, India. E.mail : padmavati@scarfindia.org

**Prabhat K. Chand**

Professor, Centre for Addiction Medicine, Department of Psychiatry, NIMHANS Digital Academy ECHO,  
National Institute of Mental Health and Neurosciences, Bengaluru. E.mail : prabhat@vknimhans.in

**Praveen A**

Senior Grade Lecturer, Psychiatry Social Work, Department of Psychiatry, Kasturba Medical College,  
Manipal - 576104. E.mail : praveen.a@manipal.edu

**Preetiparna Pattanayak**

Division of Research and Patents, Ramaiah Medical College, Bangalore  
E.mail : preetiparna1996@gmail.com

**Rahul Verma**

Senior Resident, Centre for Addiction Medicine, Department of Psychiatry, National Institute of Mental  
Health and Neurosciences, Bengaluru. E.mail : rahuldoct13@gmail.com

**Rajesh Mithur, MD, (PhD)**

Asst Professor of Psychiatry, Yenepoya Medical College, Yenepoya deemed to be University, Mangalore  
- 575 018. E.mail : drrajeshm10@gmail.com

**Rajeshkrishna Bhandary P**

Associate Professor of Psychiatry, In-charge at Hombelaku Rehabilitation Centre, Kasturba Medical  
College, Manipal - 576 104. E.mail : rajesh.kbp@manipal.edu.

**Rajshekhar Bipeta, DPM, DNB**

Professor of Psychiatry and Deputy Superintendent, Institute of Mental Health, Erragadda, Hyderabad  
-500038, Telangana, E.mail : braj111@yahoo.co.in

**Ramakrishnan K**

CEO & Managng Director - Athma Hospitals & Research Pvt. Ltd., Exe. Secretary - TRUST -  
Shanthivanam, Tiruchirappalli - 620018, Tamilnadu.

**Ravi Shankar Rao BR**

Chittadhama, Heggadadevanakote, Mysore District, Karnataka, India. E.mail : rsrao90@hotmail.com

**Santosh Kumar D**

Senior Resident, Christian Medical College, Vellore - 600126



**Sathya Lakshmi P.S**

Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CAREADD),  
St. John's Medical College Hospital, Bangalore, India.

**Shaji KS**

Dean, (Research), Kerala University of Health Sciences, Thrissur, Kerala, E.mail : drshajiks@gmail.com

**Smitha Vatwani**, M.D. Psychiatry

Advisor, Shraddha Rehabilitation Foundation, Mumbai

**Sowmyashree MayurKaku**

Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CAREADD), St.  
John's Medical College Hospital, Bangalore, India.

**Subramanyam M**

Consultant Psychiatrist, Spandana Nursing Home, Bengaluru, Karnataka

**Sujit John**

Joint Director, Schizophrenia Research Foundation, R/7A North Main Road, Anna Nagar, West Chennai  
- 600101

**Sunil Kumar Giriappa Patil**

Associate Professor, Dept. of Psychiatry, Sri Siddhartha Medical College, Tumkur, Karnataka  
E.mail : drsunilgp@yahoo.co.in

**Supreeta Santosh**

Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CAREADD),  
St. John's Medical College Hospital, Bangalore, India.

**Swaminath G**

Chittadhama, Heggadadevanakote, Mysore District, Karnataka, India. E.mail : drswamyg@gmail.com

**Swarali Kondwilkar** M.D. Psychiatry

Associate Psychiatrist, Shraddha Rehabilitation Foundation, Mumbai

**Swetha S**, Ph.D in Social Work

Sowmanasya Hospital & Institute of Psychiatry, Trichy

**Thanapal Sivakumar**

Additional Professor of Psychiatry, Psychiatric Rehabilitation Service, National Institute of Mental Health  
and Neurosciences, Bengaluru - 56002, E.mail : drt.sivakumar@outlook.com.

## CONTENTS IN BRIEF

<p><b>PSYCHOSOCIAL REHABILITATION : GLOBAL AND LOCAL VIEW</b></p> <p>Murali Thylon, Mathew Varghese, Preetiparna Pattanayak</p> <p>Psychiatric rehabilitation or Psychosocial Rehabilitation (PSR as it is called) is integral to managing chronic and serious mental illnesses. Essentially, this process enables an individual to get back into society with dignity and preservation of human rights, like any other individual who has no illness or disabilities. Rehabilitation of the mentally ill though recognized as an integral part of the care of the chronic mentally ill is not practiced in many countries. Hence the developments in different parts of the world differ from well-established rehabilitation programs to absence of any programs at all. We discuss Global and Indian scenario in this chapter.</p>	1
<p><b>REHABILITATION OF HOMELESS PERSON WITH MENTAL ILLNESS : A SHANTHIVANAM EXPERIENCE AND FUTURE PERSPECTIVE</b></p> <p>Arun Kumar N, Ramakrishnan K</p> <p>Homeless persons with mental illness (HPMI) are a fraction of people with mental illness, who out of their symptoms or social reasons wander on the streets with poor self care, are at risk of abuse, and survive hardships of nature without human dignity and rights. They remain in the streets until rescued by a significant person or organization. Offering food and cloths alone is insufficient as they need to be evaluated for physical and psychological problems. They need appropriate medicines, rehabilitation and attempts to reunite with their families. Once reunited follow up of such persons are essential to prevent further wandering. Shanthivanam is aimed at rescue, recovery, rehabilitation, reunion and follow up of such HPMI; also to disseminate stigma and discrimination against mental illness. This article details the experiential journey.</p>	13
<p><b>PSYCHIATRY REHABILITATION : REGULATORY REQUIREMENTS AND FUNCTIONING</b></p> <p>Sunil Kumar Giriappa Patil, Subramanyam M, Mahesh R Gowda</p> <p>With the growing number of people with mental illness who need rehabilitation services in the current situation of significant treatment gap, it's necessary to have a greater number of rehabilitation centers both by government and private which can give quality service in the framework of rights and regulations. The implementation of new regulations its need of hour to rethink on working of rehabilitation center with compliance to law keeping the standard of care with least financial burden on service users in developing country like India.</p>	27
<p><b>HOME TO THE HOMELESS : THE SHRADDHA EMOTION</b></p> <p>Bharat Vatwani, Smitha Vatwani, Swarali Kondwikar</p> <p>Lawfully, every individual has the fundamental right to live with dignity, inclusivity, and social security and no individual shall be deprived of his personal liberty. History of Psychiatry is evidence that individuals, who are agonized by the occurrence of mental illness, have been deprived of basic human rights described under Article 21 of Indian Constitution and Mental Healthcare Act, 2017. Vulnerable group of population such as wandering mentally ill roadside destitute, devoid of humane care and attention, deprived of the institution of family and the experience of belonging have been neglected for decades. This chapter represents a roadmap to the voyage of several such individuals suffering from severe mental illness</p>	45

wandering away from home to unknown streets of India because of inadequate care and treatment, reunited with their families post recovery, across the length and breadth of India and the neighbouring nations, the associated challenges, barriers, succour and the triumph.

**REHABILITATION OF HOMELESS PERSONS WITH MENTAL ILLNESS (HPMI) :  
CHITTADHAMA EXPERIENCE** 59

Ravi Shankar Rao B.R, Swaminath G

Persons with severe mental illness often end up wandering away from their families and becoming homeless, frequently in a totally different location. Given our huge population the number of HPMI (homeless persons with mental illness) end up as a huge public health challenge to mental health professionals, the law, general public and the government.

Chittadhama is an attempt to provide a residence for these unfortunate HPMI, who have both a disabling illness as well as a lack of a family to care for them. Tending to them from the time they are rescued from the hostile environment they inhabit to their ultimate reintegration to their families is a complex but gratifying task. Chittadhama focuses on the recovery of their physical and mental status and make them 'society ready' to enable smooth assimilation into their primary milieu.

**COMMUNITY MENTAL HEALTH INTEGRATING REHABILITATION - WHAT HAS AN NGO  
CONTRIBUTED TO PRACTICE** 71

Padmavati R, Sujit John, Kotteeswara Rao, Aynkaran J R

In India, the core concept of community care for persons with mental illness has been a practice through the ages. Much of the community care for a good period in the past century has been formally or informally delivered by non-governmental organizations throughout the country. This article is a narrative of the community based mental health programs run by the Schizophrenia Research Foundation, with a strong element of psychosocial interventions integrated into the practice. The incremental learning over the years and the incorporation of sound research methods has contributed to refining these methods in an on-going activity of delivering community mental health services.

**DAVAAND DUA** 83

Gopalakrishnan G, Arudhra Gopalakrishnan, Swetha S

Mental disorders are as old as mankind and different cultures and countries seek different methods to understand and manage the mentally ill. Tamil culture and Hindus believe that mental illness can be cured by prayer and worship at temples. The Muslim and Christian faith also have similar places of worship for the mentally ill in Tamilnadu. The temples continue to play an important role not only as places of worship, but also places of religious cures for bodily and mental illnesses. Tamilnadu is renowned for its ancient temples, some of which especially attract people suffering from mental health problems. This chapter discusses prayers and healing practices to improve mental illness.

**PSYCHIATRIC REHABILITATION IN GENERAL HOSPITAL PSYCHIATRY UNIT** 89

Amrita Roy, Bhaswati Kalita, Thanapal Sivakumar

Rehabilitation is an integral part of the holistic management of psychiatric disorders. General Hospital Psychiatric Units (GHPUs) are the most commonly opted treatment option as they have fewer stigmas attached, offer multiple specialties on one campus, and provide integrated physical and mental healthcare services. This chapter dwells on the feasibility of psychiatric rehabilitation at GHPUs, its challenges and facilitators, and possible psychiatric rehabilitation services. We also discuss some of the replicable practice-based evidence from the psychiatric rehabilitation field and the way forward.

## VOCATIONAL REHABILITATION IN INDIAN CONTEXT

103

Rajesh Mithur, Anil Kakunje

The psychiatric illness cause significant disability and cause poor psychosocial function. In psychiatric treatment the symptom recovery and social occupational functioning play an important role in functional recovery. The success of psychiatric treatment is determined by symptom recovery and social rehabilitation. Rehabilitation is the final important step in the treatment of psychiatric illness where the patient is reintegrated in the society. Vocational rehabilitation is the part of rehabilitation process where people are provided employment to sustain their living. The employment of a patient helps in patient satisfaction and symptom recovery. People with psychiatric illness have tough time in taking up jobs. In vocational rehabilitation proper employment opportunities are discovered, patient is trained and employed in spite of disabilities to get the maximum benefit. So the patients are supported and provided with secure jobs and helped to sustain a living.

## REHABILITATION OF PERSONS WITH SUBSTANCE ABUSE

111

Prabhat K Chand, Rahul Verma

Psychiatric rehabilitation services are collaborative, person-directed, and individualized, focusing on helping individuals develop skills and access resources needed to increase their capacity to be successful and satisfied in their lives. Rehabilitation usually focuses on recovery, which is poorly defined for substance use disorder. Most definitions consider abstinence as recovery, but as we know, substance use disorder is a chronic relapsing condition; hence the rehabilitation process in substance use disorder primarily focuses on making and maintaining the person abstinent from substance use.

## PSYCHO-SOCIAL TECHNIQUES USED IN PSYCHIATRY REHABILITATION

123

Rajeshkrishna Bandary P, Praveen A

Severe mental illnesses (SMI) pose challenges in treatment due to inadequate response to medications. Rehabilitation of these individuals often requires multiple non-pharmacological intervention delivered through a multidisciplinary team. Psychosocial interventions form the key components propelling them towards 'recovery'. Behavioural principles of operant conditioning and learning are used to inculcate behaviors that improve functioning and reduce problem behaviors. Reinforcement that increases the occurrence of behavior pervades most therapy forms and help in overcoming negative symptoms and cognitive deficits and developing social and vocational skills. Cognitive therapy based principles are used to reduce distress and behaviors related to anxiety, mood, obsessive-compulsive as well as the more resistant psychotic symptoms such as delusions and hallucinations. Social and community based inputs help in engaging family and community in providing the supportive environment for the client during reintegration. Nevertheless, specific interventions such as IPSRT and IPT and individualized programs can better rehabilitative outcomes.

## SCALES IN PSYCHIATRY REHABILITATION

137

Rajshekhhar Bipeta, Aditya Kashyap, Madhur M Rathi

A complete assessment is paramount before undertaking any intervention. The assessment needs to be multifaceted and multidisciplinary in terms of interventions like psychiatric rehabilitation. It needs to consider the factors related to the patient, illness, support groups, including family and caregivers, and the community to which the patient belongs. Some of the core values of the assessment for rehabilitation include- working with the patient for personally relevant goals, collaborating with the stakeholders, and decision making.

Different psychiatric rating scales play a vital role in evaluating various factors related to psychiatric rehabilitation ranging from patient assessment to the community. 90% of Indian patients live with their families. Families play an essential role in providing for the patient's basic, emotional, and financial needs. Families also play a significant role in treatment-related decisions (when, where to take treatment, rehabilitation-employment, marriage). It is essential to work closely with the families of the patient while working on rehabilitation.

#### IMPLEMENTING EARLY INTERVENTION FOR AUTISM IN INDIA : CURRENT STATUS

147

Supreeta Santosh, Athira N.D, Sathya Lakshmi P.S, Sowmyashree Mayurkaku, Nirupama Srikanth, Ashok MV

With the increasing prevalence of autism, the need for Early Intervention (EI) is paramount. Translation of guidelines and initiatives into implementation is an on-going challenge. This paper reviews the Indian scenario of EI in Autism Spectrum Disorders (ASD) - challenges and nature of available interventions. It aims to highlight potential models of care and the requisite downstream process to enable their implementation across the country. Intervention was grouped into Parent Mediated (PMI), Centre-Based and a combination of both. PMI is preferred by many Institutions to overcome the lack of availability of trained professionals. Up scaling efforts of one EI model - the ComDEALL model is noted, along with challenges. Evaluation of task shifting approaches has been minimal but promising. A clear increase in focus on public health and ensuring wider availability of services for children with ASD is evident. Evidence based models for programmatic implementation are lacking. Government initiatives such as the RBSK need to use task shifting models to achieve efficiency. Implementation studies of EI models of care are necessary. It is too early to predict the effectiveness of digital modes of intervention though they carry intuitive appeal. We must adopt locally relevant comprehensive models that can be upscaled to a larger population. Community health workers/ nurses can be options to provide manualized EI, especially in non-urban areas.

#### REHABILITATION OF PEOPLE WITH DEMENTIA

163

Nimmy Chandran, Santosh Kumar D, Shaji K.S

Dementia is a major global public health challenge. There is a sudden increase in the number of older people with dementia in India. We need to develop services for people with dementia.

Dementia care involves psychosocial rehabilitation, caregiver interventions, support and guidance. Person-centered management includes interventions which are, cognition oriented, emotion oriented, behaviour oriented, stimulation oriented and physical activity oriented. Caregivers have an important role in psychosocial rehabilitation. Long-term care and periodic reviews will help to make dementia care need based. The infrastructure for institutional care is less developed in India and is inadequate to meet the emerging demand for assisted living.



**TABLE OF CONTENTS**

<i>Sl.No.</i>	<i>Chapter</i>	<i>Page No.</i>
1	Psychiatry Rehabilitation : Global and local view	1 - 11
2	Rehabilitation of Homeless Person with Mental Illness : Shanthivanam Experience and Future Perspective	13 - 26
3	Psychiatry Rehabilitation : Regulatory requirements and functioning	27 - 43
4	Home to the Homeless : The Shraddha emotion	45 - 58
5	Rehabilitation of the homeless persons with mentally ill - Chittadhama Experience	59 - 69
6	Community Mental Health integrating Rehabilitation - What has an NGO contributed to practice	71 - 82
7	Dawa and Dua	83 - 88
8	Psychiatry Rehabilitation in General Hospital Psychiatry Unit	89 - 102
9	Vocational rehabilitation in Indian Context	103 - 109
10	Rehabilitation of Persons with Substance Abuse	111 - 122
11	Psycho-social techniques used in Psychiatry Rehabilitation	123 - 136
12	Scales in Psychiatry Rehabilitation	137 - 146
13	Implementing early intervention for Autism in India - Current Status	147 - 162
14	Rehabilitation of people with Dementia	163 - 173
15	Index	175 - 176

## **PSYCHOSOCIAL REHABILITATION : GLOBAL AND LOCAL VIEW**

Murali Thyloth<sup>1</sup>, Mathew Varghese<sup>2</sup>, Preetiparna Pattanayak<sup>3</sup>

### **INTRODUCTION**

The concept and practice of psychiatric rehabilitation has a long history in India. In its difficult journey from the colonial ages to the post-independence era, it has come across many hurdles. It has reached a significant stage today with the hard work of a few pioneers, institutes, and government reforms. Psychiatric rehabilitation or Psychosocial rehabilitation (PSR as it is called) is integral to managing chronic and serious mental illnesses. Essentially, this process enables an individual to get back into society with dignity and preservation of human rights, like any other individual who has no illness or disabilities.

### **DEFINITIONS**

Psychosocial Rehabilitation is "a process that facilitates the opportunity for individuals who are impaired, disabled, or handicapped by a mental disorder- to reach their optimal level of independent functioning in the community." There are other definitions that, in essence, incorporate various aspects of interventions which enable an individual to function adequately in society. Psychosocial rehabilitation can be defined as "a therapeutic approach to the care of mentally ill individuals that encourages each patient to develop his or her fullest capacities through learning procedures and environmental supports". Psychosocial rehabilitation includes services aimed at long-term recovery and maximization of self-sufficiency, distinguished from the symptom stabilization function of acute care.

PSR is an integral part of managing individuals with long-term mental illnesses. The components of rehabilitation for the mentally ill consists of biological factors, residual capacities of the individual, family support systems, social support systems, availability of facilities, trained human resources, and therapeutic techniques. These interventions should be person-centered, rights-based, and evidence-based and should be available to all individuals who are mentally ill. Further, it should be community-centered and address housing, employment, and personal dignity. Psychosocial rehabilitation is fundamental for establishing the individual's human rights as envisaged by the UN Convention for the Rights of Persons with Disabilities (UNCRPD, 2006). Countries that are signatories to this important convention are bound to protect the rights of persons with intellectual, psychological and physical disabilities. The World Health Organization has emphasized the protection of rights of individuals with mental illness and had launched an awareness and sensitisation program in the Quality Rights e-training launched on 12th April 2021.

In high-income countries, severe psychiatric disorders like bipolar disorders and schizophrenia have already become a major cause of disability. The LAMIC regions will also experience a similar reality. There is wide variation in accessibility and availability of services, legal provisions, policies and programs for mental health between high-income and low and middle-income countries. In addition, there is no uniformity in the practice of psychiatric rehabilitation all over the world. Geographical, cultural, familial, and socio-economic factors play a significant role

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Department of Psychiatry, Ramaiah Medical College, Bangalore.
2. Department of Psychiatry, St John's Medical College, Bangalore.
3. Division of Research and Patents, Ramaiah Medical College, Bangalore.



in models developed in one country for them to be easily replicated in another region. There are countries where practically no rehabilitation activity, legislation or mental health policy exists. So, there are bound to be discrepancies and gaps in accessing psychosocial rehabilitation for persons with mental illness. There are non-governmental organizations (NGOs) that are carrying out rehabilitation activities in some countries. Most often, these are provided in the form of charities or service rather than a human right.

#### **THE GLOBAL SCENARIO :**

Rehabilitation of the mentally ill though recognized as an integral part of the care of the chronic mentally ill is not practiced in many countries. Hence the developments in different parts of the world differ from well-established rehabilitation programs to absence of any programs at all.

In North America, the 1970s and 1980s marked a decade of transition from deinstitutionalization to community care and rehabilitation. There was remarkable growth marked by researchers in the psychiatric rehabilitation practices in different parts of the country. Evidence-based models were developed for many recovery goals, including employment, independent living, and community living skills. Illness self-management approaches included wellness recovery, action planning, and fostering the attainment of personal life goals. In other life domains, notably the interpersonal realm, social networks, friendship, and intimacy establishing Evidence-Based Practices (EBP) has been more difficult. Despite the broad endorsement of recovery as a guiding principle of Psychiatric rehabilitation, state mental health agencies in the USA, through their state Medicaid plans, continue to support outdated psychosocial services, such as brokered case management services, day treatment, and institution-based skills training. According to the state mental health leaders' annual reports for the federal block grant, approximately 2% of clients with serious mental illness have access to evidence-based psychiatric rehabilitation services, a statistic that has remained steady in reports over the last decade. Service gaps occur at three levels: states that have not adopted practices into their state plans, limited penetration within states that have adopted an approach, and limited capacity to serve clients within programs once procedures are established.

The current framework discussed above, raises the question of what percentage of this has been put into practice in European countries. Firstly, Europe is not a unified entity, not even the countries belonging to the European Union. The European Region wholly includes approximately 900 million inhabitants in 53 countries with considerable variance in economic and political conditions and a similar diversity in the provision of mental health care. The reforms in mental health started early in the UK during the mid-1950s. Health care, including mental health, is mainly provided by the National Health Service (NHS), financed by national taxation, and administered by the Department of Health. Rehabilitation services are provided in the health system as well as by non-governmental organizations.

In Germany there are good example of persons with serious mental illnesses working in an exclusive company and are taxpayers. In Italy the transfer from institutions to community was drastic and Psychosocial rehabilitation has developed based on the community. However, the Italian reforms also separated public mental health care for severe mental disorders and private mental health care for common mental disorders. Italian programs have addressed human rights issues and their rehabilitation programs incorporate those principles. Eastern European countries have not developed sufficient community facilities and rehabilitation largely remained with institutions.

Europe is currently overwhelmed with political, migration and economic issues. Differences between countries have created remarkably varied mental health service systems and psychiatric rehabilitation services. Nonetheless, European countries could unite in endorsing and implementing evidence-based, client-centered approaches to Psychiatric rehabilitation. Services could be driven by values, client preferences, outcomes research, and implementation science. Common strategies could promote recovery, social inclusion, and cost savings.

In Latin America the main aim of establishing a primary care community-based model has been a shared aspiration for most countries during the last two decades. The growing participation of patients and their families in the mental health delivery system is another crucial factor in ensuring comprehensive patient-centered psychosocial rehabilitation programs in Latin America. Health ministers of Latin America have endorsed the Caracas declaration for transforming psychiatric services in Latin America and initiated a revision of mental health legislation in several countries. Similarly, in 2013, the Brasilia consensus reiterated the need to expand a human rights perspective and promote psychosocial rehabilitation programs. These programs stressed the need to evolve from a hospital-centered into a community- and primary care-based model. Based on the Caracas declaration and the Brasilia Consensus, the laws and regulations of many countries in Latin America have been updated to improve mental health care delivery. Colombia, in 2013, enacted a new mental health law that puts forward the necessity to adapt the services delivery according to patient preferences. They introduced a robust framework for community-based care, that obligates the government to provide for social and labor inclusion of people suffering from mental disorders. Similar dispositions can be found in Peru's recent mental health law, which emphasizes community-based treatment, mental health networks, and psychiatric rehabilitation programs, including supported residential models. Latin America has some examples of psychosocial programs such as assertive community treatment, family psychoeducation, subsidized housing, and supported employment in the home group care model in Argentina, the community mental health centres in Chile, and the psychosocial community centres in Brazil.

These policies have influenced service development in various ways, but evidence-based Psychiatric Rehabilitation has not yet been prioritized and adopted in many areas. On the other hand continued hospital-based or facility-based care rather than community-based interventions has been adopted. Latin America's emerging economic resources can help achieve unique cultural assets and strengthen the community. Perhaps it can take advantage of the revolution in health information technology to develop mental health systems that are more functional, person-centered, and cost-effective than those in high income countries. Moreover, low priority for mental health in national policies and insufficient funding for mental health services are common barriers to the much-needed mental health services reforms.

Within Australia, psychosocial rehabilitation is provided through clinical and independent sectors. Public community mental health services in the clinical industry are increasingly recovery-focused and offer inpatient or community-based rehabilitation to varying extents. However, the independent sector, represented mainly by nongovernmental organizations is funded more explicitly to provide psychosocial rehabilitation and recovery support.

In Africa, services for rehabilitation of the mentally ill is non-existent or ill developed in some countries and regions. The application of psychiatric rehabilitation in Africa has utilized the integrated primary health care model supported by the World Health Organization and indigenous models. Developing countries, such as those in sub-Saharan Africa, face many challenges in

establishing and offering psychiatric rehabilitation services. They have limited resources to establish and run rehabilitation services similar to those in developed countries. In addition to poor budgets for establishing such services, these countries also have a severe shortage of appropriately trained providers. In primary health care systems, there is inadequate care for those with severe mental illness except for symptom management through the provision of ongoing antipsychotic medication.

In Asia, patients with severe mental illnesses are seen in a variety of mental health service settings, including general hospital psychiatric units, psychiatric hospitals, psychiatric nursing homes, polyclinics, and office-based practices. In Asia, psychosocial rehabilitation services are offered in a few well-resourced publicly and privately funded psychiatric hospitals and rehabilitation centers. Issues in South Asia are similar to what is existing in Africa. Facilities, resources, and trained manpower for rehabilitation of persons with mental illness is scarce. South Korea has well developed mental health care system and accessibility to rehabilitation is a reality. It is important in these regions to adapt the programs to neighbouring countries as there are cultural similarities.

#### **CONCEPTS IN PSYCHOSOCIAL REHABILITATION :**

The conceptual and theoretical basis of rehabilitation stems from the concepts in physical disability. By definition, an impairment is the loss of a structure or function. An example of this are the symptoms of mental illness. Disability resulting from the impairment is a lack of ability of individuals to perform tasks expected of them. A person with loss of a lower limb cannot walk.

Similarly, a person who has not learned or lost the skills of communication cannot communicate properly, and this can be termed one of the disabilities of mental illness. Handicap is the old term used for the disadvantage of an individual in role performance and is termed as limitation in participation.

The International Classification of Functioning, Disability and Health (ICF) provides definitions which are accepted currently. One must keep in mind that the terminologies and definitions in the area of disability and rehabilitation keeps evolving over years so as to be acceptable to all players in the field. In the ICF, disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders, and injuries) and contextual factors. Body Functions are physiological functions of body systems (including psychological functions). Body Structures are anatomical parts of the body such as organs, limbs, and their components. Impairments are problems in body function or structure such as a significant deviation or loss. Activity is the execution of a task or action by an individual. Participation is involvement in a life situation. Activity Limitations are difficulties an individual may have in executing activities. Participation Restrictions are problems an individual may experience in involvement in life situations. Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

#### **MENTAL ILLNESS AND PSYCHIATRIC DISABILITY:**

Most severe mental illnesses affect the individual at an early age, and there is no chance of learning or mastering skills. If an individual develops a disease at a later stage, the person is not in a position to use the skills during the illness process, and atrophy of skills occurs due to disuse, which can be termed disuse atrophy. The disadvantage in participation is a result of the impairments and disability. An example of this is getting and holding on to a job.

There are many ways this can be addressed. Before getting into the process, this can be viewed as a biopsychosocial issue. If we look at the biological problems in serious mental disorders like schizophrenia, there is ample evidence of dysfunction in many brain regions, especially in the prefrontal cortex. Different neurotransmitters are implicated in schizophrenia, bipolar disorders, depression, and other conditions. Medication is expected to correct the imbalance in the neurotransmitter system. Medication is the mainstay of treatment of serious mental disorders. In some conditions, psychotherapeutic techniques can be an effective adjunct to medication for ameliorating the symptoms. However, medication alone is not enough to bring back an individual to the community, or medicines cannot teach the individual how to take care of personal hygiene. Developing skills for leading a life in the community requires psychosocial interventions at the individual level. There are different approaches to this process. Psychological and environmental factors have a major role in modulating the behaviour of the individual, e.g., expressed emotions in the family, not getting a job, or segregation because of the stigma of mental illness. Many a time, there is a violation of basic human rights, and the person can get marginalized. The rehabilitation process starts when the individual starts the first consultation. In this process, the main players are the individual, family, society, and the multidisciplinary team of mental health professionals.

#### **INTERVENTIONS AT THE INDIVIDUAL LEVEL :**

There are many methods for assessment of impairments, starting with the clinical interview and the mental status examination. Today many assessments are done by using rating scales. Examples are the SCAN, SCID, MINI and depression rating scales. For a rehabilitation professional, these may not be available or may be time-consuming. In this scenario, a good mental status examination is the choice, which in turn develops a good understanding of the person. Thus, this can be done in any setting ranging from a tertiary care centre to a community centre.

Similarly, disability assessment also can be done through structured interviews like WHO DAS-2, independent living skills survey, and so on. WHO DAS-2 is a widely used scale. In India, we have the IDEAS, developed by the Indian Psychiatric Society and gazetted by the Government. The IDEAS is the official assessment instrument for government rehabilitation benefits. In practice, the best way to assess a person's functioning is to ask the individual how a day/ week is spent, which gives reasonable information about the individual's ability and disability. After the assessment there is need to prioritize disabilities and abilities which need to be taken up for interventions. This should be based on the needs of the individual, family, and society.

After this, every individual needs a program planning which is unique to that individual and family. This program planning takes into consideration the needs of the individual and family, which is realistic. A decision must be taken by the treating team on facility-based intervention or domiciliary treatment. At that point, it is important to decide how much professional input is required and what should be the extent of the families' involvement. This is the time when we discuss the availability of facilities for psychosocial rehabilitation. It is important to discuss setting goals with the treatment team, individual, and family. These can be short-term and long-term goals. Examples of short-term goals include disruptive behaviour, work behaviour, active symptoms, medication management, negative symptoms, interpersonal relationships, and social skills training. It is important to have short-term goals that are achievable in a short time, giving confidence to the whole team comprising of individual, family, and mental health workers. Long-term goals can be medication, residence, job, finances, follow-up arrangement, family arrangement, and community reintegration.

### COMMON TECHNIQUES USED IN PSR :

Techniques can be in various forms of behavioural interventions based on behavioural therapy. Coaching, Modelling, prompting, shaping overcorrection, Video feedback, Classroom teaching, Buddy training program, Cognitive training, Grain sorting, letter cancellation, and computer-based cognitive tasks. Today many computer programs offer various skills training programs. However, simple techniques like grain sorting and letter cancellation can be used in any city without many investments. To teach skills of daily living, there is a need to do a task analysis to frame the steps of interventions; for example, brushing the teeth is a very common task though many persons would really know the steps involved. The reason is that people tend to do it on a daily basis, and it becomes automatic and effortless. There is a need to break down this activity into smaller steps, and any steps which are done correctly have to be rewarded immediately. To make the techniques very effective, a task analysis and steps as given below information is important.

**Table 1**

Task Analysis : Brushing the Teeth
Steps : <ul style="list-style-type: none"> <li>* Taking the brush</li> <li>* Taking paste putting on to the brush</li> <li>* Finding a water source, wet it</li> <li>* Brushing - upward movements, side movements</li> <li>* Spitting the froth</li> <li>* Repetition of the brushing, spitting</li> <li>* Washing the mouth, spitting</li> <li>* Washing the brush, drying the brush</li> <li>* Wiping the face with towel... etc.</li> </ul>

It is also important to identify a powerful material reinforcement to reward the patient with. Each step needs to be reinforced with praise, and mistakes should not be criticized or punished. While making a mistake, withholding reinforcement is the punishment. It is also important to space the reinforcement over a period of time to improve the generalization.

### THE INDIAN SCENARIO:

The cardinal issues in PSR are the locus, focus, and modus. Locus is where the facility is available, accessible, affordable, and sustainable. Modus addresses the issues of techniques and methods used for reducing impairments and making the individual get fully reintegrated. The techniques used in PSR include therapeutic community, cognitive-behaviour therapy, group therapy, medication management, and social skills training. The rehabilitation focus is aimed at the individual to be reintegrated into their family and community. With this background, we can look at the psychosocial rehabilitation scenario in India.

At a community level, awareness, acceptance, community resources, community support, social network, and community participation are required to achieve optimal outcomes. Awareness programs are done in India by NGOs and governmental organizations. Programs run by NGOs have been found to be creative and interesting for people. Examples of these initiatives are the production of telefilms, short films, and drama and music programs with the participation of professional artists along with recovered persons. Similarly, Non-governmental organizations often associate with local religious organizations with their awareness programs during festivals. There are programs like school mental health programs where awareness programs are focused. Many stigma reduction programs have been conducted across the country to accept recovered individuals back into society. The community is rich with resources like structural facilities (building or land), volunteer and emotional support, food and clothing, and participation in programs.

### **SETTINGS / FACILITIES**

Facilities for psychosocial rehabilitation can be broadly divided into residential and non-residential. Residential facilities available in India are hospitals, halfway homes, hostels, long-stay homes, and domiciliary facilities. The first halfway home that was started in the early 70s in India is The Medico Pastoral Association and Halfway Home, Bangalore. Over the years, there have been many such facilities in the private sector as well as in non-governmental organizations in India. Common characteristics of a halfway home are limited period, homogeneity of diagnosis, nonmedical staff, family visits, structured programs, and psychosocial therapies. There are facilities for long stay home for individuals for whom the family is not there or willing to take care. These homes usually charge a fee for their services.

Non-residential facilities are those where individuals come in the morning and return to their homes in the evenings. Day-care centres are easy to manage, providing vocational and social skills and independent living skills training. Day-care centres usually have trained supervisors and professional consultation and allow heterogeneous diagnostic groups. The significant factor is that duration of the attendance is not limited. These centres are easy to manage, feasible in any part of the country, need low investments, and improve the self-esteem of the individual. The interesting feature of day-care centres is that individuals get care from mental health workers and their families simultaneously. Formation of family associations, Self-Help Groups (SHG), involvement of celebrities in mental health awareness, and people's participation in mental health care with the expansion of the District Mental Health Program to 692 districts gives hope for the future of psychosocial rehabilitation.

One of the developments in India has been the development of community-based rehabilitation with people's participation. This is slowly catching up with the involvement and participation of the community at large. Predominantly, these activities are initiated by nongovernmental organizations. One of the objectives of the District Mental Health Program (DMHP) of India, is community participation in mental health care, which is yet to take place in a meaningful way. However, some districts in different states have incorporated psychosocial rehabilitation facilities into their programs. WHO's emphasis on the rights of the mentally ill as per the UNCRPD is to be followed by all psychosocial rehabilitation centres. This is made possible by the Mental Health Care Act of India, 2017. Research in psychosocial rehabilitation is an area that needs further impetus. In this area, the Schizophrenia Care and Research Foundation (SCARF), Chennai, and NIMHANS, Bangalore have made a significant contribution.

**THE ROLE OF THE FAMILY IN PSYCHOSOCIAL REHABILITATION:**

The role of family in psychosocial rehabilitation is very important in the Indian context. Areas to be addressed in the family are the expectation, family education, coping strategies, resource utilization, expressed emotions, interpersonal aspect, family burden. This is done in many sessions by including all the family members living with the individual. Family caregivers must have full information about the illness and its treatment so that they are able to identify symptoms and deal with them in a skillful way. The family members in India do take charge of the medication management and supervise regular medicines and also act in getting the patient to regular follow up with the mental health professionals. They must be taught the early warning signs of a relapse and be able to identify this and get medical help early. They must also be taught to normalize their family rituals and routines to cause least disruption and ensure that roles are carried out. Family members also need to use all family resources and to reach out to their secondary social supports like extended family and friends. The patient and the family members must be taught communication skills to keep communication within the family simple, direct and verbal with low noise level, critical comments and hostility. They must be fully involved in supervising the patients daily schedule, daily living skills, and the rehabilitation program that has been planned for them by the treatment facility.

**INVOLVING THE FAMILY IN REHABILITATION:**

There are a number of reasons for involving the family in rehabilitation. Family members and relatives are the main caretakers of a mentally ill person in India. They supervise the medication intake and provide emotional, social and financial support for the affected member. When a family member is first affected by mental illness, the relatives usually do not know what is wrong. They notice the odd behaviors and may consider it a passing phase. They may attribute it to addiction or other explanations and do not consider the possibility of an illness. Watching a family member develop these behaviors can be upsetting. They will have fears and anxieties about the causes of these behaviors and the affected member's future. The family may want to help in the treatment of the individual but may not know how to do so and may feel helpless. The family may not have knowledge about the illness or know the importance of complying with medication. They may feel that they are responsible in some way for the causation of these behaviors and thus feel guilty. They may feel they are being blamed for the affected member's problems. They can become defensive about their role in the affected member's treatment.

The presence of an affected member changes the routine family life. The family members will have extra household chores, as the affected member is unable to contribute. Trying to keep the family life as normal as possible while simultaneously trying to help the affected member is frustrating. The family may find the affected member's behavior embarrassing and painful. They may avoid their normal socialization with others due to the stigma of having a mentally ill member. The affected member, while symptomatic, may become violent and be perceived as dangerous by the family. They may feel angry with the affected member especially when they feel that the affected member is 'lazy' or not trying to control their behaviors.

Families may experience severe stress, or marital discord or depression associated with living with this illness unless they receive help and support. The probability of the affected member relapsing is greater when the family's behavior with them tends to be over-involved, hostile, critical and dissatisfied (the components of expressed emotions). Although the family does not "cause" mental illness, the way the members interact and cope with the illness can determine the 'course' of the illness.

Family members become more involved or preoccupied with the affected member and each other than with non-related friends or neighbours and tend to withdraw from them. This increases the family isolation. They have fewer people to turn to for emotional or practical support (social support). The advantages of having social contacts are that they can be useful as temporary distractions from experiencing the pain of having an ill person. They provide general support and recreation to help the family members relieve their tensions. Social support systems prevent the family member from focusing and spending too much energy on the affected member and provide support in times of crisis.

#### **THE NEED FOR FAMILY EDUCATION, TRAINING AND SUPPORT :**

The family is an important support for the affected member. In the West it is estimated that 50-80% of persons with schizophrenia and related psychotic disorders reside with or have regular contact with a family caregiver. In India almost all persons with illness reside with their families. The family members know the affected member the best and yet often they lack the most basic information about the illness like the diagnosis, symptoms, different treatments, causes and the prognosis. They also lack knowledge about mental health resources, and care management strategies. These family caregivers, often parents and women, many of whom are elderly, are also financially strained, and often perform critical roles in support of their relatives and have less time to spend on themselves. Family members usually need to cope with their care giving responsibilities and their own emotional distress. The symptoms of the illness lead to increased stress and disruption. They also face social alienation and stigma. The financial impact of care giving is high, as they have to pay for psychiatric treatment, cut back or stop working and supervise the affected member.

Thus, they experience and report high levels of burden related to caring for their affected family member. However, they are often excluded from the treatment process, and their concerns are frequently ignored. Alienated from their ill relative, they feel guilty, stigmatized, burdened, and terrified. Families do not understand many aspects such as why an individual's behavior may be frightening and bizarre, why the person denies that anything is wrong, why there is resistance to taking medications or being hospitalized, and why very often they, the family itself is blamed by the patient and health care professionals. Families need to have timely, basic education about these painful and long-term effects of the illness on the affected member as well as themselves.

#### **CONCLUSION :**

Majority of psychosocial rehabilitation programs are influenced by Western concepts in terms of the spread of various forms of therapy. A few countries have developed indigenous ways and means of reintegration of a mentally ill person into society. Further, there may be a difference in perception of mental illness in different cultures, and some may be protective; in turn, this will reflect on the reintegration of these people into the community. There can be a variation between the urban and rural populations in this regard. Therefore, each nation must develop acceptable, accessible, and affordable rehabilitation programs for all persons with mental illness who need psychosocial rehabilitation. Very little information is available on the predictors of these services, particularly community-based ones among patients with severe mental disorders. The present concept of evidence-based treatments may be apt for biological treatment methods and may not be suitable for psychosocial interventions with family and community. The current system of evaluation of psychosocial interventions with the same parameters for measuring their efficacy may be reviewed to develop better parameters.



**REFERENCES**

- \* Bachrach LL. Psychosocial rehabilitation and psychiatry in the care of long-term patients. *Am J Psychiatry*. 1992 Nov;149(11):1455-63.
- \* Barton R. Psychosocial Rehabilitation Services in Community Support Systems: A Review of Outcomes and Policy Recommendations. *PS*. 1999 Apr;50(4):525-34.
- \* Bond GR, Drake RE. New directions for psychiatric Rehabilitation in the U.S.A. *EpidemiolPsychiatr Sci*. 2017 Jun;26(3):223-7.
- \* Chandrashekar H, Prashanth NR, Kasthuri P, Madhusudhan S. Psychiatric rehabilitation. *Indian J Psychiatry*. 2010 Jan;52(Suppl 1):S278-80. doi: 10.4103/0019-5545.69250. PMID: 21836694; PMCID: PMC3146207.
- \* Deva MP. Psychosocial rehabilitation models in the Asia - Pacific region. *Psychiatry and Clinical Neurosciences*. 1998;52(S6):S364-6.
- \* Dixon L, McFarlane WR, Lefley H, Lucksted A, Cohen M, Falloon I, Mueser K, Drake RE. The future of psychiatric rehabilitation. *Epidemiology and Psychiatric Sciences*. 2017 Jun;26(3):209-10.
- \* Dixon L, McFarlane WR, Lefley H, Lucksted A, Cohen M, Falloon I, Mueser K, Miklowitz D, Solomon P, Sondheim D. Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatr Serv*. 2001 Jul;52(7):903-10. doi: 10.1176/appi.ps.52.7.903. PMID: 11433107.
- \* Drake RE, Goldman HH, Leff HS, Lehman AF, Dixon L, Mueser KT, Torrey WC. Implementing Evidence-Based Practices in Routine Mental Health Service Settings. *Psychiatric Services* 2001 52:2, 179-182
- \* Gopinath PS, Rao K. Rehabilitation in Psychiatry: An Overview. *Indian J Psychiatry*. 1994;36(2):49-60.
- \* ICF Beginner's Guide: Towards a Common Language for Functioning, Disability and Health. WHO, Geneva 2002. Available from: [https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf?sfvrsn=eead63d3\\_4&download=true](https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf?sfvrsn=eead63d3_4&download=true).
- \* Kakunje A, Mithur R, Puthran S, Joy A, Shetty S. History of psychiatric rehabilitation in India. *Arch Med Health Sci [serial online]* 2021 [cited 2022 Sep 26];9:163-70. Available from: <https://www.amhsjournal.org/text.asp?2021/9/1/163/319379>
- \* Kigozi F, Kinyanda E. Psychiatric rehabilitation today:an African perspective. *World Psychiatry*. 2006 Oct;5(3):166.
- \* Luo H, McNeil EB, Feng Q, Li H, Chen Q, Qin X, et al. Utilization of psychiatric rehabilitation services and influencing factors among people with psychotic disorders in rural communities of Guangxi, China. *Int J Ment Health Syst*. 2018 Apr 17;12(1):17.
- \* Miklowitz D, Solomon P, Sondheim D. Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatr Serv*. 2001
- \* Mueser KT. Evidence-based practices and recovery-oriented services: Is there a relationship?Should there be one? *PsychiatrRehabil J*. 2012;35:287-8.
- \* Murali T, Tibrewal PK. Psychiatric rehabilitation in India. *Mental Health Care and Human Rights*. 2008 Jan 1;197-204.

- \* Neugebauer R. Review: World Mental Health: Problems and Priorities in Low-Income Countries. *Am J Public Health*. 1996 Nov;86(11):1654-6.
- \* Pathak A, Chaturvedi SK. A Systematic Review of Interventions in Psychiatric Rehabilitation. *Int J Med Invest* 2015; 4 (3): 272-281
- \* Rössler W, Drake RE. Psychiatric rehabilitation in Europe. *Epidemiol Psychiatr Sci*. 2017 Jan 19;26(3):216-22.
- \* Uribe-Restrepo JM, Escobar ML, Cubillos L. Psychiatric rehabilitation in Latin America: challenges and opportunities. *Epidemiol Psychiatr Sci*. 2017 Jun;26(3):211-5.



## **REHABILITATION OF HOMELESS PERSON WITH MENTAL ILLNESS- A SHANTIVANAM EXPERIENCE AND FUTURE PERSPECTIVE**

Arunkumar N<sup>1</sup>, Ramakrishnan K<sup>2</sup>

*God, grant me the serenity  
to accept the things I cannot change,  
courage to change the things I can,  
and wisdom to know the difference.*

### **ABSTRACT**

Homeless persons with mental illness (HPMI) are a fraction of people with mental illness, who out of their symptoms or social reasons wander on streets with poor self-care, are at risk of abuse, and survive hardships of nature denied human rights and dignity.

They remain in the streets until rescued by a significant person or organization. Offering food or cloth won't be sufficient, they have to be evaluated for physical and psychological conditions; start appropriate medications, rehabilitate and attempt to reunite with their family. Once reunited follow-up of such persons is essential to prevent further wandering

Our Trust Shantivanam is aimed at rescue, recovery, rehabilitation, reunion, and follow-up services for such HPMI, also to disseminate stigma and misconceptions around mental illness.

641 were rescued since 2003, 536 were reunited with their family members. 42%, were referred by Police, 32% by the public and 12% were from other NGOs. 55% were female, and 365 (56%) were from a rural background.

62% had a diagnosis of schizophrenia, 8.2% with acute psychosis, 7% with bipolar disorder, and 16% remained with psychosis unspecified. Currently, 52 persons are in rehabilitation waiting for the reunion.

Follow-up of the HPMI found equivocal results, from the caregivers, who wish them to take back, poverty, lack of significant others to care for, persistent symptoms, poor insight, and drug compliance, make them at risk to be homeless again.

This article details our experiential journey in serving HPMI.

**Keywords :** Homeless person with mental illness (HPMI), wandering, rescue, reunion, rehabilitation

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Consultant Psychiatrist - TRUST - Shanthivanam, Director - Athma Hospitals, Tiruchirappalli, Tamilnadu
2. Executive secretary, TRUST - Shanthivanam, Managing Director & CEO - Athma Hospitals, Tiruchirappalli, Tamilnadu

## INTRODUCTION

Homelessness among patients with severe mental illness remains one of the most challenging problems faced by providers of psychiatric services. The risk of becoming homeless for persons with schizophrenia and related disorders is more than ten times greater than the risk for the general population [1].

These homeless persons with mental illness are commonly exposed to severe psychological stress, as well as a range of serious physical health hazards including extremes in temperature, physical and sexual abuse, nutrition-related health problems, and potentially life-threatening infectious diseases.

Not uncommonly a person with severe mental illness walks away from home and may remain on the streets until treated, or when the acute episode subsides, negative and cognitive symptoms set up, and they may be wandering forever.



Another reason for homelessness is poverty, where the family members are unable to care for the person, who is uncooperative with the treatment and wander out.

Lack of appropriate family members and the recent death of a significant caregiver may end up in so far well-managed psychotic illness to flare up, and may wander out [2].

A hostile caregiver, for example, a brother-in-law may send a such person with unmanageable psychotic illness out voluntarily.

Last but not least a significant proportion of such homeless persons with mental illness have a symptom of "wandering", they prefer to be on the streets, or the highway.

## REVIEW OF LITERATURE

Globally the homeless population is estimated to be between 100 million to 1 billion [3].

There are 1.8 million homeless people in India, [4] and it is estimated that 20-25% of such person suffers from some form of severe and persistent mental illness [5].

Up to 14.3% of our population in INDIA has one or other forms of mental disorders, contributing 4.7% of DALYs in 2017, common among them were depressive disorders (33.8%), anxiety disorders (19%), Intellectual disability (10.8%), Schizophrenia (9.8%) and Bipolar disorder (6.9%) [6].

Illness like schizophrenia and bipolar disorder carries a higher rate of homelessness with a prevalence of 15%, which translates to around 400,000 HPMI in India [7].

The most common reason for such homelessness is poor family support, poverty, agitation, and aggression in the sufferers.

Stigma and discrimination play a major role in this process of homelessness. With inadequate support and strong gender bias, mentally ill women are rarely accepted into the family and are either abandoned or forced to fend for themselves, resulting in homelessness [8].

Many families are not willing to take care of mentally ill relatives especially if they are chronic and unpredictable behavior. Governments in developed countries have organized systems in place to help, and shelter such persons.

The National Commission for Women, India and NIMHANS collaborative study on addressing concerns of women admitted to psychiatric institutions in India based on 42 mental hospitals revealed that the majority of the recovered women patients who are staying in hospitals for >5 years is either brought through reception order or are admitted by the family members in a closed ward. These women are abandoned by the family by giving incorrect addresses, language barriers in tracing the families of patients belonging to other states, women with intellectual disabilities being unable to give their contact details, and family's reluctance to accept recovered patients by stating safety-related issues [9].

Data from a few other studies suggest that about one-fifth of the persons had mental illness before becoming homeless [10]. Many studies have pointed out that homelessness can also contribute to mental illness. Most patients were mentally ill before leaving their families and only a minority had received treatment. Stigma, misconceptions, and lack of accessible and affordable treatment were the common reasons for not initiating proper treatment at outset [11].

Most patients simply wandered away from home due to the influence of mental illness and could not go back home. Upon recovery from illness, HPMI was able to remember details of their native places. Most families expressed pleasure after receiving information about their missing HPMI family member. A relatively long time, averaging eight months and extending up to 38 months after hospitalization was required for reintegration. Only a minority of the families were not willing to take care of their patients and denied taking responsibility for their patients [12].

There are a good number of Non-Government Organizations (NGOs) in India to treat such persons like the Banyan and Anbagam in Chennai, Ashadeep in Guwahati, Samarpan in Indore, Shradda foundation in Mumbai, Chittadama in Mysore and many more.

Many states in India, doesn't have a separate rehabilitation centre for HPMI. Kerala has more NGOs that serve these people. From a Government perspective, Tamilnadu is leading by example, Government partly funds one NGO in each of 29 districts, to care for fifty HPMI per centre and nearby 1500 HPMI are under government patronage.

NGOs follow different patterns of admission and discharge procedures. Shraddha has appointed more social workers from different states and their rate of reunion is Phenomenal. They do this with a target of at least 1000 reunions per year. Banyan adopted only women patients, Now they have changed to a community based livelihood for HPWMI which is a unique one. This model also has some real challenges and risks.

### **SHANTHIVANAM - AN ABODE OF HPMI - FROM RAGS TO RICHES**

First, let us accept that the birth of Shanthivanam is not by choice. In 2002 Dr. K. Ramakirshnan then a budding psychiatrist had a call from Mrs. Viruntha Ramanan a social activist that an elder lady is found abandoned on the corner of her street, and requested if anything could be done. Dr. K. Ramakrishnan accepted the call and had sent his social worker to rescue her. It was raining heavily and the abandoned lady was shivering in cold. After the rescue, she was admitted to Athma Hospital, diagnosed with Psychosis NOS, with

the treatment, she improved and gave her details. Within 15 days she was back with her family. It was a happy moment for all of us.

Next week another teenage girl was brought by a women constable that she is loitering in the streets, on the interview, we diagnose her with Sczhopherenia, and with the treatment, she improved and reunited with her Mother. Had we not taken her, she would have been exploited and abused.



We feel it is a divine call, more and more homeless patients were brought to our hospital and from the management perspective, half of the ward was filled. Then it was decided to rent a building and the patient was shifted there. Then we felt the need for a permanent building to rehabilitate them and Shanthivanan was born.

We traveled thro thrones, and critical comments from the public to establish shanthivanam. Running the center was also extremely painful. But we stuck the task with prayers and with a determination that we will adopt as much as we could. Initial Phase we didn't look into legal aspects. Later we strengthened our process of maintaining funds. We couldn't follow the procedure to give FIR and it was very strenuous for us to the convince police department. All we did was to intimate the admission of a homeless patient to Panchayat Tahsildar and the nearby police station. With this process so far all admission procedures are going smooth.

Table 1: HPMI admission and their diagnosis

<i>Diagnosis</i>	<i>N</i>
Schizophrenia	398
Bipolar disorders	46
Acute psychosis	53
Intellectual disability with psychosis	19
Dementia	9
Severe depression with psychosis	11
Psychosis Unspecified	105

Of 641 admissions since 2003 majority were diagnosed as psychosis unspecified and later classified into major mental illness during subsequent interviews.

Table 2 : Source of Referral

Source of referral of HPMI	%
Public	32
Police	41
NGO	12
Panjayath members	5
Govt agencies	2
Media	2
Politicians	2

### CHALLENGES FACED DURING THE ADMISSION AND INITIAL MANAGEMENT

HPMI is bought under shabby conditions, with multiple rags, unbathed for months, skin lesions, old scars, poor dental hygiene, and anemia. All patients are admitted to ATHMA Hospital (Our Secretary's mental health establishment) for detailed evaluation, investigation, and medications.



Nine patients had HIV-positive status during admission; three among them were pregnant needing specialized care until delivery.

Eleven HPMI in term pregnancy were rescued, treated, and delivered with liaison with an obstetrician and the infant was referred to the appropriate child welfare committee. This shows society's attitude that mentally ill ladies were not spared from sexual abuse. Many women HPMI have shared how they were exploited and thank us for saving them. These events have made our work soul-satisfying.

Burns and fracture limbs were treated at appropriate centers with our staff as caretakers, which adds up to the cost of the initial management.

Anemia, Tuberculosis, and other medical and skin conditions were treated by our In-house physician.

Severe Mental retardation, a child with cerebral palsy, emaciated dementia, and HIV/AIDS were referred to appropriate residential care centers following the initial management.





### MANAGEMENT AND TRANSFER

The HPMI were interviewed on daily basis and pieces of information gathered are aligned to initiate psychological intervention.

It takes generally a month of In-patient admission for the initial positive symptoms to subside before they are transferred to our rehabilitation center.

Up to 12% of patients were reunited within the initial admission period. The caregivers arrived and were overwhelmed to take them back home.

The patients with such early reunion were either having acute psychosis, substance-induced psychosis with mood disorders.

Our quickest reunion was within 3 Hours, where an young girl rescued from streets with florid psychosis, meanwhile her parents had approached another police station, was contacted us and we could quickly reunite her with parents, we could see the joyful tears in her parents, she is on treatment till date.



### THE REHABILITATION

HPMI is welcomed in TRUST SHANTIVANAM upon initial management in ATHMA HOSPITAL Tiruchirapalli.

The medications are continued, and the nursing, psychiatric social workers, and Occupational Therapist staff conduct the initial assessment, they are classified into low, mid, and high functioning depending upon the clinical status, and disability using Indian Disability Evaluation and Assessment Scale (IDEAS) [13], and Brief psychiatric rating scale (BPRS) [14] is applied.

Table 3: IDEAS score of HPMI currently rehabilitated

Disability	71-99%	40-70%	<40%
Functioning	Low	Average	High
Male	3	17	4
Female	11	8	7
Total	14	25	11

Rehabilitation is aimed at improving the functioning level and maintaining clinical gains.

### HMPI WITH SEVERE DISABILITY

This group of HPMI requires monitoring of self-care, diet, medications, and physical and recreational activity. Generally, another well-functioning HMPI help them.

HPMI with a moderate level of disability.

Their self-care is good, have residual symptoms, and waiting for the reunion. They belong to the majority of the persons rehabilitated, focused on improving diet and hygiene, medication compliance. Various in-house activities that are aimed to improve physical, cognitive and social activity .



Areca plate: Biodegradable plate made from dried leaves from the areca tree. Two semiautomatic machines are functioning.

Cleaning liquid: They are prepared, bottled, and sold to neighboring hotels, schools, and hospitals. A good number of people are involved in the production and marketing of these products.

### HPMI WITH HIGH FUNCTIONING

These persons would be able to care for themselves and provide a significant contribution to caring for others. There are various social reasons for them to be in our centre for long. They are encouraged in various vocational activities.





### HURDLES IN REHABILITATION

Inmates have to be assigned work according to their clinical and cognitive status. Clinical status often varies; one cannot expect similar performance as the previous month, in comparison with any other business establishment. The finished products could nearly match what is sold in the market, the customers should prioritize purchasing them.

Careful monitoring is required when inmates are allowed to work with heavy machines, or even on agricultural land. We had two such incidents an accidental injury during areca plate making and a snake bite while collecting hay.



### TOURS AND PICNICS

Once in 4 months, our inmates are taken to tourist places, stay for a day and enjoy freedom. We have covered the whole of Tamilnadu and Kerala. This is made possible by sponsors.



### SALIENT FEATURES OF OUR MODEL

We adopt patients referred by the public or police. We get police references for every patient admitted.

All patients are admitted to a private hospital, which delivers free service.

Any co-morbidity is treated with the optimum treatment. The most common co-morbidity were Anemia, Tuberculosis, malnutrition, and Diabetes mellitus. We have treated Parkinson's disorders, Epilepsy.

We handled people with HIV and Pregnancy. All available treatments offered to private patients are offered to HPMI.

We provide risperidone to clozapine and amisulpride. Even minocycline is given to patients

with negative symptoms. We thanks our major sponsor for the same. We have succeeded in destigmatizing mental illness. The wholehearted support we get for the food and amenities from the public is evidence of the same.

We have networked with Banyan and Shraddha for the reintegration of HPMI from North Indian states.

Our Director Mr. M. Arasappan is a member of TamilNadu Government Welfare Board for Differently abled persons.

So far in 20 years, just 21 HPMI have escaped our campus. We have 27 deaths. This is very less for a service of 20 years.

### REUNION

This is the second part of the rehabilitation of HPMI.

Persons are encouraged to reveal their whereabouts as they improve, pieces of the puzzle are aligned, and Google map helps us to great extent. Once we get consistent information our community social worker would visit their place for confirmation. The work turns out to be much easier when they give a phone number.

We corroborate with Shraddha Foundation - Mumbai and similar NGOs in helping us with the reunion of HPMI.



Table 4 : The reunion of HPMI across INDIA

Northern States of India	64
Tamilnadu	430
Karnataka	12
Kerala	7
Andrapradesh	5
Srilanka	1

The duration of the reunion ranged from a few hours to 10 years.

*Mr. S, a Srilankan refugee, contacted us thro' our hotline when he was suicidal, he was rescued, found with severe depression with psychotic symptoms, and he had a severe financial loss, during the Srilanka crisis. He lost a doll manufacturing factory there and came to India and found no one to care.*

*As he improved clinically he continued to make clay and POP dolls. It attracted many and we had given a separate cubical for him to make. Production increased up to Rs 10000 per month. Though his family members were traced quickly, it took nearly five years for getting a passport back to Srilanka. We sincerely thanks our District Collector Dr. K. Venkatesh who helped him to get a temporary visa.*

*Mr. A 65 yr old treated for Dementia and was cared for 2 years, one of his friends identified him when he was on a visit to our centre. He was with his family after 10 years.*

### **HURDLES IN REUNION**

Some people improve well in a short duration. For others it takes time. The single most barrier was language. Once communication and cognition improve they share their identity, parents, sibilings' names, and their domicile. Many villages have the same names and are within the same district. We need to network to establish contact with the family.

89 of the 430 (23%) from other states were rescued and reintegrated. We thank shraddha, a pioneering NGO for helping us to reintegrate 66 HPMI.

The majority of the family accepted the HPMI with Joy and answered us to take care of them in the future. But some families resist taking them back, citing their financial difficulty. Some others see the HPMI as a taboo and stigma. "She has brought sin to us, and because of her, our community has isolated us". We had to use the goodwill of the village leaders, and police officials to make them accept.

### **CASE VINTAGE**

Mr. M an elderly mentally unstable person with a disability was rescued. He was examined & investigations showed severe anemia and also didn't have proper vision. He was given a blood transfusion and he underwent cataract surgery for both eyes. Once his vision improves his psychiatric symptoms dramatically Improve and returned to a premorbid state. While visiting his family they refused to take him. We have to influence local people to make them accept him.

Mrs. P

At admission, she has the feature of BPAD - Mania which improved very well. She gave her full address and was longing to meet her son. While taking to her residence, the family rejected her citing taboo and outcast. We brought her back. She went to the depression phase, again treated. She was rehabilitated to work as a personal attender to a consultant at Athma Hospital.

She was doing his job well and was given a salary also. Her longing to see her son intensified and refused to take food without seeing him. Again she was taken to her village and with the support of police and village leaders, forcible reintegrated. After a month time, our social worker visited her village, only to find out she is lost again.

**FOLLOW UP AFTER REUNION**

We followed up with patients reunited with their families, with the help of our community Social workers. Of the 40 families we visited, 20 were with their families, 5 were working, and 15 had wandered out. Most of them were thankful for their family member in good clinical condition after many years.

While many were not on medications, and in poor socio-economic conditions, they pleaded with us to take back the patient again, some cursed us for "bringing back the burden"

12 HPMI reintegrated into their family and found their way out to return to Shanthivanam again saying that they are comfortable there.

Beneficiaries often do not want a reunion and request to continue to be in the rehabilitation center, as they feel they are working now, and their family member cannot afford to care for them.

On many occasions, we were able to trace the family members but brought them back to our rehabilitation centre as they are orphans, only left by our siblings, or their In-laws do not want them anymore.

Few patients strangely wanted to live alone, and we had traced them working in hotels and textile companies.

Attempts are made for such persons to live in society under supervision. Our HPMI is working in hostels, hotels, and hospitals, with regular psychological support.

**SUPPORT**

The Public, police, media, other NGOs, factory union members, and celebrities create more public awareness. They sponsor food, clothes, materials, and purchase products encouraging beneficiaries.

Government authorities visit periodically, guide us, medication support, licensing, disability certificate, vaccine, and Aadhar cards. We could get voter IDs for our patients and 35 voted in the recent assembly election despite some party protests.

Friendly hospitals and doctors support us by treating medical and surgical illnesses at minimal expenses. A CSR project of a renowned hospital provide us with full medication support for the last 5 years.

Students, who visit for learning, engage our patients, teach skills, participate in group activities, and purchase the products. They also aid in reunion when language is a barrier.

Other NGOs accept patients with whom we are not equipped, such as minors, deserted women, Intellectually challenged, person with cerebral palsy, or neurological deficits, and HIV/AIDS.

### **FUTURE DIRECTION IN THE SERVICE OF HPMI**

Homelessness & HPMI both are global problems. Developed countries are also facing similar issues. Our efforts to see a world without homelessness are still a dream.

The following steps may help to reduce HPMI and prevent them from wandering again.

- \* Delivery of mental health services should be enhanced.
- \* Early identification of mental illness at the local level - Train ancillary nursing staff, self-help groups, and village leaders and train primary health physicians.
- \* Essential medicines including cheaper depot preparation should be available in all Govt. health centers.
- \* Short training courses for primary health physicians initiated by NIMHANS should enlarge.
- \* Tele Psychiatry setup should be made available in all health centres.
- \* Police and legal department should be sensitized to mental illness. They should help the psychiatric services to have hassle-free legal procedures so that psychiatrists can refer more HPM, MHCA 2017 should not be in the paper but should be practical.
- \* It's very difficult for Government alone to function independently in this service. Public and private, NGOs should be partners in the delivery of mental health services.
- \* Every psychiatrist should involve themselves in some form to reduce HPMI. Liberal use of depot preparation, prescribing cost-effective medicines and taking time to explain the NOI, prognosis, and the importance of drug adherence to caretakers are essential. Psychiatrists should give equal importance to rehabilitation as to medication.
- \* A pan India website where photos of identified HPMI can be uploaded. All stakeholders can use this portal and help each other to identify the address of the HPMI.
- \* Networking of NGOs in the service of HPMI will also help in the rehabilitation. Periodic workshops and meetings of NGOs will enhance knowledge sharing. This network can represent the government's absents and the current difficulties faced by them and give suggestions to the Government. This network can help each other in the periodic review of the reintegrated HPMI in their area of service. This will prevent the clients from going to the streets again. Support services to caregivers can be enhanced.
- \* Community-based rehabilitation should be enhanced. Training the caregivers and clients in vocational activities, helping them to market the products, and giving financial advice can go a long way in destigmatizing mental illness, and enhancing the spirit of the clients. We can give dignity and the right to live back to them.
- \* Financial stability and mental illness are inversely proportional. No amount of work in mental health will be fruitful without enhancing the economy at the individual and community level. Poverty reduction should be the utmost goal of the government.
- \* The mental health professional should help persons with mental illness to register unique disability IDs. All state governments should give the disability allowance, to PWMI on par with support to other disabilities as it is given to other disabilities.

**TAKE HOME MESSAGE**

1. Wandering the mentally ill is an infrequently discussed topic, the tedious involuntary admission procedure, and increased cost of management make us overlook it.
2. The growing population and aggravating stress, increase the incidence of psychiatric illness. Lack of adequate mental health services together with a lack of awareness mainly in rural areas. Poverty, social stigma, and lack of adequate support from significant others make the caregivers feel burdened and even let them go.
3. With proper medical care, supportive counseling, and occupational training these patients can be brought back to lead a decent life with self-dignity.
4. Psychiatrists should form a fulcrum around whom other professionals and volunteers should form an organization to bring back the dignity and self-respect of these unfortunate citizens of our society.
5. Government should frame guidelines that are practically applicable to NGOs who work in this difficult segment.
6. Networking of NGOs and the public domain to identify HPMI will ease the integration.
7. Early identification of mental illness, awareness of the destigmatizing of mental illness, and cost-effective treatment should be made available at each taluk hospital.
8. Universal brotherhood, empathy, and the value of dignity for the individual should be spread among the public and particularly the younger generation.

It's the duty of the nation not only to add years to life but to life to years.

- J.F. Kennedy

SUPPORT, NOT SYMPATHIZE WITH MENTALLY ILL...





**REFERENCES**

1. Susser E, Moore R, Link B: Risk factors for homelessness. *Epidemiologic Reviews* 15:546-556, 1993
2. Chatterjee R, Hashim U. Rehabilitation of mentally ill women. *Indian J Psychiatry*. 2015;57:S345-53.
3. Gilbert A. *An Urbanizing World: Global Report on Human Settlements, 1996*: United Nations Centre for Human Settlements (Habitat) Oxford: Oxford University Press; 1996. p. 559
4. Gopikumar V. *Understanding the Mental ill Health-Poverty-Homelessness Nexus in India: Strategies that Promote Distress Alleviation and Social Inclusion*. 2014.
5. National Resource and Training Centre on Homelessness and Mental Illness "Get the Facts". 2003.
6. The burden of mental disorders across the states of India: the Global Burden of Disease Study 1990-2017 *Lancet Psychiatry* 2020; 7: 148-61
7. The Clinical Presentation and Outcome of the Institutionalized Wandering Mentally Ill in India Gaurav Singh, Nilima Shah, Ritambhara Mehta *Journal of Clinical and Diagnostic Research*. 2016 Oct, Vol-10(10): VC13-VC16
8. Moorkath F, Vrandan MN, Naveenkumar C. Lives without Roots: Institutionalized Homeless Women with Chronic Mental Illness. *Indian J Psychol Med*. 2018 Sep-Oct;40(5):476-481. doi: 10.4103/IJPSYM.IJPSYM\_103\_18. PMID: 30275624; PMCID: PMC6149306.
9. Murthy P, Naveen Kumar C, Chandra P, Bharath S, Math SB, Bholra P, et al. *Addressing Concerns of Women Admitted to Psychiatric Institutions in India - An In-depth Analysis*. New Delhi: National Institute of Mental Health and Neuro Sciences and National Commission for Women; 2016.
10. Dean R, Craig T 1999 Pressure points' why People with Mental health problems become homeless [www.crisis.org.uk/download.php/146/pressure\\_points.pdf](http://www.crisis.org.uk/download.php/146/pressure_points.pdf)
11. Speak. S, Tripple G 2006 Perceptions, Persecution and Pity: the limitations of interventions for homelessness in developing countries. *International Journal of Urban and Regional Research* 30, 172-188.
12. Tripathi A, Nischal A, Dalal PK, Agarwal V, Agarwal M, Trivedi JK, Gupta B, Arya A. Sociodemographic and clinical profile of homeless mentally ill inpatients in a north Indian medical university. *Asian J Psychiatr*. 2013 Oct;6(5):404-9. doi: 10.1016/j.ajp.2013.05.002. Epub 2013 Jun 18. PMID: 24011688.
13. The Rehabilitation Committee of the Indian Psychiatric Society. *IDEAS (Indian Disability Evaluation and Assessment Scale) - A scale for measuring and quantifying disability in mental disorders*. Gurgaon, India: Indian Psychiatric Society; 2002.
14. Overall, J. E., & Gorham, D. R. (1962). The Brief Psychiatric Rating Scale. *Psychological Reports*, 10(3), 799-812.

## **PSYCHIATRY REHABILITATION : REGULATORY REQUIREMENTS AND FUNCTIONING**

Sunil Kumar Giriappa Patil<sup>1</sup>, Subramanyam M<sup>2</sup>, Mahesh R Gowda<sup>3</sup>

### **INTRODUCTION**

“Mental health issues” is a growing global concern. Owing to changing social, cultural and economic dimensions, mental health management is now gaining paramount importance and is drawing attention of healthcare professionals and policy makers. The history of regulating mental health dates back to Lunacy Act 1858 which laid down the rules and regulations for rehabilitating the mentally ill [1]. The Erwadi tragedy [2] is a fire accident that took place in 2001 led to kill 26 chained mentally ill people, and this prompted reforms in then prevalent Mental Health Act 1987. Persons with mental illness (PMI) are more vulnerable to abuse, neglect and human rights violations due to the nature of illness. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [3] has made a resolution in 2006 for giving equal importance to provide social care and human rights considerations for disabled individuals (including persons disabled due to mental illness), and this resolution has been ratified by India in 2008. Lack of availability of mental health facilities is significantly retarding the treatment opportunities both in developing and developed countries. However, with the implementation of new regulations like Mental Health Care Act – 2017[4] (MHCA 2017), there is more hopeful environment than before in the field of mental health. Psychiatric rehabilitation is an integral part of management of any person diagnosed with mental illness or disability, which must be initiated as early as possible to have a better functional outcome [5]. The new regulations bring the Psychiatric rehabilitation Centre (PRC) under the purview of Mental Health Establishment (MHE). There are certain grey areas in the MHCA 2017 with respect to implementation of psychiatric rehabilitation and its regulation. Thus, it is prudent that we need to have clear understanding on the PRC and its functioning in the framework of new regulations. This chapter is aimed to give an insight into the development of psychiatric rehabilitation systems based on time-tested knowledge aided by the regulations stipulated by apex bodies.

### **MENTAL HEALTH ESTABLISHMENT AS PSYCHIATRIC REHABILITATION CENTRE (PRC)**

MHCA 2017 defines the Mental Health Establishment (MHE) as any health establishment (government or private) governed by appropriate government and local authority, meant for the care of Persons with Mental Illness (PMI) [4]. MHEs can be of different kinds including, a) MHE with out-patient (OP) services, b) MHE with both OP and in-patient (IP) services with or without rehabilitation services, and c) Psychiatric Rehabilitation Centre (PRC). Rehabilitation is the process of improvement in the functional, personal, social and familial domains of PMI which helps them to integrate with social setup. These rehabilitation services can be broadly classified based on the four main models of intervention – recovery, respite, rescue, and retention [6]. The recovery model helps persons who have recovered from the illness to function optimally at a social level. Respite model is for the patients with residual symptoms. Rescue model is for the homeless and wandering mentally ill, and finally the retention model is for the patients who have resistant illness or difficult to be managed at home.

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Associate Professor, Dept. of Psychiatry, Sri Siddhartha Medical College, Tumkur, Karnataka
2. Consultant Psychiatrist, Spandana Nursing Home, Bengaluru, Karnataka
3. Consultant Psychiatrist and Director, Spandana Health Care, Bengaluru, Karnataka

Based on type of rehabilitation services provided the MHEs can be of following kinds [7]:

- (i) Day-care centre
- (ii) Vocational training centre
- (iii) Sheltered workshop
- (iv) Quarter way home (Hostel)
- (v) Residential halfway home
- (vi) Long stay home
- (vii) Community living centre for PMI

The first four facilities come under extramural set up where PMI can visit centre where as other facilities need intramural setup (MHE with Rehabilitation facilities). In addition, a full-fledged Psychiatric Rehabilitation Centre (PRC) for providing rehabilitation services is essential in MHE, especially where long-term patients and bed-strength more than 50 are there [7]. An attempt to explain different services is done below.

**Day care centre** runs for the benefit of patients who can come to centre and go back to their home by evening. Since patient will be getting stipend, this will help in involvement of family, reducing cost of in-patient care, reducing burden of family member in caring patient and allowing them to earn for the family. Centres are run by special educators or vocational trainers. Importance is given to vocational training which is relevant to local area. Day care is very affordable, more accepted and can be run in villages easily [8].

**A half-way home** is a less restrictive transitional living facility for persons with mental illness who are discharged as inpatient from a mental health establishment, but are not fully ready to live independently on their own or with the family (Section 17, MHCA 2017) [9].

**Long stay home** caters to the needs of persons with chronic schizophrenia or mood disorders who require longer duration of stay. This facility is meant for those clients where the families are unable to provide constant and continuous support in their homes due the circumstances prevailing in their lives [9].

**Sheltered workshops** solicit manufacturing jobs from local business and industry and provide support and supervision to people with disabilities in a factory - like setting owned or operated by the agency.

**Sheltered accommodation** is a safe and secured accommodation option for persons with mental illness, who want to live and manage their affairs independently, but need occasional help and support. (Section 17, MHCA 2017).

**Supported Accommodation** or Supported living is a living arrangement whereby someone, in need of support, who has his rented or ownership accommodation but has no live in caregiver, gets domiciliary care and a range of support services from an agency to help living independently and safely in privacy of his/her home. Support and help are provided to individuals in need, at their doorstep, as required to live a normal life (Section 17, MHCA 2017).

## **MHCA 2017 Vs PWD ACT NEEDS**

Persons With Disabilities (PWD) Act 2016 [11] emphasizes on preventive and promotional aspects of rehabilitation like education, employment, vocational training, creation of barrier free environment which makes them feel less discriminated and more independent. Adequate facilities and support system in infrastructure for facilitating movements of disabled people like ramp passenger way, lift, wheel chair assistance railings, and special toilets. PWD Act also facilitates provisions for disability certification, pension benefits and also reservation in travel and employment. On the other hand MHCA 2017 emphasizes more on rights of the people with mental illness. It safeguards basic rights like safety, hygiene, sanitation, leisure, recreation, dignity, privacy, and protects them from abuse. MHCA 2017 mandates need for rehabilitation and community integration as a right of PMI. Thus, it mandates government to provide such facilities to uphold the rights of PMI through mental health authority. In the following sections, a broad framework for structure and process in the PRC are discussed

### **1.1. STRUCTURE OF A PSYCHIATRIC REHABILITATION CENTRE (PRC)**

#### **1.1.1. Infrastructure**

A Psychiatric rehabilitation centre needs an infrastructure specific to a psychiatric set-up by encompassing both out-patient and In-patient facilities [7]. In-patient infrastructure of rehabilitation centre needs inpatient facilities where varied living accommodation such as single/double-bedded rooms, family accommodation and long dormitory wards are available. Separate accommodation for males and female inmates, with separate cot for each patient and accompanying attendant is also needed, wherever necessary. The facility should be well ventilated and well-lit at all times with ease of accessibility and prime importance for safety of the patient. The overall design of doors, windows, fixtures, furniture should ensure patient safety. A furnished nursing station, examination room, and interview room are advised. Adequate bathing and toilet facilities must be maintained. Safety and privacy of the patient has to be maintained, in also accordance with Persons with Disability Act (PWD Act) [11], at all times by having adequate supervision personnel and surveillance systems. PRC should have separate rooms or halls for various activities for rehabilitation with relevant infrastructure (painting room, carpentry room etc.). A CCTV (Close Circuit Television Monitoring) system should be in place for safety of the patients in PRC [7].

#### **1.1.2. Manpower / Human resource of PRC**

- a. **Psychiatrist** : A psychiatrist with minimum qualification of Diploma/MD/DNB in Psychiatry and registered with the National Medical Council.
- b. **Counsellors** : One counsellor per 30 beds. Minimum qualification of counsellor should be graduate degree in Clinical Psychology / Psychology with six-month work experience in De-addiction/rehabilitation services.
- c. **Psycho-Social workers** : One for up to 20 beds, two for 21-50 beds and three for 51 or more beds. A psychiatric social worker should have minimum qualification of PSW/MSW with six-month work experience in De-addiction services.
- d. **Nursing staff** : Number and qualification of the nursing staff can be stipulated by considering the norms of Nursing Council of India.

- e. **Support Services / Staff** : As per the requirement of the PRC staff for clerical and managerial assistance, general assistance, security, sanitations etc., can be employed either on In-house or out-sourcing arrangements, whichever is convenient. Additional skilled staff for giving training in yoga, painting, music, physical exercises, gardening, speech therapy, physiotherapy etc.
- f. **Rehabilitation Volunteers (Rehabilitators)** - Volunteers from diverse background like retired people, house wives, college students can assist persons with disabilities. Also, the patients who are recovered can work as rehabilitators to support PMIs in rehabilitation process.

The staff working in PRC are preferably required to be registered with Rehabilitation Council of India (RCI). For managing the man power in PRCs it is necessary to follow different steps including a) staff selection, b) orientation, c) frequent job evaluation and continued training. One of the challenges to PRCs is dearth of the trained staff. Thus, immediately after recruitment they have to be trained well to follow norms of PRCs and government rules and regulations stipulated for running PRCs. A table depicting possible difference between exclusive PRC and MHE is given below

<i>Area</i>	<i>Components</i>	<i>PRC</i>	<i>MHE</i>
License	SMHA License	Yes	Yes
	KPME	Y/N	Yes
	Fire	Yes	Yes
	Pollution Control	Yes	Yes
	Pharmacy	Y/N	Yes
Infrastructure	Bakery Room	Yes	Y/N
	Carpentry Room	Yes	Y/N
	Arts and Crafts Section	Yes	Y/N
	Yoga Sessions	Yes	Y/N
	Dance Classes	Yes	Y/N
	Recreational Activities facility	Yes	Yes
	Cookery Section	Yes	Y/N
	Drama Therapy	Yes	Y/N
	Music Therapy with Karaoke facility	Yes	Y/N
	Picnic Facility	Yes	Y/N
	Sports Activities	Yes	Y/N
	Gym or Exercise Facility	Yes	Yes
	Gardening	Yes	Y/N
	Vocational Training Units	Yes	Y/N
	Placement Units	Yes	Y/N

<i>Area</i>	<i>Components</i>	<i>PRC</i>	<i>MHE</i>
Staff	Artist	Yes	Y/N
	Occupational Therapist	Yes	Y/N
	Vocational Instructor	Yes	Y/N
	Psychiatric Nurses	Y/N	Yes
	PSR Counsellors	Yes	Yes
	Psychiatrist	Yes	Yes
	Psychologist	Yes	Yes
	Creative Therapist	Yes	Y/N
	Speech Therapist	Yes	Y/N
	Physiotherapist	Yes	Y/N
	Yoga Trainer	Yes	Y/N
Patients	IP Care	Y/N	Yes
	Acute Patients	No	Yes
	MHCA Sections	86	86,89,90
	Day Care	Yes	Y/N
	Procedure Room for ECT, rTMS	No	Yes
Legal	MHCA 2017	Yes	Yes
	POCSO Act	Yes	Yes
	PWD Act	Yes	Y/N
	NDPS Act	Y/N	Yes

**Table 1 - PRC Vs MHE - Possible Differences**

### **MHE for Substance use Disorders**

Any centre with inpatient facility services for substance use disorders needs to comply with MHCA 2017 and NDPS act 1985. Many centers need to be equipped with facility to manage cases with dual diagnosis. Alcoholic Anonymous (AA) meetings - Global model of group meeting for people with alcohol use disorders run by sober patients, is now being integrated in many MHE. Group therapy methods like therapeutic communities can be utilized [12].

## **1.2. Process of a Psychiatric Rehabilitation Centre (PRC)**

### **1.2.1. Admission Procedures**

Preadmission process - the patient should be preferably asymptomatic and should be having a referral letter for the need of rehabilitation process.

Admission process - After explaining the process of treatment and fees related issue to the family, patient is admitted under section 86 of MHCA 2017.

Evaluation for disability - Evaluation of the patient in terms of need of type of rehabilitation, strength, weakness, past experiences, environment needs, family support, community support and degree of disability is evaluated by standardized scales. Evaluation can also be done to know whether patient needs vocational training, supported employment or educational needs.

Assessment and certification by authorized personal regarding the requirement for admission and treatment of PMI need to be obtained.

Patients have to be assessed for their disability, family burden, coping skills, quality of life and work performance [13]. These scales will also be useful to assess their improvements and recovery on regular basis during their stay in PRC.

Education - Family should be educated regarding disability, type of interventions in centre, its outcome and also long-term issues.

Individual management plan is drafted as per strengths and weaknesses of patient, family and social support. Patient is trained in particular skills and the learning is also evaluated regularly under supervision of trained staff.

The Recovery Star is an outcome measure which enables people to measure their own recovery progress. The Recovery Star also enables organizations to measure and assess the effectiveness of the services they deliver. The star contains ten areas covering the main aspects of people's lives, including living skills, relationships, work and identity and self-esteem. For each of the ten areas, there are five stages based on Ladder of Change model such as - being stuck, accepting help, believing, learning and self-reliance. However, little is known about its reliability and external validity [14].

#### **1.2.1 a. Mental Capacity Assessment of PMI**

Mental capacity means whether the person is able to take his own decisions. Capacity assessment of PMI is very important for mental health professionals during the admission to comply with moral, ethical, and legal rules. The guidance document (MHCA 2017; Section 81) for capacity assessment should be followed [15].

#### **1.2.1 b. Seeking Consent of PMI and Nominated Representative (NR) for Admission and Treatment**

Utmost care should be taken to ensure that PMI and/or NR are properly informed about the contents in the consent form. Proceeding against the person's wishes for admission and treatment would amount to the deprivation of liberty, liable for tort, and in some cases, criminal assault. Besides, if consent is obtained from an incompetent patient, it is usually considered invalid by the law. In such a situation's physicians may face legal action for treating the person without informed consent [10]. The MHCA mandates to seek consent first from the PMI for any procedure then to follow the advance directives, if available and finally NR's consent (NR shall involve in supported/shared decision-making).

#### **1.2.1 c. Admission of PMI – Special Population**

In case of child/adolescent care in PRC (Mental Retardation, Cerebral Palsy etc), child psychiatrist and child psychologists, special educator, speech and behavior therapists, trained nursing staff are needed. Infrastructure of the PRCs should have interview and

assessment area and play and recreational area suited for children, and in-patient facilities to include stay for parents/family. Tools for IQ and disability assessments to be available. State or NGO run mental retardation homes do not come under MHCA 2017.

- i. While admitting the pregnant and lactating women MHEs, adequate number of trained staff to deliver psychiatric care for pregnant and lactating women should be ensured. Adequate facilities need to be made available to keep the infant with the mother with measures to ensure safety for both the child and mother. Availability of Pediatrician/ Neonatologist on-call basis has to be ensured.
- ii. In case of admission of geriatric population who can have psychiatric illness or dementia or both, infrastructure in PRC would require in-patient facilities to facilitate the elderly patients especially in patients with dementia. It is required to provide the Consultation Liaison from other healthcare professionals from other department to treat medical co-morbidities. Special care about nutrition and physical rehabilitation of elderly population also needs to be ensured.
- iii. While admitting LGBTQ population MHEs, trained staff/personnel who are sensitised regarding gender equity are the must. In addition, such MHEs should have gender sensitive toilets / rest rooms.

#### **1.2.3. Nutrition and Diet**

Patients should have access to wholesome food and daily dietary requirements (If an in-house kitchen is maintained, appropriate regulatory norms must be followed as per FSSAI norms). In case of PRCs admitting minors, Pediatrician / Dietician have to assess and suggest special nutritional needs.

#### **1.2.4. Sanitation**

Sanitation should be maintained in all the areas including toilets and bathrooms using disinfectants. The ratio between the number of toilets and bathrooms and number of patients should not be less than 1:5 and 1:10 respectively. There shall be separate toilets and bathrooms for male and female inpatients. Number of wash basins outside the toilets / bath rooms and in the dining area should not less than 1:12. Twenty-four-hour availability of water in wash basins, bathrooms and toilets must be ensured.

#### **1.2.5. Infection Control**

Proper measures should be taken to have adequate infection control measures and pest control policy. Institutional infection control team should be constituted to undertake institution-specific standardized infection control measures.

#### **1.2.6. Bio-medical Waste Management**

The biomedical waste should be segregated, collected, and disposed by complying with the recent and updated guidelines specified by Biomedical Waste Management Agency.



### **1.2.7. Recreation Facilities**

Indian practices that are promotive of mental health (e.g., meditation, yoga, prayer, and social support in crisis situations) should be identified and encouraged [16]. Maintenance of physical health is also to be encouraged by providing facilities for physical exercises. Other recreational activities like both indoor and outdoor sports facilities, movies, picnic, artistic works and a library with a reading facility can also be provided. Music therapy can be used by arranging singing classes and karaoke competition and also as a part of entertainment. And regular competitions or several games among the PRC inmates creates more enthusiasm to participate with more interest.

### **1.2.8. Disability Specific Rehabilitation**

PMI can have disabilities in particular domains, such as, cognitive deficits, social skill deficits, occupational deficits, and disease specific deficits. Once PMIs are asymptomatic, they need to be assessed for specific disabilities and PRC should focus on disability specific rehabilitation such as a) cognitive rehabilitation, b) social skills training, c) vocational training, d) community-based rehabilitation and e) disease specific rehabilitation. These rehabilitation attempts can help PMIs to re-integrate themselves into the society [17].

#### **a) Cognitive Rehabilitation**

Cognitive deficits are major area of concern in severe mental illness and this also hinders the person's rehabilitation process. Cognitive Rehabilitation or Cognitive Remediation is the non-pharmacological intervention that will address cognitive issues that impact functional outcomes in patients with mental illness. Thus, it has to be addressed at PRC through appropriate cognitive remediation measures for improving attention-concentration, memory, executive functions among PMIs [18]. Several techniques used in Indian setup are grain sorting, line drawing; number connection trials, color filling, design copying and also computer based cognitive programs.

#### **b) Social Skills Training**

When the PMIs have social deficits such as communication deficits, anger, and behavioral issues etc, they need to be taught specific social skills like communication skills, assertiveness training, anger management through appropriate behavioral models like token economy, behavioral contracting, reinforcement/punishment methods, time out techniques etc. [19,20].

#### **c) Vocational Training**

Studies have reported that working patients had lower symptom severity, re-hospitalization rates, duration of hospital stay, significantly higher self-esteem and perceived quality of life and better overall functioning than those who did not work. Vocational needs of PMIs are assessed and those who are in need must be provided with suitable Vocational training such as carpentry, bakery, gardening, painting, tailoring, etc [21].

**d) Community based Rehabilitation (CBR)**

There are various community resources focusing of health, education, livelihood, social and empowerment, which can be utilized for the rehabilitation of PMIs [21]. For using such community resources assistance of families, volunteers, NGOs and government setups can be taken. Telepsychiatry facilities can be utilized with help of live video teleconferencing equipment. The CBR model is a feasible model of care for chronic schizophrenia in resource-poor settings. Coordination with District Mental Health Programme (DMHP) team through National mental health program, conducting mental health camps and creating mental health awareness are part of CBR. (Section 18, MHCA 2017)

**e) Disease specific rehabilitation**

Rehabilitation services should focus on disease specific deficits among PMIs. For example, in PMIs with substance use disorders the focus of PRCs should be on de-addiction, relapse prevention, motivational enhancement and life style modification. Children with IDD, ADHD, ASD and SLDs should be provided with appropriate rehabilitation measures in the PRCs. Often PMIs have associated physical disabilities and for such individuals, physical rehabilitation measures such as physiotherapy, physical aids should be provided. PRC taking care of children with disabilities should comply with MHCA 2017 (Except MR) and RPWD act 2016 and POCSO act.

**1.3. Licensing****1.3.1. Licensing from State Mental Health Authority (SMHA)**

Once all Infrastructures and Processes are in acceptable conditions, the PRC can apply for its registration and permission from the concerned agencies and departments (SMHA). The PRC should ensure that the application for registration has been prepared as per the guidelines set by the State Mental Health Authority.

**1.3.2. Licensing from other agencies****a) Licensing from Clinical Establishment Act 2018**

The Clinical Establishment Act 2018 is operative in a number of states for registration and regulation of all modalities of medical facilities and applies to therapeutic as well as diagnostic clinics inclusive of single-doctor clinics. PRC which would like to utilise medical facility/Pharmacy should apply for License along with trade license wherever applicable.

**b) Licensing from State Pollution Control Board**

The license from the State Pollution Control Board is mandatory for PRCs and thus application should be given after fulfilling necessary guidelines and maintenance of standardized biomedical waste management guidelines (22). The in-charge of the MHE/PRC needs to apply for license from the State Pollution Control Board of the respective state or Pollution Control Committee of the respective Union Territory for Biomedical Waste Management. The license should be renewed on a regular basis.

### **c) Licensing from the Fire and Safety Department**

No objection certificate from adjoining property owners and permissions and clearance from local administration should be obtained and submitted to the Fire and Safety Department for getting the license.

### **d) Miscellaneous Licenses**

The PRCs can obtain the Pharmacy license, Schedule X License, Schedule H license (under the Drugs and Cosmetics Act 1945(23) (amended)) for using some class of drugs. The PRCs should maintain stock documentation and furnish annual statistics to the State Drug Controller.

Furthermore, the PRCs should obtain lift license, permission for the use and maintenance of generator, canteen license etc. The PRCs should also have tie-up with Employees' State Insurance Scheme, if more than 10 employees are there, and with Provident Fund scheme when employees' number is more than 10.

### **1.3.3. NABH Accreditation**

National Accreditation Board for Hospitals and healthcare providers (24) (NABH) accreditation brings with it certain quality assurances that even MHE's can benefit from. NABH Accreditation helps in maintenance of minimum required quality for health care facilities as per Quality control of India (QCI). NABH accreditation may also pave the way to MHEs/PRCs to become an empaneled hospital for insurance.

### **1.3.4. Indemnity Insurance for Mental Health Establishments and Professionals**

The medical practice has been brought under Consumer protection act. Thus, when any medical negligence, and grievance from the patients towards untoward medical consequences happen the patients can claim for compensation from the hospital authorities. Hence, it is preferred that MHEs / PRCs should be under indemnity insurance coverage [7].

## **RIGHTS AND REGULATIONS**

The MHCA - 2017 clearly advocates that the mental health professional must work in the framework of the legislation of law for the benefit of patients and should prevent possible frictions and litigations [21]. The MHCA 2017 also give importance for the rights of patients during the process of treatment of both outpatient and in-patients, and thus the psychiatric practices in MHEs / PRCs are becoming more challenging. Patient has a right to refuse rehabilitation process which cannot be forced upon as per new regulations. Patients should be managed in least restrictive environment.

### **1.1. Rights of the PMI**

The stipulated by the MHCA-2017 shall not be violated by any person. The Rights include the Right to community living, Right to live with dignity, Right to get protection from cruel, inhuman, or degrading treatment, Right to get relevant information concerning treatment, Right to communicate through phone and letters, Right to confidentiality, Right to access their basic medical records (Section 25), Right to maintain secrecy of

personal contacts and communications, Right to get legal aid (Section 27 Sub-Sec.2) and recourse against deficiencies in the provision of care, treatment, and services etc. (Sec. 28)[4]. MHEs can make institutional policies without violating the Rights of PMI.

### **1.2. Maintenance of Medical Records**

The MHE must oblige to mental health care rules stipulated by the MHCA-2017 to maintain basic medical records for three years from the last consultation of patient. PMI has the right to access his medical records through Form-A, which can be obliged by MHE by responding through Form-B within 2 weeks. The Psychiatrist is supposed to keep all copies of certificates given to patients along with relevant register.

Important registers, such as, OP attendance register, IP admissions register, psychological assessment record, and psychotherapy record, census register, treatment adverse effect monitoring record, certificate register, medico-legal register, leave of absence, escape register, restraint register, and mortality register should be maintained(25).

### **1.3. Maintenance of Confidentiality**

As per the Sec. 23 of MHCA 2017 (Right to Confidentiality), it is important to maintain confidentiality regarding mental health and treatment aspects of patients. The exceptions to release such confidential information are only if it is necessary to protect any other person from harm or violence or in the interests of public safety and security from the person with mental illness, order by concerned Board or the Central Authority or High Court or Supreme Court or any other statutory authority competent to do so. Photograph or any other information (physical and virtual/digital/electronic information) relating to a person with mental illness undergoing treatment at a PRC shall not be released to the media without the consent of the PMI (Sec. 24 of MHCA 2017). If there is doubt regarding providing information, it is necessary to consider to procure consent from the concerned patient or communicate with the MHRB for further directions to reveal or not (26).

### **1.4. Emergency Treatment**

In case of emergency, PRC must have a memorandum of agreement with nearby medical facility registered with SMHA to provide emergency medical services.

### **1.5. Punishment for Violating MHCA and MHRB Rules and Regulations**

Failure to comply with any provisions of MHCA, or violation of any of the Sections of the MHCA, or complaints given by MHRB, and subsequent proof of guilt, will lead to MHE to incur heavy penalties. However, violation of any rights of PMI by any kind of treatment setting and establishment can be investigated by the concerned MHRB.

### **1.6. Capacity building among MHE staff to comply with MHCA - 2017**

The MHEs/PRCs should conduct capacity building workshops and trainings frequently for their staff by inviting experts in law and mental health as resource persons. Such programmes will enable all staff to learn various case scenarios and to comply better with the MHCA- 2017. MHE/PRC can also consider for having a legal advisory committee to help psychiatrist to take appropriate decisions in times of difficult scenarios to comply with the Act. In case of any doubt, psychiatrist/s should take parallel opinion or request for the second opinion from colleagues or experts from the field(27).

### **REHABILITATION IN GENERAL HOSPITAL PSYCHIATRY UNIT (GHPU)**

Several psychiatry rehabilitation centres have been started in association with medical college psychiatry department. A General Hospital Psychiatry Unit (GHPU) is the psychiatric wing in a general hospital or medical college. GHPUs are currently the face of psychiatric care in India and have taken psychiatric care to the population. Functioning is based on Single session rehabilitation counselling, disability certification and unique disability ID card, welfare benefits for persons with disabilities, caregiver assisted cognitive remediation, patient and caregiver led livelihood initiatives, daycare centre, homebased rehabilitation adoption, etc. There are few challenges in this regard like human resource constraints, including the dearth of trained psychiatric rehabilitation professionals, an inadequate number of rehabilitation practitioners, and lack of coordination among team members. These are the primary causes of ignoring and disregarding psychiatric rehabilitation at GHPUs.

### **GOVERNMENT AND PRIVATE REHABILITATION CENTERS**

NIMHANS Bengaluru and CIP Ranchi are two premier institutes of government who have exclusive rehabilitation units. They are working in empowering the patients and caregivers. They are also working in terms of training other mental health professionals in rehabilitation care. Recently, the National Institute of Mental Health Rehabilitation (NIMHR) has been established in Sehore, Madhya Pradesh exclusively for training services.

NGOs and private setups are the back bone in rehabilitating patients next to Government. There are number of established NGOs since many years who are contributing magnificently for the betterment of patients along with governments aids. Although there is good facility and trained staff in private sector, there is issue of finance which will hinder the approach to many more needy patients.

### **CHALLENGES IN MANAGING PRCs**

Apart from the several challenges mentioned in the text above, PRCs may have to face additional challenges in terms of financing, legal and human rights issues.

#### **a) Finances**

Establishment and management of PRCs need huge financial investment. Financial aspects can be managed through fund mobilization by appropriate fees, loans, EMI's or wholesome investment and the use of a like-minded cohesive working groups [7]. Proper public relation ways, judicial investment, planned expenditure and income generating plans can enhance financial position of the institution. It is highly important to obtain financial support from government schemes, working in association with NGOs and taking donations from MNCs through corporate social responsibility funds. Regular auditing of accounts and tax management are also important.

#### **b) Human rights and Medico-legal issues**

PRCs can face several unique challenges in the form compliance issues, with-holding of consent, possible risk of violence, suicide attempts, sudden deaths, absconding of patients, etc. In addition, while handling of difficult patients who may show acute agitation,

sexual disinhibition towards others, craving for substances and intrusion into fellow patients' care and management should be tackled in strict legally approved measures.

### c) Miscellaneous challenges

The PRCs may encounter several challenges and unpleasant experiences from NRs/ family members of PMIs. Family members with high expressed emotions, demands and intrusion into treatment plans, lack of understanding with treating team can pose difficulties both for individual and fellow PMIs.

To overcome several of above-mentioned hurdles in PRCs it is necessary to have regular and frequent academic, clinical, and legal peer group discussions. In adversities timely guidance and professional support can be sought from organizations such as Indian Psychiatric Society and Indian Medical Association, as well as concerned government departments.

### PRC SUCCESS MODELS

In India, to cater the rehabilitation needs of PMI, both the government and private institutions are taking several steps by establishing rehabilitation centers, conducting trainings and research. In the following Table (Table-2) some of the success models are presented.

**Table 2 - Few PRC Success models in South Zone of India**

<i>Sl. No.</i>	<i>Organisation</i>	<i>Activity/s</i>
<b><u>Government Organization</u></b>		
1.	NIMHANS, Bengaluru, Karnataka	a. Establishment of OP, IP and day care center b. Established government PRC c. Different kinds of vocational services like arts, dance, yoga and recreational activities are started d. Incentives and travel allowances given (Rs.1000 for Inpatients and Rs.600 for day care attendees on the basis of attendance and work performance) e. Organizing Caregivers education and support programs and "Sanjeevani Vedike"
2.	Central Institute of Psychiatry (CIP) Ranchi, Jharkhand	a. Established government PRC. b. Conducting training of other mental health professionals in rehabilitation care.
3.	GMCH, Chandigarh, Punjab	a. The Disability Assessment, Rehabilitation and Triage (DART) services (GHPU).
4.	Manasadhara - Project of Government of Karnataka	a. District wise Day Care Center for Rehabilitation purpose in Karnataka state.

<i>Sl. No.</i>	<i>Organisation</i>	<i>Activity/s</i>
<b><u>Private Organization</u></b>		
1.	The Banyan, Chennai, Tamilnadu	Takes care of wandering PMIs at Chennai
2.	Medico Pastoral Association, Bengaluru	Half way home for catering services to patients discharged from Psychiatry hospitals
3.	The Richmond Fellowship Society, Bengaluru	Established 'Chethana'- a day care center for PMIs in Bengaluru and Lucknow
4.	Kasturba Medical College, Manipal, Karnataka	Established 'Hombelaku'- a residential rehabilitation center (GHPU)
5.	Spandana Health Care, Bengaluru	Established PRC, IP, OP rehabilitation services
6.	Cadabams Amitha, Bengaluru	Advanced rehabilitation centre for psychiatric illnesses.
7.	The Schizophrenia Research Foundation (SCARF), Chennai, Tamilnadu	Providing psychiatric rehabilitation and extensive research in this field.
8.	Indla's Shantivan, Andhra Pradesh	PRC with wide range of psycho-social rehabilitation services for patients with psychiatric illness and substance use disorders.
9.	Chittadhama Trust, HD Kote, Karnataka	Chitthadhama - Taking care of homeless mentally ill people by providing them food, shelter and treatment. (An example of Resource funding through Corporate Social Responsibility)
10.	Chellamuthu Foundation, Madurai, Tamilnadu	Rehabilitation model which suits to the native people like agriculture, cattle raring, manufacturing jute products are uniqueness of this centre.

## REHABILITATION AND ADVOCACY

The total budget outlay for the health sector in India for FY 2022-23 is Rs. 86,200.45, i.e., 2% of the fiscal outlay of the Union Government. The Budget Estimate for mental health is 0.7% of the Ministry of Health and Family Welfare (MoHFW). In the budget, a National Tele-Mental Health programme has been announced. Under this programme 23 tele-mental health centres are being launched and NIMHANS being the nodal authority, which is expected to improve access to mental healthcare services [28]. However, fund allocation for mental health in the country remains a low priority. In order to address the care-gap it is critical to strengthen and ensure the availability of mental healthcare services at the primary health and community level [29]

About 1% of the total population suffers from severe mental disorders. With the raising trends of psychiatric illness, the number of patients requiring rehabilitation services will also increase. A survey done by an NGO based in Bengaluru has explored the costs of long-term care for PMIs provided by NGOs, the private sector and costs of care at various centers. The monthly expenditure for a PMI at the centers varied from Rs. 7000 to Rs. 60,000 with an estimated average monthly expenditure of about Rs. 10,000/month for each PMI [30]. Thus, to improve access to psychiatric rehabilitation services, it's important to have role of NGO and other organizations along with the support of government schemes.

Suggested strategies include: developing a shared understanding of psychiatric rehabilitation; establishing quality legislation that's well implemented; adapting evidence-based models to develop culturally appropriate services; implementing stigma reduction and empowerment-based interventions; and, ensuring coordinated action among all stakeholders, combined with effective leadership.

## CONCLUSION

With implementation of MHCA 2017, functioning of psychiatric rehabilitation services with systematized regulations accountable administration has become essential rather than desirable. This opens up an avenue for public private partnerships to deliver patient centric psychiatric rehabilitation services. Establishment of a well-regulated PRC, using the guidelines as mentioned above along with NABH accreditation would also facilitate the other support systems such as provision of health insurance schemes, referral linkages and thereby reducing out of pocket expenditures. In our country, the current socio-cultural matrix is favourable for the establishment of much needed regulated psychiatric rehabilitation services.

## TAKE HOME POINTS

1. Psychiatric rehabilitation is an essential component of mental health care with better outcome on early initiation of treatment.
2. PRCs should respect the rights of service users while rendering high standard service in a least restrictive environment.
3. PRCs must function in the framework of new regulations with adequate standard infrastructure, staff and registration with relevant licensing authorities.
4. Various types of psychiatric rehabilitation facilities such as, day care center, halfway homes, community living, PRCs, etc should be developed to cater the needs of PMIs.



5. Based on the disabilities of PMIs, various rehabilitation services such as a) cognitive rehabilitation, b) social skills training, c) vocational training, d) community-based rehabilitation and e) disease specific rehabilitation are provided to be provided in PRCs.
6. Different regulations like MHCA 2017, RPWD Act 2016, POCSO Act, RCI Act, NDPS Act 1995, Drugs and Cosmetics Act, and Clinical Establishment Act are to be followed while running a PRC.
7. Special population needs to be addressed as per rules considering the vulnerability.
8. Financial planning is crucial to PRCs to balance fees and donations and to coordinate with government schemes to reduce expenditure burden on service users. Incentives and allowances are crucial for long term good prognosis.
9. Timely financial and administrative support from the government agencies, support of public - private partnerships and NGOs are essential to deliver affective rehabilitation services to PMIs.
10. The benefits of all available and relevant health insurance schemes must be sought both for management of PRCs and support PMIs financially.

## REFERENCES

1. Firdosi MM, Ahmad ZZ. Mental health law in India: origins and proposed reforms. *BJPsych international*. 2016 Aug;13(3):65-7.
2. United Nations. *The Convention on the Rights of Persons with Disabilities: Training Guide*. 2014. 162 p.
3. World Health Organization. *Mental Health Gap Action Programme - Scaling up care for mental, neurological, and substance use disorders*. World Health Organization. 2008;44.
4. Ministry of Law and Justice. *The Mental Healthcare Act , 2017* [Internet]. India; 2017. Available from: <https://egazette.nic.in/WriteReadData/2017/175248.pdf>
5. Torrey WC, Green RL, Drake RE. Psychiatrists and psychiatric rehabilitation. *Journal of psychiatric practice*. 2005 May;11(3):155-60.
6. Sundaram SK, Kumar S. Tracing the development of psychosocial rehabilitation from its origin to the current with emphasis on the Indian context. *Indian journal of psychiatry*. 2018 Feb;60(Suppl 2):S253-7.
7. Gowda MR, Das K, Gowda GS, Karthik KN, Srinivasa P, Muthalayapapa C. Founding and managing a mental health establishment under the Mental Healthcare Act 2017. *Indian journal of psychiatry*. 2019 Apr;61(Suppl 4):S735-43.
8. Carlos D Pratt. *Psychiatric Rehabilitation*, 2nd Ed, Elsevier Academic Press, 2007, P 181
9. <http://rfsbangalore.ngo/>
10. Carlos D Pratt. *Psychiatric Rehabilitation*, 2nd Ed, Elsevier Academic Press, 2007, P 257
11. Ministry of Social Justice and Empowerment. *The Rights of Persons With Disabilities ACT 2016*. International Human Rights 2016.
12. Joseph S, Hemalatha K. Alcohol and alcoholism in India: A historical review. *Int J Sci Healthc Res* 2020; 5:343-54. <https://legislative.gov.in/sites/default/files/A1985-61.pdf>
13. The Rehabilitation Committee of the Indian Psychiatric Society. *IDEAS (Indian Disability Evaluation and Assessment Scale) - A scale for measuring and quantifying disability in mental disorders*. Gurgaon: Indian Psychiatric Society; 2002

14. Dickens G, Weleminsky J, Onifade Y, Sugarman P. Recovery Star: validating user recovery. *The Psychiatrist* [Internet]. 2018/01/02. 2012;36(2):45-50. Available from: <https://www.cambridge.org/core/article/recovery-star-validating-user-recovery/1D1F193ED6EF820A778AA04972A17B1B>
15. Math S, Moirangthem S, Krishna K, Reddi V. Capacity to consent in mental health care bill 2013: A critique. *Indian Journal of Social Psychiatry* [Internet]. 2015 Jul 1;31(2):112-8. Available from: <https://www.indjso.org/article.asp?issn=0971-9962>
16. Vahia NS, Vinekar SL, Doongaji DR. Some ancient Indian concepts in the treatment of psychiatric disorders. *The British journal of psychiatry?: the journal of mental science*. 1966 Nov;112(492):1089-96.
17. Suresh Kumar PN. Impact of vocational rehabilitation on social functioning, cognitive functioning, and psychopathology in patients with chronic schizophrenia. *Indian journal of psychiatry*. 2008 Oct;50(4):257-61.
18. Wykes T, Huddy V, Cellard C, McGurk SR, Czobor P. A meta-analysis of cognitive remediation for schizophrenia: methodology and effect sizes. *The American journal of psychiatry*. 2011 May;168(5):472-85.
19. Bellack AS. Skills training for people with severe mental illness. *Psychiatric rehabilitation journal*. 2004;27(4):375-91.
20. Kopelowicz A, Liberman RP, Zarate R. Recent advances in social skills training for schizophrenia. *Schizophrenia bulletin*. 2006 Oct;32 Suppl 1(Suppl 1):S12-23.
21. Sivakumar T, Roy A, Reddy K, Angothu H, Jagannathan A, Muliya K, et al. Psychiatric rehabilitation in indian general hospital psychiatry unit settings. *Indian Journal of Social Psychiatry* [Internet]. 2021 Oct 1;37(4):352-9. Available from: <https://www.indjso.org/article.asp?issn=0971-9962>
22. Ministry of Environment Forest and Climate change. Biomedical Waste Management Rules, 2016 [Internet]. *Gazette of India, Extraordinary, Part II, Section 3, Sub-section (i)* 2016 p. 1-37. Available from: [http://mpcb.gov.in/biomedical/pdf/BMW\\_Rules\\_2016.pdf](http://mpcb.gov.in/biomedical/pdf/BMW_Rules_2016.pdf)
23. Ministry of Health and Family Welfare. The Drugs and Cosmetics Act and Rules [Internet]. *The Gazette of India* 2016 p. 1-635. Available from: [https://cdsco.gov.in/opencms/export/sites/CDSCO\\_WEB/Pdf-documents/acts\\_rules/2016DrugsandCosmeticsAct1940Rules1945.pdf](https://cdsco.gov.in/opencms/export/sites/CDSCO_WEB/Pdf-documents/acts_rules/2016DrugsandCosmeticsAct1940Rules1945.pdf)
24. National Accreditation Board for Hospitals and Healthcare Providers (NABH). *NABH Accreditation Standards for Hospitals*. 5th ed. 2020.
25. Gajera G, Srinivasa P, Ameen S, Gowda M. Newer documentary practices as per Mental Healthcare Act 2017. *Indian journal of psychiatry* [Internet]. 2019 Apr;61(Suppl 4):S686-92. Available from: <https://pubmed.ncbi.nlm.nih.gov/31040458/>
26. Hongally C, Sripad MN, Nadakuru R, Meenakshisundaram M, Jayaprakasan KP. Liabilities and penalties under Mental Healthcare Act 2017. *Indian journal of psychiatry* [Internet]. 2019 Apr;61(Suppl 4):S724-9. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6482688/>
27. Harbisetar V, Enara A, Gowda M. Making the most of Mental Healthcare Act 2017: Practitioners' perspective. *Indian journal of psychiatry* [Internet]. 2019 Apr;61(Suppl 4):S645-9. Available from: <https://pubmed.ncbi.nlm.nih.gov/31040452/>
28. India Mental Health Observatory. *Budget for Mental Health* [Internet]. 2022. Available from: <https://cmhlp.org/wp-content/uploads/2022/02/IMHO-Union-Budget-for-Mental-Health-2022-23.pdf>
29. Singh OP. Closing treatment gap of mental disorders in India: Opportunity in new competency-based Medical Council of India curriculum Vol.60, *Indian journal of psychiatry*. 2018. p.375-6.
30. Math SB, Gowda GS, Basavaraju V, Manjunatha N, Kumar CN, Enara A, et al. Cost estimation for the implementation of the Mental Healthcare Act 2017. *Indian journal of psychiatry*. 2019 Apr;61(Suppl 4):S650-9.

## HOME TO THE HOMELESS : THE SHRADDHA EMOTION

Dr Bharat Vatwani<sup>1</sup>, Dr Smitha Vatwani<sup>2</sup>, Swarali Kondwilkar<sup>3</sup>

### BACKGROUND

Lawfully, every individual has the fundamental right to live with dignity, inclusivity, and social security and no individual shall be deprived of his personal liberty. History of Psychiatry is evidence that individuals who are agonized by the occurrence of mental illness, have been deprived of basic human rights described under Article 21 of Indian Constitution and Mental Healthcare Act, 2017. Vulnerable group of population such as wandering mentally ill roadside destitutes, devoid of humane care and attention, deprived of the institution of family and the experience of belonging have been neglected for decades.

### INTRODUCTION

Home is often described as a space of shelter, security and belonging, associated with relationships, emotions and meanings and becoming the core experiences of human life.

Mental Healthcare Act 2017 states that every person has the right to access mental healthcare and treatment. Besides, person with mental illness living below poverty line, destitute, homeless are entitled to access to mental health treatment and services free of any charge vide Government or Non-Governmental Mental Health Establishments (MHE) [1].

Shraddha Rehabilitation Foundation is a Non-Government MHE providing protective, sheltered care and treatment to roadside destitutes and has reunited, post their recovery, more than 9000 such neglected wandering mentally-ill with their families [2].

This chapter is an attempt by the author, also the founder and backbone of Shraddha, to share the experiences, ideologies, and wisdom behind Shraddha, through this effort of expression.

### NEED FOR EFFORT

Psychiatric disorders globally amount to be the second leading cause of disease burden in terms of Disability Lived Years (DALY) until 2017. This proves to be a significant challenge to health establishments especially in lower to middle income nations [3].

The population that suffers from severe mental illness mainly Schizophrenia and Mood Disorders have a difficult and often unpredictable course and outcome. Adding to that exists a large treatment gap of over 70 % for severe mental disorders [4].

These inadequately treated individuals suffering from chronic severe mental illnesses often move away from home and family and end up wandering on streets as roadside destitute. They are often put under the umbrella term of 'homeless' or confused as 'beggars'. However, it is of utmost importance to demarcate the difference between each of these vulnerable group of population in order to effectively utilize the already insufficient resources.

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Ramon Magsaysay Awardee, 2018, Founder Trustee, Shraddha Rehabilitation Foundation
2. Advisor, Shraddha Rehabilitation Foundation;
3. Associate Psychiatrist, Shraddha Rehabilitation Foundation

**Homeless** : Individuals who become devoid of shelter, food, and social security because of multiple factors varying from natural calamities to personal tragedies.

**Beggars** : Individuals, mainly part of an organised/unorganised sector of a profession, abled or disabled, that survive on asking for money or food from public, mostly seen in urban areas.

**Wandering Mentally-ill Roadside Destitute** : Individuals who suffer from severe mental illness such as Schizophrenia, untreated or inadequately treated, consequent to their lack of insight and judgment end up leaving their houses and wander on streets in a dishevelled and disorganised state and who, when adequately cared for, can be revived and reunited with their lost families upon recovery.

#### **CAUSATION OF PHENOMENOLOGY OF WANDERING MENTALLY ILL IN INDIA**

- a) Out of a total health budget of 73932 crores for year 2022-22, only 41.8 crores were allotted to the National Mental Health Program. With Government spending 0.81% of its health budget on mental health, compared to 12%-18% in developed countries, mental illness in India has been considerably under invested in [5].
- b) The bulk of India is in lower economic range. A 2020 World Economic Forum study found 363 million Indians live Below the Poverty Line (BPL - Earning less than Rs 32 per day in rural India) [6].
- c) There are just 9000 odd psychiatrists in India (6 per million in India vis-a-vis 60-200 per million in developed countries). Assuming minimum conservative requirement of 30 psychiatrists for every million population, many districts of States within India do not have a psychiatrist [5].
- d) Severe Deficit of other Mental Health Professionals such as Clinical Psychologists, Psychiatric Nurses, Psychiatric Social workers etc.
- e) There are just 43 government-funded Mental Hospitals with 18800 beds. This coupled with 10000 beds in Psychiatry wards of Government Hospitals averages one bed available for 48000 population. Many of beds in the Mental Hospitals are occupied by chronic-long-stay patients, drastically reducing the turnover [4].
- f) In urban areas medication and psychiatrists are available. In rural areas neither psychiatrists are available nor Primary Health Centres stock psychiatric medication. Huge populations of people with major mental illness don't have access to psychiatric services [4].
- g) Report submitted by NIMHANS (National Institute of Mental Health and Neurosciences) to Government states that mental illness afflicts 13.7% of population viz. a whopping 197 million Indians, with 1.9% of population (30 million) afflicted with severe mental disorders, which if left untreated could result in patient walking out under the influence of mental illness and becoming a wandering destitute [7][8].
- h) Population Census 2011 has estimated that 1.8 million Indians are homeless. Studies have shown incidence of Mental Illness per se in homeless is 50-60%. So almost 1 million Indians are homeless & mentally ill [9].
- i) Very poor awareness about mental illness, its scientific basis, symptomatology & amenability to treatment.

- j) False folklore cultural beliefs abound, more so in rural villages, that mental illness is caused by 'external supernatural forces' 'evil spirits' 'black magic' 'spirit possession', and 'karma'. Belief in these non-medical explanations & the easy accessibility of traditional healing resources are important in not seeking medical help for mental illnesses in India. [10].
- k) In a rural village a patient suffering from schizophrenia, is assimilated within the joint family cultural system without much discrimination. But when these villages become towns, with their increase in nuclear families, care provision demands more resources and there is corresponding decreased tolerance to these psychiatric illnesses [10].
- l) Gender bias aggravates the above problems [10].
- m) Stigma, discrimination and humiliation against the mentally ill, make patients as well as relatives hesitate from seeking out treatment.
- n) The severely mentally ill have lack of insight into their mental illness. They feel that they are alright and deny illness altogether.
- o) The costs of long-term treatment (including consultation, medication costs, travelling costs to treatment centres and stay in hospital) contributes to the economic burden of mental illness, which in turn contributes majorly to the treatment gap in India. The total treatment costs are significantly higher among people who are unemployed, chronically ill, disabled, and those who visit the hospital often. The indirect costs of mental illness are often significantly higher than the direct costs [4].

*Because of above points, many schizophrenic patients from both rural and urban areas get unwittingly separated from their homes and end up as destitute – unclothed, unfed, uncared for and untreated.*

Thus, India without a massive mental health movement will see a mammoth number of homeless destitute wandering mentally-ill patients.

Shraddha works with these destitutes.

#### **METHODOLOGY AND MATERIALS**

Shraddha does not take in destitutes brought by family members or whose family antecedents are known; the idea being to focus on a single segment client definition, roadside destitutes who are lost, wandering and mentally ill and need treatment, rehabilitation, and reunion with their loved ones.

The Objectives of Shraddha are

- # To rescue maximum number of mentally ill destitutes.
- # To provide free shelter and food to the rescued patients.
- # To provide free pharmacological treatment to the rescued patients.
- # To rehabilitate them with various psychosocial interventions.
- # To trace out addresses of the patients.
- # To facilitate reunions of recovered patients with their lost families across India.

- # To follow up with as many reunited patients as possible to ensure their continued well-being.
- # To promote massive mental health awareness amongst villages, schools, families, police personnel, railway officials & general public.
- # To network with other NGOs and Government Institutions sheltering destitutes in order to generate collective efforts.

In about 90% of the destitutes, recovery is possible and some can even expect full and lasting recovery [2] [10].

#### **RESCUE - TREAT - TRACE - REUNITE - REACH OUT**

##### **Results**

By now, it has been 16 years since we started our Karjat project. Giving hardcore statistical figures we had picked up -

47 destitutes in the year 2006  
134 destitutes in the year 2007  
156 destitutes in the year 2008  
212 destitutes in the year 2009  
261 destitutes in the year 2010  
332 destitutes in the year 2011  
493 destitutes in the year 2012  
533 destitutes in the year 2013  
538 destitutes in the year 2014  
636 destitutes in the year 2015  
742 destitutes in the year 2016  
920 destitutes in the year 2017  
940 destitutes in the year 2018  
1114 destitutes in the year 2019  
309 destitutes in the year 2020  
659 destitutes in the year 2021  
520 destitutes in the year 2022 (till June end)

On a very personal level, one is never certain as to what one has done is ever, EVER, adequate. Or whether what has been done has made a difference to the quantum of the cause. Perhaps in terms of the real harshness of the situation, very little has been done.

But 8546 destitutes were picked up, treated and after recovery, reunited with their families in different parts of India. And all the inbuilt psychiatric-illness-awareness-sessions which go hand in hand with these reunions were achieved.

## **DISCUSSION**

### **The Modus Operandi of Shraddha**

Mental Illness carries Stigma - either Social Stigma or Self Stigma.

Stigma causes mentally ill people to feel ashamed for something that is in reality, out of their control. There is exclusion, poor social support, social isolation/loneliness and low self-esteem.

Stigma prevents mentally ill from seeking the help they need and remains the cornerstone of stumbling blocks in the addressal of mental illness.

Neither the patient is ready to disclose his problems to self or others, nor the relative is ready to accept the problem for himself, his mentally ill loved one or for others in society.

Ultimately, the mental illness is boxed in, closeted, riveted, festooned and plummeted. With no breathing space, the claustrophobia of thought, emotions, actions and treatment options sets in.

The illness starts multiplying internally manifold, literally becoming gangrenous in form, and at a subconscious level, ultimately manages to expunge the mentally ill from within their selves, their families and their societies. And thus, is born the wandering mentally ill.

The wandering keeps the mental illness within the patient, again at a subconscious level, in stagnated momentum, like a rolling stone, gathering no moss. No further additions/subtractions are there to the thoughts, emotions, actions and treatment options, and the wandering becomes a way of life.

The schizophrenic man, walking and disconnecting from society, in an attempt to drown his anxiety, by the physicality of his own momentum and his own wandering.

Shraddha addresses this physicality, this momentum and this wandering.

### **ROLE OF EMPATHY**

The key in connecting to the wandering mentally ill is Empathy.

By voice, body language, demeanour, eye contact and above all soul contact.

Empathy is not sympathy, it is not pity, it is not benevolence. It is beyond. It is the honest ability to communicate to the man on the streets that 'There, but for the Grace of a God above, go I. Therefore, I am you & you are I'.

The moment True Empathy is established, the claustrophobia of thoughts, emotions and actions which was festering within the psyche of the destitute, yields like a pricked balloon. The destitute agrees to receive the proffered help.

### **Anecdote A**

In one instance our female SW Farzana Ansari while travelling by train got down at a railway platform 600 kms away from our Centre, saw a male mentally ill destitute on the platform, was able to establish rapport with him to get into the train and bring him to our Centre a good 10 hours of travel time away.

**Anecdote B**

In many instances, students at neighbouring colleges who have had exposure to our work, are able to cajole the destitute walking on the street to sit on their motorcycles and bring them to our Centre.

How did she/they achieve this? The communication of Empathy. The communication of 'I am you, and you are I'.

Nobody has ever given a bath to the destitute or attended to his basic hygiene. He/she/they have never thought of it themselves, the stigma internalized against their own selves and revulsion to their own illness having set deep into their psyche, for months, years, decades. The Shraddha staff penetrates the psychic wall, and immediately takes care of their hygiene. Fresh clothes are provided, the jungle of matted hair cropped and trimmed, the outgrowths of a beard knocked off. The acceptance of him/her as human by the Shraddha staff, makes them accept themselves as humans.

John Milton's Paradise Regained, albeit the glimmer of it.

**MEDICAL CHALLENGES POST RESCUE**

The destitute goes through extremes of heat / cold / rain / starvation / sexual abuse / Anemia / Hypoproteinemia / Kochs / Enteric fever / Sexually transmitted diseases / Seizures / Grave body and scalp injuries & wounds / Severe infection with Skin wounds infested with Maggots / Fractures / Impacted finger rings / Massive injuries, all restricting administration of appropriate treatment.

Because no objective data is available, there is no information available of duration of illness, presence/absence of epilepsy / family history of mental illness / history of prior episodes and treatment/ presence of concomitant medical / neurological disease. Finally, the treatment approach becomes signs-symptoms based. There is no validity of patient's history.

The presence of co-morbid organicity (Dementia / Paralysis / Cerebrovascular episodes/ Epilepsy / Borderline Intellectual functioning) adds to the difficulty in getting good improvement and clear family details/addresses.

**NEED FOR A CULTURALLY AND LINGUISTICALLY DIVERSE REHABILITATION TEAM :**

There are many language issues in communication, different dialects are impossible to comprehend, patient remains symptomatic and irrelevant for months. In case the destitute has negative symptoms or is catatonic, it is very difficult to establish rapport. The reluctance / refusal to eat on the part of the destitute, the reluctance/refusal to take oral medicines / allow fluid administration, the tendency towards violence because of inherent illness / lack of comprehension as to what is going on, are all stumbling blocks to treatment. The issues with food preferences and tastes because destitutes hail from different regional/cultural backgrounds impede rapport development.

The Shraddha doctors attend to his/her medical needs. Menstrual hygiene is attended to, in the case of female destitutes, by the attending female staff. Every act reflecting embodied care & compassion.



The patients are cajoled to, pleaded to, in gentle soothing tones to come forward with their names, their parent's names, their sister's names, the names of their husband/wife, their children, their kith and kin, the name of the village where they were born, the district to which they belonged, the school in which they studied, the movie theatre in which they saw their favourite cinemas, the festivals which they celebrated with their families, the Gods which they revered and prayed to. Questions which no one had ever asked them before, and questions the answers to which they had almost forgotten themselves. The capacity to make a wandering mentally ill destitute believe that he has an identity and that he belongs. Simple questions, no rocket science, but interpersonal rapport at an Empathy level.

Psychiatric medication is initiated to counter the scientific base of the psychiatric problem. All along, from day one, the patient is addressed by his name, to re-establish his sense of identity.

The patient is pushed gently to join group activities like yoga, physical exercises in the open environments, group prayer meetings in a multi-cultural setting. Coming to know of his/her specific skills, the patient is often incorporated in gardening, farming, masonry, electrical repair work, cattle attending, cooking, vegetable cutting and general cleaning within the premises. The destitute is made to believe that his contributions are unique, valuable and will be cherished, even after he has gone from the Centre. The creation of the nuances of his/her individual inherent personality. A bygone psychic era, recreated. The balloon of Stigma pricked further.

The doctors at Shraddha have made it a standard protocol to have all the patients present (male and female separately), while taking their rounds. Unless physical examination of the inmate demands privacy, the doctors address each one of them by name, in front of the others. The tone, body language, demeanour, eye contact communicating empathy for one, but the visual and the aural presence of it in front of the others, disseminates the Empathy to all, within the room. Every one of the destitutes present in the large room realize that here are caring, concerned people addressing each one of us, individually.

The presence of qualified social workers (the entire Team of social workers is present during the rounds), hailing from different States of India, speaking different dialects of India, makes the patient belonging to a particular State/District/Taluka of India comfortable, because they are addressed to in a language and dialect which they understand, and which they have grown up with, and which has become a part of their Jungian collective unconscious psyche.

This often results in an ab-reactive emotional catharsis by the patients.

### **Anecdote C**

Citing an example, a patient, after about 2 months of treatment, broke down and, spontaneously reaching out for the pen from the doctor's hands, wrote a mobile number in his own handwriting, with tremulous hands. Since the destitute had recovered substantially, the immediate calling up on the number (in front of all the other patients) and making the recovered destitute speak on the phone in an emotional gut-wrenching voice (the mobile number turning out to be of his brother), with the mobile being kept on 'speaker on' mode, made the whole room full of patients reverberate with empathy, empathy and more Empathy. Each one of the patients desired and wished that this fellow inmate (nay, a fellow soulmate) goes home.

### **Anecdote D**

Sometimes the bonding is so deep, that one recovered patient comes forward and says that only after he has escorted safely the other two recovered destitute (clubbed together in the same reunion trip) would he go to his own house. Till a few months ago, these same patients were unknown to one another, but now the physical proximity had shattered the social isolation/loneliness, and the ongoing recovery (facilitated by the monitored psychiatric medication) had the destitute forging empathy bonds with each other, despite belonging to different sects/classes of society.

Humans, establishing and proclaiming their rights to be human, and interpersonal emotional rapport weaving its magic.

### **GOING BEYOND HIERARCHIES, BOUNDARIES, BARRIERS AND INCULCATING HOPE :**

Simple events like the doctors having their tea & a huge pile of biscuits, during their rounds in front of all the patients, make the patients want to partake in the biscuit fest, and the request is never turned down by the doctors. Instantaneously, the doctors and the patient become equals. On occasions, the destitute reaches out and takes the personal water bottle of the doctor and drinks water from it. He is encouraged, not denied. And all this in front of the entire group of 80 odd male patients, if the rounds are in the male ward. The worst amongst them, be they catatonic or severely depressed, perceive a flickering of hope within their innermost subconsciousness. They may take months to recover, but every act of camaraderie makes them believe in Life, and their own image in their own eyes, goes on the upswing. They are unchained from the shackles of Stigma; they are back from the skeletons of the dead.

### **POST RECOVERY, RECOLLECTION OF SOCIO-DEMOGRAPHIC DATA**

Finally, comes the planning of the Shraddha reunion trips. The trips back to their homeland. Something which by now everyone of the recovered destitute is waiting for and anticipating with bated breath, knowing that earlier to them, in every round of the doctor, averaging 12-15 patients on every round, have not only been OKed by the doctor, but have actually left the Rehabilitation Center, escorted by the SWs, hailing specifically to those particular regions. They have understood by now, deep down within their beings, that their turn too, shall come. Hope is re-kindled in lost souls. And loved ones (lost to the passage of time and forgotten because of the blunting of emotional faculties by the onslaught of mental illness) are often remembered with fervour and passion. The atmosphere of recovered patients, remembering their children, and wondering how their loved ones and dependents must be faring in their absence, make every one of them bonded, in kindred spirit.

### **EMPATHY REPLACES STIGMA**

During the reunion trips in the train itself, since the recovered destitute wear Shraddha uniform, other co-passengers often enquire as to what is going on. They show compassion for the unknown destitute and speak to them with respect. Sometimes, these fellow passengers spontaneously come forward with disclosures of their own relatives having mental illness.

Often, Shraddha Ambulance, while going on its reunion trips is provided free food, by the lodges where the Team stop for refreshments. Everything is a spontaneous outpouring of goodwill. The Team is cheered all along, unknown people sometimes chipping in with small donations, local journalists covering their sojourn.

All along, at every small step of the way, the Stigma surrounding mental illness is diluted, made null & void. While conjointly Empathy is created, cultured, watered & magnified. Small changes, perhaps in very small cross-sections of society, but the ensuing gestalt far outstripping the sum of its parts.

During reunions itself, there is an outpouring of emotional catharsis, as loved ones meet loved ones, after perhaps months/years/decades of separation. Children meeting their parents, brothers meeting their sisters, each with their own story to tell. Of the pangs of separation and everything beyond.

Sometimes when decades have passed, the last rites of the missing one have already been done and dusted with, photo frames of them have been hung and garlanded, and all the tears have been shed and dried. Only to find that Resurrection, Hope, Life and the Gods above have persevered. And the unabated/unbridled tears of Joy have won in the battle against separation.

Where the tracing out of family antecedents is difficult, help is sought from local administration, the local police and from well-meaning souls (of whom there is no dearth) within the neighbourhood. Because the SW leading the reunion trip is invariably a local belonging to that particular State, knowing local language/dialects, interest is generated spontaneously.

Since the recovered destitute is in a psychiatrically stable condition, and being attempted to be reunited after months/years of separation, the curiosity levels generated are very high. Questions are asked to him as well as the SWs about mental illness, its causation, symptomatology and treatment. Impromptu street-corner type gatherings happen.

The focus naturally and autochthonously veers towards the '**Treatability of Mental Illness**'.

#### **DIFFICULTIES FACED - DURING REUNIONS**

Tribal people (in particular female tribals) being uneducated & having poor general knowledge do not know anything beyond the name of their village. They do not know names of District, State to which they belong or even the nearest railway station. These tribals, even upon recovery, are very difficult to reunite.

Apart from different States having different languages, there is presence of different dialects even within the same States of India. Interior area dialects are very difficult to comprehend.

Recovered destitute throws a seizure or develops a medical complication (fever/diarrhoea/vomiting etc) during the journey or accompanying SW himself/herself develops some medical contingency.

Recovered destitutes with a physical handicap/challenge have to be dealt by the SW hands-on.

SWs having to travel long distances – eg. Assam / Arunachal Pradesh.

Female destitutes picked up occasionally with their offspring. Staff uncertain whether the child is marital or from sexual exploitation on roads.

Inherent nature and intensity of the schizophrenic illness fluctuating from time to time causing the most cooperative docile recovered destitute to disappear and get off the train during night travel or when SW has gone to the restroom.

Recoveries of the destitute are incomplete. Correspondingly knowledge of their antecedents and address details are also incomplete. This hamper tracing out of families & corresponding reunions.

Non-acceptance by the relatives, more likely (1:30) when the relatives traced out are distant relatives, the near-and-dear ones having already passed away.

#### Wandering Mentally-ill reunited Post-Recovery with Families in Interior India



*Pictures Courtesy : Shradha Rehabilitation Foundation*

On many occasions, people from amongst the crowds disclose the presence of psychiatric illness in their kith-n-kin, and pester the SWs for a solution. The seniors among the escorting team, carry spare basic psychiatric medication with them, and after WhatsApp discussion with the Shradha psychiatrists, dispense these medicines accordingly. Not the best of professional consultations, but the initiation of hope and succour in lost lives, and above all mental illness becoming demystified, 'out of the closet, on to the streets, and running into the open'.

On occasions when immediate relatives are reluctant to accept their mentally ill relatives (because of earlier misconduct or sporadic acts of violence committed during their mentally-ill phase), it is the genuine empathy and understanding of the family elders, the village elders and the local police, who by instilling maturity into the relatives (citing the improved mental status of the recovered destitute to drive home their point), seal the acceptance within the reunion.

Stigma, the demon hounding mental illness, is tossed out of the window, and an all-endearing, all-encompassing empathy reign supreme. Stigma and Empathy become inverse correlates in these meetings.

In the final analysis, it is not a separated loved one that Shraddha reunites with his/her family. It is the debunking of the Stigma that surrounds mental illness at the individual level, at the family level, and at the society level which Shraddha accomplishes, albeit in bits and pieces, in a fragmented journey across the length and breadth of India.

And it does this with an all-pervasive Compassion and Empathy for the plight of the common, grossly misunderstood, wretched, neglected mentally ill man.

And this perseverant Empathy kindles further Empathy for the mentally ill, within the sufferers themselves, their families, their villages & the surrounding societies at large.

#### **DIFFICULTIES FACED - AFTER REUNIONS**

- # Supervision & sending of medicines in home towns.
- # Even if a relative wants to continue treatment, medicines are not easily available in medical shops. As per current regulations, without valid prescriptions, one cannot get these medicines. An actual gap exists between relative communicating to Shraddha about medicine requirements & their hardcore couriering.
- # Lack of money by relatives to purchase the medicines.
- # Often relatives have a laidback attitude because of cultural norms & stops medicines with or without stock of medicines getting over. Patient may remain asymptomatic without medication for weeks & relative believes that God or Fate has been kind. Finally, one day patient relapses & may again disappear from home.
- # Families having refusal / reluctance to accept recovered female destitutes because of social ostracization and because in the cultural milieu they will not get married (if unmarried) or if married, the ostracization that they may have been sexually exploited.
- # The maternal family believing that the responsibility of the married recovered patient is with her husband's family and vice versa. Sometimes husbands get remarried in interim period.
- # Sometimes the caregivers themselves are too elderly and cannot supervise medication and after-care.
- # Sometimes the parents/ immediate relatives have expired.
- # Females leaving their homes under the influence of mental illness with a child and losing the child along the way. Upon recovery, huge grief at realizing the blunder.
- # The children often mocked upon by their peer group either post or prior to the reunion that their mother/ father is mental and crazy.

**CONCLUSION**

Whether the roadmap for the cause of the wandering mentally-ill was in itself lighted up, or whether the horizons of psychiatric awareness were set ablaze, or whether a single candle was lit for a single destitute, or whether nothing was lit at all, we know not. Perhaps Light prevailed, perhaps nothing prevailed at all. Being human, one is fallible, unsure and always on shaky grounds.

But an attempt was made. An honest, sincere, bottom-of-the-heart attempt WAS MADE to do that little bit for the cause of the mentally-ill downtrodden. An attempt that has left all of us at Shraddha emotionally drained but hugely and immensely emotionally-satisfied too.

And John Milton's Paradise Lost might just be Regained.

Here sharing a poem depicting the plight of the wandering mentally ill, penned years ago...

*Alone & lonely*

*Like the vulture sitting on the stark tree top,  
Like the sliver of light creasing the clouded landscape,  
Like the wisp of smoke trailing miles away,  
Alone & lonely.*

*No place to go,*

*No space left,*

*The snow trickling leaving the terrain bare,*

*Alone & lonely.*

*Like the skyscraper stranded against the bleak horizon,*

*Like a broken-down vehicle in a traffic jam,*

*Like a mangled corpse in a bombed-out wreck,*

*Alone & lonely.*

*No words to mouth,*

*No songs to sing,*

*The painting waiting for the painter's dream,*

*Alone & lonely.*

*Like the tears streaming down wrinkled cheeks,*

*Like a man in mourning in the human sea,*

*Like the body buried under the weight of grief,*

*Alone & lonely.*

*Alone & lonely.*

**TAKE HOME MESSAGE**

- # MHA 2017 states that every human being has the right to access mental health treatment and right to live within community with dignity.
- # Mental Healthcare services fall severely short of demand.
- # A huge bulk of India falls under the BPL i.e. earning Rs. 32 per day in rural India, further enhancing the inequities amidst existing inadequate services.
- # Modus Operandi of Shraddha is RESCUE - TREAT - TRACE - REUNITE - REACH OUT.
- # Key in connecting to the wandering mentally-ill is EMPATHY.
- # Wandering mentally-ill once rescued, are found to have many medical complications including nutritional deficiencies, malnutrition, and infectious diseases.
- # Cultural and linguistic diversity of the rehabilitation team plays an important role in better outcomes.
- # Rehabilitation can be an emotionally-enriching experience for the patients, caregivers and MH professionals involved.
- # Reunions often result in closure of the unresolved grief process. Once a loved one who was mentally ill, untreated, wandered off and was missing, is reunited, emotional catharsis results.
- # Challenges occur at every step of rehabilitation, beginning from rescue up until reuniting and even thereafter.
- # Working in this arena can often lead to burn out, however the outcome of the dedicated input is equally rewarding too.
- # The outcome of reunions is found better in rural areas and with an intact joint family system, but may be somewhat unsatisfactory in urban regions with evolving nuclear family systems.

Ending on a note of prayer & hope for the wandering mentally-ill

Through shimmering pain,  
 through raging storms,  
 through sheets of agony,  
 shall you pass,  
 But in grief,  
 in despair,  
 in dejection,  
 Rest not, O Wandering One,  
 Rest not, O Weary Lonely One,  
 Rest not,  
 For the darkness heralds  
 the coming of the dawn.  
 For the darkness heralds  
 the coming of the dawn...

**REFERENCES**

1. Mental Healthcare Act, 2017. 2017 Apr 7 [cited 2022 Aug 29]; Available from: <http://indiacode.nic.in/handle/123456789/2249>.
2. Shraddha Rehabilitation Foundation for Mentally ill road side destitute, Mental Rehabilitation centre, Schizophrenia patients treatment, NGO for wandering insane, NGO for wandering mentally ill, Donation for schizophrenia patients, Psychiatric Rehabilitation center, NGO, Charitable Institution [Internet]. [cited 2022 Aug 29]. Available from: <https://www.shraddharehabilitationfoundation.org>.
3. Sagar R, Dandona R, Gururaj G, Dhaliwal RS, Singh A, Ferrari A, et al. The burden of mental disorders across the states of India: the Global Burden of Disease Study 1990-2017. *Lancet Psychiatry* [Internet]. 2020 Feb. 1 [cited 2022 Aug 29];7(2):148-61. Available from: <http://www.thelancet.com/article/S2215036619304754/fulltext>.
4. The National Mental Health Survey of India (2016) : Prevalence, sociodemographic correlates and treatment gap of mental morbidity [Internet]. [cited 2022 Aug 29]. Available from: [https://www.researchgate.net/profile/Ritambhara-Mehta/publication/354178241\\_The\\_NMHS2016\\_-\\_Prevalence\\_sociodemographic\\_variables\\_and\\_treatment\\_gap\\_in\\_mental\\_morbidity\\_2020\\_IJSP/links/612a04ed2b40ec7d8bca93cc/The-NMHS2016-Prevalence-sociodemographic-variables-and-treatment-gap-in-mental-morbidity-2020-IJSP.pdf](https://www.researchgate.net/profile/Ritambhara-Mehta/publication/354178241_The_NMHS2016_-_Prevalence_sociodemographic_variables_and_treatment_gap_in_mental_morbidity_2020_IJSP/links/612a04ed2b40ec7d8bca93cc/The-NMHS2016-Prevalence-sociodemographic-variables-and-treatment-gap-in-mental-morbidity-2020-IJSP.pdf)
5. Budget for Mental Health.
6. Global Competitiveness Report 2020 | World Economic Forum [Internet]. [cited 2022 Aug 29]. Available from: <https://www.weforum.org/reports/the-global-competitiveness-report-2020>.
7. G Gururaj. NMHS,India,2015-16 [Internet]. 2016 [cited 2020 Dec 29]. Available from: <http://www.indianmhs.nimhans.ac.in/Docs/Summary.pdf>.
8. Swaminath G, Enara A, Rao R, Kumar K, Kumar C. Mental Healthcare Act, 2017 and homeless persons with mental illness in India. *Indian J Psychiatry* [Internet]. 2019 Apr 1 [cited 2022 Aug 29];61(Suppl 4):S768. Available from : [/pmc/articles/PMC6482680](http://pmc/articles/PMC6482680).
9. Houseless, Population without homes - Census 2011 India [Internet]. [cited 2022 Aug 29]. Available from: <https://www.census2011.co.in/houseless.php>.
10. Ramon Magsaysay Awardee, Dr. BHARATVA TWANI. UNSEEN UNHEARD UNSAID [Internet]. [cited 2022 Jun 21]. 23-25 p. Available from: [https://www.shraddharehabilitationfoundation.org/pdf/UNSEEN\\_UNHEARD\\_UNSAID.pdf](https://www.shraddharehabilitationfoundation.org/pdf/UNSEEN_UNHEARD_UNSAID.pdf).



## **REHABILITATION OF HOMELESS PERSONS WITH MENTAL ILLNESS (HPMI): CHITTADHAMA EXPERIENCE**

B R Ravi Shankar Rao<sup>1</sup>, Swaminath G<sup>2</sup>

*The Greatest Disease is to be Nobody to Anybody - Mother Teresa of Kolkata.*

### **ABSTRACT**

Persons with severe mental illness often end up wandering away from their families and becoming homeless, frequently in a totally different location. Given our huge population the number of HPMI (homeless persons with mental illness) end up as a huge public health challenge to mental health professionals, the law, general public and the government.

Chittadhama is an attempt to provide a residence for these unfortunate HPMI, who have both a disabling illness as well as a lack of a family to care for them. Tending to them from the time they are rescued from the hostile environment they inhabit to their ultimate reintegration to their families is a complex but gratifying task. Chittadhama focuses on the recovery of their physical and mental status and make them 'society ready' to enable smooth assimilation into their primary milieu.

### **INTRODUCTION**

Homelessness is a key issue which has been plaguing society and countries since a long time. The Universal Declaration of Human Rights defines "homeless' as those who do not live in a regular residence[1]. The UN Economic and Social Council statement has a more elaborate definition. It states "the right to adequate housing is about security of tenure, affordability, access to services and cultural adequacy"[2 ].

Homelessness, defined as house-less-ness (Census India, 2011) is a state in which persons live in places other than house with roof [3]. While there are multiple causes for this situation, homelessness and mental illness have a bidirectional cause and effect relationship. Many social and economic factors in a vicious cycle drive the homeless person with mental illness (HPMI) into the bottom strata of the society. The public health significance of this issue cannot be missed if one considers the proportion of severe mental disorders (which is associated with homelessness) as well as the large population of India [4].

There are 1.77 million homeless people in India, or 0.15% of the country's total population, according to the 2011 census consisting of single men, women, mothers, the elderly, and the disabled [1][5]. There is a doubt expressed about the veracity of the numbers, as various surveys have given different numbers varying from 46 thousand to 88 thousand in Delhi. What, however, is more relevant to this article is the high proportion of HPMI in the homeless population. Approximately one third of the homeless population have diagnosable severe mental disorders which are severely incapacitating for the individuals, resulting in very poor quality of life.

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

Chittadhama, Heggadadevanakote, Mysuru Dist., Karnataka.

Chittadhama, Heggadadevanakote, Mysuru Dist., Karnataka.

The National Mental Health Survey (NMHS) [5] looks at the extent, pattern and outcome of mental, behavioral and substance use disorders and the available resources and services. The survey reveals that mental morbidity above the age of 18 years is 10.6% with a life time prevalence of 13.7%. This means that 150 million Indians are in need of active intervention, of which many are in the working population. The treatment gap ranges from 28% to 83% for mental disorders and 86% for alcohol use disorders. 75% of persons with severe mental disorders have severe disability that affects work, social and family life and impacts family members and care givers. Stigma, a major determinant comes in way of 80% of persons suffering from mental illness seeking treatment despite being ill for more than a year. People find it convenient to abandon their kin with mental illness in Dargahs and holy places, some in hope of cure, but many due to fear – that these disorders are incurable and contagious.

### **REDRESSING SOCIETY'S BLIND EYE**

One of the outcomes of a life of suffering from severe mental illness is becoming homeless. This is probably due to the failure of the family and in turn the society to care for such individuals. A dependable support for these individuals is their families. However, a lack of this adequate and constant support to both the individuals and the caretaker families by society often results in wandering and homelessness of the person with mental illness. Therefore homelessness is a sign of failure of the system to provide protection.

There is an obligation on everyone in society to care the needy in terms of feeding, clothing, sheltering, caring and helping the helpless as well as protect their rights. The homeless persons with mental illness (HPMI) suffer indignities due to shirking of all these obligations by the society. The HPMI is denied rights such as confidentiality, privacy, safety, religion, health and not to suffer from inhuman treatment which is available to all citizens of the country. The final common pathway of HPMI is either to live in the streets, suffer in jails, end up in destitute homes or be confined in mental establishments for life, as they have nowhere to go. Of these the first three never get adequate treatment [4].

Institutional care is usually the first step to facilitate recovery of HPMI and later pave the way for their reintegration. Families are a crucial and an indispensable resource for reintegration, and support and empowerment of the HPMI by their families is an important objective. The families too require assistance as well as empowerment from the society at large to be able to provide care and protection to the HPMI. Till the time the HPMI is reintegrated into the family they have no one to supervise them and ideally require a guardian. Chittadhama performs this role of a guardian and it facilitates the processes from rescue to reintegration.

### **GUARDIAN HOME**

It is with this objective that the NGO, the Chittaprakasha Charitable Trust (Regd) (CCT) was formed. The trust has been formed by mental health professionals, care givers and those interested in the care of the homeless persons with mental illness [6]. Its mission is the "reintegration of homeless persons with mental illness into the community, with personal dignity, and free society from the stigma of such illness"[6]. The objectives of the trust were to establish a centre for care, support and rehabilitation of homeless mentally ill, to enhance public awareness and gather public support for the care of mentally ill destitute as well as to help bring about positive changes in Government policy and planning with relation to mentally ill. This centre, Chittadhama, could serve as a model for other centres which would be viable, sustainable and replicable.

Chittadhama is situated on a four and half acre land owned by the trust, adjacent to the backwaters of the Hebballa dam, in the backward taluka of Heggadadevana Kote (H D Kote) of Mysore district. The taluka famously has the Kabini dam as well as forest, famous for its tigers and elephants and has a large tribal population. This forest is part of the Nagarahole and Bandipur range and Niligiri bioreserve and has been in the news for the despicable phenomenon of the abandoning of persons with mental illness from neighbouring areas as well as some from distant states by truck drivers, who traverse these forests in the course of their shipping work.

It is on this land that Chittadhama, a rehabilitation centre for the care of homeless persons with mental illness was constructed. We found a socially conscious Corporate related Organization, the Infosys Foundation magnanimously offering to take charge of this. The foundation first built the 7500 sq.ft. building to house our residents, and later provided a substantial grant to help us in our service activities.

The trustees and advisors of Chittadhama include mental health professionals and carers from all over the country, with long standing experience in matters of psychiatric rehabilitation. The centre has a well thought out standard operating procedure which ensures a harmonious interaction with other governmental agencies such as the police and judiciary. Adequate facilities have been provided for dining, recreation and entertainment. Chittadhama follows all guidelines laid down in regulatory acts as well as various guidelines issued periodically by the state and central governments.

The rehabilitation centre has facility to house and rehabilitate 25 male and 25 female homeless persons with mental illness. The project envisages a rural agro-based rehabilitation service as it is equipped with enough land (4 acres adjacent to the backwaters) to rehabilitate all its residents in keeping with the chief vocation in the taluka. For this the required technical and infrastructural facilities have been developed.

#### **REHABILITATION OF HPMI**

The HPMI at Chittadhama go through a four - step process in their management - Rescue, Restitution, Rehabilitation, Reintegration.

##### **1. Rescue**

On receiving information about a HPMI, the Chittadhama staff accompanied by the police take the person under their protection. The person is produced by the police before the Magistrate in HD Kote who directs that he be taken to the Psychiatrist at Government KR Hospital in Mysuru for an assessment. Based on this certification and the Magistrate's assessment a Reception Order is issued for detention as an inpatient at Chittadhama. This was the procedure as per Section 24 of Mental Health Act 1987.

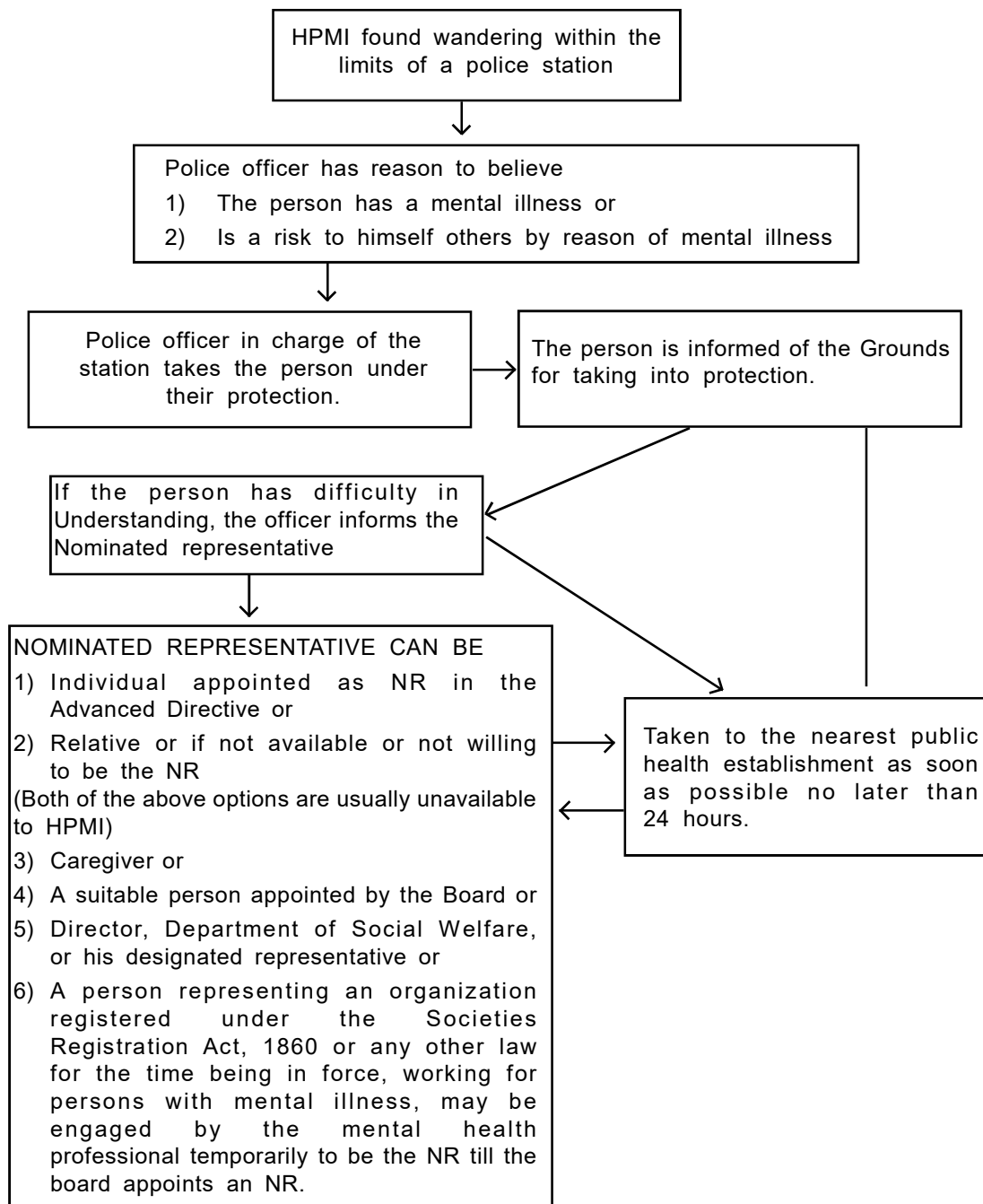
The present Mental Healthcare Act 2017 (MCHA 2017)<sup>8</sup> has kept the judiciary out of the picture and the responsibility of the HPMI now lies with the Police and the Mental Health Professional in a public health establishment.

**a) Procedure for Admission**

Any person found wandering and believed to have a mental illness and incapable of taking care of himself and at risk to himself and others is taken under protection by the officer-in-charge of the jurisdictional police station. The officer-in-charge informs the person the grounds for taking him under protection and if the person is incapable of understanding informs the Nominated Representative. Within 24 hours of being taken into protection he is taken to the nearest Public Mental Health Establishment (PMHE) for assessment of his health care needs. He cannot be detained in a lock up or prison under any circumstances. The Medical Officer (MO) in charge of the PMHE is responsible for arranging for the assessment of the person and needs of the Person with Mental Illness (PMI) as per provisions of the Act. If the MO on assessment finds that such a person does not have a mental illness requiring admission to a MHE informs the Police Officer (PO) who has taken the person into protection. It is the duty of the PO to take the person to his residence. In the case of a homeless person he is taken to a Government establishment for homeless persons. If a PMI is homeless and is found wandering a FIR of a missing person is lodged in the concerned police station and it would be the duty of station house officer to trace the family and inform them about his whereabouts. [Section 100, (1,2,3,4,5,6,7)]

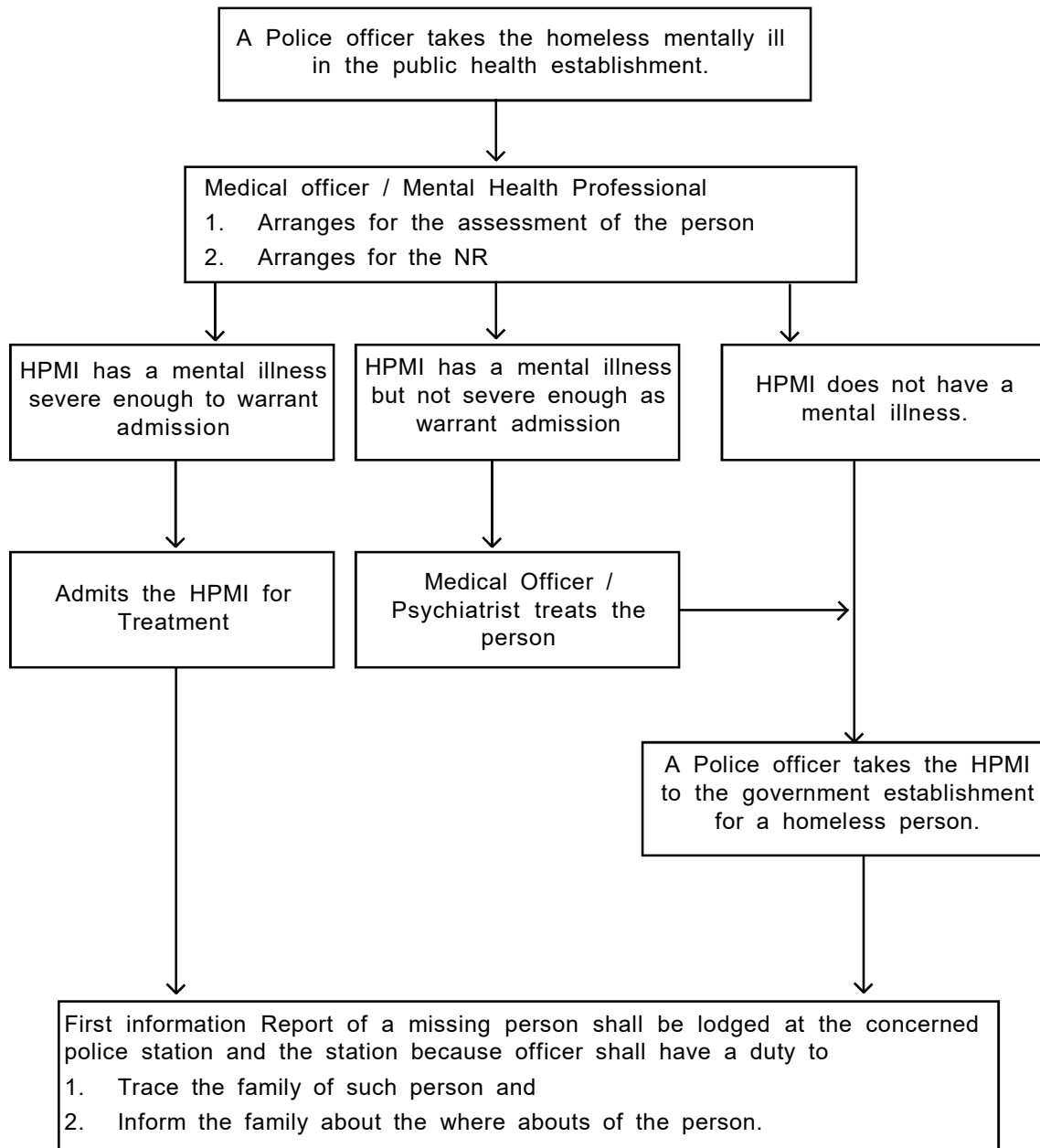
When any person with mental illness or who may have a mental illness is brought before a magistrate the person is sent to a PMHE for assessment and treatment for a period not exceeding ten days to enable MO or Mental Health Professional (MHP) in charge of MHE to carry out assessment of the person and plan treatment. [Section 102]

The pathways to the admission of a HPMI under MHCA 2017 (Flowchart 1) as well as the stages of care of HPMI in the public health establishment (Flowchart 2) is given below: [9]

**Flowchart 1**

Flowchart 1 : Pathways to care for homeless persons with mental illness according to the Mental Healthcare Act of 2017.

HPMI – Homeless person with mental illness; NR – Nominated representative

**Flowchart 2**

Flowchart 2: Stages of care of homeless persons with mental illness in the public health establishment. HPMI – Homeless person with mental illness; NR – Nominated representative

**b) Admission**

If a HPMI desires admission for treatment to a MHE the MO or Mental Health Professional (MHP) can admit him as an independent patient provided he is satisfied that he '...has understood the nature and purpose of admission to the MHE, and has made the request for admission of his own free will, without any duress or undue influence and has the capacity to make mental healthcare and treatment decisions without support or requires minimal support from others in making such decisions.' [Section 86, (1,2)]

**c) Admission and treatment of PMI with high support needs**

If the HPMI has recently threatened or has been threatening, or attempting to cause bodily harm to himself or has been behaving violently towards another person, or has caused, or is causing another person a fear of possible bodily harm, or is unable to care for himself as to be a risk of harm to himself, the psychiatrist or MHP may certify that admission to the MHE is the least restrictive care option possible. [Section 89 (1a,b,c)]

Every person admitted under this Act will be provided treatment with informed consent of the person and with the support of his Nominated Representative (NR). The NR gives temporary consent in case the person requires nearly 100% support to make a decision. In this eventuality the MO will review the capacity to give consent every seven days [Section 89 (6,7, 8)] The admission of a person to the MHE under this section is limited to 30 days. [Section 89(2)] This would be called supported admission. If the admission is required beyond 30 days the MO is duty bound to refer the matter to be examined by two Psychiatrists. [Section 89(17)]

In this eventuality it would require the NR to make an application to continue admission beyond 30 days. Two psychiatrists would then independently examine the person and certify that it is the least restrictive option possible. [Section 90 (2a,b)] All admissions and readmissions under this section should be reported to the board in seven days.[Section 90 (3)] The admission of a person may be extended for a period of ninety days in the first instance and further extended to a period of one hundred and twenty days and thereafter to a period of one hundred and eighty days each time provided the criteria for admission in this section are fulfilled. [Section 90 (8,9)]

**d) Nominated Representative**

As the HPMI has no NR, relative or caregiver or a suitable person appointed by the concerned Board, the Board can appoint the Director, Department of Social Welfare, or his designated representative as the NR. A person representing an organisation under the Societies Registration Act, such as NGO's working for persons with mental illness, may temporarily be engaged by the MHP as a NR pending appointment by the Board. [Section 14 (4e)]

**2. Restitution of Physical and Mental Health**

On admission to Chittadhama the HPMI, now called our Resident, is assisted to have a bath, the hair and nails are cared for and they are provided a hot meal. The person undergoes a physical and psychological assessment. Any immediate physical problems are addressed and an attempt is made to arrive at a psychological diagnosis where possible and medication started. Mandatory lab investigations include – CBC, RBS, Blood Urea, Serum Creatinine, VDRL, HIV 1&2 and Urine Routine Exam. Optionally an ECG, and Chest X Ray are done.

Very often when a person is admitted he/she is withdrawn and not able to give the history. Over time with medication and other interventions they show gradual improvement. The resident is put through a daily routine of attending to personal hygiene and selfcare, facilitating socialising with other residents and staff, yoga, exercise, games, working in the field in various capacities, in the dairy farm related activities and recreational TV. They all sit at the dining table together and start with a thanksgiving prayer. Depending on the resident's inclination and ability they are given a choice of activity.

### **3. Rehabilitation**

The following activities are offered which are congruent with the culture and socioeconomic status. The main focus is on agriculture and horticulture-based activity. The experience is that most of our residents are able to connect with what happens on the field and take part with varying degrees of involvement. There are jobs for everyone from pumping water with a handpump to picking fallen coconuts and plucking vegetables to tilling and planting. The dairy farm provides activities like cattle grazing, keeping the cattle and cattle shed clean to milking the cows and tending to the calves. There are some who show an inclination for housekeeping. They help in making the beds, keeping the ward and the premises clean. There are some who prefer activity in the kitchen, helping in washing vessels, cooking and learning culinary skills. Working together they are encouraged to interact socially and improve on their skills.

#### **a) Right to protection from cruel, inhuman and degrading treatment**

The Resident is treated with respect, lives in a safe and hygienic environment, has facilities for leisure, recreation, education and religious practices, privacy, proper clothing, is prepared for living in the community, has adequate provision for wholesome food, sanitation, space and access to articles of personal hygiene and women's personal hygiene is addressed particularly during menstruation, and they is no compulsory tonsuring and care is taken to see that they are protected from physical, verbal, emotional and sexual abuse. [Section 20 (2a,b,c,d,e,f,g,h,i,k)] The Resident is not subjected to any seclusion or solitary confinement and physical restraint is used only to prevent imminent and immediate harm to self or others. [Section 97 (1 a)]

### **4. Reintegration**

Residents who show improvement are most often able to provide their addresses. At times approximate addresses are given and our staff help the Resident identify their places with the help of Google maps. Aadhar cards are provided to all our residents. During this process it is realised that some of them already have been issued Aadhar cards. The address thus obtained has helped in reintegration of our residents to their families. Social media groups and personal contact have been the other methods used in reintegration.

Where addresses have been found a registered letter with acknowledgement due is posted with details of our Resident. Some families have come happily, thanked us profusely and have gratefully taken back their wards. Some have made telephonic and video contact but expressed inability to come because of poverty. Such persons have received financial assistance to assist reintegration. Some have outright rejected the Resident and have refused to take them back.



Every PMI has a right to live in and be a part of society. He need not remain in a MHE just because he does not have a family or is not accepted by the family or is homeless or due to absence of community-based facilities. Where it is not possible for the PMI to live with his family or is abandoned by the family the government has to provide support including free legal aid. [Section 19 (1b, 2)]

At Chittadhama, we explain to our Residents who have been abandoned by the family and who have capacity and express a desire to go home, about this legal provision. [Section 27(1,2)]

The Taluk Legal Services Authority at HD Kote has been approached to render free legal service. They have sent letters to the families stating the Resident's legal position. In cases where this has not helped, the Magistrate at the Court in HDKote has been approached asking for relief under Section 19 b. With the release from the reception order the residents have been accompanied to their homes by our staff. There are also long stay Residents who have improved but have not been able to provide their addresses. The Magistrate's permission is being sought to shift them to a less restrictive community-based establishment in Mysuru.

In spite of all these efforts there are several long stay Residents who cannot be reintegrated to their families because they have not been able to give their addresses or have been abandoned by their families. We find that in addition to their mental health their physical health requires attention too. Aware of the metabolic syndrome all Residents over the age of 45 years are given a yearly Master Health Check up.

#### **STORY OF RECOVERY FROM CHITTADHAMA**

Mr. G, male, aged 33 years was found wandering in the streets and was reported to be talking excessively and irrelevantly, being unpredictable, abusive, impulsive at times and tending to get violent. Later it was gathered that he had been ill for the past three months. He was admitted to Chittadhama through the court with a 'Reception Order'.

On admission he showed poor personal care, was ill kempt, restless, talking excessively and irrelevantly and appeared to be responding to voices. He was not answering any questions and as he was agitated he was given parenteral medication. For the first few days the parenteral route was preferred before he was started on oral medication. Over 2-3 weeks he settled down, was able to follow the routines of self-care, take part in walks and do simple exercises, come to the dining room by himself and take part in the rehabilitation program that involved socially interacting with residents and staff and working in the field. He improved and preferred working in the dairy farm. This involved grazing the cattle, milking the cows, and keeping the cows and the cow shed clean. He was a conscientious worker. He stayed at Chittadhama for ten months and on discharge was asymptomatic, able to care of himself and work productively. His discharge diagnosis was Bipolar Affective Disorder - Mania. He was advised to come every month for an examination and to collect his monthly supply of medicines.

He went back to his home to his 65 year old mother who was working as a daily wage labourer to support him. They stayed in a village, 60 kms away, that was remote, situated at the edge of the forest and had poor public transport connectivity.

G was seen at follow up initially regularly but soon became irregular and stopped his medication in six months.

He was seen again a year later in an excited, agitated state and the villagers had to bind him with ropes to get him to Chittadhama. He was immediately released of restraints and given intravenous sedation. He showed improvement over four weeks. On discharge he was advised Inj Fluphenazine decanoate 25 mg IM once in four weeks and Tab Divalproex 1000mg once daily. Inj Fluphenazine (the only long acting anti-psychotic available) was started hoping to assist medication adherence. He maintained improvement and came for monthly follow ups for the next five months and then dropped out. He was brought to Chittadhama in a restless state off and on when he stopped medication.

At this point we realised that in spite of a good response to medication, providing free consultation and free medicines and a long acting anti-psychotic injection for one month at a time we were not able to control the illness because of poor follow up. The reason for this was that his aged mother was the sole bread winner of the family and was supporting G. It took her a whole day to come to Chittadhama with G and get back home. She had to spend money on bus fare for both of them and in addition she lost one day's wages that she could ill afford.

We planned a video consultation and took the help of a local NGO to provide online connectivity, to help in the consultation process and collect medicines on G's behalf. This was not possible as we were not able to comply with telepsychiatry guidelines with regard to availability of medical staff at site.

As the main problem was social and financial, we planned to help him secure a livelihood and empower him financially. He had shown interest in the dairy work at Chittadhama so we decided to give him a milch cow. We would take care of the insurance of the cow and the animal husbandry aspects. G took responsibility of the cow and started looking after it in right earnest. It kept him occupied and he loved this arrangement and his new found job. Importantly he was earning money off his effort. He could now come by himself to take the medicines and had a little money to spend on his needs.

It is two years now and he has been maintaining good health till today. He comes for a regular follow up. He spends his day grazing his cow and looking after the new born calf. He has a regular income and is able to support his mother. When in doubt or difficulty he gets in touch with our staff who guide him.

## **CONCLUSION**

Chittadhama is managed with standard operating procedures drawn from the MHA 1987 and the Karnataka State Mental Health Rules 2012, now adapted to the MHCA 2017 and the current KSMHA rules notified in 2021. This adherence to the relevant Acts and Rules, it is felt, would help facilitate replication of this model. There would naturally be challenges associated in local settings that would have to be dealt with. Chittadhama caters to the HPMI and the mentally ill in a remote socio economically backward taluk of Karnataka where there is a felt need for such services. In a developing country like India in addition to Awareness, Availability, Affordability – Accessibility and Equity are important factors in delivering mental health care.

**TAKE HOME POINTS**

1. The HPMI have special needs in their management
2. There should be improved awareness of their needs amongst all stakeholders
3. The MHA 2017 guides admission and discharge, rights of HPMI, informs of available legal help, and responsibility of the state to provide long stay facilities

**REFERENCES**

1. <https://www.un.org/en/about-us/universal-declaration-of-human-rights> [Internet][cited 2022 Sep 17]
2. <https://unhabitat.org/ohchr-on-urban-development-and-human-rights-in-cities> <https://unhabitat.org/ohchr-on-urban-development-and-human-rights-in-cities> [Internet] [cited 2022 Sep 17]
3. Census of India: Reference Material [Internet]. [cited 2022 Sep 17]. Available from: [http://censusindia.gov.in/Ad\\_Campaign/Referance\\_material.html](http://censusindia.gov.in/Ad_Campaign/Referance_material.html)
4. The Hindu : National : Mental health & homelessness [Internet]. [cited 2022 Sep 17]. Available from: <https://www.thehindu.com/thehindu/2004/10/10/stories/2004101002161100.htm>
5. Gururaj G, Varghese M, Benegal V, Rao GN, Pathak K, Singh LK, Mehta RY, Ram D, Shibukumar TM, Kokane A, Lenin Singh RK, Chavan BS, Sharma P, Ramasubramanian C, Dalal PK, Saha PK, Deuri SP, Giri AK, Kavishvar AB, Sinha VK, Thavody J, Chatterji R, Akoijam BS, Das S, Kashyap A, Ragavan VS, Singh SK, Misra R and NMHS collaborators group. National Mental Health Survey of India, 2015-16: Prevalence, patterns and outcomes. Bengaluru, National Institute of Mental Health and Neuro Sciences, NIMHANS Publication No. 129, 2016.
6. Swaminath G. Indian Psychiatric Society-South Zone : Innovations and Challenges in Providing Psychiatric Services to Disadvantaged Populations : A Pilgrim's Progress. *Indian J Psychol Med.* 2015;37(2):122–130.
7. The Mental Health Act, 1987 [Internet]. [cited 2022 Sep 17]. Available from: [https://www.wbhealth.gov.in/mental\\_health/Acts\\_Rules/MHA\\_1987.pdf](https://www.wbhealth.gov.in/mental_health/Acts_Rules/MHA_1987.pdf)
8. Mental Healthcare Act, 2017.pdf [Internet]. [cited 2022 Sep 17]. Available from: <https://egazette.nic.in/WriteReadData/2017/175248.pdf>
9. Gopalrao Swaminath, Arun Enara, Ravishankar Rao, Kengeri V. Kishore Kumar, and Channaverachari Naveen Kumar. *Indian J Psychiatry.* 2019 Apr; 61 (Suppl 4): S768–S772. doi: 10.4103/psychiatry. IndianJPsychiatry\_117\_19



## COMMUNITY MENTAL HEALTH INTEGRATING REHABILITATION - WHAT HAS AN NGO CONTRIBUTED TO PRACTICE

R Padmavati<sup>1</sup>, Sujit John<sup>2</sup>, Kotteeswara Rao<sup>3</sup>, J R Aynkaran<sup>4</sup>

### ABSTRACT

In India, the core concept of community care for persons with mental illness has been a practice through the ages. Much of the community care for a good period in the past century has been formally or informally delivered by non-governmental organisations throughout the country. This article is a narrative of the community based mental health programs run by the Schizophrenia Research Foundation, with a strong element of psychosocial interventions integrated into the practice. The incremental learning over the years and the incorporation of sound research methods has contributed to refining these methods in an on-going activity of delivering community mental health services.

### INTRODUCTION

***Community mental health programs are not just about doing community mental health clinics under trees, but is all about involving communities in the access and provision of community based mental health interventions and rehabilitation*** - Dr Thara - Dr NN Wig Oration, September, 2022

Non-institutional care as a core concept of community psychiatry has been practiced through the ages [1]. In India, people with mental disorders have been traditionally contained within the community with families being the main care-providers. The larger community and traditional healers have also played a role [2]. Even today, this is ubiquitous in the rural areas of many LAMIC facilitated by the greater tolerance for illness behaviour, lowered expectations and religion-based coping as well as healing strategies by the family and community [2]. India has witnessed various forms of community care for the mentally ill in India with several non-governmental organizations (NGO) playing a central role in filling the gap and the substantial needs for mental health services. The focus has been on utilizing informal manpower resources incorporated with specialist psychiatric care and integrated with existing health care facilities. SCARF has played a pivotal and often pioneering role in the contributions to community mental health care in the country. Understanding what the community thinks of mental illnesses and persons with behavioural problems have been the foundations for implementation of many of the programs [3][4]. These programs, acknowledged widely, have played a critical role in influencing community practice in India and elsewhere. This article elaborates on the journey on community mental health practices through incremental learning over time.

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Director
2. Joint Director
3. Assistant Director
4. Community Co-ordinator

Schizophrenia Research Foundation, R/7A North Main Road, Anna Nagar West, Chennai - 600 101.

**THE BEGINNINGS :**

In the early years, SCARF's foray into community mental health began with a small year long program in Thiruvalem and Katpadi Firkas of Gudiyatham Taluk in North Arcot District of Tamil Nadu. This program was a response to a letter from a local person in Karnambut village of North Arcot. This program ran between October 1987 - October 1988. It started out as a public awareness campaign - an overwhelming response from the public was in the form of identification of a number of persons with mental illness. The felt need for clinical services resulted in the initiation of a monthly clinic operated for a population of 1,29,000 in the taluk. Clinics were located in the easily approachable village of Karnambut. Patients in the surrounding areas received psychiatric consultation, free medications and counselling as required.

The foundation of SCARF's relationship with the community was the invitation from the National Mental Health Program (NMHP) to initiate a Rehabilitation section in the program in 1987. A modestly funded project funded by the Govt of India aimed at integrating community based rehabilitation (CBR) in the NMHP was initiated in a rural catchment area, in Thiruporur Block of a population of 100,000.

The objectives were to devise simple psychosocial rehabilitation strategies that could be deployed by lay volunteers in the village itself, to examine the feasibility and efficacy of initiating a community based rehabilitation program, by elucidating data that would be required for such programs. Piggybacking on the CBR program run by Indian Red Cross Society for physically handicapped enabled the integration of mental health intervention in an existing CBR program. Testing out key components of community mental health services, like training lay community volunteers, implementing simple psychosocial interventions, networking for resource mobilisation and raising public awareness of mental health in the community[5].

Importantly, this program set the path for SCARF's contribution to community mental health interventions, rehabilitation and research traversing three plus decades and continues to be a mainstay of our programs. Over the years, several community mental health initiatives were undertaken in both urban and rural areas. Table 1 details the different programs

**Table 1 : Community Programs operated by SCARF Since 1988**

<i>Program</i>	<i>Area</i>	<i>Duration</i>	<i>Key Activities</i>	<i>Funding</i>
NMHP Project Community Outreach	Thiruporur Block in Kanchipuram District TN	10 + years	Training lay CLW Clinics Psychosocial interventions Training PHC Doctors Public Awareness	NMHP IDRC Canada
Community Outreach Program	Karnambut village in North Arcot	1 Year	Public awareness Clinics and counselling Training CLWs	Intra mural
SCARF Beatitudes program	Vyasarpadi, Chennai	1 year	Clinics, Awareness, Target - School students	---

<i>Program</i>	<i>Area</i>	<i>Duration</i>	<i>Key Activities</i>	<i>Funding</i>
Tsunami Psycho social interventions	East Coast of Tamilnadu - Population affected by Tsunami	4 years	Training community Volunteers Video Consultations Referrals for rehabilitation	OXFAM India PLAN India, Deutsche Bank Foundation, Help Age India, WHO
SCARF – MCDS programme	Patinapakkam Urban slum Clinics, outreach	2 Years	Clinics, outreach Public awareness	Montford Community Development Service
SCARF Chetpet programs	Chennai	Ongoing 10+years	Clinics	Anna Lakshmi group of hotels
CBR Program	Thiruporur	6 years (2005-2011)	Citizens' group, members of the village such as village leaders, school teachers, heads of religious institutions in the area and interested community persons.  * create awareness in the community, encourage. * help seeking, organize mental health camps in various villages. * reduce stigma * involve the community in rehabilitation of the patients. At a personal * create a small fund, tapping fiscal resources amongst themselves, to enable activities related to mental health care provision.	IDRC Canada, Cittadinanza, Italy

<i>Program</i>	<i>Area</i>	<i>Duration</i>	<i>Key Activities</i>	<i>Funding</i>
SCARF Telepsychiatry in Pudukottai (STEP)	Pudukottai		Mobile Telepsychiatry Consultation, Training community volunteers, PSR, SHGs, Rolling seed funding, linking with social benefits, Working with DMHP, & Public health services, awareness creation, family empowerment programs, etc.	Tata Education Trust

#### **COMMUNITY OUTREACH DURING DISASTER : INNOVATIONS IN MENTAL HEALTH DELIVERY SERVICES:**

SCARF's Telepsychiatry project is a pioneering program that set the tone of use of virtual teleconsultation in the country.

The Tsunami of 26 December 2004 crashed the east coast of the country and several 1000 kms of the east coast of the country was badly smashed! Over 364 villages were washed away by tidal waves rising over 7-10 meters. With the ocean intruding over one and a half kilometres inland, several thousands of families were displaced. The huge psychological trauma in the wake of this natural disaster became a priority to reach the affected population for offering psychosocial interventions.

Using videoconferencing, it became possible to reach populations over 400 kilometres away, provide counselling, and support. This early venture using a tiny videoconferencing tool soon gave way to larger television screens with better picture clarity. We also attempted to use the ISDN lines - however technology soon developed and laptops with videoconferencing facilities paved the way for better contact. We also used this medium to train lay community volunteers in counselling techniques as well. The initial support came from OXFAM.

We extended our psychosocial intervention programs to the child survivors in the schools of Cuddalore and Nagapattinam districts - interventions were done by community workers with guidance from SCARF and Child Health Education Society (CHES) teams. These included counselling of the child, parents, families, behaviour therapy in case of extreme fears and medications as required. The interventions for the children continued even after the impact of the Tsunami retreated. Freemasons of Chennai organised for the funding for this program from Grand Charities, London and Plan International [6].



Reflections on the data indicated that psychosocial needs of the survivors in the aftermath of this disaster were extensive, yet the cohesion and effectiveness of response were limited due to lack of preparedness and relevant policy. Providing the services for a period of period of 4 years (2004-2008), SCARF had the opportunity for research, the findings of which could be critical to future disaster response and preparedness. We undertook research on the challenges, success and limitations of psychosocial interventions in alleviating post-traumatic symptomology. The key challenges to conducting research were that both community-level workers and researchers were limited in their preparedness to carry out tasks related to response. Language barriers, cultural differences, and a gap in long-term services limited the breadth and scope of research that was able to be completed. Lack of policy, poor coordination of services, lack of trained researchers and limited resources were challenges that emerged during this period and various strategies were adopted to meet these challenges. Continued research and evaluation of data has brought crucial considerations to light, including the various changes in symptomology, effective tools of measurement, and the nuanced response of survivors [7].

#### **COLLABORATIVE COMMUNITY BASED INTERVENTIONS - THE COPSI STUDY**

With evidence to suggest that community-based services for people with serious mental disorders can be successfully provided by community health workers, when supervised by specialists, in low-income and middle income, the Community care for People with Schizophrenia in India (COPSI) trial to compare the effectiveness of a collaborative community-based care intervention with standard facility-based care, was undertaken as a multisite study [8]. This was a multicentre, parallel-group, randomised controlled trial at three sites in India, done over a two year period between Jan 1, 2009 and Dec 31, 2010. Patients with a primary diagnosis of schizophrenia (ICD-10-DCR) were randomly assigned (2:1), to receive either collaborative community-based care plus facility-based care or facility-based care alone. The primary outcome was a change in symptoms and disabilities. Participants randomised to the collaborative community-based care plus facility-based care group were 187 and 95 were randomised to the facility-based care alone group; Ninety percent participants completed follow-up to month 12.

In the collaborative care group, intervention comprised five components (psycho-education; adherence management; rehabilitation; referral to community agencies; and health promotion) to be delivered by trained lay health workers supervised by specialists. The intervention underwent a number of changes as a result of formative and pilot work. Multiple level discussion ensured that all the components were acceptable. However, it was also noted that experiences of stigma and discrimination were inadequately addressed; New components to address stigma were added to the intervention to strengthen, the collaborative nature of service provision. Criteria were evolved for the selection and training of the health workers based on participants' expectations. A multi-level supervision system was developed, and delivery of components was made more flexible [9].

Psychopathology and disability scores were modestly lower in the intervention group, with a significant reduction in symptom and disability outcomes in rural Tamil Nadu site. The collaborative community-based care plus facility-based care intervention was reported to be modestly more effective than facility-based care, especially for reducing disability and symptoms of psychosis. The researchers also opined that intervention was best implemented as an initial service in settings where services are scarce, for example in rural areas [10].

### **SCARF'S TELE-PSYCHIATRY PROGRAM IN PUDUKKOTTAI (STEP)**

SCARF's tele-psychiatry program in Pudukkottai (STEP) aimed to test whether videoconferencing could be adapted to increase its utilisation especially in remote rural areas. Our strategy was to use tele-psychiatry consultations by integrating tele-medicine with mobile clinics and low-cost technological solutions. At that time, around 18 years ago, Pudukkottai district had very little access to any form of mental health care. This program helped to reach out to the several thousands of persons with serious mental disorders.

The objectives of the research component of the program were to test the effectiveness of the program in terms of its reach, its outcome and sustainability. The research also explored whether teleconsultation through mobile clinics was better than consultations offered from a fixed line? The program itself consisted of enlisting lay community volunteers who were trained to identify mental health problems in the community. Research assistants screened and recruited subjects who were given treatment after consultations with the psychiatrist sitting in the headquarters at Chennai. Efforts were made to keep tabs on the physical health of the patients as well. All patients were provided medications as need at the clinics at no cost. In addition, psychosocial rehabilitation strategies that included, individually tailored interventions by the CLWs, improving access to government offered disability cards and welfare schemes, linking to job opportunities were emphasized on. Our data demonstrated that we could facilitate mental health care across large populations which would result in good outcomes [11][12].

What were the predictors that promoted access to care in the STEP project? Among 422 participants with SMD, 74% had at some point in time accessed mental health care services. Logistic regression showed only education level of the patients with SMD turned out to be significantly associated with seeking mental health care services. Those with higher education sought help earlier. Improving literacy and awareness on the mental illness and its treatment options will help the patients with mental illness to seek care early leading to favourable outcomes [13].

STEP Project helped to understand various clinical aspects of serious mental disorders (SMD) in the community. One of the key studies was on understanding excess mortality in persons with serious mental disorders, especially in the context of scant literature on this from the low and middle income countries including India. Our study sought to estimate the standardized mortality ratio (SMR) of patients with SMD from a rural community in Tamil Nadu for the years 2011-2015. Data on patients with SMD from four taluks of Pudukkottai district, during the years 2011-2015 included sociodemographic details, alive/dead status, and cause of death from the clinic registers and patient case records. A mortality rate two times higher amongst persons with SMD was observed. Using crude death rates for rural Tamil Nadu for the years 2011-2015 for the calculation of SMR, the SMR of patients with SMD was 3.33, 2.76, 2.11, 1.91, and 1.89 in the years 2011-2015. Of the 74 total deaths in these 5 years, 62 (83.7%) were due to natural causes, while 12.2% died by suicide. Statistically significant differences were observed in age, education, and marital status between patients with SMD who were alive and dead. The findings indicate that further research is needed to examine the reasons for increased mortality among patients with SMD and interventions to reduce this excess mortality. Attention needs to be paid to the physical health of the patients [14].

One important outcome of STEP program was that the several organisations and mental health professionals reached out to SCARF to learn this technique. Today this has become a part of the District Mental Health Program. We have enabled the population to get locally available treatment at the DMHP - this would ensure sustainability for treatment. Community level workers have demonstrated commitment to serve the community long after the funders has ceased [15].

### **THE COVID PANDEMIC AND REACHING MENTALLY ILL IN THE COMMUNITY**

The corona virus disease 2019 (COVID-19) pandemic has caused disruptions in services to mentally ill globally [16]. Services to the rural worsened during the pandemic. With SCARF providing clinical and rehabilitation services to a larger rural population, we looked at how the service providers adapted and responded to the challenges of providing service during the pandemic and the specific issues faced by the mentally ill. Using several methods to reach patients across large geographical areas and the barriers imposed in cutting across several regions, we had to use relay methods of transporting medications and life sustenance material in the form of provisions. Our band of researchers in the field and community level workers came up with several ingenious methods of the tasks over several months. An understanding of adaptations to ensure continuity of care to mentally ill during disruptions and insights from strategies are crucial to help plan for resilient community-based mental health care services [17].

### **KEY ELEMENTS OF SCARF PROGRAMS**

Several key features of SCARF's community programs have been evident across all our program [18]. These continue to remain crucial to community programs

**Training of lay community workers** - Volunteers who had completed school level education were trained in recognition and identification of mental health problems in the community and referral to appropriate sources of treatments. Using a participatory approach and reinforce sessions, the training served empower the young people in a task that would have otherwise remained unrecognised and unattended to.

**Operating community clinics** : It was not enough to recognise mentally ill in the community. The prevalent situation was inaccessibility of mental health services for most parts of rural Tamilnadu, several decades ago. This demanded that psychiatric services were available at the "door step". In all out-outreach programs, we ensured that clinics were operated.

**Increasing public awareness on mental disorders** : There was extensive use of folk-dance music and drama in the rural areas and street plays in the urban communities. It helped not just in creating awareness, but also in demystifying mental illnesses as a whole

**Networking for rehabilitation** : The networking was with government and other NGOs in the community, to facilitate mobilisation of resources for rehabilitation

**Training CLWs in implementing simple psychosocial rehabilitation** : The focus was on the adaptation of case management techniques that could be delivered by the lay volunteers.

### **FACTORS THAT AFFECT THE PLANNING AND EXECUTION OF COMMUNITY PROGRAMS BY NGOS**

Community based initiatives for management of mental illnesses and the rehabilitation of persons with serious mental disorders is well evidenced by the numbers of such programs

described in various reports and publications. The book published by Patel and Thara (2003) [19] is a meaningful collection of experiences from several non-governmental organizations (NGOs) across India in the field of mental health which provides an understanding of the various non-formal efforts in mental health care delivery in India. However, several factors appear to influence the operation of community mental health programs, by NGOs

**Community acceptance** was promoted by the involvement of the local population in all our programs. Integrating programs within the framework of the cultural values included the attempts to co-exist with existing traditional belief systems. Provision of clinic based psychiatric consultations and pharmacotherapy resulted in improved clinical outcomes and return to productivity. A transparent accountability in project operations and in financial management has found credibility with the local public and the funding sources. More recently, linking with the District Mental Health Programs, available in every district of the state has facilitated better access to medical care and SCARF continues to be involved in the process of Rehabilitation [15].

**Management strategies** : The COPSI study and the STEP programs demonstrated that it was possible to develop community interventions including psychosocial interventions in the rural populations. With adequate orientation and supervision in the use of anti-psychotic medications it is possible to effectively involve the community level workers in the treatment of mental disorders. Domiciliary delivery of medications has proved to be an important strategy in the management of mentally ill especially in the rural community [20]. The use of depot medications was reported to be more cost-effective when compared to oral medications [13]. SCARF outreach programs in the urban areas too worked, although these were time - limited due to reasons of funding.

**Sustainability** : What determines if the community based programs, whether clinical services of rehabilitation centric, sustain over time.? From an NGO perspective, this becomes a critical issue. SCARF's program in Thiruporur, set up in 1989, existed for about 10 years and comprised of various components such as training of the primary health center staff, setting up a referral system, setting up of a Citizen's Group, and self-employment schemes.

In 1999, we had to withdraw from the area due to lack of funds, A follow up was initiated in 2005 to determine the status of the schemes as well as clinical status of the patients registered at the clinic. This we believed would lead to indicators to help evolve future community based programmes. The follow up showed that a very small group of patients referred to the government facilities remained in treatment. Over three quarters of those not on treatment were acutely psychotic. The Citizen's group was functional for only a year and apart from chicken rearing, all other self-employment schemes were discontinued within a period of 6 months to 3 years. Multiple factors contributed to the failure. Limited access and associated expenses entailed in seeking treatment, inadequate knowledge about the illness, lack of support from the family and community and continued dependence by the family on the service provider to provide solutions were some primary reasons. This implied that community based initiatives in the management of mental disorders however well-intentioned will not be sustainable unless the family and the community are involved in the intervention program with support being provided regularly [3].

**Human resources for a community based program** : While it can be argued that the family and community are very integral part of community care of persons with mental illnesses, there is evidence that sustaining programs without human and fiscal resources

becomes difficult [19][21]. Community level health workers (CLWs) are an important component of community health services and play multiple roles such as delivering care at the door step of persons with mental illness, increasing mental health awareness, implementing anti-stigma interventions, facilitating of help seeking to the appropriate medical sources, ensuring follow up, and liaising with various government departments for facilitating benefits to their clients. SCARF has preferred to use young women with high school level of education as CLWs in several of its programmes - women are seen as less threatening and can more easily gain entry into rural households [22].

We have also noted that this group of community workers often need supervision, making it essential for a top-down approach to service delivery and sustenance. Leadership roles of community coordinators become significant.

**Ethics** : Several ethical concerns exist in the context of implementation of community care. Successful implementation of community mental healthcare will become possible only when based on a set of principles that relate to the value of the community, the importance of self-determination and the rights of people with mental illnesses as people and citizens [23]. Scaling up of mental healthcare based on the principle of cost effectiveness is not only clinically imperative, but also a pivotal means to ensure that the severely mentally ill are accorded the same universal rights as those enjoyed by others [24].

SCARF's programs have consistently upheld core ethical principles of justice, beneficence and non-maleficence. This ensured community acceptance. Informed consent procedures for research and confidentiality have been consistently applied. For example the training provided to the lay workers as part of COPSI study, emphasized on the need for confidentiality (COPSI 2010) Our programs have demonstrated moral obligations and leadership over the decades (25).

### **CHALLENGES**

Challenges abound in the planning and delivery of community mental health care. In a recent study [26], staff from the STEP program, three community project coordinators and six community level mental health workers were individually interviewed using a semi-structured pro forma to understand the challenges faced by them in delivering mental health services to the people in the community. The data indicated that different challenges surfaced at different points in time from different people, for example, during identification and referral for treatment, home visits, and facilitation of welfare schemes for persons with severe mental disorders.

While SCARF has demonstrated the feasibility of operating community mental health programs over decades, the challenge lies in sourcing adequate fiscal support, coordinating with existing resources and sustaining programs [18].

### **WAY FORWARD**

Community mental healthcare services, including psychosocial rehabilitation exist globally and are considerably heterogeneous. From an NGO perspective, the way forward needs to incorporate building strategic coalition and effective task shifting, by utilising and partnering locally available resources such as lay health workers and traditional healers [22]. The process of rehabilitation can be achieved through public-private partnerships. Active referrals to government welfare schemes, and/or incorporating home-grown micro-financing schemes

for entrepreneurs will have better acceptance than the replication of models developed in the high-resource countries. With respect to research in psychosocial interventions during disasters, future research should explore relevant factors into consideration including barriers to care. Research to understanding the local language and religious beliefs are significant resources in understanding the nature of survivors' trauma response and effective means of coping. Lastly, limitations regarding time frame and scope of research should be evaluated to provide more effective, comprehensive methods in future studies.

## CONCLUSION

What has an NGO contributed to community based mental health programs and research over the past decades? It is evident over most of our programs that the key features have been diligent program design, incorporation of sound research methods nested within the plan, collaboration with public health care systems, communities, families, mobilising of resources and innovation. These core features have provided the foundations of similar programs across the country.

## TAKE HOME MESSAGES

- \* Incorporate building strategic coalition and effective task shifting, by utilising and partnering locally available resources such as lay health workers and traditional healers.
- \* Build public - private partnerships.
- \* Engage the stakeholders actively.
- \* Understand local languages and religious beliefs.

## REFERENCES

1. Chandrasekhar, C R and Parthasarathy R (1999) Community Psychiatry In J N Vyas and N Ahuja (eds) Textbook of Post graduate Psychiatry, Second edition (pp 985-992) New Delhi: Jaypee Medical.
2. Isaac M. Introduction. In Community Mental Health in India Ed. BS Chavan, N Gupta, P Arun, A Sidana and S Jadhav, Second. Vol. 1. Jaypee Publishers New Delhi; 2012.
3. Thara R, Islam A, Padmavati R. Beliefs About Mental Illness: A Study of a Rural South-Indian Community. *Int J Ment Health* [Internet]. 1998 Sep [cited 2022 Sep 19];27(3):70-85. Available from: <https://www.tandfonline.com/doi/full/10.1080/00207411.1998.11449435>
4. Cohen A, Padmavati R, Hibben M, Oyewusi S, John S, Esan O, et al. Concepts of madness in diverse settings: a qualitative study from the INTREPID project. *BMC Psychiatry* [Internet]. 2016 Dec [cited 2022 Sep 19];16(1):388. Available from: <http://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-016-1090-4>
5. Nagaswami V. Integration of psychosocial rehabilitation in national health care programmes. *Psychosoc Rehabil J* [Internet]. 1990 Jul [cited 2022 Sep 20];14(1):53-65. Available from: <http://doi.apa.org/getdoi.cfm?doi=10.1037/h0099455>
6. Vijaykumar L, Thara R, John S, Chellappa S. Psychosocial interventions after tsunami in Tamil Nadu, India. *Int Rev Psychiatry* [Internet]. 2006 Jan [cited 2022 Sep 20];18(3):225-31. Available from: <http://www.tandfonline.com/doi/full/10.1080/09540260600655912>
7. Padmavati R, Raghavan V, Rera H, Kearns M, Rao K, John S, et al. Learnings from conducting mental health research during 2004 tsunami in Tamil Nadu, India. *BMC Public Health*. 2020 Oct 29;20(1):1627.

8. The COmmunity care for People with Schizophrenia in India (COPSI) group, Chatterjee S, Leese M, Koschorke M, McCrone P, Naik S, et al. Collaborative community based care for people and their families living with schizophrenia in India: protocol for a randomised controlled trial. *Trials* [Internet]. 2011 Dec [cited 2022 Sep 20];12(1):12. Available from: <https://trialsjournal.biomedcentral.com/articles/10.1186/1745-6215-12-12>
9. Balaji M, Chatterjee S, Koschorke M, Rangaswamy T, Chavan A, Dabholkar H, et al. The development of a lay health worker delivered collaborative community based intervention for people with schizophrenia in India. *BMC Health Serv Res* [Internet]. 2012 Dec [cited 2022 Sep 20];12(1):42. Available from: <https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-12-42>
10. Chatterjee S, Naik S, John S, Dabholkar H, Balaji M, Koschorke M, et al. Effectiveness of a community-based intervention for people with schizophrenia and their caregivers in India (COPSI): a randomised controlled trial. *The Lancet* [Internet]. 2014 Apr [cited 2022 Sep 20];383(9926):1385-94. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S014067361362629X>
11. Thara R, John S, Rao K. "Telemental Health in India" in *Telemental Health in Resource Limited Global Settings*, Editors Barkil-Oteo, Jefe-Bahloul & Augusterfer. Oxford University Press. 2017 Jun;
12. Rao K, John S, Kulandesu A, Karthick S, Senthilkumar S, Gunaselvi T, et al. Psychosocial Rehabilitation of Persons with Severe Mental Disorders in Rural South India: Learnings from Step Project. *J Psychosoc Rehabil Ment Health* [Internet]. 2022 Sep [cited 2022 Sep 21];9(3):335-43. Available from: <https://link.springer.com/10.1007/s40737-022-00275-7>
13. Raghavan V, Cherubal AG, John S, Rao K, Padmavati R, Thara R. Predictors of Access to Mental Health Care Services Among Persons with Severe Mental Disorders: A Community-Based Study from Rural South India. *INDIAN J Ment Health Neurosci* [Internet]. 2021 Jan 1 [cited 2022 Sep 21];4(01):34-40. Available from: <http://journals.myresearchjournals.com/index.php/ijmhns/article/view/6792>
14. Raghavan. Mortality among patients with severe mental disorders from a rural community in South India [Internet]. [cited 2022 Sep 21]. Available from: <https://www.indjsp.org/article.asp?issn=0971-9962;year=2021;volume=37;issue=4;spage=418;epage=422;aulast=Raghavan>
15. Thara R, Sujit J. Mobile telepsychiatry in India. *World Psychiatry* [Internet]. 2013 Feb [cited 2022 Sep 21];12(1):84-84. Available from: <https://onlinelibrary.wiley.com/doi/10.1002/wps.20025>
16. Li L. Challenges and Priorities in Responding to COVID-19 in Inpatient Psychiatry. *Psychiatr Serv* [Internet]. 2020 Jun 1 [cited 2022 Sep 21];71(6):624-6. Available from: <https://psychiatryonline.org/doi/10.1176/appi.ps.202000166>
17. Nair S, Kannan P, Mehta K, Raju A, Mathew J, Ramachandran P. The COVID-19 pandemic and its impact on mental health services: the provider perspective. *J Public Health* [Internet]. 2021 Oct 8 [cited 2022 Sep 19];43(Supplement\_2):ii51-6. Available from: [https://academic.oup.com/jpubhealth/article/43/Supplement\\_2/ii51/6383624](https://academic.oup.com/jpubhealth/article/43/Supplement_2/ii51/6383624)
18. Padmavati R. Community mental health care in India. *Int Rev Psychiatry* [Internet]. 2005 Apr [cited 2022 Sep 21];17(2):103-7. Available from: <http://www.tandfonline.com/doi/full/10.1080/09540260500073562>
19. Patel V, Thara R. Meeting mental health needs in developing countries. *NGO innovations in India*. Sage, New Delhi; 2003.

20. Thara R, Padmavati R, Srinivasan TN. Focus on psychiatry in India. *Br J Psychiatry* [Internet]. 2004 Apr [cited 2022 Sep 21];184(4):366-73. Available from: [https://www.cambridge.org/core/product/identifier/S000712500007793X/type/journal\\_article](https://www.cambridge.org/core/product/identifier/S000712500007793X/type/journal_article)
21. Thara R, Rao K, John S. An Assessment of Post-Tsunami Psychosocial Training Programmes in Tamilnadu, India. *Int J Soc Psychiatry* [Internet]. 2008 May [cited 2022 Sep 21];54(3):197-205. Available from: <http://journals.sagepub.com/doi/10.1177/0020764008090421>
22. Thara R, John S, Chatterjee S. Community mental health teams in low- and middle-income countries. *Epidemiol Psychiatr Sci* [Internet]. 2014 Jun [cited 2022 Sep 21];23(2):119-22. Available from: [https://www.cambridge.org/core/product/identifier/S2045796014000079/type/journal\\_article](https://www.cambridge.org/core/product/identifier/S2045796014000079/type/journal_article)
23. Thornicroft G, Tansella M. Translating ethical principles into outcome measures for mental health service research. *Psychol Med* [Internet]. 1999 Jul [cited 2022 Sep 21];29(4):761-7. Available from: [https://www.cambridge.org/core/product/identifier/S0033291798008034/type/journal\\_article](https://www.cambridge.org/core/product/identifier/S0033291798008034/type/journal_article)
24. Patel V, Bloch S. The ethical imperative to scale up health care services for people with severe mental disorders in low and middle income countries. *Postgrad Med J* [Internet]. 2009 Oct 1 [cited 2022 Sep 19];85(1008):509-13. Available from: <https://pmj.bmj.com/lookup/doi/10.1136/pgmj.2009.081596>
25. Padmavati R. Community mental health services for the mentally ill: Practices and ethics. *Int Rev Psychiatry* [Internet]. 2012 Oct [cited 2022 Sep 19];24(5):504-10. Available from: <http://www.tandfonline.com/doi/full/10.3109/09540261.2012.712953>
26. Raghavan V, Kulandesu A, Karthick S, Senthilkumar S, Gunaselvi T, Rao K, et al. Challenges faced by community-level workers in delivering mental health services for a rural community in South India. *Indian J Psychiatry*. 2021 Jun;63(3):307-8.



## **DAVA AND DUA**

Dr. Gopalakrishnan G, Dr. Arudhra Gopalakrishnan, Dr. Swetha S

### **FOREWORD**

I thank Professor Aniti Pralakthi, Ex-Professor of Psychiatry, University of Helsinki, for introducing me to the topic of spirituality and mental health and inspiring me to explore this area.

### **INTRODUCTION**

Mental disorders are as old as mankind and different cultures and countries seek different methods to understand and manage the mentally ill. Tamil culture and Hindus believe that mental illness can be cured by prayer and worship at temples. The Muslim and Christian faith also have similar places of worship for the mentally ill in Tamilnadu.

The temples continue to play an important role not only as places of worship, but also places of religious cures for bodily and mental illnesses. Tamilnadu is renowned for its ancient temples, some of which especially attract people suffering from mental health problems. The temples of Gunaseelam, Thiruvaidaimaruthur, Shollingur are a few examples among many. Erwadi and St. Antony's Church, Thoothukudi have also been attracting psychiatric patients for long.

### **GUNASEELAM**

This Vaishnavite shrine at Gunaseelam is on the northern banks of River Cauvery, 20 kms. away from Tiruchirappalli on the Trichy-Salem-Bangalore highway. The presiding deity is Sri Prasanna Venkatachalapathy, whose worshippers consider him to be as powerful as the Lord Venkateshwara of Tirupati, Andhra Pradesh. This temple is in existence for the last 200 years.

Legend has it that Lord Venkateshwara appeared to Gunaseela Maharishi with the promise to cure the illness of those who worship at this shrine. The majority of visitors to this temple are those suffering from neurotic and psychotic disorders. A short stay of 48 days (one mandala) is advised for people with emotional distress and setbacks in life. Advice on the treatment is usually given by the temple priest. After bathing in the Cauvery which is a few yards way from the temple, clients are taken to the temple for puja. There is a special prayer done for clients at 6 am, 12 noon and 8 pm. They shower the holy water on the face of all clients. No break is allowed during the stay period of 48 days. Family members usually stay with the client.

---

Disclosure statement: Authors do not have any conflict of interest and did not receive any funding for this work. Reprint requests maybe sent to [sowmanasya@gmail.com](mailto:sowmanasya@gmail.com).

1. Founder, Managing Director, MD (Psy), Sowmanasya Hospital and Institute of Psychiatry, 6, V N Nagar, Karur bypass road, Trichy -620 002, Tamilnadu.
2. Executive Director, MD (Psy), Sowmanasya Hospital and Institute of Psychiatry, Trichy, Tamilnadu.
3. PhD Social Work, Sowmanasya Hospital and Institute of Psychiatry, Trichy, Tamilnadu.

### **GUNASEELAM SOP**

The rehabilitation centre at Gunaseelam was established in 1996 after unchaining of all patients, a practice that had been existing for over 200 years. The new rehabilitation centre was built in 2002 with a donation of Sivanthi Aaditanaar, the media baron of Daily Thanthi, a widely circulated Tamil daily. The centre is provided with 15 rooms equipped with a kitchenette and toilet, apart from a common hall and doctors consultation rooms. OPD clinics are run for screening of clients by psychiatrists thrice a week. A residential social worker and four health workers apart from security staff are present at the centre. All clients are encouraged to stay not less than 48 days on the advise of the psychiatrist. Regular follow up of clients is available after discharge. Usually those with severe mental disorders of both sexes are admitted. Care is being taken not to admit those with substance abuse and mental retardation. Let us briefly explain the religious rituals that take place. As mentioned earlier, clients are encouraged to attend to their personal hygiene before entering the temple. The clients are allowed only at certain times of the puja. Every client is given a small thread band which is to be worn throughout the period of stay. All clients are encouraged to participate in the bhajan done at the temple. This rehabilitation centre has been operational since 2003. The psychiatrist visit and medicines are being provided free of cost by Sowmanasya Hospital and Institute of Psychiatry (accredited by National Board of Examinations and Dr. MGR Medical University for post graduate training and research in psychiatry, psychology and social work.) All the clients are provided with free stay, clothes and food. Patients are encouraged to take part in yoga and other traditional healing practices.

The occupational therapy includes unique activities such as plucking of flowers from the temple garden and making of garlands for the Lord. The clients are also encouraged to separate the holy tulusi leaves off the garlands which were offered earlier, and make it available for dispensing to devotees. They also use the dried flowers to make rangoli and kolam powder, and coloured powder for Holi. Baskets, bags and dolls are also made from dry palm leaves. A vegetable garden is also maintained by the clients.

People of different religious faiths have been noticed to come to this centre to get relieved from their problems. Care is taken not to force people of other religious faith if they have reservations.

### **EMERGENCY CARE AND REHABILITATION OF HOMELESS MENTALLY ILL ( ECRC )**

This project was started with the participation and help of Banyan, a NGO, the temple trust and district mental health program apart from Sowmanasya Hospitals providing free services. Adequate staff support are provided and funded by NGO. The protocol for ECRC includes rescuing of patients from the streets around the taluk of Trichy district with the help of police, local authorities and health care workers. They are brought to the rehab centre. Proper consent is taken after filing of first information report (FIR) at the local police station. Physical and mental examination is done by the doctors of Sowmanasya Hospital. They are provided with food, clothes and shelter by the temple. During the course of their stay, they are given vocational training for improving their livelihood and participate in community activities and improve socialisation. Efforts are made to give them relief from symptoms, improve daily activities, and try to reintegrate them with their families whenever possible. Significant number of them have been reintegrated with their family. Where necessary, Aadhar card and ration cards are being given to them with the help of the State Revenue department at the rehab centre.



Premises and Facilities at Gunaseelam



*Garlands and baskets done by patients at rehab centre*



*Patients inside Temple premises*

'Home Again', a halfway home for the clients who have partially or fully recovered is also a part of the program at a nearby place. All their needs are looked after with a caretaker monitoring the program.

The ECRC data includes a period of June 2021 to September 2022.

Outreach	-	177.
Rescue	-	49
Reintegration with family	-	29
Death	-	1
Walkout	-	5
Inpatient	-	10
Transfer to other NGO for long-term care	-	4

**MEDICAL FACILITIES**

Many of the clients as and when required, many clients are provided with medical evaluation and treatment. All the clients are provided with medicines like anti-psychotics, oral and long-acting injections, free of cost by Sowmanasya Hospital and Institute of Psychiatry.

**FUTURE AHEAD**

Plans are underway for regular psychiatric services on a daily basis and an inpatient strength of 200 beds in the next 5 years. It is pertinent to mention that the funds are all provided by devotees of the temple and NGOs. The centre is duly licensed since 2002 till date.

**WHY DAVA AND DUA**

It is pertinent to mention that the morbidity in India is around 10.5% as available from the National Mental Health Survey conducted in 2016. 82% of common mental disorders and 47% of severe mental disorders never came in contact with medical practitioners. The Erwadi tragedy had awakened the reality and need for looking after the mentally ill at these faith healing centres. The studies are far and few in terms of transcultural psychiatry, anthropology and health psychology. To reduce the MH gap and making large number of patients requiring treatment to access the care available with less stigma and no-cost for treatment is the aim of Dava and Dua. Officially the Dava and Dua project was started in Gujarat in 2018 by Dr. Ajay Chauhan. 38500 people were reached out to and were beneficiaries of this project in Ahmedabad. WHO and NHRC has recommended this project to the other parts of India. Gunaseelam has catered to over 8000 new outpatients and 10000 inpatients for the last two decades. The training of faith healers at Erwadi and government support to them has enhanced the community-based mental health delivery program. To mention last, Dava and Dua are realistic, community based, culturally acceptable, reduces MH gap and provides care at the least cost with participation of the community at large. More studies are needed to make SOPs, make Indian methods of rehabilitation which are culturally relevant and cost effective. This Dava and Dua model would reduce stigma, care giver burden, and increase self esteem of the patients with severe mental illnesses.

We would like to mention our special thanks to the Gunaseelam Temple Trust, Banyan, Government of Tamilnadu, Dr. C. Ramasubramaniam of Madurai and other stakeholders in the success of the Gunaseelam project. We recommend the following books for such of those who wish to go through the uniqueness of faith, religion and psychiatry.

**REFERENCES**

1. Religion and mental health. Behere, Prakash B.; Das, Anweshak; Yadav, Richa1; Behere, Aniruddh. Indian Journal of Psychiatry: January 2013 - Volume 55 - Issue Supplement 2.
2. How can India's faith healers play a role in mental health care? Mahima Jain, May 2021, Devex.
3. Faith Healing Practice is the pathway to care for mental illness - A study from Kashmir. Rehana Amin, Saba Younis, Zaid Ahmed Wani.
4. Healers and healing practice of mental illness in India - The role of proposed eclectic healing model. Ramakrishna Biswal (NIT, Rourkela), Chittaranjan Subudhi (Central university of TN) and Sanjay Kumar Acharya (Department of Psychiatry, Ispat General Hospital, Rourkela, Odisha). J Health Res Rev 2017;4:89-95.
5. Role of religions and cultural beliefs with regard to mental illness in India and France. TY - Jugal Kishore, RCJjiloha, Nicholas Daumorie, Patrick Bantman, Jenny Luc Roelandt. PY - 2019/04/04, 10.24321/2581.5822.201905
6. Journal of Advanced Research in Psychology & Psychotherapy, Volume 2, Issue 1, 2019, Pg 24-31
7. Mental Health Services in India-challenges and innovation, Dr Manik Inder Sangh Sethi, Postgraduate Medical journal, blog British Medical Journal, June 4 2021
8. Sunbathing the mind: Faith healing in India, Karen De Looze, Belgium, Jan.22,2017, Hekoten International
9. Experiences of religious healing in psychiatric patients, Campion J, Bhugra D. Experiences of religious healing in psychiatric patients in south India. Soc Psychiatry Psychiatr Epidemiol. 1997 May;32(4):215-21. doi: 10.1007/BF00788241. PMID: 9184467.
10. Resort to faith healing practices in the pathway to care for mental illness: A study of psychiatric inpatient in Orissa, Nilamadhab Kar, Taylor and Francis online, Nov. 2008, 11 (7) pg. 720-740.

## PSYCHIATRIC REHABILITATION IN GENERAL HOSPITAL PSYCHIATRY UNIT

Amritha Roy<sup>1</sup>, Bhaswati Kalita<sup>2</sup>, Thanapal Sivakumar<sup>3</sup>

### ABSTRACT

Rehabilitation is an integral part of the holistic management of psychiatric disorders. General Hospital Psychiatric Units (GHPUs) are the most commonly opted treatment option as they have less stigma attached, offer multiple specialties on one campus, and provide integrated physical and mental healthcare services. This chapter dwells on the feasibility of psychiatric rehabilitation at GHPUs, its challenges and facilitators, and possible psychiatric rehabilitation services. We also discuss some of the replicable practice-based evidence from the psychiatric rehabilitation field and the way forward.

### INTRODUCTION

The psychiatric unit of a medical college or general hospital is referred to as the General Hospital Psychiatry Unit (GHPU). GHPUs cater to a large spectrum of therapeutic (including inpatient, outpatient, and emergency departments, consultation-liaison services, specialized clinics, de-addiction, and community outreach services), educational (graduate and postgraduate training of physicians, nurses, social workers, and psychologists), and interdisciplinary research. GHPU services are offered by public, private, corporate, and charitable trust-run organizations. GHPU is a predominant model of providing integrated mental and physical healthcare. GHPU is currently the face of psychiatric care in India and has taken psychiatric care to the masses [1][2].

Psychiatric rehabilitation has been conceptualized and defined diversely by various authors. While differing in meanings in different contexts, psychiatric rehabilitation appears to share common concepts and values. Bachrach summarizes eight essential, fundamental, and interrelated concepts underlying the field [3]. First, rehabilitation enables the fullest potential of the person. Second, rehabilitation is individual-centered as well as stresses environmental modification. The environment has to be modified to reduce the barriers and make it conducive to helping the person. Third, it focuses on the strengths and what the person is capable of doing despite one's illness. Fourth, rehabilitation is positive in its philosophy and aims to restore hope and self-esteem in the person. Fifth, it aims to optimize a person's vocational potential, essential for regaining self-confidence and leading a dignified life. Sixth, it addresses various social and recreational needs. Seventh, it requires the person's active involvement in their treatment, interventions, and care needs. Thus, psychiatric rehabilitation emphasizes that decision-making should lie with the person. Eighth, psychiatric rehabilitation is an ongoing and continuous process that needs patience and sustained efforts by the service providers. In a nutshell, psychiatric rehabilitation enables people to achieve their life goals, which they would have otherwise done without the illness.

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Assistant Professor, Jindal Institute of Behavioural Sciences, O.P. Jindal Global University, Sonapat, Haryana.
2. Psychiatric Social Worker at Assam Medical College and Hospital, Dibrugarh - 786 002
3. Additional Professor, Psychiatric Rehabilitation Services, Department of Psychiatry, National Institute of Mental Health and Neurosciences, Bengaluru - 560 029

Three sectors offer psychiatric rehabilitation in India- the non-governmental sector, hospitals (tertiary mental healthcare institutes and GHPUs), and community-based initiatives. Though the importance of psychiatric rehabilitation is discussed frequently, its utility and utilization acceptance remains relatively low [4]. GHPUs, the most accessed treatment setup, must lead by example in offering psychiatric rehabilitation services.

### **FEASIBILITY OF PSYCHIATRIC REHABILITATION IN GHPU**

In the current scenario, mental health demands outweigh the supply of psychiatric care services. Psychiatric rehabilitation is an essential aspect of psychiatric care, and the need for early psychiatric rehabilitation is unequivocal. Owing to the potential advantages of GHPU, such as less stigma, inter-specialty collaboration, and mainstream presence, several patients can be helped if psychiatric rehabilitation services are offered in GHPU settings. Many psychiatric rehabilitation interventions have been deemed feasible in a GHPU setting. Individual-centered interventions include functional assessment, motivational interviewing, skills training (social, daily living, vocational), and recreational therapy. Family centered interventions include family therapies, family training programs, formulating self-help and advocacy groups, and interventions to strengthen the family support system. Community-based interventions include community outreach services, resource identification and mobilization, and community awareness programs [5][6][7]. In subsequent paragraphs, we evaluate and discuss some challenges and facilitators of practicing psychiatric rehabilitation in GHPU.

#### **Challenges and Ways to Overcome**

Most GHPUs face a high patient load and are run only by psychiatrists and nurses. Most GHPUs do not have the luxury of a multi-disciplinary team comprising Mental Health Professionals (MHPs) such as Clinical psychologists, Psychiatric social workers, Psychiatric nurses, Occupational therapists, and Vocational trainers. Consequently, GHPUs predominantly follow a medical model, and psychiatric rehabilitation interventions are often overlooked, assigned the least priority within psychiatric services, or considered the last resort in management. Many Indian studies have documented the challenges faced by GHPUs [1][7][8]. Table 1 discusses these challenges and measures to overcome them.

#### **Facilitatory Factors**

- a. Growth and expansion of GHPUs under the National Mental Health Program (NMHP) - Started in 1982, the NMHP had three main components - treatment, rehabilitation, and promotion of positive mental health. The NMHP changed gears from the X five-year plan and implemented human resources and infrastructure development schemes, including setting up / strengthening postgraduate training departments of mental health specialties, modernization of state-run mental hospitals, and upgradation of psychiatric wings of medical colleges/general hospitals [9].
- b. Mental Health Policy and Mental Healthcare Act mandating psychiatric rehabilitation - After the formulation of the 'Mental Health Policy' in 2014, initiatives were taken to incorporate promotive activities for positive mental health (such as school mental health services, life skills education, counseling services, support for families) and community-based rehabilitation services [10]. The Mental Health care Act, 2017 has mandated the 'right to access mental healthcare,' including rehabilitation services. The Act defines mental health care as "analysis and diagnosis of a person's mental condition and treatment as well as care and rehabilitation of such person for his mental illness" [11]. These developments have brought psychiatric rehabilitation to the forefront and



necessitate structural and functional changes in service delivery to develop and expand psychiatric rehabilitation services.

- c. Increased involvement of Non-Governmental Organizations (NGOs) in psychiatric rehabilitation - There has been an exponential growth in the number of mental health NGOs across India in the last few decades. They offer a range of services, including providing psychiatric rehabilitation services. 17% of states reported an encouraging trend of growing NGO involvement with the government psychiatric hospitals to provide rehabilitation services [12][13]. These advances offer scope for GHPUs to collaborate and use mutual expertise to start and run psychiatric rehabilitation services.

Starting psychiatric rehabilitation services may not require huge funds but additional effort and zeal. Rehabilitation is a long journey involving infinite small steps with multiple roadblocks and pauses. Every small step is likely to improve a patient's rehabilitation outcomes. The adoption of exemplary rehabilitation practices by several GHPUs demonstrates the feasibility of offering psychiatric rehabilitation in GHPU settings (Table 2).

**Table 1: Ways to overcome challenges faced by GHPUs**

<i>Challenges faced by GHPU</i>	<i>Ways to overcome</i>
Human resource constraints/ Insufficient number of MHPs	<p><b>Starting postgraduate courses</b> - While many GHPUs in medical colleges offer postgraduate psychiatry courses, some have recently started postgraduate courses in psychiatric social work, clinical psychology, and psychiatric nursing. This is likely to improve the human resource availability to offer psychiatric rehabilitation interventions in GHPUs.</p> <p><b>Involving caregivers</b> - Caregivers have lived experiences of handling patients and are a readily available resource. The caregivers can be crucial assets in the rehabilitation process by assisting the MHP team in designing, developing, and implementing various rehabilitation programs; delivering some of the interventions with their assistance; willing caregivers can also be hired and trained as vocational trainers, job coaches, or administrative staff in rehabilitation settings.</p> <p><b>Adopting a 'Case Management' approach</b> - This is a process to coordinate the efforts of different professional teamwork, such as health care or social services, to offer the patient the benefit of expanding a range of needed services. This approach helps limit the crisis arising from patients running from pillar to post for coordinating services from service providers, from the problem of fragmentation of services and staff turnover. Considering an overload of patients in a GHPU, this approach can be used for identified patients requiring psychiatric rehabilitation, and each MHP can follow up on their designated cases.</p>

<i>Challenges faced by GHPU</i>	<i>Ways to overcome</i>
Minimal or informal training in psychiatric rehabilitation/ Dearth of trained rehabilitation professionals	<p><b>Exposure / Posting to Psychiatric Rehabilitation Unit</b> - There is a need to inculcate a rehabilitation orientation and learn rehabilitation interventions during training. Exposure to rehabilitation practices can be ensured by posting students to rehabilitation units/settings for an adequate duration to enable them to include rehabilitation as part of their clinical practice [14].</p> <p><b>Starting certificate/postgraduation diploma/ fellowship courses in psychiatric rehabilitation</b> - National Institute of Mental Health and Neuro Sciences (NIMHANS) runs postdoctoral fellowship and Ph.D. courses in psychiatric rehabilitation. Similar courses can be started by other Institutes as well.</p>
Lack of awareness among service users and poor utilization of existing services	<p><b>Conducting caregiver awareness programs</b> - Students and trainees can be actively involved in designing and proving psychoeducation programs for service users and caregivers. The awareness programs can be carried out while they wait in the outpatient departments before visiting a psychiatrist to utilize the waiting time effectively.</p> <p><b>Caregiver support/advocacy groups</b> - Caregivers can be motivated to formulate support or advocacy groups to share their experiences and conduct various awareness and empowerment programs.</p> <p><b>Peer support groups</b> - Peer support groups can be formulated to promote mutual social and emotional support, boost self-esteem and confidence, and create social networks. Thus, increasing the likelihood of acceptance and utilization of services.</p>
Lack of funding for offering psychiatric rehabilitation services	<p><b>Using goodwill to help needy patients</b> - Every psychiatrist encounters situations where the family of a recovered patient offers help to the psychiatrist of the treatment and care they received. Such family members can be requested to help others by sponsoring their medication, education, or training.</p> <p><b>Utilizing Corporate Social Responsibility (CSR) funds</b> - CSR is a noble initiative by companies to spend 2% of their revenue on social initiatives. This can be tapped for psychiatric rehabilitation as well. A project proposal must be designed to seek financial resources, citing the need and ways of utilization with justification, which can be utilized under approved heads. Many Indian corporates, including Tata trusts and Infosys foundation, have come forward to address issues related to mental health. CSR funds can be used to sponsor medications or skills training programs, set up daycare and halfway homes, conduct awareness programs, and provide community outreach services.</p>

<i>Challenges faced by GHPU</i>	<i>Ways to overcome</i>
	<p><b>Exploring other funding options</b> - Other strategies to ensure funding for rehabilitation services include seeking donations from affluent patients and families, availing government funding options, and using research project funds to develop resources/services.</p>
Lack of standard practice guidelines	<p><b>Replicating evidence - based and / or pragmatic indigenous models-</b> Until the government develops norms for delivering psychiatric rehabilitation services, GHPUs can follow the best practices. First, one must take the initial steps to start the services that cater to the setting's demand.</p>
Emphasis on a medical model	<p><b>A shift of focus from the medical to the biopsychosocial model of mental health care</b> - A shift from the current focus on treating symptoms and crisis intervention to helping people lead meaningful lives is imperative. It is often not the resource constraints but the attitudinal barriers and hesitation that hinder the adoption of the biopsychosocial model.</p> <p><b>Comprehensive psychiatry care</b> - A comprehensive model safeguards that rehabilitation services adopt a right-based approach and thus ensure inclusion, equity, and respect.</p>
Lack of multi-disciplinary team and coordination among team members	<p><b>Need for a principled leader</b> - Principled leadership is needed to instill mutual trust and respect among team members, best utilize the available human resources, ensure coordinated team services, and maximize rehabilitation outcomes. He/She must have intelligent human and financial resource management, effective public relations skills, and adopt a transparent and unbiased approach. Differential reinforcement for efficiency, transparency, honesty and effective grievance redressal mechanisms help sustain team morale.</p> <p><b>Role clarity and synchronization among team members</b> - A committed and dedicated team, clear role demarcation, and synchronization of team efforts are critical to ensure quality rehabilitation outcomes. Periodic meetings/ reviews, openness to criticism, and willingness to apply corrective measures help to improve the team's efficiency.</p>

**Table 2: Pragmatic indigenous GHPU rehabilitation models**

Government Medical College and Hospital (GMCH), Chandigarh	The Disability Assessment, Rehabilitation and Triage (DART) services is a daycare-based rehabilitation setting that runs services such as neurocognitive rehabilitation clinic, vocational rehabilitation clinic, social skills clinic, disability clinic, placement cell, and occupational health services. Many services are offered in collaboration with NGOs, including crisis resolution, home-based treatment, and vocational training. Project 'Umeed' (the brainchild of Late Professor Bir Singh Chavan, Professor, and Head of Psychiatry department, GMCH) comprises innovative and sustainable models of facilitating livelihood. 'Umeed food express' - a mobile food catering van operated by patients within the city offers Chinese and South Indian fast food. Several ice-cream kiosks were also started across the city under the initiative and are run by patient-caregiver pairs [15].
Kasturba Medical College, Manipal	'Hombelaku' (meaning 'light with golden hue' in Kannada) is a residential rehabilitation setting. The center offers individualized rehabilitation programs and therapies planned and administered by a multi-disciplinary team consisting of psychiatrists, clinical psychologists, psychiatric social workers, psychiatric nurses, occupational therapists, and vocational instructors. The patients are involved in structured activities, including daily living skills, vocational skills (tailoring, baking, arts and crafts), and recreational activities (indoor and outdoor games, gardening, and picnics). Community integration and work placement are facilitated. Many patients are placed within the hospital (lab, pharmacy) and nearby stores; and are visited by a vocational trainer to followup on their work performance. The student trainees from the hospital are placed for 4 to 8 weeks and carry out many psychosocial interventions, including social skills training, individual and group therapies, behavior therapies, and family interventions [16].

**PSYCHIATRIC REHABILITATION SERVICES AT GHPUs**

Many psychiatric rehabilitation interventions can be done by individual practitioners and do not essentially need a dedicated setting or a multi-disciplinary team. In subsequent paragraphs, we discuss the plausible services that all GHPUs can provide:

**Rehabilitation Assessment and Planning**

Assessment is the foremost step to understanding the person's rehabilitation needs. Both the person and family members are enquired about the perceived rehabilitation needs. For this, additional history on a person's aspirations, life goals, available opportunities, efforts made, challenges encountered, and lessons learned are collected. The person's strengths and skills, family and social support, community networks, and resources are assessed. The nature of rehabilitation inputs varies person-to-person. Executing the plan requires effective coordination between various stakeholders (family, friends, community, employers, NGOs, etc.). The MHP plays a facilitatory role in prioritizing the goals, preparing an action plan in discussion with the family, and accomplishing those goals.

A person who needs a job, work history, reasons for job change/discontinuation, and workplace challenges are collected. Based on the assessments, the person may be recommended vocational skills and social skills training (who has not worked before), or efforts can be directed towards sheltered or supported employment (with previous work history but currently unemployed). Similarly, someone who discontinued education may need help joining/ completing a course according to interest, ability, and availability. Likewise, a homeless person with mental illness will need safe shelter, treatment, and reintegration with family.

### **Motivational Interviewing and Rehabilitation Readiness**

The rehabilitation process deals with a person's life goals and is thus tailor-made. Even a firm intention and push by MHP or family members can go in vain if the person is not convinced about the need for rehabilitation. Initially developed for treating alcohol addiction, motivational interviewing is widely used to empower patients, overcome resistance, and support self-efficacy to take responsibility for their recovery. Thus, motivational interviewing helps create optimism and hope about rehabilitation among patients who are not rehabilitation - ready. Rehabilitation readiness is judged on five parameters [17] :

- # A need for change (arising from past experiences / dissatisfaction / failures, etc.)
- # A commitment to change (arising from an intrinsic motivation that drives the person to believe in the required change)
- # Personal closeness (support systems at home/ community)
- # Self-awareness (awareness about one's interest/ values)
- # Awareness about the environment (awareness about his/her needs in the context of his/ her environment)

### **Outpatient - Based Rehabilitation Counseling**

Rehabilitation counseling is essential to share rehabilitation-related information with the patient and caregivers. Once the rehabilitation assessment is done, discussions can be focused on improving care giver awareness, preparing a rehabilitation plan, and identifying available resources and support systems. It equips the patients and caregivers with vital information which would be helpful in the recovery process. MHPs may use the information and educational materials developed by central institutes and government websites. Single-session counseling helps provide the required information in resource constrained settings [18].

### **Disability Certification and Unique Disability ID (UDID) Card**

There exists a wide variation in the number and clinical profile of patients receiving disability certificates across Indian centers [19]. A disability certificate is issued for persons with >40% (benchmark disability) by a recognized medical board. UDID is an online process of obtaining disability certification for all the twenty-one disabilities identified under the 'Rights of Persons with Disability Act, 2016'. Most Government run GHPUs have the authority to issue disability certificates; others can tie-up with the nearest authorized centers. MHPs must inform and/ or assist in initiating the procedure of UDID (Figure 1). Information can be displayed on notice boards for mass awareness. A disability certificate / UDID is mandatory to get various social welfare benefits.

### **Welfare Benefits for Persons with Benchmark Disabilities**

Welfare benefits for persons having benchmark disabilities include disability pension, unemployment allowance, travel benefits (concessional bus pass and train tickets), income tax deductions, and pension transfer. Some schemes are under the central government, while those offered by the states vary. MHP must be aware of the welfare benefits available in their respective states and counsel the patients and caregivers about the same. A poster detailing the welfare benefits can be displayed in the outpatient waiting area. Patients with good income can avail of the income tax deduction, whereas patients with low family income can benefit from an unemployment allowance and disability pension (Figure 2).

### **Referrals to Utilize Government Schemes**

MHPs should make an appropriate referral for the utilization of several government schemes as per the requirement:

- # Various schemes for persons with Intellectual disability, autism, cerebral palsy, and multiple disabilities are provided under the 'National Trust Act' [20]. MHPs can search the website to identify nearby NGOs implementing various schemes under the Act. 'Niramaya scheme' is the most utilized scheme that helps to reimburse medical expenses.
- # Pradhan Mantri Bhartiya Janaushadhi Pariyojana (PMBJP) is a scheme to provide quality generic medications at affordable prices for all. The list of available drugs and the location of nearby PMBJP kendras can be accessed through its dedicated website.
- # Pradhan Mantri Kaushal Vikas Yojana (PMKVY) is an initiative for free training of any unemployed Indian citizen aged 18 to 35 years. The details of vocational courses and the location of centers are available on its website. Initially, MHP can liaise with nearby PMKVY centers for high-functioning patients, follow-up, monitor the patient's progress, and identify any challenges the patient or the organization faces. Once the initial organizational resistance is overcome and the arrangements are in place, other moderate-to-low functioning patients can be referred gradually [21].

### **Liaising and Networking with Stakeholders**

Involving stakeholders is quintessential for the psychiatric rehabilitation field. A list of administrators (district/taluk health officer, disability welfare officer), volunteers (socially conscious people, entrepreneurs, and influential people of the community), organizations (special schools, training centers), and resources available in the community can be gathered gradually. Involving multiple stakeholders translates to a strengthened community support system for patients and their families. Liaising and networking with various stakeholders can be used for the following purposes:

- # Volunteers can be valuable for arranging/sponsoring medications and food, helping with getting a job or shelter in the community, and addressing other day-to-day needs
- # Local employers and corporate chains can employ recovered patients
- # Non-profit organizations like Lion's club/ Rotary club can be involved in mental health-related awareness and activities
- # Local government officials can facilitate the sanction of welfare benefits

### Partnership with NGOs

Partnership with NGOs facilitates psychiatric rehabilitation and community integration of patients. Partnerships can be considered with NGOs in the disability sector running special schools, long-term residential facilities, daycare centers, and vocational training centers. An MHP can conduct a health camp or organize training programs for the NGOs, and they can be invited to discuss their services and schemes. NGOs can help to provide financial, technical, and operational inputs for running various rehabilitation services.

**Table 3 discusses a real-life case scenario where some of the above-mentioned rehabilitation services were carried out in a GHPU setting.**

**Table 3: A case scenario**

Mrs. P, 45 years old, married but separated female, educated up to primary school, from rural background, was brought by her elder daughter, with a history of wandering behavior, irrelevant talk, disorganized behavior, and increased anger with blunt affect. Her socio-occupational functioning was affected, and she was unmanageable at home. The family took her for private treatment, but the patient refused to take oral medication, suspecting harm. When brought to the GHPU, the patient was initially put on injectables and electro-convulsive therapy and then shifted to oral antipsychotics. Interventions included :	
Medication adherence	The treating psychiatrist took care of symptomatic management. Family members were explained the need for supervision of medication, which had to be given with food as she would refuse medicines.
Rehabilitation needs assessment	A detailed psychosocial workup by the social worker found that the patient had left home after repeated quarrels with her husband. Her family of origin too did not give her shelter. It is unclear whether she had a mental illness when leaving home or whether the frequent fights resulted from illness. Her husband remarried, and her daughters got married recently. Daughters were not in a position to take long-term care of the patient. Her sister occasionally agreed to support her financially, but her brothers and husband refused to help. The social support was thus poor.  Immediate needs of the patient were a shelter post-discharge and availability of medications. Long-term needs were to find sources of/ generate finances for her stay and procurement of medication, identity proof to establish her identity, and lead a dignified life.
Liaising with volunteers	An attempt was made to contact the people who helped the patient reintegrate with her family. It was learned that both of them have helped other mentally ill patients receive medical treatment earlier. They were interested in helping this patient further but needed directions. The volunteers were appraised of her immediate and long-term needs. The volunteers knew the geographical area and were socially recognized for their efforts, making it feasible for them to work on ground level.

Finding a shelter	Due to the paucity of long-stay rehabilitation homes in the vicinity, arrangements were made in an old-age home. The volunteers also generated funds for medicines for a couple of months. The need for medication supervision was informed to the staff. The social worker visited the shelter home for follow-up. The family members were kept in the loop, and their consent was taken.
Facilitating disability certification and welfare benefits	Disability certification could help her get a disability pension of Rs.1000, but the challenge was that her official documents were not available. A bank account, identity proof, and proof of address was necessary to avail disability pension. Discussions were held again with the volunteers, who then visited one of the banks to enquire about the procedure of legal guardianship and the feasibility of a joint account. For legal guardianship, a petition was given to the district court and would take at least six months to materialize. Simultaneously, the patient's class 10th registration and admit card could be found, which was used to process a PAN and Aadhaar card with the support of district administration and gram panchayat.
Skills training	Parallely, the patient was trained in activities of daily living such as self-care, cleaning, and washing. The patient was good at weaving and took an interest in it. She made several pieces of woolen clothing, such as socks and mufflers. Volunteers were informed about the weaving skill to enable them to find suitable training or work in the community to generate income through it.

#### **INNOVATIVE PRACTICE-BASED EVIDENCE OF PSYCHIATRIC REHABILITATION**

M. S. Chellamuthu Trust and Research Foundation is a Madurai-based NGO working towards accessible, affordable, and holistic mental health care. The NGO runs various services, including residential, daycare, vocational training centers, and community outreach services. They have successfully involved community members in training patients in farming, preparing manure, dairy farming, goat rearing, and poultry, which are widely practiced in nearby villages and are a sustainable and significant source of livelihood. They have formulated a caregiver fellowship group that plays a vital role in training and facilitating employment for patients, spreading community awareness, and taking an active part in mental health advocacy. The NGO has also capitalized on CSR funds to run telepsychiatry services and a digital mental health training center [22].

'The Banyan', a Chennai - based mental health NGO offers multi-disciplinary and comprehensive psychiatric rehabilitation services. The NGO has remarkably contributed to rehabilitating homeless persons with mental illness. It runs long-term residential rehabilitation centers for homeless following all the essential psychosocial rehabilitation principles such as shared decision-making, mutual respect, task-sharing, emphasis on individual strength, and promoting self-determination and empowerment. Many recovered patients have been successfully reintegrated with their families. Some recovered women run a bakery and canteen, while a few others assist and supervise newly joined members (i.e., homeless mentally ill women) in their rehabilitation journey [23].



National Institute of Mental Health & Neuro Sciences, Bengaluru, has a psychiatric rehabilitation team under the department of Psychiatry. The team has instituted three livelihood generation programs for daycare service users. First, a 'green skills program' that prepares eco-friendly products ('eco-friendly Holi colors,' 'eco-friendly Diwali kits,' 'eco-pens,' and 'paper-dust products'), which are sold to the public, and profits are shared with patients. Another initiative, named 'Roses café,' is a patient-run healthy snack eatery that started on a small budget by catering snacks to members of the psychiatric rehabilitation team. However, today it gets orders from different departments of NIMHANS for meetings, student presentations, workshops, and conferences. Recovered clients handle the purchase, cooking, and finance-related matters of the café and earn a monthly income. Third, an outpatient area-based photocopying unit is run by patients [24][25].

The Integrated care for the needs of vulnerable persons with severe mental disorders (INCENSE) program is run at LGB Regional Institute of Mental Health (Tejpur) and Regional Mental Hospital (Pune) in partnership with two NGOs (Parivartan and Sangath). The program aims to develop local networks to support community housing and livelihood for people with severe mental disorders (long-stay inpatients and homeless persons). Hospital/ community-based and supported employment opportunities are facilitated. Trained lay recovery support workers provide community-based rehabilitation services [26].

## **WAY FORWARD**

### **Need for a Multi-Disciplinary Psychiatric Rehabilitation Team**

A substantial proportion of patients cannot be helped with medications alone, thus highlighting the valued role of a multi-disciplinary team. Several rehabilitation interventions are carried out by non-psychiatrists, including psychiatric social workers, clinical psychologists, psychiatric nurses, occupational therapists, and vocational instructors. It is easier to offer psychiatric rehabilitation interventions when a multi-disciplinary team is available. GHPUs having only psychiatrists may consider recruiting other MHPs gradually. Vocational trainers can be recruited when vocational units are started. All MHPs must be treated as equal partners of the team.

### **Community and Home - Based Rehabilitation Services**

Home/community outreach services are vital to ensure the continuity of the rehabilitation process. Different areas/community centers/district hospitals can be covered on different days, or each MHP can adopt a community/ village. Community outreach services may include but are not limited to awareness programs, liaising with stakeholders, identifying volunteers, and prospective follow-up and training centers. A structured activity plan (a combination of daily living skills, skills training, informational, and recreational activities) can be prepared by the MHP team based on the person's interests and capabilities. Socio-culturally relevant activities can be identified for patients to enable them to earn a livelihood in their community settings.

### **Starting a Daycare / Transitional Center and Halfway / Long - Stay Homes**

The stay of inpatients in GHPUs is usually for symptomatic control. This imposes a time limit on GHPUs and hinders the provision of holistic psychiatric care. Thus, having a daycare or transitional center will spare additional time to deliver structured rehabilitation services. Daycare programs are not expensive and can benefit many patients and family members in many ways. Advantages for patients might include day-structuring, learning new skills, an opportunity

for socialization, improvement in socio-occupational behavior, etc. Families can benefit from getting time for self-care, a decrease in caregiver burden, and a positive attitude towards illness and recovery. Further, starting a residential facility, a halfway/ long-stay home can be considered for patients requiring intensive rehabilitation interventions.

### **Vocational Training and Income Generation Activities**

The next step on the ladder can be vocational training in the GHPU. Vocational units that teach market-relevant skills boost patients' chances of securing jobs in the open market. Many rehabilitation setups, like NGOs and tertiary mental health care institutes, have started or converted vocational activities into income-generation activities for patients. Products made for training purposes can be sold to earn revenue that is shared with the patients. A range of products, such as paper, textiles, food, and handicrafts, can be prepared and sold based on raw material availability and the demand for products [27] [28]. GHPUs can start with small ventures such as making paper bags / envelopes, which can be internally purchased to dispense medication in the pharmacy department. Other initiatives that can be useful for internal consumption include a bakery / food processing / masala grinding unit to cater to the dietary-related needs of inpatients, a tailoring unit to make staff uniforms, use / instead curtains / covers /bedsheets for inpatient wards, a printing unit can cater to print and / or photocopy various forms / applications / documents that GHPUs use. Then gradually, ventures can be started to meet the needs of the public visiting GHPUs, such as eatery outlets.

### **Hiring Recovered Patients and Supported Employment Services**

Many patients fail to get mainstream employment despite a complete functional recovery. The primary aim must be to facilitate entry and improve retention rates in mainstream employment via providing supported employment services. However, when we do not do it ourselves, we cannot preach to other people/employers to hire persons with mental illness. Willing recovered patients can be hired by the GHPUs and utilized in various departments such as medical records, dietary, laundry, waste management, or administrative departments based on qualification and skills. They can also be hired as gardeners, security staff, ward boys, and support staff; and trained on the job.

### **CONCLUSION**

With a limited number of tertiary mental healthcare setups in the country, GHPUs are the primary and popular treatment option for the masses seeking psychiatric treatment. Many psychiatric rehabilitation services, such as rehabilitation assessment and planning, outpatient-based counseling, facilitating UDID and utilization of welfare schemes, liaising and networking with stakeholders and NGOs, and making referrals to utilize various government schemes, can be offered in resource - constrained GHPUs. More resource-intensive rehabilitation interventions can be offered when an adequate human resource/ multi-disciplinary team is available. Several practice - based evidence from Indian psychiatric rehabilitation centers, mental health NGOs, and GHPUs, signify the feasibility of such services. The way forward for GHPUs is to extend and expand their repertoire of psychiatric rehabilitation services.

**TAKE HOME MESSAGE**

- # GHPUs are the leading source of treatment, training, and research. Being the most accessed mental healthcare treatment setup, GHPUs should strive to offer comprehensive psychiatric care, including psychiatric rehabilitation services.
- # Despite having resource constraint, many psychiatric rehabilitation services are feasible in GHPUs, such as rehabilitation assessment and planning, outpatient-based counseling, facilitating disability certification and utilization of welfare schemes, liaising and networking with stakeholders, and making referrals to utilize various government schemes.
- # Some measures to overcome the challenges faced by GHPUs include starting postgraduation courses, exposure to rehabilitation practices during training, involving caregivers, facilitating peer and caregiver self-help groups, conducting awareness programs, and utilizing goodwill and CSR funds.
- # A presence of multi-disciplinary team will make it easier to implement additional resource-intensive rehabilitation services, expand the range of services, extend services beyond GHPU and start daycare or residential facilities.

**REFERENCES**

1. Chadda RK and Sood M. General hospital psychiatry in India: History, scope, and future. *Indian J Psychiatry*. 2018; 60(Suppl 2): 258-263
2. Sivakumar T, Roy A, Reddy KS, et al. Psychiatric rehabilitation in Indian general hospital psychiatry unit settings. *Indian J Soc Psychiatry* 2021; 37(4): 352-359
3. Bachrach LL. Psychosocial rehabilitation and psychiatry in the care of long-term persons. *American J Psychiatry* 1992; 149: 1455-1462
4. Chavan BS and Das S. Is psychiatry intervention in Indian setting complete?. *Indian J Psychiatry* 2015; 57(4): 345-347
5. Shihabuddeen TM I and Gopinath PS. Possible PSR Interventions in a General Hospital Psychiatric Units in India. *Indian J Psychol Med* 2003; 26(2):11-14
6. Shihabuddeen TM I, Anand S, Gopinath PS. Brief social skills training (BSST) in a general hospital psychiatry unit in India. *Indian J Psychol Med* 2008; 30(1): 59-61
7. Shihabuddeen TM I and Chandran M. Psychiatric rehabilitation in India: Prioritizing the role of a general hospital psychiatry unit. *Delhi Psychiatry J*. 2011; 14: 51-53
8. Sood M and Chadda RK. Psychiatric rehabilitation for severe mental illnesses in general hospital psychiatric settings in South Asia. *BJPsych International* 2015; 12(2): 47-48
9. Khurana S and Sharma S. National mental health program of India: a review of the history and the current scenario. *Int J Community Med Public Health*. 2016 Sep 20;3(10):2696-2704
10. Gupta S and Sagar R. National Mental Health Policy, India (2014): Where Have We Reached? *Indian J Psychol Med*. 2021 Oct 25;02537176211048335
11. Ministry of Law and Justice. The Mental Healthcare Act. New Delhi: Government of India; 2017
12. Murthy P, Kumar S, Desai N, Teja B. Mental Health Care in India [Internet]. New Delhi: National Human Rights Commission; 2016 [cited 9 September 2022]. Available from: [https://www.researchgate.net/publication/329643213\\_Mental\\_Health\\_Care\\_in\\_India](https://www.researchgate.net/publication/329643213_Mental_Health_Care_in_India)

13. Thara R and Patel V. Role of non-governmental organizations in mental health in India. *Indian J Psychiatry* 2010; 52(Suppl1): 389-395
14. Vijayakumar HG and Sivakumar T. Need for Psychiatric Rehabilitation Training for Mental Health Professionals. *J Psychosoc Rehabil Ment Health* 2022; 9: 325-328
15. Department of Psychiatry, Government Medical College & Hospital, Sector 32, Chandigarh, India [Internet]. Gmch.gov.in. [cited 14 September 2022]. Available from: <http://gmch.gov.in/overview-12#show-block-rvs-main-menu>
16. Homebelaku - Rehabilitation Centre for the Chronic Psychiatrically ill [Internet]. Manipal: Department of Psychiatry, Kasturba Medical College, Manipal University; [cited 14 September 2022]. Available from: <https://manipal.edu/content/dam/manipal/mu/documents/mahe/psy.rehab.centre%20brochure.pdf>
17. Anthony WA and Farkas MD. A primer on the psychiatric rehabilitation process. 1st ed. Boston: Center for Psychiatric Rehabilitation, Sargent College of Health and Rehabilitation Sciences, Boston University, 2009
18. Desai G, Thanapal S, Gandhi S, Berigai NP, Chaturvedi SK. Single session rehabilitation counseling. *J Psychosoc Rehabil Ment Health* 2015; 2: 75-77
19. Sivakumar T, Jadhav P, Nabi J, et al. Sociodemographic and clinical profile of patients receiving disability certificates for psychiatric disorders: An Indian Psychiatric Society Multicentric study. *Indian J Psychiatry* 2022; 64(4): 335-341
20. Lakshmi J, Sivakumar T, Angothu H, Jayarajan D, Kishore MT. Book Review: Precious Souls: A Journey into the Inspiring Lives of Special Children and Their Families. *Indian J Psychol Med*. 2021: 02537176211045346.
21. Thekkumkara SN, Jagannathan A, Sivakumar T. Pradhan Mantri Kaushal Vikas Yojana (PMKVY): Implications for skills training and employment of persons with mental illness. *Indian J Psychol Med* 2021; 44(2): 173-176
22. M S Chellamuthu Trust and Research Foundation. Centre for Psychiatric Rehabilitation [Internet]. Msctrust.org. [cited 14 September 2022]. Available from: <https://www.msctrust.org/rehabilitation-programme/institution-based-rehabilitation/centre-for-psychiatric-rehabilitation/>
23. The Banyan. The Banyan Collective [Internet]. Thebanyan.org. [cited 14 September 2022]. Available from: <https://thebanyan.org/the-banyan-collective/>
24. Roy A, Sivakumar T, Jayarajan D, et al. Eco-friendly holi colors: hospital based 'income generation activity' for persons with mental health challenges at a quaternary mental healthcare facility in India. *J Psychosoc Rehabil Ment Health* 2019; 6(2): 217-225
25. Rao S. Bengaluru: Nimhans café run by mentally ill patients boosts their confidence. *The times of India* [Internet]. 2019 [cited 14 September 2022]. Available from: <https://timesofindia.indiatimes.com/city/bengaluru/nimhans-caf-run-by-patients-boosts-their-confidence/articleshow/71382436.cms>
26. Tata Trusts. Integrated Community Care for the Needs of Vulnerable People with Severe Mental Disorders - The INCENSE Program. Tata Trusts; 2015
27. Roy A, Jayarajan D, Sivakumar, T. Income generation programs for persons with mental health challenges: Practices from 13 Indian mental health rehabilitation centers. *Indian J Psychol Med* 2022; 44(2): 160-166
28. Roy A, Sivakumar T. 'Income Generation Programs' for Patients at Psychiatric Rehabilitation Centers. *Indian J Behav Sci* 2022;25(01):60-68

## VOCATIONAL REHABILITATION IN INDIAN CONTEXT

Rajesh Mithur<sup>1</sup>, Anil Kakunje<sup>2</sup>

### INTRODUCTION

The psychiatric illness cause significant disability and cause poor psychosocial function. In psychiatric treatment the symptom recovery and social occupational functioning play an important role in functional recovery.

The success of psychiatric treatment is determined by symptom recovery and social rehabilitation. Rehabilitation is the final important step in the treatment of psychiatric illness where the patient is reintegrated in the society. Vocational rehabilitation is the part of rehabilitation process where people are provided employment to sustain their living. The employment of a patient helps in patient satisfaction and symptom recovery. People with psychiatric illness have tough time in taking up jobs. In vocational rehabilitation proper employment opportunities are discovered, patient is trained and employed in spite of disabilities to get the maximum benefit. So the patients are supported and provided with secure jobs and helped to sustain a living.

Vocational rehabilitation consists of pre vocational training and supported employment. Mental illnesses cause significant psycho social disability. Due to this impairment the patients have significant problems in finding proper employment. Studies are available worldwide stating the levels of employment and precisely indicate the levels of rehabilitation opportunities. But only few studies are available in developing countries like India on the rate of employment.

A recent study by Khare et al; studied the rate of employment among the mentally ill in India [1]. This study covered subjects with mental illness and found that around 50 % of them were employed. They found that up to 79.4% of men and 35.9% of women were employed in the study location. According to this study agriculture was the primary mode of work and most employability was seen in rural areas (77.8%), than in urban areas (48.9%). But in rural areas the work performance was only seen for few hours and led to poor income generation among mentally ill and this led personal problems.

Another study was conducted by Khare et al on the rate of employment in people with only severe mental illness [2]. This study was mainly done on patients attending a public psychiatry hospital which showed better employment in Indian context compared to western world. The study showed that up to 40% of patients were into self employment.

Prasad et al; conducted a study in India specifically on the working status of severe mental illness. This study covering severe mental illness like schizophrenia and bipolar disorder found 42% working status but high unemployment period among them of 75.92% [3]. But among these two illnesses bipolar illness had better employment status of 65% than schizophrenia. These above studies give us a fair idea that mental illness cause significant work disability and again prove the importance of vocational rehabilitation.

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

Dept. of Psychiatry, Yenepoya Medical College, Mangalore

### **IMPORTANCE OF VOCATIONAL TRAINING**

Vocational training plays a significant role in employing people. The Community intervention in psychotic disorders (ColnPsyD) project was community intervention program conducted in Thirthahalli of Karnataka [4]. This study by Suresh et al; mainly concentrated on schizophrenia patients in a rural village in India. 37.3% of the sample was agriculturist and 28.9% did household jobs. The study results showed that two third of persons with schizophrenia had satisfactory work function in rural India which was contradictory to the finding from high income countries. Rural community setting and predominant agricultural background significantly contributed to this finding among schizophrenia sample in rural India. But most of these patients were disabled and unskilled.

Independent living in community is a serious deficit faced by mentally ill. With the intense suffering from mental illness and disability they often lose the ability to lead an independent life. Srivastava et al; studied the long term ability to work and ability to live independently in society [5]. On follow up for 10 years it was found that up to 60% of cases were unable to return to work after 10 years which suggested the need for support.

### **FACTORS DETERMINING EMPLOYABILITY**

Several factors are said to contribute to employability of the individual. Looking into the Indian context we can notice from study by Nirmala et al; on the patients with substance use disorders [6]. This study shown multiple barriers into the employment of psychiatric patients. They broadly classified in to individual factors, interpersonal factors, employment factors, and social factors [6]. The study further says that better communication, family support, treatment, and training were strategies to improve employability. Proper treatment and continuous adherence to medication, emotional support by family members and colleagues are the employment aiding factors.

Similarly the study by Khare et al showed that [2] psychological factors like stress, illness per se and work factors like difficulty in finding job led to unemployment in mentally ill.

Kumari et al also stressed that stigma, ignorance also contribute to difficulty in employability of mentally ill [7]. Lack of insight and fluctuating nature of mental illness contribute to poor work performance of psychiatric patients. Poor income generation due to this illness leads to lesser money generation and thus make these patients less attractive for employers.

### **SUPPORTED EMPLOYMENT**

In supported employment program an individual with psychiatric illness is placed in a job and is supported by a consultant or coach and allowed to work indefinitely. This helps the person with illness sustain a living. Supported employment is gaining ground in India recently.

Individual Placement and Support (IPS) model is found to be the most effective model of supported employment compared to traditional vocational rehabilitation worldwide. But this model is not effective in resource constrained developing countries like India. So the Harish et al and Jagannathan et al; developed the Supported Employment Program (SEP) Model suitable of India.

Jagannathan et al; studied the feasibility of supported employment Program in India [8]. This study with 63 participants showed that supported employment program had significant benefits in successful employment of severe mental illness. This study utilized the professionals from

social work and psychosocial rehabilitation in training people with schizophrenia and BPAD in employment. This study utilized five steps of assessment, counseling, networking and liaison, training and placement and finally follow-up.

The perceived benefits of enrolling in the supported education program as experienced qualitatively by the participants included [8],

- (a) Job placement and referral
- (b) job-related skill development
- (c) Learning about cognitive aids that could help in doing job
- (d) Improvement in social skills
- (e) continued therapeutic support
- (f) Improved coping with job stress
- (g) Improvement in independent living skills
- (h) Improvement in daily structure of activities
- (i) Recovery from illness
- (j) Change in caregiver's attitude towards participant
- (k) Understanding one's strengths and limitations
- (l) Improved motivation to seek and join job and
- (m) Social welfare benefits counseling.

#### **INCOME GENERATION PROGRAM**

Income Generation Program (IGP) was defined by Roy et al; as activities done for productive engagement or skills training, which result in the manufacturing of products suitable for sale [9]. This category of program consisted of skills training, supported employment, self-employment, and home-based work programs. Roy et al studied the Income Generation Program of 13 rehabilitation centers in India. The study fairly demonstrated the various rehabilitation processes carried out in multiple centers in India. Patients were motivated to involve in diverse range of activities including manufacture of household consumables, paper products, textiles, handicrafts, food products, or jute products; animal husbandry and horticulture and running shops. Some centers even involved family members in the rehabilitation process.

This study was able to give a good picture of the status of rehabilitation process in India [9]. The IGP were selected in every center mostly based on the market demand and sales of products. It also depended on ease of doing the process, interests of the subjects, their abilities, exposure, and experience of clients and availability of resources around the center. Rural centers mostly depended on animal husbandry, dairy farming, preparation of saplings and horticulture. Good functioning patients were involved in procedures like stitching clothes.

#### **Profitable IGPs Vs Therapeutic IGPs**

This study by Roy et al surveyed the importance of different types of IGPs in India. The profitable IGPs mostly ran IGPs as business ventures were patients the highly efficient clients were mostly used. These centers were adequately staffed to improve the outcome to meet the orders available. In contrast the therapeutic IGPs mostly ran on day care basis and

concentrated on improving their social interaction. Most of these patients could start with therapeutic IGP and later progressed to profitable IGP but in most centers the primary importance was given to rehabilitation and profit generation was only a secondary concern.

#### **FAMILY INVOLVEMENT IN VOCATIONAL TRAINING**

Family involvement is of prime importance in rehabilitation. The study by Roy et al surveyed 13 centers and found that 4 centers actively involved family in rehabilitation process. The family involvement helped them get good idea in the process and indirectly helped the client get good support. The experienced families were more responsive and sensitive to clients needs causing mutual benefits. This training to family members helped them earn a living and also motivated them to involve in business ventures.

The study also highlighted the failure of process in certain centers due to poor sale of products [9]. Candle making center gave poor outcome due to lack of sales. The paper cover making also generated poor income due to time consuming process.

Income generation was a challenge for most centers in India. Running stalls in public events was most common mode of income generation for most of these centers. They mostly spread news by word of mouth and advertised the stalls. In spite of regular and seasonal sales they generated only poor sales and income. Sales were less than 5000 rupees per month. The centers even sold products lower than market price to sell their products and cover for the labor cost. The goodwill gesture of the known people and family members who bought for charity was the major buyers of the products.

The trainers in this study were involved in survey to find the challenges involved in IGPs in India [9]. They found that lack of funding, space constraints, changing market demands were some of the problems encountered during the program. Limited sales and profits, unsold products, difficulty in the transportation of products for sales, lack of marketing expertise, handling finances, and laborious accounting and record keeping also caused poor success of IGPs in some centers. This study also highlighted that most centers had unsold stock of product which were attributed to customers questioning the quality of their product. The market even had cheaper alternatives from companies producing the same product competitively at cheaper price and failure to cater in bulk orders. Thus authors suggested that joint ventures, innovation and e commerce were the right decisions to make in this direction.

Waghmare found that poor income generation and lack of incentives were significantly effecting work function of working patients in tertiary hospital [10].

#### **ACCOMMODATION AT WORK PLACE**

Reasonable accommodation is the concept put forward in RPWD 2016. Reasonable accommodation (RA), defined as "necessary and appropriate adjustments, without imposing a disproportionate or undue burden in a particular case, to ensure to persons with disabilities, the enjoyment and exercise of rights equally with others" was a major inclusion in the Act [11].

People suffering from severe mental illness face challenging situation at work place [12]. The psychiatric symptoms, medication side effects, poor working environment, stigma, and demoralization at work place significantly contribute to the problem. But factors like good coping mechanism, motivation, skills and progressive environment like good service co-ordination and supportive employer can change this work area into a therapy.



Rangarajan et al; studied the level of accommodation of people suffering from severe mental illness at work place. In this study done only on professionals with good education standards it was found that the following themes were important in accommodation of mentally ill in work place.

1. Modification of work schedule.
2. Support and increase in work efficiency
3. Modification of work environment.
4. Supportive employers
5. Improved appraisal
6. Integrative services.

The cognitive deficits significantly affected the work performance. Thus factors like extended periods of training were absolutely necessary for people with mental illness for work efficiency. Good support from the employers like observation for symptom relapse, paid leave for treatment and admission, were needed. The patients also needed flexibility in work and extensive mentoring throughout their career. With the implementation of these services undue burden on the patients was avoided.

#### **PEER SUPPORT PROGRAM**

Peer support involves the provision of support and services to persons with mental illness by individuals who have a current or past experience of mental health problems [11]. In this model of rehabilitation, the psychiatric patient is introduced and placed in contact with fellow patient who has improved from his illness. The fellow patient with his experience and suffering would be better able to empathize and guide the patient to handle his problems and facilitate recovery. The peer modeled learning helps the patient to learn new life skills necessary in psychiatric illness and thus help improve his self efficiency.

Pathare et al; studied the peer support program in India and provided insights into the above system [14]. Peer support volunteer system was introduced in India for the first time in Gujarat in 2014. As a part of this project a weekly peer meeting was organized. The peer support groups called "Maithri groups" were organized. The peer supported groups were trained in achieving recovery and improvement of basic communication skills. For the work the PSVs were provided a honorarium for the travel expenses. By 2016 the state mental health authority of Gujarat provided financial aid and led to further success of this program.

PSVs regularly approached the center shared their experiences and listened to the patients suffering which brought transitional changes in the patient. Thus the communication significantly improved self esteem and brought functional recovery. The important point to stress here is that the peer support system is still in its infancy in our country. As the author quotes the joint family system and mental health policy in India are still not in very favor of developing this area of mental health. Further research and development in this area is needed and will be seen only in future.

Developments have also happened recently with development of peer support systems suitable for prison setting by Thekkumkara et al. but further studies are needed in that direction to see its practical success [15].

**TRANSITIONAL EMPLOYMENT IN INDIA**

Transitional employment is a unique form of rehabilitation recently gaining ground [16]. This mode of rehabilitation involves the club house model where a club is involved in part time employment of the mentally ill on short term basis. The mentally ill are recruited for around a period of 6 months and provided training with regular support. Once the person is said to be fit he can move to an independent employment of his own. This mode of therapy is only provided in a unstructured basis in few centers and slowly developing these days in India. Significant study is necessary in this direction for developing countries like India.

**VOCATIONAL EMPLOYMENT OPPORTUNITIES**

Rehabilitation can be offered to mentally ill individuals through various individually planned activities or job opportunities. The rehabilitation centers in India offer diverse range of activities to their clients. These set of jobs help the individual improve his cognitive skills and provide symptom recovery [9].

**Vocational Rehabilitation activities in India :**

- \* Production of candles, covers, mask, clothes, stationary and paper products, desktop materials, lamps, vase, pots.
- \* Preparation of handicrafts, decorative greeting cards, bags, lamps, carpets, handbags.
- \* Sanitary pads, phenyl, cleaning items, soaps.
- \* Tailoring, cloth items, dress materials, mats, aprons, sling bags, hand kerchiefs.
- \* Pooja items, incense sticks, rangoli and holi colours, organic items, clay pots, jewelry, paintings, decorative items.
- \* Book binding, packing goods.
- \* Bread making, preparation of bakery products, spice mixtures, snacks, food items.
- \* Caring for animals, dairy products, gardening, masonry, growing vegetables, organic farming, manure and fertilizer preparations
- \* Manage small shops or eateries, laundry, food supply, helper, computer related jobs

**CONCLUSION**

Vocational rehabilitation is an often significantly neglected part of psychiatric treatment. With the increasing number of psychiatric patients and development of mental health in our country vocational rehabilitation is going to have promising prospects in future.

**REFERENCES**

1. Khare C, Mueser KT, Fulford D, Watve VG, Karandikar NJ, Khare S, et al. Employment functioning in people with severe mental illnesses living in urban vs. rural areas in India. *Soc Psychiatry Psychiatr Epidemiol.* 2020 Dec;55(12):1593-606.
2. Khare C, Mueser KT, Bahale M, Vax S, McGurk SR. Employment in people with severe mental illnesses receiving public sector psychiatric services in India. *Psychiatry Res.* 2021 Feb 1;296:113673.
3. Prasad HG, Acharya V. A cross sectional study of employment pattern in patients with severe mental illness. *Indian J Occup Ther.* 2014 May;46(2):35-40.
4. Work functioning of schizophrenia patients in a rural south Indian community: status at 4-year follow-up - PubMed [Internet]. [cited 2022 Sep 26]. Available from: <https://pubmed.ncbi.nlm.nih.gov/22419163/>
5. Srivastava AK, Stitt L, Thakar M, Shah N, Chinnasamy G. The abilities of improved schizophrenia patients to work and live independently in the community: a 10-year long-term outcome study from Mumbai, India. *Ann Gen Psychiatry.* 2009 Oct 13;8:24.
6. Nirmala BP, Roy T, Naik V, Srikanth P. Employability of people with mental illness and substance use problems: Field realities. *J Fam Med Prim Care.* 2020 Jul;9(7):3405-10.
7. Kumari S, Ojha GJ. Employment Status of Persons Living with Mental Illness in India: Ground Reality. 2020;(10):8.
8. Jagannathan A, Harish N, Venkatalakshmi C, Kumar CN, Thirthalli J, Kumar D, et al. Supported employment programme for persons with severe mental disorders in India: A feasibility study. *Int J Soc Psychiatry.* 2020 Sep;66(6):607-13.
9. Roy A, Jayarajan D, Sivakumar T. Income Generation Programs for Persons with Mental Health Challenges: Practices from 13 Indian Mental Health Rehabilitation Centers. *Indian J Psychol Med.* 2022 Mar;44(2):160-6.
10. Waghmare A, Sherine L, Sivakumar T, Kumar CN, Thirthalli J. Rehabilitation Needs of Chronic Female Inpatients Attending Day-care in a Tertiary Care Psychiatric Hospital. *Indian J Psychol Med.* 2016 Feb;38(1):36-41.
11. Narayan CL, John T. The Rights of Persons with Disabilities Act, 2016: Does it address the needs of the persons with mental illness and their families. *Indian J Psychiatry.* 2017;59(1):17-20.
12. Rangarajan SK, Muliya KP, Jadhav P, Philip S, Angothu H, Thirthalli J. Reasonable Accommodation at the Workplace for Professionals with Severe Mental Illness: A Qualitative Study of Needs. *Indian J Psychol Med.* 2020 Sep;42(5):445-50.
13. Davidson L, Chinman M, Sells D, Rowe M. Peer support among adults with serious mental illness: a report from the field. *Schizophr Bull.* 2006 Jul;32(3):443-50.
14. Pathare S, Kalha J, Krishnamoorthy S. Peer support for mental illness in India: an underutilised resource. *Epidemiol Psychiatr Sci.* 2018 Oct;27(5):415-9.
15. Thekkumkara SN, Jagannathan A, Muliya KP, Murthy P. Development and validation of a peer support programme for the prisoners with mental and substance use disorders in India. *Indian J Psychiatry.* 2022 Jun;64(3):316-21.
16. What We Do - Clubhouse International [2022 Oct 4]. Available from: <https://clubhouse-intl.org/what-we-do/overview/>



## REHABILITATION OF PERSONS WITH SUBSTANCE ABUSE

Prabhat K. Chand<sup>1</sup>, Rahul Verma<sup>2</sup>

### ABSTRACT

Psychiatric rehabilitation services are collaborative, person-directed, and individualized, focusing on helping individuals develop skills and access resources needed to increase their capacity to be successful and satisfied in their lives. Rehabilitation usually focuses on recovery, which is poorly defined for substance use disorder. Most definitions consider abstinence as recovery, but as we know, substance use disorder is a chronic relapsing condition; hence the rehabilitation process in substance use disorder primarily focuses on making and maintaining the person abstinent from substance use.

### INTRODUCTION

According to the psychiatric rehabilitation association, psychiatric rehabilitation promotes recovery, full community integration, and improved quality of life for persons diagnosed with any mental health condition that seriously impairs their ability to lead meaningful lives. Psychiatric rehabilitation services are collaborative, person-directed, and individualized. These services are an essential element of the health care and human services spectrum and should be evidence-based. They focus on helping individuals develop skills and access resources needed to increase their capacity to be successful and satisfied in their choice's living, working, learning, and social environments [1]. Rehabilitation is a process that a person undergoes to recover from illness. According to the substance abuse and mental health service administration, recovery is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential. Recovery from substance use disorder is subjective as there are no standards for measuring and defining [2]. Betty Ford Institute defines recovery from substance use disorder as achieving complete abstinence and personal well-being [3]. At the same time, most other studies have taken total abstinence as a recovery [4]. The lack of set standards has created confusion about what kind of rehabilitation process to choose and where to end, as substance use disorder is a chronic relapsing condition associated with many physical, social, and occupational consequences. The rehabilitation process involved in substance use disorder usually focuses on reducing these physical, social, and occupational consequences and reintegrating the person back into society. Here we will discuss some of the processes and models which are used in the rehabilitation of people with substance use disorder.

### HISTORY

Residential treatment is the oldest form of rehabilitation service used since ancient times for substance use disorder. Egyptians used private homes, while Romans recommended public and private asylums for those addicted to alcohol. Dr Benjamin Rush (Father of American Psychiatry) proposed for the first time to treat the problem of alcohol with medical care and residential treatment. Since then, many residential treatment programs have initially focused

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Professor, Centre for Addiction Medicine, Department of Psychiatry, NIMHANS Digital Academy ECHO, National Institute of Mental Health and Neurosciences, Bengaluru.
2. Senior Resident, Centre for Addiction Medicine, Department of Psychiatry, National Institute of Mental Health and Neurosciences, Bengaluru.

on alcohol. Dr Jansen B. Mattison founded Brooklyn Home for Habitues and was the first to focus exclusively on chemical addiction other than alcohol. A significant step toward rehabilitation of substance use problems came in 1935 with the opening of the first federally supported residential drug treatment centre in Lexington called the "Narcotic Farm" for the treatment of persons addicted to habit forming drugs. It was built and run like a minimum security prison in a 1000 acre land with farm and cow, field working there was considered therapeutic. Its name was changed to U.S. public health service hospital in 1936. There started the study of addiction as a disease in a residential setting, and their work continuing today at the National Institute of Drug Abuse in Baltimore [6]. Community treatment for substance use disorder began in 1950 when outpatient treatment through social workers for individuals who have finished detoxification was given [7]. These early attempts were unsuccessful; however, religious organizations continued to provide medical and psychological treatment as outreach services for drug addiction. These community - based treatments started becoming popular when Synanon, therapeutic communities, and new legislation permitted the use of agonist and antagonist treatment in community facilities [8].

**MODELS OF REHABILITATION**

The United Nations Office on Drugs and Crime has given a comprehensive approach involving the process involved in rehabilitating people with substance use disorder.

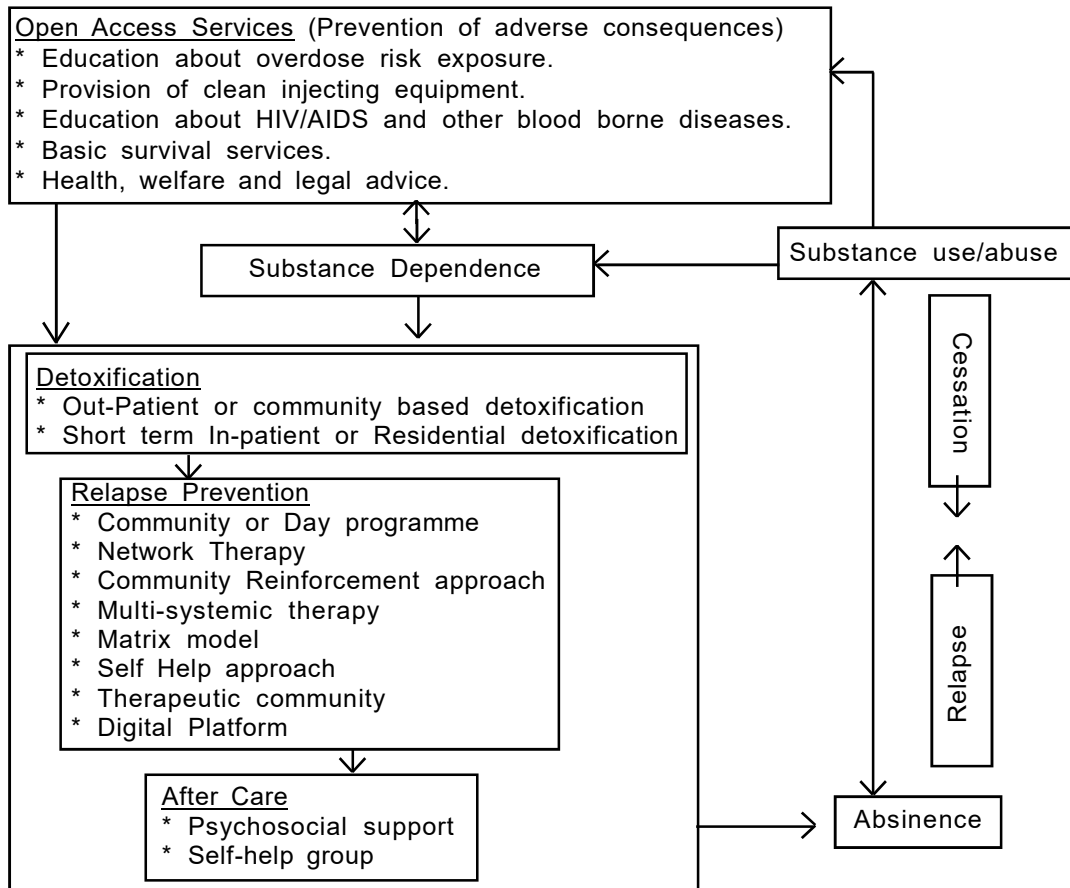


Fig. 1 Rehabilitating approach in substance use disorder.

**a. Outpatient or Community - Based Detoxification**

This is suitable for people with mild to moderate withdrawal. Here, detoxification starts at the treatment center or the person's home with a substitution agent. After stabilization, the person is gradually withdrawn from the substituting agent over a period ranging from a few days to several months. During this time, the person is motivated to receive psychosocial treatment through counselling or other support services [9]. The drawback is the increased risk of relapse due to easy access to substances. Also, in community-based treatment; people can easily choose not to keep their appointment and fail to complete detoxification [10].

**b. Short-term Inpatient or Residential Detoxification**

This is suitable for people with severe withdrawal or those who will not be able to complete detoxification in the community. Therefore they need a supervised environment for detoxification. Along with detoxification, they receive education about their illness, relapse prevention therapy, and onward referral if required. The advantage of inpatient detoxification is that many people also have additional physical or mental conditions that may interfere with complete abstinence; these other illnesses can also be taken care of in short-term inpatient detoxification by professionals through constant care. Inpatient treatment also serves as a short-term method of separation from substances. The drawback is its relatively higher cost compared to outpatient or community methods. It may also increase a person's dependency on the hospital [10][11].

**c. Community or Day programmes**

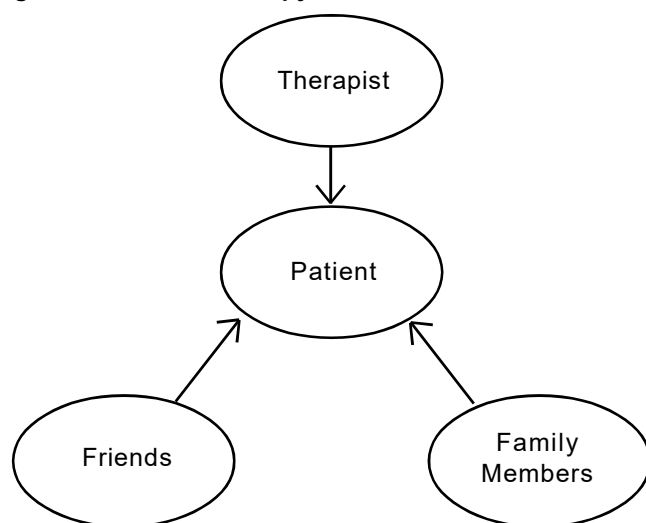
This programme is usually designed for individual persons to meet the needs of each participant using a case management approach. A case manager is allotted to each individual. They offer psychotherapy or general counselling based on a care plan. Case management is based on a comprehensive assessment of personal resources, existing problems, social support, and stressors done by a specialist clinician or social worker. After the evaluation, personal treatment goals for the individual are made, and progress towards the goal is regularly monitored. Case management also includes liaison and referral to other support services the client needs and onward referral to other specialists if required. Drug abuse counsellors in many countries use the cognitive behavioural, motivational and client-centred framework and offer treatment ranging from brief intervention to complete structured programs lasting for several months. Treatment goals are based on helping the client increase awareness and understanding of their substance use behaviour to reduce the harmful consequences of substance use and avoid substance use. A structured program involving drug-free days is found in many countries. In the extensive program, people are expected to attend sessions 4-5 days a week [11].

**d. Network Therapy**

This treatment is usually beneficial for those who cannot control the intake of substances after first intake-loss of control, who had multiple past relapses, and who are not willing to cut down or stop their substance - taking behavior. Marc Galanter first gave the concept of network therapy as a combination of individual and group therapy approaches to enhance the success of office-based treatment for substance use disorder patients by using both cognitive and psychodynamic approaches to individual therapy while engaging the patient in a group support network comprising of peers and family members [12][13].

Its appeal is threefold 1. Relapse prevention by cognitive behavior approach. 2. Support the patient's natural social network by involving selected family members (pre-existing everyday social network) and friends (specifically developed networks to facilitate the patient's treatment). 3. Community reinforcement technique to support rehabilitation by aiming at activities outside the therapy context [14]. An experienced therapist and addiction counsellor deliver it. The core of network therapy is to extend the treatment beyond the individual. The goal is to achieve prompt abstinence with relapse prevention. Initially developed for cocaine users but can also be used for other substance use disorder patients [15].

**Figure 2 Network Therapy**



**e. Community Reinforcement Approach**

This is a comprehensive package of behaviour treatment based on the social learning theory model that focuses on managing behaviour associated with substance use and other disrupted areas of life. It was given by Azrin initially for people with alcohol use disorder and contained four components that each interferes with drinking by providing satisfaction in different aspects of life 1. Help in providing jobs of a kind which is a full time, steady, satisfying and well-paying. 2. Marriage and family counselling will increase the person's satisfaction in his family or marriage such that they will be involved more continuously and pleasurably in family activities. 3. A self-governing social circle or club for people abstaining from substances to provide them with enjoyable social events, especially during evening hours or on weekends. 4. People with substance use are encouraged to involve in recreational activities and pleasurable hobbies to provide them with alternatives to substance use [16]. It utilizes social, familial, vocational, recreational and other community reinforcers to aid patients in the recovery process, to help people adopt a healthier and pleasurable lifestyle that is more rewarding than a lifestyle filled with substance. Although it was first developed for alcohol, this intervention is used successfully for substance use where pharmacological intervention is not available or required, like solvent, cocaine or cannabis use. In terms of evidence, the studies have



shown the benefits of reducing substance use in the community reinforcement approach[16][17]. Due to its effectiveness, the Community reinforcement approach has been developed to target some specific population.

Adolescent - Community Reinforcement Approach (A-CRA) targets the adolescent population specifically. The unique element of A-CRA is that it involves care givers-family members or guardians with whom the adolescent is living. The caregiver attends four sessions, two alone, where parenting rules and basic skills including communication and problem-solving, are discussed. Two sessions of caregiver along with adolescence who use a substance is taken where the focus is on improving adolescence-caregiver relationship through increasing positive communication skill and the practice of problem-solving exercise that they are asked to do outside therapy sessions.

Another variant is Community Reinforcement and Family Training (CRAFT), which is designed for individuals who refuse to engage in treatment, as the family members of these individuals often suffer from emotional trauma by living with substance abuse. It is derived from operant conditioning. Here the individual is not forced to attend treatment; instead, it operates indirectly through the concerned family member called the Concerned Significant Other (CSO). The therapist shows the CSOs how to change the home environment of treatment non-seeker by rewarding the behaviour that promotes abstinence and withholding the reward when the person is using the substance<sup>18</sup>.

**f. Multi - Systemic Therapy (MST)**

It is a comprehensive family and community-based treatment model specially designed for adolescents with severe conduct problems or substance use (residential treatment, incarceration). Bronfenbrenner's (1979) social-ecological model provides the framework for MST. According to this, behaviour is primarily determined based on proximal system functioning (i.e. family, school, peer and neighbourhood), which surrounds the individual and the reciprocal interplay between these systems. The basic assumption of MST is that the caregivers are the key to achieving and sustaining beneficial long-term outcomes. The interventions focused on enhancing caregivers' ability to acquire the resources and skills needed to parent, manage and care for their children effectively. As the caregiver's skill increase (abstinence from drug use, ability to provide supervision), the therapist guide the caregiver to address other problems of adolescents like the association with a deviant peer or parental unemployment. The intervention also aims to help caregivers with support from friends, family and community members to help sustain the changes achieved during treatment. A team delivers MST of two to four expert therapists, a part-time master's or doctoral level supervisor and administrative support. One MST therapist handles 4-6 families. Treatment ranges from 3-6 months, but the intensive intervention involves 60-100 hours of direct contact with the family and other members of the adolescent with substance use behaviour. MST is highly individualized and does not follow a fixed treatment plan. The nine principles of MST provide the underlying structure and framework upon which the therapist plans their intervention. Early in the treatment process, the target problem behaviour is specified, and specific goals for treatment are set at individual, peer, family and social network levels. Several effectiveness studies on MST have shown to reduce adolescent externalizing behaviour and youth offences and improve parenting[19]. However, a Swedish randomized control trial (RCT) did not find a favourable outcome. Still, it was found that the outcome became favourable once the therapist gained experience during the process of RCT [20].

**Table 1 Principles of Multi-Systemic Therapy**

PRINCIPLES OF MULTI-SYSTEMIC THERAPY (MST)	
1	Finding the fit.
2	Focussing on positives and strengths.
3	Increasing responsibility.
4	Present-focused, action-oriented and well-defined.
5	Targeting sequences.
6	Developmentally appropriate.
7	Continuous effort.
8	Evaluation and accountability.
9	Generalization.

**g. Matrix Model**

The matrix model was developed in response to the cocaine epidemic in the United States in 1980. There were no suitable and appropriate treatment options for stimulant users then, who usually do not need inpatient care and could not relate to targeted treatments for alcohol use. So matrix model as an integrated outpatient substance use treatment programme was developed. It incorporated empirically supported treatment elements, including education, relapse prevention and family involvement, into a manualized, structured, and non-confrontational cognitive/behaviour programme that addresses the specific needs of stimulant abusers in outpatient treatment settings. It is a directive, non-confrontational approach focusing on current issues and behaviour change. The intervention components are individual counselling sessions, relapse prevention groups, family education groups and urine and breath alcohol testing. The model was later broadened to treat opioid, and alcohol dependence and manuals were developed to target specific problems of these substance use disorders. The efficacy of the matrix model has not been established, but a review of these studies has justified the support for this approach. Methamphetamine and cocaine users respond positively to MST treatment and in some cases have sustained the benefit for two years [21].

**h. Self Help Approach**

Many organizations to help people with substance use, mostly alcohol, have been in practice for years, like the Washington group, Oxford Group, etc. Still, none had a proper structure and direct focus in helping people quit alcohol. Hence many such groups came and dissolved. The one which became very popular and persisting till now is Alcohol Anonymous (AA) which was founded by a New York stockbroker (William Wilson) and a physician (Robert Smith) in response to Oxford Group's nonspecific focus on alcohol and religious emphasis. AA was distinct because it focused exclusively on helping individuals recover from alcoholism. It simultaneously developed a policy of being

fully self-supporting, declining outside contributions, and having no opinion on any issues of any kind with the intention of minimizing distraction, disunity and controversy [22]. To share their ideas and way of working, the founding members of AA wrote the book initially titled Alcohol Anonymous : The Story of How More Than One Hundred Men Have Recovered from Alcoholism, from which AA drew its name. This book is also known as the "Big Book" or Bible of AA. It follows a 12-step programme in which members of the group admit that they are powerless over alcohol and require help from a higher power. They seek strength and guidance through meditation and prayer from God or a higher power of their understanding, take moral inventory with care and become ready to remove character deficits [23].

**Table 2 12 Steps of Alcohol Anonymous**

12 STEPS OF ALCOHOL ANONYMOUS	
1.	We admitted we were powerless over alcohol-that our lives had become unmanageable.
2.	Came to believe that a power greater than ourselves could restore us to sanity.
3.	Made a decision to turn our will and our lives over to the care of God as we understood Him.
4.	Made a searching and fearless moral inventory of ourselves.
5.	We admitted to God, ourselves, and another human being the exact nature of our wrongs.
6.	We were entirely ready to have God remove all these defects of character.
7.	Humbly asked Him to remove our shortcomings.
8.	Made a list of all persons we had harmed and became willing to make amends to them all.
9.	Made direct amends to such people wherever possible, except when doing so would injure them or others.
10.	Continued to take personal inventory, and when we were wrong, promptly admitted it.
11.	We sought through prayer and meditation to improve our conscious contact with God as we understood Him, praying only for knowledge of His will for us and the power to carry that out.
12.	Having had a spiritual awakening as the result of these steps, we tried to carry this message to alcoholics and to practice these principles in all our affairs.

Today, this organization comprises around 100000 registered groups involving around 2 million members in over 150 countries. Its widespread acceptance, adoption, and perceived effectiveness in helping people to get away from alcohol have led to the origin of several other organizations inspired by it. The more well-known are cocaine anonymous, Narcotics Anonymous, Women for Sobriety, Self-Management and Recovery Training (SMART). In terms of evidence, studies have shown self-help groups as a helpful adjunct to substance use disorder treatment. Concerning subpopulation, non-religious or less religious people have shown equal benefits as more religious people, and women have also demonstrated similar benefits as men. However, the effect of self-groups in dual-diagnosis patients is moderated by their psychiatric comorbidity [24].

#### **i. Therapeutic Community**

As a treatment approach, a therapeutic community is suitable for people who are less likely to benefit from outpatient treatment like those with a history of multiple treatment failures. The therapeutic community views substance use as deviant behaviour rather than illness [15]. The approach of the therapeutic community can be described by the phrase "Community as a method," meaning the community is both a method and a way for social learning and personal change [25]. A therapeutic community is a form of a residential rehabilitation programme. Two types are described. Short-term residential rehabilitation programme starts with detoxification as the first stage and last 30 to 90 days. Other long-term residential rehabilitation programmes, also known as therapeutic community, usually do not provide detoxification but just allow the individual to stay in a residential home and lasts from 6 months to a year. Both short and long term residential rehabilitation programme share some features like staying together with other drug users in recovery process, individual and group counselling for relapse prevention, individual case management, training and vocational experiences like housing and resettlement services, skill building for daily living and aftercare support. They are also aligned with other self-help groups like cocaine anonymous, narcotics anonymous. Some of the residential programme also provides half way houses which are group living environment but semi-independent and are usually close to main residential programme. It provides opportunity to the client to prepare him/herself to return to the community while continuing to receive formal support as needed [11]. A systematic review has shown the benefit of the Therapeutic community in terms of reducing substance use and legal outcome. Also, there was a benefit in terms of better employment and psychological functioning. Participation in the aftercare process and length of stay in treatment were the main predictors of outcome and recovery status [26].

#### **j. After Care Arrangements**

Aftercare is included in some structured treatment programmes as a less intensive treatment after the client has completed the main programme. Usually lasting for a month or sometimes longer after the treatment has finished. Ongoing support and care to the client is provided to maintain the benefits and goals. Scheduled appointments, unscheduled or drop-in visits, and regular phone calls are part of the aftercare programme. The effectiveness of such services has not been formally evaluated, but there is a general obligation to their value and availability [11].

**k. Open Access Services**

They are part of an integrated treatment response. They do not provide formal treatment but act as a point of first contact for people with substance-related problems and those concerned about substance use (e.g. Friends, spouse, siblings, and parents). They are commonly known as "street agencies" and are usually run by a non-governmental organization and provide the following services [11].

1. "Drop-in" services for accessing basic information and advice.
2. Community outreach and advice.
3. Appointment-based general counselling services.
4. Telephone helpline for anonymous, confidential advice.
5. Onward referral information and advocacy.
6. Community aftercare and support services.
7. Family groups

**l. Digital Platform for Rehabilitation**

As the internet has become a part of daily human life, the digital platform has also become popular in social, occupational and personal life. Many such digital media has become popular for treating substance use disorder. The most popular FDA-approved reSET-O is a prescription digital therapeutics for opioid use disorder. It is a mobile phone app-based program with a community reinforcement approach to cognitive behaviour therapy. It is a 12-week prescription-only treatment for patients with opioid use disorder to increase abstinence from opioid use and increase retention in outpatient treatment [27]. Apart from this, many other digital platforms are being used but need further study. Broadly the online-based interventions are divided into four categories 1. Web-based intervention 2. Online counselling and therapy 3. Internet-operated therapeutic software 4. Other online activities.

**Table 3 Summary of Rehabilitation Approaches for Substance use Disorder**

<i>Intervention</i>	<i>Salient Features</i>
Out-Patient or Community based detoxification	<ul style="list-style-type: none"> <li># For Mild to moderate withdrawal.</li> <li># Detoxification starts in treatment centre or home.</li> <li># Increase risk of relapse and compliance is questionable.</li> </ul>
Short term In-patient or Residential detoxification	<ul style="list-style-type: none"> <li># For severe withdrawal.</li> <li># Short term method of separation from substance.</li> <li># Receive treatment for additional physical or medical condition.</li> <li># Higher cost compared to out-patient detoxification.</li> </ul>

<i>Intervention</i>	<i>Salient Features</i>
Community or Day programme	<ul style="list-style-type: none"> <li># For harmful use of substance.</li> <li># Client centred approach with help of case manager.</li> </ul>
Network Therapy	<ul style="list-style-type: none"> <li># For non-motivated people</li> <li># 3 fold appeal -Relapse prevention, strengthen patient natural support system, community reinforcement.</li> <li># Initially developed for cocaine users but can be used for all substance users.</li> </ul>
Community Reinforcement approach	<ul style="list-style-type: none"> <li># Useful for drugs for which pharmacotherapy is not available.</li> <li># Focus on behaviour associated with substance use.</li> <li># Utilizes social, vocational, familial and other community reinforcers to aid in recovery.</li> </ul>
Multi Systemic Therapy	<ul style="list-style-type: none"> <li># For Adolescent substance users.</li> <li># Comprehensive family and community based treatment model, based on 9 principles.</li> <li># Assume caregiver is the key to achieve long term benefits.</li> <li># Delivered by a team of 4-6 people.</li> </ul>
Matrix Model	<ul style="list-style-type: none"> <li># For stimulant users.</li> <li># Out-patient treatment programme involving education, relapse prevention and family involvement.</li> </ul>
Self Help Group	<ul style="list-style-type: none"> <li># For all substance users as adjunct to other treatment.</li> <li># Includes alcohol anonymous, narcotic anonymous etc.</li> <li># Admit themselves as powerless over alcohol and seek help from external power.</li> </ul>
Therapeutic Community	<ul style="list-style-type: none"> <li># For people with multiple treatment failures.</li> <li># Residential treatment programme- short and long term.</li> <li># Provides opportunity to client to prepare themselves for return to community.</li> </ul>
Aftercare Arrangement	<ul style="list-style-type: none"> <li># Less intensive treatment after completion of main treatment.</li> <li># Continue ongoing support to maintain the benefits.</li> </ul>
Open Access Service	<ul style="list-style-type: none"> <li># For all substance use disorders.</li> <li># Education and preventive methods are used.</li> </ul>
Digital platform (reSET-O)	<ul style="list-style-type: none"> <li># Prescription only treatment for opioid use disorder.</li> <li># CBT for 84 days along with medical management.</li> </ul>

## CONCLUSION

Rehabilitation services play a significant role in managing substance use disorder as these are the only intervention that helps maintain the person's abstinence from substance and reintegrate him back into the community. The rehabilitation process should always be integrated into substance use disorder treatment. The complete onus of maintaining abstinence lies with the individual, but the therapist who guides the individual in rehabilitation is also essential.

## TAKE HOME POINTS

1. The rehabilitation process focuses on recovery.
2. Recovery from substance use disorder focuses on maintaining abstinence.
3. The choice of the rehabilitation process will depend on the individual and the type of substance used.
4. Different approaches used in the rehabilitation process are client-centred, supportive, behaviour and cognitive, or community-based.
5. The goal is to reintegrate the individual back into the community.

## REFERENCES

1. About PRA | PRA - Psychiatric Rehabilitation Association. [cited 2022 Sep 5]. Available from: <http://www.uspra.org/about/who-we-are/about-pra>
2. Webb L. The recovery model and complex health needs: What health psychology can learn from mental health and substance misuse service provision. *Journal of health psychology*. 2012 Jul;17(5):731-41. doi: 10.1177/1359105311425276.
3. Panel TB. What is recovery? A working definition from the Betty Ford Institute. *Journal of Substance Abuse Treatment*. 2007 Oct 1;33(3):221-8. doi: 10.1016/j.jsat.2007.06.001.
4. White WL. Recovery/remission from substance use disorders: An analysis of reported outcomes in 415 scientific reports, 1868-2011. *Drug & Alcohol Findings Review Analysis*. Pittsburgh, PA: Philadelphia Department of Behavioral Health and Intellectual disAbility Services and the Great Lakes Addiction Technology Transfer Center. 2012.
5. Kosten TR, Gorelick DA. The Lexington narcotic farm. *American Journal of Psychiatry*. 2002 Jan 1;159(1):22-.
6. Kurth, D.J., Kalira, V., Hurley, B. (2015). Residential Treatment. In: el-Guebaly, N., Carrà, G., Galanter, M. (eds) *Textbook of Addiction Treatment: International Perspectives*. Springer, Milano. [https://doi.org/10.1007/978-88-470-5322-9\\_57](https://doi.org/10.1007/978-88-470-5322-9_57)
7. De Leon G. The therapeutic community: Theory, model, and method. doi.org/10.1891/9780826116673
8. White WL. The history of recovered people as wounded healers: I. From Native America to the rise of the modern alcoholism movement. *Alcoholism treatment quarterly*. 2000 Jun 23;18(1):1-23. doi: 10.1300/J020v18n01\_01. doi: 10.1300/j020v18n01\_01
9. Prater CD, Miller KE, Zylstra RG. Outpatient detoxification of the addicted or alcoholic patient. *American Family Physician*. 1999 Sep 15;60(4):1175
10. Hayashida M. An overview of outpatient and inpatient detoxification. *Alcohol health and research world*. 1998;22(1):44.

11. United Nations Office on Drugs, Crime. Drug Abuse Treatment and Rehabilitation: A Practical Planning and Implementation Guide. United Nations Publications; 2003.
12. Galanter M, Keller DS, Dermatis H. Network therapy for addiction: Assessment of the clinical outcome of training. *The American journal of drug and alcohol abuse*. 1997 Jan 1;23(3):355-67. doi 10.3109/00952999709016882
13. Galanter M, Brook D. Network therapy for addiction: bringing family and peer support into office practice. *International Journal of Group Psychotherapy*. 2001 Jan 1;51(1):101-22. doi 10.1521/ijgp.51.1.101.49734
14. Galanter M, Dermatis H, Keller D, Trujillo M. Network therapy for cocaine abuse: Use of family and peer supports. *American Journal on Addictions*. 2002 Jan 1;11(2):161-6. doi: 10.1080/10550490290087938
15. Murthy P. Guidelines for psychosocial interventions in addictive disorders in India: An introduction and overview. *Indian Journal of Psychiatry*. 2018 Feb;60(Suppl 4):S433. doi: 10.4103/psychiatry.IndianJPsychiatry\_35\_18
16. Azrin NH. Improvements in the community-reinforcement approach to alcoholism. *Behaviour Research and therapy*. 1976 Jan 1;14(5):339-48. doi.org/10.1016/0005-7967(76)90021-8
17. Smith JE, Meyers RJ, Delaney HD. The community reinforcement approach with homeless alcohol-dependent individuals. *Journal of Consulting and Clinical Psychology*. 1998 Jun;66(3):541. doi.org/10.1037/0022-006X.66.3.541
18. Meyers RJ, Roozen HG, Smith JE. The community reinforcement approach: An update of the evidence. *Alcohol Research & Health*. 2011;33(4):380.
19. Borduin CM, Mann BJ, Cone LT, Henggeler SW, Fucci BR, Blaske DM, Williams RA. Multisystemic treatment of serious juvenile offenders: long-term prevention of criminality and violence. *Journal of consulting and clinical psychology*. 1995 Aug;63(4):569.
20. Henggeler SW, Schaeffer CM. Multisystemic therapy®: Clinical overview, outcomes, and implementation research. *Family process*. 2016 Sep;55(3):514-28. doi.org/10.1111/famp.12232
21. Obert JL, McCann MJ, Marinelli-Casey P, Weiner A, Minsky S, Brethen P, Rawson R. The matrix model of outpatient stimulant abuse treatment: history and description. *Journal of Psychoactive Drugs*. 2000 Jun 1;32(2):157-64. doi:10.1080/02791072.2000.10400224
22. Alcoholics Anonymous. Twelve steps and twelve traditions. New York: Alcoholics Anonymous World Services; 1953.
23. Bill W. Alcoholics Anonymous: The story of how many thousands of men and women have recovered from alcoholism. Alcoholics Anonymous Pub.; 1955
24. Kelly JF. Self-help for substance-use disorders: History, effectiveness, knowledge gaps, and research opportunities. *Clinical psychology review*. 2003 Oct 1;23(5):639-63. doi.org/10.1016/S0272-7358(03)00053-9
25. De Leon G, Unterrainer HF. The therapeutic community: a unique social psychological approach to the treatment of addictions and related disorders. *Frontiers in psychiatry*. 2020 Aug 6;11:786. doi: 10.3389/fpsy.2020.00786
26. Vanderplasschen W, Colpaert K, Autrique M, Rapp RC, Pearce S, Broekaert E, Vandevelde S. Therapeutic communities for addictions: a review of their effectiveness from a recovery-oriented perspective. *The Scientific World Journal*. 2013 Oct;2013. doi.org/10.1155/2013/427817
27. Kawasaki S, Mills-Huffnagle S, Aydinoglo N, Maxin H, Nunes E. Patient-and Provider-Reported Experiences of a Mobile Novel Digital Therapeutic in People With Opioid Use Disorder (reSET-O): Feasibility and Acceptability Study. *JMIR formative research*. 2022 Mar 25;6(3):e33073. doi:10.2196/33073



## PSYCHO-SOCIAL TECHNIQUES USED IN PSYCHIATRY REHABILITATION

Rajeshkrishna Bhandary P<sup>1</sup> and Mr. Praveen A<sup>2</sup>

### ABSTRACT

Severe mental illnesses (SMI) pose challenges in treatment due to inadequate response to medications. Rehabilitation of these individuals often require multiple non-pharmacological interventions delivered through a multidisciplinary team. Psychosocial interventions form the key components propelling them towards 'recovery'. Behavioural principles of operant conditioning and learning are used to inculcate behaviours that improve functioning and reduce problem behaviours. Reinforcement that increases the occurrence of behavior pervades most therapy forms and help in overcoming negative symptoms and cognitive deficits and developing social and vocational skills. Cognitive therapy based principles are used to reduce distress and behaviors related to anxiety, mood, obsessive-compulsive as well as the more resistant psychotic symptoms such as delusions and hallucinations. Social and community based inputs help in engaging family and community in providing the supportive environment for the client during reintegration. Nevertheless, specific interventions such as IPSRT and IPT and individualized programs can better rehabilitative outcomes.

### INTRODUCTION

Rehabilitation Psychiatry during its early days focused more on institutionalization of the people with severe mental illness and providing them a safe environment to live in. With the introduction of Chlorpromazine [1] as pharmacological agent for mental illness in the 1950s as well as the rights movement [2], the process of deinstitutionalization took place. However, due to the lack of preparedness of both the mentally ill, as well as the community, we saw the 'revolving door' phenomenon [3]. One of the outcomes of such phenomenon was the advent of community psychiatry and the other, emphasis on interventions beyond medications for reintegrating patients in to the community. Non- pharmacological interventions, even though known to have started much earlier in the form of occupational therapy in the mental hospitals as early as the 18th Century [4], grew during the 1920s and the focused intervention towards reintegration to community, possibly started only in the 1970s. The 1990s recognized the relevance and importance of such non-pharmacological interventions in the process of rehabilitation, to the extent that the term 'Psychosocial Rehabilitation' was deemed more appropriate and replaced the older term of Psychiatric Rehabilitation [5]. This chapter will focus on the various psychosocial techniques used in the process of rehabilitation and provide the reader an overview of the various components of psychosocial rehabilitation.

Current etiological theories of mental illnesses promote the comprehensive Bio-Psycho-Social Model. Even though pharmacotherapy plays a key role in severe mental illnesses for control of symptoms, ignoring the psychosocial aspects of the illness have plunged patients towards poorer outcomes. Literature shows that symptom reduction is a reality in less than half of

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Associate Professor, Psychiatry, Department of Psychiatry, Kasturba Medical College, Manipal -576104, Udupi, Karnataka.
2. Senior Grade Lecturer, Psychiatric Social Work, Department of Psychiatry, Kasturba Medical College, Manipal -576104, Udupi, Karnataka.

people with serious mental illness (SMI) and many suffer from persistent symptoms ranging from psychotic, mood, anxiety, negative and cognitive symptoms that impede functioning causing disability [6]. Psychosocial Rehabilitation aims at improving these functional deficiencies. In the recent times, consumer driven models have redefined rehabilitation with the concept of 'recovery'. Recovery, in terms of rehabilitation, focuses on the client's satisfaction with their level of functioning and reflects upon their quality of life [7]. These are often dependent on the socio-cultural background, community characteristics and the environment necessitating interventions that are multimodal in nature and delivered through a multidisciplinary team.

### **REHABILITATION SETTING**

Rehabilitation intervention delivery can be at individual or group level; at home, day care or at residential rehabilitation settings. Home based rehabilitation may be initiated as a preventive approach in early phases of illness. When deficits are prominent, residential and day care services might be more useful followed by transition to home based inputs. Group interventions are a common mode of service delivery in rehabilitation settings for being resource efficient. From a therapy point of view, groups provide cohesiveness, acceptance of deviant behaviour by peers, peer mediated and social learning, ready support group, mirrors few of the dynamics of community living and provides opportunity to develop social skills [8].

### **PSYCHO-SOCIAL TECHNIQUES**

#### **BEHAVIOURAL TECHNIQUES**

Behavioural principles are ubiquitous with the process of learning or change in behavior and its principles find integrated into many other therapies across various populations in the process of rehabilitation. The behavior training in children with intellectual deficits and autism, the voucher system in deaddiction, social skills training and intervention for negative symptoms in Schizophrenia, exposure therapy in anxiety, all use the behavioural principles. Hence, it is essential that a practitioner of rehabilitation psychiatry is thorough with these techniques and utilizes them appropriately.

The two laws of operant conditioning; law of effect (frequency of behavior is determined by the consequences of the behavior) and law of association by contiguity (two events will come to be associated with each other when they occur together) govern the learning process and behavior retention in rehabilitation. The section below provides an overview of the different behavioural techniques used [9][10].

**Reinforcement** : Reinforcement is a behavioural technique that is used to increase the occurrence of a desired behavior. Two types of reinforcement exist. Positive reinforcement and Negative reinforcement. In positive reinforcement, a pleasurable stimulus is given to increase the behavior, while in negative reinforcement an unpleasant behavior. The choice of reinforcers needs appropriate consideration. Simple reinforcers such as food and objects of special interest for the client serve as the primary reinforcers in the process. Higher order/ value of reinforcers are paired for larger gains in the therapy. Social reinforcers such as recognition, acknowledgement and appreciation by peers can also be used to motivate. Over the course of therapy, schedules of reinforcement are changed in order to prevent extinction of the behavior upon delay or discontinuation of the reinforcer.

**Punishment** : In this behavioural technique, the intention is to reduce an unwanted behavior. Positive punishment introduces noxious stimuli to reduce a behavior and the negative punishment removes a pleasant stimulus in order to reduce a behavior. Some of the behaviourists also

talk about Extinction in this context, where non response to a behavior reduces the occurrence of such behavior.

For individuals with severe mental illnesses Positive and negative reinforcement are used most often followed by the negative punishment. Positive punishments are not accepted in rehabilitation practice. Variable schedules of reinforcement and contingency management can be used to prevent extinction of the desired behaviour.

**Shaping** : This technique involves breaking down larger goals into smaller and easier to attain goals and then shape the behavior. Example for this would be to make a person be at the place of activity as a first step while aiming for the person's participation in activity in the long run.

**Prompting** : Cognitive deficits and negative symptoms related to the SMI may make it difficult for the client to grasp instructions quickly. As part of the learning of the new behavior/ skill, they will need to be given simple directive instructions, clues which may be verbal or non verbal to facilitate acquisition of the behavior. Subsequently these prompts are turned to questions for the client to recall and internalize the behavior over time.

**Chaining** : When a complex behavior needs to be learnt and there are multiple steps involved, the steps are learnt step by step allowing the person to master a step before proceeding to the next one. The steps are linked to one another like a chain and the individual learns the complex behavior. Based on the sequence of training, one can opt for backward chaining or forward chaining.

**Modelling** : The behavior that is learnt through copying the behavior demonstrated by the therapist or by imitating behaviours of co-clients in the group settings.

**Token Economy** : Token economy is a behavioural technique, which uses systematic reinforcement system with the use of tokens to increase performance in predefined desired behavior [11]. Key difference here is that the tokens as compared to other reinforcers, has no value of its own. However, it can be exchanged for person's choice of reinforcer (secondary reinforcer) at select shops or settings and may exchange for objects or access to certain privileged services.

Though largely restricted to wards with long-stay patients, token economy programmes were widespread in the 1970s and were particularly aimed at changing negative symptoms of schizophrenia - such as poor motivation, poor attention and social withdrawal [12]. In deaddiction settings, tokens are exchanged for vouchers and passes to go out of the centre.

## **BEHAVIOURAL ACTIVATION**

Behavioural activation or in simple terms activity scheduling has its roots in the treatment of major depression. Behavioral activation though less studied in Schizophrenia and other population, can be easily incorporated in to a rehabilitation program since it does not rely much on reasoning ability. An open trial in patients with Schizophrenia in the UK [13] found that it was well received and was very effective in reducing both depression and negative symptoms. Activities such as newspaper reading, exercise, walks, engaging in conversations, short games, simple vocational tasks serve as base intervention to help clients work through the negative symptoms [14]. Of course, this requires periodic review, feedback and use of reinforcers to motivate the client and maximize the chances of completing the task.

## COGNITIVE TECHNIQUES

Cognitive Therapy (CT), Cognitive Behaviour Therapy (CBT) and Metacognitive therapy (MCT)

Cognitive therapy and Cognitive behavioral therapy are standard of care techniques for anxiety spectrum disorders and dysphoric mood states. The principles of cognitive therapy revolves around dealing with dysfunctional thoughts (also called as negative automatic thoughts) arising due to cognitive errors/distortions such as over generalization, maximization, all or none thinking, personalization, control fallacies, jumping to conclusions etc. Identifying, challenging and restructuring these thoughts to arrive at more adaptive, rational and appropriate ones is the core process involved in CT/CBT. Journaling and imaginative exploration of worst case, best case and most likely scenarios empowers the client to independently manage their dysfunctional thoughts. The behavioural component of CBT therapies includes activity scheduling, role playing and relaxation primed exposure to experimental and real situations. People with severe mental illnesses may need such interventions to deal with co-morbid mood symptoms following insight in to illness, post schizophrenic depression and dealing with anxiety/panic related to persistent delusions / hallucinations [15][16].

**Exposure and Response Prevention** : A specific form of CBT in the treatment of OCD that requires client's to be exposed to triggers that generate the obsessions while therapists after preconditioning through relaxation prevents yielding to compulsions. Repeated such exposures bring down the intensity and duration of the post exposure anxiety till they become insignificant. Rehabilitation settings can facilitate better outcomes by ensuring frequent sessions, adequate monitoring and preventing compensatory behaviors post therapy. Cognitive therapy, distraction and thought stopping techniques may be used for predominant obsessions.

**Cognitive and Metacognitive therapy for delusions** : The technique focuses on reshaping patterns of distorted thinking, alternative thinking, guided discovery, and reality testing. Alternative explanations to the events other than the delusional explanation are weighed with each other. These techniques can reduce conviction related to the delusion and thereby the associated distress, helping the client to cope better and improve functioning [17]. Metacognitive approaches requires clients to learn and identify the cognitive distortions and guide them to objectively evaluate and critically reflect on the thinking process and change their current beliefs. Literature also supports its usefulness during prodrome and recovery. These methods can be beneficial during early signs of relapse. CT and MCT approaches can be used to challenge the emerging delusional beliefs [15] [16].

**CBT for Hallucinations** : This technique focuses on reducing the perceived power of voices rather than reducing the voices per se. This is specifically applicable in patients who have command hallucinations. The therapist here encourages the client to not yield to the instructions given by the voices by providing support through their presence and reassurance. The feared consequences such as, torture to self or others are challenged by demonstrating that the feared consequence did not occur despite defiance to the command [18]. A crucial element in CBT for psychotic symptoms is the client's trust in the therapist and a strong therapeutic alliance, else the venture may worsen the condition [18].

Distraction techniques can be a simple coping strategy to reduce the distress related to hallucinations. Distraction can be behavioural (carrying out a physical task - walking the pet, exercise, outdoor games etc.), cognitive (thinking differently and making self reassuring statements) or physiological which would be to seek different sensory stimuli (shower which

produces tactile sensations, watching TV - visual or even focusing on music, environmental sounds) [19]. Rational responding, schema based techniques and mindfulness have evidence base for use. Other methods such as attentional training, working with imagery, acceptance and commitment strategies, voice study and voice postponement strategies have shown some promise in reducing the awareness of and distress related to the hallucinations [20].

## **TRAINING INTERVENTIONS**

### **Occupational Therapy**

Occupational therapy as a method in the rehabilitation process developed in tandem with the vocational rehabilitation concept. While occupational therapy aims at engaging the client in activities that are therapeutic in nature and serves as a venue for skill assessment and development, the vocational rehabilitation focuses on the means to reach gainful employment. Occupational therapy found its place in Indian mental health settings as early as the 1920s at CIP, Ranchi. Occupational therapy consist of a series of simple activities using psychotherapy techniques such as developing creative expression, increasing communication skills, gaining insight, and supporting socialization. These practices include a wide variety of leisure time and sometimes skill based activities that are implemented under the leadership of persons specialized in the field [21]. Some of these activities such as painting, music, dancing, drama, handcrafts etc. easily fit into a behavioural activation program and the therapist encourages participation in the activities. These activities serve as an effective means of engaging the individual in an interest generating, often game based tasks to alleviate some of the symptoms, even in the acute conditions. Maintaining client engagement requires innovative activities that mandates creativity and assertiveness as therapist attributes. Infrastructure needs of a special practicing place, materials and trained human resource are likely to increase the investment costs [15].

### **ADL and IADL Training**

The activities of daily living (ADLs), a phrase coined by Sidney Katz in 1950 is a term used to collectively describe the fundamental skills required to independently care for oneself, such as eating, bathing, and mobility [22]. Instrumental activities of daily living (IADL) are those activities or skills that enable the individual to live independently in a community [23]. Both of these domains are affected to varying degrees in severe mental illness depending on the duration of illness and subtype of the illness. Training in ADL significantly reduces the caregiver burden. IADL on the other hand, looks at improving quality of life of the individual and facilitates better living conditions and employment opportunities. ADL training requires comprehensive inputs from psychology, occupational therapy and nursing care providers. It uses behavioural therapy techniques such as the shaping, chaining and reinforcement to inculcate the behavior [22]. The major domains of IADLs include cooking, cleaning, transportation, laundry, and managing finances which are trained through educational sessions, role plays and simulated settings [23]. Occupational therapists' role seem vital in determining the level of assistance the client requires and foster these skills for use during reintegration in to the community [24].

### **Cognitive Remediation and Retraining**

The concept of cognitive remediation and retraining has its origins in the treatment of post head injury clients. Extending such training programs for people with SMI was propelled by research identifying various subtle cognitive deficits in these individuals such as attention

deficits, working memory, verbal and visuo-spatial learning, planning, speed of processing and social cognition. Cognitive deficits have been identified as the lead contributing factor to cause disability levels in these individuals, even more than the persisting positive symptoms [25]. Cognitive remediation programs include tasks that when repeated at optimal intensity can produce enduring change. The words cognitive remediation and retraining are conceptually different with retraining focused on regaining of lost skills and remediation looking at utilizing existing skills better to compensate for lost skills. Neuroplasticity research indicate that the brain is capable of forming new connections provided the appropriate environmental stimulation is given [15] [25]. It is important to streamline cognitive tasks to ensure client's participation by keeping it interesting and relevant for their future needs. The nature of tasks may include computer-based, paper pencil based or even game based. Basic cognitive processes such as reacting quickly to stimuli and holding information in working memory are best trained through simple repetition of the tasks. Simple tasks such as grain sorting, letter cancellation, gaming cards based activities, Sudoku, Maze solving can be used to train in some of the cognitive process. These tasks can be based on computer programs such as Lumosity, Headapp etc. Higher level, complex cognitive tasks such as problem solving, planning and emotion recognition will need in-person therapy [15]. Neuropsychological Educational Approach to Cognitive Remediation (NEAR) is one such a program which can be applied across settings for people with SMI [26]. Meta-analysis by Wykes et al (2011) found cognitive remediation to be useful in improving overall functioning and reported stronger effects when such interventions are integrated with other rehabilitative inputs [27].

### **SOCIAL SKILLS TRAINING**

Bellack (2004) defined Social Skills as the 'interpersonal behaviours that are normative and/or socially sanctioned. They include such things as dress and behaviour codes, rules about what to say and not to say, and stylistic guidelines about the expression of affect, social reinforcement, interpersonal distance, and so forth' [28]. People with severe mental illness have social skill deficits as part of negative symptoms as well as positive symptoms. The core social skills such as the interactional skills, interpreting skills, responding and conveying skills play an important role in interpersonal relationships.

Bellack (2004) gave one of the manualised therapy model for enhancing social skills [28]. Components of such program would include initiating, maintaining, handling difficult questions and finishing a conversation. Conversation skills are broken down in to smaller components such as greeting, responding to questions, active listening skills, body language, use of open-ended questions, identifying emotions in others and learning appropriate reactions to the context [29][30]. Therapists can use tasks such as describing an object, say things in a different way for increasing word output, while role-plays and group activities can help promote turn taking during conversations [15][30]. Social skills training when incorporated in to various activities, coupled with group settings and simulated safe real-life situations using family and friends can facilitate easy transition and generalizability to real-life contexts. Therapist needs to individualize the program to provide inputs specific to the context, where the client is expected to communicate effectively after returning to the society [16][29][30]. A recent approach has been to target deficits in social cognition through training in emotion recognition tasks [31]. An Indian version of training of affect recognition (TAR) program demonstrated usefulness in such tasks thereby reducing misinterpretation during conversations [32].

## **VOCATIONAL TRAINING AND REHABILITATION**

Vocational rehabilitation programs in the community provide a series of graded steps to promote job entry or reentry [15]. Therefore, vocational rehabilitation has been a core element of psychiatric rehabilitation since its beginning. The three major approaches, i.e., supported employment, transaction employment and sheltered workshop serve a variety of client population under the umbrella of vocational rehabilitation. The supported employment (SE) or 'place and train' approach, is one of the most effective approaches in vocational rehabilitation. The patients under SE are placed in competitive employment according to their choices as soon as possible and receive continuous support to maintain their position. In transitional employment or 'train and place' approach, a temporary work environment is provided to teach vocational skills, which should enable the affected person to move on to competitive employment. Sheltered workshops or 'in-house training' approach, provides vocational training in a protected environment [33].

Having severe disabilities, poor motivation, non-availability of training centres, non-availability of suitable job and discrimination in work place are the common barriers for vocational rehabilitation program. Work place interventions such as awareness, errorless learning, spot training through support of family, co-workers and periodic inputs by vocational trainers can help maintain employed status for longer periods [4].

## **OTHER THERAPIES OF RELEVANCE IN REHABILITATION**

### **Adherence Therapy**

One of the major hurdles in treatment of mental illness is the compliance and adherence to medications. Compliance indicates the process of taking medications on regular basis. Adherence in contrast necessitates clients to stick to the prescribed format of medication/therapy. Lack of insight is the most common reason for such occurrence, besides stigma, medication side effects and myths about illness and treatment. Psychoeducation with aim to improve insight, motivational interviewing and cognitive behavioural approaches are sub components under this adherence therapy [15]. Adherence therapy involves recognizing patterns of medication use in the past, responding to client's beliefs (including normalizing of non-adherence behavior), helping clients link better functioning periods to when they have been adherent and adjusting medication doses and administration to suit client's situation. A good therapeutic alliance and collaborative decision-making involving client are crucial in this therapy. When cognitive deficits seem to be interfering in the process, involving support systems such as family, colleagues at work or local network can enhance medication adherence [15][34].

### **Supported Education**

The onset of most major mental illnesses occurs in the age of 20s. Mental illness disrupts these career developing, relationship forming and social networking years that are much needed for engaging in work and living meaningfully within their communities. Once disrupted, it is extraordinarily difficult to recreate the learning process. Supported Education programs help consumers pursue their individual educational goals. Offered in tandem with Supported Employment, these programs help consumers develop a sense of self-efficacy, independence and enable them to plan for their future. It provides an important step to help consumers use their innate talents and abilities to improve long-term work opportunities and pursue their personal recovery goals. Supported Education follows the "choose-get-keep" model, which helps consumers make choices about paths for education and training, get appropriate education and training opportunities, and keep their student status until they achieve their goals [35].

Collaboration with educational and training institutions facilitates this need-based education. Use of technology and online education platforms in the recent times have been able to provide self-paced learning opportunities. Volunteer groups who may have the expertise may be engaged for reviving the knowledge and skills lost during the illness.

## **SOCIOLOGICAL INTERVENTIONS - FOR REINTEGRATION**

### **Working with Families**

The onset of mental illness triggers major role changes in families that are not dissimilar to the role changes experienced by families of persons with other disabilities. In typical families, parents serve a crucial caregiving role for other family members. While this is particularly evident in the case of supporting young, dependent children, this caregiving role often extends to adult family members who need special support [7] [36].

Psychiatric Social workers (PSW) play a crucial role in supporting families through negotiating and clarifying with families the varied roles that they play. Professionals can be observant of the changing needs, abilities, and willingness of families and be assertive in suggesting and encouraging their assumption of new roles. Negative approaches from family are often a result of caregiver burden and burnout that need specific intervention. Negative expressed emotions when present need to be intervened through psychoeducation, reducing face-to-face time and communication training. Utilize families as collaborative adjuncts to a professional practice [7]. Most families want to work cooperatively, and both the professional and the disabled's family member will discover valuable benefits from such a collaborative relationship [36]. Periodic educational sessions covering topics such as crisis management, stress management, availability of welfare benefits and personal growth through caregiving helps families to learn more about the illness and support their ward effectively [15].

### **Peer Support and Peer Mediated Interventions**

Peer support refers to a framework of interactions in which patients with similar problems support each other emotionally and socially. People with SMI have a tendency to be alone and away from treatment settings. Peer support reassures the client that they are not alone in this and facilitate the initial step towards socialization as they feel less stigmatized. Peer influence and peer mediated learning can be tapped into for improving treatment compliance and better involvement in rehabilitative interventions [37]. Club house model, one of the pioneer approach in psychosocial rehabilitation is a classic example of peer driven service [7]. Peer support can be useful in providing skill training, vocational opportunities, reaching out for health services, getting welfare benefits, financial assistance, accommodation and such other services [15]. Peer mediated self-help groups can help participants share their experiences, get guidance from experienced patients and serve as co-therapist to each other and motivate in the recovery process [38].

### **Community Engagement in Psychiatric Rehabilitation**

Psychiatric rehabilitation programmes must involve the local community for successful reintegration of persons with mental illness. Working together with communities opens access to resources and support networks that are available in community to assist people with SMI [39]. Awareness raising campaigns and large-scale dissemination of knowledge and skills would help in reducing the stigma attached to illness [15]. An enlightened community can complement vocational training or placement, skills training, fund raising, accommodation,



endorse their products, accept people as valuable units of the community, and involve them in all social and cultural activities [39]. Extensive outreach activities, witnessing recovery of those affected and community engagement can increase referral by community members, acceptance by community, lessen the duration of stay and limit dropouts after community reintegration [15][40].

### **Supportive Therapy and After Care Services**

Rehabilitation process and reaching recovery point can be overwhelming, taxing and paved with various hurdles. Periodic advice, reassurance, guidance and ventilation are essential to ensure continued efforts at participating in the rehabilitative program. Reintegrating in to the community, though a positive and anticipated event in the process of recovery, can be quite taxing for a person with SMI due to the higher self, family and societal expectations from him/her. Unexpected life events and unanticipated hurdles may shake the client's confidence. Hence, providing support in the initial days of reintegration to reach the "recovery" point can reduce recidivism. Developing newer coping skills, identifying and dealing with stress/ stressful events, anticipating and planning for future can be some of the contents of such supportive sessions. After care services for SMI tend to reduce readmission rates [41].

### **Case Management and Assertive Community Treatment**

The main goal of case management (CM) is to provide practical assistance to the patient or an individual with SMI in areas such as drug acquisition or use, financial resource acquisition, provision, or retention of suitable sheltering environment, and when necessary, transportation to the hospital. Instead of conventional case management interventions conducted from health care settings, case management practices are conducted within communities in close contact with the patient and his/her living environment. The case manager serves as the link to the professional team to meet the client's needs as fast and effectively as possible. This method is particularly useful when client has little or no family support [15] [42].

Assertive community treatment (ACT) is an integrated community-based treatment method where the patient is regularly monitored in their own environment (home, community, workplace) and unlike case manager approach, is visited by a team of professionals consisting of a psychiatrist, a nurse, additional professionals as the need may be and a social worker. The case manager is also a member of this team who provides the 24x7 service for a given number of patients. Clients receive on-site intervention in case of any event or emergency and if felt necessary, hospitalized. In addition to their medical and psychological treatment requirements and personal needs such as shelter and food are met, their legal rights are secured, and effort is made to place them in jobs [15][43]. Both CM and ACT models have shown to reduce symptom severity, re-hospitalization, hospital stay, and homelessness and improve quality of life in general. Both methods are well established in western countries. Adopting to Indian context is challenged by lack of trained professionals, economic limitations and diverse socio-cultural settings and require local adaptations in order to ensure that the ventures are sustainable. Modified adaptations of ACT outreach programs can be found at programs run by MHAT Calicut [44] and Manipal Version of Assertive Community Treatment (M-ACT) at Manipal [45].

## **OTHER SPECIFIC THERAPEUTIC INTERVENTIONS**

### **Yoga**

Yoga, often described as a way of life, works at harmonizing the mind and body through maintaining certain body postures and coordinating it with breathing exercises. Yoga serves as both an exercise to make the body flexible as well as provide relaxation to the mind. Literature has shown that yoga as an adjunct to pharmacotherapy can be a useful tool in alleviating positive, negative as well as cognitive symptoms [46] [47]. In addition, yoga interventions seem to benefit client in terms of reducing antipsychotic induced weight gain [17].

### **Interpersonal and Social Rhythm Therapy (IPSRT)**

IPSRT, a therapy specifically designed for patients with Bipolar disorder is aimed at preventing relapse through enhancing skills in managing interpersonal problems and maintaining the biological and social rhythm. The therapy focuses on interpersonal relationship problems, role conflicts, relationship needs and loss-related problems. Usually introduced after an episode or while recovering from a depressive episode, the therapy also emphasizes on organizing day today activities to maintain a good physical and mental health. Fixed sleep-wake cycle, exercises, following a daily schedule, reorganizing one's daily routine, maintaining mood chart/diary, identifying, planning for and coping with triggers that may precipitate an episode are components of maintaining the social rhythm [15] [48].

### **Integrative Psychological Therapy (IPT) for schizophrenia**

IPT is a manualized cognitive behavioral group therapy program for schizophrenia patients (5-8 participants). It integrates concepts of cognitive remediation and social skills training to provide a comprehensive skill program aimed at improving functioning. It consists of 5 sub programs with increasing levels of complexity (Neurocognition, Social cognition, Communication, Social skills and Problem-solving skills) and to be administered sequentially. Participation in all IPT subprograms resulted in sustained benefits during the follow-up phase as compared to those who took only some of the components [15] [49].

### **Assisted Technology in Rehabilitation**

**Self Management Apps** : With advent of smartphones and digital diaries, technology can be used to track mood, sleep, biological rhythm disturbances and monitor for relapse. Smart planners help clients to work through the cognitive deficits and fulfill their commitments. Pill reminder system helps ensure compliance. Apps that produce white noise may help counter hallucination. Computer assisted CBT for dealing with anxiety, mood and recently even for delusions are available [50].

**AVATAR Therapy for Hallucinations** : Invented by Julian Leff in 2008, Audio Visual Assisted Therapy Aid for Refractory auditory hallucinations (AVATAR therapy) is a new technology assisted therapy that creates a digital representation (both auditory and visual representation - avatar) of their presumed persecutor. The therapist facilitates dialogue between the voice and the hearer by switching between the voice of avatar and the therapist and guides the hearer to gain power and control over the voices making it less threatening over time [51].

## CONCLUSIONS

Psychological and sociological interventions are vital components of any rehabilitation program aimed at functional improvement and best delivered through multidisciplinary team. Behavioural principles are the building blocks of most psychosocial interventions useful for learning and utilizing skills necessary for achieving larger goals in the rehabilitation process. Cognitive interventions build confidence, help monitor and manage difficult to treat symptoms by reducing distress and preoccupation related to the disturbing thoughts and voices. Client involvement and individualized interventions are crucial for achieving 'recovery' from client perspective. Family and community level interventions are the final steps in facilitating smooth reintegration in to the society. Frequent service utilizers may be incorporated into after care services such as long-term supportive therapy or integration into community based rehabilitation services. In conclusion, optimal outcomes require designing interventions at individual, family as well as community levels.

## TAKE HOME MESSAGE

- \* Rehabilitation involves more of non-pharmacological techniques requiring multi-disciplinary approach to deal with persistent symptoms.
- \* Components of Behavioural, Cognitive, Modeling and such other process of learning are used in various combinations to bring about change.
- \* Improvement in functioning and translation of gains in to real life settings takes time. Therapists need to persevere, be patient and learn to recognize small gains and provide positive feedback to motivate client further.
- \* Innovations in therapy components and service delivery such as use of technology, collaboration and personalization are needed to meet up to clients from varied socio-cultural backgrounds.

## REFERENCES

1. Rosenbloom M. Chlorpromazine and the Psychopharmacologic Revolution. *JAMA*. 2002;287(14):1860-1861. doi:10.1001/jama.287.14.1860-JMS0410-6-1
2. Brown P. The mental patients' rights movement and mental health institutional change. *Int J Health Serv*. 1981;11(4):523-40. doi: 10.2190/CU8G-D0RJ-YY54-UC3F. PMID: 7333723.
3. Botha UA, Koen L, Joska JA, Parker JS, Horn N, Hering LM, Oosthuizen PP. The revolving door phenomenon in psychiatry: comparing low-frequency and high-frequency users of psychiatric inpatient services in a developing country. *Soc Psychiatry PsychiatrEpidemiol*. 2010 Apr;45(4):461-8. doi: 10.1007/s00127-009-0085-6. Epub 2009 Jun 18. PMID: 19536445.
4. Ernst W. The role of work in psychiatry: Historical reflections. *Indian J Psychiatry*. 2018 Feb;60(Suppl 2):S248-S252. doi: 10.4103/psychiatry.IndianJPsychiatry\_450\_17. PMID: 29527056; PMCID: PMC5836346.
5. Rössler W. Psychiatric rehabilitation today: an overview. *World Psychiatry*. 2006 Oct;5(3):151-7. PMID: 17139342; PMCID: PMC1636112.
6. Howes, O.D., Thase, M.E. & Pillinger, T. Treatment resistance in psychiatry: state of the art and new directions. *Mol Psychiatry* 27, 58-72 (2022). <https://doi.org/10.1038/s41380-021-01200-3>

7. Warner R. Psychiatric Rehabilitation Methods. H.L. McQuiston et al. (eds.), Handbook of Community Psychiatry, (pp223-232). DOI 10.1007/978-1-4614-3149-7\_19, © Springer Science+Business Media, LLC 2012
8. Caruso R, Grassi L, Biancosino B, Marmai L, Bonatti L, Moscara M, Rigatelli M, Carr C, Priebe S. Exploration of experiences in therapeutic groups for patients with severe mental illness: development of the Ferrara group experiences scale (FE- GES). BMC Psychiatry. 2013 Oct 1;13:242. doi: 10.1186/1471-244X-13-242. PMID: 24083824; PMCID: PMC3851601.
9. McLeod, S. A. (2018, January, 21). Skinner - operant conditioning. Simply Psychology. [www.simplypsychology.org/operant-conditioning.html](http://www.simplypsychology.org/operant-conditioning.html)
10. Menon S. Psychosocial Rehabilitation : Current Trends. NIMHANS Journal Volume: 14 Issue: 04 October 1996 Page: 295-305
11. Hackenberg TD. Token reinforcement: a review and analysis. J Exp Anal Behav. 2009 Mar;91(2):257-86. doi: 10.1901/jeab.2009.91-257. PMID: 19794838; PMCID: PMC2648534.
12. Dickerson, F. B., Tenhula, W. N., & Green-Paden, L. D. (2005). The token economy for schizophrenia: review of the literature and recommendations for future research. Schizophrenia research, 75(2-3), 405-416.
13. Mairs H, Lovell K, Campbell M, Keeley P. Development and pilot investigation of behavioral activation for negative symptoms. BehavModif. 2011 Sep;35(5):486-506. doi: 10.1177/0145445511411706. Epub 2011 Jul 11. PMID: 21746764.
14. King R & Kavanagh DJ. Activation and Related Interventions. In King R, Lloyd C, Meehan T, Deane, FP, Kavanagh DJ. Manual of Psychosocial Rehabilitation. (First Edition, pp 95-109) Blackwell Publishing Ltd. Published 2012.
15. Yildiz, M. (2021). Psychosocial Rehabilitation Interventions in the Treatment of Schizophrenia and Bipolar Disorder. Archives of Neuropsychiatry, 58(Suppl 1), S77.
16. Morin L, Franck N. Rehabilitation Interventions to Promote Recovery from Schizophrenia: A Systematic Review. Front Psychiatry. 2017 Jun 12;8:100. doi: 10.3389/fpsy.2017.00100. PMID: 28659832; PMCID: PMC5467004
17. Ganguly P, Soliman A, Moustafa AA. Holistic Management of Schizophrenia Symptoms Using Pharmacological and Non-pharmacological Treatment. Front Public Health. 2018 Jun 7;6:166. doi: 10.3389/fpubh.2018.00166. PMID: 29930935; PMCID: PMC5999799.
18. Sommer IE, Slotema CW, Daskalakis ZJ, Derks EM, Blom JD, van der Gaag M. The treatment of hallucinations in schizophrenia spectrum disorders. Schizophr Bull. 2012 Jun;38(4):704-14. doi: 10.1093/schbul/sbs034. Epub 2012 Feb 24. PMID: 22368234; PMCID: PMC3577047
19. Hayward M. Evidence-based psychological approaches for auditory hallucinations: Commentary On... Auditory Hallucinations In Schizophrenia. BJPsych Advances; London Vol. 24, Iss. 3, (May 2018): 174-177. DOI:10.1192/bja.2017.11
20. Swyer A, Powers AR 3rd. Voluntary control of auditory hallucinations: phenomenology to therapeutic implications. NPJ Schizophr. 2020 Aug 4;6(1):19. doi: 10.1038/s41537-020-0106-8. PMID: 32753641; PMCID: PMC7403299
21. Schwartz, K. B. (2003). The history of occupational therapy. In E. B. Crepeau, E. S. Cohn, & B. A. B. Schell (Eds.), Willard and Spackman's occupational therapy (10th ed., pp. 5-13). Philadelphia: Lippincott, Williams & Wilkins
22. Edemekong PF, Bomgaars DL, Sukumaran S, et al. Activities of Daily Living. [Updated 2022 Jul 3]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK470404/>

23. Guo HJ, Sapra A. Instrumental Activity of Daily Living. 2021 Nov 21. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. PMID: 31985920.
24. John A, Gandhi S, Prasad MK, Manjula M. Effectiveness of IADL interventions to improve functioning in persons with Schizophrenia: A systematic review. *Int J Soc Psychiatry*. 2022 May;68(3):500-513. doi: 10.1177/00207640211060696. Epub 2021 Nov 22. PMID: 34802260.
25. Wykes, T., & van der Gaag, M. (2001). Is it time to develop a new cognitive therapy for psychosis--cognitive remediation therapy (CRT)? *Clinical Psychology Review*, 21(8), 1227-1256. [https://doi.org/10.1016/S0272-7358\(01\)00104-0](https://doi.org/10.1016/S0272-7358(01)00104-0)
26. Medalia, A. &Freilich, B. (2008). The Neuropsychological Educational Approach to Cognitive Remediation (NEAR) Model: Practice Principles and Outcome Studies. *American Journal of Psychiatric Rehabilitation*, 11(2), 123-143
27. Wykes T, Huddy V, Cellard C, et al. A meta-analysis of cognitive remediation for schizophrenia: methodology and effect sizes. 2011. In: Database of Abstracts of Reviews of Effects (DARE): Quality-assessed Reviews [Internet]. York (UK): Centre for Reviews and Dissemination (UK); 1995-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK81563/>
28. Bellack, A. S. (2004). Skills Training for People with Severe Mental Illness. *Psychiatric Rehabilitation Journal*, 27(4), 375-391. <https://doi.org/10.2975/27.2004.375.391>
29. Williams P L & Lloyd C. Social Skills and Employment. In King R, Lloyd C, Meehan T, Deane, FP, Kavanagh DJ. *Manual of Psychosocial Rehabilitation*. (First Edition, pp 137-151) Blackwell Publishing Ltd. Published 2012.
30. Mueser, K.T., Gottlieb, J.D. and Gingerich, S. (2013). Social Skills and Problem-Solving Training. In *The Wiley Handbook of Cognitive Behavioral Therapy*, S.G. Hofmann (Ed.). <https://doi.org/10.1002/9781118528563.wbcbt12>
31. Javed A and Charles A (2018) The Importance of Social Cognition in Improving Functional Outcomes in Schizophrenia. *Front. Psychiatry* 9:157. doi: 10.3389/fpsyt.2018.00157
32. Thonse U, Behere RV, Frommann N, Sharma P. Social cognition intervention in schizophrenia: Description of the training of affect recognition program - Indian version. *Asian J Psychiatr*. 2018 Jan;31:36-40. doi: 10.1016/j.ajp.2017.12.015. Epub 2017 Dec 27. PMID: 29358102.
33. McDowell C, Ennals P and Fossey E (2021) Vocational Service Models and Approaches to Improve Job Tenure of People With Severe and Enduring Mental Illness: A Narrative Review. *Front. Psychiatry* 12:668716. doi: 10.3389/fpsyt.2021.668716
34. Byrne MK & Deane P. Treatment Adherence..In King R, Lloyd C, Meehan T, Deane, FP, Kavanagh DJ. *Manual of Psychosocial Rehabilitation*. (First Edition, pp 123-134) Blackwell Publishing Ltd. Published 2012.
35. Unger, K. V. (2011). Evaluating Your Program. *Supported Education: A Promising Practice. Evidence-Based Practices KIT (Knowledge Informing Transformation). Substance Abuse and Mental Health Services Administration.*
36. Power, P. W., &Orto, A. E. D. (1986). Families, Illness & Disability. *Journal of Applied Rehabilitation Counseling*, 17(2), 41-44.
37. Solomon P. Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatr Rehabil J* 2004;27:392-401
38. Muralidharan A, Peeples AD, Hack SM, Fortuna KL, Klingaman EA, Stahl NF, Phalen P, Lucksted A, Goldberg RW. Peer and Non-Peer Co-Facilitation of a Health and Wellness Intervention for Adults with Serious Mental Illness. *Psychiatr Q*. 2021 Jun;92(2):431-442. doi: 10.1007/s11126-020-09818-2. PMID: 32794087; PMCID: PMC8059447.

39. Killaspy H, Harvey C, Brasier C, Brophy L, Ennals P, Fletcher J, Hamilton B. Community-based social interventions for people with severe mental illness: a systematic review and narrative synthesis of recent evidence. *World Psychiatry*. 2022 Feb;21(1):96-123. doi: 10.1002/wps.20940. PMID: 35015358; PMCID: PMC8751572.
40. Saha, S., Chauhan, A., Buch, B., Makwana, S., Vikar, S., Kotwani, P., & Pandya, A. (2020). Psychosocial rehabilitation of people living with mental illness: Lessons learned from community-based psychiatric rehabilitation centres in Gujarat. *Journal of family medicine and primary care*, 9(2), 892.
41. Berekatani M, Maracy MR, Rajabi F, Baratian H. Aftercare services for patients with severe mental disorder: A randomized controlled trial. *J Res Med Sci*. 2014 Mar;19(3):240-5. PMID: 24949032; PMCID: PMC4061646.
42. ?ncedere A, Y?id?z M. Case Management for Individuals with Severe Mental Illness: Outcomes of a 24-Month Practice. *Turk PsikiyatriDerg* 2019;30:245- 252
43. Bond GR, Drake RE, Mueser KT, Latimer E. Assertive community treatment for people with severe mental illness: Critical ingredients and impact on clients. *Dis Manag Health Out* 2001;9:141-159
44. Kumar, T. (2018). Community psychiatry-Transcontinental lessons of the last quarter century. *Indian Journal of Social Psychiatry*, 34(4), 292-295. doi: 10.4103/ijsp.ijsp\_75\_18
45. Arahantabailu P, Purohith AN, Kanakode R, Praharaj SK, Bhandary RP, VenkataNarasimha Sharma PS. Modified assertive community treatment program for patients with schizophrenia: Effectiveness and perspectives of service consumers from a South Indian setting. *Asian J Psychiatr*. 2022 Jul;73:103102. doi: 10.1016/j.ajp.2022.103102. Epub 2022 Apr 6. PMID: 35452965.
46. Gangadhar N, Varambally S. Yoga therapy for schizophrenia. *Int J Yoga*. (2012) 5:85-91. doi: 10.4103/0973-6131.98212
47. Paikkatt, B., Singh, A., Singh, P., Jahan, M., & Ranjan, J. (2015). Efficacy of Yoga therapy for the management of psychopathology of patients having chronic schizophrenia. *Indian Journal of Psychiatry*, 57(4), 355-360. doi: 10.4103/0019-5545.171837
48. Frank E, Kupfer DJ, Thase ME, Mallinger AG, Swartz HA, Fagiolini AM, Grochocinski VJ, Houck P, Scott J, Thompson W, Monk T. Two-year outcomes for interpersonal and social rhythm therapy in individuals with bipolar I disorder. *Arch Gen Psychiatry* 2005;62:996-1004.
49. Roder V, Mueller DR, Schmidt SJ. Effectiveness of integrated psychological therapy (IPT) for schizophrenia patients: a research update. *Schizophr Bull*. 2011 Sep;37Suppl 2(Suppl 2):S71-9. doi: 10.1093/schbul/sbr072. PMID: 21860050; PMCID: PMC3160121.
50. Ben-Zeev, D., Davis, K. E., Kaiser, S., Krzsos, I., & Drake, R. E. (2013). Mobile Technologies Among People with Serious Mental Illness: Opportunities for Future Services. *Administration and Policy in Mental Health*, 40(4), 340-343
51. Leff J, Williams G, Huckvale M, Arbuthnot M, Leff AP. Avatar therapy for persecutory auditory hallucinations: what is it and how does it work? *Psychosis PsycholSocIntegr Approaches*. 2014;6(2):166-176. doi:10.1080/17522439.2013.773457.

## SCALES IN REHABILITATION PSYCHIATRY

Rajshekhar Bipeta<sup>1\*</sup>, Aditya Kashyap<sup>2</sup>, Madhur M Rathi<sup>3</sup>

### INTRODUCTION

A complete assessment is paramount before undertaking any intervention [1]. The assessment needs to be multifaceted and multidisciplinary in terms of interventions like psychiatric rehabilitation. It needs to consider the factors related to the patient, illness, support groups, including family and caregivers, and the community to which the patient belongs. Some of the core values of the assessment for rehabilitation include- working with the patient for personally relevant goals, collaborating with the stakeholders, and decision making [2]. Different psychiatric rating scales play a vital role in evaluating various factors related to psychiatric rehabilitation ranging from patient assessment to the community. 90% of Indian patients live with their families [3]. Families play an essential role in providing for the patient's basic, emotional, and financial needs. Families also play a significant role in treatment-related decisions (when, where to take treatment, rehabilitation- employment, marriage) [4]. It is essential to work closely with the families of the patient while working on rehabilitation.

Assessment in psychiatric rehabilitation involves different domains [5] at the following levels: 1. Patient 2. Family 3. Rehabilitation Setting 4. Community. Rehabilitation assessment is not a one-time process. Furthermore, it is a dynamic and continuous process. Multiple social factors influence the patient's needs and goals. Hence, it is necessary to be in constant touch and make appropriate modifications. The management cycle specified in the 'World Health Organization - Community Based Rehabilitation' guideline helps to conceptualize the dynamic process. It gives an example of 4 steps [6].

1. Situation Analysis
2. Planning and Design
3. Implementation and Monitoring
4. Evaluation

**The subsequent paragraphs describe some salient assessment tools used in psychiatric rehabilitation.**

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

\* Corresponding Author

1. Professor of Psychiatry and Deputy Superintendent, Institute of Mental Health, Department of Psychiatry, Osmania Medical College, Hyderabad, Telangana. e.mail : braj111@yahoo.co.in
2. Senior Resident of Psychiatry, Department of Psychiatry, Government Medical College, Siddipet, Telangana.
3. Senior Resident of Psychiatry, Institute of Mental Health, Department of Psychiatry, Osmania Medical College, Hyderabad, Telangana.

**ASSESSMENT TOOLS AT THE LEVEL OF THE PATIENT****Tools for assessing psychiatric rehabilitation needs**

1. The Camberwell assessment of needs (CAM)
  - \* Introduced in the UK in 1980 [7]
  - \* Licensed tool
  - \* Translated for use in different Indian populations, but limited utility in the Indian context.
  - \* 22 items
  - \* Interviewer rated
  - \* Two versions for clinical use and research use - CAM-C, CAM- R
  - \* Good face validity, criterion validity. [8]
  - \* Low test-retest reliability.
2. The Rehabilitation Needs Assessment Schedule (RNAS)
  - \* Developed by SCARF, Chennai
  - \* Eight domains include employment, vocational training, leisure activity, psychosocial attitude modification, and skill training. [9]
3. Supplementary Needs Assessment Schedule (SNAS)
  - \* Developed by PGIMER, Chandigarh
  - \* Includes domains relevant to the Indian population - free treatment, insurance, more time with a clinician, social support, travel concession, etc. [10]

**Tools for Assessment of Disability**

1. World Health Organization Disability Assessment Scale (WHODAS)
  - \* High reliability
  - \* Current version WHODAS 2.0 [11]
  - \* It has two versions - 36 items (self-report) version and 12 items short version.
  - \* Six major domains scored from 0 to 4
  - \* Two scoring systems - simple and complex
2. Indian Disability Evaluation and Assessment Scale (IDEAS)
  - \* Developed by the Rehabilitation subcommittee of Indian Psychiatric Society in 2001 [12]
  - \* Addresses 4 areas- self-care, interpersonal activities, communication and understanding, work
  - \* Each item rated from 0-4
  - \* Good internal consistency, face / content / construct and criterion validity [13]



3. The NIMHANS Index for SLD

- \* Developed by the department of clinical psychology at NIMHANS in 1991
- \* It consists of tests of reading, writing, spelling, and arithmetic abilities
- \* Two levels - level 1 (5-7 years), level 2 (8-12 years)
- \* Adequate psychometric properties [14]

**Tools for Functional Assessment**

1. Client's assessment of strengths, interests, and goals (CASIG)

- \* Interviewer administered tool
- \* Assesses treatment outcomes [15]
- \* Two parallel versions - one for the client's self-report and one for the informant's report.

2. Independent living skills inventory (ILSI)

- \* Evaluates different skills necessary for living within a community.
- \* It covers four major areas- selecting an independent living situation, setting up an independent living situation, surviving in an independent living situation, and a training model to implement training in any of those areas. [16]

3. Nurses Observation Scale for Inpatient Evaluation (NOSIE)

- \* Developed in 1965 [17]
- \* Tracks client's behavior during hospitalization
- \* Thirty behaviors are scored for frequency of occurrence over the past three days.
- \* Easy to administer, easy to use.

4. Global Assessment of Functioning (GAF)

- \* Developed to rate the axis 5 of DSM 4
- \* Clinician rated [18]
- \* On 100 points scale, ratings are made for the past week.
- \* No prior training is required.
- \* Limitation- excessive focus on symptoms.

**Tools for Assessment of Recovery**

1. Recovery star

- \* It contains ten areas covering different aspects of life
- \* Underpinned by a five-stage journey of change model.
- \* Copyrighted tool. [19]

**Quality of Life**

1. World Health Organisation Quality of Life (WHOQOL)
  - \* Two standardized instruments
  - \* WHOQOL 100 - 6 Domains with 24 facets in all, each facet has four items, each item scored from 1 to 5
  - \* WHOQOL - BREF - has 26 items scored across four domains - physical health, psychological health, social relationships, and environment.
  - \* They are validated across cultures and disabilities.
  - \* Available for use in 20 languages. [20]
2. Quality of Life Scale
  - \* The QLS is a 21-item scale
  - \* Semi-structured interview.
  - \* Developed for assessment of deficit symptoms in schizophrenia [21]

**Tools for Vocational Assessment**

1. Vocational Assessment Tool for Substance Use Disorder (VATSUD)
  - \* NIMHANS developed a vocational Assessment Tool for Substance Use Disorder.
  - \* Employs multiple questions across five domains marked on 5 points being always/ frequent/ occasional/ rarely or none.
  - \* It is brief and has good validity and high reliability [22]
2. Work rehabilitation Questionnaire (WORQ)
  - \* Work rehabilitation Questionnaire was developed based on ICF (the International Classification of Functioning, Health, and Disability) [23].
  - \* It has good reliability.
  - \* Two versions, interviewer rated and patient-rated.

**Tools for assessment of Social Skills**

1. The SCARF Social Functioning Index (SSFI)
  - \* Assesses functioning across four domains, including self-care, occupational role, role in the family, and other social roles.
  - \* The items are rated on a 5-point scale.
  - \* Available in English and Tamil
  - \* It can be used by grass roots - level mental health workers [24].
2. NIMHANS Social Skills Assessment Proforma
  - \* It is a 20-item questionnaire spanning three domains.
  - \* The items are rated as either adequate or inadequate.
  - \* It has two questions that evaluate the client/ caregiver's perspective on the need for social skills training.
  - \* The response may be interviewer rated, based on observation or review of case files [25]

**Tools for assessment of stigma**

1. The internalized stigma of the mental illness scale (ISMI)
  - \* It consists of 29 items organized into five domains: stereotype endorsement, social withdrawal, discrimination experience, alienation, and stigma resistance. [26]
  - \* Used worldwide for Mental illness, AIDS, leprosy, etc

**Tools for assessment of medication side effects**

1. Abnormal Involuntary Movement Scale (AIMS)
  - \* 12-item clinician-rated scale
  - \* Assesses severity of dyskinesias
  - \* The items are rated on a 5-point severity scale.
  - \* It assesses oro-facial as well as extremity/truncal movements.
  - \* It also qualifies the overall severity, incapacitation, and the patient's level of awareness of the movements and distress associated with them. [27]
2. Simpson Angus Rating Scale for Extrapyramidal side effects
  - \* Interviewer rated 10 item scale
  - \* Rated on a 5-point scale from 0 to 4 [28].
  - \* The final score is given as a mean of the score on the ten individual items.
  - \* A cut-off of 0.3 is used for the diagnosis of extrapyramidal side effects.
  - \* It has good reliability and validity.
3. Barnes Akathisia Rating Scale (BARS)
  - \* The interviewer administers the scale.
  - \* It looks at three domains: the objective component, the subjective component, and a global clinical assessment of akathisia [29].
4. Glasgow Antipsychotic Rating Scale (GASS)
  - \* It is a 22-item self-report tool for identifying antipsychotic medication-related side effects.
  - \* A score of 21 is used as a cut-off for side effects.
  - \* It covers a range of side effects including cardiovascular/ genitourinary/ central nervous system/ anticholinergic/ hyperprolactinemia/diabetes/weight gain/ gastrointestinal and extra pyramidal side effects [30].
  - \* A valid and reliable tool.

## **ASSESSMENT TOOLS AT THE LEVEL OF FAMILY**

### **Tools for Assessment of Family Burden and Distress**

1. Scales for Assessment of Family Distress (SAFD)
  - \* This scale was developed in NIMHANS
  - \* An excellent tool to gauge the family distress differentially across symptoms.
  - \* It has 26 questions/items, organized into eight categories of symptoms of mental health conditions.
  - \* This scale can be a self-report from the caregiver/family member or can be administered by the rater.
  - \* The scale allows for a family member to report distress related to symptoms with a score ranging from 0 to 100, with 100 being very distressing.
  - \* The scale also has a 5-point Likert scoring for each item.
2. Burden Assessment Schedule (BAS)
  - \* The BAS was developed jointly by the Department of Psychiatry, Government General Hospital and SCARF, Chennai, India [31].
  - \* It has 40 items categorized into nine factors that can be graded from 1 to 3, with higher scores indicating higher frequencies of distressing/demanding situations.
  - \* This scale aims to identify burnout in caregivers early on in caring for persons with mental illness.

### **TOOLS FOR ASSESSMENT OF EXPRESSED EMOTIONS**

1. The Camberwell Family Interview
  - \* It was developed to assess expressed emotion in family members of persons with mental illnesses [32].
  - \* It assesses the three domains of criticality, hostility, and extreme emotional over-involvement.
  - \* The caregiver is considered to have high expressed emotion if he/she rates one or higher on the scale hostility, or six or more critical utterances, or rates three or higher on the emotional over-involvement scale.

### **TOOLS FOR ASSESSMENT AT THE LEVEL OF A REHABILITATION FACILITY**

#### **Tools to assess staff competency**

1. The competency assessment instrument (CAI)
  - \* It has 55 items over 15 sub-scales, each assessing a particular provider competency.
  - \* It has shown good inter-rater and test-retest reliability [33].
  - \* It covers a wide range of competencies and has good validity.
  - \* The average time taken to complete it was found to be 18 minutes, which ensures it is used even in busy centers.

2. The Recovery Knowledge Inventory
  - \* It was developed to assess the knowledge and attitudes of mental health care/ rehabilitation service providers towards recovery-oriented practices [34].
  - \* It is a 20 item tool that explores the different domains of recovery.
  - \* The staff responses on this scale gauge their belief/knowledge about recovery.
  - \* It finds use in the training of mental health/ rehabilitation professionals.
3. The Recovery self-assessment - Provider Version
  - \* It is a 36 item tool, rated on a 5 point scale ranging from strongly disagree to agree [35] strongly.
  - \* Five domains are covered: Life goals versus symptom management; Diversity of treatment options; Consumer involvement and Recovery education; Rights and Respect and Individually tailored services.
  - \* It is used to facilitate reflections on the strengths and limitations of service amongst providers.

#### **TOOLS TO ASSESS THE RECOVERY FOCUS OF AN AGENCY**

1. Elements of a Recovery Facilitating System (ERFS)
  - \* It is a 20 item self-administered questionnaire.
  - \* It helps to distinguish recovery-oriented services from traditional models.
  - \* The items encompass four domains of recovery oriented services: person-centered, consumer-driven, community-focused, and accessible / integrated. It has separate questionnaires for adults and children/youth.

#### **FIDELITY SCALES**

1. The fidelity scale for individual placement and support
  - \* This 15 item scale was developed to check the extent to which vocational rehabilitation programs adhered to the Individual Placement and Support (IPS) model of supported employment [36].
  - \* A trained interviewer administers it.
  - \* High inter-rater reliability.
  - \* The scale can also differentiate IPS models from other supported employment models.

#### **TOOLS FOR ASSESSMENT AT THE LEVEL OF COMMUNITY**

1. WHO - Assessment instruments for mental health services.
  - \* It is a tool for collecting essential information about the mental health systems of a region.
  - \* Mental health systems include all activities aimed at promoting, restoring, and maintaining mental health.
  - \* The revised version of this tool, the WHOAIMS2.2, looks at six domains [37].
  - \* This information is used to improve mental health systems and track changes.

**REFERENCES**

1. Thanapal S, Sudheer N, Philip S, Chaturvedi S. Assessment tools in psychiatric rehabilitation [Internet]. [www.researchgate.net](http://www.researchgate.net). 2021 [cited 28 September 2022]. Available from: [https://www.researchgate.net/publication/348187393\\_ASSESSMENT\\_TOOLS\\_IN\\_PSYCHIATRIC\\_REHABILITATION](https://www.researchgate.net/publication/348187393_ASSESSMENT_TOOLS_IN_PSYCHIATRIC_REHABILITATION)
2. Principles and practice of psychiatric rehabilitation: Second Edition: An empirical approach [Internet]. Guilford Press. [cited 28 September 2022]. Available from: <https://www.guilford.com/books/Principles-and-Practice-of-Psychiatric-Rehabilitation/Patrick-Corrigan/9781462526215/reviews>
3. Isaac M. Cross-cultural differences in caregiving: The relevance to community care in India. *Indian J Soc Psychiatry*. 2016;32(1):25.
4. Thara R, Padmavati R, Srinivasan TN. Focus on psychiatry in India. *Br J Psychiatry*. 2004;184(4):366-73.
5. Anthony WA, Farkas M. A Primer on the Psychiatric Rehabilitation Process [Internet]. Boston: Centre for Psychiatric Rehabilitation, Boston University; 2009 [cited 28 September 2022]. 49 p. Available from: [https://www.researchgate.net/publication/267161886\\_A\\_Primer\\_on\\_the\\_Psychiatric\\_Rehabilitation\\_Process](https://www.researchgate.net/publication/267161886_A_Primer_on_the_Psychiatric_Rehabilitation_Process)
6. WHO | Community Based Rehabilitation (CBR) [Internet]. WHO. [cited 28 September 2022]. Available from: <http://www.who.int/disabilities/publications/cbr/en/>
7. Marshall M, Hogg LI, Gath DH, Lockwood A. The Cardinal Needs Schedule--a modified version of the MRC Needs for Care Assessment Schedule. *Psychol Med*. 1995;25(3):605-17.
8. Phelan M, Slade M, Thornicroft G, Dunn G, Holloway F, Wykes T, et al. The Camberwell Assessment of Need: the validity and reliability of an instrument to assess the needs of people with severe mental illness. *Br J Psychiatry J Ment Sci*. 1995;167(5):589-95.
9. Nagaswami V, Valecha V, Thara R, Rajkumar S, Menon MS. Rehabilitation needs of schizophrenic patients - a preliminary report. *Indian J Psychiatry*. 1985;27(3):213-20.
10. Grover S, Avasthi A, Shah S, Lakdawala B, Chakraborty K, Nebhinani N, et al. Indian Psychiatric Society multicentric study on assessment of health-care needs of patients with severe mental illnesses as perceived by their family caregivers and health-care providers. *Indian J Psychiatry*. 2015;57(2):181-9.
11. WHO | WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) [Internet]. WHO. [cited 28 September 2022]. Available from: <http://www.who.int/classifications/icf/whodasii/en/>
12. Guidelines for the purpose of assessing the extent of specified disability in a person included under the Rights of Persons with Disabilities Act, 2016 (49 of 2016) [Internet]. Available from: <http://www.swavlambancard.gov.in/public/files/ProceduresGuidelines.pdf>
13. Grover S, Shah R, Kulhara P, Malhotra R. Internal consistency & validity of Indian Disability Evaluation and Assessment Scale (IDEAS) in patients with schizophrenia. *Indian J Med Res*. 2014;140(5):637-43.
14. Panicker AS, Bhattacharya S, Hirisave U, Nalini NR. Reliability and Validity of the NIMHANS Index of Specific Learning Disabilities. *Indian J Ment Heal*. 2015;2(2):175.
15. Wallace CJ, Lecomte T, Wilde J, Liberman RP. CASIG: a consumer-centered assessment for planning individualized treatment and evaluating program outcomes. *Schizophr Res*. 2001;50(1-2):105-19.

16. Vogelsberg RT, Anderson J, Berger P, Haselden T, Mitwell S, Schmidt C, et al. Programming for Apartment Living: A Description and Rationale of an Independent Living Skills Inventory. *J Assoc Sev Handicap*. 1980;5(1):38-54.
17. Nurses Observation Scale for Inpatient Evaluation (NOSIE): Psychometric Properties [Internet]. [cited 28 September 2022]. Available from: [http://currentnursing.com/pn/nurses\\_observation\\_scale\\_for\\_inpatient\\_evaluation.html](http://currentnursing.com/pn/nurses_observation_scale_for_inpatient_evaluation.html)
18. Aas IM. Guidelines for rating Global Assessment of Functioning (GAF). *Ann Gen Psychiatry*. 2011;10(1):2.
19. Recovery Star | Mental Health Partnerships [Internet]. [cited 28 September 2022]. Available from: <https://mentalhealthpartnerships.com/resource/recovery-star/>
20. WHO | The World Health Organization Quality of Life (WHOQOL) [Internet]. WHO. [cited 28 September 2022]. Available from: [http://www.who.int/mental\\_health/publications/whoqol/en/](http://www.who.int/mental_health/publications/whoqol/en/)
21. Heinrichs DW, Hanlon TE, Carpenter WT. The Quality of Life Scale: an instrument for rating the schizophrenic deficit syndrome. *Schizophr Bull*. 1984;10(3):388-98.
22. Sethuraman L, Subodh BN, Murthy P. Validation of vocational assessment tool for persons with substance use disorders. *Ind Psychiatry J*. 2016;25(1):59-64.
23. Finger ME, Escorpizo R, Bostan C, De Bie R. Work Rehabilitation Questionnaire (WORQ): development and preliminary psychometric evidence of an ICF-based questionnaire for vocational rehabilitation. *J Occup Rehabil*. 2014;24(3):498-510.
24. Padmavathi R, Thara R, Srinivasan L, Kumar S. Scarf social functioning index. *Indian J Psychiatry*. 1995;37(4):161-4.
25. Bholra P, Basavarajappa C, Guruprasad D, Hegde G, Khanam F, Thirthalli J, et al. Development of a Social Skills Assessment Screening Scale for Psychiatric Rehabilitation Settings: A Pilot Study. *Indian J Psychol Med*. 2016;38(5):395-403.
26. Boyd JE, Adler EP, Otilingam PG, Peters T. Internalized Stigma of Mental Illness (ISMI) Scale: A multinational review. *Compr Psychiatry*. 2014;55(1):221-31.
27. 38. Lane RD, Glazer WM, Hansen TE, Berman WH, Kramer SI. Assessment of tardive dyskinesia using the Abnormal Involuntary Movement Scale. *J Nerv Ment Dis*. 1985;173(6):353-7.
28. 39. Simpson GM, Angus JW. A rating scale for extrapyramidal side effects. *Acta Psychiatr Scand*. 1970; 212:11-9.
29. 40. Barnes TRE. A Rating Scale for Drug-Induced Akathisia. *Br J Psychiatry*. 1989;154(05):672-6.
30. 41. Waddell L, Taylor M. A new self-rating scale for detecting atypical or second-generation antipsychotic side effects. *J Psychopharmacol (Oxf)*. 2008;22(3):238-43.
31. Thara R, Padmavati R, Kumar S, Srinivasan L. Instrument to assess burden on caregivers of chronic mentally ill. *Indian J Psychiatry*. 1998;40(1):21-9.
32. Brown GW, Birley JL, Wing JK. Influence of family life on the course of schizophrenic disorders: a replication. *Br J Psychiatry J Ment Sci*. 1972; 121(562):241-58.
33. Chinman M, Young AS, Rowe M, Forquer S, Knight E, Miller A. An Instrument to Assess Competencies of Providers Treating Severe Mental Illness. *Ment Health Serv Res*. 2003;5(2):97-108.
34. Pedregal LE, O'Connell M, Davidson L. The Recovery Knowledge Inventory: Assessment of Mental Health Staff Knowledge and Attitudes about Recovery. *Psychiatr Rehabil J*. 2006;30(2):96-103.

35. O'Connell M, Tondora J, Croog G, Evans A, Davidson L. From rhetoric to routine: assessing perceptions of recovery-oriented practices in a state mental health and addiction system. *Psychiatr Rehabil J*. 2005;28(4):378-86.
36. Bond GR, Becker DR, Drake RE, Vogler KM. A fidelity scale for the Individual Placement and Support model of supported employment. *Rehabil Couns Bull*. 1997;40(4):265-84.
37. WHO | WHO-AIMS Instrument Version 2.2 [Internet]. WHO. [cited 28 September 2022]. Available from: [https://www.who.int/mental\\_health/publications/who\\_aims\\_instrument/en/](https://www.who.int/mental_health/publications/who_aims_instrument/en/)



## IMPLEMENTING EARLY INTERVENTION FOR AUTISM IN INDIA - CURRENT STATUS

Supreeta Santosh\*<sup>1</sup>, Athira N.D\*<sup>1</sup>, Sathya Lakshmi P.S\*<sup>1</sup>, Sowmyashree MayurKaku<sup>1</sup>, Nirupama Srikanth<sup>1</sup>, Ashok MV<sup>1,2</sup>

### SUMMARY

With the increasing recognition of autism, the need for providing for Early Intervention (EI) is of paramount importance. Translation of guidelines and initiatives into implementation is an on-going challenge. We present the current Indian scenario of EI in Autism Spectrum Disorders (ASD) -the nature of available interventions, the challenges and highlight potential models of care and the requisite downstream process to enable their implementation across the country. Articles from online sources published between 2012 to 2020 were evaluated using keywords; finally, 10 articles were reviewed, and we grouped the interventions into 3 categories - Parent Mediated (PMI), Centre-Based Interventions and a combination of both. Parent Mediated Interventions are preferred by many Institutions to overcome the lack of availability of trained professionals. Upscaling efforts of one EI model - the ComDEALL model is noted. Evaluation of task shifting approaches has been suboptimal, but promising. A clear increase in deliberations focus on public health in ensuring wider availability of services for children with ASD is evident. However, evidence-based models for programmatic implementation are lacking. Government initiatives such as the RBSK will need to use task shifting models to achieve efficiency. In this regard, implementation studies of evidence -supported EI models of care are necessary. It is too early to predict the effectiveness of digital modes of intervention though they carry intuitive appeal. We must adopt locally relevant comprehensive models that can be upscaled to a larger population. Community health workers/ nurses can be options to provide manualised EI, especially in non-urban areas.

### IMPLEMENTING EARLY INTERVENTION FOR AUTISM IN INDIA - CURRENT STATUS

Autism Spectrum Disorders (ASD) is a neuro-developmental disorder, symptoms of which typically are noticed before 3 years of age. Children with ASD develop uniquely in contrast to typically developing children and those with global developmental delay [1] and have delays in language, social, and cognitive skills [2]. They have difficulty understanding figurative language, making friends and social interaction, but they also might be good at solving puzzles, math, and computer problems [3]. On the other hand, children with global developmental delays often show fairly uniform delays in all aspects of development [4]. The varied delays in different aspects of development make ASD unique and complex.

There is an agreement that the prevalence of reported ASD is increasing globally. Improved awareness, broadening of diagnostic criteria, better diagnostic tools and improved reporting,

---

Disclosure Statement : The authors Supreeta Santosh, Athira N.D, Sathya Lakshmi P.S, Sowmyashree Mayur Kaku, Nirupama Srikanth and Ashok M.V declare that they have no financial interests to disclose. We wish to state that we use the Com DEALL intervention model for Early Intervention at CAREADD. NirupamaSrikanth had worked as a Clinical Co-ordinator and Master Trainer at The Com DEALL Trust till 2014. There was no role of any funding agency for this work.

\*All contributed equally.

1. Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CAREADD), St. John's Medical College Hospital, Bangalore, India.
2. Department of Psychiatry, St. John's Medical College Hospital, Bangalore, India.

maybe possible explanations for this apparent increase in the rate of ASD [5]. An estimated 1 in 270 children have ASD worldwide (6). A recent publication estimates that about 1 in 100 children in India under the age of 10 could have ASD [7].

ASD can potentially be detected from even 6-18 months of age. A diagnosis of ASD by an experienced professional by age 2 can be considered very reliable [8]. However, most children do not get a final diagnosis until they turn much older [9]. ASD needs assessments by a multidisciplinary team (10) to ensure that children receive services and support to reach their full potential, monitoring, screening, evaluating, and diagnosing children at the earliest possible age [11]. For children who are at high risk (due to pre-term birth, low birth weight, or other risk factors such as having a sibling with developmental delays), systematic surveillance is essential [12].

WHO states that rehabilitation refers to interventions designed to optimize functioning and reduce disability in individuals with health conditions, in their interactions with their environment. It is a fundamental component of healthcare. Children with physical, mental, intellectual, or sensory impairments may benefit substantially from rehabilitation which in turn optimizes participation in life activities and well-being. To provide holistic care for such children and adolescents, an eclectic approach employing a multidisciplinary team which allows collaboration between professionals is required to provide consultations, problem-focused services, therapy services, education, mentorship, and support. Intuitively and based on clinical experience as well as some published evidence, Early Intervention is believed to make a significant positive impact on outcomes in ASD and lessen the need for later active rehabilitative efforts.

As alluded to, in the previous paragraph, evidence exists that early diagnosis leading to early intervention has better long-term outcomes, as well as improved quality of life, not just for the child but for the entire family [13][14]. Early intervention (EI) happens at or before preschool, as early as two or three years of age. It takes advantage of the brain's plasticity and critical period of learning, which provides intervention methods with a higher probability of achieving longer-term effectiveness [15].

In most parts of India, parents are forced to move from one place to another to access varied components of EI services. In the absence of quality services for such young children, they are advised to come later when they become older, thus missing the critical period of development. The adverse effect of failing in early identification and early intervention can lead to irreversible developmental damage [16]. Ideally, an Early Intervention (EI) curriculum should have components demonstrated in figure 1.

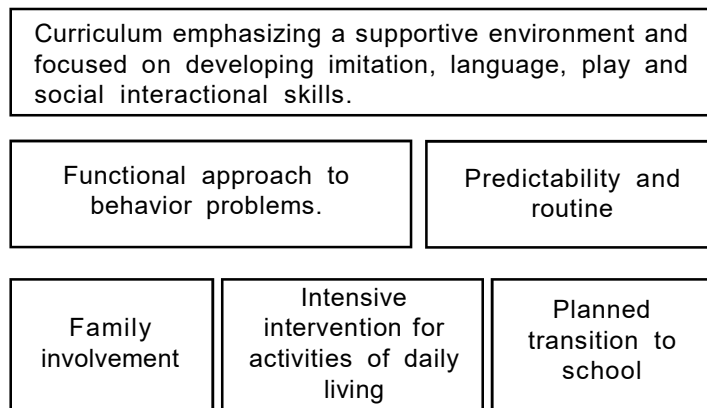


Fig. 1: Components of an early intervention curriculum ((As per MoHFW, Setting up DEICS, Reference 20).

The Rehabilitation Council of India has laid out operational guidelines enlisting what constitutes an Early Intervention Centre and its workings. Figure 2 explains the services to be provided by the EI centre. Even though the concept of EI is evolving in India, intervention relies on a chain of events which, at the current time, is much broken and lacking.

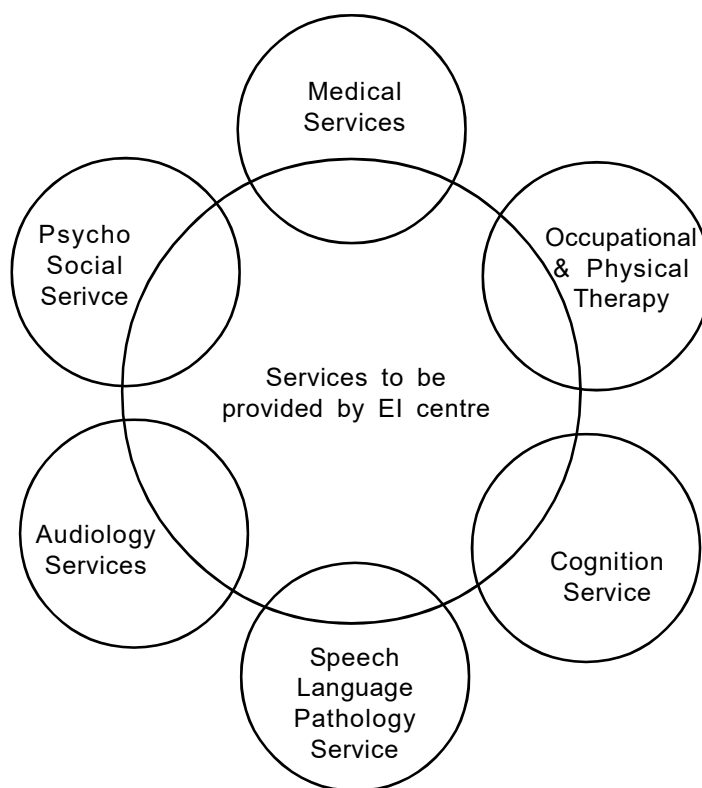
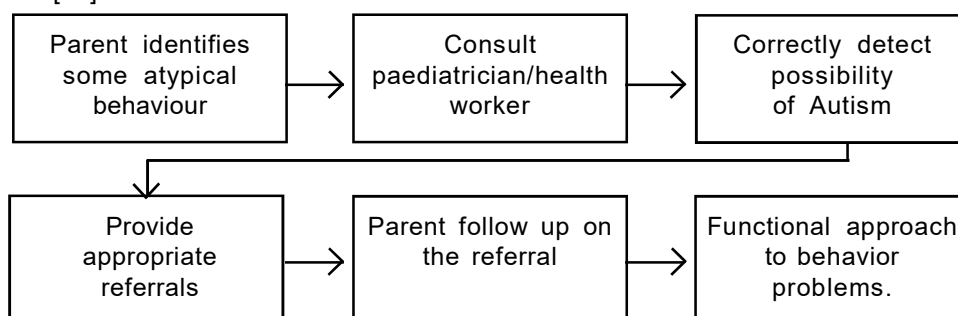


Fig 2: Services provided by the EI centre ((As per MoHFW, Setting up DEICS, Reference 20).

Medical services involve professionals like doctors who evaluate and diagnose children and treat those suffering from diseases and deficiencies. Occupational and physical therapy services relate to therapists working on self-help skills, adaptive behavior and play, sensory, motor and postural development and sensory integration; these services prevent or lessen movement difficulties and related functional problems. Speech-language pathology and audiology services are provided by speech therapists who work on children's communication skills (language acquisition, comprehension as well as pragmatics of language use) and/ or with oro-motor skills such as weakness of muscles around the mouth or swallowing and evaluating, diagnosing, and rehabilitating children with hearing impairment. Cognition services aid in identifying cognitive delays and providing intervention to enhance cognitive development, adaptive and learning behaviors. Psychological services are provided by psychologists who administer and interpret psychological tests and evaluate a child's behavior related to development, learning and mental health as well as planning services including counselling, consultation, parent training, behavior modification and knowledge of appropriate education programs.

Special educators double up as early interventionists and use various models for stimulating language development besides improving basic pre-academic concepts in these children. Psychologists with or without special training in educational services may perform the role of a special educator. Some psychologists prefer working with behavioral interventions while others prefer working with developmentally informed interventions such as RDI (Relationship Development Intervention), ESDM (Early Start Denver Model), etc. However, use of behavior methods of intervention is more evident. Often in urban areas, an overlap of roles across special educators and speech language therapists is noticeable. Also, the role definitions for each professional may vary based on centre, availability of professionals, nature of the interventions chosen, etc. The term Early Intervention (EI) therapist may be at times used to refer to professionals trained in eclectic models or formally certified by some of the organizations running RCI approved programs or sometimes as a catch-all term. There are as yet, no clear guidelines on roles of each professional defined by RCI in the context of disability interventions. While comprehensive models need a multidisciplinary team from the point of diagnosis, we strongly believe that a child without significant expressive language by 30 months of age must be provided access to formal speech-language therapy services, whether or not he has received help from special educators / psychologists previously.

The Rashtriya Bala Swastya Karyakram (RBSK) an ambitious program launched by the Government of India focused on multiple chronic disorders affecting children, envisages setting up a District Early Intervention Centres, to address neurodevelopmental disabilities. This requires a chain of events involving the identification and intervention process as outline in figure 3 [20].



**Fig. 3: Chain of events involved in the identification and intervention process (As per MoHFW, Setting up DEICS, Reference 20).**

Children referred from the periphery are expected to be provided basic services at the block level. It is anticipated that multitasking community personnel trained in more than one developmental domain (multiple domains) will provide these services. This is an important approach but requires two fundamental things to run it effectively and safely: [1] the diagnosis needs to be reasonably established at first by medical experts; [2] when the multitasking team is in doubt, there should be nodal centres with domain-specific experts to allow expert advice. These multitasking professionals must also get periodic training in a higher centre to sharpen their skills, but must serve the children nearer to their homes, with a family-centered approach - either at the community level or at the block level. It is expected that after early identification, they will be making appropriate referrals to intervention centers. However, it is unclear as to what models of EI are defined as acceptable under this program. Further, once done, there is a need to implement and evaluate such models of care within the RBSK/ DEIC system. However, specifically regarding ASD, a sustained mode of EI program is not adequately mentioned in this document, although there is a suggestion that nurses would be expected to support such activities.

The EI scenario about Autism in India is presented here to highlight potential models of care and the requisite downstream process that would enable their implementation in the country. We wish to spotlight the challenges regarding the access to EI services as well as the nature of available interventions. We aim to provide points for discussion on developing cost-effective intervention modules and for increasing its outreach, to match the scale of autism population in India. We explored articles in the last ten years that had autism, ASD, early intervention in India and early intervention models as key words. We limited our search to those reports focused on children below 6 years of age. Based on this search, we found that research in indigenously developed Autism Specific Interventions in India is relatively limited. Most centers use adaptations of the popular western intervention modules. Many EI centers have developed their own modules of EI; however, not all are evidence-based. The programs in most centers are modified to cater to the needs of each child and family. The socio-economic contexts often determine delivery of interventions in terms of nature, duration, and frequency.

Interventions in developed countries for developmental delays are addressed under different provisions, by different set of therapists (for e.g., those focused on ADLs and ID related challenges on one hand and those for ASD specific interventions on the other) and in different settings; the autism-specific interventions are discussed separately and carried out in more specialized settings or under special provisions of care. We believe that these may be neither desirable nor feasible in most Indian contexts. Instead, we have divided the research conducted in different parts of India into 3 different groups :

- A. Parent Mediated Interventions (PMI)
- B. Centre Based Professional Led Interventions
- C. Parent - Professional Led Integrated Intervention

Parent Mediated Intervention (A) and Parent - Professional Led Integrated Intervention (C) can be differentiated where the former involves parents being trained by a variety of staff including community health workers, at their home or district health centres. These community workers are in turn trained and overseen by a multidisciplinary team and are also provided manualized modules or curriculum to follow throughout the parent training process. Where the professionally qualified therapists are directly involved with parent training, their goal is to transfer knowledge

and skills to parents rather than directly working with the children. The latter - integrated model (C) involves child being accompanied by parents and receiving intervention directly from therapists at the centre for a fixed duration along with parents being trained in intervention strategies, who then carry forward the intervention at home (post the centre-based intervention period) along with regular follow ups with the therapist. Thus in this model, professionals are working with the children too. A vast majority of centres would use various combinations too, with professionals sharing their work with semi-trained (not necessarily approved) staff and use available professional services in an as-available manner.

A) Parent Mediated Interventions (PMI) :

<i>Study by</i>	<i>Population &amp; Age Range (ASD Children)</i>	<i>Study Design</i>	<i>Intervention / Methodology</i>	<i>Duration</i>	<i>Main Findings</i>
Juneja et al, 2012 (29) New Delhi	16 children < 6 years undergoing interventions	Retrospective study	Parent-mediated, non-structured, individualized manner (naturalistic)	At least 6 months	Significant improvement in the development, social and expressive language quotient, and also in autism severity and behavioural problems
Nair et al, 2014 (30) CDC, Kerala	52 children Age <6 years.	Quasi-experimental, Pre-post design	Home based interventions, parents trained by developmental therapists	6 months	Significant improvement in severity of autism, social and language skills was observed.
Patra et al, 2015 (31)	12 children 3-12 years	Quasi experimental before after study	Psycho educational intervention module developed based on parental felt needs	Over 12 sessions, delivered fortnightly	Significant change in total perceived stress (emotional and social stress, in specific) and parental knowledge post intervention.
Rahman et al., 2016 (32) Goa, Rawalpindi	32 children age of 2-9 years.	RCT	12 sessions of PASS (plus TAU) Parent mediated interventions delivered by non-specialist health workers	8 months	Parental synchrony and initiation of communication by the child improved.

Table 2: Summary of 'parent-mediated intervention' models in India

Intervention is provided by community health workers either at the child's home or at district health centres under the supervision of a multidisciplinary team of therapists. Both parents and health workers are provided with modules to use during the parent training process and for further reference at home.

The success of a parent-mediated intervention program is largely dependent on the partnership between the family and the training personnel, the key factors being adequate communication and coordination. Every family has different needs; hence a one size fits all model will not work. The advantages and challenges of parent mediated therapy have been enlisted in Fig. 4.

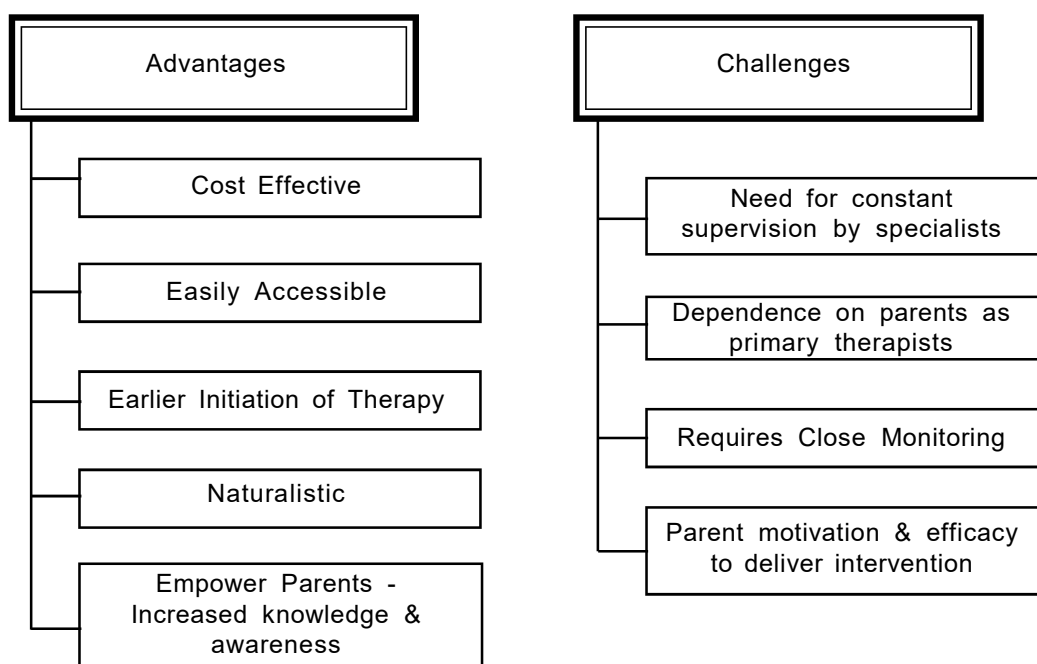


Fig 4: Advantages and challenges of parent-mediated intervention

Additionally, one must also consider the other hidden variables that contribute to the success of the intervention program. The variables such as financial status and cultural and educational background will have a bearing on the effectiveness of the intervention program. Hence in any parent-mediated intervention program, the assessment of the family becomes a crucial deciding factor.

Parents as co-therapists partially addresses the problem of limited-service resources and may be an effective alternative intervention strategy for children with ASD. It has been the primary mode of therapy implementation in India for several years even before it was reported in Western literature [27], albeit still limited to major Institutions and urban areas. However, such models may not account for the constantly emerging challenges in a child with autism. A team constantly cued into the child's evolving needs, is not widely available. Hence some of these models run out of effectiveness after initial 5-6 months. Be it the WHO-led CST (Caregiver Skills Training) or the PASS program or any other similar program, there is a need to follow

up and constantly review further needs and develop newer plans as appropriate. This eventually calls for Professional oversight and / or active involvement from their side.

#### B) Centre Based Professional Led Interventions

<i>Study by</i>	<i>Population &amp; Age Range (ASD Children)</i>	<i>Study Design</i>	<i>Intervention/ Methodology</i>	<i>Duration</i>	<i>Main Findings</i>
Karant P et al., 2010 (34) ComDEALL Bangalore	102 Children Age <6 years.	Quasi-experimental, pre-post design	Centre-based interventions on core deficits in ASD, motor, language, and adaptive skills.	8 months	Improvement in developmental skills and behavioural issues reported. 75% children were integrated into mainstream schools, at 1 year follow up.
Mukherjee et al., 2014 (35) Mumbai	18 Children aged. 4-15 Years	Retrospective study	Integrated therapy (special education, speech and occupational therapy)	3 Years	Younger age, duration of therapy and lesser baseline symptom severity, was associated with positive outcomes.

Table 3: Summary of published 'centre-based' intervention models in India

The centre-based model reduces the burden on the family. The parental stress & burnout is indirectly addressed. The group intervention strategies wherever employed reduce the cost of intervention. However, the greatest challenge is the availability & sustainability of the multidisciplinary team in a centre.

Com DEALL model is one such indigenously developed model that has a multidisciplinary team of a physiotherapist/occupational therapist, speech-language therapist & developmental educator who provide profile-based manualised intervention to a group of children. The program is developed within a broad-based developmental framework, to address the challenges of intervention in India. Despite a group approach to skill building, the child's needs decide the course of intervention. The multidisciplinary assessments feed into the profile-based intervention program - thus broadly addressing the child's needs. This model has been successfully up-scaled across various centres in India [28].

More centre-based professional led setups are incorporating the team approach towards intervention to holistically work on the child's development. While both the models mentioned in Table 3 are primarily addressing the needs of children with ASD, all other developmental delays and behavioral issues associated with ASD are also addressed through this broad-based approach.



Centre based approaches are common in urban areas of the country. Apart from the above-mentioned models, we highlight a few more of the well-known models of care in the country are listed below.

- \* Action for Autism (AFA), a parent initiative started in Delhi in 1991, has established processes aimed at providing support and services to persons with autism and their families, and to create an environment in India where people with ASD can fulfil their potentials. They started 'Aakaar' which is a comprehensive EI program for children with ASD up to seven years. The program is child-centric, play-based and family-focused. The primary aim of the program is to help the child 'learn to learn' by working on various school readiness skills and prepare the child for successful inclusion in the mainstream classroom. (<http://www.autism-india.org/>). Their program, Aakaar aims at helping the mother understand the unique learning styles of the child with ASD [38].
- \* Ummeed Child Development Centre runs the WHO Caregiver Skills Training Program for children aged between 2 - 9 years, having development and communication challenges, to improve their child's communication, play, behaviour, and independent living skills (besides varied therapies based on child's needs). This evidence-based program is running successfully in almost 40 countries with India running its 4th batch successfully. This centre in Mumbai is in the forefront of training a variety of other centres achieve capacity in EI models, amongst others (<https://ummeed.org/>)
- \* Systematic professional lead (varyingly integrated with parent training) EI programs are also reported from Latika Roy Memorial foundation, Dehradun which has a systematic plan to hand over children to varied forms of care as necessary, over subsequent years (39) (<https://latikaroy.org/>)
- \* Sethu, Goa is an organisation that has been pioneering EI efforts in Goa (40) and building supports for children with ASD (<https://sethu.in/>)
- \* Centre for Child Development and Disabilities in Bangalore (41) has proprietary tools and online portals to guide parents. (<http://www.cccd.in/>)

Many of the above listed centre-based interventions aim to be comprehensive and incorporate combinations of interventions. While many such well conceptualized multipronged interventions await formal outcome evaluation, they exemplify the strides in this area in the last decade and more, in urban areas of the country. These centers have further ventured into training other professionals and have been catalyzing EI models in different parts of the country.

### C) Parent - Professional Led Integrated Intervention

<i>Study by</i>	<i>Population &amp; Age Range (ASD Children)</i>	<i>Study Design</i>	<i>Intervention/ Methodology</i>	<i>Duration</i>	<i>Main Findings</i>
Karanth P et al, 2012 (34) ComDEALL Trust, Bangalore.	26 children age 3.5 to 6.5 years.	Non-controlled	Family Mediated Intervention Program (FMIP)	24 months, 2 sessions per week, 3 trials.	Children showed progress improvement. Increased input from families.
Krishnan et al., 2016 (36)	77 children. <6 years	Retrospective chart review	Completed 12-week center based intervention followed by home-based training	At least 12 weeks	Improvement noted in developmental age, perception, fine motor, gross motor, eye-hand coordination, cognitive performance, and verbal domain. No difference in intervention effects between the groups (based on autism severity).
Panchal P et al., 2017 (37) NIMHANS Bangalore.	2 - 10 years children.	Quasi Experimental	Intensive parent training on home-based training	2-3 weeks inpatient training	Feasibility of inpatient parent training. Improvement in developmental gains, reduction in autism severity and parental stress.
Manohar H et al., 2019 (33) JIPMER, Puducherry.	50 children, age 2-6 years	Pilot RCT	Parent-mediated intervention. Addressing parental stress from a cultural perspective	5 sessions taken over 12 weeks	All children had improvement in autism severity.  Parental knowledge, understanding and competence were significantly better in the intervention group.

Table 4: Summary of 'centre based parent-mediated' intervention models in India

Parent training is an integral part of this intervention program; constant supervision, monitoring and guidance by the multidisciplinary team ensures adherence to the quality of intervention. The advantages of this model are numerous, such as easier accessibility of all intervention services, involvement of parents under the expert guidance of a multidisciplinary team, cost-effectiveness and adapted to the needs of the family. That said, fidelity in carrying out the program needs to be monitored closely, and the transfer of skills to the parent must be closely examined. Arguably, the two reports from NIMHANS and JIPMER may well fall under PMI as described under A. This attests to the eclectic models even with regard to therapy delivery modes that exist in the country. The FMIP by the ComDEALL team is, by far the most intensive of such Professional-Parent led integrated Interventions. And has the ability to focus on evolving needs and adapt to challenges, stemming from prolonged connect between professionals and parents. This needs trained man-power and has the potential to be the best-rounded program amongst those available in the country today. Unlike PMIs of fixed duration, this has the capacity to demonstrate gains in expressive language and social communication while also supporting co-morbid developmental needs.

The focus in all the programs is on enhancing foundational pre-requisite learning skills (joint attention, compliance), play skills, parent-child interaction profiles along with working on developmental domains of motor skills, communication, social interaction, adaptive skills and addressing behavioral issues. The majority of the studies (parent-mediated interventions-PMIs) reported improvement in parent knowledge, parent child interaction, joint attention and play behaviors (29). The domains of language and social communication showed the least and slowest improvement as they require some degree of stabilization of pre-requisite skills. There is a growing belief (36) that it is feasible to provide parent mediated early intervention for children with autism in low child-mental-health-resourced countries such as India. That said, the evidence base is small. This can challenge implementation research efforts in this regard. One needs to keep parents own health and need for respite in mind; this and the varied ability to learn such skills, may not permit such approaches to be ideal for all. During the recent pandemic, many families have expressed distress in carrying out the interventions from home, when supervised online training was widely explored by many centres in urban parts for the country. PMI may still be an option for those who live in areas without easy access to services. There is a need to compare outcomes between systematic centre-based interventions with PMIs delivered by varied non-professional staff. Also, it is important to compare PMIs delivered in centres versus those delivered online.

Systematic EI efforts have also been noted from Academic Medical Institutions. Many centers tend to combine their efforts for helping all children (across ages) with ASD including those needing EI methods (Nair hospital and Sion Hospitals, Mumbai) while some specify EI models (Maulana Azad Medical College, Delhi; Christian Medical College, Vellore; NIMHANS, Bangalore). Some hospitals prefer bolus training of parents through admissions periodically (42). This is not a comprehensive list and we have just shown some exemplars. That said, the First Global Autism Convention, held in Bangalore in 2011, organized by the last author, indicated that while many tertiary institutions in India had begun to provide Autism intervention services, hardly any had structured and manualised EI programs on their campus. One important model, named 'Badthe Kadam', developed at AIIMS, New Delhi, was an ICMR funded program that resulted in a manual for parent mediated intervention (Savita Sagra and Tanuja Kaushal, Presented at the Second Global Autism Convention, 2018). Further implementation studies based on this experience are awaited.

To summarize, the nature of early intervention in ASD is multidisciplinary. Children need a range of interventions; they may need different interventions and different combinations of interventions at different stages. The profile of the child receiving the intervention will change over time. Hence continuous monitoring needs to be a fundamental feature of parent-mediated interventions. The available studies (tables 2-4) indicate utility and to an extent efficacy, across short time-periods, based on the content of the program and the ages of the children included.

Specifically, parents have been trained in intervention strategies and often provided with resources to act as therapists for their child. Such methods have focused on building knowledge in parents regarding their child's condition, with some of them evaluating parental stress and its management too. Parents have reported feeling more at ease with respect to working with their child in a naturalistic setting (home) and studies have highlighted the improved bonding between parent and child. Reduction in parental stress has been reported by some of these studies. However, there is no systematic follow up of these children to review and plan further training, based on evolving needs. And in children with autism, needs change across time and newer challenges emerge as they grow-up. The studies that implemented centre-based intervention programs also emphasize the need to include parents in the early intervention process, as they provided the best chance of generalizing and maintaining the interventional gains of their child. This is in line with the WHO caregiver skills training program and other models that emphasize need for training parents to make up for the resource gap in developing countries.

As the nature of EI is complex and involves many different components, we cannot assume that there is a single ideal intervention program for autism. Though there are very few RCT studies done for intervention, there are large differences in the published intervention literature and it is still early to debate the superiority of one intervention over the other. There are many variables such as age ranges/ age groups, type of intervention, duration of intervention, assessment tools used, and outcome measures employed that prevent us from conclusively stating the superiority of one intervention over the other. However, the chosen intervention program should address and focus on the core deficits of social communication, social interaction, and behavior. The essential components of intervention that will impact a child's progress need to be specified in the program as highlighted in the study by Mukherjee et al, in 2014. An integrated, inter disciplinary approach is the gold standard for early intervention for a child with ASD. While studies referred above have also talked about the need for comprehensive intervention, the challenge is finding enough professionals to deliver the intervention. Manualized intervention programs and an eclectic approach to intervention needs to be explored in implementation research. Parents/ caregivers must be included in the intervention process. This can also generalize therapy goals in different settings and situations.

Due to the nature of high-intensity therapist-based intervention, the reach of multidisciplinary EI services will be limited. Dissimilarities in resources across the urban-rural settings will influence the selection of the appropriate intervention program for the child with ASD. Some of the interventional programs ideal for delivery in a primary care setting can be done so by non-specialists, whereas centre-based/inpatient interventional programs can address additional comprehensive care - these may effectively be delivered at secondary and tertiary care hospitals. As described by Preethi Kandasamy in 2018, primary care physicians could conduct routine screenings, explain, and appropriately refer for early intervention any child who may be 'At Risk' for ASD. This will need systematic training for these physicians in the

use of presently available screening tools. Secondary care hospitals should strengthen liaison with child guidance centres for early detection and diagnosis, provide EI programs and follow-up with the families regularly. They may coordinate with the DEICs and District Mental Health Psychiatrists for short- and long-term care, especially in rural areas. Tertiary care institutes should focus on providing hands-on training and create resource materials for parents and professionals. Implementing such hierarchical models of care and evaluating them are urgently needed. A proposed theory of change in the health system to improve EI in India [37] has suggested that national professional bodies enlist parameters of practice for professionals, monitor and certify organizations, develop, and form policies for screening and EI programs, as these require expert and in-depth knowledge of many factors.

"Task shifting" or "task sharing" is suggested by the WHO and aims to deal with the severe shortage of a specialist workforce by allocating healthcare tasks in such a way that less qualified and more cost-effective workers are trained to deliver components of the intervention, under the support and supervision of skilled specialists, to enhance access and cost-effectiveness (36, 43). This is brought out by the PASS study by Rahman et al where it was carried out on a smaller scale. In a recent follow-up study, the same authors (2019) observed adequate feasibility, as reflected by high fidelity of interventions, by health workers and favorable on dyadic social communication as well as improved maternal mental health outcomes. While these studies show that interventions can be implemented using community health workers/ nurses, it needs to be ensured that personnel are employed specifically for this purpose and not juggle with other healthcare tasks. Continuous follow-up with a team of professionals along with intermittent training sessions is a must, in order to solve problems and ensure that the quality of intervention is maintained.

While parent training programs ranging from 3-10 sessions to up-to-a-year have been described in the Indian context, sustained efforts by parents covering the full ambit of EI across 2 to 6 years of age, under constant supervision is the real need and has not been much attempted in India. Manualized programs such as the ComDEALL program that probably fits this need, ought to be further studied from this point of view, at least in urban contexts. On a different note, app-based interventions aiming to support such parent mediated efforts are being attempted to mitigate the lack of professionals and such efforts are likely to gain traction from research funding agencies, given the intuitive ability of such digital modes to bridge the gap in professional availability (36). Technology based intervention that uses artificial intelligence is an emerging field worth exploring for intervention in Autism.

The urban support systems present vary significantly from rural set-ups and may impact the outcome of the intervention program. The need of the hour is easy accessibility of intervention services across different health settings. So, it would be worthwhile exploring whether graduates from appropriate backgrounds, particularly nurses, can be provided intensive training to deliver at least a good part of EI in peripheral centers. We also need to consistently evaluate the implementation of such services. Though it is conceivable that they may fall short of intensive programs that professional-rich centers can offer, they could represent the minimum program that can benefit a larger number of parents in non-urban areas. Given the ambitious RBSK vision, exploring and evaluating such models further, is necessary.

In India, government policies, guidelines and initiatives exist for EI in Developmental disabilities. Translation into practical implementation, at the ground level is a work in progress. There is a need to document the barriers and deficits in autism intervention in India. A comprehensive

documentation of existing services can also help prepare a framework in this regard. Many intervention centers attempt to implement multidisciplinary team approach, thus adhering to the RCI guidelines, but the difficulty lies in the scarcity of trained professionals, especially when it comes to upscaling these efforts. A relevant indigenously developed specialized autism EI program, that can be delivered by specially trained health care professionals such as Nurses / Community health workers is the need of the hour.

This necessitates that we adopt a locally evolved (and hence not expensive for adaptations) and relevant specialized autism EI program and adapt them to serve task shifting frameworks. Such models need to focus on both ASD symptomatology as well as co-morbid developmental and behavioral challenges. Some work in this regard has been showcased in this chapter. Developing them further and evaluating implementation in public health settings is imperative.

## REFERENCES

1. Miller LE, Burke JD, Robins DL, Fein DA. Diagnosing autism spectrum disorder in children with low mental age. *Journal of autism and developmental disorders*. 2019 Mar;49(3):1080-95.
2. Lloyd M, MacDonald M, Lord C. Motor skills of toddlers with autism spectrum disorders. *Autism*. 2013 Mar;17(2):133-46.
3. Kalandadze T, Norbury C, Naerland T, Naess KA. Figurative language comprehension in individuals with autism spectrum disorder: A meta-analytic review. *Autism*. 2018 Feb;22(2):99-117.
4. Riou EM, Ghosh S, Francoeur E, Shevell MI. Global developmental delay and its relationship to cognitive skills. *Developmental Medicine & Child Neurology*. 2009 Aug;51(8):600-6.
5. Neggers YH. Increasing prevalence, changes in diagnostic criteria, and nutritional risk factors for autism spectrum disorders. *International Scholarly Research Notices*. 2014;2014
6. Vos T, Lim SS, Abbafati C, Abbas KM, Abbasi M, Abbasifard M, Abbasi-Kangevari M, Abbastabar H, Abd-Allah F, Abdelalim A, Abdollahi M. Global burden of 369 diseases and injuries in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet*. 2020 Oct 17;396(10258):1204-22..
7. Arora NK, Nair MK, Gulati S, Deshmukh V, Mohapatra A, Mishra D, Patel V, Pandey RM, Das BC, Divan G, Murthy GV. Neurodevelopmental disorders in children aged 2-9 years: Population-based burden estimates across five regions in India. *PLoS medicine*. 2018 Jul 24;15(7): e100
8. Zwaigenbaum L, Bryson S, Lord C, Rogers S, Carter A, Carver L et al. Clinical Assessment and Management of Toddlers with Suspected Autism Spectrum Disorder: Insights From Studies of High-Risk Infants. *PEDIATRICS*. 2009;123(5):1383-1391.
9. Lord C, Luyster R, Guthrie W, Pickles A. Patterns of developmental trajectories in toddlers with autism spectrum disorder. *Journal of consulting and clinical psychology*. 2012 Jun;80(3):477.
10. Subramanyam AA, Mukherjee A, Dave M, Chavda K. Clinical practice guidelines for autism spectrum disorders. *Indian journal of psychiatry*. 2019 Jan;61(Suppl 2):254.
11. Zwaigenbaum L, Bauman M, Choueiri R, Kasari C, Carter A, Granpeesheh D et al. Early Intervention for Children With Autism Spectrum Disorder Under 3 Years of Age: Recommendations for Practice and Research. *PEDIATRICS*. 2015;136(Supplement): S60-S81.
12. Jones EJ, Gliga T, Bedford R, Charman T, Johnson MH. Developmental pathways to autism: a review of prospective studies of infants at risk. *Neuroscience & Biobehavioural Reviews*. 2014 Feb 1; 39:1-33.

13. Vivanti, Giacomo, Margot Prior, Katrina Williams, and Cheryl Dissanayake. "Predictors of outcomes in autism early intervention: why don't we know more?" *Frontiers in pediatrics* 2 (2014): 58.
14. Elder J, Kreider C, Brasher S, Ansell M. Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. *Psychology Research and Behaviour Management*. 2017; Volume 10:283-292.
15. Landa R. Efficacy of early interventions for infants and young children with, and at risk for, autism spectrum disorders. *International Review of Psychiatry*. 2018;30(1):25-39.
16. Lakhan R. Inclusion of Children with Intellectual and Multiple Disabilities: A Community-Based Rehabilitation Approach, India. *Journal of Special Education and Rehabilitation*. 2013;14(1-2):79-97.
17. Narayan C, John T. The rights of persons with disabilities act, 2016: Does it address the needs of the persons with mental illness and their families. *Indian Journal of Psychiatry*. 2017;59(1):17.
18. Rao G, Ramya V, Bada M. The rights of persons with Disability Bill, 2014: How "enabling" is it for persons with mental illness? *Indian Journal of Psychiatry*. 2016;58(2):121.
19. National Health Mission [Internet]. 2021 [cited 29 May 2021]. Available from: <https://nhm.gov.in/>
20. [Internet]. 2021. Available from: [https://www.nhmmp.gov.in/WebContent/RBSK/01-08-16/OG\\_DEIC.pdf](https://www.nhmmp.gov.in/WebContent/RBSK/01-08-16/OG_DEIC.pdf)
21. Schreibman L, Dawson G, Stahmer A, Landa R, Rogers S, McGee G et al. Naturalistic Developmental Behavioural Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2015;45(8):2411-2428.
22. Manohar H, Kandasamy P, Chandrasekaran V, Rajkumar R. Brief Parent-Mediated Intervention for Children with Autism Spectrum Disorder: A Feasibility Study from South India. *Journal of Autism and Developmental Disorders*. 2019;49(8):3146-3158.
23. Harshini M, Preeti K. Autism Behavioural Interventional Research in low-resource settings: Overcoming prevailing challenges an Asian perspective. *Asian Journal of Psychiatry*. 2017; 25:224-227.
24. Desai M, Devan G, Wertz F, Patel V. The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*. 2012;49(3-4).
25. Kaul S, Mukherjee S, Ghosh AK, Chattopadhyay M, Sil U. Working with families to implement home interventions: India. Odom, SL Odom, MJ Hanson, J. A. Blackman, & S. Kaul (Eds.), *Early Intervention Practices Around the World*. 2003:111-28.
26. Manohar H, Kandasamy P, Chandrasekaran V, Rajkumar RP. Brief parent-mediated intervention for children with Autism Spectrum disorder: A feasibility study from South India. *Journal of autism and developmental disorders*. 2019 Aug;49(8):3146-58.
27. Juneja M, Sairam S. Autism spectrum disorder-An Indian perspective. *Recent Advances in Autism*. 2018.
28. Karanth P. History of communication DEALL, Autism Early Intervention Program Bangalore [Internet]. Available from: <https://www.communicationdeall.com/history>
29. Juneja M, Mukherjee SB, Sharma S, Jain R, Das B, Sabu P. Evaluation of a parent-based behavioural intervention program for children with autism in a low-resource setting. *Journal of pediatric neurosciences*. 2012 Jan;7(1):16.
30. Nair MC, Nair GH, Beena M, Princly P, Chandran SA, George B, Leena ML, Russell PS. CDC Kerala 16: Early Detection of Developmental Delay/Disability Among Children Below 6 y-A District Model. *The Indian Journal of Pediatrics*. 2014 Dec;81(2):151-5.

31. Patra S, Arun P, Chavan BS. Impact of psychoeducation intervention module on parents of children with autism spectrum disorders: A preliminary study. *Journal of neurosciences in rural practice*. 2015 Oct;6(4):529.
32. Rahman A, Divan G, Hamdani SU, Vajaratkar V, Taylor C, Leadbitter K, Aldred C, Minhas A, Cardozo P, Emsley R, Patel V. Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial. *The Lancet Psychiatry*. 2016 Feb 1;3(2):128-36.
33. P. K. Harshini Manohar, "Autism Behavioural Interventional Research in low-resource settings: Overcoming prevailing challenges an Asian perspective," *Asian Journal of Psychiatry*, vol. 25, pp. 224-227, February 2017.
34. Prathibha Karanth, "Efficacy of communication DEALL--an indigenous early intervention program for children with autism spectrum disorders," *Indian Journal of Pediatric*, vol. 77, p. 957-962, September 2010.
35. Mukherjee S, Rupani K, Dave M, Subramanyam A, Shah H, Kamath R. Evaluation of effectiveness of integrated intervention in autistic children. *The Indian Journal of Pediatrics*. 2014 Apr;81(4):339-45.
36. Krishnan R, Alwin Nesh MT, Sudhakar Russell PS, Russell S, Mammen P. The effectiveness of an intensive, parent mediated, multi-component, early intervention for children with autism. *Journal of Indian Association for Child & Adolescent Mental Health*. 2016 Jul 1;12(3).
37. Kandasamy P. Early intervention of Autism Spectrum Disorder: Translating research into practice. *Indian Journal of Mental Health and Neurosciences*. 2018 Jul 14;1(1):1-7.
38. 2019. Action for Autism. [online] Available at: <http://www.autism-india.org/Aakaar-Early-Intervention-Program.php>.
39. Chopra, J., 1994. [online] Available at: <https://latikaroy.org/our-story/> [Accessed 29 May 2021].
40. 2005. Child development and family guidance. [online] Available at: <https://sethu.in/>
41. Mundkur, N., 2006. Centre for child development and disabilities. [online] Available at: <http://www.cdd.in/>.
42. Krishna D, Muthukaruppan SS, Bharathwaj A, Ponnusamy R, Poomariappan BM, Mariappan S, Beevi A, MacLachlan J, Campbell Z, Anthonypillai C, Brien M. Rapid-Cycle Evaluation in an Early Intervention Program for Children with Developmental Disabilities in South India: Optimizing Service Providers' Quality of Work-Life, Family Program Engagement, and School Enrolment. *Frontiers in public health*. 2020 Nov 30; 8:822.
43. World Health Organization (WHO) HS and S (HSS). Task Shifting to Tackle Health Worker Shortage [Internet]. Available from: [https://www.who.int/healthsystems/task\\_shifting/TTR\\_tackle.pdf?ua=1](https://www.who.int/healthsystems/task_shifting/TTR_tackle.pdf?ua=1)



## REHABILITATION OF PEOPLE WITH DEMENTIA

Nimmy Chandran<sup>1</sup>, Santosh Kumar D<sup>2</sup>, K.S.Shaji<sup>3</sup>

### DEMENTIA

Dementia is a major global public health challenge. There is a sudden increase in the number of older people with dementia in India. We need to develop services for people with dementia.

Dementia care involves psychosocial rehabilitation, caregiver interventions, support and guidance. Person centered management includes interventions which are, cognition oriented, emotion oriented, behaviour oriented, stimulation oriented and physical activity oriented. Caregivers have an important role in psychosocial rehabilitation. Long-term care and periodic reviews will help to make dementia care need based. The infrastructure for institutional care is less developed in India and is inadequate to meet the emerging demand for assisted living.

### INTRODUCTION

Dementia is one of the greatest health challenges of our generation. In the years ahead, societies and health systems will have to cope with a staggering increase in the number of people with dementia, which is set to reach 78 million by the end of this decade, with most of these people living in low and middle income countries [1]. India is in the midst of rapid demographic aging and we too are witnessing a sudden increase in the number of older people with dementia.

Most conditions which cause the syndrome of dementia have no cure. We are yet to develop and implement public health strategies which can prevent or postpone the onset of dementia. With no curative treatment available, we now have to rely on the provision of good quality care in a coordinated manner, to halt the debilitating impact dementia has on people and communities. Though a condition like dementia is most often not reversible or curable, most people with dementia and their caregivers will benefit from evidence informed, person centered care. Better understanding of the condition has led to a consensus which is capable of informing and guiding dementia care, especially home based dementia care [2]. A well informed care and support system will be helpful to improve the quality of life of the people living with dementia and their carers. Caregivers are better designated as care partners as they actively participate in day today care and decision making along with those who deliver formal health or social care services.

This chapter proposes to outline the important dimensions of dementia care. Clinicians and other healthcare professionals should recognize that many things can be done for people affected by dementia. It is important that health professionals communicate this fact clearly to the families and offer follow-up care to all people affected by dementia. Chronic disease management is all about providing support and guidance for management. Dementia care involves psychosocial interventions which include caregiver interventions. This chapter will give a brief outline of all such interventions. Though this chapter has a focus on dementia care, many suggestions and recommendations may be useful for the care of older people with other disabling neuropsychiatric conditions.

---

Disclosure Statement : Authors do not have any conflicts of interest and have not received any funding for this work.

1. Assistan Professor of Psychiatry, Govt. Medical College, Palakkad, Kerala.
2. Senior Resident, Department of Psychiatry, Christian Medical College, Vellore - 600 126.
3. Dean (Research), Kerala University of Health Sciences, Thirissur - 680 596, Kerala.

Most people with dementia live with their families. Living in a familiar environment with their family members will help them to have a better quality of life [3]. Along with the cognitive decline, people with dementia often have behavioral symptoms, mood symptoms and disturbance in sleep-wake cycle [4]. Most people with dementia will have multimorbidity, which indicates presence of two or more health conditions which require long-term management. Multimorbidity makes chronic disease management more challenging and presence of a condition like dementia makes it even more difficult. Caregivers often do not have access to good quality information which will help and guide them in managing symptoms and other health related issues. It is often difficult to manage the behavioural and psychological symptoms of dementia. The physical and social setting of dementia care may have to be suitably modified to make home-based care more effective and less burdensome to co-resident family members.

### **ASSESSMENT**

Early assessment and diagnosis of dementia or cognitive impairment is very important. All persons with memory or behavioural symptoms and history of definite cognitive decline need to be screened for evidence of significant cognitive impairment. A detailed assessment will be needed, especially when the symptoms are mild but persistent or progressive. Such detailed assessments can be made in a hospital or in the community depending on the locally available resource and expertise. Initial assessment should include evaluations of cognitive symptoms, behavioral symptoms, psychological symptoms, physical comorbidities, activities of daily living, quality of life and the caregiver burden. The clinicians should assess cognitive symptoms and other behavioural symptoms and make decisions about the potential usefulness of medications. While cholinesterase inhibitors are well tolerated and useful in mild to moderate cases of Alzhiemers disease, this will have to be prescribed by clinicians with good understanding about its indications and side effects. Follow up is essential and thus cholinesterase inhibitors will have to be used under supervision only. Indications for other drugs, especially drugs like antipsychotics are limited. They have to be used sparingly and only short-term if indicated. The family needs to be told about the potential for harm before these drugs are administered. Vitamins may be prescribed as many of the affected individuals may have or are likely to develop difficulties with food intake.

Other illnesses, especially comorbidities needing long-term care, will have to be assessed in detail and a comprehensive management plan will have to be made in advance. Care plan has to be monitored by one clinician and also by another responsible person, who often could be the primary care giver. Periodic follow up can be done by visits to the clinic by the care partner and also by evaluation of the person with dementia preferably as and when needed, at home or at the clinic.

### **PERSON CENTERED CARE**

Person centered comprehensive management plan should be prepared for each person with dementia. Person centered care has four elements namely; values, individualised approach, the perspective of the person living with dementia and the social environment [5]. This approach lays lot of importance in protecting the dignity of the individual and the right to make informed choices. Non pharmacological management is always the mainstay of dementia rehabilitation. Various caregiver training programs which focus on non-pharmacological interventions are found to improve the mood and behavioral symptoms and the cognition and quality of life of the persons with dementia [6]. These interventions also help to delay institutionalization and reduce the risk of mortality of persons with dementia. Use of unnecessary and inappropriate

medication has no place in dementia care. A structured activity plan should be made for each person with dementia. Those with mild cognitive impairment and mild dementia may benefit from attendance at daycare centres. Caregivers need to be informed and educated about the usual causes, symptoms and various stages of dementia as well as the impairments associated with the progressive stages of the illness. This will allow them to be prepared. The workers employed in the community out reach services can be given a brief training in dementia care so that they can make home visits and follow up community resident older people with dementia. They can be equipped to deliver brief interventions like providing information and guidance to people with dementia and co-resident care givers and also the staff members employed in the day care facilities. This kind of simple easy to deliver interventions are feasible in community settings in India and can be useful for families engaged in dementia care [7].

### **CARE IN THE COMMUNITY**

The providers of community outreach services like Accredited Social Care Activists (ASHAs), Public Health Nurses, Palliative Care Nurses, Anganwadi Workers and other community health workers can be trained to identify the needs of people with dementia and their caregivers. Caregivers can be provided further support and information based on their needs. Caregiver training can be implemented in various ways. The clinic based health services staff in the government or private sector could consider designating one person as the care manager who will then coordinate the access and provision of community based health and social care services. The second option is to provide brief training for the care givers during their periodic visits to the clinic / hospital. A third method is to provide online training or training through distribution of material useful for information and education like booklets, CDs and other educational materials. A dementia care booklet which includes details about the illness, its symptoms, associated symptoms, useful tips to aid memory and information about the management of behavioral symptoms in the local language can be given to caregivers.

It is important to make necessary changes in the way family members communicate with the person affected by dementia. Care givers should be instructed to use simple language and short sentences. They should always make proper eye contact and try to make use of gestures whenever needed. There should be minimum distractions while speaking to the person with dementia and they should speak slowly and clearly. Use brief, clear elaborations as and when needed. Persons with dementia need positive reinforcement for the communication which come from their part [8].

Caregivers also need emotional support. This is very important. Dementia care can have negative impact on the mental and physical health of the caregiver. Caregivers need to take care of their health and well being and they need to be specifically told to do that. Support groups of caregivers will help to improve the care giving skills and the wellbeing of the caregivers. Manuals or booklets or CDs can be used to teach them successful coping strategies which will foster the mental health of the carers [9].

Persons with mild cognitive impairment or mild dementia can attend the day care centres along with older people with no cognitive impairment. Attending daycare centres will help them to remain engaged and provide opportunities for cognitive stimulation which will help to improve their mental well-being.

### **COGNITION ORIENTED INTERVENTIONS**

These interventions generally focus on the cognitive functions of people with dementia. Cognitive stimulation is done by engagement in general activities which in turn stimulate cognition. Cognitive stimulation can improve the quality of life and well being [10]. Cognitive training involves guided training to improve the cognitive abilities by executing particular tasks which require use of various faculties like attention, working memory, visual perception and processing speed. These can be done by direct training or web based training or through integration with activities of daily living [11][12][13][14]. These can be applied individually or can be given as group based interventions. Cognitive rehabilitation uses a holistic approach, in which a person with cognitive impairment works with his or her caregiver and therapist to identify his or her personal goals and then work together to achieve it and function optimally. The aim is to obtain and maintain as much of their independence as possible [15].

Cognitive rehabilitation can be promising for patients with dementia. But earlier studies had shown mixed results. One multicentric study enrolling 201 subjects with dementia could not find any improvement in the daily functioning [16]. Another multicentric study did show that cognitive rehabilitation improves the memory-related daily functions [17]. Yet another study conducted in people with Dementia associated with Parkinson's Disease showed that cognitive rehabilitation is superior to relaxation therapy or treatment as usual, in outcomes like patient satisfaction and attainment of goal-directed activities [18].

Cognitive rehabilitation interventions includes both enhanced learning methods and introduction of compensatory strategies. Enhanced learning methods include modelling, prompting and expanding the rehearsal of information. [19][20] Some activities will be broken down into steps, and practised, one step at a time, until the whole sequence of steps has been mastered. Compensatory strategies and memory aids may be introduced, with the support of the cognitive rehabilitation practitioner, where appropriate. A multicentred study in India is looking at the feasibility of implementing Cognitive Stimulation Therapy (CST) in people with mild to moderate dementia. It appears to be feasible to deliver CST after adaptation to suit the local language and cultural practices [21]. It is important to note that these therapies are best delivered along with a package of dementia care interventions suitable for the local population along with attempts to raise the awareness about dementia [22]. We need to develop and implement cognition oriented interventions that suits the individual with dementia and the sociocultural context of dementia care. It is feasible to offer such therapies or training through a team which often requires three key participants; the clinician or nurse, outreach service provider and the co-resident caregiver.

### **TECHNOLOGICAL ASSISTANCE FOR COGNITIVE TRAINING**

Assistive technologies are becoming more acceptable to people living with dementia and their caregivers. There are many newer web based programs and mobile applications focusing on cognitive training, rehabilitation or stimulation [23]. These applications and programs focus on multiple cognitive domains. These can be used by persons at their home according to their own convenience. These applications allow varying number of cognitive exercises, which a person can use while at home. Most of these exercise packages generally start with easy ones in the beginning and then gradually move on to ones with higher difficulty levels. Depending on the cognitive ability of the person, one can start with whatever is easy and can progress to more difficult ones depending on their ability. Some of these applications have the provision to use cognitive assessment tools. Some applications give progress reports on

a person's performance with these cognitive exercises. A few of them have combined physical activities with the prescribed cognitive exercises. There are certain applications which use group cognitive therapy which help in promoting social interactions of people with dementia. One study from Denmark showed that cognitive remediation delivered via mobile application improved patients goal attainment and satisfaction [24]. These interventions appear to be feasible and they seem to be acceptable to people with dementia and their caregivers.

Recently cognitive rehabilitation using 3D simulation games has been used to improve the cognitive functions of person with dementia. One small study conducted in 10 individuals showed improvement in processing speed and decision making [25]. Clearly the use of assistive technology to improve cognitive functions is an area which awaits more efforts at innovation and design thinking. We may soon have devices or technologies to overcome the limitations due to cognitive decline in dementia and may come up with effective strategies to slow down cognitive decline with newer technology driven strategies.

### **EMOTION ORIENTED INTERVENTIONS**

Droes defined 'emotion-oriented care as care aimed at improving emotional and social functioning, and ultimately the quality of life, of persons suffering from dementia by supporting them in the process of coping with the cognitive, emotional and social consequences of the disease and by linking up with individual functional possibilities and the subjective experience of the person in question [26]. Emotion oriented approaches include supportive psychotherapy, validation therapy, sensory integration, stimulated presence therapy, and reminiscence.

Persons with dementia can have depression and apathy. Literature shows that many interventions were tried to improve the emotional state and apathy of persons with dementia [27]. Many investigators have tried to improve the emotional state of patients with dementia via various methods. One study showed that singing and listening to music improved the mood, attention and executive function of patients with dementia [28]. Obviously we need more evidence.

### **BEHAVIOUR ORIENTED INTERVENTIONS**

Behavioural symptoms of dementia include repetitive questioning, aggression, wandering behaviour and sleep disturbances. Those symptoms are usually very disturbing to affected individuals and caregivers. Non-pharmacological interventions are the mainstay of management [29]. Keeping calendars, notice boards, and clocks will help to tackle frequent forgetfulness. Setting mobile reminders and alarms will help them to take medicines on time. It may be helpful to label the things the patient needs. It is also important to simplify the environment. Keep only the necessary things in the patient's room. Better organization of the immediate environment will reduce distractions and reduce errors of judgement

The targeted symptoms approach is useful for improving symptoms like sleep disturbance. Staying active during the day time, avoiding stimulating drinks in the evening, maintaining a nighttime routine, and keeping the bed time quiet will help to manage symptoms like sleep disturbances. Principles of sleep hygiene can be of use.

If the patient has a wandering habit, always keep the Identity card with the name, address and phone number of a relative with the patient. For managing frequent aggression, antipsychotics can be given; but start with very low dosage. This can be given only if there are definite indications and it is always meant for short term use. Please refer to relevant clinical practice guidelines for its use [30]. We need to be extremely careful about the side

effects of antipsychotic in dementia patients and these drugs will have to be avoided in patients with Dementia with Lewy Bodies as it can cause severe adverse events due to neuroleptic sensitivity.

### **STIMULATION ORIENTED INTERVENTIONS**

Stimulation activities include simple household activities, cooking, gardening, listening to music, watching television and other recreational activities. These activities can be done in the daycare centres and also at home. The daycare staff and caregivers should be trained. Patient can choose the activities according to their preference. Most of these activities do not need any kind of training. Patient can do it at their home according to their wish. Group based recreational activities may need training. The group based occupational therapy targeting cognitive functions is found to be effective in improving day-to-day memory functions [31].

### **PHYSICAL ACTIVITY ORIENTED INTERVENTIONS**

Exercises can improve the balance and mobility of the people with dementia [32][33]. Exercises can be done at home or as part of group training. Exercises can be aerobic, resistance or functional exercises. We need to choose the exercises according to the physical abilities of the person with dementia. While giving exercise training, it is important to use simple instructions. They need support and encouragement and need repeated reassurances. Often there is a need repeat demonstration of exercises so that they can comprehend it better. Many a time the pace of instruction and practice has to be slowed down giving due consideration to their understanding and ability to execute the task. Make sure that the environment is safe and has good lighting. The risk of falls and injuries need to be kept in mind when these tasks are implemented. Care giver support should be there and it is always better to have the caregiver nearby for help if needed. Exercises will be useful only if it is well integrated with the routine activities of the person and if the person is regular with this. There is also this suggestion that regular exercises reduce the risk of falls [34]. However, there is lack of proper evidence and guidelines for the types and details of exercises for people with dementia. Further research is needed to determine its feasibility and usefulness as an intervention to improve health and well being of older people with dementia.

### **CONTINUATION OF CARE AND MANAGEMENT OF ADDITIONAL SYMPTOMS**

Persons with dementia continue to develop new cognitive and behavioural symptoms during the course of their illness. It is important to have regular contact and follow-up with people with dementia and their caregivers. Home visits, visits to clinics, even online or telephonic follow-up will help them to express their concerns with care providers and get reassurance and guidance regarding management of new symptoms. It will also help them to avoid unnecessary hospital visits. We have learned more about the potential usefulness of telemedicine and provision of online support and care during the present pandemic. Let us make best use of the lessons learnt during the Covid-19 pandemic and consider adding value to the rehabilitation services for older people. Use of technology along with the use of behaviour checklists by outreach service providers and caregivers will enable us to identify behavioural symptoms early and to institute feasible interventions.

### **INSTITUTION BASED DEMENTIA REHABILITATION**

The availability of institution based care is less in India when compared to developed economies which have a sizable proportion of older people in their population. Frailty and disability increase with age and more people above the age of 80 years will need assistance for basic activities of daily living. This need is likely to become more evident as the demographic aging advances across the country. We will need more assisted living facilities in India for people with dementia. This is important as we are in the midst of rapid social changes. There is a reduction in the average size of the household. Most adult family members including women work outside their homes during working hours. There is a progressive diminution of the size of households in India also adds to the strain of home-based care.

There has to be norms for institution based dementia care and it is proper to maintain a basic minimum quality for institutional care. There should be a person centered treatment plan for people with dementia who get admitted for getting long - term dementia care in institutional settings. The persons living in the nursing homes or long term facilities can have more physical and cognitive impairment. This can make dementia rehabilitation a more complex exercise for care providers. There are many difficulties in working in these settings which lack the usual kind of social or family support. The nursing staff need to be trained. There has to be programs to update the knowledge and skills of formal care providers through mandatory training. District Mental Health Programs and other community care programs shall design special services, especially training programs for those who provide dementia care in these settings. The physical and social environment should be made safe, simple and friendly for the residents affected with dementia.

Many studies have tried to engage the persons with dementia in meaningful activities in nursing homes [35]. Meaningful activities include art work, drawing, singing songs, agricultural activities, computer based games and computer based occupations. Group based activities include group based story telling, talking about familiar topics or discussing about spiritual or religious topics [36][37][38]. They found that engagement in meaningful activities has the potential to improve the physical and mental health of persons with dementia apart from having a positive impact on quality of life [39][40][41].

Many researchers introduced multilevel approaches to improve the engagement of persons who are residents of care homes. These include multiple approaches like staff training and socio cultural and environmental changes to improve the activities of the persons with dementia [42][43]. However there are many barriers in engaging persons with dementia in meaningful activities on a regular basis. Physical comorbidities and disabilities, affected person being in the moderate to severe stage of dementia and staff shortage etc. are some of the barriers which are frequently encountered in these settings. Government and the civil society has to initiate seamless efforts to develop evidence informed, user friendly dementia care provision in institutional settings.

### **CONCLUSION**

Dementia care, whether it is home-based care or institutional care, involves long-term rehabilitation of older people with multiple disabilities and multimorbidity. Provision of care for an increasing number of people with dementia demands deep commitment from the health and social care services and collaboration with many other sectors in the government and the civil society. It is time that we re-affirm the need for multisectoral collaboration in designing

and delivering userfriendly dementia care services which are culturally acceptable, evidence informed, accessible and affordable to all those are affected by this disabling illness. The information presented here is based on our understanding of the available literature and our experience in developing dementia care services in Kerala. Dementia research is yet to gain momentum in India and other countries in South Asia. However, it is important to make best use of the information available from the rest of the world.

We need to lobby with the central, state as well as local self governments, to allocate more funds for dementia care services. The PanchayathiRaj system of governance in India allows local self governments to design and fund health and social health care for older people. Deliberations about aged friendly local governance had been initiated at the national level and many Panchayth Raj Institutions in many states of India are moving forward with new initiatives for older people. It will be most appropriate to sensitize administrators and policy makers about the need to take proactive steps to address the huge public health challenge posed by dementia for a rapidly aging populations of India.

Renewed efforts are needed to provide rehabilitation services for people with dementia at their homes or in nearby institutions. Scaling up of these services are needed across the country. Mental health professionals have a pivotal role to play. We shall take up the responsibility of guiding and supporting the governments and the civil society in their efforts to develop good quality services for people affected by dementia. We will continue to care for people with dementia and their families in our clinical practice.

- \* The number of older people with Dementia is on the increase in India
- \* Dementia is a disabling health condition which is often associated with multimorbidity.
- \* Rehabilitation is the most important ingredient of health and social care services for people with dementia.
- \* Person centered care is the way forward.
- \* All clinicians should support and guide care of people with dementia.
- \* Mental health professionals have a major role in providing leadership in the development and scaling up of dementia care services in India.
- \* Dementia is a major public health challenge of our times.
- \* Mental health professionals need to advice the governments and the civil society to consider dementia as a public health priority.



**REFERENCES**

- 1) World Health Organization. Global status report on the public health response to dementia. Geneva: World Health Organization; 2021 (<https://www.who.int/publications/i/item/9789240033245>); A blueprint for dementia research. Geneva: World Health Organization; 2022, <https://www.who.int/publications/i/item/9789240058248>
- 2) Chandran N, Shaji KS. Supporting Home-Based Dementia Care. In *Dementia Care 2021* (pp. 155-167). Springer, Singapore.
- 3) Luppá M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord*. 2008;26(1):65-78.
- 4) Shaji KS, George RK, Prince MJ, Jacob KS. Behavioral symptoms and caregiver burden in dementia. *Indian journal of psychiatry*. 2009 Jan;51(1):45.
- 5) Brooker D. What is person-centred care in dementia? *Reviews in Clinical Gerontology*. Cambridge University Press; 2003;13(3):215-22.
- 6) Sun Y, Ji M, Leng M, Li X, Zhang X, Wang Z. Comparative efficacy of 11 non-pharmacological interventions on depression, anxiety, quality of life, and caregiver burden for informal caregivers of people with dementia: a systematic review and network meta-analysis. *International Journal of Nursing Studies*. 2022 Feb 12:104204.
- 7) Dias A, Dewey ME, D'Souza J, Dhume R, Motghare DD, Shaji KS, Menon R, Prince M, Patel V. The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. *PLoS One*. 2008 Jun 4;3(6):e2333. doi: 10.1371/journal.pone.0002333. PubMed PMID: 18523642; PubMed Central PMCID: PMC2396286.
- 8) O'Rourke A, Power E, O'Halloran R, Rietdijk R. Common and distinct components of communication partner training programmes in stroke, traumatic brain injury and dementia. *International Journal of Language & Communication Disorders*. 2018 Nov;53(6):1150-68.
- 9) Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, King D, Livingston D, Mummery C, Walker Z, Hoe J, Sampson EL. Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *Bmj*. 2013 Oct 25;347.
- 10) Aguirre E, Woods RT, Spector A, Orrell M. Cognitive stimulation for dementia: a systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing research reviews*. 2013 Jan 1;12(1):253-62.
- 11) Quayhagen MP, Quayhagen M, Corbeil RR, Roth PA, Rodgers JA. A dyadic remediation program for care recipients with dementia. *Nursing research*. 1995 May.
- 12) Davis RN, Massman PJ, Doody RS. Cognitive intervention in Alzheimer disease: a randomized placebo-controlled study. *Alzheimer Disease & Associated Disorders*. 2001 Jan 1;15(1):1-9.
- 13) Galante E, Venturini G, Fiaccadori C. Computer-based cognitive intervention for dementia: preliminary results of a randomized clinical trial. *G Ital Med Lav Ergon*. 2007 Jul 1;29(3 Suppl B):B26-32.
- 14) Neely AS, Vikström S, Josephsson S. Collaborative memory intervention in dementia: caregiver participation matters. *Neuropsychological Rehabilitation*. 2009 Oct 1;19(5):696-715.
- 15) Wilson BA. Towards a comprehensive model of cognitive rehabilitation. *Neuropsychological rehabilitation*. 2002 Mar 1;12(2):97-110.

- 16) Kurz A, Thöne-Otto A, Cramer B, Egert S, Frölich L, Gertz HJ, et al. CORDIAL: cognitive rehabilitation and cognitive-behavioral treatment for early dementia in Alzheimer disease: a multicenter, randomized, controlled trial. *Alzheimer Dis Assoc Disord*. 2012 Jul-Sep;26(3):246-53.
- 17) Clare L, Kudlicka A, Oyebode JR, Jones RW, Bayer A, Leroi I, et al. Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multicentre randomised controlled trial (the GREAT trial). *Int J Geriatr Psychiatry*. 2019 05;34(5):709-21.
- 18) Hindle JV, Watermeyer TJ, Roberts J, Brand A, Hoare Z, Martyr A, et al. Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease-A pilot randomised controlled trial. *Int J Geriatr Psychiatry*. 2018 05;33(5):718-28.
- 19) Dunn J, Clare L. Learning face-name associations in early-stage dementia: Comparing the effects of errorless learning and effortful processing. *Neuropsychological Rehabilitation*. 2007 Dec 1;17(6):735-54.
- 20) Voigt-Radloff S, de Werd MM, Leonhart R, Boelen DH, Olde Rikkert MG, Fliessbach K, et al. Structured relearning of activities of daily living in dementia: the randomized controlled REDALI-DEM trial on errorless learning. *Alzheimers Res Ther*. 2017 Mar 23;9(1):22.
- 21) Spector A, Stoner CR, Chandra M, Vaitheswaran S, Du B, Comas-Herrera A, Dotchin C, Ferri C, Knapp M, Krishna M, Laks J. Mixed methods implementation research of cognitive stimulation therapy (CST) for dementia in low and middle-income countries: study protocol for Brazil, India and Tanzania (CST-International). *BMJ open*. 2019 Aug 1;9(8):e030933.
- 22) Stoner CR, Lakshminarayanan M, Mograbi DC, Vaitheswaran S, Bertrand E, Schmidt Brum P, Durgante H, Ferri CP, Mkenda S, Walker R, Dotchin C. Development and acceptability of a brief, evidence-based Dementia Awareness for Caregivers course in low-and middle-income countries. *Dementia*. 2022 Feb;21(2):598-617.
- 23) Irazoki E, Contreras-Somoza LM, Toribio-Guzmán JM, Jenaro-Río C, van der Roest H, Franco-Martín MA. Technologies for Cognitive Training and Cognitive Rehabilitation for People With Mild Cognitive Impairment and Dementia. A Systematic Review. *Front Psychol*. 2020;11:648.
- 24) Øksnebjerg L, Woods B, Vilsen CR, Ruth K, Gustafsson M, Ringkøbing SP, et al. Self-management and cognitive rehabilitation in early stage dementia - merging methods to promote coping and adoption of assistive technology. A pilot study. *Aging Ment Health*. 2020 11;24(11):1894-903.
- 25) Burdea G, Polistico K, Krishnamoorthy A, House G, Rethage D, Hundal J, et al. Feasibility study of the BrightBrainer™ integrative cognitive rehabilitation system for elderly with dementia. *DisabilRehabil Assist Technol*. 2015;10(5):421-32.
- 26) Dröes, R. M. (1998) Emotion-oriented care for persons with Alzheimer disease. 6th International Conference on Alzheimer's disease and Related Disorders, Amsterdam 18-23 July.
- 27) Di Domenico A, Palumbo R, Fairfield B, Mammarella N. Fighting apathy in Alzheimer's dementia: A brief emotional-based intervention. *Psychiatry research*. 2016 Aug 30;242:331-5.
- 28) Särkämö T, Tervaniemi M, Laitinen S, Numminen A, Kurki M, Johnson JK, et al. Cognitive, emotional, and social benefits of regular musical activities in early dementia: randomized controlled study. *Gerontologist*. 2014 Aug;54(4):634-50
- 29) Gitlin LN, Kales HC, Lyketsos CG. Nonpharmacologic management of behavioral symptoms in dementia. *JAMA*. 2012 Nov 21;308(19):2020-9.

- 30) Shaji KS, Sivakumar PT, Rao GP, Paul N. Clinical Practice Guidelines for Management of Dementia. *Indian J Psychiatry*. 2018 Feb;60(Suppl 3):S312-S328. doi: 10.4103/0019-5545.224472. PubMed PMID: 29535467; PubMed Central PMCID: PMC5840907
- 31) Griffin A, O Gorman A, Robinson D, Gibb M, Stapleton T. The impact of an occupational therapy group cognitive rehabilitation program for people with dementia. *AustOccupTher J*. 2022 06;69(3):331-40
- 32) Zeng Z, Deng YH, Shuai T, Zhang H, Wang Y, Song GM. Effect of physical activity training on dementia patients: A systematic review with a meta-analysis. *Chinese Nursing Research*. 2016 Dec 1;3(4):168-75.
- 33) Lam FM, Huang MZ, Liao LR, Chung RC, Kwok TC, Pang MY. Physical exercise improves strength, balance, mobility, and endurance in people with cognitive impairment and dementia: a systematic review. *Journal of physiotherapy*. 2018 Jan 1;64(1):4-15.
- 34) Burton E, Cavalheri V, Adams R, Browne CO, Boverly-Spencer P, Fenton AM, Campbell BW, Hill KD. Effectiveness of exercise programs to reduce falls in older people with dementia living in the community: a systematic review and meta-analysis. *Clinical interventions in aging*. 2015;10:421.
- 35) Kielsgaard K, Horghagen S, Nielsen D, Kristensen HK. Approaches to engaging people with dementia in meaningful occupations in institutional settings: A scoping review. *Scandinavian Journal of Occupational Therapy*. 2021 Jul 4;28(5):329-47.
- 36) George DR, Houser WS. "I'ma Storyteller!" exploring the benefits of timeslips creative expression program at a nursing home. *American Journal of Alzheimer's Disease & Other Dementias*®. 2014 Dec;29(8):678-84.
- 37) Kinney JM, Rentz CA. Observed well-being among individuals with dementia: Memories in the Making®, an art program, versus other structured activity. *American Journal of Alzheimer's Disease & Other Dementias*®. 2005 Jul;20(4):220-7.
- 38) MacKinlay E, Trevitt C. Living in aged care: Using spiritual reminiscence to enhance meaning in life for those with dementia. *International journal of mental health nursing*. 2010 Dec;19(6):394-401.
- 39) Roland KP, Chappell NL. Meaningful activity for persons with dementia: Family caregiver perspectives. *American Journal of Alzheimer's Disease & Other Dementias*®. 2015 Sep;30(6):559-68.
- 40) Holthe T, Thorsen K, Josephsson S. Occupational patterns of people with dementia in residential care: an ethnographic study. *Scandinavian journal of occupational therapy*. 2007 Jan 1;14(2):96-107.
- 41) Perrin T, May H, Anderson E. Wellbeing in dementia: An occupational approach for therapists and carers. *Elsevier Health Sciences*; 2008 Jun 27.
- 42) Smith R, Wood J, Jones F, Anderson L, Hurley M. Active residents in care homes: A holistic approach to promoting and encouraging meaningful activity for residents living in care homes: *Innovative Practice*. *Dementia*. 2019 Jul;18(5):1942-7.
- 43) Brooker DJ, Argyle E, Scally AJ, Clancy D. The enriched opportunities programme for people with dementia: a cluster-randomised controlled trial in 10 extra care housing schemes. *Aging & Mental Health*. 2011 Nov 1;15(8):1008-17.



**INDEX****A**

Adherence Therapy	129
Admission	32
Advocacy	41
Assertive community treatment	131
Autism spectrum disorders	147
AVATAR therapy	132

**B**

Behavioural activation	125
Black magic	47

**C**

Case management	131
Chaining	125
Chittadhama	59
Cognitive rehabilitation	34,126,127
Common techniques	6
Concepts	4
COPSI study	75
Covid pandemic	77

**D**

Dava	82,87
Day care centre	28
Dementia	163
Destitute	46
Dua	82,87

**E**

Early intervention	148,149,151
Empathy	52
Evil spirits	47

**F**

Facilitatory factors	90
----------------------	----

**G**

GHPU	89
Global scenario	2
Guardian home	60
Gunaseelam	83

**H**

Half way home	28
Homeless person with mental illness	13

**I**

IDEAS scale	18
Income generation program	105
Indian scenario	6
Innovative practice	98
Involving the family	8

**L**

Licensing	35
Long stay home	28

**M**

Maintenance	37
Matrix model	116,120
Mental capacity	32
Mental Health Establishment	27,45
Mental health issues	27
MHCA 2017	27
Models of rehabilitation	112
Motivational interviewing	95
Multi system therapy	115

**N**

Network Therapy	113,114
Nominated representative	63,65

**O**

Organization	39
--------------	----

**P**

Prompting	125
Psychiatric Rehabilitation Centre	29,31
Psychosocial Rehabilitation	1
PWD act	29

**R**

Reintegration	66
Rescue	60
Restitution	65
Reunion	21
Role of family	8

**S**

Scales	137
Shanthivanam	15
Shaping	125
Sheltered accommodation	28
Sheltered workshop	28
Shraddha	45
Social skills training	34
Supported employment	104
Sustainability	78

**T**

Task sharing	159
Task shifting	159
Telepsychiatry	74,76
Token economy	125
Treatability of mental illness	53

**U**

UDID card	95
UNCRDP	27

  
**Vipca**  
Vortioxetine 5,10, 20 mg Tablets

**Quel**  $\frac{25}{100} \mid \frac{50}{200}$   
Quetiapine Fumarate Tablets

**Sove**   $\frac{6.25}{12.5}$   
Zolpidem Extended Release Tablets

## **INDIAN PSYCHIATRIC UPDATE**

Official Publication of Indian Psychiatric Society  
South Zonal Branch



### Previous Topics

#### **March 2021**

Obsessive - Compulsive & Related Disorders  
Editor : Rajshekhar Bipeta

#### **June 2021**

Culture Bound Syndromes  
Editor : Anil Kakunje

#### **September 2021**

Behavioural Addictions  
Editors : Vidhukumar K, Adishesamma Tiruvaipati

#### **December 2021**

Bipolar Disorders  
Editor : Vikas Menon

### Forthcoming Topic

Rating Scales in Mental Health  
Editors : Rajshekhar Bipeta, Vikas Menon