

Handbook for social workers giving hands-on support for Social Recovery of residents in Mental Hospitals



Anjali
Kolkata

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Foreword

Tracing the history of mental healthcare in India as well as the world in general, one can gauge the influence of the biomedical model and henceforth the dominance of medicines in treating persons with mental health conditions and psychosocial disability. The biomedical approach taken by most mental health professionals and institutions posits that mental disorders are brain diseases and emphasizes pharmacological treatment to target presumed biological ‘disorders’.

What this model does is it puts the complete onus of the mental illness on the individual alone thus absolving the responsibility and accountability of the society and its associated factors altogether. The focus of the biomedical model is primarily on the illness and diagnosis per se with limited or no focus on the individual, thus depriving them of the care they may need. So, what it leads to is vehement human rights violations, incarceration, pathologizing, lack of any kind of person-centric care and increased stigma, discrimination and marginalisation.

In 1999-2000, when I started working with just a few women inside Calcutta Pavlov hospital, a state-run mental institution in Kolkata, I was exposed to and appalled by the way individuals residing inside the hospital are treated; the overt pathologization of residents compelled to fit into society’s notion of the normative or ‘normal’, with medication that was not revised through regular prescription audits, electroconvulsive therapy (although these have admittedly been infrequent in West Bengal till Anjali's advocacy managed to bring it to a complete halt) and punishment through isolation and neglect.

It has been about two decades since I started working and must admit that there have been various changes over the years through various levels of advocacy and hands-on dialogue with the authorities and the government. However, the overdependence on the medicinal model still remains a concern. While I acknowledge the need and importance of medicines for certain situations, it has been proved time and again that medicines alone cannot in any way cater to an individual’s well-being or recovery, especially when other factors contributing to the individual’s distress remain underserved.

Further, as a mental health professional and social worker, while talking about the biomedical model, I feel it is apt that we also focus and reflect on the nuances of diagnosis. Diagnosis has both positive as well as negative implications: in terms of its potential, diagnosis encourages the individual to seek help, manage their condition, alleviate symptoms as well as develop a better understanding of oneself to communicate with others on it. However, what diagnosis also leads to is increase in prejudice and judgement, bias, stigma and discrimination. Having said that, it's not just that we need to be mindful of our knowledge on what constitutes mental illness, we need to also question why, as social workers, do we need to diagnose people at

all. Will these labels eradicate the structural barriers that may have led to it? Will these labels justifiably define the lived experiences of these individuals surviving and coping with poverty, abuse, family loss and the pandemic?

So, when I registered Anjali as an organisation, it was crucial for me to ensure holistic care for persons with psychosocial disabilities. This made me look into alternative models of recovery to reduce over-dependence on biomedical methods. As a humane alternative, I felt that we need to turn our gaze towards the distress and difficulties experienced and work towards dismantling those structural barriers causing it.

The social recovery model is that counterbalance of the biomedical model that propels society and other factors' responsibility to acknowledge the systemic changes imperative for the well-being of persons with psychosocial disability. The social recovery model, though often neglected within the conceptual framework of recovery, is a key dimension of mental health recovery.

This approach propels person-centric care and focuses towards regaining social recognition, acceptance, participation and identity, i.e., the holistic well-being of the individual. In contrast to the biomedical model, it takes into consideration all the socio-economic-environmental factors that may contribute towards the individual's experiences of exclusion, discrimination and marginalisation, thus making the community and other stakeholders accountable for the same. Also, the biomedical model has better chances of success if it is complimented by the social recovery model, both working in tandem to ensure a continuum of care.

Finally, having Chandana with us to lead this piece of work was hugely rewarding. Having been a therapist for so many years with constant exposure to intersecting social issues that perpetuate psychosocial disabilities was a primary reason I wanted her on board. It's a rare feat in most clinical practitioners. Chandana is also willing to be challenged and welcomes critical perspectives, which is important for me and Anjali. Further, she has versatile writing skills that make for easy yet effective understanding.

It has been a pleasure working on this handbook. I hope you, the readers, find it engaging and useful. Your acknowledgement, application and promotion will go a long way in establishing a much-needed discourse on rights of persons with psychosocial disabilities.

Ratnaboli Ray,
Managing Trustee and Director,
Anjali

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Special mention must be made of Ms. Jolly Laha, Senior Psychotherapist and Specialist in Play Therapy, Kolkata and Dr. Debabrata Majumdar, Consultant Psychiatrist and Former Associate Professor of Psychiatry, WBMES, for their valued inputs when I reached out to them for expert advice.

Chandana Baksi
Kolkata
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Introduction

This handbook provides guidelines for caregivers, across the board, interacting directly with persons with mental illnesses. This would cover everyone involved in the recovery of the ailing person, from outreach workers to support staff in mental health institutions, from administrators and managers to paramedics and professional counselors along with trainers and group and peer facilitators.

The purpose is to foster a partnership amongst the caregivers and care-receivers in a **holon***. Such a holon or a sub-system for healing necessarily needs to be semi-permeable, allowing a free flow of ideas, warmth and action between the confines of the hospital wards and the outside world, ensuring ‘recovery’ within the broader social framework.

As in any partnership, the one between the caregivers and care-receivers can only happen on the basis of a commonality of goal, equitable agency of all the partners involved and an enabling environment fostering equitable participation in the process.

The content of this handbook is an attempt to bring together the wisdom gathered primarily from experiences of hands-on workers in the field; it borrows from the experiences of the social workers (caregivers) and those of the persons ‘recovered’ and socially integrated (care-receivers). It is also informed of ideas from the social recovery model. **This is in no way a training manual** and it does not try to provide solutions to the multitude of problems that arise in hands-on work. What it seeks to offer is an embracing approach to facilitate mental wellbeing of all partners across the whole spectrum of ‘care’ and certain principles of intervention premised on the principles of equity, respect, transparency, understanding and relevance.

The handbook is divided into **5 chapters**. The first chapter **critiques the mainstream ‘medicinal’ model** as generally practiced in our state and shares the concerns that necessitated the writing of this handbook.

The second chapter explicates **The Social Recovery Model And Its Tenets** as a necessary and a complimentary model to the medicinal one. It suggests some ways of incorporating elements of the social recovery model in a traditional hospital set up thus facilitating a transition from the medicinal model to the more embracing social recovery model in a milieu that is full of stigma around mental health in general and the mentally ill in particular.

The third chapter focuses on certain **Principles Of Interaction Amongst Partners**. It exemplifies the good and effective practices of Anjali and builds on them to indicate appropriate first responses and interventions while working together with persons with mental illnesses.

The fourth chapter looks into **Community Integration** of persons who do not need institutional management any further. It talks about the “challenges” one is likely to face in the process of reintegration and how to foster an understanding between the person ready for reintegration and the members of her family and community.

The last chapter is devoted entirely to **Caring For Caregivers**. This is of immense importance as mental health and mental illness are the two ends of a continuum; absence or presence of care for the caregiver or the care-receiver determines one’s position in the continuum and propensity of movement towards either direction. This chapter attempts to offer optimum understanding of the distress affecting the identified individuals and some awareness about the impact of psychiatric medicines on the body and the mind. It also includes a matrix for mapping change in behaviour and attempts to measure the effectiveness of the partnership between the caregiver and the care-receiver. Finally, it highlights some suggestions for emotional replenishment and self-care of the caregivers.

*A holon is a Greek word that means simultaneously a part of something which is also a whole in itself. This concept is borrowed from the systemic school of *family therapy*.

The Rationale behind Another Model

The mainstream ‘medicinal model’ invests primarily on treating the **illness** that has caused mental distress in the person under treatment, disturbed the status-quo of her immediate eco-system and disrupted her functionality, so much so, that she has become a social liability. Bio-chemical intervention addresses symptoms as and when they present themselves in a doctor’s clinic and the primary motive of intervention is eradication or lessening of the symptoms. This is indeed necessary to facilitate remission of the illness, but this alone is far from sufficient. This is probably because the medicinal model, as generally practiced, is concerned about addressing the illness with limited focus on the **person**. Not only is the holistic need of the person not usually addressed here, it also has very little space for the voice of the person concerned in the whole process of her recovery.

But there are other issues as well. The etiology of mental illnesses is embedded in both nature and nurture. While some forms of emotional distress might be caused entirely by environmental factors, in others where genetic loading, organic malfunction or injury is identified as the primary cause, the immediate environment influences the frequency, intensity and duration of the “de-ranged behaviour”. The medicinal model, as regularly practiced, does not necessarily engage with these social factors.

The medicinal model is individualistic. In effect, it absolves the society and the state of their responsibility for ensuring emotionally healthy living conditions and for creating an environment conducive for a state of emotional wellbeing. It does not necessarily embrace all the tenets of mental health and focuses primarily on pathology and its treatment as manifested in an individual whose behaviour does not conform to social expectations. It does very little to empower this individual to carve out a life of choice for herself and stay positive on her own terms without causing harm to self or anyone else. The medicinal model, though humane in its intent, does not engage with the rights of the person who is mentally ill.

Inherent in the medicinal model is a hierarchy and judgment that is likely to diminish a person with mental illness further in a heavily stigmatized society. It often translates into a unilateral decision by the specialist for ‘what is best for the patient’ and tends to perpetuate for her the all-engulfing ‘patient’ identity along with her social isolation and stigma. This runs contrary to the feminist rights-based



The medicinal model is individualistic.

empowerment paradigm that aspires to change the core-margin dynamics of a discriminatory society and seeks to establish an equitable society for all with or without identifiable disabilities, with equal access to laws and equal rights over assets, and equal opportunities to participate in decision making in matters affecting an individual's life and times.

The medicinal model with its very robust scientific framework, detailed and specific investigation of presenting symptoms and highly measured and tested repertoire of bio-chemical intervention, is indeed more concerned about addressing the de-ranged parameters of thought, affect and action rather than the person defined also by her values, beliefs and experiences. The process has the risk of isolating the ailing individual from her surroundings instead of securing maximum support and acceptance from others who can offer her a healing space and a healthy holding. Most important, the medicinal model does not and cannot help her 'recover' her dignity and social position, if it had ever existed that is, as denial of dignity is a social malady in a society upholding centralized power and authority. Thus while it facilitates remission of the illness, medicines alone do very little to enhance the subjective quality of life and living conditions of the individual.

Professional counselling steps in often times to address issues that are outside the purview of the medicinal model. These mental health interventions can be made only after medication restores an optimum touch with reality in the person with such an illness. The primary objective of counselling is to work with the thought process; it is here that medicines cannot make any dent. While a chemical can reduce one's level of stress and agitation or induce energy and positive excitement or bring about a balance in one's mood or even facilitate sleep, it can do very little to interfere in the meaning making process of one's experiences. This is a very important segment of brain function and the meaning one makes of an experience determines the way in which one feels and eventually the way in which one acts. Again, in a certain kind of mental illness the stages in-between 'experience' and 'action' are disjointed and without any coordination. Here counselling trains the individual to bring an alignment between her experience and action through conditioning and engaging with her thought processing mechanism.

Then, is medication together with counselling enough for a person with mental illness to enjoy a state of emotional wellbeing? This probably depends on the severity and nature of the illness and her circumstances. In cases where the person is so distressed that institutionalization is the only option (or the person stays socially isolated even in her home), her recovery and social reintegration would require much more than medicines and professional counselling.

Mental illness robs a person of her dignity, space and voice in society; it reduces life to a mere existence with a very damaged sense of 'self' and without much goal beyond 'not causing inconvenience' to others. Medicines can do very little to prevent aggravation of the 'identified problem' by society; neither medicines nor professional counselling can ensure social safety for such a person. Medicines cannot instill confidence, hope and skills in her to assert for her rights and negotiate with others in society for herself. Professional counselling does contribute towards these but in the context of a one to one therapeutic safe space. To transfer the skills learnt within a safe and protected therapeutic space or assert the new-found confidence and hold on to her newly discovered hope in the real world that is often indifferent and even hostile, is not easy.

It is primarily via learning from day to day living in a real community of other hospital residents and staff that social recovery and reintegration of such a 'lost' individual is possible. The primary testing ground for her very own idea of wellbeing is very often a hospital space held by the social workers and other hospital staff.

Reintegration with families and communities is a two way process. While social awareness and at times social vigilance prepare the soil for integration, the individual for whom the soil is being prepared has her share of responsibility as well, towards self and towards her family and community. She has to learn to deliver such responsibilities through practice. Increasing the 'threshold of tolerance' or enhancing the ability for acceptance of the reality and managing oneself thereafter,

are skills that are learnt from modeling and practice in the wards. Such skills that are so integral to social recovery and integration are acquired by the residents from the space co-created by the whole team of social workers in hospitals.

Social behaviour is learnt mostly by following model behaviour in real life situations by observing how caregivers interact with them and with each other. Techniques of self-management in a social environment are best learnt through conditioning in a situation that is natural and real. Caregivers' and social workers' role as guides and facilitators here cannot be exaggerated.

Indeed, **social workers** spend a lot of unstructured hours with the hospital resident. They assist her in every nitty-gritty of her existence in an unfamiliar habitat that is shared by many others with similar challenges. Thus the social workers are the best resources for preparing the family members and the individual resident for reintegration.



Social workers are an integral part of the recovery process.

They are the primary holders of the care process in hospitals. They are almost always available to the resident with mental illness, very often the first contact for

her in the institution and responsible for making the first response to any emergency situation stemming from the illness. They are an integral part of the recovery process.

In the medicinal model, the role of the social worker is invisible where as the social recovery model hinges around the support from these holders of the recovery and reintegration process. It is the social worker or the hospital staff who constitutes the immediate environment for the resident post institutionalization. The social workers are neither her family nor an officious professional; they are more like companions walking the entire course of treatment with the resident. The social worker constantly dialogues with her to foster ownership of the process of recovery and encourages participation and agency. They are supposed to be approachable, understanding and available without being emotionally attached to the residents.

Let us try to understand the social recovery model in some detail before we go onto describing the principles that social workers need to be cognizant of while interacting with their companions or partners (hospital residents).

The Social Recovery Model and its Tenets

This chapter is divided into two sections. The first section is devoted to a conceptual understanding of the social recovery model and its theoretical underpinnings. The second section is devoted to a collection of sample designs for conducting group sessions with the tenets of the recovery model as objectives.

Section One

Social recovery is defined as “people’s ability to lead meaningful and contributing lives as active citizens while experiencing mental ill health”, according to Tew, J.* This is built on the notion of personal recovery on the one hand and the notion of active social participation on the other. What needs to be understood is that social recovery is not talking about restoration; it’s not about facilitating a person to necessarily fit into the mainstream social norms; rather, it talks about facilitating her in creating a kind of society where she has authorship as well as membership. This is a deeply philosophical concept that challenges many forms of polity and society.

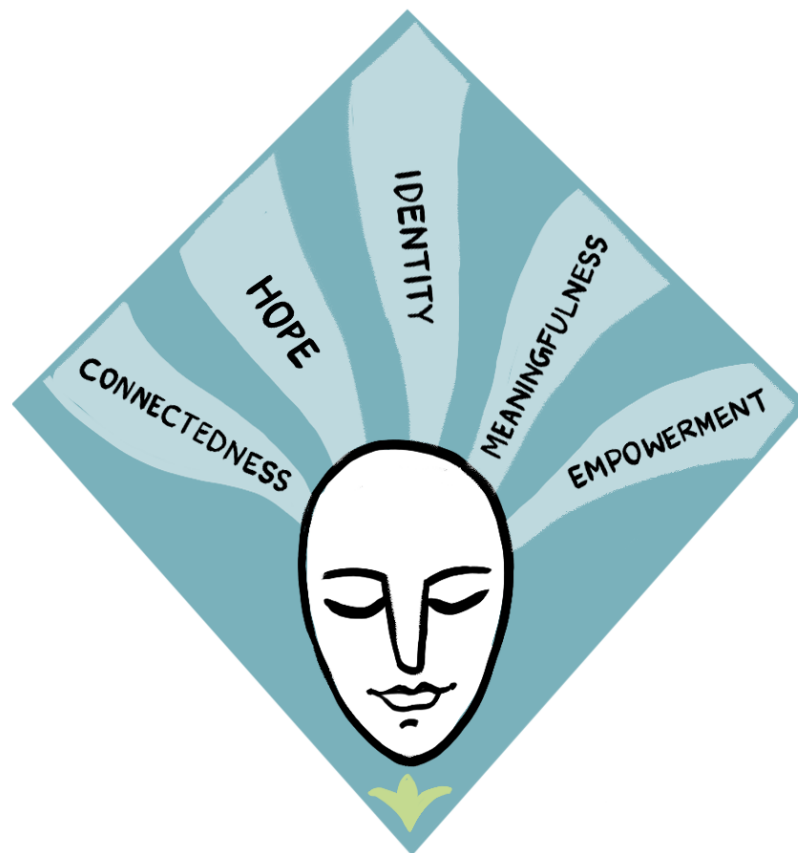
If we want to facilitate agency in the person experiencing mental illness, then the means to this end is as important as the end it-self. The means or method involves (i) Shared Decision Making (ii) Co-Production and (iii) Active Citizenship.

In very simple terms ‘shared decision making’ would involve active participation of the person experiencing mental illness in the decision making with regard to her ‘treatment’. It is a protracted process and she may not be able to take decisions initially but as she moves from one end of the continuum of mental health to the other, she has to be informed progressively about her illness, the tentative prognosis and the treatment options available to her and encouraged to take decisions after facilitating a cost benefit analysis.

Co-production looks at involving the person with lived experience of mental illness in mental health surveys, research and, ultimately, policies. Thus, this is a paradigm shift from policies **for** the mentally ill person to policies **with** the mentally ill. This addresses the ‘otherization’ of the medicinal model and is also congruent with the understanding that every human being is likely to have varying degrees of health

issues, physical and mental.

Active citizenship in the context of mental health is defined as “the strength of a person’s connections to the rights, responsibilities, roles, risks, resources and relationships that society offers to people through public and social institutions”. It believes in the potential and actual capacity of persons with lived experience of mental illness for self-governance and their collective responsibility for the social recovery of people with mental illnesses. This requires a state with a socio-political structure and systems supportive of this.



The 'CHIME' framework provides partners with a personal recovery plan.

In order to facilitate a hospital resident’s social recovery, a personal recovery plan has to be in place in the hospitals that is aligned with the tenets of social recovery. The ‘CHIME’ framework provides the partners with such a personal recovery plan.

This framework has five inter-related tenets; *connectedness*, *hope*, *identity*, *meaningfulness in life* and *empowerment*. It is believed that for social recovery (ability to lead a meaningful and contributing life), one needs to be *socially connected* to family, neighbors, pharmacists, barbers, grocers, peers and state agents

amongst others. Increased skill for social interaction and greater social acceptance generates *hope and optimism* in her about herself and around enhancing the quality of her life. This hope can be about setting a target for daily exercises or taking full responsibility for hospital follow-up consultations, etc. Each baby step towards fulfillment of her hope shapes her *identity* and she feels confident. With her sense of identity finding a firmer footing, she seeks self-expression in ways *meaningful* to her. This can be a pursuit of art or a skill or nurturing a natural positive quality. The whole process is *empowering* which finds further fruition in awareness and exercise of rights and participation for expansion of rights. These rights pertain to general human rights, rights of persons with identifiable disabilities, rights pertaining to dignity, vocation, housing, equity and justice amongst others.

These tenets are essentially values that can be fostered by caregivers who may or may not have any technical skill. However, it is important for them to have conviction in these values and to live by them in their own lives. They have to realize and accept mental illness as a health issue, similar to physical illness that affects all of us in varying degrees in terms of intensity, frequency and duration. They have to have faith that ‘otherization’ is not a way out for addressing differences between the caregiver and the care-receiver; it is only through feeling deeply with the care-receiver that she can understand her and accept her primarily as a ‘person’ and hope to establish a trusting, equitable and respectful rapport with her and engage in a partnership for her social recovery.

To help the residents inculcate the values embedded in CHIME, short and simple group sessions can be considered. These will provide a space for engaging with these values, practicing skills that are hinged around these values and learning from peer support and peer appreciation.

Some easy sample sessions are provided in section two below, for the consideration of the caregivers. These are structured sessions following some ‘do’s and don’ts’ that facilitating caregivers have to be aware of while conducting the sessions.

Section Two

Session Objective: Facilitating Awareness Around Identity (1)

Group size: 8-12 participants per facilitator

Time: 1 hour

Key Points for Facilitators:

- All of us have an identity and there are various components of our identity; some, of which we obtain from birth

- There are certain components of our identity that we establish later in life.
- The components of the identity we shall talk about today are the ones we are born with viz name, address, biological sex, age, nationality, mother tongue, etc.

Methodology: Plenary Discussion

Activity: Participants sit in a circle; the facilitator asks an open question, “Today we shall talk about ourselves. Who would like to tell us something about yourself?” As a participant responds, he can start from anywhere he pleases; an abrupt account of the family to which he belongs, his name or something he likes doing or something or someone he is missing. The facilitator listens taking in how bits and pieces about himself emerge from the maze of his account. Once he stops or gets repetitive or starts rambling, the facilitator might ask open but directed questions to cull out some basic information from him (name, biological sex, age, language, family members, address, nationality). The data generated is organized into a format as the primary identity of the participant. The facilitator asks the group as to who would go next.

It is better if these are noted down by the co-facilitator and in a subsequent session the participants are helped to transfer the information about their identity in an activity book.

The purpose of the exercise is not investigative; it is to facilitate awareness generation amongst residents about their own identity and the identity of co-residents.

Session Objective: Facilitating Awareness Around Identity (2)

Group size: 8-12 participants per facilitator

Time: 1 hour

Key Points for Facilitators:

- There are components of our identity that we acquire by dint of our abilities, work and interests
- Today we shall discuss about our abilities and our interests

Methodology: Plenary discussion

Activity: The participants sit in a circle. The facilitator addresses the group and asks an open question, “ Today we will discuss about some of the skills that we have; something that we have done before and the skills that we would like to acquire or things we want to learn. Who would like to share first?”

As the participants respond, the data generated is noted down. These are added to the individual Activity Book.

This is the second layer of identity development that is fostered.

There can be multiple sessions on identity development across a whole range of personal, social, political, professional identities.

Session Objective: Fostering Connection (1)

Group size: 8-12 participants per facilitator

Time: 1 hour

Key Points for Facilitators:

- When we stay in a hospital or in our home, we stay with other people. This requires knowing each other and understanding each other’s likes and dislikes
- Bonding helps us to look after each other when one is hurt or ill and even have some fun time together like playing together
- Bonding also helps us to do things together so that we can bring about some changes in our life in the hospital or outside

Methodology: Game (Hot seat)

Activity: Participants sit in a semi-circle. The facilitator sits in the gap and keeps a vacant chair beside her. The facilitator says, “Today we shall see how much we know each other. One person has to occupy the hot seat and other participants have to share something about her. Who would like to take the hot seat?”

As a participant occupies the seat and 4/5 other participants share 4/5 sentences about her, the facilitator initiates a clap of applause and invites the next willing participant to the hot seat.

As and when the interest level of the group drops, evident from their body posture, the game is concluded for the day. It can be taken up again on another day.

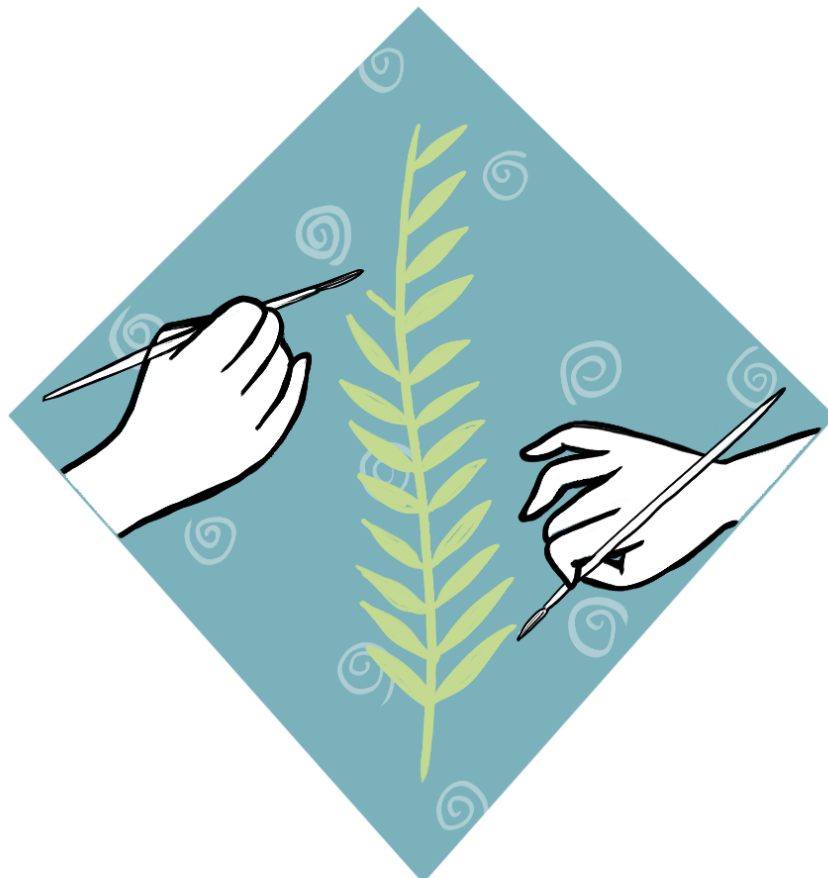
It can be conducted in another format where some participants are invited to be part of an inner circle while those at the outer circle share something about each member at the inner circle.

This exercise is likely to enhance peer bonding and strengthen self-esteem.

Session Objective: Fostering Connection (2)

Group size: 20 participants per facilitator

Time: 1 hour 30 minutes



When something is created together, something very rich and interesting emerges.

Key Points for facilitators:

- When something is created together, something very rich and interesting emerges with the coming together of many ideas and skills
- When we contribute to the creation of something big and see our inputs in the final product, we feel that we have achieved something together, our contribution has some value and that we belong to a larger group.

Methodology: Art with Play Dough

Activity: Participants are each given a lump of play dough and some more clay is left at the centre of the room. The facilitator addresses them, “Today we will create a play garden together with the help of the play dough. Each one of you have a lump of play dough with you with which you can create anything that you want to keep in your garden. If you want to keep more than one thing in your garden, you can take some more play dough and make it.”

After a time limit everyone is asked to place their creations in the middle of the room and the co-facilitators and the facilitator, with the help of the participants, arrange them in a colorful garden.

Such exercises will facilitate sharing of space and co-working habits as well.

Session Objective: Generating Hope (1)

Group size: 8-12 participants per facilitator

Time: 1 hour 30 minutes

Key Points for facilitators:

- Hope is for achieving something that will enhance the state of emotional wellbeing
- This session focuses on setting small targets for self; a target behavior, a new habit, a target personal care activity. Small targets will be set for each participant with regard to these and a weekly review of how the target could be achieved, will be conducted based on self assessment and peer feedback.

Methodology: Individual work and plenary discussion

Activity: Each participant mentions in the activity book a specific *behaviour* that she wants to set as a target; example, she wants to verbalize what she would like to do when angry instead of acting it out. Then she would mention a *habit* that she

would like to cultivate; example, she would keep her bed clean and tidy. Lastly, she sets a target for *self-care*; example, she will brush her teeth every day. Each participant is likely to have a different set of targets and they create a checklist to mark each of the targets achieved for each day. Peers are facilitated to discuss how they can help each other to achieve the targets by acknowledging the effort, giving reminders and motivating them.

With time the targets will be directed towards taking responsibility of her psychological wellbeing like taking medicines, joining group activities, accessing counselling etc; of social behaviour example, stop pushing, spitting, hitting or calling names; of self growth and self expression.

The targets are eventually likely to include creating something together in the hospital, taking responsibility for each other within the hospital, negotiating with hospital authorities and the state for change. Whatever be the target, small or big, its benefit for the individual has to be made very clear before bringing in the perspective of the collective.

The targets have to be easily relatable to the self of the participant and set backs have to be addressed with more support and encouragement from peers and the facilitators.

Sample checklist for an individual participant:

Behavior	Mon	Tue	Wed	Thu	Fri	Sat	Sun
No Spitting outside the washbasin							
Talking to 2 other residents							
Going for counselling							

Session Objective: Facilitating Meaningful Existence

Group size: 8-12 participants per facilitator

Time: 1 hour

Key points for facilitators:

- Meaningful existence has two aspects in the context of mental health; on the one hand it means living for developing one's potentials and on the other it means contributing to society.
- While vocational training classes can take care of nurturing and developing one's potentials, the group space can be utilized for facilitating empathetic responses amongst the participants in realistic situations thus encouraging them to become socially contributing individuals.

Methodology: Role-play

Activity: Participants sit in a semi circle. The facilitator sits in the gap and narrates a situation where a person needs assistance of some sort. Any participant is invited to play the role of the person who needs assistance; others are encouraged to come forward to assist him in different ways. This is a dry run for situations they are likely to face in society once they are reintegrated.

Some possible situations:

1. A baby is alone and needs babysitting.
2. A person has high fever and is in a lot of physical discomfort.
3. A hospital inmate is very sad and feeling lonely.
4. A student needs help in studies.
5. In a flood situation, some people are scared and some others are trying to guide them to a safe place.

After the role-play each participant is asked to give feedback on how she felt while enacting the role and what her takeaway from the role-play was. The facilitator might add a couple of practical tips to help them intervene more effectively in the event of such a crisis in real life.

Session Objective: Facilitating Empowerment

Group size: 8-12 participants per facilitator

Time: 1 hour

Key points for facilitators:

- Power comes from access and control over resources.
- Money, information, connections, time are some of the very important resources that we have to have some access and control over in order to strengthen our power.
- The vocational training classes help us to earn money and enhance our self-reliance and power to some extent.
- Information about our rights also help us to feel confident and powerful.
- The group session can be utilized for increasing our knowledge about our rights.

Methodology: Interactive Lecture

Activity: Participants sit in a semi-circle; the facilitator takes 4 to 5 clauses of the Mental Health Act of 2017 for one session and goes by each clause very slowly, enquiring how that particular clause has helped the participant and where do they see its application in the hospital setting. For the clauses not yet implemented by the state, the participants are asked how such a clause would be helpful for them. The process of implementation can be explained to them; how they can place a demand for their implementation can be explored. It is to be remembered that the participants have to be asked how each clause is relatable to their individual wellbeing in the first place.

It is important to break up the Act into small parts and take each part for a session; the next session can start with a quick recapitulation of the clauses discussed in the last session. There is no need to avoid clauses that have not yet been implemented. The transfer of information has to be as transparent as possible as the Act has direct bearing on the participant's quality of life. It has to be explained that implementation is a process and it is not automatic, it takes time. Often a lot of effort by organizations like Anjali goes into it. But sooner or later they are implemented. So they need to wait and meanwhile plan how they would communicate their demand to the authorities for implementation of certain clauses.

Do's and Don't's of Group Work

#	Do's	Don'ts
<u>1</u>	Facilitator plays a supportive role, encouraging peer appreciation and peer feedback	Facilitator does not single out an individual to either praise or condemn. This will reduce the chances of feeling discriminated and jealous.
<u>2</u>	The facilitator lets a participant be in a group session if he is unwilling to participate; he can co-explore his area of alternate interest and facilitate his engagement there.	The facilitator will not pressurize a reluctant participant to take an active part in a group session.
<u>3</u>	The facilitator has to inform the group of residents in a positive way about the participant's disengagement with this particular group work (example, it can be said that he has some idea about the skills that are being practiced here and wants to develop his skills in an alternate area).	The participant should not be withdrawn from the group without informing others; by way of explanation it should not be said that he 'doesn't' have interest in this skill and hence he is trying out something else; such a communication is likely to demotivate other participants.
<u>4</u>	The facilitator has to work around specific and concrete issues affecting the participants directly; skits or storylines for role-play has to be based on reality or at least realistic.	Discussion around abstract ideas and fantasy has to be avoided especially for residents with schizophrenia as this might further confuse them.
<u>5</u>	Participants have to be treated with respect and equitably; it is best if all are seated at the same level, spoken to at an audible even volume, with a respectful tone of voice and body language,	Hierarchy has to be avoided in seating arrangements, tone of voice and verbal and non-verbal communication.

#	Do's	Don'ts
6	Time and space sharing has to be encouraged in the group sessions in a positive way; some guidelines for working together can be co-created with the participants to facilitate expansion of threshold of tolerance on the one hand and learning to share on the other. Peer feedback in cases of non-compliance and adherence to the guidelines has to be encouraged.	The facilitator cannot be either indulgent / ineffective or judgmental in holding the group space. She has to co-hold it with the participants with the responsibility of monitoring and reviewing group guidelines shared amongst participants.

*Recovery Capital: What enables a sustainable recovery from mental health difficulties? By Jerry Tew in European Journal of Social Work 16, 2013.

Principles Of Intervention In Caregiver - Care-receiver Partnerships

Intervention and partnerships are the twin pillars of our discourse in this chapter. In fact, in the Caregiver – Care-receiver holon, the two go hand in hand. The principles of partnership presuppose the principles of effective, appropriate and relevant intervention by social workers and other hospital staff in daily interactions with the hospital residents.

Looking at some real examples from Anjali’s experience will help us to understand the linkages better. First let’s look at an **effective partnership**.

In the hospital setting, the different partners involved in the process of recovery may have different opinions about resident participation in the vocational training sessions. While some caregiving partners might feel that a certain level of remission (absence of positive symptoms for example) is necessary before a resident is introduced to vocational training, some others might feel that a vocational training is a necessary step towards her recovery and reintegration with society - the presence or absence of symptoms should not be given much importance. An individual care-receiver might be especially motivated to be a part of such a vocational training program while another might be very reluctant to put in any proactive effort. How will partnership work in co-charting a way forward where such diverse minds are at work?

I would like to share an example from Anjali’s experience in this regard. A resident in a district mental hospital with visible negative symptoms was brought into a structured group session on art.

The immediate goal of the activity was skill development in art. However, the upfront objective behind the activity was emotional wellbeing by facilitating expression of self and boosting creativity; the underlying objective was an initiation into working as a team and capacity development for economic self-sufficiency.

The individual concerned was observed by the social worker as disinterested and totally passive throughout the session. The social worker took him aside and

initiated a dialogue with him trying to understand what was bothering him. He shared quite bluntly that none of the group sessions interests him and he finds nothing of any relevance to him. He also added that engaging with a group in a structured space is stressful for him.

The social worker continued to have dialogues with him over several days. Such dialogues would also include silences and occasional sharing. After a couple of such sessions, the inmate shared that he would sometimes feel like writing. The social worker encouraged him to write. Slowly he started writing and sharing those write-ups with the social worker. A co-exploration with all the residents and social workers about how to bring the creative spaces together gave birth to the idea of putting up a wall magazine where residents would contribute their write-ups and paintings.

The concerned participant felt comfortable to engage with his peers who were interested in contributing to the wall magazine. Learning from peers is a very effective form of learning and slowly all the participants started contributing to the wall magazine. The magazine was a success as all participants were happy to showcase their creative work. They received acknowledgement and compliments from other residents and hospital staff. This encouraged the original initiator further to take a more proactive part in the activity. Eventually he became the person in charge of the wall magazine, encouraging some others to write as well and creating more options for creative expression for the residents.

Thus, a partnership between two individuals to begin with (a caregiver and a care-receiver), extended into a partnership between caregivers and hospital residents and paved the way for a breakthrough result achieving the objectives that the original activity hoped to achieve, if not more.

Before we move on to articulating key principles of partnerships that were operational here, it will be interesting to look at the story of an **unsuccessful partnership**.

A young wife approached Anjali's kiosk that was operating from a suburban unit. She sought help for her husband who was increasingly becoming suspicious and violent in his behaviour. The marriage was okay at the beginning, according to her. This untrusting behaviour and the consequent conflict spread beyond the marriage in his interpersonal relationship with other members of his family, all staying in the same house.

The wife was proactive in cooperating with Anjali's outreach workers and was involved in the whole process from hospitalization and subsequent release of the gentleman after a few months. The other members of his family stayed away from the whole process so far. When he returned, with marked improvement in his behaviour and his mood, the other members of his family influenced him to stop taking the prescribed medicines. The wife got totally isolated and could not engage



The common goal is social recovery and emotional wellbeing of all concerned.

with her in-laws or even her husband to convey her concerns around the abrupt withdrawal of medication.

About six months later he started getting agitated over small things and matters came to a head when one day he attacked his wife with a knife. The wife left the house and eventually divorced him. Members of his family blamed his wife's actions for his mental illness. The members of the family did not respond to Anjali's follow up visits favourably as they did not experience the social workers as their allies and probably identified them as supporters of the "erring" wife.

This is a classic example where the wife and the social workers worked for the social recovery of the person with mental illness but other stakeholders remained outside the partnership. The worst sufferer in the whole incident was the man with the mental illness who was left distressed and uncared for and is presently incapable of enhancing his state of wellbeing on his own.

The two examples obviously ended on completely different notes. As we shall see, the effectiveness of the first example was based on an alignment with certain key principles of an effective partnership*.

Principles underlying Effective Partnership

The partnership we are talking about is amongst all the stakeholders in the social recovery of a person with a lived experience of mental illness; the group obviously includes the caregivers and the care-receivers amongst others. The common goal is social recovery and emotional wellbeing of all concerned.

It is a given that individuals involved in the partnership for social recovery would come into the space with their diverse subjectivity. The first principle to address the multiplicity of contexts and ideas of such a partnership is ***Diversity***. Partners operating from different contexts and with unique ideas have to be facilitated to explore each other's motivation, values and underlying interests; this will build understanding, foster inclusion and encourage appreciation of the added value that comes from diversity.

The other important principle without which a proper partnership cannot take place is that of ***Equity***. Equity is built by truly respecting the views, attributes and contributions of all stakeholders involved. A partnership in which some partners are marginalized and some others are privileged, has serious problems that need to be addressed. Co-ownership and co-accountability of the process of social reintegration has to be necessarily premised on equity.

Partnerships quickly get stuck where there are hidden agendas. ***Openness*** and transparency are therefore integral parts of an effective partnership. There is a difference between information that needs to be kept confidential for legal reasons and information that are being intentionally kept a secret. In order to build trust it is necessary to be transparent even if that leads to disappointment, sadness or temporary discomfort. It is indeed a small price to pay for building something as important as trust.

A partnership will be effective only when it talks about ***Mutual Benefit*** or wellbeing for all. There has to be a conscious effort to understand and respect the rights of all partners and explore how all stand to gain from the collaboration.

Last but not the least, ***Courage*** is another vital principle operating in all effective partnerships. There is no courage without fear, as it is said. Perhaps the only thing that all partners have in common at the start of any partnership is their uncertainty about each other, the partnership itself and what it will demand of them. Partners have to be bold rather than tentative if they are to achieve results. Courage most definitely leads to breakthrough results.

In Anjali's story of a successful partnership, *diversity, equity and courage* are some of the principles that were visibly operational. In the second story however, *diverse stakeholders were not part of the process and therefore neither was there equity nor openness*.

Let us now consider the other crucial pillar of our present discourse, ‘interventions’. Using examples from Anjali’s experiences with residents at the hospitals, we shall try to understand how the social workers can implement certain principles of interventions in their interaction with residents. These principles are informed of a theoretical understanding of the nature of the malady affecting the residents and experiences of practitioners in the field.

Intervention Principles

While the principles of an effective partnership has more to do with the appropriate approach or strategy vis-à-vis the recovery process and the right **attitude** amongst all the partners involved in a hospital context, ‘intervention’ to facilitate recovery of persons diagnosed with ‘schizophrenia’ also requires an understanding of the most appropriate **method** for transferring skills and social education.

Learning through modeling and role-play has been found to be most effective empirically in training persons with schizophrenia. Residents learn from observing the behaviour of the team of care providers towards each other and towards them. The residents learn about how to share space, how to listen to others, how to communicate with respect, how to mitigate difference without hurting self or the other, how to help each other and cooperate with each other and work together with enthusiasm and positive energy i.e. all about social education in a nutshell, through observation and skills practice within the hospital set up. Structured group sessions are very useful for skills practice and collective learning. This has already been elaborated in the previous chapter.

Apart from transferring social education skills, caregivers are responsible for providing first responses to various untoward situations arising daily in the hospital premises. Here are certain principles that can be followed by caregivers in intervening in conflict situations amongst residents.

1. Relatable to the self

The primary thing that one needs to keep in mind is that any and every response has to be **relatable to the self** of the resident. The motivation to change one’s behaviour for the benefit of the other has little or no appeal for most of us. However, what matters to us is the social consequence (our image, dignity, other repercussion, etc.). Empathy as a factor prompting change in behaviour is not uncommon amongst humans. Such a person has to personally experience empathy and at that point of time, has to be in a better state emotionally than the person she is empathizing with. For someone who is socially ostracized and who is in ‘as bad an emotional state as the other’ if not worse, a change in behaviour is likely to come about if she can understand how such a change will help her satisfy her own needs better.

Example:

A resident kicks another for no apparent reason when the latter was sleeping at night in his own bed. What could be an effective way of responding to the complaint of the latter to the social worker?

First of all, the resident who was hurt has to be taken aside and given a safe, and if possible, exclusive space to share all that he has to say about the incident. The social worker has to listen to him, validate his feelings, support him emotionally and explore what remedy he seeks. He has to be assured that some definite steps will be taken to make the 'offender' responsible for his behaviour and motivate him to change his behaviour. If he wants to make an official complaint against the behaviour of the offending resident, he can be helped to do so. It can be explored if he wants to stay separately from the other for some time and a request for shifting temporarily to another room can be processed.

With regard to the resident who kicked his peer, it has to be understood by the social worker that by 'kicking' he wanted to communicate something. May be something about the peer had angered him in the morning which he did not know how to communicate. Nothing can be for 'no reason'; the reason may even be imaginary but he will have his own reasons. So the task of the social worker will not be to reprimand him and to make him feel ashamed for his behaviour. On the contrary, it will be to help him express verbally what he had wanted to communicate through his action. The social worker needs to be patient, respectful and supportive in helping him articulate what was going on in his mind. After listening to him the social worker has to explore with him how else he can express himself instead of kicking or physically hurting someone.

The benefit of changing his behaviour would be that he will be able to communicate more clearly what had disturbed him; also his behavior, if imitated by others, is likely to increase the tension and chaos of the space. He can be asked if he would prefer a safe and secure space or one full of chaos and confusion.

The professional counsellor can take it up from here in helping the resident to articulate his needs rather than acting them out.

In order to measure the effectiveness of the first response and the counselling intervention and to motivate the residents to change their behaviour, they can be provided with a personal behaviour checklist which can be discussed in a group; the changes in behaviour can be acknowledged; in case of no significant change recorded, they can be given more assistance and support wherever required by the social workers and the peers. A sample self-monitoring checklist is provided in the previous chapter.

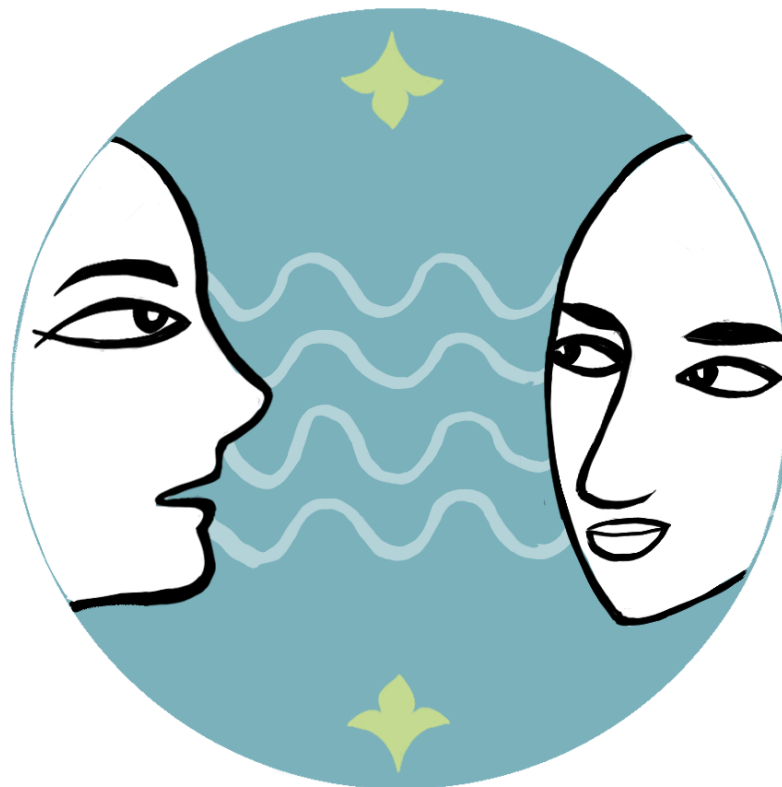
2. Practical and concrete

Another principle that is likely to be most effective with residents having ‘thought’ difficulties, like schizophrenia, is that any suggestion for change in behaviour has to be **practical and concrete**, not something undefined and left to the resident’s discretion.

Example:

A resident sharing the room with many others, keeps the volume of the television to the maximum, to the utmost discomfort of others. Another resident of the same room complains to the social worker that the TV volume disturbs his sleep.

The social worker has to listen to the discomfort of the complaining resident and express her understanding of the problem. Then she approaches the resident who has



The social worker has to listen to the discomfort of the complaining resident.

kept the television on full volume and enquires about the programme he is watching and what he is enjoying about it. The social worker has to validate his wish to take in the programme as much as possible. After this she can show him the scale of volume and invite him to find together the optimum unit of volume that allows him to hear the programme properly. The social worker practically reduces the volume

unit by unit, asking at every step if he could hear the programme properly at that reduced level of the volume. So step by step an unit can finally be co-identified by the social worker and the inmate at which level he can comfortably listen to the television programme without having to raise the volume to the maximum. This new learning by the resident can be reinforced by a couple of follow-up reminders or checks on subsequent days to ensure that he maintains the volume at the level optimum for his hearing.

3. Exploring and validating the personal meaning of a wish

Yet another principle of intervention or interaction with the resident is **exploring his very personal meaning of a wish** or demand by asking very specific and pointed questions and **validating** the wish genuinely. No attempt should be made at reasoning it out with him at the stage of exploration of the meaning and validation of the wish. In fact, instead of reasoning it out with him, relevant information can be shared and he can be helped in finding a way of enhancing his level of satisfaction within the constraints of the reality.

Example:

A resident asks the social worker everyday about her date of release from the hospital as she wants to go back home, to her family. This has been going on for a prolonged period and the social worker knows that the family is in no hurry to take her back.

The social worker can ask her very specific questions about her home; instead of asking, ‘what does home mean to you?’ she can ask about the colour of the house, the number of rooms, where she would spend most of the time, members of her family and what would be the 4 or 5 things in her home that were her favourites. The inmate’s wish to return to her home has to be validated thereafter. Sharing the details of her home and validation of her wish will emotionally comfort her to a large extent that she is heard and understood.

After this she has to be given relevant information on the process of release from the hospital, variables involved in the process and Anjali’s role in all of this and limitations. But the conversation should not end here.

She can be asked to choose from her favourite objects from home and if inclusion of any one or two of them in her room or bed in the hospital would help her feel a little bit more at home at the hospital set-up. The team of caregivers can consider arranging for something similar to her favourite object to facilitate greater acceptance of her present situation at the hospital and lessening of emotional pain.

4. Facilitating agency

Another important principle of intervention by a social worker is facilitating the **agency** of the residents and **involving them in the process of problem solving**.

Example:

Complaints against the food served at the mental hospital is very common among the residents. A group activity can be initiated amongst the residents where they share their wants with regard to food. They can share their preferences in terms of the (i) variety of vegetables and non-vegetarian food, (ii) spice level – spicy or bland and (iii) taste – sweet, salty, sour or bitter.

An inclusive list can be made and handed over to the hospital authorities with the understanding that at least twice a week their lunch or dinner would include an item from the list. If the kitchen can announce beforehand the item that would be served on the stipulated day, the residents would look forward to it with positive excitement, feel validated and empowered. This would help them to become solution focused rather than complaint oriented. This shift would go a long way in increasing their threshold for adjustment when they are reunited with their family members who might not be in a position to afford a dish of their choice all the time.

5. Facilitated in giving a considered opinion

The resident has to be **facilitated in giving a considered opinion**; his opinion has to be given due **weightage** and there has to be **appropriate information sharing** about things affecting him.

Example:

When a resident who is part of the recovery program either openly refuses to take medicines or spits them out surreptitiously, the social worker has to take him aside and ask him about his concerns around medicine. These concerns have to be listened to and accepted genuinely as his concerns without volunteering to offer him a different perspective at this stage of communication.

After he has shared his concern, he has to be asked how he was at home before coming to the hospital and if he thinks there has been any change in him between then and now and if he feels any better. He has to be asked how the change came about. It is here that the contribution of the psychiatric treatment has to be showcased. He can be invited to share his concerns about continuing with the medication with the consultant psychiatrist. Some of his concerns may be addressed via the psychiatrist and some others by the professional counsellor.

6. A combination of immediate responses and some long-term strategies to address the deeper issues

Bullying is a common phenomenon among hospital residents. The old pals bully the fresher and in Anjali's experience the participants bully the hospital residents who are not part of Anjali's programme.

Bullying is not a problem exclusive to mental hospitals. It is the most common and easy recipe for bonding, venting aggression and claiming power amongst peers across communities.

This problem has to be approached with a combination of immediate response and long-term strategies for both the one who is bullied and the bully.

The complaint of the resident who was at the receiving end of the bullying episode has to be listened to with full empathy, his feelings validated and wishes for resolution explored. A reporting mechanism has to be in place whereby he can report about the incident formally. He has to be assured that measures will be undertaken to hold the concerned person accountable and assist him change his behaviour.

Alongside, a process has to be undertaken to strengthen the former's self-esteem. This will take time but will help him immensely in the long run. He can be facilitated in identifying his progress from the time he was admitted in the hospital and the positive qualities, potentials and skills that he possesses. He can be helped in identifying spaces where he can express his grievances and provide feedback to the erring resident. He can also be helped in the preparation for expressing himself and giving feedback to the concerned person. The facilitated group meeting can be a space where such a feedback is given to the resident who has bullied and it can be reframed as a target behaviour change for the latter.

With regard to the one(s) who has bullied, a discussion has to be organized around what his intention was. The response of the social worker will depend on the response of the resident. If he says that he was only doing it for fun then it can be said that it is understood that he wants to have some fun but something can be considered as fun only when all involved enjoy it. If anyone feels bad then it is no longer fun and that method has to be discarded. He can be encouraged to discuss and find out alternative ways of having fun together.

So far as the need to assert power is concerned, this individual or group of individuals can be divided into multiple committees with specific responsibilities, example, games committee, celebration committee, academic committee, beautification committee etc. The work of each committee needs to be reviewed by the peers regularly and acknowledged and appreciated by them appropriately.

As a long-term strategy to stop bullying, opportunities for physical exercise have to be created to ensure that their aggressive energies are properly channelized.

Aggression can be evoked by the nature of their illness, their state of confinement, living conditions or they might also be angry at life in general. Whatever be the cause, their aggression needs safe release. Games requiring physical exercises like football, basketball, badminton etc can be built into their regular routine so that their pent up aggression is released via a fun activity that also fosters 'team' skills and facilitates bonding.

Community Reintegration

Community reintegration is a multi-pronged process involving all stakeholders in the business of health and wellbeing. Much has been said about preparing the hospital resident for a meaningful and contributing life outside the hospital premises. We shall now talk about the other stakeholders who have to be encouraged to be proactive participants in the process and made accountable for it.

Community reintegration of any individual with a physical or mental challenge is problematic in a state where the annual allocation of budget for health issues is inadequate at the level of polity and the sense of community is giving way to an urbanized and highly individualistic existence at the socio-economic front.

At the micro level, there are many families that look upon mental hospitals as a permanent solution to absolve their responsibilities towards the ailing member of their family. The Mental Health Act 2017 seeks to address this by limiting the maximum number of days a resident can stay in a mental hospital. The social worker has to play the very important role of a negotiator in such cases. The basic clauses of pre-integration negotiation between the person with a lived experience of mental illness and her family are as follows;

On the one hand, **the person with the lived experience of mental illness**, has to commit to look after herself, maintain hygiene and take medicines regularly; her **family members**, on the other hand, have to commit to providing her with clean lodging, nutritious food and medicines. All have to be assured in no uncertain terms that her condition will improve if these are maintained in all earnest.

The psychosocial education of the family has to start from the very first day of treatment of a resident at the mental hospital (provided a family member has accompanied her). At the very outset, the stigma and myths around mental illness have to be addressed.

The **social worker** plays a pivotal role in easing the flow of people and ideas between the hospital and outside. The concerns of the **family members** have to be heard and their feelings validated. A member of the family will feel encouraged to listen to the **social worker** only after he feels understood and respected. The following ideas have to be communicated to the **family members** and endorsed by the **consulting doctors**:



**Family members to provide with clean lodging,
nutritious food and medicines.**

- There is a continuum between being healthy and being ill. Anyone can move from one end of the continuum to the other under certain circumstances. Improvement and management of mental illness is **always** possible through proper intervention viz, care, medicines, therapy and training. Many mental illnesses can also be cured.
- Health does not mean absence of diseases; any person is as much liable to have mental health issues as physical health distresses. Health refers to a state of wellbeing that exists in spite of physical and mental challenges.
- Just as some physical health conditions are chronic issues, some mental illnesses can also be recurrent though relapses can be managed and even prevented with prolonged medication and other mental health interventions (example, counselling or psychotherapy).
- Just as in physical illnesses when an organ or system gets affected other organs and systems continue to remain functional, in the case of a person having mental health issues, his mind continues to remain functional in some aspects while the illness might significantly impair brain functions in some others.

- The family members have to be encouraged to identify areas where their ailing relative is functional in spite of the illness.

By engaging members of the resident's family into conversation around the illness, the myths around mental illnesses have to be explored and a rational perspective has to be offered. For example, notions like "mental illness is caused by someone casting a spell" or "it is the work of a bad spirit," have to be understood as in the light of a way of coping with the reality by blaming some external agent for it. The more a member of the family is assured of assistance and an improvement of the mental health condition, the easier it will be for him to accept the reality. This is likely to encourage him to take a proactive role in the social recovery process. Inviting family members as volunteers in the hospitals to assist the social workers will further empower them with the understanding of the ailment and is likely to enable them to be effective partners in the process of social recovery. It will foster greater connection between them and the person affected by the illness, and prepare the soil for her social reintegration.

There are also myths around appropriate diet, her right to ordinary emotional expression and sexuality. It is very important for the social worker to be clear about such misconceptions. The popular notion that certain kinds of diet enhances sexual urge and that sexual urge is harmful for a person with mental illness is as irrational and unfair as the restrictions imposed on widows in our country. Psychosocial education of family members with regard to proper nutritious diet for the member with a lived experience of mental illness has to be undertaken very seriously. The concerned person's wish has to be explored and considered in all sincerity.

Reintegration of a hospital resident is followed up by the social worker's intermittent but regular home visits. The common 'complaints' of family members during such home visits are around her expression of aggression and sexuality. The pre-integration negotiation between the family member(s) and the person reintegrated has to be discussed every time (preferably) and the state of affairs audited and re-negotiated by all concerned. With regard to expression of anger and irritation, the reintegrated person's right to emotional reaction for a justifiable cause has to be explained clearly to the members of his family.

However, all concerned (especially including the person reintegrated) has to be made aware of certain cues that necessitate mental health intervention in terms of medicines and counselling. Given below are some of the cues that would suggest that a visit to a doctor is required without further delay to prevent escalation of violence and a relapse:

Cues

- Negative thoughts (articulated)
- Reduction in food intake
- Sleeplessness
- Increased restlessness
- Acting agitated / irritability/ quick temperedness
- Feeling tense or fearful
- Excessive lack of energy
- Loss of interest in activities
- Confusion in thinking
- Worsening of positive symptoms (delusion, hallucination)

With regard to sexuality, these are natural urges and are not to be taken as an indication for relapse or an aggravator for one. In most cases, medicines lower the libidinal urges for a person treated for schizophrenia. In the context of our society, a woman with a lived experience of mental illness is less likely to complain about reduced libido. Her male counterpart will often share his concern for reduced libido with the attending doctor. The social worker has to encourage the person with a lived experience of mental illness to articulate her concerns with the doctor and the **counsellor**. In fact, it is better for a counsellor to sit the resident and her partner down, before she moves back to her home, and talk about the sexual aspect of their relationship so that the icebreaking is done at the very outset. This will encourage them to feel less inhibited to air such concerns during follow-up visits and prevent interpersonal conflict to a large extent.



Sexual intimacy is always a matter of consent between two adults.

Sexual intimacy is always a matter of consent between two adults. However, very often, the partner of the reintegrated person needs a lot of support to work on his own misconceptions and fears around sexual intimacy with a person having a lived experience of mental illness. Counselling goes a long way in facilitating an understanding between them and exploring a mutually acceptable and appropriate way of sexual gratification.

However, not all residents of a mental hospital suffer from schizophrenia. Short-term institutionalization of a person with severe distress from mood swings is not uncommon. Such a person may not have an issue with reduced libido. In fact, she may be given to impulses that are unsafe for her socially and health-wise. The social worker has to report such observations to the counsellor who will support the resident by validating her wishes, teaching her to defer impulse gratification where necessary and explore alternative ways of gratification of her sexual desires. Practice of masturbation in privacy, engaging in games involving physical exertion, physical exercises like swimming, etc. are some of the usual ways in which she might try to cope with her urges in the *absence of a safe and consenting adult partner*.

For residents institutionalized for chemical dependence, counselling goes a long way in enhancing the quality of life, giving due importance to the concerns of the resident.

A specific kind of problem arises in the case of a 'married' woman with mental health challenges. In the overarching patriarchy that influences all our systems, most of our lenses and shape societal expectations from men and women, mental health challenges of women very often stem from domestic violence and are always aggravated by inequitable domestic situation. More often than not marital homes are not welcoming towards the woman with a lived experience of mental illness. Anjali's field experience bear witness to serious reluctance to accept a 'hospital returned' wife. Psychosocial education, community pressure mobilized by activating **social leaders** together with the assistance of **local authorities** and the rule of law can make reintegration in such cases possible. However, the outcome of such a reintegration may not be very conducive for the mental health and social recovery of the woman in question.

Borrowing from Anjali's experience, in some such cases the husbands were found to have 'remarried' or in a live-in arrangement with another woman who had no correct information about his first marriage or the existence of his first wife. Here the position of both the women is precarious.

The reality of the situation is such that the reintegrated mistress of the house might not be in a position to meet societal expectations from a wife. She might not even want to have an active sex life with her partner. These are difficult situations but open discussion with all concerned might lead us to an arrangement, agreeable to all. What has to be ensured is that the reintegrated person has to be assigned the 'position' that the law of the land grants her. To begin with, she has to be assigned a small responsibility befitting her position in the household. For example, being the mistress of the house, she can be offered the responsibility of making the grocery list or the daily menu for the household.

As mentioned before, it is important for the social workers to identify **social leaders** or **community members** with a social spirit in the surrounding locality where the reintegration has taken place. These community members can be the local grocer or the pharmacist, or the roadside tea-stall owner, the barber, the leader of the local club and so on and so forth.

Some ways of involving the local community could be as follows:

- a) **Awareness generation** camps for eradication of stigma around mental health
- b) **Community vigilance** to ensure family support and social dignity for the reintegrated person

- c) **Encouraging local clubs and social leaders to assist** people with lived experience of mental illness to access public utility and welfare schemes (housing, ration, medical camps, doles etc.)
- d) **Encouraging inclusion** of people with mental challenges in the community programmes; some events could be with them and some by them.
- e) **Encouraging local enterprises to transact** with people having lived experiences of mental illness wherever possible and in whichever capacity (consumers, suppliers or employees)
- f) To ensure that the commitment on the part of the family members are binding, it is important to keep the **local administrative authorities** and **state agents** in the loop especially during negotiation* with the family.

Some important ways in which a reintegrated person can meaningfully contribute to society is via *volunteerism*. She can volunteer to visit mental hospitals and speak to hospital inmates about her recovery and management, invest some structured time and energy to old age homes and orphanages.

Being aware of one's rights and accessing them is another expression of social participation. Exercising *adult suffrage*, protesting against denial of rights and demanding expansion of rights, *accessing public utility and welfare schemes* of the state are some other ways in which people marginalized in various capacities, move towards increased self-reliance on the one hand and contribute towards creating a socio-political identity for their community on the other.

Collaborating with local authorities in various programmes for the welfare of the local community is another very meaningful way to exercise membership and authorship by a reintegrated individual. Awareness generation campaigns around physical health issues like dengue, malaria and Covid 19 could offer a creative opportunity for some to make posters, paint graffiti and write pamphlets. Of course, everyone can participate in distribution, an activity that provides plenty of opportunities for social interaction.

The reintegrated person can be the best collaborator with organizations like Anjali to **encourage community mental health services**. They can acknowledge and appreciate in different public forums the contribution of people from their community towards social reintegration of a person with a lived experience of mental illness. This will not only encourage other members from the community to follow suit but will possibly also tilt the biased power dynamics in society towards evenness.

Caring for Caregivers

The ‘grace’ of care by a human agent for another has to be understood with deep attention. The caregiver needs to be nurtured and replenished by a system that is both informed and truly empathetic. This is true for any form of caregiving. A caregiver fostering social recovery of a person with mental disability or a chronic mental condition is facilitating her empowerment. Such a caregiver needs to be empowered herself to be able to do that, as empowerment cannot be achieved by reducing the change agent to a mere instrument. Empowerment is achieved through a process that needs to be empowering for both the caregiver and the care receiver, a process of partnership premised on equity, transparency and commitment.

In order to facilitate such a partnership, the caregivers have to experience equity, transparency and commitment in their engagement with their line managers as well. Moreover, they would need access to relevant psychosocial information as much as the person with a lived experience of mental illness or the members of her family where she would be reintegrated. Additionally, a self-care system has to be in place for the caregivers and spaces created for their emotional replenishment and stress management to prevent burnout.

Capacity development of caregivers has been a time-tested method of strengthening their knowledge and skill base thereby enhancing their level of confidence. An orientation training on mental health and structured sessions on handholding and supervision with regard to appropriate responses and intervention in their interaction with residents are very likely to improve the quality of care provided and reduce the stress levels of the caregivers. Such learning has to be reinforced and updated from time to time and skills honed at regular intervals to minimize loss from intrusion of old habits.

Caregivers of Anjali are very resourceful, drawing from their work experiences at the mental hospitals. However, there is a need to collate the effective practices and get some specialists’ perspective on them as well. Digging into the repertoire of practices all over again or risking a personal judgment every time they need to take a decision might get stressful at times. Though gut feeling can and should never be ignored, a clearly stated body of principles to be followed for caregiver interventions goes a long way towards creating a more enabling work situation. Chapter 3 tries to indicate some of these basic principles.

Similarly, the system of having checklists for eligibility to different programmes might help in an unbiased and rational selection process that a social worker might have to undertake. It is to be remembered that a checklist indicates what needs to be observed. It is neither exhaustive nor a replacement for a sincere attempt to engage with a resident to understand her. Given below is an example of such a checklist:

Checklist For Assessing Resident's Readiness For The The Social Recovery Programme

1. Optimal grooming (cleanliness, hygiene)
2. Responsiveness (verbal / non-verbal) to an invitation to communicate (This may or may not include eye contact)
3. Ability to engage for some time / can pay attention for sometime
4. Presence of 'curiosity to know'
5. Social behaviour which can be assessed by eliciting response from the roommates via an open question about the level of peace in the room, issues of conflicts and how each one feels about it and what they do about it. One has to take note of complains against individuals initiating, escalating, partaking in violence/ behaviour unacceptable to the others



Information about the possible adverse effects of medicines would enable caregivers to intervene.

Some basic information about the possible adverse effects of some of the medicines that are administered to residents would enable the caregiver to intervene effectively when required. The common as well as rare adverse effects, their management and when to report them to a doctor or a counsellor, would assist the caregiver to manage her own emotions in such circumstances better, intervene with dexterity and provide reassurance to the resident.

Some side effects of common antipsychotic drugs, as provided by Consultant Psychiatrist Dr. Debabrata Majumdar are given in the chart below with some suggestions for intervention.

Antipsychotic Drugs	Side Effects/After Effects	Intervention
Haloperidol (oral/injectable), Trifluoperazine, Zuclopenthixol (injectable), Chlorpromazine	<ul style="list-style-type: none"> • Tremor- • Repetitive muscle contraction and rigidity- • Slowness in movement- • Excessive salivation/ dribbling of saliva • Restlessness • Sedation (drowsiness, low energy)- • Weight gain - • Reduction in sexual energy- • Secretion of milk in non-lactating women- 	All side effects are to be discussed with the doctor; some go away on their own while some are addressed by drug adjustments, changed medication or additional medicines; excessive salivation or dribbling can be addressed by using a pillow towel while sleeping during sleep time and having a routine for oral hygiene in place during waking hours; weight gain for medication is marginal and it is more due to increased appetite and carb intake which has to be consciously offset by a proper diet and regular exercise and the social workers/ family members have to motivate the concerned person for this; if the reduced sexual energy does not pick up by a month then it has to be reported to the psychiatrist; social workers have to encourage the concerned person and her family to bring it to the doctor's notice.

Antipsychotic Drugs	Side Effects/After Effects	Intervention
Olanzapine, Risperidone, Quetiapine, Aripiprazole, Amisulpride, Ziprasidone, Lurasidone, Paliperidone, Clozapine	<ul style="list-style-type: none"> • Sedation (drowsiness, low energy)- • Weight gain -Restlessness • Postural hypotension (drop in blood pressure due to change in body position)- • Reeling sensation- • Reduction in sexual energy- • Erectile dysfunction – • Difficulty in attaining orgasm • Secretion of milk in non-lactating women - • Unusual involuntary face, limb or body movements - • Blood sugar related issues - 	All side effects are to be discussed with the doctor; some go away on their own while some are addressed by drug adjustments, changed medication or additional medicines; weight gain for medication is marginal and it is more due to increased appetite and carb intake which has to be consciously offset by a proper diet and regular exercise and the social workers/ family members have to motivate the concerned person for this; if the reduced sexual energy does not pick up by a month then it has to be reported to the psychiatrist; social workers have to encourage the concerned person and her family to bring it to the doctor's notice.

Special Vulnerability of Caregivers to Burnout

Stress and burnout are occupational hazards in any field of work that is demanding on the worker's physical and mental capacities. Those involved in the caring profession have some special vulnerability to stress and burnout because of the nature of their work. Here we shall discuss these with special attention to caregivers involved in the social recovery model of work.

- Mental health is a comparatively new field of study and social recovery is an emerging model of intervention. Caregivers are primarily figuring out how to be more effective from their daily experiences with persons having a lived experience of mental illness. This learning 'on the go' can itself be exciting as well as stressful.

Group sharing of experiences amongst caregivers and documentation of effective practices would create a pool of ideas to draw from and alleviate the stress to some extent. It has to be understood that it is okay to make mistakes though it is very important to learn from mistakes.

- The chronic nature of some illnesses, physical and mental, make it quite demanding on caregivers who have to be ever alert and vigilant, trying their best to prevent a relapse.

Proper understanding of the ailment and reinforcement of this understanding are required here. Self-care strategies that could include nurturing inner resources of the caregiver; reaching out to trusted people and doing things for her emotional replenishment are necessary to ensure the caregiver's wellbeing.

- Personal triggers are also rampant in the field, taking a toll on the emotional wellbeing of caregivers. One has to be careful about caring without getting personally attached to the person she is looking after. This is easier said than done but it is probably the only way.

It is best to reach out to a professional counsellor to discuss such issues; group counselling or personal counselling can be considered for this.

- Relapses and setbacks and the despair around the thought of 'starting all over again' are almost inevitable.

Clarity around the role and the limitations of caregiving in such cases and revisiting the nature of the ailment, are important here. What is also important is a reinforcement of conceptual understanding of mental health as something that exists in a continuum.

- Physical condition of hospitals in the state is also mostly not conducive for one's emotional wellbeing. The systems are often not enabling thus making the job of negotiating with hospital authorities quite challenging.

This is a reality that needs to be accepted before one tries to change it. Some stress management strategies, if built into the regular routine of a caregiver, are likely to help in reducing her stress levels and enhancing greater flexibility in her. Relaxation exercises along with some other strategies mentioned below might be considered.

- Multitasking is unavoidable in a sector where resource allocation is in a perpetual crunch. The mix of caregiving work with work related to documentation and / or administration necessitates working from different

mind-frames. A quick switching from one mind-frame to another causes a huge drain of energy.

Prioritizing, realistic target setting in terms of daily deliverables and time management are the key actions that need to be undertaken for this. Breaking up the responsibility into small action items and tracking each one to completion have proven to be effective in managing work, time and keeping up the morale. Negotiating with the authorities around role expectations, if feasible, should certainly be considered.

- The primary challenge of reintegration that the caregiver experiences stems very often from having to negotiate amongst multiple stakeholders involved in the process. Negotiation becomes specially challenging when multiple and often conflicting perspectives appear valid from their respective viewpoints.

Community work requires a specific skill set. Social workers responsible for this need capacity development for effective intervention in this area that entails negotiation and partnership with multiple agencies.

Suggestions for individual self-care strategies for caregivers:

- Personal Counselling and handholding support
- Work-life balance
- Nurturing potentials and talents and hobbies
- “Me” time to be integrated in regular routine
- Adequate Rest, Optimum Exercise and Healthy and Tasty Diet

Suggestions for collective care of caregivers:

- Creating spaces in team meetings for showcasing big and small professional achievements by individual caregivers
- Spaces created for giving and receiving specific, actionable and respectful feedback
- Structured or unstructured group sessions for sharing stressful situations experienced by the caregivers and mobilizing peer support and suggestions to address the stressors
- Recreational activities and activities for fostering connection amongst team mates
- Structured personal growth sessions for processing personal and professional experiences to be facilitated by experts in the field

While there cannot be any substitute for prevention to burnout and self-care strategies, the elixir to keep alight the flame of a caregiver’s dedication can only be



“Me” time to be integrated in regular routine.

the outcome of her efforts. There is no substitute for the satisfaction derived out of a fair assessment of impact of such work.

Given below are some benchmarks for measuring social recovery of a person with a lived experience of mental illness. Each benchmark can be measured on a scale of 1 to 5, 1 being the lowest in the scale of recovery and 5 being the highest.

The evidential component against each benchmark is provided.

No	Benchmark	Behavioural Evidence
1	Awareness about Identity beyond ailment	<ul style="list-style-type: none"> • Knows and can tell her Name, Age, Sex • Keeps herself hygienic, clean and tidy • Can share personal strengths (capacity, quality, preferences) • Is invested in self-growth • (learns new skills, upgrades skills and has set a target for growth) • Takes care of her emotional wellbeing through pursuit of interests, counselling, doing things she likes
2	Awareness about surroundings	<ul style="list-style-type: none"> • Knows and can recall her Address • Knows and can recall Locality related information • Knows and can share Information about family • Knows and can recall Information about emergency contacts, information about police thana, councilor, local pharmacist, grocer, barber, bank, telephone booth. • Knows Information about the socio-political and geographical climate and has an opinion on socio-political matters and reasons behind her opinion
3	Responsibility of managing basic needs	<ul style="list-style-type: none"> • She receives Shelter, food clothing, medicines obtained from neighbours. • She gets Shelter, food clothing, medicines from her family • She arranges for her Shelter, food clothing, medicines with partial assistance from family • She accesses Shelter, food clothing, medicines from public welfare schemes • She is self reliant for Shelter, food clothing, medicines and not necessarily dependent on welfare schemes

No	Benchmark	Behavioural Evidence
4	Responsibility of managing mental illness	<ul style="list-style-type: none"> • Compliant when medicines are administered • Knows and can talk about her illness and cooperates with administration of medicines and accesses other mental health care services • Takes medicines on her own • Takes medicines on her own and reports to the social worker, counsellor and doctor regularly • Takes medicines on her own, is aware of cues and contacts social workers, counselors or doctors for preventing relapse
5	Relationship with family	<ul style="list-style-type: none"> • Has purely functional interaction with family members • Spends some social time with family beyond functional requirement • Contributes to family resources (shares physical work, time, makes monetary contribution) • Empathizes with family member(s) and offers support as a response • Emotional and or sexual intimacy restored with sibling / partner / significant member
6	Relationship with community	<ul style="list-style-type: none"> • Responds positively when approached by community members • Increased social interaction at the community level that is sometimes initiated by the reintegrated person herself • Participates in organized community events • Communicates independently as a consumer or as a service provider in the community • Volunteers for community work
7	Livelihood/ vocation	<ul style="list-style-type: none"> • Participates in vocational training for jobs or self-employment • Is in Apprenticeship/ internship/ assistantship with business with or without stipend • Makes small earning, can keep a job and takes more professional responsibility than before • Can deliver independently, attained financial subsistence with small savings and chases targets for improvements in skills and earning. • Financially self-sufficient with health insurance and pension plan

No	Benchmark	Behavioural Evidence
8	Awareness about rights	<ul style="list-style-type: none"> • Informed and can share some important rights affecting her • Understands the implication of her rights and demands access to those • Makes a conscious effort to undertake the responsibilities corresponding to the rights she enjoys • Protests against violation of rights • Demands expansion of rights
9	Contribution to social recovery	<ul style="list-style-type: none"> • Shows curiosity to know about her treatment and prognosis, cooperates with mental health interventions • Reports progress in recovery, problems around medicines, recognizes cues and negotiates for treatment / change in treatment • Accesses citizen's rights and fulfills corresponding responsibilities • Participates in campaigns for change or protest against violations, partakes in surveys and research on mental health services • Acts as a peer leader amongst persons with lived experience of mental illness and spreads awareness around mental health rights, collaborates with civil society organizations for propagation of mental health rights in the public domain

This is at best a **blueprint** of a tool appropriate for measuring social recovery of persons with lived experience of mental health and not a finished tool. What is noteworthy is that it focuses more on quality of life enjoyed by a reintegrated person rather than remission of symptoms.

It leans heavily on the philosophy of empowerment where the ability of an individual to access rights, make informed choices, nurture and define her own wellness along with her material self-reliance and proactive social membership, are given prime importance in measuring her social recovery.

General References

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