



RE

Bridging the
Care Gap

FRAME

RE Bridging the Care Gap FRAME

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Message from the Founder

It has been an eventful year since I last wrote for 'ReFrame'. As I had hoped, in this period MHI was able to support a range of mental health concerns, eventually working on national advocacy.

Mental Health (MH) issues directly affect over 150 million Indians. Among young persons in the 10-24 age group, suicide is the country's leading cause of death – and still, MH is conspicuous by its absence in the political agenda. MHI was part of a coalition of campaigners who aimed to raise political commitment to work on MH by showing that action on MH matters to voters. The 'Bridge the Care Gap' campaign approached political parties, raised general awareness about rights-based MH, and received multi-sectoral support and signatures for its public petition. 2019 became a milestone year, with MH being mentioned in political manifestos for the first time. Such accountability is a key premise for further progress in the area of rights-based MH, and is cause for cheer.

Apart from the work on advocacy, we joined hands with eight new partners – in new locations, and with new focus areas. I am deeply grateful to our first four partners for trusting us as new funders and being patient with us as we learned more.

Through these years, two factors have struck me as crucial to work in MH. Firstly, any approach to MH must be driven by an overarching respect for human rights. Human rights violations in the name of treatment have plagued the field of MH – not just historically, but in our own times as well – worsening already prevalent stigma, and reinforcing popular reluctance to reach out for support. We must work to bring about systemic change if we are to ensure a human rights- based approach to MH by practitioners, policy makers and all stakeholders, so as to center informed consent, and to abide by and promote international human rights standards. Second, and complementary to the principle of human rights, is the necessity of an intersectoral approach. MH needs to be recognized not just as a health issue alone, but also as a development issue. It is well understood today that socio-economic factors play a key role in determining mental health. Collaborations across sectors such as housing, education, livelihood, and access to food and water, alongside more traditional MH services, would therefore have a positive impact on MH.

So, I invite you all, whether philanthropist or CSR-based initiative, in the sphere of health or of education or some other sector, to explore how you could introduce facets of MH in the work you do.

Thank you!

A handwritten signature in black ink, which appears to read 'Harsh Mariwala'.

HARSH MARIWALA

Note from the Editor

This is the second issue of 'ReFrame', a journal through which we endeavor not only to transform existing discussions around mental health (MH), but also to widen the scope for participation in these crucial conversations. Our last issue highlighted the need for funding rights-based MH work, given that the MH sector has not been a priority in philanthropy or CSR in India.

As I sat down to write this note, I received a forward from one of the most prestigious global media houses, seeking to talk to people who had "suffered mental health issues, taken medical help and achieved something big in her life ... in areas like sports, arts..." Such messages reinforce the dubious but widespread assumption that "inspirational" narratives about persons with mental illness being "productive" against all odds will help reduce stigma. Anti-stigma campaigns, used worldwide for over 60 years now, have tended to communicate people's experiences of mental health in a particular way – promoting "cures" and "recoveries". In similar vein, statistics (that the mainstream media like to quote) about the "treatment gap" suggest that the number of persons with mental health concerns denotes a demand for mental health services that outstrips supply, due to a lack of qualified MH professionals. Such approaches reflect dominant notions about MH, with their narrow focus on diagnosis, drugs, and experts who "fix" problems – on cure, rather than care.

Are these useful lenses to employ as we work towards mental health for all? The treatment gap, anti-stigma campaigns, and indeed the psy disciplines themselves are, in India, largely borrowed – and applied in cut-and-paste fashion – from Western discourse and practice. Yet how does each fit into the sociopolitical and economic structures, and environmental forces in our part of the world? Does the ensuing emphasis on the individual mean that failure to be cured is an individual failure? Are "expert" voices the only ones that matter? And does everyone need an expert to work through their mental distress?

The "treatment gap" is hardly the main problem for the country's MH sector, with its lack of respect for informed consent, blatant human rights violations, and policy stasis. We believe we need to question the expert-driven biomedical model so that we might consider systemic changes in how we see, define, and respond to mental illness. This is why the theme for this year's edition is 'Bridge the Care Gap'.

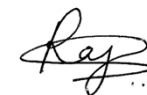
The journal is divided into three sections. The first, 'Re-vision', explores paradigm shifts in the psy disciplines. Pathways to Mental Health by Pathare et al foregrounds the concept of the "care gap" by highlighting some critical policy, advocacy, and service interventions that emerge when we look beyond the "treatment gap" model. Other articles examine ethical considerations within, and the queering of, the MH establishment, critiquing the role of psychiatry in defining norms, and in othering multiple persons and bodies. AK Dave and S Jain et al challenge predominant ideas of "recovery" – one, based on lived experiences; another, based on community-based mental health

work – and ask: who do we exclude when we put out positive stories of recovery?; and, are we talking of recovery in ways that make sense in our social contexts?

How do we foreground lived experiences and knowledge from the margins in transforming our MH system, which is still saddled with approaches derived from the old Western standard for normalcy, that of an able-bodied cis-heterosexual male? The second section, 'Contexts', brings us voices of persons oppressed or marginalized in multiple ways, even within the MH establishment. I Walk the Line delves into the experiences of service users; Enhancing Livelihoods, written by P Thiruselvi, has recommendations based on her experience as a survivor of mental illness and homelessness, and as a counselor. Once the label of mental illness is affixed, what does it take to access basic citizenship rights? One article recounts the work involved in getting voting rights for persons living in a mental health institution. Additionally, we see how a reductive biomedical approach further invisibilizes and pathologizes, as Deepa Pawar speaks of collective trauma in communities that face caste-related violence, and Nidhi Goyal writes on the mental health gap for persons with physical and sensory disabilities.

While the first two sections offer nuanced critiques of prevalent, hegemonic approaches to MH, the section, 'Engage', highlights on-the-ground practices and experiences that foreground the idea of the "mental health care gap". Some articles narrate examples of reformulating curricula, and MH advocacy campaigns; others such as Pattie Gonsalves talk of working with varied stakeholders such as youth, and Surendranath et al of mental health within the criminal justice system. The underlying question is: how do we create local systems for MH support and services, while challenging the need for experts? Two specific programs are discussed: Fostering Resilience in the Wake of Disasters relates to MH preparedness in communities that live in disaster-prone areas; the other, The Atmiyata story on community-based rural mental health. Both these pieces reveal how communities may learn – and are potentially the best placed – to become agents for their own collective mental health.

Individually and together, these articles help us interrogate and disrupt dominant MH paradigms. Throughout, there also runs the surely unsettling (for many) indication that mental illness diagnoses are often deeply connected to social norms, or ideology, and may thus be subjective. I believe these pieces encourage us to look more closely at how the intersections of poverty, casteism, misogyny, and other forms of violence impact mental health, and to locate MH within economic, environmental, sociocultural, and political contexts.



R MARIWALA

Lack of mental well-being is located in the *psychosocial*. It's not about personal failure, but about structures that make it really difficult for us to pursue happiness, or even figure out what that happiness might mean.

POOJA NAIR

Queer Psychotherapist, Survivor

Bridging the Care Gap

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We aim to highlight a variety of topics and voices but will not be able to be exhaustive in our material. The views expressed in ReFrame are those of the contributors and not necessarily those of Mariwala Health Initiative. Articles are accepted in good faith and every effort is made to ensure accuracy.

Re-Vision

Alternatives
Paradigms
Social Structures
Advocacy

HOW *do we have* DIFFERENT
CONVERSATIONS *about* MENTAL
HEALTH? *When we consider the*
WESTERN-CENTRIC, BIO-
MEDICAL MODEL *and the*
SUPPLY-DEMAND EQUATION
that characterize the TREATMENT
GAP, *what* ALTERNATIVE
CONSTRUCTS *can we offer?*
How do we pay heed to the
CULTURALLY *and* SOCIALLY
SPECIFIC ADVERSITIES
that impact our mental health?
SHIFT THE FOCUS from the
INDIVIDUAL to the COLLECTIVE,
to STRUCTURES *and* SYSTEMS?
Design a COMPREHENSIVE
APPROACH *to mental health*
and SOCIAL CARE NEEDS *that*
can inform INTERVENTIONS,
SERVICES, SUPPORT *and*
ADVOCACY?

LAW AND POLICY

Pathways to Mental Health

Mental health in policy and praxis has multiple anchors

beyond the push and pull

Mental health has, historically speaking, been ignored in India's political agendas. Psychosocial, intellectual and cognitive disabilities have either been described in pejorative terms, or proposed as cases for charity, thus perpetuating stigma and discriminatory practices. To give a brief perspective, 70%-92% of persons with mental illness who require mental health care either do not have access to services, or — if receiving services — cannot access quality care that is affordable, easily available, and satisfactory, which is referred to as the treatment gap.¹

India had 17.8% of the global population in 2016 but accounted for 36.6% of global suicide deaths among women and 24.3% among men.² For women younger than 40, suicide is the leading cause of death, ahead of the maternal mortality rate; for men below 40, it is the second leading cause of death, after road traffic accidents. Despite the high incidence of mental health problems, estimated to affect 150 million Indians, the focus of the State has been centred on a "medical" model

of care that is mainly institution-based care.

Even within existing mental health care, a dearth of mental health care professionals, and the lack of a human rights approach, together widen the "mental health care gap". "Mental health care gap"³ is a purposive term, used to mark an ideological re-conceptualizing of the more prevalent "treatment gap". The latter carries a medical connotation, and implies biomedical treatment (or lack of it) of mental illness. This "treatment gap" is often interpreted by policymakers, planners and researchers, as well as by non-professional stakeholders, as referring exclusively to curative clinical psychiatric interventions, thereby leaving out effective psychosocial interventions.

reformulation

"Care" is a relatively comprehensive term, which allows us to acknowledge how mental health is affected by, and may impact, various social, economic, and political factors.⁴ Mental health cannot be understood in isolation

by Soumitra Pathare & Jasmine Kalha

from people's lives and contexts. The notion of a "treatment gap" frequently leaves out those psychosocial interventions that are almost always required by persons with severe mental illnesses that affect social functioning; the omission of such interventions impedes or delays recovery. "Recovery" indicates, here, not merely a reduction of symptoms⁵, but a person-centric process geared toward their being able to lead their life in accordance with their own will. For recovery, we need to address a range of psycho-social interventions along with the medical care and treatment. A study on schizophrenia⁶ demonstrates a range of psychosocial treatments are also helpful, including family intervention, supported employment, cognitive-behaviour therapy for psychosis, social skills training, teaching illness self-management skills, assertive community treatment, and integrated treatment for co-occurring substance misuse.

The mental health care gap is also concerned with the physical health care gap, because of the frequent, yet highly unaddressed, physical comorbidity conditions and premature mortality of persons with severe mental illness. Persons

“*Mental health cannot be understood in isolation from people’s lives and contexts.*”

with severe mental disorders (SMD) – i.e., schizophrenia and other psychotic disorders, bipolar disorder, and moderate-to-severe depression – die 10 to 20 years earlier than the general population⁷, which is often due to physical diseases that occur more frequently, are not prevented adequately, are not identified early enough and are not treated effectively.⁸ Despite this, little progress has been made to address physical health care and mental health care as a structured process of reform.

There is a relationship between non-communicable diseases (NCD) and severe mental health disorders which also needs to be addressed. A person's NCD symptoms can exacerbate mental health conditions, and at the same time, mental health conditions can be a risk factor for developing NCDs. In addition, individuals with mental health conditions are less likely to seek help for NCDs, and symptoms may affect adherence to treatment as well as prognosis⁹. Research also points to premature mortality among the mentally ill who live in large asylums, and the millions of people with SMD who are currently detained in prisons worldwide, who are particularly

exposed to chronic diseases (including, especially in low-income countries, infectious diseases), poor nutrition, victimization, neglect, suicide and substance abuse¹⁰.

Moreover, mental well-being is not a health issue alone, but also a development issue. People with mental illness are subjected to discrimination and stigmatization in their daily lives, bear a greater risk of physical and sexual violence, and tend to be excluded from developmental programs. Most people with mental illness face barriers not only in education and finding good jobs, but also in asserting their civil and political rights. Such exclusion and discrimination results in reduced income levels and poverty.¹¹

compounded consequences

Research has shown that poor mental health is more likely to affect people who are at a social or economic disadvantage. A recent study concluded that, as income inequality increases worldwide, “we should expect worse mental health globally in the years ahead” and that the burden will most likely fall hardest on individuals who “already bear a disproportionate burden of mental

health problems¹²”. Mental illness affects employment, too, which is complicated by the fact that the cause-and-effect factor can work in both directions: unemployment may worsen mental health; and mental health problems may make it more difficult for a person to obtain and/or hold a job¹³. The employment rate of people with common mental disorders (CMD) is 60-70%, which is 10-15 % lower than for people not diagnosed with any mental disorder. The corresponding employment rate for people with severe mental disorders (SMD) is 45-55%¹⁴. Poor mental health outcomes are associated with employment conditions, workers who perceive work insecurity, such as temporary contracts, or being employed with no contract, and part-time work experience significant adverse effects on their physical and mental health. Work conditions also affect health and health equity¹⁵.

These statistics point to the remorseless, self-perpetuating cycle of poverty associated with mental illness in India. The poor are significantly more likely to experience mental health problems, and those with mental health problems are correspondingly that much more

likely to slide into poverty. Inclusion of persons with mental illness as a vulnerable group that requires development assistance is therefore crucial.

Other social issues such as domestic violence¹⁶, sexuality¹⁷ and caste¹⁸ also negatively impact mental health. Domestic violence has a long-term impact on the mental health of women. Women who are subject to violence can experience depression, panic, anxiety, nightmares, restlessness, eating problems, and other social dysfunctions. Alcohol and substance abuse, and suicidal thoughts and attempts are also common among women who face violence.¹⁹

Till recently, existing as anything but heterosexual was a crime in India, which led to the social exclusion of sexual minorities. There has been little attention paid to the mental health needs of persons of non-normative sexualities (and genders) who are especially vulnerable due to their experiences of being bullied, discriminated against, socially excluded, and denied basic rights such as access to healthcare. Similarly, caste is yet another determinant of mental health. Caste-

based discrimination and social exclusion impact the mental health of individuals who face violence, lack of support, trauma, and isolation.

We therefore encourage an alternative conceptualization of the gaps in mental health care, where Mental Health Care Gap = Treatment Gap (as currently understood) + Psychosocial Care Gap + Physical Health Care Gap. Closing the mental health care gap requires an inter-sectoral and intersectional approach by policymakers, who need to acknowledge that mental health care is a human rights issue as enshrined in the United Nations Convention on the Rights of Persons with Disabilities²⁰. ☒

Soumitra Pathare is a Consultant Psychiatrist and Director of Centre for Mental Health Law and Policy at ILS. He has contributed to the WHO Mental Health Policy and Service Guidance Package. Soumitra has also helped to draft India's new mental health law and was a member of the Policy Group appointed by the Ministry of Health and Family Welfare, Government of India, to draft a new national mental health policy for India.

Jasmine Kalha has an M.Phil in Sociology from Delhi University and a Master of Arts in Social Work from TISS Mumbai. She has been associated with CMHLP since 2014, and is currently Programme Manager and Research Fellow for SPIRIT (Suicide Prevention and Implementation Research Initiative) a mental health program implemented by CMHLP in Gujarat.

The approach that mental illness is caused by a range of biomedical factors like genetics/ chemical imbalances. These are described as having a set of symptoms like physical illness. So, treatments = pharmacological & success = reduction / disappearance of symptoms.

The difference between the number of people who need mental health care and those who get treatment. Often stated as no. of psychiatrists available/100,000 persons or in a geographic area.

Mental Health Care Gap

Mental Health Care Gap encompasses three domains: **Treatment Gap**,

as currently understood and measured, implying the lack of

conventionally understood **biomedical** and clinical treatments,

plus a Psychosocial Care Gap, implying the lack of **psychosocial**

interventions and a Physical Health Care Gap, implying the

lack of or substandard provisions of physical health

interventions (promotion, primary prevention, curative and

rehabilitation care) for persons with mental illness.¹

Social context influences & interacts with the psychological (emotions, thoughts, feelings, reactions). Such interventions can lead to better mental health outcomes e.g. housing, education, legal support

Closing the Mental Health Care Gap requires an **intersectoral** and

intersectional approach by policymakers, who need to acknowledge

that mental health care is a human rights issue as enshrined in the

United Nations Convention on the Rights of Persons with Disabilities.²

Account and plan for disparities in mental health by assessing how they may be amplified/reduced at the intersection of social identities.

Systematic and planned collaboration between the health, social, and economic sectors through government authorities at various levels, as well as non-govt. orgs and community-based groups.

Mental Health Care Gap

=

Treatment Gap

+

Physical Health Care Gap

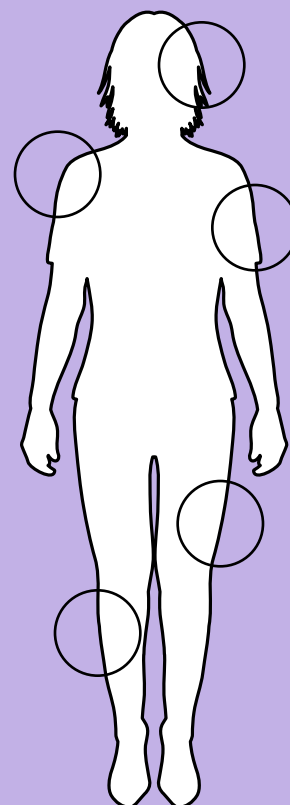
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Psychosocial Care Gap

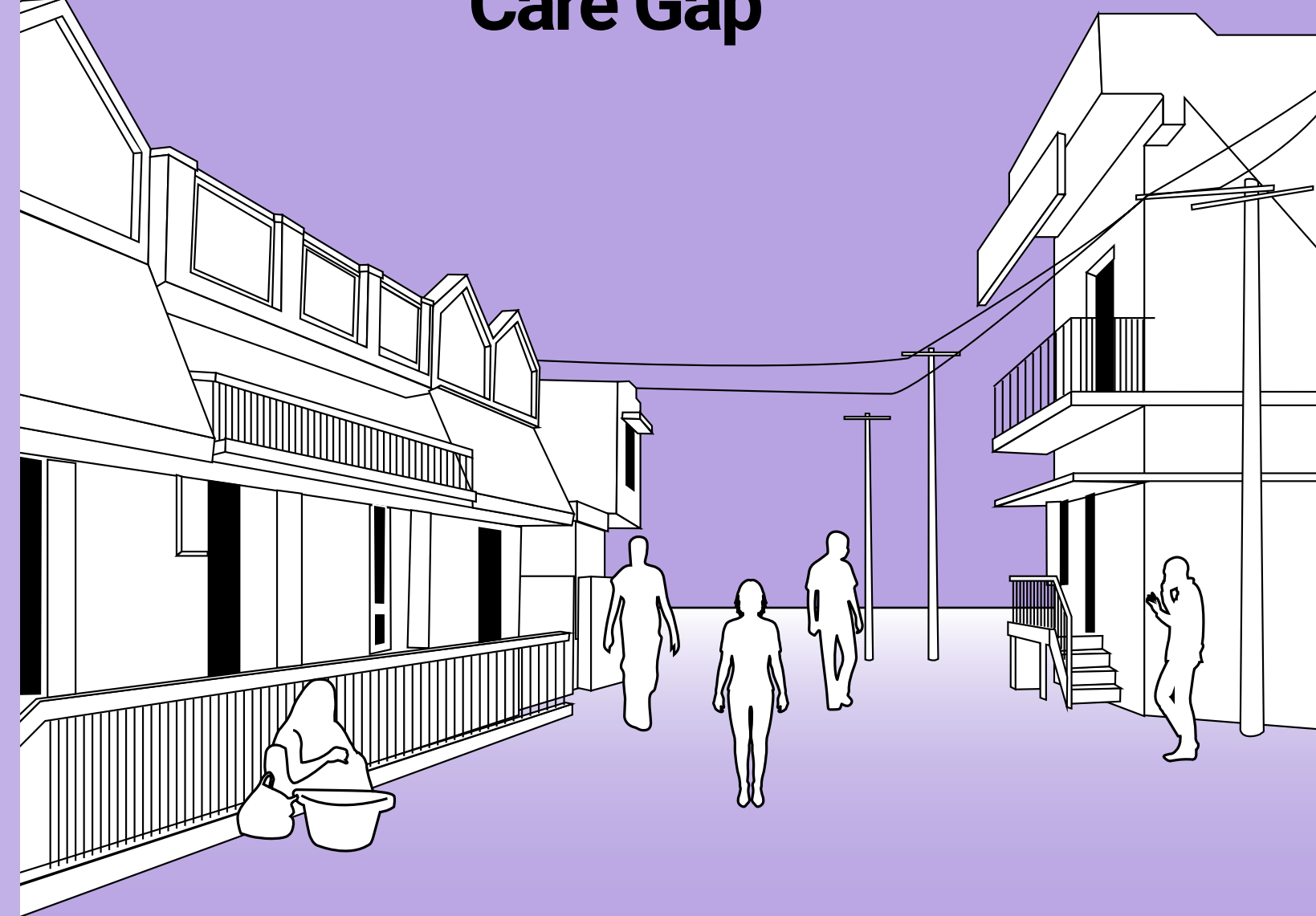
Focusing on a comprehensive mental health care gap will significantly promote much needed intersectoral partnership by giving appropriate recognition to health and other social sectors in addressing the full spectrum of needs of persons with mental illness.



Mental health is largely viewed, in India, through a biomedical lens, rather than in the context of a multifaceted coming together of individual and social contexts, challenges, marginalizations.



The lack of physical health care and interventions for persons with mental illness. People with serious mental illnesses lose from 13 to over 20 years of life compared to persons who do not live with mental illness. An awareness and knowledge of mental health needs to be built in to physical care systems.



"Psychosocial" is used to describe the connection between an individual and their environment, interpersonal relationships, community and cultural practices. Social context influences and interacts with the psychological (emotions, thoughts,

feelings, reactions). Thus, providing social supports or non bio-medical interventions is essential and can be preventative and/or curative in nature when it comes to mental health. Such interventions are intersectoral such as food security, water, housing,

shelter, education and sanitation but also legal support, employment support, skill building and inclusion in government schemes as well as activating community networks, women's groups and collectives for further support.

LIVED EXPERIENCES

The Ideal of ‘Recovery’

What does care look like?

by Amalina Kohli Dave

a psychosocial model of mental health care

I am bipolar. Within a psychosocial paradigm one may iterate this as having a psychosocial disability, or living with a diagnosis. In a medicalized framework, I have a ‘disorder’. I am something that requires ‘fixing’: a pathology-based intervention to make me ‘orderly’, to make me conform to a normative understanding of what it means to have a mind at all.

The conventional approach to ‘care’ views persons with mental health diagnoses in a linear framework: diagnosis/mental illness > care-based (expert-led?) intervention > remission or recovery. The #BridgeTheCareGap campaign has pushed us, both in policy and in praxis, to expand on the understanding of ‘care’ – to demedicalize interventions, decentralize support networks, to interrogate power, and to acknowledge people as the authorities on their own lived experience. To center communities in care, hear marginalized voices to care, to realize care is not a top-down system to be dispensed – it is a sum of all its participants: it is what makes

us value human dignity, no matter who you are, or how you experience the world. We must set up the stage for us to question the very linearity that makes current mental health interventions exclusionary.

neurotypicality as the ideal

The answers to some of the below questions arise from the neurodiversity and disability rights movements. People with psychosocial disabilities have

QUESTIONING THE INTENTIONS OF CARE

Looking at a care gap in mental health has presented an opportunity to challenge the perpetuation of a pathological, one-dimensional, mainstream narrative of mental health and has created a space to ask:

1
WHO is the subject of care?

2
WHERE is the space for user-survivors in care?

3
WHAT, for a person living with a psychosocial disability, is the desired outcome of care?

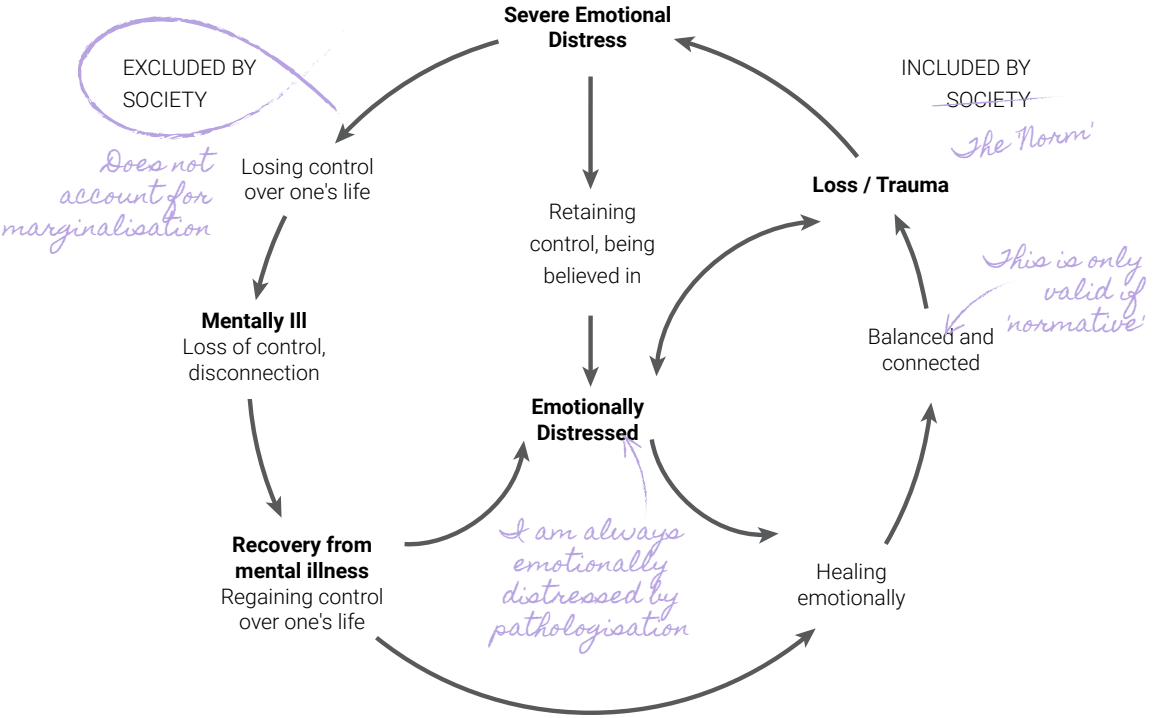
Illustration inspired by the “escalator illusion” reported by Fraser and Wilcox (1979). A Peripheral Drift Illusion (PDI), this type of motion illusion first described by Faubert and Herbert (1999).

“One must not only displace the centrality of heteronormativity, but also push back against a model of care that centers neurotypicality.

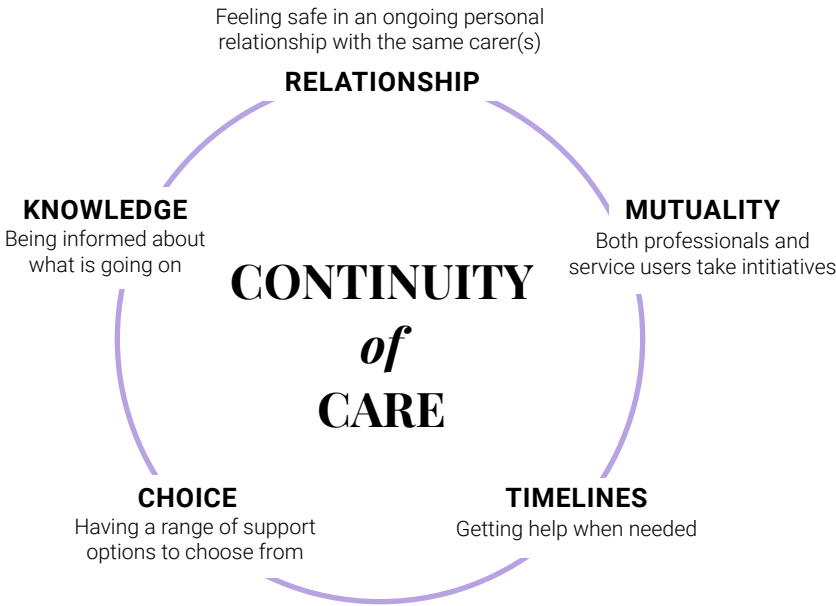
historically been marginalized because only the 'normal' (or neurotypical) mind is seen as a 'successful' mind. Mental health support and interventions have followed a script wherein the desired outcome is a person who

is either neurotypical, or is as close as possible to 'functioning' as a neurotypical person. This leads to a prioritizing of certain markers of functionality: a 9-5 job as the most legitimate form of livelihood, a heteronormative family, class and

caste specific social interactions and gender-appropriate social roles. These markers of 'success' are then viewed as the ideal outcomes of mental health interventions, which in turn reinforces other systems of marginalization.



Empowerment Model of Recovery from Mental Illness, Daniel B. Fisher, M.D. Ph.D. and Laurie Albern. Edited by Amalina Kohli Dave.



what does care look like for a queer person with a queerer mind?

While there is now increasing discussion and integration of/ from marginalised genders and sexualities within mental health, the voice that is markedly missing is that of the user-survivor; of those that are neurodivergent. One must not only displace the centrality of heteronormativity, but also push back against a model of care that centers neurotypicality. Within the current care discourse, my lived experiences as a bipolar person do not inform the praxis of mental health. Having a standardized care

model enforces a normative way of thinking about mental health; that there is only one correct way of functioning. If neurotypicality is the benchmark, then every battle I've fought to advocate for myself, build community, seek support, is erased. Acknowledging that neurological differences exist, that minds are a spectrum, necessitates that the lived realities of neurodivergent people are central to how we envision and articulate care.

If we commit to moving from a medicalized to a psychosocial model of care, then the intention of care must not be to ensure a person reaches

a point where they no longer need care, but to re-envision what constant, consistent, community-led, survivor-centered, intersectional care looks like.

Amalina Kohli Dave is a mental health activist, user-survivor, who has organised queer mental health discussion groups and co-hosted a series of workshops about mental health in theatre. She has also started support groups for people with chronic illness, including chronic pain and autoimmune illness. Her previous research includes studies on race and mental health access as well as queer persons experiences with cishet mental health professionals.

RESEARCH

Interrogating the Cut+Paste of 'Recovery'

Experts by experience build locally valid definitions

BY Sumeet Jain, Kaaren Mathias, Clément Bayetti, & Sushrut Jadhav

2. How relevant is it to the Indian context?

In parallel, Mathias, in setting up a community mental health programme called Burans in Uttarakhand⁴, faced challenges in operationalizing conventional western recovery tools. These tools were often inaccessible to people due to the way they were structured, and the lack of cultural validity⁵. Both the underpinning ideas of recovery, and the domains embedded in these tools, seemed to hold little meaning or relevance to the lives of the PPSD with whom the Burans team was working.

These challenges resulted in a one-year pilot project⁶ to develop a pictorial recovery tool relevant to the north Indian context⁷. A core idea underpinning this work was the importance of identifying "Indian vernacular concepts of 'recovery', their cognate and embodied equivalents.⁸" Our effort was to operationalize this in the context of a short project cycle. We began by holding workshops, and meetings with PPSD and carers – all of whom were "experts by experience". We used participatory methods, including storytelling, discussing photographs,

contexts for recovery

This article challenges received wisdom on existing concepts of 'recovery' from mental suffering and demands that people's voices ought to be central to future policy, clinical care, and applied research.

'Recovery' is a concept that proposes we can live fulfilling lives despite our suffering. It has been embraced by people affected by mental distress in high-income countries (HICs). Indeed, current ideas of recovery have emerged from the particular histories of mental health service user movements in HICs¹. This represents a significant shift in the idea of recovery, from being about symptom remission to suggesting a process – a "journey of change" – for the individual².

In the Indian context, whilst it has been the subject of much discussion in the mental health field, there has been limited focus on recovery in formal mental health services³. The idea of recovery has been welcomed, although the

frameworks for addressing this have been adopted rather uncritically from high-income settings. There are still almost no social recovery tools developed for Indian contexts, or together with affected persons. Data on what recovery means to Persons with Psychosocial Disabilities (PPSD), carers, and local communities, is crucial to ensuring that India's community mental health programmes embed locally valid understandings. How social recovery takes place, what aspects are central (having friends, or paid work, or being able to have fun), the measures of social recovery, and the types of support that people with mental health problems would like, all vary in different contexts.

defining "recovery"

In the early 2010s, we noted the emergence of the term "recovery" in Indian psychiatric circles and in India's new mental health policy. This led us to ask two questions:

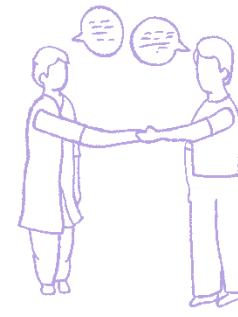
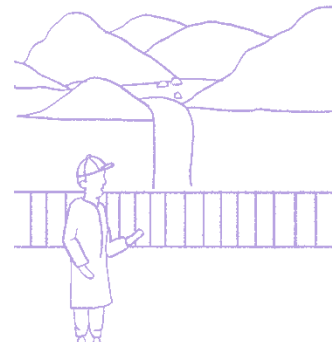
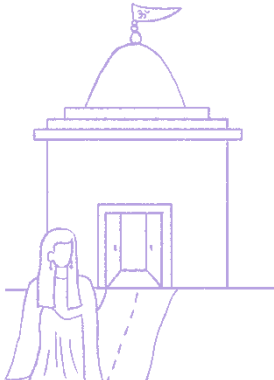
1. What is the distinctive history of this concept?



“*The important concern is how diverse voices can truly inform the priorities and directions of mental health care systems.*”



Images from *Swasthya Labh Saadhan*



drawing pictures, and focus group discussions to better understand local meanings of recovery, and generate valid domains for the tool. Two key Hindi-language terms on which the group agreed were *swasth rehna* (remaining in good health) and *theek hona* (to get well). The group named a resulting tool *Swasthya Labh Saadhan* (recovery tool for health). The aspects of recovery that emerged emphasized the importance of a person's role as an active member of the community and family, being spiritually engaged, and contributing to the family – perspectives that are missing in most western recovery tools.

A local artist created pictures representing domains of recovery, an important adaptation for settings where literacy may be a limiting factor. The use of this co-developed

mental health recovery tool among a pilot group of 26 people with severe mental illness led to improved mental health, and generated local conversations around recovery between lay workers and PPSD⁹.

translating to practice, policies and communities

Several questions that emerged from this work have relevance for India's community mental health services:

what does “recovery” mean in indian contexts?

If we are to develop services that are locally valid, it is crucial to embed a participatory process of identifying domains of recovery in each context. Conceptions of what recovery means may widely vary between policy makers, clinicians, PPSD and carers. These differences are yet to be understood in this

context, but are crucial for culturally valid visions of recovery to emerge. Independent of services, more research, including analysis of existing qualitative and ethnographic data, is needed to understand trajectories of recovery as well as the intersections of psychosocial disabilities with other forms of marginality (such as gender, religion and caste). This is crucial, given India's cultural and social diversity.

how can services better embed co-production with “experts by experience”?

The depth of our approaches was limited by project time. A recent paper by service user/survivor researchers highlights the unequal power relationships that accompany co-production in mental health care¹⁰. In our research, we soon became aware of these power differentials

between researchers/mental health workers, and people with psychosocial disabilities and carers¹¹. A first step towards mitigating these inequalities would be to ensure that the voices of “experts by experience” are heard and dedicated in planning, developing and delivering community mental health care in the country. This would, however, be only a start – the more important concern is with how diverse voices can truly inform the priorities and directions of mental health care systems? People-centred approaches to health systems offer a useful framework¹². These approaches recognize the centrality of individual, family and community perspectives, conceptualize them as participants and beneficiaries in the health system, and advocate for organizing health services around people's needs.

how do we develop supportive community environments?

A central limitation in our research was that we primarily addressed individual narratives and domains of recovery. While important, this can serve to obscure the structural issues that shape well-being and marginalization – which may be

beyond individual control and that limit service user involvement¹³. For example, we know very little about how social inequalities such as caste, identity intersect with mental health¹⁴. In thinking about recovery, research and practice must be informed by an understanding of the wider social and material forces that shape suffering, including gender, age, social class, and caste¹⁵. □

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SERVICE DELIVERY

Safeguarding Client and Counselor

Ethical dilemmas in psychotherapy in India

by Aparna Joshi

cornerstone of practice

Counseling and psychotherapy¹ are growing professions in India. Once confined to hospitals or private practice settings, counseling has made its way into several other spaces (educational institutions, communities, workplaces, NGOs), including communication media (telephone, online chat, email). While such expansion promises easier access, it also raises concerns.

By its very nature, counseling deals with narratives of distress and vulnerability. The entire edifice of the profession depends upon therapists' ability to create an environment of safety, confidentiality and trust. In such a scenario, ethics and ethical guidelines play a central role. Meara et al. list six basic principles of ethical practice: autonomy (self-determination); nonmaleficence (avoiding doing harm); beneficence (doing good and promoting client well-being); justice (fair and just treatment); fidelity (making realistic commitments and keeping promises); and veracity (truthfulness and honesty)². Ethical dilemmas may be understood as "problems for which no choice

seems completely satisfactory, since there are good, but contradictory reasons to take conflicting and incompatible courses of action"³. Here the counselor must choose between two values or principles.

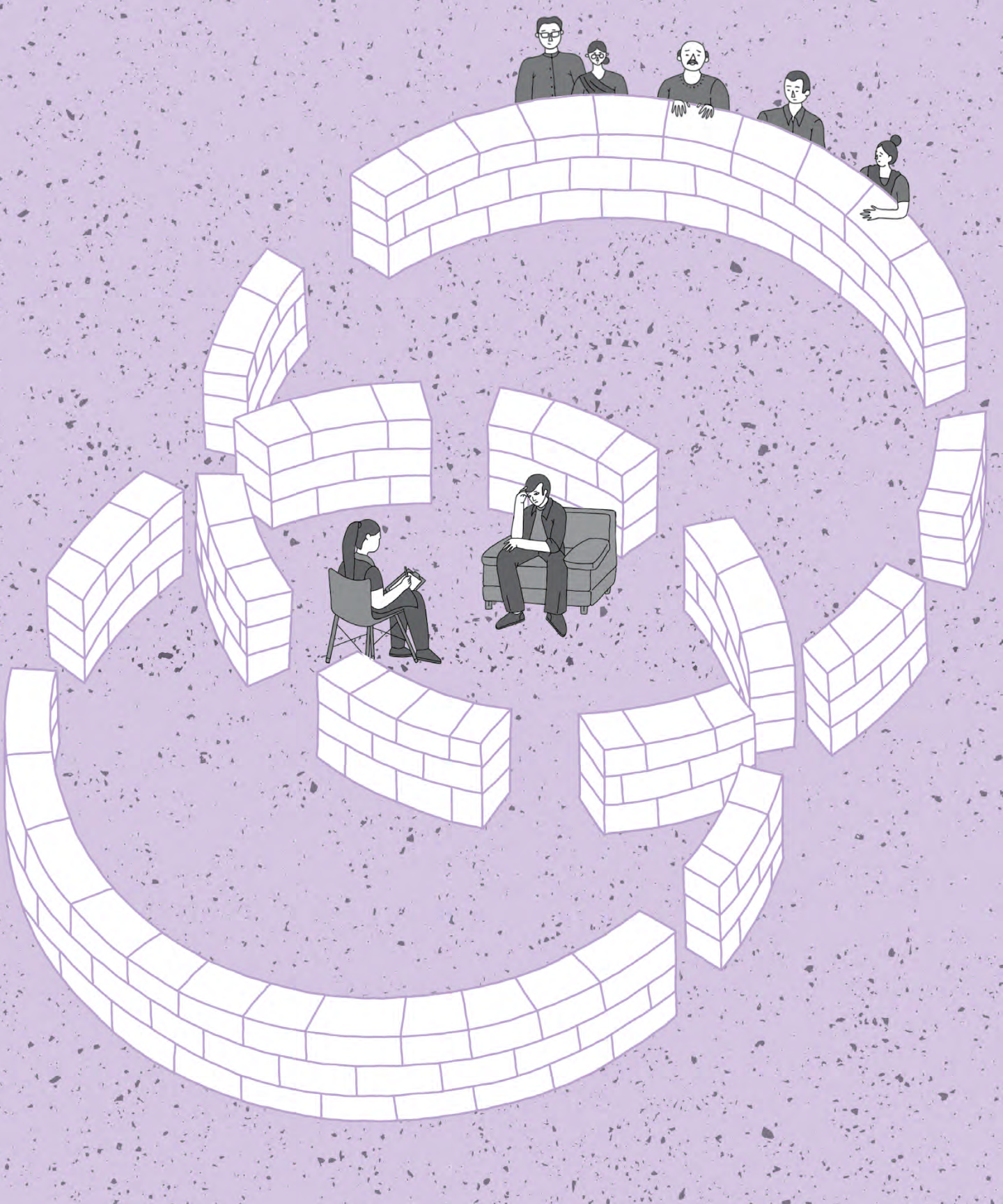
confidentiality

A major ethical dilemma, commonly faced by counsellors, may arise around confidentiality. Clients divulge information about their current and past situations, as well as their opinions and innermost feelings, to the counselor. The guarantee of complete confidentiality facilitates these articulations. However, therapists may be required to breach confidentiality in certain circumstances – as when they are learning under supervision, or working as part of a team comprising multiple professionals. Besides, all ethical codes mandate counselors to breach confidentiality when it seems clients might harm themselves and/or others (suicide, child sexual abuse, substance abuse, homicide). Counselors need to be aware of laws such as The Protection of Children from Sexual Offences (POCSO) Act that make the reporting of violations mandatory, and also of the debates

around mandatory reporting in order to ascertain their own position.

In India, given the collectivist nature of families and communities, and the interdependence among members, therapists are often expected to divulge information shared by the client. Families in India tend to be hierarchically organized (on the basis of social locations such as age, gender, caste, class, etc), with certain members wielding power over others. Members who demand confidential information may control the client's very access to therapy. The therapist may be resented, as a stranger whom the client is willing to trust with private and intimate information to which family members are not being made privy. Complications can also arise when the therapist has two or more members of a family as clients (as individuals, or in couple or family therapy). Issues of confidentiality may get further complicated when the client is a minor.

Counselors must keep in mind that many Indian laws deny persons "of unsound mind" full legal capacity in several areas of life, including contracting, political life, holding a



“The entire edifice of the profession depends upon therapists’ ability to create an environment of safety, confidentiality, and trust.

job, voting, etc.⁴ Sections of family law deny agency to individuals diagnosed with mental illness when it comes to marrying, staying married, adopting, inheriting, child-bearing or terminating a pregnancy, etc.⁵ In several reported cases, mental illness diagnoses or client records have been used by family members or significant others to deprive individuals of their rights (Aaina, 2004). Thus, the counselor needs to take all possible steps to ensure client confidentiality and rights.

Closely related to the issue of confidentiality is that of client autonomy, or the right to self-determination – making their own informed decisions. In the case of minors and even with older individuals, the family may insist on making the decisions, both about life choices and medical or therapeutic treatment. Counselors need to make efforts to maximize client autonomy, while remaining mindful of potential conflicts.

boundaries

The second dilemma pertains to boundaries in therapeutic relationships. Considering both client vulnerabilities and the power hierarchy implicit in the counseling

relationship, boundaries become necessary. Therapeutic boundary may be thought of as an invisible line that separates the therapeutic relationship from social, familial, sexual, business, and other relationships.

A boundary violation occurs when a therapist misuses their power to exploit or harm a client.⁶ Therapists must obviously refrain from any action that involves emotional, financial, or sexual exploitation. A boundary crossing, on the other hand, is a deviation from the strictest professional role, and is harder to pin down⁷. Given their limited awareness about the counseling process, clients might engage in boundary crossing – asking for friends or family members to be seen as clients, inviting counselors for social functions, or to the client’s home for a personal or professional visit, offering food and/or gifts, sending friend requests on social media, etc. Considering the collectivist nature of Indian society, notions of the autonomous self and the boundaried relationship can seem alien, even offensive, making the maintaining of strict boundaries extremely challenging for therapists. While boundary crossing may often be initiated by clients, it could also be

a matter of therapeutic intervention at the counselor’s discretion – using means such as self-disclosure, meeting the client in social situations (to end, for instance, isolation experienced due to marginalized and stigmatized identities based on sexuality or gender, or to participate in their growth process, or to appreciate their achievements), offering financial support to needy clients, engaging in non-sexual touch to convey empathy, etc. Dual/multiple relationships in which the counsellor assumes two or more roles at the same time or sequentially with a client, become unavoidable in many situations in a co-existing society like ours. Regardless of the therapeutic decision, therapists need to be motivated by clients’ needs and of the possible advantages and harms caused by this overlap or crossing.

counselor competence

Counselors must practice within the bounds of their competence, and be forthcoming with clients about their limitations. Hence, the third ethical dilemma pertains to counselor competence – is of great concern in a country like India. Given regulatory and licensing confusions, the question of “who can practice as a counselor?” becomes pertinent.

6

BASIC PRINCIPLES OF ETHICAL PRACTICE*

AUTONOMY	self-determination
NONMALEFICENCE	avoiding doing harm
BENEFICENCE	doing good, promoting client well-being
JUSTICE	fair and just treatment
FIDELITY	making realistic commitments, keeping promises
VERACITY	truthfulness and honesty

* Meara, N., Schmidt, L., & Day, J. Principles and Virtues. The Counseling Psychologist.

Answers require a clear laying down of required qualifications and competencies. In the absence of such clarity, there is a danger of clients approaching counselors who may lack the necessary training, skills, and experience. At the same time, in a resource-poor country like India which experiences a vast treatment gap, it is important to acknowledge the need for different cadres of mental health professionals and the roles each can play, and to define the competencies each requires. This would highlight the plurality needed in the mental health service sector, while setting minimum standards for quality practice.

societal values
The fourth ethical dilemma revolves around the role of values— beliefs and attitudes that provide direction to everyday living⁸, in counseling process. Counseling is often portrayed as a value-neutral process. There is, however, enough research to show that counseling is not value-neutral.⁹ It is now generally recognized that all therapists, to some degree, communicate their own values to their clients.¹⁰ At times, these values could clash with those of the client, or with existing norms. The counselors’ self is the primary instrument of healing in the counseling relationship. This makes it imperative for counselors to engage

in exercises and conversations that help them to be aware of their own values and the sources of these values, and to be mindful of choosing when to engage clients in value discussions. ‘Socially aware psychology’, for which there is a growing demand, urges that psychologists and counselors be connected to values of non-violence, equality, diversity and social justice¹¹.

ethical competence and awareness of client rights
The field of counseling and psychotherapy is expanding to new horizons. Today, the use of technology is posing new ethical challenges (confidentiality and electronic security; boundary management with respect to time, payments, and crisis handling) of which counsellors need to be aware. There is also need to increase awareness among counselors of the interface between ethics and laws such as POCSO, The Protection of Women from Domestic Violence (PWDVA) Act, marriage laws, the Mental Health Care Act, the Section 377 verdict which decriminalized same sex relationships between consenting adults.

Despite its importance, the ethics training received by counselors in

India is often patchy, even absent in some cases¹². Coupled with clients' poor awareness about the counseling process and of their own rights, this may lead to rights violations or exploitation.

Ethical awareness is a continuous process. Psychology and counseling curricula not only need to acquaint counselors with various ethical codes, dilemmas and their resolution, but also help counselors translate some of the ethical principles that have originated mainly in Western contexts into their clients' socio-cultural contexts.

Client (or user-survivor) voices are conspicuous by their absence within the larger field of mental health in India. Client voices should be encouraged, and must inform counseling education and practice. Concerted efforts are needed to increase awareness among clients about the counseling process, and about their own rights. An important step towards protecting client rights is to seek informed consent. Clients should be encouraged to ask questions about different aspects of the process. The counselor ought also to seek regular feedback from the client, to gauge whether

FOUNDATIONS FOR ETHICAL PRACTICE

CONFIDENTIALITY

BOUNDARIES

COUNSELOR COMPETENCE

ROLE OF SOCIETAL VALUES

ETHICAL COMPETENCE

AWARENESS OF CLIENT RIGHTS

the therapeutic process matches client goals and expectations. This would help in holding counselors accountable in their practice, and also in improving the quality of practice.

Feminists remind us of the need to share power with clients to create more equal relationships¹³. Counselors must find ways of sharing dilemmas with their clients and involving them in the decision-making process whenever deemed appropriate. This would create greater transparency within the counseling relationship, and help empower the client. □

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HUMAN RIGHTS

Queering Mental Health

Mental health from the margins

by Shruti Chakravarty

the role of the mental health community

Sexuality, as commonly or popularly understood, has largely been defined in ways that fail to capture its diversity and entirety. The dominant social code of heteronormativity assumes and insists that heterosexuality is the only legitimate sexual orientation. Within this system, gender is constructed as a binary – male/female – with distinct, strictly enforced gender roles. However, people's lives, identities and experiences are too varied and complex to be contained in such narrow boxes. We may be conditioned by our social institutions to aspire to a lifelong heterosexual marriage, defined by monogamy and procreation, but lived realities

are testimony to such an ideal being little more than a carefully constructed myth. The mental health (MH) community has itself played a rather significant role in pathologizing non-heterosexual sexualities, rendering invalid the lives, identities and experiences of LGBTQIA+ communities, and upholding oppressive structures by providing "cures" for non-normative individuals, thus systematically pushing them further into the margins.

After Sec 377 of the Indian Penal Code was read down by the Supreme Court on 6 September, 2018, there was a spate of announcements about "queer-friendly mental health services to the LGBTQIA+ community". The timing seemed odd. Decades of activism across the country had led to this historical moment. And Mental

Health Practitioners (MHPs) had been working with queer clients for over a decade. While there is unquestionably a need for more services, the sudden widespread interest in the mental health and well-being of queer people right after the SC verdict seemed opportunistic, hence worrisome.

It was in this context that MHI felt it necessary to interrogate and counter dominant approaches to sexuality in the mental health sector. As an MHI Advisory Board member, I approached some MHPs based in Mumbai, and a team of six emerged. We asked ourselves how we could generate and operationalize ways to make amends for the historical wrongdoings inflicted by the MH community upon LGBTQIA+ communities, and how we could now equip ourselves to be responsive to the particular needs of queer clients.

why is it crucial to be queer affirmative?

Is it enough to be queer-friendly while working with queer clients? Can "queer-friendly" convey the magnitude of what MHPs need to undertake in order to work with queer clients? Several of us, both within the team of six and outside, have been part of queer and feminist

movements for decades. A queer feminist perspective joins the dots and shows us how our right to love challenges the growing right wing agenda to consolidate power by instilling in us fear of the “other”. Conservative controls applied to our bodies and feelings constrict the multiple and diverse expressions of our sexualities and genders. Does a merely queer friendly service take into account this relentless erasure and marginalization of LGBTQIA+ communities? Does it hold MHPs accountable for their complicity in our historical pathologization? Is it equipped to respond to the needs of queer clients by incorporating the issues and stressors inherent in living on the margins of a heterosexually defined world? The Queer Affirmative

Counselling Practice (QACP) Course asked these and similar questions, focusing on ethical work with queer clients – work that includes: deconstructing, as MHPs, our own locations of power, privilege, and prejudice; educating our selves about queer lives; adopting an affirmative stance vs a neutral one; and advocating for the rights of all marginalized groups.

For too long in MH, queer sexuality had been considered through the lens of heterosexuality. This was an incomplete, incorrect and harmful gaze. No existing curriculum, course, trainings or materials represented the realities of LGBTQIA+ communities in valid or authentic ways. QACP was thus envisaged as an opportunity

to reorient ourselves to an anti-oppressive therapeutic practice, and to reflect on why any work in mental health needs to be political.

queer affirmative counselling practice

We created a 6-day Certificate Course that covered perspective building so as to recognize inequalities and their impact on mental health, and also provided tools to address distress and promote well-being of LGBTQIA+ persons. These perspectives and tools support MHPs in modifying their ongoing practice to make it queer affirmative. The course was opened up to MHPs – psychotherapists, psychologists, psychiatrists, social workers, counselors, preferably with experience of working with queer-identified clients, or families of queer-identified individuals. Over the first six months, we conducted three rounds of training with 50 MHPs, in three major Indian cities (Mumbai, Bengaluru, New Delhi). Other cities and small towns are next.

In the QACP Course, we challenged the idea of expert, objective, universal knowledge as being the only source of valid knowledge, and demonstrated the validity

“IS IT ENOUGH TO BE QUEER-FRIENDLY WHILE WORKING WITH QUEER CLIENTS?”

of experiential, situated, multiple knowledges. QACP draws on disability studies, user-survivor narratives, mad studies, histories of struggles, and queer feminist politics, to create ways to modify current MH practice. When applied, how does the queer affirmative lens help us rework diagnostic frameworks, protocols, and policies? What modifications may be required in our traditional approaches to clinical and counseling practice? How do we reframe notions of recovery and neuro-typicality so that we are responsive to a spectrum of experience?

QACP is not only about working with LGBTQIA+ communities and queer clients – it is an initiative that invites MHPs to reckon with the idea that in order to do ethical work they need to queer mental health practice overall. The QACP trainings are leading to the creation of a copyleft training manual for Queer Affirmative Counseling Practice that interested practitioners will be able to access free of charge.

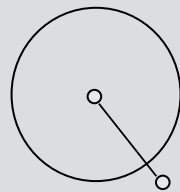
politics of responsibility

QACP reflects the politics of responsibility that we carry as queer feminist activists and MHPs. The lure of the pink rupee and the reading down of Section 377 saw many players entering the field of queer mental health with enthusiasm, but without an anti-oppressive framework or even any real understanding of our lived realities. Our own critical voices needed to be registered as part of the discourse. Our curriculum development process was an unprecedented phenomenon of sorts: with six queer-identified MHPs and trainers with different lived realities, strengths, and competencies, converging, brought together and supported by MHI, a funding agency that shares our values and politics. Words fail me in attempting to describe the organic synergy of this process as it unfolded.

Given that the edifice of QACP was based on shared politics and values, it followed that this foundation

would inform our pedagogy. The methods of delivering QACP were participatory, experiential, feminist, and queer. In creating the curriculum, there were specific challenges that came from wanting to contextualize the knowledge we were producing. Most writing and research on queer theory and mental health has been produced in western countries with mainly white populations. Working with a constant awareness that an uncritical transplanting of such knowledge would be of little benefit to MHPs or queer clients in the Indian context, we concentrated on building relevant content and frames of analysis.

Queer affirmative knowledge is knowledge generated by queer people – knowledge drawn from our lives, our politics, our struggles, and based on our lived realities and felt experiences. Committed as it is to countering dominant narratives of queer sexuality and gender, QACP foregrounds knowledge from the margins. □



queer
affirmative
counselling
practice

CERTIFICATE COURSE

Contexts

Access
Justice
Lived Realities
Sociocultural
User-centric

*How do HISTORICALLY MARGINALIZED COMMUNITIES experience MENTAL HEALTH, and what are the CHALLENGES they face in ACCESSING mental health SERVICES? How do we BRIDGE the GAPS in MENTAL HEALTH CARE while taking into account DIFFERENT LIVED REALITIES? To gain a nuanced UNDERSTANDING of these GAPS, it is critical to CENTER the EXPERIENCES of PERSONS LIVING *with* MENTAL ILLNESS. What areas are in need of a PARADIGM SHIFT in order to ENSURE JUSTICE in MENTAL HEALTH CARE?*

Voices in Contexts

We need to shift focus from individual pathology to structural oppression.

Many marginalised communities or those who have faced historical oppression have been overrepresented in diagnoses or invisibilised by the psy disciplines.



RESEARCH

I Walk the Line

Mental health service user
Experiences of treatment

by Lorelle Mariel Murzello

democratizing mental health

This article is a glimpse of my MA dissertation of the same title (which quotes a song by Johnny Cash that also became the title of a biopic about the late country singer.) The study explored treatment experiences of users, and their explanatory models of mental illness. Attaching value to life stories and narratives, it attempted to juxtapose these with prevailing paradigms of mental health service and, by extension, the body of “scientific” knowledge to which psychiatry and psychology belong.

Arthur Kleinman’s seminal work ‘The Illness Narratives’ (1988)¹ draws on the value of explanatory models of illness that emerge from patients’ cultural experiences, highlighting how much more complex these are than the corresponding medical models. The user-survivor² network in mental health has long championed the campaign ‘Nothing about us, without us’, speaking up against human rights violations; the lack of agency given to users in decisions impacting their own health; and the narrow medico-centric gaze³. Brookbanks’ (2014)⁴ vision for a ‘post-psychiatry’ argues for a postmodern approach, and

pushes for a more critical look at the values of objectivity, value-neutrality, universalism, and for an acceptance of multiple truths, perspectives, and ways of being. Such an approach is crucial for divergent perspectives, and to democratize mental health instead of it being a set of authoritative codes. The shift from an expert-driven stance is essential to rethinking the dominant mental health narrative, and thus improving overall accessibility to mental health care.

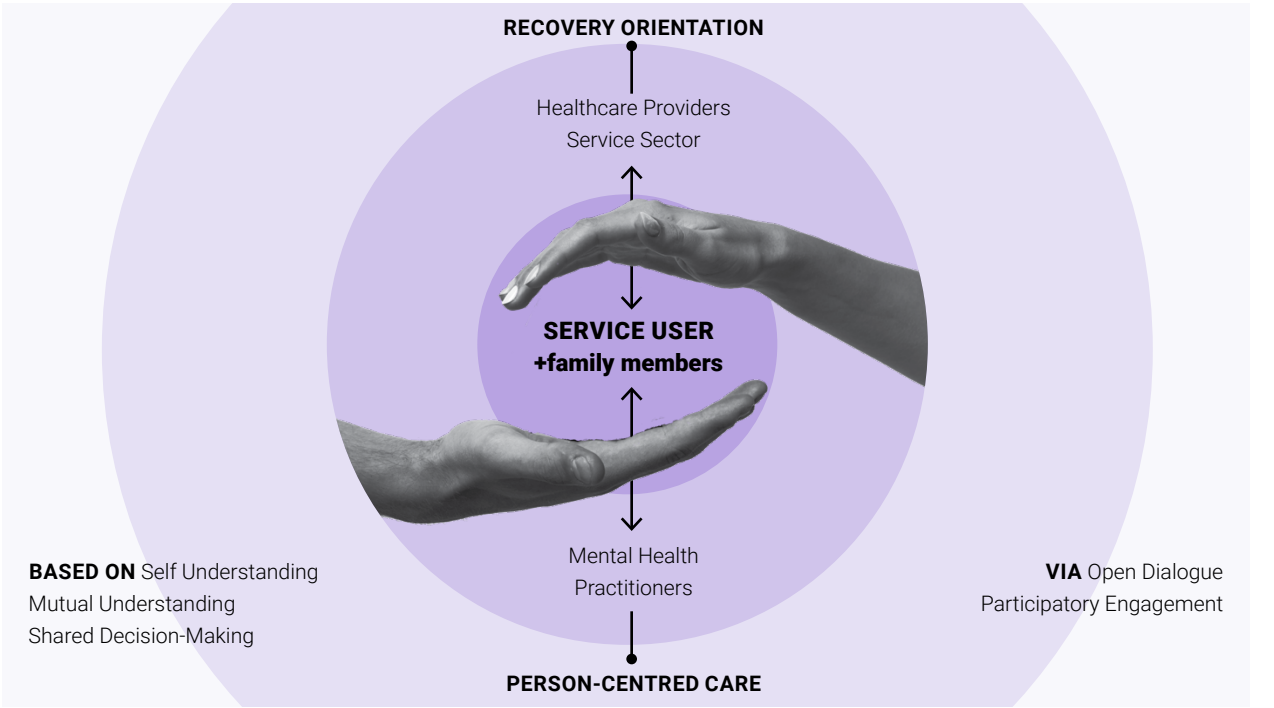
As part of my Master’s (2015-2017), I set out to explore the experiences of mental health service users against the background of this intersection of critical science studies and user narratives. This qualitative study, using a narrative methodology for analysis, gathered narratives of persons who sought mental health treatment from private or government health facilities. The participants, from ages 18-25, were from Mumbai, Bangalore, and Pune. One of the most interesting insights the study afforded was how an individual’s “illness narrative” was never separate from the larger context of their lives. Experiences of mental illness were usually accompanied

by stories of past trauma, losses, abusive relationships, and the roles played and expectations placed on participants as child, sibling, friend, student, employee. However, these life stories were not necessarily always seen as having caused the mental illness – rather, as being intertwined with the illness story. While some participants said that these stories had not been elicited in the clinical space, others said that clinicians often gave overriding emphasis to some factor such as the loss of a parent, or having had to move constantly in their formative years, even when the participant did not necessarily agree that these factors had been significant.

finding agency

Interestingly, participants drew a large part of their knowledge about their illnesses from information off the internet, from their psychology textbooks and college classes, and from peers who were going through similar socio-emotional experiences. They had found this combination of factors, in addition to treatment-seeking, helpful in piecing together an experience that sometimes felt chaotic and overwhelming –

COLLABORATIVE PRACTICE FRAMEWORK FOR SERVICE ORIENTATION



a piecing together that, for many, began even before accessing mental health care, and continued even after, on account of the limited information they received in the clinical space as against their desire to know more about their illness and deal with it more effectively.

Participants' coping and healing, too, often came from mechanisms

they had developed over time, and not just from their interaction with the mental health professional. While one participant found solace in the idea that "Every day is a new day, presenting a new challenge", to deal with her rapid emotional shifts; another discovered his acquired ability to look at himself and his situation objectively (a technique he called "self-surveillance"). Both

these instances indicate deep levels of self-awareness, control, and recognition of non-linearity in the process of recovery.

Several people also derived some sense of legitimacy from the diagnostic labels they had received. A participant recounted how her therapist's use of terms like "a bad phase" instead of "depression"

was the latter's way of making it seem less of a monster, but for the participant, "calling a spade a spade" or calling depression "depression" helped her deal with it accordingly. Another individual expressed her frustration on account of her Mental Health Professional's selective focus on the "symptoms of depression" that prevented him from looking for contradictory evidence. Yet another participant narrated, that while her MHP blamed her for her "mood swings", they refused to acknowledge the role of her father's dominating and passive-aggressive nature; further, she often felt "slut shamed" and was asked by her MHP to behave in a "gender appropriate manner" – a narrative that points not only to how the clinical space may be unable to understand the participants' social realm, but also to the pressing need for a feminist lens in therapy.

shifting power

Although participants' knowledge about mental health, understanding of their mental health situations, and discovering ways of coping often came from spaces and situations outside the clinical, their narratives show them negotiating through and accommodating scientific explanations. Some who

were students of social sciences even critiqued the existence of diagnostic categories in psychiatry. Mental health care accessibility issues, stigma, clinicians who seemed impersonal or cold – such experiences strengthened their critiques. Several participants referred to their clinical interactions as being "quick", "brief", "cold", "unemotional", "restricted to business". Borg and Kristiansen (2004)⁵ emphasized the need to re-evaluate these professional boundaries, in a study that described professionals as aiding in recovery when they treated users with kindness and patience, displayed a sense of humour, shared power, made the treatment process collaborative, and communicated a sense of hope about recovery.

The sharp contrast between the narratives by users and those of mental health professional serves to underline how the mental health sciences have recreated spaces of systemic oppression in what are meant to be safe and therapeutic spaces. The implications of this study go far beyond telling the stories of my eight participants; they point to larger systemic gaps in existing health care, internalized

and public stigma around mental health, and the often inaccessible nature of mental health care (in more than just a physical sense – with its pigeon-holed categories and pill-centered conversations). Harding (1992)⁶ writes of the importance of contextual, culturally and politically embedded science. Even while a "biopsychosocial approach" has been long advocated, valuing user narratives and stories is crucial in helping psychiatry destabilize its power and create a reflective mental health practice that is more tolerant of divergent perspectives. □

Lorelle Mariel Murzello completed an MA in Social Work in Mental Health from TISS, Mumbai, in 2017, and has been working in the education space ever since. Her research interests include mental health, culture, and gender studies.

HUMAN RIGHTS

Does Every Citizen Have the Right to Vote?

Accessibility for persons with psychosocial disabilities

by Adrika Sengupta

of rights-based organizations that strive for civil, legal, and social rights. In this context, we realized our vision would not be served by getting the residents voters' cards that openly stated where they lived. Following lengthy negotiations with relevant law enforcement entities, and the Election Commission, we won: the voter identity cards had photos, names and addresses – but no mention of any mental hospital. The individuals concerned would not have to carry that burden with them for the rest of their lives. For Anjali, this was a crucial step towards fulfilling its vision of destigmatization and deinstitutionalization.

navigating exclusion in legal, civic and societal systems

The Representation of the People Act, 1950, says under Section 16 (b) that a person "of unsound mind and [who] stands so declared by a competent court" may be disqualified as a voter. But what of the hundreds of recovered individuals who, having been abandoned to live out their lives in institutions, must bear the brunt of such exclusionary laws? Pollock and Mulla² have said that past treatment for mental illness is only prima facie evidence, and nobody may be barred from voting on that basis. The right to vote in genuine, periodic elections

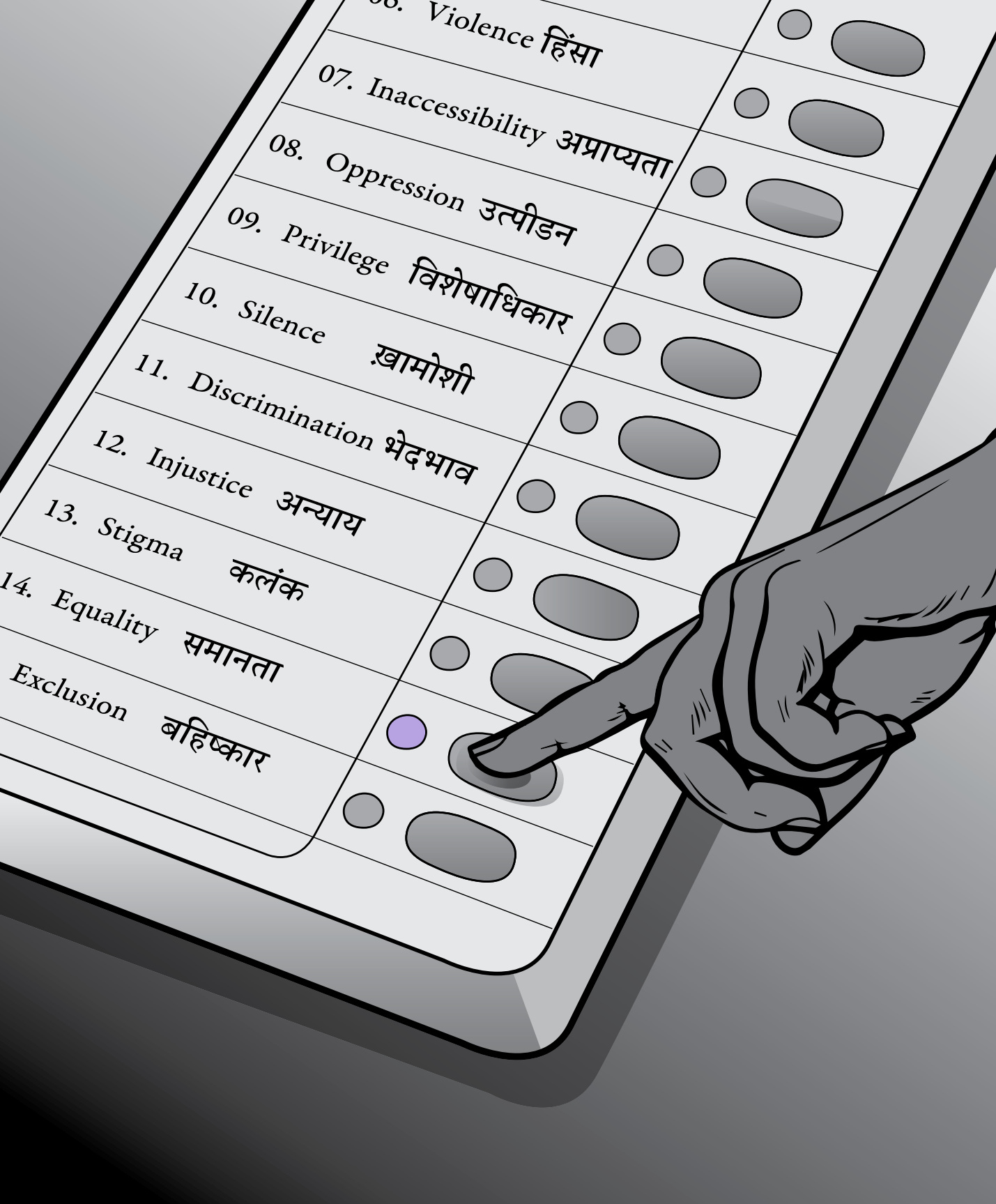
exercising rights of a citizen

"Of course I know which political party I want to vote for; do you think I'm not updated?" exclaimed one of the group, when Anjali's team visited residents in a mental health institution (an NGO) to conduct an orientation on political parties and the current political scenario. The excitement in the usually dingy room was palpable as 64 eager faces glistened with hope. The conversations on voting itself had been fairly simple. We are often asked how we decide who gets to vote. We asked residents in hospitals whether they were keen to vote. Some were, some weren't. We left it at that.

Voting has been, for Anjali, an issue of development, social justice, and human rights, as well as a feminist issue. It is an instrument by which we are able to counter so many incapacitating narratives – stigma, lack of access to knowledge and mental health care, social exclusion – and to make visible an ever-

disenfranchised population. Before setting out, we had often asked ourselves why we were so keen on this program – what would our residents achieve, and how tangibly would their lives improve? Were we striving for liberty, for agency? What might these terms even mean to people who know that after they cast their votes they would be bundled off to the hospitals again? For what would they be voting? What were their hopes? There were never any singular answers. We could only reiterate our conviction that this could eventually open up a whole realm of possibilities in the lives of people with psychosocial disabilities locked away in mental health institutions.

Lamichhane (2014)¹ reinforces what we have long known – that not only does mental health care have precious few resources allocated to it, most of these resources are used to treat people medically. Lamichhane says that in working with people with psychosocial disabilities we must follow the lead



ADVOCACY

Where Social Justice Meets Mental Health

by Deepa Pawar

is intrinsically linked to a number of other human rights, the enjoyment of which is crucial to a meaningful electoral process. These rights include the right to freedom from discrimination, the right to freedom of expression, and the right to freedom of movement.

Many aspects of social exclusion require us to pay attention to structural oppression in society, and to broader policy initiatives. Psychiatrists have a role to play in highlighting the links between policy, institutionalization, and psychosocial disabilities. Inclusion is pertinent to the experience of users/survivors, and must be treated as non-negotiable in a rights-based mental health system. Being part of the electorate is perhaps the most conventionally significant way of being acknowledged as a citizen, whose interests the State must not disregard.

During our conversations about the impending elections, one resident said, “I am a citizen of this country but have no certificate to prove it. Isn’t it my basic right?” Another person added, “Just because I suffered from mental illness at some point, it doesn’t make me any less human or any less of a citizen

of India!” It was during this time that we completely rejected the suggestion made by many – hospital authorities, doctors, even government departments – that voting booths be made available inside the hospitals, for the convenience of the residents. To us, this represented a pitiful and disgraceful method of continuing with the invisibility and othering of people who live in institutions – of perpetuating the sense of being locked away from society. We also had conversations about CRPF jawans being present in the voting booths, which we realized could cause agitation, and rake up frightening memories. What if these policemen rounded them up again and took them to some other mental institution? These were some of the musings of the dispossessed individuals with whom we spoke. On the day of the elections, in the scorching heat, under the debilitating influence of psychiatric medicines, amidst faulty electronic voting machines that took three hours to fix, through the sardonic murmurings of the police officers – “maybe these people pressed the buttons so hard that the machines malfunctioned” – the residents held their own. They resisted the suggestion that they be given preferential treatment and be

allowed to form a separate line so that they could be done faster: “No, we will wait our turn, we’ll stand with the rest of the public.”

There were moments throughout, as we went along, that made us feel that somehow this process had helped achieve some semblance of equity. Yet, even as we helped a frail, old woman up some steps, lamenting the State’s lack of concern for accessibility, we realized that the road to equity was going to be a long one. We also understood that it wasn’t us who were determining the process and its outcome. The residents had been facilitating these in their own way, all along. But our sense of truly being a rights-based organization that works for social inclusion with excluded persons was certainly reaffirmed. □

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Working with communities for collective mental health

realisation

I believe deeply in the idea that “The personal is political”, and shall therefore begin with a personal story. In 2003, after many difficult struggles, I passed my 12th Std exams with a First in Commerce – without any coaching, mentoring, or extra study materials. This was while living in a 10x10 ft room with eight other family members, and helping my father in his blacksmith’s workshop. They didn’t understand what these Board exams meant, or the importance of doing well in them. It was only when neighbors started dropping in, and saying I had stood second in my college, that my family realized I had achieved something. I hardly had time to congratulate myself, either, being worried about being able to continue with my studies with no money at home for that sort of thing. And my fears were fulfilled: my higher education ended for the want of 3,000 rupees. For almost a year, I held myself responsible, and would not look my friends and teachers in the eye. I lived with mental stress that was wholly internalized,

never made visible; certainly, I had no access to any mental health resources. It was an unbearably painful period. I had demonstrated capability, aspirations, the will and readiness to work hard. Why had my journey then come to a halt?

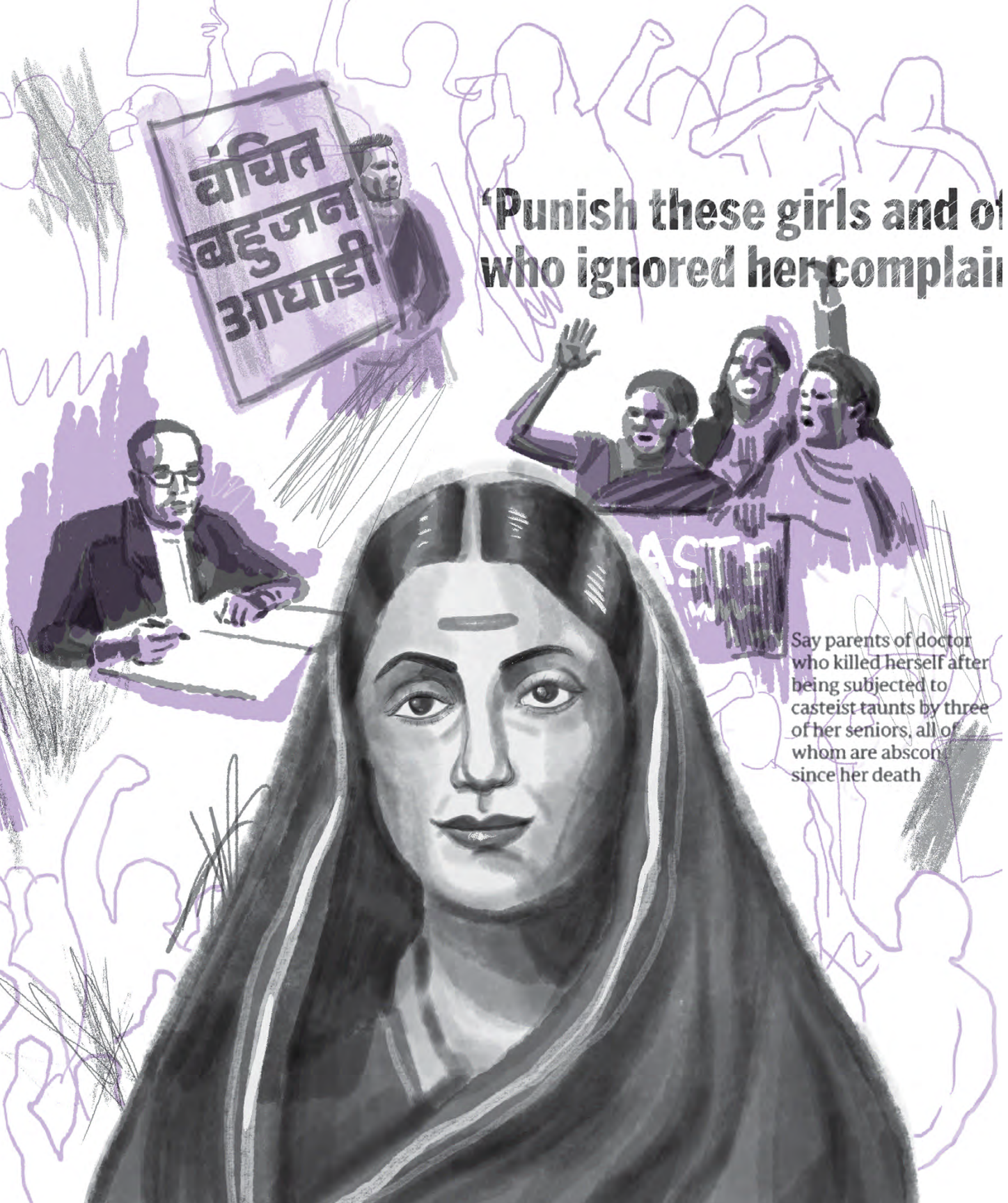
Had I had counseling at that point, I would probably have been diagnosed with extreme nervousness or mild depression. But counseling was never an option, coming as I did from a nomadic, displaced tribal community and family for which social identity, security, and development remain faraway dreams. It is a community marked by addiction, unemployment, insecurity, illiteracy, and mental stresses related to all these factors. It was only later, when I entered the social development field, and built up my own understanding of caste, gender, and religious patriarchy, that I realized I was not personally responsible for my situation.

social hierarchies and collective expectations

Social structures and systems create

an environment where an entire community or society has “collective expectations” from a single person or group – for instance, a newlywed woman constantly being asked when she will be sharing the “good news” (pregnancy). Perhaps she maintains her mental balance for the first few months, but how long can she deal with the mounting pressure? Another example is that of the child who, growing up like every other, begins to realize she feels like a girl while everyone else believes her to be a boy. Will social expectations allow her to be herself? And if the child belongs to a vulnerable community, she is likely to face further violence. When someone is unable to live up to society’s collective expectations, it is common practice to isolate, excommunicate, denigrate them, or coerce them into meeting expectations – measures bound to affect their mental health negatively. Besides, when an individual’s mental health is affected, their family and community are not immune either.

Collective social expectations, no matter if they stifle a person’s dignity, expression, participation, and development, follow a political design that ensures there is no danger to the existing Brahmanical



'Punish these girls and of who ignored her complain

Say parents of doctor who killed herself after being subjected to casteist taunts by three of her seniors, all of whom are abscond since her death

patriarchy^{1,2}. The suicide of Dr Payal Tadvi is a recent example: a Bhil Muslim adivasi, she had overcome complex social barriers to become a medical doctor. Her colleagues at a Mumbai hospital, other doctors who had bought into the vicious caste rules that expect doctors to come only from certain powerful social strata, allegedly harassed Dr Tadvi till she took her own life. Viewing this incident through the lens of mental health, we may see how the doctors and the system that enabled such behavior violated Dr Tadvi's right to both dignity and mental justice; cast her family into a situation of acute mental stress; and sent a clear message to the entire Bhil Muslim community – that anyone else trying to overcome caste barriers would be similarly treated – a threat with undeniable implications for collective mental health.

Many other situations playing out currently are affecting the mental health of entire communities: the heart-rending incidents of "mob lynching" of Muslims³; extreme sexual violence against Dalits⁴ everyday discriminations based on caste, gender, religion, region, sexuality, and disability. Existing mental health services do not even

begin to meet the growing need. The "treatment gap" approach, besides being biomedical, focuses on the individual rather than addressing the trauma and exclusion collectively experienced by communities.

It is necessary to link individual mental health to family and community. Our social and political systems must center the mental health of marginalized communities in ways informed by concepts of social justice and dignity. Our educational institutions, too, need to be part of a multi-sectoral plan to educate and empower youth and marginalized communities for better collective mental health.

constitutional morality

As in other law-based movements (the campaigns around the Domestic Violence Act 2005, or the Right to Education Act 2009, etc.), there is an acute need in the mental health movements for grassroots platforms, resources and leadership that facilitate community voices and articulations about collective mental health justice needs. India already has the progressive and inclusive Mental Healthcare Act, 2017 (MHCA 2017), which all social institutions must engage with,

and implement. This, along with adhering to the Indian Constitution's values and Preamble, would help ameliorate situations where mental health is affected by disturbances in the social fabric. As Article 15 of the Constitution says, "No citizen shall, on grounds only of religion, race, caste, sex, place of birth or any of them, be subject to any disability, liability, restriction or condition." In other words, every person has the fundamental right to dignity, respect, development, and participation, which seems like a basic formula for mental health and social justice. ☐

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Enhancing Livelihoods

Care and recovery are intersectoral

by P Thiruselvi

societal complicity

With awareness about mental health concerns growing, it becomes essential to protect the rights of people with mental illness, and promote better livelihood options for them. They may have been rendered emotionally vulnerable due to societal or personal crises. In the absence of timely counseling and support, certain symptoms might appear, or become exacerbated – such as insomnia, lack of appetite, excessive appetite, hallucinations, talking to oneself, becoming dysfunctional (not all of which are necessarily related to mental illness).

People with mental illness tend to face additional deteriorations and multiple harms due to the inherently inequitable nature of human society. They might lose everything they have earned prior to the onset of illness – work, family, children, relationships, home, property, respect. Physically and mentally, they might begin to internalize a sense of inability to achieve life goals. We see families taking responsibility and making efforts for a person's recovery when it comes to most health issues, yet the very same families often abandon people with mental illness. Society further discredits the mentally ill,

labeling them “mad”. The associated stigma pushes them further to the fringes, and excludes them from several areas of daily living. It may be said that people with mental illness endure lives filled with many losses and humiliations.

Mental illness is no more untreatable than any other illness, and needs to be perceived in the same manner. However, as things stand, people with mental illness are subjected to persistent social exclusion and isolation. One way of addressing this injustice is to expand and improve livelihood opportunities for people with mental illness. Mental illness does not arise or exist in a vacuum divorced from the individual's environment. Family, society, and prevailing structural inequities, all play their own roles. Society as a whole, then, bears responsibility for helping people with mental illness access necessary care and find livelihoods.

care extends to livelihood opportunities

Persons with mental illness must at the outset be acknowledged as part of their families and communities. Facilitating access to treatment is a necessary next step. However, care does not end merely

with offering biomedical solutions, but calls for supportive measures that can help individuals concerned to progress towards their aspirations and goals in life. Opportunities for transformation should be doggedly offered. An effective way of doing this would be to reconnect persons with mental illness to their rightful access to resources, thereby renewing their sense of well-being.

Although most government hospitals offer mental health treatment services, these alone are inadequate for improving quality of life. Counseling facilities need to be allied with skill development initiatives – along with housing and employment opportunities that would allow people with mental illness to participate more fully in their communities.

Every person should be offered the chance to resume the education or work that they may have had to discontinue during a period of serious illness. Both public and private organizations must provide employment opportunities for people with mental illness. Reservations are needed in government jobs; it may also be worthwhile to make concerted efforts for a specific quota

in private institutions. Regular employment and an assured income are known to help instill confidence. Besides, when they are no longer perceived as “burdensome” dependents, people with mental illness would be able to live with greater respect from both family and society.

building different types of care into mental health systems

Access to housing needs considerable work. Legal action against those who discriminate against the mentally ill also must be pursued resolutely. Those without designated carers or places to stay – people who are homeless, or living in shelters – need to be acknowledged as a critical subgroup requiring greater attention. Social entitlements such as voter IDs, ration cards, banking facilities, and easy access to pensions should be made available. Carers, too, need to be offered jobs in the system if the person they are caring for is indisposed because of a serious mental illness. If carers are employed at minimum wage or unemployed, this can result in extreme impoverishment that may affect recovery. Hence mental health systems need to

develop work options for such carers, to allow a better standard of living and quality of life.

Many people with mental illness belong to social strata that are below the poverty line, and must be offered all rightful social care options and subsidies.

Facilitating employment alongside care for people with mental illness can play a major role in their recovery. Supporting people with mental illness to return to work can help eradicate the pejorative tag of “mad”, thereby paving a way for them to return to ordinary, everyday life. ☒

We could not print this article in the original language, Tamil, due to multiple technical issues. The original is available on our website: mhi.org.in

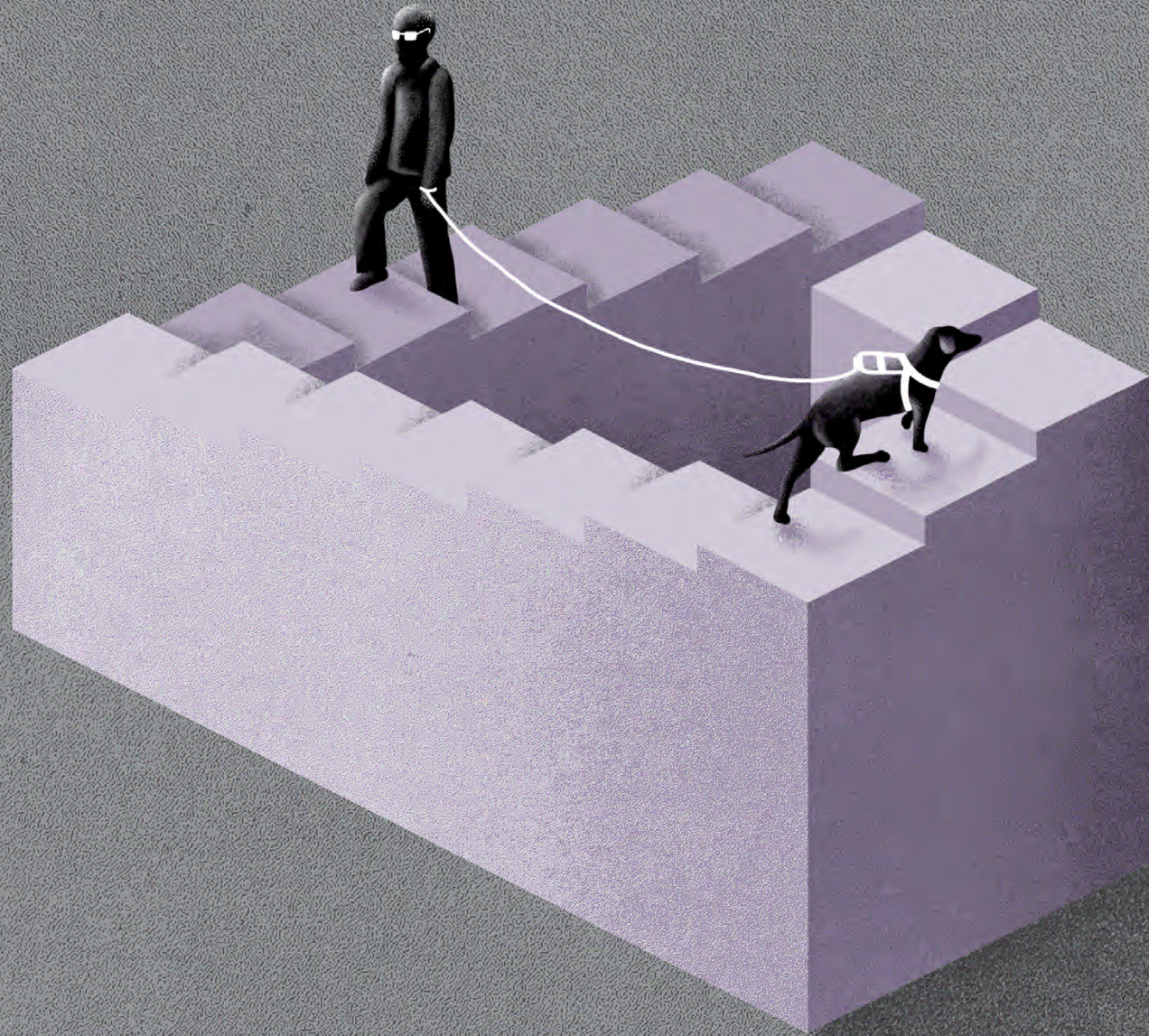
P Thiruselvi, as counselor at Ashwini Adivasi Hospital, Gudalur, Tamil Nadu, has connected hundreds of distressed people to mental healthcare. Her own recovery trajectories, through homelessness and mental illness, have been diverse. A Fellow at The Banyan Academy of Leadership in Mental Health (BALM), she is a single parent taking care of her mother and son while pursuing an MSc in Psychology. Tiruselvi has recently started working as a case worker at the Ooty One Stop Center, under the Ministry of Women and Child Development (MWCD).

LIVED EXPERIENCE

Unrecognized and Unaddressed

The mental health of persons with disabilities

BY Nidhi Goyal



trauma of an ableist world

"Survival of the fittest" was not just a Darwinian theory in our 6th Std school textbooks; over the years, we observe that it is a concept in which the majority believes. What then happens to those who are considered unfit – defective, less, disabled? Not many people might call you "defective" to your face if you live with a disability, but the raised brows, the "hmm"s, the discomfort that non-disabled persons exhibit, and the inaccessibilities they encourage and perpetuate, speak volumes to the person with a disability.

The constant subtext in the messages that surround persons with disabilities (PWDs) is that they are not worthy, they are incapable, they are a burden, and they are not needed. Just like the trees in the Solomon Islands that are popularly believed to die – and thus become easier to cut down – when cursed, many PWDs succumb to the negative messaging and start doubting themselves. Some of them become convinced that

they are somehow lesser beings, forced into dependence, and begin feeling "not normal" all the time. On the other hand, some PWDs, as a defence mechanism, fake ableist independence, or almost kill themselves trying to prove to the non-disabled world that they can overcome whatever hurdles are thrown at them, because they are expected to be superhumans and are under a scanner all the time.

Imagine a life where judgments and conclusions about you are arrived at with just a glance (in cases of visible disability), or you are disbelieved, even suspected to be lying (in cases of invisible disabilities). PWDs live with this trauma. They are constantly questioned, prohibited or only reluctantly "allowed" by nondisabled society to do "normal" things that others take for granted, like education, access to public spaces, socializing, work, relationships, marriage, and so on. Discrimination is a constant, with abuse and violence not far away. In such an environment, many PWDs tend to internalize

the stigma and behaviors they encounter. These realities shape the conversation around PWDs, which is generally couched in terms of their basic survival, rather than of their right to live their lives to the fullest.

PWDs are not a homogenous group. Individual experiences differ, depending on factors such as the nature of the disability, and privileges or otherwise of location, gender, etc. There is one significant difference – that between congenital (born disabled) and acquired (late disabled through accidents, disorders etc.) disability. In both situations, similar discriminations and difficulties prevail, but in the case of an acquired disability the individual themselves may carry an ableist mindset as they transition from one world to another. They may have predetermined notions about their life, potential, and future, which are not grounded in fact but rooted in stereotypes. So most often when people acquire their disability, the first thing they believe is that life cannot be lived with blindness, deafness and so

AIDS TO ACCESSIBILITY Help provide equal access opportunity to PWDs



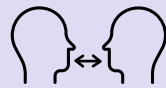
motor disability Ramps, Elevators, Wheelchairs, Walking Cane, Crutches, Motorised Scooters, Adapted Vehicles, Keyboard Navigation, On-Screen Keyboard, Voice Recognition, Assistance Dogs, Prosthetic Devices, Orthotic Devices



visual disability Audio Descriptions, Alt Text, Auditory Notifications, Braille, Captions, Text to Speech, Transcripts, Screen Magnification, Reduced Interface, Guide Dogs



hearing disability Sign Language, Symbols, Hearing Aids, Hearing Dogs, Closed Captioning, Alerting Devices (connect to a doorbell, telephone, or alarm to let someone with hearing loss know that an event is taking place)



speech disability Augmentative and Alternative Communication (AAC) devices help people with communication disorders to express themselves. These devices can range from a simple picture board to a computer program that synthesizes speech from text, sign language



cognitive disability Easy-To-Read Text, Screen Magnification, Reduced Interface, Keyboard Navigation, On-Screen Keyboard

on. They believe they would not be able to work, they won't be fit for social participation etc., all based on ignorance and access to stigmatized messaging and information when they were non-disabled.

mental health gap for persons with physical and/or sensory disabilities

So what happens when you are disabled? Disability is generally viewed through the medical lens of

disease, and correction. For those with a physical/sensory disability, some medical rehabilitation, however imperfect, is usually possible. However, what is neither routinely recommended nor provided is any kind of mental health rehabilitation and support. This extremely important need is hardly recognized.

Most problems that PWDs face tend to be attributed to their disabilities. So if they don't get admission in an

institute or face challenges there, it is not because of lack of reasonable accommodation, it is because of their disability is what is told to them; when a disabled woman is harassed while seeking assistance she is told that it is because she is disabled and needs help. Discrimination and abuse add their own weight to the already present guilt and shame many PWDs experience. Traumatic experiences accompany being disabled almost like a package deal, and this not only

normalizes the trauma, it prevents the PWD from speaking out against it or seeking external help to cope with it.

Mental health and physical disability together form a difficult intersection, both being highly stigmatized. This intersection is seldom recognized, and rarely discussed. The idea persists that PWD are disabled, not "mad", and therefore do not require mental health support. This view serves only to perpetuate the stigma around mental health concerns, and makes it extremely challenging for PWDs to access mental health care.

Access barriers exist at multiple levels. To begin with, many PWDs need mobility and transport assistance, which is provided (if at all) mainly by family members. As a consequence, the PWD rarely has privacy in interactions with counselors or therapists or doctors. This becomes particularly complex when the trauma inflictors are the family members themselves. If the PWD is deaf or has other hearing or speech impairments, they have to take along an interpreter because almost no medical practitioners know sign language. Additionally, the clinics or centers may not be physically accessible.

The bigger barriers are the intangible ones. Training and sensitizing about the needs and concerns of PWD are not a part of medical or counseling curricula. Most practitioners, then, come with the popular ableist and stereotyped beliefs about disabled persons. Many might never have interacted with a single disabled person in their entire lives and careers. PWDs are routinely infantilized, which means that in most cases they are not directly addressed, or believed – the counselors or doctors talk to or question their family members, instead. Such an approach strips PWDs of their agency; obtaining consent from a disabled person gets reduced to a formality and is rarely real, informed consent.

Therapists who cannot unravel these several layers often do more harm than good. They may even end up suggesting coping techniques that are ableist, and better suited to non-disabled persons, or in other words, better suited to fit into the nondisabled/ableist world.

Living with a disability is not easy, particularly in the current environment of inaccessibility. The gaps in physical care are visible and

substantial. But the void in mental health care and support is invisible, and unrecognized. The impact of this care gap is immense, allowing an entire community to remain mired in guilt, shame, low self-esteem, too often with under-utilized personal potential – just surviving, rather than living life to its fullest. ☹

Nidhi Goyal is an activist, writer, researcher, trainer, and comedian who works on disability rights, gender justice, and leadership building. She is the Founder and Executive Director of the non-profit Rising Flame that works for rights of women and youth with disabilities. As a disabled feminist, Nidhi is committed to changing lives of persons with disabilities particularly women, through her work with national and global organisations and networks.

The Invisible Crisis

Sexism, twin taboos & mental
Health oppression

historical neglect

24 years ago, Bhargavi V. Davar¹ wrote, “In the mental health scenario, professional and institutional attention has so far not focused on the mental health needs of Indian women.” In 2019, India is still held back in this regard by the old vulnerabilities, compounded by patriarchal households and a sexist medical community that hinder bodily autonomy and trivialize women’s experiences.*

Premenstrual dysphoric disorder (PMDD) is a typical example. In 1994, PMDD appeared as a depressive disorder in DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, 4th Edition) and, in 2019, it was classified under genitourinary disorders, as per the widespread consensus that the disorder is expressed in the brain but triggered by increased sensitivity/reactivity to normal hormonal fluctuations. PMDD is extremely undiagnosed in India, with not only the general public but the majority of doctors being oblivious to its existence.

An estimated 3-8 percent of women fit the criteria for a PMDD diagnosis,

which means that approximately 2.216 crore women in India are potential PMDD sufferers – suffering in silence, and enduring failed treatments and mis-diagnosis. Suicide rates among Indian women are highest in the reproductive ages. While many complex biological, psychological, and social factors act as causal pathways, we do need to recognize that one of the dangerous symptoms of PMDD is suicide ideation, with almost 20% of women who suffer from PMDD attempting suicide.

The medical community’s apathy to women’s needs is not a new phenomenon; nonetheless, it remains utterly shocking. The erasure of women’s unique mental health experiences may be observed in biomedical research as well as in clinical practice. The persistent stereotype of hysteric, attention-seeking, exaggerating women has undoubtedly cost Indian women far too many QALY (quality-adjusted life years).

sexism across stakeholders

Historically, the combination of the pharmaceutical industry, psychiatrics,

by Anuhya Korrapati

and gynecologists has medicalized women’s bodies – often through coercion, and manipulation of information. Meanwhile, even today, biomedical research predominately uses male subjects, arguing that the natural rise and fall of sex hormones in women’s bodies disrupt trial results. Should medications for any condition, that have not been tried on women, even be prescribed to and used by women? It would seem there is substantial reason to move away from hormonal treatments and SSRIs (commonly prescribed antidepressants) that further medicalize women’s bodies. Where do women’s health and well-being stand, in the patriarchal context? How do we provide mental health services to women with PMDD, without over-diagnosing them and without trivializing their menstrual-mental health experiences?

We need to start by addressing the lack of medical discourse on menstruation and mental health. There seems to be a disconnect between understanding menstruation and holistic well-being. Both PMDD and PME (premenstrual exacerbation) have mental health implications that are specific to females, but

are surrounded by a deafening silence that may be understood as deriving from the twin taboos of menstruation and mental health.

Mental health concerns are still widely stigmatized, while menstruation is such a taboo that it is relegated to reproductive health even within the medical community. For instance, instead of PCOS (Polycystic ovary syndrome) being treated like the endocrine disorder that it is, it is treated as a fertility issue with the first line of treatment being a prescription of hormones.

women as community

Evidence indicates that more women report, and consult doctors for, both physical and psychological symptoms than men do. However, we have a disproportionate number of men as mental health service providers. Considering how PMDD manifests through both physical and affective/psychological symptoms, there is a need to encourage more women to enter mental health care occupations. In addition, there is a need for focused discussions on the menstruation-mental health link, along with inclusive menstrual health sensitization through sustained interactions on this subject.

The label-oriented, isolating, drug-the-feelings approach of patriarchy will never replace the mental health that arises through women working together in community, and across differences. The only way to enable access and quality, and to curb gender-based discrimination, is a community-oriented approach where women have freedom to choose their treatment with full informed consent, along with the presence of peer support from other women diagnosed with the same condition. In fact, women diagnosed with PMDD often feel relieved with the diagnosis: knowing just what to expect in their menstrual cycles enables women to gain control over their lives – for instance, cognitive behavioral therapy has proven effective during the luteal phase.

Self-regulating techniques, peer-led support systems, and enabling families and partners to support women with PMDD will allow for long-term, sustainable treatment plans that help to demolish the treatment gap. ☒

**EDITORS NOTE: Data and research available on PMDD uses only the gender label of woman. We do not have the figures for trans and non-binary individuals in India who may experience PMDD. We believe more work needs to be done to explore how PMDD is experienced at multiple gender locations.*

Anuhya Korrapati is an intersectional feminist, health economist (University of York), menstrual activist, and founder of BeyondBlood (An organisation that initiated menstrual-mental health movement by focusing on PMDD, PME and PMS). Her areas of interest include menstruation, mental health, and gender equity and intersectionality in health.

Engage

Operations
Practices
Psychosocial Factors
Sustainability

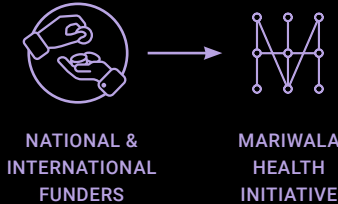
WHAT *are the ways in which*
ALTERNATIVE CONSTRUCTS
can be built? How do we address
MENTAL HEALTH CARE GAPS
in TANGIBLE, SUSTAINABLE
WAYS on the GROUND? *In what*
DIVERSE WAYS *and* VARIED
CONTEXTS *have such* CARE
GAPS *been* OPERATIONALIZED
in mental health SERVICES and
ADVOCACY EFFORTS? *This final*
section highlights some PRACTICES
and EXPERIENCES *around the*
application of PSYCHOSOCIAL
FACTORS *in mental health work.*

Framework

Moving away from the two building blocks of supply and demand in the treatment gap. This section explores pathways to operationalise bridging the care gap and moving toward a transformative, accessible mental health ecosystem. Here we show MHI's funding and strategic support to connect and collaborate with stakeholders, and also the key variables that play important roles as change agents.

1 VIA FUNDING & DIRECT AID

MHI provides funding and strategic support for innovative mental health interventions while connecting stakeholders to encourage exchange of ideas and potential collaborations.



2 FUNCTIONS

The knowledge and dialogue generated by activists, service providers and researchers enables constructive, context specific engagement and shaping provisions for bridging the care gap with communities, public and private institutions, and policy.



3 STATE & CIVIL SOCIETY

The adoption of a rights based, user led, mental health approach by the governmental, non governmental institutions, enterprises and communities moves us toward collaborations to extend psychosocial support and accountability for a vibrant mental health ecosystem.



4 PUBLIC MENTAL HEALTH

Once the state and civil society drives rights based, intersectional mental health care and support, the foundation can be laid for approaches, services and social safety nets that lead to inclusive public mental health by dint of being accessible to all, irrespective of gender, gender identity, sexual orientation, language, ability, age, class, caste, region and religion.



LAW AND POLICY

Mental Health & Criminal Law

A chasm in need of a bridge

by Dr Anup Surendranath & Maitreyi Misra

criminal justice system and mental health

A convenient site for observing the care gap in the criminal justice system (CJS) is the prison, where an infrastructure for care already exists. However, any assumption that the CJS is accurately able to identify people with mental illness who are in need of care calls for closer scrutiny. The CJS for adults interacts with mental health most explicitly when assessing the fitness of the accused to stand trial¹, and when an accused takes the insanity defense². To a much lesser extent, it plays into the court's discretion in deciding punishment, particularly the death penalty³. At all these stages, however, the excessively narrow approach of the law takes into account only those mental illnesses that appear on the psychotic spectrum⁴. As a result, other mental illnesses fall by the wayside, and thus go unaddressed. This points to a previously unexplored site that the care gap question needs to explore, namely, the court – along with procedural and substantive criminal law.

criminal processes, access to justice, and the care gap

Competence to stand trial, and the insanity defense, both revolve around

the issue of capacity. Indian criminal law continues with its orthodox, all-or-nothing approach towards gauging capacity – either the accused has capacity, or not at all – which also restricts mental health professionals (MHPs) from bringing to light the gradations inherent in mental illness. The rejection of a nuanced understanding of mental health results in the justice system's inability to formulate appropriate responses, and a consequent care gap.

Even within the little space that criminal law accords to mental illness, there are concerns about the system's ability to identify it accurately. Unless these illnesses have previously been documented, usually through treatment, the system depends on judges and lawyers to identify mental illnesses and consider related issues. Not trained in the field, these interlocutors tend to rely on observable manifestations of “abnormal” symptoms – an understanding of mental illness that derives from popular depictions of “mad” people, and enters the vocabulary of the law. Add to this the fact that lawyers rarely meet prisoners to discuss their life histories, which would include histories of mental health.

Yet another barrier to identification is that the right to legal representation is understood in a limited way, as merely, access to a lawyer. Prison rules do not allow MHPs access to the prisoner, even if the MHP is part of the defense team. The defense, then, has little opportunity to introduce evidence of previously unidentified mental illness. This penalises, in particular, accused persons from socio-economically vulnerable communities who barely have access to mental health care and treatment and, therefore, may have no records of their illness. While this problem has recently found a solution in the context of prisoners sentenced to death⁵, it remains a barely addressed issue otherwise.

This exclusion of MHPs practically ensures that the CJS is unable to identify persons with mental illness; let alone fulfill the goals of providing accommodation, support, and care. For instance, in one death penalty case in which Project 39A⁶ was involved, the prisoner's mental health situation, possibly prevalent since childhood, was brought to light only much later in the judicial process. The prisoner had been taken to a faith healer for many years in connection with some “abnormal issues”,



never receiving formal treatment, which meant there were no medical records. We were able to unearth the prisoner's history of mental illness only after multiple meetings with him and with his family, and after consulting MHPs who had to provide their opinion based solely on the information collected by us.

prison and the care gap

A similar scepticism and lack of imagination is evident in the prison system as well. Prisons become receptacles for accused persons with mental illness⁷ who are neither diverted to mental health hospitals nor discharged into the community⁸. Acknowledging that prison is a risk factor for poor mental health, the National Mental Health Policy (2014) recognized prisoners as a vulnerable population. The Mental Healthcare Act (2017) extends to prisoners the right of persons with mental illness to access quality treatment, and obliges prison authorities to ensure the fulfilment of this right.⁹

Prisons, however, face a resource crunch with respect to the infrastructure for mental health treatment. In the mental health study undertaken by Project 39A, for which 88 death row prisoners were interviewed across Delhi,

Chhattisgarh, Madhya Pradesh, Karnataka, and Kerala, many respondents reported a troubling lack of quality mental health treatment in prison¹⁰. The Prison Statistics India (2016) report also reveals that in many states there are either no sanctioned positions for psychologists or psychiatrists in prisons, or that sanctioned posts have not been filled. For instance, Maharashtra has eight sanctioned posts but only three have been filled¹¹.

In the course of the study, we identified 30 death row prisoners with major depression, an overwhelming majority of who were not being provided treatment. Five of these prisoners went on to attempt suicide in prison. This reveals a fatal gap in timely identification and care of prisoners with certain kinds of mental illnesses that might have no observable symptoms – which, in turn, is likely to make the illness all the more debilitating.

conclusion

It was only recently that the Supreme Court of India explicitly acknowledged the inability of criminal law to account for “broad-spectrum” mental illnesses, as a result of which prisons have ended up housing a large number of persons with mental

illness. The Court commented on the “realities within prison walls”, and other factors inherent in prisons, such as overcrowding, lack of privacy, and inadequate healthcare facilities, all of which adversely affect the mental health of the prisoners, and may further exacerbate mental illnesses.

This rare self-reflexivity by the Court indicates a growing awareness of shortcomings in the criminal justice system, and represents an opportunity to undertake a comprehensive investigation into the precise contours of the chasm between the fields of mental health and criminal law. □

Anup Surendranath is Executive Director of Project 39A and an Assistant Professor of Law at National Law University, Delhi, where he teaches courses on constitutional law, legal methods, jurisprudence, and comparative rights adjudication.

Maitreyi Misra, a founding member of Project 39A, leads its work on mental health and criminal justice. She assisted Senior Advocate Anand Grover in his work as UN Special Rapporteur on the Right to Health, and has worked with the Association for Civil Rights, Tel Aviv, as an International Law and Human Rights Fellow.

SERVICE DELIVERY

Fostering Resilience in the Wake of Disasters

Disaster-related distress

by Raj Mariwala

Every year, thousands across the globe are affected by natural disasters, armed conflict, or both. Because such events are unpredictable as well as highly destructive, they cause significant mental distress¹. Research indicates that such distress is two to three times more prevalent in disaster-affected communities than in the general population². Besides, disaster-related distress lingers for a long time³. According to a study of disaster survivors

from 80 countries, 25% reported that their distress impaired their ability to perform everyday tasks and fulfill family or employment obligations for years afterwards.⁴

Despite available evidence of the impact on mental health, disaster response approaches have not, traditionally, included mental health services. Disaster preparedness and response activities focus solely on immediate humanitarian needs such

as water, shelter, food, and physical safety and health. And yet, disasters tend to disrupt social networks, besides destroying livelihoods and community resources. In such circumstances, persons with mental health conditions may lose access to their support systems, modes of care, or medication – leading to further mental distress.

What of communities living in disaster-prone areas? Kerala experienced grave flooding and landslides in 2018, and again in 2019. The state's mental healthcare program, housed in community health centers, saw patient numbers almost double, from 14,000 in 2017 to 25,000 in 2018. Many persons reported that the 2019 floods had intensified their post-traumatic stress, or increased their anxiety.

employing a psychosocial lens

Typically, mental health services – when provided in the aftermath of disasters – take the form of mental health clinics within relief camps that follow a biomedical approach to diagnosing and treating mental distress. Such treatment has limitations and may be time-bound, failing to address the more long-term impact on mental health.

It is vital, therefore, that such initiatives employ a psychosocial lens. This would mean an inter-sectoral approach, with multiple agencies involved, and various levels of non-specialized and specialized support in terms of mental health interventions as well as basic services such as food, water, shelter, and physical health care.

Such an approach would consider, for instance, how overcrowding, and lack of privacy and safety, in disaster relief camps increases distress for vulnerable groups such as women and children. It would draw upon a community's inherent resources – which might include the ways in which people have dealt with adversity previously, and traditional solidarities that provide mutual support. In situations of disaster, these networks and mechanisms for psychosocial well-being and mental health may face undue strain or break down, making it all the more imperative to revive them. Fostering a community's ability to manage distress using its own resources is a sustainable, holistic approach.⁵ Disaster-response initiatives can foster resilience by tapping the knowledge, skills, resources and insights of community members themselves.^{6,7}

“FOSTERING A COMMUNITY'S ABILITY TO MANAGE DISTRESS USING ITS OWN RESOURCES IS A SUSTAINABLE, HOLISTIC APPROACH.

fostering resilience in cyclone-fani-affected communities

When Cyclone Fani devastated 14 districts in Odisha, early warnings and evacuations prevented large-scale casualties. The state government coordinated an immense mobilization effort, employing tens of thousands of volunteers, emergency workers and officials, and tapping civil society organizations, to evacuate 1.34 million people. It also leveraged the expertise of National Institute of Mental Health And Neuro Sciences (NIMHANS) to provide mental health services to affected communities. However, given that Odisha is repeatedly devastated by cyclones, it is at least as crucial to invest in fostering resilience among disaster-prone communities in the state.

Our partner, Basic Needs India (BNI), has worked for decades in some of the disaster-affected districts of Odisha, implementing community-based mental health programs. This includes interventions in six of the most affected blocks of Odisha, in coordination with its partner organizations Youth Council For Development Alternatives and Utkal Sevak Samaj. Its approach includes both, sensitizing government functionaries, and using community volunteers, to address the psychosocial needs of affected communities.

Select government functionaries from the departments of health, child protection, women and child welfare, Integrated Child Development

Services, along with community leaders and representatives from community-based organizations, receive intensive training in psychosocial interventions. Efforts are made to include traditionally marginalized voices from across caste, class, and gender.

Volunteers informally associated with essential government services and community organizations are also trained in psychosocial intervention skills. These are volunteers from the affected communities, which they understand well, and so they are able to work directly with families and individuals. They are also trained to mobilize community members to take ownership of disaster-response efforts. The attempt is to involve persons from across social hierarchies in all discussions, decisions and actions – including resource-deprived marginalized groups that traditionally lack influence, and are usually silenced or isolated.

sustainability

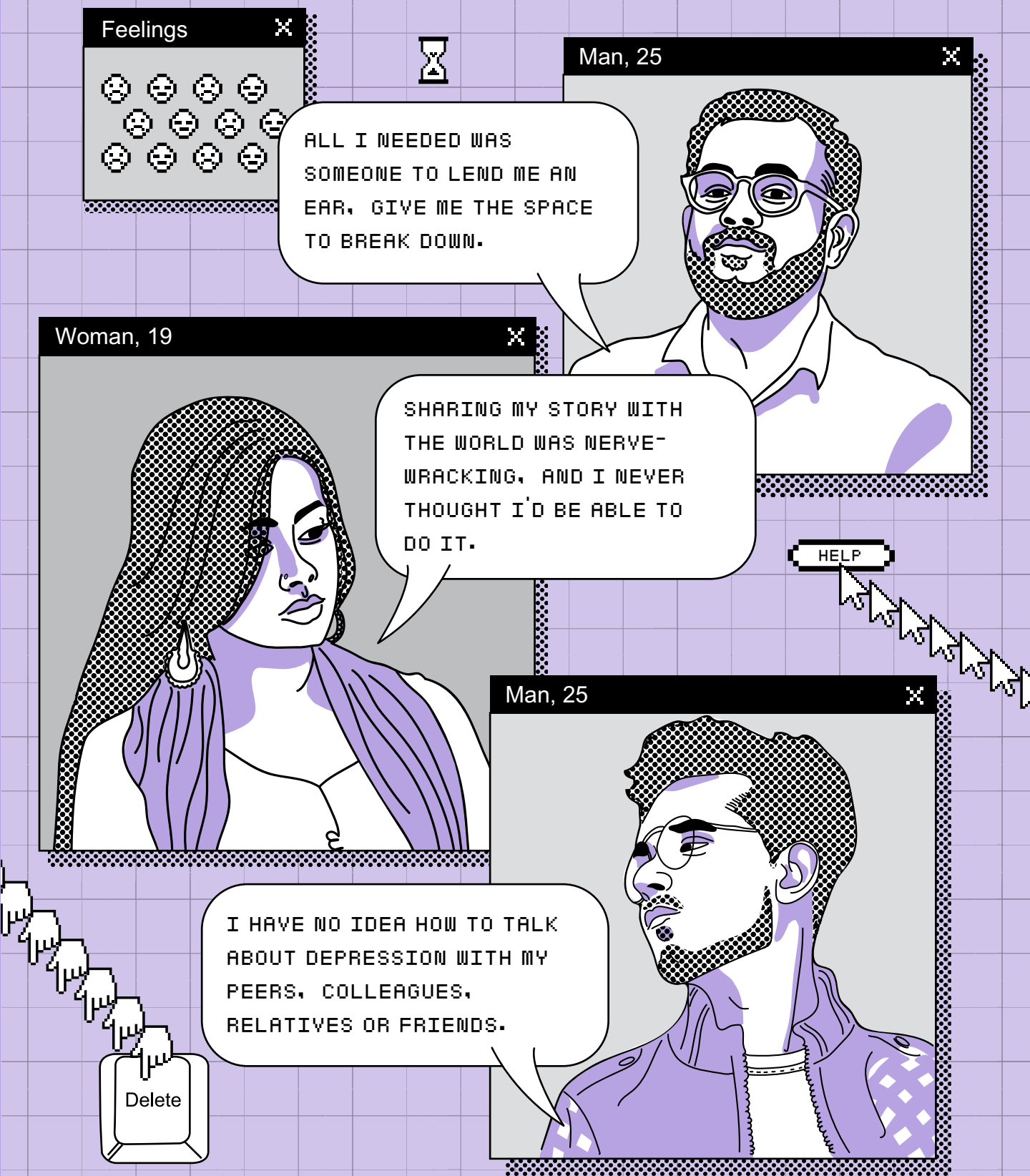
In order to facilitate genuine community participation, the community volunteers are sensitized to address social inequities and power structures. They strive to

establish relationships of trust, work with the formal and informal local leadership, and offer psychosocial support to the community. They encourage individuals to share their experiences, anxieties, and other stressors. Thus, instead of relying on external support, the community begins to respond collectively to its own needs. The volunteers are also trained to re-establish the community support structures and self-help groups that may have been temporarily disrupted or disbanded in the wake of a disaster. In addition, they are ready to play a key role in reviving communal cultural practices and rebuilding communal bonds.

In the event of any disaster, both sets of trained groups are all set to work in tandem for four months, to address community distress. During this phase, BNI will offer refresher training to Training of Trainers, volunteers, and partner teams, and further support as required. Persons needing specialized care will be referred to mental health service centers. Over the next four months, the volunteers will phase out their active involvement, while the follow-up work is continued by partner organizations with a focus on people who require mental health services. In the final

four months of the year-long project, identified individuals and families will be integrated into ongoing programs of partners. Throughout, partner organizations will coordinate implementation, and BNI will offer constant technical support.

The idea is that when, after a year, BNI moves out of active intervention, communities are not adversely affected, because the intervention remains sustainable – it will, in fact, have built resilience and strength. Such interventions, that are sustainable and that build community resilience, have the potential to be scaled throughout India, in other communities and districts that frequently experience natural hazards. ☒



RESEARCH

Young Indians Speak About Mental Health

Insights gained from stories
Shared online

by Pattie Gonsalves

exploring youth mental health

I hope that reading my story might help others feel less alone. It is important to know that other people are fighting the same battles. This is for anyone who feels stuck, overwhelmed or hopeless. You are not alone. (Woman, 24, www.itsoktotalk.in)

We spend a great deal of time and resources on the research, design and implementation of various mental health interventions, often without acknowledging the central role of users' experiences in shaping the efficacy of these interventions. I am not sure if I realized, when I began my work with 'It's Ok To Talk', a young people's mental health project in India, just how powerful and central people's stories could be.

India has the world's largest population of young people in the 10-24 age group¹, and mental health problems are a major health concern in this period. In fact, suicide is a leading cause of death for young Indians. And yet, fewer than 10% of young Indians have access to formal mental health services, highlighting

an urgent need for innovative strategies to promote mental health for this age group nationally^{2,3}. The negative impacts of youth mental health problems are starkly reflected in the strong association between poor adolescent mental health and long-term social disability.^{4,5,6}

There is now a growing interest in the use of social media platforms for mental health promotion and stigma reduction, particularly among young people. The 'It's Ok To Talk' website, inspired by "Depression: Let's Talk" – the WHO theme for World Mental Health Day, 2017 – invites young people to share their personal experiences of mental health needs, resilience, and recovery, in any media form of their choice.

social media as safe space

We recently carried out a qualitative research study based on submissions to this website from 33 young authors. A group of eight of the authors came in as collaborators, offering us feedback and suggestions on our coding framework and on the paraphrasing of selected quotes,

and reviewing our final manuscript⁷. Four overarching themes were identified through the narratives: living through difficulties; mental health in context; managing one's mental health; breaking stigma, and sharing hope. Almost all submissions contained personal experiences of distress, with the embodied experience of mental health difficulties as being physically and mentally overwhelming. Loneliness, isolation, and a strong desire for connection were manifest, mirroring findings from other qualitative studies of youth narratives in high-income countries^{8,9}. The scope for articulating and sharing these painful experiences appeared to be an important function of the website.

Though public discourse on social media use often emphasizes their negative impacts, more recent research suggests that the effects may depend on the way these platforms are used¹⁰. Individuals with stigmatized illnesses often avoid seeking healthcare¹¹. In such situations, reading or hearing about the experiences of others can

related decision-making¹³. Young people with mental health difficulties report that one of their primary reasons for connecting with others online is to feel less alone^{14,15,16}. We found young persons were more inclined to seek mental health care if they felt able to express their feelings, and have information about mental health issues as well as available sources of support.¹⁷

social media referencing the psychosocial

Several authors described their mental health difficulties with reference to their socioeconomic and cultural contexts. The submissions thus went beyond accounts of internal experiences alone, to explore and challenge the societal and political contexts of psychological distress, and offer a rich, multi-dimensional understanding of mental health. Narratives highlighted how rigid social norms often contribute to poor mental health by forcing oppressive and unrealistic expectations on young people, which exacerbate stress. In India, stress related to academic performance, and resulting from failure in exams, has been noted as a predictor of suicidal ideation¹⁸. This is consistent with research

in other low-income and middle-income countries, which has found academic, interpersonal and family difficulties to be among the key social determinants of poor mental health and suicide in young people^{19, 20, 21}.

Anxiety and depression felt like parts of me that would take over at different times. Seeing yourself as mentally unwell makes you feel helpless about how to handle it. (Man, 23)

I feel caged from within. It's exhausting to keep up with the struggle. I am afraid I might be losing the battle. A part of me is dying everyday. (Man, 25)

The influence of stigma was prominent in narratives around recovery; whereas an acceptance of mental health problems appeared to play a central role in many authors' journeys of recovery. Some authors expressed a personal motivation to mitigate public stigma, reduce self-stigma, and help others:

We must talk about mental health at every level – in schools, at work, with medical professionals and in the media. We need more information and awareness so that people can spot problems and

get help. It's not just ok to talk, it is absolutely essential! (Woman, 29)

Being responsive to young people's views, and ensuring their voices are part of building strategies, is absolutely critical to addressing the care gap and meeting their needs. Such personal narratives provide a window into young people's priorities, as well help highlight specific themes for future awareness-building and service design efforts. These stories, and the key messages contained in them, are invaluable both for promoting the mental health and well-being of young persons, and informing us of attitudes regarding mental health needs in the wider community. ☒

Pattie Gonsalves is currently a Project Director at Sangath (India) with the PRIDE research program, where she works on a digital mental health intervention for school-going adolescents in low resource settings. Pattie also leads 'It's Ok To Talk' (www.itsoktotalk.in), a national anti-stigma campaign, under which the 'Mann Mela' project is setting up immersive media museums for youth mental health.

CAPACITY BUILDING

The Need for a Rights-Based Lens in Education

Gender and sexuality in medical curricula

by Raj Mariwala

neutrality and objectivity are myths

The field of medicine has been critiqued for its gender biases, and for not considering the social determinants of health conditions. Gender bias permeates many aspects of medicine in India: clinical practice, research, health program delivery, and – not least – medical education. In curricula, the male body is the norm; the framework heteronormative. The women's health movement in India has long been

highlighting the complicity of modern medicine in continued gender-based oppression, and its lack of gender parity, whether in gynecology, general medicine, or mental health. This complicity is evident, for instance, in the medical misconceptions that lead practitioners to prescribe marriage as a solution for menstrual pain and other health conditions. Or in how doctors are conditioned to assume that persons who are not married are not sexually active. Or

the belief that producing progeny after marriage is necessary for a healthy life.

The edifice of mental health and psychiatry in India has been particularly responsible for pathologizing non-normative genders and sexualities. Homosexual men were criminalized, incarcerated, or administered aversion therapy. Women, too, were attempted to be "cured" through ECT, and given punishments such as chemical emetics¹. Other medical disciplines learned from these measures, and there were even surgical interventions (including hysterectomy, ovariectomy, clitoridectomy, castration, etc.) to "cure" homosexuality. Such discriminatory structures typically focus on "cure" rather than "care".

How do we challenge these pathological representations of LGBTQIA+ lives, and systemically counter such a legacy of violence and discrimination, in mental health and medical practice today? This is no longer an ethical imperative alone, it is now also a legal one. The Mental Health Care Act 2017 required medical professionals to affirm the rights of persons from communities marginalized by gender and sexuality, and to develop and

and sexuality, and to develop and provide appropriate services. And the National Health Policy 2017 acknowledged the crucial role of social determinants of health, and the need to address these urgently in health services. Then in 2018, the Supreme Court read down Section 377 of Indian Penal Code, effectively decriminalizing consensual same sex relations between adults.

However, despite these legal and policy changes, the old social dynamics are still at play. Medical professionals and their frameworks, which continue to be largely cisgender and heteronormative, come backed by tremendous power and privilege that greatly influence practitioner-client interactions.

The alternative, on the ground, would be for doctors, health care providers and MHPs to be responsive to the specific needs of persons with marginalized sexualities and genders. Their sexual health and reproductive rights must be recognized and respected by the health system. This signals an immense need for sensitive gynecologists, endocrinologists, surgeons, besides MHPs – so that, for instance, trans persons desiring specific medical

“DISCRIMINATORY STRUCTURES TYPICALLY FOCUS ON “CURE” RATHER THAN “CARE”.

interventions might access them safely and securely. The overarching need is for radically altered medical and mental health syllabi, so as to include issues of gender and sexuality in all their complexity.

incorporating lived realities into curricula

In 2017, CEHAT (Centre for Enquiry into Health and Allied Themes), along with trained medical faculty, carried out a review of the MBBS curriculum across the disciplines of Community Medicine, Gynecology and Obstetrics, Forensic Science and Toxicology, Medicine and Psychiatry. Among their findings: “sex” was not distinguished from “gender”; concepts of sexuality, sexual orientation, or of gender identities other than man or woman were missing – despite multiple health concerns related to sexuality being raised in health settings².

Mental health implications and interconnections were conspicuously missing. The review project led to gender-integrated modules being designed to redress the knowledge gaps, with specific components on understanding gender and sexuality, sexual health, and the varied needs of different communities.

However, these modules, which foreground a rights-based, affirmative approach, can only be integrated into medical education as well as clinical practice through an in-depth training of educators. With MHI’s support, CEHAT plans to facilitate their delivery in three medical colleges in Maharashtra, reaching a minimum of 25 medical educators. Also, as part of the project, evidence will be collected on the health system’s existing responses to LGBTQI persons seeking health

QUEERING PSY DISCIPLINES

MHI’s 3 essential programs

Queer Affirmative Counselling Practice

Certification for mental health practitioners

Peer Support Practice

Trainings to support LGBTQIA+ activists & collectives

Gender Sexuality and Mental Health from the Margins

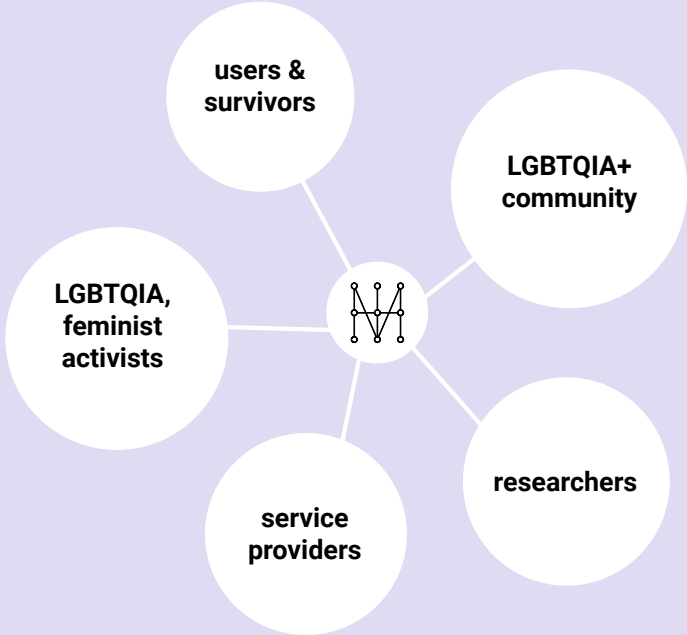
A program which runs workshops with students & teachers in colleges.

services, and medical educators’ attitudes towards the health issues of LGBTQI communities.

Project goals include making the modules more effective through training at least 30 psychiatry medical educators in the selected colleges for competency to teach as well as deliver gender sensitive clinical care and mental health services. Also being developed is a three-day course that focuses on understanding gender and sex, intersectionality,

discrimination, physical and psychological health consequences, and building related skills. All these training programs will be delivered to medical educators across medicine, psychiatry, gynecology, forensics, and community medicine departments.

The project will also work to facilitate gender sensitive psychiatric care by assisting in, and documenting, the implementation of clinical protocols, and collating evidence for best practices. This stage will



have two advisors from MHI’s Advisory Board, a mental health professional and a queer-identifying user-survivor, as we believe that lived experience and knowledge from the margins must be foregrounded in any such initiative. Affirmative health practices must not just take on board marginalized narratives; they call for fundamental changes in methodology as well as praxis. ☒

#BridgeTheCareGap

Campaigning for mental health

by Raj Mariwala

anti-stigma campaigns

For years, mental health campaigns have focused on destigmatization. There have been anti-stigma campaigns the world over since 1996. The British ‘Time to Change’ campaign used best practices on a large scale, with clear evaluation protocols. “Disappointingly, there was no improvement in knowledge or behaviour among the general public, nor in user reports of discrimination by mental health professionals. A few indicators showed a negative change over the study period, ironically including increased discrimination reported by those with most exposure to the Time to Change program.” Research confirms that change resulting from such campaigns is slow: hit or miss; often

unsuccessful – especially when no critical shift takes place in attitudes. There have also been concerns about the ethics of raising mental health awareness when there are not enough resources or services to deal with any increased demand.² While anti-stigma campaigns encourage disclosure, and seem to suggest that if only attitudes regarding mental health were to change, more people would come forward to use mental health services, they don’t simultaneously lobby for adequate, accessible, affordable, quality mental health services. Besides, such campaigns tend to focus on the individual, and to be framed around personal responsibility, instead of addressing underlying factors

like structural violence or other sources of psychosocial distress. An article published in the ‘Israeli Journal of Psychiatry and Related Sciences’ asserts that not only is the biomedical approach towards mental illness that dominates current anti-stigma campaigns ineffective, it actually tends to increase stigma; conversely, communication based on psychosocial explanations of mental health has been found to be effective in reducing stigma³. Campaigns also need to address mental health-related rights violations, lack of access to quality care, low government budgetary allocations – and the much larger barriers of social and economic inequality and discrimination.

a campaign and its building blocks

The challenge before us, then, was to effect a campaign paradigm shift while avoiding the traps of previous anti-stigma campaigns. In light of India’s rights-based Mental Health Care Act (2017), as well as the upcoming general elections, we decided to advocate for the implementation of, and adequate budgets for, existing government provisions for mental health care. We wanted to spur political will towards acting for mental health. And so were born the #BridgeTheCareGap

hashtag-cum-slogan, and campaign. “Care gap” reflects a conscious departure from the more usually evoked “treatment gap” with its biomedical underpinnings. We aimed to build meaning into the phrase “care gap” by focusing on the implementation of laws and policies meant to safeguard the rights of persons living with mental health issues, to provide accessible and affordable quality mental health services, and to address the social and economic disparities that compound psychosocial distress.

putting mental health on political party manifestos

This advocacy-based campaign to ensure the implementation of India’s Mental Health Care Act was conceived and carried out by a core group of mental health organizations including Mariwala Health Initiative, and individual activists. As national political parties were working on their election manifestos at the time, campaign coalition members decided to use the opportunity to meet the various political representatives, explain our demands, and provide inputs for use in manifestos. Our goal was simple enough: to have a mental health promise included in every major political party’s manifesto. Historically, mental health had never

found a place on any manifesto of any Indian political party – and so, we were really asking for a fundamental shift in perspective. We were asking that politicians, and the public at large, recognize the importance of mental health. An arduous road lay ahead, of large-scale sensitization.

reframing our communication

Thus began our work of creating effective communication material: simple to comprehend, and accurate; prioritizing the voices of those with lived experience; foregrounding the structural and systemic issues germane to the rights of persons with psychosocial disabilities. One of our main pivots comprised videos highlighting the challenges faced by a range of users of mental health services, caregivers, and

other stakeholders. These videos centered marginalized voices, such as the experiences of structural violence in queer and trans lives; included testimonies from three mental health professionals with relevant lived experiences; and suggested multiple pathways towards resilience for persons living with anxiety, depression, schizophrenia, and bipolar disorder. Instead of talking about “cures” or “help”, the videos shared stories of agency, and of how people had accessed psychosocial support through different kinds of therapy as well as peer support networks. Through these videos, we wanted to reframe the idea of mental health – locating it in the psychosocial realm, and laying emphasis on the rights and agency of persons with

BRIDGE THE
CARE GAP

“THE BIOMEDICAL APPROACH THAT DOMINATES CURRENT ANTI-STIGMA CAMPAIGNS IS INEFFECTIVE

mental illness. Given the dearth of mental health-related materials in languages other than English, we ensured that our videos included other languages such as Marathi, Bengali, Tamil. Our infographics, informed by the same approach, spoke of employment, domestic violence, and structural aspects that gravely impact mental health.

leveraging online media

We launched an online petition that people were invited to sign, in order to convey to political representatives that action on mental health was important to win signatories' votes. Over 11,000 people from across the country signed the petition. We sent out material via WhatsApp, stormed Twitter and got #BridgeTheCareGap to trend, and ensured that our videos, Facebook posts, and tweets were shared and reshared – till the mainstream media took notice. Much

to our delight, every major print and online media outlet in the country covered the campaign. Journalists dubbed it a “guerrilla campaign”, and explained the meaning of the care gap in mental health as well as the Mental Health Care Act’s provisions – thus expanding the knowledge base we had worked to create.

collaborating widely

Approaching mental health, as we do, as an issue of development as well as intersectoral and intersectional, one of our aims was to collaborate widely across development-related sectors. We shared our initial plans with a number of grassroots groups, and multiple civil society platforms, inviting suggestions on how to mobilize for mental health action on the ground, particularly with regard to providing services and upholding human rights. The nation-wide #BridgeTheCareGap campaign

received support from many other mental health organizations, as well as from groups working on child rights, women’s rights, law and policy, LGBTQIA+ concerns, human rights, and livelihood issues. Approximately 55 organizations endorsed the campaign petition, and supported the campaign by publicizing our materials or sharing details with the communities within which they worked. Some supporters leveraged their own networks to get us meetings in political offices. It was through such collaborative efforts that #BridgeTheCareGap made history, with mental health finding a mention in the manifestos of two political parties.

next steps

The next round of the campaign envisions monitoring the implementation of legal provisions in mental health care, and creating “report cards” to flag shortfalls, provide accessible and affordable psychosocial services and support, and focusing on both accountability and more accurate local knowledge of the mental health ecosystem in India. ☪

SERVICE DELIVERY

The Atmiyata Story

Centering community as a resource

by Raj Mariwala

challenges in rural mental health

Approximately 70%-90% of the Indian populace does not have access to mental health treatment and care¹. It is safe to say that these services are disproportionately available in urban areas; the mental health care system in rural India has all the shortcomings and failings of India’s rural physical health system. These include an insufficient number of trained health care providers, poor quality of available services, the need to travel long distances to avail of any service at all, and the exorbitant costs usually involved. The National Mental Health Survey of India 2015-16 estimates spends of Rs 1000-1500 per month on travel just to access mental health care. Adding to the psychosocial stressors

for rural communities are multiple barriers to accessing education and social benefits, besides shelter and livelihood vulnerability due to the vagaries of climate. The “treatment gap” construct, with its biomedical focus, is inadequate for addressing these challenges, and exploring solutions for rural mental health.

Mental health issues are clearly linked to the psychosocial sphere, and can adversely affect participation in everyday social, work, family activities. It is important, then, to go beyond a “symptom reduction approach”, and work towards social inclusion via multiple pathways – such as employment, skills training, community education, and community support. While the prevailing treatment gap model

erases this range of interventions, the “mental health care gap” construct proposes to combine the treatment gap approach with psychosocial care interventions, and also to take on board physical care gaps and needs for those living with mental illness.

mental health mitras and champions in communities

A rural mental health program called Atmiyata, currently run by the Center for Mental Health Policy and Law (CMHPL), employs all these strategies. It trains and develops the capacity of two tiers of community volunteers (“Champions” and “Mitrās”) to identify and provide primary support and counseling to persons with emotional stress and common mental health disorders, and make referrals to the public health system in instances of severe mental illness. In order to reduce stigma and create awareness about mental health and well-being, both sets of volunteers work with existing self-help groups, farmers’ collectives, the Sarpanch and Gram Panchayat leaders, Anganwadi workers, ASHA (Accredited Social Health Activist) workers, Primary Health Centre staff, and others who are trusted and respected in the community.

“COMMUNITIES WORK TO SUPPORT THEIR OWN MEMBERS, THEREBY INCREASING COMMUNITY COHESION AND RESILIENCE

Atmiyata Champions are given smartphones loaded with the Atmiyata app, which contains training materials as well as films meant to build community awareness about issues related to distressing everyday social situations: domestic violence, alcoholism, unemployment, spousal conflict, etc. The films can be shared via Bluetooth, encouraging wider discussion and helping depathologize the subject of mental health. This focus on psychosocial stressors, common causes of distress versus the biomedical approach is critical – whether in trainings, providing services, or the type of language used.

The Champions receive in-depth training, and provide interventions that include evidence-based, low-intensity counseling techniques

such as active listening, problem solving, and behavioral activation—a therapeutic intervention that is often used to treat depression. They are also trained in facilitating access to social benefits such as pension allowances, disability benefits, unemployment benefits, besides providing information about social benefits available for caregivers². They also make referrals in cases of domestic violence and substance abuse, for legal aid, shelter homes, and employment generation. Atmiyata Mitras (Friends) have a different role – they work to identify distress and reduce stigma, while building their community’s understanding of mental health.

For persons who might require further help, Atmiyata leverages

the District Mental Health Program by facilitating referrals for mental healthcare needs to public healthcare facilities and district hospitals, as well as to relevant district authorities in the public health and social justice system.

communities are experts in their own contexts

Atmiyata is premised on tenets of community-based mental health that have informed rural mental health initiatives for some decades now. It shares similarities with other programs – like the Goa-based MANAS that trained rural community mental health workers to work alongside primary care physicians and mental health specialists, or the initiative in rural Pakistan that trained primary health workers to address post-natal depression^{3,4}.

Yet Atmiyata has some distinctive features of its own: the Mitras are informal caregivers and community members, not primary health workers – an aspect that moves away from task-shifting, and re-delegates specific care services to trained non-specialists. This allows for a high level of intervention by individuals who have a close connection with the social fabric

ATMIYATA OUTREACH

Villages covered	432
Population covered	0.8 million
Champions	537
People with CMD who underwent counseling	7899
People with SMD who underwent counseling	1791
People assessed to get social benefits	4085
People who viewed the films	41599

of the place, share the living circumstances of persons needing care, and are able to communicate about mental health using context-specific and accessible language. The program is distinctive also in its use of low-cost smartphones to enhance learning, build awareness, record feedback, and evaluate psychosocial interventions. Such recorded evidence is key to looking not only at scalable models of community mental health but also at discovering better ways to move on from the treatment gap model and to articulate more relevant approaches to the complexities presented by mental health care gaps in rural India.

Additionally, Atmiyata’s reliance on informal care by trained volunteers

from the community lowers program costs, and helps in building trust. It effectively means that communities work to support their own members, thereby increasing community cohesion and resilience. Community stakeholders being involved and centered in the training and evaluation processes both enriches the program, and makes possible a sense of community ownership.

The Atmiyata program provides community, primary, secondary and tertiary care, even as it harnesses the public health system for specialized care. The underlying principle is that because the public health provisions are mandated by law, it is more cost-effective and sustainable to strengthen these public services than to turn to private or other

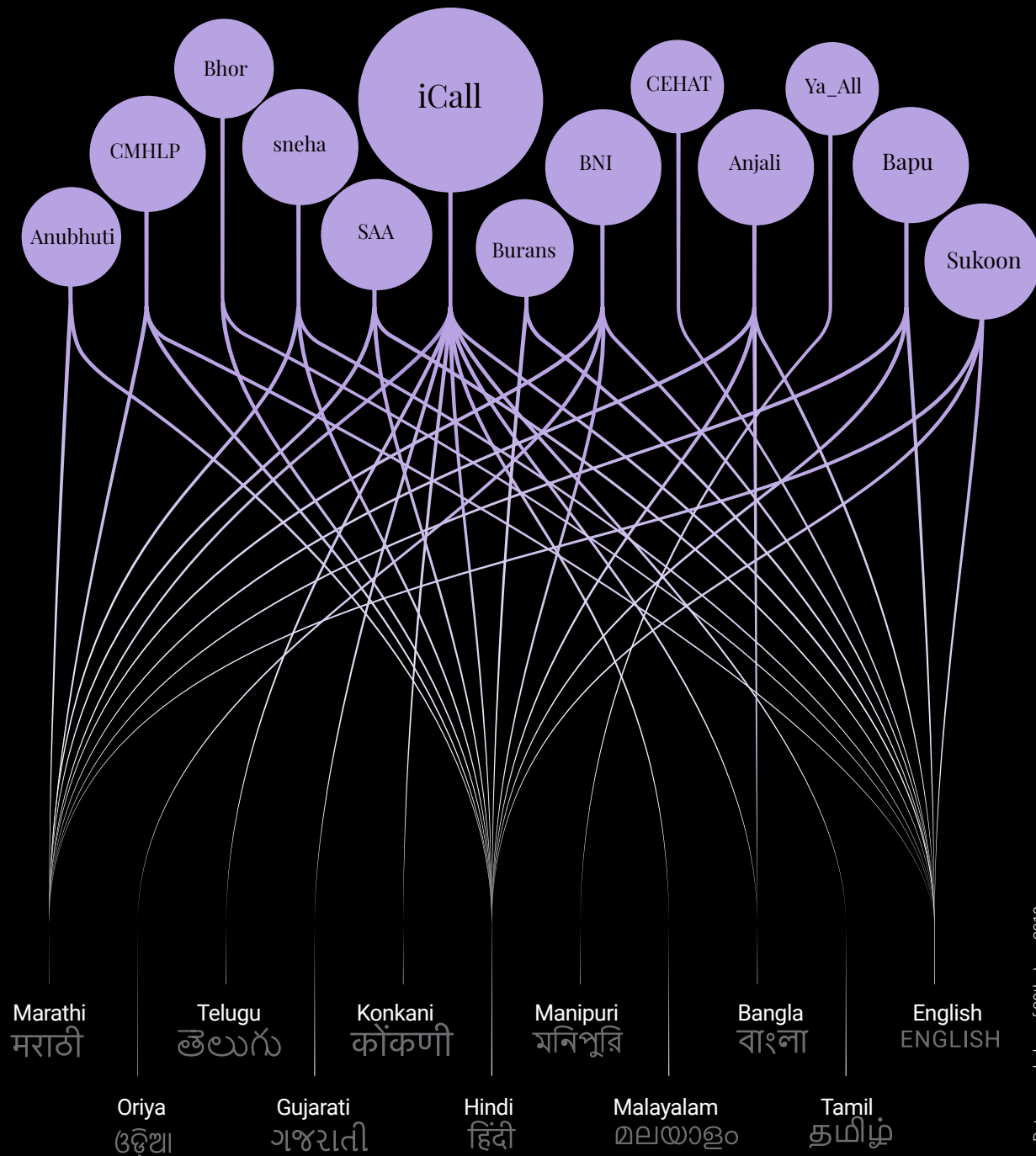
expert-led services. The Champions and Mitras use a well-established referral chain, and carry out follow-ups with psychiatrists working at the district level⁵. This ensures timely diagnosis of mental health issues, and adherence to treatment in case of severe mental illnesses – thus bridging the gap between the shortage of trained mental health professionals and unmet mental health needs in rural India. ☐

Partners

Innovation
Insights
Philanthropy
Challenges
Lived Realities

*We work with OUR PARTNERS
to nurture a MENTAL
HEALTH ECOSYSTEM *with*
multiple STAKEHOLDERS*
– INDIVIDUALS,
COMMUNITIES,
ORGANIZATIONS, AND – *not
least* – POLICY MAKERS *and*
GOVERNMENT. *We engage
with our partners not only with*
FUNDING SUPPORT *but
also through* TRAININGS,
KNOWLEDGE SHARING,
and NETWORKING, *to
build* ORGANIZATIONAL
CAPACITIES.

Languages

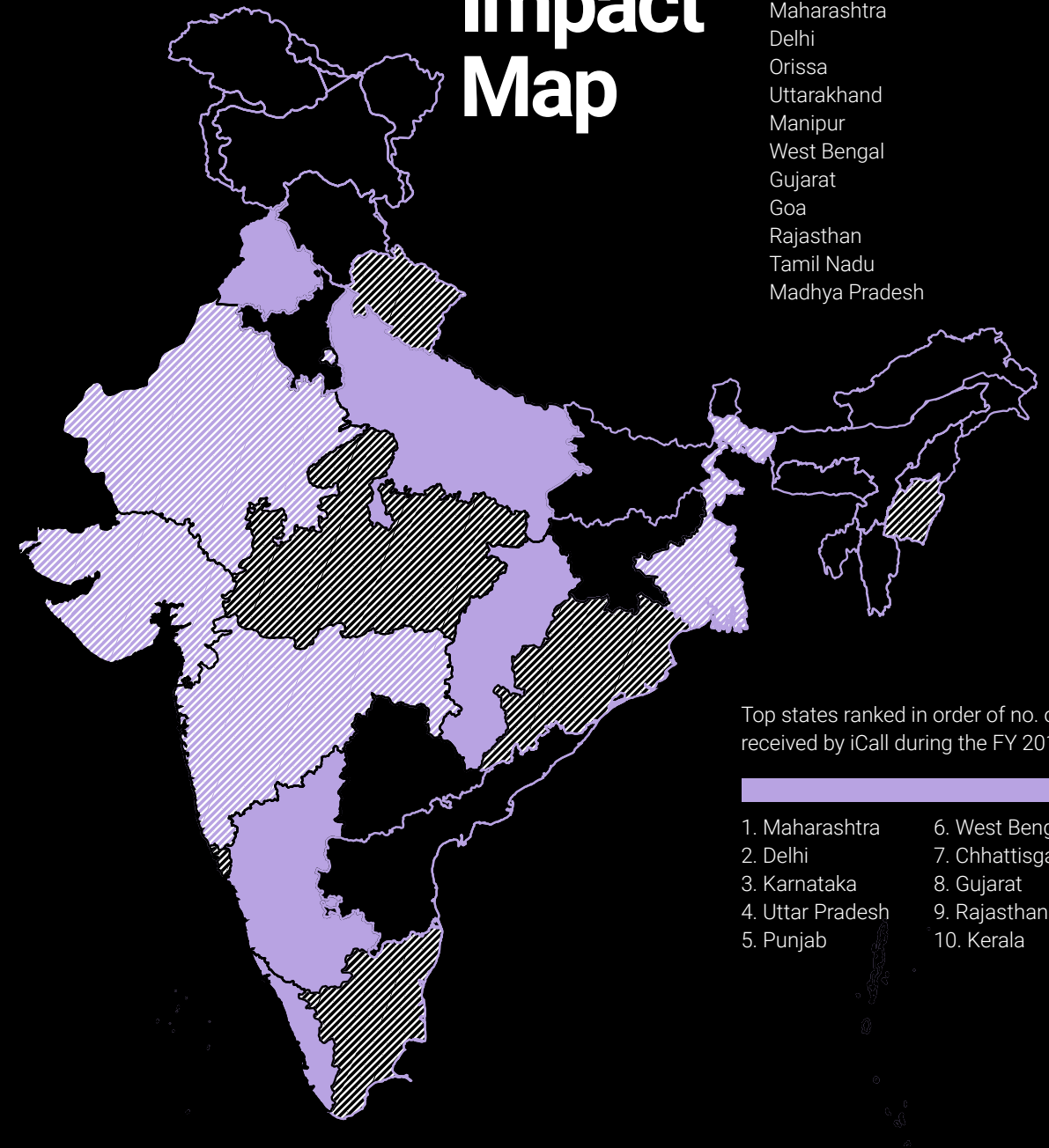


Primary Impact Map

States where partners have operated during FY 2018-19.



Maharashtra
Delhi
Orissa
Uttarakhand
Manipur
West Bengal
Gujarat
Goa
Rajasthan
Tamil Nadu
Madhya Pradesh



Top states ranked in order of no. of calls received by iCall during the FY 2018-19:

- | | |
|------------------|-----------------|
| 1. Maharashtra | 6. West Bengal |
| 2. Delhi | 7. Chhattisgarh |
| 3. Karnataka | 8. Gujarat |
| 4. Uttar Pradesh | 9. Rajasthan |
| 5. Punjab | 10. Kerala |

The 5 Pillars

MHI uses a 360 degree approach comprising of 5 pillars to support quantum change and encourage innovation, scalability and capacity building.

awareness

Lack of information combined with stigma around mental health inhibits persons with mental health needs from approaching friends, family and mental health professionals for support and care.

effective service delivery

Overall, there is minimal access to mental health services, which are marked by both poor availability as well as poor quality. Accessible, holistic, rights-based services in multiple delivery formats need to be made available to all.

capacity-building

Building the capacity of individuals, organizations, communities and institutions, through training and knowledge sharing, is of critical importance.

references & linkages

Strong linkages need to be forged between mental health service providers, and allied services concerned with livelihood, health, gender, sexuality, education, legal support, as well as government welfare schemes.

research

A thriving and responsive mental health ecosystem must rest on a support base of research that documents and records context and community-specific experiences in the field, along with evaluating the efficacy and impact of a variety of interventions.

92,339 PERSONS

28,137 PERSONS

34 PRESENTATIONS + PUBLICATIONS

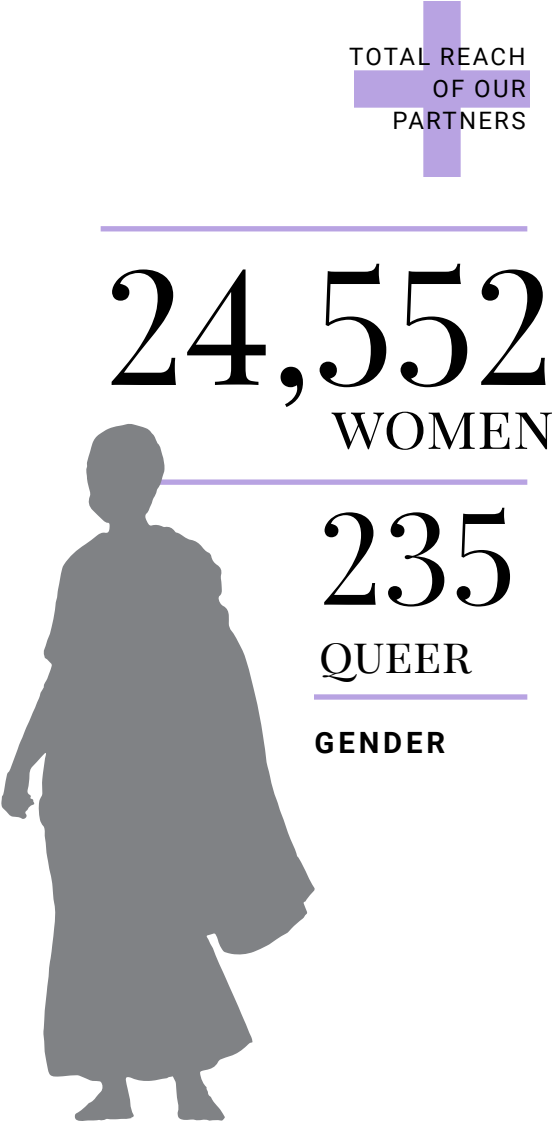
3,463 PERSONS

4,464 PERSONS

SUM OF PERSONS IMPACTED
1,28,403

Demographic Snapshot

MHI goals include reaching out to and making mental health accessible to marginalized populations and communities. To bridge the mental health care gap for persons facing structural oppression — it is even more important to provide psychosocial interventions and supports.



Overall, Anjali has provided services for 20,232 persons, Anubhuti for 941 persons, and Bapu Trust for 45,469 persons. Basic Needs India reached 5,790 persons, and Bhor Foundation reached out to 455 persons. CMHLP served 35,223 persons, iCall has provided services to 19,072 people, and Sukoon to 1,221 persons. The overall outreach is 1,02,879 people.




Partners

As of June 30th, MHI works with 14 partners on 17 projects, in 11 languages with communities, institutions and governments for service delivery, advocacy, deinstitutionalisation, capacity building, community mental health, law and policy, LGBTQIA+ and youth mental health.

partners are

-  Activists
-  Service Providers
-  Researchers







that affect state & civil society at these levels

-  Government
-  Institutions
-  Communities

Please refer to the Framework Diagram on pages 49-50

Anjali

Anubhuti

PROJECT / INITIATIVE	voices	janamanas	mental health justice & empowerment in higher education
NATURE OF PARTNER			
STATE & CIVIL SOCIETY			
LOCATION	West Bengal	West Bengal	Maharashtra
DETAIL	<p>Voices began as a response to the food and water scarcity, inadequate healthcare, and human rights violations in mental health institutions. It is an institution-based capacity building program that redesigns services, centering a human-rights approach. Its replicable model can be adopted by different state governments.</p> <p>Voices also works to relocate persons with mental illness, who face continuing hostility and stigma, back in their communities – through capacity building, empowering participants to speak up for their rights, and livelihood skills.</p>	<p>The Janamanas Community Health Program, in partnership with urban municipal wards, aims to create community hubs for access to mental health, with a special focus on women and adolescents. It currently operates in five underdeveloped localities in Kolkata, through kiosks managed by trained women from the community. The project includes counseling of family members, advocacy for inclusive urban planning, awareness camps, and a three-month training in mental health, the self and rights, gender and sexuality, and society and leadership.</p>	<p>4 out of 10 students in India experience depression, and there is one suicide hourly. Those dealing with multiple marginalizations – of caste, gender, class – are particularly vulnerable. Yet educational institutions are ill-equipped to deal with mental health issues. Anubhuti’s program seeks to redress this situation. A rights-based, intersectional, feminist module trains school teachers to counsel students, and enables specialist referrals if required. ‘Mann Mela’ (a mental health fair) is held to encourage students, families, and communities to seek help.</p>











Anubhuti

Bapu Trust

Basic Needs
India

Bhor
Foundation

Burans











PROJECT / INITIATIVE	community mental health project	seher		merchants of madness	community mental health project
NATURE OF PARTNER					
STATE & CIVIL SOCIETY					
LOCATION	Maharashtra	Maharashtra	Odisha & Maharashtra	New Delhi	Uttarakhand
DETAIL	<p>This program is implemented in communities marginalized by their caste, and minority religious or Adivasi identity – all with large populations of unemployed youth and daily wage workers, whose many multiple mental health stressors are compounded by oppressive social systems. Committees comprising community members are trained to provide basic counseling and referrals, while striving to enhance mental health awareness and advocate with area authorities for development-related concerns. The increased use of services, and reductions in stigma, point to the program’s efficacy.</p>	<p>Through its Community Wellness Centres, this model service program links development, disability, communities, and mental health. Seher envisions sustainable psychological health through community development, and the creation of caring communities by building on their inherent emotional resources. It fosters conversations about well-being within low-income communities in Pune via informal street corner meetings and group sessions inside homes. The program aims to prevent distress, and provide support for those with psychosocial disabilities, while ensuring specialized services for diverse mental health needs.</p>	<p>BNi seeks to bridge the gap between government and communities by strengthening community MH services, and building the capacity of existing community-based organizations to address the needs of those living with mental illnesses and psychosocial disabilities. The program, spanning five districts across Odisha and Maharashtra, connects persons living with mental illness to state MH care, reintegrate them with families and community, enhance awareness through trainings, and link with disability and health movements to sensitize media, police, and the judiciary.</p>	<p>The Merchants of Madness (MM) Festival – was brought to Delhi by Bhor Foundation / Jhilmil Breckenridge in collaboration with The Red Door, Pune. MH activist Val Resh conceptualized MM as a way to express and co-exist with “madness” through art and performance. It aimed to challenge popular discourse by reclaiming the term “madness”. Explorations of mental health through drumming, creative writing, poetry, open mics, as well as informative talks, enabled people to relate to, and speak openly about, their experiences of madness, depression, anxiety.</p>	<p>Uttarkashi in northern India is a rural area with no MHPs and no access to psychotropic medications through public services – forcing people to travel long distances to access treatment. Burans has supported over 1,000 people with psychosocial disability in the region, and facilitated access to care through its home-based program. The project works through Community Health Action groups, sensitization workshops, and programs in two district blocks for social and financial inclusion, youth resilience, violence-free communities, and to increase the MH knowledge and skills of women.</p>

CEHAT

Centre for
Mental Health
Law and
Policy

iCALL
Psychosocial
Helpline

Schizophrenia
Awareness
Association









PROJECT / INITIATIVE	incorporating gender, sexuality, and mental health in medical education	atmiyata	capacity building program, Mental Health Care Act 2017		arts based therapy
NATURE OF PARTNER					
STATE & CIVIL SOCIETY					
LOCATION	Maharashtra	Gujarat & Maharashtra	Pan-India	Pan-India	Maharashtra
DETAIL	<p>The CEHAT (Centre for Enquiry into Health and Allied Themes) project aims to facilitate sensitive health care through a gender and sexuality lens, and implement clinical protocols in select medical colleges in Maharashtra towards mental health care as per the Mental Health Care Act (2017). A three-day curriculum centered on marginalized sexualities and their rights – to understand gender and sex, intersectionality, discrimination, health consequences, and develop skills to respond to unique community needs – will be delivered to medical educators across medicine, psychiatry, gynecology, forensics and community medicine departments.</p>	<p>Atmiyata trains and develops the capacity of two tiers of community volunteers to provide support and counseling to persons with emotional stress and common mental health disorders. Volunteers have smartphones loaded with awareness-building films they share via Bluetooth; and are trained to facilitate access to pensions and other social benefits. In instances of severe mental illness, Atmiyata leverages the District Mental Health Program through referrals to public mental healthcare facilities, and district hospitals, as well as to relevant district authorities.</p>	<p>India's current Mental Health Care Act (MHCA) represents a paradigm shift in mental health care, promoting a rights-based approach towards persons living with mental illness. Some of its content is new to various stakeholders, including those entrusted to implement or safeguard its provisions. Workshops explaining the relevant aspects are therefore held for paralegals, MHPs, caregivers, service users, and government authorities. A Code of Practice publication was created, and a mobile app for stakeholders – to be contextualized according to location.</p>	<p>A psychosocial helpline, iCall offers free professional and confidential counseling in nine languages via email, telephone, and chat, to individuals in distress. Callers are assured of patient listening, confidentiality, and consistent, sustained support. Besides its counseling services, iCall conducts sessions on mental health concerns and related strategies for a wide range of stakeholders, and has directly trained more than 5000 counselors and mental health professionals through its capacity building efforts.</p>	<p>SAA, Pune, began as a caregivers' organization for persons living with mental illness, particularly schizophrenia, and for their family members. It runs a Day Rehabilitation Centre, besides public awareness initiatives and advocacy campaigns, and offers an Art-Based Therapy (ABT) program for persons with mental illness – music, singing, painting, clay work, dance, drama, yoga, gardening, cooking, embroidery, tailoring, sports, aerobics – alongside counseling services. ABT has been proven to better mood and cognition, boost confidence, improve communication, and to enhance therapeutic outcomes.</p>

SNEHA

Sukoon

Resource Cell
for Juvenile
Justice

Ya_All

PROJECT / INITIATIVE	adolescent nutrition, sexuality, and mental health	counselling in family courts	study for high court	peer counseling center for LGBTQI youth
NATURE OF PARTNER				
STATE & CIVIL SOCIETY				
LOCATION	Maharashtra	Maharashtra	Maharashtra	Manipur
DETAIL	<p>SNEHA (Society for Nutrition, Education And Health Action) works to improve the health and nutrition of vulnerable women and children living in urban settlements, through training, capacity building, and advocacy within communities and with public health systems and healthcare providers to address gender-based inequalities. Its EHSAS program focuses on adolescents (and other young people in the 10-21 age group), via sessions on health, gender equity, sexuality, employability, and creating support structures in homes, schools, and communities by sensitizing parents, community members, schoolteachers, and healthcare staff. The program includes counseling services, and referrals to public mental healthcare facilities.</p>	<p>Sukoon provides free counseling within Family Court premises in Maharashtra, with a gender-sensitive, rights-based, non-pathologizing approach. Most cases relate to marital discord, child custody, maintenance, and restitution of conjugal rights. The project strives to help individuals and couples resolve conflicts amicably, devise future plans, and makes referrals to other psychosocial services when needed. Sukoon aims to work with the court ecosystem, including judges and staff, to build sensitivity, and represents a replicable model of counseling services in a legal setting.</p>	<p>RCJJ was set up with the objective of working on the social and legal concerns of Children in Conflict with Law (CICL) using a rights-based approach. The mental health of a child deemed to have committed legal offences is crucial – institutionalized children routinely deal with violence, uncertainty, separation from family, besides changes in food, clothing, and living conditions. RCJJ's Help Desks in Observation Homes help children (and their guardians) navigate through the Juvenile Justice system, while enabling children to interact with family members, and referring health concerns to specialists. Currently, RCJJ is conducting a qualitative research study to highlight existing gaps in the system for CICLs, and advocate for better provisions and policies.</p>	<p>Manipur lacks queer affirmative MH care services. Stigma, discrimination, bullying, isolation – these factors increase the risk of depression, substance abuse, and suicidal ideation among queer adolescents and youth. The youth-led Ya_All collective works to enable easy access for queer-identifying youth to information and services in health, education, and sexuality. At its health resource hub/ drop-in center, queer-friendly counselors and peers provide free MH services to queer youth, for whom the center also serves as an informal space to interact.</p>

Glossary

ABLEISM A pervasive system of discrimination and exclusion that oppresses people who have mental, emotional, and physical disabilities. Deeply rooted beliefs about health, productivity, beauty, and the value of human life combine to create an environment that is often hostile to those whose physical, emotional, cognitive, or sensory abilities fall outside the scope of what is currently defined as socially acceptable. (Rauscher and McClintock 1997)

BIOMEDICAL APPROACH TO MENTAL HEALTH An approach towards mental health issues based on a disease-prevention model that prioritizes the use of medication for treatment and situates mental health issues in the 'brain' while ignoring experiences of abuse, poverty, racial, caste and gender inequalities.

COGNITIVE BEHAVIOUR THERAPY (CBT) is a form of psychotherapy that focuses on how a person's thoughts, beliefs, and attitudes affect their feelings and behaviors.

COMMUNITY-BASED INTERVENTIONS Community-based interventions help implement a decentralized pattern of mental health care and services for people with mental illnesses. They are more accessible and responsive to needs of the local community and reduce need for costly in-patient mental health care delivered in hospitals. Community mental health services promote social inclusion of

persons with mental illness and uphold their dignity and human rights that are often at risk of neglect and abuse in mental hospitals.

DEINSTITUTIONALIZATION This refers to actively promoting non- discriminatory and inclusive stay and care facilities for persons with mental health issues and / or disabilities and supporting them to lead their lives as they deem fit. Institutions are characterized by segregation and no respect for bodily rights and personal space of the users. Deinstitutionalization aims to change that.

HETERONORMATIVITY The individual, institutional, and societal/ cultural beliefs and practices based on the belief that heterosexuality is the only normal and acceptable sexual orientation. Heteronormativity privileges heterosexuality and consequently discriminates against other forms of sexual desire, expression or relationship.

INTERSECTIONALITY This approach recognizes that multiple levels of oppression (gender, race, class, caste, sexual identity, sexual orientation, ability) may intersect and interact with each other, affecting the health and overall well-being of an individual. For instance, a lesbian woman with a motor disability will experience oppression stemming from not just her gender but will also on her disability and sexual orientation. An intersectional understanding of mental health ensures that stakeholders

understand that there are many sites of oppression and all of them, singularly or as a sum of a few marginalized identities, affect an individual's access, choice and rights to mental health systems.

LIVED EXPERIENCE This term is used to describe the first-hand accounts and impressions of living as a member of a marginalised or oppressed group. It's a recognition that is attentive to feelings, bodily states, interactions and identities that tend to be devalued or ignored. 'Lived experience' can be used for giving voice and making the invisible visible as a response to oppression. This allows for focused acknowledgment of how experience is influenced by wider social structures, and constructed socially.

MAD STUDIES Mad studies is a field of scholarship, theory, and activism about the lived experiences, history, cultures, and politics about people who may identify as Mad, mentally ill, psychiatric survivors,, service users, patients, neurodiverse, and disabled. Mad studies originated from user survivor movements in the West.

MENTAL HEALTH ECOSYSTEM Refers to creating a large mental health community in India, bringing together a diverse cross section of stakeholders. This includes grassroots and community-based organizations, counselors, psychologists, psychiatrists, activists, researchers, caregivers, user-survivors, policy makers

and governmental institutions. A mental health ecosystem will help foster a culture of constant interaction, dialogue and networking between these varied groups of stakeholders.

NEURODIVERSITY Neurodiversity recognizes and respects neurological differences as any other human variation. The neurodiversity paradigm represents a new and fundamentally different way of looking at conditions that were traditionally pathologized.

NEUROTYPICALITY Neurotypicality is the belief that privileges neurocognitive functioning that falls within dominant societal norms and pathologizes other displays of neurological differences.

PATHOLOGIZATION This refers to a) branding persons with mental health issues as 'ill' b) over-reliance on medication and 'expert' diagnosis of one's mental health. This often puts persons with mental health issues at risk of abusive, unethical and involuntary treatments and forced institutionalization.

PSYCHOSOCIAL APPROACH Psychosocial is the connection between a person and their environment, interpersonal relationships, community and cultural practices. Social context influences and interacts with the psychological (emotions, thoughts, feelings, reactions).Taking into account social, cultural, context factors

as influencing a person's mental health is critical in providing support and care. Additionally, providing social supports or non bio-medical interventions is essential and can be preventative and/or curative in nature when it comes to mental health. Such interventions are intersectoral such as food security, water, housing, shelter, education and sanitation but also legal support and employment support.

PSYCHOSOCIAL DISABILITY As defined by the United Nations Convention of Rights of Persons with Disabilities this refers to the interaction of actual or perceived mental 'impairments' with various barriers that may hinder a person's 'full and effective participation in society on an equal basis with others'. Persons with psychosocial disabilities face many forms of stigma and discrimination, as well as barriers to exercising their civil, economic, social and cultural rights.

RIGHTS-BASED APPROACH A rights-based approach to mental health ensures that every person has the capacity to make decisions regarding their mental health care and treatment plans and give or withhold consent to any medical procedures. It will also require advocating for laws that can help secure the rights of persons with mental illness and recognizing that their rights will be legally enforceable.

SOCIAL DETERMINANTS OF HEALTH The conditions or circumstances in which people are born, grow, live, work and age are shaped by the distribution of money, power, and resources at global, national and local levels. These social circumstances create societal hierarchies and are responsible for health inequities among different groups of people based on social and economic class, gender, and ethnicity.

SOCIAL INCLUSION People with disabilities and/ or mental illness are often denied opportunities to work, play, learn and develop social relationships with others (particularly with people without disabilities). They are excluded from communities, their identities are ignored or invisibilized and their sexualities and desires infantilized or criminalized. Social inclusion encourages the establishment of humane, mutually supportive systems, centres the desires and aspirations of marginalized and disabled persons and ensures that people are not prevented from being active participants of society on the basis of gender, race, gender identity, sexual orientation, caste, religion, ethnicity and disability status.

SOCIAL MODEL OF DISABILITY This model says that disability is caused by social attitudes that prevent persons with disabilities from accessing their right to equal opportunities. While the medical model of disability focuses on fixing and

References

treatment, the social model advocates removing any barriers that stop persons with disabilities from achieving their goals and living a full life.

STRUCTURAL INEQUALITY This refers to inequalities and biases deeply embedded in social, political and economic institutions, arising out of dominant ideas around gender, race, caste, religion and sexuality, that lead to systematic oppression of those at the margins, thereby denying them access to and opportunities for growth and justice.

USER-SURVIVOR APPROACH This refers to persons with lived experiences of (currently or formerly) and those who may have survived mental health issues, psychosocial disabilities, psychiatric and mental health services and institutions. A user survivor approach centers the voices and experiences of these persons.

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ReFrame, a journal by the Mariwala Health Initiative is a platform to challenge existing norms and explore diverse voices within the mental health space — expanding horizons for who gets to participate in such conversations in an effort to firmly ground mental health in a contextual, intersectional, right-based, intersectoral framework. It is envisioned as a tool for mental health practitioners, advocates, activists, scholars, students, experts, funders, government officials and non-profit organizations — and those from closely allied sectors.



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