

## **How can attention to ‘particularity’ enhance universal access to community mental health care?**

### **Summary**

The field of global mental health aims to have a major influence on mental health policy and practice in low and middle-income countries through initiatives that argue for evidence-based ‘scaling-up’ of services, including community mental health care. Ensuring universal access to mental health care is a key public health priority to address the high burden of mental health problems faced by individuals and carers. The global mental health literature interprets ‘access to care’ primarily in terms of increasing availability of mental health personnel and pharmaceutical and psychosocial interventions. ‘Access to care’ is measured in particular ways and access is to particular forms of care. Global mental health advocates argue that universal classification of mental disorders and approaches to treatment ensure access to care, whilst critics make the point that the same universal conceptions may obscure and silence locally relevant responses.

The central argument that I will make in this paper is that attention to social, cultural and ecological particularities is crucial to ensuring universal access to community mental health care. Drawing on longitudinal ethnographic case studies from community mental health in northern India, I will illustrate how global conceptualizations of ‘access’ and ‘care’ that assume a universal applicability may serve to inhibit acceptability and hence universal access to care. By not engaging with the social and cultural particularities that shape recovery, community mental health services limit their own ‘access’ to some of the most important aspects of people’s suffering, and constrain the relevance of mental health services to a wider population. Conflation of universal access with universal models of care obscures the circumstances that shape individual and collective decision and action in response to psychological distress, and perpetuates a linear understanding of the relationships between ‘access’, ‘care’ and ‘recovery’. Technical-universal conceptualizations of ‘access’ and ‘care’ obscure individual & collective decisions and actions in response to distress. Contextualizing the local significance of ‘diagnosis’, ‘access’, ‘care’, and ‘recovery’ may open up new ways of engaging with those suffering from mental health difficulties, their families and communities.

Such a contextualization reveals complexities and raises important questions about how community mental health might be conceptualized and structured to achieve universal access to care. First, what kinds of ‘care’ should global mental health envision? There is a need to consider multiple forms and meanings of ‘care’ and the factors that shape different way of caring. ‘Care’ and ‘recovery’ should be contextualized and reformulated in relation to lived experiences. Second, linked to this is the question of what is needed for community mental health practice to shift to be able to undertake such reformulations? A central challenge is that existing ways of creating ‘models’ for community mental health rely on ‘scaling up’ of particular forms of evidence, excluding other forms. This limits the scope of services to attend to the needs and experiences of diverse groups, thus restricting ‘access to care’. Existing approaches to ‘evidence’ must be complemented with ethnographic evidence and evidence from ‘experts by experience’. This should form the basis for new approaches to ‘scaling’ that account for local innovation and the specific conditions under which such innovations emerge.

## **Introduction**

Ensuring universal access to mental health care is a key public health priority to address the high burden of mental health problems faced by individuals and carers. Universal health coverage and universal access to health care are inter-related, universal coverage requires universal access. The WHO delineates three dimensions of access: physical accessibility, financial affordability and acceptability (Evans, Hsu and Boerma, 2013). This paper will focus primarily on the acceptability aspect of access to community mental health care. Drawing on longitudinal ethnographic data from northern India, I will illustrate how attention to social, cultural and ecological particularities can be crucial to ensuring universal access to community mental health care. I will argue that a central challenge to achieving universal access is that existing approaches to creating 'models' for community mental health rely on 'scaling up' of particular forms of evidence, excluding forms of evidence that might highlight important particularities in each local context. This limits the scope of services to attend to the needs and experiences of diverse groups, thus restricting 'access to care'. Shifting away from the current conflation of universal access with universal models of care will require greater emphasis on diverse sources of evidence including ethnographic data, and evidence from 'experts by experience'. This should form the basis for new approaches to 'scaling' that account for local innovation and the specific conditions under which such innovations emerge.

I will begin by briefly considering how issues of access are addressed within global mental health. Second I will describe the ethnographic methods and the local context of the research. Third, I will present two ethnographic case studies and discuss the implications for discussions around universal access to community mental health care. Finally, I will conclude by asking how community mental health care might be conceptualized and structured to achieve universal access to care.

## **Global mental health**

The field of global mental health aims to have a major influence on mental health policy and practice in low and middle-income countries through

initiatives that argue for evidence-based ‘scaling-up’ of services (Lancet Global Mental Health Group, 2007), including community mental health care. Global mental health (GMH) is an emerging discipline whose aim is to improve access to mental health care and reduce inequalities in mental health outcomes within and between nations’ (Patel, 2012) and a linked organization, the Movement for Global Mental Health (Patel et al, 2011). This global movement of knowledge and expertise in mental health is primarily a north-south flow of knowledge and expertise – including diagnostic systems (White, Jain & Giurgi-Onucu, 2014), though increasingly there are developments to consider how knowledge from the global south might re-shape mental health in the global north. Critics question the cross-cultural applicability of the GMH ‘evidence’ base, and argue interventions promote medicalization of distress and edit local particularities (Das and Rao, 2012). Others argue that GMH models may limit or eliminate other forms of healing (Davar, 2014) and that more attention should be given to ensure that GMH better reflects the perspectives of service users and local communities (Mills, 2014; Orr & Jain, 2015; White & Sashidharan, 2014).

A recent commentary in *The Lancet* titled “Expanding access to mental health care: a missing ingredient” (Jack et al, 2014) argues that the failure to integrate mental health into primary care since the 1970s necessitates a new approach for policy advocacy emphasising the economic costs of not treating mental disorders. The authors highlight how an advocacy campaign emphasizing the economic benefits of psychological therapies in the UK resulted in the British government investing large resources on CBT. A core aim of GMH is to improve ‘access to care’. The global mental health literature interprets ‘access to care’ primarily in terms of increasing availability of mental health personnel and pharmaceutical and psychosocial interventions. The 2007 call for action to scale up services for mental disorders in *The Lancet* stated:

“...we argue that the overall volume of services provided to treat people with mental disorders needs to be substantially increased in every country...so that the available care is proportionate to the

magnitude of need. We refer to this process as scaling up.” (The Lancet Global Mental Health Group, 2007: 1241)

Two of the core indicators for monitoring progress focus on increased numbers of trained staff and availability of psychotropic medications.

Thus, ‘access to care’ is measured in particular ways and access is to particular forms of care. This is linked to the idea of a ‘treatment gap’ – the difference between those who need care and the availability of that care. However, care is primarily defined as biomedical psychiatric treatment and is interpreted as increasing availability of mental health personnel, pharmaceuticals and psychosocial interventions – see as a universally applicable model of care. Two assumptions are implicit 1) a linear process in which diagnosis leads to treatment and re-emergence of a ‘recovered’ subject and 2) a conflation that universal access to care primarily depends on a universal model of care.

## **Methods**

This work draws on longitudinal ethnographic research from northern India that examines the nature of engagement (and non-engagement) of rural people with a government community mental health programme, the district mental health programme. Initial field work was conducted over 18 months between 2004 and 2006 including ethnography of a community mental health team, rural communities in the team’s catchment, and sites of state and national policy making. This was followed by two short periods of field work in 2013 and 2016, and continued engagement with the field site between 2006 and 2016. The aims of the most recent period of field work are to:

- a) Map individual and communal understandings of ‘mental distress’ and help-seeking trajectories in this particular context in northern India over the medium to long term;
- b) To understand how people’s experiences of chronic ‘mental health’ problems, their understandings of these problems, and their resort to help-seeking shift and evolve over time;
- c) To examine the evolving nature of community mental health policies and provision in this area.

Specifically, I wish to address two questions: 1) how does a person's experiences with 'distress' shift over time? 2) How does this relate to shifts in services and policies?

Data is based on longitudinal research with eight individuals and their families. These 'illness careers' will be examined in relation to the individual's life-course, wider socio-economic changes in the local area impacting on community and family circumstances, and shifts in the nature of mental health services and policies. It is anticipated that this will contribute to enriching the evidence base of 'global mental health' with data emphasizing the voices and experiences of individuals with a 'psychological problem', their families, and their communities. As I develop this longitudinal approach, I would welcome thoughts on and a discussion around how long-term ethnographic fieldwork might help us to understand global mental health and improve community mental health care.

### **Local context: the socio-political, policy and 'service-delivery' environment**

Some aspects of the policy and practice environment related to community mental health, from my previously published work on this site, are important to re-emphasize (Jain and Jadhav, 2008 & 2009). A central dynamic in the development of community mental health policy and its delivery is the idea of a standard community mental health policy template – crafted at the 'centre' in Geneva and Delhi, and reproduced at the local level. This is illustrated in a quote from a senior Indian community psychiatrist who expressing frustration at the failure of states to properly implement central programmes stated: 'We have the plan, it just needs to be photocopied'. Such an approach ignores the dynamics of implementation and local need. Biomedical diagnostic systems are replicated on the wall of the local health centre where biomedical categories of psychiatric illnesses are displayed. This translates into what happens in the clinic where clinical dialogues are constrained within these categories, and 'patients' and their family members are unable to talk about distress on their own terms. Psychiatric treatment within this particular government programme in the state is primarily about psycho-tropic medication – and my earlier findings demonstrated an over-reliance on medication notwithstanding the presence of psychologists and

social workers on the team, and a national mental health programme that emphasizes the social aspects of mental health. Despite the dedication of the professionals who staff this team, a major limitation of the programme is the cultural distance between the programme and communities. This has been compounded since 2009 when the monthly mental health clinic in my field work areas essentially stopped operating due to the transfer of the psychiatrist who had ran the programme since the late 1990s.

The field site is located in Kanpur district, Uttar Pradesh state in the northern part of India. Field work was primarily conducted in a rural part of the district. The district mental health team was located at a government hospital in Kanpur city and visited a community health centre in this rural area approximately once a month. The rural area is primarily an agricultural area – the main cash crops are potatoes and watermelon. Further details on the political economy of the field site can be found in Jain and Jadhav (2009).

### **Interrogating ‘access’**

I will examine how notions of ‘access’ and ‘care’ are played out via analysis of the experiences of two individuals, one of whom I had much contact with and the other whom I encountered via her family and fellow villagers. I want to focus on three questions that are emerging from initial analysis of the data:

- 1) What does ‘access’ mean in both cases?
- 2) What shapes or facilitates ‘access’ over time?
- 3) What are the impacts of these dynamics on the individual and family?

### Inderjeet (Male, 45 years)

When I met Inderjeet (age 45) at the psychiatric clinic in 2005, he was rather frail, gaunt man, with deep-set eyes, and messy strands of greying, yellowish hair. He seemed more like a shadow, hardly speaking or responding to my attempts to initiate a conversation. Mamta, his wife, looked worn out and displayed a cold suspicious stare when I first spoke to her. I sensed both anger and strength within her as she physically guided Inderjeet towards the doctor and then to collect his medicine. Inderjeet had been given a diagnosis

of 'psychosis' by the clinic. He was a farmer from the dominant landed caste group in the area but lived in a rather ramshackle *kutchra* (non-permanent) house. Inderjeet and his son related a scattered history of help seeking including help from local traditional healers, received ECT and medications from a private psychiatrist, all resulting in significant debt over a period of ten years. Holding the sides of his head with both hands, Inderjeet told me at the time '*dimak karab ho gaya*' (my mind has gotten spoiled) and that when he was unwell he would swear (*ghaali dhaina*) and run away. They started accessing local mental health services in mid- 2005, as he had gotten worse. At the time, he was hearing a noise like that of a truck or bus in his head. He had little hope of anything getting better ('*koi umeed nahi tha*'). However he said 'the doctor ended that noise' (*voh awaaz doctor sahib nai band kar liya*). Inderjeet's problems imposed a significant burden on Mamta. She invested a lot of energy in making sure that Inderjeet completed certain tasks that would be expected of him as head of the family. In one incident, she got very angry with him in my presence for leaving their buffalo untied. And, on another occasion I was the target of her anger after an incident in which the psychiatrist scolded her for asking about the timing at which she should give medicines to her husband. I had been in the clinic room at the time, and when I subsequently visited the family at home, she yelled at me asking why I did not say anything that day. She stated that they have so many problems ('*musibath*') and they are taking these to the doctor and he is 'talking to us like this'.

After completing field work in 2006, I returned to meet the family in late 2013. I found Inderjeet and his son irrigating a potato crop in a field some distance from their home. He looked very different – had acquired a pot belly, and more fat on his face and body. He seemed much more alert than when I had seen him at his worst in 2006. I learned that Inderjeet had stopped attending the local clinic after the earlier psychiatrist had left his post. While a replacement doctor ran the clinic, he was not as regular in attending the monthly clinic. Inderjeet had stopped attending this clinic after his first psychiatrist left and was not aware that the team still came to their local centre. He continued taking the medication prescribed by this psychiatrist

which he obtained from a local pharmacy. In the previous six years, Inderjeet had consulted a city-based private psychiatrist, 2 years ago as the earlier medication was 'not working' (they couldn't explain how or why). However, this private medication didn't help so he resumed his older medication regime. Inderjeet's son was keen to know if there were any services for people like his father and they expressed interest in returning to the clinic when they learned that it still ran (I connected them to the team and provided a note for the doctor).

Inderjeet's social functioning had changed over time – suggesting the emergence of a 'recovered identity'. He was now able to attend social function such as marriages and helped his son with agricultural work and the buffalos. Other villagers viewed him as a '*minded admi, vo davai chabara hai*' - as someone who had 'mind' problem but was 'chewing' medication. According to his son, there were several other villagers who were 'minded' and taking medication.

In Inderjeet's situation, access to free formal psychiatric care initially had a positive impact, at least in terms of removing the sounds from his head. Access to a regular mental health service was curtailed due to the team failing to undertake regular visits and build trust with patients of the previous psychiatrist. This had a self-fulfilling effect – as patients didn't turn up, so the new psychiatrist also lost interest – something attested to by long-standing members of the team. A once bustling monthly psychiatric clinic driven by the local connections and personality of the old psychiatrist had dwindled to a few patients a month with the new doctor. Both the nature of 'access' and 'care' shifted for Inderjeet. While earlier he had access to a regular service (albeit one that mainly provided medication), he now had no regular follow up – and 'access' only meant regular trips to the local pharmacy to collect repeats of earlier medication and the old prescriptions which he preserved. Sometimes he would visit a private city based psychiatrists when some of the 'meds stopped working' but soon resumed his old medications.

While my previous writing on this clinic had characterized it as a 'noisy grocery shop' that dispensed medication without space for the voices and

concerns of patients, I would argue that this 'grocery shop' was potentially a superior level of 'care' than access to an unqualified pharmacist – both for the regular follow up and because of the free medication provided, which Inderjeet valued and needed. Ironically, however, Inderjeet's health improved despite a lack of 'access' to the type of formal 'care' mandated by national and international policies.

Malti's anger with the Psychiatrist's words reflected a deeper frustration with the family's condition and the day-to-day struggle of economic survival compounded by a disabled husband. The family benefited from accessing the clinic by receiving low-cost treatment. However, this only had a limited impact – it removed Inder's immediate symptoms but did not address the other difficulties engendered by his illness, such as his inability to support the family. Inderjeet's ability to attend the clinic and access medication was shaped by a gendered economic imperative that drove Malti to 'care' for Inderjeet given his position as a male 'breadwinner'. It is not clear to me how Malti's caring role had shifted over time, as I was unable to meet her on my 2013 visit.

#### Roop Rani (Female, 37 years)

Roop Rani (approximate age 37 years) belonged to a family from the dominant Katiyar caste. Her parents have a large, *pucca* (permanent), home in the centre of the *Katiyar* (one of the dominant caste group) section of the village and were in the middle economic strata of their caste group. I was told that Roop Rani was *pagal* or mad and wandered around the village where I was living. Her brother told me that she had been ill for about 8-9 years and had two daughters. Slowly after marriage she had lost her 'mental balance' (*'derai derai dimak santolan bigargaie'*) as she realized that her husband was an alcoholic. As her father said 'She became mad through sadness' (*'woh toh gam mein pagal ho gayi'*).

Initially they had taken her to various traditional healers (*ohjas*) however in the second year of her illness, she was taken to 'Agra' – referring to Agra Mental Hospital (this was traditionally the main source of biomedical mental health care in the area and as approximately 300 km from their village)

and stayed there for three months. For one year after that, she did not require any medications. Now the family were giving her medications but it was only by hiding it in her food, about 3 times a week. Her brother explained that if they gave the medicine more frequently it would cause 'heat' in the body (*koi bhi davai mai garam hothee, islyai hum doh theen bar haftai mai daitha hai*). If they tried to give her medication without hiding it, she would get very angry and sometimes violent. A neighbour told me that she had tried to explain to her the need to take medication.

During my first visit to the house, Roop Rani was initially not at home. However, the family asked me not to disclose my identity to her if she came. When she did eventually return, she walked straight into the house without saying anything or looking at anyone. I was introduced as a school 'master' (teacher). I was told by villagers that she wanders around the village and goes to people's houses. A middle-aged *Katiyar* woman told me that she would sometime come to their house, sit downstairs, and eat. She said she was afraid of her. However, Roop Rani's family told me that people generally accepted her in the community. The family's worry was that in the course of wandering she might go and eat in the home of a *Dalit* ('low' caste) family and they would be dishonoured (*'kissee harijan kiya khanna khaolao, aur hamara baizzati ho jay'*). For this reason, they made sure that she ate at home, even if it meant having to track her down, bring her home and endure her swearing on them. An older male *Dalit* villager stated that they see her as 'a daughter' and no one 'misbehaves' with her.

I met Roop Rani's father and brother on several occasions. Over 1.5 years (between 2004 and 2006), I saw a perceptible change in their attitude to her, as they grew more pessimistic about her condition. On one occasion, I asked her father why they did not take her to the local mental health clinic especially given that the psychiatrist was from the same caste and village and would presumably be helpful. He said that he has other things to do; that he had to get his other daughter married and take care of his agricultural work. Ruefully he told me: 'I have other things to do, it is out of helplessness that we can't do anything for her now' (*'aur bhi cheezen hai karne ke liye, majburi mein nahin kar pa raha hai'*). He seemed resigned to her fate stating 'what is

written in her fate, that will be' (*jo bhag mein likha hai vo....voi hoga*). He said that they wanted to get her admitted to Agra Mental Hospital again but hospital policy now required that a family member stay with the patient and this would be difficult for the family.

In my recent period of field work, a number of changes had taken place both in Roop Rani's visibility in the village and the attitudes of her family. Unlike in the earlier 18 months of field work when I would hardly see her around in public spaces, during this short field work, I saw her quite often – wandering into people's homes to ask for food or sitting in more public places such as around a fire in the evening. Her brother stated in recent times she was hardly at home – and didn't eat at home which made mixing her medication difficult. The other observation was that her brother's pessimism about her future had not diminished – he said that 'he was alone now' and was not able to arrange for treatment for her. I learned later that he indeed was alone – as his elder brother had split off from the family and left the village leaving him as the head of the household. The responsibility for his own family as well as Roop Rani's daughters (now studying in University) left him with a heavy burden.

In contrast to Inderjeet, Roop Rani, as a woman, lacked agency to gain 'access' to formal care. Her 'care' was rooted in the domestic sphere - in the physical provision of food, a roof, hidden medication and the emotionality of family relationships. While, the experiences of Roop Rani and the choices of her father and brother are not unusual for families dealing with serious mental illness, her situation continues to raise questions for me that a return trip to the field didn't answer.

'Care' and 'neglect' by her family conspire in her case to limit her access to the psychiatric clinic. If she was to receive treatment and socially recover, this might lead to other types of stigma for the family – that of having a daughter living at home. The label of '*pagal*' and the acts of caring for her, perhaps provides a convenient label to justify her presence in the village. Care for Roop Rani was perhaps embedded in her father and brother's choice to not access treatment for her. An act of caring, allowing her to be nurtured in

a caring community by family and neighbours in contrast to being subject to a far-away mental hospital, the ambiguities of psychiatric treatment, and the inconsistent availability of local mental health services.

The family's reactions might be considered in the context of their social position in the village. They were a reasonably well off family; but in relation to their economic position, they did not have a strong social presence in the village commensurate with that of other families of similar economic status. Roop Rani's brother was rarely visible in local political and social events. The 'stigma' of Roop Rani's problems and her wandering around appeared to 'brand' the whole family. An additional source of anxiety for them was an unmarried daughter. Their reluctance to 'access' further 'treatment' for Roop Rani can be interpreted in multiple ways. Mental health policy might characterize the family's reluctance to use the service as evidence of 'ignorance' or 'neglect'. Fellow villagers usually displayed sympathy for the family and saw their decision to not seek treatment as appropriate given other priorities. Additionally, in the context of village life, prolonged biomedical treatment was financially challenging even for better off families.

## **Conclusion**

The two case studies there is not a clear-cut relationship between 'access to care' and 'recovery'. Rather, medium term ethnographic engagement with the 'field' permits an unfolding 'picture' of these relationships, particularly consideration of how social, cultural and economic factors such as caste, gender and 'treatment fatigue' shape 'access to care' and the meanings and boundaries of 'recovery' for individuals, families and communities. Such a contextualization reveals complexities and raises important questions about how mental health services might be conceptualized and structured in the 'resource poor settings' that global mental health seeks to act on.

Returning to the title of this paper – how can attention to particularity enhance universal access to community mental health care? I suggest two questions need consideration. First, an ethnographic focus on context and lived experiences raises the question of the kinds of care that global mental

health should envision? The case studies suggest the importance of multiple forms and meanings of 'care' and the factors that shape different ways of caring. Thus, for Roop Rani – the family and community reactions and 'non-compliance' might be re-interpreted as a form of care. Such a re-formulation potentially opens up new pathways for dialogue between health services and those caring for Roop Rani that might provide better outcomes, and improve acceptability of community mental health care. 'Care' and 'recovery' should be contextualized in relation to 'lived experiences'.

Second, linked to this is the question of what is needed for community mental health practice (in this region, and more broadly) to shift to be able to undertake such reformulations? A central challenge is that existing ways of creating 'models' for community mental health rely on 'scaling up' of particular forms of evidence, excluding other forms. This limits the scope of services to attend to the needs and experiences of diverse groups, thus restricting 'access to care'. For example, in the case of the programme in this area, an over-reliance on a biomedical lens to frame suffering and deliver services constrains potential engagement with Roop Rani's family and a limited ability to address the issues faced by Inderjeet.

This links to a wider question about the nature of 'evidence' in global mental health – and a need to complement existing approaches to 'evidence' with ethnographic evidence and evidence from 'experts by experience'. Technical-universal conceptualizations of 'access', 'care' and 'recovery' obscure individual and collective decisions and actions in response to distress. A shift in the forms of knowledge that inform the content of services may contribute to more contextualized understandings of the local significance of concepts such as 'diagnosis', 'access', 'care', and 'recovery'. This carries potential to open up new ways of engaging with those suffering from 'mental health' difficulties, their families and communities. Existing approaches to 'evidence' must be complemented with ethnographic evidence (Jain and Orr, in press) and evidence from 'experts by experience' (Mills, 2014). This should form the basis for new approaches to 'scaling' (Adams, Craig and Samen, 2015) that account for local innovation and the specific conditions under which such innovations emerge (Jain, 2016).

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