

Human rights in the community: user perspectives and the role of NGOs

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Introduction

The 21st century witnessed radical changes in perspectives about mental illness (MI) and persons afflicted by it. These changes were mainly characterised by shift in the paradigm of care from custody to community; from asylum to household; from isolation to integration. The shift was attributed mainly to pharmacological advances in drug therapy for MI, social and political sensitivities to human rights concerns and finally inclusion of mental health as part of the general health agenda in many countries (1). The grand culmination of these diverse historical forces in the last two centuries witnessed the birth of the UN Convention for Rights of Persons with Disabilities, or "CRPD" (also known as the "Convention") (2). Domesticating the Convention involves legal reforms and changes in the existing laws to incorporate the broad principles and ensure that there is no conflict of interests between CRPD and the local laws.

Limitations of institutional models

Historically, human rights activism for persons with MI in India was the initiative of the Supreme Court of India and was concerned with the incarceration of mentally ill prisoners without treatment (3). NHRC commissioned a survey of mental hospitals in the country and exposed the plight of many recovered patients in mental hospitals that led to the study on quality assurance in hospital services (4). The institutional model of State sponsored human rights activism had no relevance for users in family care who constitute around 90% of users in the country as a whole (5, 6). The Mental Health Act 1987 (herein after known as MHA) was inadequate to protect the interests and rights of patients outside the institution.

Rights based perspective to mental health care

Until the passing of the Persons with Disabilities Act (hereinafter known

as PDA) in 1996, the participation of Mental Health NGOs (MHNGOs) (7) and User advocacy groups in policy lobbies was negligible (8). On 26th July, 2007, Action for Mental Illness (ACMI, an NGO of which the author is Director and trustee) was invited by the Ministry of Health and Family Welfare, GOI for a presentation on the legislative reforms in MHA thus breaking years of silent stonewalling. Unlike other disability lobbies or even the victims of TB, Cancer or HIV/AIDS, mental health users were unknown, unseen and unheard. This representation for user groups is a desirable shift. The UN Convention marks a shift in orientation from welfare to human rights by mainstreaming of persons with mental and intellectual disabilities, firstly within the disability scheme and then within the broad human rights agenda (9). It embodies the 21st century thinking on human rights as an undivided holistic package of rights covering all aspects of life, health, civil, economic, social, political, etc. More details on MHA, PDA and CRPD and their implications are discussed in the subsequent sections.

"Mental Illness is not so much about loss of sanity, but of self respect" - user from Bangalore.

This paper seeks to a) examine the Rights perspectives of mental health users or MHUs, including the current debate about the definition of Users and the description of their rights perspectives. b) illustrate NGOs' role for facilitating rights based community initiatives using the Public Private Partnership (PPP) strategies currently in vogue.

Definition of Users and Rights

"User" is a misnomer in India because it implies users or consumers of mental health services whereas nearly 80% of the 20 million requiring mental health care are believed to be outside the purview of psychiatric treatment until the recent revival of the NMHP under the 11th Plan (10). Popular reference to Mental Health Users (MHUs) as 'mental patients' has an illness connotation, used mostly in clinical settings and in government health departments. In day-to-day parlance, they are still referred to as "mad persons" or "lunatic" in the vernacular. Of late, reference to MI persons in the context of rehabilitation is "mentally challenged or mentally disabled persons". In legal parlance, they are identified as persons of "unsound mind" (in the MHA and in Indian Contract Act). The idea of such apparently crude descriptions of the users in Law is to protect their rights in case they are being taken advantage of. Identity of the MHU in India is presently

reduced to a sane-insane dichotomy. Unlike the three-decade old consumer movements in the West, the decade old Indian user activism is still to emerge as an organised and independent pressure group (1).

The reasons for a lack of synergy in this area are many. MHU is an ambiguous sociological entity. Many persons with severe mental illness live in rural India. Besides the rural-urban divide, there are three broad categories of users in India. These are the users within or requiring institutional care, those in family care (this terminology is a more realistic description than community care. In urban areas, there is really no community that helps a family in distress. Existing community care facilities run by the voluntary sector are expensive and inadequate). Thirdly, there are the homeless persons living on the streets (who though legally entitled to all the rights under the CRPD are literally "non-users"). MHU is a broad category that primarily includes current users, potential users and even treatment dropouts as well those who fall under the clinical category of persons with major MI. We believe that the users must include all those persons suffering from MI; irrespective of medical status, all are entitled to rights under the Law of this land; and are also capable of independent articulation of their rights within the limitations posed by their disabling illness. It is learnt that in some states, disability certificates are not issued to destitute MI persons residing in long-stay homes because they are unable to give their home address. The 'significant others' who are involved in the everyday life situations of the affected MI persons like the family, service providers, Mental Health NGOs (MHNGOs), medical professionals and the local community, have a strong influence on the MHU rights perspectives. In fact, the emotional, physical and social proximity of the family as care provider has given rise to doubts whether the users have any independent views of their own at all? So much so that many believe that the category of users also includes the family, irrespective of its clinical profile of MI.

User vs Family or User and Family?

Commenting on User groups, WHO finds that "*Opinions vary among consumers and their organizations about how best to achieve their goals. Some groups want active cooperation and collaboration with mental health professionals, while others want complete separation from them. There are also major differences as to how closely to cooperate, if at all, with organizations representing family members of patients*" (1). Since the majority of Indian users are under the family care

model, their perception of rights, just like the perception of themselves and their illness, is likely to be deeply influenced by family- centric decision making style. Shankar and Rao claim that "...*The experiences and interpretations of psychiatric conditions by **users- families and patients***-(emphasis added by the author) *have a substantive role to play in the development of meaningful health delivery systems as only those services that are perceived as compatible with the users beliefs are likely to be utilised*" (11). Accordingly, any understanding of User rights is inevitably linked with the existential context of the family so much so that it is empirically difficult to delineate User rights as an independent variable. They (patients) *may* experience that "*their choices can be very limited compared to others around them. Further, decisions affecting their life choices are taken for them and without reference to them*" (12).

The apparent conflict of interest seen in the Family-User relationship has raised an important question about the role of family- is it a barrier or facilitator for Users rights? The bias against family probably has its origins in the fifties theories of psychiatry or anti-family ideology of some human rights advocates under the influence of the West. These are at best tendentious arguments not warranting generalisations beyond a point. Protagonists of the family as Users argue that "*Mental illness is not about one individual but the entire family. Life is never easy for a care-giver. The health care provider may, at best, show the way but the burden of decision rests solely with the care-giver*", observes the author of *Sepia Leaves* who discovered life as a child care giver (13). The exclusion of family from the definition does not mean its exit from the rights agenda of consumer movements.

NGOs such as Ashadeep (Assam), AMEND (Bangalore), Aasha (Chennai), SAA (Pune), NAMI India (Mumbai), Turning Point (Kolkata) illustrate the emergence of family support groups as community care providers to supplement the acute shortage of care facilities. Hence it is simplistic to take a negative view about the family only based on its overwhelming presence. Phenomenological insights of taking the Users "for granted" by the family, are necessary but not sufficient to dismiss the Indian User as passive or an oppressed recipient of services.

At the same time, any definition of MHU that includes the family contradicts the very basic principles of human rights and social justice advocated in the CRPD. As stakeholders, family is not to be identified with Users because it is necessary to delink the two for validating User advocacy for

rights. Our view is that the family is a critical resource, with proper guidance and education can turn out to be a positive change agent. MHU as an independent category of advocacy, delinked from the family, are in line with the national and international legal norms. Adopting a legal definition of Users helps to understand the social dynamics underlying their position for self advocacy and peer advocacy. So we take the view that Users have their own autonomous role in exercise of their rights, not clubbed together with the family but related to it in terms of dialectics of care, control, and interdependence.

Varying User perspectives

The second major factor that gives limited scope for fostering independent User perspectives is the unstable nature of the illness, social attitudes, denial by the users, stigma, lack of disability doles that support such causes elsewhere in the world etc. User perspectives of illness vary too. *"For example, some are happy to accept the idea that they suffer from illnesses such as schizophrenia; or affective disorders; they accept the language of psychiatry. Others reject the notion of mental illness completely, and are incensed that they might be forced to take medication and have their liberty taken away because their distress is interpreted in terms of illness; these people reject the language of psychiatry. Other groups lie somewhere between these extremes. Despite their differences, they share a common belief in their right to interpret their experiences in their own way, and to receive help accordingly."* (14) Commenting on consumer advocacy movements, WHO observes that *"Among the strongest themes that have emerged are: the right to self-determination; the need for information about medication and other treatment; the need for services to facilitate active community participation; an end to stigma and discrimination; improved laws and public attitudes, removing barriers to community integration; the need for alternative, consumer-run services; better legal rights and legal protection of existing rights; and an end to keeping people in large institutions, often for life"* (1).

Cross-cultural variations in User perspectives is only a matter of degree, depending on the quality of life parameters in their respective countries. *"If one talks to mentally ill people, it is easy to realize that they have the ability to make decisions necessary to carry out development work in their own communities, and that they must be accorded their rightful place in society. In the process of development, one can assume with*

a fair degree of certainty, that the pursuit of basic needs will also slowly lead to the achievement of basic rights" (13).

Some NGO approaches to ensure user rights

The logical culmination of the argument that unmet needs are unfulfilled rights seems the most appropriate yardstick for understanding user perspectives – be it from MHUs themselves or by their "significant others". A care giver-cum-service provider states, "At Aasha we have broken down the principles to which we adhere, in simple Do's and Don'ts:

| The Aasha approach (15) | |
|---|---|
| Treat them (patients) like adults | DO NOT look down at them |
| Treat them as equals | DO NOT treat them like school children |
| Tell them CLEARLY as to what decisions they can take and what they must refer to the supervisor | DO NOT force them to do what they don't wish to |
| Treat them professionally - be firm when firmness is required, reward them when they do well. Train them in pre-determined modules - little each day. | |
| If they were accountants before being stricken by the illness, they may want to do accounting work only. ENCOURAGE this trend. | DO NOT look over their shoulders when they are working. |

Instead of explicit and elaborate references to human rights, Aasha's principles reflect a sense of implicit respect for the selfhood of the user that finds its brilliant expression in the CRPD. Echoing the same view, another care giver turned NGO believes that *"To me, it appeared that it is the 'human right' of the person concerned to stay and continue his treatments within the family.... The Human Rights workshop helped the beneficiaries at Turning Point....to fight for their remunerations in an assertive way"*(16).

Fourth Sector NGOs are initiatives by individuals who have been deprived of equal opportunities either due to social barriers or due to setbacks like

disability that motivates them into positive action. The Fourth Sector is a shift from the institutional and community to family and Individual as the basis and agent of change. Fourth sector NGOs like Aasha, AMEND and Turning point show the change from a medical mindset to a rights based worldview (17) .

Others like CAMH view the linkage of needs and rights as a dichotomy giving freedom and personal liberty greater priority than treatment rights (18). Holistic cure and alternative medicine are advocated as more humane than forced treatment. *"....Psychological sciences have made no effort to surmount patient recalcitrance through expertise. Instead they have opted for convenience and stream rolled patients into submission with the force of law."* (19)

Resolving the divide

The resultant schism within MHU has led to the polarisation of the rights dialogue into a service model as against the advocacy model. Most MHNGOs are in the former and in fact, shy away from any rights based advocacy dialogues as superfluous in the light of utter lack of services in the community. Human rights, no doubt are an end in itself, but in the course of achieving it, we must not compromise on the means. NGOs in the development and disability sector can play a decisive role to narrow down the gaps between the two models as is seen from the following approach to family advocacy by ACMI. (This was described in chapter 8)

Incompatibility between MHA and community care principles

User rights have also faced major handicaps due to incompatibility between MHA and the principles of community care. The MHA is not rights oriented on account of its institutional bias and dyadic mindset about the users as either *sane* or *insane*, and nothing in between. Official preoccupation with MI prisoners or custodial confinement of recovered patients made no sense to the problems in family care posing a major hurdle for the exercise of rights by Users or by family members on their behalf. The case history of "X" (Box 1 below) is a classic illustration of the manner in which the complex process of Law can obstruct the course of social justice in the community.

| BOX 1MHA: Case history of X | |
|-----------------------------|--|
| 1989 | X is a well built Karate expert, shows signs of emotional disturbance |
| 1991 | Diagnosed as suffering from Schizophrenia. Treatment starts by regd. Govt Psychiatrist of a leading mental health hospital. |
| 1991-2007 | Intermittent discontinuation of medicines by X. He gets violent during these phases and admitted to Govt Hospital with police help . |
| 2007 | Stops taking medicine and becomes aggressive towards mother and sisters. He wants them to leave the house. They live in fear. |
| March 2008 | X becomes highly symptomatic. Refused to go to the hospital. Letter from Govt Psychiatrist to the Magistrate for Reception Order because Police refuse to help without Reception Order. Mother files affidavit for Reception Order in court and starts running around to court for multiple hearings. All prescriptions since 1991 are also produced for Magistrate's reference. |
| April 08 | X gets more hostile and threatens "bloodbath". More delusions follow. |
| May 08 | Magistrate directs X to be produced on 19 May 2008 |
| 16 May | X assaults his two sisters without any provocation, threatening to kill them. Mother, sisters and grandchildren run out of house. Police called. X threatens them also. Police advise the family to stay elsewhere for their safety, they run out without even a change of clothing. |
| 17 May | FIR lodged. They (Police) register a case of assault against X. . |
| 19 May | X is presented before magistrate on 21 st May because it was dismissed on 19 th May |
| 22 May | Magistrate dismisses the Reception Order case on 22 May. Family runs to Human Rights Commission. They |

| | |
|----------------------------------|--|
| | direct the police to assist the family to admit him in the hospital. |
| 23-25 May | Police not available due to inauguration of BLR new airport 23 th and Karnataka elections on 24 th . They say that X can be picked up only on the basis of the assault case and MI. |
| 26 May | Finally Police arrest X on assault case, produce before Magistrate and he directs him to Custody in Central Jail instead of admission as a patient. X is now a criminal and not a patient! |
| 28 May | Medical Authorities at Central Jail understand that X is mentally ill and he is taken to the same Govt hospital where he was treated. He is presently admitted in the prison ward of the hospital. |
| Till 3 rd week of Jun | X is administered counseling & treatment in the Govt Hospital for about 3 weeks. After this he is sent back to the Central Jail and treatment and counseling continues there by the prison psychiatrist. |
| Early 1 st week July | Prison psychiatrist is comfortable with the improvement of X. Family contemplates bringing X back home rather than risk him spending long time in jail. What if X stops medicine or gets violent again? There is no doorstep service to help X overcome his criminal record. |
| Later 1 st week | X is back home and is doing well but unfortunately with a criminal record. |

Written by a relative of X and edited by the author

ACMI is in the forefront of legislative activism with the MoHFW for recognising family as "enablers" rather than as "enemies" of the Users that is implicit in the present Law (ACMI's correspondence with the Health Ministry was initiated in Sept 2006 and continues till date). Few cases of family abuse are exceptions and not the rule; by making the exceptions into rules in the name of protecting the user rights, the genuine cases like that of X (in Box-1 above) suffer untold misery. Among other things our demands include simplification of admission procedures, information on rights to patients and families, self rights and rights of natural guardians for nomination of legal guardians, review of closed wards, police

intervention to be supplemented by crisis and emergency management services; Sec 37 wherein the composition of Board of Visitors to include user and family groups, consumer lobbies, Rotarians, other disability advocacy activists, representation from professional bodies etc. Minimum standards to be worked out in facilities with resident MHU keeping user rights and needs in mind, not based on the availability of resources alone. The positive response of the Ministry is already felt at the State level wherein Rule 22 has been amended (under sec 94 of the Act) to include the above recommendations. With the advent of CRPD, knowledge of the law by families and NGOs is indispensable to ensure full and free participation of MHU in the exercise of their rights.

Moving forward

The MHU perspectives underwent significant changes in the last twenty years. The passing of the PDA, and the recognition of MI as one among the disabling mental disorders, marked a paradigm shift from service orientation to the broader context of rights in civil society. AMEND, the first autonomous SHG in the country, actively lobbied for inclusion of MI persons in the Persons with Disabilities Act (17). It circulated information booklets in English and Kannada, prepared with the help of faculty of NIMHANS. SAA from Pune used visual media by making the film "Devrai" to convey the merits of positive family support. Third sector NGOs like Aasha and Cadabams developed job skills of the users by opening shops catering to the community. User advocacy issues range from "challenging psychiatrist driven mental health programme", advocated by CAMH (18) to demand for social security benefits and life-long pension for MI persons above 45 years and safe property rights by NAMI India (21). In 2000, AMEND got the disability certification protocols into place in the state of Karnataka. In association with other MHNGOs in the country, AMEND and ACMI succeeded in obtaining income tax rebate for persons with MI and their family providers. The office of Disability Commissioners at State levels handled cases of violation of PDA at State levels.

Disability certification for mental illness

The integration of mental disabilities into the overall disability sector gave rise to CBR initiatives in rural areas by NGOs such as Basic Needs, a CBR Forum in Bangalore (Karnataka). SCARF (Chennai) organised workshop on disability caused by mental disorders in 1999 where attention was drawn to the question of measurement of disability in MI. Further research on this

resulted in the designing of IDEAS that was formally recognised by the GOI in 1996. ACMI's first legal literacy workshop on Law and MI for the family and user lobbies in May 2006 put forward an eighteen point demand that laid the foundations of dialogue with the Ministry of Health about amendments to MHA and certification of rehabilitation centres under the PDA instead of the present license system under MHA. Tamil Nadu has already put this into practice. Political inertia regarding NMHP, lack of a rights based mental legislation, and discrimination towards MI in PDA prompted ACMI to file affidavits in the Supreme Court (10) and Karnataka High Court. (22). Bapu Trust organised a series of national consultations and brought out a Charter of Rights (18).

Federation of MHNGOs

An all-India federation of MHNGOS was formed in 2003 as an umbrella organisation to work for the cause of persons with MI. It demanded job opportunities for MHUs in the private sector by giving incentives to the employers. In 2006, ACMI in association with Torchbearers, Delhi joined the NGOs led by Lawyers Collective to protest against the new Patent Ordinance (23).

By drawing the MI lobbies out of the medical orientation to one of social justice, the PDA brought about some attitudinal change towards persons with MI. Networking with other disabilities led to greater awareness and acted as a stigma buster in a limited way. PDA was not a comprehensive rights based law as far as MI was concerned. Starting with the definition of MI (copied from MHA), denial of Job quotas to MHU (Ch VI), the very language of the text loaded in favour of physical disabilities and the failure of the government to amend the Act were hurdles that the MHU is yet to be overcome. MHNGOs across the country have protested against the neglect of mental disabilities and their rights in PDA. The advent of the UN CRPD is forward step towards realisation of the rights missed out by PDA.

From national to global Integration

The UN CRPD is a radical departure from all previous disability policies applicable in the country. Besides allowing room for State Parties to adopt definitions that are culturally, socially, financial and legally acceptable to their localised scenarios, this broad and inclusive approach results from strategic and active campaigning by the civil society participants of the Ad

hoc Committee (AHC), collectively called the International Disability Caucus (9). On 30 March 2007 India also joined the community of 82 countries to have signed the UN CRPD on the very day it was adopted and opened for signature and ratified it on October 1st 2007. Since May 5th 2008, India is bound by the international charter of human rights universally applicable to all disabilities recognised by PDA.

Domesticating the Convention involves legal reforms and changes in the existing laws to incorporate the broad principles and ensure that there is no conflict of interests between CRPD and the local laws. *"Article 12 embodies the foundation for a whole new vista of rights for persons with mental and intellectual disabilities.* The language of Article 12 of the Convention was hotly debated up until the 7th and 8th sessions of the AHC (*Ad hoc* Committees) reflecting an ideological divide within the civil society groups (9). Concern among many MHNGOs and mental health professionals was about the consequences of full legal capacity for the MI in symptomatic phase of the illness that could have fatal consequences such as the one that was witnessed in Virginia Tech campus in USA (25). The issue here is not protecting the civil society from the *client patient*; on the contrary, it is one of supporting him/ her with timely 'enablers' **to cherish freedom without fear of Law**. Finally it was resolved "by qualifying legal capacity to imply, (a) recognition of legal capacity of all persons with disabilities; (b) introduction of the tailor-made supported decision making model in place of replacement/ substitution by personal representative; and (c) proportionality of the support provided. (9) ACMI in association with SCARF, Chennai based MHNGO conducted a brainstorming workshop on the implications of CRPD for the rights of MHUs. Reports have been submitted to MoHFW and MoSJE.

NGOs in Rights-based interventions: PPP model of advocacy

Public Private Partnership is the "mantra" in India's for strategic resource management to overcome the inefficiencies in public services today. Illustrative examples of such PPP models are emerging from different parts of the country and have been provided in chapter 8. The ACMI in Bangalore worked with the Disability Commissioner to negotiate a crisis ambulance service through a PPP model involving the State Mental Health Authority, government department of health, the Rotary Club and the police.

Conclusion

The CRPD is a broad human rights framework to fit other laws of the land. It is the overall responsibility of the civil society to "make it happen". The Health Ministry and NHRC must throw open its doors to consumer representatives in all policy making initiatives rather than adhering to non-participatory decision making process. Critical among these are attitudinal changes and communication skills (especially listening skills) for "significant others" including mental health professionals as a symbol of respect for user lobbies and MHUs. It is time we think on the lines of setting up an autonomous and nodal agency such as a National Mental Health Corporation to oversee the transition from the medical to human rights model in a manner that coordinates the work of the two ministries involved in the cause.

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