

"I have been living with serious mental health problems for the last 20 years, but it is only in the past year that I have felt that I am getting back my life getting back my life."

"I didn't know what was happening to me"

Juan

The experience of Juan is an example of unmet mental health care needs, to find himself in a situation where his rights are being violated. The fact that Juan had to live with his mental illness for 20 years without being able to comprehend his own situation is a reflection on the violation of his right to health. As per the Article 12 of International Covenant on Economic, Social, and Cultural Rights (ICESCR), which states: "[t]he States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health", is evidently not being upheld in the case of Juan.

More specifically, the right of access to care finds its basis in the Right to Health, as stated in section 1 of the General Comment 14 on the ICESCR which states that-

"Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. The realization of the right to health may be pursued through numerous, complementary approaches, such as the formulation of health policies, or the implementation of health programmes developed by the World Health Organization (WHO), or the adoption of specific legal instruments. Moreover, the right to health includes certain components which are legally enforceable."

The U.N. Declaration of Human Rights and in General Comment 14 on the ICESCR, the right to health – including mental health to focus on four aspects: 'Publicly funded health facilities and services must be available in sufficient quantity; treatment, care and information must be geographically and economically accessible to all persons without discrimination; facilities and services must be acceptable, meaning appropriately delivered for vulnerable or minority groups such as women, children, and ethnic or cultural minorities and respectful of medical ethics; and care must be of good quality.'

Moreover, Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) states that it is the State's responsibility to ensure the health services as close as possible to people's own communities, including in rural areas. It also requires health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care."

Juan's inability to understand his own symptoms and experiences also hint upon the invisibility of mental illness in the community. Had the above mentioned, legally binding mandates been realized, Juan's experience would have been different by being aware of

signs and symptoms of his illness and would have had the opportunity to seek help for the same. Moreover, Juan's symptoms of illness would have not resulted in his loss of source of livelihood, housing, and family.

Given the lack of affordable, quality care being available, the care-giver (mother) chose the institution of mental hospital to address the illness when it had significantly progressed rather than addressing it when the illness symptoms had begun. The option of mental hospital saw Juan's human rights being violated, from being 'locked-up' to not getting sufficient quantity of food. The lack of quality of care led to a worsening of his illness.

Clearly, the lack of an explanation about his diagnosis and the need for his medication led to his repeated escapes and further repeated hospitalization which we later see; could be easily be addressed at a facility close to his house where he can receive psycho-social care and counselling within his social support. Within the institution, Juan was a witness to abuse and restraint. Juan's medical condition now seemed to make him a legal subject which can be seen in his interaction with the police and further abuse even at home and later, at the mental hospital.

These incidents only further highlighted the violation of the provisions under International Covenant on Civil and Political Rights (ICCPR) which contain important rights relevant to people with mental disabilities. These include the right to freedom from torture and cruel, inhuman or degrading treatment or punishment, the right to marry and found a family.

Article 26 of CRPD also enlists the right to habilitation and rehabilitation that requires the State Parties to work address the issue of employment.

Some of the positives for Juan was the engagement of health professionals at the time of his discharge when he was referred to psychiatric outpatient unit where he received free medication and treatment on a regular basis. Staff's positive attitude in itself was reflected in him continuing his treatment. However, the cost of mental health care being incurred for travel to the clinic was addressed with the services being available in his municipality, at the level of primary care, and he was supported by State's social support scheme.

Reflection on accessibility question in India

Juan's testimony is not uncommon in India. Mental health care needs are unmet to a great extent, be it due to stigma and discrimination and a lack of affordable, accessible, quality care being available. While in India, there is a structure and a framework for all levels of care: primary, secondary and tertiary, the systems are dysfunctional and need to be strengthened. The overall budget on health care is less than 2% and within that, mental health funding remains even lesser. Moreover, this funding is primarily spent on the maintenance and upkeep of colonial institutions of mental hospitals.

The eminent need for moving away from institutional care to community care cannot be emphasized on enough. Unfortunately, community care itself seems to be influenced by coercive practices which are primarily bio-medical in its approach. People with mental illness are legal subjects with their inclusion in a web of laws. The Mental health care act allows for admission in institutions without the user's consent.

My experience of working with QualityRights Gujarat and assisting in the assessment visits using the QualityRights Toolkit clearly demonstrate the differences between an integrated mental health care into general health care versus an institutional framework. However, violation of basic human rights even with the integration prove a need towards an innovative means to address the issue of mental health which talks of psycho-social needs such as housing, employment, education, through the provision in the community. It is possible to give people the right to be included in their community and be on the path to recovery. An inclusion of mental health in the political purview and with the growing global burden of mental illness, issues of accessible care is possible.

This would require interventions at a personal level to address stigma and discrimination, and also at a systematic level. Even the public health system in India leaves much to be desired, thus the efforts to address mental health cannot ignore the general health care facilities.