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Experiences of Cis-Women & Girls in Mental Health Institutions in India

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Background & Context

In 1961, Erving Goffman in his seminal piece 'Asylums', highlighted the deliberate processes within mental health institutions that lead to the depersonalisation of individuals receiving services.[1] Goffman compares these spaces to 'total institutions' such as prisons or concentration camps, where patients are isolated from the rest of society. Their agency is forcefully taken away and their interactions with their service provider is impersonal and apathetic.[2] In India, while the National Mental Health Policy (2014) and the Mental Healthcare Act (2017) call for a reform of mental health establishments, the processes observed by Goffman in 1961 continue to persist till this day.

Within these institutions, the mistreatment and abuses faced by cis-women and girls who are either living with or perceived to be living with psychosocial or intellectual disabilities are far more pronounced and deleterious. Reports often highlight the multiple acts of discrimination and rights violations that individuals are subjected to.

However, as prescribed under Article 4 of the Convention on the Rights of Persons with Disabilities (CRPD), it is imperative to understand and ensure "measures that guarantee them (persons with disabilities) the exercise and enjoyment of the human rights and fundamental freedoms". The disproportionate focus on negative violations without adequate attention to the "full development, advancement and empowerment of women (with disabilities)" is frequently observed in India.[3] In 2014, the Human Rights Watch (HRW) conducted a qualitative study to assess the state of human rights violations faced by women and girls admitted in mental health institutions in the country. The report, titled '*Treated Worse than Animals: Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India*', interviewed 68 women and girls and reviewed the conditions of 24 mental health establishments.

The report focused on the treatment of women and girls with respect to the conditions they live in, the attitudes of their families towards them, their access to health care and legal aid, and the agency they are given in making their own decisions.

In 2016, the National Commission for Women (NCW), in collaboration with the National Institute of Mental Health and Neuro-Sciences (NIMHANS), conducted a survey with the objective of determining the veracity of the HRW report by evaluating which aspects were arbitrary references or overgeneralizations and to provide a counter narrative to the existing accounts on psychiatric hospitals in the country. The NCW report titled '*Addressing concerns of women admitted to psychiatric institutions in India: An in-depth analysis*' had a significantly larger sample size, interviewing 245 women admitted in 10 mental health institutions, along with caregivers, service providers and administrators.

This brief is a comparative analysis of the recurrent themes observed in both reports. Further, it elaborates on their shortcomings and outlines common gender-specific recommendations to address violations and abuses, improve conditions and reform the approach to care and treatment, within institutions.

Methodology

HRW researchers visited 24 institutions that were selected to account for geographic diversity, the kinds of institutions available for women and girls with psychosocial disabilities including organisations such as Asha Kiran, and the suggestions from organisations working for the rights of disabled persons. The team conducted in-person and telephonic interviews with 263 stakeholders in all: women (n=53) and girls (n=15) admitted in these institutions between the age of 9 and 80 years, family members (n=12), caregivers (n=53), and psychiatrists (n=26), among others. Most interviews were conducted on an individual basis, however, exceptions for group interviews were made for the comfort of some interviewees. Interviews were conducted in settings where staff members were out of earshot. This was followed by a thematic analysis of the interview transcripts to highlight gendered experiences in mental health institutions relating to abuses and access to justice. While HRW had a qualitative approach to the issue and focussed mainly on rights violations and gender discrimination, the survey by the NCW employed a more quantitative approach in tandem with on-site observations and aimed to assess mental health institutions on a wider range of parameters.

The NCW study comprised 3 activities: (i) joint site visits by NIMHANS and NCW to 10 hospitals (selected from Inspection Committee Reports, Ministry of Health & Family Welfare) (ii) interviews with women patients (n=245), family caregivers (n=21), service providers and administration (n=~100) along with on-site reports; and (iii) analysis of a questionnaire sent to 43 mental health institutions, seeking gender specific and background information about the women as well as facility related issues. In the report, no information regarding the age of participants is provided, and it is not known whether minors were included in the study. While both reports had similarities, there were certain glaring differences in their findings that are depicted in the tables below categorized by specific themes.

Infrastructure, privacy and staff shortages

The NCW survey is exhaustive in its assessment of physical infrastructure and amenities and finds that women and girls admitted in these institutions overwhelmingly express satisfaction with the facilities, except regarding overcrowding and the consequent privacy violations. They also report an overall improvement in basic living conditions in most institutions since previous inspections.

HRW and NCW both report similar findings on the acute lack of staff and the overcrowding of patients across all institutions surveyed.

Most institutions had several vacant posts for psychiatrists and clinical psychologists. As per the NCW report, Regional Mental Hospital (RMH), Yerwada, Pune was found to be especially under-equipped with the post for a psychologist lying vacant since 2001.

Other staff were lacking in strength, too, which resulted in neglect of the patients in the institution. The NCW survey also corroborates HRW's findings on poor sanitation and lack of privacy.

Table 1: Themes observed under infrastructure, privacy and staff shortages in both reports

Key themes	HRW Report	NCW Report
Physical Infrastructure and Amenities	Indicate a shortage of facilities although physical infrastructure did not form a major component of the interviews. Unsanitary conditions were prevalent. For instance, the Pune Mental Hospital had 25 toilets for 1850 people admitted and open defecation was reportedly the norm.	Overall, high rates of satisfaction among women patients across diverse parameters: 90.6% for the basic facilities provided, 86.5% for the food and dining facilities, 82.8% for facilities for personal hygiene and comfort and 86.9% for the sleeping and resting facilities.
Overcrowding and Violations of Privacy	4/24 institutions visited were extremely overcrowded. Most institutions are working at several times their capacity.	54% were dissatisfied on account of overcrowded living facilities. 33% indicated there was no privacy while bathing, using toilets and changing clothes.
Lack of Staff and Poor Training	The staff are greatly inadequate in strength. The lack of staff leads to further neglect in providing adequate healthcare. In 16 of the institutions, support staff and attendants who were responsible for the daily care of the patients were insufficiently trained, lacking awareness about their mental illnesses and insensitive to their needs.	Acute lack of staff across all institutions surveyed. RMH Yerwada had no psychologist available for the last 15 years. The feedback from a self-reported survey completed by 43 psychiatric institutions report inadequate staff as an area of concern, particularly female staff.

Rights violations

Both the HRW and NCW report a disregard for patient consent. Persons with mental illness were not informed about the specifics of their diagnosis, treatment, and its potential side-effects. There was no room for the person undergoing treatment to make informed decisions or withdraw consent, had they wished to. The HRW report highlighted instances where refusal to take medication resulted in forceful or involuntary methods to administer medication which included lacing food with medication. Further, 96% of the respondents in the NCW survey said they were never informed of their rights and 56% were unaware of whom they could report complaints to.

The HRW report also reveals that in the few cases where consent is sought for treatments such as electroconvulsive therapy (ECT), it is taken from a guardian, with no provision for the person undergoing treatment to provide consent. Further, ECT is employed beyond its intended psychiatric use, as a coercive measure to handle 'unmanageable' patients. Segregation of women and girls with disabilities was justified on claims of their being 'dirty' or 'unclean'; leading to further exploitation, where women and girls with more severe disabilities were made to perform tasks such as sweeping, bathing others, and cleaning toilets..

Table 2: Themes observed under rights violations in addition to emotional, social and health-related needs

Key themes	HRW Report	NCW Report
Emotional and Social Well-being	Education is denied to the girls and there are no meaningful activities to keep both women and girls occupied or emotionally, socially and intellectually stimulated. Discriminatory practices in the form of spatial segregation between women with intellectual and psychosocial disabilities and those without were observed in two facilities. Schools themselves are ill-equipped to cater to girls with special needs, so they are forced to remain in the institutions.	86.5% considered their emotional needs, such as being treated with respect, being allowed personal possessions, having access to letters as being adequately met. 61% expressed dissatisfaction regarding lack of access to phones, 40% for lack of access to newspapers and magazines, 45% for lack of social activities, and 54% for not being allowed to go out of their wards.
Information about Specifics of Treatment	Information is not shared with those who will receive the treatment as they are considered as having an 'unsound mind'.	65% claimed their treatment was not explained to them and 82% did not have access to their records.
Lack of Agency Regarding Treatment Decisions	Involuntary treatment was found to be the norm, the most prevalent form being verbal and physical coercion to take medication. Overmedication was observed in institutions, without any due consideration of adverse side effects on the women.	8.98% said they were treated against their wishes.

Key themes	HRW Report	NCW Report
Lack of Informed Consent and Confidentiality	Consent is sought very rarely, if ever. Of the few consent forms that were obtained for ECT, none were signed by the patients themselves, but instead by their guardians.	Lack of obtaining consent across all institutions, especially in BMH Murshidabad (100%) and MHC Kozhikode (72%). Overall, 60.41% said confidentiality was not maintained during treatment.
Involuntary Admission and Abandonment	All 52 women interviewed were admitted without consent, 25 of whom were abandoned by their families.	85% of admissions are voluntary. In most institutions, voluntary admissions outnumber involuntary ones. However, 16/43 institutions still largely reported involuntary admission according to the self-reported survey, It must be noted that there is limited information on the scope of a voluntary admission. Admission forms and admittance through caregivers may not be considered fully voluntary as it may involve coercion to a certain extent.
Information about Rights	Most women are completely unaware of their rights and the redressal mechanisms in place, which are already scarce.	96% stated that they were never informed about their rights and 56% said they did not know who to complain to.
Segregation and Conditions of Confinement	Segregation was observed on the basis of degrees of disability, practised by the staff as well as among the women admitted themselves. Women deemed 'unclean' were kept out of kitchens.	No statistics on practices of segregation. 29% reported that they were kept in restraints for more than a day.
Access to Justice and Legal Representation	Access to justice is severely limited and entirely dependent on the caretakers. None out of the 128 cases of abuse reported were successfully filed as FIRs. Cases of abuse are usually to be reported to the institution's staff, who may themselves be the abusers. Testimonies are not taken seriously on grounds of an 'unsound mind'.	27% required legal representation but were not provided any.

Key themes	HRW Report	NCW Report
Denial of Adequate and Appropriate Healthcare	Medical needs are overlooked due to lack of staff in providing them, and the stigma and discrimination faced in hospitals.	With regards to decisions on their health, 71% state they are not allowed to take healthcare related decisions. The report further does not probe into conditions of patients with physical comorbidities and their access to care and treatment.
Sexual & Reproductive Health of Women	The women have no information about testing and treating sexually transmitted diseases. Reproductive healthcare check-ups are rarely administered, and only in cases of pregnancies.	The only parameter on the sexual and reproductive health of women is on testing for HIV and Sexually Transmitted Infections (STI), in which 31% stated they were administered HIV/STI tests. There is no mention of whether consent was solicited prior to the administration of the tests. Tonsuring without consent was practised in all institutions, most notably in RMH Pune (40%) and IPHB Goa (40%). The practice of tonsuring is a violation of sexual rights, and has not been explicitly addressed as so in the NCW report.

Gender-based violence and abuse ♂

The HRW report documents various forms of abuse faced by 128 women and girls in these institutions, ranging from insensitive and unacceptable language to physical violations such as rape or physical restraint. Further it identifies reasons why patients choose not to reveal incidents of sexual coercion. The report probes into the specific challenges faced by women and girls with psychosocial disabilities recognising they are more vulnerable to sexual abuse and less likely to receive adequate legal aid and emotional support to cope with it. Their legal complaints are mediated by their caretakers and staff members, many of whom are the abusers themselves, and their testimonies are dismissed on grounds of 'unsound mind', supposedly making them unfit to decide for themselves whether they were actually abused.

While the NCW survey assesses the quality of infrastructure, limited attention is given to experiences that are most strongly determined by one's gender, such as sexual harassment. Of the 245 women interviewed, only 4 (1.6%) reported 'sexual advances' from the 'treating team'. While the number of reports of sexual advances are the same in the HRW and NCW report, it should be noted how fear of disclosure, power-dynamics between the interviewer and the interviewee, presence of staff members, lack of access to emotional support and legal aid, as well as a possible lack of understanding of what counts as 'sexual advances', may influence disclosure of incidents of sexual harassment or abuse.

Table 3: Themes observed under gender-based violence and abuse

Key themes	HRW Report	NCW Report
Verbal and Physical Coercion	Found 12 cases of verbal abuse and 38 cases of physical violence during the field visits to institutions. Common occurrence across all institutions. Medications are commonly administered using physical coercion or verbal threats of being subjected to ECT. Women with severe disabilities are also exploited and forced to do tasks such as cleaning the toilets. The staff do not treat the women with respect and often use terms such as 'mentally retarded' or 'pagal'.	In personal interviews with patients, 10.61% reported being threatened by staff, 8.57% said they were physically harmed by staff and 10.20% said that hurtful language was used on them.
Sexual Abuse	Only 4 cases of sexual violence were reported to the HRW team, but deeper investigation brought to attention the role played by power-dynamics, lack of agency, stigma, and legal barriers in the decision to disclose experiences of sexual violence.	Similar to the HRW reports, 4 women (1.6%) reported facing sexual advances from treating staff. Reports from site visits highlight circumstantial instances of sexual abuse perpetrated by staff or family members if they were disclosed by staff.

Shortcomings of both reports

Philosophical pitfalls

Both the reports raise serious ideological concerns and illustrate how persons with psychosocial disabilities continue to be looked upon as devoid of any agency. The reports' view recovery from a medical lens demarcating between subject and objects, wherein residents of these institutions are viewed as objects to be acted upon, rather than centering their interests and facilitating their participation in their own treatment and care.

Goffman in Asylums describes hospitals and institutions for persons living with mental illness as 'total institutions' within which each aspect of life is regimented, with little to no space for self-expression or participation in the recovery process.

Goffman characterised a 'total institution' as a space where (i) life is experienced and controlled by a singular central authority, (ii) activities of daily living are undertaken in groups or in the presence of a large groups, and (iii) all phases of daily activities are planned, with one activity leading into another to meet the needs of the institution, rather than the individual.[1]

A close reading of the NCW-NIMHANS gives an insight into how institutions for persons with mental illness continue to operate as 'total institutions' more so in the case of women, given the socio-cultural context of India, where women are frequently infantilised with little to no say in their everyday lives and healthcare decisions.

Glimpses of the rights-based lens being used is visible in both the NCW-NIMHANS and HRW reports, however social recovery is a neglected dimension in both. The social recovery model includes taking into account the individual's perceived needs and operates on the principles of developing a sense of community, participation, and agency in defining what 'recovery' means. Both reports neglect exploring aspects of social recovery and whether or not these institutions facilitate social recovery. Despite there being a body of evidence, which shows the importance and role of the subjective perspectives and lived experiences in recovery, approaches and intervention for persons with psychosocial disabilities lack this perspective. The various parameters upon which these two reports assess institutions operate within the narrative of the medical lens, completely overlooking aspects of social recovery.

Experiences of gender and sexual minorities

Both the HRW and the NCW reports fail to discuss crucial determinants of being vulnerable to rights violations such as belonging to gender minorities such as transgender, non-binary and gender non-conforming communities, marginalised castes and sexualities. These social determinants work in tandem with gender identity and can significantly alter one's experience of being in overcrowded residential institutions where discriminatory behaviour is the norm and consent and agency nearly non-existent. Generalising of experiences by these reports across castes, and sexualities is likely to erase the specific forms of oppression experienced by already vulnerable groups, by neglecting the way in which such determinants operate within and beyond such institutions.[4]

Sexual and Reproductive Health Rights

Neither the HRW nor NCW sufficiently look into the state of sexual and reproductive health and rights of women in these institutions. This is particularly concerning given that violations of reproductive rights (e.g. forced hysterectomies) are rampant in mental health institutions.[5]

The articulation of sexuality and the sexual experiences of women in the reports is unidimensional and reductive. There is a perpetuation of harmful stereotypes of women in institutions which includes wrongful assumptions surrounding their sexuality wherein they are viewed with a compulsively heterosexual lens and their own desires are regarded asexual in nature.[6]

Usage of electro-convulsive therapy (ECT)

The NCW report fails to probe into the conditions under which treatments such as ECT are administered. While the HRW report documents the use of involuntary ECT, the only available information in the NCW report is from the self-reported survey from 43 institutions, where 79% indicate that an ECT register is maintained, however details of conditions under which ECT treatment are not provided.

Gender sensitive infrastructure and amenities

Even though both reports describe in detail the physical infrastructure of these institutions, they do not adequately address the need to design and construct facilities that take into consideration gendered experiences of end users within such spaces. There are various aspects that need to be gender responsive and sensitive including lighting, access to water, sanitation, circulation space, safety and privacy.[7] For women and girls living with psychosocial disabilities, a nuanced perspective that captures the importance of creating enabling and empowering physical spaces considering the intersection of both these identities has been neglected.

Methodological concerns

The questionnaire used by the NCW report to interview women patients appears to be semi-structured with a focus on close-ended questions. Thus, the summarised findings do not capture qualitative insights particularly in areas of reported dissatisfaction.

The terms 'satisfaction' and 'dissatisfaction' themselves are far from objective, as the rating of experiences on these scales would be relative and subjective depending upon the individual's context and past experiences. Moreover, there is no clear indication of how participants to be interviewed were chosen and the conditions in which the interviews were conducted. Though the surveys were meant to be conducted in the absence of staff members, this was only a guideline and not a prerequisite. All these factors may have influenced interviewee responses and their willingness to disclose the truth particularly on questions concerning staff treatment.

Recommendations

Both reports provide a comprehensive set of recommendations directed to stakeholders within mental health systems. We have summarised a few that address the points raised in the above discussion, supplementing them with provisions from the Mental Healthcare Act, 2017 and other relevant legislations.

- The Ministry of Health and Family Welfare and Ministry of Social Justice and Empowerment should begin the process of deinstitutionalization by ensuring that funding for new institutions is reallocated towards running, funding, and providing access to community-based services for persons with mental illnesses. Both Central and State Governments should ensure budgets are allocated for refurbishment to improve conditions of existing institutions. This is reaffirmed by Section 19 of the MHCA as per which provisions are to be made for less restrictive community-based facilities for persons who no longer require treatment in restrictive mental health establishments.

- Mental health institutions should manage and address human resource deficiencies at all levels and ensure that an adequate gender ratio of staff particularly attendants is prioritized. Staff must be trained and sensitized towards gender-related issues as well as the rights of personhood for women. Specific attention should be paid to make women with psychosocial disabilities within these institutions aware of their individual rights, participation in decision making processes, psychoeducation about their condition and treatment plan. Most importantly it must be ensured that informed consent is sought at every stage including for pre-admission, treatment, and subsequent interventions.

- The Central Government through the Central Mental Health Authority should develop and implement guidelines for minimum standards of sanitation, hygiene, and living conditions, prohibiting arbitrary detention without judicial review and involuntary ECT. This is reinforced under Section 20 of the MHCA, the provisions of which protects persons living with mental illness from cruel, inhumane, and degrading treatment. Infrastructure and amenities within such institutions should be gender sensitive, taking into account factors such as space, lighting, access to water, privacy, and ambience. Further, section 95 prohibits the use of electro-convulsive therapy without the use of muscle relaxants and anaesthesia and its use on minors.

- Mechanism for monitoring by independent bodies and quasi-judicial bodies that include the National and State Human Rights Commission, National and State Commission for Women and National and State Commission for Protection of Child Rights must be created for periodic review of adherence to guidelines. The National Commission for Women in its 2018-19 Annual Report has reported that it conducted an inspection of 8 psychiatric homes and shared its remedial action plan with the authorities. Whether or not these remedial action plans were implemented, is unknown and not available in the public domain. To measure progress, it is necessary that the findings and recommendations from previous inspections be tracked and reported periodically, and an accountability mechanism be established for the same.

- Institute an independent grievance redressal mechanism that can receive and investigate complaints about ill-treatment of persons in institutions while maintaining confidentiality. As per section 77 of the MHCA, Mental Health Review Boards are to address such complaints if an application has been made to them by a person living with a mental illness or their nominated representative. The NCW reports also calls for the formation of a Sexual Harassment Committee in all mental healthcare hospital and custodial care settings. Further, the Sexual Harassment of Women at Workplace Act, 2013 too necessitates the establishment of Internal Complaints Committees (ICC) at the workplace to hear and redress complaints of sexual harassment within organisations.

- Mental health establishments in general must prioritise making the institutional environment accessible to women and girls from all backgrounds. Accessibility would involve developing guidelines, support resources, consent forms, in local languages and accessible formats or other tools to facilitate supported decision-making mechanism through drafting of Advance Directives or appointing a Nominated Representative.

While the NCW in its Annual Reports provides a brief summary of inspection activities of mental health institutions that house women and girls, a similar assessment has not been undertaken since 2016. There is little evidence to suggest that the proposed recommendations have been implemented as no follow-up reports are available in the public domain.

The shift to community-based care is a long upward climb. In the meantime, it is essential that the rights of marginalised groups, such as women and girls are not neglected, and the scope of such evaluations are broadened to include individuals with diverse gender identities. In this regard, we propose the following considerations that would make such evaluations more gender-inclusive.

- Use of a right-based approach for collecting data from person belonging to transgender, non-binary and gender non-conforming communities, ensuring the active and meaningful participation of individuals from these groups throughout the entire process of data collection. Since accessibility, stigma and legal repercussions may prevent meaningfully engaging with persons from these communities, it is important that representative NGOs and CSOs are appropriately involved in this process.

- Authorities or researchers who collect data on individuals from gender minorities in institutions, through either interviews or surveys should receive gender and cultural awareness training.

- Develop a sensitive gender affirmative set of standards and protocols for all service providers who engage with individuals from gender or sexual minorities living with mental illness that protect their rights to self-identification (personal choice to disclose, withhold and/ or self-define a person's identity), privacy, confidentiality and dignity.[8]

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