

HUMAN RIGHTS WATCH

# "Treated Worse than Animals"

Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India



## "Treated Worse than Animals"

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#### Terms

Beggars' Home	A place of detention to which a person who is found guilty of begging in the streets, for the first time, by a court of law can be sentenced for up to three years with a mandatory minimum of one year. Under the Bombay Prevention of Begging Act (1959), enacted by several states in India, <sup>1</sup> people with leprosy or psychosocial disabilities can also be detained.
Catatonia	A syndrome that is usually associated with schizophrenia and mood disorders. A person with catatonia can display striking and extreme variations in movements ranging from a lack of movement (stupor) to excessive movement (excitement). <sup>2</sup> Electroconvulsive therapy is often prescribed for catatonia.
Disabled Persons' Organizations (DPOs)	Organizations where persons with disabilities constitute the majority of members and the governing body and which work to promote self- representation, participation, equality, and integration of all people with disabilities. <sup>3</sup>
Electroconvulsive therapy (ECT)	A psychiatric shock therapy which consists of placing electrodes on the patient's head and passing electricity through the brain to stimulate an artificial seizure. ECT is generally prescribed for severe depression, mania, schizophrenia, and other mental health conditions when other treatment has failed to work or for quicker results. In its modified form, ECT is administered under general anesthesia, with muscle relaxants, and oxygenation and can result in headaches as well as short-term memory loss. <sup>4</sup> Unmodified ECT (without anesthesia or muscle relaxants) continues to be practiced in settings with poor access to anesthesia or anesthetists. The risks of unmodified ECT include dental damage, spinal and pelvic fractures, and muscles injuries. <sup>5</sup> A typical course of ECT involves six to twelve sessions given two to three times a week. <sup>6</sup>

<sup>&</sup>lt;sup>1</sup> "The Bombay Prevention of Begging Act, 1959," undated,

http://delhi.gov.in/wps/wcm/connect/f2214e0043383b63b2d1f3cf71a315bd/THE+BOMBAY+PREVENTION+OF.pdf?MOD=AJP ERES&Imod=-716342930&CACHEID=f2214e0043383b63b2d1f3cf71a315bd (accessed February 12, 2014).

<sup>&</sup>lt;sup>2</sup> National Institute for Health and Care Excellence (NICE), "Guidance on the Use of Electroconvulsive Therapy (TA59) - Clinical Need and Practice," October 2009, http://publications.nice.org.uk/guidance-on-the-use-of-electroconvulsive-therapy-ta59/clinical-need-and-practice (accessed February, 12, 2014).

<sup>&</sup>lt;sup>3</sup> Disabled People's International, "Constitution of Disabled People's International," 1993, http://www.dpi.org/Constitution (accessed February 20, 2014).

<sup>&</sup>lt;sup>4</sup> ECT-team, Department of Psychiatry, National Institute of Mental Health and Neuro Sciences, *ECT Administration Manual*, 2nd edition, 2013, p. 47.

<sup>&</sup>lt;sup>5</sup> Chittaranjan Andrade et al., "Position Statement and Guidelines on Unmodified Electroconvulsive Therapy," *Indian Journal of Psychiatry*, 54 (2012): 119–133, accessed January 26, 2014, doi: 10.4103/0019-5545.99530.

Institutions	Refers to state-run (unless specified otherwise) mental hospitals, government or NGO-run residential facilities, and rehabilitation facilities. Some government or NGO-run residential facilities are open to anyone, with or without a disability, while others cater specifically to persons with psychosocial or intellectual disabilities.
Intellectual disability	A condition characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. Intellectual disability forms a subset within the larger universe of developmental disability, but the boundaries are often blurred as many individuals fall into both categories to differing degrees and for different reasons. <sup>7</sup> Examples of intellectual disability include Down Syndrome and some forms of cerebral palsy.
Legal capacity	The right of an individual to make his or her own choices about his or her life. <sup>8</sup> The concept of legal capacity encompasses the right to personhood, being recognized as a person before the law, and legal agency, the capacity to act and exercise those rights. <sup>9</sup>
Mental hospital	Refers to government hospitals (unless otherwise specified) that specifically treat persons with mental health conditions.
Psychosocial disability	The preferred term to describe persons with mental health conditions such as depression, bipolar disorder, schizophrenia, and catatonia. This term expresses the interaction between psychological differences and social or cultural limits for behavior, as well as the stigma that the society attaches to persons with mental impairments. <sup>10</sup>

<sup>6</sup> National Institute for Health and Care Excellence (NICE), "Guidance on the Use of Electroconvulsive Therapy (TA59) – The Technology," October 2009, http://publications.nice.org.uk/guidance-on-the-use-of-electroconvulsive-therapy-ta59/clinical-need-and-practice (accessed February, 12, 2014); ECT-team, Department of Psychiatry, National Institute of Mental Health and Neuro Sciences, *ECT Administration Manual*, 2nd edition, 2013, p. 47.

<sup>7</sup> Human Rights Watch, *Futures Stolen: Barriers to Education for Children with Disabilities in Nepal*, August 2011, http://www.hrw.org/sites/default/files/reports/nepalo811ForWebUpload.pdf.

<sup>8</sup> Committee on the Rights of Persons with Disabilities, "General Comment on Article 12: Equal Recognition before the law," April 11, 2014, http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en (accessed May 15, 2014), pp. 1, 3.

<sup>9</sup> International Disability Alliance, "Legal Opinion on Article 12 of CRPD," undated,

http://www.internationaldisabilityalliance.org/sites/disalliance.e-

presentaciones.net/files/public/files/LegalOpinionLetterArt12FINAL.doc (accessed June 1, 2014).

<sup>10</sup> World Network of Users and Survivors of Psychiatry, "Manual on Implementation of the Convention on the Rights of Persons with Disabilities," 2009, http://www.chrusp.org/home/resources (accessed December 20, 2013), p. 9.

# SUMMARY AND KEY RECOMMENDATIONS

HUMAN RIGHTS WATCH | DECEMBER 2014

# "Treated Worse than Animals"

Photographs by Shantha Rau Barriga/Human Rights Watch

The nurses would make us have the medications in front of them. If I complained that there were too many tablets, the nurse would sometimes forcefully put the pills in my mouth and stroke my throat to send them down, the way I feed my dogs....I woke up one night and I couldn't move; my body was in intense physical pain. A nurse came and jabbed an injection into my body, without even taking off my clothes. You are treated worse than animals; it's an alternate reality.

- Deepali, a 46-year-old woman with a perceived psychosocial disability, Delhi, August 25, 2013.

## I feel suffocated here. I don't like it here, it's a hospital. Will you take me home with you?

-Priya, a 22-year-old woman with an intellectual disability institutionalized against her will, to a Human Rights Watch researcher, June 13, 2013.

> Women with perceived or actual psychosocial disabilities sleep on the floor in the women's ward of Thane Mental Hospital, a 1857-bed facility in the suburbs of Mumbai. The close sleeping arrangements contribute to many women in the facility having lice.



A woman with a disability stands at the window of a night shelter run by Iswar Sankalpa, a Kolkata-based NGO, where women receive food, basic care, and access to voluntary treatment until they are ready to go back to their communities.



Vidya, a 45-year-old woman was alone at home in Mumbai one night a few years ago when three people knocked on her door. Posing as government health workers conducting vaccinations in the area, they ignored her attempts to resist them, sedated her, and took her away. The next morning, she awoke in a private mental hospital, where she was forced to stay against her will for over a month with virtually no contact with her family or friends and medicated against her will. Without her consent or knowledge, she was also forced to endure electricity passing through her brain in order to induce seizures, a process known as electroconvulsive therapy (ECT). "I was like a vegetable," she said. "It was only many years later that I found out that I was being given ECT."

Vidya is perceived as having a psychosocial disability, or mental health condition. She later discovered that her husband had institutionalized her, which he was able to do under the terms of the Mental Health Act without the need for a court order. Even after she was discharged from the mental hospital, her husband continued to take her to a local private clinic where she received electroconvulsive therapy under anesthesia without her knowledge or consent. Vidya claims that her husband wanted to label her as "insane" to be able to get a divorce without paying alimony. Her mother finally managed to get her discharged from the hospital over a month later.





A seclusion room in the Home for 'Mentally Retarded' Women, a government institution for people with intellectual disabilities in Bengaluru. Based on research in Delhi, Mumbai, Pune, Kolkata, Bengaluru, and Mysore, this report focuses on abuses against women and girls with psychosocial or intellectual disabilities in India. Between December 2012 and November 2014, Human Rights Watch visited 24 mental hospitals and state residential care facilities and interviewed over 200 women and girls with psychosocial or intellectual disabilities, their families, caretakers, mental health professionals, service providers, government officials, and members of the police.

The 2011 Census data estimates that only 2.21 percent of the Indian population has a disability – including 1.5 million people with intellectual disabilities and a mere 722,826 people with psychosocial disabilities. However, the Indian Ministry of Health and Family Welfare claims over 6-7 percent of the population has psychosocial disabilities alone. Yet just 0.06 percent of India's federal health budget is devoted to mental health and available data suggests that state spending is similarly negligible.

Available data suggests that at least 70 million Indians live with psychosocial disabilities and over 1.5 million have intellectual disabilities. Yet just 0.06 percent of India's federal health budget is devoted to mental health and available data suggests that state spending is similarly negligible.

Human Rights Watch found that stigma, the dearth of appropriate government community-based services, and a lack of awareness about disability and available services among family members and individuals with disabilities make those with psychosocial or intellectual disabilities especially vulnerable to institutionalization.

The prevalent mindset is that people with disabilities, particularly women and especially those with intellectual or psychosocial disabilities, are incapable, weak, and lack the capacity to make any meaningful decisions about their lives. Institutions to which they are sent are overcrowded and poorly managed: all women and girls with psychosocial or intellectual disabilities currently or formerly living in institutions interviewed by Human Rights Watch experienced forced institutionalization; most faced a range of abuses in institutional care, including neglect, physical or verbal abuse, and involuntary treatment.

For instance, Deepali, a 46-year-old mother of four, told Human Rights Watch that her family institutionalized her against her will in 2012, after she had a fight with her husband and eldest child— despite her medical file and a letter from her treating psychiatrist stating she did not have bipolar disorder and did not need medication or hospitalization.

Two bills currently before parliament, the Mental Health Bill and the Rights of Persons with Disabilities Bill, do not fully guarantee the rights of women with psychosocial or intellectual disabilities. Instead, they perpetuate institution-based care instead of shifting to a community-based model of services and support mandated by the disability rights treaty.

The government should ensure that the bills protect the rights of women and girls with psychosocial or intellectual disabilities and promote adequate and accessible voluntary community-based services, in full compliance with the Convention on the Rights of Persons with Disabilities (CRPD), which India ratified in 2007.

#### LACK OF GOVERNMENT SERVICES AND SUPPORT

Human Rights Watch found that there is a severe shortage of accessible and appropriate government services for women with psychosocial or intellectual disabilities and their families. Although women and girls with disabilities are technically included in healthcare, education, rehabilitation, and employment schemes that the government provides for all women and children, in reality they often lack meaningful access. There is also a gap in services, particularly gendersensitive health care, geared towards supporting women and girls with psychosocial or intellectual disabilities in their daily lives.

India's public health system faces an acute shortage of human resources, a fact reflected in the mental health sector. There are 43 state-run mental hospitals and three psychiatrists and 0.47 psychologists per million people in India. Although a number of private institutions have mushroomed across the country, they do not always have legal registration and are not adequately monitored.

The dearth of mental health services is particularly striking in rural areas where 72 percent of the population lives but only 25 percent of the health infrastructure is located, resulting in a severe treatment gap. Although the government launched the National Mental Health Programme in 1982 to provide community-based services, its reach is limited and implementation is seriously flawed in the absence of monitoring mechanisms. The District Mental Health Programme is only present in 123 of India's 650 districts and faces a number of issues including lack of accessibility, manpower, integration with primary healthcare services, and lack of standardized training.

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities provides multiple schemes and services, including health insurance, for persons with developmental or intellectual disabilities, but its scope and reach are limited. As a result, families lack awareness and support in their day-to-day lives. Unable to cope with caring for a relative with a psychosocial or intellectual disability, families often dump them in state mental hospitals or residential care institutions. Once in there, people with disabilities experience a range of abuses and even death.

Women with psychosocial disabilities sleep all day on the floor of the women's ward in Thane Mental Hospital. Women's hair is forcibly shaved or cut short due to rampant lice.







The electroshock therapy room in Thane Mental Hospital. On the bed lies the headpiece through which an electric current passes to the patient's brain in order to provoke a seizure.

#### FORCED INSTITUTIONALIZATION

Human Rights Watch interviewed 52 women and girls with psychosocial or intellectual disabilities who were in institutions at the time of the interview or formerly in institutions, all of whom were admitted without their consent. In several institutions visited, women and girls called out to Human Rights Watch researchers, "send me home" or "take me home with you."

In 25 cases documented across five cities, Human Rights Watch found families had hidden or abandoned their female relatives in mental hospitals or residential facilities due to stigma and the lack of support services available to them. In the case of psychosocial disability, the Mental Health Act allows a family member or guardian to admit a relative to an institution without their consent or any judicial review.

The police also pick up women and girls with psychosocial or intellectual disabilities found wandering on the streets if they have reason to believe they are "dangerous" to themselves or others, or incapable of taking care of themselves.

The women are then admitted to these institutions through court orders with no real possibility of appeal. They are unable to leave the institution and can be kept there for life if no family member comes to take them home.

In one of these cases, a woman who was declared "fit for discharge" in the 1990s was still in the institution as of August 2013 because of the lack of alternative settings for her.

Once in these closed institutional settings, women with psychosocial or intellectual disabilities have no say in what happens to them. Several Indian incapacity laws classify persons with psychosocial or intellectual disabilities as being of "unsound mind," stripping them of their legal capacity—the right to give consent or make decisions about one's life. Under the Mental Health Act, either a family member or guardian, including the head of a residential institution, is authorized to make decisions on their behalf.

A person with a psychosocial or intellectual disability may be deprived of the right to exercise legal capacity in India in three main ways: (1) if he or she is declared to be of "unsound mind" by a competent court; (2) if parents assume de facto guardianship following a medical diagnosis; or (3) upon a request made for guardianship to a committee set up by the Board of the National Trust, a body set up under the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999. Laws depriving legal capacity violate India's obligations under the Convention on the Rights of Persons with Disabilities (CRPD), which grants legal capacity to all persons with disabilities on equal basis with others.



A board outside the electroshock therapy room illustrates that 19 women were receiving electroshock therapy in Pune Mental Hospital, Maharashtra, on that day in June 2013. The head of the hospital told Human Rights Watch that in routine cases they do not take the patient's consent before administering ECT.

#### **CONDITIONS IN INSTITUTIONS**

Once they are in institutions, women with psychosocial or intellectual disabilities face a range of abuses, including prolonged detention, unsanitary conditions, neglect, involuntary treatment and violence.

Four of the government institutions for people with intellectual or psychosocial disabilities Human Rights Watch visited were exceptionally overcrowded, dirty and lacked adequate sanitation.

For example, as of November 2014, Asha Kiran or Avantika, a government institution for persons with intellectual disabilities in Delhi, is home to just under 900 people, nearly three times its capacity. At Pune Mental Hospital, Dr. Vilas Bhailume, the hospital's superintendent, told Human Rights Watch that there were just 25 working toilets for more than 1,850 patients. "Open defecation is the norm," he said. Researchers found that lice were rampant in most state-run institutions visited: during interviews at 10 government institutions, women and girls constantly pulled lice from their hair. Instead of providing medicated shampoos and improving hygiene, many women were forcibly shaved, further humiliating them. Ameena, a 40-year-old woman with schizophrenia described receiving soap just once a week, on a Friday. "We don't even get towels. We brush our teeth with tooth powder using our fingers. We change clothes every two days and have to stay naked while the laundry is being done," she said.

In three of the residential institutions visited, girls with psychosocial or intellectual disabilities were not given adequate access to education, even though India has passed the Right to Education Act that mandates free and compulsory education for all children between the ages of six and 14. Some girls with psychosocial or intellectual disabilities in two of these institutions attend non-formal education within the institution or at a local school. However, the curriculum is not adapted to their needs, limiting their learning.

As one member of the child welfare committee at an institution told Human Rights Watch: "We send children to Asha Kiran with a very heavy heart because we know whatever skills and socialization—shaking hands, basic conversation and tasks—they have learned here will go [away] in a couple of weeks."

Women with psychosocial or intellectual disabilities also do not have any meaningful activities to keep them engaged within institutions. Aparna, a woman with bipolar condition and epilepsy, told Human Rights Watch: "I have studied a little and can read a book if you give me one, but they don't give books here. Nothing happens here. You wander around, eat, drink, sleep, that's all."



A toilet in Pune Mental Hospital. With only 25 working toilets for 1,850 patients, open defecation is the norm.

#### FORCED TREATMENT AND DENIAL OF ADEQUATE AND APPROPRIATE HEALTHCARE

In many institutions that Human Rights Watch visited, women and girls with psychosocial or intellectual disabilities are routinely forced to take medication. The staff in these mental hospitals and residential care institutions openly shared with Human Rights Watch that they hold down women and girls with psychosocial disabilities or forcibly open their mouths to coerce them to comply with medication. If that fails to work, staff members told us that they routinely force-feed women food and drinks, such as bananas or tea, laced with medicines. Women can be given medication up to three times a day but they may not even know it.

Human Rights Watch documented cases of 20 women and 11 girls who had undergone electroconvulsive therapy (ECT)



without their consent. Some women, like Vidya, are not even informed that ECT is being administered. In a government hospital, a psychiatric nurse admitted that ECT was commonly used not only on violent and suicidal patients but also on new admissions who tend to be unmanageable. ECT is even used as a threat to coerce people to take their medicines or to scare them if they do not listen to staff. A nurse in a government mental hospital said:

They fear this (ECT). We say, 'if you don't take your medicine, we will take you to the ECT room' and immediately they say, 'please don't take me to that room, I won't do that again.'

In February 2013, the UN special rapporteur on torture called on all states to impose an absolute ban on forced electroconvulsive therapy.

Women and girls living in residential care institutions lack access to appropriate and adequate general healthcare. For even minor ailments, staff has to take women and girls with disabilities to the closest government hospital for treatment. And as a result of limited staff and vehicles, women or girls with disabilities requiring treatment in the institutions A board with a 'definition of mental retardation' displayed in Asha Kiran, a government institution for people with intellectual disabilities in Delhi. As of November 2014, Asha Kiran was home to close to 900 people—nearly three times its capacity.

Human Rights Watch visited are often denied adequate medical care for days.

Even when women and girls with psychosocial or intellectual disabilities are taken to general hospitals for treatment, they are often low on the priority list. According to Dr. Sanjeev Jain, professor of psychiatry and former head of the department of psychiatry at the National Institute of Mental Health and Neurosciences (NIMHANS):

Most government hospitals refuse to admit 'mentally ill' people in ICU [Intensive Care Unit] care. They ask: 'Why are you blocking a bed that could be put to better use?' This year, one of our patients died. She was diagnosed with breast cancer two or three years ago so we took her to a government hospital. The doctor there said, 'Please think if you would be adding anything to her life by giving her treatment.'

#### **VIOLENCE AND EXPLOITATION**

Human Rights Watch documented cases of women and girls who had faced physical, sexual and verbal abuse at the hands of caretakers in institutions, many of whom are not adequately trained. For example, staff use derogatory language such as "pagal" (mad) or "mentally retarded," perpetuating the social stigma against these women and girls. In 12 of the 24 institutions visited, residents or staff exploited women and girls with psychosocial or intellectual disabilities, forcing them to cook, clean toilets, or bathe other women with more severe disabilities.

In the course of its visits to institutions, Human Rights Watch found 12 cases of verbal, 38 of physical, and four of sexual violence against women and girls with psychosocial or intellectual disabilities. While physical and verbal abuse is an everyday occurrence in every state-run institution and mental hospital Human Rights Watch visited, sexual violence remains hidden as victims are less likely to talk about it.

A welfare officer at a residential care institution for women told Human Rights Watch:

Women have gone to [a hospital] for three months and have come back one month pregnant. It's happened in a lot of cases but when the woman can't say who got her pregnant, what can we do? We found out this because...the women undergo a check-up and mandatory urine pregnancy test [when they are re-admitted into the residential care facility].

#### LACK OF ACCESS TO JUSTICE

While access to justice continues to be a concern for many in India, particularly disadvantaged groups, women and girls with disabilities face unique barriers. Among the 128 cases of institutional abuse that Human Rights Watch documented, none of the women or girls had successfully filed a First Information Report (FIR) or accessed redress mechanisms for being institutionalized against their will or facing abuse within the institution. Most of the women and girls with psychosocial or intellectual disabilities interviewed were not even aware of mechanisms for redress.

One major factor that hinders their access to justice is dependency on caretakers. In the cases of the women and girls with intellectual or psychosocial disabilities documented by Human Rights Watch, many had been abused by family members or caretakers on whom they relied for financial or other support.

Women with psychosocial or intellectual disabilities told Human Rights Watch that they seldom report abuse against caretakers and fellow residents for fear of the repercussions. In the 24 institutions and hospitals Human Rights Watch visited in 2013, there were no adequate mechanisms to report abuse. The only existing mechanism in some institutions was to report abuse to the institution's staff, which does not constitute an independent mechanism, as staff themselves may be perpetrators of the abuse.

#### **THE WAY FORWARD**

One key concern is the lack of adequate monitoring of both state-run and private mental hospitals and residential care institutions for women with psychosocial or intellectual disabilities. It is essential that State Mental Health Authorities as well as independent bodies such as the National Human Rights Commission regularly monitor residential care institutions as well as community-based services such as the District Mental Health Programme to ensure quality of care and informed consent. States that have passed the Clinical Establishments (Registration and Regulation) Act (2010) can also leverage it to regulate and monitor mental hospitals.

Despite India's international obligations under the Convention on the Rights of Persons with Disabilities (CRPD), the rights of persons with psychosocial or intellectual disabilities, particularly women, continue to be restricted and violated. Under the treaty, this population has the right to access all services including education, health care, and rehabilitation on the same basis as others. The government is also required to provide access to the support they may need in exercising their legal capacity. However, India's courts continue to appoint guardians to take decisions related to financial, legal, and health care matters without the free and informed consent of people with psychosocial or intellectual disabilities.

Human Rights Watch calls on the Indian government to amend the bills currently before parliament to ensure that they are in full compliance with the CRPD and protect the rights of women and girls with psychosocial or intellectual disabilities. The government should adopt policies and mechanisms to prevent and redress abuses against women and girls with psychosocial or intellectual disabilities in institutions and develop adequate and accessible voluntary community-based mental health and support services. International donors should work with the Indian government to fund programs and appropriate services and provide technical assistance to such community-based services.

As Dr. Jain told Human Rights Watch:

Ultimately all the restrictions governing people who are not of sane mind need to go. They should be able to operate a bank account, get admission in college, have access to employment, be able to join the armed services, stand for election and even be the president of India. The government of India can't have laws that discriminate.



Posters on the wall of an out-patient community clinic in Delhi, sponsored by the state's district mental health program, give information on different mental health conditions.

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# **KEY RECOMMENDATIONS**

#### **TO THE CENTRAL GOVERNMENT**

#### FOR MENTAL HEALTH FACILITIES AND RESIDENTIAL CARE INSTITUTIONS

- Ensure the human rights of people with psychosocial or intellectual disabilities are respected by:
  - developing guidelines for sanitation, hygiene, and living conditions and prohibiting involuntary electroconvulsive therapy and arbitrary detention without judicial review.
  - developing and implementing guidelines that prioritize making the institutional environment accessible and making medical forms, particularly consent forms, available in local languages and in easy-to-read formats.
  - ensuring the central mental health authority has adequate funding and staff, meets regularly, and effectively monitors the work of state mental health authorities.

#### FOR LEGAL REFORM AND POLICY IMPLEMENTATION

- Create and implement a deinstitutionalization policy and a time-bound action plan for deinstitutionalization and prevention of further institutionalization for all persons with disabilities, based on the values of equality, independence, and inclusion for persons with disabilities.
- Ensure that this plan does not aim to transform existing institutions but is targeted towards progressively closing them down and developing a wide range of community-based alternatives that are rooted in the will and preference of the individual with a disability.
- Make sure that preventing institutionalization is an important part of this plan and that persons with disabilities, DPOs, and NGOs working on deinstitutionalization are invited to participate in the formation of this plan.
- Pass the Rights of Persons with Disabilities Bill, with the following amendments:
  - Instead of using a medical definition of disability, take a rights-based approach using the CRPD definition of disability, which views disability as a result of the interaction between persons with impairments and attitudinal and environmental barriers that hamper their full participation in society.
  - Recognize the legal capacity of all persons with disabilities on an equal basis with others and the right to exercise it. Remove clauses that allow for plenary or limited guardianship. Instead provide accommodations and access to support where necessary to exercise legal capacity.
  - Ensure a twin-track approach with regard to inclusion of women and girls with disabilities in the bill; in addition to covering them under general clauses, provide special protections for them through dedicated articles.
  - Include all persons with disabilities under the bill, including persons with psychosocial disabilities, instead of covering them under the mental health law.

- Only pass the Mental Health Care Bill after consulting with disabled persons' organizations and advocates representing persons with psychosocial disabilities and with at the very least the following amendments:
  - Recognize the legal capacity of all persons with disabilities on an equal basis with others and the right to exercise it. Remove clauses that allow for plenary or limited guardianship, "supported admission," and a "competency test" which could result in treatment without informed consent of the person concerned. Instead provide accommodations and access to support where necessary to exercise legal capacity.
  - Ensure that advance directives cannot be overruled by mental health professionals, caregivers, or family members. Ban all forms of involuntary treatment, including electro-convulsive therapy, without the person's free and informed consent.
  - Mandate a shift from institutional care to access to voluntary community-based mental health and other support services for people with psychosocial disabilities.
- Develop a time-bound plan to shift progressively towards providing access to voluntary community-based services for women and girls with intellectual or psychosocial disabilities, including adequate and appropriate education, mental health, and reproductive health services. Extend the district mental health program to all districts to ensure it has sufficient resources and trained staff. Support efforts by nongovernment organizations, including disabled persons' organizations, to provide community-based services for persons with psychosocial or intellectual disabilities.

#### **TO STATE GOVERNMENTS**

#### FOR MENTAL HEALTH FACILITIES AND RESIDENTIAL CARE INSTITUTIONS

- Immediately improve conditions in all mental hospitals and residential care institutions, including in the private sector, to ensure the human rights of people with psychosocial or intellectual disabilities are respected by:
  - developing guidelines for sanitation, hygiene, and living conditions and prohibiting arbitrary detention without judicial review and involuntary electroconvulsive therapy.
  - developing and implementing guidelines that prioritize making the institutional environment accessible and making medical forms, particularly consent forms, available in local languages and in easy-to-read formats.
  - create an independent complaint mechanism that can receive and investigate complaints, including on a confidential basis, about ill-treatment of persons with psychosocial or intellectual disabilities in institutions.
  - ensuring that the state mental health authorities are fully functional, adequately funded and staffed, and regularly and effectively monitor institutions for persons with disabilities and community mental health services, particularly district mental health programs.
- Progressively end institutionalization by ensuring that the Ministry of Health and Family Welfare, the Ministry of Social Justice and Empowerment, and the National Trust no longer provide funding for building new institutions or major refurbishments for existing institutions. Ensure that running, funding, and providing access to community-based services for persons with disabilities are top priorities.
- Create specific budget lines for community support programs and independent and supportive living arrangements for persons with disabilities, particularly psychosocial or intellectual disabilities.
- Integrate mental health into general healthcare services and train general practitioners to identify mental health conditions.
- In consultation with disabled persons' organizations, disability experts, and persons with disabilities themselves, develop adequate community-based rehabilitation services.
- Implement a time-bound plan to shift progressively towards providing access to voluntary community-based support and services, including for education, reproductive health, and mental health. Extend the district mental health program to all districts to ensure it has sufficient resources and trained staff. Support efforts by nongovernment organizations, including disabled persons' organizations, to provide community-based services for persons with psychosocial or intellectual disabilities.

#### TO NATIONAL AND STATE HUMAN RIGHTS COMMISSIONS, COMMISSIONS FOR WOMEN, AND COMMISSIONS FOR PROTECTION OF CHILD RIGHTS

• Ensure regular and periodic independent monitoring of conditions in residential care institutions for persons with psychosocial or intellectual disabilities, particularly women and children, and mental hospitals.

#### TO INTERNATIONAL DONORS, INCLUDING THE WORLD BANK, ASIAN DEVELOPMENT BANK, AND BILATERAL GOVERNMENT DONORS

- Encourage the Indian government to respect its international commitments to implement laws protecting rights of persons with disabilities, in line with the Convention on the Rights of Persons with Disabilities.
- Support the government of India and DPOs through funding and technical assistance to protect the rights of persons with disabilities, particularly women with disabilities and people with psychosocial or intellectual disabilities.
- Earmark financial and other forms of support and assistance toward support and community-based mental health services. Ensure these programs are gender-sensitive.

### Methodology

In India, research on disability or women has rarely focused on women and girls with psychosocial or intellectual disabilities living in institutions. This report attempts to fill this void.

Research was conducted from December 2012 to November 2014, based on field work by two Human Rights Watch researchers in four states across India: Delhi in the North, Karnataka in the South, Maharashtra in the West, and West Bengal in the East.

Implementation of disability and mental health laws and delivery of disability-related services is the responsibility of state governments. As a result, Human Rights Watch conducted the research for this report in four geographically diverse states with varying track records in service provision for women and girls with psychosocial or intellectual disabilities. We also selected these states because of the presence of strong local partners, particularly disabled persons' organizations.

The vast majority of service providers are located in urban India, so we chose to document the situation of women and girls with disabilities in metropolitan cities such as Delhi, Kolkata (West Bengal), Mumbai (Maharashtra), Pune (Maharashtra), Bengaluru (Karnataka), and Mysore (Karnataka). However, some cases reflect the situation in rural India since the women and girls living in institutions have often come from rural regions. Although the field research was primarily conducted in these states, we have included relevant data and information from other Indian states to illustrate that women and girls with psychosocial or intellectual disabilities experience abuses across the country.

Human Rights Watch research indicates that people with psychosocial or intellectual disabilities in rural areas often face abuse at the hands of spiritual and traditional healers for various reasons, including lack of awareness among family members, individuals with these disabilities, and the population at large, as well as the lack of community-based support and mental health services. However, such issues lie beyond the scope of this report. Researchers visited 24 mental hospitals or general hospitals with psychiatric beds, residential care facilities, including facilities registered with the National Trust (under the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999), and rehabilitation facilities. Human Rights Watch chose the institutions based on geographic diversity, type (mental hospital or government, NGO or privately-run residential care facilities), and suggestions by local disabled persons' organizations (DPOs) and other partners.

Facilities visited include the Institute of Human Behaviour and Allied Sciences (IHBAS), Asha Kiran (Avantika), Nari Niketan, Children's Home for Girls I & II, Maitrav Chhaya, Thane (Yerwada) Mental Hospital, Beggars' Home for Women-Chembur, Masina Hospital, Pune Mental Hospital, Lumbini Park Mental Hospital, Pavlov Mental Hospital, the National Institute of Mental Health and Neurosciences (NIMHANS), State Home for Women-Bangalore, "Home for Mentally Retarded Women"-Bangalore, and Manasa Kendra-Bangalore.

Human Rights Watch researchers were given a tour of each facility, and spoke to residents and staff. IHBAS and NIMHANS allowed us to speak to staff but not to persons with disabilities to protect their privacy and for reasons of confidentiality. Human Rights Watch was also unable to visit certain mental hospitals and homes because the ministry concerned either did not grant permission or the administrators did not authorize entry.

Human Rights Watch interviewed a total of 263 people for the report including 53 women and 15 girls with psychosocial or intellectual disabilities between the ages of nine and 80, 12 family members, 53 caregivers, 26 psychiatrists, 10 psychologists, three social workers, 26 nursing staff, 10 Child Welfare Committee members, and 5 police officers. Human Rights Watch also interviewed nine government officials, and 41 representatives of local nongovernmental organizations (including DPOs) and disability advocates. Of the women and girls with disabilities interviewed, 52 out of a total of 68 were current or former residents of institutions.

In addition to speaking directly to women and girls with disabilities, Human Rights Watch documented 128 cases of abuse based on interviews with family members, caregivers, and disability advocates.

While women with physical and sensory disabilities also experience abuse, Human Rights Watch has consciously chosen to focus on the specific types of violence and challenges experienced by women and girls with psychosocial or intellectual disabilities in institutions. This is because of their isolation and the common perception that they are weak or incapable, making them among the most marginalized people even within the disability community.

Men with psychosocial or intellectual disabilities in institutions may also face stigma and human rights abuses. However, this report focuses on the experience of women and girls with psychosocial or intellectual disabilities because of the gender-based discrimination and violence they often experience.

In this report, the word "girl" is used to refer to a female child, and "child" refers to anyone under the age of 18. The Convention on the Rights of the Child states, "For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier."<sup>11</sup> No single definition of a "child" currently exists under Indian law. However, the Juvenile Justice (Care and Protection of Children) Act of 2000 defines a child as "a person who has not completed eighteenth year of age" (article 2(k)), and a person is deemed to have reached "majority" on completion of 18 years under the Indian Majority Act of 1875 (article 3).

Human Rights Watch informed interviewees of the purpose of the interview and the manner in which the information would be used. No remuneration or incentives were promised or provided to people interviewed. The interviews were conducted, both in person and on the phone, in English, Hindi, Kannada, or in Bengali through an interpreter, who was either a member of a partner disabled persons' organization (DPO) or a disability rights advocate. All researchers and interpreters were women.

Women and girls with disabilities were asked for their consent prior to and multiple times during the interview and were informed they could decline to answer questions and end the interview at any time. Interviews were conducted on a voluntary basis, individually (except in cases where the woman or girl felt more comfortable being interviewed in a

<sup>&</sup>lt;sup>11</sup> Convention on the Rights of the Child (CRC), adopted November 20, 1989, G.A. Res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, India acceded to the CRC on December 11, 1992, art. 1.

group), and lasted between 30 minutes and 3 hours. When within institutions, interviews with women and girls with disabilities were conducted without the presence of staff and out of their hearing range. In order to respect confidentiality and protect the women and girls from reprisals from family or from staff in institutions, they have been assigned pseudonyms and all identifying information, such as location or date of interview, has been withheld. In a few cases, names of staff members working at mental health institutions have also been withheld to protect their identity.

Researchers made every effort to corroborate claims through direct observation, medical files, and interviews with other residents and staff. For some of the cases mentioned in the report, it was not possible to speak to the woman or girl with a psychosocial or intellectual disability directly or she herself was not aware of her diagnosis or treatment received, including in the case of electroconvulsive therapy. In such cases, Human Rights Watch compiled information through the examination of psychiatric records, medico-legal documents, accounts from health workers, family members or NGO representatives, and news articles, where relevant.

Human Rights Watch also consulted a number of international disability experts at different stages of the research and writing. Human Rights Watch reviewed relevant domestic and international media reports, official government documents and reports by state-run mental health facilities, United Nations documents, World Health Organization publications, NGO reports, and academic articles.

#### I. Background

There are no clear official government records or estimates of the prevalence of psychosocial or intellectual disabilities in India.<sup>12</sup> The 2011 Census estimates that only 2.21 percent of the Indian population has a disability – including 1.5 million people (0.1 percent of the population) with intellectual disabilities and a mere 722,826 people (0.05 percent of the population) with psychosocial disabilities (such as schizophrenia or bipolar condition).<sup>13</sup> These figures are strikingly lower than international estimates by the United Nations and World Health Organization which estimate that 15 percent of the world's population lives with a disability, which equates to roughly 187 million people in India. The Indian Ministry of Health and Family Welfare claims a much higher percentage of the Indian population is affected by psychosocial disabilities with 6-7 percent (74.2 - 86.5 million) affected by "mental disorders" and 1-2 percent (12.4 - 24.7 million) by "serious mental disorders."<sup>14</sup>

The disaggregation of data on persons with disabilities is limited to types of disabilities and gender but does not extend to other categories. For example, currently government surveys such as the National Family Health Survey or bodies such as the National Crimes

http://www.thehindu.com/news/national/census-reveals-only-marginal-increase-in-the-differentlyabled-

<sup>&</sup>lt;sup>12</sup> Estimates of the size of the population with disabilities in India differ greatly amongst sources. The lowest estimates come from the Census of India 2011, which has been criticized as inaccurate by several disability rights groups (Aarti Dhar, "Census Reveals Only Marginal Increase in the Differently-abled Population," *The Hindu*, December 30, 2013,

population/article5516279.ece (accessed January 3, 2014). The census claimed that about 1.5 million people (0.1 percent of the population) were found to have intellectual disabilities and a mere 722,826 people (0.05 percent of the population) had psychosocial disabilities. These figures are strikingly lower than the cited estimates from the Ministry of Health and Family Welfare. The Indian Ministry of Health claims much higher percentage of the Indian population is affected by psychosocial disabilities with 6-7 percent (74.2-86.5 million) affected by mental disorders and 1-2 percent (12.4-24.7 million) by serious mental disorders. See Office of the Registrar General & Census Commissioner, "Census of India 2011: Data on Disability," December 27, 2013, http://wadhwani-foundation.org/wp-content/themes/wadhwani-

new/img/ond/Disability\_2011\_Data\_Release\_Dec\_2013\_PPT\_%2827.12.13%29.ppt (accessed December 12, 2013); Press Information Bureau, Government of India, "Burden of Mental Disorders on the Rise; Committed to Provide Adequate Attention: Azad," February 15, 2011, http://www.pib.nic.in/newsite/erelease.aspx?relid=69858 (accessed December 12, 2013); Ministry of Health and Family Welfare, Government of India, "Annual Report to the People on Health," December 2011,

http://mohfw.nic.in/WriteReadData/l892s/6960144509Annual%20Report%20to%20the%20People%20on%20Health.pdf (accessed August 20, 2014), p. 33, Gary N. Siperstein, Keerthi Sugumaran, Jennifer Norins Bardon, and Robin C. Parker, "Attitudes of the Public in India towards People with Intellectual Disabilities," undated, http://media.specialolympics.org/soi/files/healthy-athletes/Research-Studies/India\_FullReport.pdf (accessed January 3, 2014).

<sup>&</sup>lt;sup>13</sup> Office of the Registrar General & Census Commissioner, India, "Presentation on Disability, Census of India 2011: Data on Disability," December 27, 2013, http://censusindia.gov.in/default.aspx (accessed January 5, 2014).

<sup>&</sup>lt;sup>14</sup> Press Information Bureau, Government of India, "Burden of Mental Disorders on the Rise; Committed to Provide Adequate Attention: Azad," February 15, 2011, http://www.pib.nic.in/newsite/erelease.aspx?relid=69858 (accessed December 12, 2013); Ministry of Health and Family Welfare, "Box 2.10," *Report of the National Commission on Macroeconomics and Health*, 2005, http://www.who.int/macrohealth/action/Report%200f%20the%20National%20Commission.pdf (accessed December 30, 2013), p. 65.

Record Bureau do not currently collect disaggregated disability-related information. In addition, official attempts to estimate the prevalence of psychosocial or intellectual disabilities in India resulted in wide variations because of different definitions of disabilities as well as underreporting due stigma and lack of awareness. The absence of accurate and disaggregated data represents a significant obstacle in providing adequate services for this neglected population.<sup>15</sup>

Statistics about psychosocial or intellectual disabilities in India, despite their divergences, all convey the same message: there is a major, unmet gap in support services, including mental health, reproductive health, and rehabilitation in India. Latest available data showed that only 0.06 percent of India's federal health budget is devoted to mental health and the only available data suggests that state spending is similarly negligible.<sup>16</sup>

Moreover, less than 20 percent of men and women as well as boys and girls who need mental health care have access to treatment.<sup>17</sup> Access to appropriate health care and services in India is severely limited due to shortage of human resources and inadequate infrastructure.

#### Inadequate Services and Support

According to the World Health Organization (WHO), more than 450 million people worldwide have psychosocial disabilities such as schizophrenia or bi-polar disorder and 75 percent of people with such disabilities in developing countries will not receive treatment.<sup>18</sup> One in four people will, at some point in their lives, be affected by a mental

<sup>&</sup>lt;sup>15</sup> In its 2004 situational analysis of women and girls in West Bengal, the National Commission for Women stated that the lack of "suitable data often becomes a major constraint in policy formulation for disadvantaged groups," including women with disabilities. Mukul Mukherjee, "A Situational Analysis of Women and Girls in West Bengal," National Commission for Women, 2004, http://ncw.nic.in/pdfReports/Gender\_Profile\_West\_Bengal.pdf (accessed January 8, 2014), p.106.

<sup>&</sup>lt;sup>16</sup> World Health Organization, "India - Country Profiles, Mental Health Atlas 2011," 2011,

http://www.who.int/mental\_health/evidence/atlas/profiles/ind\_mh\_profile.pdf (accessed December 13, 2013); Saju C. Mannarath, "Mental Health Financing in India, Basic Needs," 2009, http://basicneeds.org/download/PUB%20-%20Financing%20Mental%20Health%20Care%20in%20India%20-%20BasicNeeds%20Policy%20Study%202009.pdf (access December 17, 2013). World Health Organization and Ministry of Health Uttarkhand, "WHO-AIMS Report on Mental Health System in Uttarkhand, India," 2006, http://www.who.int/mental\_health/uttarkhand\_who\_aims\_report.pdf (accessed December 18, 2013).

 <sup>&</sup>lt;sup>17</sup> Professor Srinivasa Murthy et al., "Mental Health Care by Primary Doctors, 4th Edition," 2005, *National Institute of Mental Health and Neuro Sciences*, http://www.nimhans.kar.nic.in/dmhp/manuals/man1.pdf (accessed December 12, 2013), p.14.
 <sup>18</sup> World Health Organization. Flyer on Mental Health. 2012.

http://www.who.int/mental\_health/mental\_health\_flyer\_2012.pdf (accessed December 12, 2013).

health condition.<sup>19</sup> Every 40 seconds, someone commits suicide.<sup>20</sup> Yet, psychosocial or intellectual disabilities draw only limited state attention.<sup>21</sup>

Gender is a major factor in mental health conditions. Depression, which is the leading cause of disability and is expected to be the second largest cause of the global disease burden by 2020, is reported to be twice as common in women when compared to men.<sup>22</sup> Discrimination, gender-based violence, poverty, and the pressure of multiple roles are among the most cited vulnerability factors that contribute to poor mental health among women.<sup>23</sup>According to the WHO, given the high incidence of sexual violence they suffer, women are also disproportionately affected by Post Traumatic Stress Disorder (PTSD).<sup>24</sup>

The dearth of mental health professionals is a function of a larger human resource problem with which the public health system in India is grappling. The World Health Organization Mental Health Atlas 2011 shows that India has 3,643 psychiatrists for a population of over 1.2 billion; or 3 psychiatrists per million people<sup>25</sup>—far short of the Indian Council of Medical Research's recommendation of 10 psychiatrists per million people.<sup>26</sup>

Most psychiatrists work in the private sector, and their geographical distribution is uneven; they are concentrated in urban areas and disproportionately in southern states, leaving

<sup>19</sup> Ibid.

<sup>20</sup> Ibid.

<sup>&</sup>lt;sup>21</sup> World Health Organization and The World Bank, "World Report on Disability," 2011,

http://whqlibdoc.who.int/publications/2011/9789240685215\_eng.pdf (accessed December 10, 2013).

<sup>&</sup>lt;sup>22</sup> United Nations Expert Group Meeting on Mental Well-being, Disability and Development, "Conclusions and Recommendations for Inclusion of Mental Well-being and Disability into Key Goals and Outcomes of Upcoming International Conferences," May 2013, http://www.un.org/disabilities/documents/hlmdd/UNU\_EGM\_MWDD\_2013.pdf (accessed December 12, 2013); World Health Organization, "Mental Health: A Call for Action by World Health Ministers," 2001, http://www.who.int/mental\_health/advocacy/en/Call\_for\_Action\_MoH\_Intro.pdf (accessed December 19, 2013), p. 6.
<sup>23</sup> Ibid.

<sup>&</sup>lt;sup>24</sup> Department of Mental Health and Substance Dependence, World Health Organization, "Gender Disparities in Mental Health," undated, http://www.who.int/mental\_health/media/en/242.pdf (accessed December 17, 2013), p. 6; World Health Organization, "Gender and Women's Mental Health," undated,

http://www.who.int/mental\_health/prevention/genderwomen/en/ (accessed December 12, 2013).

<sup>&</sup>lt;sup>25</sup> Planning Commission of India, High Level Expert Group Report on Universal Health Coverage for India, November 2011, http://planningcommission.nic.in/reports/genrep/rep\_uhco812.pdf (accessed May 12, 2014), p. 19; World Health Organization, "India - Country Profiles, Mental Health Atlas,"

http://www.who.int/mental\_health/evidence/atlas/profiles/ind\_mh\_profile.pdf.

<sup>&</sup>lt;sup>26</sup> National Human Rights Commission, "Care and Treatment in Mental Health Institutions – Some Glimpses in the Recent Period," 2012, http://nhrc.nic.in/Documents/Publications/Care\_and\_Mental\_Health\_2012.pdf (accessed December 13, 2013), p.109.

segments of the country without a single mental health specialist.<sup>27</sup> In addition, there are only 0.47 psychologists per million people, instead of the recommended 15.<sup>28</sup> The scarcity of paramedical staff in general and in psychiatric care is even more acute.<sup>29</sup>

In addition, India lacks community-based mental health services. In 1982, India launched the National Mental Health Programme (NMHP) in order to guarantee minimum mental healthcare services for all, encourage the integration of mental and general healthcare, and support community participation in mental health service development. While the NMHP has been revised several times, its implementation is flawed. The absence of proper monitoring mechanisms and integration with state health systems has resulted in a lack of accountability, shortage of human resources, lack of standardized trainings, and the reluctance of states to take over funding.<sup>30</sup>

Although the NMHP's flagship intervention, the District Mental Health Programme (DMHP), was launched in 1996 to reduce stigma by integrating community mental health with primary health care (PHC) services, its success has been limited. The DMHP is only present in 123 of India's 650 districts and faces a number of issues including lack of accessibility, manpower, integration with PHC services, standardized training, coordination, and absence of monitoring.<sup>31</sup> Even when they have been set up, many State Mental Health

<sup>&</sup>lt;sup>27</sup> D. Nagaraja and Pratima Murthy (eds.), "Mental Health and Human Rights," *National Human Rights Commission and National Institute of Mental Health and Neuro Sciences*, 2008, http://www.bhrc.bih.nic.in/Docs/Mental-HealthCare-and-Human-Rights.pdf (accessed December 13, 2013), p.159; M. Thirunavukarasu and P. Thirunavukarasu, "Training and National Deficit of Psychiatrists in India – A Critical Analysis," *Indian Journal of Psychiatry*, 52 (2010): 83-88, accessed December 26, 2013, http://www.indianjpsychiatry.org/article.asp?issn=0019-

<sup>5545;</sup>year=2010;volume=52;issue=7;spage=83;epage=88;aulast=Thirunavukarasu.

<sup>&</sup>lt;sup>28</sup> World Health Organization, "India - Country Profiles, Mental Health Atlas,"

http://www.who.int/mental\_health/evidence/atlas/profiles/ind\_mh\_profile.pdf; S. P. Agarwal, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India, "Mental Health: An Indian Perspective 1946-2003," 2004, http://mhpolicy.files.wordpress.com/2011/05/mental-health-e-book\_published100ct20041.pdf (accessed January 4, 2014), p. 15.

<sup>&</sup>lt;sup>29</sup> "India Faces 50% Nursing Shortage," *Zee News*, March 29, 2012, http://zeenews.india.com/exclusive/india-faces-50nursing-shortage\_5462.html (accessed December 20, 2013); Human Rights Watch interview with Dr Sanjeev Jain, professor of psychiatry and former head of department, NIMHANS, Bengaluru, December 18, 2013.

<sup>&</sup>lt;sup>30</sup> The NMHP interventions such as the flagship District Mental Health Program (DMHP) are funded by the central government for the first five years after which states become responsible for funding the program. Ministry of Health and Family Welfare, Government of India, "Regional Workshops on National Mental Health Programme – A Report, 2011-2012,"

http://mohfw.nic.in/WriteReadData/l892s/ComprehensiveReport%20Part%201-78786581.pdf (accessed December 20, 2013), p. 6-7; Policy Group DMHP, "XIIth Plan District Mental Health Programme," June 29, 2013,

http://mhpolicy.files.wordpress.com/2012/07/final-dmhp-design-xii-plan2.pdf (accessed January 3, 2014).

<sup>&</sup>lt;sup>31</sup> Ministry of Health and Family Welfare, Government of India, "Regional Workshops on National Mental Health Programme – A Report, 2011-2012," http://mohfw.nic.in/WriteReadData/l892s/ComprehensiveReport%20Part%201-78786581.pdf (accessed December 20, 2013), p. 6-7; Policy Group DMHP, "XIIth Plan District Mental Health Programme,"
Authorities (SMHA) are dysfunctional and incapable of monitoring the DMHP. For example, the Maharashtra SMHA was set up in 1996 but failed to conduct even one meeting after 2006. "Retaining human resources is a challenge due to low salaries, high turnover of contractual staff, stigma and working conditions. Coordination between the mental health team and the general health system is also a challenge," explained Dr. Pankaj Kumar, assistant professor at the Department of Psychiatry at IHBAS and coordinator of the Delhi DMHP.<sup>32</sup> Furthermore, the DMHP continues to perpetrate a model focused almost exclusively on providing medication without effective follow-up, meaningful psychological support, and rehabilitation services.

According to leading advocate and founder of Bapu Trust for Research on Mind and Discourse, Bhargavi Davar:

[U]sually the state-run mental health models focus only on medication. Typically again the community mental health programme is a satellite of the larger institution that is present in a particular city or state.

While the DMHP is supposed to be staffed with a psychologist who provides counseling, due to unfilled vacancies certain DMHPs do not have a psychologist on staff. In addition, the conditions (i.e. short duration of DMHP hours, time spent per patient) do not allow for meaningful counseling or regular follow-ups.

An internal review conducted by the Indian Ministry of Health and Family Welfare found that only 25 percent of the 957 clients of the DMHP interviewed had access to counseling, clinical psychologists were employed in only 49 DMHP districts, and psychologists and social workers were performing administrative tasks instead of providing clinical support.<sup>33</sup> Although India's 12th five-year plan (2012-17) promises to fill in the gaps and re-energize the DMHP, its impact is yet to be felt.<sup>34</sup>

http://mhpolicy.files.wordpress.com/2012/07/final-dmhp-design-xii-plan2.pdf; Human Rights Watch Interview with Dr. Ajit Kumar Yadav, psychiatrist in a District Mental Health Programme team, Delhi, November 4, 8, and 9, 2013.

 <sup>&</sup>lt;sup>32</sup> Human Rights Watch interview with Dr. Pankaj, assistant professor in psychiatry, IHBAS, Delhi, October 23, 2013.
 <sup>33</sup> Policy Group DMHP, "XIIth Plan District Mental Health Programme," http://mhpolicy.files.wordpress.com/2012/07/final-dmhp-design-xii-plan2.pdf, p.8.

<sup>&</sup>lt;sup>34</sup> The Indian economy is based on five-year plans that determine how the country will allocate its resources and grow for the next five years. The Planning Commission of India develops and monitors the progress of the country's five-year plans. The commission formulated India's first five-year plan in 1951. Human Rights Watch interview with Dr. Ajit Kumar Yadav, psychiatrist in a District Mental Health Programme team, Delhi, November 4, 8, and 9, 2013; Human Rights Watch interview with Dr. S. Pandey, clinical

According to the Indian Ministry of Health, as of 2011, there are only 43 state-run mental hospitals across the country with a total capacity of 17,836 beds and an additional 10,000 psychiatric beds in general hospitals.<sup>35</sup> Most states have only one or two mental hospitals located in remote areas.<sup>36</sup>

The lack of mental health facilities is particularly serious in rural areas, where more than 72 percent of the Indian population resides,<sup>37</sup> but only 25 percent of the health infrastructure and mental health professionals are located.<sup>38</sup> In these conditions, a treatment gap is unavoidable. The lacuna in the mental health system reflects the problems with the Indian public health system. In addition, many of these facilities are dilapidated with buildings that are more than a 100 years old.<sup>39</sup>

In addition, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999), provides multiple schemes and services for persons with intellectual disabilities but their scope and reach is limited. For example, their Samarth scheme, launched in 2005, funds for a period of eight years residential care facilities (for both respite care and prolonged stay) that are free for adults with intellectual disabilities who are below the poverty line and children who are destitute.

After eight years, the Samarth centers are expected to become self-sufficient and fundraise from alternative government or private sources. Of the 119 Samarth centers across the country, only 55, catering to a total 1,397 people, received funding in 2012-2013.<sup>40</sup> The

hospitals/article4895586.ece (accessed December 29, 2013).

psychologist, District Mental Health Programme, Delhi, November 4, 2013; Human Rights Watch interview with Dr Pankaj Kumar, assistant professor, department of psychiatry at IHBAS, October 23, 2013.

<sup>&</sup>lt;sup>35</sup> World Health Organization, "India - Country Profiles, Mental Health Atlas,"

http://www.who.int/mental\_health/evidence/atlas/profiles/ind\_mh\_profile.pdf.

<sup>&</sup>lt;sup>36</sup> Professor Srinivasa Murthy et al., "Mental Health Care by Primary Doctors, 4th Edition,"

http://www.nimhans.kar.nic.in/dmhp/manuals/man1.pdf, p.5.

<sup>&</sup>lt;sup>37</sup> "Census of India 2011, Rural–Urban Distribution,"

http://www.censusindia.gov.in/(S(zkmkuuvoa3piyf55qily4szi))/Census\_Data\_2001/India\_at\_Glance/rural.aspx (accessed November 24, 2014).

<sup>&</sup>lt;sup>38</sup> Anant Kumar, "Mental Health Services in Rural India: Challenges and Prospects," *Health 3*, 12 (2011): 757, accessed December 20, 2013, doi:10.4236/health.2011.312126.

<sup>&</sup>lt;sup>39</sup> J. Venkatesan, "SC Issues Notice to States, Centre on Condition of Mental Hospitals," *The Hindu*, July 8, 2013, http://www.thehindu.com/news/national/sc-issues-notice-to-states-centre-on-condition-of-mental-

 <sup>&</sup>lt;sup>40</sup> National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities,
 "National Trust Annual Report 2012-2013," undated,

http://www.thenationaltrust.co.in/nt/images/stories/annual%20report%202012-13%20english.pdf (accessed February 16, 2014), p. 102.

quality of care across these (Samarth) homes can also vary significantly depending on which organization or association is running it.<sup>41</sup>

The National Trust also started a scheme called Gharaunda (Group Home and Rehabilitation Activities under National Trust Act for Disabled Adults) in 2008 to provide lifelong shelter and care. However, only 12 Gharaunda centers were planned and only four of these were functional as of 2013.<sup>42</sup> According to the National Trust, while there is a considerable demand for lifelong support and shelter, there is a serious lack of the infrastructure and support arrangements.<sup>43</sup> Finally, the National Trust's flagship scheme, Niramaya,<sup>44</sup> which provides health insurance specifically for people with intellectual disabilities, only has 125,245 people enrolled since its inception in 2008.<sup>45</sup>

Besides the infrastructure deficits, existing facilities and services are also underutilized. The current mental health and support services system is in itself a barrier to care-seeking behavior. The distance to mental health services and the cost of treatment are key deterrents to the utilization of care facilities. Statistical information on access to services for people with disabilities at a local level in India is hard to come by.

However, in a village survey carried out in Uttar Pradesh and Tamil Nadu in 2005, 20.5 percent of people with disabilities declared they were not able to access health facilities due to lack of transport and 70.5 percent stated that they could not afford services.<sup>46</sup> Furthermore, a review conducted by the Indian Council of Medical Research (ICMR) found that in order to access mental health treatment, more than half the patients had to travel more than five kilometers and nearly 40 percent were obliged to travel 10 km.<sup>47</sup> In addition, they incurred on average 43.5 rupees (less than US\$1) in transportation costs to the hospital.<sup>48</sup>

 <sup>&</sup>lt;sup>41</sup> Human Rights Watch interview with Poonam Natarajan, former chairperson, National Trust, Delhi, April 4, 2013.
 <sup>42</sup> National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, "National Trust Annual Report 2012-2013," http://www.thenationaltrust.co.in/nt/images/stories/annual%20report%202012-13%20english.pdf, p. 13.
 <sup>43</sup> Ibid.

<sup>&</sup>lt;sup>44</sup> The Niramaya scheme is designed to provide people with autism, cerebral palsy, intellectual disabilities, and multiple disabilities health insurance up to Rs. 1 lakh (US\$ 1,635) per year irrespective of age, severity of disability or pre-existing conditions.

<sup>&</sup>lt;sup>45</sup> Ibid., p. 16.

<sup>&</sup>lt;sup>46</sup> Human Development Unit, South Asia Region, World Bank, "People with Disabilities in India: From Commitments to Outcomes," July 2009, http://documents.worldbank.org/curated/en/2009/07/11027298/people-disabilities-indiacommitments-outcomes (accessed December 15, 2013), p. 48.

<sup>&</sup>lt;sup>47</sup> Policy Group DMHP, "XIIth Plan District Mental Health Programme," http://mhpolicy.files.wordpress.com/2012/07/finaldmhp-design-xii-plan2.pdf, p.9-10.

<sup>4&</sup>lt;sup>8</sup> Ibid.

Furthermore, Parivaar, a national confederation of over 230 parents' associations and NGOs working across India to empower persons with intellectual disabilities and their families, conducted a survey in 2011-12 in 58 districts across 10 Indian states and found that roughly 61 percent of people with intellectual disabilities did not have a disability identity card, a prerequisite to access subsidized or free government services for example aids and appliances, concessions on public transport, disability pension, scholarships or access to special schools, insurance schemes, legal aid, and job under reservations.<sup>49</sup> In addition, the disability card facilitates access to National Trust schemes for people with intellectual or developmental disabilities such as the Niramaya Insurance scheme. However the survey found that more than 72 percent were not able to obtain a Niramaya Health Insurance card, and 40 percent did not benefit from any services at all.<sup>50</sup>

People with psychosocial disabilities also face difficulty in obtaining a disability identity card as they are often confronted with administrative obstacles such as lack of documentation to prove identity, address, or disability.<sup>51</sup> Additionally, people with psychosocial disabilities face financial strain as private or public health insurance in India does not consistently cover treatment of mental health conditions.<sup>52</sup>

In India, protection, support and gender-sensitive services for women and girls with psychosocial or intellectual disabilities are largely absent.<sup>53</sup> Mita Banerjee, commissioner for persons with disabilities, government of West Bengal, said:

There are no specific programs for women with disabilities, only some homes for destitute women...Security of women with disabilities is the biggest challenge. Women with disabilities don't get support from their

<sup>&</sup>lt;sup>49</sup> Kartik Kashyap, "Trends of Utilization of Government Disability Benefits among Chronic Mentally Ill, 54 (2012): 54-58, accessed December 12, 2013, doi: 10.4103/0019-5545.94648.

<sup>&</sup>lt;sup>50</sup> Parivaar, *A Study on Understanding the Socio-Economic Status of Persons with Intellectual and Developmental Disabilities and their Families in India*, (Bangalore: Paarivaar, 2011-2012), pp. 1, 24-25.

 <sup>&</sup>lt;sup>51</sup> Human Rights Watch phone interview with Ratnaboli Ray, founder, Anjali: Mental Health Rights Organization, November 26, 2013.
 <sup>52</sup> D. Nagaraja and Pratima Murthy (eds.), "Mental Health and Human Rights," *National Human Rights Commission and National Institute of Mental Health and Neuro Sciences*, 2008, http://www.bhrc.bih.nic.in/Docs/Mental-HealthCare-and-Human-Rights.pdf, p.228.

<sup>&</sup>lt;sup>53</sup> Shampa Sengupta and Jeeja Ghosh, *Socialization of Women with Disabilities*, ActiodAid India – Kolkata Regional Office, September 2003; Human Rights Watch group interview with Mr. Venkatesh, Mrs. Kalapana, Vijay Kant, founding members, Karnataka Parents' Association of Mentally Retarded Children (KPAMRC), Bengaluru, April 1, 2013; Human Rights Watch interview with K.S. Rajanna, disability commissioner, Karnataka, Bengaluru, April 1, 2013; Human Rights Watch interview with G. Mohan, district disability welfare officer, government of Karnataka, Bengaluru, March 30, 2013.

families. They are deprived at home. We need to motivate parents who think they are a burden...There are also no special programs for abuses against women with disabilities.<sup>54</sup>

Furthermore, according to one study in Orissa, women with disabilities are less likely to seek care and services because of lack of awareness, negative past experiences as well as discriminatory provider attitudes.<sup>55</sup>

#### *New Mental Health Policy*

In October 2014, the Indian Ministry of Health unveiled its first ever mental health policy which sets as its primary goal to reduce the treatment gap by providing universal access to mental health care through increased funding and human resources. The policy draws attention to the paucity of data on mental health in India and the stigma, marginalization, and discrimination that people with psychosocial disabilities face. It recognizes the absence of "available, effective and affordable services" for persons with psychosocial disabilities and their families and how this can result in abandonment and homelessness.<sup>56</sup> The policy further acknowledges that "violation of their rights is a common reality for persons with mental health problems" and amongst others, singles out women, children, and persons living in custodial institutions as vulnerable populations.<sup>57</sup>

Some of the policy's most noteworthy features include amending or replacing laws or policies that discriminate against persons with psychosocial disabilities, providing wideranging support for families or caregivers, creating assisted living services, including persons with psychosocial disabilities in the design, implementation, and monitoring of mental health programs, and removing barriers to enable full participation of persons with

<sup>56</sup> Ministry of Health and Family Welfare, *National Mental Health Policy*, October 2014,

<sup>&</sup>lt;sup>54</sup> Human Rights Watch interview with Mita Bannerjee, commissioner for persons with disabilities, government of West Bengal, Kolkata, April 5, 2014.

<sup>&</sup>lt;sup>55</sup> Government of India, United Nations Development Program, Shanta Memorial Rehabilitation Centre, A Multi State Socio Economic Study of Women With Disabilities in India, 2007,

http://www.undp.org/content/dam/india/docs/a\_multi\_state\_socio\_economic\_study\_of\_\_with\_disabilities\_in\_india.pdf (accessed November 26, 2013), p. 56; Human Development Unit, South Asia Region, The World Bank, "People with Disabilities in India: From Commitments to Outcomes," July 2009,

http://documents.worldbank.org/curated/en/2009/07/11027298/people-disabilities-india-commitments-outcomes (accessed December 15, 2013), pp. xv, xvi.

http://www.mohfw.nic.in/index1.php?lang=1&level=2&sublinkid=4523&lid=2964 (accessed November 10, 2014). 57 lbid.

psychosocial disabilities in society including in the fields of education, housing, and employment. Despite several references to community-based services, the policy does not include an explicit call for deinstitutionalization nor a shift from institutional to community-based care. It also continues to refer to "mental illness", instead of the disability community's preferred language: "psychosocial disability". At time of writing, the policy had only just been published and it will be necessary to monitor its implementation over its first few years in order to make a full assessment of its impact.

# Loss of Legal Capacity and Lack of Support to Exercise it

Multiple pieces of legislation—most of which have origins in the colonial period—restrict the rights of people with psychosocial or intellectual disabilities in all areas of life simply on the grounds of their disability.<sup>58</sup>

Family laws, for example, deny capacity to marry, adopt, or inherit, for people of "unsound mind." The Registration Act does not allow organizations of people with "unsound mind" to register in order to defend their rights collectively, representing a critical barrier for persons with psychosocial disabilities seeking justice.<sup>59</sup>

Under section 14 of the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999), a Local Level Committee, a threemember body set up by the Board of the National Trust, is empowered to appoint legal guardians for persons with intellectual disabilities above 18.

The role of the guardian is to take care of the person with a disability and to take all legal decisions on their behalf, including with regard to property. The person with the disability is regarded as a minor before the law and is seen as being "unfit" to make decisions for themselves. The guardian's decision becomes binding on the person with the disability, even if it does not take into account their will, capacity, or preferences. The act also provides for limited guardianship for people with cerebral palsy and multiple disabilities, which allows for varying degrees of independence. A parent, sibling, relative, or voluntary

<sup>&</sup>lt;sup>58</sup> Bhargavi V. Davar, "Legal Frameworks for and against People with Psychosocial Disabilities," *Economic & Political Weekly*, 47 (2012):123-31, accessed February 5, 2014,

http://www.academia.edu/2457828/Legal\_frameworks\_for\_and\_against\_people\_with\_psychosocial\_disabilities; Human Rights Watch phone interview with Maitreyi Misra, research officer at Lawyers' Collective, June 26, 2014.

<sup>&</sup>lt;sup>59</sup> "Indian Registration Act, 1908," undated, http://lawcommissionofindia.nic.in/1-50/report34.pdf (accessed August 10, 2014).

organization working in the area of disabilities may apply for guardianship of the person with an intellectual disability.

Similarly, persons with psychosocial disabilities in India can also lose legal capacity once they are declared to be of "unsound mind" by a competent court. For example, section 23 of the Mental Health Act authorizes the police to pick up a person from the street "believe (d) to be so mentally ill as to be incapable of taking care of himself" or who is "believe(d) to be dangerous by reason of mental illness." After a medico-legal examination and a mental status examination by a psychiatrist, the police should produce the person before a magistrate within 24 hours. Based on the medical reports, the magistrate can issue a reception order for treatment at and admission to a mental hospital. After treatment, the person is either rehabilitated to his or her family if they can be traced or is sent to a state or NGO-run residential care home.

People with psychosocial disabilities can also lose their legal capacity in a de facto manner if a family member claims that they are of "unsound mind" based on a medical diagnosis. For example, under section 19 of the Mental Health Act (1987), family members and friends have the power to admit people to mental hospitals after examination by a medical officer in-charge and upon presentation of two medical certificates (including one from a medical practitioner in the service of the government). The person may be required to stay up to 90 days at a time, which can be extended with a magistrate's court order. In lieu of the presentation of two certificates, the medical officer in-charge can also require that two medical practitioners in the hospital examine the person.

In some cases involving children, institutionalization may be ordered by the local Child Welfare Committee (CWC).<sup>60</sup> The CWCs are established under the Juvenile Justice (Care and Protection of Children Act, 2000) to deal with cases of children in need of care and protection living in the community as well as in institutions. The CWC typically consists of one chairperson and four members who generally come from a social work background.

<sup>&</sup>lt;sup>60</sup> Under the Juvenile Justice (Care and Protection of Children) Act (2000), Child Welfare Committee (CWC) were set up across India to deal with cases of children in need of care and protection living in the community as well as institutions. The CWC typically consists of five members who collectively have the same powers as a bench of judicial magistrates. If a child is found wandering on the street or is rescued from exploitation, they are taken before a CWC that decides the best course of action. For details, see Juvenile Justice (Care and Protection of Children) Act, Act 56 of 2000, http://wcd.nic.in/childprot/jjact2000.pdf (accessed November 20, 2013).

Although the CWC may have no members with any formal legal qualification or experience, the CWC enjoys the power of a bench of judicial magistrates under the Juvenile Justice Act.

If a child is found wandering on the street or is rescued from exploitation, he or she is taken before a CWC, which decides the best course of action. The CWC normally takes a decision to place a child in a residential institution while the family is traced. If the child is perceived to have an intellectual or psychosocial disability, they may also be sent to a mental hospital or institution for children with intellectual disabilities. The child's will and preferences are not taken into account in function of his or her evolving capacity.

# India's Obligations

The Convention on the Rights of Persons with Disabilities (CRPD), which India ratified in 2007, challenges the inequality and discrimination inherent in laws that infantilize individuals with disabilities, particularly women.<sup>61</sup> Respect for inherent dignity, independence, individual autonomy including the freedom to make one's own choices, and non-discrimination are among the CRPD's core principles.<sup>62</sup>

The convention requires states to base all laws, policies and practices on the premise that people with disabilities have the same rights and equal recognition under the law as all others. The CRPD does not allow for any circumstances under which a person with a disability may be deprived of the right to recognition as a person before the law. According to the Committee on the Rights of Persons with Disabilities, the body of experts who monitor the implementation of the treaty, there is a distinction between mental capacity and legal capacity.

A person's mental capacity, the ability to make decisions, can vary depending on environmental or social factors; however, legal capacity is "a universal attribute inherent in all persons by virtue of their humanity" and can therefore not be stripped of it.<sup>63</sup> In its interpretation of the treaty provisions, the committee explained, "At all times, including during crisis situations, the individual autonomy and capacity of persons with

<sup>&</sup>lt;sup>61</sup> Convention on the Rights of Persons with Disabilities (CRPD), adopted December 13, 2006, G.A. Res. 61/106, Annex I, U.N. GAOR, 61st Sess., Supp. (No. 49) at 65, U.N. Doc. A/61/49 (2006), entered into force May 3, 2008.

<sup>62</sup> Ibid, art. 3.

<sup>&</sup>lt;sup>63</sup> UN Committee on Rights of Persons with Disabilities, General Comment No. 1, Equal Recognition before the Law, U.N. Doc. CRPD/C/4/2 (2014), para. 8.

disabilities to make decisions must be respected."<sup>64</sup> The state retains the right to restrict the legal capacity on an equal basis with others in specific situations such as bankruptcy or criminal conviction.

The CRPD also acknowledges that persons with disabilities may need support in exercising their rights. However, the need for support should not be a basis for removing the person's legal capacity.

The Committee on the Rights of Persons with Disabilities has repeatedly stated that state parties must "review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences."<sup>65</sup> The imposition, according to the committee, of substituted decisionmaking systems such as guardianship based on the medical diagnosis of a person, is discriminatory.

It is the state's obligation to provide support for persons with disabilities in exercising their legal capacity, including intensive forms of support. A person's unconventional mode of communication, at times understood by a select few, must not be a barrier to obtaining support in decision-making.<sup>66</sup> All forms of support must be based on the will and preference of the person and the person with a disability retains the right to refuse, end, or change the system of support at any time.

<sup>&</sup>lt;sup>64</sup> Ibid, para. 16.

<sup>&</sup>lt;sup>65</sup> Ibid, para. 22. Concluding observations: China - 27 Sept 2012, para. 32, Hungary, 27 Sept 2012, para. 26, Australia – 2-3 December 2013, para. 24-26, Austria (CRPD/C/AUT/CO/1), El Salvador (CRPD/C/SLV/CO/1), Peru (CRPD/C/PER/CO/1), Spain (CRPD/C/ESP/CO/1), Tunisia (CRPD/C/TUN/CO/1).

<sup>&</sup>lt;sup>66</sup> UN Committee on Rights of Persons with Disabilities, General Comment No. 1, Equal Recognition before the Law, U.N. Doc. CRPD/C/4/2 (2014), para. 25 (c).

# **II. Abuses in Institutions**

Most women and girls with psychosocial or intellectual disabilities currently or formerly living in institutions interviewed experienced a range of abuses including forced institutionalization and neglect, physical or verbal abuse, and involuntary treatment while in institutional care.

# Stigma and Discrimination

Most children are abandoned, either because they are severely disabled or for financial reasons. People have told me, 'Why are you spending so much on them? You should do a gun shot on them. They don't contribute; they're a burden on society.'

Madhuri Abhyankar, director of the Society for Friends of Sassoon
 Hospitals (SOFOSH), Pune, August 13, 2013.

In India, women and girls face multiple forms of discrimination based on their gender, age, marital status, caste, tribe, and disability. Women with psychosocial or intellectual disabilities are among the most stigmatized and marginalized, enduring stigma and discrimination in every sphere of life—personal, professional, and public.<sup>67</sup>

Even though there is a growing effort to replace demeaning terminology that was commonly used to describe people with intellectual disabilities, many people in India from family members, caretakers, mental health professionals, and some government officials and government documents continue to describe people with intellectual disabilities as "mentally retarded," a derogatory term which is often regarded as an insult. Similarly, people with psychosocial disabilities are dismissed as being "*pagal*" (mad) or "mental" which exacerbates the stigma and marginalization.

<sup>&</sup>lt;sup>67</sup> Human Rights Watch interview with Bhargavi Davar, advocate and director, Bapu Trust, Pune, February 15, 2014. Human Rights Watch group interview with Ratnaboli Ray, Sudeshna Basu, and Radha Debroy, founder and staff, Anjali Mental Health Organization, Kolkata, April 4, 2013; Human Rights Watch interview with Shampa Sengupta, advocate and director, Sruti Disability Rights Centre, Kolkata, April 3, 2013; Human Rights Watch interview with Vidya, woman with a psychosocial disability, Mumbai, August 15, 2013; Human Rights Watch group interview with seven mothers, names withheld, Mysore, March 31, 2013.

### Social Exclusion

While data disaggregated by disability is hard to come by, available evidence confirms that women and girls with disabilities often grow up in the confines of their home, excluded from social life, rarely attending school, getting married and having children, seeking employment, or participating in society.

A study in four districts of Gujarat found that people with disabilities were discouraged from attending weddings.<sup>68</sup> Another study in Orissa found that only 27 percent of women with intellectual disabilities leave their homes and 19 percent can take part in social activities.<sup>69</sup> Furthermore, only about one-third of women and girls interviewed had ever attended school prior to being admitted to institutions. These negative attitudes sideline women with psychosocial or intellectual disabilities, preventing them from discharging any societal roles to their full capacity and consigning them to social invisibility.

Families can find it challenging to take relatives with psychosocial or intellectual disabilities out for events or social occasions due to societal stigma and fear the person might say or do something to cause embarrassment.

Human Rights Watch interviews and newspaper reports and studies show that a lack of understanding of disability and mental health, especially in rural areas, can cause many people to believe that psychosocial or intellectual disabilities are a result of past sins, a curse, or possession by a spirit.<sup>70</sup> A mother of a 15-year-old girl with an intellectual disability told Human Rights Watch, "Even now, people say to me 'You are so nice, why did

<sup>&</sup>lt;sup>68</sup> UNNATI: Organisation for Development Education and Handicap International, "Understanding Disability: Attitude and Behaviour Change for Social Inclusion," 2004, http://www.unnati.org/pdfs/books/research-eng.pdf (accessed January 6, 2014), p. 2.

<sup>&</sup>lt;sup>69</sup> Dr. Sruti Mohapatra and Dr. Mihir Mohanty, "Abuse and Activity Limitation: A Study on Domestic Violence Against Disabled Women in Orissa, India," 2004,

http://swabhiman.org/userfiles/file/Abuse%20and%20Activity%20Limitation%20Study.pdf (accessed December 12, 2013), p. 10-11. <sup>70</sup> Human Rights Watch interview with Dr. S. Pandey, clinical psychologist, District Mental Health Programme, Delhi, November 4, 2013; Human Rights Watch Interview with Dr. Ajit Kumar Yadav, psychiatrist, District Mental Health Programme, Delhi, November 4, 8, and 9, 2013; Human Rights Watch phone interview with Gunjan Sharma, senior correspondent, *The Week*, November 5, 2013; Human Rights Watch phone interview with Dev Ankur Wadhavan, journalist, *Headlines Today*, November 6, 2013; Human Rights Watch interview with Dr. Vilas Bhailume, superintendent Pune Mental Hospital, Pune, June 12, 2013; Jugal Kishore, Avni Gupta, and Patrick Bantman, "Myths, Beliefs and Perceptions about Mental Disorders and Health-seeking Behavior in Delhi, India," *Indian Journal of Psychiatry*, 53 (2011): 324-329, accessed November 20, 2013, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3267344/. Bharathi Ghanashyam and Swaminathan Nagarathinam, "India is Failing the Mentally III as Abuses Continue," *The Lancet*, 376 (2010): 1633-1634, doi:10.1016/S0140-6736(10)62083-1; "Even Educated People Believe in Witches," *Times of India*, December 17, 2012, http://timesofindia.indiatimes.com/city/guwahati/Even-educated-people-believe-in-witches/articleshow/17650445.cms? (accessed February 15, 2014).

you get a child like this?"<sup>71</sup> These beliefs often lead people with psychosocial or intellectual disabilities and their families to seek medical advice only as a last-resort.<sup>72</sup>

Some mental health professionals told Human Rights Watch that that in many parts of rural India, visits to faith healers reinforce this misconception.<sup>73</sup> Dr. Vilas Bhailume, superintendent of India's largest mental hospital, said that "90-95 percent of patients come to us after first visiting faith healers in *dargahs* [shrine of a saint]."<sup>74</sup>

Human Rights Watch documented over 25 cases where families hid or abandoned female members with psychosocial or intellectual disabilities. A mother of a 32-year-old woman with an intellectual disability told Human Rights Watch how she has not told her extended family about her daughter's disability, "In our family, no one knows about her."<sup>75</sup> In one extreme case, the mother of a woman with schizophrenia even published a notice in a newspaper stating she had cut off all ties with her daughter in order to avoid taking custody of her daughter whom she left in an institution.<sup>76</sup>

#### Stigma in Institutions

Women and girls with psychosocial or intellectual disabilities also face stigma and discrimination within large-sized custodial institutions, virtually the only model of care available. These closed institutional settings further isolate women and girls with psychosocial or intellectual disabilities, making violence and abuses against them difficult to discover and report. Many such institutions restrict freedoms and mobility to such an extent that they are like prisons; most refer to their residents as "inmates."

In nearly half of the institutional settings visited, at least one or more staff members said that it was a waste of time to speak to women and girls with psychosocial or intellectual disabilities because they cannot communicate, their testimonies cannot be believed, or

<sup>&</sup>lt;sup>71</sup> Human Rights Watch with a mother, Mysore, details withheld.

<sup>7&</sup>lt;sup>2</sup> Professor Srinivasa Murthy et al., "Mental Health Care by Primary Doctors, 4th Edition,"

http://www.nimhans.kar.nic.in/dmhp/manuals/man1.pdf, p.14.

<sup>&</sup>lt;sup>73</sup> Human Rights Watch interview with Dr. Vilas Bhailume, superintendent Pune Mental Hospital, Pune, June 12, 2013; Human Rights Watch phone interview with Dr. Shiv Gautam, former superintendent Psychiatric Centre Jaipur and current head of Gautam Institute of Behavioral Sciences and Alternative Medicine, November 15, 2013.

<sup>&</sup>lt;sup>74</sup> Human Rights Watch interview with Dr. Vilas Bhailume, superintendent Pune Mental Hospital, Pune, June 12, 2013.

<sup>&</sup>lt;sup>75</sup> Human Rights Watch interview with a mother, Mysore, details withheld.

<sup>&</sup>lt;sup>76</sup> Human Rights Watch interview with staff nurse, detail withheld. Sarla, psychiatric records, details withheld.

simply because "they are mad and will say anything."<sup>77</sup> When asked about the marital status of pregnant women in a mental hospital, a staff nurse told us, "Nobody is going to marry someone with 'mental retardation', these are mostly abuse cases."<sup>78</sup>

In a government home in Delhi, a staff member explained that women with psychosocial or intellectual disabilities are barred from cooking or even entering the kitchen. She told Human Rights Watch:

The mental girls don't cook because the other girls refuse to eat food made by them. They say we won't eat food made by the hands of a 'mental' person. Also because they're not clean.<sup>79</sup>

In two residential care homes for women with psychosocial or intellectual disabilities and women without disabilities, Human Rights Watch researchers visited in Delhi and Maharashtra, these two groups were even spatially segregated. The women with disabilities were locked in a separate room or section of the facility, preventing them from accessing common areas and mingling with women without disabilities.<sup>80</sup> According to interviews with staff, this is in part due to attitudes that these women are considered "unmanageable" or "dirty."<sup>81</sup> In a government home, Parvati, a 30-year-old woman who has epilepsy, told Human Rights Watch:

I'm not friends with them [women with severe psychosocial or intellectual disabilities]. I feel sad. They only stay on their side and can't go to the other side; the door stays locked.<sup>82</sup>

A group of psychiatrists in Delhi told Human Rights Watch that the stigma attached to psychosocial disabilities extends to the mental health profession, which discourages doctors from specializing in psychiatry and causes many general physicians to resist

<sup>&</sup>lt;sup>77</sup> Human Rights Watch interview with caretaker, Mumbai, details withheld.

<sup>&</sup>lt;sup>78</sup> Human Rights Watch interview with staff nurse, name and details withheld.

<sup>&</sup>lt;sup>79</sup> Human Rights Watch interview with staff member, Delhi, details withheld.

<sup>&</sup>lt;sup>80</sup> Human Rights Watch interview with Shruti, Mumbai, details withheld.

<sup>&</sup>lt;sup>81</sup> Human Rights Watch interview with attendant, details withheld. Human Rights Watch interview with attendant, details withheld.

<sup>&</sup>lt;sup>82</sup> Human Rights Watch interview with Parvati, details withheld. Parvati does not identify herself as a woman with a disability.

mental health training.<sup>83</sup> This, they felt, contributed to India's acute shortage of mental health professionals. Mental health professionals from Delhi, Mumbai, and Pune consistently said that such stigma impeded recruiting and retaining staff.<sup>84</sup>

For example, one psychiatric nurse with nine years' experience working in a mental hospital in Pune told Human Rights Watch:

My job here makes my family tense; they worry about me. If I talk too loudly or I crack a joke that my family doesn't understand, they look at each other and say I have lost my mind working at a mental hospital. Even the bus driver looks at me strangely when I ask him to drop me off at the hospital every morning.<sup>85</sup>

A staff member who works at a night shelter for women said, "My sister is concerned that I won't get married because I work with mad people."<sup>86</sup>

In some cases, the physical location of a mental health facility or residential care institution next to a prison or tuberculosis sanitarium can aggravate the stigma for mental health professionals as these locations are often perceived as being "undesirable."<sup>87</sup>

# Lack of Alternatives to Institutionalization

The government offers few services in the community for women and girls with intellectual or psychosocial disabilities. Those that do exist, such as the District Mental Health Programme (DMHP), are extremely limited, short-staffed, lack resources, and suffer from

<sup>&</sup>lt;sup>83</sup> Human Rights Watch group interview with six psychiatrists, Delhi, details withheld.

<sup>&</sup>lt;sup>84</sup> Human Rights Watch interview with Dr. Pankaj Kumar, assistant professor, department of psychiatry at IHBAS, Delhi, October 23, 2013; Human Rights Watch group interview with six psychiatrists, Delhi, details withheld; Human Rights Watch interview with Dr. Ajit Kumar Yadav, psychiatrist, District Mental Health Programme, Delhi, November 4, 8, and 9, 2013; Human Rights Watch interview with Madhuri Abhyankar, director of the Society for Friends of Sassoon Hospitals (SOFOSH), Pune, August 13, 2013; Human Rights Watch interview with Dr. Shirsath, superintendent, Thane Mental Hospital, Mumbai, August 14, 2013.

<sup>&</sup>lt;sup>85</sup> Human Rights Watch interview with psychiatric nurse, Pune Mental Hospital, Pune, details withheld.

<sup>&</sup>lt;sup>86</sup> Human Rights Watch group interview with staff at a night shelter, Kolkata, April 3, 2013.

<sup>&</sup>lt;sup>87</sup> Human Rights Watch visit to Nirmal Chhaya Complex, Delhi, November 2013; Human Rights Watch visit to Home for Mentally Retarded Women, Bengaluru, March 30, 2013; Human Rights Watch interview with Syed Zahiruddin, office manager, head office, department for the differently abled and senior citizens, Bengaluru, March 30, 2013.

an absence of monitoring.<sup>88</sup> Furthermore, the DMHP's community outreach is limited and women in particular do not come forth.<sup>89</sup>

Six out of 12 parents of women and girls with psychosocial or intellectual disabilities interviewed by Human Rights Watch said that they lacked information on their child's disability and did not know of any government-sponsored community services to assist caregivers in their daily tasks and responsibilities in taking care of children with disabilities. According to Vibhas Shukla, member of PARIVAAR, "For mothers, how to handle children with disabilities is a trauma. We [members of PARIVAAR] try to stand by parents...to try to [develop] coping skills. It has always remained a problem."<sup>90</sup>

Parents from at least four different cities in India said they are obliged to turn to NGOs, start their own support groups, or become service providers themselves but even parentled initiatives such as the creation of special schools or vocational centers do not meet the need.<sup>91</sup>

Due to the absence of adequate and accessible government services in the community, families who find it challenging to cope with the demands of caring for a relative with a psychosocial or intellectual disability may have no choice but to admit the relative to mental hospitals or residential institutions or abandon them altogether.

As Dr. Rajendra Shirsath, superintendent of Thane Mental Hospital, a 1,857-bed facility in the suburbs of Mumbai, explained, "mental hospitals ae a dumping ground" for families trying to dispose of relatives with psychosocial disabilities whom they see as a burden.<sup>92</sup> An NGO worker at Anjali: Mental Health Rights Organization, echoed his description: "Mental hospitals are a dumping ground; not a place where you get well to go home."<sup>93</sup>

<sup>&</sup>lt;sup>88</sup> Human Rights Watch interview with Dr. Ajit Kumar Yadav, psychiatrist, District Mental Health Programme, New Delhi, November 4, 8, and 9, 2013.

<sup>&</sup>lt;sup>89</sup> Ibid.; Human Rights Watch interview with Dr. Pankaj, assistant professor in psychiatry, IHBAS, Delhi, October 23, 2013.
<sup>90</sup> Human Rights Watch group interview with Vibhas and Shukla, parents and members of MENTH (parents organization), Kolkata, April 4, 2013.

<sup>&</sup>lt;sup>91</sup> Human Rights Watch interview with anonymous [name and details withheld at request of person], Bengaluru, March 29, 2013; Human Rights Watch group interview with seven mothers, names withheld, Mysore, March 31, 2013; Human Rights Watch interview with Vasant Thakar, president, Savali, Pune, April 10, 2013; Human Rights Watch group interview with Vibhas and Shukla, parents and members of MENTH (parents organization), Kolkata, April 4, 2013.

 <sup>&</sup>lt;sup>92</sup> Human Rights Watch interview with Dr. Shirsath, superintendent, Thane Mental Hospital, Mumbai, August 14, 2013.
 <sup>93</sup> Human Rights Watch interview with Sudeshna Basu, staff member, Anjali: Mental Health Rights Organization, Kolkata, April 4, 2013.

Under the Convention on the Rights of Persons with Disabilities, however, governments are required to facilitate the inclusion and participation of persons with disabilities in the community by providing accessible schools, appropriate health care, rehabilitation, and independent living services.

Furthermore, the state has an obligation to ensure the right of persons with disabilities to make their own decisions, including where and with whom to live, and to facilitate this by providing adequate support in decision-making where necessary. All decisions should be based on the will and preferences of women or girls with disabilities.

### Abandonment in Institutions

Women and girls with psychosocial or intellectual disabilities are typically placed in three types of institutions for mental healthcare, shelter, or protection:

- 1) Mental hospitals;
- 2) Government or NGO-run residential care facilities; and
- 3) Short-term rehabilitation facilities.

Some government institutions are open to anyone, with or without a disability, who is found wandering on the street by the police (if they have reason to believe them to be "dangerous" or incapable of taking care of themselves) or is found to need shelter, care, or protection by a court.<sup>94</sup>

Other government or private institutions are specifically for people with intellectual disabilities such as Asha Kiran, a government institution, in Delhi, or the "Home for Mentally Retarded Women," another government institution in Bengaluru. In both government and private institutions that Human Rights Watch visited, men, women, boys and girls live in separate wards.

Mental hospitals are geared toward providing mental health care but also house people with intellectual disabilities if they also have a mental health condition. In some cases, a

<sup>&</sup>lt;sup>94</sup> The police are empowered to pick up people with psychosocial or intellectual disabilities and courts have the authority to institutionalize these people under the Mental Health Act (1987), the Bombay Prevention of Begging Act (1959), and the Juvenile Justice Act (2000).

person with an intellectual disability may recover from the mental health condition but can continue to stay in the mental hospital because they have nowhere else to go.<sup>95</sup>

Based on visits to six government institutions in five cities, Human Rights Watch researchers found that abandoning relatives at these [government] institutions and leaving false contact information was common practice.<sup>96</sup> A psychiatric nurse in a mental hospital in Pune explained:

We have patients from all over the country including Assam, Karnataka, Tamil Nadu, West Bengal, and Manipur. Relatives hear of a big mental hospital in Pune so they abandon these women by putting them on a train by themselves to Pune...Relatives just dump patients at the hospital and think that's it. They put fake addresses and phone numbers on the registration forms so we cannot contact them again. They give excuses such as they can't take care of the patient because of a wedding at home or because of their son's exams.<sup>97</sup>

Women and girls with psychosocial or intellectual disabilities are often institutionalized for unique gender-specific reasons. Staff at a night shelter in Kolkata city said families often prefer to leave their daughters with psychosocial or intellectual disabilities in the custody of an institution where they feel they are safe, out of fear that women with such disabilities may become easy targets for sexual violence if at home.<sup>98</sup>

Asha, a woman living with schizophrenia, told Human Rights Watch how she was first admitted to a mental hospital in 1981 when she was 18 years old: "Neighborhood people told my brother: 'She's young, wrong things will happen, so admit her in an institution.'"<sup>99</sup>

<sup>&</sup>lt;sup>95</sup> Human Rights Watch visit to Thane Mental Hospital, Mumbai, June 13, 2013; Human Rights Watch visit to IHBAS, Delhi, August 2013.

<sup>&</sup>lt;sup>96</sup> Human Rights Watch visit to Pune Mental Hospital, Pune, June 12, 2013; Human Rights Watch visit to Thane Mental Hospital, Mumbai, June 13, 2013; Human Rights Watch visit to IHBAS, Delhi, August 2013; Human Rights Watch visit to Nari Niketan at Nirmal Chhaya Complex, Delhi, November 11, 2013; Human Rights Watch visit to Lumbini Park Mental Hospital, Kolkata, May 5, 2013; Human Rights Watch interview with Sudeshna Basu, staff member, Anjali: Mental Health Rights Organization, Kolkata, April 4, 2013; Human Rights Watch interview with Dr. Reeti Chanchal Briswas, program director, Paripurnata: half-way home and Centre for Psychosocial Rehabilitation for Women, Kolkata, April 6, 2013; Human Rights Watch interview with Lakshmi, superintendent of Home for Mentally Retarded Women, Bengaluru, March 30, 2013.

<sup>&</sup>lt;sup>97</sup> Human Rights Watch interview with a psychiatric nurse, Pune Mental Hospital, Pune, June 12, 2013, name withheld.

<sup>&</sup>lt;sup>98</sup> Human Rights Watch group interview with staff at a night shelter, Kolkata, April 3, 2013.

<sup>&</sup>lt;sup>99</sup> Human Rights Watch interview with Asha, woman with a psychosocial disability, Bengaluru, August 20, 2013.

Children with intellectual disabilities who have been separated from their families, been abandoned, or whose parents have died, spend their lives first in children's institutional care and then, once they turn 18, in adult institutions.

Under the Juvenile Justice (Care and Protection of Children) Act (2000), children removed from the street, child labor, trafficking, or sex work, including children with disabilities, are placed in residential institutions by Child Welfare Committees (CWC) until their families are traced. However, in the case of girls with intellectual disabilities, the girl may not know or remember her name or home address. Kamla Lekhwani, chairperson of a Child Welfare Committee in Delhi, told Human Rights Watch:

We try to identify who are the parents. More than 50 percent of inmates are not able to speak and can't tell us their names.... Restoration should happen within four months for a child below 18 but it is technically not possible. Most children are abandoned intentionally and come here through the police. Some parents bring their children here [Asha Kiran].<sup>100</sup>

Human Rights Watch also found that, in some cases where girls or women with psychosocial or intellectual disabilities had sexual relationships out of wedlock, eloped, or were raped, their families chose to institutionalize the girl or woman for fear of shame and dishonor. For example, a social worker recounted the case of an 18-year-old woman living with a psychosocial disability, who was admitted to a mental hospital by her parents and brother "because of her behavior." She had run away from home two or three times, and eventually stayed with a male friend for a month. After she was found, her family refused to take her home for fear of shame and instead admitted her to a state-run mental hospital.<sup>101</sup>

### Involuntary Admission, Arbitrary Detention

All are forcibly committed in institutions by families...Once you get in, you don't get out.

Ratnaboli Ray, founder, Anjali: Mental Health Rights Organization,
 Kolkata, April 4, 2013.

 <sup>&</sup>lt;sup>100</sup> Human Rights Watch interview with Kamla Lekhwani, chairperson, CWC-5 at Asha Kiran Complex, Delhi, June 10, 2013.
 <sup>101</sup> Human Rights Watch interview with social workers, Pune, details withheld.

In 15 government and NGO-run institutions that Human Rights Watch visited, several women and girls with psychosocial or intellectual disabilities called out to Human Rights Watch researchers saying, "send me home" or "take me home with you," hoping that such a visit could help them get out of the institution.

Priya, a 22-year-old woman with an intellectual disability, was institutionalized in a staterun mental hospital by her mother for nearly two years from 2010 to 2012. When Human Rights Watch met her in July 2013, she had been institutionalized again against her will for three months after being diagnosed with psychosis and she told Human Rights Watch, "I feel suffocated here. I don't like it here, it's a hospital. Will you take me home with you?"<sup>102</sup>

Under section 19 of the Mental Health Act, which regulates the admission of "mentally ill persons under special circumstances," the patient's consent is considered irrelevant because of the perception that people with psychosocial or intellectual disabilities are not in a mental state to make the decision to seek treatment or shelter. Instead, relatives or a friend can commit a person to an institution against their will if the medical-officer-in-charge is convinced it is in the person's interest. Since the person with a psychosocial disability is perceived as lacking capacity, staff in mental hospitals characterizes admission by a family member or friend by the misnomer "voluntary admission." As a psychiatric nurse confirmed:

Voluntary admission is up to the relatives; the patient is not in a position to decide. Patients are brought to the hospital by relatives because they do not want to take care of them. The relatives sign the hospital admission forms (not the patient).<sup>103</sup>

Under section 49 of the Mental Health Act, a person has the right to appeal any order by a magistrate passed under the act to the District Court within sixty days. However, in none of the 52 cases of women and girls committed to institutions documented by Human Rights Watch was the woman or girl informed of her right to appeal or provided the opportunity or assistance to do so. When a woman is admitted to an institution under a court order

<sup>&</sup>lt;sup>102</sup> Human Rights Watch interview with Priya, details withheld.

<sup>&</sup>lt;sup>103</sup> Human Rights Watch group interview with a psychiatric sister and auxiliary midwife nurse (ANM), Pune Mental Hospital, Pune, June 12, 2013.

sought by the police, she is often seen as lacking capacity and is not given access to legal aid, although she is entitled to it. Moreover, based on interviews in five cities, Human Rights Watch found that in practice, the woman is not even given access to a lawyer.<sup>104</sup>

Vidya, an articulate 45-year-old woman, recounted how she was abducted from her home and forcibly institutionalized for over a month in a private mental hospital in 2004:

My husband had taken out my two children to buy them chocolates. At around 10:30 pm, the doorbell rang. A doctor, a nurse, and a ward boy came and said they had to give compulsory vaccinations for malaria to everyone in the building on behalf of a government body. I told them I was a naturopath and didn't believe in vaccines but they insisted that they couldn't leave anybody out. Somehow they convinced me to let them come in and before I knew it, they injected me with something that made me drowsy. The last thing I remember is being dragged out of the house and my head falling on the nurse's shoulder in the lift. The next morning when I got up, I saw barbed wired windows and wondered where I was. Everyone else was very dazed. Another lady in the ward told me 'This is the psychiatric ward at [private mental hospital, name withheld] Hospital.' I couldn't get out, I couldn't make any phone calls, and nobody came to visit me. I was just like a prisoner with no way out. Later I found out that my husband had planned it all. My mother finally got me out over a month later.

Vidya's husband signed her admission form and at no point was she brought before a magistrate or allowed to appeal her institutionalization.<sup>105</sup> Vidya claims that her husband wanted to label her as "insane" to be able to get an easy divorce without paying alimony. In 2007, her husband initiated divorce proceedings on grounds of cruelty and "mental illness." The court had recently ruled in Vidya's favor, denying her husband the divorce stating that there is no proof of "mental illness" and no grounds for cruelty.

<sup>&</sup>lt;sup>104</sup> The right to legal assistance is provided by sections 91, 181 and 182 of the Mental Health Act (1987). Section 74 of the Legal Services Authorities Act (1987) ensures legal aid to "e very person who has to file or defend a case," including persons with disabilities.

<sup>&</sup>lt;sup>105</sup> Human Rights Watch interview with Vidya, woman with a psychosocial disability, Mumbai, August 15, 2013.

Deepali, a 46-year-old woman who is perceived as having a psychosocial disability and mother of four, had a similar experience. Under stress following the collapse of her management consultancy business, Deepali was also trying to raise her children on her own while her husband travelled for work. Shortly after the birth of her third child, her husband started abusing her sexually. When she could not make her marriage work any longer, she tried to leave her husband but her parents did not support her. In 2007, when her husband contracted dengue fever, she had a panic attack in the hospital and was forcibly picked up by the police and taken to a mental hospital in Delhi.

Ten male and female cops surrounded me, started kicking me against my shin with their boots and they were laughing when they pushed me into the police van. They took my phone and purse and wouldn't tell me why I was being picked up...I later found out that my father had got my husband to sign my commitment papers... They kept me sedated for two weeks. I felt like a zombie. I used to drool, my hand would shake because of the sodium valporate [medication to treat bi-polar disorder]. The psychiatrist would ask me every day, "Do you feel guilty?" By the fortieth day, I said, 'Yes, yes' because I just wanted to go home. My story was shown on TV and somebody mentioned 'possible bi-polar;' since then the label has stuck although there was no conclusive testing.<sup>106</sup>

Deepali was subsequently institutionalized by her family against her will in 2012, although she had her medical file and a letter from her treating psychiatrist stating she did not have the diagnosis of bi-polar disorder and did not need to be on medication or hospitalized.

Deepali was finally released after a campaign by disability advocates. During her stay in the institution, Deepali's husband filed for divorce on grounds of "unsoundness of mind" and moved to the United States with their children. Although there is a court order in Deepali's favor stating that her husband must bring their youngest son back to India, she is still unable to see him.

In Asha Kiran, a government institution in Delhi intended exclusively for people with intellectual disabilities, Human Rights Watch found a few women and girls who had no

<sup>&</sup>lt;sup>106</sup> Human Rights Watch interview with Deepali, woman with psychosocial disability, Delhi, August 25, 2013.

such disability but instead had hearing or speech disabilities. Because no special educator or sign language interpreter is present to facilitate communication, the women are automatically classified as having an intellectual disability by the police and subsequently during an Intelligence Quotient (IQ) test administered at the institution or a mental hospital.

Kamla Lekhwani, chairperson of the Child Welfare Committee in Delhi, which oversees the Asha Kiran Complex explained: "Those who are deaf and dumb/hearing and speech impaired are also being labeled as 'mentally challenged'. The criterion for admitting someone is an IQ of 40-50 or below."<sup>107</sup>

Article 14 of the CRPD prohibits unlawful or arbitrary detention and categorically declares that the existence of a disability cannot be used as a justification for the deprivation of liberty. In her 2012 report on violence against women with disabilities, the UN special rapporteur on violence against women, Rashida Manjoo, denounced forced institutionalization as a form of violence.<sup>108</sup> The UN special rapporteur on torture, Juan Mendez, also stated that:

[A]s detention in a psychiatric context may lead to nonconsensual treatment, the mandate has stated that deprivation of liberty based on the grounds of a disability and that inflicts severe pain or suffering could fall under the scope of the Convention against Torture.<sup>109</sup>

#### Prolonged and Arbitrary Detention

When women and girls with psychosocial or intellectual disabilities are admitted to residential care facilities or mental hospitals, they may remain there for years, often with little judicial oversight.

<sup>108</sup> UN Commission on Human Rights, Report of the Special Rapporteur on Violence against Women, Rashida Manjoo, Report of the Special Rapporteur on violence against women, its causes and consequences, A/67/227, August 3, 2012, http://www.ohchr.org/Documents/Issues/Women/A.67.227.pdf (accessed December 10, 2013), para. 38.

<sup>&</sup>lt;sup>107</sup> Human Rights Watch interview with Kamla Lekhwani, chairperson, CWC-5 at Asha Kiran Complex, Delhi, June 10, 2013.

<sup>&</sup>lt;sup>109</sup> Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53, February 1, 2013,

http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\_English.pdf (accessed December 28, 2013).

For example, in Pavlov Mental Hospital, the majority of adults are committed for five to ten years.<sup>110</sup>In the case of multiple long-stay patients in another mental hospital, Human Rights Watch found seven cases in which court orders had expired many years before yet the adults were being kept at the mental hospital.<sup>111</sup>

In two of these cases, the original court orders admitting people to mental hospitals ("reception orders") had been lost.<sup>112</sup> In another two of these cases, women were admitted to the mental hospital under the Indian Lunacy Act (1912), which was repealed in 1987, but had not been allowed to challenge their detention because they were not brought before a magistrate. Although both women's files said: "obtain reception order, conversion from Indian Lunacy Act sections to Mental Health Act sections," Human Rights Watch could not determine any steps that have been taken by the institution to address the situation.<sup>113</sup> In one of these cases, a woman declared "fit for discharge" in the 1990s was still in the institution as of August 2013 because of the lack of alternative settings for her.<sup>114</sup>

In at least five residential care institutions and closed wards of mental hospitals of the 24 institutions that Human Rights Watch visited, women and girls, including those with disabilities are rarely allowed to leave the immediate premises of the institution or even take a walk in the larger complex, mainly because staff fear that they will try to escape.<sup>115</sup>The only exception, in residential facilities for girls, is that school-going girls can leave for school once a day, accompanied by staff.

 <sup>&</sup>lt;sup>110</sup> Human Rights Watch interview with Dr. Raghabesh Majumdar, superintendent, Pavlov Mental Hospital, Kolkata, April 4, 2013.
 <sup>111</sup> Human Rights Watch interview with staff nurse, details withheld; Veena, psychiatric records, details withheld; Geeta, psychiatric records, details withheld; Sarla, psychiatric records, details withheld.

<sup>&</sup>lt;sup>112</sup> Human Rights Watch interview with staff nurse, details withheld; Padmini, psychiatric records, details withheld; Roopa, psychiatric records, details withheld.

<sup>&</sup>lt;sup>113</sup>Human Rights Watch interview with staff nurse, details withheld; Sonali, psychiatric records, details withheld; Tara, psychiatric records, details withheld.

<sup>&</sup>lt;sup>114</sup> Human Rights interview with staff nurse, details withheld; Aditi, psychiatric records, details withheld. Sonali, psychiatric records, details withheld.

<sup>&</sup>lt;sup>115</sup> Mental hospitals in India often have three types of wards: closed, semi-closed, and open wards. Patients in open wards are typically free to enter and leave the ward as they please and family members can be permitted to stay with them. In semiclosed wards, the doors to the wards are usually left open although the freedom of movement of its residents can be restricted and family members may visit regularly but not always stay with the patients. In closed wards, the doors are kept locked at all times, patients are not allowed to leave the ward except if it is to receive treatment in another wing of the hospital/in a general hospital or on very rare occasions such as an organized outing. Visitors need special permission to visit members in a closed ward and may do so only certain times a week. Human Rights Watch interview with welfare officer, Nari Niketan at Nirmal Chhaya Complex, Delhi, November 10, 2013; Human Rights Watch interview with staff nurse, IHBAS, Delhi, August 2013; Human Rights Watch interview with Sadaf, welfare officer, Children's Home for Girls I at Nirmal Chhaya Complex, Delhi, November 4, 2013; Human Rights Watch group interviews with Archita Sobta, Pradeep Kaur Grewal and Jyoti Singh, psychologists at Manas Foundation, Delhi, November 2013.

# **Conditions of Confinement**

We need to do something about closing down these institutions [residential care facilities]. Dismantle this structure, find places for these children. —Poonam Natarajan, former chairperson of the National Trust, Delhi, April 4, 2013.<sup>116</sup>

### Overcrowding, Poor Sanitation and Hygiene

Due to the severe shortage of facilities for people with psychosocial or intellectual disabilities, the existing model is one of large-scale institutions that are difficult to maintain and manage.

For example, Pune Mental Hospital (also known as Yerawada Mental Hospital), reputedly the biggest government-run hospital in Asia, has 1,864 patients spread across 74 acres.<sup>117</sup> Built during British colonial rule, the 100-year-old infrastructure and wastewater drainage system can no longer tolerate the burden of its massive population. According to Dr. Vilas Bhailume, the hospital's superintendent, there are only 25 functional toilets for more than, 1,850 patients. "Open defecation is the norm," he said.

For people who are not always in control of their bowel movements, this is particularly distressing and poses a serious health risk given that many women and girls in the hospital walk around barefoot. In 12 mental hospitals or institutions visited, Human Rights Watch researchers witnessed fly-infested toilets overflowing with feces. The nauseating stench permeated the adjoining wards.

Overcrowding is another serious problem in some institutions.<sup>118</sup> As of November 2014, Asha Kiran or Avantika in Delhi is home to 891 people, close to three times its capacity.<sup>119</sup> Activists have been drawing attention to the appalling conditions in Asha Kiran since 1990 and calling for it to be shut down, but progress has been limited.<sup>120</sup>

<sup>&</sup>lt;sup>116</sup> Human Rights Watch interview with Poonam Natarajan, former chairperson, National Trust, Delhi, April 4, 2013.

<sup>&</sup>lt;sup>117</sup> Human Rights Watch interview with Dr Vilas Bhailume, superintendent Pune Mental Hospital, Pune, June 12, 2013.
<sup>118</sup> Human Rights Watch visit to Chembur Beggars Home, Mumbai, August 16, 2013.

<sup>&</sup>lt;sup>119</sup> Human Rights Watch phone interview with Rachna Bharadwaj, superintendent female wing, Asha Kiran Complex, Delhi, November 11, 2014.

<sup>&</sup>lt;sup>120</sup> Ambika Pandit and Abhinav Garg, "Need to Monitor Asha Kiran," *Times of India*, July 25, 2012,

http://timesofindia.indiatimes.com/city/delhi/Need-to-monitor-Asha-Kiran/articleshow/15133692.cms (accessed February

A recent Right to Information request by a social activist revealed that there had 24 deaths in approximately 6 months in 2014 (between February 1 and August 15) and 131 deaths from 2009-2013 at Asha Kiran.<sup>121</sup> Even the Delhi government has acknowledged that the mortality at Asha Kiran is higher than at other institutions in the city.<sup>122</sup> The National Commission for the Protection of Child Rights (NCPCR) has stated that the reason for the deaths is negligence.<sup>123</sup> An expert on institutions for people with intellectual disabilities in India said, "Seeing the state that children are in is absolutely shocking. Places shouldn't be like Asha Kiran."<sup>124</sup>

Part of the problem is that Asha Kiran is specifically named in Delhi's CWC guidelines as the first and primary place to send children with intellectual disabilities who are picked up from the streets or abandoned by their families.<sup>125</sup> B. C. Hessa, superintendent of the male wing at Asha Kiran, told Human Rights Watch, "We have no option; if the court or CWC issues an order, then the government can't refuse to take the children."<sup>126</sup>

Overcrowding in turn puts a strain on staff and resources. Residents' personal hygiene suffers due to staff neglect, water shortages, and congested living quarters.

Ambika's daughter was put in an institution for people with intellectual disabilities after the police found her on the side of a highway. She told Human Rights Watch:

<sup>123</sup> Harish V Nair, "At Asha Kiran, 228 Inmates have Died Since 2005," *Hindustan Times*, August 30, 2012, http://www.hindustantimes.com/india-news/newdelhi/at-asha-kiran-228-inmates-have-died-since-2005/article1-922086.aspx (accessed January 28, 2014).

<sup>25, 2014);</sup> Human Rights Watch interview with Rajiv Raturi, director of disability rights at Human Rights Law Network, Delhi, October 4, 2013.

 <sup>&</sup>lt;sup>121</sup> Human Rights Watch phone interview with Rajhans Bansal, right to information activist, November 11, 2014. Heena Kausar,
 "Delhi Mental Home Witnesses a Death Every week Due to Govt Apathy," *Mail Today*, September 24, 2014,

http://indiatoday.intoday.in/story/delhi-mental-home-death-asha-kiran-centre-rohini-sector-1-kiran-walia-mangat-ramsinghal/1/384725.html (accessed September 25, 2014).

<sup>&</sup>lt;sup>122</sup> Utkarsh Anand, "More Residents Die at Asha Kiran than Other Homes: Govt," *Indian Express*, March 21, 2012, http://archive.indianexpress.com/news/more-residents-die-at-asha-kiran-than-other-homes-govt/926227/ (accessed February 20, 2014).

<sup>&</sup>lt;sup>124</sup> Human Rights Watch interview with expert, details withheld.

<sup>&</sup>lt;sup>125</sup> Delhi Child Welfare Committee Guidelines state, "In case a woman is admitted in the shelter home is found mentally retarded in by the medical professionals of government hospital, then she will be transferred to Asha Kiran or any other specialised home for such patients."

<sup>&</sup>lt;sup>126</sup> Human Rights Watch interview with B. C. Hessa, superintendent of the male wing, Asha Kiran Complex, Delhi, June 10, 2013.

In that home, they keep people like cows, herd them like cows.<sup>127</sup>

As a consequence of sleeping close together on the floor or sharing beds, most women that Human Rights Watch spoke to complained that they had lice. During interviews with Human Rights Watch at 10 government institutions, women and girls constantly pulled out lice from their hair. Rakhi, a 19-year-old living in a residential care facility for women told us: "Everyone has lice."<sup>128</sup> Instead of providing an anti-lice shampoo, staff simply forcibly shave women's heads, further undermining their dignity.<sup>129</sup>

Ameena, a 40-year-old woman with schizophrenia, finds it hard to adjust to the lack of hygiene in the mental hospital where she is admitted. She told us:

They only give us soap on Fridays; the rest of the days, there's no soap. We don't even get towels. We brush our teeth with tooth powder using our fingers. We change clothes every two days and have to stay naked while the laundry is being done. They don't give us *chuddies* [underwear] here...when I first came I wasn't used to not wearing a *chuddy*. They gave me a frock to wear and I used to feel naked underneath.<sup>130</sup>

Shruti, a 38-year-old woman who lives in a government institution for women, described: "I bathe twice a week and wash hair once in two weeks...We have only one pair of clothes, we change when we bathe. One comb for all. One towel for all."<sup>131</sup>

### Denial of Education, Lack of Stimulation

One major problem in institutions is that there are no meaningful activities to keep residents occupied, which can lead to a deterioration of their condition as well as a sense of profound boredom and uselessness. Rita Darira, member of the CWC at Asha Kiran,

<sup>&</sup>lt;sup>127</sup> Human Rights Watch interview with Ambika, details withheld.

<sup>&</sup>lt;sup>128</sup> Human Rights Watch interview with Rakhi, resident, women's home, details withheld.

<sup>&</sup>lt;sup>129</sup> Human Rights Watch interview with psychiatrists and medical officers in-charge, details withheld. Human Rights Watch interview with Smita, details withheld.

<sup>&</sup>lt;sup>130</sup> Human Rights Watch interview with Ameena, resident, mental hospital, details withheld.

<sup>&</sup>lt;sup>131</sup> Human Rights Watch interview with Shruti, resident, women's home, details withheld.

lamented the fact that the women and girls "are not being taught anything. There is no dignity, no engagement. Nothing is being done for their self-esteem."<sup>132</sup>

In half of the 24 institutions visited by Human Rights Watch, women and girls with intellectual or psychosocial disabilities spend their days doing nothing but sleeping and wandering around aimlessly. For Aparna, a woman with bipolar condition and epilepsy, the absence of activities is deadening: "I have studied a little and can read a book if you give me one, but they don't give books here. Nothing happens here, you wander around, eat, drink, sleep, that's all."<sup>133</sup>

At best, the institution provides a television or a music system, a few board games, and a vocational training class that consists of making envelopes or candles.<sup>134</sup> Although visits to some institutions included a guided tour of rooms for arts and crafts, weaving, or even a beauty salon most residents do not use them because they are either not taken to them or there are simply no teachers.<sup>135</sup>

Thirty-five-year-old Smita, who stays in a women's residential institution with her baby, told us: "I don't do anything after breakfast, just roam around. There are no toys for the baby and I don't go to class because they don't send me. After lunch, I and the others roam around, there's nothing else to do—just roaming and roaming."<sup>136</sup>

Archita Sobta, a psychologist with an NGO called Manas Foundation, working within a women's residential institution said:

I never see classes going on...There's only stitching. So many of the psychiatric patients would behave much better if they had proper classes...In class, what happens is that the women with 'psychiatric

 <sup>&</sup>lt;sup>132</sup> Human Rights Watch group interview with Kamla Lekhwani, chairperson, CWC-5 at Asha Kiran Complex, June 10, 2013.
 <sup>133</sup> Human Rights Watch interview with Aparna, details withheld.

<sup>&</sup>lt;sup>134</sup> Human Rights Watch visit to State Home for Women, Bengaluru, April 2, 2013; Human Rights Watch visit to Home for Mentally Retarded Women, Bengaluru, April 2, 2013; Human Rights Watch visit to Pune mental hospital, Pune, June 12, 2013; Human Rights Watch visit to Thane Mental Hospital, Mumbai, June 13, 2013; Human Rights Watch visit to IHBAS, Delhi, August 2013.

 <sup>&</sup>lt;sup>135</sup> Human Rights Watch interview with Salma, details withheld; Human Rights Watch interview with Poonam, welfare officer, Nari Niketan at Nirmal Chhaya Complex, Delhi, November 11, 2013; Human Rights Watch group interview with Archita Sobta, Pradeep Kaur Grewal, and Jyoti Singh, psychologists, Manas at Nirmal Chhaya Complex, Delhi, November 2013.
 <sup>136</sup> Human Rights Watch interview with Smita, details withheld.

illnesses' get distracted and are slow so girls complain: 'if the girls with disabilities come to class then (we) won't go.'

In custodial homes and closed wards of mental hospitals, women and girls with disabilities are not even allowed to leave the immediate premises of the institution or ward to go for a walk in the larger complex.<sup>137</sup>

B. C. Hessa, superintendent of the male wing at Asha Kiran, explained:

We do not allow children to leave the premises as the responsibility to take care of them lies with us. There is no space for the children to play. When they become violent, then it becomes problematic. They run off here and there, hit one another, tear clothes off, bite each other and beat the house aunty [caretaker]. Due to non-availability of programs, activities are not being performed as are needed so the children have too much energy. Children should be taught day-to-day living skills.<sup>138</sup>

In institutions such as Asha Kiran, even the most basic life skills training is absent due to a shortage of staff to manage the overcrowded population and a sense that people with intellectual disabilities are incapable of learning. One Child Welfare Committee member said: "We send children to Asha Kiran with a very heavy heart because we know whatever skills and socialization—shaking hands, basic conversation and tasks—they have learned here will go [away] in a couple of weeks."<sup>139</sup>

Despite the Right of Children to Free and Compulsory Education Act (2009), which makes elementary education in a neighborhood school free and mandatory for all children, girls with psychosocial or intellectual disabilities living in institutions are excluded in practice. For example, in the Children's Home for Girls I & II within the Nirmal Chhaya complex, <sup>140</sup> a

<sup>&</sup>lt;sup>137</sup> Human Rights Watch interview with Angela, welfare officer, Nari Niketan at Nirmal Chhaya Complex, Delhi, November 10, 2013; Human Rights Watch interview with staff nurse, IHBAS, Delhi, August 2013; Human Rights Watch interview with Sadaf, welfare officer, Children's Home for Girls I at Nirmal Chhaya Complex, Delhi, November 4, 2013.

<sup>&</sup>lt;sup>138</sup> Human Rights Watch interview with B. C. Hessa, superintendent of the male wing, Asha Kiran Complex, June 10, 2013.
<sup>139</sup> Human Rights Watch group interview with child welfare committee members in Delhi, names withheld, November 8, 2013.
<sup>140</sup> The Nirmal Chhaya Complex contains two institutions for girls, an aftercare home for women aged between 18 and 21, a short-stay facility for women, a long-stay residential care institution for women (Nari Niketan), and a Beggars Home for Women. The Nirmal Chhaya complex neighbors Tihar jail, one of the largest prison complexes in South Asia.

residential care facility housing 212 girls with and without disabilities, most girls with psychosocial or intellectual disabilities are not sent to school.<sup>141</sup>Jyoti and Rashmi, counselors at the children's home for girls, told Human Rights Watch:

There are no specialized activities for the 'mentally challenged' except arts and crafts, beauty culture [skills to become a beautician] and non-formal education. The low IQ children sit with the normal children and don't get any specialized attention. We have moved a file [made a request] for a special educator but it hasn't moved. Plus, resources are limited...There's nothing to play with—no swings, nothing to spend their energy on.

This is a custodial home so they don't get out and instead take out their aggression on each other. They don't attend school, they don't learn, they don't play. In class zero [the entry level in the non-formal education system], you have girls aged four and 10 in the same class which means girls lose interest because they can't understand what goes on.<sup>142</sup>

In a handful of cases where girls with mild intellectual disabilities living in institutions do go to school, staff told Human Rights Watch that they do not learn much as the curriculum is not adapted and special educators are not present.<sup>143</sup>

According to Sadaf, a welfare officer at a residential care institution for girls, "It is no use sending girls with disabilities to school. They are not learning anything because they don't get any specialized attention."<sup>144</sup>

The Maharashtra Commissioner of Disabilities, Bajirao Jhadhav, shared this view:

<sup>&</sup>lt;sup>141</sup> Human Rights Watch interview with Sadaf, welfare officer, Children's Home for Girls I at Nirmal Chhaya Complex, Delhi, November 4, 2013. Human Rights Watch group interview with Reeta Mathews, Rajesh Solanki, and Rachna Srivastav, members, CWC 7 - South West District at Nirmal Chhaya Complex, November 25, 2013.

<sup>&</sup>lt;sup>142</sup> Human Rights Watch interview with Jyoti and Rashmi, counselors, Children's Home for Girls I & II at Nirmal Chhaya Complex, November 22 & 25, 2013.

<sup>&</sup>lt;sup>143</sup> Human Rights Watch interview with Sadaf, welfare officer, Children's Home for Girls I at Nirmal Chhaya Complex, Delhi, November 4, 2013.

<sup>&</sup>lt;sup>144</sup> Ibid.

In general, the quality of education is poor and needs to improve. Unless there is quality education, children with disabilities cannot survive...These children need special care—we are giving that care. The facilities require further materials for playing, quality of accommodations.<sup>145</sup>

### Lack of Adequately Trained Staff

In 16 government and private institutions, Human Rights Watch found that attendants or support staff who are primarily responsible for the everyday care of women and girls with psychosocial or intellectual disabilities, are insufficiently trained, if at all. Reeta Mathews, a CWC member of a children's residential care institution, said: "Every NGO-run home should have a qualified and trained counselor...At the moment, they have counselors but not all are well-qualified. They need good counselors so children open up."<sup>146</sup>

One "house aunty" explained, "We do not receive any training when we join, we are just shown the ropes on the first day...They do not teach us how to handle the patients in practice, especially the complicated cases."<sup>147</sup>As a result, these staff—who have the most daily contact with residents—often lack awareness about psychosocial or intellectual disabilities and are not trained to deal with people with disabilities in a sensitive manner —for example, attributing outbursts to patients "doing drama" [acting up].<sup>148</sup>

Archita Sobta, a psychologist working with the Manas Foundation in a government residential facility for women in Delhi explained, "There is low sensitivity even among staff; casual use of the word '*pagal*' leads to emotional issues for the patient. They see it as a very negative word."<sup>149</sup> Human Rights Watch found that staff members habitually refer to women with intellectual disabilities as "mentally retarded" or "MR" and to women with psychosocial disabilities as "*pagal*" or "mental."

<sup>&</sup>lt;sup>145</sup> Human Rights Watch interview with Bajirao Jhadhav, commissioner of disabilities-Maharashtra, Pune, April 10, 2013.
<sup>146</sup> Human Rights Watch interview with Reeta Mathews, Rajesh Solanki, and Rachna Srivastav, members, CWC 7 - South West District at Nirmal Chhaya, Delhi, November 25, 2013.

 <sup>&</sup>lt;sup>147</sup> Ibid. Female attendants in residential facilities who are sometimes known as "ayas" [nannies] or "house aunties."
 <sup>148</sup> Human Rights Watch interview with attendants, details withheld; Human Rights Watch interview with house aunties, details withheld.

<sup>&</sup>lt;sup>149</sup> Human Rights Watch group interview with Archita Sobta, Pradeep Kaur Grewal and Jyoti Singh, psychologists at Manas Foundation, Delhi, November 22, 2013.

# Denial of Adequate and Appropriate Healthcare

Basic rights get compromised as soon as you have 'mental illness'; it's not just your right to freedom but also your right to health.

Dr. Sanjeev Jain, professor of psychiatry and former head of department,
 NIMHANS, Bengaluru, December 18, 2013.

Government institutions and mental hospitals fail to provide basic physical and mental health care to women and girls with psychosocial or intellectual disabilities, including reproductive health care or dental and eye care. As illustrated in the background section, lack of access to health care is a concern for the population at large in India.

However, the state has an obligation to ensure appropriate standards of care for individuals in state institutions. Yet, in cases documented by Human Rights Watch, people with psychosocial or intellectual disabilities living in institutions are prevented from even attempting to access adequate and appropriate healthcare in a timely manner either as a result of discrimination due to their disability or their inability to leave the premises when they want.

In 20 of the 24 institutions that Human Rights Watch visited, women and girls with psychosocial or intellectual disabilities have to be taken to the closest government hospital if they have even a minor ailment because there are no medical personnel on staff or on the premises. Transport, however, is a major challenge since institutions do not always have ambulances or vehicles available.<sup>150</sup>

In addition, when a staff member accompanies the girl or woman to the hospital and has to spend the night there, it means that one less person can look after the other girls and women living in the institution. This often leads to delays and neglect of the girls or women requiring medical attention.

Rachna Bharadwaj, the superintendent of the female wing of Asha Kiran, a residential facility, told us about a girl with an intellectual and psychosocial disability who was sent to a mental hospital for treatment for a month and returned with a broken arm. Although the

<sup>&</sup>lt;sup>150</sup> Human Rights Watch group interview with house aunties, details withheld.

girl was in pain and could not move her arm, which was hanging limp on her side, staff in the mental hospital had not bothered to take her to a general hospital to treat her injury. In the end, the injury required two surgeries to mend.<sup>151</sup> In another case, one women came back to the institution after staying in a mental hospital for treatment with an ulcer on her foot that was infected with fat black worms that the mental hospital hadn't bothered to treat.<sup>152</sup>

Even in general hospitals, women and girls with psychosocial or intellectual disabilities are low on the priority list. According to Dr. Sanjeev Jain, former head of department of psychiatry at NIMHANS:

In India, the life expectancy of people with 'mental illness' is 15 years shorter than that of healthy people. Even in government hospitals, it is difficult for example to get an angioplasty for someone with schizophrenia. The services are extremely limited or they don't admit people with mental illness in a general hospital unless it has a license for psychiatry. Most government hospitals refuse to admit 'mentally ill' people in ICU care. They ask, 'Why are you blocking a bed that could be put to better use?' This year, one of our patients died. She was diagnosed with breast cancer two or three years ago so we took her to a government hospital. The doctor there said, 'Please think if you would be adding anything to her life by giving her treatment.'<sup>153</sup>

The patient was only treated for breast cancer after doctors from NIMHANS insisted they wanted her to receive care.

Large-scale mental hospitals and government residential care institutions do not provide appropriate reproductive health care, access to HIV/AIDS testing to women with disabilities at risk.<sup>154</sup> Although anti-psychotic medication and other mental health drugs

<sup>&</sup>lt;sup>151</sup> Human Rights Watch interview with Rachna Bharadwaj, superintendent female wing, Asha Kiran Complex, Delhi, August 6, 2013.
<sup>152</sup> Human Rights Watch interview with Poonam, welfare officer, Nari Niketan at Nirmal Chhaya Complex, Delhi, November 11, 2013.
<sup>153</sup> Human Rights Watch interview with Dr. Sanjeev Jain, professor of psychiatry and former head of department, NIMHANS, Bengaluru, December 18, 2013.

<sup>&</sup>lt;sup>154</sup> Human Rights Watch visit to Pune Mental Hospital, Pune, June 12, 2013; Human Rights Watch visit to Thane Mental Hospital, Mumbai, June 13, 2013; Human Rights Watch visit to Nari Niketan at Nirmal Chhaya Complex, Delhi, November 11, 2013; and Human Rights Watch visit to Asha Kiran Complex, Delhi, June 10, 2013.

can affect menstruation cycles, leading to irregular or an absence of periods, women and girls in 15 institutions Human Rights Watch visited do not provide reproductive health checkups or access to them, except in the case of pregnancy.<sup>155</sup>

Thirty-five of the 68 women and girls Human Rights Watch interviewed had either experienced sexual violence or had multiple partners. However, unless they were previously involved in sex work, staff in 15 institutions told Human Rights Watch that women and girls with psychosocial or intellectual disabilities living in institutions do not have information about or access to testing and treatment for HIV/AIDS and other sexually transmitted diseases.

In 15 of the institutions visited, Human Rights Watch found a lack of access to eye and dental care. In five cases, women complained of being unable to see because their spectacles had been broken or stolen in the institution. In one case, a woman complained of not being able to eat food as her teeth had been damaged during fights with fellow residents and she did not have subsequent access to dental care.<sup>156</sup>

In eight institutions and community programs, mental health was mainly psychiatry and medicine-driven with little emphasis on therapy or counseling. For example, women and girls in Asha Kiran meet a clinical psychologist for an annual check-up just once a year.<sup>157</sup>

#### Involuntary Treatment

In many institutions that Human Rights Watch visited, women and girls with psychosocial or intellectual disabilities are routinely forced to take medication. The staff in these mental hospitals and residential care institutions openly shared with Human Rights Watch that they hold down women and girls with psychosocial disabilities or forcibly open their

<sup>&</sup>lt;sup>155</sup> Anti-psychotic medication and other mental health drugs can cause a number of reproductive health issues including menstrual irregularity, amenorrhoea, polycystic ovary syndrome, and hyperprolactinaemia. "Medications for Bipolar Disorder," *Royal College of Psychiatrists*, August 2013,

http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/medicationsbipolardisorder.aspx (accessed July 15, 2014); Mukund P. Murke, et al., "Study of Menstrual Irregularities in Patients Receiving Antipsychotic Medications," *Indian Journal of Psychiatry*, 53(2011): 79–80, doi: 10.4103/0019-5545.75550; "About Medication," January 2013, *National Alliance on Mental Health* (NAMI),

http://www.nami.org/Template.cfm?Section=About\_Medications&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID= 51&ContentID=20851 (accessed July 15, 2014).

<sup>&</sup>lt;sup>156</sup> Human Rights Watch interview with Mukta, details withheld.

<sup>&</sup>lt;sup>157</sup> Human Rights Watch interview with Baburam Raman, clinical psychologist, Asha Kiran, Delhi, June 10, 2013.

mouths to coerce them to comply with medication.<sup>158</sup> If that fails to work, staff members told us that they routinely force-feed women food and drinks, such as bananas or tea, laced with medicines.<sup>159</sup> Women can be given medication up to three times a day but they may not even know it.

A caretaker working at Pune Mental Hospital said, "Sometimes we have to powder the medicine and hide it in the patients' food, otherwise they get excited and it's dangerous."<sup>160</sup> Suprabha Alahat, director of an NGO-run residential care facility for women on the outskirts of Pune, admits, "If someone does not take the medicine, we forcefully give it in the chai [tea] or milk. Somehow we have to put it in the stomach."<sup>161</sup>

Informed consent is a bedrock principle of medical ethics and international human rights law, and forcing individuals to take medicines without their knowledge or consent violates their rights.<sup>162</sup> The UN special rapporteur on violence against women has condemned forced psychiatric treatment as a form of violence.<sup>163</sup> In addition, the UN special rapporteur on torture has stated that "involuntary treatment and other psychiatric interventions in health-care facilities" may constitute forms of torture and ill-treatment.<sup>164</sup>

Vidya, a naturopath who was involuntarily institutionalized by her husband, remembers being forced to take medicines:

<sup>&</sup>lt;sup>158</sup> Human Rights Watch interview with staff nurse, Pune Mental Hospital, Pune, June 12, 2013; Human Rights Watch interview with Saraswati, caretaker, Manasa Kendra, August 20, 2013.

<sup>&</sup>lt;sup>159</sup> Human Rights Watch interview with Kamlesh and Prabhveer Singh, staff nurses, IHBAS, August 26, 2013.

<sup>&</sup>lt;sup>160</sup> Human Rights Watch interview with a caretaker (name withheld), Pune Mental Hospital, Pune, June 12, 2013.

<sup>&</sup>lt;sup>161</sup> Human Rights Watch interview with Suprabha Alahat, director, Vatsalyadham, August 13, 2013.

<sup>&</sup>lt;sup>162</sup> International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976, arts. 7 17 (1). International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force January 3, 1976, art. 12; Beijing Declaration and Platform for Action, Fourth World Conference on Women, September 15, 1995, A/CONF.177/20 (1995), art. 108(e); United Nations Educational, Scientific, and Cultural Organization (UNESCO), Universal Declaration on Bioethics and Human Rights, adopted October 2005, SHS/EST/05/CONF.204/3 REV, arts. 6 and 9.

<sup>&</sup>lt;sup>163</sup> UN Commission on Human Rights, Report of the Special Rapporteur on violence against women, Rashida Manjoor, Report of the Special Rapporteur on violence against women, its causes and consequences, A/67/227, August 3, 2012, http://www.ohchr.org/Documents/Issues/Women/A.67.227.pdf (accessed December 10, 2013), p. 10, 13.

<sup>&</sup>lt;sup>164</sup> Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53, February 1, 2013,

http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\_English.pdf (accessed December 28, 2013), 15.

Normally I never took any medicines. After hospitalization, I was totally sedated. Four times a day, they would be putting tablets in my hand. The nurse was very rude, she would say 'It's compulsory' and 'Take it fast.' There was no time to think, I was just sleepy all the time. I had terrible side effects: my hand started trembling and I couldn't stretch it, I couldn't walk, I was very slow, my tongue started trembling and stuttering.<sup>165</sup>

Deepali, a 43-year-old woman who is perceived as having a psychosocial disability, was forcibly institutionalized twice times by her family and treated against her will each time.

The nurses would make us have the medications in front of them. If I complained that there were too many tablets, the nurse would sometimes forcefully put the pills in my mouth and stroke my throat to send them down, the way I feed my dogs. The patient's word is never considered...I was scared. You have no control over anything they do there. They hold power over you and do what they want. I conformed because there was no point in throwing tantrums. I woke up one night and I couldn't move; my body was in intense physical pain. A nurse came and jabbed an injection into my body, without even taking off my clothes. You are treated worse than animals; it's an alternate reality.<sup>166</sup>

#### Electroconvulsive Therapy

Electroconvulsive therapy (ECT), which consists of passing electricity through the brain in order to induce a seizure, is used in mental hospitals in many countries, including throughout India.<sup>167</sup>In the seven hospitals Human Rights Watch visited, ECT was administered in its modified form (with anesthesia, muscle relaxants and oxygenation) but mental health professionals mentioned cases in rural areas where ECT without anesthesia

<sup>&</sup>lt;sup>165</sup> Human Rights Watch interview with Vidya, woman with psychosocial disability, Mumbai, August 15, 2013.

<sup>&</sup>lt;sup>166</sup> Human Rights Watch interview with Deepali, woman with a psychosocial disability, Delhi, August 25, 2013.

<sup>&</sup>lt;sup>167</sup> Electroconvulsive therapy, also known as electroshock or ECT, is a controversial type of psychiatric shock therapy involving the induction of an artificial seizure in a patient by passing electricity through the brain. ECT is used to treat bipolar disorder and severe depression in cases where antidepressant medication, psychotherapy, or both have proven ineffective. See Human Rights Watch, *Like a Death Sentence: Abuses against Persons with Mental Disabilities in Ghana*, October 2012, http://www.hrw.org/reports/2012/10/02/death-sentence-o.

was administered, due to the shortage of anesthetists.<sup>168</sup> In India, ECT is prescribed for patients with suicidal tendencies, severe depression, tendency, catatonia, bipolar disorder or acute psychosis.<sup>169</sup> Prior to ECT administration, patients' fitness for anesthesia is checked and they are made to fast overnight.<sup>170</sup>

Human Rights Watch documented cases of 20 women and 11 girls, between the age of 14 and 17 years, who were currently or recently given ECT without consent across 4 mental hospitals. Section 104 of the new Mental Health Bill before Parliament bans the use of unmodified ECT on children<sup>171</sup> However, the new bill allows for the use of modified ECT on children in circumstances where the child's treating psychiatrist deems it necessary, with the consent of the child's guardian and permission of the concerned medical board.<sup>172</sup>

The bill does not make provision for the wishes of the child to be taken in to account nor for the evolving capacities of the child, which means that even if a child explicitly refuses to undergo ECT, the treating psychiatrist can still forcibly administer ECT as long as they have the consent of the guardian and the medical board. This falls short of India's obligations under the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, which provide for the evolving capacities of a child to participate in decision-making.<sup>173</sup>

<sup>&</sup>lt;sup>168</sup> A 2001-2002 survey of teaching hospitals in India showed that ECT was carried out in its unmodified form (without anesthesia or muscle relaxants) on an estimated 52 percent of those receiving ECT at 33 institutions in India. The risks of unmodified ECT include dental damage, spinal and pelvic fractures, and muscles injuries, to name a few.

Chittaranjan Andrade et al., "Position Statement and Guidelines on Unmodified Electroconvulsive Therapy," *Indian Journal of Psychiatry*. 54(2012): 119–133, doi: 10.4103/0019-5545.99530 ; Human Rights Watch phone interview with Dr Pratima Murthy, professor & chief, Centre for Addiction Medicine, department of psychiatry at NIMHANS, June 9, 2014; Human Rights Watch group interview with six psychiatrists, Delhi, details withheld ; Human Rights Watch phone interview with Gunjan Sharma, senior correspondent for *The Week*, October 2013.

<sup>&</sup>lt;sup>169</sup> ECT-team, Department of Psychiatry, National Institute of Mental Health and Neuro Sciences, *ECT Administration Manual*, 2<sup>nd</sup> edition, 2013, p. 10. Human Rights Watch interview with Dr. Sanjeev Jain, professor of psychiatry and former head of department, NIMHANS, Bengaluru, December 18, 2013; Human Rights Watch group interview with six psychiatrists, Delhi, details withheld; Human Rights Watch group interview with two nurses in-charge of ECT room, details withheld; Human Rights Watch interview with nurse in-charge of ECT room, October 24 & 25, 2013, details withheld.

<sup>170</sup> Ibid.

<sup>&</sup>lt;sup>171</sup> "Section 104, Mental Health Care Bill, 2013,"

http://www.prsindia.org/administrator/uploads/general/1376983253~~mental%20health%20care%20bill%202013.pdf (accessed May 30, 2014), p. 43.

<sup>172</sup> Ibid.

<sup>&</sup>lt;sup>173</sup> Convention on the Rights of the Child (CRC), adopted November 20, 1989, G.A. Res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, art. 5, 14. Convention on the Rights of Persons with Disabilities (CRPD), adopted December 13, 2006, G.A. Res. 61/106, annex I, U.N. GAOR Supp. (No. 49) of 65, U.N. Doc. A/61/49 (2006), entered into force May 3, 2008, art. 3.
The World Health Organization Resource Book on mental health, human rights and legislation states that ECT should only be administered in its modified form (with anesthesia and muscle relaxants) and with informed consent and "there are no indications for the use of ECT on minors [defined as anyone below 18], and hence this should be prohibited through legislation."<sup>174</sup>

Some mental hospitals have elaborate consent forms specifically for ECT. However, Human Rights Watch found very few consent forms in the psychiatric records reviewed. Of seven consent forms Human Rights Watch saw, none was signed by the patient. The ECT consent forms in two hospitals visited did not even have the option for the patient to sign, and instead allowed only for the signature of a guardian.<sup>175</sup>

Vidya, who is perceived as having a psychosocial disability and was 35 years old when she started undergoing ECT, recounts how she was forced to undergo ECT treatments in a private hospital and subsequently in a private clinic:

I used to get severe headaches after ECT...ECT was like a death tunnel. I used to hold my husband's hand tight. For the next two or three days, my hand would be swollen....The doctor used to only talk to my husband; he only met me two or three times in two years. When my medication was reduced, I started asking questions. Till then I was like a vegetable. The doctor said, 'We're going to do eight or nine blood tests on you.'....It was only many years later that I found out that I was being given ECT.<sup>176</sup>

Sara, a 25-year-old woman with schizophrenia, remembered with a shudder what happened to her:

Nobody told me what was happening...They took me to another room; I didn't want to go but they still made me. There they gave me a *nasha* 

 <sup>&</sup>lt;sup>174</sup> World Health Organization, "Resource Book on Mental Health, Human Rights and Legislation," 2005, http://www.who.int/mental\_health/policy/resource\_book\_MHLeg.pdf (accessed January 20, 2013).
 <sup>175</sup> On file with Human Rights Watch.

<sup>&</sup>lt;sup>176</sup> Human Rights Watch interview with Vidya, woman with psychosocial disability, Mumbai, August 15, 2013.

injection [anesthesia] and suddenly my stomach lurched. I felt like vomiting but I didn't.<sup>177</sup>

Devika, a 39-year-old woman with schizophrenia living in one of India's psychiatric hospitals, said:

I said to the doctor that I've had enough of shocks, I can't take it anymore. I told the doctor again today but I still got shocks. He won't feel bad if I tell him again, no? Because of the shocks, my memory is suppressed.<sup>178</sup>

ECT can cause short-term memory loss. NIMHANS as well as international guidelines recommend that hospitals conduct cognitive assessments, including age-appropriate memory testing for children.<sup>179</sup> Staff in five hospitals indicated to Human Rights Watch that this procedure is rarely used.<sup>180</sup>

In the case of a person who does not have a family, a psychiatrist gives consent for the ECT. Staff in a mental hospital in Delhi told Human Rights Watch that in the case of women or girls from a residential institution, the superintendent or the CWC gives consent. However, hospitals also do not approach government institutions such as Nari Niketan and the Children's Home for Girls I & II in Delhi for consent although many of their residents receive ECT.<sup>181</sup> Poonam, a welfare officer at Nari Niketan, said:

We have no interaction with [the mental hospital]; they don't tell us what treatment goes on. We only get a discharge slip that mentions what current medication the patient is on. We don't even know the diagnosis. From the

<sup>&</sup>lt;sup>177</sup> Human Rights Watch interview with Sara, details withheld.

<sup>&</sup>lt;sup>178</sup> Human Rights Watch interview with Devika, details withheld.

<sup>&</sup>lt;sup>179</sup> The NIMHANS ECT Administration Manual says "close monitoring of cognitive deficits is recommended in all patients receiving ECT. A baseline assessment should be conducted before commencing the treatment and then repeated weekly throughout the course of ECT...If gross deficits are present, a change of ECT technique or adjustment of medications should be considered. The evaluation should include at least orientation and memory." ECT-team, Department of Psychiatry, National Institute of Mental Health and Neuro Sciences, *ECT Administration Manual*, 2<sup>nd</sup> edition, 2013, pp. 23, 41.
<sup>180</sup> Human Rights Watch interview with two staff nurses, Delhi, details withheld. Human Rights Watch interview with staff nurse, Delhi, details withheld. Human Rights Watch interview Rights Watch interview with staff nurses.

Watch interview with staff nurse, Mumbai, details withheld.

<sup>&</sup>lt;sup>181</sup> Human Rights Watch group interview with Reeta Mathews, Rajesh Solanki, and Rachna Srivastav, members, CWC 7 -South West District at Nirmal Chhaya Complex, November 25, 2013. Human Rights Watch group interview with child welfare committee members in Delhi, names withheld, November 8, 2013.

prescription, Manas [a mental health NGO] guesses what the patient has been diagnosed with. Nobody tells us.<sup>182</sup>

In one case, Human Rights Watch also found incomplete consent forms without impartial witness signatures and another in which the psychiatrist gave consent and signed as the impartial witness.<sup>183</sup>

In a government hospital, a psychiatric nurse admitted that ECT was commonly used not only on violent and suicidal patients but also on new admissions who tend to be unmanageable.<sup>184</sup> ECT is even used as a threat to coerce people to take their medicines or to scare them if they do not listen to staff. A nurse in a government mental hospital said:

They fear this (ECT). We say, 'if you don't take your medicine, we will take you to the ECT room' and immediately they say, 'please don't take me to that room, I won't do that again.'<sup>185</sup>

According to the NIMHANS ECT administration manual, a typical ECT course lasts 6 to 12 sessions and if there is no visible improvement within 6 sessions, the technique should be changed.<sup>186</sup> However, if despite an alteration in technique, the patient's clinical response plateaus then the course should be terminated. In some cases, after the initial course, ECT can be given once a month up to six months.<sup>187</sup> This is called maintenance ECT.

However, in one government hospital Human Rights Watch came across an adult patient with catatonic schizophrenia who was given more than a hundred sessions of ECT over the course of a year, all without her consent. The frequency of ECT sessions was much more than what was allowed, averaging two sessions a week.<sup>188</sup>A staff nurse commented on the

<sup>&</sup>lt;sup>182</sup> Human Rights Watch group interview with Poonam and Angela, welfare officers, Nari Niketan at Nirmal Chhaya Complex, November 11, 2013.

<sup>&</sup>lt;sup>183</sup> Human Rights Watch interview with staff nurse, details withheld. Human Rights Watch interview with Anu, psychiatric records, details withheld.

<sup>&</sup>lt;sup>184</sup> Human Rights Watch interview with a psychiatric nurse, details withheld.

<sup>&</sup>lt;sup>185</sup> Human Rights Watch interview with a psychiatric nurse, details withheld.

 <sup>&</sup>lt;sup>186</sup> ECT-team, Department of Psychiatry, National Institute of Mental Health and Neuro Sciences, *ECT Administration Manual*, 2<sup>nd</sup> edition, 2013, p. 10.

<sup>187</sup> Ibid.

<sup>&</sup>lt;sup>188</sup> Human Rights Watch interview with staff nurse, details withheld; Human Rights Watch interview with staff nurse, details withheld; Human Rights Watch interview with Anu, psychiatric records, details withheld.

condition of the patient who had to be admitted to the psychiatric ICU, "I can't say her condition has improved with ECT." However, an ECT specialist at one of the leading mental hospitals in India, Dr. Gangadhar, told Human Rights Watch, "Two to three patients a year respond well to ECT. But 100 ECT sessions, more often than once a month, is not good."<sup>189</sup>

The UN special rapporteur on torture has called on all states to impose an absolute ban on non-consensual electroconvulsive therapy.<sup>190</sup>

#### Physical, Sexual, and Verbal Violence

In institutions, where women and girls have little control over their surroundings, it is common for them to experience verbal, physical, and at times even sexual violence.

While physical and verbal abuse is an everyday occurrence in every state-run institution and mental hospitals Human Rights Watch visited, sexual violence remains hidden as victims are less likely to talk about it.

In the course of its visits to institutions Human Rights Watch found 12 cases of verbal, 38 of physical, and four of sexual violence against women and girls with psychosocial or intellectual disabilities. Most of these abuses were recent and had happened between 2012 and 2013. Human Rights Watch researchers witnessed staff walking around with sticks in three residential care facilities and hitting women if they did not move fast enough.

Shruti, a 38-year-old living with a psychosocial disability who was picked up on the streets by the police and admitted to a residential institution for women, said:

The police hit me a lot. I feel like crying. [The caretaker]<sup>191</sup> also hits me if I make a mistake. If I say I don't want to sleep here, or if I say I don't want to work, or I don't throw away the garbage, sometimes she hits me with a stick. They all hit. One of them slaps. I feel like crying.<sup>192</sup>

 <sup>&</sup>lt;sup>189</sup> Human Rights Watch interview with Dr. Gangadhar, psychiatrist, NIMHANS, Bengaluru, December 18, 2013.
 <sup>190</sup> Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53, February 1, 2013, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\_English.pdf (accessed December 28, 2013).

<sup>&</sup>lt;sup>191</sup> Name withheld.

<sup>&</sup>lt;sup>192</sup> Human Rights Watch interview with Shruti, details withheld.

Rubina, a 19-year-old girl with an intellectual disability who lives in a government institution in Delhi, told Human Rights Watch: "When I said I don't know how to light the gas in the kitchen or when I don't go to class, [the staff] swear at me or hit me with anything at hand...it's a bad scene."<sup>193</sup>

Rakhi, a 19-year-old living with bipolar disorder in a government residential care institution for women, said:

[The welfare officer] hit me.<sup>194</sup>She hit me with a fat wooden stick on my back, hands, and cheek. She hit me twice but hasn't after that. The first time, she had just opened the office and she started hitting me—I hadn't said anything. She asked me, 'Where will you go?'...Then she hit me. The madams [institution staff] hit me here. They laugh at me. They say: "*haramzadi, randi kutiya, tu yahan saregi*" ["bitch, whore, bitch, you will rot here"]. They hit me with a stick on the back of my legs and hands.<sup>195</sup>

Karishma, an 11-year-old-girl with a mild intellectual disability who lives in a government residential care institution, told Human Rights Watch:

The aunty [institution staff] who drops me to school hits me. She hits me here [in the institution] too. She slaps me hard with her hand; it hurts. When she hits me, I feel like crying and I feel sad. I feel like crying in school too...The house aunty gives me *gaalis* (swears) every day. When I don't feel like going to school, she hits me. I want to leave this place. <sup>196</sup>

Based on interviews with women, girls, caretakers in two mental hospitals and institutions, Human Rights Watch found that women and girls with psychosocial or intellectual disabilities who try to run away are harshly beaten to set an example for the others.<sup>197</sup>

<sup>&</sup>lt;sup>193</sup> Human Rights Watch interview with Rubina , details withheld.

<sup>&</sup>lt;sup>194</sup> Name withheld.

<sup>&</sup>lt;sup>195</sup> Human Rights Watch interview with Rakhi, details withheld.

<sup>&</sup>lt;sup>196</sup> Human Rights Watch interview with Karishma, girl with an intellectual disability, details withheld.

<sup>&</sup>lt;sup>197</sup> Human Rights Watch interview with Mukta, details withheld; Human Rights Watch interview with Rubina, details withheld; Human Rights Watch interview with Shalini, details withheld.

Mukta, a woman with schizophrenia, tried to escape from a mental hospital in Maharashtra but was caught by hospital staff. She told Human Rights Watch, "When I escaped, the warden hit me with a stick. For one year after that [the warden] did not let me go out [of the ward]."<sup>198</sup>

Shalini, a girl living with an intellectual disability in a government residential institution for children, said: "Girls tried to run away from here. When they got caught, they [staff] hit them a lot because otherwise, aunty would have lost her job."<sup>199</sup>

The presence of male staff on night duty in female wards puts women and girls living in institutions at even higher risk of sexual violence. Human Rights Watch found three instances in which only male staff were appointed to female wards at night.<sup>200</sup>

Radha, a social worker at Anjali Mental Health Organization in Kolkata, recounts the case of a woman staying in Pavlov Mental Hospital who experienced sexual violence in 2012:

In the evening, group D staff [caregivers] came to give medicines. [The perpetrator and woman] went inside the bathroom and locked the door. Women generally don't come outside [of their rooms]. Sisters [nurses] were frantically looking for her. The door opened, the guy came out, the girl behind him. Initially she said nothing. The girl was very uneasy with her clothes and her back was wet. In the morning, she told a sister that she was assaulted the previous night. The hospital suspended the guy. They filed an FIR [First Information Report] at the local police station and the department of health created an [external] committee [to review the situation].<sup>201</sup>

This is one of the few cases that Human Rights Watch documented where an FIR was registered.

<sup>&</sup>lt;sup>198</sup> Human Rights Watch interview with Mukta, details withheld.

<sup>&</sup>lt;sup>199</sup> Human Rights Watch interview with Shalini, details withheld.

<sup>&</sup>lt;sup>200</sup> Human Rights Watch interview with Richa, details withheld; Human Rights Watch interview with Priyanka, details withheld.
<sup>201</sup> In India, a complaint lodged with the police is called a First Information Report (FIR). Once an FIR is registered then the police can start investigating the incident; Human Rights Watch group interview with Ratnaboli Ray, Sudeshna Basu, and Radha Debroy, founder and staff, Anjali Mental Health Organization, Kolkata, April 4, 2013.

A welfare officer at a residential care institution for women told Human Rights Watch:

Women have gone to [a mental hospital] for three months and have come back one month pregnant. It's happened in a lot of cases but when the woman can't say who got her pregnant, what can we do? We found out this because...the women undergo a check-up and mandatory urine pregnancy test [when they are re-admitted into the residential care facility].

When you ask the woman, she says I slept with my husband. One woman was married but her husband couldn't be found yet she kept saying she slept with her husband so what can I say to the mental hospital? Was she abused by a staff member or resident? We don't know. They can't even understand the meaning of sleeping with someone so we can't highlight it. I used to be in the children's home earlier, there are one or two cases even there.<sup>202</sup>

#### Exploitation

In several institutions visited, Human Rights Watch found that women and girls with mild intellectual disabilities are exploited by fellow residents or staff. In residential care facilities for children (with and without disabilities), this manifests itself in the form of bullying and making girls with disabilities do chores. Sadaf, a welfare officer at a residential care institution for girls, told Human Rights Watch:

The 'normal girls' use the girls with 'MR' [mental retardation]. For example, they send them to do their kitchen duty or wash their clothes. The girls with MR feel pressurized so they do the work and don't go to class. We observe the girls and tell the normal girls not to dominate the others. But after 7 pm... the guard and caretakers are not that educated, so how can they control?<sup>203</sup>

At the outset, staff in institutions differentiate between the women with disabilities who listen to them and those who do not; the "good" or "intelligent" and the "bad" ones. The "good" women with disabilities become their "helpers" and perform a variety of tasks,

<sup>&</sup>lt;sup>202</sup> Human Rights Watch interview with welfare office, details withheld.

<sup>&</sup>lt;sup>203</sup> Human Rights Watch interview with Sadaf, welfare officer, Children's Home for Girls I at Nirmal Chhaya Complex, Delhi, November 4, 2013.

including those that the staff does not want to deal with, for example, cleaning toilets. Shruti, a 38-year-old woman with a psychosocial disability living in a state-run residential institution in Maharashtra told Human Rights Watch, "Everyone dirties the bathroom— [woman with psychosocial disability, name withheld] cleans."<sup>204</sup>

In many institutions, the shortage of staff aggravates the exploitation of women and girls with disabilities. Manju, a woman living with a psychosocial disability in another state-run residential care institution in Delhi, told Human Rights Watch: "I bathe everyone and wash their clothes every morning. I sweep, swab and clean toilets and give everyone food."

Parvati, a woman with a psychosocial disability living in a government residential care institution in Delhi, said: "My hand hurts when I wash clothes so I only wash for myself and a few other girls. I bathe the mental girls and wash their clothes."<sup>205</sup>

In certain institutions, such as the state-run beggars' home in Chembur, some women and girls are trained and ordered to wash clothes, clean the bathroom, bathe the other girls, tend the garden, and do other chores.<sup>206</sup> Under the Bombay Prevention of Begging Act, those who perform tasks are supposed to be paid a meager stipend of Rs. 5 per month (US\$0.083), an amount that has remained unchanged since the law was introduced in 1959. However, according to the staff in one of these beggars' homes, residents do not receive this when they are released.<sup>207</sup>

<sup>&</sup>lt;sup>204</sup> Human Rights Watch interview with Shruti , details withheld.

<sup>&</sup>lt;sup>205</sup> Human Rights Watch interview with Parvati, details withheld.

<sup>&</sup>lt;sup>206</sup> Human Rights Watch interview with attendant in Chembur Beggars' Home for Women, details withheld.

<sup>&</sup>lt;sup>207</sup> Human Rights Watch interview with Pallavi Thakare, social worker, Koshish at Chembur Beggars Home for Women, Mumbai, August 16, 2013.

# **III. Access to Justice**

The justice system can be very challenging for people with disabilities, particularly people with psychosocial or intellectual disabilities. Article 13.1 of the CRPD attempts to address this by obligating states parties to:

[E]nsure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

Under the Criminal Law Amendment Act (2013), some positive accommodations have been included for women and girls with disabilities, for example, that police can visit the woman's home or at a convenient place of her choice to take her testimony, in the presence of a special educator or interpreter, and for the information to be video recorded.<sup>208</sup> Since implementation of the act had just started at time of writing, it will only be possible to make a full assessment of its impact after a few years.

While access to justice continues to be a concern for many in India, particularly disadvantaged groups, women and girls with disabilities face unique barriers. Among the 128 cases of institutional abuse that Human Rights Watch documented, none of the women or girls had successfully filed a First Information Report (FIR) or accessed redress mechanisms for being institutionalized against their will or facing abuse within the institution. Most of the women and girls with psychosocial or intellectual disabilities interviewed were not even aware of mechanisms for redress.<sup>209</sup>

<sup>&</sup>lt;sup>208</sup> The Criminal Law Act, April 2, 2013, http://indiacode.nic.in/acts-in-pdf/132013.pdf (accessed January 23, 2014).
<sup>209</sup> Human Rights Watch came across only nine cases of abuse against women with intellectual or psychosocial disabilities in which a First Information Report (FIR) was registered and a judicial process initiated. Six of these were instances of women and girls who had experienced sexual violence, two were divorce and custody battles prompted by husbands, and one was a property rights case. Human Rights Watch interview with Smita, Delhi, details withheld; Human Rights Watch interview with Deepthi, Delhi, details withheld; Human Rights Watch interview with Jeet, Delhi, details withheld; Human Rights Watch interview with Anuja, Delhi, details withheld; Human Rights Watch interview with Meera, Delhi, details withheld; Human Rights Watch interview with Sarla, Delhi, details withheld; Human Rights Watch interview with Sarla, Delhi, details withheld; Human Rights Watch interview with a psychosocial disability, Mumbai, August 15, 2013; Human Rights Watch interview with Deepali, woman with a psychosocial disability, Delhi, August 25, 2013.

One major factor that hinders their access to justice is dependency on caretakers. In the cases of the women and girls with intellectual or psychosocial disabilities documented by Human Rights Watch, many had been abused by family members or caretakers on whom they relied for financial or other support.

Women with psychosocial or intellectual disabilities told Human Rights Watch that they seldom report abuse against caretakers and fellow residents for fear of the repercussions. In the 24 institutions and hospitals Human Rights Watch visited in 2013, there were no adequate mechanisms to report abuse. The only existing mechanism in some institutions was to report abuse to the institution's staff, which does not constitute an independent mechanism, as staff themselves may be perpetrators of the abuse.

In some cases, women with psychosocial or intellectual disabilities are also convinced into thinking that it is their fault. Devika, a woman with a psychosocial disability, said:

Those who don't listen; they get hit [by staff] sometimes. The staff pulls their hair and throws them on the floor. Whoever fools around here, their head is pulled to the floor. I was hit but I don't remember why; I must have made a mistake. Once I was hit so hard on the eye that I felt like I must have lost my eye; I lost sensation in it.<sup>210</sup>

Other factors that may hamper their access to justice include isolation, patriarchal and misogynistic attitudes, and paternalistic stereotypes.

Women and girls with psychosocial or intellectual disabilities often have no or limited access to legal aid. For example, the National Legal Services Authority is supposed to provide a lawyer to every Child Welfare Committee (CWC), so that in cases involving children, the child has a legal representative to present their interests. However, as of October 2013, the position in three out of seven CWCs in Delhi remained vacant.<sup>211</sup>

<sup>&</sup>lt;sup>210</sup> Human Rights Watch interview with Devika, details withheld.

<sup>&</sup>lt;sup>211</sup> Human Rights Watch group interview with Reeta Mathews, Rajesh Solanki, and Rachna Srivastav, members, CWC 7 - South West District at Nirmal Chhaya Complex, November 25, 2013.

## Lack of Faith in Testimonies

Women and children face barriers to reporting and having criminal complaints registered and investigated in cases of sexual violence or child sexual abuse.<sup>212</sup> In the case of women and girls with psychosocial or intellectual disabilities, this difficulty is compounded since the police often refuse to register a case because they are not convinced that the survivor is telling the truth or can identify or remember the perpetrator. For instance, one police officer told Human Rights Watch:

If she is MR, she is not in a conscious mind, how can she say that she is being raped? She won't be able to tell or identify the accused. Generally we don't accept [her testimony]...A *suo moto* case [in which a government official or court acts on its own initiative without the need for a party to commence proceedings] can be registered if the doctor says she has been raped. In such a case, the complainant has to identify the accused. But it will become a false case if she does not know - then how will it stand up in court? This is a problem so we don't register *suo moto* cases in rape cases...If she is MR, she does not know that it is rape so how can she say that? If we come to know through physical marks on her body or when we suspect, then we get her to medical exam. If there are no marks on the body, then we take her straight to NIMHANS."<sup>213</sup>

Another police officer told Human Rights Watch, "Sometime in rape cases, we register a case and an investigating officer is assigned. IHBAS has to declare the woman "fit for statement" for us to believe her."<sup>214</sup>This attitude is mirrored by family, caretakers, and government institutions.<sup>215</sup>

<sup>&</sup>lt;sup>212</sup> Human Rights Watch, *Breaking the Silence: Child Sex Abuse in India*, February 2013,

<sup>http://www.hrw.org/sites/default/files/reports/india0113ForUpload.pdf, p. 4; Human Rights Watch,</sup> *Broken System: Dysfunction, Abuse, and Impunity in the Indian Police*, August 2009, http://www.hrw.org/sites/default/files/reports/india0809web.pdf, p. 9.
<sup>213</sup> Human Rights Watch interview with Hemalatha R., subinspector, Adugodi police station, Bengaluru, August 20, 2013.
<sup>214</sup> Human Rights Watch group interview with Vinit Kumar & Ashish Kumar, sub-inspectors, Dilshad Garden Police Station, August 7, 2013.

<sup>&</sup>lt;sup>215</sup> Human Rights Watch interview with Suprabha Alahat, director, Vatsalyadham, August 13, 2013; Human Rights Watch interview with welfare officer, institution for women, Delhi, details withheld; Human Rights Watch group interview with psychiatric sister and an auxiliary nurse midwife, June 12, 2013, details withheld.

In one example, a woman with an intellectual disability living in a mental hospital informed a social worker that a security guard in a previous residential care institution had sexually abused her. However, the social worker told Human Rights Watch:

We have no proof and since she's MR, we can't trust what she says. She can't give details and she can't recognize him because he used to come after dark. We can only keep her statement with us, we can't use it as proof.<sup>216</sup>

Women with intellectual or psychosocial disabilities are also confronted with lack of awareness and prejudice on the part of medico-legal personnel who often disbelieve their accounts, particularly reports of sexual violence.

Rakhi, a woman living with bipolar disorder, told Human Rights Watch:

I tried to tell a doctor about what happened to me but he would say I am lying. He didn't do anything about it. He didn't even listen to me. The police didn't speak to me so I couldn't tell them. They just brought me here [a custodial institution for women]. Only when someone talks to me, can I tell them, no?<sup>217</sup>

Also, according to the Criminal Law (Amendment) Act, 2013, if the victim has a disability the police are supposed to go to the woman's home or at a convenient place of her choice to record her statement and in the presence of a special educator or interpreter.<sup>218</sup>

#### **Challenges in Reporting**

According to Kumari Selja, former Indian minister for social justice and empowerment, "women with disabilities are the most vulnerable" and "most cases [of abuses against them] go unreported."<sup>219</sup> Women with psychosocial or intellectual disabilities may be less likely to report incidents of abuse because of intimidation and negative past experiences in which their complaints were dismissed or ignored. As India has no victim

<sup>&</sup>lt;sup>216</sup> Human Rights Watch interview with a social worker, details withheld.

<sup>&</sup>lt;sup>217</sup> Human Rights Watch interview with Rakhi, details withheld.

<sup>&</sup>lt;sup>218</sup> "The Criminal Law Act, April 2, 2013," http://indiacode.nic.in/acts-in-pdf/132013.pdf (accessed January 23, 2014).

<sup>&</sup>lt;sup>219</sup> Human Rights Watch interview with Kumari Selja, minister, ministry for social justice and empowerment, government of India, New York, September 25, 2013.

and witness protection program, retaliation for reporting instances of violence can have a more devastating impact on these women and girls because of the limited support services available.

Women and girls with psychosocial or intellectual disabilities are most often not even aware of their rights because of the lack of information in formats accessible to them and lack of redress mechanisms. Based on interviews with social workers and police officers in four cities, Human Rights Watch found that special educators or other types of external gender-sensitive assistance are rarely brought in to facilitate communication in police stations, courts, or hospitals. In 24 mental hospitals, shelters, and homes visited, Human Rights Watch found that none had appropriate recourse or complaints procedures.

Shampa Sengupta, head of Sruti Disability Rights Centre in Kolkata and an advocate for the rights of women with disabilities, said: "There is a need to train the police. One cannot expect a woman with an intellectual disability to tell the case one year later."<sup>220</sup>

Human Rights Watch found that the judiciary, police, medico-legal staff and personnel in mental hospitals lack sufficient training in interacting and communicating with people who have psychosocial or intellectual disabilities and can often be insensitive and inattentive to their needs. As a party to the CRPD, India has obligations to "promote appropriate training for those working in the field of administration of justice, including police and prison staff" to ensure effective access to justice for persons with disabilities.<sup>221.</sup>

In 2011, B. K. Gupta, the commissioner of Police Delhi, issued "Standard Operating Procedures regarding Duties of Police Officers to Deal with Mentally III Persons" to police officials across the city. However, according to mental health professionals working on the ground in Delhi, the police still lack awareness and sensitivity in dealing with persons with psychosocial disabilities.<sup>222</sup> Human Rights Watch conducted interviews with police officers in five police stations across three different cities but none of them reported receiving training on how to interact with persons with disabilities.

 <sup>&</sup>lt;sup>220</sup> Human Rights Watch interview with Shampa Sengupta, director, Sruti Disability Rights Centre, Kolkata, April 5, 2013.
 <sup>221</sup> CRPD, art.13.2.

<sup>&</sup>lt;sup>222</sup> On file with Human Rights Watch. Human Rights Watch interview with Dr. Pankaj Kumar, assistant professor, Department of Psychiatry at IHBAS, October 23, 2013. Human Rights Watch interview with Dr. Shweta Sharma, counselor in the Mobile Mental Health Unit, IHBAS, Delhi, October 23, 2013.

# IV. Alternatives to Institutions/Community-Based Strategies

In 12 residential facilities Human Rights Watch visited, rehabilitation initiatives were nonexistent or basic at best. Mental health professionals and staff interviewed in institutions said services geared towards rehabilitation and re-integration into the community are inadequate.<sup>223</sup>According to Dr Pankaj, assistant professor in psychiatry at IHBAS, "It [the mental health system] is too treatment focused; rehabilitation is not adequately addressed in the current model."<sup>224</sup> Residential care rather than day-care facilities still seem to be the norm.

In order for people with psychosocial or intellectual disabilities to realize their full potential, community-based services, independent living arrangements and rehabilitation are good alternatives to institutional care. These services empower women and girls with psychosocial or intellectual by providing them with greater agency and freedom to realize their potential as human beings. They also increase community awareness of their needs and reduce the stigma, discrimination, and violence to which they are subjected.<sup>225</sup>

According to the National Institute of Rehabilitation Training and Research, 90 percent of people with disabilities live in areas with no access to rehabilitation services.<sup>226</sup>The Ministry of Social Justice and Empowerment launched the Scheme to Promote Voluntary Action for Persons with Disabilities in 1999, which became known as the Deendayal Disabled Rehabilitation Scheme (DDRS) in 2003.

<sup>&</sup>lt;sup>223</sup> Institute of Human Behaviour & Allied Sciences, Sambandh Health Foundation, and World Association for Psychosocial Rehabilitation, National Workshop on 'Mental Health Rehabilitation' (Stakeholders' Consultative Meeting), October 28, 2011. Human Rights Watch interview with Dr. Sanjeev Jain, professor of psychiatry and former head of department, NIMHANS, Bengaluru, December 18, 2013; Human Rights interview with Dr Merin, junior resident in psychiatry, IHBAS, Delhi, August 26, 2013; Human Rights Watch group interview with CWC members, Delhi, November 8, 2013; Human Rights Watch interview with CWC members, Delhi, November 8, 2013; Human Rights Watch interview with Mandakini, NGO worker, Saheli, Pune, August 12, 2013.

<sup>&</sup>lt;sup>224</sup> Human Rights Watch interview with Dr. Pankaj, assistant professor in psychiatry, IHBAS, Delhi, October 23, 2013.

<sup>&</sup>lt;sup>225</sup> World Health Organization and The World Bank, "World Report on Disability," 2011,

http://whqlibdoc.who.int/publications/2011/9789240685215\_eng.pdf (accessed December 10, 2013).

<sup>&</sup>lt;sup>226</sup> "DDRC," undated, *National Institute of Rehabilitation Training and Research*, http://www.svnirtar.nic.in/?q=node/16 (accessed December 7, 2013).

Under the DDRS, the government provides a range of services including assistance for independent living and assists NGOs in rehabilitating people with disabilities. Under this scheme, the government also funds District Disability Rehabilitation Centres (DDRC) and Composite Regional Centre for Persons with Disabilities (CRC), which offer a few services, namely psychological support, targeted at people with psychosocial or intellectual disabilities. However, their reach is still limited as the DDRCs only provided assistance to an average of 230,000 beneficiaries annually between 2007-11 and there are only five CRCs (in Srinagar, Sundernagar, Lucknow, Bhopal and Guwahati) in the country.<sup>227</sup>

"After the 2001 Erwadi incident, we believed quite strongly that the government would come out with a roadmap for a shift from institutional to community-based services but paradoxically, they liberalized the creation of private institutions," explains Bhargavi Davar, leading advocate and founder of Bapu Trust for Research on Mind and Discourse.<sup>228</sup>

The few local community support and independent living initiatives available in India are run by NGOs. Although NGOs have implemented some creative and innovative models to provide essential services, without government support they cannot meet the vast need for violence prevention and community-based services, which remain the responsibility of the public sector.

NGOs such as Anjali: Mental Health Rights Organization and Bapu Trust for Research on Mind and Discourse have proved that providing voluntary and sustainable communitybased services for people with psychosocial disabilities is possible. Anjali trains local community leaders in urban areas and slums in Kolkata to provide peer support and guide women and girls with psychosocial disabilities to the appropriate services. By collaborating with women from the community, Anjali has created an environment where community members feel safe seeking help when required, help that will be provided by members of their own community with a deeper understanding of their situation and concerns.

 <sup>&</sup>lt;sup>227</sup> Human Rights Watch group interview with Mr. Venkatesh, Mrs. Kalpana, Vijay Kant, founding members, KPAMRC, Bengaluru, April 1, 2013; Planning Commission, "Twelfth Five-Year Plan (2012-2017): Social Sectors," 2013, http://planningcommission.gov.in/plans/planrel/12thplan/pdf/12fyp\_vol3.pdf (accessed January 24, 2014), p.265.
 <sup>228</sup> On August 6, 2001, there was a fire in the faith-based Moideen Badusha Mental Home in Erwadi village, Tamil Nadu. Twenty-eight residents of the home perished in the fire as they were bound by chains and could not escape. Human Rights Watch interview with Bhargavi Davar, founder, Bapu Trust for Research on Mind and Discourse, Pune, February 14, 2013.

The Bapu Trust works in some of Pune's inner city slums to promote the participation, agency and dignity of persons with psychosocial disabilities in the community. Taking a holistic approach, field workers employ various activities such as home visits, group or street meetings, exhibitions and awareness programs. For example, Bapu Trust organizes poster exhibitions or meetings at street corners to discuss mental health issues in the slums. They also have support groups for women and men that meet on a monthly basis.

The Banyan, an NGO in South India, has demonstrated a viable alternative to institutional care that is based on the provision of mental health services in the community and support for independent living. The Banyan has developed a gamut of services for rural (50 *panchayats*, elected village councils) and urban (Chennai city) settings, including housing with supportive services in the community, mental health clinics, social care services, psychiatric outpatient facilities, health care services, a day care center, financial support, support groups, community networking, awareness, and sensitization campaigns. Banyan also has a transit center called Adaikalam, where homeless women with psychosocial disabilities rescued from the streets can access comprehensive services such as food, shelter, clothing, medical and psychiatric care, psychological therapies, occupational interventions, social care, rehabilitation and legal aid. Once the woman better understands her disability and is ready for rehabilitation, she journeys back to her family or community or chooses to access housing with supportive services. The center can accommodate 160 women at a time. Since its inception in 1993, the center has rescued 1,650 women with disabilities and successfully reunited 1,300 of them with their families and the community.<sup>229</sup> Fifty women live in a cottage style open facility in a rural setting co-located with the organization's academic Institute and social enterprise initiatives. Fifty-six live independently in shared homes in the community or with graded levels of support from The Banyan.<sup>230</sup>

 <sup>&</sup>lt;sup>229</sup> Human Rights Watch phone interview with Lakshmi Narasimhan, senior research associate at Banyan, November 7, 2014.
 <sup>230</sup> Ibid.

To ensure that women and girls who are homeless and vulnerable to violence on the street, Iswar Sankalpa, a Kolkata-based NGO, started a night shelter. A team of social workers identifies and approaches women on the streets and in the community, and asks if they would like spend the night at the shelter in safety. Iswar Sankalpa provides food, clothing, and cares for the women's basic hygiene. The women are at liberty to come and go as they please. In the first few days, women are provided with medical care and given time to settle down. Once they are comfortable in their surroundings, the shelter emphasizes that they do their own chores (cooking, washing, cleaning) to ensure they can cope once they go home.

Once the women recover, the shelter restores them to their families or, if that is not an option, resettles them in the community. The shelter also focuses on rehabilitating women through vocational and income generating activities. Social workers from the shelter also try to create a local community support system for each woman who comes to the shelter; they try to identify caregivers who can help keep a look out for the woman on the streets, for example, a *chaiwalla* [tea shop owner] or local street vendor who can alert the shelter if the woman needs additional support. Staff from the shelter has also successfully reached out to the Kolkata police, who now refer women, including women with disabilities, to the shelter.

# V. Legal Framework

Under international and national law, India has an obligation to respect the rights of persons with disabilities. However, in practice it has done little to safeguard their rights and ensure enforcement.

### **Key International Obligations**

India is a party to most major international human rights conventions, including the International Covenant on Economic, Social and Cultural Rights (ICESCR),<sup>231</sup> the International Covenant on Civil and Political Rights (ICCPR),<sup>232</sup> the Convention on the Elimination of Discrimination against Women (CEDAW)<sup>233</sup> and the Convention on the Rights of the Child (CRC).<sup>234</sup> India is a signatory to the Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment (Convention against Torture),<sup>235</sup> though it has yet to ratify it. In 2007, India ratified the Convention on the Rights of Persons with Disabilities (CRPD) but it has not signed its Optional Protocol.<sup>236</sup>

The CRPD makes explicit that the human rights enumerated in other major human rights documents apply with equal force and in particularly important ways to individuals with disabilities. The treaty shifts the paradigm from old stereotypes that a person's impairment was the root cause of the "problem," and focuses instead on the "disabling" barriers erected by society and the state's responsibility to remove them and to meet the needs of persons with disabilities.

<sup>&</sup>lt;sup>231</sup> International Covenant on Economic, Social and Cultural Rights, G.A. res. 2200A (XXI), U.N. Doc. A/6316 (1966), entered into force January 3, 1976, acceded to by India April 10, 1979.

<sup>&</sup>lt;sup>232</sup> International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 2200A (XX1), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976, acceded to by India April 10, 1979.

<sup>&</sup>lt;sup>233</sup> Convention on the Elimination of Discrimination Against Women (CEDAW), adopted December 18,1979 by G.A. resolution 34/180, entered into force on September 3, 1981, signed by India July 30, 1980 and ratified by it on July 9, 1993 with certain reservations.

<sup>&</sup>lt;sup>234</sup> Convention on the Rights of the Child, G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, acceded to by India December 11, 1992.

<sup>&</sup>lt;sup>235</sup> Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment (CAT), adopted December 10, 1984 and entered into force on June 26, 1987, in accordance with article 27(1) by General Assembly resolution 39/46, signed by India October 14, 1997.

<sup>&</sup>lt;sup>236</sup> CRPD.

The convention's guiding principles include inherent dignity, individual autonomy including the freedom to make one's own choices, independence, full and effective participation, inclusion, non-discrimination, respect and acceptance, equality of opportunity and accessibility for persons with disabilities.

#### Right to Equality and Non-Discrimination

The ICESCR, ICCPR, CEDAW, CRC, and the CRPD all expressly prohibit discrimination and require States Parties to take measures to eradicate all forms of discrimination against individuals, including persons with disabilities.<sup>237</sup>

The CRPD articulates that "all persons are equal before and under the law and are entitled without discrimination to the equal protection and equal benefit of the law."<sup>238</sup> Article 5 of the CRPD obligates all States Parties to prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds and to take all appropriate steps to ensure that reasonable accommodation is provided.

#### Rights of Women with Disabilities

Under article 6, the CRPD obligates states parties to take due cognizance of the multiple discrimination that women and girls with disabilities endure and to take the required measures to ensure the "full development, advancement and empowerment of women,"<sup>239</sup> for the purpose of guaranteeing them the exercise and enjoyment of all human rights and fundamental freedoms.

The CEDAW Committee, which monitors implementation of the CEDAW, recommends special measures by States Parties to ensure equal access to education, employment, health services and social security for women with disabilities, so as to facilitate their full participation in social and cultural life.<sup>240</sup>The committee also addresses the issue of gender-based violence and condemns it as "a form of discrimination that seriously inhibits

<sup>&</sup>lt;sup>237</sup> ICESCR, art. 2 (1). ICCPR, art. 2(1). CEDAW, art. 5. CRC, art. 2 (1).

<sup>238</sup> Ibid., art. 5.

<sup>239</sup> Ibid., art. 6.

<sup>&</sup>lt;sup>240</sup> CEDAW General Recommendation No. 18 (tenth session, 1991), General recommendations made by the Committee on the Elimination of Discrimination against Women, Division for the Advancement of Women, UN Department of Economic and Social Affairs, http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm.

women's ability to enjoy rights and freedoms on a basis of equality with men."<sup>241</sup>The committee has expressed its concern for "the situation of disabled women, who suffer from a double discrimination linked to their special living conditions."<sup>242</sup>

#### Right to Equal Recognition before the Law

Article 12 of the CRPD introduces a significant shift in approach to legal capacity, giving agency to persons with disabilities and empowering them to make decisions and exercise rights on one's own behalf. It requires States Parties to recognize that persons with disabilities are persons before the law who enjoy legal capacity on an equal basis with others in all aspects of life.<sup>243</sup> The CRPD rejects the presumption that persons with disabilities are unfit to exercise agency, and makes it clear that persons with disabilities that the will and preferences of the person should be respected. The treaty further obligates States Parties to provide support as may be required to exercise one's legal capacity.

#### Right to Live in the Community

Article 19 of the CRPD establishes the right of all persons with disabilities to live in the community, with choices equal to others, and obligates States Parties to take the appropriate measures to ensure their full inclusion and participation in the community.<sup>244</sup> Under the CRPD, persons with disabilities have the right to choose their place of residence and with whom they live. Governments are required to provide access to a range of in-home, residential, and other community support services to prevent isolation from the community, including personal assistance, and ensure that community services and facilities are available and responsive to their needs.<sup>245</sup>

#### Freedom from Exploitation, Violence, and Abuse

Protection against all forms of exploitation, violence, and abuse including their genderbased aspects is enshrined in article 16 of the CRPD, requiring States Parties to take all the appropriate legislative, administrative, social, educational, and other measures to this

 <sup>&</sup>lt;sup>241</sup> CEDAW General Recommendation No. 19 (11th session, 1992), General recommendations made by the Committee on the Elimination of Discrimination against Women, Division for the Advancement of Women, UN Department of Economic and Social Affairs, http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm (accessed June 30, 2010).
 <sup>242</sup> Ibid.

<sup>&</sup>lt;sup>243</sup> Ibid., art. 12.

<sup>&</sup>lt;sup>244</sup> Ibid., art. 19.

<sup>&</sup>lt;sup>245</sup> Ibid., art. 19.

effect. These measures should include "the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse."<sup>246</sup>

The CRPD also requires governments to effective monitor all facilities and programs designed to serve persons with disabilities through independent authorities. States should also promote the physical, cognitive, and psychological recovery, rehabilitation, and social reintegration of persons with disabilities who become victims of any form of exploitation, violence, or abuse.<sup>247</sup> These rights are also recognized in the ICCPR, CRC, and CEDAW.

#### Right to Liberty and Security of the Person

Article 14 of the CPRD introduces strong safeguards against arbitrary detention and deprivation of liberty for persons with disabilities, providing them better protection than the provisions of article 9 of the ICCPR. Article 14 not only prohibits arbitrary detention but also categorically declares "the existence of a disability shall in no case justify a deprivation of liberty."<sup>248</sup>

# Freedom from Torture or Cruel, Inhuman, or Degrading Treatment or Punishment and Right to Protection of Personal, Mental, and Physical Integrity

The ICCPR, CRC, and the CRPD all prohibit subjecting any person to torture or to cruel, inhuman, or degrading treatment or punishment, including non-consensual medical or scientific experimentation.<sup>249</sup> Furthermore, the CRPD requires all States Parties to "take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment."<sup>250</sup>

<sup>246</sup> Ibid., art. 16.

<sup>&</sup>lt;sup>247</sup> Ibid., art. 16.

<sup>&</sup>lt;sup>248</sup> CRPD, art 14b. Committee on the Rights of Persons with Disabilities, "Statement on article 14 of the Convention on the Rights of Persons with Disabilities," September 2014,

http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183&LangID=E#sthash.ErjRRgos.9wBvLiwR.dpu f (accessed October 30, 2014).

<sup>249</sup> ICCPR, art. 7; CRC, art. 37; CRPD, art. 15.

<sup>250</sup> CRPD, art. 15.

Although India has not ratified the Convention against Torture, it is bound by the prohibition in international law of torture and cruel, inhuman or degrading treatment or punishment and the prohibition set out in article 15 of the CRPD.

This prohibition against torture or cruel, inhuman, or degrading treatment "relates not only to public officials, such as law enforcement agents in the strictest sense, but may apply to doctors, health professionals and social workers, including those working in private hospitals, other institutions and detention centers."<sup>251</sup>

According to the UN special rapporteur on torture, forced psychiatric intervention on the grounds of disability alone are forms of torture and ill treatment.<sup>252</sup>The CRPD also recognizes the right of every person with disabilities to respect for his/her physical and mental integrity on an equal basis with others.<sup>253</sup>

#### Right to Health

The highest attainable standard of physical and mental health is a fundamental human right enshrined in numerous international human rights instruments, including the Universal Declaration on Human Rights, the ICESCR, the CRC, CEDAW and the CRPD. Article 12 of the ICESCR specifies that everyone has a right "to the enjoyment of the highest attainable standard of physical and mental health".<sup>254</sup> According to the Committee on Economic, Social and Cultural Rights, the body charged with monitoring compliance with the ICESCR, access to health facilities, goods and services should be non-discriminatory, especially for "the most vulnerable or marginalized sections of the population,"<sup>255</sup> including individuals with disabilities.<sup>256</sup>

The CRPD further requires access to health services that are gender-sensitive for persons with disabilities. Additionally, it stipulates that health information be accessible to persons with

<sup>&</sup>lt;sup>251</sup> See General Comment No. 2 (2008) of the Committee against Torture on the implementation of article 2 of the Convention (CAT/C/GC/2), para. 17. See also U.N. Commission on Human Rights, Report of the Special Rapporteur on torture and cruel, inhuman or degrading treatment or punishment, Session 7, A/HRC/7/3, para. 31.

<sup>&</sup>lt;sup>252</sup> Juan Mendez, "Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment," February 1, 2013, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/ Session22/A.HRC.22.53\_English.pdf (accessed December 5, 2014) para.58.

<sup>&</sup>lt;sup>253</sup> CRPD, art. 17.

<sup>&</sup>lt;sup>254</sup> ICESCR art, 12.

<sup>&</sup>lt;sup>255</sup> CESCR, General Comment No. 14, para 12(b).

<sup>&</sup>lt;sup>256</sup> Ibid. para 18.

disabilities and that the delivery of health services not discriminate on the basis of disability. It also explicitly requires the full and informed consent of persons with disabilities to medical treatment.<sup>257</sup>

Under the CRPD, states also have an obligation to provide comprehensive rehabilitation services, especially with regard to health, employment, education, and social services. These services must be voluntary and should be made available at the earliest possible stage, as close as possible to their communities.<sup>258</sup>

### Indian National Laws

The Constitution of India guarantees fundamental rights to all its citizens including persons with disabilities. Dignity of the individual is an essential notion underpinning all the fundamental rights guaranteed under Part III of the Constitution of India. Although disability is not defined in the constitution, certain clauses direct the state to make effective provision for securing the right to work, to education, and to public assistance in cases of disability, among others. With increasing awareness of disability-based discrimination, some explicit legal safeguards have now been introduced, building on the old legal framework.

Following India's ratification of the CRPD in 2007, the government began re-drafting India's mental health and disability laws to bring them into line with the new international treaty. Two new laws are currently pending before parliament: the Rights of Persons with Disabilities Bill (RPD Bill) repeals the Persons with Disabilities (Equal Opportunities Protection of Rights and Full Participation) Act (1995) and the Mental Health Care Bill (MHC Bill) would replace the Mental Health Act (1987). Both bills are discussed in more detail below.

### The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

The National Trust Act (NTA) establishes an administrative body called the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, which is primarily responsible for creating an enabling environment that will

"TREATED WORSE THAN ANIMALS"

<sup>&</sup>lt;sup>257</sup> Ibid. art. 25(d).

<sup>&</sup>lt;sup>258</sup> CRPD, art 26.

allow persons with disability to live "as independently and as fully as possible within and as close to the community to which they belong," including facilitating support, and for monitoring legal guardianship of persons with developmental or intellectual disabilities.<sup>259</sup> The NTA details the procedures for appointment of a guardian by the local level committee. The NTA is also in the process of being replaced with a new bill that would be in line with the requirements of the CRPD.

# *The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995*

The Persons with Disabilities Act, 1995, (PWDA) focuses on promoting and ensuring equality and full participation of persons with disabilities. Under the PWDA, "mental retardation" and "mental illness" are recognized as forms of disability.

The act lacks any protection of civil and political rights, and only partially covers economic and social rights, such as education, social security and creation of a barrier-free environment.<sup>260</sup> For example, one critical missing issue is mechanisms for access to justice for people with disabilities.<sup>261</sup>The PWDA is also strikingly silent on the issue of legal capacity, a crucial right impacting many other rights for persons with disabilities.<sup>262</sup>

#### The Rights of Persons with Disabilities Bill, 2013

The RPD Bill is due to replace the PWDA, 1995, and addresses the latter's flaws and failures. For example, the RPD bill provides new mechanisms for redress by establishing the National and State Commissions for Persons with Disabilities.

The earlier draft of the RPD was drawn up in consultation with DPOs but has since been greatly diluted. Significantly, the emphasis of the latest bill does reflect the rights-based model of disability enshrined in the CRPD. In addition, the bill still foresees the possibility of plenary guardianship, and does not guarantee the right to exercise legal capacity, leaving the door open to involuntary institutionalization and treatment.

<sup>&</sup>lt;sup>259</sup> National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, "About Us," http://www.thenationaltrust.co.in/nt/index.php?option=com\_content&task=view&id=94&Itemid=143 (accessed February 16, 2014).

<sup>260</sup> lbid., p. 214.

<sup>261</sup> lbid., p. 220.

<sup>262</sup> DAVAR, op.cit. 8, p. 2.

One of the most alarming aspects of the bill is that the clause on discrimination is not absolute: "No person with disability shall be discriminated on the ground of disability, unless it is shown that the impugned act or omission is appropriate to achieve a legitimate aim." The RPD bill does not follow a twin-track approach with regard to including women and girls with disabilities in providing special protections for this population as well as integrating them into all other general clauses.

#### Mental Health Legislation

The proposed Mental Health Care Bill (MHC Bill) is meant to replace the Mental Health Act (1987). In effect, compared to the Mental Health Act, the MHC bill offers little additional protections for persons with psychosocial or intellectual disabilities, particularly as the MHC bill continues to allow institutionalization and treatment without consent in more than extremely limited circumstances.

The MHC bill creates a right to access mental health care in mental hospitals as well as through a range of different services such as shelter homes, supported accommodation, and community-based rehabilitation. The proposed bill also provides the right to community living, right to protection from cruel, inhuman and degrading treatment, right to equality and non-discrimination, right to confidentiality, right to access medical records, right to legal aid, and right to make complaints about deficiencies in provisions of services, among others.<sup>263</sup>

Persons with psychosocial disabilities also have the right of a safe and hygienic living environment, with adequate provision of food, facilities for recreation, privacy, etc., and shall not be subjected to physical or sexual abuse or forced to undertake work. Furthermore, the bill states that the Insurance Regulatory Development Authority will ensure that all insurance providers cover treatment for mental health conditions on an equal basis with treatment for physical illnesses.

A key advancement in the MHC Bill is undoubtedly the recognition that every person, including a person with a psychosocial disability, is *a priori* deemed to have the capacity to make decisions about her or his mental health care and treatment. However, what is

"TREATED WORSE THAN ANIMALS"

<sup>&</sup>lt;sup>263</sup> The MHC bill, 2013, chapter V.

highly problematic is that to be recognized as capable the person with a psychosocial disability has to pass a "competency test," the criteria of which are detailed in the bill: the ability to understand the information, to retain the information, use or weigh that information, and communicate a decision (clause 4).<sup>264</sup>This clause allows the possibility for persons with psychosocial disabilities to be treated without their consent.

The MHC Bill seeks to provide two alternative means of decision-making when a person with psychosocial disabilities is deemed unable to make choices about treatment: advance directives (AD), and nominated representatives (NR). An AD is a document in which a person, in a moment of clarity, explains the choices of treatment they want to be respected in the future. An AD must be approved by the Mental Health Review Board (MHRB) and signed by a medical practitioner. It cannot be contrary to law, and can be amended, cancelled, or revoked at any time.

Once all of these conditions are fulfilled, an AD becomes binding on psychiatrists. Nevertheless, these numerous conditions considerably weaken the power of an AD as a means of expressing choice of treatment, especially as the AD does not apply to any "emergency treatments."<sup>265</sup> Plus, section 11 (1) & (2) allows the AD to be overruled, after review by a board, if a mental health professional, care-giver, or relative so 'desires' and in circumstances including it the "person is not sufficiently well-informed to make the decision." Section 11 dilutes the function of an AD altogether.

In addition, guardians can make ADs on behalf of children, which may be incompatible with the CRPD's principle that requires respect for the evolving capacity of children. Finally, nowhere does the bill oblige the State to take steps to ensure the informed consent of the person.

The other alternative to decision-making provided by the MHC bill is NRs. Using an AD, a person with a psychosocial disability can appoint an NR of his/her choice to assist them in making decisions. However, if the person with a disability has not appointed anyone in the AD, then the bill allows for a relative, caregiver, another suitable person or the director of the department of social welfare, or his designated representative, to be deemed or

<sup>&</sup>lt;sup>264</sup> The MHC bill, 2013.

<sup>&</sup>lt;sup>265</sup> The MHC bill, 2013, clause 9.

appointed as the NR.<sup>266</sup> Given that the NR may be appointed by someone other than the person with a disability and may even be someone who is entirely unknown to him/her, local disability advocates and others have raised concerns that the person may not be aware of, or respect the will and preference of, the person with a disability.

Furthermore, there are no safeguards in place to prevent the NR from making decisions on the person's behalf rather than limiting their authority and role to assisted-decision-making. For example, an NR is empowered to take decisions on behalf of a person with a psychosocial disability who "fails" the "competency test", with "all-encompassing rights-to make treatment decisions, admission, discharge, appeals, proxy consent for research conducted on their ward."<sup>267</sup> In the MHC bill, the person with psychosocial or intellectual disability and his or her NR are referred to interchangeably, hence implicitly maintaining a system of substituted decision-making, far from CRPD requirements.

Furthermore, the MHC bill shifts from "involuntary admission" to "supported admission," and allows for the automatic review of any supported admission by the Mental Health Review Commission within a period of seven days. A "supported admission" is the institutionalization and treatment, without consent, of a person with a psychosocial disability (with high support needs) in a mental health establishment for up to 30 days. However, the bill eliminates review of the admission by a magistrate and leaves admissions and discharges to a quasi-judicial board composed of psychiatrists and district judges.

The MHC bill prohibits electro-convulsive therapy (ECT) on adults without the use of muscle relaxants and anaesthesia, as well as forced chaining of persons with psychosocial disabilities. The bill fails to prohibit ECT without consent of the individual concerned. ECT on minors [defined as anyone below 18] is prohibited in most cases but "if, in the opinion of psychiatrist in charge of a minor's treatment, electro-convulsive therapy is required, then, such treatment shall be done with the consent of the guardian and prior permission of the concerned Board."<sup>268</sup> The bill fails to recognize and take into account the evolving capacity of children to weigh in on medical decisions. As stated by the UN special

<sup>&</sup>lt;sup>266</sup> The MHC bill, 2013, clause 14(4).

<sup>&</sup>lt;sup>267</sup> Bhargavi V Davar, "Legal Frameworks for and against People with Psychosocial Disabilities," p. 129.
<sup>268</sup> The MHC Bill, art. 102.2.

rapporteur on torture, ECT without informed consent amounts to cruel and degrading treatment, even with the use anaesthesia and muscle relaxants.<sup>269</sup>

The MHC continues to allow for the use of physical restraint in certain circumstances and decriminalizes suicide under section 124 but assumes that people attempting suicide are doing so under severe stress and therefore require care and treatment from the state. Section 124 does not provide any safeguards against people who have attempted to commit suicide from being institutionalized or treated against their will. The bill further allows for research to be carried out on persons with psychosocial disabilities "who [are] unable to give free and informed consent but does not resist participation in such research," as long as the concerned state authority accords permission. This is in clear violation of article 15 of the CRPD.

Another criticism of the bill is the lack of clarity about the government's concrete duties and the timeframe. For example, clause 19(2) provides that, "The appropriate Government shall, within a reasonable period, provide for or support the establishment of less restrictive community based establishments."

See Kothari, Jayna and Chatur, Dharmendra, "Moving Towards Autonomy and Equality: An Analysis of the New Mental Health Care Bill," 2012, *Centre for Law and Policy Research*,

http://www.academia.edu/3323909/Moving\_Towards\_Autonomy\_and\_Equality\_An\_Analysis\_of\_the\_new\_Mental\_Health\_C are\_Bill\_2012 (accessed December 12, 2013), p.9.

<sup>&</sup>lt;sup>269</sup> Juan E. Méndez, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53, February 1, 2013,

http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\_English.pdf (accessed December 28, 2013).

# **Full Recommendations**

#### To the Central Government

#### For Mental Health Facilities and Residential Care Institutions

- Immediately improve conditions in mental hospitals and state and NGO-run residential care institutions to ensure the human rights of persons with psychosocial or intellectual disabilities are respected by:
  - developing guidelines for sanitation, hygiene, and living conditions and prohibiting arbitrary detention without judicial review and involuntary electroconvulsive therapy;
  - developing and implementing guidelines that prioritize making the institutional environment accessible and making medical forms, specifically consent forms, available in local languages and in easy-to-read formats;
  - ensuring that children with psychosocial or intellectual disabilities have access to inclusive public education.
- Ensure that the Central Mental Health Authority has adequate funding and staff, meets regularly, and effectively monitors the work of State Mental Health Authorities.
- Ensure that all mental hospitals and residential care institutions for persons with psychosocial disabilities are regularly monitored by state mental health authorities and state councils in states that have enacted the Clinical Establishments Act.
- Ensure that all residential care institutions for people with intellectual disabilities are monitored by the National Trust and in cases of children in institutions, relevant Child Welfare Committees.
- Create an independent and confidential complaint mechanism that can receive and investigate complaints, including on a confidential basis, about ill-treatment of persons with psychosocial or intellectual disabilities in institutions.
- Require all government and privately-run institutions to provide accessible information to persons with psychosocial or intellectual disabilities and inform them about their rights and complaint procedures.

- Progressively end institutionalization by ensuring that the Ministry of Health and Family Welfare, the Ministry of Social Justice and Empowerment, and the National Trust no longer provide funding for building new institutions or major refurbishments for existing institutions. Make running, funding, and providing access to community-based services for persons with disabilities a top priority.
- Progressively ensure that all issues pertaining to persons with disabilities, including persons with psychosocial or intellectual disabilities, are covered by the same ministry. For example, the concerns of persons with psychosocial disabilities should no longer be covered by the Ministry of Health but instead by the Ministry of Social Justice and Empowerment that oversees all disability affairs.

#### For Legal Reform and Policy Implementation

- Recognize institutionalization based on disability as a form of discrimination and institutionalization without consent of the individual as a form of arbitrary detention.
- Create and implement a de-institutionalization policy and a time-bound action plan for de-institutionalization, based on the values of equality, independence, and inclusion for persons with disabilities. Ensure that this plan does not aim to transform existing institutions but is targeted towards progressively closing them down and developing a wide range of community-based alternatives that are rooted in the will and preference of the individual with a disability. Make sure that preventing of institutionalization is an important part of this plan and that persons with disabilities, DPOs, and NGOs working on deinstitutionalization are invited to participate in the formation of this plan. When necessary, seek out the experiences of other countries that have fully undergone deinstitutionalization.
- Amend or repeal all domestic legislation that violates the CRPD, including the National Trust (For welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities) Act (1999) and The Mental Health Act (1987), and ensure that persons with psychosocial or intellectual disabilities are guaranteed legal capacity, equal recognition before the law, freedom from discrimination, protection from violence including involuntary detention and forced treatment, and supported decision-making as opposed to guardianship (plenary and limited).

- Amend legislation to remove clauses referring to persons of 'unsound mind.'
- Pass the Rights of Persons with Disabilities Bill, with the following amendments:
  - Instead of using a medical definition of disability, take a rights-based approach described in the CRPD, which views disability as a result of the interaction between persons with impairments and attitudinal and environmental barriers that hamper their full participation in society.
  - Recognize the legal capacity of all persons with disabilities on an equal basis with others and the right to exercise it. Remove clauses that allow for plenary or limited guardianship. Instead provide accommodations and access to support where necessary to exercise legal capacity.
  - Include all persons with disabilities under the bill, including persons with psychosocial disabilities.
  - Ban all forms of involuntary treatment, including electroconvulsive therapy, without the person's free and informed consent.
  - Adopt a twin-track approach to including women and girls in disabilities: dedicating specific provisions to their protection and well-being as well as including them in general provisions.
  - Ensure that women with disabilities and persons with psychosocial or intellectual disabilities are adequately represented in the National Commission for Persons with Disabilities and State Disability Commissions. Ensure that the National and State Commissions for Persons with Disabilities have adequate resources and an independent monitoring capacity to investigate complaints of abuses against persons with disabilities, including women and girls.
  - Consult with DPOs from across the disability spectrum to ensure inclusion, particularly with women with disabilities and persons with psychosocial or intellectual disabilities. In consultation with DPOs, progressively develop state and NGO-run independent and assisted living services.
- Only pass the Mental Health Care Bill, after consulting with disabled persons' organizations and advocates representing persons with psychosocial disabilities and with at the very least the following amendments:
  - Recognize the legal capacity of all persons with disabilities on an equal basis with others and the right to exercise it. Remove clauses that allow for plenary or

limited guardianship, "supported admission," and a "competency test" which could result in treatment without informed consent of the person concerned. Instead provide accommodations and access to support where necessary to exercise legal capacity.

- Ensure that advance directives cannot be overruled by mental health professionals, care-givers, or family members. Ban all forms of involuntary treatment, including electroconvulsive therapy, without the person's free and informed consent.
- Mandate a shift from institutional care to providing access to voluntary community-based mental health and other support services for people with psychosocial disabilities.
- Remove pejorative language such as "mental retardation," "lunatics," "mental illness" people of "unsound mind" and other similar phrases from all government legislation, documentation.
- Ensure that the Juvenile Justice Act, the Protection of Children from Sexual Offences Act, and the Right of Children to Free and Compulsory Education Act (2009), are effectively implemented to include all children with disabilities, with particular attention to the needs of children with psychosocial or intellectual disabilities.
- Ensure the mainstreaming of disability issues in all government programs and schemes by strengthening coordination among relevant ministries (as required by Article 33) and increasing awareness among government officials on disability inclusion.
- Develop a time-bound plan to shift progressively to providing access to voluntary community-based services for women and girls with psychosocial or intellectual disabilities, including adequate and appropriate education, mental health, and reproductive health services. Extend the District Mental Health Program to all districts to ensure it has sufficient resources and trained staff. Support efforts by nongovernment organizations, including disabled persons' organizations, to provide community-based services for persons with psychosocial or intellectual disabilities.
- Ensure that the Chief Commissioner for Persons with Disabilities and state commissioners for disability have adequate resources and an independent

monitoring capacity to investigate complaints of abuses against persons with disabilities, including women and girls with psychosocial or intellectual disabilities.

• Provide gender and disability-sensitive training to the police to sensitize them on interacting with persons with disabilities, particularly women with psychosocial or intellectual disabilities.

#### Data Collection to Inform Policy

- Conduct a survey, in conjunction with disabled persons' organizations, of the conditions in all institutions for persons with psychosocial or intellectual disabilities.
- Ensure that periodic surveys like the National Family Health Survey and others disaggregate data based on gender and disability, including psychosocial or intellectual disability.
- In consultation with disabled persons' organizations, improve census data collection on persons with disabilities to better inform policy decisions.

#### For the Promotion of Mental Healthcare and Delivery of Services

- Progressively end institutionalization by ensuring that the Ministry of Health and Family Welfare, the Ministry of Social Justice and Empowerment, and the National Trust no longer provide funding for building new institutions or major refurbishments for existing institutions. Make running, funding, and providing access to community-based services for persons with disabilities a top priority.
- Create specific budget lines for community support programs and independent and supportive living arrangements for persons with disabilities, particularly women with psychosocial or intellectual disabilities.
- Integrate mental health into general healthcare services and train general practitioners to identify mental health conditions.
- In consultation with disabled persons' organizations, disability experts and persons with disabilities themselves, develop adequate community-based rehabilitation services.

- Conduct a public information campaign to create awareness about persons with disabilities, particularly psychosocial or intellectual disabilities. Target service providers and law enforcement agencies.
- Ensure persons with disabilities are aware of their rights and complaint mechanisms. Make information on health, reproductive services, and access to justice available in accessible formats, including easy-to-understand formats.
- Train more doctors and paramedical staff, including psychiatrists, psychiatric nurses, psychologists and counselors, particularly in free and informed consent.
- Facilitate training of child welfare committees, welfare officers, and counselors in residential care institutions to ensure they are sensitized to the rights of persons with disabilities, particularly women with psychosocial or intellectual disabilities.
- Create a dedicated budget line and create a monitoring mechanism to implement the protocol for treatment of rape survivors, particularly with regard to ensuring the accommodations for women and girls with disabilities.
- Ensure women's and children's helplines are sensitive to the concerns of persons with disabilities and are trained to assist them.

### To State Governments

#### For Mental Health Facilities and Residential Care Institutions

- Immediately improve conditions in all mental hospitals and residential care institutions, including in the private sector, to ensure the human rights of persons with psychosocial or intellectual disabilities are respected by:
  - developing guidelines for sanitation, hygiene, and living conditions and prohibiting arbitrary detention without judicial review and involuntary electroconvulsive therapy;
  - making the institutional environment accessible as a matter of priority, including by making medical forms, specifically consent forms available in local languages and in easy-to-read formats;
  - creating an independent complaint mechanism which can receive and investigate complaints, including on a confidential basis, about ill treatment of persons with psychosocial or intellectual disabilities in institutions;

- ensuring that the state mental health authorities are adequately funded and staffed, meet regularly, and effectively monitor institutions for persons with disabilities and access to community mental health services, particularly district mental health programs.
- Develop a time-bound plan to shift progressively to providing access to voluntary community-based mental health services. Extend the district mental health program to all districts to ensure it has sufficient resources and trained staff. Support efforts by nongovernment organizations, including disabled persons' organizations, to provide community-based services for persons with psychosocial or intellectual disabilities.
- Reduce overcrowding in institutions such as Asha Kiran by progressively developing voluntary community-based assisted living services and other forms of support to allow persons with psychosocial or intellectual disabilities to live independently and in the community.
- Train more doctors, paramedics and other health professionals, including psychiatrists, psychiatric nurses, psychologists and counselors, and provide existing mental health professionals with periodic refresher trainings, particularly on free and informed consent.
- Provide gender and disability-sensitive training to the police to sensitize them on interacting with persons with disabilities, particularly women and girls with psychosocial or intellectual disabilities.
- Ensure that the state commissioners for disability have adequate resources and an independent monitoring capacity to investigate complaints of abuses against persons with disabilities, including women and girls with psychosocial or intellectual disabilities.
- Hold accountable medical professionals who practice or facilitate involuntary sterilizations of women and girls with disabilities.
- Hold accountable mental health professionals who administer or facilitate unmodified electroconvulsive therapy or electroconvulsive therapy without consent.

#### For the Promotion of Mental Healthcare and Delivery of Services

- Create specific budget lines for community support programs and independent and supportive living arrangements for persons with disabilities, particularly women with psychosocial or intellectual disabilities.
- Integrate mental health into general healthcare services and train general practitioners to identify mental health conditions.
- In consultation with disabled persons' organizations, disability experts and persons with disabilities themselves, develop adequate community-based rehabilitation services.
- Create a body composed primarily of experts with disabilities to monitor and assess the effectiveness of community-based support services. Incorporate the conclusions of this body into future policy on the provision of social services.
- Conduct a public information campaign to create awareness about persons with disabilities, particularly psychosocial or intellectual disabilities. Target service providers and law enforcement agencies.
- Ensure persons with disabilities are aware of their rights and complaint mechanisms. Make information on health, reproductive services, and access to justice available in accessible formats, including easy-to-understand formats.
- Train more doctors and paramedical staff, including psychiatrists, psychiatric nurses, psychologists and counselors, particularly in free and informed consent.
- Facilitate training of child welfare committees, welfare officers, and counselors in residential care institutions to ensure they are sensitized to the rights of persons with disabilities, particularly women and girls with psychosocial or intellectual disabilities.
- Create a dedicated budget line and create a monitoring mechanism to implement the protocol for treatment of rape survivors, particularly with regard to ensuring the accommodations for women and girls with disabilities.
- Ensure women's and children's helplines are sensitive to the concerns of persons with disabilities and are trained to assist them.
- Ensure that staff in general hospitals and at crisis centers are trained to accommodate people with diverse disabilities, particularly women, and are sensitive to their needs.

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- Make available special educators and trained interpreters at mental hospitals, custodial homes and institutions for persons with disabilities, police stations and courts.
- Facilitate adequate and appropriate legal aid to persons with disabilities living in institutions.

# To the Management of Mental Hospitals and Residential Institutions for Persons with Psychosocial or Intellectual Disabilities

- On a priority basis, improve infrastructure in mental hospitals, including providing adequate and accessible toilets, sufficient supply of water, food, lice medicine, soap, sanitary napkins, clothes, and footwear.
- Immediately ban all types of violence and forced treatment and create an appropriate and confidential mechanism to report abuse and facilitate redress through judicial means.
- Establish rights-based guidelines on treatment of persons with psychosocial or intellectual disabilities that are in line with the CRPD and in consultation with experts with psychosocial disabilities and self-advocates with intellectual disabilities.
- Immediately fill staff vacancies to address the overburden of existing resources.
- Sensitize and train staff to be attentive and responsive to the concerns and needs of persons with psychosocial or intellectual disabilities, particularly women.
- Immediately provide appropriate and adequate activities and access to education within institutions, in consultation with DPOs and NGOs. Develop creative techniques to motivate persons with disabilities to learn skills.
- Immediately prohibit discriminatory practices against persons with disabilities such as spatial segregation and use of derogatory words.
- Immediately review the judicial status of long-stay patients to ensure persons with psychosocial or intellectual disabilities are not detained beyond the date stated in the court order.
- Restore and rehabilitate persons with psychosocial or intellectual disabilities only after investigating family background to ensure there is no possibility of abuse.

- Progressively move toward Outpatient Department, daycare services and shortterm, voluntary in-patient care rather than long-term admission.
- Sensitize families to the needs and rights of persons with psychosocial or intellectual disabilities and involve them in caring for relatives.

### To National and State Human Rights Commissions

• Ensure regular and periodic monitoring of conditions in mental hospitals and institutions for persons with psychosocial or intellectual disabilities. The investigating team should be independent and not include management from these institutions and should pay particular attention to the situation of women and children.

### To National and State Commissions for Women

• Ensure regular and periodic monitoring of conditions in residential care institutions for women and girls with disabilities.

### To National and State Commissions for Protection of Child Rights

• Ensure regular and periodic monitoring of conditions in residential care institutions for children with disabilities.

# To International Donors, including the World Bank, Asian Development Bank, and Bilateral Government Donors

- Encourage the Indian government to respect its international obligations under the CRPD, particularly its principles of equality, non-discrimination, independence and inclusion.
- Support the government of India and DPOs through funding and technical assistance to protect the rights of persons with disabilities, particularly women with disabilities and persons with psychosocial or intellectual disabilities.
- Earmark financial and other forms of support and assistance towards support and community-based mental health services. Ensure these programs are gender-sensitive.

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# "Treated Worse than Animals"

Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India

Women and girls with psychosocial or intellectual disabilities in India experience widespread violations of their rights, including denial of legal capacity—the right to make one's own decisions—and a lack of community-based support and services. They are particularly vulnerable to being admitted without their consent to institutions where they face a range of abuses, including neglect, verbal and physical violence, and involuntary treatment.

Through over 200 interviews conducted across six cities in India, "Treated Worse than Animals" reports on abuses against women with psychosocial or intellectual disabilities in institutions in India. It documents their involuntary admission to mental hospitals and residential care institutions, where they experience prolonged detention, unsanitary conditions, denial of adequate and appropriate healthcare, and forced treatment, including electroshock therapy. Finally, it analyzes the challenges that women with psychosocial or intellectual disabilities experience in reporting abuses and accessing justice.

Human Rights Watch recommends that India undertake urgent reforms to guarantee the legal capacity of people with psychosocial or intellectual disabilities and take steps to shift from institutional to community-based care and services for people with disabilities. India should ensure that both the Mental Health Care and Rights of Persons with Disabilities bills are fully in line with its obligations under the international Disability Rights Convention.



(above) Jamila, a 19-year-old woman diagnosed with bipolar disorder, puts her arms through the bars of her locked isolation cell in Thane Mental Hospital, Mumbai.

(front cover) A resident sits on the floor in the women's ward of Thane Mental Hospital, a 1,857-bed facility in the suburbs of Mumbai.

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