**Submission on behalf of Sruti Disability Rights Centre, Point of View and CREA**

**Introduction**

People with disabilities are inhibited from realizing their full human rights by multiple physical and attitudinal barriers. Women with disabilities often face multiple forms of discriminations, based on race, class, socio-economic status, gender and age, due to restrictions imposed by social norms inherent to these aspects of their identities or gender expression. It is not possible to effectively work to advance the rights of women with disability without also understanding and addressing issues related to sexuality, sexual and reproductive health gender and rights, and recognising the cultural, social and legal norms that deeply influence them.

**About Sruti Disability Rights Centre**

Sruti Disability Rights Centre is a non-funded advocacy group which works at policy level on intersections of disability and gender rights issues.

**About Point of View**

Point of View is a Mumbai- based non profit organisation established in 1996. It amplifies women’s voices and removes barriers to voice, speech and expression. Through media, education, technology, and art, Point of View works at the intersection of gender, sexuality and violence. At its sexuality and disability program, Point of View believes that girls and women with disabilities are sexual beings just like anyone else. Love, Sex, Romance, Intimacy, Having children, Dealing with the ins and outs of relationships - These are all everyday aspects of sexuality. But women with disabilities are often cut off from these life experiences, mainly because they’re seen as asexual. Point of View empowers women with disabilities by helping them change their ideas of themselves. Point of View’s pioneering site, sexualityanddisability.org, provides information on everything from body image and menstruation to sexual harassment and abuse. Our flagship workshops do the same - on the ground.

**About CREA**

CREA is a feminist human rights organisation based in New Delhi, India, working with partners (in India, Nepal and Kenya) from a diverse range of human rights movements and networks, to advance the rights of women and girls, and the sexual and reproductive freedoms of all people. To advance its goals, CREA uses an intersectional approach in all of its work, including work on disability and sexuality, through capacity building and direct advocacy and lobbying. CREA's work on sexuality and disability addresses misconceptions and prejudices about disabled women's sexuality and sexual and reproductive health and rights (SRHR). It seeks to provide women with disability information, change public perception on these issues and influence laws and policies to be more inclusive of disabled women's rights.

**Laws affecting people with disability**

In 2016 India passed the Rights of Persons with Disabilities Act (2016 Act)[[1]](#footnote-1). This Act replaces the Persons with Disabilities Act, 1995. A major concern with the 2016 Act is clause 3(3) which states that “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.” This clause gives unfettered power to the implementing authorities to discriminate against persons with disabilities, on the pretext of serving a legitimate aim, whatever that may refer to. However, despite this, the 2016 Act is a step towards recognising the rights of persons with disabilities. The Act makes specific provisions for social security, health, rehabilitation and recreation, which is an improvement, given that affirmative action for the disabled until now has only referred to reservations (apart from a dole erroneously called pension), with a few concessions thrown in.

In 2017 India passed the Mental Health Care Act[[2]](#footnote-2). The Act ‘marks a paradigm shift from viewing persons with psychosocial disabilities requiring institutionalisation, to persons enjoying equal rights, legal capacity and autonomy’[[3]](#footnote-3). The Act, for the first time, provides for the right to health care while expanding access to treatment. The Act further goes on to decriminalise attempt to suicide.

On the other hand, a few years back India introduced a unique identification system known as the ‘Aadhar’ which was intended to work as a singular identification using biometrics and retina scans. In Point of View’s engagement with women with disabilities in their work in a district is Karnataka, a state in India, difficulties in connection with the highly contested aadhaar has been bought to their notice. There has been a failure to verify iris/retina scans and fingerprints (especially persons with cerebral palsy or muscular disorders); but persons with disabilities are also encountering troubles in the enrolment phase itself. This exclusion being faced is being reported in [the enrolment stage](http://www.thehindu.com/news/cities/chennai/aadhaar-a-double-whammy-for-the-disabled/article20629931.ece) for [Aadhaar cards](https://www.telegraphindia.com/1170321/jsp/calcutta/story_141786.jsp) in the media too across the country. The mandatory enforcement of connecting Aadhaar [which is being contested in the Supreme Court](https://www.medianama.com/2018/03/223-supreme-court-defers-mandatory-linking-of-aadhaar/) is still being enforced by the government and several private entities for access to services especially social welfare schemes. Despite [Calcutta High Court questioning the government](https://timesofindia.indiatimes.com/india/hc-questions-centre-on-disableds-aadhaar-woes/articleshow/61586558.cms), a permanent relief to persons with disabilities is yet to be provided and access to social welfare schemes and insurances, irrespective of their Aadhar status.

**Discrimination faced by women with disabilities in the healthcare sector**

Point of View’s work in the Chikballapur district of Karnataka demonstrated the prevailing discrimination faced by HIV positive women with disabilities within the health system. In a location like Chikballapur which is away from the city, the stigma attached to being HIV positive is high and thus alienating the woman with disability from the support and medical help she needs. There is also a prevailing fear that if people around find out, she will face further discrimination - hence there is isolation as well.

There is also a lot of discrimination faced by women with disabilities in the hospitals where they go to seek care. For example, a partner of Point of View was denied a pap smear test because the attendant assumed that she was not sexually active. In another case, a woman with disability explained that because of the inaccessible infrastructure in hospitals, she often gave consent to the attendants to lift her to the examination table, knowing fully well that this might result in sexual violation. However, since the tests needed to be performed she didn’t know any other way.

The situation in India is also grim when it comes to rehabilitation of people with physical disability. As has been reported in The Wire[[4]](#footnote-4), States in India such as Madhya Pradesh, Chhattisgarh, Andhra Pradesh, Telangana, Maharashtra, Gujarat, Odisha, Assam, Tripura, Nagaland, Mizoram, Sikkim, Jharkhand, Haryana, Punjab and Delhi do not have Physical and Medical Rehabilitation Centres despite nearly two decades since the directive by the Medical Council of India.

**Free and informed consent regarding healthcare**

While the 2016 Act categorically prohibits any procedure without the express consent of the women, in general in India there is lack of consent because of lack of agency for women with disabilities. There is lack of access to information and services particularly those that can be accessed independently. As a result the consent is influenced by others such as dominant adults, caregivers, teachers and interpreters. Due to the minimal sexual and reproductive health information available to women with disabilities, we often hear experiences where there is misconception around the difference between emergency contraceptive and oral contraceptive pills. Hence, the lack of information results in consent which is often not informed consent. Such as, in a group of deaf women in Mumbai, a city in India’s state of Maharashtra, we found that they were unable to differentiate between these two modes of contraception and assumed that they were the same. We spent a long period of time in understanding the difference and ensuring that the two pills are not mistaken for each other.

Since women with disabilities are imagined to not be equipped to be mothers, there are many cases we see where women with disabilities are either forced into abortions or contraceptives are forced on her. This is even reflected in the [Medical Termination of Pregnancies Act, 1971](https://scroll.in/pulse/831667/the-dilemma-when-a-pregnant-woman-seeks-to-abort-a-foetus-with-a-detected-disability). In another instance, a father of a vision impaired woman gave her a bottle of tablets, after her marriage, informing her that they were vitamin tablets to be eaten every night. After a year of not conceiving, her husband took the pills to a pharmacy to find that they were contraceptives.

Similarly, the two women with disabilities who were HIV positive in Chikballapur told us that they only discovered that they were HIV positive when their husbands passed away and they were subsequently tested for HIV on discovery of their husbands cases. There is limited agency to exercise even within marriages because of a fear of abandonment; hence the women in this case had not asked their husbands to be tested or pressured them to use any contraceptives.

In all of these instances we can see that choice and informed consent are taken out of the hands of women with disabilities repeatedly at multiple stages.

1. http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf [↑](#footnote-ref-1)
2. http://www.prsindia.org/uploads/media/Mental%20Health/Mental%20Healthcare%20Act,%202017.pdf [↑](#footnote-ref-2)
3. Mental Health Care Bill A Step Forward, Peoples Democracy , Vol. XLII No. 12 [↑](#footnote-ref-3)
4. When It Comes to Rehabilitation Facilities, India's Medical Community Remains Grossly Lacking; The Wire, 4th March 2017 [↑](#footnote-ref-4)