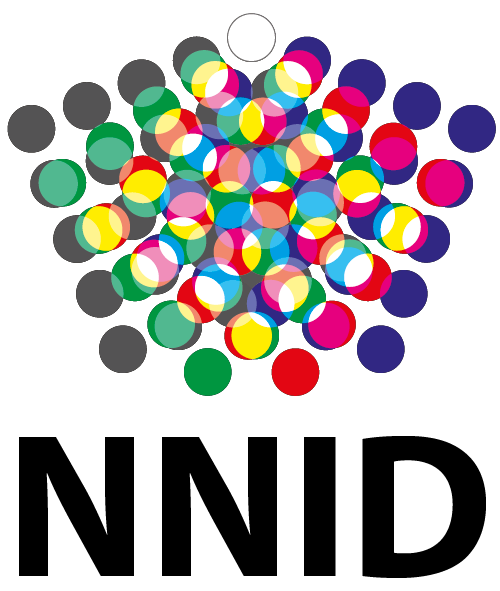
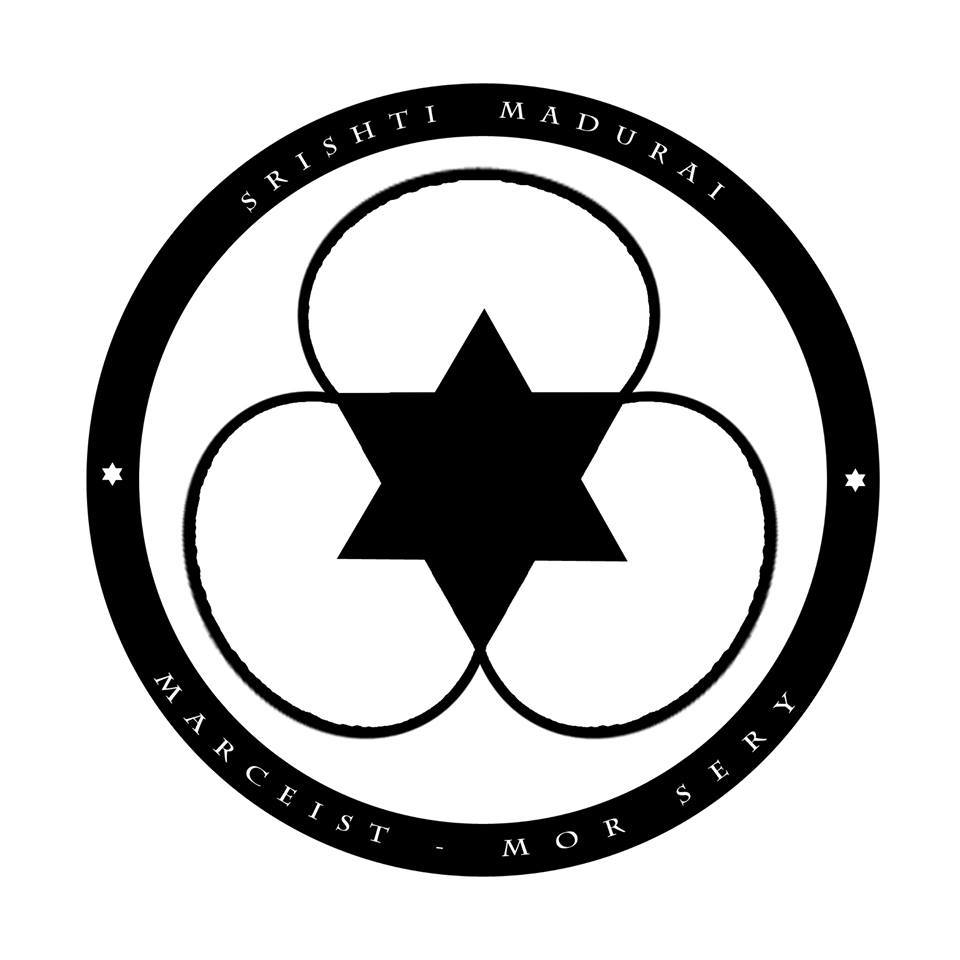
The Rights of Intersex People in India



NGO submission for the 22nd session of the Committee on the Rights of Persons with Disabilities (CRPD)

1st Periodic Review of the Republic of India

**Joint NGO submission by:**

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## Executive summary

Intersex refers to the experiences of persons born with bodies that do not meet the normative definition of male and female. Intersex people in the Republic of India are often faced with discrimination, stigmatisation and bullying and through this may struggle with access to education, employment, identity documents and marriage. Furthermore, intersex children are at risk of being subjected to non-necessary medical interventions without their prior, free and fully informed consent at an age that they are not sufficiently mature to provide consent. Finally, reports of infanticide are worrying. Therefore, Intersex people in the Republic of India seek protection under Articles 5, 15, 16, 17, 18, 23, 24, 25, 27 and 29 of the Convention on the Rights of Persons with Disabilities, and General Comments No. 4 and No. 6.

## Key words

Prior, free and fully informed autonomous consent, intersex, sex diversity, sex registration, healthcare, psychological integrity, physical integrity, rights of the child, self-determination, sex characteristics

## I. Introduction

1. This NGO report is a joint submission by Srishti Madurai and NNID Foundation aimed at informing the Committee on the Rights of Persons with Disabilities about issues faced by intersex people in India. Srishti Madurai and NNID Foundation would appreciate the consideration of these issues by the Committee on the Rights of Persons with Disabilities in the dialogue with the State Party during the 22nd session of CRPD in which the 1st Periodic Report (CRPD/C/IND/1) will be considered.
2. Srishti Madurai is a self-funded student volunteer movement which works on intersex human rights, education, visibility, and community support, and is based in India. NNID Foundation is an intersex-led human rights organisation working for the equality, rights, and visibility of intersex people, and is based in the Netherlands. (hereinafter: the NGO’s)
3. This report discusses how intersex relates to the Convention, and recent policy and legal developments in India. Followed by a discussion of human rights violations against intersex people under the Convention on the Rights of Persons with Disabilities and introduces suggestions for improvements and recommendations to the State Party.

## II. Intersex and the Convention on the Rights of Persons with Disabilities

1. Intersex people in the Republic of India seek protection under Articles 5, 15, 16, 17, 18, 23, 24, 25, 27 and 29 of the Convention on the Rights of Persons with Disabilities, and General Comments No. 4 and No. 6.
2. Intersex refers to the experiences of persons born with bodies that do not meet the normative definition of male and female.
3. The Convention of the Rights of People with Disabilities addresses many of the human rights violations intersex persons experience globally. By approaching disability from a social perspective as described in General Comment No. 6 Article 2 and 3 intersex falls under the Convention on the Rights of Persons with Disabilities. Many intersex persons are not born differently abled or with long-term impairments, even though some require medical care. However, society treats intersex people as disabled by approaching intersex through a medical model and ‘reducing’ intersex people to an ‘impairment’ leading to medical interventions that can lead to long term impairments and requiring life time medical care. These interventions are often conducted without prior, free and fully informed autonomous consent. Some intersex people experience multiple and intersecting forms of discrimination on the perception of disability. However, the violation of their human rights based on intersex is very similar to the (potential) violation of human rights of all intersex people. Therefore, the NGO’s request the Committee to consider all intersex people when making recommendations, and not only those who are confronted by intersecting forms of discrimination based on disability.[[1]](#footnote-1)

## III. Recent legal and policy developments in India

1. In 2017, Srishti Madurai sent a petition to the National Human Rights Commission of India (NHRC) to ban sex reassignment surgeries on intersex children. The NHRC forwarded the petition to the Ministry of Health and Family Welfare in Union Government and directed them to reply within eight weeks. In response to the petition, the reply by Dr. Anil Sain, Assistant Deputy Director General of the Ministry states: “The medical fraternity is well aware of the existence of Intersex persons in the community as they study this subject as part of the medical curriculum. Also, any kind of invasive medical procedure including sex reassignment surgeries are done only after thorough assessment of the patient, obtaining justification for the procedure planned to be conducted with the help of appropriate diagnostic test and only after taking a written consent of the patient/guardian”.[[2]](#footnote-2)
2. On 22 April 2019 Hon. Justice G.R. Swaminathan of the Madras High Court issued a decree to ban non-necessary medical interventions on intersex children in the state of Tamil Nadu. The state government was directed to comply with the directions within 8 weeks. This judgement clearly stated that the consent of parents/guardians does not equal prior, free and fully informed autonomous consent.[[3]](#footnote-3) Due to the Indian elections, this process has been delayed a little. The Health Minister has worked closely with Srishti Madurai and the resolution to ban ‘normalising’ interventions and set up a committee to develop a human rights-based health protocol for intersex people is expected to pass soon. The NGO’s are very appreciative of this development and recommend that this resolution will be adopted throughout the Republic of India.

## IV. Discrimination against intersex people

1. In spite of the guarantee of protection of human dignity in the Constitution of India, intersex people often encounter discrimination, bullying and stigmatisation. There are no specific anti-discrimination laws for intersex people as exist for other minorities. This is opposed to Article 5 of the Convention on equality and non-discrimination. These issues are often also faced by the parents of intersex children, both in the family, society and in health care. Joseph et al. describe that parents of intersex children reported that they had been bullied by family members and that their children had been described in pejorative terms.[[4]](#footnote-4) The emancipation of intersex persons in India will require the involvement of organisations that represent intersex people. However, these organisations are often entirely self-funded. The NGO’s recommend the State Party allocate financial resources to support organisations representing intersex persons, and develop mechanisms to ensure the full, inclusive, strategic and active involvement participation of organisations of intersex persons in the planning and implementation of all legislation and measures that affect the lives of intersex persons.
2. Srishti Madurai has received reports that intersex people in India face issues receiving education and finding employment due to bullying. In an interview intersex activist Gopi Shankar describes having been forced to change school every two years due to bullying and receiving death threats when running as the first openly intersex candidate in the last Tamil Nadu assembly elections.[[5]](#footnote-5) Joseph et al. also report that parents would not send their children to school out of fear of rumours and stigmatisation.[[6]](#footnote-6) This practice is contrary Article 24 of the Convention on education and General Comment no. 4 Article 10, 12 (e, f), 13 and 15 on the right to inclusive education, Convention Article 27 on work and employment, and Convention Article 29 on participation in political and public life.
3. The Constitution of India regards the right to education as a fundamental right and even right to employment is a statutory right. However, there are no specific social welfare schemes for intersex persons. The NGO’s recommend that the State Party develops a comprehensive and coordinated legislative and policy framework for inclusive education and employment and conduct awareness-raising campaigns aimed at the general public, schools and the families of persons with intersex.
4. Srishti Madurai has received reports that some intersex persons experience difficulties in obtaining identity documents, which is opposed to Article 18 of the Convention on the right to obtain, possess and utilise documentation of their nationality or other documentation of identification. There are no State laws to prescribe the framework for obtaining identity documents for intersex persons. A few states have enacted local laws for this purpose.
5. Marriage laws in most states of India, except for Tamil Nadu, retain gender-specific provisions for legal recognition and registration of marriage. Therefore, Intersex persons face difficulties with getting their marriage recognised and registered, which is a violation of Article 23.1a on the right to marry based on free and full consent of the intending spouses. Tamil Nadu state is currently an exception due to the Madras High court decree from 22 April 2019. The background for this decree was the refusal of registry officials to register the marriage between an intersex woman with transgender experiences and her husband. Hon. Justice G.R. Swaminathan investigated the human rights situation of intersex people and decreed that the marriage in this case, and future marriages of intersex persons and transgender persons are legally valid in Tamil Nadu and must be registered.[[7]](#footnote-7) The judgment given by High Courts does have the value of a precedent, and hence, the interpretation given by Justice G.R. Swaminathan is applicable to other states as well. Due to the low level of awareness at the national level, other states are yet to act upon it. The NGO’s recommend that the State Party develop a comprehensive and coordinated legislative and policy framework to ensure all intersex persons have access to identity documents and marriage on the basis of equality.

## V. Harmful practices in health care

1. As a solution to the issues faced by intersex persons, several hospitals offer medical treatment aimed at fitting the bodies of intersex children within the normative definition of male and female. This type of health care for intersex children is based on ‘predict and control’: when an intersex child is born, health professionals try to predict the future gender of the child and control the outcome of this prediction by means of medically unnecessary and irreversible surgery, treatment with hormones, other normalising treatments and psychological support, without the prior, free and fully informed autonomous consent of the child. In some cases, these decisions are made in conference with the wishes of the parents. This predict and control method is a violation of the right of self-determination of the child and of the right to the highest attainable standard of physical and mental health. The term ‘predict’ is misleading, as it is very uncertain at the young age in which surgery is oftentimes conducted, how the identity of the child will develop in the future. This practice is a violation of Convention Article 15 on the right to freedom from torture or cruel, inhuman or degrading treatment or punishment, Article 16 (1, 2) on the right to freedom from exploitation, violence and abuse, Article 17 on protecting the integrity of the person, Article 25 on health which requires free and informed consent, and General Comment 6 Article 66.
2. In 2013, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment called on states to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalising surgery, involuntary sterilisation, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also called upon them to outlaw forced or coerced sterilisation in all circumstances.[[8]](#footnote-8) This statement is in line with Article 15 of the Convention.
3. Walia et al., Khadilkar et al. Vasundhera et al. and Raveenthiran[[9]](#footnote-9) show that in several cases these interventions include non-emergency genital surgeries and medical procedures to adjust sex characteristics of children, at an age that these children are unable to provide prior, free and fully informed consent themselves. Raveenthiran argues from a utilitarian medical ethics perspective that early sex reassignment is recommended to avoid prolonged uncertainty of gender.[[10]](#footnote-10) This is opposed to deontological human rights ethics, described for instance in Article 17 of the Convention which speaks of the right to physical and mental integrity.
4. Health professionals often believe that sex assignment through medical and surgical intervention of intersex children is not an issue.[[11]](#footnote-11) However, recent European research has shown that five per cent of ***all*** intersex children change their assigned gender, including those with forms of sex diversity that are usually not recognized at birth. In about 80% of those cases, the shift occurs before puberty.[[12]](#footnote-12) Parents of intersex children in India often prefer to assign their child the male sex due to social advantages offered to men.[[13]](#footnote-13) Three doctors told The Times of India about their discomfort with these decisions as it is easier to create functional female organs, and that sexual function cannot be promised when male sex organs are created.[[14]](#footnote-14)
5. It is impossible to predict which of the children will belong to the group that will reject the assigned sex. Therefore, 'normalising treatment' is a violation of all intersex children. Parents may not realise that they are de facto opting for experimental treatment for their children.[[15]](#footnote-15) This is a violation of Article 15 of the convention which states that “no one shall be subjected without his or her free consent to medical or scientific experimentation”. The NGO’s therefore highly recommend the government to protect children against unproven and unscientific medical treatments.
6. Consequences of surgical and medical interventions can be severe and irreversible: unnecessary surgery at a young age often leads to lifelong physical and mental health issues due to the irreversible character.[[16]](#footnote-16) When children grow older, and their identity becomes clear, they might be confronted with a body that goes contrary to their identity, as a consequence of medical interventions. They will never be able to alter this. Therefore, it is not surprising that the recent European intersex study mentioned above showed that the number of participants with psychological problems is 4.3 times higher than in the control group and that the number of participants who attempted suicide is 3.5 times higher than in the control group. Moreover, the researchers state that in reality the percentage of suicide attempts might be higher because a significant number of respondents refused to answer the question about suicide.[[17]](#footnote-17) Srishti Madurai has received several reports of intersex persons committing suicide.[[18]](#footnote-18)
7. It is unknown whether psychological problems and the high percentage of suicide attempts are symptoms of the DSD diagnoses (DSD stands for Disorders of Sex Development, the medical term used for intersex people). Percentages for mental health issues and suicide attempts are also greatly increased in sexually abused children.[[19]](#footnote-19) Some medical treatments and studies (including a test described as ‘clitoral sensory testing and vibratory sensory testing’[[20]](#footnote-20)) for intersex children can be classified as sexual abuse.[[21]](#footnote-21) Scientists and agencies consider the medical treatment undergone by a group of intersex children to be comparable to Female Genital Mutilation (FGM).[[22]](#footnote-22) A growing number of intersex people claim to have experienced medical attention as (sexual) abuse.[[23]](#footnote-23) All this research suggests that medical attention is likely the cause, and not the diagnosis itself. The NGO’s recommend the State Party prohibits and criminalises the practice of non-necessary medical interventions on intersex persons, in the absence of prior, free and fully informed autonomous consent provided at a sufficiently mature age to guarantee bodily integrity, autonomy and self-determination to the children concerned and that supported decision-making mechanisms and strengthened safeguards are provided. It also recommends that the State party raise awareness of such practices as harmful.
8. Medical staff is often insufficiently trained in intersex matters, which leads to difficulties for intersex persons in accessing health care and with being treated respectfully. Medical staff is often not familiar with the difference between intersex and transgender people. Joseph et al. report cases of children being treated as a medical curiosity and of derogatory comments made by hospital staff. For instance, a 13 year old girl from a conservative Muslim family was forced to remove her clothes, and in spite of her strong and vocal objections a group of physicians took pictures of her genitalia with their mobile phones. In another case news was spread to hospital staff about the birth of an intersex child, some of whom came to look and laugh at the child’s genitalia.[[24]](#footnote-24) These practices are in clear violation of Article 25 of the Convention and General Comment no. 6 Article 66 on health. The NGO’s recommend the State Party raises awareness of such practices as harmful, ensures the training of relevant professionals, and provide families with intersex children with adequate counselling and support. Adopt plans and allocate resources to ensure that mainstream health services, including sexual and reproductive health services and information, are accessible to intersex persons. Health professionals in mainstream health services should be trained in communicating with and treating intersex persons in health-care settings, observing the right to prior, free and fully informed autonomous consent and other rights enshrined in the Convention.

## VI. Right to life

1. The NGO’s are concerned about instances of infanticide of intersex children in India. Srishti Madurai has received reports about infanticide of intersex infants. Joseph et al. describe the account from a father of an intersex boy from Rajasthan that in his community intersex children used to be buried alive in the past.[[25]](#footnote-25) There is no defined mechanism to find out the statistics and cases related to intersex infanticide. Infanticide of intersex infants is in clear violation of Article 10 of the Convention on the right to life. The NGO’s recommend the State Party establishes measures to guarantee the right to life for intersex persons and provide equal access to justice and to safeguard intersex people from abuse, ill-treatment, sexual violence and exploitation.

## VII. Suggested Recommendations

The NGO’s respectfully request the Committee on the Rights of Persons with Disabilities to make the following recommendations to the Republic of India:

1. Prohibit and criminalise the practice of non-necessary medical interventions on intersex persons, in the absence of prior, free and fully informed autonomous consent provided at a sufficiently mature age to guarantee bodily integrity, autonomy and self-determination and that supported decision-making mechanisms and strengthened safeguards are provided. Also, raise awareness of such practices as harmful, ensures the training of relevant professionals, and provide families with intersex children with adequate counselling and support.
2. Establish measures to guarantee the right to life of intersex persons, and ensure equal access to justice and to safeguard intersex people from abuse, ill-treatment, sexual violence and exploitation.
3. Adopt plans and allocate resources to ensure that mainstream health services, including sexual and reproductive health services and information, are accessible to intersex persons. Health professionals in mainstream health services should be trained in communicating with and treating intersex persons in health-care settings, observing the right to prior, free and fully informed autonomous consent and other rights enshrined in the Convention.
4. Develop a comprehensive and coordinated legislative and policy framework for inclusive education that ensures teachers and all other professionals and persons in contact with children understand the concept of inclusion and are able to enhance inclusive education for intersex children to prevent exclusion from education on the basis of intersex. Also, conduct awareness-raising campaigns aimed at education and employment to the general public, schools and the families of persons with intersex.
5. Develop a comprehensive and coordinated legislative and policy framework to ensure all intersex persons have access to identity documents and marriage on the basis of equality.
6. Allocate financial resources to support organisations representing intersex persons, and develop mechanisms to ensure the full, inclusive, strategic and active participation of organisations of intersex persons in the planning and implementation of all legislation and measures that affect the lives of intersex persons.

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