

தேசிய இடையிலிங்க
மனித உரிமைகள் கருத்தரங்கம்

1st National Intersex Human Rights Conference

Information Toolkit

Human Rights of Intersex Persons in India





Holy Mother Sri Sarada Devi

Patron of Srishti Madurai



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I. JOURNEY OF SRISHTI MADURAI (2011-2019)

This year, we are celebrating nine years of our journey as India's first Genderqueer and Intersex led human rights movement. We began our journey with a humble aim to create a space for Genderqueer, Intersex and LGBTQA+ Indians in the public discourse. Through its activities, Srishti Madurai has continuously worked to generate discussions, solution-oriented research, scholarship and publications on SOGIESC issues in Tamil Nadu/India.

At every step in the journey, we have made an attempt to engage constructively with all stakeholders to work towards holistic protection of human rights of LGBTQIA+ and Genderqueer people. We've tried to fill crucial gaps in law and policy by bringing into focus the rights of Intersex persons as per India's constitutional scheme.

As a self-funded movement/organisation, none of our accomplishments would have been possible without the overwhelming love and support we got from people of all walks of life. We are deeply grateful to everyone- all individuals and organisations who have supported us in our work so far. Special mention of thanks and gratitude to the support we received from OII Chinese Taiwan, IHF the Astraea Lesbian Foundation for Justice, Intersex Asia, COC Netherlands and NNID.

The journey so far...

On 2 September 2011, a handful of student volunteer team inspired by each other in Madurai started a forum for non-binary, genderqueer & Intersex people in Madurai we named our team as Srishti Madurai inspired by Anjali Gopalan.

2012: Our movement started with a 24X7 phone helpline for genderqueer people in three South Indian languages. In the same year, Srishti Madurai organized the Alan Turing Rainbow Festival 2012 which was essentially a Genderqueer Education festival to mark the birth centenary celebrations of Alan Turing. We reached out to more than 600 school children in Madurai. In the same year, we organised Asia's first genderqueer pride festival which included participation of Anjali Gopalan, A. Revathi and several key persons.

2013: In this year, we took up the case of Champion Athlete Santhi Soundarajan who is now one of the committee members of Srishti Madurai. Regional Tamil terms for Genderqueer identities were coined by Team Srishti Madurai at the American College, Introduced Gay literature, and Transgender literature as part of curriculum at the American College in Madurai. Srishti Madurai started offering courses on Indian Philosophy, Psychoanalysis, Trekking Team of Srishti Madurai started monthly Trekking events for Madurai queer community and allies to discover the History of Madurai in SOGIESC lens.

2014: First Tamil book on LGBTQIA+ genderqueer rights was published, this book was launched by Tamil Nadu BJP leader Srimathi Vanathi Srinivasan in the presence of several volunteers from RSS. Later, this book became part of the curriculum for Intersex Human Rights Studies for Tamil PG Research Department at the American College in Madurai. Now, this book is also available in all public libraries in Singapore. It has created strong influence in Tamil diaspora in the South Asian region. Team Srishti Madurai theatre performance on Bio Art - Genesis was initiated by John Marshal. Team Srishti Madurai started the Kannagi Study Circle to spread the Tamil Philosophy in SOGIESC perspectives.

2015- Srishti Madurai was invited to witness the passage of the Transgender person's Rights Bill presented by Tiruchi Siva in the Rajya Sabha (Parliament of India). Srishti Madurai requested MPs from both upper and lower house of Parliament of India to present the issues pertained to intersex human rights in India.

2016- Justice for Santhi campaign was initiated by Srishti Madurai to highlight the discrimination faced by Female Athletes, the campaign reached more than 1 Million people. Srishti Madurai was instrumental in getting a Government Order for (permanent job) Santhi Soundarajan as athletic coach in Sports Development Authority of Tamil Nadu.

Srishti Madurai launched an important petition to ban sex selective surgeries on infants born with Intersex traits to the National Human Rights Commission of India.

2017- Srishti Madurai started engaging with various Religious bodies and faith communities to create awareness on SOGIESC issues.

Srishti Madurai engaged with Buddhist, Jain, Islamic faith leaders/communities and also with the National Council for Churches in India. JM John Marshal and Gopi Shankar contributed to various interfaith dialogues and primary book project to educate the religious leaders from the church on SOGIESC. Especially Srishti Madurai contributed to the book "Definitions- Understanding Gender, Sex, and Sexuality. A Theological Reader on Human Sexuality and Gender Diversities: Envisioning Inclusivity"

Srishti Madurai was part of Madrid Summit 2017 and World Pride, Madrid, Spain. Srishti Madurai was one of the signatories and key speaker at Madrid Summit Declaration along with the officials from the UNESCO, the EU parliament and the UN. Also politicians from 11 EU countries were present in this event.

Srishti Madurai was invited to ILGA Asia Regional Conference at Cambodia-first time Intersex Human Rights in India was discussed at the Asian forum.

Gopi Shankar Madurai was elected as Intersex Representative and Executive Board Member of ILGA Asia region

Our former Trustee and advisory board member Nandini Murali penned the book – Life in In Trans Activism A. Revathi - by Zubaan Publication.

Self-funded till 2017

2018- Main focus-

Srishti Madurai became one of the founding members of Intersex Asia (Asia's first collective forum for Intersex activists, individuals and Intersex led organisations) in Bangkok.

Students from more than 12 countries visited Srishti Madurai for learning SOGIESC issues in Indic perspective, Inspired number of scholars

Srishti Madurai organised the Matrixial Intersex Festival supported by the Intersex Human Rights Fund, Dr. Bracha Ettinger renowned scholar delivered the keynote address.

2019: OII Chinese Taiwan and RFSL Sweden supported Srishti Madurai to attend ILGA World Conference in Wellington- for the first time Intersex Youth Panel was formed and Gopi Shankar Madurai was elected to the Youth Steering Committee of ILGA World.

Volunteers from Srishti Madurai for the first time attended the ILGA Asia conference in Seoul & 2nd Asian Intersex Forum at Seoul, South Korea.

Srishti Madurai inspired the landmark judgment from the Madras High Court (Madurai Bench) to ban sex selective surgeries on Intersex Infants/Children in Tamil Nadu which directed the Ministry of Health and Family Welfare of the Government of Tamil Nadu to pass a Government Order within 8 weeks from the court order.

Srishti Madurai jointly with Intersex Asia organised 1st ever policy briefing meeting to pass the Government Order, was co-sponsored by COC Netherlands.

Srishti Madurai along with NNID Netherlands jointly submitted a report in CRPD treaty bodies meeting on September 2 2019 sponsored by COC Netherlands.

Historic Victory

The State Government of Tamil Nadu, India passed a Government Order to ban sex selective surgeries on Intersex infants with the inputs from Srishti Madurai.

II. UNDERSTANDING INTERSEX HUMAN RIGHTS IN INDIA AND NEPAL

-Gopi Shankar Madurai

This article shares interventions on intersex people, predominantly of India and Nepal. The insights shared here are crucial to be brought in light to the global intersex activists.

People with intersex traits are often wrongly identified as transgenders, hijras or third gender. But many indigenous gender variants are not okay with the term third gender. The etymological sense of this word derives from Sanskrit word “*tritiya prakriti*”, which translates to ‘beyond dual nature’. This is the term that is used to refer to non-binary genders. But putting them under one umbrella term, when there are many different ways a person could be intersex, is unfair to the community. It is one of the reasons behind the homogeneity of different gender identities.

Ambiguities between the terms ‘Hijra’, ‘transgender’, and ‘intersex’ exist. For instance, in India, renowned authors like Arundhati Roy, don’t know the difference between them. Initially, Anjum, a lead character in her recent work, is described as an intersex person and later on, she is said to be a Hijra.^{1 2} It is also noteworthy to mention here that even most of the intersex people are unaware of the term ‘intersex’, and/or if they can identify themselves with this term as well. To better understand the difference between them, it is important to first understand the differences between sex, gender, and sexual orientation. To start with, sex is usually determined by birth based on biological characteristics. Gender is a socially constructed concept; it refers to the social role played by a person based on his/her sex. Sexuality, or your sexual orientation, is decided on the basis of whom you are attracted to.

Intersex people are born with reproductive or sexual anatomy that does not fit the typical definitions of female or male. Though some think of intersex anatomy as an inborn condition, it doesn’t always show up at birth.

Transgender or transsexual people, on the other hand, are born with typical male or female anatomies but feel they’re born into the wrong gender. For instance, a transgender/transsexual person may have typical female anatomy but feel like a male. All Hijras come under the transgender umbrella but not all transgender people are Hijras. A few intersex people choose to identify as transgender but that’s not the identity of their entire community. Most of the people with intersex conditions identify as male or female rather than transgender or transsexual. This implies that only a small portion of intersex

¹ Godhawat, Jyoti. “Read Why Gopi Shankar Calls Attention of Arundhati Roy To Intersex Community.” *Indian Women Blog*, 24 Nov 2017, www.indianwomenblog.org/read-why-gopi-shankar-calls-attention-of-arundhati-roy-to-intersex-community/

² Madurai, Gopi Shankar. “Arundhati Roy’s New Book Can Undo Decades of Work Done By Intersex Activists” *Youth Ki Awaaz*

people experience the gender identity problems faced by transgender or transsexual people. We must also recognise that being intersex relates to biological sex characteristics and is distinct from a person's sexual orientation or gender identity. An intersex person may be heterosexual, lesbian, bisexual or asexual; and may identify as female, male, both or neither.³

The social stratification in India has seen major changes in the post-colonial era. Section 377 of the Indian Penal code, introduced by the British in its colonies in 1861, criminalized non vaginal sexual acts including same sexual activities predominantly criminalized not only applied for the larger LGBTQ+ communities but also for Intersex people too. And it's not only India that was affected by the stringent law; there are 42 other Commonwealth countries which were under some kind of British rule, like contemporary Pakistan and Bangladesh, that have been influenced by the same.

Even before the term 'LGBT' was originated, the Hindu community knew about the different indigenous gender variants. They've existed for more than 2000 years. But now we have put them under one label, i.e., 'LGBT'. This term, which was originated in the U.S., has caused a lot more confusion and other identities have got hidden. It has led to the homogeneity of clearly different Indigenous gender variants and identities.

The South Asia region is predominantly culturally influenced by the mainland India and China. Its philosophy, starting from the pre-Abrahamic traditions, originated in India. In Vedic times, India had great indigenous culture, ancient temples, and intersex gods. Even after Pakistan and Bangladesh separated from the mainland India as separate countries, India has been a force in culturally influencing the culture of South Asia including Myanmar, Nepal, and Afghanistan. This is very evident with the Indigenous gender-variant communities in South Asia and some parts of South East Asia.

In Hindu tradition, ancient Tamil Sangam literature uses the word 'Pedi' to refer to people born with the intersex condition; it also refers to *antharlinga vashi* and diverse indigenous non-binary sex identities. The ancient Sanskrit term for Intersex is Kleeba and it became root syllable (Mantra) for Devi worship in India, Nepal and Tibet. The Aravan spiritual tradition in the Koovagam village of Tamil Nadu is a folk tradition of the Trans women who are predominantly assigned as male at birth. The members of the community enact folk stories of indigenous gender identities during an annual 3-day festival. This is completely different from the sakibeki spiritual tradition of West Bengal, where Trans women don't have to undergo sex-change surgery or shave off their facial hair. They dress in feminine clothes; still retaining their 'masculine' features and sing in praise of Lord Krishna.

³ 4th Asian Intersex Forum Statement 2018 - <https://intersexday.org/en/intersex-asia-2018/>

In Tamil society, Trans women completely change themselves to fit a more cisnormative idea of a 'woman'. In ancient times, even Indian religion had its own way of accepting these communities. The indigenous communities of India include The Nupi Manbis of northeastern India, the Bachura Devi worshipped in Gujarat and the Jogappa spiritual tradition of Karnataka. There are even different kinds of dialects and languages that are spoken by these communities which differ from region to region. Like, 'Hijra Farsi' is the transgender community dialect, a mix of Urdu, Hindi and Persian spoken in the northern belt of India, Pakistan, and Afghanistan, and 'Kothi Baashai' is spoken by the transgender community in Karnataka, Andhra, Orissa, and parts of Tamil Nadu. They even have sign languages and typical mannerisms to communicate. The peculiar clap is one such; but they were very clear about intersex people and referred to them as **Mabedi Usili** and gave a distinct identity to denote them.

Most newborns with intersex conditions come to medical attention because doctors or parents notice something peculiar about their bodies. In many of these cases, the doctors perform sex corrective surgeries on them based on the assumption that only binary sex categories exist.

It is regularly performed without informed consent of the person concerned (in this case the infant, who is too young to make the decision), these procedures are completely against human rights of people living with intersex traits.

In India, such procedures are frequently justified on the basis of discriminatory beliefs about intersex people and their integration into society. Moreover, there's no national child policy in place to protect the right of these babies. This is one of the reasons why, just like female infanticide, intersex infanticide exists in India. Midwives in villages are forced to indulge in ending the lives of babies born with immature genitals or intersex traits. In India, 99% of parents insist on their child with Difference of Sexual Development (DSD) being made a "boy" during sex-selective surgeries. ⁴The senior pediatric surgeon, Dr. Aniruddha Shah says that families, especially from India prefer a male child for inheritance purposes. Urology surgeon, Dr. Heman Baxi says that parents refuse to listen to logic that child may become a psychologically disturbed adult when it will grow up.

The very first Intersex case to approach the court of justice in India:

In 2008 Geeta Luthra, a senior lawyer practicing in the Delhi High Court, came across the case of an intersex woman, who was born with ambiguous

⁴ Sharma, Radha. "Parents prefer male child in intersex operations in Gujarat". *Times of India*, 5 Feb 2014, timesofindia.indiatimes.com/articleshow/29879738.cms?utm_source=contentofinterest&utm_medium=text&utm_campaign=cppst

genitalia.⁵ Faizan Siddiqui's phenotype was that of a man, but the genotype was that of a woman, says Geeta. "Of course, she cannot bear children, but she took the necessary hormonal injections to look very much like a woman and cleared the examinations of the Border Security Force (BSF). Yet, the government did not give her a job, saying she was physically unfit. She cleared the written exam, but could not clear the medical as she was asked to appear before the BSF medical board. They failed her on the ground that she will not be able to have children as her reproductive organs were not normal." Geeta filed a writ petition in the High Court and won the case and Siddiqui got the job in 2011.

I am one of the founding members of Srishti Madurai India's first LGBTQIA+ Student Volunteer Movement, and I became the first openly intersex and genderqueer candidate to contest in Tamil Nadu Legislative Assembly election in 2016.^{6 7}

Srishti Madurai also works with Indic religious communities to protect the indigenous gender specific rituals in India. In 2015, we urged the Indian parliament to include intersex people in bill protecting trans rights. We also launched an official complaint to National Human Rights Commission of India to ban the forced sex selective surgeries on intersex infants. The NHRC issued directions to the Secretary Union Health Ministry Government of India to respond to it within 8 weeks.⁸ The ministry replied to it by saying, "Any kind of invasive medical procedure, including sex reassignment surgeries, is 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 parent or guardian." The government and the parents are not willing to accept the plight of people with intersex conditions. While the government should be creating awareness about these issues, they themselves are ignorant. This is evident in the Rights of Transgender Persons Bill tabled in Parliament, where they have confused the definition of transgender person, and have left out intersex persons completely. In fact, by their definition, intersex persons are implicitly assumed to be trans.

⁵ translaw.clpr.org.in/wp-content/uploads/2018/09/Faizan-Siddiqui.pdf

⁶ Mathew, Pheba. "This intersex person is contesting TN polls, 'ze' wants to change your mind on sexual minorities". *The news minute*, 24 April 2016, <https://www.thenewsminute.com/article/intersex-person-contesting-tn-polls-ze-wants-change-your-mind-sexual-minorities-42103>

⁷ "Intersex person to contest from Madurai North". *The Hindu*, 30 April, 2016,

<https://www.thehindu.com/todays-paper/tp-national/tp-tamilnadu/intersex-person-to-contest-from-madurai-north/article8539185.ece>

⁸ "India urged to include intersex people in bill protecting trans rights". *Pink News*, 29 Aug 2015, <https://www.pinknews.co.uk/2015/08/29/india-urged-to-include-intersex-people-in-bill-protecting-trans-rights/>

For activists like me, what's important is that the fundamental rights of intersex persons be respected. "In a country where female infanticide is still prevalent, can you imagine what people would do to intersex infants?⁹ When there is no awareness about us, when we're not even part of the Census, how can the government get away with such a lethargic response to such a serious issue?"

On 22 April 2019 the Madras High Court (Madurai Bench) passed a landmark judgment and issued direction to ban Sex-Selective Surgeries on Intersex Infants based on my work, the Court took note of the issue of the rampant practice of compulsory sex reassignment surgeries performed on inter-sex infants and children. The Court also expressed its gratitude to Shankar, noting that Shankar's work has had been a *humbling and enlightening experience for the Court*.¹⁰

International organisations like Human Rights Watch¹¹ and some of the renowned Intersex Organisations like InterAct in the United States, Europe and the Pacific regions praised the Madras High Court historical verdict considering the fact that it is the first time anywhere in the world that a judicial body has imposed a legal ban on this procedure on Intersex infants/children, which is downright inhuman.ⁱ Very first legislation to protect Intersex infants/children has been passed earlier in places like Malta. European Union also adopted a resolution, even European council adopted a resolution to protect the rights of intersex individuals. Few of my fellow activists like Tony Briffa and Morgan Carpenter, is working with the Australian government for the same. However, in entire Asia, this is the first-time judicial bodies are asking a state to pass a Government Order (GO) in this regard. Though Malta is the first place to pass legislation in 2015, they don't have any committees to work on it till date. The policy only exists on paper. Legislations and policies, only when they are practical and when they have a committee to work on them, can be implemented and otherwise are nothing but a piece of paper. the ban is just the beginning of a long path that needs to be traversed with no direction whatsoever. All over the world, there are just a handful of places with similar legislation but that's not the problem. The real problem is that they have been left just there, suspended in mid-air, with no subsequent actions. None of these countries have any sort of medical protocols to support these orders, thus rendering them practically obsolete.

⁹ Karthikeyan, Ragamalika. "Activists say surgical 'correction' of intersex babies at birth wrong, govt doesn't listen" The News Minute, 3 Feb, 2017,

<https://www.thenewsminute.com/article/activists-say-surgical-correction-intersex-babies-birth-wrong-govt-doesnt-listen-56739>

¹⁰ <https://www.livelaw.in/news-updates/transwoman-regarded-as-bride-madras-hc-bans-sex-re-assignment-surgeries-intersex-children-144467>

¹¹ Indian Court Decides In Favor of Informed Consent Rights for Intersex People – Human Rights Watch (<https://www.hrw.org/news/2019/04/29/indian-court-decides-favor-informed-consent-rights-intersex-people>)

But how hard it must be to come up with a list of medical procedures? Apparently, actually the first thing that we need to understand is that there is no mechanism in place and also there is no protocol in place of how the doctors identify such babies and what they should do immediately after identifying them. So, the Indian Medical Association needs to come up with a solution. But it doesn't stop just there, with an intersex infant while there are some procedures which are urgent and integral, there are others which are medically irrelevant and amidst all the misinformation it becomes difficult to ascertain when surgery is required and which is not.

Biologically you can't change the sex but what you can do is perform some cosmetic procedures which will hurt them so as to make them fall into binary of sexual identity by reshaping their genitalia during the early sex selective surgeries on Intersex infants/children.

Once the surgery has been averted, we suggest after all the tests, the doctor can assign a sex to the child for the sake of the fact that the baby needs to go to school. At the same time, the privacy needs to be protected with the doctor and the parent that the child is intersex. There should be a special intersex clinic where children can go and have counseling every month. So, we need to train medical professionals and counselors on this particular subject. Also, how much parents are willing to bear for their children matters. It is not about the child because they are too young to have a take on the issue.

Complying with the specific direction of the Madras High Court, the state government of Tamil Nadu passed a Government Order banning the practice of sex reassignment surgeries on intersex children except on life-threatening situations. This is a first major normative step towards a comprehensive legal protection regime for intersex children. While we welcome this measure, we have few recommendations for strengthening the enforcement mechanism of the order.

The Directorate of Medical Education (DME) has been entrusted with a task of appointing a committee to determine the 'life-threatening situation'. The Order also prescribes the composition of the committee. The GO has prescribed the following composition of the committee which has to be constituted by DME- (1) Paediatric Surgeon/Urologist (2) Endocrinologist (3) Social Worker/Psychology Worker/Intersex Activist and a (4) Government Representative. With regard to the composition of the committee, we have recommended that Medical Geneticists must be included in the Committee so as to better inform the whole process of determining 'life-threatening situation.' World over, the view of medical geneticist is given due consideration on this subject.

The Order includes a specific directive for DME to ensure that the exceptional clause is not misused in any way which affects the implementation of the ban.

It is a moment of great pride for Tamil Nadu as it has become the first state in India to have guidelines for the protection of human rights of intersex infants and for respecting the spirit of the historic judgment by the Madras High Court. While this is a great first step, there are few shortcomings of the Government Order. Being an executive action, it is but natural for the GO to have limitations. Till the time a comprehensive law is enacted on this issue, the implementation of the Government Order can be strengthened by issuing a Clarification/Guidance Note which should include the following:

- Listing specific medical surgeries which have been banned
- Prescribe a Standard Medical Protocol and accreditation process for Specialized Centres
- Prescribe Guiding Principles for the Committee constituted by DME
- Rules for Conduct of Business for the Committee constituted by DME
- Directive to give special attention to concerns of intersex community
- Include a Penal clause for violation of the ban

Regardless, this was a much-needed step and will go a long way in ensuring protection of bodily integrity of intersex children in Tamil Nadu.

We are lobbying this with the Central Government of India to enact the Madras High Court Judgement throughout India so after Malta, Taiwan, Germany, Australia, India will become 5th country where Intersex infants/children will have exclusive laws and protection.

The other important cause my organisation Srishti Madurai serving is to protect the rights of female athletes with hyperandrogenism and intersex traits. It is a medical condition which is characterized by excessive levels of androgen (sex hormones such as testosterone) circulation in the female body. The issue became prevalent in 2006 when Santhi Soundarajan became the first woman athlete to be screened for sex verification test since the abolishing of the compulsory testing in sports.

She underwent a sex test shortly after winning a silver medal in the women's 800m at the 2006 Asian Games in Doha. She was told that she did not possess the sex characteristics of a woman.¹² After the results of the test were published, she was stripped of her silver medal and told that she cannot compete in sports anymore. In 2014, the fate of Santhi was repeated for another Indian sprinter Dutee Chand. Dutee had been banned since 2014 summer after failing a hormone test.¹³ However, in a historical verdict on July 2015, the Court of Arbitration for Sport (CAS) had suspended the

¹² Madurai, Gopi Shankar. "Why India Must Not Fail Santhi Soundarajan." *Swarajya*, 29 Dec 2016,

swarajyamag.com/sports/why-india-must-not-fail-santhi-soundarajan

¹³ "Dutee Chand: I lost all my honour in landmark gender case." *BBC Sport*, 28 July 2015
www.bbc.com/sport/athletics/33690274

International Association of Athletics Federations' (IAAF) "hyperandrogenism" gender test rules for two years and termed the gender test 'unscientific'.

But that didn't stop the IAAF to announce even stricter rules for athletes with this condition. According to their guidelines, which were published last year, female athletes with hyperandrogenism are required to decrease their testosterone levels to 5 nanomoles per liter of blood. Previously they were required to have testosterone levels to 10 nanomoles per liter of blood, which is double than what the current regulations ask for.¹⁴ The IAAF intended to bring in new rules on 1 November last year and the struggle of Semanya Vs IAAF continues.

Many sports federations aren't aware about the problems faced by intersex athletes. They need to be educated about intersex conditions to make fair policies for them.

So, my responsibility is not just to put an end to mutilating and 'normalising' practices such as genital surgeries, psychological and other medical interventions through legislative and other means but also to ensure that the Intersex people must be empowered to make their own decisions affecting their own bodily integrity, physical autonomy and self-determination. To put an end to preimplantation genetic diagnosis, pre-natal screening and interventions, and selective abortion of intersex fetuses.

To put an end to inappropriate medical practices and protocols, including the administration of medication for gender selection and medical interventions on fetuses and newborn babies, as a result of lack of awareness about intersex people and intersex variations. I must ensure that all key partners that have a specific role to play in intersex people's wellbeing such as, but not limited to, health care providers, parents and professionals working in the area of education, as well as society in general, are instructed on intersex issues from a human rights perspective.

My holistic work is also focused to end sex verification tests that violate the fundamental privacy and dignity of intersex people, and ensure they are able to participate in competitive sport, at all levels, in accordance with their legal sex. Intersex athletes who have been humiliated or stripped of their titles should receive reparation and reinstatement.

We all hold the responsibility to raise awareness around intersex issues and the human rights of intersex people in communities and society at large. We must ensure that our Government provide comprehensive sexuality education that includes references to intersex people and experiences, as well as human-rights-based intersex education at all levels of education. We must hold our Judicial body and policy makers to provide adequate

¹⁴ Press Release. "IAAF introduces new eligibility regulations for female classification." *IAAF*, 26 Apr 2018
www.iaaf.org/news/press-release/eligibility-regulations-for-female-classifica

acknowledgement of the suffering and injustice caused to intersex people in the past, and provide adequate redress, reparation, access to justice and the right to truth.

Nepali Government and Intersex Human Rights

In 2007, its Supreme Court of Nepal asked the government to abolish all laws that discriminated on the basis of sexual orientation or gender identity.¹⁵ The court also demanded that the government establish a third sex category that includes people who present or perform a gender that is different from the one that was assigned to them at birth, as well as those who do not feel that the male or female gender roles dictated by their culture match their true social, sexual or gender identity. The 2011 Nepal census was the world's first to allow people to register as a gender other than male or female.

Despite such progressive legislation, however, popular prejudices about sex and gender remain more or less unaltered. In fact, greater access to hormonal and surgical technologies has only helped reinforce them.

Again, there is a woeful lack of research in this area; but, going by anecdotal evidence, there seems to be an upswing in the number of parents asking doctors to change the sex of their intersex child to male.¹⁶ Adult intersexuals also appear to be opting more frequently for sex reassignment to become fully female or male—mostly the former.

Intersex people belong to the most marginalized communities in Nepal. They're marginalized even within the LGBT community. In the public and in government bodies the near total lack of awareness of intersex as a natural variation persists, leading to severe stigma and discrimination.

Intersex children from less affluent families are even denied the privilege of Health Care. These compounds to their suffering caused by Intersex Genital Mutilation (IGM) practices. These practices include non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures based on prejudice that would not be considered for “normal” children, without evidence of benefit for the children concerned. Typical forms of medicalized IGM include “corrective” genital surgery, sterilizing procedures, “masculinizing” and “feminizing”, the imposition of

¹⁵ “Nepal Prohibits Discrimination on Grounds of Sexual Orientation and Gender Identity.” *Equal Rights Trust*, 16 Jan 2008, www.equalrightstrust.org/news/nepal-prohibits-discrimination-grounds-sexual-orientation-and-gender-identity

¹⁶ Sharma, Radha. “Parents prefer male child in intersex operations in Gujarat.” *Times of India*, 5 Feb 2014 timesofindia.indiatimes.com/articleshow/29879738.cms?utm_source=contentofinterest&utm_medium=text&utm_campaign=cppst

hormones, forced genital exams, and vaginal dilations, and cause lifelong severe physical and mental pain and suffering.

StopIGM.org and Esan Regmi (Blue Diamond Society, Nepal) submitted Intersex NGO Reports to CEDAW in early 2018, raising and substantiating violations against intersex children, adolescents, and adults in Nepal.¹⁷

Consequently, discrimination of intersex persons, infanticide of intersex children, abuse of intersex persons and forced marriage of intersex person are some issues that were included in the committee's LOI for Nepal under harmful practices. However, in its reply to the LOI, the Nepali government simply ignored all questions on intersex.

To this day, the government refuses to take effective legislative, administrative, judicial or other measures to protect intersex children but instead allows medical IGM and other harmful practices on intersex children to continue with impunity and against better knowledge.

Profile of Gopi Shankar Madurai:

Gopi Shankar Madurai (*ze/they*) is an Indian Dharmic indigenist, equal rights activist, author and public speaker. Gopi is the founder of Srishti Madurai LGBTQIA+ Student Volunteer Movement. Gopi is one of the core committee members of Intersex Asia; it is the Asia's first collective forum for Intersex Individuals and organizations.

Gopi is one of the youngest, first openly intersex and genderqueer person to contest Indian State Legislative Assembly elections from Tamil Nadu, Madurai North Constituency. Gopi coined the regional Tamil terms for Genderqueer people and wrote *Maraikkappatta Pakkangal* the first book on LGBTQIA+ Gender-Variant identities in Tamil language: it is widely used as part of syllabus at various universities in Tamil Nadu and it's the first book on LGBTQIA+ rights indexed in all national public libraries of Singapore. Ze also organized Asia's first Genderqueer Pride Parade in 2012 and organized more than 100 seminars on SOGIESC issues which impacted more than 2 million students in India. Gopi's work inspired the Madras High Court (Madurai Bench) to direct the Government of Tamil Nadu to order a ban on sex selective surgeries on intersex children.

¹⁷ Seelenlos. "2018 CEDAW Nepal LOI Intersex NGO Reports" *intersex.shadowreport.org* 20 Mar 2018
intersex.shadowreport.org/post/2018/03/20/2018-CEDAW-Nepal-LOI-Intersex-NGO-Reports

III. CONCEPT NOTE-

FIRST NATIONAL CONFERENCE ON INTERSEX HUMAN RIGHTS IN INDIA

Background

Intersex human rights movement in India is currently at a crossroad with regard to development of a legal protection regime for intersex persons. In this decade, there have been several positive developments with respect to development of norms respecting fundamental rights of intersex persons. In the year 2014, the Supreme Court of India passed a historic judgment recognising the clear distinction between sexual orientation, gender identity and sex characteristics and recommended the creation of a legal protection regime.

On 22nd April 2019, the Hon'ble High Court of Madras delivered a momentous judgement banning the practise of Sex Selective Surgeries on Intersex infants/children. The judgment is regarded as historic as it was the first instance when the judiciary recognised the right of intersex persons with respect to bodily integrity. Complying with the directions of the Court, the state of Tamil Nadu issued a Government Order on August 13, 2019 prohibiting the practice of medically unnecessary sex selective surgeries on intersex infants. The state of Tamil Nadu has become the first state in India to have given normative effect to the demand for stronger legal protection of rights of intersex children in India. If adopted nationally, India is likely to become the third state in the world, after Malta and Taiwan, to have a legal regime which protects the rights of intersex children.

The judiciary in India has taken a lead in articulating the need for better protection and promotion of human rights of intersex persons. However, the other two branches of the government-legislature and executive have not stepped up to the occasion. Even after the specific direction of the Supreme Court in the NALSA judgment, the Indian state is yet to come up with a rights-based legislation for the protection of rights of transgenders persons and intersex persons.

The recently enacted law Transgender Persons (Protection of Rights) Act, 2019 suffers from serious flaws and fails to even draw the distinction between transgender persons and intersex persons. In order to have a structured approach for advocacy on nation-wide comprehensive law, Srishti Madurai is planning to organise the first National Conference on Intersex Human Rights in New Delhi. It is important to have an interaction with all the stakeholders. In this regard, it is important to have wide consultation with all key stakeholders- members of intersex community, medical professionals, genetic scientists, legal experts, relevant ministers in the Union and State Government.

Aims of the Conference

The conference is being organised to engage with the Union and State government in India to advocate for the following:

- **Enact a nationwide legislation to prohibit Sex Selective Surgeries on Intersex children/infants**

It is the responsibility of the Union government to come up with a nation-wide legislation to ensure the right to bodily integrity is guaranteed to intersex person including infants/children.

As per the *Puttaswamy* judgment, right to bodily integrity- a basic feature of right to privacy has been recognised as a fundamental right. Further, the *NALSA* judgment has also given constitutional status to the right to freedom of gender identity and gender expression.

In view of the above, the Union government must come up with a nation-wide legislation recognising the normative principles as laid down in the judgments of the Supreme Court and also the Madras High Court. It is also necessary that the legislation is drafted in consultation with all relevant stakeholders.

The consultation process must include deliberations on concerns of the intersex community, ethical and health related concerns of medical professionals and genetic scientists.

- **Constitute a SOGIESC Unit in the Social Welfare Ministry plus Women and Child Development Ministry**

With a view to affirm the mandate of the Supreme Court in the *NALSA* judgment, the Union government must formulate a dedicated department in the concerned ministries at the national level for ensuring implementation of SOGIESC rights.

- **Actively defend and develop the legal framework relating to SOGIESC rights at the international level**

In 2019, the UN Committee on the Rights of Persons with Disabilities recommended the Government of India to “*adopt measures to prevent sex assignment or “sex normalizing” surgeries, bullying and stigmatization against intersex children, ensuring their rights to preserve their physical and mental integrity.*”

The Indian government should launch a national-level consultation process with experts on SOGIESC rooted in Indian knowledge traditions to develop research on issues related to rights of intersex persons. Further, India should actively participate in the defence and development of international norms on this issue.

- **End discrimination based on nomenclature and terminology:**

Medical professionals need to be trained to ensure that intersex traits are not characterized as “disorders of sex development.” Further, intersex traits should not be considered as genetic defects/genetic disorders and terms like ‘gender dysphoria’ should not be used to characterize it.

- **Promote awareness on alternative sexuality to address discrimination**

It is the duty of the government to also fulfill the mandate of the *NALSA* Court judgment where it highlighted the need to spread awareness on issues related to SOGIESC rights. Also, the government should take positive steps to ensure social security safeguards for intersex persons.

- **Address human rights violations of female athletes with intersex traits**

The meeting will also include discussion on race and gender discrimination in sports, including in policies, regulations and practices of sporting bodies, and the relevant international human rights norms and standards.

IV. BRIEFING PAPER:
REGULATION OF SEX SELECTIVE SURGERIES ON INTERSEX INFANTS/CHILDREN

Background

On 22nd April 2019, the Hon'ble High Court of Madras delivered a momentous judgement banning the practise of Sex Selective Surgeries on Intersex infants/children. The judgment is regarded as historic as it was the first instance when the judiciary recognised the right of intersex persons with respect to bodily integrity.

To ensure enforcement of the judgment, the Court directed the Tamil Nadu government to pass a 'Government Order' (G.O.) to ensure the prohibition of such surgeries.

The Court also directed the Health and Family Welfare department of the government to file a compliance report regarding the enforcement of the ban within eight weeks from the date of receipt of the judgment.

With a view to assist the government in drafting the G.O., a policy briefing meeting was organised by Srishti Madurai in association with Intersex Asia on 5th July 2019 in Chennai. This briefing paper has been prepared to provide an overview of the whole issue and also record the concerns raised by different stakeholders in the meeting.

Outline

This briefing paper has been divided into three parts:

- Part-I will provide a brief summary of the Madras High Court judgment.
- Part-II will give an overview of the deliberations in the meeting.
- Part-III records the resolution adopted at the meeting and proposed action plan

PART I- SCOPE OF THE JUDGMENT OF MADRAS HIGH COURT

Arunkumar and Sreeja v. The Inspector General of Registration and Ors.

Issues:

1. *Validity of the decision of refusal to register the marriage between petitioners*

This case was borne out of an appeal made by petitioners-Arunkumar and Sreeja (transwoman) against the decision of the Registrar and Inspector General of Registration for refusing to register their marriage. The Court had to examine the validity of the refusal as per the mandate of the Hindu Marriage Act, 1955.

2. *Validity of practice of forced sex selective operations on intersex infants.*

The Court also took up the practice of forced sex selection surgeries while recognising the work of Gopi Shankar. The Court was examining the validity of consent given on behalf of intersex infants for undergoing such surgeries in light of the judgment given by the Supreme Court in *NALSA v. Union of India*.

Ruling:

1. *Validity of the decision of refusal to register the marriage between petitioners.*

In the view of the court, the marriage was valid as per Section 5 of the Hindu Marriage Act, 1955 and hence, the Registrar of Marriage was bound to register the same.

The respondents had argued that memorandum of registration presented by petitioners did not fulfil the statutory requirement under Section 5 of the Hindu Marriage Act, 1955. Therefore, the Registrar was well within his power to refuse the registration of marriage.

The Counsels on behalf of the government gave the following reasoning in support of their decision to disallow registration of marriage.

[A]s per Section 5 of the Hindu Marriage Act, the bridegroom must have completed the age of 21 years while the bride must have completed the age of 18 years at the time of marriage. To understand the meaning of expression "bride", in the order impugned in this writ petition, Oxford Advance Learner's Dictionary of Current English was referred to. The term "Bride" can only refer to a "Woman on her wedding day". In the case on hand, the second petitioner Srija is a transgender and not a woman. Thus, the statutory requirement set out in Section 5 of the Hindu Marriage Act, 1955 has not been fulfilled.

The Court rejected these arguments and made the following observations.

Both the petitioners herein profess Hindu Religion. Their right to practice Hindu Religion is recognised under Article 25 of the Constitution of India. The Hindu Marriage Act is a personal law of the Hindus. When the right of the transgender persons to marry has been upheld by the Hon'ble Supreme Court, in the very nature of things, they cannot be kept out of the purview of the Hindu Marriage Act. One can have a civil marriage. One can also have a sacramental marriage. The petitioners' marriage was solemnized in a temple. Therefore, their fundamental right under Article 25 has also been infringed in this case.

The Court held that the decision of refusal to register the marriage between the petitioners was discriminatory on account of sexual orientation or gender identity and therefore, it violated Article 14 of the Constitution of India which guarantees equality before law and equal protection of law.

While arriving at this conclusion, Justice Swaminathan referred to the ruling in *NALSA v. Union of India* wherein the Supreme Court upheld the transgender persons' right to decide their self-identified gender.

The central and State governments were directed to grant legal recognition of their gender identity such as male, female or third gender.

In addition to the, the court has also referred to the judgment in the case of *Justice K.S. Puttaswamy v. Union of India*. In this judgment, the Court made the following observations:

Indeed, the Court has noted it would be contradictory to recognize a right of privacy with respect to other matters of family life and not with respect to the decision to enter the relationship that is the foundation of the family in our society.

In a judgment laced with references from ancient Indian epics as well as landmark apex court decisions, the Madras High Court conclusively upheld the right of the intersex children.

2. *Validity of practice of forced sex selective operations on intersex infants.* With respect to the validity of such operations, the judgment recalled the mandate of the *NALSA* judgment which declared the following:

no one shall be forced to undergo medical procedures, including SRS, sterilisation or hormonal therapy, as a requirement for legal recognition of their gender identity.

Recognising the mandate of the above-mentioned ruling of the Apex Court, the judgment directed the Government of Tamil Nadu to issue a Government Order enshrining the aforesaid mandate so as to effectively ban sex reassignment surgeries on intersex infants and children.

Further, the Madras High Court also directed the Health and Family Welfare Department to file a compliance report before the Registry within a period of eight weeks from the date of receipt of a copy of this order.

The judgment has also acknowledged the report of World Health Organisation titled- 'Sexual Health, Human Rights and the Law' which has called for calls for a deferment of intersex genital mutilation (IGM) until the intersex persons are old enough to make decisions for themselves.

With respect to the stigma and public awareness on this issue, the Court made the following remarkable observation:

Any intersex child is entitled to and must stay within the folds of its family. The running away from the family to the margins and beyond is a fatal journey that must be arrested. Time has come when they are brought back from the margins into the mainstream. This is because even though the transgender community is having its own social institutions, the stories we hear are horrendous. The parents must be encouraged to feel that the birth of an intersex child is not a matter of embarrassment or shame. It lies in the hands of the Government to launch a sustained awareness campaign in this regard.

For the foregoing reasons, the judgment given by the Madurai bench of the Madras High Court is being hailed as a path-breaking judgment.

PART II- DELIBERATIONS OF THE POLICY BRIEFING MEETING

Scholars and practitioners from legal and medical arena were invited to deliberate on the Draft G.O. prepared by Gopi Shankar (recognised in the judgment for his work on intersex human rights) of Srishti Madurai. The list of speakers included:

- Dr. Beela Rajesh, I.A.S, Secretary, Health and Family Welfare Department Government of Tamil Nadu.
- Dr. S. Ramesh, President, Indian Association of Paediatric Surgeons (ASI)
- Dr. Anuradha Udumudi, Co-founder, GeneTech – Renowned Genetic Scientist
- Ms. Anjali Gopalan –Founder, Naz Foundation (India) Trust
- Dr. Darez Ahmed I.A.S - Mission Director, State Rural Health Mission

In addition to the above, following persons also participated in the discussion.

- Dr. Jagan Mohan, Plastic Surgeon (Heads an Intersex Clinic)
- Dr. Mohan Kumar, Professor
- Dr. Prakash Agarwal, Secretary, Pedriatics Association
- Dr. Ramesh Babu, Chairman, Association of Pediatric Urology
- Sh. Ravi Kumar, Sub-editor, The Hindu
- Dr. Srinivas Udumudi, Co-founder, GeneTech
- Dr. Xavier, Nodal Officer, Department of Medical Education
- Dr. Velmurugan, ICH

Broad Outline of the Draft G.O.

The draft G.O. which was the focus of the deliberations in the meeting is divided into 11 parts:

- I. Title and Statement of Object and Reasons
- II. Definitions of key phrases
- III. Recognition of fundamental right to dignity
- IV. Right to bodily integrity and physical autonomy
- V. Treatment Protocol
- VI. Power of amendment of the G.O.
- VII. Health Services
- VIII. Applicability of the G.O. on the operation of other laws, rules or policies
- IX. Fixing the responsibility of the government to spread awareness
- X. Code of conduct for public officials dealing with cases related to G.O.
- XI. Format of the Declaratory Public Deed

Salient points made by Gopi Shankar, Srishti Madurai

a. Background:

- i. Definition of Intersex
- ii. Ignorance of medical ethics
- iii. Impact of sex determination operations on infant children
- iv. Selection of Gender Identity- an issue of individual choice
- v. Preference of Intersex persons to live as Gender-queer person (non-binary)
- vi. Difference between sex identity, sex determination, gender identity and sex characteristics law (SOGIESC rights)- term popularized by ILGA

b. Purpose:

- i. Constructive policy for proposal to enact a nation-wide legislation
- ii. Distinction between Transgender (Gender identity) and Intersex (Sex identity)
- iii. Discrimination in sports against women
 1. The case of Saundharajan and Dutee Chand (Hyperandrogenism)
 2. IAAF's rule and CAS's judgment
- iv. Need for an acceptable nomenclature on basis of human rights

Salient points made by Dr. Ramesh Babu, Indian Association of Pediatrics Surgeons

a. Considerations of Clinician

- i. Clinical Impression and Lab Tests
- ii. Immediate Threat and Intermediate issues
- iii. Long Term follow-up
- iv. Parental Preference

b. Transition care-biggest concern of pediatrics

c. Social support

d. Need for reforms in Medical Education:

Urgent reforms are needed in medical education so as to give a holistic perspective in dealing with issues of intersex persons.

e. Ethics questions:

- i. Is it ethical to withhold treatment for ALL Intersex conditions to protect the interest of a small percentage with Gender Dysphoria?
- ii. How to handle Parental Expectations?
- iii. What are the social implications?

f. Concerns of the Medical Profession

- i. Grouping & Classification of DSD is for academic purposes & not for legal purposes
- ii. Strong need to separate Embryologic / Chemical aberrations from Gender Dysphoria
- iii. Difference between Gender Assignment & Gender Re-assignment
- iv. Difference between Genuine Medical Professionals & Unscrupulous Quacks
- v. Medical & Surgical Emergencies need to be addressed soon
- vi. Continuing Follow-up to support the child
- vii. Transition care when they grow up
- viii. Uncommon diseases being handled only by experienced staff and major institutions
- ix. Inappropriate Secondary Sexual Characteristics
- x. Cancer in the retained Gonad
- xi. Knowing the Gender of the Child is a social Emergency
- xii. Gender Plays a Significant Role in the Society
- xiii. What about Gender Related Privileges

g. Recommendations

- i. One Apex Authority- Clinical persons, NGOs, Medico-social expert, Legal, Govt. reps.
 - ii. Standard treatment guidelines
 - iii. Periodic review of policies
 - iv. Complicated cases only operated by senior clinical persons
 - v. Registered multi-disciplinary clinics across the country
 - vi. Social support
 - vii. Method to identify quack professionals
- h. Definition of medically unnecessary surgeries
- i. Need to have a helpline

Salient points made by Dr. Anuradha Udumudi

- **Develop a uniform nomenclature:** Medical professionals, scientists and non-medical community should use a uniform nomenclature.
- **Genetic counselling/consultation to be integral part of intersex clinics:** Training programs should be designed suitably to be address intersex/DSD issues.
- **Undertake Research initiatives:** Identification of knowledge gaps in current knowledge and take research initiatives
- **Develop patient education material in Indian languages:** Knowledge about genetics in simple language would go a long way in promoting sensitization in society.
- **Take a holistic approach towards genetic analysis:** Medical practitioners should not have look at genetic analysis purely as a test to determine and assign gender. The tests must be carried out with a holistic approach, to understand syndromic presentation and associated complications, and finally to arrive at an individualized management plan for condition diagnosed.
- **Increased focus on analyzing genetic data:** Genetic data and analysis should empower physicians, affected individual, families and physicians alike in taking the best possible decisions. It may also help navigate surgical and hormonal decision making in DSD.
- **Emphasis on confidentiality and integrity:** Genetic analysis should and will contribute immensely to holistic health care and clinical research and must always be performed with sincere respect for patient's confidentiality and integrity.
- **Promote research on DSD:** There is an urgent need to not only improve and accelerate the path to an accurate diagnosis but also to initiate cutting edge research on Difference of Sex Development conditions.

PART III: RESOLUTION ADOPTED AT THE BRIEFING MEETING

The discussion at the policy briefing meeting culminated with a resolution affirming a commitment to work towards strengthening the legal and policy framework regarding rights of intersex children. All the stakeholders were in complete alignment with the reference to fundamental rights in the Madras High Court judgment.

All the participants unanimously agreed that a change is required in the legal and policy framework to ensure that intersex children are not deprived of their fundamental rights. The participants also highlighted the need for greater acceptance of alternative sexuality in the mainstream.

- I. **Fundamental Right to Gender Identity:** The NALSA decision had stated that transgender persons have a fundamental right to decide their gender identity as either man, woman or third gender. Incidentally, the court also found support for this legal proposition in Hindu traditions and modern neuroscience which validates the argument of internal and external gender mismatch experienced by the transgender population.
- II. **Fundamental Right to Gender Expression:** The court reiterated NALSA in saying that gender expression and presentation are protected under Article 19(1(a) of the constitution, and the State could not “prohibit, restrict or interfere” with a transgender person’s expression of the same.
- III. **Right to Equality:** The court also referenced NALSA to reiterate that the fundamental right to equality was available to “all persons” and not just men and women.

Therefore, Article 14 (equality) finds discrimination on the basis of gender identity unconstitutional.
- IV. **Dignity and Privacy:** The court also found, following NALSA, that the gender identity discrimination offends the fundamental right to dignity and privacy protected under Article 21.

ACTIONS ON PART OF TAMIL NADU GOVERNMENT

The primary aim for the briefing meeting was to arrive at a consensus regarding the broad framework of the Government Order prohibiting sex selective operations. The judgment delivered by the Madras High Court provides a set of guiding principles for the same.

All the stakeholders who participated in the meeting concurred with the principles laid down by the High Court judgment.

Therefore, it is expected of the Tamil Nadu government to pass a Government Order which is in alignment with the spirit of the judgment.

- **Prohibit Sex Selective Surgeries on Intersex children/infants**

The State government of Tamil Nadu has a golden opportunity with this government order to present a model law for the entire country.

In this regard, it is necessary to consult all stakeholders to arrive at a consensus regarding the policy framework which is in tune with our civilizational values as highlighted in the Madras High Court as well as the constitutional position laid down in the *NALSA* case.

- **Promote awareness on alternative sexuality to address discrimination**

It is the duty of the government to also fulfill the mandate of the *NALSA* Court judgment where it highlighted the need to spread awareness on issues related to SOGIESC rights. Also, the government should take positive steps to ensure social security safeguards for intersex persons.

ACTIONS ON PART OF STAKEHOLDERS

At individual as well as group level, all the stakeholders present in the meeting have agreed to be part of a national-level steering committee to advocate for legislation at the national level.

Srishti Madurai- the lead organiser of the meeting along with Intersex-Asia will ensure formation of national level steering committee and also pursue the advocacy efforts at the national level.

V. GENETIC PERSPECTIVES ON INTERSEX

*Salient points made by **Dr. Anuradha Udumudi**, Founder, GeneTech at High level board meeting on State Intersex Policy Negotiation conducted by Srishti Madurai in association with Intersex Asia on 5th July 2019*

Background

Dr. Anuradha Udumudi was invited to the High-level board meeting on State Intersex Policy Negotiation conducted by Srishti Madurai in association with Intersex Asia on 5th July 2019 as a Medical Geneticist and as the Founder Director of GeneTech, a leading genetics and genomics laboratory with extensive work on genetic disorders in India. Dr. Anuradha has diagnosed, counselled and worked with more than 200 cases of DSD (Difference in Sex Development). This statement is a written summary of the opinions expressed at the meeting. Dr. Anuradha Udumudi can be reached at **anu@genetech.co.in**.

Terminology

The term DSD was previously defined by medical community as “Disorders of Sex Development”, a term that replaced “Inter Sex” around 2005. This is now changed to “Difference of Sex Development”. Nomenclature is still controversial.

Current Medical Practice in India for DSD

- Physicians today primarily use Karyotyping or Chromosomal Analysis as a test to determine the “genetic sex”. The test looks at the number of chromosomes and determines the presence or absence of Y chromosome – the male sex determining chromosome.
- This approach is not satisfactory because chromosomal analysis is not sufficient to determine genetic sex on its own. Genetic diagnosis of DSD is much more than mere determination of genetic sex. As one of the major root cause of DSD is genetic in nature, diagnosis of the genetic condition is important for overall medical management at birth and beyond.

Genetics of DSD

- Genetics plays a crucial role in sex development and Intersex is a biological condition that arises to changes in genetic code or expression of genes during the development of the fetus, infant, child into adulthood
- Humans have 46 chromosomes with 22 pairs of autosomes (44 non sex chromosomes) and 1 pair of sex chromosomes (2 sex chromosomes X or Y). At a gross level a human with 46,XX will develop into a female and one with 46,XY will develop into a male.

- Each chromosome harbours several genes associated with sex development and minor changes in any of them can effect different metabolic pathways resulting in differences in sex development. Because of this, a human with 46,XX can still have a male phenotype and one with 46,XY can have a female phenotype. There are more than 100 genes identified to have an impact on sex development.
- Chromosomal analysis only looks chromosomes which are condensed structures comprising of thousands of genes. Such analysis cannot identify minor variations or mutations at single gene level. Newer technologies like Next Generation Sequencing have enabled sequencing multiple genes in a single go allowing identification of mutation or variation in all the relevant genes.
- In addition, gene and environmental interaction can result in a different *Epigenome* in individuals leading to variation in sex development.

Direction for Incorporating Genomics in DSD Medical Management

- In 70% of DSD cases, gene variations on different genes related to sex development were found. Using chromosomal analysis or karyotyping alone could not have diagnosed these cases. Therefore, using chromosomal analysis alone for diagnosis is outdated. Genomic technologies (like Next Generation Sequencing – NGS) offer better insight and need to be incorporated along with chromosomal analysis as first-tier diagnosis.
- There are many forms of DSD that are intrinsically associated with complications of other organ systems or developmental problems which may or may not be obvious at birth. A complete assessment of the condition requires incorporation of genomic analysis along with chromosomal analysis. Some of the examples of such syndromic presentations are:
 - Individuals with 46,XY DSD with mutations on GATA4 and FOG2 genes will develop cardio vascular conditions
 - Apart from 46,XX and 46,XY DSD, coding variation in SOX9 gene will result in skeletal complications
 - MRKH syndrome will a combination of sex development, renal and skeletal complication
 - Variations in WT1 gene cause renal complications
 - Mutations in SF1 gene may present adrenal and gonadal complications
 - 45 variants on AR gene alone associated with wide spectrum of androgen insensitivity syndromes
 - Although CAH (congenital adrenal hyperplasia) is a common condition showing virilisation in females, there are rarer form including STAR, POR and CYP11B1 gene variations.

- Cancer risks are associated with different gene variations including gonadoblastoma, squamous cell carcinoma and others
- Obesity, diabetes, hypertension and cardiovascular risks associated with gene variations in DSD associated genes

Worldwide Consensus

- 2005 DSD TRN (Disorders of Sex Development and Translational Research network Practice) consensus conference in Chicago released it's statement which says:
 - Many patients with DSD have historically experienced long diagnostic odysseys, in part because of uncoordinated diagnostic approaches, and many more never receive definitive diagnosis
 - A genetic diagnosis including multi gene sequencing is indispensable in these cases
 - Genome sequencing has yielded better diagnosis where endocrine testing has been ambiguous and critically modified clinical management and even helped in orienting gender identity.
 - A list of 78 genes has been published with association to DSD
 - Use of genomic technologies as first tier diagnostic tool should become the norm in the near future
- 2018 Expert Consensus Document (published in nature) on caring for individuals for DSD says:
 - Parameters clinicians need to consider when deciding on the appropriate treatment strategy include body appearance, psychosocial support, social cultural influences, gender related development, genetic background, biochemical background in addition to ethical, legal and human rights implications
 - The ultimate goal of diagnostic investigations is to obtain a diagnosis at the molecular (DNA) genetics level to allow prognostic predictions and genetic counselling and to set up an individualised management plan.
 - Individualised care plan includes informed consent, diagnostic investigations (both genetic and biochemical), information and psychological support, genetic counselling for families, transition of care, multidisciplinary care in adulthood, hurdles in practical implementation, data collection across ages, genital assessment in neonates, children and adolescents, long term outcome of surgical procedures, cancer risk assessment, assessment of other organ systems and complications, adolescent growth, long term follow up studies and assessment of psychological outcome.
 - Optimising quality of life should be the primary goal of holistic care and focussed research in the area of DSD.

Further Recommendations

- There is a need to have a consensus on **nomenclature** to be used in India by medical professionals, scientists, non medical communities and support groups
- Development of nationwide **Registry** for DSD with medical data, diagnostic data, genetic analysis data, genetic counselling data to be available online with protected patient confidentiality
- Genetic counselling/consultation to be an integral part of intersex clinics. Based on the demand, **training** program for professional genetic counsellors addressing Intersex/DSD issues must be developed.
- **Research initiatives:** Establishment of genotype-phenotype correlations and addressing the identified gaps in our current knowledge and primary tasks of research that needs to be taken up.
 - Genetic screening of Intersex population in India to identify gene variants specific to the region
 - Develop protocols or guidelines for genetic diagnosis and analysis specific in Indian population
 - To develop genetic counselling protocols specific to Indian community instead of adopting processes that are in practiced by western societies
 - Develop economical genetic tests for the community and families
 - Epigenetic studies to understand gene – environment interactions in DSD
- Need for **patient education material** in vernacular languages with input on genetics in simple understandable language. Programs sensitizing society must be initiated.
- A strong **teamwork** of Neonatologists, Pediatricians, Pediatric urologists, Pediatric surgeons, endocrinologists, Geneticists, Obstetricians, Ethicists, Patient support groups and Intersex/DSD community is highly desired
- Development of national level guidelines to help physicians, geneticists and other specialities to offer standardised diagnostic, management and follow up care for DSD.

Suggested changes in GO

- Replace the word “chromosomes” with “Genetic Testing (including both Karyotyping and Genomics)”
- Incorporate Genetic Counselling in appropriate sections
- Incorporate need for genetics research for holistic understanding of Intersex/DSD
- List and classify DSD in the document

Summary

- Medical practitioners should not see genetic analysis purely as a test to determine and assign gender. The tests have to be carried out with a holistic approach, to understand syndromic presentation and associated complications, and finally to arrive at an individualised management plan for the condition diagnosed.
- Genetic data and analysis should empower physicians, affected individual, families and physicians alike in taking best possible decisions. It may also help navigate surgical and hormonal decision making in DSD.
- Genetic analysis should and will contribute immensely to holistic health care and clinical research, and must always be performed with sincere respect for patient's confidentiality and integrity.
- There is an urgent need to not only improve and accelerate the path to an accurate diagnosis but also to initiate cutting edge research on Difference of Sex Development conditions.

References

Can be provided on request

VI. The Rights of Intersex People in India¹⁸

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

Report accepted by Office of the United Nations High Commissioner for Human Rights

Joint NGO submission by:

Srishti Madurai

NNID Foundation

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. 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

3. 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.
4. Intersex refers to the experiences of persons born with bodies that do not meet the normative definition of male and female.

¹⁸ Report available at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/SessionDetails1.aspx?SessionID=1342&Lang=en

5. 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.¹⁹

III. Recent legal and policy developments in India

6. 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".²⁰
7. 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,

¹⁹ **OII Europe.** Statement of OII European Intersex, Disability and the UN Convention on the Rights of People with Disabilities. April 2015. https://oieurope.org/wp-content/uploads/2015/05/CRPD_2015_Statement_OII_Europe.pdf

²⁰ **Karthikeyan R.** Activists say surgical 'correction' of intersex babies at birth wrong, govt doesn't listen. The News Minute 03 February 2017. <https://www.thenewsminute.com/article/activists-say-surgical-correction-intersex-babies-birth-wrong-govt-doesnt-listen-56739>.

free and fully informed autonomous consent.²¹ 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

8. 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.²² 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.

9. 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.²³ Joseph et al. also report that parents would not send

²¹ **Swaminathan GR.** Madurai Bench of Madras High Court. Arunkumar, and Sjeera vs. The Inspector General of Registration, The District Registrar, The Joint Registrar no. II. The Secretary to Government, Health and Family Welfare Department, and Director of the Ambedkar Foundation. Case no. 4125 of 2019 and no. 3320 of 2019. 22 April 2019.

<http://164.100.79.153/judis/chennai/index.php/casestatus/caseno#>.

Rao M. Ban sex reassignment surgeries on intersex infants, Madras HC tells TN govt. The News Minute. 23 April 2019. <https://www.thenewsminute.com/article/ban-sex-reassignment-surgeries-intersex-infants-madras-hc-tells-tn-govt-100565>.

²² **Joseph AA, Kulshreshtha B, Shabir I, Marumudi E, George TS, Sagar R, et al.** Gender Issues and Related Social Stigma Affecting Patients with a Disorder of Sex Development in India. Archives of Sexual Behavior. 2018;24(2):361-367.

²³ **Nair S.** Start with education system for change, says intersex activist. The Indian Express. 6 June 2019. <https://indianexpress.com/article/india/start-with-education-system-for-change-says-intersex-activist-5767432/>.

their children to school out of fear of rumours and stigmatisation.²⁴ 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.

10. 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.
11. 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.
12. 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.²⁵ 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

²⁴ **Joseph AA, Kulshreshtha B, Shabir I, Marumudi E, George TS, Sagar R, et al.** Gender Issues and Related Social Stigma Affecting Patients with a Disorder of Sex Development in India. Archives of Sexual Behavior. 2018;24(2):361-367.

²⁵ **Swaminathan GR.** Madurai Bench of Madras High Court. Arunkumar, and Sreeja vs. The Inspector General of Registration, The District Registrar, The Joint Registrar no.II. The Secretary to Government, Health and Family Welfare Department, and Director of the Ambedkar Foundation. Case no. 4125 of 2019 and no. 3320 of 2019. 22 April 2019. <http://164.100.79.153/judis/chennai/index.php/casestatus/caseno#>.

Rao M. Ban sex reassignment surgeries on intersex infants, Madras HC tells TN govt. The News Minute. 23 April 2019. <https://www.thenewsminute.com/article/ban-sex-reassignment-surgeries-intersex-infants-madras-hc-tells-tn-govt-100565>.

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

13. 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.
14. 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.²⁶ This statement is in line with Article 15 of the Convention.
15. Walia et al., Khadilkar et al. Vasundhera et al. and Raveenthiran²⁷ show that in several cases these interventions include non-emergency genital

²⁶ Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Medez, Human Rights Council, 1 February 2013 (A/HRC/22/53).

²⁷ **Walia R, Singla M, Vaiphei K, Kumar S, Bhansali A.** Disorders of sex development: A study of 194 cases. *Endocrine Connections*. 2018;7(2):364–371. <https://doi.org/10.1530/EC-18-0022>.
Khadilkar KS, Budyal SR, Kasaliwal R, Sathe PA, Kandalkar B, Sanghvi BV, et al. Ovotesticular disorder of sex development: A single-center experience. *Endocrine Practice*. 2015;21(7):770-776. <https://doi.org/10.4158/EP15606.OR>.

Vasundhera C, Jyotsna VP, Kandasamy D, Gupta N. Clinical, hormonal and radiological profile of 46XY disorders of sexual development. *Indian Journal of Endocrinology and Metabolism*. 2016;20(3):300-307. <https://doi.org/10.4103/2230-8210.179999>

Raveenthiran V. Neonatal sex assignment in disorders of sex development: A philosophical introspection. *Journal of Neonatal Surgery*. 2017;6(2). <https://doi.org/10.21699/jns.v6i3.604>.

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.²⁸ 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.

16. Health professionals often believe that sex assignment through medical and surgical intervention of intersex children is not an issue.²⁹ 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.³⁰ Parents of intersex children in India often prefer to assign their child the male sex due to social advantages offered to men.³¹ 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.³²
17. 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.³³ 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.
18. Consequences of surgical and medical interventions can be severe and irreversible: unnecessary surgery at a young age often leads to lifelong

²⁸ **Raveenthiran V.** Neonatal sex assignment in disorders of sex development: A philosophical introspection. *Journal of Neonatal Surgery*. 2017;6(2). <https://doi.org/10.21699/jns.v6i3.604>.

²⁹ E.g.: “For physicians it is obvious and unequivocal that a person with CAH and an XX karyotype has a female gender identity,” **Binet A, Lardy H, Geslin D, Francois-Fiquet C, Poli-Meroi ML.** Should we question early feminizing genitoplasty for patients with congenital adrenal hyperplasia and XX karyotype? *Journal of Pediatric Surgery*. 2016;51(3):465-468.

³⁰ **Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczner J, Nordenstrom A, Roehle R, et al.** Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. (<https://doi.org/10.1530/ec-18-0031>).

³¹ **Joseph AA, Kulshreshtha B, Shabir I, Marumudi E, George TS, Sagar R, et al.** Gender Issues and Related Social Stigma Affecting Patients with a Disorder of Sex Development in India. *Archives of Sexual Behavior*. 2018;24(2):361-367.

³² **Sharma R.** Parents prefer male child in intersex operations in Gujarat. *The Times of India*. 5 February 2014. <https://timesofindia.indiatimes.com/india/Parents-prefer-male-child-in-intersex-operations-in-Gujarat/articleshow/29879738.cms>.

³³ **Liao L-M, Wood D, Creighton SM.** Parental choice on normalising cosmetic genital surgery. *BMJ*. 2015;351.

physical and mental health issues due to the irreversible character.³⁴ 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.³⁵ Srishti Madurai has received several reports of intersex persons committing suicide.³⁶

19. 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.³⁷ Some medical treatments and studies (including a test described as 'clitoral sensory testing and vibratory sensory testing'³⁸) for intersex children can be classified as sexual abuse.³⁹

³⁴ **Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczer J, Nordenstrom A, Roehle R, et al.** Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. (<https://doi.org/10.1530/ec-18-0031>).

³⁵ **Falhammar H, Claahsen-van der Grinten HL, Reisch N, Slowikowska-Hilczer J, Nordenstrom A, Roehle R, et al.** Health status in 1040 adults with disorders of sex development (DSD): a European multicenter study. *Endocrine Connections*. 2018. <https://doi.org/10.1530/ec-18-0031>.

³⁶ **Nair S.** Start with education system for change, says intersex activist. *The Indian Express*. 6 June 2019. <https://indianexpress.com/article/india/start-with-education-system-for-change-says-intersex-activist-5767432/>.

³⁷ **Browne A, Finkelhor D.** Impact of child sexual abuse: A review of the research. *Psychological Bulletin*. 1986;99(1):66. <https://doi.org/10.1037//0033-2909.99.1.66>. 4.

Cook A, Spinazzola J, Ford J, Lanktree C, Blaustein M, Cloitre M, et al. Complex trauma in children and adolescents. *Psychiatric annals*. 2005;35(5):390-398. <https://doi.org/10.3928/00485713-20050501-05>.

Fergusson DM, Horwood LJ, Lynskey MT. Childhood Sexual Abuse and Psychiatric Disorder in Young Adulthood: II. Psychiatric Outcomes of Childhood Sexual Abuse. *Journal of the American Academy of Child & Adolescent Psychiatry*. 1996;35(10):1365-1374. <https://doi.org/10.1097/00004583-199610000-00024>

³⁸ **Yang J, Felsen D, Poppas DP.** Nerve sparing ventral clitoroplasty: analysis of clitoral sensitivity and viability. *The Journal of urology*. 2007;178(4):1598-1601. <https://doi.org/10.1016/j.juro.2007.05.097>

³⁹ **Alexander T.** The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse Rohnert Park, CA, USA: Intersex Society of North America; 1997. URL: <http://www.isna.org/articles/analog>.

Dreger AD. Rejecting the Tranquilizing Drug of Gradualism in Intersex Care [Blog]. 2015 [bewerkt 21 november 2015; geraadpleegd 24 november 2015]. URL: http://www.alicedreger.com/DSD_human_rights.

Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. *Intersex: Stories and Statistics from Australia*: Open Book Publishers; 2016. <https://doi.org/10.11647/OBP.0089>.

Knight K, Tamar-Mattis S. "I want to be like nature made me": Medically Unnecessary Surgeries on Intersex Children in the US. New York, NY, USA: Human Rights Watch / interAct, July 2017. Nr. 978-1-6231-35027.

Scientists and agencies consider the medical treatment undergone by a group of intersex children to be comparable to Female Genital Mutilation (FGM).⁴⁰ A growing number of intersex people claim to have experienced medical attention as (sexual) abuse.⁴¹ 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.

20. 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

Wiesemann C. Ethical Guidelines for the Clinical Management of Intersex. *Sexual Development*. 2010;4(4-5):300-303. <https://doi.org/10.1159/000316232>.

⁴⁰ **Dreger AD.** "Ambiguous Sex"—or Ambivalent Medicine?: Ethical Issues in the Treatment of Intersexuality. *Hastings Center Report*. 1998;28(3):24-35. <https://doi.org/10.2307/3528648>.

Earp BD, Steinfeld R. Genital Autonomy and Sexual Well-being. *Current Sexual Health Reports*. 2018;10(1):7-17. <https://doi.org/10.1007/s11930-018-0141-x>. **Ehrenreich N, Barr M.** Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices". *Harvard Civil Rights-Civil Liberties Law Review*. 2005;40:71.

Fraser S, Reisel D. Constructing the female body: using female genital mutilation law to address genital-normalizing surgery on intersex children in the United States. *International Journal of Human Rights in Healthcare*. 2016;9(1). <https://doi.org/10.1108/IJHRH-05-2015-0014>.

Gleichstellungs- und Frauenministerinnen und -minister, -senatorinnen und -senatoren der Länder (GFMK), redactie Beschlüsse. 24. Konferenz der Gleichstellungs- und Frauenministerinnen und -minister, -senatorinnen und -senatoren der Länder (GFMK); 2014 1-2 oktober; Wiesbaden, Deutschland: Hessisches Ministerium für Soziales und Integration . **Green FJ.** From clitoridectomies to 'designer vaginas': The medical construction of heteronormative female bodies and sexuality through female genital cutting. *Sexualities, Evolution & Gender*. 2005;7(2):153-187. <https://doi.org/10.1080/14616660500200223>.

Office of the United Nations High Commissioner for Human Rights. Good practices and major challenges in preventing and eliminating female genital mutilation - Report of the Office of the United Nations High Commissioner for Human Rights. United Nations - General Assembly, 2015. Rapport Nr. A/HRC/29/20.

Pūras D. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. United Nations, General Assembly, 4 april 2016. Nr. A/HRC/32/33.

⁴¹ **Blair K.** When Doctors Get It Wrong. *Narrative Inquiry in Bioethics*. 2015;5(2):89-92. <https://doi.org/10.1353/nib.2015.0029>.

Frader JE. A Pediatrician's View. *Narrative Inquiry in Bioethics*. 2015;5(2):139-142. <https://doi.org/10.1353/nib.2015.0040>.

Meoded Danon L. Time matters for intersex bodies: Between socio-medical time and somatic time. *Social Science & Medicine*. 2018;208:89-97. <https://doi.org/10.1016/j.socscimed.2018.05.019>.

Monro S, Crocetti D, Yeadon-Lee T, Garland F, Travis M. Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Huddersfield, UK: University of Huddersfield, October 2017. Nr. 978-1-86218-151-9.

Viloria H. Born both: an intersex life. New York, NY, USA: Hachette Books; 2017.

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.⁴² 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

21. 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.⁴³ 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:

- a) 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

⁴² Joseph AA, Kulshreshtha B, Shabir I, Marumudi E, George TS, Sagar R, et al. Gender Issues and Related Social Stigma Affecting Patients with a Disorder of Sex Development in India. Archives of Sexual Behavior. 2018;24(2):361-367.

⁴³ Joseph AA, Kulshreshtha B, Shabir I, Marumudi E, George TS, Sagar R, et al. Gender Issues and Related Social Stigma Affecting Patients with a Disorder of Sex Development in India. Archives of Sexual Behavior. 2018;24(2):361-367.

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.

- b)** 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.
- c)** 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.
- d)** 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.
- e)** 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.
- f)** 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.

VII. MOMENTOUS ACHIEVEMENTS FOR INTERSEX RIGHTS IN INDIA⁴⁴

-COC Netherlands

August and September of 2019 saw two major wins for intersex rights in India. In August, the government in the southern Indian state Tamil Nadu issued new policy to protect the rights of intersex people following a ruling in favour of an intersex woman at the High Court in Madras. This regulation prohibits “sex-normalising” or “sex assignment” surgeries on intersex babies and children. The following month, the United Nations Committee on the Rights of Persons with Disabilities (CRPD) included several recommendations for India to adopt human rights measures for intersex people in their concluding observations. Both of these outcomes will play a strong role in the adoption of human rights protections for intersex people in India as a whole.

Stopping Unnecessary Surgeries in Tamil Nadu

The decision to ban “sex-normalising” surgeries in Tamil Nadu comes following a lawsuit started in April by an intersex woman and her husband at the High Court in Madras. “Sex-normalising” surgeries are legal and common in most countries and are often performed without the consent of the child or parents. Doctors will not be allowed to perform surgeries to “correct” the sex characteristics of intersex babies and children, however, they will still be allowed to perform surgeries in life-threatening cases.

The ruling from the Madras High Court concludes: “The government after careful examination of all the above points and based on the opinions of the experts as forwarded by the Director of Medical Education, have decided to ban sex reassignment surgeries on intersex infants and children except on life-threatening situations and ordered accordingly.

The life-threatening situation shall be decided by the Government based on recommendation of the Director of Medical Education who shall form a committee [including a Social Worker / Psychology worker / intersex activist]. The Director of Medical Education shall take every step to ensure that the above exceptional clause of life-threatening situation shall not be misused in any way by anyone which shall affect the implementation of the ban on sex reassignment surgeries on intersex infants and children.”

COC Netherlands and Nederlandse Organisatie voor Seksediversiteit (NNID) supported Srishti Madurai- an Indian intersex organization led by Gopi Shankar Madurai-to organize a policy meeting with government representatives and other stakeholders.

This meeting focused on preparing and implementing this High Court ruling. Currently, the focus is on Indian Prime Minister Narendra Modi to promote this legislation throughout the rest of India.

⁴⁴ <https://international.coc.nl/news/momentous-achievements-for-intersex-rights-in-india/>

Indian Intersex Rights at the United Nations

In September 2019, the United Nations Committee on the Rights of Persons with Disabilities (CRPD) included several recommendations for India to adopt human rights measures for intersex people in their concluding observations.

The CRPD is a Treaty Body for all rights relating to people living with a disability. All UN member states that have signed the Treaty can then be held accountable by a committee of experts who review how well they are doing and give concluding observations that are intended to be binding.

This achievement is a direct result of the lobbying efforts by Srishti Madurai, supported by COC Nederland and NNID. Following the successful lobbying campaign in Geneva, the CRPD recommended that the Indian government make a number of policy changes in order to guarantee human rights for intersex people. The recommendations are:

- The government must implement awareness-raising programs and training to promote human rights and protection from prejudice and harassment for intersex people.
- The government must adopt measures to ensure that intersex individuals are given a right to life, meaning that they will be protected from mercy killings, attacks, and other harmful practices. The government must also enforce investigations into these incidents, and sanction perpetrators.
- The government must protect intersex children against attacks on their lives and all related harmful practices.
- The government must take measures to prevent “sex assignment” or “sex-normalising” surgeries on intersex children. The government must also guarantee the right of intersex people to maintain their physical and mental integrity.
- The government must take measures to prevent rejection, stigmatisation, and bullying of intersex children, and to revise the regulations to guarantee access to education, to combat stereotypes, and to set up mechanisms for filing complaints and imposing sanctions in cases of discrimination.

This is the first time the United Nations Human Rights Commission Treaty Bodies Committee has given a recommendation on intersex human rights to the Republic of India. These binding recommendations from the CRPD, alongside the win in the High Court of Tamil Nadu against “sex-normalising” surgeries, are momentous achievements for intersex rights in India. These outcomes will be used to further the adoption of human rights measures and protections for intersex people by the government of India as a whole. Following these results, Srishti Madurai intends to continue engaging with the Indian government on all levels to ensure the adoption of these recommendations and rulings.

VIII. SUGGESTIONS BY SRISHTI MADURAI

THE TRANSGENDER PERSONS BILL, 2019

I. Introduction

The aim of this submission by Srishti Madurai is to inform the Parliament of India about the required changes in the Transgender Persons Bill, 2019 (“The Bill”). In the *NALSA* judgment, the Supreme Court had directed the Union and the state governments to undertake steps to fulfill the mandate of the judgment. In particular, the judgment declared the need for legal gender recognition of transgender persons. The Court also recognised the obligation of the government to address the needs of persons who did not conform to binary notion of gender identity- male or female. The judgment recommended the government to adopt anti-discriminatory and social welfare measures.

With the bill, the Union government has an opportunity to ensure fundamental rights are guaranteed to all persons regardless of their sex characteristics and gender identity. However, the bill has not lived up to the mandate of the normative articulation in the *NALSA* judgment and hence, it suffers from serious flaws. In this submission, we hope to offer concrete suggestions regarding each of the chapters in the bill. Here’s a summary of our suggestions.

- The title of the current bill should be “Gender Identity, Gender Expression and Sex Characteristics (Protection of Rights) Bill”.
- The definition of ‘transgender persons’ needs to draw distinction between transgender persons and intersex persons.
- The bill should prohibit non-necessary and non-consensual sex selective surgeries and sex reassignment surgeries and also make it an offence.
- The bill should also provide for setting up a Working Group on Intersex Persons.
- The bill should clearly identify the specific health needs of transgender persons and intersex persons.

II. Suggestions for Chapter-I

- **Title:** The title of the current bill should be “Gender Identity, Gender Expression and Sex Characteristics (Protection of Rights) Bill”.

The title of the current bill is “The Transgender Persons (Protection of Rights) Bill, 2019”.

The current title of the bill is exclusionary in its current form as it does not accommodate all persons whose legal protection it seeks to recognise.

The bill is also expected to address the needs of intersex persons. However, the current title does not give the impression that it accounts for protection of rights of intersex persons.

- **Definition of ‘Transgender persons’:**

The current bill provides for the following definition:

“a person whose gender does not match with the gender assigned to that person at birth and includes trans-man or trans-woman(whether or not such person has undergone Sex Reassignment Surgery or hormonetherapy or laser therapy or such other therapy), person with intersex variations, gender-queer and person having such socio-cultural identities as kinner, hijra, aravani andjogta.”

The current bill conflates the condition of intersex persons with transgender persons by incorporating them under the same category. World over, there is a clearly recognised scientific distinction between the transgender persons and intersex persons. Barring few overlaps, the legal and welfare needs of intersex persons are different from those of transgender persons. Therefore, the definition should highlight this distinction between transgender persons and intersex persons enabling them to exercise the rights which they are entitled to. Some infants/persons born or living with intersex traits can live with a non-binary identity or may choose to. The bill should also provide for definition of key terms- ‘gender identity’, ‘gender expression’ and ‘sex characteristics’.

III. Suggestions for Chapter-II-Prohibition of certain acts

This chapter essentially prescribes anti-discriminatory norms for persons and establishment under specified contexts.

- **End discrimination based on nomenclature and terminology:** It should also contain a direction for medical professionals to ensure that intersex traits are not characterized as “disorders of sex development.” Further, intersex traits should not be considered as genetic defects/genetic disorders and terms like ‘gender dysphoria’ should not be used to characterize it.
- **Prohibition of non-compulsory and non-consensual Sex Selective Surgeries/Sex Reassignment Surgeries:** It shall be unlawful for medical practitioners or other professionals to conduct any sex reversal treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent: Provided that such sex assignment treatment and, or surgical intervention on the sex characteristics of the minor shall be conducted if the minor gives informed consent through the person exercising parental authority or the tutor of the minor.

Such Medical or Surgical Treatment should be undertaken only in specialized centres which have Multi-disciplinary clinical team. The specific nature of the intervention should be taken as a consensus by this multi-disciplinary team of experts with experience in handling intersex conditions and should be guided by standard medical protocols. For exceptional cases, where the decision-making is difficult, should be referred to Government working group/ committee for approval.

IV. Suggestions for Chapter III-Recognition of Identity of Transgender Persons

Even after the *NALSA* judgment which declared that medical procedures are not a necessity for self-identification, the Health Ministry has admitted that medical procedure including sex reassignment surgeries are being done in India. The Ministry has given the justification that it is only done 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.

When this response was presented before the High Court of Madras in the case of *Arunkumar and Sreeja v. The Inspector General of Registration and Ors.*, it slammed the Health Ministry and imposed a ban on the practice of SRS on intersex infants/children. The Court held that the consent of the parent cannot be considered as the consent of the child. Hence, such surgeries should be prohibited.

Recognising the mandate of the Madras High Court judgment and the *NALSA* judgment (Direction 5, para 129)., the bill must ban such medical procedures to ensure that transgender persons and intersex persons are not compelled to undergo such unnecessary medical procedures for recognition of identity.

V. Suggestions for Chapter IV-Welfare Measures by Government

The bill should prescribe specific measures to address education needs and health needs of transgender and intersex persons. Further, the bill should also prescribe provisions to ensure compliance of anti-discrimination measures in labour markets. In each sector, there should be specific laws prohibiting discriminatory practices on the basis of gender identity, gender expression and sex characteristics.

Other recently enacted social welfare laws provide an acceptable template for this chapter as they recognise specific areas of welfare such as education, health, employment, insurance, pension, food security and sanitation.

VI. Suggestions for Chapter V-Obligations of Establishments and Other Person

In this section, the right to bodily integrity of transgender persons and intersex persons must be recognised in a way that no establishment shall ever compel any individual to undergo any non-consensual and non-necessary medical procedure.

VII. Suggestions for Chapter VI- Education, Social Security and Health of Transgender Person

- **Education:** In this chapter, specific revision of existing laws and regulations must be mandated so as to prevent discrimination in the form of bullying or harassment in educational institutions based on gender identity and sex characteristics. Special measures must be taken to ensure that transgender persons and intersex persons do not face any discrimination while appearing for competitive exams for jobs in public services. Further, this provision should prescribe training of schoolteachers and staff in educational institutions. The curriculum of textbooks also needs to be revised so as to ensure inclusive education.
- **Health:** In this chapter, distinct health needs of transgender and intersex persons needs to be identified. Genetic counselling/consultation to be integral part of clinics for intersex persons. Training programs should be designed suitably to be address intersex/DSD issues.

All persons seeking psychosocial counseling, support and medical interventions relating to sex or gender should be given expert sensitive and individually tailored support by psychologists and medical practitioners or peer counseling.

The government should introduce indigenous medical knowledge like ayurvedic counselling along with allopathic medicine. Our civilizational ethos never treated conditions of gender variants as any kind of disorder/mental health/dysphoria.

- **Society Security:** Social security needs of the transgender persons and intersex persons must be clearly identified and listed down in the law in a non-exhaustive manner. The government should be obligated by law to prepare resource and informative materials in all Indian languages pertaining to the awareness on issues related to transgender persons and intersex persons. This material must be disseminated to parents, educational institutions and to the general public.

In addition to preparation of material, the Ministry in charge must be obligated by law to conduct adequate awareness programmes in all parts of the country on regular interval through different public authorities.

VIII. Suggestions for Chapter VII- National Council for Transgender Persons

This chapter provides for the institutional framework for protection of rights of transgender persons. There should be a specific working group for intersex persons. It should include member of the medical profession as well as genetic scientists.

Composition of Working group on Intersex:

- The working group shall consist of a Chairperson and nine members.
- Two persons as chair. One- Medical genetists- 15 years of experience. Second- The Chairperson shall be a Professor or Senior Associate Professor of Pediatric surgery from a Government medical College with at least twelve years of experience in dealing with intersex conditions
- The nine members shall be five medical personnel from government or private sector (pediatrician, pediatric surgeon /urologist, pediatric endocrinologist, genetic scientist, plus a doctor representing department of health) and four non-medical experts (one human rights expert, one expert in Community Health and medical ethicists one medical sociologists/ psychologist and one lawyer specialized in Indian Constitutional law.

IX. Suggestions for Chapter VIII-Offences and Penalties

The law should prescribe punishment for those persons and establishment who perform any non-consensual and non-necessary sex selective surgeries on infants/children.
