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ISSUE BRIEF

The Vanishing Females: A Case Study of Preimplantation Genetic Diagnosis in India

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In the last three decades, ART facilities have emerged all across India. In addition to the domestic demand for infertility treatment services (mostly unregulated) offered by ART clinics.

INTRODUCTION

Since the 1950s, technologies aiding reproduction have increased in number, enhancing the likelihood of conception and bringing pregnancies to term. Assisted Reproductive Technologies [ARTs] offer a variety of techniques ranging from intrauterine insemination [IUI] to in-vitro fertilisation and embryo transfer [IVF-ET] that treat the inability to conceive and facilitate fertilisation. In the last three decades, ART facilities have emerged all across India. In addition to the domestic demand for infertility treatment services (mostly unregulated) offered by ART clinics, a significant portion of their services are availed by overseas clients primarily due to relatively lower costs.

This paper seeks to highlight the ethical concerns of sex selection via PGD and the risk it poses to India's already skewed sex ratio. PGD can be used to decide the sex of the baby preemptively. In a country where preference for a male child is normative, it is essential to look at the impact of an unregulated sex selection tool on the society. The following sections attempt to explain the impact of sex selection via PGD on sex ratio, reasons behind preference for a male child, existing laws to tackle the problem, and what more can be done to address the issue.

Artificial Reproductive Technology in India: An Overview

A 2017 report by Times of India showed that less than 20% of IVF clinics and only 2% of ART centres operating in India are registered with the Indian Council of Medical Research (Dey 2017). Currently, 580 ART Clinics are registered with the National Registry of ART Clinics and Banks in India [NRACBI] of ICMR. Another 1000 or so have applied, which puts the number of ART clinics operating in the country over 20,000 (National Registry of ART Clinics and Banks in India 2021). Since there is no regulation within the industry, there are no statistics on the number of infertility clinics that use ART in the country.[1]

Reports, independent studies, anecdotal evidence and an influx of applications to register with NRACBI suggest a steep rise in accessibility to ART. Rising incomes and lower costs of the process are fueling this increase, so are shifting views about fertility treatments sustained by a cycle of good outcomes at IVF clinics which inspire other aspiring parents to give it a try. Even in non-metropolitan regions, ART clinics are rapidly mushrooming. For example, according to the National Registry of ART Clinics and Banks in India, 8 of Uttar Pradesh's 18 clinics are in Tier 2 cities, including Meerut, Agra, Bareilly, Hapur, and Muzaffarnagar (Raza 2018).

ART's growing popularity is a cause of concern as no laws regulate this industry. The industry is functioning through actors such as doctors, parents, and government officials collaborating at various levels. Such collaborations occur in an environment with no binding standards or regulations, giving way to medical malpractice and ethical concerns. The ART sector is plagued by a lack of accountability in terms of costs and services, making it easier to perform illegal procedures, including pre-implantation genetic diagnosis for sex selection or gender screening.

One form of ART, which became publicly available in the 1990s, is Preimplantation Genetic Diagnosis [PGD], "a process designed to investigate the genetic characteristics of a pre-embryo prior to its transfer into the uterus" (Paonessa 2007). PGD is a selective method used during IVF to identify genetic problems in embryos using various genetic techniques and make sure to implant only those free of genetic abnormalities.

[1] Not including a handful that have applied to the registry.

In medical practice, PGD is employed in two situations. First, when a person is at risk of having a child with a genetic illness. Then PGD procedures are used to determine the absence of the disorder before embryonic implantation. Second, when a person has in-vitro fertilisation later in life[2], prophylactic screening of the embryo for any genetic problems is performed to enhance the chances of the child bearer completing the pregnancy successfully.

However, PGD is also being employed as a reliable tool for gender selection. Because it may determine the sex of the embryo, many couples want PGD for sex selection, which might be driven by cultural, social, ethnic, or psychological factors. The use of PGD for non-disease sex selection has sparked a moral outcry over not implanting healthy embryos when they are discovered to be of the 'wrong' sex (Kovacs 2013). The risk of sex discrimination and the persistence of injustices against women have often been raised as objections (ibid).

Preimplantation Genetic Diagnosis poses the potential threat of being used widely for sex selection, especially in countries like India, where there is a culture of son preference and discrimination against daughters. India's social and cultural environment is rooted in a deeply patriarchal society, with female children being killed at birth for many years because they lacked the "Y chromosome" (Downing 2005). The outdated look has hardly changed. The only difference is that state-driven interventions have made sex-determination illegal. According to a UNICEF research, 8,000 Indian women had abortions in 1984 after receiving the findings of sex-determination ultrasounds. Of these, 7999 female foetuses (Oberman 2003).

With the introduction of assisted reproductive technologies, Indian couples were confronted with novel and unusual techniques of modifying genetics in order to achieve the "much-desired birth of a male offspring" (Downing 2005). United Nations Population Fund report of 2021 states that close to 400,000 female births are projected to be missed in India each year due to gender-discriminatory sex selection. This is equivalent to around 3% of all female births (Kulkarni 2020). In most northern and western states, the degree[3] is high, moderate in Uttar Pradesh, Himachal Pradesh, and Madhya Pradesh, and low or negligible in most eastern and southern states. The outcome is a catastrophic gender demographic shift in the Indian society, which many fear will never be compensated for, even if quick governmental action is taken. The male population, per 100 females, will be in excess even after the year 2100 (Department of Economic and Social Affairs 2019).

This paper seeks to highlight the ethical concerns of sex selection via PGD and the risk it poses to India's already skewed sex ratio. PGD can be used to decide the sex of the baby preemptively. In a country where preference for a male child is normative, it is essential to look at the impact of an unregulated sex selection tool on the society. The following sections attempt to explain the impact of sex selection via PGD on sex ratio, reasons behind preference for a male child, existing laws to tackle the problem, and what more can be done to address the

[2] The child bearer of advanced maternal age, couples with a history of recurrent pregnancy loss, or couples with repeated IVF failure.

[3] Number of female births missed as a percentage of total female births.

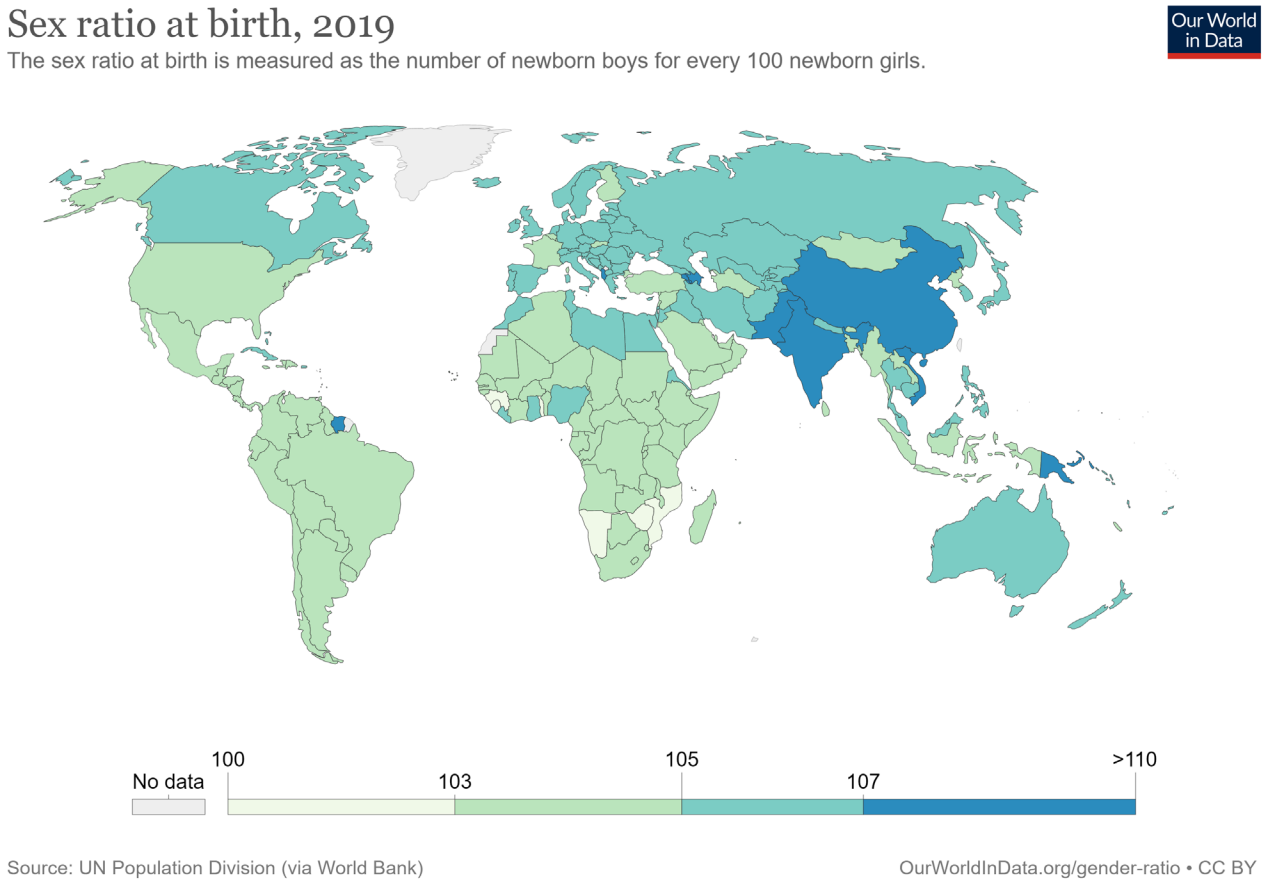
issue.

India's Skewed Sex Ratio and PGD

Sex-selective abortion is the practice of ending a pregnancy based on the baby's expected gender. Selective abortions of females are widespread in nations where the society emphasises male offspring over female, such as India (Lemoine and Tanagho 2007). While statistics on sex-selective abortion are difficult to come by, male-to-female ratios in many nations are hints enough (Mohapatra 2013). The sex ratios of a population are indicative of whether a population practises sex-selective techniques or not. The typical male-to-female sex ratio should be between 104 and 107 boys for every 100 girls (ibid.). However, when this ratio is skewed within a community, it implies the use of sex-selective abortions or other sex-selective procedures.

In 2020, the sex ratio of the total population in India was 108.18 males per 100 females. With about 110 boys born for every 100 girls, India has the world's 5th most skewed sex ratio at birth after China, Azerbaijan, Vietnam, and Armenia (Department of Economic and Social Affairs 2019)(Figure 1 below). This number is well above the margin of error, making it clear that sex-selective practices prevail and adversely influence the sex ratio.

Figure 1: Sex ratio at birth, 2019

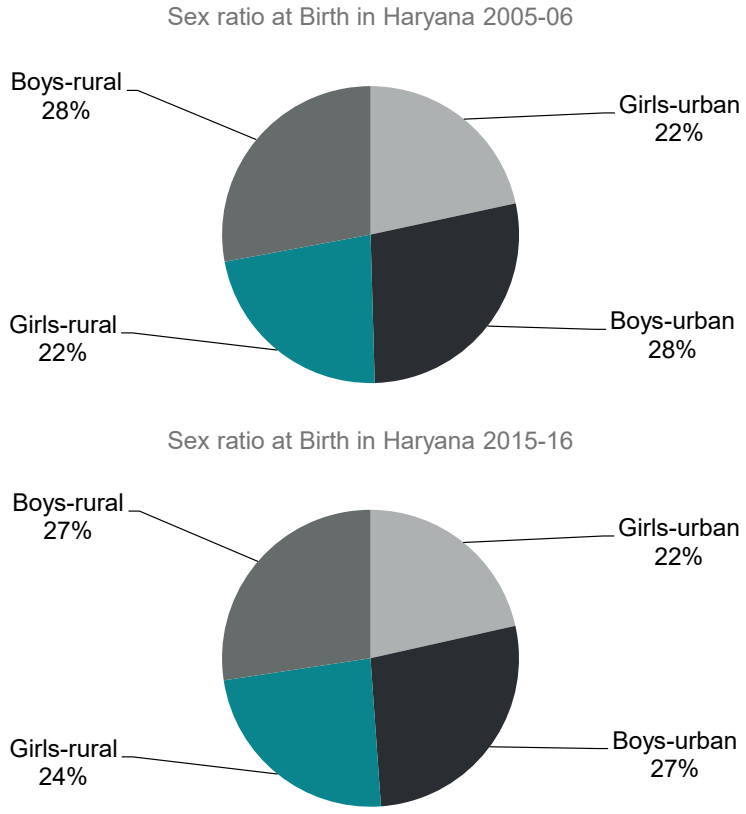


Source: Our World in Data (2019)

Although, the first reported case of female infanticide goes back to early eighteenth century (Lemoine and Tanagho 2007), sex-selective abortion as medical technology have made infanticide easier. Selective abortions became more prevalent in India as ultrasounds became available and accessible. In a study conducted in Pune, 430 of the 450 women informed that they were expecting a girl, chose abortion. Whereas, all 250 women expecting a boy elected to take their pregnancies to term (Lemoine and Tanagho 2007).

The lopsided sex ratio in India indicates that sex-selective activities are widely used. The sex ratio in cities is worse than in rural regions (National Family Health Survey 4 2016). There are 1009 females per 1000 men in rural areas, but there are only 956 females per 1000 males in urban areas[4]. In the last few years, rural area's sex ratio at birth has improved slightly, going from 914 to 919 girls per 1,000 boys. Yet, urban India recorded an abysmal 899. The overall child sex ratio at birth in Haryana was 836, up from 762 in 2005-2006 (Figure 2). However, despite the launch of the 'Beti Bachao, Beti Padhao' programme, the sex ratio is as low as 785 in urban Haryana (Figure 3). Urban Rajasthan has dropped below the state average from the 2000s decade, with a sex ratio at birth of 845. According to the most recent statistics, the sex ratio in rural Rajasthan is 973, whereas in urban Rajasthan, it is 928 (Figure 4).

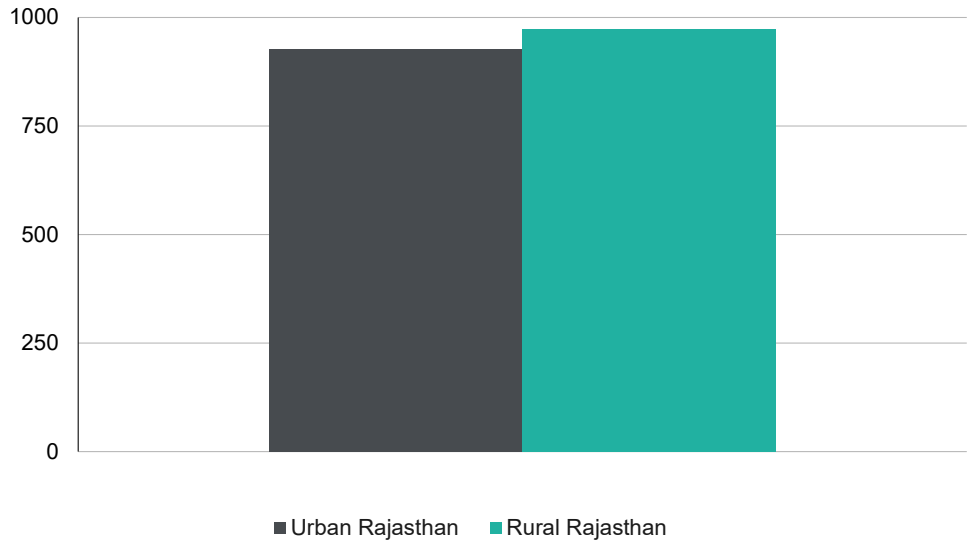
Figure 2 & 3: Sex Ratio at Birth in Haryana 2005-06 and 2015-16



Source: National Family Health Survey 3 (2007) and National Family Health Survey 4 (2016)

[4] Sex-ratio in rural areas is better than the urban ones partly due to out-migration of males from former to latter in search of employment. The ratio in urban areas is still more than 104 males to every 100 females. This ratio is above the error margin which accounts for migration, suggesting prevalence of sex-selection practices.

Figure 4: Female Births per 1000 male births in Rajasthan



Source: NFHS 4 (2016)

According to an Ernst & Young Report (2015 as cited in Dey 2017), 55% of ART treatments take place in metropolitan cities in India. PGD is easier to avail in states in proximity to Delhi, such as Rajasthan, Haryana, and UP. Urbanised populations from nearby regions travel for the cutting-edge ARTs. However, concluding that sex selection through PGD or abortion is an exclusive urban phenomenon would be reductive.

The cost of PGD is anywhere between 1.5 to 2.5 lakh. Since most of the clinics are unregistered, the prices of these services are not regulated (Dey 2017). Since upper class populations in rural areas have witnessed a rise in their income in the past few years, it has made procedures like PGD accessible. The rural economy saw an immense change in income from remittances such as rent and sale of property, indicating an upward increase of 528% (Ranganathan, Tripathi, and Rajoriya 2016). The share of remittances registered a steep increase among Brahmins, Forward Castes, and OBCs, while it was lower for SCs and STs.

The Commission on Status of Women's presentation to Planning Commission indicates that sex selection is practised by urban, educated, and aspiring middle-class people. Plus, there is an increase in ART clinics in Tier 2 cities as well. The rural income data suggests usage of PGD is not an exclusively urban phenomenon, especially for rural areas near metropolitans (Ranganathan, Tripathi, and Rajoriya 2016). Therefore, accessibility to PGD is restricted to the upper-class demographic but not solely to the urban one.

Child sex ratios[5] urban regions are typically higher than in rural areas (Jha et al., 2011). At the same time, evidence suggests that gender-biased sex selection is spreading to rural areas, as technology becomes more accessible in these settings (Nandi and Deolalikar 2013; Retherford and Roy 2003). Unregulated access of PGD via rapidly increasing ART clinics for sex selection all over the country is a cause of concern that can have a disastrous impact on the sex ratio.

[5] Number of female children per thousand males.

Sex selection cases in India and abroad

While there are several examples of PGD sex selection within India, the practise is not restricted to the country's borders. Countries with lax regulations such as Dubai and Thailand are becoming attractive sex selection destinations for Indians. Below are examples of some of the notable cases that bring to light the gravity of the issue.

In 2018, a complaint was filed with the Maharashtra State Commission for the Protection of Child Rights alleging that fertility clinics were using genetic abnormalities screening technology to assure the delivery of male infants (Vora 2018). Shubhangi Bhostekar, the complainant, alleged that her husband, Prakash Bhostekar, hired a surrogate who had delivered a boy without Shubhangi's knowledge. The claim was that sex selection at conception allowed for the boy's birth. The commission's head, Pravin Ghuge, stated that Prakash Bhostekar had infringed the rights of his daughters by neglecting them in pursuit of a male offspring and also of the newborn baby. Surrogacy was chosen solely for the goal of producing a male kid (Vora 2018).

In January 2019, the Delhi Health Department's Pre-Conception and Pre-Natal Diagnostic Techniques [PC-PNDT] cell raided a hospital in Karol Bagh, New Delhi. The institution was accused of using PGD to determine the sex of the embryo and charging INR 8.5 lakh for the treatment. The clinic, according to officials, operated out of a contact centre where over 300 workers provided in-vitro fertilisation [IVF] to clients in India. Furthermore, the clinics promised to take the clients a male child, all while also offering to take them to locations such as Thailand, Singapore, and Dubai (Saxena 2019).

The Indian publication, News Minute, spoke to around 30 doctors about the growing concerns of PGD and found that these clinics get approximately 30-40 requests per month (Ram 2020). But over the last few years, the stringent regulations have reduced the number of requests. While this has lowered the number of people opting for PGD in India, many head to Thailand or Russia to avail these facilities. There is a huge demand in these countries for sex selection, and Indians are skirting the ban on preconception sex selection by travelling to these countries (ibid.).

Existing Laws: What is being done?

As established, the ART industry in India is not regulated. Only one law (Pre-conception and Pre-natal Diagnostic Techniques Act) has been put in place to ban and penalise preconception sex selection. However, it's inadequate since the industry is not regulated and monitored under an exclusive law.

Through the work of health and human rights advocates, a ban on prenatal diagnostic procedures for sex selection was enacted in local communities. The Indian Pre-Natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act [PNDT] was enacted in 1994. The enactment was a consequence of similar efforts on a national level, as well as suggestions from women's and civil rights organisations to a parliamentary subcommittee (Mohapatra 2013). In India,

the PNDT Act prohibits sex discrimination in any form. This law has not been implemented effectively due to the complacency of the government officials and medical professionals. If the doctor/technician is aware that the parents would prefer a boy, they may just "wink or wince" to announce the gender of the foetus (The Law Library of Congress 2009).

The PNDT Act was finally passed in 1996, but it was frequently disregarded, and sex selection remained a common practice (The Law Library of Congress 2009). In 2001 and 2003, the Supreme Court of India issued decisions criticising the practice of sex-selective abortion and urging for more rigorous execution of the Act in response to advocacy organisations and a Public Interest Litigation petition (Sarkaria 2009). The revision of the Act to accommodate pre and during-conception procedures, such as X and Y chromosome separation through Pre-implantation Genetic Diagnosis, was the second purpose of submitting the Public Interest Litigation [PIL]. In response to these concerns, the PNDT Act was changed to the Pre-conception and Pre-natal Diagnostic Techniques (Prohibition of Sex Selection) Act [PCPNDT Act]. It limited the use of prenatal diagnostic methods to medically essential cases (Sarkaria 2009). Despite the Act's amendments, enforcement remains a challenge owing to the complicity of the medical community and government authorities and the absence of regulation.

The Assisted Reproductive Technology (Regulation) Bill (2020), was introduced in Lok Sabha to bring the ART sector under Government Regulation. This bill is an important step in overseeing the industry as it creates an overseeing and registry body. Clause 26(2) of the bill prohibits sex determination or selection during PGD.

Clause 26(3) reads, "A person shall not knowingly provide, prescribe or administer anything that shall ensure or increase the probability that an embryo shall be of a particular sex, or that shall identify the sex of an in-vitro embryo, except to diagnose, prevent or treat a sex-linked disorder or disease." There are several ethical concerns associated with such screening, and the ability granted to the Registration Authority to accept such specified diseases opens the door for any ailment to be included in the pre-screening, which might be harmful and may lead to easier sex determination (Department Related Parliamentary Standing Committee on Health and Family Welfare 2021).

Sex selection is already banned under PCPNDT Act, 1994, and ART Bill must prevent sex determination, with exceptions for treating pre-existing disorders or genetic diseases. But Clause 26(3) allows for a loophole for a number of diseases, even non-life-threatening or ones that don't affect the quality of life, to be tested by PGD, increasing the chance of sex determination by couples or their complicit doctors. The sex-related ailments and diseases must be specified in rules and regulations, or the Bill risks encouraging an illegal eugenics programme, accidentally promoting sex determination and selection, resulting in unjustified gender prejudice and societal problems (Department Related Parliamentary Standing Committee on Health and Family Welfare 2021). On the pretext of avoiding sex-linked diseases such as Rett syndrome, incontinentia pigmenti, pseudohyperparathyroidism, vitamin D–resistant rickets, etc., which children inherit from their parents, sex can be determined, and the parents can have an abortion separately. One of the challenges in implementing this

regulation would be that while prenatal sex determination is prohibited, abortion is permitted. It's tough to show a link between the two operations because they're generally performed by different people in different places.

Overall, the bill is a step in the right direction and a much-needed intervention to stop sex selection and sex determination by Indians within India, but many countries are becoming sex selection destinations for them too. The root cause of the problem cannot be solved by legal interventions alone. Re-education and sensitisation regarding male preference is going to be crucial to tackle this. As the following section demonstrates, preference for male children is rooted in entrenched attitudes.

Son Preference: Why Do Indians Prefer Male Children?

Son preference has a long history in India. It may still be seen in anthropological field research, hospital records, regional demographic, and health censuses. For instance, the number of "missing" girls in Punjab increased from 1981 to 1991, implying that sex-selective practices such as female infant neglect and female infanticide are primarily practised among the lower castes in rural areas, and persisted well into the late twentieth century (Gupta 1987). However, in India, the strongest forms of son preference seem to be restricted to certain regions and castes. For example, son preference is most pronounced in the northwestern states and the southern state of Tamil Nadu, including among the relatively affluent Jats, Rajputs, and Gujars (Downing 2005).

This prejudiced mindset originates from the assumption that Indian women are a financial or societal burden. "Grooming a girl is like watering a neighbor's garden," says an old Indian proverb (Downing 2005). In India, it is common for the wife's family to give the husband's family a marital dowry. The dowry evolved from a practice known as streedhan, in which a wife's family gave property to her husband when they married (ibid.). In India, dowry is also practised by Muslims, and it is known as Jahez. Sons are favoured since they may participate in and develop a family business (Downing 2005). Second, whereas boys are responsible for caring for ageing parents, girls are more likely to leave their parents and assist their elderly in-laws (Farell 2002).

Conclusion: A Glance Across the Globe

Ideally, gender identification in itself should not be a problem, and it is mostly not in Western countries, but when it leads to gendercide, it raises a slew of ethical difficulties. Many nations have banned various forms of sex discrimination. Some laws make it illegal to determine and reveal the fetus's gender unless it's for medical reasons. Sex selection is forbidden for any purpose in Austria, New Zealand, South Korea, Switzerland, and Vietnam. Thirty-one other nations that govern sex selection restrict it for social or "non-medical" reasons but allow it for medical ones, such as preventing the birth of children with sex-related disorders (Mohapatra 2013).

Sex selection is illegal in the United Kingdom unless there are medical reasons for it, such as real worries about the transmission of sex-related genetic disorders. The law was first enacted in 1993. It was updated in 2007 to prohibit all sperm-sorting procedures. Germany, too, forbids sex discrimination. In Germany, the Embryo Protection Act of 1990 makes non-medical sex selection criminal with up to a year in jail. Sex selection is already banned in India under PCPNDT Act, and the new ART Bill will help regulate the industry via creating a registry. But as discussed above, the Indian problem is rooted in cultural practices. Even regulation of the industry won't help if measures to change the culture of son preference doesn't change. The legislations may only fight the symptom, not the cause.

PGDs ought to be brought under the purview of legal regulations, which the new ART Bill will do, barring one required change (mentioned above). Licensing of IVFs after due process is crucial. Medical professionals and government officials often sympathise with parents in their demand for a boy and are complicit in these procedures. Regular monitoring and audit of records of these ART clinics would be required to confront this matter.

South Korea might be used as an example of a society that has begun to handle the issue of son preference successfully. They concentrated on improving female education to help minimise the practice of sex selection (The Economist 2010). Public awareness campaigns regarding son preference have caused some to conclude that it is outdated and not needed (ibid.). India could follow in South Korea's footsteps and emphasise education and gender equality in the legal system.

It is easier to use legal procedures to prohibit gender identification or selection technologies than to employ the legislation and re-education initiatives to achieve the more essential and long-term aim of reducing son preference. However, mere legal measures have proven ineffective so far. A combination of legislation, sustained public awareness programs, and more opportunities for women in education and employment will have a greater impact on sex selection practices in India.

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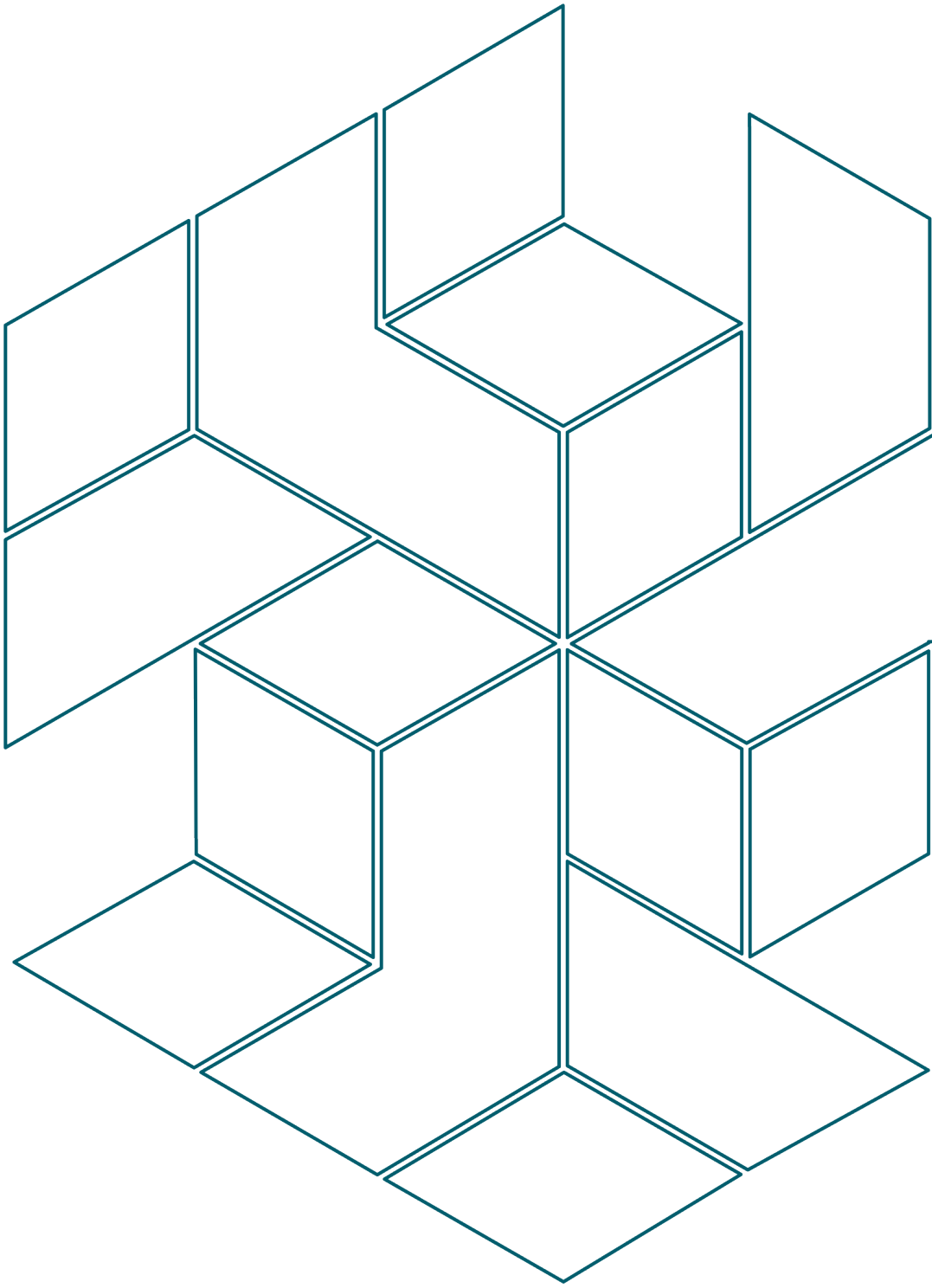

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