

## **Notion of 'Wunschkind/Vansh'<sup>1</sup> expressed in Prenatal Diagnosis and Selective Abortions in Germany and India**

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**Organised by:** Sheela Saravanan & William Sax,

Department of Anthropology, South Asia Institute, Heidelberg University,

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### **Abstracts**

#### **Reprogenetic Technologies: From Desired Babies to Designer Babies.**

**Jyotsna Agnihotri Gupta**

The combination of use of technologies for human reproduction with genetic technologies offers prospective parents the possibility to choose the characteristics of their future offspring. This can be done to select the sex of the child for socio-cultural reasons or to rule out genetically inherited diseases and disabilities. For some reproductive choice goes even further. They advocate the use of reprogenetic technologies to intervene in the reproductive process to create human beings who would live longer and healthier lives, possess enhanced physical and intellectual capacities and perhaps more refined emotional experiences. I will first discuss various examples of pre- and post-conceptual selection and enhancement with the use of different technologies. Thereafter, I will focus on the use of reprogenetic technologies within pre-natal care in India based on my empirical research.

The increasing use of reprogenetic technologies not only affects women's experience of pregnancy, but (will) have serious and far-reaching implications for cultural perceptions regarding health and disease, besides creating new ethical dilemmas and new professional and parental responsibilities. I will conclude with a general discussion on the technologies and the challenges they pose for us. We have no information about the long-term consequences of these interventions not only on the health of children born as they grow up and become adults, but also what the effect of these permanent changes is likely to be on future generations. They beg questions such as: Are these technologies value neutral? As more and more societies are offering these technologies as part of pre-natal care are we heading towards a society where there would be a moral obligation for parents to use them? Where will we draw the line between desired children in the name of reproductive freedom and designer children with specific characteristics in the pursuit of perfection?

#### **Gender-biased Sex Selection and Sex Selective Elimination in India: Implications and Ground Realities.**

**Rizwan Parwez**

Even after two decades of legislation on gender-biased sex selection, several states in India continue to have a child sex ratio below the national average. This is attributed

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<sup>1</sup> *Wunschkind* and *Vansh* are the commonly used local expressions in Germany and India. *Wunschkind* in German language means 'desired children'. In India, a lineage or an inheritor is referred to as '*Vansh*' or '*Waaris*'.

to a perceived 'unwantedness' towards girls and a preference for sons over daughters in India. This biased attitude towards girls has worsened in the last two decades with easy access to 'unregulated' ultrasound technology, largely misused to determine the sex of the foetus. In India, both pre and post conception sex selection, and sex selective elimination during pregnancy is a criminal offence under the Pre-Conception and Pre-Natal Diagnostic Techniques (PCPNDT) Act of 1994, and the Indian Penal Code (IPC) respectively. The Medical Termination of Pregnancy (MTP) Act, 1971 was later enacted to avoid grave injury to a woman's physical and mental health arising due to incidents such as pregnancy caused by rape and failure of contraceptives.

But the influx of technology like ultrasound together with the government's failure to regulate its 'misuse' has over the years aggravated the practice of sex selective elimination which was happening earlier through the misuse of amniocentesis. The government has undertaken several measures to stop sex selective elimination but as a matter of fact, these measures never targeted sex selection. Furthermore, such steps led to an opposition from the women's and civil society groups for its detrimental repercussions on pregnant women. At present, the foremost challenge before the government, civil society and medical fraternity is to give access to safe abortion services to women under the MTP Act, as unsafe abortion is the third largest cause for maternal death in India, and at the same time ensure that no pregnancy is terminated based on sex selection. Improvement in child sex ratio clearly, by itself does not guarantee social change in attitude towards women and girls but restriction on sex selection is important to maintain a demographic balance.

### **Embodied Notions of Wunschkind/Vansh in Germany and India in the Context of Prenatal diagnosis and Selective abortions.**

**Sheela Saravanan, Alicia Finger, Jonas Wachinger & Poonam Kamath**

Prenatal and pre-implantation genetic diagnosis makes it possible for people to choose their desired children based on genetic attributes such as; gender and disability. The known reasons for such selective abortions include attributes such as; (un)desirable gender, sensory, cognitive, or physical impairment, or desired genetic properties. Ethical voices and the gender/disability rights movement worldwide raise concerns that selecting attributes of children based on gender, disease or disability is morally problematic because it embodies and reinforces prejudices. The notion of desired children (*Wunschkind*) is embedded in the larger social context that defines acceptability through regimes of values, biological citizenship, kinship, and religious perceptions and a range of socio-economic considerations. The study applies Scheper-Hughes and Lock's 'mindful body' to examine the notions of *Wunschkind/Vansh* embodied in the self-social body experiences expressed in the context of prenatal diagnosis and selective abortions in Germany and India. Qualitative methodology was used in clinical and family settings to in-depth interviews with 20 pregnant women, 3 of their spouses, 2 medical practitioners, 2 midwives in Germany and 30 pregnant women, 3 of their spouse, one group discussion with 20 men and 5 medical practitioners in India. The cross-cultural analysis is a significant aspect of this study as it aims to bring out the deeper life mechanisms that are embedded in different cultural frameworks.

The research revealed that in general, the embodied fear regarding a girl child in India was similar to that for disability in Germany. The boundary of the self includes several basic human rights in Germany which streamlines women's perceived notions of 'Wunschkind' and decision making regarding prenatal diagnosis. Whereas for pregnant women in India the embodied notions as phenomenally experienced by the individual body-self and as a social body, a symbol of social/structural relationships between nature, society, and culture is far more complex which, for some, may also exclude free choice to education, employment opportunities and life course planning. Overall, there was a disapproval expressed towards sex selective abortions by pregnant women in Germany and India and a comparatively more acceptance for disability abortions.

### **Impact of Prenatal Diagnostic Techniques on Rights of Unborn Child: A Study from Disability Perspective.**

**Tushti Chopra**

Prenatal diagnostic techniques can be used for the purposes of detecting limited kinds of genetic abnormalities or metabolic disorders or chromosomal abnormalities or certain congenital malformations or sex-linked disorders. Early detection may check and prevent certain birth defects thereby ameliorate the conditions of unborn child. However, these techniques can be misused for gender selection and on certain manifest defects being developed in unborn child, parents can abort the unborn child within 24 weeks of it begotten. Legally, an unborn child is considered beholders of rights such as to property or can claim damages sustained being in womb, mainly subject to the child being born alive. Viability is the key factor to recognise a child in womb as a juristic person and thus, beholder of rights. A study will be done on the prenatal diagnostic techniques, extent these techniques can assist in checking disability and if in turn affect the rights of unborn child, if technology is being misused to stifle the rights of differently-abled persons. In this context, the adequacy of statutory provisions in India and the judicial response to protect the rights of unborn child will also be studied and recommendations, if any, will be provided.

### **Legal Situation of Prenatal and Pre-Implantational diagnosis in Germany from a Human Rights Perspective.**

**Marion Albers**

Prenatal tests, in particular genetic diagnoses, play an increasing role in the course of pregnancy. Pre-implantation diagnosis is admissible in many countries as well as, under particular restrictions since a law reform in 2011, in Germany. Both techniques are relatively independent fields but influence each other in particular respects. The contribution illuminates the legal situation of prenatal and pre-implantational diagnosis in Germany. It analyses the complex ensemble of rights and duties of involved parties, which includes, among other, the medical civil liability. The focus lies on various, partially opposed human rights, i. e. dignity, autonomy, right to life or protection against discrimination. In this respect, protected goods and addressees of protection, lines of argumentation and dilemmata are worked out. The impacts of legal provisions prove to be multifarious and, especially when we differentiate individual rights and societal effects, ambivalent. Future visions, e. g. regarding the

developments of genetic therapy, embryo research and artificial reproduction, will expand the difficult problems „Wunsch Kinder“ lead to.

### **Governing non-invasive prenatal testing in Germany: fundamental questions and fragmented responsibility.**

**Kathrin Braun & Sabine Könniger**

Non-invasive prenatal genetic testing (NIPT) is a socio-technical innovation that bears the potential of profoundly altering the meaning, experience and practices of prenatal care, and possibly of pregnancy and parenthood altogether. In Germany today, NIPT has become a matter of public controversy and concern. Experts, policy-makers, regulators, and civil society actors tend to agree that with NIPT, fundamental social and ethical issues are involved and need to be considered. Yet, what exactly this means and where and when such considerations should take place, is much less clear. Actors seem to agree that NIPT requires responsible governance, yet who is responsible for what, who accounts for what, and who, in the end, is responsible for addressing fundamental social and ethical issues at all, is, as we will show, a matter of struggle and contestation.

Drawing on the pragmatic sociology of critique as developed by Boltanski, Thevenot, and Chiapello, we focus on the ways actors account for their own part within the governance and innovation process, either to us in the interviews or publicly through reports, press releases, position papers, and the like. Based on narrative interviews, document analysis and participant observation, we examine whether and how various actors interpret and allocate responsibility, and reflect upon their own part within it – or not. We show, first, that allocation of and reflection on responsibility is linked to the way actors construct the “whatness” - the question/point of what is at stake: as just another method for achieving well defined and accepted ends or a new screening practice, a medical product or a selection technology, a means of risk elimination and reassurance or a manifestation of ableism? Decision-makers, we hold, tend to construct the issue in technical terms, as a matter of method and/or procedure, bracketing substantive questions of ends and purposes. Second, we argue, public reflection about social and ethical issues only came up when civil society actors disrupted institutional routines of fragmented responsibility from outside and insisted on addressing substantive questions as well. Nevertheless, third, we see a tendency of shifting responsibility for substantive questions, in contrast to technical ones, to either forums with no decision-making authority, such as public debate or the German Ethics Council, and/or counselling arrangements. Meaning, that in the end, NIPT gets governed by the individual and the market.

### **Beyond informed choice in medical maternity care in Germany - prenatal decision making from a praxeographic approach.**

**Eva Sanger**

In Germany, maternity care and the monitoring of pregnancy is performed almost exclusively by obstetricians. Check-ups and ultrasound examinations are directed at detecting risks or jeopardized health in pregnant woman and foetuses as early as possible in otherwise healthy pregnancies. From the point of professional medical ethics, it is argued that the offer of diagnostic testing and screening helps women and

their partners to make better and more informed choices about their future life as parents. In my talk I would like to highlight how the offer of invasive and noninvasive prenatal testing and screening procedures is embedded in the routine processes of medical maternity care and routine ultrasound examinations. Drawing on praxeographic perspectives and empirically based on participant observation of maternity care and ultrasound examinations in obstetricians' offices I want to call into question that more choice is a source of empowerment and freedom. I will explore how the assumption of informed consent and autonomous decision making is framed in the routine practices of maternity care and how "choice" comes to represent a specific form of government. I will discuss Annemaries Mols (2008) suggestion to switch from a "logic of choice" to a "logic of care" and how this approach might benefit medical maternity care and be more in accordance with how prenatal decisions are actually made.

### **The Exploitation of Fear: How Wunschkind/Vansh have to be perfect. Renate Klein**

Over the last 25 years, pregnancy has become increasingly medicalised and controlled. Under the guise of 'preventing' less than healthy babies, women's excitement about their pregnancy is disrupted by 'experts' who strongly suggest an increasing battery of prenatal tests. Joy turns into fear and this fear makes pregnant women easy prey to exploitation. The exploitation comes not only in the form of more prenatal tests but, should the final result be 'positive', in the advice to 'have an abortion and try again ...' and next time use IVF and pre-implantation diagnosis (PID). This is great news for the stagnating IVF industry which is keen to recruit new customers: fertile women from both the general population of pregnant women with so-called 'high risk pregnancies' (ever increasing in numbers), and fertile women who act as egg 'donors' and so-called surrogate mothers. The recent advent of CRISPR (gene editing technologies) promises to add more profits.

In my presentation, I will look at the increasing intersection of IVF technology with 'ordinary' pregnancies, as well as at the normalisation and acceptance that such eugenic thinking is achieving in mainstream society. What will it mean for women's wish to have their Wunschkind/Vansh when they internalise the technologists' beliefs that their bodies are not good enough to give birth to a healthy child without high-tech intervention? What will it mean for the lives of people with disabilities, whether from birth, by disease or accident? How did we get to this point where the exploitation of fear is seriously interfering with people's enjoyment of life? What can we do to recapture the rebellious spirit of the 1980s, when the emerging reproductive technologies and genetic engineering were critically assessed and rejected by a diverse section of the community including feminists, churches and unions in both westernised and Asian countries.

### **The Political Discussion and Clinical Practice of Prenatal Diagnostics in Austria - A Qualitative Analysis. Erich Griessler (corresponding author), Mariella Hager**

This contribution analyses how prenatal diagnosis (PND) is debated in Austria in the political, and practiced in the clinical domain. It describes several areas of tension: in

the political domain, a controversy between actors who advocate the right of “self-determination” and those who object abortion; in the clinical domain, it analyses the tension between the “desire for a perfect child” and a self-reinforcing “spiral of anxiety” because of PND. The contribution is based on 33 in-depth qualitative interviews with women who underwent PND, physicians, psychologist, a midwife, and a nurse as well as with politicians, civil servants, ethicists and representative of NGO. In Austria - like in many countries - PND is for the most part an unquestioned routine of maternity care. Nevertheless, it is also a sensitive political issue. PND can contribute to the birth of healthy children but it can also support negative and positive eugenics, depending on a society’s attitude towards physical or mental challenges. PND can lead to the decision for abortion, which in many countries is contested. In general, there is little political discussion about PND in Austria. Nonetheless, PND is a hot issue because it touches upon latent conflicts and taboos in Austrian society such as the controversy about abortion in the 1970s and eugenic atrocities during the Nazi period. Once the issue of PND, abortion and the embryopathic indication are raised in public debate, the discussion rapidly becomes heated, irreconcilable and fundamental. Despite this political sensitivity, PND is well integrated in maternal care and public health insurances covers basic treatment of PND. It is possible to delineate several types of users of PND, i.e. the “conscious chooser” and the “user” (which in our study was the majority) and the “conscious refuser” (which we did not find empirically). In addition, several types of patients can be delineated depending on the results of PND and the consequent decisions made. These types include the “relieved”, the “shocked”, “abortion”, and the “accepting” women.

PND offers new chances and certainties for physicians and pregnant women, but it also creates new anxieties, risks and stress, they have to cope with. PND is embedded in, and reinforces a dynamic of mutual coercion towards oneself and the other. In interviews women express their desire for a healthy child and their anxiety that “something might be wrong”, they report also about pressure from society to have a healthy child; physicians expect them to be “good”, i.e. compliant patients which also accept a responsibility to proactively get information about pregnancy (i.e. from the Internet). Physicians, on the other hand, report in interviews that they felt increasingly under stress not to miss any “abnormality”, they feel confronted with increasing forensic risks and a pressure from patients who expect a perfect child; they report the necessity for every increasing documentation and continuous training as well as competition between providers and psychological stress. The technology of PND transforms pregnancy by changing the roles and responsibilities of pregnant women and physicians, it changes the co-created expectations about oneself and the other that define and arrange their relationship as well as the social process and understanding of pregnancy.

### **The decision Trap: Pregnancy, Prenatal Tests and the Transformation of Autonomy.**

**Silja Samerski**

During the 1970s and 1980s genetic counseling grew into a modern service for pregnant women and prospective parents. The ideas of risk and prevention found their way into medical prenatal care, and new examination techniques, most notably ultrasound, created a new patient: the unborn child. Today, various prenatal tests offer

“knowledge,” “prevention,” and female self-determination via a prenatal health check. In order to enable the pregnant women to become autonomous decision makers, doctors and geneticists ask her to become aware of risks and fix her gaze on a possible outcome. They require her to internalize a statistical calculated future as reality - a future of “ifs” and “mights” that is mere speculation.

Once their coming children have been redefined as faceless risk profiles, pregnant clients have been maneuvered into the decision trap. There is now nothing else they can do but choose between calculated risks and risk management strategies. This decision trap is common in risk medicine, but is especially momentous when a pregnant woman is called upon to make an informed decision. It fosters the myth that the outcome of a pregnancy depends on the pregnant woman’s responsible decision making. The pregnant women must abandon her good hope and resolve to weigh her options. Prenatal decision making lessons turn even a refusal into a predetermined and risk-laden option. Thus, the woman is forced to take responsibility for a future that can be statistically accounted for but in reality, is still unknown. This opens up a completely new possibility of victim blaming. No matter what the client has decided, it is always she who made the choice - and it is she who took the risk. Whether it be it a miscarriage as a result of the amniocentesis, or a child with Down’s syndrome, she is responsible.