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## CHAPTER 9 REPRODUCTIVE RIGHTS AND REPRODUCTIVE TECHNOLOGIES

### *Introduction*

From the 20<sup>th</sup> century up to the present, questions concerning human reproduction emerged as one of the major battlefields of moral reasoning. The term “reproductive technologies” encompasses the modern technologies concerning assisted reproductive technologies (ART) that emerged since the second half of the 20<sup>th</sup> century. Today, these include genetic tests applied to early forms of human life, pre-implantation and prenatal genetic diagnosis especially. I will, however, start the discussion of reproductive technologies as emerging from the context of birth control based on the assumption that first, population control is one important historical context of reproductive technologies, and second, the ethical claim of reproductive autonomy embraces both birth control and ART. It might now be tempting to divide the global landscape into those parts of the world where states try to establish efficient systems of birth control, and to the other parts of the world where individuals or couples, sometimes funded by their national healthcare system, are medically assisted in procreating; while in this picture one part of the world is eager to control the *quantity* of children who are born, the other part is eager to assist couples who wish for a child of their own and at the same time to control the *quality* of the offspring. The concepts of ‘developing’ and ‘developed’ countries could then serve as the division line between the quantitative and qualitative approach, and both would be addressed in the claim of reproductive rights. However, this division conceals the fact that even if development is still a category of international politics, it is not constrained to geographical or political borders.<sup>1</sup> Rather, birth control and ART exist alongside each other in almost any country, and individuals may find themselves invested in both avoidance and assistance of reproduction over the course of their lives.

Evidently, poverty, lack of education, poor healthcare and gender inequality are increased by the lack of access to birth control; the major changes of adults’ biographies in those milieus where a decent standard of life, education, access to healthcare, and gender equality are given may serve as indications for the higher demand of ART. Technologies play a crucial role in both scenarios: the introduc-

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1 A. ESCOBAR, *Encountering Development: The Making and Unmaking of the Third World*, Princeton 1995. But cf. also the post-development approach (R. MAJID/V. BAWTREE, *The Post-Development Reader*, London 1997). They criticize the concept of development as part of a colonial approach to countries that do not fit into the conceptual understanding of human flourishing and the ‘Western’ normative order dividing the world into the ‘North’ and ‘South’.

tion of chemical contraceptives has or may have a major impact on the reproductive freedom of billions of people, and the introduction of assisted reproductive technologies as well as the development of genetic tests applicable in early stages of human development address infertility and/or inherited diseases. From a technological perspective, the newer developments of reproductive technologies are just one further step of scientific progress, helping couples and, moreover, women, to either avoid pregnancies or to establish them at a time of their life that they themselves may choose. Science and technologies are thereby considered as instrumental to *individual and social values*: reflecting and increasing the freedom of individuals and at the same time serving the public good.<sup>2</sup>

For political ethics, access to contraceptives is considered one of the central means of national or global policies to control population growth. Access to birth control can be considered as one field in which *social* policies aimed at raising especially women's standards of living intersect with *ecological* policies aimed at reducing population growth and decreasing the effects of climate change. In the emerging debate on the interrelation of population control and social as well as climate policies, the perspective of the public good may easily result in trumping the individual reproductive freedom rights of those women who are most vulnerable to such policies.<sup>3</sup>

In bioethics, however, human reproduction has so far predominantly been presented as a question of women's reproductive freedom and autonomy – claiming the right not to be hindered in one's own choices, whether to avoid or to seek procreation – a right that must be granted by the social and political institutions dealing with human reproduction and family policies. The negative formulation of this right is commonly shared by most ethicists. The positive formulation – the right to medical and/or social *assistance* in matters of reproduction – is contested; it requires justifying the scope and limit of the right.<sup>4</sup> Apart from the normative question of reproductive rights, both birth control and reproductive technolo-

2 Cf. A. HONNETH, *Freedom's Right. The Social Foundations of Democratic Life*, New York 2014.

3 For a discussion on the reemergence of the concept of public good cf. NUFFIELD COUNCIL ON BIOETHICS, *Public Health: Ethical Issues*, London 2007 ([nuffieldbioethics.org/wp-content/uploads/2014/07/Public-health-ethical-issues.pdf](http://nuffieldbioethics.org/wp-content/uploads/2014/07/Public-health-ethical-issues.pdf)); and for the concept of solidarity in bioethics cf. B. PRAINSACK/A. BUYX, *Solidarity: Reflections on an Emerging Concept in Bioethics*, Princeton, NJ 2011. R. TER MEULEN, *Solidarity, Justice, and Recognition of the Other*, in: *Theoretical Medicine and Bioethics* 37/6 (2016), 517–529.

4 Dan Brock gives a good survey of the discussion in D. W. BROCK, *Shaping Future Children: Parental Rights and Societal Interests*, in: *The Journal of Political Philosophy* 13 (2005), 377–398. For a thorough analysis of the moral dimensions of reproductive freedom cf. A. BUCHANAN/D. W. BROCK/N. DANIELS/D. WIKLER, *From Chance to Choice. Genetics and Justice*, Cambridge, MA 2000.

gies must be seen in the context of the personal and social *values* connected with human procreation. While the globally diverse contexts of social and cultural interpretations certainly shape the *empirical* discourse of reproductive technologies, the relation between empirical studies, hermeneutical ethics, and normative ethics is far from clear.<sup>5</sup> Studies in cultural anthropology show, for example, that the conceptual understandings of kinship, the family, parenthood or personhood are embedded in diverse traditions of *interpretation*. That these interpretations and traditions need to be addressed in ethical analyzes, too, together with their implicit or explicit normative claims, is not contested; what is contested is the status of social values and social norms with respect to moral norms.

In the Western context, the two major hermeneutical frameworks which are relevant for an ethics of reproductive rights and reproductive technologies are, first, parenthood as a *gift of love* and second, parenthood as a *choice of a life-form*.<sup>6</sup> Rather than resting with the descriptive analysis of these interpretations that emerge in social practices, hermeneutical ethics examines the ethical implications of the conceptual understandings and relates them to the normative argumentation of ethics; there, the validity of the claims will be scrutinized in view of established normative standards, such as the human rights framework.

Only looking at concepts of reproduction from the point of view of kinship relationships may easily result in the indifference towards socio-economic frameworks underlying the understanding of reproduction: for many families who

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5 For a discussion of empirical, contextual, or experiential ethics cf., for example, K. A. APPIAH, *Experiments in Ethics*, Cambridge, MA 2010. E. VAN LEEUWEN/M. DE VRIES, *Reflective Equilibrium and Empirical Data: Third Person Moral Experiences in Empirical Medical Ethics*, in: *Bioethics* 24/9 (2010), 490–498; A. MUSSCHENGA, *Empirical Ethics, Context-Sensitivity, and Contextualism*, in: *The Journal of Medicine and Philosophy* 30/5 (2005), 467–490. M. PARKER, *Two Concepts of Empirical Ethics*, in: *Bioethics* 23/4 (2009), 202–213; H. HAKER, *Ethik und Empirie*, in: W. SCHAUPP (ed.), *Ethik und Empirie. Gegenwärtige Herausforderungen für Moralphilosophie und Sozialethik* Freiburg i. Br. 2014, 19–40.

6 Elsewhere, I have identified several concepts of parenthood, however still based upon Western contexts and philosophical concepts, namely the *natural law concept* that considers reproduction as the telos of sexuality; the *romantic concept* that is linked to reproductive autonomy as authenticity; the *social freedom concept* that links reproductive autonomy to a relational and social understanding of freedom; and the *economic concept* that links reproductive autonomy to market exchange relations. Hence, the concept of reproduction as a gift of love is closely linked to a teleology of sexuality represented in the natural law tradition, while the concept of choice can be understood in line with either the romantic authenticity concept, the social freedom concept, or the economic-exchange concept. Cf. H. HAKER, *Eine Ethik der Elternschaft*, in: G. MAIO/T. EICHINGER/C. BOZZARO (ed.), *Kinderwunsch und Reproduktionsmedizin. Ethische Herausforderungen der technisierten Fortpflanzung*, München 2013, 267–290. Below, I will focus on the framing of parenthood in the context of reproductive autonomy, i.e. different interpretations of parental choices.

have no financial means or security, children are the only way to be looked after in phases of dependence, either by illness or by age. Rather than emphasizing individual freedom rights, reproductive rights concern the socio-economic rights to a decent life, sustained by family planning rather than political-legal institutions. If reproduction is constrained without replacing the social security of families by appropriate state systems, the results are catastrophic for the most vulnerable population – not (only) because an abstract freedom right is violated but (also) because the normative constraints of families are overlooked. Even though bioethics did not address global justice issues for a long time, reproduction is one of the most important practices in which individual rights, social values and social norms, and socio-political frameworks are negotiated. In the following, I will take a closer look at different practices of reproductive technologies, and end with some thoughts about the future of reproductive rights and global ethics.

### 1. *The Emergence of Reproductive Technologies*

#### 1.1 BIRTH CONTROL AS CONTEXT OF REPRODUCTIVE TECHNOLOGIES

The development of chemical contraceptives in the 1950s and 1960s paved the way to major social changes of reproduction: for the first time in history, heterosexuality could be practiced without the immediate concerns of pregnancy. With this change, family-planning became part of almost every (heterosexual) adult's biographical planning in those countries where contraceptives were available.<sup>7</sup> Access to contraceptives is a condition for the reproductive freedom of men and women alike: birth control enables women and men to live the life they choose with respect to procreation, and this freedom right may well be the main factor for their own flourishing. Although some religions or denominations (such as the Catholic Church) link sexuality and reproduction on *moral* grounds, interpreting the conception of a child as the ultimate expression of the love bond between a married couple,<sup>8</sup> the separation of sexuality and reproduction has been broadly welcomed by the end of the 20<sup>th</sup> century: first as sexual liberation in Western societies and then as part of international policies aimed at improving life and health conditions of women. In countries, regions or social communities with patriarchal social structures, the denial of reproductive rights is often the result of a lack

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7 For the social changes of (Western) families cf. E. BECK-GERNSHEIM, *Reinventing the Family: In Search of New Lifestyles*, Malden, MA 2002; A. GIDDENS, *The Transformation of Intimacy: Sexuality, Love, and Eroticism in Modern Societies*, Stanford, CA 1992.

8 Cf. the latest instruction of the Vatican's congregation of the doctrine of faith: CONGREGATION OF THE DOCTRINE OF FAITH, *Dignitas Personae – On Certain Bioethical Questions*, Roman Catholic Church 2008, [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_20081208\\_dignitas-personae\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20081208_dignitas-personae_en.html).

of overall social rights for women, such as access to healthcare and education; in these contexts, women are therefore often caught in structures of life-long dependence on their families.<sup>9</sup> By the end of the 20<sup>th</sup> century, international efforts like the United Nations Millennium Goals, now reformulated as Sustainability Development Goals, have therefore identified these social structures, together with poverty and lack of access to healthcare, as main factors that block or inhibit the realization of women's rights.<sup>10</sup> In sum, birth control is considered an *individual's* human right that must not be denied by states.

Nevertheless, even in countries where women have access to contraceptives, a vast amount of pregnancies still occur unintentionally.<sup>11</sup> In the newer human/women's rights tradition, access to *abortion* is therefore considered a part of women's reproductive rights. Abortions require medical facilities in order to be performed without major health risks for women, and medication abortions can be performed at a very early stage or before a pregnancy is established without doubt. However, since abortion in its different kinds is not provided for in all countries *and* also contested by several groups on moral grounds, it has stirred an on-going debate that has not left the struggle for reproductive rights unaffected. As a result, birth control has framed the ethical debate on reproductive technologies long before it was introduced as a measure of assisted reproduction: first, it has started the debate on the concept of reproductive autonomy and freedom, particularly as part of women's rights, including by now the social and economic rights to well-being. Second, especially with the turn to abortion as part of the reproductive rights of women, it has reinforced the debate on the moral status of human embryos.

While these debates focus, above all, on individuals' rights and responsibilities, birth control has also led to a re-interpretation of population control over the second half of the 20<sup>th</sup> century.<sup>12</sup> International policies of population control, too,

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9 WORLD BANK, *World Development Report 2012: Gender Equality and Development*, <http://sitere-sources.worldbank.org/INTWDR2012/Resources/7778105-1299699968583/7786210-1315936222006/Complete-Report.pdf>. M. C. NUSSBAUM, *Women and Human Development. The Capabilities Approach*, Cambridge 2000.

10 R. T. COOK, *International Human Rights and Women's Reproductive Health*, in: *Studies in family planning* 24/2 (1993), 73–86.

11 According to the US Center for Disease Control and Prevention, for example, it is estimated that in 2006 roughly 50% of all pregnancies occurred unintentionally, with higher figures in teens and other subgroups, especially low income and cohabitant. Cf. J. SANTELLIE A., *The Measurement and Meaning of Unintended Pregnancy*, in: *Perspectives on Reproductive and Sexual Health* 35/2 (2003), 94–101 for a thorough discussion.

12 S. W. MOSHER, *Population Control. Real Costs, Illusory Benefits*, Piscataway, NJ 2008; M. CONNELLY, *Fatal Misconception. The Struggle to Control World Population*, Cambridge, MA 2010.

emerge as quantitative and as qualitative measures: the *quantitative* approach is certainly on the agenda of numerous states, and until recently it was also an explicit goal of global development policies; for example, it was a legal practice until recently in China's so-called one child policy. Population based birth control is echoed in some *qualitative* approaches that apply reproductive technologies, and they are tightly connected to the new social norm of responsible reproduction, which I will address below: in several countries, mandatory genetic tests are required before marriage by either state or religious authorities – this is the case in some Arab countries, Iran, or Cyprus who have established genetic carrier screening programs – or couples are encouraged to participate in voluntary programs to diagnose, for example, monogenetic disorders such as sickle cell anemia, beta thalassemia, or Tay Sachs.<sup>13</sup> These programs combine the modern measures of (individual) birth control with the availability of genetic tests. Furthermore, in some countries such as India and China, abortion is also subject to social norms rather than the object of individual autonomy: sex selective abortions are carried out for social or economic reasons, with legal institutions passively accepting these practices (India) or actively supporting them (China). Interpreting these practices only as the result of *individual* reproductive autonomy and choice ignores these contexts and the force of social norms that shape and potentially constrain the freedom they declare to promote. Hence, individualistic theories of human action have little to say about the interrelation of social contexts and individual actions. Complementing the normative, universalistic dimension of ethics, hermeneutical ethics interprets exactly this interaction of social norms and imageries and individual values and life concepts.<sup>14</sup> I will show at the end why this meta-ethical debate matters for a global ethics.

## 1.2 ASSISTED REPRODUCTIVE TECHNOLOGY AND PREIMPLANTATION GENETIC DIAGNOSIS

Like birth control, ART increases the scope of action for those individuals or couples who wish to have a child but need medical services in order to realize their wishes. Traditionally, couples who could not reproduce sought to raise a child via adoption. Since the second half of the 20<sup>th</sup> century, international adoption has be-

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13 J. ZLOTOGORA, *Population Programs for the Detection of Couples at Risk for Severe Monogenic Genetic Diseases*, in: *Human Genetics* 126/2 (2009), 247–253.

14 H. JOAS, *The Genesis of Values*, Chicago 2000. CH. TAYLOR, *Modern Social Imaginaries*, Durham, NC 2008. C. MACKENZIE/N. STOLJAR, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, New York 2000. They provide a critique of an individualistic interpretation of autonomy – this was also the object of the debate on Liberalism and Communitarianism of the 1990s.

come more and more regulated in order to protect children's rights, but when there is a tendency to rather provide individuals or couples with a child than to provide children with a social family, this becomes a problem, because parental interests and children's rights may clash.<sup>15</sup> Since the introduction of ART in the late 1970s, reproductive technology has become an alternative service for those who cannot procreate via sexual intercourse. In cases where hormonal therapy or insemination is not successful, couples are offered in vitro fertilization (IVF), i. e. the fertilization of ova and in vitro development of embryos, before transferring some or all of these to a woman's womb. It is estimated that in the first 40 years of assisted reproduction, 5 million children were born via IVF.<sup>16</sup> Couples often need more than one treatment over the period of several years before a pregnancy is established and before they can "take home" a child – furthermore, it is estimated that on average about 30 embryos are created for every child to be born.<sup>17</sup> Many factors add to the success rate, which is usually stated as 25-30% per cycle, depending on several factors such as the number of transferred embryos, maternal age or medical history.

As a second standard procedure, ICSI or intracytoplasmic sperm injection was developed and first introduced in the early 1990s in cases of male infertility. In addition to these treatments that involve a couple's gametes, sperm and/or oocyte donation is an option in cases where infertility renders the use of a couple's own gametes impossible; while sperm donation is widely accepted at least under certain conditions, oocyte donation is more contested because of the related health risks for the donors, such as the ovarian hyperstimulation syndrome.<sup>18</sup> Mainly due to these risks, oocyte donation is either prohibited or strictly regulated in several countries, while in other countries financial incentives have created an oocyte donation market that transforms the donation of human tissue into a com-

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15 Historically, however, the rise of children's rights is only a recent accomplishment, echoed in the Convention of the Rights of Children of 1996. UNITED NATIONS GENERAL ASSEMBLY, *Convention on the Rights of the Child*, United Nations New York 1989, <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>.

16 EUROPEAN SOCIETY OF HUMAN REPRODUCTION. <http://www.eshre.eu/ESHRE/English/Press-Room/Press-Releases/Press-releases-2012/5-million-babies/page.aspx/1606>.

17 Only an estimated 50% of all couples seeking ART succeed in having a child through ART. A. M. BERGART, *The Experience of Women in Unsuccessful Infertility Treatment*, in: *Social Work in Health Care* 30/4 (2000), 45–69.

18 Cf. for guidelines and a short summary JOINT SOCIETY OF OBSTETRICIANS AND GYNAECOLOGISTS OF CANADA-CANADIAN FERTILITY AND ANDROLOGY SOCIETY CLINICAL PRACTICE GUIDELINES COMMITTEE, *The Diagnosis and Management of Ovarian Hyperstimulation Syndrome*, in: *International Journal of Gynaecology and Obstetrics* 116/3 (2011), 268–273.

mercialized good.<sup>19</sup> In case a woman cannot become pregnant herself, surrogate motherhood is possible in some countries, using the gametes of the future parents or, if this is not possible, donor gametes. The result of these different techniques of reproduction is a multiplied or split parenthood: in addition to its social parents, a child may have different kinds of biological parents: a) a genetic father and genetic mother who are identical with the social parents, b) a sperm donor as genetic father plus the genetic/social mother, c) an egg donor as genetic mother plus the biological/social father, d) a gestational 'surrogate' mother plus the genetic/biological mother and father, e) both male and female donors as genetic fathers and genetic mothers who are not identical with the social parents; and f) male and female donors plus surrogate mothers plus heterosexual or homosexual couples, or single parents.

From the beginning of the development of ART, questions concerning the future children's health were raised. Embryos are, for example, examined morphologically before transferred to the woman's womb, and usually, pregnant women are monitored closely. With the development of genetic diagnosis and genetic tests, however, the possibility to detect health risks before birth led to the introduction of prenatal diagnosis as a measure of pregnancy monitoring – since IVF clients were offered prenatal diagnosis, too, it became a question of time before the genetic testing of embryos was also offered to this group. By the turn of the century, Preimplantation Genetic Diagnosis (PGD) was introduced as part of ART, but then broadened to those couples who can conceive sexually but carry the risk to transmit monogenetic diseases identifiable via genetic tests.<sup>20</sup> In the next step, PGD for individuals was broadened to pre-implantation genetic screenings (PGS), aimed at the detection of chromosomal disorders that often result in early miscarriages.<sup>21</sup> With the combination PGD or PGS, assisted reproduction goes beyond a treatment of infertility or involuntary childlessness; rather, it has become a method to select from a number of embryos the one or two embryos for the transfer to a woman's womb. Over the last decades, the application of PGD has been steadily broadened, although each step has been followed by public de-

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19 For example, oocyte donation is prohibited in Germany or Austria, whereas the European Union Tissue Directive prohibits only the trading of oocytes and sperms; in the USA, oocyte 'donation' is unregulated at the Federal level but subject to state regulation and self-regulation via the medical association. Cf. from a feminist perspective D. DICKENSON, *Commodification of Human Tissue: Implications for Feminist and Development Ethics*, in: *Developing World Bioethics* 2/1 (2002), 55–63.

20 Nevertheless, PGD is prohibited in several countries legally, or permitted only under strict conditions.

21 When PGS was introduced in the 1990s, there was hope to raise the success rate of IVF – but this was, to the surprise of many, not the case.

bates: while in the beginning the future health of an embryo was used as the criterion for PGD, it is now performed as carrier screening to identify children who will not be affected by a particular disease themselves but carry the risk to transmit it to their own offspring; PGD is performed to select embryos whose DNA match with a sibling who needs it for his/her own medical treatment; PGD is performed to select the sex of an embryo for 'social' reasons (in other words: to accord with parental wishes (or economic needs) to either have a girl or a boy); and it is performed to choose a particular genetic profile, such as deafness. Considering this development it is evident that the parental and medical care for a child's future health as justification for PGD has – to say the least – been complemented, if not replaced by the paradigm of a medically-assisted parental choice of the kind of child they want to have.

### 1.3 GENE EDITING AND THE MODIFICATION OF HUMAN EMBRYOS

Over the last few decades, the international community has developed a general consensus, expressed in several international ethical guidelines and legally binding documents, ranging from UN Conventions to regional Charters to national legislation, that prohibits research and practices that alter the genetic make-up of human embryos with the purpose of reproduction. Germline genetic modifications, most ethicists would have stated up to a few years ago, clearly falls under this category of prohibited practices. This changed with the possibility of the so-called method of CRISPR/Cas9 and related methods of gene editing.<sup>22</sup> In the same year, some scientists called for a public debate, contextualizing germline gene editing with the methods of PGD and related methods to circumvent the birth of children with known genetic diseases:

The CRISPR technique has dramatically expanded research on genome editing. But we cannot imagine a situation in which its use in human embryos would offer a therapeutic benefit over existing and developing methods.<sup>23</sup>

Even though international meetings were held and several reports have been issued since 2015, tackling the scientific, ethical, and oversight or governance problems, scientists have proceeded with their research – and in at least one case allowed the birth of gene-edited children – anyway.<sup>24</sup> At the First International

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22 A milestone was set when researchers showed, though in non-viable embryos, that gene editing may indeed be possible with the method of CRISPR/Cas9. Cf. P. LIANG ET AL., *CRISPR/Cas9-Mediated Gene Editing in Human Trippronuclear Zygotes*, in: *Protein & cell* 6/5 (2015), 363–372.

23 E. LANPHIER ET AL., *Don't Edit the Human Germ Line*, in: *Nature News* 519/7544 (2015), 410.

24 The case of Chinese scientist He Jiankui caused tremendous uproar just before the third international summit meeting in November 2018. His actions were condemned by the international community, by Chinese scientists, and the Chinese authorities initiated a criminal investigation.

Summit Meeting in 2015, I proposed a 2-year moratorium on any research that could involve the genetic modification of human embryos, including so-called basic research that often cannot be clearly separated from applied research – to the dismay of many present researchers.<sup>25</sup> The concluding Statement of the NAS Summit Meeting called for public discussion, *but* at the same time it objected to any slowdown of research. Rather, it stated that

[...] it would be irresponsible to proceed with any clinical use [...] unless and until (i) the relevant safety and efficacy issues have been resolved [...] and (ii) there is broad societal consensus about the appropriateness of the proposed application. At present, these criteria have not been met for any proposed clinical use: the safety issues have not yet been adequately explored; the cases of most compelling benefit are limited; and many nations have legislative or regulatory bans on germline modification. However, as scientific knowledge advances and societal views evolve, the clinical use of germline editing should be revisited on a regular basis.<sup>26</sup>

I argued, in contrast, that time was needed for a public discussion. The NAS did not propose any concrete procedure for how to complement research with a public discussion. Only one year later, more and more research projects were being launched, with no sign of a broad public debate. Then in 2017, the International Summit statement had considerably shifted: “from forbidden until criteria are met, to permitted if criteria are met – even though the criteria have not yet been agreed upon.”<sup>27</sup> In 2018, a group of scientists called for a global moratorium on applying germline gene editing but explicitly not on research, calling instead of prohibitions for voluntary national pledges and transparent rules of application, and a global genome editing observatory.<sup>28</sup> The authors do, however, acknowledge that therapeutic goals can mostly be achieved with current technologies:

In most cases, suitable embryos are available for transfer following PGT. However, when only a few are available to begin with, there might be no suitable ones after the test. Couples can repeat the process, and they might succeed on subsequent tries, but some might never obtain unaffected embryos.<sup>29</sup>

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However, following his public appearance at the summit meeting, it has become clear that numerous scientists knew of his plans and were in fact consulted.

25 A short summary of the panels can be found in A. R. LABARBERA, *Proceedings of the International Summit on Human Gene Editing: a Global Discussion – Washington, DC, December 1–3, 2015*, in: *Journal of assisted reproduction and genetics* 33/9 (2016), 1123–1127.

26 D. BALTIMORE ET AL., *On Human Gene Editing: International Summit Statement, 2015*, 2. <http://www.cas.cn/sygz/201512/PO20151204477369531116.docx>.

27 M. BRAUN/D. MEACHAM, *The Trust Game: CRISPR for Human Germline Editing Unsettles Scientists and Society*, in: *EMBO reports* 20/2 (2019), 1–3, 2.

28 E. S. LANDER ET AL., *Adopt a Moratorium on Heritable Genome Editing*, in: *Nature* 567 (2019), 165–168.

29 *Ibid.* 167.

The authors also acknowledge that germline gene editing will only affect a “tiny fraction” of couples: “These couples can never be helped by IVF coupled to PGT alone, because 100% of their embryos will be affected.” They point to the societal decision: “societies will need to weigh the legitimate interests of such couples against other issues at stake.”<sup>30</sup> However, the question is whether it is legitimate for couples to dismiss the obvious alternative, namely gamete donation, which would render gene editing unnecessary.

He Jiankui’s announcement in December 2018 that he had modified the germline of human embryos, and twins had been born already, was a bombshell just days before the well-orchestrated third summit meeting took place in Hong Kong. As has been revealed by now, however, He Jiankui’s project was not only known by several high-ranking scientists; moreover, it was more in line with the welcoming gestures than the organizers of the gene editing summits try to convey.<sup>31</sup> The disconnect and the gap between science and society is, in my view, dangerous for both sides, because it leaves societies without a thorough understanding and a voice in a direction of science that is contested and potentially irresponsible; and it leaves scientists without the necessary corrective of and by the public. But what should be discussed? Furthermore, who sets the agenda for the debates?

The main concern that the scientific community has so far addressed is the *safety* and effectiveness of the procedure. Medical ethics speaks of ‘minimal harm’ and ‘minimal burden’ for those who participate in medical research. In the case of germline gene editing, this does not only concern the parents, but also their children and the following generations. Germline gene editing, however, is not only a matter of safety – it also concerns all ethical questions that must be raised in the overall evaluation of ART and genetics. The *goal* of germline gene editing is to intervene on behalf of the health of future children, and to assist parents in *their* responsibility to ensure that their children are given the best medical support possible. The public as such does not have an active role in the decision whether a given or future technology is safe – this is an expert discourse. Although mostly, scientists are also providing the ethical analyzes – in ethics committees that render scientists, sociologists, or legal experts also experts in ethics. *Ethical* arguments are (often distorted beyond recognition) represented in some paragraphs of the ethics reports, and those who depart from the dominant liberal framework are often associated with religious worldviews. Furthermore, *social* arguments

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30 Ibid.

31 J. COHEN, *The Untold Story of the ‘Circle of Trust’ behind the World’s First Gene-Edited Babies*, in: Science Magazine August 1, 2019, <https://www.sciencemag.org/news/2019/08/untold-story-circle-trust-behind-world-s-first-gene-edited-babies>.

are regarded as important background considerations but not *immediately* relevant for the decisions how to proceed in the research at stake. In fact, social scientists and social ethicists turn to the social shifts of assisted reproduction over the last decades; they warn against the commodification of human reproduction, and a new marketplace eugenics. Historians remind us of the 20<sup>th</sup> century history of eugenics and the connection between human genetic research and racism. Scientists assure us that they will provide oversight, but as the research proceeds, even this minimal requirement is proven wrong, because in the leading countries of research – USA, China, and the UK – researchers seem to proceed without the very caution they promise.

## 2. *The Ethics of Reproductive Technologies*

Assisted reproduction, genetic diagnosis or screening of embryos, and germline gene editing all raise multiple ethical questions, and many of these have been studied in myriads of books and articles over the last decades. The re-interpretation of parenthood as reproductive autonomy and choice serves, however, as the predominant hermeneutical-ethical framework, and it also shapes the way normative questions are addressed. The Human Rights Declarations state the right of any human being to be protected against violent and/or discriminatory actions; they condemn practices that restrict the individual's freedom without justification, and the justification must not override a person's integrity and autonomy, which is sometimes expressed in the concept of human dignity and freedom. In the case of reproductive technologies, several specific human rights treaties shape the normative framework of the political-ethical deliberation; most prominent are the Universal Declaration on the Human Genome and Human Rights and the Council of Europe's Convention of Human Rights and Biomedicine. From this perspective, I will address three areas of concern: a) women's health risk through reproductive technologies, b) the protection of human embryos, c) future children's health. A fourth area addresses d) the difficulties to establish a coherent framework of reproductive justice in an age of a reproductive consumer market.

### 2.1 THE RE-INTERPRETATION OF PARENTHOOD

It is hard to underestimate the new freedom that has accompanied the technological development in the area of reproduction, especially for those couples who otherwise could not or did not dare to have children of their own; that some of the new constellations of parenthood applying reproductive technologies are closer to the traditional concept of adoption than to the traditional concept of biological parenthood, is, however, striking because ART was introduced as a

means to have *biologically*-related offspring. Given the variety of family constellations that I indicated in the last section, the new forms of bio-social parenthood seem to resonate, however, with studies from cultural anthropology, which have shown the plurality of the overall concepts of kinship relations.<sup>32</sup> While many (Western) societies still debate whether same sex marriage should be legalized and same sex adoption is (still) controversial, ART has become a rather common practice for same sex couples who wish to procreate. And indeed: if reproductive freedom is a right and kinship is a bio-social concept anyway, it is hard to see why same sex couples should be denied a technology that is offered to others under otherwise equal conditions.

The social changes have been analyzed descriptively and/or empirically but they also need to be critically examined in their normative implications.<sup>33</sup> Reproductive technologies are particularly critiqued in the name of (the Foucauldian concept of) “biopower”, assuming that in an age of biotechnology and “biopolitics”, power does not function as domination but rather as a self-disciplining force constituting the social institutions or practices via bodily and embodied practices of (self-)surveillance, constraining freedom rather than increasing it.<sup>34</sup> Other approaches, mostly from a liberal philosophical perspective, emphasize, however, that the freedom of choice is the central concept underlying reproductive autonomy. In their by now famous book, *From Chance to Choice*, the authors emphasize that from a liberal ethics perspective, the meaning of parent-child relations should rather be framed according to the framework of chosen relationships than according to a framework of chance or givenness.<sup>35</sup> While the tradi-

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32 Analyzing all major studies on kinship relations, beginning in the early 20<sup>th</sup> century, Carsten shows convincingly that kinship always integrated social and biological ties, and even though blood relations are of primary concern in many countries, they do not make up for all kinship relations. Cf. J. CARSTEN, *After Kinship*, Cambridge UK 2004. This finding is particularly interesting in view of the new developments in reproductive technologies, which show an overall tendency to re-interpret the concept of the family. Cf. among many others B. ALMOND, *The Fragmenting Family*, Oxford 2006; M. W. AUSTIN, *Conceptions of Parenthood. Ethics and the Family*, Aldershot 2009.

33 Among many other studies, cf. E. BECK-GERNSHEIM, *Reinventing the Family*; D. S. DAVIS, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures*, New York 2001; S. FRANKLIN, *Embodied Progress. A Cultural Account of Assisted Conception*, New York 1997.

34 M. FOUCAULT, *The History of Sexuality*, Vol. 2: *The Use of Pleasure*, New York 1985. M. FOUCAULT, *The History of Sexuality*, Vol. 3: *The Care of the Self*, New York 1988. M. FOUCAULT, *The History of Sexuality*, Vol. 1, *An Introduction*, New York 1978. M. INHORN, *Reproductive Disruptions. Gender, Technology, and Biopolitics in the New Millennium*, Oxford/New York 2007.

35 A. BUCHANAN/D. W. BROCK/N. DANIELS/D. WIKLER, *From Chance to Choice*. For a critical discussion cf. J. HABERMAS, *Die Zukunft der menschlichen Natur. Auf dem Weg zu einer liberalen Eugenik?*, Frankfurt a. M. 2001; H. HAKER, *On the Limits of Liberal Bioethics*, in: M. DÜWELL/CH. REHMANN-SUTTER/D. MIETH (ed.), *The Contingent Nature of Life*, Berlin et al. 2008, 191–208.

tional IVF or ICSI treatment may not be a problem in this respect, the parental choice to pass on a *multiplied* biological heritage to the child is, however, not unproblematic if considered from the child's perspective.<sup>36</sup> Ethics must attend to these questions, because family constellations following ART demand a more reflective approach.

Reproductive freedom and/or rights are inevitably entwined with *social* expectations and norms, as with moral responsibilities – the question is how these can be identified and ultimately justified. New social and ethical expectations arise, for example, when infertile couples are recommended by their families, friends or doctors to seek ART; after all, in many countries, women's biographies are socially shaped by the ideal of motherhood.<sup>37</sup> *Responsibility*, however, becomes the key *social* concept with respect to genetic diagnosis as part of the parental care for their child: As prenatal genetic diagnosis and pre-implantation genetic diagnosis enable couples (or individuals) to avoid giving birth to children with particular genetic traits or chromosomal disorders, future parents are expected to seek the necessary (genetic) information of their future child in order to make responsible *qualitative* reproductive choices based upon information and knowledge.<sup>38</sup> The

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36 O. O'NEILL, *The 'Good Enough Parent' in the Age of the New Reproductive Technologies*, in: H. HAKER/D. BEYLEVELD (ed.), *The Ethics of Genetics in Human Procreation*, Aldershot 2000, 33–48. O'Neill raises these questions with view to the Kantian terms of perfect and imperfect obligations; comparing the (assumed) adopted children's and IVF children's perspective she states: "Children can often look on their adoption as a result of the unforeseen even unforeseeable misfortunes of their birth parents, and their adoptive parents may be seen as rescuing them from intolerable situations. It may be harder for children to see a plan to bring them into the world with a confused and ambiguous heritage and without contact with their genetic parents or gestational mother as amounting even to 'good enough' parenting (p. 43). This reaction is echoed in blogs by IVF children who demand to know their genetic and/or gestational parents.

37 Several studies have shown that the relationship between the ideal of individual choices and socially mediated standard biographies is more complicated than bioethical studies sometimes reflect; especially women may struggle with the social expectation to become mothers, and their desires may be complex even though they seek ART. M. FRÄNZNICK/K. WIENERS, *Ungewollte Kinderlosigkeit. Psychosoziale Folgen, Bewältigungsversuche und die Dominanz der Medizin*, Weinheim/München 1996. The (social) imagery of the 'natural' female desire for a child is contrasted by the growing number of women who deliberately choose not to have children. This does not question of course that many women (and men) suffer tremendously because they cannot conceive other than via ART.

38 This case is made by A. BUCHANAN/D. W. BROCK/N. DANIELS/D. WIKLER, *From Chance to Choice*, but also by utilitarian bioethics, such as John Harris or Julian Savulescu: J. SAVULESCU/G. KAHANE, *The Moral Obligation to Create Children with the Best Chance of the Best Life*, in: *Bioethics* 23/5 (2009), 274–290. J. HARRIS, *Enhancing Evolution. The Ethical Case for Making Better People*, Princeton 2007. For a critical analysis cf. L. ANDREW, *Future Perfect. Confronting Decisions about Genetics*, New York 2001.

shift from the emphasis (and celebration) of the newly gained reproductive freedom to new social norms of reproductive responsibilities is a particular concern, not the least because it is hard to see how a newly defined voluntary eugenics can be avoided. Apart from the complex history of eugenics that rarely only functioned as coercive eugenics but rather implemented exactly the same language of parental responsibility that liberal and utilitarian bioethics uses today, the choices of genetic traits, based on judgments of quality of life, may violate future children's rights to an open future, as Jürgen Habermas has argued; evidently, they are also prone to discriminatory judgments of disabilities.<sup>39</sup> It is therefore necessary to clarify what the paradigm of choice means with respect to RT.

## 2.2 REPRODUCTIVE FREEDOM AND WOMEN'S HEALTH RIGHTS

The debate on the scope and limits of parental freedom and responsibilities, i. e. their right (or duties) to determine what kind of kinship relations should be allowed, and on what conditions embryos may be tested, selected, or genetically modified, over against the protection of human embryos and future children, has become a major field of ethical analysis and debate. Medical ethicists have argued that in applying ART and PGD or PGS, they act in accordance with traditional ethical principles, namely the physician's obligation to care for the patient ("neminem laedere"), the obligation not to harm the patient ("primum non nocere"), or to seek a patient's health as primary concern of their actions ("salus aegroti suprema lex"). These traditional principles are complemented by the modern ethical principle to respect the freedom right of their patient, and the political-ethical principle of justice<sup>40</sup> – but it is not exactly clear *whose* rights must be protected and/or respected in ART and PGD, and what exactly a reproductive justice framework must entail.

Reproductive freedom rights must – to say the least – be correlated to the health rights of couples, but in particular, to the health rights of women, because they must undergo potentially risky treatments to obtain ART. Several health risks need to be considered: for all women, ovarian hyper-stimulation syndrome occurs in a minority of cases, while minor side-effects of the hormone stimulation are more common but seem to have no long-term effects;<sup>41</sup> severe physical

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39 J. HABERMAS, *Die Zukunft der menschlichen Natur*. H. HAKER, *Hauptsache gesund? Ethische Fragen der Pränatal- und Präimplantationsdiagnostik*, München 2011. G. LANDSMAN, *Reconstructing Motherhood and Disability in the Age of Perfect Babies*, Oxford 2008.

40 For a 'classical' argument for the combination of traditional medical ethical principles complemented by autonomy and justice cf. T. L. BEAUCHAMP/J. F. CHILDRESS, *Principles of Biomedical Ethics*, Oxford/New York 2001.

41 JOINT SOCIETY OF OBSTETRICIANS AND GYNAECOLOGISTS OF CANADA-CANADIAN FER-

and psychological health risks may occur during pregnancy, mainly caused by multiples pregnancies, caesareans, premature births, or childbirth complications; additional psychological risks concern so-called fetus reduction, abortions in multiple pregnancies. In contrast to the expectations raised in the early phases of IVF, the success rate of the so-called baby-take-home per cycle does not extend 25-30% (and in women over 40 years it decreases to about 10%). ART may take several years, resulting in considerable life-style monitoring and psychological stress for the persons involved. In bioethics, the psychological effects on couples who fail to give birth has not gained much attention. With respect to male infertility or subfertility, IVF raises another ethical question, namely whether a woman's health and well-being may be put at risk in order to treat the reproductive condition of another person, usually her partner or husband. The same question needs to be answered with respect to oocyte donors and surrogate mothers whose health risks are often ignored in advertisements; in both cases, liberal ethics considers consent as a sufficient condition – but from a human rights perspective, the normative relation of autonomy (consent by contract) and the physician's obligation to care for the well-being of the patient is far from clear. The global reproductive technologies market applies the rhetoric of choice and altruistic donation without much attention to the health risks – since women consent to the procedures, the moral question is mostly reduced to the liability of the companies and/or clinics. However, while in the medical context, “minimal harm” and “minimal burden” are justified side-effects when treatments benefit the persons who are treated in the global market, not all practices are directly linked to the immediate benefit of the involved parties. For example, men and women donate their sperm and eggs, but still count on the monetary compensation, or they respond to incentives that enable them to pay for the ART treatment themselves.<sup>42</sup> In order to protect the female donors' health and to exclude exploitative practices in the field of reproductive technologies, international legislation and better control strategies of trafficking are still needed.<sup>43</sup>

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TILITY AND ANDROLOGY SOCIETY CLINICAL PRACTICE GUIDELINES COMMITTEE, *The Diagnosis and Management of Ovarian Hyperstimulation Syndrome*.

42 Cf. H. WIDDOWS, *Border Disputes across Bodies: Exploitation in Trafficking for Prostitutions and Egg Sale for Stem Cell Research*, in: *International Journal of Feminist Approaches to Bioethics* 2/1 (2009), 5–24.

43 Trafficking and commodification is banned by several UN conventions, as well as by the UN and EU bioethics treaties and EU Directives.

## 2.3 THE MORAL PROTECTION RIGHT OF HUMAN EMBRYOS

With the possibility of IVF, human embryos are created independent of sexual intercourse and outside of a woman's body. As was already the case in the moral debate on abortion rights, the moral status of human embryos *ex vivo* or *in vitro* comes with particular challenges. Often, more embryos are fertilized than needed for one cycle. Depending on the legal regulations, some are selected and others discarded, many are frozen for future cycles, and so-called surplus embryos may be handed over to other couples or used for embryo research. Practically, human embryos are therefore treated as "things" or commodities. In order to avoid this effect, the human rights' treaties demand the protection of embryos dignity, and hence include them as distinct beings, subject to certain, yet entirely unclear moral rights. In the ethical debate, several arguments have been brought forward to determine the moral status both in line with the Human Rights frameworks and the scientific knowledge of embryology:<sup>44</sup> hence, the moral status has been linked to the Aristotelian concept of *potentiality* of the embryo to develop as (or into) a moral agent, to be distinguished from the mere *possibility* that in the process of fertilization a new human being may come to existence; some argue that one must assume a *continuity* of a human being's life starting with fertilization, and some, taking embryonic development into consideration, argue that an individual *identity* is established with the emergence of a new genome. A more process-oriented argument refers to the *gradual* development of the fertilized egg into a human being, with different qualitative leaps in this development: they argue, for example, that nidation is more decisive than fertilization, while others argue that a limited self-perception is the condition for moral protection. Still others argue that the decisive point for the moral and legal protection is the day of birth when the *public* legal and moral *recognition and right* of a person is established.<sup>45</sup>

Up to the present, there is no philosophical consensus on this central question of the starting point of moral protection. Yet, two apparently extreme claims seem to be weakly argued: on the one hand, the *personhood claim* does not distinguish the moral status of an embryo from the status of any 'other' person, thereby ignoring the process of human development; and on the other hand, the *neutrality claim* does not distinguish embryonic cells from other somatic cells, thereby ignoring that human embryos are not only possible but potential future children. It

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44 For a discussion cf. H. HAKER, *Ethik der genetischen Frühdiagnostik. Sozialethische Reflexionen zur Verantwortung am menschlichen Lebensbeginn*, Paderborn 2002.

45 The UN Convention of the rights of children proves that changes in the social recognition of particular groups are ultimately echoed in the (international) rights systems – how these changes occur is more difficult to describe. UNITED NATIONS GENERAL ASSEMBLY 1989, *Convention on the Rights of the Child*.

may therefore be helpful to remember that human embryos do not develop without pregnancy; an embryo's development is dependent on a woman's biological and psychological *capability* to carry a child and bring it to term. Under the conditions of ART, it is also dependent on her *decision* to become pregnant at all. Hence, embryo protection must not be isolated from the context of a woman's pregnancy; quite to the contrary, the (prospective) gestational mother carries the weight to respond to the existential needs of an embryo.<sup>46</sup> Considered as a relational right, the moral status of an embryo must therefore respect the particular position – and rights – of the woman as first addressee of obligations.<sup>47</sup>

#### 2.4 RIGHTS OF CHILDREN

With respect to reproductive technologies, *children's rights* concern, first of all, their well-being, second, their freedom, and third, their right to know their genetic heritage.<sup>48</sup> While bioethical studies rarely address children's rights as such, medical studies consider the children's well-being as part of the quality control of ART. By now, several long-term studies have been published which show that children born after IVF or ICSI show indeed some developmental difficulties, but in most cases, these seem to be compensated around puberty.<sup>49</sup> Especially children born prematurely, however, mostly due to multiples pregnancies caused by ART, face more and considerable health and development risks. Surprisingly, the cases of so-called wrongful life have been much more debated within bioethics than health issues caused by assisted reproduction: wrongful life cases seem to prove that the quality of life may decrease below a threshold of a 'good' life due to genetic conditions, as argued by some children themselves;<sup>50</sup> these cases have

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46 Philosophically, it is possible, of course, to contest either the human rights framework as relevant for moral reasoning, or the applicability of human rights to human embryos, or both. However, as I said above, several human rights declarations relevant to reproductive technologies are already in place, and they are the result of international debates and negotiations. In addition to the specific Declarations I quoted above, others need to be considered, too, in the context of reproductive namely women's rights, children's rights, and rights of persons with disabilities serve *de facto* as the normative human rights framework.

47 Therefore, the reproductive freedom turns into an ethical concept of reproductive autonomy that first and foremost needs to address the parents' responsible response to the *existential* right claim, which has priority over the health right. Even if an embryo may not be considered to have a right, parents are still *somehow* responsible for an embryo (or a number of embryos) who without their intervention would not have come to existence.

48 E. FUCHS, *Children's Rights and Global Civil Society*, in: *Comparative Education* 43/3 (2007), 393–412. UNITED NATIONS GENERAL ASSEMBLY 1989, *Convention on the Rights of the Child*.

49 Cf. M. HANSEN/C. BOWER ET AL., *Assisted Reproductive Technologies and the Risk of Birth Defects – A Systematic Review*, in: *Human Reproduction* 20/2 (2005), 328–338 (with literature).

50 For a discussion of the 'threshold' argument cf. M. C. NUSSBAUM, *Frontiers of Justice. Disability, Nationality, Species Membership*, Cambridge, MA 2006.

been used to argue in favor of prospective parents' responsibility to determine their future child's genetic health status. Hence, a couple may not only have the *freedom* but rather the *duty* to refrain from having a *particular* child, and women may be at least strongly recommended to terminate a pregnancy.<sup>51</sup> This claim, however, runs contra *all* existing normative treaties concerning reproductive rights; in fact, it is a violation of women's freedom rights, embryos' basic protection rights, future children's welfare rights, and potentially even their future freedom rights, especially in the case of germline gene editing. In contrast to this conclusion about parental responsibilities, assisted reproduction practices carrying a greater risk for the future child's health themselves need to be studied more closely and communicated to the prospective parents. In particular, multiples pregnancies and births – due to multiple embryo transfers – should be avoided even if this will reduce the overall success rate of IVF.

As mentioned above, another problem concerns a child's right to know their genetic and/or biological heritage: anonymous sperm or oocyte donations obviously violate this right. Donors, for example, often demand anonymity, or clinics do not want to store the data for several decades. Central databases are rarely established, with the effect that children who wish to claim their right to know their genetic parents fail to find the necessary data. In summary, from the ethical perspective of children's rights, reproductive technologies do not yet provide a satisfying framework that grants children the rights they are guaranteed under the international ethical and legal frameworks, and in many countries throughout the globe, national legislation needs to be reframed in order to catch up with the more and more advanced reproductive technologies.

## 2.5 REPRODUCTIVE JUSTICE

In recent years, reproductive justice has become an issue within bioethics, and it has even been argued that a radically new framework of reproductive justice is needed.<sup>52</sup> In bioethics debates, this is predominantly discussed as distributive justice, addressing access rights and the equal treatment of individuals or couples who seek ART. Different countries handle financial costs differently: some countries leave it to the private market, others consider ART as part of the healthcare service that is covered by insurances, and yet others have constrained IVF to infertility treatment. Independent of national legislation, however, reproductive

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51 This argument is made by Allen Buchanan and his colleagues in: A. BUCHANAN/D. W. BROCK/N. DANIELS/D. WIKLER, *From Chance to Choice*.

52 Cf. for a short overview: E. GALPERN, *Assisted Reproductive Technologies: Overview and Perspectives Using a Reproductive Justice Framework*, Center for Genetics and Society Oakland, CA 2007, <http://geneticsandsociety.org/downloads/ART.pdf>.

technologies and reproductive services are offered on the global market, enabling those individuals or couples who can afford it to buy the treatment they want.<sup>53</sup> If, however, reproductive autonomy is not only a negative right but rather a positive right to have access to reproductive technologies, the addressee of this right needs to be determined. Bioethics therefore enters into yet another discussion, namely the debate on (global and national) healthcare justice and public healthcare. It is unclear how medical services for social reasons (as is the case in ART for same sex couples but also for healthy couples risking to pass on particular genetic traits) rather than infertility treatment can be solved without creating new injustices in other fields of public healthcare – bioethicists therefore seem to be hesitant to claim reproductive rights as positive rights and rather accept the injustice of a private market solution.

However, the questions about justice do not only concern access rights. Rather, a reproductive justice theory needs to embrace the socio-economic impact of the reproduction industry: by the beginning of the 21<sup>st</sup> century, reproductive services have developed into a consumer market, and the image of a physician helping couples or individuals in their desperate struggle to overcome childlessness conceals the fact that reproductive services contribute at least in part to a competitive market. Reproductive services are offered in almost any country independent of their public basic healthcare services; genetic tests are developed and marketed at an ever-earlier stage of human development suggesting that the genetic make-up is the decisive factor for the future child's health; for the purpose of oocyte or sperm trading, concealed as donation, gametes can be ordered via internet and chosen from catalogues according to one's preferences. Advertisements in US college students' magazines regularly look especially for young women whom they offer large sums as compensation for their services; surrogate mothers are paid to intentionally give birth to children they will never parent. Agencies systematically ignore the physical and psychological risks of these surrogates with the argument that consent to a contract justifies the exploitation of a person's body for the reproductive interests of another person. Reproductive services, including medication, clinical services, and gamete trade, have an estimated annual value between \$3-5 billion in the USA alone; this market seeks its consumers who welcome the commercial offers addressing their alleged reproductive fears or desires.<sup>54</sup> Furthermore, reproductive technologies companies advertise the quality of the genetic 'material' they are selling, implying that their clients will

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53 Oocyte trafficking and surrogacy are especially of ethical concern and cannot be addressed by distributive justice only.

54 This highly naïve approach to capitalist economy is criticized by Donna Dickenson who shows how desires (and fears) are created for the consumers' market; Cf. D. DICKENSON, *Body Shopping: The Economy Fuelled by Flesh and Blood*, London 2009.

want oocytes or sperm of high genetic quality, but in fact the criteria for “good quality” are prone to genetic discrimination or even racism.<sup>55</sup>

All these practices are not private in the sense of the privacy of personal relations; rather they are private in the sense of the economic cooperation with interacting partners who exchange goods in the global market; neither the contribution of medical professionals who participate in these exchanges nor the ethical self-regulations of agencies can conceal the role of this consumer market for the shaping of the new concepts of parenthood.<sup>56</sup> Ultimately, societies need to discuss whether the chosen kinship relations are to be interpreted in light of the consumer market or in light of human relations that are exempted from commodification, and ART, PGD, and germline gene editing cannot escape the fact that they are part of this dynamic that may transform the social understanding of human reproduction and parental responsibility, namely to have a particular “fit” and healthy child. *Moral* autonomy goes beyond the autonomy to make rational choices in line with a particular, libertarian, concept of freedom that seem to infiltrate the practices of ART; it means the claim to acknowledge that any human being is vulnerable to one’s actions, and as an agent the subject of freedom rights that must be respected.<sup>57</sup>

### Conclusion

Reproductive technologies have changed the overall possible constellations of parenthood and thereby increased the reproductive freedom for millions of people. A new concept of kinship relations as chosen relations emerged, resulting in a re-interpreted concept of parental responsibility. In one interpretation, it is claimed that prospective parents are responsible for the health risks of their offspring; in this view, ‘good parenthood’ entails the use of ART and PGD. Others argue that the concept of reproductive rights needs to be interpreted in relation to other human rights and an overall framework of reproductive justice. In this view that I have taken here, reproductive rights concern, first, women’s health rights; second, they need to embrace the relational rights of embryos (related to the gestational mothers and relative to their decision to become pregnant); and third,

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55 D. ROBERTS, *Killing the Black Body. Race, Reproduction, and the Meaning of Liberty*, New York 1997. I have not addressed the discriminative potential of genetic testing with respect to disability. Cf. for a defense that individual eugenics is not discriminatory: A. BUCHANAN/D. W. BROCK/N. DANIELS/D. WIKLER, *From Chance to Choice*.

56 Axel Honneth shows how the social concept of family relations, constituted as emotional bonds over time, is thereby likely to be ‘over-ridden’ by the socio-economic concept of market cooperation, constituted by reciprocal, yet instrumental relations. A. HONNETH, *Freedom’s Right*.

57 Cf. chapter 5 in this volume.

they need to embrace rights of future children, especially the right to well-being and freedom. Reproductive rights that attend to these other rights are one important element of a framework of reproductive justice, striving to provide any person a decent standard of living and the freedom to live the life he or she chooses.

Looking at reproductive technologies in the broad understanding I have adopted in this essay, the tension between the two main concepts cannot be overlooked: on the one hand the public, if not even the global interest, population control becomes once more prominent in view of the necessary requirements of food, water, or energy security, threatening the accomplishments of the 20<sup>th</sup> century struggle for reproductive rights. The global reproductive technologies market, on the other hand, has contributed massively to an over-individualized interpretation of reproductive claim-rights. Not only biomedicine but also bioethics has mainly been complicit to this interpretation of human reproduction, and has closed its eyes for a long time to the reality of a market-economy driven over-determination of the practices. Translating desires into needs, needs into consumer choices, and choices into rights that cannot be denied, ART mirror exactly the dynamics of any consumer good, thereby obliterating the distinction between a good that may indeed be exchanged and also substituted, and the relation to a future child. Individuals who have undergone the ART treatment see the tension between their desires and ideal to have a child and the reifying understanding of the scientific stance in ART.

For an ethics that aims to function globally, reproductive rights are one, if not the most important means in the struggle against poverty. After a period of opposition, stirred and supported by several religious groups, birth control will most certainly re-appear on the agenda of any international institution in the coming years. It remains to be seen whether the intersection of the social and ecological impasse will increase the pressure on the Catholic Church to change its powerful anti-birth control position. Still, ethicists will insist that reproductive rights are ultimately always individual rights, and even though one may disagree with particular decisions on moral grounds, the negative right must be maintained over against any political, religious, or social argument. Unless women defend their accomplishment of the negative reproductive freedom right globally, I expect it to come under new fire – it would not be the first time that political goals are used to trump the rights of individuals.<sup>58</sup> For women and families living in so-

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<sup>58</sup> The fight against abortion rights in the USA that has reemerged since the election of Donald Trump in 2016, with the majority support of (white) Evangelicals and (white) Catholics, is an indication for the contradictory positions regarding women's reproductive rights on the one hand, and the ignorance of the reproductive technology market on the other hand. Since many conservative members of the Republican Party who are in the forefront of the effort to renegotiate Roe

cially and economically insecure conditions, having multiple children – as well as seeking abortion – may rather be a desperate choice resulting from their social conditions than a happy choice; access to birth control without changing the social conditions will not only not suffice, it would be unethical. Likewise, practices of selective abortions, egg selling or surrogate pregnancies must be seen in light of background structures creating exactly the atmosphere of indirect coercion that 19<sup>th</sup> century critics of an exploitative market economy identified to contradict the moral vision of the public good. To respond to these challenges globally in order to secure individual rights together with ameliorating structural injustice will involve, among other things, the re-interpretation of those social values that take women hostage to (reproductive) choices that others, men and women alike, make for them, disregarding their status as moral agents.

The aforementioned dialectic between hermeneutical and normative ethics is crucial for the overall ethical reflection: human reproduction is not just a biological or medical fact; it is also the site for individual, social, cultural, and ethical interpretation, and interpretations are as diverse as the contexts in which reproductive practices occur. For the majority of people, especially women who are denied a decent standard of living, children do not have the same function as for those who have the means to realize their desire for a child with the help of ART. For those who are dependent on bearing and raising children in order to survive poverty, both quantity (the number of children) and quality (children's health) matter – but both the number and the health of their offspring play a decisive role in their own basic well-being and are therefore interpreted differently than the wishes of well-off consumers the reproductive technologies market targets. For ethics, both contexts must be distinguished and yet, they both must be addressed in a manner that does not simply play off the desires and rights of some against those of others.

One could certainly argue that the human rights framework that has been the normative premise of this essay, has a Western touch in spite of its institutionalization in the United Nations to which almost all nation states belong as voting members. However, even if one accepts the human rights framework, it cannot be denied that on practical terms it is mostly used rhetorically, leaving human rights violations the rule rather than the exception. The often raised suspicion against the appeal to human rights in the global ethics discourse is therefore understandable. Criticism of human rights is prominent, however, also within the discipline of bioethics; in the discourse of reproductive ethics, rights are spelled

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v. Wade (the decision that legalized abortions in the USA) are libertarians regarding economics, poor women and women and men from minority groups are, again and again, the victims, if not the targets, of these campaigns.

out first and foremost as freedom rights, and freedom rights as rights to choose – an interpretation that has been widely criticized as overly reductionist. Furthermore, the new emphasis on the common good or public good, associated with a new emphasis on population control in recent years, is prone to override individual rights in the name of greater interests unless it takes individual rights as the limit of (political) intervention.

In summary, reproductive rights need, first, to be defended against social value traditions that have a long history of discriminating against women; second, they will need to be defended against policies indifferent to women's (and families') socio-economic status. Finally, reproductive rights must be defended against a market model that interprets moral rights as consumer choices, and transforms human reproduction into one commodity among others. Since none of these three areas can be addressed locally or nationally, a global ethics of reproduction needs to be developed in view of and in line with the UN Sustainable Development Goals. Since reproductive technologies are one important context of human reproduction, it remains to be seen whether the human rights framework is strong enough and still sensitive enough to ethically orient the ever-changing understandings of reproduction and kinship relationships.

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PART THREE

POLITICAL THEOLOGY AND CRITICAL POLITICAL ETHICS  
— THEORETICAL REFLECTIONS

