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Reproductive Autonomy in Light Of Responsible Parenthood

With new science comes the need for a new ethical discourse.

BY HILLE HAKER

Illustrations by Anna Bushan

I. For a critique of the "mainstream" ideology of individual autonomy as a consumerist concept, see Onora O'Neill, Autonomy and Trust in Bioethics (Cambridge University Press, 2002).

EPRODUCTIVE AUTONOMY HAS ALWAYS BEEN ONE of the most important issues for different kinds of women's movements, and in different phases of these movements. The movements have demanded that family-planning matters not be decided by men alone, or by religious authorities or the state. Reproductive autonomy as a political slogan in the context of planned motherhood can be constructed as a negative right—in this case, the right to non-interference in a woman's decision-making capacity, and the right to nonviolation of female bodily integrity.

Reproductive autonomy is not synonymous with liberty in the sense of mere individual autonomy—this concept is often (mis-) represented in bioethical reasoning.¹ Rather, it takes women seriously as moral agents who must decide what kind of life they want to live, together with others, in particular social contexts and given particular institutional constraints.

Stating that women have moral reproductive rights and calling for these to become recognized as legal rights in all countries has a political side as much as an ethical one: politically, it asserts the right to autonomy; ethically it implies that every woman claims to be considered as a moral agent, and, as such, to be accountable for the reproductive decisions she makes.

As far as this argument rests upon modern ethical reasoning, women should not have had a problem gaining support within the ethics community for their position and struggle. When medically assisted abortion became a political issue in the 1970s and 1980s, however, it was soon identified with the much broader scope of women's reproductive autonomy. Ethical opposition to abortion was raised especially by religious (Christian) leaders who grounded their objections to the reproductive rights' movements in a specific version of natural-law theory and an ontological anthropology, or in the faith-based assumption of the sanctity of life.

Neglecting the historicity of anthropological concepts and ignoring the necessity to balance conflicting rights, a reductive, unmediated application of the concept of human dignity was held up against the concept of reproductive autonomy. As a result, the opponents of the women's movement denied not only women's moral

agency but also the possibility of dilemmatic moral situations during pregnancy, furthermore ignoring the practical moral conflicts many women would have expressed with respect to their need to be assisted in their (actual and prospective) parental responsibilities, had they been asked.

Feminist ethicists became trapped in the reductive polarization of "pro-choice" and "pro-life," because it seemed that they could not uphold the right to abortion without questioning the right to life of an embryo, and vice versa. The basic feminist argument of reproductive autonomy thus seemed to conflict with the ethical claim that the hierarchy of rights must be consistent, favoring (embryonic) life over (women's) autonomy. To escape this trap—which I would call the trap or fallacy of simplicity—many ethicists simply did not acknowledge a right to life on the side of embryos or fetuses, while others argued for the acknowledgment of a practical moral dilemma in cases of unwanted pregnancies.

Although I am convinced that the latter position is stronger than the first, my point here is that the concept of reproductive autonomy makes sense in an ethical discourse only if the women's capability for and obligation to moral decision-making is acknowledged and, likewise, societal responsibility is taken seriously.

ITH THE INTRODUCTION AND implementation of assisted reproduction, women's reproductive autonomy became an important focus within bioethical reflection. In ethical debates of the 1970s and 1980s on reproductive medicine, a negative right was turned into the positive right to have access to assisted reproductive technology (ART). The assumed "natural striving" of women to give birth to children was presupposed in many debates about in vitro fertilization (IVF), and the metaphor of "giving nature a helping hand" became a rhetorical phrase for the self-understanding of physicians who saw themselves as helping women (and only secondly men) to fulfill their natural

Several feminists criticized ART as being one more means to keep women in their social place as mothers and, moreover, as an excuse to experiment with human reproduction without considering the side effects these experiments could have on women and offspring alike. On the other hand, factions of the women's rights movement, especially in countries with a strong liberal tradition, strongly endorsed reproductive medicine as part of the women's struggle for autonomy, claiming women should at least have access to ART. These feminists saw modern reproductive technologies as a useful tool to achieve the overall goal of women's liberation and autonomy. Because ART is dependent on financial, medical, and sometimes psychological support that societies or individuals pay for, however, the status of the right needs to be clarified. If ART is

role—namely, to be parents.

taken only as a negative right—namely, the right not to be stopped from having access to ART as a tool to become pregnant—clearly well-off couples who can pay for the procedure are favored. But in places where there is public funding for and access to ART—as in, for example, Germany—the just distribution of health care goods becomes an obvious and more and more urgent problem. Liberal approaches have tried to respond to the situation with the justice-based claim to "equal access," but this claim seems to be unrealistic given the scarcity of health care resources.

Exhaustive answers to these questions have not yet been found, but it seems clear that today the focus of the debate is shifting from individual ethics to social ethics, emphasizing concerns of political and social justice over the individual freedom to choose health-related services.

HEN PRENATAL GENETIC DIAGNOSIS WAS IMPLEmented on a larger scale during the 1980s and 1990s,
the same period when assisted reproduction was increasing, issues of autonomy and reproductive rights shifted from a discussion about the *right to procreation* to a debate about the *right to a*healthy child. Whereas prenatal diagnosis was initially introduced
to avoid the birth of children with a high risk of "serious hereditary diseases," it soon became a common component of pregnancy
monitoring. In non-Western countries—India and China in particular—an emphasis on the risk of poverty as well as state policies
on birth control resulted in a large-scale sex-selection practice via
prenatal diagnosis, to the disadvantage of girls. The difference between medically indicated interventions and socially motivated sex
selection was thereby blurred.

With the introduction of pre-implantation genetic diagnosis (PGD) in the early 1990s, a next step was reached. Intended first to raise the success rate of assisted reproduction, it soon became the focus of a new way of family planning, based on preventing offspring with certain genetic risks, implementing pre-pregnancy and prenatal predictive tests such as those for cystic fibrosis, but also including tests for late-onset diseases such as Huntington's chorea and Alzheimer's disease. Rarely were the well-known side effects of in vitro fertilization and its risks for women, especially the so-called hyperstimulation syndrome, weighed against the interests of couples to diminish the risk for future children. At present, we can observe the next step, to promote enhancement technology as part of medical intervention, thereby enforcing normative concepts of the "healthy" child.

In the last decade, another major step has taken place with the new possibilities of regenerative medicine. Embryos have become a promising resource for research going far beyond assisted reproduction. For the time being, embryonic stem cell research is dependent on donors of "surplus" embryos from IVF procedures, or on women as donors (or sellers) of egg cells, in order to perform the so-called nonreproductive cloning via somatic nuclear cell transfer.

In addition to growing concern about the exploitation of women as egg-cell "donors," similar to the exploitation of organ donors in the "gray market" of organ trafficking (cases of Eastern European

^{2.} The shift from using genetics for infertile couples to fertile couples was not difficult, since several genetic dispositions are accompanied with subfertility.

women who were paid for their "donations" by British IVF centers were debated in the summer of 2005), embryonic stem cell research is in part ethically questioned because it shifts embryo research from reproduction to regeneration and transplantation of tissue. It thereby advances the bio-economic perception of embryos (and women's body parts), and separates embryo research and egg cell donation from purposes related to reproduction.

I have stressed the development of reproductive technologies to see more clearly where we have come with respect to reproductive autonomy. But several issues need further analysis: ethnic

and cultural diversity in regard to reproduction; class differences; the prospect of an all-embracing monitoring of pregnancy in the Western world while the priorities of global health care are pushed to the background;³ the expansion of predictive tests; the problem of insurance not being provided if certain tests are not performed; second- and third-trimester abortions;

As partner and love relations have become more reflective, so too has the parent-child relationship.

health risks for women and children caused by IVF or intra-cytoplasmic sperm injection (ICSI); and socially motivated sex selection and family balancing as an underpinning of the normative social construct of the "good family."

It is often argued that the political right to autonomy be achieved by leaving the choice for the above-mentioned services and practices to women, but this position is weakened when considered from a social-ethical perspective. Feminist bioethicists in particular are now faced with a critique initially levelled at main-stream bioethics: namely, that they ignore social and political constraints of reproductive and genetic technologies and endorse the traditional modern liberal theory of the self. The critique raised by care-ethical approaches raised in early feminist ethics was renewed by critical theory; feminist philosophers and scholars of the history of sciences have articulated their critique for some time, but it has still not been adequately addressed by feminist liberal bioethicists.

Critics accuse proponents of the "individual autonomy" model of naïveté, of underestimating the social construction of this concept in the context of ART and genetic diagnosis, and of uncritically endorsing mainstream bio-economical policies and biomedical definitions, thereby eclipsing social understandings of "life," "parenthood," or "human development." These critics demand that feminist ethics pay attention to the rhetorical use of the (feminist) concept of reproductive autonomy, and analyze the disempowering effects that assisted reproduction, genetic diagnosis, and egg-cell donation have on women.

REPRODUCTIVE AUTONOMY MUST BE SEEN NOT ONLY in the context of technological development, but also in the context of societal developments and changes in family structures over the last 50 or so years.

In Western societies technological and biomedical progress has been accompanied by changes not only in family structures but also in parent-child relations and health care systems. As social 3. It would be erroneous to assume that there are no major concerns in developed countries, too. The example of the United States may suffice: here, more than 40 million people have no health insurance. Given that poverty hits women and children more often and usually harder than men, this grievance is as important a consideration as the introduction of ART and genetic technologies into private health sectors of developing countries.

and historical studies have shown, kinship and parenthood have shifted from being understood in a common naturalistic way to being understood in relation to a couple's decision-making. And as partnership and love relations have become more reflective, so too has the parent-child relationship.⁴

While birth control resulted in a considerable drop in the number of births per woman, assisted reproduction is an ambiguous practice: on the one hand, it advances the distinction between genetic, biological, and social parents and thus questions the traditional biological concept of parenthood. On the other, however, it implicitly maintains the concept of biological parenthood by responding to the assumed (female) desire to become pregnant with the rhetoric of reproductive autonomy and rights. If the biologically related child had not been upheld as a more or less unquestioned ideal of parenthood, assisted re-

production, with its serious risks for women and offspring and a still rather low success rate, would never have become a serious option for couples.

Just as assisted reproduction has changed the concept of parenthood, so too has prenatal genetic diagnosis. Given the changes in (middle-class, white) female biographies, it is not surprising that prenatal diagnosis—endorsed by societies that objected to discriminating against "disabled persons" but at the same time openly discussed the use of genetic diagnosis to prevent further births of disabled childrenwas welcomed by women who did not want to endanger the independence they had only just gained. Unlike male liberals, feminist liberals argued from this background of well-known dependence and the experience of having liberated themselves from it. The growing societal toleration of terminated pregnancies made it easy to accept not only the *legitimacy* of terminations for

medical reasons, but also of an assumed health-related *obligation* to "prevent" giving birth to a child with serious health risks or symptoms of disability.

Supporting and promoting this concept, many bioethicists began to spell out parental responsibility as a duty to prevent the birth of children with genetic risks. Translated into practical terms, couples are to understand their new responsibility in terms of pre-pregnancy tests, or terminating pregnancies with genetic or chromosomal disorders such as Down syndrome. Once more, women and feminist bioethicists seemed to be trapped between Scylla and Charybdis—between the obligation to set aside their (possibly conflicting) personal interests in favor of caring for a child with disabilities, or the necessity to ignore any bond between themselves and their (originally wanted) child by following the argument of parental responsibility as prevention.

Two social-ethical factors are given too little attention here. First, the pressure on women or couples to undergo tests and



4. For a thorough analysis, see Hille Haker, Ethik der genetischen Frühdiagnostik. Sozialethische Reflexionen zur Verantwortung am menschlichen Lebensbeginn (Paderborn 2002).

procedures in order to assure a "healthy" child is underestimated, and needs further analysis, especially in regard to class and race. Second, the normative concept of parenthood must be reconsidered in general in relation to the new challenges of social and technological changes. Reproductive medicine endorses a concept of parenthood that is sufficient for the libertarian autonomy model of individual choice, but is insufficient for an autonomy model based on relationality and moral responsibility. The tension between these understandings of autonomy will haunt the discussion about reproductive rights in the next few decades.

In the context of regenerative medicine, namely, of embryonic stem cell research, the concept of parenthood seems to disappear almost completely. In this field the rhetoric of encouraging the altruistic collaboration of couples with research and science is complemented by the rhetoric of autonomy as the claim of property rights (on human embryos) and commodification (of body parts), where women (and couples) are considered the "owners" of surplus embryos after in vitro fertilization procedures and "owners" of egg cells, which they should be free to make available on the market of bioscience.⁵

Apart from many problems, especially concerning the market for egg cells, this approach divides the moral perception of an embryo into being the object of property in the pre-implantation phase, and being a person with its own rights after birth.6 Contrary to this biomedical neutralizing tendency with respect to embryos, especially those with genetic risks or chromosomal symptoms, pregnant women of "normal," "healthy" embryos are confronted with more and more norms of social conduct in order to protect and support their embryo's or fetus's development. It seems that the current practice is ethically contradictory in its judgments of how to deal with embryos and fetuses in general, and how to deal with specific embryos in particular. In this situation, ethical reflection based on the notion of reproductive rights must seek to offer arguments to orient moral agents in their own deliberation. And these must go well beyond the well-known reductions of pro-life or pro-choice positions.

s I HAVE ARGUED, AUTONOMY REFERS NOT ONLY TO a self-determined life's involving no (violent) interference by another person or institution, but also to the concept of moral responsibility. Likewise, moral autonomy does not emphasize the rights of the players in the bio-economic market, couples and women among them, but rather the dimension of responsibility on the basis of the individual's freedom to decide for herself or himself. Moral autonomy connects the responsibility to lead one's own life with the responsibility to take into consideration the goals, needs, interests, and rights of others. Thus, responsibility does not contradict freedom, but rather it is the *moral approach* to freedom: Freedom without the concept of responsibility is merely egoism, but responsibility without freedom is force.

The desire for a child is a goal that can be, but is not necessarily, part of a person's identity. Many aspects of the feminist discussion of motherhood and female identity can be interpreted as the search for a pluralistic and tolerant model to empower women to live a life

5. Donna Dickenson, "Commodification of Human Tissue: Implications for Feminist and Development Ethics," *Developing World Bioethics*, vol. 2, no. 1 (May 2002): 55–63.

6. I borrow the term "object of property" from Patricia Williams who has related this to the history of slavery; The Alchemy of Race and Rights (Cambridge University Press, 1991, 216-238). The analogy is not meant to identify slavery with embryo research—this would obviously ridicule the former; rather, it is the neutralization of human beings that is at stake here. This, I would hold, is unethical in its arbitrariness of moral respect. Sadly, it is part of the history of the concept of human rights that it did not live up to its own universal claim, but was based initially on the arbitrary exclusion of women, children, and minorities. Thus, the critical approach to ethics requires the self-reflective questioning of one's own assumptions.

they choose for themselves, with or without children. This liberal presupposition of feminist ethics, based on the concept of negative freedom and the right to autonomy, remains valid.

How could reproductive autonomy, understood as moral autonomy, then, be spelled out in the "age of reproductive medicine and genetic diagnosis"? I will address this question by looking at the concept of parental responsibility.

To explore parental responsibility, the consideration of *actual* parenthood is constructive for either pre-pregnancy or prenatal *prospective* parenthood. Parents, perhaps more than any other

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people in various social relations and constellations, are irreplaceable in their responsibility, though replaceable as individuals. This is the reason social parenthood faces no serious ethical problem, as history teaches. What is indispensable is the concept of parenthood itself, changing over the years with the child's physical and psychic development. The specific asymmetry of the parent-child relationship places the child in absolute dependency on his or her parents; the way parents interact with their child has radical effects on personal

development. Conversely, in addressing the parents and showing the need to be cared for, the child is implicitly or explicitly urging them to respond responsibly.

Considered from a moral point of view, parents who are indeed free to respond or refrain from their responsibility are nevertheless confronted with a moral quest, which ethics reflects upon as a moral claim: What can be demanded of parents? Where are the limits? What kind of institutional support do parents need to be able to respond responsibly? The parents' responsibility cannot be shaped by the model of contractualism or reciprocal relationships between the partners. Asymmetrical relations call for a model that liberalism cannot offer; rather, they call for the self-reflective and social deliberation of what kind of response is right, good, and possible without violating the parents' own justified interests.

What must be clarified in the coming decades is whether new technologies will force us to extend this concept to prospective parenthood, rather than referring to the traditional borderline of birth as the beginning of actual parenthood. To me, the focus on birth is both misogynic—the child must be perceivable by the public eye—and obsolete in regard to the new visualization of the fetus in vivo. What we need today is a reflection on the particularities of prospective and prenatal parenthood, and this turn of the perspective should correct the focus on the moral status of the embryo—a question that in my view is too much influenced by the concept of reciprocal respect of persons.

It is quite evident that parental responsibility in the era of ART and genetic diagnosis starts earlier than pregnancy. In the case of assisted procreation, it starts with medical intervention in the woman's body. Already in this phase (hormone treatment and monitoring, retrieval of ova, etc.), the "future child" is envisioned, similar to the imagination in any planned pregnancy. Prospective parental perception is strongly entangled with aesthetic and ethical

^{7.} The development from an asymmetrical to a symmetrical relationship between parents and children, enabling children to become "autonomous" selves, is a continuous process; hence Hans Jonas's emphasis on this "telos" of parenthood, in *The Imperative of Responsibility: In Search of an Ethics for the Technological Age* (University of Chicago Press, 1985). Jürgen Habermas similarly stresses reciprocity as part of the concept of parenthood, in *The Future of Human Nature* (Polity Press, 2003).

imagination about a future child, so that this biographical perspective should at least complement the biomedical perspective.

Apart from these hermeneutical aspects, the normative question today is whether the recognition of, and respect for, an embryo as such, or respect for the condition of a future child's assumed health, on the condition of his or her sex or other features couples might seek, affects the *general* concept of autonomy and responsibility in parenthood. Regarding the effects on the moral

concept of parental responsibility, there is some evidence that, independent of progress in other fields concerning disability rights, social tolerance of children with genetic health risks or disabilities is declining.8 On the reflective level, the influence of the prevention model in biomedical ethics is growing, although it is rarely discussed thoroughly. To me, it seems to be in conflict with the individual and societal care and solidarity for those children (and families) who in fact have a positive right to different kinds of medical, educational, and professional services. Is this care to be limited to born children, while the birth of children with hereditary or chromosomal disabilities is to be avoided even if this goal can only be achieved by way of health risks for their mothers? These questions need to be addressed in public discourses, as well as in the discourses of academic ethicists.

The liberal model of promoting technological progress and at the same time not interfering in family-planning decisions—well intended to broaden couples' reproductive choices - might in fact reduce the options of prospective "parents at risk," to become parents without medical intervention, if it becomes more unacceptable to give birth to a child that does not meet the health conditions the couples themselves, physicians, and the society behind them consider necessary for general quality of life. Who will decide the thresholds of "quality of life"? How will just access to the reproductive services be possible, once the prevention model is endorsed in the sphere of public health? The liberal approach does not yet have satisfying answers, and mere reference to "private choices" is not a solution but rather the expression of the problem. Here again, the social-ethical perspective—emphasizing the interdependence of individual and social norms and socially disadvantaged groups' lack of a chance to live up to social expectations — should prevent feminist ethics from being uncritical.

HE DESIRE TO BEAR CHILDREN MAKES WOMEN VULNERable, because the desire may be (and socially still is) tightly connected to their identity as women. In the context of clinical biomedicine, infertility is viewed as a technical problem, which can be repaired by a highly sophisticated medical procedure. Even though women are asked for their consent to all kinds of



8. Some ethicists have argued that a certain borderline of the future child's life quality and life expectancy must not be crossed lest the concept of responsibility and (societal) solidarity be ridiculed. Others have gone further and claimed a future child's right not to live in cases of (severe) disorders. The quality of life argument can be seen from the parents' perspective, from the child's perspective, or from the societal perspective. Here, I am only concerned with the notion of parenthood. The future child's right to health becomes a problematic claim, however, if life itself is undermined by judgments about the health status usually only based on probabilistic genetic data.

biomedical procedures, it is obvious that there is a *technological* domino effect, especially when alternatives are rarely discussed. In vitro research on embryos turns the traditionally necessary connection of an embryo and a woman (and a man or another prospective parent) into a contingent relation. With the new developments of embryonic stem cell research and nonreproductive cloning, women are made to play a specific role as "donors" or "sellers" of ova that are "harvested" from their body after hormone stimulation, and thus are turned into the owners of bodily property. And couples are asked to donate "surplus" embryos once considered possible future children. Traditional (modern) concepts of embodiment and asymmetrical relationships are challenged—and answers are demanded by the whole society, not just the scientific community.

Seen in the light of biographical and social constructions of the family, the precedence of the scientific construction of the embryo is an expropriation from prospective parents rather than an enforcement of their autonomy. To (re-)claim the relational understanding of prospective parenthood would, first, (re-)connect the embryo to the concept of parenthood, and, second, would encourage further reflection on the normative implications for the parent-child relation given ART, genetic diagnosis, and regenerative medicine.

With reference to the notion of reproductive autonomy in an ethical dimension, it might be instructive to stress the connection between the (dominantly Western) perspective on reproductive and predictive technologies and the international agenda of women's reproductive rights, which is much broader than the biomedical focus suggests. Here, the concept of reproductive autonomy has a very different connotation, for the individual moral autonomy as well as for the social-ethical consequences: If all parents are responsible for their (present and future) children, and all societies must ensure that they are capable of living up to these responsibilities, the moral burden today rests much more on societies and institutions than on women and parents.

Moral respect toward children and the moral concept of parental responsibility are only recent normative claims, resulting in the United Nations Declaration of Children's Rights in the 1990s. As is well known, in many contexts societies do not in fact fulfill their obligations to support parents in their family planning (e.g., access to birth control information), not to mention assisting them in caring for their children, be it in providing health services, education, or even food or clean water. Millions of parents, but in particular mothers, are left alone in their struggle to provide children with their most basic needs, and lack basic quality of life themselves.

For the majority of women, this is the context of their struggle for reproductive autonomy. As much as ART, genetic diagnosis, and embryonic stem cell research need to be discussed in the context of medical research ethics, they must also be seen in this much broader context of reproductive rights and family care. Analysis of the reproductive-rights catastrophe in developing and developed countries could help create a more useful context for the ongoing political debate on—and perhaps overhasty reference to—the moral status of the embryo.

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