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Selecting Against Difference: Assisted Reproduction, Disability and Regulation

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SELECTING AGAINST DIFFERENCE: ASSISTED REPRODUCTION, DISABILITY AND REGULATION

SUZANNE HOLLAND*

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I. THE “PROBLEM” AT HAND

In 1993, Martha Field suggested a standard for parental discretion in cases of abortion and in cases concerning what she referred to as “handicapped” newborns.¹ She argued against parental discretion to control the fate of a handicapped newborn when that fate involves ending the newborn’s life. Similarly, on the grounds of equal protection from discrimination, Field insisted “that whatever the moment at which a right to life begins for children who do not have handicap, the same stage of development defines the right to life of children who do have handicap . . . [and that] [t]his antidiscrimination approach applies not only after birth, but even before.”² In other words, on the basis of equal protection from discrimination, we ought not kill newborns with handicaps; nor should we deprive them of the right to be born, whenever that right obtains to other fetuses.

Professor Field’s provocative analysis opens a window into a question that we have more reason to be concerned about than we did nine years ago when her article appeared: the issue of prenatal testing for genetic selection and identification. What of the pre-implantation embryo that is found to be “defective”? What constitutes an identifiable “defect” in the realm of prenatal diagnosis that could subsequently result in a handicapped newborn? The answer is rather straightforward in one sense: some chromosomal mutations are readily identifiable and are clearly linked to genetic conditions such as trisomy, hemophilia, Cystic Fibrosis, Tay-Sachs disease, Huntington’s disease, and others. Some forms of deafness, blindness, intersexuality, and other conditions less readily identifiable by the

* Associate Professor of Religious & Social Ethics and Chair of the Department of Religion at University of Puget Sound in Tacoma, Washington. This Article was originally presented at the Florida State University College of Law Conference on Genetics and Disability in March, 2002, and was intended to be a response to Professor Martha Field. I thank my hosts at Florida State for the opportunity to write on such an important issue.

1. Martha A. Field, *Killing “the Handicapped”—Before and After Birth*, 16 HARV. WOMEN’S L.J. 79 (1993). Recognizing that disability is a preferred term for persons with impairments, Field uses the term “handicapped” in part because it is the case that “in the newborn context the more degrading term is the norm.” *Id.* at 79 n.1.

2. *Id.* at 132.

term “disease” are also genetically linked. Prenatal genetic testing for single gene traits makes it possible to abort “defective” fetuses, but today, technology has the potential to increase the options for eugenic selection by parents. Termination of pregnancy is not the sole option. It is also possible, prenatally, to select out for certain undesirable traits and conditions, even as it will be increasingly possible to perform types of genetic engineering that would alter the genetic composition of the pre-implantation embryo, or the fetus.

Although it may border on stating the obvious, I want to suggest that eugenic practices are widespread in our culture. Earlier this year, for example, we had the news that prenatal genetic diagnosis (PGD) was used to select an embryo without the gene for early onset Alzheimer’s, resulting in a disease-free baby born to a woman who has a gene for a specific form of Alzheimer’s, thus sparing the baby the fate of the mother.³ Similarly, Britain’s Human Fertilisation and Embryology Authority (HFEA) found itself considering whether to allow parental use of PGD in order to select out a pre-implantation embryo free of thalassaemia, a rare genetic blood disorder fatal in children.⁴ I will not elaborate upon the ethical issues accompanying each of these cases, but it is important to be clear that each time we make use of genetic technologies to accomplish desired genetic ends, we are practicing eugenics, for good or for ill. We have already heard much about such issues in this conference, but my aim in *these* remarks is to pose some questions and challenges to the regulatory framework surrounding the primary site of eugenic practices, the assisted reproduction industry. I do so not from the perspective of the law, since that is not my discipline, but from the perspective of ethics.

In the interest of disclosure, I feel I should say that, on one hand, I do not think of myself as having any first-hand experience with disability, and so I feel that my remarks lack the kind of authenticity of one who has lived with impairment on an intimate and daily level. And on the other hand, there is something distinctive about my otherwise quite privileged life that does guide much of my thinking on this issue of genetics and disability, and that is that I live my life as a homosexual person in a deeply heteronormative culture. The life that is open to me to live is therefore constrained in some very real ways by virtue of the fact that I have what I think can be rightly called something of a social handicap, though it is certainly not a disability in any legal sense.

3. Denise Grady, *Baby Spared Mother’s Fate by Genetic Tests as Embryo*, N.Y. TIMES, Feb. 27, 2002, at A-16.

4. BBC News, *‘Designer’ Baby Decision Due* (Feb. 22, 2002), available at http://news.bbc.co.uk/1/hi/english/health/newsid_1833000/1833990.stm (last visited January 29, 2003) (on file with author).

Not surprisingly then, I am particularly interested in some of the murkier cases of eugenic intervention—by murky I mean the so-called behavioral conditions that are found to have genetic linkages, such as intelligence, alcoholism, aggression, homosexuality, and so on. Persons having these traits are not generally considered to be disabled and do not fall under the protection of the Americans with Disabilities Act.⁵ However, such persons might reasonably be viewed as having impairments that affect one’s emotional and social life perhaps more than one’s physical well being; although the latter can certainly be affected as well. Being a homosexual male in a heterosexual male culture, for example, often imperils one’s bodily integrity and safety. Here is an instance where the social construction of disability appears brightlined: the “problem” with being homosexual is not the fact of one’s basic sexual orientation; it is the problem of a previously established social norm against which the homosexual appears to be abnormal, or otherwise defective. The problem is similar for differently-abled persons, as well: society construes their difference to mean less than normal, less than desirable. That difference matters is a sign of its social construction, as Adrienne Asch has long pointed out.⁶

Thus, I proceed to a brief overview of the assisted reproductive technologies (ARTs) sector. Following this, I look at the issue of human flourishing—what is required for a good life in the Aristotelian sense. With this view in mind, I next consider the problems and possibilities of genetic intervention in assisted reproduction, and examine some of the issues of regulation⁷ brought about by ARTs and eugenics.

II. THE ASSISTED REPRODUCTION TECHNOLOGIES INDUSTRY (ARTs)⁸

The assisted reproduction services sector is one of the fastest

5. Americans with Disabilities Act, 42 U.S.C. § 12211 (2000) (characterizing homosexuality and bisexuality as insufficient impairments to classify as disabilities under this chapter).

6. See Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315 (2003). See also Adrienne Asch, *Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy*, 89 AM. J. PUB. HEALTH 1649 (1999).

7. In using the term “regulation” throughout this Article, I do not necessarily mean legal regulation, although I do not rule it out. I do favor, however, robust and binding guidelines, or Codes of Ethics, that specify the ethical content of eugenic intervention in prenatal testing and genetic selection in the ARTs sector.

8. Mary Mahowald prefers the acronym MART (Medically Assisted Reproductive Technologies) instead of ARTs because MART indicates the use of technologies that depend on medical assistance, versus some forms of ARTs, as Mahowald notes, that “can be accomplished without medical assistance.” Mary B. Mahowald, *Medically Assisted Reproductive Technology: Variables, Verities, and Rules of Thumb*, 6 ASSISTED REPROD. REVS. 175, 175 (1991). In this Article I am exclusively using ARTs in the former sense.

growing industries related to advances in genetics. Over the last ten years, the industry has grown so voraciously that estimates of its growth are represented by some 300-plus clinics, for a combined value exceeding two billion dollars per year.⁹ None of this is regulated by the federal government, although some piecemeal state regulations do exist.¹⁰ What began as a rather benign effort twenty-plus years ago to help infertile couples conceive has today become a vast industry offering a dizzying array of services to make conception not simply possible, but highly selective. In a society that prizes freedom of choice, it is hard to see, *prima facie*, what could be wrong with such a scenario.

The question arises, however, whether freedom of choice ought to be unbounded. That is to say, should the fertility industry remain an unregulated oasis of genetic choice for anyone who can afford its offerings, or should we seek somehow to draw boundaries around the eugenic selections it makes possible, and if so, on what basis? And whose values will determine those boundaries? Of course we will get a very different answer to the question if we proceed from the vantage point of those with handicap or disability.

I propose, against Robertson and others,¹¹ that reproduction is a bounded right. Because it is both personal and social, it has corresponding social obligations.¹² One of those obligations, the one I wish to examine here, is to vulnerable populations. By this I mean to suggest that among the ethical imperatives of society is support of and advocacy for its most vulnerable members. Such an obligation must begin by *listening* to these members of society and acknowledging their epistemological privilege—that such persons have a valuable standpoint on knowledge gathered by virtue of their lived experiences, and that they ought to be involved in the decisions and policies that most affect their lives, as Field has suggested.¹³ This social obligation, I believe, extends to regulatory guidelines for the allowable uses of assisted reproduction with respect to vulnerable population groups. Those who have reason to fear that, had the technology been possible earlier, they might not have been born, or might not have

9. Michael Selz, *Birth Business: Industry Races to Aid Infertile*, WALL ST. J., Nov. 26, 1997, at B-1.

10. See generally LORI ANDREWS & DOROTHY NELKIN, *BODY BAZAAR: THE MARKET FOR HUMAN TISSUE IN THE BIOTECHNOLOGY AGE* (2001).

11. See JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* (1994). For opposing views on this subject, see Cynthia B. Cohen, *Selling Bits and Pieces of Humans to Make Babies: The Gift of the Magi Revisited*, 24 J. MED. & PHIL. 288 (1999). See also MAURA A. RYAN, *ETHICS AND ECONOMICS OF ASSISTED REPRODUCTION: THE COST OF LONGING* 43-62 (2001).

12. See Bonnie Steinbock, *Sex Selection: Not Obviously Wrong*, HASTINGS CENTER REP., Mar.-Apr. 2002, at 23.

13. Field, *supra* note 1, at 115-24.

been selected with the particular genetic configuration that they now possess—these are the persons whose epistemological standpoint must be sought. These are the persons who must be given voice in any discussion of industry regulations or guidelines. Justice demands this of us.

Indeed, the case can be made that the increasing reliance on reproductive technologies to select genetically desirable children on the part of those who can afford those technologies raises several justice questions.¹⁴ One such question is that of fairness in distribution of benefits and burdens of these unregulated technologies. Another question has been raised by Professor Field—that of justice as equal protection and freedom from discrimination for handicapped newborns.¹⁵ Similarly, Dorothy Roberts raises issues of racial justice in critiquing the reliance on reproductive technologies to strengthen the genetic ties of the white dominant culture.¹⁶ I wish to bring a focus on justice into deliberations on the fertility industry, vis-à-vis the role it plays in eugenic selection for the elimination of disability and difference. It is a matter of justice to suggest that human beings ought not to be constrained unduly, but allowed to reach their full capacities, as Martha Nussbaum tells us.¹⁷

III. HUMAN FLOURISHING, DISABILITY AND REGULATION

In *Women and Human Development*, Nussbaum outlines what she calls “central human functional capabilities,” by which she means to suggest that there are basic capacities common to all human beings across all cultures.¹⁸ Nussbaum argues that a good society is one that supports a minimal threshold by which its citizens can realize ten central capabilities.¹⁹ She does not consider whether her claim of basic capacities inherent in being human also holds for disabled citizens in society (other than economically and gender disadvantaged persons), but I think it might be useful to open the issue here, and to try and extend the capabilities to our topic.

I will not enumerate all ten capabilities, though I wish to elaborate upon a few that seem to me to be fruitful for my exploration. Nussbaum claims that among the central human functional capabilities are these six: life, bodily health, bodily integrity, practical reason, affiliation, and control over one’s environment, both political and

14. I do not propose to answer all of these questions, or to advance any theory of justice pertaining to disability rights, although this is surely a paper in need of an author.

15. Field, *supra* note 1, at 96-105.

16. See Dorothy E. Roberts, *The Genetic Tie*, 62 U. CHI. L. REV. 209 (1995).

17. See MARTHA C. NUSSBAUM, *WOMEN AND HUMAN DEVELOPMENT* 75-80 (2000).

18. *Id.* at 78.

19. *Id.* at 75.

material.²⁰ To parse these more fully, Nussbaum offers the following content: “Life,” she describes as, “[b]eing able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.”²¹ “Bodily Health,” she defines as, “[b]eing able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.”²² “Practical Reason” means, among other things, the ability “to form a conception of the good and to engage in critical reflection about the planning of one’s life.”²³ Finally, “Control over One’s Environment” specifies both political and material content, though it is the material content that interests me here.²⁴ Nussbaum writes that material control over one’s environment means “[b]eing able to hold property . . . in terms of real opportunity; and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others.”²⁵ When Field suggests, for example, that the right to live in community is a fundamental right for human flourishing of some persons with disabilities,²⁶ this would seem to cohere with Nussbaum’s capacity for control over one’s environment.

It seems to me that the content specified by Nussbaum’s capabilities list is relevant to the issue of genetics, disability, and government regulation. I imagine we would like to insist that all persons living with disabilities deserve access to, for example, “Life” as Nussbaum defines it: “Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.”²⁷ While it is implicit that this means government must provide basic necessities to secure the fulfillment of life so defined, for our purposes we might want to make it explicit that it devote enough monies that such a capacity can be attained for every baby born in this country. Perhaps we should prioritize funding and research dollars for these kinds of public health concerns, rather than approving of more research dollars for genetic selection and enhancements. To secure life and bodily health, as Nussbaum defines them, means that many more resources would be needed for public health care, particularly for the prenatal care for all mothers-to-be. More would also be needed in terms of funding for disabilities so that disabled persons can be assured of living to the end of a hu-

20. *Id.* at 78-80.

21. *Id.* at 78.

22. *Id.*

23. *Id.* at 79.

24. *Id.* at 80.

25. *Id.*

26. Martha A. Field, Address at the Florida State University College of Law Conference on Genetics & Disability (Mar. 1, 2002).

27. NUSSBAUM, *supra* note 17, at 78.

man life of normal length. Of course this is just a start, and this list is necessarily partial.

Nussbaum's theory of capabilities, with its emphasis on full personhood and human flourishing could provide a moral grounding for genetic interventions in assisted reproduction. Focusing on the obligation of society to assist its members in realizing their capacities for flourishing, it would seem reasonable to discourage any practice of selecting out undesirable behavioral traits. Similarly, we also ought to discourage prenatal selection of embryos by parents-to-be who believe that the life of the future child will be perhaps more socially difficult.²⁸ Nussbaum argues persuasively that persons living under disabling conditions in developing countries, for example, can attain to most of the capacities with sufficient social resources.²⁹ By extension, children whose chromosomal configurations seem less than optimal (when viewed in the petri dish) ought to be allowed to reach their full capacities, however inconvenient for society. In relation to our topic, the capabilities theory is most helpful, I think, in providing us a set of standards by which society can measure itself as a welcoming society for people who are differently abled, or stigmatized with social handicaps. After all, what is so objectionable about providing persons with the resources to flourish, given the lives that are theirs to lead?

In short, I think that Nussbaum's capabilities do provide a way to begin to reframe our thinking about ARTs and genetic intervention. Certainly, they highlight for us the crassness of a society that seeks the genetic quick fix, rather than the cultivation of adequate social resources that might foster the embrace and appreciation of all persons with differences, and all differences in persons.

IV. PROBLEMS AND POSSIBILITIES

I have hinted at some of the problems of the assisted reproduction industry and its relationship with genetic selection. Specifically, I locate four problems to which one solution is regulation.³⁰ First, a personal problem. I have already alluded to a fear that I share with many disabled persons—the fear of elimination. Such a fear is both irrational in my case (we cannot select out the gene or genes for homosexuality because we do not know them, and if we did, it may raise more issues than it could “solve”), and such a fear is also partly rational: homosexuals everywhere face outright bigotry. The data

28. For a related discussion, see Robert Wachbroit & David Wasserman, *Patient Autonomy and Value-Neutrality in Nondirective Genetic Counseling*, 6 STAN. L. & POL'Y REV. 103 (1995).

29. NUSSBAUM, *supra* note 17, at 78-80.

30. *See supra* note 7.

Jeffrey Botkin cites in his talk, for example, indicate the presence of a rational basis for fear of elimination since twenty-seven percent of college-age students surveyed would terminate a homosexual pregnancy if they had knowledge of one.³¹ However, since sexuality itself is infinitely complex and appears to be the mysterious result of environmental and biological factors, along with free will, my fear is a slippery slope concern that does not itself constitute an argument. As with most slippery slope concerns, it constitutes a warning.

But second, I have a concern that the popularization of reproductive technologies through internet sites, magazines, advertisements and marketing encourages and magnifies “genetic ties,” to use Dorothy Roberts’s term³²—to the exclusion of other forms of family and relationship. In this sense, it fosters a culture of genetic determinism that is as dangerous as it is based on false assumptions about the significance of genes to human flourishing. It is dangerous precisely to the extent that it focuses our attention away from social solutions to solvable problems, and portrays false hopes of biological solutions to social issues. Violence, for instance, is surely more of a social problem than a biological one and even if it were proven to be genetically correlated, we could not “eliminate” the condition in eliminating some of the genes. (After all, we are not even able to eliminate breast cancer by genetic intervention, though we know of two of the genes for inherited breast cancer—BRCA1 and BRCA2).

Third, I believe that ARTs encourage the commodification of entities that are intimately connected to our sense of personhood, such as eggs and embryos, for example.³³ Indeed, ARTs make possible, in both a literal and metaphorical sense, the commodification of reproduction. The rhetoric of commodification is carefully circumscribed in the assisted reproduction industry, so that no one would ever ask, “how much did *your* baby cost?” But, buying a pregnancy is actually what occurs in the unregulated marketplace of reproductive technologies. The question I pose sounds crass to the ears, but for those of us who are concerned with the reaches of new genetic technologies and their eugenic implications, the question of “how much did your baby cost?” might come to lose its crass edge as, increasingly, people who can afford to do so elect to give their progeny all of the advantages that genetics can provide via assisted reproduction.

My final problem with ARTs is that they are wholly unregulated, a point to which I and others in this symposium have already al-

31. See Jeffrey Botkin, *Prenatal Diagnosis and the Selection of Children*, 30 FLA. ST. U. L. REV. 265 (2003).

32. Roberts, *supra* note 16, at 212.

33. For a fuller discussion on this point, see Suzanne Holland, *Contested Commodities at Both Ends of Life: Buying and Selling Gametes, Embryos, and Body Tissues*, 11 KENNEDY INST. ETHICS J. 263 (2001).

luded. They are almost entirely for profit, and extremely expensive. Thus, as currently constituted, the ARTs industry represents a challenge to the principle of justice in the following respects. Rather than promoting equality and nondiscrimination, a principle Martha Field urges on us,³⁴ ARTs encourage a culture of discrimination and selectivity; rather than being broadly accessible, they are only available to the elite. This poses a challenge to justice as fairness.

A capabilities approach, as I have argued, can provide a clear set of basepoints against which to measure the success or failures of any society with respect to fostering that Aristotelian notion of human flourishing. Moving toward a regulatory framework that might encompass some of my earlier suggestions would help bring ARTs into accord with the telos of society as promoting human flourishing, and foster the conditions by which each member can realize his or her capabilities. This telos, grounded in respect for and commitment to human personhood, is what anchors my suggestion for regulations on the kinds of choices available to those seeking medically assisted reproduction. For example, just as in this country we have actively discouraged embryo selection on the basis of sex,³⁵ so we ought openly to discourage embryo selection for all behavioral traits thought to put one at a social disadvantage.

V. CONCLUSION

I have proposed that assisted reproductive services be subject to regulation for at least three reasons: (1) they are, in effect, dealing with the commodification of human entities; (2) they facilitate selecting out who gets to live a human life; and (3) they have a rhetorical association with the history of eugenics that is perpetuated by increasing the options offered to couples for eugenic uses of genetic technologies, specifically those options that encourage selecting out undesirable behavioral traits and enhancing “desirable” ones. Because commitments to human personhood for society as a whole can be undermined by the increasing reliance on genetic technologies that make eugenic selection more acceptable, I believe that the burden of proof for making eugenic choices in fertility clinics falls on those who wish to use them, rather than on those who argue against them.

Oversight and regulation will not be an easy task, and I am aware that the suggestion will be irksome to my libertarian critics. It is,

34. Field, *supra* note 1, at 96-105.

35. In 2001, The American Society of Reproductive Medicine became the focus of controversy for what appeared to be conflicting policies on the ethics of using sex selection by its member practitioners. For a detailed report of this conflict, see Steinbock, *supra* note 12, at 24-25.

however, a matter for public debate and discussion, and one that we would do well to begin before prenatal genetic selection takes us far down an uncharted path where it may be difficult to use a moral compass to find a clear way through.