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DifferenTakes

Pre-Implantation Genetic Diagnosis and Selection: From Disease Prevention to Customized Conception

by Tania Simoncelli

Many expectant parents hope that their child will be a girl or a boy, but should people be allowed to use high-tech fertility techniques for the sole purpose of customizing a child's sex?

Pre-Implantation Genetic Diagnosis (PGD) is a technology that is used in conjunction with in vitro fertilization (IVF) to screen embryos for genetic conditions. In PGD, a single cell from a 3-day old embryo is removed, fertilized in vitro, and then analyzed for specific genetic abnormalities. Embryos free of the genetic mutation in question are then implanted into the woman's uterus. Since its first use in 1990 to screen for cystic fibrosis, some 50 clinics worldwide have begun offering PGD to avoid a range of conditions, including Down's Syndrome, Tay-Sachs disease, and Sickle Cell anemia. Approximately 2,000 children have been born worldwide from the procedure.[i]

Until recently, PGD was used exclusively for medical purposes. In 2001, Dr. Norbert Gleicher requested the American Society of Reproductive Medicine (ASRM) to endorse the use of PGD for sex selection for "gender balancing" ("gender balancing" refers to selecting for a child of one sex when a family already has one or more children of the other sex.) Gleicher, a fertility specialist overseeing nine fertility clinics in the New York and Chicago areas, argued that PGD should be allowed for sex selection because it is a "more accurate" technology than pre-conceptive methods of sex selection, such as sperm sorting, which were deemed ethically permissible by the Society's Ethics Committee.[ii]

The ASRM ultimately denied Gleicher's request, and upheld its 1999 policy which states:

"The initiation of IVF with PGD solely for sex selection holds [even greater] risk of unwarranted gender bias, social harm, and the diversion of medical resources from genuine medical need. It therefore should be discouraged."[iii]

Although Gleicher's organization, the Center for Human Reproduction, issued a statement that it would abide by the ASRM's recommendation, it continues to implicitly promote PGD

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c/o Population & Development Program
Hampshire College-CLPP
Amherst, MA 01002-5001 USA
413/559-6046 fax 413/559-6045
http://hamp.hampshire.edu/~clpp/popdev.html

for sex selection.[iv] Other U.S. clinics, such as the Tyler clinic in Los Angeles[v] and the Sher Institute for Reproductive Medicine in Las Vegas,[vi] have performed PGD for sex selection in blatant disregard of the policy. Some, such as the Fertility Institutes, unabashedly advertise the availability of the technique for these purposes.[vii]

Screening for sex is not new. Indeed, some of the first applications of PGD were to select for sex, only the intent was to avoid passing on severe, sex-linked conditions, such as hemophilia and Duchenne's muscular dystrophy. Applying PGD for the sole purpose of gender preference marks a clear departure from medical to nonmedical uses of this technology. If non-medical sex selection goes unchallenged, there is little to prevent PGD from being used for other genetic traits currently under investigation, such as skin color, musicality, or IQ.

Sex selection, even for the purportedly benign purpose of gender balancing in families, is discriminatory because it reinforces a devaluation of one sex in favor of the other. From a wider policy perspective, such a practice condones the use of low-tech sex discrimination in other parts of the world, where strong cultural pressures to have male children have led to the widespread use of female infanticide and selective abortion. Significant demographic imbalances and an estimated 100 million "missing" women in South and East Asia have resulted from these crude sex selection techniques.[viii]

PGD remains an experimental procedure, and the jury is still out as to whether or not damage caused to the early embryo by removing one of its cells has long-term health consequences. Furthermore, PGD requires IVF, a burdensome and risky procedure. Hormonal treatments required for egg extraction have caused major, long-term health problems in women. Low implantation rates and the high costs of the procedure encourage fertility specialists to implant several embryos at one time, resulting in high rates of multiple births. Recent studies have shown that even in cases of single births, IVF infants have an increased risk of low birth weight[ix] and twice the risk of major birth defects than those conceived naturally.[x]

Given the various social, ethical and safety concerns associated with PGD, why are a growing number of U.S. fertility clinics offering it for a previously unthinkable use? The answer lies in: 1) the recent explosion of a range of applications of PGD that are serving to normalize the technology; and 2) a 'laissez-faire' U.S. regulatory climate which allows a profit-driven fertility industry to disregard even its own rules.

Non-medical sex selection is only one of several new troubling uses of PGD. In just the past two years, medical applications of PGD – once reserved for the prevention of severely debilitating or fatal conditions that strike in early childhood – have expanded in at least three new dimensions. In 2002, a U.S. clinic provided PGD to a woman diagnosed with a genetic mutation for a severe form of Alzheimer's disease which strikes adults in their 30's and 40's. This case raises new questions of whether it is appropriate to provide PGD for prevention of an adult-onset disease and to a woman who may not be able to care for or even recognize her child in a few years.[xi] Next, some fertility clinics have recently started to advertise PGD for selecting against breast cancer or prostate cancer, by selecting for boys or girls, respectively.[xii] Finally, a growing number of couples have undergone PGD to select a tissue match for another child with a disease. These tissue-typing scenarios raise a new series of concerns around the potential instrumentalization of the "sibling saver," and the pressure the children might face to donate tissues or organs on a continuous basis, should the initial transplant fail to correct for the disease.

One need not be clearly opposed to each of these new PGD applications to be discomforted by the pace at which the technology is moving ahead. The growth of PGD can only be expected to accelerate in the foreseeable future as the march continues to associate single genetic mutations with diseases. As one PGD program director predicts, "Soon PGD will be used as regularly as amniocentesis now is."[xiii] Aggressive research in behavioral genetics seeking to link genes to complex personality traits and behavior,

such as shyness, lack of self-esteem, schizophrenia and alcoholism, is likely to be applied to the development of new predisposition screening tests. Routine screening for all IVF patients, currently being implemented in select fertility clinics as a means of boosting IVF success rates, will dramatically increase the number of children born from the procedure in the coming years. Conditions involving multiple genes will soon be open to screening through the advent of new techniques. "Gene chips," miniaturized and robotized versions of the screening tests, allow for the simultaneous assessment of the condition of hundreds of thousands of genes in a single determination.

The rapid expansion of PGD applications is alarming considering that there is no formal federal regulation of PGD. While the FDA regulates drugs and devices used in fertility procedures, it does not regulate the procedures themselves, nor does it oversee general operations of fertility clinics. In the absence of federal oversight, the fertility industry's existing ethical and policy guidelines have been generally established by the ASRM. While the Society claims to hold its members to its policies,[xiv] a disregard of ASRM's sex selection policy by multiple ASRM members indicates otherwise.

A lack of government involvement in PGD is symptomatic of the general dearth of U.S. public policy in reproductive matters, due largely to the history and fierceness of the U.S. abortion debate. Ironically, opposing forces on abortion have together encouraged the privatization of reproductive technologies. While anti-choice forces prohibited federal funding of research involving embryos, the pro-choice movement has worked feverishly to keep government "out of the bedroom."

Keeping the government at arm's length has been crucial for those of us committed to achieving and maintaining abortion rights. But a right to terminate a pregnancy is one matter; a right to select the genetic make-up of a child is quite another. Most promoters of unlimited uses of PGD frame their arguments in the language of reproductive choice and procreative autonomy. This is a dangerously incomplete framework that disregards the need to balance individual rights with social costs. For each new application of PGD, rather than simply assuming any new "choice" is a welcomed one, we should be asking: What *kind* of choice is this? Who will have access? Are women's choices really being expanded, or, ultimately, narrowed with increasing social pressures to utilize PGD?

Unfettered development of PGD applications is providing parents and fertility specialists an increasing and unprecedented level of control over the genetic make-up of their children. Indeed, if ever there was a case for a "slippery slope," this is it. Advances in PGD, together with cloning and genetic engineering, are tending towards a new era of eugenics. Unlike the state-sponsored eugenics of the Nazi era, this new eugenics is an individual, market-based eugenics, where children are increasingly regarded as made-to-order consumer products.

In recognition of PGD's eugenic aspects, many countries have outlawed or severely limited its use. PGD is prohibited for any use in Austria, Germany, Ireland, Switzerland and Western Australia. France, the Netherlands, Belgium, Italy, Greece and the United Kingdom have all limited the use of PGD to the prevention of severe genetic conditions. The United Kingdom established a separate regulatory authority – the Human Fertility and Regulatory Authority (HFEA) – to license and oversee fertility procedures, including PGD. In 2002, the HFEA ruled that PGD could be used in tissue typing only in cases where it is also used to protect the selected child from inheriting a serious disease. The intent of this decision was to ensure that the procedure is performed first and foremost for the welfare of the child being selected, rather than for the benefit of another person.

The U.S.'s "laissez-faire" approach is clearly an anomaly. Unfortunately, the international dimensions of technology development, marketing and use are such that other countries' regulatory systems are being pressured to lower their standards. It can only be assumed that an announcement in 2002 by the HFEA that it will reconsider its position on sex selection is in response to an increasing demand by fertility specialists, eager to attain a piece

of a highly lucrative market. As one U.S. bioethicist remarked, "All it takes is one [clinic] to offer gender selection for nonmedical needs and they will all follow suit."[xv]

Recent developments in PGD have brought us to the brink of customizing conception. The U.S., in particular, must step up to the plate to responsibly regulate the development of PGD, rather than dragging the rest of the world down to a lowest common denominator. PGD should not be offered for clearly nonmedical purposes, such as sex selection. All other uses of PGD remain controversial and warrant a space for extensive, public deliberation. Consideration of PGD and other genetic and reproductive technologies must balance social consequences with individual rights if we are to prevent the ushering in of a new consumer eugenics.

Tania Simoncelli currently works for the International Center for Technology Assessment (ICTA) in Washington, D.C. This article was written while she worked as a Program Director for the Center for Genetics and Society in Oakland, CA. Ms. Simoncelli holds an M.S. in Energy and Resources from the University of California, Berkeley and has worked as a policy analyst, researcher and activist on a host of environmental and public health issues.

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