May 13, 2007

THE NATION

Genetic Testing + Abortion = ???

By AMY HARMON

SARAHLYNN LESTER, 32, considers herself a supporter of abortion rights. She gives money to the National Abortion Rights Action League and volunteers for Planned Parenthood.

But as a woman who continued a pregnancy after learning that her child would have Down syndrome, she also has beliefs about the ethics of choosing, or not choosing, certain kinds of children.

“I thought it would be morally wrong to have an abortion for a child that had a genetic disability,” said Ms. Lester, a marketing manager in St. Louis.

As prenatal tests make it possible to identify fetuses that will have mental retardation, deafness, early-onset Alzheimer’s disease and a range of other conditions, such personal deliberations are adding a new layer to the fraught political debate over abortion.

Abortion rights supporters — who believe that a woman has the right to make decisions about her own body — have had to grapple with the reality that the right to choose may well be used selectively to abort fetuses deemed genetically undesirable. And many are finding that, while they support a woman’s right to have an abortion if she does not want to have a baby, they are less comfortable when abortion is used by women who don’t want to have a particular baby.

“How much choice do you really want to give?” asked Arthur Caplan, chairman of the department of medical ethics at the University of Pennsylvania School of Medicine. “That’s the challenge of prenatal testing to pro-choicers.”

For many women and their partners, the decision to terminate a pregnancy after a prenatal diagnosis of a serious genetic defect can be harrowing, often coming after a painful assessment of their own emotional and financial resources.

And there is widespread support for such an option: 70 percent of Americans said they believe that women should be able to obtain a legal abortion if there is a strong chance of a serious defect in the baby, according to a 2006 poll conducted by the National Opinion Research Center.

“This issue underscores the importance of families making personal, private decisions without political interference,” said Nancy Keenan, president of Naral Pro-Choice America, in a statement. “The decision should be with women, their families, and their doctors.”

http://www.nytimes.com/2007/05/13/weekinreview/13harm.html?_r=1&oref=slogin&pagewanted=print
But as more tests become available for conditions that do not involve serious disabilities, childhood diseases or death in early childhood, the emerging ethical questions may inject more nuance into a perennially polarized discussion.

“It will capture where the mainstream of Americans are on prenatal testing and abortion,” Dr. Caplan added. “Which is, some reasons seem good, and some don’t.”

Traditional anti-abortion advocates, from conservative politicians to Pope Benedict, have in recent months criticized the growing use of prenatal testing as a subtle form of eugenics. But the specter of fetuses being selectively targeted for elimination also has the potential to disturb solid supporters of abortion rights.

Some disabilities rights advocates, for example, are pressing the need to reconcile protecting abortion rights with a democratic imperative to embrace human diversity.

“If the response is simply, ‘You all are just anti-women’s-right-to-choose,’ I think that misses some of the important disabilities rights issues that are being raised,” said Andrew Imparato, president of the American Association of People With Disabilities.

Mr. Imparato said he was disturbed to learn recently that in several states with legislative efforts to restrict abortion rights, groups like Planned Parenthood often lobby for an exemption for women who learn their child would have a disability.

But he said that the person who alerted him was a Planned Parenthood lobbyist who was herself troubled by the tactic because it seemed to run counter to the progressive political agenda that supports both choice and tolerance of human difference.

“You’ve got these two basic liberal values on a kind of collision course,” said Rayna Rapp, an anthropologist at New York University who has studied attitudes toward prenatal testing.

Ms. Rapp argues that it doesn’t need to be that way. One solution, she said, is to make sure the world is a more welcoming place for people with disabilities. Other disabilities rights advocates emphasize the need to educate prospective parents about the positive aspects of raising disabled children.

Still, social policy may be unable to sway a seemingly strong personal preference for avoiding children with perceived genetic defects. About 90 percent of women who learn they are carrying a fetus with the extra 21st chromosome that causes Down syndrome choose an abortion. Studies have shown that many women choose to abort for diagnoses of less serious conditions.

And a growing number of fertile couples are using in vitro fertilization to gain greater control over the genetic makeup of their children. Under a procedure known as preimplantation genetic diagnosis, doctors screen embryos for a high risk of developing breast cancer or arthritis, and implant only embryos with the desired genetic makeup.
The questions may only become murkier if testing extends to traits like homosexuality or intelligence.

But Kirsten Moore, president of the pro-choice Reproductive Health Technologies Project, said that when members of her staff recently discussed whether to recommend that any prenatal tests be banned, they found it impossible to draw a line — even at sex selection, which almost all found morally repugnant. “We all had our own zones of discomfort but still couldn’t quite bring ourselves to say, ‘Here’s the line, firm and clear’ because that is the core of the pro-choice philosophy,” she said. “You can never make that decision for someone else.”

The rhetoric of “choice,” however, can take on a more troubling resonance when it comes to selecting children with new reproductive technologies, disabilities rights advocates say. “It so buys into this consumer perspective on our children,” said Marsha Saxton, a senior researcher at the World Institute on Disability in Oakland, Calif., who is an abortion rights supporter.

With a new, more conservative Supreme Court, which has just upheld a law banning a procedure critics call partial-birth abortion, disabilities rights advocates say they fear that the reproductive rights movement sees such discussions only as an opening to abortion opponents.

“The fear is that this will be used as an excuse to limit women’s access to abortion,” said Sujatha Jesudason, associate director of the Center for Genetics and Society, a nonprofit group promoting limits on reproductive technology. “But as these selective technologies are getting popularized we need to try to agree on a set of principles without giving up the fight for reproductive rights.”

If that doesn’t happen, some abortion rights supporters say they are worried that their opponents may hijack the discussion. “Some religious conservatives say that they trust God to give them the child that is meant to be,” wrote Ann Althouse, a law professor in Madison, Wis., who identifies herself as an abortion rights supporter on her legal blog. “But isn’t there something equivalent for social liberals? Shouldn’t they have moral standards about what reasons are acceptable for an abortion?”