Unnatural selection: is prenatal testing a triumph for reproductive freedom – or brazen discrimination?

By Ilana Yurkiewicz | September 17, 2012 | 4

On Sunday, Slate republished an article from New Scientist, written by Harriet A. Washington, that reflected on the “anxieties and dilemmas” that may stem from peeking into a fetus’s genome before birth. “Do You Really Want to Know Your Baby’s Genetics?” the title asks.

The piece is a response to a new technological advance in looking at a baby’s genetic makeup while it’s still in utero. Over the summer, two teams of researchers at the University of Washington in Seattle and Stanford University independently reported that they could now map a fetus’s entire genome during the first trimester by drawing Mom’s blood that contains bits of fetal DNA.

Prenatal genetic testing is not new. Chorionic villus sampling can detect chromosomal abnormalities as well as some genetic diseases such as sickle cell disease, cystic fibrosis, and Tay-Sachs disease. Amniocentesis can detect chromosomal abnormalities as well as several other genetic disorders, including sickle cell disease, cystic fibrosis, and Tay-Sachs disease. Now, we face the possibility of whole genome scanning.

Advances in technology were expected. As a result, discussions on the ethical implications of knowing a baby’s genetic makeup have been in full swing for a while.

In light of the new advances, I am re-posting an article I wrote a little over a year ago that was recommended by the Hastings Center. The dilemmas remain the same, and the ethical implications of whole genome scanning a triumph for reproductive freedom – or will it lead us down a path of prejudice? As more information becomes available, how should we use prenatal genetic testing beneficially and responsibly?

(From the archives: the following piece originally appeared with slight changes)
modifications in Science Progress on July 18, 2011

In July 2011, 37 parents and supporters in New Zealand brought a complaint to the International Criminal Court accusing their state, and in particular the Minister of Health, of crimes against humanity. The Minister encourages prenatal screening and selective abortion of unborn babies diagnosed with Down syndrome, they wrote. “This is government funded social engineering and is also eugenics where only the perfect may be born.”

The case comes on the heels of a scientific discovery in December 2010, when two research teams independently reported that they could reconstruct fetal DNA taken from the mother’s blood. Analyzing this DNA would allow testing for a range of genetic conditions, including one of the most common chromosomal disorders, Down syndrome, earlier in pregnancy than ever before. Additionally, the simple blood draw would evade the risk of miscarriage that comes with current methods of prenatal screening, including amniocentesis (which involves sticking a needle through the abdomen and into the uterus) and chorionic villus sampling (done either by a needle through the abdomen or by prodding a tube through the vagina and cervix). An early, noninvasive test could in theory become an option for all pregnant women, not just those who carry a high risk of genetic disease.

Due to the earlier testing methods, Down syndrome births decreased 11 percent between 1989 and 2006. Currently, over 80 percent of fetuses diagnosed with Down syndrome are aborted in the United States. These figures hit 91 to 93 percent in the United Kingdom and other parts of Europe. Learning a prenatal diagnosis at nine weeks, in contrast to the 10 to 12 weeks typical for chorionic villus sampling and 15 to 20 weeks for amniocentesis, could alleviate some of the physical and emotional burdens that accompany later abortions, causing these numbers to spike even higher.

A scroll through the online comments to the news stories reveals that the reaction in New Zealand was not unique. “Where do we draw the line?” one user asks. “Screen for autism? Screen for ADD? Abort those kids? How about just screen for anyone with an IQ <100? This notion of ‘designer babies’ is just appalling!” Another laments, “Welcome to the world of ‘Gattaca,’ designer babies and a new ‘master race.’” And yet another: “Anybody who aborts a child with a disability will never know what they are missing, and it is truly your loss, and the world’s loss. I weep for all those unborn babies who never will be able to share their gifts … an unspeakable tragedy.”

Hold that thought.

The Internet critics are right to make the point, as Marcy Darnovsky at Science Progress and many others have, that new developments in the laboratory necessitate profound moral reflection outside of it. But how much of these fears are justified? Is this really eugenics by abortion?

Like it or not, we are afforded a lot of liberty when it comes to reproductive decision-making. Parents may choose how to use their reproductive capacities, what kinds of children they want, and how to raise them according to their own standards of what they believe is best, free from government interference “unless the state could show compelling justification for the restriction,” writes bioethicist John Robertson. This freedom has a legal backing too, with the Supreme Court long protecting the rights of people to make their own decisions with regard to marriage, procreation, motherhood, family, and child rearing. If it’s “designer babies” we are worried about, we are already there. Women can now seek egg donors with criteria as specific as ethnicity and minimum height and SAT scores. Preimplantation genetic diagnosis involves screening for genetic blemishes in embryos created through in vitro fertilization and...
cherry-picking only the healthy ones to implant.

There is also the freedom not to have kids at all. Regardless of one’s personal opinion on the matter, abortion is legally permitted in this country. Moreover, a woman does not have to disclose her reasons for that choice. If we say yes to abortion for no reason at all, it seems illogical to forbid it for a well-defined reason, such as genetic disease.

So what’s the problem? Answering that means figuring out whether prenatal genetic testing is categorically different—or different only in degree—from what is accepted and established.

Bioethicists have spilt a lot of ink doing just that, and many of their arguments have converged on a similar sentiment. We live in a society in which we nobly aim to promote acceptance of diverse groups. Genetic testing undermines that aim, the argument goes, for it sends an intrinsically offensive message that the lives of people with disabilities are less valuable. As bioethicist Adrienne Asch opined, “As with discrimination more generally, with prenatal diagnosis, a single trait stands in for the whole…. The test sends the message that there’s no need to find out about the rest.” More recently, the New Zealand claimants agree: “The screening programme… devalues children with Down syndrome and is offensive to parents.” Allowing or even encouraging selective abortion based on a single “undesirable” trait is discriminatory, and it should be condemned when directed toward a fetus just as it is when targeting those who have already been born.

Genetic counselors have apparently done little to ease this concern. Counselors and the disability community have a “tenuous relationship,” claims one recent article, in which counselors often hold more negative perspectives on disability than those who are directly affected. These attitudes influence how counselors communicate with patients about prenatal decisions, causing disabled people to feel judged in clinical settings. Adding to the shaky trust is the fact that the National Society of Genetic Counselors, which represents the profession in the United States, has publicly connected itself more with abortion service providers than with disease advocacy organizations.

Doctors are not sporting spotless images either. One analysis concluded that written materials about prenatal screening are often insufficient, and the limitations of testing are not adequately explained. The latter shortcoming is especially problematic in genetics, where testing is probabilistic by nature and thus demands a nuanced explanation to be accurate. Unfortunately, a whopping 45 percent of obstetric fellows say their training on how to deliver a prenatal diagnosis is “barely adequate” or “nonexistent.”

Still, the critique of discrimination relies on an assumption: an attitude toward a diagnosis in a fetus, particularly one’s own fetus, represents an attitude toward an existing person. And social science research shows this may not be true. One discerning study surveyed 197 pregnant women about their beliefs on testing for Down syndrome in their own fetuses along with their attitudes toward the Down syndrome community at large. While unfavorable attitudes toward people with Down syndrome did indeed correlate with the women’s intentions to screen, favorable attitudes toward people with Down syndrome could not predict whether screening would be used. That is, many women who expressed positive attitudes toward the Down syndrome community still wanted to test their own prospective children.

The authors explain this result by pointing to previous research showing that people often make clear mental distinctions between people with a disability who are already born and those yet to be born. As a result, it is perfectly compatible to respect those with Down syndrome while hoping to have a baby without it. One sociologist has dubbed this two-fold position “important to test, important to support.”
Which brings up another big flaw in the testing-is-discrimination rebuke: it puts extraordinary pressure on any given person. Who doesn’t want a healthy baby? A parent’s priority is cultivating the best possible life and opportunities for their children. Asking her to forgo valuable disease testing for the sake of expressing a socially appealing message is making a child into a sacrificial lamb. Some take this argument even farther, saying that prenatal disease testing is not just something parents should do, but rather an ethical obligation. It would be negligent not to screen for genetic diseases if the opportunity to do so existed.

A similar case can be made for nonmedical traits. Want to screen for height genes? For whatever reason, studies have shown that taller people in both genders reach more leadership positions and make more money—an extra $1,000 a year or so—even after factoring out experience and education. And who says it has to end there? We could then open ourselves to the really contentious issue of favoring males because of the regrettable realities of a sexist world. The bottom line being: You can hardly fault a parent for wanting to optimize her child’s social lot. Don’t hate the player; hate the game.

But that doesn’t render the original grievance invalid. Live in a world where everyone acts in his own best interest, and the result could be the so-called “tragedy of the commons” situation, where the group as a whole loses. A powerful example is the selective abortion of female fetuses in India and China, which has caused a noticeably skewed gender ratio leading to a surplus of bachelors unable to find brides. In societies that value marriage as a staple of social acceptance, officials fear an increase in crime by the new male “outcast” group, greater use of the sex industry, and even an increase in the kidnapping of women. Extreme cases like this demonstrate that it can’t be on the shoulders of individuals to do the right thing for society at large. It becomes the law’s responsibility to step in and regulate whatever it is that would damage things for all of us.

This clash in priorities, with the competing interests of parental freedom on one hand and our antipathy toward intolerance (with a worst case scenario of dangerous social ills) on the other, is where the debate often comes to a halt. Both are important values, and saying one overrides the other is a matter of personal inclination.

But maybe there’s a way around taking a blanket stance to support either side. It involves acknowledging that that not all traits are created equal—at least not for prenatal testing purposes. Screening is morally acceptable for some but not others. A clever idea for making that distinction comes from Sara Goering, who uses the values of philosopher John Rawls to distinguish between morally acceptable and objectionable forms of genetic engineering (actually manipulating a fetus’s genome to give it preferred traits, rather than simply testing for what is already there). Some traits are inherently good, she says, regardless of environment. Other traits are only deemed valuable because of subjective prejudices that vary based on your time and place in the world. She gives the examples of cystic fibrosis and Tay-Sachs disease as belonging to the first category and race, height, and sexual preference in the second. Using science to our benefit while rejecting discrimination would involve engineering only those qualities in the first group, she argues. Otherwise, we would be exacerbating arbitrary bias, making us complicit in an unjust system.

An obvious interpretation of Goering’s ideas with regard to testing is drawing the line between medical and nonmedical traits. Based on the unfortunate mental and physical confines of disease, good health can be seen as an objective way of having a better life. In contrast, tallness as better is a societal construct. There is no intrinsic benefit of being tall (maybe they can reach higher things; but they also are worse at escaping notice). Rather than yielding to these prejudices, we should be striving to rectify the existing injustices.
Of course, this is not a perfect science. There is bound to be enormous disagreement over objective versus subjective good. Just look at the dispute over deafness. While most people view hearing loss as a disability, there are those in deaf community who see it as a lifestyle that they want to share with their children.

Realistically, much of this theoretical handwringing may prove moot. Are our prejudices so overpowering that we’d pick abortion over a child with the “wrong” height or eye color? Some people would undoubtedly favor testing without even considering abortion, but rather to prepare better for the baby. Others would opt not to know at all. Characterizing these preferences would require further empirical investigations, and there would surely be very different considerations in societies where biases are more engrained. But intuitively, at least in the United States, it is hard to picture large masses of people opting for prenatal testing of traits like eye color as the deciding factor for whether their child should be born.

This is a passionate issue. People have begun to speak out, whether through semianonymous Internet comments or an official complaint to the International Criminal Court. The concerns are legitimate. Detractors do not need “what if?” slippery slope arguments, often accompanied by references to science fiction, to vindicate their objections. They also do not need emotionally charged analogies to heinous past crimes of eugenics to grant them credibility. There are issues in science that have become so entwined with politics—where people split along predictable party lines, and a presumed clash of values automatically demonizes any opposing view—that open discourse is vetoed before it can begin. Making moral headway in prenatal testing requires that it doesn’t join those ranks.

There is something to be said for following our moral intuitions. There is even more to be said for a rational analysis of their validity, for an informed and respectful exchange of ideas.

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The views expressed are those of the author and are not necessarily those of Scientific American.
The notion that reason will bear any sway in these issues is as blindly optimistic as anticipating conscientious concern from an oil company. Right or wrong, when people are confronted with reasonable dissuasion on moral grounds against their desires, usually moral arguments lose. It is always the legalistic argument that inevitably colors these issues not moral thinking. Nowadays the legal arguments really only predict the lies we are likely to hear. In other words, people cannot be expected to do right things, the opposite is the correct expectation every time. So welcome the well endowed sociopaths and laugh at their insensitive jokes or prepare your kid to wash their cars. This is the world you demanded. Or, if you want to maintain your optimism, try altering the course. Already words like sociopathy or any moral reference whatever are considered bad taste. The gravitation is way beyond the scope of this article, the English language is changing to cover the symptoms.

Sorry but if medicine has come down to ways to save $$ $$ $$, then the issue of how much we spend on a severely deformed and forever helpless child needs to be addressed. People are all over “octa-moms” stuff, due to not being able to afford a billion kids, but how about one kids costing a billion? Are we being kind using technology to keep kids alive who 30 years ago surely would die? This issue is so complex that there will never be a consensus but has to be left up to the parents to decide what is right for them (but that won’t stop politicians shoving their will down people’s throats or those of the “god is watching this stuff and it is up to take care of his screw ups” abortion protesters.

My dad got polio when he was a kid. He is partially disabled. I fully accept his disability and don’t look down on him. However, i would also rather not have my child have polio either and I will for sure vaccinate my child to prevent it. So does not wanting my child to become disabled like my father make me discriminate against my father? No. The whole argument is a political correctness mumble jumble. Down syndrome and other genetic disorders are diseases. While we should not treat those who have these diseases less than any other people, it also does not mean we need to gladly create more of them. Just as we should not discriminate against AIDS patients but let’s not spread HIV around.

Trulahn, your logic and knowledge fails you in a number of ways. First of all, down syndrome is NOT a disease in it’s most accurate definition. Second of all, immunizing a living creature against a disease is completely different than killing that creature to eliminate the “disease”. When you try to prevent AIDS from spreading, you do so by eliminating the virus. When you try to eliminate down syndrome you are...
I realize the crux of our disagreement may come down to whether you believe abortion is simply preventing a life from existing or whether you believe that it’s killing an existing life. I think science clearly proves that beyond any reasonable doubt, we are talking about a developing human being in its early stages and not some “other” thing that will somehow transform into a human at a later date.