What about Prenatal Testing?

What was originally only recommended to women at elevated risk of bearing a child with chromosomal defects is quickly becoming standard procedure for all pregnancies. While prenatal testing certainly has the potential, at least eventually, to improve the health of the unborn, the practice has an undeniable association with abortion.

Prenatal testing is the medical practice of testing a fetus for common genetic defects. Conditions and diseases commonly tested for include Down syndrome, cystic fibrosis, fragile X syndrome, and sickle cell anemia; hundreds more can be detected. In the US, ultrasonography and maternal blood tests are routinely offered by doctors to all pregnant women, typically during the first and second trimesters of the pregnancy. These tests are noninvasive, meaning they do not involve physically interacting with the fetus or the womb, and so do not put the baby in any danger.

If these tests come back positive for one or more of the tested for conditions, additional tests are recommended; most common are amniocentesis and chorionic villi sampling (CVS). In amniocentesis, a needle is inserted into the womb and a small sample of amniotic fluid is collected. In the fluid are cells shed from the fetus which contain the child’s DNA. These cells are then collected and the DNA is tested in a lab for abnormalities. In CVS, a needle is used to collect sample cells from the placenta. While rare, both of these invasive tests have a risk of causing a miscarriage: 1 in 500-1,000 in amniocentesis, and 1 in 500 in CVS. In 2013, a new form of blood test, called cell-free fetal DNA (cfDNA) testing. cfDNA testing is performed by collecting fetal DNA circulating in the mother’s blood. Though highly accurate, this test is expensive ($800-$2,000), generally not covered by insurance, and only works for singleton pregnancies.

But while prenatal screening appears to offer a great advantage for caring for the unborn, the reality of the situation does not agree. Of the hundreds of genetic conditions that can be detected, few are now treatable. Consider Down syndrome, occurring in 1 in 700 people in the US and the most common genetic disorder. According to an analysis in Prenatal Diagnosis, 61%-93% of women who find out through prenatal testing that their unborn child has Down syndrome choose to end the pregnancy. According to The New England Journal of Medicine, cfDNA testing can be performed as early as nine weeks of gestation. This is before the cutoff date of many state laws regulating most abortions, effectively circumventing the law for non-emergency situations.
Many bioethicists are also deeply concerned that prenatal testing is often targeted directly to consumers. These tests are not regulated by the FDA for safety and effectiveness. While it is obviously in a company's interest to make a product that satisfies its customer's expectations, this trend is troubling. Building consumer demand for a product faster than regulatory bodies are able to ensure quality and ethical practice is a highly commercial direction for medicine—a direction most would find undesirable for something as serious as health.

This is not to say, however, that prenatal screening is without very real benefits. By identifying how far along a pregnancy is, doctors can give a good estimate of when the child will be born. Identifying multiple pregnancies is also of great benefit for all involved, as is alerting doctors to other complications that can arise during the pregnancy and delivery. When prenatal surgery is possible, lives can be enhanced or even saved because of early detection. Even when treatment is not possible, early detection can allow parents with a special needs child time to emotionally and logistically prepare themselves.

Gilbert Meilaender, professor emeritus of Christian Ethics at Valparaiso University and member of the President's Council of Bioethics, sees prenatal screening as placing conditions on whether it is good for another human being to exist. He believes this is a judgment call that we finite humans should not try to make. Bioethicist Kris Dierickx offers a valuable reminder that we should not think of any type of medical screening as without cost. According to the World Health Organization, the following principles should be used for determining whether or not to screen:

1. The condition should be an important health problem.
2. There should be a treatment for the condition.
3. Facilities for diagnosis and treatment should be available.
4. There should be a latent stage of the disease.
5. There should be a test or examination for the condition.
6. The test should be acceptable to the population.
7. The natural history of the disease should be adequately understood.
8. There should be an agreed policy on who to treat.
9. The total cost of finding a case should be economically balanced in relation to medical expenditure as a whole.
10. Case-finding should be a continuous process, not just a 'once and for all' project.

Simply wanting to know for the sake of knowing is shaky justification. Also, who precisely is being treated: the child with the genetic defect, or the woman carrying the child?

But what about screening only to learn the sex of the child? Sex can very easily be tested for with blood tests, and is even plainly visible with ultrasound. While the practice itself seems harmless enough, convenience, as with other screens, is weak justification for going forward with the test. There is little benefit to such a test beyond satisfying our curiosity. More grimly, sex screening is commonly practiced so that parents can ensure that they do not have a girl
(most notably in China and India, where the law does not prohibit sex-selective abortion). Today an estimated 117 million women who ought to be present are missing throughout Asia due to sex-selection and infanticide." Although this kind of discrimination is illegal in the US and while many would never consider aborting their child because of the baby’s sex, is this a practice we wish to associate ourselves with?

Also of concern are more subtle forces that can promote particular medical practices. Insurance, whether private or from the government, can offer explicit or implicit incentives by covering or not covering different procedures and forms of assistance. From a strictly financial standpoint, it may very well be preferable to cover for extensive prenatal screening and abortions instead of subsidizing the additional expenses of raising a child with a severe disability. Furthermore, what happens to the medical data collected from tests? If parents do not want to know some of the results, is that information recorded by the lab? Is the data eventually destroyed or is it preserved? Some insurance providers may have an interest in acquiring this information about their members. Knowing, for example, that a child has a high probability of developing a type of cancer later in life may make a provider reluctant to cover him or her. This sort of “insider trading” would be unfair to those born with such conditions and predispositions.

It is also unfortunate that society pressures women to not give birth to children with severe genetic abnormalities. Julian Savulescu, Professor of Practical Ethics at the University of Oxford, argues for genetic screening based on IQ:

“A common objection [to screening for IQ] is that being smarter does not make life better. In this study, researchers were concerned with those with an IQ between 70-85. Below 70 is classified as intellectual disability but an IQ of 70-75 is similar to mild intellectual disability.

Even for individuals with an IQ between 75 and 90 there are still significant disadvantages. Job opportunities tend to be the least desirable and least financially rewarding, requiring significant oversight. More than half the people with this IQ fail to reach the minimum recruitment standards for the US military. Individuals with this lower level of intelligence are at significant risk of living in poverty (16%), being a chronic welfare dependent (17%) and are much more likely to drop out of school (35%) compared to individuals with average intelligence. Studies show that there is also an increased risk of incarceration and being murdered."\vi

According to this line of thinking, it would almost seem like a disservice to the child and society as a whole to give birth to someone with lower-than-normal intelligence, given such gloomy prospects.

In the same article, Savulescu offers two solutions: hormone supplementation, and selection through in vitro fertilization (IVF). Research suggests that for some, thyroid hormone supplementation could be used to increase intelligence for individuals with an IQ of 70-85. More proactively, Savulescu suggests screening embryos conceived via IVF for low intelligence and choosing not to implant them (this implies that unchosen embryos would either be kept frozen indefinitely, discarded, or destroyed for research).
While Savulescu undoubtedly has the betterment of society at heart, this is a disturbing direction to suggest. Does the difficulty faced by individuals of lower intelligence reflect a problem with them or with society at large? What cultural enterprise are we undertaking that is so important we cannot afford to slow down and accommodate people who lack gifts that happen to be fashionable – whether they be physical strength, powers of oratory, industriousness, or IQ-intelligence? Hopefully not just the increase of our wealth or comfort!

Wesley J. Smith, writer for the blog Human Exceptionalism and bioethics attorney, aptly asks what the response would be if the targets of selection were gays or people of color? After all, ethnic minorities commonly face greater difficulties than majorities, and those practicing a homosexual lifestyle commonly have poorer health than those who do not. Yet historically, we have responded to these inequalities with civil reform and greater public attention. Why should IQ be any different? Attempts in the 1930s to “improve” society with eugenics programs have long been discredited as grossly unjust. Do we want to go down that same road again?

Many also seem to be misinformed about the realities of raising a child with a significant disability, especially Down syndrome. The condition has a nearly mythic status in our culture as some wretched affliction that prevents any possibility of a happy and fulfilling life for those born with it and a life of poverty and burdensome responsibility for the parents. Yet many parents of children with Down syndrome, according to researchers, are not given accurate information about the condition, and doctors are not always well-equipped to counsel couples about raising a child with this disability. While the effects of Down syndrome seem daunting, including intellectual disabilities, low muscle tone, and congenital heart defect), most parents rate their quality of life as just as good as before.

It must be noted, though, that the greater financial cost of raising a child with a disability than a child without one is very real. With insurance providers unlikely to incentivize having children with costly disabilities, it may very well be up to Christians and churches to assist families in need. Such a clear expression of generosity and love for all would loudly communicate the value we place on every life, whether or not some popular individuals, government agencies, or powerful companies happen to find them useful.

Prenatal testing cuts to the heart of why we practice medicine in the first place. We invest a great deal of time, wealth, and talent into finding ways to improve the lives of the unfortunate and the health of the unhealthy. The unborn are perhaps the most vulnerable of all of our members. Ought we subject them to our own invented standards of value? Who are we, as humans, to determine what it is that makes another, equally human person valuable? Prenatal testing certainly has great potential as a source of information and grounds for early treatment. Perhaps one day we will even be able to cure many genetic abnormalities. But when a practice, no matter how well-intended, has such a deplorable track record, we have to ask ourselves: Are we compassionate enough to use this technology?

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