Prenataal testen: een dubbel snijdend zwaard

Perverting Information in the Pursuit of Perfection

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Peering into the womb and glimpsing the developing new life within is an exhilarating experience made possible through ultrasound technology. Yet the marvels of ultrasound are meant for more than allowing parents to lovingly gaze upon their unborn child. This is a powerful, non-invasive tool for diagnosing numerous medical conditions, some of which can be corrected prior to birth.

Maternal blood tests that look at the alphafetoprotein levels can suggest the presence of neural tube defects like spina bifida, a deformity of the spinal column, and anencephaly, an absence of all or part of the brain and skull. This test can also be a marker for Down syndrome. More invasive tests include amniocentesis and chorionic villi sampling. These allow the direct examination of fetal chromosomes in order to detect genetic abnormalities. These tests are more accurate, but they also carry more risk for the unborn child. The decision to undertake any form of prenatal testing must weigh the risks against the potential therapeutic benefits derived from the information provided by such procedures.

While prenatal testing offers the opportunity to correct some abnormalities or to prepare to adjust to others, it is unfortunately often utilized to screen for diseases and abort unborn children who are deemed defective. In 2007, the American College of Obstetrics and Gynecology (ACOG) changed their recommendations for prenatal screening from offering tests to pregnant women over age 35 to offering them to all pregnant women. Their rationale was that while women over age 35 had the greatest risk for conceiving a child with Down syndrome, most children with Down syndrome were born to women under the age of 35. The expanded screening would allow for these cases to be detected prenatally.

Currently, 92% of all children with Down syndrome in the United States are aborted. A newly developed maternal blood test, the MaterniT21, can be administered as early as 10 weeks gestation and has a nearly 100% success rate in detecting Down syndrome. The prospect of such a test has pushed Denmark to declare that they will eliminate Down syndrome in the Scandinavian country by 2030 through increased screening and abortions. In the Affordable Care Act, also known as Obamacare, such screening will be offered to all pregnant women free of charge.

The quest for the “flawless” child has led mothers to abort their child for easily correctible abnormalities like cleft palate. With the exponential growth in the use of in vitro fertilization (IVF), the pursuit of perfection has intensified. The Church rejects the use of IVF because it separates the procreative and unitive aspects of human sexuality. It dehumanizes the embryos and reduces them to manufactured products. This is most evident when the embryos created are then screened for genetic abnormalities in a process called preimplantation genetic diagnosis (PGD). Those embryos found “defective” are destroyed. Sometimes, the only “defect” is that the embryos are the wrong gender. They are discarded because it is feared they will somehow unbalance the family. Embryos have also been destroyed because they carry the genes for breast cancer or colon cancer. Such actions presume that it would be better to never be born than face the possibility of cancer in future decades. Think of the people you have known whose lives have been cut short by cancer or other serious illness. Would it really be better if they had never existed? Were their lives really so meaningless?

In the April 2012 issue of The American Journal of Bioethics, authors Janet Malek and Judith Daar make the case for both a moral and legal obligations for parents to screen embryos for genetic abnormalities. They argue that a moral case exists based on three principles, the first being that genetic screening produces a child with increased well-being. They claim that any positive outcomes experienced by an individual with a serious genetic disease cannot make up for the decrease in well-being resulting from such a malady. The second principle is based on expanded self-determination: individuals with serious genetic diseases have fewer life choices with regards to careers, hobbies and relationships. Therefore, parents have a moral duty to produce a child free of such limitations if possible. Finally, the authors claim that a sense of justice requires parents to produce a child that will not be subjected to the inequalities inherent in living with a serious genetic disease. They argue that the answer to societal inequalities is to eliminate those embryos unable to compete due to genetic defects.

One flaw in each of these assertions is that the authors do not regard each embryo as a unique individual. It is true that the child without a genetic abnormality who is ultimately born will often have greater health, expanded life choices, and more equal opportunities to succeed in society than a child born with a serious genetic abnormality. But the screening does nothing to increase the well-being, life choices, and equal opportunity of the children found as embryos to have genetic defects. In fact, those human beings suffer greatly because they are destroyed as embryos and all chances for well-being, self-determination, and success are irreversibly eliminated.

Malek and Daar further declare that a legal duty exists to screen for genetic diseases. Their argument is based on the premise that “once parents initiate the reproductive process, they have a duty to execute that process in a manner that produces the least harm to a resulting child.” Again, their logic suffers because it denies the harm inflicted on the children found to have genetic abnormalities who are destroyed as embryos.

The advocacy for extensive prenatal genetic screening currently focuses on embryos conceived by IVF because the screening procedure adds little burden or risk to the IVF process. As of now, genetic screening of unborn children in utero requires amniocentesis or chorionic villi sampling, so routine evaluation of fetal chromosomes for genetic defects is impractical. This may change with the announcement that researchers at the University of Washington were able to sequence the entire genome of a fetus using maternal blood and saliva from the father. The fetal genome is then scanned for abnormalities. A mere one month after this announcement, Stanford University announced that its research team had sequenced the fetal genome with maternal blood alone. Neither of these tests is ready for clinical use. However, when they are, will the arguments of Malek and Daar apply? Once the burden and risk of detailed genetic testing are removed will every fetus be analyzed for potential genetic diseases with the expectation that they will be aborted if not perfect?

Seeking to rid a population of genetic disease through controlling reproduction is not a new endeavor. On July 14, 1933, Germany enacted the Law for the Prevention of Genetically Diseased Offspring. Any man or woman who was afflicted with “feeblemindedness,” schizophrenia, manic-depressive disorder, epilepsy, Huntington’s chorea, genetic blindness, genetic deafness, severe physical deformity or chronic alcoholism were brought before hereditary health courts. The courts then mandated these individuals be sterilized. By 1935 the law was amended so the patients had no avenue for appeal and there were fines for physicians who failed to report patients who met the criteria for sterilization. This law was followed by the creation of Information Centers for Genetic and Racial Hygiene to identify potential targets for sterilization. By 1945, 400,000 Germans had been forcibly sterilized. It was this expanding quest to create the “master race” that precipitated so many of the atrocities of the Holocaust.

Clearly, prenatal testing in and of itself is not morally evil. The use of ultrasound images in crisis pregnancy centers has been highly effective in convincing women considering abortion to continue their pregnancies.

Advances in prenatal medicine and surgery allow lifesaving interventions in many conditions that are discovered through prenatal screening.
When the information gleaned from prenatal testing is perverted for the pursuit of some arbitrary standard of genetic purity or perfection, however, a line is crossed. We have seen the horrors that ensue when the strong seek to weed out the weak through racial and genetic cleansing. We cannot allow anyone to stand in judgment of the unborn and designate those who are fit for life and those who are inferior and should be aborted. Every human life, regardless of his or her genetic composition, is of inestimable worth because every human life, from the moment of conception is made in the image of God.