

TEN INTRODUCTORY LECTURES ON BIOETHICS

PRENATAL TESTING AND THE DISABILITY CRITIQUE

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28th November, 2015

WHAT IS PRENATAL TESTING (PT)?

- Testing of the fetus *in utero*
 - Maternal alpha-fetal protein testing
 - Tests the mother's blood; minimally invasive but needs follow-up
 - Amniocentesis: removal of amniotic fluid
 - Usually done between 14 and 20 weeks
 - Risk of miscarriage very low: .6%
 - Chorionic villus sampling (CVS)
 - Usually done between 9 and 12 weeks
 - Small risk of miscarriage (slightly higher than amniocentesis)
 - Ultrasound
 - Least invasive
 - Can reveal neural tube defects and Down syndrome (most common disorder in PT)

WHAT IS THE PURPOSE OF PT?

- To prevent the birth of a child with a serious genetic or chromosomal disease
- Reassurance: 98% of all prenatal tests reveal no abnormality
 - Without prenatal testing, many with family history of genetic disease would forego reproduction
- To prepare for the birth of a child with special needs
 - E.g., cesarean section for spina bifida
- Give prospective parents the opportunity to abort and “try again” for a baby without disabling condition
 - Between 75- 90% of women choose to terminate with Down diagnosis

WHO IS OFFERED PT?

- PT used to be offered only to women over 35 (US) or with family history of genetic disease
 - Risk of Down syndrome increases with age
 - Balance risk of miscarriage against risk of Down's
 - 2006: ACOG recommending that testing for Down syndrome be offered to all pregnant women
 - Even if risk increases with age, most babies with Down's born to women under 35

PREIMPLANTATION GENETIC DIAGNOSIS (PGD)

- Used prior to pregnancy, in conjunction with IVF
 - Eggs removed from woman's body, fertilized in vitro, grow to 8 cells
- 1-2 cells removed from embryo and tested
 - Those with genetic abnormalities are discarded or donated for research purposes
 - Healthy embryos are transferred to a uterus for implantation or frozen for future use
- No abortion (as in amnio, CVS, ultrasound); only embryo discard
 - Many regard embryo discard as morally preferable to abortion

A COMMON MISUNDERSTANDING

- “Prenatal testing ensures the birth of a health baby.”
 - Should be done “for the sake of the child” – like taking prenatal vitamins, not smoking, etc.
- Wrong on two counts
 - PT Can’t ensure the baby will be born healthy
 - Not all diseases can be detected by testing
 - Not all poor outcomes are caused by disease
 - Congenital defects caused by problems in labor and delivery
 - PT does nothing to promote/protect the health of THIS baby
 - Rather, substitutes for the affected fetus a different, hopefully disease-free, fetus in a subsequent pregnancy
 - PGD discards affected embryos, substitutes disease-free ones

OPPOSITION TO PT

- Those opposed to all or most abortions oppose PT because it usually leads to abortion
 - US Surgeon General C. Everett Koop called PT a “search and destroy mission”
- But even some who are “pro-choice” about most abortions oppose/are deeply troubled by abortion for “fetal indications”
- And some even oppose PGD to prevent the birth of a child with a serious genetic disease

THE DISABILITY CRITIQUE

- The rationale/need for PT based on ignorance/prejudice:
 - Living with a serious disability involves terrible suffering
 - Research indicates that people living with disabilities are about as happy as those who are able-bodied
 - Most find their lives well worth living
- Insofar as there are disadvantages that come from a disability, they are *socially constructed*
 - The solution is to make society more welcoming and accessible to everyone, including those who have disabling conditions

IS DISABILITY A DISADVANTAGE?

- Some disability rights advocates reject the “medical model” which regards disability as a medical problem to be fixed
 - Deafness, autism
- Others acknowledge that many disabilities are disadvantageous, and ought to be prevented
 - Reject the idea that PT and selection is prevention
 - Morally right to prevent a disabling condition in an individual
 - Pregnant women should take folic acid, not smoke, not binge-drink or take illegal drugs
 - Morally problematic to prevent disability by preventing a disabled person from coming into existence

ADRIENNE ASCH

- Abortion is morally acceptable if the woman does not want to become a mother
 - Does not want *any* child
- Abortion is morally problematic if the woman does not want *this* child because he/she is likely to have a disability
- Her rejection of this child stems from inaccurate ideas about living with disability or parenting a child with a disability
- If we reject abortion for sex selection, we should reject abortion for disability

MY RESPONSE TO ASCH

- Even if many of the disadvantages in disability are socially constructed and can be socially remedied, it is reasonable to wish to avoid disability, and reasonable for parents to prefer to have a non-disabled child
 - If it were not, we could not criticize pregnant women who binge-drink
- There are considerable burdens that come with having a child with a serious disability; it is as reasonable to wish to avoid these burdens as it is to avoid other burdens that motivate abortion

ASCH'S VIEW IS INCONSISTENT WITH BEING PRO-CHOICE

- Asch: good parents are willing to accept burdens and sacrifices for their children
- Steinbock: This begs the question; it assumes that the fetus is already a child and the pregnant woman already its mother
 - A plausible position for someone who is generally opposed to abortion, but not for Asch, who claims to be pro-choice
- On a pro-choice perspective, the pregnant woman still has the choice whether to become a mother in these circumstances, given these burdens

WHERE WE AGREE

- All prospective parents should be given accurate information
 - Prenatal testing is not “good for the baby”; it prevents disability by preventing the child’s birth
 - Most people living with disability have very good lives, lives they value. They do not wish they’d never been born
- Medical professionals should not assume that all women will want to be tested, nor that all will use the information of disability to choose abortion

CONCLUSIONS

- Prejudice and discrimination against people with disabilities is wrong
 - Measures to make society more accessible to those with disabilities should be adopted
 - Better services and information will lead some to eschew prenatal testing and selective abortion
- But some people will prefer to have a child without a serious disability, no matter how good the services or how inclusive the society
- This is not an ignorant or shameful attitude, or one indicative of the inability to be a good parent
- There is no conflict between respecting the rights of existing disabled people and respecting the rights of women to make their own choices about whether to have PT and what to do with the information