

Christian Reflection A Series in Faith and Ethics

Focus Article:

(Disability, pp. 68-78)

### What do you think?

Was this study guide useful for your personal or group study? Please send your suggestions to *Christian\_Reflection@baylor.edu*.

#### **Christian Reflection**

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## The Lure of Eugenics

In contemporary society "prenatal care" and "prenatal screening" are taken to be synonyms, but they become antonyms in practice when the refusal to test a fetus is portrayed as unnecessarily risky and aborting a disabled child is portrayed as a relief.

Prayer

#### Scripture Reading: Psalm 139:13-18

#### **Meditation**<sup>+</sup>

Scientists should find the gene that makes people pick on those who are different. Then our lives would be better.

A person with a learning disability

#### Reflection

As the science of prenatal testing develops, Brian Brock says, "it will soon seem nonsensical not to check if our nascent children have genetic defects. It will be hard for modern states that face mounting healthcare costs not to strongly encourage this routine fetal testing regime, and it will be difficult for parents to resist using it. Who, after all, would willingly choose the hardship, financial challenges, and social stigma associated with raising a disabled child? With the advent of painless genetic testing which 'just happens' to young parents as a matter of routine, every new parent will begin life with their children having had to make a choice about whether to continue or abort each pregnancy."

Prenatal testing often is used to screen for selective abortion, a practice that "destroys human community at its foundations by setting up a criterion against which every human life must justify itself before being granted the right to enter human society." A related problem is the message that this practice sends to people with disabilities: if their condition is now reason enough to abort a fetus, then what value do they have as existing persons?

To help us understand the moral quandaries of prenatal screening, Brock draws an analogy with the famous Berlin Wall: more than a concrete barrier dividing the great city, it required a vast network of people just 'doing their daily jobs' — "soldiers, police (secret and explicit), and a judicial and legislative system as represented by immigration officers...that penetrated every nook and cranny of the society that it regulated." Likewise, prenatal screening for abortion is about more than new technologies; it is about a "wall in the mind" dividing "them" from "us" that *precedes* and *sustains* how we are using the techniques. That wall, too, requires a network of actors to maintain it.

Geneticists and laboratory technicians must find a clear boundary. Prenatal diagnosis has grey areas and judgment calls, Brock notes: "Amniotic fluid must be extracted, cells cultured from it, chromosomes separated, and then a judgment made about the health (or otherwise) of the fetus's genes." In testing labs where geneticists (usually male) oversee the work of less educated technicians (typically female), they know the process involves fallible craftwork, but rarely "admit the interpretive nature of their work." Furthermore, since science has "very incomplete knowledge of how any given genetic anomaly will be expressed as a child matures," autopsies are routinely performed on aborted fetuses to confirm the diagnoses.



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- Genetic counselors (rather than geneticists) lead pregnant women to this boundary and explain what it means. "Counseling sessions...have four main goals: establish the primacy of scientific discourse, establish the authority of this discourse, communicate risk, and construct a family history narrated in medicalized terms." While counselors see their work as value neutral, they are gatekeepers for a value-laden health establishment that expects "some conceptions are expendable."
- Parents must decide whether to end a pregnancy. Brock highlights the social pressures on the "informed decision" required of parents. Learning the scientific terminology is daunting for many. Since amniocentesis yields a diagnosis late in pregnancy (though new techniques are changing this), a mother may have to painfully separate herself from the one in her womb whom she wanted. Parents face disapproval if they fail to test, or refuse to abort an abnormal fetus. Those who bear live disabled children may face anger or disappointment from medical staff, and feel pressure to institutionalize their children. Sexual politics between a mother and father may complicate the decision. In our culture, mothers often must make reproductive choices as private individuals.

Others have supporting roles: researchers advance testing techniques, medical personnel perform abortions, and legislators frame laws on abortion, prenatal testing, and support for parents with a disabled child. "Christians should welcome the fact that technologies developed to aid screening can now be used in the service of care," Brock concludes. "The essential ethical insight to grasp, however, is that there is a vast difference between using those technologies to care for children in the joyous receipt of a divine gift, and deploying them as an expression of the ideologies of control, management, expertise, and risk avoidance."

#### **Study Questions**

- 1. How does prenatal screening for selective abortion impact people with disabilities?
- 2. Consider how prenatal screening is distorted by what Tom Reynolds (in the previous study) calls "the cult of normalcy."
- 3. How can your congregation best engage with Christian love each of the primary actors in prenatal screening for selective abortion?

## Departing Hymn: 'O Lord, Life is Sacred' (verses 1 and 2)

O Lord, life is sacred, a gift from above; each person is worthy of honor and love. your works are so marvelous, we're wonderfully made; we each bear your image, conception to grave.

Your hands shaped and formed us before we took breath; You knit us together and clothed us with flesh. You give us our life and ordain all our days; Your works, Lord, are wonderful; we lift our hearts in praise.

Susan H. Peterson (1998) Tune: GORDON

† Quoted in John Swinton and Brian Brock, eds., *Theology, Disability and the New Genetics: Why Science Needs the Church* (2007), 1.

# The Lure of Eugenics

## Lesson Plans

Abridged Plan	Standard Plan
Prayer	Prayer
Scripture Reading	Scripture Reading
Reflection (skim all)	Reflection (all sections)
Questions 1 and 3	Questions (selected)
Departing Hymn	Departing Hymn

## Teaching Goals

- 1. To understand the complex network of actors through whom prenatal care is distorted to prenatal screening for selective abortion.
- 2. To discuss how we can best engage these various actors with Christian love.
- 3. To consider how prenatal screening for selective abortion impacts the lives of people with disabilities.

## Before the Group Meeting

Distribute copies of the study guide on pp. 8-9 and ask members to read the Bible passage in the guide. Distribute copies of *Disability (Christian Reflection)* and ask members to read the focus article before the group meeting. For the departing hymn 'O Lord, Life is Sacred' locate the familiar tune GORDON in your church's hymnal or on the Web in the Cyber Hymnal<sup>TM</sup> (*www.hymntime.com/tch/*).

### Begin with an Observation

'The consequences of advances in genetic knowledge and the huge proliferation of prenatal tests, has not...been therapy, treatment or 'cure' for a fetus detected as having an impairment; the anticipated outcome of a positive prenatal test for impairment remains abortion. Hardly surprising then, that many in the disability community, and their supporters, are deeply concerned that societal acceptance, even welcoming, of increased genetic testing signals powerful messages about disabled people's fundamental right 'to be,'' explains Linda Ward, a professor of disability and social policy at the University of Bristol, UK.

She is concerned that 'The lack of explicit, public acknowledgement that the outcome of increased prenatal screening and testing is an increase in abortion on the grounds of fetal impairment has eased the rapid growth and routinization of prenatal testing, without concurrent public debate on the two issues most centrally involved: abortion and disability.' (Linda Ward, 'Whose Right to Choose? The 'New' Genetics, Prenatal Testing and People with Learning Disabilities,' *Critical Public Health* 12:2, 188)

#### Prayer

Invite members to share their personal celebrations and concerns with the group. Provide time for each person to pray silently. Conclude by asking God to guide you to care for parents who face decisions about prenatal testing and its results.

#### **Responsive Scripture Reading**

Ask a group member to read Psalm 139:13-18 from a modern translation.

## Meditation

Invite members to reflect on the meditation during a period of silence.

#### Reflection

The previous study, "Disability and the Cult of Normalcy," introduced the idea that disability is a social construction: through a process that is largely unacknowledged and unexamined, our society constructs an idea of normalcy and then "disables" persons with certain physical and mental impairments that it considers

"abnormal" by excluding them from common social activities. Tom Reynolds called this process "the cult of normalcy" because we internalize the standards of normalcy constantly and in so many ways. In this study Brian Brock helps us understand how our practice of employing the techniques of prenatal testing to screen out and abort certain individuals is a particularly troublesome example of the cult of normalcy.

### Study Questions

- 1. The increasing use of prenatal testing to screen fetuses for selective abortion signals to people with disabilities certainly those individuals who have the impairments that are being screened for, but perhaps others as well that they are a burden on others and that their lives are not as valuable as others. Brian Brock writes, "Some have protested that testing and aborting fetuses with genetic anomalies is not necessarily a judgment about citizens currently living with those conditions. Addressing these objections, Hans Reinders concludes that it is very difficult to separate strong claims about the benefits of screening out the disabled from judgments about the perceived negative impact of the living disabled on society. To 'test' implies making 'selections' that rest not only on judgments about the health of the human genome, but also on judgments about the quality of life experienced by disabled persons who already exist. Empirical studies confirm that, when faced with a diagnosis of genetic anomaly, virtually every mother or couple draws on anecdotal experiences and accounts of the lives of the disabled and their caregivers in deciding whether or not to abort."
- 2. Tom Reynolds writes, "society disables people by representing impairment as a flaw or deficit, by constructing what is 'normal' and thereby creating the difference between bodies that are 'able' and those that are 'disabled.' Medical communities commonly fuel this problem by cultivating curative practices to remedy such flaw or deficiency. Arthur Frank puts it this way: 'Society prefers medical diagnoses that admit treatment, not social diagnoses that require massive change in the premises of what that social body includes as part of itself.'" Reynolds describes these attitudes about normalcy a "cult" because its promulgation is so pervasive in media, education, moral codes, law, economics, and so on.
- 3. Consider how these cultural attitudes about normalcy influence the thinking of the various actors that Brock describes. Would they make the same decisions, or make them in the same way, if they had not absorbed these attitudes?
- 4. Form three study groups to focus on the primary actors that Brock discusses: the geneticists and laboratory technicians, the genetic counselors, and the parents. Consider how your congregation can support, encourage, instruct, and (when appropriate) confront them. (If time permits, you might form groups to focus on the supporting actors Brock mentions: the researchers, the medical personnel who perform abortions, and the legislators.)
- 5. Brock writes, "Confessing in worship that the sinful man still lives resisting life with the disabled and pining for an easier life protects us from undue deference to expert calculators of risk." How are the actors invited into your congregation's worship of God? How does your congregation help them envision all of their work and decisions as forming praise (or anti-doxology) of God's good gifts? How can you be present to support them in making difficult decisions, and in living with the consequences of them?

## **Departing Hymn**

If you choose not to sing the hymn, you may read the text in unison or silently and meditatively as a prayer.