The Lure of Eugenics

BY BRIAN BROCK

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

The science of prenatal testing is reaching its maturity with the development of a non-invasive blood test that can detect genetic conditions such as Down syndrome cheaply and safely.[1] Just as it now seems perverse not to test pregnant women for conditions that are potentially catastrophic for the health of the child, such as for toxoplasmosis, AIDS, or hepatitis, 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.

I will cast light on this new landscape from two directions. First I will explore how self-protective walls can become destructive, cutting off the lifeblood of human communion. The Berlin wall is a classic case. It was both physical—constructed of concrete, topped by barbed wire, and surrounded by exclusion zones—and very human. Humans guarded its gates and ran the vast ancillary system of tracking people that certified who was allowed to cross the wall and who was not. The physical wall was only the most visible part of a highly developed apparatus for segregating people. Because it rested on the continual efforts of vast numbers of soldiers, police (secret and explicit), and a judicial and legislative system as represented by immigration officers, this wall penetrated every nook and cranny of the society that it regulated. The East German theologian Wolf Krötke came to see its brutalizing presence as a paradoxical living nothingness—a type of human living driven by death, separation, and lies.

> When I looked through the window I could see the Berlin Wall scarcely five hundred meters away. …What was playing itself out before my eyes was absurd. A boundary which threatened the natural communication of its citizens, families, and friends was drawn right through the middle of a vibrant city. It was spectral, but exactly as such also real in brutal ways. In itself it was *nothing*, but exactly as such it was dreadfully significant. And yet, it was passed off as something truly good by a great mass of shameless lies. The same structure clearly repeats itself wherever people do that which we call "evil."[2]

As a second way of casting light on the landscape of prenatal testing, I will ask what it means to live, procreate, and parent in the mode of praise or doxology to the Trinitarian God. Does this mean that we, as Christians, should welcome these new techniques, or is something problematic in their proliferation?

Martin Luther characterized human sin as organizing our daily lives by way of anti-doxologies (acts of praise of self and idols) that are the antithesis of doxology (praise of the true God).[3] Sin is made up of concrete, aberrant responses to God's gifts, which are personified anti-doxologies. In contrast, the saints are drawn together by songs that refuse to praise any other God, magnifying the Lord alone: "The LORD's right hand has done mighty things" (Psalm 118:15-16, NIV).[4] "Singing" thus names the cast of all speaking that properly marks the Christian ethos. "Under 'singing'," says Luther, "I include not only making melody or shouting but also every sermon or public confession by which God's work, counsel, grace, help, comfort, victory, and salvation are glorified before the world. … As [Psalm 118:14] puts it: 'The Lord is my Strength and my Song; He has become my Salvation.'"[5]

Those who are caught up in God's work are learning to see and praise the manifold works of God, and thereby coming to live an embodied recognition of God's grace and care. This contrasts with faith in human works that is sustained by idolatrous anti-doxologies that exalt the salvific power of other persons and forces. Thus by looking at what people praise we can expose their self-protective walls. I will employ praise-analysis as a mode of social criticism of the eugenic practices of our age, making audible our own reasons to resist praising the Lord for some lives he has created.

PRENATAL SCREENING: POLICING THE BORDERS

The evil of the Berlin Wall was invented neither by the guards who stood at the border with guns, nor the officials who issued passports, nor the legislature that decreed the norms for entry and exit. But all upheld it. Similar social dynamics are visible in prenatal screening. Medical researchers develop diagnostic tests. Legislators—acting on the advice of managers, accountants, lawyers, and physicians—legislate permissible modes of policing the boundary of human life. Genetic counselors explain and validate the notion of borders to parents who often have ambivalent feelings about bearing a disabled child. And at the end stands the techniques of violence wielded by the medical practitioners who perform abortions.

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Here I am distinguishing between abortion on demand and *selective* abortion. Selective abortion 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. Because violence undermines the political nature of human life, by definition there can be no genuine freedom to destroy humans whose genes appear to differ from that which we currently take to be the norm. Prenatal screening and abortion of the disabled is a classic case of what Wolf Krötke calls "nothingness," in that if one is labeled "disabled" one is forcibly denied entry into the community of the living. It is never solely a parent's choice to bar the gates to an individual life: such denials can only be carried out by a wide range of humans oriented by intertwining anti-doxologies.

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.[6] 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.[7]

These two strategies—setting up criteria to judge the unborn and then attempting to disengage these criteria from living disabled citizens—are general forms of what I have called embodied anti-doxologies. But more specific anti-doxologies attract us today. In order to discern what is being praised as salvific, we must listen to how people in our society understand themselves and where they go to gain control over their lives. On this theme Rayna Rapp's detailed anthropological account of the rationales behind what is called genetic screening is highly illuminating. Her *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* draws on extensive research in the late 1980's and 1990's on the main participants in the drama of amniocentesis in New York. Though the techniques of prenatal screening have been improved significantly since the time of her study, the aims of the screening process are essentially unchanged today.

Before any of the physical barriers that make up walls can be constructed, societies must reach collective agreements about boundaries between "us" and "them" that need to be protected. This "wall in the mind" thus *precedes* and *sustains* any techniques of prenatal testing. How do such boundaries form in the collective consciousness, what makes them solid, and what drives the final decision to deny a supposedly substandard human entry into the body politic? Tracing the paths of three actors in this drama—the geneticists and laboratory technicians whose technical expertise supports the claim that there is a clear boundary *here* at *this* point, the genetic counselors who lead pregnant women to this boundary and explain to them what it entails, and the woman (and perhaps father) who will make the decision about whether to end a particular pregnancy—will allow us to discern the more specific doxologies that drive their investment in maintaining a barrier between those who may enter life and those who are denied. Many other supporting actors—like the medical personnel who carry out the decision to abort, the researchers and technologists who push testing techniques forward, and the legislators who frame laws on abortion, prenatal testing, and the social provision which would support parents raising a disabled child—will have to remain in the wings even though they play vital roles in sustaining the environment in which these three main actors meet to police the border between "us" and the disabled.

GENETIC COUNSELORS: INTERPRETING TEST RESULTS

Prenatal diagnosis through amniocentesis is a complex affair. 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. The aim of these complex processes is to produce a clear genetic diagnosis from what are essentially grey areas and judgment calls, leading Rapp to call testing labs "laboratories for fact construction" (p. 192). Most of the bench work in this process is undertaken by less educated women while the geneticists who oversee the work and make the final diagnoses are usually highly trained males specializing in cell biology, embryology, and pediatrics. Though both lab workers and expert doctors are very aware that each stage of the process involves craftwork and that false moves may be made which may invalidate the final diagnosis, Rapp discovered that all parties involved had strong reasons not to admit the interpretative nature of their work (p. 208).

This problem is compounded by the fact that medical science still has very incomplete knowledge of how any given genetic anomaly will be expressed as a child matures. This is why autopsies are routinely carried out on selectively aborted fetuses to determine the actual effects of the diagnosed genetic anomaly. Heartbreakingly, it is only at this point that some parents become aware that prenatal diagnosis is far from foolproof, despite its having been so presented. Rapp quotes one woman's response as she realized that her aborted fetus was being sent to pathology:

> When the doctor took a tissue sampling I asked him why, and he said, "To send to pathology to confirm the diagnosis." And I started howling, I was just screaming my head off: "If there's anything that even possibly needs confirming, what am I doing here?" (p. 241)

Geneticists used to deal directly with parents, but now this work has been handed over to genetic counselors whose stated aim is to assist women's reproductive choice by providing information about hereditary risk to prospective parents. In practical terms they prepare parents to take the test and to explain the meaning of the laboratory results to others. Counseling sessions therefore 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. Again, the vast majority of practitioners (95%) are female (pp. 56-57).

Rapp notes an inherent confusion in these activities of the genetic counselor who thinks of herself as value neutral even as she plays the role of gatekeeper. The biomedical and public health establishments that employ genetic counselors presume that some conceptions are expendable or even burdensome. Thus genetic counselors are prone to reproduce this bias in an unreflective manner that "assumes that scientific and medical resources should be placed in the service of prenatal diagnosis and potential elimination of fetuses bearing chromosome problems. In principle, then, counselors are trained to offer a value-charged technology in a value-neutral manner" (p. 59). Prenatal diagnosis thus expresses a biomedical picture of healthcare in which prenatal *screening* precedes and is more fundamental than prenatal *care*. During genetic counseling the prospective parents must learn to evaluate themselves and their growing offspring within the screening framework *before* making what is termed an "informed" decision for or against embracing a given pregnancy.

Theologically we need to note that the paeans of praise to concepts like value-neutrality, individual choice, risk avoidance, and the authority of expertise are problematic in themselves, and they become a deadly cocktail when unreflectively teamed with decisions about whether to eliminate humans perceived to be a burden. While each concept might conceivably find a place in a song of praise to the creating and redeeming God, in the contemporary usage just described they clearly preface any sense of wonder and thankfulness for the gift of conception with a prior anti-doxology lifting up the promises of perfect control, benevolent expertise, and a life free of "accidents." Not only is this to praise the gods of fertility and quality assurance who are bound to disappoint us with children who do not conform to our expectations, but also it is to undermine with a benevolent smile the hurdles facing the socially marginalized for whom "genetic risk" is a very small part of the life challenges they daily face. In systematically directing attention away from the concrete life-barriers facing mothers and suggesting that their hopes and fears are most appropriately attached to a realm of *possible* choices, genetic counseling illustrates a classic instance of how evil is a non-reality even as it is embodied in concrete words and actions. The substitution of the imagined for the concrete is a familiar political ploy, in this case played out by perhaps unwitting genetic counselors speaking for a state (or for-profit medical system) whose offer of help to those mothers who most need social support has been reduced to the offer of an abortion. This political role is sustained by genetic counselors' embrace of the psychologists' self-understanding as non-directive (and therefore apolitical) precisely as they serve the widespread use of the technologies of elimination. In theological and pastoral terms, the net effect of this anti-doxology is the loss of attentive empathy and concern for the whole of life in service to the state's interest in minimizing economic cost.

PARENTS: MAKING CHOICES

Rapp's detailed descriptions of how pregnant women made the decision to undergo amniocentesis and then chose to abort a conceptus diagnosed as abnormal is by far the most difficult terrain to summarize. I will set out what I take to be the findings most relevant in our search to understand the anti-doxologies of our age.

Prenatal testing presents mothers with a bewildering set of social pressures. As it is currently configured, amniocentesis yields a diagnosis late in pregnancy, demanding that mothers take up a stance of distance from someone in their womb whom they may have wanted and are certainly beginning to experience as an independent living being (p. 179). Often mothers face subtle and not-so-subtle moral disapproval if they do not test, or refuse to abort a fetus diagnosed as abnormal (p. 263). Many women who had borne live disabled children told of having been the object of anger and disappointment from medical staff (pp. 266-267), and expressed their own amazement and disgust at the rapidity with which adoption or institutionalization of their children was offered (pp. 269-270). In addition, Rapp found that women from lower socio-economic strata often opted out of testing simply because the prenatal care available to them was so poor and time consuming to procure that they gave up in frustration (p. 109).

The new forms of prenatal genetic testing will resolve the problems of expense and danger that are associated with amniocentesis, as well as its relatively late verdict on a pregnancy. But they will not make interpreting test results any less difficult for less educated mothers—for whom comprehending the language of science and risk is daunting. The sexual politics of the decision to test or abort will also remain highly complex: for example, some women seek tests in order to garner greater paternal involvement, while some men invoke patriarchal privilege to deny testing—here the permutations are myriad and unsettling. For all these reasons and more, mothers deserve compassion and social support.

Yet the fact remains that they too have been drawn into the role of gatekeepers, whether by choice or as participants in a culture that demands the final judgment on a pregnancy to be pronounced by the mother or both parents. Our interest in the remainder of this section is in discerning the doxologies that orient parents, especially mothers, as they digest a diagnosis of a fetus with an anomalous genetic inheritance.

In our society women are positioned to approach their reproductive choices as private individuals. In this space of privacy Rapp found many women undergoing transformations of self-understanding and new levels of self-reflection in being forced to articulate their reasons for continuing a pregnancy or not. This is not to imply that prenatal testing forces women to become more reflective about their relationships with medicine and their conceptus; as testing becomes wholly routine the sense in which a woman has any choice in the matter will become less evident. As we will see, the theologically critical innovation is that women are expected either to collate the information on which a “rational” choice to continue a pregnancy can be made, or to give reasons, against the grain of the medical establishment, why they ought not be asked to make such a decision at all.[8] Rapp came to view the vast majority of mothers who confronted the issues raised by prenatal screening as “moral philosophers of the private” who struggled to discern the way forward in their state of isolation from any tradition of explicit thought about these issues. Living within an enforced but at times empowering privacy, they are surrounded by the cacophonous opinions of medical professionals, newspaper pundits, friends, family, and other children (pp. 306-307).

Rapp found a range of reasons given for pursuing amniocentesis and potentially aborting a fetus diagnosed as anomalous. Two priorities recur: the capacity to mother a disabled child, and the impact of a disabled child on the mother’s most intimate relationships with the child’s father, other children, and extended family members. Four broad types of justification solidified the boundary being constructed against a genetically anomalous fetus. The first was a discourse of “selfishness,” which narrates killing as an act of love in praise of “protecting the children.”

> Some people say that abortion is hate. I say my abortion was an act of love. I’ve got three kids. I was 43 when we accidentally got pregnant again. We decided there was enough love in our family to handle it, even though finances would be tight. But we also decided to have the test. A kid with a serious problem was more than we could handle.

> And when we got the bad news, I knew immediately what I had to do. At 43, you think about your own death. It would have been tough now, but think what would have happened to my other kids, especially my daughter. Oh, the boys, Stephan and Alex, would have done ok. But Livia would have been the one who got stuck. It's always the girls. It would have been me, and then, after I'm gone, it would have been the big sister who took care of that child. Saving Livia from that burden was an act of love. (*Mary Fruticci, 44, white homemaker*) (p. 247)

Prenatal testing is forcing women, concludes Rapp, to become "philosophers of the limit": in order to take the test they needed to imagine the outer limits of their maternal embrace (p. 308). Under the shadow of their perceived responsibilities as mothers and women, and imagining life with a disabled child, they were forced to articulate a set of values ostensibly located in the private realm but formed by (and forming in turn) the life of society as a whole.

The anti-doxologies that we have just heard sung are as pervasive as "commonsense." The praises of "protective limits," "knowledge as power," "acting to improve life," "protecting the children," and "free private choice" are ubiquitous in our age, explored and lived into as salvific promises by parents and many others in all walks of life. Lost to the singers of this anti-doxology is the notion that new life is a gift that is inherently enriching. Rapp found it remarkable that among those considering abortion, the focus on limits almost always excluded any consideration that positive effects might accrue to siblings of a disabled child or to themselves as parents (p. 248). These anti-doxologies also subvert the collective will to support women, parents, and families, which leaves them with the sense that the decision to embrace a disabled child is tantamount to economic and personal suicide. The anti-doxologies of these women thus mesh with the anti-doxologies that demonize the desire to share medical costs or the cost and labor of childrearing. They likewise hide the voices of parents who have raised children with disabilities and understand their experiences in terms of a journey toward acceptance, appreciation, and enrichment (p. 264).

From a theological perspective, prenatal testing is built on the assertion that in order not to take on more than we can bear, we must choose who we will accept into the human community. We can now see what a shameless lie and self-justifying evasion it is for those of us living in liberal democracies to believe that iron curtains were only a problem in communist states. In our joyous praise of the free market system, we are not well placed to resist the anti-doxology of prenatal testing. John Swinton explains:

> Neo-liberal capitalism offers a picture of human beings as fundamentally individual beings who choose to join together to form societies, the primary purpose of which is to attain the greatest benefits for the largest number of individuals. In other words, the individual *precedes* the community. …Thus we begin with individuation, separation, and

> distancing and move towards unity and relationship, a unity and relationship that is *optional, tentative,* and *dependent* on the child fulfilling certain criteria….[9]

The marketers, political spin-doctors, and MBA-trained pastors who are so influential in neo-liberal societies are deeply invested in an account of freedom that rests, finally, in the supremacy of choice. In such a landscape, prenatal testing is one more mechanism serving the worship of freedom defined as "choice." It therefore sounds nicely like the many other praises we sing of the techniques that can save individuals and families from "accidents" that will destroy the lives we have imagined for ourselves. But if human beings are never "accidents," then instructing people that they have a choice and insisting on how they should make it is an induction into an anti-doxology that refuses to praise the Trinitarian creator for fertility and new life. Thus when they entail the elimination of human beings, philosophies of limit are, by definition, anti-doxologies. They cannot be glosses on the song "The LORD's right hand has done mighty things"; rather they sing "we must act to save ourselves from 'them' or be drowned."

THE DISABLED: SINGING SONGS OF ANNUNCIATION

In the face of these anti-doxologies, it makes sense for Bernd Wannenwetsch to suggest that the disabled are "angelic messengers" who invite us to see God's working anew. The fetus we label disabled is not silent, but is a positive word of grace and liberation to those praising their own fetters. Remarkably, it was the annunciative character of a genetically anomalous fetus that transformed Raya Rapp from an abortion activist and privileged academic into a genuine inquirer. She ends her study of amniocentesis with this elegiac dedication to her aborted offspring:

> Mike named the fetus XYLO, or X-or-Y for its unknown sex, LO for the love we were pouring into it. Together, we watched XYLO grow; together we chose to end his life after a prenatal diagnosis of Down's. My personal pain and confusion as a failed mother led me to investigate the social construction and cultural meaning of amniocentesis…. XYLO's short life pointed me toward these vital concerns; his ending marked the beginning of my search for contextualized knowledge. If the work accomplished in this book helps others to think about these evolving issues, his short life will have been a great gift. (p. 318)

In the light of God's self-annunciation from the manger in Bethlehem, the Christian is enabled to say in faith (without the intervening and instrumentalizing "if") that XYLO was indeed a great gift in exposing the shameless lies permeating the culture that united to refuse him entry into life with his parents. With the cultural landscape Rapp has described now fully in view, we too can now hear XYLO's repetition of the angel's message to Mary and the shepherds: "Fear not." In this annunciation our enslavement to the control that wishes the disabled not to exist ends. The "fear not" that they speak, writes Wannenwetsch,

> implicitly feeds on the resurrection of the one *angelos tou theou* who did not recoil from having his wings clipped (Philippians 2:5-8) or from sharing the human life of fear and anxiety, yet was triumphantly raised from the dead to offer transformation and new life to those who recognize him and their own existence as human beings in the faces of his most dependent brothers and sisters (Matthew 25:40).[10]

The disabled, whether born or unborn, announce an end to our need to draw boundaries between them and us, for community is not maintained by violence, but by openness to being surprised by the birth of the unexpected.[11] These babes speak Jesus Christ's own message: "For he is our peace; in his flesh he has made both groups into one and has broken down the dividing wall, that is, the hostility between us" (Ephesians 2:14). What we call "disability" is thus central, rather than peripheral, to theological conceptions of personhood or the image of God. The disabled, from embryo to old age, invite us to give up self-definition by violently separating ourselves from those who seem unlike us.

In contemporary society the terms "prenatal care" and "prenatal screening" are taken to be synonyms, but they become antonyms in practice when, as we have seen, the refusal to test is portrayed as unnecessarily risky and aborting a disabled child is portrayed as a relief. Christians, of course, should welcome the fact that technologies developed to aid screening can now be used in the service of care. 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. Given our internalized fears of the other and the ever-growing imperative to control chance and deviance, the witness to the divine annunciation "fear not" can only be proclaimed by a Church that has been confronted by liberating grace and thereby had its idolatrous praise of "freedom of choice" exposed.

We must undertake the intellectual and practical work of unlearning the patterns of exclusion and denial of the other as we discover what it means to inhabit Christian praise. 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. The self-annunciation of Jesus Christ remains the lifeblood of the Church which as a community has been freed to name the forces that enslave it, and can serve society by bringing them to light as anti-doxologies.

NOTES

1 For a survey of the technological state of the art, see "A New Safe Blood Test to Diagnose Down Syndrome," *Laika's MedLibLog* (March 13, 2011), accessed August 28, 2012, *laikaspoetnik.wordpress.com/2011/03/14/a-new-safe-blood-test-to-diagnose-down-syndrome/*.

2 Wolf Krötke, *Sin and Nothingness in the Theology of Karl Barth*, Studies in Reformed Theology and History New Series, 10, translated and edited by Philip Zeigler and Christina-Maria Bammel (Princeton, NJ: Princeton Theological Seminary, 2005), x-xi.

3 For a more detailed discussion, see Brian Brock, *Singing the Ethos of God: On the Place of Christian Ethics in Scripture* (Grand Rapids, MI: Wm. B. Eerdmans, 2007), chapter 7.

4 Scripture quotations marked (NIV) are taken from the Holy Bible, New International Version®, NIV®. Copyright © 1973, 1978, 1984, 2011 by Biblica, Inc.™ Used by permission of Zondervan. All rights reserved worldwide. The "NIV" and "New International Version" are trademarks registered in the United States Patent and Trademark Office by Biblica, Inc.™

5 Martin Luther, "Psalm 118," translated by George Beto, in *Luther's Works, Volume 14, Selected Psalms III*, edited by Jaroslav Pelikan (Saint Louis, MO: Concordia Publishing House, 1958), 81.

6 See Hans Reinders, *The Future of the Disabled in Liberal Society: An Ethical Analysis* (Notre Dame, IN: University of Notre Dame Press, 2000), chapter 4, and "Life's Goodness: On Disability, Genetics and 'Choice'," in John Swinton and Brian Brock, eds., *Theology, Disability and the New Genetics: Why Science Needs the Church*, (London, UK: T & T Clark, 2007), 163-181.

7 Rayna Rapp *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, (New York: Routledge, 2000), chapters 3 and 6. Further citations to this book will be in the text.

8 Barbara Katz Rothman, *The Tentative Pregnancy* (New York: W. W. Norton & Company, 1993 [1986]), 51, 83-85.

9 John Swinton, *Raging with Compassion: Pastoral Responses to the Problem of Evil* (Grand Rapids, MI: Wm. B. Eerdmans, 2007), 200.

10 Bernd Wannenwetsch, "Angels with Clipped Wings: The Disabled as Key to the Recognition of Personhood," in Swinton and Brock, eds., *Theology, Disability and the New Genetics*, 182-200, here citing 195.

11 Hannah Arendt, *The Human Condition* (Chicago, IL: University of Chicago Press, 1958), chapter VI.

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