Toward a Moral Theology of Genetic Screening

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Christian communities regularly celebrate new pregnancies, births, baptisms, and dedications together. But when prospective parents enter the obstetrician's office, the ultrasound room, the genetic counselling clinic, or even the abortion facility, they do so alone. In these environments, their church community and tradition is present to them only through the prayers of friends and family and through whatever good habits of memory, thought, imagination, and action they can recall under stress. For those who desire to worship God faithfully in the strange land of modern medicine, it is crucial that their communities help them inculcate the practices they need to be followers of Christ, even at times of crisis. One such crisis is when doctors recommend a genetic test or reveal there has been an "unexpected" result, and couples face decisions about prenatal screening, preimplantation screening, and genetic selection. In this paper, I propose six elements for a moral theology of reproductive genetic screening. A comprehensive moral theology is necessary, I argue, because mainstream Christian ethics too often considers screening only in terms of abortion and personhood. These discussions are worthwhile, but typically do not expose how demand for genetic screening is produced by our description of the world, our understanding of the purpose of children and the scope of suffering, and our fundamental vision of who we are and what we desire. My thesis is that these questions are best considered through the traditions of Christian theology and worship. To defend my claim, I will define genetic screening and why it is a concern, summarize a representative mainstream Christian bioethical analysis of screening in James C. Peterson's Genetic Turning *Points*, and outline a more theological approach to genetic screening, one rooted in the shared practices of the church.

What Is Genetic Screening?

The *Encyclopedia of Bioethics* defines reproductive genetic screening as "techniques ... the aims of which are to detect fetal anomaly." For this paper, I use genetic screening, genetic testing, and genetic diagnosis as rough synonyms. Genetic selection, however, is the *selection* of human embryos and fetuses according to genetic criteria. So, then, genetic selection depends on genetic screening, but genetic testing without selection is possible. Therefore, as I will not consider non-reproductive uses of genetic testing, my precise topic is the ethics of genetic testing, diagnosis, and selection at the prenatal and preimplantation stages. *Prenatal* refers to procedures during pregnancy, such as a pregnant mother confirming a diagnosis of Down Syndrome and choosing to have a selective abortion, while *preimplantation* refers to procedures

¹ Nancy Press and Kiley Ariail, "Genetic Testing and Screening: I. Reproductive Genetic Testing," in *Encyclopedia of Bioethics*, ed. Stephen G. Post, vol. 2, 3rd ed. (New York: Macmillan Reference, 2004), 996.

before an embryo is implanted in the host mother, such as an infertile couple selecting the "best" embryos to implant during in vitro fertilization. Finally, I primarily address *genetic* testing, not non-genetic prenatal tests such as ultrasounds, although similar issues are involved.

All forms of genetic screening involve tests to confirm the presence or absence of a particular genetic trait. Figure 1 lists the typical opportunities for genetic testing during pregnancy. First is preimplantation genetic diagnosis, routinely done after in vitro fertilization. After extracted eggs are fertilized and grown for two days, a cell is removed from each embryo to be tested, which will not harm the future fetus. After testing, chosen embryos are implanted in the mother; the rest are frozen, discarded, or used for research. Next is chorionic villus sampling, which is done around week 10 of pregnancy. It extracts a piece of placental tissue, which is genetically identical to the fetus; this adds about a 1 percent chance of miscarriage. Last is amniocentesis, which is done from 16 to 20 weeks, involving the extraction and testing of amniotic fluid, and is estimated to increase the risk of miscarriage by a bit more than 0.1 percent. Because chorionic villus sampling and amniocentesis can cause miscarriages, they are routinely recommended only for older mothers, who have a higher risk of having a child with chromosome abnormalities such as Down Syndrome. (At age thirty-five, Down Syndrome occurs spontaneously in about one in every 750 pregnancies; the risk increases yearly.) Otherwise, chorionic villus sampling and amniocentesis are normally suggested after non-genetic tests maternal blood tests and ultrasounds—indicate the fetus may have Down Syndrome or other abnormalities. Obviously, there is considerable pressure to make these tests available earlier during pregnancy to lessen the trauma of abortion, which is considered the only "treatment" for many genetic conditions.

Indeed, our current inability to cure genetic disorders provides parents with few options when a genetic disease is detected. After a prenatal diagnosis, they can do nothing, leaving three to six months to imagine how their doctor's abstract language will be manifested, or they can abort the "defective" fetus. In the case of Down Syndrome, abortion is typical, with termination rates of 85–100 percent measured in the US, Britain, and France.² Against that background, it is naïve to consider prenatal testing and selection separately, or to suppose many parents will use genetic information to prepare to care for an "abnormal" child. Rather, testing and selection today form a single paradigm, a *device* that increases the availability of normal children by avoiding the birth of aberrant ones.³

² See, respectively, T. M. Caruso, M. N. Westgate, and L. B. Holmes, "Impact of prenatal screening on the birth status of fetuses with Down syndrome at an urban hospital, 1972-1994," *Genetics in Medicine* 1 (December 1998): 22-28; David Mutton, Roy Ide, and Eva Alberman, "Trends in prenatal screening for and diagnosis of Down's syndrome: England and Wales, 1989-97," *British Medical Journal* 317 (October 1998): 922-923; C Julian-Reynier et al., "Attitudes towards Down's syndrome: follow up of a cohort of 280 cases," *Journal of Medical Genetics* 32 (August 1995): 597-599.

³ See Albert Borgmann's discussion of the modern "device paradigm" in *Technology and the Character of Contemporary Life: A Philosophical Inquiry* (Chicago: University of Chicago Press, 1984), 40ff.

Mainstream Christian Ethics

How, then, should we as Christians respond? One answer is provided by James C. Peterson, a young professor at McMaster Divinity with success in both evangelical and secular contexts. Peterson's first book, *Genetic Turning Points*, is based on his dissertation with noted ethicist James Childress and aims to provide a comprehensive Christian perspective on new and future genetic technologies and their ethical issues for a primarily non-Christian audience. His discussion builds from genetic research and testing to more futuristic techniques; I focus on the "Genetic Testing" section where he treats genetic counselling, new reproductive technologies, zygote screening, and prenatal screening.

For Peterson, genetic counselling is a valuable source of neutral information for parents. Unlike some who declare certain lives are not worth living, a genetic counsellor does not force any decisions but "just tells the parents what their life or the life of the fetus is likely to be like." He admits this ideal is not entirely realistic, as the selection of information and procedures to offer, as well as words and body language, can encourage one decision or another. Still, Peterson believes the nondirective model "does well" and "should be pursued," and suggests counsellors need only be honest about their convictions to avoid influencing their clients.⁵

Peterson is similarly positive about assisted reproduction, including gamete selection and in vitro fertilization. He rejects views that nature is "God-given," including the Roman Catholic position that humanity should recognize and conform to "the order of nature," and Craig Gay's concern in *The Way of the Modern World* that we have lost any possibility for nature to discipline what we choose and construct.⁶ Rather, Peterson argues that we are "created to naturally change nature," and so we should "sustain, restore, and improve ourselves." The naturalness of intervention forms the primary framework for Peterson's analysis of assisted reproduction. For example, he suggests that since neither painkillers during labour nor Caesarean sections detract from God's purposes in procreation, neither can egg or sperm selection. Peterson believes that the ideal place to welcome new life is in "rightly lived sexual intimacy," but he suggests that as God chose to incarnate himself without sexual union, procreation without intercourse cannot be "inherently evil." He acknowledges that the use of donor gametes causes "some asymmetry in genetic relationship," but cites studies that families formed by artificial reproduction "function quite well." Overall, Peterson rejects arguments against new productive

⁴ James C. Peterson, *Genetic Turning Points: The Ethics of Human Genetic Intervention* (Grand Rapids: Eerdmans, 2001), 162.

⁵ Ibid., 164.

⁶ Ibid., 186-8.

⁷ Ibid., 190.

⁸ Ibid., 192.

⁹ Ibid., 181.

techniques that rest on their artificiality, their separation of sexual union and procreation, or their negative effects on children.

Peterson also defends zygote selection, or preimplantation genetic diagnosis followed by selective implantation. (Zygote is the technical term for an embryo not yet implanted.) He acknowledges the first question is whether a zygote is a person, before going on to consider what zygote selection means provided a person is not present. Peterson criticizes the objection that selecting a child's characteristics is bad practice for parenting. He counters that "giving one's child the best start one can is part of good parenting." Furthermore, the technology's availability makes parents responsible either for "selecting the child's genetic endowment or for not doing so." 11 Choosing is inevitable. Peterson also asserts that the expense of in vitro fertilization is not a question of justice, given how parents sacrifice so their child can have the best available college education. Peterson also disagrees with C.S. Lewis's concern that our power over nature will become the power of some over others. He argues that parents should act "out of beneficence" and improve their children's abilities and choices, not limit them. For example, he rejects the use of zygote screening by deaf parents to select zygotes with congenital deafness, because he feels such action would not "increase the opportunities their children would have in life."¹³ Peterson finishes by concluding disabilities should be prevented before a person is present, if possible. He does quote a warning to not always equate disabilities with suffering or assume they are incompatible with happiness, but overall Peterson is enthusiastic about the potential of zygote screening, primarily because he argues earlier that zygotes are not persons.¹⁴

When it comes to prenatal screening, however, Peterson's enthusiasm ends. He insists abortion is wrong before the stages of development tested by chorionic villus sampling and amniocentesis, and he therefore questions the tests and their associated "options." Peterson also highlights how the standard recommendation to do amniocentesis and increase the risk of miscarriage for mothers over thirty-five implies that the birth of a Down Syndrome child would be worse than the miscarriage of a normal fetus, which is hardly neutral. Ultimately, though, his view of prenatal screening rests on personhood. "If a person is present at [that] stage of pregnancy," abortion is wrong. ¹⁶

In summary, Peterson's ethics of genetic screening prioritizes respecting individual autonomy, improving the human condition, giving children the best possible start to life, and preventing suffering. He also presupposes that information is neutral and desirable and that

¹⁰ Ibid., 194.

¹¹ Ibid., 195.

¹² Ibid., 198.

¹³ Ibid., 199.

¹⁴ See ibid., 123–37.

¹⁵ Ibid., 201.

¹⁶ Ibid., 202.

intervention in nature is inevitable and admirable. The primary difference between Peterson's ethics and those presented in a secular bioethics textbook, such as *Bioethics in Canada*, is his refusal to see abortion as justified to relieve suffering. But although I agree with some of Peterson's objections to prenatal selection and testing, I am not convinced he provides an ethic sufficient to address the whole context in which genetic screening takes place. Indeed, I suspect his confidence that personhood is the best lens for evaluating the ethics of screening may blind him to other questions raised by new reproductive powers. In contrast, I will present six insights of virtue ethics and moral theology that could overcome these shortcomings and illuminate our response to genetic screening. A theological approach, I argue, recognizes the priority of character, theology, and desire over decisions, relevance, and definitions; it reveals the situated quality of our late modern ideas of normality, suffering, and disability; it remembers the nature of children as God's gift of strangers; and it recovers the centrality of the church and its practices to embody generous hospitality.

Ethics Is Not About Decisions

First, ethics is not about making good choices or the right decision, but about character and description. This is an ancient insight, although it may sound novel, due to the modern perspective that dominates how we think about ethics today. For example, students in ethics are presented with a familiar variety of ethical systems, chief among them deontological or dutybased ethics, and utilitarian or consequence-based ethics. Deontological ethics is often summarized as always follow universal rules; utilitarian ethics, as always act for the greatest good. Students then learn to apply these systems to hypothetical quandaries or dilemmas, which often involve forced choices between killing one innocent to save many, or doing nothing and letting many die. The former "solution" is utilitarian, while the latter is deontological. Of course, no-win situations rarely occur, and when they do, few have the presence of mind to reason through which ethical system to use. But the greater mistake of modern ethics is it assumes dilemmas are the primary moral issue, when our daily lives generally consist of mundane situations—hardly "dilemmas"—that nevertheless strongly shape who we are. In contrast, virtue ethics recognizes that character precedes action: who we are comes before what we do. With that insight, decisions are still important, but as Stanley Hauerwas argues, decisions first depend on having a "self' sufficient to take personal responsibility for one's action." ¹⁸

Now, we generally assume all human beings can act responsibly, and need only the proper protection of their rights to exercise their freedom. But this common view supposes we are free whenever there is more than one option and no external pressure. It ignores the real problems that arise when we have insufficient character or skills of perception to choose or even

¹⁷ Indeed, although I do not endorse their conclusions, the authors of *Bioethics in Canada* provide a nuanced discussion of new reproductive technologies, genetic counselling, and prenatal testing. See David J. Roy, John R. Williams, and Bernard M. Dickens, *Bioethics in Canada* (Scarborough, ON: Prentice Hall Canada, 1994), 132-189.

¹⁸ Stanley Hauerwas, *A Community of Character: Toward a Constructive Christian Social Ethic* (Notre Dame, IN: University of Notre Dame Press, 1981), 113. This and the next section draw heavily on Hauerwas' work.

see the more difficult choice. Yet, "we can only act within the world we can envision, and we can envision the world rightly only as we are trained to see." Rather than every situation being equally open to every person, our moral freedom *depends* on our character and perception, or lack thereof. Therefore, as Hauerwas contends, "The kind of 'situations' we confront and how we understand them are a function of the kind of people we are." ²⁰

So human freedom is not developed primarily through the removal of external limitations, but through growth in character. Indeed, growth in character will reduce our need to "face dilemmas" and "make difficult decisions." This paradox is because virtues involve dispositions that entail decisions: virtuous individuals may appear to make momentous or even heroic decisions, yet simultaneously feel they had no choice but to do what they did if "they were to be faithful to their characters."21 However, this does not imply virtue will make our lives easier. Being virtuous "challenges us to face moral difficulties and obstacles that might not be present if we were less virtuous."22 And this ancient understanding of ethics creates another complication: since the learning of any skill—including the skills of description and character only takes place in relationship, it follows that our freedom depends on the communities to which we belong. This contradicts the modern idea that personal enlightenment consists in autonomy, or freedom from all stories and commitments except those we freely choose. Yet what if being bound to others is not a barrier to freedom, but the means of creating it? What if being self-absorbed is the greatest threat to authentic existence?²³ Then meeting the needs and demands of others, including those tested by genetic screening, would be an opportunity to live an authentic human life.

Christian Ethics Should Be Christian

Second, Christian ethics should be Christian. This sounds tautological, but much of modern Christian ethical discourse is dominated by attempts to avoid or apologize for theological claims. Indeed, the entire field of Christian ethics is a modern invention, insofar as Christians have traditionally understood the discernment of their moral calling to fall under pastoral and moral theology. Even that distinction—between moral theology and theology "proper"—is a distortion, as it is not clear the New Testament authors or church fathers distinguished between theology and pastoral direction. Nor were they alone: for the ancient Greeks, the study of philosophy involved submitting to a master "in order to gain the virtues

¹⁹ Stanley Hauerwas, *The Peaceable Kingdom: A Primer in Christian Ethics* (Notre Dame, IN: University of Notre Dame Press, 1983), 29. Hauerwas here expands an insight of Iris Murdoch.

²⁰ Hauerwas, A Community of Character, 115.

²¹ Ibid., 114.

²² Ibid., 115.

²³ Hauerwas, *The Peaceable Kingdom*, 44.

necessary to be a philosopher."²⁴ The unity between theology and virtue continued to be assumed through the time of Aquinas, and can still be seen in Calvin's *Institutes*. But after the breakup of Christendom and the Wars of Religion, the philosophers of the Enlightenment worked to find moral principles that were not tied to any particular tradition. They thought only a moral philosophy derived from reason alone could save Europe from unending religious debate and war. Yet according to Alasdair MacIntyre's analysis in *After Virtue*, their project has failed, leaving us with apparently incompatible moral systems and a fragmented, reductionist moral language.

It is in this context that Christian theologians have attempted to translate theology into supposedly more universal language. Of course, Christians have always sought relationship with those outside the church to witness about the God revealed in Christ Jesus: the difference today is that some theologians also stand outside the Christian tradition, discussing why it "can no longer pass muster." Even if Christian ethicists avoid that extreme, it is still unclear how their ethics differs from other ethics. Medical ethicists are particularly vague on this point: indeed, Hauerwas observes that the development of medical ethics was a boon for "religious ethicists' as it seemed to provide a coherent activity without having to [ask] what makes Christian ethics Christian." Rather, they could focus on issues like death, truth telling, covenant, trust, and autonomy.

To be clear, these issues are vital, and so is the work done on them by thinkers like Paul Ramsey and James Childress. And since these scholars work as religious ethicists or just plain "ethicists," they need not be concerned with their relationship to the Christian tradition. But adopting such an approach is dangerous for Christians: it makes them complicit in their own marginalization. For, as Hauerwas argues, if even theologians believe theology is "but a confirmation of what can be known on other grounds or can be said more clearly in non-theological language," then why bother with theology? Why not just do philosophical ethics, and dispense with the "Christian" qualifier? With our society's genuine lack of consensus on the meaning of the good life or the purpose of medicine, we will continue to be tempted to downplay our particular convictions in the interest of toleration and harmony. But doing so only confirms the common assumption that theological claims are irrelevant to how we understand modern medicine and the questions it raises.

James Peterson's work reflects this problem. Although he claims to present a consistently Christian viewpoint, Peterson's use of Scripture and theology rarely adds any ethical nuances

²⁴ Stanley Hauerwas, "How "Christian Ethics" Came to Be," in *The Hauerwas Reader*, ed. John Berkman and Michael G. Cartwright (Durham, NC: Duke University Press, 2001), 37. Hauerwas here refers to the work of Robert Wilkin and Pierre Hadot.

²⁵ Stanley Hauerwas, "On Keeping Theological Ethics Theological," in *The Hauerwas Reader*, 53.

²⁶ Stanley Hauerwas, Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church (Notre Dame, IN: University of Notre Dame Press, 1986), 71.

²⁷ Hauerwas, "On Keeping Theological Ethics Theological," 53.

beyond the condemnation of abortion. Rather, such elements tend to enter his chapters on genetic testing only when needed to contradict other, more cautious Christian perspectives. In Peterson's chapter on genetic testing and the family, he mentions four biblical texts: Paul's words on wives and husbands' bodies in 1 Corinthians and Ephesians, the commandment against adultery in Exodus, and the "one flesh" passage in Genesis. All are exegeted solely to illustrate how they should not apply to egg or sperm donation.²⁸ The incarnation is mentioned once, as a divine refutation of the need to keep conception and sexual union together.²⁹ Peterson cites works by Paul Ramsey and Gilbert Meilaender, but primarily as examples of excessive caution.³⁰ Indeed, compared with the ethic advanced in a secular text like the aforementioned *Bioethics in Canada*, Peterson's analysis of screening suggests that religious reasoning is largely redundant, apart from issues of abortion. Therefore, I argue Peterson's ethic illustrates how the modern call to make Christian claims more palatable can become an invitation to self-marginalization.

Definitions or Desires?

So what difference does it make for Christian ethics to be unapologetically Christian? Since Christian ethics, unlike other ethics, is properly a form of theology, we can move beyond a purely external ethic to consider whether—and how—we are obeying the great commandments to love God and our neighbour. Indeed, that is the first question of ethics, for as Augustine argues in *The City of God*, "in order to discover the character of any people, we have only to observe what they love." Examining our desires and their formation allows us to overcome another gap between modern and ancient Christian ethics. Today we often think of sins as sinful *actions* and Christian ethics as a tool to identify whether a particular act is sinful or not, which fits remarkably well with the modern focus on decisions and rules. But for Augustine and other church fathers, sin was above all a question of what we desire and whom we love. As Paul Griffiths writes, for Augustine sin is "a turning of the face from what is supremely good toward what is less good." Sin is turning away from God, the supreme good, and turning in toward ourselves, or other creatures, alone.

Now Augustine did not believe created things were evil, or that it was wrong to love the creation. In his own words, "sin is not a desire for naturally evil things but an abandonment of better things."³³ This abandonment happens when we grasp at creatures as if they were good or desirable independent of God.³⁴ Again, Augustine agrees we should love all of God's creation,

²⁸ Peterson, Genetic Turning Points, 180-2.

²⁹ Ibid., 191-2.

³⁰ See especially ibid., 191, 195-6, and 198.

³¹ Augustine, *De Civitate Dei*, 19.24. See also James K. A. Smith's discussion of Augustine and Heidegger in *Desiring the Kingdom: Worship, Worldview, and Cultural Formation* (Grand Rapids: Baker Academic, 2009), 46ff.

³² Paul J Griffiths, Lying: An Augustinian Theology of Duplicity (Grand Rapids: Brazos Press, 2004), 56.

³³ Augustine, *De Natura Boni* 36. Griffith's translation.

³⁴ Griffiths, *Lying*, 59.

including children and other human beings. But we must love them as they are: creatures ultimately dependent on God. To love them as things to be enjoyed or possessed *in themselves* is to love wrongly. Sin is always first an offense against God, caused by a disordered desire to grasp at creatures without God, and the cure for sin is a rightly ordered love that rejoices in God's creation by also rejoicing in God.

Augustine's understanding of sin is therefore a needed complement to virtue ethics. After all, having the character to make a better but harder choice is useless to someone who does not desire the good. Yet this is where many ethics of genetic screening flounder. Because the law provides the ultimate sanction for modern behaviour, we often begin by asking what should be permitted and what should be outlawed. For the issue of screening, debates typically revolve around whether an embryo or a fetus is a person, and if so, what legal and moral obligations society has to them, versus what rights remain with the parents. This seems reasonable, because we believe a good society begins with protecting persons from interference with their freedom to choose how to live their lives.³⁵ But while these questions are helpful, starting with them neglects the priority of character and desire. We cannot create a good society without people of character who can choose the good and *want to*. Therefore, we should discuss genetic screening by first questioning what we want—especially our desires to avoid suffering and to have children.

For these reasons, although I agree with Peterson's opposition to prenatal screening, I suspect his arguments do more harm than good. By focusing on the legal status of the unborn, Peterson leaves intact the desires that produce demand for screening. Worse, the justifications for zygote screening he endorses are equally popular justifications for prenatal screening: to avoid disabilities and give children a better start to life. Peterson's objection to prenatal screening rests primarily on his conclusion that a fetus is a person. Therefore, readers who accept prenatal screening because they believe abortion does not kill a person, or is only a relative evil, or is justified to prevent suffering, will find little else to challenge them in Peterson's book. They might even be encouraged by his conditional language—"if a person is present" or "if a zygote is a person"—and his admonition to avoid disabilities before a person is present. This is *not* Peterson's intent, but such incongruity makes sense, given how distant arguments over personhood are from our everyday moral language.

What is Normal?

Instead, I argue we should carefully examine our everyday language of "normal," "suffering," and "disability." Although the definitions of these terms are debated by doctors, Christians, and others, their prevailing meanings remain imprecise, conditioned by popular

³⁵ In this way, the liberal public sphere is analogous to the free market: both rely on a concept of negative freedom that is ultimately nihilistic. See D. Stephen Long's discussion of abortion in *The Goodness of God: Theology, Church, and Social Order (Grand Rapids: Brazos, 2001), 218-22;* and William T. Cavanaugh's application of Augustine in *Being Consumed: Economics and Christian Desire* (Grand Rapids: Eerdmans, 2008), 9ff.

images of what it means to have a good family and normal children. And because popular discourse lacks the stability provided by specific communities and traditions, it can more easily be manipulated.

Normal, for example, can often come to mean "the ideal" rather than "the usual." Again, when Peterson reflects on zygote selection, he argues that parents should do whatever they can to give their children greater opportunities. Evidently, having more opportunities is better—but better for what? Being more productive? Acquiring wealth and power? Achieving happiness, success, and independence? Joel Shuman and Brian Volck illustrate how the appeal of technology to fulfill our desires for children usually involves redefining "the sad, the unpromising, the imperfect, the dependent, and the slow as abnormal." Apparently, having limitations is no longer part of the human condition but a deficient state. Similarly, Therese Lysaught agrees that ideas such as what is "normal" and "undesirable" have a way of being "read into nature or human biology," which is then used as "a warrant to provide an 'objective' basis for a socially constructed belief or position." ³⁷

This is troubling, given the historical alliance of genetics with eugenics, a movement that flourished in North America in the first half of last century. The eugenics movement focused on reducing the population of "defectives" by preventing their marriage, forcing their sterilization, committing them to institutions, and even killing them. Genetic science was too young to understand the targeted traits' actual inheritance, or lack thereof, but many leading geneticists and Christians still supported the movement. Eugenics mostly died out after the Second World War due to its association with the Nazi regime; yet even as late as the 1960s, many Western countries sterilized thousands every year. Today, however, eugenic goals can be achieved without coercion or force. As Gerald McKenny argues, contemporary desires for perfect children are stimulated through "health information, advertising, prenatal and neonatal monitoring ... and the fear of having an imperfect child in a society that ... constantly measures persons [by] their usefulness." No authoritarian legislation is necessary, because parents "freely" desire these narrowly defined images of perfection. Therefore, unless parents have alternative images to inform their desires and imagination, protecting their freedom to choose is pointless.

Just as our concepts of "normal" and "defective" are conditioned by society, so too are our views of "suffering" and "disability." For example, even if unnecessary suffering should be prevented, how do we understand and define "unnecessary"? Is any experience of pain, unhappiness, or frustration unnecessary? If so, how could we eliminate such suffering? Some suffering is part of the human condition, and can only be prevented by preventing existence

³⁶ Joel James Shuman and Brian Volck, *Reclaiming the Body: Christians and the Faithful Use of Modern Medicine* (Grand Rapids: Brazos Press, 2006), 87.

³⁷ M. Therese Lysaught, "From Clinic to Congregation: Religious Communities and Genetic Medicine," in *On Moral Medicine: Theological Perspectives in Medical Ethics*, ed. Stephen E Lammers and Allen Verhey, 2nd ed. (Grand Rapids: Eerdmans, 1998), 554.

³⁸ Gerald P. McKenny, "Bioethics, the Body, and the Legacy of Bacon," in *On Moral Medicine*, 318.

itself. Therefore, to ask "should we prevent suffering or not" is to create a false dichotomy. Rather, we must first question our descriptions—what we mean by "unnecessary" and "suffering." And in particular, what does it mean to say people with Down Syndrome or other mental disabilities suffer greatly? Of course, they suffer from disease and anguish like anyone else, but it is unclear whether they suffer unusually more from being disabled. As Hauerwas comments, people with mental disabilities likely understand they are different, and they may "perceive that there are some things some people do easily which they can do only with great effort or not at all."³⁹ But in itself, this does not imply extreme hardship. We all, especially children, have to confront and live with limits. And sadly, many of the limits the disabled struggle with are caused by living in a society we have made. We are inhospitable to them actively and through indifference, and the limited care they do receive is largely thanks to "those who have found themselves unexpectedly committed to care" for a disabled person. 40 Worse, as the number of people with disabilities dwindles, our sympathy is increasingly rooted in ignorance, not empathy. As Hauerwas argues, since we usually cannot imagine or understand what a life with disabilities is like, we imagine instead what our life would be like if we were disabled. 41 Our arguments then sound plausible, but only reproduce our own fears and desires, not those of someone different from us.

What Are Children For?

Examining who we are and what we desire brings us to a curious but crucial question: what are children *for*, exactly? It sounds impolite to ask, but we need to be reminded that children are God's gifts to us, not our personal property or products. Indeed, the science fiction concept of children as products is already common; consider the justification of so-called "wrongful life" lawsuits, where a disabled child (or their parent) sues those "responsible" for the failure to prevent their birth and their subsequent economic harm. As Gilbert Meilaender writes, this strange responsibility is a logical outcome of the supposed freedom granted by selective abortion:

If we create a product for certain purposes, we can be held responsible for the quality of that product. Traditionally, of course, parents conceiving a child did not think of themselves as producing a product. ... [But] as technology makes possible a more complete responsibility for the child's well-being, so it also lays upon all who use it a heavier burden of responsibility. Complete freedom, godlike freedom, gives rise to utter responsibility. "Wrongful life" suits simply recognize the fact that we have begun to think of ourselves not simply as cooperators with a power greater than our own but as ultimate life givers. And then we cannot avoid the impetus toward "quality control."

³⁹ Hauerwas, Suffering Presence, 171.

⁴⁰ Ibid., 163.

⁴¹ Ibid., 174.

⁴² Gilbert Meilaender, *Bioethics: A Primer for Christians*, 2nd ed. (Grand Rapids: Eerdmans, 2005), 53-4.

Moreover, as selecting for some traits must preclude other possibilities, we should not be surprised when parents who genetically select or modify their child's abilities (or refuse to) are also subject to lawsuits.

So what *are* children for? Joel Shuman and Brian Volck give a powerful answer. They argue children are not sophisticated pets, consumer items, or our hope for the future, but extravagant gifts to be received with gratitude, and they suggest that the practice best suited to encourage and train the gratitude with which we need to raise children is "hospitality toward strangers." ⁴³ Indeed, rather than being understandably ours, "children are always already strangers to us, springing from the womb with characters and callings beyond our control." ⁴⁴ This insight challenges our jealous protection of our own plans for life and our tendency to see children as projects. From what I have seen, children are difficult gifts. You rarely receive what you expect. They are much more expensive and demanding than pets, and they have a unique capacity to make parents' lives miserable. And more seriously, children suffer. Sometimes they suffer horrendously, and sometimes they die before their parents do. Indeed, Paul's "troubles" surely include children when he observes, "those who marry will face many troubles in this life" (1 Cor. 7:28). In short, having children can appear to be a bad idea: bad for parents, bad for children.

Therefore, perhaps in modern times parenthood only makes sense when we admit our children are not *ours*, but God's. Sarah Williams has written a heart wrenching account of her experience of carrying to term a baby with a dysplasia that is almost inevitably fatal at birth. Later on in the book, after her labour has begun, an image comes to Sarah's mind of a horse and rider coming with incredible urgency to rescue Cerian, her unborn child.⁴⁵ She then shares the picture with her husband, Paul, who replies:

You are only doing what every parent has to do. We have to let Cerian go and give her back to God. One day we'll have to let Hannah and Emilia go too. That's the goal of parenthood: releasing them to God. They are his anyway; we are merely guardians. Every contraction may be taking us further from Cerian, but they're taking her closer and closer to God, where she belongs. 46

Medicine Needs the Church

Finally, medicine needs something like the church. That is, for medicine to remain a moral art with a generous practice of presence and care—rather than becoming a consumer driven peddler of cures—we need communities of hospitality that embody the presence of God's peaceable kingdom. Hauerwas puts it more strongly: "medicine needs the church ... as a

⁴³ Shuman and Volck, *Reclaiming the Body*, 80-3.

⁴⁴ Ibid., 83.

⁴⁵ Sarah C. Williams, *The Shaming of the Strong* (Vancouver, BC: Regent, 2007), 122.

⁴⁶ Ibid., 124.

resource of the habits and practices necessary to sustain the care of those in pain over the long haul."⁴⁷ Such claims may seem unrelated to the previous five points, but they all move in this direction. If our ethics and freedom depends on who we are and how we describe the world, then the narratives and traditions of our communities are, for good or ill, decisive. Similarly, our desires for our children are shaped by our communities, which is why Gerald McKinney suggests a community that did not "measure themselves or others by ... productivity, beauty, and success" would lack the desire to produce bodies according to popular norms. ⁴⁸ And if Christian ethics should be Christian, our understanding of what it means to be Christian should be mediated first by the church. Otherwise, our modern individualism, consumerism, and instrumentalism will continue to reinforce our narrow understanding of sin and extreme fear of physical and mental disabilities. In short, communities matter, and we may soon be in a society where only an alternative community can form the people needed for virtuous medicine.

But why the church? Although the distance between reality and ideal may seem greater for the church than any other institution, it still perseveres, preaching the Word and celebrating the sacraments. And indeed, the sacraments have enormous implications for bioethics: they challenge our modern anthropology, our view of what it means to be human. For example, Gilbert Meilaender begins his *Bioethics* by grounding rights, individuality, and community in the sacrament of baptism. He writes, "In baptism God sets his hand upon us, calls us by name, and thereby establishes our uniquely individual identity and destiny. ... [Baptism also] brings us into the community of the church."⁴⁹ From this perspective, baptism is a radical action that we too routinely perform, without regard for how it should change our understanding. Consider that Christians do not reserve baptism or child dedication to only those infants with particular abilities, but instead welcome those who are incapable of knowing what the event means or choosing to participate. Therefore, infant baptisms and dedications demonstrate the extravagant abundance of God's grace for children regardless of what they can do or what standards they meet. So, as Therese Lysaught argues, we need to remember we do not understand identity and normalcy according to genetics, but instead interpret genetics according to our baptism and new identity in Christ, and our appreciation and love for God's diversity over genetic uniformity.⁵⁰ Baptism thus points forward to communion, where we celebrate God's undeserved hospitality to us through Christ Jesus. Ideally, communion is a place where all the faithful, without distinctions of appearance or ability, can receive and extend God's hospitality and thereby model the kingdom of God and the church's mission in the world. Insofar as our congregations are segregated and homogenous, they demonstrate our sinfulness, but this does not—cannot—negate our call to base hospitality to children and the unborn on the doctrine and practices of the church.

⁴⁷ Hauerwas, Suffering Presence, 81.

⁴⁸ McKenny, "Bioethics, the Body, and the Legacy of Bacon," 322.

⁴⁹ Meilaender, *Bioethics*, 2.

⁵⁰ Lysaught, "From Clinic to Congregation," 554-5.

Therefore, I suggest Christians have already in the church the vocabulary and habits they need to make sense of the strange world of modern medicine. Perhaps Christians rooted in the church could find genetic selection offensive, not because we have carefully defined what a person is, but because we recognize screening is a radical restriction on which children we will extend hospitality to. We could be proud that we do not test children to meet conditions for inclusion, but instead accept them as extravagant gifts. Similarly, our openness to diversity in communion could equip us to recognize and reject the imposition of uniformity. Our meditation on the humiliation of Christ, and our humble service to the world's "misfits" and "defectives," could provide us with the alternative images necessary to imagine a community and a love not so desperate to correct the other. Finally, our education in the difficult virtues of compassion might give us the wisdom needed to discern those hard cases truly incompatible with life or goodness. Our communities would then have less need of abstract debates about what constitutes suffering or a person, because we would have our own functioning moral language and the training in virtue to use it rightly.