

# The Paradox of Disability

*Responses to Jean Vanier and  
L'Arche Communities from  
Theology and the Sciences*

*Edited by*

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## Supererogation and the Riskiness of Human Vulnerability

BRIAN BROCK

### Introduction

What does it mean to *investigate* human fragility? And what counts as *knowledge* or *results* from such investigations? Theology and the empirical sciences will give different but related answers to these questions, answers that will, we hope, mutually illuminate one another (Brock, Dörfler, and Ulrich 2007).

Theologians and scientists pursue at least two strategies for answering these questions in this book. One investigative strategy is to rearrange cultural conditions so that people are made to feel vulnerable under controlled and observable conditions. Another is to seek out those places in our own cultures where people say they feel vulnerable as a mode of social analysis. Both are empirical investigations, differing only in whether they investigate by *creating* or simply by *discovering* people's existing sensations of vulnerability. As Hans Reinders has already reminded us in his introduction to this volume, the sensation of vulnerability is related in complex ways to the actual vulnerabilities produced by mental and physical impairments. If our interest is in analyzing our own societies, we must keep both aspects of this complex field of relationships in view. Hauerwas asks us to begin our exploration of human fragility by thinking theologically about one existing group of communities in which the interplay of these two forms of vulnerability is exposed, the L'Arche communities (preceding chap.). In so doing, Hauerwas seeks to learn what this way of life teaches us about how to live with fragility in all spheres of human existence. He stud-

ies L'Arche as a "given" to be understood, moving from there to suggest what kind of people we have to be if we are to take seriously the witness of that community of care. To attend to such a community of care, therefore, represents a discrete mode of investigating the virtues necessary to accept and live in solidarity with all human fragility.

In this chapter I investigate a conceptual complex from the discourse of medical ethics, which seems to set up barriers to the embrace of the vulnerable lives around which a community like L'Arche orbits. I will assess the role of the concept of "supererogation" from a theological perspective. Put in the simplest possible terms, my claim will be that, when used in the context of medical ethics, supererogation suggests that loving our family members with a disability, particularly when this involves our children, is somehow special — or more sacrificial — than loving other, "normal" people. My analysis will examine one very influential account of medical ethics, namely, the one presented by Tom Beauchamp and James Childress in *Principles of Biomedical Ethics*. I will suggest that the use of supererogation in their account fuels trajectories within Western medicine that seek to eliminate human vulnerability, and with it those human beings who are characterized as "defective." I hope to show that this use of "supererogation," in combination with conceptions of genetic risk, renders the carrying of a disabled fetus to term a heroic act, at best, and a callous one, at worst. I am not suggesting, of course, that the concept of supererogation as used in this textbook of medical ethics is *causally* operative in the process of eliminating vulnerability. Instead, I will draw out why this account of medical ethics has no internal resources to stand against a rising tide of resistance to human vulnerability in one particular field: prenatal testing. Before turning to supererogation, however, I will consider the practical context in which mothers and parents face questions of genetic risk and of the space of genetic counseling.

### Being for and Bearing the Vulnerable: The Problem of Prenatal Testing

It is by now well documented that many pregnant women in highly medicalized Western societies feel strong, sometimes coercive resistance to their decisions not to abort what has been diagnosed as an "affected" fetus. Here the proximity of actual and felt vulnerability is particularly apparent. Leisa Whitaker, who has a form of dwarfism, relates her experience of pre-

natal genetic testing in terms only slightly more stark than that of many women.

I remember sitting in the [genetic specialist's] rooms listening as he explained that there was a 25 percent chance that our child could still inherit the dominant achondroplasia gene and the dominant pseudo-achondroplasia gene — a combination that they had never seen before anywhere in the world. They had no idea of what effect this would have on the baby. . . . Having told us this the specialist offered us an abortion. He asked us to think about whether we wanted to bring another dwarf baby into the world. It was something I hadn't even thought of. This was our child! Why would we not want her? Why would the world not accept our child? (Tankard Reist 2006, 214)<sup>1</sup>

Rayna Rapp (2000) attempts to give some sociological purchase on the forces producing the medical "common sense" that would lead to the assumption that the reasonable course of action for a pregnant woman would be to abort a "defective" fetus. It draws on extensive anthropological research collected in the late 1980s and early 1990s on the main participants in the drama of amniocentesis in the city of New York. I will focus here on her findings regarding one of the many actors involved, the genetic counselor. Rapp found that genetic counselors play a prominent role in exposing the *conceptual* assumptions underpinning the view that bearing a disabled child is an irrational choice. What is simply assumed in related peri- and neonatal fields comes explicitly to expression in the work of the genetic counselor.

Genetic counseling is a subfield that grew from research genetics in the 1970s, and it took over the pastoral and educational task of linking the world of the scientific laboratory and that of parents. As Rapp suggests, their task is conceived of as primarily focused on counseling (Rapp 2000, 56-57), and it is directed toward the facilitation of nondirective value-neutral advice, with the stated purpose of assisting women's reproductive choice. Thus the basic aim of the discipline is on the surface straightforward: the genetic counselor provides information about hereditary risk to prospective parents. The practical task of the counselor is to prepare parents to take the test, and to explain the meaning of laboratory results. The

1. This volume collects nineteen first-person narratives by women who experienced medicalized pre- and postnatal care as antagonistic to the continuation of their pregnancies.

counseling session reflects four main goals in how it proceeds: to establish the primacy of scientific discourse, to establish the authority of this discourse, to communicate risk, and to construct a family history narrated in medicalized terms.

Establishing the primacy of scientific discourse involves explaining what chromosomes are, how they work, and how "defects" produce disabilities. In this sense, genetic counselors are science educators who simultaneously establish and maintain the authority of the scientific expert. Since the accuracy of the geneticist's diagnosis is the premise of the counselor's work, there is a strongly pro-expertise bias built into genetic counseling.

Explaining the functioning of chromosomes is a prelude to introducing the crucial concept of *risk*. This is thoroughly statistical territory, in which it is assumed that rationality and choice can be meaningfully tied to percentages of risk. The aim of the discourse of risk is to construct an "appropriate" or "numerically rational" sense of anxiety, which is tied to those features of procreation that are susceptible to genetic analysis. Genetic counseling is, Rapp continues, thoroughly wedded to this medicalized and statistical understanding of pregnancy.

The technology of prenatal diagnosis was developed explicitly to allow the selection and abortion of fetuses facing serious disabilities because of atypical chromosomes and genes. The language of genetic counseling is intended to enhance awareness of the age-related risk of chromosomal problems, but counselors rarely speak directly about disability or abortion decisions unless a problem is detected. Counselors describe their goals quite differently: to give reassurance. . . . This language of "added risk," "background risk," and "reassurance" is consistently deployed by all the genetic counselors I have observed at work. It thus foregrounds a statistical, medical, age-related, universal and wholly individual model of risk. (Rapp 2000, 70)

Risk is communicated in more or less sophisticated ways, depending on the mother being addressed.

To someone perceived as scientifically sophisticated, at Middle or Elite Hospitals: "At 35, a woman's risk of bearing a live born child with Down syndrome is one in 385; at 40 it increases to one in 106; at 45, it is one in thirty" . . . . Another counselor said of advanced maternal age: "It's like

crossing a street with each pregnancy, and when you are older, it's a little easier to be hit by a car. But suppose there is a traffic light. Then, you want to cross on the green. This test puts you back to the green light. Oh, you might still get hit by a crazy hit-and-run driver, but it's not too likely. At the red light [without the test], your age makes you a more likely target for an accident." (Rapp 2000, 68)

Though the heavy use of statistical language lends an air of objectivity and value-neutrality, the last quotation's comparison of some births with an "accident" that ought to be avoided highlights the value-laden nature of the exercise.

Until prenatal genetic testing is universally administered, for technical reasons, testing must be targeted. The main goal of the early part of the counseling session is to teach and guide parents in renarrating their family history in medicalized, "diagnostic" terms. Parents are asked many questions that could be considered surprising or unsettling in normal life: "Have you recently come into contact with cats?" or "Have you taken drugs or had unprotected sex?" or even "Could the child's father be your relative?" Such questions orient the laboratory's investigation of specific anomalies that are linked with these behaviors. In this process the counselor teaches the pregnant woman to reconsider her own biography within the terms of the medical self-understanding, thus constructing a subject who understands herself to carry a certain specifiable "genetic risk" on the basis of this newly constructed narrative of the self.

Rapp observes that there is an inherent confusion shot through these activities of the genetic counselor, who thinks of herself as value-neutral while playing the role of gatekeeper. The biomedical and public health establishments that employ genetic counselors assume that some conceptions are expendable or even burdensome. Genetic counselors simply 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" (Rapp 2000, 59). This lack of self-reflexivity is verified by the surprise of genetic counselors when their advice or even some of the information they have to offer is refused by parents who have decided that abortion is not appropriate for some conditions (Katz Rothman 1986, 256).

It appears, then, that prenatal diagnosis as just described expresses a

biomedical account in which prenatal *screening* precedes and is more fundamental than prenatal *care*. At the point that the genetic counselor enters the mix, 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 the pregnancy. Western society as a whole has learned to "live by the numbers," and the genetic counselor ensures that pregnancy is also understood first in these terms. However, Rapp found that this statistical rationality not only framed the activity of amniocentesis, but barred some from it.

[I]ronically, the very populations most at risk — less privileged "older" women having more pregnancies with more partners; experiencing more reproductive, perinatal, and infant mortality; and higher death rates throughout their life cycles — may be least likely to live by the numbers precisely because they understand their risks to be spread over a greater territory than chromosome analysis in pregnancy describes. . . . [P]recise biomedical notions of risk are constantly put to empirical challenge by the encompassing and uneven life chances through which women and their supporters encounter them. (Rapp 2000, 312-13)

Much of theological interest appeared in these cases, in which some parents could not or would not evaluate their pregnancies in terms of this metanarrative. Concepts such as value-neutrality, individual choice, risk avoidance, and the authority of expertise are as such not necessarily theologically problematic; but they may become a cocktail that is poisonous to the most vulnerable when they are unreflectively teamed with decisions about whether to eliminate humans perceived to be a social burden. Genetic counselors express the decision of a state, perhaps unwittingly, whose offer to help those mothers most in need of social support has been reduced to the offer of an abortion. This political role is sustained as genetic counselors embrace the role of nondirective (and therefore apolitical) advisor while serving the widespread use of the technologies of elimination. In theological and pastoral terms, the net effect is the loss of attentive empathy and concern for the whole of life while ostensibly in service of the state's interest in minimizing economic cost.



## Supererogation in Medical Ethics

In the medical landscape just described, in which some pregnancies are considered too risky for a rational person to seriously consider bringing to term, the concept of supererogation cannot but color the medical professional's sensibilities about the moral nature of parents' decisions to receive pregnancy as a gift rather than as a burden, risk, or threat. My contention is that this is true even when introduced as solely an aspect of professional ethics.

Beauchamp and Childress's *Principles of Biomedical Ethics*, first published in 1979 and now in its fifth edition, has arguably been the most influential account of medical ethics to form the moral aspirations of a generation of medical students in the English-speaking world. Its final chapter turns to describe the ideal medical professional, a moral agent who knows that "what counts most in the moral life is not consistent adherence to principles and rules, but reliable character, moral good sense, and emotional responsiveness" (Beauchamp and Childress 1994, 462). The authors' focus here is on the *virtues* a medical professional must possess, and this suggests that these traits of character cannot — indeed, must not — be confined to professional life alone. Beauchamp and Childress are suggesting here what kind of *people* health-care professionals should be. When medical professionals live the virtues of caring in a consistent way, they build up social capital and come to be seen as "persons of high moral character [who] acquire a reservoir of good will in assessments of the praiseworthiness or blameworthiness of their actions" (Beauchamp and Childress 1994, 464).

I would suggest that the authors need this thick account of the moral aspirations of medical professionals as a buffer against an overly rigid or heartless application of the system of rules and principles that the bulk of their treatment is devoted to explicating. In it they define the virtues of medical professionals: compassion, discernment, trustworthiness, and integrity. Again, it is noteworthy that these virtues are universal: it is inconceivable to think of persons as compassionate, discerning, trustworthy, and possessing moral integrity in their *professional* duties while being callous, undiscerning, untrustworthy characters in the rest of life. Beauchamp and Childress clearly want medical professionals to aspire to be certain kinds of moral agents. The question is whether the moral agents who possess these traits can set them aside when evaluating their patients' decisions.

Here the introduction of the concept of supererogation in the authors' account complicates matters exponentially. They define the concept of su-

pererogation as applying only to specific acts. These acts stand on a spectrum between what is commonly accepted as moral — the ordinary standards of behavior expected of everyone in society — and heroic acts, which can never be demanded of everyone and are not undertaken out of any universal duty. A supererogatory act, according to Beauchamp and Childress, has four features:

First, a supererogatory act is optional, neither required nor forbidden by common morality standards. Second, supererogatory acts exceed what is expected or demanded by the common morality. Third, supererogatory acts are intentionally undertaken for the welfare of others. Fourth, supererogatory acts are morally good and praiseworthy (not merely undertaken from good intentions). (Beauchamp and Childress 1994, 483)

Let us map this definition of the supererogatory act onto what we have learned about how medical professionals understand prenatal testing. Under the first and second criteria, it is safe to assume that common morality predicates that, all things being equal, it is obligatory to continue an “unaffected” pregnancy. Therefore, to continue an “affected” pregnancy is by definition a decision to go beyond this lower threshold, moving in the direction of a supererogatory or even a heroic act.

The third criterion might also allow a mother’s decision to continue an “affected” pregnancy to be interpreted as a decision “intentionally taken for the welfare of others.” But as we have seen, many expecting mothers today experience medicine very differently: their choice for the vulnerable is repudiated as serving no one’s welfare, not even that of the unborn child. This points to the paternalistic sting in the final criterion, which suggests that for an act to be supererogatory it must be *actually* good and praiseworthy, not just well *intentioned*. In a medical context in which the bearing of a disabled child is explicitly cast in terms of an avoidable accident, the bearing of a disabled child must be understood as a violation of the last criterion of the supererogatory act. If not interpreted as an irrational act because it violates the last criterion, it can, in these terms, be at best considered a decision by idiosyncratic individual parents to go far beyond what the system of prenatal screening assumes parents can reasonably be asked to bear.

Furthermore, Beauchamp and Childress explicitly tie their definition of the threshold between morally obligatory and supererogatory acts in professional life to how much *risk* the subjects take on. It is the level of risk

faced as one makes a decision that defines its demands as one of universal moral obligation, or as only an option to be chosen by those inclined to take on a more than average level of risk. The point of the concept of supererogation is to "refrain from holding people to standards that are arduous, risky, and frightening" (Beauchamp and Childress 1994, 487).

In this version of moral medicine, it is the perception of levels of risk, then, that defines an action as supererogatory, or optional and beyond "normal" morality. While presented by the authors only as a criterion within the professional ideal, I have suggested already why these moral aspirations are difficult to confine to strictly professional spheres. Maintaining this separation of professional and private moral aspirations is especially difficult when faced with a pregnant woman who may deny that "perceived risk" is the basic criterion by which carrying a child with a disability is morally defined. When we bring this self-understanding together with the mechanisms of prenatal testing that systematically accentuate certain narrow aspects of the riskiness of pregnancy, we can see some of the reasons why human vulnerability appears to medical professionals in this context as something to be avoided. In this light, the concept of supererogation functions to heighten the extant social stereotypes within which women who wish to accept the most vulnerable in their wombs are portrayed as, at best, making a heroic decision, at worst, an immoral one.

### The Theological Critique of Supererogation

While there may be a historical connection between medieval and modern concepts of supererogation, it may be wiser not to insist on a direct line of descent, because there is at least one important dis-analogy, which appears in how Kant defined the concept. Kant not only reintroduced the concept into modern moral discourse, but his definition of the term also shapes most modern usage, including that of Beauchamp and Childress. Kant's reasons for seeking a concept to distinguish between the duties owed to all people from those owed only to some under special circumstances, draws on a concept of morality as transtemporal and exceptionless because based on universal reason. In the medieval tradition, however, "supererogation" was primarily used as an *ecclesial* distinction, distinguishing between higher and lower paths of virtue. But the critical confluence between the two thought systems is the presupposition that there is a "regular" duty to the neighbor and a "special" duty not incumbent on everyone. In any case,

the ethics of Kantian neo-Protestantism attempted to recover a distinction with this function, and thus returned to this term.

With regard to this presupposition, Calvin expresses the protest of the magisterial Reformation to any bifurcation of moral claims in this manner: "Since we are unduly inclined to hypocrisy, this palliative ought by no means be added to soothe our sluggish consciences" (Calvin 1960, 2.8.58). Such disavowals were to have a long history in Protestant theology, as marked by its anathematization in the Anglican Thirty-Nine Articles (Art. 14): "The works of supererogation cannot be taught without arrogance and impiety" (O'Donovan 1986, Appendix I). Indeed, it is not going too far to say that the Reformation began with exactly this worry about the notion of a "higher way" on which a long and developed theological account of supererogation and vocation had rested. Such moral exception clauses appeared to cut the vital cord of transformative faith to yield a culturally conservative and conformist Christianity (Luther 1966, 17-33; 1957b, 44-45).

Luther was reacting at a fundamental and theological level against a medieval development of a firm distinction between following both Christ's commands (charity, understood through the cardinal virtues) and his more strenuous counsels (poverty, chastity, and obedience). This distinction was mapped onto the monastic-laity distinction, with the nomenclature of "vocation" linked to the higher way, as in Aquinas's *Summa Theologica* (Aquinas 1906, 2a, 2ae, 185.6). In the theologies of the Reformation, the concept of vocation was decisively reformulated and applied both to activities as apparently different as the work of the priesthood, trade, parenthood, and government. This leveling or sacralization of all spheres of human work has had a deep and enduring effect on the ways moderns conceive their lives and work, and, as I have tried to show, has deeply problematized attempts such as those of Beauchamp and Childress, which assume that sharp distinctions can be drawn between "personal" and "professional" ethics (Taylor 1989, part III).

The English term "supererogation" marks its direct descent from theological usage in being a derivation of the Latin *erogare* (meaning "to pay or expend") as it prominently appears in the (Latin) Vulgate in Jesus' parable of the Good Samaritan. The Samaritan, having rescued the injured neighbor, cares for him, takes him to an inn, tells the proprietor to care for him, and promises to reimburse his expenses, as it says in Luke 10:35, "and whatever you spend besides" (*quodcumque supererogaveris*). Zacchaeus's superabundant restitution (Luke 19:8-9) and Paul's using his own funds to

support his ministry (Acts 20:34; 1 Thess. 3:8-9) also serve as paradigmatic examples of supererogation. Whereas Thomas Aquinas and others had solidified the distinction between commands and counsels in a highly technical manner (*Summa Theologica*, 1a2ae 108.2-4), Luther argued that we could in truth obey neither Christ's counsels nor his commands, and so are constantly thrown back on grace and into love of the neighbor without hesitation or moral hairsplitting — completely without reserve (Luther 1957a, 348; 1966, 33).

Luther bequeathed to evangelical ethics a sensitivity to the difference between embarking on projects of moral calculation and justification, yielding a two-tier morality, and the single-tier morality of attentiveness to the neighbor. The Lutheran doctrine of spontaneous good works is, among other things, an insistence that it was no accident that Jesus answered the question about what it means to love one's neighbor with the story of the Good Samaritan. With this story Jesus revalues the Pharisee's question, "Who, then, is my neighbor?" He refuses his interlocutor's assumption that morality begins with trying to define the other "out there" to whom empathy and solicitude is due. His question is wholly different: Who *turned out* to have been a neighbor? Faithfulness here appears as a transformed consciousness in which one's own self-interest is wholly tied to the well-being of the other. Jesus thus suggests the moral force of a specific form of attentiveness to others. Jesus is depicted in the Gospels as trying to inflame this kind of attentiveness in his hearers.

In terms of this attentiveness to the neighbor, the spontaneous responsiveness of the Good Samaritan turns out not to be "irrational" or "unpredictable," but a very practical rationality. Jesus asks us to become people whose investigation of human fragility does not begin by our distancing of ourselves from others as "subjects," but by training ourselves to respond without excuse and without forethought to existing human need. I take this spontaneity to be the *premise* out of which a laboriously cultivated way of life such as L'Arche can emerge. As Jean Vanier himself puts it, L'Arche is a school for relationships, a community where people can discover the fecundity of divine love through attentiveness to others. To discover such spontaneity is a gift of the Spirit that cannot be ensured or legislated by any law, but begins in the prayer that requests it. Such love, as Jesus' parable suggests, requires *conversion*, not simply information or education.

This answer has appeared to most modern Christian moralists as an insufficiently broad account of the foundations of Christian ethics. But that is to overlook the fact that the parable of the Good Samaritan also im-

plies that a steady emphasis on the occasional and gratuitous nature of Christian responsiveness is not opposed to more hardheaded institutional thinking (*pace* Reinhold Niebuhr 1932), but in fact demands it (Ulrich 2005, 109). The Good Samaritan, after all, took his neighbor to an inn for care. Institutions are not the opposite of spontaneity; institutions may aim at or thwart our being turned out of ourselves and toward others. An inn, as a meeting of economic, political, and interpersonal cultures, may be a better or worse place for the Good Samaritan to leave his ward. This insight grounds the cultural criticism of Christian ethics, which is at every point a social ethic.

This understanding of neighbor love combines with Christian commitments to the good of noncoercion in political affairs to yield a refusal of any suggestion that such Spirit-enabled spontaneity can be imposed on all of society. A properly Christian political ethic will thus seek social structures that can protect and promote the space for spontaneous attentiveness to occur, even though the focus on Christlike attentiveness to the neighbor cannot be reduced to or translated into the language of secular rationality. Christians living in communities such as L'Arche can thus be nothing more than witness, one that has *political* benefits that Christians have a duty to offer to a secular political society that cannot conceive it on its own terms (Wannenwetsch 2004, chap. 8).<sup>2</sup> Such a witness stands as a word from outside and above us about the necessity of listening to the voices of those who challenge our presuppositions by wishing to bear and live with the most vulnerable of humans.

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2. Wannenwetsch is commenting on the influential claim to this effect of Karl Barth in "The Christian Community and the Civil Community," sec. 14.

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