

Dignity, Disability, and Bioethics

By D. Christopher Ralston, M.A.

Death with dignity. Human dignity. The dignity of human life. Respect for dignity. These phrases are heard repeatedly in contemporary, bioethical debates from disputants on opposing sides of the same argument, which begs the question: What do these phrases *mean* and how can they be used in such seemingly contradictory ways? This paper aims to provide initial answers to these questions by focusing on human dignity and the uses to which that idea is commonly understood. Given this modest objective, what follows amounts to a cursory sketch. Still, this overview should provide a sufficient starting point for gaining a deeper appreciation of the potential promises—and perils—of appeals to human dignity in advocating on behalf of persons with disability in the public square.

Human Dignity and Its Sources

The notion of dignity is ubiquitous in contemporary bioethics literature. Some thinkers endorse the notion, while others reject it altogether. Despite the currency of the term, there is little agreement as to the meaning, scope, or implications of the concept. Ruth Macklin, in fact, has recently argued that the notion is “useless” and can be reduced, without remainder, to the notion of “respect for persons.”¹ In an effort to defend and elucidate the concept, the President’s Council on Bioethics recently published a volume of essays² addressing the concept, “with the aim of clarifying whether and how it might be a useful concept in bioethics.”³

As Adam Schulman observes, the notion of dignity is routinely invoked on opposing sides of numerous controversies in bioethics. Thus, to borrow Schulman’s illustrative example, different “conflicting intuitions” about human dignity might yield radically different answers to the question of whether or not, and under what circumstances, it would be appropriate to withdraw life-saving (or life-prolonging) medical treatments from a critically ill patient in a neonatal intensive care unit who, if he or she survives, is likely to do so only with severe mental or cognitive deficits.

- If one thinks that human dignity rests on our higher mental capacities, then one might argue that it is wrong to bring a person into the world with a devastating, lifelong mental incapacity, and conclude on this basis that the most “dignified” course of action would be to allow the child to die a “humane” death.
- Alternatively, one might appeal to a notion of the equal dignity of all human life, regardless of functioning, in order to insist that every reasonable measure be taken to preserve and prolong the life of the child.
- Yet again, one might appeal to a notion of dignity rooted in the value of autonomy (very roughly, the ability to rationally direct one’s choices and actions in accordance with one’s own values) in

order to claim that the decision ought ultimately to be left up to the parents in this sort of case, out of respect for their *dignity and autonomy*.

All three advocates appeal, in one way or another, to notions of dignity—yet they arrive at very different conclusions as to the appropriate course of action. Thus, Schulman suggests that human dignity is, at the very least, “problematic as a bioethical concept,” for “a variety of strong convictions can be derived from powerful but conflicting intuitions about what human dignity demands of us.”⁴

One reason for this difficulty lies in the origins of the concept of *dignity*. The term arises from a number of different sources, each of which has a positive contribution to make, but also “brings its own peculiar difficulties to the application of the concept of human dignity to bioethical controversies.”⁵ Schulman identifies four principal sources of the notion of dignity: (1) classical antiquity, (2) biblical religion, (3) Kantian moral philosophy, and (4) 20th century constitutions and international declarations.

Classical Antiquity

One notion of dignity comes to us from “classical antiquity.” As Schulman explains, the Greco-Roman term for dignity arises from the Latin *dignus* and *dignitas*, the approximate meaning of which is “worthiness for honor and esteem.” The basic idea here is that dignity is ascribed to an individual who possesses a quality that is “rare and exceptional”—in the Greco-Roman context, usually an “excellence and distinction” associated with one’s rank or social status.⁶

This notion of dignity immediately raises an important question: “What is it about human beings as such that we find distinctive and admirable, that raises them in our estimation above other animals?” It also raises at least two key problems for its application in a contemporary setting. First, if human dignity is to be understood as rooted in excellence, what then is the relationship between technology and human dignity? If we can enhance or modify human beings technologically, do they then possess greater dignity than unenhanced individuals? Do technological and/or pharmaceutical interventions into human nature *enhance* or *diminish* human dignity?⁷

This first problem highlights a second problem for the classic sense of human dignity—namely, that “it lends itself to invidious distinctions between one human being and another.” How is a notion of dignity grounded in excellence to be squared with equally powerful, but potentially competing, notions and ideals that also hold sway in contemporary democratic societies—notions such as equality, freedom, tolerance and an easygoing attitude? Given these fundamental ideals to which most contemporary democratic societies are committed, in order for such a conception of dignity to be of use as a “robust bioethical concept for our age,” Schulman suggests, “one would have to show that dignity can be something universal and accessible to all human beings as such.”⁸

Biblical Religion

A second major source of “a broader, shared notion of human dignity” is the biblical account, particularly as found in Genesis 1–3, according to which man was created by God, “in his image” (*imago Dei*). As Schulman notes, this notion has been interpreted and developed in a number of ways; nevertheless, a central implication of this notion can be identified—namely, that “human beings, because they are in some respect godlike, possess an inherent and inalienable dignity.” In the biblical narratives and surrounding tradition, man is pictured as having both dominion and stewardship over creation. These two pictures, however, can be understood in ways that lead to potentially conflicting prescriptive imperatives. For example, the picture of man as having dominion over creation conveys a sense of responsibility, perhaps even a perfective one, according to which man is responsible, in some sense, to serve as co-creators with

God in an effort to perfect or finish his creation. Understood in this way, the dominion mandate might be taken as positive warrant for such practices as *in vitro* fertilization, genetic engineering, or even cloning, here understood as “fixing nature in a godlike way.”⁹

By contrast, the biblical picture of man as steward of creation pulls in a different, more humble direction, toward an understanding of man as *created*—as “creatures, not creators.” Here,

... “made in God’s image” has the implication that all human beings, not only those healthy and upright but also those broken in body or soul, have a share in this God-given dignity. . . . Seeing human beings as created in the image of God means, in some sense, valuing other human beings in the way a loving God would value them. It means seeing dignity where some might see only disability, and perhaps seeing human life where others might see only a clump of cells.¹⁰

Since these twin pictures of man derived from the biblical account appear to pull in different directions, it is not *immediately* obvious how the biblical account can provide action-guiding direction in controversial questions. Thus, to cite the example Schulman gives here, what are we to say, from a biblical perspective, about embryonic stem cell research? On one hand, we might appeal to the equal dignity shared by all human beings, including embryos, to argue that such research is a direct assault on human dignity. On the other hand, we might argue that the inherent dignity of man makes healing our preeminent duty even at the cost of justifying all kinds of otherwise morally questionable research.¹¹ The point, for present purposes, is not to settle the dispute,¹² but rather to demonstrate that the notion of human dignity, even when rooted in a concept of man as being made in the *imago Dei*, can be appealed to by advocates on *both* sides. So merely appealing to the biblical notion of human dignity—without further argumentation and clarification—will not necessarily yield unambiguous implications with respect to controversial bioethical questions.

Kantian Moral Philosophy

Immanuel Kant’s (1724–1804) moral philosophy understands human dignity as “the intrinsic worth that belongs to all human beings and to no other beings in the natural world.” For Kant, “all men possess dignity because of their rational autonomy, i.e., their capacity for free obedience to the moral law of which they themselves are the authors.”¹³ Kant thus locates the source of intrinsic worth, or dignity, in rationality—specifically, rational autonomy. All and only rational creatures—whether human or non-human—possess this dignity and must be treated with equal respect. This implies a prohibition on the instrumental use of persons—that is, the use by one person of another as a means to his or her own end.

This understanding of human dignity, which locates its origins and action-guiding force in the possession of rational autonomy, has had a profound impact on the development of ethical thought in general, and on bioethics in particular. This influence can be seen clearly in concerns with clinical and research ethics regarding obtaining valid, informed consent, as well as in the protection of vulnerable subjects used in medical research.

Nevertheless, the Kantian approach presents a number of difficulties. First, it appears to be an overly restrictive account of the moral life. In locating human dignity entirely in rational autonomy, Kant denies any moral significance to other aspects of our humanity, including our family life, our loves, loyalties, and other emotions. The Kantian approach may be limited in its applicability to a whole range of controversial bioethical questions.

A second difficulty with Kant’s approach to human dignity is that the doctrine of rational autonomy itself can be difficult to apply in practice. For example, if rational autonomy is the source of human dignity, then what are we to say of infants, individuals with dementia, those who are permanently comatose, or those with certain congenital mental impairments? Do such individuals—those who either do not yet have,

have lost, or who never will possess the relevant “powers of rational autonomy”—fall below a minimum threshold for human dignity? What are the limits of rational autonomy? How and to what extent do mood-altering drugs and the like affect it? Answers to these sorts of questions are less than immediately obvious in the Kantian approach.¹⁴

Twentieth-Century Constitutions and International Declarations

Finally, notions of human dignity have enjoyed a prominent place in a number of twentieth-century political constitutions and international declarations. Many such documents were drafted in the wake of World War II, with an explicit view toward preventing a repeat of the atrocities committed during that time. For example, in the preamble to the *Charter of the United Nations*, the drafters indicate that one of their purposes, among others, is “to reaffirm faith . . . in the dignity and worth of the human person . . .”¹⁵ Similarly, the United Nations’ *Universal Declaration of Human Rights* (1948) acknowledges “the inherent dignity and . . . the equal and inalienable rights of all members of the human family . . .”¹⁶ Moreover, since 1945, some 37 nations have ratified national constitutions that include an explicit reference to human dignity.¹⁷ Importantly, these appeals to notions of human dignity in various political constitutions and international declarations have left the term dignity entirely undefined. In these consensus documents, various groups—with different ideas about the origin, grounding/justification, and scope/implications of human dignity—appealed to dignity in an attempt to reach political agreement. The framers of such documents had practical, pragmatic objectives in mind. Thus, they eschewed an attempt to develop a *theoretical* account of human dignity, in favor of arriving at a *practical* commitment to a notion of human dignity—however conceived—as the basis for a system of inviolable and inalienable human rights, a system that (it was hoped) would be sufficiently strong to prevent the future occurrence of such atrocities as occurred during World War II. As such, human dignity in these documents amounts to a sort of placeholder standing in for that feature—whatever it may be—in virtue of human beings may be said to be entitled to certain fundamental rights and freedoms.¹⁸

Yet it is precisely this formal and indeterminate character that renders such appeals to human dignity, as found in these political constitutions and international declarations, largely impotent to provide action-guiding direction with respect to controversial bioethical questions. On the one hand, appealing to human dignity may have the salutary effect of encouraging thoughtful reflection on the deeper question of what it is that *grounds* (i.e., justifies) the notion. Moreover, appealing to universal human dignity in order to establish “a baseline of inviolable rights—in effect, a floor of decency beneath which no treatment of human beings should ever sink,” may provide valuable resources for use in attempts to prevent “the most egregious abuses of the new biotechnologies (e.g., the deliberate creation of animal-human chimeras).” Still, as Schulman notes:

... if we are content to regard human dignity as nothing more than an unspecified “Factor X” in virtue of which we are obliged to treat all persons with respect, then, some bioethicists have wondered why we should bother invoking it all. Why not dispense with dignity and simply spell out precisely what “respect for persons” demands of us?¹⁹

This is, of course, precisely the approach that Ruth Macklin and others like her advocate. For Macklin, respect for persons can be specified in terms of “the need to obtain voluntary, informed consent; the requirement to protect confidentiality; and the need to avoid discrimination and abusive practices.”²⁰ On this approach, vague appeals to human dignity can be replaced with concrete requirements— informed consent, confidentiality, and prohibitions of abuse and discrimination—that are, in turn, rooted in the notion of respect for persons. Thus, in Macklin’s view, appeals to human dignity are superfluous at best and should therefore be rejected. Here again, our purpose is not to settle this dispute, but rather to show

that the vague appeals to human dignity found in many twentieth-century political constitutions and international declarations are unlikely—absent further theoretical work—to be taken seriously by many in the bioethics community.

What should be abundantly clear from this survey of these four prominent sources of notions of human dignity is that there is a fundamental question that simply cannot be ignored—namely, the question of what exactly it is that grounds human dignity. Without an answer to that question, the normative (i.e., action-guiding) implications of any appeal to human dignity will remain obscure at best. The need to consider, and to develop thoughtful accounts of, the answer to this question is more important now than ever due to the power of technology to reshape human nature in unprecedented ways.

From a Christian perspective, theology is crucial to providing such an adequate account of dignity. Any such account of the notion will need to be such that it does not deem certain subsets of the human community (e.g., persons with intellectual or cognitive impairments) to be lacking in dignity.²¹ In light of this concern, Christians must look to theology to supply valuable conceptual resources that constrain and correct other approaches to the notion of human dignity.

Conclusion and Action Points

The foregoing overview of the sources and uses of the concept of human dignity suggests a number of key guidelines, or action points, for those who would advocate on behalf of persons with disability in the public square—particularly for those who would invoke notions of human dignity in the course of such advocacy, and would do so from an explicitly Christian point of view.

First, we can identify a number of essentials that any adequately *Christian* account of human dignity must satisfy. Specifically, we need a concept of dignity that will:

- Be universally shared by and accessible to all human beings. Such a concept must not arbitrarily divide the human community into those who have and don't have dignity.
- Avoid making dignity an achievement of human beings; instead, it will understand dignity as being *conferred* by God on human beings, independent of their achievements.
- Illuminate the relationship between technology and human dignity.
- Illuminate the relationship between the biblical pictures of stewardship and dominion and provide guidance as to how those pictures yield specific prescriptive imperatives.
- Explain the significance of the *imago Dei* for human dignity.
- Provide an adequate account of the moral life.
- Provide a rationale for theological engagement with issues in the public square.
- Become widely applicable to and relevant for a variety of bioethical questions/issues.

Such an account of dignity must offer a clear definition of the term; say something about the origins, grounding, and scope/practical implications of the concept; and make transparent the assumptions—religious/theological, ideological, etc.—upon which it rests.

Second, when seeking to articulate a Christian perspective on disability, dignity, and bioethics in the public square, it is crucially important to clearly articulate what one means by key terms such as *dignity*, *person*, *human being*, etc. We have seen that, broadly speaking, on a secular account of dignity, the concept is closely connected with notions of autonomy and the exercise of rational capacities—that is, human dignity is rooted in rational agency. In a Christian account, human dignity is ultimately rooted in the *imago Dei*—that is, since human beings are created by God in his image, their dignity is neither something that is achieved nor something that can be lost, even in the midst of suffering, the loss of autonomy, or inability to exercise one's rational capacities.

Dignity Is Conferred by God—Rather than Achieved by Human Beings.

In this light, it clears that when secular bioethicists refer to human dignity they often mean something very different than the Christian means. A similar disconnect is likely to be present with respect to other key terms (person, human being, etc.), so the Christian engaging in public discussion of controversial bioethical issues must be aware of this possibility.

Third, and finally, we must vigorously defend a robust and distinctively *Christian* view of dignity. We must suggest—contrary to secularist critics like Ruth Macklin—that theology really *does* have valuable resources to add to the discussion. In particular, further intellectual work is needed on the theological, philosophical and anthropological *grounding* of the notion of human dignity. If the concept of dignity is to be employed fruitfully in public discussions of controversial bioethical issues, it must be defended against the attacks of its critics and positively shown to be a relevant concept for contemporary bioethics.²² At the end of the day, this task is a crucial one for the church. From a Christian point of view, theology has a crucially important role to play in public discussions of controversial bioethical questions in which concerns about human dignity are implicated. In this regard, Christoph Schwöbel sums up the role that the church, in light of its distinctively theological view of human nature and dignity, can—indeed, *must*—play in such debates:

... it is clear that the contribution of the church will have to be both critical and affirmative. It will have to criticize all views of what it means to be human—as they are expressed in the sciences, in politics, and in the economy—which define human dignity on the basis of observable attributes based on the capacities of human nature that humans may possess to a greater or lesser degree. Against all such views the church must uphold the principle that human dignity as it is grounded in God's relationship to us requires absolute respect in all stages of human existence and in all forms in which a human life is lived, and cannot be ascribed relatively in proportion to our capacities or incapacities. This critical role will be convincing only if it is enveloped by the gospel the church has to communicate. In virtue of the dignity bestowed upon them by God, all forms of human life carry the marks of creatures who are called to be images of God.²³

The specific challenge for the church then becomes one of articulating a Christian view of dignity in language that makes sense to those who do not share these same fundamental commitments. This suggests a potentially fruitful research project for Christian thinkers doing work in this area, as well as an urgent and practical mandate for the church as a whole.

Notes

1. Macklin, Ruth. "Dignity is a Useless Concept." *British Medical Journal*, 327, 2003, p. 1419.
2. President's Council on Bioethics, 2008.
3. Schulman, A. "Bioethics and the Question of Human Dignity." In *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics*. Washington, D.C.: President's Council on Bioethics, 2008, p. 3.
4. *Ibid.*, pp. 4–5, italics in original.
5. *Ibid.*, p. 6.
6. *Ibid.*, p. 6.
7. *Ibid.*, pp. 6–7.
8. *Ibid.*, p. 7.
9. *Ibid.*, p. 8.
10. *Ibid.*, pp. 8–9.
11. *Ibid.*, p. 9.
12. An obvious possible solution would be to argue for a rank-ordering of the two "pictures," where human "dominion" over the created order is limited by our status as "stewards" (rather than "owners") of creation.
13. Schulman, 2008, p. 10.
14. *Ibid.*, p. 11.
15. United Nations, (1948) *Universal Declaration of Human Rights* <http://www.un.org/en/documents/charter/preamble.shtml> and United Nations. (1948) *Universal Declaration of Human Rights* <http://www.un.org/en/documents/udhr/>
16. *Ibid.*
17. Schulman, 2008, p. 12.
18. *Ibid.*, p. 13.
19. *Ibid.*, pp. 13–14.
20. Macklin, 2003, p. 1419.
21. Hans S. Reinders takes this up with respect to persons with intellectual and cognitive impairments in: *Future of the Disabled in Liberal Society: An Ethical Analysis*. South Bend, IN: University of Notre Dame Press, 2000. "Human Dignity in the Absence of Agency." In R. K. Soulen & L. Woodhead (Eds.), *God and Human Dignity* (pp. 121–139). Grand Rapids, MI; Cambridge, UK: Eerdmans, 2006. *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology and Ethics*. Grand Rapids, MI: Eerdmans, 2008.
22. For recent efforts to engage in theological consideration of issues related to disability, including human dignity, see: Reynolds, T. E. (2008). *Vulnerable Communion: A Theology of Disability and Hospitality*. Grand Rapids, MI: Brazos Press. Soulen, R. K., & Woodhead, L. (Eds.). (2006). *God and Human Dignity*. Grand Rapids, MI; Cambridge, UK: Eerdmans. Sulmasy, D. P. (2009). "Dignity, Disability, Difference, and Rights." In D. C. Ralston & J. Ho (Eds.), *Philosophical Reflections on Disability* (pp. 183–198). Dordrecht, The Netherlands: Springer.
23. Schwöbel, C., "Recovering Human Dignity." In R. K. Soulen & L. Woodhead (Eds.), *God and Human Dignity* (pp. 44–58). Grand Rapids, MI; Cambridge, UK: Eerdmans, 2006.

About the Author

D. Christopher Ralston, PhD, MA is a freelance writer/editor and an Adjunct Professor of Bioethics at Trinity International University in Deerfield, Illinois, where he is also a Fellow in The Center for Bioethics & Human Dignity's Academy of Fellows. From 2013–2020 he worked in the publishing and public policy departments at Joni and Friends, during which time he served as Senior Editor of the *Journal of the Christian Institute on Disability*. He is co-editor of *Philosophical Reflections on Disability* (Springer, 2009) and for several years taught courses in Disability Studies at California Baptist University. He is a graduate of Rice University (PhD, Philosophy), Trinity International University (MA, Bioethics), and Biola University (BA, Communications; MA, Philosophy of Religion and Ethics). His research, writing, and public speaking draws on his own experience as a person with a physical disability, and centers around issues at the intersection of disability, bioethics, philosophy, and theology.