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Radical Bioethics: Difference, Disability, and Desiderata

Mary Jo Iozzio

Abstract

With diatoms—globally abundant single cell algae—as both a model and an extreme example of diversity among a single species, Radical Bioethics examines narrow constructions of human diversity as a failure of imagination and a refusal to recognize disability as another instance of difference. Along with other disciplines, bioethics has been slow to consider its biases, inherited from a history of social constructions, against people with disability. Both desire and desiderata offer an alternative to harms committed against people with disability in matters relating to initiatives that foster their inclusion as critical participants in and rightful recipients of the commonweal.

Keywords: bioethics, desire, desiderata, disability, diversity, historical consciousness, theological anthropology, United Nations Convention on the Rights of Persons with Disability, World Health Organization

1. Introduction

Knowingly or not, disability in the human community is a global reality about which too few register a thought concerning its prevalence. As a result of this unrecognizability, this failure to register, too few people without immediate experience of or any regular encounter with persons with disability remain unconcerned with this largest and most diverse minority of people across the globe (by the World Health Organization estimates, at least 15% of Earth's human population). Moreover, the likelihood of able-bodied/able-minded persons joining this minority increases with age if not by accident or by diagnosis of, for example, Alzheimer's Disease, arthritis, depression, diabetes, heart disease, mental illness, multiple sclerosis, Parkinson's, and other conditions. No geographic location is immune from this prevalence, particularly in relation to the vicissitudes of contemporary life—for example, travel, trudging, terrorism. Unsurprisingly, both poverty and place of residence both increase and exacerbate the vulnerability to being born with or acquiring a disability in one's lifetime. My focus on "Radical Bioethics" offers one response to a dearth of theo-ethical and bioethical reflection on a critical concern for this population. This concern includes the requirements of justice that have been largely ignored in the vein of care for the support and development of basic human functioning capabilities that are available in the common good, the means of which "commons" would be distributed with a preferential justice and safeguard for persons and communities of people with disability [1].

The ethics of critical medical and essential health care for people with disability remains under-considered explicitly, except perhaps as an aside to the focus of

research in bioethics and healthcare ethics more broadly. Nevertheless, a growing number of academics in the humanities and social sciences recognize the need for bioethical, philosophical, and religio-theo-ethical reflection on the subject of disability. Many have begun to notice and reflect upon the ways in which people with disability have been ignored and/or grossly underestimated as participants in and rightful recipients of the commonweal: the common goods of health, education, recreation, employment, commerce, social and political affairs, and religious observance.

What follows continues work I have done on theological anthropology, exploring the diversity of creation, and the radical dependence that characterizes all people—not singularly or especially people with disability but—a dependence that characterizes all people, from the most robust to the infirmed. Such dependence raises critical questions of procedure in theological ethics, bioethics, and healthcare. Among the obstacles frequently encountered in this work are the persistent attitudes, notably identified by the social constructions of disability, that preclude many initiatives that would attend to both critical and basic health care for people with disability. Nevertheless, and even as most are not likely to have been exposed to the histories of the many tragic and rather appalling experiences that people with disability have endured, the good news is as important as the sad and scandalizingly brutal treatment people with disability have received at the hands of their caregivers, communities, and medical professionals in addition to abuse from strangers. Thus, as more people with disability participate today in many different settings where previously they had been excluded *de rigueur*, nondisabled people have become more accustomed to both casual and commercial interactions with them; my hope is to further the work of removing the obstacles to care and the inclusion of people with disability throughout the commons of human encounter.

In this essay I offer a broad look at the current lack of sustained attention in bioethics to the social forces and inherited assumptions that the field has failed to recognize particularly in an unexamined critique of its power and influence to shape the medical and social imaginary. Before entering into bioethics, I offer two precisés, first a theological anthropology of radical dependence and second why radical bioethics—both viewed through a lens that includes an often-overlooked history of the experiences that people with disability have endured over the millennia. Theology undergirds the challenge of wholesale inclusion of people with disability in the main as well as in considerations of how people with disability are to be engaged in participatory bioethics like other moral agents in their exercise of autonomy and self-determination. I then explore the contours of a radical bioethics as it is rooted in principles with which I approach bioethics, namely, a radical posture and proclamation that people with disability are people first. I move then to difference and diversity as key to the root of the participation of people with disability in the commons and the professions. I conclude with a *desiderata*-like meditation on a radical embrace of flourishing for all.

2. A theological anthropology of radical dependence

People with disability and the non-disabled belong to a common humankind that is deigned the *imago Dei* and in which, through the *Kenosis*, God identifies with all human joys and sorrows, births and growth, disability and deaths, as well as the past and the future. As *imago Dei*, humankind takes its primary data from the Christian tradition's teaching on creation, the Incarnation, and Trinitarian theology. The implications of this theology extend beyond a facile nod to the identification of God with humankind: if the Trinity is the theo-anthropological ground

of being human, then the Trinitarian symbol of God must function as a template for all divine and human affairs [2]. The critical importance of a Trinitarian theological anthropology cannot be overstated. If the datum of the tradition is to be believed, then we must be earnest in engaging with God and with one another along the lines of relationship and relationality that is the manifest expression of God for Us [3].

The Christian tradition has long discussed and defended the doctrine of the Trinity and the Trinity's action in the world as Father, Son, and Holy Spirit. However, the Trinity carries doctrinal importance beyond the formulaic introduction to prayer: the doctrine of the Trinity holds the potential of transformative practice among believers and nonbelievers alike. If every person is created in the image and likeness of God, and as God has been revealed to us in triune relationality *in se* and *ad extra*, then relationality—not isolating autonomy or dogged self-reliance—is the form of the *imago Dei*.

“Trinitarian theology is the language of relationality *par excellence*” [4]. not only *in se* but *ad extra* for us and for our salvation. The relationality that subsists within the Trinity is a relationality of a willed quasi-dependence of the Three Persons in One God. We Christians do not know God in any other way than in this Tri-Personal Relationality. This relationality is as God wills it to be in salvation history, *in se* and *ad extra* dependent in form and matter though uniquely unified and subsistent in effects: “the economic trinity is the immanent trinity and *vice versa*” [5]. It is thus *in se* wherein God enjoys/relates in God's own company and *ad extra* wherein God enjoys/relates to all that God has wrought for us—the symbol of a relational God functions.

“That symbols are signs is certain: they are expressions that communicate a meaning; this meaning is declared in an intention of signifying which has speech as its vehicle” [6]. Christian theology speaks of God in the terms of an I-Thou relationship. If the symbol of God functions in a vehicle of relationality and to be in relation suggests dependence within the one and the three, then relational dependence holds first place in the ways that we are to envision the *imago Dei*.

Of course, dependence in inter- and intra- Trinitarian relationality differs exponentially from the dependence experienced by the *imago Dei*, nevertheless dependence is in this anthropology relieved of its burdensome negative connotations. Dependence in this sense is neither a bad word nor a bad idea. It is, alternately, liberative. I am suggesting that unity in diversity translates to the *imago Dei* as radical dependence, human dependent relationality: we human beings are dependent upon God and upon one another from our conceptions and births, through childhood, adolescence and adulthood (to think otherwise is foolhardy) [7]. This symbol of God for us expresses intentional relationality as the ontological ground for understanding the function of the symbol that is the *imago Dei* rightly inclusive of every manifestation of God's creative incarnate sanctifying love or wrongly exclusive of any.

In this theology, relations exist on account of difference. God is conceptualized through a medium of difference or diversity as the Trinity of Divine Persons, different *and* related: God as Father and Creator, God as Son and Incarnate Word/Jesus of Nazareth/the Risen Christ of Faith, and God as Holy Spirit and Transcendent Love within the Godhead and to all the world. “The mystery of God is revealed in Christ and the Spirit as the mystery of love, the mystery of persons in communion who embrace death, sin, and all forms of alienation [e.g., difference] for the sake of life” [8]. In Christian terms, the only way for us to know God is through God's own self-disclosure as the divine being in relation with Godself in Trinitarian union and in relation with the rest of creation and perhaps we human beings in particular, in anthropological terms. As beings created in God's own image, we human beings are

known only in relation to God and to one another: our self-knowledge is dependent on the diversity of persons and all other beings and things in the world.

I propose that we take difference or diversity as the key to our being in the world and in relationality with all reality thereby. While we may hesitate to consider disability as the *sine qua non* condition of humankind, it behooves us to recognize diversity and the dependence that attends to all beings and to all of our relationships, of intimate and of distant or impersonal kinds. This dependence on “the other”—all too frequently assumed true especially (only?) for people with disability—unfolds in both deliberate and indeliberate ways, by choice or by literal or figurative accident. However, whatever our present status on the ability- disability spectrum, our task is to become ever more mindful of the other(s) among us and to recognize the webs of connection in place of potential self-loathing or of rejection, disdain or fear of the unfamiliar/not related/unrelatable other. Such a potential is a blasphemy against God in whose image we are all created and by whose begetting us makes us members of a single family, more than neighbors, sisters and brothers all. And we need to confess the sins and the near occasions of these blasphemous sins against God, ourselves, and our siblings near and far. The radical dependence of being in the world belies autonomy and the “self-made man.”

Thus, when we turn to disability identity with a posture of humility, we may soon discover the magnificent diversity in the ways that persons become themselves and we may soon find them and ourselves beautiful. Consider the tendency of delight many of us experience at the sight of a majestic mountain scape, a field of wildflowers, a herd of buffalo, a night sky filled with stars, or the songs of wild birds. We marvel at nature’s diversity, but we may be stingy in recognizing diversity in humankind. In the world of dualistic segregations, superficially identifiable differences have been used to categorize and, invariably, establish hierarchies that ranked individuals and communities on the basis of their conformity to a norm. In the case of human norms the dualisms of male/female, spirit/body, white/non-white, heterosexual/homosexual, and non-disabled/disabled have designated *de facto* the second part of each pair as a defective version of the first part; those designations subsequently led to the oppression or patronization of the second by the first. However, when diversity, inclusive of people with disability, is presumed as normative, these dualisms lose their power to elevate one expression of diversity, however narrow or large, over the diversity of other expressions. When diversity is normative dualisms no longer make sense and an anthropology of inclusion can emerge in their place.

3. Why “radical” bioethics?

3.1 Meanings and implications of Radicality

The *Oxford English Dictionary* offers three meanings of the term “radical,” each referring to the defining nature of someone or something as 1) fundamental or basic, essential, quintessential; 2) inherent or innate, intrinsic, structural; and 3) comprehensive or constitutive, organic, root [9]. I start with the notion of “radical” as root to agitate any personal complacency toward what we in the “west” have inherited as a hierarchy of being, at least since Linnaeus in the eighteenth century if not well before, with the 6th century BCE pre-Socratic philosophers to the Aristotelian trajectories in metaphysics of the 4th century BCE. Additionally, with the anti-racist, feminist, and LGBTQ critiques, I hold a view toward a socio-political and theological kind of disruption about the taxonomic hierarchy and the subsequently normative ways of thinking about ourselves as members of the family

hominid, genus *homo*, and species *Homo sapiens*. I challenge determinations at the root of “Who Counts” as members of the human fold at the fundamental, inherent, and comprehensive levels of this hierarchy. And I challenge the agency that some members of the species have exercised in determining restrictively the agency of most others—those many others classified as marginal to the social, political, and religious, let alone the academic and professional elite.

I am suggesting a radical/root change in the way people with disability are perceived by many among the nondisabled community and the subsequent ways in which they—people with disability—are disabled by the social, medical, philosophical, political, and theological constructions of non-normative “being” in the world. The idea of constructions that cohere with the now widely accepted rejections of and efforts to dismantle racial, ethnic, and gender biases is critical to the work of dismantling stereotypical assumptions about disability and about people with disability. Briefly, the social construction approach presents the contemporary critique of long-held-to-be true determinations about individuals and groups of “like” individuals such that all persons belonging to the class have uniform experiences of “being” a Woman or Black or Indigenous or Gay ... or Disabled. Moreover, individuals and the groups to which they have been “assigned” are stigmatized for being ... women, non-Anglo, Native/Indigenous, Queer, and/or Disabled [10]. Thus, following the lead of people with disability and their co-agitators in the radical disability movement, my approach to disability has matured from a focus on individual problems experienced by individual persons with this or that particular impairment “to the wider oppression and social barriers that [have historically] excluded and disabled people” [11].

For all its efforts to promote autonomy, beneficence, nonmaleficence, and justice, bioethics is not immune to the inherited social constructions of disability. These constructions hold alongside the inherited assumptions about people with disability and the various ways in which they, people with disability, have been and continue to be calcified, categorized, and classified as, mostly, unfit to share space with the nondisabled. However, since none of us are immune from these inherited assumptions and their subsequent applications to real people, it is important to unpack the assumptions about disability for the dangers that lurk within them. Similarly, it is important to dismantle the oppressions that accompany the constructions that build on these assumptions. Granted, none of us likes to think that we can be mistaken about the values inherent to this or other concepts (like beauty, strength, and adaptability). Nevertheless, glaring examples of the misappropriation of personhood abound: for example, some of the handing down of religious practices from generation to generation were conducted under penalty of death if refused and, just as mistakenly, imperial conquests (e.g., by the Portuguese, Spanish, British, French, Chinese, Ottomans, and the United States) denied the humanity of many indigenous peoples in Africa, the Americas, and Asia. Let us not be fooled. Many people today suffer enslavement in the form of human trafficking for exploited labor, organs, or reproductive service, and sex [12]. In ways similar to the contemporary enslavement of people who occupy places hidden from a decidedly prejudicial social history and from “polite” company, too few people register a thought about the similarly prejudicial, marginalizing, and oppressive experiences of people with disability.

With exceptions, people with disability have not been treated well. Their treatment has been identified and outlined for us by social science academics, psychology and nursing professionals, and humanities scholars in a system of models that distinguish one manner of treatment—with positive or negative effect—from another manner. Contemporary studies offer an approach to this history through the models of disability, developed by people with disability, that are related closely

to the ways in which the non-disabled and dominant codified their perceptions of people with disability according to the social roles to which they were assigned. The most common models of disability are the religious-moral model where individuals or their parents or communities are responsible for disability as a punishment from God for sin or sins committed; the medical model, which “conceptualizes disability as deviance and lack within the individual, and therefore all medical interventions are geared toward bringing the individual as close to normalcy as possible” [13]; and the social construction model of physical and attitudinal barriers of exclusion, like stairs and inaccessible educational, commercial, health, political, or recreational opportunities. In addition to these three, other precisions have been offered with the tragedy/charity, expert/professional, rehabilitation, economic, and rights based, customer/empowering models [14]. Parallel to these models are social roles to which people with disability have been assigned as their being sick or sub-human, a menace, pitiable, a burden, holy innocent, inspirational, amusing, and a blessing [15]. Regardless of model or role, each of these assignments includes greater or lesser degrees of stigma: the defining mark of otherness that clears the way to marginalization and to greater or lesser degrees of direct marginalization, oppression, and violence [16]. The models offer a shorthand reference to understanding the presumptive attitudinal barriers that people with disability and their companions encounter all-too-frequently to this day [17].

As disability advocates remind us: “it’s important to remember here that throughout recorded history all forms of inequality, injustice, and oppression have been sanctioned in one way or another on the basis of assumptions of biological inferiority” [18]. Contemporary efforts to decry these injustices and to reject these assumptions, such as to include the perspectives and insights of people with disability, are rare and, when present devolve all-too-easily into patronizing thanks and nods. “Why, at almost the end of the second decade of the 21st century, are the [basic and fundamental] human rights of people with disability still ignored?” [19].

As suggested above, those with the power to make and shape societies have been grossly mistaken in their judgment about the inherent human value and dignity belonging to people with disability and others who do not conform to hegemonic norms. Those mistaken judgments are the bases of a history of maltreatment that people with disability have endured, a history that has been largely ignored and likely intentionally unrecorded; in effect, people with disability themselves and their stories of success and failure and of loves and losses have been silenced over the course of time. However, that culture of silence is no longer acceptable: the truth to be told is that newborns, infants, children, and adults have been neglected, abused, and exterminated on account of the presence of disability in their lives [20].

I now turn to the historically prevalent exclusion of people with disability to contextualize their experience and its residue in the main and in bioethics today.

3.2 A brief survey of historical experiences

With 15% to potentially 25% of people worldwide having one or more disability today (up to 1.75 billion of 7.6 billion people), it is undeniable that people with disability have been among the members of the human economy from antiquity to the present. Combining the models of disability (medical, moral, and social) to parallel social roles (menace, burden, clown), individuals were identified taxonomically as other. Given the lessons that contemporary retrievals of the historical experiences of many members of minority populations have uncovered, this “othering” of people with disability has resulted in their oppression as a class that, like racism and sexism, can no longer be tolerated.

To the extent that those who have held power and authority record history, resolutions concerning people with disability resulted in their marginalization on account of the causes those powers presumed were at fault from: divine punishment for some sin (either one's own or one's parents) or a pre-emptive warning show of divine power; consorting with evil; an imbalance of humors; maternal stress during pregnancy; bestiality; menstruation; and astrology. Each of these causes encouraged perceptions that people with disability were more animal or otherworldly than human, that they could tolerate environmental extremes and malnutrition, and that they were dangerous to the societies in which they lived—conclusions that gave license to harm them with impunity by taming, exhibiting, sequestering, and worse.

Scandalously, many individuals with disabilities—feared and/or loathed by the non-disabled—would have been exposed at or near birth or otherwise ostracized once the presence of a disability became known [21]. Infanticide by exposure was widespread and, in some state-sponsored cultic systems, the practice was mandatory. Some early Greek medical texts instruct on recognizing defects at birth, in the first months, and early years so as to determine a child that is not worth raising [22]. Aristotle too recommended laws to prevent the rearing of “deformed” children and to deny deaf children access to schools, since they would burden the progress of the non-disabled children/boys of the community [23]. In Greco-Roman antiquity it would not have been uncommon for newborn girls or a newborn with observable disability to be abandoned or left in a crude cradle at a crossroads or near a market, gymnasium, or temple with some possibility of being taken (and likely enslaved), or tossed into a river by their patriarchs. Equally troubling and perhaps more horrifying, some parents or overseers and other wardens, who depended on “income” from begging, would mutilate their biological or “adopted” children with disability to increase the pity-value that patrons might assess on them and thereby increase almsgiving to their cause of household maintenance [24]. Among other curiosities, the Roman gladiator games included the spectacle of fights between little people, the deaf, other people with varying disability, women, and animals. Less brutal but not less disturbing were practices that exhibited individuals with disability in courts of power: as a sign of blessing, entertainment, or pity to extend telethon-like charity.

The early medieval period made way for the custom of caring for the sick, those with disability, and the poor. Outside of the support of their natal homes, people with disability were reduced often to poverty and they resorted to begging as a principal means of income. Wanting to follow the example of Jesus, who attended to those who were marginalized for this or that stigma, Christians began to extend compassion on the less fortunate. By the height of the Middle Ages in Europe, a “period of organized beggary” led to guilds open to people with disability wherein leaders emerged, and rules and languages developed by guild members [25]. The guilds represent a welcome initiative by today's standards. Yet, this same period saw the institution of “idiot cages” that kept people with disability confined, while the cage protected those beyond the bars. And where cages were insufficient or when the masses tired of this or that caged group, the “ship of fools” provided another form of distance to keep people with disability separate and exploited as members of a traveling carnival-horror-freak sideshow for port residents and visitors alike.

And then came the development of institutions. Founded as a result of a system of hostels for pilgrims on their way to a holy site for both blessings and cures, hospitals for the sick and incurable became asylums for the insane and invalid. With the advent of the Enlightenment project to reject the old and quaint in favor of a rational order, new scientific ways of conceiving the individual in society and the common good brought to the fore utopian concerns of a more perfect communion, overtly including an underlying concern for the dangers lurking in any near

presence of people with disability. The isolation of institutions provided safety for the non-disabled as well as it gave rise to better or worse care for those institutionalized where—up to and including the 21st century—as a captive population, they could be studied “objectively.” With concentrated access to people with a diverse array of disabilities, doctors and scientists began to investigate the causes of disabilities using then newly advanced medical and empirical methodologies. Some of this early science fueled the later nineteenth and early to mid-twentieth centuries’ eugenics movements through the subsequent sterilization of people with disability and other suspicious folk [26]. Consider the scientific “proofs” of a biological basis for the categories of race and the subsequent discrimination against non-white peoples, especially peoples of African descent, that labeled many deviant. People from Mediterranean countries and Asia were considered to be of “questionable genetic stock” and likely to increase the number of feeble-minded or criminals that would become wards of the state; it would be better to prevent them from reproducing altogether [27]. As long as people were institutionalized and isolated from general human commerce, they were—and those who remain institutionalized are—vulnerable to abuse, exploitation, and other dehumanizing injustices.

The confluence of social progress, science, and rational self-interest led to the systematic individualization and medicalization of all persons—those deemed “normal” and those deemed “othered”—as subjects (the normalized) and as objects (the aberrant/abnormal/disabled). This systematic program led to a widespread ideology of disdain for, dis-ease with, and distrust of any who did not/do not conform to the hegemonically putative/normative/ideal modern man. By the twentieth century, eugenic initiatives were set in Europe and the United States with sterilization programs and final solutions in a murderous holocaust of untold, unnumbered, and unaccounted hundreds of thousands of people with disability. Scandalously still, eugenics and euthanasia by a different name continue apace with neonates, children, adolescents, and adults in their prime and elderly with disability as today’s principal populations that are vulnerable to medical-social-scientific control. While eugenics may not be institutionalized, it holds ideological power and is practiced widely in reproductive medicine and the selective abortion of fetuses. Similarly, euthanasia remains a threat as the contemporary equivalent of exposure by withholding life support from a person—neonate or adult—who could thrive if given the chance, not with heroic or extraordinary intervention but with the radical bioethics notion of ordinary care.

4. A disability-informed bioethics

4.1 Disability is multi-dimensional and multi-experiential

“Disability is a multi-dimensional concept, which should be understood in terms of a continuum” [28]. This continuum is true for all people once born and throughout the days of our lives. Even so, a disability continuum may have more dramatic punctuations than the general population. As such, bioethics attention to the multifaceted experiences of people with disability has the potential to integrate disability experiences in both critical interventionist care for things like substance abuse or cancers as well as the more mundane and presumably easier access to routine health checks and preventive holistic services like nutritional support, exercise, education, and social interaction in arts and leisure and recreation. Bioethics will need to approach the subject with humility, since any attempts to categorize disability in generic terms will fail, especially since the human organism is itself complex; nevertheless, the phenomena of disability are expressed in the literature

as physical impairments, sensory impairments (e.g., blind and deaf), cognitive and/or developmental difficulties, mental health, and chronic illness.

While disability has been a feature of human life throughout the millennia, the contemporary climate suggests that the phenomena is rare or, if not rare, better to be left unspoken and closeted. The history above belies the rarity of disability and the suggestion that a culture of glamor or power or the accumulation of wealth is sufficient to disguise the presence, the challenges, the joys, the hopes and sorrows, as well as the contributions of persons with disability in ways grand and small yesterday and today [29]. The initiatives of the United Nations in its *Convention on the Rights of Persons with Disabilities* (2006) are key for advancing the cause of recognition and self-determination for all people with disability. Although the United States has signed, it has not ratified the *Convention* and remains thereby not bound by its statutes. Article 4 notes nonetheless that “States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability” [30]. The full realization of all human rights requires that persons with disabilities, like the nondisabled, have access to the basic goods of safe housing, potable water, nutritious food, education, family relations and friendships, healthcare, employment, recreation, public services, and religious or other spiritual practice. Additionally, Article 10 reaffirms “that every human being has the inherent right to life and [States Parties] shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others” [31].

In 2001 the World Health Organization published the *International Classification of Functioning, Disability, and Health* (ICF) and in 2007 the *ICF-CY* (children and youth) as the framework for measuring health and disability at both individual and population levels. In these texts and in the related 2011 *World Report on Disability*, WHO conceptualizes a person’s level of functioning as a dynamic interaction between her or his health alongside environmental and personal factors, with a comprehensive basis for the definition and measurement of health and disability [32]. The idea of functioning as a measurement standard was inspired by the work of economist Amartya Sen and philosopher Martha Nussbaum, who developed the “capabilities approach” to discern an individual’s functional development and attainment of health [33]. In brief, the capabilities approach holds that all human beings have a virtual obligation to develop the abilities—inherent to each albeit in variable and disproportionate measure across the capability spectrum—as a positive natural right and the province of human initiative that lead, if given the opportunity, to flourishing and a good human life. Nussbaum articulates these capabilities as the basic human rights to acquire functional development of life: bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliation; concern for other species; play; and control over one’s environment [34].

As used in the ICF, the capabilities approach offers a holistic metric to determinations of health and well-being based on individuals’ development of abilities aligned with the personal, local, regional, national, and global infrastructures—of educational, occupational, medical, recreational, and social opportunities—that are necessary to support that development. In matter-of-fact straightforwardness, WHO admits “Disability is part of the human condition” [35]. WHO argues further:

[The] ICF is named as it is because of its stress is on health and functioning, rather than on disability. Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking. We want to make [the] ICF a tool for measuring functioning in society, no

matter what the reason for one's impairments. So, it becomes a much more versatile tool with a much broader area of use than a traditional classification of health and disability.

This is a radical shift. From emphasizing people's disabilities, we now focus on their level of [functioning and] health [36].

4.2 A radical shift in understanding disability

The ICF distinguishes between body functions, body structures, activities and participation, and environmental supports or lack thereof. To use the language of more common parlance: the functions reflect the purpose of mental, sensory, voice, organ, metabolic, reproductive, neural-muscular-skeletal, and skin systems; the structures refer to the engagement of procedures or steps involved with voluntary and involuntary movement. Activities and participation consider the degree to which individuals engage both functions and structures from cognition, affect, and locomotion, to self-/family-/community-/social-/civic-care. Environmental factors include considerations of the presence or absence of support for integral human development and flourishing.

Thus, given the complexities of functions and structures, disabilities fall into one or multiple classifications. In a similar vein, many people have co-occurring symptomatic dysfunctions, particular disabilities, and health complications with their primary mental, sensory, voice, organ, metabolic, muscular-skeletal disability. Under the Americans with Disabilities Act (ADA), the categories that qualify a person for accommodations of individualized support or relief are expressed in physical or mental impairments that interfere with major life activities [37]: Affective Disorders, Autism, Blindness, Cognitive Disability, Deafness, Emotional/Development Delay, Hearing Impairment, Intellectual Disability, Muscular/Physical/Skeletal Impairment, Neurological Impairment, Other Health Impairment, and Specific Learning Disability. These initiatives and legal precedents cohere with a baseline understanding of human capability that takes the contexts and particularities in which individuals and communities live as key to unlocking and supporting everyone's basic human functioning capabilities. Nevertheless, "People with disability are characterized by low human and social capital" [38]. Thus, to consider health on the basis of functional capabilities development is both promising and dangerous for people with disability. Promising since focus is placed on the determinations of an individual's capabilities and efforts in collaboration with social systems to develop those capabilities; dangerous since location will determine access to those necessary support systems. As a cause and consequence of disability, poverty remains the single most difficult obstacle to overcome, and poverty is directly related to an individual's ability to both develop and then exercise her/his basic functioning capabilities and thereby to thrive.

5. The difference of radical bioethics

The thing I propose as "radical" here is not in the sense of "protocol-be-damned" but in the more mundane and more nuanced frame of the ways in which a fundamental set of attitudes and actions can take hold in matters pertaining to bioethics in general, to the subject of disability and, more importantly, toward persons with disability in particular. The radical nature of this inquiry hearkens to the origins of the discipline of bioethics begun with the Hastings Center in New York (1969),

the Kennedy Institute for Ethics at Georgetown University (1971), and to Van Rensselaer Potter (1970), the oncologist who coined the term (at least in its English usage) [39]. Potter was particularly interested in the intersections and shared information of findings between the biological sciences and the humanities so as to ensure the benefits of research would yield results that attend to real persons and the eco-systems that support life: “global in scope, transdisciplinary in method, and, most importantly, compelled by a commitment to action that demanded personal engagement with social issues” [40]. This inquiry is radical in its adherence to the foundations of the discipline per Potter and our early colleagues at the Hastings Center and Kennedy Institute—many if not most of whom were trained as undergraduate students in philosophical and/or theological disciplines and for whom the sciences of medical care and interventions were perforce designed for human health and the social good. Further, my project invites you to adopt this interdisciplinary approach of a radical bioethics of dependence on the whole sphere of human commerce, with dependence as a normative key thereby for all persons inclusive of persons with disability across the millennia.

Difference is key to appreciating the diversity of persons and the perhaps even greater diversity of experiences among people with disability as equal to those among the general population. In order to ensure a comprehensive view, the insights of sociological critiques, which approach bioethics with quasi casuistry from the particularity and context of specific cases, offer a compelling argument that attends to lived experience, institutional culture, and structural injustice as the starting places to uncover the realities that honor persons with disability [41]. These approaches recognize that determinations of functioning capabilities depend upon considerations of interpersonal relations, institutional structures, and the overall social world wherein the subjects of concern, whether persons with disability or women or people of color, are situated in real time and place.

Moreover, “We cannot reduce the complexity of disability to either a biological problem, a psychological problem, or a social problem” [42]. All the factors of an individual’s life must be considered and interventions—of medical and rehabilitation kinds, assistive devices, psychological support, barrier removal, welfare benefits, legal protections, and cultural change—must be engaged at different and particular levels for the benefit of the individual in need of care (there is no one protocol that fits all persons adequately). As many in the field of Disability Studies argue forcefully, disability may present as a health concern, but it is more an issue of social and economic concern. As noted above, across the world people with disability lack access to basic health and rehabilitative services as well as a lack of social support in the development of their basic human functioning capabilities. “They face barriers and prejudice, or poorer quality of healthcare. This [subpar access to care] means their health outcomes are worse—not as a result of their underlying impairments, but because of failures of [access to] general care” [43].

But what is difference at its root? Difference is a condition of being or a relation of distinction or diversity between one thing or person and another. An older Latin connotation points difference in the direction of diversity and is suggestive of variety, a point of dissimilarity but similar enough as to be recognizable as this or that thing or person. I have argued that diversity is the distinguishing feature of all creation, human beings included [44]. And I argue that diversity is the signature of God’s handiwork throughout the known world and beyond. I recognize this diversity as God’s own “calling card” and the way that God, in the Christian tradition, reveals Godself to us in relation with self and with others.

6. Radical bioethics: desiderata

I have long avoided the question of desire in Ref. to interrogating my own life and its wondrously circuitous and amazing turns except to ponder the opportunities given alongside the choices made that brought me to this moment in time, and to give thanks. I've led a charmed life, not without roadblocks here and there but, charmed, nonetheless. For an even more conscious period of time, I have avoided the question of desire in Ref. to the lives of people with disability. I like to think that this avoidance is rooted in a posture of humility by virtue of not knowing in any intimate sense what life is like in another person's shoes. I cannot truly fathom another person's "longing for something lost or missed," "to feel the loss of," or "to be wanting" [45], the root meaning of desire. Nevertheless, I am drawn now into this subject in recognition of the sad history of medical and social treatment that people with disability have experienced across the millennia—from exposure to bullying, abuse, and murder—and to conversations that many academics, medical professionals, and policy makers have regarding the spoken and unspoken assumptions that "they"/people with disability would be better off dead. I am drawn also into the subject of desiderata by genuine calls initiated by some persons with disability and their family members, friends, and caregivers for interventions that promise rightly to relieve some of the conditions—especially physical pain and the internalized suffering of rejection—that compromise human flourishing.

"Disability, in everyday thought, is associated with failure, with dependency, and with not being able to do things. [Many of the nondisabled] imagine it must be miserable to be disabled. [But] both empirical evidence and anecdotal testimony reveals that for many people with disabilities, life is surprisingly good" [46]. Moreover, when asked, many people with lifelong disability say, "we don't want to be cured." For many, except for bouts of pain (it is initially very different for people who acquire disability in their teen and adult years), their lives are fulfilling the way they are and their disability is part of their identities such that it is near impossible to envision a life without disability. "The medical focus of cure and change [is] linked to an assumption that disabled people want to be cured. ... The dominant discourse fail[s] to recognize disability as a desired differentness, which can be core to an individual's identity" [47].

Despite the best of intentions of family members and caregivers, like the non-disabled, persons with disability are themselves the principal subjects of their own lives and desires and they are thereby entitled to the exercise of autonomy. I am presuming a degree of cognitive and communicative autonomy that may be absent on account of age or developmental disability. Age aside, unfortunately, their desires were rarely taken into account across the standard practices of paternalism, such that past discussions in the medical arena on life with disability were often limited to questions of "to treat or not to treat" (and to let die) [48]. Today, with increasing Disability Rights Advocacy and given the voices of people with disability on the subject of cure, questions of intervention point more directly toward facilitating life with disability through barrier removal alongside of relief for sickness when autoimmune responses or influenza or cancer or diabetes or other calamity present. Thus, not unlike preferred choices when it comes to the dinner menu, decisions regarding this or that intervention, care protocol, or cure demand the exercise of personal autonomy and must be solicited from persons with disability in as equally an informative measure and accessible language as are decisions solicited from the nondisabled: the desires of people with disability must be honored.

As I return then to desiderata, a minimum desire among the communities of people with disability is to recognize their agency. Granted, the spectrum of

conditions that qualify as disabling are themselves diverse and often overlapping, both identity and agency diversities will emerge between physical, cognitive, and developmental disabilities but social stigma—the historically definitive construction of people with disability as inferior “to the main” and, as such, “other”—remains a common experience across the spectra. The de-construction of stigmatizing “otherness” remains the principal desiderata of my work. From that recognition, the tangible desires voiced by people with disability include minimally [49]: 1) the removal of barriers both physical and attitudinal to wholesale inclusion throughout the many avenues of social commerce—oppression remains the single most problematic of personal barriers to overcome; 2) reasonable accommodations to facilitate participation (e.g., accessible communication formats like sign language, braille, and illustrations); 3) an overall slower pace in language and in movement from place to place and for task to task; 4) attention and equitable access to basic and critical healthcare, education, and employment; and perhaps most of all 5) friendship and other personal relationships beyond kith and kin in educational, social, commercial, employment, political, recreational, and religious arenas.

What else is to be desired?

Since many disabilities are acquired over the course of a person's life, prevention of disabling impairments is an obvious desire. Hence, practical initiatives to reduce acquired disability include hard hats and other protective gear for manual laborers, immunizations from communicable diseases, reduction of exposure to hazardous materials, balanced diet for all and nutritional support especially for women who are pregnant or planning pregnancy, moderate alcohol and other “recreational” drug consumption, respect for speed limits and traffic conditions, avoidance of violent games and guns. We delude ourselves into thinking that any of us are immune from any of these eventualities.

On immediately practical and tangible levels, people with disability globally face obstacles to living and to living well that many of us see only as voyeurs during newscasts or from charity appeals for help. But the daily needs of most people with disability are embarrassingly simple: mobility aids like wheelchairs and rollators, barrier removal, reliable electricity, access to potable water, protein and carbohydrate, contained human and animal waste, basic healthcare and primary education. Let us recognize that meeting the desires of people with disability is not rocket science but, until we break free of these attitudinal and ideological barriers to recognition that people with disability are people first, these basic needs of common goods remain out of reach. It's rather simple to admit, but not easy to make the changes necessary for a tomorrow that all can better enjoy.

7. Concluding thoughts on radical bioethics

I started this work with an invitation to consider today's more than one billion people with disability as one of the most diverse populations—15% to potentially 25% of the 7.6 billion people worldwide. This population is a mass of people relegated to the margins of the larger social groupings to which they belong. In a time when gender, race, and bio-ecological diversity are championed and barriers to inclusion dismantled for some, the margins of human commerce to which many if not most people with disability are consigned are no longer tolerable.

Truth be told, medical and healthcare professionals have approached care concerning persons with disability with a jaded view and a jaded past regarding their worth as marginal at best or their status as less than deserving of either routine or critical care. In response, I suggest, this “radical bioethics” that 1) invites healthcare and bioethics professionals to recognize that a patient with disability

is a patient first; 2) points to a lack of attention on the part of these professionals and the discipline of bioethics to be aware of the similarities and differences that disability presents in deliberations of treatment protocols; and 3) as WHO admits, “from emphasizing people’s disabilities, we [have made a radical shift to] now focus on their level of [functioning and] health.” Thus, following the lead of members of the communities of disability who have engaged legal argumentation on behalf of their vulnerable sisters and brothers with disability who have not received a fair hearing regarding their care, this disability consciousness is best informed before considerations about medical interventions available to persons with disability are pronounced.

As Professor of Law and Bioethics Alicia Ouellette observes:

“bioethicists tend to support individual choices to refuse medical care, family decision making, and advance directives. Members of the disability community are often skeptical of or opposed to these practices. Some disability experts view medically assisted nutrition and hydration as a basic human right; bioethicists tend to think of medically assisted nutrition and hydration as no different from other medical treatments [that may be withheld or withdrawn]. Bioethicists support efforts of doctors to “fix” physical impairments; disability scholars question the need to “fix” the bodies of individuals with disability and look instead for societal solutions. Many bioethicists view persistent vegetative state as something entirely different from other disabling conditions; some disability activists deny those differences. [And] many people in bioethics seek to resolve individual cases without taking into account social and community concerns, whereas social and community concerns are central to the disability community” [50].

Desiderata.

And a final word regarding the title of this work. Philosopher and lawyer Max Ehrmann wrote the poem “Desiderata” in 1927, it was published posthumously in 1948. Its popularity may have waned of late but we human beings continue to burn with desires/*desiderata* of many kinds, some mundane and others profound. Whatever the desires of people with disability, their family members, friends, those who care for and about them, and those who do not, I think we can take Ehrmann’s word to head and heart in our strivings for a better tomorrow:

Go placidly amid the noise and haste, and remember what peace there may be in silence.

As far as possible, without surrender, be on good terms with all persons.

Speak your truth quietly and clearly;

And listen to others, even to the dull and ignorant; they too have their story.

...

Beyond a wholesome discipline, be gentle with yourself.

You are a child of the universe, no less than the trees and the stars;

[And] you have a right to be here.

...

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Author details

Mary Jo Iozzio
School of Theology and Ministry, Boston College, Boston, MA, USA

*Address all correspondence to: mary.jo.iozzio@bc.edu

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