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# Bioethics as Ideology: Conditional and Unconditional Values

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For all its apparent debate bioethical discourse is in fact very narrow. The discussion that occurs is typically within limited parameters, rarely fundamental. Nor does it accommodate divergent perspectives with ease. The reason lies in its ideology and the political and economic perspectives that ideology promotes. Here the ideology of bioethics' fundamental axioms is critiqued as arbitrary and exclusive rather than necessary and inclusive. The result unpacks the ideological and political underpinnings of bioethical thinking and suggests new avenues for a broader debate over fundamentals, and a different approach to bioethical debate.

**Keywords:** bioethics, disability, ideology, normalcy, Schiavo, review

#### I. INTRODUCTION

Where is Wesley J. Smith? Why is the cranky critic of bioethics not writing in our journals or invited to speak at our convocations, that of the American Society of Bioethics and the Humanities (ASBH), for example? His critique of the field, *The Culture of Death* (2000), outsells most books on bioethics by a magnitude of at least ten. More to the point, Smith's arguments have found a wide general readership including, among others, *Washington Times* columnist Nat Hentoff (2001). The long-time liberal writer praised Smith and his work for "the range, depth and accuracy of his research," urging everyone read Smith's critique of bioethics "if only in self-defense."

The assumption that average citizens need defending from bioethicists explains in part why we do not invite Smith to our meetings, or to write in

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our journals. His argument is a challenge that resonates among average citizens; one argued at a level we do not wish to engage. It scares us because it *is* fundamental, advancing an opposing and consistent set of values most bioethics reflexively refuse to engage. Simply put, Smith's argument is ideologically incompatible with those most bioethicists—a loosely inclusive term including those philosophers active in medical areas of interest, and medical personnel who have taken training in applied ethics—typically espouse. His ideology exposes the arbitrary, limited, exclusionary nature of our own.

#### II. IDEOLOGY

Religious or secular, scientific or social, all ideologies build a set of practical, operational principles based upon a small set of axiomatic beliefs. The principles are then taken as self-sufficient because the underlying axioms are assumed to be not simply necessarily but obviously true. Any argument or position whose perspective violates those axioms, or their operational, corollary principles, will be rejected as unworthy of consideration. Only arguments at the level of principled application in accord with the ideologically accepted axioms are then entertained. The result is a protected orthodoxy advanced as clear, self-evident, and objective.

While most bioethicists—those who consider ethical procedures and policies in medicine generally—reflexively deny an ideological posture (Singer, 2005), bioethics is, as Daniel Callahan recently argued, an ideology whose axioms present "a set of essentially political and social values brought into bioethics, not as a formal theory but as a vital background constellation of values" (Callahan, 2003a, p. 298). The general acceptance of its axiomatic values represents "the almost complete triumph of liberal individualism" (p. 298) based upon "political and social values" that are, however, arbitrary, derived, and restricted (Baily, 2002). That they are political and social reflects the degree to which bioethics's core values are derived from a greater ethical frame operative in societies advancing an individualistic philosophy rather than from any uniquely clinical value set drawn from specifically medical experience. The effect is the "systematic marginalization of religious and conservative perspectives," that are typically treated with "disdain and hostility" (Callahan, 2003b, p. 498).

The result is an orthodoxy in which "fundamental values are already assumed" (Singer, 1995b, p. 4) and debate is restricted to operational judgments based upon them. Challenges that might lead to different perspectives and actions, what Singer calls "ultimate choices," (p. 4) are marginalized, where they are not reflexively disallowed. The real question thus becomes: who is conservative, Smith or ourselves? The issue is hard to raise in a climate that strongly discourages discussion of fundamental principles and values that are at the heart of contemporary bioethics (Callahan, 2003a, 2003b).

The axioms of contemporary bioethics embedded in its principled code (Beauchamp & Childress, 1979) assert as the primary phoneme of ethical discourse the primacy of the discrete individual defined conditionally by a set of physical and cognitive attributes, and secondly, a more or less utilitarian perspective as an operative principle of ethical decision making and resulting policy. Where those attributes are seen as deficient when compared to those of a "normal" person, one with unremarkable physical or cognitive attributes, the individual's right to continuance—his or her place in the protected circle of the socially protected community—is diminished. This is often expressed as an altruistic recognition of a deficient "quality of life" rather than the result of distaste for difference, even though, in many cases, life quality arguments are asserted as justifications despite individual beliefs or a wealth of historical data (See, for example, Dreger, 2004).

This is true of both principled bioethics and, as the "alternate constructions" section of the article argues, bioethical arguments advancing apparently different general constructions (for example, pragmatism) whose core values remain fundamentally unchanged. In the main, contemporary bioethics thus rejects a more traditional axiomatic value such as that, argued by Smith, of human life as a good in and of itself. In this it similarly rejects alternate constructions defining the person not as a discrete, fungible social being but as a relational person indivisibly joined to others to whom harm is done by their non-care and their resulting deaths (McBryde Johnson, 2003). To accept the relational is to skate perilously close to an axiomatic value of unconditional membership, and thus of the sanctity of human life that most contemporary bioethics reject.

What results is a posture that is typically agnostic, eugenic, and utilitarian. It masquerades as objective and scientific, hiding its allegiance to a set of axiomatic values in a cloak of rationalism (see Singer, 2005) and scientism. Perversely, despite its supposed empowerment of the individual, it typically denies the existential worth of any individual human being, and especially the individual of difference (Koch, 2004). The failure of bioethics to engage Smith and others whose fundamental values are similar to his (see, for example, Lugosi, 2001) signifies an ideological circling of the wagons that rejects the fundamental concerns of the many outside its narrow, mainline consensus. As a result, it erodes the very value it most advances, the axiomatic protection of the individual him or herself. It denies as well the original role of bioethics as a critic engaged in public debates over health care policies and values.

## III. LIFE VERSUS THE WORTHY LIFE

Wesley J. Smith's central argument is that "bioethicists have generally abandoned the sanctity-of-life ethic that proclaims the inherent moral worth of all people" (Smith, 2000, p. xiii). The result is that unconditionally protected

humans have become unprotected beings who earn a conditional but untenured place in the protected moral community "by possessing certain relevant characteristics" without which they are "denigrated as non-persons, who have little or no moral worth" (Smith, 2000, p. xiii). In trading the axiom of unconditional protection for one of conditional membership in a protected community, Smith argues, bioethicists violate the values of traditional Hippocratic medicine and Judeo-Christian ethics and become, in the words of the subtitle of the book, "merchants of death."

In this Smith is indisputably correct. In 1995, Peter Singer proclaimed that, "after ruling our thought and decisions about life and death for nearly 2,000 years, the traditional western ethic has collapsed" (Singer, 1995b, p. 1). That collapse provided an opportunity for bioethicists to craft new categories of contingent personhood whose result has been the marginalization, and some say dehumanization of the fragile. As Thomasma admitted in a 1993 article, "beings on depersonalized maintenance may no longer be as human as the rest of us" (p. 172). Nor did he see this as bad, of course. In 1997, Thomasma and Lowry argued for a continuum of personhood based on cognitive and physical abilities and potential, each step of the continuum carrying different ethical obligations. They began with the fetal pre-person whose moral value rested in future potential (if "normal") and then moved on to the persistently unconscious person (the PVS "being"), a post-person whose lack of response, if perceived as permanent, would diminish social obligations to its (no longer his or her) continuance.

True, some bioethicists continue to argue with Margaret A. Somerville that human life is "sacred in some unique and special sense" (Somerville, 1996, p. ix). Irrespective of ability or purpose, to be human is or should be to have a more or less protected place in the human community. Replacing the unconditional axiom of protected human life with conditional attributes makes this a necessarily sentimental argument, however. Rejecting the axiomatic value of human life demands the rejection of that "special sense" as speciesist. If life is not unconditionally valued it is necessarily conditionally defined. If we are beings whose value lies in our attributes, it does not matter if the being is *Homo sapiens*, a chimpanzee, or a creature from *Alpha Centuri*. One then can ask, as Peter Singer famously has, whether there is any fundamental ethical difference between members of these species? The answer is that once it is the conditional attribute rather than class membership that is important it makes little difference at all. The "special sense" becomes merely a sentimental prejudice that is difficult to defend.

# IV. EUGENICS

For those like Smith who argue an unconditional life value, the removal of some from the protected community on the basis of physical or psychological

differences leads inevitably to the operational termination of potential persons in utero, neonates with physical or cognitive anomalies, and, inevitably, persons who develop restrictive physical and cognitive conditions. This transposes the general argument from values into what he and others may see as eugenic termination of persons of difference. The eugenics argument that blossomed in the United States in the late 19th and early 20th centuries (Pernick, 1996) was simple: Some people lacked the capacity to be useful workers in a society that principally valued the social participation and economic production of the individual. Those unable to participate and produce were defined as a drain upon the economy and social body of the nation-at-large. Some who might find work were still to be removed because their physical differences were so sufficiently unaesthetic that their physical traits were not to be perpetuated. People who did not possess a minimal set of socially sanctioned attributes would be better off not being born, and if they were, society has a right to hasten their death either passively, through the withdrawal of care, or actively through medical intervention.

In the United States, this view with its attendant values culminated in the famous case of Buck v. Bell (1927) legalizing forced sterilization of "defective" women by the state in an attempt to prevent "future generations" of cognitively, physically, or socially deviant persons. More generally, it promulgated eugenic ideals, and indeed eugenics itself, as a social value. Chief Justice Oliver Wendell Holmes called this decision, one he was proud of authoring, "The first principle of real reform" (Reilly, 1991, p. 88). It was, Stephen J. Gould later wrote, "one of the most famous and chilling statements of our [American] century," and one with extraordinary repercussions (Gould, 1981, pp. 335-336). Based in part on this American perspective (Pernick, 1996, p. 165), eugenics later was advanced in Germany with Binding and Hoche's (1992) famous argument in the 1920s on "Permitting the destruction of unworthy life." Not only was euthanasia advanced for those with disabling diseases like multiple sclerosis (Burstyn, 1991, 1993), active euthanasia of "defectives" (cognitive, physical, racial, or social) was advanced as a clinical and social policy necessitated economically and for the good of future generations. As a result, at least 70,000 abnormal infants and adults with limiting and degenerative diseases were systematically allowed to die, urged to suicide, or killed as a matter of national policy in Germany (Goldhagen, 1996).

In the early post-war period state eugenics was briefly rejected in both Europe and in the United States where *Buck v. Bell* (1927) eventually was overturned by the U.S. Supreme Court decision *Roe v. Wade* (1972). That took the right of eugenics from the state and gave it solely to the prospective female parent, shifting to the individual the right (and some would say obligation), to prevent the conception of persons-of-difference or to terminate their development during pregnancy. It is a triumph of feminism as a political movement, and bioethics' principle of individualism and individual

autonomy, that the decision removed even the prospective male parent from an official voice in a fetus's future. For many, it exemplified the death of social and medical "paternalism" advancing in its stead individual sovereignty in medical decision-making.

It did this, however, by denying any fundamental voice either for the prospective male parent or society-at-large. And because it occurred in a context in which children of difference were to be born in a state without state support adequate to their needs, it implicitly advocated a type of utilitarian consumerism in which choices on the future of a fetus might be made on the basis of familial concern over the cost of raising a child of difference. Can we afford to have a child of difference with that prospective child's attendant needs? Isn't it better to abort and wait for a more cost-effective child who will, by the way, better answer our expectations and needs? As a result the person-to-be, in Thomasma's language, the fetus, became a commodity without human agency, rights, or stature. In this way *Roe v. Wade*, while overturning *Buck v. Bell*, advantaged eugenics at the level of the prospective person rather than that of the state or other members of the potential family, especially the male parent. It opened the door to the sanctioned termination *in vitro* of infants of difference.

By extension, the infant born with differences, no matter how minor, was similarly unprotected and devalued. His or her life has, over bioethics's tenure, been subjected to a restrictive judgmental economy on the basis of perceived "harm," and judgments on prospective "quality of life" that, where different, are assumed to be insupportable. This was the message of both most bioethicists and medical authorities in the landmark cases of Baby Doe and Baby Ross, for example (Van Leeuwen & Kimsma, 1993). The argument was that smart parents would allow children with Down syndrome, and by extension a host of disabilities, to die. The potential "suffering" such persons of difference might experience in life, and the limited "quality of life" that experts (medical and ethical) assumed they might enjoy, were sufficient rationale for their typically passive termination. That all evidence suggests the opposite is true (Albrecht & Devlinger, 1998; Dreger, 2004; Koch, 1998, 2000a, 2002b) remains a fact that is ignored in favor of the assumptions asserted as constant and true. Instead, termination is argued for the infant of difference's own good and only sub rosa for reasons of economy or aesthetics.

The result is a scenario in which individual choice reigns, social responsibility is limited and cost, calculated in dollars or utilitarian "life years" is the default means by which a being's attributes and potential are assessed. To argue against this order is to reject the idea that modernity's "good eugenics," reflexively promoted by bioethicists and most medical authorities, is different from the "bad eugenics" of the first half of the twentieth century (Horgan, 1993). Bioethics thus adopts a more or less aggressively eugenic face in its axiomatic assertion of the conditional nature of the

valued being. John Harris (2002), for example, argues that virtually any difference—deafness, for example—is sufficient to define a harmful existence in a damaged creature whose life should be terminated at the earliest possible point, preferably at the fetal stage. Others disagree, and argue that Harris's posture is too extreme in degree, if not in kind (Singer, 2005). Still, the eugenic pruning of the human tree of potential persons of difference, such as those with Down syndrome and those who may develop adult diseases like familial breast cancer or Huntington's Disease, is no longer a matter of official debate but accepted practice (Koch, 2003a).

That the decision is solely the female parent's on the advice of a physician or counselor rather than a judgment of the state or necessarily of the parental couple is no triumph, however. In abandoning the protection of the human being irrespective of difference, society is free not to adequately provide social support for persons of difference. What is perceived as an ethical advance empowering feminism and choice is simultaneously an abandonment of the reflexive legitimization of persons of difference. We know, with a nudge and a wink, that persons will make the "logical" choice and maximize both their hopes and their support while minimizing costs. Only those beings will survive whose characteristics attributes are at least mundane if not potentially superior.

In this I like Peter Singer not for his argument but for its clarity. "Singer lays it all out," McBryde Johnson writes, "applying the basic assumptions of preference utilitarianism, he spins out his bone-chilling argument for letting parents kill disabled babies and replace them with non-disabled babies who have a greater chance of happiness" (McBryde Johnson, 2003, p. 53). Writing not in the *Journal of Bioethics* but the *New York Times*, lawyer McBryde Johnson, a person with congenital physical differences, personalizes both the Singerian perspective and the greater argument that powers it, and most bioethics today. "He insists that he doesn't want to kill me, he simply thinks it would have been better, all things considered, to have given my parents the option of killing the baby I was, and to let other persons kill similar babies as they come along and thereby avoid suffering that comes with lives like mine and to satisfy the reasonable preferences of parents for a different kind of child" (2003, p. 50).

# V. "DISABILITY" IN GENERAL

McBryde Johnson writes, as do Hentoff and Smith, in the public rather than the bioethical arena because bioethicists do not easily entertain such arguments, especially when argued on the basis of personal experience. McBryde Johnson's strongest case is not only presented in her legal briefs or her public writing but the fact of her existence, the in-your-face proof that one can have attributes that differ negatively from the mundane norm and be happy, intelligent, and socially engaged.

Harris argues "we must separate the question what is of use to existing disabled people from the question of what constitutes disability and the ethics of minimizing its occurrence in the future" (Harris, 2002). Singer (2005) also insists that care for persons among us whose difference is accidental, or at least unanticipated, is distinct from that of persons whose birth could be avoided. And yet while her birth may have been avoidable McBryde Johnson stands as an example, with many others, of the communal importance of those whose attributes are distinct but whose life quality is positively asserted and whose value within the greater society, the fact of the article stands here as testimony, undeniable. To separate the issues is to accept two value systems, one assuming inferiority based on distinction that should be avoided and the other humanely but perhaps condescendingly accepting those who were like us and now, by accident or disease, are become distinct.

The extreme of this argument concerns persons in persistently unconscious states; those bioethicists call, in medical language, persons in a "persistent vegetative state." With most, perhaps, Peter Singer perceives as "weird" a family's decision to keep alive and care for a person in a persistently unconscious state despite the arguments of those who do (McBryde Johnson, 2003).

In the recent case of Terri Schiavo, a Florida woman in a persistently unconscious state for 13 years, bioethicists almost universally sided with her husband for her death, and excoriated "disability activists" for advocating with her parents, her continuance (Goodman et al., 2004; Koch, 2005). It is not simply weird, they argued, but unseemly for persons to contend for the life of a permanently unconscious person whose death would presumably serve her and us all. The individual is served by a dignified death rather than a presumably undignified life that depends on sustained care, although it is unclear how dignity affects a consistently unconscious person.

The 2005 decision of the federal court to honor her husband's request for his wife's withdrawal of hydration and nutrition, while a triumph of the surrogate's right to choose a "natural" and dignified death seemed, to others, unacceptable termination of a person loved by her parents who sought her continuance. The extraordinarily contentious international debate over Mrs. Schiavo's life, and the manner of her death, highlighted a greater and more general divide over the sanctity of life generally and the value of the restricted life specifically.

Those who typically write against the continuance of such persons rarely admit the historical difficulties of diagnosing a "permanent vegetative state" or the likelihood of error in diagnosis (see, for example, Andrews, 1996; Childs, Mercer, & Childs, 1993), however. They assume both the appropriateness of the diagnosis and the dehumanizing language—the person as "vegetable"—with which persons in a persistently unconscious state exist. In such cases, and those less extreme, bioethicists instead talk about "quality of life" and harm,

often against the desires of the family members whose judgment may differ from that of the official medical-ethical mainstream.

This was the case, for example, in Wangle where a woman's husband sought his wife's continuance over the objections of the physician who saw the persistent vegetative state (PVS) status as "futile" (Cranford, 1991; Post, 1995, p. 108). But life quality is what bioethicists assume it might be compared to the norm they are familiar with, not what persons of difference or their families report experiencing. Increasingly they assume, too, the decision for continuance by family members is one that should be discouraged, and in such cases reversed, irrespective of the surrogate's desire or the person in question's own beliefs.

For those whose differences are less extreme than persistent unconsciousness, the litmus case for such legislation, bioethicists typically ignore the argument of those with different physical and cognitive attributes who insist their life quality is just fine, thank-you, if different, perhaps, from that of the mundane person (Koch, 2001b; McBryde Johnson, 2003). Ignored, too, is the argument of their caregivers who insist the continuing person, while physically or cognitively limited, is worthy of care and support even in the extremes of the persistently unconscious (see, for example, Post, 1995, pp. 107–108). This literature, based on personal experience and personal values, while vast is at best shrugged off as a "fact," minor but real (Singer, 2005, p. 130). That some insist even relatively severe differences (blindness, paraplegia, etc.) need not diminish and may enrich life is, where not dismissed reflexively, then shrugged away as a "paradoxical" finding (Albrecht & Develiger, 1998).

## VI. BIOETHICS: ALTERNATE CONSTRUCTIONS

Bioethicists argue a range of constructions that give an appearance of diversity in their consideration of ethical issues in medicine and medical research. Within this diversity, however, most hold to a set of axiomatic values similar to the principled, expressing an ideology based on individuality and a "quality of life" which diminishes where physical or cognitive abilities are restricted (Koch, 2004) irrespective of the specific conceptual frame of their arguments. Thus some will argue that while all this may be true of the class of principled bioethicists, and perhaps of utilitarian and consequentialist writers like Harris and Singer, other bioethical voices assure an unrestricted dialogue in which a range of values can contend. That hope is rarely realized, however. Challenges within bioethics typically are voiced with notable exceptions—as restricted, variations upon a dominant value system whose tenants are remarkably consistent even if their means of expression somewhat distinct. Any review of these bioethical variants in a journal article section must be cursory and incomplete. Space considerations restrict what, in a "universal" critique (Singer, 1995b, 4), would be

more extensive. This section therefore briefly considers several of the more prominent bioethical variants as they relate to the value of human life as a conditional or absolute value.

#### A. Communitarianism

In his criticism of the ideology of bioethics, Daniel Callahan (2003a, 2003b) offers as a corrective a communitarian posture that is, in his words, ecologic. Its principal value is social rather than individual. Society's organizing virtue—and Callahan's critical axiomatic value—should be the maximum utility for society as a whole rather than the maximization of the individual life. "I hold that the first set of questions to be raised about any ethical problem should focus on its social meaning, implications, and context, even in those cases which seem to affect individuals only" (2003b, p. 287). This "ecological communitarianism," typically argued in terms of resource allocation (Callahan, 1987), has little to do with ecology, however. Indeed, as I have argued elsewhere, it quickly transposes into a more general utilitarian posture, albeit one with a veneer of societal concern (Koch, 2002, pp. 76–77; 181).

Ecology pays attention to the dynamic interaction of members of species whose individual niches are mutually dependent and interdependent within a broad habitat shared with others. Callahan's communitarianism simply devalues the individual, arguing his or her sacrifice for a "greatest good" without real attention to the ecological conditions (and interdependent relations) of the individual species or species member embedded in a well populated, sometimes fragile, social and physical environment. Thus, he would likely find the maintenance of a persistently unconscious person uneconomical and thus dysfunctional, because it involves taking monies from society that would be better spent elsewhere. An ecological perspective would seek to consider the continuing place of the unconscious person in and to the family members that seek the unconscious person's continuance (Post, 1995, pp. 107–108).

# B. Pragmatism

One might assume that pragmatism would serve as an antidote to both narrowly principled prejudices and the communitarian/utilitarian argument's disinterest in the individual in relation. Its typical advance in current bioethical debates (Tollefsen, 2000; Trotter, 2003), however, presents less a fundamental challenge than a refocusing of the scale at which bioethicists address specific issues. It is more about practice and methodology than fundamental critique. For example, pragmatists argue for "abbreviated statements of those actions or policies that have been found to work in the past" (Arras, 2003, p. 608). Pragmatists typically reject abstract debate for the concrete practice in a manner that cedes the game from the start. They deny a challenge

based on the values that underlie past and current practice. How we define past efficacy in light of current effects is, however, what fundamental challenges at the level of values are all about.

Some pragmatists in bioethics do, for example, caution against excessive individualism. Trotter notes, for example, "both Royce and Tocqueville see the greater good as supervening, at least to a degree, on independent creative efforts of small communities and individuals" (Trotter, 2003, p. 665). But the distinction is typically more of cautionary degree than of substantial kind. "They [pragmatists] endorse a robust political principle of subsidiarity—holding that freedom of association, local autonomy and individual rights should hold sway, wherever this is workable without direct harm" (p. 665).

The assignment of harm results from an application of values rather than objective, pragmatic assessment. Were it otherwise that "harm," and its effect on life quality, would be considered within the context of reported experience and with an eye to maximizing a person of difference's life potential rather than simply arguing his or her termination. "Harm" in the language of pragmatism is analyzed only within the frame of what is assumed to work based on the limited literature of what has worked. Because pragmatism abjures discussion of principles and values, a pragmatic challenge of current bioethical policies and argument is impossible because, in the end, it's *all* about values and the principles that result. Thus, to be pragmatic and "non-judgmental" is to give up the game from the start.

# C. Narrative-Casuistry

This is a point made in the largely narrative literature of and from difference in which mainline values are challenged on the basis of individual perspectives in a manner that would seem to advance an ethical casuistry (Jonsen, 1995). While in theory narrative and casuistry are, and perhaps should be, distinguished, they are, in effect, typically conflated, at least in bioethics. Axiomatically, casuistry insists that ethics and the values it exposes must be considered at the scale of the individual case rather than of the abstract, axiomatic value. It is, in Clifford Gertz's language (1973), "thick" rather than "thin," narrative and social rather than philosophical and discrete. The question becomes, however, what stories are we to tell and how shall they be credited? The bioethics literature is replete with the stories of the ethicists and their interpretation is a gloss on its ethic.

Casuistry and narrative in bioethics typically engages not the narratives of those who have lived with difference, whose lives are, like McBryde Johnson's, ciphers for a different set of values. Rather it has typically focused upon the clinical case from the perspective of a medical model that sees difference as, if not a failure, certainly not a human triumph. It thus typically stands not as a challenge or a critique but as propaganda elucidating and

advancing bioethical and clinical values. In the literature of difference, on the other hand, the values *are* distinct and inclusiveness is more typically argued. That literature, however, is infrequently addressed by bioethicists who typically devalue (where they do not totally ignore) the alternate literature of being. Like pragmatism, casuistry in bioethics is therefore not a stance before the world but a means of operationalizing a prior stance, of advancing values rather than exploring them and the ideology that results from them.

Pragmatically, perhaps, we would better consider the arguments of those who live with a proscribed set of conditional attributes over those who argue a clinical standard without familiarity of the lived experience. As casuists we would better credit the arguments of those who know best about the quality of life they experience, such as those who live with difference, than we would those who argue it abstractly (Menzle et al., 2002; Ubel et al., 2003) As communitarians, real communitarians involved in social and individual values and postures, our values would need to come from the community rather than from the abstract assumption of a greater good that ignores the individual him- or herself. As ecologists like Callahan, we would seek the methods of maximizing the potential of persons within society, and of species members in their niche within the shared habitat, rather than assume the individual's place in that shared space to be insupportable. Any of these actions would open the door, however, to Smith's fundamental argument for the value of life as an existential good to be protected rather than an individual commodity to be assessed against the mundane norm.

## VII. DISCUSSION

Singer (2005, p. 130) argues: "Bioethics is a branch of applied ethics, which in turn is a branch of philosophy, and the hallmark of Western philosophy since Socrates has been its willingness to question everything, including conventional beliefs, no matter how unpopular such an approach may make one." And yet, like most others in applied bio- and medical ethics, Singer rejects out-of-hand the suggestion of a bioethical ideology, "a self-reinforcing package that is beyond reasoning and critical scrutiny" (p. 130). The argument here has been that bioethics indeed has become a self-reinforcing package that does not easily consider arguments based on different value sets.

Singer's argument suggests ethical theorizing can be somehow divorced from the political ideals and social perspectives within which ethical arguments are necessarily embedded and from which they typically devolve. Just as *Buck v. Bell* limited individual reproductive rights on the basis of social economics, contemporary bioethical values cannot be divorced from the political values whose result is the context of modern medicine. As I have argued elsewhere, this is made clear by any consideration of "lifeboat ethics"

in the healthcare system-at-large, and more generally in the valuation of productive individuality over social relations and general vitalist arguments advanced by, for example, McBryde Johnson or Wesley J. Smith.<sup>2</sup>

What Singer does not accept—but Callahan at least recognizes—is that the rational arguments we make and the clinical valuations we accept are ultimately value laden. They exist not outside the political and economic values that organize society, but within that value system. They are about those among us that we accept and that which we reject from the circle of our protection (Koch, 1998) based on both fundamental values and on modes of argument (principlism, utilitarianism, pragmatism, etc.) that enforce some values and reject others. The result is often contradictory and arbitrary. A useful example of this is Lugosi's (2001) review of a British judicial decision to separate conjoined twins over the objections of their Roman Catholic Parents (Re A, 2000) and Dreger's more general discussion of the issue of conjoined twins and their separation (Dreger, 2004).

The decision to separate the twins, dooming one to death, was a fundamentally utilitarian decision—better to save one than have both die—that violated, if not long-standing legal valuations of life as a state interest, certainly, the presumably principled right of surrogates to make decisions for those unable to choose for themselves—even when those decisions are not what bioethicists and physicians agree with. The result in this case was "to violate the bodily integrity and sanctity of life of the weaker twin," killed so her sister might survive, "in involuntary human sacrifice [that] violates the fundamental principles of individual autonomy and the Nuremberg Code" (Lugosi, 2001, p. 124).

That it occurred over the objections of the legal surrogates, the parents themselves, is significant. Like the Wangle case, it presents the refusal by lawyers and medical ethicists to accept the judgment of designated surrogates whose values are different from those of most bioethicists or the courts. And yet, it is the idea of individual choice that bioethics supposedly empowers. In theory, applied ethics greatest triumph has been its critique of medical and legal paternalism in the advance of individual autonomy and choice. And yet, in this case (and in others) the bounds of such decisions are carefully proscribed by other values that are implicit and yet enshrined in the legal codes advanced by bioethicists. At the least the result is inconsistent and at worst stunning bad faith.

The older value of a blanket valuation of protected human life, on the other hand, assured all a measure of security, each individual his or her place. It does not deny the choices and perceptions of the individual or individual surrogate but adds to those individual perceptions a greater social protection and value. By restricting protection to conditional beings based on a set of characteristics and attributes, in contemporary bioethics the protected individual is protected only as long as he or she measures up in the sense that his or her social niche is acceptably cost efficient.

No wonder Wesley J. Smith argues his case not here but in best selling books and in British newspaper columns. No surprise that McBryde Johnson makes her case in the *New York Times* rather than the *American Journal of Bioethics*, or perhaps, the *New England Journal of Medicine*. The result is that the public-at-large and its legislators increasingly reject the presumed consensus in bioethics. This is a potential lesson of the ethical, legal, and public debate over the survival or termination (by withdrawal of hydration and nutrition) of the Floridian woman, Terri Schiavo (Koch, 2005). While for most bioethicists her ending was appropriate, the general public result in many states was a demand to change default policy in such cases from withdrawal of care to continued maintenance (Goodman et al., 2004).

The remedy is to accept, as Callahan has, first that bioethics is at heart value laden. For bioethics own sake, as well as society's, those values require constant review and debate in a manner that is both public and grounded in the lives of those affected. It must be pragmatic in a way that accounts not simply for the survivors—the stronger twin—but for the deaths of the weaker that are the results of our choices. And for pragmatism to serve both clinically and socially, bioethical values must be advanced in a way that is publicly understood and endorsed.

When Callahan argued (2003a, 2003b) the need for fundamental debate over bioethical values he signaled dissatisfaction within the academy, a growing recognition of the limits of contemporary bioethical approaches to complex problems. In this he followed David Thomasma's 1997 argument that bioethics presented a socio-cultural value system that was limited rather than universal, contrary to what many believed. It is here, perhaps, that Smith has done bioethics a favor. The popularity of his critique insists bioethics meet the challenge of a competing ethical value system or permit its public position be eroded in silence. The latter it cannot do because its underlying claim to legitimacy was from the start as a public surrogate, an educated amateur's participation in debates on medical practice and policy (Koch, 2003b). To stay silent in the face of fundamental challenge—and worse to deny its existence—is to reject the public role that gave the discipline its original impetus (Koch, 2003b).

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#### **NOTES**

1. For the purpose of brevity and simplicity, narrative and casuistry are here conflated. There are important narrative accounts in the bioethics literature, though they are few. Those that exist typically

- describe the experiences of a disabled author (for example my own story in Koch, 1994, 176–198). This is simply the way it is, however, not the way it necessarily has to be. For an example of the use of non-authorial, personal narrative in bioethics see, for example, Koch, 1993, 218–224)
- 2. As a peer reviewer suggested, this article is incomplete without a closer look at the relation between politics and political argument, and bioethics. That, however, requires a different article that can tease out the relationship of the greater political discourse, laden with economic content, and the specific consideration of medical choices that is bioethics specific focus. A separate article on these issues is in progress.

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