
The Difference that Difference Makes: Bioethics and the Challenge of “Disability”

Tom Koch

University of British Columbia, Vancouver, BC, Canada

Two rival paradigms permeate bioethics. One generally favors eugenics, euthanasia, assisted suicide and other methods for those with severely restricting physical and cognitive attributes. The other typically opposes these and favors instead ample support for “persons of difference” and their caring families or loved ones. In an attempt to understand the relation between these two paradigms, this article analyzes a publicly reported debate between proponents of both paradigms, bioethicist Peter Singer and lawyer Harriet McBryde Johnson. At issue, the article concludes, are two distinct axiomatic sets of values resulting in not simply different styles of rhetoric but different vocabularies, in effect two different languages of ethics.

Keywords: disability, eugenics, euthanasia, language, McBryde-Johnson, Peter Singer, PVS.

I. INTRODUCTION

Two rival paradigms permeate bioethics. One favors eugenics, euthanasia, assisted suicide, and other methods for those with severely restricting physical and cognitive attributes (Koch, 2000a). The other opposes these and favors instead ample support for “persons of difference” and their families or loved ones. At the center of the struggle between these opposing paradigms is a debate over the understanding or construction of the notion of *personhood*. Different perspectives on its meaning shape the positions each take on substantive issues. For example, those who favor such things as euthanasia, assisted suicide, or eugenics typically understand personhood in terms of autonomy, self-determination, and independence of action. Those in the other group more typically define personhood in a relational or communal rather

Address correspondence to: Tom Koch, Ph.D., Department of Geography (Medical), University of British Columbia, 1984 West Mall, Vancouver, BC V6T 2S1, Canada. E-mail: tokoch@atglobal.net

than individual sense. Let us call those in the first group “critics of difference” (e.g., Harris, 2002; Singer, 1995) and those in the second, “critics from difference” (e.g., Feder Kittay, 1999; Silvers & Wasserman, 1998).

In general, the critics of difference assume the superiority of persons whose physical attributes and cognitive abilities are at least normal, if not superior. Those with physical or cognitive limits lose a measure of their personhood to the degree their autonomous participation in society is limited. From this perspective, extreme limits (negative deviations from the norm) result in a duty not to care for the individual so restricted. Critics from difference, on the other hand, insist that physical or cognitive difference should be no barrier to full personhood and as a result of that status not limit full social support for their continuing care. They emphasize not the limits resulting from difference but the richness of a life lived in a body or with a mind different from that of the norm (Evans, 2001; also, Campbell, 2003). Where cognitive, physical and sensory limits are “harms” to the critics of difference, to those arguing from difference “harm” is the social failure to fully accept persons of difference irrespective of eccentric cognitive or physical profiles.

To say the distance separating critics of and for difference is rooted in principal definitions is to argue a distinction at the level of the codes with which we invest human states with meaning (Lindemann Nelson, 2002). The frame of accepted language, of axiomatic definitions, bounds the grammar underlying all resulting arguments, tilting the resulting judgment this way or that. What results is an “attitude,” an ethical posture structuring perceptions and argument in a profound manner.

As Hilde Lindemann Nelson pointed out (2002, p. 33), in an essay owing much to Elliott’s (2001, p. 102) interpretation of Wittgenstein, “to treat someone as a person involves taken up a certain *attitude or stance* toward her” [emphasis added]. In a very real way, those who argue from difference speak a different language that enables an attitude or stance not simply distinct from but practically opposed to that of those whose positions they seek to criticize.

The summary by lawyer Harriet McBryde-Johnson of an exchange in 2002 with bioethicist Peter Singer at Princeton University serves nicely to introduce both of these perspectives. Their different vocabularies reflect different definition sets that result in distinct ethical perspectives. As a lawyer involved in “disability rights,” and as a woman whose physical differences distinguish her from the norm, McBryde Johnson represents, personally and professionally, persons of difference. Singer is perhaps the best-known contemporary bioethicist espousing a paradigm that seeks to limit negative deviations from the mundane

human norm (Singer, 1995). The views of both are presented here as emblematic of more general arguments of and for difference. Because both McBryde Johnson and Singer are used here as ciphers, representatives of broader positions, other authors are cited wherever possible in an attempt to enrich the analysis and broaden its perspective.

II. CONSCIOUSNESS AND CARE

In a paradigmatic exchange between Singer and McBryde Johnson the difference in their respective vocabularies reads as if they were speaking different languages that often times used the same words. For example, McBryde Johnson spoke of visiting a family who “took loving care of a non-responsive teenage girl, acting out their unconditional commitment to each other, making all the other children [in the family], and me as their visitor, feel safe” (McBryde Johnson 2003, p. 55) Assuming, Singer asked, an individual we know will never regain consciousness, “don’t you think continuing to take care of that individual would be a bit—weird?”

“No,” McBryde Johnson replied, “done right, it could be profoundly beautiful.”

But what about the caregiver, Singer asked, the person who must care for the unresponsive other? Wasn’t it “weird” to advance the caring role for one who will receive no potential return, no reciprocal benefit? Not at all, responded McBryde-Johnson. The “burden” of caring for another is a function of society’s failure adequately to support those who care for a fragile other, not a failure of the caring relationship itself.

The distance separating their respective vocabularies was sufficiently vast to exclude a common ground in their dialogue. Both were left, in the end, with value-laden adjectives—“weird” and “beautiful”—to summarize their respective stances. As a result, readers like John Lantos, president of the American Society for Bioethics and the Humanities, assumed the debate was “as much about aesthetics as it is [sic] about morality . . .” (Lantos, 2003, p. 2).

Lantos, however, mistook the punch line for the story. The judgments summarized by the aesthetic adjectives resulted in each case from a rigorous ethic and a consistent moral posture. In fact, their disagreement was *all* about ethics, and the moralities that result. But the point was lost because their arguments were not engaged at the level of the definitions on which their respective, principled positions are built. Here those definitions are considered and contrasted

in an attempt to understand the distinct core of both arguments from and for difference. What this reveals is that, at heart, the two proponents employ very different definitions of personhood.

III. PERSONHOOD: SINGER

Personhood as a moral term defining the set of human characteristics we choose to value as a society (Elliott, 2001). As a noun it defines the properties one must have to be considered a person, and thus to have a serious right to continuance and social support (Beauchamp, 1999; Tooley, 1983). “Our psychological states, their bodily representations, others’ uptake of these representations, and the treatment based on that uptake all play a part in the formation and maintenance of personhood” (Lindemann Nelson, 2002, p. 34).

Definitions of personhood are themselves not simply ethically or morally important but defining. They determine our attitude toward difference, constructing society’s vision of inclusion or exclusion. “It is not enough just to ask whether a given characteristic is morally important; we also have to ask what a particular group of human beings has made of that characteristic. A biological characteristic becomes something for moral consideration when human beings make something of that characteristic” (Elliott, 2001, p. 97).

Thus personhood is a subset of humanness, a noun itself imbued for some but not for all with moral and ethical significance. Singer’s “uptake” (1995), one common in contemporary bioethics, is that of the person as a self-conscious individual capable of autonomous, independent thought and action within a population of similarly autonomous individuals sharing a distinct and clearly defined set of attributes. For Singer, self-consciousness serves as a defining criterion not simply for its own sake but because it is a predicate necessary for other, corollary attributes of personhood including: the ability to communicate, self-awareness, and at least the potential for intellectual (and interpersonal) growth and development (Thomasma, 1989). Inherent in this is the ability to self-reflectively relate to and with others in a community of similarly defined individuals. So, too, is a “locus of self-control” and of independent activity within one or another presumably productive social venue (Waller, 2002).

The reduction or loss of those defining qualities in an individual results in a diminishment or withdrawal of personhood status, and thus of the protection we are obliged to accord those in whom these qualities are fully evident. For some, this permits a continuum of personhood in which “pre-persons” are

those who will obtain consciousness, self-awareness, and the potential for interpersonal action in the future, and “post persons,” those who had but no longer possess these qualities (Thomasma & Loewy, 1997). Non-persons are those who are and most importantly will be incapable of manifesting the qualities defining personhood.

This is distinguished from an earlier definitional set in which humanness—species membership irrespective of individual characteristics—was a core attribute of protected personhood. Where caring was once assumed necessary because of the sanctity of human life, and thus of each individual human person, it is, in this new definition, conditional on the presence or absence of specific physical and especially cognitive attributes defining the protected person irrespective of species membership. As a result, the once dominant sanctity of human life standard becomes a restricted measure for the conditional sanctity of individual persons who manifest distinct attributes in a specific measure. As Singer put it: “After ruling our thought and decisions about life and death for nearly 2000 years, the traditional western ethic,” with life being defined as continued respiration by a species member, is now superseded by the sanctity of conscious life of an individual member of the species (Singer, 1995, p. 1).

Margaret Somerville (1996, p. ix) argued humanness is, in some general way, “sacred in some unique and special sense.” But this becomes difficult to defend when communicable self-consciousness and autonomous activity within a productive community become the defining qualities of protected personhood. Because species membership is no longer defining, its relevance is necessarily diminished. If communicable, self-conscious, and autonomous activity permitting productive social interaction defines the personhood of those we would protect, whether the protected life is *Homo sapiens* or not that of a chimpanzee becomes less relevant. In this way humanness is transformed into a frequent but not necessary qualifier of personhood.

In Singer’s language, the defining characteristics of conscious and socially interactive personhood to be valued, irrespective of species, are not goods for their own sake. Rather, they serve because they enable interaction and association within a greater community, permitting the individual to realize his or her maximum contribution to (and participation in) the aggregate good of society-at-large. Personhood thus reflects a status of social contribution and participation. Secondarily, it serves as a legitimizing attribute permitting an individual to demand resources from society as a whole. And it is here, at the level of social need, function, and interaction that Singer (1995) situates protected personhood irrespective of species membership.¹

Where qualities of personhood are present in full measure, the person is granted complete status. Where the defining qualities are less evident, the status of the individual is necessarily diminished as a result. Similarly, as the status of personhood is reduced, the impetus to care may be lessened by an equal measure.² In this formulation too, the focus is on “fungible,” interchangeable (and thus replaceable) individuals both contributing to and drawing from society and the sum of its good, however that is defined. This quintessentially utilitarian position is not unique to Singer, of course. His is simply the most complete and best-articulated application of it to contemporary bioethical thinking.

Where the absence of those defining characteristics is extreme, it becomes “rational” (Thomasma, 1996) to assume that those with the greatest measure of personhood characteristics, or in the case of the fetus at least a potential for them, should receive the bulk of our commitment. To do otherwise necessarily diminishes the sum of social goods through a misallocation of scarce resources.

Personhood is therefore *always* conditional, based on the presence or absence of defining attributes. As importantly, it is future-oriented. The status of protected personhood may be assigned provisionally to a child in the expectation that he or she eventually will develop into a full-fledged person. But it also may be withdrawn from a person—whatever his or her age—who had but has now lost these attributes, through illness or injury, without hope of their return. Whatever their past social involvement they become non-persons whose limits prevent the individual activities that in this formulation define the person. Bluntly, they become burdens unable to self-consciously participate in society or contribute to societal good.

“Quality of life” is a corollary notion describing the degree to which defining characteristics of personhood are present or absent. Where an individual’s set of cognitive, motor, and sensory characteristics is diminished but still clearly measurable the “quality of life” is assumed to be limited to an equal degree. Implicitly, the status of protected personhood necessarily is reduced as a result. Where critical characteristics are wholly absent the status of personhood is withdrawn.

The term “weird” well describes, from this perspective, continuing the care of an individual in a persistent vegetative state (PVS) who, by definition, lacks the requisite qualities of personhood. He or she is incapable of self-conscious relation or social contribution. The result is a non-person whose maintenance is at best sentimental. For some, the idea of maintaining a PVS body therefore may be ethically distasteful in the context of society’s limited, health-related resources. It is expensive to maintain a non-person for sentimental

purposes, a procedure that diverts scarce resources from the care of “real” persons who may contribute fully to the aggregate good of society at large.

IV. PERSONHOOD: MCBRYDE JOHNSON

To McBryde Johnson, and to those who agree with her, personhood has a wholly different meaning. It does not distinguish between humans on the basis of individual characteristics but rather takes persons in relation within a human society as its indivisible phoneme. Individuals are not interchangeable (“fungible”) ciphers; each with a core set of attributes, and the good society is not made up of discrete but interchangeable contributors. Personhood therefore is not a conditional status that can be diminished or withdrawn. It is absolute, irrespective of qualifiers; defined not by the capacity of the solitary individual but relationally through, in McBryde Johnson’s story, the “unconditional commitment” of the parents of the non-responsive teenager to their child, their children, and, finally, the greater society personified by the visitor, McBryde Johnson. As a result, Society is defined as the sum of the set of relationships of all its members irrespective of their individual attributes.

In this formulation personhood is by definition relational but not necessarily reciprocal. The unresponsive teenager is perceived as an active member of the family, the center of a complex familial network that extends to include McBryde Johnson herself. One cares about the teenage daughter because one cares about those with whom she lives and who care for her. Because one cares about the sum of relationships rather than the qualities of an individual, the teenager’s personhood is assured no more or less than the personhood of anyone in society.

The argument is implicit in McBryde Johnson’s language. The teenager is “non-responsive,” not in a “persistent vegetative state” because to equate the adolescent with a plant would be to deny her humanity and thus her personhood, assigning her the status of a plant organism. To define the teenager in this way (“vegetative state”) is similarly dehumanizing and depersonalizing for those who live with and care for her. The personhood and humanity of both the teenager and her family (and McBryde Johnson in her visit) are affirmed by the ongoing, caring relation.³ What is “beautiful,” therefore, is the affirmation of a mutually dependent, caring humanity that maintains as essential a human relation irrespective of the observed abilities of an individual participant in that relation.

Neurologist Oliver Sacks has frequently argued this attitude toward human personhood—relational, unconditional, and non-quantifiable—in a range of case studies and theoretical writings. “One cannot have a Parkinsonian person,” Sacks has argued, because “the person, the ‘I’ can never be ‘Parkinsonized’ . . . and yet the ‘I’ may be subjugated and enslaved by this “It” (Sacks, 1982, p. 252). To define personhood by a set of conditional attributes, à la Singer, is to define a person as a clinical “It” (Parkinsonian, PVS, etc.) rather than the “I,” the person in relation to another.

Neither the humanity nor the personhood of Sack’s *Encephalitis Lethargica* patients was therefore in question in his mind. They were in a “therapeutic place” where others related to and with them, in a “home” where their personhood and humanity were affirmed through the caring relation of those who assured their physical care (and were, for their part, affirmed by that act) (Sacks, 1982, p. 253).

“Feeling the fullness of the presence of the world depends on feeling the fullness of another person, as a person; reality is given to us by the reality of people; reality is taken from us by the unreality of unpeople; our sense of reality, of trust, of security is critically dependent on a human relation . . . a single relation . . .” (Sacks, 1982, p. 238). Simply, the world we share is cooperative and communal. A single relation is sufficient to insist upon the personhood of an individual irrespective of cognitive, motor, or sensory ability, and to warrant that persons place within the greater society (“presence of the world”) we share.

Sacks’ attitude, like McBryde Johnson’s, insists that while disease or injury may subjugate conscious or physical activity, the fact of caring or being cared *for* assures the humanity and the moral personhood of caregiver *and* receiver. Despite restrictions attendant upon even the most limiting conditions, persons are defined not by the effect the disease but by their capacity for relations *or* of others to relate to them. Sacks’ description of a woman with ALS summarizes this ethic:

“She may scarcely be able to move or speak, but she is still in their [her family and friends’] eyes a total person, still part of the family and community. She will remain at home in the bosom of her family and community, in . . . dignity and personhood, up to the day of her death” (Sacks, 1997, p. 137).

Similarly, Stephen G. Post described a woman in a persistently unconscious state maintained at a nursing home by her husband who every Sunday during football season dressed her in a Cleveland Browns football sweatshirt (he wore one, too) so they might together watch on TV “their” favorite team play. “This story indicates that for some people, even the PVS condition does

not disqualify a loved one from equal moral standing under the principle of 'do no harm.' It further suggests that the concept of quality of life might be replaced by the quality of lives, including family members" (Post, 1995, pp. 197–198).

In Sacks' case, the person with ALS, full consciousness persists through the course of progressive muscular dysfunction. Cognition remains unaffected. For the PVS person, however, consciousness itself appears to be extinguished. For many, maintenance of the ALS patient can be argued far more strongly than that of the permanently unconscious person in Post's example. In that case the only argument for continuance, the "purpose," is for the caring other in an ethic that replaces focus upon the individual with that of the individual-in-relation, the "quality of lives," rather than the quality of life.

Some insist, however, that continuation of the ALS patient, of a physically limited but cognitively active individual, even where requested by the person and his family, is foolhardy (see, for example, Bindeman, 1993.). The resulting life is so divergent from the norm as to be unworthy. Those arguing from difference disagree. They may do so on theoretical grounds, or functionally, on the evidence of demonstrable social contributions by persons with such limiting conditions. Experientially, the argument is made based on the statements of those who despite such restrictions insist upon the value of their continuance and their place within familial and social relationships (For a literature review, see, Koch, 2001, 2000b.).

For the critics of difference, the maintenance of the permanently non-responsive patient, one without demonstrable cognition, is a "harm" both to the person-that-was and to a society whose limited resources must be invested in the patient's clinically futile care. It perpetuates at great expense the husk of a non-person in a way no rational person presumably would request. Those who, like the man in Post's example, disagree therefore are assumed to act in a non-rational fashion.

But in the language of McBryde Johnson, Post, and Sacks, "harm" results instead from the failure to support the permanently unconscious person whose status as a person is affirmed by the husband's care: the teenager loved by parents and siblings; the *Encephalitis Lethurgica* patients Oliver Sacks helped care for. This is what McBryde Johnson described as potentially beautiful, the manner in which the "It" of a restrictive condition was overcome by the relational "I" of a caring context. The result conferred meaning, and confirmed the humanity of the non-responsive teenager, the family members who vouchsafed her personhood, and their visitor, McBryde Johnson. To limit care and caring on the basis of even extreme cognitive, sensory, or physical differences

is, from this perspective, not only unjustified but harmful, depersonalizing and dehumanizing for caregiver and receiver alike.

Legal interpretations

Understanding these distinct codes of meaning permits insights into relevant and well-known case law. Consider, for example, the Wangle case in which the husband of the permanently unconscious Helga Wangle argued with her physician for her continuation despite the limits of her condition. For his part, the physician argued that Mrs. Wangle's clinical status made continuing care "non-beneficial," or "futile" (Miles, 1991; Post 1995, pp.107–109). The court ruled that what Wangle's husband believed both personally and as the articulate representative of a longstanding shared relationship was defining.

Here "medical futility," a professional judgment that treatment will not result in a clinical benefit, must be distinguished from decisions that while ethical and appropriate from the critique from difference will in no way be curative, where no return to normalcy can be expected. Where personhood refers to a set of defining characteristics whose absence cannot be returned to a patient, the futility argument insists that technologically sustained maintenance serves neither an ethical nor a clinical goal. But in Sacks and Posts' construction, continuing care is not futile where it serves both to preserve the human person (the "I") and the caring relation dependent upon it.

For Mr. Wangle, his wife's personhood was not contingent but instead absolute, its continuance affirmed by his ongoing relationship with her. Her care was not "futile" because it kept her body alive and thus maintained his and her historical relationship (Post, 1995, pp. 108–109). Nor, in this trope, was the issue of her "quality of life" defined solely by her non-responsive state. It was instead relationally constructed through her husband's continuing and active involvement in her care. "Harm" would result—to him *and* to her—if the "It" of her disease were to trump the "I" of the individual in relation irrespective of one partner's condition.⁴

This argument from difference places a very different interpretation on the famous Bland decision. Tony Bland's parents asked the courts to permit the withdrawal of life-sustaining medical support from their son, described by clinicians as being in a persistent vegetative state. In his judgment, Lord Keith of Kinkel wrote that to society as well as "to an individual with no cognitive capacity whatever, and no prospect of ever recovering any such capacity in this world, it must be a matter of complete indifference whether he lives or dies"(Airedale v. Bland, 1993).

But it is *not* a matter of indifference if a society must choose between different attitudes defining what it means by personhood and the level at which it is to be maintained. It matters as well because of the effect of such judgments on corollary, qualifying descriptors (“futility,” “harm,” “quality of life,” etc.) as they are applied to persons of difference whose physical or cognitive limits, while real, are less extreme.

It obviously matters to the caregiver but also, albeit less obviously, to the unconscious person. Our most profound preference is typically for the health and well-being of our loved ones, those with whom we share, in the language of phenomenology and existentialism (Fullbrook & Fullbrook, 1994), an *essential* relation critical to our (and their) existential being. Maintaining a non-responsive person at the request of the parent, sibling, or spouse affirms that relationship, and in so doing affirms the personhood and humanity of caregiver and receiver alike. To do otherwise would be to reduce the essential relationship to a conditional one based on the cognitive, physical, or sensor capacities of a member of the relation.

From the critique from difference it is unclear what to think when the caregiver is the one who, as in the Bland decision, seeks the withdrawal of life support, the termination of the relation. Sacks appears to suggest that the relation of the professional caregiver (irrespective of the concerns of relations) is sufficient to maintain the personal “I” over the “It” of restrictive cognitive physical, or sensory limits. McBryde Johnson appears to suggest that a desire to terminate support may result primarily from the failure of society to provide emotional, financial, and social support for the familial or institutional caregiver. The request for termination—by a person with chronically limiting conditions or one in relation to that person—is therefore *not* a response to the diminished capacity of the person him or herself but to society’s failure to support caregiver and care receiver in these situations (Koch, 1993; 1996). Agreeing with those wishes is to accept that social failure as appropriate rather than prejudicial.⁵

For those who believe we are all becoming contingent within the context of a technocratic, utilitarian, social order (Siep, 2003), the argument from difference presents a corrective re-moralization of personhood, and secondarily, of humanness as a valued attribute (Bayertz, 2003). It denies the depersonalization of the individual, rejects the conditional, and assigns meaning to the relational person and the community in which he or she is maintained.

At another level, the argument from difference insists that persons are embedded in a social body whose meaning is derived from the sum of its

relations, essential *and* contingent, historical and contemporary. To make membership contingent upon a specific set of individual characteristics is to deny that greater relational base. By emphasizing the primacy of the social context, society itself is constructed as the sum of its essential relations irrespective of the specific abilities an individual brings at any moment. To not care thus becomes harmful to society and the relational definitions by which it is defined.

Genetics and Eugenics

If personhood defines a conditional status based on individual abilities, then it is, in Singer's language, "weird" to argue for the individual whose set of qualifying characteristics is severely restricted. By extension it is similarly nonsensical to argue for the continuation of a pregnancy whose result will be an individual whose characteristic set of abilities will be deficient in those areas that are assumed to define an individual's personhood. Singer's argument for the rational decision for termination of genetically distinct pregnancies whose result will be, sooner or later, a person of difference follows naturally from this argument. Those who share this general view encourage the eugenic pruning of the human tree by limiting the possibility of future persons whose genetic profiles will differ from those of the norm. For many critics arguing from difference, this appears to be modern bioethics', and perhaps society's, default position (Koch, 2003, Roeher Institute, 2002, p. 6; Smith, 2000).

"Singer lays it all out," McBryde Johnson wrote, "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). Not surprisingly, perhaps, McBryde Johnson personalized both the Singerian perspective and the greater eugenic argument that naturally evolves from his set of definitions.

He insists that he doesn't want to kill me," writes McBryde Johnson. "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)

Singer's vocabulary is based upon a utilitarian perspective of individuals as essentially interchangeable, and personhood as a conditional attribute. From this perspective it makes perfect sense to limit the birth of those whose distinct set

of characteristics may limit his or her participation in and contribution to the commonweal. Others have drawn from this a corollary argument that defines as harmful (irrespective of parental choice) the bringing into being a child of difference (see, for example, Harris, 2002).

“To knowingly bring into the world a child who will live with an impairment,” Asch wrote, in summarizing this literature, “is unfair to the child because it deprives the child . . . by limiting some options” (2002, pp. 132–133).

If personhood is defined by the sum of a set of characteristics that permit a range of self-conscious, autonomous activities, then to bring forth a child whose abilities will necessarily be diminished is to doom him or her to a limited life whose functional personhood will be necessarily restricted by those inherited differences. It is more efficient and more rational (and, perhaps, more humane!) to support future persons whose personhood will be assured and whose participation in the common good will be fuller. If, however, personhood is essential and not contingent—defined by the “I” of relation rather than the effect of the “It” of a condition—this conception of “harm” must be rejected.

Social Contexts

If contingent personhood is based on the individual’s ability to act independently and self-consciously in the world, anything that limits that independence necessarily will diminish the person that results, and at least for a classical utilitarian like Harsanyi (1975), society’s duty to care will be lessened by an equal degree. Why, “other things equal,” not avoid the dilemma by avoiding the birth of the individual who will be so limited?

But other things are rarely equal, McBryde Johnson insists. As she and others have noted (see, for example, Nussbaum, 2001), because one is physically *unable* does not mean one is necessarily *disabled*, or that one’s personhood is diminished as a result. Being physically unable to play at the beach like other children never meant, she explained in her exchange, she did not enjoy the beach. Because she rolls rather than strides does not diminish her enjoyment of travel. Her differences do not lessen the experiential richness of her daily life. Difference should not necessarily diminish, therefore, anyone’s personhood.

From this perspective, suffering results first and foremost not from the fact of difference but from the attitude that assumes an individual’s life and life quality is determined by it. That is to define the person of difference solely by the “It” of his or her clinical status. It is unwarranted to assume that difference

will be diminishing, that a blind, deaf, developmentally delayed or mobility-limited person's life is by necessarily inferior.

Born with achondroplasia, Sir Thomas Shakespeare is frequently asked, "Wouldn't you rather have been not short?" a question he takes as meaning, "Wouldn't you rather have not been born?" (Kristof, 2003). A husband, parent, and scientist, Shakespeare insists that a life of difference does not deny a person the richness of the human experience, or society of a worthy member. The real harm, Shakespeare suggests, resides in the utilitarian, eugenic attitude and its effect: "To hear people discuss a world in which you don't exist," he says in relation to abortion of fetuses on the basis of genetic difference, "can be very hurtful" (Kristof, 2003).

Social Science Studies

There is a wealth of social science literature that argues for the rich quality of life experienced by persons of difference irrespective of their cognitive, physical or sensory differences. For critics of difference who assume a conditional view of personhood this is "paradoxical" (Albrecht & Devlieger, 1999). But for those arguing from difference it is expected and confirming. In this literature, adults who as a result of accident or disease develop a diminished set of defining characteristics typically report a generally positive sense of life and life quality (Koch, 2000, 2000c). Indeed, some report an improved sense of self and of life quality following a restricting injury or the onset of progressive chronic conditions like amyotrophic lateral sclerosis (ALS) (Asch, 2002; Koch, 2001; (Young & McNicoll, 1998). The consensus in this evolving literature seems to be that physical limitations may be experientially balanced (or outweighed) by an increasingly satisfying relational world of enriched essential and condition relationships with family and friends (for a review, see Koch, 2001).

Of special note in this literature is that of parents of children of difference who typically do not seek genetic testing when considering a future pregnancy. Instead they "generally reject the idea of prenatal testing and abortion of subsequent fetuses even if those fetuses are found to carry the same disabling trait" (Asch, 2002, p.139). The importance of their existing child's "differences" seems minimal compared to the rewards of the parent's relationship with their children, irrespective of difference. Simply the possibility of another child with an atypical set of characteristics ceases to matter (see, for example, Zuckoff, 2002, pp. 235–237). That the child who results may face social stigma represents, in this literature, the failure of society and not the limits of the child himself or herself.

For this reason social science increasingly distinguishes between *primary* conditions, clinically defined deviations from the norm, and *secondary* conditions reflecting socially constructed limits (Wilber et al., 2002). “Harm” results primarily from the latter rather than the former. A similar distinction is made elsewhere in the literature between sensory, motor, or cognitive “impairments” and inhibiting “dysfunctions” (Silvers, 1998). The former refers to the “fact” of (primary) difference and the latter to (secondary) functional limitations resulting from discriminatory social policies, or social indifference. In both cases, the literature appears to support an attitude similar to Post’s, Sacks’s and McBryde Johnson’s, that asserts an individual’s personhood irrespective of characteristic differences.

V. CONCLUSION

“It would not surprise me,” Carl Elliott wrote, “to hear an anthropologist speak about one culture that revered . . . damaged children and another culture that simply discarded them, and that each attitude was tied in complex and subtle ways to the culture’s religion, structures of kinship, beliefs about health and illness, and so on (2001, pp. 98–99).”

One need not seek elsewhere for that society . . . it is ours. McBryde Johnson and Singer represent members of a society whose respective perception of persons of difference of every age is strongly opposed in precisely this way. Their distinct perspectives are grounded in complex and subtle attitudes defining what it means to be a human being, what a person is, and how these definitions are operationalized clinically and socially. The arguments of both are logical, precise, and relatively consistent in their ethical positioning. They are, however, based on different definitions of the person, his or her nature and value. As a result, corollary definitions (“quality of life,” for example) differ as well. What results are opposing perspectives of not only individual difference but also what it means to be a human being, and a person in society.

It is tempting to dismiss the differences between critics of and for difference as irresolvable. One cannot simply argue a “continuum” between their two poles because at a fundamental, definitional level they are fundamentally opposed. But because the issues are so opposed a frame is needed that permits the relative merits of both perspectives to be judged. For myself, that frame insists upon the superiority of the critic from difference represented here by McBryde Johnson.

One reason is simply McBryde Johnson herself. Would we be better off had she not been born? The reality of her condition, distinguished as it is from the norm, is an essential element in her argument for the full personhood of persons of difference. To the extent we value her voice in this quintessentially human debate over personhood, over who and what we are, we therefore must value her equal personhood, and by extension, that of others whose physical or cognitive profiles are similarly distinct. The argument from difference, and especially by those who are persons of difference, carries an experiential weight that gives their position a force that is unanswered by that of critics of difference.

The point is not that she is exceptional, an articulate mind. Those who would argue we might keep her, but not a person with Down syndrome, or the teenager in an unconscious state whose life she debates with Singer, miss the deeper point. She is an exemplar only of the life lived in difference, of the community enlarged by the relational perspective she and others in the disability community espouse. We do not know what we'll learn from those of difference or what they'll contribute to us until and unless we both insist upon their place in society and assure they are fostered as would be any mundane person.

Some would argue that harm does accrue, that not all lives of difference are as successful. This is the "caregiver burden" argument. This reflects not the "burden" of a person of difference so much as a social disavowal, the limits of social support for those who live with difference and their caregivers (Koch, 1993, 1994). It ignores, too, the caring "benefit" that McBryde-Johnson perceives, the lessons learned from living with one whose physical or cognitive frame is different from the mundane norm.

Opposed to notions of "harm" and burden for the caregiver is a powerful, experiential literature arguing for caring as a critical virtue and a fulfilling activity (See, for example, Feder Kittay, 1999). This humanist and egalitarian perspective is advanced by organizations like the Canadian Down Syndrome Society (2004) which refuses to define its members as medically or socially inferior, as just people whose lives—in the family and society at large—are neither necessarily better or worse in quality than any other. This ethos, and the more general narrative literature in this area, is fundamentally relational and supportive of McBryde Johnson's argument. In addition, definitions relying on autonomy and individual ability that promote the disease-based model of damaged personhood (and autonomy) are increasingly being challenged by those arguing a "relational" rather than distinct autonomy (Burgess & d'Agincourt-Canning, 2002; MacKenzie & Stoljar, 2000). The mixture of theoretical and experiential, epitomized by McBryde Johnson in this article, is to me, decisive.

Finally, I agree with Wright (2000) that the critics of difference represented here by Singer present a “slippery slope” argument whose effects are real. Wright argued the ethical onus in such situations lies with those who would start us down that slope. One must be certain, in other words, and have that certainty proven before embarking down a path with cascading ramifications. For me, Singer has not answered the experiential argument of the persons of difference or the theoretical posture of the critics from difference. Given that, the argument from difference seems to me necessarily preferable to one critical of difference, the argument for unconditional personhood stronger than the one of conditional personhood.

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NOTES

1. Singer thus advances the primacy of a healthy chimpanzee, for example, over that of the anencephalic infant, or a patient in a persistent vegetative state. The former has claims the latter does not because of the chimpanzee’s demonstrable, self-conscious intelligence, and activity within its community, are qualities the latter examples cannot demonstrate (Koch, 1998, pp. 25–27; Singer, 1995).
2. One might argue the inverse, that the impetus to care may be strengthened as the status of active personhood is reduced. McBryde Johnson’s argument suggests but does not insist upon this, however.
3. Some might extend this argument to pets, and especially those that serve their human partners in a functional capacity, seeing-eye dogs, for example.
4. The case study of a male spouse of a woman with advanced multiple sclerosis offers a similar conclusion (Koch, 1994, pp. 13–48).
5. Because it was not an element reported in the McBryde Johnson-Singer debate the issue of social resources and their scarcity in health care is here left unconsidered.

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