

Disability: An Agenda for Bioethics

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Contemporary bioethics has been somewhat skewed by its focus on high-tech medicine and the resulting development of ethical frameworks based on an acute-care model of healthcare. Research and scholarship in bioethics have paid only cursory attention to ethical issues related to disability. I argue that bioethics should concern itself with the full range of theoretical and practical issues related to disability. This encounter with the disability community will enrich bioethics and, potentially, society as well. I suggest a number of items that the bioethics agenda should include, such as the development of a casuistry of the right to healthcare and to community integration and an advocacy role in fostering an understanding among the public and policy makers of the need to reform research and treatment related to disability.

If I were listing the most dangerous people in the U.S. today, bioethicists, aka medical ethicists, would top my list—way above skinheads, whose beliefs they appear to share.

—Alice Mailhot, *Mouth* (1994)

Not-Dead-Yet Web site

www.notdeadyet.org/bioethic.html

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Bioethics has not devoted a good deal of attention to the study of issues related to disability or to rehabilitation care. What attention has been given to disability has largely focused on requests to terminate potentially life-sustaining treatment or requests for assistance in dying such as those of Dax Cowart, Elizabeth Bouvia, and Larry MacAfee. In fact, it is probably only in recent years that the names Dax Cowart and Elizabeth Bouvia would suggest disability issues to bioethicists, having for years simply been discussed as right-to-die cases. This tendency to reduce all questions to those of life and death has sometimes, as in the quotation above, been interpreted as advocating death over life with disability.

The inattention to disability is probably not due to any genuine malice on the part of ethicists. Ethicists have been a guest in the house of medicine and, in order to survive in that environment, have had to align themselves with money and power. Being present in the intensive care units, the organ transplantation services, and the molecular genetics laboratories has had a larger payoff than rounding in the department of physical medicine and rehabilitation possibly could. Of course, ethical frameworks tend to reflect the context within which they take shape. So it is not surpris-

ing that ethicists should see questions of death and dying wherever they look.

That bioethics has gotten a late start in discovering disability should not deter bioethicists from joining and fostering the dialogue in this important area. As often happens in our society, legal approaches precede philosophical appreciation of social problems. Disability issues have followed this model as the disabled have used the legislative process and the courts to try to regain entry to society. Of course, appeals to law will generally be appeals to rights claims, especially within a liberal democratic society. As a result, questions concerning the disabled are usually seen as questions of rights.

It is my belief that bioethics can be helpful to the disability community in a variety of ways. The most obvious of these is to use the rhetorical power of bioethics to foster a more disability-friendly treatment and research environment within society. Furthermore, bioethicists can contribute to the philosophical analysis of the rights-based approach that has dominated public disability advocacy. This approach, like any framework, has certain strengths but also brings accompanying weaknesses. A rich understanding of disability requires that the phenomenon does not become lost in the theory. There are likely to be other more subtle

contributions that can come from bioethicists engaging the disability community.

And, equally important, the disability community can be helpful to bioethicists. Philosophers first crossed the street and entered the clinic in order to lend a broader perspective to healthcare decision making than medicine affords. In a sense, philosophers were supposed to be representative of the perspective of the general public but with more precise analytic abilities. As philosophers have become bioethicists, that is, specialists in clinical ethics, this perspective may have been lost. Now that ethicists have acclimated to the clinical setting, overidentification with the medical profession may be festering and the concerns and questions bioethicists address may be those posed by physicians rather than patients. Disability studies thrusts the perspective of a grittier consumer front and center in the discussion of the way the healthcare system meets or fails to meet patient and client needs.

In essence, bioethicists must do what they do best. Bioethicists long ago abandoned top-down theoretical approaches to problems and have focused on balancing considerations and delineating the scope and limits of principles. In practice this has often taken the form of facilitation of consensus among viewpoints. By including a disability perspective in this societal roundtable, any ethical consensus will be built on a firmer, more broadly-based foundation.

I believe that these are good reasons for bioethicists to take disability more seriously. Of course, bioethicists have not been able to escape this encounter altogether, and some important work has been done (Asch 1998). Because bioethicists are colleagues of the healthcare providers, this work has generally been written from the perspective of rehabilitation professionals. A rehabilitation ethics literature that is akin to the medical ethics literature has sprung up (Gervais, Vawter, and Spilseth 1995). This literature has, of course, made thematic a number of ways that rehabilitation care differs from acute-care medicine (Caplan, Callahan, and Haas 1987), including rehabilitation's greater emphasis on educational and event models of informed consent (Haas 1993; Purtilo 1984); its need for the family to take an active role in decision-making and care-giving (Kuczewski and Pinkus 1999, esp. 143–155); and its substitution of the healthcare team-patient relationship for that of the traditional doctor-patient model (Purtilo 1988). Such a corpus stands in striking con-

trast to the disability literature that is generally written from the perspective of the consumer (Davis 2000; Frank 2000; Robillard 1999). Nevertheless, this encounter is sufficient to engender a number of conclusions about the agenda for an extended encounter between disability studies and bioethics. In one sense these are conclusions that are in search of good arguments. They are rather obvious and hard to dispute. But, they are also convictions that require courage to implement. They call for a lived response.

Five Convictions to Guide Bioethicists

Conviction 1: Bioethics should concern itself with the full range of theoretical and practical issues related to disability.

Bioethicists should not confine their discussion to the “sexy” issues of medicine that attract media attention and copious funding. We must not simply foster a bioethics of the rich and famous. To do so is wrong on two counts. First, such a focus will always skew the work of bioethicists. The profession that was born to give voice to the perspectives of the sick and dying and to thereby empower patients will have the opposite effect. That is, a failure to give a prominent place to the consideration of disability issues does not only mean that important areas of healthcare go unconsidered; it also means that many issues bioethicists consider will be distorted. Since many of the fundamental concerns of persons with disabilities are not about medicine at all but about the living of life, they point the way to transcend *medical* ethics and restore the original meaning to *bioethics*.

Second and closely related, the field of bioethics must itself develop a conscience and dedicate itself to advocacy for those who have no money or power to offer this new profession. Bioethicists routinely chastise medicine for being too concerned with cure and ignoring the duty to care. For 25 years, bioethicists have denounced the medical profession's preoccupation with technology and intervention at the expense of the autonomy and best interests of patients. Yet, in our preoccupation with the life-and-death dilemmas that technology poses, we mirror medicine's failures. As a discipline that is both philosophical and a contributor to public policy—a “demi-discipline” in the words of Al Jonsen (1997)—bioethics must concern itself with health services and strategies that affect people where they live. Bioethicists must pay more attention to rehabilitation care, long-term care,

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home care, and respite care. Unless bioethicists do so, not only will their philosophical picture continue to be out of focus and incomplete, but their policy recommendations will be skewed and will underemphasize the services that most contribute to the common good.

Let me be clear on two points. First, bioethics will be as enriched by a greater emphasis on disability issues as disability studies will be by a dialogue with bioethics. While bioethicists will gain a broader context for their research, the disabled will benefit from the spotlight, complete with its media and policy-maker access, that bioethicists enjoy. Furthermore, by engagement with a policy-oriented field such as bioethics, disability studies may be able to augment its intensely subjectivist approach with an understanding of the meaning of disability that has pragmatic implications. Second, despite this potentially symbiotic relationship, engagement between the two worlds requires that bioethicists give from their substance. The institutional structures that have sustained bioethics within the acute-care setting are not available beyond acute care. Grant funding is usually far more available for the study of issues raised by technology than those raised by social barriers. Similarly, as easy as it is to deride the culture of continuing medical education (CME), CME has been an inroad to dialogue with physicians. It is much harder to find widely attended educational forums that are utilized by healthcare professionals who work in home care, rehabilitation care, and long-term care. Thus, encounters with the world of the disabled generally must be classed as part of a bioethicist's service mission rather than his or her research or educational duties.

Although all educational institutions espouse a tripartite mission of education, research, and service, clearly the least of these is service. Academics are seldom rewarded for excellence in service. As a result, any substantial undertaking in this area must generally be seen as rewarding to the profession of bioethics rather than to individual bioethicists. I suggest that bioethicists consider the model of the legal profession and have a guideline for an amount of time, e.g., 5 to 10%, which is tithed to work that is not remunerated in the traditional manner. As I noted, this is not actually charity work since it will enrich bioethics. However, unless bioethicists approach it in the commitment and spirit of pro bono work, it is unlikely to be sustained and ongoing. Thus, bioethicists should routinely make a point of spending a fixed percentage

of time in work related to venues such as independent living, long-term care, rehabilitation care, and care of the indigent.

Conviction II: Bioethicists should develop a casuistry of the right to healthcare and the right to community integration.

Disability has been dealt with in the United States in a way that is analogous to the civil rights movement for minority groups. It is conceived first and foremost in terms of antidiscrimination legislation. One can easily see the central piece of disability legislation, the Americans with Disabilities Act (ADA), as an extension of the Civil Rights Act of 1964. In a sense, the ADA simply adds one more category, the disabled, to the list of those people specifically protected from discrimination. As a result, our thinking about disability embodies the strengths and weaknesses of that kind of rights-based thinking.

This kind of thinking is literally correct. It is wrong to discriminate against giving someone a particular job simply because he or she has an impairment. Similarly, many things in society are arbitrarily designed and do not serve the majority. For instance, the heights at which grocery shelves are stocked and the clothing sizes commonly found on store racks are not necessarily appropriate for most persons. Analogously, choices that mainly affect impaired minorities—such as curbs as opposed to curb cuts, the amount of pressure it takes to open a door, and the heights at which pay phones are mounted—are all arbitrarily made when left to free enterprise. A particular choice is and should be judged discriminatory if it excludes a particular segment of society from participation in society's benefits without clear justification.

The ADA also set forth the concept of "reasonable accommodation" regarding access to employment and public accommodations. This concept places disability within the context of the spectrum of human variation and requires that the most fundamental of society's goods be available to the sizable minority known as the disabled. In this way it treats impairments in the way society has come to treat pregnancy, as a condition of a sizable minority that must be accommodated in the workplace and the public square, where possible. This kind of thinking accords nicely with the high premium placed on individualism in the self-understanding of Americans.

Americans are quick to tout the virtues of self-reliance and hard work. Artificial and discrimina-

tory barriers that impede individual initiative are seen as unfair. This kind of reasoning is much quicker to gain widespread acceptance than is reasoning that is dependent on notions such as the common good or the community's responsibility to the less fortunate. Such reasoning is also easily codified and can be objectively applied. Thus, law can be the engine of change rather than waiting for the hearts or minds of the populace to change.

Of course, rights-based thinking also has its inherent limitations. Although it can guarantee an access ramp to a place of employment, it does not guarantee the provision of a wheelchair or prosthesis to enable the use of the ramp. This is a glaring theoretical inadequacy and an enormous practical problem.

Bioethicists have often been concerned with the issue of access to healthcare (Daniels 1994). U.S. bioethicists seem to have arrived at a general consensus that morality requires universal access to a basic package of healthcare benefits in this society (Churchill 1994). This consensus seems to cut across theoretical commitments, as the conclusion follows from pragmatic, deontological, and utilitarian considerations. However, proposed schemes for just allocation of healthcare resources are generally unable to deduce exactly which healthcare services should be covered. Furthermore, the kind of assistance that the impaired require does not neatly fall within the category of healthcare. That is, assistive devices such as a wheelchair, personal assistance such as an attendant, or a van that is adapted to be driven by a person who uses a wheelchair are not obviously healthcare in the same way that antibiotics are, especially when considered from the vantage point of a medical insurer. Healthcare or not, they are tremendously important to the health and well-being of many, many Americans.

Because theories generally fail to yield the kind of specificity in resource allocation that we would like, bioethicists may wish to think of their role as fostering a societal dialogue that yields a casuistry of the services that promote not only health but also community integration (Kuczewski and Fiedler n.d.). Bioethicists must set a course between creating a theory that yields too much in the way of entitlements and giving in to a despair that surrenders to a facile libertarianism. The theoretical contributions bioethicists make will be largely negative in derailing ideological and dogmatic challenges to society's responsibility to provide for such services. But, exactly which services should be

provided, and how, are matters that only a dialogue that crosses the divides among academia, government, and the citizenry can provide.

Such a dialogue will begin with the idea of equal opportunity but will soon require opening a Pandora's box of equity issues. The public has sometimes demanded the provision of a service, for example, extended maternity stays after delivery, when that service is seen as likely to be used by them or by people envisioned to be just like them. Because many would prefer to think of themselves as impervious to impairment, they may not have an immediate empathy with the needs of persons with disabilities. This leads to our next point.

Conviction III: Bioethics must assist in the public's understanding of disability in the life cycle.

Developing an effective casuistry of the provision of resources requires that those deliberating are able to appreciate the perspective of those affected by the outcome of the deliberative process. Clearly the evidence shows that even those who work most closely with the disabled underestimate their quality of life (Albrecht and Devlinger 1999; Cushman and Dijkers 1990). As a result, when a community is asked to rank the effectiveness of treatments for various conditions, the ranking of services for the disabled is likely to be deflated (Menzel 1992; Capron 1992; Nelson and Drought 1992; Mason 1992). The able-bodied fail to appreciate how much they would enjoy their life if they acquired an impairment.

Able-bodied persons are likely to actively court denial regarding disability. Being injured in an accident or losing the ability to do certain activities of daily living are things one would not generally pursue imagining. Furthermore, those who are able-bodied may have additional difficulty relating to persons from different economic circumstances such as African-American teenage males who become disabled from gunshot wounds or those who have congenital disabilities. Bioethicists must work with the community to overcome an us-versus-them mentality regarding the needs of those with disabilities.

In general, bioethicists can perform a valuable service to society by fostering an appreciation of the place of disability in the life cycle. The way that bioethicists have handled death is in some ways a paradigm for this effort. The first generation of work regarding death focused on developing a widespread consensus on a legal framework to govern decisions regarding life-sustaining treat-

ment (Meisel 1992). Only in recent years have bioethicists and healthcare professionals begun to foster a consciousness of what death is actually like and provided thick descriptions of the context of decision making and the process of death (Byock 1997; Barnard et al. 1999). Similarly, the efforts of disability advocates have focused largely on legal antidiscrimination efforts. Bioethicists can assist the next generation of disability advocacy by fostering a more widespread understanding of the role of disability in the lives of millions of Americans.

Let me provide a facile, almost silly, example that has some resonance. In the United States we pride ourselves in polite company on using non-offensive and politically correct terminology. We sometimes refer to persons with disabilities as being “differently abled” in order to connote that they have their own particular strengths and abilities. We try to pretend that we think that athletic events for the disabled are real athletic events but often hold that these are things “normal” people would not actually do. Of course, this duplicitous attitude is sometimes just plain wrong, as in the case of the use of wheelchairs and wheelchair races.

In the United States, as a result of our duplicity, we artificially restrict entry to wheelchair divisions of marathons to the “physically challenged.” We see the winners of the wheelchair competitions at marathon races as somehow not genuine athletes. This attitude ignores the fact that if you took the runners who compete in the footrace and asked them to compete in the wheelchair division, they would not do very well. The athletes who compete in wheelchairs are genuinely “differently abled.” Of course, the development of this ability is usually precipitated by an impairment that leads the person to use a wheelchair. As a result, if we opened the division to all who could compete, as is the case in Canadian marathons, those who have an impairment that necessitates the use of a wheelchair in daily living would still usually win the competition. Failure to recognize the legitimate nature of this athletic competition and these athletes has some practical consequences for the general populace.

If wheelchair races were seen as genuine athletic competitions, young, able-bodied persons might learn to navigate a wheelchair and compete in gym class and other venues. This would have the benefit of reducing the tendency of those who can walk to see those who use wheelchairs as “other.” And, it would mean that many persons who will come to use wheelchairs at some point in their lives

due to injury or aging, would already have the skill of using this instrument. This would make adjustment at that point in their lives much simpler. Wheelchair racing, if seen for what it is, is a genuine “life sport” in a way that those that are usually so heralded—for example, tennis and aerobic dance—simply are not.

Conviction IV: Bioethics should aid in the understanding and reform of research and treatment related to disability.

Bioethicists are quite often seen to be far more powerful than they are. If truth be told, it is difficult to imagine a less powerful profession. As academics, bioethicists generally have far fewer members with the kind of tenure protections that are routine in most liberal arts specialties. As healthcare professionals, the power of clinical ethics consultants is, at best, derivative of the power of key administrators or physicians within the particular institution in which they operate. However, this lack of intrinsic power also highlights the fact that bioethicists have often been successful through their powers of persuasion. Policy makers, healthcare professionals, and the popular media have all shown an interest in making the practice of medicine more ethical and therein show interest in the insights bioethicists have to offer. Bioethicists have a responsibility to use these powers of persuasion to reform the orientation of healthcare treatment and research regarding disability.

The analytic ability of bioethicists and their rhetorical abilities can reform disability-related research and care by becoming the ally of “disability culture.” Although virtually all involved in such research and care now espouse a social model of disability, this paradigm has not impacted on the research and care agenda (Oliver 1996).

The transformation from a medical model to a social model means that disability is no longer conceived in terms of an illness of an individual to be cured by medical treatment or rehabilitation. The social model sees impairment as a physical manifestation but disability as a result of the person with the impairment encountering an unsupportive environment. If this environment is unyielding and unaccommodating to the point that important life opportunities are denied to the person with an impairment, that impairment becomes a handicap. The importance of this model is that it takes the focus off the individual and does not see a

handicap as inevitable (World Health Organization 1980; Institute of Medicine 1997).

It is obvious that the social model of disability is behind the public access and employment provisions of the ADA. However, by their very nature, medicine and biomedical research operate in terms of the medical model. When a person has a life-changing injury or illness, medicine responds aggressively. Minimizing the effects of the injury and restoring health and function are the goals. Care may initially be delivered in an intensive care unit or medical/surgical unit followed by an inpatient stint of rehabilitation care. During this period, the patient is treated primarily in the sense of being the passive recipient of interventions that are delivered. As the rehabilitation phase progresses, the patient must become a more active agent, a participant in his or her regimen. During the acute and rehabilitation phases of care, the emphasis is on technology. Whether that technology is being used on the patient in the acute phase or is the assistive device that is manipulated in the rehabilitation phase, the technology is "delivered" in the treatment setting, but outcomes will be judged as favorable or unfavorable based on the degree of functional independence and community integration the patient achieves after leaving these settings. Research follows a similar paradigm.

Biomedical research regarding disabilities is likely to focus on interventions at the acute phase that can improve survival or minimize the loss of functional status. In other words, it is literally medical research. Research regarding assistive devices follows a similar pattern. A need is perceived or assessed by the healthcare professionals who design the technology (e.g., a toilet seat or lapboard) that is then introduced to the patient in the acute or immediate postacute phase of care. Of course, how helpful such research ultimately is for the client's community integration is not something that can be immediately determined. But, common sense indicates that this methodology is too removed from its ultimate end to be maximally effective.

If the goal of intervention is the community integration of the client, the community should probably be the locus of research. Because assistive devices are meant to be used in the home and community environment, they should be introduced there and assessed for their effectiveness. They are probably best designed there as well. For instance, one can change the research paradigm such that the focus is on finding devices that individuals have

designed and use within their homes; then refining those devices for widespread use. Rather than introducing such devices in the acute-care phase, peer education within the home or community environment could potentially lead to more effective use.

Similarly, while high-tech interventions in the trauma setting are welcome, the emphasis on the delivery of services in the acute and immediate postacute phase is probably less than optimal. When a person suffers a traumatic injury, the change in life prospects may be radical. One must not only undergo acute treatment and then participate in rehabilitation care, but there is an enormous amount of health and living information to process, cognitively and emotionally. As our discussion regarding assistive devices has suggested, a greater focus on the delivery of information and meeting the health needs of clients who have returned home is needed.

The disability literature documents an animosity toward the medical establishment. This tension is between the agenda of researchers and providers and the disabled. However, bioethicists are positioned to see that this tension is not the product of a conspiracy of medical professionals but simply a by-product of the way medicine and research are organized. The evolution of medical care has simply been geared toward acute rather than chronic care, and this trend is only beginning to be tempered. The focus on acute care as defining healthcare has, in many ways, been exacerbated by some insurance schemes. Furthermore, managed care and evidence-based medicine have increased the demand for immediately quantifiable outcomes and results. This reinforces the tendency toward a research agenda that is only minimally helpful to persons with disabilities. As we said earlier, it is easier to fund a project on building the better lapboard than on the sharing of homemade technology.

Bioethicists must use their access to policy makers to explain the need to reorient the research establishment. The efficient delivery of services beyond the acute phase is likely to follow the collection of qualitative and quantitative data that demonstrates effective strategies for empowerment and community integration. Research funding must not always be tied to traditional outcome requirements (e.g., for short-term quantifiable data) that thwart the pursuit of new and novel strategies. Results will be forthcoming in the long run.

It is obvious that these strategies for healthcare

delivery and community integration build upon the successes that the disabled themselves have had. The strategies are an attempt to work with the disabled rather than to have the biomedical establishment determine what is best for them. In one sense this is about liberating healthcare professionals from the dominant paradigm of financing and delivery so that they can create new innovations. Of course, this is also about using the tools of healthcare and research to foster disability culture by drawing upon its innovations and making them accessible to others. This approach can draw upon the culture of congenital disability as well as acquired disability.

Conviction V: Bioethicists must not be scared away from disability scholarship.

I noted at the outset that there are a variety of reasons that bioethicists have not had a good deal of interaction with patients beyond the acute-care setting. These were largely practical and institutional. But, there are a variety of other, more deliberate reasons that bioethicists might shy away from the encounter with disability.

The opening quotation indicates that bioethicists might not receive a warm welcome from the disability community. To engage disability issues, bioethicists must be willing to deal with confrontation with impassioned and sometimes angry activists. Our quiet, academic meetings may no longer be so quiet and academic (and they certainly will be less self-congratulatory). Furthermore, we must overcome the idea that the study of ethical issues relating to disability must be left to the disabled alone. Although one should never seek to usurp the right to speak for any disenfranchised group, the failure to engage in dialogue with that group about issues of concern is a more serious problem. For instance, although it might be ridiculous for white, male healthcare professionals who sit on institutional review boards to consider themselves feminists or Black studies experts, they must certainly be concerned with the representation of women and persons of color in research. And the more they can engage those communities in dialogue, the better the research community will understand the needs and concerns of those communities. A research establishment run by white males that is only concerned with research on white males would be an impoverished research community. The same is true of the relationship of bioethics to the disability community.

There are fundamental value judgments that

divide the mainstream of the bioethics community from many in the disability community. Bioethics has made much of its name in asserting the right of patients to refuse treatment, including life-sustaining treatment. Bioethicists have also been advocates of universal health insurance. In advocating for such reform, they have been interested in eliminating ineffective treatment in order to make resources more widely accessible. Both of these efforts have been the targets of derision by members of the disability community.

In advancing the right to refuse treatment and rational allocation of healthcare resources, bioethicists face the charge that they devalue the lives of the disabled. Behind the right to refuse life-sustaining medical treatments, the disabled hear a voice saying, "I would rather be dead than live like you." Behind resource-allocation schemes, they see a conspiracy to deprive them of what few resources the system provides. For, if the majority see their lives as not worth living, they will not rank the efficacy of their treatments high on any list of financing priorities.

I think that bioethicists can benefit from this encounter. We may have to ask that those with whom we engage not vilify us. Nevertheless, such an encounter will call us to examine, in a more penetrating way, the values behind the recommendations we make. For instance, the current consensus on forgoing life-sustaining treatment can be supported by a vision of individual autonomy, a view of what constitutes a good death, a vision of the proper ends of medicine, or a view of what constitutes a reasonable quality of life. But, not all of these foundations lead to the same conclusions when applied to difficult cases or to related issues such as assisted suicide. Dialogue with persons with disabilities calls into question our assumptions about meaningful autonomy. Our ethic of autonomy, an ethic that is in danger of becoming a vision of the good life, will be challenged when encountering others who value dependency differently.

Bioethicists claim that autonomy is an instrumental good, not a vision of the good life, but a survey of the bioethics literature can readily convey the impression that bioethicists are implicitly working with an ideal of the good life that favors complete choice, control, and any needed assistance in reproducing; a lifespan that includes access to multitudinous information regarding one's health status and future risks; fully informed but easy access to the latest clinical trials when one is

seriously ill; and advance care planning that leads to a quick and painless death when one is very sick. Little mention is made of life with a long-term chronic illness or life with various impairments. Perhaps this is a misimpression. But only through genuine dialogue can that be determined. I do not wish to prejudge the results of such a dialogue, but I suspect that both groups will be changed, perhaps transformed, by the encounter.

Conclusion

I have asserted that bioethics needs to be more concerned with issues related to disability and to engage the disability perspective. I have made fairly strong claims both concerning the need for this re-orientation and the benefits to be derived therefrom. Those benefits will be distributed across the bioethics community, the disability community, and society at large.

I anticipate two criticisms. First, some may say that much of the work I am calling for has been done by health educators, psychologists, social workers, and a variety of related professions that have examined the presentation of information in the home setting and clients' perceptions of their quality of life. These professions may have already departed significantly from the acute-care paradigm of disability. No doubt there is merit to this point. I certainly do not wish to argue that bioethicists must ride to the rescue and single-handedly save the day. However, what work has been done has not generally impacted public policy, the attitudes of healthcare professionals, or the general public in the way that it could. Bioethicists, true to their hybrid calling of scholarship and public policy, can contribute to the research agenda directly but can contribute more by helping healthcare professionals, policy makers, and the general public understand the need to reform the research and healthcare agenda.

The main challenge I anticipate is that I have reified disability—that is, that I have made it a “thing” in its own right, when it really is simply a name that applies to any of a large number of physical ailments or impairments. These often have different characteristics and defy conceptual generalizations. Some impairments involve an ongoing disease process that is best treated on a medical model; others do not. Some impediments open the opportunity for the development of valuable alternative skills; others do not. Some disabilities are best construed as a part of the dying process; others are not. Meanwhile, I have spoken of engaging the

“disability community” as if disability is a homogeneous phenomenon with representative spokespersons. These criticisms are salient and I accept them as valid. However, rather than doom my convictions, they form part of the research agenda for the future.

Understanding the concerns and needs of the disabled involves both quantitative data gathering that provides generalizations and qualitative data gathering that highlights subtle differences among the various lived experiences. It will involve exercises and information for the general public that highlights the similarities between those with disabilities and other members of the larger society and also shows the special needs of some persons. Bioethicists must facilitate dialogue that engages disability advocates as well as less agenda-oriented members of the many disability communities. This is grounds for optimism, not pessimism.

In many ways, understanding disability mirrors understanding the women's movement in the United States or the approach bioethicists have taken to reforming the phenomenon of death in America. To truly understand the situation of women in the United States, one must engage leaders of women's organizations and women from across the full range of socioeconomic and demographic variables. Similarly, the fact that dying is not a uniform phenomenon and that not everyone's attitudes are the same about it have not prevented bioethicists from doing enormously valuable work on death and dying. This work has included advocacy for types of care (i.e., palliative and hospice care) that accord with a vision of death that is or can be widely appreciated and, if generally accessible, will improve the lives of millions. But this does not rule out discussion and appreciation of alternative cultural and religious ideals of a good death.

I am arguing for a dialogue on disability that brings together the best of bioethics—that is, a concern for the model of the person that underlies our deliberations and a pragmatic casuistry that is sensitive to differences among types of cases and situational variations. This is probably best described as a “communitarian casuistry” (Kuczewski 1997). The communitarian aspect asks us to make clear the vision of the person presupposed when we consider disability. Clearly, engaging the disability community will make explicit the relationship between the traditional autonomy of bioethics and the place of dependency, dignity, and opportunity in personhood. But, such a refinement of our self-

understanding should not be used deductively to answer all questions from a few premises. Rather, the model serves as a heuristic tool to help us appreciate the many values at stake in the multifarious phenomena. This is bioethics at its best. This is bioethicists being true to their calling. ■

References

- Albrecht, G. L., and P. J. Devlinger. 1999. The disability paradox: High quality of life against all odds. *Social Science and Medicine* 48:977–988.
- Asch, A. 1998. Distracted by disability. *Cambridge Quarterly of Healthcare Ethics* 7(1): 77–87.
- Barnard, D., A. Towers, P. Boston, and Y. Lambrinidou. 1999. *Crossing over: Narratives of palliative care*. New York: Oxford University Press.
- Byock, I. 1997. *Dying well: The prospect for growth at the end of life*. New York: Riverhead Books.
- Caplan, A. L., D. Callahan, and J. Haas. 1987. Ethical and policy issues in rehabilitation medicine. *Hastings Center Report* 17(Supplement): S1–S19.
- Capron, A. M. 1992. Oregon's disability: Principles or politics? *Hastings Center Report* 22(6): 18–20.
- Churchill, L. R. 1994. *Self-interest and universal health-care: Why well-insured Americans should support coverage for everyone*. Cambridge: Harvard University Press.
- Cushman, L. A., and M. P. Dijkers. 1990. Depressed mood in spinal cord injured patients: Staff perceptions and patient realities. *Archives of Physical Medicine and Rehabilitation* 71:191–196.
- Daniels, N. 1994. *Just healthcare*. New York: Cambridge University Press.
- Davis, L. J. 2000. *My sense of silence: Memoirs of a childhood with deafness*. Urbana-Champaign: University of Illinois Press.
- Frank, G. 2000. *Venus on wheels: Two decades of dialogue on disability, biography, and being female in America*. Berkeley: University of California Press.
- Gervais, K. G., D. E. Vawter, and E. Spilseth. 1995. Readings in rehabilitation ethics. *HEC Forum* 7(2): 183–197.
- Haas, J. 1993. Ethical considerations of goal setting for patient care in rehabilitation medicine. *American Journal of Physical Medicine and Rehabilitation* 2(4): 228–232.
- Institute of Medicine. 1997. *Enabling America: Assessing the role of rehabilitation science and engineering*. Washington: National Academy Press.
- Jonsen, A. R. 1997. The birth of bioethics: The origins and evolution of a demi-discipline. *Medical Humanities Review* 11(1): 9–21.
- Kuczewski, M. G. 1997. *Fragmentation and consensus: Communitarian and casuist bioethics*. Washington: Georgetown University Press.
- Kuczewski, M. G., and I. Fiedler. n.d. Ethical issues in spinal cord injury rehabilitation: The redevelopment of autonomy and community integration. *American Journal of Physical Medicine and Rehabilitation*, forthcoming.
- Kuczewski, M. G., and R. L. Pinkus. 1999. *An ethics casebook for hospitals: Practical approaches to everyday cases*. Washington: Georgetown University Press.
- Mailhot, A. 1994. *Mouth*. Not-Dead-Yet Web site. Available from: <http://www.notdeadyet.org/bioethic.html>.
- Mason, T. 1992. Sullivan made the right choice in rejecting the Oregon plan. *Health Matrix* 2(1): 85–88.
- Meisel, A. 1992. The legal consensus about forgoing life-sustaining treatment: Its status and prospects. *Kennedy Institute of Ethics Journal* 2(4): 309–345.
- Menzel, P. T. 1992. Oregon's denial: Disabilities and quality of life. *Hastings Center Report* 22(6): 21–25.
- Nelson, R. M., and T. Drought. 1992. Justice and the moral acceptability of rationing medical care: The Oregon experiment. *Journal of Medicine & Philosophy* 17(1): 97–117.
- Oliver, M. 1996. *Understanding disability: From theory to practice*. New York: St. Martin's Press.
- Purtilo, R. B. 1984. Applying the principles of informed consent to patient care: Legal and ethical considerations for physical therapy. *Physical Therapy* 64:934–937.
- . 1988. Ethical issues in teamwork: The context of rehabilitation. *Archives of Physical Medicine and Rehabilitation* 69(5): 318–322.
- Robillard, A. B. 1999. *Meaning of a disability: The lived experience of paralysis*. Philadelphia: Temple University Press.
- World Health Organization. 1980. *International classification of impairments, disabilities, and handicaps: A manual of classification relating to the consequences of disease*. Geneva: World Health Organization.