

Distracted by Disability

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The “Difference” of Disability in the Medical Setting

People with disabilities use more medical care and see health professionals more often than do those of the same age, ethnic group, or economic class who do not have impairments.¹ An indisputable medical goal is “preventing, ameliorating, or curing disease and its associated effects of suffering and disability, and thereby restoring, or preventing the loss of, normal function or of life.”²

Bearing in mind the frequent contact between many people with disabilities and the medical profession, and this goal of medicine, it would seem obvious that the purpose of the healthcare system is fully in accord with the needs of people who have chronic health problems or disabilities.³ To the dismay of clinicians, service providers, and many in the field of bioethics, however, an increasing number of people with disabilities are coming to believe that their problems reside largely in society rather than in their atypical biology. This article explicates the concerns of those people with disabilities who contend that clinicians’ attitudes toward disability often perpetuate negative stereotypes and exacerbate the “difference” of disability.

When members of disadvantaged racial, ethnic, or socioeconomic groups protest the treatment they receive (or fail to receive) under the current healthcare system, sensitive clinicians often recognize that bias toward a group, or ignorance of unique cultural traditions, might subvert the intent to provide respectful care. Other papers in this issue elucidate how provider/patient differences in ethnicity, language, and social class may create serious problems that constitute insensitivity to a patient’s values and needs, and that can reinforce disadvantage. Nonetheless, an emergency room physician who favored an Anglo boy over a Latino boy comparably injured in a car accident would be censured by colleagues. It would be patently unjust for health professionals to base a treatment decision on a patient’s racial or ethnic status; similar physical injuries warrant similar interventions. Disability, I contend, interacts differently from these other characteristics of patients taken up in this issue; patients, families, and bioethics and medical professionals struggle to understand in what ways disability is a biological characteristic that warrants attention in medical decisions, and in what ways it is best seen as a background social variable not pertinent to decisions about any particular medical situation.

Before considering the ways in which a patient’s disability complicates treatment decisions, let me highlight that the difference of disability is not identical to that of race or ethnicity. The disabled person departs from what is understood to be species typical. A woman who is deaf will not hear a Beethoven

symphony, and a man who is paralyzed will not walk to a mountain peak. How much someone must depart from typical to be described as disabled or ill is a complex question and gives rise to the “boundary problems” Lebacqz discusses elsewhere in this issue, but is beyond the scope of this article.⁴ Although deafness and paralysis are both departures from what is customary in humans, they differ from each other in terms of the type and amount of healthcare they require. Many people with sensory impairments have no underlying disease process that leads them to maintain ongoing contact with medical professionals; some people with impaired mobility, on the other hand, confront recurrent infection that may require more frequent clinical care.

Until the 1960s, and regardless of how often and for what reason a person with a disability received medical care, virtually all clinicians, educators, and policymakers were convinced that a disabled person’s life would differ radically from the life of a sister or brother without such a condition. If a man could not hear to use the telephone or did not have comprehensible speech, those incapacities explained a fourth grade reading level, joblessness, and isolation from the hearing world. Inability to read print, and not the lack of Braille or recorded material, explained why blind people were similarly poorly educated and unemployed. People with impaired mobility were perceived as in their homes and not out shopping because they couldn’t walk, not because stores and restaurants had narrow aisles and flights of steps that barred access for people in wheelchairs.

The Minority Group Model and the Quality of Life

Many clinicians, bioethicists, service agencies such as the Muscular Dystrophy Association, family members, and people with disabilities continue to ascribe negative aspects of a disabled person’s life solely to the biological characteristics of the condition.⁵ During the last twenty-five years, however, people with disabilities have argued that only some of their limitations and problems could be attributed to their physiology; others stemmed from rejecting attitudes, discriminatory practices, and physical and institutional obstacles that could be remedied.⁶ Using a sturdy wheelchair in an area without curbs, steps, and narrow doors, a girl could attend her neighborhood school. When she grew older, she could go to work if she could board the public bus; and she could live where and with whom she wished if she could obtain assistance with toileting, dressing, and cooking from people she hired and trained. This scenario is in sharp contrast to the picture of disability—especially mobility disability—of unremitting pain, suffering, confinement and isolation, and loss of dignity in being “cared for” by others.

The doctor or bioethicist who evaluates the quality of life for people with disabilities based solely on encounters with people in crisis may forget that there are many means to achieving the same goal. Despite the reverence for autonomy in North American bioethics, most writers construe the term quite narrowly when it comes to evaluating what gives life a certain quality. According to the reigning model of doctor–patient relationships, physicians should discuss how a particular course of treatment will affect the patient’s life, and patients should then decide—based on their own values and preferences—what to do in a given medical situation. Insofar as the patient requests the physician’s expertise, experience, and skill but remains in charge of the deci-

sion process and outcome, everyone involved affirms that the patient is in charge and is acting independently. Consulting with a physician does not deny dignity and adulthood to the patient. When, however, bioethicists and clinicians discuss how a person with some disability accomplishes daily routines of dressing, bathing, going from one place to another, or obtaining written or spoken information, they imagine that the person providing assistance is actually in charge of the activity. The person with the disability is viewed by the professional as someone who is “dependent” and “cared for” simply because he or she is unable to manage a particular set of life tasks without another’s help. Needing such help is perceived as constituting a loss of dignity and adulthood.⁷ Designers of scales to evaluate quality of life give higher scores for the independent execution of the activity of dressing or shopping and rate the life as of lower quality with each increase in human assistance that is required.

Although some disability prevents people from dressing, using the bathroom, or preparing meals and eating without help, people with such disabilities do not automatically perceive themselves as ashamed, dependent, and lacking in self-direction or autonomy. When disabled persons obtain assistance from others who provide that help out of a caring personal relationship or in a respected and dignified employment relationship, they and their assistants retain self-respect.⁸ The father or mother who accompanies a child to a sporting event supervises the child even if they are both driven by an assistant because the child is too young to drive and the parent’s seizure disorder makes driving unsafe. The woman with a mobility impairment whose personal assistant shops for food she selects is no less in charge of her life than the woman who trades shopping for babysitting so that she and her friend can both maintain homes and work lives. For some people with disabilities, then, autonomy requires that they be able to conceive of themselves as in charge of how, when, by whom, and in what ways certain tasks are performed; they themselves need not execute those tasks. The tasks of dressing, cooking, and traveling are precursors to the goal of participating with others in ordinary activities and relationships.

Of course, many disabled people lack knowledge of available service programs or lack the resources to pay for assistance with personal hygiene, maintaining a home, traveling, reading, or the like; they may feel compelled to ask friends and family members for such help, and the help may be reluctantly given and awkwardly received. Help obtained under such circumstances may indeed contribute to the loss of a sense of control over one’s life. Disabled people may be viewed by their helpers—and may come to view themselves—as having lost dignity and adult status. Being viewed as a burden, as someone who only takes from and never contributes to personal relationships, surely corrodes the psyche and the soul; such feelings could diminish anyone’s appreciation of her life. These consequences are not intrinsic to the biological facts of an impairment but to the arrangements individuals, families, and societies make to manage the variations in needs we all have.

The bioethics and medical literatures have not fully absorbed the reports of people with disabilities or of social researchers indicating that the majority of disabled people consider their lives somewhat or very satisfying.⁹ Canadian teenagers who had been extremely low birthweight (ELBW) infants were compared with nondisabled teens and found to resemble them in terms of their own subjective ratings of quality of life. “Adolescents who were ELBW infants suffer from a greater burden of morbidity, and rate their health-related quality

of life as significantly lower than control teenagers. Nevertheless, the vast majority of the ELBW respondents view their health-related quality of life as quite satisfactory and are difficult to distinguish from controls."¹⁰

Although the 1994 survey of the National Organization on Disability found that nondisabled people were more satisfied with their lives than were the disabled adults, two-thirds of the disabled respondents considered their lives very or somewhat satisfying. Their dissatisfactions, moreover, stemmed not from their own health status but chiefly from their financial problems and their difficulties in maintaining a full social life. The respondents may correctly attribute their financial worries and disappointment with their social lives to the complications of having a disability, but these complications may not result primarily from pain, weakness, or fatigue that would limit social life and employment; instead, they may stem from the frustrations of social rejection, of physically inaccessible movies and restaurants, of inadequate transportation to social gatherings, or of discrimination in the workplace. Understanding the impact of a disability on anyone's quality of life entails looking beyond the correlation of disability with unemployment or loneliness to discover if or how health status is connected to disappointment in an area of life. If these frustrations arise from forces outside an individual's pain, energy, or alertness, the solutions may require social changes and may be beyond what medicine can provide for a particular patient.

Medicine and bioethics should not conclude from these last remarks that their professions are off the hook because "the disability problem" is not medical. Quite the contrary, in fact, is the case. Too many clinicians and bioethicists are ready to question or qualify statements by people with disabilities that do not conform to their predictions of unhappiness. Commenting on the findings of the relative contentment of Canadian teenagers, Tyson and Broyles suggested that the disabled youth and their parents (but not the nondisabled youth) might have given "inflated" reports about their own quality of life, and the authors remarked that denial was a useful defense.¹¹ When professionals don't question the results of research that shows life satisfaction, they frequently contend that happy disabled people are the exceptions. Discussing the decisions of disabled people to opt for ending their lives (which I consider later), Powell and Lowenstein describe those who go on living as heroes and wonder whether "it is also not clear if acts of heroism always help the heroes as much as they help the rest of us."¹² Doctors and bioethicists shape decisions of individual patients and families, and they cannot help others make genuinely informed decisions about how to handle life with a disability if they themselves continue to be disbelieving or astonished that people with a variety of impairments can pursue life plans they find satisfying.

Simply because one or thousands of people with cancer, Down syndrome, spinal cord injury, or ALS find life rewarding tells nothing about the next patient. As the diagnostician and gatekeeper to treatment and information, the physician can be crucial in helping people appraise how a traumatic injury or the progress of a chronic degenerative disease is likely to affect them. If nondisabled clinicians and ethicists cannot themselves drop the perspective of the nondisabled public regarding life with disability, then they must at least learn what others with a range of experiences of disability would say about their lives. Not everyone who has a disability is satisfied with life; and as both surveys reported, teens and adults with disabilities gave some parts of their

lives lower ratings than people without disabilities. Yet, if overall disabled people believe that they can achieve enough of their goals to make life worthwhile, then the profession must hear that message and impart it as a piece of the information they convey to new patients evaluating how changes in their health will impinge on their own life goals.

As the national debate on physician-assisted suicide grows more intense and as more states consider whether to adopt their own versions of Oregon's plan for allocating resources, healthcare providers and institutional ethics committees will be called upon to design guidelines for their own institutions. As institutions, states, and the nation struggle with these controversial topics, voices of disabled people will need to be heard. Many people with disabilities would say that policies about resource allocation and about physician-assisted suicide could harm their efforts at pursuing equal access to society because such policies might reflect the majority view that a life with disability is inevitably less worthwhile than a life without it. If the disability community correctly perceives the dominant view to be one that questions whether a life with disability can be rich enough to warrant access to scarce medical resources, then physicians and bioethicists who become sensitized to the disability community perspective may do a lot to educate the rest of society on these issues.

Before applying these ideas about a social view of disability and quality of life to these two topics, let me make a brief comment on the phrase "the disability community." As with concepts like "the gay community," or "the working class," or "feminists," specifying what makes a particular person with a disability a part of the "community" is indeed difficult. Some have estimated that people with disabilities are roughly one-sixth of the nation,¹³ but as I pointed out earlier, disabilities vary greatly. Undoubtedly some people will claim that people with cognitive disabilities have nothing in common with the mobility-impaired, and that people with invisible conditions like heart disease or back problems share nothing of the experience of someone who is stared at because cerebral palsy produces a noticeably unusual gait. To further fragment any possibility of "community," disabilities occur at different times in everyone's lives, and they typically occur after people have reached middle age and have formed significant group memberships based on religion, language, or race, for example. Nonetheless, what people with disabilities share is the experience that their departure from what is species typical makes them the objects of unequal treatment such as denial of employment or education for which they qualify. According to the 1994 survey I mentioned earlier, more than half of the respondents perceived themselves to be a member of a minority and accepted the notion that they were indeed members of a disability community.¹⁴

Rationing Healthcare Resources

When people with disabilities worry about rationing, they fear that they will be denied access to a scarce service or resource based on others' beliefs that their disability makes them a poor candidate for a precious good that will sustain or improve their life. A year ago outrage was turned into victory when Sandra Jensen, a 34-year-old woman with Down syndrome, received a heart-lung transplant she had fought for for two years.¹⁵ Having been denied the transplant by two major centers, she finally obtained it after pointing out that the Americans with Disabilities Act protected her against denial of services based on her

disability. The ADA applied to her situation because a healthcare institution, and not a family, refused to provide treatment from which the patient could benefit, based on views about her disability. Whether the denial rested on the hospitals' beliefs that her Down syndrome would make her unable to follow the postoperative regimen, or whether it arose because doctors believed that the scarce heart and lungs would be better used by a patient without Down syndrome, the hospitals turned down Ms. Jensen based on beliefs about how a disability would affect her life. Here is perhaps the classic feared scenario. No claim was made that the individual could not benefit from the treatment or wasn't healthy enough to undergo the surgery. The institutions did not even explore her particular situation, cognitive abilities, supports, life situation; rather, they concluded that simply having Down syndrome made her ineligible.

In some instances, an individual's disability may be extremely relevant to a treatment decision for a subsequent medical problem; heart disease may preclude surgery for removing a tumor. To take another example, some women with diabetes or multiple sclerosis are advised against pregnancy because it may exacerbate the condition. If a woman becomes pregnant, she may need monitoring for particular problems. An infertility clinic might be leery of undertaking infertility treatments and a pregnancy with someone whose health made any pregnancy a danger to her own well-being. If the same infertility center denied services to a man, woman, or couple based on the belief that a disability precluded effective parenthood, the clinic might be substituting social judgments about which people should be parents for medical ones regarding whether people could derive medical benefit from the service.

The original Oregon plan contained several instances in which an underlying disabling condition was used as the basis for denying a treatment that would have sustained or improved life, but which would not have ameliorated the residual disability. Dan Brock has carefully analyzed the moral implications of the Oregon rationing scheme, and I agree with his conclusions that the original plan would have been unfair to people with disabilities because it presumed that people with disabilities would receive less benefit from treatment than would those who were not impaired. And it suggested that the lives of disabled people were less worthwhile, and less worthy of public support, than the lives of persons who would not have disabilities. Brock notes that the framers of the plan could arrive at such judgments because they used the perspectives of people who were not disabled, who knew very little about how people with a range of disabilities could enjoy life, and therefore rated the quality of life of people with disabilities as lower than the quality of life of people without them.¹⁶

In all of these instances of rationing, the "difference" of disability has been used to deny people their opportunity for sustaining, restoring, or improving health and life because no improvements will eradicate or cure all of an individual's impairments. These situations are most likely to occur when people who have lived with a disability for some period of time seek medical care for a new, perhaps wholly unrelated, health problem. If physicians screen at the bedside and deny care or give less treatment than might be afforded someone else without the first disability, the disabled individual and her family may never be aware of such actions. However, an alert patient and vigorous supporters may prevail in convincing physicians, as occurred in the case of Sandra Jensen's heart-lung transplant. She prevailed not only because of the provisions

of the ADA, but because she and her supporters were clear about their own views on the worthiness of her life and of her ability to handle the treatment.

Ending Treatment and Physician-Assisted Suicide

Most of the time, when people with disabilities seek to end their lives, they are choosing death over the unknown. For example, in several cases that have received national attention, people who became quadriplegic in accidents decided they couldn't endure life with disability; when Larry Macafee and David Rivlin made their decisions they had had relatively little contact with others who were negotiating life as a disabled person. Thus, when a newly disabled person seeks to forgo life-sustaining treatment, the decision may be being made out of fear of the future, shock at a major change, depression, and the conviction that all goals for the future are no longer attainable.

If autonomy consists of the ability to make informed, voluntary choices about the course and direction of one's own life, then it is necessary for persons to fully understand the options and opportunities that are available to them. When the onset of impairment is sudden and unexpected, it may take time for persons and their family and friends to comprehend and adapt to the reality of their condition. While such persons may be competent to make decisions, they may not fully understand or be prepared to listen to what health care providers or those with impairments wish to convey.¹⁷

These authors urge health professionals to adopt an educational approach with patients who are contemplating irrevocable decisions with inadequate information about what type of future might be possible for them. The healthcare professional and other persons have lessons to impart before a newly disabled person can be said to be making an informed decision. The necessary patient-professional dialogue must be tailored to the patient's life goals, values, and circumstances, no matter how idiosyncratic. Here is a time when physicians, family, and patient need to examine how goals may be achieved even if the means of pursuing them may change.

Clinicians do patients a great disservice if they too quickly leap to accepting desires for "death with dignity," instead of ensuring that patients' desires for death do not come from fears of life in a new situation or fears of loss of valued roles and relationships that might not actually be lost. Depression and hidden problems may spark requests for withdrawal of treatment or requests for death, when, in fact, the problem might be addressed. A patient may believe that avoiding a life of disability is socially acceptable (as many courts have deemed it by their responses to Bouvia, Macafee, and Rivlin); perhaps the patient's genuine fear is of isolation or abandonment, which he deems less acceptable. If isolation were abated, would death be chosen?

"Rules governing doctor/patient relations must rest on the premise that anyone's wish to help a desperately pained, apparently helpless person is intertwined with the wish to hurt that person, to obliterate him from sight."¹⁸ Such a stark characterization of the complex responses of helping professionals to those in their care at first demands to be opposed and rejected. Yet Robert Burt compels us to acknowledge our socially, psychologically, and culturally

ambivalent responses to people who are severely ill or disabled in some ways noticeably different from their helpers in appearance, capacity, and behavior. These ambivalent and uncomfortable responses to disabled patients may make more sense when we acknowledge that disability represents a failure of medicine to solve all problems, cure all ills, make everything pure and whole. No wonder the desire to obliterate the person who cannot be cured. Powell and Lowenstein note that when disabled people seek physician assistance to end their lives, they may be responding to what they perceive as “a certain enthusiasm on society’s part for their suicide.”¹⁹

Whether or not clinicians, bioethicists, or the larger society are conscious of any such wishes, it seems clear that when people with serious disabling conditions express a desire for ending their lives, counseling and efforts to alleviate depression that might have been considered when others talk of suicide are not immediately deemed appropriate. Ever since Elizabeth Bouvia asked Riverside Hospital to assist her in ending her life, people with disabilities have argued that doctors, civil liberties lawyers, and the bioethics world failed to grasp the essence of Bouvia’s plea. This was not a typical “right-to-die” case in which a person who was terminally ill and had only weeks or months to live preferred death to unrelievable pain. They contended that Bouvia’s pain was not principally caused by her contractures from cerebral palsy; rather, it was the pain of a string of profound losses and disappointments that would have devastated anyone: the ending of a marriage, the miscarriage of her first pregnancy, the death of her brother and serious illness of her mother. Added to these were the denial of funding for attendant services due her by the state of California, and the dismissal from school by a dean who believed that she could not perform as a social worker because of her disability. None of these undeniable life stresses was apparently discussed as having any possible bearing on her depression and despair. Psychiatrists’ depositions, briefs filed in her behalf, and appellate court opinions focused exclusively on her physical circumstances; they gave no attention to whether psychotherapy, increased pain medication, the reinstatement of attendant care funds, or reentry into a more welcoming graduate program might make any difference in her view of her life prospects. Only her disability, along with the judge’s characterization of her life as a “pitiable existence,” was perceived as her reason to end her life.²⁰

Such attitudes on the part of health professionals and lawyers showed many with disabilities that their analysis of Elizabeth Bouvia’s situation differed radically from that of others. She needed not death, but help to recreate her life. David Rivlin, a man who became quadriplegic in an accident a few years before his death, decided to end his life after he learned that he could not get sufficient funding for attendants to leave the nursing home in which he had been staying. While the Michigan court spoke of his case as involving a competent person’s “right to die,” people with disabilities again saw it as the response of a disheartened individual to society’s failure to enable people with disabilities to have opportunities for lives of productive work and rewarding personal relationships. If the medical and legal systems, and the entire society, affirmed our profound connection with our disabled members instead of separating from them, perhaps we would then expend resources to make everyone’s lives more worthwhile. And perhaps, until we make such social commitments, clinicians will face wishes for death from disabled people who have tried life and discovered that despite their best efforts, they cannot find

financial security, meaningful activity, or a place in a loving family and community. People wish death when they feel that no significant life goal is attainable.

Health professionals must aid disabled people to see whether it is disability itself that blocks the goals, or obstacles that are socially created. If David Rivlin had obtained resources to live in the community and not in a nursing home, he might have had less interest in dying.²¹

Only by carefully differentiating what is inherent in a disability from what is socially created (and thus socially remediable) can patients truly begin the process of deciding whether they want to live or die. Even if a person recognizes that it is not the inherent limits of the condition but rather the society that poses obstacles, the person will not conclude automatically that she should live and struggle. People may still choose to end life-sustaining treatments or to forgo extensive rehabilitation rather than undergo life in a world not truly hospitable and well-designed for those with disabilities. Trying to create the social and physical environment to permit flourishing may prove a daunting task. People may perceive that even if attainable, the costs of pursuing their goals are too high.

Yet clinicians can recognize that some patients, some people, give up on life, and still work with their patients to give them the best chance for enjoying the lives they have. If people with traumatic injuries and progressive disabilities receive substantial information about life options, and if they are afforded substantial contact with others of similar disabling conditions, they might make different choices.

Implications for Clinicians and Bioethicists

Hospitals, long-term care facilities, and even rehabilitation centers rarely employ people with severe disabilities in responsible professional positions; nor do they furnish newly disabled people the options of contact with others who have lived with the conditions over a period of years. Findings like those of the Canadian and U.S. surveys discussed earlier offer an important source of information about potentials and problems of life with disability. These findings, and the personal contact with others who live with disabling conditions, go far beyond the facts of pain, medications, and physical sequelae to the heart of social living—consequences for relationships; vocational and recreational opportunities; information about creating a more barrier-free environment; laws guaranteeing supportive services and prohibiting discrimination in public programs, education, and employment; information about service agencies, family support groups, and advocacy organizations of people with disabilities.

Returning to Burt's point about the complex mixture of desire to help and to avoid people with disabilities evident in the health profession, we must be especially apprehensive about the quality and tone of information given to those with disabilities primarily by nondisabled institutional staff. If, in fact, such professionals are as unaware of their ambivalence as Burt suggests (and as other literature documents),²² it is especially problematic to combat possible institutional bias that flavors presentation of difficulties and possibilities.

Before entertaining a refusal of treatment or rehabilitation, or before cooperating in the request for physician-assisted suicide, professionals must address their own difficulties and fears about life with disability by obtaining information about it from those who live with various conditions. Once informed, their

professional responsibility encompasses addressing understandable patient and family apprehensions about life with disability by strongly encouraging and facilitating contact with knowledgeable disabled people and representatives of independent living and disability rights groups. Hospital prognosis or ethics committees should similarly include knowledgeable persons with disabilities, not limiting themselves to rehabilitation professionals as the sole sources of information and perspective.

Imbued with this perspective it is possible that the difference of disability would diminish in the minds of clinicians, and disabled persons seeking health-care might feel that they are allied with the professionals who are there to assist them in making decisions.

Notes

1. DeJong G, Banja J. Health care and physical disability. In: Reich WT, ed. *Encyclopedia of Bioethics*. revised ed. New York: MacMillan, 1995:615–22.
2. Brock D. Quality of life measures in health care and medical ethics. In: Nussbaum M, Sen A, eds. *The Quality of Life*. New York: Oxford University Press, 1993:95–132, 116.
3. Public policies entitle people who depart from norms of health to certain services, income supports, and protections against discrimination. Despite differences that may be especially relevant in the clinical context, laws like The Americans with Disabilities Act consider conditions of Down syndrome, diabetes, and deafness all to be disabilities. In deference to the increasing use of the term “disability” in law, this article will use the term “disability” to include people whose diverse conditions are sometimes described as “chronic illness,” along with those more commonly described as having a “handicap” or “disability.”
4. How short someone should be to be included as a member of Little People of America and to be a candidate for clinical intervention is a problem I note but do not address in this article. Likewise, I do not discuss the intriguing question of when an individual’s personality characteristics depart sufficiently from the norm to warrant a diagnostic label with the attendant possibilities of medication or “reasonable accommodation” at work.
5. Examples of bioethics literature that attributes a poor quality of life to the presence of a disability are discussed in Asch A. Reproductive technology and disability. In: Cohen S, Taub N, eds. *Reproductive Laws for the 1990s*. Clifton, N.J.: Humana Press, 1989:69–124; and Asch A. Disability I: attitudes and sociological perspectives. In: Reich WT, ed. *Encyclopedia of Bioethics*. Revised ed. New York: Macmillan, 1995:602–8.
6. Important treatments of these ideas can be found in Gliedman J, Tooth W. *The Unexpected Minority: Handicapped Children in America*. New York: Harcourt, Brace, Jovanovich, 1980. Bowe F. *Rehabilitating America: Independence for Disabled and Elderly People*. New York: Harper and Row, 1980; Gartner A., Joe T. eds. *Images of the Disabled: Disabling Images*. New York: Praeger, 1987.
7. An illustration of this approach is found in Callahan D. Families as caregivers: the limits of morality. *Archives of Physical Medicine and Rehabilitation* 1988;69(5):323–28. See also the language of the scales clinicians use to assess quality of life Brock describes, see note 2, Brock 1993.
8. For discussions of personal assistance services from the perspective of the disability rights/independent living movement, see Litvak S, Zukas H, Heumann JE. *Attending to America: Personal Assistance for Independent Living*. Berkeley, Calif.: World Institute on Disability, 1987. For use of this perspective as applied to cases in bioethics, see Asch A. Abused or neglected clients—or abusive or neglectful service systems? In: Kane RA, Caplan AL, eds. *Ethical Conflicts in the Management of Home Care: A Case Manager’s Dilemma*. New York: Springer, 1993:113–21.
9. National Organization on Disability. *NOD/Harris Survey of Disabled Americans*. New York: National Organization on Disability, 1994. Saigal S, Feeny D, Rosenbaum P, et al. Self-perceived health status and health-related quality of life of extremely low birthweight infants at adolescence. *JAMA* 1996;276(6):453–9.
10. See note 9, Saigal, Feeny, Rosenbaum 1996:453.
11. Tyson JE, Broyles RS. Progress in assessing the long-term outcome of extremely low birthweight infants. *JAMA* 1996;276(6):492–3.

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12. Powell T, Lowenstein B. Refusing life-sustaining treatment after catastrophic injury: ethical implications. *American Journal of Law, Medicine, and Ethics* 1996;24(1):54-61.
13. Estimates of prevalence of disability vary depending upon the definition of disability employed, the ages of the population considered, and whether institutionalized and non-institutionalized will be counted together. For brief discussion of different definitions and estimates of the size of population, see Asch A, Murdick N. Disability. In: Edwards RL, ed. *Encyclopedia of Social Work*. 19th ed. Washington, D.C.: NASW Press, 1995:752-61, 753.
14. See note 9, National Organization on Disability 1994. Also see Scotch RK. Disability as the basis for a social movement: advocacy and the politics of definition. *Journal of Social Issues* 1988; 44(1):159-72.
15. Goldberg C. Her survival proves doubters wrong. retarded woman recovers from transplant she had been denied. *New York Times* 1996 March 3;12A:1,6.
16. Brock D. Justice and the ADA: does prioritizing and rationing health care discriminate against the disabled? *Social Philosophy and Policy* 1995;12:159-84.
17. Caplan AL, Callahan D, Haas J. Ethical and policy issues in rehabilitation medicine. *Hastings Center Report* 1987;17(4)[Special Supplement]:1-20.
18. Burt RA. *Taking Care of Strangers: The Rule of Law in Doctor/Patient Relations*. New York: Free Press, 1979.
19. See note 12, Powell, Lowenstein 1996.
20. Elizabeth Bouvia's circumstances are described in Disability Rights Coordinating Council. Declaration of Carol Gill. *Bouvia v. Riverside*. Los Angeles: Disability Rights Coordinating Council, 1983. The court's words are found in *Bouvia v. Superior Court of the State of California*, 225 Cal. Rptr.
21. For a review of many of the court cases of people with disabilities, see Herr SS, Bostrom BA, Barton RS. No place to go: refusal of life-sustaining treatment by competent persons with physical disabilities. *Issues in Law and Medicine* 1992;8(1):3-36.
22. See the entire issue of the *Medical Humanities Report* of Michigan State University Center for Ethics, Humanities and the Life Sciences, Fall 1996, which documents the complex reactions of bioethicists Howard Brody and Tom Tomlinson to their contact with Not-Dead-Yet, a disability advocacy group protesting physician-assisted suicide.