

Disabled Persons

We hold all human life to be sacred as created in God's image. This includes persons who might be regarded as disabled or handicapped. The importance of a person does not reside in the functioning of the body or mind or in the person's ability to contribute to society, but rather in his or her intrinsic value as God's creation.

We believe the Bible teaches our mutual interdependence. All people, including disabled persons, are responsible to realize their potential insofar as possible. The family holds the primary responsibility for the additional support needed by the disabled person. The family's resources should be supplemented by those of the church and community.

The role of the physician and dentist is to provide appropriate medical care as needed. In all cases, our response should be characterized by an attitude of compassion, free of condescension and marked by action. In the case of extreme disabilities, legitimate questions may be raised regarding the appropriateness of various levels of treatment.

Having accepted our own spiritual disability and God's forgiveness, we desire to honor, assist, and bring healing to the physically, mentally, and spiritually disabled in our community.

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Passed with 52 approvals, 7 opposed, 1 abstention
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Explanation

One of the tragic results of the secularization of medical ethics is the prominence given to individual human interests in current discussions of ethical issues. Gone from much of the debate is the supremacy and sovereignty of God and the concept of the inherent worth of the individual. This human-centered, secular view is clearly portrayed in Romans 1:18-32 where Paul reports that God's wrath has been kindled against mankind because they "exchanged the truth of God for a lie, and worshiped and served created things rather than the Creator" (v 25). This perspective easily leads to the assessment that there are some handicapped individuals on whom we should not expend medical resources.

Christians retain the theocentric view that human individuals are created by God, in His image, and thus have a special value which is greater than that of other created beings and "a little lower than the angels". God reminded Moses that He is the creator of all, even those who are deaf or blind (Exodus 4:11). The God-centered, sanctity of life perspective means that human dignity and worth are ascribed by God, and need not be earned by human ability. Thus individuals are not to be judged by their productivity.

CMDS developed their statement on **Disabled Persons** to affirm the inherent worth of each individual, and to counter the idea of expendable persons. They also tried to emphasize the responsibility which each Christian has, whether as a healthcare professional, a church member, or a family member, to assist persons with diminished physical or cognitive abilities to reach their maximum potential. It is not sufficient to accept persons with disabilities as valuable humans, and then to merely place them in custodial facilities to be fed and kept warm.

The Quality of Life

Some who subscribe to this sanctity of life ethic, however, interpret this precept to mean that all human life must be preserved as long as is physiologically possible. They contrast sanctity of life (Christian) and quality of life (secular) perspectives and believe them to be mutually exclusive. This theological vitalism seems to ignore the fact that human life in this fallen world is finite; all will die. In addition, each individual has a quality to his or her life. That quality assessment is very subjective. Many persons tolerate seemingly intolerable situations without complaint; others complain loudly because of much less severe, or even temporary, disabilities.

Quality of life cannot be ignored, it is a fact of life. This comes into play when professionals are caring for individuals with severe irreversible disabilities. When life-threatening crises intervene, decisions about the appropriate goals and level of treatment are often difficult. There may be legitimate differences of opinion, even among those who solidly believe that human life is sacred, about the proper treatment plan. Hopefully, these differences can be resolved by looking to Scripture, spiritual leaders, and the Holy Spirit for guidance.

Abstracts

Hadorn DC. The problem of discrimination in health care priority setting. JAMA 1992; 268(11):1454-1459

Increasingly stringent fiscal restrictions on the scope of medical services available to patients have resulted in calls for explicit health care priority setting. Several commentators have called for the application of decision-analytic principles to such efforts, which would assign services priority based on the extent to which they produce preferred health outcomes. The Oregon Medicaid exercise is an example of such a process. An important challenge to these utilitarian efforts is the need to avoid discrimination against people with medical disabilities. Both of the key elements entailed by decision-analytic approaches to priority setting---estimation of outcomes and assignment of values to those outcomes---are vulnerable to charges of discrimination, primarily because both the medical outcomes expected in disabled individuals and the values they place on those outcomes may differ from the general public. Priority-setting efforts must proceed carefully to avoid the appearance (and reality) of discrimination.

Disabled Peoples International (Australia) Limited. Lives of inestimable value: life worthy of life. Issues in Law & Medicine 1991;7(2):245-262

An Australian disabilities rights group responds to the National Health and Medical Research Council's: Discussion Paper on the Ethics of Limiting Life-Sustaining Treatment". In their conclusion they state "Contrary to the NH&MRC paper, severe disability does not necessarily mean a tragic existence. Rather, it is inadequate and inappropriate support services which handicap people with disabilities and serve to create a low quality of life. With appropriate support, people with disabilities can go on to lead happy and productive lives pursuing their choice of life-style. This is in marked contrast to a stereotype of an institutionalized person with a disability who lacks dignity and exists on welfare." They go on to call for the withdrawal of the position paper and conclude with the statement "We affirm the inherent worthiness of the lives of all people regardless of their ability and/or disability."

Miller PS. The impact of assisted suicide on persons with disabilities---is it a right without freedom? Issues in Law & Medicine 1993;9(1):47-62

The discussion over the right to die has been co-opted by individuals and groups who do not understand, nor even care to identify, the perspective of persons with disabilities, their unique concerns, history, or context. With over forty-three million persons with disabilities in the United States, they are the largest minority group encountering prejudice and discrimination. Yet, third parties counsel persons with

disabilities on their right to die without any sensitivity to their unique characteristics as a minority group. Without being offered a choice of independent living alternatives and counseling, with special emphasis on psychological issues facing persons with disabilities, the right to assisted suicide is no right at all; it is the inevitable manifestation of society's prejudice.

Hauerwas S. *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church*. Notre Dame, IN: University of Notre Dame Press, 1986

The author, a professor of Christian ethics, says he is not even sure if [he] believe[s] in medical ethics as a specifiable discipline or area. He does, however, believe that medicine and religion are unavoidably interrelated, and that the Christian community should be present to the ill even as they suffer. In this book, he uses the Christian teaching about the care of the weak to formulate theological reflections on living, dying, and experimentation in Part Two. In Part Three, he addresses caring for the mentally handicapped. While challenging the dominant paradigms of contemporary ethics, he articulates a well-formed theological perspective which illustrates for believers how philosophical and theological ethics can be linked.

Bibliography

Allen DF, Allen VS. *Ethical Issues in Mental Retardation: Tragic Choices/Living Hope*. Nashville: Abingdon Press, 1979

The authors, a psychiatrist and a journalist, describe the range of feelings, attitudes, and options open to the families of mentally retarded persons. Often there are troubling and tragic choices to be made. But even more often there is hope---the very real expectation that mentally retarded persons can lead happy and even valuable lives. *Issues in Law and Medicine*

This quarterly peer-reviewed journal began in 1985 as a cooperative effort of the National Legal Center for the Medically Dependent & Disabled, Inc, the Horatio R. Storer Foundation, and the American Academy of Medical Ethics, Inc. It takes a strong conservative editorial stance as an advocate for persons with disabilities, but it does publish contrasting views as well. It publishes observations and opinions on such issues as limitation of treatment, assisted suicide, euthanasia. This journal publishes annually a review of judicial decisions and legal trends entitled "Medical Treatment Rights of Older Persons and Persons with Disabilities". Its publication office can be reached at P.O. Box 1586, Terre Haute, IN 47808-1586.

Lynn J. *Ethical issues in caring for elderly residents of nursing homes*. Primary Care June 1986; 13(2):295-307

Residents of nursing homes commonly need the active assistance of their physicians to enhance the quality of their lives and, when possible, to retain authority over the choices affecting them. Physicians need to encourage advance directives, enhance competence, defend the rights and interests of incompetent patients, treat symptoms vigorously, and manage well the residents' inevitable dying. Cost-containment concerns require physicians to re-examine their role as patient advocate.

Maxson, G. 'Who's life is it, anyway?' Ours, that s whose! in *On Moral Medicine: Theological Perspectives in Medical Ethics*. Grand Rapids, MI: Eerdmans, 1987:470-472

Objecting to the film *Whose Life Is It, Anyway?*, which regards the lives of persons with disabilities as not worth living, this disabled author attests to the fullness of life which she and her disabled friends experience. Rejecting the film's premise that disabled persons should choose to commit suicide or resort

to euthanasia, she acknowledges her reliance on Christ as "that Presence who stands near but outside my harsh circumstances, and molds them into coherence and beauty."

Hauerwas S. The Christian, society, and the weak: A meditation on the care of the retarded. In On Moral Medicine: Theological Perspectives in Medical Ethics. Grand Rapids, MI: Eerdmans, 1987:591-594

Writing specifically to Christians, the author warns of the dangers of using humanistic principles to support their care of the retarded. He contends that such humanism may lead Christians to justify seeking the good of society at the expense of the few and may foster the belief that the only achievable good lies within this life. Thus, he urges Christians to boldly appeal to their Christian faith in caring for the retarded, remembering that "[s]erving the weak in the name of man is not enough; God calls us to love and care for the weak just as He has loved and cared for us."

Verhey A. The death of infant Doe: Jesus and the neonates. In On Moral Medicine: Theological Perspectives in Medical Ethics. Grand Rapids, MI: Eerdmans, 1987:488-494

Prefacing his essay with a consideration of Jesus' unqualified love for all children, the author contends that the decision in the 1982 Bloomington, Indiana "Infant Doe" case to forgo treatment of an infant with Down syndrome and esophageal atresia was morally wrong. He contends that the "impartial reasoning" on which this decision was based is inadequate to address such an issue and invokes the Christian narrative of Jesus and the children in defending his position. He asserts that the "eschatological vision of Christianity---and the entire Christian story, including the story of Jesus and the children- --provides a resource to support the fragile Hippocratic tradition of medicine, for it enlists us on the side of life and health in a world where death and evil still apparently reign."

Zweibel NR, Cassel CK, eds. Clinical and policy issues in the care of the nursing home patient. Clinics in Geriatric Medicine August 1988; 4(3)

This special issue of a quarterly journal on geriatric medicine focuses on clinical and ethical issues in the care of patients in long-term care facilities. The 14 articles address multiple issues, including treatment of infection, nutrition and hydration, bowel and bladder problems, dementia, psychiatric disorders, falls, management of medication, dying patients, quality assessment, decision-making for incompetent patients, and the withdrawal of life-sustaining treatments.

Kleinman A. The Illness Narratives: Suffering, Healing, and the Human Condition. New York: Basic Books, 1988

The author, a psychiatrist and anthropologist, shares what he has learned during twenty years spent studying and treating chronic illness. His most telling point is that we must listen to what patients, as well as those closest to them, tell us about their illness or disability and what it means to them.

Nagler M (ed). Perspectives on Disability. Palo Alto, CA: Health Markets Research, 1990

This anthology of previously published pieces is arranged under ten topics: What it means to be disabled; Societal Attitudes about disability; Social encounters; Family Experiences; Sexuality and disability; Educational opportunities and barriers; Employment and disabled workers; Legal issues; Medical concerns; and What it means to be different.

Eareckson-Tada J. Disabled doesn't mean you're sick. Physician July-August 1991:2-4

The author writes a first-person account of encounters with laypersons and healthcare professionals who consider that she is ill because she is a quadriplegic in a wheelchair. She encourages all who deal with

people who have disabilities to change their approach from the "medical model" to the "independent-living model".

May WF. The Patients' Ordeal Bloomington, IN: Indiana University Press, 1991

Instead of taking the traditional perspective of the clinician or the ethicist, this ethics book looks at dilemmas from the perspective of the patient and the family. Rather than asking "what should we do?", May asks "how are we going to manage to rise to the occasion?" It includes chapters on the burned, the retarded, the aged, the battered, and others.

Biebel A. Suddenly disabled. Focus on the Family January 1992:2-4

The mother of a child who developed a neurological disability at age 6 describes her pain and healing and that of her family. She offers constructive ways others may offer comfort, and specific guidance for parents about how to "go to bat" for their disabled child.

Scofield GR. Ethical considerations in rehabilitation medicine. Archives of Physical Medicine and Rehabilitation 1993;74:341-346

As the number of patients with chronic illness or disability grows, rehabilitation professionals will face increasingly difficult questions. Traditional concepts of medical ethics can help find solutions to some, but not all of those questions. Rehabilitation medicine needs an expanded vision of informed consent, one that embraces the needs of patients and promotes rehabilitation's educational model in contrast to the critical care model.

Bernat JL. Ethical Issues in Neurology. Boston: Butterworth-Heinemann, 1994

This textbook for clinicians who treat patients with neurological problems includes chapters on "Dementia" (chapter 10) and "Mental Retardation" (chapter 11). Each presents an overview of the topic, encourages the physician to be an advocate for the patient with diminished capacity, and offers practical advice on specific questions which arise in the clinical and social arenas. This scholarly text includes dozens of references at the end of each chapter.

Supplement to the American Journal of Physical Medicine & Rehabilitation. 1995; 74(1)

This special issue offers 12 articles on ethical issues encountered in the care of chronically ill and disabled persons. Issues discussed include goal setting, allocation of resources, resuscitation decisions, quality-adjusted life years, severe neuromuscular diseases, AIDS, professional relationships, and others.

Thobaben JR. Long-term care. Dignity and Dying: A Christian Appraisal. Grand Rapids, MI: Eerdmans, 1996:191-207

Asserting that the failure of the current health care system to meet adequately the needs of disabled persons may lead to their requests for physician-assisted suicide, the author calls for reform in both Christian and secular health care settings. He presents a brief analysis of disability in the United States, draws a parallel between conditions experienced by the disabled and those and those which are used to advocate or justify euthanasia, considers social sanctions for euthanizing those with disabilities, and urges Christians to employ a model of care designed to value the disabled.

Special issue on ethics and rehabilitation psychology. Rehabilitation Psychology 1996;41(1)

A special issue of this journal (of the Division of Rehabilitation Psychology of the American Psychological Association) has five articles on "Rehabilitation ethic and ethics" , "Rehabilitation psychology practice,

ethics, and a changing health care environment", "Ethical issues in pediatric rehabilitation: exploring an uneven terrain" , "Ethical issues in psychological evaluation of patients for organ transplant surgery", and "Life-sustaining treatment decisions by rehabilitation patients: the uncontested high ground."

Treloar LL. Lessons from Joy: Living with disability. Journal of Christian Nursing 1998;15(2):9-13

The parent of a disabled child offers insights into characteristics of health care professionals which are most appreciated by family members providing home care