

Ethics and Intellectual Disability

Court Authorizes Withdrawing of Ventili- lator and Nutrition

Robert M. Veatch

In a case of interest to those concerned about persons with intellectual disabilities, a Massachusetts court has authorized the state's Department of Social Services to withdraw life support, including a ventilator and a feeding tube, from eleven-year-old Haleigh Poutre, a youngster believed to be in a permanent vegetative state as a result of a severe beating allegedly at the hands of her adoptive mother and stepfather. The case is unique in putting a state on record that withdrawing life support from a permanently unconscious person can be the best choice when there is no advance directive from the patient and no family surrogate qualified to make the choice based on family beliefs and values.

The case is a tragic one. The Westfield, Massachusetts girl was hospitalized last September after allegedly being kicked and beaten with a baseball bat to the point that she was left in what was then believed to be an irreversible vegetative state. The

(Continued on page 3)

Book Review

Quality of Life and Human Difference

Robert Leider

In the introduction of *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, [Cambridge University Press, 2005, \$20.00] the book's three editors, David Wasserman, Jerome Bickenbach, and Robert Wachbroit, tell us its purpose: to combine into one anthology viewpoints on the conceptualization and measurement of "quality of life" with writings on the ethical ramifications of testing designed to detect disabilities before conception or birth (page 15). Their book accomplishes this task well, though I have concerns about the omission of some important perspectives on these issues.

Of these two literatures, *Quality of Life and Human Difference* best presents the first. With the ever-increasing cost of health care, and the inescapable reality that health care demand exceeds its supply, attempts have been made to measure, as objectively as possible, the impact disease and disability have on the quality of life.

(Continued on page 4)

Symposium on Disability

The journal, Ethics, this last October published an entire issue devoted to a symposium on ethical issues related to disability. We provide the table of contents for any who wish to pursue the articles, written by some of the leading ethicists in the field.

Ethics

An International Journal of Social, Political, and Legal Philosophy

VOLUME 116 OCTOBER 2005 NUMBER 1

1

Editorial
by John Deigh

SYMPOSIUM ON DISABILITY

5

Introduction
by Christopher Heath Wellman

9

Reciprocity, Justice, and Disability
by Lawrence C. Becker

40

Justice through Trust: Disability and the "Outlier Problem" in Social Contract Theory
by Anita Silvers and Leslie Pickering Francis

77

Causing Disabled People to Exist and Causing People to Be Disabled
by Jeff McMahan

100

At the Margins of Moral Personhood
by Eva Feder Kittay

132

The Nonidentity Problem, Disability, and the Role Morality of Prospective Parents
by David Wasserman

153

Invisible Disability
by N. Ann Davis

Court Authorizes Withdrawing of Ventilator and Nutrition

VEATCH (Continued from page 1)

condition is similar to that of Terri Schiavo and other patients in a long line going back to Karen Quinlan and Nancy Cruzan. Courts have often authorized withdrawal of life support in such patients, but in the past the decision has been

While permanently vegetative persons sometimes retain enough lower brain function to breathe spontaneously... it remains unclear what her level of consciousness is.

based on what the patient herself had wanted or what the next-of-kin had determined would be best. Nancy Cruzan and Terri Schiavo all involved formerly competent adults who, the court determined, had sufficiently expressed their views that the withdrawal of life support could be based on the patient's own decision. Karen Quinlan left some evidence of her own wishes and her parents also supported forgoing of ventilatory support. [See the analyses by Hans Reinders in last summer's issue of this newsletter.]

Other cases have recognized that families sometimes have to make difficult judgments about life support. The courts have recognized a certain familial discretion in such cases even if the family decides

against life support. The court in all these previous cases has not had to decide which option is the best possible choice, only what the state can tolerate when an individual or a family decides to stop treatment. In the Poutre case, the facts forced the state to finally make a choice whether forgoing life support can be the best choice for a permanently unconscious person who has never expressed her views and who has no family surrogates to express an opinion. While Haleigh Poutre had not been mentally impaired prior to the beating, she was left with total lack of mental function. Many advocates for those with intellectual disabilities are concerned about the implications for those with severe, but not total, impairments.

The facts are sad and disturbing. Haleigh was placed for adoption by her birth mother and adopted by the birth mother's sister, Holli Strickland. After the beating, Ms. Strickland and her husband, Jason, who had never formally adopted Haleigh, were accused of the attack. Ms. Strickland was found dead along with Haleigh's grandmother in what was believed to be a murder-suicide. That removed the adoptive mother from any possible role in deciding about the child's medical care and avoided the question of whether she should be disqualified from that role because of her alleged involvement in the beating.

When the state agency considered

withdrawing life support, Jason Strickland, opposed that choice, claiming he was the *de facto* parent who should have the authority to make the choice. He would stand to be charged with a homicide if the

He would stand to be charged with a homicide if the girl died, but claimed to be on the side of life . . .

girl died, but claimed to be on the side of life and opposed to the death of the child and not merely to be insisting on life support to avoid the legal charge.

The court claimed he failed to show "that his participation in (Haleigh's) life was of a loving or nurturing nature." He was thus disqualified from the medical decision-making role. This left Haleigh as ward of the state, which had to make an independent decision about what was best for her without any possibility of letting the next-of-kin's opinion shape the choice. There were no family members left who might offer such opinion. This odd and tragic set of circumstances created what is believed to be the first case in which the state had to make a decision to forgo life support without the involvement of a patient or surrogate. The authorization to forgo the ventilator and feeding tube is thus a

(Continued on page 4)

VEATCH (Continued from page 3)

formal recognition that at least in one state in one set of circumstances it is really better not to oppose the dying process, not merely a toleration of some individual's preference.

Presumably, this decision will make it even more important to distinguish carefully between persons with mental impairments and those who are totally and irreversibly unconscious. Clearly, even if the state believes that permanent unconsciousness warrants forgoing life support, it does not follow that this would be best for those with lesser impairments.

In a strange twist, soon after the court authorization, doctors reported that new tests revealed that Haleigh could respond to stimuli and was breathing on her own. While permanently vegetative persons sometimes retain enough lower brain function to breathe spontaneously (Karen Quinlan and Terri Schiavo did), it remains unclear what her level of consciousness is. In the meantime all decisions to forgo life support have been suspended and Massachusetts governor Mitt Romney has appointed a commission to review how Haleigh's case was handled.

Robert M. Veatch is Professor of Medical Ethics at Georgetown University's Kennedy Institute of Ethics.

Book Review: *Quality of Life and Human Differences*

LEIDER (Continued from page 1)

These measurements, including "quality adjusted life years" and "disability adjusted life years," also attempt to measure the efficacy of different treatments by comparing their ratios of benefits to costs. The contributors to this book who write on this topic present many interesting deficiencies of these measures.

. . . is it ever morally mandatory to abort fetuses that, if allowed to be born, will have a short and painful life, such as those suffering from Tay-Sachs Disease?

Wachbroit, for instance, argues that these measures are necessarily value-laden. Because measures for quality of life appear objective, while containing normative judgments, he argues that these imbedded normative judgments will not be subject to public deliberation, thereby short-circuiting the democratic process (40). He does not object to "clinical uses" of these measures, however (41). Ron Amundson, in contrast, takes a more radical view, basing his argument on how these "objective" measures are conceived. He notes that not having a certain capacity is irrelevant until society values it. As a result, the harm caused by disease

and disability must be analyzed by also looking at how society is structured (110).

This book presents a variety of viewpoints on this issue, as well as providing some suggestions for reform. While the book contains a good variety of perspectives in its objections to measuring health-related quality of life, unfortunately, the editors included no selections that offer a broad-based defense of the concept. I doubt seriously that any objective measure of health-related quality of life will be entirely satisfactory, and I think it would have been beneficial to include a defense of what these measures, in substantially their current form, contribute to the health care debate notwithstanding their shortcomings.

The second major topic in *Quality of Life and Human Difference* concerns the ethical issues surrounding prenatal and, in some cases, preconception testing for genetic disability. With the legalization of abortion, prospective parents often decide to abort abnormal fetuses, and this leads to several ethical questions. For instance, when, if ever, is it wrong to abort a fetus because it will be disabled? Conversely, is it ever morally mandatory to abort fetuses

(continued on next page)

Book Review: *Quality of Life and Human Difference*

LEIDER (Continued from page 4)

that, if allowed to be born, will have a short and painful life, such as those suffering from Tay-Sachs Disease? And, one question I found particularly interesting, do members

Although these authors generally come from a philosophical background, they approach these questions in very different ways.

of the disabled community have standing to complain when parents choose to abort fetuses that will have disabilities (Asch and Wasserman 183-184)?

With one notable exception, described below, the editors do an excellent job of collecting different answers to these questions. Although these authors generally come from a philosophical background, they approach these questions in very different ways. Asch and Wasserman, for example, argue that decisions to abort abnormal fetuses result from “harmful stereotypes, unreasonable expectations, or relentless institutional pressures” (209). They call this phenomenon “synecdoche” (173). McMahan, in contrast, thinks different considerations can support both

“preventing the existence of a disabled person” (142) and the retrospective judgment that parents who have had disabled children lead better lives by “having had a disabled child” (161). The philosophers’ contributions, though varying in complexity, remain accessible to all readers.

One chapter was written by Tom Shakespeare, who is a sociologist rather than a philosopher. Shakespeare defends allowing individual choices on whether to abort since he does not believe there is a “universal response” to this ethical dilemma

. . . in giving “a clear introduction to what is at stake, practically, conceptually, and ethically,”... I think they have succeeded.

(Shakespeare 219). I thought having a contribution from a sociologist provided a good rounding to the perspectives.

Nevertheless, while I generally thought that the editors collected opinions from a wide spectrum, I found troubling the lack of opposition to selective abortion based on the sanctity of life.

Dan Brock does not oppose the use of abortion to prevent some disabilities, and in fact, he claims some diseases, including Tay Sachs and Lech Nhyan, make life unbearable and not “worth living from the standpoint of the person whose life it is” (70). And even though Asch and Wasserman, as noted above, generally argue against selective abortion, they “remain uncertain at the margins” (209). I was disappointed that the editors included no argument from this perspective, especially given the fact that arguments based on sanctity of life currently hold considerable influence in the political debates on these issues.

Of course, in the end, it is important to keep in mind that it is not the editors’ purpose to provide the complete spectrum of views. This remains a book with a mission: in giving “a clear introduction to what is at stake, practically, conceptually, and ethically,” the editors of *Quality of Life and Human Difference* “hope that this volume succeeds in persuading scholars, advocates, and policy makers of the value of examining any of those issues in the context of the other two” (21). In this, I think they have succeeded.

Robert Leider is a Ph.D. candidate, concentrating in bioethics, in the Philosophy Department at George-

New Edition of Wolfensberger's "Guideline on Protecting the Health and Lives of Patients."

The History of This Monograph

- ◆ Introduction
- ◆ Dangers to Patient Health in Contemporary Hospital Settings
- ◆ Special Dangers to Societally Devalued People
- ◆ Conceptualizing the Functions of Advocates/Protectors
- ◆ Measures to Protect People in Hospitals
 - ◆ General Considerations
 - ◆ Measures to Prepare a Patient for Hospitalization or Visits to an Emergency Service
 - ◆ Advantages and Disadvantages of Different Rooms in a Hospital
- ◆ Suggested Guidelines for Carrying out the Functions of Advocates/Protectors
 - ◆ General Points
 - ◆ Special Consideration During the Hospital Admission Process, or in the Emergency Room
 - ◆ Keeping the Environment Clean
 - ◆ Assuring or Providing Bedside Care
 - ◆ Uplifting the Patient's Spirit
 - ◆ Promoting the Patient's Mobility and Independence
 - ◆ Protecting Patient Rest
 - ◆ Issues of Food, Feeding, and Nutrition
 - ◆ Orienting the Patient to Reality
 - ◆ Enhancing and Monitoring the Quality of Medical/Nursing Care
 - ◆ Monitoring the Prescription (Mind) Drugging of the Patient
 - ◆ Dealing with Visitors

A second edition of *A Guideline on Protecting the Health and Lives of Patients in Hospitals, Especially if the*

Though not the most catchy title, the volume by Wolf Wolfensberger addresses many issues critical to those with mental retardation.

Patient Is a Member of a Societally Devalued Class has been published by the Syracuse University Training Institute for Human Service Planning, Leadership, and Change Agency.

Though not the most catchy title, the volume by Wolf Wolfensberger addresses many issues critical to those with mental retardation. As abstracted by the publisher, the volume covers central issues for vulnerable populations:

Several trends in society have been greatly increasing the risks to health and life of patients in hospitals, and especially in patients who are members of a societally devalued class, such as the mentally retarded, mentally disordered, physically impaired, elderly, poor, racial minorities, homeless people of the streets, et al. Recent reports by

numerous prestigious authors and bodies on the dangers of hospitalization (e.g., hard-to-treat infections, drug errors, "medical misadventure") have underlined this risk. Therefore, in order to maximize the likelihood that a person who goes into a hospital as a patient will come out of it alive, and hopefully well, special protective measures have to be taken. This monograph provides extensive instruction on how to protect, and advocate for, hospitalized patients and it should be in the possession of anyone likely to be in the role of advocate for a vulnerable person who is in a hospital. A great deal of this material spells out specifically what can or should be done by those who in the *Guideline* are called advocates or protectors of a patient who is a member of a societally devalued class. But the *Guideline* has also proven enormously helpful in instances who hospital patients were not members of devalued groups, and were therefore merely at "ordinary" risk.

The first edition of this monograph was published in 1992, and reprinted several times since. This is a new revised edition and is longer by about 25% than the earlier edition. It includes much that has been learned from the experience of people who have done such hospital protection

(continued on next page)

College for Persons with Intellectual Disabilities

WOLFENBERGER
(continued from page 5)

of devalued patients. The sidebar on page 6 shows a table of contents.

A great deal of this material spells out specifically what can or should be done by those who in the Guideline are called advocates or protectors of a patient who is a member of a societally devalued class.

The volume is available from the Syracuse University Training Institute, 800 South Wilbur Avenue, Suite 3B1, Syracuse, NY 13204, for \$10 plus \$2 postage and handling. The volume is available from the Syracuse University Training Institute, 800 South Wilbur Avenue, Suite 3B1, Syracuse, NY 13204, for \$10 plus \$2 postage and handling.

BIBLIOGRAPHY (continued from page 8)

Thompson, S. Anthony. My research friend? My friend the researcher? My friend, my researcher?: mis/informed consent and people with developmental disabilities. In: *Walking the Tightrope: Ethical Issues for Qualitative Researchers*. Toronto; Buffalo: University of Toronto Press, 2002.
Tremain, Shelley, ed. Foucault and the Government of Disability. Ann Arbor: University of Michigan Press, 2005. 340 p.

Harriet Hutson Gray, MSLS, MTS, is the Reference and Digital Services Librarian at the National Reference Center for Bioethics Literature, Kennedy Institute of Ethics, Georgetown University.

Academic programs for students with intellectual disabilities are being developed at two colleges in New Jersey. The National Down Syndrome Society is providing \$50,000 grants to Mercer County Community Collect and the College of New Jersey on a yearly basis for them to develop programs designed to integrate students with mental retardation into the college environment.

Six to eight students a year are to be admitted to take or audit courses, which will be part of the regular curriculum of the schools.

The program will include a faculty mentor and pairing of the enrollees with other students to ease the transition.

According to the story by Rebecca Aronauer in the Chronicle of Higher Education, the students will pay fees to take classes. The Down Syndrome Society is seeking federal financial aid and other sources of funds for this purpose. Other college programs for those with intellectual disabilities have begun at the University of Southern Maine and Bellevue Community College in Washington State.

MAILING LIST

To add your name to the mailing list for
The Network on Ethics and Intellectual Disability write to:

Prof. de Johannes S. Reinders
Institute for Ethics
Free University
Amsterdam, The Netherlands
J.S.Reinders@esau.th.vu.nl

OR

Robert M. Veatch
Joseph P. and Rose F. Kennedy Institute of Ethics
Georgetown University
Washington, DC 20057 USA

The Newsletter of the Network on Ethics and Intellectual Disability is published twice a year and is a publication of the Network. Address correspondence to The Joseph P. and Rose F. Kennedy Institute of Ethics, Georgetown University, Washington, DC, 20057-1065, USA or the Institute of Ethics, Free University, Amsterdam, The Netherlands.

Bibliography Harriet Hutson Gray

These books and articles have been added recently to the collections of the National Reference Center for Bioethics Literature (NRCBL). Similar citations may be found online by searching PubMed database at the National Library of Medicine and the ETHX on the Web database at the NRCBL. Access and tips for searching may be found at the NRCBL website at <http://bioethics.georgetown.edu>.

- Baumrucker, Steven J.; Davis, Mellar P.; Stolick, Matt; Morris, Gerald M.; and Sheldon, Joanne. Sisters to the end: the rights of the mentally retarded to refuse treatment [case study] *American Journal of Hospice and Palliative Care* 2005 January-February; 22(1):61-65.
- Bramstedt, K.A.; Morris, H.H. and Tanner, A. Now we lay them down to sleep: ethical issues with the use of pharmacologic coma for adult status epilepticus. *Epilepsy & Behavior* 2004 October; 5(5):752-755.
- Cantor, Norman L. *Making Medical Decisions for the Profoundly Mentally Disabled*. Cambridge, MA: MIT Press, 2005. 307p.
- Eastgate, G. Sex, consent and intellectual disability. *Australian Family Physician* 2005 March; 34(3):163-166.
- Gill, A.W.; Saul, P.; McPhee, J; and Kerridge, I. Acute clinical ethics consultation: the practicalities. *Medical Journal of Australia* 2004 August 16; 181(4):204-206.
- Goodheart, L.B. Rethinking mental retardation: education and eugenics in Connecticut, 1818-1917. *Journal of the History of Medicine and Allied Sciences* 2004 January; 59(1):90-111.
- Hougham, Gavin W. Waste not, want not: cognitive impairment should not preclude research participation. *American Journal of Bioethics* 2005 January-February; 5(1):36-37.
- Johnson, Harriet McBryde. Overlooked in the shadows (opinion) *Washington Post* 2005 March 25; p.A19.
- Johnson, L. First, do no harm--an argument against mandatory high-stakes testing for students with intellectual disabilities. *Mental Retardation* 2005 August; 43(4):292-298.
- Kellett, K.; Gruman, C.; Robison, J.; Nuss, L. and Kerins, G. Research issues related to individuals with intellectual disabilities. *Connecticut Medicine* 2004 September; 68(8):525-529.
- Kittay, Eva Feder. Caring for the vulnerable by caring for the caregiver: the case of mental retardation. In: *Medicine and Social Justice: Essays on the Distribution of Health Care*. Oxford; New York: Oxford University Press, 2002.
- Lachapelle, Y; Wehmeyer, M.L.; Haelewyck, M.C.; Courbois, Y.; Keith, K.D.; Schalock, R.; Verdugo, M.A.; and Walsh, P.N. The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research* 2005 October; 49(Pt 10): 740-744.
- Ladd-Taylor, Molly. The sociological advantages of sterilization: fiscal policies and feeble-minded women in Interwar Minnesota. In: *Mental Retardation in America : A Historical Reader*. New York: New York University Press, 2004.
- Lerner, B.H. Last-ditch medical therapy - revisiting lobotomy. *New England Journal of Medicine* 2005 July 14; 353(2):119-121.
- Lin, Jin-Ding; Yen, C.F.; Li, C.W.; and Wu, J.L. Health, healthcare utilization and psychiatric disorder in people with intellectual disability in Taiwan. *Journal of Intellectual Disability Research* 2005 January; 49(part 1):86-94.
- Lombardo, P.A. Taking eugenics seriously: three generations of ??? are enough? *Florida State University Law Review* 2003 Winter; 30(2):191-218.
- Louhiala, Pekka. *Preventing Intellectual Disability: Ethical and Clinical Issues*. Cambridge, UK; New York: Cambridge University Press, 2004.
- Mahowald, Mary B. Aren't we all eugenicists? Commentary on Paul Lombardo's "Taking eugenics seriously". *Florida State University Law Review* 2003 Winter; 30(2):219-235.
- Malhotra, S.; Balhara, Y.P.; and Varghese, S.T. Organ donation in mental retardation: a clinical dilemma. *Indian Journal of Medical Sciences* 2004 October; 58(10):444.
- Marcus, Amy Dockser. A brother's survey touches a nerve in abortion fight; mothers were asked how they found out their babies had Down syndrome; teaching his sister to read. *Wall Street Journal* 2005 October 3; p.A1, A8.
- Meininger, H.P. Narrative ethics in nursing for persons with intellectual disabilities. *Nursing Philosophy: An International Journal for Healthcare Professionals* 2005 April; 6(2):106-118.
- Murphy, G.H. and O'Callaghan, A. Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine* 2004 October; 34(7):1347-1357.
- Noll, Steven; Trent, James W. *Mental Retardation in America: A Historical Reader*. New York: New York University Press, 2004.
- Noll, S. The public face of Southern institutions for the "feeble-minded". *Public Historian* 2005 Spring; 27(2):25-41.
- Oliver, Matthew N.I.; Miller, Trisha T.; and Skillman, Gemma D. Factors influencing direct-care paraprofessionals' decisions to initiate mental health referrals for adults with mental retardation. *Mental Retardation* 2005 April; 43(2):83-91.
- Perske, Robert. Search for persons with intellectual disabilities who confessed to serious crimes they did not commit. *Mental Retardation* 2005 February; 43(1):58-65.
- Reinders, H.S. Introduction to intellectual disability, genetics and ethics. *Journal of Intellectual Disability Research* 2003 October; 47(Pt 7):501-504.
- Santiago-Delpin, E.A. Ethical dilemmas: transplantation in prisoners and the mentally disabled. *Transplantation Proceedings*. 2003 August; 35(5):057-2059.
- Servais, L.; Leach, R.; Jacques, D. and Roussaux, J.P. Sterilisation of intellectually disabled women. *European Psychiatry: The Journal of the Association of European Psychiatrists* 2004 November; 19(7):428-432.
- Sheppard-Jones, Kathy; Prout, H. Thompson; and Kleinert, Harold. Quality of life dimensions for adults with developmental disabilities: a comparative study. *Mental Retardation* 2005 August; 43(4):281-291.
- Silber, Tomas Jose and Batshaw, Mark L. Ethical dilemmas: evaluation and decision making. In: *Children with Disabilities*, 5th ed. Baltimore: Paul H. Brookes, 2002.
- Sugimoto, T. [Informed consents for family of children with mental retardation in pediatric clinics] No To Hattatsu: Brain Development 2004 May; 36(3):230; discussion 231. Japanese.
- Tang, Re-Feng. Does eugenics exist in China? Ethical issues in China's law on maternal and infant healthcare. In: *Bioethics—Asian Perspectives: A Quest for Moral Diversity*. Qui, Ren-Zong, ed. Dordrecht; Boston: Kluwer Academic Publishers, 2004.

(continued on page 7)