



Disabilities: Ethics or Advocacy?

by Scot Yoder

Center for Ethics & Humanities in the Life Sciences

Not Dead Yet, a disabilities group organized to resist the legalization of assisted suicide, demonstrated at two ethics conferences sponsored by the Center for Ethics and the Humanities in the Life Sciences this past June. The conferences were the *6th Annual Conference on Medical Ethics for the 90's* and the *Advanced Summer Bioethics Workshop, The American Disabilities Act: New Challenges for Institutional Ethics Committees*. This issue of the *Medical Humanities Report* is devoted to the impact of Not Dead Yet on those events.

It is not easy to characterize the involvement of Not Dead Yet at the conferences. The group came to protest, targeting days on which physician-assisted suicide and the American Disabilities Act were being discussed. Among other things, members protested the fact that no one with disabilities was invited to speak on these issues. However, the involvement was not limited to demonstration. At both events the group was invited, more or less on the spur of the moment, to participate in parts of the conference and representatives were given time to make a presentation. Their input was thoughtful and reasonably moderated. Moreover, given this opportunity to participate, members of Not Dead Yet did not attempt to further disrupt the proceedings even though they could easily have done so. Nevertheless, while this transition from protest to participation diffused some of the overt tension, a high level of discomfort remained.

Judging from the conference evaluations, the reaction of the registered participants was mixed and ambivalent. Some reacted positively, saying that the participation of the group added an otherwise missing dimension to the conference and heightened their awareness of disabilities issues. Many were ambivalent about the group's involvement, saying that the situation was "handled well" by the conference organizers, but not elaborating further. Still others expressed resentment suggesting that Not Dead Yet's participation disrupted the conference, undermined open two-way communication and hindered the learning experience.

To help sort out some of this ambivalence the *Medical Humanities Report* asked three people involved in the conference to reflect on the experience. Stephen Drake is a research associate at Syracuse University and a member of Not Dead Yet. Howard Brody and Tom Tomlinson who are both faculty members at the Center were organizers of the conferences.



Demand to Be Heard

by **Stephen N. Drake**

Not Dead Yet

If my parents had listened to the doctor who delivered me, I wouldn't have been in Michigan last June. I probably wouldn't be *anywhere*.

As a result of a forceps delivery for a breech presentation, I experienced severe brain damage at birth. As my parents worried about my fate, the doctor who delivered me came in with the following attempt at comfort. He told my parents not to pray for me to live, since I would certainly be a "vegetable" if I did survive. My parents, luckily for me, sought out a pediatrician who was committed to doing whatever it took to ensure my survival and asked the original doctor not to return.

That commitment included an all-night vigil during my first precarious night on the planet to ensure that any crisis would be met speedily and earnestly. It is obvious to me now why such a vigil was necessary. Many infants with disabilities don't make it past the first hurdle - the pronouncement of a medical professional that the infant will not have "a life worth living."

In many ways, I am a relative newcomer to this issue; in others, it has been an issue that serves as a backdrop for my life.

I am a doctoral student who is currently involved in analyzing the language that professionals use to define and construct their notions about people with disabilities. Over the past couple of years, my research efforts and my work have involved communication on the internet. Among other things, two contradictory issues have caught my attention. One is the increasing concern expressed by people with disabilities in regard to access to health care and access to supports in the community. The other is the growing popularity of the "right to be killed" movement, whose message is that life with a disability is not worth living.

I learned about Not Dead Yet and the Michigan actions through the internet. Spending money and time I could not afford to spend, I went to Michigan to join others in my community - the disability community - to express outrage at the bland acceptance of Kevorkian's killing spree and the arrogance of medical ethicists who were scheduled to discuss "safeguards" for killing people who don't have a guarantee to adequate medical care, pain management, or supports in the community. The agendas of the conferences were especially outrageous as these discussions were to take place without any representatives from the group of people the discussions would affect.

I can tell you that we were ready to be arrested if need be in our efforts to be heard at the ethics conferences. That turned out to be unnecessary. The hosts of the conferences invited us to participate rather than protest, and we accepted. As a result, I am sure that the other participants in the conference had a much different experience than had been expected or planned. Embedded in the stories of medical negligence, coerced Do Not Resuscitate orders and other tales from "real life", the following demands were presented to the conference participants:

1. Endorse policies prohibiting physician-assisted suicide and prohibiting non-consensual or non-informed Do Not Resuscitate orders.
2. Endorse policies mandating qualified disability peer counseling for all persons with disabilities and illness if they request physician-assisted suicide or refuse life-sustaining medical treatment.
3. Endorse policies requiring expert representation by people with disabilities on medical ethics committees.

I came away from the actions and the conferences with some new, tentative and fragile hope. It was obvious that at least some of the participants at the conference were affected by what we had to say and had made a start at seeing the issues somewhat differently. How deep that change is or how long it lasts is another matter. The real source of my new found hope is the fact that I now know I have brothers and sisters out there who I can join my voice to - to demand justice, to demand to be heard.



Ethics, Education and Politics

by **Howard Brody**

Center for Ethics & Humanities in the Life Sciences

Shortly after the "confrontation" between our Center and Not Dead Yet, I was speaking to a co-worker who was seriously injured in an auto accident many years ago and now walks with a cane. She is "handicapped," at least if one believes her parking sticker. I asked her for her views on the people we had heard from at our summer conference. She replied that she had never joined any of those groups because they seemed to her mostly to be angry, and her own view of the world is that being angry is not the best way to be if you want to accomplish important things. "I think I can understand why they are angry, though," I said. She replied, "I still think many of them were angry even before they developed their disabilities."

I want to try to bear these comments in mind while not dismissing or denigrating the educational value Not Dead Yet provided for our conference. I plead guilty to having been extremely slow to see how the unique perspective of the disability community needs to become a central feature of ethical discussions in a wide variety of health care issues. I think I had my consciousness raised on that score principally through participating in two exercises where the inclusion of persons with disabilities was mandated - first, the Michigan Commission on Death and Dying, which addressed legislation on assisted suicide; and second, the ethics working group of the now-much-maligned Hillary Clinton task force on health care reform.

Let me mention just one bit of evidence of my own blindness. In promoting a cautious model for legalizing and regulating physician-assisted suicide, I have endorsed requiring consultation with a panel of experts chosen for their ability to propose alternative treatments which would maintain quality of life. Who should those experts be? In keeping with much of the existing literature on the subject, I have generally mentioned two types of expertise: palliative care or hospice; and psychiatrists trained in distinguishing treatable depression from the effects of chronic or terminal illness. I now realize I should add a third group - those with expertise in diagnosing and managing the social and psychological needs of persons with disabilities. Hospice workers and psychiatrists do not necessarily possess that knowledge or have any practical experience in meeting the real needs of that group. Yet the Kevorkian "case series" shows that many persons with disabilities are likely to request assisted suicide.

So, having benefited so much from this consciousness-raising (realizing of course that I still have a way to go there), why do I have mixed feelings about Not Dead Yet and similar groups? On the educational level, I am somewhat bothered by the fact that they have a political agenda which is not necessarily compatible with an educational agenda. On the clinical level, I am distressed at the message they send to individuals struggling with life with disability - that there is one (political) way to be a "good" person with a disability, and you have to tell one sort of story about yourself if you are going to be that sort of person. (I have had patients with disabilities complain to me that the disability-rights activists demand that each person conform to this model of a "good" person, and if they insist on being individuals and refuse to conform, those activists no longer have any use for them.)

My experience on the Michigan Commission on Death and Dying was perhaps typical of what I fear happening. I came to like very much the representatives of the disability community who served on that panel. I learned a lot from them. But I became convinced at the end that they were not really members of the commission; they were instead using the commission as a convenient soap-box from which to proclaim their political agenda. I did not mind that so much because I happen to think that their political agenda is largely worth while and needs a hearing. But there were times when the commission was trying to reach compromise or consensus on issues related to assisted suicide, where the disability activists were really not willing to be part of the process. To do that would require that they subsume or mute their distinctively disability message.

I have similar ambivalence about the demand that if anyone is going to talk about the ethics of something related to the care of persons with disabilities, then someone with a disability should be on the panel to speak, or else the educational process is corrupt and should be shut down. I don't think that is a valid educational strategy; taken to its logical extreme, we would never finish any educational program because an indefinite number of people would have to be invited as panelists. (Don't forget that my non-angry co-worker would need to be on the panel too.) Instead, the demand is a way of getting attention to make a political statement. The political statement is an important one, and I am glad we were able to be a vehicle for this during the past summer. Thank goodness we were also able to complete our educational agenda as well; and I am grateful for the spirit of cooperation exhibited by the Not Dead Yet folks that allowed us to serve both valid ends.



Cowed by Moral Fever

by Tom Tomlinson

Center for Ethics & Humanities in the Life Sciences

Good things came from Not Dead Yet's visit to the 6th annual medical ethics workshop. The stories they told of medical arrogance and social neglect communicated the concerns and needs of disabled persons in forceful and striking ways. Aspects of the assisted suicide and allocation of resources debates were highlighted that otherwise may have not gotten the attention they deserve. Finally, and not least of all, Not Dead Yet got a public forum and national publicity for its cause.

There was, however, another aspect of their appearance that was not so positive. This was, remember, a workshop on medical ethics which had stressed the importance of frank dialogue and debate as tools of moral deliberation. Open expression of disagreement, testing of moral limits, and confession of moral perplexity and uncertainty are critical to the process of ethical dialogue and the deepening of ethical thinking. They had emerged over the previous two days as the participants began to feel more comfortable and competent. But once Not Dead Yet entered the conference, frank dialogue came to a dead halt. Where before we had not hesitated to challenge the people at the front of the room, and each other, we now acted like cowed school children being lectured by stern headmasters whom we dared not contradict. The lone exception, notable for its contrast with the surrounding silence, was a question tentatively but courageously raised by John Burow (chaplain at Michigan Capitol Medical Center), who wondered how the needs of disabled people could all be fairly met within the constraints of limited resources. The censorious and sloganizing responses from Not Dead Yet ("I pay taxes too!") were not intended to explore the question but to demonize it and the one who dared ask it.

Why did we all bite our tongues when the group was in the room, and not just the ethics rookies, but the veterans as well? Surely it wasn't because we now all agreed with them that assisted suicide should not be a legal option or that allocation of limited resources should not take quality of life into account. As I consider my own motivations, other explanations surface, some more honorable than others, and not all to be laid at the feet of Not Dead Yet. In what follows, I don't mean to impute these motives to anyone but myself. The reader will have to decide whether this is merely the Tom Tomlinson Story.

The first and most obvious consideration was a practical one: if we keep quiet, they'll go away a lot sooner, and we can get back to the conference we had planned to do. This was the rationale most commonly expressed by the conference planners and attendees. There's no doubt that this Taoist passivity served its purpose well. Finding no resistance, the group soon tired of shadow-boxing, and went off to battle some more combative (and energizing) opponent, like Geoffrey Feiger. "You guys are too easy," one member of the group told me, obviously disappointed.

As I thought about it, I wasn't convinced that simple practicality was an adequate explanation of my behavior. Why couldn't they have been included in the conference we planned to do, open disagreement and debate included? After all, it wasn't as if their concerns were not directly

pertinent to the agendas for both Saturday and Sunday. Why did I want to slyly get them out of the room as soon as possible?

Was it because I thought that they were incapable of respectfully listening and responding to disagreements in a reasoned way? Not Dead Yet sure did its part to create this impression, including one person on Sunday who held up a sign reading "BS" while Haavi Morreim was speaking. But I, for my part, did nothing to confirm that this was indeed true. Since I remained silent along with the rest, I couldn't really know what their capacities were for respectful dialogue. Was there a kind of condescension in my so easily presuming they were incapable of any real dialogue with me?

Was it because I feared that I would become a target for attack, some of it accusatory and personal? Some members of the group sure seemed capable of this. But what sort of excuse could that be for me? Of what real value are my skills in ethical dialogue if I'm so insecure or thin-skinned that I'm afraid to employ them in places where people have fervent, and not just academic, ethical convictions?

Was it because I knew that any open disagreement would degenerate into a shouting match, with no chance of advancing anyone's moral understanding? Even if it is likely that this would have happened, who would have been responsible? It takes two to fight. Was I silent because I feared I would lose control of my own responses?

Was it only because I didn't want to risk saying anything that might give offense, e.g., by suggesting that it's a bad thing to have a disability? What's with the kid glove treatment? Do I think they are so lacking in self-confidence that the merest suggestion from me will throw them into a tail-spin of self-doubt? Who is it who really has the problem here?

It was Not Dead Yet who didn't really want the dialogue, wasn't it? Speaking for myself, I'm not so sure.



Berg Joins CEH Faculty

The Center welcomes Jessica Berg to the faculty. Jessica is replacing Judith Andre who is on sabbatical this year.

Since receiving a law degree with honors from Cornell University in 1994 Jessica has completed fellowships at both the University of Virginia and the University of Massachusetts Medical Schools. At the University of Virginia she held a joint appointment in the Institute of Law, Psychiatry, and Public Policy, and the Center for Biomedical Ethics. At the University of Massachusetts Medical School she was affiliated with the Department of Psychiatry, the Institute for Law and Psychiatry, and the Office for Biomedical Ethics. Her duties there included teaching medical ethics to medical students and research ethics to doctoral students, lecturing for residents, and serving on both the hospital ethics committee and an Animal Care and Use Committee.

Her present interests are in health law and biomedical ethics. Building on her undergraduate degrees in psychology and philosophy much of her research and writing has been in the area of mental health law. She is currently a consultant for the American Medical Association Council on Ethical and Judicial Affairs, and is co-authoring a revised version of *Informed Consent Legal Theory and Clinical Practice* with Drs. Paul Appelbaum and Charles Lidz.

Jessica will be involved in a variety of assignments with the Center. She will teach ethics in both the College of Human Medicine and the College of Osteopathic Medicine, and lecture to medical students and interns at Genesys Hospital in Flint. She will also serve on the Sparrow Hospital Ethics Committee and the Institutional Review Board for the State Department of Health. In addition to these duties she will be a preceptor in the Community Dialogue Project, "Genome Technology & Reproduction: Values & Public Policy" at the Grand Rapids site.



Center News & Announcements

Regular readers may notice the revised format of the *Medical Humanities Report*, including the new logo. The revisions are primarily stylistic. The logo, however, is a first for the Center. Rather than wax philosophical about its meaning, we will allow the following comment by a faculty member to suffice, "The new logo is of course abstract and impressionistic and could be used as a Rorschach test, I suppose; but some of us at least take it to mean that we try to shed a little more light than heat upon controversial issues involving ethics, humanities, and the life sciences."

On September 28th **Leonard Fleck** addressed the annual meeting of the Michigan Lupus Foundation in Lansing on "Just Caring: Health Care Rationing, Chronic Illness, and Managed Care."

On October 10th **Leonard Fleck** was the keynote speaker at the Kellogg Center for the "Managing Managed Care" conference sponsored by the Labor Education Program at MSU. The title of his presentation was "Ethical Issues in Managed Care."

Howard Brody participated on a panel for the Society for Health and Human Values meeting in Cleveland, discussing the book, *The Wounded Storyteller*, by Arthur Frank, October 13th.

Howard Brody will speak on medical ethics and primary care education at various sites in Japan, including Kawasaki Medical School, Saga Medical School, Hiroshima Medical School, a new family practice residency being established in Hokkaido, and the Japan Academy of Family Practice annual meeting in Tokyo, October 20th through November 10th.

From October 24th to 26th **Leonard Fleck** will give four workshops at the annual meeting of the Florida Osteopathic Medical Society in Fort Myers. The workshops are titled: "Just Caring: Ethical Issues in a Changing Health Care System," "Just Caring: Managed Care and the Physician Gatekeeper," "To Feed or Not To Feed: Ethical Issues in Withdrawing Artificially Provided Nutrition," "Physician-Assisted Suicide: A Moral and Public Policy Perspective."

Judith Andre is on sabbatical this year. During the fall semester she is a Fellow with the Center for Biomedical Ethics at the University of Virginia, and will spend two weeks as a Visiting Scholar at the Minnesota Center for Healthcare Ethics.

Tom Tomlinson has begun work on a book to be published by Routledge, under the working title, *Theories and Methods in Medical Ethics*. It will be a critical survey and synthesis of the variety of ethical methodologies being advocated in medical ethics. The book will be one of the first to be published in the "Reflective Bioethics" series being edited by Hilde and James Nelson.

Judith Andre spoke on England's National Health Service to audiences at St. Catherine College, Minneapolis, and at St. Olaf College, Northfield, Minnesota. She also presented "Bioethics as a Practice" for the Minnesota Center for Health Care Ethics.

The Center is involved in "Genome Technology & Reproduction: Values and Public Policy," a joint project with the University of Michigan's School of Public Health. **Leonard Fleck** is coordinating a series of community dialogue sessions in which focus groups will discuss values and ethical questions pertaining to genetic and reproductive issues. Sessions will be held across the state this Fall and next Spring. Locations include Kalamazoo, Saginaw/Bay City, Holland, Ann Arbor, Grand Rapids, Detroit, and Lansing. In addition to Fleck, **Jessica Berg** from the Center will also be leading sessions.

Leonard Fleck has a chapter in The Annals of the New York Academy of Sciences volume *Apolipoprotein E Genotyping in Alzheimer's Disease* (1996). His chapter is titled "Just Caring: The Moral and Economic Costs of APOE Genotyping for Alzheimer's Disease."

Leonard Fleck will be giving a paper on November 21st in San Francisco at the annual meeting of the American Association of Bioethics. That paper is titled: "Rational Democratic Deliberation, Rationing, and Managed Care."

Leonard Fleck will chair a workshop at the Eastern Division Meetings of the American Philosophical Association for The Committee on Philosophy and Medicine, in December. The workshop is titled "Ethical Issues in Managed Care: Three Current Problems." Those problems include: (1) Non-Compliant Patients and Health Care Justice, (2) Business Ethics/Medical Ethics: What Moral Framework Should Govern Managed Care? (3) Managed Care and Morally Adequate Consent to Rationing Decisions. Judith Andre will present on the second of those topics.