

## Conference Transcript Socially-Assisted Dying: Media, Money, & Meaning

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CONFERENCE TRANSCRIPT  
SOCIALLY-ASSISTED DYING:  
MEDIA, MONEY & MEANING

Conference held April 10 and  
April 11, 1997 at the Northwestern University  
School of Law, sponsored by:

*The Rehabilitation Institute of Chicago Program in Disability Ethics;*  
*The Northwestern University Medical School Department of Physical  
Medicine and Rehabilitation;*  
*The Northwestern University School of Law;*  
*The Northwestern University Institute for Health Services Research  
and Policy Studies;*  
*The Northwestern University Medical School Program in Medical  
Ethics and Humanities;*  
*The University of Iowa Law, Health Policy and Disability Center*

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INTRODUCTION

MR. BIENEN: I'd like to introduce myself. I'm Henry Bienen, the President of Northwestern University. It's a particular pleasure for me to welcome you all to this very important conference on socially-assisted death. For me, it's especially important that so many parts of Northwestern University have collaborated in putting this conference together. Obviously our medical school and Institute for Health Sciences and Health Policy as well as our law school, in whose precincts you all are, and other schools are vitally interested in this because of all the tremendously important questions and issues raised by the topic.

This conference was more than a year in the planning, and that planning involved not only many parts of Northwestern University, but also the University of Iowa. Our good friend, Peter Blanck, from the University of Iowa, has been very instrumental in the conception of this conference and in putting it together. I will be, in a moment, turning the podium over to my friend, Henry Betts, the Chairman and CEO of the Rehabilitation Institute of Chicago (RIC), which has been our partner in this endeavor. The conference was envisioned before the United States Supreme Court agreed to hear the major cases that are confronting it.

I don't want to say too much more, except again to express my thanks to those parts of Northwestern as well the University of Iowa and the RIC that have been so instrumental in putting the conference on.

Henry Betts is the Chairman and CEO of the Rehabilitation Institute of Chicago, which is recognized worldwide as the leading rehabilitation institute in this country. Henry Betts is a Chicago institution. In the two or more years since I have had the privilege of being President of Northwestern, he has become a good friend as well as a collaborator. So he will forgive me for not giving him his due and listing all the distinguished things he has done and all that he represents to our community.

DR. BETTS: This conference highlights an immense number of subjects. One of them is that it represents a very intimate alliance between the Institute and Northwestern University. That, it seems to me, is a wonderfully productive way to get things done. I have been here since 1963. The alliance between our institutions downtown and whatever goes on in Evanston has not been intimate. Henry Bienen has made a very strong effort to bring these two campuses together. There will be nothing except immense productivity accomplished through that. So that is a wonderful aspect of the conference.

Certainly in the country today, there is not much that's discussed more than health care, and in particular, the cost of health care. None of this can be considered and no solutions will be found, as far as I am concerned, until the ethical issues are determined. There are a lot of ways to cut down on health care. Euthanasia of everybody over sixty-five would have been a very useful way. Euthanasia of all sorts of children who don't have long life expectancy and who are disabled is another way. There are a lot of ways to cut down on the cost of health care.

All of these issues in some way surface out of the minds of some members of the population. I actually have people say to me—they would like to imply somewhat facetiously—"why are you doctors keeping all those old people alive?" Very nice people sometimes just say that to me. So there are sort of filthy rumblings through the minds of some Americans, as wonderful as so many of them are.

People with disabilities have quite rightfully risen up and determined that there must be ethical considerations given to the way they get treatment and the way their lives are considered. In health care we have seen incentives being given to health care workers to do less for people. We see access to care diminished in many instances in order to save money. We see cost cutting in the numbers of health care professionals. We see any number of things going on which can affect the lives of people. People with disabilities recognize a great hazard. A great deal of this cost cutting applies to them. That's one aspect of their care.

The other is the more esoteric one involving who should live, who judges whom, and who judges whose life as being worth living anyway. We think that in this country that doesn't really enter our lives very much. Hugh Gallagher, who will speak later, has written very eloquently about the way this kind of approach existed in Nazi Germany, where "mercy killings" were done by nice, well-meaning doctors.<sup>1</sup> They, themselves, were judging whether somebody had a high enough quality of life and whether that person wanted or deserved to live.

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<sup>1</sup> See HUGH GREGORY GALLAGHER, *BY TRUST BETRAYED: PATIENTS, PHYSICIANS, AND THE LICENSE TO KILL IN THE THIRD REICH* (1995).



The matter of judging—one person judging the quality of life of others, and therefore what medical care should be offered to them, and also whether they indeed should live at all—is an extraordinarily sensitive, significant, and pertinent ethical issue at this time in this country. It should be dealt with directly, carefully, dramatically, and vigorously in every possible way.

This conference is the beginning of that. Our Center at the RIC should take a lead in that. I'm grateful for all of you who have come to participate. I'm grateful to the University for being a participant. Most of all, I'm grateful for people with disabilities who are offering their time and input into this. It should be the beginning of an immensely important dialogue extending relevance even beyond the community of people with disabilities.

The person who makes this most possible is somebody that we trained at the Institute, a physiatrist, a specialist in physical medicine/rehabilitation who has gone on to study ethics and who is now the Director of our Program of Disability Ethics, Dr. Kristi Kirschner.

#### I. SESSION ONE: LEGALIZING ASSISTED SUICIDE: PROPONENTS AND OPPONENTS FROM THE DISABILITY COMMUNITY

DR. KIRSCHNER: Thank you. This conference is a product of a large committee of people representing the law school, the school for health policy research, the medical school, and RIC, as well as the University of Iowa. It's been a very collaborative effort. We're delighted you are with us today. We have passed out to you on arrival a survey. We would like to use this survey as a tool to learn more about who we are in the audience today and to stimulate the process of thinking rigorously about this topic.

Physician-assisted suicide is an issue that has sparked tremendous passion and conflict in our society with factions squaring off and delineating their positions. Our hope today is that we can resist the urge to stake out positions, but rather open our minds to hear from a multitude of perspectives and engage in respectful dialogue. If there is one starting point we should all be able to agree upon, I would hope it is that physician-assisted suicide is a complex social issue which deserves our careful thought and consideration.

What is it that we are really talking about here? If it's a simple question of the rights of terminally ill patients to determine the timing and manner of their death, why are we raising issues of disability and social justice in this context?

To begin the process of thinking critically about this issue, I would like to start out with a few definitions. Some of you may be curious why

we chose the phrase “socially-assisted dying.” Physician-assisted suicide, which is usually defined in our society as a physician giving to a terminally ill patient who has requested it, a prescription for a lethal dose of medication that the patient can take on his own, is an issue that is on a continuum. We are going to be discussing the continuum today.

Now, on the continuum you could consider palliative care, or using medications to treat symptoms, even if they may as a consequence hasten death. This concept is also known as the principle of double effect. The medication is not given with the *intention* of hastening death but with the *intention* of treating symptoms. Also in the continuum, we have the issue of withdrawing and withholding life-sustaining treatment. Then we have physician-assisted suicide, and farther along on the continuum is the issue of active euthanasia in which the physician directly acts to end the patient’s life and thus, suffering.

All of these actions can be considered forms of assisted dying. In our country, the legislative movements and the United States Supreme Court cases have focused on physician-assisted suicide in the context of terminal conditions, but that is by current social convention. In the Netherlands, for example, euthanasia and assisted suicide are available to people with intractable suffering, whether they are terminally ill or not. In all of these actions, there are medical as well as social components. We will be talking about what are the appropriate roles and responsibilities for society in supporting both the living and the dying process, as well as in protecting rights and interests of disempowered groups.

Now I would like to introduce Dr. Peter Blanck. I have had the pleasure of working with Peter over the last year in coordinating and planning this event. Peter comes to us from the University of Iowa where he is a Professor of Law and Psychology and the Director of the Iowa Law, Health Policy, and Disability Center. He has also been a Senior Fellow at the Annenberg Washington Program, focusing on the Americans with Disabilities Act (ADA). He is a recognized expert on the ADA and is frequently called to lecture or testify about issues having to do with disability and discrimination.

DR. BLANCK: Thank you, Kristi, for that kind introduction, and President Bienen and President Betts for your support and words, and thank you Marca Bristo from the National Council on Disabilities.

It’s truly a privilege to be here today to introduce and moderate this opening dialogue of what I believe will be an extremely important two-day event. It’s a privilege to be here among this distinguished audience of speakers, advocates, persons from varying disciplines, and others to examine one of the most controversial issues of our time, what we have called socially-assisted dying.

As many of you know, this issue is currently before the United States Supreme Court in *Vacco v. Quill* and *Washington v. Glucksberg*.<sup>2</sup> More than thirty briefs were filed in opposition to physician-assisted dying and more than a dozen in support of it, reflecting views on the debate from all sides of the disability community and from many different disciplines.

My role today is to facilitate the opening discussion and dialogue. Our goal together is to begin the examination of the complex social, medical, legal, and very personal implications of this topic. The debate today, I believe, on assisted dying is really illustrative of our democracy at work, perhaps our democracy at its best. It is a debate of individual privacy and of extremely personal decisions. It is a debate of societal and State interests, of defining social norms within our constitutional bounds, of the extent to which the State may attempt to protect individuals from harm, or from what is perceived as undue or unfair pressures, whether based on economics, paternalistic decision-making, or a skewed public opinion. It is a debate of the extent to which the State may sometimes become an unwarranted and unwelcomed intruder on individual rights.

The opening dialogue and our discussions over the next two days will span the various disciplines of medical, moral, philosophical, and legal thought. It will pay particular attention to the perspectives of persons with disabilities, women, the poor, and vulnerable groups in society. We will examine the relation of our topic to areas of self-determination, equal protection under the law, and fundamental constitutional rights in our democratic society.

On our first panel we have four extraordinary individuals, each committed to justice, equality, individual dignity, and human respect and autonomy. They are each committed to the value and sanctity of human life, yet they are here today to reflect different perspectives from the disability community on the topic of socially-assisted dying.

In preparing for this dialogue, questions have been raised by these four panelists and others including: Is it paternalistic to treat all people with disabilities as a vulnerable class? What is the relation among disability rights activism, individual self-determination, and the right to determine the circumstances of one's death? In the context of the assisted dying debate, is the Disabilities Rights Movement only about an individual's self-determination, or is it also about the historical prejudice and the harsh economic conditions that have faced millions of Americans with disabilities in this country and around the world? How are we to

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<sup>2</sup> The Supreme Court released its opinions after the conference. See *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997); *Vacco v. Quill*, 117 S. Ct. 2293 (1997).

analyze issues of personal autonomy for people with disabilities in the context of the recent and dramatic transformation of the health care system in the United States? What is the value of life for persons with disabilities, and how does the debate we are engaged in today emphasize death with dignity or grant dignity to the lives of people with disabilities? Would legalizing or not legalizing the right to die discriminate against people with severe disabilities, perhaps in violation of the Americans with Disabilities Act (ADA)? If a constitutional right to die is found, what will be the limits of that right in practice and what safeguards will be in place for people with terminal and nonterminal disabilities and for others? Finally, if a constitutional right to die is found, what will it reflect about our society's norms today and those we hold for the lives of millions of unborn Americans with and without disabilities, now and in generations to come?

We have four panelists. Dr. Paul Longmore cannot be here with us today. He will be presenting via videotape and also will be hooked into the conference via telephone. Two panelists, Mr. Andrew Batavia and Dr. Hugh Gallagher, will discuss the views of proponents from the disability community about the right to assisted dying. Two panelists, Dr. Longmore and Dr. Carol Gill, will address what opponents from the disability community say.

The first panelist is Andrew Batavia. Mr. Batavia was the lead attorney on the amicus brief for respondents, the coalition of people with disabilities, in one of the cases now before the United States Supreme Court. He has participated in a similar role in the case before the Florida Supreme Court, and he has served as Executive Director of the National Council on Disabilities. He has also been a special assistant to Attorney General Thornberg and a White House Fellow. He has been Associate Director of the White House Domestic Policy Council. Currently, he is counsel to the law firm of McDermott, Will & Emery in Miami, Florida, and a Visiting Associate Professor at the School of Policy and Management at Florida International University in North Miami.

Dr. Hugh Gallagher, the next panelist, has fought for the civil rights of people with disabilities for over forty years. In the 1960s and 1970s, he was actively involved in making much of Washington, D.C. accessible to people with disabilities. He is the author of several prize-winning books. His articles have appeared in major newspapers and journals across the country in areas related to medical ethics, euthanasia, and physician-assisted dying, particularly as they relate to people with disabilities. He also filed a personal statement in the right-to-die cases currently before the United States Supreme Court. He has been awarded an honorary Ph.D. from John Jay College. I'm pleased to say here that he was a

1995 winner of the Henry Betts award for lifetime career achievement for improving the quality of life for persons with disabilities.

Dr. Paul Longmore is a Professor of History at San Francisco State University. He specializes in United States History. He has written many scholarly articles related to cultural depictions of people with disabilities. He is the director of the San Francisco State University Institute on Disabilities, a pioneering multidisciplinary research center and community service program. He has been the recipient of many honors and fellowships related to his work in the area of disability studies.

Finally, Dr. Carol Gill is Assistant Professor and Director of the Chicago Center for Disability Research, Institute on Disability and Human Development at the University of Illinois at Chicago. As a clinical psychologist, Dr. Gill has worked with hundreds of people in clinical, medical, and counseling settings. In her articles and books and many speaking activities, she has been extremely active in the debate on physician-assisted dying. This goes back to her involvement in 1983 with the Elizabeth Bouvia case. Dr. Gill has filed a declaration in the Oregon decision, and she has recently testified before Congress on the effects of legalized assisted suicide.

The speakers on this truly blue-ribbon panel will have roughly fifteen minutes each to state their positions. Mr. Longmore will present his views via videotape, and then he'll be available via telephone hookup. After opening remarks, we will continue with a discussion among the panelists, which, knowing these individuals, I may or may not be able to moderate successfully. If time permits, we will allow questions to panelists from the audience. I would like to assure you that over the next two days, there will be ample time for discussion, both formal and informal, and also time for reflection.

MR. BATAVIA: I am very pleased and honored to be here this morning to discuss a topic that is extremely important to me as a person with a disability, and that has enormous implications for people with or without disabilities everywhere.

In 1973, when I was sixteen years old, I was a passenger in an auto accident in upstate New York, and I sustained a high-level spinal cord injury. At that time, very few people survived with my level of injury—C23-3 quadriplegia. I was fortunate to have been admitted to one of the finest rehabilitation facilities in the world, Rusk Institute in Manhattan. At Rusk, I was prepared well for the challenges associated with living with a disability for the remainder of my life.

I had no illusions then that I was going to be walking again, and that did not particularly bother me. What truly disturbed me, though, was the possibility that I might have to live my entire life in severe pain and discomfort and the related possibility that I would never be able to be-

come fully productive. I did not see the point of living if either of those circumstances occurred. Fortunately, they did not, and I have been able to live a happy and productive life.

However, back at that time, I did not know how things would turn out, and my anxiety level was therefore fairly high. I knew that, at the very least, the years to come would be extremely difficult. There was one thought that helped me keep going during those difficult times. That thought was, if things got as bad as they possibly could, I would find a way to end my life and my suffering. Although I did not know how I would do it, I knew that there would always be some way. It was not what I wanted, and fortunately it never came to that, but the thought alone gave me great peace of mind and allowed me to move ahead with my life.

At the same time that I was at Rusk, there was another fellow, who I will call Mike, in the room directly across the hall from me. Mike also was a quadriplegic. He had been back to Rusk on several different occasions because he had severe bed sores (decubitus ulcers) all over his buttocks and his hips. Mike was an extremely bright fellow. He came from a good family and had resources available to him. But because of his sores, he was going to have to spend the vast majority of the rest of his life on his stomach. He would only be able to sit up in his wheelchair for brief periods of time. He would not be able to pursue a career. He would not be able to engage in most social activities. He was constantly getting infections from his bed sores, despite the fact that he had the best care in the world.

On three different occasions, Mike decided that he simply did not wish to live like that. The first time, he grabbed a knife to the extent that he could with his mostly paralyzed hands, and he attempted to impale himself in the chest. He failed in his objective, but managed to wound himself severely. He was in great pain, and he developed more infections. His wounds finally healed, and then several months later he tried again, using the same approach. Again he failed and his wounds ultimately healed, but he remained on his stomach due to his bed sores, and his prospects for a life that could ever be satisfying to him remained the same.

Finally, I was told several years after I left Rusk, that, during a brief period in which Mike was able to sit up in his wheelchair, one day he managed to go up to the roof of the facility, and with whatever strength he could muster, he pulled himself over and threw himself off the roof to his death. He was obviously not willing to risk failure on this third attempt. This was clearly not the impulsive act of a person who had not thought it through adequately, or the coerced act of a person incapable of autonomy. It was an act of self-determination by a person with a disabil-

ity based on his own assessment of his life. I deeply regret that my friend, Mike, did not have available to him the assistance of his physicians to help him end his prolonged pain and suffering.

Recently, in three major court cases, I had the honor of representing two coalitions of people with disabilities who believe that they have the right to end their lives with the assistance of their physicians in the event of a terminal illness. The two cases before the United States Supreme Court are *Washington v. Glucksberg* and *Vacco v. Quill*. The case before the Florida Supreme Court is *Krischer v. McIver*.<sup>3</sup> Because the individuals who seek assistance in ending their lives in these cases are all terminally ill, and therefore have very little life left, the State's interest in preserving and prolonging their lives against their wills is particularly weak. Consequently, I believe that these cases are even stronger than the case that Mike would have had to bring.

Interestingly, as I was drafting my briefs, I had an experience that gave me additional personal insight into the issue of physician-assisted death. In reviewing the several briefs filed by disability organizations opposing recognition of a right, I began questioning whether my position was right. What if my opponents were correct that this would be the beginning of the next holocaust for people with disabilities? A good lawyer can convince an open-minded person of most anything.

Just as I began questioning myself, something happened that convinced me that my position was correct. My wife and I had recently adopted two children from Russia, and one day one of them came home from school with a horrible flu. The next thing I knew, I was coughing incessantly and unable to breathe. My wife called 911 and the ambulance came with oxygen. After being in the emergency room and intensive care, I had an opportunity to be reflective. What if this were not a short-term episode? What if the terror that I was experiencing in gasping for my next breath was part of a terminal condition, and I would continue to experience it for some indeterminate period of time? Wouldn't I want to be able to have the assistance of my physician to end that suffering? Wouldn't it be horrible for the State to be interfering with my decision at my deathbed? I have not questioned my position again since.

There are several disability-related arguments that you will be hearing from the other side over the next couple of days of this conference. I would like to address them briefly here.<sup>4</sup>

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<sup>3</sup> The Supreme Court of Florida released its opinion after the conference. See *Krischer v. McIver*, 697 So. 2d 97 (Fla. 1997).

<sup>4</sup> See generally Andrew I. Batavia, *Disability and Physician-Assisted Suicide*, 336 NEW ENG. J. MED. 1671 (1997) (discussing disability related arguments against physician-assisted suicide).

First is the slippery slope argument. This is the concept that physician-assisted death cannot and will not be limited to the voluntary decisions of terminally ill individuals, and that it will inevitably be expanded to people who are not terminally ill and to individuals who have not voluntarily decided to end their lives. Disability organizations that make this contention claim that the next step after recognition of physician-assisted suicide for terminally ill people will be active involuntary euthanasia for people with disabilities generally. I do not believe that this would be the case. I believe that we can impose regulations and enforce them rigorously to ensure that people are not killed against their will. While I would never support involuntary euthanasia, I strongly support the right of people with terminal illnesses to exercise autonomy in ending their own lives.

The second argument that you will be hearing is that this right is based on a societal misconception that people with disabilities have a diminished quality of life. Although many people have this misconception, it is not the basis for the right to physician-assisted suicide. The right is based on the autonomy and self-determination of individuals to assess the quality of their own lives.

A third argument that is made repeatedly by disability advocates who oppose physician-assisted death concerns the alleged "vulnerability" and "oppression" of people with disabilities. I do not consider myself either vulnerable or oppressed. The vast majority of people with disabilities whom I know do not consider themselves vulnerable or oppressed. We do not believe that our physicians would be eager to end our lives, and even if we did believe this, we would never allow our physicians to control such decisions. We recognize that there are significant problems with the way in which our society treats many people with disabilities. We also recognize that some people with disabilities are, in fact, vulnerable to coercion, and many have very limited options available to them. These individuals, such as some people living in institutions, may require special safeguards and protections. However, the fact that some disabled people may be vulnerable or even oppressed is no reason to deny all terminally ill people who are suffering horribly from ending their lives with the assistance of their physicians.

Finally, opponents of the right to physician-assisted suicide are fond of saying, how can our society allow this right when it has not allowed a right to health care generally. To me, this argument is a red herring. I personally favor the establishment of universal health insurance in this country, though my preferred approach to developing such a system is probably quite different from that of advocates on the other side of this issue. Irrespective of our personal policy preferences, our society has not yet made a commitment to universal health insurance, and this is not a



legitimate justification for denying terminally ill individuals assistance in ending their suffering.

It is dangerous for people with disabilities to compromise their autonomy over any aspect of their lives. To me, autonomy is the fundamental basis of the disability rights movement in this country. Paternalism, which is evident in all of the opponents' arguments, is precisely what the movement has always aimed to eliminate. I resent disability being used as a justification for denying a basic right to all Americans. All Americans can potentially contract a terminal disease, and may wish to have access to physician assistance in hastening their deaths under such circumstances. I particularly resent one group of disabled people attempting to limit the autonomy of another group of disabled people, people in the terminal stages of AIDS and other diseases.

DR. GALLAGHER: Drew, that was a remarkable statement. Thank you for it.

Drew and I happened to be talking about this issue about four years ago. We had just met at a cocktail party. In our discussion, we came to realize that we had a shared experience. Both Drew and I had found profound comfort in the knowledge painfully gained from the most critical days of our recovery. We learned that if the pain becomes too great, death becomes an easy alternative. When I was in the iron lung breathing through my tracheotomy for three months and then, during the several years of rehabilitation, I always had present the knowledge that if the suffering got to be too much, if I couldn't hack it, then I would find a way to die. I was very, very sick and it would have been a simple thing to give up and die. I felt that this thought empowered me to keep going. And during my rehabilitation, there were times when I would go to bed at night and say, well, in the morning, we will see about whether to keep on living.

The second thing that is similar is that I had pneumonia this winter, too. It came on very quickly, and it certainly brought memories of being in the iron lung and being unable to breathe. The experience reminded me that death comes not as an enemy, but as a friend.

I wrote a book called *By Trust Betrayed* which is about patients and disabled people in Nazi Germany during the 1930s and into the 1940s. At the beginning, many of the people participating had the best of intentions. Their theory was that institutionalized disabled people, mentally-ill people, people paralyzed, blind, and deaf had poor quality of life and were suffering, and it would be an act of charity to put them out of their misery.

Germany is a very hierarchical society, and during the 1930s it was even more so. At the top of the pyramid were physicians. At the bottom of the pyramid were disabled people. The physicians had not a doubt in

the world that they had the knowledge and the right to judge the quality of life of their patients. That is the distinction between what we are talking about today and Nazi Germany. Over 200,000 to 300,000 German citizens were put to their death against their will by their doctors, sometimes fighting physically against them.

Suicide was illegal. There was one case of a young girl in a mental institution who was so desperate she attempted suicide. She failed. But by attempting suicide, she had broken the rules of the institution, so they killed her.

What I am talking about today is the final stage of a terminal illness of a competent person. I see this as a civil rights issue. My whole professional life has been in the civil rights area. I worked on Capitol Hill for the Judiciary Committee during the Civil Rights debates of the 1960s, and I wrote the first Civil Rights Act relating to disabled people in 1997. I believe that people's rights, people's wishes, should be respected at all times, and, I believe, especially at the end of life.

I believe that disabled people should have the same access to treatment as able-bodied people even though the care of disabled people costs a good deal more than the care of nondisabled people. A society that respects the right of each individual should not make decisions on the basis of cost. I have lost over fifty friends from AIDS, and I have watched their dying. Each case is very different.

There is no across-the-board situation, a rule that would apply to all. People have different pain thresholds. Some people can stand great pain and have the quality of life and fight on. Other people are not that good at it, or are not that strong in that sense.

Different religions: the Roman Catholics do not allow assisted suicide, but they allow palliative care, which can amount to the same thing. The Shintos, Japanese Shintos, do not believe the moment of death, or death itself, is the same thing that the Christians believe. For example, they believe that if your stomach is still functioning, you are alive. If you have a transplant, then you are no longer perfect, so you cannot be accepted into heaven. Ethnic traditions, and family traditions vary immensely.

There is the will to live. People die when they have a will to die. Some people in the final stages of a disease live indefinitely, and other people decide to die, and they do. Also the strength of the disease, the complications of the situation, and the physical strength of the patient are factors. So each case is different.

The civil rights of disabled people have changed greatly in my lifetime. When I first got polio, the disabled were still oppressed and in extraordinary ways: unable to marry, unable to enter certain professions, unable to be priests, denied public education, denied the vote, denied

their constitutional rights. We were not supposed to be on the street much either because we were an embarrassment. By and large, we were seen as incapable children who never got well, and it was thought we were not competent to make adult decisions. Well, this has changed, and it has been changed by disabled people insisting upon autonomy, insisting upon control over their lives, control over their bodies, and control over the medical treatment they receive.

Now, if disability rights is about control, then surely disability rights do not end with terminal illness. To me the most personal control issue is whether to live or whether to die. I do not want doctors deciding whether I will live or die. I do not want governments deciding whether I will live or die. I don't want outsiders meddling with what is mine. It is my liberty right.

Probably the most famous words ever to have been written in the United States say that all men are endowed by their Creator with these inalienable rights: life, liberty, and the pursuit of happiness. Surely this most personal right of all, life or death, is for me to decide. And I would no more presume to tell another person how he must live his final hours on earth any more than I would allow him to tell me. It's my own decision, and it's yours. Thank you.

DR. BLANCK: Now, we will go to the videotape of Dr. Paul Longmore.

DR. LONGMORE: If physician-assisted suicide is legalized, it will take place within the context of a health care system and a society that are already pervaded with prejudice and discrimination against people with disabilities. Let me give a couple of examples. The *Guidelines for Health Care Providers* recommended in the fall of 1996 by the Colorado Collective for Medical Decisions regarding CPR advised: "CPR should be unusual if it is known that the patient had significant physical or mental impairment prior to the cardiac arrest." Now, the guidelines did not define "significant." This recommendation seemed on the face of it to many disability rights activists to be prejudicial and discriminatory. I am told, although I have not been able to verify this, that when those advocates protested against this recommendation as being discriminatory, it was withdrawn.

But it seems ominous that it was proposed in the first place. People with significant disabilities have also been reporting that when they enter hospitals for life-sustaining treatments, they have repeatedly been pressured to sign Do Not Resuscitate (DNR) orders. Let me quote from Not Dead Yet, a disability rights group opposing legalization of physician-assisted suicide:

Yvonne Duffy had hospital personnel constantly urging and demanding that she sign the order. Robert Powell, a

wheelchair rider, was denied admittance to a hospital when he refused to sign a DNR. More recently, Joe Ehman of The Mouth staff declined to sign a DNR prior to hospital admission for back surgery. Hospital staff actually followed him home, harassing him to sign.<sup>5</sup>

What sort of “choices” are being offered for these individuals with disabilities regarding their health care? Surely not free and uncoerced ones. So that’s the first point I want to make: if physician-assisted suicide is legalized, it will be within the context of a system that is already discriminatory and indeed abusive of many people with disabilities.

Second, many advocates of legalization have from the beginning of their movement aimed to establish physician-assisted suicide, not just for those who are terminally ill, but for persons with disabilities as well.

Derek Humphry and Timothy Quill have both said in interviews, in articles, and in Humphry’s book, *Final Exit*, that once physician-assisted suicide is legalized for terminally-ill persons, they hope to see it extended to persons with chronic conditions.<sup>6</sup>

In addition, the advocacy of legalization has always been riddled with prejudice against people with disabilities, on the part of some advocates of physician-assisted suicide. Not surprisingly, the most blatant bigotry has been expressed by Jack Kevorkian. Most of the suicides he has abetted have been by people with disabilities, not by people who were terminally ill.<sup>7</sup> The two most recent were a woman with arthritis and a man with a spinal-cord injury. Kevorkian justified his activities to a Michigan Court in August 1990. He said: “The voluntary self-elimination of individual and mortally diseased or crippled lives, taken collectively, can only enhance the preservation of public health and welfare.”<sup>8</sup>

Now, this statement and his actions regarding persons with disabilities alarm many disability rights activists. They wonder why the news media have failed to report Kevorkian’s highly prejudicial views. Why instead have the media typically portrayed him as some sort of eccentric folk hero? Why also, many of us wonder, have advocates of physician-assisted suicide failed to condemn Kevorkian’s—well, let me put it bluntly—neo-Nazi bigotry against people with disabilities? Why instead do they confine themselves to lamenting his actions as unregulated, but

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<sup>5</sup> Private email message from Stephen N. Drake, Nov. 15, 1996 (quoting Joint Statement from Evan Kemp and Justin Dart) (on file with speaker); see also Carl Weiser, *Protesting Assisted Suicide Disabled People Shout, “We’re Not Dead Yet!”*, COURIER-J. (Louisville), Jan. 9, 1997, at 4A.

<sup>6</sup> DEREK HUMPHRY, *FINAL EXIT: THE PRACTICALITIES OF SELF-DELIVERANCE AND ASSISTED SUICIDE FOR THE DYING* (1991).

<sup>7</sup> See *infra* note 71 & accompanying text.

<sup>8</sup> Nat Hentoff, *Not Dead Yet*, WASH. POST, June 8, 1997, at A15 (quoting Jack Kevorkian, written statement to Oakland County, Michigan, Superior Court, August 17, 1990).

go on to praise him for having forced to public awareness the important issue of patient suffering and of the need for legalized physician aid-in-dying? We wonder also, some of us, if the handful of disability rights activists who have aligned themselves on the side of legalization have demanded of their nondisabled allies that those allies publicly denounce Kevorkian's contempt of people with disabilities.

The third point I want to note is that the arguments justifying physician-assisted suicide are often based on social attitudes and deeper cultural values that are extremely prejudicial toward individuals who are sick or disabled. *Time Magazine*, interviewing Jack Kevorkian, asked, "How do you decide whom to help? Does the patient have to suffer from a life-threatening illness?" "No, of course not," said Kevorkian. "And it doesn't have to be painful, as with quadriplegia. But your life quality has to be nil."<sup>9</sup>

Well, all too many people with disabilities have had all too many doctors dismiss their "quality of life" as "nil" and recommend withholding medical treatment that would sustain their lives, recommending instead that they'd be better off dead, and that their families would be better off with them dead.

This phrase "quality of life" is used frequently to justify physician-assisted suicide. Janet Good, a sometime collaborator with Jack Kevorkian in abetting the suicides of several individuals with disabilities, told the *Washington Post*:

Pain is not the main reason we want to die. It's the indignity. It's the inability to get out of bed, or get onto the toilet, let alone drive a car and go shopping, without another's help. I can speak for literally hundreds of people whose bedside I've sat at over the years. . . . they've had enough when they can't go to the bathroom by themselves. Most of them say, "I can't stand my mother, my husband, wiping my butt." That's why everybody in the movement talks about death with dignity. People have their pride. They want to be in control.<sup>10</sup>

One disability rights activist, a man with a disability himself, responded to this statement of Janet Good. This is what he said:

Many people with disabilities need such assistance in the bathroom, assistance which they are in charge of and

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<sup>9</sup> *Kevorkian Speaks His Mind*, *TIME*, May 31, 1993, at 38 (John Hull interviewing Dr. Kevorkian).

<sup>10</sup> Richard Leiby, *Whose Death Is It Anyway? The Kevorkian Debate. It's a Matter of Faith, In the End*, *WASH. POST*, Aug. 11, 1996, at F1.

which they do not regard as undignified. It's a shame that Ms. Good doesn't convey a more respectful attitude toward her "clients." Instead she reinforces and lethally acts out the devaluing attitudes of our society that tell sick or disabled people they lack dignity because they need assistance with basic activities of daily living, and would be better off dead. Have we really gotten to the point in this country that we will sanction and abet the suicides of people because they can't wipe their own behinds? People who have internalized society's contempt as self-hatred? That Janet Good thinks this justifies facilitating suicides shows what little progress we have made in rooting out disability prejudice.<sup>11</sup>

When proponents of physician-assisted suicide set quality of life as a justifiable reason for aiding deaths, they almost always invoke "dignity," and they simultaneously raise the specter of "dependency." What they fail to note is that these are not objective descriptions of illness or disability. Instead, they are highly value-laden terms that shape perceptions. They are rooted in American values that make absolute personal autonomy and complete physical self-sufficiency cultural ideals. They express a myth, and that myth is that real Americans are rugged individualists who quite literally stand alone, stand on their own two feet. The ideal, the authentic, American is not in any way dependent on others. Or at least, so the myth teaches us to pretend. To become sick or disabled in America is to lose one's social validity. It is to acquire a relentlessly and radically negative identity. It is to become the inversion of what a real American is supposed to be.

That's why the Disability Rights Movement has fought the values and myths that are dominant in this culture about personal autonomy, because inevitably those values have produced discrimination against people with disabilities. That's why disability rights activists have typically sharply criticized dominant notions of individual autonomy for having the effect, in part, of masking the structural arrangements of power and privilege, advantage and economic opportunity that have marginalized people with disabilities. That's why disability rights activists have argued for recognition of the fact that quality of life is constructed by public policies and by socio-economic conditions that are often forced upon people with disabilities by present arrangements. That's why disability rights activists have fought for independent living and for government programs to liberate people with disabilities from nursing homes.

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<sup>11</sup> See *The Real Hemlock Society*, (visited Feb. 8, 1998) <<http://www.acils.com/NotDeadYet/hemlock.htm>>.

Many people with disabilities have expressed the feeling that they would rather be dead than be in nursing homes. The Disability Rights Movement has fought to eliminate the pressures that have forced some people with disabilities to choose between the nursing home and the grave.

That's why disability rights activists have fought for the Individuals with Disabilities Act, the Americans with Disabilities Act, and access and accommodations and full access to health care. That's why disability rights activists are currently fighting to protect all of those rights from the current fierce attack that is being mounted against them.

Yet, when courts in right-to-die cases make their rulings, their reasoning typically expresses the reigning prejudices instead of condemning them. Take, for example, the Ninth Circuit ruling.<sup>12</sup> It claimed in general that it was establishing the right to a physician-assisted suicide only for those who are terminally ill. But, in fact, the court ruling included, or intended to include, persons with disabilities as well. The court noted the concerns of "some representatives of the physically impaired, including the fear that certain physical disabilities will erroneously be deemed to make life 'valueless.'"<sup>13</sup> The court said:

While we recognize the legitimacy of these concerns, we also recognize that seriously impaired individuals will, along with non-impaired individuals, be the beneficiaries of the liberty interest asserted here—and that if they are not afforded the option to control their own fate, they like many others will be compelled, against their will, to endure unusual and protracted suffering.<sup>14</sup>

In other words, what the court was saying was, first of all, physician-assisted suicide should be available to people with disabilities because, they assume, as many nondisabled people assume, that "suffering" is inherent in any disability. The court also ignored the history of prejudice and segregation, and even at times in some places, extermination of people with disabilities. The court completely disregarded that the suffering of many people with disabilities is socially constructed, inflicted by public policies, power arrangements, and denial of access to society. The court wanted to guarantee the right of persons with disabilities to control their own fate regarding their dying; this at a time when the civil rights guarantees of self-determination regarding every other sphere of life are under assault.

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<sup>12</sup> See *Compassion in Dying v. Washington*, 79 F.3d 790 (9th Cir. 1996), *rev'd sub nom. Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

<sup>13</sup> *Id.* at 825.

<sup>14</sup> *Id.*

The fourth thing I would like to note is that for all these reasons the vast majority of disability rights activists have been insisting in the current debate about physician-assisted suicide that we focus on economic issues. We note that the United States has not yet guaranteed a basic right to health care for Americans. We note that medical decisions increasingly are being made, not by doctors, let alone by patients, but by profit-minded managed-care executives. We note that abuse under that system is not only inevitable, it is already occurring, and leading to the deaths of some individuals.

Yet, in legalizing physician-assisted suicide, the Ninth Circuit declared, "in a society in which the costs of protracted health care can be so exorbitant, it is improper for competent, terminally ill adults to take the economic welfare of their families and loved ones into consideration."<sup>15</sup> The court said it didn't have any authority to make any rulings about access to health care. It left that to the legislature. The court also dismissed concerns that legalization might expose "the poor and minorities to exploitation."<sup>16</sup> It rejected such concerns as "disingenuous," "fallacious" and "meretricious."<sup>17</sup> The court wrote, "The argument that disadvantaged persons will receive more medical services than the remainder of the population in one, and only one, area—assisted suicide—is ludicrous on its face."<sup>18</sup>

Only affluent, privileged white people who enjoy the advantages of the current economic system could be so arrogantly scornful of the concerns of many people in minority communities as well as people with disabilities, who are often poor themselves. Only people with such advantages could convince themselves that physician-assisted suicide operates without abuse. People with disabilities, who are often disadvantaged, cannot afford to indulge in such naiveté.

To most of the civil-rights activists, this is simply acquiescing in the current health-care system and the current economic system, which in our view are not only increasingly unjust, but downright savage. As one activist said, "In a profit-oriented system [pervaded by prejudice and ignorance about disability], so-called patient choice to die will not long remain any choice at all."<sup>19</sup>

What we finally want to note, what we want to warn everyone about, is that while the threat of legalization of physician-assisted suicide within the current system is especially great to those who are sick and

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<sup>15</sup> *Id.* at 826.

<sup>16</sup> *Id.* at 825.

<sup>17</sup> *Id.*

<sup>18</sup> *Id.*

<sup>19</sup> Harvey Lipman, *Disabled Group Urges Supreme Court to Reject Assisted Suicide*, ALBANY TIMES UNION, Jan. 8, 1997, at B2 (quoting Michael Volkman).



those who are disabled, legalization of assisted suicided within the present system will ultimately prove dangerous to everyone.

DR. GILL: I thought I would start today by reading a statement that's alluded to often in this debate. The statement is based on the Equal Protection Clause of the Fourteenth Amendment. Basically, it says: All persons similarly circumstanced shall be treated alike. It's a simple but profound statement. It's the stuff that inspires social justice movements.

Over the last three decades, our brothers and sisters with disabilities have argued and lobbied and participated in sit-ins and at times even gotten arrested to uphold that principle. All persons similarly circumstanced shall be treated alike. You may not discriminate on the basis of our disabilities. That principle has been used by us to get jobs and escape institutions and emerge from third-rate segregated schools and assert our right to transportation, gain access to the built environment. We even used the principle of nondiscrimination to save our lives when we defeated plans to ration health care based on quality of life judgments.

But now proponents of physician-assisted suicide want the government to sanction, and the medical system to carry out, deliberate discriminatory treatment on the basis of physical condition. They want people with disabilities who express the desire to die to be treated differently from nondisabled people who express the desire to die. They would betray the hard work of all those tireless disability rights activists who have held the line against discrimination.

These proponents, I believe, make several very important errors. They severely underestimate the threat of discrimination in our lives, and they downplay the gravity of social oppression in preventing people with disabilities from having real choices to live. At the same time, I feel, they overestimate the effectiveness of safeguards and guidelines to control what they seek to unleash on the disability community.

I hear a lot of false reassurance that I shouldn't worry so much. For example, the Ninth Circuit Court opinion that Dr. Longmore quoted points out that there are plenty of disability advocacy groups that protect us.<sup>20</sup> Of course, those of us on the Boards of such organizations who have tried to intervene in right-to-die cases involving disabled persons have been told by the court that we have no legal standing in such a private matter.

Derek Humphry, founder of the Hemlock Society, tells his followers that the disabled are amply protected from harm by two factors: first, the National Council on Disability, which he says is just rolling in bucks

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<sup>20</sup> See *Compassion in Dying*, 79 F.3d at 825.

from the federal government, and second, the Americans with Disabilities Act. I guess he has never heard of the war on unfunded mandates.

Now we have Hugh Gallagher and Andrew Batavia telling us that we are not experiencing the threats to our freedoms that we thought we were. Mr. Batavia takes issue with our characterization of people with disabilities as oppressed, and I was interested to hear that the majority of his friends are not oppressed. Actually, I am very glad to hear that. But I think he may not be acquainted with a lot of people with disabilities that I know.

Dr. Gallagher, in a statement to the Supreme Court, reassures me by saying this:

In our generation, great strides have been made to welcome people with disabilities into society as equal members with equal rights. For the first time, people with disabilities have assumed control over their own lives, without fear of sterilization, internment, segregation, and ostracism, and the denial to their rights to vote, hold property, enter legal contracts, and obtain public education, transportation, and accommodation.<sup>21</sup>

Nonetheless, I do worry. My perspective on these matters has been shaped by my role and experience as a clinical psychologist, a researcher, and a woman with a disability. I am a trained crisis therapist, and I have worked extensively with suicidal people, both disabled and nondisabled. I have also read the work of our country's leading suicide experts. The conclusion is clear. Once you peel away the rhetoric and look at reality, suicide is not much of an act of freedom. It's a forced decision that occurs when a person loses hope of finding a way to get what he or she needs to make life worth living.

Furthermore, most people die for socially mediated reasons, not pain. Even the best physicians agree about that. People die because of shame, loss of self-worth, loneliness, fear, feelings of uselessness or guilt over hurting others.

A point that can't be stressed too much about suicide is that ambivalence is always present in suicide whether it's easily detectable or not. A major problem with physician-assisted suicide is that once a second or third person participates in an individual suicide, the whole dynamic changes. It ceases to be a private decision between the individual and the individual's soul. He or she is no longer free to be so ambivalent, to waiver. The process goes into motion and there are not as many degrees

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<sup>21</sup> Brief for the Amici Curiae: Gay Men's Health Crisis and Lambda Legal Defense and Education Fund at 3a, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (Nos. 96-110, 95-1858) (statement of Hugh Gregory Gallagher).

of freedom in the act itself. So, an assisted suicide always becomes a completed suicide.

This certain path to death is actually very different and unequal to what nondisabled people get when they are suicidal. First, what do nondisabled people get when they are suicidal? They get disagreement, generally. People say: "you shouldn't do it." They get intervention. Last but not least, they get the chance to fail to die by suicide.

When we look at the safeguards that are commonly recommended to control physician-assisted suicide, we find that they demonstrate misconceptions about suicide and about the real experience of people with disabilities. One that's commonly offered is that the suicide wish should be persistent over time. But the persistence of suicide expressions is a very poor predictor of whether an act of suicide will be completed or not. Expressions of suicidal feelings that last for months are quite common in people with disabilities going through a disability adjustment process and at different points in their life thereafter.

Another safeguard is professional assessment: that two or more health professionals should assess the competence of the person in making the suicidal wish. Well, first of all, people with disabilities don't have access to mental health services in general from professionals who understand their experience. Secondly, physicians are notorious for overlooking signs of depression in people with health complaints. There is a whole literature about that. Next, physicians cannot ensure that people with disabilities are fully informed about their options because, let's face it, aside from the physicians in this room, most don't know what our options are, and they don't even know that they don't know. But perhaps most distressing of all, physicians in general demonstrate very negative attitudes about disability and quality of life, and they reinforce each other's biases, so having two doesn't help.

I could review for you, if I had more time, the literature on physician attitudes towards disability. But let me summarize it and say that number one, it shows that health professionals' attitudes and beliefs about disability are unfortunately as negative and often more negative than the attitudes of the general public. Number two, health professionals often take a significantly dimmer view of our lives than we do in the aggregate.

Just one example, in one recent study, 86 percent of spinal cord injured high-level quadriplegics rated their quality of life as average or better, 86 percent. But only 17 percent of emergency room doctors,

nurses, and technicians thought that they themselves would have an average or better quality of life if they acquired quadriplegia.<sup>22</sup>

In one study of women with disabilities, the author says:

The women in this study regularly reported bad experiences of health professionals, in particular doctors, describing them as punitive, patronising, dismissive, and unhelpful . . . . Every now and then a woman might come across a general practitioner or a consultant who was helpful and acted in partnership with them. The gratitude, enthusiasm, and warmth with which these women described such contact suggests that they are rare encounters.<sup>23</sup>

Last, but not least, among the proffered safeguards, proponents say we should rule out coercion as a factor in the decision. There is no way to rule out social coercion in the lives of people with extensive disabilities who are so devalued. The kind of coercion that undermines the desire to live for people with disabilities is not something blatant like a malicious family member who doesn't want this person around. It can be a lot more difficult to put your finger on. It can be as subtle as feeling like a burden or fearing the imminent abandonment of a spouse, or just having a doctor validate your suicide as a possible solution for you.

We don't have adequate research to know what the impact of that doctor's agreement to do this act is. We don't have that research yet. But we do know that the doctor's message can be a determining factor for parents who make treatment decisions about disabled newborns.

I want just to look at some of the facts of oppression in disabled people's lives that we do know. We know that people with disabilities are, indeed, oppressed in our society, and it's especially severe for women and for people of color with disabilities. A third of all people with disabilities live at or near the poverty level;<sup>24</sup> 70 percent of us of working age are unemployed.<sup>25</sup> We suffer tremendous social isolation. We have to rely on restrictive health care coverage. We are also at high risk for domestic violence. We are physically, sexually, and emotionally assaulted by our partners, family members, personal assistants, and, yes,

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<sup>22</sup> See Kenneth A. Gerhart et al., *Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers*, 23 ANNALS OF EMERG. MED. 807-12 (1994).

<sup>23</sup> SUSAN LONSDALE, WOMEN AND DISABILITY: THE EXPERIENCE OF PHYSICAL DISABILITY AMONG WOMEN 52 (1990).

<sup>24</sup> See Ellen M. Yacknin, *Helping the Voices of Poverty to be Heard in the Health Care Reform Debate*, 60 BROOK. L. REV. 143, 166 n.47.

<sup>25</sup> See Peter David Blanck, *Employment Integration, Economic Opportunity, and the Americans with Disabilities Act: Empirical Study from 1990-1993*, 79 IOWA L. REV. 853, 873 n.95 (1994) (citing a 1994 Harris Survey of Americans with Disabilities).

health professionals at approximately twice the rate experienced by nondisabled women.<sup>26</sup>

A study by the DisAbled Women's Network (DAWN) in Canada found a significant association between suicide, depression, and abuse. Of 371 women with a variety of disabilities, 60 percent had contemplated suicide, and almost half of those had attempted suicide at least once. The more types of abuse a woman had experienced, in fact, the more likely she was to consider suicide.<sup>27</sup>

I have interviewed many women with disabilities. When I listen to their stories, I hear of broken dreams, people who want to do things like go to school, get jobs, become parents, live in their own homes rather than being forced to live with abusive spouses or other family members. They are not getting to do what they want to do, live.

People with disabilities in my research have also talked in particular about the oppression they experience in health service settings. Again, I don't really have time to talk about this much today. Suffice it to say, people with disabilities don't feel heard, understood, or accepted as full human beings by most of the people in the health service system that they come into contact with. And, yes, some of them with more privileges have good experiences, but that doesn't typify the majority.

The proponents of assisted suicide say: keep the government out of this personal decision; don't tamper with my right to control my life. My response is: okay, it's a deal. Keep suicide private; keep the government out of it; don't codify it into law. In other words, commit suicide privately if you feel that's your right, but do not tamper with my medical system's policies. Leave my right to nondiscriminatory suicide intervention alone.

Drew, it's interesting to hear about your acquisition of disability twenty-four years ago. I worry that if you acquired your disability now, even though the medical technology is better, you might not survive the emergency room. I was at a conference a few years ago. A senior rehabilitation physician got up and said people with quadriplegia are dying wrongfully every day in emergency rooms because the ER staffs make decisions to let them go. Separate standards are never equal. I think that's why African-Americans who know that so well have joined the minority opposition to assisted suicide.

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<sup>26</sup> See Catherine F. Klein & Leslye E. Orloff, *Providing Legal Protection for Battered Women: An Analysis of State Statutes and Case Law*, 21 HOFSTRA L. REV. 801, 808-09 n.5 (1993); Maura Beth Johnson, Note, *Home Sweet Home?: New Jersey's Prevention of Domestic Violence Act of 1991*, 17 SETON HALL LEGIS. J. 234, 240 (1993).

<sup>27</sup> See S. Masuda, Research Summary, SAFETY NET/WORK COMMUNITY KIT: FROM ABUSE TO SUICIDE PREVENTION AND WOMEN WITH DISABILITIES (1996).

In conclusion, I would like to address the proponents of physician-assisted suicide directly. In over two hundred years of United States history, the right to assisted suicide has never been legal. In my opposition to physician-assisted suicide, I am not denying you something that's yours. You have never had it. Why now, now before we have our rights to live, now in the new age of managed care, and now before its impact on our community has been adequately studied?

I will defend your right to equality in access to work, relationships, transport and education. You already have the right to refuse treatment, the right to be left alone, and the right to get palliative care, so you don't suffer the way Mike did in Mr. Batavia's story. But it seems that you want more than that. You want a special privilege, and you want it now. You are willing to strike down my legal protections and set a precedent for my discriminatory treatment in order to get it. You would deprive me of rigorous suicide prevention to get it. You will risk encouraging disability prejudice in doctors, and you will change my medical system to get it.

If that's not enough, you want something even beyond what nondisabled people have. You want a certain easy death. That, I believe, is a most unreasonable accommodation. Society and doctors must never be complicit in the suicides of people on the basis of physical difference. The risk of even one wrongful death in the disability community is too much.

DR. BLANCK: Dr. Gallagher, Drew Batavia, are you betraying the Civil Rights Movement involving persons with disabilities?

DR. GALLAGHER: I just don't see it. This business of oppressed minority and victimhood is a difficult one, and it's a popular one. But I often think that a person who feels that he is oppressed by his society all the time and at every turn is giving up. I think this victimhood can be like paranoia, and that it becomes a self-fulfilling prophecy. You get into a position where you say, "I can't do it because I am disabled." It tends to lead to inaction and it's often a symptom, as Carol knows, of depression.

Just one other thing in terms of an oppressed minority, I agree with virtually everything that Carol Gill said about social attitudes and so forth. But it's some kind of interesting oppression when you consider that approximately one dollar out of every twelve spent by the federal government is spent on the care for the living and needs of disabled people. When you think of how America in our time has rebuilt itself in curb cuts and busses and public transportation, it's a completely different world than it was thirty years ago.

When you consider the lobbying power that the disabled people demonstrated to get the Americans with Disabilities Act (ADA) passed,

when they overturned the most powerful lobbies in Washington—small business and transport—they overcame the opposition of the Bush cabinet, and they convinced President Bush. They've got some kind of power—they're right up there with the senior citizens.

MR. BATAVIA: I agree with all of what Hugh Gallagher just said. I would just like to add that to me, there is nothing more oppressive and no more pernicious type of discrimination than one group of people with disabilities telling another group with disabilities that they can't control their lives, particularly at the very end of their lives when they are suffering horribly.

The Disability Rights Movement to me is about control over one's life. That's the bottom line. Any way that the opponents put it, you are getting in the way of my right and the right of other people with disabilities who don't feel oppressed, who don't feel victimized, who just want to control our lives, like other people.

DR. GILL: Well, I challenge the notion that recognizing your oppression leads necessarily to being passive and depressed. I didn't see that during the black Civil Rights Movement. I didn't see that during the Women's Movement. I didn't see that in almost any other social justice movement. I think that I need to prescribe for you to go to your next ADAPT demonstration and see if you see a lot of passive people there.

As for lots of federal health dollars going into the support of people with disabilities, of course, the nursing home industry alone sucks up a good portion of that and as do other inflated health care costs while the managed care organizations get rich and the people who manufacture wheelchairs get rich and so on. I don't think we can be blamed for how much it costs for us to have decent lives.

DR. LONGMORE: Well, I listen to a lot of these discussions with the ears and mind of a historian, and what always strikes me is how much of the discussion on the proponent's side is really American myth-making about personal autonomy. Somebody said to me this morning, there is no real freedom if you don't have any real choices. The vast majority of people with disabilities are denied real choices about most aspects of their lives. The problem is that given the pervasiveness of the prejudice and discrimination we still face if physician-assisted suicide is legalized, a good many of those people are going to find themselves under pressure to make a "choice" to end their allegedly miserable lives rather than being given access to society.

We may have gotten the ADA passed, but it's been under assault constantly since its passage. There's been a widespread refusal to implement it. The reality for most people with disabilities in this society is that they don't have real choices regarding the rest of their lives.

DR. BLANCK: Is there a middle ground?

MR. BATAVIA: There is, I believe, some common ground. We recognize that there are some major problems in our society with the way in which people with disabilities are treated. We must rigorously address those problems. But in doing so, we can't do it in a way that's going in any way to compromise the autonomy or control over their lives by people with disabilities, because it's too risky. Once we do that, we compromise the basic premise of this movement, which has been so valuable and important for all of us.

DR. BLANCK: Hugh Gallagher, what do you hope to see for the rest of your lifetime?

DR. GALLAGHER: First, I want to say that I am troubled by this idea of speaking on behalf of the disabled. It's very difficult. I see no polls of substance that could tell how disabled people feel. There have been a couple of indications. One, I saw seven friends in death seriously disabled: a professor, a doctor, an editor, a writer, a lawyer, and an entrepreneur. They all insisted upon the right for themselves, should at the end of their life, they wish suicide. But they, too, do not approve of it for society.

There was an issue of *New Mobility*. They asked readers to write in the mail. According to the editor of *New Mobility*, the responses were running 80 percent in favor of having the right to assisted suicide. I think we have a lot to contribute to this debate. We know about pain and illness and quality of life, and how they are not related. We have learned lessons that the able people are only to learn as they approach old age, becoming decrepit, or diseased, and they need to have reassurance from us; they need to learn what we have to offer. It's an important contribution that we can make to all of society. I hope we do, and I hope we don't alienate ourselves from this discussion by thinking of it in terms of a conspiracy.

DR. LONGMORE: I think the Disability Rights Movement in one way has ironically benefited from this current debate. It's compelling us to elaborate on the ideology of disability rights. The Disability Rights Movement has always been about much more than personal autonomy. It has even defined personal autonomy in different ways than in the dominant society. But the movement also has been about an analysis of structural inequities, of the allocations of economic resources, of the maldistribution of power, and of the basis of community, not just among people with disabilities, but in general. This whole debate can help us further develop our analysis and critique—an agenda that will benefit not just people with disabilities, but help in a much needed reassessment of American society. I think we have a lot to contribute on that score.

DR. GILL: My first piece of advice would be to defer this whole thing, delay it. Don't legalize physician-assisted suicide. Dr. Gallagher



has conceded that we don't know enough. We don't even know enough about what people with disabilities would think about all of this if they had access to information. I say that we need to work with people with disabilities on establishing equal access to health care for everyone. We need to start doing some research to get in touch with our people, but don't do skewed research where you don't even go to nursing homes and ask people with disabilities who are incarcerated there what they think. Most surveys avoid that population.

I think that we need also to start working in partnerships much more with physicians and other health care professionals, so that they learn about our lives, and so that we can tell them the options that people with disabilities can use to live dignified lives. And let's get personal assistant services for everybody federally funded so we can live with dignity in our own homes.

## II. SESSION TWO: THE SEMANTICS AND CONCEPTS UNDERLYING PHYSICIAN-ASSISTED DYING

DR. KIRSCHNER: Our panel this afternoon will be examining in depth some of the language and the concepts we use in discussing physician-assisted suicide—some of the concepts and language that we have taken for granted. We will be exploring issues such as autonomy, self-determination, suffering, quality of life, and hopelessness.

Our first speaker is Dr. Haavi Morreim. She has been a professor in the College of Medicine from the University of Tennessee in the Department of Human Values in Ethics for twelve years, for the four previous years at the University of Virginia School of Medicine. She has done clinical teaching and consulting in medical ethics. Although her research spans a variety of topics, it particularly focuses on the ethical and legal implications of medicine's changing economics.

She has over seventy publications in journals of law, medicine, and ethics, including the *Journal of the AMA*, the *Hastings Center Report*, and the *Wall Street Journal*. Her book *Balancing Act: The New Medical Ethics of Medicine's New Economics*, first appeared in 1991 and has been republished in paperback by Georgetown University Press in 1995.

DR. MORREIM: Each of us was invited to focus on one particular dimension in this whole nest of issues at which we are looking today. I was invited to look at autonomy, and at what exactly is going on in the autonomy argument behind assisted suicide. Therefore, you will find that some important things will be missing from my remarks. They are not intended to be an all-encompassing view of physician-assisted suicide or socially-assisted suicide.

The essence of the autonomy concept is quite simple and familiar. Basically, the principle says that if I am capable of doing so, then I ought

to be able to make my own decisions regarding my own life. I must live with the consequences, and I should be able to use my own values to make my decisions. The autonomy argument can also go a bit deeper. It seems to me that in order to be morally accountable agents—in other words, to be people who can be held responsible for what we do—we must have the liberty to be able to shape ourselves, our character, and our personal histories according to the values that we hold dear. Otherwise, if we are just buffeted about here and there by forces outside our control, then we are not really accountable for ourselves. We are just a product of what others have done.

As we move from basic notions of autonomy to the more specific idea that perhaps somebody might be entitled at some point to end his own life, it's useful to go beyond just the suicide concept. It is clear, for instance, that competent adults are permitted to forego medical life-support for any reason of their choosing. This is not actually considered suicide, but rather a refusal of unwanted interventions. One can also think, more broadly still, of occasions in which a person is willing to sacrifice or endanger his life for the sake of something that one regards as being more important than his life. Some of these involve religious commitments. When a Jehovah's Witness forgoes blood in order to observe Biblical dictates, even at the cost of his life, he is not committing suicide. He is, however, placing that spiritual value higher than life. Other examples involve people who commit or risk self-sacrifice for the benefit of other people, from fire fighters, police, and military heroes, to parents rescuing their children. So there are a variety of ways in which people are permitted in our society to place something ahead of preserving their own lives. All these are reflections of the value our society places on personal autonomy and its exercise.

In the context of assisted suicide, the relevant values prompting someone to lose a desire for further living will often concern that person's judgments about the quality of his life, and the kind of life that is worth living. The need for assistance from others in ending that life can arise from several factors. The individual may be physically unable to perform the necessary actions on his own; he may lack information about what methods would work effectively and comfortably in ending his life; or he may be legally unable to obtain access to the means for accomplishing the desired end. In the latter instance, patients can only obtain legal access to drugs via physicians, who have exclusive control over them. For those who wish to end their lives, drugs would often appear to be a more benign means than firearms or other alternatives. Hence, our focus evolves from autonomously placing certain values above life, to foregoing life-support, to suicide, to assisted suicide, to physician-as-

sisted suicide. In the last set of cases, it is difficult for someone to act on his autonomous wishes without enlisting help from others.

The Ninth<sup>28</sup> and especially the Second Circuit<sup>29</sup> opinions took note of this in their decisions about physician-assisted suicide, as they discussed the different position of those people who are dependent on mechanical life-support, versus those who are not. The former are permitted to enlist physicians' help by asking them to remove these interventions, but because the latter are not machine-dependent, they therefore can only die quickly if some new death-producing process is introduced, such as a lethal dose of drugs. Because those drugs are unavailable without prescription, they can only be obtained with physicians' help. To some observers, it seems unfair to permit the one group a relatively easy escape from unwanted life, while requiring the other to endure unwanted suffering. In either case, after all, the physician must be involved, and yet while courts have clearly authorized the former sort of assistance, the latter remains deeply disputed. In the near future, the United States Supreme Court is expected to render its own judgment on this matter.<sup>30</sup>

If physicians are to be permitted to assist in suicide by making prescription drugs available, or even if they are merely to honor a request to abate aggressive life-support, there are several caveats, which have been mentioned elsewhere. If assisted suicide is to be even potentially acceptable according to the principle of autonomy, the person must not be in the midst of transient despair or depression; the diagnosis and prognosis must be accurate to the best of reasonable medical knowledge; undue pressure must not be exerted by family, physicians, hospital people, nursing home people, or whomever; and one must identify cases that are not actually a request for suicide, but a cry for some other kind of help.

It seems to me that two issues are particularly important here. One is empirical and the other is normative. Realistically, we can be quite sure that abuses and errors will happen if assisted suicide is legally permitted. The empirical question is how prevalent, how likely, how frequent, and how severe and regrettable these occasions are going to be. The other question is the value question: given that there will be errors and abuses to one degree or another, how shall we manage the uncertainties? Where shall we draw the balance?

On the one hand, we could draw such strict safeguards that almost no one will be permitted to commit suicide or to seek assisted suicide. In that case, those who will suffer are those who want, but are unable to

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<sup>28</sup> See *Compassion in Dying v. Washington*, 79 F.3d 790 (9th Cir 1996), *rev'd sub nom.* *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

<sup>29</sup> See *Quill v. Vacco*, 80 F.3d 716 (2d Cir. 1996), *rev'd*, 117 S. Ct. 2293 (1997).

<sup>30</sup> See *supra* note 2.

secure, that kind of exit. On the other hand, if we permit assisted suicide fairly freely, some other people will suffer. More lenient criteria mean higher possibilities for abuse, and some people would thus die who did not want or need to. Some of the other speakers at today's forum encourage us to take this hazard very seriously, particularly regarding disabled persons.

In essence, then, the value question is a weighing of the uncertainties: who will get the benefit of the doubt, who should bear the higher chance of falling victim to error, and how do we define what constitutes a "benefit?" There are vitalists who believe that life is infinitely precious, and is a benefit no matter what its quality. On the other side, there are those who believe that, at least under some conditions, the quality of life is too poor to justify its further extension. Those with a robust view of autonomy not only favor the latter approach, but believe that competent adult individuals should be permitted to make and carry out that decision regarding their own lives. The question, then, is whether citizens should have the freedom to make such choices, or whether the possibility of serious errors should ward us off in favor of other resolutions.

DR. KIRSCHNER: Our next speaker is the Honorable Paul Steven Miller. Mr. Miller comes to us from Washington, D.C., where he serves as one of the four Commissioners on the United States Equal Employment Opportunity Commission (EEOC). He has served in this capacity since 1994. He also serves as a Co-Chair on a Commission-wide task force to develop an alternative dispute resolution program for the EEOC and as a member of the Executive Committee of the President's Committee on the Employment of People with Disabilities.

Prior to his work with the EEOC, Mr. Miller served as the Director of Litigation for the Western Law Center for Disability Rights, a non-profit legal services center specializing in disability rights issues. He has addressed the British Parliament on disability rights and served as a member of an American Delegation to Japan on disability rights and is the author of many articles on the civil rights of people with disabilities.

MR. MILLER: Although I respect the fact that this subject has prompted a range of perspectives from the community of people with disabilities, I am hopeful that we can use the discussion over the next two days to broaden the areas upon which we agree and to narrow the issues upon which we disagree. I believe that both those with disabilities who support physician-assisted suicide and those who oppose it begin with the notion that people with disabilities should be empowered to make choices regarding their participation or nonparticipation in the health care system. Moreover, those on both sides would likely acknowledge that the current health care system leaves many individuals with disabilities without an adequate range of choices, and in some cases forces dis-

abled people to accept interventions that are unwarranted or harmful, such as involuntary commitment and the like.

I believe that the debate in the disability community around assisted suicide centers on this concept of individual autonomy and dignity.<sup>31</sup> Some of us believe that we have an alienable right to die and should be able to enlist assistance in carrying out this choice. Others believe that the concept of a government-sanctioned suicide system is inherently suspect given the pressures that are likely to bear on people with disabilities, our families, and the health care system.

I come down on the side of those who oppose physician-assisted suicide because of the widespread cultural devaluing of people with disabilities which still exists in this country, and some of the unlikely and unwarranted results if we make it easier for people to end their lives with the assistance of doctors. I find it ironic that at this same historical moment when a disabled person's civil rights have begun to take root in federal law, the right-to-die movement is reinforcing the stereotypical notions about the tragedy of a disabled person's existence.

From my perspective, the most troubling thing about the assisted suicide movement is how it defines the concepts of personal autonomy, freedom, and dignity which are being used to empower people with disabilities to kill themselves, rather than to enable people with disabilities to live independent lives with dignity. Such basic civil rights concepts are literally turned on their heads to reinforce stereotypical roles (leading to an acceptable and rational death for people with disabilities), rather than to create and strive for equal opportunity and independence. The debate over assisted suicide emphasizes "death with dignity," but it ignores the possibility, I believe, of recognizing the dignity of a disabled person's existence while living with that disability.

In addition to encouraging society at large to regard the suicide of a person with a disability as rational, such prejudices reinforce the alienation of people with disabilities with regard to how they feel about themselves and the world around them, particularly in the time immediately following the onset of a disability. This resulting self-hatred can result in a "rational act of suicide."

I also believe that we cannot ignore the lessons of history on this topic. In his 1990 book, *By Trust Betrayed*, Hugh Gallagher has written about the organized programs of active euthanasia which resulted in the victimization of people with disabilities in Nazi Germany, and more recently in the Netherlands.<sup>32</sup> In such environments as Nazi Germany and

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<sup>31</sup> See generally Lois Shepherd, *Dignity and Autonomy after Washington v. Glucksberg: An Essay about Abortion, Death, and Crime*, 7 CORNELL J.L. & PUB. POL'Y (forthcoming 1998).

<sup>32</sup> See GALLAGHER, *supra* note 1.

the modern Netherlands, people with disabilities are often viewed by others and by themselves as burdens on society and as burdens on their family. This, I think, results in an inordinate cultural pressure on people to exercise their free will, their right, so to speak, to suicide.

We heard earlier about the Hemlock Society and how they are pitching this same issue. The focus of such groups as the Hemlock Society is on the right of persons with disabilities, not terminal folks, but persons with disabilities to voluntarily end their own lives.

While I understand that there is a desire to separate the money questions from the meaning questions for purposes of organizing these panels at this conference, I believe that we must all start with the realization that questions of money and resources are behind much of the fear and mistrust in the disability community around assisted suicide. With the growth of managed care, the overburdened federal and state Medicaid budgets, and the increasing efforts on the part of employers to avoid providing health care benefits for their employees, people with disabilities have very real concern about a health care system and government that may determine that their lives are not worth the cost of keeping them alive. As the cost of health care increases in this country, the pressure to resort to assisted suicide for a disabled family member will be great, and is sure to increase if assisted suicide becomes sanctioned and more readily accessible and available.

The choice between life and death must, I think, be left to the individual alone. Government has no place substituting its judgment in such private and personal decisions. However, government, I believe, is responsible for ensuring that an informed, voluntary, nonbiased, and noncoerced judgment is made. That delicate balance exists between individual autonomy and the impact of the prejudice of situational and clinical depression for people with disabilities. Because disabled people are subject to this prejudice that devalues their very right to exist, I believe that often their decisions to commit suicide are not informed or voluntary. Therefore, a disabled person's request for assistance with suicide on its face should never be immediately acceded to or unquestionably accepted. The involvement of the third party in assisting suicide is not only coercive, but dangerous.

The simple fact is that society's response to an individual who expresses a desire to commit suicide should be no different for a disabled person than for an able-bodied person. Before we consider whether assisted suicide should be a right, we should ask ourselves whether the underlying reasons for persons with disabilities choosing death are valid and whether we should first attempt to create the option of a dignified life for a person with a disability. I think that people with disabilities deserve that option. Only then will the suicide be requested by a free

will and the choice not be coerced. Otherwise, there is substantial risk that the right to assisted suicide will become a duty of assisted suicide.

In closing, let me just say that I think that there is a lot of naiveté out there on the part of many well-intentioned people in the disability community with respect to this issue. Drew Batavia is a friend of mine, and I think Drew Batavia is right. He and I, we are not oppressed. We are the disabled elite. I am not worried about Ivy League lawyers like myself and Drew Batavia being oppressed by the health care system. I am very worried about the great majority of people with disabilities who are not of our economic status and who are being oppressed by a health care system.

No individual doctor would make a decision to kill her patient, but it is very naive to think that a single doctor makes that decision alone. A decision is increasingly made on the basis of economics. Just look at the attempts in this country to ration health care. And last, it is very naive to think that disabled people control their lives in this health care system with managed care. I think it is simply and sadly naive.

DR. KIRSCHNER: Our third speaker is Dr. Robert Weir. Dr. Weir comes to us from the University of Iowa College of Medicine where he serves as the Director of the Program in Biomedical Ethics and has a professorship in pediatrics and religious studies. Dr. Weir is a recognized expert on a number of ethical issues ranging from genetics, organ transplantation, issues at the end and the beginning of life, and critical care medicine. He is the primary author, with the Multidisciplinary Ethical, Legal and Social Implications Committee, of the paper entitled, *I.R.D. Guidelines for Genetic Research*, and the editor of the book entitled, *Physician Assisted Suicide: Ethical Positions, Medical Practices and Public Policy Options*.

DR. WEIR: I was asked to speak with you about the concept of quality of life as that figures into the debates about physician-assisted suicide.

I am going to begin with a poem and then I am going to give several quotations to indicate examples of differing quality of life perspectives that apply to physician-assisted suicide. I am going to discuss some problems that we have in talking about physician-assisted suicide in the context of disabilities. I am going to draw some distinctions that might be helpful as we think about these complex issues. Then I want to provide a format for thinking, a way that at least I find helpful for thinking about quality of life issues as they pertain to life and death decisions.

First of all, a poem. This is a well-known poem by Edward Arlington Robinson, an American poet:

*Richard Cory*

Whenever Richard Cory went down town,  
 We people on the pavement looked at him:  
 He was a gentleman from soul to crown,  
 Clean favored, and imperially slim.  
 And he was always quietly arrayed,  
 And he was always human when he talked;  
 But still he fluttered pulses when he said,  
 "Good morning," and he glittered when he walked.  
 And he was rich—yes, richer than a king—  
 And admirably schooled in every grace:  
 In fine, we thought that he was everything  
 To make us wish that we were in his place.  
 So on we worked, and waited for the light,  
 And went without the meat, and cursed the bread;  
 And Richard Cory, one calm summer night,  
 Went home and put a bullet through his head.<sup>33</sup>

It matters a lot in making quality of life judgments whether we are making quality of life judgments about our own lives or the lives of other people. In the poem you have an example. We could all recite numerous similar examples in our own lives in which we have heard about the suicide of this individual or that individual, and we have been stunned because we had thought that they had a very good quality of life and wanted to continue living.

Now, some differing perspectives on physician-assisted suicide that reflect differing quality of life judgments. This is a quotation from a 1993 court decision in British Columbia involving a woman named Sue Rodriguez:

Ms. Rodriguez suffers from amyotrophic lateral sclerosis (ALS), . . . her life expectancy is between 2 and 14 months, but her condition is rapidly deteriorating. Very soon she will lose the ability to swallow, speak, walk, and move her body without assistance. Thereafter, she will lose the capacity to breathe without a respirator, to eat without a gastrostomy, and will eventually become confined to a bed. . . . She does not wish to die so long as she still has the capacity to enjoy life. However, by the time she no longer is able to enjoy life, she will be physically unable to terminate her life without assistance.<sup>34</sup>

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<sup>33</sup> EDWARD A. ROBINSON, *COLLECTED POEMS* 82 (1924).

<sup>34</sup> *Rodriguez v. British Columbia*, 107 D.L.R.4th 342, 349 (Can. 1993).



Here is a description of another patient involved in a legal case having to do with physician-assisted suicide. This is one of the three patients involved initially in the case arising in New York that involves Timothy Quill. This patient is known only as Jane Doe, and she says:

I have a large cancerous tumor which is wrapped around the right carotid artery in my neck and is collapsing my esophagus and invading my voice box. . . . The cancer has metastasized . . . . It is not possible for me to reduce my pain to an acceptable level of comfort and retain an alert state . . . . At the point at which I can no longer endure the pain and suffering associated with my cancer, I want to have drugs available for the purpose of hastening my death in a humane and certain manner.<sup>35</sup>

William Barth is another patient involved in that same New York case. William Barth says:

In May 1992, I developed a Kaposi's Sarcoma skin lesion. This was my first major illness associated with AIDS . . . . In September 1993, I was diagnosed with cytomegalovirus . . . which caused severe diarrhea, fevers, and wasting . . . . In February 1994, I was diagnosed with microsporidiosis, a parasitic infection for which there is effectively no treatment.<sup>36</sup>

Then, he adds that he also has severe diarrhea, extreme abdominal pain, nausea, and concludes by saying, "I understand that there are no cures. I can no longer endure the pain and suffering."<sup>37</sup> Three patients with different medical conditions, all who have decided, at least in part on the basis of their assessments of their own quality of life, to seek assistance in committing suicide so that they can end their lives.

Now, in opposition to these are examples of persons who have come to different kinds of conclusions. Ira Byock, a hospice physician in Missoula, Montana, has a recent book on dying entitled, *Dying Well*. This quotation comes from a paper by Dr. Byock, which appeared in my edited book. Dr. Byock writes that, "care of the dying includes at the minimum the following: the provision of shelter from the elements, the provision of hygiene, assistance with elimination, the offering of food and fluid, the keeping of company"—which is his way of talking about nonabandonment—and what he calls "bearing witness" by recognizing

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<sup>35</sup> *Quill*, 80 F.3d at 720.

<sup>36</sup> *Id.*

<sup>37</sup> *Id.* at 721.

the essential value of each individual, and also “the relief of suffering.”<sup>38</sup> It is Dr. Byock’s view that there are other medical, moral, and legal alternatives that are preferable to physician-assisted suicide.

Finally, a quotation from a document that was being handed around by members of Not Dead Yet in Washington at the time of the Supreme Court arguments on the cases in January of 1997: “Americans with disabilities don’t want your pity or your lethal mercy. We cannot allow euthanasia to become the law of the land. If we hope to stop it, we have only a few weeks to mobilize an entire nation.”<sup>39</sup>

So six quite different perspectives, all of them using variations of a quality of life argument to try to make points about physician-assisted suicide. I would like to simply point out some problems that we all have, persons with disabilities as well as able-bodied individuals, when we think about quality of life judgments in the context of physician-assisted suicide. One of those problems is that many of us tend to overestimate the difficulties connected with disabilities because we cannot imagine being disabled. Many of us tend to undervalue persons with disabilities by ignoring them, avoiding them, stigmatizing them, or discriminating against them. As many in this audience know far better than I, there seem to be many who only respond to persons with disabilities with either pity or criticism.

One of the problems in this ongoing discussion has to do with physicians and the rest of us who are inadequately trained to provide appropriate care for persons with disabilities. In addition, some physicians because of their training as well as their own value systems may be inclined to give up too quickly when responding to requests for physician assistance by persons with disabilities. On the other side, some persons in the disability community may be inclined to criticize physicians and other persons with disabilities and perhaps criticize them too quickly when they opt for or argue in favor of physician-assisted suicide.

Now, these are some distinctions that may be helpful in thinking about physician-assisted suicide and especially about quality of life judgments as they relate to that subject. One obvious distinction is between my assessment of my quality of life versus my assessment of your quality of life or, for that matter, your assessment of my quality of life. It is obvious that it matters a great deal who is doing the assessing of whose quality of life.

Another distinction about which it is sometimes helpful to remember is the distinction between a somewhat objective assessment by, per-

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<sup>38</sup> Ira R. Byock, *Physician Assisted Suicide is not an Acceptable Practice for Physicians*, in *PHYSICIAN-ASSISTED SUICIDE* 107, 114 (Robert F. Weir ed., 1997).

<sup>39</sup> For similar comments by members of Not Dead Yet, see Hentoff, *supra* note 8, at A15.

haps, a multiple disciplinary group or a committee of quality of life versus the subjective contentment of the person with that quality of life. It is certainly entirely possible for many persons to judge that an individual's quality of life is very low and yet that particular individual will be quite content with the quality of life he or she has.

Then it's helpful to distinguish between the disabling conditions that a person has and the person who has those disabling conditions. It is unfortunately too easy simply to refer to persons with disabilities by naming the disabling condition the way that some health professionals refer to patients, not by name, but by the number of their room, or by the medical condition that they have. It's important to distinguish between descriptive statements about disability as opposed to evaluative statements about disability. Finally, there is a difference between assessing the quality of life of an individual and assessing the quality of life of persons affected by that individual.

During the last decade when there was a great deal of debate in our country about what should be done with infants born very prematurely and with serious disabling conditions. It was often very important to try to isolate what kind of projections we might make about the quality of life that a baby might have if he or she survived a number of years, and to put aside, to the extent that we could, the effect that child's life would predictably have on the quality of life that would be enjoyed by parents and by siblings of the child.

It's so terribly easy when we talk about quality of life of individuals to expand it to include persons affected by that quality of life—people whose quality of life are also affected by that individual. I think it's helpful to narrow our perspective and try to talk only about the quality of life of a person who is thinking about continued living or hastening death, whether the person thinking about this is an individual thinking, and perhaps acting, in isolation or, perhaps a physician and a patient having communication with one another about the quality of life that the patient has at the moment.

So how can we think about quality of life matters as we think about life-and-death decisions? I find that this particular format is helpful in thinking about a number of important variables that apply to the quality of life an individual patient has or might be expected to have in the future. I group these variables into two groups. One of them, I refer to as "objective" variables, and I put the word objective in quotation marks because these are as objective as medicine can be objective, and there are four of these. I will not elaborate on them. A lot more could be said about each one of these.

The first variable that obviously is important is to try to get some kind of handle on the *severity* of a patient's medical condition. Fortu-

nately physicians have numerous diagnostic tools at hand according to which they can gain a fairly sophisticated judgment about the severity of an individual's medical condition compared with all patients, and also compared with other patients having that particular kind of medical condition.

A second variable to think about has to do with the *reversibility* of this medical condition with medical treatment: what is available for us to treat it, to cure it, to reverse it. For persons with disabilities, it is often very important to try to think about what other kinds of options are available for providing a better quality of life for those individuals.

A third variable that's important in thinking about these kinds of quality of life judgments at the end of life or possibly at the end of life has to do with the *achievability* of important medical goals. There are at least eight acceptable medical goals in the care of any individual patient. It's important to try to get a handle on what is the particular medical goal being sought in an individual case, and what is the likelihood of accomplishing that goal. For example, is the goal to relieve the patient's suffering? Is the goal to prolong the patient's life? What does one do when these two goals are in conflict in an individual case?

The fourth variable has to do with the presence of *serious neurological impairments and/or the presence of serious physical disabilities* and how neurological impairments and/or physical disabilities lead into the assessments of the person's quality of life by that individual.

Then, there are four subjective variables when we think about the quality of life or continuing life or hastening death. One of those has to do with the *presence of unrelieved pain*. One of the things that American physicians as a group are not very well-trained to do is to assess pain and to try to treat it effectively.

A second variable that has to do with patient perceptions of quality of life is the kind of *physical suffering* the patient may be experiencing and/or the kind of *psychological suffering* the patient might be undergoing. So here I have in mind on the physical suffering side: things like pain, things like adipsia [absence of thirst], diarrhea, constipation. On the psychological side, things like anxiety, fear, despair, helplessness, hopelessness.

The third variable on the subjective side has to do with *a patient's perspective on an intolerable life*. It's my view that all of us have some border or some line that we can cross under certain circumstances that will lead us to conclude that life, as we're presently experiencing it, is intolerable. Fortunately that threshold is not one that very many of us pass very often. But I would suspect that almost everybody in this audience can think of someone, a friend, a relative, who had a number of problems, ongoing problems in life, and then there was one more prob-

lem that beset that individual, and at that point life became intolerable. Then that person decided to opt out by committing suicide or asking for assistance in committing suicide.

Finally, the bottom line in all of this is trying to determine the *best interest of the patient*, trying to determine whether it makes sense to continue living, or to try to hasten death in some way. The bottom line, unfortunately, perhaps is subjective, and it has to do with trying to balance the burdens of continued living, that is, burdens to that person and compare those with benefits to that person through available medical treatment.

DR. KIRSCHNER: Our next speaker is Dr. Linda Emanuel. Dr. Emanuel comes to us today from the American Medical Association (AMA), where she is the Vice President of the Ethics Standards Division and the Director of the Institute for Ethics. Prior to joining the AMA, Dr. Emanuel was the Assistant Director for the Division of Medical Ethics and an Associate Professor of Medical Ethics at Harvard Medical School. She has published and lectured extensively on clinical ethics including advance directives, the patient-physician relationship, the definition of death, and professionalism. She was on the faculty at the Massachusetts General Hospital in general internal medicine before moving to Chicago this year.

DR. EMANUEL: We have been assigned the task of talking about words in this dilemmatic issue. Usually people have associated the phrases, "compassion in dying," or "aid in dying," almost exclusively with physician-assisted suicide and euthanasia. I would suggest that all dying people should have aid and all dying people should have compassion. I would attribute this association largely to strong media and advocacy. I want to raise the question: is the problem with society or with the medical system? If both, then in what proportion?

I am going to share with you some data that is so hot off the press that I've only seen it for a matter of hours myself.<sup>40</sup> The data that I refer to comes from surveys of just short of a thousand people who were given less than six months by their physician before they were expected to die. They are a random sample representative of the nation taken from physicians' references, oncologists, internists, pulmonologists, and cardiologists, also randomly selected across the nation. We found some interesting things.

By contrast to the high proportion of the people in the famous support study who were found to be dying in moderate to severe pain, we found 48 percent, about 10 percent less, but 67 percent had their desired

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<sup>40</sup> Data on file with Dr. Emanuel.

level of pain treatment; 21 percent wanted more treatment, but 8 percent wanted less.

What about personal meaning for those who are dying? Between 62 and 87 percent said that they were fulfilled in that they had someone to love, someone to confide in, and their personal faith was sustaining them.

What about physician performance? From 83 to 96 percent of these patients said that their physician knew how to tell bad news well, had their complete trust, showed them respect, listened to them, provided clear information, and shared decisions with them.

What about economic hardship? Of the people who we talked to, between 2 and 9 percent (these are ranges because they're all separate questions) had to spend down their earnings to be eligible for Medicare/Medicaid, had to borrow, had to sell property or change their work in order to pay their bills. So that's 2 to 9 percent. It's bad again, but nowhere near as bad as we had thought.

Now, here is something that I thought was much worse than we thought, about the burden of care to the people around the person who is dying and to the person who is dying. Only 1.5 percent said that they had a volunteer coming to help them from the community, and 53 percent had no help whatsoever for their nursing care needs at home.

So I would suggest that contrary to our previous assumption, our failure is at our community level, perhaps our family support level as well. Indeed, we live in a death denying culture. We have done so since the dawn of the scientific era. We care about our youthful appearances. We have face lifts and tummy tucks and hair transplants, and we send our dying to institutions. We have lost track of the grounding adjustment to dying that bespeaks a healthy civilized society and a healthy personal psyche.

Death has been a taboo subject, and we don't know how to talk about it. So this is an area where doctors can help. We have been making attempts to teach physicians how to go through the process of talking about and planning for a terminal illness with patients. It is a process. It is not a one time conversation. It is a longitudinal conversation that is woven in and out of clinical care. There is a core structured deliberation that needs to take place which ideally should be done around a validated worksheet with a doctor in the loop somewhere.

It is very important that doctors know how to structure those discussions to help those patients and members of society who do not know how to have them. In order for doctors to do this, they must be taught themselves because they are no better at this than other members of society.

We went so far as to put words into our trainee doctors' mouths. Exactly how do you raise the subject? Exactly how do you bring the

proxy or family member in and start building a team? It takes a team to care for any patient and certainly a dying patient.

I would like to tell you, also, about a project that we will be launching from the American Medical Association's New Institute for Ethics, which is called the Compassionate Competent Care Project or CCC. We gave it that title because we wanted to bring those words back into traditional caring associations. In that program, we plan over the next two years to train all practicing physicians, half directly and half indirectly, in several very important areas. Every single practicing physician needs to be competent in symptom management—at least competent enough to know how and when to refer patients when situations are beyond their expertise. They need to be competent in the recognition and treatment of psychiatric complications of terminal illness, depression most importantly, but also hallucinations and so forth. They need to be competent in the communication planning and decision-making area that I refer to and in the team-building area.

Toward that end, we have also put forward the idea of guidelines somewhat different in philosophy from Dr. Weir's. We have some baseline assumptions that physician-assisted suicide and euthanasia are not medical procedures. Physicians should not provide them and many who consider physician-assisted suicide or euthanasia are in need of care or assistance which, once provided, makes these considerations simply disappear. While physicians should not provide assisted suicide and euthanasia—and may need to say so frankly—patients or family members who consider or request it should not be abandoned. Rather, they should be provided with care that will meet as many needs as possible for patient autonomy, dignity, and compassionate care of symptoms.

This is an illustration of a clinical approach. It's very familiar to those of you who are in clinical care and I am going to highlight it piece by piece. It allows a physician to have some sense as to how to go forward when they are faced with a patient who is asking for assisted suicide and euthanasia. To just say "no" is not enough.

Assess the depression, of course. First of all, it's not widely enough known that amongst patients who request assisted suicide, many are depressed. We're not talking about rational suicide. We're talking about depressed patients. Of course, if they are depressed, there is treatment for depression. If they are not depressed, then assess their competence. That's another important screen. Then, engage in the structured deliberation that I have been describing and attempting to talk to physicians about.

Now, during structured deliberations, it has become eminently clear to me from my own clinical practice that people who have been requesting assisted suicide drop the request for a number of reasons. They real-

ize that they are not going to be abandoned. They realize that there are ways of handling the burden put on those they love so it won't be excessive. They realize that their version of dignity can be obtained without recourse to assisted suicide. They realize that other things that they fear, such as pain, can be managed even if it is necessary to go to something as extreme as terminal sedation. The intent to end life is just not necessary.

In this context, let me remind you that very few of those who request assisted suicide are in intractable pain.<sup>41</sup> This is not a dominant reason for requesting assisted suicide. The dominant reasons are depression, fear of abandonment, fear of burdening loved ones, fear of being undignified, and fear of, but not actual pain. The reasons are all in the psychosocial realm. They are not in the realm of physical suffering.

Step four of the same general approach notes that the real issue is to find and address directly the root causes of the request for assisted suicide. Is it physical suffering? We know how to handle that. Is it psychological suffering? We know how to handle that, too. Is it suffering in the social context? Well, we do not know how to handle that, but we should, and it is not a reason to start in with assisted suicide. Is it spiritual suffering? We can ask for help there too.

The guidelines have an additional set of counterparts—guidelines for addressing family members when they are interested in assisted suicide for the patient, a very worrisome possibility. Unfortunately, we have data from this group published in the *Archives in Internal Medicine* last year that show that family members are more interested in assisted suicide for the patient than the patient.<sup>42</sup>

We have another worrisome problem, and that is when a physician leans toward physician-assisted suicide, because physicians sometimes do. Physicians need to know how to call for help when that happens, and they need to know that they have gone beyond a limit which should not be surpassed. Unfortunately, we have data which suggests that this is a very real threat. Russell Portenoy and his colleagues found that when they interviewed physicians, nurses, and social workers, those who favor assisted suicide had three troubling characteristics in common: Their personality profiles were less empathic, their technical skills in symptom management were lower, and they spent less time with their patients.<sup>43</sup>

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<sup>41</sup> See Back et al., *Physician Assisted Suicide and Euthanasia in Washington State*, 275 JAMA 919, 924 (1996).

<sup>42</sup> See Harold G. Koenig et al., *Attitudes of Elderly Patients and Their Families Toward Physician-Assisted Suicide*, 156 ARCHIVES OF INTERNAL MED. 2240 (1996).

<sup>43</sup> See Russell K. Portenoy et al., *Determinants of the Willingness to Endorse Assisted Suicide: A Survey of Physicians, Nurses, and Social Workers*, 38 PSYCHOSOMATICS 277 (1997).



So we have many reasons to worry about physician-assisted suicide being terribly misused. We also have very strong reasons to try and reclaim the words “compassion” and “aid in dying” for traditional, hospice, and palliative care in our care of dying patients.

DR. KIRSCHNER: Our next speaker is Dr. Thomas Strax, a psychiatrist, who comes to us from New Jersey where he serves as Professor and Chairman of the Department of Physical Medicine and Rehabilitation at the University of Medicine and Dentistry of New Jersey at the Robert Wood Johnson Medical School, and is the Medical Director for the JFK/Johnson Rehabilitation Institute. Tom is a former President of the American Congress of Rehabilitation Medicine and is the current Vice President of the International Rehabilitation Medicine Association.

In addition to his professional experience, Tom has had significant personal experience growing up with a disability. Tom shared with me that he was the first child with a developmental disability to be mainstreamed in New York. During his residency at New York University, he developed a program for college-bound disabled adults. He has been the recipient of a number of awards, including the New Jersey Governor’s Award and the New York University Alumni award.

DR. STRAX: I have been asked to talk about function instead of disease in defining quality of life. On my way to a speaking engagement in Sydney, Australia, in 1995, I stopped in New Zealand. The headline of the largest paper in New Zealand had a story about a man whose crutch was stolen. For three days the newspaper continued the story of the stolen crutch and its implications. Ironically, towards the back of the same newspaper, there appeared an article which throughout the rest of the world had been front page headlines!

I was born fifty-five years ago. The obstetrician that delivered me told my parents that they were young and healthy, and that I was better off dead. At that time, the world was at war. One of the leaders in that war felt that those with developmental disabilities, those with retardation and mental problems, should be put to death.

A great philosopher has said, “We see what we’re looking for, we look for what we know, and what we don’t know, we never see.” Assumption is far more important than diagnosis. In another story, a one hundred-year-old man goes to see his physician and says, “Doctor, my right knee hurts.” “What do you expect,” the physician replies; “you are one hundred years old.” “But my left knee is also a hundred years old, and it does not hurt,” retorted the old man.

I’d like to address the issue of function. The World Health Organization has three terms which I think are worth redefining: impairment, disability, and handicap. Impairment is something that you might lack: physical, mental, emotional. A disability is something that you cannot

do because of your damage. Handicap, on the other hand, has the social implication. It is something that you have to do that you cannot do because of your impairment or disability.

In some cases, an impairment such as being deaf, gives you an advantage if you are going to be a sandblaster. Somebody who wears a foot or ankle prosthesis can do fine if she is a CEO of a company, but will be handicapped if she is a patrolman on the beat.

I have cerebral palsy. It took a court, someone that owed my father a favor, an ex-Naval officer who was president of a union to get me into school. I can spend hours telling you stories of discrimination and triumph.

However, I'd like to describe two stories that have to do with attitude. I bought my first house and had just returned from the store when a car pulled into my next-door neighbor's driveway. I ran out and held my hand out, and said, "Hi, I'm your new neighbor." The driver said, "The new people live over there." I said, "Right, I'm your new neighbor." He said, "You must be mistaken; my new neighbor is a doctor." I said, "Yes, I'm a physician."

Often when I walk through the halls of my own institution, patients and families will come up to me and tell me how well I am doing. Sometimes they ask me what room I am in, and, of course, I will give them a room number!

Each of you has a chance of spending ten years of your life with some kind of disability. In the blink of an eye, you can be like me. Think of it. How will the health care and legal community view you? Will they view you for standard of care or diagnoses, or will they consider your functional status in considering the quality of your life?

Quality of life, and with it a reason to go on, depends upon what you can do and enjoy doing, how you feel about it, as well as those who are available to share your life, dreams, and aspirations. The technical, medical, and social resources that are available help preserve and increase your function, and this is extremely important in defining the quality of life.<sup>44</sup>

I believe in the right of the individual to self-determination, providing the individual is competent both mentally and emotionally and also has been given a clear and comprehensive view of what is available to improve the quality of his or her life. Function is far more important than diagnosis.

DR. KIRSCHNER: Our next speaker is Reverend Monsignor Kenneth Velo. Monsignor Velo is a Chicago native who has spent most of

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<sup>44</sup> At this point in the discussion, Dr. Strax played a video that showed, in eight-year segments, the life of a child born without any extremities.

his professional career in Chicago working first as a pastor, and then since 1981 with the Archdiocese of Chicago. Most recently, he served as the executive assistant to the late beloved Joseph Cardinal Bernardin. In 1994, he was appointed President of the Catholic Church Extension Society by Pope John Paul II and continues in this capacity today.

MONSIGNOR VELO: I come not as a moral theologian, not as an ethicist, but really as a Roman Catholic priest, yes, the primary caregiver of the late Joseph Cardinal Bernardin, and most of all, as a fellow human being on the journey of life.

In preparing my remarks, I was reminded these last few days of the beautiful passage from the Old Testament Book of Ecclesiastes:

There is a point of time for everything. A time for every matter under the heavens. A time to be born and a time to die. A time to plant and a time to uproot the plant. A time to kill and a time to heal. A time to tear down and a time to build. A time to weep and a time to laugh . . . .<sup>45</sup>

Allow me for a few moments to share a story. A second-year high school student began a study of biology. He was walking through the woods. He saw a cocoon on the side of a path. Very excited, he picked up the cocoon. He took out his pocketknife and slit the cocoon open. As the light peered into the cocoon, he saw life. He saw a butterfly. He thought he would be helpful. He slit the rest of the cocoon open, opened it up to allow the butterfly to get out. The butterfly began to move, flutter its wings. But soon after, it fell, fell to the ground and died.

Shortly thereafter he was in class with his teacher and a number of classmates, and he told them the story of how he was excited to find that cocoon and how he slit it open and saw life and then opened it up all the more so that the butterfly could be released. It was then that he found out what had happened. His teacher, and his classmates, told him that, really, it is in the cocoon that the butterfly stretches its wings and gains strength. As it moves, the cocoon opens; as it releases itself in the struggle, it finds life. It finds its ability to fly. That is the way it was meant to be.

Now, you may wonder, why would I mention a story like that at a conference like this. I have two reasons. First of all, together we're slitting open the cocoon just a little bit—the cocoon of life itself all around us—to look at an important issue, to shed light on it, to see that there is life, and to learn from it. Secondly, it's in the struggles of life that we find energy and new life. It is part of the Christian tradition. As the Lord said, we must die ourselves to gain new life. As part of the

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<sup>45</sup> *Ecclesiastes* 3:1-4 (King James).

Christian tradition we understand that his suffering and the cross brought us life.

I would like to tell you about two Josephs: One you don't know; one perhaps you do know. The one Joseph is a nephew, the husband of one of my nieces. At the age of thirty-six, this last March, he succumbed to multiple sclerosis and its complications. For four years he was in a wheelchair. He couldn't pick up things; he noticed all sorts of problems. It got worse eventually. He was confined to a wheelchair, couldn't do anything for himself. His wife and three children cared for him.

Now, most people around him saw him get weaker and weaker and weaker. Through the eyes of faith, we also saw him get stronger and stronger and stronger as he dealt with the issues, as he confronted the problems, as he continued to do what he could to be an example for his children. As he suffered and struggled, there was new life.

The other Joseph you may know about. He was one of the greatest religious leaders of our times. He died on November 14, 1996. He served as Archbishop of Chicago from 1982 to 1996, fourteen years. Throughout his life, and throughout his priesthood, he addressed life issues. These past years were a struggle. First of all, through a terrible allegation, he was accused of having abused someone, a minor. He stood up to that, dealt with that. Through that struggle, there was strength; there was life, new life.<sup>46</sup>

But in June of 1995, in a doctor's office in Chicago's south side, he learned that he had pancreatic cancer. The doctors said it would most likely be his life-ending event. Although the tumor was removed, although there was no sign of cancer for a number of months, in August of 1996 in a doctor's office after an MRI, he was told that the cancer had returned. He faced the ultimate event quietly and simply, but in the course of those last months spoke to us about life and about dying and about new life. Through the struggle, there was life. Through the struggle, there was new life.

He was disabled during this time. Because of radiation and chemotherapy, there was osteoporosis and other problems. He couldn't walk as he wanted. He couldn't maintain the normal course of activity. But it was during this time, too, that he also helped us as he addressed a significant life issue: physician-assisted suicide. He had prepared to address the United States Supreme Court Justices because he knew that they would be handling this particular matter: The question of the right of the people to end life. He wrote on November 7th this letter:

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<sup>46</sup> For a more detailed discussion of Cardinal Bernardin's life, see *THE GIFT OF PEACE, JOSEPH CARDINAL BERNARDIN* (1997).

Dear Honorable Justices: I am at the end of my earthly life. There is much that I have contemplated these last few months of my illness. But as one who is dying, I have especially come to appreciate the gift of life. I know from my own experiences that patients often face difficult and deeply personal decisions about their care. However, I also know that even a person who decides to forego treatment does not necessarily choose death, rather, he chooses life without the burden of disproportionate medical intervention.

In this case, the court faces one of the most important issues of our times. Physician-assisted suicide is decidedly a public matter. It is not simply a decision made between a patient and a physician. Because life affects every person it is of primary public concern. Our legal and ethical tradition has held consistently that suicide, assisted suicide, and euthanasia are wrong because they involve a direct attack on innocent human life. And it is a matter of public policy because it involves a violation of a fundamental human good. There can be no such thing as a right to assisted suicide because there can be no legal or moral order which tolerates the killing of innocent human life, even if the agent of death is self-administered. Creating a new right to assisted suicide will endanger society and send a false signal that a less than perfect life is not worth living.

Physician-assisted suicide also directly affects the physician-patient relationship and through that, the wider role of physicians in society. As has been noted by others, it introduces a deep ambiguity into the very definition of medical care if care comes to involve killing. Beyond the physician, a move to assisted suicide and perhaps beyond that to euthanasia creates social ambiguity about the law. In civilized society, the law exists to protect life. When it begins to legitimate the taking of life as a policy, one has a right to ask what lies ahead for our life together as a society.

In order to protect patients from abuse and to protect society in a dangerous erosion in its commitment to preserving human life, I urge the court not to create any right to assisted suicide. With cordial good wishes, I re-

main sincerely yours, Joseph Cardinal Bernardin, Archbishop of Chicago.<sup>47</sup>

Those next seven days after he wrote this letter, the Cardinal remained in the cocoon of life, struggling. There was weakness. There was great discomfort. He was at peace, but, yes, at times late at night or in the early morning before the sun came up, there was anxiety. "What will these next few days, these next few weeks be like?" he asked.

On November 14th, at 1:30 in the morning, he was called home. It was through the struggle that there was life, through the struggle that there was much more new life.

When we talk about physician-assisted suicide, some people may think we're talking about a right. Let's stand up because what we really are speaking about is taking life before its time, exterminating the opportunity for growth, strength and new life, even in the struggle. Thank you.

DR. KIRSCHNER: Next on our distinguished panel, we have Dr. Jesus Rodriguez. Dr. Rodriguez is a board certified chaplain and the Director of the Educational Programs for the AIDS Pastoral Care Network here in Chicago. Dr. Rodriguez has worked with and counseled HIV positive and AIDS patients for the last five years, four years at the Cook County Hospital HIV Primary Care Center, and the last year in his current position at the AIDS Pastoral Care Network.

DR. RODRIGUEZ: Folks, I want to say up-front that I fully respect a person's decision to choose assisted suicide. I also want to say that I do respect a doctor who, on an individual basis, is willing to facilitate that process for a patient. However, when it comes to legalizing and furthermore institutionalizing the practice, I must say that I have a great, great many reservations with this issue. My concerns are not with the act of suicide itself. My concerns are at a deeper level. My concern, and thus my subject, is with the *ethos* and the *locus* of the decision-making process as we as a nation move forward in considering legalizing and institutionalizing assisted suicide.

Now, before explaining how the *ethos* and the *locus* interface with the decision-making process of legalizing and institutionalizing the practice of physician-assisted suicide, I would like to "plant an idea" at this point as a way of making in advance the point of my entire discussion. To do that, I would like to invite you to please take part with me in a brief exercise.

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<sup>47</sup> For further discussion of Cardinal Bernardin's letter, see *Assisted Suicide: Hearing of the Health and Environment Subcommittee of the House Commerce Committee*, FED. NEWS SERVICE, Mar. 6, 1997 (statement of Cardinal Bernard Law quoting Cardinal Bernardin) [hereinafter *Assisted Suicide Hearing*].

Take a good look at the persons sitting to your left and to your right side. Are you done? This is the end of the exercise. Please remember the people at whom you just looked. In a few moments you will find a practical application of this exercise.

Let me now address the issue of the *ethos* and the *locus* of the decision-making process in the discussion of legalizing and institutionalizing the practice of physician-assisted suicide by framing these concepts within a cultural perspective.

#### DEFINITION OF TERMS:

By *ethos* I mean the guiding beliefs and influence mass society has over a given issue. I like to say “mass society” rather than “the white folks,” because the term is less racially motivated; it sounds better, and these days, is a more politically correct term, right? By *locus or locus of control* I mean “where the power to decide” resides. I will address separately each of these concepts.

*Ethos*. Three questions in three different areas: societal, cultural, and institutional levels, can be asked to discover the *ethos* of this issue:

1. From the *societal* perspective, the question here is *who or which sector of our society* is talking about patient assisted suicide. Once you ask yourself that question, then you can begin to answer the stated issue regarding *who or which* sector of our society is engaged in the issue.

I ask you: Having seen a minute ago at your left and at your right, ask yourself, are the African-Americans, Latinos, and other minorities of our nation talking about physician-assisted suicide?

By now you know that we can count (in this audience) the number of Hispanics, Latinos, or African Americans we have here on two hands. Now, why is it that representatives of these minorities are not here today? I really don't think they just missed the bus or the train coming here, and I am sure that with the organizational capacity present in this institution to promote events of this nature they were sent a promotional invitation. I think indeed that their absence in this auditorium speaks “loudly” about where they may be with regards to this issue. I suppose that with their absence they are saying, “we're not engaged in this discussion.”

My point is that the *ethos* in our “public” discussion is very narrow. It is certainly not representative of the African-American community. It is clearly not representative of the Latino/Hispanic community. Neither is it representative of the Filipinos, Native Americans and other minorities.

So we need to be clear about who is talking and who is not. It is the mass society who is talking about this issue. In that sense, the question then is whether we as minorities are part of this *ethos* or not. Having

asked that question then, the obvious next question is whether physician-assisted suicide is another issue that is going to be imposed on others by the guiding beliefs and values of the mass society? That's a very powerful ethical question that we as a nation need to consider because if the minorities are not part of the informing ethos, then I have to assume that physician-assisted suicide is being forced upon us and that potentially serious consequences may follow.

2. From the *cultural* perspective the question is about values. We can ask, how the beliefs and guiding values of the mass society are informing this process? And, to whose cultural values are we listening? Which values of the mass society are informing this process? Are we considering the cultural values of African Americans, Latinos, Native Americans and other minorities?

Obviously all these are questions of a political nature and power, a very important concern to the mass society. And so after asking these questions then, the answer is clear. The composition of this audience suggests to me that we are not listening to the mix of cultural values of the African-American, Hispanic and many other minorities that "make" this nation.

People, like me, who work in hospital environments know that on the question of minorities' values regarding euthanasia and physician-assisted suicide, minorities respond differently than persons from the mass society. My experience is that when the doctor approaches a minority person and asks them the question regarding their preferences, "wellness or longevity," or "to feel better or to live longer," often minorities tend to answer that they would rather live longer. However, in the same situations, usually the folks from mass society will prefer wellness. In minority communities people talk about living longer regardless of what it takes.<sup>48</sup>

Our communities have been so used to living with the minimum in many contexts that while quality of life is an important issue for us, we have learned to live with little, and we are more concerned about living longer than living better. We are people with survival mentalities, and survivalists are concerned with issues of continuation, endurance, resistance and subsistence, not termination, eradication and discontinuation.

If you want to see this survival mentality attitude exemplified, take the train down to Humboldt Park or go to the South Side of Chicago. You see Latino people trying to live longer, although they have little, and the African-American folks living with little but seeking to live longer.

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<sup>48</sup> See Lori Montgomery, *Blacks Fearful of White Doctors Pulling the Plug*, WASH. FREE PRESS, Feb. 26, 1997.



As a theologian I ask, “What is the relationship between God and power in a capitalistic society that makes the mass society think about issues of suicide from a control perspective rather than from other coping or surviving perspectives?” This is a matter that needs further attention and I suggest that you read a study conducted between 1977 and 1988 by the National Opinion Research Center with 8,384 Americans to discern their attitudes towards euthanasia.<sup>49</sup> The findings suggest that those highly educated, politically liberal respondents with a less religious self-perception are most likely to accept active euthanasia or suicide for terminally ill patients.<sup>50</sup> As you may be aware, categories such as “highly educated and politically liberal,” usually do not speak of minorities’ socio-economic reality. I want you to know that right now as we speak many illegal immigrants in this nation are afraid that the beliefs and guiding values that inform the immigration laws of the land, and that have defined their inability to exist in this nation, are the same values that may influence the legislative processes around the physician-assisted suicide issue.

I was in a support group a couple days ago, and while trying to explore their opinions on the physician-assisted suicide issues, I posed to them the question. An illegal immigrant framed the issue of values in this way: “*Suddenly, if it’s not legal to be in this nation, it is not legal to live in this nation.*” That’s how he translated physician-assisted suicide—in fear of the values that inform this debate.

3. From the *institutional* perspective, the question is which sector of our medical institutions are talking about patient assisted suicide. Is this an issue informed by legitimate concerns of our medical institutions? Has this issue been financed by health insurance companies?

In the HIV community, there is a deep fear, I don’t want to say paranoia, but it’s a legitimate fear that suddenly now we’re talking about this issue in the context of a very strange marriage that looks to us more like “adultery” than a marriage between health care systems, insurance companies and managed care. The timing of this whole notion of physician-assisted suicide is suspicious and my patients are asking what is behind this alliance.

I suppose that they have legitimate reasons to ask this question because it is only recently that we have learned that all those studies that we have heard about for generations and generations that said nicotine has nothing to do with health and that tobacco did not cause cancer were financed by whom?

AUDIENCE MEMBERS: Tobacco companies.

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<sup>49</sup> See David C. Caddell & Rae R. Newton, *Euthanasia: American Attitudes Toward the Physician’s Role*, 40 Soc. Sci. Med. 1671, 1671-81.

<sup>50</sup> See *id.*

DR. RODRIGUEZ: Say it in unison. By the tobacco companies.

So my patients who are really struggling with health systems and insurance companies who have denied them all their medical needs, are puzzled by this strange marriage. Is this marriage financing the whole discussion about physician-assisted suicide? Maybe as with the tobacco companies, we will have to wait forty or fifty years to find the answer to that question.

A patient of mine related to me this concern in the best way possible. She said:

I wonder how insurance companies are financing this discussion and manipulating at some very subtle level the minds of Americans. It seems that with the new pro-tease inhibitors we're too costly to keep alive, and they are trying to buy our conscience by using the language of merciful killing, dying with dignity, and so on and so forth. You know Rev., that can be a very politically-oriented language, too. Some one can say to you: Oh, you know, be gentle to yourself, die with dignity and in the peace. Yeah! I translate that as: You cost us half a million dollars. So think about dying with dignity in the presence of the Lord, and we will get you a nice Chaplain that will help you die with dignity and pray with you.

*Locus or locus of control.* Again, by locus I mean where the power to decide resides. When we are talking about physician-assisted suicide, are we asking or expecting doctors to decide for us, or are we keeping the decision-making process in the hands of the person who is choosing this option? If so, are we going to have in place a number of safeguards that will ensure the appropriate practice of physician-assisted suicide?

Because we have not been there yet, we need then to look into how others who have legalized this practice have succeeded in what we are just beginning to do here. Obviously, the places to visit are the countries in which the practice has been established. In this case the Netherlands is the best candidate.

Tony Snow from The Detroit News comments that when doctors in Holland were authorized to euthanize the sick, they designed strict standards to ensure that the locus of control in deciding physician-assisted suicide was "prudent" and ethical.<sup>51</sup> However, "protocols" came into tension with issues of human indifference. The protocols' red tape was bypassed within six years. Consequently, the Dutch medical community

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<sup>51</sup> Tony Snow, *Comment: Assisted Suicide a High-risk Issue*, DET. NEWS, Oct. 8, 1996, at A7.

had abandoned most of its so-called "guidelines." "A stunning study in 1990 discovered that doctors that year killed 2,300 patients who wanted to die, assisted in the suicides of 400 others—and did away with more than 1,000 others who never asked for fatal 'help.'"<sup>52</sup> Victims included everybody from handicapped children who had stomach aches to accident victims who doctors figured would be too expensive to keep alive and, therefore, were given lethal injections without the knowledge or consent of family members. Moreover, it was found that the right to die curdled into something far more appalling. What began as an attempt to humanize suffering and death with compassion evolved from benevolence in understanding the needs of the ill, to being annoyed by the sick, to finally, impatience for the sufferers. It is suggested that for a period of time, most requests for euthanasia in the Netherlands came not from patients, but from their families. Mr. Snow adds that if a parent seems less vibrant and more expensive than they did in the good old days, Dutch kids get on the phone and summon the angels of death.<sup>53</sup>

A 1995 study of the practice of physician-assisted suicide and euthanasia in the Netherlands suggests that during the past two decades, the Netherlands has moved to a point of giving legal sanction for euthanasia not only of the terminally ill, but also of those who are chronically ill and those with psychological distress.<sup>54</sup> The study also suggests that while involuntary euthanasia is not legally sanctioned by the Dutch, almost 20 percent of the physicians' cases of euthanasia reported in this 1995 study involved ending a life without the patient's consent.<sup>55</sup>

Clearly in both cases what started as a dignifying process to alleviate the suffering of the ill ended in abuse of power. Why? Because the locus of control shifted from the patient to the doctors and others who decided to euthanize the patient disregarding the established guidelines and protocols. So, what makes us think that something similar will not occur in the USA? In fact, a parallel situation has already happened here in the States. Just consider what happened at Tuskegee. The locus of control was not in the hands of the patient, but in the hands of doctors who responded to an institutionalized attitude towards black men and used them as guinea-pigs in syphilis studies.

Because I am skeptical about how our society will handle these issues, I will respect in specific cases a person's right to choose assisted

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<sup>52</sup> *Id.*

<sup>53</sup> *See id.*

<sup>54</sup> *See* Herbert Hendin et al., *Physician-Assisted Suicide and Euthanasia in the Netherlands: Lessons From the Dutch*, 277 *JAMA* 1720, 1720 (1997).

<sup>55</sup> *See id.* at 1721; Joseph P. Shapiro, *Euthanasia's Home: What the Dutch Experience Can Teach Americans about Assisted Suicide*, *U.S. NEWS & WORLD REP.*, Jan. 13, 1997, at 24.

suicide. I can also respect a doctor's choice of facilitating that process, but I am not ready to consider institutionalizing the practice.

Essentially, and finally, the issue of the locus of control is very important for me. Will you place the decision-making power, externally or internally? Is it mine, the doctor's or someone else's decision to make? Where will the power reside?

I do not think that American society is so foolish as to place this decision-making power in the hands of doctors, or medical institutions or insurance companies alone. History is filled with bad scenarios when you place such power in someone else's hands.

I respect a person's decision in this process. But because I am a Hispanic person, and because I work with patients whom the medical and health insurance systems manipulate and oppress, I can endorse the concept of physician-assisted suicide, but I have to be very suspicious of it at the same time.

So, because I am not clear of where the ethos and the locus of this whole discussion are, I have a problem of dislocation. I want to respect the right of any person to choose the way that he or she wants to live and die, and I want to respect the doctors who will choose to follow that decision. If somebody calls me to facilitate the process as a clergy, I will be present. I will be there, but I cannot vote in favor of legalizing this process, not now.

There is an issue of equality that has not been resolved. There are too many voices that we are not listening to. There are too many people that are, politically speaking, handicapped. They are, politically speaking, disabled, and they are not in the process. I think that this is a good time to test democracy, and I think this is a good time also to test our political ability to dialogue as a nation. But it cannot happen until we listen to those who do not have a voice in this "debate."

A final recommendation. Since the minorities of this nation, their values and their worries on this issues are not listened to, I will suggest, and can only dream, that funding be allocated to replicate this event for the African-American, Hispanic, Native American and other minorities in their native languages, according to their needs. Only then we will be able to speak and decide as a nation, and mirror eloquently to the rest of the world, how to be inclusive in a process of this nature. Suicide is a terminal decision and it needs to be considered seriously.

Thank you for your attention.

DR. STRAX: I have one comment. The largest minority group in this country is women. If men had babies, if they had breast cancer, we would see different kinds of health care.

The second largest group in this country is the physically disabled. If all men were disabled, we would see a different kind of health care.

What has happened is the masses have been able to keep the minorities separated. If the minorities recognized that they were minorities and got together, we would have a different health care system. Go and do it.

AUDIENCE MEMBER: I have a question for Dr. Weir. I am a disability rights activist.

My question for you is, in evaluating quality of life, what about the fact that physicians routinely undervalue the quality of life of the disabled and the fact that almost everyone I know in the disability rights movement has been told, including myself, at one time or another that we wouldn't live through the night; that we were dying. I was supposed to die when I was five weeks old. That was more than twenty years ago, I promise. So, how do you evaluate those kinds of errors or, you know, realities, into the equation that you are putting together for quality of life?

DR. WEIR: I think it's clearly true that physicians and, for that matter, other health professionals in this country are largely not well-trained to assess pain. I also indicated earlier that physicians and other health professionals and a lot of us have not been adequately trained to understand persons within the disability community, and life with disabilities that we may not have.

The format that I proposed was one that would apply to a patient, an individual doing his or her own quality of life assessment. If that's done in conversation with the physician, it would seem to be clearly in that person's best interest, if that patient is disabled, to factor in this expectation that the physician may undervalue the kind of life that is being assessed.

AUDIENCE MEMBER: I work for the National Council on Disabilities. I do not have a medical background at all, but I wanted to ask Dr. Emanuel a question. Do you think physicians should be trained in pain management?

DR. EMANUEL: Pain management was in the first category of areas I mentioned, in which doctors are to be trained on how to manage symptoms of the dying. There are some twenty very common symptoms of the dying. Pain is most certainly one of them.

AUDIENCE MEMBER: I represent Psychiatric Survivors. I have heard the word depressive used here all afternoon as though it's a medical condition. I want to state my strong objection to pathologizing what I would consider normal feelings, especially for people who have debilitating, and maybe life-threatening conditions. I also happen to live with cancer. If you had cancer, you would be depressed, too.

I'd also point out to you that what happens to people when they do try to commit suicide can be worse than death itself: to be locked up, to be strapped down, to be thrown into rooms without clothing, to be

drugged with drugs that are very dangerous and debilitating, and to be labeled for the rest of your life for the crime of having thought about killing yourself. For me that is worse than death. I don't know if you have thought through these things, but many of us have. They are very important issues and we are the largest group of disabled people in America.

DR. STRAX: In fact, your issue and the one on pain go together. Many people who have major changes in their ability go through major depression requiring treatment.<sup>56</sup> Most medical schools do not really push this issue. Even in many rehabilitation centers, you will not find patients being treated properly for major depression.

Same with pain. There is a society called the American Pain Society, which is a professional society, that had as its mandate this year to develop clinical pathways in dealing with pain, both acute pain and cancer pain and post-operative pain and chronic pain from cancer and back pain, et cetera. I believe this is an undertreated area, and only through the demands of huge numbers of people in need of these kinds of treatments will we get professionals to change.

It is true that the HMOs do not wish to deal with this because an HMO is interested only in limited situations. They don't want people who are going to continue needing something because that means they will lose money. There is a need for a national program to look at health care, to look at disincentives, to look at the way people are discredited, and maybe to look at the fact that we don't pay for it in the healthcare system. All we're doing is cost shifting. That means if you don't take the thirty-five year old woman who is disabled with two kids and treat her, then all you do is put her in a wheelchair. If you do treat her, or treat the cancer patient, they will go back to work.

AUDIENCE MEMBER: With all due respect, sir, you totally missed my point. The point is not to diagnose people who have feelings with diseases like depression for which the treatment is forced medication. Because that's all HMO and managed care companies will pay for. They don't pay for this wonderful minister to come sit and talk to me. Oh, no. They will pay for Prozac. You all laugh because every single person in this room knows someone who is taking Prozac. You all laugh because you all know somebody who took Valium in the '80s and Ritalin in the '90s for kids and Miltown in the '50s.

You know, this is pathologizing the human condition. Sadness, feeling bad because you are sick; these are normal responses to normal phenomena, which do not need psychiatric interventions, especially unwanted psychiatric interventions.

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<sup>56</sup> See *Assisted Suicide Hearing*, *supra* note 47 (statement of Lonnie R. Bristow, M.D.).

DR. EMANUEL: You are absolutely correct, that to pathologize normal feelings would be wrong and is wrong when it happens, and unfortunately it does happen too much. There are very clear clinical ways to distinguish between situation appropriate sadness—even to the point of feeling that life is not worth living—and depression, which disorders one's thinking.

However, it's worth going through some of the cases that were well described by Dr. Weir and asking whether those really are situations in which death is preferable or assisted suicide is necessary. Because we have considerable—extensive, actually—ability to control the way in which we die now, we have the ability to withhold and withdraw life-sustaining intervention, and to provide aggressive comfort care. We're just beginning to teach physicians exactly how to provide that.

So although I completely agree with you that we should not pathologize what is normal, don't let us make that an endorsement of assisted suicide.

DR. MORREIM: Tying together several of the things that have been said today, I want to observe that much of my research and writing concerns the changing economics of health care. As Deep Throat said to Woodward and Bernstein during the Watergate era, "follow the money." In this case, careful analysis of the financial structures behind our health care institutions can reveal remarkable insights into our ethical challenges.

Reverend Rodriguez very correctly pointed out that minority people in this society are not ordinarily frightened of getting too much medical care. Rather, health care money has been directed heavily toward the "mass society," rather than toward minority groups. I like that expression. The money has been so lavish that people in my community have actually been subjected in many instances to excessive health care, to the point where Caucasians sometimes must beg, plead, and find a lawyer to say "please back off" from unwanted interventions. Numerous court cases, from Karen Quinlan and on, feature well-insured Caucasians who have been subjected to interventions they did not want—forcibly in a number of cases—and who were compelled to resort to litigation to secure their autonomy and freedom. Not surprisingly, the excess medical care is where the generous funding has been, and it is there where people have had to fight against excess. Reciprocally, people who receive too little care are fighting the battle for more care, not for less.

I'll turn now to the question of why physicians seem to underdiagnose some of the problems that disabled persons face, and why they don't always seem to understand important facets of a disabled person's quality of life. Here, too, "follow the money." In medicine, research hitherto has not focused very much on ordinary people with ordinary

problems, or on quality of life issues. Thus, we have not spent huge sums on how to make a person with, say, rheumatoid arthritis, maximally functional.

There are some fairly clear economic reasons for this. Until recently health care companies, particularly manufacturers of drugs and devices, made money by developing exciting new toys. After all, as soon as a new drug or device is approved, it is almost automatically paid for by insurers. That is, government approval of a new intervention as “safe and effective” almost automatically renders it mandatory, i.e., “medically necessary,” so that health care insurers must cover it. And so, of course, the economic incentives have favored development of exotic new technologies, rather than any steady study of mundane maladies or quality of life concerns—despite the importance of these to so many people. If a company can develop and sell a fancy new device or a costly new drug that will dramatically save lives and earn you money, they will be significantly rewarded.

Similarly, physicians had incentives to focus on exotic conditions. They are much more likely to receive promotions, lab space, research grants, and public recognition for dramatic life-saving discoveries than for cheerful care of more ordinary problems. Likewise, we have focused our medical education on the “interesting” or exotic case, not on making life easier for the vast number of people in this country who are struggling daily against a chronic illness or a disability.

Only recently has it become highly important for health plans to learn how to save money, how to do better by doing less. Hence, only recently do we see a plethora of “outcomes studies,” clinical guidelines, and other measures directed at the care of ordinary patients with routine problems. Medicine is now being rewritten, from the ground up. It will take time, but the money we “follow” is now heading towards people whose needs have traditionally been underrecognized.

From this point I’ll move to psychiatric care, which was the focus of the question from the audience. For a number of years, very large amounts of money went into mental health care, particularly the inpatient care of psychiatric patients. So long as that was true, a wide array of life problems and emotional difficulties were identified as mental illnesses or disorders—they were “pathologized,” as the audience member pointed out, and many psychiatric hospitals and other providers made vast profits. Now, however, funding for mental health care is considerably scarcer. It should come as no surprise that as the money shrinks, we are witnessing some reduction, not just in the array of diagnostic categories, but more importantly in the frequency with which mental health diagnoses are being ascribed. If excessive pathologizing and unwanted interventions were once the problem, it is my prediction that this will subside,



giving way to the opposite problem: insufficient care for people with very real disturbances who could benefit from the help.

DR. KIRSCHNER: Thank you.

### III. SESSION THREE: KEYNOTE: KEVORKIAN AS FOLK HERO

MR. VAN ZANDT: I'd like to welcome everyone. My name is David Van Zandt. I'm the Dean of Northwestern Law School. I am extremely proud to be one of the hosts for this event. I think it's an extremely important event, an event that plays very well to some of the strengths here at Northwestern University, namely, the medical school, the Rehabilitation Institute, and the law school. I'm extremely proud to be part of this event.

I would also like to thank both Kristi Kirschner and Leigh Bienen who played a lead role in organizing this conference. I think they put together a fantastic conference. Finally, I'd like to thank all of you for coming. I have met some of you. I look forward to meeting more of you. Again, I just want to welcome you and hope you have an exciting day. Thank you.

DR. KIRSCHNER: Good morning and welcome back. We have a very exciting day today. We're going to start this morning with Mr. Joseph Shapiro. Joseph Shapiro comes to us from Washington, D.C., where he is a Senior Writer for *U.S. News & World Report*, covering social policy issues for the magazine since 1987.

Joe Shapiro won the Alicia Patterson Foundation Fellowship in 1990 which he used to study the history of the civil rights movement as it relates to people with disabilities. He is the author of the award-winning book *No Pity: People With Disabilities Forging a New Civil Rights Movement*. I personally think this book should be required reading for all health care providers.

Joe currently holds the Kaiser Media Fellowship in Health and is using the fellowship to study long-term care and aging issues. Joe has written for *U.S. News & World Report* on a wide variety of social policy issues, including physician-assisted suicide, gay and lesbian issues, churches and charity, teen pregnancy, and the Kennedy assassination.

He has received numerous awards for his writing, including honors from the Society of Professional Journalists at Harvard University's Joan Shorenstein Center on the Press, Politics, and Public Policy and the Unity Award for coverage of civil rights and the disadvantaged.

Of course, I can't properly introduce Joe without mentioning our common bond as alumni of our beloved liberal arts college in Northfield, Minnesota, Carleton College. It is my privilege and pleasure to introduce to you Mr. Joseph Shapiro.

MR. SHAPIRO: Thank you very much.

In Washington D.C. where I live, we put great faith in pollsters and polling. President Clinton, the first Democratic president since Franklin Roosevelt to be elected to two consecutive terms, has an approval rate right now at about 54 percent.<sup>57</sup> The Speaker of the House, Newt Gingrich fares a lot worse. His approval rating now is 25 percent.<sup>58</sup> So 24 percent for Newt Gingrich; 54 percent for President Clinton. There's also polling on Jack Kevorkian. His approval rating is higher than the rating for Bill Clinton, twice as high as that for Newt Gingrich. Between 52 and 58 percent of Americans say they approve of Jack Kevorkian assisting people who want to commit suicide;<sup>59</sup> and about three-quarters of Americans, whether they approve of Kevorkian's methods or not, say they believe that a terminally ill person should have a right to assisted suicide.<sup>60</sup>

So whatever you think about Bill Clinton and Newt Gingrich, I think there's something very striking about the fact that more people approve of Jack Kevorkian because Kevorkian, as Americans know, is a bizarre man on the fringe of medical practice. This is a man who got the nickname Dr. Death because as a medical resident he pushed around a bulky mounted camera so that he could take photographs of people's eyes at the moment of death. He would tape open the eyelids of a dying patient and then focus his camera. This is a man who experimented with transfusing blood from corpses into live patients. One friend of Kevorkian's got such a bad case of hepatitis from cadaver blood that his eyeballs turned orange.

You may have read a few weeks ago that Dr. Kevorkian had a show of his art that opened in Michigan. He is a talented artist, but his paintings are gruesome and disturbing. He has pictures of severed heads and cannibalism and maggot-filled corpses. On some of the paintings on the picture frames he has used his own blood to stain the picture frames. And his take on Christmas is less than cheery. In one painting you see Santa Claus's boot coming down a chimney, but this is not exactly the traditional image of jolly Saint Nick because in this one Santa's boot is

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<sup>57</sup> See *President Clinton's Job Performance*, GALLUP ORGANIZATION (visited March 18, 1998) <<http://www.lib.uconn.edu/RoperCenter/clintgal.htm>> (listing President Clinton's approval ratings from January, 1993 to the present).

<sup>58</sup> See Chris Black, *Stalled House is Grousing: Gingrich Faces GOP Ire on Return From Recess*, BOSTON GLOBE, Apr. 6, 1997, at A1.

<sup>59</sup> See ROPER CENTER AT UNIVERSITY OF CONNECTICUT, Dec. 15, 1993 (52 percent approved of Kevorkian helping terminally ill people who want to commit suicide); ROPER CENTER AT UNIVERSITY OF CONNECTICUT, Dec. 6, 1993 (58 percent approved of Kevorkian helping terminally ill people who want to commit suicide).

<sup>60</sup> See Judy Foreman, *Assisted Suicide Seen Gaining Favor*, BOSTON GLOBE, Feb. 1, 1996, at 3; Jeff Hooten, *The Fatal Attraction of Dr. Death: Kevorkian's Bizarre Ideas Gain Frightening Support*, RECORD (Bergen County, N.J.), Sep. 23, 1996, at A15.

crushing a baby lying in the fireplace. So, this is a weird man on the fringe of medical practice, and yet Americans seem to approve of what he does. We give him celebrity, and we give him honor.

At the end of last year, pollsters for *Newsweek* magazine asked Americans to vote for the newsmaker of the year in the sciences. Kevorkian was chosen as the man who in 1996 had done the most for the sciences. He beat out David Ho, America's leading AIDS researcher. Now, *Time* magazine put David Ho on the cover as the person of the year; but when the choice was put to the American people, *Newsweek* magazine readers by a wide margin picked the inventor of the suicide machine over the man who was finding cures for AIDS.<sup>61</sup>

In Michigan, Kevorkian's home state, people seem particularly tolerant: 73 percent of the people in Michigan think that prosecutors should quit taking Kevorkian to trial.<sup>62</sup> Last year, voters defeated the prosecutor who has brought Kevorkian to trial, and they voted in another prosecutor who said that he wouldn't bother.

Just this week you may have seen Larry King's column in *USA Today* in which he had one of those epigrams of his that seem to come out of nowhere: he praised Dr. Kevorkian and said, "Nobody agrees with what Jack Kevorkian does except the majority of the U.S.A."<sup>63</sup> That's actually sort of a nice way of summing it up. Nobody agrees with what Jack Kevorkian does except the majority of the U.S.A. Jack Kevorkian, this overzealous pathologist, makes us uneasy, and yet Americans think he's doing a good thing. We cheer him on despite this quirky, messianic campaign of his. We cheer him on, yet we make fun of him at the same time.

He's become a staple of David Letterman's Top Ten List. In Letterman's top ten promotional slogans for the suicide machine, he had things like: "Just try it once, that's all we ask." Or, "If you're not dead in thirty minutes, it's free." So what's going on that this bizarre man gets a higher approval rating than the President of the United States or the Speaker of the House? Now, this may speak to our cynicism about politicians, but that's a matter for another conference.

There are a couple reasons for Kevorkian's popularity. Reason one: modern dying has become something that we fear. Doctors now possess the technology to forestall death almost indefinitely. Too often patients' wishes get ignored. Living wills and advanced directives are ignored. Doctors are reluctant to talk to patients about dying. Too often the terminally ill suffer needless pain; they're kept alive with no hope; and fami-

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<sup>61</sup> *The 100 Newsmakers of 1996*, NEWSWEEK, Winter 1997 (Special edition), at 4.

<sup>62</sup> *Michigan Poll Backs Kevorkian*, NEWS & OBSERVER (Raleigh, N.C.), June 30, 1996, at A9.

<sup>63</sup> Larry King, *Larry King's People*, USA TODAY, Apr. 7, 1997, at 2D.

lies hold a harrowing deathwatch. So Kevorkian becomes a hero because he promises control over this nightmarish vision of death.

Reason two: we're becoming a chronic disease nation. About one in four Americans have a chronic medical condition. It actually depends on which survey you're looking at, what you're counting as a chronic medical condition; but the important point is that most of us will die of chronic progressive illness, usually one that gradually worsens over the years before we die.

That's very different from the way of death just a few generations ago. At the turn of the century the average life span was about forty-nine years.<sup>64</sup> At the beginning of the century, people died from accidents; women died in childbirth and infant mortality rates were high. Now, most of us will live to an old age. The median life span is now about seventy-six years old.<sup>65</sup> Two researchers recently estimated that half the people in the United States, half the people in this room, would not be alive today if the mortality rates were still at 1900 levels.<sup>66</sup> Antibiotics and medical advances have allowed us to live to old age, but as we live longer, our bodies wear out, our arteries clog, our sight, our vision, our hearing diminishes. I've seen one number that about half the people eighty-five and older have Alzheimer's or some form of dementia. The eighty-five-year-plus population is the fastest growing age cohort in our country.<sup>67</sup>

Just look at nursing homes. It's very different than it was a generation ago. There are different estimates, but between 50 percent and maybe 60 percent of people who live in nursing homes now have some form of dementia.<sup>68</sup> So we have become a chronic disease nation, and it scares us. It scares us because we know that as the life span expands, so does our chance of living with chronic illness and disability. As people in this auditorium know, we live in a society that is afraid of aging and very afraid of disability.

By the way, baby boomers are the most skittish about aging. One poll recently showed three out of four boomers think that they look younger than their age.<sup>69</sup> Statistically it's not possible, but eight out of ten boomers think that their faces look younger than the faces of other

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<sup>64</sup> See Brad Edmondson, *The Facts of Death*, AM. DEMOGRAPHICS, Apr. 1997, at 47.

<sup>65</sup> See Richard E. Coleson, *The Glucksberg and Quill Amicus Briefs: Verbatim Arguments Opposing Assisted Suicide*, 13 ISSUES L. & MED. 3, 5 (1997).

<sup>66</sup> See Diane Crispell, *Lucky to be Alive*, AM. DEMOGRAPHICS, Apr. 1997, at 25 (discussing research of Kevin M. White and Samuel H. Preston).

<sup>67</sup> See Mary Leonard, *Boomers Try to Stop Time at 50, Many Deal with Aging by Seeking to Redefine it*, BOSTON GLOBE, Oct. 5, 1997, at E1.

<sup>68</sup> See Pearl S. German et al., *The Role of Mental Morbidity in the Nursing Home Experience*, 32 GERONTOLOGIST 152, 156, 158 (1992).

<sup>69</sup> See Tamara Henry & Karen S. Peterson, *Academic Standards Agency to be OK'd*, USA TODAY, July 16, 1996, at D8.

people their age.<sup>70</sup> So you can imagine how boomers feel about chronic illnesses and disabilities and the things that go along with aging.

Assisted suicide advocates talk about offering assistance to the terminally ill, but two-thirds of the people whom Jack Kevorkian has helped die were not terminally ill. Instead, they had chronic conditions. They had things like Multiple Sclerosis, Alzheimer's and spinal cord injuries. According to a recent survey, at least seventeen of the forty-seven people he has helped to die could have lived indefinitely, and in thirteen cases the people had no complaints of pain whatsoever.<sup>71</sup>

So I want to talk a little bit today about the myths about physician-assisted suicide, public myths, media myths, what they are, why those myths exist, and if they are myths, then what is the reality. So let me identify four public and media myths about assisted suicide. Myth number one, I think, is the legend of the heroic individual. By this I'm referring to the notion of the terminally ill person being seen as somebody who is making a deliberate choice in seeking assisted suicide; and in doing so she or he is seen as taking a courageous and a heroic action to control dying. This is an American archetype, not just a journalistic one. This is the American hero, the American individual making sense out of the lawlessness, out of the wilderness of death; the American, the rugged individual, standing up for himself, standing up for what's right, standing up for freedom and the civil rights of others, standing up against a cold and uncaring medical system, and taking on what is most fearsome to others.

So Kevorkian casts himself as one of these heroes on the edge of the law, but correcting an unjust and corrupt medical system, and Americans are inclined to agree. There's this belief we have in that kind of individual. Journalists play into this notion. We play into it in the way we present right-to-die patients. So let's talk a little bit about why that myth exists and how journalists and the public miss the reality.

First, the journalist is a witness. We tell stories; we look for stories that are moving, stories that are compelling. We depend on case studies. Jack Kevorkian understands this. He understands the need of journalists to bear witness, to see what they portray, particularly television or news magazines which depend very much on images, pictures.

That's one reason why Jack Kevorkian tapes; he videotapes the people who come to him asking for death. He will tape them carefully or passionately explaining why they have come to him, why they feel their lives are not worth living, why they want this extraordinary act of assisted suicide. The first trial that Kevorkian faced was for his role in

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<sup>70</sup> See *id.*

<sup>71</sup> See *Dr. Death's Chronology*, UNITED PRESS INT'L, May 14, 1996; *The Kevorkian Files*, NEWSDAY, Sep. 8, 1996, at A49.

assisting a thirty year-old man named Thomas Hyde who had ALS—Lou Gehrig's disease. Just before the trial, Kevorkian released tapes of Hyde to some filmmakers, and it led to an extraordinary moment on the PBS documentary program *Frontline*.

Here was Thomas Hyde, this man that we had seen in pictures, ruggedly handsome, athletic, an all-American hero. Now he was gaunt and paralyzed. He was barely able to speak; and he choked out his words very slowly on the videotape. He said, "I want to end it. I want to die."

There was something epic about Thomas Hyde's story. Here was this young man and now he had ALS, this horrible disease. Thomas Hyde, we learned, liked to work outdoors; liked to work with his hands. He was a construction worker; a landscaper. He enjoyed rock climbing, hiking, and camping. Then one day at work he has trouble holding onto his hammer, he starts losing his balance, he falls off his motorcycle. The disease progresses quickly. He can't lift his infant daughter. Within a year he lost the ability to walk. He lost the ability to speak clearly, and he knew he faced a difficult death. Even in death, Thomas Hyde turned out to be Jack Kevorkian's strongest witness because at the trial they played this videotape of Thomas Hyde requesting death, and several jurors wept openly in the courtroom. There was no sign in the videotape that Thomas Hyde was being coerced. There was no sign that he was asking for something he really didn't want. He said he had given the matter careful thought and that he wanted to die.

What is more mysterious than the act of killing oneself? Suicide is considered a sin, a crime, a sickness; and now here was somebody claiming it as his right. Thomas Hyde was cast as taking this heroic stand against death. But there was something less than heroic in the way he died: on a mattress in the back of Jack Kevorkian's rusty Volkswagen van parked in an alley behind Kevorkian's apartment. At the trial, Kevorkian played into these public views about heroes who defy the law. Kevorkian got on the stand, and he compared himself to Ghandi, willing to go to jail to win freedom for others. Kevorkian's lawyer drew parallels between Kevorkian and the heroes of the civil rights movement. He drew parallels between the prosecution of Kevorkian and the persecution of Jews, Catholics and gypsies in Nazi Germany. But mostly Kevorkian and his lawyer talked about Thomas Hyde and his right to the death of his choice; and these arguments resonated with the jury. Kevorkian was very quickly acquitted. One juror said, "I believe Dr. Kevorkian is doing the right thing, but he's not necessarily going about it the right way." There's King's epigram again: "Nobody agrees with what Jack Kevorkian does, except the majority of the U.S.A."<sup>72</sup>

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<sup>72</sup> King, *supra* note 63, at 2D.

So the myth is that we've got these heroic individuals fighting so that all of us can control death, fighting for the right of all of us to choose how we die. That plays into these very celebrated American models of American individualism, and it plays into journalism's need to witness compelling stories.

So what's the reality? Well, I think it's very different. Thomas Hyde was an exception. He wasn't a model. What got lost at Kevorkian's trial was the rarity of Thomas Hyde's choice. Dr. John Bach teaches at the University of New Jersey Medical School, and he studied people like Thomas Hyde. He studied people with the most debilitating and frightening disabilities. Dr. Bach did a study of eighty-nine people with ALS, the same disease as Thomas Hyde's, but Dr. Bach talked to people whose ALS was even more advanced than Thomas Hyde's. He talked to people who were already using a respirator. Of the eighty-nine people with advanced Lou Gehrig's disease surveyed by Dr. Bach, only two out of those eighty-nine said that they regretted being alive, only two out of eighty-nine said they regretted being on that respirator.<sup>73</sup>

So exceptional cases like Thomas Hyde's end up spreading misconceptions that people with chronic conditions and disabilities want suicide. These case studies that we love as journalists and we love as readers, spread the misconceptions that the desire for death is logical and it's usual and that, therefore, the most compassionate thing that society can do is to provide people like Thomas Hyde with a way to end their lives.

Now, Dr. Bach conducted another fascinating study. He found that doctors almost always underestimate their patient's desire to live. In the second study, Dr. Bach surveyed six-hundred adults with advanced neuromuscular conditions that required them to use a ventilator. All the six-hundred respondents were people on ventilators. He asked them whether they were satisfied with their life as a whole. Then he went to the doctors and nurses who worked with these six-hundred adults on ventilators and asked them: what would you predict these six-hundred patients said about whether they were satisfied with their life as a whole? The results were surprising, and they fly in the face of this idea of the heroic individual facing disability and wanting death, the image of assisted suicide that's portrayed by Kevorkian and a compliant press. In Bach's survey, 82 percent of the severely disabled people said, "Yes, we're satisfied with our life as a whole."<sup>74</sup> That is 82 percent. But only 24 percent of the doctors and nurses guessed or predicted such positive answers.<sup>75</sup>

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<sup>73</sup> See Joseph P. Shapiro & David Bowermaster, *Death on Trial: The Case of Dr. Kevorkian Obscures Critical Issues - and Dangers*, U.S. NEWS & WORLD REP., Apr. 25, 1994, at 35.

<sup>74</sup> *Id.*

<sup>75</sup> *See id.*

Here's what Dr. Bach concluded. He told me: "Doctors assume that because they wouldn't want to be disabled themselves, their patients wouldn't want to be disabled, and that therefore their patients are better off dying." But Dr. Bach added, "Patients almost never feel that way themselves." It's often assumed that it's the elderly and the disabled who clamor for assisted suicide; but if you look closely at the polling, it turns out it's the young and the healthy who support this. One Harvard study showed that 79 percent of people age eighteen to thirty-four believe a physician should be allowed to give lethal injections to the terminally ill, but only 53 percent of older Americans agree.<sup>76</sup> As Dr. Rodriguez noted yesterday, the right to die is a matter of civil rights for white affluent people. He said that the poor and minorities worry more about not getting access to health care.

So when journalists present compelling case studies like the story of Thomas Hyde, we often fall into the stereotype that to be severely disabled is a fate worse than death. Journalists reflect the reality of our own fears rather than the true wishes of people who face chronic illness or even a difficult death.

Myth number two: We fear that death is inevitably painful and inevitably undignified. What's the image of the dying process that we get in the press and in the popular media, television shows and movies? Well, either you get shot by some crazed gunman or you die a natural death, which frequently means being hooked up to some beeping, wheezing life-support machine. It means being kept alive by a machine for months on end in the intensive care unit of some cold and sterile hospital. Why does this myth exist? Well, partly it's because medicine today can and sometimes does needlessly forestall natural death. It exists because some people do die in pain. But most do not die in pain; that so many do is a reflection of poor medical practice.

One survey of patients with metastatic cancer found that of those that had pain, 42 percent were undermedicated.<sup>77</sup> There are many reasons that doctors fail to control pain. They are not taught how to use drugs effectively. They fear falsely that they're going to turn their patients into drug addicts. Or they fear falsely that they will knock them into drug-induced stupors. Or they fear that their use of pain control medicine will get them in trouble with the law.

Much of the journalism about the rare people who seek assisted suicide depicts these people as being in a race against pain; it depicts them as being in a race against an undignified death. The most recent case was the story of a man named Noel David Earley, another younger man,

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<sup>76</sup> See *id.* at 39.

<sup>77</sup> See Robert J. Blendon et al., *Should Physicians Aid Their Patients in Dying?*, 267 JAMA 2658, 2659 (1992).



forty-seven years old, with Lou Gehrig's disease. His death became a public spectacle. He invited ABC's Nightline and other reporters to watch him die. The first newspaper story about Noel Earley's plan carried this headline: *Fatally Ill Man Wants Freedom to Choose Death*.<sup>78</sup>

This first story in Earley's hometown newspaper in Providence, Rhode Island started out predictably. It started by talking about the progression of his ALS, how he first noticed something was wrong when he tried to stand on tiptoes to get a book from a bookshelf and couldn't stand on his toes. The story then went on to talk about how he lost the ability to play the piano and how he knew that soon he would have trouble moving. Let me just quote a bit of the story:

Through it all, his maverick mind will remain alert. Now Earley, 47, wants to make his choice: He wants to choose the moment and method of his death. He wants to avoid the last stages of his disease, the drooling, the indignity, the total dependence. He wants, at a certain point in the coming months, to kill himself with a doctor's help.<sup>79</sup>

So again, the story of Noel David Earley gets told in these epic proportions. Dying man has a simple request: He wants the freedom to control his death. He wants a death free of pain. He wants a death that's free of the indignity of disability.

Now, a couple of things made this tale a little different than the way it was depicted. First of all, Earley didn't really need a right to suicide. Like many people who insist on assistance in dying, they do find willing medical professionals, doctors, nurses, and others, who privately help them die. In this case, an unnamed medical professional had provided Noel Earley with a needle, syringe, and drugs. A second thing that made this case different from the way it was portrayed, is that Earley never exercised his right to die. Perhaps it can be argued that having the lethal drugs by his bedside gave him some peace of mind, but Earley died peacefully in his sleep.

So we hold this belief that death is inevitably painful and undignified, and this belief persists in part because of advances in technology and in part because of the failures of doctors to provide adequate pain control. It exists partly because of the way that journalists and the popular media depict death. But once again, the reality is very different. Most people spend the bulk of their final days in their own home in the company of friends and family. I'm referring to a study that was done of

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<sup>78</sup> Felice J. Freyer, *Fatally Ill Man Wants Freedom to Choose Death*, PROVIDENCE SUN-  
DAY J., Mar. 3, 1996, at A1.

<sup>79</sup> *Id.*

older people dying in Connecticut. About one-third died at home, and almost half were transferred to a hospital or a hospice shortly before dying. Nine out of ten saw their family, friends, relatives within the last three days of their life. Most died fully aware of their surroundings; most died without pain; more than half died peacefully in their sleep.<sup>80</sup>

In most cases, their health did not decline until close to the end of their lives; more than half were in good or excellent health a year before their death; about one quarter were in good physical condition in the month before their death; 61 percent had no pain the day before they died; 52 percent could breathe freely the day before they died; and 69 percent needed no medication the day before they died; 62 percent were upbeat, not depressed in the last month of life.<sup>81</sup>

So when journalists write about dying as something inevitably painful and undignified, once again, we're speaking more to our own fears than to reality. The problem with such writing about death is that we end up arguing the wrong point. There's a danger when public attention becomes so focused on whether there should be a right to socially-assisted dying. There's a danger that we end up debating whether we should help people commit suicide when what we really ought to be discussing is how do we take the physical pain, the emotional suffering, and the financial ruin out of dying. There's a danger that in our rush to establish a right to assisted suicide, we overlook or we underfund or we stall these important first solutions: providing better access to health care, developing good hospice and home care, and understanding aggressive pain control.

Public policy ends up getting driven by a handful of compelling and extreme cases. We have policy by case study, some extreme compelling cases of sick people, people perhaps who are depressed declaring that they choose death. Instead we should make policy based on the more common cases that speak to more universal needs.

Myth number three: Seeking death is a rational choice. Now, this fits in again with our image of the heroic individual choosing death. We think, "I wouldn't want Lou Gehrig's disease," or "I wouldn't want to have Alzheimer's disease," or "I wouldn't want to live in a nursing home"; so we assume that somebody who is facing disability or illness who wants to die therefore is making a rational choice.

One of the first criminal charges, by the way, against Jack Kevorkian was dropped. The Detroit trial judge felt that it made sense that Donald O'Keefe, a seventy-three year old man with terminal bone cancer, would want assistance in dying. The judge termed O'Keefe's ac-

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<sup>80</sup> See William Booth, *Most Elderly Go Gently*, WASH. POST, July 22, 1991, at 43.

<sup>81</sup> See *id.*

tions rational, and he ruled that the state law banning assisted suicide was too broad. Journalists, judges, and the public assume that when someone is disabled or terminally ill, and they say they want to die, that a rational decision is being made. But that's usually not the case. In fact, sometimes it takes a person with a disability to see that someone who is asking for assistance in dying is often depressed.

Historian Paul Longmore has pointed out things about Elizabeth Bouvia's case that journalists miss.<sup>82</sup> She was one of the first cases of a disabled person seeking a right to die. This was a woman with cerebral palsy. Hundreds of thousands of people live with cerebral palsy and live good lives, but she said that it was too much for her and that she wanted to die. Now, Paul Longmore points out that her marriage had broken up. She was financially troubled. She had been forced to withdraw from graduate school. A judge said she should be helped to die, given what he called her helpless condition.<sup>83</sup>

But Bouvia was far from being helpless. She was far from being this helpless woman that is described by the court. As Longmore noted, Bouvia was "a woman who operated a power wheelchair and was on her way to a master's degree and a career in social work. This [was] a woman who married, made love with her husband and planned to become a mother."<sup>84</sup> This was a woman who still could and might do all those things if she had been given appropriate psychiatric and medical treatment. Instead she was given a right to die.

Do you know what happened to Elizabeth Bouvia? She apparently never got the psychiatric and medical treatment that she could have used. She's still alive. She never exercised that right to die. She has spent the years since 1983, most of them, apparently miserable living in a darkened hospital room.

Now, journalists are not trained psychiatrists; but often reporters when writing about people who say they want to die, turn up details that I think suggest depression. Like Bouvia, Noel David Early had been judged competent. He had been judged rational by mental health professionals. He said, "I'm not depressed," and he said, "Depressed people should not seek to die." But was he depressed? I don't know. I couldn't tell; but I always wondered about this man who seemed to have very little support as he lay dying. His parents were dead. He had one brother, but they were estranged. He was divorced. He had no children.

Many of you may know that for me a quadriplegic named Larry McAfee did a lot to change and influence my thinking on these issues.

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<sup>82</sup> See Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Good Prejudice*, 3 ISSUES L. & MED. 141 (1987).

<sup>83</sup> See *id.* at 156.

<sup>84</sup> *Id.* at 158.

In my book *No Pity*, I wrote a chapter about Larry McAfee.<sup>85</sup> He was a thirty-eight year old man who had gone to court in Georgia to get the right to die. He wanted to turn off his respirator. The court said that was a rational decision. But once McAfee got that right, like Elizabeth Bouvia, he chose not to commit suicide. When I went to visit him, I found somebody who was very different from this right-to-die champion as he had been depicted in the media. Yes, Larry McAfee was very angry about the loss of control over his body, but he was more angry about the loss of control over his life.

As I wrote in *No Pity*, McAfee had been moved from one nursing home to another with no say over where he lived or how he was treated—no say in when he got up, when he got dressed, when he was fed, when he was shaved, when he went to bed, or what he could do. Against his wishes he was sent to nursing homes far away in Ohio and Alabama, far away from the little support he had, far away from his family, far away from his friends. When he went to court seeking the right to die, he had been stuck in the intensive care unit of a public hospital. He was in stable health. He didn't belong in a hospital, much less in the intensive care unit. In the hospital he had no privacy. He didn't even have a television. Nurses rarely got him out of bed.

When McAfee's parents brought his electric wheelchair to the hospital, the staff locked it in the closet. They just let him stay in bed for eight months. He was at the hospital because no nursing home would take this quadriplegic who needed more care than some of the ambulatory elderly patients they had. He was at the hospital because Georgia had no program to provide personal assistance service and independent living to younger people with disabilities. That's why Larry McAfee went to court for the right to die. He'd been in the intensive care unit for so many months, dying was the last thing that he thought he could control. But we didn't look at those social reasons as to why Larry McAfee wanted to die. We saw a man, a quadriplegic, very unhappy with his life, and we said, "That's a rational decision. We'll give you the right to die."

Larry McAfee told me that he understood the stigma of being disabled. Larry was from rural Georgia. He was known as Bubba to his family. He was not a particularly introspective man, but he understood the stigma of disability. He told me, "You're looked upon as a second-rate citizen. People say, 'You're using my taxes. You don't deserve to be here. You should hurry up and leave.'"<sup>86</sup> The judge, journalists, and the public saw a man who was making a rational choice to die. They wouldn't want his life so they figured he had a right to end it.

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<sup>85</sup> JOSEPH P. SHAPIRO, *NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT* 258-88 (1993).

<sup>86</sup> *Id.* at 262.

The reality is that people are almost always depressed when they ask for assisted suicide. Psychiatrist Yeates Conwell has studied this issue. He says, "there is rarely, if ever," such a thing as a rational suicide.<sup>87</sup> In one study of forty-four end-stage cancer patients, Conwell found that only three had seriously considered suicide.<sup>88</sup> Each of them, he said, had clear clinical depression.<sup>89</sup>

What makes an expanded right to suicide so dangerous is that physicians rarely spot depression in patients, particularly in older ones. The depression of the elderly or the terminally ill is not like the psychotic disorders that are more common in younger people who commit suicide. Depression in the elderly is among the most treatable kinds of depression, something that's often easily treatable with therapy and drugs. Also contrary to conventional wisdom, the terminally ill are only slightly more likely to commit suicide than those without terminal illnesses. Americans with terminal illnesses make up about 1.4 percent of the population and only 2 to 4 percent of suicides.<sup>90</sup>

Myth number four: We believe that safeguards will prevent a right to die from being abused. There's an important difference between Kevorkian's vision of assisted suicide and the vision in the two federal court cases that are currently before the Supreme Court. Lawyers in those cases argue that assisted suicide should be a right only for terminal patients in the final stages of their illness. They argue that we can put safeguards on assisted suicide.

Most Americans have this great faith in the law and great faith in rationality. We agree that there should be some built in safeguards, for example, that people who get assistance should be truly terminally ill or their choice must be demonstrably free. But there is experience to make us question the reliability of safeguards. Larry McAfee's case showed that courts often confuse terminal illness and disability. Here was a man who had been using a respirator for five years. He was in stable medical condition. Yet the court ruled that to turn off the respirator was the equivalent of declining medical treatment.<sup>91</sup>

In this country efforts to create state statutes have made a distinction. They allow a doctor to provide a lethal prescription, but they leave it to the person to take it. That's attractive because it's really one step removed from euthanasia. The terminally ill person, not the doctor, controls the moment of death. But control is often ambiguous.

<sup>87</sup> See Shapiro & Bowermaster, *supra* note 73, at 38.

<sup>88</sup> See Yeates Conwell & Eric D. Caine, *Rational Suicide and the Right to Die*, 15 *NEW ENG. J. MED.* 1100, 1101 (1991).

<sup>89</sup> See *id.*

<sup>90</sup> See Flora Johnson Skelly, *Don't Dismiss Depression, Physicians Say*, *AM. MED. NEWS*, Sept. 7, 1992, at 28.

<sup>91</sup> See SHAPIRO, *supra* note 85, at 275.

Consider what happened to Lisa Belkin, a reporter for the *New York Times Magazine*. She wanted to write about assisted suicide, and she hooked up with a group called Compassion in Dying and the Reverend Ralph Mero. This is a group that advocates for assisted suicide and members of Compassion in Dying counsel people who are terminally ill and who want assisted suicide. They try to get doctors involved, and they will support that person who wants to die. They will help them through the assisted suicide process.

So through Compassion in Dying, the *New York Times* reporter is put in touch with a woman named Louise Jay. She is a woman with a degenerative neurological disease, and she wants assistance in dying. The reporter flies out to Seattle, interviews Louise, and then returns home.

A few days later she gets a phone call from Mero who asked her to go back to Seattle as soon as possible. Mero said that Louise was “rapidly deteriorating” and that “her physician [felt that] if she [didn’t] act before the weekend, her window of opportunity [would] slam shut.”<sup>92</sup> So the reporter flies back across country: suddenly she finds herself in the uncomfortable position of dangerously skirting the line between being an observer and being a participant in assisted suicide. The reporter finds that it’s not so clear that Louise really wants to die. The reporter sees her in her bedroom, and just blurts out: “Your doctor feels that if you don’t act by this weekend you may not be able to. . . .”<sup>93</sup>

It turns out this was news to Louise. There’s what the reporter describes as a wrenching silence. Louise shoots her mother a sharp look, and it’s clear that Louise had not been told of the doctor’s diagnosis. Louise suddenly looks very frightened, and her mother tries to calm her and says, “It’s O.K. to be afraid.”<sup>94</sup> At this point Louise says, “I’m not afraid. I just feel as if everyone is ganging up on me, pressuring me.”<sup>95</sup>

Now, Dr. Herbert Hendin, a psychiatrist and an expert on suicide, read this account and concluded: “Like many people in extreme situations, Louise expressed two conflicting wishes—to live and to die—but only for death did she find support. . . . Although those around her acted in the name of supporting Louise’s autonomy, Louise began to lose her own death.”<sup>96</sup> Eventually Louise decided to go ahead with the suicide; and with her mother and friend, and members of Compassion in Dying present, she took a fatal mixture of sleeping pills. But something went

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<sup>92</sup> Lisa Belkin, *There’s No Simple Suicide*, N.Y. TIMES, Nov. 14, 1993, § 6 (Magazine), at 48.

<sup>93</sup> *Id.*

<sup>94</sup> *Id.*

<sup>95</sup> *Id.*

<sup>96</sup> HERBERT HENDIN, *SEDUCED BY DEATH: DOCTORS, PATIENTS, AND THE DUTCH CURE* 39 (1997).

wrong, and after six and a half hours she had not died. Later Mero suggested that he was ready, if necessary, to use a plastic bag to suffocate her. Now, that would have made those present, witnesses not to a voluntary suicide, but to a homicide, to euthanasia.

The reality is that this was a death that was not easily controlled. It wasn't easily controlled for the reporter; it wasn't easily controlled for the dying woman. It's good to talk about safeguards, but we have to remember that they are rarely a sure thing when it comes to something like death. Death cannot be controlled.

Belkin wrote what I think is maybe the best account that I've seen about an assisted suicide, and it showed that there are no perfectly rational decisions. In fact, there's a real danger that a right to die becomes a duty to die. As they tried to support Louise, her doctor, her family, her friends seemed to be suddenly encouraging her, encouraging her fears that she had become a burden. Louise felt lonely; she felt useless, and she was ashamed of her disability.

I've indicated that I would say a little bit about the Dutch practice of assisted suicide and what we can learn from the Dutch. For starters we can talk about the Dutch experience with safeguards. Euthanasia technically remains illegal in the Netherlands. However, since the 1970s there's been this informal agreement between physicians and the government. Doctors who follow certain procedures will not be prosecuted. The guidelines were drawn up by doctors, and then they were endorsed by the government.

The patient must be mentally competent; the patient must request death voluntarily and repeatedly; the patient must be suffering without the prospect of relief, and the doctor must consult with another physician. But what started out as a right for people with terminal illness grew into something very different. Euthanasia is now allowed for people who face mental anguish. One doctor provided suicide pills to a twenty-five year old woman who had a history of anorexia.<sup>97</sup> In another case, a woman grieving over the death of her two sons was given lethal medicine by a psychiatrist.<sup>98</sup> Because the Netherlands is the only country in the world that allows euthanasia, Holland is seen as a model for good or for evil by both sides of the debate over physician-assisted suicide.

Jack Kevorkian went to the Netherlands; Dr. Timothy Quill, who was the lead plaintiff in one of the cases before the Supreme Court, went to the Netherlands. Kevorkian and Quill found a compassionate model

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<sup>97</sup> See Shapiro, *supra* note 55, at 27.

<sup>98</sup> See *Suicide, Assisted Suicide and Euthanasia, Before the House Judiciary Committee Subcommittee on the Constitution*, May 1, 1996, FED. NEWS SERVICE (Prepared Statement of Herbert Hendin, M.D.).

for death where patients can speak honestly about dying to supportive physicians.

But critics have gone, too, and they've found something different, critics like Dr. Hendin, who is the author of a new book, *Seduced By Death*. He describes Dutch practice as irreversibly tumbling down a morally slippery slope, where involuntary killing goes unpunished and the courts grant ever-dubious acceptance to whom can be euthanized.<sup>99</sup>

So I went to the Netherlands in December to talk to the advocates—not to the opponents, but to the advocates of this system. I wanted to ask them, “Do you think this is something that we should do in the United States?” I was surprised that every one of them said, “No.” They said, “We like what we do here in the Netherlands; we think it works for us, but it would be a disaster for you.”

I talked with Dr. Herbert Cohen, who is one of the leading practitioners of euthanasia in the Netherlands. He said, “Look, unlike the United States, we have universal access to health care here. Nobody seeks euthanasia because they can't get access to medical care.” Ninety-nine percent of the Dutch have health insurance.<sup>100</sup> They have access to comprehensive care including long-term care. In the United States, forty million people, 15 percent of the population, have no insurance at all.<sup>101</sup>

In the Netherlands, said Dr. Cohen, “Euthanasia is not a way out of social misery. . . . You don't have to request euthanasia because you can't get any medical attention.”<sup>102</sup> Indeed, the most common reason the Dutch seek euthanasia (56 percent of cases) is to avoid what is called “useless suffering.”<sup>103</sup> Americans, however, are more likely to be motivated by another reason. They don't want to be a burden. They fear being a burden on their family and their friends.

In a study in Washington State last year, not wanting to be a burden was the reason given by 75 percent of people requesting assisted suicide.<sup>104</sup> That's very different. That reason doesn't exist in the Netherlands, or at least the polling I saw did not show it. In the United States, hospitalization and nursing home costs can impoverish people. The Dutch face virtually no out-of-pocket expenses at the end of life.

I also spoke to Dr. Gerrit Kimsma, another family practitioner in the Netherlands, and indicated that unlike in the United States, doctors in the Netherlands have a personal relationship with their patients. Sometimes you, or maybe even a family member, have seen the same family practi-

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<sup>99</sup> See Shapiro, *supra* note 55, at 24; HENDIN, *supra* note 96, at 60-75.

<sup>100</sup> See Shapiro, *supra* note 55, at 26.

<sup>101</sup> See *id.*

<sup>102</sup> *Id.*

<sup>103</sup> *Id.*

<sup>104</sup> See Back et al., *supra* note 41, at 922.



tioner for decades. Kimsma visited one man, one patient of his who was dying. He visited him every day during the final weeks of this man's life, and he never charged him a cent for these end-of-life activities. He said, "Some activities have no price tag." Can you imagine in the United States doctors spending that much time with somebody and not charging? We have different bottom-line pressures here.

I spoke to Petra Visscher, the legal advisor to the Dutch Voluntary Euthanasia Society. It's the group that advocates expanding the right to assisted suicide. She suggested that unlike the United States, Holland is a small secular and homogenous nation, where it's easy to come to consensus. The Dutch pride themselves on being able to carry out a respectful public discussion of the difficult issues without the kind of shouting from the extremes that marks debate in the United States.

I asked Eugene Sutorous, the attorney who has defended most of the doctors who have been prosecuted in the Netherlands. He said: "Unlike the United States, the Dutch are not litigious. Malpractice suits are very rare. A Dutch family doctor may spend about a hundred dollars a year on malpractice insurance." In this country a family physician spends about \$10,000 a year on that insurance.<sup>105</sup>

I asked Dr. Johannes Van Delden, a physician in a nursing home. He said: "Unlike the United States, we don't see assisted suicide as a right. It's something private, personal to be worked out between a doctor and a patient. We don't have the rights-based society that you have in the United States."

There are still problems with the Dutch system. Contrary to the law, three-fifths of assisted suicides go unreported.<sup>106</sup> This includes about one thousand cases each year that are particularly vexing where a doctor acts on his own.<sup>107</sup> The doctors say that in about 80 percent of those cases, they knew what the patient's wish would have been, but the person had gone into a coma and couldn't express that wish. But there are cases where doctors just act on their own.

Carlos Gomez, an American physician, went to the Netherlands and interviewed doctors. He discovered cases that seem to suggest that once a doctor has the authority to end life, he will use it. He will do so even in ambiguous cases. One doctor told Gomez that he had killed a child born with Down's syndrome. The child's parents had refused life-saving surgery, so the doctor ended the life of the child.<sup>108</sup>

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<sup>105</sup> See Shapiro, *supra* note 55, at 25-26.

<sup>106</sup> See *id.* at 26.

<sup>107</sup> See *id.* at 27.

<sup>108</sup> See *id.*; CARLOS F. GOMEZ, REGULATING DEATH: EUTHANASIA AND THE CASE OF THE NETHERLANDS (1991).

Another doctor said he had ended the life of a man in a coma following an accident. The doctor said, he wanted “to spare the grieving family any hard decisions about treatment.”<sup>109</sup> Yet, what was surprising was despite these problems, I didn’t find much of a backlash against assisted suicide from groups representing people with disabilities, or the elderly. The opposition still tends to come largely from pro-life advocates. Now, maybe it’s the differences in culture, in politics, in history that explain why there’s not this backlash.

I talked to a disability activist named Bas Treffers. He’s one of the leaders of the independent living movement in the Netherlands. He had been to the United States recently because he was doing a report for the Dutch government about the Americans With Disabilities Act. He said the number one issue of disabled people in the Netherlands is to try to get some kind of legal protection against discrimination, a law like the ADA, but he said assisted suicide was not an issue among the disabled in the Netherlands. I went to a nursing home. I asked older people, and I asked younger people with disabilities, “Are you afraid of the practice of euthanasia?” They looked at me sort of blankly. It was not an issue for them.

The place where I did find the most concern about euthanasia, though, was at a hospice. Dr. Zbigniew Zylicz, who runs the Rozenheuvel Hospice, told me that the easy availability of euthanasia had made it hard for them to spread the notion of hospice care. Hospice care in the Netherlands, was years behind that in the United States. Dutch doctors didn’t understand it. The patients didn’t understand it. I talked to a woman named Ineka Verloop. She was a sixty-five year old woman; she was dying of cancer. She made an appointment to go to her doctor to request euthanasia. She was in great pain, and her doctor didn’t know how to stop her pain. She had never heard of hospice, and only by accident did she find out about Dr. Zylicz.

At the doctor’s hospice, he found a way to resolve her very tricky pain. He actually got on the Internet and he described the problem. Overnight he had an answer back from a doctor in South Korea. When I met Mrs. Verloop, she was pain-free, and she was accepting of death. She told me, “Here they take away your pain and they put you at peace. They give you a sense that you are a person, not a patient.”

I have to say that when I left the Netherlands, I was feeling sort of wistful about that country’s ability to have polite discussion about even the most difficult issues. It truly is a rational society where they like to sit down and talk things out. In the United States we’ve got the exact opposite. Extreme voices are raised. You have to shout to be heard.

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<sup>109</sup> Shapiro, *supra* note 55, at 27; GOMEZ, *supra* note 108.

People call each other names. They scream; they yell. Well, that's the American way. That's just the way we do things.

I think that explains the Kevorkian phenomenon. The Dutch can't understand Kevorkian. They're much more comfortable with someone who is more deliberate and thoughtful like Dr. Quill.

Yesterday historian Paul Longmore, criticized the media coverage of Kevorkian. He asked, "Why does the press portray him as some kind of an eccentric folk hero?" Paul asked, "Why doesn't the press call him a Neo-Nazi bigot against people with disabilities?" Perhaps part of the answer is that Kevorkian plays a role in our society. In some ways he's done a service. His zealotry has forced us to consider death and dying. His zealotry has forced us to confront an issue that traditionally we have avoided, doctors and the rest of us.

Kevorkian doesn't sugar-coat assisted suicide with talk of making it safe. He talks very bluntly and directly. Kevorkian argues that if we allow assisted suicide as a right, then we have to accept it as a right for anyone—the terminally ill or not—who says she or he is suffering and that she or he wants to die. So in no small measure, it is due to Jack Kevorkian that we're having a national debate about socially-assisted dying. It's a noisy, angry, impolite debate, but it's a very American debate.

One positive result, I think, is that journalists for the first time are writing seriously about alternatives to physician-assisted suicide. I've seen some very thoughtful, in-depth reporting about hospice care for the first time from newspapers in St. Paul, in St. Petersburg, in Boston. Reporters for the first time are starting to ask, "Should doctors do a better job of controlling pain so that people wouldn't feel the need to legalize assisted suicide?" At *U.S. News & World Report*, my colleagues Shannon Brownlee and Joannie Schrof did a very good cover story last month asking just those questions.<sup>110</sup>

Finally, this conference is on disability and assisted suicide, so I want to close with a point about the role of the disability community. I spent the last several months on a fellowship from the Kaiser Family Foundation studying long-term care and aging issues. The disability community is light years ahead of the aging community in providing the type of long-term care settings that most people want, settings that are in the community, assistance that maximizes independence. The disability community is light years ahead when it comes to talking about stigma.

In January, when the United States Supreme Court heard oral arguments on the right-to-die cases, the lasting television image was of a band of disabled protesters on the Supreme Court steps. It wasn't the

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<sup>110</sup> Shannon Brownlee et al., *The Quality of Mercy*, U.S. NEWS & WORLD REP., Mar. 17, 1997, at 54.

AARP with its thirty million members saying, "Wait a minute. Is this a good thing for older people to have this expanded right to die?"

It was Not Dead Yet, a disability group on a shoe-string budget, that dominated the newspaper and television images forcing us to think about what an easy right to die might mean during an era of health care rationing and increased bottom-line pressures.

I liked Dr. Betts's phrase yesterday. He talked about the "filthy rumblings," the comments of well-meaning people who say, "Why do you spend all this money to keep old people alive? Aren't they better off dying?" The aging community has a lot to learn from the disability community.

I have been thinking a lot about images of aging. We celebrate George Bush jumping from an airplane at the age of seventy-two; we celebrate the Delany sisters at a hundred, writing books and sharing wisdom.<sup>111</sup> Why do we celebrate them? We celebrate them because they calm our fears about aging. They calm our fears about what it means to grow old.

What's the new buzz word in the aging field? Productive aging. That's the idea that we're living longer and we're living in better health, that there's a new middle age, that to be sixty or seventy is what being forty or fifty used to be.

Now that's a nice sentiment. There's a lot of truth to it, and it's supposed to be an attack against ageism. It says, "See, getting old isn't so bad." You can jump out of an airplane, if that's what you want to do. But to disabled people in the audience, doesn't this sound a little familiar? The disability rights movement was a reaction against society's two dominant images of disability: one, a disabled person was supposed to be pitied; or two, a disabled person was supposed to be an inspiration.

We cheer a paraplegic who climbs a mountain or a blind sailor who attempts to sail an ocean; and people with disabilities have a pejorative term for these superachievers, these overachievers. They called them: Supercrrips.

They say, "Sure, extraordinary achievement is laudable." But disabled people tell us, "Look, we're expected to prove that our disabilities are meaningless. Before society gives us common respect, we are forced to show that we can overcome our disabilities. But this requirement is not to benefit us, it's not to benefit disabled people. It's simply to assure nondisabled people. It's to calm their fears about disability."

Disabled people say, "Our challenges are much more basic than that. They're much more basic than climbing mountains. We have daily

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<sup>111</sup> See SARAH DELANY & A. ELIZABETH DELANY, *HAVING OUR SAY: THE DELANY SISTERS' FIRST 100 YEARS* (1993).

challenges we have to climb. We have to climb over prejudice. Two-thirds of us are unemployed.” Suppose a person in a wheelchair can convince an employer to hire her or him; then she or he has got another challenge: just getting into that building, getting up the steps into the front door of that workplace.

The disability movement gets very little recognition. Yet it has so much to teach America. For one thing, it teaches us the danger of believing that there’s a right way or a wrong way to age. If we celebrate productive aging, then aren’t we also further stigmatizing the seventy-two-year-olds who don’t want to jump out of airplanes, who can’t jump out of airplanes? Don’t we end up stigmatizing those who don’t live up to this fantasy of what old age should be?

So disabled people are teaching us that disability is a part of life. It’s something to be accommodated more than feared. Disabled people also teach us to accept the value of all people. The disability movement warns us of the danger of using subjective standards of quality of life, especially when it comes to deciding who should live and who should die. Thank you.

AUDIENCE MEMBER: How can we more effectively get the whole story about Kevorkian into the media and the whole story about people with disabilities into the media? I think that we need to use the media to let people know what our lives are really like.

MR. SHAPIRO: I think that’s right. You have compelling stories to tell. They get told when people present another side. We also know that this is a large community and it’s a mixed community with many different points of view even on this issue. I think maybe you need to fight compelling stories with other compelling stories of your lives and what you’ve done.

We heard many of these stories yesterday, people saying that disabled people of all faiths were being told that they were expected to die or not to have productive lives. Those are stories that I think do have an impact. I think journalists are starting to pay attention to these things.

AUDIENCE MEMBER: It hasn’t been answered yet.

MR. SHAPIRO: I have found that often when you talk with people in hospice care, they talk about the importance of dealing with spiritual matters and how important it is to deal with dying. I think just about everyone I’ve ever met in a hospice, whether it was in the Netherlands or here—and I was in some hospices recently in Florida—says they’re surprised at how many people still have never heard of hospice care. They haven’t heard of it until they’ve reached that terminal condition. Somebody mentions it to them and they don’t know what it is.

It’s very common for people when they face a diagnosis to consider briefly something like assisted suicide. They’re very surprised by what

else is out there. Journalists and all of us do need to write more about some of these alternatives that exist.

But the spiritual side I find is often a very important aspect of it. There are actually some interesting studies that show the importance of prayer and spirituality in helping people not only to cope, but actually to improve the level of their lives.

AUDIENCE MEMBER: How does the religious community show up in these polls?

MR. SHAPIRO: Well, we know that a state like Oregon, which did narrowly pass a law that would allow assisted suicide, is one of the two or three most secular states in our country, a state where the fewest number of people go to church regularly. We know that the Netherlands, outside of some of the former Eastern European countries, is the most secular country in Europe. There is a correlation between secular places and an acceptance of assisted suicide.

AUDIENCE MEMBER: Joe, I have a question. I think there's some kind of irony in the name Hemlock Society, given the historical precedent for how assisted suicide occurred. Throughout the country this year in forty-nine of the fifty states there's been an introduction of a bill about assisted suicide. I find that incredible as a grass-roots effort and wonder if there's been any research on how funding for that occurred—to have such a concurrent and persistent effort in forty-nine of the fifty states. I mean, I haven't seen such an effective effort to mobilize around an issue since the attempt at health care reform.

AUDIENCE MEMBER: Follow the money.

MR. SHAPIRO: I wasn't aware that bills had been introduced in that many states. A lot of it is grass roots. It does come from sort of a grass roots level. I know there's been a more coordinated effort on the West Coast, but I don't know what's going on nationally in that way. A lot of people are concerned about this, and I think, as I said, the fight will end up at the state level.

AUDIENCE MEMBER: I have a concern in part of the discussion as I heard it both yesterday and today: I seem to hear you running together the issues of euthanasia and physician-assisted suicide. I don't understand those as being the same thing. Could you clarify your definitions on that issue?

MR. SHAPIRO: Well, I was referring to euthanasia in the Netherlands. That is why this conference is titled Socially-Assisted Dying, to make the distinction. By the way, in the Netherlands, there are two options: you can have a physician actually inject you with a lethal mix of drugs or you can have the physician prescribe it to you and you take it yourself.

The method of choice, the choice for death, overwhelmingly, is for a doctor to do it. They have found in the Netherlands that in many cases where people take the pills themselves, it doesn't go right. There's a problem. The person ends up living. That is a botched assisted suicide, which is why the book *Final Exit* actually talks about using a plastic bag to help people die if it doesn't go right.

In this country, because there's something so loaded about having a physician actually be there and be involved, we've talked more about assisted suicide, whether it's a medical professional who provides the drugs and who may be present, or whether it's some friend or family member, or a group like Compassion in Dying, who is there to follow somebody through this process.

DR. KIRSCHNER: We're going to take one more question. We'll take one more question from Mr. Batavia.

MR. BATAVIA: But my question to you is: What would you say to my friend Mike whose situation I described in some detail yesterday? He was not a depressed individual. He was an individual who was facing a situation that was very dire, and he decided for himself that he did not want to keep going on. He was a thoughtful, introspective individual with a disability. He had a disability for a number of years. He was from a supportive family. He had access to psychological services. If he was depressed, I would say it was very rational depression in response to his physical situation. What would you have told him?

MR. SHAPIRO: Thanks, Drew. I did hear you describe him yesterday. I don't know enough about him to know exactly what to say. Somebody yesterday suggested that now, thirty years later, there might be better pain control, better things to help him live a better, more independent life.

MR. BATAVIA: That was not on this point.

MR. SHAPIRO: Okay.

MR. BATAVIA: He would still be on his stomach for the rest of his life with terrible, terrible bed sores.

MR. SHAPIRO: It may have been Paul Miller who pointed out yesterday that there's danger in making this a legal right. In extreme cases something will end up being worked out between a patient and a physician.

MR. BATAVIA: In which case it goes underground where it is right now and where people are hanging themselves. Desperate people are taking drugs that they're prescribing to themselves. Sometimes they end up in comas; sometimes they impose brain damage upon themselves. This is a horrible thing for our society to do to its citizens.

MR. SHAPIRO: This is where we were yesterday, where this conversation, what this debate comes down to. How do you deal with a few

extraordinary cases like that, which do exist, but also protect others against the subtle stigma that very quickly arises when we create a right to die? How do we prevent a right to die from becoming a duty to die? I think it's very, very difficult in this society to prevent that from happening.

MR. BATAVIA: I think that we can define the right to die narrowly, and we can provide safeguards. I just want you to know that there is another side to their safety, another disability rights perspective on this that's legitimate. I believe they're actually the majority in the disability community, once you get beyond the leadership to the rank and file in the community. We have support for that. Not strong support because there haven't been adequate surveys on this issue. One Harris poll, with admittedly small numbers, indicates 66 percent of people with disabilities support the right. I have two much more significant studies of people with AIDS that say that between 63 percent and 90 percent of people with AIDS who are affected by this disease want this right.

MR. SHAPIRO: We also heard from Dr. Rodriguez yesterday that the people who he counsels with AIDS are poor people, Hispanic people who have trouble getting access to services and who have a very different view than other people with AIDS. They're much more suspicious of getting the right to die.

MR. BATAVIA: I respect that.

MR. SHAPIRO: One thing that the disability movement teaches us is that it's a very diverse movement. We've heard that in your presentation and in Hugh Gallagher's presentation yesterday. It's a diverse movement. In its diversity I think it does allow for these differences of opinion. It says to other civil rights movements that we shouldn't expect that there's one way of viewing things, or that there's one dogmatic thing that you have to believe to be part of the disability movement, or to be part of the civil rights movement.

I think that this is a movement that generally does have pretty good conversation and communication among the people in it. I think that there's a lesson for all civil rights groups and all minority groups to see the disability community and how it generally does accept difference.

DR. KIRSCHNER: I'd like to thank Joe for his brilliant and riveting talk. We've been honored to have him with us today.

#### IV. SESSION FOUR: MONEY, LAW AND SOCIAL CONTEXTUAL ISSUES

DR. KIRSCHNER: I'd like to introduce to you Dr. Peter Budetti. I've had the pleasure of working with Dr. Budetti as a member of the planning committee for this conference.



Dr. Budetti came to Northwestern University in 1996 from George Washington University where he founded and served as the Director for the Center for Health Policy Research. He currently holds a similar position at Northwestern University as the Director of the Institute for Health Services Research and Policy Studies. He is also a Professor of Health Services Management in the Kellogg Graduate School of Management and holds professorships in the law school and the Department of Preventive Medicine in the medical school.

Dr. Budetti served as a member of the Legislative Drafting Group for President Clinton's Health Security Act throughout 1993 and was on leave from George Washington University to serve as a member of the professional staff for health reform of the Senate Committee on Finance during 1994.

He was appointed to the Advisory Committee on Health Care Access and Quality for the Commonwealth Fund in 1994 and was elected to membership in the National Academy of Social Insurance in 1996.

DR. BUDETTI: Thanks very much, Kristi. Like all of the panelists this morning, I'm very pleased to be here. I think it really is an outstanding conference, and I was very privileged to have been involved in the planning.

Our first speaker, Kathryn Tucker, is an attorney with Perkins, Coie, the Northwest's largest law firm. She was lead counsel for the Plaintiffs in *Washington v. Glucksberg* and *Vacco v. Quill*, the first cases brought to the United States Supreme Court challenging the constitutionality of state statutes that prohibit assisted suicide.<sup>112</sup>

Ms. Tucker served as counsel to the sponsors of Proposition No. 119, the first legislative initiative to legalize physician aid in dying for mentally competent, terminally ill patients. She provides counseling and handles litigation on a wide variety of issues that are of concern to physicians, patients, and health care institutions and organizations. She is also an affiliate professor of law at the University of Washington School of Law.

MS. TUCKER: I feel that I will be a bit of a lone voice today, and I'll just mention for any journalists that may be in the audience that I think that the presentations are speaking largely to the anti-choice perspective. I will be speaking in favor [of socially-assisted dying] because my clients have been physicians, patients, and nonprofit organizations who believe that this is a choice that mentally competent, terminally ill patients should have.

I do hope that in my short time I'll be able to give some comfort to those of you who are concerned about how broad the scope of what

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<sup>112</sup> See *supra* note 2.

we've tried to achieve through our lawsuits is: it's really quite limited. Because this conference has focused on disability perspectives, I will just say at the outset that these lawsuits really have nothing to do with the disabled community or disabled individuals, as such. I'll talk about that a little bit more when I get into who is within the scope of the claims of the lawsuit.

In both Washington and New York and in many, many states there exist criminal statutes prohibiting, in just a very general sense, assistance with suicide. Those statutes have been understood to include within their ambit the conduct of a physician providing assistance in dying to a patient who, confronted by death and what that patient finds to be intolerable suffering, would desire a more humane, hastened death. Because those statutes would operate on that patient's choice and that physician's conduct, we challenged two of those state statutes in federal district courts in Washington and New York.

The scope of the claims has been limited to mentally competent individuals, and that, of course, assumes within it patients who are not suffering from depression. These are terminally ill individuals. These are individuals who are confronted with imminent death and who do not have the choice for a life with dignity. These are patients who have lost their life due to the progress of terminal illness and are now facing death. They are on the edge of death. So the possibility of a life with dignity is not among the possibilities for this group of patients. Therefore, the group of patients we're talking about does not include disabled persons *per se*.

A person with a disability would not be empowered to make a choice for an assisted death merely by virtue of having a disability. If a person with a disability became terminally ill and was in the final phases of dying and would choose to make that choice, our view—although it's not covered in the lawsuits in any explicit way because we did not have a disabled person who came forward as a plaintiff—would be that that disabled person should have the same right to make that personal choice as another similarly situated person. Perhaps additional safeguards in the context of a person with a disability who would be making this choice may well be appropriate.

I'll briefly talk about the lawsuits. There are really two theories in the cases. The Fourteenth Amendment is the source for both theories. The first theory is a liberty claim. Our federal Constitution protects liberty. The reproductive rights cases have, through a long series of cases, respected and recognized the right of individuals to choose whether to bear children, and whether to conceive children. The early cases dealt with contraception. The later cases, of course, have dealt with abortion. But through a long line of cases, our federal high court, the United States

Supreme Court, has respected and protected the right of individuals to make this decision for themselves. It is because it's a personal decision; it involves one's own body, one's future life course. That kind of a decision, such a life-shaping decision, is viewed as one that should be reserved to the individual and not usurped by a surrogate decision-maker or by the State.

That kind of reasoning has bearing, we contend, at the end of life where a profoundly personal, momentous decision is being made about one's own body and one's own future course of life, although, of course, that remaining course of life will be short. But the argument from the federal reproductive rights cases is that this is the same kind of momentous, life-shaping decision.

The *Cruzan*<sup>113</sup> case is a separate source of authority supporting our liberty claim. This is the one decision where the United States Supreme Court considered the withdrawal of life support. In *Cruzan*, the Court upheld a state law which ultimately prevented the withdrawal of life support from a patient because the Court found the end-of-life decision to be so momentous and so personal, and because the information about what the patient herself would have wanted was not well-known. She was a permanently, irreversibly, unconscious patient. The Court found that it was appropriate for the State to impose a high standard to ensure that the patient would want withdrawal.<sup>114</sup>

Recognizing that the decision is a personal one and should be reserved to the individual also bears very much on the question of whether a patient can express his or her wishes regarding the end of life. Shouldn't that decision be reserved to the individual? Those were the two lines of precedent that we urged to the Court in support of a liberty claim.

The second line of argument was also from the Fourteenth Amendment. Our Fourteenth Amendment protects all citizens equally, and the Equal Protection Clause forbids arbitrary discrimination among classes of persons. Because citizens have the right to direct the withdrawal of life support, be it from a ventilator or a feeding tube or what have you, and thereby bring about a hastened death with attendant medical assistance, to deny a patient who does not happen to be on life support the right for equivalent medical assistance in acquiring a lethal dose of medication to hasten death is discrimination that's really quite arbitrary. Those are the two theories to give you the ballpark overview of what the legal theories have been.

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<sup>113</sup> *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990).

<sup>114</sup> *See id.* at 284.

I think that the focus on Dr. Kevorkian is sadly misplaced. Kevorkian is very much the back-alley provider. I think the reason why he's a folk hero, and the polling data reflects that, is because most citizens in this country believe this is a personal choice, that the State shouldn't make it, the Catholic church shouldn't make it, and right-to-life groups shouldn't make it. It should be the individual's choice.

Unfortunately, that sentiment carries over to Jack Kevorkian who, I think, really does have disturbing practices. I think that the back-alley provider is only necessary because we don't permit this to go on in an above-board manner between patients and their treating physicians. I think Jack Kevorkian would quickly be put out of business if patients could turn to their own doctor.

Of course Kevorkian is flamboyant, but it's well known that there is quite an extensive covert practice from time immemorial of physicians assisting their patients in dying. Many say, why isn't that sufficient? Why not let it be a decision reached quietly and privately with that doctor and that patient? I'll just throw out a couple of problems with that response.

When it's covert, it's utterly random. You don't know when you desire this whether you'll be fortunate enough to find a physician who is sympathetic. So it's utterly random. It tends to be something that only the very aggressive consumers of medical care are able to access because they will seek it out; and those tend to be more affluent and more educated consumers, making it a very elitist sort of thing.

The abuses that go on with the covert practice are rampant, and I think Kevorkian illustrates some of those. The problem is that when you have a physician acting covertly under the onus of a criminal statute, that physician is not going to call for a second opinion. We're talking about establishing this as an option only for the mentally competent, terminally ill. It may well be entirely appropriate to have second opinions on both of those prongs. Let us have a second opinion, and perhaps a specialized psychiatric opinion, on whether this is indeed a patient who can make a rational decision as opposed to a depressed individual. Let us have a second opinion on whether the patient is, in fact, in the final phases of the dying process. Let us have an additional consultation on palliative care. Let's make sure that no patient is motivated to make this choice because they have inadequate pain care or because they have not been offered hospice.

Dr. Timothy Quill, who is my lead client in the New York case, is himself a director of a hospice facility. He has deep roots in hospice. His view is that hospice should be the standard of care. And it absolutely should be! Every patient who is dying should be offered hospice, and they should be offered it much earlier than it's offered now.

What Tim Quill will say when he speaks on this subject is that a patient who, in his or her own estimation, is dying a death that cannot be made comfortable or bearable even with the most excellent hospice care, and who would make this choice, is experiencing a medical emergency. That patient must not be abandoned by his or her doctor, but must be able to work through this question with his or her doctor.

I watched Dr. Emanuel from the AMA present the long flowchart of steps to be taken by doctors if a patient raises this issue: "First see whether he's competent; and then the question, see if he's depressed; next whether he's rational." She went all the way through this long flowchart. When you actually worked your way to the bottom of the flowchart, if the doctor had answered "yes, competent," "yes, rational," "yes, terminal," "yes, still desires the choice," the final box said, "tell the patient forget it and offer more palliative care."

That flowchart is absolutely wonderful; everyone should employ it. But when you get to that box at the bottom, don't just disregard or override your patient's wishes. Those patients who meet all those criteria, who want to exercise this choice, need the assistance of a physician in a humane and dignified manner.

The notion that all of these patients who would make this choice are depressed is false. I think it's appropriate to have differential diagnosing to make sure that you don't have a depressed patient. You will end up with a fraction of patients who are not depressed despite the speculations of some of the other speakers. The *McAfee* case was discussed earlier,<sup>115</sup> and the comment was made that it was really sad in some sense that this patient was given the right to direct the withdrawal of his life support. This was a patient who was not terminally ill; it was a patient who had a long life span but had a disability. He was given the right to direct the withdrawal of his treatment.

For nonlawyers the distinction between withdrawal of treatment and assistance in dying gets a little bit fine. I think you have to keep in mind that the right to direct the withdrawal of treatment is a much broader right than the right to seek affirmative assistance in hastening death through a lethal dose of medication. That's partly because the sources of the right to direct withdrawal of treatment are twofold. The right to direct withdrawal involves not just the autonomy and individual decision-making issues that we have been discussing with regard to assisted suicide; it also has deep roots in battery and informed consent law. The right to be free of an unwanted bodily invasion is viewed as almost absolute by the law. So, an individual directing the withdrawal of life support really has an additional legal ground that does not exist where a patient is

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<sup>115</sup> See *supra* note 85 & accompanying text.

seeking the lethal dose that we're talking about in an assisted death situation. That is why patients like McAfee are empowered to do that.

Certainly, there should be suicide intervention where a patient is directing withdrawal of life support and has depression as a motivating factor. I think that the disabled community and other right-to-life groups that are concerned about these end-of-life decisions should really be looking carefully again at the end-of-life decision-making that relates to withdrawal of life support. I was involved in a terribly troubling case in which I represented a disabled man who was a stroke survivor. He could not move; he could not speak, but he did communicate with an eye-gaze board and a letter board. His family directed the withdrawal of his feeding tube because they thought it was merciful to bring about the end of his life. He had been active and athletic. Now he could not move; they didn't think he would get better. They directed the withdrawal. They didn't direct the withdrawal based on any information that he was terminal or permanently unconscious. It was simply that they thought his quality of life was low.

The hospital where he was a patient acceded to that request and withdrew the life support. His friend, who was his former spouse, visited him and told him this had happened. He communicated to her that he wanted continued life support. We had to go to court and get a court order to have him hooked back up. We couldn't get it for five days. So he laid there for five days with no food or water, not knowing whether he would be rescued. We did succeed in rescuing him.

The defense from the medical community—the doctors and their experts in a subsequent medical malpractice case that I brought on the patient's behalf against the hospital and the doctors who withdrew this man's life support—was that it was permissible for surrogates to direct the withdrawal of treatment from such a patient without following any of the Washington State Supreme Court's procedures that governed the matter.

The medical community did not believe that the procedures embraced by the state supreme court, which had considered withdrawal of life support in this context, needed to be incorporated into medical community standards, and they weren't. That was the defense. The jury never had any instructions that the law of Washington required that certain procedures be followed before treatment be withdrawn, and they returned a verdict for the defense. The patient subsequently died, and the case was dismissed as moot, so there will never be appellate review of the case.<sup>116</sup>

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<sup>116</sup> This case is discussed in detail in Kathryn L. Tucker, *Surrogate End of Life Decision-making: The Importance of Providing Procedural Due Process, A Case Review*, 72 WASH. L. REV. 859 (1997).

The lesson I take away from that case is that any end-of-life decision, be it through a withdrawal or through a lethal dose, is enormously momentous and profound and should be carefully and deliberatively made and should be subject to safeguards. There really aren't any safeguards on the withdrawal decision today, and those decisions are much, much more common than the lethal dose decisions that we're talking about in a physician-assisted suicide situation.

Turning to the safeguards issue, I do think that there are a number of excellent models that have been published in the legal and medical journals. They tend to overlap enormously, and I think that overlap is a good sign. I take it to mean that there's quite a bit of agreement on how this practice should go forward, if it is to go forward. What you see are a lot of regulations to assure voluntariness, competence, and that the decision is informed, reasoned and reflective. Again, I think all those safeguards should apply in the withdrawal of treatment context also. Those can all be addressed through regulation as well.

Some people who don't favor the legalization of physician-assisted suicide favor keeping it covert because they don't want all those regulations. Certainly Kevorkian would not want all those regulations. I think that the regulations are essential protections.

I will say a couple of things about what will happen depending on how the pending cases come out. Even if the Court does reject the liberty and equal protection claims, at a minimum it is going to indicate, as the states have argued, that this is something appropriately left to the state legislative processes. We've seen Oregon pass a law that's quite restrictive. I think that the reality of going through the political process is that you will see quite restrictive laws. There's such an active right-to-life movement. The Catholic Church, in particular, has participated in these campaigns, aggressively seeking to thwart the enactment of laws regulating physician-assisted suicide. What happens in the course of political campaigns, then, is that proponents make a narrower and narrower, more stringent law to make it palatable to more voters. So what you see in Oregon, for example, really is an extremely limited law.

One interesting thing to keep in mind is that if you went the legislative route, you would not have to, in theory, limit the universe of patients for whom this option would be available to terminally ill patients. I think as a practical and political matter you would, but legally you wouldn't have to. Whereas in the judicial forum, when crafting the constitutional argument, it was important to our argument and the constitutional balancing that the patient, in fact, be terminally ill; that is not so in the legislative forum.

Some of the proposed legislation was not limited to the terminally ill, including, I think, the proposed model statute published in the

*Harvard Journal on Legislation*,<sup>117</sup> drafted by a number of distinguished legal and medical professionals associated with Harvard University. It referred to incurable cases and suffering. A broader universe could be addressed through legislation as opposed to judicial reform. I don't think that the issue is going away. I think that whatever the Court does, there will be a lot of activity regarding how assisted suicide should be regulated through state legislative processes. Certainly the disability community can and should be involved in the lobbying and crafting of that legislation.

If the right is rejected, and the Court basically sends it back to the state legislatures, I think it's quite clear, as one of the members in the audience pointed out, that there are many pieces of legislation being introduced. Oregon passed a measure that is apparently destined to go into effect. I think that is likely to be the trend. If the Court rejects the constitutional arguments, we will see state legislative activity. Then, that will open up the process to the political realm.

I think a couple of comments are in order to follow up on what some of the earlier speakers had to say. The notion that the portion of society that is "clamoring," to the extent that there's a clamor for assisted suicide, is young and healthy is really not so. If you look at the polling data, it is true that certainly among the young and the educated segments of society, the more highly educated tend to favor assisted suicide in greater numbers.

My clients have been only dying patients who are not young and healthy. They were not elderly persons, however, so the issue is not whether the elderly would automatically be eligible. It's really patients who have, at whatever age, progressed through a terminal illness to the point where they are now on the edge of death.

On the question of semantics, one of the questions asked at the last panel was, "What's the difference between physician-assisted suicide and euthanasia?" The reason why physician-assisted suicide is a term that I embrace is that it does include within its ambit the notion that the patient making this choice takes the final act him or herself. That is all that's at issue in these lawsuits and all that's at issue in the pending legislation that I'm aware of. I think that's important. I think that the patient taking the final act is an additional indication of voluntariness which is important.

On the other hand, while I embrace the term physician-assisted suicide for that reason, I don't think that the term "suicide" has application here at all because we're not talking about an individual cutting short a

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<sup>117</sup> See Charles H. Baron et al., *Statute: A Model Statute to Authorize and Regulate Physician-Assisted Suicide*, 33 HARV. J. LEGIS. 1 (1996).



life that could otherwise go on. The baggage that comes with the term “suicide” is very heavy indeed. I would just remind people that as we hear the term “suicide” we are not talking about suicide in any classic or definitional way. We’re really talking about a patient at the end of life who seeks a humane death and believes that hastening imminent death with a lethal dose is an appropriate choice for him or herself.

DR. BUDETTI: Thank you very much. We are continuing to put things into a societal context, and barraging you with a panel of nothing but doctors and lawyers. Next is Diane Coleman, also a lawyer, who comes to us from the Progress Center for Independent Living in Oak Park, Illinois, where she is the Executive Director. Before that she was in Tennessee as the Client Assistant Program Coordinator for Tennessee Protection and Advocacy, assisting people with disabilities in obtaining employment-related training and services. She also served as the co-director of Technology Access Center and as Policy and Funding Analyst for the Tennessee Technology Access Project.

Her other appointments have included serving on the Tennessee State Advisory Committee to the U.S. Civil Rights Commission, the Advisory Committee to the Tennessee Human Rights Commission, the State Independent Living Council, and the Board of Directors of the Tennessee Health Care Campaign.

In 1996, she co-founded Not Dead Yet, a national disability rights organization opposing the legalization of assisted suicide. She has written and lectured extensively on issues of disability advocacy, physician-assisted suicide, including being lead counsel on an amicus brief opposing the legalization of physician-assisted suicide in the cases before the Supreme Court.

MS. COLEMAN: I first became involved in this issue in 1985, when I was invited by fellow board members of a center for independent living to participate in a rally and protest outside the offices of the American Civil Liberties Union (ACLU) in Los Angeles. At the time I was a proud member of the ACLU, which I thought would be defending my civil rights as a person with a disability. Instead, I found out that the ACLU was involved in defending the request of Elizabeth Bouvia, a woman with cerebral palsy, to receive social assistance in starving herself to death with pain and comfort care in a hospital setting.

Not only had Miss Bouvia experienced the break-up of her marriage and been forced out of her master’s level program due to financial aid problems, but in addition, her brother had died and she’d had a miscarriage. As a child her parents had institutionalized her. She’d had a pretty rough life.

I went to the protest and said, “You know, if a nondisabled woman were asking for this kind of help, it would not be offered to her, so why

is Elizabeth getting it? Why do people think that her desire to die is rational?" I couldn't even get the reporters to understand the question. As a woman asked earlier, "How can we get the disability community's concerns publicized?"

Ever since the Bouvia case, I've been writing articles, testifying in legislatures, and filing amicus briefs in court cases involving people with disabilities who have requested a so-called right to die, and they've always been granted that right to die. The press has consistently ignored the concerns of both minority and disability communities about the oppression in our society.

Well, what a number of us finally figured out is that the only way we were going to bring our concerns to the public's attention was to form a protest group. That group is Not Dead Yet. After getting five hundred of us to the steps of the U.S. Supreme Court in January, people are more and more beginning to pay attention to the possibility that the assisted suicide issue is not just the pro-choice progressives versus the religious right. This is not just a two-sided issue. There's a third perspective, a civil-rights based, minority-based, oppression-concerned perspective on this issue, which must be considered.

People with disabilities are concerned about the legalization of assisted suicide, first, because of ableism. Ableism, like racism and sexism and ageism, is the word for the bias that this population feels towards people with disabilities.

The court in the Bouvia case made a very complete statement about how people feel when it gave Elizabeth Bouvia a right to die that it would not have granted to a nondisabled woman who was in a similar state of despair. The court wrote:

Petitioner would have to be fed, cleaned, turned, bedded, toileted by others for 15 to 20 years! Although alert, bright, sensitive, perhaps even brave and feisty, she must lie immobile, unable to exist except through the physical acts of others. Her mind and spirit may be free to take great flights, but she herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation, and dehumanizing aspects created by her helplessness. We do not believe it is the policy of this . . . to inflict such an ordeal upon anyone.<sup>118</sup>

That decision is the first in a long line of existing court decisions which have concluded that the State does not have the same interest in preserv-

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<sup>118</sup> Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 1143-44 (Cal. Ct. App. 1986).

ing the lives of people with disabilities that it does in preserving other lives.<sup>119</sup>

Assisted suicide is not about autonomy. Any one of you here today could go to a physician or health care provider and say, "I want assisted suicide." The question is, which of us would have that right granted? It's the doctors—the medical professionals who decide. They decide whether you're on the assisted suicide track, or you're on the suicide prevention track. It's not about your autonomy; it's about their decision-making. They make their decisions based on biases; the same biases that prevail in the culture at large.

In addition, they're increasingly making their decisions based on economics. It's now the day of managed care. It's not only voluntarily through your employer anymore. This year in Illinois—and this is happening all over the country—the publicly funded health care systems of Medicaid and Medicare are converting to managed care. Ableism is a concept that isn't even understood by the culture. When managed care is about to hit us all, this is not the time to legalize an easy way out.

I'd like to talk a little bit about safeguards because I really think these laws are about legal presumptions—burdens of proof. The *Bouvia* line of cases, including *Rivlin*, *Bergstedt*, and many others, involve some people with disabilities who are dead now; dead because the court case didn't take quite long enough for them to get over their suicidal urge. *Bouvia* and *McAfee* at least chose not to exercise the right they were given, but many others did because they feared being incarcerated in nursing homes and other factors. This line of cases has already concluded, on this issue, that people with disabilities are about the same as terminally ill persons for legal purposes. So how can we have any confidence that prosecutors, juries, and courts are going to protect us as they would nondisabled people under some proposed set of regulations or safeguards?

Over two-thirds of Kevorkian's victims were not terminally ill,<sup>120</sup> but you can't get prosecutors to prosecute, or juries to convict, Kevorkian. In fact, I feel that we people with disabilities are like the African-Americans of the '50s or '60s. People are being killed because of their minority status, but the prosecutors won't prosecute and juries won't convict. It finally took the federal government to go into the South to do anything about the problem.

It doesn't give me any comfort to know that the majority of this culture believes that assisted suicide ought to be legalized; it doesn't give me any comfort that Mr. Batavia, who is arguing on the other side of this

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<sup>119</sup> See e.g., *Mckay v. Bergstedt*, 801 P.2d 617 (Nev. 1990).

<sup>120</sup> See *The Kevorkian Files*, *supra* note 71, at A49.

issue, allegedly from a disability community perspective, continually brings up his nonterminally ill friend Mike as someone who somehow ought to have had this right. He clearly does not intend it to be limited to the terminally ill. In fact, most of the proponents' words, the people who argued for aid in dying for years, intend the slippery slope and to expand its application. They count on legalization to create a more tolerant attitude.

For example, Derek Humphry in his book *Final Exit* says, "What do most of us who sympathize with a justified suicide by a handicapped person do to help? When we have statutes on the books permitting lawful physician aid in dying for the terminally ill, I believe along with this reform, there will come a more tolerant attitude to the other exceptional cases."<sup>121</sup> This gives me little comfort.

I'd like to look also at the safeguard of voluntariness. I think choice is an empty slogan in an environment where we have limited support for living. As an independent living center director, I've got a job, a decent-paying job; I can "make it." But most of the people with whom my staff works do not have the choices that economic security brings. They're living on \$474 a month.

What are they going to do when managed care tells them, "No, I'm sorry, we aren't going to pay for that motorized wheelchair. No, you're going to have to leave the hospital the day after surgery. Sorry, we can't pay for any more prescriptions." Medicare doesn't pay for prescriptions. A lot of older people have to choose between food and medication. What kind of world is that? What kind of choices are we offering?

Then there are well documented medical journal studies reporting about involuntary Do-Not-Resuscitate (DNR) orders. I don't have any confidence that the medical system is going to function very nicely based on voluntariness. Then there's the Netherlands, a thousand involuntary assisted suicides a year.<sup>122</sup> Well, that's in a small country. Let's translate that figure to the U.S.

In fact, Joe Shapiro, in his article in *U.S. News & World Report* in January of 1997, pointed out that if you extrapolated the number of assisted suicides there in proportion to the size of the population here, the number in a year, by the time this gets underway, would equal the number of vehicular deaths and homicides combined.<sup>123</sup> I'm very doubtful that investigators and prosecutors are going to have the time, energy, and resources to carefully make sure that every assisted suicide of a disabled or terminally ill person was done with all of these regulations carefully observed.

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<sup>121</sup> HUMPHRY, *supra* note 6.

<sup>122</sup> See Shapiro, *supra* note 55, at 27.

<sup>123</sup> See *id.*

Let me just mention two more points: First, the threat to incompetent individuals. It's interesting that Ms. Tucker talked about the gentleman who was almost starved and dehydrated to death for five days. Luckily, he had her to save him in a healthcare system that obviously wasn't very careful about all the rules and regulations about withdrawal of treatment that we're supposed to have, i.e., two doctors' opinions, voluntariness and all the rest.

Already regulation is not working. But we don't have a lot of information. Withholding and withdrawal of treatment studies are not being conducted. We don't know who's having treatment withdrawn, or why, what their socioeconomic status is, their insurance status. Those studies need to be conducted.

Finally, I don't see how enforcement is realistic in the context of the current social pressures when the primary witness to what really went on is dead. When you weigh the risks of abuse against this desire for a "right," supposedly for a narrow few, maybe the rest of society thinks those risks are acceptable, but my brothers and sisters are already dying. Kenneth Bergstedt, Wallace Spollar, Christine Busalacchi. The list is very long. I object. People with disabilities need to object, and we need to be heard.

DR. BUDETTI: Our next speaker is Sallyanne Payton, a Professor of Law at the University of Michigan. She's a graduate of Stanford Law School. She has practiced law in Washington D.C., both in private practice and in the government. At the University of Michigan, she has taught administrative law and regulation.

She became involved in health care, in health care reform, and she served on the Task Force in the early days of the Clinton Administration, which is where I came to know her when I was involved with the drafting team. She continues to advise the United States Senate on health care reform. She joins us now to speak about the state deregulations.

MS. PAYTON: I want to come back and pick up after Kathryn Tucker and talk a little about how we got to where we are. For all the rhetoric about a personal "right to die," the real issue is the role of the State, the duty of the State, in ensuring that persons on the edge of life have access to medical care and some control over what can be done to them.

This problem starts, in the law, with the case of Karen Quinlan. Remember that before *Quinlan*<sup>124</sup> it was understood that to want to take one's own life under any circumstances, including resisting medical treatment, was a sign of the inability to make rational decisions, and therefore, of mental incompetence. So it was quite normal for resistant

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<sup>124</sup> *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

patients in hospitals to have the hospital staff petition for guardianship and then treat the patients over their objection.

By the 1970s, the public was having a backlash against high-tech dying in modern hospitals; and patients and their families turned to the law to resist. In order to do so they needed to persuade the courts not only not to authorize treatment against the will of the patient, but actually to put the patient's family or surrogate in a position to control the patient's care. This was a radical challenge to medical authority.

Now here is the problem for the State, as it was presented in *Quinlan*. Karen Quinlan was permanently unconscious. The State has the ultimate responsibility for such a person under its *parens patriae* power. The probate court appoints a guardian to look after the person, the ward, but the power the guardian exercises is the power of the State and the State is accountable.

One of the historically unequivocal duties of the State or guardian to the ward is to provide the necessities of life, including appropriate medical care. A guardian has both the duty to furnish and the power to consent to medical care for the ward. Karen Quinlan's family, after much consultation with their spiritual advisers in the Catholic Church, attempted to withdraw consent for the aggressive life-supports that were keeping Karen alive. The hospital resisted, and Karen's father, Joseph Quinlan, petitioned the court for the guardianship, announcing that if he were appointed guardian, he would refuse "extraordinary care" for Karen and let nature take its course.

The Quinlan challenge therefore forced the New Jersey Supreme Court to answer this question: when, if ever, is it permissible to allow a guardian to act in a manner that the guardian knows is almost certain to bring about the ward's death? The answer to that question turns out to be, as we know, "when the patient is permanently unconscious and the doctors and the patient's family and the hospital administrators all agree to give up on treatment and there is no substantial threat of lawsuit by others who disagree," but the court could hardly put it quite that way. So what it invented was a new way of talking about patients' rights.

What the New Jersey Supreme Court said was, "we're going to talk about this as an individual right, that belongs to Karen." Karen, while conscious, would have a right to refuse treatment; therefore she has the same right while unconscious. The pivotal point in the reasoning was when the court said that it could understand why someone who was to be permanently unconscious might want to stop the treatment, that the treatment itself might be a burden more than a benefit. The guardian therefore has the power to refuse treatment on the patient's behalf.<sup>125</sup>

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<sup>125</sup> See *id.* at 663-64.

But wait. Guardians cannot be given this power unsupervised, because this line of reasoning authorizes simple murder, first-degree murder in every state. On the other hand, it was important to allow the medical profession to decide how to stop treating patients where there was no more medical point to the treatment. The solution the New Jersey court devised was to give guardians power to withdraw consent, thereby eliminating the physicians' duty and power to treat; but to regulate the guardians by forcing them to respect medical authority and institutional norms.<sup>126</sup>

So if you read the order in the *Quinlan* case carefully you will see that it requires that the physicians be the ones who decide to terminate treatment, after consultation with the family and guardian. The guardian may not act on his own, and the physicians are not required to obey the guardian. The guardian is given a carefully hedged, regulated power that must be exercised in the context of professional standards applied by a regulated, publicly accountable profession and only in the relatively public setting of a hospital, itself a regulated institution. The real oversight power of the state is just a telephone call away.

After *Quinlan* there were more than twenty years of litigation before the United States Supreme Court addressed refusal and withdrawal of treatment in the *Cruzan* case,<sup>127</sup> in which it affirmed the general approach of *Quinlan*, but allowed the states to put some safeguards on the withdrawal of treatment to make certain that the patient would have wanted it done. So now we have this odd situation in which the language of the law is about individual rights while the actual practice is euthanasia.

But the euthanasia is accountable third-party decision-making under regulation, not the kind of unconstrained, eccentric, arbitrary, non-rational, expressive decision-making that is the right claimed by those who advocate the right to physician-assisted suicide as a right of personal autonomy.

There we have the problem. Is committing suicide the kind of activity in which the power of the autonomous person ought to be allowed to have its full expression? If so, there are many ways to exit this life that are more interesting than being poisoned by one's physician, and autonomous individuals and their willing collaborators can be expected to think of them. It is hard to understand why, if there is really a right to autonomy at the core of this, the right ought to extend only to the assistance of physicians.

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<sup>126</sup> See *id.* at 665-69.

<sup>127</sup> 497 U.S. 261 (1990).

In point of fact, the assistance of physicians points to another set of problems that makes the assisted suicide issue look a lot more like the refusal and withdrawal of treatment problem. There is every reason to worry that the patient's right to assisted suicide, just like the patient's right to refuse treatment, will become in practice a license for physicians to kill their patients. The word "suicide" means self-killing, but we understand from the experience of the Netherlands that administration of what kills is not always by the hand of the patient, and that some patients will prefer that way. The difference between "assisted suicide" and euthanasia blurs.

Who is to prevent the blur? The medical profession? Managed care is rearranging the physicians' incentives in ways that make it hard to be sure that individual physicians will be able to resist their own interest in hastening the deaths of some of their patients. For many of the patients, being alive is not cheap, and the State and the insurance carriers may be paying huge bills and pushing some of their financial risk off onto the physicians. The days when physicians were reliable protectors of life are over.

So where are we? Physician-assisted suicide needs to be regarded, realistically, as physician-assisted dying on the part of those whose medical condition is not yet so hopeless that they qualify for treatment under the refusal and withdrawal of treatment cases. It needs to be regulated in much the same manner, for the protection of the weak, toward whom we owe the greatest duty.

It is not realistic, however, in the economic crisis of the health care industry, to expect the medical profession to do the regulating. Partly because of economic competition, the medical profession has lost the professional infrastructure that once allowed it to stand up collectively for high standards of care and ethical behavior towards patients. Its present weakness translates into the inability to assume reliably the role of monitor for physician-assisted suicide.

Under these circumstances it seems dangerous to plunge ahead. The advocates of physician-assisted suicide have formulated their position in the context of a world that is passing away, a world in which the medical profession could be trusted with the instrumentalities of death because they could be trusted to use them only for the purpose of healing, a world in which physicians were rewarded for treating their patients, not for withholding treatment from them. In this new world the physicians are no longer in charge. Perhaps we ought not put them in the paths of temptation when it comes to their most vulnerable patients.

DR. BUDETTI: Our next speaker, Dr. Charles Von Gunten, is the Director of the Center for Palliative Medicine, Education and Research here at Northwestern Memorial Hospital. He serves as the Group Leader



for the Program in Palliative Care and Rehabilitation of the Robert Lurie Cancer Center of Northwestern University, which is a National Cancer Institute designated Clinical Cancer Center. He also serves as the Medical Director of the Hospice/Palliative Medicine Consultation Service, the hospice program at Northwestern Memorial Hospital. He's a recognized expert and has written extensively on the subjects of hospice care, palliative medicine, pain education, and the palliative care of AIDS.

DR. VON GUNTEN: I have been asked to speak to a physician's perspective on the slippery slope issue, providing the point of view of a physician at the bedside. I'm speaking primarily as a physician who specializes in palliative medicine. Although I'm trained as an oncologist and as a general internist, I mostly care for patients within an acute care hospital in a large metropolitan city. I see patients throughout the hospital for whom palliative care is at least being raised as an issue.

First, let me define palliative care for you and describe how it is implemented at Northwestern. Then, let me make a couple of remarks about general issues that come up around questions of assisted suicide, and then let me finish with one clinical vignette that we're currently caring for.

Palliative medicine has been defined as the total care of patients with progressive, far-advanced disease for whom the prognosis is limited and the focus of care is quality of life. When you define quality of life, I think the hospice literature and Cicely Saunders are so useful. Quality of life, meaning the absence of suffering, has four domains: physical, psychological, social, and spiritual.

In providing palliative care consultation I work with nurses, social workers and chaplains, and we are trying to bring palliative care to the general hospital setting. As we are an academic service, fellows, residents and medical students rotate on the service as well. We see patients in the intensive care units, general medical wards, surgical wards, emergency room, and on our acute palliative care hospice unit. We are asked to see fifty to eighty new patients per month, comprising 750 to 800 patients a year. About half of the patients have cancer. The remainder have a variety of non-cancer diagnoses such as congestive heart failure, chronic obstructive pulmonary disease, stroke, trauma, gastrointestinal bleeding, AIDs, and dementia. That's a large volume, and I would also observe that we are the only hospital in Chicago that has a service like this.

My first general comment is that around times of crisis and when suffering is acute, it is always compelling to me how much time and effort it takes to work through, not just the physical suffering, which is sometimes the easiest to take care of, but also the psychological, social, and spiritual suffering. That is because each individual and that individ-

ual's family, care givers, close associates are all at different places, have different needs, and identify problems differently.

Often it takes days of close attention and hard work with patients and families who are questioning and trying to cope with the acute hospital setting, trying to weigh the burdens and the benefits of therapy. Should we go with the therapy? Should we try the chemotherapy? Should I have the operation? Should I not? Can this pain be under better control? If I go home, how am I going to afford this? What am I going to go home to? Why do I have this illness? Why did it happen now? Tremendously time-consuming questions in a health care system that really isn't set up to deliver palliative care.

My second general comment concerns the financial aspect since this is a session on money and its effect on the law and social contextual issues around assisted suicide. The grief that we get from insurers as soon as the word "palliative" appears on the chart, or the word "hospice" is whispered, or a Do Not Resuscitate status is instituted is unbelievable. The insurer says, "Well, they don't need to be in the hospital any longer." Now, that stuns me. These are the sickest patients in the hospital, but every day of our life in the hospital, our team deals with the financial pressures to discharge patients. That is both in the general hospital setting as well as in our acute hospice/palliative care unit.

Let me finish with a clinical vignette of one patient for whom we are currently caring in order to describe how, from my perspective as a physician, the issues being discussed here get played out. We were asked to see a gentleman with widely metastatic stomach cancer. He's a highly educated, very involved man, who has been married for a few years to a professional woman. His wife is away from home for two or three days at a stretch for her work, and she is back close by for the rest of the time. He lives in a rural area of Wisconsin, on a farm which he loves dearly, and he has had very aggressive chemotherapy.

When we met him, he wanted to live pretty much at all costs even though he was clearly bed-bound and no chemotherapy could be administered because it would kill him in his condition. He was experiencing constant nausea and vomiting. His bowel was obstructed due to his tumor. In addition, he was experiencing a considerable amount of abdominal pain as well as diffuse body pain. He's being cared for by a group of oncologists in the hospital who are generally very good at pain control and symptom control.

After we were consulted it took several days to work through the issue of why palliative care was being suggested to him in the first place. As you can imagine, having someone from the palliative care/hospice service come to see you is often perceived as a sign that the doctors are giving up. We often go through a process of saying, "Palliative care is

not about giving up. Our goal here is to help improve your quality of life.”

Physicians’ goals, historically, are to relieve suffering and to prolong life. Too often, physicians and patients focus on the prolonging life part. We can relieve the suffering and prolong life. The two can go together. What we said to this patient was, “Our goal here is to help you live better. We can’t change where your cancer is right now. We can, though, help you with how you’re feeling.”

Northwestern has more than one thousand physicians on staff, twenty medical oncologists, multiple surgical oncologists; and quite a few people had already been involved in this patient’s care. It just so happens that because of my interest and involvement in palliative care and my reading of the rather obscure literature, I knew of a way that could make this man’s physical suffering less, by relieving his obstructive symptoms. He agreed to move to the palliative care unit just for a couple of days where his symptoms got better. Then he said to me, “Well, this is it, right? I mean, the cancer. All right, I agree, I understand the cancer is advanced. There’s no more chemotherapy available. So why not end it? Doctor, end it.” He said this to me when I was seeing him with our whole group on rounds. His physical symptoms were much better than when we first saw him but certainly not under complete control. A nurse said to him, “Aren’t there other reasons to continue to live? Aren’t there other things that are important to you?” He answered: “Well, I’m no longer able to be productive. I can’t do what I was doing. Let’s just end it.” He was clearly competent to make that decision, the decision to end his life.

Then he reflected and said, “Well, you know, my wife, she’ll be upset if I’m gone.” Over the course of the next three or four days, combining aggressive use of medications along with team approach to the non-physical aspects of suffering led to a change in his point of view. When I saw him three days later, after a lot of work by the nurses, doctors, social workers and chaplains, he said these days were probably the most meaningful time in his life. He had reached a sense of connection with his wife and a sense of himself that he had never thought possible and would never have imagined. He was so grateful for that period of time. If you had asked me at the time what his prognosis was, I would have said two days, maybe three; and I see dying patients every day. That was a month ago.

I’m not quite sure why this patient is still alive. He is still receiving the therapy; as far as I can tell, he is still obstructed. He is not getting much in the way of nutrition. He’s certainly not getting much in the way of fluids. He’s very happy in the hospital setting. This is therapy that

could not be administered anywhere else because of the complicated medical regimen and the nursing expertise required.

His wife is now able to work. She leaves and is able to come back in and visit him. He's feeling very comfortable with the people at the hospital, the volunteers, and the nurses. The nurses say that he's speaking more slowly, or sort of dragging things out in order to keep people in the room as long as possible because he's enjoying the attention.

It is very expensive for this man to be in the hospital, and I cannot tell you how great the pressure from the insurer is to have this man move on. Yet, he clearly is experiencing relief of suffering, and wholeness of life. It is only because of a relatively unique set of circumstances: my interest in this area, my hospital's support of me and our palliative care service in the hospital, that we were able to achieve this. There are only four other units like ours in the entire country, and there are maybe twenty-five or thirty palliative care consultation services in the country.

My experience is that when a patient, like this man, requests help in dying, the patient is suffering on multiple levels. When the suffering is relieved using a broad model of care, the request is withdrawn. In our experience the most common source of requests for assistance in dying is from family members and sometimes the medical staff, and it always involves projection. "Oh, can't we relieve his suffering: it is going on and on and on. Can't you see? Can't you see the patient is suffering? What's the use of all this? Can't we just be done with it? We would all feel so much better. He would feel so much better if you would end all this." But when you ask the patient he says, "Oh, I'm fine, comfortable."

Severe illness in the hospital affects everyone in the family. "Should I be at the bedside? Should I go to work? If I don't work, I can't pay the insurance premiums to keep him here. I've got other family, other people elsewhere who also need me." There's a pressure to have this be over. It is easier, and cheaper to end life than to work to relieve the suffering of patient and family. The other aspect that's often left out is physicians. Physicians suffer terribly when their patients are ill and when they can't make them better. I can't tell you how often my role as a consultant is to help the attending physician cope with the loss of someone with whom the physician feels very close and with whom he or she has built a relationship over time. In this case I've presented to you, if you had asked for a second opinion from any of the rest of the medical staff, save one or two other people, none would have known about the way to treat this man's intractable nausea and vomiting. The safeguard was the prohibition against euthanasia and the drive to relieve his suffering.

From my point of view, the safeguards and the push to do more, to do better, to offer better palliative care, and to take the time brings in-

credible benefits that I think are not always apparent to people prospectively. I can't tell you how many patients and family members who have asked for assistance in dying have a totally different view once the patient begins to receive palliative care. The family has a very different view when it is over and the patient has died.

DR. BUDETTI: Now I come at this from a very different perspective, the perspective of somebody who spends a lot of time thinking about health care insurance and health care coverage. I'm going to try to focus on an economic issue that has come up repeatedly throughout the conference. I want to focus on managed care in a very specific way. I want to focus on how it is a potential threat to the very concept of the physician. What are we thinking about when we think about what a physician is, and who that physician is, that could be asked to or expected to, assist with suicide?

Most of the discussions so far have focused on traditional ethical conflicts facing physicians—the physician's duty to do whatever is possible to help cure the patient contrasted with asking that physician to do something actively to shorten the patient's life. Even if we get to the point where some people might agree that it might conceivably be that it was in somebody's best interests to die, we're still left with the question of whether it should be a physician who, in fact, assists with bringing about death.

Many aspects of that dilemma are being discussed during this conference, and I think that a prior question really needs to be, what are our assumptions about the physician? What are our assumptions about the role of the physician and the physician-patient relationship in our society? Are they changing in a way that affects this discussion about physician-assisted suicide? Is that relationship undergoing such a profound change that our traditional ways of analyzing these ethical dilemmas are now missing the mark? Is the concept of a 'physician' being compromised by the financial interests of physician employers or by third-party payers such that their own decision-making is not taking place within the framework which we otherwise might have thought it was?

We talked a lot about financial considerations in the nonmanaged care setting, in the traditional fee-for-service indemnity setting. People always questioned whether physicians were acting in their patient's best interests by ordering every test and performing every possible procedure and administering every possible treatment, as long as the patient was legally alive. The question then, was whether physicians were merely acting out of the patient's best interests in offering them any hope, however slim, or whether their decision-making might have been compromised somewhat by the fact that administering all these treatments and keeping the patient around long enough to sustain the course of therapy

was financially lucrative to the physicians. So there's always been this question about the financial conflict of interest.

However, in that setting, at least what the physicians were doing was consistent with their fundamental obligation, our fundamental obligation, to do everything possible for patients, and we analyzed the ethical conflicts in that context. Now the question is whether that setting has changed. Nowadays, of course, there's concern that HMOs and other managed care organizations, create incentives to do so little for patients that we really need to rethink what it is we're asking of physicians.

In an antitrust case a couple of years ago, the *Marshfield Clinic* case, judge Richard Posner, echoed these sentiments. He said, "Many people . . . fear that HMOs skimp on service. . . . From a short-term financial standpoint . . . the HMO's incentive is to keep you healthy if it can, but if you get very sick, and are unlikely to recover to a healthy state involving few medical expenses, to let you die as quickly and cheaply as possible."<sup>128</sup>

Concerns such as these have now been taken into the physician-assisted suicide context. Mary Grayson, in an editorial in the *Journal of Hospitals and Health Networks* under the headline *Knockin' on Heaven's Door: Public Debate Over Physician-Assisted Suicide*, requires managed care companies to explain their policies. Grayson says, "Managed care leaders are downright furious that people think that they would withhold treatment or deliberately encourage the terminally ill to end their lives just to save money. . . . And fairly or unfairly, there is a growing unease in this country about what managed care firms might do, particularly in the wake of drive-through deliveries and 24-hour hospital stays for mastectomies."<sup>129</sup>

Now, this is at one level. This discussion really focuses on the corporate interest of the managed care entity and the pressure that you've heard about from other speakers that can be put on physicians. My concern goes one step further: whether the physicians themselves are being put into situations in which their decision-making is now being compromised, not just by the managed care plan's bottom line, but by the physician's own personal financial interests. In other words, are the physicians themselves now highly conflicted to the point where their decision-making is questionable?

A recent Harris survey conducted for the Commonwealth Fund addressed the issue of physician incentives and found that among physicians with patients who needed approval for specialty services, 10 percent reported that they had a financial incentive not to refer patients to

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<sup>128</sup> *Blue Cross & Blue Shield v. Marshfield Clinic*, 65 F.3d 1406, 1410 (7th Cir. 1995).

<sup>129</sup> Mary Grayson, *Knockin' on Heaven's Door: Public Debate Over Physician-Assisted Suicide*, 70 J. HOSPITALS AND HEALTH NETWORKS 7 (1996).

specialty or subspecialty care in cases when they had some doubt about the necessity of such services. Ten percent doesn't sound like much, but this is a rapidly growing side of the equation; and the point here is that doctors used to be expected to do whatever they thought might offer some hope. Now in legal terms it's turning around the burden of proof. If there's some doubt, now doctors seem to consider whether there is a financial incentive not to administer the treatments.

Moreover, physicians' working arrangements are changing. That same Harris poll indicated that less than half of physicians actually own their practices, or were owners in their own practices, and more than half were on salary for all of their practice income.

This is a startling development. Physicians now are largely salaried employees and not employees of professional corporations that they themselves own. So they are now employees who have to respond to some sort of corporate interest. Physicians are also put into positions where they get extensive bonuses based upon their performance, and in large part, that's a financial performance.

Another related development, of course, that you've heard a fair amount about is the breakdown of the continuity of the relationship between the physician and the patient. At the same time that physicians are developing these financial interests that conflict with their decision-making, they are also losing touch to some degree with their patients. A lot of the plans average a complete turnover of all the enrollees in health plans every three years, and with that turnover there is a turnover of physicians as well as patients.

Judge Reinhardt, in the *Compassion in Dying* case when it was before the Ninth Circuit, acknowledged that the day of the family doctor who made house calls and knew the frailties and strengths of each family member have disappeared, but he went on to say, in an optimistic statement: "We believe that most, if not all, doctors would not assist a terminally ill patient to hasten his death as long as there were any reasonable chance of alleviating the patient's suffering, or enabling him to live under tolerable conditions."<sup>130</sup>

This is an optimistic view, but I think it hearkens back to a narrow view of the physician as someone who, in fact, is there exclusively for the patient's interests. I'm concerned that our concept of the physician is not adequately reflecting the complexity of the situation in which physicians now increasingly find themselves. Thus, my question is whether either the tradition of physicians discreetly helping patients to die or the emerging question of physicians actively helping their patients to die

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<sup>130</sup> *Compassion in Dying v. Washington*, 79 F.3d 790, 827 (9th cir. 1996), *rev'd sub nom.* *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

should still be viewed in the context of our traditional assessment of their ethical obligations, given the emergence of these firsthand financial incentives that I believe could compromise their position.

These financial incentives, by the way, have themselves been subject to intense scrutiny in a number of states. The question is whether physicians are violating their ethical obligations and their obligations under licensure statutes by signing contracts that: call on them to withhold treatment from patients under financial pressure; or prohibit them from discussing with patients the availability of alternative treatments; or that bar the patient from knowing what the financial incentives are that the physician works under. A number of states are looking into the ethics of those situations wholly outside of the question of physician-assisted suicide. The ethics of physicians entering into these kinds of employment relationships is itself being questioned.

If society is questioning whether physicians, whom it educates and licenses, should be allowed to enter into these arrangements, what does that say about our concept of the physician when we turn to issues as difficult as assisting suicide? I believe that this is a question that needs to be factored into the debate: What is the relationship between the traditional concept of a physician and the role of the physician in assisting suicide?

Our next speaker is Leigh Bienen. Leigh Bienen is a Senior Lecturer in Law at Northwestern University and a criminal defense attorney. Her areas of expertise include capital punishment, sex crimes, and rape reform legislation. She directed a study of all homicide cases in New Jersey after the reposition of capital punishment and drafted the model sex offense statute, which was the basis for rape reform legislation in a number of states and was enacted in New Jersey in 1979. She has been intimately involved in the planning and organization of this conference, and she also has another professional life as a published author of fiction, but that's for a different conference.

MS. BIENEN: My comments are about assisted suicide as a subcategory of homicide. We've been hearing about assisted suicide as a legal, medical, moral, philosophical, religious, and ethical question today; but, of course assisted dying is also a circumstance, a set of actions by individuals and groups, which has the potential to land some in the middle of the criminal justice system.

Assisting suicide is a crime under almost all state criminal codes, but it is not the same crime in every state. The penalty structures vary greatly. Not only are there over fifty independent legislative bodies—that's omitting the United States Congress—demographically dominated by older white men, but there are also literally thousands of independent prosecutors in the states whose jobs are to enforce these laws, and



thousands upon thousands of criminal trial and appellate judges whose jobs are to administer and interpret them.

The state legislatures have the power, first, to continue to criminalize assisted suicide for doctors and others; second, to enact statutes regulating physician-assisted suicide—basically decriminalizing or legalizing assisted suicide under certain restricted circumstances as the individual legislature sees fit; or, third, to abstain from the issue, leaving the existing criminal statutes prohibiting assisted suicide or the common law in place, as they exist in all but a few jurisdictions.

The traditional state statutes prohibiting assisted suicide are part of the states' homicide provisions. Statutes such as the Oregon Death with Dignity Act<sup>131</sup> either repeal these criminal statutes or create a defined exception to them. Some of the recently enacted statutes combine decriminalization with some legalization or regulation.

The New Jersey law is a typical traditional statute: "A person who purposely aids another to commit suicide is guilty of a crime of the second degree if his conduct causes such suicide or an attempted suicide, and otherwise of a crime of a fourth degree."<sup>132</sup> These statutes carry over a common law offense. They are essentially a variation on manslaughter provisions and stipulate a legally imposed punishment for causing the death of another.

Causing suicide, that is, harassing a person to the point where he or she kills him or herself, is in most jurisdictions a form of murder. Attempted suicide is usually not a crime, but a misdemeanor. Suicide is not a crime, although there may be legal consequences for the heirs, and this issue should be discussed in the policy debate over assisted suicide. Life insurance policies may prohibit heirs from inheriting from a suicide, and these consequences can influence the decision of a patient or a family.

In 1979, in New Jersey when the criminal code and common law offenses were being revised, the principal legislative committee came close to eliminating the provision criminalizing assisted suicide. In 1979, the legislature was not envisioning its application to the circumstances primarily talked about in this conference. There was a general feeling that the preferred policy choice was to leave the provision in place. The statute would then be there should circumstances arise in which a prosecution was appropriate. I was in the Committee room at the time, and I was struck by how close the Committee came to decriminalizing assisted suicide, and also, incidently, solicitation for the purposes of prostitution. In fact, the discussion of the two issues was similar: Why have a criminal statute which is never used?

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<sup>131</sup> OR. REV. STAT. § 127.800-897 (Supp. 1996).

<sup>132</sup> N.J. STAT. ANN. 2C:11-6 (West 1995).

The existing statutes in the states create ample opportunity for prosecutorial discretion. Any one of the thousands of county or local prosecutors in the states has the authority to decide whether or not to prosecute a case. Then, one of the thousands of trial court judges, who regularly sit in criminal court hearing cases of robbery, assault, credit card theft, or murder, will have an unusual day and preside over a trial for assisted suicide, and perhaps decide upon the sentence. Of course, in most cases it's the judge who sentences even though the jury will decide guilt, or perhaps the judge will also decide guilt.

Criminal statutes are not self-executing. The county prosecutors in all but two states are elected. In those states where local or county prosecutors are not elected, their appointment is a very political process. In the elections of prosecutors and judges, their appearance in the evening news and in the press influences voters. The election and appointment of prosecutors and judges are governed by numerous factors, including political, legal, and geographical considerations. A widely reported prosecution in an assisted suicide case under a new or traditional assisted suicide statute has the potential for a large positive or negative effect upon a prosecutor or local judge and court. In many states all judges, including appellate judges and state high court judges, are elected. The judges will be mindful of the potential, favorable or unfavorable, media exposure.

In a direct confrontation, such as when Dr. Kevorkian presents the county prosecutor with a proven factual basis for a prosecution for assisted suicide—a dead body and a videotape—the local prosecutor finds his discretion preempted, or at least severely tested. The publicity generated by the actions of another, take Dr. Kevorkian, for example, forces the local prosecutor to prosecute, or to explain why he is not prosecuting.

These are exceptional circumstances, however. Ordinarily how would a local county prosecutor know about a circumstance of assisted suicide? Only if the doctor reports or if the family reports. If a nurse or observer reports, none of these could force the prosecutor to prosecute for the crime of assisted suicide. The family or observer could put public pressure on the prosecutor, but the local prosecutor would decide whether, when and how to prosecute. Or, a prosecutor wishing to act on this issue can seek out a case by asking those who might be in a position to know of such circumstances to inform him or her. Cases do not get into court by themselves. How the case is prosecuted can also vary greatly.

Suicide has traditionally been studied by criminologists, using analyses of cause of death, circumstances of death, and observations of patterns by age, race, sex and geographical distribution.

Of course, suicide has also been analyzed by lawyers and criminologists in terms analogous to a homicide: what is the *actus reus*, the act-causing death; what is the *mens rea*, the intent to cause death. The question of intent is particularly interesting in the assisted suicide context because in theory you have an intent to cause death on the part of the person who is being killed, and you also have an intent to cause death on the part of the person assisting in the suicide. Two people have the criminal intent, and one is the person killed.

Let's look at some traditional analyses of suicide, in comparison to analyses of homicide. The number of deaths by suicide for February of 1996, was 2,050, for a suicide rate of 9.8 per 100,000.<sup>133</sup> That compares with 1,620 homicides for February of 1996, and a homicide rate of 7.7 per hundred thousand.<sup>134</sup> In other words, there are many more suicides than homicides, a fact surprising to many. The majority of suicides, more than 60 percent, were gun suicides, more than the actual number of homicides committed with guns.<sup>135</sup>

A person is more at risk from dying of suicide than from many serious diseases. The rate of suicide among whites was close to twice the rate for blacks, and the rate for white men was more than four times the rate for white women.<sup>136</sup> Suicide was the ninth leading cause of death in the United States in 1994, right after deaths due to HIV.<sup>137</sup> The official data on suicides in 1994, show a total of 31,142 suicides in 1994, and 31,102 in 1993, in comparison to approximately 22,000 homicides in 1996.<sup>138</sup> In contrast, the number of deaths for the same period from motor vehicle accidents was 44,040 or 16.7 per hundred thousand.<sup>139</sup> The number of deaths in motor vehicle accidents was about the same as the number of deaths of women from breast cancer.<sup>140</sup>

The number of deaths from homicide including what are euphemistically called "other legal interventions," meaning the police killing a person, was about the same as the number of deaths from chronic liver disease.<sup>141</sup> The number of deaths from suicide was more than the number of deaths from cancer of the pancreas and only a few thousand less than the total number of deaths from prostate cancer, and about 75 percent of the number of deaths ascribed to HIV or AIDS during the

<sup>133</sup> See CENTERS FOR DISEASE CONTROL AND PREVENTION, *Births, Marriages, Divorces, and Deaths for March 1996*, 45 MONTHLY VITAL STATISTICS REP. 14 (Sep. 26, 1996).

<sup>134</sup> See *id.*

<sup>135</sup> See *id.* at 15.

<sup>136</sup> See *id.* at 10-12; John L. McIntosh, *U.S.A. Suicide: 1994 Official Final Statistics*, at 2 (visited Feb. 12, 1998) <<http://sun1.iusbu.edu/~jmcintos/Suicidestats.html>>.

<sup>137</sup> See McIntosh, *supra* note 136, at 7.

<sup>138</sup> See *id.* at 2; CENTERS FOR DISEASE CONTROL AND PREVENTION, *supra* note 133, at 14.

<sup>139</sup> See CENTERS FOR DISEASE CONTROL AND PREVENTION, *supra* note 133, at 14.

<sup>140</sup> See *id.* at 13.

<sup>141</sup> See *id.* at 14.

same period.<sup>142</sup> The majority of suicides were gun suicides. So what are we to make of this? There are more suicides than homicides and more and a greater proportion of gun suicides than gun homicides, although you wouldn't have that impression from reading the newspapers.

Breaking down the comparison of suicides and homicides by age and gender, homicides and suicides trade rankings back and forth. Homicides are greater than suicides as a cause of death for the ages fifteen to twenty-four, and especially for men between those ages.<sup>143</sup> There's relative parity between homicide and suicide for women between the ages of fifteen and twenty-four. For women between twenty-four and forty-four, more die from homicide than suicide, whereas more men die of suicide than homicide in the twenty-five to forty-four age group.<sup>144</sup>

Those over sixty-five disproportionately killed themselves with guns, but, again, more than 60 percent of all suicides were gun suicides.<sup>145</sup> Suicides are far more likely to be committed by men than by women, although women attempted suicide three times more often than men.<sup>146</sup>

There are strong regional variations among the incidence of suicide, with Nevada having the highest rate and the mountain states having a rate almost twice as high as those for New England and the Middle Atlantic states. Washington D.C. had the lowest rate which may or may not reflect the racial demographics or the generic optimism of those in politics.<sup>147</sup> In the category of persons aged sixty-five to seventy-four, the suicide rate per hundred thousand was 15.3, rising to 21.3 for the ages seventy-five to eighty-four, and 23.0 for those eighty-five and older.<sup>148</sup> For the equivalent age groups the homicide victimization rate was much lower.

Is suicide a public health problem? The discrepancies for men and women and between blacks and whites are particularly provocative. Of the more than fifty Kevorkian people, well over forty are women. Why are women overwhelmingly asking for help in dying, especially from Dr. Kevorkian? What is the age and gender distribution for the diseases from which people are suffering when they request suicide? Little or no data are available to answer this question.

Do we know how many of the reported suicides are assisted suicides, similar to those in the circumstances discussed today? No, but it's

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<sup>142</sup> See *id.* at 14-15.

<sup>143</sup> See 1996-97 INJURY CHARTBOOK, NATIONAL CENTER FOR HEALTH STATISTICS 155, 158 (1997).

<sup>144</sup> See *id.*

<sup>145</sup> See McIntosh, *supra* note 136, at 4.

<sup>146</sup> See *id.* at 3, 6.

<sup>147</sup> See *id.* at 8-9.

<sup>148</sup> See *id.* at 8 (figures from 1994).

a good guess that 60 percent of the suicides—gun suicides—are not physician assisted. Typically doctors, even Dr. Kevoorkian, do not go marching into the patient's room with a handgun. It seems there are no data on the number of "assisted suicides" or even on "possible assisted suicides."

Presumably, some subset of the 40 percent of the 31,000 plus suicides a year are potentially "assisted" suicides. That would be approximately 12,400 nongun suicides, which could potentially be "assisted" suicides.

Should suicides be analyzed as a subcategory of violence? Certainly. Perhaps gun sellers should be viewed as facilitators with a theory of transferred liability applied to them, such as that applied to bartenders or social hosts in some jurisdictions. There's an eerie similarity between the way assisted suicide is perceived by the public and the form legalized capital punishment takes in America in the 1990s, death by lethal injection. After all, if we're going to give our worst criminals a "lethal injection," and perceive it as an easy and predictable death, why shouldn't we be doing the same for our nearest and dearest? Isn't it the same as taking your old cat or dog to be put to death and sent to pet heaven? Isn't it the humane thing to do? Perhaps, if pet cats and dogs were being killed the way we kill our criminals under the authority of capital punishment statutes, there would be more public outcry.

Why not a "lethal injection" for those whom society no longer wishes to care for, or pay for the costs of institutionalization? One favored argument for capital punishment, after all, is the argument that it's cheaper than keeping the bad guys, worthless members of society, in prison. So what about the old, the infirm, the less than perfect? As Dr. Betts noted, there is some darkness there. People's attitudes, or their expression of opinion, may seem, or be, cynical, until the issue comes close to home.

The suicide rate has been declining from 1989 to 1994.<sup>149</sup> Surprising to me, was that the suicide rate has declined since 1933, although there has been an increase for men, but not for women, or the country as a whole in the past decade.<sup>150</sup> The rate for whites has declined dramatically since 1933, and has increased a small amount for nonwhites. The suicide rate for those sixty-five and over has declined precipitously since 1933, from forty-five per hundred thousand to about nineteen per hundred thousand, which allows me to end this brief statistical profile on an optimistic note.<sup>151</sup> A small group of people may be asking for help in killing themselves, but a smaller number of people are committing suicide than at any other time in this century.

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<sup>149</sup> See *id.* at 13.

<sup>150</sup> See *id.* at 12-13.

<sup>151</sup> See *id.* at 13.

DR. BUDETTI: Our next speaker is a nationally and internationally distinguished physician and scholar, James Bowman. Dr. Bowman is Professor Emeritus in the Departments of Pathology and Medicine and the Committees on Genetics and African-American Studies at the University of Chicago. He's a Senior Scholar of the MacLean Center for Clinical Medical Ethics and is a Fellow at the Hastings Center in New York. He was the Director of the pathology laboratories of the University of Chicago from 1971 through 1981, having served as Professor and Chairman of the Department of Pathology at Shiraz Medical Center in Iran from 1955 through 1961.

He's a recognized expert and scholar in hematological population genetics and general human genetics. He's won a number of awards and honors including the Alumni Award for Distinguished Post-Graduate Achievement in the fields of medical research and education at Howard University and the Gold Key Award from the University of Chicago Biological Sciences Alumni Association. He's the author of over ninety publications and is currently writing two books with very provocative titles, one entitled *Eugenics Never Died* and the other entitled *Standing on the Shoulders of Giants: The African-American Legacy of the University of Chicago*.

DR. BOWMAN: Thank you very much. I would like to first thank the organizers of this conference for inviting me, and I would like to personally thank Professor Sallyanne Payton, who was my daughter's mentor and favorite professor at the University of Michigan Law School. This is the first time that I have had the opportunity to meet her.

I speak with some expertise because I have been disabled many times through my seventy-four years of life. I had a coronary twenty-four years ago. They said it was mild, but there's no such thing as a mild coronary as far as I'm concerned. I had a bleeding ulcer, aspirin-induced. I had a radical left adrenalectomy and nephrectomy for cancer of the kidney nine months ago; I have ocular hypertension; and I have had hearing aids for the last month. So I'm an expert in all these fields, too.

There are over 800,000 references to assisted suicide on the *Infoseek* web site alone. On the same web site there are over one million references to health care, United States. Someone from Mars who accessed these would have surmised that assisted suicide is almost as much of a public policy issue as health care.

Ethical problems with socially assisted dying, however, pale alongside the problems of our health care system, which is inferior to that of all of the other major industrialized countries. Our infant mortality rate is higher than that of twenty-two other countries, even Cuba's infant

mortality rate is lower than ours.<sup>152</sup> We castigate President Castro about freedom, but a larger proportion of our infants is also free: free to die. We parrot the shibboleth: health care resources are scarce, but we should append this catchphrase. Health care resources are scarce for poor people.

I have termed our health, educational, economic and social inequities, "Passive Eugenics."<sup>153</sup> Passive Eugenics is societal hypocrisy about an inequitable health care system that is inferior to that of all other major industrialized countries, even though politicians and leaders of our commercial and so-called—and I emphasize that—not-for-profit health care industry persist in proclaiming the hoax that our health care system is the best in the world. It is not.

Passive Eugenics is the societal acceptance of infant and other mortality rates, which are extremely high. Passive Eugenics is a society that countenances homeless mothers and children living on the streets in sub-zero weather while academic poverty pimps make tenure and fortunes by investigating why poor children have lower test scores and achievements than their classmates, who have extensive libraries at home, parental assistance, computers with educational CD-ROMs, and access to the Internet.

For the purpose of this panel, I place Passive Eugenics with socially-assisted dying, or suicide with socially sanctioned dying, or, to put it bluntly, active and passive euthanasia. For example, several years ago, a working poor black father and mother attempted, at about two o'clock in the morning, in the winter, to obtain emergency care for their very sick two-month-old child at a medical center in Chicago. Several other hospitals had turned them down, and eventually the parents had to take their child to Cook County Hospital, where he died. Can you imagine yourself in that situation? If the child had been that of a member of the board of trustees or the medical staff, or a faculty member, or anyone who was distinguished or important, the child would have been admitted with alacrity. The parents knew why their pleas were in vain. The next day the parents were interviewed on television and said that if they had not been poor, their child would be alive. They were never heard from again.

These are the defenseless, silent, working poor who believe in our so-called democracy, the salt of the earth, whom we dump on daily. If they had been drug dealers, rapists, child or wife abusers, or wife killers, they would have had daily episodes about them on television, radio, and

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<sup>152</sup> See 1997 ALMANAC ATLAS AND YEARBOOK 173, 288 (Otto Johnson ed., 50th ed. 1997) (listing the infant mortality rates for Cuba (8/1000) and the United States (8.3/1000)).

<sup>153</sup> See James E. Bowman, *The Road to Eugenics*, 3 U. CHI. L. SCH. ROUNDTABLE 491-517 (1996).

in the newspapers and numerous magazines, and defense lawyers would trample on one another to proclaim their rights.

Tragically, I heard no one from the right-to-life movement who opposed assisted suicide but claimed this child's right to life. This working poor black family was not news, even though they had fulfilled all the precepts of our market democracy. Both of them worked; they had never been on welfare; they may have even had the ultimate keys to the kingdom: Churchgoers. But I'm not certain of this. Even so, passive, not active euthanasia had been perpetrated on this innocent infant. The specter of socially-assisted dying is an absolute disgrace.

We pontificate while there are forty million uninsured in the neglected class—I hate the word “underclass.” These Americans in this the most affluent of societies face societal euthanasia, but perhaps they are fortunate. No one would allocate thousands of dollars a day to keep them forcibly as living dead on machines. We say that they are free and we are free, unlike the freedom in our enemy countries. Oddly, we never mention the lack of freedom and human rights atrocities in our friendly countries. Yes, our neglected class is free. To paraphrase Anatole France, the neglected class has, like the wealthy, the same freedom to live under bridges and beg in the streets.

Our health care establishment, with a few exceptions, is loudly silent about executives of managed care systems who individually siphon millions of dollars yearly from their captive health care subscribers by denying access to appropriate medical care. This is unabashedly premeditated murder. They apply cost-benefit analysis to human life, which is disgraceful.

Now, it has been inferred that a major objection to assisted suicide is that it will be disproportionately practiced on poor minorities and lead to genocide. I think this is nonsense, because the denial of health care which is practiced every day is cheaper. They would not even get in the door. The specter of genocide is waved to dupe poor people into believing that society cares for them, but they know better. Poor people are daily on the front lines of health, economic, social, and political discrimination, where there are no trenches or bomb shelters to hide.

But please do not wave the Constitution in my face. Slavery, lynching, school and racial segregation, the denial of voting rights to women and blacks and other atrocities were all at one time constitutional, and many of these inhumanities are still with us today.

The awesome power of the State is also now descending with unspeakable horror to deny health care to Mexican immigrants and health care and schooling to their children. These much maligned immigrants are merely recouping lands that we stole from their ancestors and taking



jobs that U.S. citizens shun. This is my final example of active societal euthanasia, but the examples are endless.

When health care workers, physicians, theologians, academicians, politicians, jurists, and legislators who oppose assisted suicide become ethically consistent and also challenge socially sanctioned dying, and active and passive euthanasia by our inequitable health care system, I will then respect their position, but I will still dissent.

AUDIENCE MEMBER: I would just like to follow up on Professor Payton's remarks by saying that another consequence of the withdrawal of treatment cases has been the withdrawal of treatment from infants with disabilities that, in fact, are not inconsistent with a normal life span and a reasonable quality of life. That's another very drastic fall down the slippery slope.

AUDIENCE MEMBER: A question for Professor Bowman. Since persons with disabilities were the ultimate victims of euthanasia in Nazi Germany and the ultimate victims of eugenics, do you believe that since eugenics never died, this is the continuance of that sort of philosophy, that the passive euthanasia that you were talking about is a continuance of that policy for persons with disabilities?

DR. BOWMAN: I think that eugenics is alive and well in the United States, and we can talk another couple of hours on that with respect to prenatal diagnosis. But I still will defend the woman's right to make her own decision as far as what's going to happen to her body with respect to prenatal diagnosis and abortion.

AUDIENCE MEMBER: I'm a member of Not Dead Yet, and I would like to make a point for the audience's benefit. Not Dead Yet is emphatically not a part of the right-to-life movement. We have nothing to do with the right-to-life movement; we don't want to be identified with them; we are a specialized group of persons with disabilities that have organized around this one issue because we agree with Dr. Bowman that eugenics never died.

I would like to address a question to Ms. Coleman. Ms. Tucker talked about the constitutional right to assisted suicide in her legal remarks, and I would also address this question to her if she were here. Do you see a problem with confining a constitutional right to assisted suicide exclusively to people with terminal illnesses, or is there a danger of expansion, and if so, how and why?

MS. COLEMAN: I think that if there is a constitutional right found, it would be difficult to limit that right. That's basically the nature of a constitutional right: if something is declared a constitutional right, then limitations on it are very heavily scrutinized.

I suspect that the right-to-die proponents who brought these cases not only hand-picked their plaintiffs to be the very extreme cases that Mr.

Shapiro was alluding to this morning, but also that they have the strategy of asking for a constitutional right, knowing that that is a completely absurd concept. In fact, they intend in effect to negotiate the second point. If it is declared unconstitutional, then it's a states' rights issue. I feel, frankly that the so-called right to die should be found unconstitutional under the Equal Protection Clause as it's currently being proposed, because some people, based on health status, would have this so-called right to live which would not, in fact, be granted to people who don't have that health status. So it is, in fact, a violation of the Equal Protection Clause to create the kind of supposedly narrow right to die that proponents are talking about.

MS. PAYTON: In the interest of balance, I would respect the characterization of the proponents of the right here. I think a good many of the proponents and a good many of the people in Michigan who are involved in litigation are the able-bodied elderly and persons with a terminal illness, persons who were never disabled, and persons who were probably not thinking about the disabled community when they filed their lawsuit. What they are concerned about is their own control. They are people who have historically had mastery over themselves and they wish to continue that. I know that the question of death with dignity is a matter of grave concern for many high-status elderly people.

MS. BIENEN: I would like to add that I assume that the lawyers who have been arguing the cases *pro bono* for the right to die would say that: "Well, that's what courts are for, to make distinctions. Yes, it's not an easy bright line distinction, and equal protection has been something which has been interpreted by the courts for hundreds of years. Yes, it's changed. Yes, there are contradictions, but that's what courts are for." I think that's how the proponents would respond.

Of course they hand-pick their cases, but anyone who brings that kind of litigation always does that. I don't know whether the decision deliberately to have plaintiffs who do not include anybody who could be classified as disabled was part of that choice or not. Sometimes these lawsuits develop and you don't have as much control as you thought you would.

## V. SESSION FIVE: REFLECTIONS BY MARCA BRISTO

MS. RYAN: Good afternoon, I am Shirley Ryan. I am the Chairman of Pathways Awareness Foundation in Chicago, Illinois and the President of Pathways Center for Children in Glenview, Illinois [and a member of the National Counsel on Disability]. I have the great pleasure of introducing Marca Bristo. Marca has also asked me to say a few words on the issue of youth and children with disabilities.

Let me start by saying: "Happiness is a thing called hope," and "Where there is life, there is hope." As a mother of a child with a disability, whom I love as I do my other two sons, and as a person who has helped co-found a center where thousands of children with physical disabilities have come for physical and speech therapy with their parents, I am encouraged by this conference focusing on the personal worth of a person with a disability.

A few minutes is not enough time to cite Marca's biography, for she is a unique and distinctive leader in the world of disability rights. As President and Chief Executive Officer of Access Living, Marca is nationally recognized for her innovative and entrepreneurial attempts in every direction to open doors and to open minds to the potential of persons with disabilities.

In 1979, Marca helped found Access Living, Chicago's only non-residential independent living program for people with disabilities. Marca is a past president of the National Council on Independent Living, which she co-founded. She served on a congressionally appointed task force on the rights and empowerment of Americans with disabilities, which helped create the ADA. Marca was the 1993 Henry B. Betts laureate, which many of us know and recognize as the Nobel Prize awarded for outstanding work in the field of disability.

It is through serving with Marca, who is our Chair on the National Council on Disability, that I have come to know Marca well and admire her work. The National Council on Disability is a presidentially appointed committee of fifteen whose mandate is to advise the President and the Congress on a myriad of public policy issues related to disability.

We began working together several years ago when the ADA first was passed. I at the Chicago Community Trust and Marca at Access Living helped create the first publication in magazine format that explained to the Chicago general public the Americans with Disabilities Act in 1990. We attempted to create a supplement which would help educate the public about the hopes, the history, and the rights of children and adults with disabilities.

My personal focus in disability is on issues concerning children and youth. It is very interesting to see the way that Marca has taken on the issues of children and youth and understood them, although these issues were not her original concerns. What Marca has understood is that children, youth, and adults encounter the same barriers; that children and youth are a powerful voice for waking the American conscience in order that many adult members of the society can learn to understand the potential of persons with disabilities.

In 1985, we created Pathways Center for Children, where children work hundreds of hours on state-of-the-art physical and occupational

therapy to learn the language of physical movement. We soon understood that it was "the stares, not the stairs which are harder!" We realized there was a need to create an organization that would reflect the parents' vision of the potential of a child with a disability.

People stare at children and talk to their parents instead of the child. Worse, people often ignore the parents and the child, or worse still, express pity about the child to the parents. On this I can speak on my own behalf and on behalf of many parents who I have known personally through Pathways Awareness and Pathways Center: how much the parents appreciate that child's life. They may have other children, but they are so grateful for the joy that child has brought them. The parents are grateful for that child's life!

Pity is an uninformed response. Parents know that their child with the disability has raised their conscience to the potential of each person. Parents are grateful for they understand the quality of life that has been brought to their life by their own child who has a disability, how much the experience has cemented their entire family by elevating family function beyond that of simple coping. The family attitude becomes one of, "Let's pull together as a team, and let us appreciate what each can do."

Children and youth have three major issues, and it is the purpose of Pathways Awareness to address all of these issues. Pathways Awareness provides education for and about early detection, early intervention, and inclusion of children with physical differences. Early detection is something we all understand. Early intervention is physical therapy and ongoing support so that the child will be able to function fully to his or her maximum potential. Inclusion for children and youth deals with inclusion not at the employment level, but inclusion into school and neighborhood activities with the proper supports, so that inclusion can be successful for everyone.

Inclusion means that my child will be able to participate in after-school activities, karate, scouting, dance, music, sports, not in a "separate and equal" environment, but in an inclusive environment with other children in order that all can share gifts. It is not what I will do for you, but what we do for each other by increasing each other's understanding of life that matters.

Inclusion also involves health care. How many times have parents with children, who happen to have disabilities, come to a physician who is both nervous and/or pitying? What inappropriate responses when, in the eyes of the parents, love raises the child beyond barriers. Life and hope are the questions that we are talking about.

I must compliment the conveners for their vision, for their courage, and for the enormous effort that they put in to present the balanced perspectives before us. All of us walked in here with a point of view and

many of us walked in with an emotionally charged point of view. We have heard many perspectives, many voices talking about things that are important. What is more important to us than our own life and our own ability to affect the quality of our life? Life has many levels of wisdom.

Marca understands the balance and the importance of each person's contribution to the disability movement. She understands the children, the youth, the adults and the multi-disability perspectives. My own mother was a public health nurse and Marca is a nurse. Marca approaches these issues with the judgment and experience of a fine medical practitioner, someone who understands the special quality in each of us and the gifts that each of us have to bring to each other.

So I present to you Marca Bristo.

MS. BRISTO: I was asked to reflect on the previous discussions and that's a different role for me. I spent the last two days or the last day and a half really listening to all of you, listening for elements of this issue that I may have missed. So I came into this without notes, without knowing what I was going to say. I'd like to ramble a little, if I may, and help you understand why the National Council on Disability has reached the very difficult position we did in the paper on physician-assisted suicide that I hope all of you picked up.

First, to Drew Batavia and Hugh Gallagher, I said to them a little while ago, "This is a first. This is the first time I'm able to look at a 'crip' and call him truly courageous." You were. Thank you. As I watched the film of the little baby learning her independence, I reflected back on one of the first employees of Access Living, a woman named Jill who was hired to run our personal-assistance program. Much like the baby in the film, she was born without arms and legs. When Jill was born, the doctor threw her away. She was breathing; she was living, but he threw her in the trash. The nurse recovered her and brought her to her mother. Her mother made certain she knew that story. She didn't shield her from the truth. She turned that truth into that girl's strength.

My mind wandered on after that to reflect on the deaf woman who came to her priest after an operation where both breasts had been removed in a bilateral mastectomy, which she did not know she was undergoing because an interpreter had not been provided. She was embarrassed to tell the practitioner she couldn't read his notes. Or, the young woman with severe cerebral palsy who came to see me—when I was a nurse—with a Ouija board pointing out her message to me. The tears started to flow, and she told me she just had a hysterectomy that she didn't want. No one had taken the time to listen to her.

I thought of my family member who is living with AIDS right now, defying all the odds for twelve years, twelve years. I thought of how when he first told us, he talked about helping him end his life, and how

grateful I am that he did not elect to do that. He's held out for all those twelve years for this right, and now he's beginning to change his thinking because of signs that technology has put drugs on the market that extend the lives of people with AIDS. But that technology is out of reach for so many because they can't afford it.

I thought how similar that discussion was to the people you've heard from today, people who talked about how they want to live in the community, but they are forced into institutions. For example, my current employee, Ann, developed a respiratory complication post-polio, and just adjusted to a ventilator. Her doctor called me to say, "What are we going to do? The managed care plan will send her to the nursing home but won't give her the limited period of time she needs with a skilled practitioner to help her learn vent care until she can do it herself."

I thought of my best friend who yesterday had a second, "Hail Mary" bone marrow transplant that is not likely to work. I thought of how many times he and I sat in the most painful discussion talking about the issue of physician-assisted suicide, he trying to convince me that was the most important act of empowerment he had before him, and me trying to convince him that he just hadn't looked at it the right way yet.

We've sat here for two days talking about these things. We are at a moment in time, a moment in time framed by a vote that yesterday overwhelmingly passed in the House of Representatives, which no one has mentioned, that bans federal funding for assisted suicide. I shared that with someone. He said, "But they are jumping the gun. They are looking at the funding before they've asked and answered the question, Should we do this?"

I thought of Drew and his friend Mike, and many questions came to my mind. Number one, why did Mike have so many repeated requests to die. Maybe he did; maybe he didn't have access to the \$400 cushion that I sit on to avoid the kind of sore he suffered from. Maybe he did; maybe he didn't. Why was he giving up when the leader of the disability political computer network, Fred Faye, has been lying on his stomach for the last twenty years mobilizing all of us into action. I don't think it's because he desperately needed the right to die. I think it's because no one had helped him get inside himself to believe in his ability to have a meaningful life whatever the challenges were. Why?

When we organized ten years ago and passed the Americans with Disabilities Act, I have to say to you from my heart: Physician-assisted suicide is not the right for which I thought we were fighting. It is not the right for which people went to jail. It is not the right for which people wrote hundreds of diaries, telling the world and the Congress what it means to be disabled in America. This is not what we had in mind. We

had in mind the reversal of discrimination, not the perpetuation of it through stereotype.

So I say to myself, how is it that friends like myself and the gentleman I referred to, friends such as Drew and Hugh and their friends, why is it that we can work so closely and so hard together on this issue and yet fundamentally disagree? I don't really have the answer. I have confidence in our belief in each other and that we will come through this. But when they speak to me of choice and self-determination, to me that choice is subterfuge. Death should not be our choice. Life should be our choice. Somehow I feel like we've gotten sidetracked.

The ADA was a tool for us. Yes, it was a tool, a legal tool, and as such it helps us fight discrimination. But it was so much more, is so much more than that to us. Have we forgotten the symbolism of what this law has meant? Have we forgotten the statement embodied in this law: for the first time in the world, a statement that disability is a normal part of life? Have we forgotten how important this message has been all around the world? The universality of disability happens to all of us everywhere. Have we forgotten that we embrace those values?

What would it mean if we took this path, right now, as a nation? What would it mean to all those millions of disabled people, 500 million plus and growing all around the world, who have looked into this country and have seen what we have seen, that is, the hope that there can be a different and better future?

Only last year, or the year before, the UN finally began the process of labeling discrimination against people with disabilities as a human rights violation. For the first time in history, we deplored China's treatment of disabled girls in the "dying rooms" where they put those little disabled kids to starve and die. We deplored it and called it a human rights violation, and yet here we are talking about legalizing that and calling it assisted dying.

We are at a fork in the road, and we can't have it both ways. We can't embrace the hope that the ADA embodies and choose a course that leads our people to death. Liberty interests? What liberty? What liberty for the 70 percent of the 49 million disabled people who are unemployed?<sup>154</sup> For some of my friends here who are black and female, that number goes up significantly.<sup>155</sup> What liberty? The ADA was about changing all of that.

So I then say, Why now? Why now seven short years after the world has begun to tackle the most difficult type of discrimination? Be-

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<sup>154</sup> See Blanck, *supra* note 25, at 873 n.95.

<sup>155</sup> See *id.* at 876 n.106.

cause it does take more than an attitude change. It sometimes takes some money. Why now?

I'm not a conspiracy-theory person, but I am a person who learns lessons from history, particularly from other movements that have preceded us. I'd like to tell you something about another moment in history that began when the women's movement was just about to claim some victories.

Pulitzer Prize-winning author Susan Faludi in her book, *Backlash*, talks about the movement.<sup>156</sup> Although the backlash is not an organized movement, that doesn't make it any less destructive. In fact, the lack of orchestration, the absence of a single string-puller only makes it harder to detect and perhaps more effective. A backlash against women's rights succeeds to the degree that it appears not to be political, that it appears not to be a struggle. Faludi goes on to say that the backlash adopts disguises. I want you to think about the discussion we have had here today as I tell you what those disguises look like and see if you recognize any of them.

The backlash pursues a divide-and-conquer strategy pitting working women against homemakers, middle against working class, married against single women, pitting us against each other. It remarkets old myths as new facts. Joe Shapiro told us about myths, lots of myths. They go underground in us. The backlash points the finger inward where it does its greatest damage, where we begin to believe we are the burden. We are the burden.

Someone talked to us about the studies in the Netherlands. We heard that the greatest reason people turn to this course of action is because they don't want to be a burden.

So when we say "why now," I think we need to remember that the year before last they were not disguising the effort. Amendments were being put up to derail, remove, and eliminate the Americans with Disabilities Act. They were fighting health care reform. They were devolving Medicaid and letting the states decide who is disabled and who is not. They found many more direct ways to try to turn the clock back in time.

When they realized that the American people didn't like such a direct attack, maybe, maybe they shifted our attention from the civil liberties to this discussion. You've heard so much about the costs of living with disability. You've heard so much about the wasted lives of people who are not given the opportunity to live independently.

There is a certain irony that the debate we've been having carries the same acronym, PAS, physician-assisted suicide, as the lifeline for the disability community, another PAS, personal-assistance services. I have

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<sup>156</sup> SUSAN FALUDI, *BACKLASH* (1991).



to believe that if the Rehabilitation Institute hung up a poster in Northwestern's law school and medical school that said, we are going to have a major meeting on personal-assistance services, this auditorium would have been empty. Why? Why? I can't answer that. You have to answer that.

I'm left, however, feeling that there are too many unanswered questions. In light of all those questions that haven't been asked, the discussions that haven't been had, how can we move down this path? Questions like, if self-determination is the ultimate litmus test, are you willing to deregulate it completely so that my friend Ray, a psychiatric survivor, who I might point out under current proposals would not have this civil liberty because she's crazy, would have this right. It's as if we are all on different lines: the crazy line, the able-bodied line, and the cripple line. We all get routed into different directions. In the civil rights movement, they called that redlining. What a type of redlining.

When the National Council sat down to have this discussion, I had neatly and tidily in my own little mind asked and answered the questions. I knew exactly where to go, thank you very much. Then my friends started challenging me, my family members, my dear friends, all of these people, and I went all the way back and started over again, as I'm sure many people in this room have done. I came full circle, not without a lot of difficulty and pain. We reached a consensus on the Council, although not always for the same reasons.

My friend who represented the psychiatric survivor community rejected this so-called choice because it wasn't a choice for them. It was not equal. They also rejected this "choice" because of how much power we would be putting in the hands of the medical profession.

Is it really a matter of choice and power when you have to get permission to do it? Though we came at it from very different places, we ended up together, able to say: the liberty interests of the few, who are not able to afford this course of action on their own right now, are far outweighed by the risks to the many, seven short years after the Americans with Disabilities Act was passed.

I'd like to close not on a note of despair because that is not where I am. I and my colleagues here are motivated by a very strong sense of purpose exemplified by one of my new-found heroes, Deval Patrick, the former Assistant Attorney General for Civil Rights. He says that the unifying theme of our work is very broad. The real and ultimate agenda is to reclaim the American conscience. Our true mission is to restore the great moral imperative that civil rights is all about. This nation, as I see it, has a creed. That creed is deeply rooted in the concepts of equality, opportunity, and fair play. Our faith in that creed has made us a prideful nation and enabled us to accomplish feats of extraordinary achievement

and uplift, and yet in the same instant we see racism and unfairness all around us. In the same instant we see acts of unspeakable cruelty and even violence, based upon race or ethnicity or gender or disability or sexual orientation. These present a legal problem to be sure, but they also pose a moral dilemma. How can a nation founded on these principles, educated to such a creed, sometimes fall so short? Let me assure you that is a question asked not just by intellectuals and professionals, it is asked by simple, everyday people of each other and of themselves every day.

To understand civil rights, you must understand how it feels: how it feels to be hounded by uncertainty and fear about whether you will be fairly treated; how it feels to be trapped in someone else's stereotype, to have people look right through you. You must understand that the victims of discrimination feel a deep and helpless pain and ask themselves the very question of morality I have just posed. What will be our answer as a society? Will we sit back and claim that we have no answer, or that it is not our business to devise one? Will we shrink from the moral dimension of our work? The answer is no. We will not shrink. There is a moral dimension, and we will assert it. Thank you.

## VI. SESSION SIX: A FORUM FOR PRESENTERS AND AUDIENCE TO INTERACT

DR. BLANCK: Why don't we reconvene. What a fabulous two days so far, and one thing that we always hear when we do conferences of this sort is that we need a lot of time and opportunity for interaction and free discussion with the participants, and by the participants I mean not only the speakers but the audience as well.<sup>157</sup>

This is your time to convey your opinion, to address anybody in particular. We will have basic town-hall type meeting rules. Common courtesy will prevail. Those of you in the front, if you raise your hand, a microphone will be brought to you, or to those of you who cannot get to the assistant half way up. There are no formal remarks here. Why don't we begin the discussion.

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<sup>157</sup> During the conference, audience members received questionnaires asking for general biographical information. The audience consisted of 82 men and 119 women. In attendance, there were 6 lawyers, 16 ethicists, 14 physicians; 29 disability advocates, 39 medical students, 6 law students, 18 allied health professionals, 24 nurses, 15 specialists in rehabilitation, and 21 religious leaders. People filling out the surveys were also presented with nine scenarios involving palliative care, withdrawing and withholding life sustaining treatment, physician-assisted suicide, and active voluntary and involuntary euthanasia. For each scenario, respondents were asked to mark whether they believed the scenario was: 1) clearly an example of physician-assisted suicide, 2) clearly not an example of physician-assisted suicide, or 3) perhaps an example of physician assisted suicide. Dr. Carol Gill and Dr. Kristi Kirschner will release the results later in 1998.

First question. Please tell us who you are addressing it to. If you want it to be a comment, that's fine as well. We ask that you be as brief as possible.

AUDIENCE MEMBER: I'm here as a health care professional. I'm a physical therapist, and I'm also a part-time, fill-in personal attendant and a student of bioethics, so my question is to everybody in general. I try to understand the perspective of individuals with disabilities, but at this conference I've heard such different views expressed. One person says, give me the choice. Another seems to say, continue to look for another way. How do I distinguish among opinions?

DR. GILL: I think in some ways you are in a position that a lot of men are in with respect to women and women's rights groups, versus women who are not in women's rights groups. It isn't just the disability community in which there is a range of opinions. There is also, however, consensus about rights.

I know even when I interact with women who don't consider themselves feminists, who don't identify with some of the ideas that I have about being a woman, part of me has to respect the difference; and yet I still feel that I have to listen to their experience and what they say about it through a rights perspective.

As far as interacting with people with disabilities who are despairing, I think it's always appropriate to ask why: What's going on? I think, in fact, it's not only appropriate, I think it's our responsibility wherever we encounter anyone in despair to try and find out why. The next question is, What can we do? The individual, himself or herself, doesn't always have the answer.

I think we also have to realize that with asking why, there comes a responsibility not only to try to understand what the individual knows to ask for, but also to try to present additional options for that individual. Then, at some point, you have a responsibility to yourself, too, not to go beyond what you feel is right in doing what an individual asks you to do. It's complicated.

AUDIENCE MEMBER: Are you saying that assisted suicide should be an option, so that they have more options available, or that it shouldn't be considered as an option because then you are feeling that we are offering it because they are disabled? Do you know what I'm saying?

DR. GILL: Say it again.

AUDIENCE MEMBER: You say that more options are better, but some people say that assisted suicide shouldn't even be an option.

DR. GILL: I think that one of the areas lacking in clarity has to do with suicide as a personal option versus legalizing assisted suicide, which requires changing our laws and changing protections that vulnera-

ble classes have now. By “vulnerable,” I don’t mean people who are passive and unable to practice self-determination. I mean people who are devalued to such an extent in society that they are endangered.

There are some alternatives that are not good. There are alternatives that would endanger other people. As Marca indicated, perhaps the privileges that would benefit a few people have to be weighed against the danger and the deficits that those privileges would bring to the majority. I think that’s a situation that we need to assess with our own conscience and our own sense of morality, but always bearing in mind the values and the rights and the dangers that other people in our society experience.

DR. BLANCK: Leigh Bienen, you wanted to jump in.

MS. BIENEN: I just wanted to say that this issue emphasizes, again, for me how much we live in a polity. We live in a large and diverse community. These decisions govern the lives and futures, and behavior and health of all of us. Of course, these are political decisions, and we expect easy answers.

We think it’s going to be: Well, are you for it or against it? If one thing has emerged in this conference, which is quite shocking, it is how little of a factual basis we have for making these decisions. We have no reliable data.

You know, we don’t have a good, sound factual analysis of our health care system. We can’t possibly have an open and informed debate on access to medical care, availability of long-term care, without a factual basis for the discussion. These issues are not on the agenda for serious discussion by the electorate. And we live in this society. We all live in it, and it’s going to be the kind of society we allow it to be, because of the way we behave, the way we do what we do. It’s not going to be someone else who decides it. It’s going to be us.

DR. BLANCK: Diane Coleman?

MS. COLEMAN: Responding to your comment about the perspective and the various perspectives of the disabilities community, I’ve had the opportunity since co-founding Not Dead Yet to speak to many groups, particularly groups of people with disabilities about this issue. What appears to be true, although I can’t say I’ve taken any formal survey, is that most folks over the last decades have been shaped in their opinion by the kind of media coverage that Joe Shapiro alluded to and described this morning, which is full of myths. Pretty much the debate so far has been framed as that of progressive, compassionate folks who favor legalization and expansion against folks who really want to hold the line based on primarily very rigid religious views. I feel that there has not been a lot of attention paid to the issues of oppression, prejudice, and economics.

Ironically in a way, I think, that what Haavi Morreim said yesterday about “follow the money” is really one of the most significant avenues to pursue in this context. But what I have found when I present the factual information is that most folks with disabilities have a different view after they hear about the Bouvia case, hear the court quotes, hear what different folks have said about the issues, when they learn about the medical profession.

DR. BLANCK: Thank you.

MR. BATAVIA: This whole issue has been absolutely fascinating to me because it disclosed to me something I hadn’t realized about the disability community before. That is that different people with disabilities have entirely different views of themselves, their society, and other people with disabilities. I hadn’t realized that there was this much of a divide. It’s almost analogous to what we’ve discovered from the O.J. Simpson trial and the division between how blacks and whites view O.J. Simpson’s guilt or innocence.

I recently had a debate with Paul Longmore. I thought at the beginning of our debate that we were going to be able to find significant areas of agreement. As we discussed this issue for about an hour and a half, I came to realize that Paul Longmore and I looked at this issue and our society in a fundamentally different way. Paul regards people with disabilities as an oppressed minority. I don’t.

We obviously have had very different life experiences. I think in some sense we may well be talking about two entirely different disability communities here: that community of people who consider themselves autonomous and not oppressed—Paul Miller called us elitists the other day, maybe we are, I don’t know—and the other community; and I acknowledge that there is a significant group of people with disabilities who are in institutions and may consider themselves oppressed.

In addressing this issue and the multitude of disability issues that come before us, we have to address the concerns of both of these groups. I have heard the arguments on the other side. I have great respect for Marca and the other opponents of this right. I hear, loud and clear, what they are saying. With respect to myself and that group of people with disabilities who don’t consider ourselves oppressed, I’m simply not willing to give away that right to autonomy, which is still the way I define this issue.

When I went to Berkeley back in 1975, I was among those at the very initial stages of the disability rights movement who were asserting our right to autonomy, and I listened to the leaders back then. They told me that I should take control of every aspect of my life. I bought into that idea, and I think that is one of the reasons for my success and happiness in life.

Now twenty or so years later, I'm told that I should take control of every aspect of my life except control over my death should I become terminally ill. I can't agree to that, and I'll never agree to that. I do agree, however, that in recognizing this right, we do need to protect those vulnerable people with disabilities who are, in fact, vulnerable; and we need to recognize that there is this great diversity in the disability community.

DR. BLANCK: Thank you. Let's take some more questions.

AUDIENCE MEMBER: Having been in a vegetative state for two weeks and knowing people who have been in that state for much longer, I believe that for another person to decide that a person's quality of life is not going to be any good is a poor way of judging quality of life. I wouldn't be here today if somebody had decided and convinced my husband that I had no quality of life. The issue that we are dealing with is not a matter of dying. Dying is easy, folks. Living is the challenge. Living takes a lot of struggle, a lot of effort.

I wasn't born disabled. I was disabled later on in life, so I know both sides of the coin. If anybody thinks there is a safety net out there and that anything is going to help you when the time comes—and that's every able-bodied person in this auditorium—the time is going to come when you are going to get hit in the face like I was. And like a lot of other people, you are going to find out that the people sitting around you who call themselves disabled know full well what the issue is.

To make a broad statement that 60 percent of the population of the disabled community wants assisted suicide is absolutely wrong. Before you say that, you have to go into the nursing homes. Go and talk to the people working in the independent living centers, the people that I work with on a day-to-day basis.

People with disabilities want to talk for themselves. You are entitled to your opinion. I'm entitled to mine, but globally we have to come together. Thank you very much.

DR. BLANCK: Any responses to that? Or, another question?

DR. GILL: I was just going to say that Drew Batavia was talking about the split between people who support legalizing assisted suicide and those who don't, but there is another split in our community. I think that's a split between people who are seeking an individual or personal right—and this comes right off of your comment—and those who are not just coming from a personal perspective and personal experience, but are trying to also take into consideration the collective, the right of the community or the concerns or benefits of the community.

I don't think Paul Longmore's personal experience is all that different from Drew Batavia's, except that he was disabled, of course, early in life. But I do think that what he represents every time I hear him speak is

what he reads about and hears about as the dynamics affecting our entire community.

MR. BATAVIA: There are those of us who believe that the best way to pursue the interests of the community is to do so through the individual rights of every person with a disability within the community. By guaranteeing those rights to autonomy, we best enhance the situation of the community. It's just a different perspective and a different approach toward disability rights.

DR. GILL: Right. I think we agree on how we disagree.

DR. BLANCK: Another question?

AUDIENCE MEMBER: I come from the hospice profession. Mine is more of a comment than a question. I want to applaud Mr. Shapiro for his awareness of and advocacy for the hospice movement because I believe that in the cases of terminally ill patients that we can provide a very viable and enriching alternative to physician-assisted suicide.

MR. SHAPIRO: Thank you for that comment. I just want to say that I've written recently about something that is really sort of a threat, I guess, to the hospice providers, and that is the issue of the audits from Operation Restore Trust. The Department of Health and Human Services is basically cracking down on hospices. The federal regulation for providing Medicare payments for people in hospices requires that they have life expectancies of six months.

We know that it's almost impossible to predict how long somebody is going to live, and the Department of Health and Human Services and the Inspector General's Office have gone around and conducted audits at various hospices and have asked for a repayment in many cases where people are living for longer than six months. In a majority of cases they are saying that these people were admitted too soon.

The Inspector General's Office sees a health care benefit that has grown substantially in recent years. If it's grown that fast, there must be some abuse; there must be some fraud involved.

Hospice providers are saying: look, we are expanding. We are providing important care that people need, and this kind of auditing will have a chilling effect on doctors referring patients to hospices. We've seen that effect already in states where these audits have gone on. It's an interesting case, for it shows, again, this tension between providing service and trying to limit health care expenditures.

DR. BLANCK: Thank you.

DR. BOWMAN: I think the most important thing is for us all to fight for health care for all because if we allow ourselves to be divided up, then we will be split and conquered. Many of those problems could be resolved if we had an equitable health care system with access for all.

The other statement I'd like to make is that I hate the term "limited resources." We've been brainwashed. We say "limited resources," and I see billions of dollars being spent on airplanes that don't fly and many other things. That, I will not accept, just like I will not accept the notion that health care resources are scarce; they are not. The important thing is that if we were to reach a consensus about everything, then I'd be worried.

Somebody once asked me, Dr. Bowman, why don't you all have a leader—one leader amongst the African-Americans? I said that's the most dangerous. He would either be shot or infiltrated or bought off; and that's what will happen.

The important thing is to stick together, all of us, because we are all potentially disabled or disabled or going to die. There is no doubt about that. If we could get equitable health care for all and get each organization to fight for it and not take no for an answer, then many of our problems that we've been discussing would be resolved.

DR. BLANCK: Hugh Gallagher, are you going to die?

MR. GALLAGHER: I was going to say that we are the wealthiest country in the history of the world. We have, I believe it to be true, the lowest personal tax rate of any of the industrialized countries. We have a national budget that is closer to balance than any of the major industrial countries.

We are the only industrial country in the world—aside from South Africa—that does not have universal health care. It's a matter of priority. This nation happens to be going through a very selfish phase. It's a problem larger than this conference.

I'd like to say to the woman who was talking about the diversity of disabled people: We are as diverse a group as America itself. We are left wing. We are right wing. We are rich. We are poor. We vary from people like Fred Faye who has lived on his stomach for twenty years to O. J. Simpson who has a bad knee.

It's difficult for us to speak on behalf of the disabled community because there is no consensus of view. It is no more possible than to say America thinks this or America thinks that. But then I'd like to get back to the point that I am an American. I am a human being. I'm a Christian. I am a disabled person, but I am not only a disabled person. I am not only a Christian. As an American, I take great pleasure, pride, and value in the rights that I have in the Bill of Rights and the right to run my own life, my own individual decision-making. I will not presume to intrude on anyone else's decision-making, but I will not let anyone else intrude upon mine.

I feel that suicide is a sin, but God allows man to sin. I must retain my personal rights, but I do not want to break with the disability move-



ment. I believe in everything it has stood for, and I will continue to work for it.

DR. BLANCK: Let's take some more questions.

AUDIENCE MEMBER: In the last seven weeks, I've personally had five deaths in my family. I have not heard anyone say anything about support to families coping with death.

DR. BLANCK: Very good point.

AUDIENCE MEMBER: My comment on that is that often we don't have family support because our family may not share our view of disability with us. As you've seen, there are some very strong opinions about disability in this room and how we see ourselves, and I was sharing with Joe earlier that my family and I disagree on nearly everything.

AUDIENCE MEMBER: There is an important question, and I think it ties in to what the woman who is studying to be a physical therapist asked earlier. We look to the medical community a lot when people become disabled, when people acquire disabilities, to tell us: How are we going to be able to live the rest of our lives? What resources are available?

I think part of the problem, if you will, with physician-assisted suicide or physician-induced dying, as I started to call it—because everything else is a misnomer—the fact is when we talk about physician-induced dying and disability, one of the problems is that the medical community as such is woefully misinformed, disinformed, uninformed, however you want to put it, about the resources for people with disabilities to live in this world, whether they are physical therapists or physicians.

If you are lucky enough to have a medical plan that will allow you to get into the Rehabilitation Institute of Chicago and if you're lucky enough that they happen to have a bed for you at the time, then maybe you will be one of that small percentage of people with disability who will get decent rehab care. But even then, you may be discharged into a nursing home or, as we more often call them, nursing prisons.

Marca Bristo talked about PAS in terms of personal-assisted services. The real issue is, What are the resources to live? Rather than, What are the resources to die?

Ignorance is the problem that we bring to the medical community. We say, "You can have palliative care for people who are terminally ill." We think that's wonderful. We think that all these other things you are putting in place are great, but you don't know about the resources that we need to live. And you are not doing anything to inform yourselves, and that makes us mad. You are out there offering us the option to die without offering us any options to live. That's what formed Not Dead Yet. Thank you.

DR. BETTS: I'm Henry Betts and I'm a doctor, and the previous speaker really touched on part of what I wanted to say and that is, offering the option to live rather than to die.

First of all, I'd like to say that I think Hugh Gallagher is correct. I think that the largest embarrassment in the country is that in the richest country in the world, there are people who really can't get care. And the people who need care are struggling through the most incredible degree of bureaucracy.

The other thing is that—and remember I'm a physician—disabled people have a pretty bad deal in finding a physician who can help determine whether there is a way you can live reasonably and with a high quality of life. There is no problem finding a physician who can help you die. But you will not find a physician very easily who can help you determine whether there are ways to help you want to live. The reason is that in medical schools, I would say only five percent of medical students ever get exposed to someone who has a disability. But don't attack the doctor too badly.

Just to add to what was said earlier about coming out of vegetative states, I want to tell an anecdote. We have a medical student here who saved a lot of people in a burning building and inhaled a lot of smoke and went into a coma, and he was in a coma over at Northwestern Memorial Hospital. Perhaps the most famous neurologist in the country, not a very agreeable one, but the most famous one in the country, arrived in town having written a great deal—he eventually wrote a book on coma. He got to the bedside of our medical student with his residents and other students and said, "Now, here is an example of what's wrong with modern health care. Here is somebody who is being kept alive, lots of money being spent on him to no end result that is going to be worthwhile. He should never have had his life saved after that burning building, and he just isn't allowed to die. And here you are keeping him alive, spending a lot of money on him here in this expensive hospital." That's what he said. That's what he chose to say to the medical student.

Well, that medical student came out of his coma. He came to the Institute. He was rehabilitated. He went back to medical school, and he became a neurologist. Then he read that this neurologist wrote the book on coma; and my medical student wrote him and said, I can't believe that you have written a book on coma. I remember your standing by my bed and I remember what you said. If there is anyone in the world who should not write on coma, it is you.

DR. BLANCK: Thank you, Dr. Betts.

AUDIENCE MEMBER: At least two or three people on different panels addressed the issue of Elizabeth Bouvia who is the first person who went to court to ask for the right to die.

There were some aspects of the case that were not spoken about, and I know because I became very interested in it wondering, why would a woman want to go to court and ask to be given permission to die?

Elizabeth Bouvia married a man who was just out of prison with whom she had been a pen pal. When she got married the services that had been provided to her were taken away. She lost her personal care attendant. She lost transportation. She also lost a baby. Her brother died. Her husband, who was underemployed, did not know how to take care of her, and he left her.

I became interested in Elizabeth Bouvia because I wanted to understand the circumstances that led up to her not wanting to live anymore. So the point that the young woman made is that it's easy to die in this county, but it can be very hard to live. There are many Elizabeth Boviias in this country right now who are dealing with services that are inadequate and who lack support. So, for me it's not about the right to die, but, again, going back to Elizabeth Bouvia it's about saying, I want a right to live, but I want to do it with dignity and not have to fight these systems in order to make sure that I can have the services I need.

DR. GILL: The point is Elizabeth Bouvia didn't say, "I want resources to live." The point is that she said, I hate my body and I want to die. And that's all that anybody heard, and that's all her case was decided upon. You heard Ms. Coleman today talk about how the court saw her. They didn't see all those factors you just mentioned. All they heard was one thing, "I want to die; I'm tired of being disabled." That's the danger here.

AUDIENCE MEMBER: I want to say two things: The first is that I think that we've been speaking sort of interchangeably about two very different things. Whether any of us agree with either, neither, or both of these things, I think that we have to speak very carefully about the distinction between saying that people who are imminently, terminally ill ought to have access to physician-assisted suicide, whether or not they have disabilities, and saying that people who have disabilities and find life intolerable ought to, in the absence of terminal illness, have access to physician-assisted suicide.

The other thing is that one speaker very wisely said that we've learned a lot here today both about what we do and don't know. I think that one of the things that I have noticed is that we don't know much about why it is that some people have found the lack of access to suicide, in fact, empowering.

Many people with disabilities and other very serious life situations said to me, when I worked in health care, that they were glad that they had no choice but just to go on one day at a time because it got them through things. Other people have said that they wished they had had

access to suicide. We don't know enough about that. We don't know enough about the different ways that people adjust not only to disability and terminal illness, but to all kinds of adversity.

Among those of us who agree with physician-assisted suicide and those of us who don't, I think the common thread is that we all want to do the best we can for people who are in desperate circumstances, the best that we think we can. If that's true, then I think we need to know a lot more about that question, about the differing ways that people adjust to adversity, disability, terminal illness, and imminent death.

MS. COLEMAN: I think you are very right that it's important to be clear about the differences between people with terminal illnesses and people with significant disabilities; but the next question is, "What is our culture going to do about that?"

The fact is that courts are not clear and that courts have already ruled that they are, for legal purposes, one and the same thing virtually. In addition, I think that it's important to look at what the proponents are saying about the reason why they support the right. The reason isn't terminal illness. They are concerned about "dignity."

Let me read a quote that came up yesterday because I know there are a lot of people who are here today who weren't here yesterday. This is a quote from Janet Good, who has been collaborating with Kevorkian and who is founder of the Hemlock Society in Michigan. Her quote is typical of proponents' comments in more recent times:

Pain is not the main reason we want to die. It's the indignity. It's the inability to get out of bed, or get onto the toilet, let alone drive a car and go shopping without another's help. I can speak for literally hundreds of people whose bedside I've sat at over the years . . . . They've had enough when they can't go to the bathroom by themselves. Most of them say, I can't stand my mother, my husband wiping my butt. That's why everybody in the movement talks about death with dignity. People have their pride. They want to be in control.<sup>158</sup>

We are insulted by this. Many people with disabilities need somebody to wipe their butt, and that does not mean that they're not in charge, and it does not mean that they're lacking in dignity. Yet, the press has over and over again supported these kinds of comments as fact. It is based on this representation of disability and so-called "dignity" that society is making this move to legalize assisted suicide.

MS. BIENEN: I just want to comment that I think it's so important that we all continue to first ask the question, Who is deciding for us?

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<sup>158</sup> Leiby, *supra* note 10, at F1.

And then, to push the people who are saying that they are deciding for us to make their decisions upon the facts; to make a serious compilation of facts, an analysis of the facts, and not just rely upon anecdotes, one person's statement. We need to subject these views to scrutiny. This is supposed to be a democracy, and we are here to ask questions and continue to push people.

One of the most troubling things to me is the extent to which politicians are allowed to get away with just relying upon the polls. Polls are wonderful and they tell you a lot of things, but they certainly don't tell you everything important. What they tell you is how somebody answers a poll on a particular day and a particular time, and that may or may not reflect a lot of things.

DR. BLANCK: Joe's point about what the Supreme Court is going to do is also very interesting because next year we are going to be sitting here grappling with fifty different decisions from fifty different states.

Other questions?

AUDIENCE MEMBER: I'm a hospice nurse. I am from southwest Michigan. I am here today because I think that the discussion we are talking about affects my work. And I have been so impressed with the quality of the speakers. Everyone has been so eloquent.

I would like to clarify and also to reinforce the distinction that was made earlier. We are talking really about two different issues: disability versus terminal illness. I'm one of those nurses who goes into the home of someone who has been diagnosed with a terminal illness, and I have to sit there and tell that person this is not about dying; this is about quality of life; and live each day to your fullest.

Then, this gentleman brought up the issue of family—when someone is diagnosed with a terminal illness, you are looking at tremendous stress, not just on the patient. You are looking at the family. You are looking at how everyone interacts with that person. I do not dispute your right to self-determination. This is directed at Hugh. I think you have the right to control your life, and it is very simple just not to eat. Okay. No one says that you have to live. You can be made comfortable.

My problem is when you say you want my help or you want a physician's help—and I can tell you when I go into homes and I monitor morphine drips for pain control—and we can get the pain under control easily, okay—it's a challenge, but it takes time and we monitor wherever the patient is at.

My problem is when you ask me to cross the boundary. The boundary is: You are asking me to help you end your life. I know of no hospice nurse and no hospice physician who will willingly take on that responsibility. So you have a right to maintain control, but you have no right to ask another individual to do it for you.

Dying is like birthing. You all know it takes nine months for a pregnancy. Labor and delivery are not pleasant. It is painful, and the pain can be under control now; but birthing is a process, and the whole family needs that time to get ready for this baby.

Well, the whole family needs time to let that individual that they love; let them go. The patient needs to hear a family member tell them how much they love them. You need the time because the analogy about the butterfly and the cocoon was so perfect. That butterfly needs time to get stronger.

That's the process, the dying process: letting go of your life, letting go of your friends, letting go of your family, and finally letting go of the last breath. It is a process that needs to be reflected upon.

To say, "I want a shortcut," is not fair to the family. It's not fair to society because society should value life, and we should all value life.

AUDIENCE MEMBER: I'm from Albany, New York, and I've been struggling with coming to terms with some people who think that people with disabilities are not oppressed in this country. I would just share a comment that I heard from a very wise gentleman who is very much involved in monitoring the changes of managed care in this country. That comment is that it's the large corporations' dollars that drive the HMO plans and tell them what they will pay for, what they will not pay for. What we have seen with regard to people with disabilities is that where it used to be under a "fee for service" plan, people with disabilities were a profit opportunity for providers, now we are a cost center.

I come from a state that spends \$5 billion a year to stick people in nursing homes. How much do you think we spend on personal-assisted services in the community? It's a fraction of that. It's very, very important to look at the big picture, what's going on, what the effect is for the broader community, not just for people with disabilities, but for all of us.

AUDIENCE MEMBER: I'm a dietician, and I used to work at Cook County Hospital. I also worked at a County sister facility in Oak Forest. When you are too old and sick to stay at County, they put you at Oak Forest. When I was working there it had 2,500 chronic disease patients. Being a dietician, I was in charge of their nutrition and hydration.

Eighteen years later because of myasthenia gravis and encephalitic coma and a few other tricks in my life, I ended up as a patient in Oak Forest; and many of my patients were still there. My concern is that people are getting dumped into places like Oak Forest. Those people are not represented on stage.

There was not one of us there who was not on a stretcher. You just got a hospital gown. That's the only thing you owned because they took everything else away. That's the limbo situation that I've lived for three years.

But God bless her, my roommate had been there thirty-two years and only could move her eyeballs. They had her falsely diagnosed as retarded on her chart. All that time they treated her like a sack of potatoes, and finally Joann and I learned that she could just barely move her eyeballs and we established a system so that we could spell.

We started spelling for three years night and day and even at the end, when I was considered her family on her chart, because she had none that would come visit her anymore, we spelled out her living will. It was denied because they didn't want the chart to look messy; because she had been there a long time; because they didn't want to make sure that indeed this woman had been feeling all of these years, when they had treated her like a bag of crap.

She wasn't even the person who had been there the longest. There was a guy there sixty-two years. Those long-term care folks are stuck in the indigent facilities right now, not the nursing homes, which are nice in comparison. You had one towel a week, if you were lucky. You had one shower a week, if you were lucky.

Those are the people in limbo that I fear is the alternative that we are facing right now before we can even reach either the concept of choice to die or the choice, as you've been putting it, to live in quality.

DR. GILL: I'm feeling a real pang of conscience here or else I wouldn't try to strain the moderator's patience with me. I feel so much has been said about the diversity of opinion in the disability community that I think it's almost misleading. Of course we are a diverse community. So are African-Americans. So are women. So are gay people. But we come together on issues.

We did pass the ADA against immense opposition, and a lot of those people with diverse opinions realize that this was important for everyone in our community. Subsequent to that, I think it was the National Council on Disability, before Marca joined it, did a survey to find out how many in our great, huge, diverse community even know about the Americans with Disabilities Act; and we found that the same number that is quoted as the majority who would support assisted suicide in the disability community were people who didn't even know about the ADA.

In other words, we came together and fought for a law to protect people in our community, the majority of whom didn't even know about it. So, I mean, think about that when we think about how important majority representation is. We are diverse, but we do come together, and it's important for us to come together to protect our community.<sup>159</sup>

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<sup>159</sup> The conference concluded with an original production entitled *Forever Profaned* (by her condition). Susan Nussbaum created the two-person dialogue especially for the conference. Susan Nussbaum and Tekki Lomnicki performed the program.