S. HRG. 109–80

HEALTH CARE PROVIDED TO NON-AMBULATORY PERSONS

HEARING

OF THE

COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS UNITED STATES SENATE

ONE HUNDRED NINTH CONGRESS

FIRST SESSION

ON

EXAMINING HEALTH CARE PROVIDED TO NON-AMBULATORY PERSONS, FOCUSSING ON THE MEDICAL, SCIENTIFIC, AND ETHICAL ISSUES INVOLVED IN THE DIAGNOSIS, TREATMENT, AND DECISION-MAKING FOR PATIENTS WITH DISORDERS OF CONSCIOUSNESS RESULTING FROM SEVERE BRAIN DAMAGE

APRIL 6, 2005

Printed for the use of the Committee on Health, Education, Labor, and Pensions

U.S. GOVERNMENT PRINTING OFFICE

20–539 PDF WASHINGTON : 2005

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512–1800; DC area (202) 512–1800
Fax: (202) 512–2250 Mail: Stop SSOP, Washington, DC 20402–0001

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HEALTH CARE PROVIDED TO NON-AMBULATORY PERSONS

WEDNESDAY, APRIL 6, 2005

U.S. SENATE,
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,
Washington, DC.

The committee met, pursuant to notice, at 9:32 a.m., in Room 562, Dirksen Senate Office Building, Hon. Mike Enzi, chairman of the committee, presiding.

Present: Senators Enzi, Burr, and Kennedy.

OPENING STATEMENT OF CHAIRMAN ENZI

The CHAIRMAN. Good morning. I will call to order this hearing. Welcome to the hearing of the Committee on Health, Education, Labor, and Pensions. Today, the committee will be exploring some of the key issues involved in the care of those unable to express their wishes for their health care treatment.

Before I continue with my opening statement, I want to clarify an important point about today's hearing. This hearing is about more than Terri Schiavo. Terri Schiavo very dramatically brought these issues to the attention of the Nation, and their importance didn't fade or diminish with her loss. Because there are so many individuals in similar situations, we need to increase our focus on the challenge of providing appropriate health care to millions of people who require additional health care services, especially those who are so severely injured that they cannot even communicate their wishes to their caregivers.

To address these issues, we have assembled a panel of experts to talk about the difficulties of providing health care services to individuals who cannot express their health care wishes and to inform us and the American public on the critical health care, legal, and planning issues that we, as a nation, have been discussing so intensely for the past few weeks.

The national dialogue that began with Terri Schiavo must continue so that many more American families will discuss and document their beliefs and desires about what health care measures they would want to receive following a catastrophic injury or illness. Families need to discuss these difficult issues now, before their loved ones are unable to express their particular wishes.

Beyond advance directives and living wills, Americans should also consider long-range financial planning to deal with the costs of long-term care. According to the National Association of Insurance Commissioners, the cost of a nursing home ranges from

$30,000 to $80,000 per year, and even home and community-based care can cost up to $50,000 a year. Regardless of where this care is provided, these costs add up. Thus, there is a need for every family to discuss the critical financial issues surrounding long-term care.

I also hope this hearing provides us with an additional opportunity to examine disabilities due to catastrophic brain injuries. It is easier to resuscitate the heart than it is to resuscitate the brain after a traumatic event, so more and more people are living with the effects of severe brain injuries. It can be challenging for doctors to make an appropriate diagnosis when a simple diagnostic test will not provide an easy answer.

There is so much that we still do not know about the brain and how it functions. We need a better understanding of the state of art of diagnosing brain injuries and how much more we need to do to find some of the elusive answers to our questions about the human brain. We also need to understand the state of potential rehabilitation efforts and therapies for individuals who have acquired a brain injury or other related disability.

It is appropriate for Congress to explore these issues in settings like this. We as a nation all need to focus on what actions are appropriate under the tragic circumstances in which someone cannot direct his or her own health care. From advanced medical directives to living wills to financial planning, Americans need to know how to prepare themselves for the unthinkable, and we need to continue to make advances in the diagnosis and treatment of the significantly disabled so they can benefit from the tens of billions we spend on medical research each year.

As is the tradition of this committee, only the chairman and ranking members are recognized to deliver opening statements. I ask unanimous consent that opening statements from all colleagues on the committee can be entered into the record. Without objection, so ordered.

But before I recognize Senator Kennedy for his opening statement, I want to thank him for the comments he made a couple of weeks ago regarding Terri Schiavo. Senator, you said that you would do all you could to see that any action Congress takes is constructive and free from partisan politics. I want to thank you and your staff for working in that spirit with me and my staff. Our teams consulted closely as we identified our witnesses to put together this morning. I think our exploration of many of the issues raised over the past few weeks will benefit from this collaboration. I look forward to working with you and the rest of our colleagues on this committee as we explore the impact of these catastrophic injuries and the challenges that these injuries impose on the severely injured and their families as they struggle to make health care decisions.

Senator Kennedy?

OPENING STATEMENT OF SENATOR KENNEDY

Senator KENNEDY. Thank you very much, Mr. Chairman. I want to commend you for holding this important hearing on the issues that we all must face as we consider our own lives and the lives of those that we love. This is a complex issue, as our chairman has

pointed out, and all of us on this side of the aisle appreciate the extremely responsible way in which you have approached this hearing.

There are few things in life that tear at our hearts more than the thought of a beloved mother or father, spouse or child, lying in a hospital bed after a serious injury or major illness. In those painful circumstances, we must face the terrible choice of continuing treatment or allowing a loved one to pass away in dignity. There are few moments that test our faith, our humanity, and our love more than that choice. The decision is made more difficult when patients have not left clear instructions on what they want.

All of us who followed the tragedy of Terri Schiavo have asked ourselves what we would do if she were part of our family. In addressing this question honestly, we may come to different judgments. One thing is sure, that families facing these painful decisions deserve better than political theatrics from the United States Congress, and Republican leaders abused their positions of power to play politics with Terri Schiavo's life. These are solemn family decisions. They are times for deep prayer, wise counsel, not craven politics.

Yet Republicans sought to legislate based on a 5-year-old videotape. They ignored the detailed findings of the neurologist who had extensively examined Mrs. Schiavo in person, numerous experts, five different courts, and three legal guardians, one of whom was appointed by Governor Jeb Bush himself. And House Republican Leader Tom DeLay has even threatened the judges who acted in this case, just as extremists were threatening their lives. That is reckless and irresponsible, and now the Senator from Texas has joined Tom DeLay's chorus in tearing down our independent judiciary. Apparently it is not enough for Republicans to rule the White House and Congress. They want power over the independent judiciary, too. Checks and balances so vital to our democracy are for them merely an inconvenience.

We owe it to our citizens to approach this issue compassionately, thoughtfully, and responsibly. No injury is so profound or disability so severe that we should diminish the fundamental dignity of a human being.

There are hundreds of families every day who face the same decision as the Schindlers and the Schiavos. In fact, in almost half of the cases of deaths in intensive care units involving decisions to end treatment, there is disagreement in the family. The role of Congress cannot be to intervene and interfere with their private lives in each and every case. Instead, our role in Congress should be to support families as they make the end-of-life decisions, and if there is a dispute, it should be settled by impartial judges, not by a show of hands in the U.S. Senate.

There is much we can do, however, to support families in this situation and I look forward to hearing the ideas of our witnesses today.

Of first importance is making certain that care is available for those with serious illness and disabilities so that they can be assured of treatment and rehabilitation. Families facing end-of-life decisions need to know that this is the case. Shamefully, in the same month that Congress intervened in the case of Terri Schiavo,

the House of Representatives approved a budget that would deny care to thousands of Americans who, like Terri Schiavo, rely on Medicaid for their health and hope. Many of our colleagues who led the effort to intervene are also urging Congress to impose the arbitrary caps on the very kind of medical malpractice awards that sustained her life.

Clearly, we need to reverse the life-threatening cuts in the President's budget and reject the arbitrary malpractice caps that jeopardize the most severely injured patients. We should also consider three additional steps.

In the short term, we need to improve ethical guidelines to hospitals, doctors, families on end-of-life care. Medical progress is constantly expanding frontiers of medicine and sustaining lives. Our ethical guidelines must keep pace with these developments.

We also know that endless additional anguish and heartbreak can be avoided if persons have shared clear and thoughtful instructions on their goals for medical care with those closest to them, if they have appointed a trusted person to speak for them, and if they have given their loved ones a chance to air their concerns.

In addition, Congress must complete the long-awaited legislation to provide affordable health insurance to families with disabled children. Senator Grassley and I introduced the Family Opportunities Act 5 years ago. It has 60 cosponsors. Yet Congressional leadership has delayed its enactment into law. The bill would be a lifeline to families unable to afford health coverage for their disabled children, some of whom today actually are forced to give up custody of their disabled children so they can get health care. How many more families will be forced to give up custody of their disabled children before this Congress will act?

Citizens with disability also need more realistic ways to lead independent lives at home and in the community, and I hope Congress can pass bipartisan legislation supporting new insurance strategy for them. A strategy enables Americans with disabilities to afford the service and support they need to lead the independent lives.

Once again, I thank our chairman for holding this thoughtful hearing. I thank our witnesses for appearing before the committee this morning and I look forward to their testimony and working with our colleagues to enact appropriate ways to meet these basic challenges.

The CHAIRMAN. Now we will hear from our first and only panel of witnesses. We will introduce the panelists all at once. They will give their statements, and then we will move to questions, and I will ask each of you to summarize. We are going to have some difficulties this morning with a vote that has been scheduled, so we will have to recess to be able to vote and come back. I ask everyone's indulgence for that.

The first member of the panel is Rud Turnbull. Mr. Rud Turnbull is a researcher, teacher, consultant, and advocate. He is the father of a 37-year-old man, Jay, who has several disabilities, a daughter, Amy, who administers programs on behalf of individuals that are homeless, many of whom have emotional, mental disabilities, and Kate, an actress in New York City. Mr. Turnbull is

the author of 16 books, 49 monographs and technical reports, 131 articles, and 68 chapters.

He has served as a Chairman of the Board of Trustees of the Judge David Baselon Center for Mental Health Law, President of the American Association of Mental Retardation, Chairman of the American Bar Association Commission on Disability Law, Secretary of the ARC of the United States, and Treasurer of the Association for Persons with Severe Disabilities. His peers in the field of developmental disabilities and special education have described him as one of 36 people who in the 20th century changed the course of history in intellectual disabilities, and during the 19th and 20th century as one of the leaders of the field of special education.

He has testified before Congress on nearly a dozen occasions, served as counsel to committees of the North Carolina General Assembly, and been a Joseph P. Kennedy, Jr. Foundation Public Policy Fellow attached to the U.S. Senate Subcommittee on the Handicapped, where in 1987 and 1988 he did the staff work that led to the enactment of the Assistive Technology Act.

Mr. Turnbull will discuss the appropriate legal advocacy for individuals with disabilities, including advocacy related to financial well-being of the family, which may include the purchase of long-term care insurance or other insurance products.

The second member of our panel, Dr. James Bernat, hails from New Hampshire. Dr. Bernat, a medical doctor, has been a professor of neurology at Dartmouth Medical School and staff neurologist at the Dartmouth Hitchcock Medical Center in Lebanon, NH, since 1977. Currently, he holds hospital appointments as a staff neurologist, Dartmouth Hitchcock Clinic, attending neurologist, Dartmouth Hitchcock Medical Clinic, and consultant neurologist at the V.A. Medical Center.

Prior to 1977, Dr. Bernat was the Chief of Neurology Section at the V.A. Medical Center and Co-Director for the V.A. Northeast Regional Center for Clinical Ethics, and Co-Director, Senior Scholar for the V.A. National Center for Clinical Ethics. He was also Assistant Dean for Clinical Education from 1996 to 1999 for the Dartmouth Medical School. Dr. Bernat has been published in 100 journals, ranging from the Journal of Neurology, Neurosurgery, and Psychiatry, to JAMA, to the Journal of Clinical Ethics and quoted for his expertise in the New York Times.

The doctor will discuss the difficulties in diagnosing brain injuries and any advancements related to the care of individuals sustaining brain injuries.

Dr. Deborah Warden is the National Director of Defense and Veterans Head Injury Program and Associate Professor of Neurology and Psychiatry at the Uniformed Services University of Health Sciences. After completing residencies in neurology and psychiatry at the University of Rochester and Georgetown University, Dr. Warden directed the home program component of the randomized trial of cognitive rehabilitation at the Walter Reed Army Medical Center. Out of this study grew the Defense and Veterans Head Injury Program, an eight-center military, veterans', and civilian partner brain injury disease management system that delivers state-of-the-art clinical care, conducts clinical research, and provides fo-

cused education on brain surgery. She has lectured and published widely on neurobehavioral aspects of traumatic brain injury.

Dr. Warden will discuss treatment and rehabilitation options and services for individuals who have sustained a brain injury and any advancement related to the care of individuals sustaining brain injuries.

Dr. J. Donald Schumacher, a doctor of psychology, has been the President and CEO of the National Hospice and Palliative Care Organization since October 2002 and President of the National Hospice Foundation since June 2003. He also serves as President of the Foundation for Hospices in Sub-Saharan Africa.

Dr. Schumacher graduated from Massachusetts School of Professional Psychology in June of 1986. His doctoral dissertation was on the psychological care of the terminally ill patient. Prior to attending Massachusetts School for Professional Psychology, Dr. Schumacher graduated from the State University of New York at Buffalo with his Master's degree in counseling psychology. From 1978 to 1989, he was the CEO of Hospice West in Waltham, Massachusetts. He served as the President and Chief Executive Officer of the Center for Hospice and Palliative Care in Buffalo, New York, from 1989 to 2002. Dr. Schumacher currently serves on the Board of the National Health Council. He has lectured nationally on the psychological care of the terminally ill patient and the expansion of hospice care both nationally and internationally. Dr. Schumacher is licensed as a clinical psychologist in both Massachusetts and New York State.

Dr. Schumacher will discuss the importance of discussing end-of-life issues with family members and what steps people should take to plan ahead.

We will now hear from our first witness, Mr. Turnbull.

STATEMENTS OF RUD TURNBULL, CO-DIRECTOR, UNIVERSITY OF KANSAS BEACH CENTER ON DISABILITY, LAWRENCE, KS; JAMES L. BERNAT, M.D., PROFESSOR OF MEDICINE, DARTMOUTH MEDICAL SCHOOL, HANOVER, NH, ON BEHALF OF THE AMERICAN ACADEMY OF NEUROLOGY; DEBORAH L. WARDEN, M.D., NATIONAL DIRECTOR, DEFENSE AND VETERANS HEAD INJURY PROGRAM, WASHINGTON, DC; AND J. DONALD SCHUMACHER, PRESIDENT AND CHIEF EXECUTIVE OFFICER, NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION, ALEXANDRIA, VA

Mr. TURNBULL. Senator Enzi, Senator Kennedy, thank you very much. My name is Rud Turnbull. I am the father of Jay Turnbull, a 37-year-old man who has mental retardation, autism, rapid cycling bipolar condition, an irregular heartbeat, and challenging behaviors. At this rate, he is going to have every diagnosis in the DSM.

I am also a professor of special education at the University of Kansas, former Chairman of the Department of Special Education, co-founder and Co-Director of the Beach Center on Disability, which studies the effect of public policy on families, and former courtesy professor of law at the University of Kansas. Thank you for the opportunity to give you some of my views and speak for some people with significant intellectual disability who have be-

come my friends and to give you a precipe of their perspectives, as I understand them, about Federal policy.

Senator Enzi, a few moments ago, you talked about people who were unable to express their wishes. That phraseology goes right to the heart of the matter in these debates, which has to do with self-determination.

If either of you were to ask Jay Turnbull where he wants to live, work, with whom he wants to associate, how he wants to be in his community, what church he wants to attend, he would tell you in a word or two or by some behavior. If you, on the other hand, were to ask him where his deceased grandparents are, he would tell you they are in heaven with Baby Jesus. His answers to those two questions would be genuine, complete, and credible.

My point is simply this. Jay, like many people with significant intellectual disability, is situationally competent. He knows about the life he leads today. He chooses the life he leads today. But he has very little knowledge about the medical procedures that he must undergo and he has very limited capacity for the abstract. For him, death is the permanent absence of a person whom he loves from his life and the permanent presence of that person with God.

Having, I hope, helped you understand this business about competency, let me talk about the historical context in which you all are operating. I barely have to remind either of you. People with disabilities have always been subject to discrimination. That is one of the reasons Congress has enacted laws granting rights in housing, education, employment, and now the question has to do with discrimination in health care and where do we turn for answers?

Some people will turn to Hippocrates, who asked the question, which children should be raised? It is interesting. Plato answered that by admonishing us not to be taken in by the lifeless phantom that is not worth wearying, and Aristotle admonished the fathers to kill their severely deformed and crippled children.

One would have thought that we would be, in our enlightened age, beyond debates about which life is worth living, but that is not the case. Today, there is still a debate. What are the essential elements of humanness? That debate frightens me and I suggest it should frighten all of us, because the slippery slope is slick and it awaits all of us.

One reason Congress enacted the Americans with Disabilities Act was to respond to that potential and that reality of discrimination. In the ADA, Congress declared that disability is a natural part of the human experience and should not diminish the rights of people with disabilities simply because they have a disability. Congress also declared that the national policy is to advance the self-determination of people with disabilities, assure their equal protection under the law, and promote their independent living.

The implicit message of this language about the natural condition is that each one of us at some point in our lives, should we live long enough, may have a disability that would disable us from making a choice such as we would want to make had we not had the disability. So the question, it seems to me, at this point is what role does Congress have to play, and that role is played in the middle of a public debate that asserts in part that I would not want

to live like that. I would not want to be a person who suffers from mental retardation or a disability so much that I would continue living.

Let me assure you, Jay Turnbull does not suffer from mental retardation. If he suffers from anything, it is the failure of society and law to accommodate to him according to how he, like the rest of us, would want to be accommodated to.

Congress has responded. You in 1984 enacted the Child Abuse Prevention and Treatment Act. In that act, you laid out policies that I think should guide us now. First, discrimination on the basis of disability is wrong, no matter how severe the disability, no matter its cause.

Second, the disability should never be the basis for making a decision about health care.

Third, what medical care is available, it should always be provided.

Fourth, at the edges of life, there is always a presumption in favor of life.

And fifth, that presumption may be rebutted when the person is in a coma, that care would be futile, or the pain would be so great—and by the way, this word "coma" bothers me because it talks about persistent vegetative state. I would hope we could find another word than "vegetative."

So what issues should Congress address? Well, of course, the States have the primary responsibility in protection, but this is a civil rights matter and it is a Federal civil rights matter and, therefore, Congressional consideration is appropriate. If the Congress were to choose to move forward, I suggest there are three kinds of cases that it should address.

First, the person is not near death but most certainly will die if the medical care, hydration, and nutrition are withdrawn.

Second, there is no clear advance directive or other reliable evidence of what the person would want.

And third, there is an irreconcilable conflict among the family and guardian members and that conflict cannot be resolved.

Now, if Congress were to act, here are, I think, are some of the issues that we have to take up. First, expedited appeals and hearings. Second, standing to sue. The burden of proof. The standard of proof. The criteria for third-party decision making. The use of independent medical judgment. And then the grounds for overruling a State court decision.

I believe, and I think most of us believe, that the government that compels a life to be lived is a government that is ethically obliged to support that life to be lived well. Civil rights are the necessary precursors for rights and entitlements of the service system, and that is why I want to talk about preserving Medicaid, about not reducing the benefits, about not tightening the eligibility. Congress can give the States a great deal of leeway without pulling the guts out of Medicaid. There are other programs that Jay and his peers rely on—housing, Section 8 housing, rehab, Medicaid, Medicare, SSI, SSDI, IDEA, ADA, protection and advocacy. We have to keep those going.

Senator Kennedy just a moment ago talked about the Family Opportunities Act. It and MICASA need to be enacted. If not this year, when?

In summary, Jay looks to you to preserve his civil rights, to maintain and to expand the existing programs, to rely upon principles for decision making that have been with us since 1984, and to assure a proper Federal role in these matters.

I ask my testimony be entered into the record in full, the written testimony, and I thank you for the opportunity to be with you.

The CHAIRMAN. Without objection.

[The prepared statement of Mr. Turnbull follows:]

PREPARED STATEMENT OF H. RUTHERFORD TURNBULL, III

Senator Enzi, Senator Kennedy, Senator Roberts, Senator Harkin, and members of the committee. I am Rud Turnbull, the father of Jay Turnbull, a 37-year-old man with significant mental retardation (measured IQ of approximately 40, mental age of approximately 6), rapid cycling bi-polar illness, autism, an irregular heart beat, and frequently challenging behaviors.

At the University of Kansas, I am a professor of special education, former chairman of the department of special education, co-founder and co-director of the Beach Center on Disability (a research center focused on the effects of policy on families who have children with disabilities), and former courtesy full professor of law. Before coming to the University of Kansas in late-1980, I was professor of public law and government at the University of North Carolina at Chapel Hill, beginning in 1969.

Here and today, I speak for no organizations. Instead, I have been asked and am pleased to share my perspectives as a father and friend of many people with intellectual and associated disabilities and their families, and to provide a précis of what I have learned about policy from their perspectives.

There are literally millions of people with intellectual and associated disabilities. So whatever you do on this topic we discuss today will change their lives dramatically. But you will also affect those who will acquire a disability as they age. That population includes nearly every one of us, should we live long enough.

After Jay was born and his disability confirmed, I responded by shaping my life to his and his peers and their families. I have learned a great deal about their lives by being an active participant in developing services locally; advocating at the local, State, and Federal governmental levels for my son and his peers and their families; researching and writing about them in over 250 publications; and carrying out research, training, and technical assistance on their behalf, in nearly every State, for nearly 35 years.

Although I do not personally know these millions of people whom you can affect, I know how they have experienced discrimination and sometimes been surprisingly successful in overcoming it, and I have a solid sense about their aspirations for how they want to live.

Many of them are in the same position as my son: graduates of special education under the Individuals with Disabilities Education Act; beneficiaries of the Home and Community Based Services Waiver under Medicaid; and recipients of SSDI or SSI; supported employment services under the Rehabilitation Act; and rent subsidies under Section 8 of the Housing Act. Some of them live according to their choices; my son does, because of these programs.

Many, however, live according to how policies and service systems find it convenient for them to live. Unlike Jay, they are not supported to be self-determined.

Allow me to talk about self-determination, for it is at the heart of debates about health-care decision making. And allow me to give you the example I know best, my son.

If you were to ask Jay where he wants to live and work, who his friends are, and how he wants to be a fully participating member of his community, he would tell you, by words, behavior, or both, and you would have no doubt about the authenticity of his answer.

If you ask him where his deceased grandparents are, he would tell you, "In Heaven with Baby Jesus." Here, too, you would know his answer to be utterly genuine and complete.

I tell you this because I want you to understand that Jay, like many people with mental retardation or associated intellectual disabilities, is "situationally com-

petent." Whether he has sufficient ability to be self-determined depends wholly on the situation he faces and on who asks him, how much he trusts that person, and how familiar he is with the questions. That can be true of his peers, too.

Jay knows about his life as he leads it, day by day. He has, however, little knowledge about the various medical procedures that he must have, especially those involving surgery. And he has no concept about death.

For Jay, death is the permanent absence of a loved one from him and the permanent presence of that person with God.

This snapshot of Jay is important to you because you need to understand the world that Jay and his peers live in. You need to understand that people with intellectual and associated disabilities have always been subjected to discrimination. Often, they have been put to death or allowed to die when they might have been kept alive. The discrimination that they have experienced in education, employment, and housing are matters that you have addressed by various laws. More to the point today is the discrimination in health care that they have experienced.

The roots of that discrimination are ancient. They originate in the debates of the Greek philosophers, Hippocrates, Socrates, Plato, and Aristotle.

Hippocrates posed the question, "Which children should be raised?"

Plato answered by writing that a State's "medical and judicial provision" will "leave the unhealthy to die, and those whose psychological constitution is incurably corrupt, it will put to death." He added, ". . . we must look at our offspring from every angle to make sure we are not taken in by a lifeless phantom not worth the rearing."

Aristotle agreed: "With regard to the choice between abandoning or rearing an infant, let there be a law that no crippled child be raised."

And the pre-Christian Romans' Twelve Tables, their equivalent of our Federal constitution, admonished the head of the family to "kill quickly . . . a dreadfully deformed child."

One would have thought our more enlightened age would have settled the question about which individuals should be treated so that they will live.

Yet, even nowadays the debate rages: what are the indispensable elements of being, the sine qua non of human-ness. Those debates frighten me, and they should alarm you, too. The slippery slope is slick and awaits us all.

In our own country, Justice Thurgood Marshall, in his opinion in *City of Cleburne v. Cleburne Living Center* (473 U.S. 432 (1985)), which struck down exclusionary zoning that targeted only people with mental retardation, characterized this country's discrimination against people with mental retardation as "grotesque."

That case and others from the Supreme Court, as well as our own laws, affirm that the stigma attached to disability of all kinds is simply abhorrent and has no role in public policy.

To remedy the discrimination as a matter of Federal law, Congress enacted the Americans with Disabilities Act, 15 years ago. That bi-partisan law, bravely sponsored by Senators Harkin, Hatch, Kennedy, and my own former Senator, Bob Dole, and powerfully supported by President Bush and many senior-level members of his Administration, declared that

- disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society, and
- the Nation's policy for people with disabilities is to assure their equal protection under the law, advance their self-determination, and promote their independent living.

The implicit message of ADA's "natural experience" language is that each of us at some time may have a disability, especially as we age, but that we should not therefore lose our rights, including our rights to choose what happens to us, whether in health-care decision making or other aspects of life.

Among the many questions before you nowadays is this simple one: What role, if any, does Congress have in responding to

- theories that people with disabilities are not human enough to have rights, and, if they pass some test of being human, still have no rights, much less the right to live,
- a sense among the some Americans that "I would not want to live like THAT!," that a person with a disability "suffers" from the disability when, often, it is not the disability that causes the suffering but our social and legal refusal to support the person,
- a sense among some in the public and media that living as a person with a disability is such an undesirable condition that death itself is preferable to life,
- public perceptions that people with disabilities are useless consumers of public and private resources,

• cost-containment pressures and rationing criteria within the health-care and insurance industries, and

• public opinion that too often is not ashamed to say that, when it comes to protecting and allotting health-care resources to people with disabilities, they should, in the words of former Governor Lamm of Colorado, "Just roll over and die."

So, as the first order of business, in any bill it enacts Congress should

• affirm and recommit itself to the ADA principles of self-determination (in constitutional terms, liberty and autonomy), independent living, and equal protection, and

• proclaim in no uncertain terms that these policies are still the Nation's law for people with disabilities and that they apply to health-care and end of life decision making.

Second, in that same bill, Congress should recognize that

• people with significant intellectual and other associated disabilities are situationally competent,

• their abilities vary according to type and severity, and in contexts and over time,

• they need and under the ADA have rights to be supported to be as self-determined as they can be at the times when they and their designated representatives must make choices, and

• the families of newborns, infants, children, and adults with disabilities are the core social units for them and for society itself, and that it is proper for the Nation to commit its resources to supporting those families.

Third, Congress should recognize that there already are principles guiding health-care decision making and that these principles have garnered widespread consensus from healthcare providers and organizations representing people with disabilities and their professional caregivers.

Those principles are the foundations for the regulations implementing the Child Abuse Prevention and Treatment Act (42 U.S.C. Sec. 5101; 45 CFR Part 84, Section 84.55). As one who helped draft the Principles some 20 years ago, I know them well, and I urge you to consider reviewing them and weighing their appropriateness for any policy you decide to enact.

The Principles and regulations, taken as a whole, state that

• discrimination against any person with a disability, regardless of the nature or severity of the disability, is morally and legally indefensible,

• the rights of people with disabilities must be recognized at birth (and, I believe, at the other edge of their lives),

• when medical care is clearly beneficial, it must be provided,

• it is impermissible to take into account any anticipated or actual limited potential of a person or lack of resources,

• there is a presumption in favor of treatment at the edges of life,

• the presumption is rebuttable and it is permissible in law and ethics to withhold or withdraw medical or surgical procedures that are clearly futile and will only prolong the act of dying and when the person is in an irreversible coma or the treatment would be so painful as to render it unconscionable, and

• the person's disability itself must never be the basis for a decision to withhold treatment.

Fourth, Congress should recognize that its actions will affect millions of people, not just those with disabilities but also children, the aged, and their families.

Fifth, Congress should recognize that the primary responsibility for legislating health care and protecting against abuse and neglect in health care traditionally has resided in State legislature and State courts. However, given the significant Federal civil rights issues involved, it is appropriate for Congress to consider the extent of any Federal role. Later in my testimony I suggest principles for Congressional action.

Sixth, Congress should recognize that end of life decision making, however much it may be guided by various legal instruments or other reliable expressions of self-determination, is a dynamic process, and that people's conditions change with prompt, state-of-the-art treatment, and so do their and their families', other designated representatives', and health/medical caregivers' judgments about how much to honor the previously executed instruments or expressions of autonomy.

Seventh, Congress should acknowledge that any government that compels a life to be lived is ethically obliged to provide the person with a right to individually chosen and appropriate supports necessary to implement the ADA "natural experience" declaration and the ADA national policy aspirations. Civil rights are the necessary precursors to rights and entitlements within service-delivery systems.

Eighth, Congress should not retreat from the laws that already commit our Nation to enhancing the quality of life of people with disabilities and their families.

More than that, Congress should enhance existing rights and benefits and create new ones.

• Preserving Medicaid as an entitlement is absolutely necessary for people with disabilities. It is desirable for the Federal Government to give States greater flexibility in structuring their Medicaid programs, including by adding more self-determination and self-direction to the service system. But it would be devastating to present and future Medicaid beneficiaries for the Federal Government to tighten the present eligibility criteria and reduce the present benefits.

• Preserving the eligibility and funding for the programs that my son and millions of other people with disabilities rely on to live as full citizens, consistent with ADA, is also absolutely essential. These include Section 8 rental assistance, supported employment programs, SSDI and SSI, Medicare, the Developmental Disabilities Act and its family support provisions, the Federal respite-care assistance program, and the Protection and Advocacy Systems.

• Enacting the Family Opportunities Act and MICASA in order to strengthen families and assure greater self-determination for them and for people with disabilities is way overdue.

Ninth, knowledge is a precursor to good decision-making, so Congress should authorize and enable a wide range of parent and family training and information centers, in both the disability and non-disability arenas, to offer objective and current information about the legal instruments that individuals may execute and about the treatment options that the health-care and hospice systems can offer at the end of life.

Lastly, there are various issues that Congress might well consider if it debates whether it is desirable to enact a law that allows for Federal intervention in end of life decision making.

Among those issues are the cases in which Federal intervention is warranted. In my judgment, the cases would be ones in which

• the person is not near death but most certainly will die if the treatment, hydration, or nutrition is withheld, or

• there are no clear advance directives from the person or other reliable, at the clear and convincing level, expressions of the person's autonomy, or

• there is irreconcilable disagreement among family members concerning the decision to be made.

If Congress does indeed debate a Federal role, it may well also consider such issues as

• expedited hearings and appeals,
• standing to sue,
• burden of proof,
• standard of proof,
• criteria for third-party decisions,
• utilization of independent medical judgments, and
• grounds for overturning a State court decision.

For just a moment and in conclusion, please allow me to return to the beginning of my testimony, to my son Jay. He has two parents who agree among themselves about his care; two sisters and a brother-in-law who know him extremely well, love him devotedly, and have thought carefully about their and his lives and the decisions they will make for themselves and for him; and friends who also know him well and honor his self-determination. In Jay's case, the issue is not one of rights, but of going beyond rights.

Rights and their associated principles and regulations direct us, but they cannot fully answer our questions about what to do for Jay and people with intellectual and other disabilities. So family, friends, and Jay himself invariably turn to those two elements that have added quality to his life—to trust, hard-earned over time, and compassion, generously shared and untainted by disability discrimination.

William Faulkner told a family's story in his book, "As I lay dying," and I want to borrow that phrase and say that, when the time comes that I lie dying, I will have confidence that Jay's family and friends will do for him what he most would want done for himself, if he could decide. His life—not his disability—gives them a warrant for action. And the "them" who will carry out that warrant are those whom he has trusted and who have made his life an intrinsic part of their own. Jay's most enduring social security is his circle of family and friends.

But he and millions of others also look to you to preserve his civil rights under the Constitution, the ADA, and other laws; maintain existing rights and entitlements and expand, not shrink, them; rely on principles for decision making that have wide support and that have protected many newborns and infants with disabilities; and assure an appropriate Federal role in reviewing state-based decisions.

Thank you for the opportunity to testify and for your careful and deliberate consideration about how to proceed on behalf of all of the present and future "Jays" of our country.

H. RUTHERFORD TURNBULL, III,
Lawrence, Kansas.

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The CHAIRMAN. In fact, all complete testimonies will be a part of the record, and we will even have the record open for a while so that additional questions from other members of the panel can be submitted. We hope that you will answer those questions and expand on any remarks based on anything else that was said during the hearings. Thank you.

Dr. Bernat?

Dr. BERNAT. Good morning. Mr. Chairman, I thank you and Senator Kennedy for holding this hearing and for inviting me on behalf of the American Academy of Neurology to testify about the medical, scientific, and ethical issues involved in the diagnosis, treatment, and decision making for patients with disorders of consciousness from severe brain damage.

The American Academy of Neurology is the principal scientific, clinical, educational, and policy organization for North American neurology, representing over 18,000 neurologists and related clinicians and scientists. The Academy has a long and distinguished concern for optimizing the care of patients with disorders of consciousness.

Although my comments today will be scientific and conceptual, I want to emphasize that I am mindful of the profound human tragedy of the patients I describe. The objectivity of my comments should not be construed as implying any lack of compassion for their tragic plight or for the unspeakable suffering endured by their families.

In my limited time, I wish to briefly clarify the medical syndromes causing disorders of consciousness. In my written testimony, I have provided further detailed information regarding diagnosis, treatment, and elements of clinical decision making for these patients. I have also included practice guidelines from the American Academy of Neurology.

Human consciousness has two clinical dimensions: First, wakefulness, served by the brain stem ascending reticular activating system and its connections, and the second dimension is awareness of self and environment, served by the thalamus, the cerebral cor-

tex, and their connections. Coma is an eyes-closed form of pathological unconsciousness that is characterized by neither wakefulness or awareness.

The vegetative state is a disorder featuring the ironic combination of wakefulness, but absent awareness, caused by damage to the thalamus, the cerebral cortex, or the connections between them. Vegetative state patients have intact sleep-wake cycles. Their eyes are open when awake and closed when asleep. They breathe, blink, move their eyes, and make noises, although no words, and show reflex responses. But to the fullest extent testable, they have no awareness of themselves or of their environment. When this state has been present for at least a month, it has been called the persistent vegetative state, or PVS.

Another state, recently called the minimally conscious state, is a disorder of limited responsiveness in which patients retain awareness, but in which their responses are so deficient that evidence of their awareness may be difficult to detect. The most common causes of both PVS and the minimally conscious state are head trauma, brain damage from lack of oxygen during cardiac arrest, and stroke.

I want to emphasize the biological limitation to our ability as clinicians to know the awareness of another person. Of course, we cannot get inside another person's mind and experience what they experience. Therefore, we can know their level of awareness only by inference. We interact and stimulate them and we study their responses. We infer whether they are aware by analyzing the quality of their responses and judge if a response they make is one that could be made only by an aware person. Responses produced by reflexes or so-called stereotyped responses don't count as awareness because they are integrated at a subconscious level.

Physicians diagnosing persistent vegetative state have an important duty, and that duty is to show the complete absence of any evidence of awareness. The testing of the patient should include observing the patient, interacting with the patient during a neurological examination, talking to nursing caregivers and family members, examining laboratory tests such as EEGs and neuroimaging studies such as CT scans or brain MRIs.

The examination should be directed toward eliciting any sign of awareness. We talk to patients. We see if they can respond appropriately to commands. Can they make eye contact, follow a moving object with their eyes consistently and intently, reach for an object, react to emotional stimuli, such as seeing a photograph of a loved one or talking about a loved one. The examination is long, tedious, repetitive, and thorough. Because random response might be interpreted as showing awareness, we test to see if it is reproducible. We interview nursing staff and family members to see if they have observed any responses that they believe prove the patient has awareness. If so, we ask them to demonstrate it to us.

Only in the utter absence of evidence of awareness should we issue the diagnosis of PVS. EEGs commonly show diffuse, profound abnormalities. Neuroimaging studies in such patients show shrinkage of the brain, particularly if the illness or the injury was much earlier.

The level of treatment we give patients is based on their prior stated wishes in light of their prognosis. We aggressively support and treat patients who would have wanted that level of treatment and cease treatment when patients have indicated they would not want to be maintained on life sustaining treatment in their current condition. If the patient has left no clear directives, we seek advice from family members and primary care physicians about their understanding of the patient's preferences for treatment in light of their diagnosis and prognosis.

It is the responsibility of the medical team and the family to fulfill the patient's wishes for treatment. We do everything possible to achieve that goal.

During the question and answer time, I hope we can further discuss the difficult issues of medical treatment, the complex ethical issues in medical decision making on these tragic patients, the importance of clear and compassionate communication with families, and some of the innovative scientific investigations that are now being performed to better understand their illnesses. Thank you very much.

The CHAIRMAN. Thank you very much.

[The prepared statement of Dr. Bernat follows:]

PREPARED STATEMENT OF JAMES L. BERNAT, M.D.

Good morning ladies and gentlemen. Thank you, Senator Gregg, for the kind introduction. I thank Senators Enzi and Kennedy for inviting me on behalf of the American Academy of Neurology to testify about the medical, scientific, and ethical issues involved in the diagnosis, treatment, and decision making for patients with disorders of consciousness resulting from severe brain damage.

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The vegetative state usually is classified as a state of unconsciousness, but the terminology is ambiguous because, although PVS patients are unaware, they are

awake. Because awareness is the most relevant component of consciousness, the loss of awareness counts as unconsciousness despite their open eyes.

There is a biological limitation to our ability to know the awareness of another person. We cannot get inside their minds and experience what they experience. Therefore, we can know their awareness only by inference: we interact and stimulate them and study their responses. We infer whether they are aware by analyzing the quality of their responses and judge if a response is such that could be made only by an aware person. Responses produced by reflexes or so-called stereotyped responses do not count because they are integrated at a purely subcortical level.

Physicians diagnosing PVS have the duty to show the complete absence of any evidence of awareness. Testing should include observing the patient, interacting with the patient during a neurological examination, talking to nursing caregivers and family members, and examining laboratory tests such as EEGs and CT scans or MRIs. The examination should be directed toward eliciting any sign of awareness. We talk to patients to see if they respond appropriately to commands, make clear eye contact, follow a moving object with their eyes consistently and intently, react to emotional stimuli such as seeing a photograph of a loved one or talking about a loved one. The examination is long, tedious, repetitive, and thorough. Because a random response might be interpreted as showing awareness, we test to see if it is reproducible. We interview nursing staff and family members to ask if they have observed any responses that they believe prove the patient is aware. If so, we ask them to demonstrate it to us. Only in the utter absence of evidence of awareness should we issue the diagnosis of PVS. EEGs commonly show diffuse, profound abnormalities and neuroimaging studies show brain atrophy if the injury or illness was many months or years earlier. Newer technologies such as brain PET scanning and functional MRI have an important role in research—to help us learn about the brain centers necessary for awareness—but are not currently used in clinical diagnosis.

The prognosis for recovery of awareness in PVS has been quantified. In general, the prognosis depends on the cause and duration of PVS. It is worse after cardiac arrest and after a long duration of PVS. Patients remaining in PVS for greater than 3 months after cardiac arrest have only a slight chance of recovery of awareness. Recovery of awareness is unprecedented after 2 years. With head injury causing PVS, the times necessary to show these levels of prognostic certainty are 1 year and 5 years respectively.

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EXECUTIVE SUMMARY

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The CHAIRMAN. Dr. Warden?

Dr. WARDEN. Senator Enzi, Senator Kennedy, I am pleased to appear before you today to speak about a very common type of brain injury that may result in long-term health care needs.

Brain injury is not a homogeneous entity. For example, the nature, location, and extent of brain injuries differs in trauma, TBI, stroke, and global lack of oxygen to the brain, or anoxic brain injury, and thus, there are very different recovery patterns and care needs. Today, I will speak about traumatic brain injury.

TBI is a significant public issue. The CDC estimates that 80,000 to 90,000 individuals with traumatic brain injury annually experience permanent disability from their injury. An estimated 5.3 million Americans, or two percent of the population, are currently living with lasting effects of their TBI. The CDC suggests that these numbers likely underestimate the problem. The cost to society is great, estimated in 1985 annually in the United States as $37.8 billion.

TBI includes closed and penetrating brain injury, both of which can result in widespread, diffuse, and local focal brain injury. A head striking a windshield in a motor vehicle accident causes the gelatinous brain to move forward in the skull. The brain, tethered on the brain stem, may be affected by rotational as well as acceleration and deceleration forces. The brain moves within the skull, cushioned only by a lining of cerebral spinal fluid. The long axons, or the communication fibers of the brain cells, may be stretched or even torn in severe injury. Recovery of the individual depends on many factors, not all of which we currently understand.

Two important points follow from this mechanism of injury. First, the front and side parts of the brain are particularly likely to be injured, resulting in deficits in planning, initiation, motivation, judgment, and problem solving, known as executive functioning, as well as memory and emotions. To a lesser extent, sensory and motor functions are impaired.

Second, most of the persons with long-term disabilities will be ambulatory patients. These persons have impaired social, interpersonal, and occupational functioning which can result in lost jobs and disrupted families.

TBI may be acquired in association with other injuries. Soldiers who incur any polytrauma, including limb amputation, may have more difficulty assisting in the care of their other injuries if they have also sustained a traumatic brain injury. Similarly, civilian studies demonstrate that TBI accompanying significant physical injuries complicates outcome from TBI and leads to greater disability.

Persons with TBI recover most rapidly in the first months to 1 year after injury, but improvements can be made up to several years after TBI. The potential of TBI patients to learn new skills over years underscores the need for treatment programs to facilitate recovery. Unfortunately, these patients are at high risk for falling through the cracks due to their brain injury. Someone with a short fuse who angers easily and has poor memory and organizational skills may be unlikely to negotiate our health care systems.

A Scandinavian study of 15-year follow-up of patients with severe traumatic brain injury now living at home reported that the most distressing symptoms to their families were not their physical

impairments and care needs, but rather their inappropriate behaviors and poor social functioning.

Most TBI patients with long-term needs recover from the majority, and often all, of their physical, motor, and sensory injuries, yet have ongoing disability from deficits in memory, concentration and motivation, fatigue, and difficulty modulating emotions, including anger. Long-term unemployment rates for individuals with moderate to severe TBI is about 50 percent.

Research is needed to identify the most cost-effective treatments so these individuals may experience the best quality of life, including working, when possible. TBI therapies range from inpatient rehabilitation strategies to job coaches and mental health follow-up. Attached in the testimony are evidence reviews outlining specific rehabilitation interventions.

Once again, I thank you for the opportunity to address the committee regarding traumatic brain injury resulting in disabilities, often of people who are ambulatory. Thank you.

Senator KENNEDY. [presiding]. Thank you, Doctor.

[The prepared statement of Dr. Warden follows:]

PREPARED STATEMENT OF DEBORAH L. WARDEN, M.D.

Mr. Chairman and members of the committee, I am pleased to appear before you today to give testimony regarding one very common type of brain injury that may result in long-term care needs, specifically traumatic brain injury (TBI). Brain injury is not a homogeneous entity; for example, the nature, location, and extent of brain damage differs in trauma (TBI), stroke, and global lack of oxygen to the brain (anoxic brain injury), and thus there are very different recovery patterns and care needs. Today I will speak briefly about TBI, including the magnitude of the problem, the effects on the brain, the types of disability that may result, and long-term health care needs of these individuals.

TBI is a significant public health issue. The CDC estimates that at least 1.4 million people sustain a TBI annually. Of those, 50,000 die, 235,000 are hospitalized, and 1.1 million receive care and are released from an Emergency Room (Langois et al., 2004). The CDC estimates that 80,000 to 90,000 individuals with TBI annually experience permanent disability from their injury. An estimated 5.3 million Americans (2 percent of the population) are currently living with disability due to a TBI. Because of the nature of the models used here, the CDC suggests that these numbers likely underestimate the problem. The short term and long term effects for those who have sustained a TBI, their families, and society come at an enormous cost. Estimates in 1985 placed the annual cost to the United States as $37.8 billion. This includes $4.5 billion in direct hospital and extended care/other medical services, $20.6 billion on work loss and disability, and $12.7 billion on lost income due to death (CDC, 1999; Thurman et al., 1999).

TBI includes both closed brain injury and penetrating brain injury. Both closed and penetrating brain injury can result in widespread (diffuse) and local (focal) brain injury. If one imagines a head striking a windshield in a motor vehicle accident, the gelatinous brain will move forward in the skull at the moment of impact. Acceleration and deceleration forces affect the brain when the moving head strikes an immobile object. The brain, tethered on the brain stem, may also be affected by rotational forces. The brain moves within the skull, cushioned only by a lining of cerebral spinal fluid. The long axons, or the communication fibers of the brain cells, may be stretched, or even torn in severe injury. Patients may be rendered unconscious and may be unable to form new memories for an additional period of time after they regain consciousness. Recovery of the individual depends on many factors, not all of which we currently understand.

Two very important points follow from the manner in which the brain is injured. First, the frontal and temporal lobes, along with their connections, are particularly likely to be injured. The human functions that are affected by these injuries include higher level abilities such as initiation, motivation, planning and problem solving (known as executive functioning), as well as memory, and emotions. Individuals may also experience headache, dizziness, ringing in the ears, and visual changes. To a lesser extent, sensory and motor functions are impaired.

Secondly, most of the persons with long-term disabilities will be ambulatory patients. These persons may have impaired social and interpersonal abilities which can cause them to have difficulties maintaining work and family relationships. This could render the individual without a job and without previously supportive family members.

Individuals may sustain a TBI in association with other injuries. For example, soldiers who sustain a TBI in addition to a limb amputation may have a more challenging recovery as they are trained with their prosthesis, etc. Patients who incur any polytrauma are likely to have additional problems assisting in the care of their other injuries if they also have sustained a TBI. Evidence from civilian injuries supports this, as it has been demonstrated that TBI in addition to other significant physical injuries (e.g., traumatic amputations, spinal cord injury, etc.) complicates outcome and leads to greater disability (Dimopoulou, et al., 2004; Macciocchi, et al., 2004).

Persons with TBI recover most rapidly in the first 6 months to 1 year after injury. But, improvements can be made up to several years after TBI. We understand these improvements as primarily compensatory gains (learning to adapt better to disabilities) but new research in brain plasticity suggests that improvements may also relate to a strengthening of brain cell connections.

The potential of TBI patients to continue to learn new skills over years underscores the need to have treatment programs available to facilitate their recovery. Unfortunately, these patients are at high risk of "falling through the cracks." Patients may drop out of our health care systems because of the disability caused by their brain injury. Someone with a "short fuse" who angers easily and has poor memory and organizational skills may be unlikely to negotiate our health care systems to keep appointments, reschedule appointments when necessary, provide the necessary forms when asked, or independently follow-up with treatment recommendations. Because of their brain injuries, these individuals may not even appreciate that they are impaired. They may not trust the health care system, and focus rather on a physical impairment ("All I need to do is to stop having these headaches, and then everything would be fine"). Our health care systems need to have trained providers who can address these patients' physical and neurobehavioral problems as well as mechanisms to follow patients to ensure they have not dropped through the cracks.

Penetrating brain injury can also affect the frontal lobes. In the well known case of Phineas Gage, an explosion resulted in a tamping iron lodging in his frontal lobes. Though he appeared to be normal, he had severe disabilities in the form of personality changes caused by the injury resulting in his erratic, unpredictable, and inappropriate behavior. While he had previously functioned as a foreman on the railroad, with the ability and skills to supervise others, he was now rendered a pariah due to his behavior. He could neither supervise others nor act responsibly enough to keep any job. Mr.Chairman, I would submit that a person who has sustained such an injury to his executive functions, lost his livelihood, and in essence, is described as a loss of himself "Gage stopped being Gage" (J.M. Harlow, 1868 quoted in Damasio et al., 1994) has sustained a serious long term disability, despite his ability to walk and talk.

Long term health care needs:

A Scandanavian study of a 15 year follow-up of patients with severe TBI now living at home reported that the most distressing symptoms to their families were not their physical impairments and care needs, but rather their inappropriate behavior and poor social functioning. These behavioral and psychological impairments interfered with the ability of the families to have normal interactions with these persons and with their communities (Thomsen, 1984).

TBI patients with long term care needs include the small number of individuals who do not regain consciousness and others who require institutionalization for ongoing medical and/or behavioral needs and assistance with activities of daily living (ADL's). However, most TBI patients with long-term needs recover from the majority (and often all) of their physical injuries, yet have ongoing disability from deficits in memory, concentration and motivation, fatigue, and difficulty modulating emotions, including anger.

As such, long term care needs encompass the relatively few who require inpatient comprehensive care and the ambulatory majority whose treatment needs range from supervised living situations to periodic treatment and follow-up as outpatients.

When someone requires inpatient physical care, the treatment needs are clearer. When someone has ongoing cognitive and neurobehavioral problems, the medical care systems often do not reach the patients who need long term outpatient care. Research is needed to see which models of care delivery can provide cost effective

care for these individuals. Different patients require different amounts of intervention and have different potentials. Many patients will be able to perform some type of paid or volunteer work while receiving outpatient care.

Certainly not everyone who sustains a TBI has ongoing health care needs. Many of us have experienced a concussion (mild TBI) in the past. Even young individuals who have sustained moderate to severe TBI may have substantial recovery and return to their jobs within 1 year. (Salazar et al., 2000)

However, a significant proportion of individuals will need ongoing intervention. When TBI patients in Colorado who had required hospitalization were surveyed 1 year after injury, approximately one-third of them were still experiencing difficulties due to their disabilities (CDC, 1999). Long-term unemployment rates for individuals with moderate to severe TBI is about 50 percent (Malec et al., 1995, as cited in Chesnut et al., 1999). Risk factors for poor recovery include severity of injury, complications (e.g., increased intracrainial pressure, a drop in blood pressure, inadequate oxygenation, and infections during the acute period of injury), increasing age of the individual, associated injuries, and previous TBI.

TBI therapies range from inpatient rehabilitation strategies to job coaches and mental health follow up (specific rehabilitation interventions with the most evidence are reviewed in Cicerone et al., 2000 and Chesnut et al., 1999). It is important for individuals to realize that the emotional or cognitive changes they may experience are related to their brain injury. Fortunately, education regarding the patients? symptoms and expected recovery can help to decrease the number and severity of symptoms seen in mild TBI (Ponsford et al., 2001).

Once again, I thank you for the opportunity to address the committee. I hope this has been helpful in underscoring the large number of ambulatory patients with traumatic brain injury and ongoing health care needs.

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Senator KENNEDY. Dr. Schumacher?

Mr. SCHUMACHER. Senator Kennedy, thank you very much. My name is Don Schumacher and I am the President of the National Hospice and Palliative Care Organization. I am here testifying on

its behalf and on behalf of the 1 million patients who are receiving hospice care during the year 2005.

The National Hospice and Palliative Care Organization is the largest and oldest not-for-profit leadership organization in the United States, representing over 3,200 hospice programs and 1,800 palliative care programs under which or through which the hospice benefits are provided largely through Medicare, the hospice Medicare benefit, Senator Kennedy, of which you were a major sponsor some years ago.

It is an indisputable fact that all of us are going to die, but we do not plan for it. In fact, most families spend more time planning for their annual summer vacation than they do for a health care emergency. Research by the National Hospice Foundation showed that Americans are more likely to talk to their children about safe sex and drugs than to terminally ill parents about their choices in care at the end of life. One in four citizens over the age of 45 said they would not bring up these issues related to their parents' death even if the parent had a terminal illness and had less than 6 months to live. One of every two Americans say they would rely on family and friends to carry out their wishes, but 75 percent of these people have never taken the time to clearly articulate how they wish to be cared for during life's final journey, a difficult time for all patients and their family members.

Talking about death provides a great deal of discomfort for most people. However, we do have a responsibility to our families and our loved ones to make our end-of-life care wishes known. Whether it is around the kitchen table or behind the witness table here in Congress, the American public needs to start a dialogue about how they want to be cared for at the end of life, and that may be the only good that has come out of the situation that we have seen play out in Florida these last several weeks.

This year, the National Hospice and Palliative Care Organization launched Caring Connections, a consumer education initiative funded with support from the Robert Wood Johnson Foundation. Caring Connections provides free resources about advanced care planning, including state-specific advance directives to help families better understand options for care at the end of life. The Caring Connections Web site, caringinfo.org, also provides information on caregiving, pain, hospice, palliative care programs, and financial issues at the end of life.

So far this year, Caring Connections has disseminated advance directives and resources to more than 15,000 consumers, and over the last 2 weeks, we have had over 200,000 downloads on our Web site about advance directives state-by-state by members of the United States public. In a single day, NHPCO staff fielded more than 900 phone calls and processed more than 2,000 e-mails from people across the country requesting copies of state-specific directives.

But requesting this form is not enough. You must complete the form and take some additional steps. These include giving the completed form to your doctor, your family and friends, and then use the form to talk to people that you love about your wishes and your thoughts about what you would like to have happen for you at the end of your life. No matter what side of the issue of this current

debate one comes down on, one thing remains clear. This issue could have resulted in a very, very peaceful death several years ago had Mrs. Schiavo's wishes been written down on a piece of paper and made known to her family and her friends and had been given to her physician.

It is important to note that advance directives are not only focused on what treatments you want, they are equally applicable and viable to indicate the treatments that you do not want, and I think that is just as important a point.

Through this Robert Wood Johnson Foundation grant, NHPCO is launching a national consumer education initiative this month and it is called, "It's About How You LIVE." The LIVE acronym is a call to action and empowerment for consumers. Learn about the options of end-of-life services. Implement your plans to ensure that your wishes are honored. Voice your decisions and plans to family, friends, spiritual care, and health care providers. And Engage in personal community or national efforts to improve end-of-life care, L-I-V-E.

The national effort is the first step of our organization in implementing a far-reaching consumer information campaign. We are seeking national, State, and community partners to join in our efforts in promoting these important messages to people across the country.

Congress also has the opportunity to take the next step in improving legislation that will highlight and strengthen advance directives, and I have three suggestions and encouragements for Congress to make.

S. 347, the Advance Directives Improvement and Education Act, a bipartisan bill introduced by Senator Bill Nelson, Senators Lugar and Rockefeller, is a bill that NHPCO has supported for a number of years in previous Congresses and we have recently reiterated our support for the bill's provisions.

This bill encourages all Medicare beneficiaries to prepare advance directives by providing a free physician office visit for the purpose of discussing end-of-life care choices and other issues involving decision making in time of incapacitation. Physicians would be reimbursed for spending time with their patients to help them understand situations in which advance directives would be useful and their medical options, the Medicare hospice benefit, and other concerns. The conversation would also enable physicians to learn about their patients' wishes, fears, religious beliefs, and life experiences that might influence their medical care choices. These are important aspects of a physician-patient relationship that are too often under-addressed.

Another part of the bill would provide funds for the Department of Health and Human Services to conduct a public education campaign to raise the awareness of the importance of planning for care near the end of life. This campaign would explain what advance directives are, where they are available, what questions need to be asked and answered, and what to do with the completed, executed documents. HHS directly or through grants would also establish an information clearinghouse where consumers would receive state-specific information and consumer-friendly documents and publications.

The bill also contains language that would make all advance directives portable, that is, useful from one State to another. As long as the documents were lawfully executed in the State of origin, they would be accepted and honored in the State in which they are presented, unless doing so would violate State law.

All of the provisions of the Advance Directives Improvement and Education Act of 2005 are there for one reason, to increase the number of people in the United States who have advance directives, who have discussed their wishes with their physicians and their loved ones, and who have given copies of the directives to their health care providers, family members, and their legal representatives.

As you may know—this is my second point—the authority for health professions programs expired several years ago. As this committee turns its attention to the reauthorization of these programs, we encourage you to address the professional needs we are discussing here today by establishing Hospice and Palliative Care Academic Career Awards modeled after the Geriatric Awards currently receiving $6 million under this program. Hospice and palliative medicine is an emerging field in medical training. The proposed awards would provide funds for junior faculty and require that they spend at least 75 percent of their time training interdisciplinary teams of health care providers in hospice and palliative medicine.

The legislation introduced last year by Senator Wyden, my third point, the Palliative Care Training Act, is a positive forward-looking response to the tragic struggle we have just witnessed. We urge your consideration of palliative medicine as you pursue the reauthorization of the health professions programs.

So much more needs to be done. Understanding human suffering and how to help patients and their families face the end of life with dignity is essential. The baby boomers, as you know—I am a proud card-carrying member and we are walking toward Medicare with quite a clip and we will probably be the largest group of United States citizens who are going to resist talking about death because we believe we have a right to everything, that we do not have to make difficult choices or have difficult conversations. I urge this committee and Congress to take on the leadership to make sure that every American recognizes that their choices can be respected and honored with a very simple document that can be downloaded off of many different Web sites. Thank you very much.

Senator KENNEDY. Thank you very much.

[The prepared statement of Mr. Schumacher follows:]

PREPARED STATEMENT OF J. DONALD SCHUMACHER

Mr. Chairman, members of the committee, ladies and gentlemen, it is a privilege to be here today.

My name is J. Donald Schumacher, and I am President and CEO of the National Hospice and Palliative Care Organization and am testifying on its behalf today. The National Hospice and Palliative Care Organization is the largest and oldest nonprofit leadership organization representing hospice and palliative care programs and professionals in the United States. Our organization is committed to improving end-of life-care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

The National Hospice and Palliative Care Organization offers information on local hospice and palliative care programs across the country, operates a toll-free HelpLine at (800) 658–8898, and maintains a Web site at **www.nhpco.org.**

Talking about death makes most people uncomfortable. However, we have a responsibility to our families and loved ones to make our end-of-life wishes known. Whether it is around the kitchen table or behind the witness table here in Congress, the American public needs to start a dialogue about how they want to be cared for at the end-of-life. In response to recent headlines, tens of thousands, if not millions, of people have requested information on advance care planning and hopefully, those personal conversations have started.

It is an indisputable fact that all of us will die. Yet, until the past several weeks, Americans have for the most part been unwilling to plan for this eventuality. In fact, most families spend more time planning for their annual summer vacation than they do for a health care emergency.

Research by the National Hospice Foundation showed that Americans are more likely to talk to their children about safe sex and drugs than to their terminally ill parents about choices in care as they near life's final stages. According to this research, one in four citizens over the age of 45 say they would not bring up issues related to their parent's death—even if the parent had a terminal illness and had less than 6 months to live. One out of every two Americans say they would rely on family and friends to carry out their wishes, but 75 percent of these people have never taken the time to clearly articulate how they wish to be cared for during life's final journey.

This year, the National Hospice and Palliative Care Organization launched Caring Connections, a consumer education initiative funded with support from the Robert Wood Johnson Foundation. Caring Connections provides free resources about advance care planning; including state-specific advance directives to help families better understand options for care at the end of life. The Caring Connections Web site, **www.caringinfo.org** also provides information on care giving, pain, hospice, financial issues and grief. So far this year, Caring Connections has disseminated advance directives and resources to more than 15,000 consumers.

In a single day, the National Hospice and Palliative Care Organization's Caring Connections HelpLine staff fielded more than 900 phone calls and processed more than 2,000 e-mails from people across the country requesting copies of state-specific advance directives. But, requesting a form is not enough. You must complete the form and take additional steps. These include giving the completed form to your doctor, family, and friends, and then use the form to talk to people about these issues and your wishes at the end-of-life.

It is important to note that advance directives are not only focused on what treatments you do not want. They are equally applicable and viable to indicate all of the treatments that you do want. This information gets lost in the information about their utility. Whether you want your health care providers to try every possible life-prolonging treatment until the moment you die, or to solely focus on providing comfort care at the end-of-life, you still need to document and talk about your wishes.

Through a Robert Wood Johnson Foundation grant, NHPCO is launching a national consumer education and engagement campaign this month called "It's About How You LIVE." The LIVE acronym is a call to action and empowerment for consumers:

- Learn about options for end-of-life services and care.
- Implement plans to ensure wishes are honored.
- Voice decisions and plans to family, friends, spiritual care and health care providers.
- Engage in personal, community or national efforts to improve end-of-life care.

This national effort is the first step for our organization in implementing a far-reaching consumer information campaign. We are seeking national, State, and community partners to join our efforts in promoting these important messages to people across the country.

Congress also has the opportunity to take the next step by approving legislation that will highlight and strengthen advance directives. S. 347, The Advance Directives Improvement and Education Act, introduced by a bipartisan group of Senators, is a bill that NHPCO has supported for a number of years in previous Congresses and we have recently reiterated our support for the bills' provisions.

The Advance Directives Improvement and Education Act encourages all Medicare beneficiaries to prepare advance directives by providing a free physician office visit for the purpose of discussing end-of-life care choices and other issues around medical decision-making in a time of incapacitation. Physicians would be reimbursed for spending time with their patients to help them understand situations in which an advance directive would be useful, medical options, the Medicare Hospice Benefit,

and other concerns. The conversation would also enable physicians to learn about their patients' wishes, fears, religious beliefs, and life experiences that might influence their medical care wishes. These are important aspects of a physician-patient relationship that are too often unaddressed.

Another part of the bill would provide funds for the Department of Health and Human Services to conduct a public education campaign to raise awareness of the importance of planning for care near the end of life. This campaign would explain what advance directives are, where they are available, what questions need to be asked and answered, and what to do with the executed documents. HHS, directly or through grants, would also establish an information clearinghouse where consumers could receive state-specific information and consumer-friendly documents and publications.

State-specific information is needed because in addition to the Federal Patients Self-Determination Act passed in 1990, most States have enacted advance directive laws. Because the State laws differ, some States may be reluctant to honor advance directives that were executed in another State. The bill contains language that would make all advance directives "portable," that is, useful from one State to another. As long as the documents were lawfully executed in the State of origin, they must be accepted and honored in the State in which they are presented, unless doing so would violate State law.

All of the provisions in the Advance Directives Improvement and Education Act of 2005 are there for one reason: to increase the number of people in the United States who have advance directives, who have discussed their wishes with their physicians and families, and who have given copies of the directives to their loved ones, health care providers, and legal representatives.

I am honored to have been asked to testify today about public educational efforts focused on decision making at the end of life, but, I would also like to address the delivery of such services in the setting that I know best. It's an approach to care that each year meets the needs of over 1 million terminally ill Americans and their families. Of course, I am referring to hospice care.

The modern day American hospice movement began in 1971 in Connecticut. The first freestanding hospice in this nation was the Connecticut Hospice in New Haven and it was founded on the model of care best identified with Dame Cicely Saunders, M.D., who opened her now famous Saint Christopher's Hospice in 1967 in Sydenham, England. Her center became the model for comprehensive whole person and family care at the end of life (i.e., spiritual, psychological and medical team-driven care of the terminally ill patient and his/her family).

While hospice began as a movement in this country, it was made part of the Medicare program in 1982. Since enactment, the Benefit has afforded millions of terminally ill Americans and their families an avenue toward a death with dignity.

Hospice is not "a place." It is an approach to end-of-life care focused on pain relief and symptom management, and hospice care is offered primarily in a patient's home. It can also be provided in a nursing home, assisted living facility, a hospital, or in a hospice inpatient facility.

No one is ever forced to use hospice care. People either choose hospice care themselves or their health care surrogate, designated as responsible for their best interest, makes the decision. Normally, a physician outside of hospice is involved in the decision and he or she must certify that the patient's illness is terminal and that they have a limited life expectancy.

Simply defined, hospice care focuses on whole person care, and is not, as too often is thought, just a place to die. Hospice embraces these principles:

- Supports and cares for persons in the last phases of incurable disease so that they may live as fully and as comfortably as possible;
- Recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life;
- Exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them; and,
- Offers palliative care to terminally ill people and their families without regard for age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay. (NHPCO Standards of Hospice Program of Care, 1993)

Far too many patients die without ever being referred for hospice care. This is often the result of patients and families being unaware of hospice and palliative care programs available to them. This lack of consumer education regarding compassionate end of life care can lead to tragic and unnecessary pain and suffering—

physical, emotional and spiritual—for the patient and their families. That kind of suffering does not have to happen in your city or anywhere else in the country.

There are nearly 40 million senior citizens in the United States, but in the next 30 years, that number is expected to double to 80 million as baby boomers reach age 65. Surprisingly, 90 percent of the respondents to the NHF study didn't realize that all inclusive hospice care is available to this aging population, as Medicare beneficiaries.

Once the subject of end of life care is broached, it is clear what we want. The NHF research indicates what people would choose when provided end of life care:

- Someone to be sure that the patient's wishes are enforced,
- Being able to choose the type of service they could receive,
- Emotional support for patient and family,
- Control of pain,
- Opportunity to get one's life in order,
- Spiritual support for patient and family,
- Care by a team of professionals,
- Being cared for in one's own home,
- Continuity of care, and
- Relief of burden on the family and friends.

In fact, these are the guiding tenets of hospice care.

Congress recognized the need for such care in 1982 when it enacted the Medicare Hospice Benefit to provide compassionate and specialized care for the dying. While millions of terminally ill older Americans and their families have had the opportunity to experience more comfortable and dignified deaths, the reimbursement rate has not kept pace with the changes in end of life care—especially due to increasing costs of prescription drugs and outpatient therapies, as well as decreasing lengths of service. Medicare Hospice Benefit reimbursement rates need to be maintained if hospice programs are to continue to provide high quality care and related services that our Nation's most vulnerable population needs and deserves.

Once a patient chooses hospice care, he or she is afforded the per diem reimbursement as the only Medicare payment for all costs related to the terminal illness, including physicians' oversight services, nursing care, counseling, spiritual support, bereavement counseling, medical appliances, drugs, home health aides, homemaker services, physical and occupational therapies, dietary advice, and volunteer assistance. An interdisciplinary team provides medical, social, psychological, emotional and spiritual services to the hospice patients and their loved ones.

In 1982, when hospice care was added as a Medicare benefit, the routine home care rate was set at $41.46 per day. When the benefit was established, the reimbursement rate did not include an annual inflationary update. Rather, Congress provided specific rate increases and later tied the hospice reimbursement rate to the hospital market basket to provide for inflation. Unfortunately, the rate has not kept pace with the growing cost of delivering care to terminally ill Medicare beneficiaries. The fiscal year 2005 routine home care rate, at which more than 95 percent of all Medicare hospice patients are billed, is $122.

Unfortunately, the current reimbursement rate does not begin to cover all of the expenses incurred in delivering compassionate and specialized care to dying Americans. A hospice cost study by Milliman & Robertson (M&R) states, "*the trend is clear that Medicare hospice per diem payments do not cover the costs of hospice care and result in significant financial losses to hospice programs throughout the country*." M&R notes several other factors driving the losses that hospices are experiencing today.

According to the M&R study, "*new technology, including breakthrough therapies and prescription drugs, has increased hospice costs far beyond Medicare's annual market basket update. For example, when Medicare set hospice payments in the 1980s, prescription drugs for hospice patients represented about $1 of the per diem reimbursement rate. M&R noted that these costs increased to approximately $16 per day by the late 1990s (an increase of about 1,500 percent)*." Drug costs have skyrocketed, making pain relief and symptom management, cornerstones of hospice care, much more expensive. Many of the most effective and widely used drugs for relief of cancer patients' discomfort are shockingly expensive. Duragesic, one of the most commonly used pain relievers for cancer patients, can cost up to $36 per dose. Zofran, an effective anti-nausea drug, costs almost $100 per day—exceeding the entire routine home care rate paid by Medicare to the hospice provider.

But escalating drug costs are not the only problem facing hospices.

For a variety of reasons, more and more patients are being admitted to hospice programs very late in their illness, when they require a greater intensity and variety of services. Their hospice care needs, including pain and symptom management

and personal support, are often greatest in the first few days following admission and in the final days and hours before death.

The Medicare Hospice Benefit was designed to balance the high costs associated with admission and the period immediately preceding death with the somewhat lower costs associated with periods of non-crisis care. However, the median length of service for hospice patients has fallen rapidly in recent years leaving fewer "non-crisis" days. The very short lengths of service and advances in clinical practices, both significant cost factors, were not anticipated at the time the original rate structure was formulated. These added financial pressures are having a devastating impact on hospices.

In the longer-term, Congress needs to undertake a review of the assumptions under which hospice reimbursements are made. New drug treatment modalities and types of medications have come to establish new areas of medical practice, and we need to have them available to the hospice practitioner and other health professionals. We in hospice know how to alleviate pain and control symptoms. But, far too often, the skyrocketing cost of such treatments force us to seek other less expensive and perhaps less effective alternatives. In its May 2002 Report to Congress, MedPAC recommended that the Secretary of Health and Human Services study ways to develop a high-cost outlier policy to address these issues.

By adopting the Medicare Hospice Benefit in 1982, Congress took an important step in changing a deeply embedded aspect of our culture, one that denies the inevitability of death and ignores the value of the end of life. We continue to believe today, that hospice care is our best response to caring for people at the end of life.

Yet, there are any number of obstacles to ensuring access to hospice care for individuals in this country. In fact, we are witnessing an alarming decline in the lengths of service for hospice patients, which is turning hospice into a "brink of death" benefit. The National Hospice and Palliative Care Organization's data show that the number of hospice patients has steadily increased, totaling over 1 million individuals last year. In 2003, their median length of service fell to just 22 days, which represents a 24 percent decline since 1995. This means that over ½one half of all hospice patients—50 percent of men, women and children in hospice care—die within 1 month of admission. This is happening at a time when access to hospice care should be deepening and broadening, not contracting.

When designing the Medicare Hospice Benefit, Congress recognized that predicting when death will occur is not an exact science. Even the Office of Inspector General (OIG), after its exhaustive 3-year audit and investigation of the hospice provider community, concluded that "[o]verall, the Medicare hospice program seems to be working as intended." But the cloud of concern raised by these efforts continues to impede appropriate access to hospice care for the terminally ill.

In its 1997 report, "*Approaching Death, Improving Care at the End of Life*," the Institute of Medicine warned:

> "Although hospices should not be immune from investigations of possible fraud or abuse, the committee urges regulators to exercise extreme caution in interpreting hospice stays that exceed 6 months as evidence of anything other than the consequence of prognostic uncertainty. To do otherwise would inappropriately penalize hospices and would threaten the trust that dying patients need to have in those who care for them. It might also discourage more timely admission to hospice of patients now referred only a few days before death, after important opportunities for physical, psychological, spiritual and practical support have already been missed."

The overall effect of these policies and activities has created a climate in which hospices and, most importantly, attending physicians fear that unless they can predict with certainty that a patient will live no longer than 6 months, they will be subject to increased government scrutiny and possible sanctions for hospice admissions or referrals. The end result of this atmosphere usually relegates patients to continued hospitalization at far greater costs to the Medicare Trust Fund. But a referral to hospice can save Medicare money. A Lewin (1995) study cited savings of $1.52 to the Medicare program for each $1.00 spent on hospice.

We are awaiting the release of a cost efficiency study conducted at Duke University that was funded through a grant by the Robert Wood Johnson Foundation that we hope will also demonstrate substantial cost savings for the Medicare program while providing high quality end-of-life care.

There is no better success story in Medicare than the Hospice Benefit. It is serving over 1 million patients and their families annually with a well structured, comprehensive and cost-effective benefit. Yet, the combination of policies and actions has conspired to impair access to hospice care. We need help to reverse this cycle

and reduce the growing climate of concern that now engulfs physicians and hospices as they struggle to admit and care for our most vulnerable citizens.

We applaud and support the efforts to eliminate Medicare fraud. However, in the spirit of the Institute of Medicine's warnings and in the face of unquestionable suffering and need, it is troubling that the unintended effects of these actions may limit timely access to hospice care.

Hospices need a supportive environment that focuses on issues that matter to the quality of care in hospice programs. Terminally ill citizens and their families need a strong, clear and consistent message that encourages the earliest consideration of hospice care within the dying process and that ensures access to this specialized form of care becomes more readily available to our most vulnerable population.

Apart from the hospice setting, we need to focus attention on the inadequacy of pain management for chronically and terminally ill patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) on how persons died in hospitals reported inadequate pain management and inattention to a patient's express wishes in their choice of care as common. Clearly, these and other issues, including a self-determined life closure, a safe and comfortable dying, and appropriate and effective bereavement need to be addressed if we are to improve the process of dying in America.

In providing whole-person care, health care professionals must take the time, even in the present managed care environment, to listen attentively, and enter into dialogue with their patients. These same health care professionals must also understand and practice state-of-the-art pain and symptom management (such as those developed and honed over the past 25 years by hospice and palliative care programs). It is within this context that the government needs to devote additional resources to further develop and advance the scientific understanding of pain and symptom management and make the information widely available to physicians, pharmacists, hospitals, research institutions, local governments, community groups and the general public.

Far too many medical education institutions are deficient in addressing suffering and palliative medicine as an integral part of their curricula. Established medical practitioners (other than hospice professionals) often lack an aggressive commitment to alleviate the distress and suffering of the dying. Concern about the use of opiates abounds. Palliative care physicians working with hospice-trained nurses and others can, in virtually all patients, control the physical distress of dying. If patients are provided timely and appropriate care, they will have been receiving opiates or other medications, if needed, for some time prior to their death. In that situation, escalation of medications if required to manage severe pain, is well tolerated and will not hasten death, but will allow a more peaceful and dignified dying.

Our health professions' schools need additional resources to develop and implement programs to provide ongoing education and training to their students in all phases of palliative care. Once these professionals are armed with the knowledge of new and constantly updated pain and symptom management techniques, they need to be assured that their aggressive treatment of pain and symptom management will not be hindered by outdated concepts or misguided legal review. As practicing health care providers, we need access to readily available and state-of-the-art guidelines for the treatment of pain.

As you may know, authority for the Health Professions programs expired on September 30, 2002. As this committee turns its attention to the reauthorization of these programs, we encourage you to address the issues we are discussing today by establishing Hospice & Palliative Care Academic Career Awards (PACA) modeled after the geriatric awards (currently receiving $6 million). This is an emerging field in medical training. The proposed awards would provide funds for junior faculty and require they spend at least 75 percent of their time training interdisciplinary teams of health care professionals in hospice and palliative medicine.

One valuable lesson in the health care cases watched by the world over the past few weeks is how important expert, sensitive, compassionate medical care is at the end of life. Many hospices and hospitals are interested in hiring physicians with training in this field, but there are very few training programs available. A crucial step forward would be the support of young faculty in palliative medicine to ensure that the Nation's medical schools are training future generations of physicians how to properly care for patients with advanced illness, as well as their families.

In order to prevent distressing struggles with health care choices, it is critically important that physicians be trained how to help patients and families come to terms with their conditions and make the difficult choices that are so common, especially near the end of life. The legislation introduced last Congress by Senator Wyden; the "Palliative Care Training Act" will do this by encouraging the hiring and training of Palliative Medicine experts, who are skilled in helping patients and

families through this challenging time. This legislation is a positive, forward looking response to the tragic struggle we have all witnessed.

Trained palliative care specialists can upgrade the skills of all the physicians they work with, and improve the "standard of care" of patients with life-limiting diseases. As we confront the complex issues of how to pay for the care of our aging population, palliative care is one of the few areas in which the best care is often less expensive, because it can be done at home. Hospitals are finding it financially advantageous to pay the salaries of such specialists because the patients get more comfortable quickly, families feel more able to cope, and the discharge home happens sooner, reducing the costs significantly. Health care dollars would go much farther if they were used to provide expert palliative care at home or in a hospice inpatient unit, rather than in a hospital. By adding significantly to the number of teachers in this new field, this act could generate substantial savings, while relieving the suffering of distressed families. We urge your consideration of this legislation as you pursue the Health Professions Reauthorization.

Effective pain and symptom management needs to be recognized as a core service of our health care community. Longer-term solutions involve exploring the legal and regulatory barriers to pain management, the level of competence in treating pain by physicians around the country and how the reimbursement policies of both the Federal health programs and private health insurers affect pain management.

Hospice programs and organizations have a responsibility to educate patients, medical students, residents, health care professionals, managed care systems, our communities, and our congressional leaders about quality end-of-life care and for whom and when it is appropriate.

The Medicare Hospice Benefit has served as a wonderful basis for paying for hospice care. Its reimbursement rates need to be dramatically increased in order to bring it current with new technologies and treatment modalities. However, as our knowledge and experiences grow, we need to think about how we can better extend hospice and palliative care to children, minorities, and persons with advanced chronic, non-curable diseases to ensure universal and timely access to hospice services when desired and appropriate, not just in the last few days or months of life.

This list of recommendations is certainly not all-inclusive. So much more can be done. Understanding human suffering and how to help patients and their families face the end-of-life with dignity is essential. By enhancing the educational process and focusing public attention on end-of-life issues, we will increase the awareness of when patients will most benefit from non-curative, supportive hospice and palliative care, thus providing timely hospice referrals and understanding where such care fits in the continuum of medical care.

It is time to re-examine how we care for our most vulnerable citizens, the terminally ill and their families, so they might enjoy living to the fullest—even as they approach death. Thank you.

Senator KENNEDY. This has been an extraordinary panel and you have had a lot of very constructive and suggestive ideas. I know that when we develop our approach on this issue, we are going to want to incorporate many of those ideas and get your reactions to it.

As you probably know, since you are all old, or young, witnesses, as the case might be, that when that bell rang, it meant 20 minutes. As you can see on the clock, that 20 minutes of time has run out. Our chairman will be back momentarily, but it necessitates that I will have to recess this hearing for just a moment. I had some questions and I will look forward to reading the answers.

But I think Dr. Schumacher probably responded to the question that people that are watching this program are thinking, what can I do today? What can I do? I think it was outlined with the Nelson bill.

Mr. SCHUMACHER. Yes.

Senator KENNEDY. We have to pass that legislation. They are viewpoints that we certainly hope would be initiated.

I was interested about what, when most people write down their wishes, what they do write down. I would be interested in what the panel's reaction to that is, and how much of a problem these con-

flicts are and how they are generally resolved? Those are areas that I was kind of interested in. I am going to have to recess here, but if you do have a chance, maybe in the quick recess, give a little thought to those and maybe make a comment on it when the chairman comes back, I would very much appreciate it. But I want to give you the assurance that your views are going to be carefully considered.

Dr. Schumacher, I just found out about hospices years ago with Phil Hart, who is a very distinguished Senator from Michigan whom the Hart Building is named after. I was completely unfamiliar with it, and he had the most extraordinary, if you can call it a successful experience——

Mr. SCHUMACHER. It began in Ireland, you know.

Senator KENNEDY. There you go. [Laughter].

Senator Burr is here, so we don't need to recess. We were just talking about Ireland, Senator. There you go.

And then a very good friend, Frank Church, who is another Senator from Idaho and went through this. So we welcome the opportunity to be a strong supporter of the program.

Mr. SCHUMACHER. Thank you very much.

Senator KENNEDY. Listening to the whole panel here has been enormously useful and productive. You all have been of great help to us in helping us formulate policy, so I thank all of you very, very much.

You will excuse me, Mr. Chairman. This splash of orange, as many would understand in the Ukraine, is for President Yushchenko, who is going to be here and honored with a Joint Session. It is awkward, because we all have to be in a number of different places, but he certainly was an extraordinary figure in terms of democratic values and the Joint Session will honor his presence. I am going to have to excuse myself from these hearings, but I thank you all very, very much. Thank you, Mr. Chairman.

The CHAIRMAN. [presiding]. Thank you, and thanks for keeping this going while I went over to vote. I do appreciate the outstanding testimony, and I apologize for not being present for part of it. I do appreciate your submitting your testimony in advance so that I would have a chance to review it. There is some tremendous information here today. It takes quite a while to assimilate it, I am sure, but some excellent information.

I will ask a few questions here and then turn it over to Senator Burr.

Mr. Turnbull, given that you work with individuals who no longer may be able to or maybe never have been able to advocate for themselves, what are some of the key legal documents that everybody should have in place? What public or private entities exist that can provide legal advocacy for individuals who are not able to advocate for themselves?

Mr. TURNBULL. Senator, I think it begins with the training in the public schools. We can train people to be more competent than we are training them in special education and general education. So I would begin the training on self-determination very early.

That may make it possible for many more people to execute the appropriate documents. Obviously, a last will and testament and power of attorney, durable power of attorney, a living will, and if

not by the person, then by the person's family and friends, a discretionary trust. There are other state-based documents, such as limited guardianship, and I really mean limited, and in some cases some plenary guardianship is necessary.

You asked about various entities that might assist in this. Certainly Dr. Schumacher has listed a few. There are professional organizations in the field of intellectual disability. There are family organizations. It would be wonderful if Congress would authorize and enable these organizations to educate their constituency.

Very few people have six degrees in the family, as my wife and I do. Very few of them have the access to information that we have. There is a huge need for the families, and particularly the persons with disabilities, to understand more about what they are doing, and I would emphasize that this outreach can be carried out through some existing entities, the government funds, the Parent Training and Information Centers, protection and advocacy agencies, university centers on excellence in disabilities, and the Developmental Disability Councils at the State level.

So I think there are ways to get informed consent, and oftentimes what we aren't getting is the information element in the consent.

The CHAIRMAN. Thank you. Dr. Schumacher, you mentioned that it is estimated that less than 20 percent of Americans have prepared advance directives. Obviously, in working with hospice providers, you deal with end-of-life issues on a daily basis, which is why you are urging others to have those discussions now. Do you have any ideas about how Congress might encourage more Americans to address this issue in advance, and what sort of issues should they consider when putting a document together? How would you ensure that one's spiritual and moral beliefs are captured in such a document?

Mr. SCHUMACHER. Absolutely. I, while you were out voting, encouraged Senator Kennedy to focus in on S. 347, which is cosponsored by Senators Nelson, Lugar, and Rockefeller It actually does a very good job at helping Congress to focus in on messaging to the American public. What are some of the key issues that are important when one looks at one's end-of-life care planning? That planning includes not just filling out a piece of paper, which one can download off a number of Web sites, including ours, but it is also around the kitchen table, around your church activities, families at Thanksgiving, having the conversation about what it is as an individual that you do and you do not want specifically to happen to you if you are in a medical emergency and you are not able to make decisions for yourself.

It is those conversations that I think are almost as important as are the documents that need to be filled out. Those conversations, had they been secured and had been written down in this situation we looked at in Florida, probably would have precluded all of the last 15 years of pain that both of those families endured, along with Mrs. Schiavo.

So Congress, I think, in supporting legislation that would really make it a very visible, positive thing—it is largely for Medicare beneficiaries in this legislation—for the conversations, the specific technical language on forms to be downloaded or be given to fami-

lies, have conversations with the physicians, have them filled out, have the records actually be kept at home, in your doctor's office, and on your own person or a family member that is making decisions for you, these are the most effective ways, I think, of us precluding situations like the one we did see in Florida to continue.

The CHAIRMAN. Thank you. My time on the first round is almost expired, so I will turn to Senator Burr.

Senator BURR. I thank the chairman. I apologize to the witnesses for not being here for your testimony, but let me assure you I will go back and read it in great detail.

Dr. Bernat, let me ask you, were a patient to enter the emergency room today and the attending physician limited the diagnostic options that they had and a misdiagnosis was made of the illness and that patient died, in today's atmosphere, would that generate a lawsuit?

Dr. BERNAT. Senator Burr, if I understand your question correctly, a patient comes in the emergency room, you said there is limited diagnostic tests available?

Senator BURR. No. The attending physician determines only to do one or two diagnostic tests, but not the full battery of what might give a very accurate diagnosis. Would the attending physicians be susceptible in today's atmosphere to a lawsuit?

Dr. BERNAT. Well, I think it would depend on what the standard of care is for that particular evaluation. If the standard of care required doing the full battery, as you put it, then certainly there would be a liability. If the standard of care did not require that, then I would think there would be less liability.

Senator BURR. I am certainly asking a question that deals with the decision or the lack of the decision to choose a PET scan as it relates to Mrs. Schiavo, but I am not here to focus on that particular instance. I am here more to focus on the decisions that are made in health care and understanding that we are not here to practice medicine. We are here to ask tough questions and to set policy.

Mr. Turnbull, I would especially like to thank you for being here because I think you have become a very strong advocate, and as the parent of a child that is disabled, I think you speak for a lot of people in the country.

My concern is that this one incident has suggested that there are some things that Congress has no role in. I would like to say that I sort of agree from a standpoint of Congress practicing medicine. But I don't believe what we did was practice medicine. I don't think we were second-guessing the diagnostic decisions that were made, even though they certainly didn't exhaust every option that was out there.

I think what we exercised was the fact that we understand that we set a precedent with everything that we do in Congress, but we also set a precedent with everything we choose not to do and that this was one of those situations where to do nothing sends a signal to future legislators that this didn't raise to the level of a second review, or as some might suggest, a third or a fourth or a fifth in the system that it had gone through.

And I would just challenge each one of you, because I think the criticism was unfair. I believe that this is a great day for the mem-

bers of the House and the Senate, take the fringes and stick them to the sides a little bit to the core of the members, because for once they weren't Members of Congress or legislators. They were parents. And they said, here is an issue that raises to a level that, you know what, as society, we ought to take one second look at this issue.

So I would challenge you from a standpoint of whether a decision about a patient and the fact that you didn't exhaust every diagnostic tool didn't open you to a lawsuit in today's atmosphere. I believe that it would. I believe the tendency because of that is to do everything possible to try to understand the exact state of a person who is ill. It disappoints me that we didn't go to that length in this particular case, but it also encourages me that when I am not here, when Mike Enzi is not here, when most of you are not here at the panel, that a future Congress will look at the fact that we did say there are some things that rise to the occasion, that they override whether it is State or Federal jurisdiction. But for the long-term future of the country, we should set a precedent that you do stop and you do ask questions and possibly you do act, but you don't go over it like a speed bump in a parking lot, like it had no importance whatsoever.

I want to thank all of you for your willingness to come in, for the value of your testimony. I am sure this won't be the last discussion we have about the world of palliative care and consequently what our responsibilities continue to be to the disabled. But it is about the future of the country and it is about the example that you on that side of the table and us on this side of the dais set for our children and our grandchildren as to what we expect them to pay attention to. I thank each one of you.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

I have a few more questions here. Dr. Warden, as the National Director of the Defense and Veterans Brain Injury Center, in your testimony, you mentioned traumatic brain injury (TBI) and acquired brain injury (ABI). Can you help provide additional clarity about the distinction between TBI and ABI? I am particularly interested in this given that the Traumatic Brain Injury Act expires this year and I want to understand this distinction.

Dr. WARDEN. Certainly. Traumatic brain injury, which results from trauma, has a particular constellation of symptoms and physical results. As I mentioned, it can be either closed or penetrating, and what really characterizes, for example, closed traumatic brain injury would be the potential for the brain to keep moving within the skull and acquire injuries, both in terms of those connection fibers and focally in terms of possible bruises or contusions in the brain or impinging from the outside of the brain. This typically results in a group of people who may be severely injured initially, and in a small percentage in an ongoing way, but a much larger percentage of people who will have some disability or persistent effects later.

I would also mention that the demographics are somewhat different, so here, the people at greatest risk are typically males between about 18 and 24 years and the elderly are especially at risk from falls, whereas another type of acquired brain injury, for exam-

ple, strokes, as we know, is more typically an illness of the elderly, though younger people can have strokes, as well, and this is generally focal brain injury. So there is an area of bleeding or an area of the brain that doesn't get oxygen. So that is a specific area of the brain is affected, but not the entire brain, unless, of course, there have been other things that have happened in the past to affect the rest of the brain. So that is an important distinction, both in the individuals and in the types of treatments which ensue from the ages and the types of brain injury.

The other type that I mentioned would be anoxia or global lack of oxygen to the brain, and that is a more diffuse and catastrophic brain injury. So there is a broad range among those three.

The CHAIRMAN. Thank you. I have some more technical questions on that, but because they are technical and they could put people to sleep, but are very important to our testimony, I will be asking you those in writing.

Dr. Bernat, one controversy has been the distinction between the persistent vegetative state (PVS) which Mr. Turnbull said he would like a different name for, and I agree with him or minimally conscious state (MCS). Can you outline how you would make a differential diagnosis between PVS and MCS? What sort of radiological or other diagnostic evidence might a clinician use in these circumstances?

Dr. BERNAT. Thank you, Senator Enzi. I would agree with Mr. Turnbull that that is a poor term. I think those of us regret that our colleagues came up with this term 33 years ago when it was coined. But like many things, once it exists and it is used, it is hard to discard, but I certainly feel that that kind of a word has a derogatory sound to it. It certainly wasn't intended by those who coined it, but it can certainly be interpreted that way.

Now, to answer your question about the clinical differential diagnosis between persistent vegetative state and minimally conscious state, the essential difference is that the minimally conscious state patient does show evidence of awareness. That is, they can follow commands. They can utter a few words. They can reach for objects. They do things that only people who are aware of themselves and their environment can do. Despite the fact that they have global brain damage, despite their severe disability and the fact that their responses are diminished, they show unequivocal evidence of awareness.

So there is really all the difference in the world between those two states. Persistent vegetative state, zero evidence of any awareness. None of the behaviors of the patient suggest that they have any capacity of awareness, whereas the minimally conscious patient does show evidence of awareness.

There is also a difference in testing. Senator Burr, when he was here, raised the question about a PET scan. There are studies that have been done on using PET scanning and functional MRI studies that can distinguish the features of persistent vegetative state from minimally conscious state. In a minimally conscious state, many of the language activation studies show widespread activation of networks of cortical neurons that are fairly normal and look like those of an aware patient, suggesting that the minimally conscious state patient may be quite conscious, whereas in the persistent vegeta-

tive state patient, there is no widespread activation of those types of networks.

These tests are currently research tools. They have not yet developed the necessary standardization to be available clinically. They need to be tested. They need to be correlated with outcomes before we will use them clinically to rely on.

The CHAIRMAN. Is MRI imaging useful in this, or is that a technology that doesn't apply?

Dr. BERNAT. Ordinary MR imaging or CT imaging looks at the anatomy of the brain. If there has been a devastating injury to the brain that happened some time ago, many months or years ago, we see the effect of that with severe shrinkage of the brain due to loss of brain cells. So the ordinary MRI and CT scanning can show that.

But the tests that I was talking about are functional tests, that is, a functional MRI. The paradigm here is that you give some stimulus to the patient and you record over the brain to see if that stimulus evokes an activation of neurons, suggesting that it has some—looking for normal patterns of activation that would suggest that it is getting in, if you will. That is not an ordinary MRI. That is a so-called functional MRI, or FMRI. That one and the PET scan, which is an analogous functional imagining modality, are—those studies are now being done to try to investigate both the normal patterns of activation that are seen in people that have normal consciousness and awareness and then to map out the patterns that are correlated with the various abnormal patterns.

Right now, they are not quite ready for prime time, but there does seem to be, even in the few patients that have been studied, that they can discriminate between the ones that have intact awareness from those that don't.

The CHAIRMAN. Thank you. Mr. Turnbull, changing drastically here on the subject, do you have any particular recommendations for what people should be doing in respect to financial planning, what sorts of end-of-life or long-term care financial planning you could suggest? Do you think more individuals should be purchasing long-term care insurance, or are there other answers out there, other options or alternatives?

Mr. TURNBULL. Senator Enzi, certainly, long-term care insurance is something that is desirable if the family can buy it. It is expensive. It sometimes is out of reach for many families. It may not take into account the extraordinary costs of extraordinary people. It is a product tailored to a mass market, and people with intellectual disabilities and other disabilities may not be within that marketplace that is the basis for the policies. So I would encourage it, but I am cautious about its effectiveness.

Second, with respect to the long-term care insurance and particularly the so-called discretionary or special needs trusts, I am also very cautious that those might be used as deemed assets which would then disqualify a Medicaid or a Medicare or other Social Security recipient from benefits.

The best thing we can do is what I think most of us in this room do. We marshall our assets, both in the private and the public sectors. I am cautious about how we might proceed with respect to long-term care and special needs trusts.

My next recommendation would be that every family has to keep records. At one point a year or so ago, I had to prove that my son had mental retardation. Well, he has had that since he was born at Johns Hopkins 37 years ago. In order to prove that, I had to haul a file cabinet over to the local Social Security office. Thank God I had kept the records. It seems to me very important that there be an easier administrative process for the families.

I believe that predictability is one of the core values of the law, and for families and persons with disabilities to plan for their future, they must have the ability to reasonably anticipate and rely upon the predictability of programs that we currently have. I would say that even though I have been involved with the American Bar Association, there are still lawyers who do not have sufficient knowledge about how to structure their services to people with disabilities and their families. Further education of the Bar is important.

And finally, I would think very strongly about reversing the bias that exists within Medicaid. The bias in Medicaid is pro-institutional. For 20-some-odd years, we have been reversing that bias bit by bit. I think now is the time for us to put our biases aside, our prejudices aside, and to make Medicaid not only a community-based biased program, but more than that, to examine whether, in fact, that program is becoming too narrowly medically modelized and not sufficiently a means for supporting a person in the community. It is not just a matter of how you do things on the private sector, but it is also very important that we respond to the self-determination wishes of the families.

Those are a few comments, Senator, and I appreciate your asking the question.

The CHAIRMAN. Thank you. I have got to say, just a little diversion here, that on my way over to vote, I was on the subway with Senator Bunning, who also provided his thoughts. He had some personal instances that he wanted to share with me of some situations that fit in with the testimony that you are giving.

Dr. Warden, I am going to shift gears here again. Could you please clarify when individuals with a brain injury are transferred to your center? Does it generally occur after a person has had an acute brain resuscitation and has stabilized, or do you have a chance to work with the person soon after the injury occurs? What advantages are there to being able to treat individuals with brain injury earlier in the process?

Dr. WARDEN. Yes. Thank you. We often get patients—many patients are referred to Walter Reed Army Medical Center from Iraq currently through Landsduhl, and as I believe you are aware, there is really superb on-the-ground medical care and surgical care being provided in Baghdad and with very sophisticated transport. So by the nature of who we take care of, yes, we do receive patients after they have had acute care previously.

We also function as part of a network of care between the military and the veteran and then community reentry program so that we can help facilitate movement through those different levels of need.

So I think to your question, yes, it is very helpful to first identify problems, identify the brain injury, to assess the brain injury, and

then to begin a treatment plan that can then be typically executed over multiple levels of care, always reassessing—multiple levels of care meaning acute, sub-acute, hopefully on into the community, and then reassessing how people are doing and their progress.

The CHAIRMAN. Thank you. Shifting once again, Dr. Bernat, there has been little controversy over whether individuals who have had their nutrition and hydration withdrawn can feel pain. Although most of the medical community would assert that someone in a persistent vegetative state cannot feel pain, it has been reported that some patients in these circumstances should receive morphine to alleviate pain. Could you explain why clinicians may decide to prescribe morphine to someone with a diagnosis of a persistent vegetative state? What is the rationale for such a prescription?

Dr. BERNAT. To the fullest extent that we can tell, and I will qualify it with that to start, if someone is in a persistent vegetative state because they have an utter absence of awareness, that also means that they lack the capacity to feel, to experience pain, and that means to suffer as a consequence of that pain.

Now, I already mentioned earlier that there is a biological limitation to our ability ever to know the experience of another person because we can't get inside someone's mind, but there is a consensus within the medical community that that statement I made is correct, assuming that the diagnosis of PVS was made correctly.

Now, to get to your question, why would, in that setting, why would it be necessary, then, to administer morphine or other medications to someone in a persistent vegetative state who is dying, there are reasons that this is commonly done within hospices because—I would say there are two reasons.

The first reason is that some family members still believe that the person has the capacity to feel pain and this is making certain that if that were the case, that that would be covered. There seems to be little harm in doing that. It is—opiate treatment is commonly given to dying patients in hospice care, and if there is a concern about a family member, rather than saying, oh, well, don't worry about that, I think compassionate physicians would say, well, even though we feel it isn't essential, we will do this to put your mind at rest.

It is the case that people in vegetative states do have certain movements. There are reflex movements. Some of those could be construed as representing evidence of suffering according to families, not according to the doctors. So it is basically addressing the emotional needs of the family and there seems to be little downside in doing so.

The CHAIRMAN. Thank you. Dr. Schumacher, given that many individuals receive hospice care while they are dying and given that hospice care centers focus on providing adequate pain and symptom management, can you discuss in general what sort of pain and symptom management would be typical in hospice for someone who has opted to have his or her feeding tube removed? What pain and symptom management services do hospices provide in that kind of a scenario?

Mr. SCHUMACHER. Not being a medical doctor but a clinical psychologist, I can tell you what I have observed, having managed hos-

pice programs for over 26 years. The identification of an opioid, morphine, is something that is oftentimes used to reduce, I think as Dr. Bernat said, more family distress or symptomatology than patients. Those patients are oftentimes very comfortable, very relaxed, and live the remainder of their days very, very peacefully.

One of the things that I think is the trademark of hospice care, which people are especially—report especially fondly of after their loved ones have died is that the patient was cared for with a level of intensity that they oftentimes don't see in hospital settings, and that would include such things as mouth care, which is, for many individuals who are watching someone die, can be very, very difficult.

So I think that the symptom management that hospice provides, one portion of it certainly would be making sure that there was an opiate on board should there be any distressing symptoms. But the whole focus of hospice is to treat all of the distressing symptoms of the patient and the family so that we engage in behaviors and support to that patient so the family is seeing that their loved one is being managed not only medically competently, but psychologically, spiritually, and socially very supported, as well.

Many of the people that I have seen over the years that have not come into hospice, postdeath of the patient, will come into my office and say something like, "No one told me my mother was dying. She did not receive not only good competent opioid support in the setting in which she was dying, but also the level of intensity of the staffing was not adequate to meet her needs, my mother's needs, as an example, and our family's needs, as well."

So hospice really does focus on the medical competency, the medical needs, the distressing symptoms that the patient experiences, but also the psychological support which long-term, postdeath of the patient, oftentimes casts a very long shadow in the life of that family. And if they saw their mom or dad not only be in physical pain, but not getting the good hands-on care, mouth care, supportive care, and loving care that is the hospice trademark, those are the kinds of things that people do walk away remembering, either positively or very, very negatively.

Mrs. Schiavo died in a hospice program where she received the best that humankind can offer, and that, I think, is something that is the hallmark of hospice care. We stay with our patients. We don't abandon our patients. We live within the letter of the law, as that program did, and provided to that individual what it was that she needed—to die comfortably.

The CHAIRMAN. Thank you. Today we have talked about some of the most difficult, emotional things that we can possibly discuss.

I do have some additional questions. I am sure that Senator Kennedy has some additional questions, and we will be submitting those to you and hope that you will respond to us.

I really appreciate the level of expertise that we have here today and the information that you shared with us and the way that you shared it. It has been very helpful. So I thank all of you for your testimony and appreciate all the people that attended for their interest and attendance.

We have raised a lot of critical issues for all families to discuss and address to ensure that individuals who cannot advocate for

themselves are still able to guide their health care decisions. I hope this hearing and the information that comes out of it will provide further opportunity for a national dialogue about planning ahead both with the legal documents, such as advance directives and living wills (which I understand are escalating dramatically across the country). As an aside, I have talked to some attorneys who said that they are backed up through June now on writing those, as well as financial arrangements, which may include the purchase of long-term care insurance.

As I mentioned, members of the committee can still submit questions and statements. We would appreciate a timely response to the questions. The record will remain open for an additional 10 days for those questions and further statements from my colleagues and any expansion on your testimony that you would like to do.

You have been very helpful. I appreciate it. Thanks for your participation.

The hearing is now adjourned.

[Additional material follows.]

ADDITIONAL MATERIAL

RESPONSE TO QUESTION OF SENATOR ENZI BY J. DONALD SCHUMACHER

Question. Dr. Schumacher, can you comment on why you feel as if Medicare and Medicaid should provide reimbursement for assisting families in making these determinations? Do you believe that physicians are the best individuals to be performing these consultations? Is the health care context the best setting for these familial discussions?

Answer. Both Medicare and Medicaid health systems are appropriate mechanisms to afford a setting for the discussion of advance care planning for a variety of reasons. These health care delivery systems serve an ever increasing assortment of patients with serious and life limiting illnesses which will only undergo further expansion with the aging of the baby boomer generation. As the health care systems treating the elderly and poor, these systems are most likely to encounter the vast majority of our Nation's most vulnerable and fragile citizens.

There are two goals of our Nation's health care delivery system that might be served by including such planning opportunities within the Medicare and Medicaid systems. First, and probably most important is the notion that the patient and family ought to be empowered with appropriate information so that they might make informed decisions about their health care options. Informed consent should not be viewed as the minimum necessary to gain the patient's signature on a printed form, but rather an expansive discussion about the range of options, probable outcomes, and an appreciation of the goals of treatment. Only with a knowledgeable patient may we have truly informed consent. Such discussions would help meet this goal.

A second goal that would be served is the responsibility of health care providers to be good stewards of the Federal health care dollar. Such discussions would enable health care professionals to better understand the wishes and desires of their patients and avoid unnecessary procedures and futile treatments if their patients are more knowledgeable and better informed. It is important to note that these discussions with health care professionals are not intended to be one-time events, but rather ongoing and regular conversations about health care choices, as they should be. Each health care event or crisis carries with it a series of issues that impact the decision making process and should be considered within the context of the patient's expressed wishes.

By suggesting that Medicare and Medicaid are appropriate systems to provide a means to engage in such conversations, they should not be viewed as exclusive sources of information. As I mentioned in my testimony, these conversations also need to take place around the kitchen table with our family and friends, as well as with our legal advisors, and spiritual counselors. We need not only private conversations within families, but also a national conversation, to better understand the range of options that are available so that we can make clear expressions of our particular choices for our end of life care.

Many patients, especially the elderly, put a great deal of trust and faith in their health care professionals and look to them for advice and counsel. It is in these settings that questions can be addressed about treatment options and the likely outcomes associated with particular courses of care. Physicians, and other health care professionals are well suited to assist in this exchange of information and decision making process. Inherent in this process is an assumption that the health care professionals are well equipped to facilitate the discussions and are able to provide the requisite information in an appropriate setting.

The language of S. 347 should be expanded to also include members of the hospice interdisciplinary team as qualified providers of advance care planning information. These specially trained and experienced teams are particularly well suited to facilitate such discussions. A fundamental precept of hospice and palliative care is patient self-determination and such skilled and trained professionals successfully fulfilled these goals for more than 1 million patients and families last year. By including such teams in the legislation, the patients and families would have the benefit of a physician, nurse, social worker and/or spiritual counselor, as well as other members of the hospice and palliative care team to facilitate a more well informed discussion of the range of choices and decisions that might be appropriate. Ultimately, the goal of this process is to better determine the patient's wishes and make sure that they are carried out.

In addition, hospice team members, as part of their everyday practice, provide services in the patient's homes, assisted living facilities, long term care facilities, hospitals or wherever the patient may reside. Perhaps these settings are more comfortable or conducive for such discussions, but should not be considered the exclusive venue for the decision making process.

The conversations and evaluations that are inherent parts of the legislation are complex and require a great deal of time on the part of the health care professionals. Patients and their families need sufficient time to spend with their health care professionals and the mechanism implementing such conversation needs to take into account the nature of the exchange and the amount of time that is required to adequately address the wide range of complicated issues that comprise such discussions.

RESPONSE TO QUESTION OF SENATOR ENZI BY DEBORAH L. WARDEN, M.D.

Question. Dr. Warden, is it possible for civilians to receive treatment at your center? If so, what is the process for that?

In your testimony you referenced the high unemployment rate for people with a brain injury as well as specific individual's needing specific supports, such as job coaching. What other types of supports are available to assist people who work and live in the community? In your opinion, what types of supports or rehabilitation methods have been successful in helping people achieve these goals? I'm particularly interested in this, given that the Workforce Investment Act, and specifically title IV, the Rehabilitation Act of 1973 is to be reauthorized this year.

Answer. FECA (Federal Employment Compensation Act) permits all civilian dependants, beneficiaries, Mil Ret, & Ret Veterans treatment in a MII/VA Hosp. Civilian DOD and Contractors are covered under the War Hazard Act in time of War. All civilians injured on site or near are allowed emergent care then transfer.

Problems With Return to Work After TBI

The research literature documents extensive difficulties with return to work after TBI, particularly for individuals with moderate to severe injuries. Individuals with moderate injuries (GCS=9 to 12) have rates of return to work of 50–60 percent; while only 20–30 percent of individuals with severe injury (GCS-3 to 8) return to work (Levin et al., 1979; Brooks et al., 1987; McMordie et al., 1990). Individuals with mild injury (Glascow Coma Scale of 13 to 15) are usually reemployed after their injuries (60–85 percent at 1 year postinjury) and remain employed up to 15 years following injury (Dikman, Temkin, Machamer, et al., 1994; Schwab, Grafman, Salazar, et al., 1993, Edna and Cappelen, 1987; Fraser, Dikman, McLean et al., 1988, Colantonio et al., 2004). Stability of work postinjury has been found to be correlated with injury severity, age, and driving independence (Kreutzer et al., 2003). Fifty-six percent of active duty service members with Penetrating Head Injury from the Vietnam war were working 15 years after injury, placing them in the range of moderately injured patients (Schwab et al., 1993).

Job Coaching

The nature and consequences of the executive function deficits that are common after moderate to severe TBI provide a strong theoretical basis for the application of supported employment programs for TBI survivors that incorporate structure and supervision. The research literature also suggests that supported employment programs, including job coaching, may be helpful in increasing successful return to work for individuals after TBI (Chesnut, et al., 1999; Wehman et al., 1995; Wehman et al., 2003), thus providing empirical evidence in support of the theoretical considerations. Randomized studies have not been conducted that would provide definitive evidence, and various models of supported employment and approaches to job coaching have been proposed (Chesnut, et al., 1999). However, several large observational studies comparing individuals who received supported employment programs with individuals not provided supported employment (some received day treatment, others no treatment, or pre-employment vocational counseling, etc.) have shown better rates of return to work for individuals receiving supported employment (Malec, et al., 2000; Chesnut, et al., 1999). The selection of particular types of patients for these studies limits the generalizability of findings, but the studies suggest some patients clearly benefit. The success of these programs with severely injured TBI patients is particularly compelling. And, the programs appear to be cost effective, as additional earnings for individuals with TBI provided supported employment has been shown to exceed the costs of the program (Wehman P, Kregel J, Keyser-Marchus L., Sherron-Targett P, Campbell L, West M, Cifu DX, "Supported employment for persons with traumatic brain injury: a preliminary investigation of long-term follow-up costs and program efficiency," Arch Phys Med Rehabil. 2003 Feb; 84(2):192–6.)

Evaluation of Existing Programs

Wehman, et al. (2005) review existing programs designed to support and encourage work among TBI survivors. They list a wide variety of programs offered through

Vocational Rehabilitation, Social Security Disability, Medicaid, etc. designed to promote and facilitate work among this population. The programs available are not widely utilized, partly because potentially eligible recipients do not know of their provisions. The authors recommend additional research on mechanisms of facilitating return to work among individuals with TBI, and an expansion in programs that have been shown in observation studies to help, and efforts to promote new approaches to work in the TBI population (such as Telework, business ownership, etc.).

Work currently being done by the CDC on prevalence and incidence of TBI is extremely important to any consideration of treatment needs in TBI.

Karen Schwab, Ph.D., Assistant Director of Epidemiology, Defense and Veterans Head Injury Program, assisted formulating these responses.

RESPONSE TO QUESTIONS OF SENATOR HATCH BY JAMES L. BERNAT, M.D.

Question 1. Dr. Bernat, you said that new technologies such as PET scans and functional MRI's are used in research but not in clinical diagnosis. Could you please explain the difference?

Answer 1. Only a few patients with persistent vegetative state (PVS) and minimally conscious state (MCS) have been studied using functional MRI (fMRI) and PET scanning. The results are quite interesting and seem to correlate well with the clinical features of the conditions. Thus, in PVS patients who appear to be totally unaware, the PET and fMRI shows failure to activate distributed neural networks following a variety of stimuli as expected in someone without awareness. By contrast, in MCS patients who are known to be aware, the studies show more normal patterns of activation of widely distributed neural networks after stimuli that are consistent with awareness. But these are research results. The tests are not available for general clinical use because we do not know how predictive these findings will be in prospective patients since too few patients have been studied to date. Until many more patients are studied, and we can obtain reliable and reproducible data, we cannot recommend the use in clinical situations to assist diagnosis. They just are not ready yet.

Question 2. Do you agree with Mr. Turnbull that medical advances affect how much we should honor an individual's clear expressions regarding end of life decisions? Mr. Turnbull's statement: "Congress should recognize that end of life decision making, however much it may be guided by various legal instruments or other reliable expressions of self-determination, is a dynamic process, and that people's conditions change with prompt, state-of-the-art treatment, and so do their and their families', other designated representatives', and health/medical caregivers' judgments about how much to honor the previously executed instruments or expressions of autonomy."

Answer 2. I agree with Mr. Turnbull's statement to a point. His statement raises a subtle issue that requires a careful explanation. Surrogate decision makers of incapacitated patients have the duty to try to reproduce the exact decision that the patient whom they represent would have made in the clinical situation in question. Therefore, when they are asked by the patient's physicians to consent to or refuse an offered therapy on behalf of the patient (including the artificial provision of hydration and nutrition), they must ask themselves if the patient would have wanted the therapy in question and consent for it only if the answer is yes.

In making a treatment decision on behalf of a patient, the surrogate decision maker should consider several sources of information. From the physician, the surrogate learns the diagnosis and prognosis with and without the treatment in question. From the patient, the surrogate considers his knowledge of the patient's expressed wishes, including preferences expressed in written advance directives; what the surrogate can deduce from how the patient has lived her life; information contained in her letters and comments; and the patient's religious beliefs. Knowing the patient's values and preferences and thereby her health care goals, and knowing the patient's diagnosis and prognosis with and without treatment, the surrogate should attempt to reproduce the precise decision the patient would have made.

A patient's wishes expressed in a written advance directive are a powerful source of information about the patient's true treatment preferences. Physicians usually assign great weight to a patient's written advance directive because it comprises her clearly expressed treatment wish. But in my experience as a physician caring for critically ill patients, and as an ethics consultant called for advice in ethically conflicted cases, I have encountered two situations in which I believed that the right course of action was to ignore the patient's previously written statement. Although these are admittedly exceptional circumstances, considering them helps illuminate the limitations of written directives.

The most common exceptional circumstance is that in which the health status that comprised the context for a patient's previously written directive no longer exists, rendering the directive ambiguous. For example, suppose as a healthy and independent 72-year-old, Mrs. J indicated in a written directive that she wished to undergo cardiopulmonary resuscitation (CPR) if she suffered a cardiac arrest. She hoped to continue living many more independent years. Five years later Mrs. J suffered a large stroke rendering her paralyzed, unable to communicate, and requiring indefinite nursing home treatment. Her physician at the nursing home asked her surrogate if she would consent to CPR for Mrs. J in the event of cardiac arrest or if Mrs. J should have a Do-Not-Resuscitate (DNR) order. The surrogate was conflicted. On the one hand, everything she knew about Mrs. J told her that Mrs. J would want to have a DNR order in her present situation. Yet Mrs. J's previously executed advance directive directed her physician to administer CPR. What should be done? Clearly, the health context in which Mrs. J indicated she wanted CPR no longer exists. Having CPR now cannot achieve Mrs. J's overall health goals of independence. Therefore, Mrs. J's surrogate is right in ignoring her previous directive because she is upholding Mrs. J's more general treatment preferences.

A second exception is when the patient does not understand the terms of a written directive she has signed. I have seen several cases in which elderly patients had previously completed detailed pre-written medical directive forms asking for treatment preferences in a variety of clinical scenarios. In some cases, there were striking inconsistencies in the preferences listed, such as a patient indicating under the general preferences that she did not wish to receive life-sustaining treatment in the face of a terminal illness, and later in the same form indicating that she wished to undergo CPR if terminally ill. Subsequently, in the context of an ethics consultation, when I asked about these inconsistencies, the patient's adult children pointed out that their mother simply misunderstood the questions, and therefore, her signed directive should be ignored.

In my opinion, if a surrogate makes a decision that contradicts a patient's previously written directive, this situation requires oversight by a hospital ethics committee to assure that the true wishes of the patient are being followed. A written directive serves as an important guide for surrogates and physicians. But most important is for a patient to identify a surrogate decision maker whom the patient knows and trusts, to communicate with that surrogate about the patient's health care goals and values, and to empower that surrogate to make decisions for the patient when the patient becomes incapacitated. Surrogates need guidance from the patient that includes written instructions. But the surrogate also needs the flexibility to respect and follow the patient's general health goals in previously unanticipated clinical situations, including the authority to override a previous written directive in exceptional circumstances that are strictly justified.

RESPONSE TO QUESTIONS OF SENATOR HATCH BY H. RUTHERFORD TURNBULL, III

Question 1. Mr. Turnbull, in your written testimony, you said that Congress should recommit itself to the ADA principle of self-determination. At the same time, you said that advances in medical treatment affect how much third parties should honor an individual's expressions regarding end of life decisions, apparently no matter how clear or reliable those expressions are. I'd like you to address what might appear to be tension between these two ideas.

Answer 1. The Schiavo case has drawn people's attention to the issues surrounding living wills. Individuals may also execute various powers of attorney, including health powers of attorney. Together, these instruments should be sufficient to guide care-givers in end-of-life decision making, particularly under two circumstances. The first is that the individual executing them continually updates them to take into account changes in medical technology and changes in his or her views concerning life, dying, and death. The second is that the instruments are consistent with the person's understanding about technology, life, dying, and death as verbally expressed to the individual's family, friends, physicians, and other caregivers. Any Federal technical assistance about end-of-life decision-making must headline the importance of current instruments that are consistent with each other and with other expressions of an individual's autonomy.

Question 2. Mr. Turnbull, you said that Federal intervention is warranted in cases meeting certain criteria. Accepting those as legitimate criteria for the moment, I'm wondering what you mean by "intervention" and what you believe the legal or constitutional basis for the Federal Government's intervention might be?

Answer 2. The nature of any Federal intervention is a matter for exceedingly careful and unrushed deliberation. I reaffirm, however, the three grounds for inter-

vention, and the principles guiding Federal intervention, as set out in my testimony. I did not address the constitutional issues involving federalism and separation of powers. These are matters on which Congress must seek the counsel of constitutional-law experts; predictably, there will be various and probably conflicting opinions about the constitutionality of Federal intervention. I prefer to defer to individuals more expert than I on constitutional law and Federal intervention in end-of-life matters.

[Whereupon, at 10:54 a.m., the committee was adjourned.]

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