

Witness:

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Testimony

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 competent.” 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 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 health-care providers and organizations representing people with disabilities and their professional care-givers.

Those principles are the foundations for the regulations implementing the Child Abuse Prevention and Treatment Act (42 U.S.C. Sec. 5101; 45 C.F.R. 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 care-givers' 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.

As I lay 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.

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