



STATE OF CONNECTICUT
OFFICE OF PROTECTION AND ADVOCACY FOR
PERSONS WITH DISABILITIES
60B WESTON STREET, HARTFORD, CONNECTICUT 06120-1551

James D. McGaughey
Executive Director

Phone 1/860-297-4307
Confidential Fax 1/860-297-4305

**Testimony of the Office of Protection and Advocacy for Persons with Disabilities
Before the Public Health Committee**

Presented by: James D. McGaughey
Executive Director
March 20, 2013

Good morning and thank you for this opportunity to comment on **Raised Bill No. 6645, An Act Concerning Compassionate Aid in Dying for Terminally Ill Patients**. This bill would legalize what it terms as "aid in dying", but what is often more commonly referred to as physician assisted suicide. Like many disability rights organizations, our Office has consistently opposed proposals to legalize physician assisted suicide, and we oppose this bill as well.

The other organizations I am referring to are nationally recognized, mainstream groups that have a solid record of promoting civil rights, consumer control and generally progressive social policy. They pushed for passage of the ADA and the Fair Housing Act; virtually invented the independent living movement; have fought to close large, congregate institutions; end the institutional bias in Medicaid; secure inclusion of children with disabilities in their school communities; and challenge discrimination in employment, housing, voting rights and access to public places. These are not socially conservative groups. They include the National Council on Disability (NCD), the American Association of People with Disabilities (AAPD), TASH (formerly The Association for the Severely Handicapped), the National Council on Independent Living (NCIL), the National Spinal Cord Injury Association, the Disability Rights Education and Defense Fund (DREDF), and the World Institute on Disability to name a few. Their positions on civil rights and social policy issues invariably reflect a deep sense of respect for the principle of personal autonomy. Indeed, individual choice and personal autonomy are fundamental tenets of the disability rights movement. Yet, they have all adopted positions opposing the legalization of physician assisted suicide – a concept which proponents say is all about compassion, choice and personal autonomy. So why are these organizations, and why is our Office so opposed?

Part of the reason is rooted in the disability experience. Advocates who have worked with newly disabled individuals, or who may remember their own experiences are deeply concerned about the impact legalization would have on people who may be struggling with difficult personal adjustments and, not infrequently, with rejection and loss of hope. Indeed, even people who have lived with disabilities for long periods of time can go through rough patches. The annals of the disability rights movement are punctuated with stories of individuals who "just wanted to die" before coming to realize they could still lead good, contributing lives. Advocates worry that some people would never get to the other side of a difficult adjustment if assisted suicide becomes legal. People who have personal histories of trauma or unresolved personal issues (and who doesn't have some of those), or who have difficult relationships with caregivers, or who just feel like they are a burden to family members would be especially vulnerable. If the mechanism laid out in this bill becomes law, we believe we will lose people who would otherwise have many years of life ahead of them.

influenced by unconscious value judgments about what they believe to be an unacceptable quality of life. I do not find that the definitions, requirements or procedures laid out in this bill are in any way sufficient to protect a person with a significant disability from the effects of such variations, confusion or value judgments on the part of physicians, much less from the possibility of undue influence by others who might stand to benefit from the person's death.

I also find it worrisome that, if enacted, this proposal carries the potential to more broadly legitimize suicide – an act that society has traditionally discouraged and even otherwise attempts to prevent. Legalizing it, and involving doctors – professionals to whom we have traditionally turned for advice and support in times of distress – can only encourage people, including people with disabilities, to see it as a legitimate alternative to “burdening” family members or expending resources on care that would otherwise be available to benefit others. The experience in Oregon, which, along with Washington State is one of only two states that permit physician assisted suicide, is instructive in this regard. Doctors in Oregon who write lethal prescriptions are required to supply certain after-the-fact data. While there is reason to question whether all of them do so, and the data being collected is minimal, a ten year statistical summary of the reports that were submitted indicates that most of the people who sought lethal prescriptions acted out of fear of future disability, not worries over dying in pain. The “suffering” people reportedly sought to avoid by committing suicide involved anticipated loss of “dignity” and “autonomy”, the prospect of losing control of bodily functions and needing personal care, and worries over the “burden” that continuing to live might place on others. In other words, the same things with which hundreds of thousands of people with disabilities contend on a daily basis.

This is not to say that the care currently afforded to people who are, in fact, dying is always good and acceptable. So much depends on whether or not a person has resources and committed caregivers who will advocate and stay with him or her. Even in-home hospice services, which can aggressively manage pain and other symptoms, and, at the same time, help create an atmosphere of respect and support, are usually only helpful if the person has friends, family members or the resources to obtain paid caregivers who can stay with him or her at the end. But, this and other current shortcoming are a reason to pursue improvements, not to adopt a radically new paradigm of medical practice. Would it not be better to invest in truly compassionate care, to expand the availability of first class palliative medicine and enlarge the scope of hospice programs than to open the door to abuses and cross into the highly problematic, morally questionable territory of legalizing assisted suicide?

Thank you for your attention. If there are any questions, I will try to answer them.