



**STATE OF CONNECTICUT**  
OFFICE OF PROTECTION AND ADVOCACY FOR  
PERSONS WITH DISABILITIES  
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Testimony of the Office of Protection and Advocacy for Persons with Disabilities  
Before the Public Health Committee

Presented by: James D. McGaughey  
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Good morning and thank you for this opportunity to comment on **Raised Bill No. 5326, An Act Concerning Compassionate Aid in Dying for Terminally Ill Patients**. Our Office opposes this measure.

Our agency's interest in this proposal derives from cases where we have represented people with disabilities who were perceived or described as being terminally ill, but who lived on for many years after receiving those diagnoses. In fact, some of those people are alive and well today, many years after having been identified as terminally ill. The pronouncements that they were "terminal" were usually made in order to justify a decision not to initiate some form of treatment or intervention: a decision not to initiate dialysis, or not to insert a feeding tube, or not to provide nutrition and hydration, or not to attempt resuscitation if the person experienced a respiratory or cardiac arrest (e.g. to enter a Do Not Resuscitate - DNR order to the person's chart). While decisions of this sort may certainly be appropriate in certain circumstances, in those cases they had more to do with perceptions about the person's disability and quality of life than with his or her medical condition. And, while most of those individuals were people who would not qualify as competent to request a lethal prescription under this bill, the experience of advocating for them taught us how easy it is for some in the medical world to apply an outcome-oriented prognosis of "terminal" to people with disabilities whom practitioners perceive as "suffering", especially when they have little awareness of the possibilities for those people to live good lives. As an advocate, I am concerned that the system proposed by this bill would create another avenue for that kind of thinking, and that we will lose people with disabilities who are despondent or depressed, but who otherwise would have many years of life before them.

While I would not represent to you that all people with disabilities share this view, I will point out that a number of well-respected, mainstream disability organizations, including the National Council on Disability, the American Association of People with Disabilities (AAPD), the National Council on Independent Living (NCIL), the National Spinal Cord Injury Association, the World Institute on Disability, Justice For All, TASH (formerly called The Association of the Severely Handicapped), the Disability Rights Education and Defense Fund (DREDF), and grass roots groups such as ADAPT and Not Dead Yet have all adopted positions opposing this type of proposal.

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I am aware that the proponents of this bill intend its provisions to apply only to people who are within six months of death. But, even where there is no underlying disability to consider, the business of predicting the timeframe for an individual's death is just not that precise. Hospice programs commonly report that they have seen patients who were admitted to care because they were thought to be within six months of death, but who subsequently were discharged because their disease process was not progressing as expected and they no longer met the criteria for hospice care. In fact, research on the question has demonstrated that medical prognostications regarding the prospective timeframe for an individual's death are often unreliable, sometimes missing the mark by years. Add the complications inherent in long term progressive conditions such as the various types of Muscular Dystrophy or Multiple Sclerosis, or any number of other chronic conditions, and things get even murkier. What about people who are born with disabilities that involve complex medical problems or genetic syndromes that can, but do not always, result in shortened life expectancy? Or people with physical disabilities who may experience repeated episodes of life-threatening infections or inflammatory processes that can periodically make them sick to the point where their lives are threatened? What about people who depend on life-support technologies to breathe or to eat? At what point would these people be considered "terminally ill" or "within six months of death"? Given the considerable confusion that often exists in the medical world about the degree to which people with disabilities are "suffering", there is a very real risk that people with these types of significant disabilities who are despondent about their futures and the lack of support options available to them, but who could otherwise have many years of life in front of them, will ask for and be given lethal prescriptions.

I am aware that proponents cite the experience in Oregon as evidence that enactment of this legislation will not have any detrimental effects. I believe you will hear today from others who have examined the record in Oregon more closely than I have and have come to a different conclusion about what it shows. What I know about the experience in Oregon is limited to the statistical reports posted by the Oregon Department of Health. Several trends are notable: First, both the reported numbers of lethal prescriptions written, and the reported number of deaths resulting from ingestion of those prescriptions have steadily risen over the past 16 years. Second, the three "end of life concerns" most frequently cited by those taking lethal prescriptions were: loss of autonomy (93.0%), decreasing ability to participate in activities that made life enjoyable (88.7%), and loss of dignity (73.2%). Concern about inadequate pain control (or the possibility of it) was among the least frequently cited reasons (23.7%) people sought lethal prescriptions. In fact, losing control of bodily functions (50%) and becoming a burden to family, friends and caregivers (40%) were cited about twice as often as concern over pain.

These figures offer cold comfort for people who live with significant disabilities, many of whom live with the daily reality of needing assistance with personal care. Most adapt to that reality, and, in fact, come to think of personal care as simply a way of getting simple things done so that they can then do other, more important things. However, for people who live with significant disabilities, it is deeply troubling to see a state offering policy rationales that serve to validate the view that death is a legitimate and even preferable alternative to needing care from others; that needing personal assistance somehow translates into a "loss of dignity".

It is also deeply troubling that physicians – medical professionals to whom we have historically turned for comfort, advice and treatment – are writing prescriptions that are used to end life. Not only does this represent a significant departure from thousands of years of professional tradition, but it cloaks the act of ending one's life with the trappings of medical legitimacy. This is a slippery slope – one which can be seen in some of the trends that have emerged in the Netherlands over the past several decades. Physician assisted suicide has been tolerated there for nearly 40 years, and "euthanasia laws" have been formally adopted. Surveys reveal that many Dutch doctors now consider having a long-term disability with a "poor prognosis" for improvement as justification for writing a lethal prescription. In addition to practicing active euthanasia - administering lethal injections to newborns with significant disabilities and to older people with dementia - some physicians see no problem with directly administering deadly doses of drugs at the request of people who have no physical signs of disease, but who are experiencing chronic emotional distress from conditions such as anorexia nervosa. And in neighboring Belgium, which has allowed physician administered euthanasia for the past twelve years, the slippery slope is also operative: Last year two brothers who were deaf and who relied on manual language to communicate, requested and received euthanasia because they were losing their vision, and feared they would no longer be able to communicate with each other. Just last month the Belgian Parliament adopted a measure permitting even young children to request and be given lethal doses of drugs, provided they meet certain conditions and have parental consent.

The lesson from the places that have been doing this the longest is clear: Once it becomes culturally and professionally acceptable to involve medical doctors in the business of ending life, we run the risk that rationalizations can emerge for carrying the practice far beyond what was originally intended. For people who are truly at the end of life's journey, palliative medicine and hospice programs offer relief from both the physical and emotional suffering they can experience. Unfortunately, these options are not always accessed in time. We would do better to address that problem rather than take the route outlined in this bill.

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