Statement to the Senate Judicial Proceedings Committee

Re: Senate Bill 676 – "Death with Dignity"

Tuesday, March 10, 2015

OPPOSE

Chairman Zirkin and distinguished Committee members, I appreciate the opportunity to testify this afternoon and register my strong opposition to Senate Bill (SB) 676, entitled the *Richard E. Israel and Roger "Pip" Moyer Death with Dignity Act.*

While I represent no particular organization or disability group, it is important that you hear a perspective shared by millions of Americans who live daily with a variety of disabilities and lead productive, meaningful lives.

Over a dozen major grassroots disability organizations whose members are self-advocates living with a range of disabilities are on record in strong opposition to legalization of assisted suicide,[1] as is *The ARC Maryland*. These various groups recognize the grave threat that assisted suicide poses to persons with disabilities like me and many others.

I ask you to ponder what the motivating forces are for many people who are adamant proponents of the legalization of assisted suicide. Is it primarily to provide a means of alleviating intractable pain or to establish a semblance of control over the dying process or self-autonomy? I would suggest to you that from the experience we have had in Oregon and Washington States where assisted suicide is the law of the land, it is neither. Rather, reports from these states show that the primary motivation of many individuals advocating for assisted suicide is the fear of disability, a fear grounded on some basic

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[1] ADAPT (American Disabled for Attendant Programs Today), Association of Programs for Rural Independent Living, Autistic Self Advocacy Network, Disability Rights Center, Disability Rights Education and Defense Fund, Justice For All, National Council on Disability, National Council on Independent Living, National Spinal Cord Injury Association, Not Dead Yet, TASH, The World Association of Persons with Disabilities, and The World Institute on Disability

stereotypes prevalent in our society that living with a disability is a life not worth living, i.e., living a life that is lacking in wholeness or somewhat less than whole. Data collected so far in Oregon and Washington indicated that it is fear of being vulnerable, of losing autonomy, of losing the ability to engage in activities taken for granted, and even the fear of loss of bodily functions.[2] Inadequate pain control or the concern about it amounted to only 31.4% of the end of life concerns for Oregon residents and 36% for Washington State residents.[3] Along with this fear of vulnerability is a fear of dependence or being a burden to their loved ones and society in general. In other words, it is a fear of living with a disability like mine.

It may shock some people to know that our lives can be rewarding and exciting. My disability of cerebral palsy is a life-long reality, and I have acquired additional disabilities along the way, including a diagnosis of bi-polar disorder shortly before my first wedding anniversary, and chronic pain due to aging with cerebral palsy. Additionally, in 2000, I successfully underwent prostate cancer surgery, and thus consider myself a cancer survivor. I am happily married to a loving, supportive woman, and we have two wonderful adult children, and a great son-in-law. By profession I am an attorney, retired after thirty-two years of service with the U.S. government and several years in private practice. I am also a potter, and currently spend my time in the studio when I am not traveling nationally and internationally. This does not negate the fact that my disabilities have presented obstacles along the way. I would be lying to myself, and to you, to say that my life has been without difficulties, as has each person in this room this afternoon faced their own trials.

In experiencing the deaths of my father and father-in-law who both died while under hospice care, I can also attest to the fact that I am no stranger to the dying process and the sadness and grief that one experiences in suffering such a loss.

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[2] Table 1, *Oregon's Death with Dignity Act (DWDA)—2014* Annual Report, released by the Oregon Public Health Division February 12, 2015, reported the three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%), https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf; Table 2, *Washington State Department of Health 2013 Death with Dignity Act Report (DOH 422-109 2013)* reported the three most frequently mentioned end-of-life concerns were: loss of autonomy (91%), less able to engage in activities making life enjoyable (89%), and loss of dignity (79%), http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2013.pdf.

[3] Ibid.

However, in both instances, I was fortunate to witness the dignity and respect for the dying person that the natural dying process engenders.

In addition to a direct attack on the dignity and worth of persons with disabilities, SB 676 exacerbates the potential for increased levels of elder abuse that proponents of the bill argue are being cared for by its passage.[4] As can be seen from the most recent data from Oregon and Washington, more than half of those availing themselves of assisted suicide are seniors.[5] Legalizing physician assisted suicide increases the potential for caretakers and others with financial interests in an elderly person's affairs to exert undue influence on such an individual to make the decision to commit suicide so as not to be a continuing burden. Physician assisted suicide is dangerous public policy because there is no statutory construct that can effectively protect those most vulnerable in our society, including those who are elderly and/or live with disabilities, against such abuse and coercion. The purported safeguards in SB 676 fail to provide protection against coercion which can be as subtle as an adult child or grandchild mentioning to [or reminding] their elderly loved one that the option of the suicide pills is always available. Such a statement coming from a likely caretaker could easily plant a seed of doubt regarding self-worth in the elderly person who may already feel that he or she is a burden to the family.

I am very concerned about the ramifications untreated depression can have in situations where assisted suicide is a ready option.[6] SB 676 contains no mechanism requiring that depression screening be mandated before making the decision to choose assisted suicide upon the diagnosis of a terminal illness, nor does it provide options for access to mental health services before making the decision to terminate one's life. From my own experience looking into the abyss of darkness caused by depression, I personally feel that it is very dangerous to make readily available lethal drugs that may be used to provide a false and

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[4] There is no accurate data on the extent of elder abuse. Estimates of elder abuse range between one and ten percent of the population with further estimates of only 1 in 25 instances being reported for financial abuse. http://www.ncea.aoa.gov/Library/Data/#problem.

[5] op. cit., Out of the 105 deaths reported under the DWDA during 2014, most (67.6%) were aged 65 years or older. The median age at death was 72 years. In Washington State, out of 159 reported deaths, 74% of the individuals were 65 years or older.

[6] The 2014 Oregon data shows that only three (2.85%) of the 105 DWDA patients who died during 2014 were referred for formal psychiatric or psychological evaluation. The 2013 Washington State data showed that only 6 (4%) individuals had been referred for psychiatric or psychological evaluation. The Washington data was available for 146 of the 159 participants in 2013 who died.

irreversible solution to a sometimes undiagnosed and treatable illness. Once the abyss of taking the prescribed lethal drugs is crossed, there can be no turning back or seeking effective treatment.

With the current skyrocketing cost of medical care and pressure on doctors to see more and more patients, legalizing assisted suicide offers a cost saving alternative to providing appropriate palliative and hospice care, and, in fact, creates a disincentive to continuing development of better and more effective forms of pain relief. It should be recognized that Senator Young who introduced SB 676 in the Maryland Senate spoke publicly of the cost savings that physician assisted suicide would provide to families and governments.[7] Further, there is the real potential for insurance companies to adopt cost containment measures that cover the costs of the cheaper suicide drugs, rather than covering the costs of more expensive medical care. This is not a hypothetical possibility, but has already occurred in Oregon where assisted suicide is legal.[8]

Another concern that I have on both a personal level and a public policy perspective is the untenable position placed on the medical profession by such laws. As we request that doctors take the Hippocratic Oath, which in part provides, and I quote "I will give no deadly medicine to any one if asked, nor suggest any such counsel," we are asking that they take actions contrary to the very nature and purpose of the medical profession. Further, by requesting doctors to make decisions on prescribing such lethal drugs to particular individuals, we are not only asking them to violate the basic fundamentals of the healing profession which they have chosen, we are asking them to make decisions as to the quality of life of a particular individual. Although SB 676 specifically excludes disability as a terminal illness, it is not implausible to argue that significant debilitating disability justifies categorizing such condition as eligible for assisted suicide. I would suggest to you, with respect to individuals with significant disabilities, that the lives of those with disabilities are judged, not on

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[7] Rodgers, Bethany, *The Frederick News-Post*, posted online 1-14-15.

[8] A 64-year-old Oregon woman, whose lung cancer had been in remission, learned the disease had returned and would likely kill her. Her last hope was a $4,000-a-month drug that her doctor prescribed for her, but the insurance company refused to pay. However, what the Oregon Health Plan did agree to cover were drugs for a physician-assisted death. Those drugs would cost about $50. https://www.google.com/#q=Insurance+coverage+of+assisted+suicide+drugs.

the basis of their inherent dignity as fellow human beings, but rather on the basis of prevailing societal standards of productivity and the ideal of a non-disability reality. These attitudes were reflected in the testimony of several of the proponents of SB 676 in their descriptions of individuals with significant disabling conditions who advocate for passage of this bill.

The proponents of SB 676 imply that decisions to obtain the lethal drugs are made in the context of a strong, longstanding patient-physician relationship. However, closer analysis of the data presented in both Oregon and Washington does not bear this out. For example, the 2014 Oregon data reveals that the duration of the patient-physician relationship is a median of 19 weeks. Washington State reported that for 51% of the assisted suicide patients in 2013, the physician-patient relationships were less than 25 weeks.

As you may know, these laws establish eligibility criteria that require the individual seeking the assistance of the physician in obtaining the lethal drugs to be diagnosed as having a terminal illness with a life expectancy of six months or less. Determining such a timeframe has proven in the first two states to enact assisted suicide laws to be highly problematic and unpredictable. This alleged safeguard has, in fact, been proven useless. This is further affirmed by a recent article appearing in the August 6, 2014 *Washington Post* concerning hospice care[9]. The article reported statistics showing live discharge rates from hospice at 35-41% and that more than one-third of patients who were released alive from hospice did not re-enroll in hospice and were still alive six months after being released.

It is a great irony that in 2015, as we celebrate the 25th anniversary of the *Americans with Disabilities Act*, Federal legislation recognizing the dignity and worth of individuals living with disabilities, we, as persons with disabilities, are fighting for our lives in states throughout this great country, and indeed in countries throughout the world. While we celebrate access in education, employment and public facilities, we are threatened by laws that single out our

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[9] http://www.washingtonpost.com/business/economy/leaving-hospice-care-alive-rising-rates-of-live-discharge-in-the-us-raise-questions-about-quality-of-care/2014/08/06/13a4e7a0-175e-11e4-9e3b-7f2f110c6265_story.html .

community as the only one worthy of sanctioned suicide. For all others suicide is seen as a tragedy, and prevention programs abound. But for those of us whose quality of life is questioned and feared, suicide is offered as the "compassionate choice." I would suggest to you ladies and gentlemen that this is a very insidious form of discrimination that we must fight with all the forces that we can muster.

I would like to thank you for giving me the opportunity to testify this afternoon and highlight the dangers posed by SB 676 to those with disabilities in the State of Maryland.

Submitted by:
James Martin Benton
Legislative District 21
7101 Rhode Island Avenue
College Park, Maryland 20740-3743