

Second Thoughts Connecticut

Advocates against the legalization of assisted suicide

Testimony supporting the full restoration of state funding of Independent Living Centers
(Department of Rehabilitation Services) for FY 2014 –2015
HB 6350, An Act Concerning the Budget for the Biennium Ending June 30, 2015

To the co-chairs and members of the Appropriations Committee:

My name is Stephen Mendelsohn. I am one of the leaders of Second Thoughts Connecticut, which advocates against the legalization of assisted suicide from a disability rights perspective. I am also an autistic adult. Due to this hearing being on Friday evening, which for me is Shabbat, the Jewish Sabbath, I am unable to testify in person. I do wish to add our voices here at Second Thoughts Connecticut to the many others in the disability community who will be testifying in strong opposition to the line item in the budget of the Department of Rehabilitation Services which eliminates all funding for Connecticut's five Centers for Independent Living.

Connecticut's five Centers for Independent Living provide critical services that enable people with disabilities to live independently in the community rather than in expensive and restrictive institutions. They are invariably led by people with disabilities who have first-hand experience dealing with the numerous barriers, attitudinal as well as physical, that still keep far too many of us from living up to our full potential as productive citizens. Other speakers will be informing you of the specific services that Connecticut's CILs provide, from information referral, advocacy, training, and peer support to helping transition hundreds of people every year out of institutions through our state's Money Follows the Person program, and much more.

From a purely fiscal perspective, elimination—or even reduction—of state funding for Connecticut's CIL's is a classic case of being penny wise and pound foolish. By enabling people with disabilities to leave expensive institutions, gain employment, and become productive, taxpaying citizens, CILs save the half million or so dollars they are receiving from the state many times over. They are a wise and productive investment of our tax dollars.

While it is important to get Connecticut's fiscal house in order, we should not look at CIL funding in purely economic terms. People's lives are at stake here—literally. Many of us see a war on people with disabilities in Connecticut. The Malloy administration has too often pitied rather than empowered people with disabilities. Governor Malloy's 2011 Thanksgiving Proclamation (<http://www.governor.ct.gov/malloy/cwp/view.asp?Q=491448&A=4010>) is a dramatic example. Near the end of his message, he said:

“It is bad that some of our fellow residents are afflicted with handicaps that make their lives immeasurably difficult, and leave them hovering on the edges of our society. But it is good that we have service providers who work tirelessly and selflessly to care for and comfort them. To bring them hope where maybe they have only felt hopelessness.”

It is precisely this pitying attitude, reminiscent of Tiny Tim in Charles Dickens' *A Christmas Carol*, which Centers for Independent Living work so hard to change. Those of us with disabilities "hover on the edges of our society" only when public policy excludes us from society. Discriminatory and exclusionary public policies, not "afflictions" and "handicaps," make our lives more difficult. CILs work tirelessly to keep people with disabilities from "hovering on the edges of our society," not by being "service providers," but by enabling those of us with disabilities to take charge of our own lives.

Other disturbing public policies and proposed policies regarding people with disabilities over the last two years include:

- the Malloy administration's failure to appoint an ADA coordinator for nearly a year
- failure to include people with disabilities participating in the PCA Medicaid waiver programs in the discussions that led to Executive Order 10 unionizing PCAs
- last year's attempt to merge the Office of Protection and Advocacy into the Commission on Human Rights and Opportunities, which was, thankfully, rejected by this committee
- the multitude of bills filed this year seeking to deprive people with psychiatric labels of fundamental civil rights, including proposals to enact involuntary outpatient commitment (forced drugging in the community), psychiatric profiling, and violations of confidentiality in therapeutic relationships
- most recently, the push to legalize assisted suicide under the rubric of "compassionate aid in dying" or "death with dignity," steering people with disabilities toward suicide and denying us lifesaving medical care.

It is this last issue in particular that relates to the importance of fully funding CILs. In Oregon, where assisted suicide has been legal for a number of years, that state's own statistics show that people are requesting "aid in dying" because of disability-phobic attitudes, not because they are in pain. From 1998-2010, only 21.3% of those requesting assistance to die under Oregon's Death With Dignity Act did so because of "inadequate pain control." In contrast, a stunning 91.2% cited "a steady loss of autonomy," 88.1% stated that they were "less able to engage in activities making life enjoyable," and 84.1% feared a "loss of dignity." <http://public.health.oregon.gov/providerpartnerresources/evaluationresearch/deathwithdignityact/documents/year13.pdf>

These are disability issues. These are issues that CILs address in their daily work.

People with severe disabilities—including members of Second Thoughts Connecticut—have shown that one can have autonomy and dignity even with limited (and often declining) physical abilities. In Oregon, and now Washington, people are killing themselves, with doctors' assistance, because they do not have the perspective and resources that CILs offer.

They are also killing themselves because Oregon has made a public policy choice to deny people like Barbara Wagner and Randy Stroup potentially lifesaving chemotherapy under that state's health plan, but will pay the roughly \$100 for suicide pills. Oregon has sent a clear message that people with severe disabilities, especially those whom doctors view as having poor prognoses (often erroneously), are too costly for the state and would be better off dead.

What message will Connecticut send? Will we go down the same path as Oregon and Washington, and foreign countries like the Netherlands, Belgium, and Switzerland, which have gone even further toward euthanasia, and send the message that disability is a fate worse than

death? Or are we better than that? And if we are better than that, and I hope we are, then we need to start supporting those services, like self-directed attendant care and other independent living services, which enable people with disabilities to live with autonomy and dignity. Restoring funding for Connecticut's five Centers for Independent Living would be a first step in sending the right message that people with disabilities, even severe disabilities, are fully valued in our state.

Stephen Mendelsohn
171 Hartford Road, #19
New Britain, CT 06053-1532
smendelsohn5845@att.net