

**TESTIMONY
CT. GENERAL ASSEMBLY
PUBLIC HEALTH COMMITTEE
March 19, 2014**

**RE: Raised Bill No. 5534 (in support of)
LCO # 2289**

Senator Gerratano, Representative Johnson, and Representative Srinivasan; my name is Patrick Johnson and I live in West Hartford, CT.

As a member of a family with two members who are intellectually disabled and totally blind I am testifying on behalf of not only my own family but all families who are struggling with how to sustain safety and a decent quality of life that enable people with disabilities to live with dignity as independently and productively as possible. My wife, who is legal guardian for her severely disabled brother, and I are profoundly disturbed by the seven years of flat funding and cuts to the private nonprofit agencies that deliver the bulk of services in the disability community in CT. This is unconscionable given the impact on the lives of those organizations and the care givers who work for them. These dedicated people who have pursued careers in caring for the most vulnerable among us deserve to be treated in the same manner as state employees and not driven into poverty by the state.

The movement to increase options for in-home care is to be lauded, but five things need to be in place:

1. There needs to be a clear multiyear plan promulgated by the Dept. of Developmental Services that demonstrate how this will be phased in and how residential services will be maintained for those who can not live at home or independently in in the community. The plan must include proposed resource allocation. Such a plan must reflect best practice and not comparisons with states where the quality of care is more characteristic of third world countries.
2. This phase-in, according to national experts in the field, will need additional resources during the phase in period if it is to be successful. Those resources must be assured by the legislature. How you can cut \$30,000,000 from the DDS budget and expect the successful implementation of new vital models of care is a mystery; particularly on top of seven years of cuts and flat funding. (Stop for a moment and imagine of state revenue remained exactly the same or declined from where it was seven years ago.)
3. The DDS must stop taking money from higher wage nonprofits who seek to provide a living wage to staff. In some cases this money is not state money but charitable donations funding modestly higher wages that DDS takes away in an effort to drive down wages and benefits. This practice may be illegal since the state has no claim on charitable dollars.
4. Direct support professionals and indeed all staff; nurses, social workers, physical therapists, speech and language pathologists, teachers, supported work staff, and all others working with people with disabilities need annual wage adjustments to keep pace with inflation and at minimum, a living wage. This is vital to continuity of care, quality services, and safety.
5. Last but not least DDS leadership needs to stop telling people the only way they will get critical services is when their care taking parent is dead. This is so disturbing on so many levels!!! DDS needs to stop their rigid bureaucratic ways and work with families and community based nonprofit providers to be flexible and creative to achieve what is in everyone's best interest. This must include the provision of rental subsidies if people are going to live as

independently as possible in the community. Flexibility and creativity are vital to the success of all new and innovative approaches to serving as many as possible with scarce resources.

In addition as DDS seeks to reduce its footprint in state run institutional care it is imperative that the resources committed to this effort remain in the system of care and not simply revert to the general fund with the attitude that can only be interpreted as "people with disabilities and those that serve them be damned;" as I heard a desperate parent express in a meeting this weekend.

My family is grateful to all of you for your thoughtful consideration of this bill and for the creation of the DD Caucus by our Senator Beth Bye and others. Please support bill # 5534.

Respectfully submitted; Patrick J. Johnson Jr.
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