

6668

Testimony: Heather Leigh Northrop
In favor of Bill 6668

Hello, my name is Heather Leigh Northrop and I am a Connecticut citizen with a disability who lives in the community.

I support the Quality Home Care Council bill because I support quality home care for seniors and people with disabilities.

Although my condition appears to be of a genetic nature, it did not begin to affect my activities of daily living until I was an adult. At that point, adapting to using a wheelchair for mobility, while living alone, working full-time and trying to lead a fulfilled life, was challenging, to say the least. I sought out the support of other acquaintances that used wheelchairs and they "taught me the ropes." Through these connections, I found out about the five Centers for Independent Living in our state, and how they were a great source of support and information for people with disabilities, largely due to the fact that they are staffed by people who have first-hand knowledge of disability from their own personal lives. I ended up leaving my career in a prominent museum in our state, because of the lack of support they were willing to give to me in my employment now that I had a disability, and went to work at an IL Center. I worked with teenagers with disabilities, facilitating a Youth Group where they could express their challenges and successes in growing up with a disability. The one issue I heard again and again, was "It's not right that I have to live at home because my parents do all my personal care! I want to

go to college or get my own apartment like my friends are doing.” I also heard heartbreaking stories of embarrassment as young girls were growing up but still having to have their fathers bathe and toilet them because their mothers could not physically do the work, or were unavailable. These stories continued as I moved on in my work with youth with disabilities throughout the state. These youth continually requested speakers and information on Personal Care Assistant (PCA) services, how to utilize waivers and ways to effectively live independent lives when you have a disability. I worked to connect the youth with adults with disabilities living in our state, who used PCA services to function in their daily lives. These professional adults didn’t have all the answers however and many times the discussions came down to the same dilemmas.

The biggest challenges I have seen to allowing individuals with disabilities to obtain quality home care, have been:

- ✓ **High turn over:** it’s hard to find and keep qualified workers and the stress of training and re-training people on a continual basis is difficult and frustrating for many consumers.
- ✓ **Lack of a formal back up system:** when a Personal Care Assistant doesn’t show up for work, there often is no one to replace them which can mean the consumer must miss work and/or stay in bed for the entire day, with their needs unmet.
- ✓ **Lack of a state registry:** workers are hard to find and in dealing with work of such a personal nature, consumers need a confidential,

safe list of people to go to; they often resort to "want ads" or flyers on school walls, but that has often led to dangerous situations.

- ✓ Lack of benefits and adequate wage increases for personal care assistants: because consumers are often locked into rates set by other entities, all they can offer these assistants is low wages and no benefits; the work being done is critical to the life and well-being of the consumer and should be compensated as such.

I believe that a solution for these quality home care issues is the creation of the Quality Home Care Council. The council will work towards:

- ✓ Connecting people who need services with workers through a statewide directory of qualified caregivers.
- ✓ Providing backup services when a home care worker is unavailable.
- ✓ Preparing the program for future growth by reducing turnover and providing voluntary training while helping control Medicaid costs.
- ✓ Maintaining consumer control and direction, particularly the ability to hire, fire, train, and supervise.

NOTE: Similar Quality Home Care Councils have worked in other states—Michigan, California, Wisconsin, and Oregon and most recently Massachusetts

Please support the quality home care council. Quality home care for seniors and people with disabilities should not be just an option, but a right.

Thank you

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