



STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR
PERSONS WITH DISABILITIES
60B WESTON STREET, HARTFORD, CT 06120-1551

JAMES D. McGAUGHEY
Executive Director

Phone: 1/860-297-4307
Confidential Fax: 1/860-297-4305

Testimony of the Office of Protection and Advocacy for Persons with Disabilities Before the Human Services Committee

Presented by: James D. McGaughey
Executive Director
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Good afternoon, and thank you for this opportunity to comment on **Raised Bill No. 6486, An Act Concerning Home Health Care Services and the Establishment of a Personal Care Attendant Workforce Council.**

The role of Personal Care Attendant (PCA) – some say Personal Care Assistant - was first defined in this country over forty years ago by people with significant physical disabilities seeking to escape the confines of institutional care and pursue lives in their own homes and communities. These pioneers began what came to be called the Independent Living Movement, a movement that presented not only a radically different view of where and how people with significant disabilities could live, but also a fundamental redefinition of their identities, needs, contributions and rightful place in the world.

One of the core principles of the movement is its rejection of the “medical model” – a pervasive tendency to view people in terms of diagnoses and to place all efforts to meet their support needs under the general category of “healthcare”. So long as they were seen as “patients” who needed healthcare, the founders of the independent living movement realized they would not be respected as fully autonomous, equally worthy members of society. To be truly free, they needed to escape both the physical confines of nursing homes, and the powerful social imagery and judgmental control structures associated with healthcare agencies.

And so the PCA was born – an ordinary person hired and trained by someone with a disability himself or herself, to do pretty ordinary things – like getting out of bed, washing and dressing, eating, driving to work or the grocery store. Things like that. It turned out that there was more to it than just making sure that everyone understood that this was not “healthcare”. One of the big reasons the PCA approach has worked so well is because it allows so much individualization. No two people’s needs and preferences are identical, and the roles, tasks and especially the relationships established by people with disabilities and their PCAs can and do vary considerably. Indeed, much of the value of PCA services lie in their highly individualized nature, which is a function of the ongoing management relationship that the person who does the hiring and training – the person with the disability – establishes with the PCA. The person with the disability sets his or her own goals and expectations, chooses who he or she is comfortable working with, trains and directs that person (or persons) in ways that make sense in the context of his or her life.

My major concern with this proposal is that it does not reflect an understanding of the essential nature of that individual relationship – the thing that makes the PCA relationship unique. The bill would establish a central structure - the Personal Care Attendant Quality Home Care Workforce Council - which would be charged with tasks, such as training, that properly belong to the person with the disability who employs PCAs. There is a strong likelihood that the type of standardized training which the proposed Council would be charged with developing would undermine the value of the individual training provided by the employer with the disability – individual training that helps establish rapport, and is an indispensable step in defining the way the PCAs relates to the person for whom he or she works. At the very least, standardized training would introduce confusion about who a prospective PCA is actually working for, an effect that would likely be further magnified by the fact that the training is to be ordained by a large statewide power structure - the proposed Council - that would also set policy, bargain with collective bargaining representatives over wages and benefits, and maintain a registry of people working or seeking work as PCAs.

History is filled with examples of centralized policy-making authorities that were established with the best of intentions, but which ultimately became the very type of power structure that the first independent living pioneers worked so hard to escape. I urge you to proceed with caution in this area, and not establish an entity that could undermine the inherently individualized nature of PCA services.

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