



STATE OF CONNECTICUT
OFFICE OF PROTECTION AND ADVOCACY FOR
PERSONS WITH DISABILITIES
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Testimony of the Office of Protection and Advocacy for Persons with Disabilities
before the Labor and Public Employees Committee

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Thank you for this opportunity to comment on Raised Bill No. 5433, An Act Creating a Procedure for Personal Care Attendants to Collectively Bargain with the State. I apologize for not being here in person, but a prior commitment has required me to be out of the state today.

As I have previously testified when earlier versions of this Bill were considered, our Office has concerns about this proposal. To understand those concerns, it may be useful to revisit a bit of the history behind Personal Care Services, and the central role they have played in freeing people with disabilities from situations of dependence.

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. Those 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, orientation 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.

As the concepts of self-determination/self-direction and individual and family supports entered the lexicon of services for people with intellectual and cognitive disabilities – people who, in earlier times, had been served only in institutional centers, group homes, and similarly supervised settings – the PCA concept was adapted and extended to allow people with those kinds of disabilities and their families to construct individualized support arrangements. Often, those arrangements include agreements with neighbors, family friends, co-workers and others with whom the individual and his or her family members are familiar and comfortable - agreements to provide supports that are relevant to the needs of the particular individual and which reflect his or her priorities. Again, it is a central precept that hiring, training and supervisory decisions are to be handled by the individual person with the disability and/or his or her family, precisely because, if the individual with the disability and his or her family are really in charge, that personal employer/employee relationship can transcend the limitations imposed by agency-based “home care”, and will support a level of personal choice that was previously unattainable. When the “consumer” is the employer, he or she has control over both the configuration of support services, and the interpersonal qualities of those hired to provide them, resulting in a much better “fit” between personal needs and the assistance provided to meet those needs

My major concern with this proposal is that it does not reflect an understanding of the highly individualized, personally empowering nature of the employer-employee relationship – the very thing that makes the Personal Care Services unique. In fact, the Bill would establish a centralized power structure - the Personal Care Attendant Quality Home Care Workforce Council - which would tend to compete with the role of the Personal Care Service consumer as employer. The Council would not only study and develop policies related to Personal Care Services, but would also engage in activities which have traditionally been reserved for the consumer/employer, such as providing “training” and establishing “standards”. The training issue is particularly important because the role of the PCA is to assist the individual in exactly the way he or she wishes to be assisted, not in a generic, “this is how I was trained to do it” way. The fact that the consumer/employer (or, sometimes in the case of DDS clients, that person’s family) does the training helps differentiate PCA services from services provided by home health aides or others who are hired, trained and managed by agencies. It also reinforces a fundamental cornerstone of the independent living movement for people with significant disabilities - that the individual with the disability is in charge of his or her own life and can successfully, independently accomplish the ordinary tasks of daily life by competently managing an employment relationship with his or her PCAs.

Other features of the proposed Council would also be in conflict with fundamental precepts of Personal Care Services. As described in the Bill, the Council would be dominated by State agencies, and would serve as an “employer” for purposes of collective bargaining. In fact, as its title suggests, the ultimate goal of the Bill is to establish (or recognize) not one, but two powerful structures – the Council, and one or more collective bargaining agents with which the Council would then bargain over “state reimbursement rates, benefits, payment procedures, contract grievance arbitration, and training, professional development and other requirements and opportunities appropriate for such personal care

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attendants”. The Bill even boasts a provision for impasse arbitration which empowers an arbitrator – whose background would be in the arbitration of labor disputes, not in deciding questions related to Personal Care Service policy – to choose between the “last best” contract offer of either the Council or the collective bargaining agent. Defining the Council as an “employer”, and directing it to bargain with a recognized a collective bargaining agent will send mixed messages to PCAs about who their real employer is. Perhaps more insidiously, however, the ongoing process of negotiating the institutional interests of the State and the Union will come to dominate decisions about the direction and operation of PCA programs.

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, please feel free to contact me.