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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 Human Services Committee

Presented by: James D. McGaughey
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Good morning and thank you for this opportunity to comment on **Raised Bill No. 6668, An Act Providing Quality Care, Financial Oversight and Nursing Home Funding Reform.**

Section 1 of this bill would require the Long Term Care Planning Committee to develop a multi-faceted plan to address concerns about staffing, administration and funding of nursing homes. One element of that plan would be a new requirement for preadmission screening in order to: "ensure that individuals with certain psychiatric disabilities or a history of physical or sexual abuse are not inappropriately admitted..." This language is problematic: It seems to equate psychiatric disability, or at least "certain" unspecified psychiatric disabilities with abusive or violent conduct. As such it perpetuates an inaccurate stereotype about individuals with psychiatric disabilities and implies that nursing homes and their residents need to be protected from them.

This is not to say that independent pre-admission screening, as called for in the bill, would not be an improvement over current practice. Despite federally required pre-admission reviews that are intended to protect people with primary psychiatric diagnoses from being warehoused in nursing homes, nursing homes have increasingly come to serve the same function as the back wards of the old state mental hospitals – an out-of-the-way place to put people with mental illnesses who do not need and cannot stay in acute care hospitals, but who have, for one reason or another, lost their places in the larger world and have no one to help them start over. By some estimates there are as many as several thousand people with primary mental health diagnoses currently living in Connecticut nursing homes – people who could be much better served through supported housing programs and other recovery-oriented options. Applying greater scrutiny to the admission process could help limit admissions of people who fall into this category. However, that scrutiny would need to be applied according to non-discriminatory standards, and would truly benefit people only if options for housing and relevant recovery supports become more generally available.

Section 2 of the bill would establish a 13 member Personal Care Attendant Quality Home Care Workforce Council comprised of various state officials and persons with disabilities, surrogate decision makers and advocates. The council would be charged with assuring the quality of long term personal homecare that is funded through a number of different programs and agencies.

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On the surface, the duties related to that assignment sound innocuous – recruiting, training, recommending a certification process, creating a back-up respite service, and establishing an accurate listing of individuals currently employed by people with disabilities as Personal Care Assistants (PCAs). However, the Committee should be aware that an earlier, much more expansive draft of this proposal was recently circulated by representatives of a healthcare employees union – and that draft has stirred considerable controversy amongst people with disabilities who directly employ personal care assistants. It is clear from the original language that the council was to serve as a form of program "management" with which the Union could conduct collective bargaining.

The role of Personal Care Assistant originated when people with significant physical disabilities first sought to escape the confines of institutional care and live in their own homes and communities. Rejecting medical interpretations of their daily support needs, and seeking to assert control over all aspects of their lives, these individuals insisted on being recognized as bona fide employers who are responsible for hiring, firing, training, scheduling and directing the activities of their PCAs. There is more than ideology at stake here: no two people's needs and preferences are identical, and the roles, tasks and relationships established by people with disabilities and their PCAs vary considerably. Indeed, much of the value of PCA services lie in their highly individualized nature.

As with any human endeavor, not everything is always sunny in the PCA world. Recruitment and scheduling are sometimes difficult, retention can be problematic, and the various governmental programs that fund PCA services essentially set the pay rates, and those rates are generally low. However, while it is tempting to think that centralizing the functions listed in Section 2 under the auspices of the proposed council might make those things better, there is also reason to be skeptical. 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.