

Testimony of the Office of Protection and Advocacy for Persons with Disabilities
Before
The Committee on Program Review and Investigations

Submitted by: James D. McGaughey
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Thank you for this opportunity to comment on two of the bills on your agenda today: **Raised Bill No. 752**, An Act Implementing the Recommendations of the Program Review and Investigations Committee Concerning Assessment of the Needs of Aging Individuals with Developmental Disabilities; and **Raised Bill No. 753**, An Act Implementing the Recommendations of the Program Review and Investigations Committee Concerning Planning for the Needs of Aging Individuals with Developmental Disabilities.

I also want to thank you for recognizing the importance of addressing the problems confronting individuals with developmental disabilities who are getting older, and to compliment your staff for the excellent study they issued in December. Through both our advocacy and our investigation casework, our Office sees the issues you have surfaced and the effect they have on individuals and families. With the demographic tsunami of aging baby boomers fast approaching, we have to do better by these people.

In most respects, the problems and needs that confront people with developmental disabilities as they age are the same as those that we all face as we age – only perhaps a little more so. Like the vast majority of people who are getting older, people with developmental disabilities tell us they want to continue to be connected with their families, friends and communities, to continue to live in their own homes, to be respected as individuals who have real rights, who can make choices, and who have something to contribute. Their needs for support may increase with age, but the fact of increasing need does not mean that they have to surrender their identities or their rightful places in the world. Unfortunately, however, because we are not planning well, that is what often happens.

As your study pointed out, and our Agency's casework confirms, too many people with developmental disabilities are turning up in nursing homes where their programmatic needs are not met and they are separated from places and people who are familiar. In our experience, there is no single reason for this: many people who experience increased needs do remain living in the homes and programs where they have long resided, while many others with identical conditions and support needs are admitted to long term care

facilities. The variables seem to have more to do with resource availability and inconsistent practices between providers than with the health care needs of particular individuals.

Once admitted to a nursing facility, the service system can too easily forget the people who are there. So I am pleased to see the provisions in Bill No. 752 calling for DPH surveyors to contact DDS regional nursing home coordinators when they come across someone who is not receiving recommended services, and that the assigned DDS case manager must then be notified and must act. Let's make it harder to forget about people in nursing homes. But, let us not delude ourselves – systems can employ people to review charts, complete checklists, send notifications, document justifications and still wind up doing the wrong thing. The double-check envisioned in Bill No 752 will help, but it cannot substitute for a coherent statewide policy direction that simply says:

“Wherever possible, we will support people who are aging to live in their homes and their communities, and to maintain the relationships and roles that are important to them. We will not send people with developmental disabilities to nursing homes or other congregate facilities unless their need for skilled health care is so critical and overwhelming that it is simply not possible to support them in their homes or communities. And, we will affirmatively devote resources and energy to develop the expertise and capacity we know we will need to support people while they ‘age in place’.”

Last October, the Connecticut Developmental Disabilities Network, which includes our Office, sponsored a symposium on Aging in Place for People with Disabilities. Initial recognition that we needed to foster discussion about this issue grew from our experience operating the State's Fatality Review Board – where we saw that, despite legal restrictions on admissions, many of the people whose deaths we reviewed had been living in nursing homes, in some cases for many years. But what brought many participants to the symposium were strong concerns about proposals (or rumors) that were circulating that involved building or converting facilities specifically to house people with developmental disabilities who are aging. The participants, who came from different backgrounds and regions, identified and discussed core principles that define the concept “aging in place” for people with long time disabilities. I am attaching a copy of those principles and the “next steps” to my testimony. I would hope that any funds reserved in the special account envisioned in Raised Bill 753 would be expended in ways that further those principles and lead to realization of the coherent policy we need.

Again, thank you for studying this important issue. If there are any questions, I will try to answer them.