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Legislative Program Review and Investigations
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Hartford, CT 06106

Senator John W. Fonfara
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Submitted by:

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Brother of Thomas Dwyer, a resident of Southbury Training School

My brother, Tom Dwyer, turns 54 years old this November. Tom is developmentally disabled, what was once referred to as profoundly retarded, as well as suffering from severe autism and bi-polar disorder. Tom has physical problems, including middle stage Parkinson's Disease and a loss of vision through an irreparably detached retina in one eye and a cataract in the other. He tends to swallow his food without chewing, so all of his meals must be ground or pureed so he won't choke. He has had periodic PICA issues, which means that he will pick up small items and try to swallow them. This behavior resulted in a blockage of one intestine and perforation of the other requiring extensive surgery several years ago. Tom does not speak, and cannot brush his teeth or go to the toilet by himself. He also stumbles when he walks and requires that someone hold onto a large belt around his waist whenever he seeks to do so. Tom requires that someone be with him during all his waking hours.

When he was four years old, my parents determined that they were unable to provide the level of attention he needed at home. They enrolled him in a series of schools and institutions over the years, trying to find facilities that were appropriate to his needs as his body developed through childhood and adolescence and into adulthood. For the last thirty eight years, he has been at Southbury Training School in Connecticut. This is his home. This is his community. At Southbury, Tom has a level of comfort and familiarity that are vital to his well-being.

Tom lives in a cottage that is specifically maintained for residents with PICA. The staff is trained to address all of his dietary requirements, as well as those of the other residents. He sees doctors and case workers regularly, and the staff is in close contact with our family to ensure that we are able to actively participate in his care and treatment. We speak by telephone and meet in person regularly.

I cannot stress how important it is that Southbury has offered Tom the opportunity to forge long term relationships with his caregivers and his peers. He is currently undergoing treatment for an intestinal disorder. His attendants noticed a problem and took him off grounds to a nearby hospital for tests, where one of STS' staff stayed with him for the duration of his stay. He initially refused to cooperate with the tests, and it was only because a Southbury staff member who was familiar with him was able to persuade him to respond that the tests were performed.

When people talk about moving people out of ICF's/MR and into group homes in the community, they are acting on behalf of those who can and should live in the general population, who can thrive in group homes. But there are some, like Tom, who cannot adapt to this type of environment. These people need an environment like the one provided by Southbury. The proponents of community facilities often portray Southbury and other congregate facilities as being horrible institutions, conjuring up images of overcrowding and negligence, of patients living in filth. Nothing could be further from the truth. I invite you to come see Southbury. Residents live in cottages and apartments, all quite similar to group homes, that offer similar comforts and community involvement but that provide a higher ratio of caretaker to clients, expanded medical facilities, and other population specific amenities not afforded by or available in individual group homes. Southbury offers an excellent alternative to group homes, and fills a void in providing services that individual facilities cannot possibly provide. The level of care and contact at Southbury exceeds that of individual group homes, but meets the requirements of this small but significant population. It is far more cost effective for the State of Connecticut to operate a facility like Southbury than it would be to provide this level of service in an equivalent number of group homes.

Of course, cost effectiveness is not what concerns families most. Families like mine embrace the high quality, federally licensed supports that STS offers my brother Tom and others with profound disabilities. STS residents receive compassionate support from a highly trained staff, people with whom they have long term relationships and a high level of communication and understanding. The STS community *is* their home; it *is* their community.

STS provides a safe and expansive setting to allow maximum independence. Attendance at events, outings to local restaurants and shops also ensure that STS residents are truly integrated in the broader Southbury community. Families of the residents of STS do not want our loved ones to be moved out of Southbury. We believe that the life that would await them in smaller settings would be more isolating, offer less oversight and protection, and have a higher potential for tragedy.