

**Hearing I/DD Caucus Bill S.B. 1088**  
**An act concerning services for individuals with intellectual disability.**

March 18, 2015

Dear Members of the Public Health Committee:

I wrote a little poem many years ago. Perhaps, now is a good time to reveal it.

Do not forget this place  
For you have known it well  
You have watched it challenge the wind  
Dispel the fog  
Catch the swirling snow in the silence of the night.  
You have run its grassy hills  
And embraced its autumnal colors  
Been sensitive to its expressions  
And listened to its feelings  
You have forged it and fashioned it  
And with unshakable strength  
You have encouraged it  
To advanced confidently.

Charlie was admitted to Southbury Training School in 1942. His sister Gracie was admitted at the same time. He lived there for 56 years and she for 69. It was their home - their caring, loving, compassionate, and benevolent home. It was a beautiful, safe campus that attended to their every need. Both were born profoundly disabled. I became the guardian when their parents died.

My Brother Michael was admitted to STS in 1948 and lived there for 66 years. Michael was born with marked asphyxiation being self-abusive, extremely destructive and severely disabled.

In the early years there were no group homes. There was no choice. Most of the time family pain was overwhelming. My parents and others devoted their lives to enriching STS. I remember as a youngster, traveling to Hartford to the hearings, the discussions, and the debates to petition for improved care. My father served on the very first Governor's Council, my mother was appointed to the first human rights committee.

There were no day programs in the early years. We appealed, implored, and solicited the State to improve conditions. Finally, STS became ICF – a lifetime of work and a state of the art facility.

There should be choice. The Training School serves a noble purpose. For the most part, those who remain are non-ambulatory, physically distorted, medically fragile, and elderly. The majority cannot go to work. Some cannot participate in daily activities. Many cannot

speak, or lie in bed being rolled every hour or two. Numerous residents are in wheel chairs. Respiratory therapy, physical therapy, feeding tubes and frequent medical visits to the clinic dominate daily activity. Still, STS is their loving home.

David came to Southbury in 1953. James was admitted in 1957. Our parents had a common cause and became lifelong friends. When David and James' parents died, I became their guardian. I visit every week – sometimes several times a week.

In the early days my parents and their friends would have discussions about their disabled children, the effects on family members, future care, etc. One particular memory remains in my 72-year old mind to this day. They wished that Gracie, Charlie, Michael, David and Jamie would die before they did - so no one else would have to bear the “burden.” Those comments disturbed me for years. Now I understand what they meant.

Please keep STS open for those who require very specialized, continual medical attention. Include skilled-nursing facilities, enhance the medical and dental programs (more than 500 from the community come to STS for dental care), and provide respite cottages. Perhaps legislators could vote to repurpose or reopen STS for those who would benefit from its services.

I completely understand what “Families Can't Wait” are going through. I signed their petition. We went through the same – so very many years ago – defending, protecting and safeguarding the disabled.

Thank you for your time and kind consideration in this very important discussion.

Respectfully submitted,

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