

My name is Joan Gurski and I live in West Hartford. I'm writing to support SB1088. My thanks to Senator Gerratana, Representative Ritter and the members of the Public Health Committee for raising this bill. I urge you to pass it out of committee. I work at the Channel 3 Kids Camp, a DDS respite provider. I am in regular contact with families of children and young adults with developmental disabilities. We serve young people of all abilities ranging in age from 8 to 21 in summer overnight and day camp and monthly respite weekends.

We routinely survey parents of all children who participate in our year round programs. This year I have been overwhelmed by the literal sense of fear I am reading on the part of parents of teenagers and young adults with I/DD. We all know that those with Developmental Disabilities are a vulnerable population in many ways.

But it is not right for a very small number of individuals to receive care in an institutional setting, albeit one in which their relatives say they're happy and well cared for, when there has been so much testimony before this committee and others that equally good care is available in community based group homes at a third of the cost. Is it fair that a small number of individuals receive services that cost so much more—so much more that thousands of equally deserving individuals receive, comparatively, nothing? I am somewhat new to advocacy and have sat in this building and been brought to tears by elderly parents of children my age explaining that they literally have to die or become incapacitated before their child is assigned a top priority on the waiting list. I have seen teenage siblings of those with DD who have accepted as a fact of life that when their parents pass they will become the caregiver for their sibling. These same families face further issues, and even crises, should the cuts proposed by Governor Malloy to post grad, day programs, respite care and other family support services not be overturned. There are families where a parent will have to quit a job to provide the care their child needs, causing them still further financial hardship.

I respect the individuals who live at Southbury and understand their families' unwillingness to consider moving them to a community based setting. But do they realize how many people are not receiving residential care because of the cost of care at Southbury and the other state run congregate facilities? One of my favorite movie quotes (this may be a first in legislative testimony) was spoken by the late Leonard Nimoy in *Star Trek: The Wrath of Khan* as his character, Spock, was dying: "The needs of the many outweigh the needs of the few, or the one." I am not really a Star Trek fan but I have held onto that quote throughout my adult life and try to put it into practice whenever I can. I wish these families and the unionized state employees behind their demands to keep Southbury open had to spend a full day listening to the stories shared last week with the appropriations committee. All people who need out of home placement are as deserving as the small number using up so much in our limited financial resources. There is a logical way to eliminate the waiting list and still ensure that those who need competent, compassionate out of home care can receive it, and that is to support the plan put forth by the Arc of CT to close Southbury and the other state run institutional care facilities within 5 years, by 2020. That date is not currently on the bill before the committee.

The families we serve are worried about how cuts to day programs will hurt them in the near future, but I can tell you they are terrified that there are no resources available for the long-term needs of their children with developmental disabilities. The human, and humane, thing to do is to put the money where it works—into the nonprofit community-based organizations that do so much, with comparatively, so little. There are several community based group homes in my town. The people who live in them who are able to, have friends and neighbors in the community, they have jobs, and their families know that the care they receive is good. Isn't that what you would want for your child if you were in this situation?

The legislature has some very difficult decisions to make this session, and I urge them to make the right choices on behalf of our most vulnerable population. Thank you for your time in reading my testimony.