

TESTIMONY OF THOMAS FIORENTINO
WEST HARTFORD
H.B. NO. 5030
AN ACT MAKING ADJUSTMENTS TO STATE EXPENDITURES FOR THE FISCAL
YEAR ENDING JUNE 30, 2015

Sen. Bye, Representative Walker, and members of the Appropriations Committee, thank you for this opportunity. My name is Tom Fiorentino. I live in West Hartford with my wife, Shelagh McClure, and our 23 year old son, Dan. Dan has Down Syndrome.

I am here to testify on H.B. No. 5030, AN ACT MAKING ADJUSTMENTS TO STATE EXPENDITURES FOR THE FISCAL YEAR ENDING JUNE 30, 2015.

Today, hundreds of families with adult children are on a DDS waiting list for residential services. Under the current inefficient system, their children have virtually no prospect of a place to live in the community.

Elderly and aging caregivers live with this fact: in all likelihood their child will never have a placement until they, the caregivers, die.

And when that last best friend of the child is gone, that is when the State will compound the trauma of the loss by moving that child to a new home. A move that could have been made so much easier if only the parent were there to help with this transition. But of course, that is impossible; and the child, having just lost his last parent, must face this move alone.

If that strikes as you cold- if it strikes you as inhumane; you should know that it is also the de facto policy of the State of Connecticut. Because barring this sort of scenario, DDS will not provide anyone on the waiting list with a home.

As a result, when those parents, go to bed, their thoughts begin to race.

You think about how your child cannot comprehend a world without you. How, in their world, you are a constant. You have always been there. You will always be there. You are the sun that rises and that will not - cannot- set.

Yet you know, of course, that the sun-no matter how much we might wish it otherwise- has always set.

The loss of your last parent is always difficult. What must it be like for someone who never thought it could happen?

So you worry, and you agonize over how your child will cope with the future that is in store for them in Connecticut.

You go to bed. But many times you don't sleep.

How did we get here? In large part, it's because Connecticut's system for providing for the developmentally disabled is spectacularly inefficient.

The good news is that there is a commissioner who recognizes that the system is unsustainable. And who is trying to reform it so that more people can be served.

The bad news is that, for the families and their children languishing on the waiting list, this is going to take too long. They need help now.

So while I appreciate the fact that the Governor's budget does not cut DDS from last year, I note that the recent \$30 million dollar cut goes unrestored.

And that with this flat funding, the people who have lost hope- the people who dread what tomorrow might bring for their children- will remain fearful and desperate. And their children will continue to face an unnecessarily harsh and insecure future.

Because there is simply not enough money in the budget to move anyone off the waiting list, unless and until the last caregiver dies.

And that is a situation that I hope and trust you will find unacceptable. Because the history of this legislature is that when the most vulnerable are in need, you have been there to help.

And right now, the many people with intellectual disabilities waiting for a home, along with their parents, are among those who most need and deserve your help.

Accordingly, I ask that when you consider HB 5030, you increase the appropriation for DDS, with the direction that the money be used to move people off of the waiting list.

I thank you for your time.