

February 18, 2016

Appropriations Committee of
The Connecticut General Assembly

H.B. No. 5044 "An Act Making Adjustment to State Expenditures for the Fiscal Year Ending June 30, 2017"

Testimony of
Eva Bunnell
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Greetings, Senator Bye, Representative Walker and distinguished Members of the Appropriations Committee. My name is Eva Bunnell. I live in East Haddam along with my husband and youngest son. My husband Chuck and I raised four children here in Connecticut.

I have worked with many of you in various capacities over the years; as a constituent, or a colleague on a task force, as a former senior member of Congressman John Larson's district staff, as a member of the Oak Hill board of directors (our state's largest provider of services to people with disabilities, and in my mind *the* benchmark provider), and finally and most importantly, as a parent of a young woman with disabilities.

This March 12th, will mark the seventh year of the passing of our oldest child, our precious daughter, Jacinta Skubel Bunnell. As you can imagine, to say we miss her would not adequately convey how deeply. The pain goes even further because of the time I was robbed of with my daughter while she was here. Let me explain.

I knew from nearly the moment of her birth, that Jacinta's life would be excruciatingly short. Hard to get your heart and head around. But believe it or not, there was something that to this day I cannot get my heart or head around. I and countless others simply cannot fathom, that individuals with disabilities, parents, caregivers and providers are here once again, in another session having to ask for the right things to be done.

I don't believe it's out of mal-intent, but time with my child was taken, no- *stolen* from her family because we were constantly having to come to the LOB or meetings with policymakers, etc. to try to protect the precious resources that protected my daughter's life and the lives of those like her.

Regardless of the economy, in any given legislative session in any given year, self-advocates, parents, and other advocates and experts in the field have had to come to protect the precious resources that safeguard and support the lives of citizens with disabilities who live in Connecticut.

Jacinta's depended completely on others for all of her care needs. Her health care needs were extremely complex, requiring constant supervision in order to keep her safe and alive.

Until Jacinta was nearly 18 years old, she lived at home with us. Suffice it to say, her needs were such that I, as a working mother was exhausted in caring for her. My husband Chuck would often come home to find me crying because I was terrified that Jacinta would suffer from my exhaustion in some way. I knew I could not maintain the care she deserved. With everything I am I wish that were not the case. If human beings were made differently and parents could care for their children with profound physical and/or intellectual disabilities and/or medical needs without ever becoming exhausted or ever having to die not knowing who was going to continue to care for their child, we might not be here today. However, that's not reality.

I believe that even if I were a full-time, stay-at-home mom, I alone could not maintain Jacinta's health and safety. I'm sure for some it's hard to imagine what that might feel like. To this day, I have nightmares that I fell asleep and missed feeding my daughter through her gastro-tube, or forgot to give her the medicines she required for seizures or suction her.

It wasn't until we found out about Oak Hill and its residential program that we were able to see some hope of doing all that we could to give Jacinta all that she needed to maintain her optimum level of health. Oak Hill opened a group home in Middletown for six young adults whose medical needs were as complex as Jacinta's. This move made all the difference in the world not only for Jacinta and her family, but for reducing all of the hospitalizations that the Connecticut Medicaid program and our private insurance was helping to pay for. Through Oak Hill, Jacinta had round the clock care from people who came in shifts-who weren't going to potentially sleep past a med dose, or miss a mild choking episode that could turn into pneumonia. Jacinta suddenly had a full social life, going out to concerts and shopping with friends when her health permitted. At home, I alone in providing her care did not often have the time to ensure that she got out to enjoy her life.

I saw Jacinta nearly every day after her move to Middletown. Finally, because of the sharing of care with the staff at Oak Hill, I got to be what I wanted to be from the moment of Jacinta's birth; just her Mom. What a gift. That gift was and continues to be threatened by cuts to state funding to providers such as Oak Hill. Because I've been there, I can imagine what families whose children are on the waiting list are experiencing right now. I worry for them and how much longer they can wait without a sacrifice to the health and wellbeing of their entire family. What they're enduring is as far from good policy as we can possibly get.

I am heartened by the work of Governor Malloy, his administration, and Commissioner Mornay who are working hard to look at the system of care as a whole, meeting with all stakeholders to find out what is working and where, and shore up those programs, services and providers that have the most meaningful impact on the lives of individuals with disabilities. Resources are finite and we should do all we can to ensure that every precious dollar creates the best in outcomes and impact. I believe the Governor should be commended for this approach. Dollars appropriated should be based on this, and not on politics or history and habits. There experts who will testify today about how to structure a better system of care. They can be of tremendous help to you as you work to pass a budget that gets the most of every dollar.

The cuts presently being proposed will mean that the nightmares not only continue, but in fact EXPAND for the individuals with disabilities, for families and the system of private providers that provide the state's core services and their employees. Please, please, do not let this happen. Do not allow more people to be robbed of time that will never be regained. Time that should be used by some to create precious memories.

I realize, with great horror, that there are some in this world, perhaps even in this room who believe that people as profoundly disabled as my daughter have nothing of value to contribute to society as a whole. I have pondered often if this is why we all meet here year after countless years. I leave you with this story.

Jacinta was a small warrior. She had a friend, Senator Chris Dodd, who was a warrior in larger scale. They met in church, shared a birthday. Jacinta defied the prognosis of her disease by many years, facing significant pain with courage. When doctors declared that her life would probably not last beyond three years, she did the impossible and lived nearly twenty-seven thanks to the outstanding care she received from Oak Hill. Along the way she changed policies that stood in the way of those who were like her from experiencing a happy life. Her friend Chris continued to work every day authoring policies that enhanced the quality of our lives. He fought for policies that others declared impossible. He worked anyway. For seven long years, giving credit to his friend Jacinta, he fought to pass the federal Family and Medical Leave Act that has benefitted millions of working Americans.

In our hearts, we know that there were millions of situations faced by families everywhere that inspired Chris to the work he has accomplished, FMLA not the least of those. However, in a tribute of true friendship to Jacinta, he attributed to her this jewel of legislation on countless occasions- most poignantly in his eulogy at her funeral Mass.

Jacinta was as kind a person as we have ever met. Chris returned her kindness with loyalty. The kind of loyalty that transcends any kind of barrier that life, or even death, can place in front of us. Jacinta did not forget her friendship with Chris Dodd. He did not forget his friendship with her. Each and every time a good battle was to be fought by either, they remembered the other.

Everyone has a mission in this life. Your help in prioritizing the lives of our state's most vulnerable citizens will undoubtedly make a world of difference. Please help.