138

April 23, 2015

Note to the legislators of CT

I have a 23 yr old disabled child and I have witnessed the degradation of the DDS system for all of these years. This has been on ongong crisis which only will get worse with the increase in the prevalence of autism as well as the budget cuts in early intervention. However this year, the budget cuts are on the level of inhumane and devastating to thousands of families.

I am here today because I am a success story. We had a decent budget from the state , from a Medicaid waiver many years ago and IHS. With this funding, we had many aides throughout the week. This allowed us to work and pay our mortgage ..My husband worked during the day and I worked many evenings. Our son had many sleep issues, common to his diagnosis of Tuberous Sclerosis. He also suffers from unpredictable seizures , autism, behavior outbursts (biting, strangling) and the list goes on. I believe many of you have healthy children, so I imagine, it's hard for you to understand just what we go through. You are fortunate, if you have never experienced the job of staying up all night to ensure that your child is breathing ..That was my assignment one night after my son had a devastating seizure that put in him the postictal sate for 18 hours. Perhaps you don't know what its like to attend an all day class to learn how to defend yourself from your own child. But I do. Most people cannot live with this level of everyday stress. It tears at ones marriage and health. This is no good that comes from it and it costs money in the end.

My son Eric now resides in a group home managed by Ability Beyond. He also attends their Day Program. This system can work. My son has improved 100% and is happy He is busy all day and he has a strict behavioral plan. His outbursts are almost under control. He is much calmer. I see now that he sensed the level of stress at home. We are now a functioning family once again. We are slowly picking up the pieces and we are sleeping through the night, simple pleasures. We can even go to the movies and support our local restaurants. All of this brings money BACK to the state.

PLEASE think big picture and help the 2000 families on the residential waiting list with funding. Please fund in home supports to be fair to siblings of special needs children , allow parents to go to work, and give them the respite they need so that can make smart choices.

Penney Parkes Fairfield CT