

February 17, 2016
Testimony to the Appropriations Committee

Our son Eric is now 23. He suffers from Tuberous sclerosis, a disorder that causes benign “tubers” to form in all of the major organs in the body. Tuberous Sclerosis is the second known genetic cause of epilepsy and autism: my son has both. Add to that, OCD, aggressive behavior (biting, strangling) and a VERY significant developmental delay. He is nearly blind in one eye from a bleeding tuber. Eric has many sleep issues and is awake several times throughout the night.

He requires 24 hour supervision to assure his healthy and safety. 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 post ictal state 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 we do. Most people cannot live with this level of everyday stress. It tears at ones marriage and health. We lived with the fear that something would happen to us and no one would be there to watch over our son. Our greatest concern was that he would outlive us. It is not something we like to admit.

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.

Our State government is constantly reducing the budget of those with no voice. Please do the work to FIX OUR SYSTEM by closing wasteful state institutions. There are 2100 families, our own citizens who are suffering. Please support the funding of group homes and day programs so that the rights of ALL the people in our state are protected.

Thank you for your time.

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