

Appropriations Committee Hearing for House Bill #6380  
Friday, March 4, 2011

Thank you for taking the time to hear my personal testimony. I'm asking you to please vote against this bill, and let me tell you why.

My name is Laura, and I have an eight year old daughter, Sofia, who was diagnosed with LCA when she was 4. This is a degenerative and un-curable condition leading to complete blindness.

BESB is the reason my family chooses to live in Connecticut. We moved here in 2005, for a job that disappeared over two years ago. We are hundreds of miles from our families. My husband remains unemployed, and I commute over an hour out of state for work that pays a fraction of what is being offered in other cities.

Why are we still here? Because of BESB. We have researched services in other states. I have met with parents, researched online, and spoken with vision experts at well-known institutions in Boston and Philadelphia. All of these resources have said the same thing: Stay in Connecticut. As long as you can.

I know a mom in New York whose daughter, like ours, is legally blind. Unlike us, she lives in a state where there are no centralized resources. She told me she spent years requesting, and fighting for Braille instruction for her daughter. The school said they couldn't afford it, there weren't any teachers nearby, and the equipment was too expensive. Instead, they offered her a "note taker" – an adult who would travel with her daughter to every class, writing notes for her to enlarge on a photocopier. The mom was very happy that the school afforded the same "note taker" for her daughter's entire school career. This girl is now graduating from High School, but doesn't have plans to go to college. She can't fluently write her own. She can't even read fluently under a magnifier. She can't work without another person, a "note taker" assisting her. She is not independent. Many would consider her illiterate.

Back in Connecticut, my second grader can read with her magnifier. But Sofia can also read independently in Braille. She writes her class assignments independently in Braille. Thanks to her BESB teachers and consultants, the services and equipment provided by BESB, and the support of the local school which isn't burdened with the costs and administrative issues involved, she performs at the top of her class.

Sofia is very independent by nature, and unlike the mother I know in New York, I know that my daughter will continue her education beyond High School. With the services we receive from BESB, we fully expect Sofia to be an independent and contributing member of society.

BESB is a unique agency. It's an agency that works, and works very well. It is the reason we are proud to call Connecticut our home.

Please do not split this agency in two. Please vote against this Bill.

Thank you for your time.

Laura Manfre