

March 12, 2011

To the members of the Human Services Committee (including my own Rep. Chris Lyddy), and everyone whom it may concern:

My name is Michele Lurie, and I need to take a few minutes of your time.

I understand that our painful budget cuts are necessary for Connecticut, but I implore you not eliminate the Board of Education Services for the Blind as it currently exists--it's own agency. As a mother of a child who continues to benefit from these services, it frightens me to think of what could happen to my son if direct services are cut off, and that will happen if Children's Services is moved under the State Department of Education. Let me tell you about my Elliot.

I have a 7-year-old son who was born with Optic Nerve Hypoplasia, Fovial Hypoplasia and Pendular Nystagmus. Elliot will have low vision for life. He will never drive, he will never play team sports, and he may always need assistance to cross a street. But so far, we are a very lucky family in that Elliot has yet to develop any other diseases and lifelong conditions--physical, behavioral, hormonal--often associated with his diagnosis. It is rare for a person like him to escape with "only" a vision problem. I have held my breath for seven years and will continue to do so.

Pediatric ophthalmologists, endocrinologists and neurologists ran a battery of tests, MRIs, CT scans and exams for two years after his birth. This is excruciating enough for a parent of a new baby. But at the end of the day they hand you results, tell you there is no cure, and send you home.

This is when BESB came into my life. Lisa Pruner--a wonderfully warm, and well-versed woman--came to my door and my rescue when Elliot was just an infant. She came to our house monthly to engage and assess him, and in doing so she educated me about my son and his abilities in ways that doctors can't. She helped me overcome my fears about raising a child who had limitations, to understand his specific limits and shortfalls, and she encouraged me to let him try things from which I might have held back.

When it was time for preschool, Lisa went into the school before the start of the year to acquaint the teachers with Elliot's needs and to suggest adaptations that would help him get the most out of the experience. She swapped out every other monthly home visit to the classroom to ensure that his plan was working effectively and that the school was doing all that it could to accommodate him.

At age five Elliot was ready for kindergarten, and it was time for Lisa to pass the torch to another BESB teacher for the elementary age group. Lisa made sure the transition to both Hawley School and our new BESB teacher went smoothly. She came to our first IEP meeting before kindergarten with a list of adaptations that I could never have come up with myself. In turn, our principal and administration has been more than accommodating because they understand his needs. Between her

preparations and his wonderful kindergarten teacher, Elliot's true start to a world of formal education went very well.

It was extremely difficult for me to let go of Lisa--she had been in my corner for Elliot's entire life. Through her many years of specialized experience she understands how his brain processes what he sees in many ways that I still don't. His current BESB teacher, Lori Cornelius, has been carrying us through our new hurdles, and I am grateful for her because this is when things are starting to get scary for me again. This is first grade-- a make-it-or-break-it year for Elliot. The stepping stones to all he will learn from here are under his feet right now. He is really learning to read well, but the type in the books are getting smaller and he struggles. He is learning to write sentences, but has trouble with the light lines on standard lined paper. He needs to sit up front, but can still miss details when the teacher is teaching something new because his brain just can't process the information fast enough.

Lori is here to educate me about special equipment that is available to assist with these issues, and determine which will be helpful and which to avoid. Over the next several years, Elliot will be faced with standardized testing (including CMTs), and my very intelligent son will be at a complete disadvantage. These text-heavy, timed tests will be virtually unreadable to him. At the very least, he will require magnification equipment and extra time to take them. Lori will come to bat for him in our IEP meetings to be sure that he gets the assistance that he needs to succeed.

Please help keep BESB as an independent agency. The State Department of Education doesn't have experience with the specific needs of children like my son. Without these two women, and others like them who have been formally trained and have years of background experience specific to these very special people, children like Elliot will slip through the cracks and get lost in the system. They will not integrate through the schools to their best abilities, and there will be a domino effect on their education. Ultimately they will miss out on their full potential, and as adults will have to forgo opportunities that could be available to them if they go through childhood and adolescence with appropriate support and assistance.

Thank you for reading, and please keep our children--our future--in mind when you make your decision.

Sincerely,

Michele C. Lurie, mom to Elliot
Newtown, CT