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March 3, 2011

Senator Toni Harp
Chair of the Appropriation Committee for Bill #6380
300 Capitol Avenue, Room 5100
Hartford, CT 06106

Re: House Bill #6380

Respected Senator Harp, Senator Prague and committee members,

I am writing in opposition of House Bill #6380. I have had personal experience with an education system where the Children's Services for the Blind and Low Vision has been a part of the Department of Education and the remainder of the vision services serving the adult population has been a part of the Department of Social Services. I can strongly state without any doubt that this service delivery model DOES NOT work and is an absolute nightmare not only for the individuals and their families receiving the service but also for the individuals providing the service.

My daughter, Ayesha, is currently in Grade 11 attending Newtown High School and she has been on the honors roll since Grade 9. She has concrete plans to attend university and great potential to be gainfully employed in a field of her choice. I can unequivocally state that she has reach this potential primarily because of the well coordinated, proactive, individual centered services that she has received from the well trained, qualified and empathetic professionals at BESB since she went blind at the age of 5 ½ as a result of an aggressive eye cancer.

We lived in Danbury CT and Ayesha was in kindergarten when we were informed by her treating physicians that her eye cancer was no longer treatable and the only solution to save her life would be to remove her only seeing left eye rendering her completely blind for the rest of her life. As you can imagine this was a very difficult time in our life. Our anxieties about the prospective future of our daughter were eased when we were introduced to Jeanette Haines, Catherine Summ and John Waiculonis. These 3 individuals came to our house, Ayesha's elementary school and her daycare, prior to her eye operation in order to proactively prepare everyone of us as a family as well as all those individuals

that would come into contact with Ayesha on a daily basis. This proactive thinking and planning by BESB as an organization proved to be essential in Ayesha's ability to accept and move forward with her young life despite her sudden loss of vision. Appropriate level services throughout Ayesha's school years have continued to be exceptional and essential in the growth and development of Ayesha not only as a student but as a person.

We moved to Sandy Hook, CT during the summer of 2004 when Ayesha was starting Grade 5. The transition from one school district to another was seamless due to the coordinated services provided by BESB. Ayesha has grown into a self confident, mature, caring and loving teenager who is ready to take on the world and does not let her lack of vision interfere with any activity that she wants to participate in. She is fearless! I am proud to say that my daughter is currently a Second Degree Black Belt in Tae-Kwon-Do and is currently working on achieving her Black Belt in Muay-Tai.

During the summer of 2007, we moved to Ottawa, Ontario, Canada (the capital of Canada) as my husband was offered a fellowship in Nuclear Cardiology. Ayesha was entering Grade 8 at the time. The service delivery model in Ontario is the exact model that House Bill #6380 is proposing. On paper it seemed like an acceptable model but trust me when I say that this model DOES NOT work in practice! As you are well aware, the Department of Education does not provide direct services to the sector; their role is to establish policies and procedures and provide practice guidelines and recommendations. The delivery of direct services would then rely on the individual school boards, schools, principals and the teachers. Depending on the knowledge, skill level, resources and motivation of the professionals involved, our children can receive services that can be excellent or very poor. There is no oversight from any agency with the quality of services being provided. The individual school boards would need to provide each child not only with the a teacher of the visually impaired (TVI) and a braillist (who would adapt school materials as needed) but all of the hardware, software, equipment, technology and support that is required for a blind or low vision student to complete his/her education program. This is not cost effective, manpower effective but it is also an irresponsible way of providing services to the blind and low vision children of this great state of ours!

When we moved to Ottawa, I would proudly inform, the teachers, students and fellow parents about the BESB organized system in Connecticut and all of them would say that the BESB model is the system that really works. They all informed me that they wish that there were coordinated services for the blind and low vision population in Ontario. In fact I was informed that the BESB model was used in the Atlantic Provinces of Canada as well as in British

Columbia and that their service delivery for the blind and low vision sector is considered the best in Canada.

Due to the disco-ordination of services, Ayesha was unable to attend the school that was in our school district as no appropriate services were available. At that time it was suggested to us by the staff of Vision Services that we apply for an out of district transfer in order for her to attend a school in the city center, Immaculata High School. This particular school already had the resources present as there were two other children who were legally blind attending the school. But this was on the mercy of Immaculata school principal to accept the transfer of student. As we had no choice in the matter, Ayesha attended the city school. My husband would drive her 30 minutes to the school in the morning and I would then pick her up at the end of the day. This was because we were having our daughter attend a school out of district and no bus services were provided. We did this for 3 years!

Although Immaculata High School was considered the best school in Ottawa for services for blind and low vision, it certainly did not live up to the quality of services that we were so accustomed to in Connecticut. There were no protocols that the teaching staff could show me that were being followed. The approaches used on all of the blind students were very similar:

- If it is too visual, eliminate it
- If the student does not get the adapted material (large print, Braille) at the same time every other student does then that's ok because they can listen to the teacher
- Do not expect the student to label diagrams, understand pictures or images as it is too complicated for them
- Do not expect the blind student to understand the full subject matter as it is difficult to adapt some subjects (math, science etc.)
- The student required continual assistance in and out of class to be successful in school
- The student will require some assistance with their mobility needs

Bottom line, inadvertently expectations for the blind and low vision student was lowered significantly.

Needless to say Ayesha was an enigma to the teaching staff. They had never come across a student that was so confident, self reliant, self advocates and independent. In fact her TVI said to me," We don't know what to do with her she is too independent!" I was shocked! At that time I consulted the staff at BESB and obtained established protocols, standards of practice, guidelines, that I soon found out were readily available, and provided them to the staff in Ottawa. I met with the superintendent of the school board, TVI, staff at the School for the Blind

in order to establish standards of practice. I was informed that the staff had all intentions of establishing protocols but due to the lack of resources they have not been able to take time out.

Due to my involvement with BESB, my professional background as an occupational therapist and my active involvement with improving the Ottawa service delivery model, I was chosen by the then Minister of Education of Ontario, Honorable Kathleen Wynne, to be the representative of the Blind and Low Vision Sector of Ontario on the Minister's Advisory Council on Special Education (MACSE). This is an 18 member multi-disciplinary council which provides advice to the Minister of Education on matters concerning special education policy and procedures, the development and delivery of programs and services for exceptional pupils including the identification and provision of early intervention programs for students with special needs in Ontario elementary, secondary and high schools.

During my tenure on MACSE, it became apparent to me that although the Ministry of Education mission statement, guidelines and recommendations were supporting our children growth and development in the school systems, these principles did not translate practically in the school system. Depending on the budget, resources, manpower etc the delivery of services varied greatly from city to city, school board to school board, school to school and even teacher to teacher. This was certainly not acceptable and it was my role to bring the concerns of the sector to the attention of the Department of Education.

One of the biggest challenges that I faced in fulfilling this great responsibility placed on me was the voice of the blind and low vision population was not heard. The Ministry of Education was dealing with issues of other sectors that were larger in number such as the autism sector, the learning disability sector, the behavioural sector. Although the number of children with blindness and low vision are low in all of the children that require special education, their need is highly specialized. Without the proper skilled professionals, education, technology, equipment, services and continuing education that are available in a co-ordinated and seamless fashion the potential of our children to be independent, productive members of society is highly impacted.

Another major obstacle was that since the departments servicing children and adults were the responsibility of two different ministries, there was very little or no communication between them. This resulted in difficult, haphazard and disorganized transition plans when a student was graduating from high school. In fact transition planning during the school years was also mismanaged as no one took ownership of the recommendation made by the professionals.

It was difficult for the individual school boards to provide educational support for the blind and low vision sector; they certainly were not able to provide adequate orientation and mobility (O&M) services for Ayesha and the other children. Ayesha along with many other children have the potential to be independent in their community mobility needs however the focus of most of Ayesha's O&M sessions were how to access the community for assistance in various situations not how to develop independent mobility skills. Luckily for Ayesha she has developed excellent foundation mobility skills from her O&M instructor, John Waiculonis at BESB and very quickly surpassed all mobility expectations.

Ayesha arrived in Ottawa at an age where the development of daily living skills was essential for her to continue on the path of becoming an independent adult. Since the provision of training for essential daily living skills was not part of the Ministry of Education's mandate, we needed to contact the CNIB for rehabilitation services. Due to the lack of staffing and resources, the provision of these services was limited.

In late 2009, my husband was offered multiple employment opportunities after the completion of his fellowship. We purposely chose Danbury Hospital mainly because we knew that the education system in Connecticut is one of the best. Not only does Connecticut offer exceptional educational services for Ayesha through BESB, it also offered us an exceptional public education system for our 2 younger daughters. We subsequently contacted BESB in early 2010 informing them that Ayesha would be returning to the Newtown school system for Grade 11. This transition from Grade 10 to 11 was virtually seamless and we were very relieved to be back in Connecticut where services for Ayesha would be readily available.

Ayesha is now gearing herself to attend university and majoring in English, Creative Writing, with a minor in Social Sciences. I am confident that with the continued support of BESB services, she will not only achieve but exceed her set goal. I am very proud to be a Connecticut resident and advocate strongly for the continuation of Blind and Low Vision services through the current BESB model for all blind and low vision residents of Connecticut to become productive, independent and confident members of our society.

Trust me when I say that that the model proposed by Bill #6380 may look good to some of you on paper with regards to budget and service delivery but in practice this does not work.

Respectfully yours,

Sabeena Ali