

April 1, 2021

Dear Education and Cultural Affairs Committee,

I write this testimony to you as a mom who also carries the knowledge and experience of a National Board Certified special education teacher, former school principal, and current assistant superintendent. I am about to start my doctorate program in two weeks and my dissertation for my doctoral study will include strategies for including parents in transition plans for students with severe developmental disabilities as well as the impact parents' relationships with the school have on a child's education. The research will also include the importance of individualized plans for children with severe disabilities and examples of unique programming options for students as they transition into adulthood. Merging my two worlds together will not only help my own family but will help professionals and parents navigate the world of disabilities with open minds, respect, and kindness.

Dealing with schools advocating for my son's needs over the last fourteen years has caused great anxiety and stress for our family, much of which could have been avoided with the school listening to our opinions about our son. Each time he either ages out of programming at a school or needed a change because it wasn't working for him, you start with an entire team of new people who don't know your child. Other than the thick file that special education has. Our children are much more than paper and data scores. Our son Ryan is a sixteen-year-old young man who has Autism, Epilepsy, ADHD, and Sensory Processing Disorder. Here is a history of his school and healthy life; this information is for you to know how complex our son is. I apologize for the length of this, but for you to understand how complex our son is and how valuable our input could be to a school I felt I should include it.

Ryan's History:

Ryan was diagnosed with "autistic disorder, severe communication delays, moderate fine motor delays and mild gross motor delays" at 23 months. Since this diagnosis, we, as parents, have tried anything to help our son.

- Ryan had in-home services and we took him to MidCoast Speech and Hearing for speech and occupational services.
- Once he turned three, he began attending Woodford's pre-school with a 1:1 service provider.
- In June 2010, after four years of services through Woodfords at his IEP meeting with RSU 13 (we lived in Thomaston at the time), it was decided that Ryan would transition to the Merrymeeting Center in Bath, as it would be able to attempt to meet his needs. I drove Ryan daily to Bath with his older sister in tow five days a week and picked him up for the summer.

Then came 2014-2017. To me, these were the dark times in our life.

When Ryan was between seven and eight he went to the dentist every six weeks to attempt to learn skills and be able to have a dental cleaning (Ryan never did meet this goal). While

he was there, Dr. Higgins, his dentist noticed he had a cracked tooth and Ryan had three dental procedures. Very shortly after, he began having seizures. We had never medicated Ryan until this point. He had severe reactions from each medication we tried.

In 2015 Ryan was having 40-50 seizures a day, the school noted that the seizure medication seemed to increase aggressive behaviors. He also had regression of academic skills.

For three years after his dental procedure, Autism actually took a back seat to his seizures. Our son Ryan was diagnosed with epilepsy and we were forced to turn to medication to treat them. Ryan did not respond favorably to this plan.

We went through 13 different medications, every kind of medication that his neurologist and developmental pediatric specialist could offer; that did not stop Ryan's seizures. The medication took away our happy boy. Ryan became confined to our couch, under a blanket. It came to a point he could not even go to his school. Most families would have needed to hospitalize their child and we at times felt like we may need to as well.

Then, we had to go and have blood taken monthly to make sure the medication doesn't completely stop Ryan's liver function. Typically, it took four people to restrain him to get the bloodwork. The prescribed medication caused him to smash his head against the wall, bite himself so violently that his legs were covered in bruises, not smile for months, grow breasts and become extremely aggressive. His kidneys began to fail and was only urinating one time a day. Our child who was 98% happy all the time went to 100% miserable. Some days we spent up to 6 hours just trying to get Ryan off the couch. Sometimes 3 people were needed to try to get him off the couch. He refused to leave our house and even refused to leave our couch.

Ryan didn't sleep for over a month. He would fall asleep and wake up between 1 and 2 am daily for over a month. This felt like what I believe Hell to be like.

At the peak, we were seeing between 80-100 seizures a day.

My husband became a stay-at-home dad because of Ryan's severe needs. He has spent this time researching, listening to other parents' stories from around the world, and keeping an open mind to try and find something that would work for Ryan.

We tried something that every doctor (we were seeing 6 at the time) thought was crazy. In May, my husband put himself and my son on a strict diet. It contained raw fruits and vegetables, along with many supplements to support brain and stomach health. This worked and continues to work for our son.

In 2017, I have data that Ryan had been 34 days without any medication and no seizures. He came home from school with 0 seizures, 0 aggressive behaviors, and 0 eloping behavior. This has not happened ever.

In May of 2017, the BCBA and Clinician stated Ryan had amazing progress since last year. It no longer was taking them, two people, to get out of the van anymore! However, our family was demanded to provide a doctor's note of Ryan's diet, which we gladly provided. Several very concerning events happened at Merrymeeting involving staff making choices we felt were highly inappropriate and this caused us to look for an alternate placement for Ryan.

- Early in 2018, Ryan transitioned to Atlantic Academy in Camden, a much closer school that really did meet Ryan's needs and met our family with respect. The school created a program that focused on functional life skills, having Ryan go to the store, buy food, prepare food, etc. He responded well and the team really got to know Ryan and his unique needs.
- In March 2020, when schools across the world closed down, Ryan stopped having any direct services. While no one had direct services with Ryan because the district said they were not providing any ESY services other than virtual to anyone, we were able to meet with this modified team and began developing a blueprint of a program for Ryan's school year that would be starting in the fall of 2020 in our home.

The school district set up his IEP meeting to prepare for the school year at the end of August and we felt completely blindsided by the district's intent at the IEP meeting. They had known for many months prior to COVID that Atlantic Academy was not going to be a high school (as Ryan had aged out of this program) and that Ryan would need a new program. We do not believe there were any efforts made to try and make a plan for Ryan and his individualized needs. RSU 40 started by saying we had three options, a home program, sending him an hour and fifteen minutes away from our home, and MVHS. They didn't listen to what our family said, and it appeared they knew where they were headed before the meeting began. In the Written Notice, they stated that the team agrees a hybrid model would be best for Ryan, but as team members, we completely disagreed with this.

When Ryan went to school in Camden, he was as close to his home community as he had ever been since preschool. Since that is not an option, and Ryan has been out of school for a year, he cannot transition to mainstream high school with between 300 and 600 people. The written notice reflects that that was the team's goal, that is not our family's goal for Ryan. Our goal is to build on his strengths, meet him where he is, and gain some independence and skills for his future. Ryan's SLP at Atlantic knew him the best, she was the only person who had worked with him recently and knew his abilities. We were told she could be his case manager, then at the meeting, we were told the town high school special education teacher would be his case manager, again to try and force him into a program at MVHS. The team was advised by his SLP that MVHS, even with only 4 students in the classroom, would be too much and unsafe for Ryan in the meeting and that he is highly sensitive to loud noises and being around groups of people. This was not documented in the WN.

At one of our weekly meetings this academic year, established at my request, I stated I had not seen a post for the unique position that the district stated they were tirelessly searching for. We also noted several areas that we felt were documented incorrectly or do not

represent our feelings in the Written Notice. Not until 9/25/2020, after I brought it up at two weekly meetings, was a job posting made for someone to work in a home setting.

We have further requested if the district could not meet Ryan's needs in finding a BHP, that looking into agencies may be a viable alternative to provide services at our home for him. For example, his occupational therapist is a contracted provider, she is coming to our home to provide services and that is going wonderfully. This still has not been done as of 4/1/2021 and Ryan's IEP has not been met this entire year. It says he will receive six hours a day, he has been getting three hours since October. His speech pathologist just began working with him in March 2021. No speech all year by our district, my husband and I paid out of pocket for his previous speech therapist to come on Sundays because the district refused to hire her to work with Ryan.

At an IEP meeting on 10/16/2020, we were told the district was advised by legal counsel to not look at any compensatory services at this time as they may add on a whole additional year after his fifth year of high school. Again, we feel the district is not looking at Ryan as an individual. School is open and Ryan needs the support now, not after five years. They also said we would need to develop an Individual Remote Learning Plan and I requested Karen Brackett reach out to agencies who serve people with disabilities to see who would be able to provide services in the event that school shut down again. We continue to feel that Ryan cannot access services remotely, but would welcome a plan on how to provide meaningful services to him should there be a shutdown.

We have been experiencing an exhausting and frankly unnecessary battle since March of 2020 for our son to have an individualized plan that replicates his appropriate education from Atlantic Academy. He is entitled to an appropriate education.

In summary, Ryan needs to be looked at as an individual. Over and over again since the shutdown, we have heard "we don't do that" or "we are a public school", never looking at Ryan as an individual with specific programming needs. We feel as though the school district has been working against our family, rather than working with us to provide an appropriate educational program for Ryan. We are sure our family is not alone in this constant battle. We feel that there is a lack of initiative, responsiveness, ethics, and financial appropriation to the education of our son. This year we felt forced as a family to file a state complaint. We had never done this before. We know our son better than anyone, especially people on his team who just met him. I have watched as a teacher, principal, and parent how parents' input can just be checked at the door. That is why I'm asking you to pass this law to give parents equal parts at the table. Students are in school for a few hours a day, the rest of their time is spent with the family. Building a positive relationship and including the family's values and knowledge is crucial for student success. Thank you for your time, please reach out if you have any questions for me or my husband.

Respectfully,
Christina M. Wotton, Mom
207-701-7131
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Waldoboro

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