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Thank you, Representative Ortity and committee members, for the opportunity to share our thoughts about the delivery of special education services, particularly as it relates to a very unique population of children.

By way of introduction, we are Alan and Jennifer Shuckrow and we reside in the northern suburbs of Allegheny County. We are the parents of two children. Our oldest, Zachary, is a senior at the College of William & Mary in Virginia. Our youngest child is Abigail, age 17. At 3 months of age, Abby started having bizarre startle reflexes. As it turned out, these startle reflexes were cluster seizures. Abby was ultimately diagnosed with a terrible form of epilepsy known as Infantile Spasms. Because Infantile Spasms can profoundly delay intellectual and physical development, we tried more than 15 anti-epileptic medications, high dose steroid injections, the ketogenic diet and a vagal nerve stimulator.

Unfortunately, none of these treatments worked and Abby continues to have seizures every day. Today, her diagnosis is considered Lennox-Gastaut Syndrome which, put simply, is a generic way to denote uncontrolled seizures. Just a few months shy of her 18th birthday, our daughter still cannot walk, talk or even hold up her head without help. She is legally blind, uses a wheelchair and is dependent on others for all aspects of her care.

But, our girl is much more than just the sum of these challenges. She is beloved so it was critical that we find the right educational placement for her. Fortunately for us, Abby met the criteria for enrollment at *Western Pennsylvania School for Blind Children* **AND** our home district, North Allegheny, agreed to that placement.

Before discussing the education our daughter receives at WPSBC, we wanted to share how grateful we are to the North Allegheny School District. Not only is North Allegheny our *alma mater*, also provided our son with a top-notch education. And, at the other end of the spectrum, NA fully supported our decision to enroll Abby at WPSBC. They have met the wide polarities of educational need for the Shuckrow children with their typical dedication to excellence.

Just after her 3<sup>rd</sup> birthday, Abby started at WPSBC and this has been the best decision we have made on her behalf. Abby is in a classroom with 6 other children, each with differing abilities and needs. The classroom is led by a Certified Teacher for the Visually Impaired and supported by two instructional aides, a physical therapist, a speech-language therapist, an occupational therapist and, when necessary, other specialists push in. This team of extraordinary educators has helped Abby make important progress on her IEP goals, even while she continues to be battered by seizures.

Learning happens throughout the day for children at WPSBC. In art class, for example, students can be found rolling their wheelchairs through trays of paint and then across white sheets. This process allows the students to create their own version of Jackson Pollock's work. Abby can be included in soccer games—even though she cannot make a kicking motion—through her use of a bowling frame aimed in the general direction of the net. Likewise in horticulture class, students can touch and interact with their environment. Typically, students in wheelchairs (or with otherwise limited mobility) have a hard time reaching fields, streams, etc. because concrete/asphalt pathways rarely extend into these natural spaces. At WPSBC however, Abby can see, touch and hear an accessible trout pond in the form of a specially constructed aquarium. For children with complex disabilities and visual impairments, these multi-sensory experiences are the best ways to unlock learning.

Because of the expertise at schools like WPSBC, our special children's lives are made safer and more fulfilling. By way of example, Abby is in the process of getting a new wheelchair—one which will ultimately cost about \$10,000 and will take the better part of a year to acquire. We could not navigate this path without the help of Abby's physical therapist and occupational therapist—they sorted through the available options, added on all necessary components, wrangled with the insurance companies and, when it finally arrives, they will tailor it to fit our girl.<sup>1</sup> Without a functional, supportive wheelchair, Abby becomes a recluse, confined to her bedroom, so the efforts of our PT and OT cannot be over-valued.

We also want to thank WPBSC for its resolute determination to stay open and functional during the pandemic. As you might imagine, remote/Zoom classes for a population of intellectually disabled, visually impaired children are not ideal. The School understands that and has been able, through its cautious and caring approach, to stay open throughout this year.

If Abby were a typical child, she would be a high school senior and, in all likelihood, we would be planning to transition her to college. Given her many challenges, she will stay another 3 years at WPSBC but we are already working on another form of transition—namely her transition from the educational system to the health and human services system. And not to put too fine of a point on it, this is a transition that every parent at WPSBC dreads. Typically, children like Abby will have spent 18 years at the School for Blind Children and there is no placement—residential or day—that can offer similar high caliber experiences in a vibrant community setting. You can understand then why the WPSBC graduation is the saddest day for most families.

So, importantly, WPSBC is working now on developing an adult residential program to continue to serve these students and families. If you can whisper in your HHS colleagues' ears, we would

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<sup>1</sup> These therapists also help with the acquisition of specific home modifications, handicapped accessible vehicles, car seats, braces of all sorts, and every possible type of equipment. And since each child has unique abilities and needs, the process to acquire this equipment is similarly unique.

be most grateful if they could partner with the School so it can expand its offerings to a population in desperate need of quality post-educational choices.

As a final matter, we would like to thank this committee for its staunch support of special education in Pennsylvania—whether it happens in a home district, a charter school or, in our case, at one of the 4 chartered schools for the deaf and blind. Society often overlooks profoundly disabled children but your willingness to champion and support their education is a powerful endorsement of their great intrinsic value. You are looking past the disability and seeing the abilities—and for that, we are so very appreciative.

Respectfully submitted this 10<sup>th</sup> day of December, 2021:

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