

## Special Education Funding Formula Commission

Testimony of Amber Mintz Foote September 26, 2013

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Good morning distinguished ladies and gentlemen. Thank you for time on this important matter.

My name is Amber Mintz Foote. I am here to share with you what I know about opportunity and momentum, in the hopes that I may help you in your decisions about the Commonwealth's investment in each.

I have been a for-fee educational advocate since 2005. I have two children. One is Zoe, now twenty years old, and my son Cal, who is 15. We live in Berks County. He is the reason I am here today testifying about investments in education, both public traditional and public charter schools.

I will share with you first about Cal, who is my inspiration, and the reason I am an advocate instead of a marketing consultant. I am also here today to talk about the much bigger hidden river of opportunities and momentum that are both drifting and being pulled away from children with the label of disability.



Cal is pictured here at age 3 with Zoe. He was diagnosed in November of his second year, which was very unusual<sup>1</sup>, and even as he had consistently observable delays in basic social behaviors. He was considered “non-verbal”, having just 3 three things he would make any sound for; *more*, *no* and *all done*. Cal has collected many diagnoses; autism, PDD-NOS, and developmental delay. Labels however are not a commitment of intervention. Back then- just 13 years ago, doctors handed you a one-sided sheet of paper

after this astounding news and simply ushered you out the door. In one instance a highly regarded developmental pediatrician suggested we should plan to institutionalize Cal. That was 2000; he was barely 2 years old.

Lucky for Cal, I was persistent and resourceful, We were fortunate to snag one of a few funded slots at the local hospital for intense outpatient speech and occupational therapy and obtained rare behavioral treatment services through Medicaid, and funding from the local IU. It was my intent to help Cal learn to speak, since opportunities improve exponentially if he did. So, early funding was critical to his early success and momentum. He was one of few-- and I emphasize *few*-- to receive about 30 hours a week of state of the

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<sup>1</sup> A 2009 study found the average age of diagnosis was 5.7 years old. [▲](#) Shattuck PT, Durkin M, Maenner M *et al*. Timing of identification among children with an autism spectrum disorder. *J Am Acad Child Adolesc Psychiatry*. 2009;48(5):474–83. doi:10.1097/CHI.0b013e31819b3848. PMID 19318992.

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science<sup>2</sup> intervention, up until just before kindergarten. He was also one of a few not talking then, who is fully talking today. The odds against it were good.

In June of 2007, a milestone occurred, on I-95, on a family trip. For the first time in five years I actually wished Cal would *stop* talking. He was nine. If you have typically developing children, I suspect this might have occurred to you when they were two.

Since then Cal received years of intense speech language, occupational and special education services; academic, emotional, sensory, and organization support. He was given opportunity, developed momentum, and we found professionals able to keep him rolling, in a variety venues. He worked hard. He does not know the Boy Scout, 4-H, special events, family picnics, Kodak moments and typical childhood experiences he missed in order to grab those opportunities.

Now to funding opportunities. I must point out that services were not given freely, nor by a few phone calls. In some cases I had to travel to appeal a service reduction, forsake college funding for my daughter in order to hire an attorney to negotiate services with our district, pass on career options, and wake extra early to keep speech therapy progress momentum going. This is not unusual for families or clients I serve. It is so common as to be ordinary.

As is the case in many public schools, most students do not get services without persistence and knowledge. As an advocate, I know that no one is calling my client parents offering them needed specialized services, or training a teacher to value inclusion, or providing parent training-- or I would have nothing to do. In 2012, I turned away about 10 families who wanted their child to have opportunity but were unable to afford my fee, and thus I sent them to the local non-profit agency, where they joined a waiting list for limited help.



I believe this is mostly, though not completely, because otherwise good people who are teachers and administrators find they are in the ethically uncomfortable position of finding that dismal IDEA funding does not allow them to provide an equal authentic education to all students with disabilities. Stuck between civil rights and awkward hidden reality, reality usually wins. So, unfortunately, as my Dad might say; *the squeaky wheel gets the grease*. And many parents are not comfortable being squeaky. So learning momentum is lost, as needs are not met, and future

doors of opportunity are shut, because fundamental skills were not taught; like talking, or reading on grade level, or working independently, or simply accepting a 'no'. This is the case in brick-and-mortar schools and Charter schools. I have clients in both.

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<sup>2</sup> In 2001, the National Research Council recommended "*intensive instructional programming for a minimum of the equivalent of a full school day, 5 days (at least 25 hours) a week, with full year programming...*" available at [http://www.nap.edu/catalog.php?record\\_id=10017](http://www.nap.edu/catalog.php?record_id=10017)

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Cal is now in 10<sup>th</sup> grade, at a private college-prep school, with a 3.7 GPA. on a college-bound track, with a few accommodations. He has aptitude and motivation. He is seeing habits like productivity open more doors. Cal only got there by a momentum of fortunate opportunities, persistence and help from many known and unknown people, his schools, and the Commonwealth. In this group of adults, I include those who came before you in your public service today, who looked beyond the needs of the day's budget and funded what was Cal's *momentum and opportunity*. They put services, training, skilled professionals and school resources in place so that he go far and as fast as he needed.

So now I'd like to suggest a potential solution that is universally useful to charter schools and traditional public schools alike. I ask you to consider funding so that schools can build staff, skills and resources up to meet the entire demand. Here is why; students with skill deficits are too often pushed through and not identified for services until their deficits become big and distracting to others. So instead of forward momentum, learners stall or develop other issues. These typically include challenging behaviors due to frustration with failure or being unable to read on grade level, anxiety, poor coping skills, being overtly bullied or quietly ignored, unable to keep up with the pace of instruction, being given 'dumbed-down' work.

These problems should trigger an evaluation by a public school or charter school.

Too often however, that evaluation effort and document is anemic and vague, even as IDEA insists it be robust, full and individualized. As an advocate for the past eight years, I find this... common. I believe that this is because school staff are expected to serve their already full caseload of students, and also evaluate the steady stream of new students who are entering school with potential needs, with no additional help, time or training.

Thus, again, otherwise good people compromise quality in order to a report done in time. The funding makes it unrealistic to do what is actually needed or what science finds is effective to close a gap or build a skill. And parents, having just been dipped in the confusing world of LEA, IDEA, MDE, PTRE, IEP, ASD, ER, OT, PT, SLP, AS and so forth, are still trying to learn the vocabulary, or are disheartened and resigned to the situation, not knowing what else to do. They are not remotely prepared to suggest the evaluation missed something do not know that advocates like myself exist and school will not likely tell them. Any momentum assuredly stalls.

Meanwhile please know that there is limited help elsewhere. Parents here in Berks run into three to six month waiting lists at local hospitals, a nine-month wait down at CHOP in Philly unless your child is under two, and insurance may limit therapy to 10 sessions per year, like ours does. In addition they may discover confusing criteria applying for Medicaid. Later, they may well discover that no local providers accept new Medicaid patients. Or, in the case of one of my clients, they discover the closest speech pathologist is sixty-five miles away. Or the school therapist goes on maternity leave and the school does not fund a substitute for her. Momentum stalls. In other words, it is highly likely that a publicly funded school may be the only source of *any intervention* for a child with a disability affecting

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learning. The National Research Council notes; *“Education, both directly of children, and of parents and teachers, is currently the primary form of treatment for autistic spectrum disorders.”*<sup>3</sup>

Improving the Commonwealth’s financial commitment to schools, both public and charter, could create an avalanche of opportunity from the beginning; the evaluation, through to the critical services to follow; momentum that promotes future opportunity. It is perhaps the first barrier to equal educational opportunity for a young learner. I believe funding education of all stripes will allow more professionals to be hired, trained to best practice, and thus able to serve students early, often, and as needed.

Thank you again for the opportunity today.

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<sup>3</sup> National Research Council. *Educating Children with Autism*; Washington, DC: The National Academies Press, 2001. Available free online at [http://www.nap.edu/catalog.php?record\\_id=10017](http://www.nap.edu/catalog.php?record_id=10017)