

In 1977 during his last speech, Vice President Hubert Humphrey, "...the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life; the sick, the needy and the handicapped."

If this is how Pennsylvania was to be measured on our morality and our greatness, then we have failed. My name is Lisa and I am a proud Pennsylvanian; my children are the 4th generation in my family to be born, raised and educated in Pennsylvania. It is because I love Pennsylvania so much that I am here today to speak to you. Because I want to make PA better for my kids and for all kids.

This is my son Kevin. I generally don't like to introduce him to people by listing all of his disabilities and shortcomings, I prefer to focus on things like his warm smile, how he loves to visit Sesame Place and his love for chocolate milk and swimming. But for the purposes of today's meeting, I want to share with you some of our struggles. Kevin has a chromosome condition called dup15q. His random genetic mutation is just that—extremely random. There is nothing his father or I could have done to neither cause it nor prevent it; it just happened. As a result, Kevin has autism, has intellectual disabilities, and is non-verbal. He has cortical visual impairment, which means that his eyes work fine; his brain just doesn't do so well at interpreting the message. His hypotonia and poor motor planning is just fancy terms for being clumsy, which by itself would be ok, but he also has a high pain threshold and other sensory processing issues which makes his clumsiness very scary for me. He is independently mobile, but overall, unfortunately, he's very low functioning and participates in very little of his own self care such as he cannot fully feed or dress himself. Still, I can't imagine life without him.

Despite all of Kevin's developmental challenges, I don't consider any of them to be my biggest challenge. My biggest challenge is dealing with the school district to get Kevin the services he needs to be as independent as possible.

As a parent, I would do just about anything to not have to hang all my hopes and dreams for my child on one document, his IEP. I wish it wasn't that way, but those are not the cards I was dealt. His IEP is his only chance at normalcy. If we don't accomplish what we need to accomplish in the next 14 years, that's it. I'm already counting down the days until Kevin turns 21 and ages out of the system. Special needs parents aren't allowed to just cherish every day and every new skill. Because with our kids, the clock is ticking. The bus stops coming at age 21. We have to get in as much learning and teaching as we can, and the odds are stacked against us.

I have behavior specialists in my home every day until 5:30. He does outside therapies paid for by our private insurance and other activities paid for out of pocket. According to Autism Speaks, the average family with a child with autism spends between \$7k and \$10k annually on services for their child. We are doing as much as we can on our own.

But by and large, I have to depend on the school district to do what he needs, because that is where he spends over 30 hours a week.

This past summer, I went to the National Autism Conference organized by Pattan and PDE. The message that was given by the experts in the field was loud and clear: Autism is a public health crisis and it needs to be treated as such.

In every conference session, the experts talked about Evidence Based Programming and how we have the data and the science today to give these kids what they need. While it was encouraging to hear about what is working out in the field, I left the conference with more questions than answers, and wondering where the disconnect is. If PDE is touting evidence based programming in the schools, why aren't we seeing it? A recent Upenn study tells us that less than 40% of our schools are providing EBP with fidelity. Why is it such a struggle to get the schools to commit to providing this...as the law says they should?

It can only come down to one thing—money. Money is the big pink elephant in the room at every IEP meeting. I know, you know, and the schools know it. They don't have the money to provide what our kids need. Look, I understand the history. I know that IDEA 1975 was never a fully funded mandate. Diagnoses of kids and need for special education has skyrocketed in the past couple of decades, while state and local funding have decreased as well. Everyone is asked to do much more with less, and it's our kids that are losing.

When Kevin was age eligible for preschool, I learned about the PA Verbal Behavior Project. I was so excited to learn that one of their classrooms was very local to me. I couldn't gather his IEP team fast enough to get him placed there. They did ABBLES, VB mapping...after everything I had read about evidence based programming, I was finally hopeful that we would see some significant progress with Kevin.

My hope was short lived. The classroom, while brand new, had 13 students of different abilities in it. Even my other son's regular preschool never puts more than 8 in a classroom, let alone more than 8 all with special needs! There was 1 teacher and 3 aides. Three students, including my son, had full time TSSs with them. Add in the various OTs, PTs, and speech therapists and vision teachers that came in, and it was nothing short of a circus. If you know anything about what ABA teaching is about and how to do it successfully, you'd know that it couldn't be successfully done in an environment as busy as a train station. The room was so chaotic and crowded and busy at times, Kevin tripped over a chair and fell, and it required a trip to the ER to get stitches in his head.

This is the type of situation is not uncommon. Parents are promised one thing, and then the execution is totally different. A program like this—something we know that works, was fully supported by PDE, BSE and Pattan...where did it go wrong? It comes back to money. I'm sure it was money that prevented the classroom from having fewer students in it. A knowledgeable but young teacher did not want to make waves, so she didn't speak up and ask for help. Or, maybe experience had taught her that there was no help for her if she asked—she just had to make do. Whatever it was, those kids were all short

changed, and the burnout rate for teachers in this field is incredibly high. Can you blame them?

And after seeing all the data at the conference this summer—showing us how when it's done right, it really works. It has left me wondering how much time was lost? How much further along would he be if he received the right programming during his preschool years? How much longer are we going to let our kids, our teachers, our schools, and our society, just hobble along, hoping for the best? When are we going to find adequate, long-term solutions to these issues?

Changing the funding structure is a great first step. But we all know that there isn't enough funding and we need to make that a priority too. More than anything, I wish that my son got on the regular school bus and went to the regular school and sat in the regular classroom with his peers. I don't know of a single mom who first heard those words "your child qualifies for special education" and did not burst into tears. But those are not the cards we were dealt. We have a moral and societal obligation to help our most vulnerable citizens, those who cannot champion for themselves. Our kids have much value to offer society, if they are just given the chance and the resources that they need to be successful.

I'll close with one of my favorite quotes, by Maya Angelou: "When you know better, you do better." We know better—we know what it takes to do right by these kids. It's time for us to do better.