Melissa Suarez, Parent

Testimony for Councilperson Johnson’s Early Childhood Education hearing

10/17/2023

Good morning to all the public servants of the city of Philadelphia, thank you for your attention, and open mindedness this morning as I share with you a difficult journey our family has had to endure in part because the system we have in place is broken, and I need your help to fix it.

My name is Melissa Suarez, I am a mother of 3-boys (one set of twins who are 11y, and a son who is 7y). We live in Northeast Philadelphia, I have lived here my entire life, my children their entire life as well. I was raised by a grandmother who had an 8th grade education and my grandfather who was a firefighter in our great city.

I’m here to share some of the frustrations I’ve experienced as a parent of three wonderful boys with individualized needs and supports.

My first experience of navigating resources for special needs kids came when my twins entered PHLpreK. Within the first two months of preK their teacher suggested they be evaluated by Elwyn-Early Intervention for special education services and extended community and home supports. She also suggested that we seek out support from CBH. I wasn't entirely sure why we needed both. Later on, I was grateful for the suggestion.

What we would later understand was the waitlists for services in both systems were excessive. We were fortunate our one child took six months, the other 4 months waiting time for just their evaluation–this did not include the 60 days following the evaluation where the report was generated, and later discussed. Our last child had to be evaluated at Drexel, because the insurance barriers and wait lists were not fast enough to address the needs, which we saw were escalating.

In one year, all three had diagnoses, and again we were made to wait for providers to be available to provide the services that they were found eligible to need. The services were poor, if they happened at all. The quality of the providers was more than disappointing. ***I was accused of “making my son autistic” and was threatened with DHS calls to report Munchausen by proxy. This type of insult happened frequently.***

During the pandemic I would joke about having received a “promotion” by now being responsible for providing speech, OT, PT, education, ABA, develop programming, create and laminate pictures, and programming aids. I also became the services coordinator, educator, and also the person who provided all of the services. All of these positions I supplied three times over for THREE children.

I cried a lot. I felt abandoned with no support, no break or time to recoup. It was constant, and intense. ***I thought I was failing, and the weight of failure for me and them set me into my own depression.***

My youngest began self-injurious behaviors, and neither his early intervention team, nor his behavioral health team were there to support us. The depth of defeat, and fear that runs through your core to watch your child harm themselves, and not know how, or when it would end was the most painful experience to have ever endured. We eventually pulled him from pre-K because we couldn't trust Elwyn or Medicaid to be able to support him appropriately.

We later found ourselves being the referee between the two systems because they would NOT collaborate. Elwyn did not communicate with CBH, and CBH would not communicate with Elwyn. Because we were still so very new to these systems, we would frequently get them mixed up and have to retrace who was serving who from which agency. It was an all-consuming task for anyone, but suddenly, I was being asked to fulfill all these roles simultaneously, without support, or training.

I had to master the complexity of special education, early intervention, transitions, autism, learning disabilities, sign language, and ABA (applied behavioral analysis). If anything went wrong (as it often did) it would take considerable time away from my family which was already scarce. This meant that I had to compromise some other needed area of my life, or put aside one child’s needs for another. We were always trying to balance ourselves to keep from crisis to staying afloat.

I didn't realize that the period from age 0-5 yrs. old was a “critical window” that set the stage for children. I only became aware of this because at 3 yrs. old my youngest wasn’t talking yet. Our trust in a system to help our child had let our family down.

Educators and providers need to do better together. We all have to be partners in order for this to work. We need more robust child find systems. We need greater supports and availability of those supports EARLY before our window of opportunity closes.

AS Philadelphia embraces new leadership, I urge City Council to work with the administration to make sure all the entities providing early intervention care to work collaborate. We need leaders working together, who are committed to creating systems that support us. We cannot bear more systems that make us feel like we are in constant combat with them –and this must come from collaboration between all stakeholders. Yes, including parents.

I urge City Council and the new administration to conduct an official, comprehensive assessment of the early intervention system so that we can have a system that not only offer children brighter futures, but allow parents to rest at ease in faith of what these systems offer.

Thank you.