

My name is Rosemarie Mann. I reside in Lancaster County. I was a registered nurse, former founder and president of Na'eem's Dream, former President of the board of directors of the S. June Smith Center. I have served as a special education parent advocate for Pennsylvania Education For All Coalition, family advocate on the State Leadership and Management Team for System of Care, and a member of the Pennsylvania Citizen Review Panel and Families and Communities United Committee.

Locally, I was co-chair of the Lancaster Community Partnership for Community Wellness, and a member of Lancaster Communities That Care grant committee.

My husband is Dr. Donovan Mann, Director of Secondary Education at Conestoga Valley School District.

I want to thank Chairman Eichelberger, Senator Aument, and fellow committee members for allowing me to speak today on Education Savings Accounts. Education Savings Accounts would offer parents of children with IEPs the option of withdrawing from the public school district and being given a percentage of the per pupil cost to be used on private school or home schooling expenses.

All of my previously described positions are in the past tense because I currently serve in my most challenging position, mother of 5 children. Our children range in age from 9 to 23 years. Our three youngest children are all school age boys, are all adopted, and all have special needs and qualify for special education supports and services.

Why am I supporting Education Savings Accounts? Parents of children with special needs (hereafter called *parents*) are parenting children with varied and complex challenges in highly unique environments and with differing knowledge, resources, and goals. Education Savings Accounts would allow parents to have more flexibility over how their children achieve academic progress, social emotional growth and maturity, and are empowered to pursue their passions.

Na'eem is our youngest child. He was born into difficult circumstances. At 10 months of age he sustained a near fatal brain injury, bone fractures, and other injuries requiring emergency treatment. He endured numerous surgeries and procedures to save his life. After 3 months in the hospital, he was discharged into our care as a foster child. Needless to say, he came to us with many physical, emotional, and cognitive challenges. Challenges we never imagined.

Based on the brain injury, Na'eem qualified for early intervention supports and services through the county, and later qualified for special education supports and services through the intermediate unit and the school district. He received what he was eligible for through EI including speech, occupational, physical, and behavioral therapy as well as special instruction. He started preschool at the age of 3 and received the additional support of a full time personal care assistant during school hours. He underwent evaluation at the Hershey Medical Center Attention Deficit Disorder Clinic, as well as psychological evaluation with CCIU and received what the mental health system was able to provide. This included the provision of a Behavior Specialist Consultant and 40 hours a week of Therapeutic Support Staff.

During this time, Na'eem's seizure activity escalated. Medicaid insurance approved medical day care so that I could continue working. Na'eem's education plan became more complicated when concerns were raised about the increase in seizure activity and the possibly of requiring 1:1 medical staff during school hours.

It seemed as if the services our son was eligible to receive were numerous and addressed global rehabilitation, academic, as well as physical and mental health needs. This indeed was true. What was the outcome of these numerous and global services? Community preschool expulsion, segregated preschool withdrawal, inconsistent academic and social emotional progress, and mental health crises. I had to stop working, completely.

Why these tragic and traumatic across the board failures with such a robust system of support? The system is required to provide what the child is "eligible to receive" and "what procedure codes will reimburse for." Parents are given a menu of services that a child is eligible to receive and are then told how and where these services will be implemented. The parent gives consent.

We struggled to overcome these failures prior to Na'eem attaining the age of beginner and being required to attend school. We worked with the school district and participated in an independent education evaluation. Dr. Anitha Weaver, pediatrician, Dr. John Beaver, pediatric psychiatrist, and Rachel Mann, Attorney at Disability Rights Network, worked along side our family to advocate for what our son needed versus accepting what the school was able to offer. We were referred to the county CASSP (Child and Adolescent Service System Program) coordinator who could guide us through the system. Through the same robust and globally focused system that lead to our failures.

The issue was not that the services were unavailable or he was not eligible. This issue was not the lack of funding. The issue was not a lack of ability to navigate the system. The failures were based on:

1. wrong environment - our son could not tolerate the stress that accompanied either an inclusive public school placement or even a segregated placement. The district refused home bound instruction due to the high level of segregation and how that would impact their Penn Data.
2. too many supports delivered by too many professionals - our son could not trust even his closest family members. How was he to trust the 8 (at a minimum) clinicians and professionals that he would be required to interact with on a regular basis?
3. lack of flexibility in use of resources- Na'eem needed a sense of safety, trust of the professionals, and an academic program imbedded in a therapeutic milieu. He required the right services, in the right intensity, at the right time, in the right environment, delivered by the right person. The district offered several environments, offered 1:1 teacher ratio, and comprehensive related services. Unfortunately, these well intentioned, evidenced based, and expensive strategies were not going to meet our son's primary needs at the time.

We made the decision on March 27, 2015 that we would home school our son, and provide privately funded supports including psychotherapy and psychiatry both specializing in early

childhood trauma. I would be not only the home school supervisor, but also the rehabilitation therapists, therapeutic support staff, personal care aide, and nurse. I was not employed so this created a financial hardship for us and our debt increased due to the cost of education supplies and curriculum. The situation also took a toll on our family as a unit.

Today we look at the sacrifice and feel it has been entirely worthwhile as we see the successes our son achieves on an almost daily basis. To put it in the words of our special education evaluator with over 20 years of experience, "Never have I seen a family continue to make as much sustained progress as again demonstrated by the Mann family."

Educational Savings Accounts will offer many more parents the opportunity to increase their meaningful participation in the education of their children. ESAs will increase the flexibility to use education funds in more strategic and effective ways which improves outcomes and saves money. Most critically, ESAs will avoid students falling through the cracks, avoid possible family crises, and foster self efficacy and hope.

We also have 2 other sons with special needs. Ian and Jacob, both 11 years old and both diagnosed with Down Syndrome. Both Ian and Jacob attended public school starting in kindergarten in September 2011. It was not an easy start with lots of bumps and curves including transfer to a different building and a need to change case managers. Despite all of this the boys were beginning to make consistent progress especially with the passion and dedication of the new case manager.

In September of 2014, Ian began to have an escalation in behavioral issues included eloping from the school building. His attention and ability to remain focused decreased. We soon learned that his behaviors were related to a medical condition, Grave's disease. The school setting in which he previously was successful became too stressful due to the effects of the Grave's disease. For the 2014/15 school year Ian made minimal progress and lost his self confidence, and playful nature. His communication skills decreased.

Due to the Grave's disease and Down Syndrome, Ian required eye surgery in October of 2015. His surgery resulted in severe swelling and redness of his eyes for a period of several months. His brother Jacob was very concerned and felt a sense of responsibility for Ian's eye inflammation, "I broke Ian's eyes." Clearly Jacob had no responsibility for Ian's condition, nor did Jacob have any responsibility for the condition of his para-educator. His para educator failed to return to school in September, and when she returned in October of 2015 she was using a walker. Jacob's understanding, "I broke Mrs. Brown." Jacob's behaviors began to escalate. He was refusing to work, lying on the floor, refusing to leave the bathroom stall. At one point he remained in the bathroom stall for 2 1/2 hours. His communication skills decreased.

For both boys the school setting had become too stressful. Too stressful for Ian due to his medical condition, too stressful for Jacob due to his anxiety. Both boys were failing in the environment of the public school setting. Their failures were not due to ineligibility, nor a lack of availability. Their case manager was smart, passionate, and dedicated and attempted to provide support. However, in the public school setting a teacher cannot offer individual student support, and a sense of predictability and safety can not be guaranteed. So what happens to the right services, in the right intensity, at the right time, in the right environment, delivered by the right person?

Stress and anxiety have proven to be factors in academic progress. In Ian and Jacob's situation, ESAs would have allowed us to withdraw the boys from the district to an environment that would be less stressful, offer the predictability and safety they required, and avoid the regression in skills, behavioral escalations, and sense of failure they experienced. The ESA funds would have allowed us to continue to provide the right services, at the rightly diminished intensity, at this time of increased stress and medical complications, in the safety of our home by a consistent and trusted person.

ESAs offer this flexibility for long term planning for students like Na'eem, and also support in times of stress and crisis such as experienced by Ian and Jacob. Families would not have to worry about making the right choices for their children's educations because of lack of funds.