

Brenda Eaton Chester County Intermediate Unit (CCIU) Autism Alliance of Chester County Parent of 2 children with autism

In my role at the CCIU, as the Autism Network Coordinator, I work to help support professionals and families as well as develop programs through the blending and braiding of systems.

This legislation will provide families an opportunity to plan ahead for their special needs child. The devastation that can come with a diagnosis of a special needs child can be overwhelming for parents and can be rot with denial, stress, marital and family problems. As a family learns to cope, and as the child grows and develops, the family must learn to understand the serving systems that support their special needs child, in the hopes they are meeting their needs. To often, families are caught off guard.

- While education is responsible for the development of a transition plan that can start as early as 14 years of age with an IEP (Individual Education Plan), many professionals become aware that families are not knowledgeable about what to expect with adult systems. Many do not know what to expect after education, when their child turn 18 years of age, or if the child stays in education until they are 21 years of age. Many may have hopes of job placement, or college, but find that the necessary supports need to make their child be successful in these goals are out of reach.
- In the existing system of Mental Retardation (MR), if a child with special needs has a diagnosis MR, this qualifies the family to enroll their child in the Mental Retardation System. This will qualify their child for services provided by MR. Many families don't understand that just having a diagnosis of MR does not put you in the MR system. They must call the MR office and provide proof of the diagnosis in order to benefit from the services provided by the MR system. They then can work with a case manager who can help them navigate the system processes.
- If a special needs child has a diagnosis of autism (as 1 in 150 children have an Autism Spectrum Disorder), but does not have a diagnosis of MR, once the individual leaves the education system, they are on their own- left with no options for programs or supports. Many concerning behaviors can exist, comorbid conditions, environmental concept issues and communication problems can arise that may lead to encounters with law enforcement, all with nowhere to go for treatment. Some may end up in the Mental Health System where professionals are not expected to have the expertise to treat such individuals.

- Waivers- Pennsylvania is one of a few states that have a high number of waivers options. For those who have a diagnosis of Autism, hope exists for a waiver for individuals with autism through the newly formed Bureau of Autism Services. But the reality is, there is not enough to go around. Families can't plan effectively for their child's future on the hopes they will be moved off a waiting list or qualify for a program or waiver.

With this legislation, families can start planning for their child's future at an early age, even if they are unsure where their child's ability level will be when they are an adult. Families need hope and encouragement, to feel productive toward their child's future. The security of having money set aside for a special needs child will help families fell more confident and productive through their journey, of their child's development, as they become an adult.