

**Public Testimony -Special Education Sub-Committee , Barbara McElvaine-Smith, Chair
April 8, 2008 205 Ryan Office Building, Harrisburg, PA - Informational Hearing on Post
Secondary Transition for Individuals with Autism Spectrum Disorder.**

Submitted by Gloria M. Satriale, Esquire

1.) Introduction

Good morning, Madam Chairman, and fellow Members. I and the constituencies I represent are very appreciative of the opportunity to offer my perspective regarding the process of transitioning from the systems impacting a young adult (MH/MR, behavioral health, educational) into the adult world, the very different nature of these systems, and the difficulties faced during this process. I am grateful for your interest in this growing crisis. It is my hope and my expectation that you will conclude from the testimony that you have gathered here today that the Special Education Sub-Committee will forthwith establish a platform that will fortify existing transition services. A platform that will:

- add services, which clinically and competently transfer the skills learned in school to the community at large.
- add case management services to allow for the planning necessary to seamlessly transition into the adult world.
- **develop programs and services for these young adults to** actually transition to.

My name is Gloria Satriale. I am a practicing attorney by trade, and mother of five children ranging from 5 to 18 years of age.

I have been a member of Chester County's Mental Health/Mental Retardation Advisory Board for over 8 years and for the past 3 years I have served as Board Chair. I serve as President to a non-profit organization, Mission for Educating Children with Autism (MECA). For over a decade MECA has helped individuals with autism reach their fullest potential as productive, socially connected and personally fulfilled individuals by providing the support necessary to establish appropriate educational and community programming in the least restrictive environment possible and through raising community awareness and acceptance of autism.

Over ten years ago MECA co-founded an elementary program for children with autism. This program continues today as one of Chester County's preeminent programs serving over 50 children.

Two years ago, MECA co-founded, Preparing Adolescents for Adult Life (PAAL), a specialized transition program for individuals with autism. The PAAL program gained wide spread acclaim in a short period of time through employing innovative instructional strategies and through its focus on intensive immersion in the community. I have attached to my written testimony, informational materials on the PAAL program as well as an example of recently published research produced by myself and my colleagues at the PAAL program.

I also currently consult for the Chester County Intermediate Unit on Transition and Community Coordination Issues. Of particular relevance in that role, I wrote and administer one of the only 6 Special Education Performance grants on Transition recently awarded across the Commonwealth. I have also recently begun work with the Office of Dispute Resolution in the capacity of a due process hearing officer and an alternative dispute resolution trainer. Lastly, and most importantly, my son Nicholas is 16 and is significantly impaired with Autism. The purpose of this *CVesq* introduction is to highlight my unique synergy of experiences that have informed my understanding of the current state of transition planning for individuals with autism and their families on an individual and systemic basis. **The most critical barriers to effective and cost-effective transitioning for young adults with autism is the near total absence of a “bridge” between the educational years and adulthood and the simple fact that after graduation there is nothing for this critical bridge to connect to.**

2.) The Intent of the Transition Process –The Existing Gaps and the Lack of Post 21 Services

Transition. The process is designed to *prepare adolescents with autism* for life beyond the age of 21. In other words, the purpose of transition planning is to prepare these very complex learners for adulthood as **active and** participating citizens of the Commonwealth. Prior to 21 **-years of age**, the service delivery system is a *child serving system*. Because of the supports within our child-serving system (BHRS), complimented by education and IDEA dollars, we are doing the *preparing* piece pretty well these days. At least in some places, the **educational** transition *process* is individualized, comprehensive, intensive and implemented well. The challenge comes when individuals and families are faced with the fact that there is *nothing* for them to transition *to*. Sixty percent (60%) - *sixty-percent* of *all* children with a disability served in Chester County are children with autism. **This means that sixty percent of Chester County’s most vulnerable students and their families** will *not qualify to continue services post- 21*.

Obviously, some post-21 supports do exist as potential “transition to” resources. For those supports that do exist and for the “populations” for whom they serve (primarily those with co-occurring diagnoses of mental retardation or with serious mental illness), your investigation and analysis would look to the sufficiency of these programs as you have heard from many

today. Are there enough of them? Do they provide these populations with ample opportunity to live a life of dignity and quality - jobs, recreation, faith opportunities? I would trust you would be able to answer these questions in the affirmative. But for some populations including those with autism; these supports simply DO NOT EXIST.

Very plain, very simple, very clear. *Following their 21st birthday* individuals with autism *do not qualify for the supports, services, or interventions the child-serving system has afforded them their entire life up to that point. But at 21 their needs have not magically changed nor has the diagnosis gone away; it is just another birthday and a scary and sad one at that. In a system based entirely upon medical necessity, a birthday should have NOTHING to do with continued eligibility for services.*

3. The Current Status – Why we have Gaps in Service or No Services at All

How could this happen? Why did this happen?

Remember: It is only a mere 40 years ago that we began to understand this diagnosis. For 20 of those years the diagnoses of autism, was in many cases, a one-way lifelong ticket to institutionalization. We are actually, relatively speaking, “new” at this. Yes, we now know autism is a life long disability, but, although it is not a childhood **disorder** that can be “fixed” or that you “grow out of”, we have learned that with the proper, lifelong services and supports individuals with autism continue to learn, continue to grow and can live as involved and productive adults, at home and in their communities.

Remember: It is only a mere 14 years that we developed the child serving system that has engineered the interventions and supports that have kept these children at home with their families *instead* to going to the institutions. The Mental Retardation Act of 1966, protecting the needs of individuals with Mental Retardation has been around....well since 1966.

Remember: The only comprehensive system ever developed to date to deal with this LIFELONG disability, is a system that only serves children.

Remember: The incidence of autism has exploded from 1 in 5,000 to 1 in 150.....1 birth in every 150. Staggering - Scary.

Our current status of gaps within the system or the lack of services is not our fault. What we are realizing now is that the children we saved as children are now growing up. It is the natural progression of things that the need to now plan and establish other systems for them now hits the radar screen.

4.) Suggested Solution – The Good News

So what do we do? What can we do? We actually already know.

Also very clear and, actually, pretty simple. I do not see your role as lawmakers to understand the intricacy and complexity of diagnosis, treatment, eligibility and appropriate and effective services. In fact, we have already figured out many of those things in the development and implementation of the BHRS services in the child-serving systems. We even have the positive outcome data showing us that these services *must* continue post-21. That's the clear part.

Here's the simple part: Amend The Commonwealth of Pennsylvania, Department of Public Welfare Mental Health Bulletin Number OMH 94-04 *to include the diagnosis of autism*. This Bulletin dictates eligibility for services *as an adult* in the Mental Health System. It is my understanding that this Bulletin also substantially drives policy development for eligibility for adult services in the Health Choices system. The diagnosis of autism qualifies under the criteria set forth in the bulletin, the bulletin simply does not specifically state the AUTISM word, and therefore services available under it are denied. Amending this bulletin to cover the diagnosis of autism is an immediate fix to the funding issue.

Next, the gaps in services and/or the development of necessary services are not an agency issue, a collaboration issue, or a systems of care issue. We have the expertise necessary for proper implementation. The successes of the PAAL program over the past two years have led the way to understand exactly what is necessary to allow individuals with autism to reach their full potential as productive, socially-connected, and personally-fulfilled individuals who are embraced by the community in which they live, work and worship.

The connection between our knowledge that *nothing* exists post 21 and the solution is to allow PAAL to become the pilot for the Commonwealth. A pilot which develops the proper cadre of transition services which seamlessly become adult services leading to a competent quality of life within the community as follows:

- Establish a platform to fortify existing transition services that includes additional services, which clinically competently transfers skills acquired within the school setting into the community.
- A platform to fortify existing transition services which will also include case management services to facilitate and provide the case coordination to identify available formal and informal sources of support, provide training and instruction to community stakeholders, and create and PLAN for the opportunity for students to utilize their skills learned in school to the direct benefit of themselves, employers, and community at large or, in other words, to be included, participating citizens of the Commonwealth PRIOR to aging out of Education.

- A platform that will take immediate action to initiate a pilot which develops a service model for Adults with autism that can be replicated across the commonwealth through an amendment to Mental Health Bulletin OMH-94-04

4.) **Conclusion**

We have, in many cases, very appropriately and very competently set our children with autism out on the road of life. The child-serving system has constructed many rest stops along the way to ensure that they get what they need to continue the journey and has provided the tools to prevent breakdown, but as individuals with other disabilities are cruising up the on ramp to the adult highway, individuals with autism are barricaded at mile marker 21. There is no shoulder, no detour, **and NO BRIDGE**. The infrastructure we have spent 15 years building turns out to be a road to nowhere. The expensive infrastructure will ultimately fail and the future of individuals and their families are, subsequently, damned to dependency.

According to Penn Data, the web site with which I am sure you are familiar as the data repository and reporting system of Department of Special Education, for FY-06 there were 3,020 school aged children (K-12) in Chester County alone with the classification of autism. Given a reported average expenditure of \$33,333/year for each learner in public education (and 55,000/year for each learner in a private educational placement) the expected cost of educating all Chester County Students with autism from the time they enter Kindergarten (remember this does not include the huge early intervention budget) to the time they graduate exceeds \$1.8 billion which, statewide with 60,413 learners with autism, equates currently to an investment of \$18.25 billion dollars. We have provided most of the component parts during the transition process to allow for a quality of life, but have failed to provide the framework within which the mechanisms can function. We have provided the opportunity within transition to commute a sentence of dependency and institutionalization to a life of quality within the community, but are failing to provide the supports necessary to continue the successes and gains. The supports they will continue to require to function in society, as adults will vary - but they will all require some degree of support. Take away the supports the child-serving system put in place and you take away the life you have given them - at a cost that could, potentially, cripple all other systems.

Last week, at the first-ever conference hosted by the Speaker of the House, attended by the Chair of this committee, I could not control the silent flow of tears. Tears for the mothers sharing their stories of their sons of how they almost made it. Of how there was purpose and meaning and happiness in the lives of their sons and hence their families as their sons held jobs and participated in the community during those last few years of transition. Happiness and release for the family itself. But then the School bus stopped coming. There was no where to go, no one to help sustain everything that was good that took so many years to establish and so

much effort and so much money to put firmly into place. As one mom, Cindy Barimani, said, it seems that our children have gone from taking the bus to being thrown under it.

Chairman McElvaine-Smith, Members, you can help build the bridge. The bridge to a positive, successful adult life for these kids.

Thank you.

Respectfully submitted,

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