

**House Human Services Committee**

**Public Hearing on the Adult Disability Services System  
in Pennsylvania**

**April 16, 2015**

**Testimony of Martine De Lorenzo  
Parent and Community Advocate**

**Disability Rights Network of Pennsylvania  
Offices in Harrisburg, Philadelphia, and Pittsburgh  
[www.drnpa.org](http://www.drnpa.org)**

Thank you for this opportunity to testify. My name is Martine De Lorenzo. I'm the single parent of five boys. Three of my sons are still in school, and I am their sole source of support. I worked part time for 10 years for the Disability Rights Network of Pennsylvania and recently accepted an offer of full-time employment there. I'm here to talk about my family's experience waiting for services.

My son Anthony was born in 1994, developed seizures within hours, and was placed on life support. His doctors were hopeless that he would recover. I was prepared for him to die and removed him from all the machines that were keeping him alive. Only he didn't die. I was assured he was in a vegetative state and should be placed in an institution. I was told he'd never walk, never talk or eat, was blind and deaf, and wouldn't recognize me. Every day I went to that hospital and insisted I was taking him home until they finally stopped arguing and released him. Our lives were then filled with years of therapies and hospitalizations, not only to keep him alive and well but to give him the same opportunities as his brothers. I fought our local school district over and over again to educate him in an inclusive setting, despite his profound disabilities. In the very same classrooms as his typically developing peers. I appealed to our Senator to force his insurance company to pay for an out of state hospitalization for intensive therapy.

None of this "cured" him, but he made progress no one had ever expected. He's always a curiosity for physicians who are shocked when they come upon an MRI of his brain because it still reads like that of a person in a vegetative state and clearly he's not. He has a great personality and a fantastic sense of humor. When he was little he laughed so much I was convinced there was something else wrong with him but his neurologist assured me he was just a happy kid. Anthony does have an intellectual disability, a seizure disorder, and a swallowing disorder. He needs a wheelchair for long distances, he has trouble with depth perception, and his speech is not understandable, which leads to behavior issues. He has a co-occurring depression that requires medication. He's not toilet trained. But because of his inclusion in that typical classroom, Anthony taught himself to stand in kindergarten by watching the other kids and with therapy learned how to walk in first grade. He no longer needs a feeding tube and eats a

pureed diet. He understands people speaking to him and uses a combination of sign language, gestures, and a Dynavox to express himself.

He's come so very far, but he still needs total care. When he was little, this was easier. We took turns feeding him and carrying him and bathing him and changing his diaper. As he grew, it became more and more difficult. When he went through puberty, he developed depression. There wasn't an appropriate Extended School Year (ESY) program for him. He was headed for high school, and our local school was refusing him entry. He was home from the time he graduated 8th grade in June until January. I had to file for a due process hearing to get our local school district to allow him a Free Appropriate Public Education (FAPE) in the least restrictive environment. Because he had been home all day with nothing to do, his depression became so severe that he wouldn't bathe or even get out of bed. By the time he attended school in January, I was now dragging him kicking and screaming out of the house in the morning to the school bus.

He was physically aggressive towards me and his brothers. His behavior was interfering with my ability to work, and I was the sole financial support of our family, working several part-time jobs to keep a roof over our heads. We had to make terrible choices. If he wouldn't go to school, his little brother would have to stay home from school with him so I could work. After I broke down in his pediatrician's office, the doctor arranged for staffing in our home paid for by his Medicaid. With someone to stay with him, Anthony didn't always get to school, but his brother did and I could work.

After finding good psychiatric care and behavior support in our home, Anthony slowly recovered and found happiness in school once again. He graduates this year from a vocational program where he learned how to cook and bake. Unfortunately his education was not without struggles, and again I filed for a due process hearing. This time, he received a settlement that enabled him to obtain a neuro-psychiatric evaluation, an evaluation and purchase of an appropriate communication system, and enough funding to spend his summers with a job coaching agency instead of being babysat in ESY. His transition to adult services didn't begin until he was 18. He still has had no Office of Vocational Rehabilitation (OVR) assessment.

No one from the school has approached me about what he'll be doing when he graduates.

His insurance company has been calling me for years, every six months, reminding me to have his Prioritization of Urgency of Need for Services (PUNS) up to date and to apply for services. I was told to be sure I was on the "Waiting List." They even suggested that I apply for waivers for him for which I know he doesn't qualify just so he could have "something." They reminded me with each of these phone calls that his services would be ending when Anthony turned 21 on March 29 of this year.

Though they didn't know it, because I am an advocate, I am well aware of the process to apply for waiver and the bureaucracy surrounding it. Not that my position made it any easier. We have been in close contact with his supports coordinator for years, and his PUNS had him listed in the Emergency category as it should. His supports coordinator gave me a list of items he'd need for the application, and I provided everything for which I'd been asked. They submitted the paperwork to the Administrative Entity (AE), but there were no assurances. I contacted the Office of Developmental Programs (ODP) regional office to ask about funding for children transitioning to adulthood this year. I was told there wasn't any funding put aside. The supports coordinator sent the application to the Administrative Entity, which responded that there was no funding. The supports coordinator pressed further. The Administrative Entity suggested there MAY be funding for the Person/Family Directed Support (P/FDS) Waiver. Anthony has at least 53 hours a week of home staffing, not including the time he is in school. He received behavior support in our home. In June, he will graduate from high school, and I expect him to contribute to society and WORK. For this he will need staffing and transportation. The P/FDS Waiver doesn't even begin to cover his needs. The supports coordinator told the Administrative Entity he needs the Consolidated Waiver. As if his needs were not clearly outlined in all of the evaluations and reports, his Individualized Education Program (IEP), his Individual Support Plan (ISP), his physical, and more, the Administrative Entity again offered the P/FDS waiver. The supports coordinator reminded the Administrative Entity that Anthony needed 24/7 care with feeding, bathing, toileting and medication, behavior support, and a job. The supports coordinator reminded the Administrative Entity that I, his mother, was not

available to care for him due to my job and that we have no natural supports available. His father is not a part of his life. We have no family or neighbors on whom to rely. We have no time to develop these relationships because every waking minute that I am not working, I am caring for my son. The Administrative Entity wrote back that the supports coordinator should be focused on Anthony's needs rather than the needs of his mother. I need to work, and like any parent expect my son to have a life with as much independence as possible where he is a contributing member of society. I did not spend Anthony's entire life advocating for an Everyday Life for him only to watch him sit at home losing all the skills for which he's worked so hard. I cannot bear to think of him lying in bed again, despondent, and crying all day in the grips of depression.

Anthony knew his birthday was coming, and he was beyond excited for months prior. The pleasure that he enjoyed was in complete contrast to the agony that I was experiencing wondering how I would be able to work, or if I couldn't, how I would feed my family or keep our home, wondering if he would finish his school year or have to stay home alone.

The supports coordinator was relentless, and literally two days before his 21st birthday, Anthony received a letter stating that funding was available for the Consolidated Waiver. Lest you think this is a happy ending, I will assure you it is not. The transition has been anything but seamless. Anthony lost his behavior support, there was no time to transition to a new provider, and no time for his old provider to get qualified without assurance of funding. He cannot use the job coaching agency until OVR does its own assessment. There is no longer time to arrange a work/school schedule that will transition him to employment in June. He risks sitting at home regressing. His Support Intensity Scale (SIS) assessment isn't scheduled until late April. The Administrative Entity sent me a list of paperwork, proving that he has a disability, to be sent to it by April 26th. This list includes each and every item that has already been provided to it in the waiver application.

Due to his behavior with me, Anthony requires a residential setting. Finding an appropriate provider with an opening is difficult and time consuming, and this search cannot begin prior to his actual waiver approval, which is unlikely to happen before May.

Although he was entitled to institutional care, Anthony has been cared for by his brothers and me at home and in the community his entire life. We have saved the Commonwealth countless dollars. It's shocking to think that after 21 years, the process for transition to adulthood would be so fraught with red tape and pointless hoop jumping and trauma. At least I am aware of his rights and able to fight for him. It's heartbreaking to imagine what other families are put through who may not have access to the information afforded to me.

Thank you,

Martine De Lorenzo

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