

Testimony of Pamela Novak
Before the Pennsylvania House of Representatives
Human Services Committee
November 18, 2013

Hello, good day to everyone. My name is Pamela Novak and I am here today to talk about my son, Jeffrey J. Novak. He is 16 years old and he is diagnosed with an intellectual disability, pervasive developmental delay, autism and epilepsy.

Jeffrey currently does not speak, but he is learning to use an I-Pad for communication. He attends Pittsburgh Public School's Pioneer Education Center for students with multiple disabilities. He is in a life skills program and receives physical, occupational and speech therapy.

Jeffrey has no safety perception or stranger awareness. He cannot take care of his personal needs independently. He has choking hazards and needs constant supervision. He takes seizure meds 3X daily.

We are here today because I am a single, divorced mother. I am the primary custodial parent and I have been trying to apply for

home health aides to care for my son while I work.

Jeffrey is on the emergency list for intellectual disability services, but there are hundreds of people in Allegheny County on this list. I have also been denied this service through the insurance company four times. Each time, I have provided all of the documentation, including letters from Jeffrey's physicians, that the insurance company has asked for and we continue to be denied. Their response is that a regular unskilled babysitter can care for Jeffrey.

I, as his parent, am trying to do my best to maintain stable employment, but I cannot do it without some help. I need trained people to take care of Jeffrey so that I can work. I have had to leave jobs due to a lack of child care. I have also had to incur very expensive child care costs through agencies whose fees have been \$21.00 - \$22.00 per hour. I make \$10.00 per hour.

I want to pursue a degree in nursing by going back to school in January, 2014. I want to provide a better future for me and my

son. I fear the worst for Jeffrey's future and others with disabilities who are facing these kinds of circumstances.

Please listen to my words today. I am speaking on behalf of my family and others. And, please support funding for the waiting list for people with intellectual disabilities.

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