

Sheila Stasko Director
Pennsylvania Waiting List Campaign
4540 Best Station Rd.
Slatington PA 18080
610-767-7635

Chairman Adolph and members of the Appropriation Committee, My name is Sheila Stasko, I am the Director of the PA Waiting List Campaign and mother to John, a 40 year old man who is the center of our lives. I thank you for the opportunity to present information on the Pennsylvania Waiting List for people with intellectual disabilities and autism who are waiting for community services and supports. My role is to share the human impact on people waiting. Not funding the waiting list will for one year will have dire consequences. There is a ripple effect that will be felt for those waiting for the next 3 to 4 years.

So what are all these people waiting for? Certainly not institutional placement! If that were the case we wouldn't have 75% of people living at home. People turn to the system when we reach the limit on how much our families can withstand. During the last year of the Rendell administration only 50 people were funded and no people were funded during the first year of the Corbett Administration. Two years of not being funded devastated the system. In over 20 years I have never experienced such anguish and turmoil. Families were leaving their son or daughter home alone without supports. They had to keep a roof over their head and food on the table. Some people rushed home at lunch so they can reposition their child who was laying in bed, Waiting. One family nearly had a disaster in when they returned home and found their gas stove turned on. Other families contemplated suicide. It's really tough to listen to knowing there's nothing we could do to help.

We always ask for funding high school kids, but what about the older caregiver? They keep on going and just make do, way past the time they should. I will tell you about the 80 year old care giver was using a regular kitchen chair dragged her daughter up the steps to her bedroom. Another mom had passed away her son put a pillow under your head and stayed with her for days before someone came. When visiting an older couple, mom came downstairs a stair glide with her son on her lap. Yes, these are extreme examples, however., it begs our attention. We must bring relief for the older caregivers who spent a lifetime of caring without any type of help or support.

Many of us have experienced the trying times right before our children graduate from high school. Would they go to college? A job? Or spend some time on the

couch? How would it change your life if that time spent on the couch took decades and you needed to be home to take care of all those needs? How would your son or daughter feel never participating in the community. Everything just stops. There are especially trying in difficult times families when the child graduates from high school, and when we come to the end of the road. One mom wrote me a week ago, She had two children ready to graduate and just discovered there was no funding for her children . She stated, "Please help me. I'm freaking out!" Jeffrey is from Allegheny County. His mom posted this on Facebook in March. "Dear adults with disabilities receiving consolidated waiver in Allegheny County. I hope one of you die soon! Do I mean this? Of course not . (typing it I felt vomit in the back of my throat) but only along with moving, nursing homes, death, is one of the three options or ways my 21-year-old can receive consolidated waiver. There has to be fourth option. Perhaps something along the lines of...Dear state of Pennsylvania the time is overdue for you to free up additional funding for waivers!! Please... enough time has passed for you to realize that there's a boom of your citizens with disabilities that have or are coming close to coming of age and needed this funding yesterday so their quality of life will not be in danger of dissipating once they graduate! Please... stop making the families of these individuals feel that the need of consolidated waiver for their own adult child with disabilities rests upon the "hope" that someone else's adult child dies. Free up the funds!

There has to be a kinder. gentler way of funding people. We have placed our facts before you and our suggestions. We hope that funding will be made right for this year and people who thought they would be funded, can be helped, We are asking:

- Re-instate this years waiting list initiative.
- consider a line item for the waiting list,
- create a dedicated funding stream,
- close expensive institutions that serve few,
- fund a high school initiative for 500K

The Pennsylvania Waiting List Campaign is very grateful for your support to address the waiting list and for the opportunity to place our issue before you.