

Dear Chairman DiGirolamo and Members of the Human Service Committee,

I am so pleased to have this opportunity to share this information with you. I am the mother of a man who is nearly 40, he has an intellectual disability, hearing impairment, limited and difficult speech. John is one of six children and 13 grandchildren and 2 great-grandchildren. I am part of the sandwich generation. My mother is soon to be 90, is in a memory care facility with severe Alzheimer's. John and I visit nearly every day and make sure she is protected and cared for. It is a different kind of life. Certainly not one we would have chosen. But, we love our family and we love our 40 year old man. Our lives would crumble without supports.

I am here because there are 14,000 people waiting for community services and supports, whose lives and families will be torn apart because unrelenting caregiving. 4500 people are in Emergency need according to the county system. I attended the Human Service Appropriation Hearings in both the House and Senate. I was taken back by how strongly both sessions advocated for funding for early childhood, Drugs and Alcohol, Mental Health, long term care, etc. Legislators felt strongly that no one should wait. Why then is waiting acceptable for this group of people? We all agree that families are the mainstay of this system and even families agree they want their family member with disabilities to remain in the home until they can no longer care for them.

From the moment of birth we are dealing with a system that really doesn't fill our needs. Any parent will tell you it's all about filing out the paperwork and personal plans. We run to doctors and hospitals more. We cry more. Do battle with schools and administration. We're constantly explaining and fixing things. As families, we just want to reach a point where it's just okay. Just an 'Everyday Life' that brings on challenges and the support to help ease through transitions to a regular life.

I can honestly state that changes are finally being made. Deputy Secretary Thaler has stood up and recognized the role and importance of families in the system. She is working on and implementing change with the involvement of families. Finally!

There are policy/regulatory changes that need to happen to make our system flow for families. It's important that they are stated and recognized.

1. Address the waiting list. Families across the lifespan are struggling to care for their loved ones, including more than 4,800 who are on the Emergency List. The Governor's budget will only help 250 people, leaving nearly 4,500 without hope.
2. Address more than 1,200 on the Priority 1 List for autism services. We need a more aggressive approach to help the nearly 20-30-70K people with autism in Pennsylvania. The Bureau of Autism Services is not ready to support the 10s of thousands of families in PA who have loved ones with autism. The adult system only serves a very small number of those who will need help.
3. Shouldn't be a separation between ID and autism. The ID and Autism systems operate very differently. Many families struggle to understand which system would best meet their needs and both have waiting lists. The Office of Developmental Programs should change the process so that they understand who qualifies for both systems and make both processes for waiting list enrollment fair, transparent, based on need and easy to navigate.
4. Restore County based funding. It is a lifeline for many people. County based funding was cut dramatically in the Corbett Administration and needs to be restored. Many families on the

waiting list relied on those limited resources to help them get by until home and community based waiver funding was available.

5. Restore Family Support funding at the county level. In the past, Counties would have limited amounts of funding to offer Family Support Services. That money has essentially dried up and there is no back up. People used to be able to direct the limited support to those areas that helped them the most, like home modifications, assistive technology, respite care or summer camps for their children.
6. Provide relief for the older caregivers in Emergency status. There are 2,516 family caregivers over the age of 60 who need support. Nearly 800 are in Emergency Situations, which means their loved ones health and welfare is at risk and they need help immediately.
7. Succession of care. Not trusts and estate planning. All families, but especially those with caregivers over 60, need to plan for the future. There is information available for estate and trust planning, but they really need help in figuring out who will care for and about their family member when they are no longer around. It is a difficult and sensitive topic that does not get enough attention in our system.
8. Eliminate high school grads on a yearly basis. Essentially, the waiting list for adult services begins when a student leaves high school. If the state plans for each and every graduate from school to enroll into services, we can stop the list from continuing to grow.
9. Provide 1/2 Million in state funding for 2017 for high school graduates. Budget year 2016/17 includes high school graduates for June 2016 and June 2017. We recommend the state include ½ million dollars in this year's budget to support the June 2017 graduates. They will only need one month of support next fiscal year. They would be able to plan for their lives while they are finishing their final 6 months of school, rather than graduating to the couch for 6 months, and then maybe getting services. That gap between school and adult services causes significant loss of skills and regression, while also impacting caregiver's ability to work. There is significant investment in preparing for and obtaining competitive work while still in high school – but that investment is wasted if those workers cannot continue without follow along services only available through waiver programs.
10. Stabilize the department. Every new administration brings tremendous change to ODP. Not opposed to subtle change however drastic change (Corbett) destroyed good work and destroyed morale and families.

You have always been responsive to our needs. We have witnessed a greater understanding and willingness to support families and those most vulnerable in the system. We thank you for the help.

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