



**Testimony of Maureen Cronin, Executive Director, The Arc of Pennsylvania
Before the Human Services Committee,
PA House of Representatives, Harrisburg, Pennsylvania
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Thank you for the opportunity to provide testimony regarding the waiting list for Pennsylvanians with intellectual and developmental disabilities. I am extremely honored to speak before you today alongside Pennsylvania's most committed advocates for people with disabilities.

I am the Executive Director of The Arc of Pennsylvania which is part of The Arc US, the largest disability rights organization in the nation, advocating for and serving people with intellectual and developmental disabilities and their families. We encompass all ages and many types of disabilities including autism, Down syndrome, and other developmental disabilities. For 67 years, The Arc of Pennsylvania has worked to ensure that children and adults with intellectual and developmental disabilities receive the supports and services they need, are included in their community, and have control over their own lives. The Arc of Pennsylvania has 34 local chapters with over 8,000 members.

My testimony represents the voices of our many members and my close friends, and I'm focusing on students graduating from school. When I remember what it was like for my typically developing son graduating from high school, I remember a relatively simple and predictable process. When he entered high school as a freshman, we knew he would likely graduate in four years. In his sophomore year, the school started prepping our son on what he would need to do to go to college. They helped him plan to take the SATs, send in applications, etc. In his senior year there were only a few months of waiting to hear what college he would go to. We knew the day he graduated that in three months he would be moving to Temple University. We knew what dorm he would live in. We knew what campus supports there would be. We even knew what bank branches were on campus so we could set up a bank account for him. Everything was predictable. So while we were a little nervous for him leaving home, we had spent four years preparing and we knew we would be joining the ranks of many parents who successfully transitioned their children to college.

For that matter, most of us have a pretty good idea of where we will be in a year's time. We generally know where we will be living or where we will be working. That is not how it is for families who have sons and daughters with an intellectual disability and autism. If you ask any parent of a child with an intellectual disability or autism transitioning from school, "what is your child doing next year?", you will see their universal look of panic. They will invariably say "I don't know. I've been talking to the county and we're waiting to hear if my child is prioritized to receive services upon graduation. We don't know if he is going to receive a waiver." Even families who were strong advocates for the first eighteen years of their child's life still don't know what will happen when school is finished. One of my board directors, a

woman that has been a tireless advocate for people with disabilities, still did not know what the plans would be for her son when he would turn 21. This is so hard to understand.

Everyone knew when he would turn 21 for 21 years. Over the years he has been assessed, measured, tested, evaluated, you name it. It was clear he would need supports while both his parents worked and he could never be left home alone. Both parent's income were needed for the family to stay in their home. Yet the family still had to deal with this looming threat that if the county did not deem that his needs were enough of an emergency, one of the parents would have to quit their job to stay home with their son. Not only could they not imagine surviving on half of their income, their retirement safety net would also be cut in half. My board director's son was to turn 21 in January. The EPSDT services that included nursing services would end the day he turned 21. In October the family started to get nervous that plans were not being made for their son. The nursing agency providing services were getting nervous about the eminent transition. They worried that the county didn't have a plan to take over funding these critical services. The mother and I would talk periodically and still, in the beginning of January, there was no plan for transition. The county said that there were other families higher up on the waiting list that would receive services first. Here is someone who was going to turn 21 in a few weeks, who was medically fragile and who needed in-home supports and supports to be part of his community. I could only imagine what the other families' situations were that prioritized them higher. At the very last minute, days before he turned 21 and after many contacts to DHS' Office of Developmental Programs, the parents learned that their son would receive waiver services. The stress of not knowing what was going to happen was almost too much to bear. This is a family that adores their son and kept him at home at significantly less cost than what it would have been for him to be served in an intermediate care facility.

While this is just one story I could share endless examples of families absolutely at the end of their rope waiting to hear if their son or daughter will receive services after graduating from school. One friend had to use their retirement funds to fund their daughter's program for three months before she was enrolled in a waiver. Another waited several months for day supports. This causes a huge amount of unnecessary stress for working parents. They already rely on family and friends to help them support their child with disabilities at home far more than parents of typically developing children. The gap between school and day supports can wreak havoc for a family. Counties have impossible decisions to make when they have multiple families waiting for services. It almost seems like counties have to wait until the last minute to decide which families really don't have a way to survive the transition and that's how they decide who will get the handful of waiver services available.

The people I am talking about are people who are connected to The Arc and have resources, and yet they don't know what services will be in place when their children finish school. Our chapters can tell you about the hundreds of families waiting months and months after graduation, all ridiculously stressed out until their son or daughter is enrolled in a waiver.

We can only imagine what it is like for families who don't know who to call for help. Funding is appropriated for students graduating but in recent years the funding is released nine months after students graduate in June. Some counties scramble to string together supports until waiver funding is available. Other counties do not have the resources and are forced to let students graduate to their couches.

If funding was made available immediately upon graduation, we could break the cycle of stressing families beyond their limits. Investing in students right when they graduate from school results in lower costs and allows families to be part of the solution. Waiting for families to get to a crisis point in needing support services usually results in the need for more expensive services. Investment early on that leads to employment or being an active member of one's community prevents the need for much greater funding down the road.

In closing, I want to thank you for taking the time to understand the importance of supporting families and for your commitment to solve this problem for the many families in Pennsylvania that love their children and just need enough services to help their sons and daughters be contributing members of their community.