

Mary Anderson Hartley  
Testimony  
House Health and Welfare Committee  
March 21, 2016

My name is Mary Anderson Hartley. I'm here today, as a parent to advocate for the future needs of my, almost 16 year old son Jack and young adults just like him. I begged, even bribed him with the promise of movie, hotel and pizza to make the trip from Pittsburgh and speak, but he would not miss his work at school. That is the kind of young man he is—and worth fighting for.

I want to first thank you. Because of the work of the Pennsylvania legislature, my son will need less support than young adults like him in other states--because kids with autism, in Pennsylvania, get wrap around services, and in Jack's case, that has been invaluable.

He also received significant special education resources enabling him, ultimately, to be fully included in middle and high school.

**Autistic adults, too, might get services in Pennsylvania, but very few.** It took a lot of tremendous advocacy to get to this point, and our family is grateful for the service of those who laid the groundwork. But we need to do a whole lot more to ensure that all of our autistic adults have the opportunities for the future and that more people can get access to services—even while they wait.

For me—for many of us-- it's the uncertainty of not knowing. My husband and I work very hard to plan for Jack's future, we affectionately say that we can live anywhere, and eat bread and peanut butter, but our son will get what he needs. I hope and pray we have enough at the end (even with the help of our family) to support him.

So I'm grateful there is the hope of an autism waiver. It relieves some stress, but at the current rate of delivery, the last person on it today will wait more 20 years to see services. **The Bureau of Autism survey estimates in the next four years, 36,000 adults with autism will live in PA. We have funded 576 slots. Jack will be one of those 36,000. He deserves a chance to use what skills he is developing now, with a little more support to achieve independence in adulthood.**

I know Pennsylvania does not have the resources now for every person who will need services when my son graduates at 21. He's doing everything he can to be a success in life, to work, to live independently—and we are certainly doing our part to make sure of it.

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So today I'm asking you to do more and better with the resources we have. Yes, to increase the numbers for autistic adults, but also, to build a system for those individuals who will never get access (or will wait decades) for a waiver --to keep them out of institutional settings, hospitals, group homes, homeless shelters and prisons – far too costly options in terms of human potential and our financial resources. But they are in those places now, at too high a price.

I'm proposing that there be more help in place for everyone who is waiting.

You sign up at 18 for the adult autism waiver—but nothing happens until 21. You don't know if you even qualify. You just wait. It's first come first serve. I get that, except for the family where someone is hurting others or injuring themselves, wanders, is victimized, and is highly likely to end up in a mental institution, jail or worse and was not being treated for autism and how to fix the situation. First come first serve is a nice idea, but I seriously don't want my son to get supports before someone who is at risk of institutionalization.

Could people be assessed and categorized by need, but still be on a first come first serve basis? That way we still unlock the potential of higher functioning adults who can get some services right away and go to work, pay taxes and live independently with minimal support, but know and identify and prioritize adults with significant needs in their category. If it's truly first come first serve, I want my son to know what his number is—and I want to know—so that I can sleep at night.

I would personally like to see more county based systems set up and, if it's already a success, an expansion of the ACAP (Adult Community Autism Program) waiver that is only in 4 counties right now. It appears everyone who is on that waiting list is getting services. Could such a system support those on the waiver, but also provide drop in support or counseling to others who are waiting?

Could base funds support critical needs like respite for families who need it desperately?

There should be a significant investment in resources, training, and supports for families to understand what they can do while they are waiting –perhaps this would prevent immediate need for full blown waiver services until later in life? Connections (starting at age 18, while they are still in school) to work, like OVR, connections to social supports, behavioral health, etc.

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At least when you sign up for the Intellectual Disability waiver you are assigned a supports coordinator and have at least one annual meeting. A relationship of assessment, support, connections. Treating people with autism with less is not fair, just, nor appropriate.

I echo my colleagues. We want more and we want a long term structure to know how people are going to get off the waiting list. The Governor's budget this year proposes 100 additional slots for adults with autism while the numbers of people in need are growing exponentially. We need to be more creative to ensure that those who can be served, will be served. We also need a plan of support for autistic adults who are going to be waiting—especially recent graduates. They can still make progress, and not regress, with your support.

I know you want to do what's right and I know you can't do everything. I'd just like to ask you to do three essential things right now that ensure that more Autistic adults can get access to what they need:

- Use resources more effectively to help more people.
- Fix the intake system for the Adult Autism Waiver (I have additional suggestions I can share with you).
- Create a plan that supports Autistic adults and their families while they wait, or if they never get access to services.