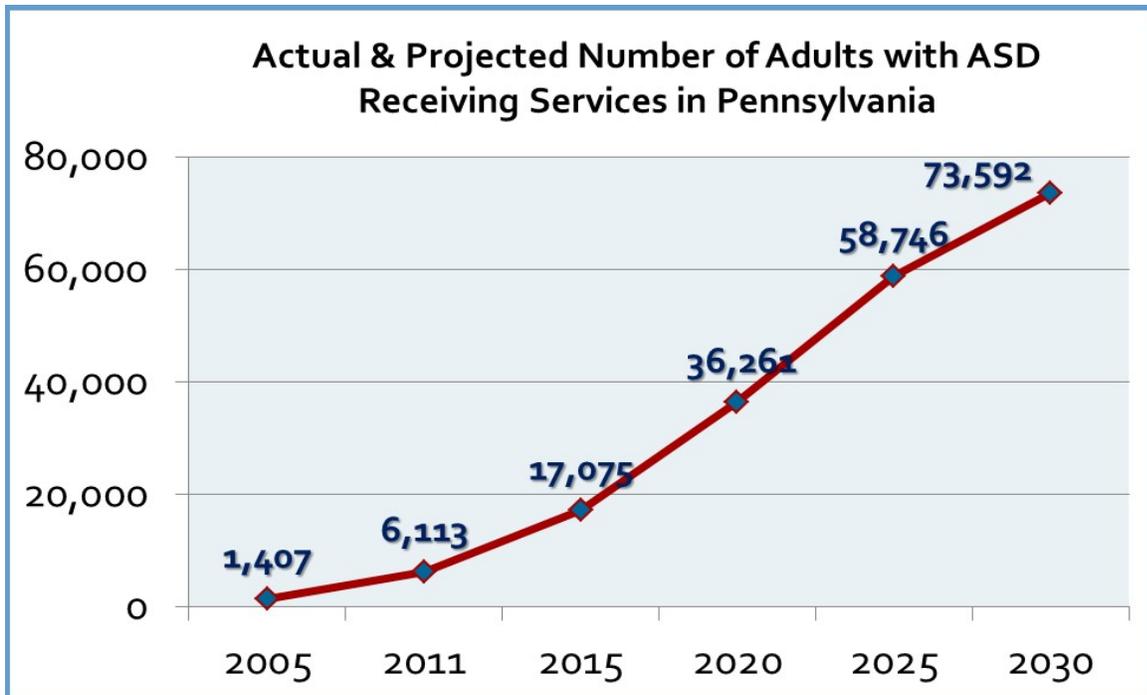


Testimony Provided by Lisa Tesler  
Pennsylvania House of Representatives  
Human Services Committee: Supporting Families  
March 21, 2016

Good Morning Chairman DiGirolamo and members of the Human Services Committee. Thank you for providing us the opportunity to speak with you today. My name is Lisa Tesler and I am the Policy Coordinator for the Pennsylvania Waiting List Campaign and a parent of a 20 year old son with a diagnosis of autism.

You have heard a great deal of information about the waiting list for Intellectual Disability (ID) services, I will address the system for individuals with autism. The Bureau of Autism Services (BAS) has a completely separate and different application and enrollment process. They maintain an "Interest List" not a Waiting List. The current autism service system provides help for 720 people, and has approximately 2,000 people on their "Interest List". So while we talk often about the Waiting List and the PUNS numbers, we need to remember that there is this other population of people who may not be counted or reflected in that data.

The Pennsylvania Autism Census Project: Final Report issued in October 2009, and updated in 2014, identified more than 17,000 adults with autism in Pennsylvania and the projections indicate increases to more than 73,000 by the year 2030.



Shea, L. (2014). *Pennsylvania Autism Census Update*. Study funded by the Bureau of Autism Services, Pennsylvania Department of Public Welfare. Retrieved from [www.paautism.org/census](http://www.paautism.org/census).

While these numbers appear overwhelming, we believe it is possible to address the need. Some of the individuals will not need waiver services, some may access supports through other programs like the Office of Vocational Rehabilitation, many are served by the ID system and others will be supported by families and other natural supports. According to the Office of Developmental Programs, only 28% of people who have intellectual and developmental disabilities access services. If that holds true for the autism population, the numbers become less insurmountable. That said, even if the state only needs to support 28% of the total population of adults with autism, the system will need sustained growth and expansion to meet their needs.

There is a great deal of time and attention paid to educating and supporting children with autism, which is important and essential. The education system and the behavioral health system have made significant strides in increasing their capacity to provide services to meet the needs of the growing numbers of students with autism. However, it is time to recognize that those children grow up to become adults. The state, policy makers, families and providers must prepare for and invest in a lifetime of supports for those who need them.

What changes are needed to support families caring for loved ones with autism?

**Reform the “Interest List” policies to assure families know whether they are eligible for the Adult Autism Waiver, understand their entitlement to an Intermediate Care Facility (ICF) and have a right to choose home and community waiver services or the ICF.**

The Office of Developmental programs should provide an initial evaluation for all people currently on the interest list and to those who request services in the future.

- Federal regulations at 42 CFR 441.302 outline assurances that States must make to the Centers for Medicare and Medicaid Services (CMS) for home and community based waiver programs. The states must assure an initial evaluation *“of the need for the level of care provided in a hospital, a NF, or an ICF/IID when there is a reasonable indication that a beneficiary might need the services in the near future (that is, a month or less) unless he or she receives home or community-based services.”*

Once evaluated, if the person is likely to meet ICF level of care, BAS should provide information to families regarding their entitlement to an ICF and offer them a choice of the ICF setting or home and community based services.

- The regulations require *“...when a beneficiary is determined to be likely to require the level of care provided in a hospital, NF, or ICF/IID, the beneficiary or his or her legal representative will be—*

- *Informed of any feasible alternatives available under the waiver; and*
- *Given the choice of either institutional or home and community-based services.”*

The current process of allowing individuals to languish on the interest list, without any evaluation of need or information regarding their right to choose their service delivery preference, from our perspective, does not meet the assurances. Additionally, it seems cruel to allow a person and their family to continue to wait for a service that ultimately they may not qualify for.

**Provide for additional capacity in Home and Community Based Waiver programs to avoid institutional placements in public or private Intermediate Care Facilities, Nursing Homes and Hospitals.**

Pennsylvania includes ICF services in the Medicaid State Plan, therefore, all individuals who have Medical Assistance and meet the Level of Care are entitled to that service...no waiting. People on the ID Waiting List and those on the Autism Interest List who qualify could choose the ICF and the Department of Human Services would be required to place them. The families don't want that, which is why they wait. They don't want isolation and segregation, they want community. However, they are entitled to be informed about their rights and to make that choice. If individuals on the waiting list or interest list exercise their entitlement, the cost to the system would be tremendous. Our public ICFs (State Centers) cost more than \$390,000 per person per year. The Consolidated Waiver costs \$123, 830 per person and the Adult Autism Waiver averages \$51,675 per person per year. It makes sense, both fiscally and morally, to expand the Home and Community Based Waiver capacity and avoid unnecessary institutionalization.

**Prioritize people waiting to assure that those most at risk are offered supports first, make the process transparent and align with ODP practices for Intellectual Disability programs.**

The Office of Developmental Programs utilizes the Prioritization of Need for Services (PUNS) evaluation for their Waiting List for ID Services. The Bureau of Autism Services maintains a separate "Interest List". ODP does not know if there are overlaps between the lists, nor do they know or understand the risks or needs of the people on the Interest List. We recommend one standard process for determination of waiting list status and waiting list enrollment across ODP programs to avoid confusion and duplication of effort. Now, families who may qualify for both systems must engage in application/request for services through 2 different doors. We also ask for the autism waiting list numbers be published monthly, just like the PUNS numbers for ID, to add transparency and accountability to the process.

**Provide some basic level of support and information to families currently waiting for services.**

People with intellectual disabilities who are on the waiting list have access to Supports Coordination, and sometimes base or county funding for very limited services. Adults with autism do not receive these supports. There was once a mini-grant program in the Bureau of Autism Services, but that was discontinued. We recommend providing some very basic services and Supports Coordination for adults with autism who need help now but cannot access waiver services.

**Scale up the program to prepare for the tremendous need as reflected in the Autism Census.**

Pennsylvania emerged as a national leader in the development and design of home and community based services for adults with autism with the creation of the Adult Autism Waiver and the Adult Community Autism Program. Our community is grateful for the groundbreaking efforts underway here. But as you can see, there is much more that will need to be done to fully meet the needs of the huge number of individuals who need support now and into the future.

To that end, we recommend:

- A commitment from our Governor and our Legislators to provide adequate and necessary funding to support sustained growth in the Autism Services system for adults.
- The Office of Developmental Programs address the structural changes necessary to expand capacity in the administration of the Adult Autism Waiver program.
- Expansion of the provider network to serve all those in need.
- Inclusion of Participant Directed Services within the autism programs to allow individuals maximum flexibility and control over their home and community based services.

In preparation for today's hearing, I reviewed many of my written comments to the Office of Developmental Programs and dusted off my testimonies from previous hearings on the Waiting List. Since 2008, when my son was 12 years old, I have been making recommendations regarding improvements to the autism system. Many of the concerns I shared in 2008 are still relevant now. I am hopeful that as we move forward, the recommendations we offer today will lead to real systems change. We all play an important role in increasing access to services and improving the quality of support across Pennsylvania and throughout the Lifespan, which will ultimately lead to Everyday Lives for all people with autism and their families.

Thank you for your time today and I am happy to answer your questions.

§ 441.302 State assurances.

Unless the Medicaid agency provides the following satisfactory assurances to CMS, CMS will not grant a waiver under this subpart and may terminate a waiver already granted:

....

**(c) *Evaluation of need.*** Assurance that the agency will provide for the following:

**(1) *Initial evaluation.*** An evaluation of the need for the level of care provided in a hospital, a NF, or an ICF/IID when there is a reasonable indication that a beneficiary might need the services in the near future (that is, a month or less) unless he or she receives home or community-based services. For purposes of this section, “evaluation” means a review of an individual beneficiary's condition to determine—

**(i)** If the beneficiary requires the level of care provided in a hospital as defined in § 440.10 of this subchapter, a NF as defined in section 1919(a) of the Act, or an ICF/IID as defined by § 440.150 of this subchapter; and

**(ii)** That the beneficiary, but for the provision of waiver services, would otherwise be institutionalized in such a facility.

....

**(d) *Alternatives***— Assurance that when a beneficiary is determined to be likely to require the level of care provided in a hospital, NF, or ICF/IID, the beneficiary or his or her legal representative will be—

**(1)** Informed of any feasible alternatives available under the waiver; and

**(2)** Given the choice of either institutional or home and community-based services.