

## THE FACTS ARE ...

### Pennsylvania Waiting List Campaign Fact Sheet Fall 2015

The Pennsylvania Waiting List Campaign’s goal is to end the devastation of Waiting Lists for persons with intellectual disability (ID) and autism who are in need of services through the Pennsylvania Office of Developmental Programs (ODP). These people are entitled to institutional care but choose to wait for home and community based services through the ODP Waiver Programs.

#### HOW MANY PEOPLE WITH INTELLECTUAL DISABILITIES AND AUTISM ARE WAITING?

<b>TOTAL ID WAITING LIST = 13,745</b>	<b>TOTAL AUTISM WAIVER INTEREST LIST = 1,771</b>
<b>Emergency (need services immediately) = 4,494</b>	<b>Priority 1 (receiving no services) = 1,270</b>
<b>Critical (need services within 2 years) = 5,657</b>	<b>Priority 2 (receiving some services) = 501</b>
<b>Planning (need services within 5 years) = 3,594</b>	<b>ACAP Interest List = 218</b>

What do we know about the people with ID on the waiting list?

- Most people are living with and being cared for by their family (84%) and some are living with friends or on their own (7%).
- Of the 11,594 people living with families, only 1,960 are waiting for a 24/7 staffed group home. Services most requested by people living with families are individual supports like Habilitation, Transportation, Employment and Respite.
- There are 757 individuals in Emergency Need and 1,742 in Critical Need who have caregivers over 60 years old.
- There are 783 individuals who are 21 years old and are losing EPSDT and School services. They need services to successfully transition from school to adult life in the community.

What do we know about the “interest list” for autism services?

- People are served on a first come, first served basis and the need for services for adults with autism will continue to grow. The Census numbers indicate dramatic increases over the next 15 years, from 17,075 people now to 73,592 in year 2030.

## How do we address the crisis in the community?

Waiting List Initiative	Number of People Served	Estimated Cost in State Dollars for Community-Based Waiver Services	Cost for Public Institutional Placement per year (Entitlement)
<b>Emergency List for ID</b>	4,494 people for 6 months	\$63.4 Million	\$1.7 Billion
<b>Priority 1 List for autism</b>	1,270 people for 6 months	\$13.5 Million	\$481.2 Million
<b>High School Graduates 2016</b>	700 students for 9 months	\$4.8 Million	\$265 Million
<b>High School Graduates 2017</b>	700 students for 1 month	\$0.5 Million	\$265 Million

Each person on the Waiting List has waived their right to institutional care, saving the commonwealth and the taxpayers billions of dollars over their lifetime, yet they languish on long waiting lists for home and community based services. If they choose to exercise their entitlement, the state would be required to serve them immediately and at a much higher cost in both dollars and freedoms. We need to close our State Centers and reinvest the funding into a robust, flexible, and responsive Community Based system.

Individuals and their families need assurance and hope that their needs will be met in their homes, with meaningful work opportunities and the basic supports they need to experience and enjoy Everyday Lives in the community of their choosing.

