

## THE FACTS ARE ...

### Pennsylvania Waiting List Campaign Fact Sheet March 2023

The Pennsylvania Waiting List Campaign's goal is to end the devastation of Waiting Lists for persons with intellectual disability (ID) and autism who need services through the Pennsylvania Office of Developmental Programs (ODP). It is the only state Medicaid program whereby you are deemed eligible but wait on a list, sometimes years, not knowing when or if new funding is allocated in a budget.

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

<b>TOTAL ID/A WAITING LIST. INDIVIDUALS WITH NO SERVICES OR UNDERFUNDED</b> <b>12,409</b>	Emergency = 5452 Critical = 4582 Planning = 2375
<b>TOTAL ID/A WITH NO SERVICES</b> <b>6962</b>	Emergency = 2879 Critical = 2596 Planning = 1487
<b>TOTAL AUTISM INTEREST LIST</b> <b>2013</b>	Priority 1 = 1677 ACAP = 336

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

- There are 1485 in the Emergency Need that are in single parent households.
- There are 765 in Emergency Need in homes with multiple individuals with a disability.
- There are 247 in the Emergency Need that are in single parent households with multiple individuals with a disability.
- Most people are living with and being cared for by their family (87%) and some are living with friends or on their own (6.5%).
- Of the 11,618 people living with families, friends or on their own, only 2573 are waiting for a 24/7 staffed home. Services most requested by people living with families are individual supports like In-home and Community Support. We also know, when people on the Emergency List are offered Group Homes, many often request in-home supports instead, which are often less costly than funding the traditional group home.
- There are 894 individuals in Emergency Need who have caregivers over 60 years old. There are 1519 in Critical Need who have caregivers over 60 years old.

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

<b>Proposed 2023 – 2024 Budget</b>	<b>850 Individuals</b> 750 Community Living Waiver, 100 Consolidated Waiver, and All High School Graduates via turnover.	<b>\$17.5 Million</b> State cost for first year funding	Versus Entitlement \$215 Million State cost per year institutional placement.
<b>Waiting List Ask: Fully Fund Emergency List, Underfunded and No Services.</b>	<b>5452 Individuals</b> (75% Community Living Waiver and 25% Consolidated Waiver).	<b>\$115 Million</b> State cost for first year funding	Versus Entitlement \$1.4 Billion State cost per year institutional placement.
<b>Or, Waiting List Ask: Fully Fund Emergency List, those with No Services.</b>	<b>2879 Individuals</b> 2779 Community Living Waiver, 100 Consolidated plus All High School Graduates via turnover.	<b>\$37.6 Million</b> State cost for first year funding	Versus Entitlement \$729 Million State cost per year institutional placement.

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 and day opportunities. Individuals should be provided the basic supports they need to experience and enjoy Everyday Lives in the community of their choosing.

Data Source: Governor’s 2023/2024 Proposed Budget and Office of Developmental Programs’ Priority of Urgency of Needs 3/1/2023 (PUNS).