

Testimony on the Waiting List for Services

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Good morning Chairmen DiGirolamo and Cruz, members of the House Human Services Committee, and staff. My name is Nancy Thaler, and I am the Deputy Secretary of the Office of Developmental Programs (ODP) within the Department of Human Services (DHS). On behalf of Secretary Ted Dallas, I would like to thank you for the opportunity to present testimony regarding DHS' efforts to support citizens of the Commonwealth with intellectual disabilities (ID) and autism and their families to achieve greater independence, choice and opportunity in their lives.

DHS provides services for over 53,000 people with ID or autism. The vast majority of the people DHS serves, 70% or 36,800 individuals, live at home with their families. Services are funded predominantly through Medicaid and with state and local funds through county government. Specifically, there are three Medicaid home and community-based services Waiver Programs, which fund services provided in the community. The three Medicaid Waiver Programs, which serve approximately 31,060 people, are the Person/Family Directed Supports (P/FDS) Waiver (13,060); the Consolidated Waiver (17,500) and the Adult Autism Waiver (560). In addition, DHS operates the Adult Community Autism Program (ACAP), which is a managed care program for individuals with Autism (152). Finally, DHS funds institutional services in private intermediate care facilities for individuals with an intellectual disability (ICF/ID) (2,260) and state-operated ICF/ID facilities (950). County programs serve approximately 20,000 additional individuals with state and county funds.

Services have been evolving over the years. We have made tremendous progress from the 1970s when almost everyone receiving services was living in an institution, away from their families and community. In today's reality, almost everyone is living with their family or in supported homes in the community.

Our progress has been more than changing the location of services. Providing services to people in the community has changed the program's focus and goals. Our goal is not simply to provide care, but to create opportunities for growth and learning, to help people get a job, practice their faith, join a health club, make friends and "hang out" with them, become civically engaged – in other words - to fully participate in their community and live a typical life, like yours and mine.

While we serve over 53,000 people in our service system, there is still a significant number of people and families who need, but do not receive, services. I will provide you with waiting list figures and explain what the Department's plans are to remove people from the waiting list at a reasonable pace.

**The number of individuals waiting:** There are two lists: As of January 2016, there are 13,933 individuals with ID waiting for services. The other list, which is maintained as an interest list for autism services, has approximately 2,000 people. Many of the individuals on the autism interest list may also be on the waiting list for ID services. In other words, there is duplication.

**Waiting list categories:** Of the ID waiting list, 4,863 people are listed as "emergency", which is defined as needing services in the next 6 months; 5,521 are listed as "critical", which is defined as needing services within the next 2 years; and 3,549 are listed as "planning", which is defined as needing services more than 2 but less than 5 years.

**Waiting and receiving services:** Of the approximate 10,384 people who have reported that they will need services within the next two years (emergency and critical categories); 7,300 are getting some level of service while the remainder are not receiving any services. Of the 4,863 in the emergency group, 3,551 are receiving services - 1,500 are enrolled in one of our waivers and have expressed a need for additional services and 2,000 are receiving some limited services from the county programs. While a large percentage of people in the emergency category are receiving some services, the services people are receiving are typically either through the P/FDS Waiver, which is capped at \$30,000 per year or through the county which provides services for a lower amount. The same pattern holds true for individuals on the critical list. Of the 5,521 individuals, 3,811 are receiving some type of service, again through the PFDS Waiver but mostly through county funds. Among the planning group, of the 3,549 individuals listed as needing services in 2-5 years, over 2,511 individuals are receiving some level of service.

**The ages of individuals waiting:** Individuals on the waiting list range between ages 3 and 88. However, almost 50% of the individuals in the critical and emergency categories on the waiting

list range between 15 years and 27 years. A large number of these individuals are young adults who are beginning the transition from school to adulthood or who have graduated from school and are home with a working aged parent or parents. Without services, they cannot navigate the community or get a job. Over time they begin to lose the skills they acquired in school.

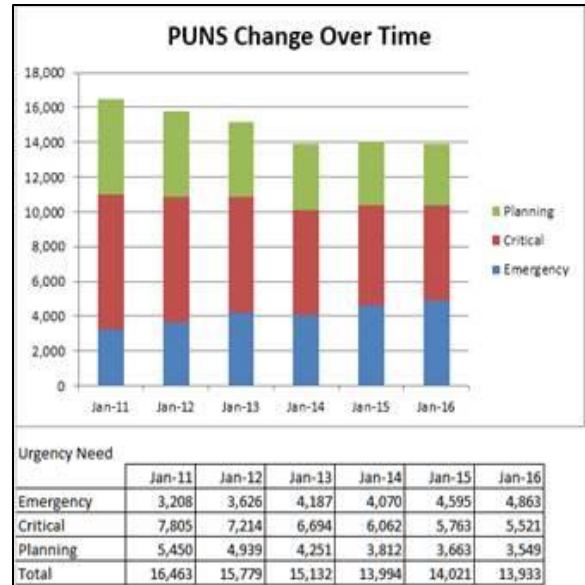
**The age of families:** Of all 13,933 individuals on the waiting list, 2,045 are living with a caregiver over the age of 60. Caregivers under the age of 60 tend to be working. Therefore, this number suggests that most of the individuals on the waiting list are living with working age families.

**What we do not know about people on the waiting list:** The instrument used to collect information on people waiting for services provides basic demographic information about each person, but it does not provide a standardized assessment of each person's clinical and support needs; nor does it provide information on each family's situation which would help us shape our program design and budget more accurately.

**To summarize the data:** There are over 10,300 people who have reported that they will need services within the next two years (emergency and critical categories); 7,300 are getting some level of service and the remainder are not receiving any services. The vast majority are individuals in their late teens to mid-twenties whose parents are working age. These families are often referred to as the "sandwich generation" because they are caring for children and their own parents as well.

The data suggests that our service expansion should focus on young adults who are transitioning or have transitioned from school as well as their families. The provision of adequate supports for these individuals would allow them to live at home or work more easily. This additional support would allow parents to maintain their family member at home rather than seek more costly out-of-home services.

**Why don't the waiting list numbers fall more quickly:** The total number of people on the waiting list has decreased overall in the past 6 years from 16,463 in 2011 to 13,933 today. This reduction has been made possible through two strategies. The first is expansion in the number of people served over the years from 27,300 in FY 10-11 to 30,000 today and the second through turnover in the existing system. Each year, between 800 and 1000 individuals are enrolled to fill vacancies made available by people leaving the service. Additionally, each month there are changes, as people leave the program and others enroll.



The waiting list does not decrease as rapidly as enrollment increases predominantly because of the impact of the baby boom demographic. The US Census Bureau reports that when persons born from 1946 to 1964, commonly known as the Baby-Boomers generation, began turning age 65 in 2011, we started to witness a rapid growth rate of persons 65 and over. The country and our state are aging. As the population of people over 65 grows, the demand for long-term care services increases. People with ID and autism are 1.55% of the over 65 population and as the over 65 population ages, the demand for services to meet their needs (for both disabled and non-disabled) grows too.

In addition, there are baby boomers now 65 or older who are not disabled themselves, but who have children with ID and autism. These aging families are losing their capacity to care for their adult children and are now seeking services. Had there been no waiting list before the baby boomers began to age, the increased demand due to the aging population would have resulted in a waiting list.

## **DHS actions to address the waiting and interest list:**

### **Service expansion:**

- The Department is currently implementing the Fiscal Year 2015-16 budget initiatives, which will reach 1050 individuals with an intellectual disability and autism.
- The Governor's Executive FY 2016-17 Budget included \$12.3 million in state funding which will reach an additional 850 individuals with and intellectual disability and autism next year.
- Through turnover, the Department will be able to accommodate approximately 800 - 1000 individuals from the waiting list each year.
- An additional \$41.2 million is budgeted in FY 2016-17 to accommodate increased needs of the people receiving services.
- Further, \$500,000 is budgeted to leverage an additional \$1.8 million in federal Vocational Rehabilitation funds to expand employment services for individuals with an intellectual disability.

### **Improving supports to families:**

Recognizing that a majority of people receiving services are living with families and that many families are looking for in home supports, the DHS is implementing program initiatives to improve supports to families.

Pennsylvania is joining the **National Supporting Families Collaborative** with 15 other states to explore together ways that state policies and programs could be transformed to better support individuals and their families throughout the lifespan. DHS will invite six counties in Pennsylvania to participate in a statewide collaborative to redesign local programs and practice. Local collaboratives will include individuals and families, local community organizations and relevant public entities to develop community solutions. Most importantly, the Supporting Families Collaborative will focus on methods of supporting families of individuals on the waiting and interest lists.

As we prepare to launch this initiative, DHS has sponsored the **Pa Family Network**, a family operated program that will provide information and training to families across the Commonwealth. The Network's efforts will build the capacity of families to plan for the future and access resources throughout the community.

**Managing resources:** DHS is launching an effort to establish a new fee schedule for residential programs. Currently, over \$1 billion supports people living in group homes. The move in FY 2011-12 from county negotiated contracts to cost based rates established by the Commonwealth was a good step toward standardizing rates and strengthening accountability. But after four years of implementation, the methodology of cost-settling every residential location has become burdensome for both providers and the Commonwealth and more importantly, has resulted in a disconnect between reimbursement and the degree of service each person needs.

A reimbursement fee schedule that more accurately matches reimbursement to individual needs will improve the management of our resources.

**Planning for the future:** DHS plans to improve the instruments and methodology used to identify and plan for people on the waiting and interest lists. The Department intends to maintain one list for people with ID and autism (while maintaining an indicator for each unique diagnoses) and to design a single assessment that will provide adequate information about each person's disability, the type and degree of support the individual needs and his or her living situation including the needs of the family in order to improve our planning and budgeting. In addition, the Department is looking to standardizing the criteria used to prioritize individuals on the waiting list for services.

Program expansion in the future should focus on supporting families with services, information and training. We must reach families early in life so that they can prepare and plan for the future, discover resources in the community, and create a positive vision for their family member. We must help families connect with other families from whom they can learn and enjoy peer support.

Our services to people living with their families should focus on employment because a good job enables more independence and having a valued role in the family and community. Ideally, we should connect with individuals before they complete their education so that the skills they develop in school are not lost but instead are used to get a job.

The renewal of the two major Medicaid Home and Community Based Waivers beginning July 2017 provides an opportunity to strengthen our ability to support people and their families.

Thank you for the opportunity to provide this information to you today. I will be happy to answer any questions you may have at this time.