

House Human Services Committee
Public Hearing on the Adult Disability Services System
in Pennsylvania

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Thank you Chairman DiGirolamo, Chairman Cruz, and members of the Committee. We truly appreciate the Committee holding this hearing today.

My name is Chava Kintisch, and I am the Director of Civic and Government Affairs for the Disability Rights Network of Pennsylvania.

The Disability Rights Network of Pennsylvania, or DRN, is the protection and advocacy system for children, youth, and adults with disabilities in Pennsylvania. The mission of the Disability Rights Network is to advance, protect, and advocate for the human, civil, and legal rights of Pennsylvanians with disabilities.

The Disability Rights Network provides free legal and advocacy services for persons with disabilities of any age, with any disability, including assistance to access home and community-based services, education, housing, employment, and transportation; to address discrimination; and for protection from abuse and neglect. We get thousands of requests for help each year from individuals with disabilities and families across the Commonwealth. We are a statewide organization with offices in Harrisburg, Philadelphia, and Pittsburgh as well as advocates across the Commonwealth, including Community Advocates who assist individuals with intellectual disabilities or autism.

You have heard compelling stories from the witnesses this morning who are people with disabilities and family members. The Department of Human Services testified about Office of Developmental Programs (ODP) and

Office of Long-Term Living (OLTL) services, and we thank the agency witnesses for being here today.

The witnesses – persons with disabilities and family members – have told us about their real-life experiences with waiting for services or trying to navigate the system to get the services they need. There are about 1.8 million children, youth, and adults with disabilities in Pennsylvania. There are thousands of people with disabilities and family members in every legislative district across the Commonwealth who have the same stories and needs as the witnesses this morning.

I would like to provide a picture of Pennsylvania today in terms of the institutionalization of adults and community living. You have heard the witnesses testify today that community living is what they want.

There are about 964 individuals in 5 State Centers in Pennsylvania [DRN data, March 2015]. There are about 4,253 persons under the age of 60 in nursing facilities who are Medicaid recipients [OLTL HCBS Activity Report SFY 2012-13 3rd Qtr through and SFY 2014-15 2nd Qtr]. I would like to add that there are about 1,507 individuals in the State Hospital system (State Hospitals, Forensic, Act 21, and Long Term Care), including about 1,087 individuals who are in 6 State Hospitals on the civil side [Office of Mental Health and Substance Abuse Services, Pennsylvania State Hospital Risk Management Summary and Indicator Report, December 2014].

Now let us take a look at the community. We ask that Pennsylvania continue to rebalance the system so that people with disabilities have the

full opportunity to live and work in the community. Yet, only 49 Nursing Home Transitions and 62 Money Follows the Person transitions of persons under age 60 from nursing facilities took place in a recent quarter [OLTL HCBS Activity Report SFY 2012-13 3rd Qtr through and SFY 2014-15 2nd Qtr]. We know that we can serve more people in the community than in institutions with the same dollars, and people with disabilities want to be living, going to school, and working in the community like everyone else [E.g., see Updated PRU Web Data from OLTL].

There is a great need for home and community-based services. There are about 14,021 individuals on the waiting list for intellectual disabilities home and community-based waivers [PA Waiting List Campaign, based on data from ODP, January 31, 2015]. This includes about 4,595 people in the Emergency Needs Category, who are those who need services immediately, within 6 months [PA Waiting List Campaign, based on data from ODP, January 31, 2015].

There are just over 1,400 individuals on the autism waiting list [according to the Bureau of Autism Services at a recent ISAC meeting]. But, there are 55,000 people known to have autism (i.e., in some service system), and there could be 133,000 more persons with autism not in any system and thus not identified in Pennsylvania [Bureau of Autism Services, PA Autism Census Update 2014]. We are also told that the number of adults with autism will grow the most in Pennsylvania [Bureau of Autism Services, PA Autism Census Update 2014]. Yet, there is only capacity for 518 persons in the Adult Autism Waiver [Department of Human Services Budget Request for FY 2015-2016, page 285].

OLTL serves about 24,813 adults with physical and developmental disabilities including brain injury [OLTL HCBS Activity Report SFY 2012-13 3rd Qtr through and SFY 2014-15 2nd Qtr]. There needs to be screening to identify children, youth, and adults with brain injury so that they can get appropriate services and recover.

There are over 100,000 transition-age youth ages 14 to 21 receiving special education services, who will be graduating in the next several years and in need of adult services [Pennsylvania Department of Education, Special Education Statistical Summary, 2013-2014, page 2].

It's budget season. The Disability Rights Network supports a budget that has full funding for disability services. As you heard this morning, funding is the difference between no or wrong services (or not enough services) and human services that mean full health, habilitation and rehabilitation, community living, and community participation for people with disabilities.

Thank you again for your time and consideration.

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