# Home And Community Based Services (HCBS) for Pennsylvanians with Disabilities

A Project of The Women and Girls Foundation

The Women and Girls Foundation launched the Training Regional Advocates to Influence Leadership (TRAIL) program in 2020, in collaboration with Dr. Josie Badger. The goal of the program is to develop a statewide legislative advocacy training program for people with disabilities. TRAIL supports advocates with disabilities in learning strategies to make systemic change.

Recommendations represent the ideas of TRAIL members and do not represent those of the Women and Girls Foundation or any partners. For additional information please contact Dr Josie Badger at Josie@JBadgerConsultingInc.org


**Written by:**

Monica Albert Still, RN, BSN has been a TRAIL member since 2020. She has advocated for disability justice at both the Commonwealth and Federal levels. She serves on the Board of Disability Rights PA and on the Adult Advisory Council of the Spina Bifida Association.

Jessica Gardner has been a TRAIL member since 2020. Service Dog Advocate and was Ms. Wheelchair Pennsylvania 2021.


Home and Community-Based Services (HCBS) originated in the 1980's in response to more Medicaid resources being used for institutional care, studies concluded that institutionalized people were able to live in the community with appropriate assistance and had a higher quality of life, and the recognition of the institutional bias of Medicaid. In addition, SCOTUS's 1999 Olmstead decision established the rights of people to live in their setting of choice regardless of the need for care. In 1981 the HCBS waiver program was initiated as an alternative to institutional care. HCBS is important for meeting the requirements of the ADA and the promise of the freedom to choose as determined by the Olmstead decision.

***Did you know?***

- According to the 2021 ODP Waiting List Report 12,377 people were waiting for HCBS and 5,140 were in need of emergency assistance.
- The length of time on the waitlist is at least 2-3 years.
- From October 2020 to October 2021, nursing facilities and waiver waiting lists enrollment has grown, potentially from stagnate state and federal funding, specifically around pay for caregivers.
- Pennsylvania has more than 220,000 direct care workers with a median salary consistently at $11.00 per hour.
- It costs an average of $10,403 per month for nursing facility care in Pennsylvania, while In-home services cost an average of $4,957 per month.
- A review of the literature has shown an improvement in quality of life when people with intellectual disabilities are deinstitutionalized.
- Depression is an extremely widespread psychiatric disorder in nursing homes; it has a negative impact on the quality of life and affects more than one fifth of nursing home residents.

"Pennsylvania is facing a dire shortage of direct support professionals who help people with intellectual and developmental disabilities bathe, get dressed, eat, exercise, socialize, and perform many other fundamental tasks. Putting an exact number on the shortfall is difficult, as employment data on these workers is lumped together with health-care aides generally, but the industry was already experiencing double-digit vacancy and turnover rates nationally before COVID-19 arrived."


# Home And Community Based Services (HCBS) for Pennsylvanians with Disabilities *Policy Recommendations*

## Increase the number of high-quality caregivers working in the Commonwealth

- Even when individuals are approved for in-home care, there is a significant shortage of caregivers. This leaves individuals without the support necessary to maintain their health and independence.
- Wages should start at a livable wage with an annual increase with the IRS cost-of-living adjustment
- Bonuses should be available based on the caregiver's time in the position, performance, and reliability
- Benefits should be provided to eligible full-time caregivers under the PA Employee Benefit Trust Fund.

## Waiver services and category should be based on function and need rather than diagnosis

- Pennsylvania has multiple waivers based on an individual's age and diagnosis. These different programs have different services and eligibility requirements which can be extremely confusing for applicants, more expensive to run, and less comprehensive.
- Unify waivers to streamline the applications and to provide better comprehensive services.

## Minimizing the need for residential or institutional care

- Residential and institutional care is often the default care option for individuals who need support. However, with adequate support, most individuals would prefer living in their home. Studies have shown that in-home care is cheaper with better care provision. Unfortunately, unless a social worker is involved (usually as a result of a hospitalization) evaluating alternative options and applying for supports is rarely completed before an individual is placed in a residential facility.
- Prior to a residential placement, Medicare and/or Medicaid recipients should receive a care audit. This review would analyze the wishes of the individual, what would be necessary to allow the individual to continue to live in the community, and the pros and cons of a residential placement.

## Improving institutional care

- When a residential facility is considered the best option, there is often minimal information available about the options. Individuals and loved ones should be able to easily review all of their options.
- Create a website of residential facilities with easy access to CMS ratings and feedback for each facility

## Encourage and support self-paid caregivers

- Some families and individuals have the financial means to pay for in-home caregivers. However, there are minimal incentives (or known incentives) for this. By promoting tax credits, some individuals may be more willing to contribute to paying for in-home care, reducing the financial burden on the state.
- Create pathways to obtain tax credits for self-payment of caregivers .

## Paid Family and Medical Leave

- Improve health outcomes, preventing hospitalization, residential care, or additional services.