

BEYOND DIAGNOSIS:

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Who We Are

Grant: Pennsylvania Disability Advocacy Fund

Project Team:

Josie Badger

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Social Media: PA Health Law Project

Heather Tomko

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The *Why* for Project Beyond Diagnosis

Most Pennsylvanians with disabilities want to live in their communities — not in institutions or nursing homes — with the supports and services that make independence possible. With the right services, people can live safely at home, work, participate in community life, and thrive.

Our Goals

- Ensure equitable access to inclusive health and human services for all people with developmental disabilities in Pennsylvania.
- Conduct research and data analysis to identify how current systems create inequities and where change is needed.
- Amplify the voices of people with lived experience—individuals with cerebral palsy and other developmental disabilities, and their families—in shaping solutions.
- Provide policy recommendations that will strengthen and expand Pennsylvania’s disability service system.

A Few Facts

- The definition of developmental disability
- The waiver programs that provide support for Pennsylvanians with a developmental disability
- The number of individuals with a developmental disability who are enrolled in Community HealthChoices
- Examples of the services and fee structures among the waivers

Direct Care Workers

Employment

Housing

Supports Brokers

Assistive Technology

Our Stories



It's just, if you want this, good luck.

Research Study: How States Support People with Developmental Disabilities

In June 2025, the Beyond Diagnosis Project, in partnership with the Pennsylvania Health Law Project (PHLP), released a groundbreaking study: *How Various States Provide Supports for People with Developmental Disabilities Other than Intellectual Disability and Autism*.

This report examines how other states' Home and Community-Based Services (HCBS) waivers serve individuals with developmental disabilities such as cerebral palsy, spina bifida, epilepsy, muscular dystrophy, and spinal muscular atrophy—populations who are often excluded from Pennsylvania's current system.

What's Happening Now?

House Resolution (HR) 134
Prime Sponsor: Rep. Melissa Cerrato: second Marla Brown and Tarik Khan



What's Next?

➤ Stories! And, more stories!

Why is living, working, and being active in the community important to you?



Contact Information

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More information: <https://patf.us/what-we-do/project-beyond-diagnosis/>