

HCBS Investments ...

Thousands of older adults and people with disabilities – including those with significant disabilities - want to remain in their homes or return to their families after a short recuperation in a nursing home. With Pennsylvania's older population growing, the urgent need for these services will increase.

Home and Community Based Services are proven to provide safe and affordable care, even to those with the most severe disabilities, but we still spend less than 20% of long-term care funding in the community.

We must accelerate the pace of rebalancing our long-term care system by investing in these programs. It makes good economic sense and it's what Pennsylvania families want.

... Must Increase

Older adults and people with disabilities are increasingly enjoying the freedom and comfort of living in their own homes and receiving high quality, safe and affordable care through Home and Community Based waiver services. Pennsylvania must continue to support the shift of funding to rebalance our long-term care system by investing in alternatives to nursing homes.

Benefits of Expanding HCBS

- ▲ Creates personal choices for how and where long-term care is provided;
- ▲ Enables people to live at home, not nursing homes and institutions;
- ▲ Services are more cost-effective (*at least 2 people can be served in the community for the cost of 1 person in a nursing home*);
- ▲ Pennsylvanians are aging, 1 in 5 residents is over age 60. We can't afford not to invest in alternatives to nursing homes.

HCBS provide long-term support services for activities of daily living that enables people to live at home, not in nursing homes and other institutional settings. Examples of HCBS services include meal preparation and assistance with eating, bathing, dressing, personal care, chores, managing medications, participating in adult day programs and home modifications.

Waiver-funded services have helped thousands of older adults and younger people with severe disabilities to transition from nursing homes into the community or remain in the community. Here are some of their stories.

JOE PEPE

Chester County

Joe is 71 years old and a former accountant, life and health insurance licensee and Philadelphia Eagles season ticket holder. He can not breathe without a ventilator and has twice lived in a nursing home.

Both times he fought hard to return to the community.

Today, Joe lives in his own apartment in Chester County and is enjoying the freedom created by the services funded by the OBRA Waiver. He is receiving services 24 hours a day, seven days a week.

Joe says the home and community-based waiver is the government tool that saved his life. He used a mouth controller to type the following message on his home computer.

“The opportunity to remain in the community means I will escape the fate of most of my helpless brothers and sisters who are doomed to live out their lives with no control of any aspects of their life; no say in what they eat; no opportunity to read a book or watch a movie; not even any guarantees of protection under the law.

Most of all, this opportunity means I can pursue my aspirations; meet my responsibilities to my family, friends and the community.”



Joe Pepe uses a mouth controller to write emails and to stay connected in ways not practical for nursing facility residents.

Even for people with the most severe disabilities who need round-the-clock care, home and community based services are realistic and safe.

MERLE SMYSER

Cumberland County

Merle Smyser was diagnosed with Parkinson’s Disease 28-years-ago. By 2005 he couldn’t stand or walk and was hospitalized with an infection. Merle and his wife Joyce decided his only option was to move into a nursing home.

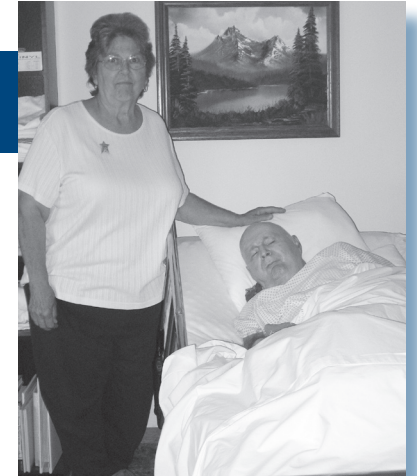
For nearly 18-months, Joyce worked during the day and visited Merle in the evening. His health slowly improved and he wanted to go home with Joyce.

In August 2006, Merle got his wish. He enrolled in the Aging Waiver Program to get the quality services he needs at his own house. Joyce says, “Merle was so happy to come home that he cried. Tears ran down his face.”

Today, Merle is 75 and has a special lift to get out of bed and uses a feeding tube. Waiver-funded personal care attendants visit his home daily to help with routine activities and a nurse checks his feeding tube.

“Merle was so happy to come home that he cried. Tears ran down his face.”

Because of the home and community-based waivers, Merle is living with significant disabilities in the comfort of his own home and enjoying his life with Joyce and their family.



Merle and Joyce Smyser in their living room. Merle lived in a nursing facility for nearly 18 months. Waiver-funded personal care attendants now visit his home daily.

KATHY HERTZOG

Erie County

Kathy has several disabilities, including a possible spinal cord injury caused at or during birth, which limit her mobility. Her secondary disabilities now include scoliosis, asthma, osteoporosis, tachycardia, migraine headaches, and environmental sensitivities.

Thanks to community based care waivers, Kathy is living a healthy and fulfilling life. She receives 13 hours of attendant care services a day and she uses the consumer directed model, which means Kathy hires and trains her waiver-funded attendants.

The freedom the services create has enabled Kathy to become a business owner and to give back to her community. She is a college graduate with a Communications degree and is on the boards and committees of numerous Independent Living and non-profit organizations.

She's also the President and CEO of an online website which provides services to landlords and property investors nationwide. She maintains and manages personal and business websites, a business blog, and moderates a free online business discussion group.

Kathy believes that without Home and Community Based waivers she would have died in a nursing home long ago.



Kathy Hertzog has several disabilities that limit her mobility. Waiver services have enabled her to live in the community, earn a college degree and own a successful online business.

DOLORES NORDIN

Montgomery County

Dolores is a retired special education teacher who is used to helping others; but now she relies almost totally on her caregivers. At age 65, she lives in excruciating pain and is unable to care for her basic needs, because of a debilitating illness. Essentially bed bound for twelve years, she stayed in a nursing home for a time.

“While the staff there was nice; they didn’t care about me the person. To them I wasn’t family. I was just one of their many patients. To me that’s what the Waiver Program is all about ... Family.”

The Aging Waiver Program has given Dolores back a life. She’s returned home to her husband, children, friend Ron and aide Tracy. Instead of being confined to a nursing facility bed she’s up everyday in her wheelchair.

Best of all she is able to be with her husband Jerry, the love of her life. “Jerry is my major caregiver. He puts the care in caregiving. I live in constant pain but when I cry at night, Jerry holds me and tells me it’ll be okay. His touch melts the pain away. In a nursing home they would just close the door. That’s the difference. The Waiver Program lets me have that hug. They keep me going with heart and family and to me that’s what life is all about.”

“I live in constant pain but when I cry at night, Jerry holds me and tells me it’ll be okay. His touch melts the pain away. In a nursing home they would just close the door. ”



When Dolores Nordin cries at night from excruciating pain her husband holds her. Their love helps reduce her pain.

PATRICIA PUGLIESI

Washington County

It was not the life she had hoped to share with her mother, but Virginia Pugliesi of Charleroi, PA is honoring her mother's wishes to remain at home. Three years ago, a devastating series of illnesses including heart attacks, mini-strokes, kidney infections, and partial removal of her stomach changed every aspect of the lives of Patricia Pugliesi and her daughter



Patricia Pugliesi requires 24 hour care. She's able to live at home with her daughter, Virginia, and grandson, River, thanks to the Aging Waiver Program.

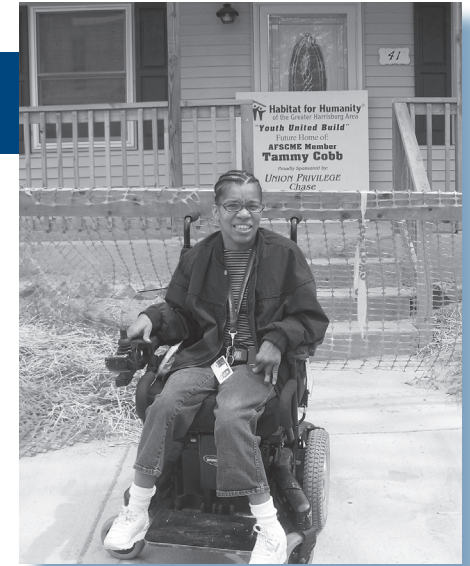
Since then Patricia, age 68, has spent a great deal of time in hospitals and nursing homes and her family feared that she would never be able to come home. Though she now requires 24 hour care, including being fed through a tube in her stomach, and needing total assistance with every need, she lives at home with her daughter and grandson, River. The Aging Waiver Program provides much needed assistance and relief to her family. The Visiting Nurses closely monitor Patricia's changing condition.

Fortunately she's making progress and is now able to take some foods by mouth and her weight is now back up to 100 lbs. Being together, and keeping her promise to her mother is what's important to Virginia and she is grateful to the PDA Waiver program for helping make it happen. "This is the best decision I ever made."

TAMMY COBB

Dauphin County

Tammy has disabilities which significantly limit the use of her arms and require her to use an electric wheelchair. She lives with her daughter and parents in Harrisburg. She is on the OBRA waiver and receives 4 hours of attendant services a day and a physical therapy session every week. Thanks to the attendant services she receives, she is able to hold



Tammy Cobb, a person with significant disabilities, poses in front of her own home. Waiver-funded attendants visit the house daily.

down a full time job and is a taxpayer. Her waiver-funded attendant gets her up in the morning, helps her wash, does her hair, gets her dressed and helps get her on the wheelchair accessible van which takes her to work. The attendant returns when Tammy comes home from work to help her change and do her household chores.

Tammy will soon realize the American dream of owning her own home. Habitat for Humanity is building a house for Tammy and her daughter (see photo). When she moves in, her waiver services will increase to teach her more independent living skills such as cooking, bill paying, doing laundry, etc. The waiver will also provide her with specially designed cookware and other adaptive equipment she will need to perform daily household chores.

Tammy is a prime example of how Home & Community Based Waivers can enable people with significant disabilities to become taxpayers and homeowners rather than permanent residents of nursing homes and other institutions.

Credits

Disability Rights Network of Pennsylvania

1414 N. Cameron St. • Suite C • Harrisburg, PA 17103
717-236-8110

Pennsylvania Association of Area Agencies on Aging

525 S. 29th St. • Harrisburg, PA 17104
717-541-4214

Pennsylvania Health Law Project

1414 N. Cameron St. • Suite B • Harrisburg, PA 17103
717-236-6310

Pennsylvania Statewide Independent Living Council

2 N. Second St. • Suite 100 • Harrisburg, PA 17101
717-364-1732

Living at Home with Major Disabilities



HCBS Waivers give people with significant disabilities the freedom to live at home rather than as permanent residents of nursing homes.