



January 27, 2016

VIA EMAIL

Theodore Dallas, Secretary
Department of Human Services
625 Forster Street, Third Floor
Harrisburg PA 17120

Dear Secretary Dallas,

We write on behalf of more than 35 organizations and individuals that serve thousands of Pennsylvanians to request that you reconsider the Department of Human Services' (DHS) decision to raise the minimum age of eligibility for Community HealthChoices.

Currently, the minimum age of eligibility for the Attendant Care, Independence and OBRA waivers is 18. However, the Community HealthChoices' Request for Proposal states,

CHC will serve adults age 21 or older who require [Medicaid Long Term Services and Supports] (whether in the community or in private or county nursing facilities) ..., and current Participants in DHS' [Office of Long Term Living or OLTL] waiver programs who are 18- to 21-years-old.

RFP at 7 (emphasis added). In other words, the minimum age for home and community based services administered by OLTL will change to 21.

Many advocacy groups, including the Pennsylvania Assistive Technology Foundation, Pennsylvania Health Law Project, and the Disability Rights Network, submitted comments opposing the age increase. See comments PHLP and DRN each submitted on the Sept. 2015 CHC Concept Paper. They urged the Department to allow participation for any 18- to 21-year-old who qualified for long term services and supports.

Unfortunately, DHS does not agree. The rationale the Department verbally provided at recent public meetings and hearings for the elimination of waiver

services for 18- to 21-year-olds is that Early and Periodic Screening, Diagnostic and Treatment (EPSDT) covers all the services these young adults need.

We strongly disagree. The majority of the people under 21 who are enrolled in OLTL waivers have physical disabilities—e.g., muscular dystrophy, cerebral palsy, spina bifida, and spinal cord injury; disabilities that significantly limit mobility. Some have respiratory or other medical conditions requiring 24 hour care. EPSDT does not cover all the important services these 18- to 21-year-olds need to avoid institutionalization, such as respite, home modifications and residential habilitation. Raising the minimum age of eligibility for Community HealthChoices will create profound gaps in services.

Below are several examples of services that keep young adults in their homes and communities and out of institutional care. Some are clearly not covered by EPSDT. Unless the Department is prepared to tell Physical Health Managed Care Plans in HealthChoices (PH-MCOs) that they must cover each of these items for any person under 21 who needs them, it is putting 18- to 21-year-olds at serious risk of institutionalization:

- Home Modifications. People with physical disabilities often need home modifications. These modifications include barrier-free showers, widened doorways, ramps into and out of a home, and stair glides. By the age of 18, these men and women are of adult height and weight – and it’s often very difficult, if not impossible, for them to be safely lifted, transferred or carried. Home modifications, one of the basic elements of OLTL waiver services, have been considered, whether rightly or wrongly, an uncovered service under EPSDT. The Department now expects 18- to 21-year-old adults and their families to pay for home modifications.
- Vehicle Modifications. Almost all wheelchair users need modifications to their vehicle to get to doctor appointments, go to the grocery store or participate in the community. Common modifications include hand controls, a ramp or lift, lowered floor and tie downs. Most wheelchairs, and certainly powered ones, do not fit in a vehicle that hasn’t been adapted. Standard adaptations cost appropriately \$22,000; the chassis of a Dodge Caravan (the least expensive vehicle that can be adapted with a lift) is approximately \$26,000. OLTL waivers include vehicle adaptations (and not the chassis) as a covered service.

- Assistive Technology (AT). AT is any device that helps a person with a disability do the things they need to do. AT devices make it possible for a person with a disability to achieve a more independent and productive life. AT includes Durable Medical Equipment (DME¹), but it also includes much, much more. Environmental controls (devices that can open doors, turn on lights), sensory-activated faucets, tablets with specialized apps, eye gaze systems and voice-activated software are all examples of assistive technology devices that do not qualify as DME. The Department construes EPSDT benefits to cover DME, but to our knowledge, the Department does not cover any other type of AT under EPSDT.
- Respite. Although home health services are a covered benefit under EPSDT, unpaid family members provide much of the supports needed by young adults with disabilities. In fact, for youth needing 24-hour care, parents are expected to devote every minute of their free time to providing that care, skilled or otherwise. EPSDT only covers services when parents are unable to or unavailable due to other responsibilities. To avoid burnout, caregivers need an occasional break. Respite is an allowable service under OLTL waivers that could make all the difference to a family.
- Residential Habilitation. Parents are not required to provide a home to their adult children, including those from 18 to 21, much less provide 24-hour care to them. Youth over 18 years of age, if not already in the child welfare system, cannot access a home or any services or supports through that system, if their parents can or will no longer do so. A 19-year-old with a respiratory condition requiring a tracheotomy or ventilator, whose single parent dies, would literally have nowhere to live but a nursing home (or similar facility), without access to residential habilitation through a waiver.

It is cruel and unrealistic to expect 18- to 21-year-olds with physical and developmental disabilities, especially those in low- to moderate-income households, to pay the full costs of these essential services and supports. Moreover, they are

¹ Durable Medical Equipment (DME) consists of items primarily and customarily used to serve a medical purpose; items reasonable and necessary for the individual participant; items that withstand repeated use; items not useful to a person in the absence of illness or injury and appropriate for use in the home.

financially impossible for any young adult with disabilities raised in the child welfare system who wants to become independent from foster care.

Raising the minimum age of eligibility for Community HealthChoices is inapposite to basic principles of adolescent development. As youth move into adulthood around the age of eighteen (often on completion of high school), their choices and challenges shift to decisions about post-secondary education or vocational training, entry into and transitions within the labor market, moving out of the family home, and sometimes marriage. These are positive milestones. But, the Department's current approach will delay, at a critical time, this transition to adulthood. Unaltered, Community HealthChoices will isolate young adults with disabilities; unnecessarily blocking their path to becoming independent and productive.

We also fail to see any fiscal benefit to raising the age of eligibility for Community HealthChoices. The cost of EPSDT covered services will transfer from HealthChoices to Community HealthChoices; and, the home and community-based supports mentioned above are already covered for individuals 18 and older under three of OLTL's existing waivers.

We urge you to fix this critical problem before the Community HealthChoices Request for Proposal (RFP) is finalized. We would be happy to meet in person or via conference call to discuss. Please contact Laval Miller-Wilson of the Pennsylvania Health Law Project (215-625-3874) so that we can coordinate a time to get together.

Sincerely yours,

Susan Tachau
PENNSYLVANIA ASSISTIVE TECHNOLOGY FOUNDATION

Laval Miller-Wilson
David Gates
PENNSYLVANIA HEALTH LAW PROJECT

Rachel Mann
DISABILITY RIGHTS NETWORK OF PENNSYLVANIA

cc (via email):

Leesa Allen, Deputy Secretary, OMAP
Jennifer Burnett, Deputy Secretary, OLTL
Jen DeBell, Policy Director

**Additional Groups & Individuals Urging Community
HealthChoices Include Young Adults Ages 18 to 21**

ACQUIRED BRAIN INJURY NETWORK OF PENNSYLVANIA (ABIN-PA)

ACTIONAIDS

ADAPT OF WESTERN PA

ALLIES FOR CHILDREN

THE ARC OF PENNSYLVANIA

THE ARC OF GREATER PITTSBURGH AT ACHIEVA

BAYADA HOME HEALTH CARE

CENTER FOR ADVOCACY FOR THE RIGHTS AND INTERESTS OF THE ELDERLY
(CARIE)

COMMUNITY LEGAL SERVICES OF PHILADELPHIA (CLS)

CONSUMER HEALTH COALITION & ITS HEALTH COMMITTEE FOR PEOPLE
WITH DISABILITIES

DARYL ANDRESS, MEMBER OF THE MANAGED LONG TERM SERVICES AND
SUPPORTS SUBCOMMITTEE OF THE MAAC

INSTITUTE ON DISABILITIES AT TEMPLE UNIVERSITY

FRED HESS, CONSUMER MEMBER OF THE MANAGED LONG TERM SERVICES
AND SUPPORTS SUBCOMMITTEE OF THE MAAC

GRACE EGUN, ADVOCATE

JENNIFER HOWELL, CONSUMER MEMBER OF THE MANAGED LONG TERM
SERVICES AND SUPPORTS SUBCOMMITTEE OF THE MAAC

JILL SPECTOR, ESQ., PARENT ADVOCATE AND PARENT OF A TEENAGE SON
LIKELY TO QUALIFY FOR LTSS

JUVENILE LAW CENTER (JLC)

KYLE MERBACH, ADVOCATE

LEGAL CLINIC FOR THE DISABLED (LCD)

LIBERTY COMMUNITY CONNECTIONS, INC.

LIBERTY RESOURCES, INC. (LRI)

MICHAEL PELLICANO, CONSUMER MEMBER OF THE MANAGED LONG TERM
SERVICES AND SUPPORTS SUBCOMMITTEE OF THE MAAC

NAMI SOUTHWESTERN PENNSYLVANIA (NAMI)

PARENT EDUCATION & ADVOCACY LEADERSHIP CENTER (PEAL CENTER)

PENNSYLVANIA COUNCIL ON INDEPENDENT LIVING (PCIL)

PENNSYLVANIA ADVOCACY & RESOURCES FOR AUTISM & INTELLECTUAL
DISABILITIES

PENNSYLVANIA HEALTH ACCESS NETWORK (PHAN)

PENNSYLVANIA HOME CARE ASSOCIATION (PHCA)

PENNSYLVANIA PARTNERSHIPS FOR CHILDREN (PPC)

PENNSYLVANIA STATEWIDE INDEPENDENT LIVING COUNCIL (PASILC)

REHABILITATION AND COMMUNITY PROVIDERS ASSOCIATION (RCPA)

REMED, A PROVIDER OF BRAIN INJURY REHABILITATION SERVICES

RICHARD KOVALESKY, CONSUMER MEMBER OF THE MANAGED LONG TERM SERVICES AND SUPPORTS SUBCOMMITTEE OF THE MAAC

SEIU HEALTHCARE PENNSYLVANIA (SEIU)

SELF DETERMINATION HOUSING PROJECT (SDHP)

UNITED CEREBRAL PALSY OF PENNSYLVANIA (UCP OF PA)

UNITED HOME CARE WORKERS OF PENNSYLVANIA

VISION FOR EQUALITY