



**House of Representatives**  
COMMONWEALTH OF PENNSYLVANIA

**HOUSE DEMOCRATIC POLICY COMMITTEE HEARING**

**Topic: Homecare in Pennsylvania**

**Baldwin Borough Municipal Complex – Pittsburgh, PA**

**October 7, 2019**

**AGENDA**

- 2:00 p.m. Welcome and Opening Remarks
- 2:10 p.m. Kevin Hancock,  
Deputy Secretary for the Office of Long Term Living  
Pennsylvania Department of Human Services
- 2:20 p.m. *Questions & Answers*
- 2:40 p.m. Panel One:
- Shona Eakin, CEO, Voices For Independence
  - Missy Stritzinger, Caregiver
  - Jennifer Bell, Caregiver
  - Grace Johnson, Member, United Homecare Workers of Pennsylvania
  - Norman Jones, Member, United Homecare Workers of Pennsylvania
- 3:10 p.m. *Questions & Answers*
- 3:30 p.m. Panel Two:
- Sherri Hewitt Laid, Owner, Caring Mission Home Care & Home Health
  - Amy Avolia, Care Director, Caring Mission Home Care & Home Health
  - Carl Berry, Executive Director, Community Resources for Independence
- 3:50 p.m. *Questions & Answers*
- 4:10 p.m. Closing Remarks

## Direct Care Workforce

Kevin Hancock  
Deputy Secretary  
Office of Long-Term Living

House Democratic Policy Committee  
October 7, 2019



**pennsylvania**  
DEPARTMENT OF HUMAN SERVICES

Thank you very much for the opportunity to present information on this very important topic. My name is Kevin Hancock. I am the Deputy Secretary for the Department of Human Services Office of Long-term living. I am presenting on behalf of Secretary Teresa Miller on the near and present staffing crisis in the long-term care system.

In short, one of the most pressing and serious challenges facing the Pennsylvania long-term care system is the reality that the population of people becoming eligible for home care services is growing rapidly, and recruitment and retention of the direct care workforce cannot keep up with this demand.

As background, direct care workers, also known as personal care workers, meet the needs of the elderly and people with disabilities who are not able to care for themselves on their own. These workers provide an estimated 70 to 80 percent of the paid hands-on long-term care and personal assistance received by Pennsylvanians who are elderly or living with disabilities or other chronic conditions. They help with bathing, dressing, and a host of other tasks associated with activities of daily living. They are considered a lifeline for those they serve, as well as for families and friends struggling to provide quality care. This includes individuals who need these services in the community or in nursing facilities.

Because of the growing aging population and the growing need for these supports, direct care workers constitute one of the largest and fastest-growing workforces in the country, playing a vital role in job creation and economic growth, particularly in low-income communities.

Currently:

- In Pennsylvania, there are nearly 220,000 direct care workers.
- The median hourly wage for direct care workers in this state is just over \$11 an hour. These wages have increased slowly in the past decade during a time when the direct care workforce is seeing growing demands.
- Pennsylvania is a rapidly aging state – our need for a robust, skilled, and dedicated direct care workforce is more important than ever.

The most significant challenge we face with this workforce which affects the stability of the long-term care system as a whole is the direct care worker turnover rate. The turnover rate is estimated at 44-65 percent each year. The reasons for this are straightforward. Low wages, inadequate benefits, few opportunities for professional growth and advancement, and the stressors of excessive workloads are causing people to seek employment in other sectors at a time when these services are most needed. More than half of the direct care workforce use some sort of public assistance benefits, and many more qualify but do not use these programs, creating additional burdens on an already stressed workforce.

The Department of Human Services is very concerned about this issue and is addressing it as part of the implementation of Community HealthChoices by working with representatives of the direct care workers to brainstorm workable solutions.

The newly implemented Community HealthChoices (CHC) program has been designed to support solutions to this challenge. The flexibility offered in a managed care model allows for opportunities for innovation and incentives that may support the development of a robust workforce needed to support a growing long-term care population.

The three managed care organizations (MCOs) participating in CHC are required to institute workforce initiatives that improve the recruitment, retention, and skills of direct care workers. These initiatives may include, but are not limited to, enhanced payments and other incentives to providers, participant-directed employers, and direct care workers to promote education, training, and other initiatives designed to enable direct care workers to become a more integral member of the person-centered planning team.

The MCOs are also pursuing a standardized training curriculum for direct care workers across the long-term care continuum in order to provide educational opportunities that advance superior care and create a pathway for those looking to make a career in this critical field. The MCOs are also exploring ways to increase wages or provide other financial incentives to direct care workers, such as loan forgiveness, benefits, housing stipends, tax credits, and peer support incentives.

CHC was designed with this very challenging and pervasive problem in mind. We are committed to monitoring the progress of this work and looking for new opportunities and methods to support the direct care workforce and the growing number of Pennsylvanians who rely on and benefit from their care through the managed care model.

In addition to CHC related activities, DHS has been working with representatives of the direct care workforce to identify opportunities to improve wages, opportunities to access health care and other employment-related benefits, and to improve training. Secretary Miller and I meet with these representatives on a monthly basis to discuss the challenges they face in their work that put their long-term commitment to this vocation at risk. We discuss and consider options and alternatives that may alleviate the turnover and are reviewing proposals that are specifically designed to address training and benefit challenges for this workforce that include a training proposal that mirrors the Long-term Care Council's suggestions to support progressive career advancement.

With these and other initiatives, Governor Tom Wolf's administration is supporting the belief that the direct care workforce is the foundation that makes a high-quality long-term care system possible for a growing number of people. Without a robust direct care workforce, the entire long-term care system is at risk.

We must also have a serious conversation about wages for this population. As I mentioned previously, the *median* hourly wage for the direct care workforce is just over \$11 an hour, meaning people starting out in this field are making less than this. Retention is a problem in this field, and high turnover affects patients needing support the most. Seniors and people with disabilities can have complex needs, and a robust, experienced field is necessary to deliver the quality of care they deserve and need to live their best quality of life.

Direct care jobs keep our economy moving. They don't just provide support to the people they care for – they enable their clients' loved ones to go to work every day or sleep at night knowing their loved one is safe and cared for. If we are going to support a high-quality home care system, investing in the people that make this possible is imperative. People pursue careers in direct care because they want to help others. We need to be sure that it is a field that they can afford to stay in and grow their careers. Investing in a minimum wage increase will help make this possible and will support the long-term health and strength of the direct care workforce.

Thank you for the opportunity and we will be happy to discuss further or take any questions.



Testimony

House Democratic Policy Hearing

Sherri Hewitt Laird

Owner, Caring Mission Home Care and Home Health

Member, Pennsylvania Homecare Association

October 7, 2019

Good Morning,

Chairman Sturla, Representative Kortz and committee members. Thank you for this opportunity to discuss home-based care in Pennsylvania. My name is Sherri Hewitt Laird, Owner of Caring Mission Home Care and Home Health. I am also a member of the Pennsylvania Homecare Association, a state trade association representing more than 700 organizations that bring medical care, by our home health agencies; personal care, provided by non-medical agencies and end of life care provided by our hospices --- all agencies provide care and support into thousands of people's homes everyday across the Commonwealth.

Joining me today is Amy Avolia, Care Director at Caring Mission Home Care. Our agencies provides services to consumers in Allegheny, Washington, Fayette, & Greene counties.

Caring Mission Home Care has been in business for 19 years while our Home Health division started providing services 11 years ago. Over the past year Caring Mission Home Care & Home Health provided services to approx. 1200 residents of Southwestern Pa. Currently, our Home Care & Home Health employs more than 185 clinicians & caregivers.

We would be more than happy to answer any questions about my testimony following my remarks.

I will lead off today's discussion providing you with a brief overview of home-based care – what it is, who we serve, and who pays, and then I will talk about the specifics of being a provider of in-home care. Finally, I will address one of the most challenging issues facing providers – the workforce shortage.

## OVERVIEW

At the Pennsylvania Homecare Association, we like to say, "There's No Place Like Home in Pennsylvania." It is the desire of most individuals to age in place, which has become even more important in our discussions with elected officials because Pennsylvania has the 4<sup>th</sup> fastest aging population in the country. These are individuals that want to, and deserve to, receive care at home and to age in place. Under the Community HealthChoices waiver, which is part of the Medical Assistance program here in Pennsylvania, individuals are receiving non-medical, personal assistance services. Agencies, like mine, provide care to over 80,000 individuals in the Southwest part of the state alone.

## ISSUES FOR PROVIDERS

As lawmakers, you will be asked to address several issues throughout this session dealing with older Pennsylvanians and individuals with disabilities. One in particular will be the state's movement to managed care when it comes to long term services and supports. Community HealthChoices has been in both the southwest and southeast regions of our state with the remainder of counties coming into managed care on January 1, 2020. This has been a tremendous shift for providers as well as consumers. Prior to managed care, agencies billed Medicaid directly – services were provided, time sheets signed and off went the bill. Now, under Community HealthChoices, providers must make sure they are contracted with all three MCOs – UPMC, PA Health and Wellness and Amerihealth. Consumers must choose which MCO they would like to have as their care coordinator.

Providers have had to learn billing systems for three different insurance companies and this year, agencies will also be required to implement an electronic visit verification system, which documents the time spent with a consumer and the types of services that were provided, outlined in the federal 21<sup>st</sup> Century Cures Act. Home Care providers under the Medicaid program are paid on 15-minute increments and depending on where the person who is receiving the service lives, reimbursement ranges from a low of \$17.52 in Pittsburgh to \$19.52 in Philadelphia.

This will increase by 2% on January 1, 2020 after a successful advocacy campaign by PHA and providers around the state. We thank you for your support.

From that hourly rate, agencies must do criminal background checks on all employees, which was \$8 in 2017 and today has increased to \$22, a child abuse check if a child resides in the home, which has increased from \$10 to \$15, \$5, and if OAPSA legislation passes, every employee will be required to have an FBI clearance, costing another \$24.

All these increases in unfunded mandates, plus training, the TB checks required by our licensure, and our desire to pay our direct care workers a living wage have home care agencies worried about how much longer they can continue to provide services under the Medicaid program in PA. With the increasing enrollment of seniors every month – it is now over 1,000, we must stabilize this provider community and address the issue of better wages for the people who are truly lifelines to thousands of older Pennsylvanians.

Governor Wolf's administration has adopted policies to enable more people to remain in their own homes for as long as possible, which is something we applaud and fully support. We also applaud this committee's willingness to hold a hearing on the issue of access to the services, that we feel is due, by and large, to workforce shortage issues.

## WORKFORCE SHORTAGE

We are proud of the work we do to ensure thousands of Pennsylvanians who wish to stay safe and independent within their communities are able to do so. But, like many others within our industry, we are facing a major workforce crisis. According to a Home Care Benchmarking Study by national data leader Home Care Pulse released earlier this year, the turnover rate for direct care workers is at an all-time high – 88% in 2018, up from 50% in 2016.

This crisis stems from the lack of funds available for agencies to recruit and retain a qualified workforce. Homecare providers struggle to compete with other care settings and industries that can pay more in wages because the Medicaid reimbursement rates for homecare are so low. Caregivers can work at Chick-Fi-La and make \$15-\$16 per hour while we receive only a \$1.50 more to take care of our seniors, hire, perform background checks, train, provide benefits, schedule & remain in compliance with 3 different CHC providers and the Department of Health. Providers across the Commonwealth rely on these state-funded reimbursement rates to not only pay our staff wages, but also to provide them with benefits, training, supplies, supervision, and transportation. As these rates continue to lag homecare providers are severely limited in our ability to recruit and retain the workforce necessary to keep up with the growing number of individuals who seek to receive care at home.

This recruitment issue affects all direct care professionals across the entire homecare industry: We are finding it increasingly difficult to recruit and retain **homecare** aides—those individuals who support disabled adults and seniors with activities of daily living.

Pennsylvania's **homecare** aides and skilled nurses do important work: The care they provide enables tens of thousands of residents to live and thrive at home, in their communities, and avoids unnecessary stays in costlier settings such as nursing homes and hospitals. We believe this important work should be fairly compensated.

Earlier this session the Governor had proposed an increase to the state's minimum wage. While PHA supports this effort and agrees our aides should be paid a living wage, the industry is unable to account for the increased costs necessary to provide a wage increase unless the legislature acts and increases reimbursement rates in tandem with these mandatory wage increases.

***Today, I urge you to consider these pressures as you make decisions that affect vulnerable Pennsylvanians that rely on home care to stay safe and independent and out of costlier settings.***

As I had stated earlier, Pennsylvania is one of the top most graying states in the country, ranking fourth in the nation with the highest population over 85 years old. Moreover, this population is expected to increase 20 times faster than the overall population. Now is the time to act. Pennsylvania will undoubtedly need qualified workers to provide the necessary care for these individuals, and I am asking you to ensure that care is available and accessible for those who need it most.



The advantages of keeping Pennsylvanians in their homes and in their communities are well known by the committee and your colleagues in the General Assembly. We commend you for recognizing the issues the home health care industry is facing and for being a part of this conversation here and now. Thank you for hearing our thoughts today. We are happy to answer any questions you may have at this time.

**House Democratic Policy Committee Public Hearing  
Regarding homecare issues impacting residents across Pennsylvania**

**MONDAY - 10/7/19  
Baldwin Borough Municipal Complex  
3344 Churchview Avenue, Pittsburgh**

**Carl Berry  
Board Member, PA Provider Coalition Association  
And CEO for Community Resources for Independence**

Thank you Chairman Sturla, Rep Kortz and other members here today for the opportunity to speak before you and describe the challenges of agencies such as Community Resources for Independence (CRI).

CRI is a community based, non-residential, non-profit corporation that provides services and supports to individuals with disabilities in order to maximize their independence and the accessibility of the communities in which they live. We provide personal assistance services in 48 counties of Pennsylvania. CRI is one of more than 500 federally funded Centers for Independent Living across the nation established by people with disabilities for people with disabilities.

I also serve on the board of the Pennsylvania Providers Coalition Association (PA-PCA), which is a statewide organization of similar community providers in Pennsylvania. Agencies that belong to PA-PCA serve seniors and people with physical disabilities receiving a range of home and community based services as participants in the PA Department of Human Services, Office of Long Term Living.

It is the mission of the PA-PCA to continuously improve and promote the availability, accessibility, and quality of the full range of home and community based services in the Commonwealth. PA-PCA strives to do so in a way that offers consumer choice, control, and personal independence to the maximum extent possible.

As you may know, the FY19-20 included a 2% increase to Personal Assistance Services (PAS) and Home Community Based Services (HCBS) services. Thank you to the State Legislature and to Governor Tom Wolf's administration for this increase. It is very much appreciated, very much needed, and a positive step in the right direction.

But, the rate for Personal Assistance Services (PAS) and Home Community Based Services (HCBS) services critically needs to be corrected beyond the 2% increase that is to be effective January 1 2020. Provider agencies need assistance in recruiting and retaining qualified and

skilled direct care workers to support our most vulnerable citizens – the elderly and people with physical disabilities - in their homes.

Prior to the increase in the current budget, the last HCBS waiver rate increase was over five years ago in 2014 for 2.1%. In 2012, HCBS waivers were reorganized from five regions into four regions, with two of the regions experiencing a decrease in rates of 5% and 8%. The 2012 waiver region reorganization followed a 2010-2011 study by the state's consultant, Mercer Consulting. Mercer clearly recommended on the front page of the study's report that the state "appropriately update the applicable fee schedule" as of June 30, 2013, and annually thereafter, but despite the consultant's recommendation, no rate readjustment happened in 2013, 2015, 2016, 2017, 2018, or 2019.

For perspective, a 2% rate increase is approximately thirty-nine cents. Our rates have gone up thirty-nine cents over five years.

Prior to 2012, the last rate adjustment was 2008 for approximately a 1% increase. Rates have not kept up with inflation, significant wage pressures, and unfunded mandates including the Affordable Care Act and program requirements like staff training and mentoring, quality assurance, and compliance. Training, for example, is not billable time, but so very necessary.

Travel time, mileage expense reimbursement, shift differentials, and overtime are facts of life in agency model home care, but these are not billable. (Overtime in the participant-directed model is funded, why not in the agency model?) Costs have outstripped rates, and the supports to people with disabilities and the aged are critically unsustainable.

I sit on a workgroup in the Governor's Long Term Living Council, which was tasked with addressing significant barriers to services in our long term living system and making recommendations for solutions. The Council produced its comprehensive Blueprint report earlier this year. A common thread and core tenant throughout the Blueprint was, increase direct care worker wages in direct conjunction with appropriate provider rates. One specific recommendation is to increase the minimum wage, but with a corresponding increase in provider rates. Indeed, a further rate increase is desperately needed regardless of changes to the minimum wage, but any raises to minimum wage should also include an increase in rates so that providers can afford higher direct care worker pay rates.

Pennsylvania's goal as stated by both Governor Wolf's and the Legislature is to drive long-term savings through expanding HCBS care. However, increasing the number of participants on HCBS programs without increasing the per unit rates to sustainable levels leads to the provider network losing money faster, jeopardizing the provider network's sustainability and thus jeopardizing the very system intended to save Pennsylvania money in the long run. In a very real-world example, in one county I serve, the county's low provider rates are below the cost to provide the services – I cannot hire direct care workers at that rate to deliver the supports and services. This shortage of direct care workers and has forced me to give notice to eighteen

elderly citizens that we could no longer afford to support them. Even in the Community HealthChoices managed care program, because of the low provider rates and the direct care worker shortage, my organization and many providers like us have to pick and choose which participants we can serve, when those participants are asking us for help.

We are at a tipping point. The number of Pennsylvanians seeking to receive their supports in their homes and communities continues to grow. The cost of providing these in-home services also continues to grow. The shortage of qualified and available direct care workers continues to worsen. The cost of the already more expensive alternative, i.e. nursing institution placement, also continues to worsen. Yet, the rates paid to HCBS providers remains stagnant.

Services to our older adults and people with physical disabilities are in a crisis. The solution will require our legislators, our Office of Long Term Living, the managed care organizations, and our providers to come together to affect positive change.

Both clients and caretakers are personally impacted by the fact that Personal Assistance Service (PAS) and Services and Home Community Based Services (HCBS) Rates had not been increased significantly in many years. Due to this lack of rate increases, these types of services are still at a tipping point, which will be devastating to both consumers and attendants.

We are at a tipping point. The inadequate PAS rate is creating an artificial and arbitrary barrier to access to services and a barrier to participants' choice of providers. Due to the PAS rate not supporting the costs and wages of providing services, PAS providers throughout the state report that they or their local counterparts are unable to accept referrals and/or are having to resort to selectively accepting consumers.

We are at the tipping point. PAS providers are competing for employees with big-box retailers, convenience stores, nursing homes, and hospitals, and a myriad of other employers. These other employers can raise their prices to offset increases in costs, including wages and benefits. However, in home personal assistance service providers cannot. So, there is a drain of direct care workers out of HCBS and into other lines of work to find higher wages, benefits, and stable schedules.

We are at a tipping point. At a recent PAPCA meeting in Harrisburg and another meeting in Erie, representatives from all three of the managed care companies have said that they have not decided whether they will pass all or any of the 2% increase on to the personal assistance services providers, and they may require more from the providers to obtain any of that 2% increase.

We are asking that the legislators in attendance today continue to work with the Administration to set appropriate budget funding by establishing a rate-setting methodology. To avoid a re-occurrence of the problems caused by a rate insufficient to cover the cost of providing this service, we are also asking the legislature to establish legislation calling for the regular resetting

of the PAS rate, using a sound and established rate-setting methodology, for both the fee-for-service system and the managed care system. We are asking the legislature to establish legislation calling for a provider rate floor for providers in Pennsylvania's Community HealthChoices managed care system, and to establish legislation calling for regular provider rate increases in Community HealthChoices that keep up with the cost of providing the services, such as minimum wage, electronic visit verification systems, insurances, and other mandates. These steps are critical so that we can step back from this tipping point and keep people in their homes and communities.

We are at a tipping point. A survey of Pennsylvania Provider Coalition Association direct service providers reveals 100% of respondents having some difficulties in hiring direct care workers due to the current PA Personal Assistance Services rates, with more than 77% of the respondents reporting significant difficulties due to the rate. The effect of low provider rates is affecting service coordination entities as well: a survey of the Service Coordination Entities shows 77% of SC respondents reporting difficulties finding PAS providers to take on participant's services.

We are at a tipping point. Personal Assistance Rates (PAS) and Services and Home Community Based Services (HCBS) cost one-half to one-third that of nursing home placement, and many consumers people prefer to age in place, in their own homes. While our area has seen some help, there has not been regular increases in the per unit rate for Office of Long Term Living Personal Assistance Services, and the rates have not kept up with the costs.

Based on data obtained from OLTL, the recent average annual cost per participant was approximately \$30,500. Under a current recommendation of a minimum of \$21.50 per hour, the average annual cost per participant would be estimated to be approximately \$34,000. To put this into perspective, the average cost of nursing home placement in Pennsylvania is \$108,000 (Genworth 2016 Cost of Care Survey).

That means for every person who goes to a nursing home because the local PAS provider cannot hire staff to meet the need, then the state pays roughly an additional \$75,000 to \$78,000 per person per year. Nursing home placement is an entitlement program. In the worst-case scenario, if there were no personal assistant service providers, then the state would have an additional 3.5 Billion cost (46,000 participants on the OLTL provided figures X \$78,000 additional cost). The number of participants continues to grow due to the aging demographic of Pennsylvania, so this figure may be low.

In comparison to the rates allowed to be paid by the Office of Long Term Living, the Office of Developmental Programs pays its providers for very similar services a rate of \$38.38 per hour, compared to a rough average of \$19.48, or approximately \$19.86 with the planned 2% increase in January. The Veterans Administration pays significantly higher per hour than OLTL, \$28 to over \$30 in some areas.

In closing, PA-PCA recommends that:

- Pennsylvania establishes a provider rate of \$21.50 per hour minimum as a start to re-establishing the rates, based on Mercer Consulting's rate study for Pennsylvania, aged to 2019 using the home health care market basket index.
- The legislature approves an appropriation to fully support an adequate provider rate, and to adjust that appropriation as necessary each budget year to properly support in-home and community based services.
- Legislation should be enacted to require a rate floor for the Community HealthChoices managed care program.
- However, this rate floor should be indexed to the home health care market basket index and adjusted yearly, and adjusted for increased costs such as an increased minimum wage.

This strategy will help us to step back from the tipping point and will help us to better serve the elderly and disabled citizens in Pennsylvania.

Thank you again for this opportunity.



For further information, please contact

- Carl Berry, Community Resources for Independence, 814-838-7222, [cberry@crinet.org](mailto:cberry@crinet.org)
- PAPCA President Tina Seidel, and legislative consultant Alex Rahn, VP, Wanner and Associates. Both can be reached at 717-378-3388, [arahn@wannerassoc.com](mailto:arahn@wannerassoc.com)





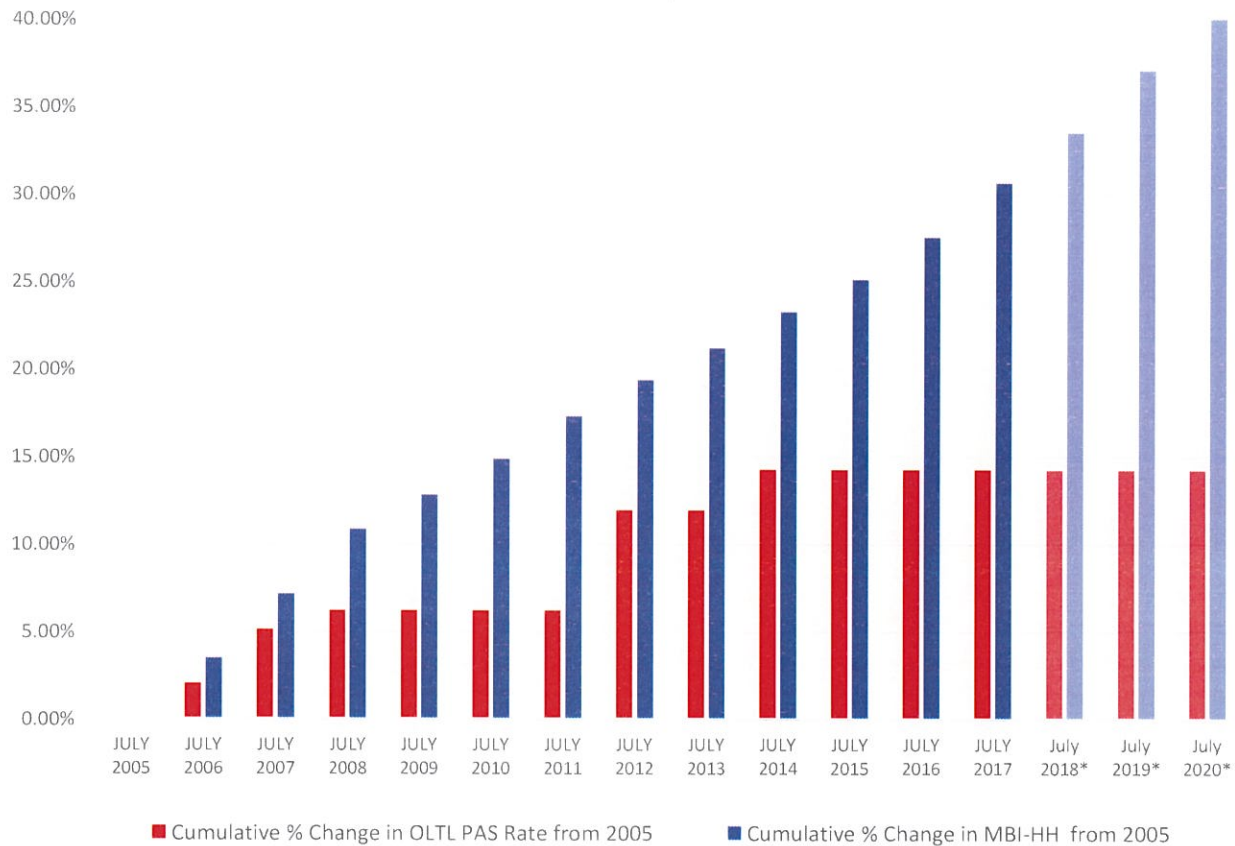
# Pennsylvania Providers Coalition Association

*Promoting Community Long Term Living Solutions*

908 North Second Street  
Harrisburg, PA 17102  
www.pa-pca.org

Phone: 717.441.6056  
Fax: 717.236.2046  
info@pa-pca.org

## History of the Cumulative Percent Change of Average OLTL PAS Rates Compared to Cumulative Percent Change in CMS Home Health Market Basket Index.



Date	Average OLTL PAS Rate	Average OLTL PAS Rate Percent Increase	Cumulative % Change in OLTL PAS Rate from 2005	Market Basket Index - Home Health Agency	Cumulative % Change in MBI-HH from 2005
JULY 2005	4.096			0.869	
JULY 2006	4.178	2.00%	2.00%	0.899	3.45%
JULY 2007	4.304	3.02%	5.08%	0.931	7.13%
JULY 2008	4.348	1.02%	6.15%	0.963	10.82%
JULY 2009	4.348	0.00%	6.15%	0.98	12.77%
JULY 2010	4.348	0.00%	6.15%	0.998	14.84%
JULY 2011	4.348	0.00%	6.15%	1.019	17.26%
JULY 2012	4.5825	5.39%	11.88%	1.037	19.33%
JULY 2013	4.5825	0.00%	11.88%	1.053	21.17%
JULY 2014	4.6775	2.07%	14.20%	1.071	23.25%
JULY 2015	4.6775	0.00%	14.20%	1.087	25.09%
JULY 2016	4.6775	0.00%	14.20%	1.108	27.50%
JULY 2017	4.6775	0.00%	14.20%	1.135	30.61%
July 2018*	4.6775	0.00%	14.20%	1.16	33.49%
July 2019*	4.6775	0.00%	14.20%	1.191	37.05%
July 2020*	4.6775	0.00%	14.20%	1.225	40.97%

\*Forecast, CMS Market Basket History and Forecasts March 2018. www.CMS.gov. Retrieved May 14, 2018



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**House Democratic Policy Committee  
Hearing on Homecare in Pennsylvania  
October 7, 2019**

On behalf of the Alzheimer's Association, we would like to thank Chairman Sturla, Representative Korts and members of the House Democratic Policy Committee for hosting an informational hearing about homecare in Pennsylvania. The Association appreciates the opportunity to submit written testimony to underscore the importance of access to quality in-home care (in addition to other community-based services) for those living with Alzheimer's Disease and other dementia, especially since those individuals are twice as likely to require home care services as those without the condition. Such services allow them to remain in their home and active in the community for as long as possible, reduce social isolation, help detect elder abuse and neglect, provide caregiver support and reduce public and private costs from unnecessary institutionalization.

The number of Pennsylvanians living with Alzheimer's and other dementia continues to rise at a steady rate, largely because the Baby Boomer Generation has reached the age when the risk of developing Alzheimer's significantly increases. Currently there are more than 400,000 Pennsylvanians living with the disease, with 676,000 caregivers providing 777,000,000 hours of unpaid care (estimated value of over \$9.73 billion) in Pennsylvania alone. The health care burden and costs associated with caring for someone with Alzheimer's is significant, reaching \$3.54 billion in Medicaid spending in Pennsylvania this year (*see also attached PA Alzheimer's Statistics Infographic*).

Even more concerning are projections that indicate the number of Pennsylvanians living with the disease will increase 14.3% by 2025, with state Medicaid spending expected to increase by 12.5%. This is an important concept to underscore given that Alzheimer's and other dementias span across a wide care continuum and the level and type of care needed for those living with the disease require increasing support as cognitive, behavioral, and physical functioning worsens over time (see Appendix 1).

In-home care (in addition to community-based services, collectively referred to as HCBS) occupy a growing portion of the care continuum needed for people living with Alzheimer's disease and other dementia. These services fall under the broader category of long-term services and supports (LTSS) funded primarily through Medicaid. Long-term services and supports includes extended care in settings like skilled nursing facilities, long-term care hospitals and nursing homes, in addition to the care options considered as HCBS, such as respite care, in-home services, adult day centers and transportation services, all of which are vital programs to those living with Alzheimer's or other dementia.





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**House Democratic Policy Committee  
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People with Alzheimer's live an average of four to eight years after diagnosis, though some live up to 20 years after diagnosis. The primary goal of HCBS is to enable people living with Alzheimer's and other dementia to remain in their home of choice and active in their community for as long as possible. Given that approximately 70% of older adults with Alzheimer's and other dementia live in the community, the availability of quality, person-centered, in-home services are absolutely vital to those living with the disease.

As previously noted, the progressive nature of Alzheimer's demands different types of care throughout the different stages of the disease. While nursing homes and other inpatient facilities play a vital role in the later stages of the disease, services performed in the home and community may be more appropriate – and more cost-effective – for the earlier and middle stages of the disease. This is especially true for those diagnosed with younger-onset Alzheimer's, who in some cases are as young as 40 years old. Those with younger-onset Alzheimer's face unique challenges when it comes to family, work, and finances and diagnosis can have a significant impact on their well-being and quality of life making access to these services even more important.

The Alzheimer's Association recognizes there are a number of factors and challenges that impact the level and quality of care provided through homecare services, which will only be complicated as the number of older adults and those living with Alzheimer's and other dementia living in the community continues to grow exponentially in the foreseeable future. In an effort to address the need to expand access to these vital services, we believe consideration should be given to the following:

- Identify means to expand the infrastructure of HCBS to account for the growing number of people living in the community with the disease;
- Develop and implement person-centered, dementia-specific care planning, assessments and other services; and
- Expand Medicaid financial and functional eligibility rules to account for cognitive impairment.

In addition, dementia training of those involved in the delivery of care can improve the quality of care and experiences for individuals with Alzheimer's and other dementias. Care workers may not have sufficient dementia-specific knowledge to effectively support those with Alzheimer's and other dementias. A cornerstone of providing quality dementia care is to ensure that all professional care staff involved in the delivery of care to people with dementia receive dementia-specific training to ensure the ability to: provide person-centered dementia care; communicate with individuals with Alzheimer's; address behavioral symptoms, including



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alternatives to physical and chemical restraints; and address specific aspects of safety, such as wandering.

Home and community based services bring so many layers of value to the lives of those living with the disease. They improve the quality of life for individuals and families affected by dementia, reduces costs for state governments by eliminating or delaying nursing home placement, and reduces the financial and emotional burden on families and those caring for them.

The Alzheimer's Association thanks Chairman Sturla, Representative Kortz and members of the House Democratic Policy Committee for the opportunity to provide written testimony on the benefits homecare services provide to the hundreds-of-thousands of Pennsylvanians living with Alzheimer's and other dementia and their caregivers, in addition to policy considerations that we believe can improve access and quality of homecare services delivered in Pennsylvania. We look forward to working with members of the Committee on this and other important matters of mutual interest.

Respectfully Submitted,  
Jen Ebersole, Director of State Government Affairs  
(717) 678-6464  
[jaebersole@alz.org](mailto:jaebersole@alz.org)



THE BRAINS BEHIND SAVING YOURS®

**House Democratic Policy Committee  
Hearing on Homecare in Pennsylvania  
October 7, 2019**

**APPENDIX 1**

<b>Pre-Clinical</b>	<ul style="list-style-type: none"><li>- Access to early detection and diagnosis services and referrals to appropriate providers</li><li>- Caregiving public awareness and education</li><li>- Advanced Care Planning and financial planning</li></ul>
<b>Mild Cognitive Impairment (MCI) &amp; Early Stage</b>	<ul style="list-style-type: none"><li>- Assessments (functional, behavioral, cognitive)</li><li>- Caregiving public awareness and education</li><li>- Initial caregiver assessment</li><li>- Referrals to community services and supports</li><li>- Home safety assessment</li><li>- Development of Individualized Care Plan</li><li>- Identification of those who live alone and referrals to resources/services</li><li>- Dementia-capable transportation services</li><li>- Dementia-capable training for HCBS providers</li><li>- Financial planning</li></ul>
<b>Mid Stage</b>	<ul style="list-style-type: none"><li>- Ongoing assessments</li><li>- Dementia-capable transportation services</li><li>- Caregiving public awareness and education</li><li>- Dementia-capable training for HCBS providers</li><li>- Home safety assessment and needs-based modification assistance</li><li>- Designated respite beds at assisted living facilities, hospitals, nursing homes (for emergency and/or weekend use)</li><li>- Ongoing review and modification of individualized care plan</li><li>- Advanced Care Planning and financial planning</li><li>- Access to adult day services and other respite services</li></ul>
<b>Late Stage</b>	<ul style="list-style-type: none"><li>- Financial assessment</li><li>- Dementia-capable training for residential care staff</li><li>- Designated respite beds at assisted living facilities, hospitals, nursing homes (for emergency and/or weekend use)</li><li>- Palliative and hospice care education</li></ul>



## # NUMBER OF DEATHS FROM ALZHEIMER'S DISEASE (2017)

4,213

## 65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE\*

\* Totals may not add due to rounding

Year	65-74	75-84	85+	TOTAL
2019	40,000	120,000	130,000	280,000
2025	47,000	140,000	130,000	320,000

### Estimated percentage change



For more information, view the 2019 **Alzheimer's Disease Facts and Figures** report at [alz.org/facts](http://alz.org/facts).

## HOSPICE (2016)

11,948

# of people in hospice with a primary diagnosis of dementia

17%

of people in hospice have a primary diagnosis of dementia

## MEDICARE

\$25,723

per capita Medicare spending on people with dementia (in 2018 dollars)

## HOSPITALS (2015)

1,409

# of emergency department visits per 1,000 people with dementia

20.8%

dementia patient hospital readmission rate

## MEDICAID

\$3.543 BILLION

Medicaid costs of caring for people with Alzheimer's (2019)

↑ 12.5%  
change in costs from 2019 to 2025

## CAREGIVING (2018)

676,000  
Number of Caregivers

770,000,000  
Total Hours of Unpaid Care

\$9,732,000,000  
Total Value of Unpaid Care

\$565,000,000  
Higher Health Costs of Caregivers

## US STATISTICS

Over **5 million** Americans are living with Alzheimer's, and nearly **14 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$290 billion** in 2019, increasing to **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three** seniors who dies each year has Alzheimer's or another dementia.