June 24, 2014

Pennsylvania Long Term Care Commission
PO Box 8025
Attn: OLTL POLICY
Harrisburg, PA 17105

Dear Commissioners:

We are writing on behalf of Seniorlink to express our views as the Commission works to develop recommendations on ways to improve the Commonwealth’s long term care system. As suggested by the Governor’s Executive order establishing the Commission, the Administration is seeking recommendations on care delivery models that are person centered, support independence regardless of age or disability, are cost effective, and promote quality outcomes. We believe that Structured Family Caregiving is a service that can help the Commonwealth achieve these objectives and support incorporation of this service into Pennsylvania’s long term care continuum.

Our organization, which has been one of the leaders in the development of this service model, is committed to enabling younger and older adults with disabilities and complex medical conditions live with dignity and independence at home. Under the Structured Family Caregiving model, we utilize qualified and committed caregivers who are trained to provide services and supports to consumers whose needs are significant enough to require around-the-clock care.

The caregivers with whom we work are typically family members who receive a modest, daily stipend for the care they provide in their own home or the home of consumers. In this way, we are able to provide one on one care, available 24 hours a day/7 days a week, dedicated to the personal care, support and safety of consumers.

We also provide necessary support to the caregiver in the community to ensure they are well-equipped for the central role they play in the consumer’s care. Seniorlink employs professional staff, typically nurses and social work care managers, to provide the assessment, person-centered care planning, and initial and ongoing training and support necessary to ensure successful stays in the community.

Finally, we deploy a community care management system in which caregivers enter daily notes, and our care teams use that data, combined with information collected from their own home visits, to monitor care, and to ensure the administration of a high-quality, highly-compliant program for state and health plan purchasers.

By ensuring the availability of essential community supports and a motivated, trained workforce, and actively monitoring the care provided in the home, Structured Family Caregiving helps to ensure that individuals with disabilities and complex conditions, who otherwise would have required nursing facility care, can
remain at home. This result is not only more consistent with the preference of most consumers, but is more cost effective from a budget perspective.

This model has been successfully implemented by multiple providers, including Seniorlink, in Massachusetts, Rhode Island, Ohio, Indiana and Connecticut, demonstrating that it can be an effective tool for state Medicaid programs seeking to rebalance long term services and supports and achieve needed budgetary savings. We also have been engaged in discussions with more than a half dozen states, including Pennsylvania, on the addition of Structured Family Caregiving as a recognized service under the Medicaid home and community-based waiver program for elderly and/or disabled individuals.

As the Commonwealth looks to new models of care delivery that can help consumers with complex health care needs remain in their homes and communities, we believe that Structured Family Caregiving is an option that should be seriously considered. The model is not the solution to the Commonwealth's long term care service and funding challenge, nor is it appropriate for all individuals with long term care needs. Rather, it is another potential tool in the Commonwealth's toolbox that can provide consumers and their loved ones with real choices for receiving safe, around the clock care in their homes and communities.

Toward that end, we believe that the Structured Family Caregiving model should be available to Pennsylvania's long term consumers as a service through the Medicaid home and community-based waiver programs and incorporated into other long term care system reforms the Commonwealth may choose to pursue in the future, e.g. managed long term care. As the Commission makes its recommendations, we would respectfully submit that the Structured Family Caregiving model be included as an alternative to improve and enhance the Commonwealth's long term care system.

Thank you very much for consideration of our views. We would be happy to provide additional information on the model or answer any questions you may have.

Sincerely,

Matthew J. Lockwood Mullaney  
VP Business Development

Rachel M. Richards  
VP Government Relations

Cc: Secretary Beverly Mackereth  
    Secretary Brian Duke  
    Deputy Secretary Bonnie Rose
August 14, 2014

Via Email and Regular Mail
Attn: OLTL Policy/Long Term Care Commission
PO Box 8025
Harrisburg, PA 17101

Re: LTC Commission Comments

Dear Commissioners:

I am writing on behalf the County Commissioners Association of Pennsylvania’s (CCAP) Human Services Committee in response to the request for comments in conjunction with the Governor's Long Term Care Commission. CCAP is a statewide, nonprofit, bipartisan association representing the commissioners, chief clerks, administrators, their equivalents in home rule counties, and solicitors of Pennsylvania’s sixty-seven counties. CCAP also has eight affiliate associations including PACAH (Pennsylvania Association of County Affiliate Homes) and PACA MH/DS (Pennsylvania Association of County Administrators of Mental Health/Developmental Services).

Pennsylvania’s counties have a vested interest in the long term care system. Counties often have oversight and control of several long term care programs as well as other human services programs that impact long term care. Counties are also on the front lines of insuring that those who are most needy are provided with necessary care and support needed to live healthy and independent lives. While all counties are organized differently, some counties in Pennsylvania have oversight of Area Agencies on Aging (AAA), county nursing homes, waiver programs, behavioral health choices programs, local mental health and developmental services programs, Medical Assistance Transportation programs, and others.

Due to the counties’ involvement in administering local human services programs, in particular long term care services, we believe that it is important that when recommending any changes impacting the long term care system in Pennsylvania the Commission consider the role of counties and their ability to provide cross-coordinated care over a variety of different service areas. In furtherance of this, we make the following recommendations:

1) Local control and oversight of programs should be preserved. Counties are in the best position to understand the varied needs of their local residents and have been providing care in some cases have been providing cost-effective long term care services for decades. Counties are also in a unique position to be able to insure quality in that not only can they provide direct, local oversight but also they are directly accountable and accessible to those constituents utilizing the services. This helps to insure that any issues in quality of service are quickly and directly addressed by the county.
2) **Regional differences and resources should be considered.** Service delivery and resources look very different in Philadelphia County than in a rural county such as Sullivan. The ability for public transportation and access to providers provides very unique settings, and local oversight among some of these programs has helped address this. Pennsylvania has many regional variations that should be considered and looked at when implementing any sort of changes to the long term care system.

3) **The ability of counties to coordinate a variety of services should be maximized.** Counties often provide a wide variety of programs that fall under long term care services and supports. Some counties oversee the AAA, a nursing facility, the MATP program, the behavioral health choices program, developmental services, and other programs that impact long term care. Due to their experience dealing with these varied program areas and their inherent overlap, they are in a good position to continue to maximize coordination among program areas resulting both in efficiency and program quality.

4) **The benefits of the current Behavioral HealthChoices Program should be examined.** The current HealthChoices structure provides a single accountable entity at the local level to support building a unified system of care, common expectations for providers, common rates, and transparency to users of services. The HealthChoices structure also guarantees local stakeholder input into service development to address the unmet needs of people recovering from mental illness and addictive disease. The structure of the program assures a local presence in the BH MCO operations which results in a more personalized relationship, problem resolution and service enhancement. When discussing the various options for providing long term services and support, there should be discussion and consideration of the current behavioral HealthChoices model.

5) **Counties should remain part of any discussion regarding improvement the long term care system.** As stated above, counties oversee many of the long term care programs at the local level. Given their ability to assess quality, improve coordination, and respond to local needs they should naturally be part of any conversation regarding changes to the long term care system. Local providers and county leaders will be able to provide a perspective that needs to be heard and understood to insure the system is able to adequately provide necessary services to the State’s most vulnerable citizens.

Thank you for taking the time to consider these recommendations made on behalf of CCAP, and for your continued commitment to improving the long term care system. We would be happy to respond to any questions or provide more information.

Sincerely,

George Hartwick, III, Commissioner, Dauphin County
CCAP Human Services Committee Chair

Cc: Beverly Mackereth, Secretary, Department of Public Welfare
Brian Duke, Secretary, Department of Aging
VIA EMAIL TO: ra-LTCCommission@pa.gov

August 14, 2014

Pennsylvania Long-Term Care Commission
P.O. Box 8025
Attn: OLTL POLICY
Harrisburg, PA 17105

Re: Pennsylvania's Long-Term Services and Supports System

Dear Long-Term Care Commission Members:

The Disability Rights Network of Pennsylvania (DRN) is the organization designated pursuant to federal law to protect the rights of and advocate for Pennsylvanians with disabilities. DRN provided comments at the Long-Term Care Commission’s hearings on May 30 and June 6. DRN now submits the following written comments and urges the Long-Term Care Commission to make the following recommendations on behalf of persons with disabilities.

1. Rebalancing Funding from Institutional Care to Home and Community-Based Services

People with disabilities should have access to the full range of home and community-based services (HCBS) in integrated settings of their choice. The Department of Public Welfare (Department) must maximize Medicaid dollars for HCBS, which will save money and protect the rights of people with disabilities under Medicaid law, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act of 1973 (504). DRN urges the Department to fully implement the new federal HCBS regulations requiring person-centered planning and settings that are integrated and provide full access to the greater community. Pennsylvania should develop

Protecting and advancing the rights of people with disabilities
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a comprehensive plan for rebalancing long-term services and supports from institutional services to services in the most integrated community setting. Pennsylvania should ensure that all new state dollars are only used for HCBS. The Department must also develop policies that prioritize and expand HCBS.

To that end, Pennsylvania must establish policies that prohibit the expansion or development of institutions and segregated settings. Institutional providers should not be financially or otherwise incentivized. Pennsylvania must develop policies that end the placement of people with disabilities in institutional settings. Policies should emphasize access to integrated home and community-based settings, including diversion procedures such as expedited intake and enrollment for people at imminent risk of institutionalization.

The Department should maintain and expand the available funding opportunities to rebalance funding from institutional services to HCBS, such as Money Follows the Person (MFP), the Balancing Incentive Program (BIP), and Community First Choice (CFC). Department staff responsible for MFP and the BIP should align efforts to ensure consistency in the strategies used to expand HCBS and to identify and utilize any lessons learned or best practices. The Department should work with the disability community to determine the best ways to use MFP and the BIP to maximize federal dollars, eliminate barriers, and expand the availability of quality HCBS.

The Department should implement CFC under the Affordable Care Act. CFC enables Pennsylvania to provide home and community-based attendant care services, purchase back-up systems, and provide voluntary training on consumer-direction through Pennsylvania’s Medicaid State Plan. CFC would bring additional federal dollars to Pennsylvania through an increased federal match. CFC services are person-centered and support choice, independence, and integration. Consumer choice and control would be supported, as participant-direction is required under CFC.
Further, children with disabilities are not often thought of in the context of long-term services and supports, but there is a very real need to consider long-term services for them. Pennsylvania boasts that it has no nursing facilities for children, but there are hundreds of children with developmental disabilities or complex medical conditions spending their childhoods in long-term care facilities. These facilities are not licensed as nursing facilities but are indistinguishable from them. In 2010, the Department reported that about 30 children under the age of three were in these facilities. Some providers serve only children, and when they reach age 21, they often transfer directly from these facilities to adult nursing facilities, leading to a lifetime of institutionalization. Other facilities have children with disabilities together with adults who have developmental disabilities.

Like adults, all children with disabilities should instead have access to HCBS. Recommendations to achieve this include lowering the age of eligibility for the Office of Long-Term Living (OLTL) waivers, prioritizing institutionalized children in the Office of Developmental Programs (ODP) Waivers, and/or creating a new HCBS waiver for all children with developmental disabilities that has a process for transitioning to an appropriate adult Medicaid waiver. The new waiver could include family life-sharing as a voluntary service outside the child welfare system, where the birth or adoptive family meets and chooses an alternative family to share responsibility for the child. This model is being used in Texas, and the Parent Education and Advocacy Leadership (PEAL) Center is highlighting the model in a transition toolkit as part of its Congregate Care Grant.

The Department should develop a Department-wide Olmstead plan that has a comprehensive strategy for ending the institutional bias and rebalancing the system to full access to integrated HCBS by children and adults with disabilities. This should include the following.

- Development of policies and procedures that:
  - Fully implement the ADA, 504, and the new federal HCBS regulations
  - End the placement of people in institutional settings and ensure that no new funding is used for institutional services
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- Prohibit the development or expansion of institutional and segregated settings
- Use a community-first approach in all situations
- Enable persons to qualify for HCBS through spend-down rules, rather than only allowing this for institutional services
- Require and incentivize providers to maximize access to and participation of people with disabilities in the community
- Streamline and simplify eligibility and enrollment procedures for prompt access to needed services and supports (#2 of this letter)
- Expedite eligibility and enrollment procedures for those who are at imminent risk of institutionalization or who are already in institutions (#2 of this letter)
- Closure of institutional beds and settings
- Robust monitoring procedures to ensure state and federal requirements on integration and community involvement are met
- Expansion of MFP and full implementation of the BIP in collaboration with the disability community
- Implementation of CFC
- Ensuring that children with disabilities have full access to HCBS

2. Streamlining Intake and Enrollment Procedures

Federal law requires that people with disabilities have prompt access to HCBS. Currently, there are significant delays in eligibility, enrollment, and planning procedures. The Department is obligated to avoid and remedy all delays.

One example is the lag time between an eligibility determination and start of OLTL services, which occurs in large part due to delays by OLTL in approving the Individual Service Plan (ISP). The OLTL quarterly activity report from the second quarter in fiscal year 2013-2014 shows over 2,700 people with “pending applications,” or persons determined eligible who are waiting for approval of their ISP by OLTL so that services can begin.

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These individuals have been determined eligible for an OLTL waiver or the Act 150 Attendant Care Program but cannot access the HCBS they need and to which they are entitled. Thus, OLTL should assess its existing intake and enrollment process, including the identification of ways that the process can be automated and streamlined, as well as an evaluation of whether OLTL and other entities involved in the process have a sufficient number of staff who are adequately trained. OLTL should also ensure that entities involved in eligibility determinations and service planning provide accurate information to applicants and participants so that people can make informed choices about available programs, services, and service delivery models.

The eligibility and enrollment process for all HCBS must include expedited enrollment, including the timely development and approval of ISPs, for people who are at imminent risk of institutionalization or who are already in an institution. Connecticut developed a system under MFP to expedite eligibility determinations to prevent institutionalization and is expanding the system statewide under the BIP. Pennsylvania should similarly use MFP and the BIP to implement a standardized procedure for expedited enrollment. The procedure must be crafted in conjunction with the disability community and widely shared.

Pennsylvania should:

- Revise HCBS enrollment and eligibility policies and procedures to streamline the process and ensure prompt access to needed services
- Ensure that all involved state and local offices have sufficient, trained staff for expeditious eligibility determinations and prompt ISP development and approval
- Robustly monitor the eligibility, enrollment, and planning procedures to ensure that timelines and other requirements are met

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- Implement expedited enrollment and service initiation for people at imminent risk of institutionalization or those in institutional settings

3. Ensuring Person-Centered Planning and Expanding Self-Direction

All people receiving HCBS should have the opportunity to drive the development of their ISP and to self-direct their services and supports. Person-centered planning and self-direction maximize the ability of people with disabilities to exercise choice and control over their daily lives concerning what services are needed, who will provide those services, and how and when the services will be provided. Pennsylvania should fully implement the person-centered planning requirements of the ADA, 504, Medicaid law, and the new federal HCBS regulations.

Self-direction correctly presumes that the person is the best expert on their service needs and the quality of services that are received. Self-directed services can be lower cost and higher quality. For example, the Employer Authority (consumer-employer) model often reduces much of the administrative costs associated with the traditional Agency Model. In addition, the quality of programs can be increased by enabling persons with disabilities to enforce personal requirements of those providing services. Self-direction should be promoted through all models of service delivery, including Employer Authority (consumer-employer model), Budget Authority, Agency Model, Agency with Choice, and any other models or combination of models.

Services My Way (SMW) is a Budget and Employer Authority model that is currently only offered in the Attendant Care and Aging Waivers. This high level of choice and control over HCBS is desired by many people with disabilities. The Department should review the use of SMW to identify

4 Id.
5 Id.
barriers to its use and opportunities for improvement. OLTL should continue to distribute the survey of the Person Driven Services and Supports (PDSS) Coalition. The Department should use the survey results to improve and ultimately expand Budget and Employer Authority into all other HCBS waivers. Further, self-direction should be available in all service delivery models. The Department should work with the Coalition and persons with disabilities in all of these efforts.

The Department should fully implement all person-centered planning requirements, include Employer and Budget Authority in all HCBS waivers, and maximize self-direction in all service delivery models.

4. Increasing Access to Housing and Residential Services

The lack of affordable, accessible, and integrated housing continues to be a barrier to children and adults with disabilities remaining in and transitioning to the community. The vast majority of people who receive Supplemental Security Income (SSI) are unable to afford housing in their communities unless they receive a housing subsidy. Housing that is available is frequently not physically accessible and is often in segregated, disability-specific settings. Accessibility adaptations under Medicaid waivers are denied or delayed. People with disabilities have also had to enter or remain in nursing facilities, medical and psychiatric treatment facilities, and correctional facilities because of a lack of housing. Adults and children with disabilities want to live in physically accessible and integrated settings with their families and friends.

In addition, Medicaid funding is not available for the cost of room and board in HCBS residential settings. As a result, people with disabilities are often

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7 Id. at 31.
8 Id. at 32.
forced to be in segregated, congregate care settings where Medicaid does cover occupancy costs; in temporary or transitional settings; with family members and friends on fixed incomes or who are aging; or in settings that are substandard or unsafe. Those who do receive funded residential services often live with incompatible roommates, without an adequate level of support, or with staff who do not have appropriate training.

Pennsylvania must ensure the availability of integrated, affordable, accessible, and safe community housing and residential service options. Increased housing and residential services are critical to prevent institutionalization and provide full access to the community. Recommendations for increasing the availability of housing include:

- Expanding current service definitions for residential habilitation to allow for additional integrated residential service settings and/or adding this service to other Medicaid waivers.
- Ensure that every Medicaid waiver covers the full range of accessibility adaptations and that the process for obtaining adaptations is expeditious. Work with other state agencies to provide other funding for accessibility adaptations.
- Incentivizing and facilitating flexible, creative, highly-individualized, and person-centered programs in agency-based or self-directed models. There are many innovative, integrated residential models that are preferred by people with disabilities.
- Implementing a housing subsidy for people with disabilities who live in their own residences. The state pays subsidies for people who are in personal care and domiciliary care homes (settings that DRN opposes). A subsidy should be provided for those who want to be in their own home.
- Exploring and utilizing available federal or state funding to at least partially pay for room and board costs.
- Revising policies to permit family members to be reimbursed for providing services. “Family caregivers are the backbone of our country’s long-term care system, providing millions of hours of care every year for

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10 See id. at 1.
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no compensation..."11 Providing family caregivers with support and reimbursement for their services will sustain their support role and enable the person with a disability to remain at home, in the community.

To accomplish change, the Department should conduct a comprehensive analysis of the use of and availability of residential services and housing options and develop a detailed work plan with people with disabilities and family members on innovative methods to address the shortage of housing and residential options. Affordable, accessible, and integrated housing and community-based residential options must be increased to rebalance Pennsylvania’s HCBS system and enable children and adults with disabilities to live in the community.

5. Ensuring Effective Transition from the Children’s to Adult System

DRN has assisted many young people in transitioning from the children’s system to the adult system and highlights two clients who exemplify the need for better transition procedures. Both of the young women have severe and complex physical disabilities and medical conditions that require constant skilled nursing supervision, and neither has intellectual disabilities. Neither have families, and both were placed in congregate care facilities for much of their childhoods because the child welfare system could not find any alternatives for them. No medical foster home provider, with rates that have not been raised in 20 years and very little respite, would accept them. The older of the two women, who we will call Sue, grew up in a facility for children described previously in these comments. A year before her 21st birthday, when she would age out of both the facility and the child welfare system, people who cared about her started to ask where she would go when she turned 21. The Department offered no community-based options to Sue, and, as a result, she moved to an acute care nursing facility with other mostly young adults who needed ventilator care. After nearly two more years of advocacy, a friend — not a caseworker

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- identified a provider who was willing to give Sue a home in the community in exchange for becoming her home health care provider in the OLTL Independence Waiver. Sue now lives in a community home in Montgomery County, but many like her have not been so lucky.

The other young woman, who we will call Lisa, benefitted from Sue's experience. After spending much of her childhood as the only verbal individual living in a 53-person facility for adults and children with intellectual disabilities and medical needs, Lisa came very close to being placed in a nursing facility on her 21st birthday. No one involved with her discharge planning even knew that the OLTL waivers existed. Even after DRN became involved, it required intensive advocacy before Lisa was able to move into the same home as Sue, under the same conditions. Neither of these young women should have grown up in facilities, and when they aged out of the child welfare system they should have experienced a seamless transition to adult community services.

As part of the Department’s stakeholder group on the health of children in the child welfare system, DRN and others have recommended that the Department bring together high-level staff from the Office of Children, Youth, and Families, ODP, OLTL, and advocates to develop policies and procedures for a seamless transition for young adults like Sue and Lisa to move into adult HCBS. DRN urges that this group become a reality.

6. Managed Long-Term Services and Supports

Managed long-term services and supports involve the delivery of long-term services and supports through capitated Medicaid managed care programs. This means that the state contracts with managed care organizations to provide HCBS and/or institutional services for a per-member per-month rate. DRN opposes managed care for HCBS.

States claim that implementing managed long-term services and supports will control Medicaid costs. DRN questions whether money will be saved by shifting HCBS to a managed care model and is concerned about the potential negative consequences: managed care companies' lack of
knowledge about HCBS resulting in a bias toward more costly institutional care; incentives on the part of the companies to limit HCBS due to the capitation model, which will result in higher medical and community costs down the road; lack of consumer choice, control, and direction; and promotion of the medical model because services will be administered by insurance companies. DRN thus opposes the implementation of a managed long-term services and supports model for Pennsylvanians with disabilities, and the Commission should not make such a recommendation.

Thank you for consideration of these comments. For all recommendations, DRN urges the Department to develop an overall strategic plan for improving Pennsylvania’s long-term services and supports system with a high level of involvement of people with disabilities, family members, and advocacy organizations at every step of the process and before decisions are made. The disability community should actively participate and have meaningful input into the development and implementation of any changes and actions. Such input is crucial to developing a plan that realizes real improvements of the system in positive ways while ensuring that people with disabilities have and maintain ready access to the services and supports that they need and to which they are entitled.

Please contact Chava Kintisch, Director of Civic and Government Affairs, at 215-238-8070, extension 210 or ckintisch@drnpa.org with any questions.

Respectfully,

Peri Jude Radecic
Chief Executive Officer

cc: Beverly Mackereth, via email
Testimony for the Pennsylvania Long-Term Care Commission
Prepared by AmeriHealth Caritas Family of Companies, August 4th, 2014

In Pennsylvania, the need for long-term supports and services (LTSS) reform is great. Despite the growing use of LTSS, the system in Pennsylvania is more fragmented and expensive than ever before. Pennsylvania is challenged with finding innovative and cost-effective ways to deliver high-quality, person-centered LTSS in the most appropriate setting.

- Pennsylvania spent 62.7% ($4.6 billion) of its long-term care budget on institutional care in 2010, versus 37.3% ($2.7 billion) on home health services in 2011.¹
- Pennsylvania has the 4th largest percentage of residents age 65 and older.²
- There are approximately 400,000 dual-eligibles in Pennsylvania, who make up a large percentage of long-term care utilization.³

As the population of Pennsylvania continues to age, the use of LTSS is expected to increase in the coming years. The 65 and over population will more than double by 2050 and the 85 and over population, which is the group of people most likely to need LTSS, will more than triple by 2050.³

The Medicaid program is the primary payer for LTSS and it represents almost 35% of Medicaid spending overall. The increasing cost of long-term care, in addition to the persistent fragmentation of the program, has led to a growing interest among states to reform their Medicaid long-term care programs, primarily utilizing a managed Medicaid long-term services and supports (MLTSS) approach. More than half of states expect to implement or have a functioning Medicaid managed long-term care programs by 2014.⁴

In addition to the MLTSS programs, many states have been pursuing a more integrated approach to long-term care through the federally-sponsored Financial Alignment Demonstrations, which aim to integrate Medicare and Medicaid services to streamline and coordinate benefits, especially long-term care, for dual-eligibles.

AmeriHealth Caritas supports a managed approach to long-term care in Pennsylvania and believes that through better management and coordination of these services and supports, quality of care will increase for beneficiaries and costs will be reduced for states and taxpayers. However, while

¹ “Medicaid Expenditures for Long-Term Services and Supports in 2011,” Truven report prepared for Centers for Medicare and Medicaid Services, June 2013
² 2010 U.S. Census
AmeriHealth Caritas agrees that a shift to MLTSS is necessary, we believe that it is a stepping stone to a more robust and integrated model of care that incorporates Medicare, Medicaid (including LTSS), and other critical services and benefits that are essential for seamless coordination and management of services. Combining the benefits and financing of Medicare and Medicaid supports appropriate payment incentives that can improve care and cost across multiple settings.

- When all the payments and services are coordinated through a single health plan, there is greater ability to improve coordination of services through robust models of care that aim to reduce the institutional bias now inherent in the system.
- An integrated approach also significantly reduces cost-shifting between the Medicare and Medicaid programs and creates strong incentives to rebalance the long-term care system.
- A fully integrated system is person-centered, with active participation of members and their families in service planning and care delivery.
- Integration provides the promise of a simpler system for consumers, with a single point of entry, single set of rules, and unified set of benefits.

Several states have been working toward a truly integrated long-term care system, utilizing several different approaches.

- The 11 states utilizing a capitated model for the Financial Alignment Demonstrations, such as Virginia, California and Ohio, are taking a fully integrated approach to care by blending both Medicare and Medicaid payments to Medicare-Medicaid Plans. These progressive states are showing that fully integrated programs have the potential to significantly impact the health and long-term care system in a positive and cost-effective manner. AmeriHealth Caritas is participating in three of such demonstrations in Michigan, Washington and South Carolina.
- Other states are using their Dual Eligible Special Needs Plans (D-SNPs) as a platform for full integration. Minnesota, Wisconsin and Massachusetts, among others, have aligned D-SNPs with their Medicaid managed care contractor to offer a robust, integrated solution.
- And some states began their journey to integration using a Medicaid Managed Long-Term Services and Support approach, that provides a foundation for broader service delivery and integration, including Delaware, New Jersey, New York, and Florida, to name a few.

The time is now for Pennsylvania to reform and strengthen the long-term services and supports system. AmeriHealth Caritas believes that a managed long-term care approach will reduce fragmentation, increase rebalancing and ultimately be cost-effective for the state. However, managed long-term care should be considered as part of the broader pathway to total integration and coordination with Medicare and other Medicaid programs and services that help keep individuals healthy and in the least restrictive setting possible. As the need for more person-centered long-term care increases, Pennsylvania cannot afford to continue with the status quo system.

AmeriHealth Caritas appreciates the opportunities afforded to us and we stand ready to work together with the administration, the Area Agencies on Aging, and all other stakeholders in the development of a more efficient and streamlined delivery system.
August 14, 2014

Secretary Mackereth and Secretary Duke
Department of Public Welfare and
Department of Aging
Harrisburg PA 17120

Re: Long Term Care Commission Request for Public Comment

Dear Secretaries Mackereth and Duke,

I am writing on behalf of the Person Driven Services and Supports (PDSS) coalition which is made up of people with disabilities, family members and the following organizations: Pennsylvania Developmental Disabilities Council, the Institute on Disabilities at Temple University; Disability Rights Network of PA; Pennsylvania Health Law Project; Pennsylvania Mental Health Consumers Association; Mental Health Association of Southeastern Pennsylvania; Values into Action-PA, Mental Health Association of PA, The Arc of PA, PA Statewide Independent Living Council, Self-Advocates United as 1, and NAMI of Southwestern Pennsylvania. The focus of our coalition's efforts is to expand and enhance person-driven services in Pennsylvania so that all people with disabilities shall have the option to design, control and direct their own services and funding.

First and foremost, thank you for the opportunity to provide input regarding improving the Commonwealth's long term care system. Our coalition's comments will focus specifically on improving options for person-driven service and supports. Person-driven options are important alternatives in our currently unbalanced and unsustainable traditional service system. A variety of person-driven models have been utilized in the Commonwealth for years. However, there are a number of barriers to people utilizing them. To improve our long term care systems, these barriers need to be addressed.

Person-driven services are home and community-based services in which a person has the authority to:

- directly recruit, hire, train and manage the people that support him/her and
• to make decisions about how the funding to support him/her is spent – this may include the purchase of specialized and/or non-specialized goods and services

Person-driven models of service can not only improve quality of life and leave people with fewer unmet needs, but can also save money: Instead of “packages of care” designed by the system, (even if a person doesn’t need that level of support), people can blend paid and unpaid services and buy just the support they need.

• The person takes on many of the responsibilities otherwise performed by agency staff, so costs can be lower.
• If offered flexibility with funding, people can have the option to purchase generic services and supports which can replace sometimes costly and unnecessary special services. For example, instead of using a combination of physical therapy and a habilitation services to exercise and maintain strength and mobility, a person could go to their local gym and use a physical trainer already at the gym to assist with their exercises. Another example would be someone paying a neighbor for mileage to drive them to an activity instead of hiring a specialized transportation service.
• In person-driven services, people can use informal supports, like friends, family or neighbors. This can help with the shortage of support service staff and offers cost-saving opportunities.
• People can use their support workers more efficiently. Current rules and regulations in waivers restrict some workers from performing some tasks that then require another paid staff to do them. For example, a habilitation service is to be used only to support a person to acquire, improve or maintain skills. A person may be working on learning to plan and prepare meals for themselves in their accessible kitchen. That same person, because of a physical disability, requires someone to do most of the housekeeping. This would have to be done by another staff person and billed as another service. If offered flexibility with funding, a person could hire one support person to do both support with learning a skill and housekeeping.

Research shows that person-driven services can produce better outcomes and save money.

Cost-Savings:
• After nine years of implementing a Cash and Counseling demonstration in Arkansas, the state reported a cumulative savings of $5.6 million. These savings do not reflect the additional savings the state reported from reduction of nursing home utilization. ²

• In another study of Arkansas’ Cash and Counseling program Dale, Brown, Phillips, Schore and Carlson concluded that initial expenses for person-driven models may be higher but that the temporary increase is offset by the reduction in later usage of expensive long-term care models. ³

• People directing their own care in the Kansas Physical Disability Waiver program spent 3% less on services than individuals in an agency directed program and hospital long-term and inpatient costs were 38-64% lower for the same individuals. ⁴

• A study of Florida’s person-driven model for people in the mental health system showed significant reductions in expensive interventions like use of in-patient treatment and forensic involvement. ⁵

Satisfaction and Quality of Life:

• People directing their own care via programs like Cash and Counseling are overwhelmingly more satisfied with services than those who do not direct their own services. ⁶

• People participating in Cash and Counseling programs reported higher quality of life than people taking part in traditional care. ⁷

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¹ Definitions of Cash and Counseling vary but the main components can be explained like this:

**Cash** - people with disabilities have the option to manage a flexible budget and decide what mix of goods and services best meet their personal care needs.

**Counseling** - providing information and assistance to individuals who direct their own services. It is a key supportive service in self-direction programs. The goal of counseling is the same: to offer flexible and personalized support to ensure that self-direction works for the participants who choose it. (*National Resource Center for Participant-Directed Services*)


Met versus Unmet Needs:

- Individuals in consumer directed programs were more likely to report that their personal assistance needs were met, and that there was more flexibility than in traditional care models.\(^7\)
- More people acquired the equipment they needed in Cash and Counseling programs than in traditional care programs.\(^8\)

Current Status of Person-Driven Services in PA

**Office of Developmental Programs (ODP).** The Office of Developmental Programs allows some consumer control for two of the three home and community-based waivers it administers. The Person/Family Directed Supports (P/FDS) and Consolidated Waiver participants who live in private residences, (not paid residential settings), may elect to use “Participant Directed Supports.” This option allows employer authority (directly hiring and managing Support Service Workers) and very limited budget authority (only the ability to determine workers’ wages from established wage ranges). The Autism Waiver does not currently have any options for person-driven services.

**Office of Long-Term Living (OLTL).** The Office of Long-Term Living offers consumer-employer models in all of its waivers except the AIDS Waiver. OLTL also offers one of Pennsylvania’s most consumer controlled options in the Services My Way program. Services My Way (SMW) is Pennsylvania’s Cash and Counseling model and is available for people in the Aging or Attendant Care Waivers. People who choose to participate in Services My Way have both employer authority and some budget authority. Though Services My Way is available, fewer than 40 people are using this model.

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Office of Mental Health and Substance Abuse Services (OMHSAS). Pennsylvania is unique in that the service of Certified Peer Specialists (CPS) is a Medicaid billable service and all counties and county joiners are required to have at least two Peer Specialists available to consumers. Peer Specialists support people with mental illness in controlling their own lives. The Delaware County Mental Health Office also supports a consumer control pilot project. The Consumer Recovery Investment Funds - Self-Directed Care (CRIF-SDC) project is a way of providing mental health services in which adults with serious mental illnesses directly control the funds spent on their recovery. In this project Certified Peer Specialists are trained to provide Recovery Coaching in a Self-Directed Care model. Participants, with the assistance of a Recovery Coach and the ability to flexibly use funds, develop a self-directed recovery plan.

Though there are a number of options for person-driven services in the Commonwealth, there are significant barriers and challenges for people opting to use these models. At a 2009 Summit on Person-Driven Services, people with disabilities, family members and other stakeholders in Pennsylvania identified these barriers as:

Informational – lack of outreach about availability and how to use the person-driven options that are currently available in the Commonwealth; no common language or definitions between service systems; no statewide source of technical assistance to help meet requirements involved in different consumer control models.

Systemic – complex system to navigate; lack of capacity for necessary support structure including Support Broker role and other models like Microboards or Self-Directed Support Corporations

Institutional – institutional bias still exists in funding services; person-driven services and supports require a fundamental re-organization of resources.\textsuperscript{10}

Coalition’s Recommendations to Improve Long Term Care in Pennsylvania
In order to create a more sustainable, cost-effective long term care system, person-driven services and supports need to be expanded and enhanced. To that end, the PDSS coalition has the following recommendations:

1. Person-driven options should be available in all HCBS Waivers.

\textsuperscript{10} Stakeholder Planning Team. (October 19, 2010). Power to the people summary and report: A summit on planning for services controlled by people with disabilities. Pennsylvania DD Council.
An immediate amendment should be submitted to CMS for the AIDS and Autism Waivers to include person-driven options. All people with disabilities who qualify for services should have the same opportunities to have the maximum choice and control over their services and supports. People with diagnosis of AIDS or autism should have the same options for self-direction as people with the diagnosis of cerebral palsy or a physical disability. Frankly, it seems discriminatory that they do not have these options. Historically, the Bureau of Autism Services has noted a concern about person-driven models and a lack of infrastructure and a concern about addressing decision-making capacity of waiver participants. Pennsylvania has extensive infrastructure in place to deliver Financial Management Services for any population of HCBS users and adequate policies to address concerns about the role of surrogates or representatives where support is needed for decision-making.

2. Person-driven options should be available in behavioral healthcare. In Pennsylvania we have had a strong pilot for self-directed care in mental health services. This model should be replicated statewide. Behavioral Health Managed Care Organizations should include self-directed care options modeled after the Consumer Recovery Investment Fund model being utilized by Magellan Behavioral Health Care MCO in Delaware County.

3. Add the option of Services My Way to all HCBS Waivers. When PA applied for and was awarded a Cash and Counseling Grant in 2004, the intent was to add the Cash and Counseling model to the majority of waivers. During the 5 year grant it was only added (as “Services My Way”) to the Attendant and Aging Waivers. Many waiver amendments and renewals have occurred since 2004 and the Cash and Counseling model was not added at any of these opportunities. The Services My Way option allows for waiver participants to more creatively meet their disability-related needs without being bound to strict menus of specialized services otherwise available through the waiver. All waivers should be amended to include the Cash and Counseling option.

4. Address implementation issues with Services My Way. Though Services My Way has been available statewide since 7/1/2012 less than 40 people are enrolled in this option. Given that Services My Way conceivably offers the most control, choice and flexibility, this is surprising and points to issues with outreach, training and implementation.

In a recent survey of Attendant Care and Aging Waiver participants:
• 70% of the survey respondents\textsuperscript{11} said their Service Coordinator never spoke to them about the Services My Way.
• 32% of Service Coordinators or Service Coordinator Supervisors responded that they "Heard about but were unclear about Services My Way" and 17% said they were "Not knowledgeable about SMW."\textsuperscript{12}
• 59% of Service Coordinators or Service Coordinator Supervisors said they were "discouraged" when asked "Do you generally feel that you have been encouraged or discouraged from offering Services My Way?" \textsuperscript{13}

(a) Significant training needs to be developed and provided for Service/Supports Coordinators. Service Coordinators and waiver participants also need access to good technical assistance related to Services My Way.

(b) Training focused on facilitating non-traditional models of care should be developed and provided. Individual Services/Supports Plans should be outcome driven and rooted in person-centered planning. This approach will also help in compliance with the new federal HCBS rules. Further, OLTL and ODP should examine rate structures for Supports Coordination that provide incentives for good person-centered planning.

(c) Materials need to be developed and significant outreach needs to be conducted for waiver participants and their families on all available models of support.

5. Improve design of Services My Way.
Two key policy changes should be made for Services My Way to really function as a Cash and Counseling option as intended. First, there should be more sensible budget development. Any services and supports that would otherwise be paid for (i.e. adult daily living services, home delivered meals, etc.) should be included in the budget development. Currently in SMW the only portion of the individual's budget that is available to them to use more flexibly is that which would otherwise be used for Personal Assistance and/or Respite. If a need is clearly identified such that it could be covered by a traditional service, the person should have the option to meet that need using Services My Way as long as they stay within the same budget. Second, some of the attraction to Services My Way is that people could conceivably save for large one time purchases that meet their disability-related needs. Currently OLTL does not allow savings from SMW to be carried over fiscal years. The intent of Cash and Counseling is for people to have the greatest choice and control over how their disability-related needs are met. Again, this change in policy would be cost neutral because the waiver

\textsuperscript{11} 47 respondents to question
\textsuperscript{12} 133 Respondents to question
\textsuperscript{13} 133 respondents to question
6. Add Supports Brokering service to all HCBS waivers.
People directing their own services often need some assistance to do so. For many people who need services, they have never managed “staff” before, never written ads to recruit support workers, never interviewed prospective employees, never submitted payroll. For many people who want to use person-driven services, they also need some assistance blending the paid and the unpaid service and supports they have in their lives. In many states a service called “Supports Brokering” is provided to fill this role. In PA, this service is currently only offered to people in the Intellectual Disability Waivers and is not actually available in most parts of the state.

In a recent survey, Attendant Care and Aging Waiver participants were asked, “If you use Consumer-Employer model or you would like to use it, do you feel like you need more help with your responsibilities as a Consumer-Employer (for example, completing payroll paperwork, finding staff or scheduling staff).” 49% of respondents said “Yes.”\(^{14}\) The need for this service was echoed loudly at the 2009 Summit on person-driven services.

(a) Supports Broker Services should be an option available in all waivers.
ODP should build the capacity for delivery of Supports Brokering statewide. The Pennsylvania Developmental Disabilities Council funded Person-Driven Services Project is building capacity in the SE Region but all waiver participants who need this service should have access. ODP should add this service in the Autism Waiver. OLTL should add this service to all of its waivers.

(b) Change Supports Broker Limitations. Currently in the Intellectual Disability Waivers, Supports Brokering is limited to people who live in private homes. There is no option for people who want to transition from Residential Habilitation (group homes or institutional) settings to self-directing services in a private home. This creates a phenomenal barrier for people who want to make this change. For a person to transition from a residential setting, they would typically need staff in place in their new home. Without a Supports Broker, the waiver participant may have no one who can assist with recruiting and hiring the new Support Service Workers. We recommend that ODP amend the waiver to allow for people transitioning from residential settings to private homes the option to use a Supports Broker during that transition. Likewise, OLTL should consider Supports Brokering an invaluable service for people transitioning from Nursing Homes to person-driven models.

\(^{14}\) 33 respondents to this question
7. Increase efficiency in person-driven models.
From the time a new waiver participant begins the enrollment process with the Financial Management Service until the time they are given the “Good to Go” and can begin using services is currently 5-8 weeks. This is a very long time for a person to wait to get needed services. This prolonged FMS enrollment needs to be addressed. We suggest that OLTL and ODP consider an expedited process with the FMS providers. When a person enrolls with the enrollment broker for OLTL waivers, if they indicate they want to direct their own services, the enrollment broker could send the initial paperwork to the Financial Management Service to begin the employer enrollment process. Likewise, if a person being enrolled in an ID waiver indicates their intention to direct their own services, the Administrative Entity could begin that process with the FMS. In both situations, the authorization for initial start-up with the FMS could also be processed at this time.

8. Technology.
In waivers that do not already include it, ODP and OLTL should add a service definition to the waivers for Smart Home Technology\(^\text{15}\), Telecare\(^\text{16}\) and Personal Emergency Response Systems (PERS) that could have cost saving potential for people who do choose to live independently and may be able to use technology instead of staffing to manage aspects of their daily lives and/or maintain health and safety.

9. Address issues related to people finding affordable and accessible housing.
A major barrier to people choosing non-residential service/institutional settings is a lack of accessible, affordable housing. We recommend the following approaches to addressing the issue:

(a) **Build capacity and availability of housing specialists and resources.** In PA, we do have some excellent organizations for assisting people to find housing. These organizations, however, are under-funded and cannot fill the need. Our Service/Supports Coordination often lacks the expertise and/or availability to assist people in the time-consuming process of budgeting for housing and locating suitable housing.

(b) **Develop a plan to prioritize the housing needs of people with disabilities.** A key component of this plan should be to reinvigorate the Local Housing Options Teams (LHOTs) and require that there is representation on all LHOTs.

(c) **Improve access to home modifications.** All waivers should include coverage for needed home modifications. Other resources like the Department of

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\(^{15}\) For example, social alert platforms (sensors in the house that monitor if the person is standing, falling, or walking outside); environmental control systems; and automated home environments (remote controls for home technology, such as lights and phones).

\(^{16}\) Telecare - Health status monitoring, activity monitoring, medication dispensing and monitoring
Economic and Community Development should be adequately funded to support the needs for home modifications. Additionally, the process for payment of contractors who provide home modifications needs to be examined. The process is cumbersome and results in delays of construction which may mean that people have unnecessarily prolonged stays in institutional settings while waiting for their homes to be modified. We would recommend that the Departments consider using Financial Management Services to process payment and consider any other solution that may assist in the timely modification of homes.

(d) Subsidies—HCBS participants who choose residential settings essentially receive subsidized housing (the ineligible billing codes). This same subsidy/assistance should be available to people who choose non-residential settings and do not have access to other federal subsidy programs like Section 8.

In summary, person-driven models hold great promise as cost-effective alternatives in a system that currently relies too heavily on institutional and segregated settings and is failing to meet the needs of many people who are on waiting lists for services. There are a number of changes, some minor and some substantial, that would vastly improve Pennsylvania’s person-driven service and support options.

Thank you so much for the opportunity to provide input. Members of the Person-Driven Services and Supports coalition would welcome the opportunity to discuss our concerns and recommendations with the LTCC. We would also be happy to answer any questions or provide additional information. Please contact me at the above number or at kahrens@temple.edu.

Sincerely,

[Signature]

Kristin Ahrens
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Written Comments for Pennsylvania Long Term Care Commission (Wednesday August 13, 2014, Final)

• Prevention and caregiver support:
  - Continue existing home and community based services programs (HCBS)
  - Empower and incentivize hospital discharge planners to share information on HCBS to consumers and their families or advocates who may be sent to nursing homes and other institutional care
  - Improve access to existing programs by serving those on current waiting lists: Medicaid Waivers, Act 150, Options and other programs which serve people with disabilities and seniors
  - Reinstitute presumptive eligibility for consumers seeking HCBS
  - Consider web based hospital reports with public updates (similar to Personal Care Homes) that detail compliance data (i.e., infection reports, lawsuits, etc.)
  - Increase public resources and collaboration for home modifications and assistive technology in Medicaid Waivers / renewals, other long term care and community based programs (DCED, PHFA, L&I OVR, etc.) which promote Independent Living (IL) to address waiting lists.
- Need for greater support for home modifications so that individuals can remain at home. Up until 2008, there was a line item called Pennsylvania Accessible Housing Programs (PAHP). It was funded at $3M and provided home modifications for individuals with disabilities and seniors who needed assistance to remain in their homes for ramps or other home modification. This program was placed over three years ago in a combined line item with a few other programs in the Keystone Communities Line Item and the line has been cut to just to between (600-700K – about 10% of line item goes PAHP) while demand remains high for this support. The program should either be moved out of DCED into another state agency or PHFA which has greater focus on housing supports for people with disabilities. Greater tracking of the need (both statewide and local) as well as improved marketing of existing resources here would be helpful.

- Increased support for Assistive Technology (AT). Like PAHP, these programs have seen dramatic reductions in funding while demand has increased. AT is a key component in empowering folks to live, work and participates in community life to the greatest degree possible.

- Consider a program to address to the service gaps for individuals with disabilities who don’t seem to fit into the current system. There are a large number of individuals who don’t neatly fit into the existing programs in Pennsylvania, but need supports and wish to avoid institutional care.

- Provider greater support and information on respite care programs. This is vital to families where one or more caregivers work and pay taxes-helps to reduce burnout.

- Increased focus on education about wellness and long-term care, particularly in educational institutions (high schools).

- Improve overall working incentives for PAS workers and attendants: increased wages and benefits (healthcare coverage, sick leave/vacation, and retirement benefits).

- Improve information on websites of state and community partners to be more concise, localized and with options for non-English speaking populations, particularly in Spanish

- Incorporate use of nurse delegation in Pennsylvania as an option for consumers receiving HCBS (this would require amending the state’s Nurse Practice Act)

- Support Community First Choice (CFC) Option for Pennsylvania to draw down additional federal dollars.

- Institute more cross training of DPW and Aging employees to have a brief knowledge of other programs for more efficient and effective referrals

- Protect access to Durable Medical Equipment (DME)

- Provide greater clarity on guardianships and rights of persons with disabilities of all ages; improved clearing house on existing resources for guardianship which are in consumer and family friendly language where possible (also including guidance on potential conflict of interest issues here); consider revision of current public policies for related reimbursements which provide parity for those in HCBS settings

• Accessibility:
- Review of long term care insurance issue—what it is, reforms needed and why it could be helpful
- Increase support for consumer model and consumer-controlled programs with the same level of resources as medical model programs to support growing needs
- Provide education, starting in high school, for students to learn about long term care needs and planning for them
- Provide and offer more community stakeholder opportunities to provide feedback on DPW’s Olmstead efforts in each division

• **Provision of services:**
  - Required education courses for hospital professionals (doctors, nurses, social workers, discharge planners) about people with disabilities and seniors, including practicums in community based settings
  - Increased use and development of telemedicine and other teleresources
  - Added technological enhancements or systems upgrades where different computer systems have challenges communicating with one another
  - Increased outreach by disability service providers to all hospitals within the region(s) that they serve, particularly discharge planners
  - Improving partnerships and collaboration between state and federal government programs (less operations in silos)

• **Quality outcomes and measurements:**
  - Better use of existing information contained by DPW and Aging on their priorities—prioritize home and community based services over nursing homes and other institutional care, particularly where those costs would be decreased
  - Review of other states, national and international data and trends pertaining to costs and best practices
  - Examine outcomes of nursing homes, state institutions and other types of institutional care and compare with HCBS.
  - Incorporate a ratings system for nursing homes and public report card on issues related to different providers
  - Consider efforts to look at a managed care system for long term care for people with disabilities and seniors in a manner that incorporates consumer control and input while offering responsible cost controls

• **Other issues of importance in Long Term Care for FY2014-15 and beyond:**
  - Provide guidance on the implementation on the US Department Of Labor Companion Care Regulation (i.e., changes to Fair Labor Standards Act of 1974 regarding home care workers) to consumers, families, providers and other related stakeholders, including, but not limited to the following areas: employer of record (it can vary from state to state-consumer, provider, commonwealth), policies governing attendants, reimbursements, time table of related issues
  - Improving access to community based healthcare: physical, mental health, dental care and specialists where gaps exist through addressing access issues: health
professionals’ shortage, particularly in rural areas; rates incentives/adjustments; physical access issues; availability of services and cultural competency concerning person with disabilities and Independent Living (IL)
- Address mobility and transportation needs of people with disabilities and seniors in partnering on: livable communities (includes curb cuts), shared ride programs, mobility management and mass transit/fixed route service, Amtrak and others where possible which will increase employment, volunteerism and community life on all levels, resulting in greater independence and saving of public funds.

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Members of the Commission,

My name is Penny Kurisko. For 25 years I was the Primary Caregiver for my parents and learned first-hand the challenges that face many older adults and their families. My caregiving days are now behind me but I am still passionate about this topic. I recently learned of the formation of the Long-Term Care Commission and attended the meeting on June 20th in Lords Valley. I was pleased to hear that you would welcome public feedback so I would like to share with you some thoughts and suggestions on Long-Term In-Home Care.

So that you can understand why I have such strong feelings on this issue I would like to tell you a little about myself and my family’s situation. I was born and raised in the Scranton area; upon graduating from college I relocated to Allentown and then to suburban Philadelphia. In between those 2 employment opportunities my Mother had her first of 2 strokes and at the age of 28 my role as “Parental Caregiver” began.

For the next 10 years I coordinated my parents’ care through various medical and aging issues while living 2 hours away. My brother, my only sibling, lived in Florida so I was our parents’ sole caregiver. At first, as is often the case, I offered advice and helped with routine tasks and decision making. As major illnesses surfaced including open-heart surgery for both of my parents, Parkinson’s and Prostate cancer for my Father, and in 1995 a debilitating second stroke for my Mother, the amount of my time and hands-on care they required steadily increased.

I was fortunate during those years to have had an employer who was extremely supportive and allowed me to return home as needed, sometimes for weeks or months at a time. Three years after the life-altering stroke that my Mother suffered in 1995 the stress of trying to arrange for the quality of at-home care she deserved coupled with my weekly commute home to be her weekend caregiver ultimately led to me resigning from my job and leaving my career and life behind to move back home to care for her full time.

I was also extremely fortunate that my Mother’s first Case Manager at the Lackawanna County Area on Aging was exceptional. Thanks to her knowledge, compassion and guidance I was able to care for my Mom at home for 15 years, well beyond her projected 6-12 month life expectancy following her stroke. During those years we received the services of a Home Health Aide first through the Block Grant Program and then through the PDA Waiver Program.

My Mother’s needs were more involved and demanding that most. As a result of her stroke her verbal skills were limited, she could no longer bathe or dress herself and she needed to be transferred into a wheelchair or commode numerous times a day. She required full time help and supervision.
It would be impossible to convey in this letter all the experiences and lessons I learned over the years and the struggles I continue to see others facing today. So I will direct my remarks to two areas: 1) In-Home Eldercare and 2) Caregiver Challenges.

IN-HOME ELDERCARE

The ability to remain in one’s home for as long as possible is a common desire for most everyone; not only as we age but also if we should be faced with a physical challenge. This of course is not always possible depending on one’s medical needs, financial resources and family support. Regardless of the specific situation the first questions raised by those facing these challenges are often the same, “What do I do? Where can I turn for help?”.

When an older adult requires help with daily personal-at-home care it is usually through word-of-mouth or at the suggestion of someone who has dealt with this situation that they are directed to the Area on Aging. Not everyone, however, needs the hands-on care they can provide. The individual or their caregiver may simply need suggestions on things such as what safety items are available for the home and where they can be purchased or how to wash someone’s hair if they are not able to get into the shower or stand at a sink. Additionally, most Eldercare services are tied to government programs that provide financial assistance and not everyone needs financial help. There’s a gap for both of these situations...where to turn for direction and where to turn for those who do not require or do not qualify for financial assistance.

Another area not addressed regardless of whether or not an individual is receiving services through an Area on Aging is a “Home Safety Evaluation”. A doctor may request that a Physical Therapist be sent into a home if a medical condition warrants; some PTs may offer recommendations on how to adapt to the home environment, not all do. For most older adults such an “evaluation” is not available.

As we age, there are many changes that can be made in a home to make it safer, more functional and easier to maneuver. Simple changes such as removing throw rugs and rearranging furniture can help prevent falls and possible injuries that could require hospitalizations and even nursing home admissions. And when possible, relocating a bedroom to the first floor, building a ramp for access to the house or adding toilet facilities to the first floor can be the difference of an older adult being able to remain in their home or requiring a permanent nursing home placement.

An important aspect of a “Home Safety Evaluation” is to be proactive. Just as families make accommodations in a home when a baby is due to arrive the same should be done as we age. Educating individuals and encouraging doctors to recommend that older patients consider and address these home issues early on rather than waiting until something happens AND providing the resources for these evaluations and their follow-through could have an immeasurable positive impact on the Commission’s key topics of PREVENTION, SAFETY and REMAINING in homes as long as possible.
CAREGIVER CHALLENGES

Over my years as a Caregiver I often heard the comment, and still do, "There's help out there, just ask". That's misleading. Yes, there are services available but they are limited and there are exclusions. For those who are eligible for these services it is important that they and their Caregivers understand that these resources are only a supplement to the significant time and financial commitments that may be required to care for an older adult at home.

HOME HEALTH AIDS are the outside helpers most older adults rely on for assistance with their daily needs such as bathing, dressing and meal preparation. One of the challenges in hiring an Aide, regardless of whether an Area on Aging or the consumer or family member is paying for those services, is that it can be very difficult if even possible to find reliable and competent Aides; particularly for hours before or after school, on weekends or for a few hours in the evening. Hiring an Aide directly through a Home Health Agency is cost prohibitive for most and partially due to the low wages paid to Aides by agencies, the abilities and reliability of their Aides is not always acceptable.

Staffing is just one issue that can be encountered when dealing with a Home Health Agency. In light of that, it was a welcomed policy change when the PDA Waiver Program began allowing a consumer to hire a caregiver of their own choosing. While the Waiver program allows for a family member to be the “employee” that family member cannot hold the consumer’s Power of Attorney. One reason given for this exclusion is concern of Elder Abuse; someone gaining financially yet not providing the necessary care to the person in need. Considering that we all choose someone closest to us as our Power of Attorney it is often that same person who steps in to provide care when it becomes necessary.

While the need for oversight and protecting the elderly is necessary excluding Caregivers with POA negatively impacts those Caregivers who are genuine, those who are already doing the job that often cannot be sufficiently filled or who must step in when an Aide is not available. It also hurts consumers who do not have other family members to take on the responsibility of POA or help with their care. Having been personally adversely affected by this policy after the passing of both my Father and Brother I implore you to reconsider this restriction.

HEALTH CARE is another area of concern for Caregivers. Cutting back work hours or as in my case leaving a job to care for a loved one may result not just in loss of an income but loss of health care benefits as well. For single individuals like myself who do not have a spouse to rely on for those benefits the cost of insurance premiums alone is monumental.

Although options under the recently implemented Affordable Care Act can dramatically lower the cost of health insurance premiums the level of coverage many of those plans offer do not cover the costs of needed medical care; and as with any individual plan these policies do not include dental or vision coverage. Offering Caregivers a comprehensive health care buy-in or offering a paid health care benefit to “Full Time Elder Caregivers” would ease their financial burden and possibly allow for more family members to be able to choose the option of caring for a loved one at home. The annual cost to the State to pay these premiums would be minimal compared to the potential cost incurred for a nursing home placement.
The PROPERTY TAX/RENT REBATE Program currently designates three eligible categories based on income limits...Pennsylvanians 65 and over, those 18 and older with disabilities and widows and widowers age 50 and older. I propose extending eligibility to include a "Full Time Elder Caregiver" who is currently or has previously provided at-home care for an aging parent either by moving a parent into their home or by moving into their parents' home for the purpose of taking on the responsibility of their care.

SOCIALIZATION opportunities for aging adults was one of the topics brought up in the Commission meeting in Lords Valley. This is also a challenge for Caregivers. I don't have an answer for how to address this issue but I have found that most people are uncomfortable discussing or even hearing about Eldercare issues; and there is little understanding of or empathy for the emotional toll that impacts Caregivers.

I lost my Dad 5 years after my Mom's stroke and I lost my brother unexpectedly 5 years after that. As more family issues arose the more friends and family distanced themselves from me, from my situation. That distance continues to this day as I try to acclimate myself back into life and at 57 years of age struggle to resurrect the IT career I left almost 16 years ago.

This lack of understanding toward Caregivers is not limited to family and friends. My Mother could not be left alone so I was primarily homebound. As time went on less services were extended to me under the premise that since I was "already there" I could address my Mom's needs on my own and should not need as much help with her care. Contrary to this way of thinking, everyone needs a break from their responsibilities from time-to-time, Caregivers included.

IN SUMMARY, please consider that the long-term impact of helping Caregivers in whatever ways possible would not only help them to continue caring for a loved one at home but would also serve as an incentive to anyone considering if they could take on this daunting task and it's financial implications. I would strongly suggest that help be in the form of benefits or financial assistance; tax credits are not helpful if an individual does not have an income.

MISCELLANEOUS:

- Eligibility for most services available to older adults consider the financial assets and income of the entire household. For an adult child willing to have their parent come to live with them or willing to move in with their parent to help in their care this policy can result in the parent being ineligible for services that they would have received if they continued to live on their own. This may discourage adult children from getting involved in their parents' care and lead to choosing a nursing home placement instead of at-home care.

- As aging individuals recognize that they or their spouse need assistance with daily tasks they are often reluctant to ask their children for help; conversely, most adult children do not always see that their parents may need help or to what extent. I believe that more families would get involved in caring for their loved ones if they were more informed, about their options, about the services that are available and if they had a support system to guide them through what can be initially be an overwhelming undertaking.
- When an older adult is assessed for their eligibility in a State program all their assets are included in that evaluation. This is not the case in programs for children; parents’ assets are not considered.

- Most laws and programs are geared toward families, particularly the parent/child relationship. Americans are living longer and the challenges of respectfully caring for our aging population are continually increasing. Not all older adults have children; some have no family at all who can help them as they age. Just as considerations have been extended to grandparents and individuals other than parents who are raising children I would encourage that similar considerations be given to anyone who is the “Full Time Caregiver” for an older adult whether that is a relative or a friend.

It was by chance that I learned of the Long-Term Care Commission and the meeting in Lords Valley. It’s unfortunate that most consumers and caregivers are not aware of your mission and therefore did not have the opportunity to relay their stories to you. Information directly from those that live it every day is invaluable. This was exemplified at the meeting I attended by the only 2 speakers that day who were not representing agencies or who were not promoting a political agenda. The insight given by Keith Williams, an employee of CIL and a consumer himself, provided a first-hand perspective of consumers’ needs; as did the comments of the Caregiver who advocated for an Adult Day Care to meet her grandmother’s socialization needs.

I’ve only touched the surface of issues I encountered in my experiences as an Elder Caregiver. I would be glad to provide you with any additional details on these or any other topics that may be of particular interest to you related to in-Home Long-Term Care.

Thank you for your efforts in addressing the topic of Long-Term Care. I appreciate the opportunity to pass along my feedback.

Sincerely,

Penny Kurisko
To: Secretary Mackereth and Members of the Long Term Commission

My name is Shona Eakin. I gave verbal testimony at the hearing held in Mercer in March 2014. I am submitting these comments so that they will become an official part of the documented record of stakeholder feedback.

I wear multiple hats. I am the Executive Director of Voices for Independence. As such, I have the privilege and responsibility to oversee the administration of personal assistance services to almost 400 people in Northwestern Pennsylvania. I am also a user of attendant services and I am the wife of/caregiver of a user of services that is a ventilator user.

I look at the issues, of which I am about to give testimony from a unique position. Today, I want to highlight three main issues:

The first, Home Modification:

Pennsylvania has this wonderful program and could use it to benefit more people and ultimately save the State significant money. In order to illustrate my point, I would like to mention my second issue which is Nursing home transition. Many people end up in nursing facilities because they cannot modify their homes to meet changing needs. Nursing facilities on average cost the State more. If you, as commission members would recommend a policy change to add home modification services to all attendant care programs, money and other resources could be saved. By the time people are forced from their homes to a nursing facility, often injury has occurred costing Pennsylvania more money in restorative services and the individual often loses community supports such as friends, family, housing and other support services resulting in longer unnecessary, costly stays in nursing facilities until they can get to the community with appropriate supports. Nursing home transition is an extremely valuable program. As you are already aware because of testimony provided to the commission earlier this year, Pennsylvania is seen by CMMS as a leading example of how well nursing home transition can be done. It is a great program, and with a few administrative changes it could be excellent.

Often the lag time in Harrisburg delays transitions. This is happening at all levels beginning with the enrollment process. People in nursing facilities should be presumed eligible, especially when already occupying a
Medicaid-funded bed. The nursing home transition process is often delayed because we are waiting for budget approvals for services and home modifications and special funding requests. The State selected their nursing home transition liaison organizations based on proven transition experience. Please empower them to make decisions on the local level within parameters. To establish these parameters use the expertise you already have. Get input from the people doing the work. It is time to pull nursing home transition workers together and find out what is working and what isn’t.

Finally, my third issue is nurse delegation in Agency-Directed Attendant Care.

People with disabilities do not perceive many of the activities required for our daily functions as invasive or even medical. Attendants should be allowed to do such things as catheter care, and bowel maintenance activities such as suppository, ventilator, care, feeding tube care, etc. It does not make sense that these activities can be performed by attendants, often the same people, under Consumer Model through PPL and they cannot be performed in Agency-Directed Attendant Care. Obviously, nurse delegation is recognized in Consumer Model, and it most definitely should be in Agency-Directed Attendant Care. I understand the need to establish parameters. Again, I think you should involve your provider network, consumers of services and the Department of Health in establishing those parameters. Act 69 should be amended to allow for nurse delegation, health maintenance and daily activities people with disabilities need support to do.

I volunteer to serve on any committee that would be established to develop solutions on all of these issues. Please feel free to contact me at Voices for Independence, 1107 Payne Avenue, Erie, PA 16503, (814) 874-0064.
Draft Principles for a Medical Assistance Managed Long-Term care Services and Support Pilot in Allegheny County

Background
HealthChoices plans, health care and service providers who serve those with long-term health and service and support needs in Allegheny County have had a successful history of working collaboratively together. Recently, a number of these stakeholders met at the invitation of the Institute of Politics of the University of Pittsburgh (IOP) and the Jewish Healthcare Foundation to discuss the need to reform how Medical Assistance-funded long-term care services and supports were provided and financed. These meetings resulted in consensus recommendations for reform amongst these diverse stakeholders, which is reflected in the Institute of Politics Report: The Future of Medicaid Long-Term Care Services in Pennsylvania: A Wake-Up Call. See: http://www.iop.pitt.edu/documents/Policy%20briefs/Medicaid%20Long-term%20Care%20in%20Pennsylvania.pdf

One of the recommendations in the IOP report is that the Pennsylvania Department of Public Welfare (DPW) should pilot managed long-term services and supports (MLTSS), utilizing many of the recommendations in the IOP Report. This paper contains concepts for discussion with DPW and the Corbett Administration for such a managed long-term care pilot in Allegheny County:

1. Initially, the pilot population would be for seniors (age 65 years and older) who are dually eligible for both Medicare and Medicaid and who have enrolled in a Medicare Special Needs Plan (D-SNP or I-SNP). We propose that these SNP enrollees in Allegheny County would be assigned to the respective company’s HealthChoices plan for their Medical Assistance (MA) benefits. This concept has several advantages:
   - It is voluntary rather than mandatory for both Medicare and Medicaid plans. Senior enrollees have already opted to enroll in the Medicare D-SNP or I-SNP plans and it does not require those in Medicare fee-for-service to make any changes. On the Medicaid side, these senior SNP enrollees could be notified that they will have

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1 Initially, it will be much less complex to focus on the dual senior population than on the younger dual eligible enrollees. This is particularly important for Pennsylvania given its demographics and the impending increase of older Pennsylvanians. This is the approach that Minnesota has also taken.
2 Enrollment would occur upon approval by CMS of the amended contract and readiness review by DPW of the HealthChoices plan.
their Medicaid benefits managed by the HealthChoices plan that is under the same umbrella company as their Medicare SNP plan (with the very same providers), unless they opt out of this arrangement. This will avoid the need for an 1115 waiver. Nor should it require a new HealthChoices procurement, but instead a contract amendment.

- Without the need for CMS waiver approval or a lengthy procurement process, the pilot can more quickly be put in place.
- Because the health care and service providers in the company’s SNP are the same as those in its HealthChoices plan, it aligns providers and promotes provider coordination.
- Although finances need to be strictly and individually accounted between the SNP and HealthChoices plans, it does provide the opportunity for financial coordination and some flexibility to meet the needs of the enrollees.
- It provides sufficient numbers of HealthChoices enrollees to allow proof of whether this concept works politically and financially for the State and provides quality consumer-centered services to HealthChoices enrollees.
- It aligns the financial interests of the HealthChoices plan with the interest of consumers, i.e., to be served in their homes rather than an expensive nursing facility.
- It will contractually require the Allegheny County Area Agency for Aging (AAA), which has the experience in managing long-term services and supports for this population, to work closely with the HealthChoices and SNP plans and providers.
- It will help to position Pennsylvania to be able to fully integrate financing and services with CMS for the dually eligible population in the future.

2. The pilot will strive to reduce costs through more comprehensive medical and services management of the senior enrollees and earlier identification and provision of services and supports of individuals at risk for Medicaid-funded nursing facility care.

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3 This is the approach taken by Wisconsin.
4 It is anticipated that the MIPPA agreements will need to be altered and a HealthChoices contract amendment will need to be made and approved by CMS.
5 Requirements for care coordination will need to be developed.
6 As of November, there were approximately 35,876 full dually eligible persons in Allegheny County, with 17,755 enrolled in D-SNPs. Approximately half of those are senior dually eligible people. With United and Keystone Health Plan West dropping their D-SNP program, the vast majority will be divided between the UPMC and Gateway plans. I-SNP enrollees not residing in nursing facilities are few in number.
3. The HealthChoices contracts should be amended to add the full scope managed long-term care services and supports, including those in the Aging Waiver, assisted living, the individual services provided by the LIFE Program\(^7\), advanced care planning, transitions of care and supportive care services\(^8\). This includes a full array of supportive services to help family caregivers, including:

- assistance in obtaining needed services,
- providing counseling to caregivers and assisting with problem solving
- follow up and support associated with discharge from a facility, where the enrollee is returning to the community,
- proactive case conferencing with consumer, caregivers and Service Providers re status changes and needed responses,
- support and resource for caregivers who are also providing support to other members of the family who may have a disability.

4. Assessment for MA nursing facility level of care should continue to be done by the Allegheny County AAA\(^9\). The AAA will also have a contract with the HealthChoices plans, to coordinate/provide long-term services and supports, but the plans will control the payment to providers, including the AAAs. Consumers may choose a service coordinator or provider other than the AAA, if in the plan’s network.


6. The pilot should contain a consumer/family education and engagement component on long-term care services and supports.

7. The pilot should include a research component on what triggers the need for nursing home placement and what services or supports are needed to avert it for both those who are presently dual eligible and those who will become eligible through spend down. The pilot could include allowing SNP enrollees to spend down for home and community-based waiver services as they would be able to do so for nursing facility

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\(^7\) Should the LIFE Program want to provide those services as part of the plan’s network

\(^8\) This includes palliative care.

\(^9\) As part of the pilot, the AAA assessment of level of care should be reviewed to possibly allow distinction between those in need of extended services vs. those fully requiring nursing home placement.
care and determining if this is cost effective and avoids unnecessary institutional care.

8. The pilot should include quality measures, including consumer and family satisfaction, and utilize some of the preliminary measures developed by the National Quality Forum. See: http://www.qualityforum.org/MAP/Dual_Eligible_Beneficiaries/#t=1&s=&p

Plans should be required to have a continuous quality improvement program and cooperate with an external quality control organization (EQRO) to evaluate outcomes and quality of care.

9. Capitations should be risk adjusted and initially provide for risk corridors and stop loss. Additionally, the pilot should provide for shared cost savings if quality measures are met.

10. Behavioral health services should be provided with every effort made to maximize the sharing of patient information (electronically where possible via electronic medical records) for better patient quality of care, consistent with state and federal laws. The pilot should explore ways to maximize integration of physical health, behavioral health and long-term services and supports and how best to jointly meet the needs of older dually eligible Pennsylvanians.

11. The pilot should include a pilot advisory committee, made up of representatives from DPW, the participating HealthChoices plans, the Allegheny AAA, consumers and consumer advocates, providers, foundations, etc., who receive monthly information on pilot operation, challenges and issues and meet monthly via conference call or in person to provide advice on quality improvement and policy issues.

12. DPW should facilitate the operation of similar pilots in other counties where the key stakeholders show a similar willingness to collaborate to provide better and more efficient, consumer-focused managed long term care services and supports, to help inform possible expansion of this model in the future. Data from the pilots and lessons learned should be shared and joint meetings held quarterly with the pilots key stakeholders to foster a learning collaborative to improve MA managed long term services and supports. For instance, speakers from other states could be invited to speak and to share lessons learned from the longer operation of their MLTSS. (The Learning Collaborative expenses might be something that foundation would be willing to fund.)

Areas for further discussion:
1. What is the full array of comprehensive medical management services?

2. What is the scope of managed long-term care services and supports? Should this include a common set for all plans with the ability to supplement with other services, as determined by the plan?

3. Should there be other factors determining shared savings, other than a set of quality measures?

4. Should we expand age eligibility to age 60+ to conform with the Aging Waiver and include those enrolled in the Independence and Attendant Care Waivers?

5. Should long-term care nursing facility residents, who are enrolled in a SNP be included? Should this include nursing home transition services?
The Pennsylvania Health Funders Collaborative (PHFC) is a network of 30 health foundations across Pennsylvania that focus their health philanthropy in communities throughout most of Pennsylvania. PHFC has focused on the need to reform how Medicaid long-term care services and supports are paid for and delivered as a priority area for our advocacy. Therefore, we appreciate this opportunity to comment on this critical issue.

The Corbett Administration has called for the reform of Pennsylvania’s Medical Assistance Program, in large part due to the impact the program has on the state budget. The Pennsylvania Medical Assistance (MA) Program presently consumes 27% of the state budget, growing by $300-$400 million each year, just to maintain the status quo. Greater strains on the state budget will occur for long-term care services and supports (LTCSS) in the future due to the following:

- **The growing number of persons needing MA-funded LTCSS.** Seventy-three percent of MA’s present expenditures are for elderly and enrollees with disabilities, who most need LTCSS. According to the United States Census Bureau 2010 report, Pennsylvania’s population grew by 3.4% between 2000 and 2010, but Pennsylvania’s population of people 85 years and older grew by 28.7%. Those 85 and older need the most LTCSS.

- **The demand for LTCSS that will need to be paid by the MA Program.** Seventy percent of Pennsylvanians reaching age 65 will need LTCSS for an average of 3 years¹. Only 4% have long-term care insurance and most would exhaust their life’s savings in one year if forced to pay for nursing facility care. Pennsylvania’s MA program will be the payer of last resort for LTCSS for this growing demographic once they exhaust their resources and have nowhere else to turn for care.

- **The fragmentation and lack of care co-ordination that leads to unnecessary reliance on expensive nursing facility care.** Adjusting for our older population, Pennsylvania’s MA Program pays 22% more on nursing facility care than the average state Medicaid program. Pennsylvania is paying for LTCSS at the most expensive price point and where most people do not want to live.

In many ways, the Pennsylvania MA long-term care “program” is similar to the MA fee-for-service in the 1990’s before the implementation of HealthChoices. Before Health Choices, consumers often had to go to the most expensive point of service, a hospital, to receive any kind of comprehensive, coordinated care, since it was generally unavailable in the community. Too often today, an older person faced with an inpatient hospital stay, but needing coordinated LTCSS upon discharge, goes to a nursing facility, because coordinated care at home cannot be arranged or is not available.

Pennsylvania Health Funders Collaborative

Pennsylvania’s MA program spends more money on nursing home care than home and community-based waiver services (HCBS) for persons who have significant LTCSS needs with more people in nursing homes than in the community. In Pennsylvania’s MA Program for FY 2012-2013:

| Percent of expenditures for nursing facilities: | 64.5% |
| Percent of expenditures for HCBS | 30.97% |
| Percent of residents served in a nursing facility | 56.2% |
| Percent of residents served with HCBS | 39.79% |

Pennsylvania needs to transform how it pays for and provides LTCSS, using lessons learned from the implementation of the HealthChoices Program:

- **Establish an Advisory Committee/Work Group to assist with the redesign of LTCSS in Pennsylvania.** The Committee should include the Secretary of DPW and Health, a Deputy from the Governor’s Office, consumer advocates and PHFC representatives. When HealthChoices was being developed, foundations funded the Pennsylvania Health Law Project to bring experts from other states who had implemented managed care in their Medicaid programs to meet with DPW Secretary Houston and the Governor’s staff on best practices and lessons learned from other states’ roll out of mandatory Medicaid managed care. Secretary Houston has since said that before it started, she thought it would be a disaster but that it was one of the more important reasons for the success of HealthChoices. The Advisory Committee continued to give DPW feedback on the roll out of HealthChoices and to offer solutions for problems that occurred. Such an Advisory Committee/Work Group should be utilized in the redesign of Pennsylvania’s LTCSS.

- **Pilot voluntary LTCSS managed care programs to determine important program components that need to be included in contracts for later mandatory LTCSS managed care programs.** Prior to HealthChoices becoming mandatory, it was piloted as a voluntary program in southeastern Pennsylvania. Many valuable “lessons learned” came out of the pilot that latter were included in the RFP for the mandatory program. It was important that the first pilot was located where plans and providers were willing to work collaboratively to prove that it could work. In Pennsylvania, two counties (Allegheny and Montgomery) have been meeting with managed care plans, AAAs, consumers and LTCSS providers in the hopes of piloting voluntary MA-funded managed LTCSS. (See Allegheny principles for pilot development and Montgomery County report on improving LTCSS for dual-eligibles.) Pilot programs that permitted consumers to voluntarily enroll could be expeditiously developed in these counties without need for federal waivers and could demonstrate that these programs successfully meet the needs of seniors while being cost effective for the state. These pilots could work out details for consumer directed services, consumer protections and rights, which are critical components of any LTCSS managed care program. As was the case with HealthChoices a gradual, voluntary roll out process allowed the development of the needed infrastructure and built trust with consumers and providers as they saw for themselves that the care delivered was superior to that under fee-for-service.

- **Roll-out mandatory managed LTCSS on a region-by-region basis and use independent enrollment counselors to help consumers select a LTCSS plan.** Pennsylvania gradually expanded HealthChoices across the state as plans and their networks developed the capacity to safely serve the target population. Pennsylvania did not realize the serious problems with the roll out of mandatory Medicaid managed care that other states did, because it did not try to expand across the state all at once, did not contract with plans with
capacity problems and did comprehensive readiness reviews before implementation. The use of an independent enrollment contractor helped to mitigate the preferences of health plans to enroll only the healthiest in their plan. As the recent bad experience in New York suggests, the need for an independent enrollment counselor is as much, if not more needed for LTCSS plans. HealthChoices has improved the quality of care, access, and care coordination that enrollees receive as compared to fee-for-service, while helping to control costs. Mandatory managed LTCSS plans can do the same for residents needing MA-funded LTCSS in Pennsylvania. The state should deliberately and prudently move toward mandatory MA managed LTCSS with appropriate quality measures, consumer protections, etc.

Additionally, Pennsylvania should include two important components in contracting for mandatory Medicaid LTCSS, not included in HealthChoices, which could save significant money and improve the quality of care:

- Managed LTCSS contracts with plans should require the provision of integrated behavioral and physical health, including the following:
  - Depression screening in primary care when staff-assisted depression care supports are in place to assure accurate diagnosis, effective treatment, and follow-up
  - Collaborative care management services, including services for depression, to ensure effective treatment, systematic follow-up, implementation of care plans, effective responses to transition-in-care, linkages to community resources, and goal-driven care

- Managed LTCSS contracts with plans should improve end-of-life care:

Twenty-eight percent of Medicare payments are for care in the last six months of life. Too often those with life-limiting conditions are receiving unwanted, aggressive medical interventions, are being shuffled from care setting to care setting and are dying in hospital intensive care units, when patients prefer to end their life in their own home and in the company of their families. Future LTCSS should require:

  - Appropriate use of the Physician Orders for Life-Sustaining Treatment (POLST) to ensure that patients’ goals and preferences for end of life treatments are in the medical orders for those patients.
  - Provide incentives for physicians serving LTCSS enrollees to take the accredited online course, Closure, that helps them obtain the communication skills, medical principles and techniques to improve the care they provide for their patients facing life-limiting illnesses.
  - Networks that include excellent access for patients needing palliative and hospice care and educational materials about their availability.
  - Payment to providers for advance care planning with patients and their families.

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At the earliest opportunity, Pennsylvania should participate in the demonstration with CMS to jointly contract with CMS for managed LTCSS for dually eligible individuals. In the United States, state Medicaid programs paid about 42% of costs for LTCSS with Medicare paying only 25%. Therefore, it is especially important for state Medicaid programs to better manage the costs of LTCSS. This is difficult given the dual funding sources of Medicaid and Medicare for dually eligible individuals. There are approximately 440,000 Pennsylvanians who are Medicare beneficiaries, and also have incomes and assets low enough to also make them eligible for MA. They are the sickest, poorest and most expensive group covered by either program. These “dual eligibles” represent about 18% of Pennsylvania’s MA enrollees, but account for about 43% of the program’s total spending, mostly for long-term care.

Pennsylvania’s dually eligible individuals are not enrolled in HealthChoices, but receive their coverage through fee-for-service. Dually eligible individuals can be needlessly ping-ponged from nursing facility care to hospital care and back again, so that nursing facilities can maximize income, with neither Medicare nor Medicaid able to do anything about it. (Nursing homes receive MA payments for holding beds for days that the patients are hospitalized. If the patient is in the hospital for three or more days and returns to the nursing home, that facility will receive the Medicare payment, which is higher than Medicaid.)

CMS has invited State Medicaid Programs to join CMS in a demonstration project to jointly contract with LTCSS plans serving dual eligibles in their state. Many large states and most of our neighboring states are participating in this demonstration program: California, Illinois, Massachusetts, Michigan, New York, Ohio, South Carolina, Virginia and Washington are doing capitated demonstrations. States are ensured up-front savings, as the capitation paid to the plan is less than the fee-for-service costs would be. The patient receives better, coordinated care paid for by integrated financing that removes the perverse financial incentives that can be harmful to consumers.

There is an urgent need for Pennsylvania to restructure how MA-funded LTCSS are provided and paid for. We urge the Long Term Care Commission and the Corbett Administration to begin this process as quickly as possible to improve the use of taxpayer resources, to support widespread reforms among numerous hospital systems in Pennsylvania and the outcomes for dually eligible older adults.

Respectfully submitted,

Ann S. Torregrossa
Executive Director
PA Health Funders Collaborative
215-514-5843
atorregro@gmail.com
August 11, 2014

Via Email
Attn: OLTL Policy/Long Term Care Commission
PO Box 8025
Harrisburg, PA 17101

Re: LTC Commission: Comments on Accessibility of Services

Dear Commissioners:

I am writing this letter to provide comments on the accessibility of long term care services for the Governor’s Long Term Care Commission. This letter is written on behalf of the Pennsylvania Association of County Affiliated Homes (PACAH), which represents all of the county nursing facilities in the Commonwealth, as well as a number of for profit, not for profit and veterans’ nursing facilities. PACAH is an affiliate of the County Commissioners Association of Pennsylvania.

While in many ways Pennsylvania’s Long Term Care System does an excellent job in providing long term services and supports to those in need, there are certainly some areas that could be improved. Our association believes that there are some improvements that can be made in terms of accessibility of services for those who are eligible for medical assistance, in particular through the County Assistance Office (CAO). Often, delays and inefficiencies at the CAO have the unfortunate effect of impacting nursing facilities in terms of receiving timely payment and impact a consumer’s ability to receive critical care. There are delays in determinations, failure to respond timely to questions, delays in processing voluminous amount of paperwork required to make the determination, and often unnecessary appeals. While this is not the case in all CAOs, there are some regions where problems are more prolific than others and it certainly has an effect on the ability of a nursing facility to provide and be reimbursed for services. When skilled nursing facilities are already reimbursed at rates that fall well below the cost of providing care, it becomes even more difficult when eligibility determinations are not made in a timely manner. County nursing facilities, in particular, are impacted by this as they are required to provide services to Medicaid patients on day one.

The brief comments below highlight the major areas of concern in terms of intake and eligibility determinations when it comes to accessibility of services for our members:

Redetermination issues:
- Frequently the CAO is not timely in sending the request for redetermination and notifying the facility there is a redetermination hearing
- Often benefits are ended based on the failure of a facility to provide information regarding residents in a redetermination hearing, yet facilities have not even received a request for information or are not even aware of a hearing.
- There should be processes in place insuring that any requests for information are sent in a timely and reliable fashion

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An Affiliate of the County Commissioners Association of Pennsylvania
Prior to ending benefits, it should be verified that any information requests necessary were in fact sent.

Delays in MA approvals

- In some areas cases are taking an average 6-8 months for approvals when it previously took 2-3 months.
- There are instances where cases over a year old still have not been approved, even after all necessary paperwork has been submitted.
- There have been instances where cases are sent to appeal and even though the CAO may subsequently receive all necessary information to make a determination, they will still wait for a determination to be made by a judge as opposed to approving prior to the appeal hearing. This seems to serve no purpose other than to delay the process. If the CAO is able to make a determination prior to the appeal hearing, policy should allow and even require that they do so in order to provide for a more efficient resolution.
- Multiple approvals have to be billed to 180 day unit when this was a rare occurrence in the past.
- There have been issues where hearings take a long time to schedule due to the overwhelming case load and then in other instances the resident or facility never receive notification of the hearing until they receive a call from the hearing judge. Once again, it should be a given that notifications always be sent in a timely and reliable manner.

Inaccuracies on PA162’s

- There have been times where the forms are missing information once completed, for example, the Home Maintenance Allowance when a resident is eligible. To correct this the facility has to wait for an updated PA 162 which can take a month or more. Ideally, updated forms would take days, not weeks to resend.
- It is also not uncommon in some regions for there to be inaccurate Medicare Part B on the PA162, either not on it when it should be, or on it and they don’t pay for their Part B so it should not be included. Again, while mistakes happen repetitive mistakes can cause a lot of delay in making determinations.

Inability to get COLA’s

- Often COLA’s are received late in January or February even though they are effective January 1, it is just another timeliness issue that can really impact a facilities bottom line.

Unresponsive case workers

- While in some regions caseworkers are responsive, there are certain CAOs where it is rare that caseworkers answer the phones or follow-up with a facility in a timely manner when it comes to questions, issues, etc. There have even been instances where the answer to questions is simply that the caseworker is really too overwhelmed to do anything about the issue.
- Caseworkers should be able to effectively handle the cases they are responsible for. If the workload does not allow for this, we are not providing acceptable services to those in need. It is difficult for both providers and consumers when a caseworker is too overwhelmed and/or unable to answer questions.
Thank you for taking the time to consider our comments. Please let me know if you have any questions, or would like more information.

Sincerely,

[Signature]

Kelly Andrisano, J.D.
PACAH Executive Director
August 11, 2014

Secretary Beverly Mackereth, Co-Chair
Secretary Brian Duke, Co-Chair
The Pennsylvania Long-Term Care Commission
P. O. Box 8025, Attn: OTL Policy
Harrisburg, PA 17105

Submitted electronically to: ra-LTCCommission@pa.gov

Dear Secretary Mackereth and Secretary Duke:

The Senior Support Coalition is comprised of Pennsylvania provider and consumer advocacy organizations that serve older Pennsylvanians and their caregivers. Our focus is to keep families together by improving home and community-based services for older adults. As the Long-Term Care Commission prepares recommendations to improve Pennsylvania’s system of long term services and supports, we hope the final report will reflect the following values and principles:

- **Support older adults in remaining at home as long as possible, if this is their choice.** It is important to keep families together by increasing participation in home and community-based services. Older adults deserve to age with dignity and independence in their own homes and communities. Consumer choice and self-determination is an important value. Pennsylvania ranked 37th in a national survey measuring support for home and community-based programs serving older adults. Pennsylvania can do better and should continue rebalancing efforts.

- **Support and empower informal/family caregivers.** More than 1.8 million Pennsylvanians are currently caring for a loved one at home. They provide more than 1 billion unpaid hours of care each year. Like older adults, caregivers should also be treated with respect and dignity. Senior Centers, Adult Day Centers, and LIFE programs all play a critical role in supporting caregivers. The Commission’s recommendations should acknowledge and support caregivers in their vital role.

- **Strengthen Pennsylvania’s infrastructure of home and community-based programs and services.** Low reimbursement rates make it difficult to recruit and retain professional caregivers which can impact access to care. It is important to support a qualified, stable workforce in all areas of home and community-based services. Regular review of the adequacy of rates for all waiver services is critical. Fourteen Area Agencies on Aging (AAAs), covering 15 counties, have had to drop out of providing service coordination for the Aging Waiver. The recent increase in rates was helpful to many, but regional rate disparities exist. The AAA network has been a vital resource for older adults and caregivers, and their role should not be diminished. Adult Day Centers serve over 13,300 families at 266 locations and yet, not all seniors have an Adult Day Center in their local communities. It is essential to have a strong home and community-based infrastructure to ensure consumers can access high quality services when they are needed.
Reduce barriers to ensure easy access to home and community-based services. While individuals can be admitted to a nursing home at any time, it can take months to receive approval for Medicaid Waiver services. In addition to improving the procedures for applying and receiving Waiver services, an expedited enrollment process needs to be available similar to the dismantled Community Choice program. Pennsylvania should complete an assessment to identify where there are gaps in services and a lack of qualified providers, and implement a plan to ensure that consumers can access needed services regardless of where they live.

Support the recommendations, goals, and strategies of the Pennsylvania State Plan for Alzheimer’s Disease and Related Disorders (ADRD). According to the plan, “Over 400,000 Pennsylvanians are likely afflicted with ADRD, and the toll of the disease extends beyond those affected to their families, friends, and communities. All told, one in 12 Pennsylvania families is affected by ADRD.” This epidemic cannot and should not be ignored. The Commission should incorporate the recommendations and strategies from the state plan to the greatest extent possible in its final report.

Preserve Lottery Funds for existing senior programs or those that help older Pennsylvanians age in place. Over the last several years, slightly more than $2 billion was diverted from the Lottery Fund at the detriment of programs that were specifically created to be funded by the Lottery. The Lottery funds the PACE and PACENET low-cost prescription drug programs, the Property Tax and Rent Rebate Program, free transit and reduced fare shared-rides, and long-term living services. For example, Lottery proceeds provided 8.3 million meals at senior centers and delivered to seniors’ homes. In FY 2012-13 the Lottery paid for almost 35 million free transit rides and more than 4 million reduced fare shared rides. On average, the Lottery helps provide more than 107,000 free and reduced-fare shared rides for older Pennsylvanians, every day. These services should be fully funded to help older Pennsylvanians age in place before any money is transferred out of the Lottery Fund to pay for General Fund obligations.

While these comments do not fully address the concerns or recommendations of each member agency, they do reflect a consensus of basic principles that are supported by the Senior Support Coalition. The members of the Senior Support Coalition thank you for your consideration.

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There's No Place Like Home

AARP CARIE PHA National Guard

Alzheimer's Association
Thank you for the opportunity to provide additional comment to the LTCC.

My name is Sandy Murphy and I am the director of Chester County Department of Aging Services. Prior to becoming an employee of the county, I was employed by a private non-profit which provided Service Coordination and in-home services to people with physical disabilities.

When I came to the aging department I was stunned when I found out that consumers who entered the aging waiver or OPTIONS program did not receive the same amount of service as someone who was enrolled in a program when they turned 60. Consumers in the under 60 waivers and Act 150, were and still are, receiving more hours of service than consumers who are in programs serving the over 60 population. Specifically, over 60 consumers in the ACT 150 program have large numbers of hours of in-home services while a consumer in NFCE OPTIONS are limited to a capped care plan.

Another inconsistency is the over 60 population must have an annual level of care assessment while the under 60 consumers are only required to have an initial level of care to determine program eligibility.

The first day I attended a state meeting regarding aging services I have heard the words “the state is striving to move the AAAs to be consistent in all practices.” My question is when is the state going to move to becoming more consistent by eliminating the care plan cap and having the same requirements across all programs regardless of the population served.

Thank you

Sandy Murphy, Director
Chester County Department of Aging Services
610-344-6378
"The best way to prepare for life is to begin to live." Elbert Hubbard

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Pennsylvania Adult Day Services Association

c/o 119 Radnor Street
Bryn Mawr, PA 19010
www.pdsa.org  email: bartonp@mladc.com

July 29, 2014

Submitted electronically to: ra-LTCCommision@pa.gov

Dear Secretary Mackereth and Secretary Duke:

As you know, the Pennsylvania Adult Day Services Association (PADSA) is the professional organization representing Adult Day Service providers that serve older Pennsylvanians, individuals with disabilities, and their caregivers. Our focus is to keep families together by improving home and community-based services for older adults, thereby preventing premature and unnecessary institutionalization. As the Long-Term Care Commission prepares recommendations to improve Pennsylvania's system of long term services and supports, we urge the Commission to include in the final report the following values and principles:

- **Focus Support upon allowing older adults to choose Home and Community Based Services in order to remain at home as long as possible.** Consumer choice and self-determination are important components of person centered planning required by the Department of Human Services (HHS) and the Commissions for Medicare and Medicaid (CMS).*

- **Improve access to home and community-based services in lieu of institutional placement.** Because individuals can be admitted to a nursing home immediately upon clinical need determination, this often becomes a default decision simply because it can take months to receive approval for Medicaid Waiver services. An expedited enrollment process, similar to the dismantled Community Choice program, should be reinstated together with full funding to eliminate waiting lists. Otherwise, for these seniors the only option for emergent immediate service becomes nursing home placement.

- **Strengthen Pennsylvania's Infrastructure for home and community-based services.** Adult Day Centers serve over 13,300 families at 266 locations but not all seniors have an Adult Day Center in their local communities or even in their county. Pennsylvania should ensure that consumers can access needed services regardless of where they live.
• Assure that service reimbursement rates are adequate and index them to provide annual inflationary increases. Low reimbursement rates make it difficult to recruit and retain professional caregivers which can impact access to care at home and community-based Waiver programs have not received a significant rate increase in 10 years. Enhanced Adult Day Service rates were specifically excluded from the state’s rate studies and thirteen Area Agencies on Aging (AAAs) have had to drop out of providing service coordination for the Aging Waiver. More will be forced out if rates are not increased and indexed to inflation. That will create further delays in referrals and approvals for HCBS.

• Rededicate Lottery Funds for existing senior programs and services that enable older adults to remain in their homes as long as possible. Until the past six years, Pennsylvania’s programs for seniors were the envy of the nation because Lottery proceeds were dedicated to funding many of those programs. Increasingly, however, the state has diverted more and more lottery money each year, over $500 million in the 2014-15 budget alone, to the detriment of programs that were created to be funded specifically by the Lottery. On average, the Lottery helps provide more than 107,000 daily free and reduced-fare shared rides for older Pennsylvanians, some of whom depend upon this service to receive care at Adult Day Centers or through other HCBS services. Additionally, it does not do any good to talk about eliminating waiting lists if reimbursement rates are too low to provide options services or to retain staff. These services should be fully funded to help older Pennsylvanians remain in place before any money is transferred out of the Lottery Fund to subsidize General Fund obligations.

This letter does not address the nuanced regulatory concerns Adult Day Centers face. We have chosen to focus upon the larger, strategic view of long-term care services and supports and will work through other avenues to address specific regulatory issues.

PADSA appreciates the opportunity to provide these views to the Commission for consideration as it prepares its recommendations. Thank you!

Sincerely,

[Signature]

Pam Barton
President

[Signature]

Jim Donnelly
Policy Chair

July 21, 2014
Via Email: ra-LTCCommission@pa.gov

Secretary Beverly Mackereth, Co-Chair
Secretary Brian Duke, Co-Chair
Pennsylvania Long-Term Care Commission
P.O. Box 8025
Attn: OLTL POLICY
Harrisburg, PA 17105

Re: Written Comment:
Recommendations for Improving Long-Term Care in Pennsylvania

Dear Secretaries Mackereth and Duke, and Members of the Commission:

Thank you for providing an avenue through which we can submit our written comments for you to consider as you prepare your report and recommendations to Governor Corbett on improving long-term care in the Commonwealth of Pennsylvania.

This firm represents health care providers, including home health care providers, in the Commonwealth of Pennsylvania. We have seen the challenges facing our clients as costs rise, reimbursements remain stagnant, and their consumer population increases. We do not wish to reiterate the many recommendations we saw provided at the Commission’s hearing in Philadelphia on July 14, 2014, but we believe that we ought to raise a few issues that we see as critical to providing Caregiver Support and to ensure Provision of Service in the future.

It is essential to identify and address barriers to home- and community-based service (HCBS) expansion in Pennsylvania. With the baby boom demographic retiring during a time of fiscal challenge, re-balancing Medicaid long-term care supports and services (LTSS) from institutions to HCBS is a priority. In the United States, the population of citizens 60 years old or greater is the fastest growing in the country. By 2030, the older adult population is projected to comprise 19.6% of the national population, more than twice the number in 2000.1 Closer to home, Pennsylvania is the fourth “greyest” state in the nation, with 2.7 million people aged 60

and older. By 2030, the older adult population is projected to exceed 3.6 million Pennsylvanians. It is estimated that 70% of older adult population will need long-term care to assist with the activities of daily living (ADLs). Industry analysts project increased state spending of $3.1 trillion in LTSS for elderly and disabled citizens by 2030. Medicaid is the largest consumer of LTSS, absorbing 40% of the national cost. It is well established that HCBS is less costly than institutional care. Yet as of 2007, Medicaid allocated 73% of LTSS spending to costly institutional care and only 23% to HCBS.

Pennsylvania’s commitment to participate in the Balancing Incentive Program (BIP) places our Commonwealth in the vanguard in expanding HCBS to vulnerable populations. Unfortunately, the current reimbursement structure and regulatory framework create obstacles to that expansion.

We believe that it is also clear that the provision of HCBS will always include a significant number of small, private, flexible community providers – family-owned businesses and community-based enterprises being the core of these providers. This is due to the passion that you no doubt saw from the owners and employees of such businesses as they testified before you this year. The difficult nature of the work they do, and the low return on investment that they see from their efforts, guarantees that larger, bottom-line oriented businesses will always leave gaps in the market that can only be filled by the passion of these smaller providers. For them, the work they do is as much a calling as it is a career.

In order to ensure that these smaller, community-based businesses are able to provide services to our fastest growing health care demographic, we believe the following issues must be addressed:

1. **Reimbursement rates for the services they provide must be raised.** Rates for home personal assistant services (PAS) are much too low. The HCBS waiver program rates have not seen significant increase in 10 years. Moreover, Act 22 standardized PAS rates at the bottom of the payment range recommended to the Department of Public Welfare by an independent consultant in 2012. The 2% increase in Governor Corbett’s 2014-15 budget is helpful; however, we believe a 5% increase is necessary for agencies to remain viable as the demand for their services grow. At the July 14, 2014 hearing in Philadelphia, one witness testified that his business provides 24/7 care to their consumers for $35/day per person – while the average rate to board a dog in the area is $50. Our

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3 Id.
6 Kaiser Commission on Medicaid and the Uninsured estimate based on CMS National Health Accounts Data, 2008.
7 U.S. Senator Tom Harkin’s 2013 report to the Health, Education, Labor and Pensions Committee cited 38 studies from 2005 to 2012 showing that HCBS is less expensive than institutional LTSS.
clients cannot raise rates as other businesses do, as they are bound to government-set reimbursement rates. These low rates inhibit the agencies’ ability to hire and limit consumer access to HCBS in Pennsylvania. Agencies must also provide health care to their employees under the Patient Protection and Affordable Care Act (“PPACA”). A number of agencies find it mathematically impossible to provide health care under PPACA while providing services at the current reimbursement rates. We believe that providing health care to home health care workers is good for our clients, our clients’ employees and their consumers. Reasonable rates should be set that allow home health care businesses to pay their workers a living wage.

2. Regulatory Burdens Must be Addressed. Smaller home care providers are subject to the same regulations as larger, institutional and clinical providers. State and federal regulatory burdens, including the Long-Term Living Home and Community Based Services regulations, the Health Care Facilities Act, the Health Insurance Portability and Accountability Act (“HIPAA”), the Health Information Technology for Economic and Clinical Health Act (“HITECH”), etc., place an enormous administrative burden on smaller providers. For example, Pennsylvania’s 2013 Long-Term Living Home and Community Based Services regulation mandates HIPAA compliance for HCBS providers. However, long term care providers are excluded from the federal ONC PA Reach programs and the Pennsylvania Medicaid Assistance EHR incentive programs to assist with EHR adoption and HIPAA compliance. We believe that the Commission’s recommendations should be formed so as to: 1) avoid increasing the regulatory burden on home health care providers; or 2) to expand compliance incentive programs to HCBS providers. Furthermore, it would be productive to provide an expedited process to allow providers to seek and receive advisory opinions from the Commonwealth on the complex web of state regulations. This would allow providers to obtain guidance on emerging regulatory areas which may have little or no other sources of guidance.

Thank you for your consideration of our comments. Please contact us directly if you require any additional information.

Respectfully,

Christopher E. Ezold

Respectfully,

Melanie Bork Graham

CEE/MBG/kh
Dear Long Term Care Commission Members:

The above attached report from the Pennsylvania Auditor General is submitted to document the flawed procurement process used to select PPL and also the numerous problems, including non-payment of wages to hundreds of homecare workers after PPL took over the financial management services in Pennsylvania.

Based on this Auditor General’s report and the ongoing problems with PPL, including poor customer services and lack of physical offices throughout the Commonwealth, the LTC Commission should recommend the reinstatement of a network of authorized FMS providers, including Centers for Independent Living. This is consistent with the principle of Consumer Choice – the ability of a Consumer to choose their FMS provider from a list of qualified FMS providers.

Under no circumstances going forward, should Consumers’ choice be limited to one provider such as PPL. DPW/OLTL should never again limit Consumer Choice. The unfair monopoly set up by former Secretary Alexander should be remedied by reopening the FMS marketplace to a choice of FMS providers available on in all geographic regions of the state.

Thank You,

Thomas H. Earle, CEO
Liberty Resources, Inc.
714 Market Street, Suite 100
Philadelphia, PA 19106
215 634-2000 Ext. 257
www.libertyresources.org

This email is written in Verdana 14-point font in accordance with LRI’s accessible email standard.
Pennsylvania Long-Term Care Commission  
PO Box 8025  
Attn: OLTL Policy  
Harrisburg, PA 17105-8025

Members of the Commission,

My name is Penny Kurisko. For 25 years I was the Primary Caregiver for my parents and learned first-hand the challenges that face many older adults and their families. My caregiving days are now behind me but I am still passionate about this topic. I recently learned of the formation of the Long-Term Care Commission and attended the meeting on June 20th in Lords Valley. I was pleased to hear that you would welcome public feedback so I would like to share with you some thoughts and suggestions on Long-Term In-Home Care.

So that you can understand why I have such strong feelings on this issue I would like to tell you a little about myself and my family’s situation. I was born and raised in the Scranton area; upon graduating from college I relocated to Allentown and then to suburban Philadelphia. In between those 2 employment opportunities my Mother had her first of 2 strokes and at the age of 28 my role as “Parental Caregiver” began.

For the next 10 years I coordinated my parents’ care through various medical and aging issues while living 2 hours away. My brother, my only sibling, lived in Florida so I was our parents’ sole caregiver. At first, as is often the case, I offered advice and helped with routine tasks and decision making. As major illnesses surfaced including open-heart surgery for both of my parents, Parkinson’s and Prostate cancer for my Father, and in 1995 a debilitating second stroke for my Mother, the amount of my time and hands-on care they required steadily increased.

I was fortunate during those years to have had an employer who was extremely supportive and allowed me to return home as needed, sometimes for weeks or months at a time. Three years after the life-altering stroke that my Mother suffered in 1995 the stress of trying to arrange for the quality of at-home care she deserved coupled with my weekly commute home to be her weekend caregiver ultimately led to me resigning from my job and leaving my career and life behind to move back home to care for her full time.

I was also extremely fortunate that my Mother’s first Case Manager at the Lackawanna County Area on Aging was exceptional. Thanks to her knowledge, compassion and guidance I was able to care for my Mom at home for 15 years, well beyond her projected 6-12 month life expectancy following her stroke. During those years we received the services of a Home Health Aide first through the Block Grant Program and then through the PDA Waiver Program.

My Mother’s needs were more involved and demanding that most. As a result of her stroke her verbal skills were limited, she could no longer bathe or dress herself and she needed to be transferred into a wheelchair or commode numerous times a day. She required full time help and supervision.
It would be impossible to convey in this letter all the experiences and lessons I learned over the years and the struggles I continue to see others facing today. So I will direct my remarks to two areas: 1) In-Home Eldercare and 2) Caregiver Challenges.

**IN-HOME ELDERCARE**

The ability to remain in one’s home for as long as possible is a common desire for most everyone; not only as we age but also if we should be faced with a physical challenge. This of course is not always possible depending on one’s medical needs, financial resources and family support. Regardless of the specific situation the first questions raised by those facing these challenges are often the same, “What do I do? Where can I turn for help?”

When an older adult requires help with daily personal at-home care it is usually through word-of-mouth or at the suggestion of someone who has dealt with this situation that they are directed to the Area on Aging. Not everyone, however, needs the hands-on care they can provide. The individual or their caregiver may simply need suggestions on things such as what safety items are available for the home and where they can be purchased or how to wash someone’s hair if they are not able to get into the shower or stand at a sink. Additionally, most Eldercare services are tied to government programs that provide financial assistance and not everyone needs financial help. There’s a gap for both of these situations...where to turn for direction and where to turn for those who do not require or do not qualify for financial assistance.

Another area not addressed regardless of whether or not an individual is receiving services through an Area on Aging is a “Home Safety Evaluation”. A doctor may request that a Physical Therapist be sent into a home if a medical condition warrants; some PTs may offer recommendations on how to adapt to the home environment, not all do. For most older adults such an “evaluation” is not available.

As we age, there are many changes that can be made in a home to make it safer, more functional and easier to maneuver. Simple changes such as removing throw rugs and rearranging furniture can help prevent falls and possible injuries that could require hospitalizations and even nursing home admissions. And when possible, relocating a bedroom to the first floor, building a ramp for access to the house or adding toilet facilities to the first floor can be the difference of an older adult being able to remain in their home or requiring a permanent nursing home placement.

An important aspect of a “Home Safety Evaluation” is to be proactive. Just as families make accommodations in a home when a baby is due to arrive the same should be done as we age. Educating individuals and encouraging doctors to recommend that older patients consider and address these home issues early on rather than waiting until something happens AND providing the resources for these evaluations and their follow-through could have an immeasurable positive impact on the Commission’s key topics of PREVENTION, SAFETY and REMAINING in homes as long as possible.
CAREGIVER CHALLENGES

Over my years as a Caregiver I often heard the comment, and still do, “There’s help out there, just ask”. That’s misleading. Yes, there are services available but they are limited and there are exclusions. For those who are eligible for these services it is important that they and their Caregivers understand that these resources are only a supplement to the significant time and financial commitments that may be required to care for an older adult at home.

HOME HEALTH AIDES are the outside helpers most older adults rely on for assistance with their daily needs such as bathing, dressing and meal preparation. One of the challenges in hiring an Aide, regardless of whether an Area on Aging or the consumer or family member is paying for those services, is that it can be very difficult if even possible to find reliable and competent Aides; particularly for hours before or after school, on weekends or for a few hours in the evening. Hiring an Aide directly through a Home Health Agency is cost prohibitive for most and partially due to the low wages paid to Aides by agencies, the abilities and reliability of their Aides is not always acceptable.

Staffing is just one issue that can be encountered when dealing with a Home Health Agency. In light of that, it was a welcomed policy change when the PDA Waiver Program began allowing a consumer to hire a caregiver of their own choosing. While the Waiver program allows for a family member to be the “employee” that family member cannot hold the consumer’s Power of Attorney. One reason given for this exclusion is concern of Elder Abuse; someone gaining financially yet not providing the necessary care to the person in need. Considering that we all choose someone closest to us as our Power of Attorney it is often that same person who steps in to provide care when it becomes necessary.

While the need for oversight and protecting the elderly is necessary excluding Caregivers with POA negatively impacts those Caregivers who are genuine, those who are already doing the job that often cannot be sufficiently filled or who must step in when an Aide is not available. It also hurts consumers who do not have other family members to take on the responsibility of POA or help with their care. Having been personally adversely affected by this policy after the passing of both my Father and Brother I implore you to reconsider this restriction.

HEALTH CARE is another area of concern for Caregivers. Cutting back work hours or as in my case leaving a job to care for a loved one may result not just in loss of an income but loss of health care benefits as well. For single individuals like myself who do not have a spouse to rely on for those benefits the cost of insurance premiums alone is monumental.

Although options under the recently implemented Affordable Care Act can dramatically lower the cost of health insurance premiums the level of coverage many of those plans offer do not cover the costs of needed medical care; and as with any individual plan these policies do not include dental or vision coverage. Offering Caregivers a comprehensive health care buy-in or offering a paid health care benefit to “Full Time Elder Caregivers” would ease their financial burden and possibly allow for more family members to be able to choose the option of caring for a loved one at home. The annual cost to the State to pay these premiums would be minimal compared to the potential cost incurred for a nursing home placement.
The PROPERTY TAX/RENT REBATE Program currently designates three eligible categories based on income limits...Pennsylvanians 65 and over, those 18 and older with disabilities and widows and widowers age 50 and older. I propose extending eligibility to include a “Full Time Elder Caregiver” who is currently or has previously provided at-home care for an aging parent either by moving a parent into their home or by moving into their parents’ home for the purpose of taking on the responsibility of their care.

SOCIALIZATION opportunities for aging adults was one of the topics brought up in the Commission meeting in Lords Valley. This is also a challenge for Caregivers. I don’t have an answer for how to address this issue but I have found that most people are uncomfortable discussing or even hearing about Eldercare issues; and there is little understanding of or empathy for the emotional toll that impacts Caregivers.

I lost my Dad 5 years after my Mom’s stroke and I lost my brother unexpectedly 5 years after that. As more family issues arose the more friends and family distanced themselves from me, from my situation. That distance continues to this day as I try to acclimate myself back into life and at 57 years of age struggle to resurrect the IT career I left almost 16 years ago.

This lack of understanding toward Caregivers is not limited to family and friends. My Mother could not be left alone so I was primarily homebound. As time went on less services were extended to me under the premise that since I was “already there” I could address my Mom’s needs on my own and should not need as much help with her care. Contrary to this way of thinking, everyone needs a break from their responsibilities from time-to-time, Caregivers included.

IN SUMMARY, please consider that the long-term impact of helping Caregivers in whatever ways possible would not only help them to continue caring for a loved one at home but would also serve as an incentive to anyone considering if they could take on this daunting task and it’s financial implications. I would strongly suggest that help be in the form of benefits or financial assistance; tax credits are not helpful if an individual does not have an income.

MISCELLANEOUS:

- Eligibility for most services available to older adults consider the financial assets and income of the entire household. For an adult child willing to have their parent come to live with them or willing to move in with their parent to help in their care this policy can result in the parent being ineligible for services that they would have received if they continued to live on their own. This may discourage adult children from getting involved in their parents’ care and lead to choosing a nursing home placement instead of at-home care.

- As aging individuals recognize that they or their spouse need assistance with daily tasks they are often reluctant to ask their children for help; conversely, most adult children do not always see that their parents may need help or to what extent. I believe that more families would get involved in caring for their loved ones if they were more informed about their options, about the services that are available and if they had a support system to guide them through what can be initially be an overwhelming undertaking...
- When an older adult is assessed for their eligibility in a State program all their assets are included in that evaluation. This is not the case in programs for children; parents’ assets are not considered.

- Most laws and programs are geared toward families, particularly the parent/child relationship. Americans are living longer and the challenges of respectfully caring for our aging population are continually increasing. Not all older adults have children; some have no family at all who can help them as they age. Just as considerations have been extended to grandparents and individuals other than parents who are raising children I would encourage that similar considerations be given to anyone who is the “Full Time Caregiver” for an older adult whether that is a relative or a friend.

It was by chance that I learned of the Long-Term Care Commission and the meeting in Lords Valley. It’s unfortunate that most consumers and caregivers are not aware of your mission and therefore did not have the opportunity to relay their stories to you. Information directly from those that live it every day is invaluable. This was exemplified at the meeting I attended by the only 2 speakers that day who were not representing agencies or who were not promoting a political agenda. The insight given by Keith Williams, an employee of CIL and a consumer himself, provided a first-hand perspective of consumers’ needs; as did the comments of the Caregiver who advocated for an Adult Day Care to meet her grandmother’s socialization needs.

I’ve only touched the surface of issues I encountered in my experiences as an Elder Caregiver. I would be glad to provide you with any additional details on these or any other topics that may be of particular interest to you related to in-Home Long-Term Care.

Thank you for your efforts in addressing the topic of Long-Term Care. I appreciate the opportunity to pass along my feedback.

Sincerely,

Penny Kurisko
To: Secretary Mackereth and Members of the Long Term Commission

My name is Shona Eakin. I gave verbal testimony at the hearing held in Mercer in March 2014. I am submitting these comments so that they will become an official part of the documented record of stakeholder feedback.

I wear multiple hats. I am the Executive Director of Voices for Independence. As such, I have the privilege and responsibility to oversee the administration of personal assistance services to almost 400 people in Northwestern Pennsylvania. I am also a user of attendant services and I am the wife of/caregiver of a user of services that is a ventilator user.

I look at the issues, of which I am about to give testimony from a unique position. Today, I want to highlight three main issues:

The first, Home Modification:

Pennsylvania has this wonderful program and could use it to benefit more people and ultimately save the State significant money. In order to illustrate my point, I would like to mention my second issue which is Nursing home transition. Many people end up in nursing facilities because they cannot modify their homes to meet changing needs. Nursing facilities on average cost the State more. If you, as commission members would recommend a policy change to add home modification services to all attendant care programs, money and other resources could be saved. By the time people are forced from their homes to a nursing facility, often injury has occurred costing Pennsylvania more money in restorative services and the individual often loses community supports such as friends, family, housing and other support services resulting in longer unnecessary, costly stays in nursing facilities until they can get to the community with appropriate supports. Nursing home transition is an extremely valuable program. As you are already aware because of testimony provided to the commission earlier this year, Pennsylvania is seen by CMMS as a leading example of how well nursing home transition can be done. It is a great program, and with a few administrative changes it could be excellent.

Often the lag time in Harrisburg delays transitions. This is happening at all levels beginning with the enrollment process. People in nursing facilities should be presumed eligible, especially when already occupying a
Medicaid-funded beds. The nursing home transition process is often delayed because we are waiting for budget approvals for services and home modifications and special funding requests. The State selected their nursing home transition liaison organizations based on proven transition experience. Please empower them to make decisions on the local level within parameters. To establish these parameters use the expertise you already have. Get input from the people doing the work. It is time to pull nursing home transition workers together and find out what is working and what isn’t.

Finally, my third issue is nurse delegation in Agency-Directed Attendant Care.

People with disabilities do not perceive many of the activities required for our daily functions as invasive or even medical. Attendants should be allowed to do such things as catheter care, and bowel maintenance activities such as suppositories, ventilator care, feeding tube care, etc. It does not make sense that these activities can be performed by attendants, often the same people, under Consumer Model through PPL and they cannot be performed in Agency-Directed Attendant Care. Obviously, nurse delegation is recognized in Consumer Model, and it most definitely should be in Agency-Directed Attendant Care. I understand the need to establish parameters. Again, I think you should involve your provider network, consumers of services and the Department of Health in establishing those parameters. Act 69 should be amended to allow for nurse delegation, health maintenance and daily activities people with disabilities need support to do.

I volunteer to serve on any committee that would be established to develop solutions on all of these issues. Please feel free to contact me at Voices for Independence, 1107 Payne Avenue, Erie, PA 16503, (814) 874-0064.
Draft Principles for a Medical Assistance Managed Long-Term Care Services and Support Pilot in Allegheny County

Background
HealthChoices plans, health care and service providers who serve those with long-term health and service and support needs in Allegheny County have had a successful history of working collaboratively together. Recently, a number of these stakeholders met at the invitation of the Institute of Politics of the University of Pittsburgh (IOP) and the Jewish Healthcare Foundation to discuss the need to reform how Medical Assistance-funded long-term care services and supports were provided and financed. These meetings resulted in consensus recommendations for reform amongst these diverse stakeholders, which is reflected in the Institute of Politics Report: The Future of Medicaid Long-Term Care Services in Pennsylvania: A Wake-Up Call. See: http://www.iop.pitt.edu/documents/Policy%20briefs/Medicaid%20Long-term%20Care%20in%20Pennsylvania.pdf

One of the recommendations in the IOP report is that the Pennsylvania Department of Public Welfare (DPW) should pilot managed long-term services and supports (MLTSS), utilizing many of the recommendations in the IOP Report. This paper contains concepts for discussion with DPW and the Corbett Administration for such a managed long-term care pilot in Allegheny County:

1. Initially, the pilot population would be for seniors (age 65 years and older) who are dually eligible for both Medicare and Medicaid and who have enrolled in a Medicare Special Needs Plan (D-SNP or I-SNP). We propose that these SNP enrollees in Allegheny County would be assigned to the respective company’s HealthChoices plan for their Medical Assistance (MA) benefits. This concept has several advantages:
   - It is voluntary rather than mandatory for both Medicare and Medicaid plans. Senior enrollees have already opted to enroll in the Medicare D-SNP or I-SNP plans and it does not require those in Medicare fee-for-service to make any changes. On the Medicaid side, these senior SNP enrollees could be notified that they will have

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1 Initially, it will be much less complex to focus on the dual senior population than on the younger dual eligible enrollees. This is particularly important for Pennsylvania given its demographics and the impending increase of older Pennsylvanians. This is the approach that Minnesota has also taken.

2 Enrollment would occur upon approval by CMS of the amended contract and readiness review by DPW of the HealthChoices plan.
their Medicaid benefits managed by the HealthChoices plan that is under the same umbrella company as their Medicare SNP plan (with the very same providers), unless they opt out of this arrangement. This will avoid the need for an 1115 waiver. Nor should it require a new HealthChoices procurement, but instead a contract amendment.

- Without the need for CMS waiver approval or a lengthy procurement process, the pilot can more quickly be put in place.
- Because the health care and service providers in the company's SNP are the same as those in its HealthChoices plan, it aligns providers and promotes provider coordination.

Although finances need to be strictly and individually accounted between the SNP and HealthChoices plans, it does provide the opportunity for financial coordination and some flexibility to meet the needs of the enrollees.

- It provides sufficient numbers of HealthChoices enrollees to allow proof of whether this concept works politically and financially for the State and provides quality consumer-centered services to HealthChoices enrollees.

- It aligns the financial interests of the HealthChoices plan with the interest of consumers, i.e., to be served in their homes rather than an expensive nursing facility.

- It will contractually require the Allegheny County Area Agency for Aging (AAA), which has the experience in managing long-term services and supports for this population, to work closely with the HealthChoices and SNP plans and providers.

- It will help to position Pennsylvania to be able to fully integrate financing and services with CMS for the dually eligible population in the future.

2. The pilot will strive to reduce costs through more comprehensive medical and services management of the senior enrollees and earlier identification and provision of services and supports of individuals at risk for Medicaid-funded nursing facility care.

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3 This is the approach taken by Wisconsin.
4 It is anticipated that the MIPPA agreements will need to be altered and a HealthChoices contract amendment will need to be made and approved by CMS.
5 Requirements for care coordination will need to be developed.
6 As of November, there were approximately 35,876 full dually eligible persons in Allegheny County, with 17,755 enrolled in D-SNPs. Approximately half of those are senior dually eligible people. With United and Keystone Health Plan West dropping their D-SNP program, the vast majority will be divided between the UPMC and Gateway plans. I-SNP enrollees not residing in nursing facilities are few in number.
3. The HealthChoices contracts should be amended to add the full scope managed long-term care services and supports, including those in the Aging Waiver, assisted living, the individual services provided by the LIFE Program\(^7\), advanced care planning, transitions of care and supportive care services\(^8\). This includes a full array of supportive services to help family caregivers, including:

- assistance in obtaining needed services,
- providing counseling to caregivers and assisting with problem solving
- follow up and support associated with discharge from a facility, where the enrollee is returning to the community,
- proactive case conferencing with consumer, caregivers and Service Providers re status changes and needed responses,
- support and resource for caregivers who are also providing support to other members of the family who may have a disability.

4. Assessment for MA nursing facility level of care should continue to be done by the Allegheny County AAA\(^9\). The AAA will also have a contract with the HealthChoices plans, to coordinate/provide long-term services and supports, but the plans will control the payment to providers, including the AAAs. Consumers may choose a service coordinator or provider other than the AAA, if in the plan’s network.

5. The pilot should be consumer-focused, provide for consumer-directed services and should be structured using the Community Catalyst checklist, “How Consumer Focused Are Your State’s Medicaid Managed Long Term Services and Supports”. See: \[\text{http://www.communitycatalyst.org/doc-store/publications/short-checklist-consumer-focused-mltss.pdf}\]

6. The pilot should contain a consumer/family education and engagement component on long-term care services and supports.

7. The pilot should include a research component on what triggers the need for nursing home placement and what services or supports are needed to avert it for both those who are presently dual eligible and those who will become eligible through spend down. The pilot could include allowing SNP enrollees to spend down for home and community-based waiver services as they would be able to do so for nursing facility

\(^7\) Should the LIFE Program want to provide those services as part of the plan’s network

\(^8\) This includes palliative care.

\(^9\) As part of the pilot, the AAA assessment of level of care should be reviewed to possibly allow distinction between those in need of extended services vs. those fully requiring nursing home placement.
care and determining if this is cost effective and avoids unnecessary institutional care.

8. The pilot should include quality measures, including consumer and family satisfaction, and utilize some of the preliminary measures developed by the National Quality Forum. See: http://www.qualityforum.org/MAP/Dual_Eligible_Beneficiaries/#!t=1&s=&p Plans should be required to have a continuous quality improvement program and cooperate with an external quality control organization (EQRO) to evaluate outcomes and quality of care.

9. Capitations should be risk adjusted and initially provide for risk corridors and stop loss. Additionally, the pilot should provide for shared cost savings, if quality measures are met.

10. Behavioral health services should be provided with every effort made to maximize the sharing of patient information (electronically where possible via electronic medical records) for better patient quality of care, consistent with state and federal laws. The pilot should explore ways to maximize integration of physical health, behavioral health and long-term services and supports and how best to jointly meet the needs of older dually eligible Pennsylvanians.

11. The pilot should include a pilot advisory committee, made up of representatives from DPW, the participating HealthChoices plans, the Allegheny AAA, consumers and consumer advocates, providers, foundations, etc., who receive monthly information on pilot operation, challenges and issues and meet monthly via conference call or in person to provide advice on quality improvement and policy issues.

12. DPW should facilitate the operation of similar pilots in other counties where the key stakeholders show a similar willingness to collaborate to provide better and more efficient, consumer-focused managed long term care services and supports, to help inform possible expansion of this model in the future. Data from the pilots and lessons learned should be shared and joint meetings held quarterly with the pilots key stakeholders to foster a learning collaborative to improve MA managed long term services and supports. For instance, speakers from other states could be invited to speak and to share lessons learned from the longer operation of their MLTSS. (The Learning Collaborative expenses might be something that foundation would be willing to fund.)

Areas for further discussion:
1. What is the full array of comprehensive medical management services?
2. What is the scope of managed long-term care services and supports? Should this include a common set for all plans with the ability to supplement with other services, as determined by the plan?
3. Should there be other factors determining shared savings, other than a set of quality measures?
4. Should we expand age eligibility to age 60+ to conform with the Aging Waiver and include those enrolled in the Independence and Attendant Care Waivers?
5. Should long-term care nursing facility residents, who are enrolled in a SNP be included? Should this include nursing home transition services?
Comments to: The Pennsylvania Long-Term Care Commission
From: The PA Health Funders Collaborative
Via: ra-LTCCommission@pa.gov August 12, 2014

The Pennsylvania Health Funders Collaborative (PHFC) is a network of 30 health foundations across Pennsylvania that focus their health philanthropy in communities throughout most of Pennsylvania. PHFC has focused on the need to reform how Medicaid long-term care services and supports are paid for and delivered as a priority area for our advocacy. Therefore, we appreciate this opportunity to comment on this critical issue.

The Corbett Administration has called for the reform of Pennsylvania's Medical Assistance Program, in large part due to the impact the program has on the state budget. The Pennsylvania Medical Assistance (MA) Program presently consumes 27% of the state budget, growing by $300-$400 million each year, just to maintain the status quo. Greater strains on the state budget will occur for long-term care services and supports (LTCSS) in the future due to the following:

- **The growing number of persons needing MA-funded LTCSS.** Seventy-three percent of MA's present expenditures are for elderly and enrollees with disabilities, who most need LTCSS. According to the United States Census Bureau 2010 report, Pennsylvania's population grew by 3.4% between 2000 and 2010; but Pennsylvania's population of people 85 years and older grew by 28.7%. Those 85 and older need the most LTCSS.

- **The demand for LTCSS that will need to be paid by the MA Program.** Seventy percent of Pennsylvanians reaching age 65 will need LTCSS for an average of 3 years\(^1\). Only 4% have long-term care insurance and most would exhaust their life's savings in one year if forced to pay for nursing facility care. Pennsylvania's MA program will be the payer of last resort for LTCSS for this growing demographic once they exhaust their resources and have nowhere else to turn for care.

- **The fragmentation and lack of care co-ordination that leads to unnecessary reliance on expensive nursing-facility care.** Adjusting for our older population, Pennsylvania’s MA Program pays 22% more on nursing facility care than the average state Medicaid program. Pennsylvania is paying for LTCSS at the most expensive price point and where most people do not want to live.

In many ways, the Pennsylvania MA long-term care “program” is similar to the MA fee-for-service in the 1990’s before the implementation of HealthChoices. Before HealthChoices, consumers often had to go to the most expensive point of service, a hospital, to receive any kind of comprehensive, coordinated care, since it was generally unavailable in the community. Too often today, an older person faced with an inpatient hospital stay, but needing coordinated LTCSS upon discharge, goes to a nursing facility, because coordinated care at home cannot be arranged or is not available.

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Pennsylvania Health Funders Collaborative

Pennsylvania's MA program spends more money on nursing home care than home and community-based waiver services (HCBS) for persons who have significant LTCSS needs with more people in nursing homes than in the community. In Pennsylvania's MA Program for FY 2012-2013:

| Percent of expenditures for nursing facilities: | 64.5% |
| Percent of expenditures for HCBS              | 30.97% |
| Percent of residents served in a nursing facility | 56.2% |
| Percent of residents served with HCBS         | 39.79% |

Pennsylvania needs to transform how it pays for and provides LTCSS, using lessons learned from the implementation of the HealthChoices Program:

- **Establish an Advisory Committee/Work Group to assist with the redesign of LTCSS in Pennsylvania.** The Committee should include the Secretary of DPW and Health, a Deputy from the Governor's Office, consumer advocates and PHFC representatives. When HealthChoices was being developed, foundations funded the Pennsylvania Health Law Project to bring experts from other states who had implemented managed care in their Medicaid programs to meet with DPW Secretary Houston and the Governor's staff on best practices and lessons learned from other states' roll out of mandatory Medicaid managed care. Secretary Houston has since said that before it started, she thought it would be a disaster but that it was one of the more important reasons for the success of HealthChoices. The Advisory Committee continued to give DPW feedback on the roll out of HealthChoices and to offer solutions for problems that occurred. Such an Advisory Committee/Work Group should be utilized in the redesign of Pennsylvania's LTCSS.

- **Pilot voluntary LTCSS managed care programs to determine important program components that need to be included in contracts for later mandatory LTCSS managed care programs.** Prior to HealthChoices becoming mandatory, it was piloted as a voluntary program in southeastern Pennsylvania. Many valuable “lessons learned” came out of the pilot that latter were included in the RFP for the mandatory program. It was important that the first pilot was located where plans and providers were willing to work collaboratively to prove that it could work. In Pennsylvania, two counties (Allegheny and Montgomery) have been meeting with managed care plans, AAAs, consumers and LTCSS providers in the hopes of piloting voluntary MA-funded managed LTCSS. (See Allegheny principles for pilot development and Montgomery County report on improving LTCSS for dual-eligibles.) Pilot programs that permitted consumers to voluntarily enroll could be expeditiously developed in these counties without need for federal waivers and could demonstrate that these programs successfully meet the needs of seniors while being cost effective for the state. These pilots could work out details for consumer directed services, consumer protections and rights, which are critical components of any LTCSS managed care program. As was the case with HealthChoices a gradual, voluntary roll out process allowed the development of the needed infrastructure and built trust with consumers and providers as they saw for themselves that the care delivered was superior to that under fee-for-service.

- **Roll-out mandatory managed LTCSS on a region-by-region basis and use independent enrollment counselors to help consumers select a LTCSS plan.** Pennsylvania gradually expanded HealthChoices across the state as plans and their networks developed the capacity to safely serve the target population. Pennsylvania did not realize the serious problems with the roll out of mandatory Medicaid managed care that other states did, because it did not try to expand across the state all at once, did not contract with plans with
capacity problems and did comprehensive readiness reviews before implementation. The use of an independent enrollment contractor helped to mitigate the preferences of health plans to enroll only the healthiest in their plan. As the recent bad experience in New York\(^2\) suggests, the need for an independent enrollment counselor is as much, if not more needed for LTCSS plans. HealthChoices has improved the quality of care, access, and care coordination that enrollees receive as compared to fee-for-service, while helping to control costs. Mandatory managed LTCSS plans can do the same for residents needing MA-funded LTCSS in Pennsylvania. The state should deliberately and prudently move toward mandatory MA managed LTCSS with appropriate quality measures, consumer protections, etc.

Additionally, Pennsylvania should include two important components in contracting for mandatory Medicaid LTCSS, not included in HealthChoices, which could save significant money and improve the quality of care:

- **Managed LTCSS contracts with plans should require the provision of integrated behavioral and physical health**, including the following:
  - Depression screening in primary care when staff-assisted depression care supports are in place to assure accurate diagnosis, effective treatment, and follow-up
  - Collaborative care management services, including services for depression, to ensure effective treatment, systematic follow-up, implementation of care plans, effective responses to transition-in-care, linkages to community resources, and goal-driven care

- **Managed LTCSS contracts with plans should improve end-of-life care**:

Twenty-eight percent of Medicare payments are for care in the last six months of life. Too often those with life-limiting conditions are receiving unwanted, aggressive medical interventions, are being shuffled from care setting to care setting and are dying in hospital intensive care units, when patients prefer to end their life in their own home and in the company of their families. Future LTCSS should require:

  - Appropriate use of the Physician Orders for Life-Sustaining Treatment (POLST) to ensure that patients' goals and preferences for end of life treatments are in the medical orders for those patients.
  - Provide incentives for physicians serving LTCSS enrollees to take the accredited online course, Closing, that helps them obtain the communication skills, medical principles and techniques to improve the care they provide for their patients facing life-limiting illnesses.
  - Networks that include excellent access for patients needing palliative and hospice care and educational materials about their availability.
  - Payment to providers for advance care planning with patients and their families.

At the earliest opportunity, Pennsylvania should participate in the demonstration with CMS to jointly contract with CMS for managed LTCSS for dually eligible individuals. In the United States, state Medicaid programs paid about 42% of costs for LTCSS with Medicare paying only 25%. Therefore, it is especially important for state Medicaid programs to better manage the costs of LTCSS. This is difficult given the dual funding sources of Medicaid and Medicare for dually eligible individuals. There are approximately 440,000 Pennsylvanians who are Medicare beneficiaries, and also have incomes and assets low enough to also make them eligible for MA. They are the sickest, poorest and most expensive group covered by either program. These “dual eligibles” represent about 18% of Pennsylvania’s MA enrollees, but account for about 43% of the program’s total spending, mostly for long-term care.

Pennsylvania’s dually eligible individuals are not enrolled in HealthChoices, but receive their coverage through fee-for-service. Dually eligible individuals can be needlessly ping-ponged from nursing facility care to hospital care and back again, so that nursing facilities can maximize income, with neither Medicare nor Medicaid able to do anything about it. (Nursing homes receive MA payments for holding beds for days that the patients are hospitalized. If the patient is in the hospital for three or more days and returns to the nursing home, that facility will receive the Medicare payment, which is higher than Medicaid.)

CMS has invited State Medicaid Programs to join CMS in a demonstration project to jointly contract with LTCSS plans serving dual eligibles in their state. Many large states and most of our neighboring states are participating in this demonstration program: California, Illinois, Massachusetts, Michigan, New York, Ohio, South Carolina, Virginia and Washington are doing capitated demonstrations. States are ensured up-front savings, as the capitation paid to the plan is less than the fee-for-service costs would be. The patient receives better, coordinated care paid for by integrated financing that removes the perverse financial incentives that can be harmful to consumers.

There is an urgent need for Pennsylvania to restructure how MA-funded LTCSS are provided and paid for. We urge the Long Term Care Commission and the Corbett Administration to begin this process as quickly as possible to improve the use of taxpayer resources, to support widespread reforms among numerous hospital systems in Pennsylvania and the outcomes for dually eligible older adults.

Respectfully submitted,

Ann S. Torregrossa
Executive Director
PA Health Funders Collaborative
215-514-5843
atorregro@gmail.com
August 11, 2014

Via Email
Attn: OLTL Policy/Long Term Care Commission
PO Box 8025
Harrisburg, PA 17101

Re: LTC Commission: Comments on Accessibility of Services

Dear Commissioners:

I am writing this letter to provide comments on the accessibility of long term care services for the Governor’s Long Term Care Commission. This letter is written on behalf of the Pennsylvania Association of County Affiliated Homes (PACAH), which represents all of the county nursing facilities in the Commonwealth, as well as a number of for profit, not for profit and veterans’ nursing facilities. PACAH is an affiliate of the County Commissioners Association of Pennsylvania.

While in many ways Pennsylvania’s Long Term Care System does an excellent job in providing long term services and supports to those in need, there are certainly some areas that could be improved. Our association believes that there are some improvements that can be made in terms of accessibility of services for those who are eligible for medical assistance, in particular through the County Assistance Office (CAO). Often, delays and inefficiencies at the CAO have the unfortunate effect of impacting nursing facilities in terms of receiving timely payment and impact a consumer’s ability to receive critical care. There are delays in determinations, failure to respond timely to questions, delays in processing voluminous amount of paperwork required to make the determination, and often unnecessary appeals. While this is not the case in all CAOs, there are some regions where problems are more prolific than others and it certainly has an effect on the ability of a nursing facility to provide and be reimbursed for services. When skilled nursing facilities are already reimbursed at rates that fall well below the cost of providing care, it becomes even more difficult when eligibility determinations are not made in a timely manner. County nursing facilities, in particular, are impacted by this as they are required to provide services to Medicaid patients on day one.

The brief comments below highlight the major areas of concern in terms of intake and eligibility determinations when it comes to accessibility of services for our members:

Redetermination issues:

- Frequently the CAO is not timely in sending the request for redetermination and notifying the facility there is a redetermination hearing
- Often benefits are ended based on the failure of a facility to provide information regarding residents in a redetermination hearing, yet facilities have not even received a request for information or are not even aware of a hearing.
- There should be processes in place insuring that any requests for information are sent in a timely and reliable fashion
Prior to ending benefits, it should be verified that any information requests necessary were in fact sent.

**Delays in MA approvals**

- In some areas cases are taking an average 6-8 months for approvals when it previously took 2-3 months.
- There are instances where cases over a year old still have not been approved, even after all necessary paperwork has been submitted.
- There have been instances where cases are sent to appeal and even though the CAO may subsequently receive all necessary information to make a determination, they will still wait for a determination to be made by a judge as opposed to approving prior to the appeal hearing. This seems to serve no purpose other than to delay the process. If the CAO is able to make a determination prior to the appeal hearing, policy should allow and even require that they do so in order to provide for a more efficient resolution.
- Multiple approvals have to be billed to 180 day unit when this was a rare occurrence in the past.
- There have been issues where hearings take a long time to schedule due to the overwhelming case load and then in other instances the resident or facility never receive notification of the hearing until they receive a call from the hearing judge. Once again, it should be a given that notifications always be sent in a timely and reliable manner.

**Inaccuracies on PA162's**

- There have been times where the forms are missing information once completed, for example, the Home Maintenance Allowance when a resident is eligible. To correct this the facility has to wait for an updated PA 162 which can take a month or more. Ideally, updated forms would take days, not weeks to resend.
- It is also not uncommon in some regions for there to be inaccurate Medicare Part B on the PA162, either not on it when it should be, or on it and they don't pay for their Part B so it should not be included. Again, while mistakes happen repetitive mistakes can cause a lot of delay in making determinations.

**Inability to get COLA's**

- Often COLA's are received late in January or February even though they are effective January 1, it is just another timeliness issue that can really impact a facilities bottom line.

**Unresponsive case workers**

- While in some regions caseworkers are responsive, there are certain CAOs where it is rare that caseworkers answer the phones or follow-up with a facility in a timely manner when it comes to questions, issues, etc. There have even been instances where the answer to questions is simply that the caseworker is really too overwhelmed to do anything about the issue.
- Caseworkers should be able to effectively handle the cases they are responsible for. If the workload does not allow for this, we are not providing acceptable services to those in need. It is difficult for both providers and consumers when a caseworker is too overwhelmed and/or unable to answer questions.

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*An Affiliate of the County Commissioners Association of Pennsylvania*
Thank you for taking the time to consider our comments. Please let me know if you have any questions, or would like more information.

Sincerely,

Kelly Andrisano, J.D.
PACAH Executive Director
August 14, 2014

Via Email and Regular Mail
Attn: OLTL Policy/Long Term Care Commission
PO Box 8025
Harrisburg, PA 17101

Re: LTC Commission Comments

Dear Commissioners:

I am writing on behalf the County Commissioners Association of Pennsylvania’s (CCAP) Human Services Committee in response to the request for comments in conjunction with the Governor’s Long Term Care Commission. CCAP is a statewide, nonprofit, bipartisan association representing the commissioners, chief clerks, administrators, their equivalents in home rule counties, and solicitors of Pennsylvania’s sixty-seven counties. CCAP also has eight affiliate associations including PACAH (Pennsylvania Association of County Affiliate Homes) and PACA MH/DS (Pennsylvania Association of County Administrators of Mental Health/Developmental Services).

Pennsylvania’s counties have a vested interest in the long term care system. Counties often have oversight and control of several long term care programs as well as other human services programs that impact long term care. Counties are also on the front lines of insuring that those who are most needy are provided with necessary care and support needed to live healthy and independent lives. While all counties are organized differently, some counties in Pennsylvania have oversight of Area Agencies on Aging (AAA), county nursing homes, waiver programs, behavioral health choices programs, local mental health and developmental services programs, Medical Assistance Transportation programs, and others.

Due to the counties’ involvement in administering local human services programs, in particular long term care services, we believe that it is important that when recommending any changes impacting the long term care system in Pennsylvania the Commission consider the role of counties and their ability to provide cross-coordinated care over a variety of different service areas. In furtherance of this, we make the following recommendations:

1) Local control and oversight of programs should be preserved. Counties are in the best position to understand the varied needs of their local residents and have been providing care in some cases have been providing cost-effective long term care services for decades. Counties are also in a unique position to be able to insure quality in that not only can they provide direct, local oversight but also they are directly accountable and accessible to those constituents utilizing the services. This helps to insure that any issues in quality of service are quickly and directly addressed by the county.
2) **Regional differences and resources should be considered.** Service delivery and resources look very different in Philadelphia County than in a rural county such as Sullivan. The ability for public transportation and access to providers provides very unique settings, and local oversight among some of these programs has helped address this. Pennsylvania has many regional variations that should be considered and looked at when implementing any sort of changes to the long term care system.

3) **The ability of counties to coordinate a variety of services should be maximized.** Counties often provide a wide variety of programs that fall under long term care services and supports. Some counties oversee the AAA, a nursing facility, the MATP program, the behavioral health choices program, developmental services, and other programs that impact long term care. Due to their experience dealing with these varied program areas and their inherent overlap, they are in a good position to continue to maximize coordination among program areas resulting both in efficiency and program quality.

4) **The benefits of the current Behavioral HealthChoices Program should be examined.** The current HealthChoices structure provides a single accountable entity at the local level to support building a unified system of care, common expectations for providers, common rates, and transparency to users of services. The HealthChoices structure also guarantees local stakeholder input into service development to address the unmet needs of people recovering from mental illness and addictive disease. The structure of the program assures a local presence in the BH MCO operations which results in a more personalized relationship, problem resolution and service enhancement. When discussing the various options for providing long term services and support, there should be discussion and consideration of the current behavioral HealthChoices model.

5) **Counties should remain part of any discussion regarding improvement the long term care system.** As stated above, counties oversee many of the long term care programs at the local level. Given their ability to assess quality, improve coordination, and respond to local needs they should naturally be part of any conversation regarding changes to the long term care system. Local providers and county leaders will be able to provide a perspective that needs to be heard and understood to insure the system is able to adequately provide necessary services to the State’s most vulnerable citizens.

Thank you for taking the time to consider these recommendations made on behalf of CCAP, and for your continued commitment to improving the long term care system. We would be happy to respond to any questions or provide more information.

Sincerely,

George Hartwick, III, Commissioner, Dauphin County
CCAP Human Services Committee Chair

Cc: Beverly Mackrell, Secretary, Department of Public Welfare
Brian Duke, Secretary, Department of Aging
August 4, 2014

Commonwealth of Pennsylvania
Long Term Care Commission
PO Box 2675
Attn: Office of Long Term Living Policy
Harrisburg, PA 17105-8025

Re: Lebanon County AAA Comments to the Pennsylvania Long Term Care Commission

Greetings,

It is my pleasure to address these comments to the Pennsylvania Long Term Care Commission on behalf of the Lebanon County Area Agency on Aging.

The Lebanon County Area Agency on Aging (AAA) has been advancing the needs of the most vulnerable older residents of Lebanon County for 40 years. Its mission is to serve as the coordinative authority for those 60 and older throughout the County, concentrating on maximum individual functioning and optimal quality of life, and the prevention of unnecessary and inappropriate institutionalization.

When the AAA was created in 1974, there were 15,000 people aged 60 and over in Lebanon County. Today there are over 30,000, or twice as many now as then. There has been much talk about the aging of the Baby Boomer generation. According to the 2010 Census, nearly 18.5% of the United States’ population is 60 years of age and older. In Pennsylvania, one of the grayest states in the nation, 21.3% of the population is 60 or older. Here in Lebanon County, 30,877 of our 133,568 citizens are 60 years of age or older, or 23.1%, surpassing the national average by 4.6%. This is the equivalent of 6,100 additional people over the age of 60 in Lebanon County.

Our demographics put us in a unique position to offer these comments regarding the future of Long Term Care in Pennsylvania.
seniors need and want, and what is available for them in Lebanon County. No one knows the local community better. AAAs are charged by the State of Pennsylvania and their own local governing boards to administer the delivery of a comprehensive and coordinated service delivery system for older adults. Continuing to centralize this function in the AAA makes sense both from the perspective of providing a seamless access to services to older adults, and in the efficiencies that this model naturally provides. People seeking services, particularly those facing an immediate need, should not have to think of which of several social service agencies to call. The local AAA should be their first thought and best option.

**Comment #5: AAAs should assess for Level of Care**

As changes to the Long Term Care system are considered, emphasis should remain with the AAA network to determine consumer needs and assess the appropriate level of care, so that finite resources can be directed to those most in need. AAAs have been assessing for level of care for many years, so that individuals may access care in nursing homes, personal care homes, and through the Attendant Care, COMCARE, Independence, OBRA, and PDA Waivers. While many other entities are entering the long-term care market, drawn by the business sense in serving this rapidly growing population, AAAs have been at the forefront of serving seniors for over 40 years. With experienced, dedicated staff, no profit motive, and a long history of working with the senior population, the AAA can remain impartial, and recommend the appropriate level of care and mix of services, no matter the provider, so that the needs of the individual are best met.

**Summary**

While these comments above are listed as distinct items, they are definitely intertwined, and speak towards the importance of providing people over 60 with access to a broad array of services through the AAA as the logical entry point, with dedicated support from the Lottery and the state long term care system.

These comments have been shared with and are supported by our management staff and our Advisory Council.

Thank you for providing this forum for comments on the future of Long Term Care in Pennsylvania. Please feel free to contact me if you have any questions or concerns.

Sincerely,

Carol A. Davies
Administrator

CAD/ed