

Impact of the Affordable Care Act on Pennsylvanians with Disabilities

A Report of the Pennsylvania Health Law Project

to the Pennsylvania Developmental Disabilities Council

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Introduction

The platitudes about the Patient Protection and Affordable Care Act of 2010 (commonly known as the Affordable Care Act) are well known, but bear repeating. For too long, too many Pennsylvanians paid the price for health insurance policies that handed free rein to insurance companies and put barriers between patients and their doctors. The Affordable Care Act (ACA) changed the old rules—e.g., prohibiting insurers from dropping coverage if you get sick, billing you into bankruptcy because of an annual or lifetime limit, or discriminating against anyone with a pre-existing condition.

If you're living with a disability, private health insurance may be hard to come by. Even if you can afford to buy it, it probably doesn't cover all of your needs. Worrying about where to get coverage and the cost of your care is the last thing you want to do. Now that the marketplace provisions of the ACA have been fully implemented, Pennsylvanians now have the security of knowing that they don't have to worry about losing coverage if they're laid off or change jobs or being rated up or denied coverage altogether due to a disability. Pennsylvanians with disabilities also have new options for long-term services and supports, particularly those that are home- or community-based.

Our overview of the impact on the ACA for Pennsylvanians with disabilities and significant health issues in Pennsylvania is separated into three broad categories: 1) Medicaid Expansion; 2) ACA and the Marketplace and 3) Long Term Services and Supports.

Part One: Medicaid Expansion

U.S. Supreme Court Ruling on Medicaid Expansion: Impact on PA

A central tenet of the Affordable Care Act (ACA) is significantly reducing the number of uninsured by providing affordable coverage options through Medicaid and new Health Insurance Marketplaces. As enacted, the ACA would increase Medicaid eligibility to nearly all low-income Americans with incomes up to 138 percent of poverty (\$16,242 per year for an individual in 2015). However, the June 2012 US Supreme Court ruling on the ACA effectively made the decision to implement the Medicaid expansion an option for states.

Then Pennsylvania Governor Tom Corbett immediately refused to make Medicaid available to its poor residents. Despite urgings from many health advocates his February 2013 budget address rejected the Medicaid expansion and turned down federal funding to provide health benefits to low-income residents. At the time Pennsylvania joined Idaho, Maine and a swath of southern states from Georgia to Texas in refusing to add more people to Medicaid. Echoing the rationales of republican governors like then Texas Governor Rick Perry, Corbett said Pennsylvania shouldn't enlarge its Medicaid program without a major overhaul of the program. " At this time, without serious reforms, it would be financially unsustainable for the taxpayers, and I cannot recommend a dramatic Medicaid expansion," Corbett told legislators. "The federal government must authorize real flexibility and innovative reforms that empower us to make the program work for Pennsylvania."

But Governor Corbett's announcement came after fellow republican governor (and now presidential candidate) John Kasich of Ohio became the fifth republican state executive to back the Medicaid expansion. In contrast to Corbett's claims about the affordability of adding more people to Medicaid, Kasich, Arizona Gov. Jan Brewer (R) and others cited the high level of federal funding as a key reason to participate. For states that expand Medicaid, the federal government will pay 100 percent of Medicaid costs of those newly eligible from 2014 to 2016. The federal share gradually phases down to 90 percent in 2020 and remains at that level thereafter. There is no deadline for states to adopt the expansion; however, the federal match rates are tied to specific years.

This was a devastating outcome that left over 600,000 low-income Pennsylvanians without health insurance coverage because non-elderly adults without dependent children (childless adults) were categorically ineligible for Medicaid if their income

exceeded \$205 a month. These adults could not use tax credits to purchase health insurance on the federal marketplace because the ACA **limits** tax credits to individuals with incomes between 100 percent and 400 percent of poverty assuming individuals **below** this level would be eligible for Medicaid based on the law's original design. In 2014, the cruel irony was a Pennsylvanian that earned **more than** 100 percent of federal poverty was required to buy insurance on the marketplace and could get a subsidy to help pay for health insurance premiums, but a Pennsylvanian earning **below** 100 percent of poverty was too poor and would not get any help at all! This injustice became known as the coverage gap.

Pennsylvanians in the Coverage Gap

In 2013 and 2014, PHLP and many other advocacy groups publicized the stories of health care injustice—i.e., poor people in the Medicaid coverage gap—to persuade policymakers to reverse course and expand coverage.

During that same period PHLP fielded nearly 500 phone calls in 2014 through our Helpline from uninsured individuals who fell in the coverage gap created by Pennsylvania not expanding Medicaid. As an expert in Medicaid eligibility, PHLP helped many sick/ill Pennsylvanians and those with disabilities who were working access health insurance by making them aware of Medicaid programs such as Medical Assistance for Workers with Disabilities (MAWD) and the Breast and Cervical Cancer Prevention and Treatment (BCCPT) program. We assisted others in piecemeal ways by identifying nearby federally qualified health centers (FQHCs) for basic health care or patient assistance programs that aid with the cost of prescription medications. But for too many Pennsylvanians—those needing treatment for chronic conditions such as heart disease, cancer and diabetes—Pennsylvania's choice to not expand Medicaid left them without access to health care they sorely needed.

Pennsylvania Proposes an Alternative to Medicaid Expansion

Consumers and consumer advocates vehemently opposed Pennsylvania's decision to not expand Medicaid. Finally, in September 2013, Governor Tom Corbett announced a proposal, Healthy PA, to both reform and expand the Medicaid program. The Governor conditioned his embrace of Medicaid expansion to: (1) the federal government agreeing to substantial changes to PA's existing Medicaid program; and (2) being allowed to place the estimated 600,000 "newly eligible" individuals who are included in the

expansion into private coverage through the federal health insurance Marketplace. The proposed changes to the current Medicaid program were unprecedented for Pennsylvania: premiums, work search requirements, the elimination of the General Assistance category, reduction of benefit packages to a high-risk and low-risk package, **and** the elimination of Medical Assistance for Workers with Disabilities (MAWD).

Consumers and their advocates were extremely concerned with all these changes and the surely detrimental impact on Medicaid recipients in particular the most vulnerable; those with physical or behavioral health disabilities and other chronic medical conditions. PHLP and many others detailed their concerns in writing to the state during a public comment period. Advocates achieved some successes: we persuaded the state to eliminate some of the most harmful aspects of the Healthy PA waiver prior to its submission to the federal government. But there was still much dissatisfaction voiced by PHLP and other advocates about Governor Corbett's proposal that was finally submitted to the federal government in the spring of 2014.

The federal government invited and received numerous comments from advocates, including several detailed comments from PHLP on behalf of disability groups. The Center for Medicare and Medicaid Services (CMS) disapproved many of Pennsylvania's most harmful requests such as premiums and the work search requirements. Unrelenting advocacy yielded another major victory in July 2014; Pennsylvania reversed course and decided **not** to eliminate the Medical Assistance for Workers with Disabilities (MAWD) program. As a result, 34,000 Pennsylvanians remained insured and working and countless others who meet the eligibility criteria continue to have MAWD as a viable health insurance option today.

However, in late August 2014 CMS did approve some disconcerting aspects of the Healthy PA proposal. CMS permitted Pennsylvania to **reduce** the adult Medicaid benefit packages to high-risk and low-risk **and** allowed new eligibles to be enrolled in new Private Coverage Options (PCO) insurance plans instead of Pennsylvania's familiar (traditional) Medicaid system (known as HealthChoices). CMS also sanctioned the use of a "medical frailty" screening instrument to determine whether Medicaid enrollees would be assigned to "traditional" Medicaid or Medicaid PCO plans despite the many potential problems identified by PHLP and other advocates. CMS also approved premiums for some adult recipients, though did not agree to implementation of such until 2016. They also authorized the elimination of the Medical Assistance Transportation Program for recipients enrolled in the Medicaid PCO plans for 2015.

In late fall 2014, while the state prepared for full implementation of Healthy PA as approved by CMS, Pennsylvanians elected a new Governor, Tom Wolf. Mr. Wolf's election platform included harsh criticism of Governor Corbett's Healthy PA and vowed to eliminate and replace it with a traditional Medicaid expansion if elected. Once in office, Governor Wolf kept his word and submitted a request to CMS to withdraw the Healthy PA application.

Healthy PA Implemented

Prior to Governor Wolf's late January 2015 inauguration, Pennsylvania (still led by Governor Corbett) proceeded with the rollout of Healthy PA and multiple problems ensued. Prior to its January 1, 2015 start, tens of thousands of Medicaid enrollees were moved out of HealthChoices and into the fee-for-service program causing huge disruptions in access to certain types of behavioral health care and payment problems for providers. In early January 2014, 8,000 existing Medicaid recipients who were receiving mental health and drug and alcohol services were wrongly placed in Medicaid PCO plans causing mass confusion, and for some, discharge from treatment programs. The newly named Pennsylvania Department of Human Services (DHS), formally known as the Department of Public Welfare (DPW), worked frantically for several weeks to correct these errors.

Meanwhile, new Medicaid applicants seeking eligibility under the expansion waited 45 to 60 days and sometimes longer to receive a determination from County Assistance Offices. An already understaffed and overworked system was simply unable to keep up with the volume of applicants. New applicants combined with a revised eligibility process and the initiation of the Medicaid PCO plans operating alongside the HealthChoices plans added to the chaos.

PHLP's Helpline experienced a twenty percent call volume increase in the first quarter of 2015 compared to the same quarter in 2014. Individuals and families who applied for Medicaid could not reach the County Assistance Office workers to find out the status of their applications; persons with disabilities and high medical needs were assigned to Medicaid PCO plans when they should have been placed in HealthChoices; callers were submitting the same paperwork two and three times to the Assistance Offices only to be told again that the information had not been received. The application process was chaotic, confusing and frustrating for many who had been uninsured for years. PHLP worked to troubleshoot individual situations while working with colleagues at

Community Legal Services, the Pennsylvania chapter of the National Alliance on Mental Illness (NAMI), the Pennsylvania Health Access Network (PHAN) and others to raise systemic issues to the state for a global fix.

Transition from Healthy PA to Traditional Medicaid Expansion

Once inaugurated as the Governor of Pennsylvania, Tom Wolf immediately moved to dismantle his predecessor's alternative to Medicaid expansion and implement a traditional plan to extend health insurance to hundreds of thousands of low-income Pennsylvanians. Wolf said the "Healthy PA" alternative plan instituted by Gov. Tom Corbett was flawed, confusing some patients and leading others to lose treatment. He called his action a step "toward simplifying a complicated process and ensuring hundreds of thousands of Pennsylvanians have greater access to the health insurance they need." In Pennsylvania, the governor did not need explicit legislative approval to move forward with Medicaid changes.

Democratic leaders, unions, and advocates for low-income populations (including traditional Medicaid managed care insurance plans and Medicaid providers) applauded Governor Wolf's shift to traditional Medicaid, while republican legislators raised questions about the costs to switch, future expenses, and whether recipients would have new disruptions in health access.

PHLP worked closely with the Consumer Subcommittee of the Medical Assistance Advisory Committee and DHS officials to gain clarity about the details of the transition process. Even though this change was ultimately positive for adult Medicaid recipients and individuals with disabilities and significant health issues in particular, the process added confusion to an already chaotic situation. PHLP was provided the opportunity to comment on DHS' notices to consumers regarding the shift to traditional Medicaid. Many of our language suggestions were incorporated; suggestions that ultimately yielded more readable notices.

PHLP's advocacy with DHS officials resulted in a "raise your hand" Medicaid Operations Memorandum for County Assistance Offices. The intent of the "Ops Memo" was to assist Medicaid recipients still receiving their health benefits through a PCO plan to a smooth transition to a HealthChoices plan. This transition was needed when people with disabilities or significant health issues had health care needs that couldn't be met by the more limited PCO benefit packages and limited provider networks. Those individuals, by self-identifying (i.e. raising their hands) to the Assistance Offices, were

to be transferred to a HealthChoices plan. We identified County Assistance Offices who were unresponsive to clients stepping forward asking for enrollment to a HealthChoices plan in order for their specific health care needs to be met. Individuals with mental health and substance abuse treatment needs were especially at risk of not having access to services such as psychiatric rehabilitation programs and halfway house drug and alcohol treatment, as the state did not require the Medicaid PCO plans to provide these levels of care.

Additionally, PHLP worked with several mental health and drug and alcohol providers whose clients were at imminent risk of premature discharge because the Assistance Offices were not cooperating to switch their coverage from the PCO plan to the HealthChoices plan. PHLP staff was effective in advocating for our clients by working collaboratively with the Offices of Income Maintenance and Mental Health and Substance Abuse Services to resolve these problems and ensure continued treatment for these affected individuals. Throughout the transition, PHLP worked concurrently with individual clients to assist in navigating new health insurance terrains while advocating with state officials to ensure the smoothest implementation from Healthy PA to a traditional Medicaid expansion. Our efforts continue as the final phase of the transition occurs.

Remaining Issues and Opportunities

Eligibility determinations for all Pennsylvanians applying for Medicaid, including those in the expansion population, continue to be cumbersome, lengthy and frustrating for applicants and their advocates. The ACA envisioned a streamlined, accurate and timely eligibility determination process for Medicaid, Marketplace and CHIP (Children's Health Insurance Program) applications. States have been granted significant flexibility in determining their verification policies and procedures for Medicaid and CHIP, including determining the data sources on which to rely and the circumstances under which the information an applicant attests to will be considered reasonably compatible with the information obtained through electronic data sources.

Part Two: ACA and Marketplace

As described above (Part One), considerable energy and attention was given to influencing whether and how Pennsylvania would expand Medicaid. However, the ACA transformation of private health insurance was just as, if not more, extensive. This section of the report highlights some of those changes including requirements for Marketplace plans (elimination of the pre-existing conditions), the mandate that plans possess ten essential health benefits, the decision to have a federal marketplace instead of a state-based one, and challenges associated with the first and second open enrollment periods for coverage that began in 2014 and 2015.

ACA Provisions Improving Coverage for Persons with Disabilities

The Affordable Care Act increased access to insurance and covered benefits for millions of Americans. One of its early benefits of the law (pre-2014) was the requirement that health plans offer coverage for young adults until the age of 26, *including persons with disabilities and chronic conditions*. This rule applied to all plans in the individual market, to new employer plans, and to existing employer plans unless the young adult has another, independent source of coverage.

The biggest components of the ACA's transformation of private health insurance began in 2014. Most significantly was the requirement that health insurers provide coverage **regardless** of a person's health condition or disability thus eliminating insurance company discrimination based on pre-existing conditions. Prior to the law, insurance plans can and did refuse to provide coverage to people with chronic health conditions or disabilities or would provide coverage at a much higher cost. Under the ACA, insurance companies cannot ask any questions regarding a person's health (except whether they smoke). The law also bans insurance companies from imposing annual and lifetime dollar limits on health benefits – freeing cancer patients and individuals suffering from other chronic diseases from worry about going without treatment because of lifetime limits.

The ACA also required qualified health plans participating in health insurance marketplaces to maintain a sufficient number of Essential Community Providers (ECPs) in their provider network. ECPs include federally qualified health centers, family planning clinics, Ryan White HIV/AIDS centers, public or non-profit hospitals, and others such as mental health and substance abuse providers and STD Clinics. They are

an “essential” and trusted source of primary care for low-income communities with the greatest health needs. Many ECPs work to reduce health disparities and provide culturally and linguistically competent services. Their inclusion is especially critical for those living in rural Pennsylvania.

Another critical piece of the ACA law, and a signature component of health care reform, is the mandate for individual and small group plans and those sold on the Marketplace to provide essential health benefits (EHBs). The ten EHBs include ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance abuse treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

The EHB requirement for *habilitative and rehabilitative services and devices* is especially significant for people with intellectual and developmental disabilities and autism. Prior to this ACA mandate, insurance companies generally provided limited rehabilitative services and did not cover any habilitative services. The distinction between the services is especially meaningful for persons born with a disability. Habilitative services refer to health care services that help a person acquire, keep or improve, partially or fully, skills related to communication and activities of daily living. These services address the competencies and abilities needed for optimal functioning in interaction with a person’s environment. Rehabilitative services include medically necessary health care services that help a person keep, restore or improve skills and functioning for daily living and skills related to communication that have been lost or impaired because a person was sick, injured or disabled.

Pennsylvania Doesn’t Choose a Benchmark Plan

While the ACA required plans to cover the ten Essential Health Benefits, states were given authority to further define these benefits. Every state was provided the opportunity to select a “Benchmark Plan” as a reference plan to define the Essential Health Benefits in their state. States that didn’t actively choose a benchmark plan would default to the largest small-group product in the state. Pennsylvania failed to select a plan and defaulted to an Aetna Point of Service (POS) plan; a lost opportunity for Pennsylvanians because state officials could have further defined and enhanced the state’s benchmark for all individual, small group and Marketplace plans.

The deficiencies of the Pennsylvania refusal to do anything more than the minimum than the default benchmark plan (Aetna POS plan, the largest small group plan) became apparent. This plan did not include habilitative services. This meant Pennsylvania based insurance plans, while still required to provide this benefit, had the freedom to define the service and the limits. As a result, no Pennsylvania plan offered habilitative services as a distinct benefit but instead combined it with rehabilitative services. The lack of distinction also proved to be problematic as habilitative services were essentially offered in name only. Pennsylvania also had the opportunity to define habilitative services but chose not to. Providing a clear and uniform definition would have validated these services as clear and distinct from rehabilitative benefits and emphasized their importance for persons with developmental and intellectual disabilities.

Pennsylvania Refuses to Operate A Health Insurance Marketplace (Exchange)

The Affordable Care Act afforded every state the opportunity to develop its own state-based marketplace (exchange) when the individual health insurance mandate began in 2014. Health insurance marketplaces are on-line clearinghouses where people can compare and buy individual health policies. They were supposed to be up and running by January 2014. States that did not build their own exchange must let the federal government operate it for them.

In November 2011, Governor Corbett announced his "commitment" to building a state-run insurance exchange rather than let the federal government operate Pennsylvania's exchange. But by the fall of 2012, that commitment changed for a combination of reasons: 1) Governor Corbett's hostility to the ACA and his refusal to embrace any part of it, and 2) the challenge of having something up and running by the fall of 2013 given that the state had no authorizing legislation (because the republican controlled General Assembly was even more hostile to the ACA than Governor Corbett). Thus, in early 2013, Governor Tom Corbett announced Pennsylvanians would need to rely on the federal marketplace, www.healthcare.gov.

Creation of & Transition to the Federal Pre-Existing Condition Insurance Program (PCIP)

As noted above, the ACA required that insurance plans eliminate pre-existing condition exclusions beginning in 2014. In the interim (mid 2010 to 2014) the ACA required states

or the federal government to develop High Risk Pools to provide coverage to people with pre-existing health conditions who were not otherwise able to get health insurance. These pools were created in mid-2010 and remained in place through December 2013. Pennsylvania established its own High Risk Pool named PA Fair Care. To qualify a Pennsylvanian had to meet citizenship requirements, be uninsured for six months, **and** have a qualifying pre-existing condition or be someone that experienced problems getting private coverage due to a pre-existing condition. Qualifying individuals received a broad package of benefits including prescription drugs, durable medical equipment, maternity care, mental health care for serious mental illness, and other inpatient and outpatient services. This insurance brought significant relief and much needed coverage for so many Pennsylvanians with disabilities and chronic health conditions who had been uninsured.

In July 2013, PA Fair Care enrollees were transitioned to the Federal Pre-Existing Condition Insurance Program. The PCIP was expected to last through December 2013 as on January 1, 2014, it then became illegal for private health insurance carriers to deny coverage, impose a waiting period, or charge higher premiums for someone with a pre-existing condition. However, as a result of the multiple challenges with the roll out of the federal Marketplace the Department of Health and Human Services made several extensions to the closing of the PCIP. Ultimately, the PCIP ended on April 30, 2014 after the final 1,300 Pennsylvania enrollees transitioned to Marketplace plans.

PHLP used our newsletters, Helpline, and trainings to keep consumers, their family members and their advocates aware of these changes.

Highlights of Open Enrollment Period One (October 2013 to April 2014)

As was widely publicized, the October 2013 launch of the federal Marketplace was fraught with problems. Users seeking coverage experienced significant delays in the enrollment process as the website (healthcare.gov) was frequently overwhelmed by the volume of consumers trying to access it.

Confusion was not solely limited to website problems. New income counting rules left many consumers and advocates struggling to discern who was eligible for what. A provision of the ACA required states to use new Modified Adjusted Gross Income (MAGI) rules starting January 1, 2014 when determining Medicaid and CHIP eligibility for certain populations-specifically, pregnant women, children, families and the adult expansion category. These same MAGI rules are also used to determine who qualifies

for the Advanced Premium Tax Credits and Cost Sharing Reductions that help reduce the costs of buying insurance through the new Marketplace.

MAGI rules do **not** apply to the elderly, blind, and disabled Medicaid populations, so these new rules did not change how these populations qualify for Medicaid. Having said that, the rules could impact a person with a disability who doesn't qualify for traditional Medicaid because of income or resources but who might qualify under the expansion category. For instance, under the prior program rules, workers compensation, veterans' benefits, and child support were counted as income, but under tax rules, they are not counted as income. Also, under the new MAGI rules, all earned income disregards (such as child care and transportation expenses) were eliminated and replaced by a flat 5 percent income disregard. To assure that no one's eligibility is adversely affected, CMS and Pennsylvania adjusted the income eligibility for each category of the MAGI population. Pennsylvania sought and was granted a waiver from CMS to implement the new MAGI rules early, so they became effective in October 2013.

PHLP staff and other consumer advocates worked with individuals and families to support them through this very frustrating process. PHLP closely monitored the Marketplace roll out and used websites, newsletters, and both in-person and on-line trainings to keep readers informed.

Additionally, PHLP counseled many individuals who contacted PHLP's Helpline with questions and confusion about using the Marketplace and problems with policy cancellations. For example, some Pennsylvanians with individual insurance policies received cancellation notices because their policy did not meet the minimum essential coverage required by the ACA. PHLP counseled Pennsylvanians about why their policies were being canceled and their options.

The end of the ACA's first open enrollment period (for coverage that began in 2014) was very successful despite the rocky opening. Slightly more than eight million Americans (318,077 were Pennsylvanians) selected a Marketplace Plan during the open enrollment period surpassing initial estimates.

Highlights of Open Enrollment Period Two (November 2014 to February 2015)

The ACA's second open enrollment period (for coverage that began in 2015) was even more successful. Slightly more than 11.5 million Americans selected a Marketplace Plan during open enrollment (472,697 were Pennsylvanians).

Despite this success there were problems unique to Pennsylvania in 2015 that required PHLP advocacy and intervention. The most notable, significant and ironic problem was Pennsylvania's belated decision to expand Medicaid starting in January 2015.

Pennsylvania's decision to expand Medicaid **after** the original January 1, 2014 ACA Medicaid and health marketplace start date created a special problem regarding newly eligible adults with incomes **between** 100 percent and 138 percent of the poverty level. This is because people in this **narrow** income category in states that did not expand Medicaid on January 1, 2014 could enroll in private health plans with significant tax credit subsidies starting on January 1, 2014 through the Affordable Care Act's federal health marketplaces. Why? The ACA provides tax credits to purchase health insurance plans through the marketplaces for people with incomes between 100 percent and 400 percent of the poverty level. But these tax credits are not available to people who earn below 100 percent of poverty (as described above in Part One) or who have access to other coverage that meets minimum standards like employer-based coverage.

Therefore, in states like Pennsylvania that did not initially expand Medicaid, a significant number of people with incomes between 100 percent and 138 percent of the poverty level were enrolled through the federal health marketplaces in private health plans with substantial tax credits to reduce the cost of their coverage. Once Pennsylvania decided to expand Medicaid, this group of people had to shift their coverage from marketplace to Medicaid. This problem was never contemplated under the ACA since the law did not anticipate the 2012 Supreme Court decision allowing states the option of refusing to expand Medicaid coverage.

To make sure no one was left behind without coverage, PHLP successfully worked with senior Medicaid officials in Pennsylvania and federal Marketplace staff assigned to Pennsylvania on outreach policies and practices to make sure people with Marketplace coverage smoothly transitioned to Medicaid.

A second enrollment problem unique to Pennsylvania was the file transfers of those who applied for health insurance through the Marketplace **but** were determined eligible for Medicaid and needed to have their information transferred to Pennsylvania's Department of Human Services (Pennsylvania's Medicaid agency). The Marketplace is not allowed to enroll people in Medicaid. In Pennsylvania, Medicaid authorization is the province of the state. However, problems with data transfers from the federal government to Pennsylvania's Medicaid program prevented enrollment. The file transfer was supposed to include all the information provided on the individual's application as well as any verification of income eligibility the Federal

Marketplace conducted. In this way, the applicant did not need to re-submit information and Pennsylvania did not have to repeat verifications already done. However, the file transfers from the Federal Marketplace to Pennsylvania were not working.

PHLP worked with the state and other consumer advocates on policies and practices that strongly encouraged individuals who were told by the Marketplace they were Medicaid eligible to apply directly to the state to ensure that their Medicaid coverage start as soon as possible. PHLP used our newsletters, Helpline, and trainings to communicate these recommendations to consumers, family members and advocates.

A third enrollment problem is unique to states like Pennsylvania that have included the optional Medicaid category of Medical Assistance for Workers with Disabilities (MAWD). Because MAWD is an optional and not a federally mandated category of Medicaid the federally facilitated Marketplace is not designed to screen for it. As such, uninsured persons with disabilities who are working will not be screened for MAWD when applying for insurance through the Marketplace. This is problematic for these individuals because MAWD is almost always more comprehensive coverage at a more affordable premium than any plan available through the Marketplace. As a result, PHLP created a publication specific to this issue entitled, “MAWD or Marketplace? What Pennsylvanians with Disabilities Need to Know about Choosing Health Insurance Coverage.” Thanks to continued funding from the Pennsylvania Developmental Disability Council, PHLP will be providing trainings for healthcare navigators and other assisters on the option of MAWD or a Marketplace plan for working individuals with disabilities.

Anticipating Open Enrollment Period Three (November 1, 2015 to January 31, 2016)

This publication is being finalized on the eve of the third open enrollment period. We anticipate a greater number of Pennsylvanians will enroll in the Marketplace. We hope people with disabilities selecting health insurance coverage will choose plans that are affordable and provide quality services and supports. PHLP welcomes the opportunity to educate navigators, assisters and consumers on the option of MAWD or Marketplace plans for working individuals with disabilities and significant health issues.

Marketplace Special Enrollment Periods

The ACA Marketplace was designed with an annual Open Enrollment Period and Special Enrollment Periods. For the inaugural year of the Marketplace the Open Enrollment Period ran from October 1, 2013 until March 31, 2014. The Open Enrollment Period for year two of the Marketplace ran from November 15, 2014 until February 15, 2015.

During this time, anyone without Minimum Essential Health coverage or affordable health insurance could enroll in a Marketplace plan and obtain premium tax credits and cost-sharing subsidies, if eligible. In year two, individuals could also change their Marketplace coverage for 2015. Special Enrollment Periods, outside of the Open Enrollment Period also exist to accommodate a variety of special circumstances. Experiencing one of the following events will give an individual a Marketplace Special Enrollment Period:

- **Life Changes:** marriage, divorce, birth or adoption, change in immigration status, or a permanent move to a new area that offers different health plan options.
- **Loss of Minimum Essential Coverage:** includes losing employer coverage, having COBRA coverage expire, or no longer qualifying for Medicaid or CHIP. This would also include situations when an employer-sponsored plan is no longer affordable or adequate. The voluntary termination of coverage, or loss of coverage due to non-payment of premiums, is not considered loss of Minimum Essential Coverage and would not qualify someone for a Special Enrollment Period.
- **Other situations:** exceptional circumstances (such as an increase in someone's income that would result in someone now being penalized for not having Minimum Essential Coverage when they had been previously exempt from the penalty), error or inaction by the Marketplace or the federal government, or misconduct by a non-exchange entity such as a navigator, an application assistor, or an insurance broker.

Another US Supreme Court Challenge Threatens Federal Health Reform (2014-15)

In late 2014, the US Supreme Court announced it would hear *King v. Burwell*, a case that challenged the legality of financial assistance (i.e., premium tax credits and cost-sharing subsidies) provided to help people buy insurance through the Federally

Facilitated Marketplace (FFM). The suit asserted that financial assistance was *only* legal in the states that ran their own Health Insurance Marketplace. Since Pennsylvania was among the 36 states that declined to operate their own exchange and instead defaulted to the FFM, the case impacted hundreds of thousands of Pennsylvanians.

Those who brought the lawsuit argued that the text of the Patient Protection and Affordable Care Act (ACA) only allows for financial assistance in the form of tax credits and subsidies through state-run exchanges. They asserted that the regulations issued and implemented by the Internal Revenue Service (IRS) should be declared invalid because they go beyond the language of the Act and allow subsidies to be provided through the FFM as well as state-run exchanges. In other words, they claimed that the IRS exceeded the authority Congress granted to it under the Act. If the plaintiffs' challenge was successful, individuals who obtained coverage through the federally facilitated Marketplace would lose their tax credits and, in many cases, their health insurance coverage since it may be unaffordable without the financial help. Only 14 states had set up their own exchanges and they received millions of dollars from the federal government for the first year of operation. The federal government's official deadline for states to apply and receive federal funding to build a state-run exchange ended in November 2014. Oral arguments in the U.S. Supreme Court were held in March 2015.

While awaiting the Supreme Court decision, in May 2015 Governor Wolf, reacting to pressure from advocates and being proactive, submitted a plan to the federal government to run a state-based Marketplace for Pennsylvanians to buy health care coverage, if necessary, should the Supreme Court decide that people who buy health insurance through the federal Marketplace are not eligible for subsidies to help them pay for that coverage. At that time, 380,000 Pennsylvanians received premium tax credits and/or subsidies to help them pay for their health insurance through the Federal Marketplace. Governor Wolf's letter did not mean that Pennsylvania had to set up a State-based Marketplace, but rather it allowed the state to pursue this option should the outcome of *King v. Burwell* cause those receiving financial help through the federal Marketplace to lose that assistance.

On June 25, 2015, the US Supreme Court ruled that individuals who receive tax credits and subsidies to buy insurance through the federal Marketplace (HealthCare.gov) can continue to receive this help. Individuals use the federal Marketplace when they live in a state, like Pennsylvania, that does not operate its own state-run exchange. The Supreme Court ruled that the overall goal and structure of the ACA indicated the intent

for tax subsidies to be supplied through both state and federal exchanges. The Supreme Court ruling is especially relevant to Pennsylvania since hundreds of thousands of residents currently have insurance through the federal Marketplace and receive some level of tax subsidy to help them pay for their coverage.

Shortly after the decision was released, Governor Wolf announced that Pennsylvania would withdraw its contingency plan to create a state-run exchange. This means that Pennsylvanians will continue purchasing health insurance coverage through HealthCare.gov and, if eligible, receive tax credits and subsidies. In addition to the positive impact for Pennsylvanians, nearly 8.7 million Americans will continue to have access to affordable health insurance coverage as a result of the Supreme Court's decision.

Pennsylvania Regulates Marketplace Navigators

Despite lobbying efforts by many navigators, the Pennsylvania General Assembly passed the “Navigator and Exchange Assister Accessibility and Regulation Act” on June 19, 2015. The Act requires any individual or organization wishing to function as a navigator to register with the Pennsylvania Insurance Department before operating as such by completing a navigator application. The Insurance Department will review each application to ensure the individual is at least 18 years of age, resides in the Commonwealth, is not disqualified for having committed an act that would be grounds for denial, suspension or revocation of a license as an insurance producer and has not had a license as an insurance producer denied, suspended or revoked. The applicant must also submit fingerprints to be reviewed for national criminal history records information from the Criminal Justice Information Services Division of the Federal Bureau of Investigation. The applicant will be responsible for paying a navigator registration fee and fees for obtaining the criminal records information. If approved by the Insurance Department, the applicant will be issued a navigator certification valid for two years.

Navigators are already certified by the U.S. Department of Health and Human Services after completing extensive training so most Pennsylvania navigators objected to this additional measure. Under the ACA, the functions of the Navigator include:

- Maintaining expertise on the Health Care Marketplace and how to use it;

- Providing information to consumers in a fair, accurate, impartial, and culturally competent manner on the Marketplace, Qualified Health Plan options, Premium Tax Credits and cost sharing subsidies, Medicaid and the Children’s Health Insurance Program (CHIP);
- Assisting consumers with selecting and enrolling into a Qualified Health Plan; and
- Making referrals to other useful resources.

Many organizations, especially in rural areas, will be burdened by the costs and paperwork involved in the requirements of the new Pennsylvania Act. Navigator organizations in rural Pennsylvania rely heavily on the recruitment of volunteers to become certified to assist residents of the Commonwealth with enrollment in Marketplace plans. PHLP and other health care advocates are very concerned that the costs may be prohibitive, resulting in fewer certified navigators to assist Pennsylvanians in the often-overwhelming process of understanding health plan options.

HHS Adopts Uniform Definition of Habilitative Services

As discussed previously, the ACA requires individual and small group health plans to provide ten essential health benefits, including habilitative and rehabilitative services and devices. The initial law did not define habilitative services leaving the states, or if not, by default, the health plans to define. However, in early 2015, the US Department of Health and Human Services (HHS) issued its Notice of Benefit and Payment Parameters for 2016 and in it provided a uniform definition of habilitative services. The HHS uniform definition is:

Health care services that help a person keep, learn or improve skills and functioning for daily living. Examples include therapy for a child who isn’t walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings.

In its Notice, HHS was clear that the uniform definition was the minimum standard but states could further define habilitative services. HHS elaborated in the Notice that adopting a baseline definition of habilitative services would minimize the variability in benefits and lack of coverage for habilitative services versus rehabilitative services.

Defining habilitative services clarifies the difference between habilitative and rehabilitative services. The uniform definition applies to health plans effective January 1, 2016.

The Notice also requires plans to distinguish habilitative services from rehabilitative services beginning January 1, 2017 with separate benefit limits, if applied, for each. Currently, many plans lump habilitative and rehabilitative services together with one limit. For example, it is common for plans to have a thirty visit per year limit on both services combined so if an individual uses all 30 rehabilitative services they don't have access to any habilitative services in that plan benefit year. Effective January 1, 2017, plans will no longer be permitted to do that.

This rule will be especially beneficial for individuals with developmental and intellectual disabilities. The rule recognizes the distinction between and need for plans to cover both habilitative services and devices and rehabilitative services and devices. Once the rule is implemented, the Pennsylvania Insurance Department and health care advocates will need to monitor plans for compliance. Consumers should be educated on the rule so they can better advocate for their health care needs.

Health care advocates in Pennsylvania and across the country can and will advocate for a more inclusive definition of habilitative services and devices. Health plans routinely view these services as narrowly defined as physical therapy, occupational therapy and speech therapy. There is a more expansive range of services to be considered such as cognitive therapy, Applied Behavioral Analysis, music therapy, aural therapy and art therapy.

Pennsylvania Chooses a New Benchmark Plan for 2017

As described above, the ACA permitted states to identify a Benchmark plan prior to the roll out of the Marketplace. Federal officials selected Pennsylvania's Benchmark plan, Aetna POS, for years 2014 through 2016. In 2015, HHS offered states another opportunity to choose their Benchmark plan for 2017. Pennsylvania was proactive this time and elicited public input in selecting a plan.

PHLP and other interested stakeholders analyzed the plan options and submitted comments with recommendations to the Insurance Department. PHLP was underwhelmed by all the plan choices, especially in their offerings of habilitative and rehabilitative services. It was discouraging and disappointing that the entire landscape of 2014 Benchmark plans is deficient in the category of habilitative services. We were

especially troubled by their numerical limits. Imposing arbitrary habilitation limits runs counter to the goal that coverage should help individuals with developmental or congenital disabilities achieve maximum functional capacity relative to their age. As such, our comments on behalf of individuals, family members and disability advocacy organizations did not recommend any of the plan options. Collectively, this group believed all of the plans offered as possible Benchmark options fell short of meeting the needs of people with significant health issues and disabilities. Instead, we asked the Pennsylvania Insurance Department to fully consider the shortcomings in each plan in making their decision.

In July 2015, the Insurance Department announced their selection of Keystone Health Plan East. PHLP and other disability advocacy organizations are concerned about using Keystone Health Plan East (KHPE) as the Benchmark, especially for habilitative and rehabilitative services. Although the KHPE definition of habilitative services is not as comprehensive as advocates would like, it does appear similar to the federal definition. However, KHPE's definition fails to include devices; an alarming omission because federal rules require plans to cover devices for both rehabilitative and habilitative services. Another concern relates to coverage for physical and occupational therapy. Under the KHPE plan, coverage for physical and occupational therapy is limited to a total of 30 visits. A number of commenters suggested that this combined visit limit did not meet federal requirements and argued instead that a benchmark plan should have no limits or, at minimum, should cover 30 physical therapy visits and 30 occupational therapy visits. Despite these limitations, the Benchmark plan is the minimum standard individual and small group plans must meet in 2017. Insurers can offer a more robust benefit package and disability advocates are hopeful that they will.

Part Three: ACA and Long Term Services and Supports (LTSS)

The Affordable Care Act included provisions and opportunities for states to expand and improve long-term services and supports for persons with disabilities and the frail elderly. Long-term services and supports (LTSS) include nursing homes and other institutions as well as community supports that allow people to remain at home. For many states, Pennsylvania included, Medicaid spends as much on institutional care as it does on home and community based services. LTSS encompass the broad range of paid and unpaid services for individuals requiring help with activities of daily living due to illness, aging or disability, and other medical needs. The ACA's provisions are designed to increase options for Medicaid funded home and community based LTSS and decrease the number of people receiving care in nursing homes and other institutional settings.

LTSS Opportunities Pennsylvania Has Embraced: Balancing Incentive Program

One ACA provision, known as the Balancing Incentive Program, allows states to obtain additional federal Medicaid funds to increase access to Home and Community-Based Services (HCBS) and supports. The intent is to transform states' long-term care systems by:

- Lowering costs through improved systems performance & efficiency
- Creating tools to help consumers with care planning & assessment
- Improving quality measurement & oversight

The Balancing Incentive Program increased the Federal Matching Assistance Percentage (FMAP) to states that make structural reforms to increase nursing home diversions and access to non-institutional LTSS. The enhanced matching payments are tied to the percentage of a state's LTSS spending, with lower FMAP increases going to states that need to make fewer reforms.

In early 2014, Pennsylvania submitted an application to CMS for increased matching funds. PHLP led a group of disability advocates to identify priorities for these dollars and communicated these priorities (verbally and in writing) to the appropriate state officials prior to their submission of Pennsylvania's application. PHLP also reviewed the state's final application. The state adopted some of the stakeholders' recommendation albeit lacking in the detailed specifics we provided.

CMS required states to submit a work plan that specifies how the state will comply with three requirements:

- Establishment of a No Wrong Door-Single Entry Point application and enrollment system for home and community based services;
- Conflict-free case management services (meaning entities that do case management cannot also provide other home and community based services); and
- Core standardized assessment instruments (the assessment instruments for all HCBS must include common core data)

In addition to improving access, Pennsylvania applied for this funding to increase the number of persons served in the Aging, Attendant Care, Autism, COMMCARE, Consolidated, Independence, OBRA, and Person/Family Directed Supports Waiver programs.

In June 2014, state officials announced Pennsylvania was approved to receive the enhanced federal funding. Once funding was approved, the state conducted an online survey to determine stakeholders' understanding of long-term services and supports in Pennsylvania and to identify gaps in the current system. Specifically the survey's intent was to:

- Get input on how people learn about and gain access to Medicaid long-term community-based supports in Pennsylvania
- Understand perspectives on how the state can increase knowledge of these programs, and
- Understand perspectives of how the Commonwealth can assist people to access these services and assure timely enrollment into these programs.

The survey results showed:

- The length of time to complete the eligibility process for LTSS is too long
- Consumers and their family members do not understand the service system; confused about which program is best for them and what is available
- There is a need to educate hospital discharge planners and medical professionals on community base services
- Waiting lists for certain community base programs is problematic

In late 2014, state officials held Regional Feedback Meetings on the goals of the Balancing Incentive Program. Five meetings were held throughout the state. PHLP, consumers, consumer advocates and other stakeholders participated in these meetings. After synthesizing the feedback from the meetings, state officials identified:

- Gaps in knowledge pertaining to what types of home and community based services (HCBS) exist in the region;
- Best practices for providing information and educational materials on community based supports;
- How the state can improve the long-term services and supports eligibility process, and how local groups and/or individuals can assist consumers with the application and enrollment process;
- Barriers for individuals who want to transition from institutional settings to the community;
- Best practices that help individuals using long-term services and supports remain in the community; and
- A plan to continue these discussions through the PA Link and strengthen existing local partnerships.

During the summer of 2015, state officials held 28 stakeholder meetings across the Commonwealth to solicit input on the No Wrong Door – Single Entry Point system.

PHLP staff participated in these stakeholder meetings and offered feedback on the benefits and challenges to organizations embracing a No Wrong Door System and highlighted the current shortcomings in the eligibility and enrollment process for LTSS.

The state is currently collating the feedback received from all 28 stakeholder meetings. The federal vision for a No Wrong Door System includes state leadership, management and oversight; public outreach and referral coordination; person-centered counseling and planning; and streamlined access to public LTSS programs.

Home and Community Based Services Waiver Transition Plan

Section 2601 of the ACA required the federal Center for Medicare and Medicaid Services to issue final regulations on Home and Community Based Services (HCBS). The final rule amends the regulations for 1915(c) HCBS waiver programs and is designed to improve the quality of services for waiver recipients. Specifically, the final rule

requires states to ensure individuals receive services in the least restrictive and most integrated community setting and that person-centered planning is at the forefront of the delivery of HCBS waiver programs. The final rules were issued January 2014 and CMS granted states one year to develop an HCBS Transition Plan to explain how they will work to come into compliance with the new regulations. States then have up to five years to become compliant with the federal rules. States were also required to hold public hearings and allow written comments to be submitted to their draft HCBS Transition Plan.

PHLP collaborated with other consumer advocates to review the state's draft HCBS Transition Plan. Advocates noted key areas of concern with the state's plan and identified areas for improvement. PHLP submitted written comments to DHS with various recommendations for improvements to the state's plan. Our recommendations included an emphasis on person-centered planning for waiver recipients who might be residing in a setting that is no longer compliant with federal rules. We also stressed the need for the state to inventory the capacity of supports and service-coordinating agencies to perform this type of person centered planning. We encouraged DHS to assist service coordinators in identifying appropriate options for those waiver recipients found to be residing in noncompliant settings.

Managed Long Term Services and Supports

Several provisions of the Affordable Care Act give new opportunities, including enhanced federal financing, to improve access to and delivery of Medicaid long-term services and supports. One of those opportunities includes aligning payment and delivery of services for individuals receiving both Medicare *and* Medicaid, and for those receiving long term services and supports through home and community based waivers or in institutions such as nursing homes. The Centers for Medicare and Medicaid Services (CMS) defines MLTSS as “the delivery of long-term services and supports through capitated Medicaid managed care programs.” *This is a significant change. In Pennsylvania managed care plans have never been responsible for LTSS.*

The Corbett administration eschewed these opportunities, but the Wolf administration appears to embrace them wholeheartedly. In March 2015, Pennsylvania announced a new ambitious initiative called Medicaid Managed Long-Term Services and Supports (MLTSS). Under this initiative, Governor Wolf aims to improve the current long term care system and increase access to services and supports so that people with physical

disabilities and older adults can remain as independent as possible in their homes and communities for as long as possible.

Recently, a number of states across the country have begun MLTSS programs to improve care coordination and service delivery and save their Medicaid programs money. In June 2015, Pennsylvania released a “discussion paper” describing the target populations, goals and objectives, various program components, a timeframe for implementation, and opportunities for public input and comment. The discussion paper officially began the stakeholder input process to inform Pennsylvania’s development of a detailed proposal. Public hearings and input sessions were held in six different locations throughout the state during the month of June.

PHLP submitted lengthy and detailed comments on behalf of our clients, the Consumer Subcommittee of the Medical Assistance Advisory Committee, which includes persons with disabilities who will be directly impacted by Pennsylvania’s proposal. We strongly advocated that dual eligibles not be required to enroll in the state’s MLTSS arrangement. We urged the state to delay implementation to allow more time to design the policies and procedures for integrating two separate and distinct programs—i.e., Medicaid and Medicare.

Our recommendations were clear in our expectation for consumer engagement: from development and testing notices and other education materials as well as the LTSS assessment tool to drafting terms of MLTSS plan model contracts and the development of rate methodologies. We requested task forces to dialogue about policies and practices. Other recommendations related to the design of MLTSS repeatedly emphasize a non-mandatory, consumer-driven program that ensures continuity of care providers for medical and non-medical supports.

Despite feedback from many consumers and stakeholders that the process is moving too quickly and without sufficient input from affected individuals, the state’s timeline to initiate MLTSS is aggressive. As this publication to DDC was being finalized Pennsylvania officials released a concept paper confirming the target population for MLTSS: persons eligible for both Medicare and Medicaid, over the age of 21, and all nurse facility clinically eligible (NFCE) non-dual eligible adults age 18 and older that are eligible for the Pennsylvania Medicaid Program. Pennsylvania’s MLTSS approach will *not* include individuals with intellectual disabilities. The program would impact approximately 130,000 adults receiving LTSS and 318,000 adults who are dual eligibles – those with both Medicare and Medical Assistance.

Pennsylvania proposes to release a request for proposals for Medicaid managed care insurance plans in November 2015 and to begin enrollment in the Southwest region of the Commonwealth in January 2017.

Pennsylvania recently created an MLTSS Stakeholder Advisory Committee, comprised of fifty percent consumers. PHLP is providing legal representation to some of the committee's consumer members. We have also spearheaded a group of consumers and consumer advocates to meet regularly to identify collective concerns to share with state officials in a uniform way with one voice. Like Medicaid expansion, PHLP will remain closely involved as MLTSS unfolds in Pennsylvania.

Unfinished Business Under the ACA: Part One—Community First Choice

The ACA affords states other opportunities impacting Medicaid-funded home and community based services. One option, Community First Choice, gives states additional federal matching funds for providing attendant care services to Medicaid recipients with severe physical or intellectual disabilities. This means states have the opportunity to include attendant care services as a Medicaid in-plan service. A Long-Term Care Commission created under Governor Corbett recommended state officials consider implementation of Community First Choice (PHLP served as counsel to the sole consumer member). It also brings other consumer benefits. For example, there would be no caps on the number of people eligible for attendant care. Pennsylvania would have to offer attendant care services to all eligible persons on Medicaid without waiting lists. This differs from the current HCBS Waiver programs where the number of participants is limited (capped), often resulting in waiting lists. Although the services provided under Community First Choice (CFC) options are more limited than those provided under the existing HCBS Waiver programs, this option would provide basic support services for individuals with disabilities who currently have no services and increase their likelihood of remaining in the community.

CFC requires the states to cover personal assistance with activities of daily living (ADLs) such as bathing, dressing, and toileting as well as instrumental activities of daily living (IADLs) such as housekeeping or meal preparation. Under Pennsylvania's existing HCBS Waiver programs, these services are known as attendant care. Community First Choice also requires that states cover assistance with the "acquisition, maintenance and enhancement of skills for the individual to accomplish ADLs, IADLs and health-related tasks" (which comes close to the "habilitation" service covered by certain existing waiver programs) along with "backup systems" which include personal

emergency response systems and can also include staff. Even though Community First Choice does not allow caps on the number of people that can be served under this option, it does allow the state to impose across-the-board caps on services, so long as the caps are not based on age or disability.

In addition to these mandatory services, the state would have the option of covering two additional services: 1) certain costs for transitioning from an institution to the community. Transition costs include first month's rent and security deposit, deposits on utilities and purchase of bedding and kitchen supplies, 2) services and equipment "that increases an individual's independence or substitutes for human assistance" in meeting a need specified in the individual's service plan. These may include home modifications and assistive technology.

The type and amount of services someone can get would be determined through a person-centered planning process. A service plan would be developed that outlines the type of services someone will get and how often the services will be provided. Services are to be "self-directed" with the state having the option of allowing eligible individuals to hire, train, fire and determine pay rates for their attendants.

Because the services provided through the Community First Choice option would be provided through the Medicaid program, individuals will need to financially qualify for Medicaid (generally, people with disabilities and older adults must have income below the federal poverty level, currently \$11,770/year for a single person, and resources below \$2,000). However, the state would have the option of deducting an individual's medical expenses from their countable income when determining financial eligibility similar to the process used for qualifying for Medicaid to cover nursing home care.

Because the Community First Choice Option provides support services to people with physical and intellectual disabilities to allow them to remain as independent as possible in their homes and communities, individuals must demonstrate that they need a level of care typically provided in a hospital, nursing home, Intermediate Care Facility (ICF) or an inpatient psychiatric facility for persons under age 21 or for those age 65 and older. Unfortunately, this means that adults age 21 to 64 with mental illness but without a physical or intellectual disability would not qualify. In addition, the option would only provide attendant care services to those with mental illness that qualify and will not provide additional mental health services not already covered under the Medicaid program.

PHLP will educate consumers, family members and providers on the benefits of Pennsylvania adopting the Community First Choice option through in-person trainings and webinars across the state. Simultaneously, we will work with other advocacy organizations to influence the state to adopt this important option for persons with disabilities, thanks to this provision in the Affordable Care Act.

Unfinished Business Under the ACA: Part Two—Including Home and Community Based Services in the Medicaid State Plan

The Deficit Reduction Act of 2005 added section 1915(i) to the Social Security Act providing states the option to offer home and community-based services (previously available only through a 1915(c) HCBS waiver) through the state’s Medicaid state plan. Prior to section 1915(i), states could receive federal Medicaid matching funds for HCBS only through a waiver or a demonstration project. The ACA builds on the Deficit Reduction Act by: expanding financial eligibility for Section 1915(i) services; establishing a new optional Medicaid coverage group for individuals who receive state plan HCBS and who are otherwise ineligible for full Medicaid benefits; allows states to target Section 1915(i) services to specific populations; expands the services states may cover under this option; and requires that state plan HCBS be provided statewide with no waiting lists. Section 1915(i) services are required to be provided in a home and community-based setting, similar to Community First Choice state plan option services.

This ACA provision allows states to target a specific population – particularly one that isn’t covered by any of the current HCBS waiver programs. For example, there isn’t a waiver specific to persons with serious mental illness. This means, unless an individual with mental illness also has a physical or developmental disability or is over age 60, they can’t qualify for any of the HCBS waivers. This provision would allow Pennsylvania to target a benefit such as personal care services to individuals with mental illness.

In addition to targeting a specific population the ACA also permits states to provide different services to different populations. For example, a state could propose one benefit that is targeted to and includes specific services for persons with developmental disabilities and another benefit targeted to persons with chronic mental illness.

The ACA also adds a new section to 1915(i) that allows states the option of providing services to individuals with income up to 300 percent of the Supplemental Security

Income Federal benefit rate. This provision does require that an individual meet the eligibility criteria for HCBS but does not require that person to be currently enrolled in a HCBS waiver program.

These ACA provisions offer exciting opportunities for consumers, advocates and other interested stakeholders to explore with state officials.

Unfinished Business Under the ACA: Part Three—Providing “Health Homes” for Medicaid Enrollees

Section 2703 of the Affordable Care Act, “State Options to Provide Health Homes for Enrollees with Chronic Conditions,” adds section 1945 to the Social Security Act and allows states to elect this option under the Medicaid State plan. This provision is an important opportunity to address and receive additional federal support for the enhanced integration and coordination of primary, acute, behavioral health (mental health and substance use), and long-term services and supports for persons across the lifespan with chronic illness. The federal government expects states’ health home providers to operate under a “whole person” philosophy. Health Homes are for people with Medicaid who:

- Have 2 or more chronic conditions
- Have one chronic condition and are at risk for a second
- Have one serious and persistent mental health condition

Chronic conditions listed in the statute include mental health, substance abuse, asthma, diabetes, heart disease and being overweight. Additional chronic conditions, such as HIV/AIDS, may be considered by the federal government for approval.

States can target health home services geographically within a state. States cannot exclude people with both Medicaid and Medicare (“dual eligibles”) from health home services. Health home services must include comprehensive care management; care coordination; health promotion; comprehensive transitional care and follow-up; patient and family support; and referral to community and social support services. States have flexibility to determine eligible health home providers. Health home providers can be:

- A designated provider: May be a physician, clinical/group practice, rural health clinic, community health center, community mental health center, home health agency, pediatrician, OB/GYN, or other provider.
- A team of health professionals: May include physicians, nurse care coordinators, nutritionists, social workers, behavioral health professionals, and can be free-standing, virtual, hospital-based, or a community mental health center.
- A health team: Must include medical specialists, nurses, pharmacists, nutritionists, dieticians, social workers, behavioral health providers, chiropractors, licensed complementary and alternative practitioners.

States have flexibility in designing their payment methodologies and can even propose alternative arrangements with CMS. States receive a 90 percent-enhanced Federal Medical Assistance Percentage for the specific health home services identified in Section 2703 of the ACA. The 90 percent enhanced match is good for the first eight quarters the health home program is effective.

As of August 2015, 19 states have a total of 26 approved Medicaid health home models. Pennsylvania has yet to pursue this ACA option. It would be well worth considering.

Conclusion

Federal health reform is making a difference. In September, new census data showed the ACA is reducing the numbers of uninsured Americans (including Pennsylvanians) to historically low levels. This is due to the efforts of those who worked hard for passage of the ACA, those who labored to get people enrolled and those who campaigned to undo the damage done by the US Supreme Court by persuading state lawmakers to extend health insurance to the lowest income families.

While we can be proud of the success we have had to date, our work is far from over. We're committed to making the enrollment process work for everyone. As noted above, the enrollment process was much smoother during open enrollment two than it was the first time around, but there is still more that needs to be done to make the system work well. To cite just one example, it seems that many people with disabilities do not know about Medical Assistance for Workers with Disabilities (MAWD) and lose out on the affordable and quality coverage they are entitled to under the law. PHLP will work to inform Marketplace navigators and other enrollment assisters about MAWD.

The political challenges to the ACA have not completely eased. The republican leadership in the US House of Representatives continues to press a lawsuit that would strip cost-sharing assistance from thousands of people and make it harder for them to access and afford medical care. That lawsuit got a recent boost when a judge in DC federal district court ruled that the House had standing to bring the suit. That ruling is likely to be appealed and ultimately overturned. Even if it were to prevail, it is not at all clear there would be any actual effect on people's eligibility for cost-sharing reductions. What is more disconcerting is how the concerns of the American people are failing to register with the political leadership in Washington that is still committed to an anti-ACA agenda even though the rest of the country is moving on.

The ACA also provides new tools for Pennsylvania to pursue health system changes. Some of these opportunities were described above and, if done properly, can improve health outcomes and lower health care costs, especially for populations that have disproportionately poor outcomes. These changes are underway at the state policy and local delivery system levels. It will be important for consumers and their advocates like PHLP to create and sustain an organized and active voice in decisions related to the

development, adoption and implementation of health system transformation to ensure reforms are responsive to the needs and concerns of consumers.