



# Legislative Budget and Finance Committee

A JOINT COMMITTEE OF THE PENNSYLVANIA GENERAL ASSEMBLY

Offices: Room 400 Finance Building, 613 North Street, Harrisburg

Mailing Address: P.O. Box 8737, Harrisburg, PA 17105-8737

Tel: (717) 783-1600 • Fax: (717) 787-5487 • Web: <http://lbfc.legis.state.pa.us>

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## Family Caregivers in Pennsylvania's Home and Community-Based Waiver Programs

Conducted Pursuant to  
House Resolution 2014-241

June 2015

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## Report Summary

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House Resolution 2014-241 directs the Legislative Budget and Finance Committee to conduct a review of Pennsylvania's Medicaid Home and Community-Based Services (HCBS) waiver programs to determine the extent to which family members serve as caregivers in those programs and any barriers that exist that preclude paid family caregiving.

We found:

***Providing care for a chronically ill, disabled, or aged family member can place a major burden on the caregiver. (pp. 2 to 3)*** Family caregivers are an essential part of the workforce to maintain care for the growing numbers of people with complex chronic care needs. More than one in six Americans working full- or part-time report assisting with the care of an elderly or disabled family member, relative, or friend. Family caregiving has been shown to help delay or prevent the use of nursing home care, and the value of informal caregiving has been estimated at \$450 billion in 2011. This care often comes at a substantial personal cost, however, with a reported 37 percent of caregivers having to quit their jobs or reduce their work hours to care for someone aged 50 or older.

***In 1981, Congress authorized the waiver of certain federal requirements to enable states to provide home and community-based services to Medicaid-eligible individuals who would otherwise require institutional services. (pp. 4 to 9)*** Pennsylvania has established ten such HCBS waiver programs: the Aging Waiver; AIDS Waiver; Autism Waiver; Attendant Care/Act 150 Waiver; COMMCARE Waiver; Consolidated Waiver for Individuals with Intellectual Disabilities; Independence Waiver; Infants, Toddlers, and Families Waiver; OBRA Waiver; and Person/Family-Directed Support Waiver.

***Generally, federal regulations preclude legally responsible individuals, such as a spouse or the parent of a minor child, from serving as paid caregivers in HCBS waiver programs. (pp. 4 to 9)*** Certain other family caregivers, such as an adult child or the parent of an adult beneficiary, can be paid caregivers in many, but not all, of Pennsylvania's HCBS waiver programs. The waiver programs that provide for paid family caregivers in their HCBS waiver applications are: Aging, Attendant Care, OBRA, COMMCARE, Independence, Person/Family-Directed Support, and the Consolidated Waiver.

***Some states allow legally responsible relatives to be paid for personal care services in their HCBS waiver programs when such services are deemed as extraordinary care; Pennsylvania allows legally responsible relatives to provide a very limited number of extraordinary care services. (pp. 4 to 9)*** The Centers for

Medicare and Medicaid Services (CMS) has adopted a policy allowing legally responsible individuals, including spouses, to be paid for providing “extraordinary care” if such a provision is included in an approved HCBS waiver. Extraordinary care is generally defined as care that exceeds the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness and which is necessary to assure the health and welfare of the participant and avoid institutionalization. Providing for payments to legally responsible individuals for such services is a state option, not a federal requirement. Several states, including Arizona, Colorado, and Oregon, allow for such payments through their HCBS waiver applications. In Pennsylvania, legally responsible individuals, including spouses, and can be paid for certain services, such as home and community habilitation and transportation, under certain circumstances in Pennsylvania’s Consolidated Waiver and Person/Family-Directed Support Waiver program.

***Family caregivers in HCBS waivers may receive a maximum of \$3.35 to \$4.00 per 15 minute unit when providing personal assistance services, but the number of units are limited. (pp. 10 to 11)*** Wages paid to family caregivers must fall within an allowable rate range set by the Commonwealth through a CMS-approved rate-setting methodology. Pennsylvania has three wage and benefit ranges depending on geographic area.

***DHS collects limited data on the extent to which paid family caregivers are used in Pennsylvania’s HCBS waiver programs, but the percentage of paid caregivers who are family members appears to range from 4 percent to 40 percent. (pp. 22 to 25)*** Among the programs that allow paid family caregivers, the Consolidated Waiver appears to have the fewest paid family caregivers (estimated at 4.4 percent), whereas the five HCBS waiver programs operated through the Office of Long-Term Living (Aging, Attendant Care/Act 150, COMMCARE, Independence, and OBRA Waivers) had an average of 40 percent being paid family caregivers. Of these 40 percent, which represent about 15,600 caregivers, 4 percent were siblings; 5 percent were parents; 15 percent were other relatives (other than a spouse); and 16 percent were adult children of a beneficiary.

***The participant-directed care model of service (as opposed to the traditional agency-direct approach) has led to greater family involvement as paid caregivers. (pp. 26 to 32)*** Participant-directed care provides beneficiaries with the ability to self-direct who gets paid to provide their care services, including certain family members. Since the original pilot in 1998, the number of states and the number of programs within those states that allow participant-directed care has grown considerably. Pennsylvania ranks 18th among the 50 states in the percentage of participant-directed enrollees when adjusted for the potentially eligible state population.

***Some states (but not Pennsylvania) have established 100 percent state-funded programs that allow legally responsible family members to be paid caregivers for their elderly or disabled relatives. (pp 27 to 28)*** Twenty-one states have established solely state-funded programs that allow payments to family members, including 12 states that allow payments to spouses and parents of minor children. Pennsylvania operates a 100 percent state-funded program (Act 150), but it does not allow payments to legally responsible individuals.

***The use of paid family caregivers has raised concerns, particularly over the potential for fraud and abuse. (pp. 30 to 32)*** Paying family members to be caregivers can help overcome some of the challenges people face finding qualified, reliable, and continuous caregivers. However, family members often have access to financial and other personal data that would not generally be available to an agency-sponsored caregiver. There may also be a higher degree of trust between a beneficiary and a family member that could be exploited by an unscrupulous family caregiver. Other issues, such as time sheet fraud or poor work performance, may be harder for beneficiaries to confront if the caregiver is a family member. CMS requires states that use paid family caregivers in the HCBS waiver programs to identify the steps they will take to address these risks as part of the waiver approval process. These steps are to include limiting the amount of services family caregivers can be paid for and establishing monitoring and review procedures to ensure that the services being paid for are actually rendered. Pennsylvania, like most states, requires that individuals who provide direct support or other services to waiver participants undergo a pre-employment criminal history check and/or background investigation as part of its effort to protect program participants.



# I. Introduction

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House Resolution 2014-241 directs the Legislative Budget and Finance Committee to conduct a review of Pennsylvania's Medicaid Home and Community-Based Services (HCBS) Waiver programs in order to determine the extent to which family members serve as caregivers in those programs and any barriers that exist that preclude family caregiving. See Appendix A for a copy of the resolution.

## Scope and Objectives Statement

1. Determine the extent to which family members currently serve as caregivers in Pennsylvania's Home and Community-Based Service Waiver programs;
2. Determine if any barriers exist that preclude family members of waiver service beneficiaries from serving as paid caregivers;
3. Determine if any such identified barriers are dictated by statute, regulation, or policy.

## Methodology

Much of the information in this report was taken from U.S. Department of Health and Human Services and Pennsylvania Department of Human Services (DHS) regulations, bulletins, waiver applications, and program manuals, as well as information developed by state and national advocacy and provider groups. During the study, we also interviewed DHS officials and program staff as well as statewide advocacy and provider groups. Information was also derived from reports from other states that have investigated the issue of paid family caregivers.

## Acknowledgements

We appreciate the cooperation and assistance we received from the Pennsylvania Department of Human Services, the Pennsylvania Health Law Project, and the various provider organizations, service coordinators, and associations who provided information to us during this study.

## Important Note

*This report was developed by Legislative Budget and Finance Committee staff. The release of this report should not be construed as indicating that the Committee's members endorse all the report's findings and recommendations.*

*Any questions or comments regarding the contents of this report should be directed to Philip R. Durgin, Executive Director, Legislative Budget and Finance Committee, P.O. Box 8737, Harrisburg, Pennsylvania 17105-8737.*

## II. The Role of Family Caregivers and Medicaid Rules on Paid Family Caregivers

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According to the National Alliance for Caregiving, over 65 million people—29 percent of the U.S. population—provide care for a chronically ill, disabled, or aged family member or friend during any given year, spending an average of 20 hours per week caring for their loved one. Unpaid caregiver services were valued at \$450 billion per year in 2009. The value of unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S.

Nearly two-thirds of caregivers are female. However, among spousal caregivers aged 75 or older, both sexes provide equal amounts of care. The majority of caregivers (55 percent) in a 2011 Gallup survey reported they had been providing care for three years or longer. The average days per month spent on shopping, food preparation, housekeeping, laundry, transportation, and giving medication is 13, and 6 days per month are spent on feeding, dressing, grooming, walking, bathing, and assistance with toileting.

A 2012 “Home Alone” study of 1,677 family caregivers conducted by the AARP Public Policy Institute found that nearly half of the caregivers surveyed (46 percent) performed medical and nursing tasks. More than 96 percent of these caregivers also provided activities of daily living (ADL) supports (e.g., personal hygiene, dressing/undressing, or getting in and out of bed) or instrumental activities of daily living (e.g., taking prescribed medications, shopping for groceries, transportation, or using technology), or both. Of these caregivers, nearly two-thirds did all three types of tasks.

A 2011 Gallup survey also found 72 percent of caregivers cared for a parent, step-parent, mother-in-law, or father-in-law, and 67 percent of caregivers provided for someone age 75 or older. More than one in six Americans working full- or part-time reported assisting with the care of an elderly or disabled family member, relative, or friend. Caregivers working at least 15 hours per week said it significantly affected their work life. Most (70 percent) of working caregivers report work-related difficulties due to their dual caregiving roles. Among working caregivers caring for a family member or friend, 69 percent report having to rearrange their work schedule, decrease their hours, or take an unpaid leave in order to meet their caregiving responsibilities. Caregivers suffer loss of wages, health insurance and other job benefits, retirement saving or investing, and Social Security benefits—losses that hold serious consequences for the “career caregiver.”

A reported 37 percent of caregivers quit their jobs or reduced their work hours to care for someone aged 50 or older in 2007. Ten million caregivers over age 50 who care for their parents lose an estimated \$3 trillion in lost wages, pensions,

retirement funds, and benefits. The total costs are higher for women who lose an estimated \$324,044 due to caregiving, compared to men at \$283,716. Lost wages for women who leave the work force early because of caregiving responsibilities equals \$142,693; for lost Social Security benefits, an estimated \$131,351; and lost pensions, an estimated \$50,000.

At \$450 billion, the value of informal caregiving exceeded the value of paid home care, was greater than Wal-Mart sales (\$408 billion), and approached total expenditures for the Medicaid program in 2009 (\$509 billion).

A 2006 study from the AARP Public Policy Institute showed that approximately 34 million family caregivers were providing caregiving services at any given point in time, ranging as a percentage from 8.2 percent of the population in Hawaii to almost 16 percent in Missouri.

Family caregivers serve numerous roles, such as:

- providing companionship and emotional support;
- helping with household tasks, such as preparing meals;
- handling bills and dealing with insurance claims;
- carrying out personal care, such as bathing and dressing;
- being responsible for nursing procedures in the home;
- administering and managing multiple medications, including injections;
- identifying, arranging, and coordinating services and supports;
- hiring and supervising direct care workers;
- arranging for or providing transportation to medical appointments and community services;
- communicating with health professionals;
- serving as “advocate” for their loved one during medical appointments or hospitalizations;
- implementing care plans; and
- playing a key role of “care coordinator” during transitions, especially from hospital to home.

According to AARP, families remain the most important source of support to older adults. Family caregivers are an essential part of the workforce to maintain the health care and support systems for the growing numbers of people with complex chronic care needs. Family caregiving has been shown to help delay or prevent the use of nursing home care. There is also growing recognition of the value of family members to the delivery of health care, and the ways families influence health care decisions, treatment, and outcomes.

## Medicaid Waivers and Rules on Paid Family Caregivers

Medicaid is a needs-based, entitlement program designed to help states meet the costs of necessary health care for low-income and medically needy populations. When a Medicaid State Plan is approved by the Centers for Medicare & Medicaid Services (CMS), states qualify to receive federal matching funds to finance Medicaid services. States have substantial flexibility to design their programs within broad federal requirements related to eligibility, services, program administration, and provider compensation.

**Medicaid Home and Community-Based Services (HCBS) Waivers.** Home and Community-Based Services are provided under Medicaid pursuant to several authorities. First, since 1970, states have been mandated to cover nursing home care for categorically eligible persons age 21 or older under the Medicaid State Plan. This includes nursing, home health aides, medical supplies, medical equipment, and appliances suitable for use in the home. Federal court rulings in the late 1990s held that home health nursing services may be provided outside the home, as long as they do not exceed the hours of nursing care that would have been provided in the home. As of 2011, almost 814,000 persons nationwide were served via the home health state plan benefit.

Second, since the mid-1970s, states have had the option to offer personal care services under the Medicaid State Plan. Personal care services were originally for assisting individuals to perform activities of daily living, such as bathing, dressing, eating, and toileting. The Omnibus Reconciliation Act of 1993, along with its implementing regulations, gave states the option to substantially broaden the scope of personal care services to furnish individuals a wide range of assistance in everyday activities, both in and outside their homes. This could include instrumental activities of daily living, such as personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. CMS now further permits states to offer the option of consumer-directed personal care services, allowing individuals who are receiving personal assistance to direct their workers, i.e., train, supervise, manage, and dismiss them (if needed).

Third, the Deficit Reduction Act of 2005 added §1915(i) to the Social Security Act, which allows states the option to provide a range of HCBS under their state plan. Section 1915(i) allows states to include any or all of the services that are listed in §1915(c)(4)(B) of the Social Security Act. These include case management, homemaker/home health aide, personal care, adult day health, habilitation, and respite care services. This new provision essentially gives states the option to offer a wide range of home and community-based services without having to secure federal approval of a waiver. Comparability is not required under §1915(i), but services must be available statewide.

Fourth, another optional state plan HCBS service was created by the Affordable Care Act when it added §1915(k) to the Social Security Act to allow states to provide “Community-based Attendant Services and Supports.” This is known as the Community First Choice Option. States that provide home and community-based attendant services and supports through their state plans receive a six percentage point higher federal match for services related to this option.

Finally, services can be provided through an HCBS waiver program pursuant to §1115 and §1915(c). In 1981, Congress authorized the waiver of certain federal requirements to enable states to provide home and community services (but not room and board) to individuals who would otherwise require institutional services reimbursable by Medicaid (i.e., services in a skilled nursing facility, an intermediate care nursing facility, or an ICF/ID). Under the §1915(c) waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are required to prevent institutionalization. Services covered under waiver programs include case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, and “such other services requested by the state as the Secretary of Health and Human Services (HHS) may approve.” Services for individuals with a chronic mental illness were added in the late 1980s, including day treatment, partial hospitalization, psychosocial rehabilitation, and clinic services (whether or not furnished in a facility).

Neither the statute itself nor CMS regulations further specify or define the scope of the listed services. However, the law that created the waiver program expressly permits the Secretary of HHS to approve services beyond those specifically spelled out in the law, as long as they are necessary to avoid institutionalization and are cost-effective. In the years since the waiver authority became available, CMS has approved a wide range of additional services.

Under §1115, states are permitted to undertake “research and demonstration” projects that further the purposes of Medicaid and that have not previously been demonstrated.

***Paid Family Caregivers Within HCBS Waiver Programs.*** Within the broad parameters of federal policy, it is up to states to define in their HCBS waiver application the particular circumstances under which relatives will be paid to furnish services to participants. States can take various factors into account, including the availability of other sources for the same services, costs of using family members to provide services versus costs of purchasing such services from conventional sources, and specific circumstances with respect to participants.

Generally, under federal regulations (see below) payments for personal care (or similar) services delivered by legally responsible individuals (e.g., the parent of a

minor child or a spouse) are not eligible for federal Medicaid matching funds. Legally responsible individuals do not include relatives such as adult children or the parent of an adult beneficiary (including a parent who also may be a legal guardian). The prohibition is based on the presumption that legally responsible individuals may not be paid for supports that they are ordinarily obligated to provide.

Federal regulations provide language specific to family members serving as paid caregivers in waiver programs as follows:

§440.167 Personal care services.

Unless defined differently by a State agency for purposes of a waiver granted under part 441, subpart G of this chapter—

(a) *Personal care services* means services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for individuals with intellectual disabilities, or institution for mental disease that are—

(1) Authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State;

(2) Provided by an individual who is qualified to provide such services and who is not a member of the individual's family; and

(3) Furnished in a home, and at the State's option, in another location.

(b) For purposes of this section, *family member* means a legally responsible relative.

Additionally, Subpart H of the federal regulations pertaining to limits on federal financial participation with regard to the waiver programs specifically prohibits spousal payments as follows:

§441.360 Limits on Federal financial participation (FFP).

FFP for home and community-based services listed in §440.181 of this subchapter is not available in expenditures for the following:

...

(g) Services furnished to a beneficiary by his or her spouse.

CMS technical guidance also states that CMS policy is that payments for personal care or similar services delivered by legally responsible individuals (as defined in state law, but typically the parent of a minor child or a spouse) are not eligible for federal financial participation.

However, in 2005 CMS amended its policy so that under a HCBS waiver, states have the option of paying legally responsible relatives in extraordinary circumstances when the provision of personal care services is determined to be necessary to ensure the health and welfare of the waiver participant, and so long as the parent or spouse meets the Medicaid provider requirements established by the state. A state seeking to receive federal funds for such services can do so through a §1115 or §1915(c) HCBS waiver application.

By extraordinary care, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age and which are necessary to assure the health and welfare of the participant and avoid institutionalization. States must identify the criteria they will use to distinguish extraordinary from ordinary care. States may also specify other limitations, such as the specific circumstances under which legally responsible individuals may be paid providers.

Providing for payments to legally responsible individuals is a state option, not a federal requirement. Pennsylvania has chosen not to include provisions for payments to legally responsible persons in its Medicaid HCBS waiver applications for personal care services with a few exceptions. In particular, legally responsible individuals can be paid for personal care type services as part of home and community habilitation (e.g., to teach the participant to complete ADLs or IADLs for himself or herself, which would be considered extraordinary care) in the Consolidated Waiver and Person/Family-Directed Support Waiver programs.

***States That Allow Legally Responsible Relatives to Be Paid Caregivers Under an HCBS Waiver.*** We could not find a comprehensive list of states that allow legally responsible family members to be paid to provide personal services through a §1115 or §1915(c) HCBS waiver, but it appears that most states do not offer this option. Some states that allow legally responsible family members to be paid caregivers under their HCBS waiver programs include:

***Arizona.*** Arizona's §1115 demonstration waiver allows reimbursement to spouses to provide needed in-home care under the provisions shown in Exhibit 1. Under the program, spouses providing care to eligible enrollees will be employed by a network contactor or register as an independent provider.

***Colorado.*** Colorado allows payments to spouses under its Consumer-Directed Support Services (CDASS) program as part of its §1915(c) HCBS Waiver as shown in Exhibit 2.

***North Dakota.*** North Dakota has structured its Medicaid waivers to allow payments to spouses for extraordinary care for the provision of personal care of similar services in the client's home. The goal of the program is to assist individuals to remain with family members and in their own communities.

## Exhibit 1

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### Arizona Provisions for Payments to Spouses Under Its HCBS Waiver

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- 1) Services provided by the Spouse as Paid Caregiver must meet the definition of a “service/support” for personal care or similar services that are rendered by a Paid Caregiver when such services are deemed extraordinary care.
  - a) Personal care or similar services – Is defined as assistance with the Activities of Daily Living (ADLs), or Instrumental Activities of Daily Living (IADLs), whether furnished in the home or the community, including personal assistance, attendant care, and closely related services such as home health aide, homemaker, chore, and companion services which may include improving and maintaining mobility and physical functioning, promoting health and personal safety, preparation with meals and snacks, accessing and using transportation, and participating in community experiences and activities.
  - b) Extraordinary care - Is defined as care that exceeds the range of activities that a spouse would ordinarily perform in the household on behalf of the recipient spouse, if he/she did not have a disability or chronic illness, and which are necessary to assure the health and welfare of the beneficiary, and avoid institutionalization.
- 2) The Spouse as Paid Caregiver must be a service/support that is specified in a plan of care prepared on behalf of the enrollee.
- 3) The enrollee who selects the Spouse as Paid Caregiver is not eligible to receive like services from another attendant caregiver.
- 4) The enrollee will remain eligible to receive other HCBS such as skilled/professional type services, home modifications, respite care, and other services that are not within the scope of the personal/attendant care services prescribed in the provider’s plan of care.
- 5) The Services must be provided by a Spouse as Paid Caregiver who meets specified provider qualifications and training standards prepared by the State for a Paid Caregiver.
- 6) The Spouse as Paid Caregiver must be paid at a rate that does not exceed that which would otherwise be paid to a provider of a similar service and does not exceed what is allowed by the State Medicaid Agency (SMA) for the payment of personal care/attendant services; and
- 7) The Spouse as Paid Caregiver will comply with the following conditions.
  - a) A Spouse as Paid Caregiver may not be paid for more than 40 hours of services in a 7-day period;
  - b) The Spouse as Paid Caregiver must maintain and submit time sheets and other required documentation for hours worked/paid;
  - c) The Spouse as Paid Caregiver may only submit claims for services that have been authorized by the Program Contractor or ALTCS FFS case manager;
  - d) The ALTCS enrollee must be offered a choice of providers, other than his/her spouse. The enrollee’s choice of a Paid Caregiver Spouse as provider must be recorded in his/her plan of care, at least annually.
- 8) AHCCCS and its Program Contractors must comply with the following monitoring requirements:
  - a) Require Program Contractors and FFS case managers to make an on-site case management visit at least every 90 days to reassess a beneficiary’s need for services, including the health, safety, and welfare status of the beneficiary serviced by the Spouse as Paid Caregiver;
  - b) Require Program Contractors to provide quarterly financial statements that include separate authorized hours and expenditure information for Paid Caregiver Spouses; and
  - c) Require AHCCCS to perform quarterly financial analysis that includes authorized hours and expenditure information for ALTCS FFS Spouses as Paid Caregivers.

Source: Special Terms and Conditions, Arizona Health Care Cost Containment System (AHCCCS) Medicaid Section 1115 Demonstration waiver.

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## Colorado Provisions for Payments to Spouses Under Its CDASS Waiver

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A spouse may be paid to furnish extraordinary care through the CDASS delivery option. Extraordinary care is determined by assessing whether an individual who is the same age without a disability needs the requested level of care, the activity is one that a spouse would not normally provide as part of a normal household routine and the activity is one that a spouse is not legally responsible to provide. A spouse may not provide more than 40 hours of attendant services through the CDASS delivery option in a seven day period. A participant and/or authorized representative must provide a planned work schedule to the FMS a minimum of two weeks in advance of beginning services under the CDASS delivery option.

An individual must be offered a choice of providers. If participants or his/her authorized representative chooses a spouse as a care provider, it must be documented on the Attendant Support Management Plan. In addition to case management, monitoring and reporting activities required for all waiver services, the following additional requirements are employed when a spouse is paid as a care provider:

- a. At least quarterly reviews of expenditures, and health, safety and welfare status of the participant by the case manager.
- b. Monthly reviews by the fiscal agent of hours billed for care provided by the spouse.
- c. A spouse who is a participant's authorized representative may not also be paid to be the participant's attendant.

Source: Colorado's §1915(c) HCBS Waiver application.

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*Oregon.* Oregon has a Spousal Pay Program funded through its Home and Community-Based Services waiver, but the program has stricter criteria for an individual to qualify than its regular in-home services program. The applicant must need 24 hour care and have a progressive, debilitating disease, a spinal cord injury, or another illness with permanent impairment that significantly limits four (out of six) activities of daily living.

### **III. Pennsylvania's HCBS Waivers**

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The nine HCBS waiver programs listed in House Resolution 241 are addressed in this chapter. A brief overview of each is listed below with descriptions of the extent to which family caregivers can be paid in each program. Importantly, waiver services are not an entitlement. All programs have limited capacity and limited funding. There is no guaranteed entrance into a waiver, even if someone meets all the eligibility criteria for a particular waiver, and some programs have waiting lists.

#### **Applying for Family Caregiver Services in HCBS Waiver Programs**

The Department of Human Services contracts with a third party through an Independent Enrollment Broker (IEB) to provide waiver enrollment services for the Attendant Care/Act 150, COMMCARE, Independence, OBRA, and AIDS Waiver programs.<sup>1</sup> In Pennsylvania, this broker is Maximus. The goal of the IEB was to simplify and streamline the applications process and to improve consistency across programs and counties. Maximus is responsible for ensuring that the initial assessment is complete. Additionally, they are to determine the applicant's functional criteria and identify the most appropriate waiver program. They are also to aid the applicant through the rest of the application process.

Upon completion of the application process, the IEB then partners the recipient with a Service Coordinator (SC) of his or her choice to coordinate care and to select a provider for those services. Another DHS contractor, PCG Public Partnerships, LLC (PPL) acts as the Commonwealth's vendor/fiscal employer agent between the caregiver and recipient if the caregiver is to be employed by the recipient. If the recipient chooses to have a family member as paid caregiver, PPL processes the worker's application and background checks and provides payroll services for the recipient, who becomes a common law employer. PPL is the payroll agent and pays workers on a bi-weekly basis.

In determining the amount of wages that a caregiver may be paid, DHS provides the maximum billable rate for caregivers. Wages fall within an allowable rate range set by the Commonwealth through a CMS-approved rate setting methodology.

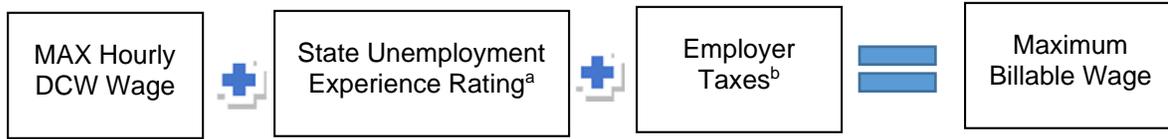
The maximum billable rate includes more than the hourly wage paid to the worker. The bill rate also includes the participant-employer's state unemployment insurance experience rating and the cost of employer taxes. The sum of these three items cannot exceed the maximum allowable pay rate for the region. See Exhibit 3 below:

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<sup>1</sup> There is no IEB for the two waiver programs under the Office of Developmental Programs, Consolidated Waiver for Individuals with Intellectual Disabilities, or the Person/Family Directed Support Waiver.

Exhibit 3

**Determination of Maximum Allowable Wage for Paid Family Caregivers**



<sup>a</sup>The state unemployment experience rating is a rating given to all employers in Pennsylvania. The state reviews each employer’s history of hiring and firing employees and gives them a rating based on the history.

<sup>b</sup>Employer taxes are the taxes that PPL pays on behalf of the employer. Every time PPL pays a worker, it also pays taxes on the employer’s behalf, such as Social Security, Medicare, and State Unemployment Insurance. This also includes the employer rate for workers’ compensation insurance.

Source: PCG Public Partnerships, LLC.

The participant-employer is able to negotiate the hourly rate with his Direct Care Worker-Caregiver at or below the MAX Hourly Direct Care Worker (DCW) Wage. SCs are to explain the wage and benefit ranges to the employer and help him or her understand how to offer a benefit allowance to promote recruitment, retention, and staff morale. Caregivers are paid every two weeks. Payment can be via direct deposit or live check.

As Table 1 shows, direct service rates for participant-directed services, both personal assistance services and respite services, vary among four regions in Pennsylvania.<sup>2</sup> Rates as shown are the maximum billable rates for fifteen minute increments. Rates shown below are for waiver programs administered by the Office of Long-Term Living. (The waivers administered by the Office of Developmental Programs have three wage and benefit rates.)

Table 1

**Maximum Billable Rates for Direct Care Workers with Home and Community-Based Services Waivers**  
(15 minute increments)

<u>Service</u>	<u>Region 1</u>	<u>Region 2</u>	<u>Region 3</u>	<u>Region 4</u>
Personal Assistance Services .....	\$3.41	\$3.26	\$3.57	\$4.01
Respite Services.....	\$3.34	\$3.20	\$3.50	\$3.93

Source: Department of Human Services.

<sup>2</sup> The counties in each of the four regions are: Region 1 – Allegheny, Armstrong, Beaver, Fayette, Greene, Washington, and Westmoreland; Region 2 – Bedford, Blair, Bradford, Butler, Cambria, Cameron, Centre, Clarion, Clearfield, Clinton, Columbia, Crawford, Elk, Forest, Indiana, Jefferson, Lackawanna, Lawrence, Luzerne, Lycoming, McKean, Mercer, Mifflin, Monroe, Montour, Northumberland, Pike, Potter, Snyder, Somerset, Sullivan, Susquehanna, Tioga, Union, Venango, Warren, Wayne, and Wyoming; Region 3 – Adams, Berks, Carbon, Cumberland, Dauphin, Franklin, Fulton, Huntingdon, Juniata, Lancaster, Lebanon, Lehigh, Northampton, Perry, Schuylkill, and York; and Region 4 – Bucks, Chester, Delaware, Montgomery, and Philadelphia.

Several oversight mechanisms are in place to ensure the efficacy of waiver programs that allow paid family caregivers. First, the agreement between DHS and PPL requires Common Law Employer Satisfaction Surveys, which PPL is to issue within 60 days to new enrollees, and annually thereafter. PPL is to submit a corrective action plan (CAP) for any issues that were identified in these surveys. DHS also requires an Organization Performance Review for PPL. Once this review is completed, PPL is to prepare a CAP and address any issues identified in the performance review. The organization is to implement and comply with any time frames for correction.

Additionally, DHS conducts a Readiness Review and performance Quality Metrics Monitoring (QMM) of PPL for each deliverable outlined in its agreement with DHS. PPL is required to correct any findings from the QMM.

Individual caregivers, such as friends and family members, must meet the qualifications outlined in the various HCBS waivers for that program and type of service. Generally, in addition to criminal and child abuse background checks, this requires individuals providing participant-direct care to be a resident of Pennsylvania or a contiguous state, be at least 18 years of age, have Workers' Compensation Insurance, be a licensed driver and have valid automobile insurance (if providing transportation services), and have the ability and training to meet the needs of the participant.

## **Pennsylvania's HCBS Waivers**

Pennsylvania's HCBS waivers are listed below, including the waivers that allow some type of paid family caregiver (Aging, Attendant Care, COMMCARE, Consolidated, Independence, OBRA, and Person/Family Directed Support). Pennsylvania's HCBS waivers only allow payments to legally responsible individuals (e.g., a spouse or legal guardian) on a very limited, service-by-service basis (e.g., unlicensed home and community habilitation and some transportation services).

### **Aging Waiver**

This is a Home and Community-Based Services waiver for individuals aged 60 and older facilitated through the Department of Human Services. It is to help enable persons 60 years and older to continue to live in their homes and communities with support and services.

Services that may be available include:

- Accessibility Adaptations, Equipment, Technology and Medical Supplies;
- Adult Daily Living Services;

- Community Transition Services;
- Home Delivered Meals;
- Home Health Services;
- Non-Medical Transportation Services;
- Participant-Directed Community Supports;
- Participant-Directed Goods and Services;
- Personal Assistance Services;
- Personal Emergency Response System (PERS);
- Respite;
- Service Coordination;
- TeleCare; and
- Therapeutic and Counseling Services.

To be eligible for the Aging Waiver, a person must be a resident of Pennsylvania, a U.S. citizen or a qualified noncitizen, have a Social Security number, be 60 years of age or older, meet the level of care needs for a Skilled Nursing Facility, and meet financial requirements as determined by the local county assistance office.

There is no cap on the services that Aging Waiver participants receive, no cost sharing, and no contributions are allowed.

Family members (other than a spouse or other legally responsible individuals) may receive payment to provide personal assistance and respite services. To be a paid family member, the family member must be at least 18 years old, but there are no formal training or qualification requirements.

Participants in the Aging Waiver can elect to have even greater control of their care providers by requesting their services through a program called Services My Way. Participants work with a case manager from the state to collaboratively determine their needs and a budget for care services and goods. This is referred to as their Individual Service Plan. Participants then determine when, where, and from whom to purchase the necessary goods and services. Neighbors, friends and certain family members (e.g., adult children of the participating elders, but not a spouse, minor child, or legal guardian) can be hired as paid caregivers. The Services My Way Program makes use of a fiscal intermediary, also referred to as an Employer Agent, which is responsible for making payments to the care providers that are approved by the program participant.

## **AIDS Waiver**

The AIDS Waiver covers persons 21 years of age or older who have symptomatic HIV Disease or AIDS and is intended to help them maintain their health and remain in their home. This program provides services that are not otherwise paid for under the Medicaid program as an alternative to hospitalization or institutionalization.

To be eligible for the Aids Waiver, one must be 21 years or older, have symptomatic HIV disease or AIDS, meet the level of care needs for a skilled nursing facility or a special rehabilitation facility, and meet the financial requirements as determined by the local county assistance office. Services available are home health services, nutritional consultations, specialized medical equipment and supplies, and personal assistance services.

DHS personnel indicated that the AIDS waiver program has fewer than 100 participants. The AIDS Waiver application does not provide for paid family caregivers, and DHS reported that the issue of family members being paid caregivers has never arisen.

## **Attendant Care/Act 150 Waiver**

The Attendant Care/Act 150 program is available to persons with disabilities to allow them to continue to live in their home and community with support and services. This program provides services to eligible persons with physical disabilities in order to prevent institutionalization and allow them to remain as independent as possible.

To be eligible for Attendant Care Services, one must be a resident of Pennsylvania, meet the level of care needs for a skilled nursing facility or a special rehabilitation facility for the Medicaid waiver; be between 18 and 59 years of age, be capable of (1) hiring, firing, and supervising attendant care worker(s); (2) managing their own financial affairs; and (3) managing their own legal affairs. For the Medicaid HCBS waiver attendant care program, the beneficiary must meet the financial requirements as determined by the local county assistance office and have a medically determinable physical impairment that is expected to last for a continuous period of not less than one year or that may result in death.

Those who do not meet the skilled nursing facility or special rehabilitation facility level of care may qualify for the Pennsylvania state-funded Act 150 program. Participants in the Act 150 program may be assessed a minimal co-payment.

Family members (other than a spouse or parent/step-parent of a minor child) may receive payment to provide personal assistance services under the Attendant Care Waiver.

## **Adult Autism Waiver**

To be eligible for the Adult Autism Waiver, a person must be age 21 or older, a U.S. citizen or qualified alien, a resident of Pennsylvania at the time of enrollment) and meet certain diagnostic, functional, and financial eligibility criteria listed below. Priority is given to people not already receiving state-funded, or state and federally-funded, home and community-based services.

**Diagnostic Criteria.** Must have a diagnosis of an Autism Spectrum Disorder (ASD), which includes:

- Autistic Disorder;
- Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS);
- Asperger Syndrome;
- Childhood Disintegrative Disorder; and
- Retts Disorder.

**Functional Eligibility.** Must have substantial functional limitations in three or more of the major life activities listed below:

- self-care,
- understanding and use of receptive and expressive language,
- learning,
- mobility,
- self-direction, and
- capacity for independent living.

**Financial Eligibility.** If the applicant has met all other eligibility criteria, including functional eligibility, the final step in the application process is for the County Assistance Office (CAO) to determine financial eligibility. All waiver programs within the Commonwealth require individuals to meet certain financial eligibility criteria. The individual must meet the resource and income limits for Medicaid Medical Assistance and Payment of Long Term Care Services. The income limit is currently 300 percent of the Federal Benefit Rate.<sup>3</sup>

Currently, this waiver only offers agency-managed services; however, DHS is considering the addition of participant-directed services at a later date.

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<sup>3</sup> The Federal Benefit Rate is the maximum dollar amount paid to an aged, blind, or disabled person who receives Social Security Disability benefits under SSI.

## **COMMCare Waiver**

The COMMCare Waiver program provides services in the community to eligible persons with traumatic brain injury to prevent institutionalization and allow them to remain as independent as possible.

To be eligible for the COMMCare Waiver a person must be a Pennsylvania resident, be 21 years of age or older, have a medically determinable diagnosis of traumatic brain injury that requires a Nursing Facility level of care, and meet the financial requirements as determined by the local County Assistance Office.

Services available may include:

- accessibility adaptations, equipment, technology and medical supplies;
- adult daily living;
- community integration;
- community transition services;
- financial management services;
- home health;
- non-medical transportation;
- personal assistance services;
- personal emergency response system (PERS);
- prevocational services;
- residential habilitation;
- respite;
- service coordination;
- structured day habilitation services;
- supported employment; and
- therapeutic and counseling services.

Family members (other than a spouse) may receive payment to provide personal assistance services. Family members who do not live in the consumer's household may be paid to provide respite services.

## **Consolidated Waiver for Individuals With Intellectual Disabilities**

This program is designed to help eligible persons with intellectual disabilities live more independently in their homes and communities and to provide a variety of services that promote community living, including self-directed service models and traditional agency-based service models.

To qualify for the Consolidated Waiver program, a person must be age three or older, have a diagnosis of intellectual disability, require active treatment, be recommended for an intermediate care facility level of care based on a medical evaluation, be determined eligible for Medical Assistance (MA), have a \$2,000 resource limit (does not apply to dependent children under age 21), and have an income limit that is within 300 percent of the Federal Benefit Rate.

Services that are available to a person qualifying for this program include:

- assistive technology,
- behavior support,
- companion,
- education support,
- home accessibility adaptations,
- home and community habilitation (unlicensed),
- homemaker/chore,
- licensed day habilitation,
- nursing,
- prevocational,
- (licensed) residential habilitation,
- (unlicensed) residential habilitation,
- respite,
- specialized supplies,
- supported employment,
- supports broker,
- supports coordination,
- therapy (physical, occupational, visual/mobility, behavioral and speech and language),
- transitional work,
- transportation, and
- vehicle accessibility adaptations.

Family members (other than spouse or parent/step-parent of a minor child) can be paid to provide services under the Consolidated Waiver for home and community habilitation,<sup>4</sup> respite care, supported employment, and transportation as

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<sup>4</sup>Home and community habilitation services are designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.

well as for educational support services. Legally responsible individuals, including spouses, can be paid for certain services (e.g., home and community habilitation, supported employment, and transportation), provided the services are considered extraordinary care (not part of the supports the legally responsible individual is ordinarily obligated to provide) and the service would otherwise need to be provided by a service provider.

## **Independence Waiver**

This program provides services to eligible persons with physical disabilities to help prevent institutionalization and allow them to remain as independent as possible.

Those eligible for the Independence Waiver must be a Pennsylvania resident, be 18 to 60 years old, physically disabled (but not with mental retardation or have a major mental disorder as a primary diagnosis or be ventilator dependent), who reside in a nursing facility or the community but who have been assessed to require services at the nursing facility level of care. The disability must result in substantial functional limitations in three or more major life activities (self-care, understanding and use of language, learning, mobility, self-direction, and/or capacity for independent living) and meet the financial requirements as determined by the local county assistance office.

Services available include adult daily living services, accessibility adaptations, equipment, technology and medical supplies, community integration, community transition services, financial management services, home health, non-medical transportation, personal assistance services, personal emergency response system (PERS), respite, service coordination, supported employment, and therapeutic and counseling services.

Family members (other than a spouse or parent/step-parent of a minor child) may receive payment to provide personal assistance service. Such family members may also be paid to provide respite services if the family member does not live in the consumer's household.

## **Infants, Toddlers, and Families Waiver**

This waiver provides services to children from birth to age three who are in need of Early Intervention services. Services include habilitation services by qualified professionals with family/caregiver participation. The Infants, Toddlers, and Families Waiver does not provide for family members to be paid caregivers.

## **OBRA Waiver**

The OBRA Waiver is a Home and Community-Based Services waiver program that may help if a person has a developmental physical disability to allow them to live in the community and remain as independent as possible.

To be eligible, a person must be a resident of Pennsylvania, age 18-59, have a severe developmental physical disability in three or more major life activities (self-care, communication, learning, mobility, self-direction, and capacity for independent living), and meet the financial requirements as determined by the local county assistance office.

Individuals living in personal care homes are eligible for this waiver as long as the services they receive do not duplicate services provided by the home or that are the responsibility of the home. Starting January 2014, OBRA Waiver recipients cannot live in personal care homes that are licensed for more than eight residents.

Available services include adult daily living; accessibility adaptations, equipment, technology, and medical supplies; community integration; community transition services; financial management services; home health; non-medical transportation; personal assistance services; personal emergency response system (PERS); prevocational services; residential habilitation services; respite; service coordination; structured day habilitation services; supported employment; and therapeutic and counseling services.

Family members (other than a spouse or parent/step-parent of a minor child) can be paid to provide personal assistance services and/or respite services.

## **Person/Family-Directed Support Waiver**

This program is designed to help persons with developmental disabilities live more independently in their homes and communities and to provide a variety of services that promote community living, including self-directed service models and traditional, agency-based service models.

To be eligible, a person must be age three or older, have a diagnosis of intellectual disability, require active treatment, be recommended for an intermediate care facility/mental retardation level of care based on a medical evaluation, be determined eligible for medical assistance, with a \$2,000 resource limit (does not apply to dependent children under age 21), and have an income limited to 300 percent of the Federal Benefit Rate. The program also has an individual cost limit of \$30,000 per person per fiscal year (excluding supports coordination).

Available services include assistive technology, behavior support, companion, education support, home accessibility adaptations, home and community habilitation (unlicensed), homemaker/chore, licensed day habilitation, nursing, prevocational, respite, specialized supplies, supported employment, supports broker, supports coordination, therapy (physical, occupational, visual/mobility, behavioral, and speech and language), transitional work, transportation, and vehicle accessibility adaptations.

Certain services, including respite care and supported employment, may be provided by non-spousal family members. Home and community habilitation and transportation services may be provided by legally responsible family members.

**Summary of HCBS Waiver Provisions That Allow Paid Family Caregivers**

	<b>Overview</b>	<b>Eligibility</b>	<b>Services Available</b>	<b>Paid Family Caregiver</b>
<b>Attendant Care/Act 150</b>	Services to eligible persons with physical disabilities.	Age 18-59; Physical impairment lasting 12 months or more; Nursing Facility Clinically Eligible standard; Mentally alert and capable of directing own care; Meet financial requirements.	Community Transition Services; Financial Management Services; Participant-Directed Community Supports; Participant-Directed Goods and Services; Personal Assistance Services; Personal Emergency Response System (PERS); Supports Coordination	Yes (other than a spouse or parent/step-parent of minor child) may receive payment to provide Personal Assistance Services.
<b>COMMICARE Waiver</b>	Services to eligible persons with Traumatic Brain Injury (TBI).	Age 21 or older; Diagnosis of traumatic brain injury; Nursing Facility level of care; Meet financial requirements.	Accessibility Adaptations, Equipment, Technology and Medical Supplies; Adult Daily Living; Community Integration; Community Transition Services; Financial Management Services; Home Health; Non-Medical Transportation; Personal Assistance Services; Personal Emergency Response System (PERS); Prevocational Services; Residential Habilitation; Respite Service Coordination; Structured Day Habilitation Service; Supported Employment; Therapeutic and Counseling Services.	Yes (other than a spouse) may receive payment to provide personal care services.
<b>Independence Waiver</b>	Services to eligible persons with a severe physical disability	Age 18 or older; Physically disabled (but not with mental retardation or have a major mental disorder as a primary diagnosis, or who are ventilator dependent); Nursing facility level of care; Substantial functional limitations; Meet financial requirements.	Adult Daily Living Services; Accessibility Adaptations, Equipment, Technology and Medical Supplies; Community Integration; Community Transition Services; Financial Management Services; Home Health; Non-Medical Transportation; Personal Assistance Services; Personal Emergency Response System (PERS); Respite; Service Coordination; Supported Employment; Therapeutic and Counseling Services.	Yes (other than a spouse or parent/step-parent of a minor child) may receive payment to provide personal assistance service and respite services if the family member does not live in the consumer's household.
<b>OBRA Waiver</b>	Services to eligible persons with a developmental physical disability.	Age 18-59; Substantial functional limitations; Other related conditions (ORCs) include physical, sensory, or neurological disabilities which manifested before age 22 and are likely to continue indefinitely; Meet financial requirements.	Adult Daily Living; Accessibility Adaptations, Equipment, Technology and Medical Supplies; Community Integration; Community Transition Services; Financial Management Services; Home Health; Non-Medical Transportation; Personal Assistance Services; Personal Emergency Response System (PERS); Prevocational Services; Residential Habilitation Services; Respite; Service Coordination; Structured Day Habilitation Services; Supported Employment; Therapeutic and Counseling Services.	Yes (other than a spouse or parent/step-parent of a minor child) may receive payment to provide personal assistance service and respite services if the family member does not live in the consumer's household.
<b>Person/Family-Directed Support Waiver</b>	Services to eligible persons with intellectual disabilities.	Age three or older; Diagnosis of mental retardation; Require active treatment ICF/MR level of care; Does not require Office of Developmental Programs licensed community residential services; Meet financial requirements.	Assistive technology; Behavior support; Companion; Education support; Home accessibility adaptations; Home and community habilitation (unlicensed); Homemaker/chore; Licensed day habilitation; Nursing; Prevocational; Respite; Specialized supplies; Supported employment; Supports broker; Supports coordination; Therapy (physical, occupational, visual/mobility, behavioral and speech and language); Transitional work; Transportation; Vehicle accessibility adaptations.	Yes (other than a spouse) for certain services. Legally responsible individuals, including spouses, can be paid to provide certain services.
<b>Aging Waiver Program</b>	Services to eligible older Pennsylvanians.	Age 60 and older; Would benefit from nursing facility care; Meet financial requirements.	Home health and personal care services; home support, attendant care; respite care; adult day care; transportation; home modifications; specialized medical equipment and supplies; counseling; extended state plan physician services; home delivered meals; personal emergency response; and companions.	Yes (other than a spouse) may receive payment to provide personal care services.
<b>Consolidated Waiver for Individuals with Intellectual Disabilities</b>	Services to eligible persons with intellectual disabilities.	Age three and older; Diagnosis of mental retardation; Require active treatment Be recommended for an intermediate care facility level of care based on a medical evaluation; Can require Office of Mental Retardation licensed community residential services; Meet financial requirements.	Assistive technology; Behavior support; Companion; Education support; Home accessibility adaptations; Home and community habilitation (unlicensed); Homemaker/chore; Licensed day habilitation; Nursing; Prevocational; Respite; Specialized supplies; Supported employment; Supports broker; Supports coordination; Therapy (physical, occupational, visual/mobility, behavioral and speech and language); Transitional work; Transportation; Unlicensed residential habilitation; Vehicle accessibility adaptations; residential habilitation.	Yes (other than a spouse) Legally responsible individuals, including spouses, can be paid to provide certain services.

Source: Developed by LB&FC staff.

## **IV. Family Caregiver Participation in Pennsylvania HCBS Waivers**

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The extent to which family caregivers participate in Pennsylvania HCBS waiver programs cannot be definitively determined because relationship data is not conclusively tracked. Pennsylvania's Office of Long-Term Living reported that it has relationship data available for only 58 percent of the direct care workers within its waiver programs. The Office of Developmental Programs (ODP) only tracks relationship data in one model of its waiver programs, the Vender Fiscal/Employer Agent model.

### **National Data**

The Kaiser Family Foundation (KFF) has data both nationally and by state as to participation in Medicaid Home and Community-Based Service programs. KFF reported that as of 2011, over 3.2 million persons were served through one of the three main programs for HCBS care: state plan services, optional personal care state plan services, and §1915(c) waiver services, with 1.45 million being served under the waiver programs. KFF reports that as of 2011, Pennsylvania had 103,017 total HCBS participants under the different HCBS Medicaid authorities, with 72,766 of that total (71 percent) being participants under Pennsylvania's HCBS waiver programs. KFF, however, has no breakdown of data based on relationship information between the participant and service provider.

The federal government provides support to family caregivers and records a certain level of data relative to The National Family Caregiver Support Program, established in 2000. Under this program, which is not an HCBS waiver program, the federal government provides grants to the states to fund a range of supports that assist and provide relief for family and informal caregivers to care for their loved ones at home for as long as possible. Services include care management, respite care, financial reimbursements for home modifications, and others. The following family caregivers are eligible to receive services:

- adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older;
- adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders;
- grandparents and other relatives (not parents) 55 years of age and older providing care to children under the age of 18; and
- grandparents and other relatives (not parents) 55 years of age and older providing care to adults age 18-59 with disabilities.

The federal government spent \$154 million for this program in 2012. The Department of Health and Human Services Administration for Community Living Aging Integrated Database (AGID) reports 5,037 caregivers served in Pennsylvania under this federal program in 2012. Of those, 4,869 (97 percent) were family caregivers. Spousal caregivers comprised 1,572 persons or 31 percent of the total.

## Pennsylvania-specific Data

Within Pennsylvania, the Office of Developmental Programs confirmed that the Home and Community Services Information System (HCSIS) does not capture whether an employee (paid caregiver) who provides HCBS waiver services is a family member of the participant receiving services. ODP did obtain some relevant information for the participants who self-direct their services through the Vendor Fiscal/Employer Agent (VF/EA) model. ODP has estimated that approximately 4 percent of paid caregivers in the Consolidated Waiver and 9 percent of paid caregivers in the P/FDS Waiver are family members within the VF/EA model.

ODP operates three HCBS waivers, the Consolidated Waiver, the Person/Family-Directed Supports Waiver, and the Adult Autism Waiver. The majority of waiver participants are served via a “traditional” or “agency” model, where a provider manages and directs who provides care to the participant. Participants may also elect to direct their own services in one of two participant-directed models, only one of which—the Vendor Fiscal/Employer Agent (VF/EA) model—captures quantifiable data on caregiver relationships.

ODP requested family relationship data be provided by the Commonwealth’s VF/EA provider for a 10 percent sample of payments to workers in September 2014 and October 2014. As shown in Table 2, approximately 4 percent of paid caregivers in the Consolidated Waiver and 9 percent of paid caregivers in the P/FDS Waiver are family members within the VF/EA model.

Table 2

### Family Relationships in VF/EA Participant-directed Care Program

Waiver	Participants	Caregivers	Average Caregivers Per Participant	Relatives	% Relatives	Non-Relatives	% Non-Relatives
Cons.	49	68	1.39	3	4.4%	65	95.6%
P/FDS	67	93	1.39	8	8.6%	85	91.4%
Total	116	161	1.39	11	6.8%	150	93.2%

Source: PA Department of Human Services.

By applying these percentages to the total population of VF/EA participants, ODP estimated the number of caregivers who are family members on any given day within the VF/EA model as shown in Table 3:

Table 3

<b>Estimated Number of Family Member Caregivers in VF/EA Participant-directed Care Program</b>				
	Distinct Participants as of 10/28/14	Estimated Caregivers (1.39)	Relatives	Estimated Caregivers Who Are Relatives
P/FDS Waiver	2,458	3,417	4.4%	150
Cons. Waiver	1,355	1,883	8.6%	162
Total	3,813	5,300	6.8%	360

Source: PA Department of Human Services.

The Office of Long-Term Living (OLTL) oversees five Medicaid HCBS waivers and one state-funded program that allow participants to employ their own direct care workers. These are the Aging Waiver, Attendant Care Waiver, COMMCARE Waiver, Independence Waiver, OBRA Waiver, and the Pennsylvania Act 150 program. DHS reports there are 26,855 direct care workers as of March 2015 actively providing services in these programs and that relationship data is available for 58 percent of those workers as shown in Table 4:

Table 4

<b>Percentage of Family Member Caregivers in OLTL HCBS Waivers and the Act 150 Program for Whom Relationship Data Is Available</b>	
<u>Relationship of Worker to Participant:</u>	<u>Percent of Workers</u>
Sibling.....	4%
Parent.....	5
Other Relative (Not a Spouse)*.....	15
Child.....	16
Not Related.....	60
Total.....	100%

\*OLTL waiver requirements prohibit a spouse from serving as a paid worker.

Source: Public Partnerships, LLC, the Financial Management Services provider for Office of Long-Term Living.

To supplement this data regarding the extent which family caregivers serve as paid caregivers in the home and community-based waiver programs, we contacted several service coordinators. These providers noted:

- One Service Coordinator (SC) has 47 percent of its participants in participant-directed model and 30 to 45 percent hire a family member as caregiver.
- One Area Agency on Aging stated that about 31 percent of its recipients use the self-directed model, but could not break down how many caregivers were family members.
- An SC that serves northeastern Pennsylvania estimated that one-third of its recipients have chosen the self-directed model, but could not break down how many caregivers were family members.
- An SC that serves southeastern Pennsylvania said that 85 percent of their clients choose a family member as caregiver. Of this 85 percent, half choose the participant directed model, and half choose the agency model with their family member being hired by a care agency.

## **V. The Move Toward Participant-directed Care**

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Participant-directed care is a service model that expands the amount of choice and the degree of control of program participants and their families in receiving home and community-based services. In 1998, a three-state demonstration was conducted to compare the Cash & Counseling participant-directed model, which often allows for paid non-spousal family caregivers, with the traditional agency-directed approach to delivering personal-assistance services.

Specifically, Cash & Counseling programs are financial and care assistance programs, usually but not always from Medicaid, which provide the beneficiary with cash assistance and the flexibility to “consumer direct” or self-direct the spending on the care providers of their choosing. The Cash & Counseling program began as a pilot Medicaid program in 15 states with the objective of increasing the participants’ control over their care services.

Traditionally, Medicaid programs would contract with home care agencies to provide personal assistance services such as help with bathing, dressing, grooming, and cooking. Under Cash & Counseling programs, care recipients were given the flexibility to choose their own home care agencies, and often family members could act as a “home care agency.” This meant that relatives, such as the adult children of aging parents, could be hired and paid for the personal assistance they provided.

Since the original pilot program, both the concept of Cash & Counseling and the number of states in which it is available has expanded considerably. In addition, the name “Cash & Counseling” is now referred to as consumer direction, participant-directed, or self-directed care. The organization tasked with the administration of the original Cash & Counseling program is now referred to as the National Resource Center for Participant-Directed Services (NRCPS).

### **Participant-directed Care Programs in Other States**

The National Resource Center for Participant-Directed Services conducted a survey of the states and found that, as of 2014, participant-directed care, in one form or another, is available in every state and the District of Columbia. The majority of states have between 1,000 to 5,000 participants enrolled in participant-directed programs. Pennsylvania is reported as having more than 10,000 participants and ranks eighteenth among the states when the number of participant-directing enrollees is adjusted to the state population that is potentially eligible.

Of the 277 participant-directed programs nationwide, the vast majority (96 percent) operate through a Medicaid waiver—that is, a §1915(b) managed care waiver, §1915(c) HCBS waiver, §1915(b) & §1915(c) concurrent waiver, or a §1115

research and demonstration project waiver—or a state plan amendment program. A fundamental aspect of participant direction is the participant’s authority to select and control who is hired to provide services. Self-direction allows participant or their representatives to hire, manage, and dismiss workers. Some programs also allow for budget authority, allowing participants the ability to negotiate wage rates and benefits.

The NRCPDS survey indicated that about 91 percent of participant-directed programs allow participants to select relatives to provide direct support services. The survey also found that hiring a legally responsible individual (i.e., spouse, parent, or legal guardian of a minor child) as a paid caregiver is allowed in 11 percent of the programs responding. Ninety-one percent of the programs prohibit spouses from serving as paid caregivers; 86 percent also prohibit parents or legal guardians; and 39 percent disallow those who hold powers of attorney from being paid caregivers.

Indiana has established an Aged and Disabled Waiver under §1915(c) that provides a variety of services to participants, including Structured Family Caregiving, in which family members or friends can become the primary in-home caregiver. The program provides caregivers with supports and financial assistance, including daily stipends. The principal caregiver cannot, however, be the participant’s spouse, the parent of a participant who is a minor, or the legal guardian of the participant. All Structured Family Caregiving settings must be approved and supervised by a provider agency, and all paid caregivers are trained and paid by the provider.

***State-funded Programs That Allow Paid Family Members.*** Twenty-one states reported that they have solely state-funded programs that allow payments to some family members to provide long-term care to their elderly or disabled relatives. Twelve states (Colorado, Kentucky, Maine, Minnesota, New Hampshire, New Jersey, North Dakota, Oregon, Texas, Utah, Vermont, and Wisconsin) allow these state-funded programs to pay any relatives, including spouses, parents of minor children, and other legally responsible relatives. Seven (Connecticut, Illinois, Indiana, Kansas, Massachusetts, Nebraska, and Nevada) prohibit payments to spouses, parents of minor children, and people who are legally responsible. Maryland’s state-funded program prohibits payments to spouses, children, stepchildren, parents, grandparents, siblings, or in-laws, but allows payment to other relatives. South Carolina prohibits immediate family members but allows aunts, uncles, and cousins.

In 2009, the Illinois General Assembly required its Department of Human Services to implement a demonstration project to assess the feasibility of allowing spouses to be reimbursed for care provided through its Home Services Program. The Department’s initial report in March 2010 determined that the demonstration

would have to be funded with state General Revenue Funds “until or unless it is incorporated in the Home Services Program Medicaid Waivers.” The report also noted that only “extraordinary services” could be claimed under the Medicaid §1915(c) waiver. Spousal payments were made under the program from mid-2010 through mid-2011, but the program was subsequently discontinued due to budget concerns.

## **New Rules for Home and Community-based Settings**

On January 16, 2014, the Centers for Medicare and Medicaid Services (CMS) issued a final rule for home and community-based settings that may further promote participant-directed care. The final rule, which became effective on March 17, 2014, amends the Medicaid regulations to provide requirements regarding person-centered plans of care, characteristics of settings that are home and community-based as well as settings that may not be home and community-based.

These requirements reflect CMS’ intent that individuals receiving services and supports through Medicaid Waivers receive services in settings that are integrated in and support full access to the greater community. The final rule applies to §1915(c) Medicaid waivers, §1915(i) State Plan home and community-based services, and §1915(k) Community First Choice attendant care services (§1915(k)). Pennsylvania has ten Medicaid home and community-based services waivers. All Medicaid waivers must comply with these requirements. The final rule includes a provision requiring states offering HCBS under existing state plans or waivers to develop transition plans to ensure that HCBS settings will meet the final rule’s requirements.

Pennsylvania has developed a transition plan to address these changes. Under the plan, Pennsylvania will use its statewide transition plan as a way to determine its compliance with CMS’s rule on HCBS. Pennsylvania will determine the current level of what state actions are needed for compliance. This will include a review of current licensing requirements, policies, regulations, rules, standards, and statutes. Assessment activities will include a review of policy documents and provider enrollment documents, a review of licensing requirements, development and implementation of a provider self-assessment, and enhancement or development of a participant monitoring tool.

Data from these activities will be assessed and provider settings will be placed into three categories: (1) setting is fully compliant, (2) setting is presumed non-compliant but evidence may be presented for heightened scrutiny review, and (3) setting does not comply. These categories will inform the order in which Pennsylvania will contact providers, starting with settings that do not comply and ending with settings that the assessments indicate are fully compliant. These activities will give Pennsylvania a provider and participant perspective on settings, which

will be followed by official DHS monitoring to validate compliance status, which will include on-site monitoring as needed to ensure compliance.

Pennsylvania will collect public comments on the transition plan through a dedicated email address for submission of written comments and through taking public comments via other forms of stakeholder involvement. In addition to posting the transition plan and related materials on the Department of Human Services website, large stakeholder groups may be contacted directly and all stakeholders will be provided with updated information on an ongoing basis through various forms of stakeholder communication.

## **Obstacles to Employing Family Members as Caregivers**

Despite the popularity of participant-directed care, there are several barriers to the paid family caregiver option, including:

**Legal Barriers.** As noted earlier, federal regulations generally prohibit legally responsible relatives, such as parents of minor children and spouses, from becoming paid caregivers. As of May 2015, persons holding power of attorney status may be paid family caregivers under waiver programs, however, DHS is planning to eliminate these exceptions as of July 2015. DHS is doing this for a variety of reasons, including seeing an increase in both physical and financial abuse cases.

**Costs.** Providing supports to keep an individual in the family home would appear to be cost-effective, given the typically higher costs of out-of-home placement. For example, one 2009 study found that the average annual cost to keep an individual in the family home ranged from \$22,956 to \$39,343, against a national average annual cost of \$43,464. Although the evidence points to lower costs for individuals living at home, it is less clear whether paying family members to provide the necessary services will result in lower costs in the aggregate.

Because the rates paid for services provided by family members can be significantly lower than those paid to out-of-home residential services providers, it makes intuitive sense that paid family caregivers is cost-effective for states. However, at least one state reports that paying family members may have added to its cost as many more families, who previously provided uncompensated care, are coming forward seeking payment for their continued caregiving.

To address the concern that paying a relative may replace the natural supports a family offers, a number of states take steps such as capping the amount of services they will pay for or not providing payment to persons who are residing with the individual in the same home.

**Application Procedures and Background Checks.** It may take longer for services if the recipient chooses a family member to provide services due to application procedures and required background checks. According to PPL, participants have expressed unhappiness with the amount of time it took before their workers could start providing services. This was due in large part to incomplete or erroneous information submitted by participant-employers that requires corrections and additional processing. Background checks are also required and, depending on the type of background check, may take several weeks. A waiver recipient may choose to have a family member become a caregiver even if that family member does have a criminal record, as long as they are fully informed of the criminal background of the worker who is providing services.

**Concerns Over Fraud and Abuse.** The potential for fraud and abuse is another policy issue that must be considered when family members are paid caregivers. Waiver recipients are often elderly and/or have some type of diminished capacity. Hiring the “wrong” person or family member can be an open invitation to abuse, and several SCs told us that they are seeing a large and growing number of financial abuse cases.

One SC stated that they are also seeing more incidents of time sheet fraud than they ever have in the past, and Area Agencies on Aging (AAAs) told us of discovering family caregivers who have reported hours worked and have not actually put in the time. Not actually doing the work is not only fraud, but is also potentially harmful to the person who needs that care.

According to DHS, SCs receive regular usage reports from PPL, and it is incumbent upon the SC to monitor the hours of care a waiver participant receives and to keep track of usage. Additionally, all SCs have been trained to see the signs of abuse, in which case the Department’s Bureau of Program Integrity is to be notified.

CMS is also concerned over the risks involved in participant-directed care, particularly as it regards paid family caregivers. As a consequence, it requires states to indicate what steps they will take to address these risks in their Medicaid waiver applications. Specifically, with regard to legally responsible individuals, states must establish procedures to ensure that:

- legally responsible individuals meet the provider qualifications that the state has established for the personal care or similar services for which payment may be made,
- the state conducts monitoring of such services, including documentation and assurance that the services are delivered in accordance with the service plan and the proper execution of a provider agreement,

- the provision of personal care or similar services by a legally responsible individual is in the best interests of the waiver participant,
- the amount of services that a legally responsible individual may furnish is limited (e.g., no more than 40 hours in a week),
- payment review procedures are established to ensure that the services have been rendered in accordance with the service plan, and
- the state has considered and addressed other foreseeable risks that might attend the provision of services by legally responsible individuals.

States must address similar provisions for paid family member caregivers who are not legally responsible individuals.

**Concerns Over Quality and Performance.** Generally, consumers rate services from qualified and capable relatives as being of high quality with a high level of satisfaction. However, if a family member is primarily focused on money, the quality of care may be low, and the person will be put at risk. Another observer noted, “Beware—the family living model has its traps and can create a system of the recipient being the only source of income for the family, thereby limiting their ability to ever leave the home.” Also, because of the family relationship, it may be more difficult to correct or improve the work of a family member than it would be an agency-based employee.

To help address some of these concerns, Louisiana has established an extensive “thought protocol” when using family members as paid support workers. For example, some of the questions and issues the planning team is to consider when using family members to provide supports include:

- *Is the use of a family member age and developmentally appropriate?* The team needs to consider the day from the person’s perspective. Sometimes having family around may be fine; other times it may not be. Does a 30-year-old generally have his mom accompany him to evenings out with friends? Not usually. Support teams must look at ways of using family as paid direct service workers in situation-appropriate times that are consistent with meeting the person’s support needs. If using family as a paid direct service worker for sometimes makes sense, then consider including non-family members for shifts involving planned socializing and peer interaction.
- *Will using family members as paid direct service workers enable the person to learn and adapt to different people and also to form new relationships?* The support team must build in opportunities to meet different people and form relationships, including making choices about selection of different direct support workers.

- *Is the person learning flexibility and skills for increased independence?* The support team and IFS provider must reinforce with the family member that he/she is not in a “caretaking” role, but rather in a supportive role that is intended to encourage autonomy and skills-building for independence in community living. The support team must ensure that the family member providing direct support approaches the job as such and does not present barriers to individual goals and treatment objectives.
- *Is this about the person’s wishes, desires, needs, or about supplementing a family member’s income?* Support teams must consider the motive and level of commitment of a family member requesting to act as a paid direct service worker. Protecting against exploitation is key. In the end, if a family member is only focused on money, the quality of care will be low, and the person will be put at risk.

Missouri has established a policy whereby if the person employs his/her own workers using an approved fiscal intermediary, the family member serving as a paid personal assistant cannot be the employer of record. Another representative must act on behalf of the person as the employer of record. This arrangement at least assures separation of these roles, giving some assurance to the individual that they can terminate the employment of the family member if needed.

Connecticut requires a review by a Prior Approval Committee to assure that provision of services by a family member is in the best interests of the individual and also comports with their policies regarding the use of relatives as providers.

While states address the issues of quality and performance various ways, some of the more common provisions are:

- the individual has a separate representative if a family member provides care under a self-directed option;
- if the provider is a guardian, the individual has a third party representative;
- restrict guardians from being paid providers;
- the employed family member may not live with the individual;
- the paid relative or guardian may not be the employer of record (in consumer-directed options);
- required use of an independent broker to monitor services; and
- counseling by brokers (or case managers) regarding conflict of interest.

## **VI. Appendices**

APPENDIX A

PRINTER'S NO. 1270

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 241 Session of  
2013

INTRODUCED BY COX, AUMENT, BENNINGHOFF, BOBACK, V. BROWN,  
CALTAGIRONE, COHEN, CUTLER, DENLINGER, EVERETT, FLECK,  
GIBBONS, GROVE, HEFFLEY, KAUFFMAN, KORTZ, McGEEHAN, MUNDY,  
O'NEILL, ROCK, SABATINA, TOOHIL, WATSON AND GILLEN,  
MARCH 25, 2013

REFERRED TO COMMITTEE ON HUMAN SERVICES, MARCH 25, 2013

A RESOLUTION

Directing the Legislative Budget and Finance Committee to  
conduct a thorough review of Pennsylvania's Medicaid Home and  
Community Based Waiver Programs in order to determine the  
extent to which family members serve as caregivers in those  
programs and any barriers that exist which preclude family  
caregiving.

WHEREAS, In Pennsylvania, the Department of Public Welfare  
administers nine Medical Assistance/Medicaid Waivers, including:  
Aging Waiver; AIDS Waiver; Attendant Care/Act 150 Waiver;  
COMMCARE Waiver; Consolidated Waiver for Individuals with  
Intellectual Disabilities; Independence Waiver; Infants,  
Toddlers, and Families Waiver; OBRA Waiver; and Person/Family  
Directed Support Waiver; and

WHEREAS, Support Services Waivers, a short term for "Medicaid  
Home and Community Based Waivers" provide funding for support  
and services to help individuals to live in their homes and  
communities and offer an array of services and benefits such as  
choice of qualified providers, due process and health and safety  
assurances; and

## Appendix A (Continued)

WHEREAS, The name "waiver" comes from the fact that the Federal Government "waives" Medical Assistance/Medicaid rules for institutional care in order for Pennsylvania to use the same funds to provide supports and services for people closer to home in their own communities; and

WHEREAS, Each waiver program has its own unique set of eligibility requirements and services and each is designed to serve a specific population of individuals with certain specific service needs; and

WHEREAS, Studies have shown that people who have family caregivers tend to have fewer hospital admissions, shorter hospital stays and informal care by adult children reduces Medicare inpatient expenditures of single older adults, as well as expenditures for home health and skilled nursing facility care; therefore be it

RESOLVED, That the House of Representatives direct the Legislative Budget and Finance Committee to conduct a thorough review of Pennsylvania's nine Medicaid Waiver Programs to determine the extent to which family members currently serve as caregivers in those programs and to identify any barriers that exist which preclude family members of waiver service beneficiaries from serving as paid caregivers to their loved ones, including whether such barriers are dictated by statute, regulation or policy; and be it further

RESOLVED, That the Legislative Budget and Finance Committee make a report with recommendations, as appropriate, and submit the report to the Speaker of the House of Representatives and to members of the Aging and Older Adult Services Committee, the Health Committee and the Human Services Committee within six months of the adoption of this resolution.



## APPENDIX B

### **Response to This Report**



COMMONWEALTH OF PENNSYLVANIA  
DEPARTMENT OF HUMAN SERVICES

Mr. Phillip R. Durgin  
Executive Director  
Legislative Budget and Finance Committee  
P.O. Box 8737  
Harrisburg, Pennsylvania 17105-8737

Dear Mr. Durgin:

Thank you for your May 26, 2015 letter sharing the Legislative Budget and Finance Committee's (LBFC) report titled *Family Caregivers in Pennsylvania's Home and Community Based Waiver Programs*, and allowing the Department of Human Services (Department, DHS) to submit comments.

House Resolution 241 directed the LBFC to determine the extent to which family members serve as caregivers and what barriers exist that preclude paid family caregiving.

One of the natural supports of caring for our consumers are family caregivers, and all of the time they spend is not tracked by DHS. The report references data obtained from several un-named service coordinators in Pennsylvania and DHS cannot speak to the accuracy of the data.

DHS believes there are some barriers that exist to preclude paid family caregiving, however two of the waivers, the Consolidated and Person/Family Directed Support (P/FDS) waivers, allow for paid family caregivers. Other than criminal background checks, the waivers have little or no existing barriers precluding able individual family caregivers from providing the approved services for their family member.

DHS agrees that family caregivers are an important part of the workforce that provide services to participants in Medicaid waiver programs. Family members such as siblings, adult children, and parents of adults have successfully provided paid care under the waiver programs for nearly 20 years.

After careful review of the report, DHS offers the following comments regarding the findings in the LBFC's report:

***Pages S-1 - "Some states, but not Pennsylvania, allow legally responsible relatives to be paid for personal care services in their HCBS waiver programs when such services are deemed as extraordinary care. (pp. 4 to 9)"***

***Page 7 - "Providing for payments to legally responsible individuals is a state option, not a federal requirement. Pennsylvania has chosen not to include provisions for payments to legally responsible persons in its Medicaid HCBS waiver applications for personal care services, but does allow legally responsible individuals to be paid for a limited number of other services (e.g., for transportation services in the Consolidated Waiver and Person/Family Directed Support Waiver)."***

**Comment:** We do not believe that those two statements are accurate. The Consolidated and P/FDS waivers pay legally responsible individuals for home and community habilitation, which includes personal-care-type services. Those waivers have specifically checked the following in section C-2-d of our waiver applications: "Yes. The State makes payment to legally responsible individuals for furnishing personal care or similar services when they are qualified to provide the services." The waivers also state that one of the services legally responsible individuals can provide is home and community habilitation. This service assists participants in acquiring, maintaining and improving self-help, domestic, socialization, and adaptive skills necessary to reside successfully in home and community-based settings. Services consist of support in the general areas of self-care among other things which qualifies as personal care. According to the CMS technical guide regarding section C-2-d, "In the context of this item, personal care or similar services mean: (a) personal care (assistance with ADLs or IADLs) whether furnished in the home or the community and however titled by the state in the waiver (e.g., personal assistance, attendant care, etc.) and (b) closely related services such as home health aide, homemaker, chore and companion services." While the home and community habilitation service should not solely be utilized to provide personal care, it may be a component of the service, especially when a legally responsible relative is teaching the participant to complete ADLs or IADLs for him or herself (which we would consider to be extraordinary care). For those reasons, DHS believes it is not accurate to state that Pennsylvania does not allow legally responsible relatives to be paid for personal care services in their HCBS waiver programs.\*

Also, DHS requests that the example of transportation be replaced with home and community habilitation in the following on **pages S-2 and 7** ***"(Legally responsible individuals, including spouses, and can be paid for certain services, such as transportation, under certain circumstances in Pennsylvania's Consolidated Waiver and Person/Family Directed Support Waiver programs.)"*** Listing transportation makes it seem as though DHS does not allow legally responsible individuals to provide direct services to participants, which is allowed for through home and community habilitation.\*

**S-1 - "Some states (but not Pennsylvania), have established 100 percent state funded programs that allow legally responsible family members to be paid caregivers to their elderly or disabled relatives. (pp 27 to 28)."**

**Comment:** Counties are allowed to use state base funds to reimburse relatives for care provided to their relatives.

**Page S-2. "Family caregivers in HCBS waivers typically receive \$3.35 to \$4.00 per 15 minute unit..."** Pennsylvania has three wage and benefit ranges depending on geographic region.

**Comment:** The dollar amounts listed are the maximum billable rate and not the actual wage the worker receives. In addition, the waivers administered by the Office of Long Term Living (OLTL) have four wage and benefit ranges depending on geographic region. The waivers administered by the Office of Developmental Programs (ODP) have three wage and benefit ranges.\*

**Page 10. Applying for Family Caregiver Services in HCBS Waiver Programs**

**Comment:** Clarification for the second paragraph under this heading – PPL acts as the vendor fiscal/employer agent between the caregiver and recipient only when the recipient chooses the participant-directed model of service whereby the caregiver is employed by the recipient. If the caregiver is employed by an agency, PPL is not involved. Also, PPL processes the applications and payroll for all participant-employed workers, not just those who are family members of the recipient.\*

**Page 11. Rates for Direct Care Workers with Home and Community Based Services Waivers (chart)**

**Comment:** The dollar amounts listed are the maximum billable rate. The chart heading could be interpreted to mean the dollar amounts are the actual wage the worker receives.

**Page 11 - "As Table 1 shows, direct service rates for participant-directed services, both personal assistance services and respite services, vary among four regions in Pennsylvania. For the waiver programs under the Office of Developmental Programs, caregivers are paid the Region 2 rate for all participants".**

**Comment:** ODP does not use the Region 2 rate for all participants. ODP uses three regions. The current regions and wage ranges for VF/EA can be found at [http://documents.odpconsulting.net/alfresco/d/d/workspace/SpacesStore/dc26bf8b-3ee4-4036-b7df-5e8a9cb08559/VF EA Wage and Benefit Ranges Informational Packet 039-14.pdf](http://documents.odpconsulting.net/alfresco/d/d/workspace/SpacesStore/dc26bf8b-3ee4-4036-b7df-5e8a9cb08559/VF_EA_Wage_and_Benefit_Ranges_Informational_Packet_039-14.pdf) \*

**Page 19 – "To be eligible, a person must be age three or older, have a diagnosis of mental retardation, require active treatment, be recommended for an intermediate care facility/mental retardation level of care based on a medical evaluation, determined eligible for medical assistance, \$2,000 resource limit (does not apply to dependent children under age 21), income limit 300 percent of the Federal Benefit Rate."**

**Comment:** Please replace the phrase "mental retardation" with "intellectual disability." The ODP waivers actually state the following "People with a diagnosis of mental retardation (now referred to as intellectual disability), as defined in the current ODP policy bulletin regarding individual eligibility for Medicaid waiver services." \*

**Page 19 – "The program also has an individual cost limit of \$26,000 per person per fiscal year (excluding supports coordination)."**

**Comment:** The individual cost limit in the P/FDS Waiver is \$30,000.\*

**Page 20 – "Available services include assistive technology, behavior support, companion, education support, home accessibility adaptations, home and community habilitation (unlicensed), homemaker/chore, licensed day habilitation, nursing, prevocational, respite, specialized supplies, supported employment, supports broker, supports coordination, therapy (physical, occupational, visual/mobility, behavioral and speech and language), transitional work, transportation, unlicensed residential habilitation, vehicle accessibility adaptations."**

**Comment:** Unlicensed residential habilitation is no longer an available service in the P/FDS Waiver and should be removed. \*

**Page 21, "Summary of HCBS Waiver Provisions that allow Paid Family Caregivers"**

**Comment:** Unlicensed residential habilitation is no longer an available service in the P/FDS Waiver.\*

**Revised Content (page 21 Adult Autism Waiver)\***

To be eligible for the Adult Autism Waiver, a person must be age 21 or older, a U.S. citizen or qualified alien, a resident of Pennsylvania at the time of enrollment, and meet certain diagnostic, functional and financial eligibility criteria (listed below). Priority is given to people not already receiving state-funded, or state and federally-funded, home and community-based services.

**Diagnostic Criteria:**

*Please note: This information reflects the diagnostic categories prior to changes in the DSM-5. Anyone diagnosed with a pervasive developmental disorder from DSM-IV should still meet the criteria for ASD in DSM-5.*

- Must have a diagnosis of an autism spectrum disorder, ASD, which includes:
  - Autistic Disorder
  - Pervasive Development Disorder, Not Otherwise specified (PDD-NOS)
  - Asperger Syndrome
  - Childhood Disintegrative Disorder
  - Retts Disorder

**Functional Eligibility:**

- Must have substantial functional limitations in three or more of the major life activities listed below:
  - self-care
  - understanding and use of receptive and expressive language
  - learning
  - mobility
  - self-direction
  - capacity for independent living

**Financial Eligibility:**

- If the applicant has met all other eligibility criteria, including functional eligibility, the final step in the application process is for the County Assistance Office (CAO) to determine financial eligibility. All waiver programs within the Commonwealth require individuals to meet certain financial eligibility criteria.
- The individual must meet the income and resource limits for Medical Assistance and Payment of Long Term Care Services. AAW financial eligibility is based on 300 percent of the Federal Benefit Rate (FBR). More information on the Federal Benefit Rate can be found at [www.ssa.gov](http://www.ssa.gov).

\*LB&FC Note: Adjustments have been made to the final report to reflect these comments.

Mr. Phillip R. Durgin

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Currently, this waiver only offers agency-managed services; however, DHS is considering the addition of participant-directed services at a later date.

***Page 23 – “ODP operates two HCBS waivers, the Consolidated Waiver and the Person/Family Directed Supports Waiver.”***

**Comment:** ODP operates three HCBS waivers including the Adult Autism Waiver.\*

***Page 26. The Move Toward Participant-Directed Care.***

**Comment:** The information under this heading could be interpreted to mean that cash and counseling is synonymous with participant-directed care. More accurately, participant direction refers to a recipient serving as the employer of their caregivers, also referred to as “employer authority.” In cash and counseling the recipient exercises “budget authority,” managing a budget to purchase needed services and supplies. Recipients in the cash and counseling model may choose participant-direction (employing their own workers), or they may choose to use an agency that employs the workers.

***Page 28. New Rules for Home and Community-Based Settings. On January 16, 2014, CMS issued a final rule for home and community-based settings that may further promote participant-directed care.***

**Comment:** The final rule applies to all models of home and community-based waiver services, both participant-directed and those where the worker is employed by an agency. Implementation of the final rule is not expected to promote participant-directed care over agency model services.

Thank you for the opportunity to submit these comments. Should you need further information or have questions please contact Mr. Abdoul Barry, Director, Office of Legislative Affairs, at 717-783-2554.

Sincerely,



Theodore Dallas  
Secretary

\*LB&FC Note: Adjustments have been made to the final report to reflect these comments.