

## Report Highlights

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

House Resolution 241 calls on the LB&FC to conduct a study of the extent to which paid family caregivers can provide services in Pennsylvania's Home and Community-Based Services (HCBS) waiver programs. The report is also to identify any barriers to expanding paid family caregiving in HCBS waiver programs.

The study found:

- **Providing care for a chronically ill, disabled, or aged family member can place a major burden on the caregiver.** More than one in six Americans working full or part time report assisting with the care of an elderly or disabled family member or friend. The value of informal family 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.
- **Pennsylvania has established ten HCBS waiver programs.** The goal of these programs is to provide home and community-based services to Medicaid-eligible individuals who would otherwise require institutional services.
- **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.** Certain other family members, such as an adult child or the parent of an adult beneficiary, can be paid caregivers in many, but not all, of PA's HCBS waiver programs.
- **Legally responsible relatives, including spouses, can be paid for personal care services when such services are deemed as extraordinary care, but relatively few states allow this option.** 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. Several states, including Arizona, Colorado, and Oregon, allow for such payments. PA allows spouses to be paid for a limited number of services (e.g., home and community habilitation) in some of its waiver programs, but not to the extent of these other states.
- **Family caregivers in PA's HCBS waiver programs can 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.** Pennsylvania has three wage and benefit ranges depending on geographic area.
- **DHS collects only limited data on the extent to which paid family caregivers are used in PA's HCBS waiver programs, but the percentage of paid caregivers who are family members appears to range from 4% to 40%.** Of the five waiver programs operated through DHS's Office of Long-Term Living, an average of 40% (about 15,600 caregivers) were family caregivers as follows: 4% were siblings; 5% - parents; 15% - other relative (other than a spouse); and 16% were adult children of a beneficiary.
- **Some states (but not PA), have established 100% state-funded programs that allow legally responsible family members to be paid caregivers.** Twenty-one states have established state-funded programs that allow payments to family members to provide care to elderly or disabled relatives, including 12 states that allow payments to spouses and parents of minor children.
- **The use of paid family caregivers has raised concerns, particularly regarding the potential for fraud and abuse.** 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. CMS requires states to take steps to address these issues, but family members are the largest category of financial exploiters of the elderly, so the concerns are warranted.