

**Legislative Budget and Finance Committee**

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

**Report Presentation by Rick Jones and Anne Witkonis, at  
June 17, 2015, Meeting**

Good morning. My name is Rick Jones, and I am staff counsel to the Committee. With me today is Anne Witkonis, one of the Committee's analysts. We'll be presenting the findings on our report on paid family caregivers in Pennsylvania's Home and Community-Based waiver programs.

The Committee was directed to do this study by House Resolution 241 of 2014, which calls on us to 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, particularly to spouses, in these programs.

We found that more than one in six Americans working a full- or part-time job report assisting with the care of an elderly or disabled family member or friend and that providing care for a chronically ill, disabled, or aged family member can place a major burden on the caregiver. The value of such informal family caregiving was estimated at \$450 billion in 2011. But this care often comes at a substantial personal cost, 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.

To help with this burden and reduce the need for institutional services, federal regulations allow certain family members, such as an adult child or the parent of an adult beneficiary, to serve as paid caregivers in the Home and Community-Based waiver programs. Pennsylvania has ten such waivers, and family members are allowed to be paid for at least some of the services they provide under seven of the ten waivers.

However, federal regulations generally preclude “legally responsible” family members, such as a spouse or the parent of a minor child, from being paid for the services they provide. The rationale behind this prohibition is that legally responsible individuals should not be paid for supports that they would otherwise normally be obligated to provide.

Despite this general prohibition, the Centers for Medicare and Medicaid Services (CMS) does allow legally responsible individuals, including spouses, to be paid for providing “extraordinary care” if a state requests such a provision in an approved HCBS waiver. Several states, including Arizona, Colorado, and Oregon, allow for such payments. Pennsylvania allows spouses to be paid for a limited number of extraordinary care services (e.g., home and community habilitation and certain transportation services) in some of its waiver programs, but not to the extent of these other states.

The resolution also directs us to determine the extent to which family caregivers are used in Pennsylvania's HCBS waiver programs. The Department of Human Services only collects limited data on the family relationship status of paid caregivers. But data is available for five waiver programs, which shows that an average of 40 percent of the paid caregivers are family members, with 4 percent being siblings; 5 percent, parents; 16 percent, adult children of a beneficiary; and 15 percent being an "other" relative (but not a spouse).

The report makes no recommendations regarding the expanded use of family members, in part due to the federal restrictions on legally responsible family members serving as paid caregivers and in part due to other concerns, such as the increased risk for fraud and abuse. Family members often have access to financial and other personal data that would not generally be available to an agency-sponsored caregiver, and there may 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 as part of the waiver approval process, but family members are the largest category of financial exploiters of the elderly, so the concerns appear warranted.

Another concern is that paying family members to provide care can, in effect, trap the beneficiary in the home because this may be the only source of income for

the family. Also, it may be more difficult for the recipient to correct or, if necessary, fire a family member than it would be if the employee was working for an agency.

Thank you and we would be pleased to answer any questions you may have about the report.