Debunking Myths Related to Self-Directed Care

Self-direction, also referred to as consumer direction or participant direction, is a long-term care delivery model for Medicaid eligible individuals and their families that enables personal choice and control over the delivery of state plan care services.
A growing alternative to traditionally delivered home health agency provided care, self-direction provides participants, or their representatives, decision-making authority and direct responsibility to manage and direct their own care, in their own homes, with the assistance of a system of support. For example, participants can recruit, hire, train and supervise a caregiver they know and trust to provide their care services. Let's learn more to better understand self-direction.

Self-directed Care with PPL

Leveraging deep local roots and decades of work in state self-directed care programs across the nation, PPL currently

- Supports 49 self-directed care programs in 22 states
- Partners with 13 managed care organizations (MCOs)
- Serves more than 127,000 participant and caregiver relationships

MYTH #1: Self-directed care is new and untested.

FACT: Self-directed care was first offered by many states in the 1990s when the Robert Wood Johnson Foundation (RWJF) awarded grants to develop these "Self-Determination" programs in 19 states. These successful projects evolved further into Medicaid demonstration programs and in 2005, the Deficit Reduction Act (DRA) authorized two more avenues for states to offer a self-directed option. Finally, in 2010, the Affordable Care Act officially and broadly authorized self-directed services for Medicaid recipients.

MYTH #2: Self-direction is only for younger people with disabilities.

FACT: Self-direction serves all ages and across all disabilities. This includes children with developmental or intellectual disabilities, persons with physical disabilities, elder care, persons with mental health issues, care for veterans, and individuals with traumatic brain injuries. According to PPL data, approximately 50% of those self-directing care are over the age of 60.

MYTH #3: Self-direction is overwhelming for the participant as they must serve as the employer of record taking responsibility for the taxes, insurance, and liabilities of an employer.

FACT: There are two models by which participants can self-direct their care. The first, and most popular, is the Fiscal/Employer Agent (F/EA) model, where participants are considered the employer of record (EOR). The participant sets the parameters of their own care and selects a caregiver they trust. They then work with a Financial Management Service vendor (like PPL) that ensures all taxes, insurance and Medicaid required reporting is properly filed and correct payments are made or distributed.
The second is the Agency with Choice or Co-Employment model. With this model, a Home Health,

Personal Care, or other agency is the employer of record. The agency provides a care worker for the participant, who can set the schedule and outline the duties needed. The agency is responsible for paying federal, state, and local taxes and insurance.

MYTH #4: You have to have a family member willing to provide care to participate in self-direction.

FACT: While the role of family caregivers has been growing, along with the expansion of self-directed care models, it is not the only way self-directed care can be provided. Many participants choose to hire neighbors, friends, referrals from their church or local communities, or people they have met through posting an ad. The key to self-direction is empowering the participant to control their hiring choices so they receive care from someone they trust and select themselves.

MYTH #5: Self-direction was a product of the pandemic, and now that COVID risks are reduced, the number of people self-directing care will decline.

FACT: Self-direction has been steadily growing since its inception in the 1990s. In fact, according to the 2023 AARP Scorecard, the number of people self-directing their care has risen by 18% over enrollment in 2019. Today, more than 1.5 million individuals self-direct their care, and with more seniors preferring to age in place and more participants seeking control and increased trust in their caregiver, the number of participants self-directing their care are expected to grow.

MYTH #6: There is extensive fraud in self-direction. State Medicaid programs are paying for personal care that participants are not receiving.

FACT: While fraud is a concern with all health care services, data clearly debunks the myth that self-direction has a high level of fraud. In the initial Demonstration and Evaluation Project, and since the Demonstration ended, very little evidence of fraud was found in self-directed programs. This is because Financial Management Service providers, like PPL, employ local staff who engage with participants and caregivers and the vendors actively monitor to identify and prevent fraudulent activities.

MYTH #7: Self-directed care workers do not have to pay taxes on the money they make because they are caring for a family member.

FACT: Just as in any position of employment, the IRS requires self-directed direct care workers to pay federal, state, and local taxes. The only exclusion is outlined in a 2014 IRS notice that explains that the IRS treats certain payments for personal care services (including self-directed care services) as "Difficulty of Care payments." These payments are excluded from federal income taxes, but state and local taxes still apply. The exclusion only covers income earned through the provision of personal care services when the Medicaid client and the caregiver live in the same household. The Financial Management Services provider associated with your state program will help you navigate and understand all of the rules for federal, state and local taxes that apply to you.