

Long-Term Services & Supports Feasibility Policy Note

The Need for Long-Term Care Services and Supports: Implications of Informal Caregiving

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1. Introduction

The demand for long-term care services and supports is rising as the aging population in the United States increases. As of 2010, over 6 million individuals age 65 years and older needed long-term care. However, long-term care services and supports are expensive and most families across the United States cannot afford to pay out-of-pocket. In Hawaii, long-term care is even more expensive (Johnson and Uccello 2005; Johnson 2008; Baer and O'Brien 2010). The national average annual cost for a semi-private room in a nursing home is about \$80,000, whereas in the state of Hawaii, the annual price is over \$124,000. The annual cost for a home health aid across the United States is over \$45,000 (Genworth 2015). In addition, private insurance for long-term care is expensive and unavailable to many low- and moderate- income people (Johnson and Uccello 2005). Thus, many people rely on informal caregiving for help with activities of daily living (ADLs), such as eating, bathing, and using the toilet as well as instrumental activities of daily living (IADLs), including running errands, cooking, and housework (Johnson and Uccello 2005).

2. Informal Caregiving in Hawaii

In a 2012, the Hawaii Long-Term Care Commission (HLTCC) reported that caregivers in Hawaii spend 22 hours per week providing informal care, more than the equivalent of a half-time job. Without financial or government support for access to formal services, the financial and other costs of caregiving fall upon one or more family members of older, frail loved ones. In addition, without financial support to pay for services, care recipients struggle with the fear that they will become a burden on their family members in the event they should need long-term care (HLTCC 2012).

Like older people across the United States, elderly in Hawaii who need long-term care would prefer to receive care at home rather than move to an assisted living facility or nursing home (AARP 2012; HLTCC

2012). The scarcity of affordable alternatives to institutional services in Hawaii is troublesome for those who desire to remain at home into old age, especially for individuals with limited mobility (Bonner and Deerfield 2011). Many Hawaii residents age 50 years and older report that they do not want to depend on loved ones for informal care in the future, yet they do not plan for formal long-term care and say they believe that family and friends would provide care if need be (AARP 2012).

3. The Detrimental Impacts of Caregiving on the Caregiver

Research shows that caring for an older, disabled parent or parent-in-law is damaging for mental and physical health of the caregiver (Bauer and Sousa-Poza 2015). Specifically, providing regular assistance with ADLs and IADLs is linked with higher levels of psychological distress, or depressive symptoms, and worse physical health among individuals who provide care (Bauer and Sousa-Poza 2015; Kohl et al. 2015). Caregiving for an older parent with conditions related to cognitive and behavioral disorders, such as dementia and Alzheimer's disease, can be particularly distressing and leads to mental and physical health decline of the caregiver. In addition, informal caregiving also negatively affects caregiver's income, employment, and family life (Bauer and Sousa-Poza 2015).

To help understand why caregivers report higher levels of psychological distress compared to non-caregivers, caregiving is viewed as an experience of "chronic stress" (Schulz and Sherwood 2008). In this sense, chronic stress refers to a distressing and burdensome experience over time. Informal caregivers tend not to provide help in isolated incidents but rather care for elderly, disabled parents regularly and often over extended periods of time without compensation (Bauer and Sousa-Poza 2015; Schulz and Sherwood 2008).

The negative effects of caregiving on caregivers' mental health are further exacerbated by secondary stressors resulting from caregiving, resulting in increased levels of depressive symptoms (Bauer and Sousa-Poza 2015). Secondary stressors arise from primary stressors, such as caregiving (Pearlin 1989). For example, secondary stressors include but are not limited to disruptions in work and family relationships as a result of maintaining caregiving duties. The struggle to maintain multiple social roles, such as spouse and employee, while also being a caregiver, can lead to heightened levels of distress as certain roles are strained in the face of caregiving responsibilities (Bauer and Sousa-Poza 2015).

Caregiving is too often viewed as "women's work" (Bauer and Sousa-Poza 2015). Responsibilities to provide care frequently fall upon female family members, including wives and daughters, of older individuals who need assistance with ADLs and IADLs. Research has shown that caregiving harms the caregiver by negatively impacting mental health, physical health, family life, and employment. These negative impacts disproportionately affect female caregivers (Pavalko and Artis 1997).

Caregiving responsibilities may derail opportunities for employment among women who are actively looking for paid work, potentially damaging their careers and resulting in financial instability. Caregiving has been linked with lower household income among women (Lee et al. 2014). In addition, research has shown that as women begin caregiving duties, they are likely to have to reduce work hours or stop employment altogether (Pavalko and Artis 1997). Though females disproportionately provide care compared to males, both male and female employed caregivers whose caregiving

responsibilities require a high level of involvement, compared with caregivers who provide less hours of care, have worse emotional health (Lee, Walker, and Shoup 2001).

In addition, research has shown that the experience of the stress of caregiving is more complex among married couples (Amirkhanyan and Wolf 2006). Living arrangements and caregiving dynamics contribute to the impact of caregiving on family life (Bauer and Sousa-Poza 2015). For example, caring for an elderly parent who lives in the household affects the family's daily living with his/her presence (Bauer and Sousa-Poza 2015).

Previous research recognizes that caregiving is not only mentally stressful task but is also physically demanding (Bauer and Artis 1997). For example, caregiving requires physical effort in helping the care recipient move around and with activities such as bathing and putting on clothes. Caregiving for mentally impaired individuals who have behavioral problems or aggressive tendencies may be particularly physically stressful (Bauer and Sousa-Poza 2015). These and other issues help explain why caregiving may be more harmful for physical help among employed individuals who provide informal care.

Current research by the Hawaii Long-Term Supports and Services Feasibility Study finds that employed caregivers report having worse physical health compared to other caregivers who are not currently employed (Kohl et al. 2015.). Additional findings from this study offer insight into the impact of caregiving on caregivers' lives. The research also shows that caregiving negatively impacts physical health even after accounting for demographic and socioeconomic factors including income and wealth. In other words, caregiving harms physical health regardless of socioeconomic status (Kohl et al. 2015).

4. Consequences of the High Cost of Long-Term Care

Among those who do not have family members willing or able to provide informal care or who want to avoid burdening family members with caregiving duties, many people look for other ways to pay for long-term care. Many middle class families are forced to sell their homes and other assets to fund or plan for long-term care services (Spillman and Murtaugh 2007). Other individuals who qualify for public assistance programs impoverish themselves trying to pay for long-term care (Johnson and Uccello 2005; Johnson 2008; Baer and O'Brien 2010). Research has shown that reducing one's wealth to qualify for programs such as Medicaid and using home equity to finance long-term care are not sustainable (Spillman and Murtaugh 2007). In addition, the trend to sell one's assets, namely the home, has long-term financial consequences for middle class families. In the absence of affordable long-term care services and supports, family members and other loved ones take on the burdens of caregiving.

5. Conclusion

Most people cannot afford to pay for long-term care services and supports or private insurance out-of-pocket. As a result, people use their assets, including their homes, or individuals impoverish themselves to purchase long-term care (Johnson and Uccello 2005; Baer and O'Brien 2010; Spillman and Murtaugh 2007). Alternatively, those in need rely on informal caregiving provided by family members who are willing. However, caregiving involves emotional, physical health, and financial costs. Numerous studies have established the detrimental impact of informal caregiving on caregivers'

mental and physical health and other aspects of caregivers' lives. The physical and mental health costs of caregiving can diminish the caregiver's capacity to provide care, resulting in lower quality care and even higher demand for professional services (Bauer and Sousa-Poza 2015). The increasing need for formal long-term care services and supports and the harmful consequences of informal caregiving demonstrate the need for more affordable long-term care.

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