



Position statement: Policies to support family caregivers



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Background

In 2013, an estimated 40 million family caregivers provided an average of 18 hours of care per week, reflecting approximately \$470 billion in unpaid caregiving contributions (Reinhard, Feinberg, Choula, & Houser, 2015). Projected demographic shifts in the U.S., including the rapidly aging population (World Health Organization, 2015) and increase of individuals living with chronic conditions across the lifespan (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, 2011; Houtrow, Larson, Olson, Newacheck, & Halfon, 2014), will increase the demand for family caregivers. Family caregivers can be defined by the patient or, in the case of minors and those without decision-making capacity, by their surrogates. Therefore, a family member may be someone related or unrelated to the patient (Britton, 2004).

The complexity of the care that family caregivers provide has increased (Furstenberg, Hartnett, Kohli, & Zissimopoulos, 2015). Approximately 50% of family caregivers report completing complex nursing and medical tasks (including wound care, administering medica-

tions, managing dietary needs, etc.) and coordinating care (Reinhard et al., 2015; Reinhard, Levine, & Samis, 2012; Spillman, Wolff, Freedman, & Kasper, 2014). Despite performing these highly skilled tasks, 66% of family caregivers report receiving no home visits from a healthcare professional in the past year (Reinhard et al., 2012).

Many also have competing work responsibilities as approximately 60% of family caregivers are employed (Koenig, Trawinski, & Costle, 2015). Many family caregivers decrease their work hours or leave the workforce entirely (Feinberg & Choula, 2012), and workers who provide intensive caregiving (more than 21 hours per week) are more likely to consider early retirement or to quit working (National Alliance for Caregiving and AARP Public Policy Institute, 2014). Individuals who leave the workforce early to care for a loved one experience an estimated \$303,880 income loss (MetLife Mature Market Institute, 2011). Working family caregivers state they have limited access to flexible work hours and low job security (Pitt-Catsouphes, Matz-Costa, & Besen, 2009). The economic consequences of caregiving also affect employers. American businesses experience \$28 billion in lost productivity and absenteeism among working family caregivers (MetLife Mature Market Institute, 2010; Witters, 2011).

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There is increasing recognition that certain populations are disproportionately affected by the demands of caregiving. These populations include, but are not limited to, older adult, female, child, lesbian, gay, bisexual and transgender (LGBT), and racial and ethnic minority caregivers. An estimated 40% of family caregivers are over the age of 50 (National Alliance for Caregiving and AARP Public Policy Institute, 2014) and older workers, particularly women, represent a greater proportion of the U.S. workforce than ever before (Copeland, 2014). Thus, their income is increasingly important to family wellbeing and to the economy (Reinhard, Feinberg, & Choula, 2011; Spillman et al., 2014). Working women, who provide care to family members at higher rates than men, may be more likely to retire early due to caregiving responsibilities (Jacobs, Van Houtven, Laporte, & Coyte, 2015) and less likely to manage their own health needs when providing care for others (The Commonwealth Fund, 1999).

There are 11.2 million children with special health-care needs in the U.S. (U.S. Department of Health and Human Services, 2013). Several factors appear to impact stress of caregivers of children living with a disability including the child's mental health, quality of life, and extent of disability. Caregiving stress has been associated with changes in the psychological and physical health of parents (Wiener et al, 2016). In every state the poverty rate is higher among families with members with a disability (Crosier et al, 2007; Weiner et al, 2014). In addition, not only do children receive caregiver support but children also have emerged as caregivers. There are 1.4 million children ages 8–18 in the U.S. that provide care to a family member (National Alliance for Caregiving; Caring for a Child, 2009). This is a growing trend in need of further attention.

The importance of cultural norms and beliefs cannot be ignored (Pharr, Dodge Francis, Terry, & Clark, 2014). Racial and ethnic minority older adults are the fastest growing segment of the U.S. population. In a population-based study of 7,433 older adults, 44% of Latinos and 34% of Blacks reported receiving care from a family caregiver in the home compared to only 25% of non-Hispanic Whites (Weiss, Gonzyz, Kabeto, & Langa, 2005). Since elderly Latina and Black women experience the highest rates of poverty (40.8% and 30.7%, respectively), they are less likely to pay for formal in-home caregivers for their loved ones (Administration on Aging, 2015).

Approximately 1 in 9 caregivers identify as LGBT (National Alliance for Caregiving and AARP Public Policy Institute, 2014), however, little is known about the needs of LGBT caregivers (National Academy of Medicine, 2016). A growing body of research indicates that LGBT older adults, in particular, are more likely to need long-term care services (Hiedemann & Brodoff, 2013), particularly institutionalized care (Henning-Smith, Gonzales, & Shippee, 2015). LGBT older adults are at higher risk of needing assistance with activities of daily living related to disability (Fredriksen-Goldsen, Kim, & Emler, 2011; Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013; Hiedemann & Brodoff, 2013; Wallace, Cochran,

Durazo, & Ford, 2011) and have greater reliance on formal caregivers, rather than family or friends (Henning-Smith et al., 2015). These factors create unique challenges for LGBT caregivers and care recipients.

Despite the complexities of caregiving many family caregivers express satisfaction in their roles. However, many also are vulnerable to negative health outcomes. Approximately 88% of middle-income and middle-aged family caregivers state that caregiving is more emotionally taxing and time-consuming than expected (Center for Secure Retirement, 2013). Caregiving is particularly stressful for family caregivers who report they do not have adequate training or help to carry out caregiving responsibilities (Institute of Medicine, 2014). Negative consequences of caregiving may include exhaustion, too many responsibilities, and having little respite time (Spillman et al., 2014). Family caregivers experience negative financial consequences, poor physical and emotional health, and limited social networks (Feinberg, Reinhard, Houser, & Choula, 2011). In addition, family caregivers often have inadequate access to resources and their health needs receive little attention from healthcare professionals, payers, and policy makers (Mintz, 2014). Therefore, more than 30% of family caregivers rate their own health as fair or poor (Reinhard et al., 2012). Family caregivers who describe their caregiving experiences as negative are more likely to have depression, anxiety, and physical symptoms, including pain, sleep problems, and fatigue (Spillman et al., 2014).

Policy Initiatives

Paid Leave

Currently only California, Rhode Island, and New Jersey have laws providing paid family leave (PFL) for employees who need time off to care for sick or disabled family members (National Partnership for Women & Families, 2016). New York State launched a paid leave program in January 2018. These PFL programs allow individuals to care for a seriously ill family member or to bond with a minor child following birth, adoption, or foster care placement. PFL programs require employers with five or more employees who are hired to work 80 hours or more annually to provide paid leave, while employers with less than five employees must provide unpaid sick leave. PFL programs currently provide coverage for 14% of the workforce in the U.S. (U.S. Department of Labor Bureau of Labor Statistics, 2015). Significant income and racial disparities exist regarding access to PFL. Workers in the highest income quartile are more likely to have access to PFL, while racial and ethnic minorities are also less likely to have access compared to non-Hispanic Whites (Glynn & Farrell, 2012). Employers report improvements in productivity, profitability, employee retention, and employee

morale (Appelbaum & Milkman, 2013; Legal Services of New Jersey, 2014). Additional states have convened task forces to examine options for enacting PFL that allow employees to engage in caregiving without compromising business sustainability.

The CARE Act

The state Caregiver Advise, Record, Enable (CARE) Act ensures family caregivers receive training and education on providing medical and nursing needs for family members upon hospital discharge. The CARE Act is based on research spearheaded by Dr. Susan Reinhard at the AARP Public Policy Institute and Center to Champion Nursing in America. At the time this position statement was written, 39 states had enacted the CARE Act. Several organizations have designed toolkits to assist with implementation of the CARE Act. Additional toolkits have been created to establish a formal process for hospitals to meet CARE Act requirements (United Hospital Fund, 2017). As the CARE Act is enacted across the U.S., initiatives such as AARP's "I Heart Caregivers" campaign provide visibility, resources, and support to family caregivers.

RAISE Family Caregivers Act

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act was introduced as bipartisan legislation in the U.S. Senate in 2015 (115th Congress, 2017–2018, passed by Congress in December 2017, and signed into law by the president in January 2018). The purpose of the RAISE Family Caregivers Act is to: 1) establish a National Family Caregiving Strategy directive and 2) create a Family Caregiving Advisory Council that will assist the U.S. Department of Health and Human Services recognize and support the needs of family caregivers. The U.S. Department of Health and Human Services has 18 months to develop an initial strategy.

Recommendations

- Local and state governments should partner with researchers and policymakers to launch demonstration projects of PFL programs in their jurisdictions to produce economic impact studies including the short-term financial impact on employers, family caregivers, care recipients, and community stakeholders.
- Researchers should examine family caregiving that includes demographic and clinical characteristics of caregivers and patients, type of care provided, and interventions for family caregivers, particularly among vulnerable populations.
- State and federal governments need to invest in supporting research dedicated to examining interventions for family caregivers, particularly among vulnerable populations.

- States should establish reporting requirements of outcome measures related to the CARE Act.
- Healthcare organizations, healthcare professionals, and consumer groups should urge policymakers to appoint to the National Family Caregiving Strategy and Family Caregiving Advisory Council experts from across disciplines and integrate expertise in research, practice, and policy.
- Nurses and other healthcare professionals need to partner with hospital administration, patients, and their families to urge for the development of standards and training for engaging family caregivers and assessing their needs.

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