



FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

RECOMMENDATIONS ON Family Caregivers

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INTRODUCTION

In California, there are over 5.88 million family caregivers providing unpaid care to a loved one. These family caregivers – unpaid relatives, partners and friends – form the largest long-term care workforce in the country. In California alone, it is estimated that family caregivers provide \$47 billion dollars of unpaid annual care services.ⁱ

Today's family caregiver is part social worker, part nurse, part financial manager, part household handy-person and all wife, partner, daughter, daughter-in-law, sister or grandchild. As a society we are living longer with more complicated chronic conditions and as a result, today's caregiving is well beyond Activities of Daily Living (ADL's) and Independent Activities of Daily Living (IADL's). **Almost half (46%) of family caregivers perform medical tasks normally associated as "nurse delegated" functions, typically with little training from health and social service systems.**ⁱⁱ

Well over half (56%) of the 5.88 million family caregivers in California are part of the Baby Boomer generation, between the ages of 45 and 64. For these mostly adult children, caregiving is a juggling act among their careers, families, and parents. Almost two-thirds (64%) are holding down full-time (55%) or part-time (9%) employment, in addition to providing an average of 15 to 20 hours a week of assistance to an older adult.

Three-quarters of California caregivers are women – meaning there are roughly 4.4 million women in California trying to successfully manage this juggling act. These women are more likely to step out of the workforce to provide care. Providing this care is not without costs, as family caregivers suffer significant physical, mental and financial consequences due to the toll of caregiving.

Many family caregivers provide care at the expense of their own health. They experience chronic stress, especially those caring for an adult with multiple chronic care conditions, or cognitive impairment such as Alzheimer's disease and related dementias. This chronic stress is associated with a variety of adverse health effects – including depression, anxiety, obesity, substance abuse, and sleep disturbance. Between 40 and 70% of caregivers have clinically significant symptoms of depression, and **women who provide care are six times as likely to suffer from depression or anxiety.**ⁱⁱⁱ

Family caregivers often sacrifice their financial resources to provide care, and frequently reduce their work hours to be with their loved one. One-third of working women report that they have decreased their work hours, passed up a promotion or training (29%), switched from full-time to part-time (20%), or quit their job entirely (16%). **For those who significantly reduce their work hours or leave the workforce to provide care, the financial impact can exceed \$300,000 over their lifetime.** One study found that nearly half of Baby Boomer women caregivers experienced financial hardship as a result of caregiving.

POLICY OBJECTIVE #1

The Legislature and the Governor should enact state legislation to integrate family caregivers into health and social service programs across state departments.

Background

Family caregivers are the backbone of the long-term services and support system for the state. However, they are largely overlooked in terms of provision of explicit direct services for caregivers, and are not fully recognized nor integrated within the health and social service system.

Moving toward integration requires adoption of performance measures that improve outcomes for both the client and the family. In turn, these performance measures will require modifying current clinical practice within service settings. These measures must be consistent across programs in order to provide meaningful information that supports providers and clinicians and drives improvement on quality of services.

Identification and assessment of family caregivers, using a uniform set of measures, is the starting point for integration. It is an opportune time to include a caregiver assessment measure as the state recognizes the need for a uniform assessment instrument for all long-term services and supports (LTSS) that span state departments and programs. This would include programs funded through MediCal waivers, Older Americans Act, general revenue and other federal and state funded LTSS programs.

Currently, there are no family caregiver assessment measures in the In Home Supportive Services, Multipurpose Services Senior Program, Adult Day Health Care in any of the Client Assessment Instruments used within those programs. While the Caregiver Resource Centers (CA Department of Health Care Services) have operated with a uniform caregiver assessment tool since 1987, there is no uniform caregiver assessment instrument in the National Family Caregiver Support Program, Title III E, Older Americans Act (CA Department on Aging).

In a current study underway by the Public Policy Institute, AARP and Family Caregiver Alliance entitled “National Inventory of Assessment Instruments and Process for Informal Caregivers within Home and Community Based Service Medicaid Waiver Programs”, there are 12 states that include an assessment of the informal caregiver within their client assessment instrument. In reviewing states that have successfully integrated family caregivers within service systems, several key factors have emerged:

- A common understanding of and support for family caregivers by leadership in government administration, community health and social service providers.
- Integration of departments that provide services to adults with chronic care conditions through an electronic client record system, common assessment, and protocols for seamless referrals across programs.
- A uniform caregiver assessment instrument that is used to determine need for services or supports and referrals to other departments or programs and also provides information about level of support provided by the family caregiver.
- Ability to analyze the client and caregiver data to determine outcomes improvement on measures of caregiver capacity to care or well-being, cost savings or background characteristics of family care systems.

Recommended Actions

If a care plan relies on informal support provided by families and others, then an assessment of the caregivers' needs should be conducted and services provided to sustain care their efforts and promote their well-being.

- A. The Legislature should request that the California Research Bureau:
- Undertake a study to assess uniform caregiver assessment measures in other states.
 - Develop a report for the Legislature by January 2014 that highlights common uniform caregiver assessment measures, identifies the cost of development and implementation, and reports on the outcomes of caregiver assessment within the care plans.
- B. The Legislature should pass and the Governor should sign legislation that:
- Requires the Health and Human Services Agency to review the California Research Bureau report (identified above) and develop a uniform caregiver assessment tool by January 1, 2015, to be incorporated into required client eligibility and assessment instruments used in MediCal waiver services (In Home Supportive Services, Multipurpose Services Senior Program, Community Based Adult Services) and in the Coordinated Care Initiative.. This assessment information should be part of the client record, and the Health and Human Services Agency should develop protocols for care planning and provision or referral of caregivers to appropriate services within the community.
 - Requires a uniform assessment be used with direct caregiver support programs (Title IIIIE, National Family Caregiver Support Program; Caregiver Resource Centers) that indicate priority needs of the family caregiver, tailored responses for the care plan and outcomes of the interventions provided
 - Mandates the inclusion of consumer representatives – such as family caregivers and advocate groups representing family caregivers – on all public task forces, advisory committees and workgroups across departments concerning health care and long-term service and support programs.

POLICY OBJECTIVE #2

The Legislature and the Governor should augment the budget for the Caregiver Resource Centers to increase the level of services and support for families in the state.

Background

The California Caregiver Resource Centers (CRCs) were established in 1984 to provide high quality services to support family caregivers, ages 18 and over, of persons with adult-onset cognitive impairments across the state and without regard to income. The CRCs use a uniform caregiver assessment to tailor consultation, training and other services to the specific needs of the family.

Currently, California budgets \$2.9 million general fund dollars for the maintenance of the Caregiver Resource Centers, down from \$12 million in 2007. In addition, there is \$15.4 million in federal dollars through the National Family Caregiver Support Program (Title IIIIE, Older Americans Act) administered by the Area Agencies on Aging. California's total annual investment in direct support services for family caregivers have decreased exactly as the need has increased in the state. **We need to better support those who provide the majority of care in our state, especially when the growth rate for those over 65 is expected to be 15% in the next five years. With the shift to a rapidly aging population, the number of family caregivers is also expected to rise.**

Recommended Actions

- A. The Legislature should convene an informational hearing on the Caregiver Resource Centers that:
- Reviews the services they currently provide, as well as the services they previously provided before budget cuts.
 - Includes testimony from Caregiver Resource Center administrators, staff and caregivers that utilize the services.
 - Assesses the funding that would be needed to restore previously eliminated services.
- B. The Legislature should pass and the Governor should sign a bill that:
- Institutes a gradual increase in general fund dollars to provide a minimum combined total of \$27 million to support caregiving families of older adults in the state.

About the Family Caregiver Alliance



FAMILY CAREGIVER ALLIANCE®

FCA is nationally recognized for its pioneering programs and research to support family caregivers. ***FCA's mission is to improve the quality of life for caregivers through services, education, advocacy and research.*** As the Bay Area Caregiver Resource Center, FCA provides a range of caregiver support services. The National Center on Caregiving (NCC), supports the development of high-quality, cost-effective policies and programs for caregivers across the states. Current national projects relevant to this policy paper relate to various aspects of caregiver assessment. More information can be found on the website: www.caregiver.org or by calling 800-445-8106.

END NOTES

ⁱ Public Policy Institute, AARP, "Valuing the Invaluable: The Growing Contributions and Costs of Family Caregiving" 2011 Update, accessed January 9, 2013, <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>

ⁱⁱ Public Policy Institute, AARP; United Hospital Fund, "Home Alone: Family Caregivers Providing Complex Chronic Care", accessed January 9, 2012, <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>

ⁱⁱⁱ Family Caregiver Alliance Fact Sheet. "Women and Caregiving: Facts and Figures", accessed January 4, 2013, http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892