A Policy Framework to Support California’s Family Caregivers

For information:

Kathleen Kelly, MPA
Executive Director

Family Caregiver Alliance
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434-3388
www.caregiver.org

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This California Family Caregiver Policy Framework is a set of principles and values that should guide public policy development and implementation. This framework provides a way to gauge the extent to which public policies support California’s 3.4 million family caregivers.

Definitions

**Care Receivers** are individuals with adult-onset long-term disability or illness, who need ongoing or intermittent assistance with everyday tasks to function and may or may not live with the family caregiver. Persons who receive care may receive all or part of their care from family caregivers, or may receive care from others. In keeping with the federal Olmstead decision, care receivers must be assured appropriate access to services and choice, including the option to remain in the community and avoid unnecessary institutionalization.

**Family caregivers** include unpaid friends, relatives, spouses, partners or neighbors who are involved in caregiving for an adult who needs help with every day tasks to function. This interpersonal relationship may involve multiple caregivers or more than one person receiving care.

**Caregiving** may include accessing, arranging and coordinating hands-on personal care, emotional and financial support, managing medical care and other care, transportation, shopping, cleaning, and decision making about health, financial, personal and legal matters. This care may be full or part time and may be shared between family caregivers.

**Public Policy** includes the laws, regulations, practices, and procedures that shape the ways care and services are interpreted, delivered, paid for, monitored and evaluated. (Levine, *Ethical Framework*)

**Policymakers** include elected and appointed officials, agency staff who implement policy at the state and local levels, and managers in private organizations that contract with government agencies to administer public programs. (Levine, *Ethical Framework*)

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California’s Family Caregivers and Public Policy

Families have long assumed obligations to care for each other in times of illness and frailty and will always play a predominant role in providing care. (Levine, Ethical Framework) Society places great value on supportive family relationships as a foundation upon which to build stable communities. This framework is intended to highlight the essential role played by family caregivers and to advocate for consideration of this role when crafting public policy.

Nearly eighty percent (80%) of all care to Californians 18 years of age or older is provided by family caregivers. Thirty-one percent (31%) of caregivers are also still responsible for raising children under the age of 18. Seventy-five percent (75%) of family caregivers are women. Caregivers average 51 years of age, usually at the peak of one’s earning potential. Fully one-half of family caregivers are employed outside the home, often needing to make adjustments in the hours they work, find different jobs that will accommodate their caregiver responsibilities, or make other difficult workplace or career compromises. The economic value of informal caregiving in the state is estimated at 45 billion dollars.

Public policies that support family caregiving must acknowledge and respect the significant societal and economic value provided by family caregivers, and enable families to continue to provide care. Offering support to family caregivers can enable caregivers to continue to provide care, work as long as possible outside the home to maintain the family’s financial security, postpone or avoid unnecessary institutionalization of the care receiver, and prevent caregivers themselves from becoming recipients of care.

However, public policy cannot automatically assume that family caregiving can or should be continued in every instance. Care receivers may choose not to receive care from family members or families may not always be available, in a position to or should not provide care. Families who provide care do not have unlimited physical, emotional or financial resources.

Most people prefer to receive care in home and community settings and be as independent as is possible. Support for family caregivers will help to ensure that care provided is safe for both the person receiving care and the family caregiver.

Family caregiving must be viewed as a workable choice by both family caregivers and care receivers, not as an irrevocable duty. Policymakers must continually examine the extent to which policies support family caregiving and understand the impact of policies on family caregivers. Care must be taken so that policies do not inadvertently treat family caregivers as unconditional and limitless “resources”, to the potential detriment of family caregiver or care receiver’s well-being.
Public Policy Framework to Support California Family Caregivers

Basic principles necessary for public policy to support California Family Caregivers are:

**Principle 1:** Public policy must formally acknowledge, value, and respect family caregivers as essential components of the community-based care system.

**Principle 2:** Public policy must recognize that many family caregivers need support.

**Principle 3:** Public policy must provide family caregivers with a voice and a choice in decisions that both affect them and the care receiver.

**Principle 4:** Public policy must ensure that supportive services are adequate, available, affordable, equitable, effective and accountable.
**Principle 1:**

Public policy must formally acknowledge, value, and respect family caregivers.

Public policy must:

a. Include consideration of the impact on family caregivers. Policies must be analyzed or evaluated to avoid shifting responsibility onto family caregivers without commensurate supports or compensation.

b. Reflect the value and respect the contributions of family caregiving. Policies should strengthen the relationships between family caregivers and those who receive care and preserve the intimacy, privacy, confidentiality and decision-making that takes place in the family setting.

c. Recognize that family caregivers have a choice in providing care. Policies must serve to support family caregivers as they balance their desire to provide care with their need to maintain their own physical, mental and social well-being.

**Principle 2:**

Public policy must recognize that many family caregivers need support.

Public policy must:

a. Include a consistent way to assess and measure the needs and choices of family caregivers and care receivers. Care receivers and family caregivers will have different needs, depending on their personal preferences, their cognitive, physical and behavioral capabilities, and their systems of support. Family caregivers have the right to consideration of their own needs and well-being.

b. Offer flexible support that complements the changing nature of caregiving. The needs, preferences and abilities of family caregivers and care receivers will change over time. Policies must be able to recognize and accommodate changes in the level, frequency and intensity of care required and provided.

c. Include mechanisms to identify and intervene in situations that could be potentially exploitive or abusive for either the family caregiver or person receiving care.

d. Reflect the diversity of California's family caregivers. Age, gender, cultural identity, sexual orientation and other individual identifying characteristics may change the types of supports that are appropriate for and acceptable to both the family caregiver and care receiver.
**Principle 3:**

Public policy must provide family caregivers with a voice and a choice in decisions that both affect them and the care receiver.

Public policy must:

a. Permit family caregivers to act as advocates for care receivers who cannot act on their own behalf. (Levine, *Ethical Framework*)

b. Make readily available information and options to help family caregivers secure the resources, assistive technology, and services necessary to provide care.

c. Make it possible for family caregivers to make informed choices about their ability and willingness to provide care of different kinds. (Levine, *Ethical Framework*)

d. Accommodate conflict resolution between family caregivers, care receivers, providers and professionals about the setting, goals, and approach to the provision of care. (Levine, *Ethical Framework*)

**Principle 4:**

Public policy must ensure that supportive services are adequate, available, affordable, equitable, effective and accountable.

Public policy must:

a. Be fair, based on defined criteria and balance the needs of urban, suburban and rural family caregivers of all socioeconomic circumstances, and recognize the particular features and needs of each. (Levine, *Ethical Framework*)

b. Result in more affordable, readily available, coordinated and quality supportive services. (National Alliance for Caregiving)

c. Result in the ability to identify unmet needs, work to fill gaps, expand capacity, avoid unnecessary duplication of effort, prevent displacement of services, and work to eliminate funding or programmatic fragmentation or isolation.

d. Collect data to determine program and service costs and benefits, measure outcomes, identify changes needed, promote evidence-based best practices, and plan for the future.

e. Include periodic and effective periodic oversight to ensure that systems of care are held to ethical and operational standards and that they meet the purpose for which they were designed.
References and Suggested Reading


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Gartia Bansah, Project Coordinator
Adult and Older Adult Program Policy
California Department of Mental Health

Donna Benton, PhD, Director
Los Angeles Caregiver Resource Center

Donna Calame, Director
San Francisco In-Home Supportive Services Authority

Judy Citko, J.D., Executive Director
Coalition for Compassionate Care

Ann Collentine
Adult and Older Adult Program Policy
California Department of Mental Health

Lynn Daucher, Director
California Department of Aging

Lynn Friss Feinberg, M.S.W.,
Deputy Director
National Center on Caregiving
Family Caregiver Alliance

Mark Helmar, Deputy Director
Office of Long-term Care
California Department of Health Services
A Policy Framework to Support California’s Family Caregivers

Dee Lemonds
Adult and Older Adult Program Policy
California Department of Mental Health

Allison Ruff, Principle Consultant
California Assembly Committee on Aging
and Long-Term Care

Carol Levine, Director
Families and Health Care Project
United Hospital Fund of New York

Andrew Scharlach, PhD, Professor
School of Social Welfare
University of California, Berkeley

Robert MacLaughlin, Consultant
California Senate Subcommittee on Aging
and Long-Term Care

Terri Thorfinnson, J.D., Director
Office of Women’s Health
California Department of Health Services

Stephen W. Mayberg, PhD, Director
California Department of Mental Health

F. Burns Vick, J.D.
Public Policy Consultant

Janet Morris, J.D.
Long-Term Care Project Director
Bet Tzedek

Joel Weeden, Aging Program Specialist
Title III-E Family Caregiver Support Program
California Department of Aging

Cheryl Phillips, M.D.
Sutter Health

Daniel Wikler, PhD
Harvard School of Public Health

Kate O’Malley, R.N.
California HealthCare Foundation

Kathleen Wilber, PhD
Mary Pickford Foundation Professor of Gerontology
Andrus Gerontology Center
University of Southern California

Susan Poor
Health Care Policy, Planning and Organizational Consulting

Staff and Consultants

Kathleen Kelly, M.P.A., Executive Director
Ethan Moore, Research Assistant
Carol Van Steenberg, Consultant
Family Caregiver Alliance

Brenda G. Klutz
Public Policy Consultant