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**Q1 Issue Statement:** [State the problem your recommendation will address. Insert links to reports where appropriate.]

Unpaid family members and friends comprise the largest segment of the workforce providing long-term services and supports to older and disabled adults. The estimated 4.7 million-strong unpaid workforce is the backbone of the long-term care system in California. Unpaid caregivers provide an estimated \$58 billion in caregiving services each year. The majority of today's caregivers are also employed, in addition to the uncompensated labor they provide to family members and friends.

Several studies suggest that caregivers feel unprepared for the tasks involved in care, lack information about caregiver services, feel stressed and/or depressed, and have difficulty navigating the system when trying to assist the care receiver. For many, providing care and support to family members with adult-onset cognitive impairment has severe consequences on the caregivers' health and well-being. Many caregivers report deficits in feelings of competency to handle physical and behavioral tasks for the care recipient. Approximately 50% of caregivers help with medical tasks in the home. The most common tasks include medication management, help with assistive devices, preparation of food for special diets and wound care.

Without proper comprehensive caregiver support, family caregivers suffer from stress, social isolation, and clinical depression; chronic illnesses (e.g. diabetes, heart disease, hypertension) are exacerbated due to caregiver burnout.

Expansion of state-funded integrated caregiver support services in Washington State led to a significant delay in nursing home placement, reduced Medicaid claims for LTSS, and reduced re-admissions for 5 DRG's. Overall, investment in caregiver programs benefit caregivers and the state budget.

Recent surveys of CA voters show overwhelming support for comprehensive caregiver support programs that address the need for resources and training. However, there are two persistent problems that make it difficult for caregivers to receive services:

- Low awareness of caregiver specific programs in CA
- Lack of self identification by family caregivers

California is set to see a rapid increase in older adults over the next decade when 20 percent of the population will be over age 65. This population – and their family caregivers - will be more diverse and younger than at any other time in CA history. Half of all older adults over 65 years living in the community have difficulty carrying out daily living activities. Two-thirds of these individuals receive assistance with these activities solely from family caregivers.

One-in-four of all caregivers is a millennial, born between 1980 and 1996. A report by Vega, W. A., Aranda, M. P., & Rodriguez, F. (2017) found that millennial caregivers accounted for almost one out of four caregivers for adults with any infirmity (24%) and one in six (15%) of all millennial caregivers assisted someone living with Alzheimer's or other dementia. This population is more likely to use the internet and social media to find information, transact business, schedule healthcare encounters and keep in touch with friends and family than are older caregivers.

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## Master Plan for Aging (MPA) Recommendation Form

**Q2** MPA Framework Goal #: [Check which goal/s this recommendation addresses. View MPA Framework document]

**Goal 1: Services & Supports. We will live where we choose as we age and have the help we and our families need to do so.**

**Q3** MPA Framework Objective #: [Check which objective/s this recommendation addresses. View MPA Framework document]

**Objective 1.2: Californians of all ages will be prepared for the challenges and rewards of caring for an aging loved-one, with access to the resources and support we need.**

**Q4** Recommendation: [Explain your recommendation in one to two sentences.]

Stabilize funding for Caregiver Resource Centers (CRCs) to increase and sustain awareness of family caregiver needs, and to ensure access to comprehensive evidence-based caregiver assessment and services.

**Q5** Target Population and Numbers: [Describe groups of Californians impacted by this recommendation, with numbers if available.]

There are an estimated 4.7 million unpaid caregivers comprising the backbone of the long-term care system in California. Unpaid family members and friends comprise the largest segment of the workforce providing long-term services and supports to older and disabled adults.

Half of all older adults over 65 years living in the community have difficulty carrying out daily living activities. Two-thirds of these individuals receive assistance with these activities solely from family caregivers.

Forty-six percent of caregivers of adults with multiple chronic physical and cognitive conditions report assisting with medical tasks.

Over 80% of caregivers indicate they need more information on caregiving-related topics.

A University of Pittsburgh Health Policy Institute analysis in 2017 showed that integrating family caregivers in the discharge process resulted in a 25% decrease in hospital readmissions.

California is set to see a rapid increase in older adults over the next decade, when 20 percent of the population will be over age 65. This population – and their family caregivers - will be more diverse and younger than at any other time in CA history. The majority of today's caregivers are also employed.

A report by Vega, W. A., Aranda, M. P., & Rodriguez, F. (2017) found that millennial caregivers accounted for almost one out of four caregivers for those with any infirmity (24%) and one in six (15%) of all millennial caregivers assisted someone living with Alzheimer's or other dementia. This population is more likely to use the internet and social media to find information, transact business, schedule healthcare encounters and keep in touch with friends and family than are older caregivers.

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### Q6 Detailed Recommendation: [Insert detailed bullet points describing your recommendation.]

Stabilize funding for Caregiver Resource Centers (CRCs) to increase and sustain awareness of family caregiver needs, and to ensure access to comprehensive evidence-based caregiver assessment and services.

Preserve and expand state and federal funding that allows CRCs to increase and improve identification of family caregivers, and to strengthen abilities of those providing care at home and in the community:

- A. Encourage and facilitate self-identification of family and other unpaid caregivers.
  - 1. Increase awareness of the current realities of family caregivers among the general public, health care professionals, health care delivery systems, and policy makers:
  - 2. Increase and sustain statewide and local outreach and marketing to target all populations, above
  - 3. Ensure that family caregivers are routinely identified, and that their needs are assessed and supported in the delivery of health care and LTSS
    - a. Public programs will include identification of family members or other unpaid caregivers in their consumer screening;
    - b. Caregivers identified in screenings will be included in person-centered plans of care.
    - c. Health care systems and professionals will develop processes to identify and provide appropriate support for family caregivers, including
      - i. Integrate family caregivers into hospital discharge processes,
      - ii. support caregivers in navigating care transitions
      - iii. provide caregivers with information and skills training to provide complex care tasks
      - iv. refer caregivers to the Caregiver Resource Centers for long-term support
    - d. Health care and social service professionals will provide proactive outreach to caregivers to help them manage complex care, including providing referral to caregiver specific support services
- B. Support pro-active outreach and assessment to identify caregivers who need additional support
  - 1. Use evidence-based assessment to capture the complexity and trajectory of care, including identifying those who
    - a. care for adults with challenging physical, cognitive and behavioral health conditions
    - b. perform medical nursing tasks and manage multiple health conditions, often accompanied by pain
    - c. are most at risk for their own physical and mental illnesses due to stress, worry, isolation and financial concerns
- C. Strengthen access to available support services.
  - 1. Expand access to affordable caregiver services and supports such as respite care, support groups, family meetings, caregiver counseling and skills training
    - a. Evidence-based caregiver assessment will lead to provision of and referral to appropriate caregiver support services
    - b. Target additional resources to address the needs of all family caregivers, particularly those engaged in complex care
    - c. Widely disseminate and implement locally those services that are shown to be effective
  - 2. Equip caregivers with easily accessible information, education and training that is specific to their situation, and is provided in culturally competent and relevant way:
    - a. Develop culturally appropriate skills training geared to the needs of diverse family caregivers:
    - b. Utilize caregiver assessments to help improve targeting of information, education and training
    - c. Develop caregiver education and training programs that prepare family caregivers providing complex care to
      - i. perform difficult personal care tasks such as bathing,
      - ii. perform medical and nursing tasks such as medication management and wound care

## Master Plan for Aging (MPA) Recommendation Form

**Q7** Evidence that supports the recommendation: [Add links or summaries of research evidence that support the recommendation. Provide links or summaries of research evidence that support your recommendation]

- <https://www.tailoredcare.com/solutions/medicare-adv-dual/>
- [http://tffc.usc.edu/wp-content/uploads/2018/07/USC\\_CA\\_TFFC\\_Report\\_Digital-FINAL.pdf](http://tffc.usc.edu/wp-content/uploads/2018/07/USC_CA_TFFC_Report_Digital-FINAL.pdf)
- <http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx>
- <https://www.transamericainstitute.org/docs/default-source/caregivers-research/the-many-faces-of-caregivers-research-report-2017.pdf>
- <https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>
- <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>
- Expanding Eligibility for the Family Caregiver Support Program in SFY 2012 Updated Findings Bridget Lavelle, PhD, David Mancuso, PhD, Alice Huber, PhD, Barbara E.M. Felver, MES, MPA April 2014  
<https://www.dshs.wa.gov/sites/default/files/SESA/rda/documents/research-8-31.pdf>
- Beach SR and Schulz R. Family Caregiver Factors Associated with Unmet Needs for Care of Older Adults. JAGS. 2017. 65:560-566. PMID: 27935019
- Rodakowski J, Rocco P, Ortiz JM, Folb BL, Schulz R, Morton SC, Leathers SC, Lu H, James E. Caregiver integration during discharge planning of older adults to reduce resource utilization: A systematic review and meta-analysis of randomized controlled trials. JAGS. 2017; 65:1748-1755. doi: 10.1111/jgs.14873. PMID: 28369687 PMCID: PMC5555776.
- Schulz R, Beach SR, Friedman EM, Martsolf GR, Rodakowski J, James EA. Changing structures and processes to support family caregivers of seriously ill patient. J Palliat Med. Epub 2017 Nov 1. <https://doi.org/10.1089/jpm.2017.0437>. PMID: 29091533.
- Beach SR, Schulz R, Friedman EM, Rodakowski J, Martsolf G, & James EA. Adverse consequences of unmet needs for care in high-need/high-cost older adults. J Gerontol B Psychol Sci Soc Sci. 2018 Feb. Epub ahead of print doi: 10.1093/geronb/gby021. PMID: 29471360. Adverse consequences of unmet needs for care are prevalent among HNHC older adults, especially those with multiple indicators, despite more disability-related compensatory efforts and larger helper networks. Helping caregivers provide better informal care has potential to contain healthcare costs by reducing hospitalization and unplanned readmissions.
- Millenials and Dementia Caregiving in the United States:  
[https://www.usagainstalzheimer.org/sites/default/files/Dementia%20Caregiver%20Report\\_Final.pdf](https://www.usagainstalzheimer.org/sites/default/files/Dementia%20Caregiver%20Report_Final.pdf)

**Q8** Examples of local, state or national initiatives that can be used as an example of a best practice: [Provide any available links and sources.] Local: State: National: Other:

- State: Washington State
- <http://tffc.usc.edu/wp-content/uploads/2017/12/Washington-State%E2%80%99s-Support-for-Family-Caregivers.pdf>
- <https://www.dshs.wa.gov/sites/default/files/SESA/rda/documents/research-8-31.pdf>
- State: California (CA Caregiver Resource Centers)
- <https://www.dhcs.ca.gov/services/MH/Pages/AdultsCaregiverResourceCenters.aspx>
- [https://archstone.org/docs/resources/USC\\_CA\\_TFFC\\_Report\\_Digital-FINAL.pdf](https://archstone.org/docs/resources/USC_CA_TFFC_Report_Digital-FINAL.pdf)

## Master Plan for Aging (MPA) Recommendation Form

**Q9 Implementation:** [Insert actions state agencies, legislators, counties, local government, or philanthropy can take to move this recommendation forward. Some of the entities listed below may or may not be applicable to each recommendation.] State Agencies/Departments: [action to be taken by Governor or specific state agencies] State Legislature: [legislation needed to implement recommendation] Local Government: Federal Government: Private Sector: Community-Based Organizations: Philanthropy: Other:

- State Agencies/Departments: [action to be taken by Governor or specific state agencies]
  - CA Department of Health Care Services can commit to permanent funding of Caregiver Resource Centers
  
  - CA Department of Aging can coordinate with Statewide Caregiver Resource Centers to strengthen support for family caregivers
  - CA Department of Employment Development Department (EDD) can work with CRCs to provide education/ information on Paid Family Leave to employed family caregivers
- State Legislature [legislation needed to implement recommendation]:
- Legislation will be needed to:
    - expand CRC purview to include family caregivers of any adult with chronic disabling conditions
    - make CRC funding permanent
- Local Government:
- Area Agencies on Aging Family Caregiver Support Programs (Title IIIIE) can work in cooperation with CA Caregiver Resource Centers to provide optimal support to family caregivers
  - Private Sector: AARP, Alzheimer's Association can work in cooperation with CA CRCs to provide optimal support for family caregivers.
  
  - Community-Based Organizations: Work Family Coalition can work in cooperation with CA CRCs to provide optimal support family caregivers.
  
  - Philanthropy:
    - SCAN and Archstone Foundations are known supporters of programs that enhance family caregiver health, well-being and support.
    - Foundations can provide added financial support for caregiver support programs recognized for comprehensive and evidence-based approach
    - Foundations can support innovation by piloting new projects/approaches
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**Q10 Person-Centered Metrics:** [Individual measures of inputs or outcomes that can be used to measure the recommended action's impact on people.]

- Number of agencies with integrated screenings for caregiver will increase
  - Percentage of increase in caregivers served by CACRCs from 2020 to 2022 will increase
  - LTSS scorecard (family caregiver) will improve ranking by 2025
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**Q11 Measuring Success:** [Describe specific metrics that could be used to empirically measure the effectiveness of your recommendation]

LTSS scorecard  
CRC system evaluation pilot 2019-2022

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## Master Plan for Aging (MPA) Recommendation Form

**Q12** Measuring Success: [How would we know that the implementation of your recommendation is successful?]

Short term: By 2020...

**Data collection begins for CRC expansion in April 2020; initial data analysis will show increased number of caregivers utilizing services in first year**

Mid term: By 2025...

**Data collection for 3-year CRC expansion is completed by June 2022; data is evaluated by December 2022, showing significant increase in numbers of caregivers identified and utilizing services.**

Long term: by 2030...

**Ongoing CRC expansion funding has been implemented; data shows continuation of increased numbers of caregivers identified and utilizing services.**

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**Q13** Data Sources: [What existing data can be used to measure success or progress?]: Existing data sources: [specify datasets, variables, and data owner/location] Suggestions for data collection to evaluate implementation of this goal when no data sources exist:

Existing: • <http://www.longtermscorecard.org/databystate/state?state=CA>

Suggested: California Caregiver Resource Centers will begin collecting data to measure numbers of caregivers identified, demographic information about those caregivers, complexity of care provided, how many and what kind of services they utilize; data will be analyzed for effect of service usage on caregiver's health, well-being and ability to continue to provide care.

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## Master Plan for Aging (MPA) Recommendation Form

**Q14 Potential Costs/Savings:** [insert any research, actuarial analysis or other evidence of the cost of this recommendation or potential savings]

Caregiver expansion project in Washington State demonstrated that: "Care receivers whose caregivers were screened post-expansion were about twenty percent less likely to enroll in Medicaid LTC services in the 12 months following screening compared to prior years (9 vs. 11 percent), despite the fact that more post-expansion care receivers were already enrolled in Medicaid medical coverage at the time of screening. Care receivers whose caregivers were screened post-expansion were slower to transition to Medicaid LTC, controlling for differences in baseline characteristics; the FCSP expansion is likely a contributing factor to this positive outcome"  
<https://www.dshs.wa.gov/sites/default/files/SESA/rda/documents/research-8-31.pdf>

<http://tffc.usc.edu/wp-content/uploads/2017/12/Washington-State%E2%80%99s-Support-for-Family-Caregivers.pdf>: 24% fewer readmissions at 180 days (RR = 0.76, 95% CI = 0.64-0.90). The majority of studies reported statistically significant shorter time to readmission, shorter rehospitalization, and lower costs of post-discharge care among discharge planning interventions with caregiver integration. Conclusion: For older adults discharged to a community setting, the integration of caregivers into the discharge planning process reduces the risk of hospital readmission

Rodakowski J, Rocco P, Ortiz JM, Folb BL, Schulz R, Morton SC, Leathers SC, Lu H, James E. Caregiver integration during discharge planning of older adults to reduce resource utilization: A systematic review and meta-analysis of randomized controlled trials. JAGS. 2017; 65:1748-1755. doi: 10.1111/jgs.14873. PMID: 28369687 PMCID: PMC5555776.

Beach SR, Schulz R, Friedman EM, Rodakowski J, Martsolf G, & James EA. Adverse consequences of unmet needs for care in high-need/high-cost older adults. J Gerontol B Psychol Sci Soc Sci. 2018 Feb. Epub ahead of print doi: 10.1093/geronb/gby021. PMID: 29471360. Adverse consequences of unmet needs for care are prevalent among HNHC older adults, especially those with multiple indicators, despite more disability-related compensatory efforts and larger helper networks. Helping caregivers provide better informal care has potential to contain healthcare costs by reducing hospitalization and unplanned readmissions.

Beach SR and Schulz R. Family Caregiver Factors Associated with Unmet Needs for Care of Older Adults. JAGS. 2017. 65:560-566. PMID: 27935019;

Schulz R, Beach SR, Friedman EM, Martsolf GR, Rodakowski J, James EA. Changing structures and processes to support family caregivers of seriously ill patient. J Palliat Med. Epub 2017 Nov 1. <https://doi.org/10.1089/jpm.2017.0437>. PMID: 29091533.

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**Q15 Prioritization:** [How would you prioritize your recommendation relative to other needs/priorities?]

**High**

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**Q16 Contact information:**

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