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Small Group Discussion

- **Select a group reporter to share the major themes of your discussion.**
- **Discuss one or more of the following questions:**
 - 1) **Why are you here today – what interests drew you here?**
 - 2) **What policy-related problems or challenges are you facing with your family caregiving work?**
 - 3) **What questions do you hope to have answered today?**

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Policies for Those Who Care:

Investing in Systems That Support Family Caregivers

Opportunities for Public/Private Partnerships

Greg Link, MA

Administration for Community Living

March 21, 2019



ACL Today

- Administration on Aging (AoA)
 - Administration on Disability (AoD)
 - Administration for Intellectual and Developmental Disabilities (AIDD)
 - The Independent Living Administration
 - Paralysis Resource Center; Limb Loss Resource Center
 - State Health Insurance Assistance Programs (SHIPs)
 - National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)
 - Workforce Innovation and Opportunity Act programs (WIOA)
 - Traumatic Brain Injury (TBI) Program
-
- ACL is charged with developing policies and improving supports for seniors and persons with disabilities of all ages.

ACL's Mission

Maximize the independence, well-being and health of older adults, people with disabilities across the lifespan, and their families and caregivers

Programs & Initiatives to Support Family Caregivers

ACL's Portfolio:

- National Family Caregiver Support Program (NFCSP)
- Lifespan Respite Care Program
- Alzheimer's Disease Program Initiative (ADPI)
 - State and Community Grants
 - National Alzheimer's Disease Resource Center (NADRC)
 - Alzheimer's Call Center
- R.A.I.S.E. Act and Supporting Grandparents Act (SGRG) – NEW!!

Additional Programs to Consider

- VA Caregiver Support Program
- State and local programs/services

The OAA, the Aging Network and Public/Private Partnerships

Older Americans Act (OAA)– Section 202(a)(11)

“...duty and function of the administration to - coordinate, and assist in, the planning and development by public ...and private organizations or programs for older individuals...comprehensive, coordinated services and opportunities for such individuals”

OAA - Title IV – Part A - Grant Programs

- Demonstration and innovation grants
- Eligible entities include public/private, institutions of higher education, faith communities, tribal entities
- **Examples:** ADRCs; NORCs; CIAIP; Pension Counseling; volunteerism; civic engagement; financial literacy for family caregivers; access to home modifications; and supportive services for Holocaust survivors.

Current ACL P/P Partnership Examples

- Co-Fund/Co-Administer
- Inform. Support. Observe
- Convene/co-convene
- Grant-driven opportunities

Aging & Disability Business Institute (Co-fund/administer)

- Since 2013, ACL has partnered with:
 - John A. Hartford (lead funder)
 - The SCAN Foundation
 - Gary and Mary West Foundation
 - The Colorado Health Foundation
 - The Buck Family Fund of the Marin Community Foundation
- Grantee: National Association of Area Agencies on Aging (n4a)
- Goals
 - Address business challenges of community-based organizations
 - build capacity of state/community aging and disability organizations to partner and contract with health care entities
 - strengthen contracting practices and support greater participation in the Age-Friendly Health Systems movement
- 2015 HHS Innovates Award winner for p/p partnership

National Collaborative to Address Elder Mistreatment (Inform. Support. Observe)

- Funders: The John A. Hartford and Moore Foundations
- Grantee: Education Development Center
- Implementing and evaluating the *Elder Mistreatment Emergency Department Care Model*
- ACL's Office of Elder Justice and Elder Abuse Prevention Services....
 - Informs – reporting to the collaborative what is going on with our grantees; and
 - Observes – using the work of the collaborative to inform ongoing/future grant activities and funding directions

Addressing Elder Abuse in Rural/Frontier Communities (convene/co-convene)

- Federal partners: ACL and Dept. of Justice
- Focus on the topic of elder abuse
- ACL and DOJ bring together NGOs (e.g., n4a, NAPSA) to identify issues and solutions for addressing elder abuse
- Multiple federal agencies work with private sector entities on a single issue
- Results: training, technical assistance, and improved stakeholder engagement

The Lifespan Respite Program (grant-driven opportunities)

- ACL funding announcements often encourage applicants to partner with private entities.
 - Alabama
 - The state's respite coalition has received community foundation grants to sustain their work
 - Partnered with Home Instead and ResCare to provide emergency respite services
 - Nebraska
 - State Lifespan Respite Coordinators engage with business to raise awareness of employee caregiver issues.
 - U. of NE Medical Center and NE Medicine now include respite information in new employee orientation

Opportunities to Partner

- Sustain/expand existing projects and demonstrations
- Further replication/translation of proven interventions
- Testing new or emerging models
- Support for scaling up smaller demos
- Direct services

Discussion

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Research Priorities to Inform Caregiver Policy

Richard Schulz, PhD
Distinguished Service Professor of Psychiatry
University of Pittsburgh School of Medicine
Pittsburgh, Pennsylvania

Research supported by National Institute of Mental Health, National Institute on Aging,
National Institute of Nursing Research, and National Heart, Lung and Blood Institute

Overview

- ① Assess prevalence and impact of caregiving
- ② Not all caregivers need help; high risk targets
- ③ Shift from efficacy to implementation — integrate CG into existing health care systems
- ④ Monetize the effects of caregiving
- ⑤ Embrace technology
- ⑥ Educate and prepare all adults for caregiving

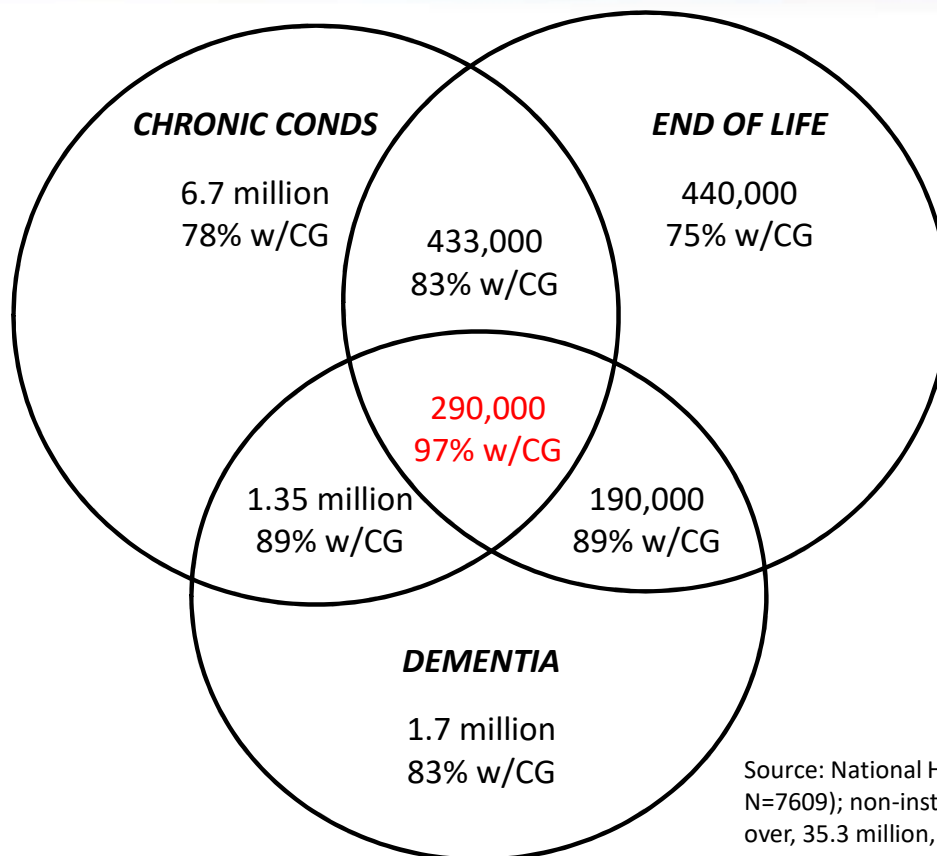
1. Assess the Prevalence and Impact of Caregiving

- ◆ Adopt consensus definition in population surveys of prevalence
- ◆ Assess population level effects on time use, finances, employment, social isolation, lifestyle changes, and health

2. Not All Caregivers Need Help — Identify High Risk Caregivers/Patients

- ◆ Many caregivers do fine, particularly in early stages of caregiving career
- ◆ Allocation of limited resources to highest need at risk caregivers
- ◆ Well-established risk profiles available

High Need/High Cost Patients and Their Caregivers



CHRONIC CONDS = at least 3 chronic conditions and 1ADL/IADL limitation; dementia excluded as chronic condition

END OF LIFE = died within 1 year of baseline assessment

DEMENTIA = diagnosis of probable dementia

NONE OF THE ABOVE
24.1 million, 67% w/CG

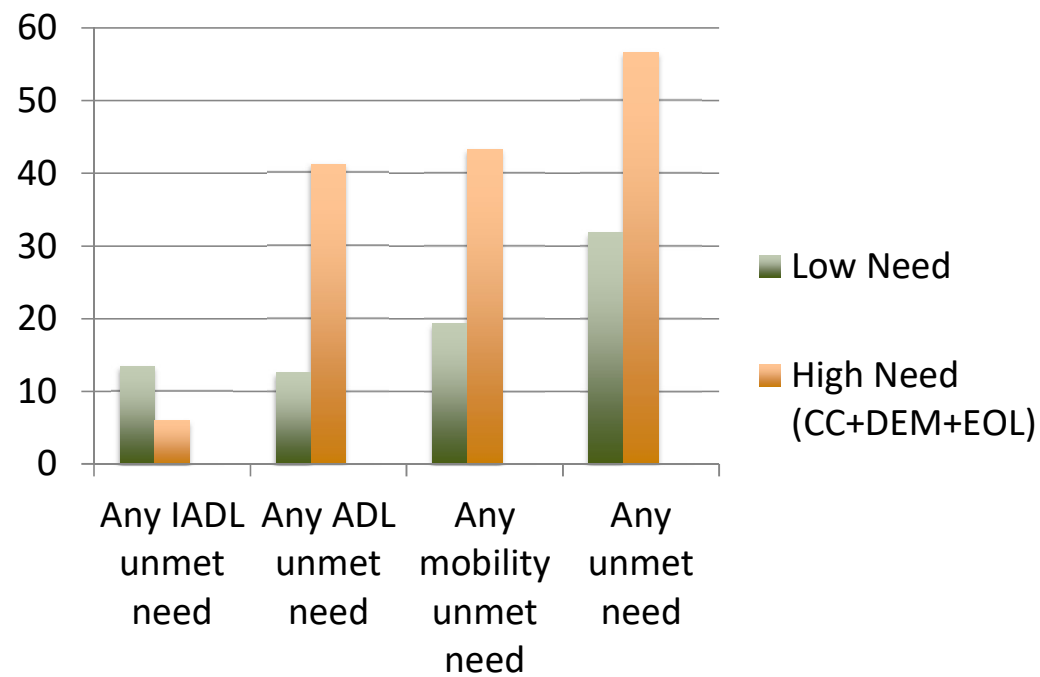
Source: National Health and Aging Trends Study (NHATS, 2011, N=7609); non-institutionalized U.S. older adults aged 65 and over, 35.3 million, weighted population estimates.

High Need/High Cost Patient Caregiver Impacts*

- ◆ More hours of care (1/3 report >100 hours per month)
- ◆ Provide help with more types of tasks
- ◆ Increased caregiver psychological and physical morbidity
- ◆ Increased financial strain (e.g., out-of-pocket expenditures, labor force participation)

*Compared to caregivers of low need patients; Schulz et al., *J. of Palliative Medicine*, 2018

Percent with Unmet Needs: Low and High Need Patients



Beach et al., *JAGS*, 2017

3. Shift from Efficacy to Implementation Research: Integrate CG into Health Care Systems

- ◆ Vast published intervention literature
- ◆ More than 50 systematic reviews/meta-analysis since 2000
- ◆ 5 systematic reviews of systematic reviews
- ◆ Intervention Strategies
 - Psychosocial Interventions
 - Meditative Interventions
 - Physical Activity
 - Cognitive Behavior Therapy
 - Respite and Care Coordination
 - Technology-based Interventions

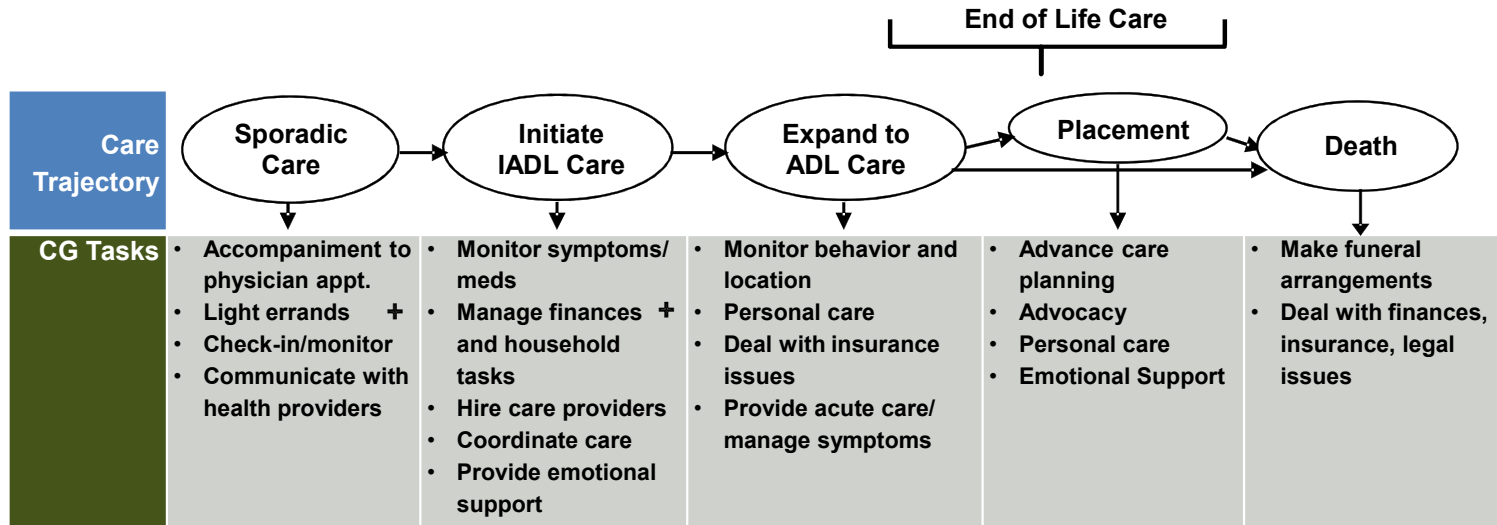
Efficacy Research - A Litany of Woes

- ◆ Small to moderate effect sizes for some outcomes
- ◆ Risk of bias in published RCTs is moderate to high
 - Sequence generation and allocation concealment not described
 - Outcome assessors not blinded (interventionist is assessor)
 - Methods for dealing with missing data not reported
 - Selective (opportunistic) outcome reporting
 - Small sample size, poor quality control in treatment implementation and data collection, limited follow-up

Successful Interventions

- ◆ Address pragmatics of providing care
 - Knowledge about illness, symptoms and progression, available support service
 - Skills to address needs of care recipient, assisting with functional disabilities, managing behaviors, accessing professional services
- ◆ Coping with emotional toll of caregiving
 - Living with, watching loved one suffer and decline with little or no ability to mitigate conditions
 - Meditative strategies and cognitive behavior therapies

Care Trajectory and Caregiver Tasks



CG = Caregiver

IADL = Instrumental Activities of Daily Living

ADL = Basic Activities of Daily Living

How do you integrate CG into Health Care Systems?

- ◆ Consensus core outcomes
 - Meaningful improvement of adverse symptoms
 - Maintain/improve quality of life
 - Societal significance — service utilization, cost
- ◆ Develop context and disease assessment tools tailored to disease and treatment trajectory

Pragmatic Trials: Dementia Specialist Coordinates...

- ◆ In-person sessions to address patient and family members' specific questions about problems, resources, and implementing care plans
- ◆ Telephone follow-up to monitor implementation of dementia care plans
- ◆ Facilitation of appointments with consultants when needed
- ◆ Caregiver support groups
- ◆ Caregiver education through a community lecture series; these monthly webinars are archived on program's website
- ◆ Referral to community-based services such as delivered meals, adult day care, care/case management, financial and legal counseling, and transportation assistance as well as caregiver training
- ◆ Systematic review and adjustment of care plan

Pragmatic Trials

- ◆ Consultation with neurology, geriatric psychiatry, psychology, or geriatrics for additional diagnostic evaluation (e.g., if there are unusual symptoms) or management of refractory complications
- ◆ Caregiver support groups, either community-based or provided by the health system
- ◆ Caregiver education through a community lecture series; these monthly webinars are archived on program's website
- ◆ Referral to community-based organizations for services such as delivered meals, adult day care, care/case management, financial and legal counseling, and transportation assistance, as well as caregiver training

4. Monetize the Economic Benefits of Caregiving

- ◆ Caregivers replace or delay formal care
- ◆ Recent review* of 45 studies — 3 studies stand out
 - Van Houtven & Norton, 2008: decreased Medicare costs
 - Torbica et al., 2015: increased healthcare costs after stroke
 - Coe et al., 2016: small (not statistically significant) reduced health care utilization

*Friedman et al., *The Gerontologist*, in press

The Ideal Monetizing Study

- ◆ Longitudinal study of representative subset of population with and without caregiver
- ◆ Capture people before they become ill
- ◆ Track work related impacts on caregiver
- ◆ Assess healthcare utilization for both care recipient and caregiver — both during and after care
- ◆ Track out-of-pocket expenditures for caregiver and care recipient

5. Embrace Technology to Support Caregivers

- ◆ Computers, smart phones, and web-based clinical care tools
- ◆ Symptom monitoring
- ◆ Advice and coaching
- ◆ Accessing services
- ◆ Barriers: digital divides, usability issues, reliability, trust

“Emerging Technologies to Support an Aging Population” (White House Report)

- ◆ Key activities of independent living — nutrition, hygiene, medication management
- ◆ Cognition — monitor changes, cognitive training and assistance
- ◆ Communication and social connectivity
- ◆ Personal mobility
- ◆ Transportation — smart cars
- ◆ Access to healthcare

6. Educate and Prepare all Adults for Caregiving

- ◆ Implement population based preventive strategies?
- ◆ Population level training on
 - Likelihood of becoming caregiver/care recipient
 - Planning for support needs
 - Roles and responsibilities of caregiving
 - Rudimentary caregiving skills

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Helping States Support Families Caring for an Aging America

Karen Lindsey Marshall, J.D.
Director of Advocacy & Engagement
National Alliance for Caregiving

March 21, 2019
Grantmakers in Health – Grantmakers in Aging



National Alliance for Caregiving

Established in 1996, the Alliance is a non-profit coalition dedicated to advancing family caregiving through **research, innovation, and advocacy**.

- Nearly 60 organizational members, including non-profits, corporations, and federal agencies
- Founder and Secretariat of the International Alliance of Carer Organizations (IACO)
- Advocacy network of 80+ state/local caregiving coalitions and caregiver advocates

A Mission-Driven Approach



- I. Research
- II. Innovation
- III. Advocacy
- IV. Taking Action

Advancing Caregiving Through Research



- **Caregiving in the U.S. (2015)** – a national snapshot of unpaid caregivers age 18+ caring for an adult, including:
 - Prevalence of caregivers in the United States;
 - Demographic characteristics of caregivers and care recipients
 - Caregiver’s situation
 - How caregiving affects caregiver stress, strain, and health
 - Information needs related to caregiving
 - Public policy and caregiver support
- Companion reports focusing on caregivers of younger adults and caregivers of adults age 50+

Full report at <https://www.caregiving.org/caregiving2015/>

Who is caring for Americans Age 50+

- ❖ 60% Women
- ❖ 40% Men
- ❖ Average caregiver age: 50.3 years
- ❖ 86% care for a relative
- ❖ 47% care for a parent or parent-in-law
- ❖ 1 in 10 cares for a spouse
- ❖ 1 in 4 caring from someone age 85+
- ❖ Average care recipient age: 74.7 years
- ❖ 63% long-term physical condition
- ❖ 29% memory problem
- ❖ 49% say they did not have a choice
- ❖ Average length of time: 3.7 years
- ❖ 50% care for a loved one living in his or her own home
- ❖ On average, 24.1 hours providing care per week
- ❖ 3 in 5 primary caregivers (e.g., sole or primary unpaid caregiver)
- ❖ Only 34% use paid assistance from aides, housekeepers or others
- ❖ 6 in 10 assist with medical/nursing tasks (43% without prior preparation)
- ❖ 38% report high levels of emotional stress, 19% report high levels of physical strain



See NAC and AARP, *Caregivers of Older Adults; A Focused Look at Those Caring for Someone Age 50+* at https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Care-Recipients-Over-50_WEB.pdf.

Supporting Caregivers Through Innovation

- The RAISE Family Caregivers Act requires HHS to engage with public and private partners to recommend a national plan to address caregiving.
- With funding from Robert Wood Johnson Foundation, NAC hosted a multi-stakeholder roundtable on advancing the caregiving agenda through innovation and research.



Full report at <https://www.caregiving.org/research/innovationfund>

From Insight to Advocacy

- Expand Caregiver Access to Supports and Services
- Protect the Financial Security of Caregivers
- Include Caregivers as Vital Members of the Health and Human Service System
- Enhance the Health and Wellness of Caregivers



Full Report at <https://www.caregiving.org/publichealth/>

Take Action!

- Support state or local caregiving coalitions
- Advocate on behalf of existing programs that support caregivers
- Educate policy makers on caregiving
- Educate health systems to understand how to work with caregivers
- Look for opportunities within broader policy efforts to acknowledge and support caregivers
- Engage with us!

Thank you!


National Alliance for Caregiving


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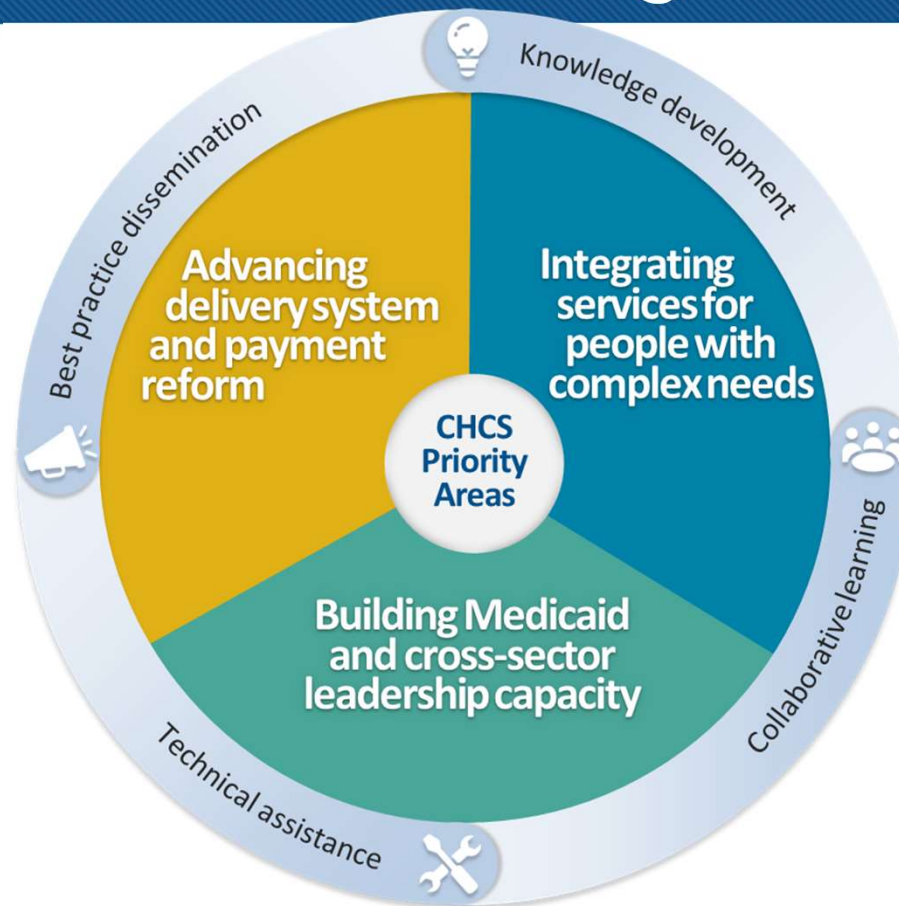
Helping States Support Families Caring for an Aging America

Courtney Roman, Senior Program Officer
Grantmakers in Health-Grantmakers in Aging Convening
March 21, 2019
Washington, DC

Made possible through support from The John A. Hartford Foundation, the Milbank Memorial Fund, the May & Stanley Smith Charitable Trust, & the Gordon and Betty Moore Foundation

About the Center for Health Care Strategies

A nonprofit policy center dedicated to improving the health of low-income Americans



Helping States Support Families Caring for an Aging America: Project Overview

- **Learning Collaborative states:** AL, ID, IA, NH, SC, VA
- **Project purpose:** To support states in shaping, re-designing, & improving family caregiving polices and programs
- **Funders:** The John A. Hartford Foundation, the Milbank Memorial Fund, the May & Stanley Smith Charitable Trust, & the Gordon and Betty Moore Foundation
- **Main activities**
 - » Multi-state learning collaborative
 - » CHCS technical assistance (TA):
 - State action plan development
 - Targeted TA via phone calls, webinars, and in-person site visits
 - In-person meetings (Winter 2019 and 2020)

State Goals, Priorities, & Innovations

Helping States Support Families Caring for An Aging America: STATES' GOALS

State	Goals	Highlights
Alabama	<ul style="list-style-type: none"> » Identify funding stream for a statewide respite care program. » Develop standards for the respite care program, including education and training. 	<ul style="list-style-type: none"> » Legislative Liaison for the AL Speaker of the House is part of the state team.
Idaho	<ul style="list-style-type: none"> » Establish a public/private partnership between payers & Idaho Commission on Aging/AAAs. » Develop statewide quality metrics for caregiver supports for AAAs. 	<ul style="list-style-type: none"> » Seeks to leverage unique managed long-term services and supports (MLTSS) program for dually eligible beneficiaries.
Iowa	<ul style="list-style-type: none"> » Develop a high-quality National Family Caregiver Support Program that is administered consistently across the state. 	<ul style="list-style-type: none"> » Hosting a LEAN design event to organize and streamline family caregiving programs.

Helping States Support Families Caring for An Aging America: STATES' GOALS (Con't)

State	Goals	Highlights
New Hampshire	» Develop a new statewide Family Caregiving Action Plan, including a family caregiver assessment .	» Focused on family caregiving across the lifespan as that fits more in line with state needs.
South Carolina	» Improve understanding of the needs of the family caregiving population , including gaps and challenges with current state programs.	» Most diverse with team members from AARP, SC Institute for Medicine & Public Health, Office on Aging, and the State Medicaid Director.
Virginia	» Implement a family caregiver assessment to better target family caregiver supports in its Medicaid MLTSS program.	» Plans to bring together a multi-stakeholder group of MLTSS plans, providers, community organizations and advocates to assess resources.

Key State Priority Areas for Supporting Family Caregivers

Seek multi-agency solutions

Gathering data to inform policy making

Align family caregiving goals with broad state policy objectives

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Lessons from the California Task Force on Family Caregiving



Policies for Those Who Care: Investing in Systems That Support Family Caregivers
Grantmakers In Health/Grantmakers In Aging
March 21, 2019



Donna Benton, PhD

Chair CTFFC

Research Associate Professor

Kate Wilber, PhD

Mary Pickford Professor

USC Leonard Davis School of Gerontology

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Picking Up the Pace of Change in California:
A Report From the California Task Force on Family Caregiving

USC Leonard Davis
School of Gerontology
California Task Force on
Family Caregiving (CTFFC)

AARP
California
Real Possibilities

ARCHSTONE
FOUNDATION



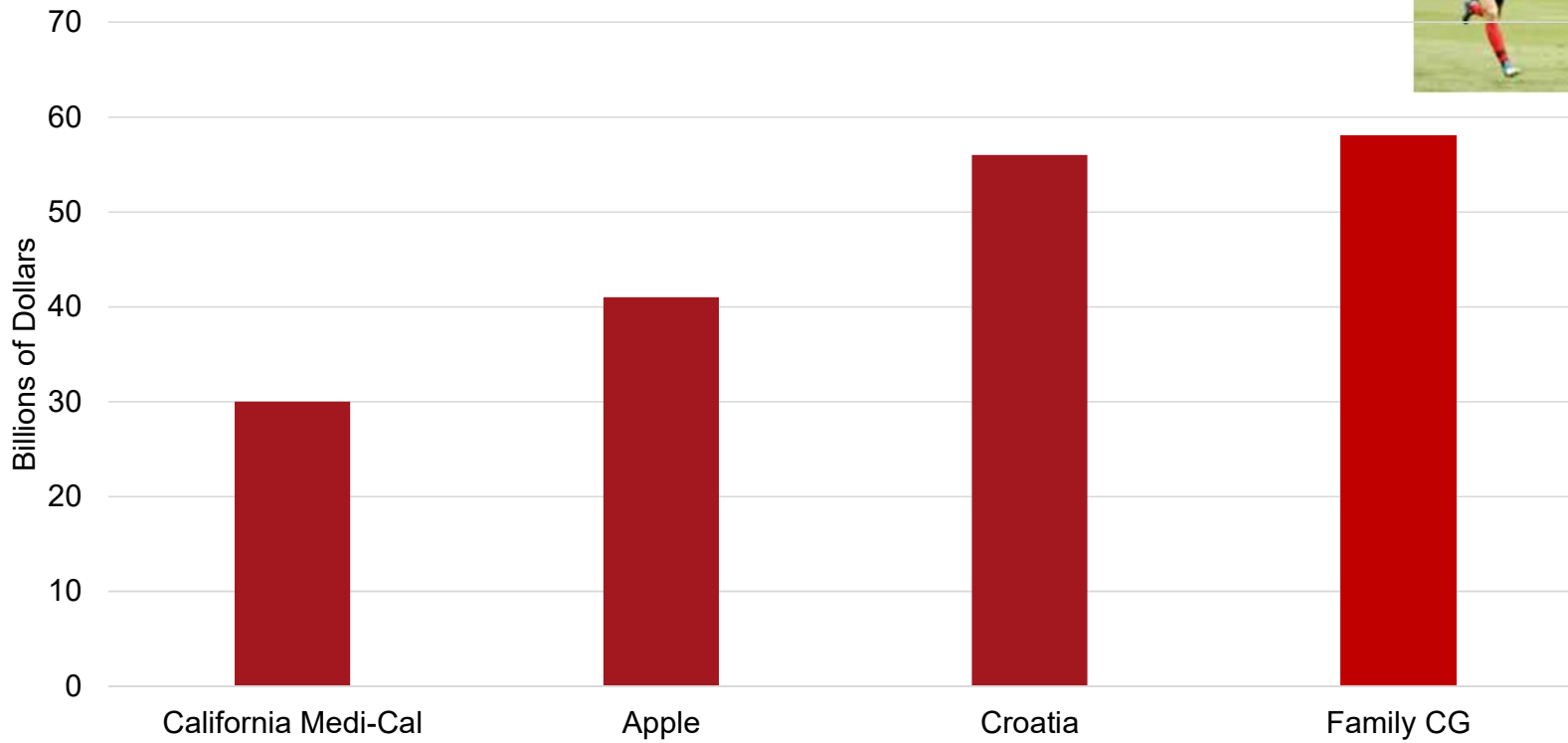
Who are the 4.5 million family caregivers in CA?

- 60% are women
- Average age 49
- 1 in 4 are Millennials
- 56% are employed
- 1 in 4 assist a person with dementia
- The average time spent is 4 years
- Value= estimated \$58 billion





Contributions of CA Caregivers: \$58B/yr.









Legislation Authority for CATFFC: Assembly Concurrent Resolution (ACR 138: Brown)

- Examine challenges and opportunities to improve support,
- Review current networks, services & supports available to caregivers,
- Make policy recommendations to the Legislature.
- Administrative support by a “nonstate organization”
- Report to the Legislature by January 1, 2017 (Interim), and by July 1, 2018 (Final).





Organization of the CA TFFC

- 12 members appointed: 6 Assembly; 6 Senate
- Elected Chair, Dr. Donna Benton; Co-Chair, Sandi Fitzpatrick
- Non-state organization (USC) supported by the Archstone Foundation and AARP
- Convened October 2016 to July 2018
 - Bi-monthly meetings, alternating by phone and in-person





Task Force members



- **Mary Ball, former President/CEO at Alzheimer's San Diego**
- **Donna Benton, PhD, Research Associate Professor of Gerontology, USC**
- **Les Cohen, Legislative Advocate Emeritus, Orange County Ombudsman**
- **Carmen Estrada, Executive Director of Inland Caregiver Resource Center**
- **Sandra Fitzpatrick, Executive Director, California Commission on Aging**
- **Kathleen Kelly, MPA, Executive Director of the Family Caregiver Alliance**
- **Karen Lincoln, PhD, Associate Professor University of Southern California**
- **Anat Louis, PsyD, Director Direct Services, Department of Aging, City of Los Angeles**
- **Eric Mercado, Research Editor, Los Angeles Magazine**
- **Douglas Moore, Executive Director of the UDW Homecare Providers Union; International Vice President of the American Federation of State, County, and Municipal Employees**
- **Edie Yau, Director of Diversity and Inclusion for the Alzheimer's Association**



The California Task Force Priorities

1. Integrated approach to care management
2. Comprehensive array & continuum of services
3. Caregiver compensation
4. Data on caregivers and services
5. Access to affordable & accessible services
6. Education and training





Developing the Recommendations

- Research reviews on each priority area at each meeting
- Compilation of work by other Task forces
- Survey of agencies serving caregivers across CA (Best Practices)
- Best practices in policymaking brief





Transparency and Communication

Follow the California Task Force on Family Caregiving on Facebook or Twitter

USC University of Southern California

California Task Force on Family Caregiving

Home About Members & Meetings News & Reports Contact

CA TFFC MEETING UPDATE

The members of the California Task Force on Family Caregiving met earlier this month to discuss financial compensation and other forms of support for family caregivers.

[Learn More](#)



California Task Force on Family Caregiving

Tweets 298 Following 263 Followers 406 Likes 163

Following

CA Caregivers
@CA_TFFC follows you

We examine the challenges faced by family caregivers and review the current network in order to make policy recommendations to the Legislature.

California, USA
#FCAcaregivers
Joined June 2017

Tweet to Message

40 Followed you here

33 Photos and videos

Tweets Tweets & replies Media

Retweeted

CA Caregivers @CA_TFFC · 13 Jul 2017

Check out are results @FCAcaregivers to see what we've been discussing at our meetings about #policy related to #caregivers

California Task Force on Family Caregiving (CA TF...
We examine the challenges faced by family caregivers and review the current network in order to make policy recommendations to the Legislature.
@CA_TFFC

CA Caregivers @CA_TFFC · Jan 10

20% of today's workforce serves as family caregivers during their off-work hours
#caregiving #caregiver

CA Caregivers @CA_TFFC · Jan 8

Considering the needs of family caregivers is an emerging workplace issue. Supporting #caregiving employees benefits employers of all sizes. Check out these three ways to support #caregiving employees. on @FCAcaregivers @FCAcaregivers #FamilyCaregiving #TuesdayThoughts

Who to follow Refresh · View all

AllStateHomeHealth @AllStateHomeHealth Follow

ITK Caregiver Training @ITK_Caregiver_Training Follow

Mary-Me @MaryMe_Me Follow

20 First people you know

Trends for you Change

Jacob Wohl 6634 Tweets

#EqualityAct Sec 23 Filed: National Partnership, and 1 more are Tweeting about this

#CollegeCountingScandal Faculty Hoffman and Lind Loughlin indicted in national college admissions scandal

Whitaker 2734 Tweets

Being T33 President Trump orders the grounding of all Boeing 737 Max 8 and 9 planes

#Bep

AMERICAN PSYCHIATRIC ASSOCIATION



Infographics to Avoid “TL-DNR” Syndrome

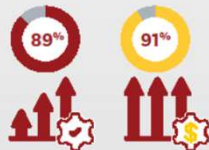
Did You Know?: LIMITATIONS OF CURRENT LEAVE LAWS IN THE STATE



FMLA applies only to employees at private companies with over 50 employees living within a 75-mile radius. To be eligible, employees must have worked at least 12 months with their employer, have provided 1,250 hours worked in the last year, and been on payroll for the past 20 weeks. Consequently, the law only covers only 55 to 60% of workers due to limitations in eligibility. ¹



Despite having the oldest paid family leave law in the nation, just 11.6% of paid leave claims in California were taken by family caregivers from March 2017 to April 2018. ²



A 2011 evaluation of California's paid leave law indicates that 89% of employers found a positive or unnoticeable effect of PFL on productivity, and 91% reported the same outcomes for profitability/performance. Very few employers were aware of any abuses of the policy. ³



Human resource departments and professionals are among the most likely to advise employees on access to PFL, but of 78% of human resource professionals indicate additional PFL training is needed. ⁴

Learn more about ways to improve leave options by viewing the final report of the California Task Force on Family Caregiving: www.tffc.usc.edu



HIGH COSTS OF CAREGIVING



Family caregivers in California provide approximately \$58 billion worth of care and assistance each year.



On average, out-of-pocket costs comprise 20% of caregivers' incomes. African-American/Black and Hispanic caregivers spend a higher proportion of their income on out-of-pocket costs to provide care than Caucasian/White and Asian caregivers, averaging 44% and 34% of annual incomes, respectively.



A 2016 study on attitudes of California residents age 40 and older conducted by the Associated Press-NORC Center for Public Affairs Research found that only 4 in 10 caregivers indicate that "they are confident they will have the resources to pay for any ongoing care they may need."



Caregivers may have pay \$25 per hour for a home care aide for when they cannot provide care themselves.



36% percent of family caregivers to adults above the age of 50 report feeling financial strain from their caregiving duties.



Given high out-of-pocket costs, 30% of caregivers report dipping into their own savings to cover the costs of providing care and 15% report lessening retirement contributions.



Caregivers spend an average of \$7,000 per year on out-of-pocket costs related to caregiving, including household costs (e.g., rent/mortgage payments) and medical expenses (e.g., medical devices).



2016 survey among Californians age 40 and older found that 82% would support for a proposal that would provide tax breaks to those providing care to a family member.



Values to guide recommendations

- Support diverse caregiver needs, including cultural awareness, cultural competency, and sensitivity
- Person- & family-centered care
- Work-life balance
- Choice & options for caregivers





Recommendation 1:

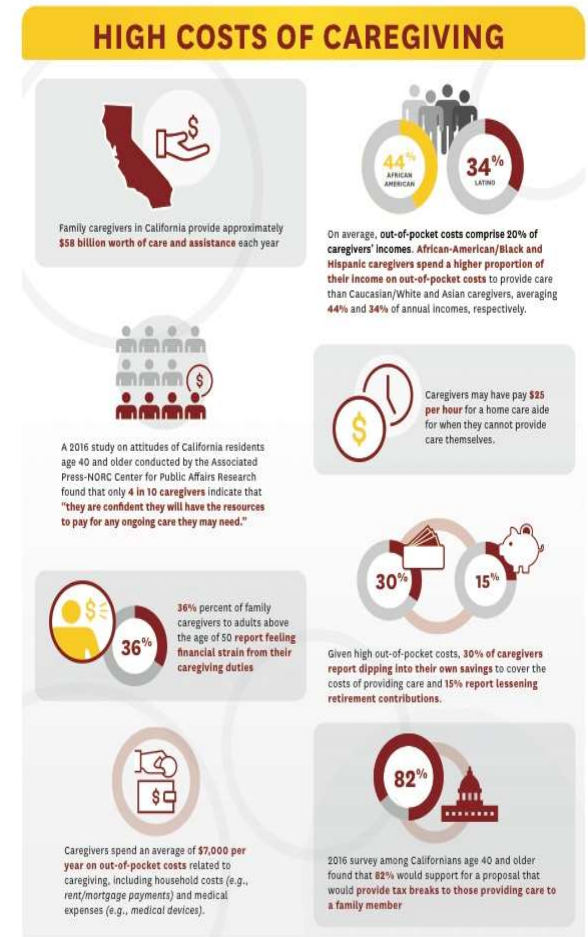
Support the financial wellbeing of family caregivers, and limit the extent to which this role contributes to an increased risk of poverty and long-term financial insecurity.





Recommendation 1

- **Tax credits for the high out-of-pocket costs of caregiving**
- **Stipend or similar program to support caregivers with the costs of community-based services**
- **Build on Family Medical Leave Act and Paid Family Leave laws**
 - **Increase awareness of existing programs**





Challenges in Leave Laws

- 40% workers not eligible
- Lack of awareness
 - HR professionals
 - Employers

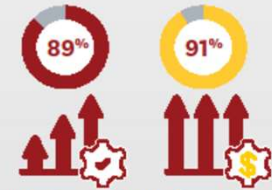
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USC Leonard Davis
School of Management
Employee Well-Being
And Quality of Work



Recommendation 2

Modernize and standardize caregiver assessments across the state to support individualization of services, reduce service fragmentation, and increase knowledge of who among caregivers in the state uses services.





Recommendation 2

- Develop and implement a standardized assessment tool
- Increase funding for caregiver assessments
- Collect representative survey data on caregivers in California
- Remove barriers across agencies that inhibit safe return of people with an intellectual disability or cognitive impairment





Recommendation 3

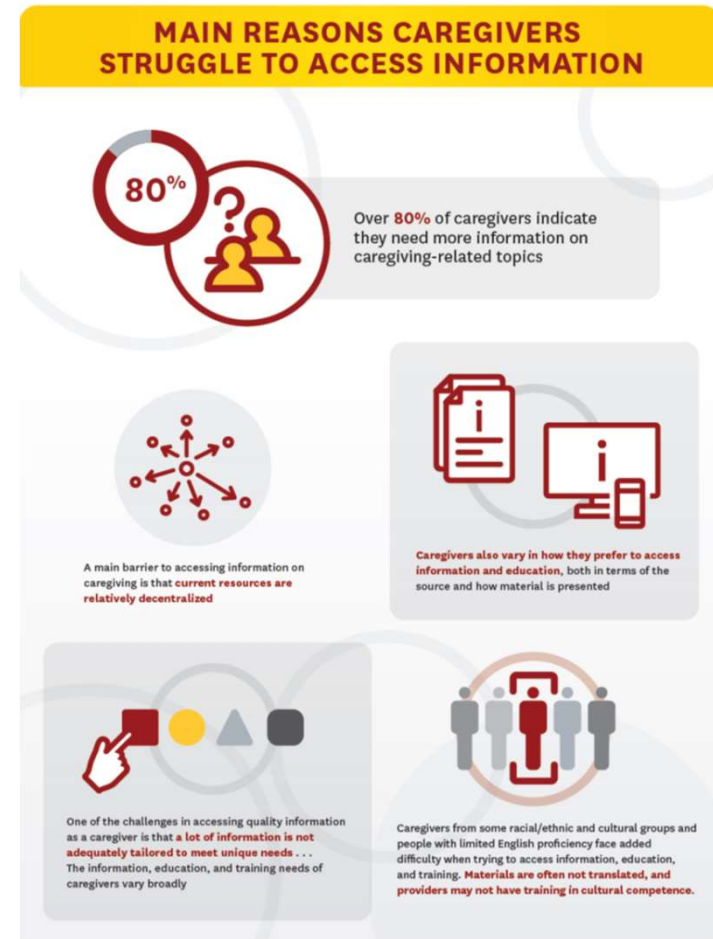
Equip caregivers with easily accessible information, education, and training that is specific to their situation, and is provided in culturally competent and relevant ways.





Recommendation 3

- Increase access to tailored education and training materials and programs
- Provide culturally competent education and training
- Increase funding to California's Caregiver Resource Centers to provide information, education, and training





Recommendation 4

Increase access to affordable caregiver services and supports, including respite care that allows caregivers to take a break.





Recommendation 4

- Grow the number of respite care providers in the state
- Expand access to affordable respite services

CAREGIVERS STRUGGLE TO ACCESS RESPITE SERVICES

Despite high interest among caregivers to access respite services, just 15% of caregivers reported ever using respite services

Caregivers may also be reluctant to schedule formal respite if they cannot access culturally-appropriate services, such as a respite provider who speaks the same language as the care recipient

Home care providers, who often provide respite, are one of the fastest growing jobs in the US, and turnover is high. One estimate suggests a 32% per year turnover rate among home care aids. Job retention also contributes to challenges in maintaining a trained workforce

One of the challenges to accessing respite is finding services

Those in rural areas are particularly likely to struggle with accessing a provider, as are caregivers seeking to schedule last-minute respite or during the evening

In addition, lack of available providers and the high costs of respite are key to low rates of respite utilization

Many caregivers must rely on expensive home-care agencies for respite at a median rate of over \$25 per hour in California

The average out-of-pocket cost for respite is \$587 per year for caregivers. Importantly, this figure excludes caregivers who cannot afford to purchase any respite.



Recommendation 5

Integrate family caregivers into hospital processes, support them in navigating care transitions and with providing complex care tasks, and increase caregiver choice in whether to complete complex care tasks.



Recommendation 5

- Allow nurses to delegate some tasks (e.g., administering medication) to qualified home health providers
- Standardize hospital discharge process to better support caregivers
- Assist with implementation of the California Hospital and Family Caregiver Act
- Ensure access to telehealth for caregivers and recipients

ENHANCING THE CALIFORNIA HOSPITAL AND FAMILY CAREGIVER ACT

Passing the California Hospital and Family Caregiver Act was an important step to better supporting caregivers providing complex care. However, there is little guidance on how to implement provisions of the California Hospital and Family Caregiver Act.



HERE ARE SOME WAYS TO IMPROVE THIS LAW:



Work with the stakeholders like the California Hospital Association to identify opportunities to improve implementation



When providing education to caregivers prior to discharge, require hospitals to assess the caregiver's capacity to provide care and their capacity to understand education provided at discharge

Require hospitals to enable recipients to list multiple caregivers in their electronic health records



Provide funding to expand access to translated materials and trainings provided to caregivers at discharge as a part of California Hospital and Family Caregiver requirements



Require hospitals to provide educational materials that families can take home and review after discharge, in addition to education provided in the hospital



Recommendation 6

Increase funding to California's Caregiver Resource Centers to expand services, including respite care and educational programs, and support innovative programs





Programs That Directly Support Family Caregivers

- **National Family Caregiver Support Program Title III-E** (established 2000)
 - ACL (Federal) to state and local aging departments (AAA)
 - Includes information, referral assistance, counseling, training support, temporary respite
 - Targets caregivers of adults 60+ except for dementia (any age qualifies)
- **California network of 11 Caregiver Resource Centers** (established 1984)
 - Provides information, assessment, educational programs, skill training, psychoeducational interventions, counseling, support groups, consumer-directed respite, legal consultation
 - CRC's services assess and address caregiver, includes respite typically through vouchers.
 - Targets caregivers of adult-onset cognitive impairments (18 and up) such as stroke, Parkinson's, head injury, dementia
 - CA Dept. of Health Care Services budget cut by 74% in 2010.



Recommendation 7

Create a statewide advisory council on matters affecting family caregivers that provides advice on integrating caregiver issues across state departments, services, initiatives, and programs, and provides policy expertise to the Legislature.





Follow-up

- October 30 & 31 Task Force Members and additional stakeholders met at AARP offices in Pasadena.
- Formed a coalition to promote legislative action
- Identified 3 priorities:
- ***Recommendation 1: Support the financial wellbeing of family caregivers, and limit the extent to which this role contributes to an increased risk of poverty and long-term financial insecurity:***
 - 1c: Increase access to current programs that support employed caregivers, particularly job protections accomplished through expanding eligibility criteria to apply to more family caregivers, and raising awareness so caregivers know these programs exist.



Follow-up

Recommendation 4: Increase access to affordable caregiver services and supports, including respite care.

- ***4b:*** Expand access to affordable respite services to family caregivers so that they can take a break without harming their financial wellbeing.

Recommendation 6: Increase funding to California's Caregiver Resource Centers to expand services, including respite and educational programs, and support innovative programs.

- ***6:*** Expand services, including administering high-quality caregiver assessments, information and referral services, evidence-based education and training programs, and raising caregiver awareness, including using digital and online programs



CA Bills Related to CA Taskforce Recommendations

- Paid Family leave (rec #1)
 - 100% wage replacement for workers making >100K
 - Forms language and easy of use
- Tax Credit (rec #1)
 - 50% of expenses up to \$5K
- Respite (rec #4)
 - Care core volunteer respite workforce with tuition credit
- Model Language for Cognitive Impairment Task Force
- ADRC single entry point (rec #3)
- CRC budget ask (rec #6)
- Master plan on Aging (rec #4)
 - Include caregiver support and respite in language



Thank you!

The Administrative and Research Team is comprised of members of the Secure Old Age lab, and includes: Ayesha Dixon, Zach Gassoumis, Natalie Kaiser, Danielle Kaiser, Janeth Marroletti, Kylie Meyer, and Kate Wilber.

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