

# SPOTLIGHT on HEALTH POLICY

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Institute for Health Policy and Leadership



#### **Policies Supporting Family Caregivers**

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AARP California







# Picking up the Pace of Supports for Family Caregivers



#### Presenter



- Nina Weiler-Harwell, Ph.D.
- Associate State Director
- Twenty-two years with AARP
- Master Plan for Aging Stakeholder Advisory Committee, LTSS Subcommittee



#### **Agenda**

- Data on Family Caregivers
- RAISE Family Caregiver Act
- Other Federal Advocacy
- State-Specific Advocacy Opportunities
  - Paid Family Leave
  - Master Plan for Aging





#### **Family Caregivers**

- Nationally, 41 million family caregivers provide care for adult loved ones -- unpaid care valued at about \$470 billion annually.
- Backbone of the care system in the US and California
- California: 4.7 million family caregivers provide unpaid care worth about \$63 billion annually





#### **Family Caregivers - Context**

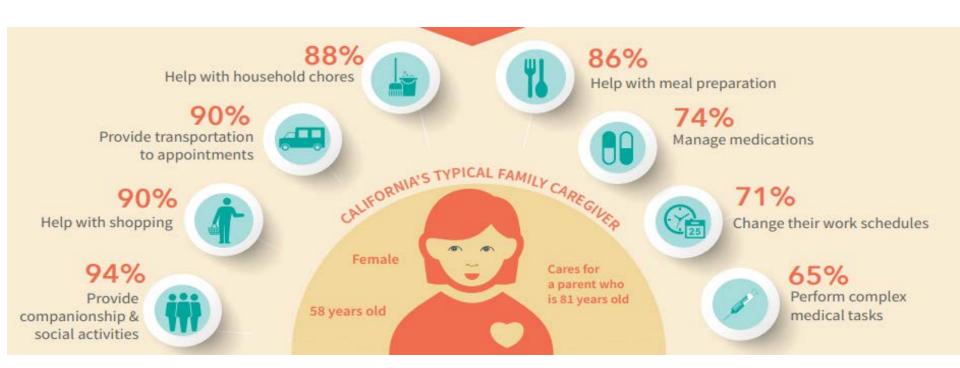


#### **Contributions of Family Caregivers**

- Help older adults and people with disabilities live in independently in their homes and communities -- where they want to be
- Save taxpayer dollars by helping to delay or prevent more costly nursing home care & unnecessary hospitalizations
- Play a vital and often unrecognized role in health care



## The role of the family caregiver has changed



Source: 2018 Survey of 1,152 California Votes Aged 40-plus. Margin of error is ± 2.9%.

https://doi.org/10.26419/res.00259.050

#### **RAISE Family Caregivers Act**

- Signed into law by the President January 22, 2018 (Public Law 115-119)
- Requires the development, maintenance, and updating of a strategy to recognize and support family caregivers
- Brings together representatives from the private and public sectors to advise and make recommendations on the strategy
- Identifies recommended actions that communities, providers, government, and others are taking or may take to recognize and support family caregivers



#### **Areas Included in the Strategy**

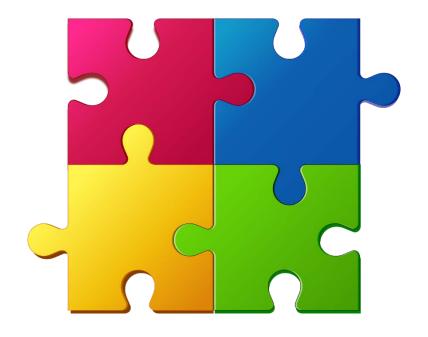
- Promoting greater adoption of person- and family-centered care in all health and long-term services and supports (LTSS) settings
- Assessment and service planning (including care transitions and coordination) involving family caregivers and care recipients
- Information, education and training supports, referral, and care coordination
  - Including hospice care, palliative care, and advance-planning services



#### **Areas Included in the Strategy**

Respite options

- Financial security and workplace issues
- Delivering services based on the performance, mission, and purpose of a program while eliminating redundancies



#### **Family Caregiving Advisory Council**

- Advises HHS Secretary and provide recommendations on recognizing and supporting family caregivers
- Not more than 15 voting members appointed by the HHS Secretary, including at least one representative of each category listed in the law
- Non-voting federal members, and heads of other federal departments or agencies as appointed by the Secretary or the Chair of the Advisory Council



#### Implementation Update

- Administration for Community Living (ACL, part of Department of Health and Human Services) is the lead federally on RAISE implementation
  - o www.acl.gov/raise
- First Advisory Council meeting on August 28-29 (in-person)
  - Members include Catherine Alicia Georges, AARP National Volunteer President
  - Presenters included Donna Benton, Ph.D., USC Family Caregiver Support Center
  - Subcommittees of the Advisory Council are meeting
  - Expect next full meeting to be virtual



#### Implementation Update – Taking Action

- ACL Request for Input Deadline Feb. 7
  - o See https://acl.gov/form/public-input-raise
- RAISE Family Caregiver Resource and Dissemination Center at **National Academy of State Health Policy -**

https://nashp.org/policy/chronic-and-complexpopulations/the-raise-family-caregiver-resource-anddissemination-center/

Public listening sessions in 2020





#### **Key Steps to Come**

- Public input opportunities (see also previous slide)
- Advisory Council issues first annual report
- Initial strategy developed and published informed by Advisory Council report; strategy updated biennially
- Law sunsets three years after enactment Jan. 22, 2021
  - RAISE extension being considered as part of Older Americans Act reauthorization bills



#### **Older Americans Act (OAA)**

First enacted in 1965

Provides services for more than 11 million older adults

 Services include: home care, congregate and home-delivered meals, case management, family caregiver support, transportation, adult day care, legal services, elder abuse prevention, and job training and employment opportunities for low-income older adults



#### Caregiving in OAA Reauthorization

- Further strengthens the National Family Caregiver Support Program (NFCSP) by encouraging use of caregiver assessments
  - Assessments help target services more effectively and efficiently
  - Help with maintaining the health and well-being of the caregiver, sustaining ability to provide care, producing better outcomes for their loved ones and preventing or delaying nursing home placement
- Extends the RAISE Family Caregivers Act
  - House 1-year extension
  - Senate 5-year extension
- Provides increased funding levels



#### Status of OAA Reauthorization

- Expired on Sept. 30
- House passed OAA reauthorization H.R. 4334, Dignity in Aging Act of 2019
- Senate introduced OAA reauthorization S. 3057,
   Modernization of the Older Americans Act Amendments
- AARP endorsed both bills
- House and Senate are working on compromise bill
- Goal to reauthorize early 2020
- AARP urging for prompt reauthorization



#### Credit for Caring Act (S. 1443/H.R. 2730)

- Introduced by Sens. Ernst (R-IA), Bennet (D-CO), Capito (R-WV), Warren (D-MA) and Reps. Sánchez (D-CA) and Reed (R-NY) and supported by AARP
- Proposed nonrefundable federal tax credit for eligible working family caregivers who incur qualified expenses
- After paying the first \$2,000 in qualified expenses, 30% credit on qualified expenses up to maximum credit amount of \$3,000
- Helps with expenses such as home care, home modifications, respite care, adult day care, transportation, travel costs, assisted living and more



#### **Credit for Caring Act**

- Family caregiver does not have to live with the person they care for and person does not have to be a dependent
- Family caregivers are spouses, adult children, parents or other relationships under the "dependent" definition
- They help a loved one, of any age, who meets certain functional or cognitive limitations or other requirements, as certified by a licensed health care practitioner



### **Credit for Caring Act**



- Phases out at higher income levels
- Coordinates with other existing tax provisions to prevent "double dipping"
- Indexes certain dollar amounts and income levels to inflation



#### **Respite Care**

 Family caregivers spend on average 24 hours a week caring for their loved one

- About 30 percent of family caregivers provide an average of 62 hours of care a week; some provide 24/7 care
- Respite gives family caregivers a temporary break from caregiving to rest, recharge, and take care of themselves
- Can extend the time an individual is cared for at home, potentially delaying costly institutional care



#### Lifespan Respite Care Program

 Lifespan Respite Care Program helps family caregivers caring for loved ones regardless of age or disability, including by providing:

- o respite services;
- training respite workers and volunteers;
- o information about and assistance in accessing services; and
- better coordinating services



## Lifespan Respite Care Reauthorization Act (S. 995/H.R. 2035)

- Sponsored by Sens. Collins (R-ME) and Baldwin (D-WI) and Reps. Langevin (D-RI) and McMorris Rodgers (R-WA) and supported by AARP
- Extends the Lifespan Respite Care Program through Fiscal Year 2024, authorizes increased funding for the program, and adds new reporting requirements
- H.R. 2035 passed the House
- S. 995 passed the Senate Health, Education, Labor, and Pensions (HELP) Committee
- Further action expected in 2020



## Spousal Impoverishment Protections – Medicaid Home and Community-Based Services (HCBS)

- For 30+ years, federal law has required states to allow the spouses of individuals receiving Medicaid coverage for nursing home care to keep a portion of income and resources to avoid impoverishment
- States had the option to provide the same protection to the spouses of some individuals receiving services in the home and community (HCBS)
- Congress required these protections for spouses of individuals receiving Medicaid HCBS more broadly for five years that ended December 31, 2018
- Since then Congress has passed short-term extensions, most recently until May 22, 2020; Congress must act by then to ensure no lapse in protection



## Spousal Impoverishment Protections – Medicaid Home and Community-Based Services (HCBS)

- If protections expire, it would put individuals at risk for losing Medicaid coverage unless they enter a nursing home; could hinder or may undermine state progress in helping individuals live in their homes and communities
- Married couples should have the same protections whether care is provided in a facility or in the community
- Protecting Married Seniors from Impoverishment Act (H.R 1343/S. 2000) introduced by Reps. Dingell (D-MI) and Upton (R-MI) and Sen. Casey (D-PA) would make the Medicaid HCBS spousal impoverishment protections permanent - Supported by AARP



#### 2020 - The Year Ahead in Congress

- Expect additional action on a number of these items
- Additional bills on other issues may be introduced
- Any bills not signed into law from this Congress must be reintroduced in the next Congress, starting in January 2021, for them to be considered

You can become an AARP e-activist by registering at action.aarp.org



## California Legislature – 2020 Legislative Year Outlook – Support for Family Caregivers

- Reconvened on January 6.
- Opportunities for improvement in Paid Family Leave.
- Master Plan for Aging opportunities





#### **Paid Family Leave**

#### California's PFL program:

- An earned benefit
- Provides up to six weeks of partial pay to eligible workers who take time off work to care for a new child or seriously ill family member. Increases to 8 weeks in July, 2020.
- Administered by the Employment Development Department (EDD).



#### **Current Job Protections**

- √ For workers taking bonding leave, job protections available if employed in a firm with 20 or more employers
- ✓ Job protections available for workers in larger firms (50 or more employees) – FMLA, state law
- √ There are NO job protections for family caregivers of adult loved ones for those working in firms with less than 50 employees, including families of deploying military (eff. 1/1/21).



## Paid Family Leave Improvements Sought in 2020

- Governor Introduced his Proposed 2020-21 budget on January 10.
- He called for expanding Paid Family Leave job protections through the state budget process.
- Budget bill language due out in February.
- We will use the budget process to insure that job protections are expanded to include \*all\* caregivers.
- Remember sign up to take action with AARP at action.aarp.org!



## Our goals for the Governor's 2020-21 Budget Proposal

✓ Further expand PFL job protections for *all* caregivers (including military family members)





## Taking Action to Expand Paid Family Leave Job Protections

- Write or call the Governor's office to assert your support for expanding job protections for all types of caregivers.
  - 916-445-2841
  - Fax 916-558-3160
- Contact Budget Chairs, and Budget Sub 4 Chairs
- Contact your Assembly and State Senate representatives
- Find your state representative: http://findyourrep.legislature.ca.gov/



#### **Master Plan for Aging Input Opportunities**

- Executive Order issued on June 10, 2019
- Three committees plus workgroups:
  - Stakeholder Advisory Committee
  - LTSS Subcommittee
  - Research Subcommittee
  - Additional workgroup: Equity Workgroup

LTSS Subcommittee report, which includes caregiving, is due on March 1.

Final report due on October 1, 2020



#### Master Plan for Aging Input Opportunities

- Receive updates, and provide input at:
- https://www.engageca.org/

#### Or

- EngAGE@aging.ca.gov.
- Submit comments by mid-April to:

**EngAGE@aging.ca.gov.** 

Opportunities for public comment at end of every meeting.









## Thank You!

Contact: NWeiler@aarp.org





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