



Family Caregiving Advisory Council Meeting

May 20–21, 2020

Day 1



Opening and Convening Remarks

Lance Robertson
Administrator/Assistant Secretary for Aging
Administration for Community Living



Roll Call, Agenda Overview and Housekeeping

Greg Link, Director
Officer of Supportive and Caregiver Services
Administration for Community Living



Agenda

May 20, 2020

- 1:00 – 1:15 – **Welcome and call to order**
- 1:15 – 1:30 – **Roll call, agenda overview, housekeeping**
- 1:30 – 2:15 – **ACL/JAHF/NASHP Project Updates**
- 2:15 – 3:00 – **RFI Analysis presentation and discussion**
- 3:00 – 3:45 – **Family leave presentation with council discussion**
- 3:45 – 4:00 – **Wrap up, open discussion, prep for tomorrow**

Project Updates

Administration for Community Living (ACL)

John A. Hartford Foundation (JAHF)

National Academy of State Health Policy (NASHP)

ACL Project Updates

- Collaboration Platform
- [Progress Toward a National Strategy to Support Family Caregivers](#)
- Secretary Azar's and Administrator Robertson's Blog: [ACL Supports Family Caregiving During the COVID-19 Pandemic Response](#)

ACL Project Updates: Report to Congress

Sarah Markel, PMP
Aging Service Program Specialist, AoA
Administration for Community Living



ACL Project Updates: Federal Inventory

Laural Traylor, MSW, FNAP
Health and Aging Policy Fellow



Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017

Inventory of Federally Funded Caregiver Support Services

Sample Template

Federal Organization				
1. Federal Department and Agency Information				
1a: Federal Department, Agency and/or Operations, Division, Staff/Contact Name.	1b: Name of program(s) or initiative(s). Please include statutory authority and date of implementation if available)	1c. Program activities and focus areas. Please consider direct services (eg. HCBS, LTSS) and/or indirect services (eg. benefits; research; surveys, evaluation; quality improvement).	1d. Eligible populations or target consumers. Please describe the eligible populations targeted and served by each program or initiative	1e. How and where do caregivers access the information described?
2. Performance Metrics and Program Analytics				
2a. Appropriations history, expenditures, match requirements.	2b. Performance measures and data for each. (if known or existing)	2c. Program evaluation results. (if available or applicable)		
3. Program Gaps				
3a. Gaps in programs and initiatives. (if known)	3b. Opportunities for program development and growth.			
4. Other Information to Consider				
4a. Organization strategic planning process? If yes, how are caregivers included or considered? (Please include dates and reports if known.)	4b. Use of evidence-based interventions in service delivery?	4c. Existing coordination efforts with other federal programs?	4d. Opportunities to innovate within existing programs and resources?	4e. Key challenges and opportunities? (in the next 5, 10 years)

John A. Hartford Foundation: Project Updates

Scott Bane, JD
Program Officer
The John A. Hartford Foundation





The John A. Hartford Foundation

Dedicated to Improving the Care of Older Adults

RAISE Act Family Caregiving Advisory Council

May 20-21 Virtual Meeting – Update on Medicare and
Family Caregivers

Scott Bane, JD, MPA

Program Officer

The John A. Hartford Foundation

The John A. Hartford Foundation

Private national philanthropy based in New York, established in 1929, by family owners of the A&P grocery chain

\$625,000,000

Grants authorized since 1982 to improve health and aging

Building the field of aging experts
Testing & replicating innovation

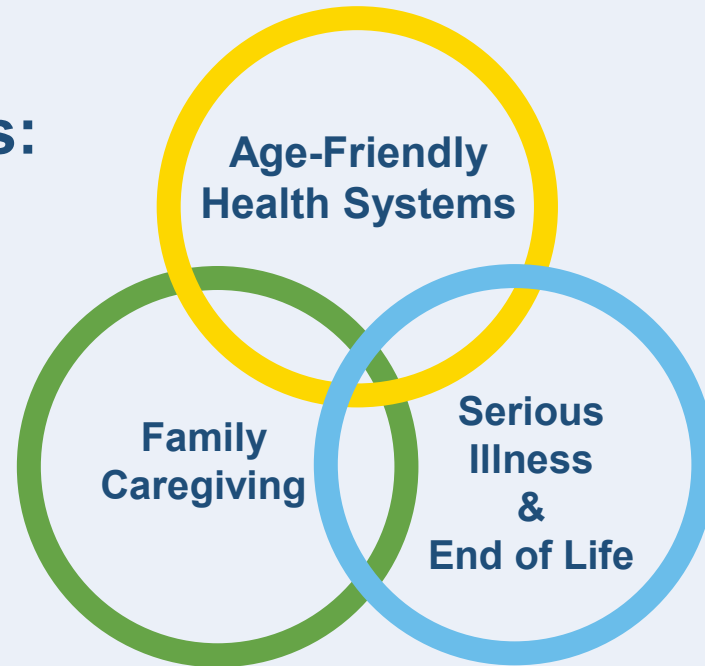


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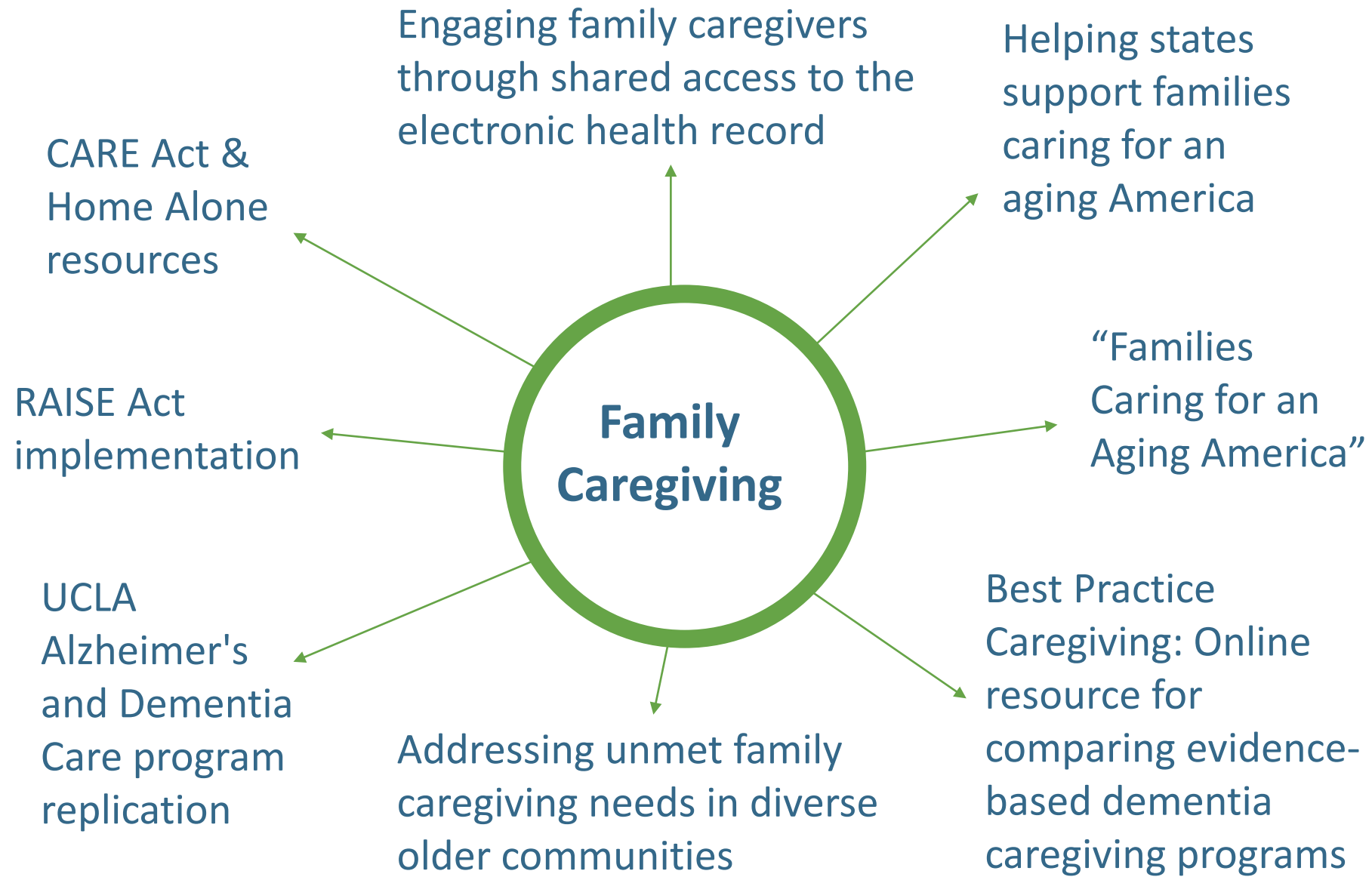
The John A. Hartford Foundation: Mission and Priorities

Dedicated to Improving the Care of Older Adults

Priority Areas:



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Medicare/Family Caregiver Analysis from the Center for Medicare Advocacy



- A national non-profit, nonpartisan law organization that provides legal assistance to help older people and people with disabilities obtain access to Medicare and quality health care
- Will produce report on Medicare and Family Caregivers



Medicare/Family Caregiver Analysis from the Center for Medicare Advocacy

- Scope of Center for Medicare Advocacy's Report on Medicare and Family Caregivers:
 - 1) Home health and home health aides
 - 2) Barriers and gaps to care for patients and challenges for family caregivers
 - 3) Recommendations
 - 4) Opportunities
- Report will be completed June 2020





Thank you!



The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults

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The National Academy for State Health Policy (NASHP) Project Updates

Kitty Purington, JD
Senior Program Director
National Academy for State
Health Policy (NASHP)



RFI Analysis Presentation and Discussion

Pamela Nadash, Ph.D.
Associate Professor
Department of Gerontology
McCormack Graduate School
University of Massachusetts



Learning from Family Caregivers

Qualitative Results – Federal Register Responses

RAISE Family Caregiving Advisory Council

May 20, 2020

Research Objectives

- Reach out to family caregivers and other stakeholders to provide multiple forums for expressing needs and challenges;
- Help identify the specific services, supports, or policy initiatives that might better meet their caregiving needs; and
- Inform the development of federal, state, and community blueprints for programs and services that can enhance the resilience of a diversity of family caregivers.

RFI Response Analysis



- Two open-ended questions
 - *One pressing family caregiving need/concern I would like to see addressed is:*
 - *I would like to offer this specific recommendation to address my need/concern:*
- One close-ended question
 - *This recommendation addresses needed actions that pertain to (Check all that apply)*
- Opportunity to identify the organization with which the respondent was affiliated
- 1613 responses
- All responses pre-COVID crisis (end date 2/7/20)

Table 1: RFI Respondents, by Category

Respondent group	N	%
Advocacy	184	11%
Community-Based Organization	154	10%
Government	31	2%
Caregivers*	1203	75%
Other Research	15	1%
University	26	2%
Total	1613	

**997 cases self-identified as individual caregivers. A further 206 were coded as such based on blank entries in the “organization” field.*

Table 2: Responses to Close-Ended Questions

	All Respondents (N=1,407)		Caregiver Respondents (N=997)	
	N	%	N	%
Service planning and or delivery	766	54.4%	538	54.0%
The greater adoption of person/family centered care	697	50.0%	480	48.1%
Respite options	647	46.0%	452	45.3%
Care transitions or coordination	633	45.0%	444	44.5%
Financial security	595	42.3%	423	42.4%
Information, education, training, and/or referral	556	39.5%	398	39.9%
Assessment	375	26.7%	272	27.3%
Workplace issues	373	26.5%	266	26.7%
Care coordination in hospice	302	21.5%	211	21.2%
Palliative care	302	21.5%	211	21.2%
Advance care planning	301	24.4%	211	21.2%

Note: These responses were to the RFI item: “This recommendation addresses needed actions that pertain to (Check all that apply)”

*The study had 1613 respondents, 1407 of whom provided answers to the close-ended questions.



Respondents reflect a diversity of experience

- Who the caregivers are
 - Caregivers who are themselves aging (including grandparent caregivers)
 - Rural caregivers
 - Long-distance caregivers
 - Also caregivers of varying racial and ethnic backgrounds and caregivers 18 and younger
- Who they care for
 - Adults and older adults with care needs
 - Children or adults with mental health needs
 - People with dementia
 - Children with special health needs

Overwhelmingly, financial issues were paramount

- Respondents expressed concern about their personal finances and future financial security
 - Ability to accommodate the care recipient's needs
 - Ability to accommodate their own (and their family's) needs, both now and in the future
- Many expressed frustration that caregiving made it difficult to work and to qualify for Social Security benefits
- The single most common issue raised in the responses was the need to pay family caregivers
 - Many also requested tax benefits or Social Security credits

“Family caregivers could benefit from a caregiver tax credit to assist families with out-of pocket costs for disability-related expenses. For those caregivers with low incomes, the earned income tax credit (EITC) and child tax credit (CTC) should be expanded.”

“Families experience hardships due the time and monetary cost of caring for a loved one. I lost my job when I first started taking care of my mother.”

Those “who take on this mantle do so at the expense of their own and their loved ones’ financial security.”

“My recommendation would be to offer a daily wage to care for a family member when it takes them away from being able to work elsewhere.”

The government should “provide supplemental retirement income for caregivers via Social Security to offset the detrimental impact of caregiving on their retirement savings and income.”

“Not only did my husband have to leave his job due to his illness, but then I had to leave my job to care for him.”

“I would like caregivers, who are saving Government many dollars by caring for our family members at home and not putting them in a public institution, be given financial recompense for their time.”

Ability to work

- Concern about how caregiving responsibilities make it difficult to work, which increases caregiver burden
- Links to need for services
 - Respite is the top service mentioned as needed
 - Adult day services are frequently mentioned
 - As a form of respite or
 - As a service (along with other services) enabling caregivers to work (although hours are unsuitable)
- Links to need for workplace protections, another big theme
 - Expanded FMLA/paid time off, flexible work, part-time options

Impact on caregivers is high

- Worries about financial circumstances and future
- Worries about ability to continue to provide care
- Impact on mental health -- Isolation, depression
- Impact on physical health

Demand for services for caregivers was high

- Again, respite was the most requested service
 - Affordable
 - High-quality
- Demand for caregiver assessments, and integration into the care planning process
- Caregiver education and training
- Information and advice – how to navigate the system, find services
- Support for caregiver mental health needs
- Social support

Much concern about the availability, affordability, and quality of services for the care recipient

- The quality and availability of direct care workers was a top theme
 - Many responses highlighted low pay for workers and explicitly linked the quality of workers to their lack of training and low pay.
- The lack of services for children and adults with mental health needs
- Lack of understanding/training among providers regarding the specific needs of care recipients
 - Lack of services targeted at specific needs

Other topics:

- Desire for inclusion, as a care partner, in all aspects of care
- Need for advocates within the system
- Supportive housing/home modifications for different types of care recipients
- Need for accessible transportation, particularly in rural areas
- Advance care planning/palliative care

Other broad themes

- Need to heighten awareness of caregiving – public awareness campaign
- Need for research and evidence
- Need for increased funding for services
 - Increase access
 - Increase quality
 - Increase affordability
- System complexity and mechanisms for navigating it effectively
 - Care coordination, discharge planning, etc

Observations

- The themes uncovered in this analysis are not new
 - Match closely with the Advisory Council driver diagram and NASHP's inventory of recommendations
- What is new is the ability to rank issues in terms of their priority from the perspective of caregivers
 - Reminder: not a representative survey
- Overwhelming level of concern about the financial impact of caregiving and the need for affordable, accessible respite

Next Step: Web-based Focus Groups

- Allow us to explore priority issues in more depth
- Planned web-based approach is ideal in the current circumstances
 - Effort to bracket issues associated with current crisis
- Will convene 12 sessions, working with project team to develop and evolve discussion guide

In-Person Listening Sessions

- Will involve key stakeholders within a given community
- Two in English and one in Spanish
- Likely to adopt a web-based approach here, too



Discussion

1. What are the big take-aways from the public input, and what recommendations should be considered?
2. How do the challenges and recommendations vary by different types of caregivers?
3. What else would the Council like to learn from the public input given that the RFI analysis can go more in-depth?
4. How can the public interest that was generated via the RFI be harnessed to further the Council's recommendations and overall work?

Thank you



COMMUNITY CATALYST

Because we all should have a say
in decisions that affect **our health**



LeadingAge
LTSS CENTER
@UMass Boston

Research bridging policy and practice

Family Leave Presentation with Council Discussion

Lynn Feinberg
Senior Strategic Policy Advisor
AARP Public Policy Institute



Family Leave

RAISE Act Family Caregiving Advisory Council May 20, 2020

Lynn Friss Feinberg, MSW
Senior Strategic Policy Advisor
AARP Public Policy Institute



Most Family Caregivers Work at a Paying Job

- More than 29 million (61%) family caregivers are employed
 - Work an average of 35.7 hours per week
- Almost 3 in 4 (72%) family caregivers ages 18 to 49 are employed
- More than two-thirds (67%) of those ages 50-64 work
- Most (61%) have made one or more workplace accommodations.



Source: National Alliance for Caregiving and AARP, *Caregiving in the U.S.* 2020.

Family Caregivers Who Stop Working Can Face Substantial Financial Risks

- Caregivers may lose income, health insurance, Social Security/retirement benefits, and career opportunities if they have to reduce work hours or leave the workforce
- Many employed family caregivers do not have paid sick days or paid family leave benefits at work
 - Or are not eligible for the *unpaid* protections of the Family and Medical Leave Act

Source: National Academies of Sciences, Engineering, and Medicine. 2016. *Families Caring for an Aging America*. Washington, DC: National Academies Press.

Definitions

Paid Sick Days

- Also known as earned sick days, paid sick leave, or paid sick time
- Generally limited to a number of hours or days (typically covering between 3 and 8 days) to allow workers to:
 - Stay home when they are sick with short-term illnesses
 - To accompany a family member to a medical appointment
 - To take limited paid hours or days off to provide care for sick family members

Family Leave

- Longer time off (either unpaid or paid) to care for a seriously or chronically ill family member

The Family and Medical Leave Act (FMLA) of 1993

- Establishes worker rights of up to 12 weeks of *unpaid*, job-projected leave to:
 - bond with a new child
 - care for oneself because of a serious health condition
 - care for certain ill family members (i.e., child, spouse, parent)
 - care for a military service member with a serious injury/illness
- Applies to private employers with 50+ employees and public-sector agencies
- Only 60% of the workforce are eligible for FMLA protections.

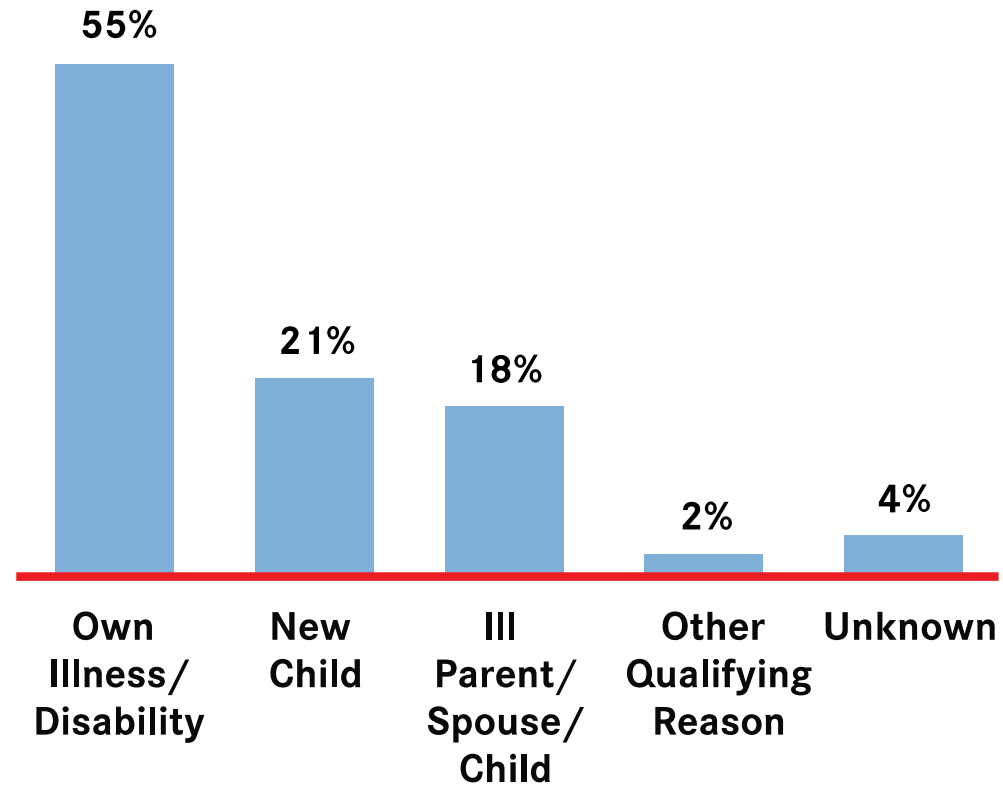


Nearly 1 in 3 States Exceed the Minimum Requirements of the FMLA

- 14 states +DC have broadened eligibility for family caregivers
 - CA, CO, CT, HI, ME, MA, MN, NJ, NY, OR, RI, VT, WA, WI
- 3 main ways:
 - Covering workers in businesses with fewer than 50 employees
 - Providing a more inclusive definition of an “eligible family member” to include domestic partners, grandparents, parents-in-laws, or siblings
 - Expanding FMLA use provisions to allow workers to take family members to medical appointments



Reasons for Taking FMLA Leave



Source: J.A. Klermon, K. Daley, & A. Pozniak, Family and Medical Leave in 2012: Technical Report, 2014

COVID-19 Has Raised Awareness of the Need for Access to Paid Workplace Leave Policies in the U.S.

- The U.S. is the only high-wealth nation without some guaranteed benefit to paid sick days or paid family leave
- Providing workers with access to workplace leave policies can:
 - Lessen the strain of caregiving
 - Provide employed family caregivers with greater financial security
 - Especially low-wage workers
 - Reduce older adults' nursing home utilization
 - Increase employee retention
 - Help maintain a productive and healthy workforce



Two New Federal Laws Address Paid Time Off for Some Workers Due to COVID-19 – Big Gaps Remain

- Families First Coronavirus Response Act (FFCRA) – 3/18/20
- Coronavirus Aid, Relief, and Economic Security (CARES) Act – 3/27/20
 - First time Congress required federal paid leave for private sector workers
 - Provides some workers up to 10 paid sick days and up to 10 weeks of paid family and medical leave until 12/31/20
 - Only for workers at businesses with 500 or fewer employees
 - Allows DOL to exempt small businesses with less than 50 employees
 - **Family caregivers have less access to paid leave than others**
 - Workers caring for adults affected by COVID-19 are *ineligible* for emergency **paid family leave** (only allowed for child care) and can only receive 2/3 wage replacement for **sick leave** when caring for anyone other than themselves



Some Employers Voluntarily Offer the Option of Paid Family Leave (PFL) Benefits

- Currently, employees can access PFL if offered by an employer
 - Only 19% of civilian workers have access to PFL through their workplace
 - Low-wage workers, young adults, multicultural workers, and those employed in small businesses are least likely to have PFL
- Most private-sector PFL is currently limited to parental leave
- Over 100 brand-name companies have voluntarily adopted or expanded PFL over the past few years— mostly covering new parents
 - Only 1 in 5 (20%) offer PFL for caregiving needs for certain family members
- Most private sector leave policies do not offer an inclusive definition of family or cover other relationships and someone’s “chosen family”

States are Leading the Way to Enact PFL Programs

- 8 states and DC have PFL programs that cover family caregivers
 - CA, NJ, RI, NY, DC, WA, MA, CT, and OR
- State programs differ in eligibility requirements, qualifying family members, amount of benefits paid, maximum length of paid leave, job protection or not, and how the program is funded.
- Utilization of state PFL programs for family caregiving needs is relatively low but climbing
 - % of PFL claims for family care
 - CA – 12%; NJ -16%; RI -23%
- Main barriers: Lack of awareness, limited wage replacement, lack of job protection, social stigma, and workplace culture



States are Leading the Way to Enact Paid Sick Days Laws that Cover Family Caregivers

- Another important workplace leave benefit for employed family caregivers is access to paid sick leave, also known as *paid sick days*.
- As with PFL, current federal policy does not require employers to offer paid sick days as an employment benefit for all workers.
- More than 1 in 4 (27%) workers have no paid sick days at their jobs
 - especially low-wage workers and service-sector workers.
- 13 states and DC mandate paid sick days
 - AZ, CA, CT, DC, ME, MA, MD, MI, NV, NJ, OR, RI, VT and WA

Paid Family Leave

- 2018 AARP Public Policy Institute paper highlights PFL benefits in early adopter states, reviews research, and discusses the implications of PFL (or lack thereof) for working family caregivers.
 - <https://www.aarp.org/ppi/info-2018/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.html>
- 2019 article in the *Journal of the American Geriatrics Society* encourages clinicians to increase awareness about PFL benefits
 - <https://onlinelibrary.wiley.com/doi/abs/10.1111/jgs.15869>

AARP PUBLIC POLICY INSTITUTE

SEPTEMBER 2018

Insight on the Issues

Breaking New Ground: Supporting Employed Family Caregivers with Workplace Leave Policies

Lynn Friss Feinberg
AARP Public Policy Institute

Take Aways

- ✓ Managing paid work and caregiving can be a challenging balancing act, a financial hardship, an emotional rollercoaster, and a health risk too
- ✓ Supportive workplace benefits that help workers remain in the workforce and continue caring for ill family members are “win wins” for employers, caregiving families, and society
- ✓ Paid sick leave and paid family leave policies are a sound investment
- ✓ Workers should not have to choose between keeping their jobs and providing care to a seriously ill family member



Family Leave Presentation with Council Discussion

1. What is the landscape and promising practices regarding family leave policies?
2. Has COVID-19 changed the way society views family and sick leave?
3. Should the Family and Medical Leave Act (FMLA) be expanded? If so, how?
4. Do employees even know about the FMLA? Could employers be encouraged to provide paid family leave and flexible work arrangements?

Contact:

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Wrap up, Open Discussion, Prep for Day 2

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National Academy for State Health Policy (NASHP)



Thank You