

Paid Care and Supporting Diverse Older Adults with Dementia and Their Family Caregivers

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Today

1. Paid Care: An Overview
2. Paid Care, Dementia, and Racial and Ethnic Disparities
3. Family Caregivers and Paid Care
4. Strategies to Strengthen Paid Care Access and Delivery



The background is a solid dark blue. On the left side, there are two large, light blue stylized graphics. The upper one is a flame, and the lower one is a globe with latitude and longitude lines. A light blue horizontal bar is positioned in the center-right of the slide.

Paid Care: An Overview

Paid Care

- Provides assistance with routine activities for people with disabilities with routine daily activities (e.g., bathing, dressing, meal preparation, medication administration)
- Traditional community settings, residential care settings (e.g., assisted living)
- Medicaid Home and Community-Based Services (HCBS); private pay; Medicare Home Health
- Medicaid HCBS Rebalancing has resulted in the shifting of state priorities from institutional care to HCBS



Who provides paid care: The Direct Care Workforce

Home Care Workers

2.6 million personal care aides, home health aides, and nursing assistants who support individuals in private homes.

Residential Care Aides

647,500 personal care aides, home health aides, and nursing assistants who assist individuals in group homes, assisted living communities, and other residential care settings

Nursing Assistants in Nursing Homes

471,000 workers providing services to individuals living in skilled nursing homes.

PHI, 2022



Who receives paid care?

Percentage of Older Adults Receiving Paid and Unpaid Help in the Last Month, by Level of Assistance (N= 2,499; Weighted N= 9.8 Million)

	3+ Self-Care or Mobility Activities ^c	1 to 2 Self-Care or Mobility Activities ^c	Only Household Activities ^d	Any Self-Care, Mobility, or Household Activity
Any paid help	50.0	28.0	29.4	34.5
Any unpaid help	94.7	95.6	94.6	95.0
Paid help only	5.3	4.4	5.3	5.0
Unpaid help only	50.0	72.0	70.5	65.5
Both	44.7	23.6	24.1	29.5

Data from National Health and Aging Trends Study, 2011; Excludes nursing home residents
(Freedman & Spillman, 2014; *Milbank Quarterly*)





Paid Care, Dementia, and Racial and Ethnic Disparities

Racial and Ethnic Disparities in Paid Care

- Research on access to and outcomes of racial/ethnic disparities in paid care is limited and mixed
- Observed differences in access may be the result of several factors (e.g., service availability, lack of culturally tailored services)
- Disparities in the initiation, provision, and quality of services like Medicare Home Health

Shippee et al., 2022; *JAMDA*

Gorges, et al., 2019; *Health Affairs*

Fashaw-Walters et al., 2022; *Health Affairs*

Joynt-Maddox et al., 2018; *JAGS*

Yeboah-Korang et al., 2011; *JAGS*



Paid Care for People with Dementia

- Older adults with dementia are more likely to use paid help than those without dementia
- Targeted supports available (e.g., Medicaid HCBS, dementia-specific care in assisted living)
- Limited dementia specific training for direct care workers
- As a result of disparities in dementia prevalence and level of disability, those from racial and ethnic minoritized groups receiving paid help may have different service needs than their White counterparts

Fabius, et al., 2022; *Journals of Gerontology: Social Sciences*

Kasper, et al., 2018: *Health Affairs*

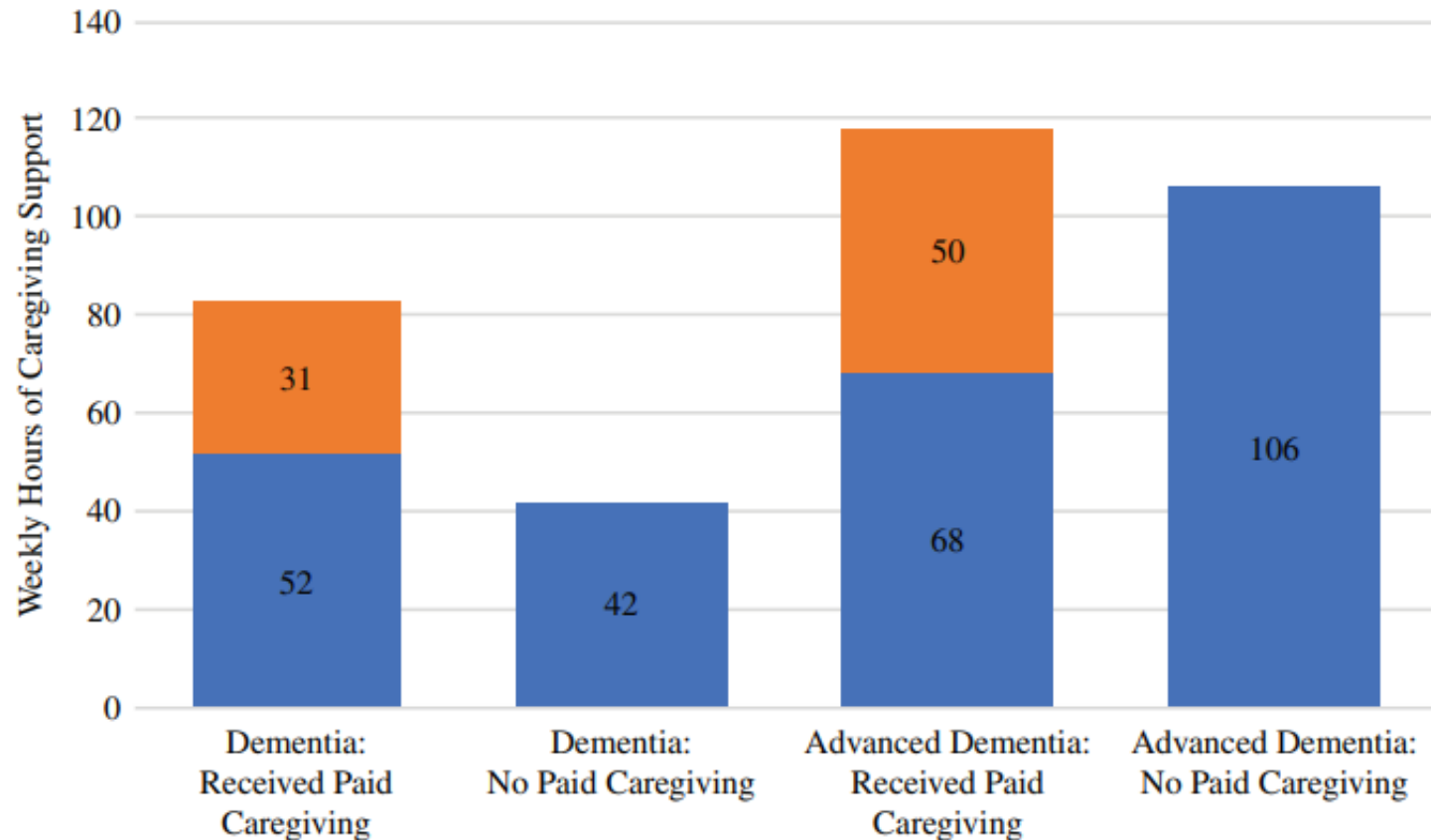
Cornell et al., 2020: *JAMDA*

Garfield, et al., 2015: *KFF*

Fabius et al., 2020: *The Gerontologist*



Paid and unpaid care varies across dementia stage



Data from the National Health and Aging Trends Study (2015); N= 899 Community-dwelling older adults aged 65 and older with dementia. **ORANGE**: paid caregiving; **BLUE**: unpaid caregiving. (Reckrey et al., 2020: JAGS)



Care experiences of those receiving paid care

Associations Between Paid Help, Race/Ethnicity and Care Experiences Among Community-Dwelling Dual-Enrollees with and without Dementia

	Any adverse consequences due to unmet need			
	No dementia		Dementia	
	AOR	p-value	AOR	p-value
Any Paid Help	1.47	0.33	2.05	0.02

Data from the National Health and Aging Trends Study (2011-2015). N=979 Medicaid-enrolled persons aged 65 and older living in community settings with disabilities. Adjusted for age, sex, race/ethnicity, number of health conditions, level of disability, living arrangement, neighborhood social disadvantage, Medicaid generosity. (Fabius et al., 2022: *Journals of Gerontology: Social Sciences*)



Care experiences of those receiving paid care

Care Experiences of Medicaid Home and Community-Based Service Participants, by Dementia Status

	Total (100%)	Dementia (54%)	No Dementia (46%)
Low social engagement, %	61.7	62.9	60.3
Hospitalizations, %	7.8	7.5	8.1
Emergency Room Use, %	8.4	8.9	7.8

Among (N = 1144) older adults (65+) receiving Maryland Home and Community-Based Services from 25 residential service agencies; comparisons based on Pearson's chi-square tests and T-tests. Dementia defined as self-reported Alzheimer's diseases and related dementias or a Bref Interview for Mental Status (BIMS) score of 12 or less. (Fabius et al., 2022: *Journal of Applied Gerontology*)





Family Caregivers and Paid Care

Family Caregivers and Paid Care

- Caregiving related race-differences exist for caregiving intensity, level of disability of care recipient, financial resources, and caregiving experiences
- Family caregivers manage paid caregivers in the home, including monitoring, training paid caregivers, and coordinating care (Reckrey et al., 2022)
- Compared to non-dementia caregivers, dementia caregivers more often supportive services that include paid care (e.g., respite).

Parker & Fabius, 2022: *Journal of Applied Gerontology*

Fabius et al., 2020: *The Gerontologist*

Reckrey et al., 2022: *International Journal of Environmental Research and Public Health*

Travers et al., 2023: *JAGS*



Family Caregiver Experiences and Paid Care

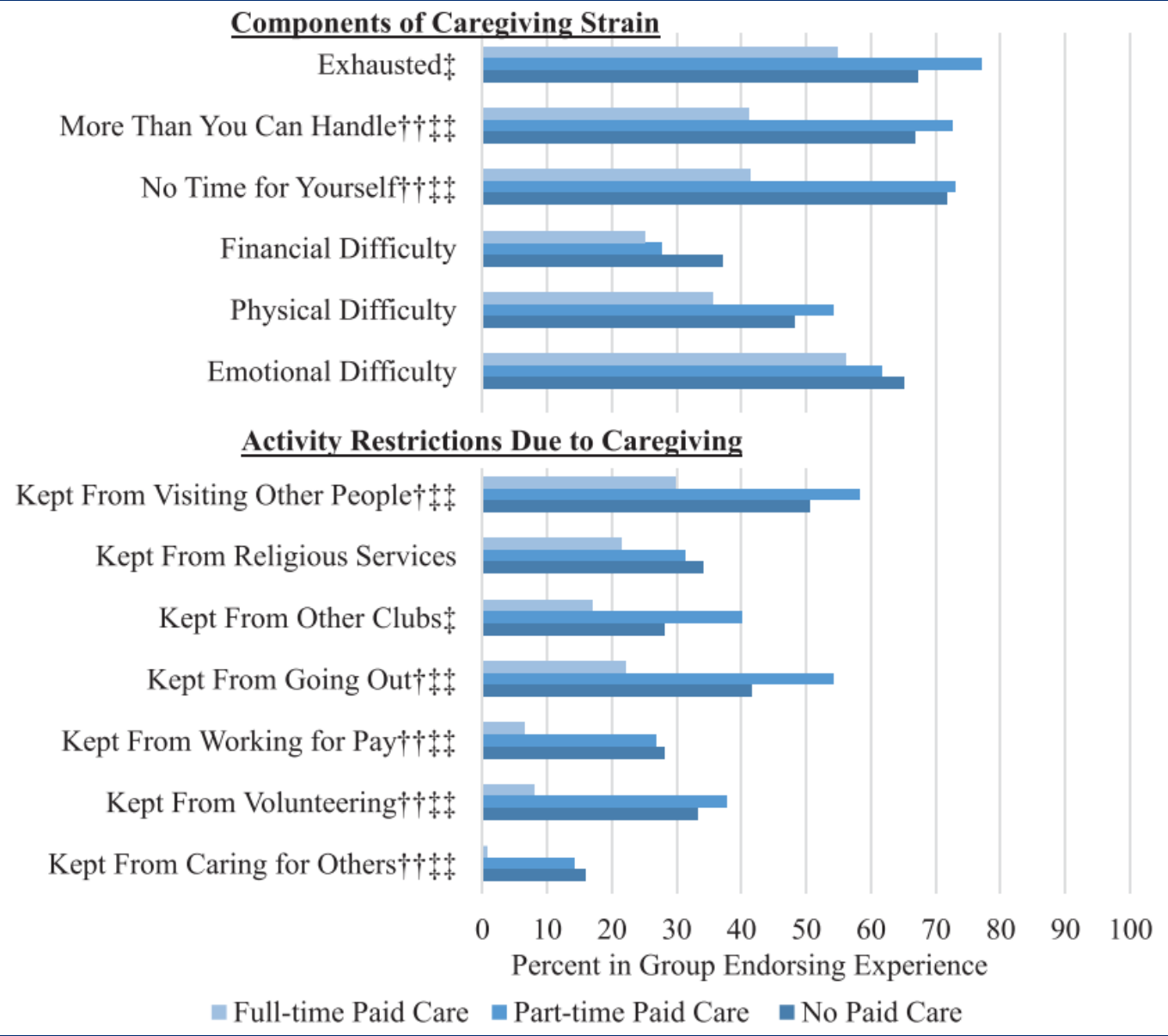
Care Experiences of Medicaid Home and Community-Based Service Participants, by Dementia Status

	Total (100%)	Dementia (54%)	No Dementia (46%)
Caregiver is overwhelmed, %**	12.9	16.9	8.3
Caregiver is distressed, angry, or depressed, %*	4.6	6.0	3.0
Caregiver is unable to continue caregiving, %*	4.6	6.2	3.8

Among (N = 1144) older adults (65+) receiving Maryland Home and Community-Based Services from 25 residential service agencies; comparisons based on Pearson's chi-square tests and T-tests. Dementia defined as self-reported Alzheimer's diseases and related dementias or a Brief Interview for Mental Status (BIMS) score of 12 or less. (Fabius et al., 2022: *Journal of Applied Gerontology*) p -value *= p <0.01 ** p <0.001



Dementia Family Caregivers and Paid Care





Strategies to Improve Paid Care

Information Exchange between Family Caregivers and Paid Caregivers

Home care agency staff and family caregivers share information and collaborate about aspects of care delivery, especially for people with dementia

“Families of people with dementia are very-- they’re always anxious, they’re always wanting to know. If you have somebody with just companionship, or a different type of care, they don’t really care about the day to day. Whereas people with dementia, they want to know everything, and that’s why I thought that the system would help us communicate, but it was always questioned, and led to way more phone calls than necessary.”

(Administrator 1)

Fabius, et al, In Press: *Geriatric Nursing*



LTSS Environment Framework (Fabius et al., 2023: Milbank Quarterly)			
Key populations: racial/ethnic minority groups, socioeconomically, disadvantaged populations, rural populations, disability populations, sexual/gender minority groups			
Environmental Domains	Environmental Levels		
	Societal (State or Federal)	Community context (local, neighborhood)	Household
	Quality (e.g., quality of services; adequacy of policy implementation)		
Social & Economic			
Economic status	SNAP generosity	SDI; poverty; education	Income and assets; education; receipt of public assistance
Sociocultural factors	Community participation	Crime; social cohesion; segregation	Religiosity; language; cultural beliefs
Health Care & Social Services Delivery			
Health Care/LTSS Financing	Medicaid HCBS generosity; minimum wage; MLTSS presence; Medicare Advantage enrollees; Title III/OAA spending	Medicaid enrollment; health insurance mix; Medicare spending	Medicaid-enrolled, source of paid help (e.g., state Medicaid program, private pay; long-term care insurance
Direct Care Workforce	Training requirements	Supply, wages	Presence & types of paid help
Family Caregiving	Availability of state paid family leave, paid sick leave	Number of older/disabled person services (e.g., adult day services)	Relationship of caregiver, hours of care
			Food stamps, meal delivery
Built and natural physical environment			
Transportation/land use	Presence of state coordination council	Zoning, population density	Car ownership, driving status, transportation
Communication infrastructure	State web accessibility regulations	Proportion of population with broadband internet	Internet use
Housing infrastructure	--	Household value to income ratio; Median housing stock age	Housing quality, residence type, rent vs. own



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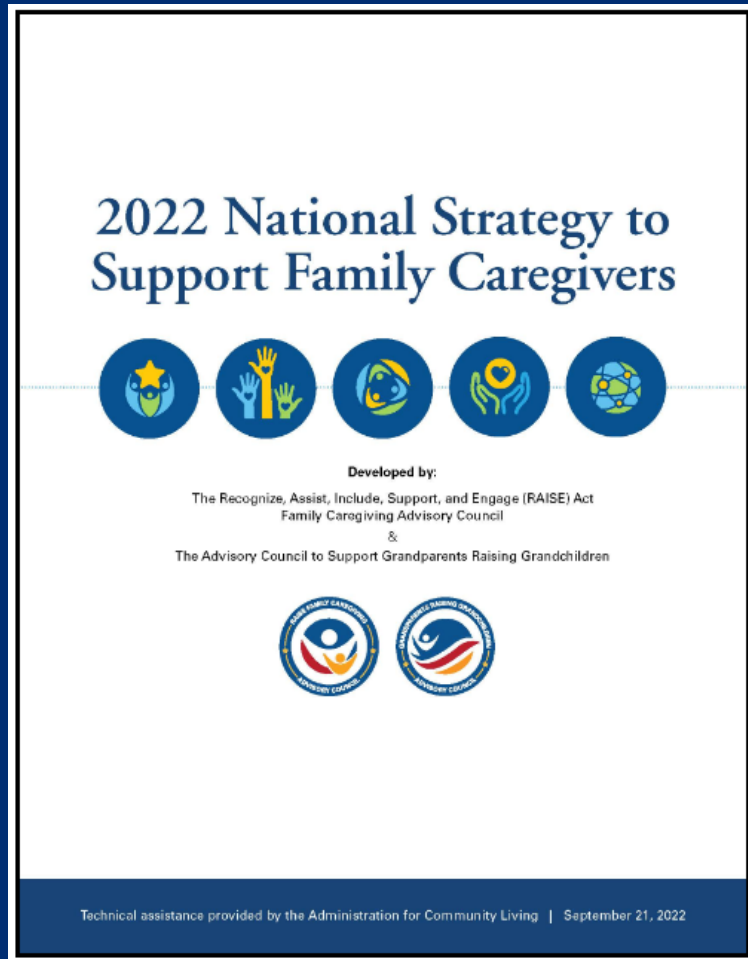
NATIONAL RESEARCH SUMMIT ON Care, Services, and Supports For Persons Living with Dementia and Their Care Partners/Caregivers

Recommendations

- Examine how health care policies and payment models differentially affect access and quality of care received by people living with dementia in community settings to guide interventions.
- Conduct culturally informed research on caregivers' well-being and the provision of caregiving supports and services
- Conduct research to strengthen the direct care workforce, including: increasing available data, understanding the interactions within caregiving teams, and developing equitable interventions.



National Strategy to Support Family Caregivers



Goals

1. Increase awareness of and outreach to family caregivers
2. Advance partnerships and engagement with family caregivers
3. Strengthen services and supports for family caregivers
4. Ensure financial and workplace security for family caregivers
5. Expand data, research, and evidence-based practices to support family caregivers

Administration for Community Living: <https://acl.gov/CaregiverStrategy>

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White House Executive Orders

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APRIL 18, 2023

Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers



► [BRIEFING ROOM](#)

► [PRESIDENTIAL ACTIONS](#)

- Improve affordability of LTSS
- Improve access to home-based care for veterans
- Enhance job quality for the direct care workforce
- Support family caregivers

The White House: <https://www.whitehouse.gov/briefing-room/presidential-actions/2023/04/18/executive-order-on-increasing-access-to-high-quality-care-and-supporting-caregivers/>



In conclusion...

- Paid care may support older adults living with dementia in the community, as well as their family caregivers
- Existing racial and ethnic disparities in paid care use and care experiences require innovative strategies to address them
- Efforts to improve paid care for older adults with dementia and their caregivers should be culturally adaptive and consider the role of and implications for the direct care workforce.



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Thank you!

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WHAT IS PUBLIC HEALTH?

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