



California Aging and Disability Research Partnership Meeting

April 19, 2024
10:00 a.m. – 12:00 p.m.

Welcome & Logistics Review

Carroll De Andreis

*Manager, MPA Stakeholder & Public Engagement
California Department of Aging*

Meeting Logistics

Webinar or Telephone only

- Live captioning and American Sign Language (ASL) interpreting streamed through webinar (Zoom)
- Meeting slides, transcript, and recording will be posted to [California Health and Human Services \(CalHHS\) Master Plan for Aging](#) webpage.
- Committee members - please update your name display in Zoom by right clicking the upper right corner of your video and selecting "rename."

Virtual Meeting Operations

- The chat function is only enabled for Committee Members and California Department of Aging (CDA) staff to share meeting-related resources and information. The public will be able to view content shared in the chat during the meeting.
- The chat and the Question/Answer functions are not enabled for comments and questions from public attendees.
- We invite the public to provide comments. Please hold comments until the end of the meeting during the designated Public Comment period.
- Additional public comments and questions can be directed to EngAGE@aging.ca.gov.

Public Comment



Attendees joining by **phone**, *press *9* on your dial pad to join line. The moderator will announce the last 4 digits of your phone number and will unmute your line.



Attendees joining by **webinar (Zoom)**, *click* the raise hand button to join line. The moderator will announce your name or your last 4 digits of your phone number and will unmute your line.

Note: Public commentators will have 2 minutes.

For additional public comment, email EngAGE@aging.ca.gov

Committee Purpose

The primary purpose of the California Aging and Disability Research Partnership (CADRP) is to:

- 1) Advance age- and disability-focused research to strengthen the evidence base for promoting equitable opportunities for Californians to thrive as they age;
- 2) Provide input on key performance indicators and data sources to inform MPA Outcomes Reports and the Data Dashboard for Aging; and
- 3) Model a research partnership between California state government and academic institutions focused on using data for action and equity that can be replicated across other CalHHS person-centered, data-driven priorities.

CADRP Stakeholder Committee Members (2024-2025)

- **Leonard Abbeduto**, UC-Davis MIND Institute
- **Zia Agha**, West Health
- **Donna Benton**, USC Leonard Davis School of Gerontology
- **Olivia Burns**, The SCAN Foundation
- **Isabella Chu**, Stanford Center for Population Health Sciences
- **Ryan Easterly**, WITH Foundation
- **Steve Hornberger**, SDSU Social Policy Institute
- **Kathryn Kietzman**, UCLA Center for Health Policy Research
- **Margot Kushel**, UCSF Benioff Homelessness and Housing Initiative
- **Jasmine Lacsamana**, Archstone Foundation
- **David Lindeman**, CITRIS Health
- **Angela Perone**, UCB School of Social Welfare
- **Nari Rhee**, UCB Labor Center
- **Kathleen Wilber**, USC Leonard Davis School of Gerontology
- **Heather Young**, Betty Irene Moore School of Nursing at UC Davis

Meeting Agenda

- 10:00** **Welcome & Logistics Review**
- 10:05** **MPA and CDA Updates**
- 10:20** **CADRP Priorities for the 2024 MPA Day of Action**
- 11:10** **LGBTQIA+ Study Next Steps**
- 11:25** **MPA Key Outcomes: Revisiting Caregiver Burden**
- 11:50** **Public Comment**
- 12:00** **Adjourn**

CA for ALL Ages & Abilities: MPA Day of Action



CA
FOR ALL
AGES & ABILITIES
DAY OF ACTION

Date: Tuesday, October 8, 2024

Location: Sacramento Convention Center

Time: Full-day; specifics TBD

**Thank you to the MPA's philanthropic partners
for supporting this event.**

Focus future work on the highest priority issues facing Californians today & Center future MPA planning on equity and lived experience.

- Gather priority recommendations from the Master Plan on Aging (MPA) Stakeholder Committees to inform the development of the MPA Initiatives for the next two years (2025 & 2026).

Celebrate progress to-date and renew our shared commitment to the MPA, California's 10-year blueprint for all ages and abilities.

- Sustain and re-invigorate diverse partners and stakeholders on California's commitment to achieve the MPA's Five Bold Goals.

Engage Diverse Partners in the "Whole of Government Approach"

- Be a model by convening state and national leaders to advance equity, collaboration, and integration among sectors in charting a path forward to prepare for the nation's aging population.

MPA Stakeholder Committees

A Roadmap to the 2025 - 2026 MPA Initiatives

1. Where Are We Now?

- Understand the Baseline
- Develop a Problem Statement

2. Where Do We Want to Be?

- Set & Define Goal(s) - policy, program, community, family, person

3. How Will We Get There?

- Brainstorm Recommendations & Strategies

4. How Will We Know We Got/Are Getting There?

- Describe the Outputs & Outcomes of Each Recommendation

Recommendation Considerations

- A. Does the recommendation provide a clear, direct, and action-based solution to the identified problem or issue?

- B. Does the recommendation focus on:
 - Equity?
 - Priority populations?
 - Policy, environment & systems change?
 - Person-centered/person-led?

- C. Does the recommendation address a pillar of the long-term services and supports (LTSS) framework?
 - Access?
 - Navigation?
 - Workforce?
 - Financing?

Recommendation Considerations, cont.

- D. Does the recommendation align with a MPA key outcome measure?
- Reduce older adult homelessness?
 - Reduce self-reported psychological distress among older adults and adults with disabilities?
 - Reduce burdens faced by family and friends caregivers?
 - Supply of the direct care workforce?
- E. Is the recommendation relevant and responsive (i.e. timely) to the priority needs of older adults, people with disabilities, and caregivers?
- F. Is the recommendation feasible/realistic to advance or implement over the next two years?
- G. Is the recommendation measurable (short, intermediate, and long-term)?
- H. What resources (i.e. fiscal, staff, technology, communications, etc.) or inputs are needed to implement the recommendation?
- I. Does the recommendation fall within the scope & roles/responsibilities of the state?

Ross Lallian

Chief of Research

California Department of Aging

CADRP 2022 Day of Action Recommendations

- 1. Identify beacons**, and associated drivers that offer optimal opportunities for achieving goals of the MPA.
- 2. Establish a research consortium** and provide seed funding to catalyze collaborative research efforts to improve the evidence base for achieving goals of the MPA.

CADRP 2022 Day of Action Recommendations

3a. Identify data priorities and reduce barriers to appropriate access to data to inform and enable monitoring of progress on the beacons and to enhance research priorities.

3b. Continue to support development of **state research and data functions** and ensure that emerging **state data assets** are designed to enable whole person data capture and exchange.

CADRP 2022 Day of Action Next Steps

- Build consensus on key outcome measures and associated drivers, metrics, and data.
- Identify and gain access to data sources to develop key outcome measures.
- Identify and launch two to three research projects.
- Host an initial working meeting to convene experts and leaders in aging and disability research.

CADRP Progress to Date: Key Outcomes

- Four key outcome measures have been identified:

Key Outcome Measure	Data Source
Reduce homelessness among older adults	Homelessness Data Integration System
Reduce self-reported psychological distress among older adults and adults with disabilities	California Health Interview Survey (CHIS)
Reduce burdens faced by family and friends caregivers	CHIS Caregiver Module, CareNav (Caregiver Resource Centers data)
Increase the provider to population ratio among the direct care workforce	Census

MPA Key Outcome Measures Demo

Key Outcome Measures Next Steps

- Publish dashboards on the Data Dashboard for Aging
- Obtain the data necessary to finalize visualizations and equity index for each Key Outcome measure.
- Continue to identify drivers and related data for each Key Outcome measure.

CADRP Progress to Date

- Two research projects were launched with involvement of CADRP members:
 - In December 2023, WHI conducted a population survey of older adults about behavioral health access, experience, and opinions.
 - In January 2024, a survey of LGBTQIA+ older adults was launched via a partnership between Openhouse, UCSF, CDA, and CITRIS.
- Continued discussions with HCAI to support a CADRP Health Payments Database data request.
- Continued discussion with the Center for Data Insights and Innovation regarding the Research and Data Hub.

CDA Updates

- CDA has hired a new research staff member who will start in July.
- The Data Dashboard for Aging has been transitioned to the MPA website (<https://mpa.aging.ca.gov/DashBoard/>)
- CDA is moving towards centralization of data assets.

Discussion

- From your perspective, what are the highest priority issues facing older Californians today?
- What areas of research do you think the CADRP should prioritize?
- What areas of research are you focusing on which may intersect with the CADRP?

CADRP Goals and Priorities

Topic	Priority
Collect qualitative and quantitative data about the experiences and needs of older adults who are part of the LGBTQIA+ community.	
Implement data tracking for key outcomes.	
Home and Community Based Service Gap Analysis	
Champion the need to link administrative data across sources.	
Evaluate efficacy of homelessness interventions.	
Administer a survey to collect data and refine prevalence estimates of psychological distress and loneliness.	
Identify associations between health status, psychological distress, loneliness, access to behavioral health services, and social determinants of health.	
Advance data collection on caregivers.	
Explore potential to evaluate efficacy of direct care workforce training.	
Advance data collection on the direct care workforce.	



LGBTQIA+ Study: From Challenges to Resilience

April 19, 2024

Survey



- California's first statewide survey documenting the needs and priorities of mid-life and older LGBTQIA+ residents across the state
- Data will help policymakers, local communities, and CDA strengthen services and programs to meet community needs and develop policy interventions to serve LGBTQIA+ older adults moving forward.

Survey Status

- January 8 - March 31
- Demographics
- Data Analysis
- Next Steps



Focus Groups

- In-depth focus group study of LGBTQIA+ and same-gender-loving older adults in California
- Targets low-income, minoritized, and geographically isolated adults
- Builds on survey
- To identify gaps in needs and highlight priorities
- Elevate stories, experiences, and community knowledge



Focus Groups Next Steps

- 10-14 focus groups throughout California
- Community partnerships
- FAQs / handouts
- Policy recommendations
- Timeline



Contact Information



For more information about the focus group project,
including participating in the study:
lgbtqia_focusgroups@berkeley.edu



PI: Dr. Angie Perone (**aperone@berkeley.edu**)



Master Plan for Aging Key Outcomes: Opportunities to use CareNav™ data

*CADRP Workgroup Meeting: Workforce
April 19, 2024*

Workforce Workgroup (1 of 2)

Goal	Indicator	Outcome or Driver?
Reduce the Burdens Faced by Family and Friends Caregivers	Number/percentage of adult caregivers who experienced financial stress, physical/behavioral health issues, or a change in job status as a result of their caregiving.	Outcome
Provide Support to Family Caregivers	Increase CRC support; Participation in state paid family leave	Driver
Ensure an Adequate Supply of Paid In-Home Caregivers to Meet the Needs of Older Adults and Adults With Disabilities	Number of in-home caregiving workforce per 1,000 adults age 60+; Home Care Workers/Aides employed through an agency; IHSS registered workers; Certified Nursing Assistants and Home Health Aides	Driver



California Caregiver Resource Centers Evaluation Team

FAMILY CAREGIVING INSTITUTE

BETTY IRENE MOORE SCHOOL OF NURSING

Heather M. Young, PhD, RN, FAAN, FGSA
Co-Principal Investigator

Janice F. Bell, MN, MPH, PhD, FAAN
Co-Principal Investigator

Jennifer Mongoven, MPH, Co-Investigator
Associate Director for Operations, FCI

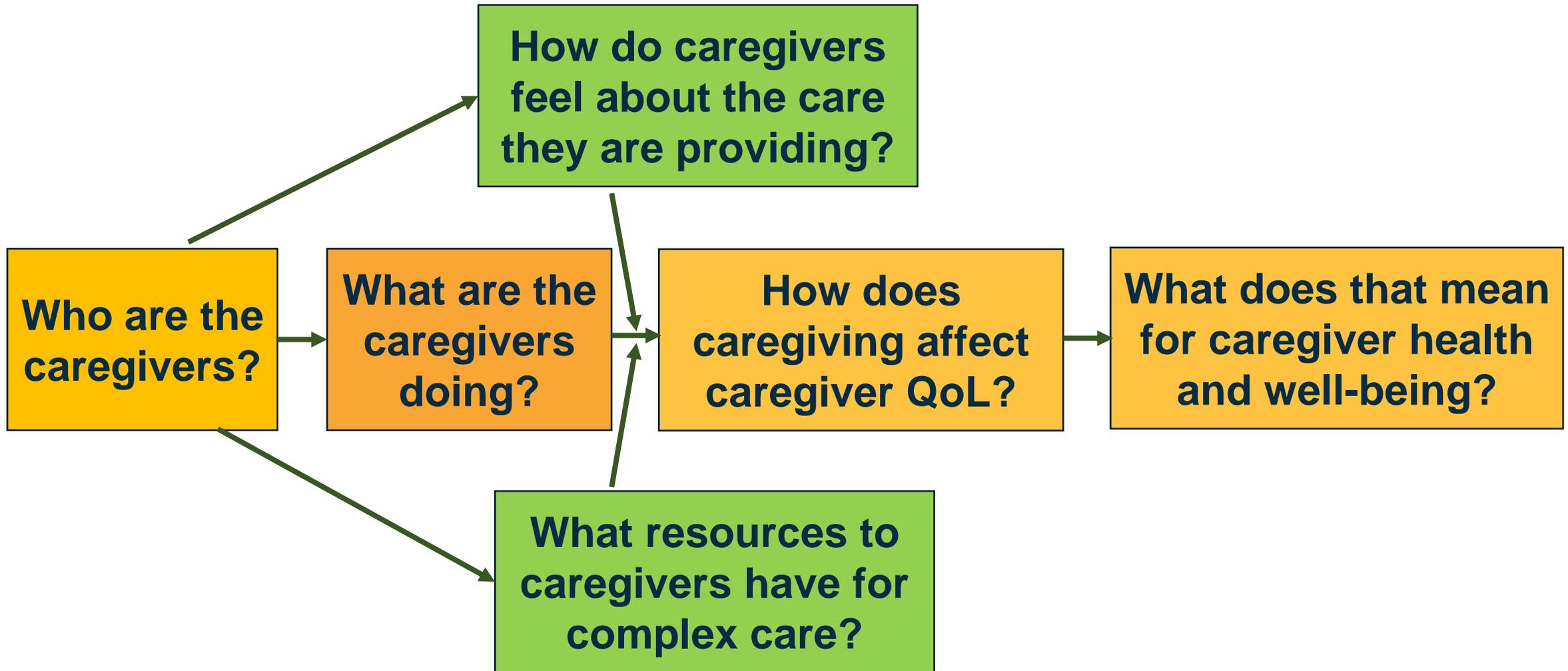
Robin Whitney, PhD, RN, Co-Investigator

Orly Tonkikh, PhD, RN, Post-Doctoral Fellow

Jessica Famula, MPH



Home Alone Model: Family Caregivers Providing Complex Care



California's Caregiver Support Network- California Caregiver Resource Centers

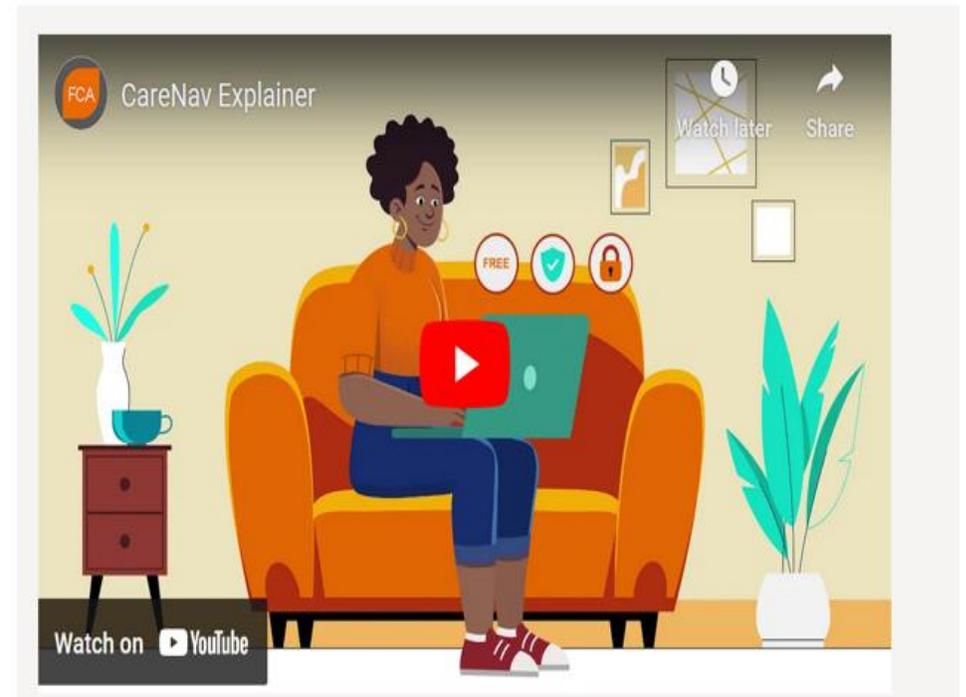
- The California Caregiver Resource Centers (CCRCs) are a network of 11 centers throughout California who serve family caregivers that are providing support for someone affected by chronic and debilitating health conditions, (i.e., dementia, degenerative diseases, traumatic brain injury, etc.)
- Core programs include:
 - Specialized Information
 - Uniform Caregiver Assessment
 - Family Consultation & Care Navigation
 - Respite Care
 - Short-Term Counseling – Individual sessions with licensed counselors
 - Support Groups
 - Education and Caregiver Training
 - Legal & Financial Consultation



CareNav™ Client Record System

- Cloud-based, HIPAA compliant, interactive
- Supports uniform intake, assessment, reassessment
- Client dashboard with tailored education, contact, care plan, secure communications,
- Reports, data exports for analysis

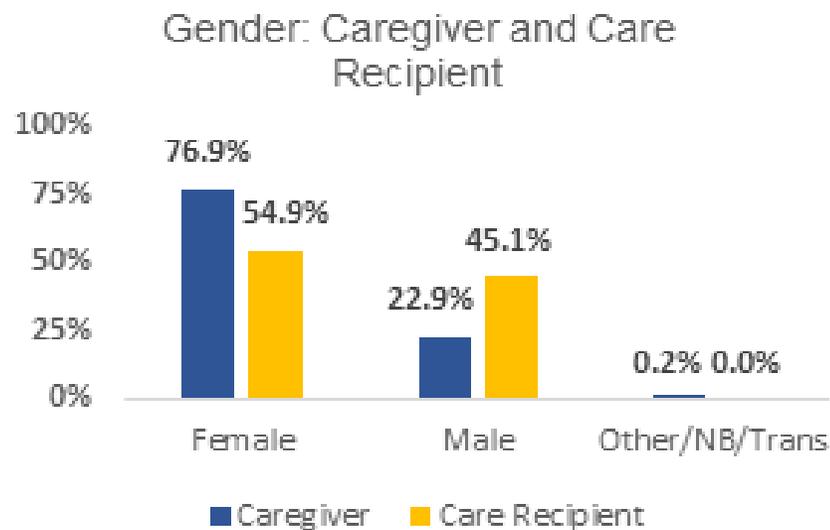
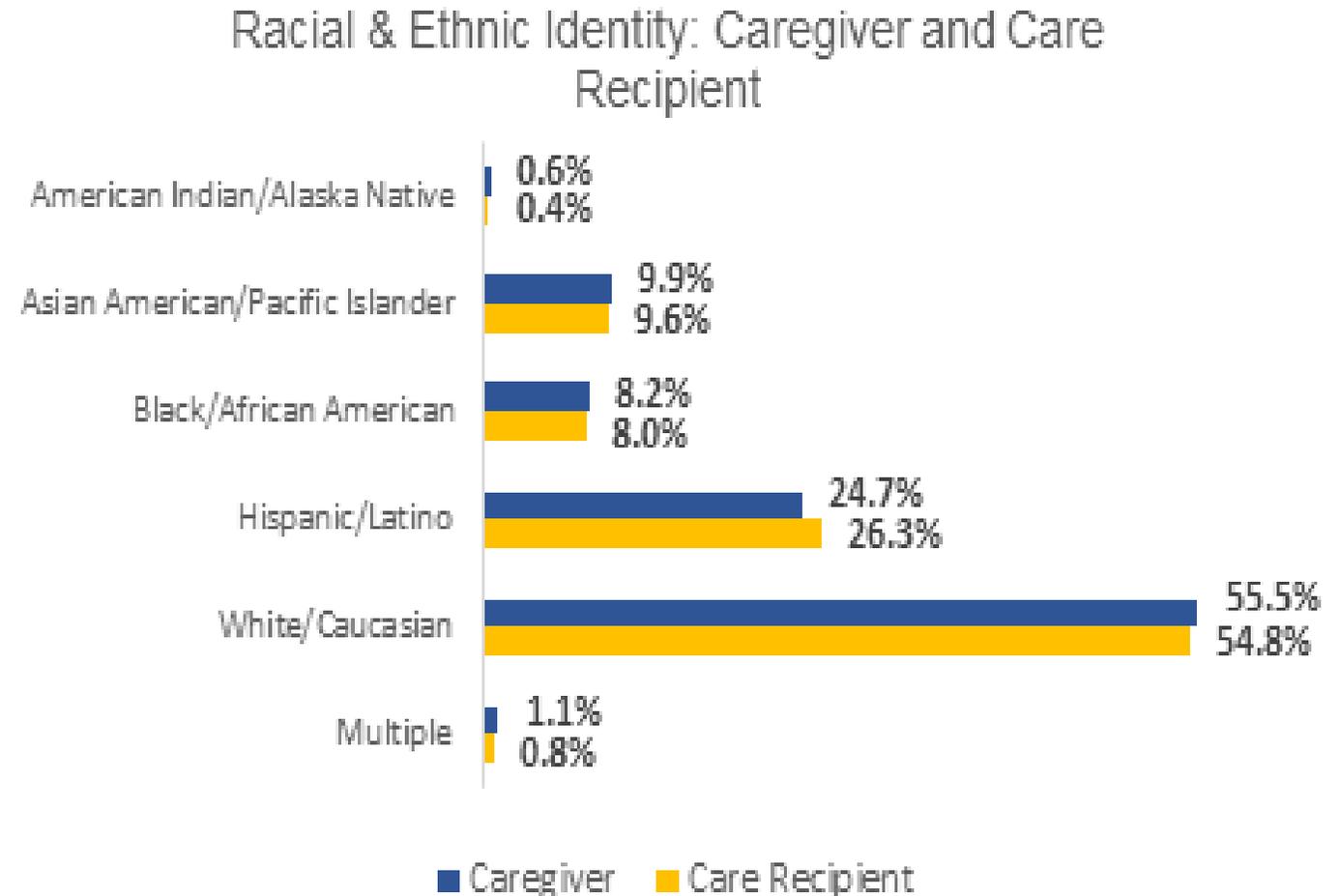
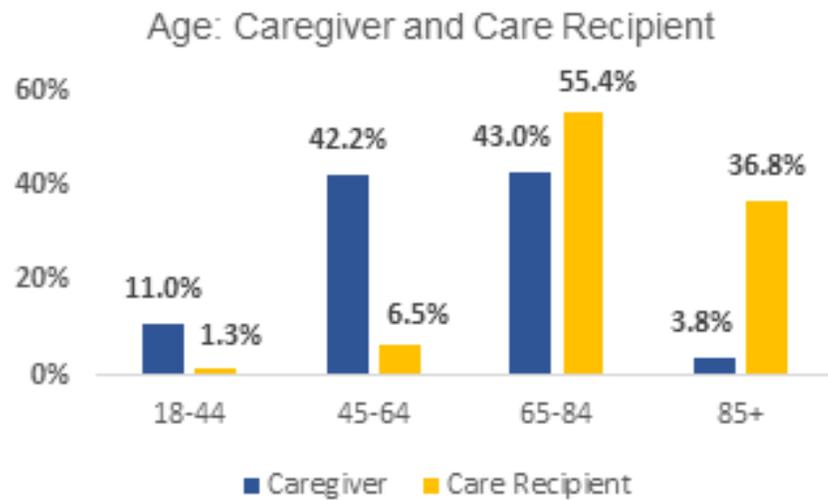
CareNav™ is a simple, user-friendly tool designed to help families navigate the complexities of the caregiving journey. Register [online](#) or call us toll-free at 800.445.8106.



<https://www.caregiver.org/connecting-caregivers/fca-carenav/>

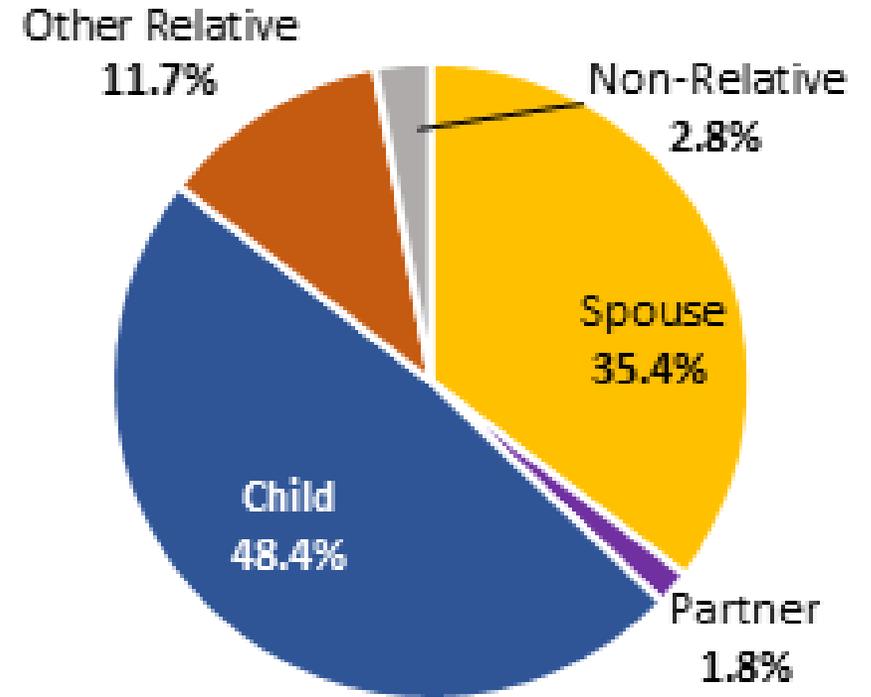
Who are the caregivers and care recipients? FY23

n = 4,433



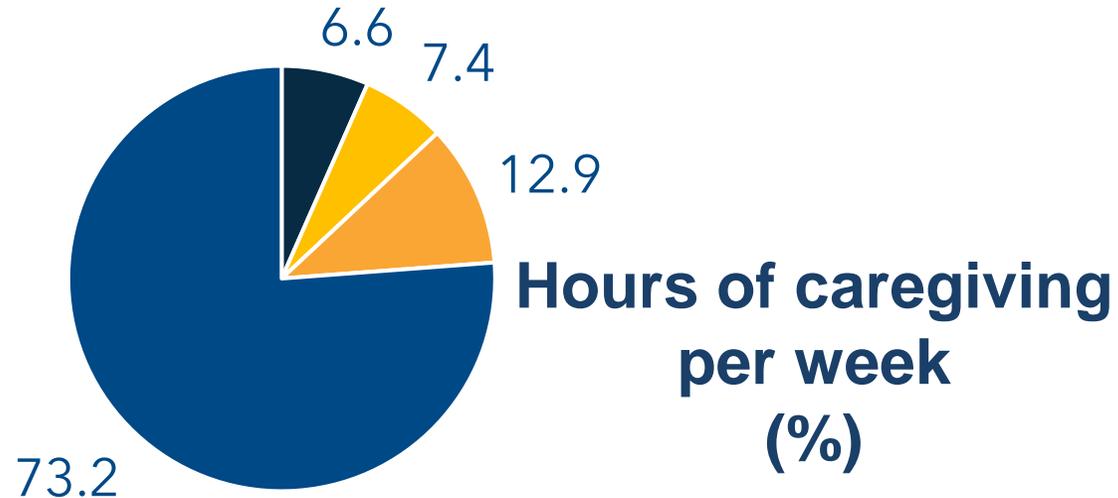
Caregiver Characteristics

- 29.4% work full-time, 10.9% part-time
- Due to caregiving:
 - 6.8% decreased hours
 - 4.9% quit job
 - 3.1% took FMLA
 - 2.7% retired
- 16.7% earn below Federal Poverty Level
- 69.4% are married or partnered
- 97.2% identify as heterosexual
- 4.4% live in a rural area



Relationship to care recipient

Drivers: Caregiving Characteristics (n = 4,433)



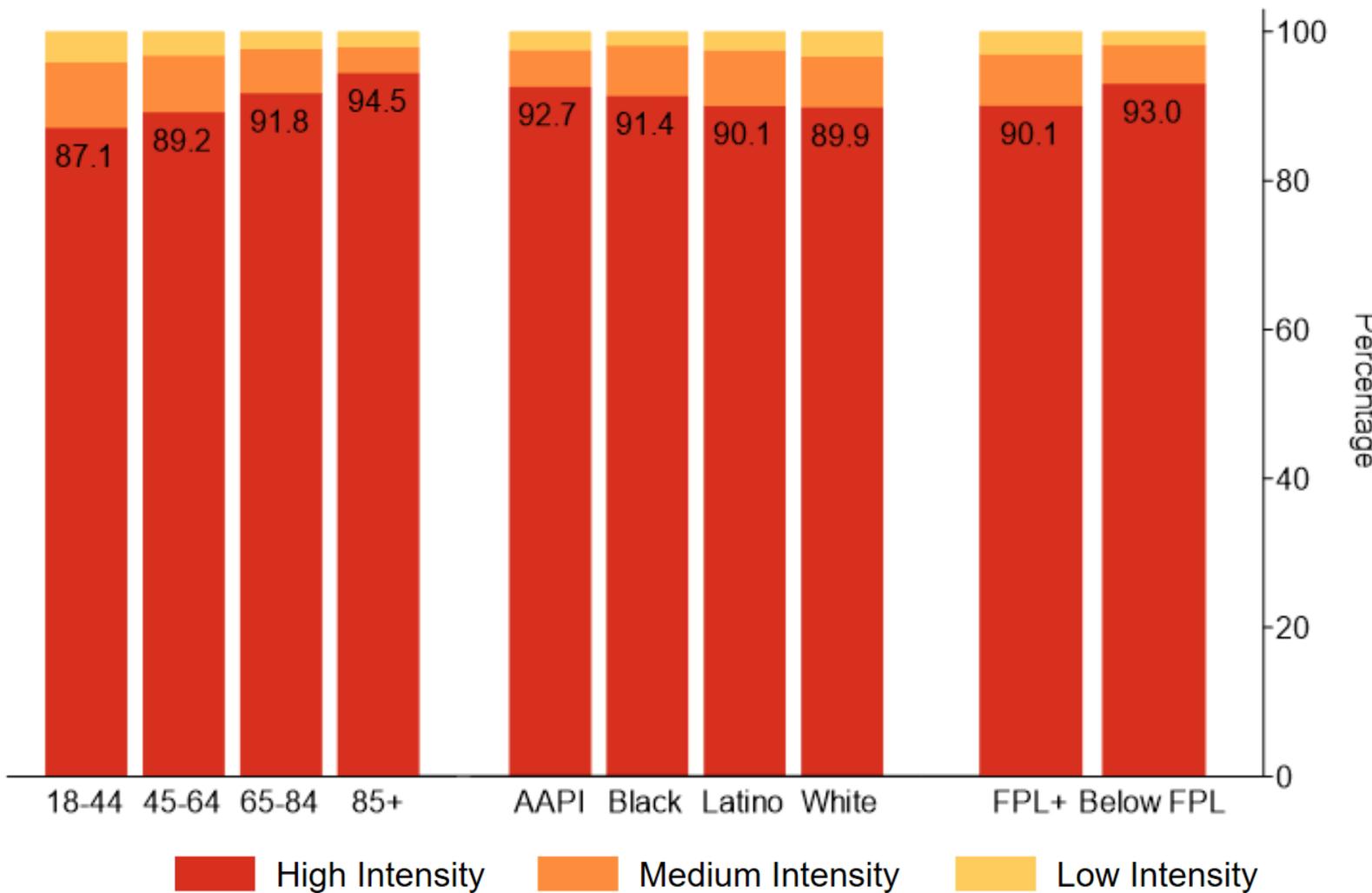
■ 0-10 ■ 11-20 ■ 21-39 ■ 40+

Caregivers go it alone
 69% receive no paid help
 48% receive no unpaid help

Level of Care AARP: weekly hours + ADL/IADLs	%
1-3	3.1
4	23.9
5	66.6

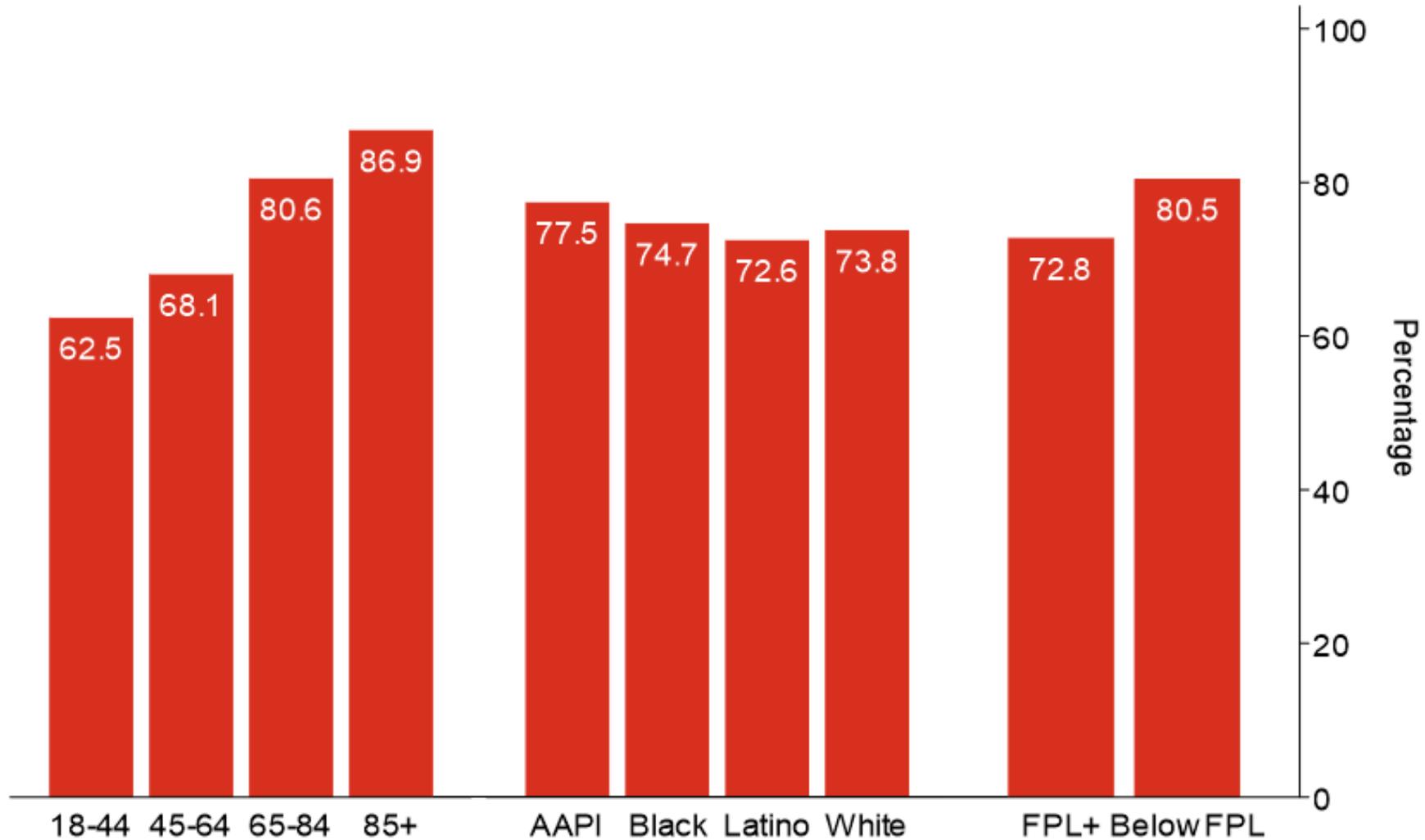
Duration of Caregiving	%
< 2 years	43.2
2-5 years	26.8
> 5 years	30.1

Drivers: Caregiving Demands and Equity

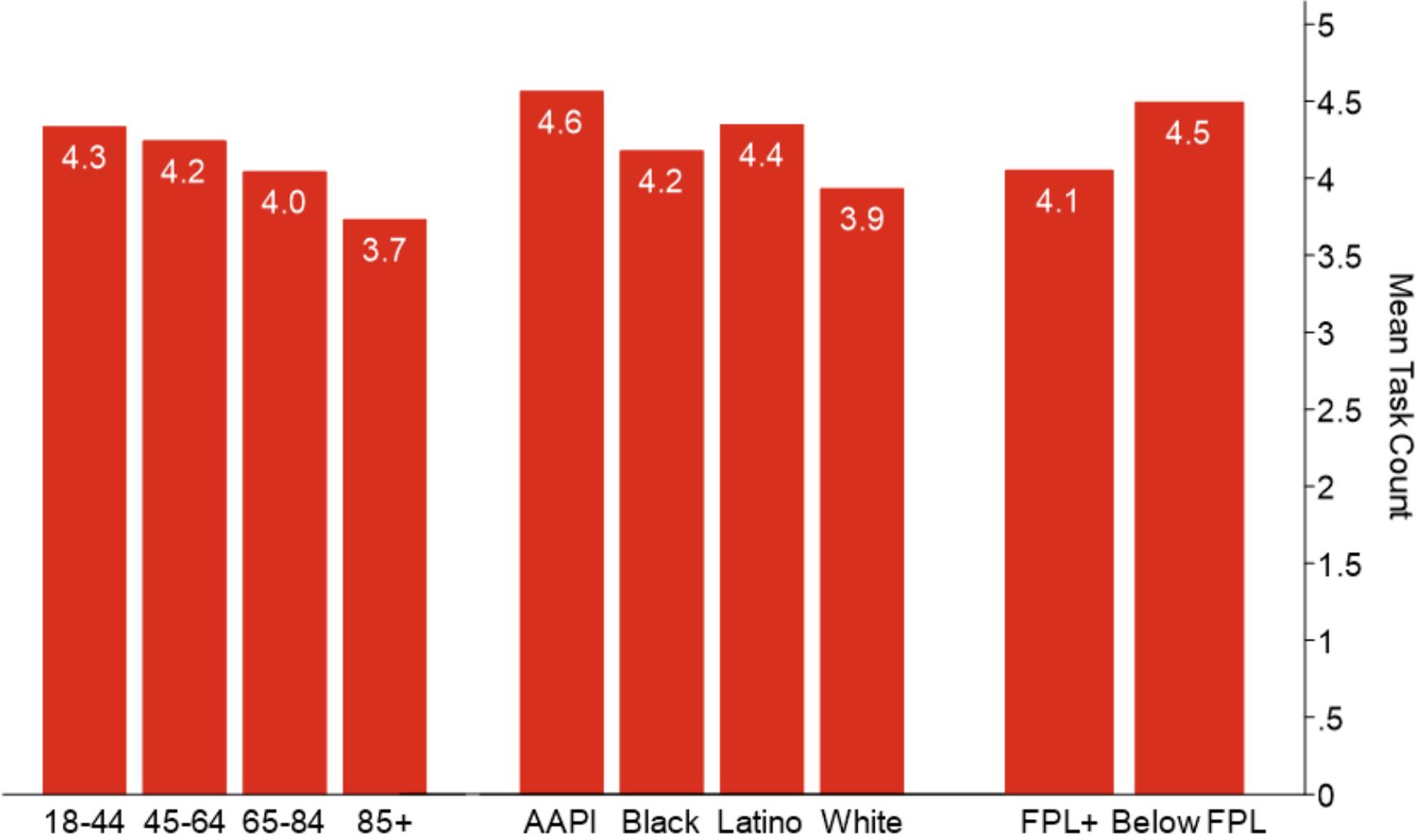


- ✓ Caregiving intensity increases with caregiver age
- ✓ More high intensity care among caregivers who identify as Asian American and Pacific Islander, Black non-Hispanic, Hispanic or Latino compared to White, non-Hispanic
- ✓ More high intensity care among caregivers living below the federal poverty level

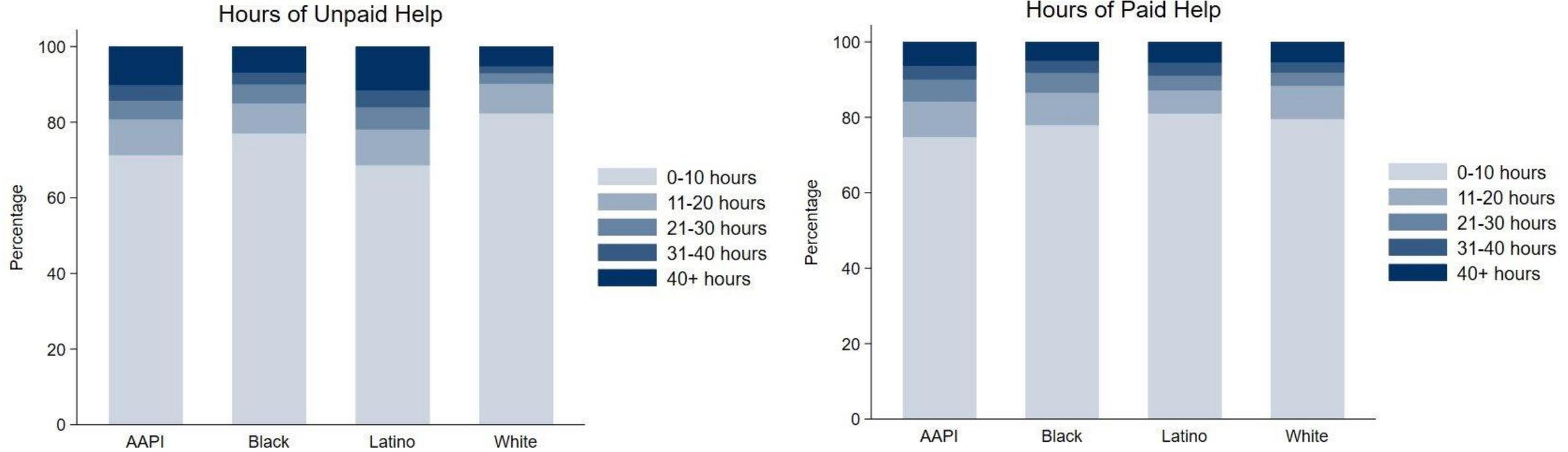
Drivers: Caregiving 40+ hours per week and Equity



Drivers: Medical/Nursing Tasks and Equity

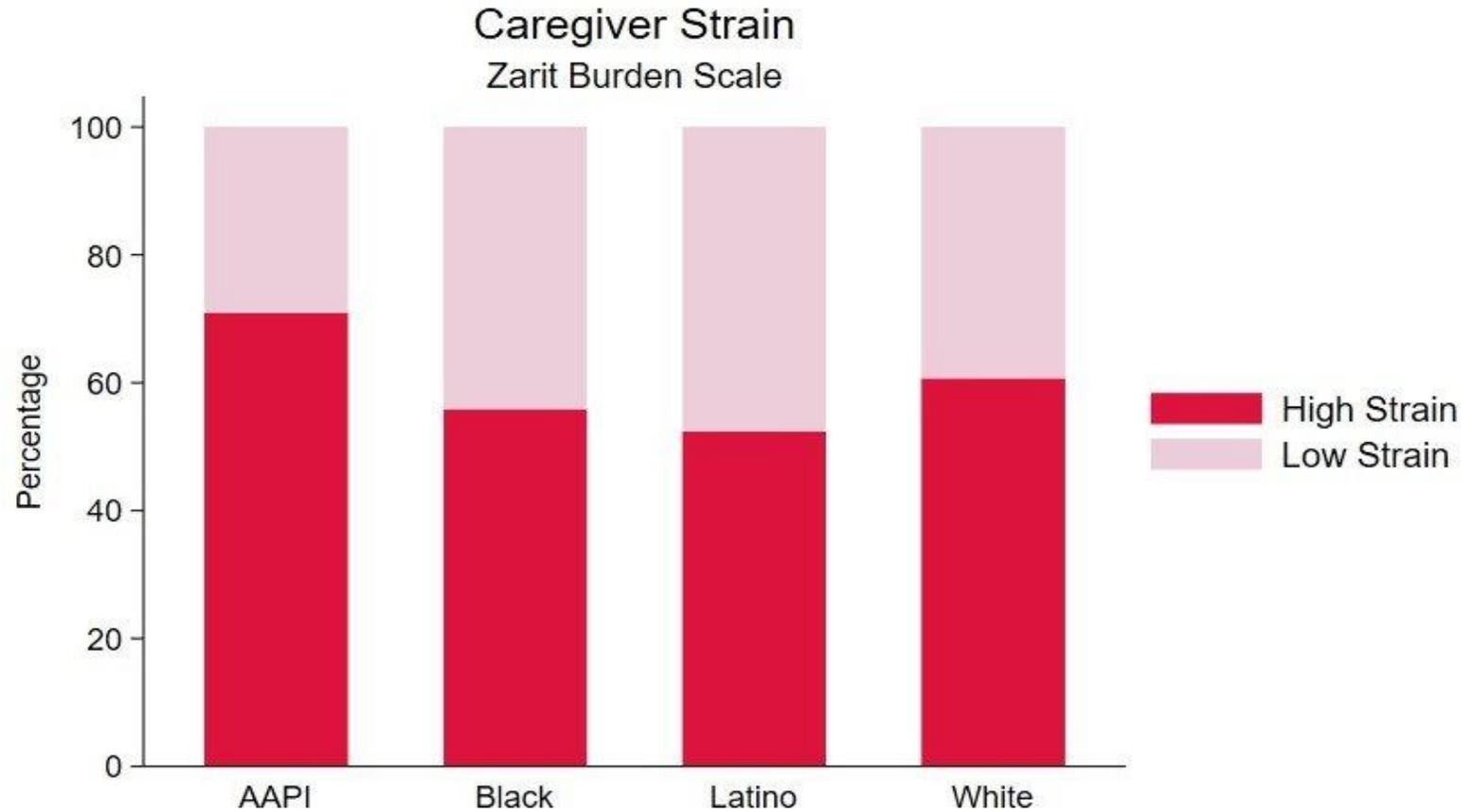


Drivers: Hours of Paid and Unpaid Help



- ✓ Most caregivers have no paid or unpaid help
- ✓ Percentages differ by race and ethnicity
- ✓ Less unpaid help with older age
- ✓ Less paid and unpaid help with lower income
- ✓ Less paid and unpaid help with rural (versus urban) residence

Outcomes: Caregiver Burden

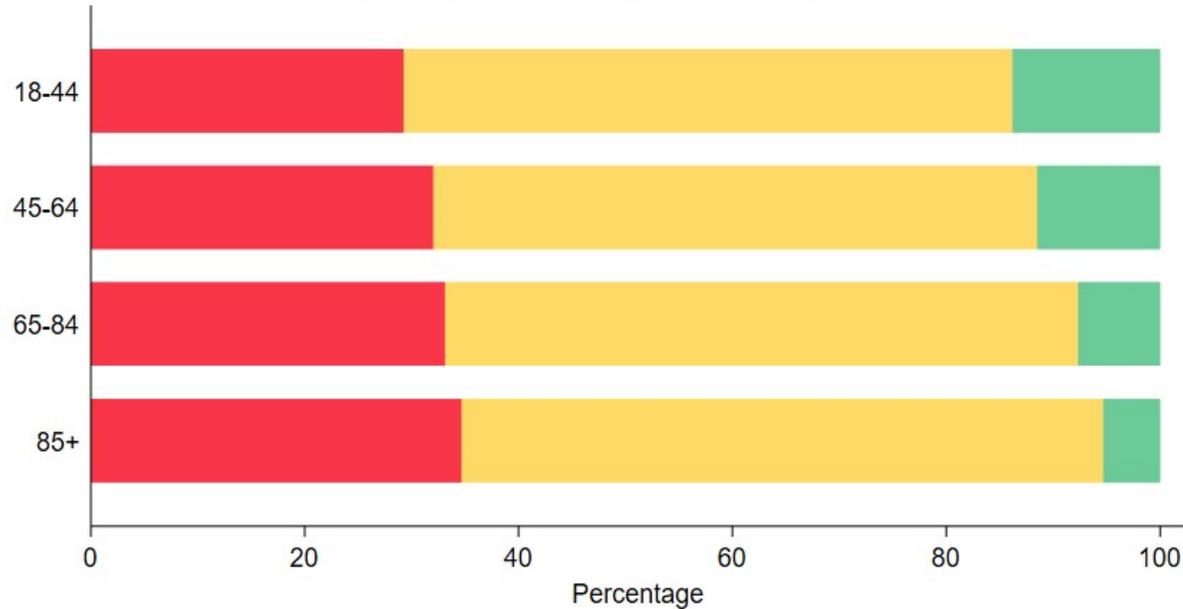


- ✓ Differences in caregiver reports of burden (feeling strained, stressed, having no time, feeling uncertain about what to do) by race and ethnicity
- ✓ Higher burden with younger caregiver age

Outcomes: Caregiver Health

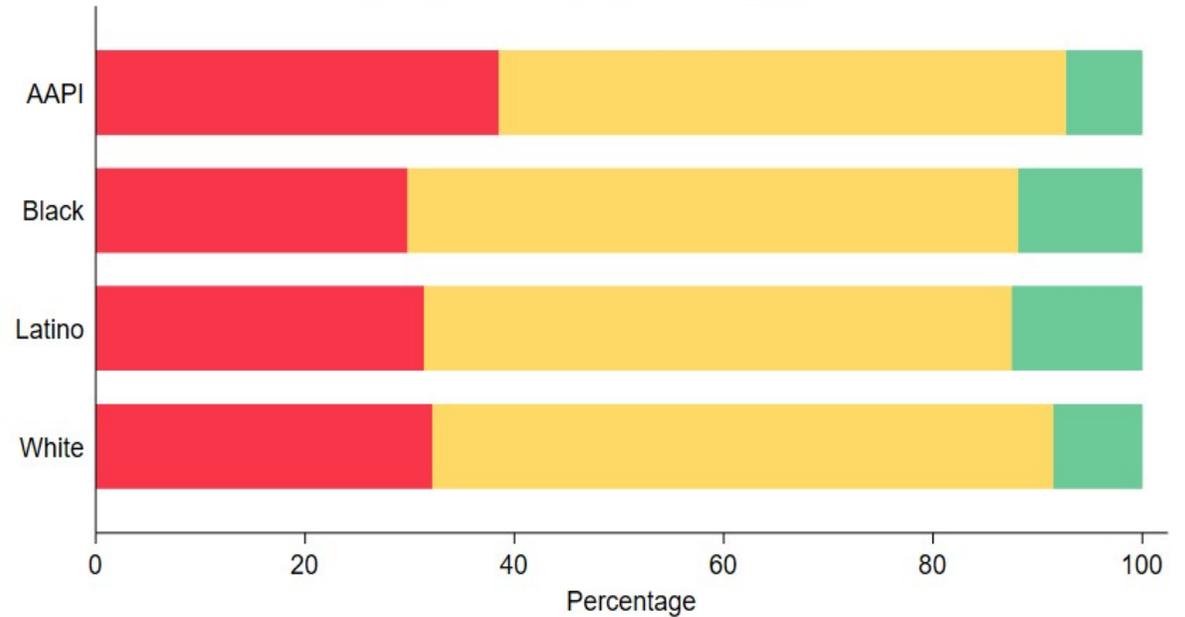
Current Health Compared to Six Months Ago

Worse Same Better



Current Health Compared to Six Months Ago

Worse Same Better



- ✓ More than 1/3 report their own health has worsened over six months
- ✓ Higher percentage with older age
- ✓ Higher percentage among caregivers identifying as Asian American or Pacific Islander
- ✓ Higher percentage among caregivers with low income

Outcomes: Caregiver Health

n = 4,433

Caregiver Health Status	%
Fair or poor health	33.4
Current health worse than 6 months ago	34.8
Depressive symptoms	
Moderate	13.2
Moderate to Severe	6.1
Loneliness	22.5
High Strain	60.5
Satisfied with support from family and friends	31.6
Satisfied with spiritual support	44.7

Strengths and Limitations of CareNav™ data

Strengths:

- Robust, large, ethnically and geographically diverse state-wide data base
- Real-time data stream with annual data synthesis available
- Includes caregivers with highest needs – highlighting sources of strain
- Longitudinal data available on a subset who are reassessed

Limitations:

- Biased sample focusing on caregivers with highest needs

Public Comment



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Closing & Next Steps

Ross Lallian

California Department of Aging

Meeting Materials & Future Dates

❖ **All meeting materials, transcript and recording are posted after this meeting on:**

➤ [CADRP webpage on CalHHS MPA website](#)

❖ **Future 2024 CADRP Committee meetings:**

➤ Friday, July 19, 2024



Learn more about the MPA at MPA.aging.ca.gov

Contact: EngAGE@aging.ca.gov

Learn more about CDA at www.aging.ca.gov



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