

# The National Strategy on Caregiving: California at the Forefront

November 17, 2022  
3:00pm-4:30pm

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# Agenda

- Welcome and Overview
- A Caregiver's Story
- From our Federal Partners: The National Strategy on Caregiving
- **California Focus: Scaling Services for a Changing Caregiver Profile**
- **Hearing From the Field: Best Practices & Emerging Opportunities for CA**

# Welcome and Overview



**Susan DeMarois**, Director, California Department of Aging

**Kim McCoy Wade**, Senior Advisor on Aging, Disability, and Alzheimer's, Office of Governor Newsom

# A Caregiver's Story

- Alayna Tillman, Family Caregiver and Advocate

# The National Strategy on Caregiving

**Fay Gordon,** Regional Administrator, Region 9,  
Administration for Community Living

# The National Family Caregiving Strategy: A Roadmap for Change

Fay Gordon

Regional Administrator, Region IX

November 17, 2022



# The Bottom Line

*Family caregiving is an issue that touches nearly every one of us in some way. Supporting the nation's 53 million family caregivers and 2.5 million grandparents raising grandchildren is critical. Successful development and implementation of a **National Family Caregiving Strategy** will require a coordinated, “all hands on deck” approach.*



# The RAISE Act: Nuts & Bolts

- Became law: Jan 22, 2018
- Three key components:
  - Family Caregiving Advisory Council
  - Initial Report to Congress
  - National Family Caregiving Strategy
- Current sunset: January 2022
- Ongoing appropriations

# The Importance of Partnerships

- The John A. Hartford Foundation
  - History of supporting ACL's efforts
  - Projects of national scope
  - Collaborated with ACL to develop concept for the RAISE Resource and Dissemination Center at NASHP
- National Academy for State Health Policy (NASHP)
  - National Alliance for Caregiving
  - UMass Boston
  - Community Catalyst
- [The RAISE Family Caregiver Resource and Dissemination Center](#)

# Public Engagement at Every Step

## **For Starters:**

- ACL RFI (2019)
  - 1613 responses
  - 75% from caregivers
- Caregiver Focus Groups
  - 13 sessions/80 individuals
  - All populations, including teens
  - Delved into RFI findings
- Stakeholder Listening Sessions
  - Aging and disability organizations
  - 60 invited/42 participated
  - 6 sessions focused on operationalizing the recommendations
- Council meetings

## **From 12/2020 - 12/2021:**

- Interviews & Listening Sessions
  - 17 key informant interviews
  - 22 listening sessions
  - 145 stakeholder organizations
- Stakeholders included
  - State entities
  - Counties
  - Employers (large and small)
  - LTSS and healthcare providers
  - Respite providers
  - CBOs/faith-based organizations



# 2022 National Strategy to Support Family Caregivers

**A roadmap to improved services and supports for family caregivers**

*Family caregivers include people of all ages, from youth to grandparents; people with and without disabilities; people providing care from a distance; and people meeting a wide variety of needs. Until now, there has been no national approach to recognize and support family caregivers.*

**2**  
Councils



**5**  
Shared Goals



**1**  
Vision for  
Holistic Support

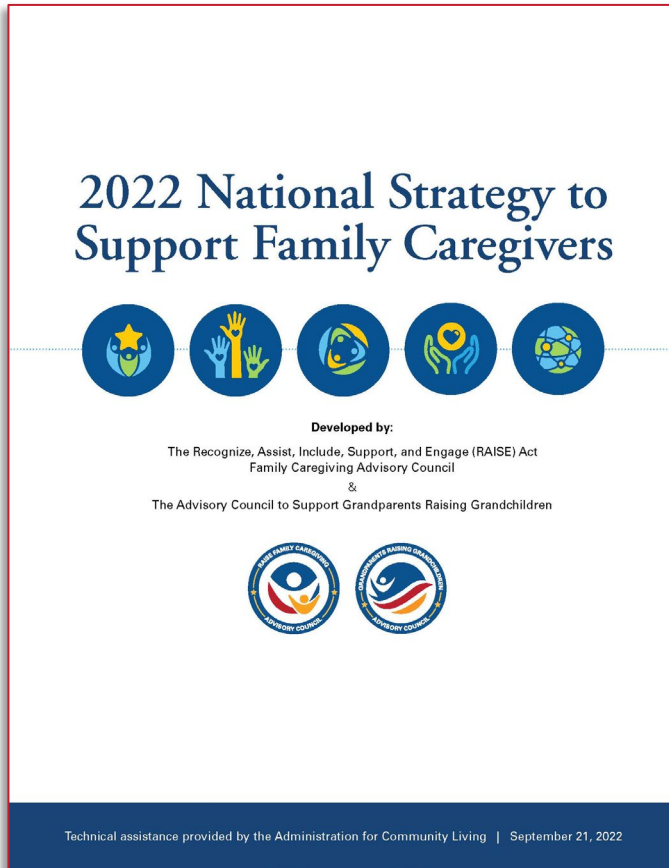
# The National Family Caregiving Strategy

Grounded in five priority areas for action:\*

- 1) Awareness and outreach
- 2) Engagement of family caregivers as partners in healthcare and long-term services and supports
- 3) Services and supports for family caregivers
- 4) Financial and workplace security
- 5) Research, data, and evidence-informed practices

\* RAISE and Grandparent Advisory Councils

# One Strategy | Four Components



[2022 National Strategy to Support Family Caregivers](#) - An overview and description of the strategy's goals and intended outcomes

[First Principles: Cross-Cutting Considerations for Family Caregiver Support](#) - Describes the four key principles that must be reflected in all efforts to improve support to family caregivers

[Federal Actions](#) - Nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy.

[Actions for States, Communities, and Others](#) - More than 150 actions others can take.



# 150 Actions for States and Communities

To create a system that truly supports families, multiple sectors—public and private—must work together. No single sector can do it alone. There is a particular need to engage the private sector—employers and industry—to better recognize and support employees who are family caregivers.

- All stakeholders can establish coalitions that bring together state officials, major employers, universities, philanthropic organizations, CBOs, FBOs, family caregivers and care recipients, and others with clearly articulated mission statements, work plans, sustainable funding, and projects. See [Massachusetts Caregiver Coalition](#) as a model. (Also supports **Goal 4**).
- States can convene or expand family caregiving taskforces to draw in stakeholders with lived experience and professional expertise to work together on behalf of family caregivers in the state. Activities can include developing an inventory of existing programs; recommended actions that improve family caregiver supports and address the other issues described in the Strategy; and ways to leverage the findings of the task force to increase funds for caregiver support services and/or pass supportive legislation.
- State agencies can develop and implement state plans (e.g., State Plans on Aging, State Developmental Disability Plans) for supporting family caregivers. These efforts should include representation from a broad range of stakeholders, including diverse caregivers and care recipients themselves.

**Goal 2: Actions to advance partnerships and engagement with family caregivers**

# Cross-Cutting Themes & Considerations

- Placing the person and family at the center of all interactions
- Addressing trauma and its impact on families
- Advancing racial equity and support for family caregivers in underserved communities
- Understanding the implications of the direct care workforce



# The Time is Now...

## **If family caregiving can be...**

- Anxiety-producing
- Empowering
- Overwhelming
- Meaningful
- Exhausting
- Gratifying
- Lonely
- Hopeful

## **Then a National Family Caregiving Strategy can...**

- Elevate the conversation
- Re-frame the narrative
- Drive change and innovation
- Promote greater recognition and inclusion of family caregivers
- Be a tool for advocacy
- Guide program planning & policy development,
- Shape research

# Thank you!

**Fay Gordon**

**Regional Administrator, Region IX**

**U.S. Department of Health and Human Services**

**Administration for Community Living**

**EMAIL: [fay.gordon@acl.hhs.gov](mailto:fay.gordon@acl.hhs.gov)**



# California in Focus: Scaling Services for a Changing Caregiver Profile



**Heather Young,** PhD, RN, FAAN, Betty Irene  
Moore School of Nursing, UC Davis



## **FAMILY CAREGIVING INSTITUTE**

### **BETTY IRENE MOORE SCHOOL OF NURSING**

#### **National Strategy on Caregiving: California at the Forefront**

Heather M. Young, PhD, RN, FAAN, FGSA  
Professor

Betty Irene Moore School of Nursing

#### **Picking Up the Pace of Change: Scaling Services for a Changing Caregiver Profile**

Janice F. Bell, MN, MPH, PhD, FAAN  
Professor/Associate Dean

Betty Irene Moore School of Nursing

California Resource Centers  
FY 2021-22 Evaluation

November 17, 2022



# 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

Benjamin Link, BS

Jessica Famula, MPH



# History & Background

- CRCs were established in 1994
- First-in-the-nation statewide network of 11 regional caregiver resource centers – community-based non-profit agencies
- Defunded by 70% during 2009 recession
- \$10M/yr augmentation for FY 2019-22 for CareNav, service expansion and evaluation

**California Caregiver Resource Centers**  
Educate. Connect. Support.

Founded in 1984, the California Caregiver Resource Centers are a network of 11 centers throughout California which serve family caregivers who are providing support for someone affected by chronic and debilitating health conditions including dementia, Alzheimer's disease, cerebrovascular diseases (such as stroke or aneurysms), degenerative diseases such as Parkinson's, Huntington's and multiple sclerosis, or traumatic brain injury (TBI), among many others.

Caring for a loved one with a cognitive disorder or another disabling condition forever changes the lives of families and caregivers. There can be devastating effects on those providing long-term care: financial pressures, legal quandaries, health problems, and emotional turmoil.

Fortunately, the California Caregiver Resource Centers offer **FREE** support throughout the state, serving thousands of families and caregivers across income categories. Every California resident has access to a CRC in their area. The CRCs are united by shared values emphasizing choice, collaboration, innovation, quality, participation, respect & diversity.

For more information on the California Caregiver Resource Centers, visit: [www.caregivercalifornia.org](http://www.caregivercalifornia.org)

"I have benefited so much from the services the California CRCs have provided, especially the counseling and respite care. They gave me guidance and hope during very difficult times."  
— Family Caregiver

**Resources for families and caregivers of adults with chronic, disabling health conditions.**

[www.caregivercalifornia.org](http://www.caregivercalifornia.org)

**Los Angeles Caregiver Resource Center**  
(800) 540-4442  
E-mail: [fcscgero@usc.edu](mailto:fcscgero@usc.edu)  
Website: [www.fcscgero.org](http://www.fcscgero.org)  
Serving: Los Angeles County

**Caregiver Resource Center OC**  
(800) 543-8312  
E-mail: [ocrcuser@stjoe.org](mailto:ocrcuser@stjoe.org)  
Website: [www.caregiveroc.org](http://www.caregiveroc.org)  
Serving: Orange County

**Passages Caregiver Resource Center**  
(530) 898-5925  
E-mail: [passages@csuchico.edu](mailto:passages@csuchico.edu)  
Website: [www.caregiverresources.org](http://www.caregiverresources.org)  
Serving: Butte, Glenn, Lassen, Modoc, Plumas, Yuba, Siskiyou, Tehama, and Trinity Counties

**Redwood Caregiver Resource Center**  
(707) 834-1636  
Email: [rcrc@redwoodcrc.org](mailto:rcrc@redwoodcrc.org)  
Website: [www.redwoodcrc.org](http://www.redwoodcrc.org)  
Serving: Del Norte, Humboldt, Lake, Mendocino, Colusa, Solano & Sonoma Counties

**Northern Caregiver Resource Center**  
(916) 268-4432 or (800) 827-1008  
Email: [scrc@caregivercenter.org](mailto:scrc@caregivercenter.org)  
Website: [www.caregivercenter.org](http://www.caregivercenter.org)  
Serving: Imperial & San Diego Counties

**Vallejo Caregiver Resource Center**  
(707) 41-8614  
Email: [info@valleycrc.org](mailto:info@valleycrc.org)  
Website: [www.valleycrc.org](http://www.valleycrc.org)  
Serving: Fresno, Kern, Kings, Madera, Mariposa, Stanislaus, Tulare & Tuolumne Counties

CareNav™ was developed in response to the changing demographics of unpaid family caregivers to reflect, younger, diverse, technology savvy, in the workforce and needing service contact outside of business hours.

*Components include:*

- Uniform Assessment, Reassessment and Client Satisfaction Questionnaire (can be self-administered)
- Client Dashboard: auto-tailored content from FCA (written, videos, podcasts); service authorization information; care plan, local resource information
- Secure communications; HIPAA compliant
- Tracking and Reporting for contracts and for individual site use
- Ability to export de-identified data for analysis



## CareNav™ Provides an Online Assessment covering:

### Direct Care

- Care recipient health\*
- ADLs/IADLs\*
- Medical/Nursing Tasks\*
- Memory and Behavior Problems\*
- Health Care Utilization
- Technology Use

### Plan Care

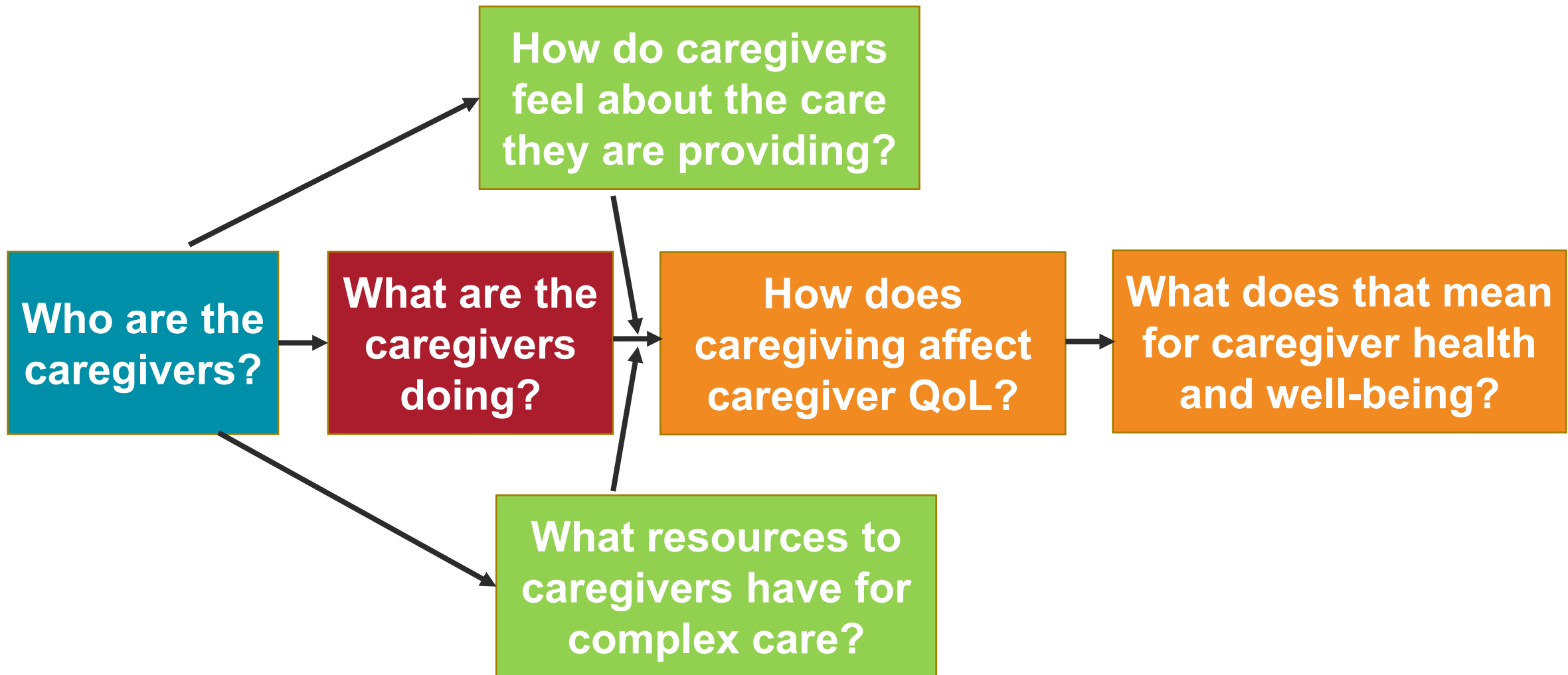
- Insurance
- Legal Documents
- Paid/Unpaid Supports

### Self-Care

- Caregiver Health\*
- Burden/Strain\*
- Depressive symptoms\*
- Loneliness\*
- Social Support\*

\* Validated, evidence-based scales





# Mixed Methods Evaluation Data Sources

CareNav™ data  
analysis

Data collected in  
reports

Surveys  
Clients, staff, leaders

Benchmark to  
external sources  
Census, CHIS, CGUS

Focus groups  
Clients, staff, leaders

Key informant  
interviews  
Leaders, clients, staff



- Completed 6,648 intake screenings and 4,433 new assessments
- Served 14,670 caregivers with clinical services (4,320 new)

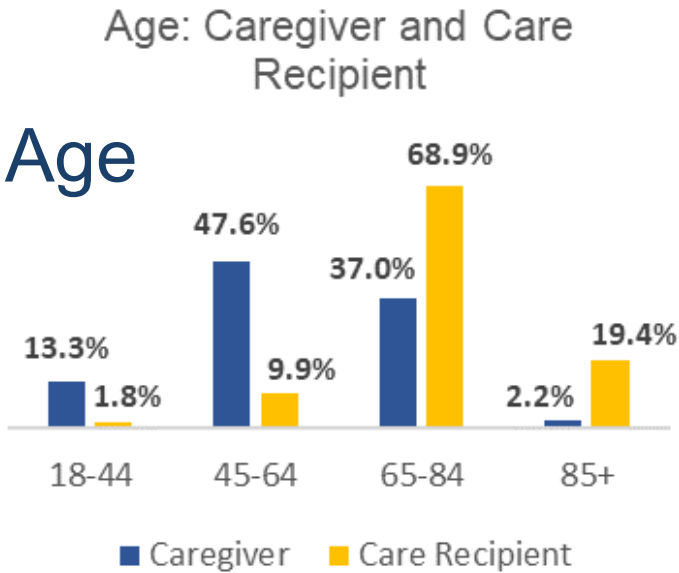
### Provided:

- 133,666 family consultations
- Counseling: 441 caregivers
- Respite: 2,080 caregivers (119,378 hrs)
- Legal/financial: 165 caregivers
- 9,884 outreach/1,039 education activities

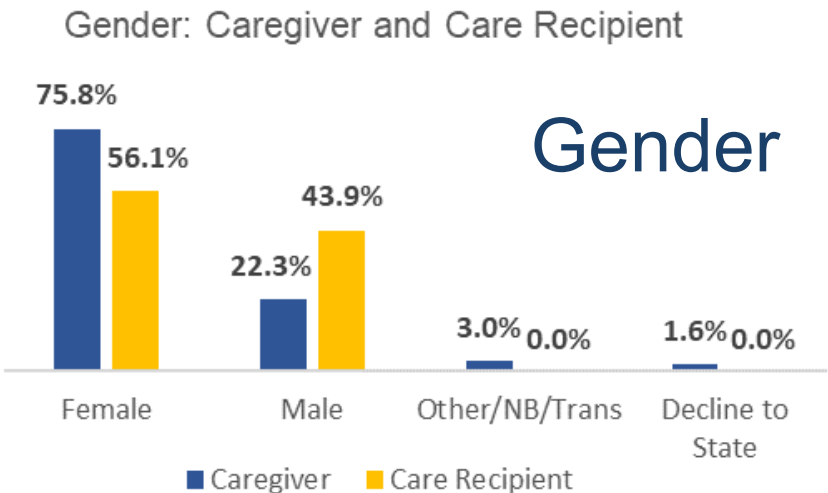
# Who are the caregivers and care recipients?

*n* = 4,433

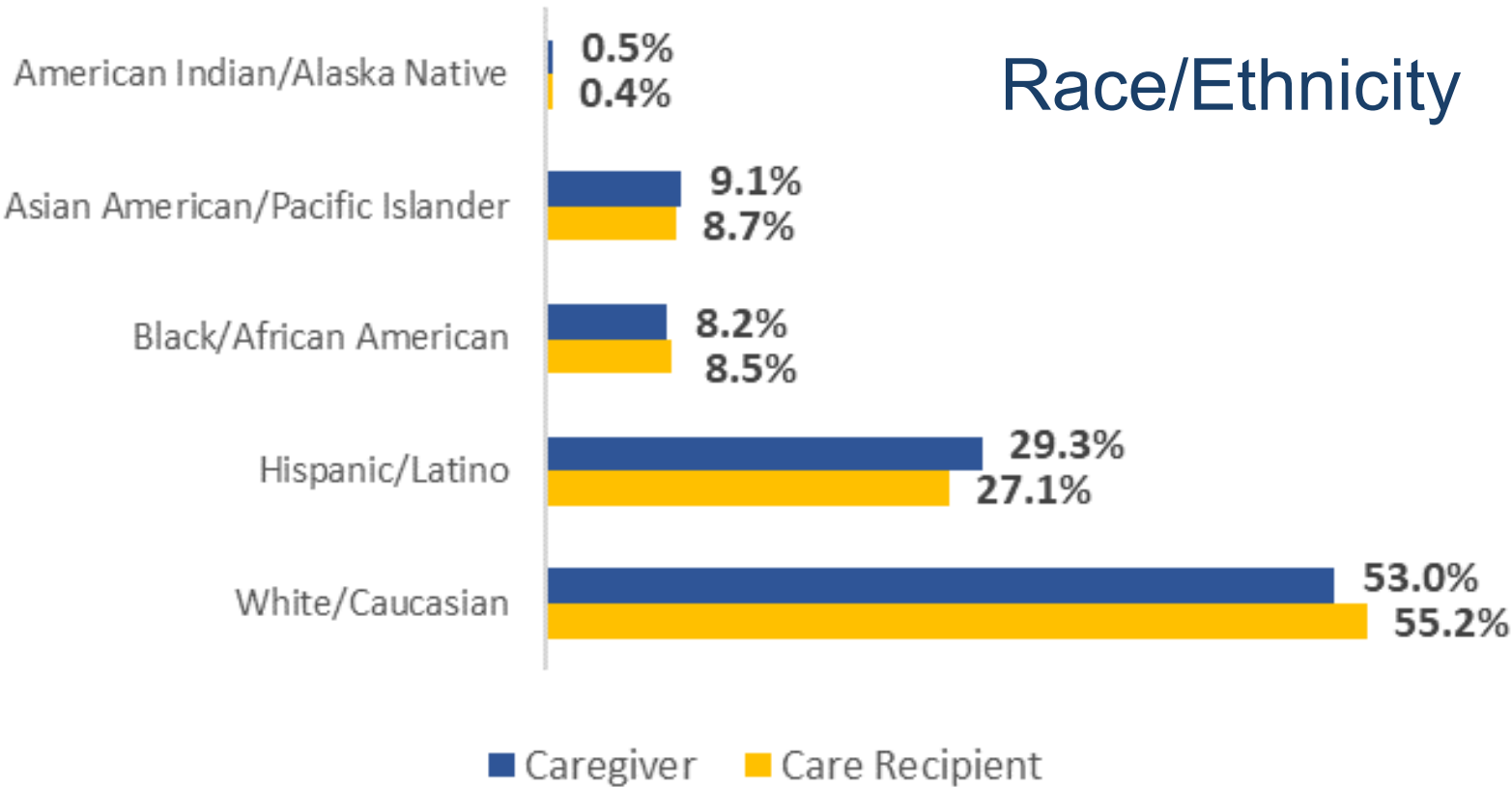
## Age



## Gender



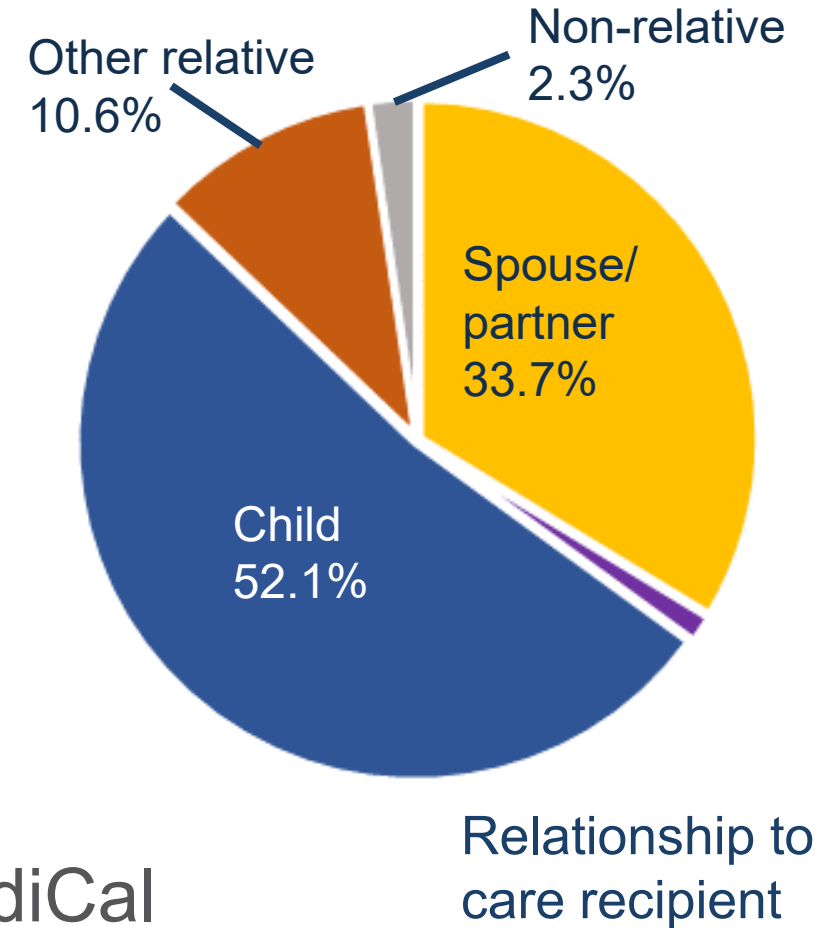
## Racial & Ethnic Identity: Caregiver and Care Recipient



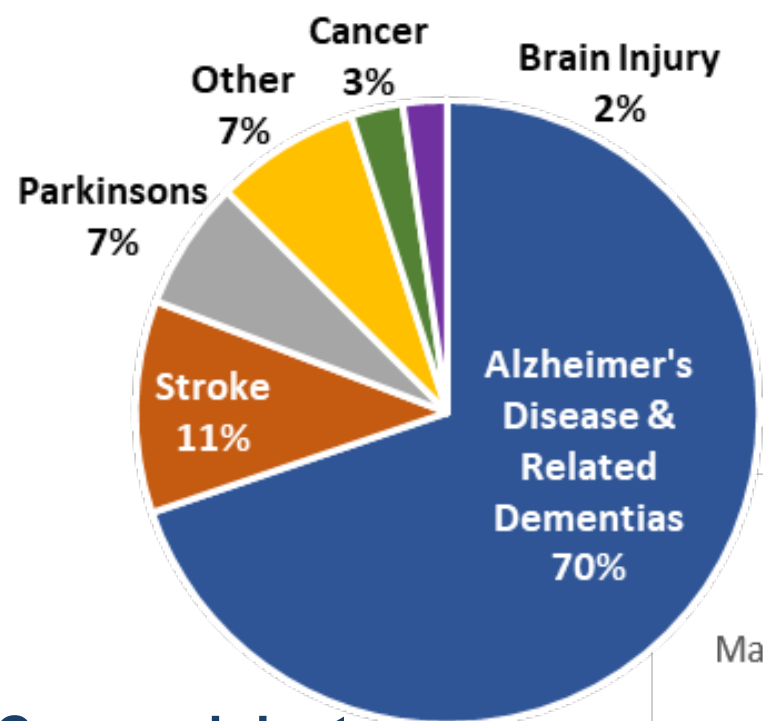
- 28.0% work full-time, 12.3% part-time
- 16.7% earn below Federal Poverty Level
- 67.9% are married or partnered
- 90.4% identify as heterosexual
- 18% provide care to multiple care recipients
- 12.8% live in a rural area

#### Insurance benefits:

- 3.7% have Veteran's Administration
- 58.2% have Medicare and 24.5% have MediCal
- 5% uninsured



# Care Recipient Health Needs

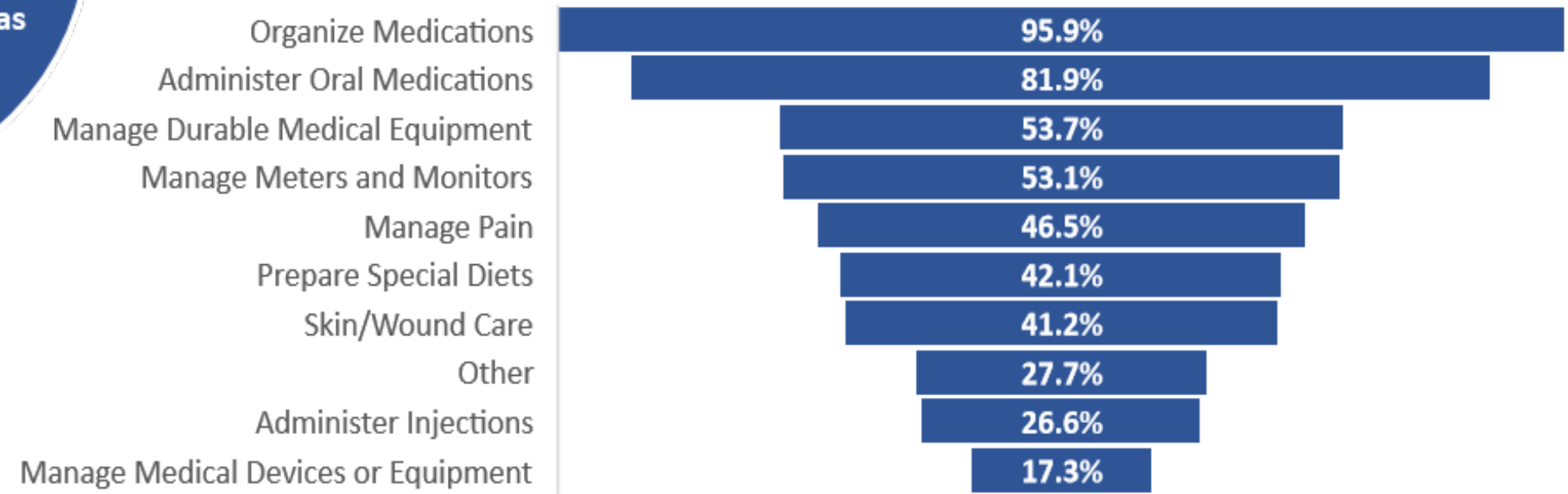


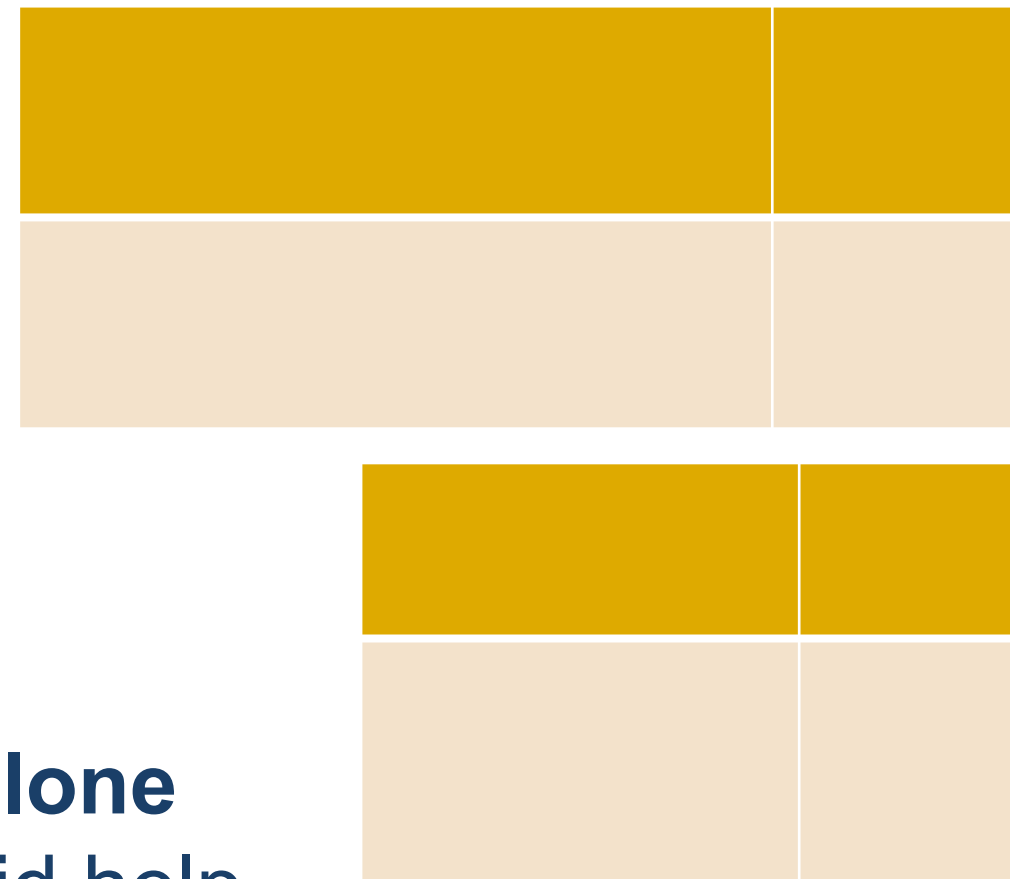
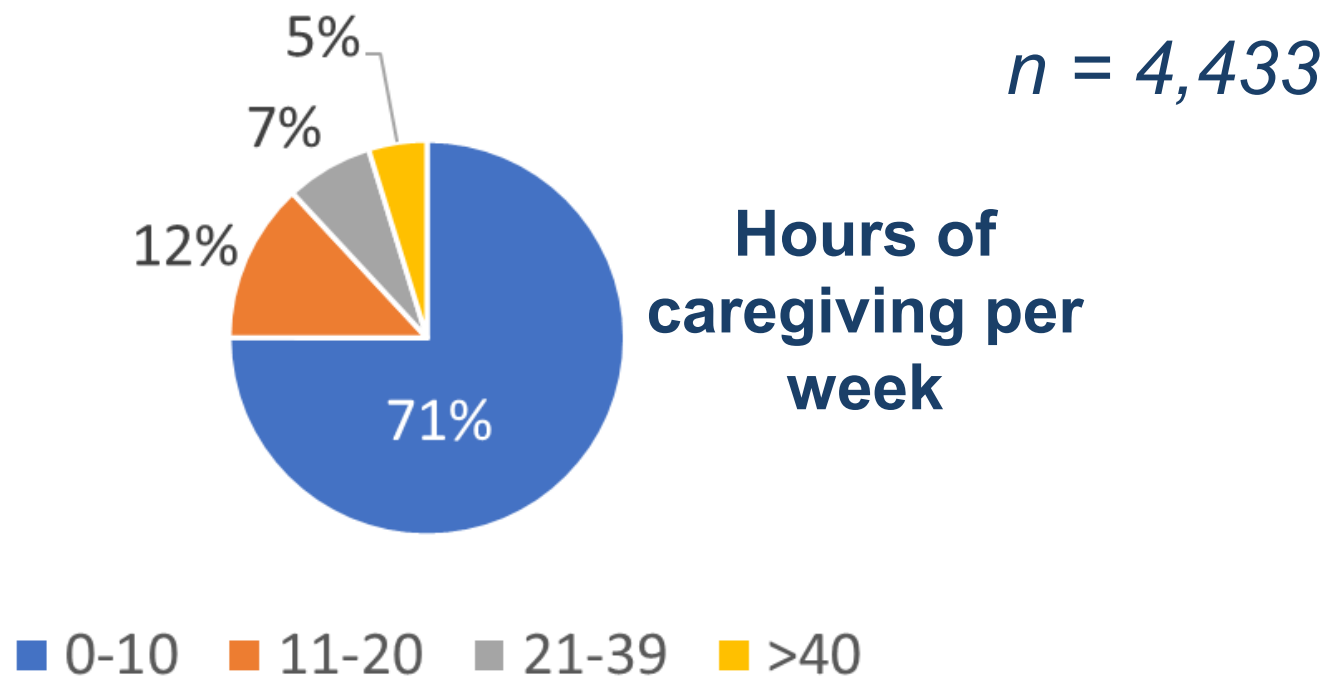
Care recipient  
primary diagnosis  
*Note: 40.5% have > 4  
chronic conditions*

*n* = 4,433

Special Needs	%
Memory Loss	92.0
Cannot be left alone	43.9
Wandering	15.8

## Medical/Nursing Tasks





**Caregivers go it alone**  
71% receive no paid help  
47% receive no unpaid help

# Caregiver Health

*n* = 4,433

Caregiver Health Status	%
Fair or poor health	33.3
Current health worse than 6 months ago	32.2
Depressive symptoms	
Moderate	13.3
Moderate to Severe	7.9
Loneliness	22.8
High Strain	59.8
Satisfied with support from family and friends	33.7
Satisfied with spiritual support	43.5



# CRC caregivers compared to state and national (%)

FY 2020-21

Dimension	CRC caregivers (n=4,299)	State (CHIS) (n = 2,995)	National (Caregiving in the US) (n = 1,627)
Age (years)			
18 – 44	13.3	17.5	34.3
45 – 64	47.7	44.1	38.5
65 or older	39.0	38.3	27.2
Gender (% female)	70.3	62.8	60.2
Race/ethnicity			
Native American/Alaska Native	0.6	0.73	
Asian American/Pacific Islander	8.2	9.55	4.8
Black non-Hispanic	6.6	3.9	13.6
Latinx	31.4	18.2	15.2
White non-Hispanic	52.2	64.6	63.6
Multi-racial/other	1.1	3.0	2.8
% working	40.0	48.4	55.6
% married/partnered	68.2	57.9	62.6

# CRC Caregiving Characteristics compared to state and national (%) FY2020-21

Dimension	CRC caregivers (n=4,299)	State (CHIS) (n = 2,995)	National (Caregiving in the US) (n = 1,627)
Hours/week caregiving (% over 40 hours)	72.9	9	32.0
Relationship to care recipient			
Spouse/Partner	34.8	19.5	16.8
Child	51.7	9.6	6.7
Other relative	9.9	54.5	64.8
Non-relative	2.6	13.0	11.7
Care recipient diagnosis (% ADRD)	68.3	5.1	5.7
Care intensity	(n=3,788)		
Low	2.8	-	43.5
Medium	6.8	-	15.5
High	90.4	-	41.0
Assists with medical/nursing tasks	78.6	-	57.7

# CRC Caregiver Health Status compared to state and national (%) FY 2020-21

	34.5	-	
UCLA Loneliness Scale (% lonely)	35.1	5.1	-

# Satisfaction with CRC Services ( $n=2,624$ )

92.4% are satisfied with CRC services – those who are not eligible for certain benefits are less satisfied

94.5% would recommend CRCs to a family or friend

## ***Benefits include:***

- Feeling more confident
- Better able to manage care
- More knowledge and awareness
- Taking better care of self/less stressed

# Diversity, Equity and Inclusion: Focus areas

- Providing culturally and linguistically congruent supports
  - Bilingual staff
  - Sharing staff across CRCs
  - Translation of materials
- Use CareNav™ data to guide outreach priorities
- Shared state-wide calendar of educational events in diverse languages
- Building community partnerships
- Tailored messages and services

# California is at the Forefront

- CRCs serve clients who are providing complex, intense and time-consuming care. They are often the primary caregiver with little additional support and pay the price with their own mental and physical health.
- CRC clients reflect multicultural groups across the lifespan
- CRCs address the unique needs of the caregiver populations in their geographic catchment areas
- Caregivers are highly satisfied with CRC services
- CareNav™ is a powerful database that can be leveraged to answer critical questions about family caregiving, services needs and delivery and to design approaches that have the highest impact

# Alignment with National Strategy

California is already on the path – can accelerate and amplify

- We have a standardized assessment with single point of entry
- Standardized assessment includes several validated instruments (e.g., depression, loneliness, strain, memory and behavior checklist, ADLs and IADLS)
- Online platform facilitates access
- We have a state evaluation of the programs underway

# California has Opportunities to Advance Further

- To achieve equity and inclusion in our diverse CA population, we need regional and state-level strategies and additional investments
  - Close digital divide for all caregivers – address access
  - Standardized assessment – trauma-informed and culturally appropriate in multiple languages
  - Expand services further to reach 5 million caregivers
- Use CareNav™ data to develop strategies to expand and improve outreach, tailoring to underserved populations
- Leverage the CRC system to optimize access and resources across all regions and communities
- Share lessons learned



# Hearing from the Field: Best Practices and Emerging Opportunities for CA



*Moderated by Shawntel Bush, Chief, Health at Home Branch, CDA*

**Donna Benton**, Executive Director, USC Family Caregiver Support Center

**Joe Cobery**, Executive Director, Passages Adult Resource Center

**Barbara McLendon**, Public Policy Director, Alzheimer's Greater LA

**Alexandra Castillo-Weisgerber**, Director, Care & Support,  
Alzheimer's Association of Northern CA and Northern Nevada

# Questions and Answers

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