



Sarah Taub Memorial Webinar 2026

Person-Centered Supports: How Does Paid Family Caregiving Measure Up?

Human Services Research Institute

ADvancing States

National Association of State Directors
of Developmental Disabilities Services



Speakers



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Webinar logistics

- Participants will be muted during this webinar. Please use the Q&A feature in Zoom to ask questions and communicate via chat with the hosts.
- The webinar will be live captioned in English and live interpreted in Spanish and ASL.
 - Live English captions can be accessed by clicking the “CC” button at the bottom of your Zoom screen
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 - Se puede acceder a la interpretación en español en vivo haciendo clic en el botón “interpretation” en la parte inferior de la pantalla de Zoom (icono del mundo). Una vez en el canal español, por favor silencie el audio original.
- Full accessibility (including interpretation) may not work if you are joining with a mobile device. Swipe on your device to find the ASL interpreter if you need to.
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.
- The webinar will be recorded and posted to YouTube at a later date, and slides will be available on our website.

Sarah Taub

Sarah Taub was the National Core Indicators Director until 2013 when her life was cut short by an aggressive cancer.

Her sense of mission and purpose was an essential part of the growth of NCI to the prominence it has today.

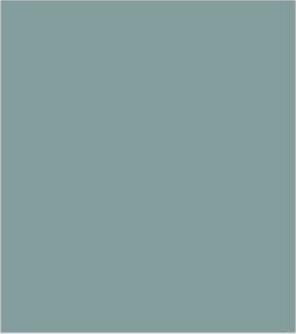
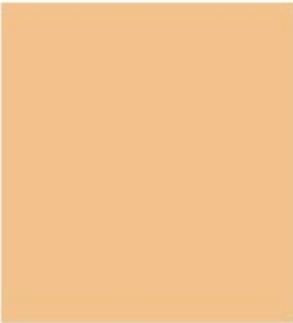
She was a fierce advocate for people with disabilities, and for their representation at all levels in the work we do. She never let us forget the people behind the numbers.



Webinar Agenda

- 1 Introduction to Issues Related to Family Caregiving**
- 2 Measuring the Quality of Paid Family Caregiving using NCI**
- 3 Enhancing Family Caregiving in GA**
- 4 Future Directions**

Introduction to Issues Related to Family Caregiving



Caregiving in America



1 in 4 Americans (63 million adults) provide ongoing care for aging parents, spouses with chronic conditions, or adults children with disabilities and serious illnesses

Just 4% of family caregivers report they were paid for care in 2025

- **Estimates** from 2022 suggest that the economic value of unpaid contributions was around \$600 billion

State family caregiving policies



In Medicaid state plans and HCBS waivers, states have wide discretion about **what types of services are covered and whether families can be paid to provide supports**

During COVID, [27 states used temporary flexibilities](#) to allow family caregivers to be paid providers

- 17 states made those flexibilities permanent

Current landscape of the LTSS workforce

- Longstanding workforce shortages result in many agencies turning away referrals due to staffing issues and long waiting lists
- OBBBA cuts to federal spending on Medicaid and Medicare require states to balance cost-cutting strategies with maximizing outcomes for LTSS users
- **Understanding how outcomes differ among LTSS users who rely on paid family caregivers versus paid staff can help inform state efforts to enhance LTSS**

Measuring the Quality of Paid Family Caregiving using NCI



National Core Indicators: People Driven Data

National Core Indicators **interviews people with disabilities and older adults who get services** from their state Intellectual and Developmental Disabilities or Aging and Disabled systems.

NCI surveys help us learn how people are doing. We share the information to people who oversee state systems. **This helps them to understand where things are going well and where things can go better.**



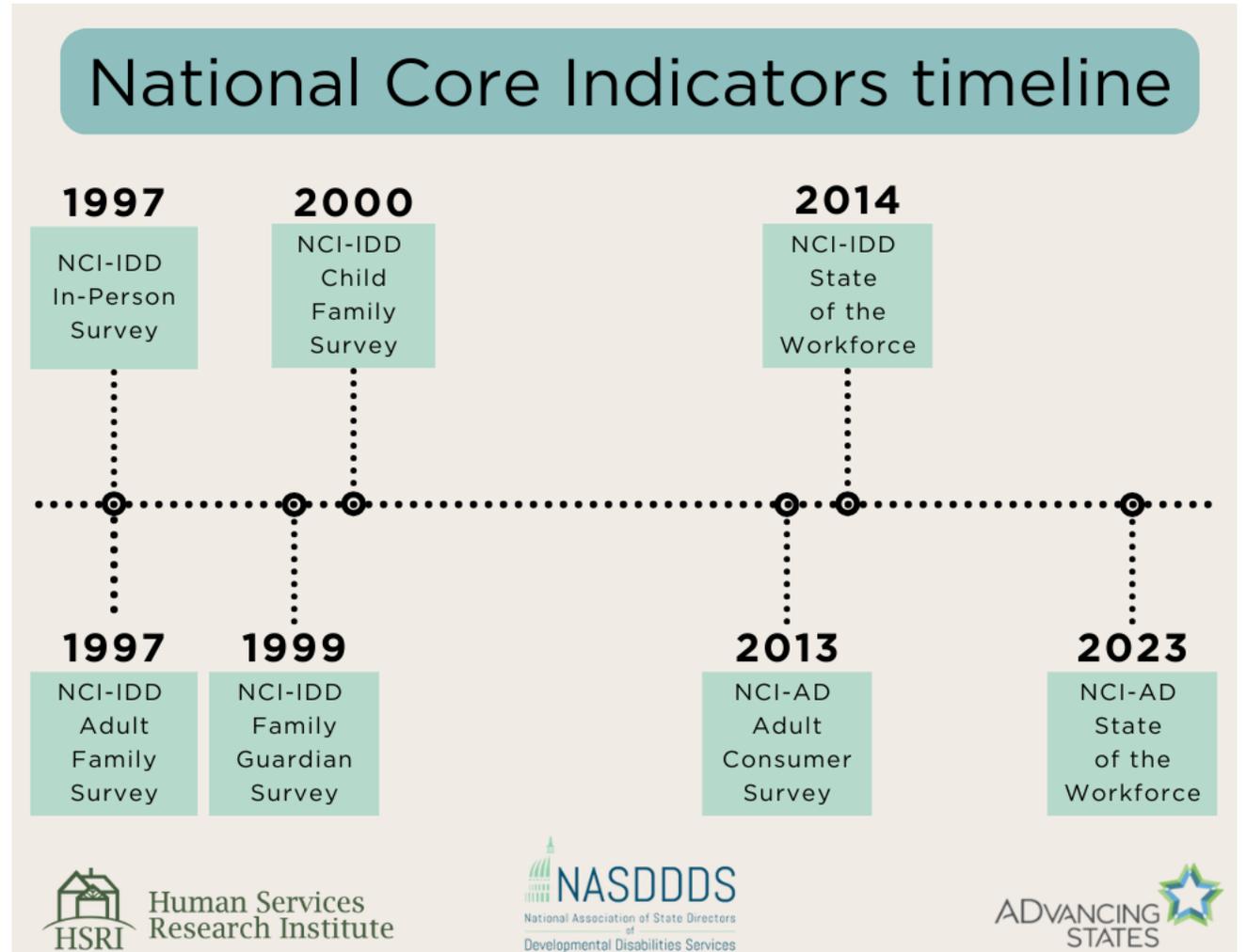
National Core Indicators (NCI)

NCI tools collect data on performance and quality of life indicators directly from:

- (1) people who use disability and/or aging services systems;
- (2) families; and
- (3) those who deliver services

Participating states:

- NCI-IDD IPS and Family Surveys: 48
- NCI-AD: 26
- State of the Workforce: 30 states for the NCI-IDD SoTW, and 10 states for NCI-AD SoTW



NCI data is available for secondary analysis

NCI Data Elements

Background information

- *Demographic factors & residential info*
- *Service plan goals*
- *Funding sources and amount of supports*
- *Diagnoses and conditions noted in records*

Individual outcomes

- Employment
- Community inclusion and belonging
- Community participation
- Choice and decision-making
- Relationships
- Satisfaction
- Affordability

System performance

- Self-direction
- Service and care coordination
- Workforce
- Access to community, needed equipment, and technology

Health, wellness, and rights

- Safety
- Health and health care
- Medication
- Wellness
- Rights and respect

NCI in National Quality Monitoring

- NCI included in HCBS Quality Measure Set put forward by CMS in Access Rule (NCI-AD 18 measures, NCI-IDD 16 measures)
- NCI measures endorsed by CMS Consensus Based Entity National Quality Forum, now managed by Batelle Partnership for Quality Monitoring.
- NCI-IDD IPS measures included in the CMCS Adult Core Set
- NCI-IDD IPS and NCI-AD ACS included in the Medicaid and CHIP Scorecard
- NCI-AD participation included in AARP LTSS State Scorecard

NCI-AD Adult Consumer Survey (ACS)



Sampling: Using NCI criteria, states design their samples to be representative of their service population

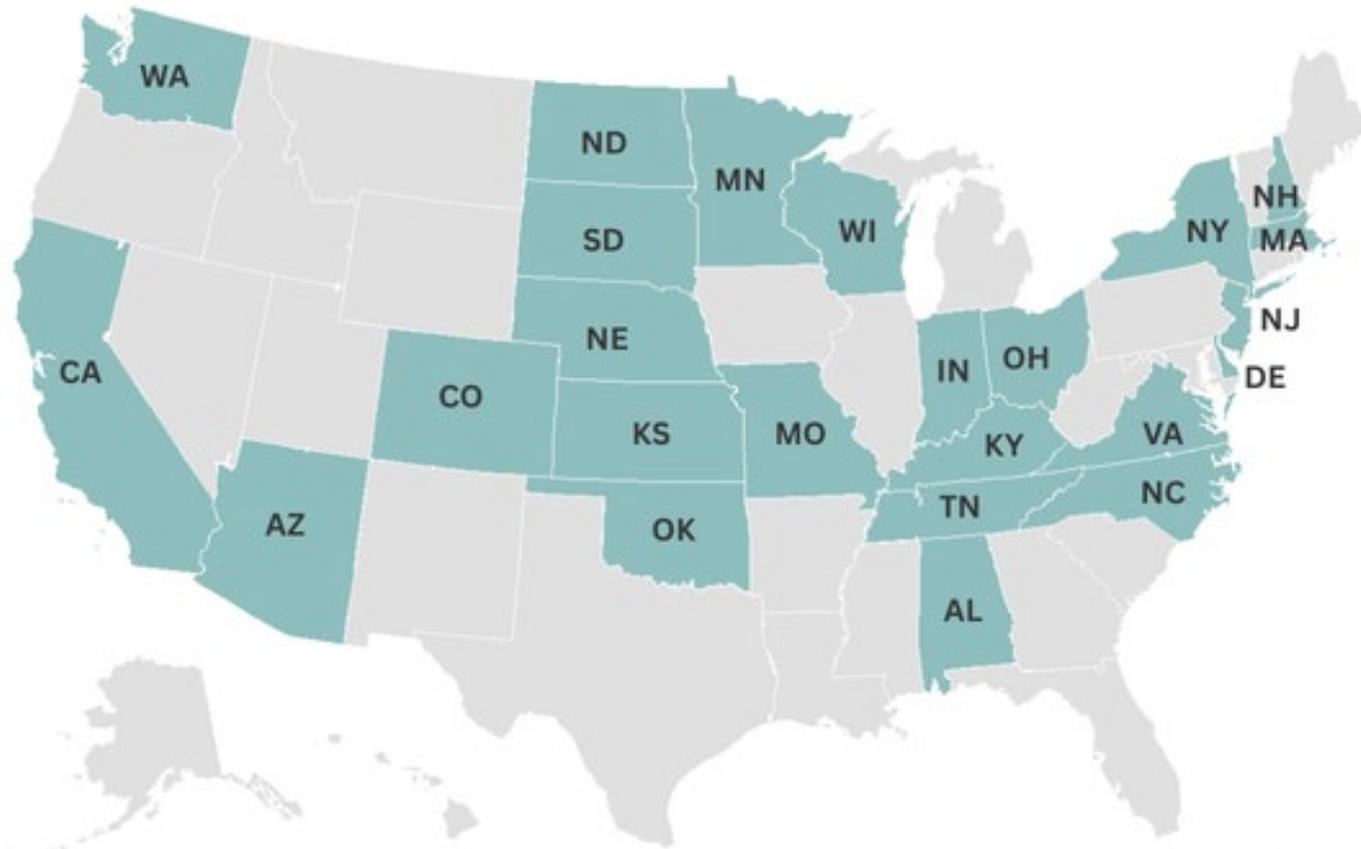
Inclusion criteria: Person receiving one “active service” at least twice a week

Consent: Those who are surveyed are informed that their services will not be impacted directly by their responses

Surveyor training: All surveyors complete standardized training.

Survey features: Flexible administration modes/methods

2024-2025 NCI-AD sample

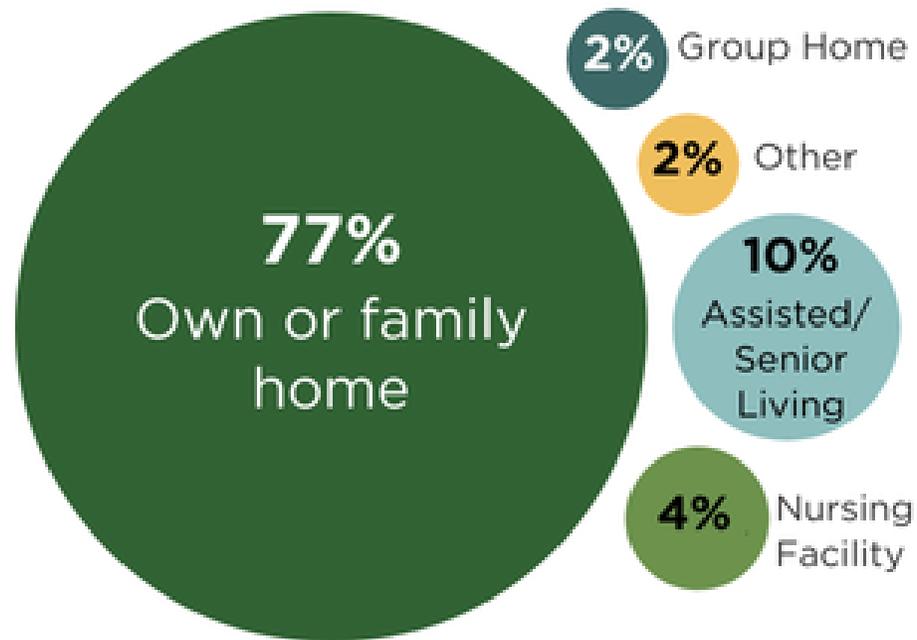


20,026 respondents

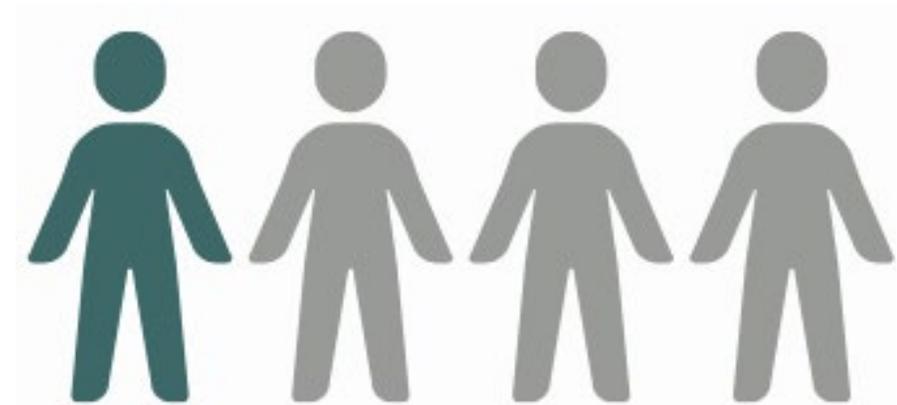
24 states

- **64% female**
- **Average age: 62**
- **Race/ethnicity**
 - *44% White; 24% Black; 15% Hispanic or Latino; 11% Asian*
- **Diagnosis**
 - *51% Physical Disability; 13% ID; 12% Alzheimer's/Dementia; 10% TBI*

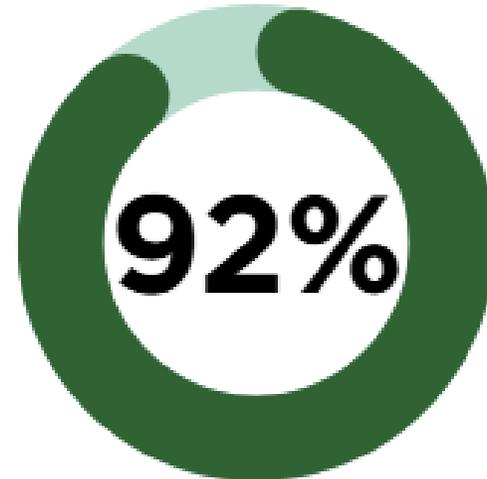
NCI-AD respondents primarily live in their own homes. Many live there alone.



Among those who live in their own or family home, more than 1 out of 4 (30%) live alone

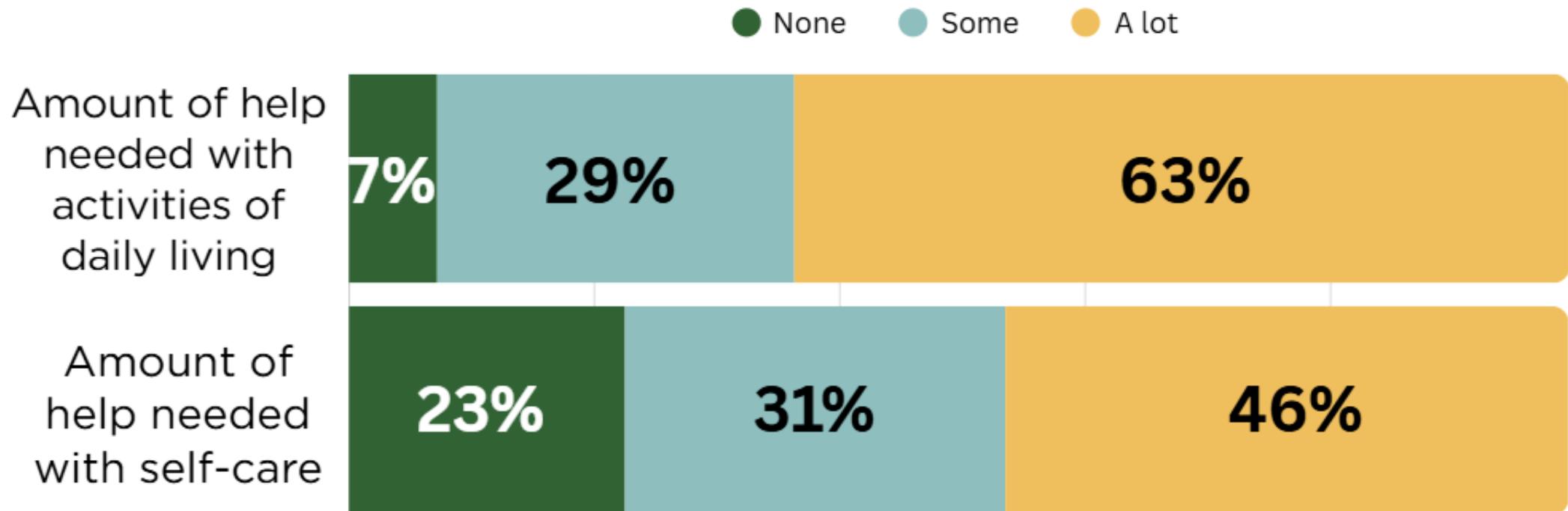


About 9 in 10 NCI-AD respondents are getting regular support



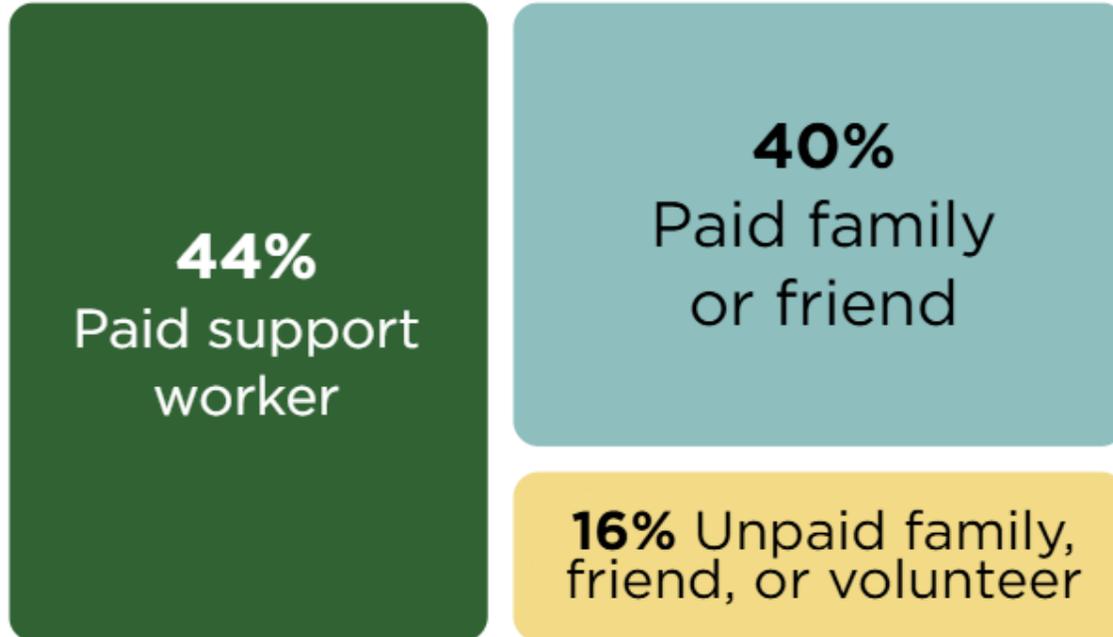
Say there is someone who helps them at home at least once per week

Overall, 2 in 3 people need a lot of help with ADLs, and nearly half need a lot of help with self-care



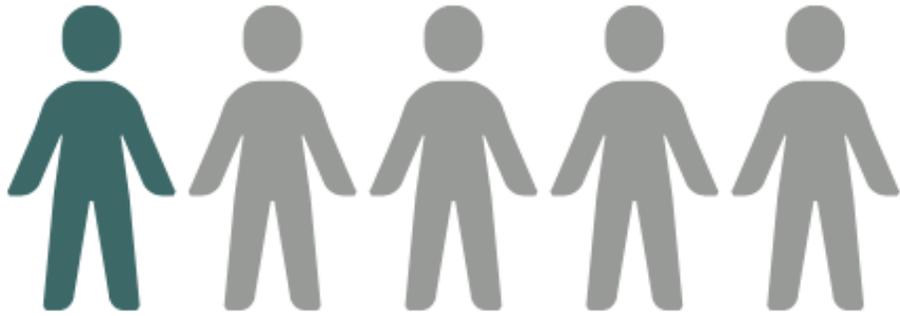
2 in 5 people say the person who helps them most is a paid family or friend. Many also have a second person who helps them.

Who helps you most often?



73% have a second helper

Over 1 in 5 people (22%) say their paid support workers change too often



22% say their paid support workers (*staff and paid family*) change too often

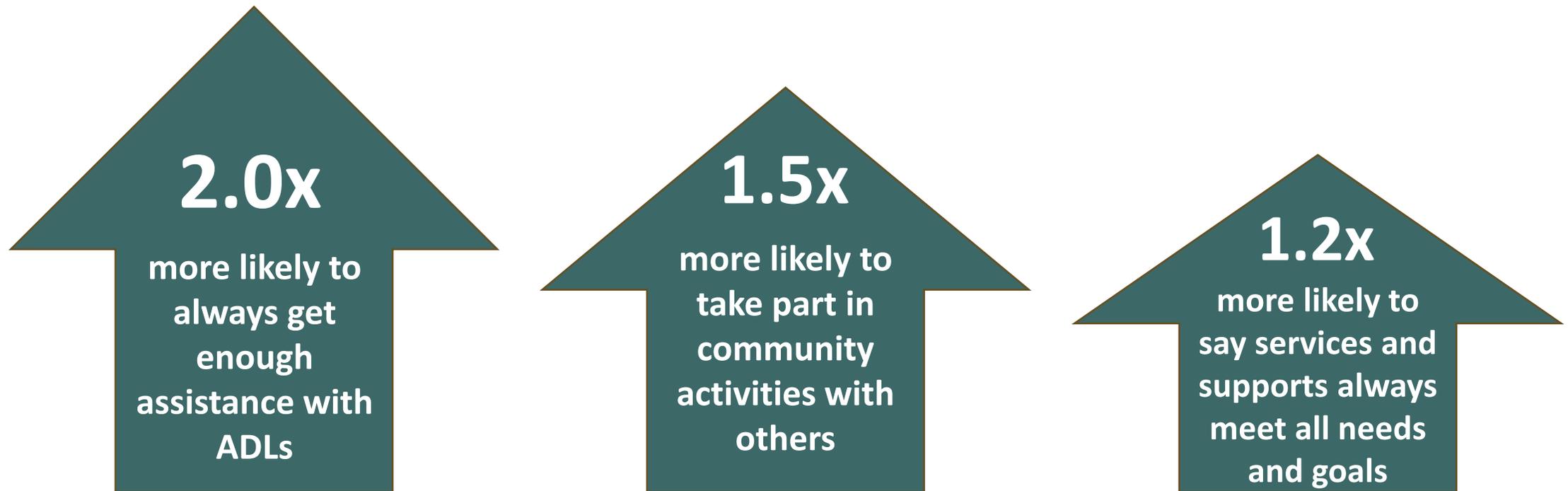
Among those who say paid family help them most often, just 10% say their paid support workers change too often.

That rate is 3x higher among those who say paid staff help them most often (30%).

There are statistically significant differences in person-centered outcomes by main helper type. In other words, these differences are unlikely due to chance alone.

Select outcomes from NCI-AD	Overall %	Main helper is		
		Paid staff	Paid family	Unpaid
Always gets enough assistance with activities of daily living (ADLs)	85%	86%	93%	78%
Services and supports always meet all needs and goals	72%	76%	79%	66%
Takes part in community activities with others as much as they want to	67%	62%	71%	64%

When compared with those whose main helper is paid staff, those whose main helper is a paid family/friend are:



All analyses are adjusted for age, gender, race/ethnicity, mobility, level of support needs, and whether person lives alone

NCI-IDD Family Surveys



Mail out surveys designed to understand the experience of families of people receiving DD system services

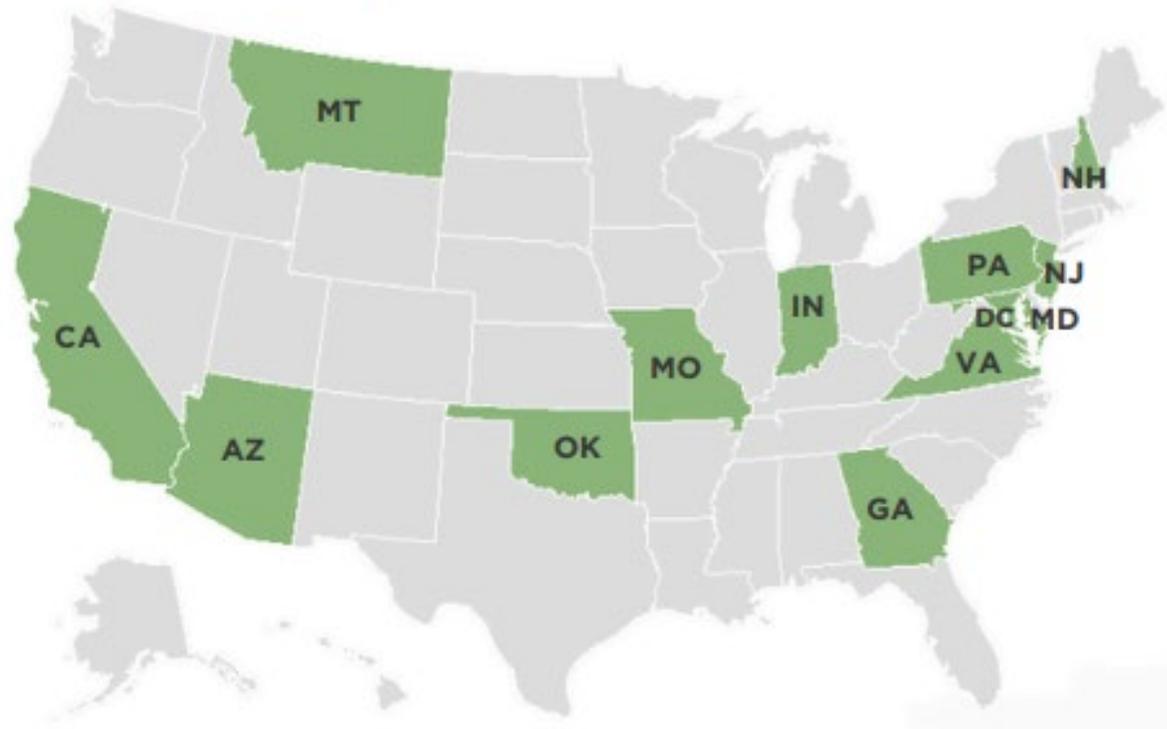
Information is answered by the **family or guardian** of the person receiving at least **one service in addition to case management**

Three surveys:

- Adult Family Survey (AFS) – sent to families who *live with* the person with IDD
- Family Guardian Survey (FGS) – sent to families who *do not live with* the person with IDD
- Child Family Survey (CFS) – sent to families who *live with* a child with IDD

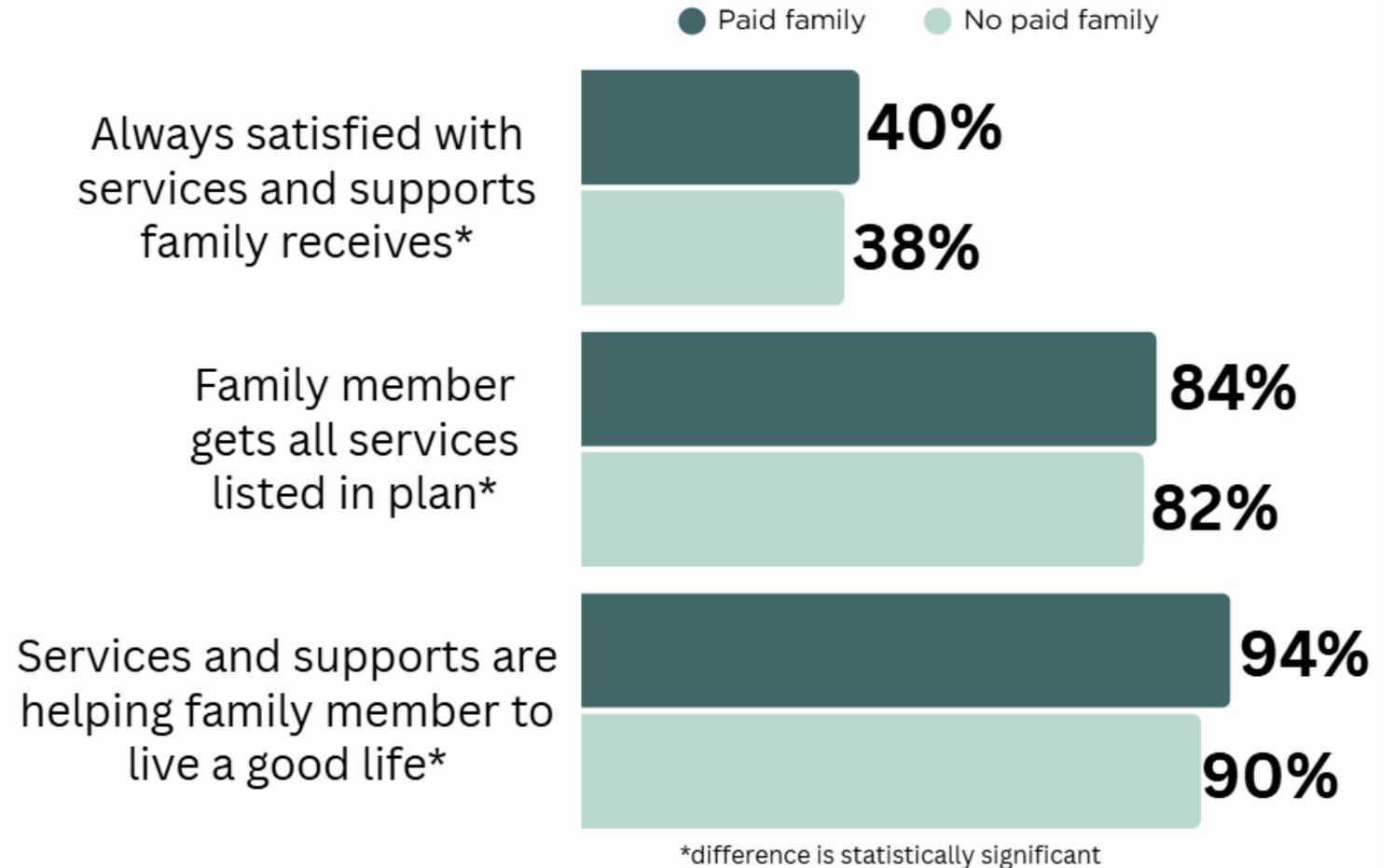
NCI-IDD Adult Family Surveys (AFS) 2023-24

18,724 respondents from **13 states**



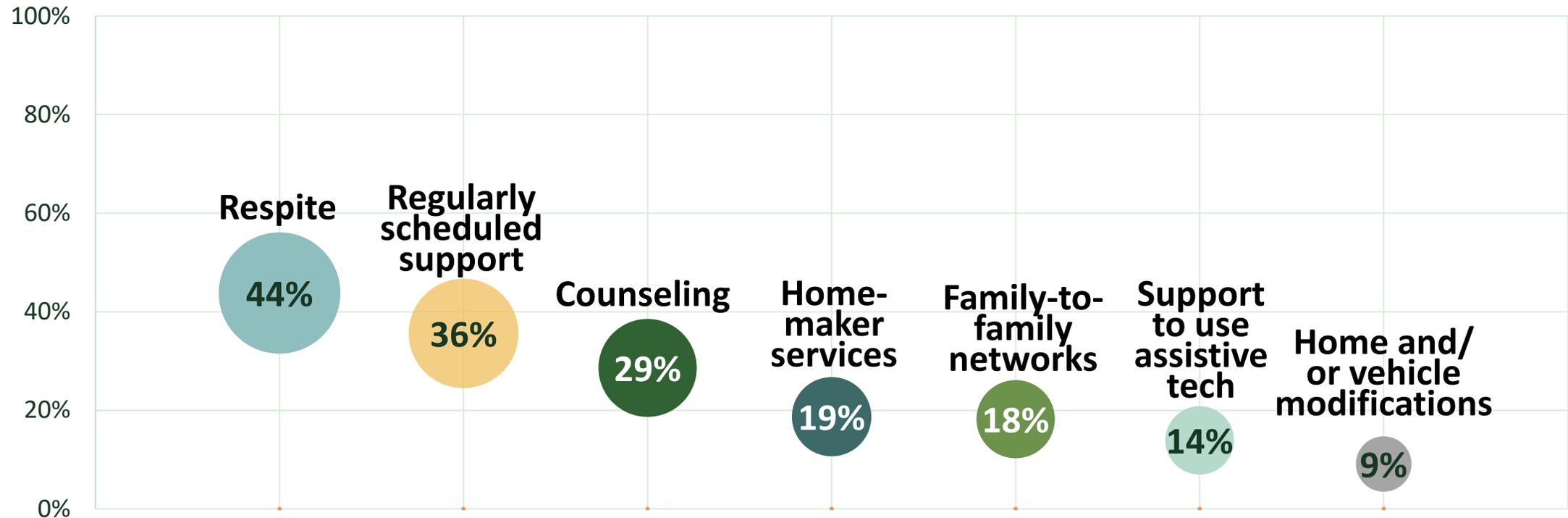
- Diagnosis:
 - 65% ID
 - 44% ASD
- Race/Ethnicity:
 - 57% White
 - 22% Hispanic or Latino
 - 12% Black or African American
 - 10% Asian
- **50% responded that a family member is paid to provide support**

Respondents who say someone in their family is paid to provide services have significantly higher rates of satisfaction with services and getting all services listed in their plan



Among those who do not have paid family caregiving, 30% say their family does not get the services and supports they need

Among AFS respondents with **unpaid family caregivers and unmet needs**, the percentage reporting each type of unmet need



Access to and quality of respite varies significantly for those with and without paid family caregivers

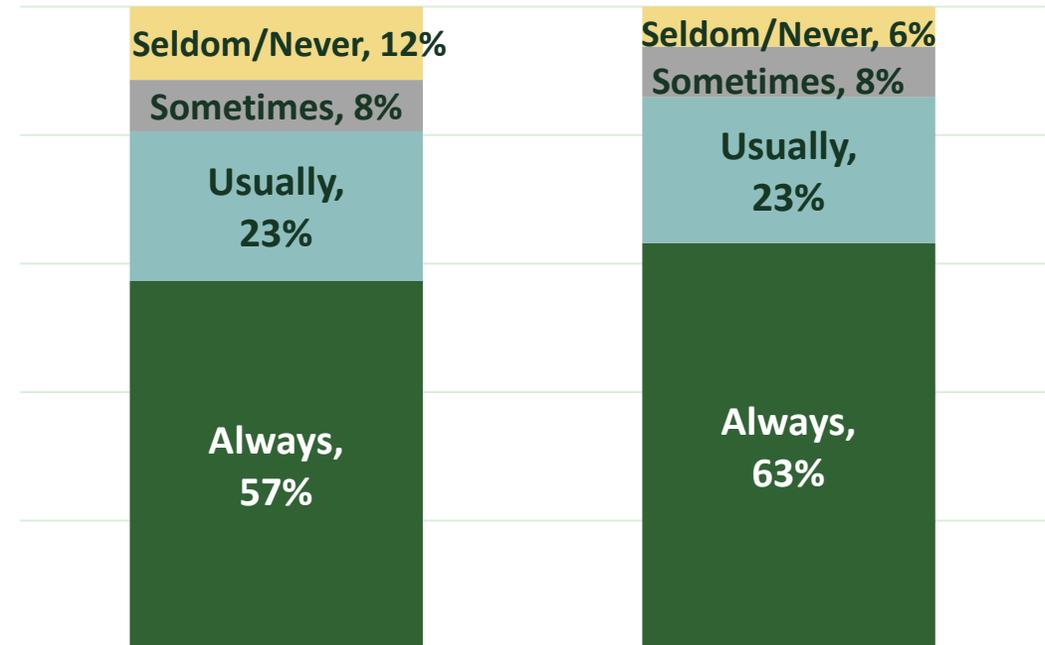
Access to respite when needed



No paid family caregiver

Paid family caregiver

Satisfied with quality of respite in past 12 months

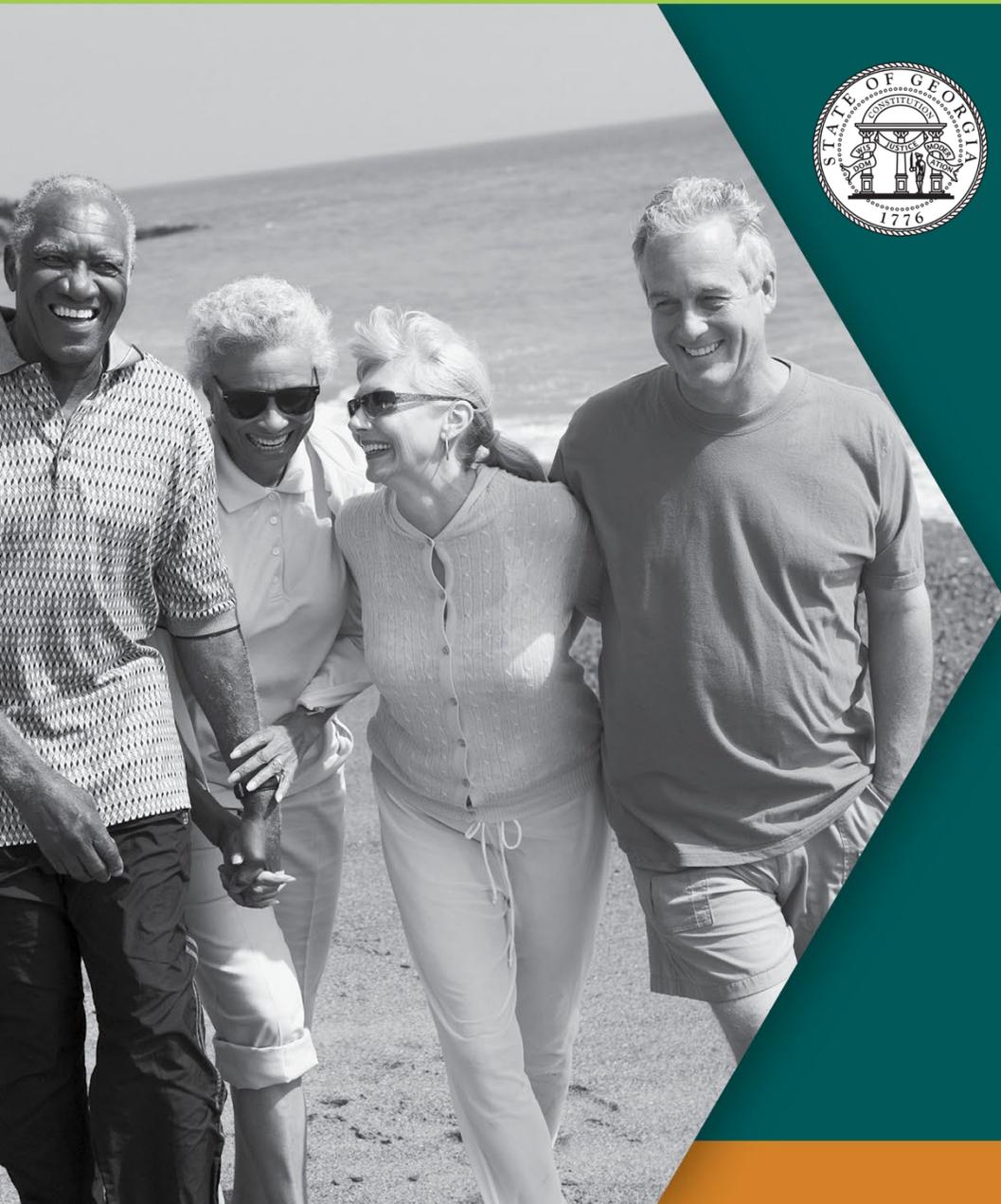


No paid family caregiver

Paid family caregiver

Enhancing Family Caregiving in Georgia





Georgia Department of Human Services
Division of Aging Services

Georgia Respite Care Study: Caregiver Services and Return on Investment

David Watkins

Caregiver Services Specialist

Georgia Respite Care Study



**Georgia Department
of Human Services**

Division of Aging Services



UNG

UNIVERSITY *of*
NORTH GEORGIA™
INSTITUTE FOR HEALTHY AGING



Respite Study Team



Members of DAS team pictured with the UNG study team

Respite care provides temporary relief for primary caregivers, offering short-term substitute care so the caregiver can rest, run errands, or handle personal matters. Respite care can help relieve stress and reduce caregiver burnout.

University of North Georgia Healthy Aging Institute

- Principal Investigator: Dr. Pamela Elfenbein
- Contracted in June 2024
- White paper published January 2026

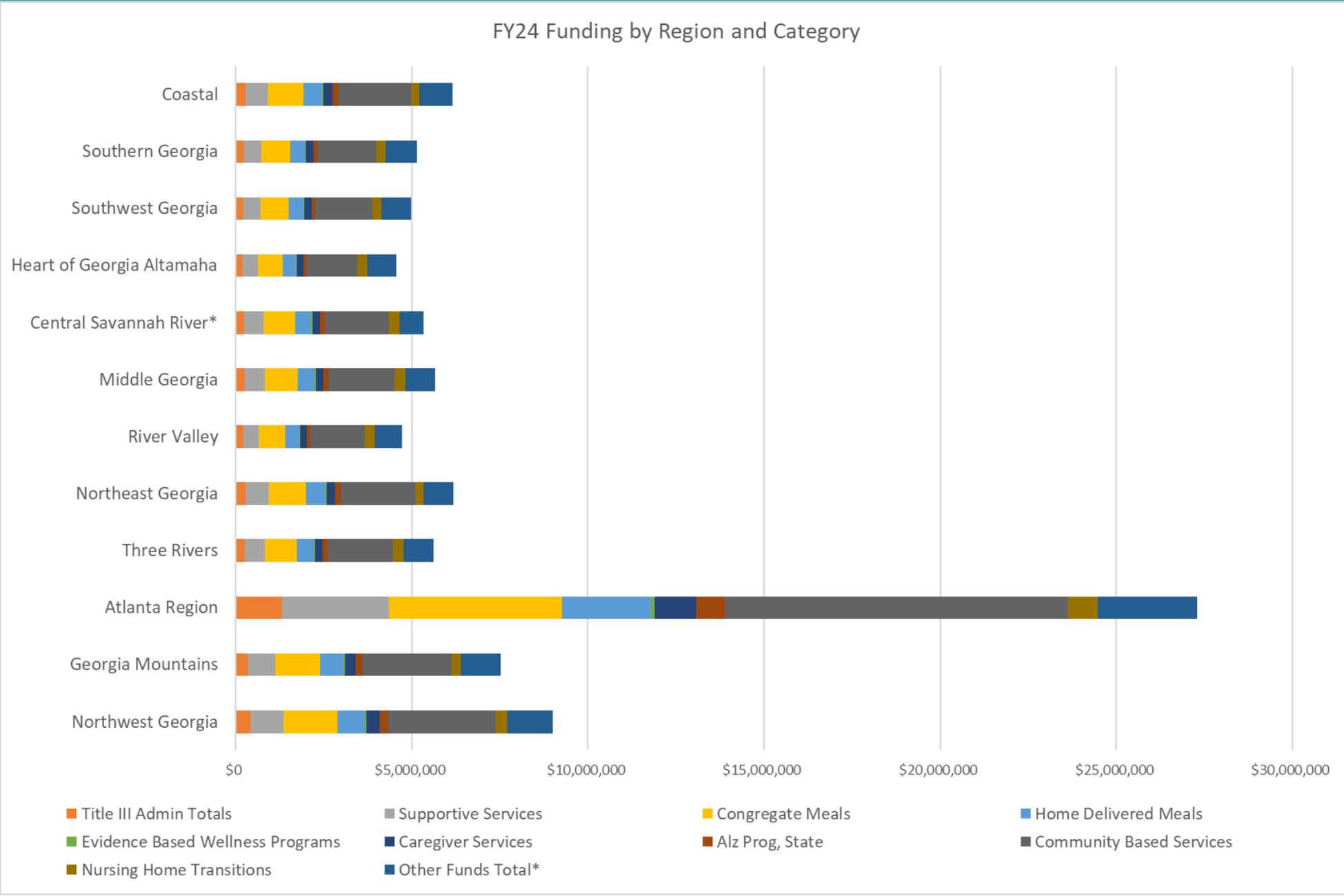
Caregiver Services

Combined Service Categories for Data Analysis

Service Type	Service
BRICC	Care Consultation
Case Management	Case Management
Home Delivered Meals	Home Delivered Meals
Homemaker - Voucher	Homemaker - Voucher
MAALL	Material Aid - Individual
	Material Aid - Assistive Technology
	Material Aid - Home Modifications/Home Repair
	Material Aid - Voucher - Individual
	Material Aid - Other - Individual - Voucher
Material Aid - Other - Individual	
Respite Care - Out-of-Home - Voucher	Respite Care - Out-of-Home - Voucher
RHIV	Respite Care - In-Home - Voucher
RIHPCH	Personal Care
	Respite Care - In-Home
	Homemaker
	Respite Care - Out-of-Home
ROHAD	Respite Care - Out-of-Home
	Adult Day Care
	Adult Day Care - Mobile



FY24 Funding by Region and Service Category



Georgia Caregiving by the Numbers

24%

of adults in Georgia are family caregivers;

that equates to approximately

2.5M

people.

20%

of Georgia's total population will be age 60+ by

2034.

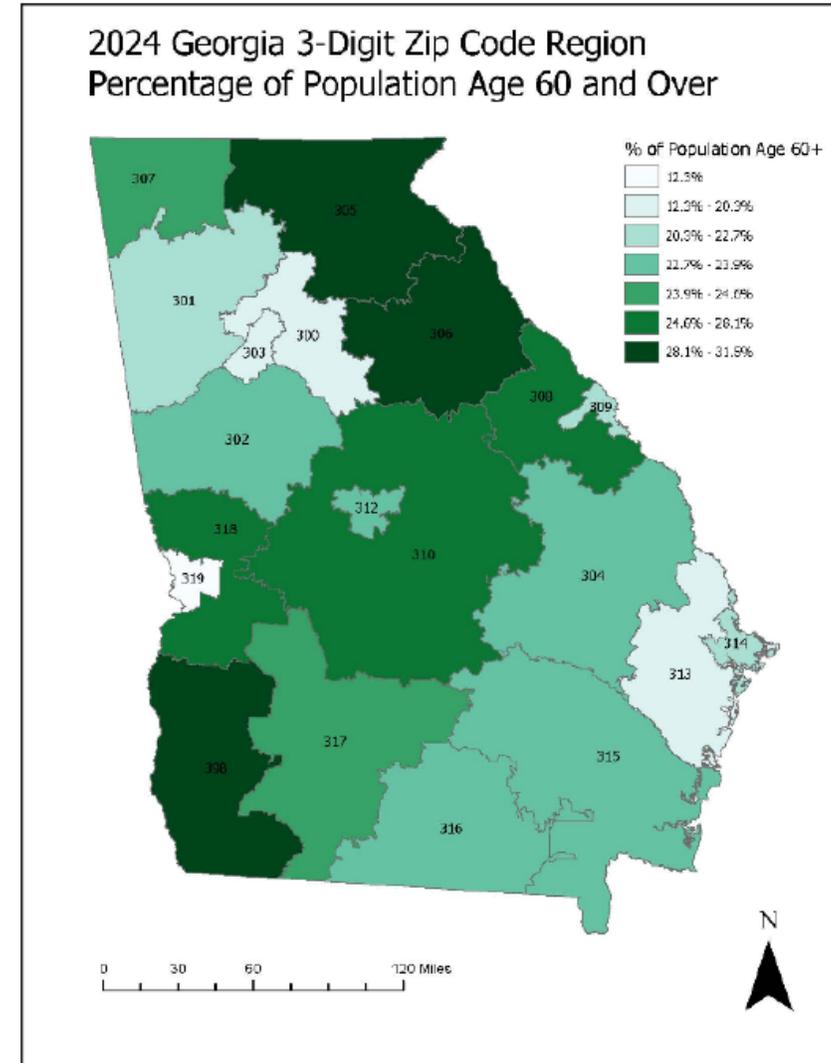
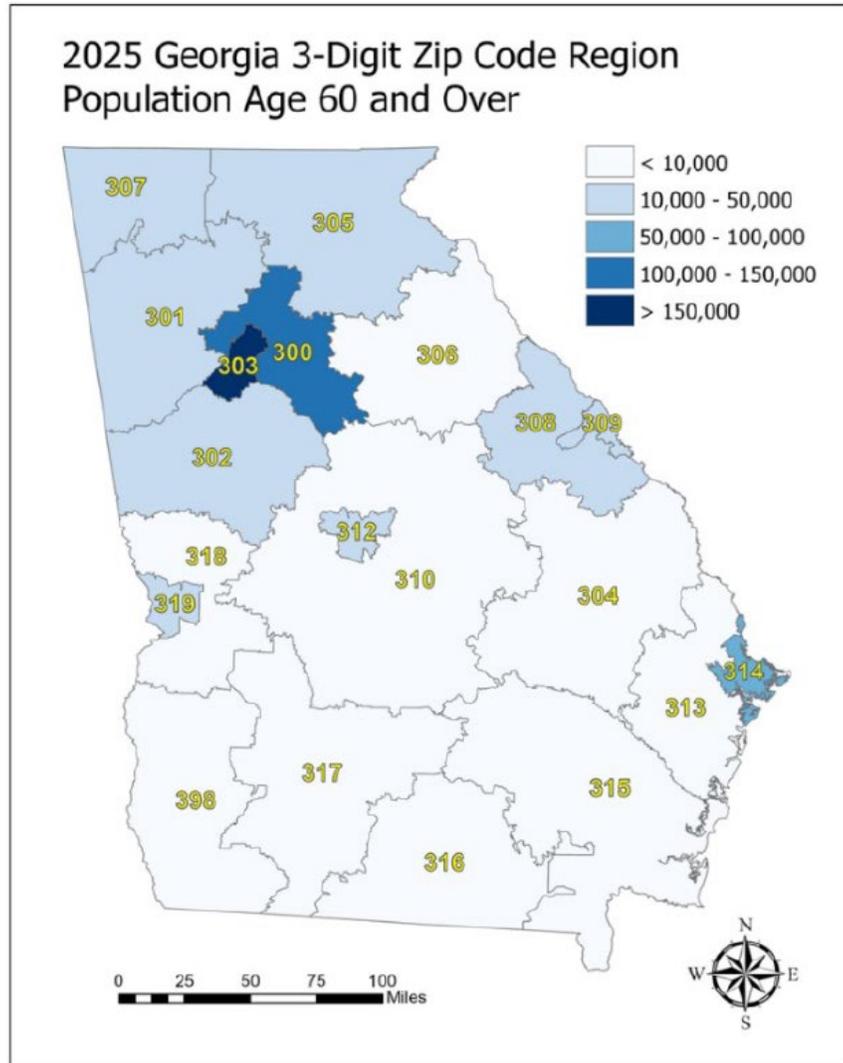


Contract Deliverables

- Provide and discuss examples of policies, programs, and/or **best practices** that could potentially be implemented in Georgia to help serve caregivers more effectively.
- Analyze and evaluate Older Americans Act and state-funded caregiver services **return on investment (ROI)** utilizing de-identified data provided by DHS-DAS.
- Present all **data analysis**, research, and discussion in a white paper format that describes the complex issues, traditional and non-traditional approaches to respite care, costs of care, and how respite care might better serve to **delay long term care placement**.



Demographics



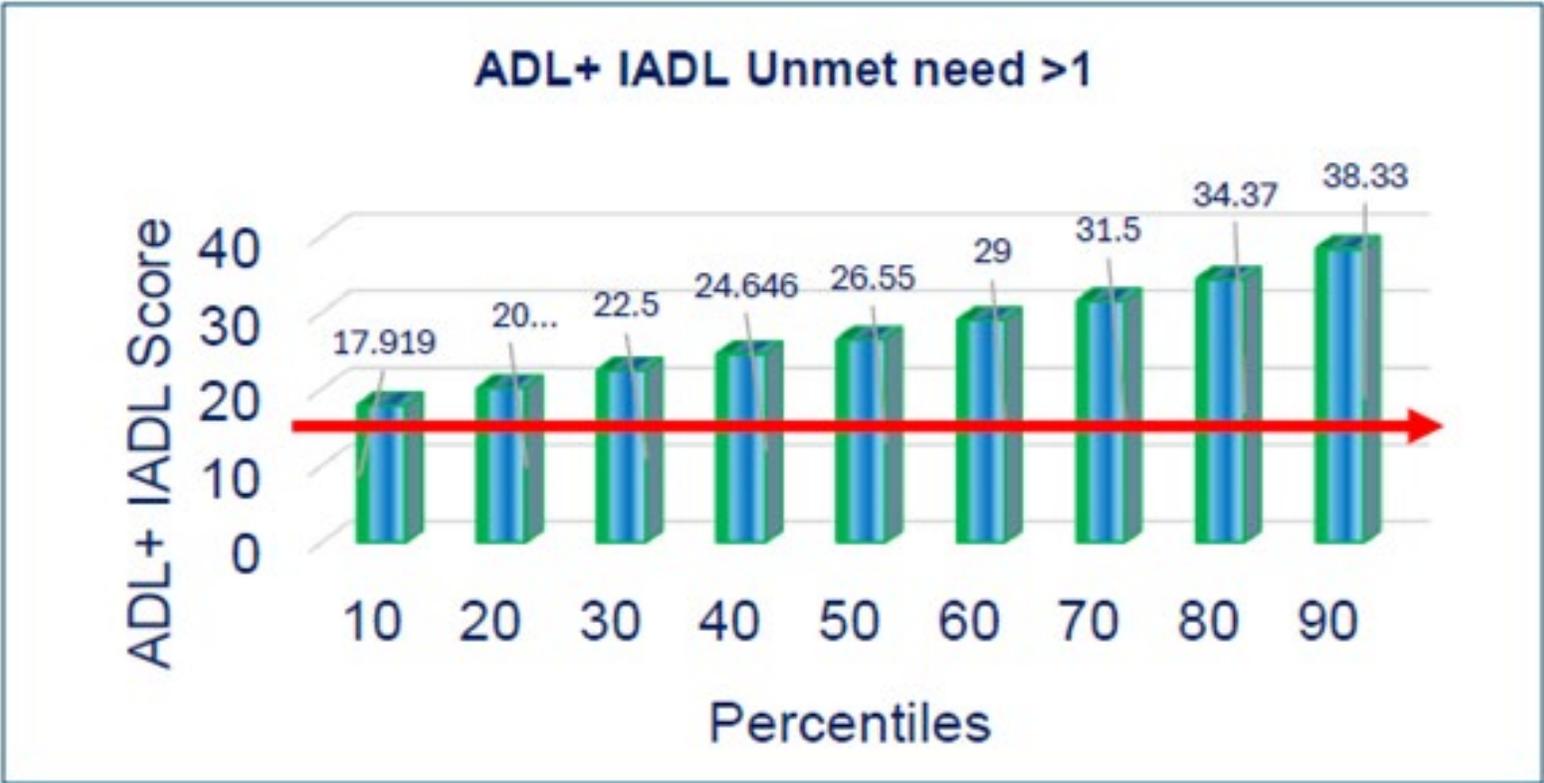
Functional Assessment

Care Receiver level of impairment is assessed using the DON-R (Determination of Need - Revised) assessment

Activities of Daily Living (ADL)
Instrumental Activities of Daily Living (IADL)

Impairment score to qualify for nursing home care = 15+1 (red arrow)

Scores for the highest 40% of clients are double (or more) the minimum required score for nursing home referral

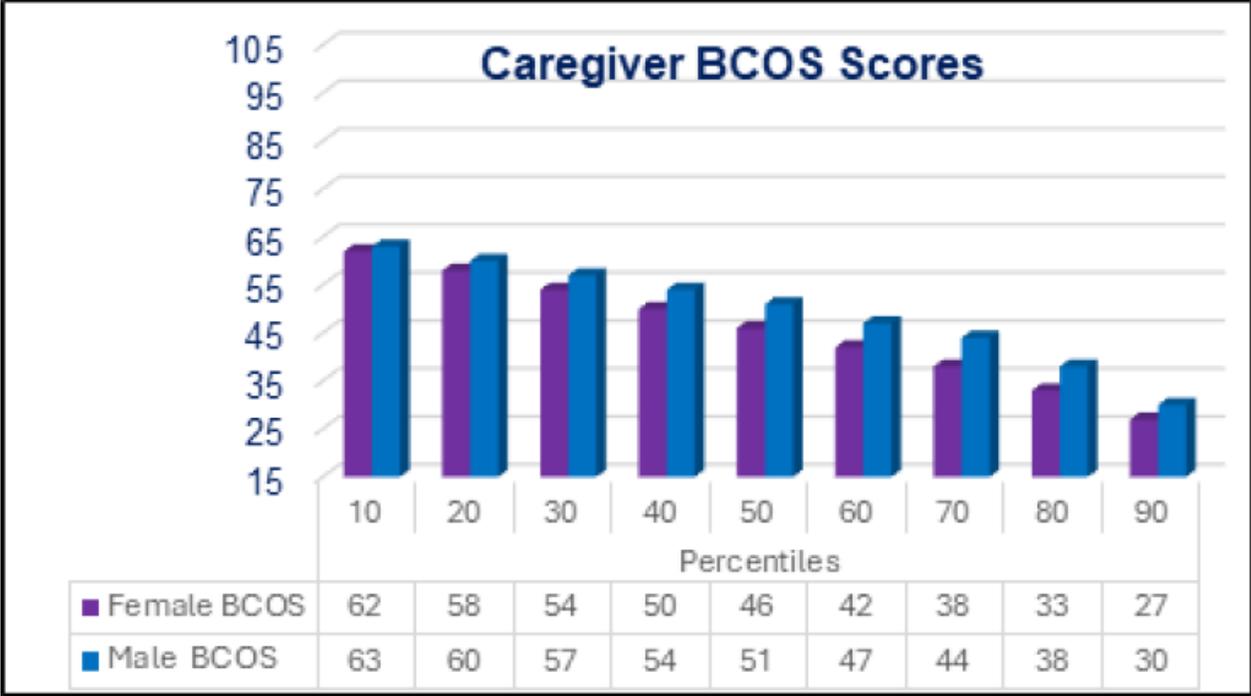


Caregiver Assessment

The BCOS assessment is a validated instrument to measure caregiver burden due to the stresses of caregiving.

Caregivers are asked 15 questions about perceived life changes, including physical health, social functioning, emotional well-being, and relationship changes.

Lower scores indicate higher burden
 Lowest possible score = 15
 Highest possible score = 105



Data Subset for ROI Calculation

Caregiver

- Age
- Gender
- BCOS score

Care receiver

- Age
- Gender
- DON-R score

Total Individuals in data set: 22,731

Required for inclusion in analysis:

- Age
- Gender
- DON-R or BCOS Scores

Individuals in final data set: 5,295

Dyads in final data set: 2,691*
(*33 caregivers are matched with more than care receiver)

- This data subset closely resembled the full data set for gender, dyad gender, age of caregiver, and age of care receiver measures



ROI Calculation Model

ADvancing States produced an infographic: The Value of Aging Well: The Older Americans Act Create Real Returns through Community-Based Care and provided a return on investment (ROI) calculation.

Days of Long-Term Care Avoided:

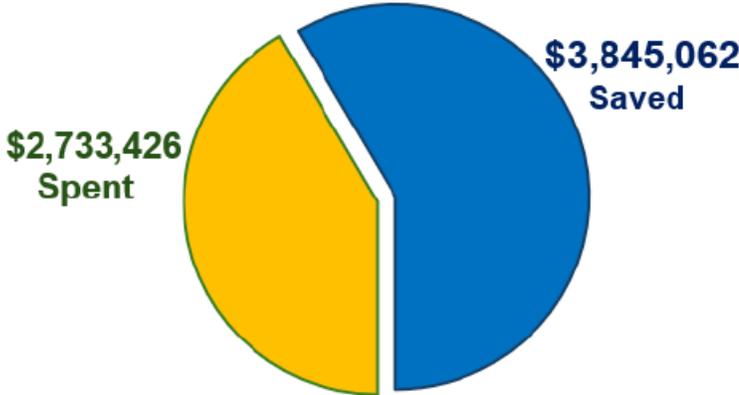
- 15% of older adults spend more than 2 years in a nursing home
- every hour of service provided per client per week results in a 6% decrease in the risk of entering residential care



ROI for CG Services SFY24

UNG used the Advancing States model to make a very conservative estimate of ROI for DAS Caregiver Services provided during SFY 2024:

636 Care Dyads received:
Hours of Case Management = 618
Hours of Respite and Personal Care = 104,323
Dollars Spent = \$2,733,426
Extra Days in the Community = 13,259
Dollars Saved = \$3,845,062
41% Return on Investment

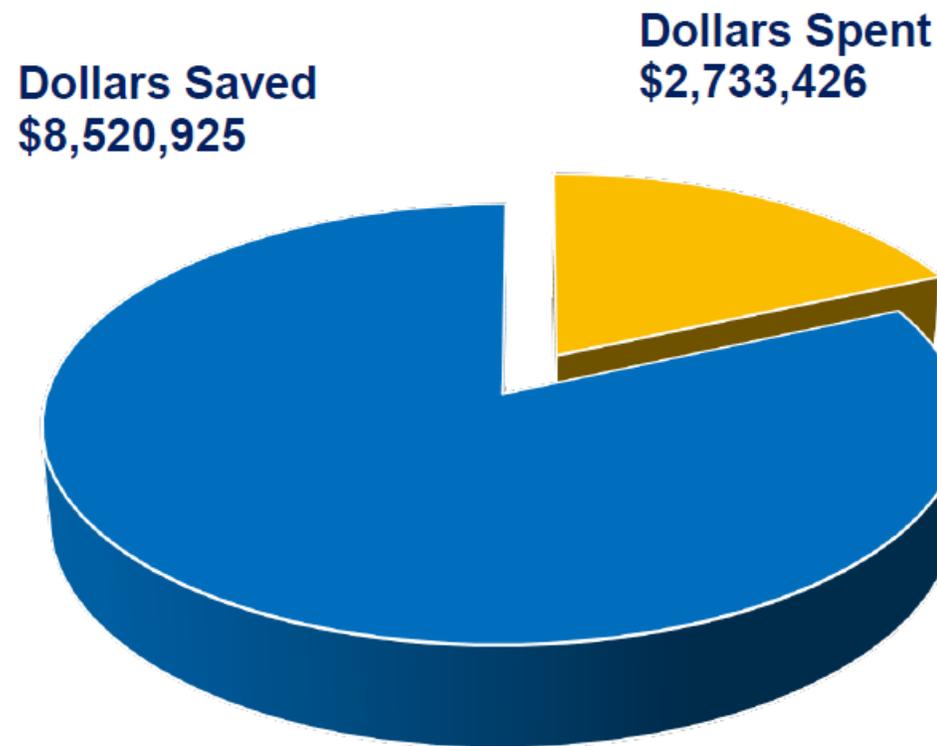


Additional Model of ROI for SFY24

UNG used an additional model to estimate ROI for DAS Caregiver Services provided during SFY 2024:

- Care Receivers 80+
- 3 or more ADLs (impairment score = 2+ including bathing and dressing)
- 115 Dyads represented in this subset

**Return of
3.12 x
Investment**



Return on Investment (ROI)

The study found that **every dollar invested in respite care generates dollars-saved** in avoided long-term care costs, **underscoring the economic efficiency of caregiver support programs.**



Every \$1
spent yields
more than **3X**
savings
in Medicaid
LTSS
expenditures



Study Recommendations

- **Strengthen caregiver navigation and access to resources.**
- **Expand respite services for underserved populations**, particularly those residing in Georgia's most rural regions and with the highest activity of daily living impairment scores and caregiving burden scores.
- **Enhance Return on Investment (ROI) measurement and tools** to better demonstrate the economic and social value of caregiver support.
- **Adopt best practice guidelines** from the Administration for Community Living (ACL), ADvancing States, USAging, and other Southeastern states to broaden service delivery and improve outcomes.
- **Address workforce shortages** through innovative recruitment and retention strategies.



Links to Study

Georgia Respite Care Study:

<https://aging.georgia.gov/tools-resources/caregiving/respite-care>

Download link to white paper:

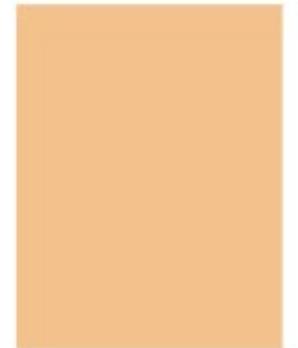
<https://aging.georgia.gov/document/document/georgia-respice-care-study/download>

Download link to key findings:

<https://aging.georgia.gov/document/document/georgia-respice-care-study-key-findings/download>



Future Directions



State and Federal Initiatives to Strengthen Family Caregiving (Paid and Unpaid)

- **ACL investment and prioritization of family caregivers**
 - RAISE Strategy to Support Family Caregivers
 - Caregiver AI Prize Competition
- **[ARCH National Respite Network and Resource Center](#)**
- **[Communities of Practice to support families across the lifespan](#)**
- **Medicaid Structured Family Caregiving (SFC)**
- **[Medicare GUIDE Model](#)**

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NCI updates newsletter



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