The Connection between Paid and Unpaid Supports with Person-Centered Outcomes for Older Adults

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Agenda

1. Overview of National Core Indicators – Aging and Disabilities
2. Results of study
3. Implications and future directions

About National Core Indicators®

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:

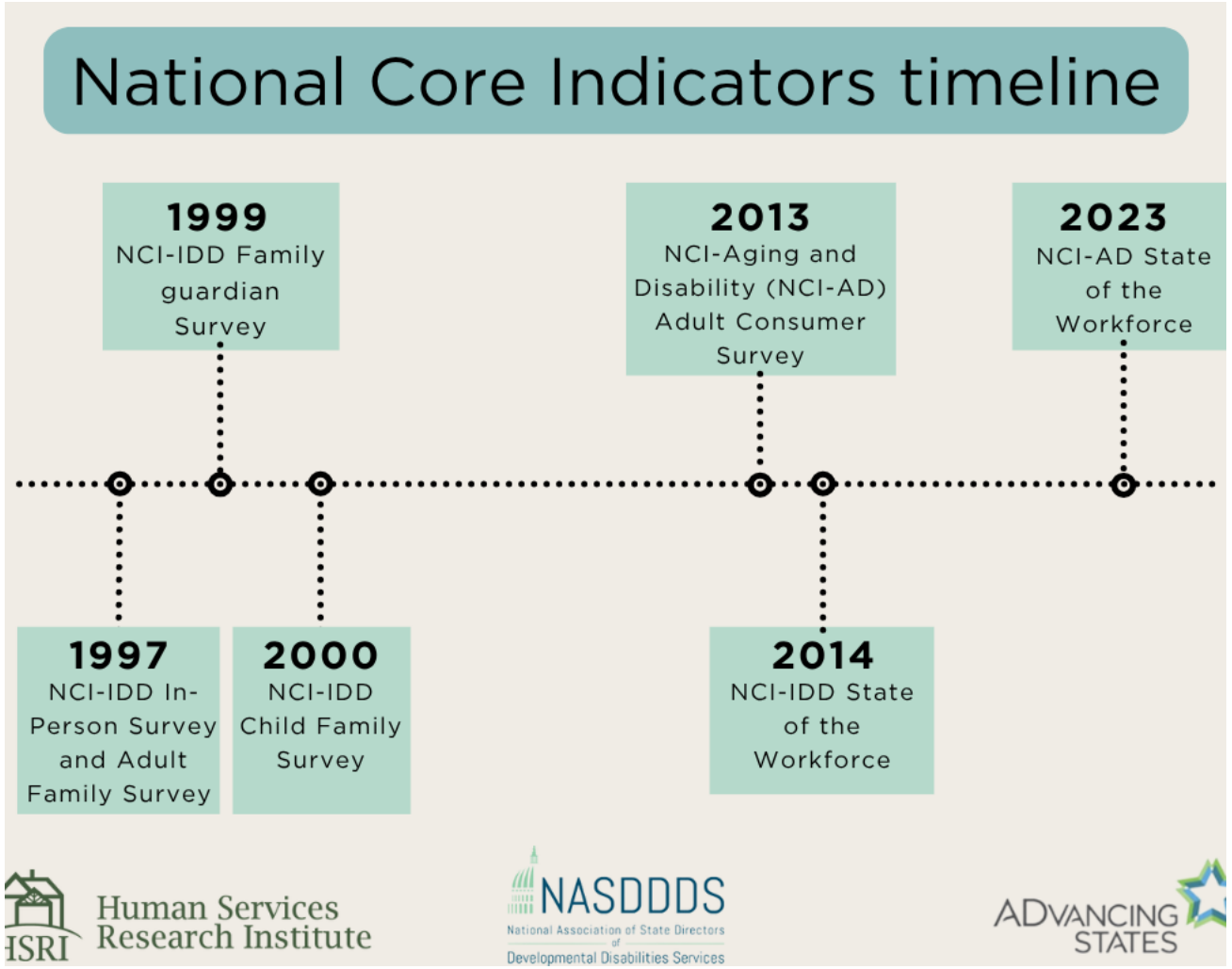
(1) people who use disability and/or aging services systems;

(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 6 states for NCI-AD SoTW



NOTE: All NCI data is available for secondary analysis!

Using NCI data for advocacy: The exit ramp

NCI data can reveal patterns and trends, but it doesn't necessarily tell you:

- The root cause(s)
- The right solution(s)

NCI data should be used to start a conversation about the **possible root causes of patterns to be sure to consider the various solutions** to improve systems.

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

- This represents a **45% increase since 2015**

Paid family caregiving

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

- Usually paid wages comparable to other direct care workers ($13-$16/hr)
- In some states, they are paid daily stipends of $40-50 day

Even when family members are paid to provide supports, they typically provide more supports than they are paid for.

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

Federal family caregiving initiatives

RAISE Family Caregivers Act of 2018 specified that HHS develop a national family caregiving strategy

- 2022 National Strategy to Support Family Caregivers released

5 goals:

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

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, many states used temporary flexibilities to enhance supports to family caregivers

Current policy around LTSS

- **OBBBA cuts federal spending on Medicaid and Medicare**
- **States will have to choose:**
  - Decrease enrollment in Medicaid
  - Decrease spending on optional services like HCBS; decrease hours/service coverage
  - Decrease reimbursements for providers

NCI-AD Adult Consumer Survey

Sampling: **States design their samples with guidance from HSRI. Final samples must reach threshold of 95% confidence level and 5% margin of error based on sample frame.**

Inclusion criteria:

- AD: Person receiving one "active service" at least twice a week

Consent: **Surveyors follow state specific consent requirements**

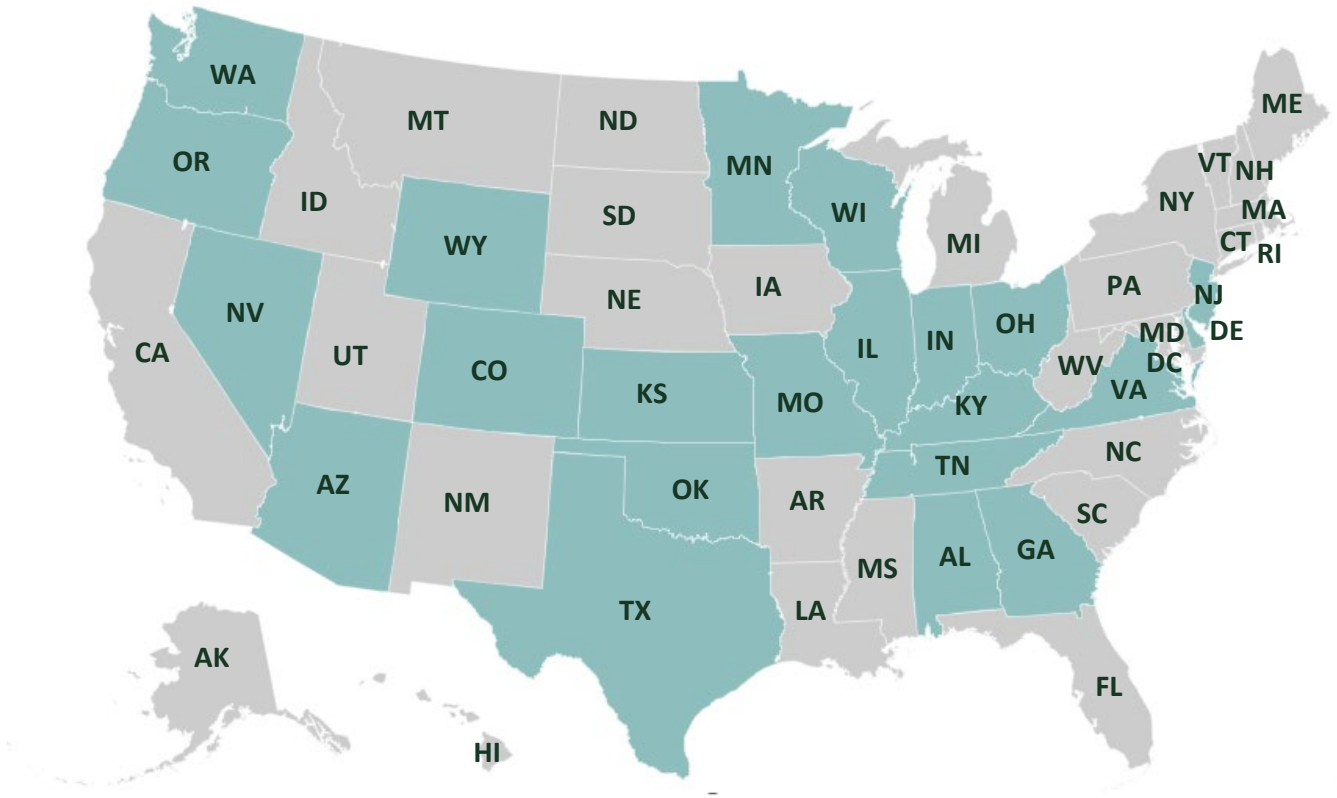
- Those who are surveyed are informed that their services will not be impacted directly by their responses

Surveyor training: **All surveyors complete standardized training.**

Survey features:

- May be conducted in-person or remotely
- Includes detailed Background Information section that primarily comes from existing records
- Surveys are available in multiple languages
- Questions may be rephrased or reworded
- Allows for use of proxy for select questions

2023-2024 Sample – NCI-AD

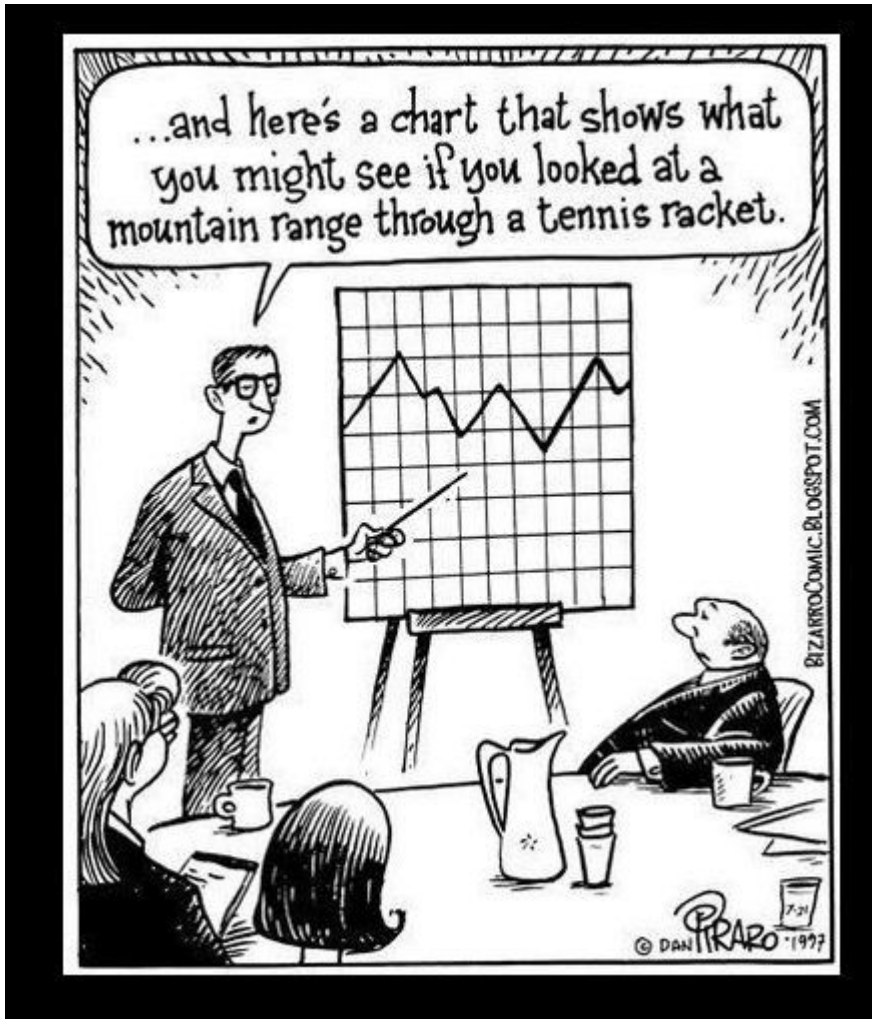


21,041 total respondents

20 states

- **37% male**
- **Average age: 62.5**
- **Race/ethnicity**
  - *57% White; 26% Black; 7% Hispanic or Latino*
- **Diagnosis**
  - *44% Physical Disability; 10% TBI; 9% ID; 12% Alzheimer's or other dementia*

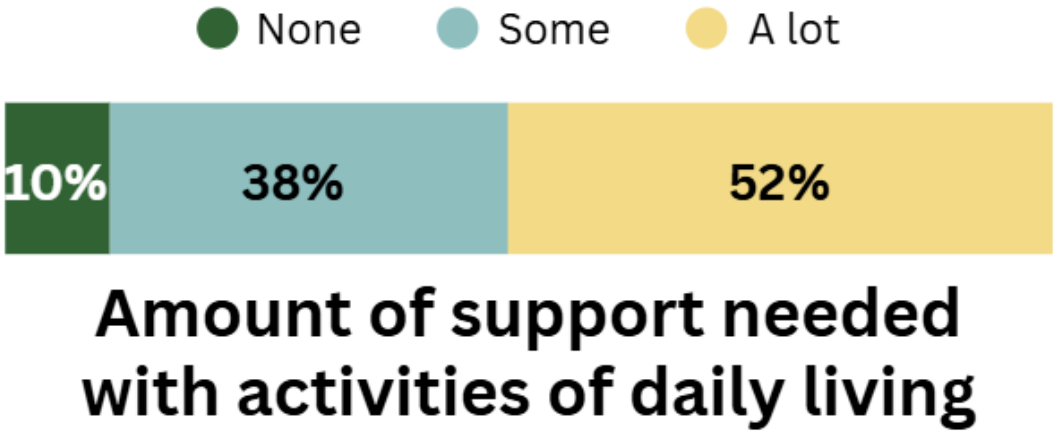
Outcomes of older adults 2023-2024



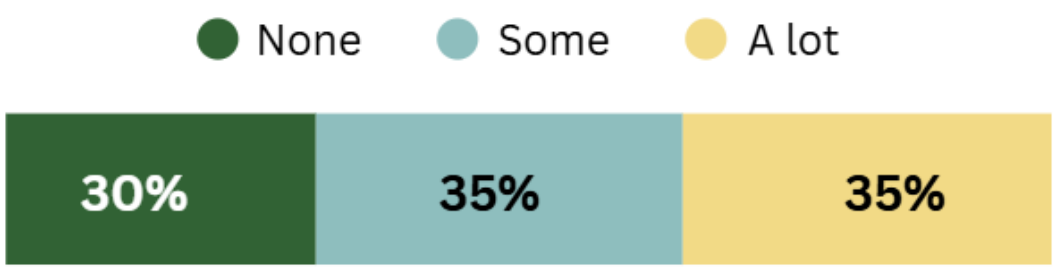
51% of older adults (65+) in the NCI-AD sample live alone

What does NCI-AD data tell us about where people live?

Most older adults need at least some help with ADLs and self-care

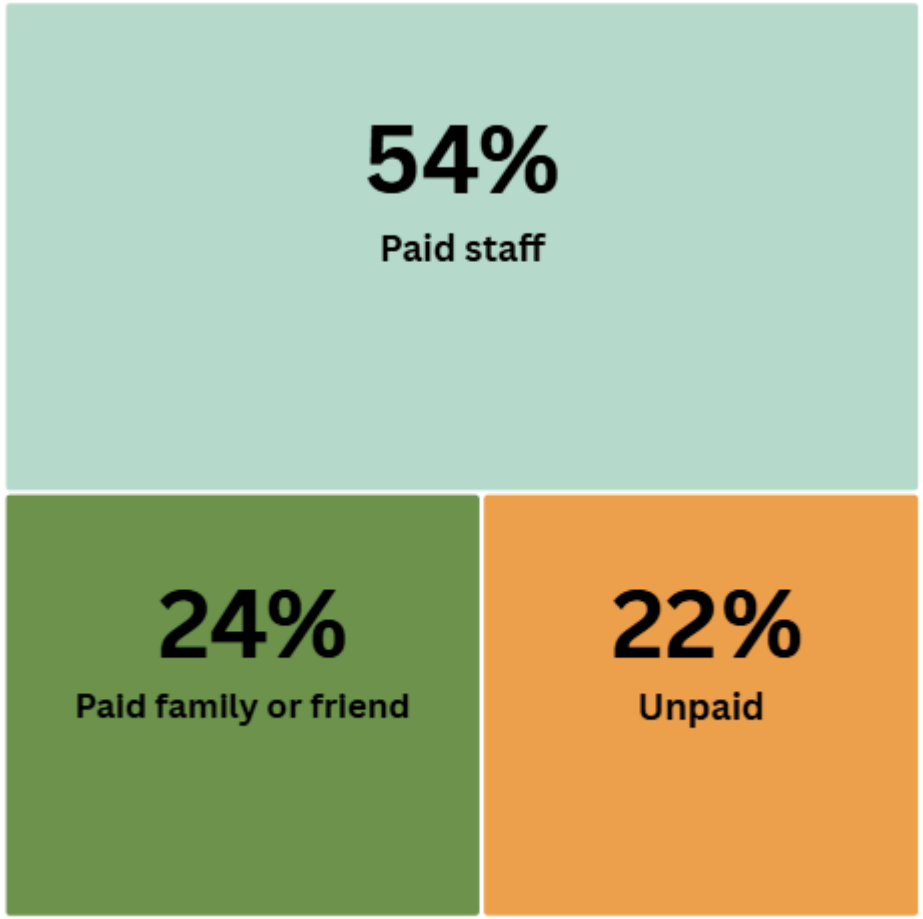


Amount of support needed with activities of daily living



Amount of support needed with self-care

More than half of older adults say paid staff help them most



Those who say paid family and friends help them most often have the lowest rates of feeling their help changes too much

25% of older adults say that the **people who are paid to help them change too often**

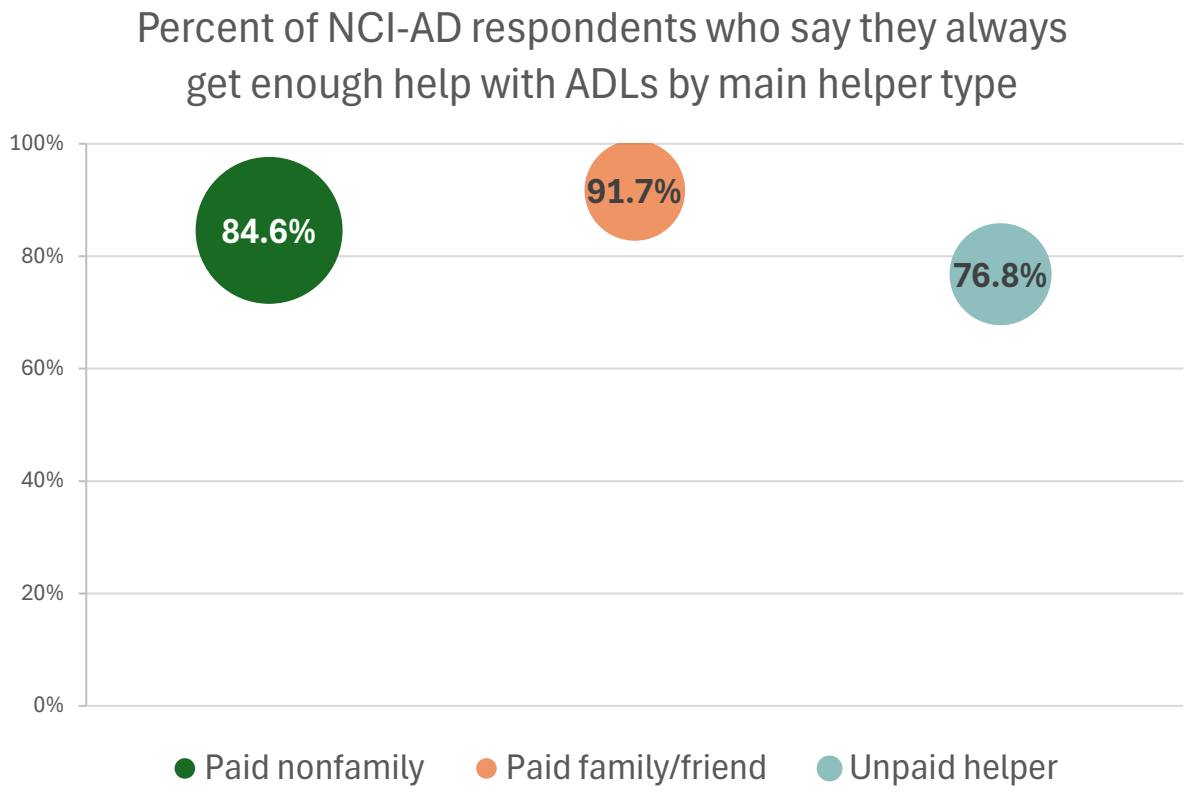
- Among those whose main helper is paid family/friends, just 13% say this

72% of older adults **have a second helper** in addition to their main provider

Person-centered outcomes among older adults

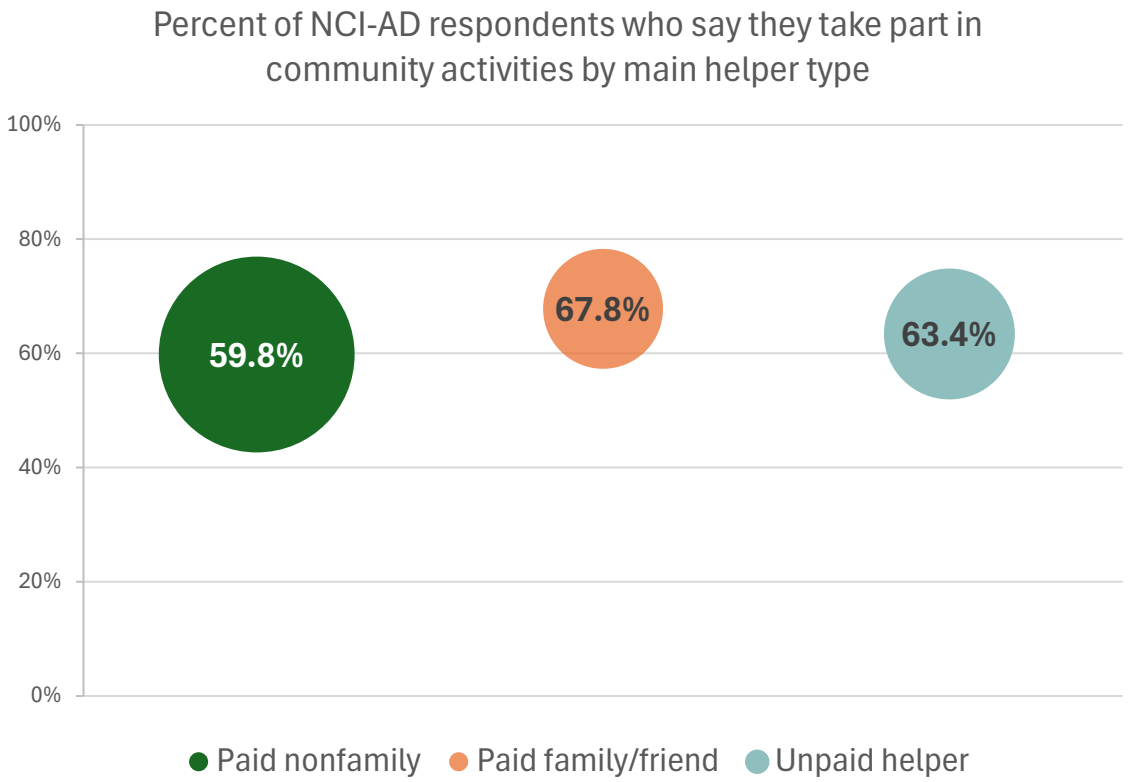
Select outcomes from NCI-AD	Overall %
Always gets enough assistance with activities of daily living	82%
Always gets enough assistance with self-care	84%
Takes part in community activities with others as much as they want to	63%
Services and supports always meet all needs and goals	75%
Always feels in control of life	75%

Paid family caregiving is associated with higher rates of always getting enough help with ADLs



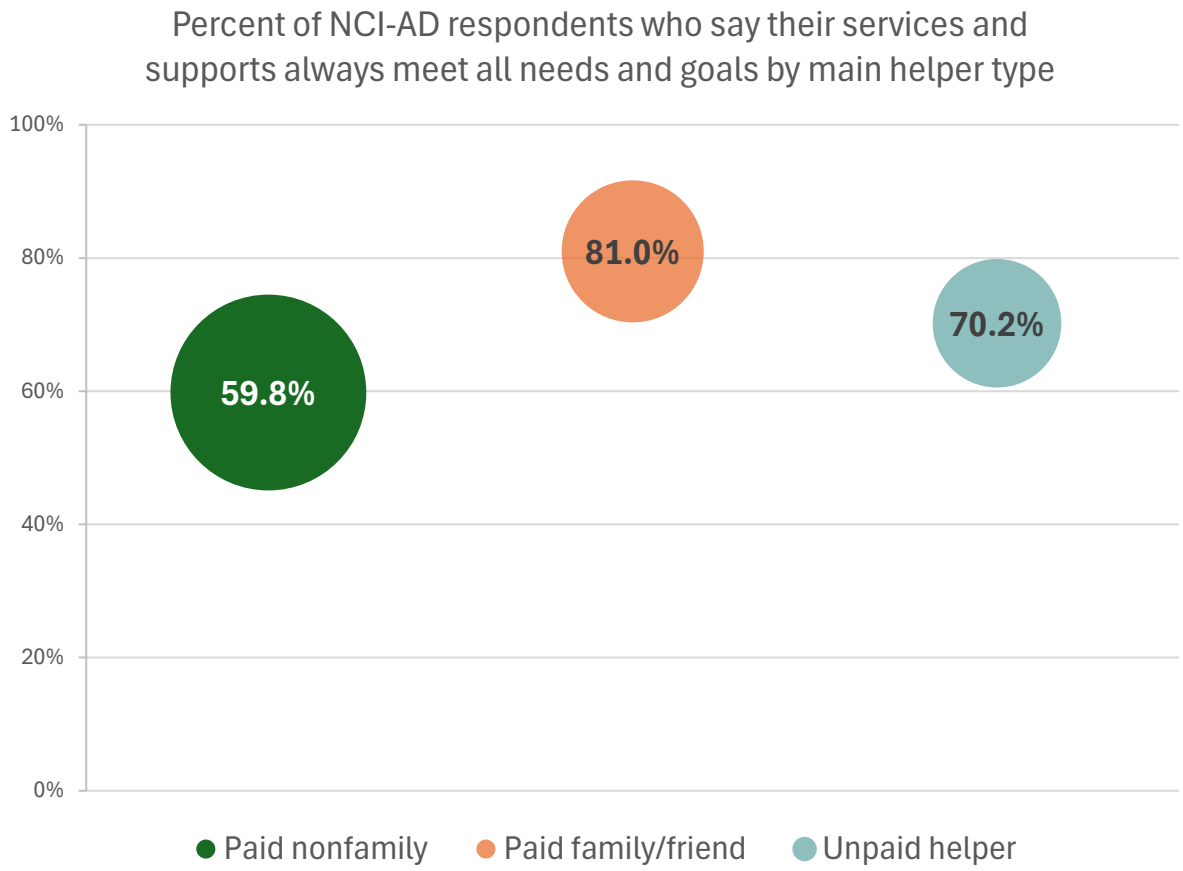
Adjusting for personal characteristics, those who say their **main helper is paid family have 1.9 times higher odds of always getting enough help with ADLs** compared to those who say their main helper is paid staff.

Paid family caregiving is associated with higher rates of taking part in community activities



Adjusting for personal characteristics, those who say their **main helper is paid family have 1.5 times higher odds of taking part in community activities as much as they want** compared to those who say their main helper is paid staff.

Paid family caregiving is associated with higher rates of say their services meet all their needs and goals



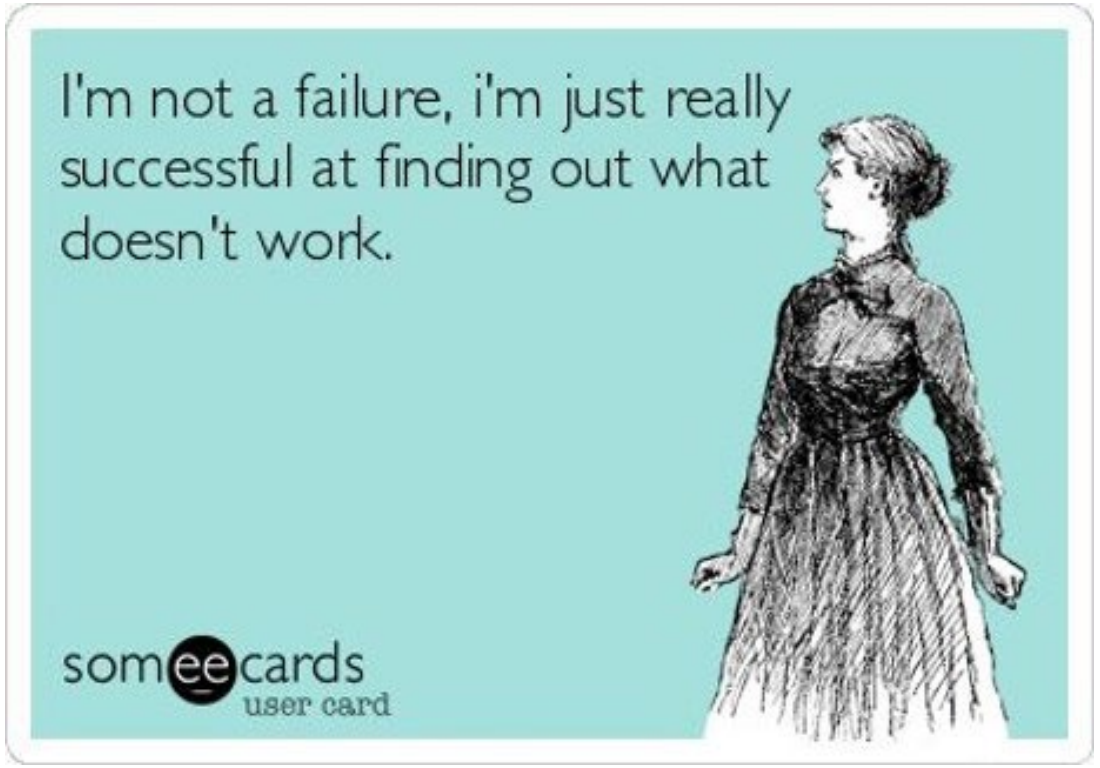
Adjusting for personal characteristics, those who say their **main helper is paid family have 1.35 times higher odds of saying services meet all needs and goals** compared to those who say their main helper is paid staff.

Next steps

Conclusions and Future directions for Knowledge Translation

These data demonstrate that there is a strong association between paid family caregivers and positive outcomes for people using services and supports

- Understanding how outcomes are impacted not just by type of main helper but also by staff stability is essential.
- This study suggests that we can enhance systems by both stabilizing the workforce AND by expanding supports for paid family caregivers



Opportunities to connect with NCI-AD data!

- Join our workshop on Saturday, 8-12
- Attend the NCI research convening on **May 27th 2026 from 12-4ET**
- Submit a data request form to access to data – reach out to nci@nationalcoreindicators.org for more information

NCI Research Convening Interest Form

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