

# Understanding HCBS Quality from the Perspective of People with Dementia

ASA OnAging

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# Abstract

Nearly 6 million Americans have an Alzheimer's disease or other dementia (ADRD) diagnoses, with a higher prevalence among Black and Hispanic individuals. ADRD diagnoses are expected to more than double to 14 million by 2060. This has implications for Home and Community-Based Services (HCBS) as people with ADRD often require at least some support. Yet, we know little about peoples' experiences with the services they receive and what programs best support people's needs. We will present data from the National Core Indicators—Aging and Disabilities Adult Consumer Survey to explore demographic trends among those with ADRD and discuss the specific type of HCBS those with ADRD use and the self-reported quality of those services.



# Welcome and Who's Here

**Who's here:**

- **Person with Lived Experience, Advocates, Caregivers, State managers, AAAs, Providers, Researchers, Others?**

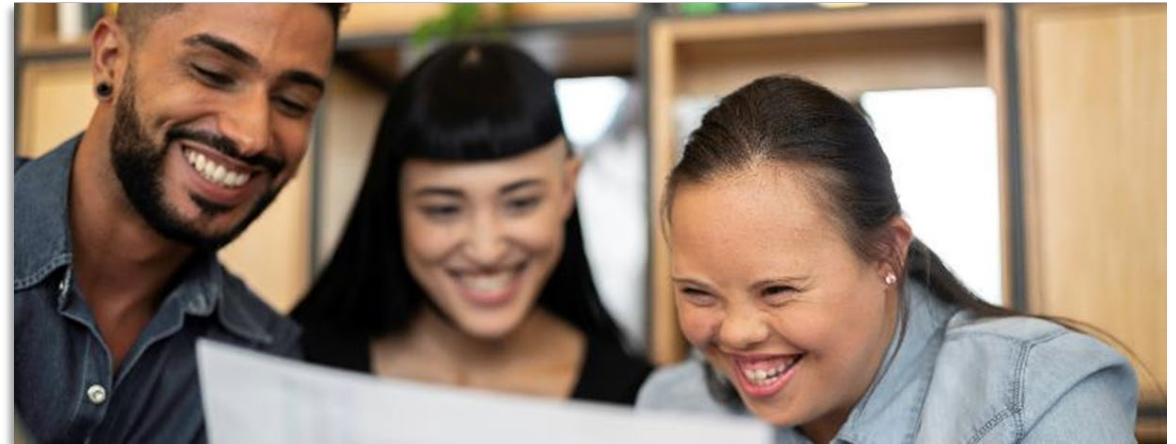
**What brought you here?**



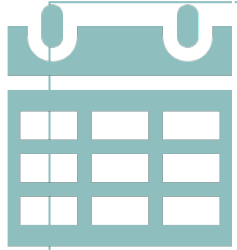
# National Core Indicators: People Driven Data

National Core Indicators is an initiative designed to **benchmark and track** performance that support **quality improvement efforts** in state systems supporting people with intellectual and developmental disabilities (NCI-IDD) and older adults and people with physical disabilities (NCI-AD).

Our goal is to **support states in their quality improvement** efforts using valid and reliable data collection efforts that hear directly from the people using and supporting systems.



# NCI-AD: An Overview



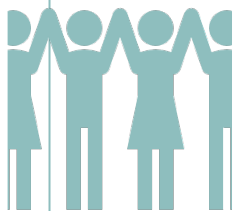
## Established

- 2015
- Grew out of NCI-IDD



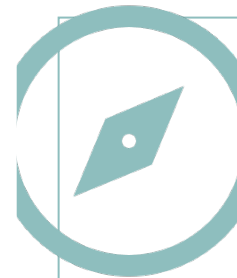
## Participating states

- 30 states



## Population addressed

- Older adults and people with physical disabilities receiving LTSS services



## Covers multiple domains

- AD domains and indicators
- **New** State of the Workforce Survey – Aging and Disabilities



## Adult Consumer Survey (ACS) A Person-Centered Approach

- **Standardized survey with a sample of individuals receiving services**
  - No pre-screening procedures
- **Survey includes:**
  - Demographic and service-related characteristics typically from existing records
  - Main survey section conducted with person receiving services
  - Some questions may be answered by a proxy respondent
- **Survey conducted in-person, via video conference, over the phone**
- **Standardized surveyor training**
- **Allows questions to be reworded or rephrased using familiar names and terms**
- **Survey portions take 50 minutes on average**
- **Minimum sample ~400**

# NCI-AD Domains

Community participation	Choice and control
Relationships	Satisfaction
Service coordination	Care coordination
Access to community	Access to needed equipment/modifications
Safety	Health care
Wellness	Medications
Rights and respect	Self-direction
Work	Everyday living
Affordability	Person-centered planning module (optional)
Access to technology	Self-direction (optional)



# Data can help measure differential experience and access to services

## Individual characteristics of people receiving services

Where people live

Gender

Race/Ethnicity

Disability

## The nature of their experiences with services

Interaction with staff and case managers

Self-direction

Choice and Control

## The context of their lives

Involvement with family and friends

Access to community involvement

Safety

## Health and well-being

Utilization of health services

Ability to manage chronic conditions

Mental healthcare



# ADRD Rates Across Years

**18%**  
**2017**

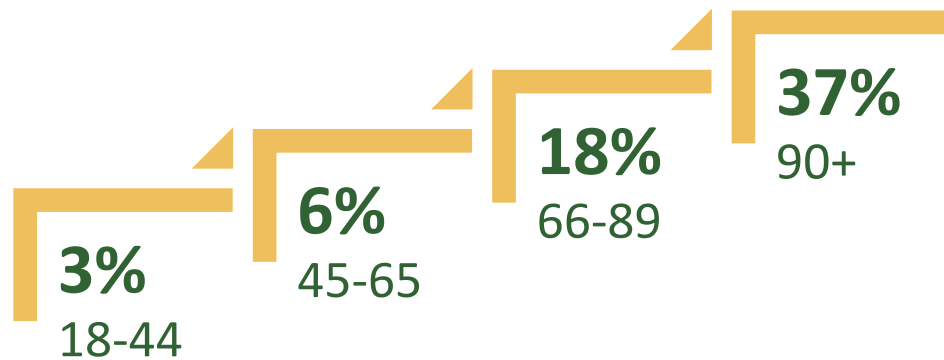
**18%**  
**2018**

**11%**  
**2021**

**14%**  
**2022**

**12%**  
**2023**

# Has Alzheimer's/Other Dementias Diagnosis



Among those 45-65:

**47% report they forget things more often than 12 months ago (47% NCI-AD Average)**

**64% who forget things more often than 12 months ago have discussed this with a doctor or nurse (68% NCI-AD Average)**

*These outcomes, along with others like frequent falls, perceived support need may suggest early onset dementia or other conditions*



# Primary Caregiver Type For ADRD Respondents

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64% Paid Non-Family

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20% Paid Family or Friend

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16% Unpaid Family or Friend

-49% receive additional support from unpaid family or friend

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1% Other



# NCI-AD State of the Workforce

## AGENCY CHARACTERISTICS



**68%**

Provide in-home supports



**84%**

Private for-profit businesses



**32%** Report a **more than 10%** increase in the number of members of the AD population enrolled in or approved for services



**29%** Report they **turned away or stopped accepting referrals** due to staffing issues.

## TURNOVER AND TENURE



**48%**

Average **turnover ratio** across states



Just over **1 out of every 3 DSWs (37%)** employed as of Dec 31, 2023 had been working at their provider agency for **2 or more years.**

In contrast, almost **1 out of every 2 DSWs (47%)** who *left* their employer in 2023 had been on staff for **less than 6 months.**





# Addressing Unmet Needs of HCBS Consumers: Select Outcomes from 2016-2019

Data come from  
2016-19 surveys

—

Analysis excluded...

- Cases with *missing outcomes* for services received and desired services
- Those who *lived in nursing homes*
- Those <65 years of age

=

ADRD n = 2,009

No ADRD n =  
9,812

## Demographics of People with ADRD

- $\frac{2}{3}$  of respondents identified as **women**
- **52% White; 19% Black; 26% Other**
- **77%** lived in Metropolitan areas
- **24%** lived alone

## Demographics of People without ADRD

- $\frac{2}{3}$  of respondents identified as **women**
- **61% White; 28% Black; 11% Other**
- **72%** lived in Metropolitan areas
- **48%** lived alone

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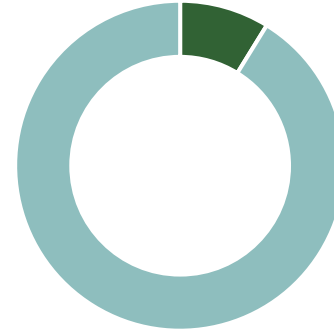
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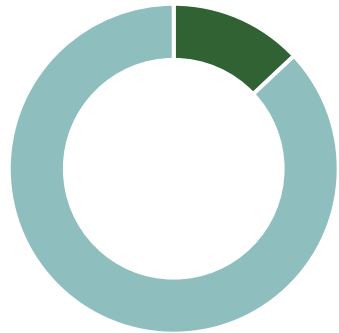
# Comorbidities of People with ADRD (n = 2,009)



Multiple Diagnoses  
( $\geq 2$ ) 55%



Developmental  
Disability  
8%



Brain Injury  
13%



Physical Disability  
50%

# Analysis uses outcomes from two questions...

## **1. What type of paid long-term care supports is the person receiving?**

- Item is collected in the Background Information Section
- Must come from administrative records
- Referred to as “Services Received”

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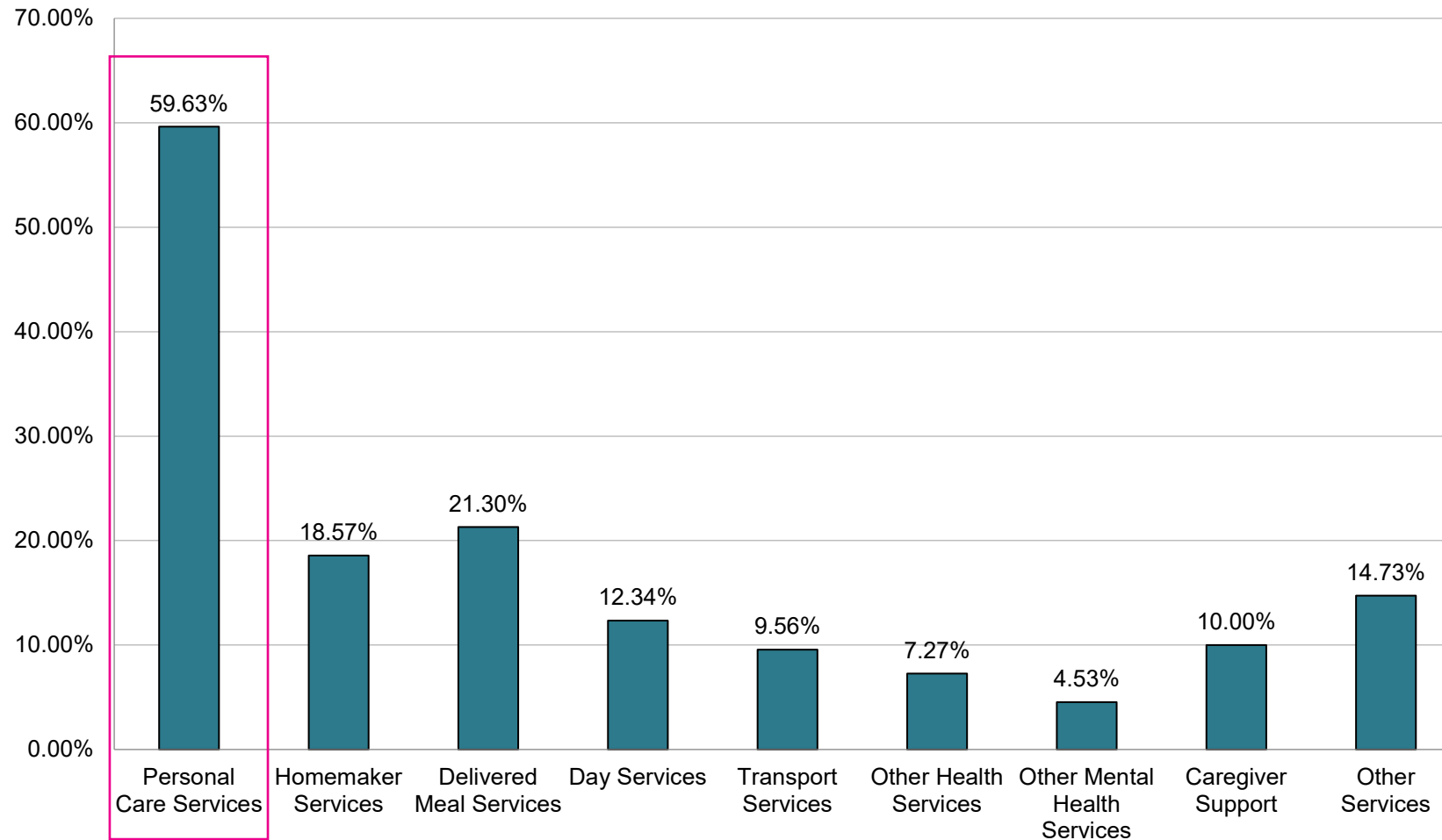
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## 2. What additional long-term care services might help you meet your needs and goals?

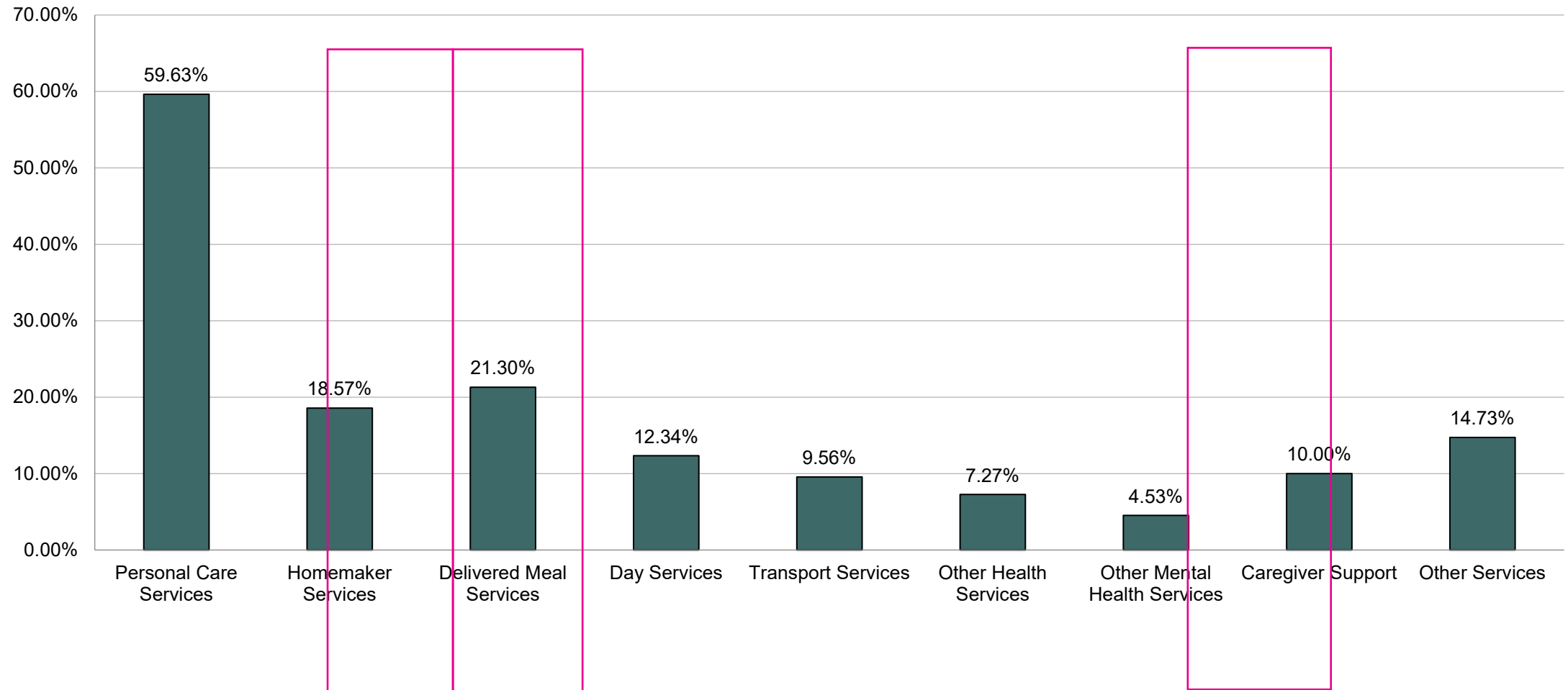
- Item answered either by the person receiving services or a proxy respondent
- Only asked of those who reported that that current long-term services and support *did not* currently meet all need
- Referred to as “Desired Services”



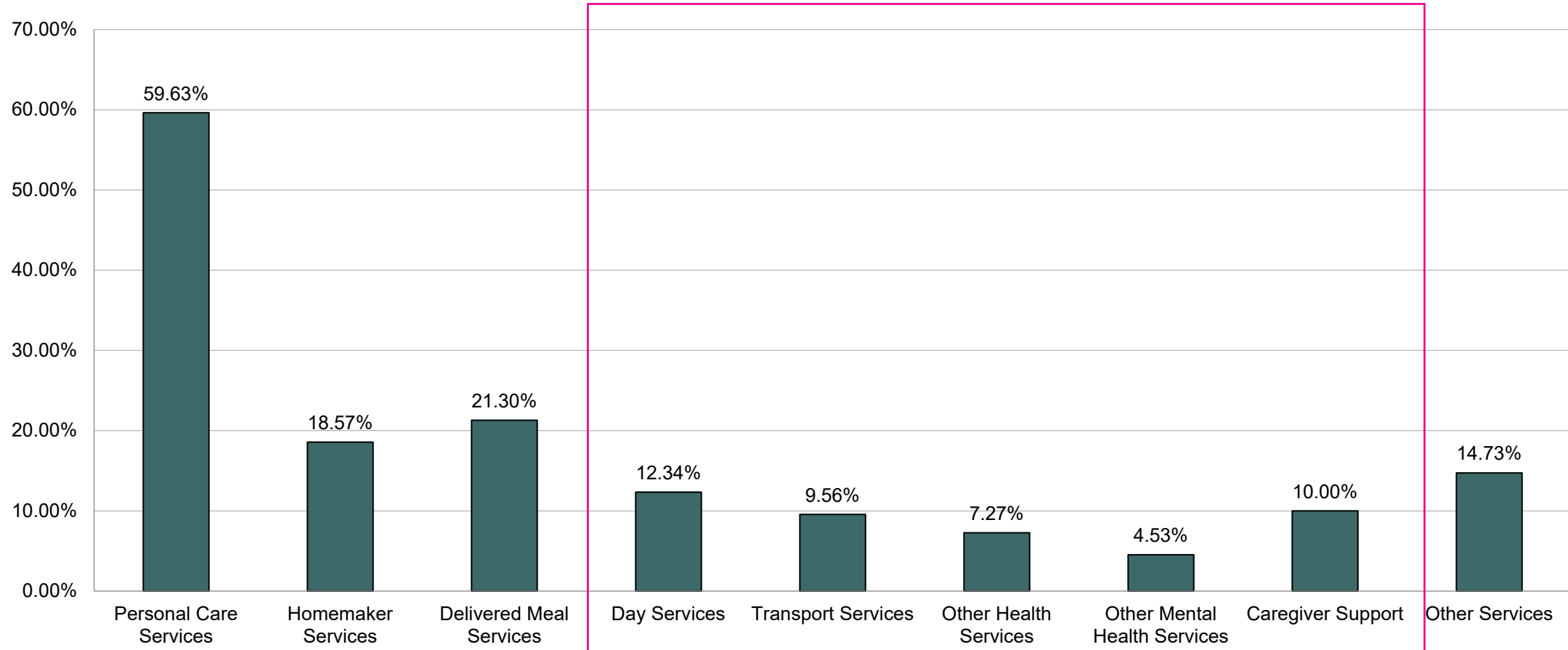
# Personal Care Services More Most Used Service Type Among People with ADRD



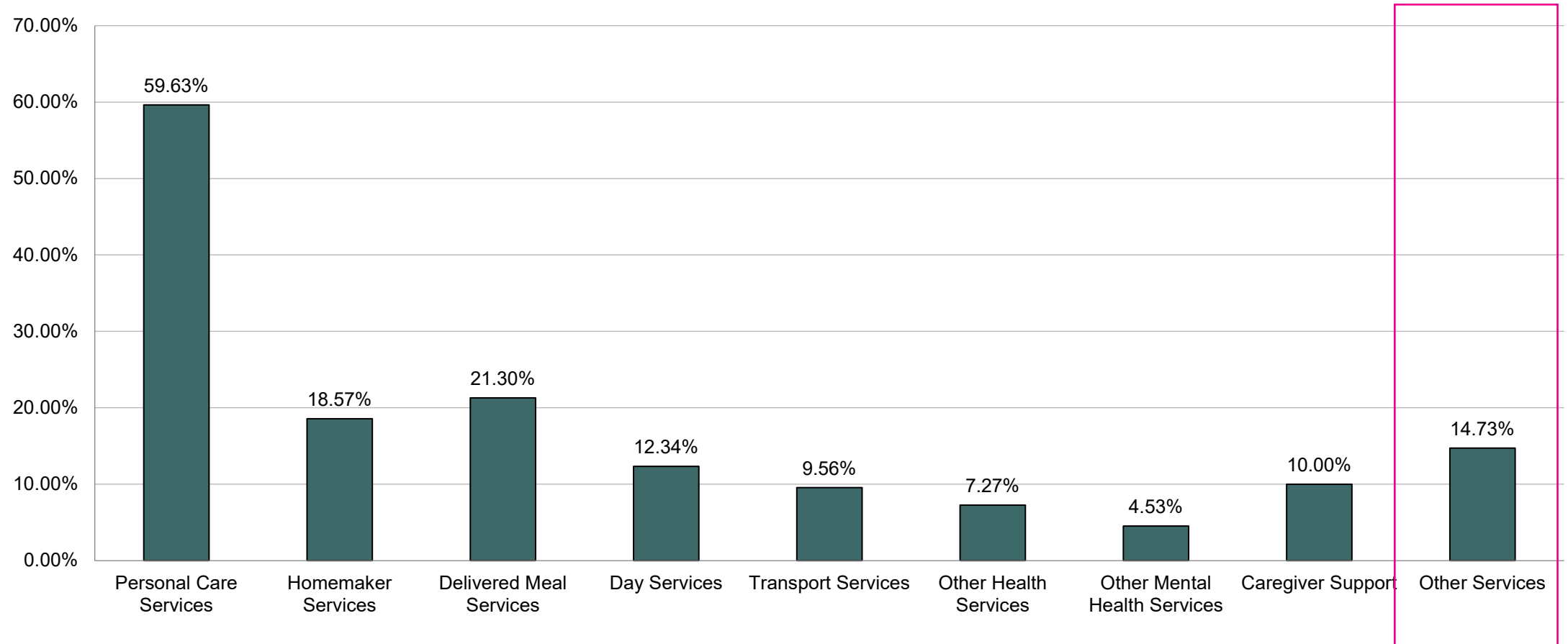
# Types of Services Received by People with ADRD: Personal Care Services More Prevalent



# Day Services, Transportation, Other Health Services, Other Mental Health Services, and Caregiver Support Were Received at Lower Rates Among People With ADRD

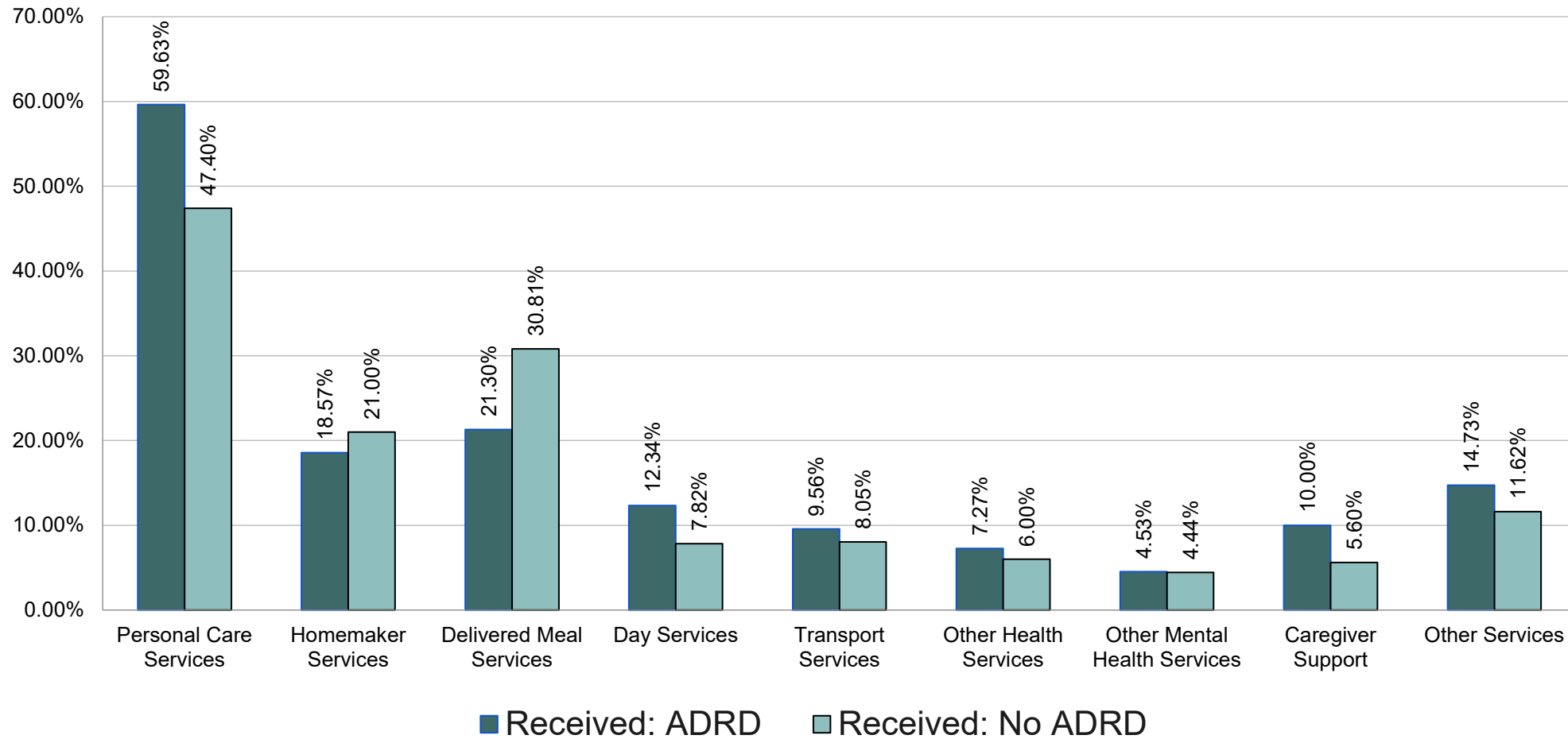


# 15% of People With ADRD Used Other Services (e.g., Home Modifications, Heating/Cooling Assistance, Pest Control)

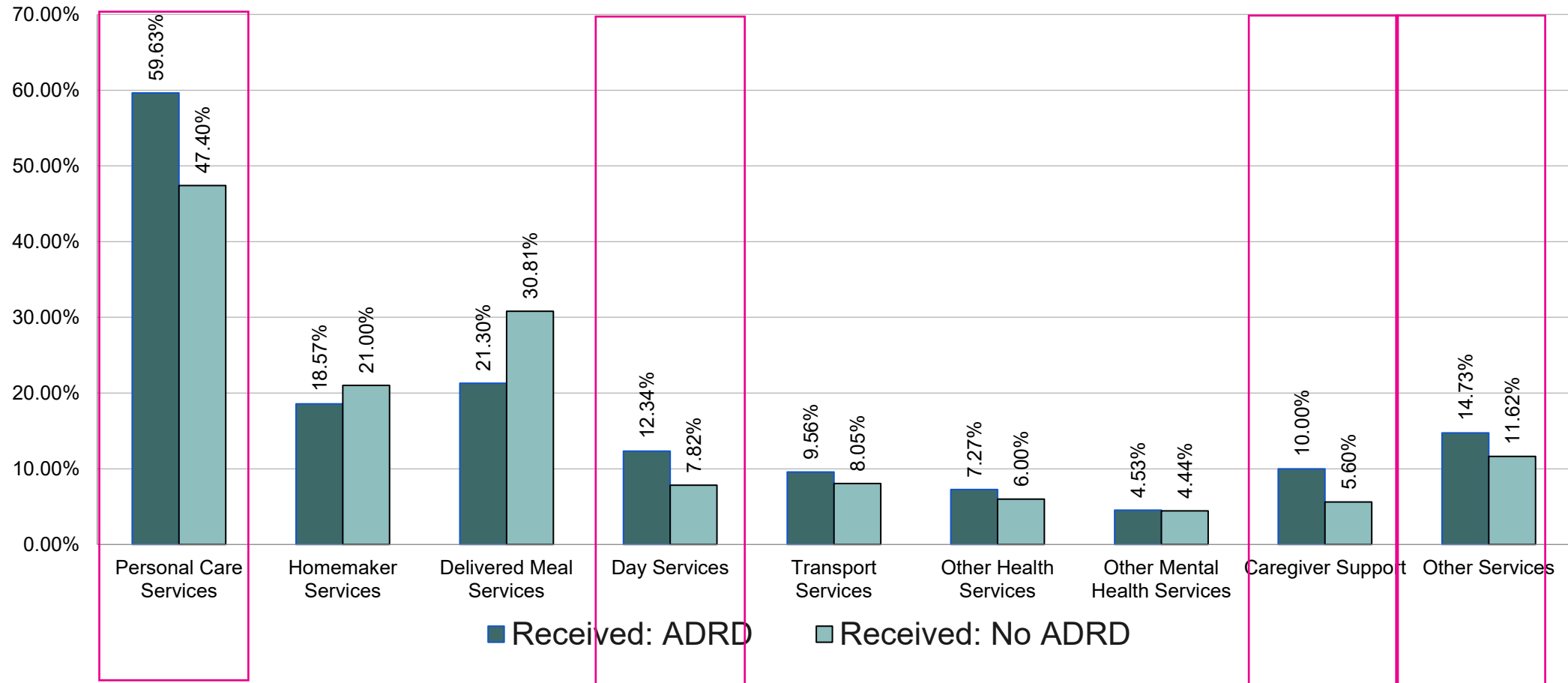




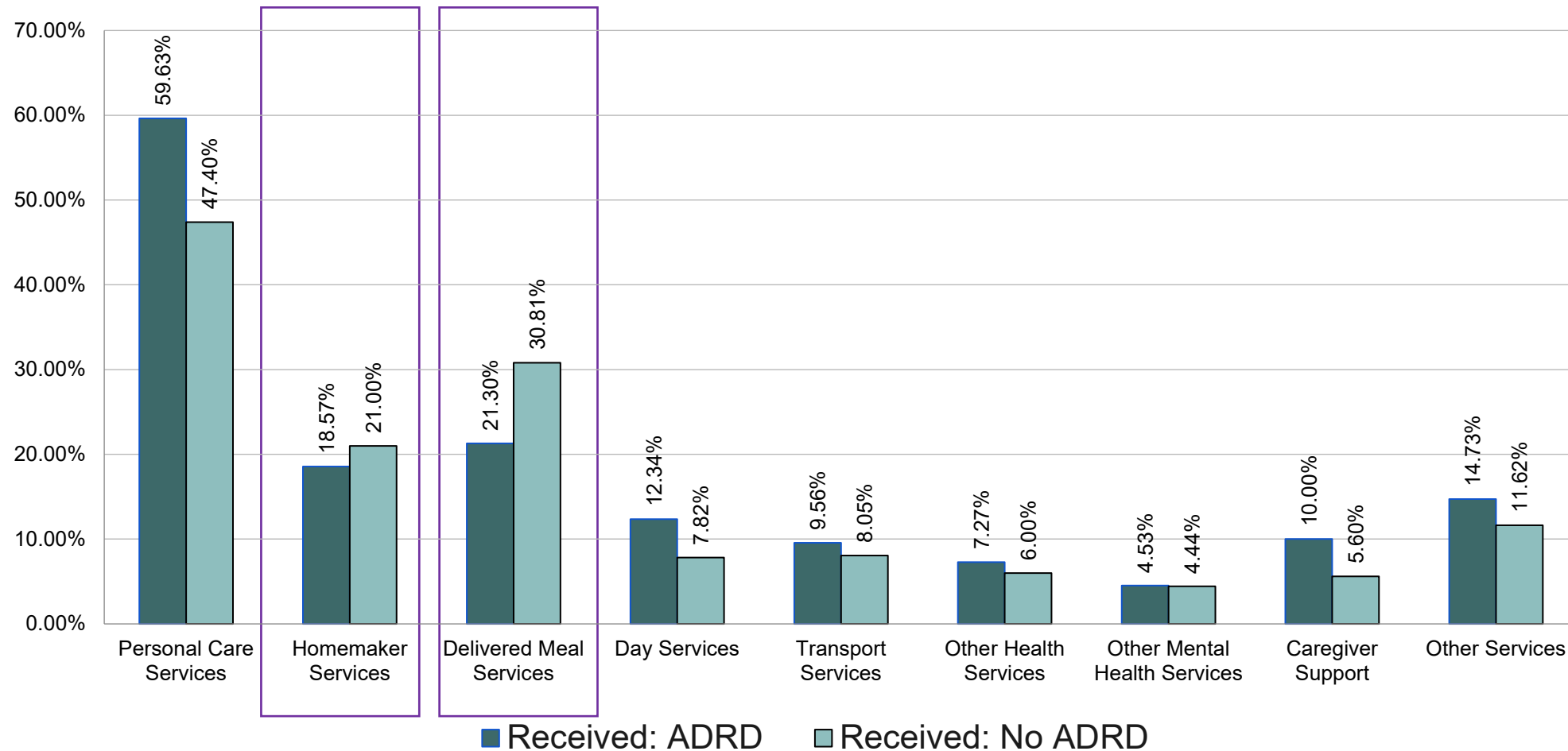
# Types of Services Received by People with ADRD vs Without



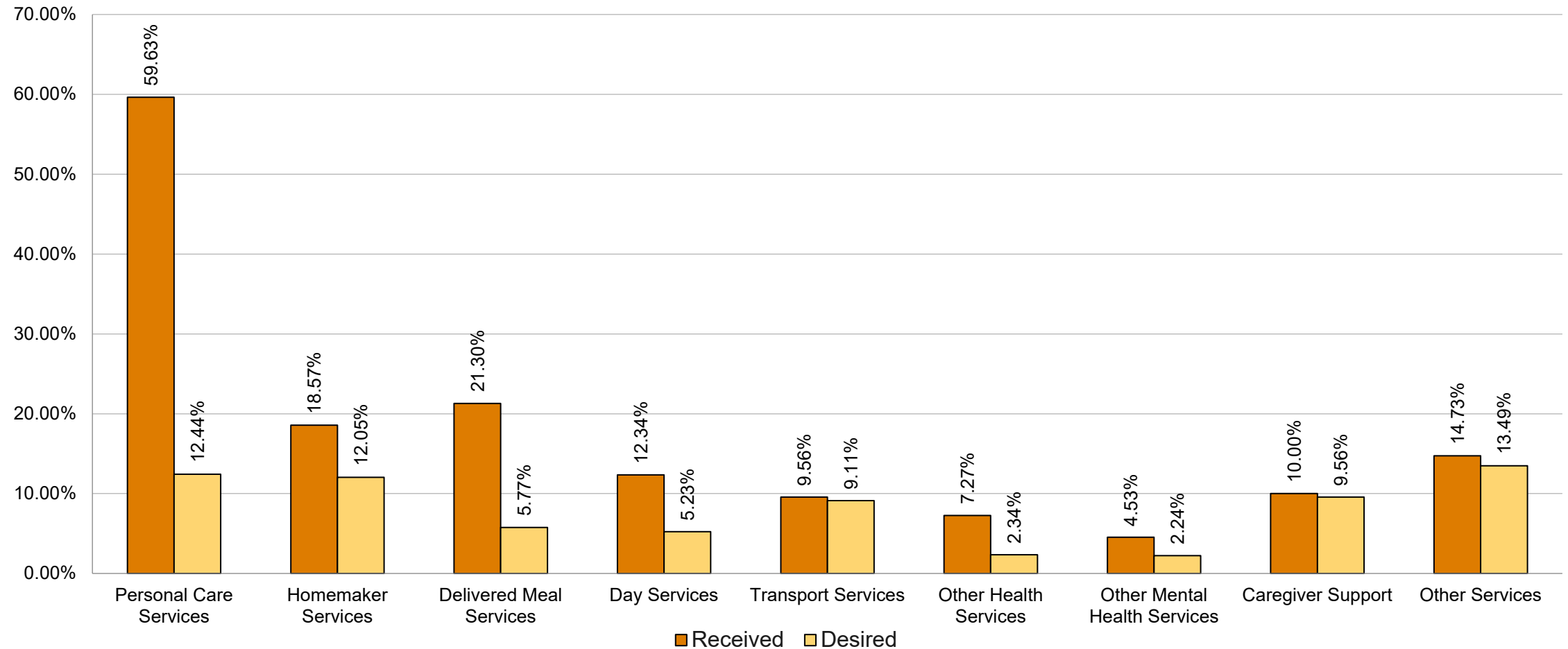
# People with ADRD Were *More Likely* Than Those Without to Receive: Personal Care Services, Day Services, Caregiver Support, and Other Services



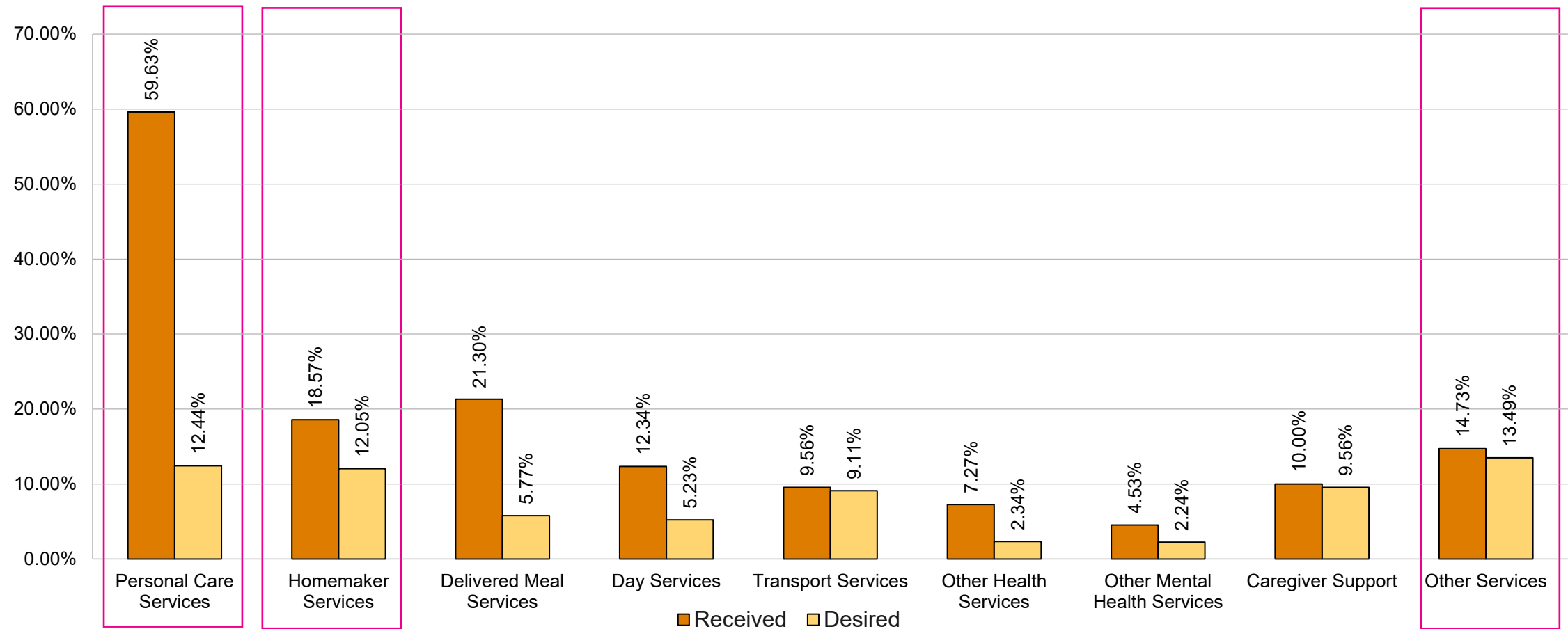
# People with ADRD Were *Less Likely* Than Those Without to Receive: Homemaker Services and Home Delivered Meals



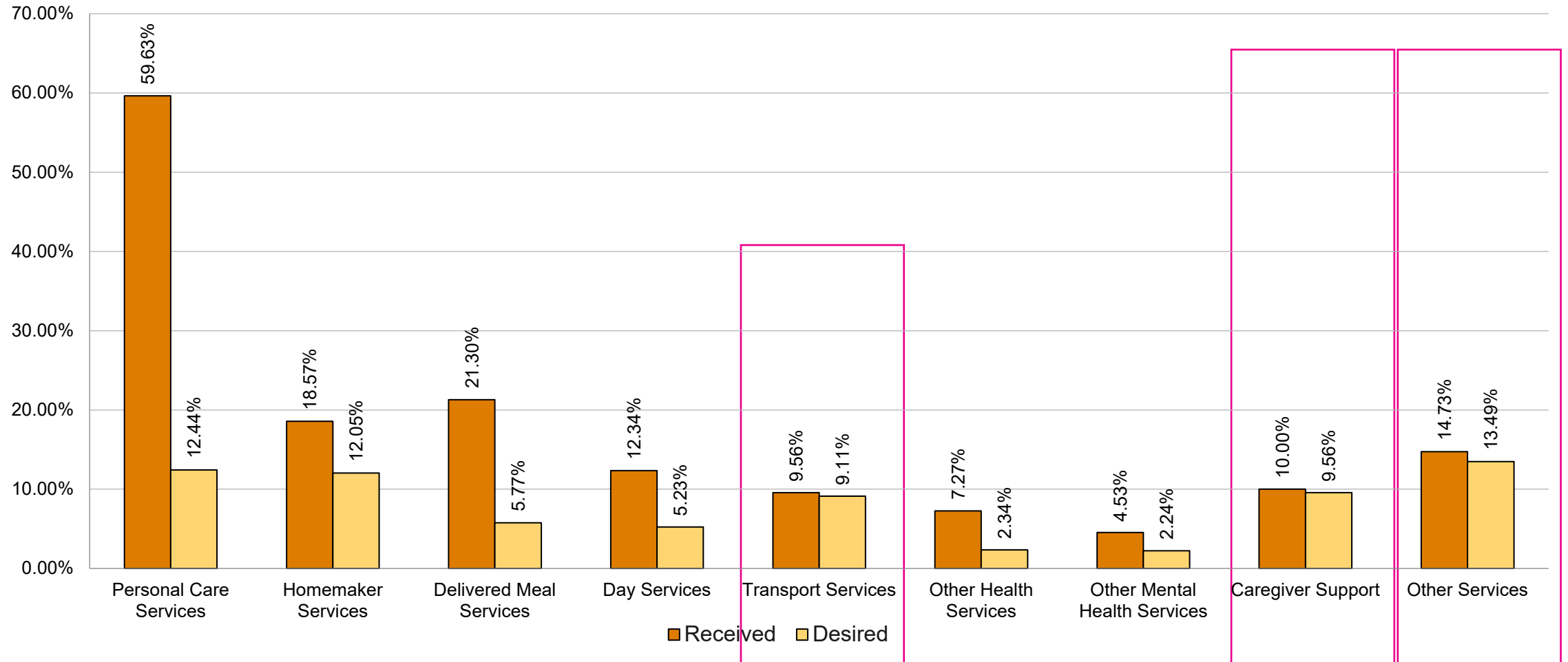
# Services Received vs. Desired Among People with ADRD



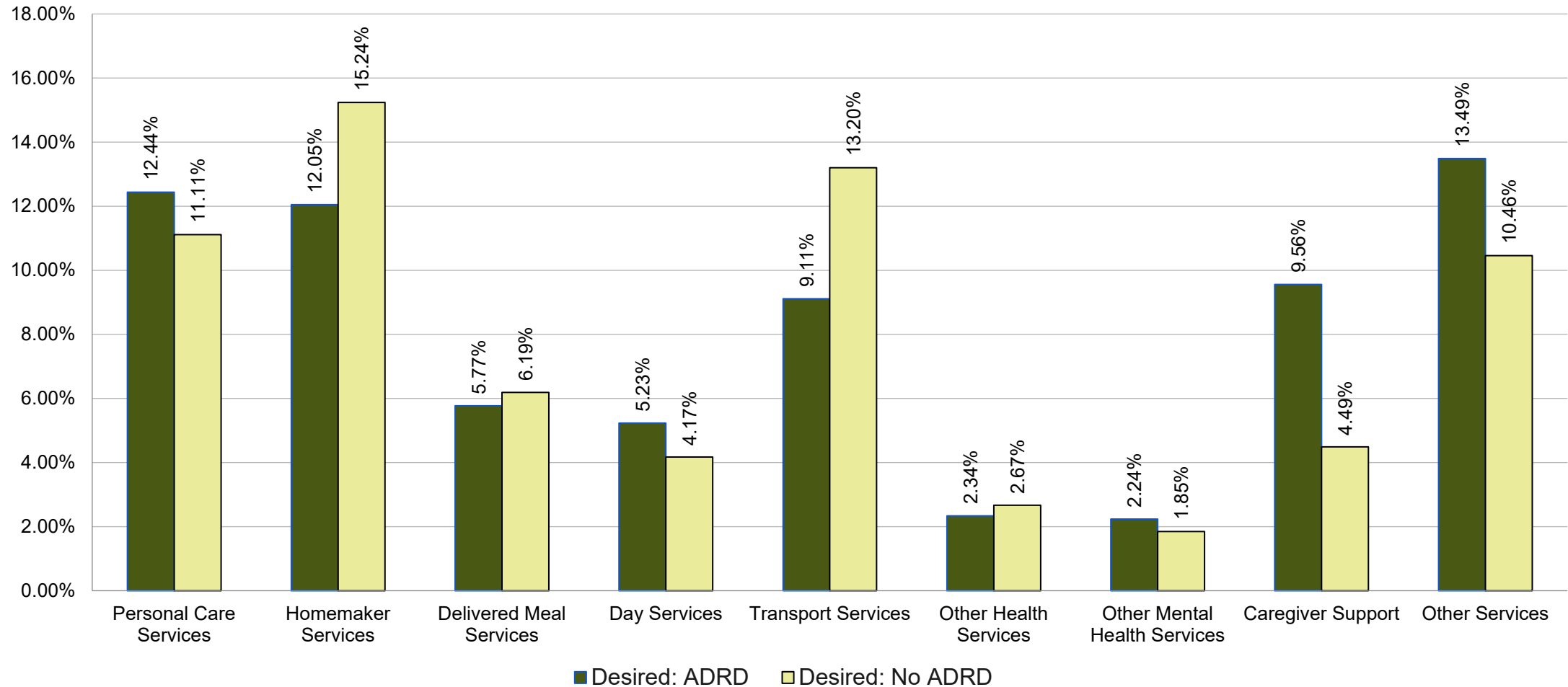
# Respondents With ADRD Reporting Needing Personal Care, Homemaker, and Other Services at the Highest Rates



# Respondents Received and Reporting Wanting Transportation, Caregiver and Other Services at Similar Levels

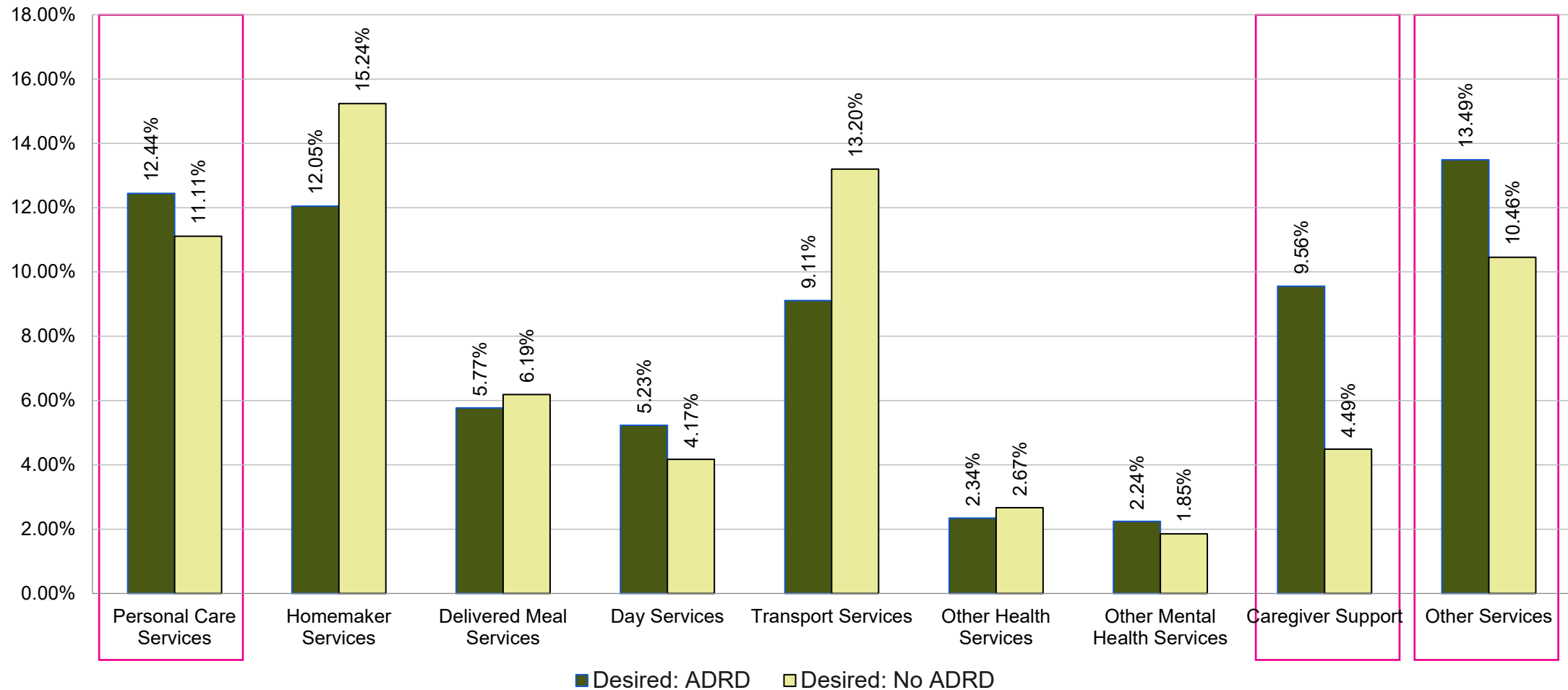


# Services Desired Among People With and Without ADRD

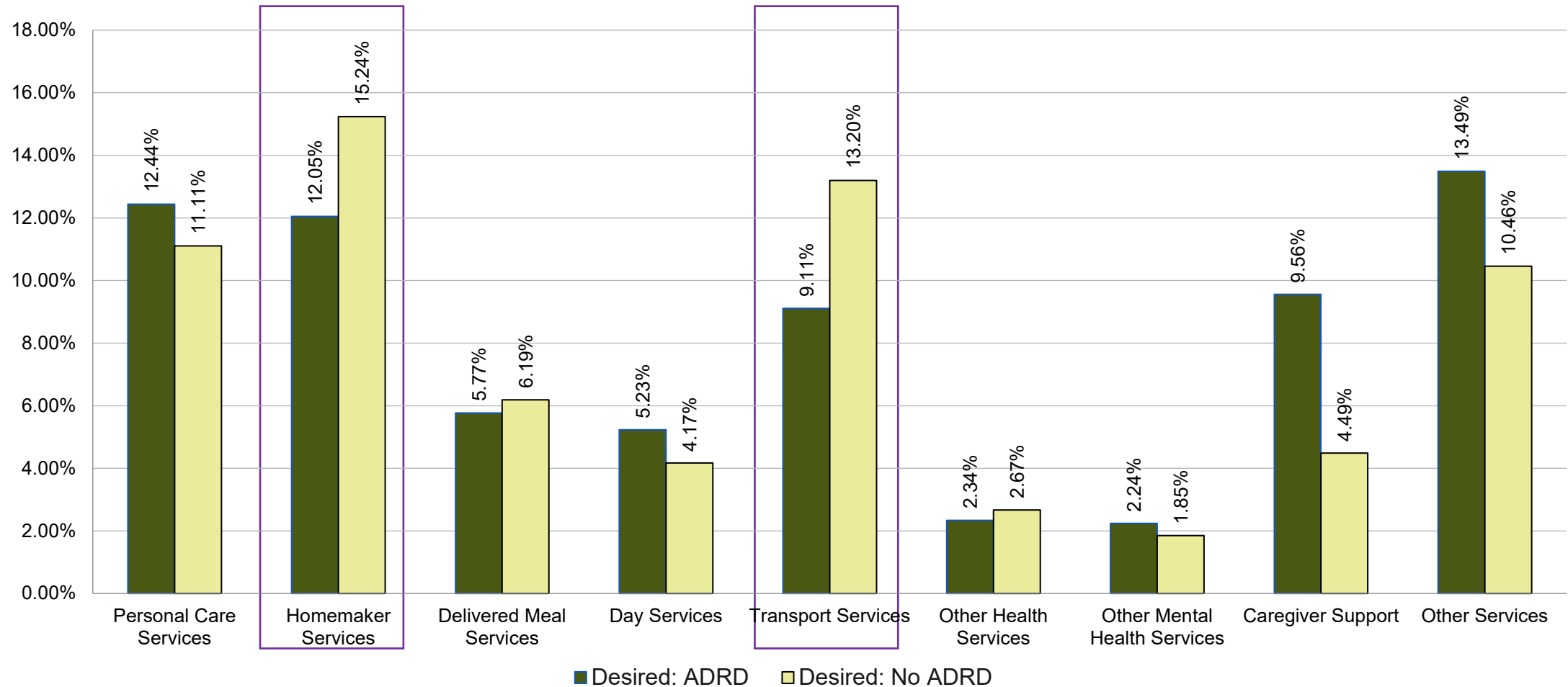




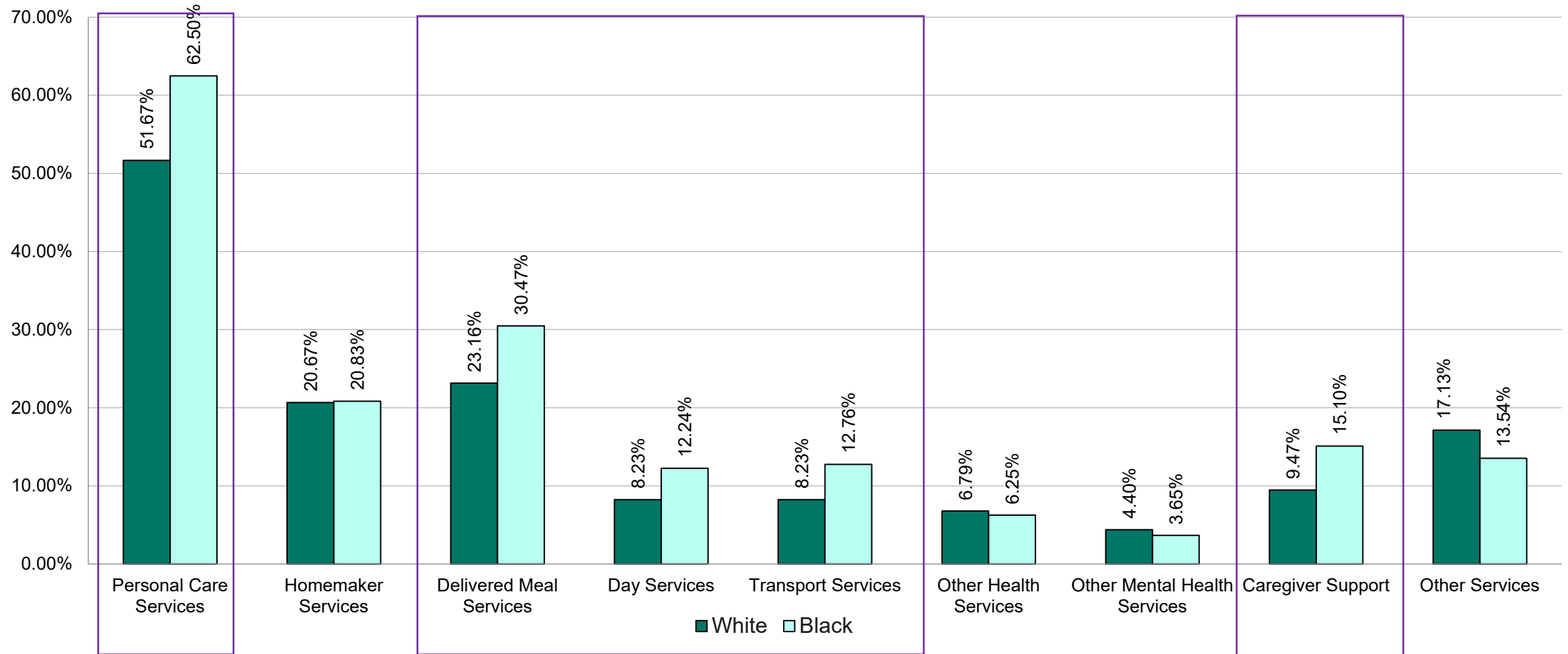
# People With ADRD Reporting Needing Personal Care, Caregiver Support, and Other Services at Higher Rates Than Those Without



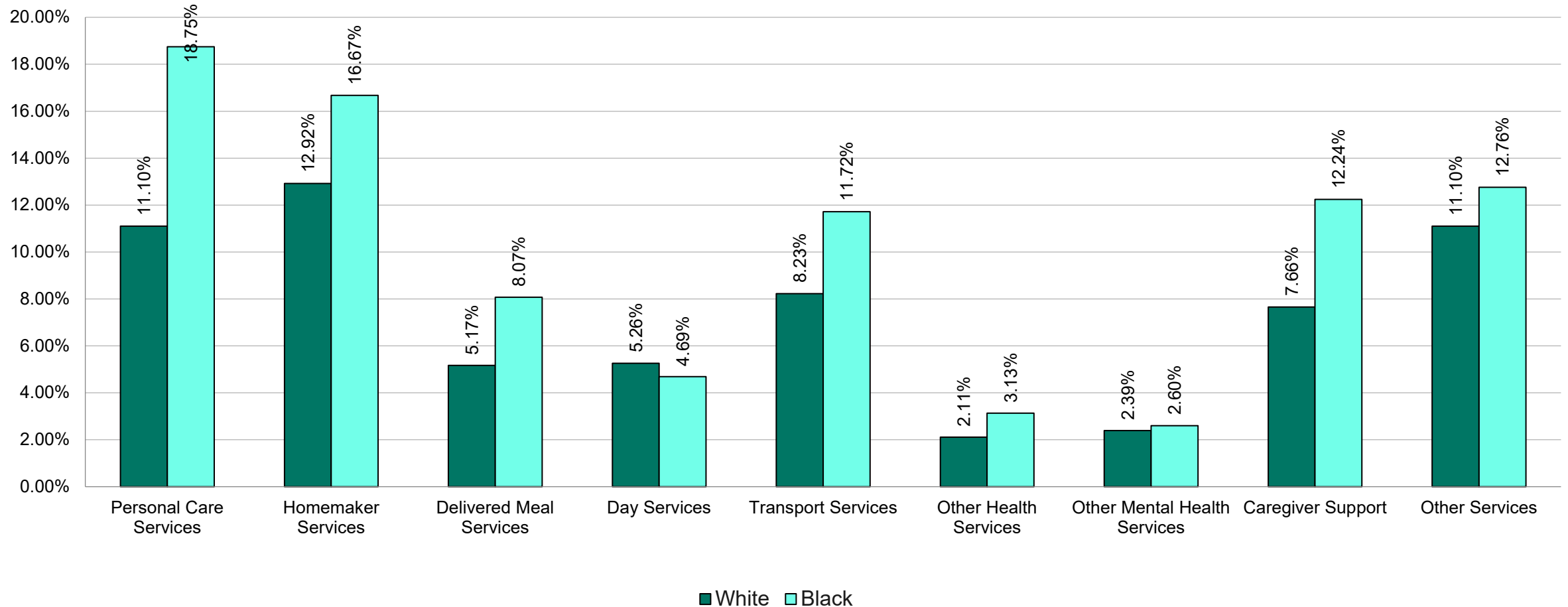
# People With ADRD Reporting Needing Homemaker and Transportation at Lower Rates Than Those Without



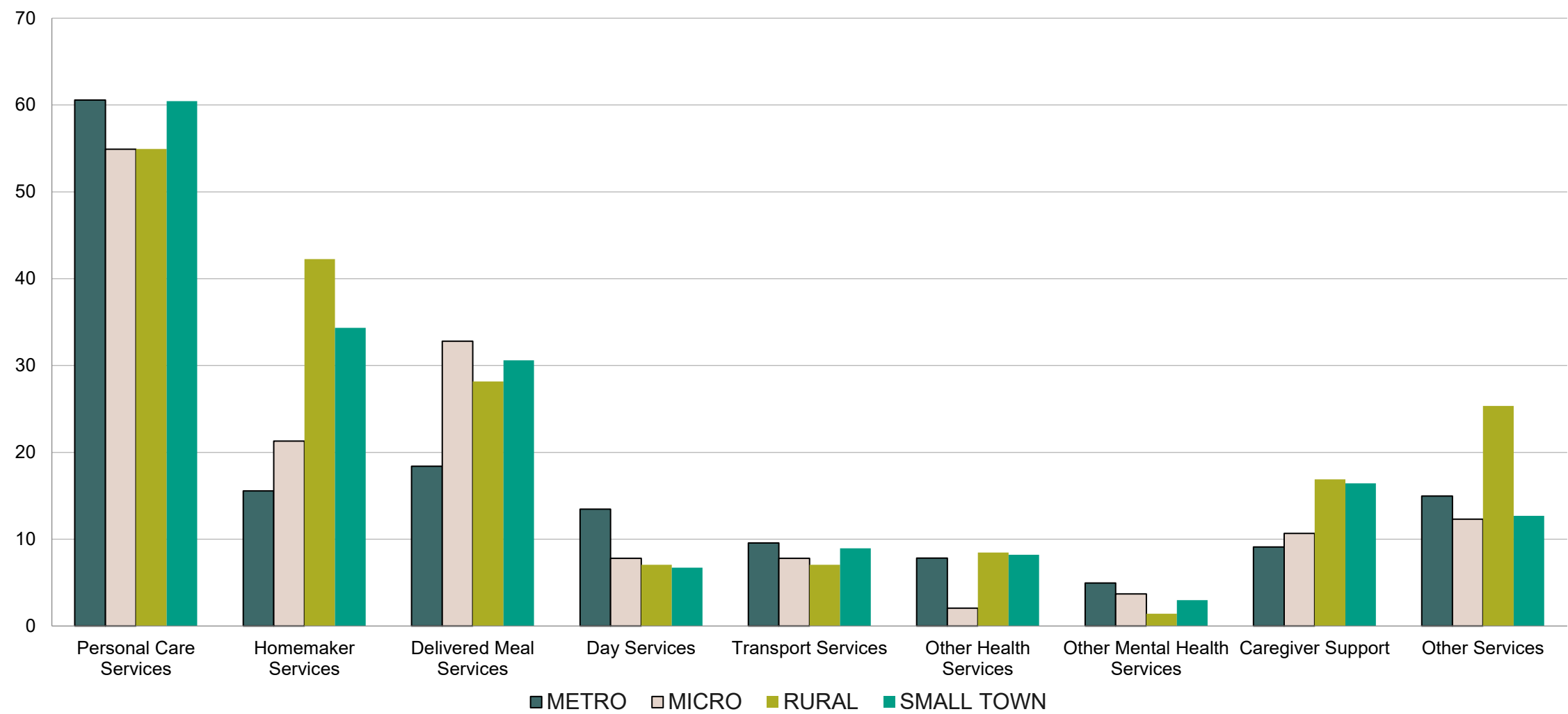
# Black Respondents with ADRD Were More Likely to Receive Individual HCBS Compared to White Respondents with ADRD



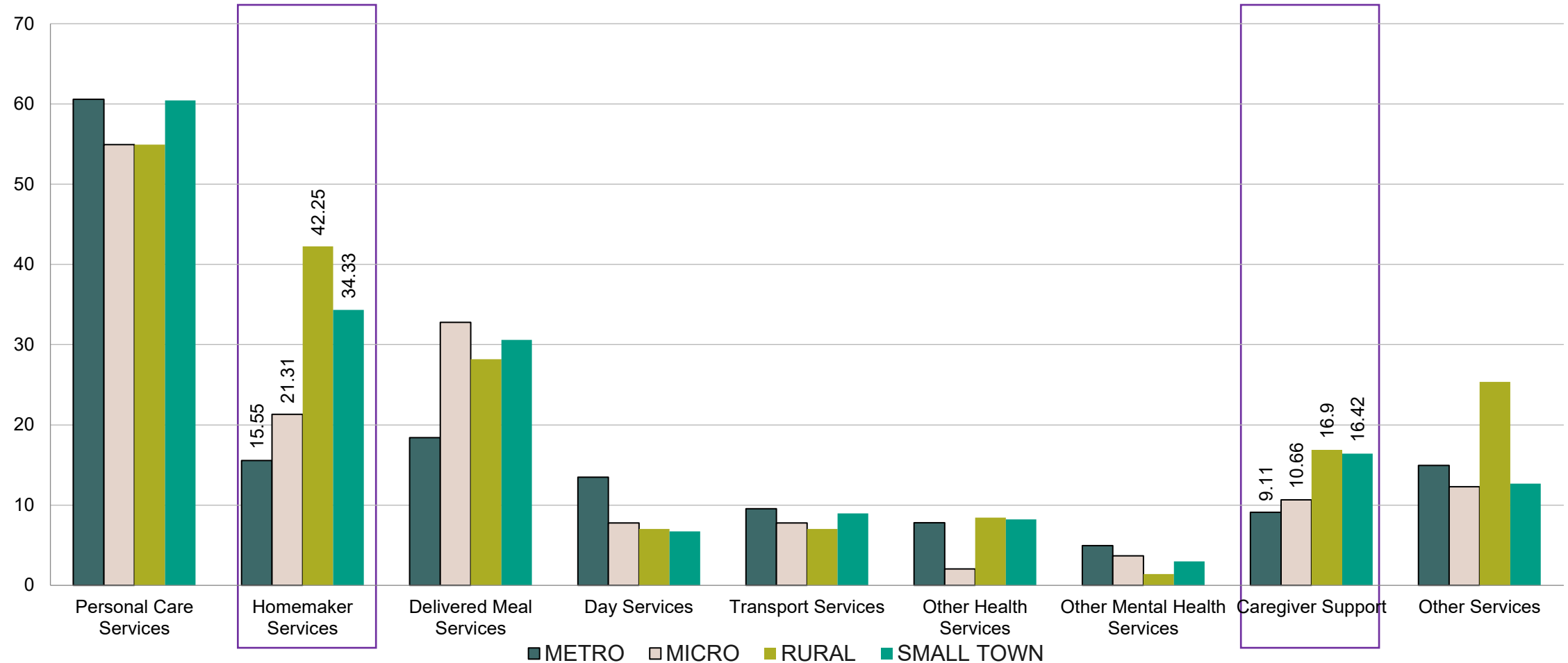
# Black Respondents with ADRD Were More Likely to Report Needing Services Compared to White Respondents with ADRD



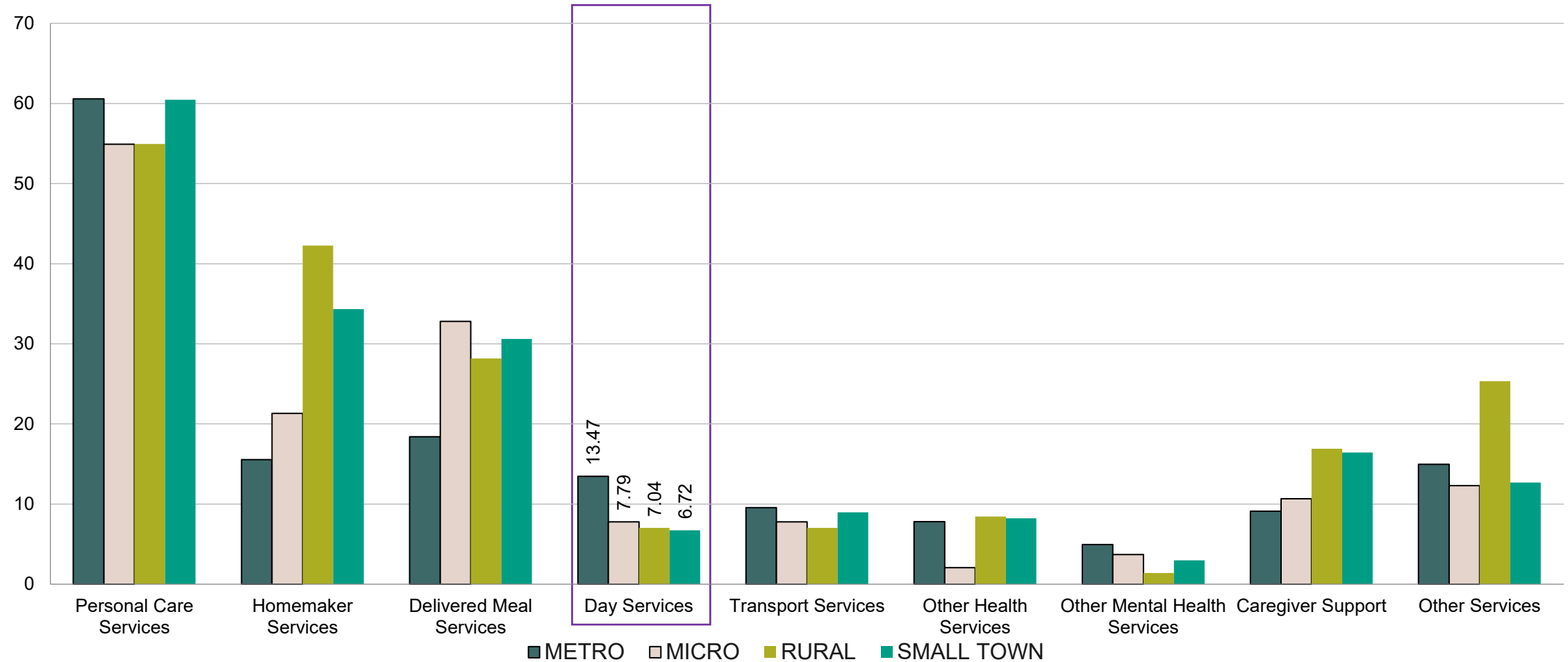
# Services Received by People with ADRD by Geography



## Homemaker services and caregiver support were more commonly used by people in rural areas compared to metro or micropolitan regions

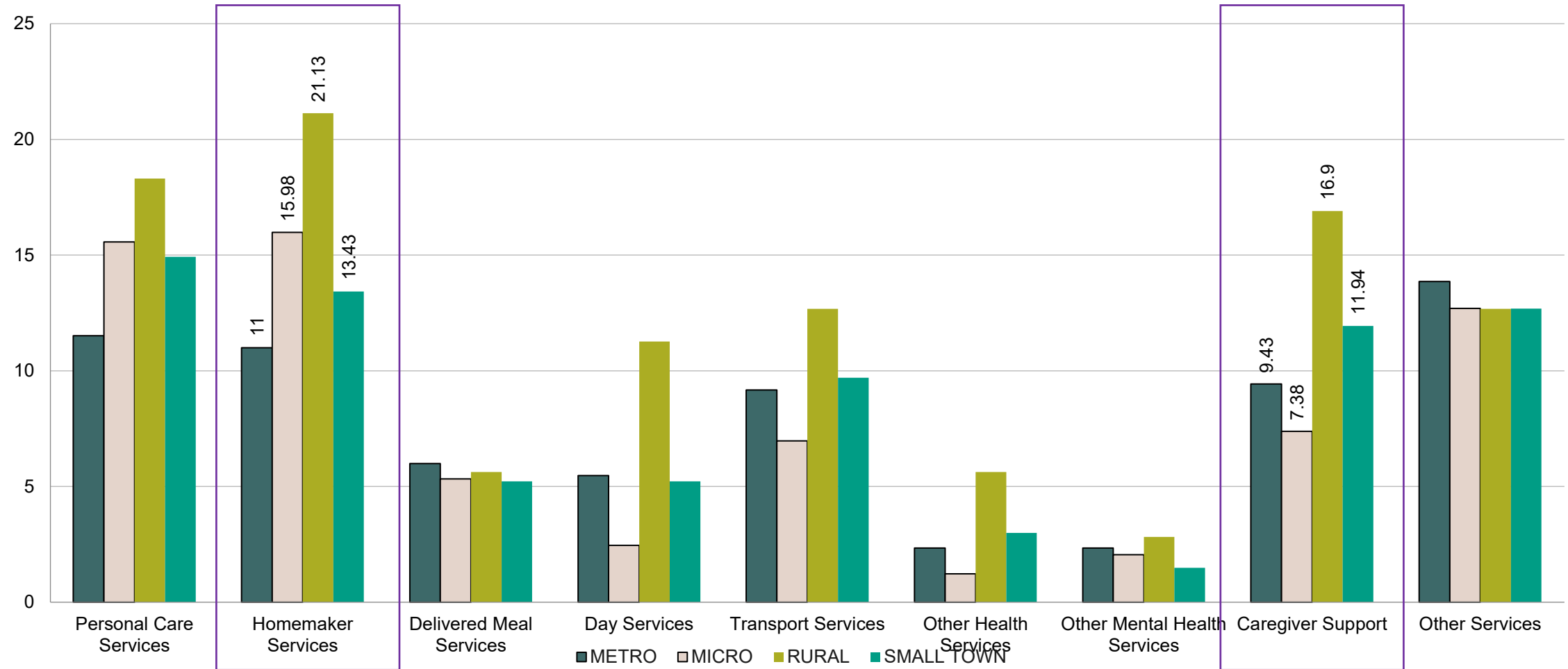


# Day Services Were More Likely to be Received in Metropolitan Areas

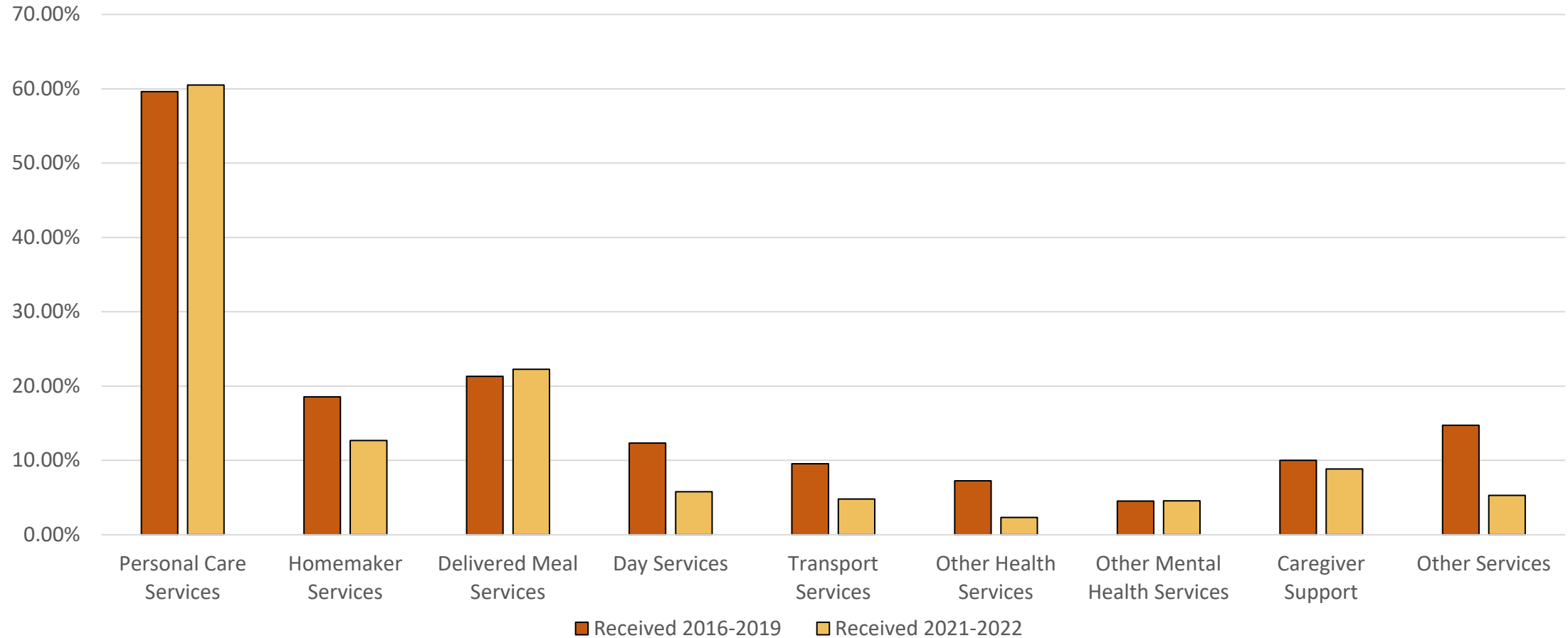




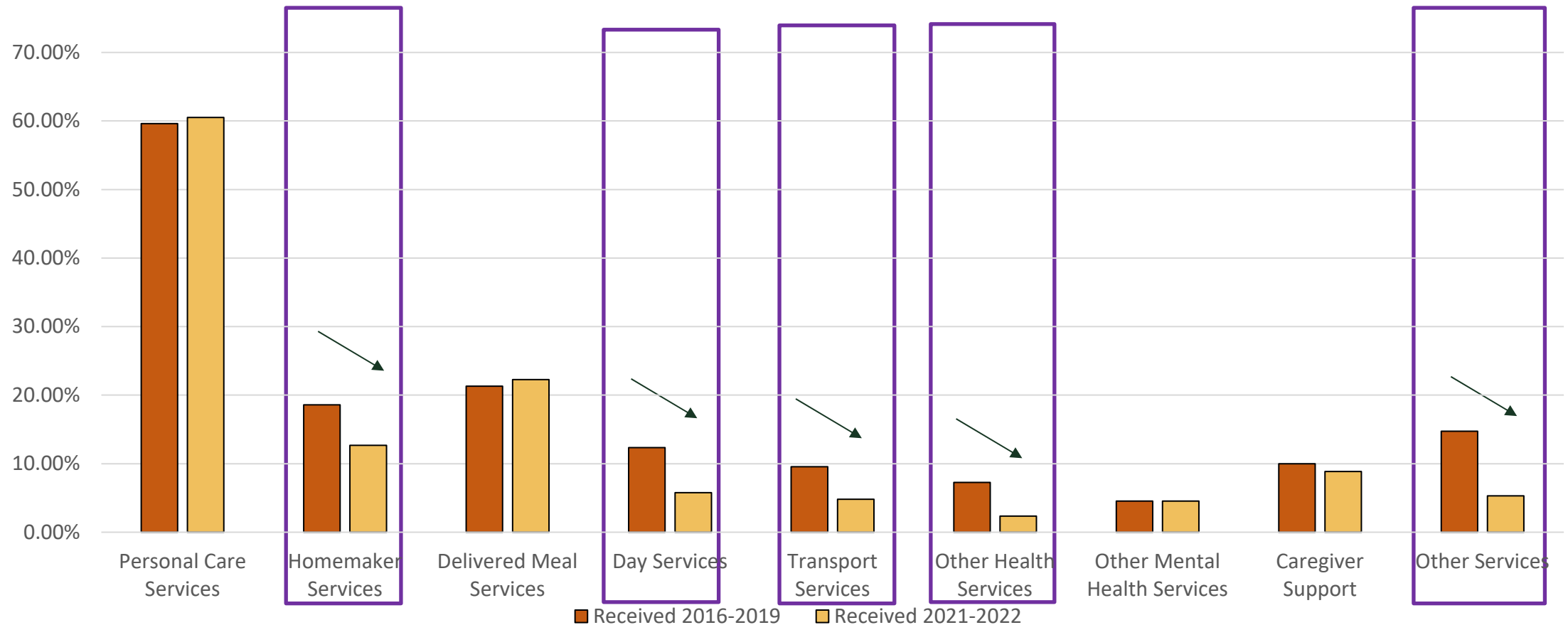
# Respondents with ADRD in Rural Areas Were More Likely to Receive Homemaker Services and Caregiver Support and Were More Likely to Report Needing These Services



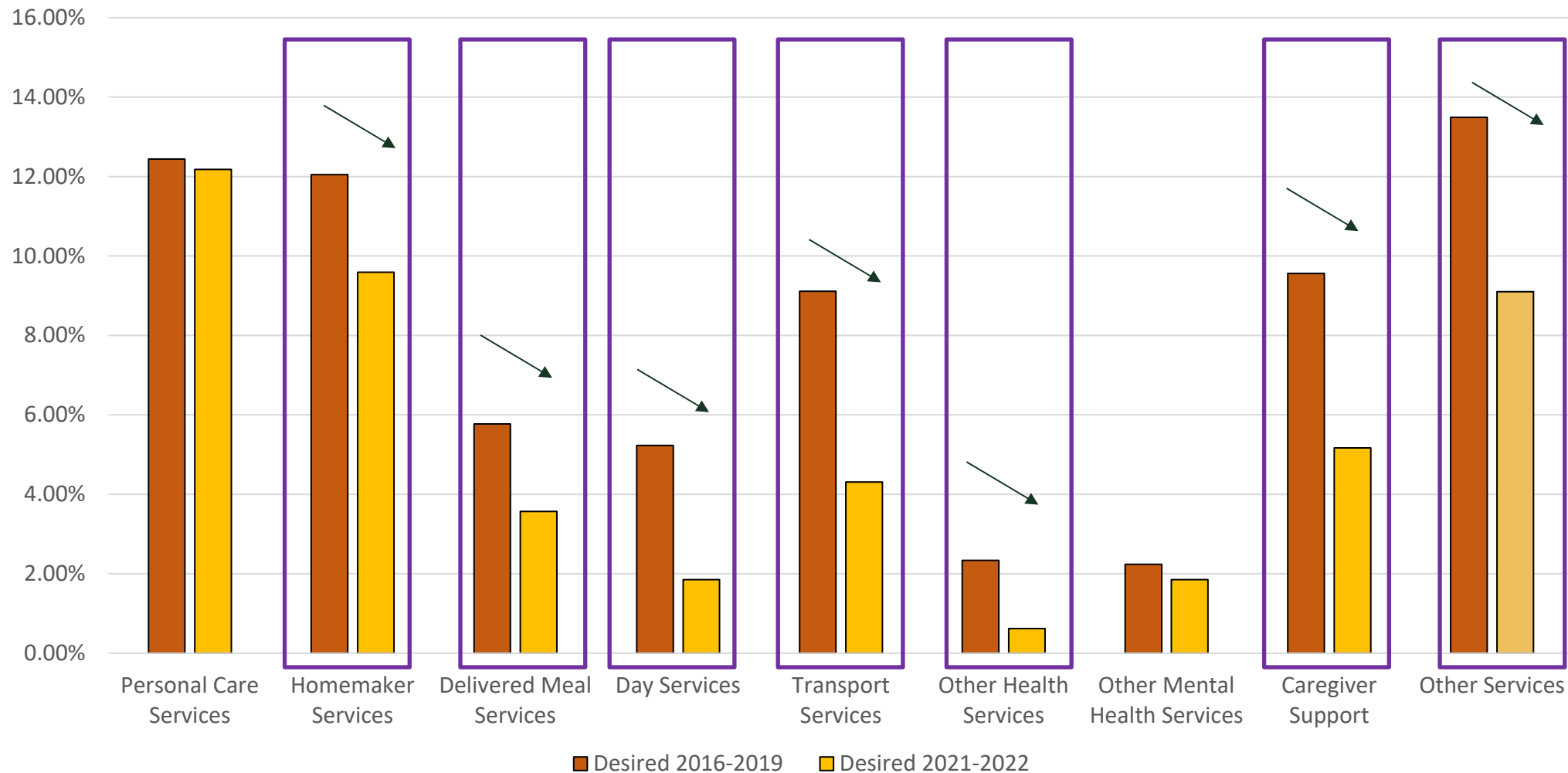
# Services Used By People with Dementia Before vs. During the Pandemic



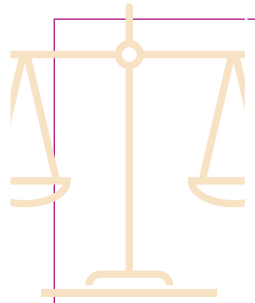
# Homemaker, Day, Transportation, and Other Services Showed a Post Pandemic Decline In Services Received



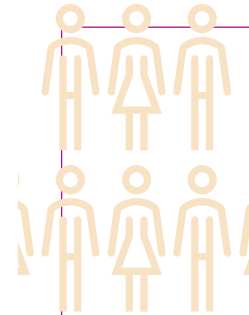
# Fewer Respondents with ADRD Reported Needing Homemaker, Delivered Meals, Day, Transportation, Caregiver Support, and Other Services Post Pandemic



# Discussion

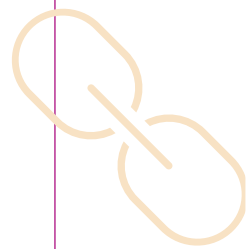


~10% of consumers w/ADRD desire additional personal care services, homemaker services, transportation and caregiver support.



Sociodemographic differences in services received and desired

- E.g., race and rural/urban differences in desired day services, transportation, caregiver support



Future work needs to examine the role of service quality as well as linking unmet needs to healthcare utilization and person-centered outcomes

# Thank you

## Contact

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## Websites

- [www.nci-ad.org](http://www.nci-ad.org)
- <https://www.sph.umn.edu/research/projects/equals/>