Describing Unmet Needs of HCBS Consumers with Dementia Using NCI-AD Data

University of Minnesota School of Public Health

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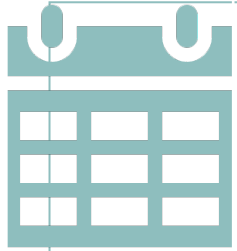*National Core Indicators –Aging and Disabilities*

Stephanie Giordano, MEPP, DLP

Rosa Plasencia, JD

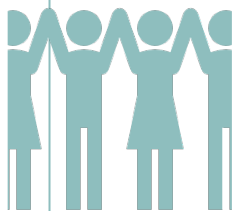# Acknowledgements

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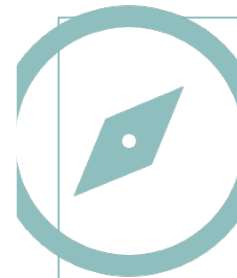# NCI-AD: An Overview

Established
- 2015

Participating states
- 23

Population addressed
- Older adults and people with physical disabilities

Covers multiple domains
- AD domains and indicators: https://nci-ad.org/resources/the-survey/

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

Person-Reported and Health Care Utilization Outcomes of HCBS Recipients With and Without Alzheimer's Disease and its Related Dementias (ADRD)

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What are the goals?

Aim 1

- **Document trends in services use** by HCBS users with and without AD/ADRD.
- Seek to understand if consumers **desire more** services.
- Test to see if **actual and desired use varies** by AD/ADRD and **state investment** in HCBS.

Aim 2

- Explore **client** and **state factors** associated with better **person-reported outcomes**.
- Assess if **person-reported outcomes** vary by **AD/ADRD** status.

Aim 3

- Link Minnesota **Medicare/Medicaid claims to NCI-AD data** [2019-2020].
- Investigate whether **person-reported outcomes** affect **healthcare utilization** for HCBS clients **with/without AD/ADRD**.

Addressing Unmet Needs of HCBS Consumers: Select Outcomes

Select outcomes from 2018-19

Who is included in these data?

Data come from 2018-19 survey cycle

- Total N (from full dataset) = **14,202**
- Number states: **16**

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Analysis _excluded…_

- Cases with _missing outcomes_ for services received and desired services (5,381 cases excluded)

- Those who _lived in nursing homes_ (2,332 cases excluded)

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Final analysis includes a total of 6,489 respondents

# Analysis uses outcomes from two questions...

- **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"
- **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"
- Other demographic information presented collected in the Background Information
  - Typically collected through administrative records
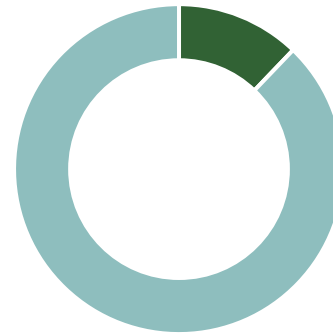 - The person or proxy may answer if information is missing in records

Demographics

- ⅔ of respondents identified as **women**

- **54%** were **≥ 65** years of age

- **61% White**; **28% Black; 11% Other**

  - **4.1% Hispanic**

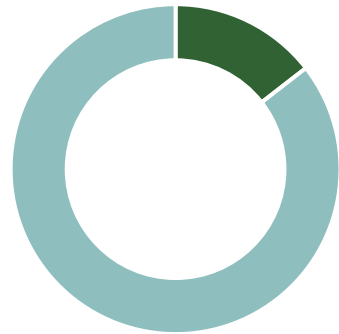- **73%** lived in Metropolitan areas

- **48%** lived alone

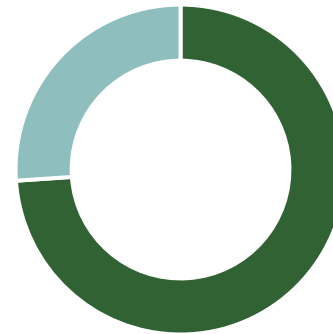# 19% of respondents had more than one of the following diagnoses…
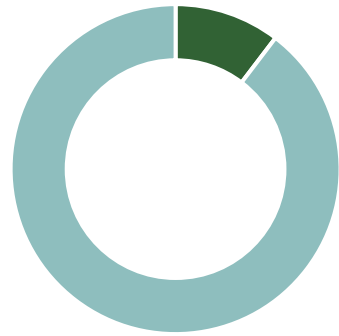
Alzheimer's or Other Dementia
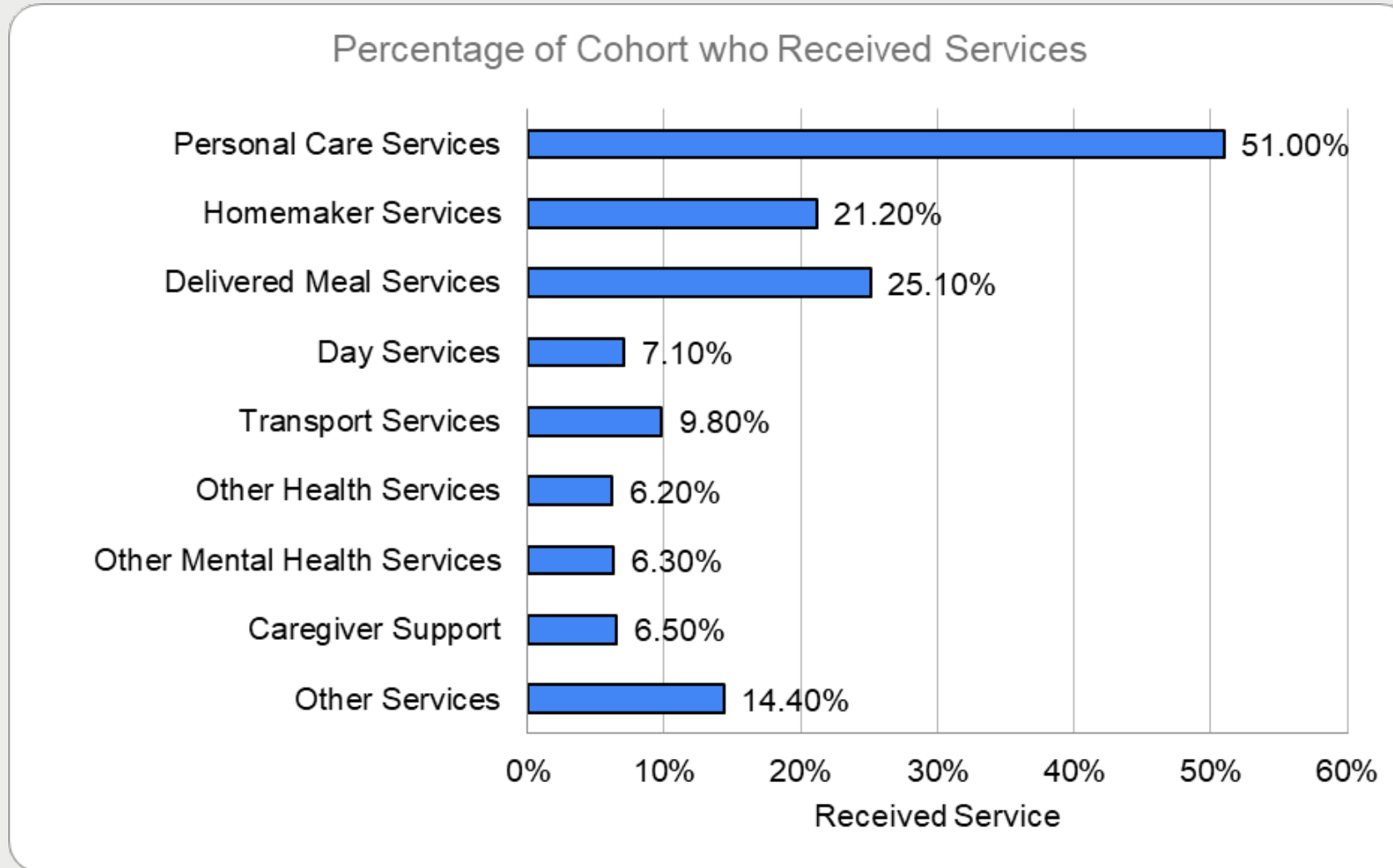10.36%

Developmental Disability
12.16%

Brain Injury
14.50%

Physical Disability
73.92%

Prevalence and Types of Services Received: Personal Care Services more prevalent

Percentage of Cohort who Received Services

Service	Received Service
Personal Care Services	51.00%
Homemaker Services	21.20%
Delivered Meal Services	25.10%
Day Services	7.10%
Transport Services	9.80%
Other Health Services	6.20%
Other Mental Health Services	6.30%
Caregiver Support	6.50%
Other Services	14.40%

Prevalence & Types of Services Desired: Transportation & Homemaker Services most frequently wanted

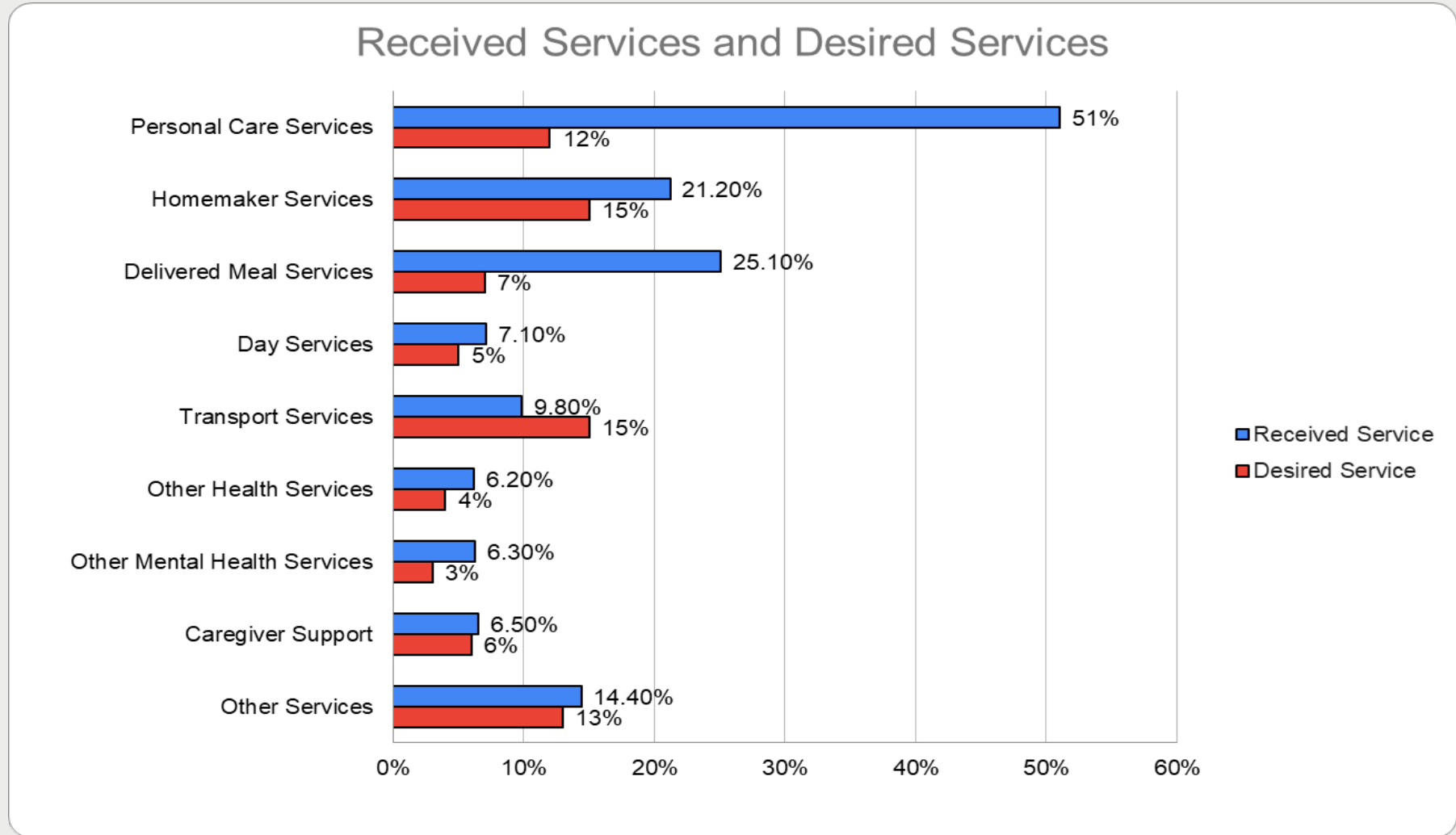Percentage of Cohort who Desired Services

Service	Percentage
Personal Care Services	12%
Homemaker Services	15%
Delivered Meal Services	7%
Day Services	5%
Transport Services	15%
Other Health Services	4%
Other Mental Health Services	3%
Caregiver Support	6%
Other Services	13%
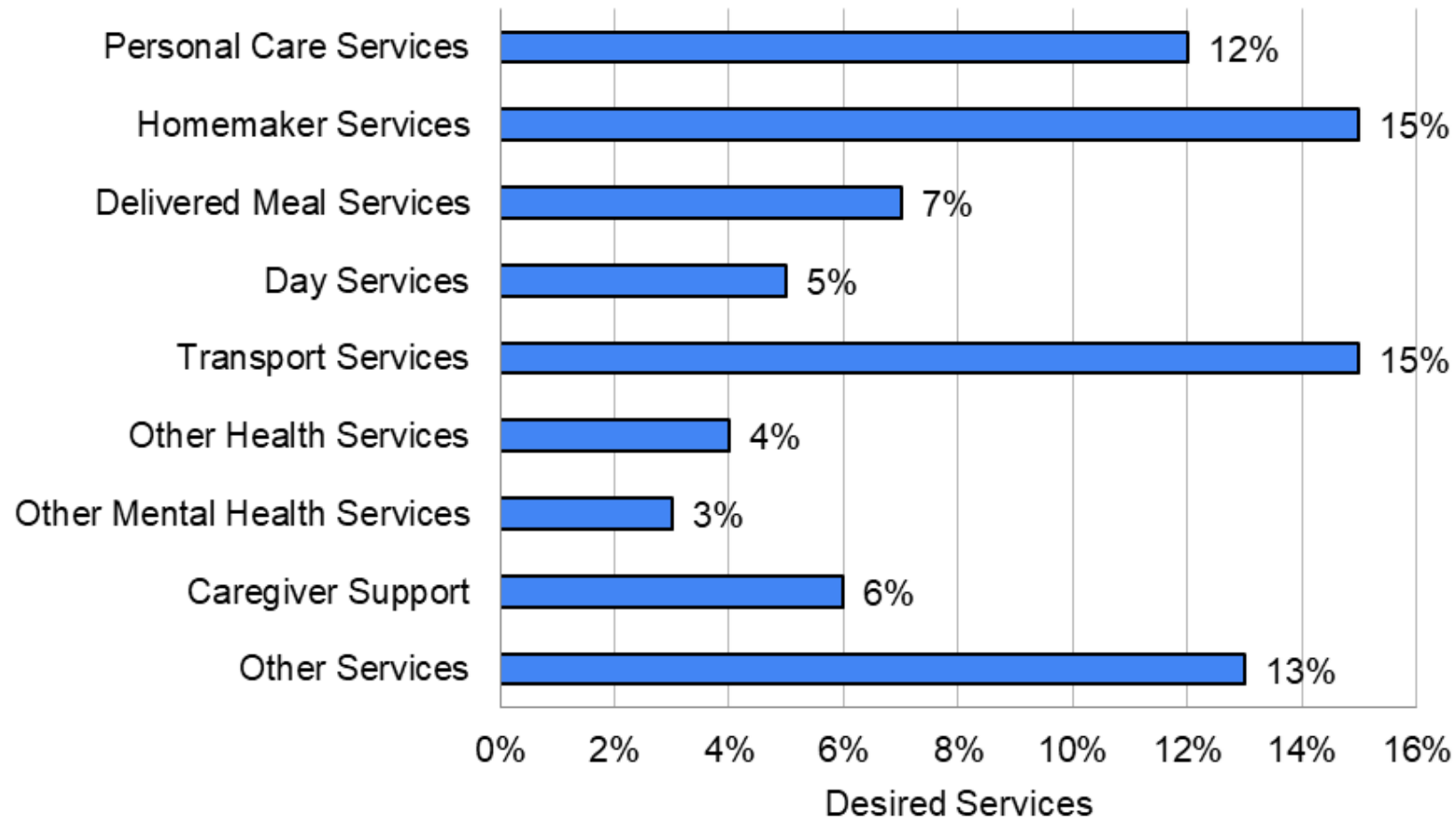
Desired Services

Proportion of respondents wanting more services than receiving them

Received Services and Desired Services

| Service	Received Service	Desired Service
Personal Care Services	51%	12%
Homemaker Services	21.20%	15%
Delivered Meal Services	25.10%	7%
Day Services	7.10%	5%
Transport Services	9.80%	15%
Other Health Services	6.20%	4%
Other Mental Health Services	6.30%	3%
Caregiver Support	6.50%	6%
Other Services	14.40%	13%

Analyses for Different Sub-Groups

How demographics impacted service use and services desired

Actual and Desired Services Among People with AD/ADRD

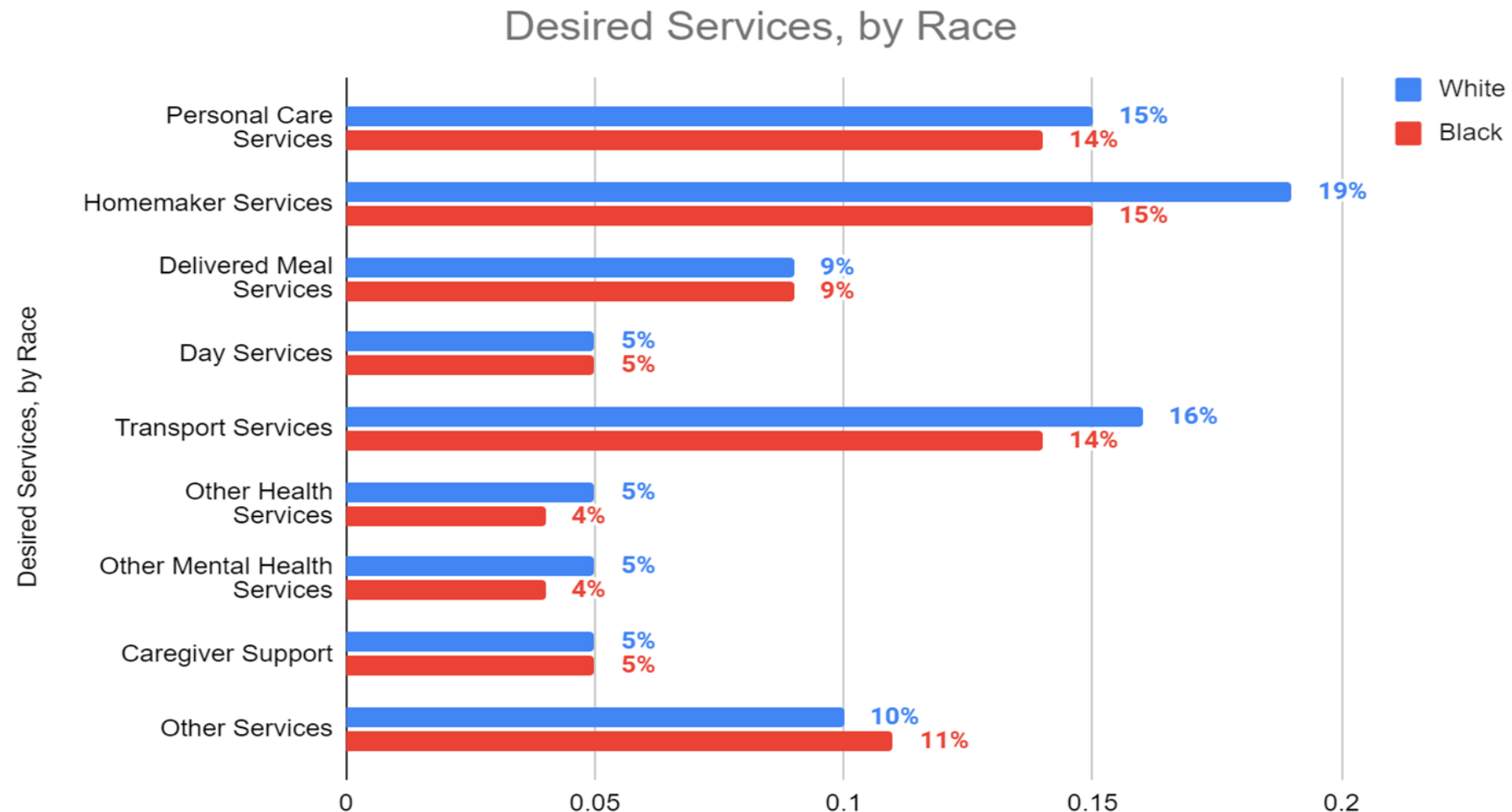Received Services and Desired Services, ADRD
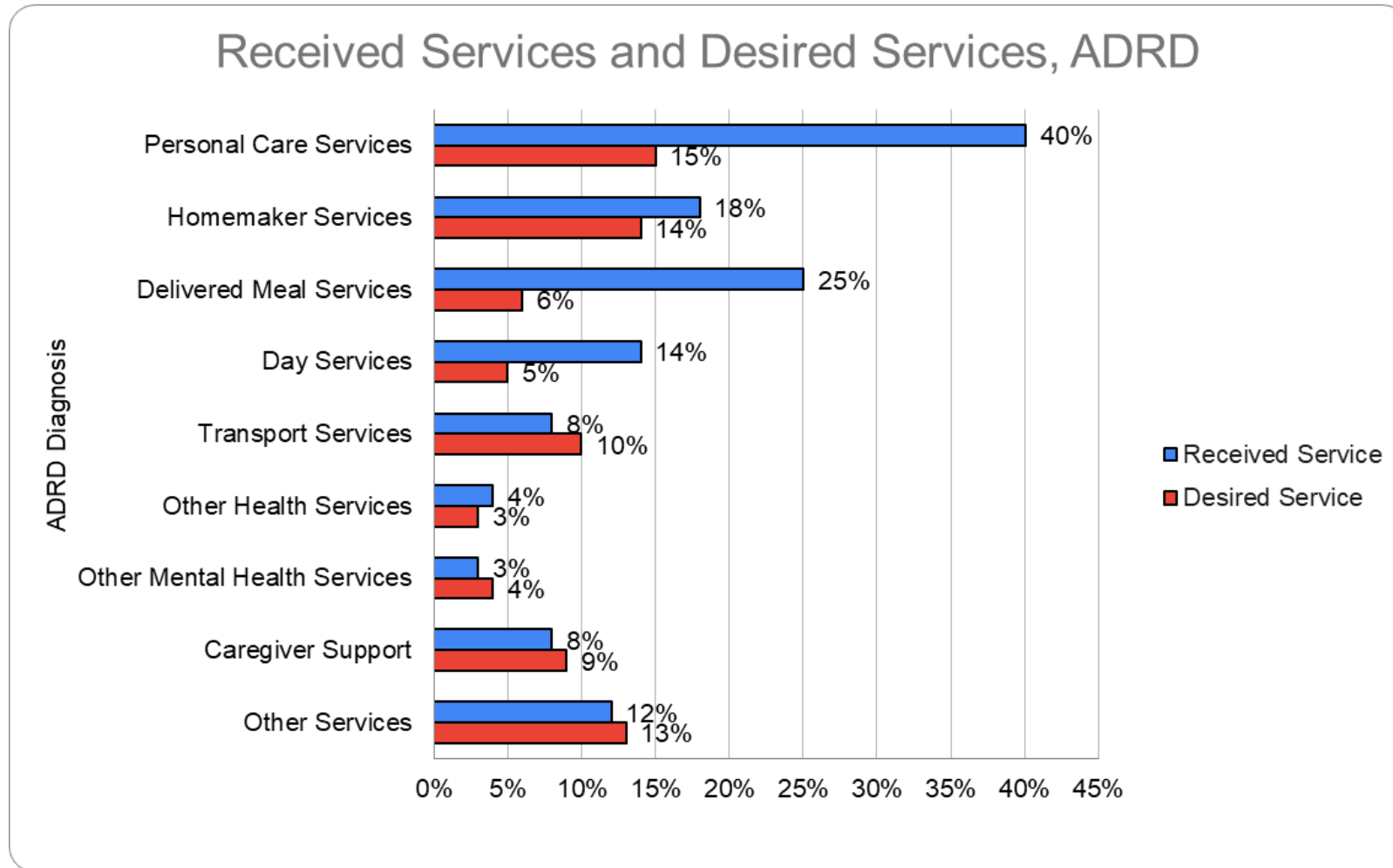
Black respondents tended to be less likely to receive most services vs White respondents...

Received Services, by Race
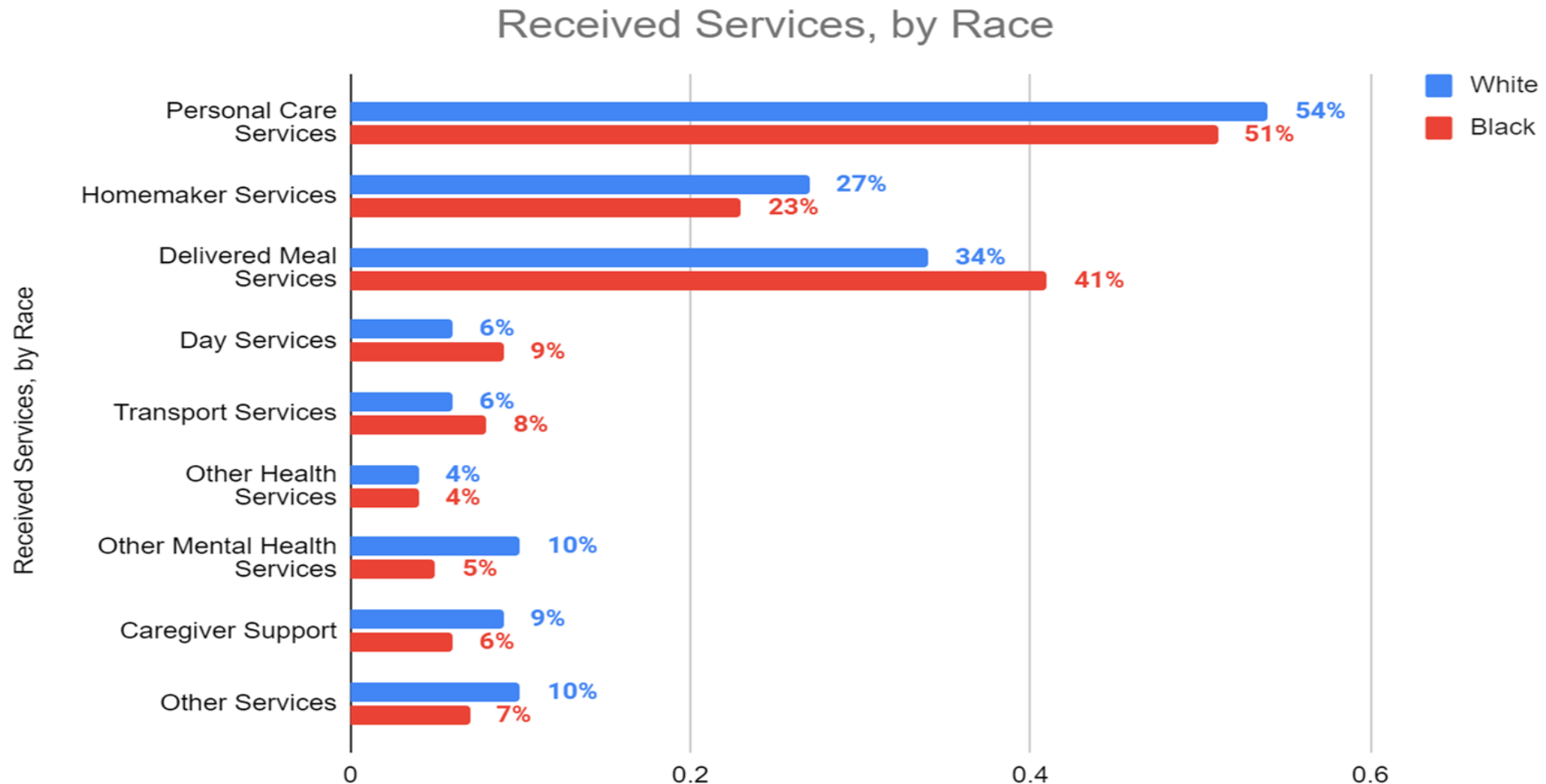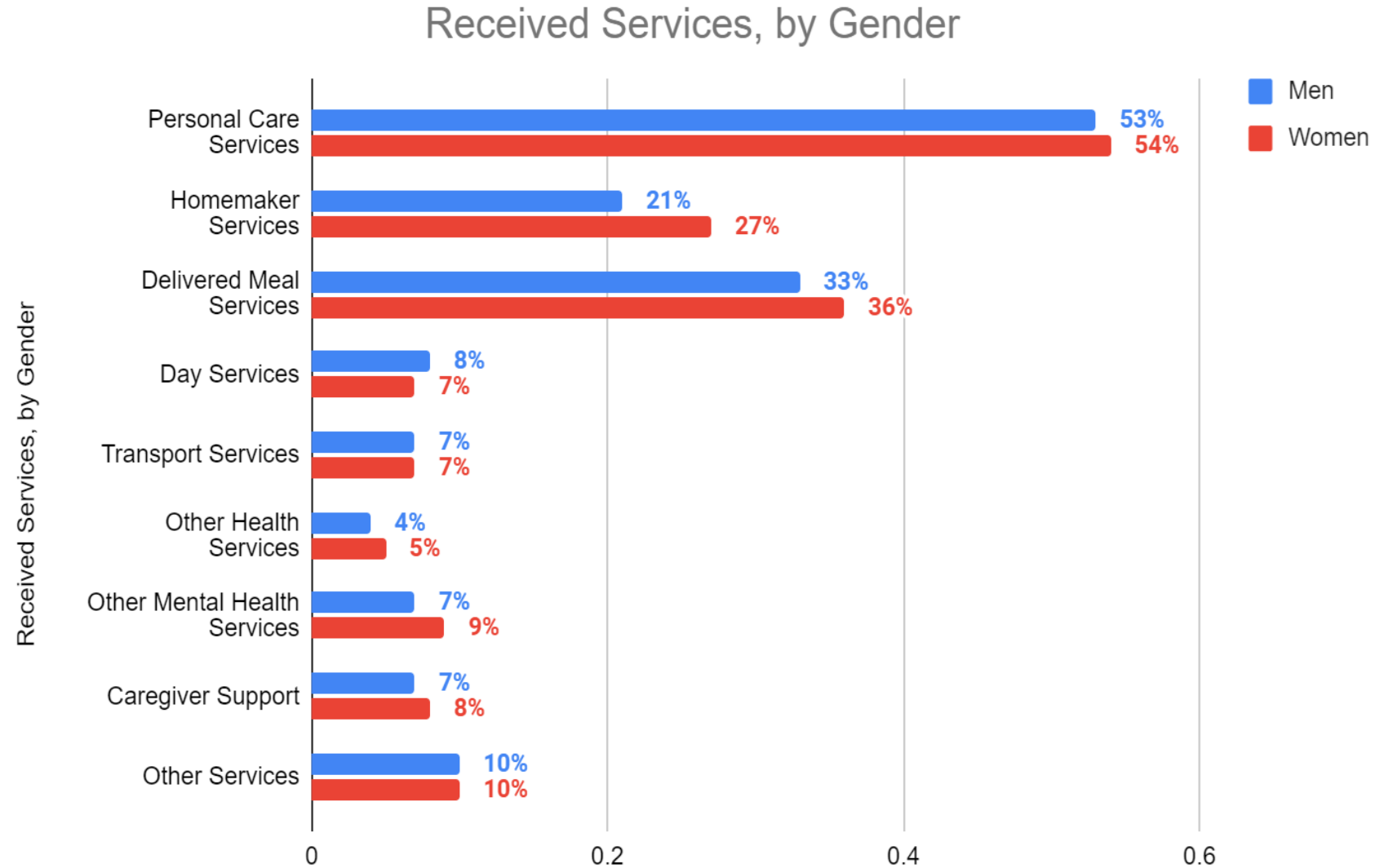
…and Black respondents tended to be less likely to report wanting additional services
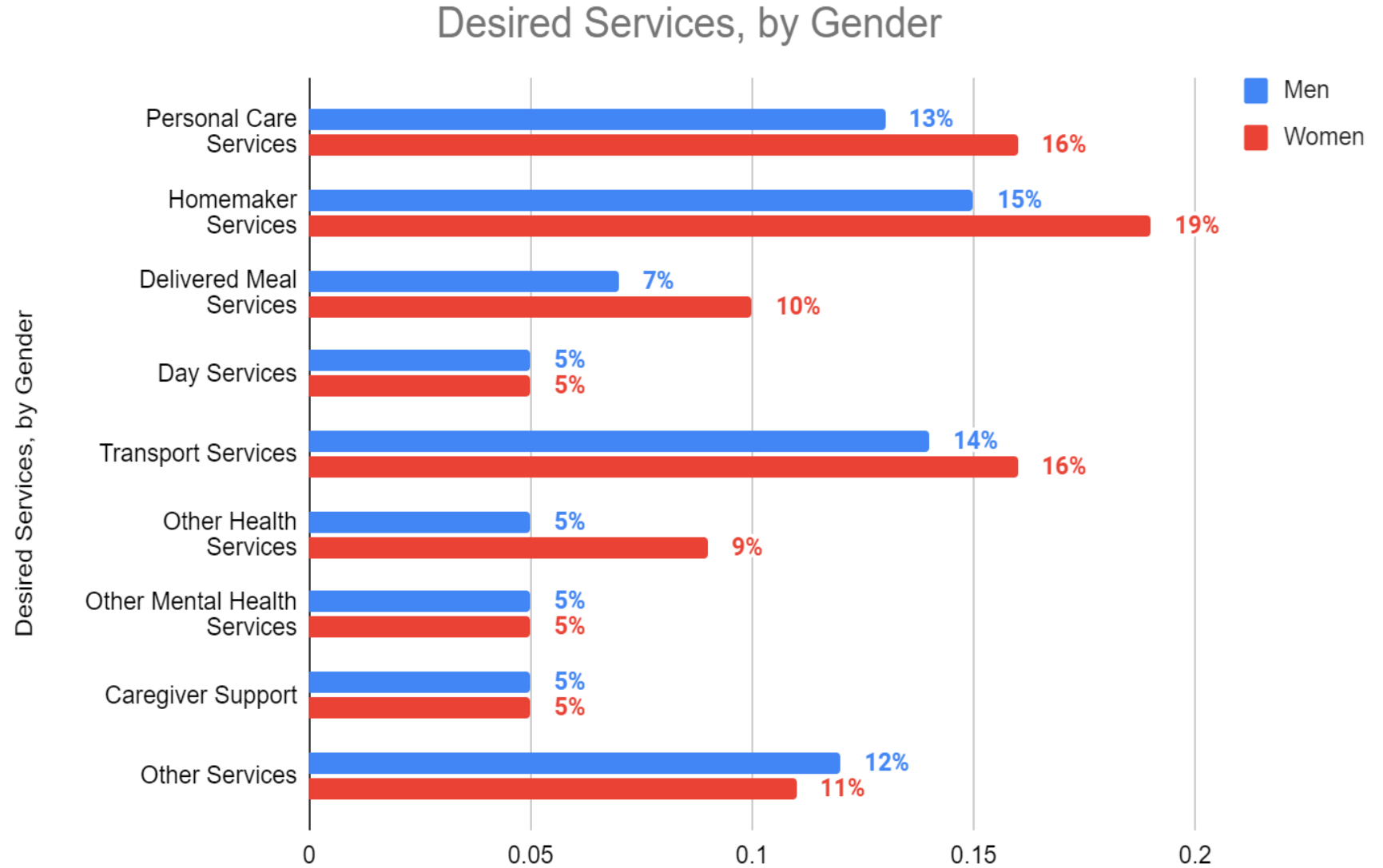

Desired Services, by Race

Women were slightly more likely to receive personal care, homemaker and home delivered meals

Men were slightly more likely to receive other mental health services

Received Services, by Gender

Service	Men	Women
Personal Care Services	53%	54%
Homemaker Services	21%	27%
Delivered Meal Services	33%	36%
Day Services	8%	7%
Transport Services	7%	7%
Other Health Services	4%	5%
Other Mental Health Services	7%	9%
Caregiver Support	7%	8%
Other Services	10%	10%

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Women tended to be more likely to report wanting additional services


Desired Services, by Gender

Those living in urban areas had higher rates of receiving most services, those in rural settings were more likely to receive home delivered meals

Received Services, by Urban/Rural Zipcode
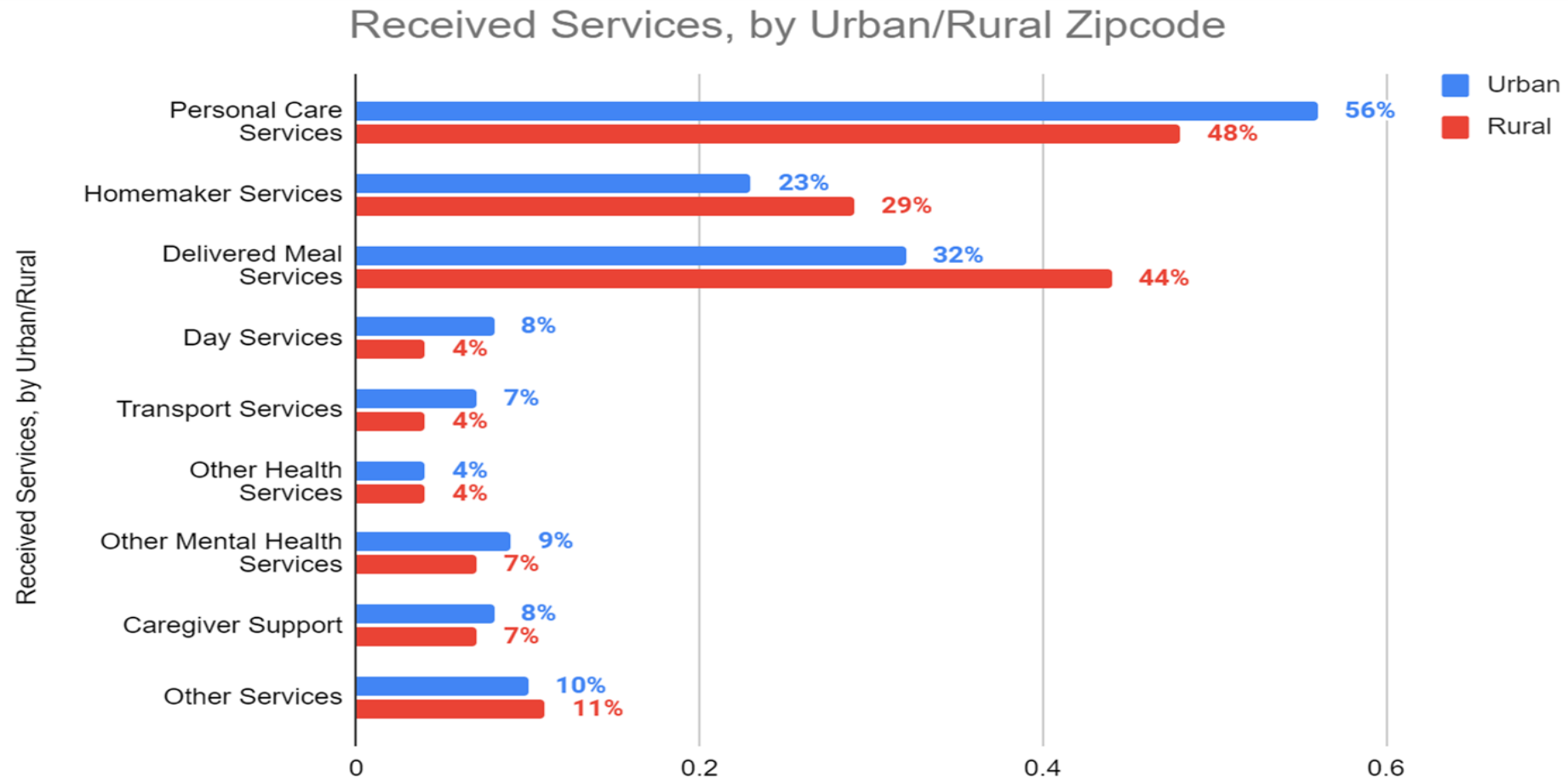
Those living in urban areas generally had higher rates of reporting wanting additional services

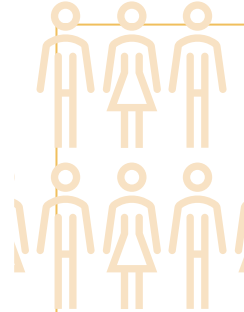Desired Services, by Urban/Rural Zipcode
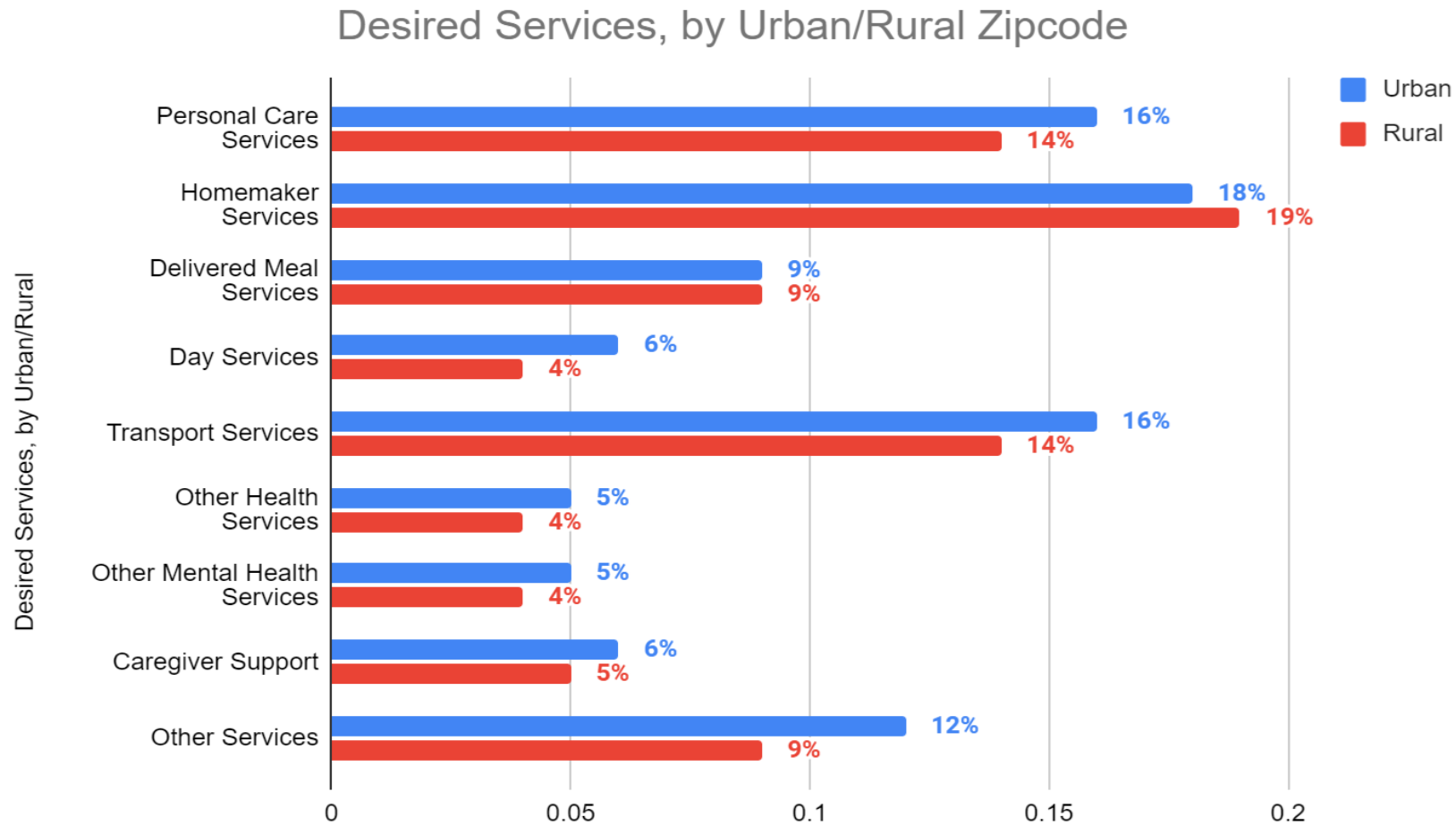
Discussion
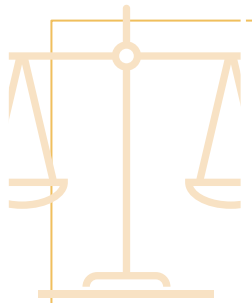
Consumers desire additional services to those currently provided
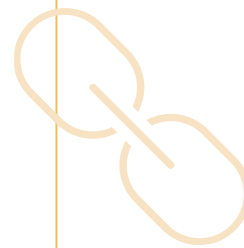- E.g., transportation

Sociodemographic differences in services received and desired
- E.g., Rural/urban differences in transportation desired
- Unmet needs by dementia diagnosis

Need for more attention to equity in how services are delivered

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

Alzheimer's Disease & Dementia Measurement

John Mulcahy, MSPH

# Identifying Alzheimer's Disease and Dementia in NCI-AD

- NCI-AD includes data from 29 different states

- Some states report dementia status from administrative records, while respondents from other states are asked to self-report their dementia status

Legend:
- Current Participant
- Past Participant
- Non-Participant
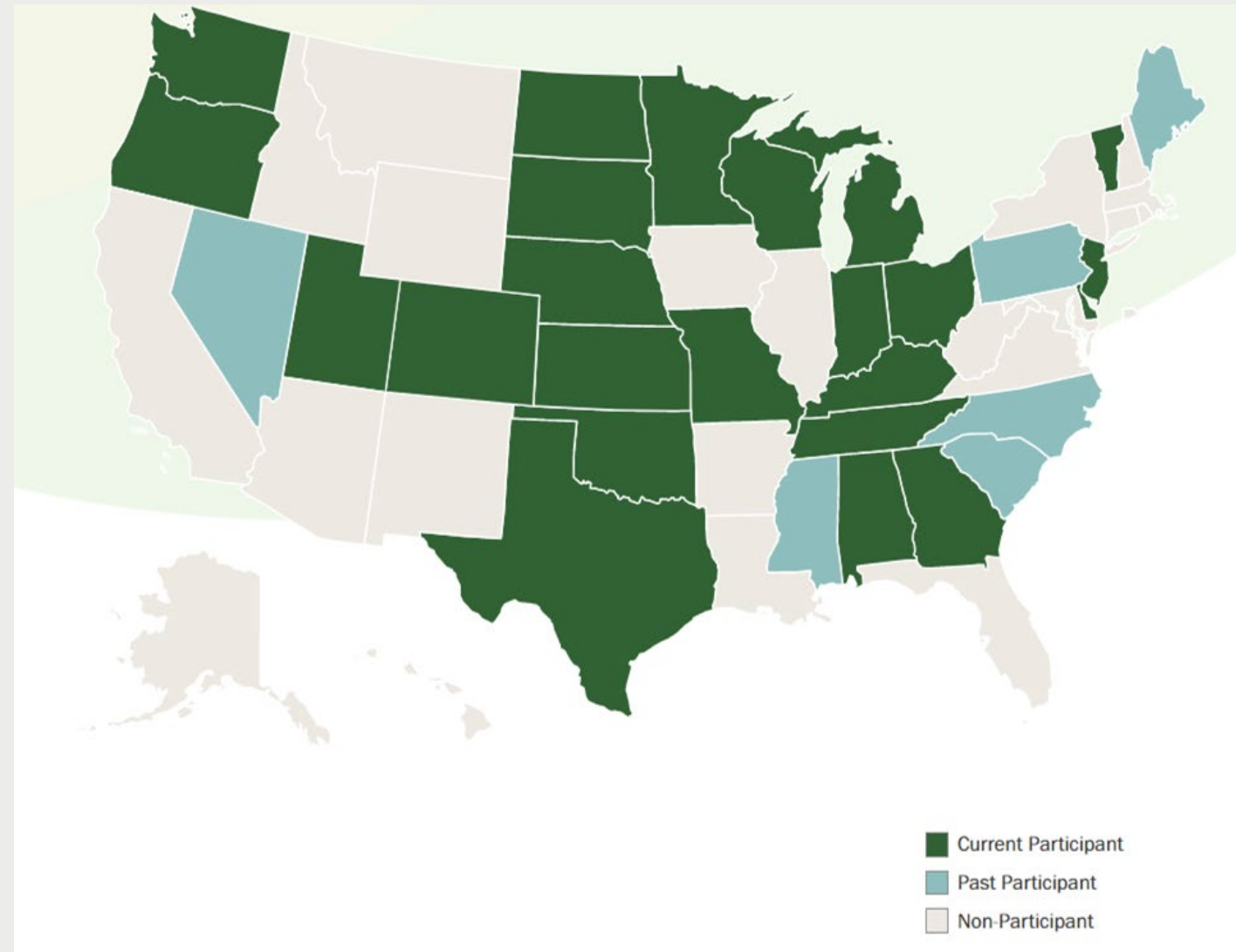
Study Approach

- We investigated how this difference in dementia classification affects accuracy.

- We fit regression models predicting dementia status.

- Models were fit separately for administrative and self-report subsets of the data.

Each model was used to predict dementia status in a subset of the data.

Percent of Respondents with Dementia Correctly Identified

- Administrative Model: 45%
- Self-report Model: 32%
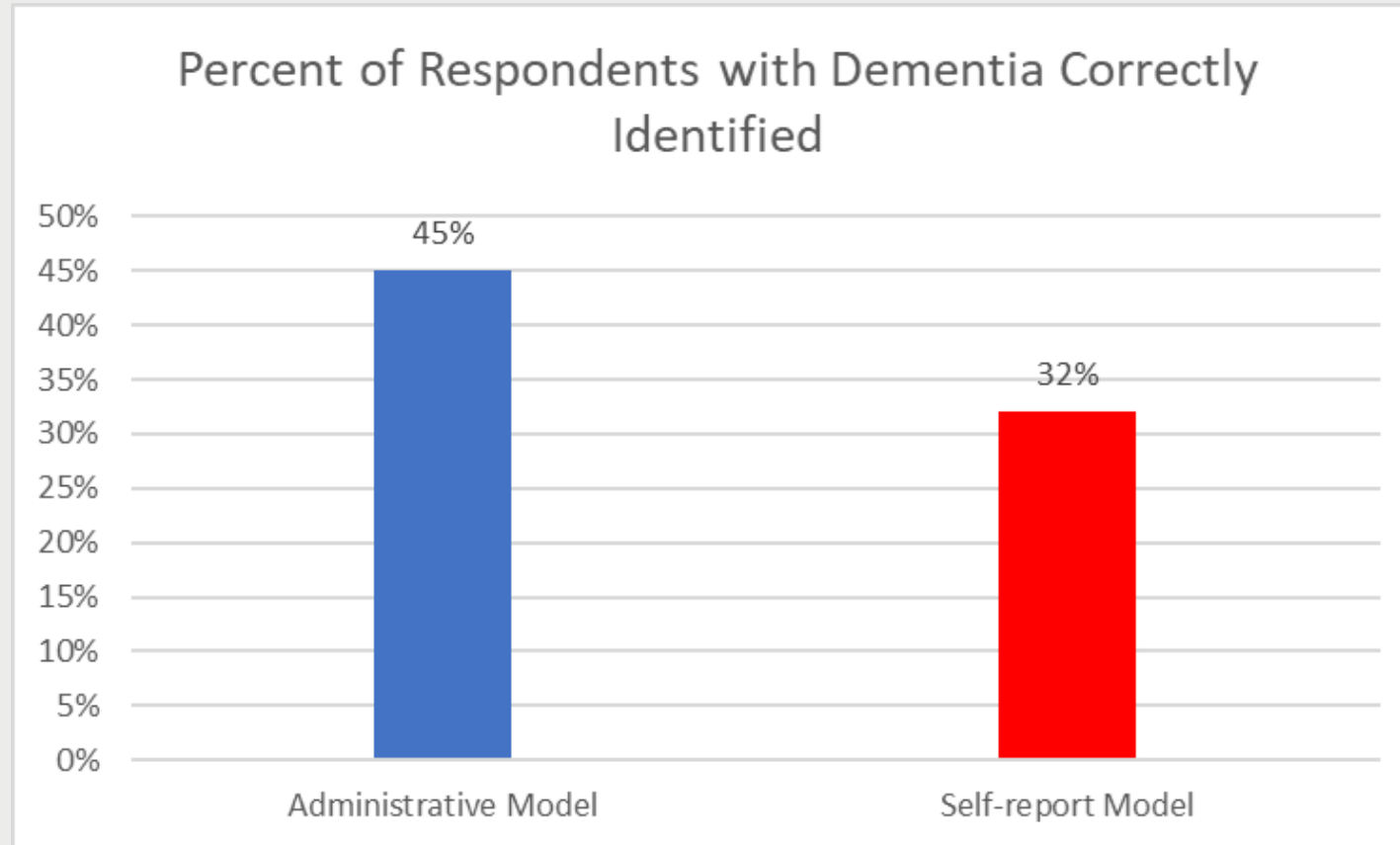
Conclusion

- These findings introduce concerns about systematic underestimation of dementia prevalence in states that rely on self-report.

- Illustrates the need to support states to collect these data consistently.

- NCI-AD is actively working with state partners to increase the number of states that share administrative records.
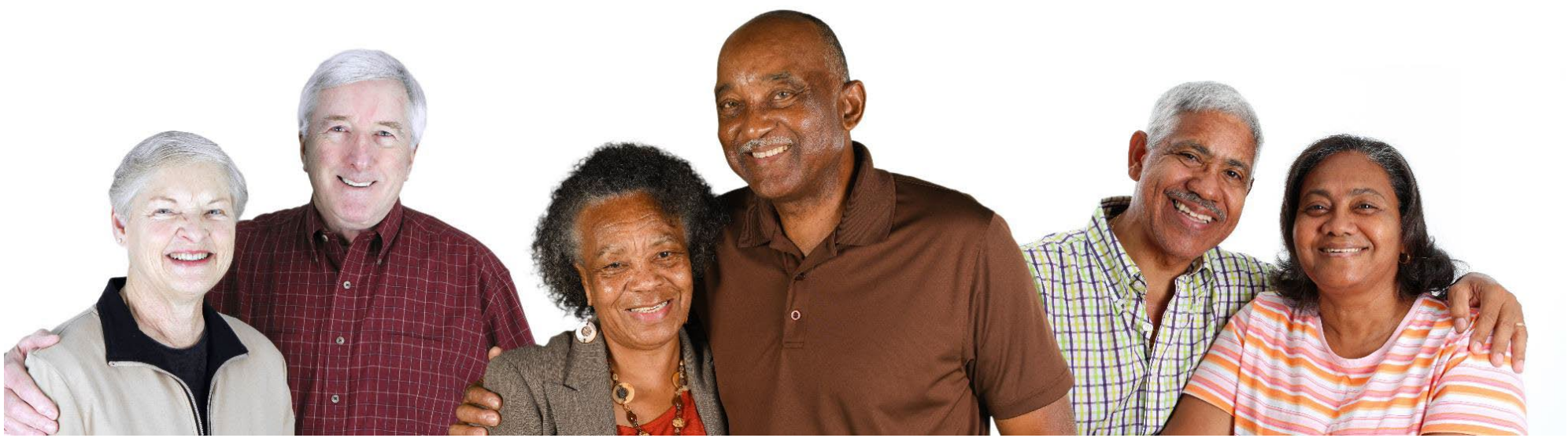
Future Directions

- There remains unmet need by both AD/ADRD status and race/ethnicity.

- Developing more comprehensive measures of quality using NCI-AD.

- Reporting of dementia and better use of administrative data.

- Pursue additional state partnerships for NCI-AD & claims data linkage to explore healthcare utilization.

Thank you

Contact

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  Co-director National Core Indicators, Human Services Research Institute

Websites

- www.nci-ad.org

- https://www.sph.umn.edu/research/projects/equals/