



Symposium on Self-Neglect

Kathy Greenlee, J.D.

ADvancing States

August 31, 2023

kgreenlee@advancingstates.org

Agenda

1. Overview and framing: Kathy Greenlee, Senior Director of Elder Justice Initiatives, ADvancing States
2. National data: Karl Urban, WRMA Inc., APS Technical Assistance Resource Center
3. Current practice panel:
 - a) Jeromy Buchanan, Director of Community Living, Aging and Protective Services, Oklahoma Department of Human Services
 - b) Corey Roybal, APS Regional Manager, Aging & Long-Term Services Department, New Mexico
4. Medicaid discussion: Bea Rector, Assistant Secretary, Aging and Long-Term Support, Washington State Department of Social and Health Services

National Adult Maltreatment Reporting System: Self Neglect Definition

A person's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including obtaining essential food, clothing, shelter, and medical care; obtaining goods and services necessary to maintain physical health, mental health, or general safety; hoarding; or managing one's own affairs.

Less Research on Self-Neglect than Elder Abuse

To characterize the severity of self-neglect, three domains of indicators have been identified:

Personal hygiene

Impaired function

Environment neglect

Epidemiology of Elder Self-Neglect, by Carmel Dyer and Carlos Reyes-Ortiz, published in Elder Abuse: Research, Practice and Policy, Springer Publication, 2017.

Health Outcomes Associated with Self-Neglect

- Higher mortality
- Functional decline
- Poor nutritional status
- Non-compliance with medical treatment
- Increased hospitalization
- Increased hospital readmission
- Higher number of emergency room visits
- Increased hospice utilization
- Increased nursing home admission

*Epidemiology of Elder Self-Neglect, by Carmel Dyer and Carlos Reyes-Ortiz, published in Elder Abuse: Research, Practice and Policy, Springer Publication, 2017.

Is it a choice or an outcome?

- Most experts feel self neglect is not a choice.
- The development of executive dysfunction has been proposed as an important etiologic factor.
- *Epidemiology of Elder Self-Neglect, by Carmel D. Dyer and Carolos A Reyes-Ortiz, Elder Abuse: Research, Practice and Policy, 2017 Springer publication

Person Centered Language

- Term self-neglect is pejorative
- Expresses contempt or disapproval
- Self neglect connotes intentionality that may not exist
- “Cases of self-neglect” is not person-centered
- Have not found a suitable synonym
- In the very least we can use “person first” language

Person experiencing self-neglect

Similar to “person experiencing homelessness”

Self-neglect is an experience, not an identity

The role of APS?

APS Practice Change

- Adopt person-centered language
- What are self-neglect investigations trying to determine?
- “Substantiation” of what?
- Many states moving toward “verifying need for protective services”
- Some states continue to characterize self-neglect as the person being their own perpetrator

Chronic/Acute

The characteristics of self-neglect and outcomes demonstration the condition of self-neglect is chronic not acute.

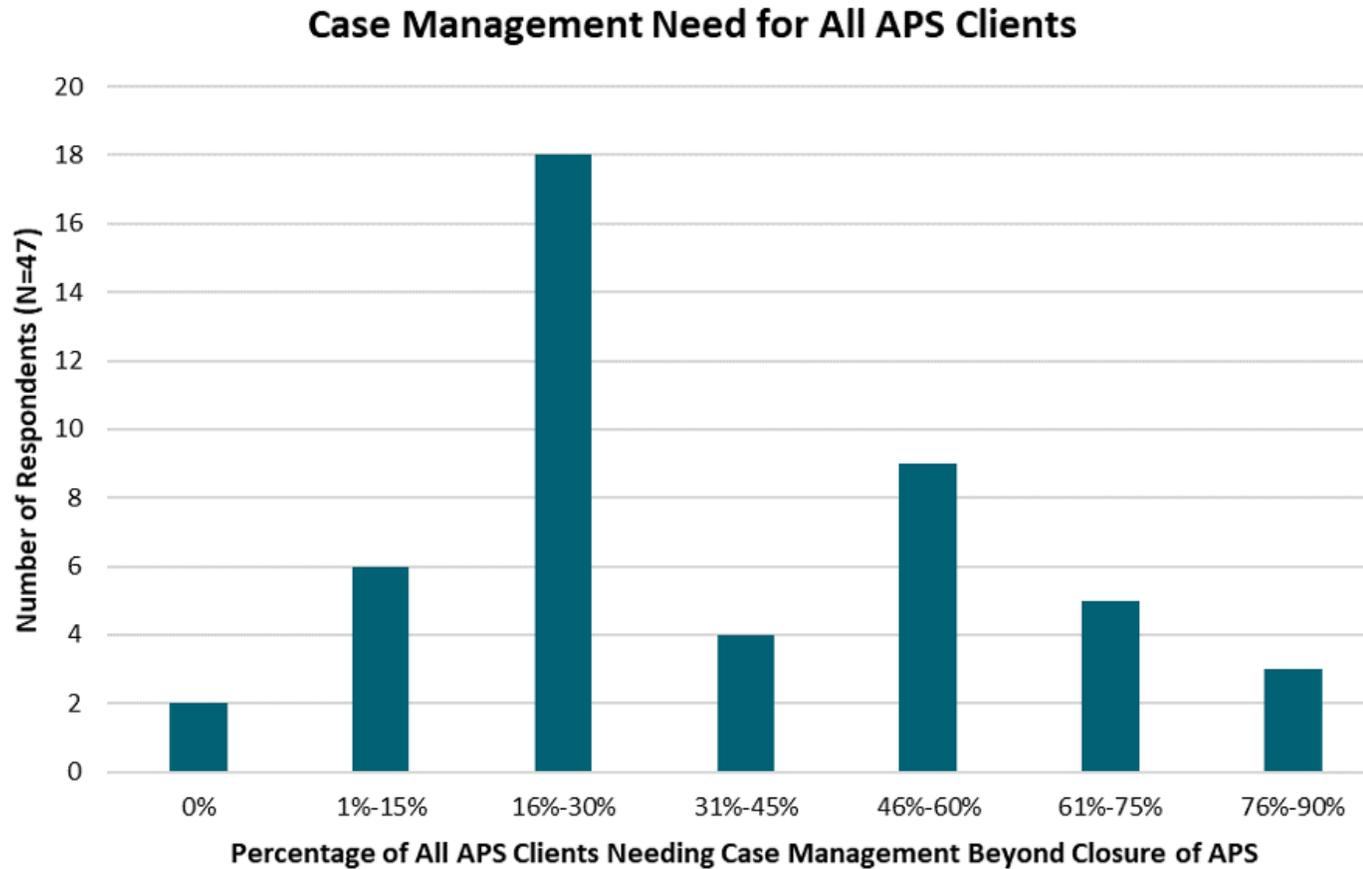
Adult Protective Services is designed for emergent problems and not for long-term support.

Cases of self-neglect have a high percent of recidivism to APS

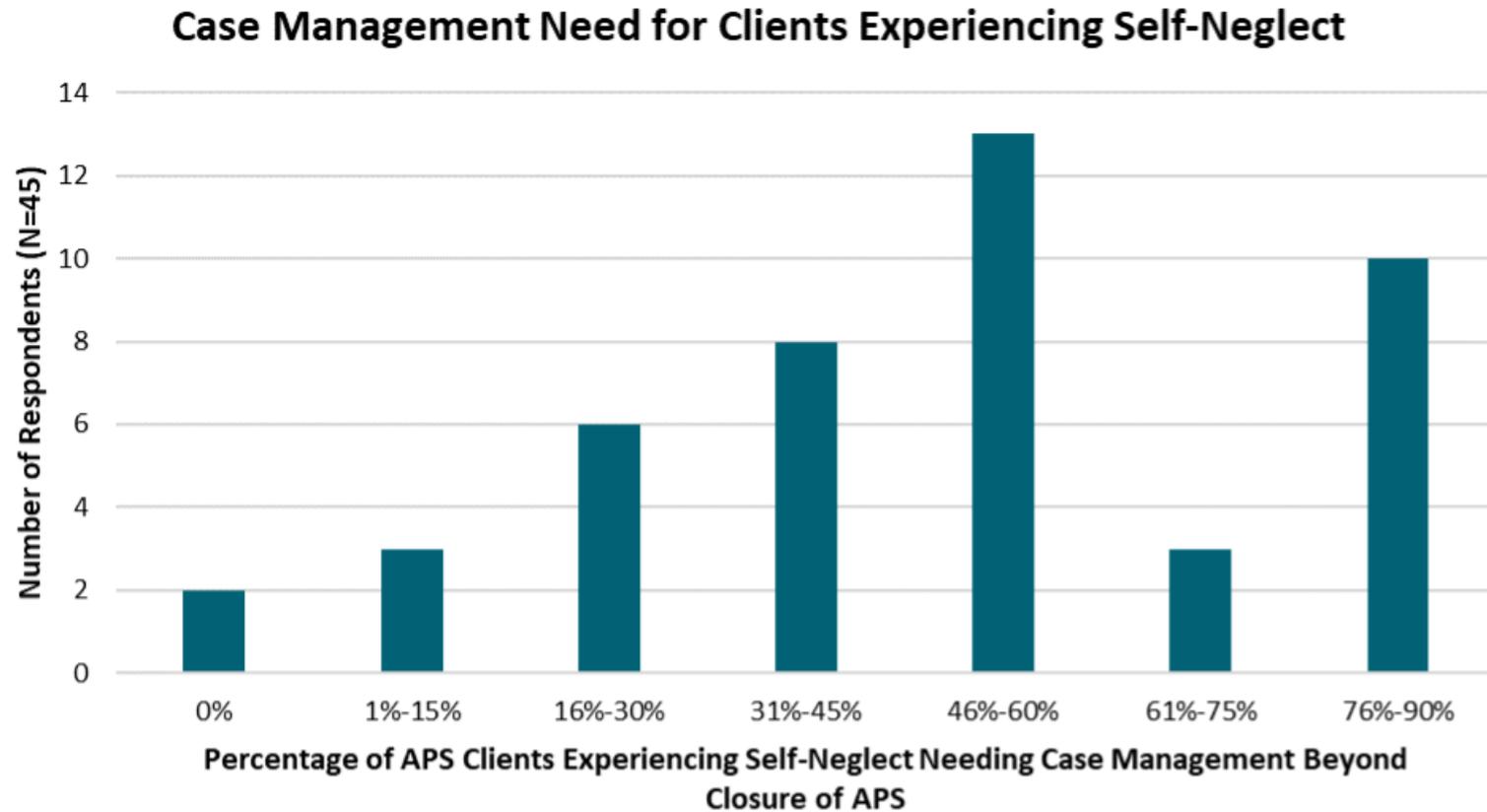
Case Management

- APS typically does not provide case management
- APS refers to community providers
- Some Medicaid programs provide a degree of case management support
- Case management services need to be intensive
- People experiencing self neglect also need medical care

Case Management: All clients*

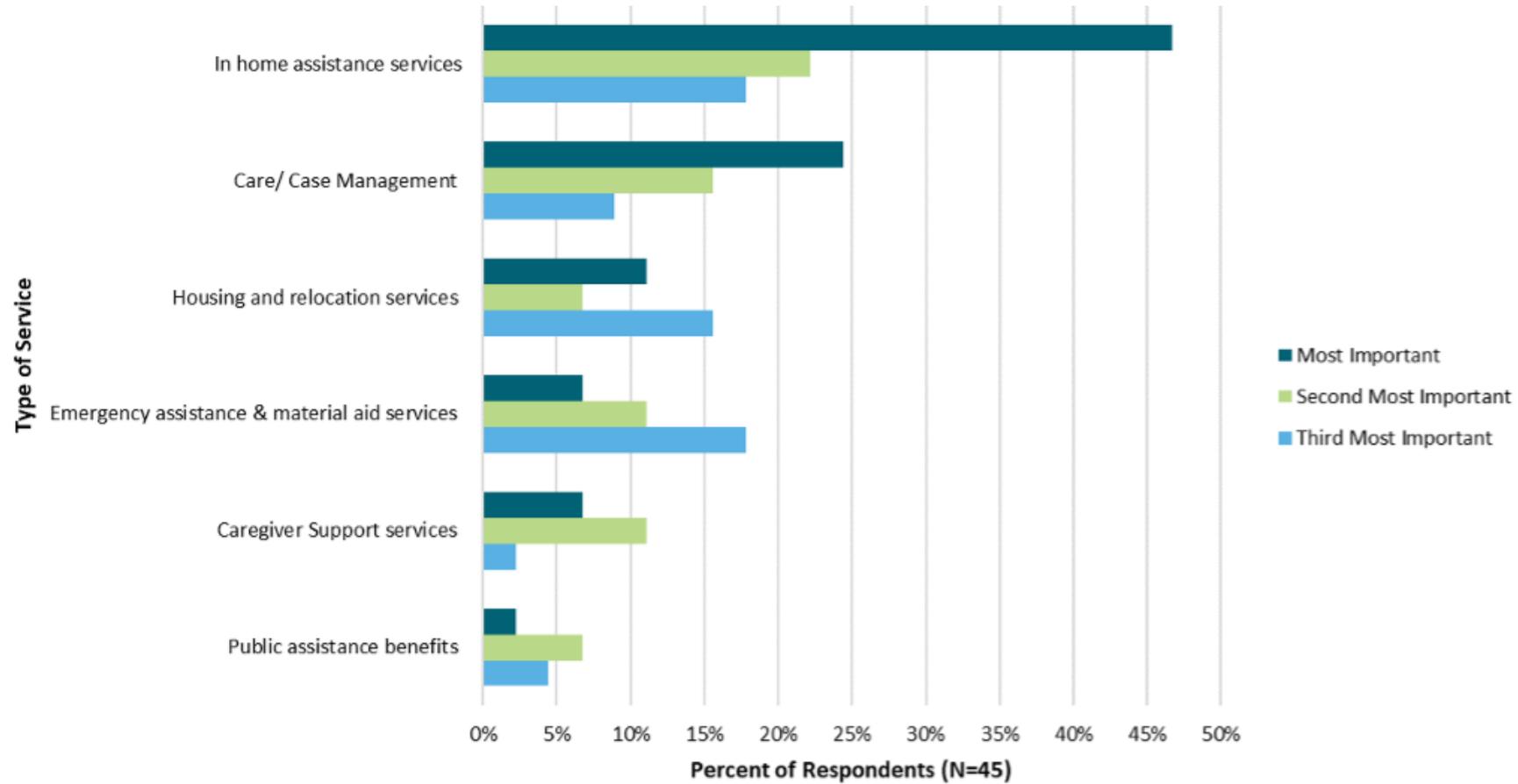


Case Management: Self-Neglect Clients

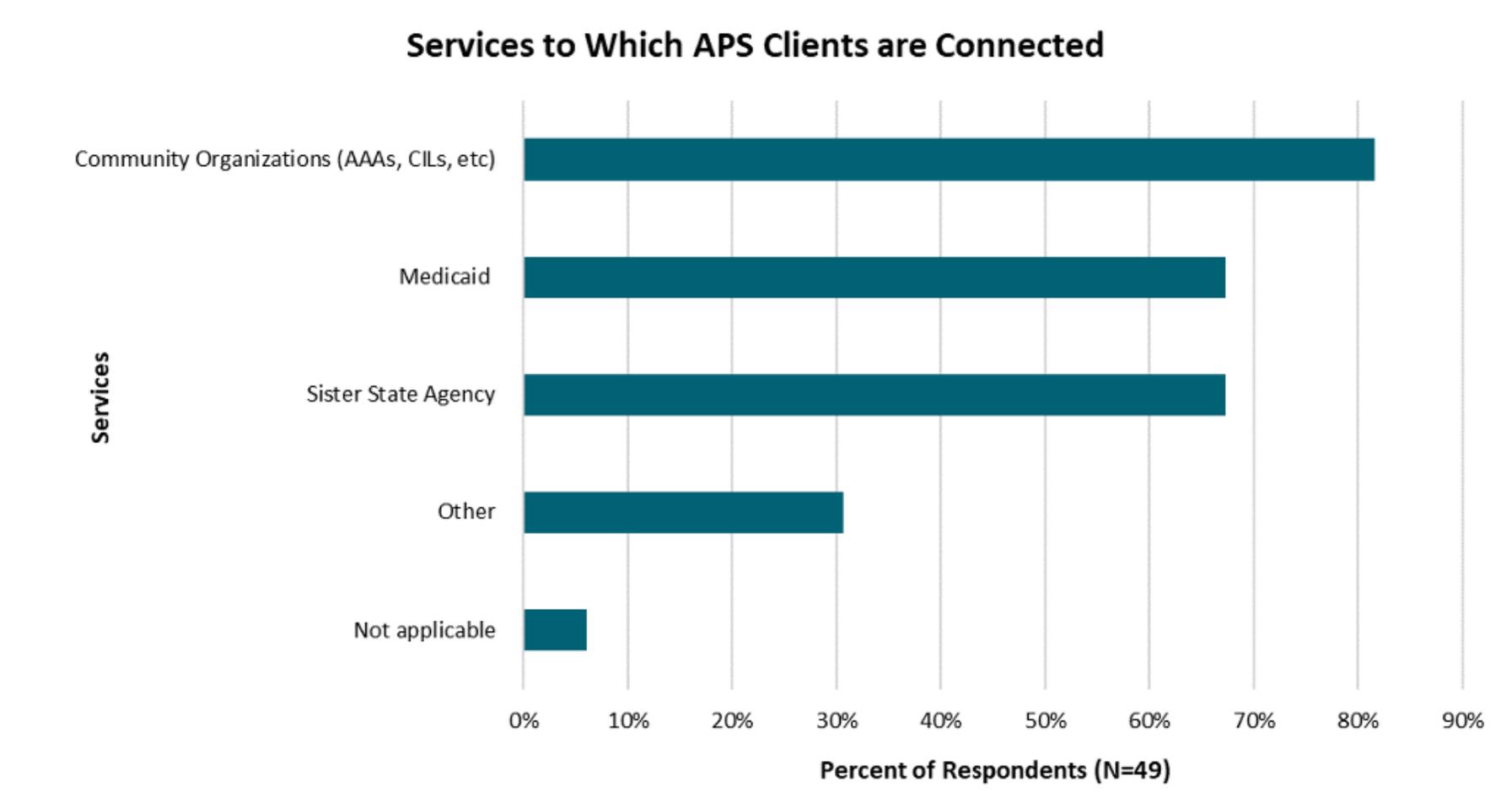


Top Six Services

Top Six Most Needed Services for Clients Experiencing Self-Neglect



Services Referrals

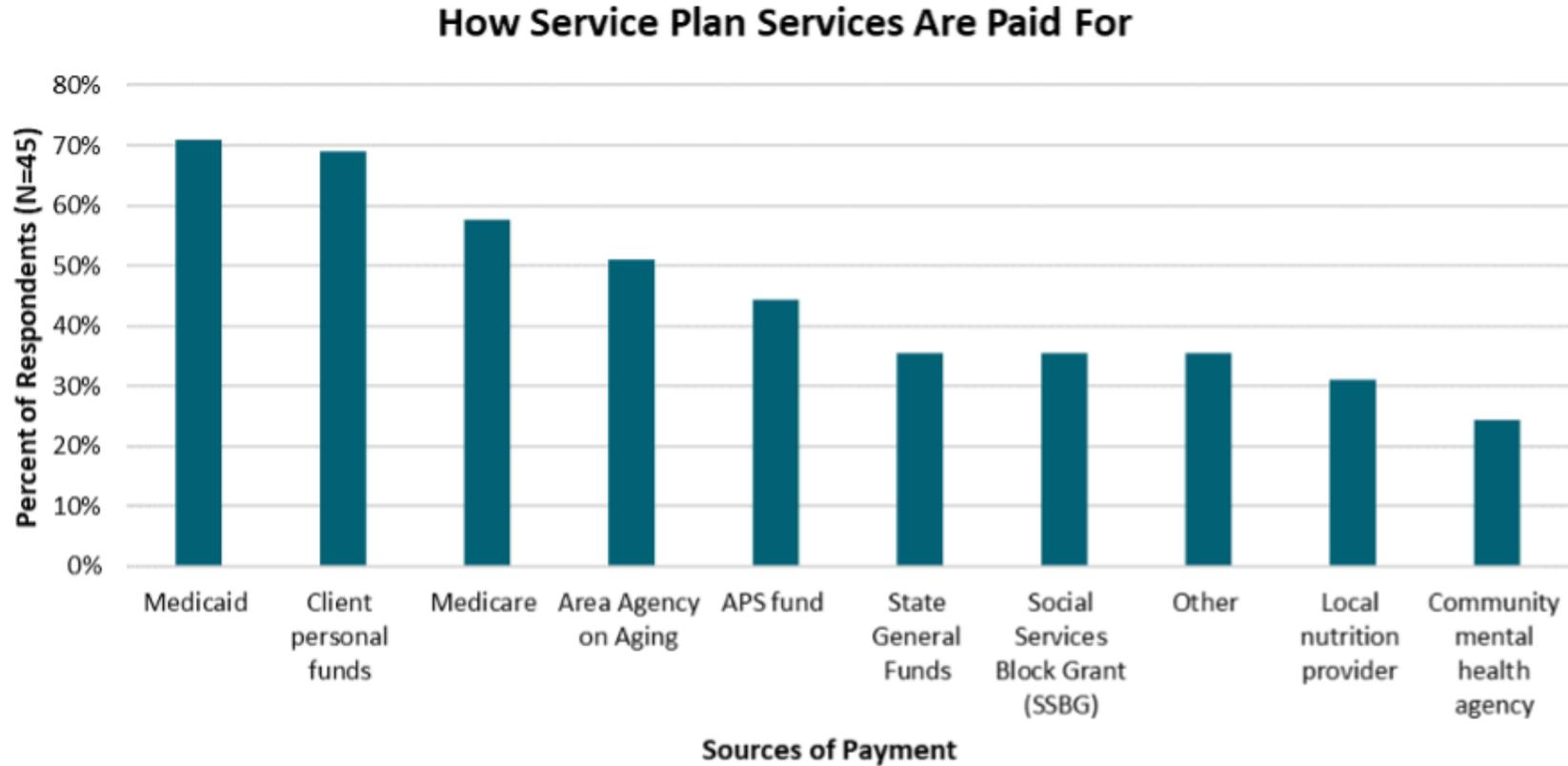


APS and Medicaid Services

What should APS finance?

What can be provided via Medicaid?

Payment for APS Client Services: Where States Turn



Services Identified in ARPA APS Spend Plans

Emergency/Temporary
Housing, Moving
assistance

Utility, rent assistance,
minor home repair

Deep cleaning, pest
eradication

Domestic goods,
clothing, and
provisions

Food, medications,
DME, transportation

In-home care, respite,
transition of care
support

Case management,
mental health services

Legal services,
guardianship

Current Practice Panel

Jeromy Buchanan, Oklahoma

Corey Roybal, New Mexico

Issues to Discuss

- APS self-neglect numbers in your state
- How do you respond?
- Types of cases you see
- APS role at its best
- Most important community partners
- Most needed services
- Successful outcomes from client point of view

Medicaid discussion

Bea Rector, Washington state

Symposium on Self-Neglect

Karl Urban, WRMA, Inc.

Adult Protective Services Technical Assistance Resource Center
(APS TARC)

Understanding the Data

- All data is from the National Adult Maltreatment Reporting System (NAMRS) FFY 2022 for states that reported case component (CC) data
- Generally, this data compares self-neglect to all other maltreatment types (excluding self-neglect), labeled as “No Self-Neglect”
- Pay attention to the notes: **representativeness of the data varies by data element**
 - # of states reporting
 - Size of individual states within the sample (Texas is excluded from several for this reason)
 - % of unknown clients
- NAMRS Definitions
 - A client is a person with an allegation
 - A victim is a person with a substantiated allegation (referred to as “Persons Experiencing Self-Neglect”)

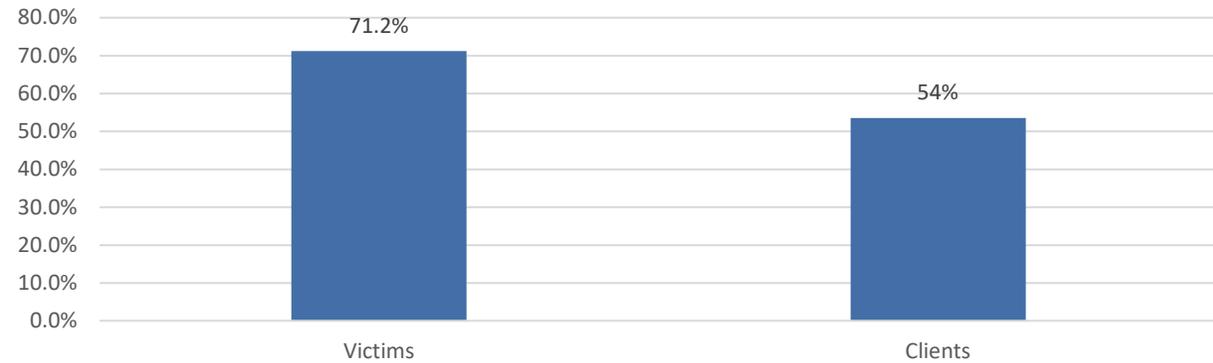
Clients with self-neglect allegations are 54% of all clients, ranging from 20% to 88% across the states.

Persons experiencing self-neglect [victims] are 71% of all victims, ranging from 12% to 96% across the states.

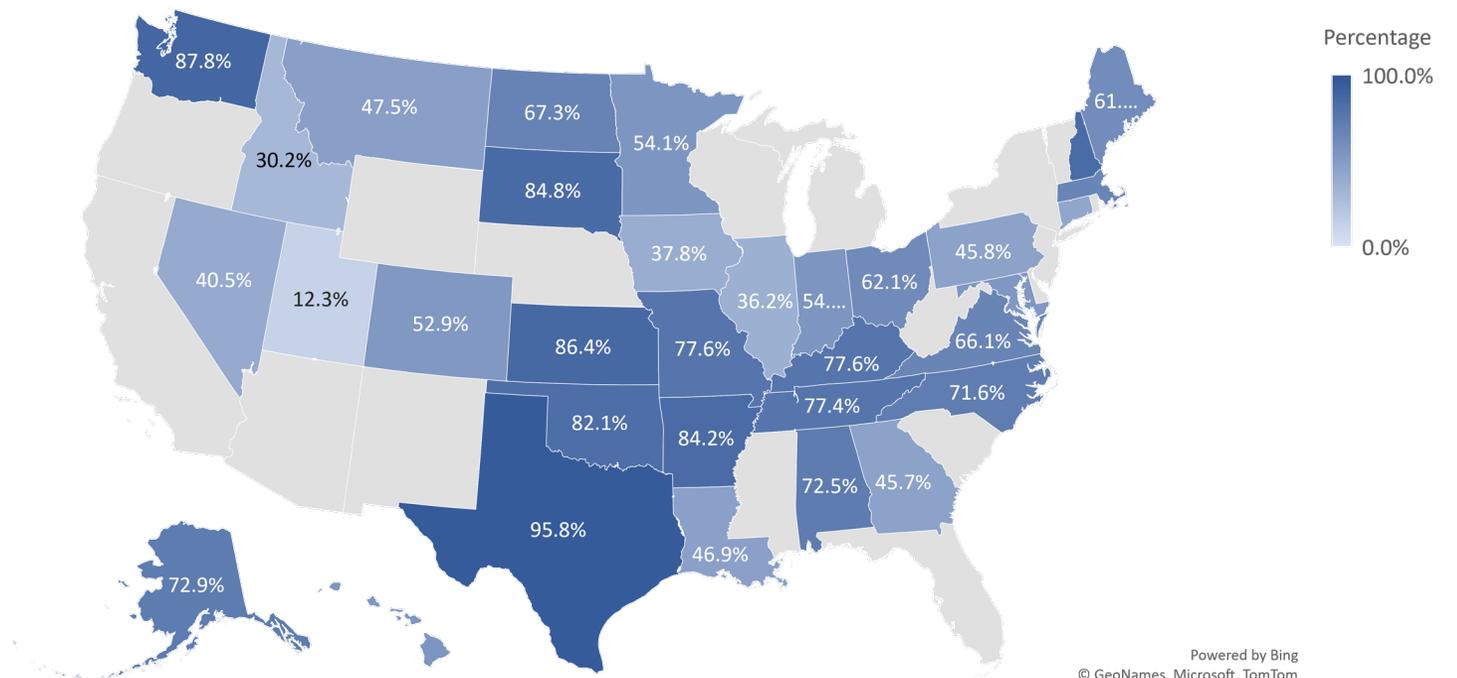
Since 2016, no change in trend.

Notes: NAMRS 2022 CC [Case Component], 33 states

Percent of Clients and Victims with Self-Neglect



Percent of Persons Experiencing Self-Neglect by State



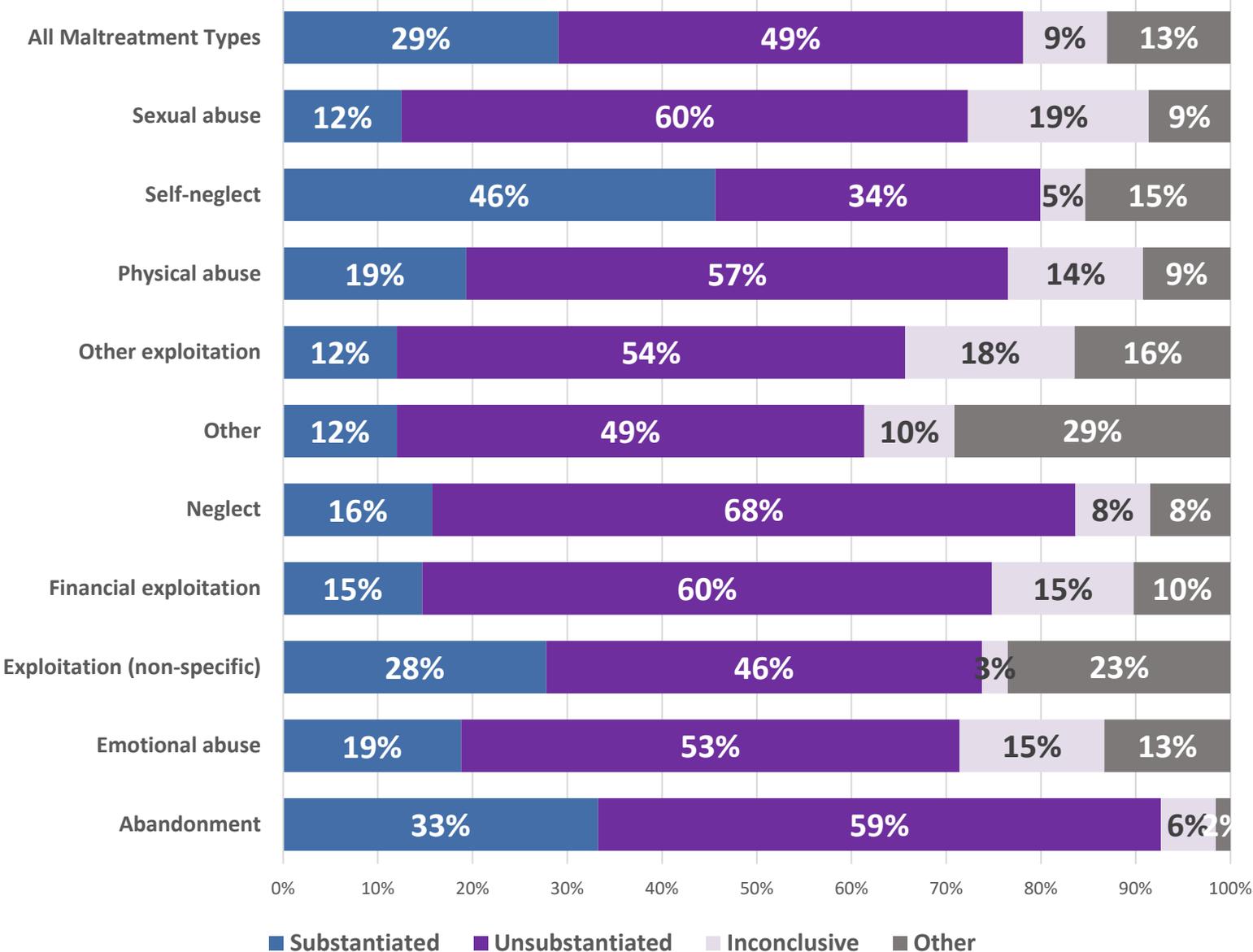
Disposition Rate by Maltreatment Type for Persons Experiencing Self-Neglect

Among maltreatment types, self-neglect has...

- The highest substantiation rate at 46%
- The lowest unsubstantiated rate at 34%
- A very low inconclusive rate at 5%

In contrast, neglect (by others) has the highest unsubstantiate rate across maltreatment types

Notes: NAMRS 2022 CC, 36 states

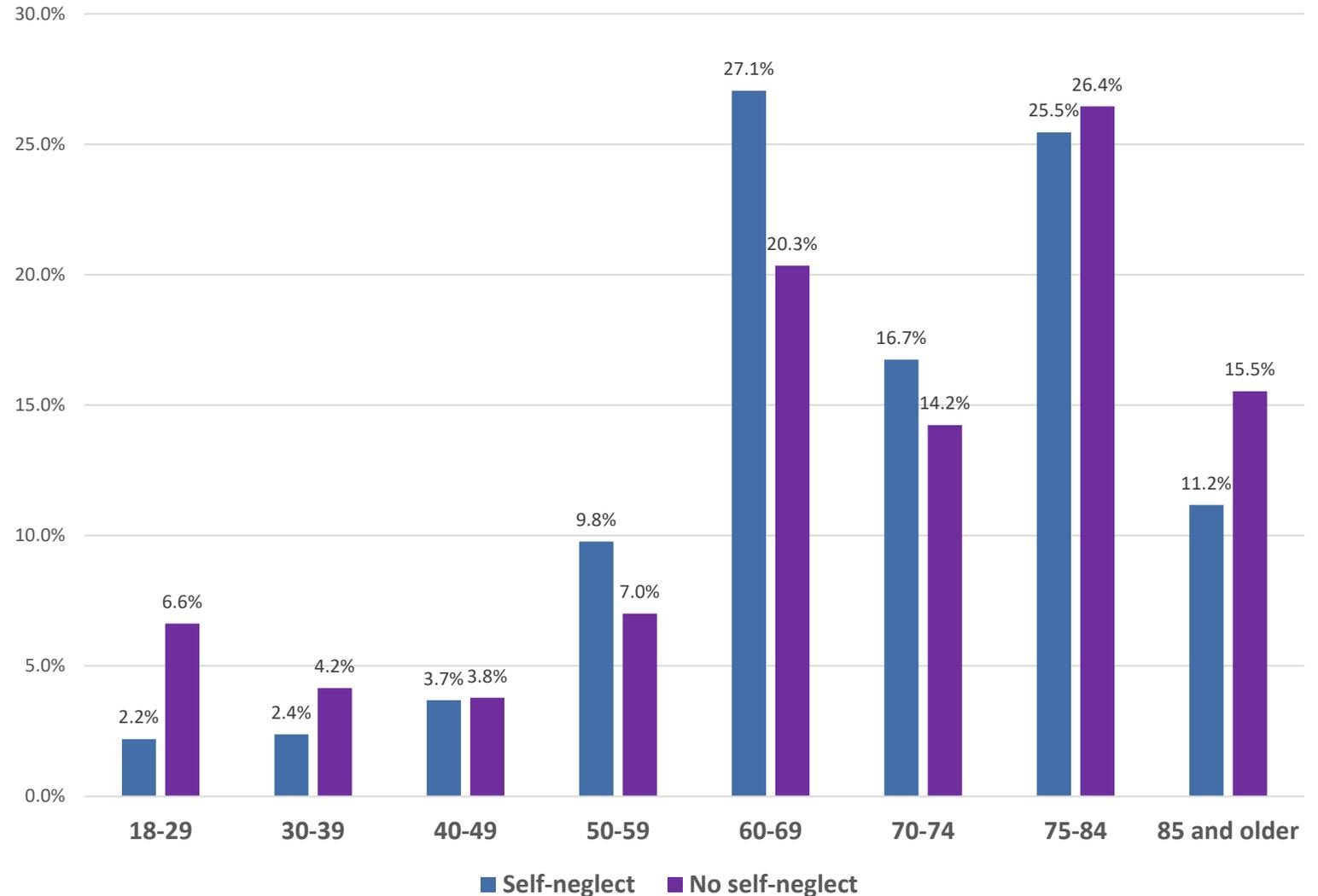


Across all age groups, age differences are minimal between persons experiencing self-neglect and other types of maltreatment.

Compared to other types of maltreatment, persons experiencing self-neglect is a higher percentage in ages 60 – 74 and a lower percentage in the 18 – 39 and 75 and older.

Notes: NAMRS 2022 CC, 33 states

Age Distribution of Persons Experiencing Self-Neglect

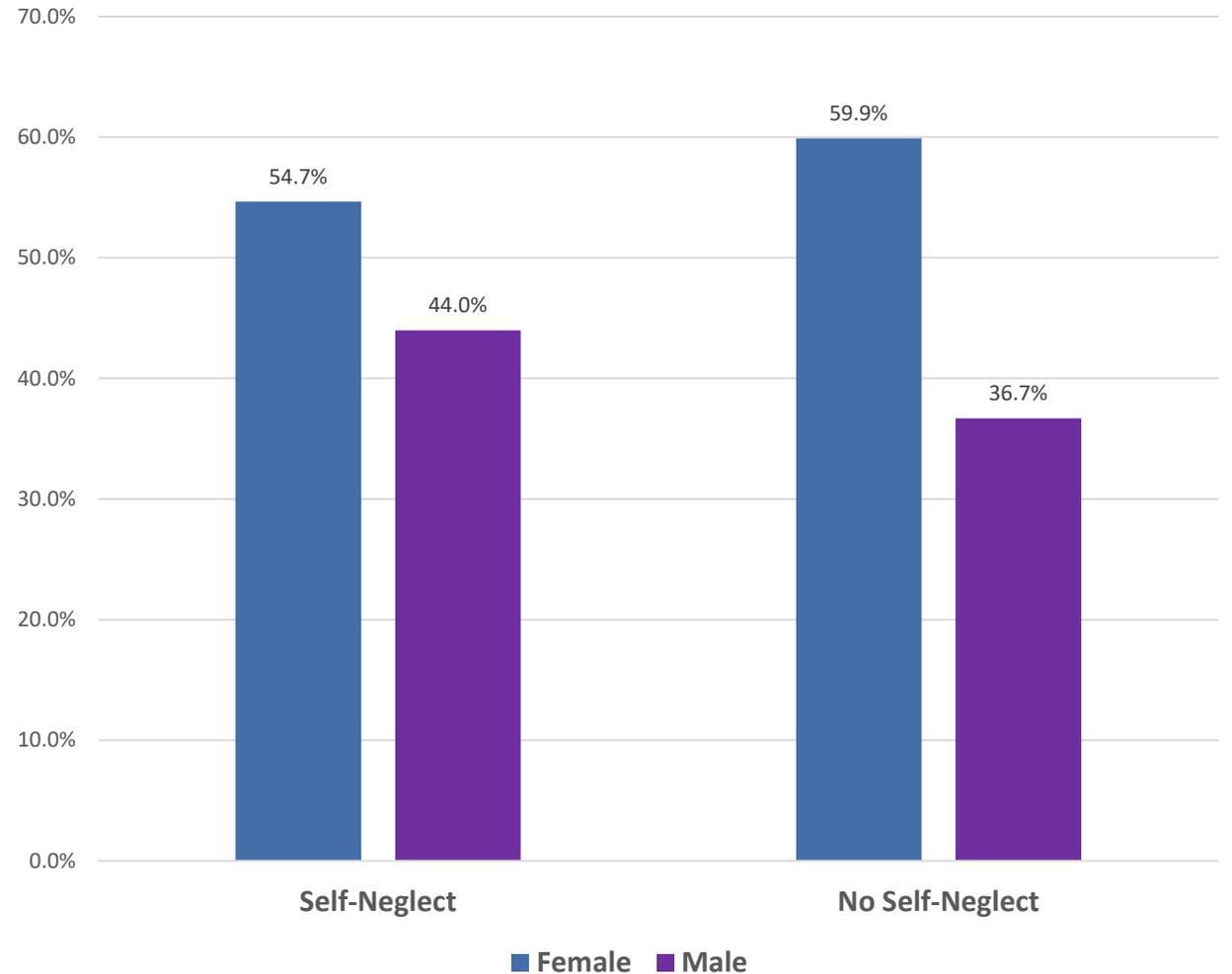


Overall, females are a higher percentage than males in both persons experiencing self-neglect and other types of maltreatment.

Males experiencing self-neglect are higher percentage than males experiencing other types of maltreatment.

Notes: NAMRS 2022 CC, 33 states.

Gender of Persons Experiencing Self-Neglect



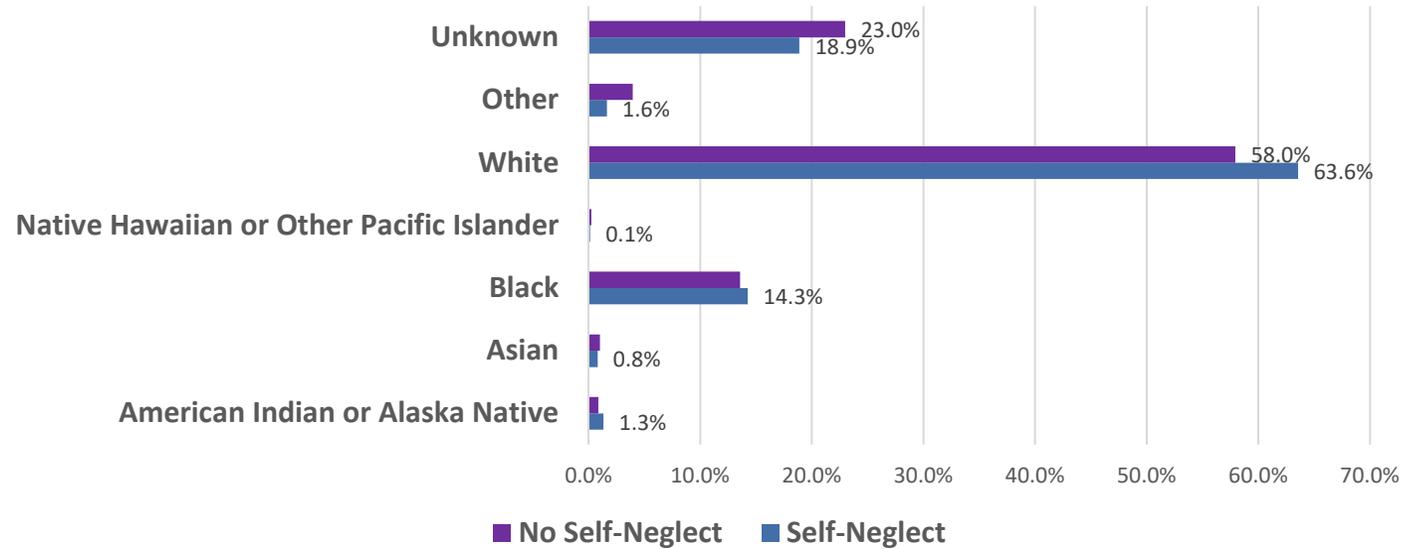
Whites are a slightly higher percentage of persons experiencing self-neglect than persons experiencing other types of maltreatment.

Blacks are a slightly lower percentage of persons experiencing self-neglect than persons experiencing other types of maltreatment.

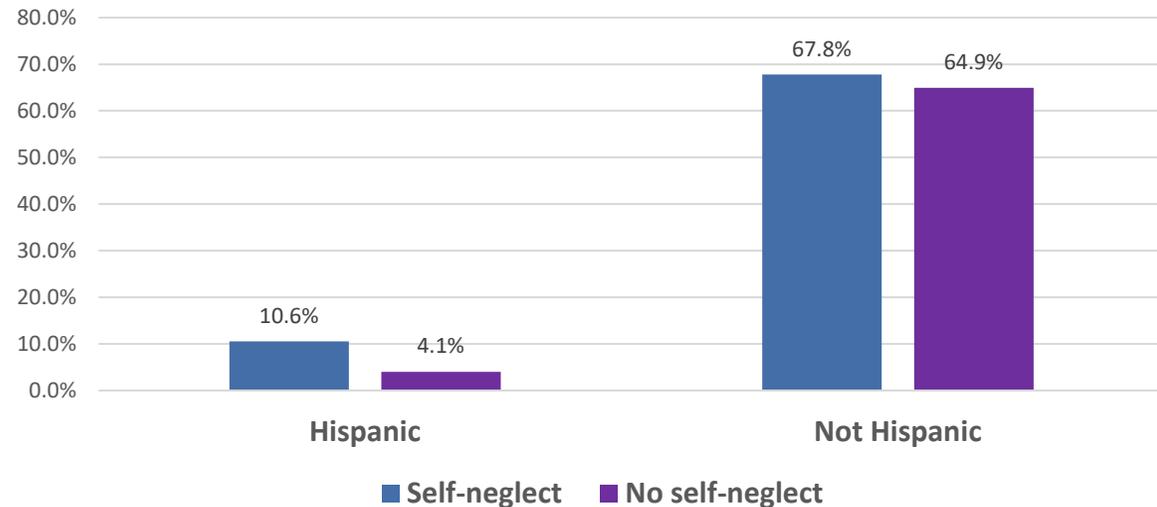
Both Hispanics and non-Hispanics are a slightly higher percentage of persons experiencing self-neglect than persons experiencing other types of maltreatment.

Notes: NAMRS 2022 CC, 31 states

Race of Persons Experiencing Self-Neglect



Ethnicity of Persons Experiencing Self-Neglect

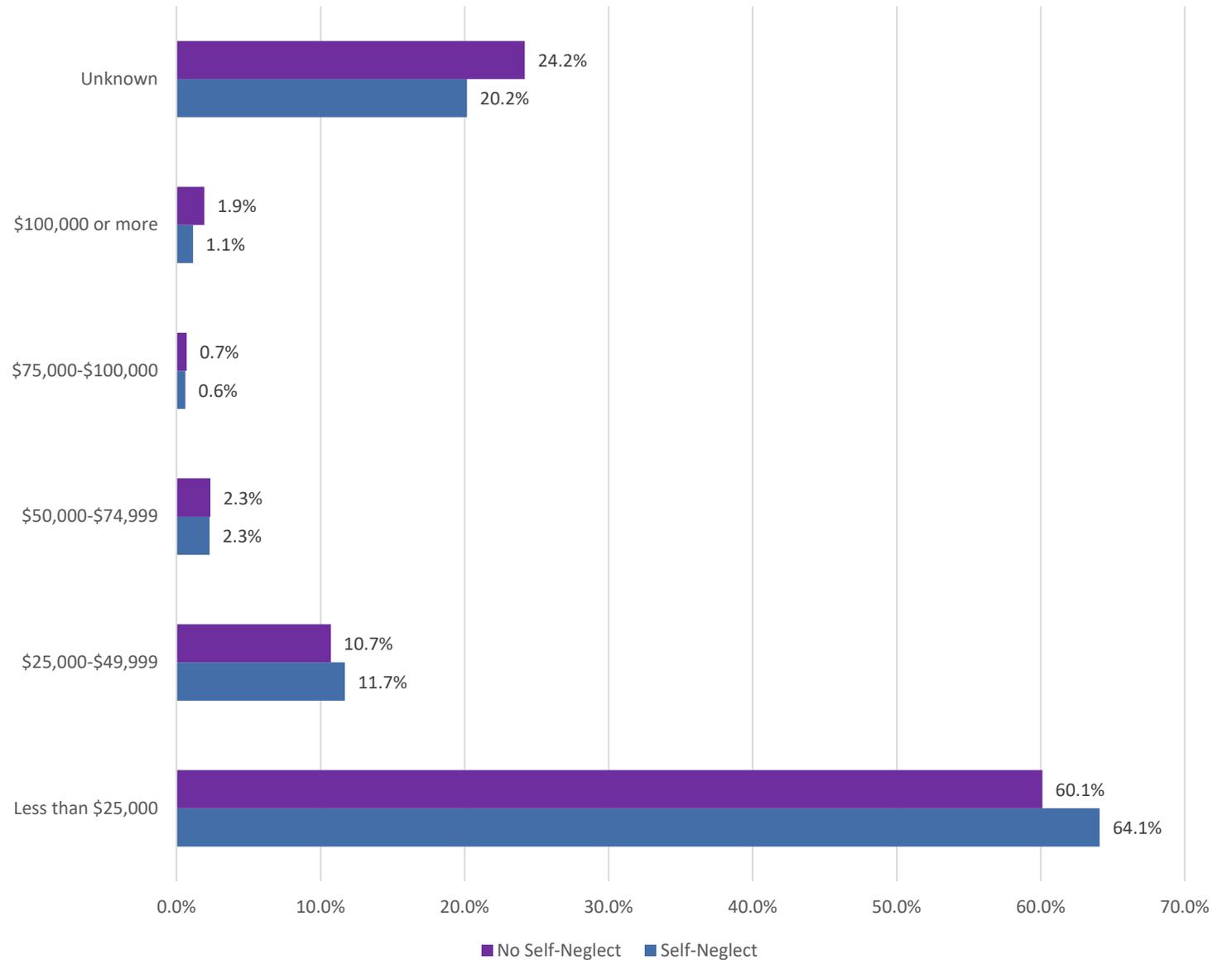


A high percentage of APS clients are low income.

Persons experiencing self-neglect have less income compared persons experiencing other types of maltreatment.

Notes: NAMRS CC 2022, 15 states.

Income of Persons Experiencing Self-Neglect



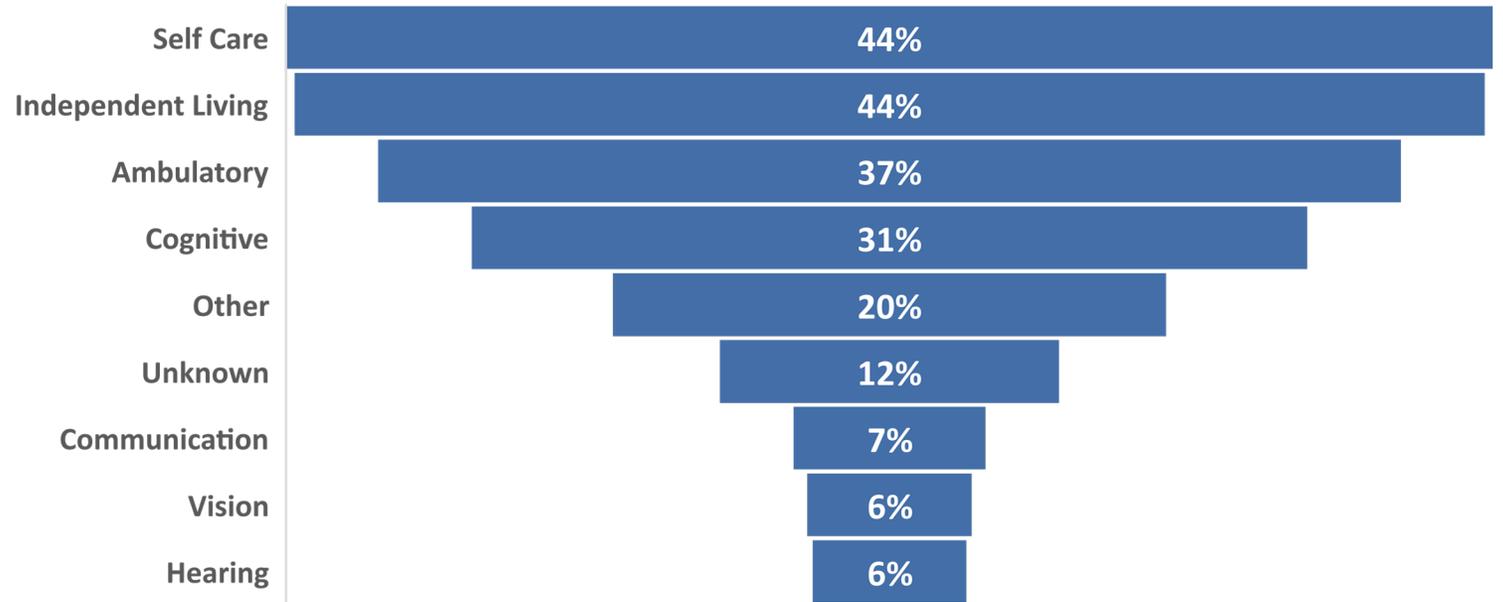
The most frequent types of disability of persons experiencing self-neglect are (in order) self care, independent living, ambulatory, and cognitive.

Overall, 80% of persons experiencing self-neglect have one or more disabilities; 51% have 2 or more.

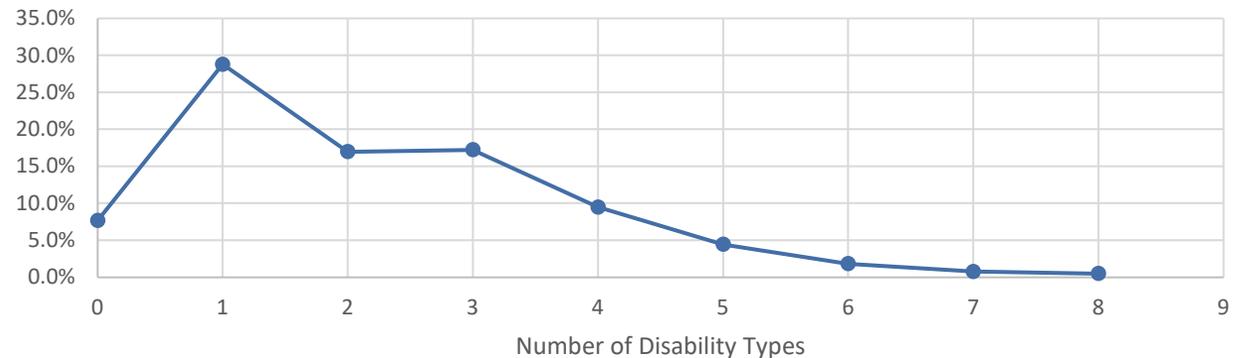
The average person experiencing self-neglect has 2.22 disabilities compared to 2.04 for other types of maltreatment.

Notes: NAMRS 2022 CC, 18 states, excludes Texas

Type of Disability of Persons Experiencing Self-Neglect



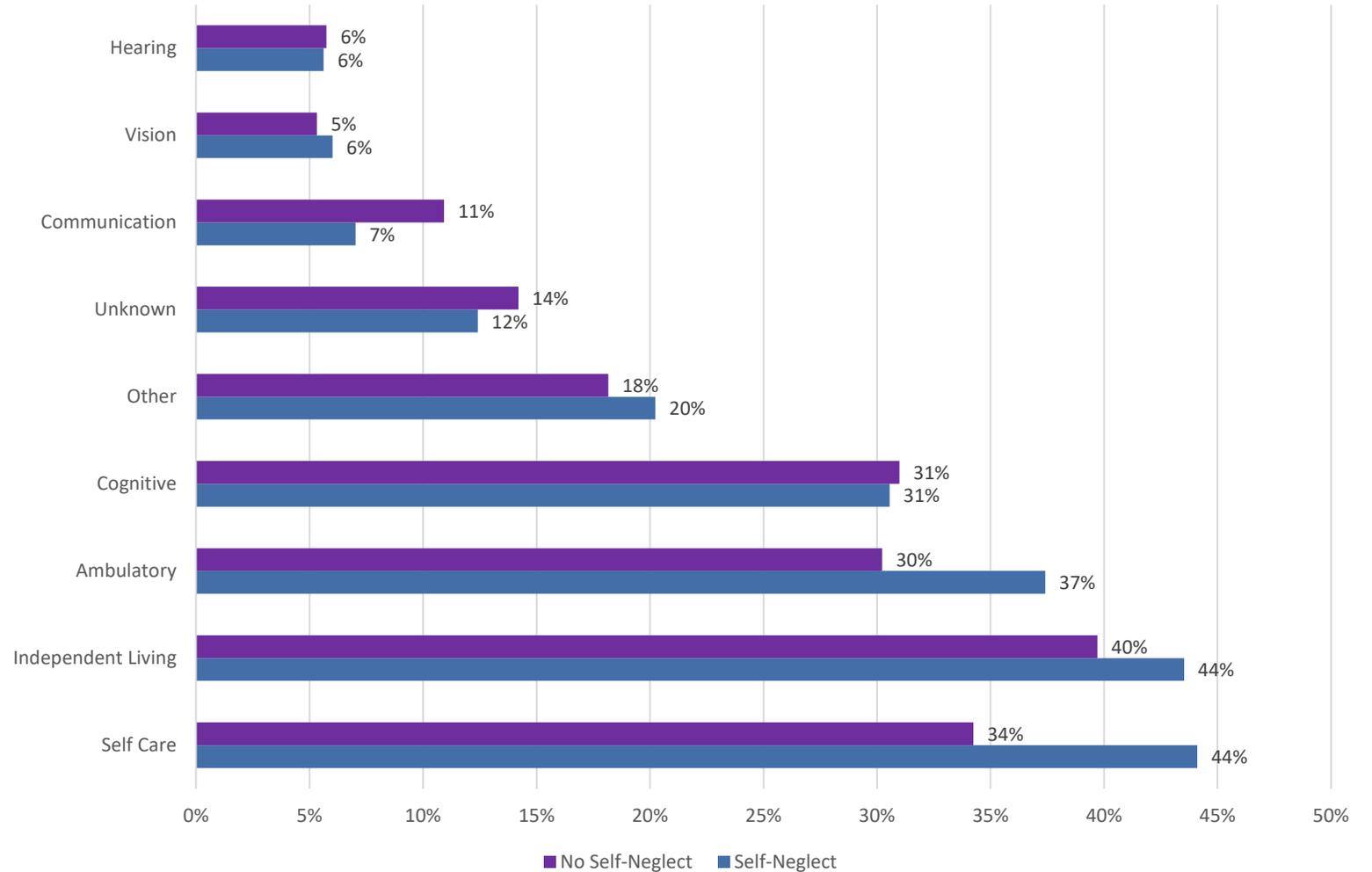
Number of Disability Types of Persons Experiencing Self-Neglect



Compared to persons experiencing other types of maltreatment, persons experiencing self-neglect have higher percentages in self-care, independent living, and ambulatory disability categories.

Notes: NAMRS 2022 CC, 18 states, excludes Texas.

Disability of Persons Experiencing Self-Neglect Comparison



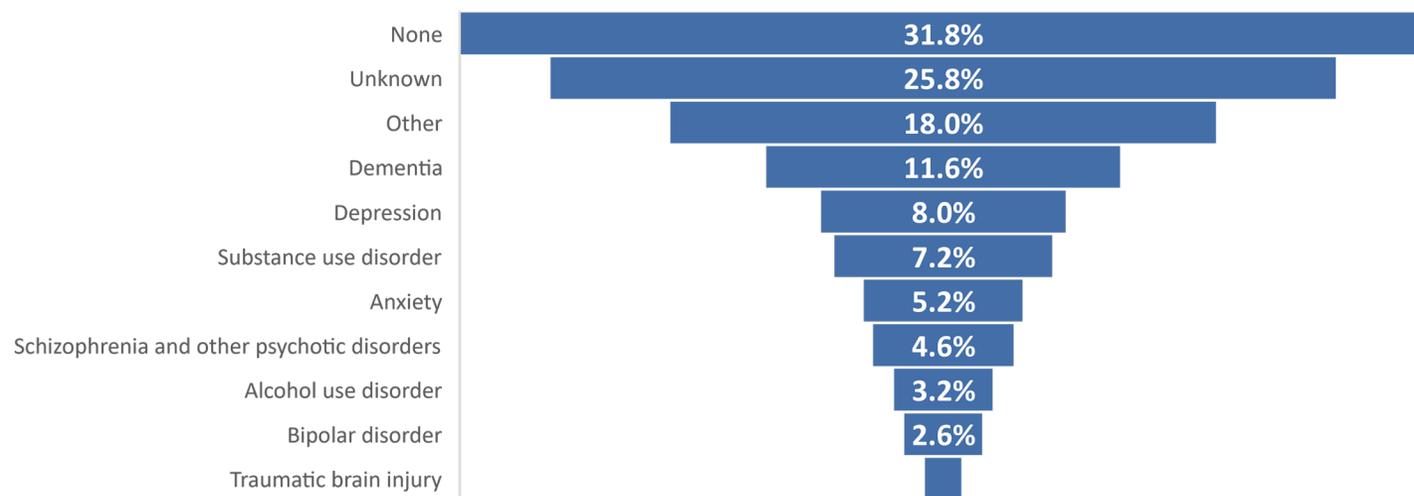
The most frequent behavioral health conditions (“**diagnosed** mental health disorders”) of persons experiencing self-neglect are (in order) dementia, depression, substance use disorder.

Overall, 42% of persons experiencing self-neglect have one or more behavioral health conditions.

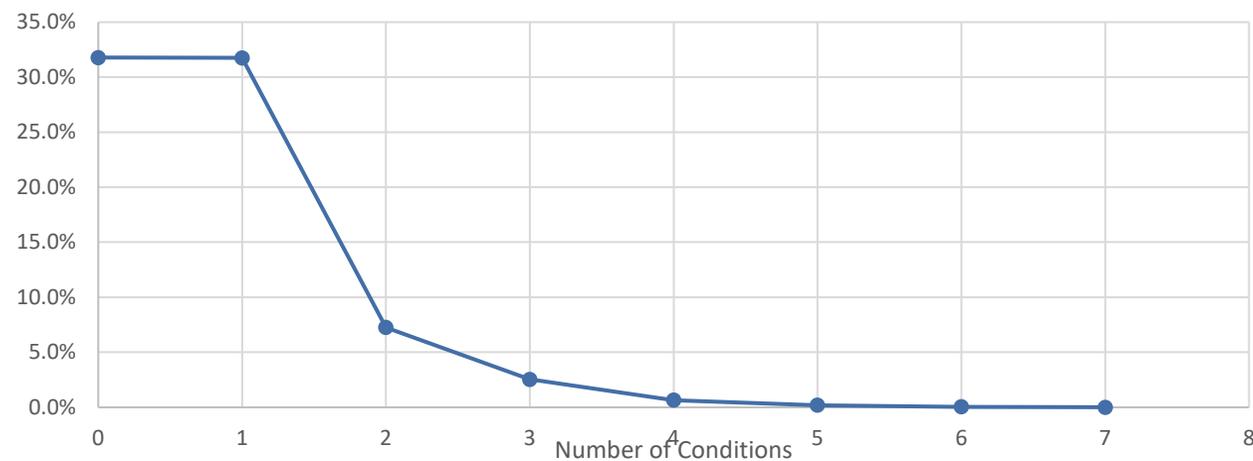
Most persons experiencing self-neglect have zero or one behavioral health conditions.

Notes: NAMRS 2022 CC, 14 states; excludes Texas. Victim may receive more than one service.

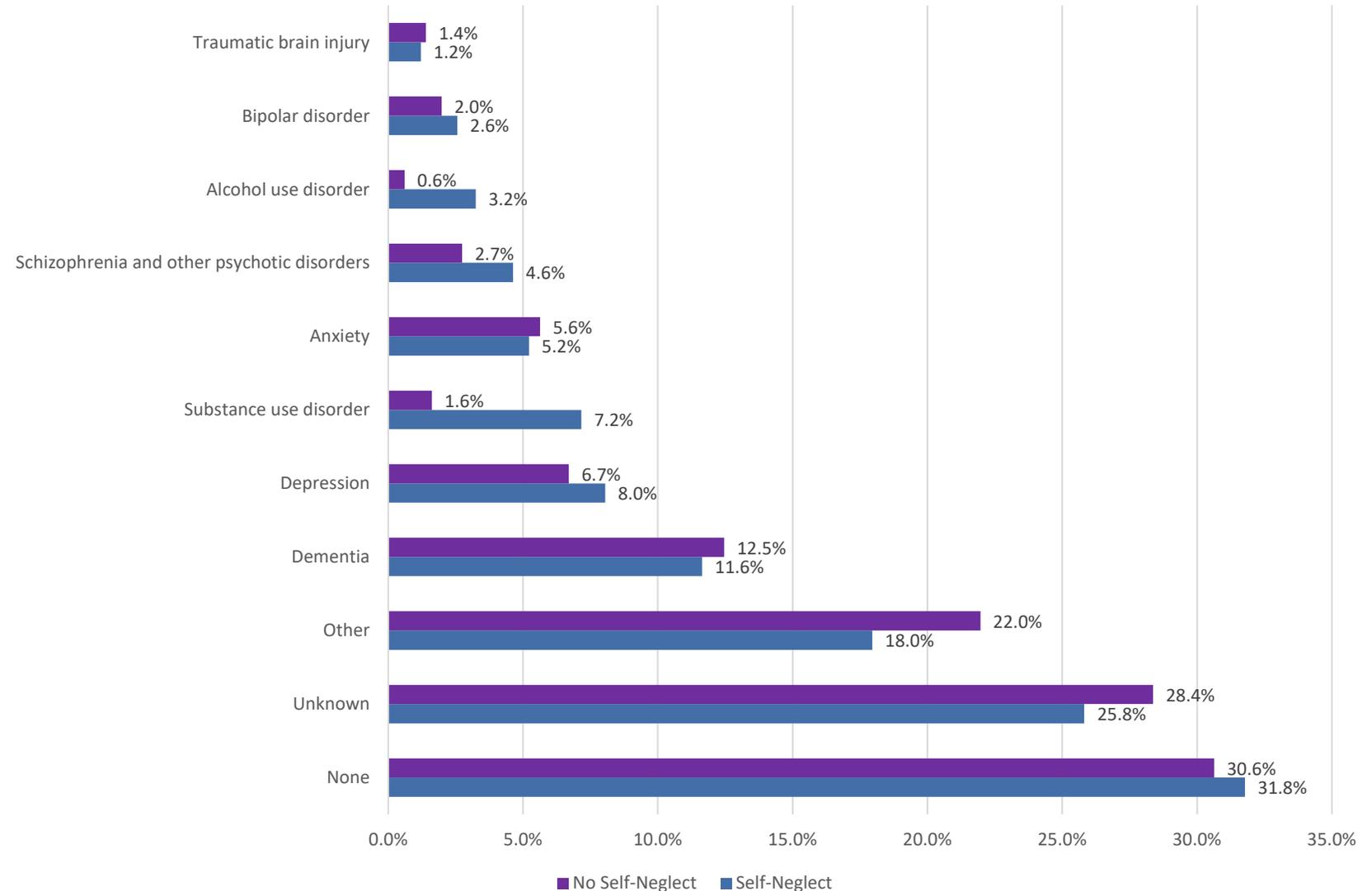
Behavioral Health Conditions of Persons Experiencing Self-Neglect



Number of Behavioral Health Conditions of Persons Experiencing Self-Neglect



Behavioral Health Conditions of Persons Experiencing Self-Neglect Comparison



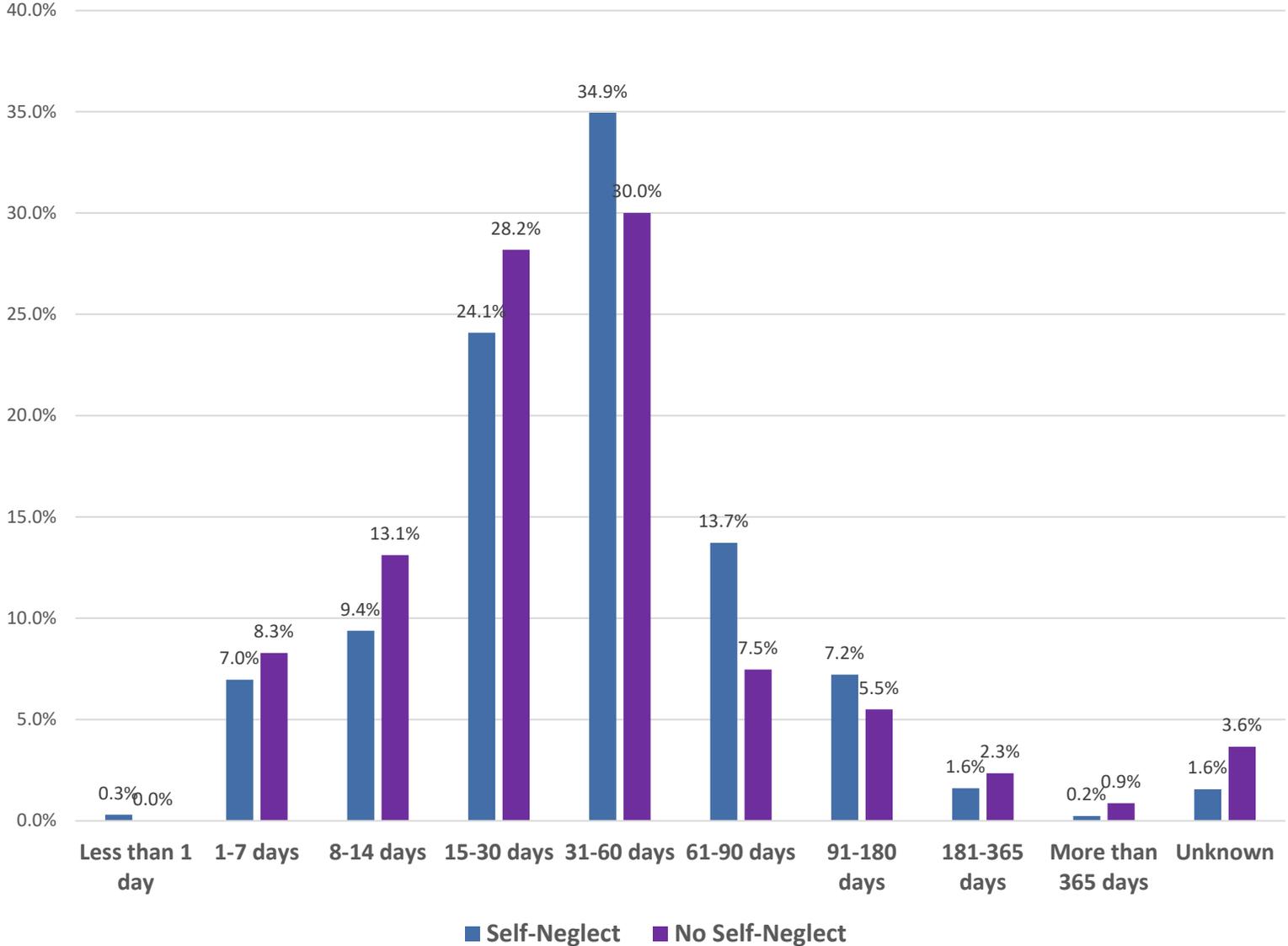
Compared to persons experiencing other types of maltreatment, persons experiencing self-neglect have higher percentages in bipolar disorder, alcohol use disorder, schizophrenia, substance use disorder, and depression categories.

Notes: NAMRS 2022 CC, 18 states, excludes Texas

Length of Investigation Duration of Persons Experiencing Self-Neglect

Compared to persons experiencing other types of maltreatment, persons experiencing self-neglect have longer investigation durations.

Notes: NAMRS 2022 CC, 30 states.

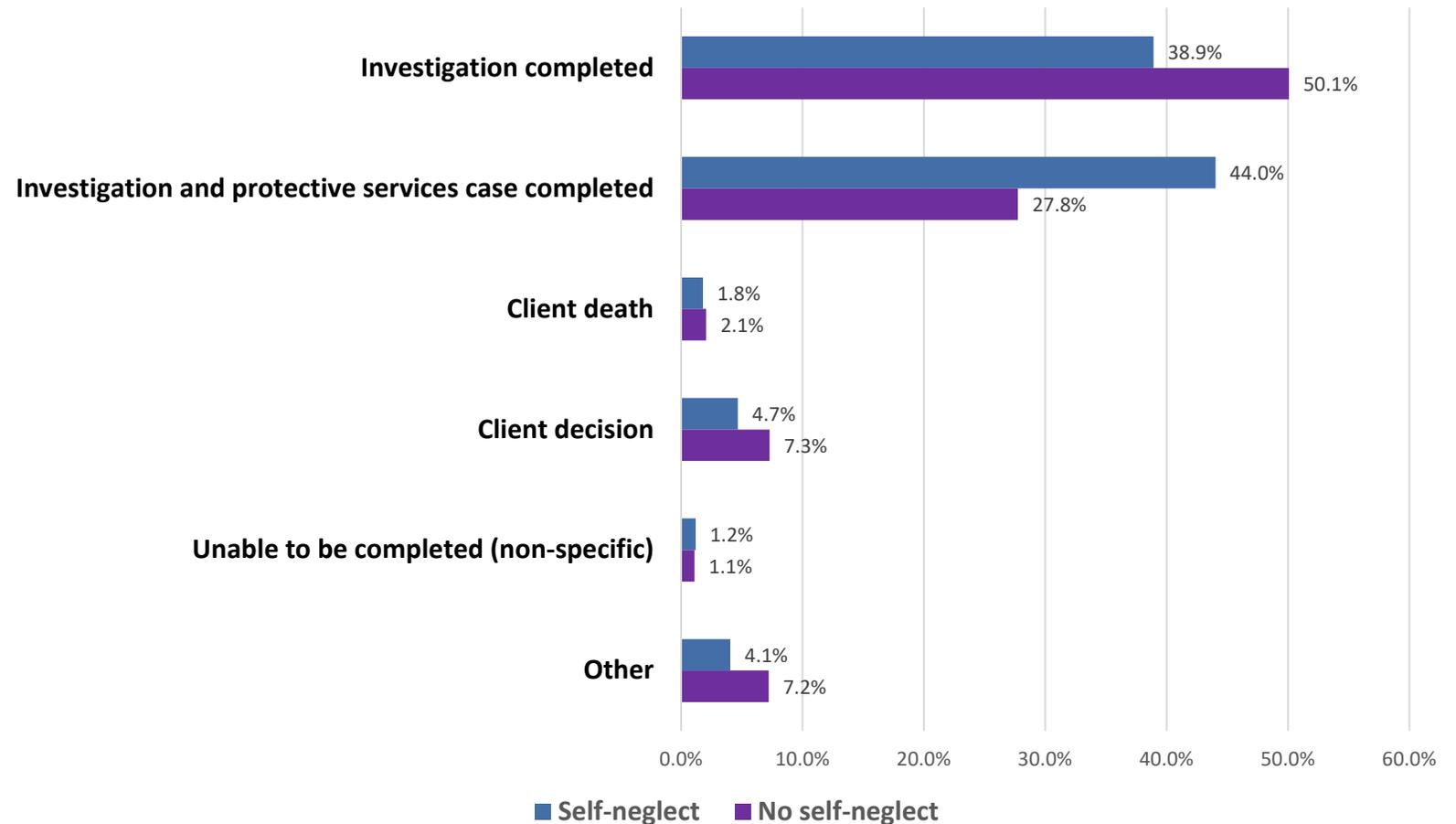


A higher percentage of persons experiencing self-neglect receive services compared to persons experiencing other types of maltreatment.

Persons experiencing maltreatment other than self-neglect are more likely to make the decision (usually by not cooperating) to close the case than persons experiencing self-neglect.

Notes: NAMRS 2022 CC, 25 states.

Case Closure Reason of Persons Experiencing Self-Neglect

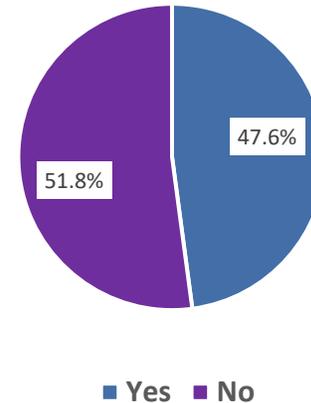


Slightly over half of persons experiencing self-neglect have a previous case.

Persons experiencing self-neglect have a slightly higher rate of recurrence than persons experiencing other maltreatment types.

Notes: NAMRS 2022 CC, 21 states.

Previous Report of Persons Experiencing Self-Neglect



Previous Report Comparison

