



Not Silent: Demographics, Quality-of-Life Outcomes and Circumstances of Nonverbal Adults with ID/DD

June 24, 2014, AAIDD Annual
Meeting

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Agenda

Agenda

- Data source
- Methods, Measures and Sample
- Findings
- Limitations
- Policy Implications

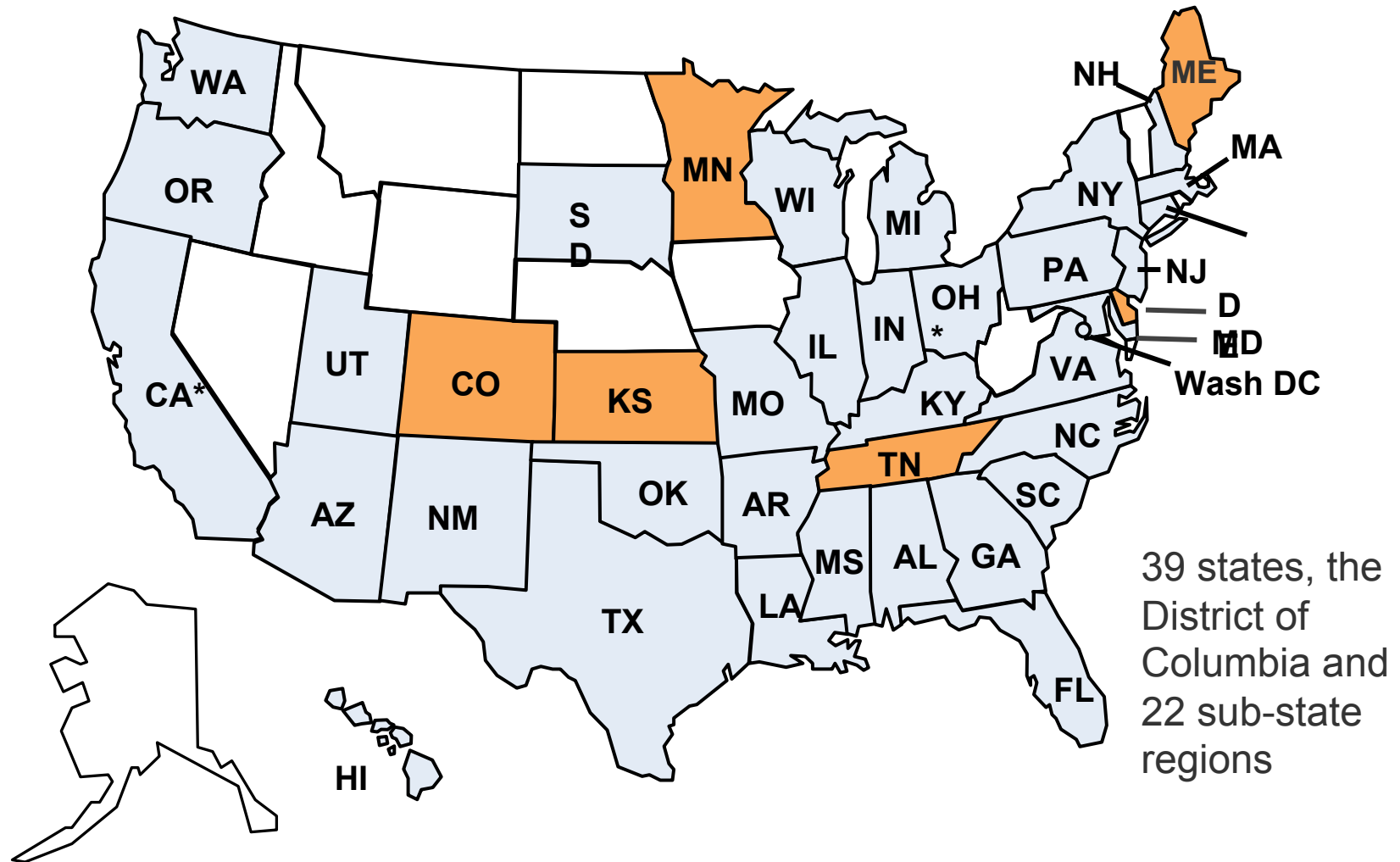


WHAT IS NATIONAL CORE INDICATORS (NCI)?

- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assesses performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 13 participating states
- Supported by participating states
- NASDDDS – HSRI Collaboration



NCI State Participation 2013-14



■ State contract awarded in 2013-14 through AIDD funding

CA*- Includes 21 Regional Centers

OH*- Also includes the Mid-East Ohio Regional Council



NCI Offers Unique View

- Person-centered
- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare



WHAT IS NCI?

- Adult Consumer Survey
 - ✓ In-person conversation with a sample of adults receiving services to gather information about their experiences
 - ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.
- Adult Family, Child Family, and Family/Guardian Surveys
Mail surveys – separate sample from Adult Consumer Survey
- Other NCI state level data: Staff Stability



NCI Design

- One overarching framework:
 - Training
 - Sampling
 - Technical assistance
 - Online data entry system (ODESA)
 - Analysis and reporting
 - Base surveys – but states can add own questions
- Valid and reliable:
 - Ongoing face and content validity evaluations
 - Revisions
 - Ongoing inter-rater reliability evaluations
 - Shadowing
 - Internal consistency
- Can be expanded to other populations



NCI-AD

- National Core Indicators – Aging and Disability
- Collaboration of HSRI, NASUAD, NASDDDS and state participating agencies
- In pilot stage – 3 states
- Older adults on waivers, older adults on OAA, younger adults with physical and other disabilities on waivers



NCI-AD

- Analysis and revision slated to take place in fall/winter 2014
- Roll-out in June 2015
- 15-18 participating states
- Yearly data collection cycle, to parallel NCI
- Would like to include people in SNFs
- Will provide data on LTSS regardless of funding source, residence, program
- Allow cross-agency and state-to-state comparisons



Goals of NCI-AD

- Document the effect of services on the day-to-day lives of the people who receive them
- Document the experience of program participants
- Manage service delivery and improve policy and practice
- Track key performance goals and outcomes
- Assess the impact of regulatory activities on individual experience
- Respond to the demands of consumers and families for information on system responsiveness
- Assess the impact of financial actions



- But, back to NCI.....



**What Do NCI Data Show Us About
Respondents Who Communicate
Verbally & Those Who Communicate
Nonverbally?
NCI 2012-13**

Why did we take a closer look at this population?

- The ability to communicate
 - adaptive skill
- People with ID/DD are often challenged by deficits in their ability to communicate.
 - can hamper independence
 - increase likelihood of challenging behaviors.
- Very little existing research into the population of individuals who communicate nonverbally
 - e.g. demographics, quality-of-life outcomes.
- Disadvantaged



Data Source: Adult Consumer Survey

- Standardized, face-to-face interview with a sample of individuals receiving services
- No pre-screening procedures → states don't filter anyone out of the sample.
- Conducted with adults only (18 and over) receiving at least one service in addition to case management
- Section I and Section II together take 50 minutes (on average)



Data Source: Adult Consumer Survey

- Background:
 - Collected from records
 - Demographic, personal and service characteristics
 - Employment, health care and wellness
- Section 1:
 - No proxies allowed
 - Satisfaction with work/home/staff/services, self-direction, safety, respect & privacy, relationships
- Section 2:
 - Proxies allowed
 - Community inclusion, choice, rights, access



Methods, Measures and Sample:

- **2012-2013** data collection cycle
- 25 states, one regional council
(AL, AR, CT, FL, GA, HI, IL, IN, KY, LA, MD, MO, MS, NC, NH, NJ, NY, OH, OR, PA, SC, TX, UT, VA, WI and the Mid-East Ohio Regional Council)
- Total N: 13,157 individuals



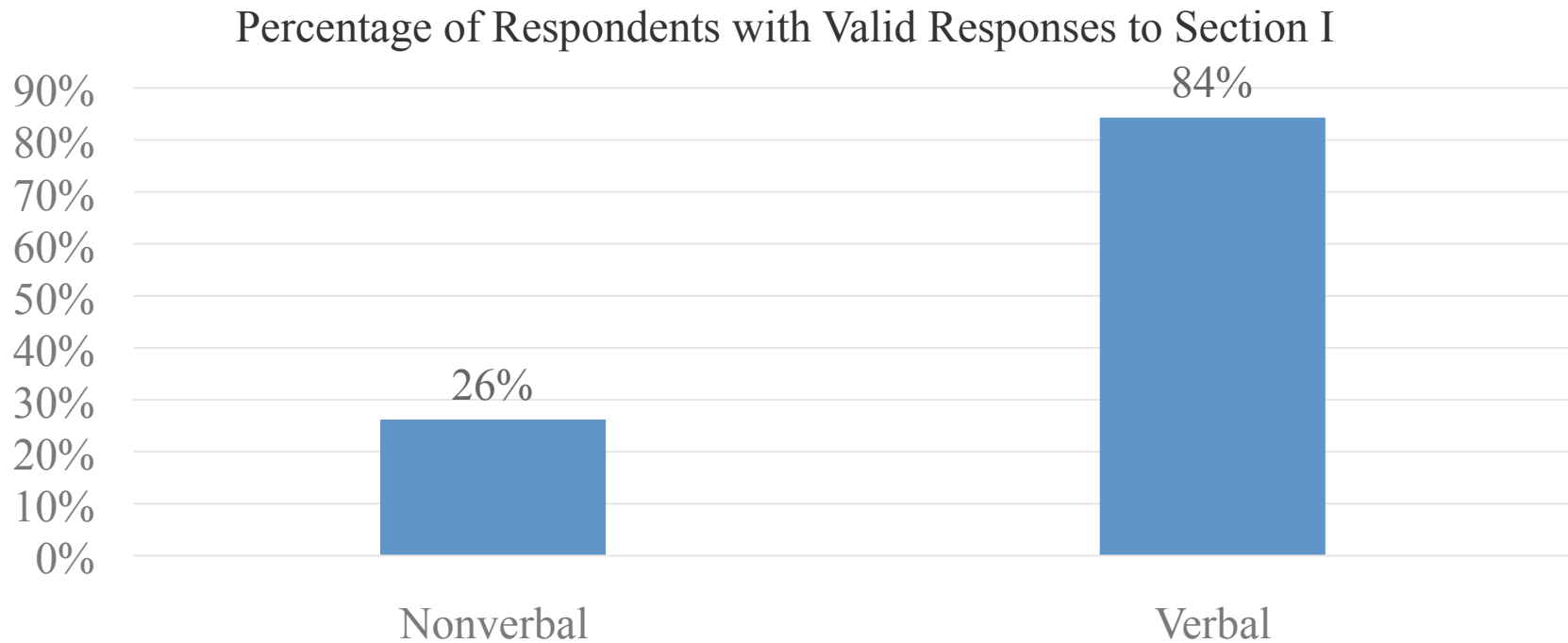
Methods, Measures and Sample:

- Source: Background Section
 - Question: What is this person's primary means of expression?
 - ___ 1 Spoken
 - ___ 2 Gestures/body language
 - ___ 3 Sign language or finger spelling
 - ___ 4 Communication aid/device
 - ___ 5 Other
- Included in sample:
 - Cases for which a response to this question was provided
 - Final sample size: 12,949 Individuals
- Items combined to create dichotomous variable
 - Verbal/Nonverbal



Respondents to the ACS

- Section I of the ACS → ONLY individual receiving services
- Section II of ACS → proxy allowed



26.2% of nonverbal had valid responses to Section I
84.3% of verbal had valid responses to Section I



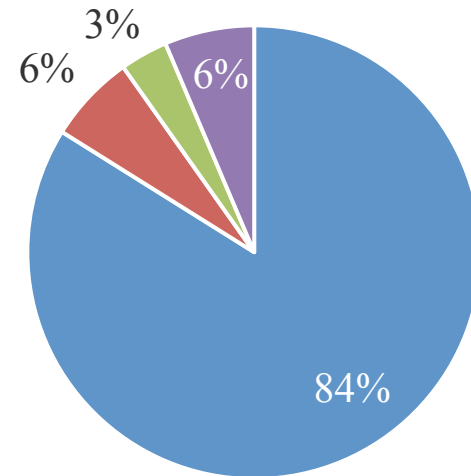
FINDINGS



Sample

Primary means of communication	Percent of total
Communicate verbally	76 %
Communicate nonverbally	24%
<i>Total (N=12,949)</i>	<i>100 %</i>

Of those who communicate nonverbally.....



- Gestures/Body language
- Sign language/Finger spelling
- Communication aid/Device
- Other

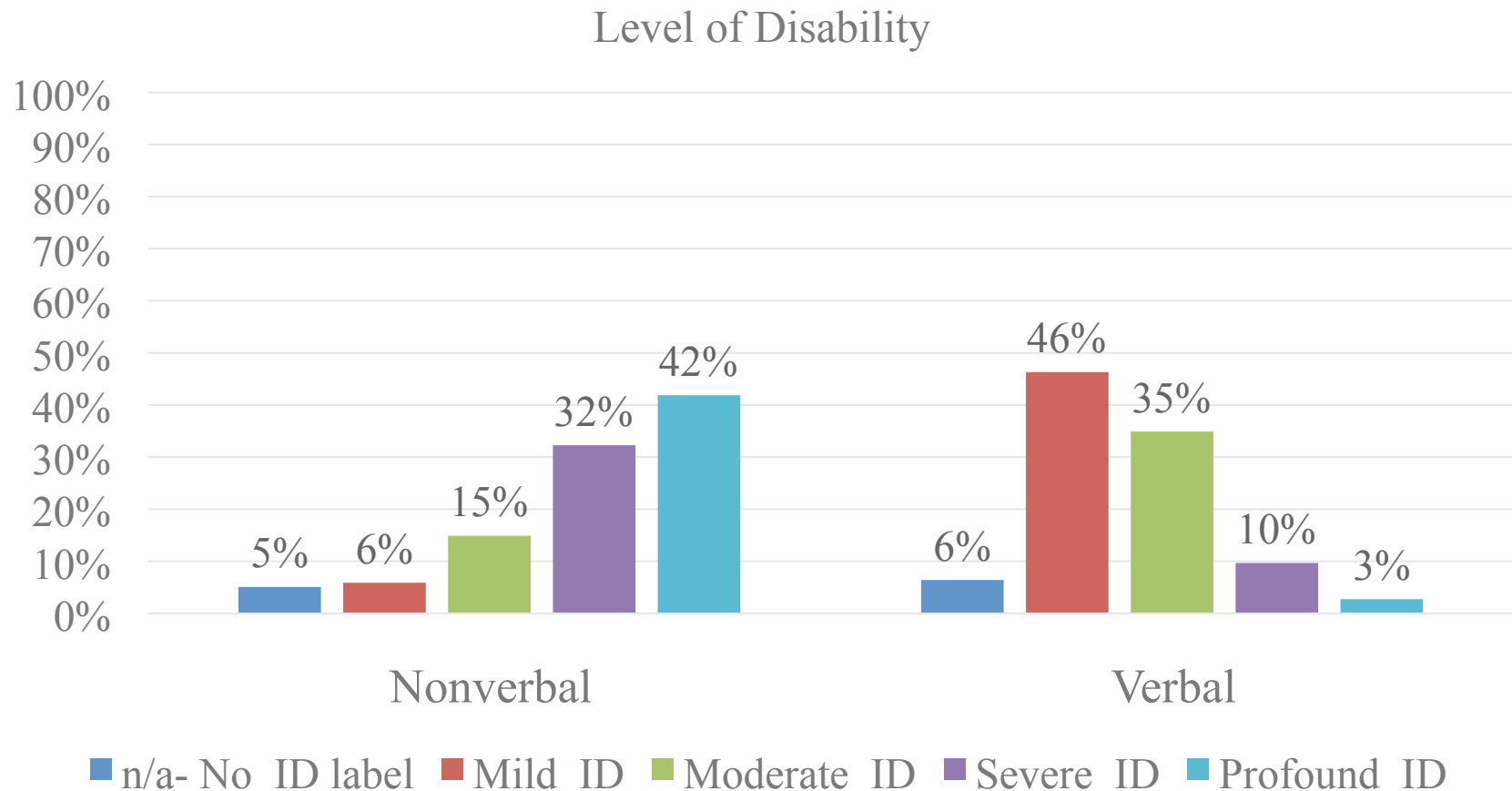


Finding

- Individuals who communicate verbally and those who communicate nonverbally differ significantly in various demographic characteristics.

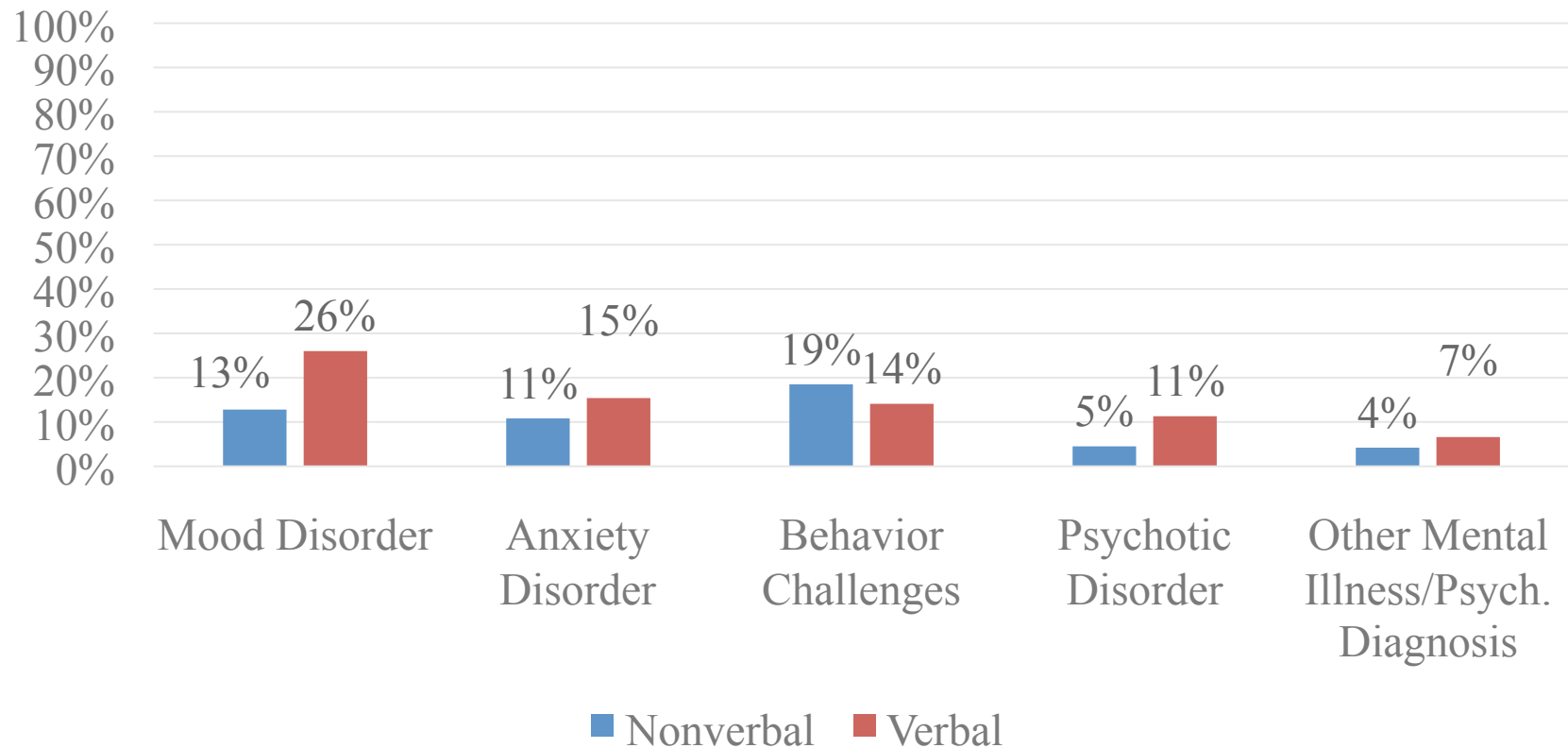


Demographics:



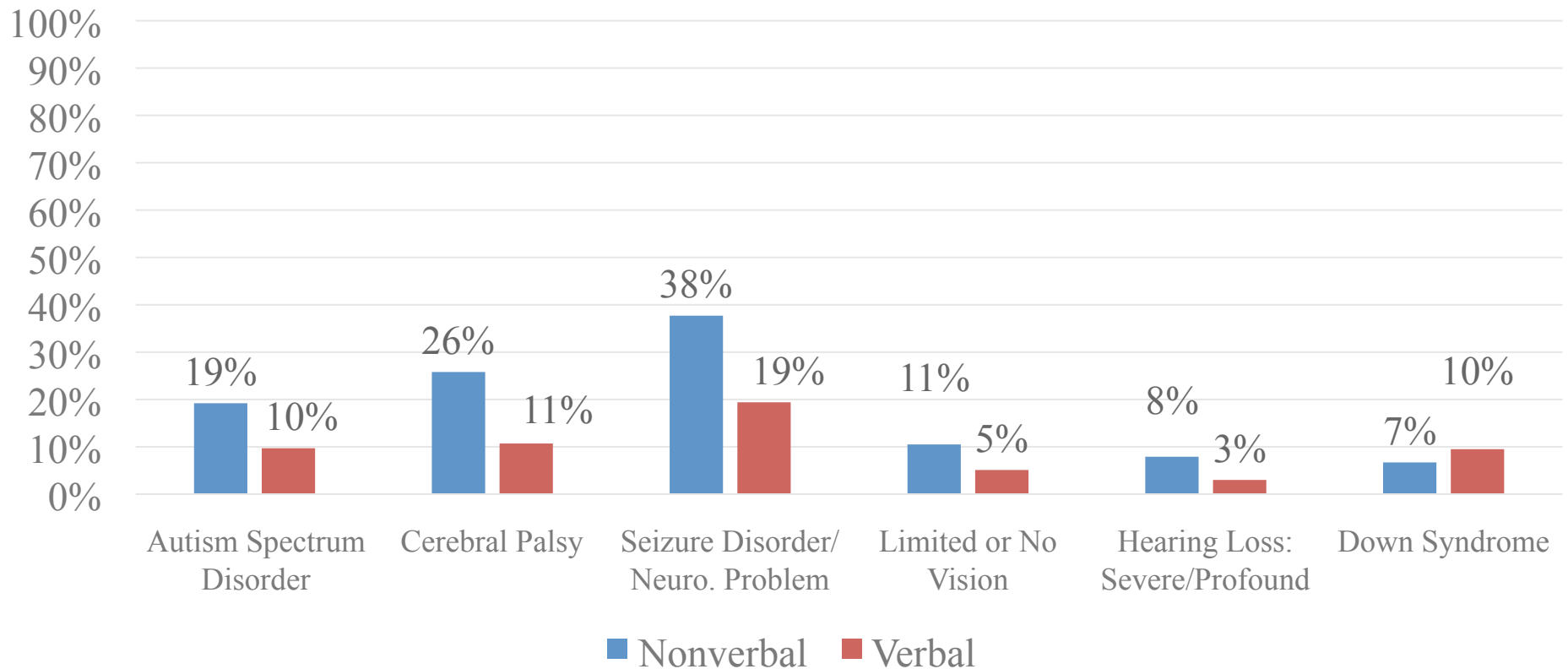
Demographics:

Other Diagnoses

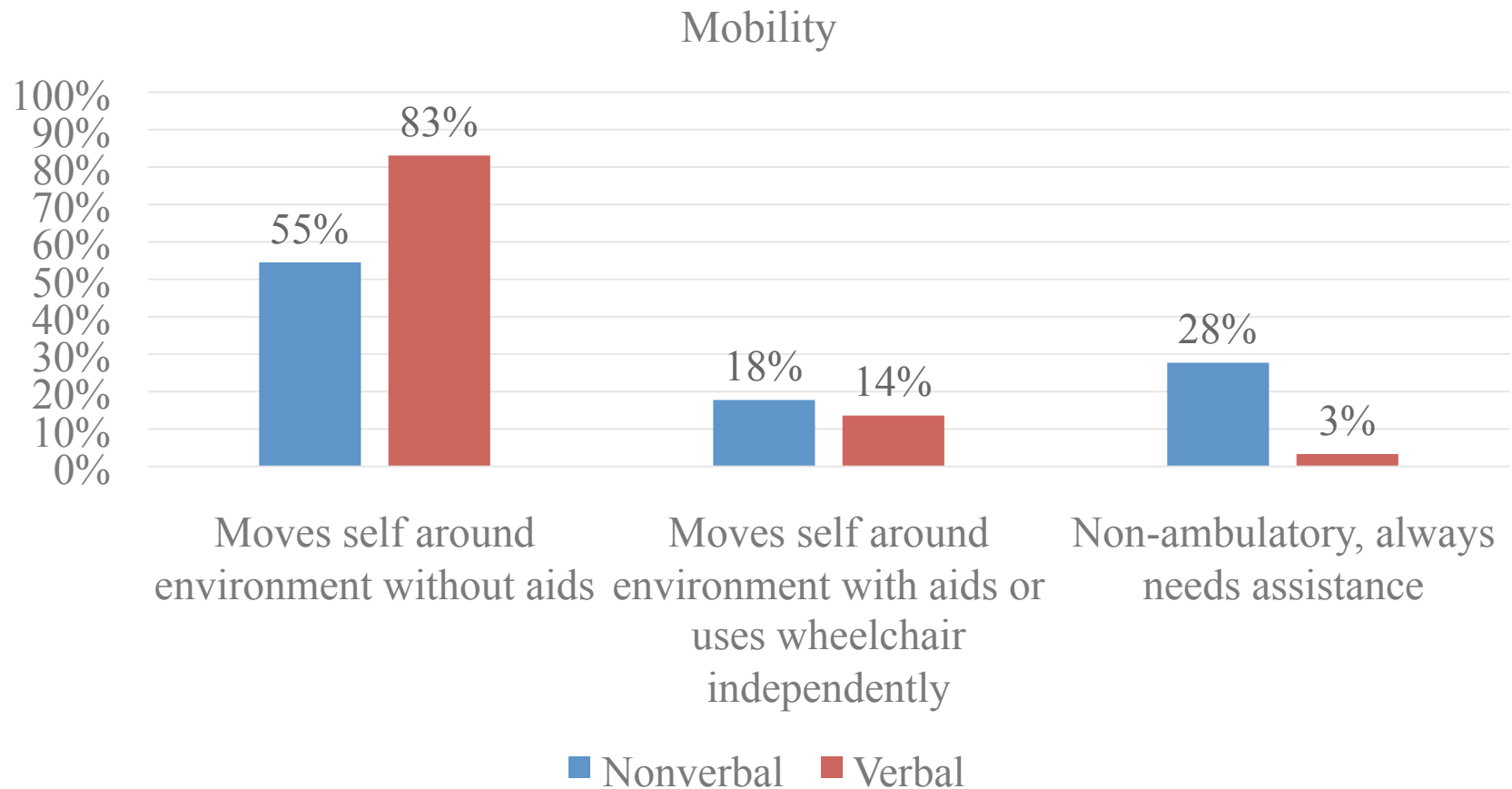


Demographics:

Other Diagnoses

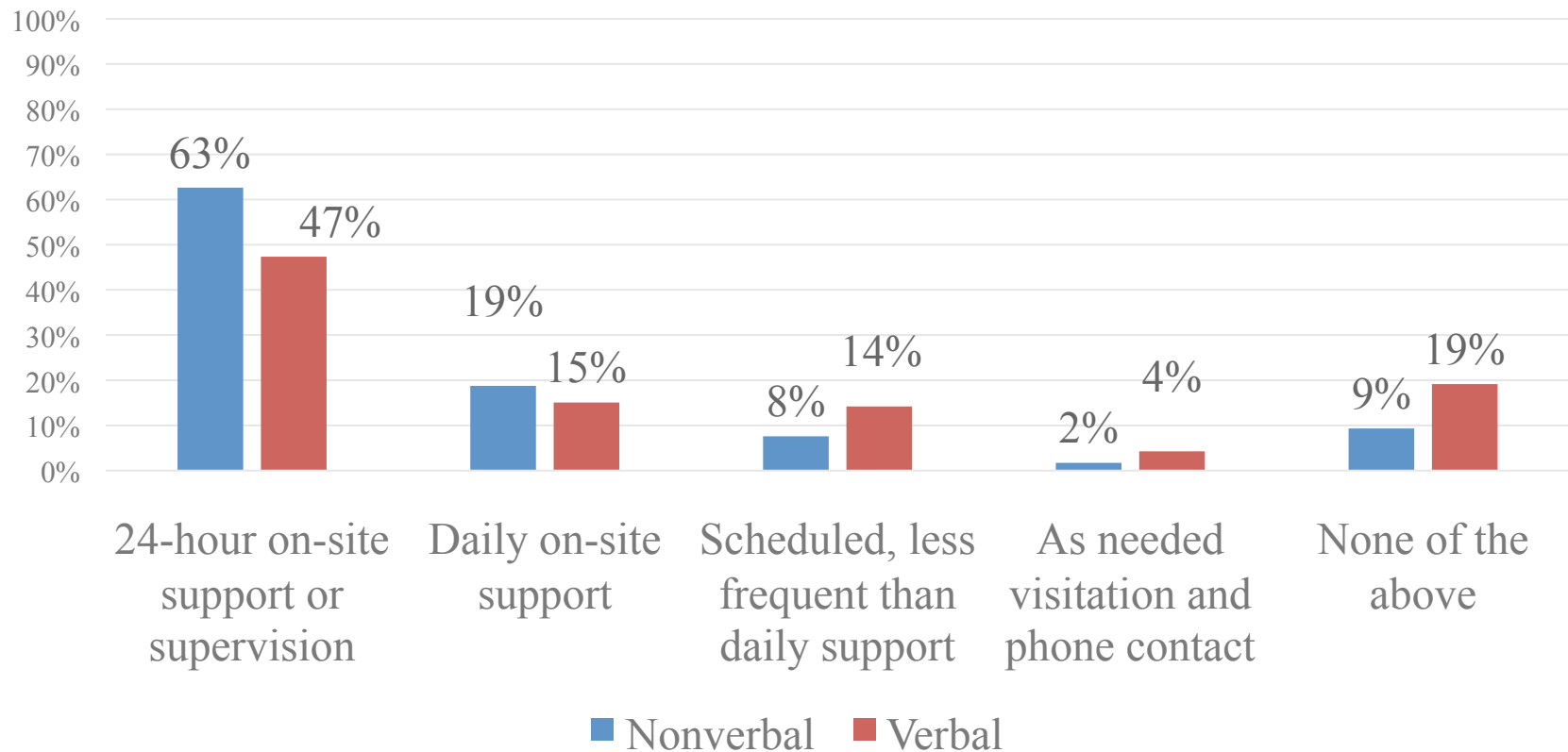


Demographics:



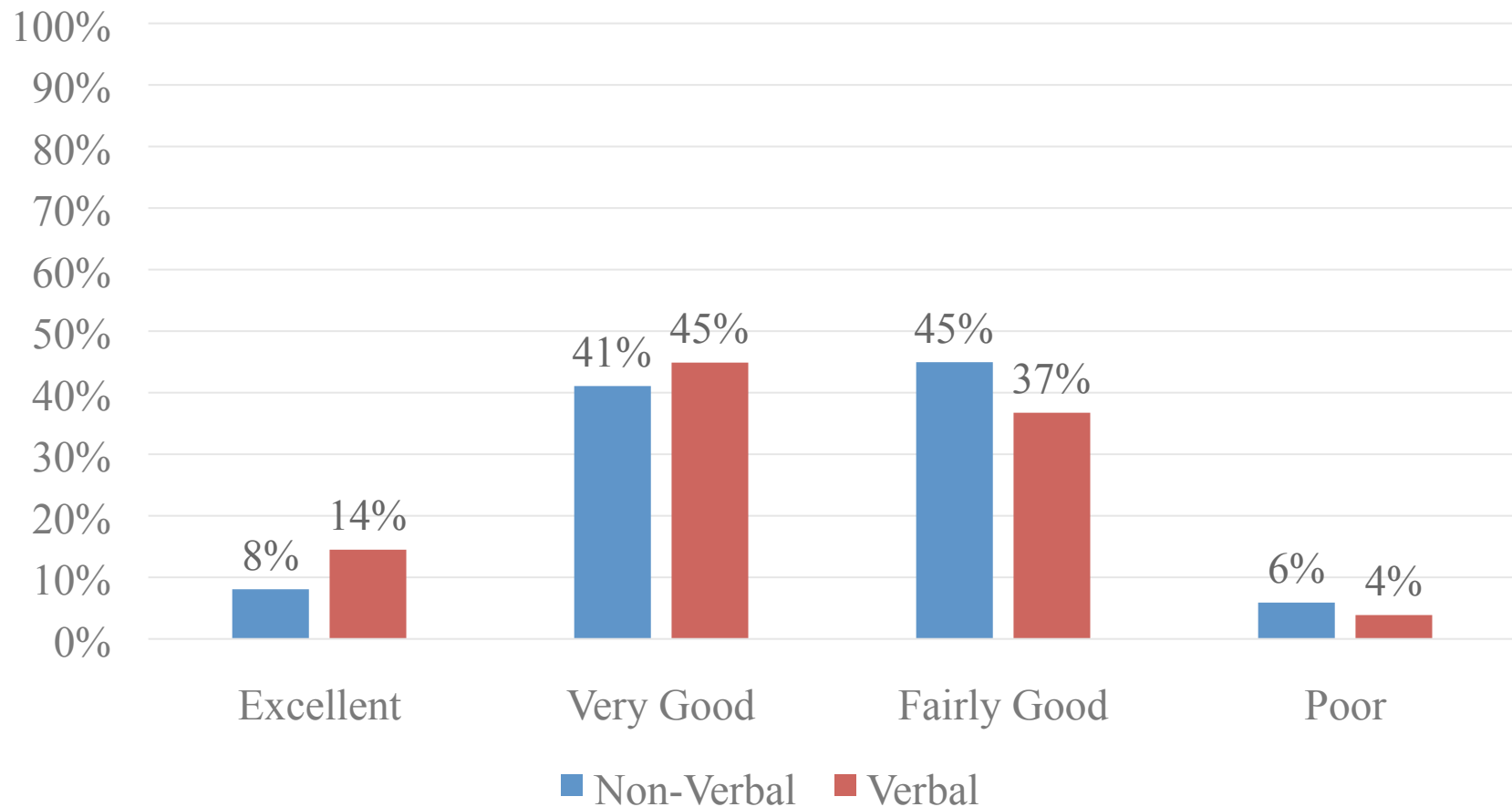
Demographics:

Amount of Staff Support Needed

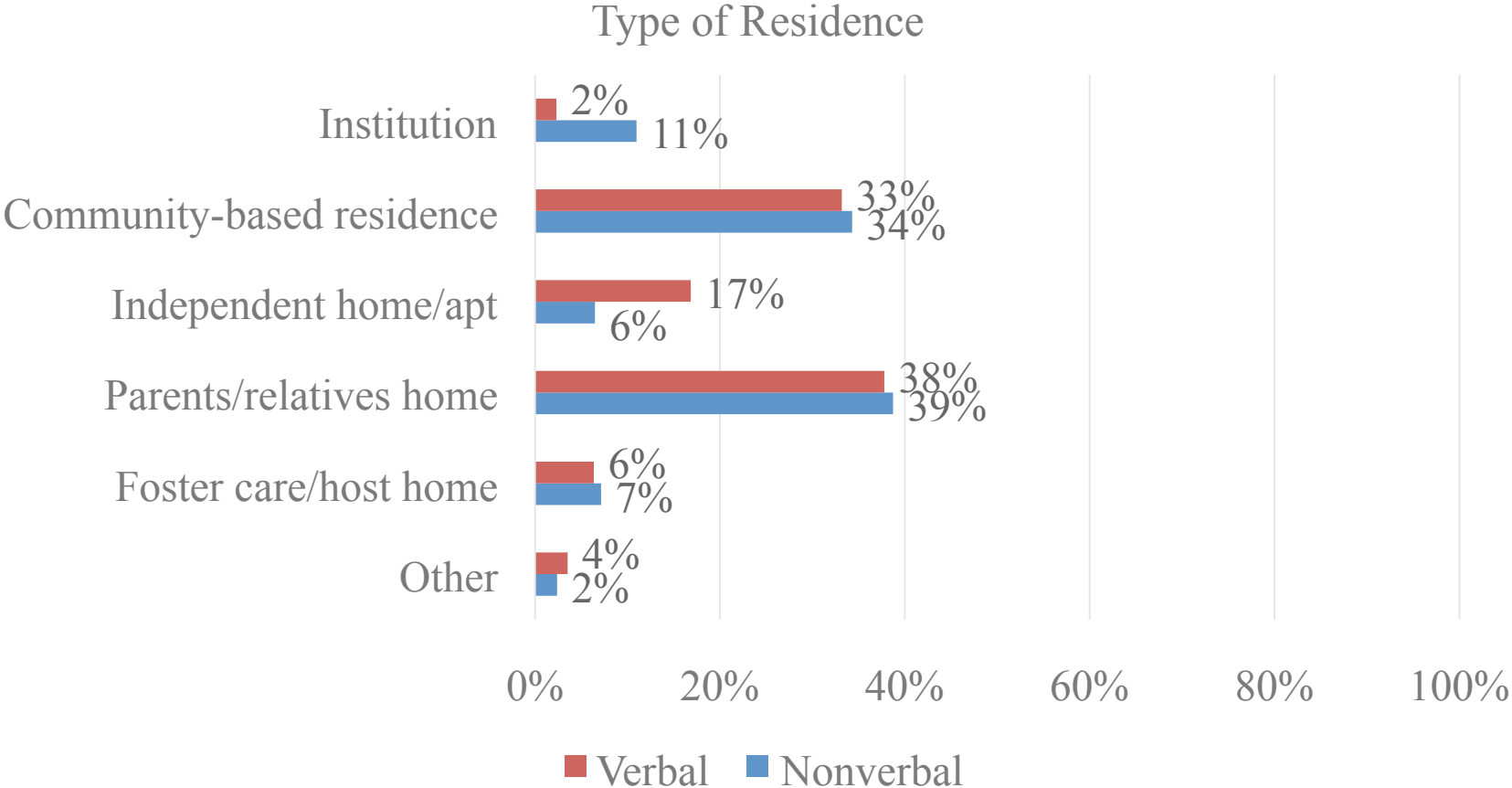


Health:

Reported Health Status

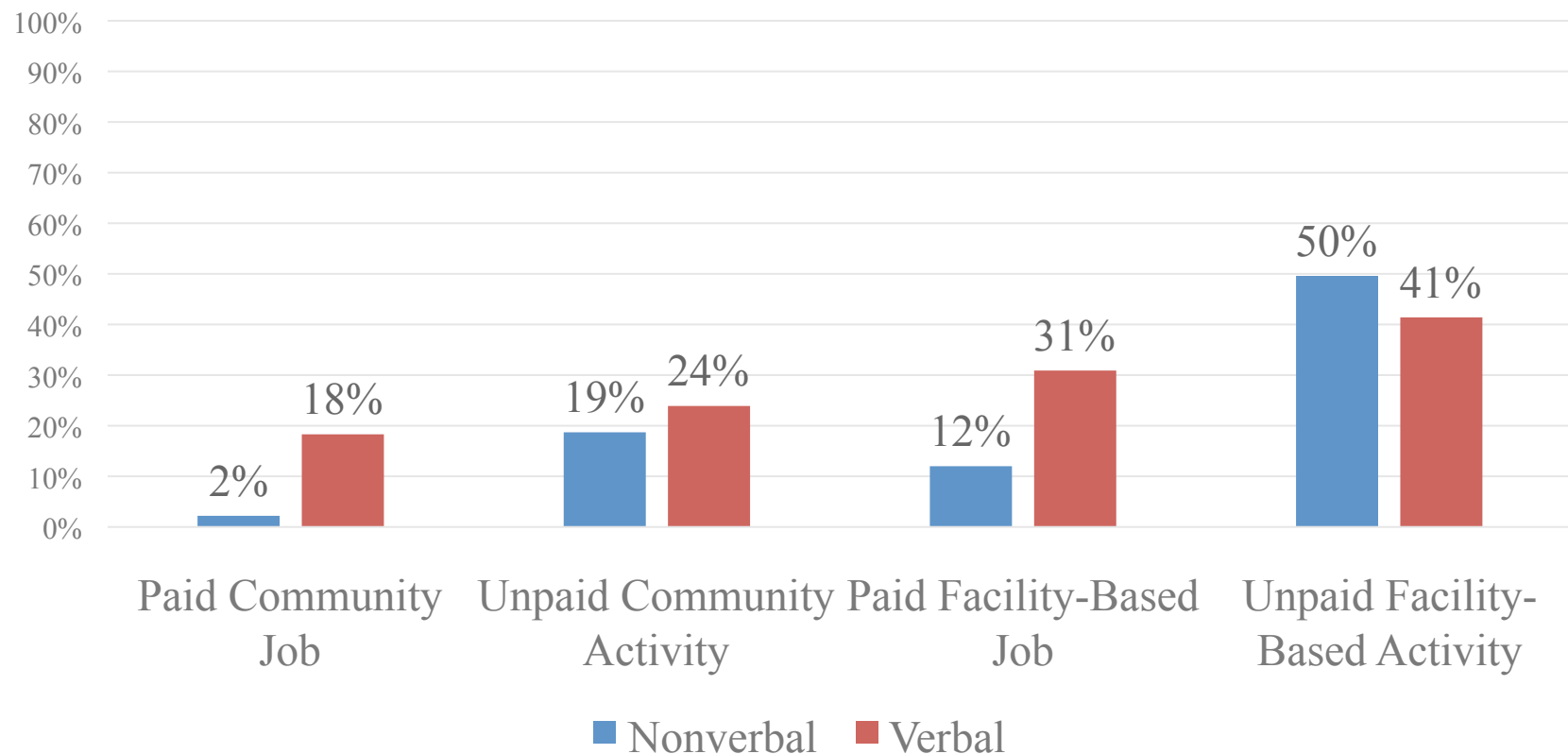


Home:



Work/Day Activity:

Participated in Work/Day Activity in Past Two Weeks



Finding

- Individuals who communicate verbally and those who communicate nonverbally also differ significantly in various outcomes



Finding: Outcomes

- Relationships:
 - Non-verbal sig. less likely to have friends other than family or staff or best friends
- Community Inclusion:
 - Non-verbal sig. less likely to have participated in specific activities in the community in the past month
- Rights and Respect:
 - Non-verbal sig. more likely to have their mail opened without permission and to not be able to use phone/or internet without restrictions



Finding: Outcomes

- Choice:
 - Non-verbal sig. less likely to have chosen or had input in choosing:
 - Home
 - Roommates
 - Staff
 - Schedule
 - What to do in free time
 - Schedule
 - Day activity
 - Case manager



Nonverbal Adults and Choice

Choice as a Value

- National disability rights movement
 - Choice
 - Self-determination
 - Self-advocacy
- Express goals and preferences
 - Supports needed to achieve goals and preferences
 - Service design, delivery and quality measurement have been influenced by these priorities



How Does NCI Measure Choice?

- NCI indicator that measures “choice”:
 - The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, what to spend money on, and social activities.

Section II of ACS. Proxy respondents are allowed.



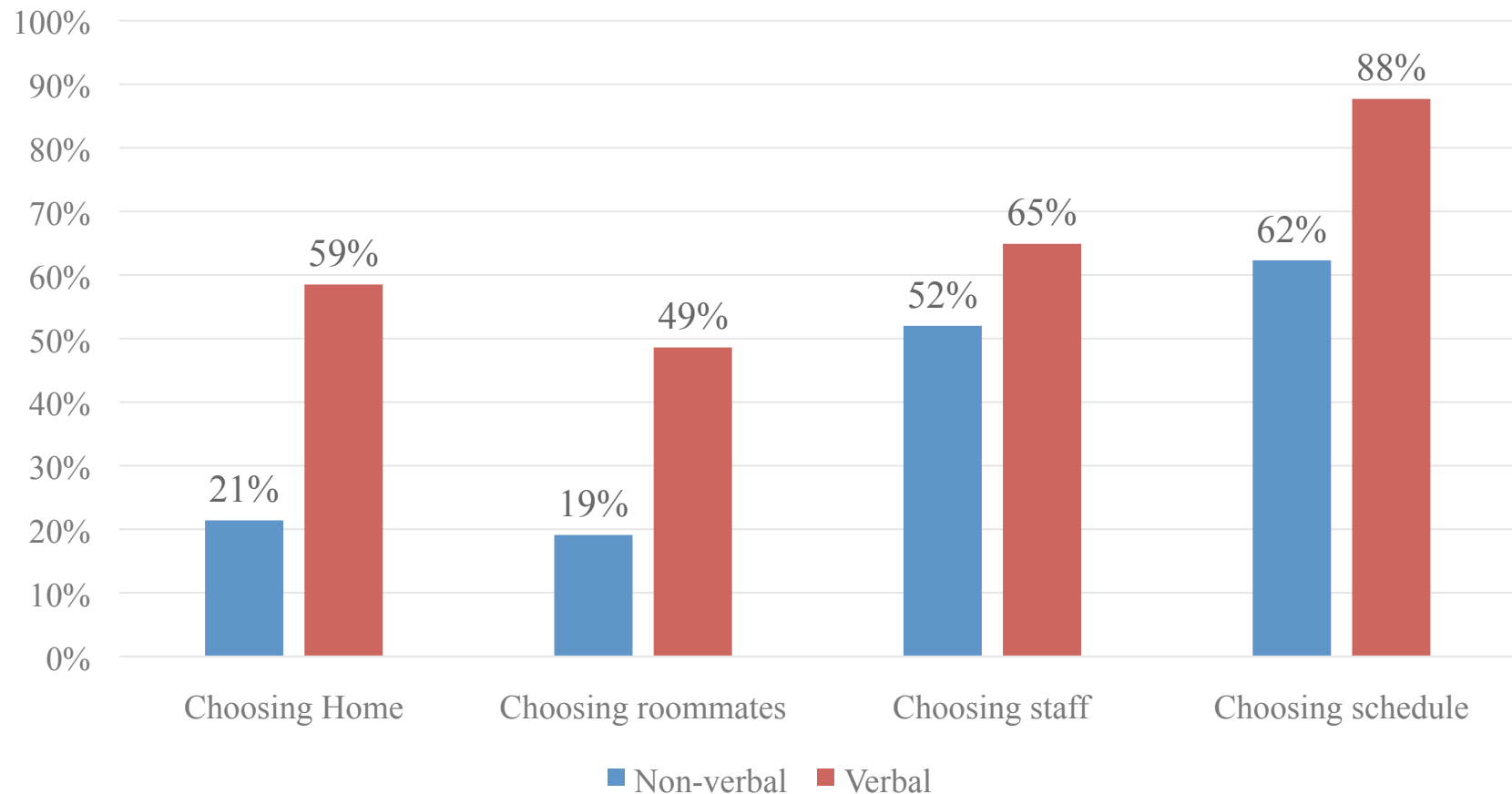
Choice

- Respondent have at least some input in the following choices:
 - Home
 - Roommates
 - Staff
 - Schedule
 - What to do in free time
 - Schedule
 - Day activity
 - Case manager



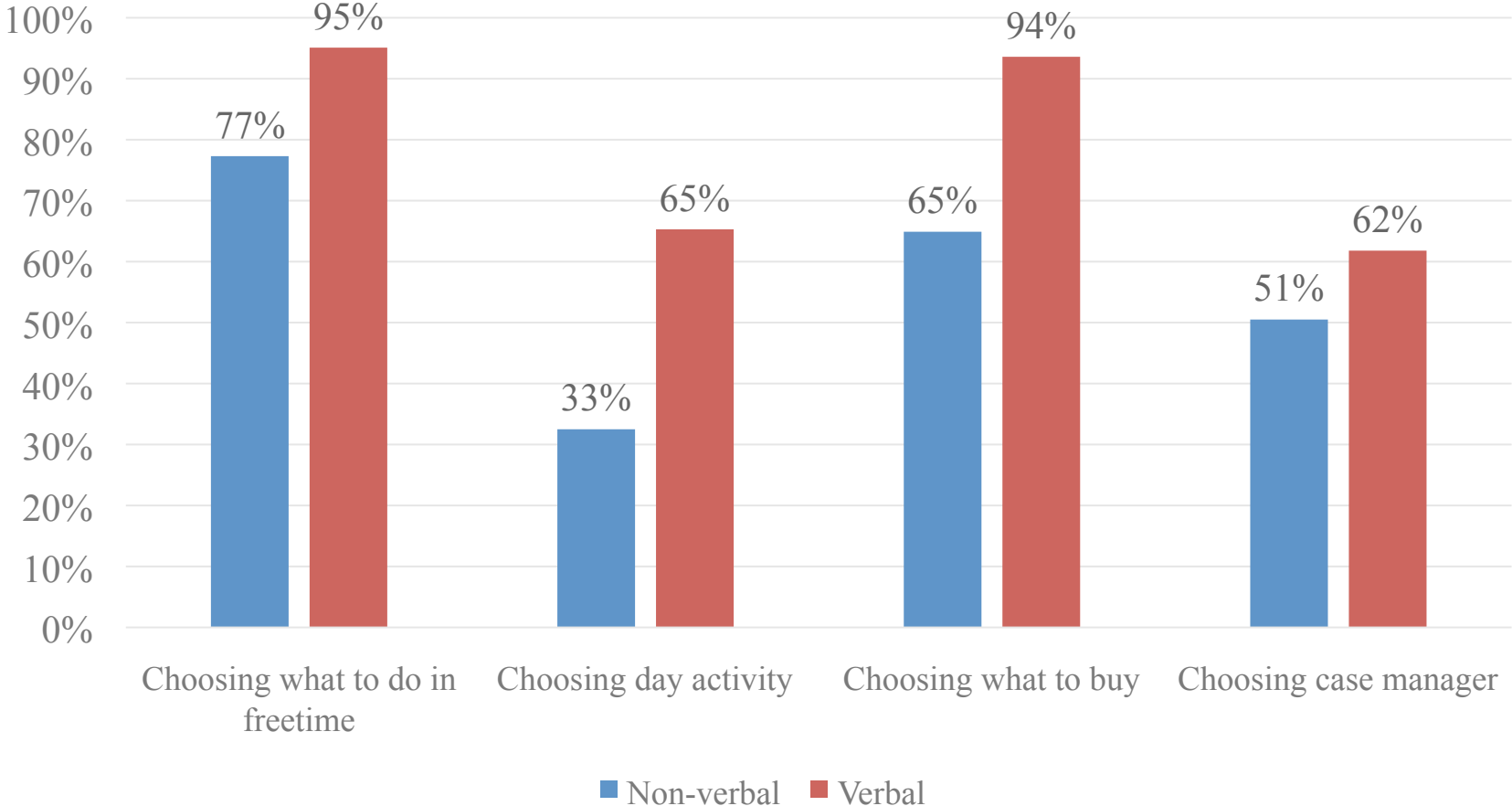
Choices:

Respondents had at least some input in....



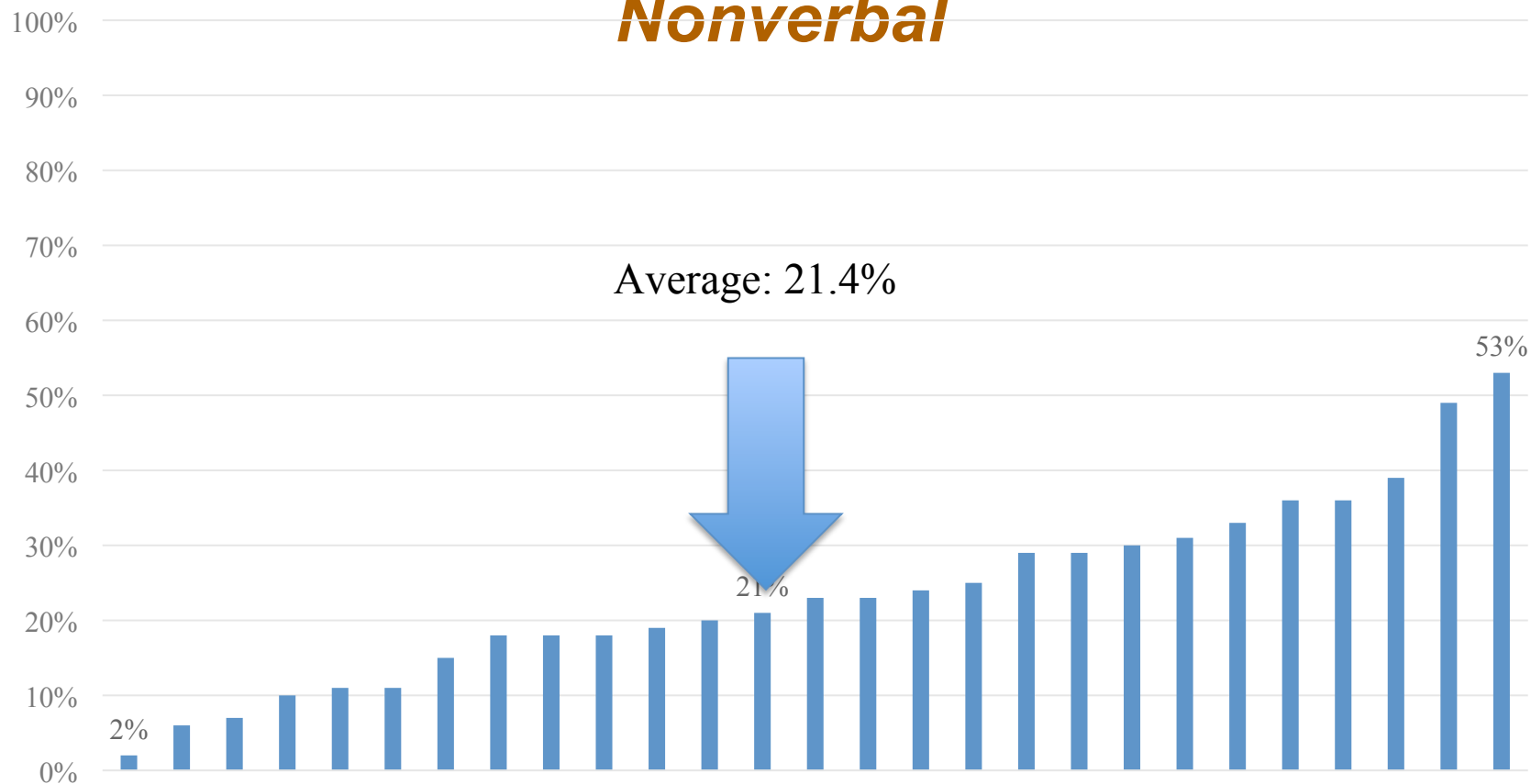
Choices:

Respondents had at least some input in....



Example of State to State Variation:

*Had At Least Some Input in Choosing Home:
Nonverbal*



Choice:

- Significant differences in the exercise of choice by means of expression (verbal vs. nonverbal)
- Differences may be due to other demographic characteristics by which individuals who communicate verbally and nonverbally differ.
 - State of residence
 - Residence type
 - Amount of paid support needed
 - Self direction
 - Support to manage disruptive behavior
 - Level of ID
 - Diagnosis with Autism Spectrum Disorder
 - Mobility



Controlling

- Ran binary logistic regressions
- Dependent variables
 - Individual had at least some input in choosing:
 - Home
 - Roommates
 - Staff
 - Daily schedule
 - What to do during free time
 - Day program
 - What to buy
 - Case manager
- Independent variables: previous slide
- **Verbal/Nonverbal communication remained a significant predictor of ALL of the dependent choice variables.**
 - **People who communicate nonverbally were significantly less likely to exercise choice.**



Where can we go with this info?

- Further research and development of ways to access the choices and opinions of individuals who communicate nonverbally
 - Some states have developed methods to administer the NCI Adult Consumer Survey
- Help inform state officials, providers and advocates to forge future policies and supports for individuals who do not use words to speak.
 - What policy implications can you think of?



- Of interest:
 - Needing behavior support was related to choice





**NATIONAL CORE
INDICATORS**

NASDDDS & HSRI

What Do NCI Data Reveal About Individuals With Intellectual and Developmental Disabilities Who Need Behavior Support?

**June 24, 2014, AAIDD Annual Meeting
Stephanie Giordano, HSRI
Cheryl Sartori, HSRI**

Importance

- Individuals with ID/DD are 3-5x more likely to demonstrate challenging behaviors
- Challenging behaviors can lead to
 - Self harm
 - Physical injury to others
 - Destruction of property
 - Limited community involvement
 - Disadvantages



Methods, Measures and Sample:

- 2012-13 data collection cycle
- Background Information Section
- Does person need support to manage:
 - Self injurious behavior?
 - Disruptive behavior
 - Destructive Behavior?
- Included in sample for analysis: 12,718



Finding

- Respondents who need behavior supports differ significantly from those who do not use such supports in various demographic characteristics.

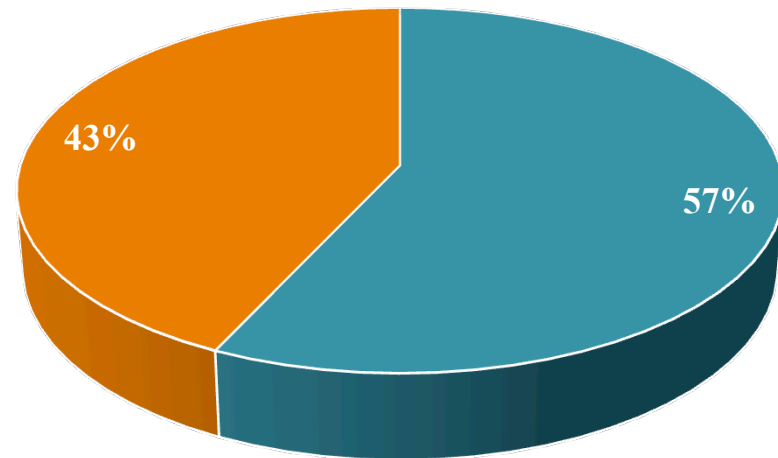


Demographics

- 43% need some or extensive support
- Of the respondents who require at least some behavior support*:
 - 51% need support for self-injurious behavior
 - 87% need support for disruptive behavior
 - 55% need support for destructive behavior

*Note that these categories are not mutually exclusive and therefore exceed 100% when combined.

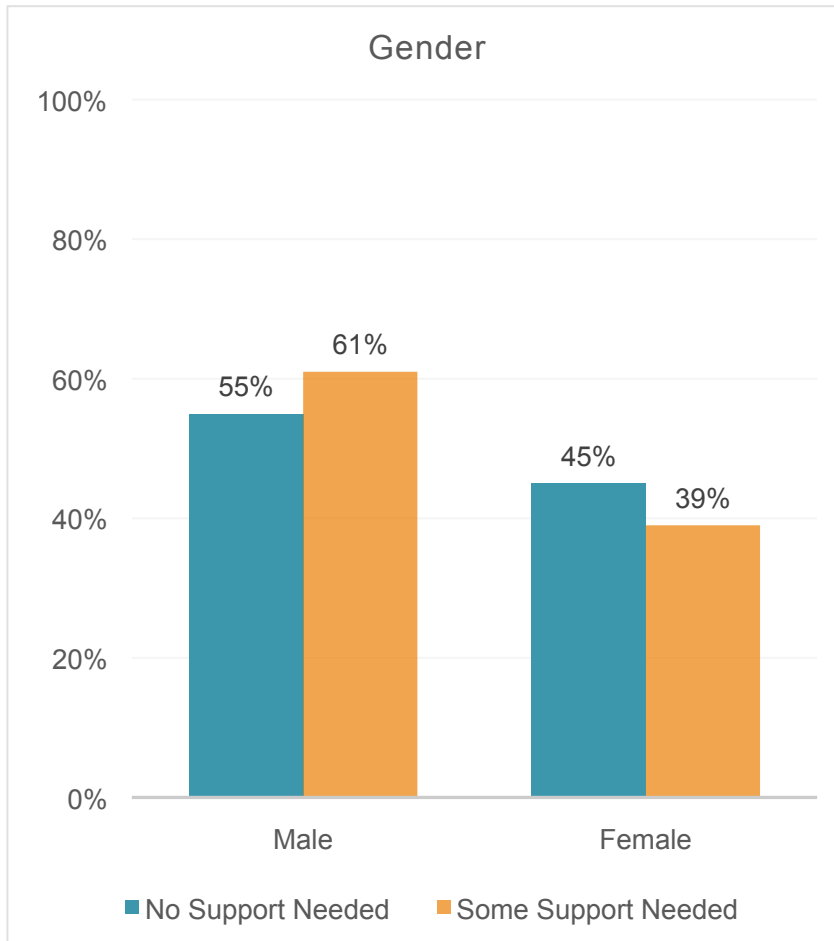
Support Needed for Behavior Challenges



- No Support Needed
- Some or Extensive Support Needed



Demographics

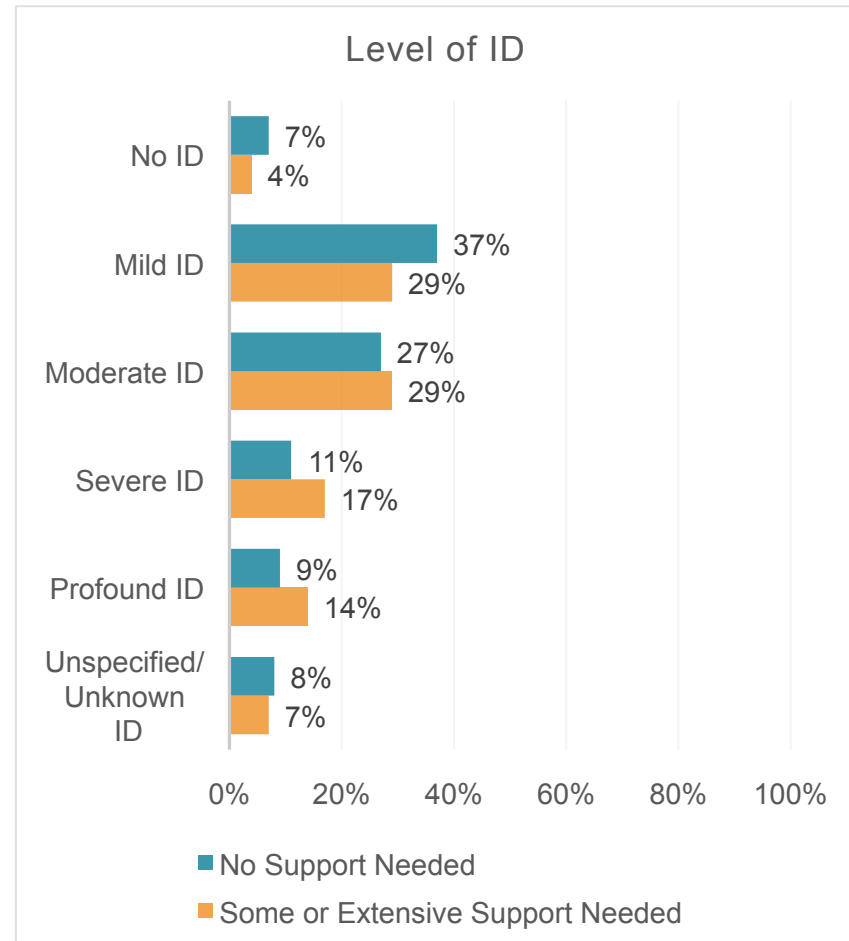


- Respondents who needed behavior supports compared to those who did not were:
 - Slightly younger - 42 v. 43
 - More likely to be male - 61% v. 55%

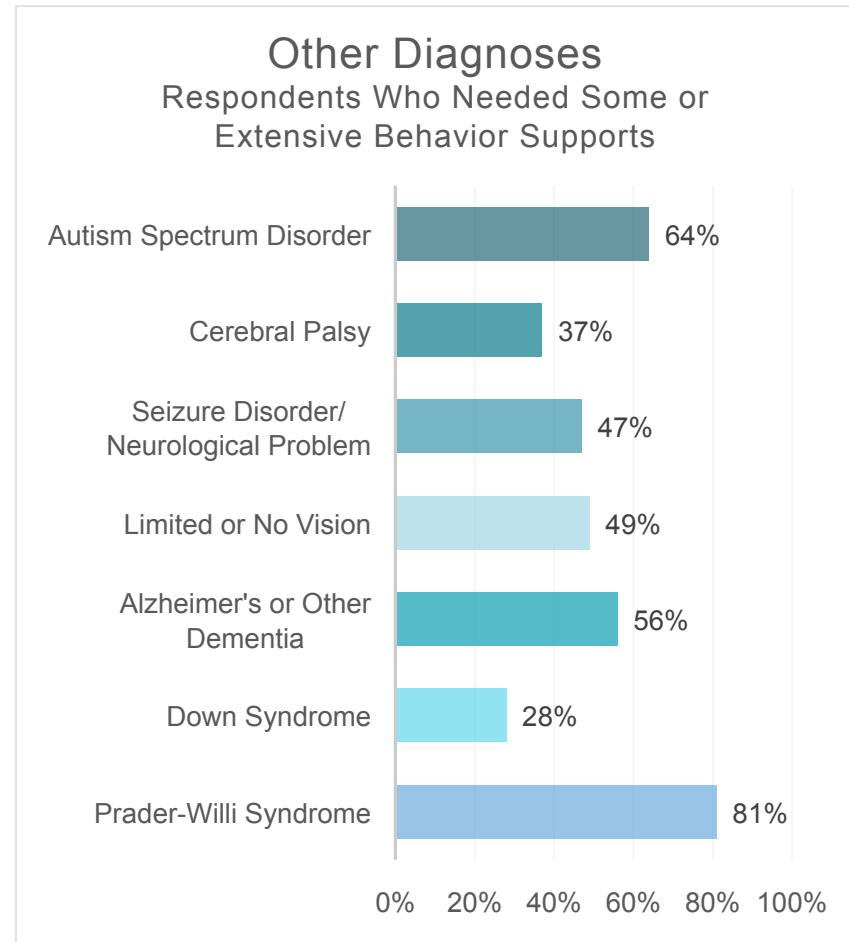
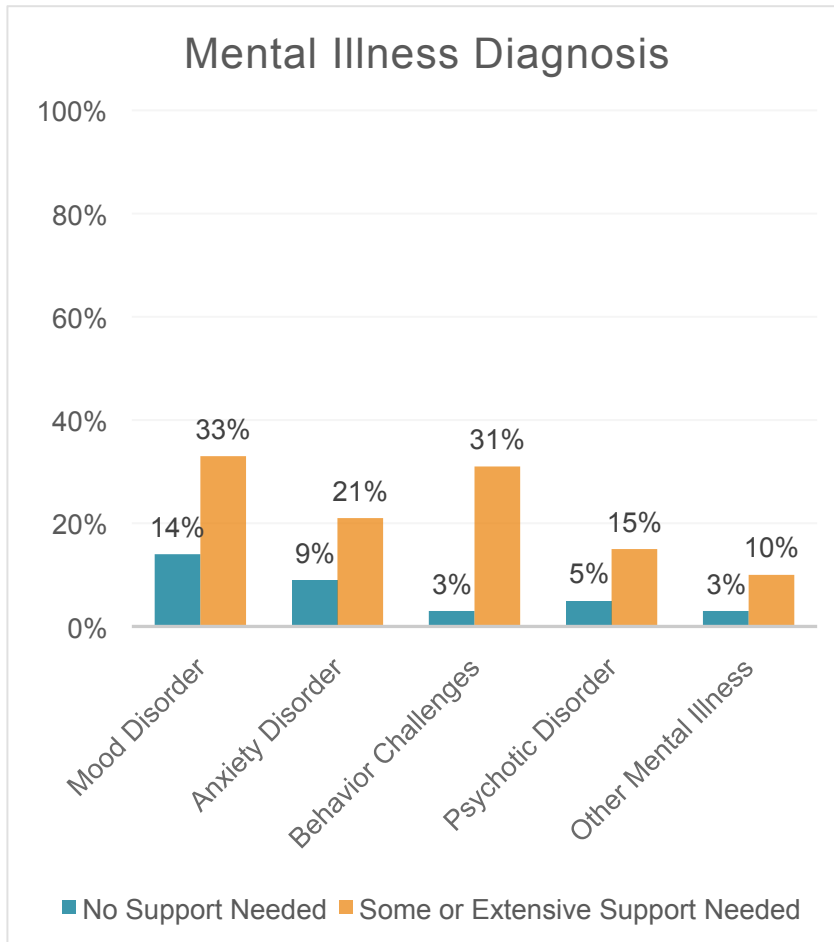


Demographics

- More respondents who needed behavior supports were diagnosed with an intellectual disability than those who did not need support:
 - 96% v. 93%
- Significant differences were also found by level of disability



Diagnoses

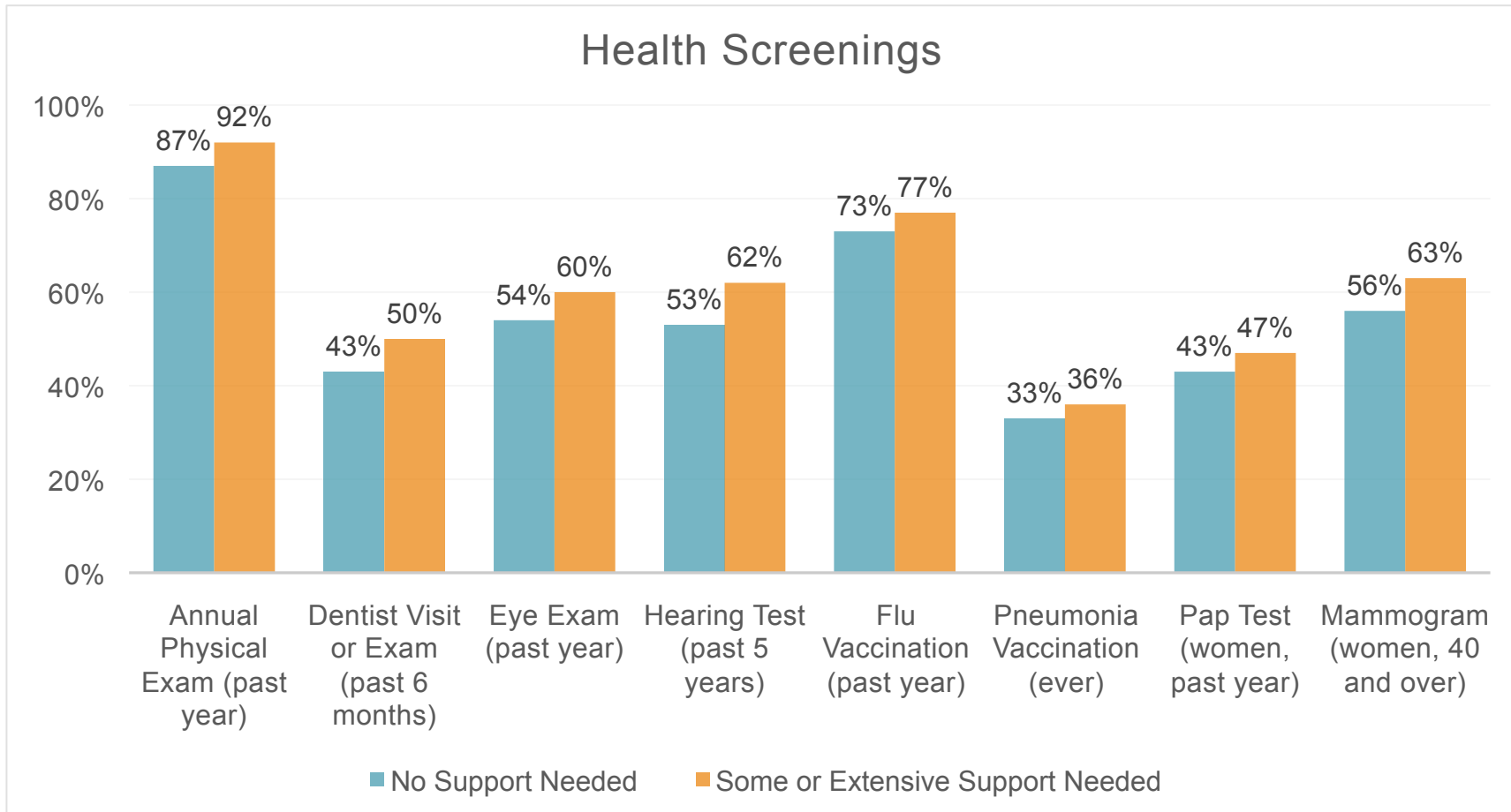


Finding

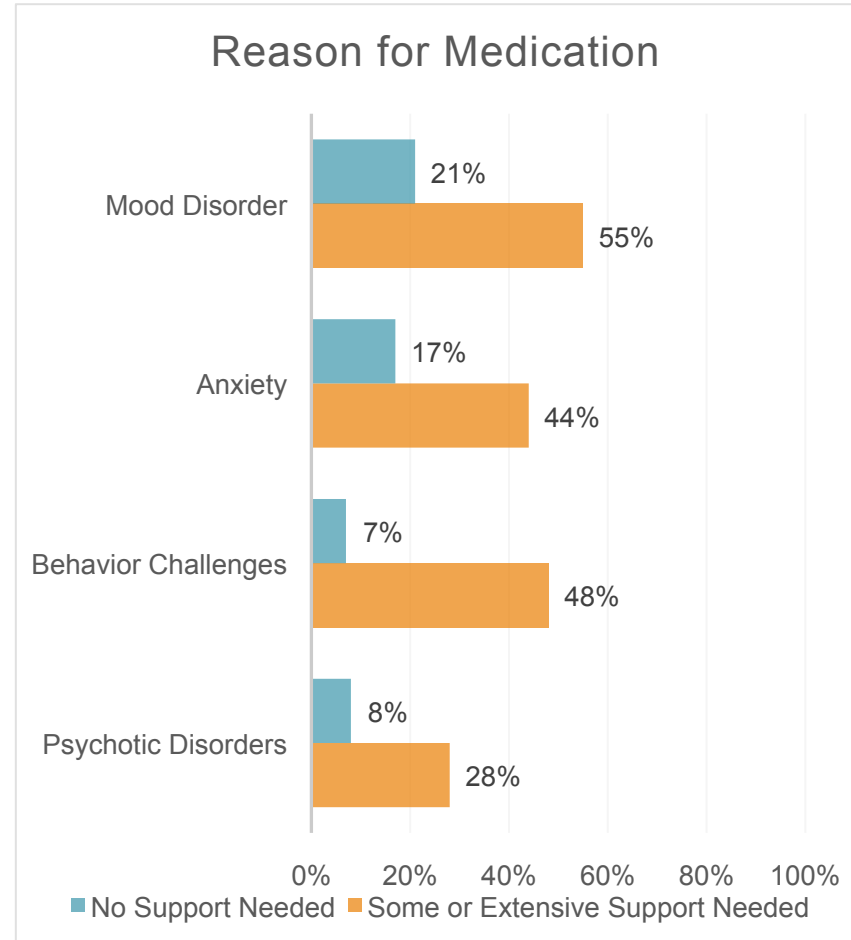
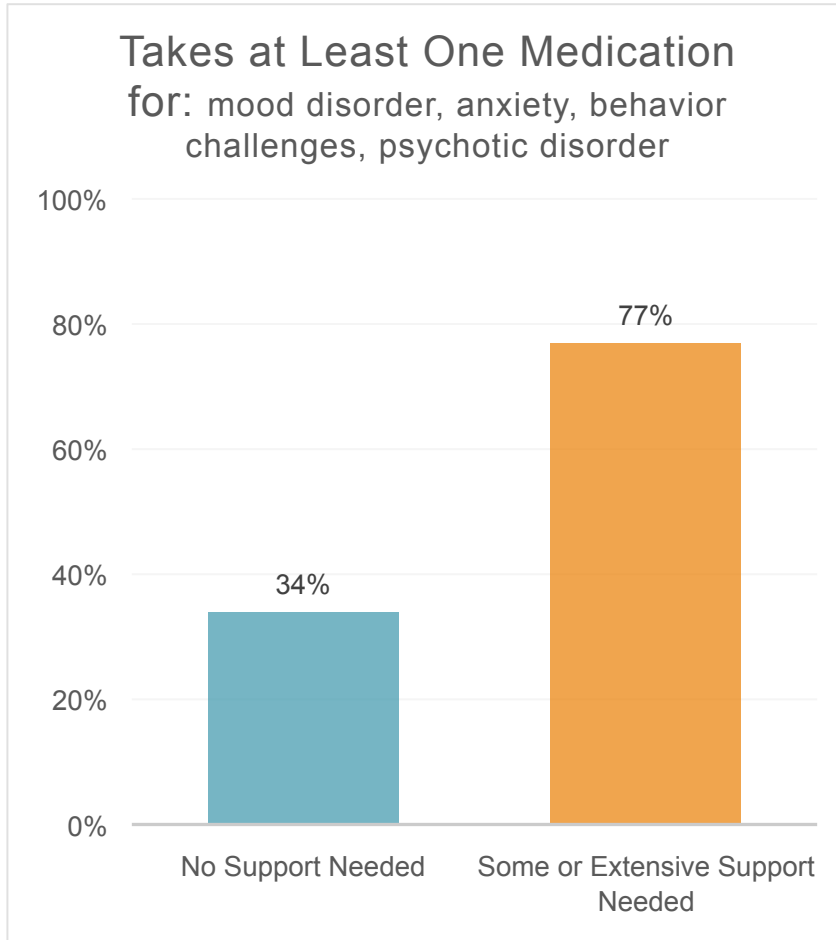
- Respondents who use behavior supports differ significantly from those who do not use such supports in various health, medication, and wellness outcomes.



Health



Medication

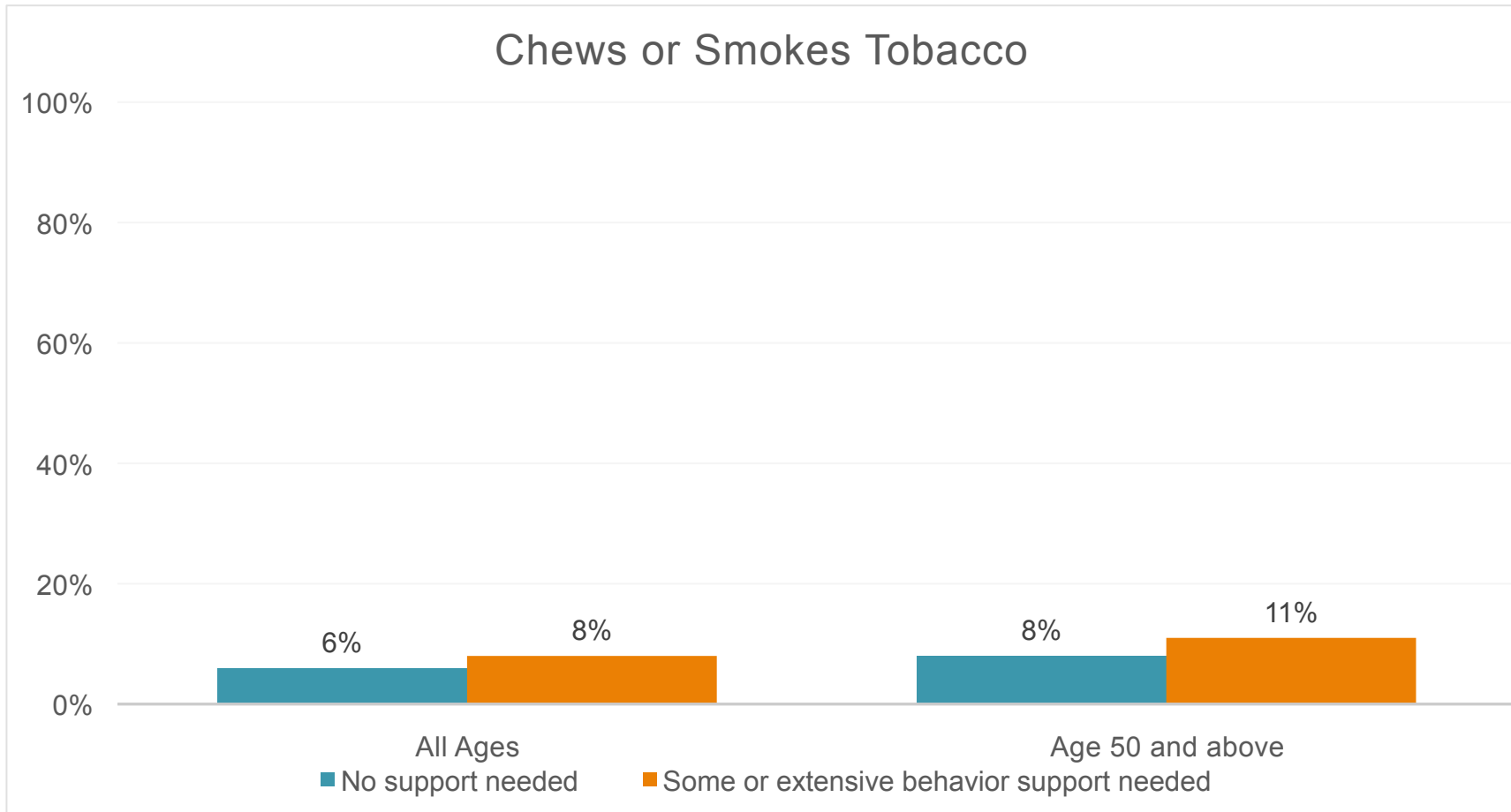


Finding

- Respondents who require behavior support smoke at a significantly higher rate than individuals who do not require such supports.



Tobacco

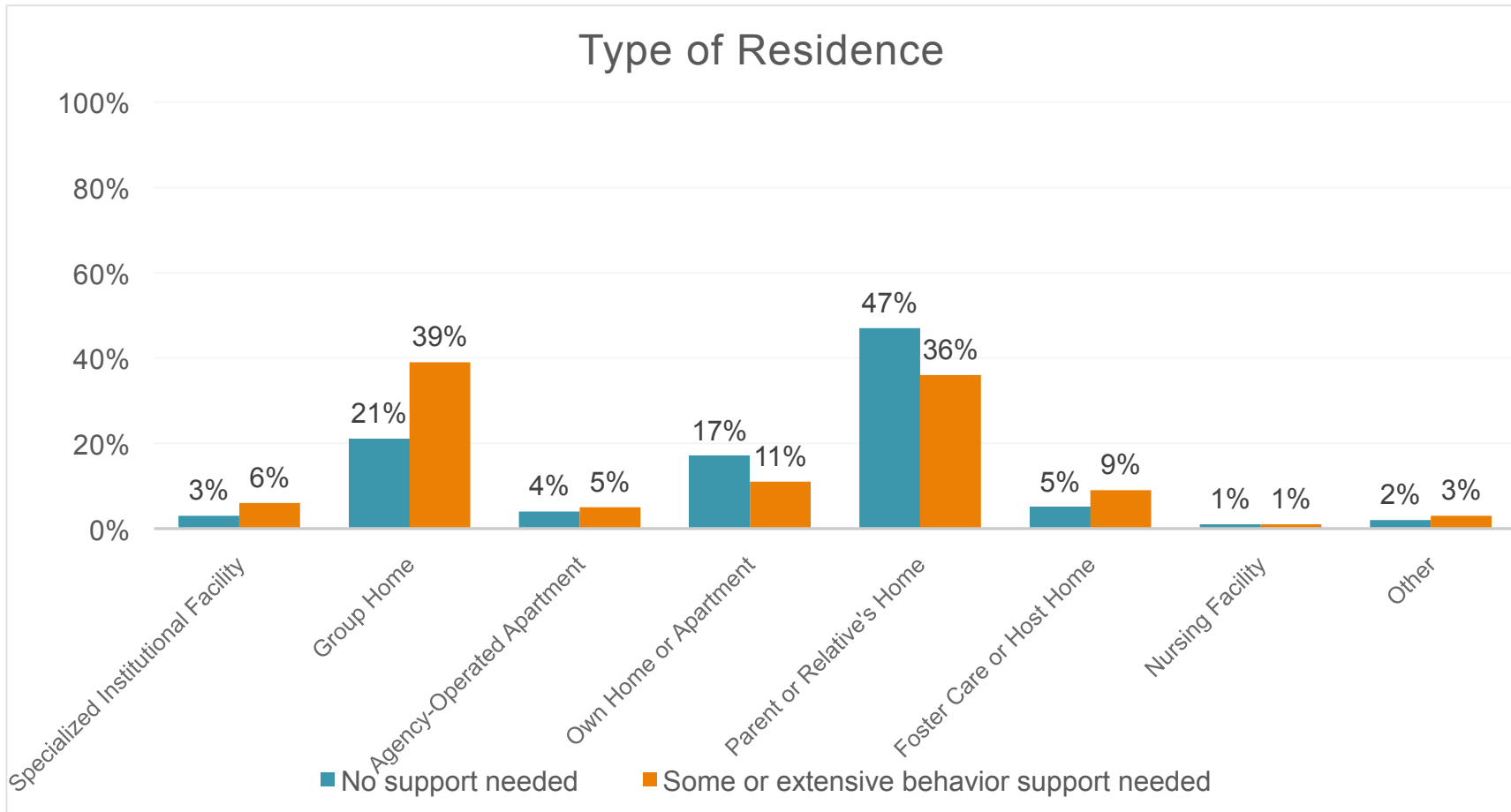


Finding

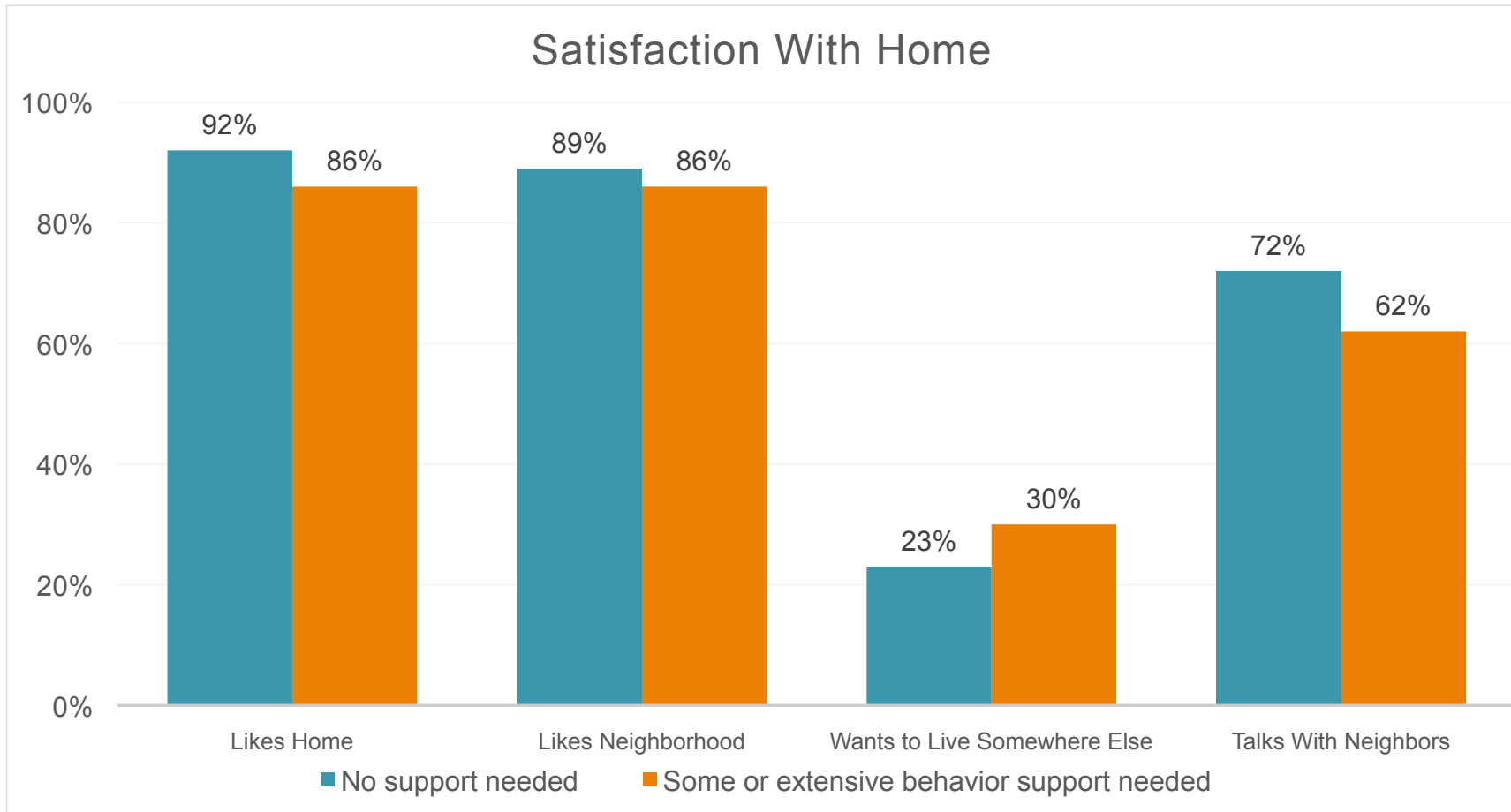
- Respondents who use behavior supports differ significantly from those who do not use such supports in where they live and their satisfaction with their living situation as well as what they do during the day.



Home

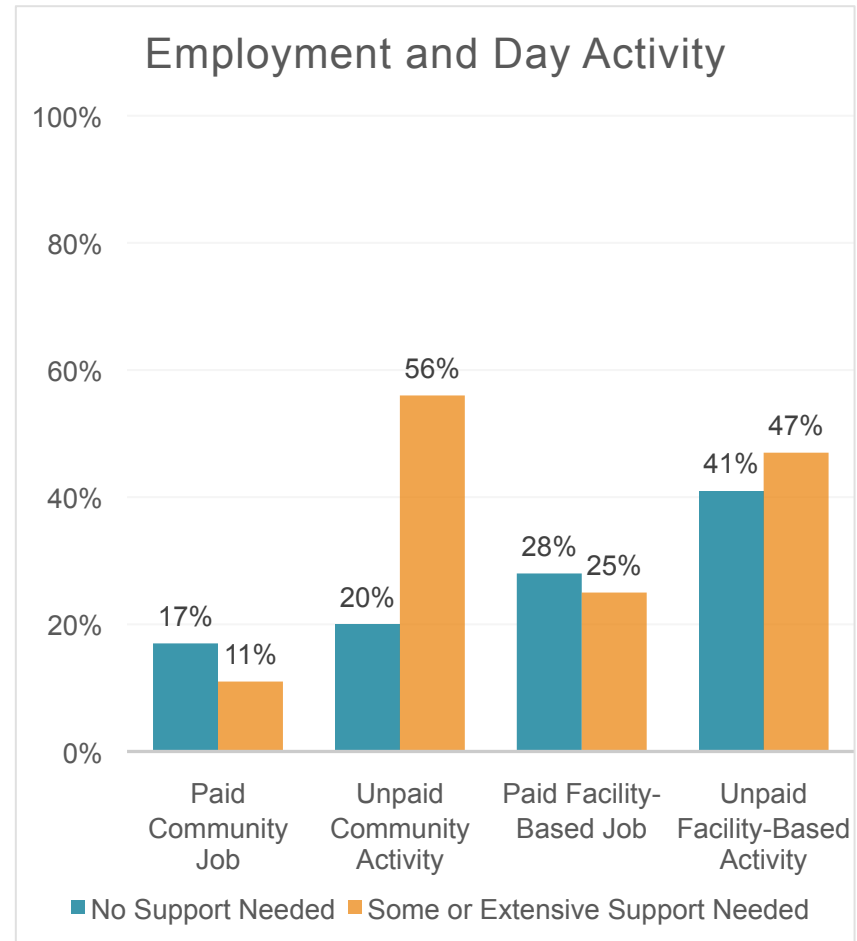


Home



Work and Day Activity

- Respondents who do need behavior support were:
 - less likely to have had a paid community or facility-based job
 - more likely to participate in unpaid community or facility-based activities



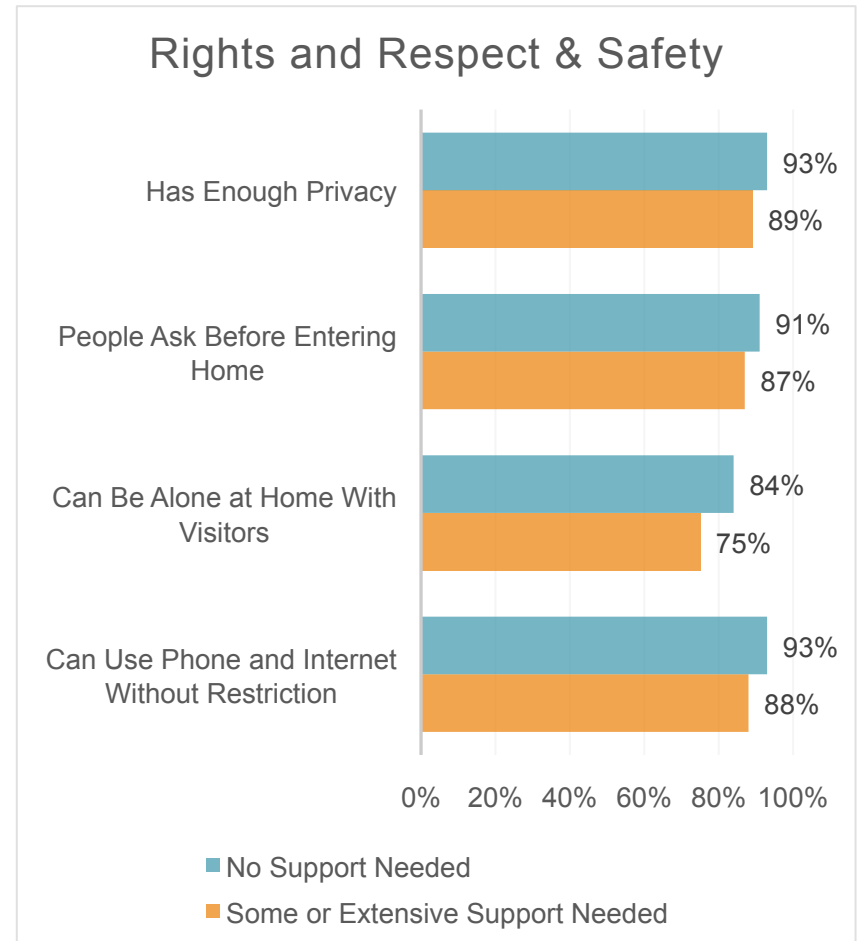
Finding

- Respondents who use behavior supports differ significantly from those who do not use such supports with regard to rights, respect, and safety.

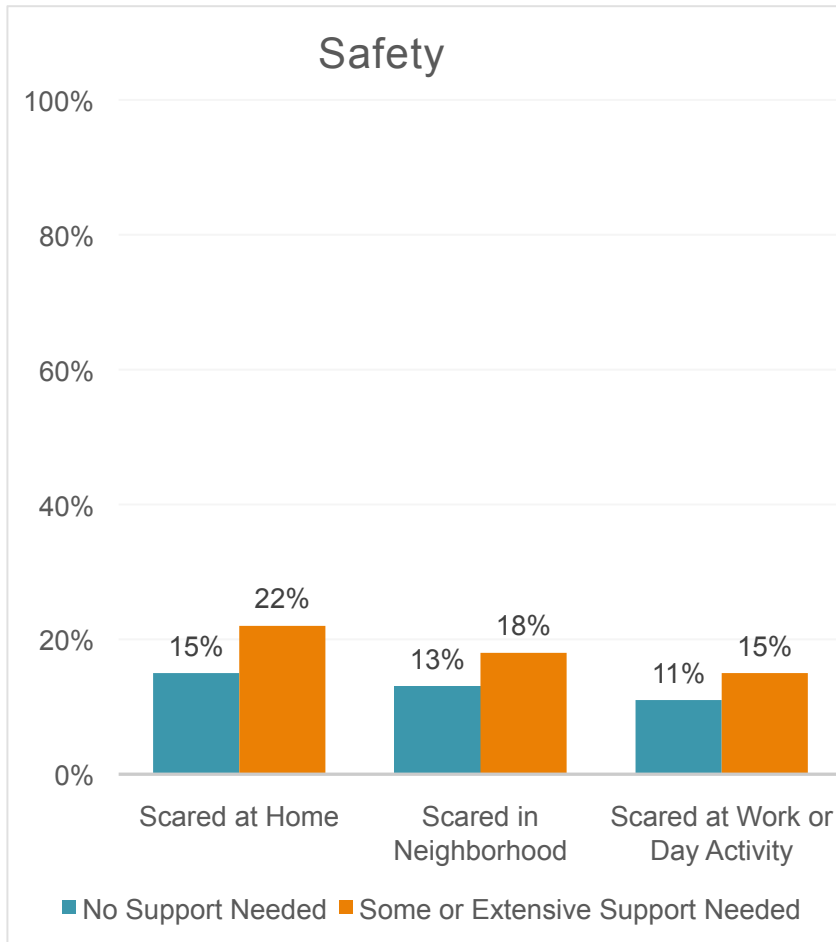


Rights and Respect

- Respondents who require behavior support reported lower rates of:
 - Being able to be home with visitors
 - People asking before entering their home
 - Having enough privacy
 - Being able to use phone and internet



Safety



- Respondents who require behavior support were significantly more likely to feel scared in their home, neighborhood, and/or day program than those who do not require support.

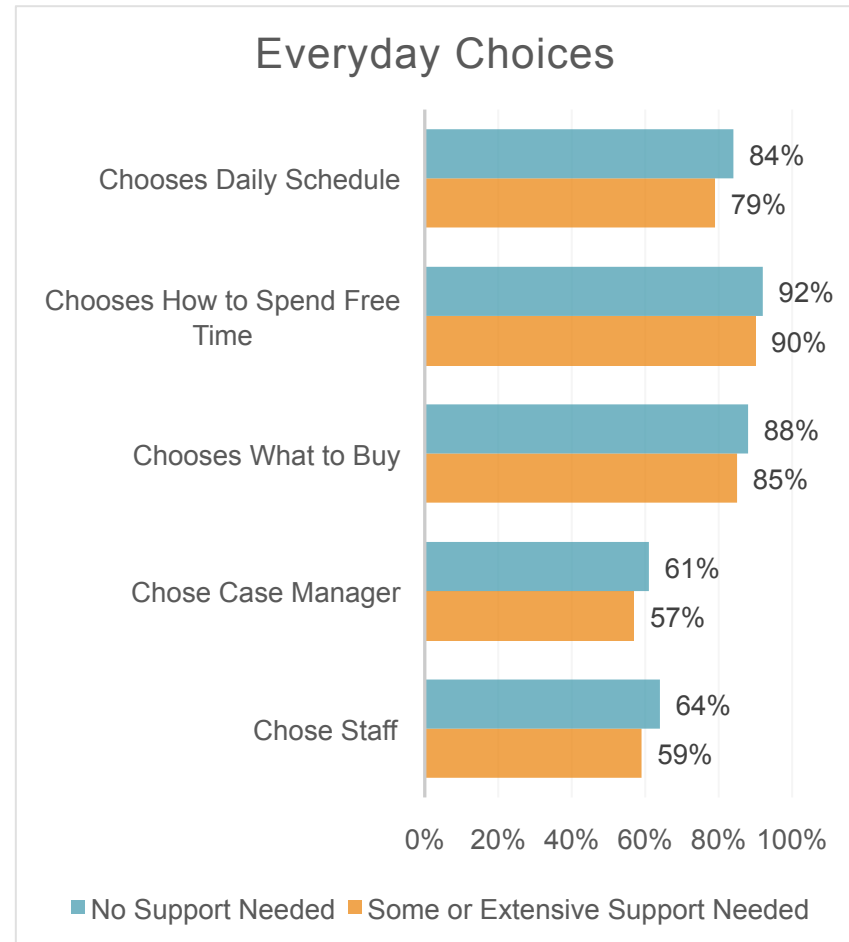
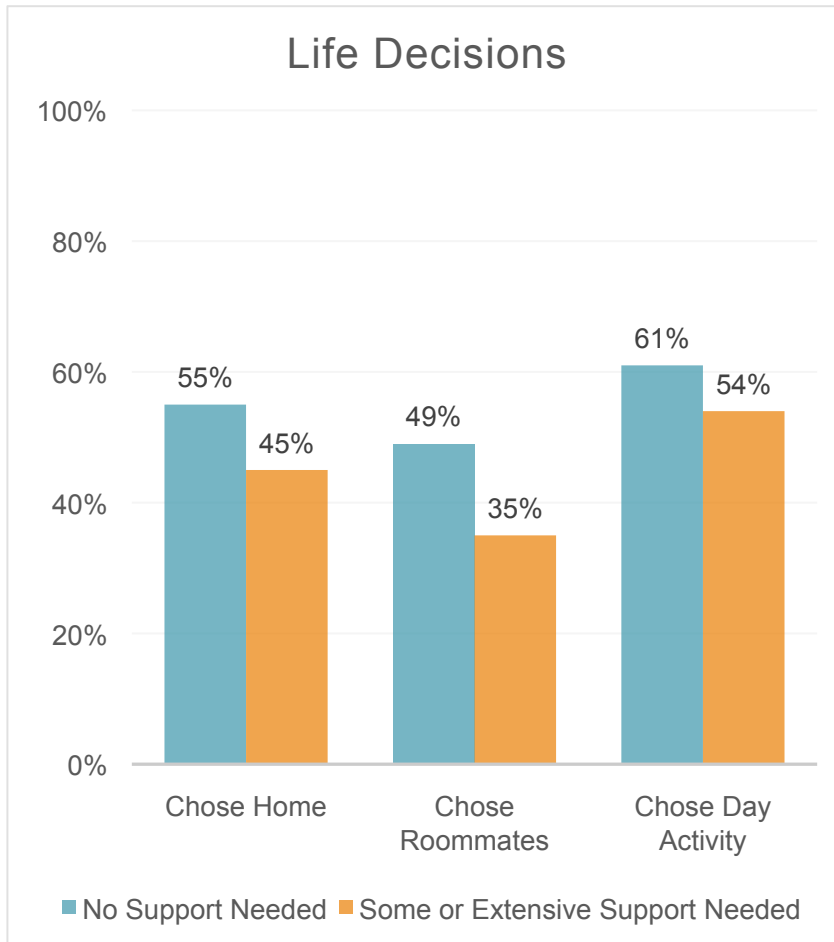


Finding

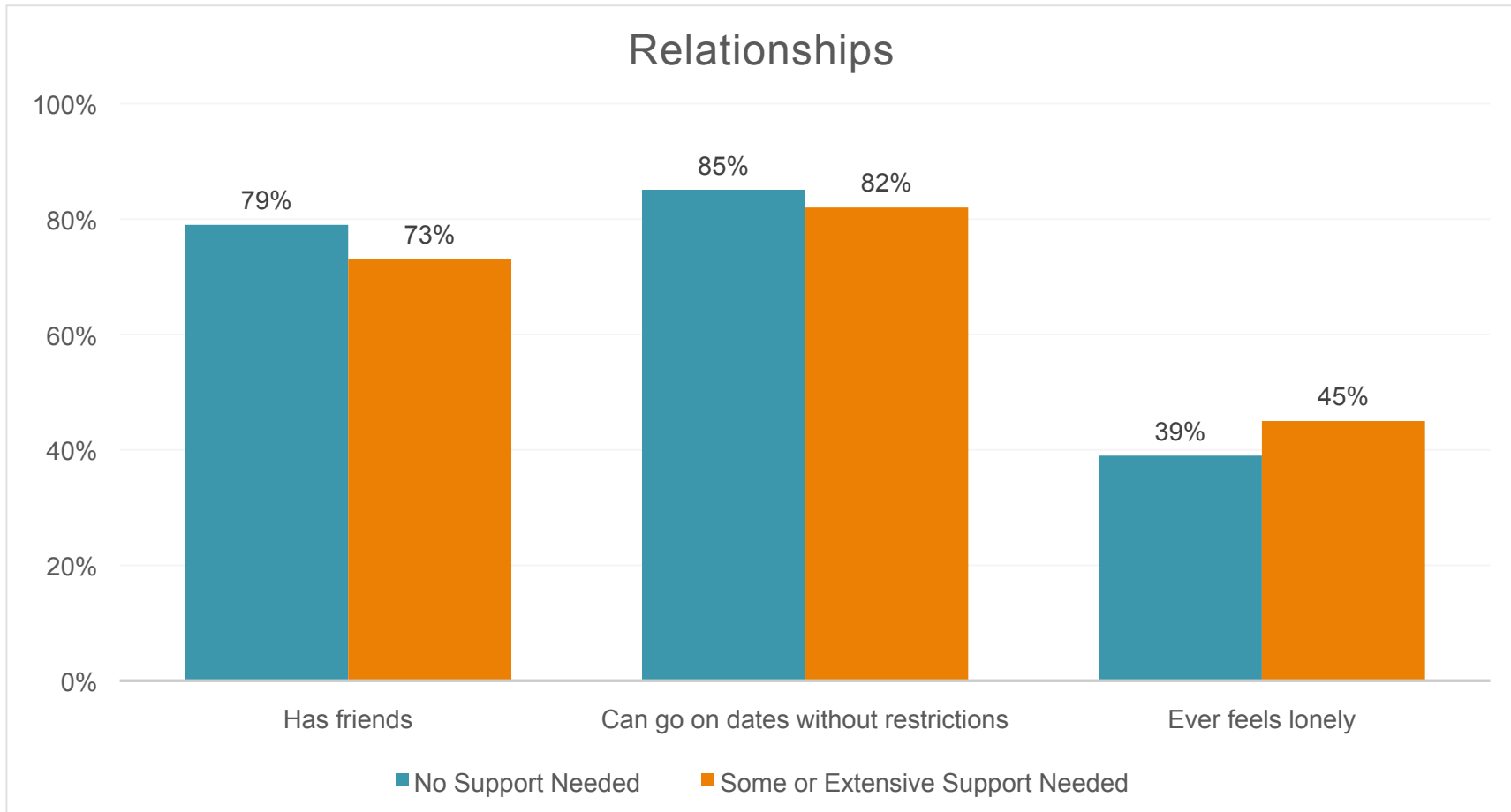
- Respondents who use behavior supports showed significantly less autonomy in everyday choices and life decisions and reported fewer close relationships.



Choice



Relationships

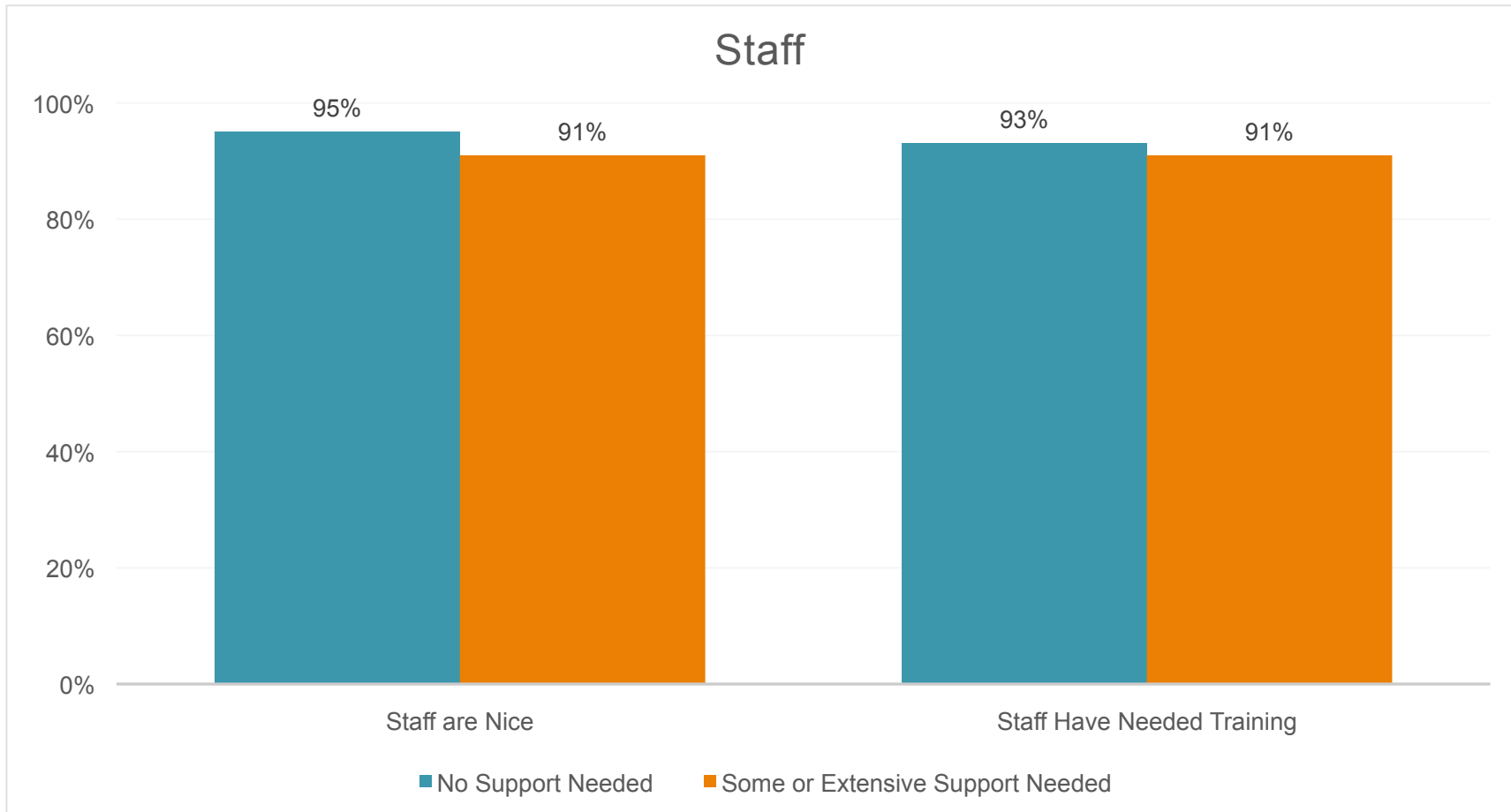


Finding

- Respondents who require behavior support were significantly less likely to report that the staff who worked with them were nice and that their staff have the necessary training to help them.



Staff

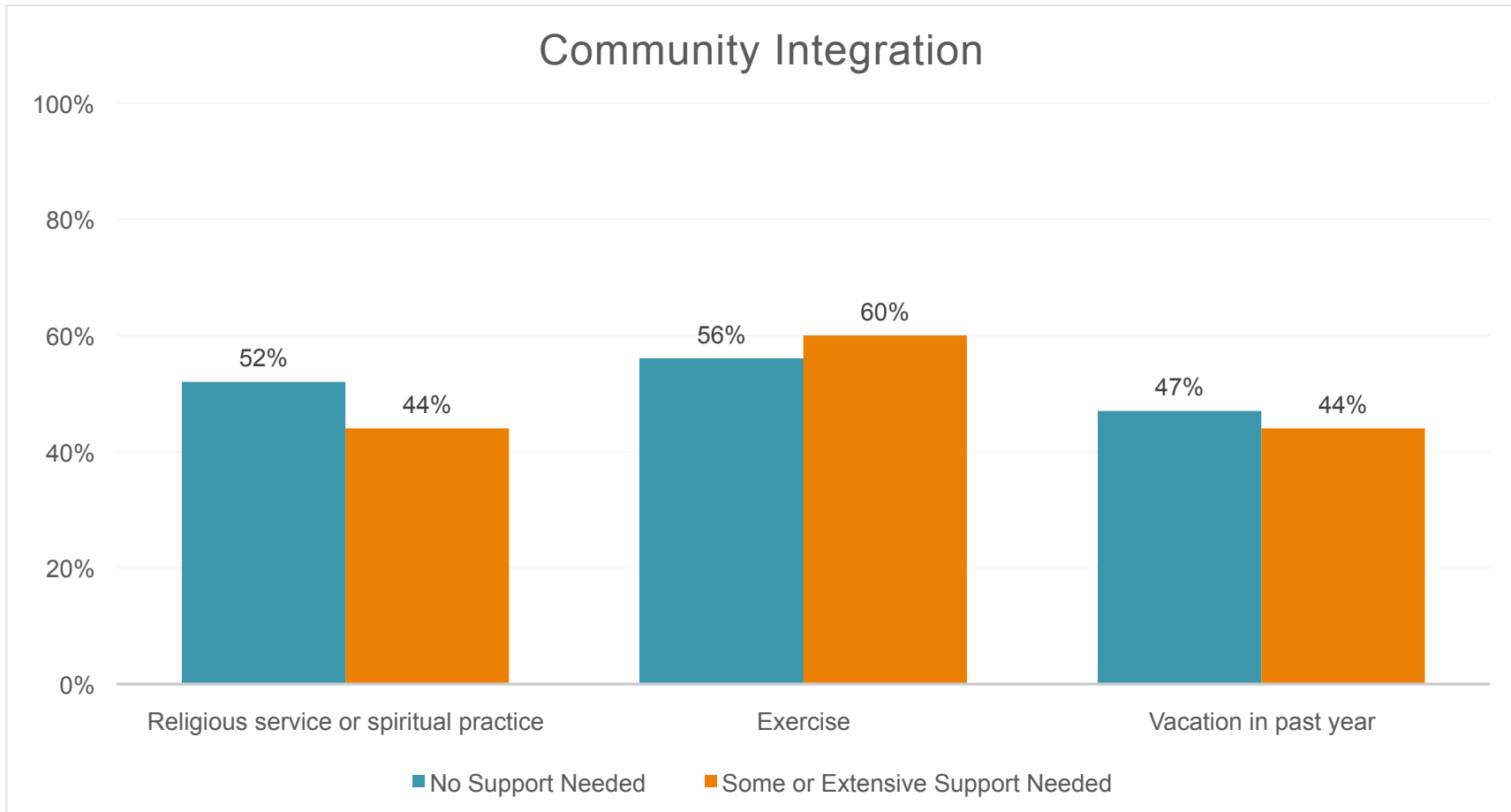


Finding

- Respondents who require behavior support were less likely to partake in a religious or spiritual practice in the past month and go on vacation in the past year. However respondents who require behavior support were more likely to go out for exercise in the past month.



Community Inclusion



Why Does This Matter?

- Respondents who need behavior support experience differences in demographics and valued outcomes:
 - Relationships
 - Home
 - Rights & respect
 - Inclusion
 - Personal safety
 - Choice
 - Health
 - Employment
- Help inform state officials, providers and advocates to forge future policies and supports for individuals who need behavior supports.



Next Steps

- Further analyses
 - Controlling for other factors
- Root causes?
- Policy recommendations



Contacts

- HSRI
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- NASDDDS
 - Mary Lee Fay: MLFay@nasddds.org
- NCI website: www.nationalcoreindicators.org



NASDDDS



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