



APHA Annual Meeting
November, 2017



Human Services
Research Institute

Characteristics and Outcomes of People with ID/DD Who Need Support for Self- Injurious Behavior:

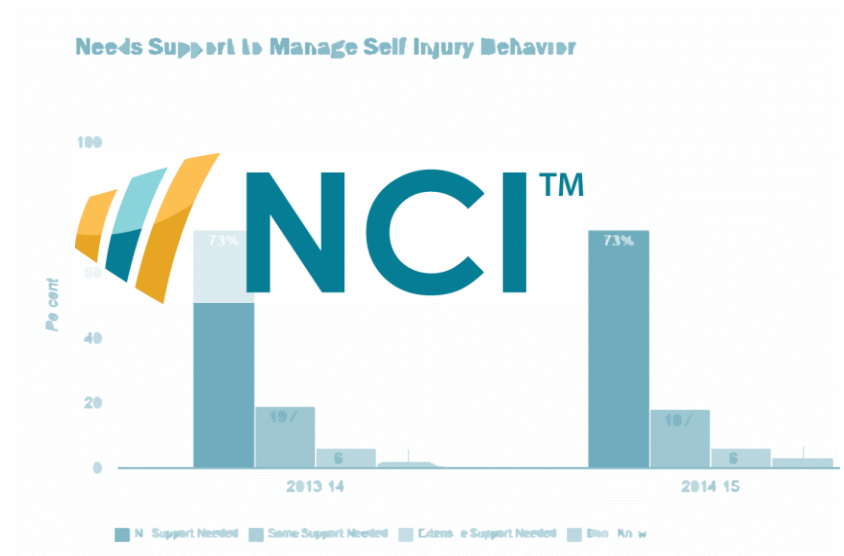
A Research and Policy Agenda

Dorothy Hiersteiner
Human Services Research Institute

NASDDDS

Agenda

- Background
- What is NCI?
- What do the data show?
- Research/policy considerations



We're invisible in the data. We can't make people believe we need more services if we don't have data to back us up.

Participant – Surgeon General's Conference on Health Disparities and *Mental Retardation* 2001



Background

- Self-injurious behavior (SIB)
 - Self-inflicted harmful behavior that can result in injury and cumulative physical damage
- For people with ID/DD
 - Affect health, QoL
 - May make it difficult to be in inclusive settings
 - Can lead to social isolation and anxiety
 - Poses caretaking challenges on families

Rojahn, J, Schroeder, SR & Hoch, TA 2007, *The Assessment and Treatment of Child Psychopathology and Developmental Disabilities: Self-Injurious Behaviour in Intellectual Disabilities*. Elsevier Science, Jordan Hill. Available from: ProQuest ebrary. [17 February 2017].

Symons, FJ, Koppekin, A & Wehby, JH 1999, 'Treatment of self-injurious behaviour and quality of life for persons with mental retardation', *Mental Retardation*, vol. 37, no. 4, pp. 297-307. DOI: [10.1352/0047-6765\(1999\)037<0297:TOSBAQ>2.0.CO;2](https://doi.org/10.1352/0047-6765(1999)037<0297:TOSBAQ>2.0.CO;2)



Prevalence Estimates

- Estimates of the prevalence of SIB within the population of adults with ID/DD
 - vary widely -- differences in assessment methods, sampling strategies, and specific populations
- Rojahn et al. (2007) meta analysis
 - US and UK
 - in both community settings and institutions
 - found that estimated rates of SIB ranged from 4% to 9%.
- Emerson et al. (2001)
 - UK study found that 4% of the sample of individuals with ID receiving services in a variety of venues were reported to exhibit SIB.
- Population with a diagnosis of autism, estimates range from 33% to 71% (Richards et al. 2012)

Rojahn, J, Schroeder, SR & Hoch, TA 2007, *The Assessment and Treatment of Child Psychopathology and Developmental Disabilities: Self-Injurious Behaviour in Intellectual Disabilities*. Elsevier Science, Jordan Hill. Available from: ProQuest ebrary. [17 February 2017].

Emerson, E, Kiernan, C, Alborz, C, Reeves, D, Mason H, Swarbrick, R, Mason, L & Hatton, C 2001, 'The prevalence of challenging behaviours: a total population study', *Developmental Disabilities*, vol. 22, no. 2, pp. 77-93.

Richards, C, Oliver, C, Nelson L & Moss, J 2012, 'Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability', *Journal of Research in Intellectual Disability*, vol. 56, no. 5, pp. 476-489.



Approaches to supporting people with SIB

- Functional Analysis
- Determining cause of behavior
 - Pain, communication barriers, etc.
- Positive Behavior Supports (PBS)
 - Aversive and painful interventions
 - Restraints

Kincaid, D & Fox, L 2002, 'Person-centered planning and positive behaviour support' in S Holburn & P Vietze, (eds), Research and practice in person-centered planning, pp. 29-50. Paul H. Brookes, Baltimore.



The National Core Indicators: A quality and outcomes survey

- NASDDDS, HSRI & State DD Directors
 - Multi-state collaboration, launched in 1997 in 6 participating states – now in 46 states (including DC) and 22 sub-state areas
 - Random sampling at the state level, public reporting of aggregate, state-level findings
- GOAL: Measure performance of public systems for people with ID/DD by examining outcomes
- Domains:
 - Employment
 - Community inclusion
 - Choice
 - Rights
 - Health
 - Safety
 - Relationships
 - Service satisfaction



NCI Adult Consumer Survey (ACS)

Random sample of adults who receive services regardless of setting



- Background Information Section
 - Data from agency records or information systems
 - Includes info on need for behavior support for SIB
- Section I
 - Individual satisfaction; no proxy allowed
- Section II
 - Fact-based objective questions; proxy allowed



NCI Adult Consumer Survey (ACS)

- **Minimum of 400 interviews** per year (participating states).
- **Random sample of adults who receive services** regardless of setting.
- State-to-state comparison of results possible within a **95% statistical confidence level** (5% margin of error)
- States may **oversample** in order to secure valid stratified intrastate results (e.g., for inter-regional comparisons)
- Statistical methods are employed to **control for differences** in consumer characteristics across the states.
- **National and state level data reports are publicly available**



NCI Adult Consumer Survey (ACS)

- **Standard survey/interview instrument.** States may not modify the basic project instrument and administration protocols. A state may add questions to address additional topics.
- **Face-to-face structured conversation** with individuals plus the collection of **background information** (health conditions) from records.
- Obtains information directly from adults with developmental disabilities
 - Assesses whether the services they receive result in valued outcomes in support of **system-wide quality improvement activities**.
- Proxy allowed for portion.



2015-16 ACS Sample

Please identify the level of support the person needs to manage any of the types of behavior listed below.

BI-55 **Self-injurious behavior**

Refers to attempts to cause harm to one's own body; for example, by hitting or biting self, banging head, scratching or puncturing skin, ingesting inedible substances, or attempting suicide.

- ☐ 1 No support needed
- ☐ 2 Some support needed; requires only occasional assistance or monitoring
- ☐ 3 Extensive support needed; frequent or severe enough to require regular assistance
- ☐ 99 Don't know

Valid responses to this Q for
15,581 individuals
in non-institutional settings



What do the 2015-16 NCI Adult Consumer Survey data tell us about people who need support for SIB?

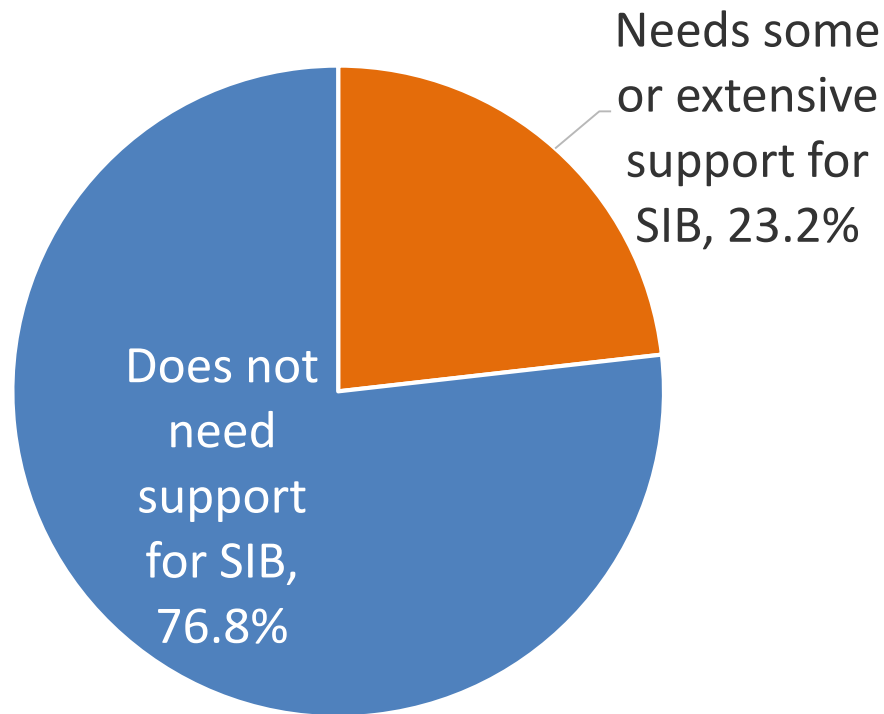


Analysis Notes

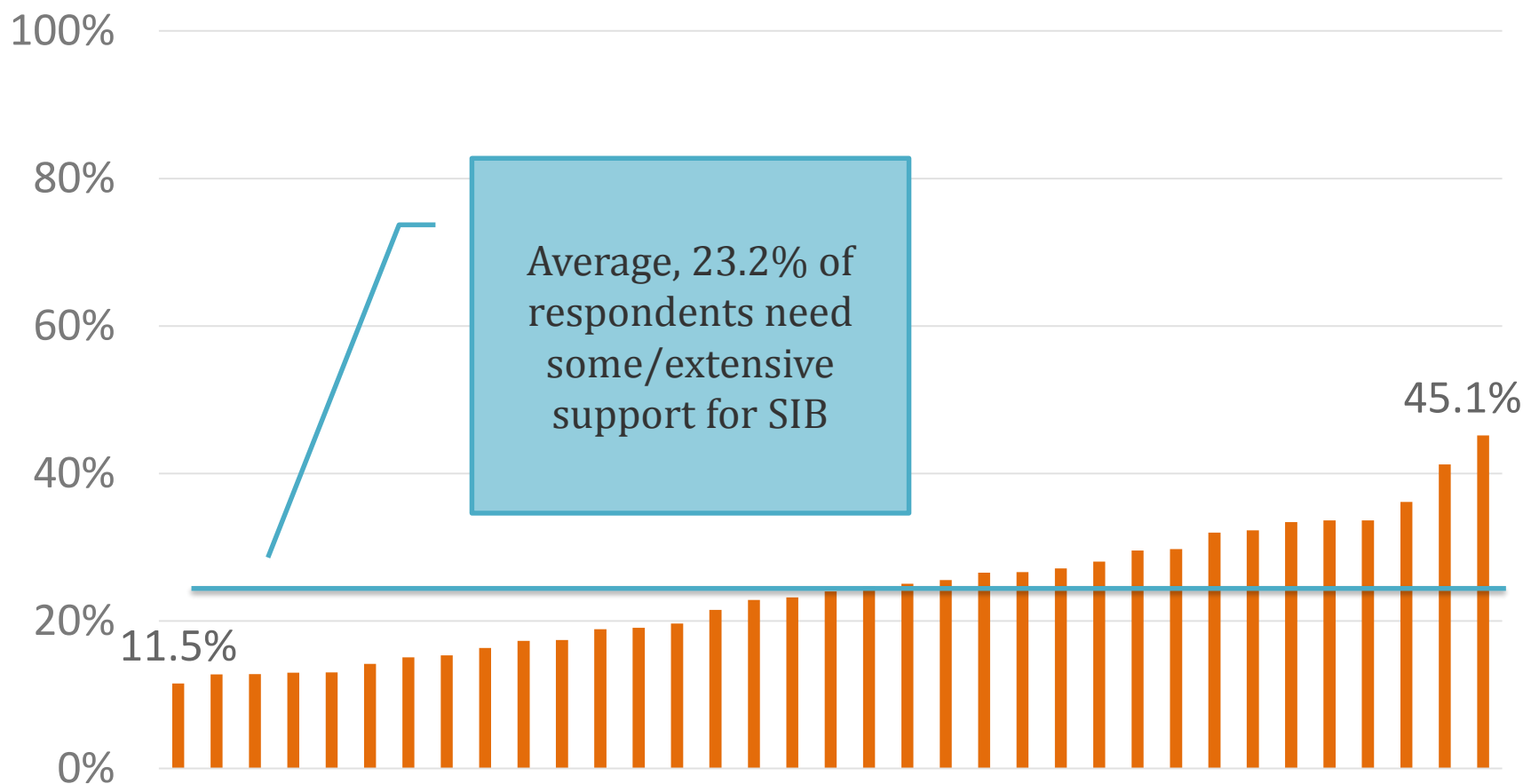
- Does not include respondents living in institutional settings
- Averages are not “average of state averages” (as in NCI public reports) but averages of all respondents
- Differences shown are significant at the $p \leq .001$ level

Demographics and Personal Characteristics

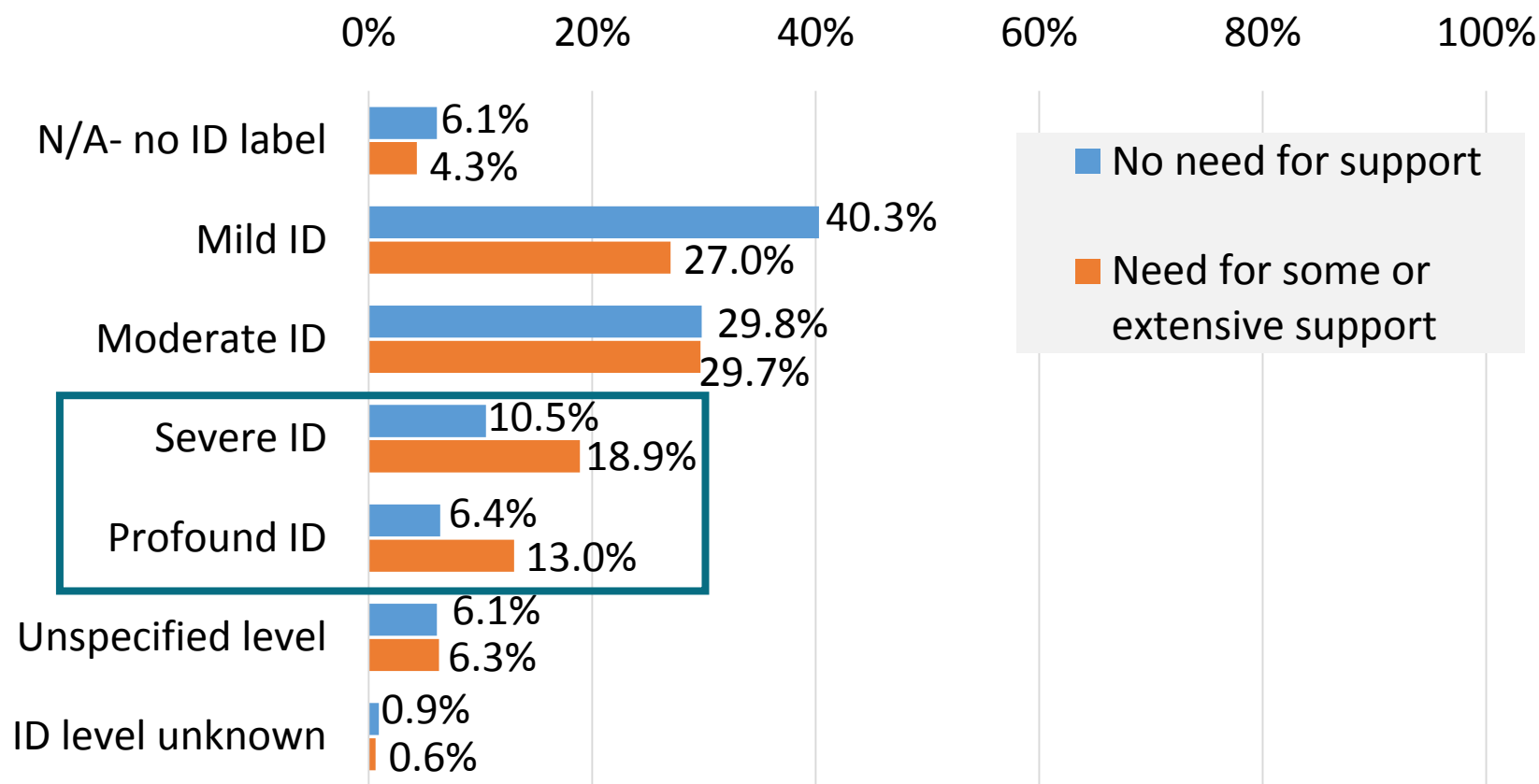
Need some or extensive support for SIB (N=15,581)



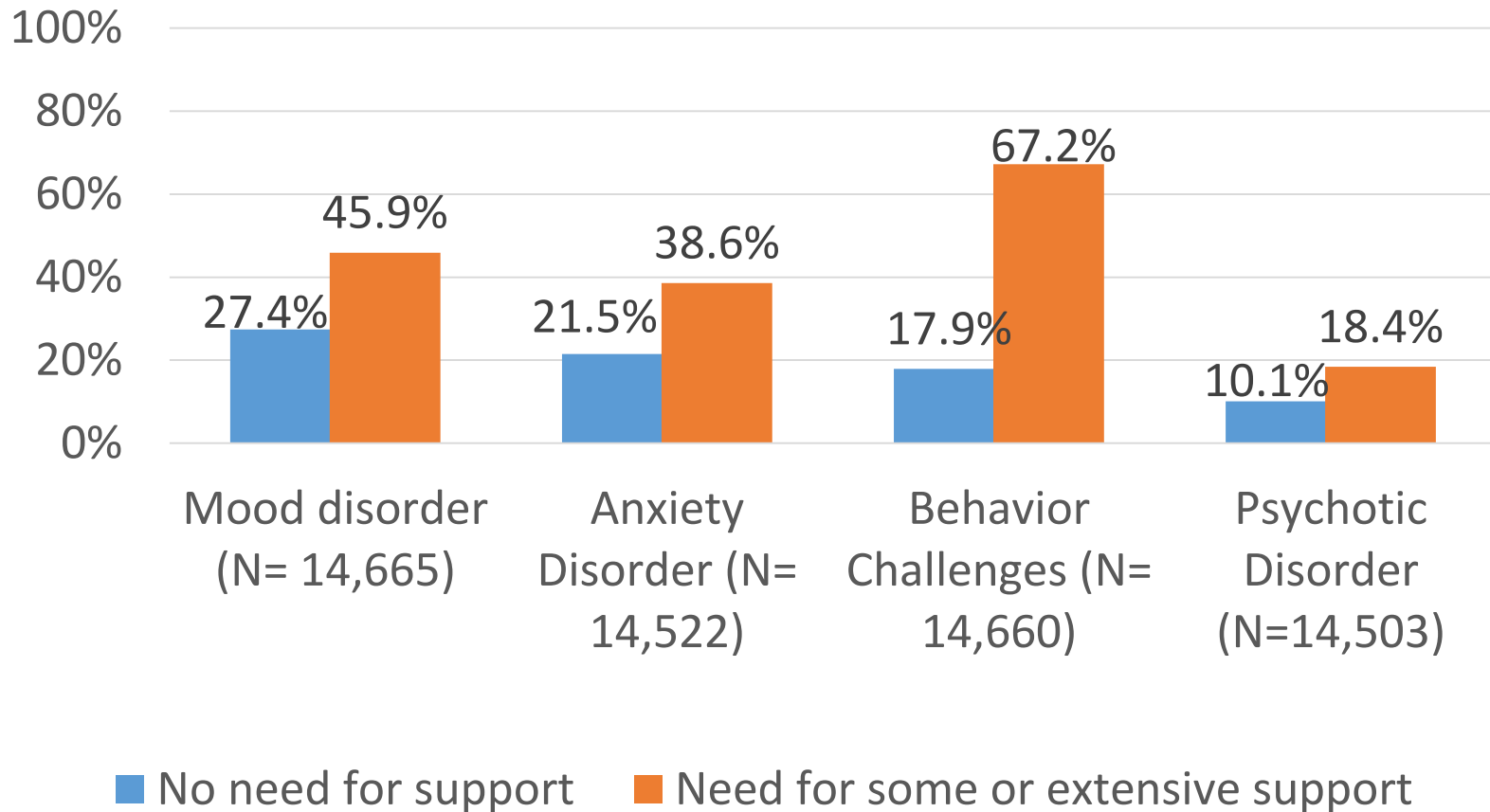
State Variation in Rate of Individuals Needing Support for SIB



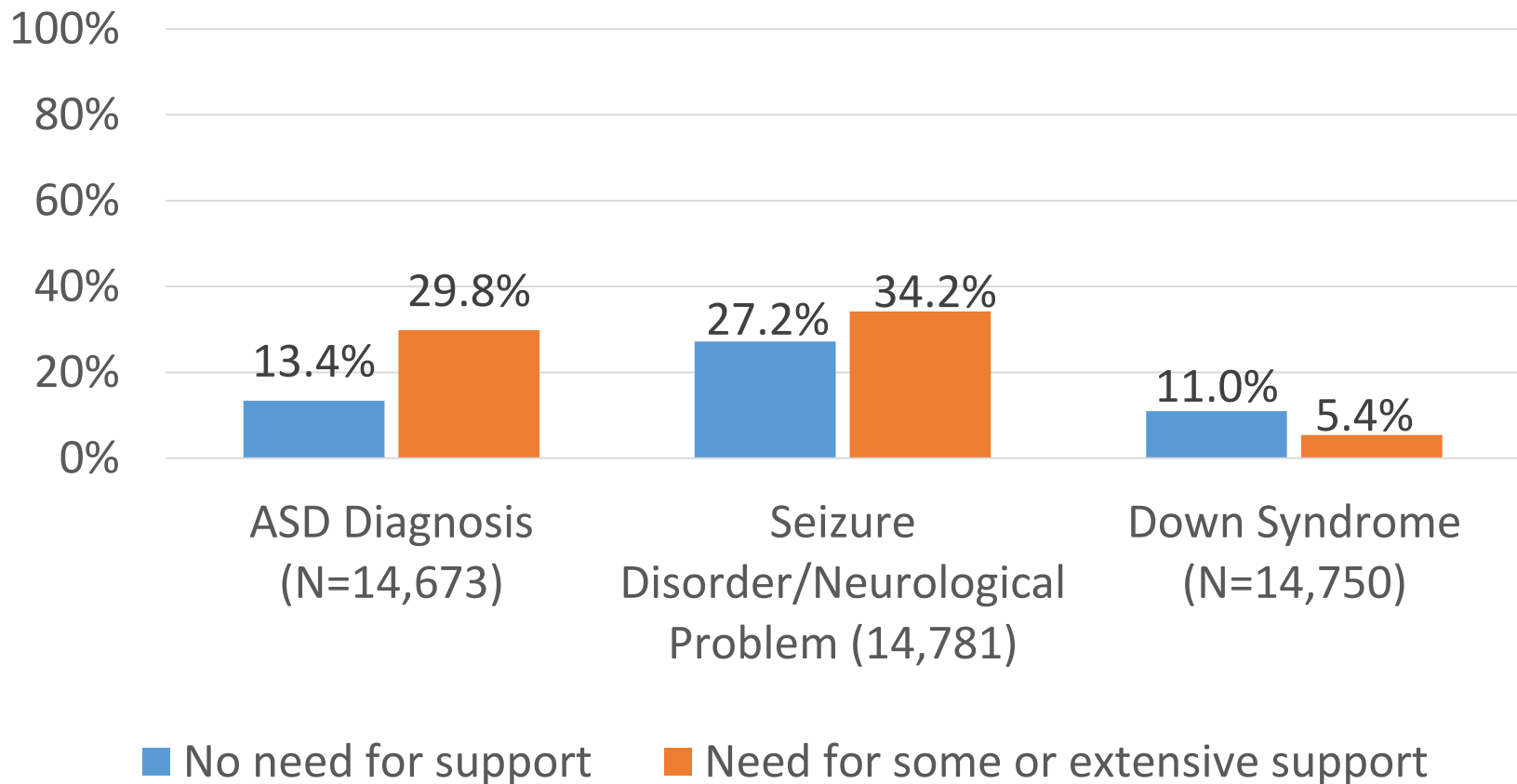
Those with SIB support needs... more likely to have severe or profound ID (N=15,301)



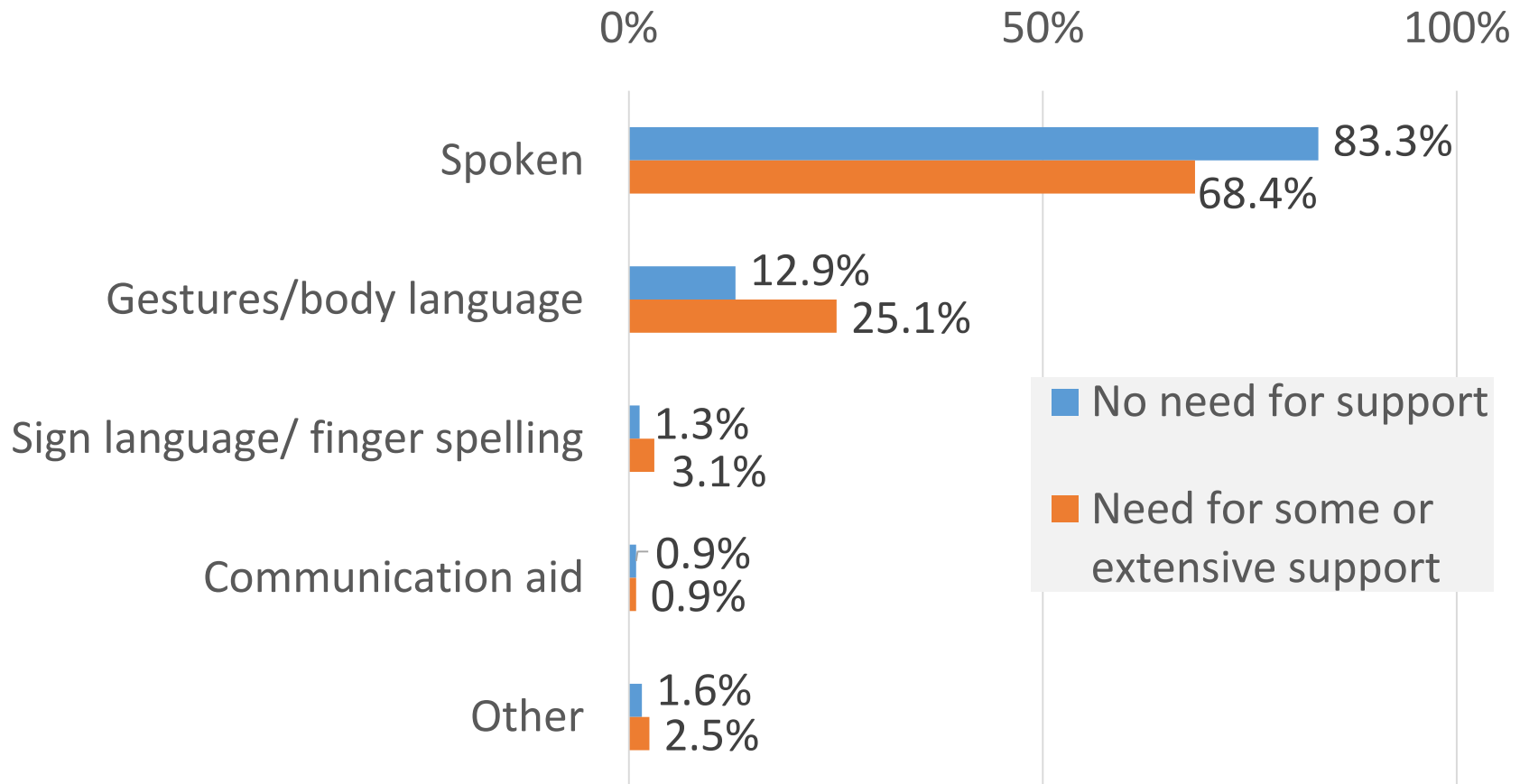
More likely to be diagnosed with mental health diagnoses



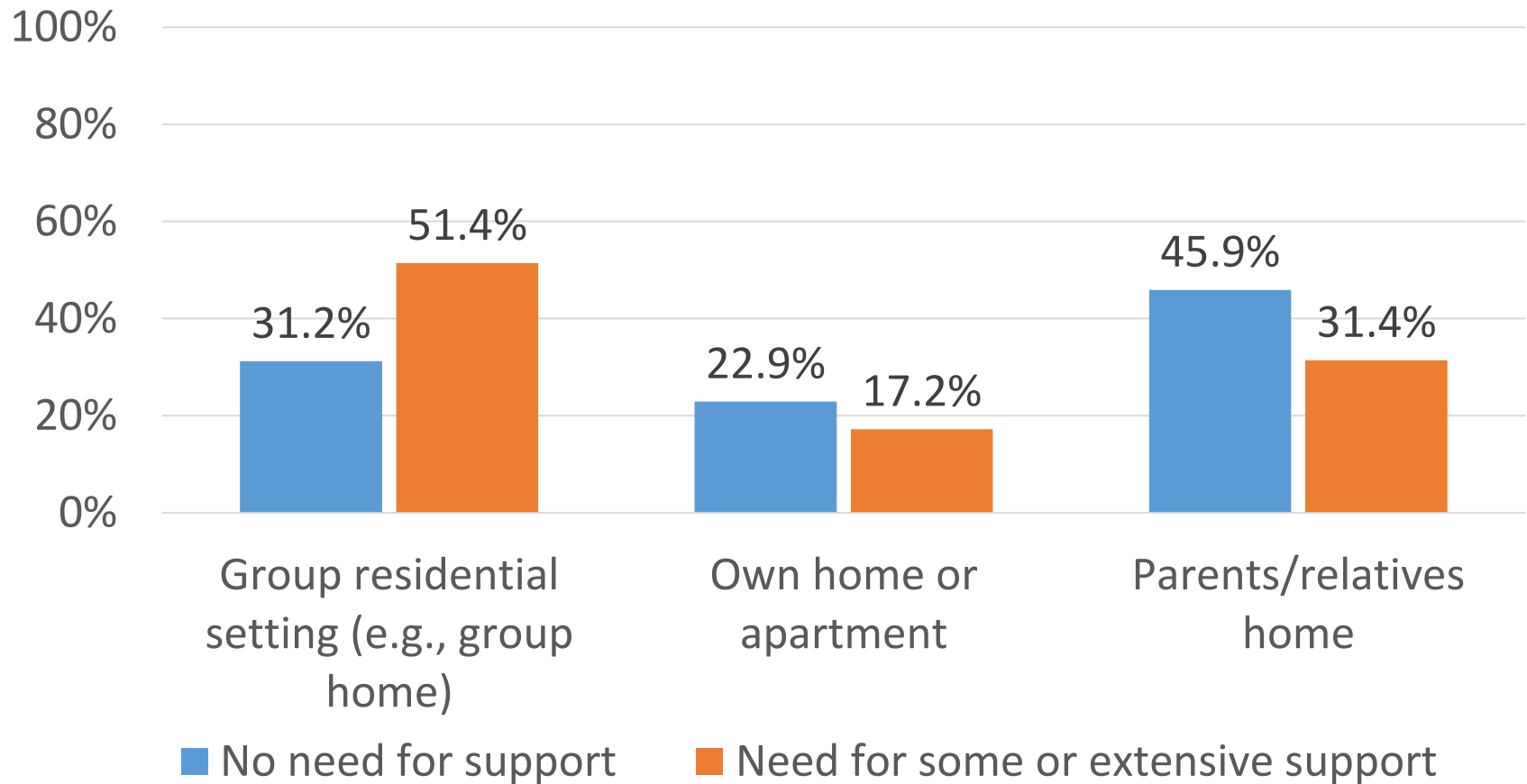
More likely to be diagnosed with ASD, seizure disorder/neuro problem; less likely to have diagnosis of Down syndrome



Less likely to prefer to communicate through spoken word; more likely to use gestures/body language (N=15,457)



Less likely to live in own home or with parent/relatives (N=14,325)



Of note...

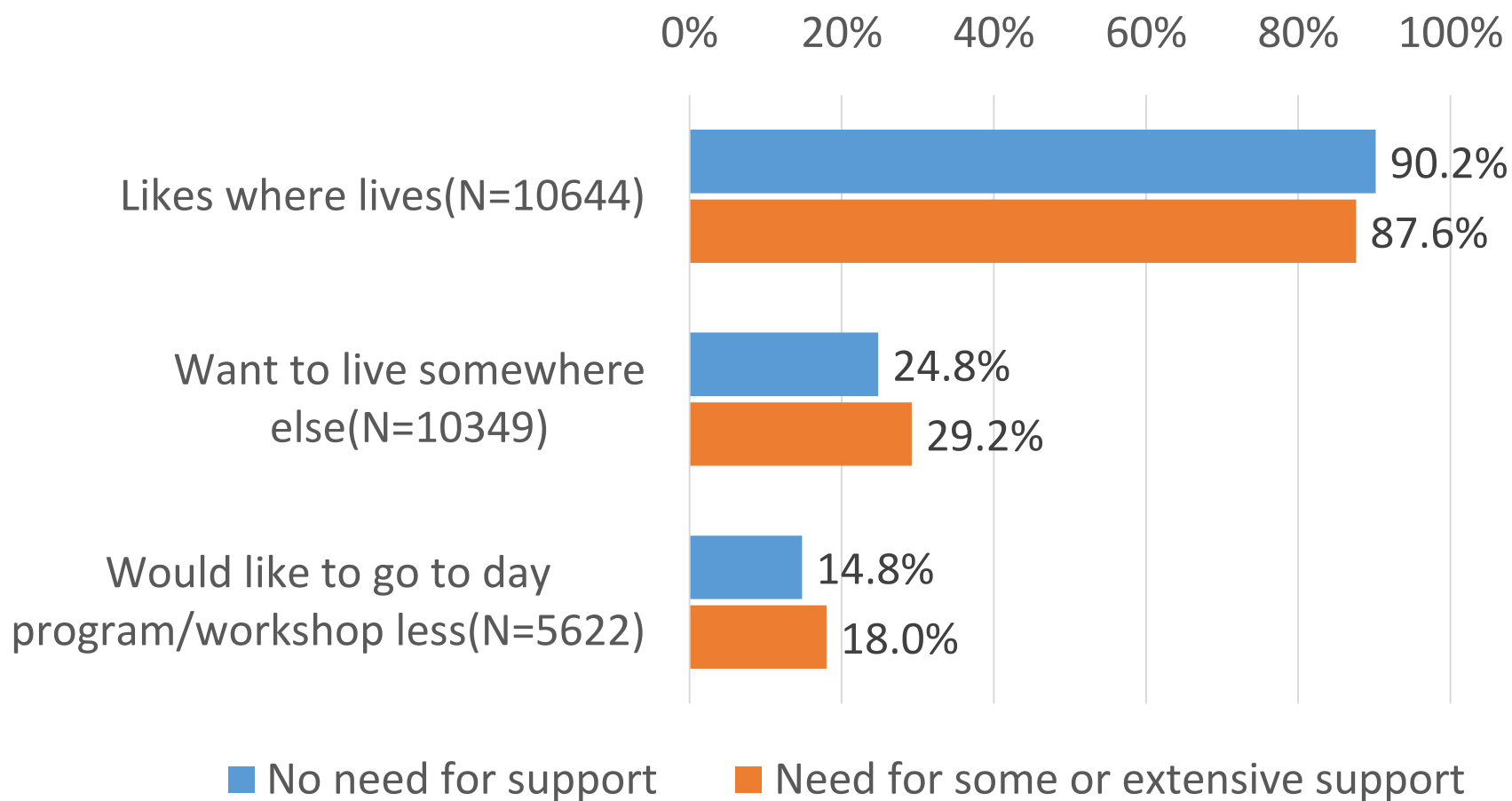
- No significant differences
 - In level of mobility
 - For those with hearing impairments
- Slightly significant difference in self-perceived health status
 - Those with SIB support needs were slightly more likely to report being in poor health

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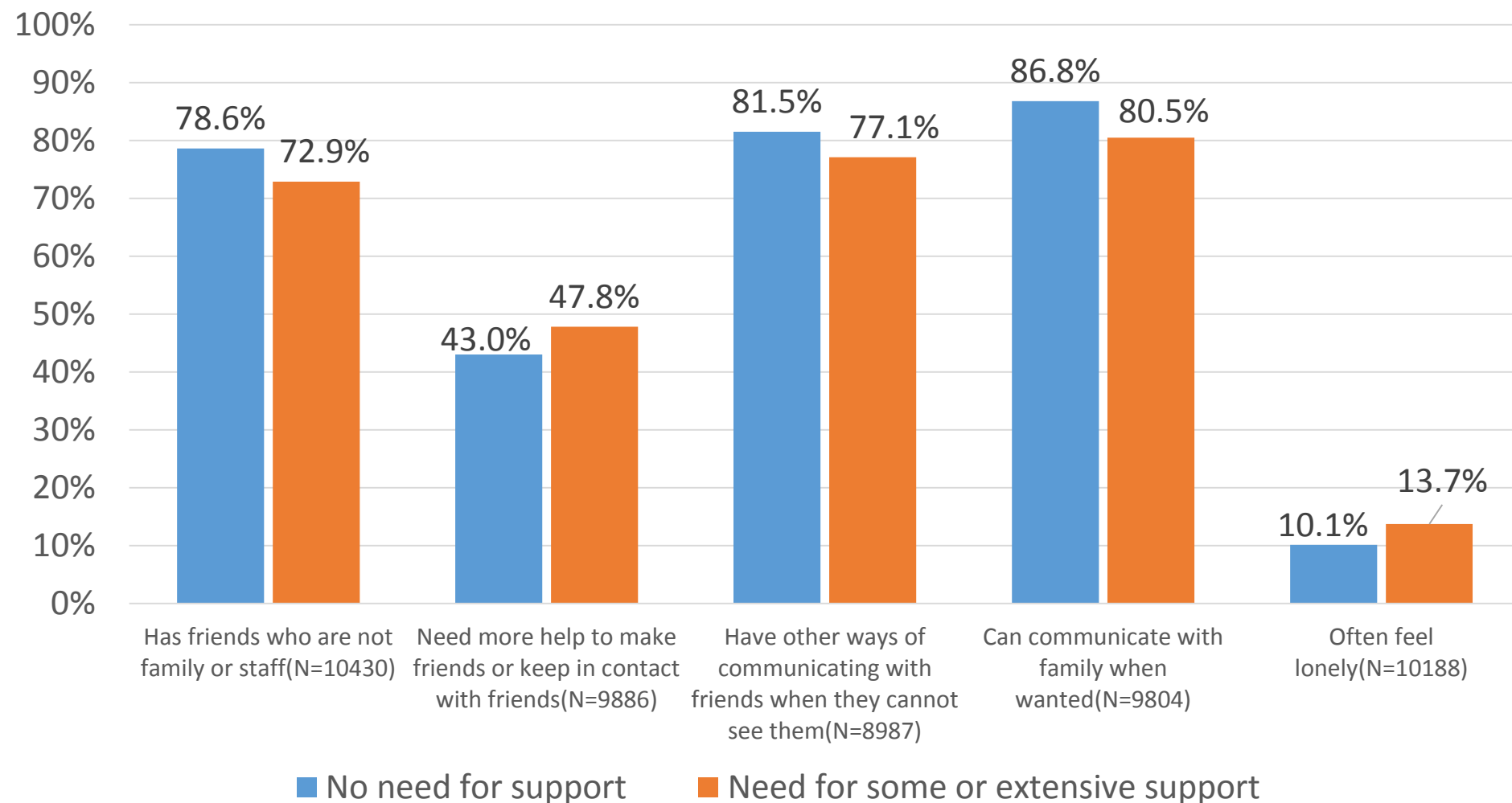


Outcomes

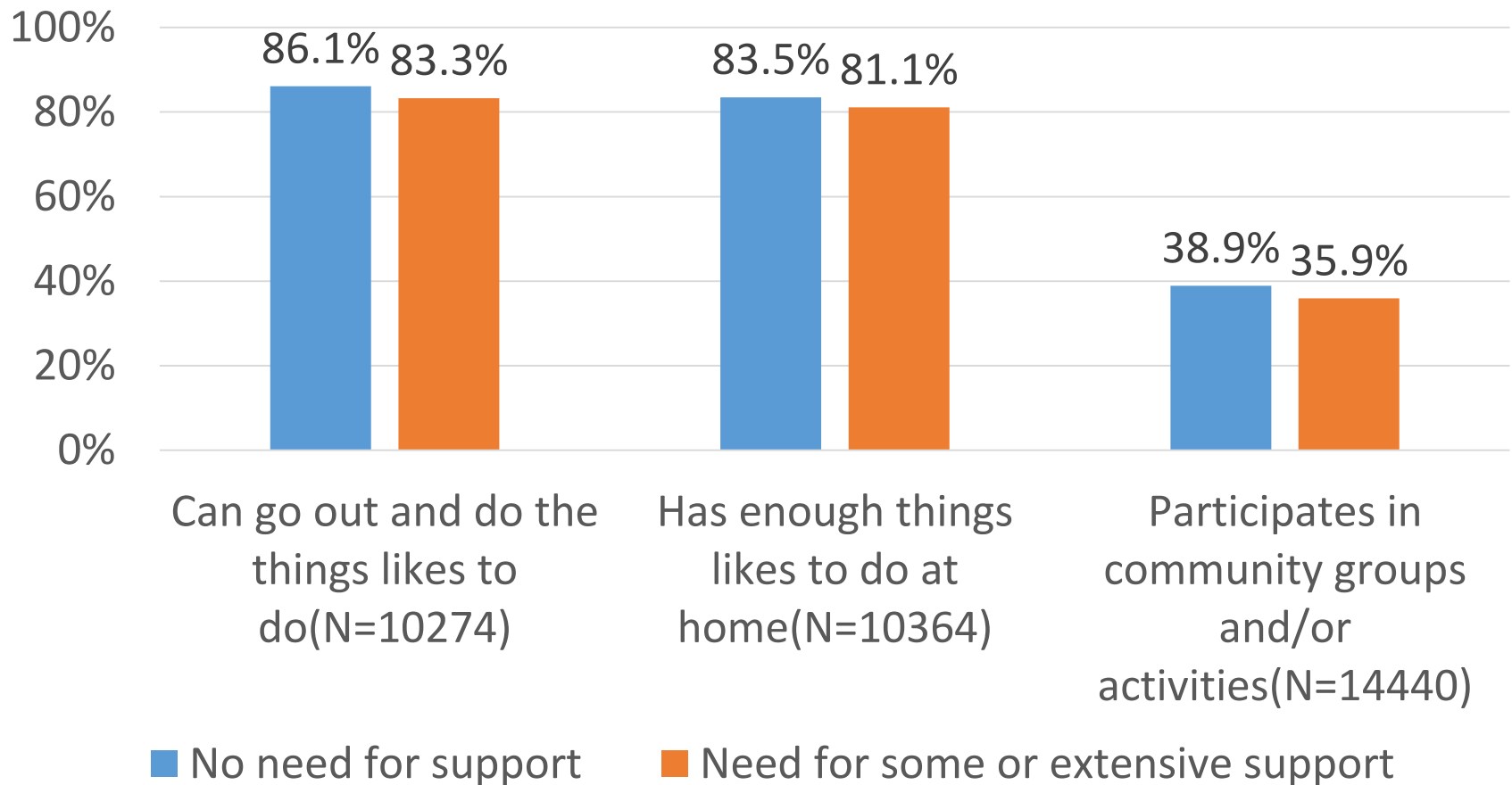
Those with SIB support needs express lower satisfaction



Less positive outcomes in the domain of relationships

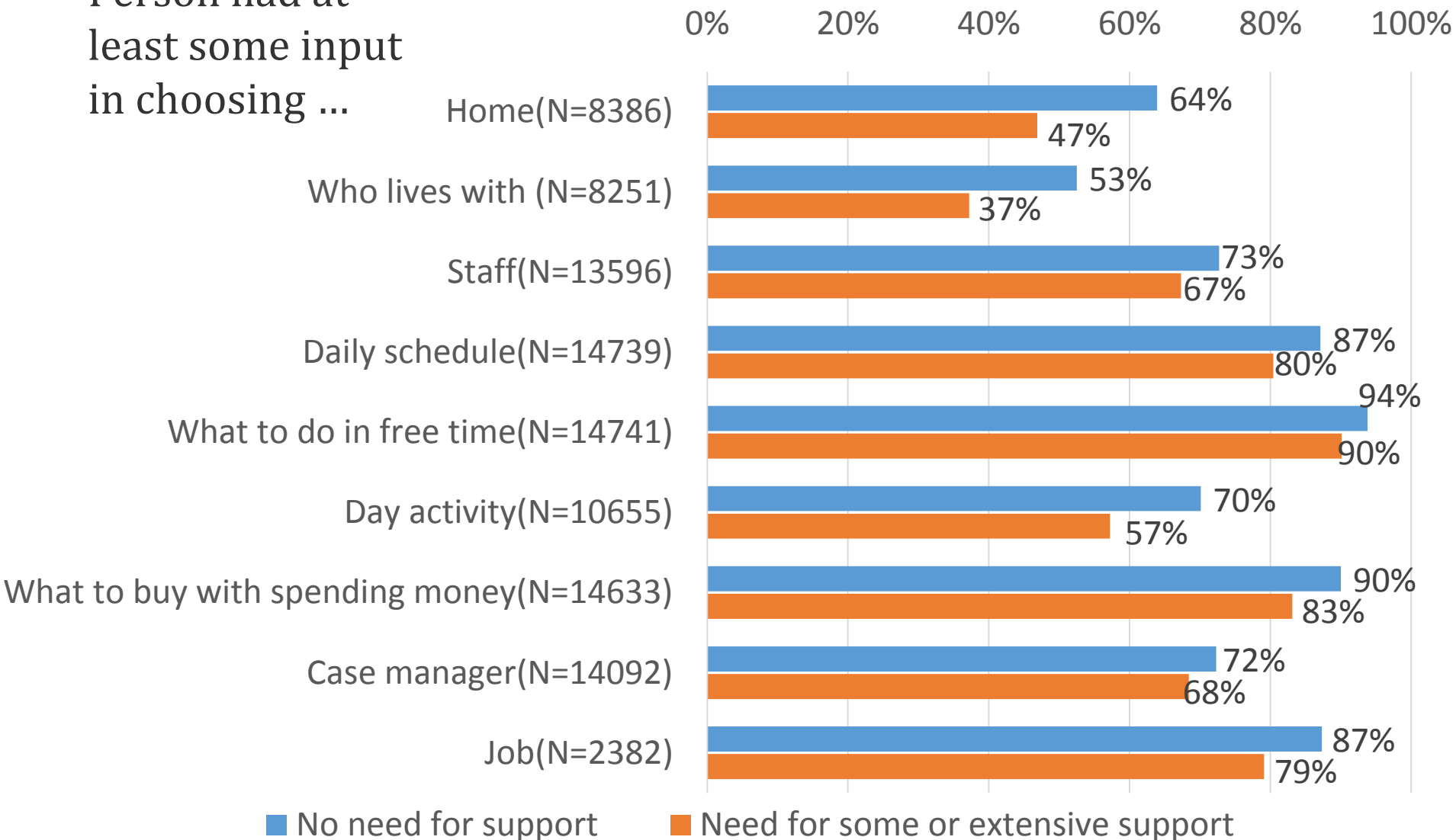


... the domain of community inclusion, participation and leisure

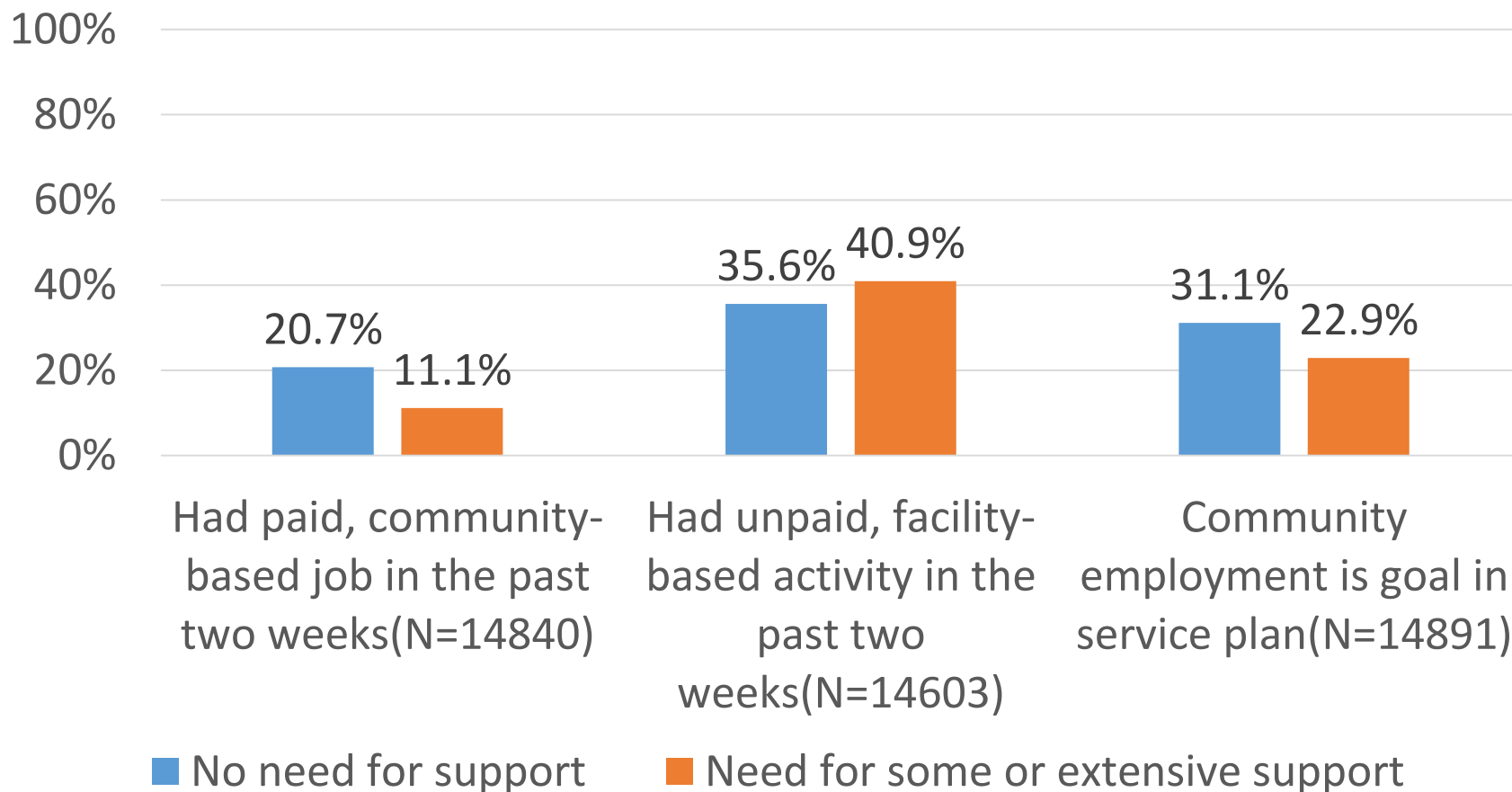


...Choice

Person had at least some input in choosing ...



And were less likely to have a paid, community-based job



Considerations for future research

- Identify system components that are related to better outcomes
 - Person-centered planning, Employment First policies, positive behavior supports
- What is the impact of other demographic/personal characteristics on outcomes for people with SIB support needs?
 - Do the presence of other factors have influence on outcomes for individuals with SIB support needs?



Considerations for public policy

- Standardized construct to facilitate accurate assessment of SIB
- Policy can reinforce the importance of functional assessment of adults with SIB; these assessments are critical to identifying potential causes and consequences of the behavior
- States can look at adoption of evidence-based practices such as positive behavior supports
- Necessitates training and education of those who implement the support



Considerations for public policy (continued)

- States can review state policy regarding behavior plans
- Public managers can look at their policies regarding aversive treatments
- States can also work to develop and maintain high standards regarding qualification, training, and quality assurance of those who provide support for SIB
- States can work to expand family supports (e.g., quality crisis and respite care)



What did she say?



Dorothy Hiersteiner
dhiersteiner@hsri.org