People With Self Injurious Behavior

WHAT DOES NCI DATA TELL US ABOUT THEIR CHARACTERISTICS AND OUTCOMES

VALERIE J. BRADLEY
PRESIDENT EMERITA, HSRI
NADD CONFERENCE, NOVEMBER 2, 2018

Overview

Introduction to NCI

Rationale for the analysis of individuals who need extensive support for self-injurious behavior

Review of the NCI Consumer Survey and the elements used for the analysis

Data on characteristics of individuals with and without need for support for SIB

Summary of data analysis

Implications for policy

What is NCI?

NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

Collaboration coordinated by HSRI and NASDDDS began in 1997

Currently 46 states and Washington D.C. represented plus 22 sub-state entities

Goals:

Establish a nationally recognized set of performance and outcome indicators for DD service systems

Use valid and reliable data collection methods & tools

Report state comparisons and national benchmarks of system-level performance
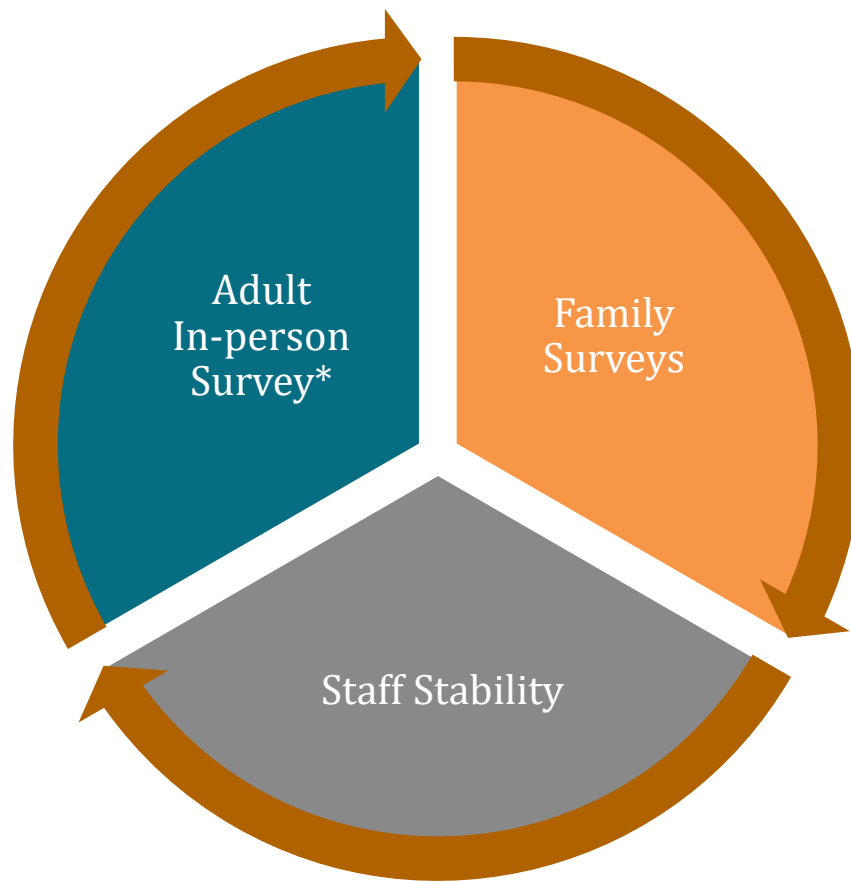
SURVEY TOOLS

*Formerly the Adult Consumer Survey (ACS)

Data Based on a Recent NCI Data Brief

National Core Indicators™
DATA BRIEF

APRIL 2017

What Do NCI Data Show About Respondents Who Need Some or Extensive Support for Self-Injurious Behavior?

What is Self-Injurious Behavior (SIB)?

Self-injurious behavior (SIB) is defined as self-inflicted harmful behavior that can result in injury and cumulative physical damage

SIB can have serious negative effects on both health and quality of life, may make it difficult to live in fully inclusive settings, and can lead to institutionalization

SIB lead to permanent physical harm

SIB can lead to social isolation and anxiety,

SIB presents significant caretaking challenges on families

Rationale for NCI Analysis

Many of the studies of SIB in the last several decades have been focused on individuals living in institutions

NCI provides information on the characteristics of individuals needing support for SIB outside of institutional settings—including individuals living with their families and in their own homes

NCI makes it possible to link data on individuals who need support for self-injurious behavior with information on outcomes (e.g., employment, place of residence, choice, etc.)

An analysis of the characteristics of this group of adults and outcomes from services provides the foundation for both policy and clinical recommendations.

Adult Consumer Survey: How is it Administered?

Limited to individuals who receive at least one service from the IDD agency, beyond case management

Face-to-face survey with the person over 18 receiving services

Survey includes three main parts:

◦ Background information – largely collected from state records (sometimes from case records, families, etc.)

◦ Section I – Subjective questions only the person can answer

◦ Section II – Objective questions can be answered by a proxy when needed

What Data Were Used?

Data in this analysis are from the 2015-2016 administration of the National Core Indicators (NCI) Adult Consumer Survey (ACS).

The total sample includes data from 35 states and the District of Columbia. The total national sample for 2015-2016 outside of institutional settings totals 16,372 cases

In the Background Information Section, there is a question on the individual's level of Behavioral Support Needs in three separate types of behavior: self-injurious, disruptive, and destructive. The response options are "no support needed," "some support needed; requires only occasional assistance or monitoring," "extensive support needed; frequent or severe enough to require regular assistance," and "don't know."

How Was the Data Analyzed?

For purposes of this analysis, "don't know" and missing responses were excluded

Of the 15,581 responses to the question, the total number individuals needing some support to manage SIB was 2,774, or 17.8% of the sample

The total number of records indicating need for **extensive** support to manage SIB was 843, or 5.4%.

And the total number of records indicating that no support was needed for SIB was 11,964, or 76.8%.
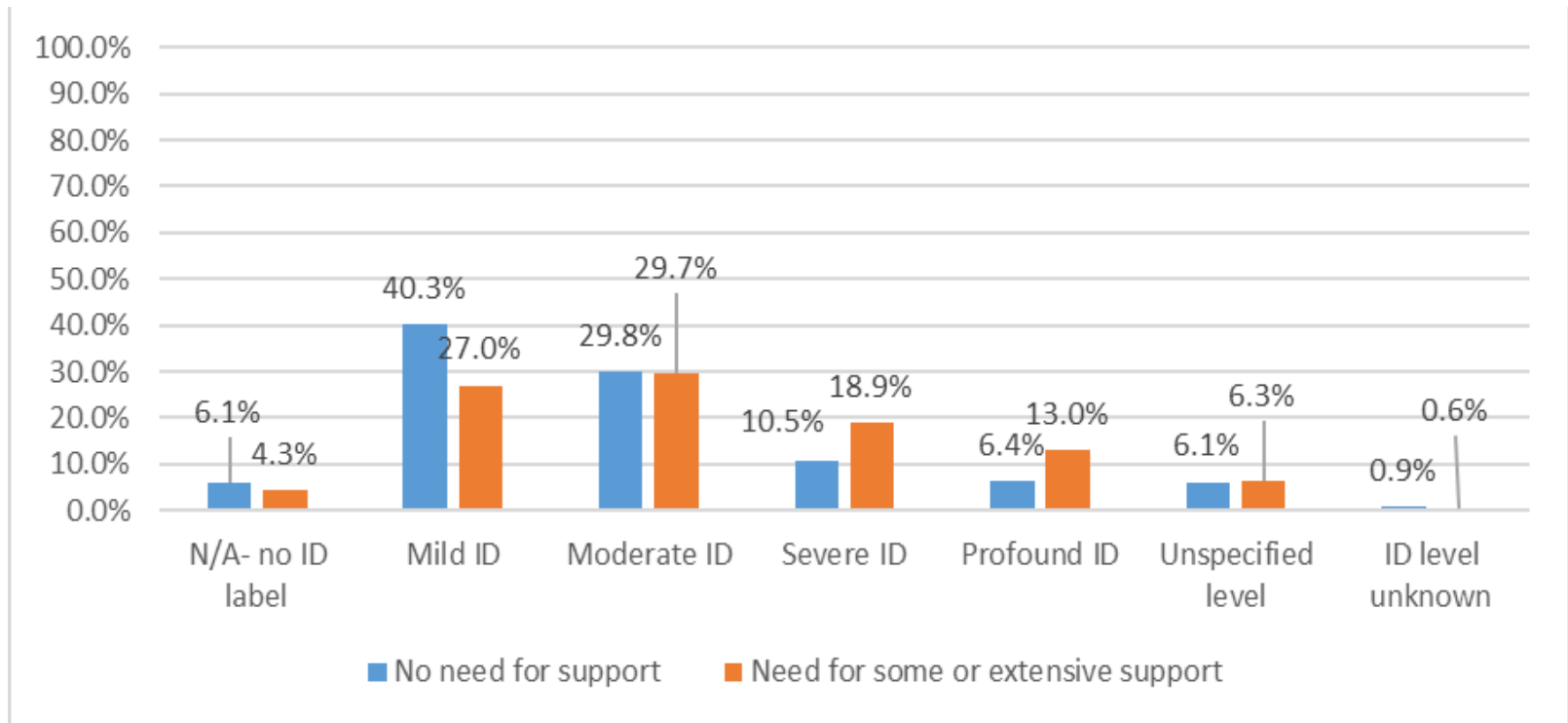
A binary variable was created in which the response options "some support needed to manage SIB" and "extensive support needed to manage SIB" were collapsed. Based on the resulting variable, 3,617 cases, or 23.2% of the total cases needed some or extensive support for SIB. **However, the range among the states was 14% to 46%**
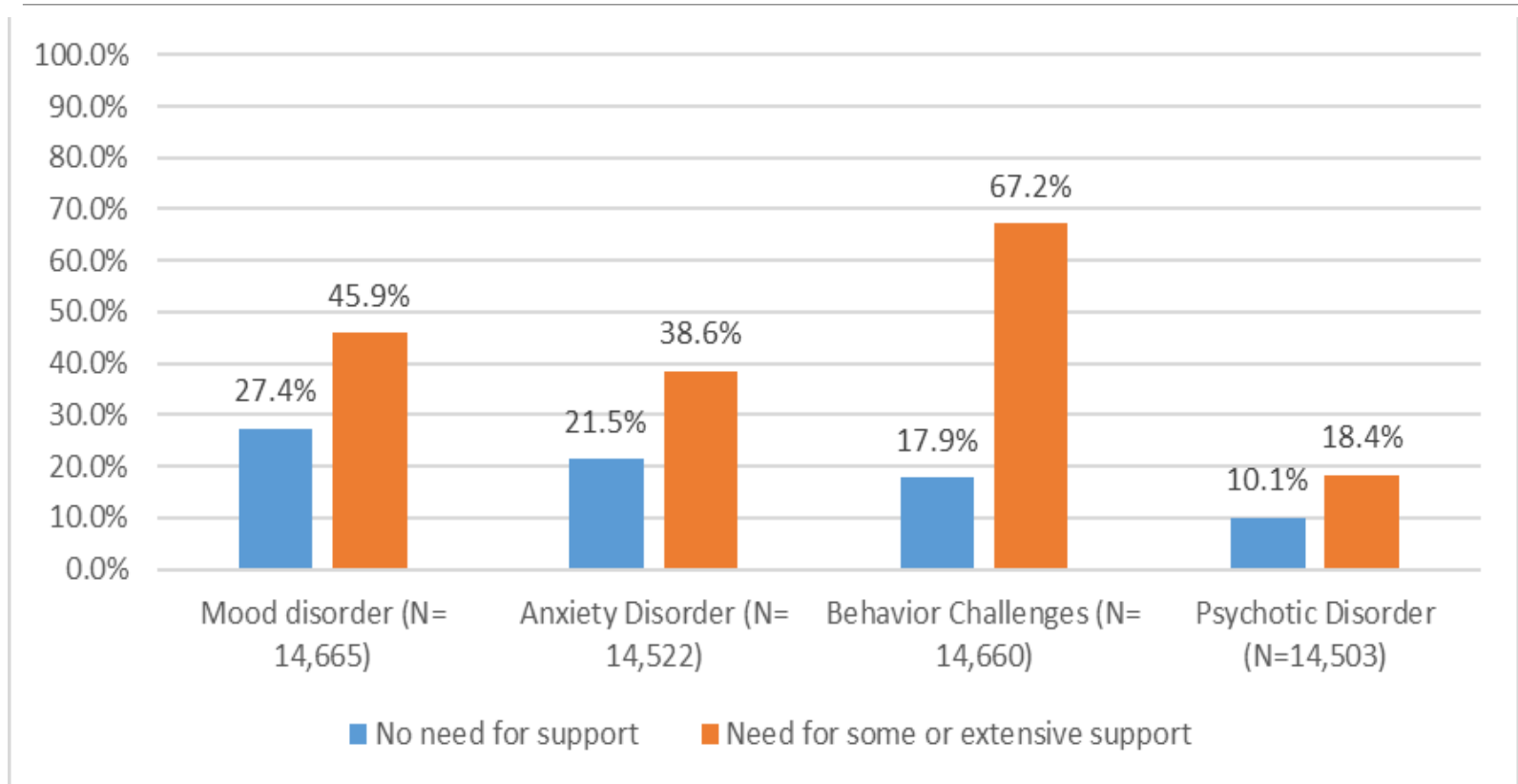
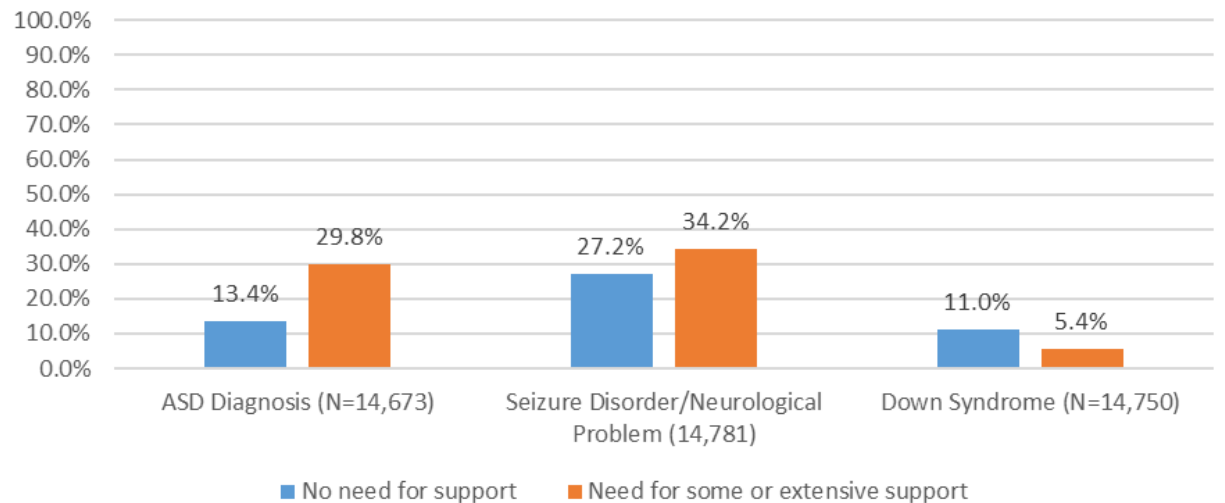# Racial and Ethnic Characteristics

N=14,252
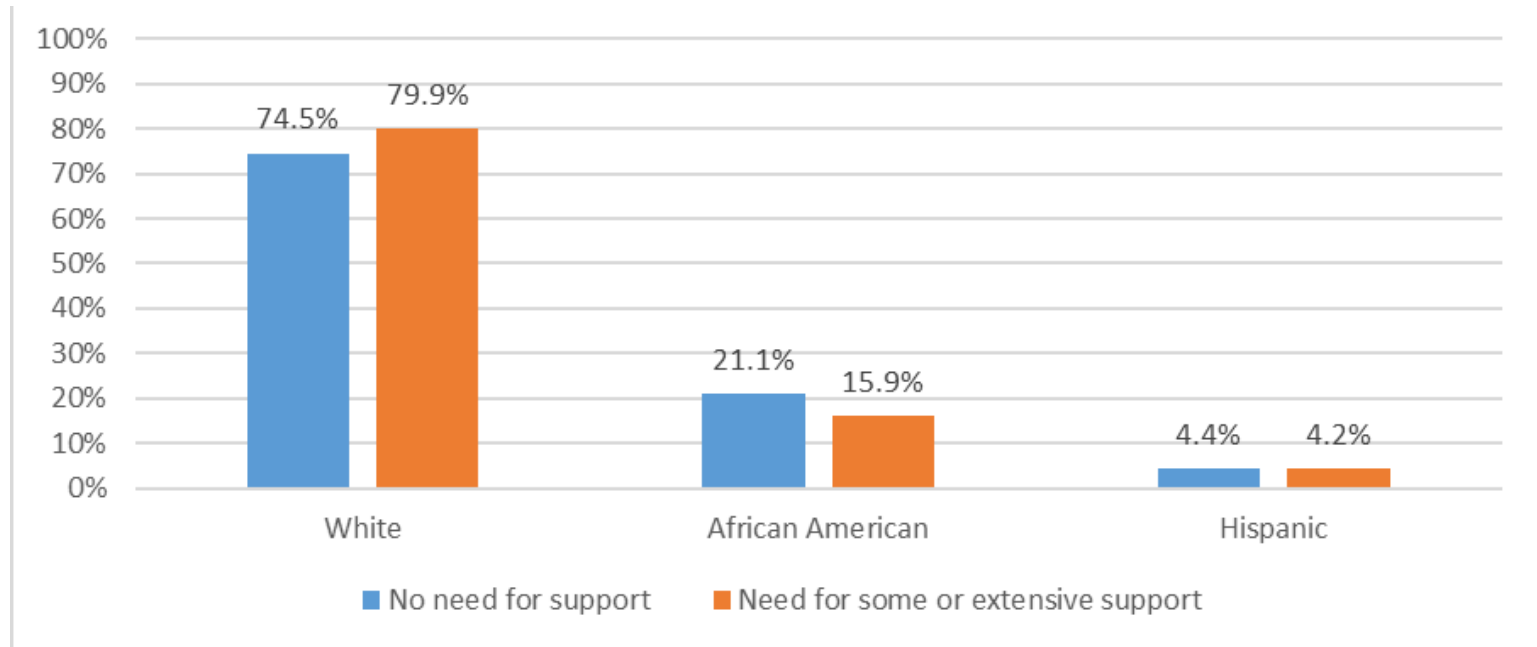
Level of Intellectual Disability

Mental Health Diagnosis

Other Diagnoses

Bar chart comparing support needs across diagnoses:

- **ASD Diagnosis (N=14,673):** No need for support 13.4%, Need for some or extensive support 29.8%
- **Seizure Disorder/Neurological Problem (14,781):** No need for support 27.2%, Need for some or extensive support 34.2%
- **Down Syndrome (N=14,750):** No need for support 11.0%, Need for some or extensive support 5.4%

Legend: ■ No need for support ■ Need for some or extensive support

Preferred Means of Communication

(N=15,457)

	Spoken	Gestures/body language	Sign language/ finger spelling	Communication aid	Other
No need for support	83.3%	12.9%	1.3%	0.9%	0.9%
Need for some or extensive support	68.4%	25.1%	3.1%	0.9%	0.9%

■ No need for support   ■ Need for some or extensive support
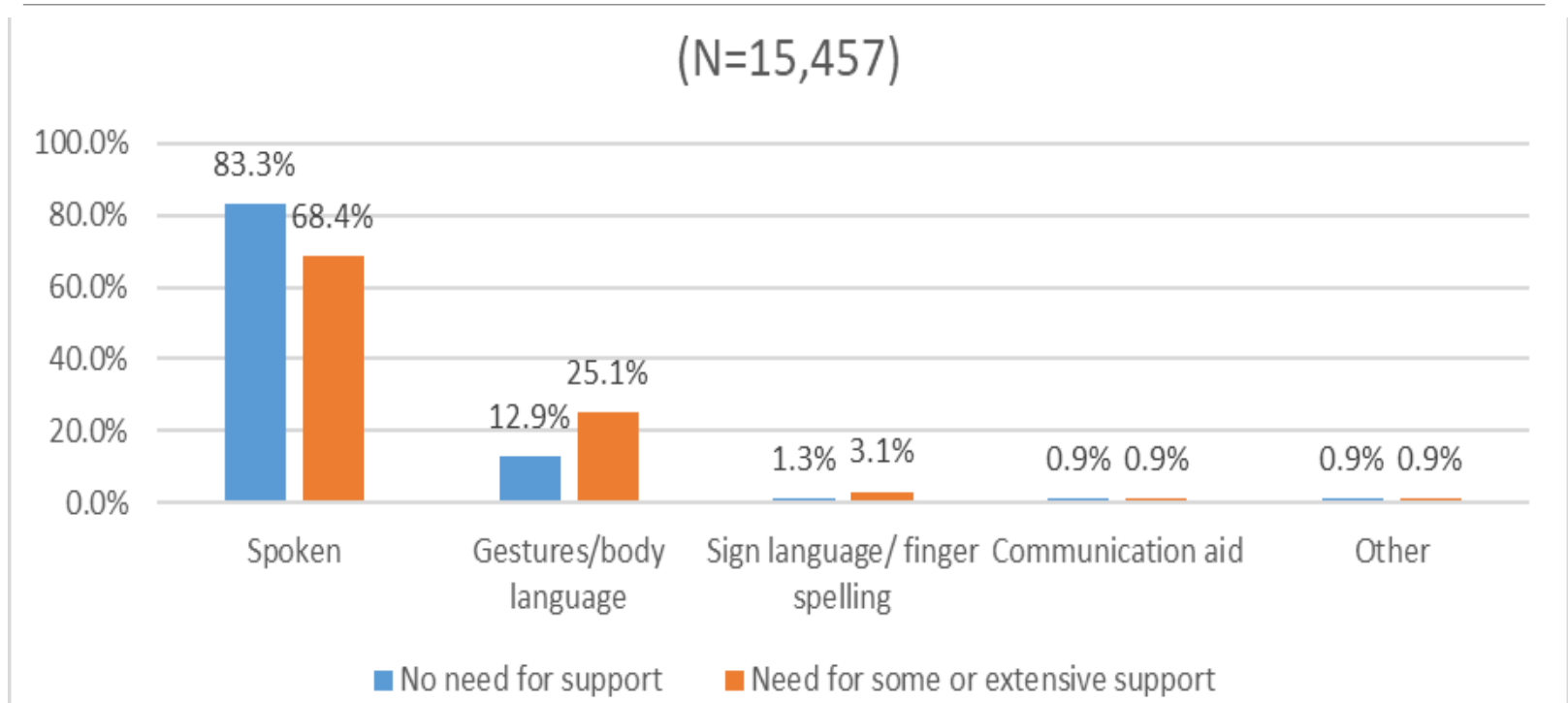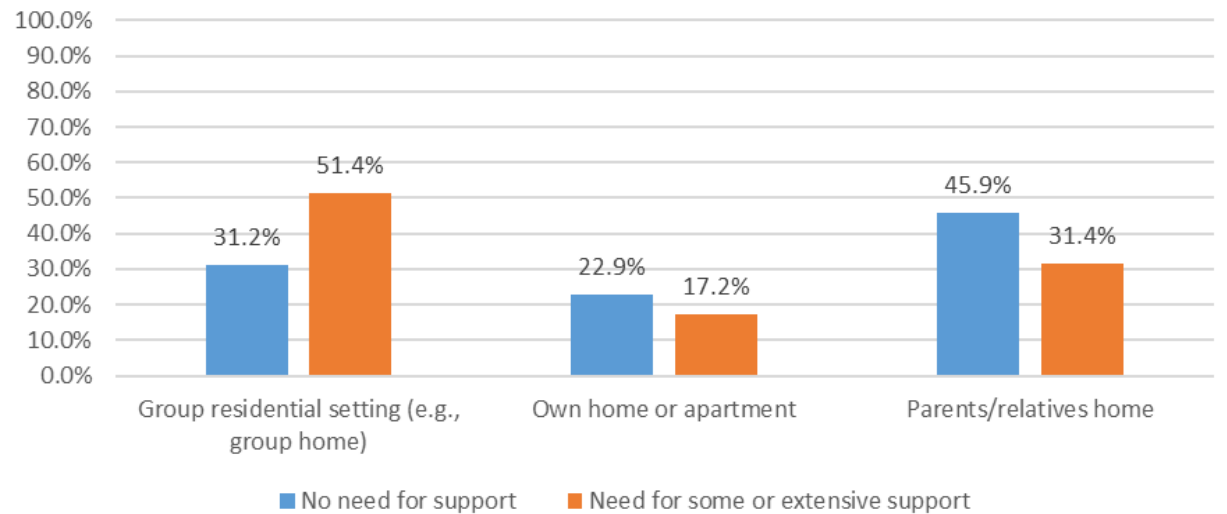
Other Behavioral Support Needs
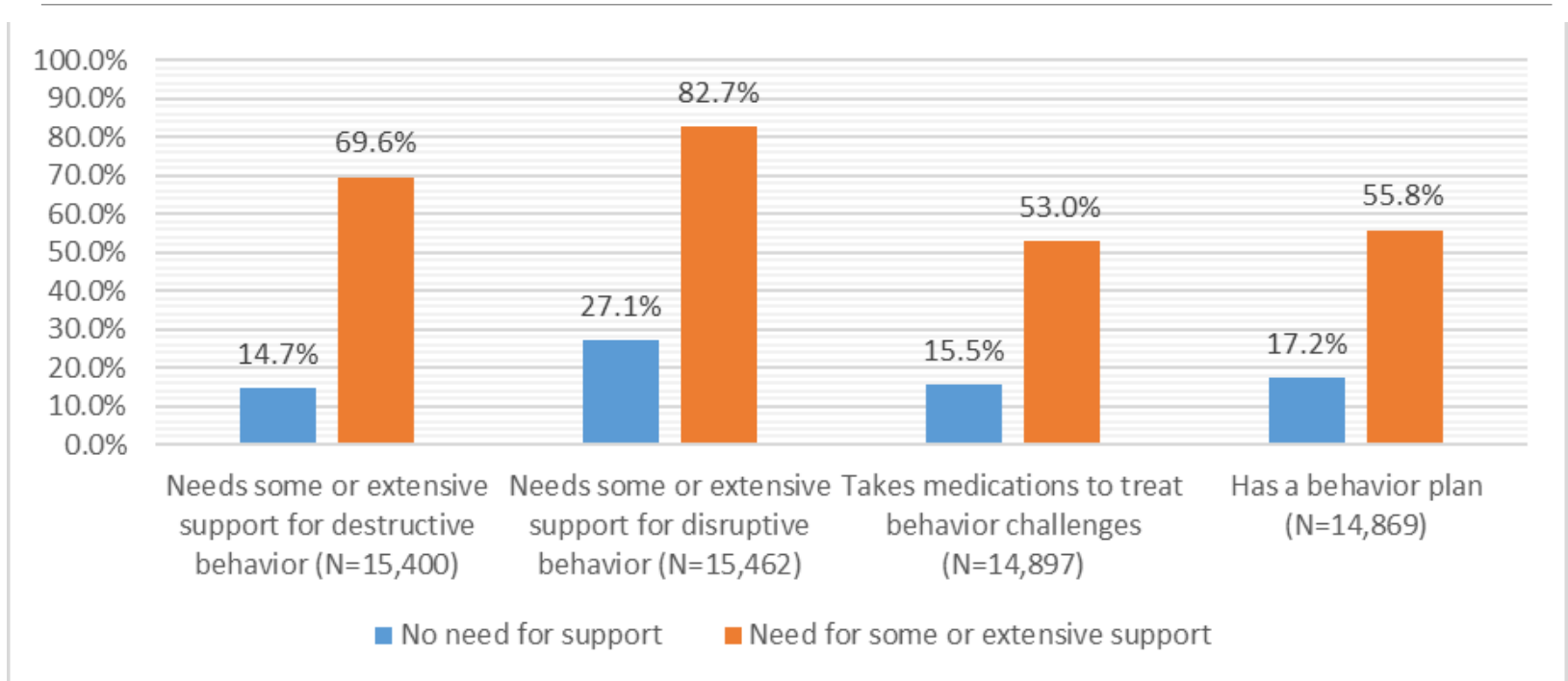
Where Do People Live?

N=14,325

Satisfaction with Supports

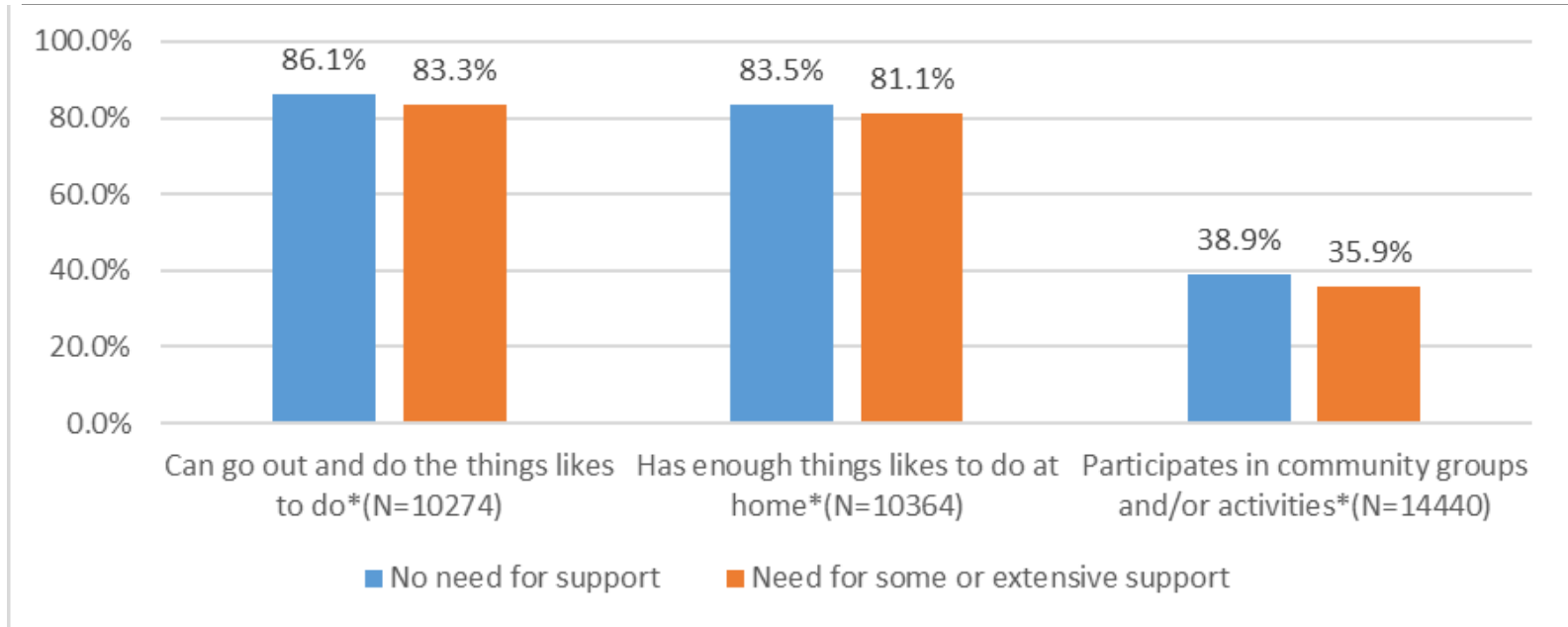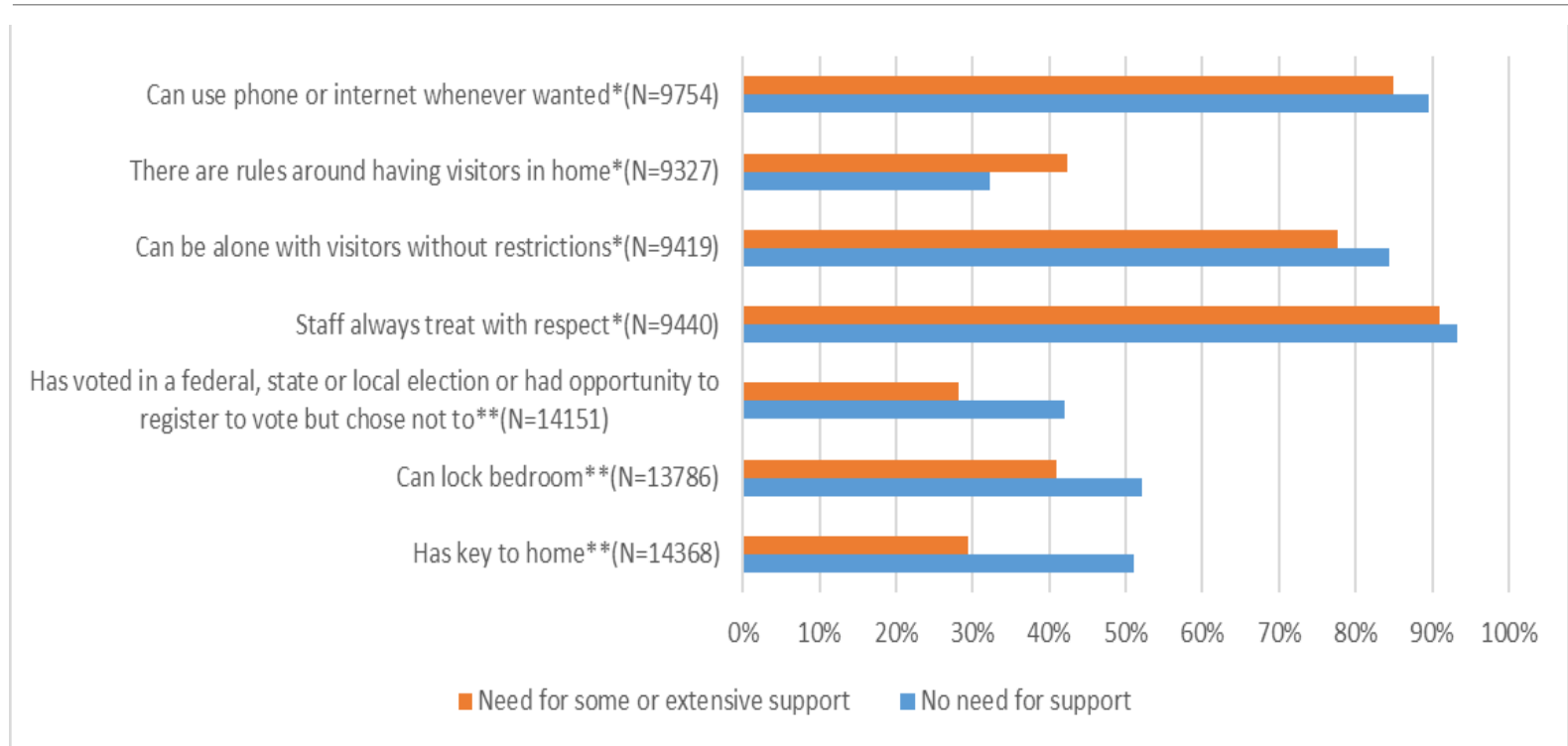| | 90.2% | 87.6% | | | | | | | |
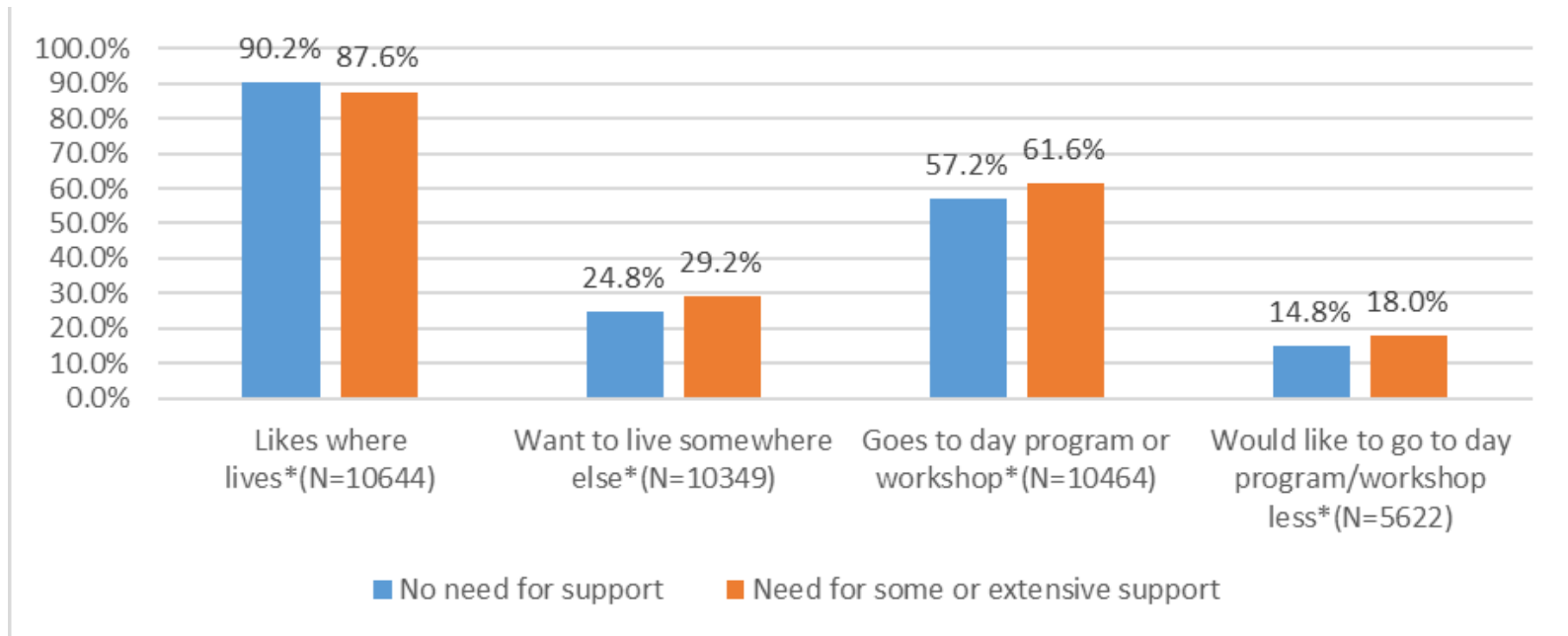
Relationships
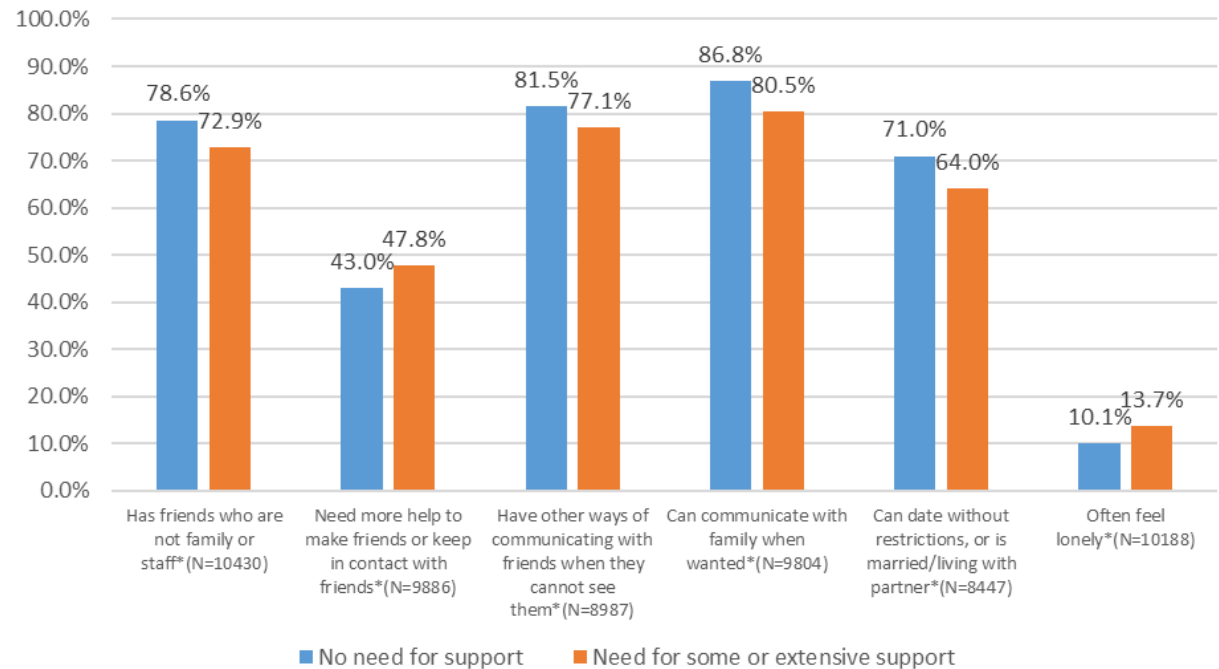
Community Inclusion, Participation and Leisure

Choice

	No need for support for SIB	Need for some or extensive support for SIB
Chose or had some input in choosing home**(N=8386)	63.9%	46.9%
Chose or had some input in choosing who lives with (if not living in family home)**(N=8251)	52.5%	37.2%
Chose or had some input in choosing staff**(N=13596)	72.7%	67.3%
Chose or had some input in choosing daily schedule**(N=14739)	87.1%	80.4%
Chose or had some input in choosing what to do in free time**(N=14741)	93.8%	90.1%
Chose or had some input in choosing day activity**(N=10655)	70.1%	57.2%
Chose or had some input in choosing what to buy with spending money**(N=14633)	90.0%	83.1%
Chose or had some input in choosing case manager**(N=14092)	72.3%	68.4%
Chose or had some input in choosing job**(N=2382)	87.3%	79.1%

Rights and Respect

Chart: Rights and Respect, comparing "Need for some or extensive support" (orange) and "No need for support" (blue) across the following categories:

- Can use phone or internet whenever wanted*(N=9754)
- There are rules around having visitors in home*(N=9327)
- Can be alone with visitors without restrictions*(N=9419)
- Staff always treat with respect*(N=9440)
- Has voted in a federal, state or local election or had opportunity to register to vote but chose not to**(N=14151)
- Can lock bedroom**(N=13786)
- Has key to home**(N=14368)

Legend:
- ■ Need for some or extensive support
- ■ No need for support
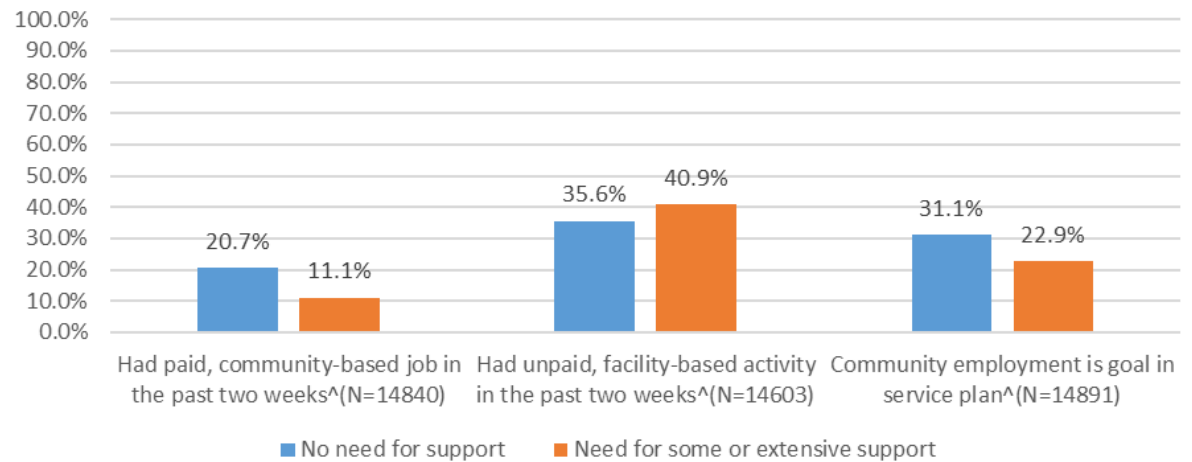
Employment

Employment by SIB support need

Summary of Characteristics of Individuals Who Need Support for SIB

People with need for support for SIB are:

More likely to have a diagnosis of ASD and/ or seizure disorder/neurological problem. They are significantly less likely to be reported to have a diagnosis of Down Syndrome.

Significantly less likely to use spoken communication, and significantly more likely to prefer using gestures/body language or sign language/finger spelling

More likely to be reported to also need some or extensive support for destructive behavior and/or disruptive behavior.

Significantly more likely to be reported to take medications for behavior challenges

Significantly more likely to be reported to have a behavior plan in place. However, said differently, NCI data demonstrate that 42.5% of those who need some or extensive support for SIB do not have a behavior plan in place.

Significantly more likely to be reported to be living in a ICF/ID, nursing facility, other institutional setting or group residential setting than those who do not need support for SIB.

Summary of Outcomes for People Who Need Support for SIB

Those who are reported to need some or extensive support for SIB are

Less likely to like where they live, more likely to want to live somewhere else, more likely to go to a day program and to want to spend less time in their day program

More likely to feel afraid in their home, day program, work, community, transport and/or other situation.

Less likely to have friends who are not family or staff, have ways of communicating with those friends when they cannot see each other, communicate with family when wanted and be able to date without restrictions. They are significantly more likely to need more help keeping in touch with friends and to feel lonely often.

Less likely to go out and do the things they like to do, to have enough things they like to do at home and to participate in community groups/activities.

Less likely to report having at least some input in critical life decisions (e.g., where to live and with whom, what to buy, etc.)

Less likely to report that they have a key to their home, can lock their bedroom if wanted, have voted in a state, federal or local election (or had the opportunity but chose not to register).

Less likely to report that staff always treat them with respect, that they can be alone with visitors without restrictions and that they can use the phone or internet whenever wanted. They are more likely to report that there are rules around having visitors in their home.

Less likely to report that they have a paid-community based job, and more likely to report having an unpaid, facility based activity in the past two weeks. They are also less likely to report having community employment as a goal in their service plan.

Implications

The proportion of individuals needing some or extensive support for self-injurious behavior ranged from 14% to 46%. This strongly suggests there is a need for better diagnosis and classification criteria

Given the diminished outcomes experienced by those who need support for SIB, there is a need for more evidence-based interventions

Given findings by Rotholz and Moseley, there is a need for more standardized training requirements for those who need support for SIB

Many states still allow aversive therapies that can cause pain – there is no evidence that these interventions ameliorate SIB

NCI data indicate that many families report that they are not able to get crisis services when they need them – there needs to be more aggressive efforts to develop crisis resources