National Core Indicators™

DATA BRIEF

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

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For people with intellectual and developmental disabilities, self-injurious behavior (SIB) can have serious negative effects on health and quality of life. Here, we examine the National Core Indicator Adult Consumer Survey data to explore the characteristics and outcomes of people with SIB support needs. Across areas such as employment, choice, community inclusion, relationships and safety, we find that respondents who need some or extensive support for SIB exhibit fewer positive outcomes than respondents without SIB support needs.

This data brief concludes with some recommendations for further research and considerations for public policy changes to ensure an evidence-based and person-centered approach to supporting individuals with SIB.

Background

Self-injurious behavior (SIB) is defined as self-inflicted harmful behavior that can result in injury and cumulative physical damage.[1] For people with intellectual and developmental disabilities, SIB can have serious negative effects on both health and quality of life[2] and may make it difficult to live in fully inclusive settings. Not only can the presence of SIB lead to permanent physical harm, it can also lead to social isolation and anxiety—and it can impose caretaking challenges on families. In some cases, the presence of SIB may lead to life in an institutional setting. Because of the intensity of need of individuals with SIB, the societal costs in terms of public and private resources are also significant.

As of now, the evidence base for effective approaches to support people with SIB is limited. Until recently, people diagnosed with SIB were often subjected to aversive and painful interventions including electric shock—and, even today, people with SIB are still often restrained. Yet some newer therapeutic interventions are showing promise. Functional analysis, which involves determining the cause of the behavior (e.g., inability to express oneself, pain, etc.), has resulted in the development of targeted therapeutic interventions. Positive Behavior Supports (PBS), for example, is a person-centered approach that assumes the behavior is a means of communication. PBS is aimed at identifying the cause of the behavior and helping the individual with their goals.

This data brief looks at the NCI sample of adults with intellectual and developmental disabilities who receive state supports. Using the NCI sample, we compare the personal characteristics and outcomes experienced by those who are identified as needing support for SIB (either some support or extensive support) to those identified as not needing support for SIB. An analysis of the characteristics of this group of adults and their outcomes from services provide the foundation for both clinical recommendations and policy considerations.

Description and Characteristics of Sample

The data in this brief are from the 2015-2016 administration of the National Core Indicators (NCI) Adult Consumer Survey. All individuals surveyed were age 18 or over and receiving at least one service beyond case management. The total sample includes data from 35 states and the District of Columbia.[3]

Many of the studies of SIB in the last several decades have focused on individuals living in institutions; this data brief offers information on the characteristics of individuals with SIB support needs *outside* of institutional settings—including individuals living with their families and in their own homes. The NCI Sample outside of institutional settings totals 16,372 people.

The questions analyzed for this data brief come from the Background Information Section and from Sections I and II of the NCI Adult Consumer Survey. **The Background Information Section** contains data that would most likely be found in agency records or information systems. In most states, this section is completed prior to a face-to-face interview with the person receiving services. **Section I** of the survey solicits information about individual satisfaction with a range of services and situations and can only be completed by the individual during the interview. **Section II** questions can be answered by a proxy who knows the person well, such as a family member or a staff person, if the individual is unable to respond. (Case managers or service coordinators are *not* allowed to respond on the individual's behalf.)

The Background Information Section contains a subsection titled Behavioral Support Needs. Those completing this portion of the survey (typically a case manager or a state agency staff member) are asked to identify the level of support needed by the adult for 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." The following analysis excludes "don't know" and missing responses from the denominator.

Of the 15,581 responses to the question regarding self-injurious behavior (not including "don't know" responses), the total number of records indicating a need for some support to manage SIB was 2,774, or 17.8%. The total number of records indicating a need for extensive support to manage SIB was 843, or 5.4%. And the total number of records indicating that no support is needed for SIB was 11,964, or 76.8%. For the purposes of this analysis, 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 people, or 23.2% of the total cases, needed some or extensive support for SIB.

Chi-squared analyses were conducted to assess whether significant relationships existed between the groups of individuals with and without SIB support needs regarding variables of interest. Throughout this data brief, the differences that are reported are significant at the p < =.001 level. The N displayed for each correlation demonstrates the number of people for which data on the independent and dependent variable were both available.

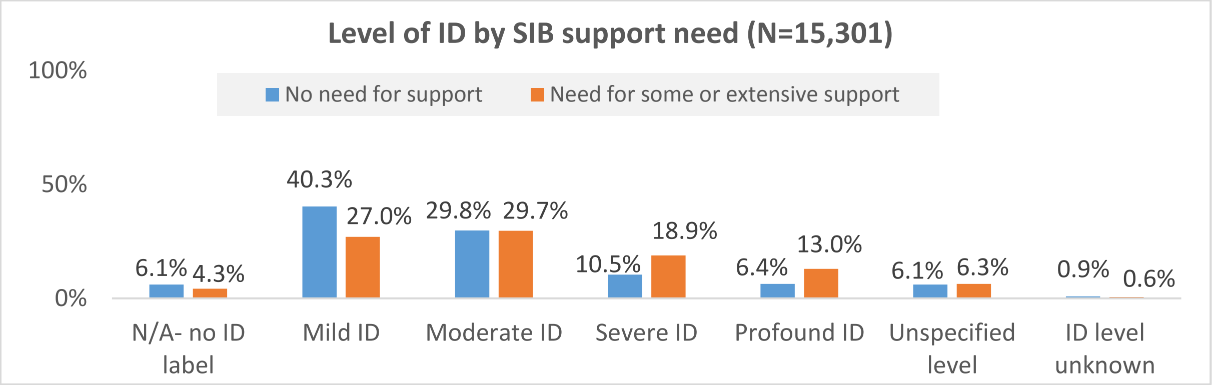
Results

State of Residence

Among the states that participated in the survey, there was a wide range in the proportions of individuals in the state samples with SIB support needs. Proportions ranged from 11.5% for the District of Columbia to 45.1% for Kansas, with a mean of 23.9%. These differences may result in part from differences in eligibility requirements for state supports (e.g., inclusion of autism spectrum disorder as part of the eligibility criteria) as well as state variations in the definition of support and of self-injurious behavior. This wide variation clearly merits further investigation. It does suggest the need for more standardized assessment protocols and training regarding the characteristics of SIB.

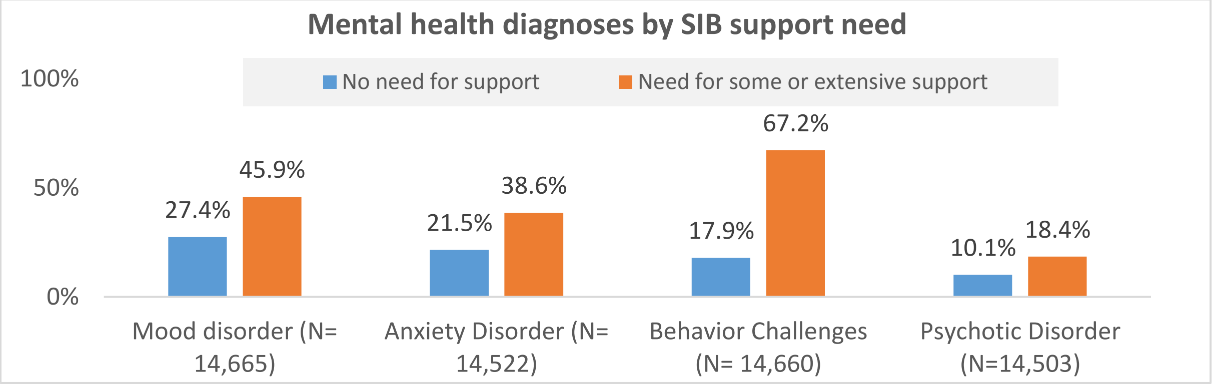
Level of ID

Data indicate that individuals with support needs for SIB and with ID are more likely to have a diagnosis of severe or profound intellectual disability: 32.0% of those with SIB support needs were reported to have severe or profound ID as compared to 16.9% of those without SIB support needs (N=15,301).



Other Diagnoses

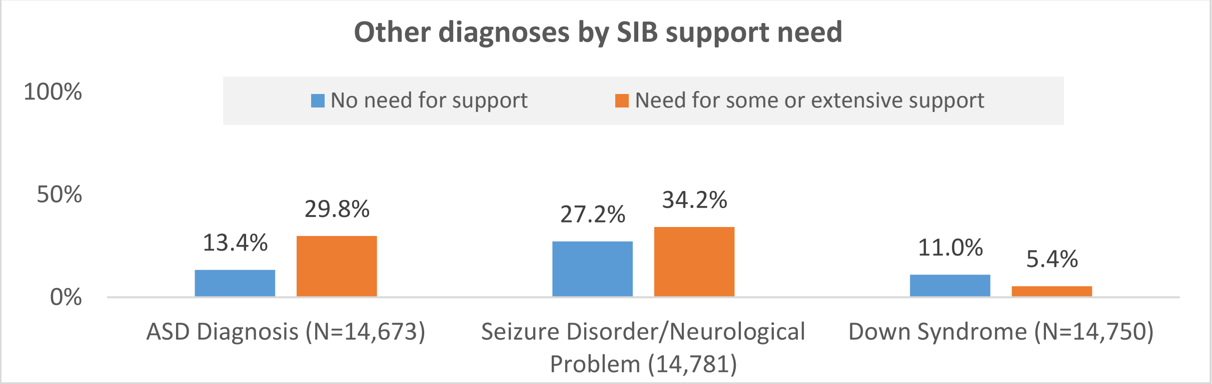
Individuals requiring some or extensive support for SIB were significantly more likely to have a mood disorder diagnosis (e.g., depression, mania, bipolar disorder) than those without SIB support needs (45.9% vs. 27.4%; N=14,665). Similarly, those with SIB support needs were more likely to have a diagnosis of anxiety disorder (e.g., obsessive disorders, panic disorders) (38.6% vs. 21.5%; N =14,522) and/or psychotic disorder (e.g., schizophrenia, hallucinations, etc.) (18.4% vs. 10.1%; N=14,503). Perhaps surprisingly, 32.8% of those with SIB support needs were not reported as having a diagnosis of behavior challenges (N=14,660). These findings are consistent with earlier studies showing that individuals who exhibit SIB are more likely to have a mental illness diagnosis.[4]



Individuals with SIB support needs were more likely to have a diagnosis of autism spectrum disorder (e.g., autism, Asperger's syndrome, pervasive developmental disorder) than those without SIB support needs (29.8% vs. 13.4%; N=14,673). As cited previously, studies have found various prevalence rates of SIB among the population of individuals with autism spectrum disorder (ASD). Estimates range from 33% to 71%.[5]

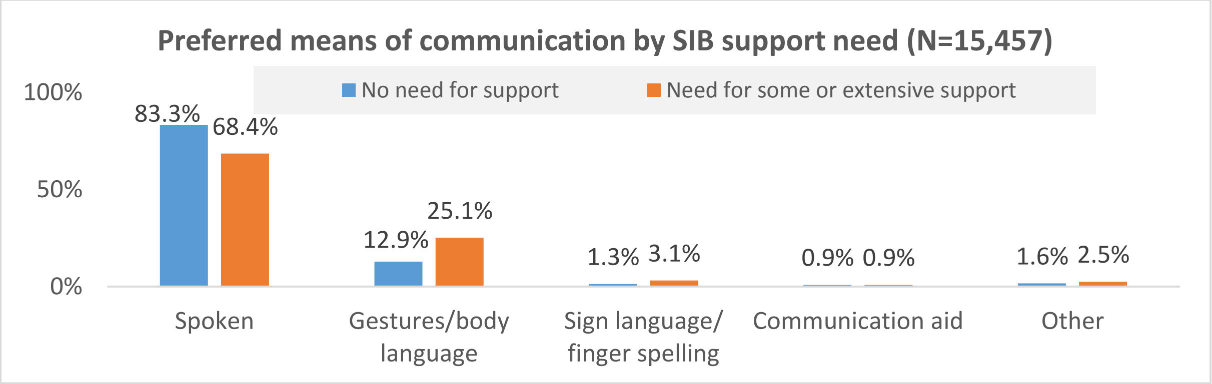
According to the NCI data, 40.2% of adults with an ASD diagnosis were reported to need some or extensive support for SIB. Among those without ASD, 19.7% needed some or extensive support for SIB.

Individuals with SIB support needs were also more likely to have a seizure disorder and/or neurological problem (34.2% vs 27.2%; N=14,781). The higher prevalence of seizure disorder among individuals with SIB is consistent with earlier findings.[6] Individuals with SIB were less likely to have a diagnosis of Down syndrome (5.4% vs. 11.0%; N=14,750).


Other diagnoses by SIB support need

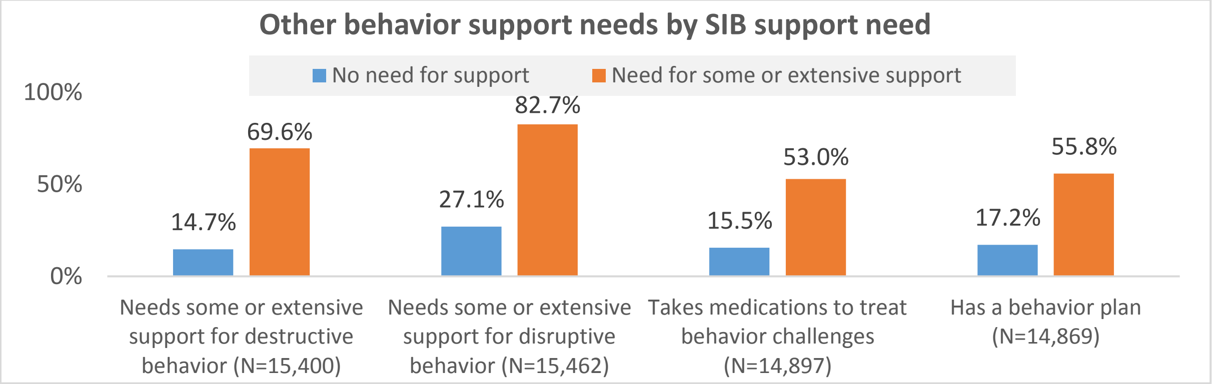
Communication

Individuals with SIB support needs were reported to be less likely to communicate via speaking (68.4% vs. 83.3%; N=15,457) and were significantly more likely to be reported to prefer to communicate via gestures/body language or sign language or finger spelling (28.2% vs. 14.2%). In addition, those with support needs for SIB were more likely to report needing additional communication technology supports and services from the state (18.6% vs. 13.1%; N=6,663.)


Preferred means of communication by SIB support need (N=15,457)

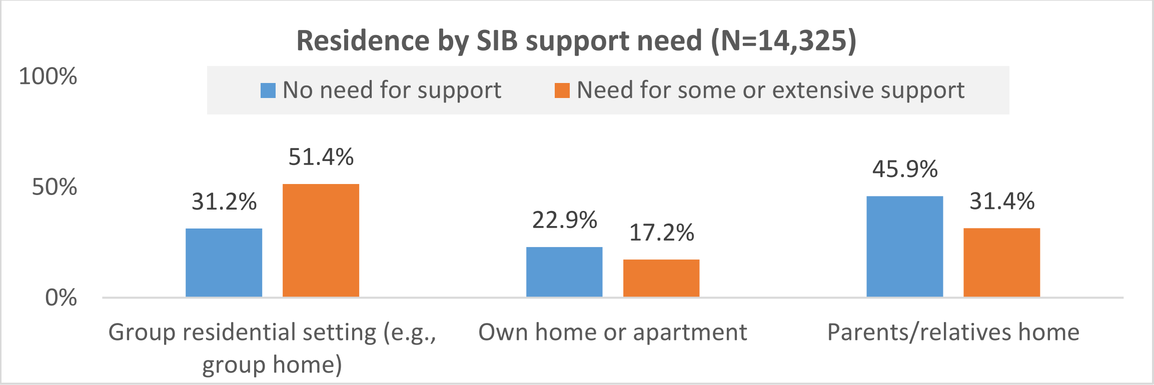
Other Behavior Support Needs

Individuals with SIB support needs were more likely to be reported to need support for disruptive behavior (82.7% vs. 27.1%; N=15,462) and destructive behavior (69.6% vs. 14.7%; N=15,400). They were also significantly more likely to be reported to take medications to treat behavior problems (53.0% vs. 15.5%; N=14,897). Similarly, they were significantly more likely to have a behavior plan in place (55.8% vs. 17.2%; N=14,869). **Notably though, NCI data show that 44.2% of those who need support for SIB do not have a behavior plan in place.**



Residence

Individuals needing some or extensive support for SIB were significantly more likely to be reported to live in a group living setting. Namely, 51.4% requiring such support live in a group residential setting, compared to 31.2% of those who do not need support for SIB. Conversely, those with SIB support needs were significantly less likely to be living in their own home/apartment or in a parent or relative's home: 48.6% vs. 68.8%.



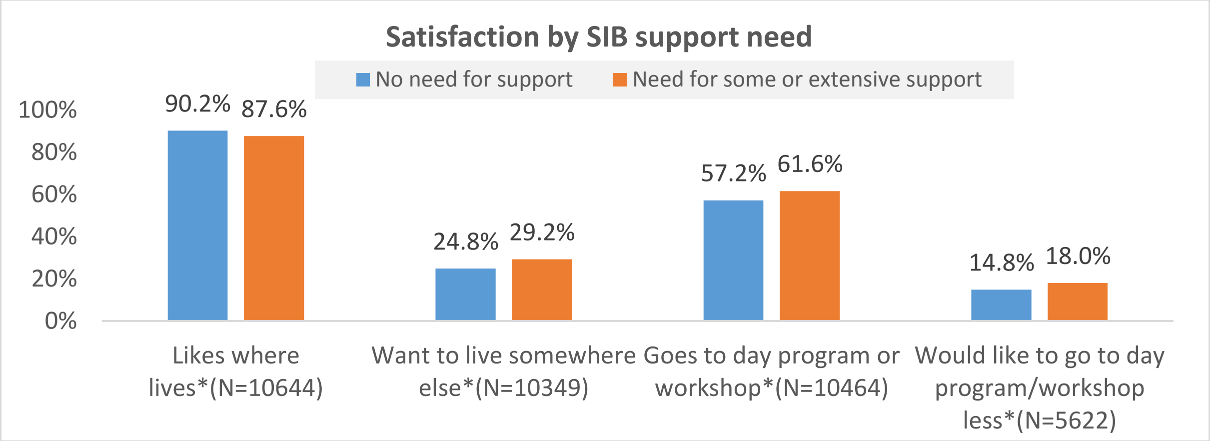
Outcomes

The data presented in this section comes from all three parts of the survey. That is, they are derived from background records, from in-person interviews with the individual receiving services, and—at times, for questions related to directly observable, measurable occurrences—from proxy respondents. Section I of the survey is completed via the in-person interview. If the individual is unable or unwilling to complete Section I, the section is skipped or deemed invalid. Individuals with some or extensive support needs for SIB were less likely to have Section I recorded as "valid" (55.7% vs. 75.1%; N=15,287). Proxy responses are allowed for Section II, which asks questions that pertain to directly observable, measurable occurrences—such as how often the person participates in specific community events. A proxy respondent can be a family member, staff person, or someone else who knows the individual very well. Case managers or service coordinators are not allowed to respond on an individual's behalf.

In the graphs in this section, questions from the Background Information Section are indicated with a ^. Questions from Section I are indicated with * and those from Section II, for which a proxy is allowed, are indicated with **.

Satisfaction

Individuals with SIB support needs were less likely to report that they like where they live compared to those without SIB support needs (87.6% vs. 90.2%; N=10,644). They were more likely to report that they want to live somewhere else (29.2% vs. 24.8%; N=10,349). They were also more likely to report that they go to a day program or workshop during the day (61.6% vs. 57.2%; N=10,464) and that they would like to go to the day program less than they currently go (18.0% vs. 14.8%; N=5,622).

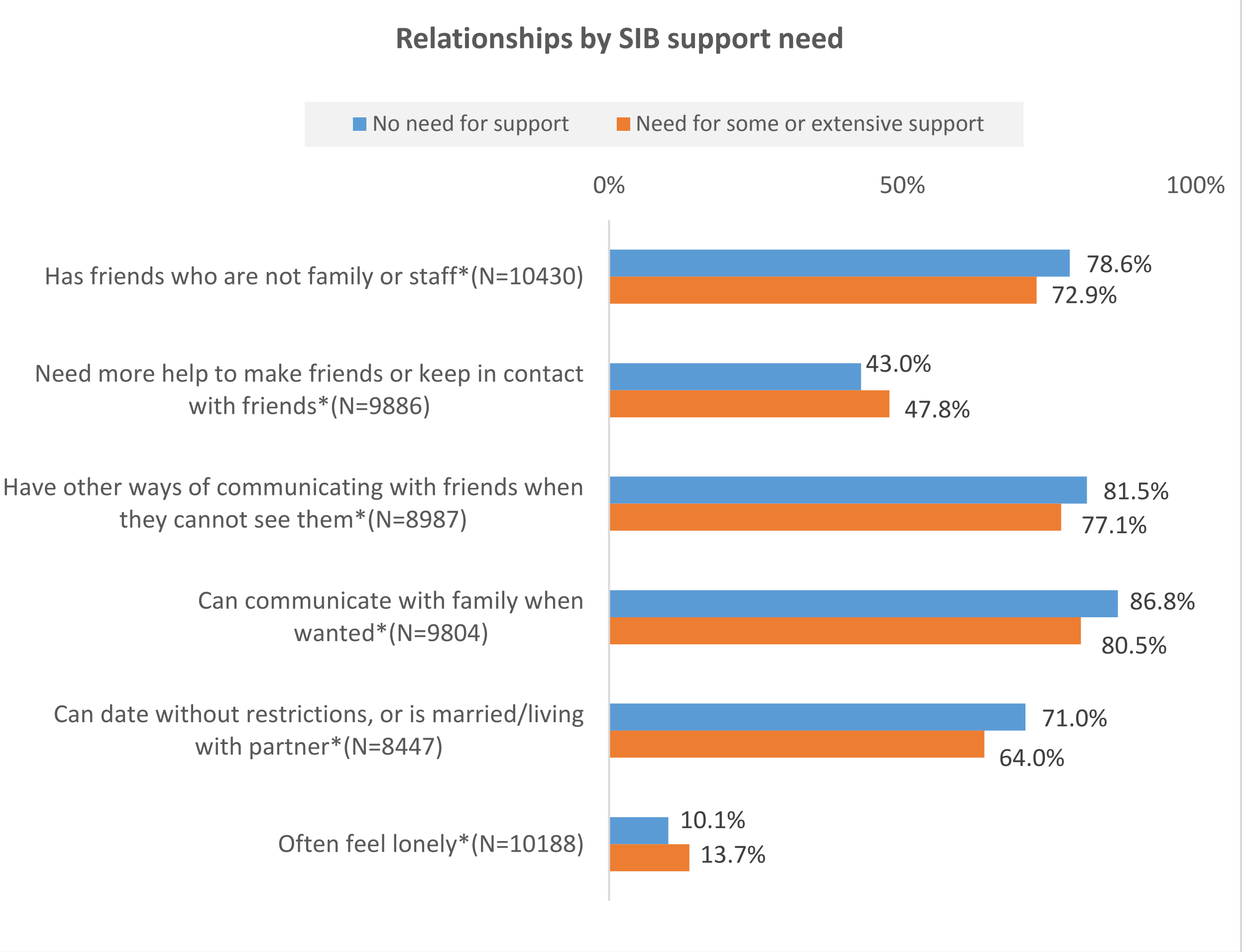


Safety

Individuals with SIB support needs were more likely to report that they feel afraid in their home, at their day program, in their workplace, in their community, when taking transportation, or in other situations (27.0% vs. 21.2%; N=9,819). More specifically, they were more likely to report feeling afraid at home (8.5% vs. 6.1%; N=10,462) or at the day program (4.4% vs. 2.5%; N=10,462).

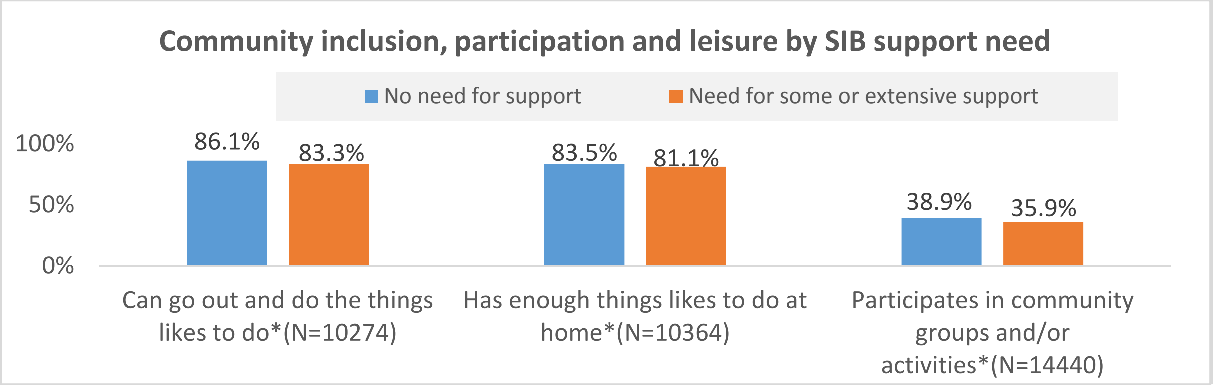
Relationships

Individuals with SIB support needs were less likely to report having friends beyond family members or staff (72.9% vs. 78.6%; N=10,430) and were more likely to report that they need more help to make friends or keep in contact with friends (47.8% vs. 43.0%; N=9,886). Those with SIB support needs were less likely to report that they have other ways of communicating with friends when they cannot see them (77.1% vs. 81.5%; N=8,987). They were also less likely to report that they can see or communicate with family when they want (80.5% vs. 86.8%; N=9,804) and that they can go on dates or are married and living with their partner (64.0% vs. 71.0%; N=8,447). In addition, they were more likely to report often feeling lonely (13.7% vs. 10.1%; N=10,188).



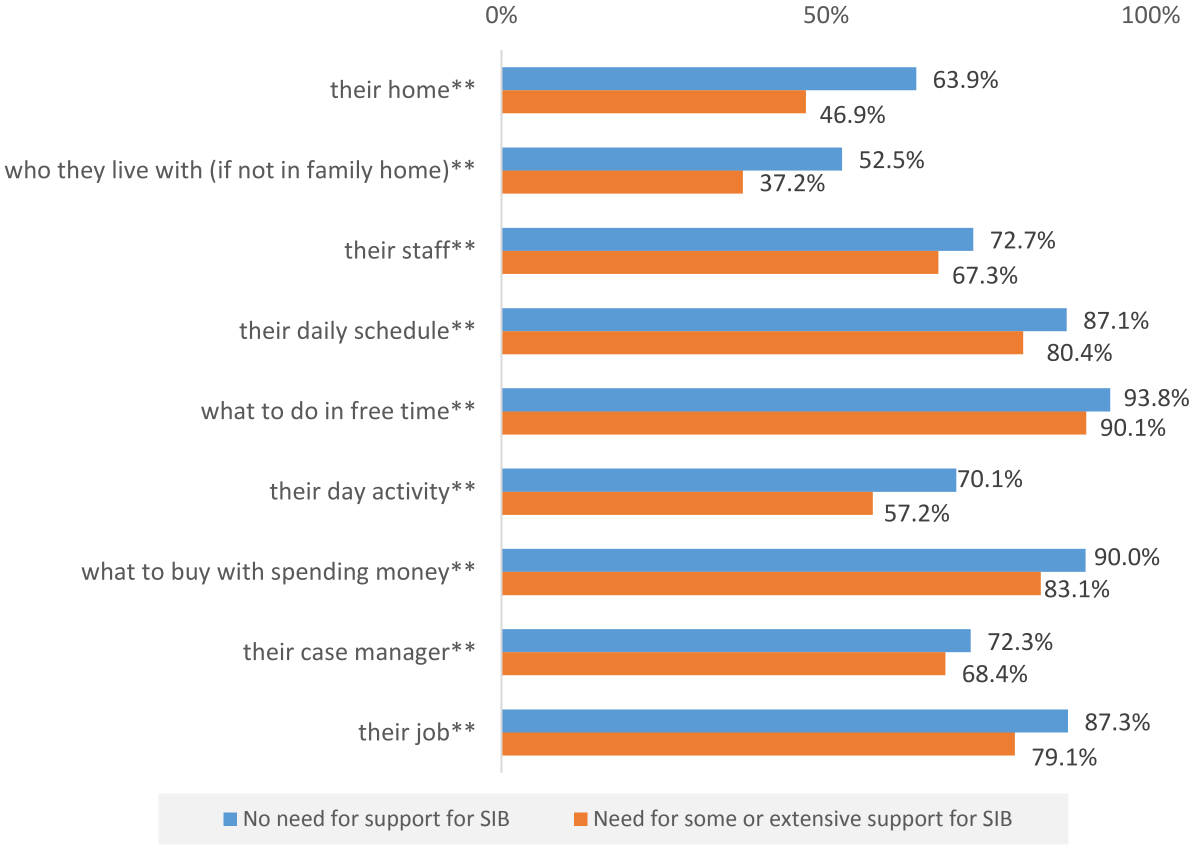
Community inclusion, participation, leisure

Individuals with SIB support needs were less likely to report being able to go out and do the things they like to do (83.3% vs. 86.1%; N=10,274) and that they have a sufficient number of things they like to do at home (81.1% vs. 83.5%; N=10,364). In addition, they were less likely to report that they participate in community groups or activities (35.9% vs. 38.9%; N=14,440).



Choice

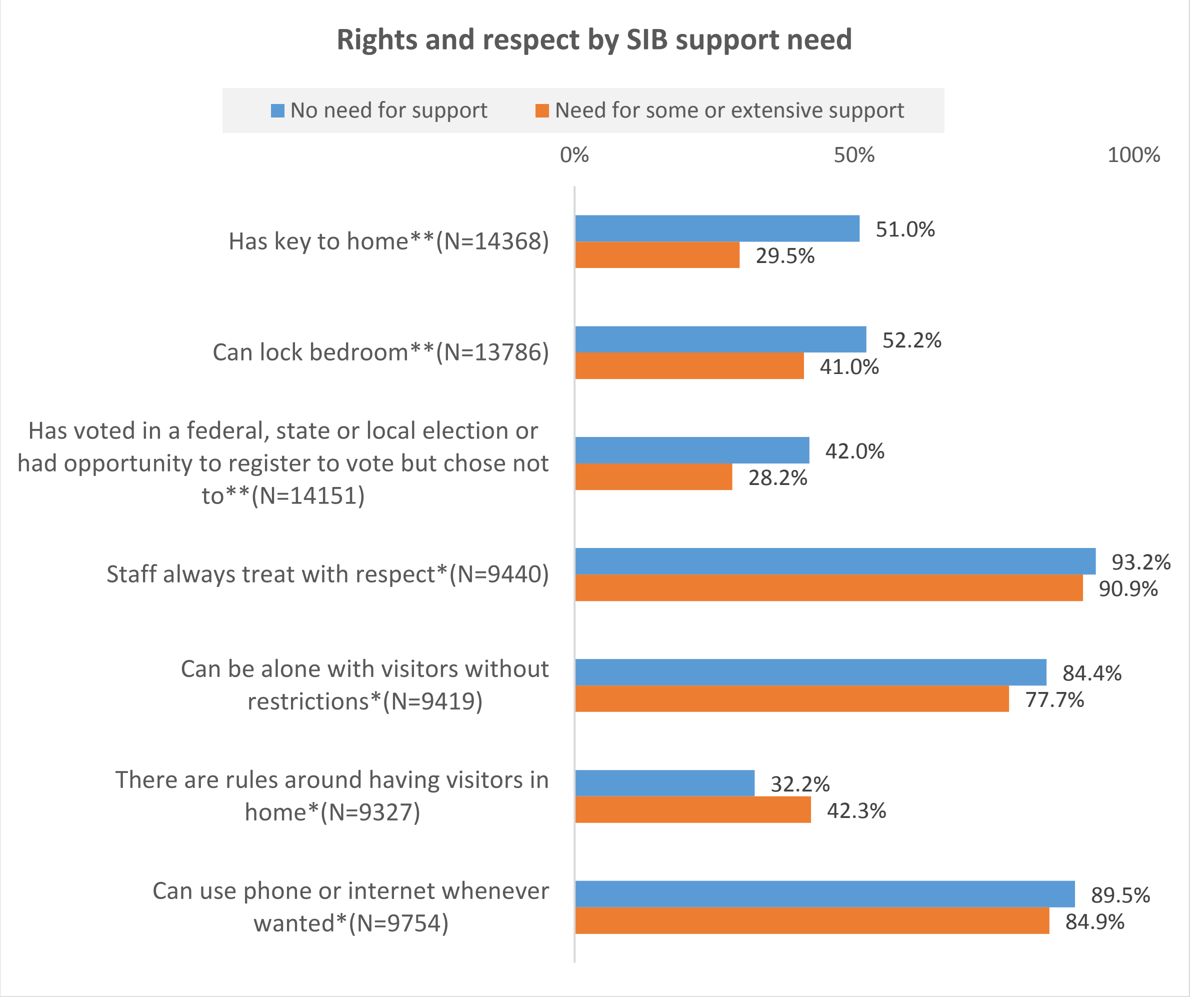
When compared to those without SIB support needs, individuals with SIB support needs were significantly less likely to report (or be reported as) having chosen or having had input in choosing:



Home (N=8386), Live With (N=8251), Staff (N=13596), Schedule (N=14739), Free Time (N=14,741), Day Activity (N=10655), Buy (N=14633), Case Manager (N: 14092), Job (N=2382)

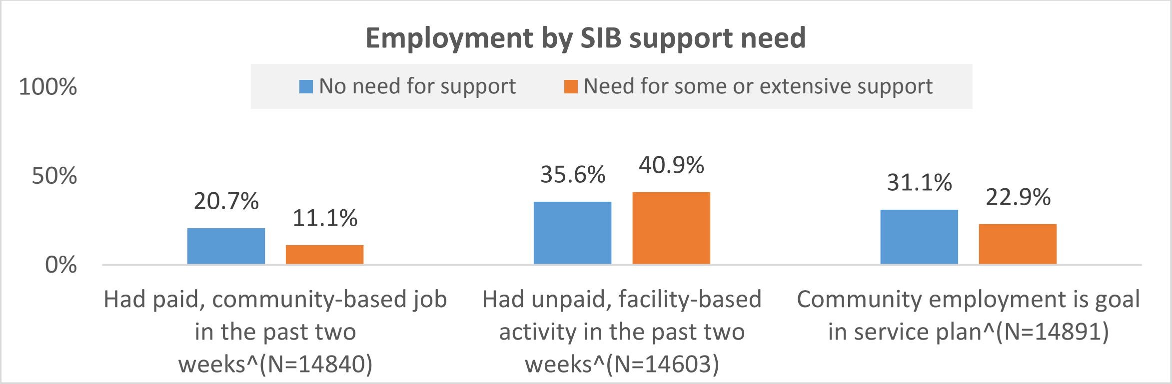
Rights and Respect

Those with SIB support needs were less likely to report having a key to their home (29.5% vs. 51.0%; N=14,368) or being able to lock their bedrooms (41.0% vs. 52.2%; N=13,786). They were also significantly less likely to report having voted in an election or having had the opportunity to do so (28.2% vs. 42.0%; N=14,151). Those with SIB support needs were significantly less likely to report that their staff always treat them with respect (90.9% vs. 93.2%; N=9,440). They were less likely to report that they can be alone with their friends or visitors in their home (77.7% vs. 84.4%; N=9,419) and more likely to report that there are rules about having friends or visitors in their home (42.3% vs. 32.2%; N=9,327). They were also less likely to report being able to use the phone or internet whenever they wanted (84.9% vs. 89.5%; N=9,754).



Employment

Compared to those without SIB support needs, those with some or extensive SIB support needs were less likely to have a paid job in the community (an individual or group job in a local business alongside peers who do not have disabilities; that is, the job is part of the typical labor market) (11.1% vs. 20.7%; N=14,840). Those with SIB support needs were more likely to have an unpaid facility-based activity during the day (40.9% vs. 35.6%; N=14,603) and were less likely to have community-based employment as a goal in their service plan (22.9% vs. 31.1%; N=14,891).



Summary of Findings

Characteristics

When compared to respondents who do not need support for SIB, individuals needing some or extensive support for SIB are…

- More likely to be reported to have a diagnosis of ASD and/or a seizure disorder/neurological problem. They are significantly less likely to be reported to have a diagnosis of Down Syndrome.
- Less likely to be reported to prefer using spoken communication, and significantly more likely to be reported 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.
- More likely to be reported to take medications for behavior challenges. However, NCI data indicate that 46.3% of respondents who require some or extensive support for SIB do not take medications for behavior challenges.
- More likely to be reported to have a behavior plan in place. However, NCI data also show that 44.2% of those who need some or extensive support for SIB do not have a behavior plan in place.
- More likely to be reported to be living in a ICF/ID, nursing facility, other institutional setting or group residential setting.

Outcomes

Compared to people without SIB support needs, people who need support for SIB are…

- Less likely to like where they live. They are significantly more likely to want to live somewhere else.
- More likely to go to a day program and to report wanting to go to their day program less than they currently go.
- More likely to report that they 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 friends when they cannot see each other, communicate with family when wanted, and be able to date without restrictions.
- More likely to need more help keeping in touch with friends and to feel lonely often.
- Less likely to report being able 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 had at least some input in critical life decisions like choosing where to live and with whom, their staff, their case manager, their daily schedule, what to do in their free-time, their day activity, and what to buy with spending money.
- Less likely to report that they have a key to their home and that they can lock their bedroom if they want.
- Less likely to report having voted in a state, federal or local election (or having had the opportunity but they 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 they want.
- More likely to report there are rules around having visitors in their home.
- Less likely to report they have a paid-community based job and that they have community employment as a goal in their service plan.
- More likely to report having an unpaid, facility based activity in the past two weeks.

Potential considerations for public policy

The data presented here strongly suggest that at the level of supports and services, there is a widely divergent conception and definition of self-injurious behavior. Previous research suggests that the prevalence rate of individuals who need extensive support for SIB is somewhere between 4% and 9%—and significantly higher for people with autism (33% to 71%). However, the National Core Indicators data indicate a wide range across states, from 12% to 46%. Even allowing for differences in eligibility criteria, these variations are still difficult to reconcile. There is clearly a need for a more standardized construct to facilitate the accurate assessment of self-injurious behavior. Further, some of the possible over-identification may be the result of inadequate assessment protocols and a failure to identify antecedent health, communication, or environmental causes that could be contributing to the challenging behavior.

Looking deeper to understand root causes and needs

To improve outcomes for individuals with SIB support needs, public managers and providers can evaluate the importance their policies place on functional assessments and/or analysis of individuals displaying self-injurious behavior. Such assessments are critical to identifying potential causes (e.g., pain, communication challenges, seizure disorder, biochemical factors, specific genetic syndromes, arousal, self-stimulation, or frustration) and consequences of the behavior. Both antecedents and consequence information can provide essential information to determine the best way to replace the problem behavior with a functionally related appropriate alternative. Similarly, the results regarding the co-occurrence of SIB and other mental health diagnoses, such as mood disorders and anxiety disorders, may prompt public managers and providers to examine the availability of mental health interventions and supports for those receiving public services.

Evidence-based interventions and behavior plans

The need to improve the well-being of individuals who exhibit self-injurious behavior underscores the importance of employing evidence-based practices, such as Positive Behavior Supports (PBS), to ameliorate the intensity or presence of SIB. The adoption of evidence-based interventions also necessitates expanded competency among those providing supports. Such competencies can be supported through training—both in the field and in universities—for individuals who design and implement behavior supports.[7] Positive behavior supports (PBS) have been found to enhance quality of life for individuals with SIB.[8,9] Given the disparity in outcomes noted in this analysis between individuals who need some or extensive support for SIB and those who do not, expansion of evidence-based practices could offer those with SIB the promise of improved quality of life. Similarly, public managers may want to look closely at their policies regarding aversive treatments. In their review of state policies and practices in behavior supports, Rotholz et al. (2013) found that of the 45 states that responded to their survey, 9 reported that they allow the use of aversive interventions “designed to cause discomfort or pain for behavior reduction.” States may examine their policies on such interventions and determine whether these policies align with desired quality of life outcomes.

In 2015, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) adopted a position statement promoting Positive Behavior Supports. They write: “PBS is a person-centered approach that begins with a vision to help an individual achieve a preferred lifestyle that includes maintaining a social network and being involved in their community.” The position statement is available here: http://www.nasddds.org/about-nasddds/nasddds-press-release-announcing-first-position-statement-on-the-use-of-pos/

The National Core Indicators survey results regarding the use of behavior plans and those with SIB support needs may also suggest the need for a review of existing state-level policies regarding behavior support plans. Rotholz et al. (2013) [10] note that there is variation among states in behavior plan definition, training, design, and review. Jurisdictions thus interested could examine their behavior plan processes and examine gaps such as, for example, the lack of required qualifications of those charged with creating behavior plans, the absence of a behavior support committee, and the lack of qualification requirements for members of such committees. Well-designed, well-monitored, person-centered behavior plans informed by evidence and research may serve to improve the outcomes of individuals who need some or extensive support for SIB.[11]

Standards and support for support providers

States should also work to develop and maintain high standards regarding qualification, training, and quality assurance of those who provide support for SIB. Rotholz et al. (2013) noted the variety in qualification standards across states and asserted that "the lack of a rigorous, professionally endorsed national standard such as medical licensure that applies to behavior supports for people with IDD raises significant questions regarding the ability of states and provider agencies to set practice criteria and assure the quality and appropriateness of the services being provided." States interested in enhancing their behavior support programs may want to work to ensure that the workforce providing supports for individuals with self-injurious behavior is well trained in person-centered planning and supports. Administrative entities should also work to determine a qualification standard that applies to behavior supports.

Another potential area for a state to consider adapting their existing policies is examining their current family crisis and respite services for families coping with a family member who has SIB support needs. Parent and family stress has been shown to impact individuals with disabilities and can reduce positive effects of interventions.[12] Increasing the availability of crisis and respite supports could serve to reduce caregiver stress (Norton et al. 2016; Whitmore 2016)[13,14] and translate to higher quality of caregiving and enhanced outcomes for individuals with disabilities.

Autism awareness

Finally, the number of individuals with autism being served by state developmental disability agencies is growing nationally. The National Core Indicators survey data suggest that individuals who need support for SIB are more likely to also have an autism spectrum disorder diagnosis than those who do not need such support. Therefore, it will become increasingly important for public managers and providers to understand the idiosyncratic needs of these individuals and the types of evidence-based interventions most likely to ameliorate the behavior.

First steps

With the broad number of possible implications for public policy managers, the best approach might be to first examine the state's specific NCI results relative to those who need some or extensive support for SIB. From those results, a thoughtful plan to identify strategies for improving the service delivery system can begin.

Hopefully, this examination of the status and outcomes of individuals with SIB support needs in the United States will provide a national and international framework for continued clinical research and more targeted public policy on the needs and outcomes of these individuals.

Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI) initiative, public reports, and past data briefs, please visit: www.nationalcoreindicators.org.
We welcome your feedback and questions. If you want to discuss this report or have questions about the NCI project, please contact: Dorothy Hiersteiner, NCI Project Coordinator, at dhiersteiner@hsri.org

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