



National Core Indicators Data Brief

May 2014

ABOUT NCI

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

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Studies show that individuals with intellectual and developmental disabilities (ID/DD) are three to five times more likely to display challenging behaviors¹ than individuals in the general population². Not only can these behaviors lead to self-harm, physical injury to others, and the destruction of property,³ they can also severely impair an individual's ability to integrate into the community^{4,5}.

During the 2012-13 survey period, nearly 45% of respondents to the NCI Adult Consumer Survey required some or extensive support to manage challenging behaviors such as self-injurious behavior, disruptive behavior, and destructive behavior. This data brief examines the population of respondents who

require such support and how their outcomes, quality of life, and experiences in public service systems differ from those who do not.

The NCI data, which are gathered in part via in-person interviews with more than 13,000 individuals receiving services, reveal that individuals who require behavior support differ significantly from their counterparts who do not in terms of demographics and in outcomes related to health, home, employment, choice, rights and respect, safety, and wellness. These comparisons can help inform state officials, providers, and advocates as they design and implement programs and policies for individuals who need behavior support.



**NATIONAL CORE
INDICATORS**

In 1997, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with Human Services Research Institute (HSRI), launched a project to help state-level developmental disabilities operating agencies measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families.

www.nationalcoreindicators.org



Description and Demographics of Sample

The data in this brief are from the 2012-2013 administration of the NCI Adult Consumer Survey (ACS) of 13,157 individuals with ID/DD from 25 states and one regional council.⁶ All individuals surveyed were age 18 and over and receiving at least one service in addition to case management.

The individuals themselves provide responses for many of the survey questions via face-to-face interviews, but survey administrators also consult agency records or information systems for background information. Additionally, a proxy respondent who knows the individual well, such as a family member or staff person, can respond to a particular section of the survey. (Case managers or service coordinators are not allowed to respond on an individual's behalf.)

The need for behavior support is assessed by three questions typically answered by data from agency records or information systems:

"Does the person need support to manage 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."

"Does the person need support to manage disruptive behavior? Refers to behavior that interferes with the activities of others, for example, by laughing or crying without apparent reason, yelling or screaming, cursing, or threatening violence."

"Does the person need support to manage destructive behavior? Refers broadly to externally directed, defiant behavior, for example, taking other people's property, property destruction, stealing, or assaults and injuries to others."

The response options are:

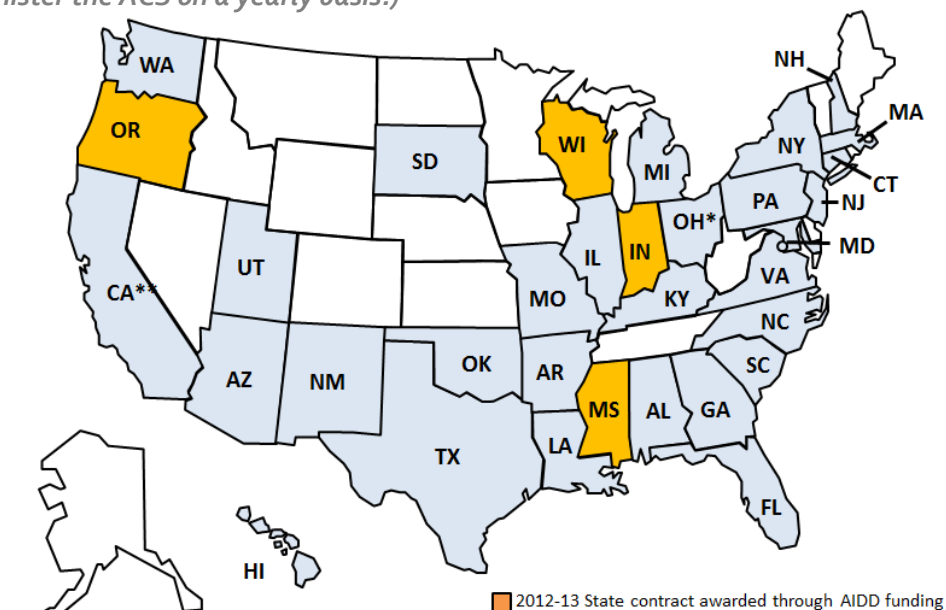
- No support needed
- Some support needed; requires only occasional assistance or monitoring
- Extensive support needed; frequent or severe enough to require regular assistance
- Don't know

For the purpose of this analysis, individuals were included in the sample only if 1) all three questions had a valid response, or 2) at least one of the responses to the three questions indicated that a level of behavior support was needed. Individuals were excluded from the final dataset if all three questions were left blank or coded as "don't know," or if some questions were blank/"don't know" and the others had "no support needed." The final dataset includes 12,718 people.

For the purpose of this data brief, only group differences that were significant at the $p < .01$ level are reported.

NCI Participation: 2012-2013

(Not all states administer the ACS on a yearly basis.)



*Includes the Mid-East Ohio Regional Council

** Includes 21 Regional Centers

Results

Demographics

From a total of 12,718 individuals, 43% need some or extensive support to manage self-injurious, disruptive, and/or destructive behavior.

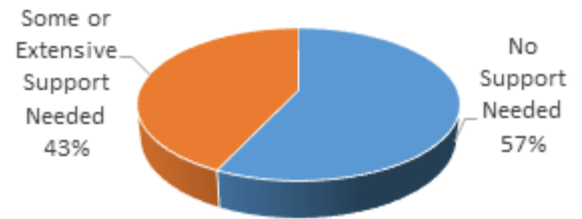
Of the respondents who require at least some behavior support, 51% need support for self-injurious behavior, 87% need support for disruptive behavior, and 55% need support for destructive behavior. (Note that these categories are not mutually exclusive and therefore exceed 100% when combined.)

Respondents who require support for behavior challenges differ from those who don't in terms of gender and age: those who require support are slightly younger (42 years old versus 43 years old) and are more likely to be male (61% versus 55%).

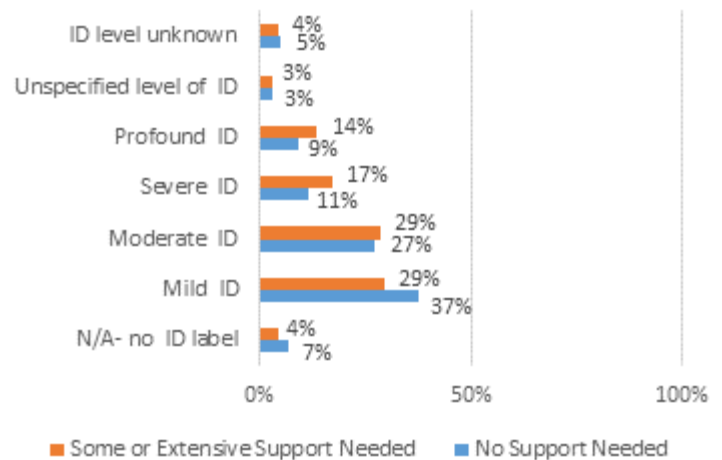
Respondents who need behavior support are significantly more likely to have been diagnosed with an intellectual disability than those who don't (96% versus 93%). Respondents who need behavior support also differ significantly from those who don't in terms of level of intellectual disability (ID). Of those who need behavior support, a combined 31% have been diagnosed with severe or profound ID; of those who don't, a combined 20% have been diagnosed with severe or profound ID.

The need for behavior support also varies by the presence of additional diagnoses. For example, 81% of respondents diagnosed with Prader-Willi and 64% of respondents diagnosed with autism spectrum disorder require some or extensive behavior support. Conversely, 28% of respondents with Down syndrome and 37% of respondents with cerebral palsy require such support.

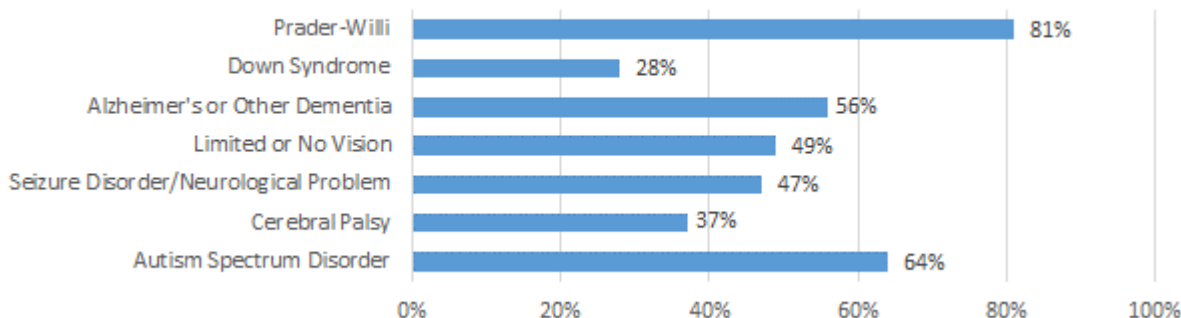
Support Needed for Behavior Challenges



Level of Intellectual Disability



Some or Extensive Support Needed



Respondents' needs for behavior support also vary by primary means of expression. Among those who do not require behavior support, 80% communicate through spoken expression; among those who do need behavior support, 72% communicate through spoken expression. Almost one-quarter (24%) of respondents who need some or extensive support for behavior challenges communicate using gestures or body language, while 17% of those who don't need support communicate using gestures or body language.

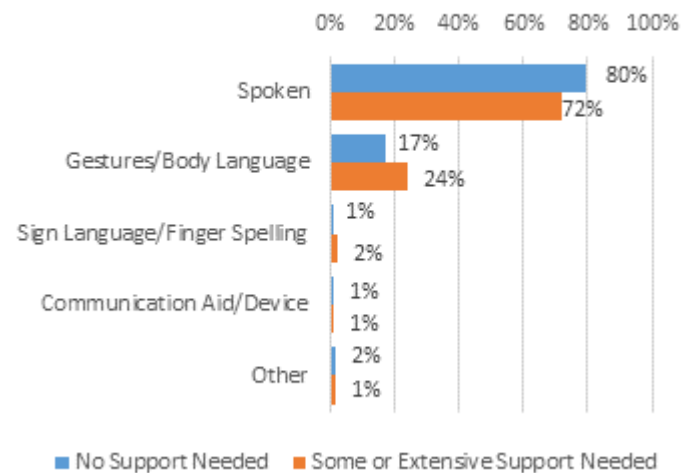
Diagnosis With Mental Illness

Respondents who need some support for behavior challenges are significantly more likely to have been diagnosed with one or more of the following mental illnesses: mood disorder, anxiety disorder, behavior challenges, psychotic disorder, and/or other mental illness. Of those who need behavior support, 33% have been diagnosed with mood disorder, 21% have been diagnosed with anxiety disorder, 31% have been diagnosed with behavior challenges, 15% have been diagnosed with psychotic disorder, and 10% have been diagnosed with another mental illness. Of those who do not, 14% have been diagnosed with mood disorder, 9% have been diagnosed with anxiety disorder, 5% have been diagnosed with psychotic disorder, and 3% have been diagnosed with another mental illness. Interestingly, 3% of those who do not need behavior support have been diagnosed with behavior challenges.

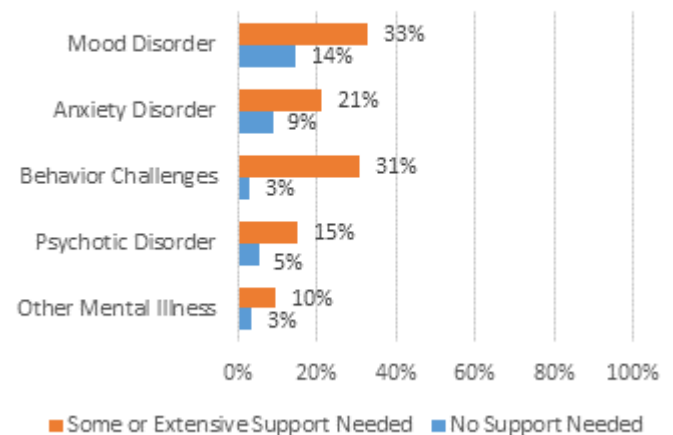
Respondents who need support for behavior challenges are more likely to take at least one medication for mood disorders, anxiety, behavior challenges, and/or psychotic disorders. Three-quarters (77%) of respondents who need support for behavior challenges take at least one kind of medication, while only 34% of those who do not need behavior support take at least one kind of medication.

Respondents who need support for behavior challenges were significantly more likely to take medications for each of the following: mood disorders, anxiety, behavior challenges, and/or psychotic disorders. It is worth noting that 7% of respondents who did not need behavior support took medication for behavior challenges. Further analysis shows that 6% of respondents who do not need behavior support and have not been diagnosed with behavior challenges take medication for behavior challenges.

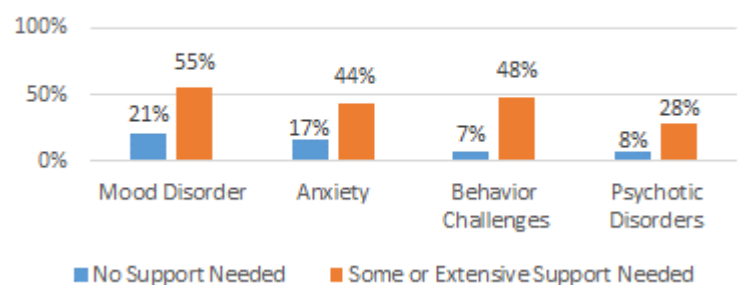
Primary Means of Expression



Diagnosis with Mental Illness

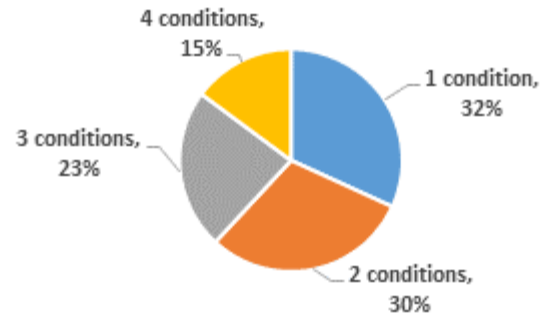


Takes Medication For...



Of those respondents who are taking medication to treat one or more of the aforementioned mental illnesses, 15% are taking medications to treat all four of the conditions. Almost one-quarter (23%) are taking medications to treat three conditions, 30% are taking medications to treat two conditions, and 32% are taking medications to treat only one condition.

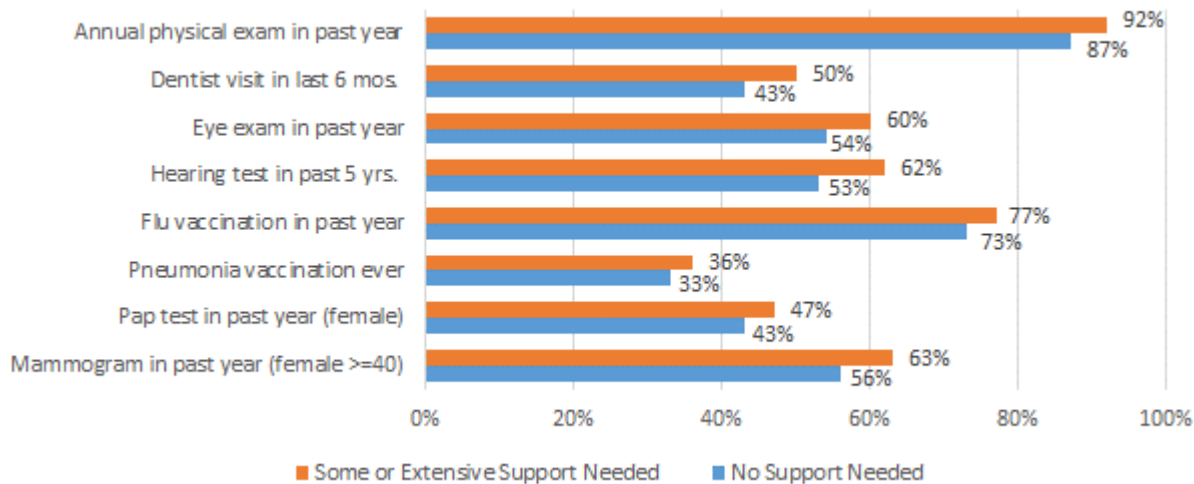
Respondents Who Need Behavior Supports and Take Medications Are Taking Medications To Treat.....



Health

NCI data show that respondents who need behavior support accessed preventive care (such as annual physical exams, dentist visits, eye exams, hearing tests, and vaccinations) within the recommended time period at significantly higher rates than those who do not need such support. In addition, women who need behavior support were more likely to have had a pap test in the past year, and women age 40 and over who require behavior support were more likely to have had a mammogram in the past year.

Preventive Care



Wellness

Interestingly, there were no significant differences between respondents who need support for behavior and those who do not in physical activity or BMI. However, the data demonstrate that, overall, respondents who require behavior support smoke at a significantly higher rate (8%) than individuals who do not require such supports (6%). Further analysis revealed that this difference is only significant for individuals age 50 and over. In other words, respondents age 50 and over who require behavior support smoke at a significantly higher rate (11%) than those age 50 and over who do not require behavior support (8%). This comparison was not significant for individuals in younger age categories.

Home

Type of residence differs significantly between those who need behavior support and those who do not. Respondents who require behavior support are somewhat more likely to live in an institutional setting (6% compared to 3%) and much more likely to live in a group home (39% versus 21%). Individuals who do not require behavior support are significantly more likely to live in an independent home or apartment (17% versus 11%) or a parent's or relative's home (47% versus 26%).

Also worth noting is that 65% of individuals who live in specialized institutional settings, 59% of individuals who live in group homes, and 57% of individuals who live in foster care or host homes require some or extensive support for behavior problems; this compares to 34% of people living in independent homes and 30% of people living with family.

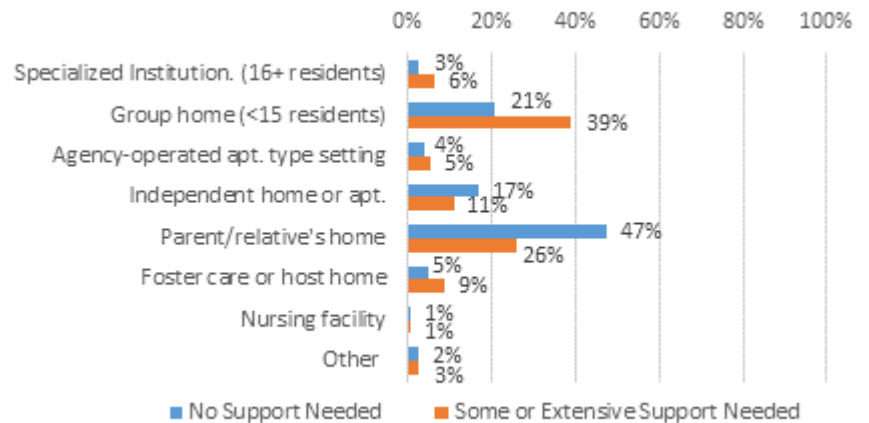
Respondents who need behavior support are significantly less likely to like their home or where they live (86% say they like their home) than those who do not require behavior support (92%); they are also significantly more likely to want to live somewhere else (30% compared to 23%). Similarly, individuals who need behavior support are significantly less likely to like their neighborhood (86% say they like their neighborhood, compared to 89% among those who do not require support) and are significantly less likely to talk to their neighbors (62% say they talk to their neighbors, compared to 72% among those who do not require support).

Employment

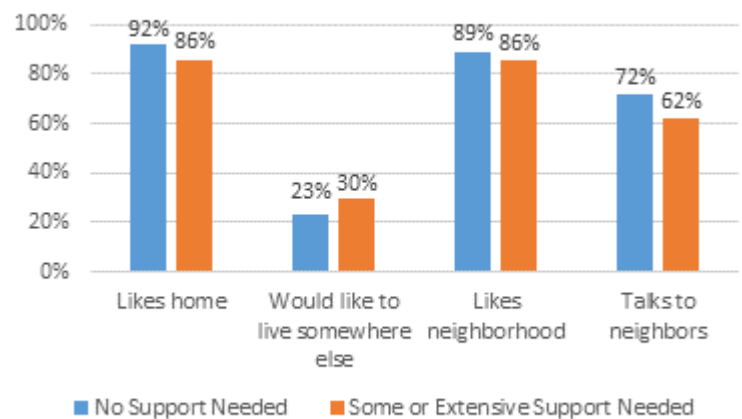
When compared to respondents who do not need behavior support, respondents who need support were significantly less likely to have had a paid community or facility-based job, and were significantly more likely to participate in unpaid community or facility-based activities.

Of the respondents who did not have a paid job in the community, those who need behavior support are significantly more likely to want a job in the community (52%) than those who do not need support (45%).

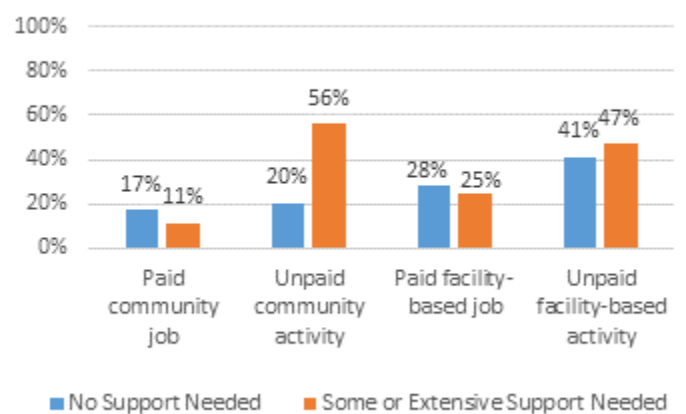
Type of Residence



Home



Employment

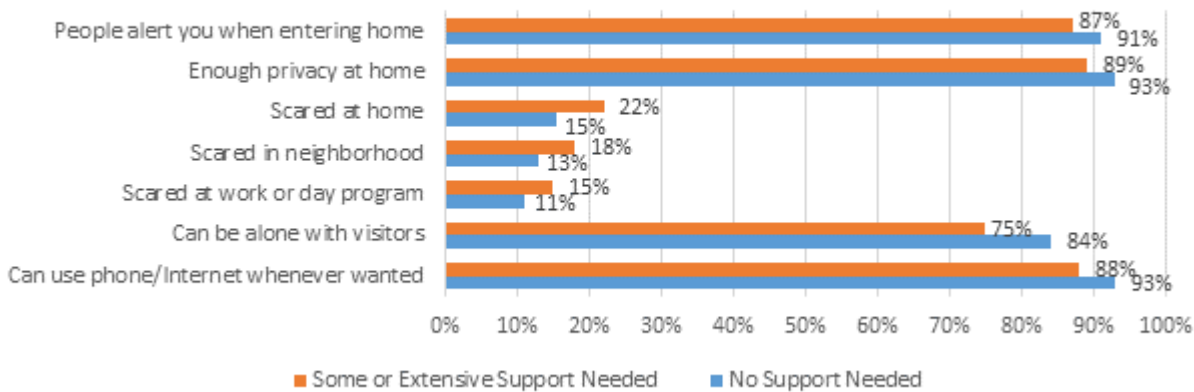


Rights and Respect & Safety

Respondents who require behavior support are significantly less likely to report that people let them know before entering their home (87% versus 91%), and significantly less likely to report that they have enough privacy at home (89% versus 93%). Additionally, respondents who require behavior support are significantly more likely to feel scared in their home, neighborhood, and/or day program than those who do not require support.

Respondents who require behavior support are significantly less likely to be able to be alone with visitors (75% versus 84%) or to be able to use the phone or Internet whenever they want (88% versus 93%).

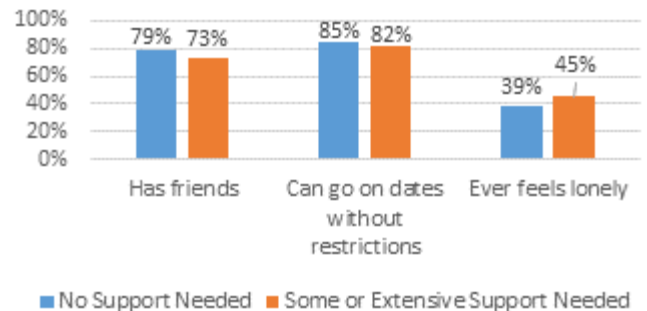
Rights and Respect & Safety



Relationships

Compared to respondents who do not require behavior support, respondents who require support are significantly less likely to report having friends (73% versus 79%) or being able to go on dates (82% versus 85%) and are significantly more likely to report ever feeling lonely (45% versus 39%).

Relationships



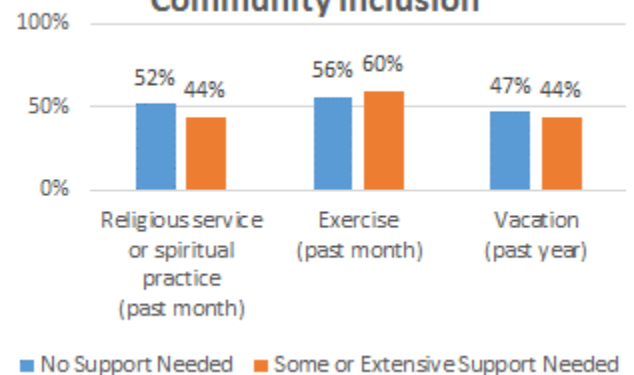
Staff

Compared to respondents who do not require behavior support, those who require support were significantly less likely to report that the staff who worked with them were nice (91% versus 95%). Additionally, respondents who require behavior support are significantly less likely to report that their staff have the necessary training to help them (91%) than respondents who do not require support (93%).

Community Inclusion

In terms of community inclusion during the month prior to the survey, respondents who do not require behavior support did not differ from respondents who do in terms of whether they went shopping, on errands, out to entertainment, or out to eat in the community. However, those who require behavior support went to a religious service or spiritual practice in the community in the past month and on vacation in the past year at a significantly lower rate. Those who require behavior support went out to exercise in the community at a significantly higher rate than those who do not need support.

Community Inclusion



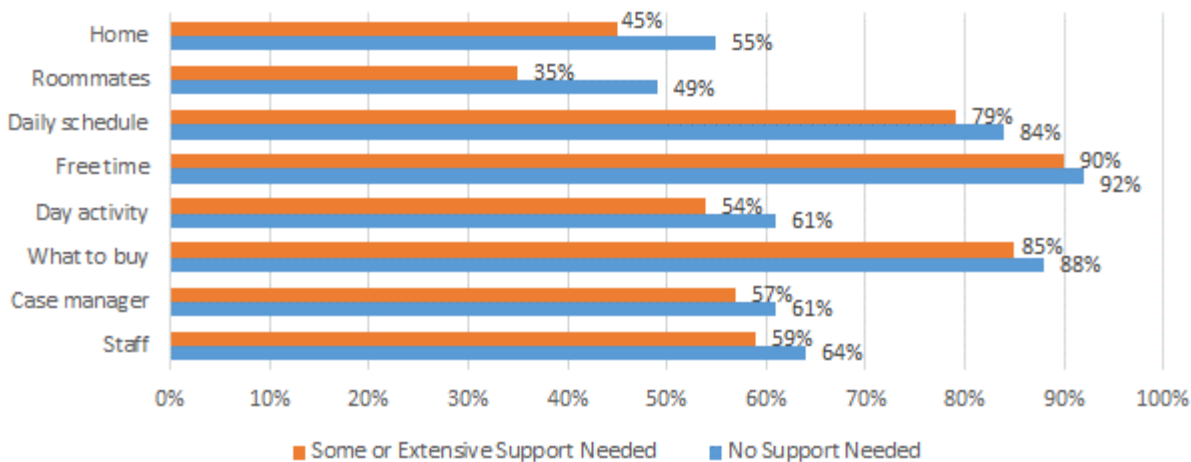
The average number of times that individuals who need behavior support went out shopping, on errands, out for entertainment and to religious practice in the month prior to the survey differs significantly from the average number of times that individuals who did not need such support participated in the same activities. On average, individuals who need support for behavior challenges went out shopping, on errands, and out for entertainment more frequently than those who did not need such support. However, individuals who do not need behavior support went to religious services or spiritual practice more frequently than those who do need support.

<i>Average number of times in the month prior</i>	Individuals who need some or extensive support for behavior challenges	Individuals who need no support for behavior challenges
<i>Shopping</i>	5.1	4.6
<i>Errands</i>	3.9	3.5
<i>Entertainment</i>	4.0	3.6
<i>Religious Service/Spiritual Practice</i>	3.6	4.0

Choice

Respondents who need behavior support are significantly less likely to have made choices or had input into choices about their living situation, their spending, and their staff than respondents who do not need support. Specifically, when compared with respondents who do not need behavior support, those who require support are significantly less likely to have chosen or had input into where they live, their roommates, their daily schedule, what to do in their free time, their day activity, what to buy with their own money, and their case manager or their staff.

Chose or Had Some Input in Choosing...



Summary of Findings

Demographics:

- 43% of respondents to the NCI Adult Consumer Survey need behavior support for self-injurious, disruptive and/or destructive behavior. Of those, 51% require support for self-injurious behavior, 87% require support for disruptive behavior, and 55% need support for destructive behavior.
- Respondents who require behavior support are slightly younger and are more likely to be male than those who do not need support. They are also more likely to have severe or profound ID.
- Support is needed at significantly different rates based on co-occurring diagnoses and primary means of expression.

Mental Illness and Medication:

- Respondents who need some support for behavior challenges are significantly more likely to have been diagnosed with one or more of the following mental illnesses: mood disorder, anxiety disorder, behavior challenges, psychotic disorder, and/or other mental illness. In addition, respondents who require behavior support are more likely to take at least one medication for one or more of these illnesses.

Health:

- Respondents who need behavior support accessed preventive care within the recommended time period at significantly higher rates than respondents who do not need support.

Wellness:

- Respondents over the age of 50 who need behavior support are significantly more likely to smoke than those over the age of 50 who do not need support.

Home:

- Respondents who need behavior support are significantly more likely to live in an institutional setting or a group home and are significantly less likely to live in an independent home or parent/relative's home. In addition, respondents who need behavior support are less likely to like their home and/or their neighborhood, more likely to want to live elsewhere, and less likely to talk to their neighbors.

Employment:

- Respondents who need behavior support were significantly less likely to have had a paid community or facility-based job. Of the respondents who did not have a job in the community, those who needed behavior support were more likely to say that they wanted a job than those who did not need behavior support.

Rights and Respect & Safety:

- Respondents who need behavior support are more likely to say they are scared at home, at their day program, or in their neighborhood; moreover, they are less likely to feel that they have enough privacy at home or that they can use the phone or Internet whenever they want.

Relationships:

- Respondents who need behavior support are less likely to report having friends, are less likely to report being able to go on dates without restriction, and are more likely to report feeling lonely.

Staff:

- Respondents who require behavior support are less likely to report that their staff are nice and are less likely to report that their staff have the necessary training to support them.

Community Inclusion:

- Respondents who require behavior support went to a religious service or spiritual practice in the community in the past month and on vacation in the past year at a significantly lower rate. Those who require behavior support went out to exercise in the community at a significantly higher rate than those who do not need such support.

Choices:

- Compared to respondents who do not need behavior support, respondents who require support are less likely to report having had at least some input into life choices—such as where to live, their roommates, their daily schedule, how to spend free time, their daily activity, what to buy with their money, their case manager, and their staff.

Limitations

The differences in outcomes among the populations of respondents who need behavior support and those who don't may be influenced by differences in other personal and demographic characteristics, such as age, socioeconomic status, gender, level of disability, and mobility level. The potential moderating role of other demographic and personal characteristics merits further attention.

Questions for Consideration

Does your state...

Encourage the use of positive behavior supports?

Require those who develop behavior support plans to have specific training in applied behavior analysis and positive behavior support as well as multiple years of experience?

Have a quality assurance process that focuses on how behavior supports are delivered and the specific outcomes of those interventions?

Provide technical support and guidance to providers and families to increase the likelihood that people who need behavior support can attain valued outcomes (including relationships, paid community employment, and choice)?

Emerging Practices

Looking for strategies to improve behavior support services in your state? Below are some examples of quality improvement initiatives from New Mexico, Ohio, and Massachusetts. For more information, please reach out to the designated contact.

New Mexico

Contact: Cheryl L. Frazine, Chief
Bureau of Behavioral Support
New Mexico Developmental Disabilities Supports Division
Email: cheryl.frazine@state.nm.us

In New Mexico, the Bureau of Behavioral Support (BBS), a bureau of the Developmental Disabilities Supports Division under the New Mexico Department of Health, has taken several steps to enhance and improve behavior support services. First, in the late 1990s, DDSD established a dedicated behavior support team by the establishment of BBS that encompasses all 5 regional offices and comprises a total staff of 12. Second, they have made a commitment to Positive Behavior Supports. The BBS aims to encourage the use of positive behavior supports by disseminating resources to community providers and collaborating with them to increase their capacity to help people live productive and fulfilling lives. The team offers guidance to providers and recipients of

Behavior Support Consultation, Socialization and Sexuality Education, Preliminary Risk Screening and Consultations, and Crisis Supports.

BBS also collaborates with the Trans-Disciplinary Evaluation and Support Clinic (TEASC) at the University of New Mexico School of Medicine to augment the availability of supports to manage challenging behaviors. TEASC performs comprehensive evaluations to establish the connection between the behavioral issues and any underlying medical, psychiatric, environmental and/or adaptive skill/cognitive factors. TEASC also runs an Adult Special Needs clinic which uses trans-disciplinary approaches to address co-occurring factors that contribute to challenging behaviors. The Continuum of Care Project, also at UNM School of Medicine, focuses on providing training to local medical practitioners and non-medical professionals regarding chronic condition management for individuals with ID/DD and Mental Illness. Finally, TEASC supports The Developmental Disability/Mental Illness Initiative works to support selected mental health providers to better serve the ID/DD and MI population. The Initiative provides tele-health

based case consultations and disseminates resources about individuals with co-occurring disorders.

BBS conducts an annual review of behavior support effectiveness, establishing benchmarks of individual experience and perception to assess support effectiveness rather than provider performance criteria. BBS collects information through site visits, interdisciplinary team meetings, support staff and family interviews, and document review. BBS also looks at the use of emergency physical restraint, law enforcement intervention, and psychoactive medication within the context of the individual's overall support. Effectiveness of support is determined through the following five key indicators we have found correlate strongly with quality of life satisfaction and positive behavior change:

1. The individual has opportunities to engage in an expanding range of community experiences if they choose. Physical presence is an initial accomplishment, with authentic social integration being the eventual goal.
2. The individual's skill development and growth in adaptive domains, particularly communication and social skills, is an essential aspect of support and is pursued consistently. This may include specific skill substitutions that accommodate the perceived adaptive function of challenging behavior.
3. The individual's family and staff have an enhanced capacity to understand and observe factors contributing to positive learning opportunities and to potential behavioral episodes. Behavior is understood as one part of a larger medical, sensory, experiential, and social contextual ecology.
4. The individual's family and staff have enhanced capacity and confidence to respond to challenging behavior. This is rated independently of its impact on intensity, frequency, and event duration.
5. The individual's challenging behaviors are positively changing with respect to intensity, frequency, and event duration.

The review results are used first to assess the life satisfaction of each individual reviewed, and to inform future support considerations. However, the review also serves as a continuous quality feedback tool that guides future BBS and service provider activities.

Ohio

Contact: Teresa Kobelt, Assistant Deputy Director
Ohio Department of Developmental Disabilities
Email: Teresa.Kobelt@dodd.ohio.gov

The Ohio Department of Developmental Disabilities (DODD) has implemented several projects and initiatives to improve system capacity for supporting people with complex needs. These initiatives are collaborative, aimed at strengthening local community systems, and align with DODD's overall shift to person-centered work and positive behavior supports.

DODD's MIDD Coordinating Center for Excellence (CCOE) involves Ohio Mental Health and Addiction Services (OhioMHAS), DODD, and the Ohio Developmental Disabilities Council. With the goal of providing appropriate treatment for individuals with co-occurring mental illness and developmental disabilities, the CCOE assists local systems throughout Ohio to increase their service capacity and foster collaboration through Dual Diagnosis Intensive Treatment (DDIT) Teams. The CCOE also provides comprehensive psychiatric assessments, educational programs, regional and local team consultation and funds technical assistance and training. The CCOE helped launch Ohio's Telepsychiatry Project.

Ohio's Telepsychiatry Project allows individuals with ID/DD and MI who live in remote and underserved areas to get access to clinicians who have expertise and knowledge of their needs. Outcomes of this project include a reduction in hospitalizations, a reduction of admissions or readmissions to state-operated institutions, and a reduction in travel costs.

Ohio's Trauma Informed Care Initiative is further collaboration between DODD and OhioMHAS. A growing body of research suggests individuals with ID/DD experience trauma at rates significantly higher than the general population, and much of what was once thought of as "behavior" is now recognized as a symptom of trauma. DODD and OhioMHAS are committed to advancing trauma-informed care through the Trauma Informed Care (TIC) Initiative. The TIC Initiative is developing, coordinating and implementing a plan for statewide transmission of trauma-informed care in a broad and cost-effective manner, using internal Ohio resources in consultation with the National Center for Trauma-Informed Care.

In addition to the systems-level work of the TIC Initiative, DODD and the MIDD CCOE have worked closely with experts to offer statewide training to expand the capacity of local teams to deliver trauma-responsive services, including 2-day trainings aimed at increasing the ability of

stakeholders to understand and support people with trauma histories and Theory-to-Practice Advanced Learning Communities that develop local experts who serve as resources for information and implementation of research-informed practices.

Finally, the *Strong Families, Safe Communities* initiative is aimed at establishing treatment models of care that focus on crisis stabilization for children and youth (8-24) with intensive needs. DODD and OhioMHAS issued grants to local systems to identify scalable, community-driven solutions that highlight cross-system collaboration and result in the best possible outcomes for children and families.

Massachusetts

Contact: Janet George, Assistant Commissioner for Policy, Planning, and Children's Services
Department of Developmental Services
Email: janet.george@state.ma.us

In January 2012 the Commissioner of the Massachusetts Department of Developmental Services (DDS) established the Positive Behavior Supports (PBS) Initiative. The Initiative established a framework for enhancing quality of life, anticipating and responding to problems, and decreasing aversive interventions. To achieve these goals,

the Massachusetts DDS committed to measuring socially valued outcomes, implementing systems to effectively execute empirically validated and practical practices and collect and analyze data to aid in decision-making. Massachusetts DDS recognized that there were systems-based changes that needed to be in place to make the initiative successful. They needed to guarantee agency commitment and buy-in and they needed a system for data collection, outcomes monitoring, and dissemination of data to inform data-based decision-making.

Between May 2013 and July 2013, DDS began a pilot project to examine the reaction to and issues involved with the implementation of PBS in the Commonwealth. Ten agencies were involved and feedback was positive. Issues with training and dissemination of materials were identified. DDS has since begun rolling out PBS in all agencies in the Commonwealth. Each agency is required to develop a PBS leadership team and a data-based action plan. In addition, each agency is required to train all staff in PBS using DDS certified restraint curriculum and categorize behavior plans into the PBS framework. All materials developed by DDS on PBS can be found at <http://ddslearning.com/dds-pbs-initiative/>.

Notes

- ¹ Challenging behavior is “of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behavior which is likely to seriously limit or deny access to the use of ordinary community facilities.” As defined in: Emerson, E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge: Cambridge University Press, 4-5.
- ² Poppes, P., van der Putten, A., Vlaskamp, C. (2010) Frequency and severity of challenging behavior in people with profound intellectual and multiple disabilities, *Research in Developmental Disabilities*, 31(6), 1269-75.
- ³ Emerson, E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge: Cambridge University Press, 4-5.
- ⁴ Matson, J., Cooper, C., Malone, C., & Moskow, S. (2008) The relationship of self-injurious behavior and other maladaptive behaviors among individuals with severe and profound intellectual disability, *Research in Developmental Disabilities*, 29(2), 141-148.
- ⁵ Symons, F. (2008) Review of self-injurious behavior in intellectual disabilities, *Journal of Mental Health Research in Intellectual Disabilities*, 1, 257-259.
- ⁶ States included in the 2012-2013 administration of the Adult Consumer Survey are 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 (MEORC).

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