

National Core Indicators Data Brief

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ABOUT NCI



What Do NCI Data Reveal About Individuals With Intellectual and Developmental Disabilities Who Communicate Nonverbally?

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The ability to communicate is an adaptive skill that facilitates optimal functioning in everyday life. People with intellectual and developmental disabilities (ID/DD) are often challenged by deficits in their ability to communicate.^{1,2} Communication limitations can hamper a person's independence³ and increase the likelihood of other problems such as challenging behaviors^{4,5}. Yet, there is very little existing research into the population of individuals who communicate nonverbally and their demographics, quality-of-life outcomes, and experiences in public service systems.

Almost one-quarter of all respondents to the National Core Indicators (NCI) Adult Consumer Survey do not communicate verbally. The NCI data, which are gathered in part via in-person

interviews with individuals receiving services, reveal that people with disabilities who communicate nonverbally have unique characteristics, service needs, and life circumstances and, as a result, are likely to face additional challenges in their ability to achieve valued outcomes.

In this data brief, we present the differences in the demographic profile as well as the attainment of valued outcomes—including rights, respect, inclusion, personal safety, choice, health, and employment—between individuals in our survey sample who communicate nonverbally and those who communicate verbally. The analysis suggests several interesting and provocative comparisons that can help inform state officials, providers, and advocates as they forge policies



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 authorities 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. Find more information on National Core Indicators at www.nationalcoreindicators.org.

Description and Demographics of Sample

and supports for people who do not use words to speak.

The data in this brief are from the 2011-2012 administration of the National Core Indicators (NCI) Adult Consumer Survey (ACS) of 12,236 individuals with ID/DD from 19 states and one regional council: Alabama, Arkansas, Arizona, Connecticut, Georgia, Hawaii, Illinois, Kentucky, Louisiana, Massachusetts, Maine, Mid-East Ohio Regional Council, Michigan, Missouri, North Carolina, New Jersey, New York, Ohio, Pennsylvania, and South Carolina.

All individuals surveyed were aged 18 and over and receiving at least one service in addition to case management.

The questions analyzed for this data brief come from the survey's Background Information Section and from Sections I and II. 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 the face-to-face interview. Section I of the survey aims to assess the individual's opinions and level of satisfaction. It may *only* be completed through a direct meeting with the individual. Section II questions are also answered by the individual if possible. If the person is unable to respond, a proxy who knows the person well, such as a family member or a staff person, may provide responses.

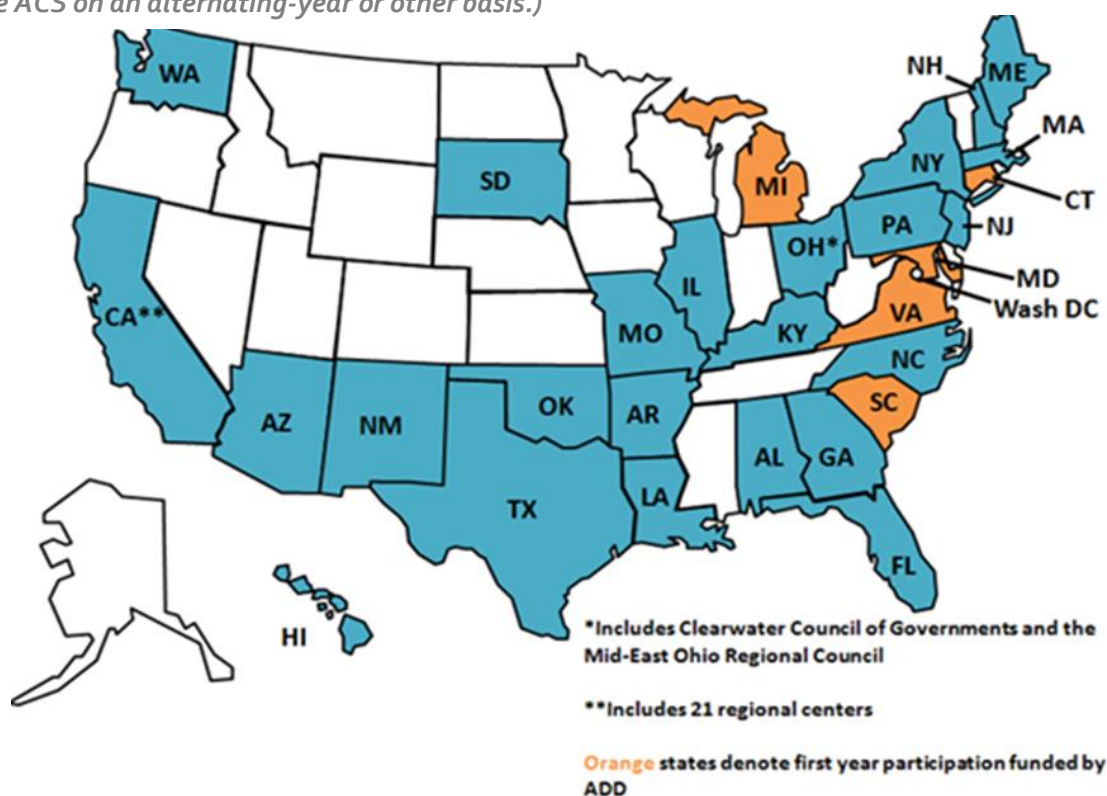
Case managers or service coordinators are not allowed to respond on the individual's behalf.

The individual's primary means of expression is assessed by a question in the Background Information Section of the ACS. For the purposes of these analyses, only individuals for whom a primary means of expression was reported were included in the sample. Respondents for whom this question was left blank or coded as "Don't Know" were excluded from the final dataset. The final dataset includes 12,041 people.

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

NCI Participation: 2011-2012

(Not all states in the graphic below are included in the dataset used for this data brief; some administer the ACS on an alternating-year or other basis.)



Results

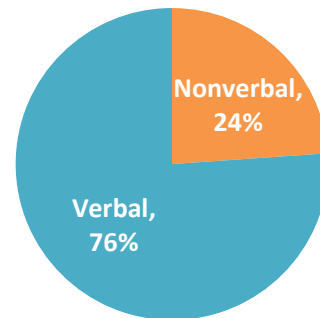
Demographics

From a total of 12,041 adult respondents with disabilities, 24% use nonverbal communication as their primary means of expression.

Of the respondents who were reported to communicate nonverbally, 83% communicate primarily with gestures and/or body language, 6% communicate primarily with sign language and/or finger spelling, 4% communicate primarily via a communication aid/device, and 7% reported "other" as their primary means of communication.

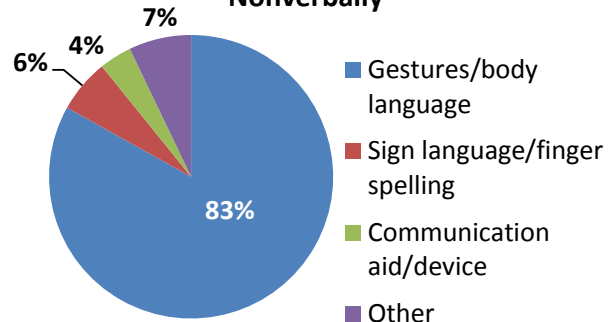
Respondents who communicate verbally and those who communicate nonverbally do not differ significantly in gender or age. However, the populations of different races and ethnicities differ significantly in their percentages of verbal and nonverbal respondents. Respondents who communicate verbally made up 78% of the American Indian or Alaskan Native respondents, 62% of Asian respondents, 74% of Black or African American respondents, 56% of Pacific Islander respondents, 78% of White respondents, and 74% of respondents who identify as another race. Among respondents of all races who identify as Hispanic, 72% communicate verbally.

Primary Means of Expression



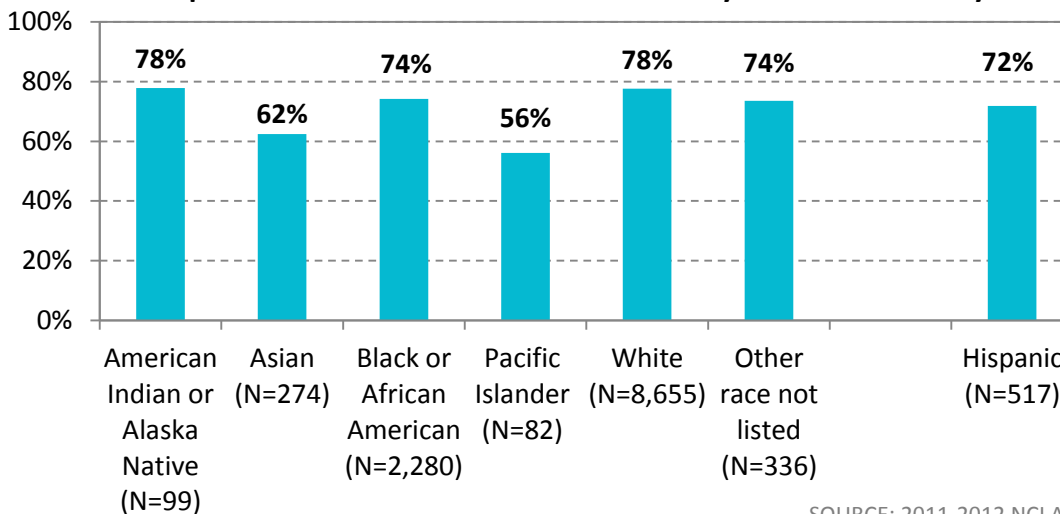
SOURCE: 2011-2012 NCI ACS

Primary Means of Expression Among Those Who Communicate Nonverbally



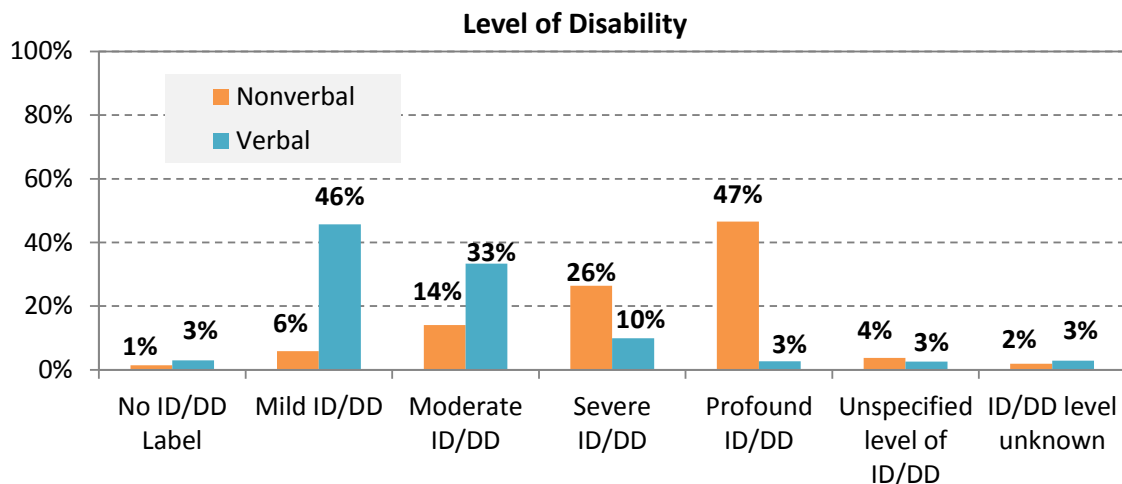
SOURCE: 2011-2012 NCI ACS

Respondents With Verbal Communication by Race and Ethnicity



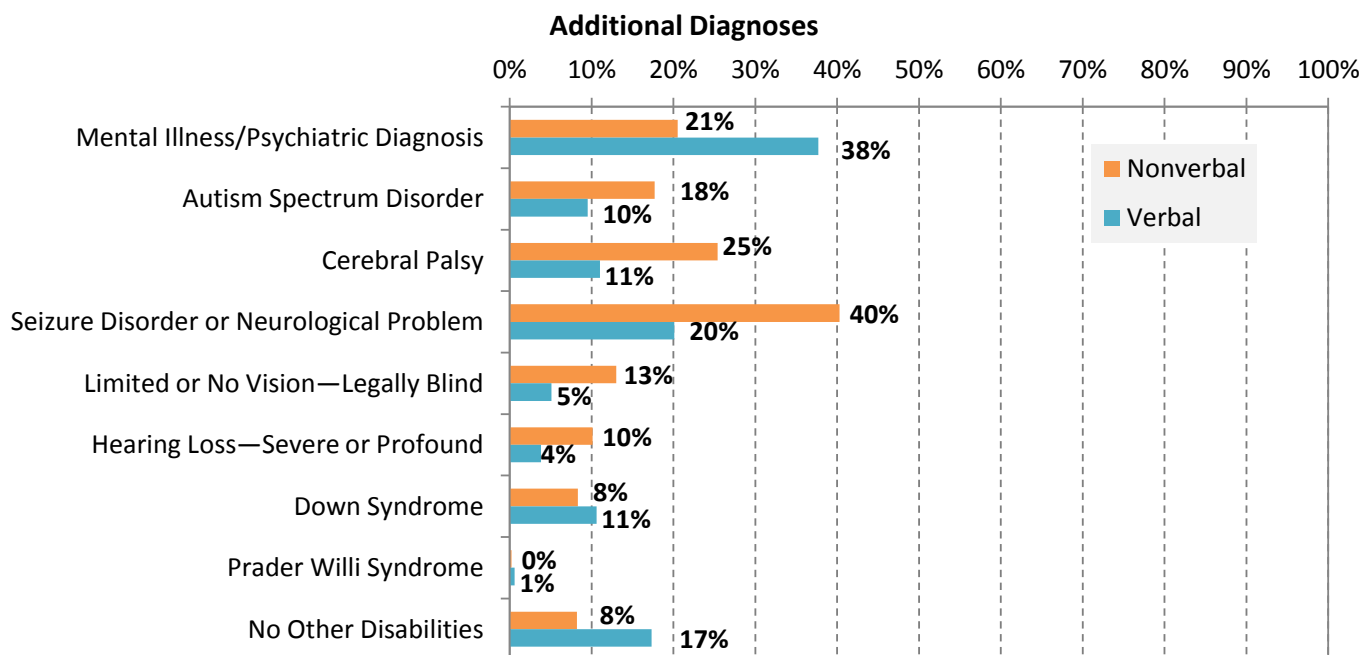
SOURCE: 2011-2012 NCI ACS

Individuals who communicate verbally and those who communicate nonverbally differ significantly in their level of intellectual disability. Of those who communicate nonverbally, 47% have been diagnosed with profound ID/DD while 6% have been diagnosed with mild ID/DD. These figures are nearly reversed among respondents who communicate verbally: 3% have been diagnosed with profound ID/DD while 46% have been diagnosed with mild ID/DD.



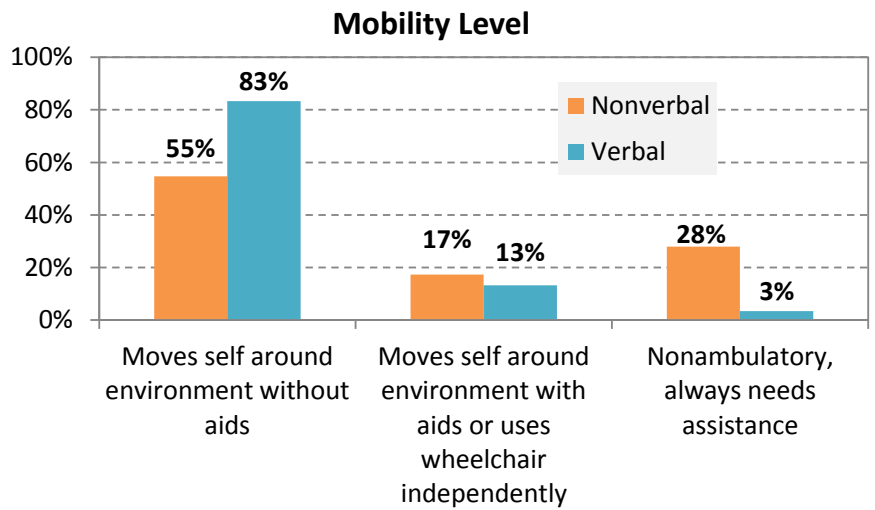
SOURCE: 2011-2012 NCI ACS

Respondents who communicate verbally and non-verbally also differ in the rate at which they are diagnosed with specific additional disabilities. For example, there is a significant difference between respondents who communicate verbally and those who communicate non-verbally in diagnosis with Mental Illness/Psychiatric Diagnosis. A full 38% of respondents who communicate verbally have been diagnosed with Mental Illness/Psychiatric Diagnosis, while 21% of respondents who communicate non-verbally have been similarly diagnosed.



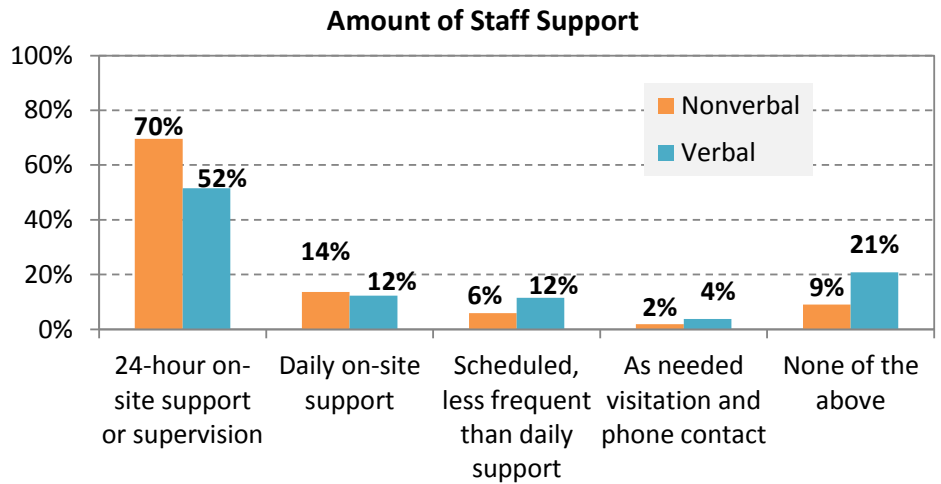
SOURCE: 2011-2012 NCI ACS

Level of mobility differed significantly among respondents who communicate verbally and those who communicate nonverbally. Respondents who communicate verbally were significantly more likely to move themselves without aids (83%) compared to those who communicate nonverbally (55%). Conversely, respondents who communicate nonverbally were significantly more likely to be nonambulatory (28%) than respondents who communicate verbally (3%).



SOURCE: 2011-2012 NCI ACS

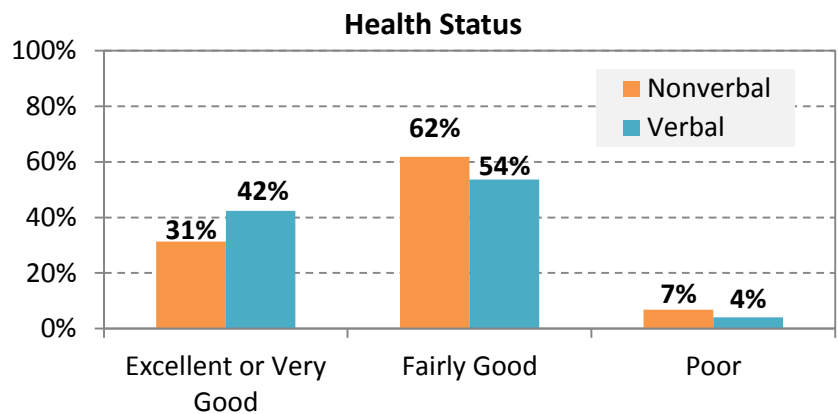
Respondents who communicate nonverbally were also more likely to require 24-hour on-site support or supervision (70%) than those who communicate verbally (52%).



SOURCE: 2011-2012 NCI ACS

Health

There is a significant difference in reported health status among respondents who communicate verbally and those who communicate nonverbally. Among respondents who communicate verbally, 42% were reported to be in excellent or very good health; the rate was only 31% among those who communicate nonverbally.



SOURCE: 2011-2012 NCI ACS

Respondents who communicate verbally and those who communicate nonverbally also differed significantly in terms of preventive healthcare. For example, a greater percentage of respondents who communicate nonverbally had routine physical exams in the past year than those who communicate verbally (93% and 90%, respectively).

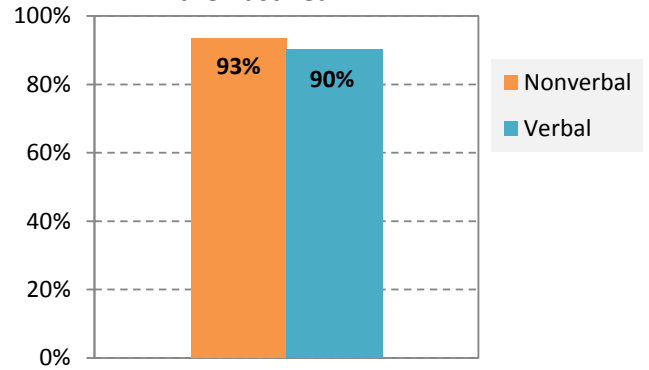
In terms of medication, nearly half of all respondents who communicate nonverbally take at least one medication for mood disorders, anxiety, behavior problems or psychotic disorders (48%). More than one-half of respondents who communicate verbally (55%) take at least one medication for those same disorders.

Home

Respondents who communicate verbally and those who communicate nonverbally differed significantly in terms of their residence type. Those who communicate nonverbally were more likely to live in an institutional setting than those who communicate verbally (12% and 2%, respectively) and were also more likely to live in a community-based setting (such as a group home or agency-operated apartment) than those who communicate verbally (42% and 37%, respectively). Respondents who communicate verbally were more likely to live in an independent home (15% versus 4%) or in the home of a parent/relative (35% versus 31%).

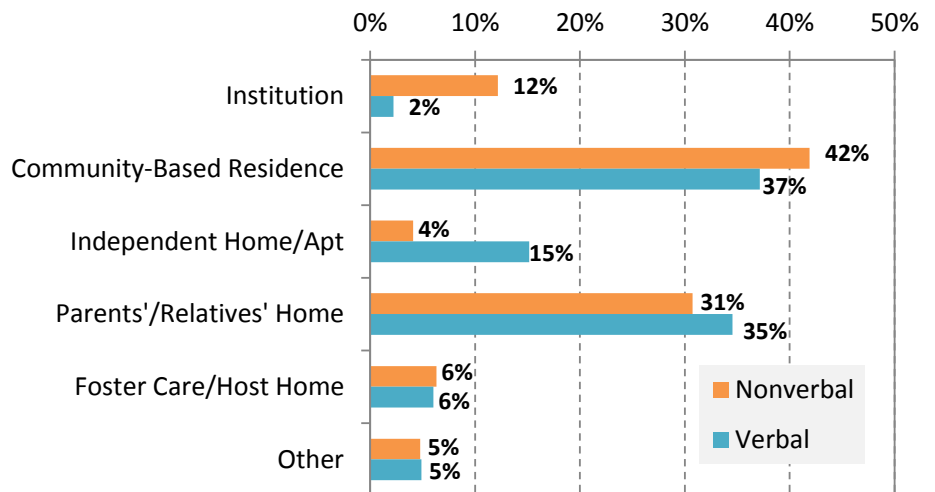
Respondents also differed significantly in their satisfaction with their home and neighborhood. Respondents who communicate nonverbally were more likely to like where they live and their neighborhood than individuals who communicate verbally (95% of respondents who communicate nonverbally like where they live compared to 90% of respondents who communicate verbally, while 93% of respondents who communicate nonverbally like their neighborhood compared to 88% of respondents who communicate verbally). Close to one-quarter (27%) of respondents who communicate verbally would like to live elsewhere, while only about one-fifth (20%) of respondents who communicate nonverbally would like to live somewhere else.

Had a Routine Physical Exam in the Past Year



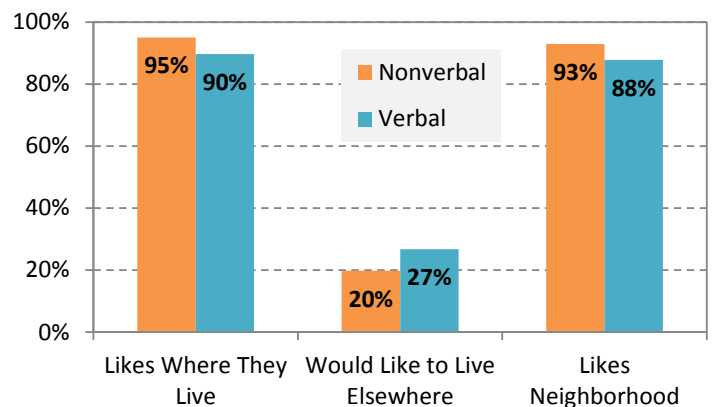
SOURCE: 2011-2012 NCI ACS

Residence Type



SOURCE: 2011-2012 NCI ACS

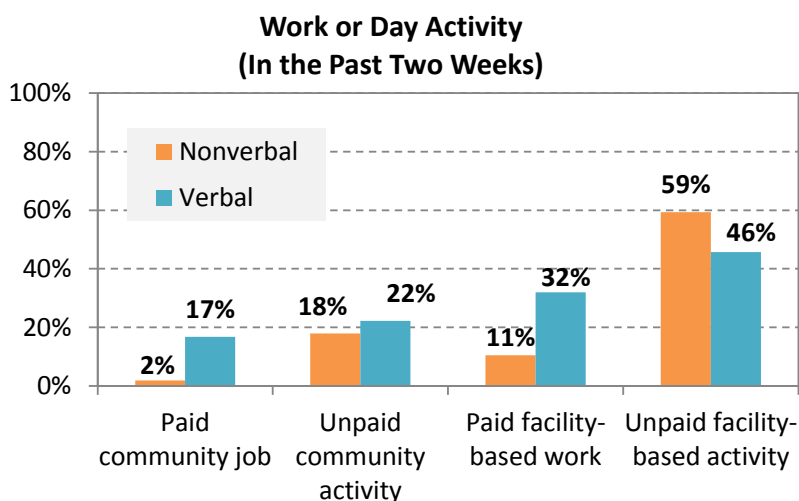
Satisfaction With Residence



SOURCE: 2011-2012 NCI ACS

Work/Day Activity

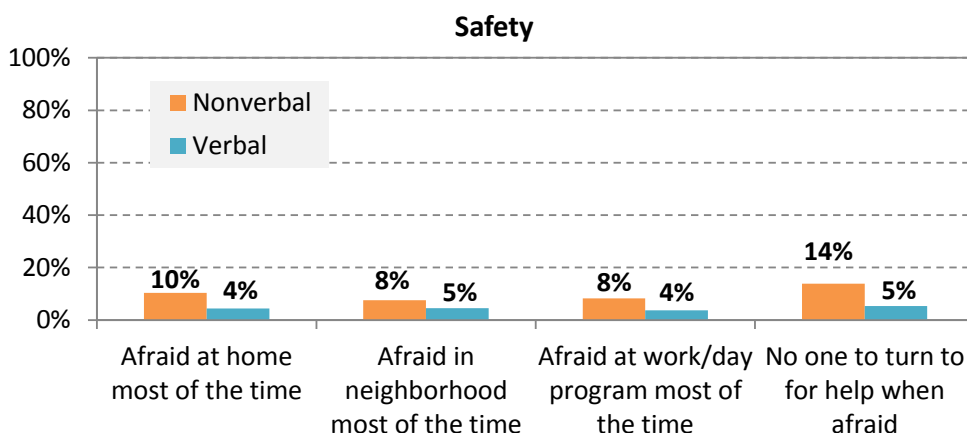
Respondents who communicate verbally and those who communicate nonverbally also differed significantly with respect to what they do during the day. Respondents who communicate verbally were significantly more likely to have paid work (community or facility-based) or an unpaid community activity. Respondents who communicate nonverbally were significantly more likely to participate in an unpaid facility-based activity.



SOURCE: 2011-2012 NCI ACS

Safety

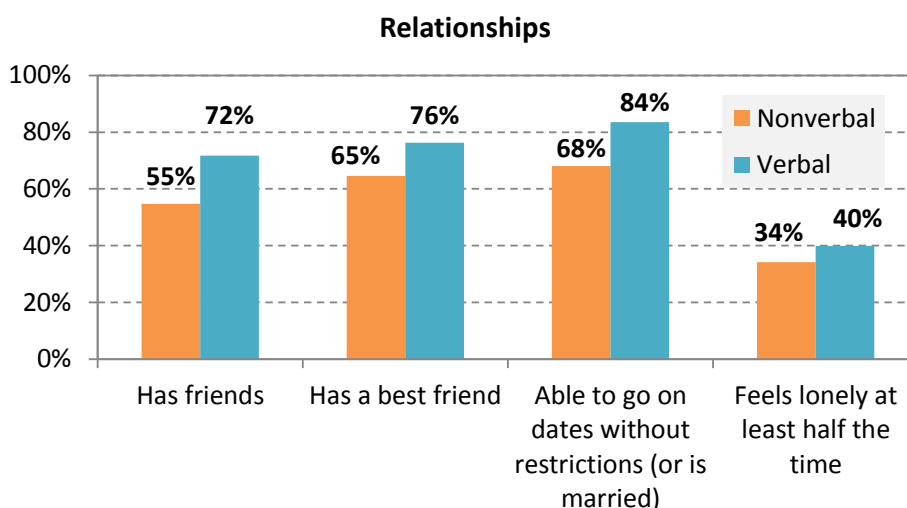
The 2011-2012 ACS data also demonstrate significant differences in subjective feelings of safety among respondents. In general, respondents who communicate nonverbally reported feeling afraid more often than those who communicate verbally. Additionally, respondents who communicate nonverbally were more likely to report not having someone to go to for help if they felt afraid.



SOURCE: 2011-2012 NCI ACS

Relationships

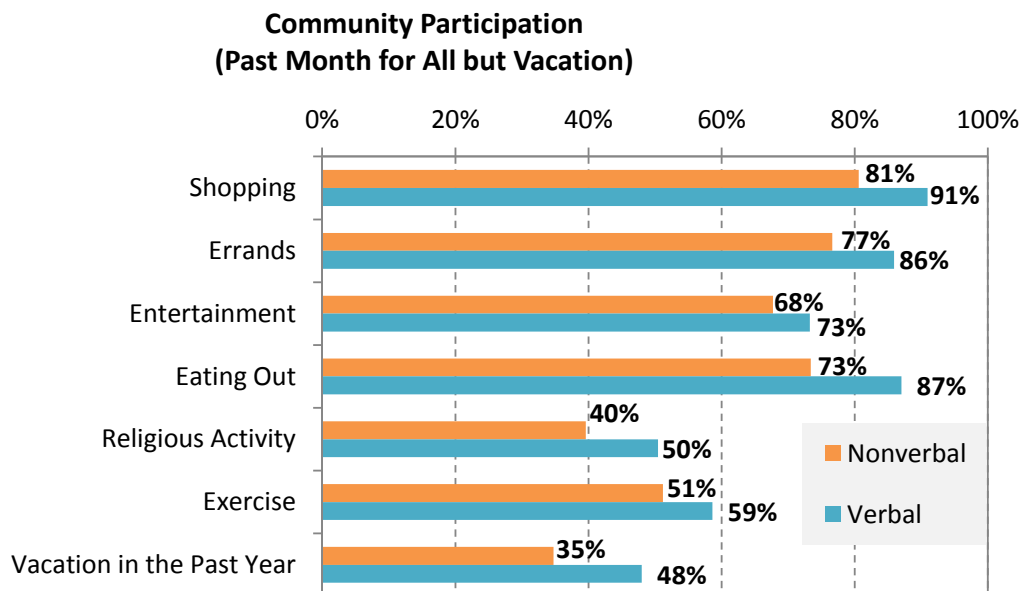
Respondents who communicate verbally reported having friends (72%), having a best friend (76%), and being able to go on dates without restrictions or being married (84%) at significantly higher rates than individuals who communicate nonverbally (55%, 65%, and 68%, respectively). However, respondents who communicate verbally reported feeling lonely at least half the time at a higher rate than those who communicate nonverbally (40% and 34%, respectively).



SOURCE: 2011-2012 NCI ACS

Community Participation

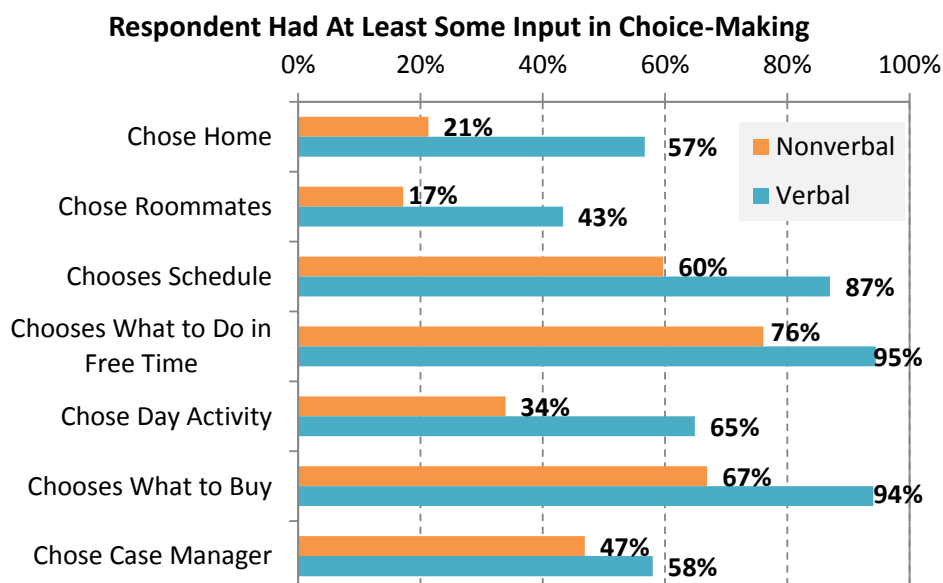
There were significant differences in the rates of community participation among respondents who communicate verbally and those who communicate nonverbally. Individuals who communicate verbally were significantly more likely to have participated, within the previous month (or past year for the Vacation category), in the community activities reported on in the ACS.



SOURCE: 2011-2012 NCI ACS

Choice

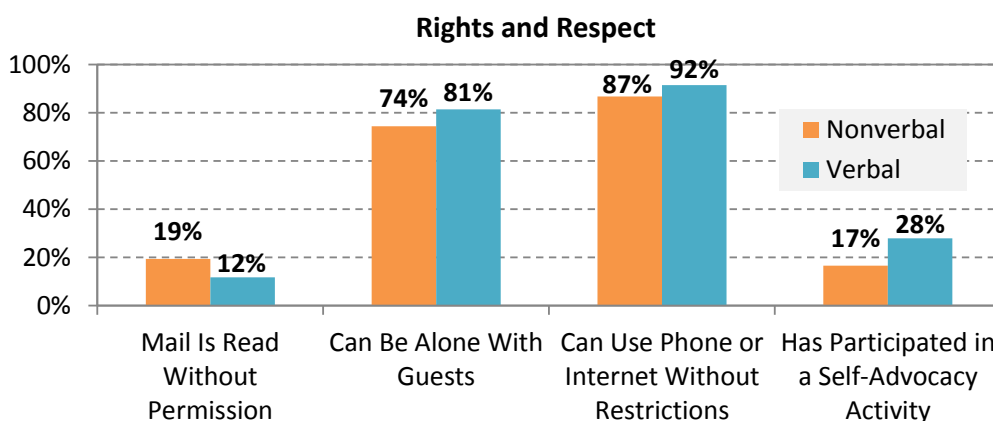
Respondents who communicate verbally were also significantly more likely to have exercised choice. Notably, 57% of respondents who communicate verbally reported having chosen their home, while only 21% of individuals who communicate nonverbally did so. Also noteworthy, 87% of individuals who communicate verbally reported that they choose their daily schedule; this compares to 60% among respondents who communicate nonverbally.



SOURCE: 2011-2012 NCI ACS

Rights and Respect

Respondents who communicate verbally and those who communicate nonverbally differ significantly in some indicators regarding rights and respect. Individuals who communicate nonverbally were significantly more likely to have their mail read without permission (19%) and less likely to have participated in a self-advocacy activity (17%) than respondents who communicate verbally (12% and 28%, respectively).



SOURCE: 2011-2012 NCI ACS

Summary of Findings

Demographics:

- Almost one-quarter of all respondents to the NCI Adult Consumer Survey do not communicate verbally (24%). Of those, 83% communicate using gestures and/or body language, 6% using sign language and/or finger spelling, and 4% communicate using a communication aid/device.
- The percentages of individuals who communicate verbally vary by race and ethnicity.
- Respondents who communicate verbally and those who communicate nonverbally differ significantly in level of disability: those who communicate verbally were significantly more likely to be diagnosed with mild ID/DD and those who communicate nonverbally were more likely to be diagnosed with profound ID/DD.
- Respondents who communicate verbally and those who communicate nonverbally differ significantly in rates of diagnosis with other disabilities. Respondents who communicate verbally were more likely to have a mental health/psychiatric diagnosis, Down syndrome, or Prader-Willi syndrome. Respondents who communicate nonverbally were more likely to be diagnosed with Autism Spectrum Disorder, Cerebral Palsy, seizure disorder/neurological condition, limited or no vision, or hearing loss.
- Respondents who communicate nonverbally were more likely to need more intensive staff support.
- Respondents who communicate nonverbally were significantly more likely to be nonambulatory. Those who communicate verbally were more likely to be self-mobile without aids.

Health:

- Respondents who communicate verbally are significantly more likely to be in excellent or very good health.
- Respondents who communicate nonverbally had routine physical exams in the past year at a higher rate than those who communicate verbally.

Home:

- Respondents who communicate verbally were more likely to live in an independent home or apartment or a parent's or relative's home; respondents who communicate nonverbally were more likely to live in an institution or community-based residence.
- Respondents who communicate nonverbally were more likely to like where they live (residence and neighborhood).

Employment:

- Respondents who communicate verbally were more likely to work in a paid job (facility and community-based) and have an unpaid community activity. Respondents who communicate nonverbally were more likely to have an unpaid, facility-based activity.

Safety:

- Respondents who communicate nonverbally were more likely to report feeling afraid most of the time at home, in their neighborhood, and in their work/day program.

Relationships:

- Respondents who communicate nonverbally were less likely to report having friends and being able to go out on dates. They were also less likely to feel lonely at least half the time.

Community Participation:

- Respondents who communicate nonverbally were less likely to participate in activities in the community.

Choice:

- Respondents who communicate nonverbally were less likely to have input into choices such as where to live, their roommates, their schedule, what to do in their free time, their day activity, what to buy, and who would be their case manager.

Rights and Respect:

- Respondents who communicate nonverbally were less likely to be allowed to be alone with guests, use the phone or Internet without restrictions, or participate in a self-advocacy activity. They were more likely to have their mail read without their permission.

Limitations

The differences in outcomes among the populations of respondents who communicate verbally and those who communicate nonverbally 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.

The Safety and Relationships charts in this Data Brief utilize variables from Section I of the ACS. Section I must be completed by the individual receiving services (not a proxy). If it's determined that the individual receiving services cannot complete Section I, the section is skipped and the interview continues with Section II (for which a proxy can be used). There is a significant difference among the populations of respondents who communicate verbally and those who communicate nonverbally in terms of valid response rates to Section I. Of the respondents who communicate verbally, 86% were determined to have valid responses to Section I as compared to 28% of respondents who communicate nonverbally. Furthermore, for those who responded to Section II, respondents who communicate nonverbally were more likely to have used a proxy. A full 85% of respondents who communicate verbally answered at least some of the questions in Section II themselves compared to just 33% among respondents who communicate nonverbally.

Data Brief was edited by Jessica Maloney

- ¹ Matson, J. L., Horovitz, M., Kozlowski, A. M., Sipes, M., Worley, J. A., & Shoemaker, M. E. (2011). Person characteristics of individuals in functional assessment research. *Research in Developmental Disabilities, 32*, 621–624.
- ² Kurtz, P. F., Boetler, E. W., Jarmolowicz, D. P., Chin, M. D., & Hagopian, L. P. (2011). An analysis of functional communication training as an empirically supported treatment for problem behavior displayed by individuals with intellectual disabilities. *Research in Developmental Disabilities, 32*, 2935–2942.
- ³ Soenen, S., Van Berckelaer-Onnes, I., & Scholte, E. (2009). Patterns of intellectual, adaptive and behavioral functioning in individuals with mild mental retardation. *Research in Developmental Disabilities, 30*, 433–444
- ⁴ Matson, J. L., Kozlowski, A. M., Worley, J. A., Shoemaker, M. E., Sipes, M., & Horovitz, M. (2011). What is the evidence for environmental causes of challenging behaviors in persons with intellectual disabilities and autism spectrum disorders? *Research in Developmental Disabilities, 32*, 693–698.
- ⁵ Ringdahl, J. E., Call, N. A., Mews, J. B., Boelter, E. W., & Christensen, T. J. (2008). Assessment and treatment of aggressive behavior without a clear social function. *Research in Developmental Disabilities, 29*, 351–362.