

NCI DATA BRIEF

VOLUME 6 ISSUE 2

May 2008

What does NCI tell us about people with autism?

The 2006-2007 National Core Indicators Consumer Survey Report provides descriptive and outcome data on 12,193 adults (18 years and older) receiving publicly financed developmental disabilities services in 20 states. This Data Brief explores characteristics and differences in the responses of a subset of individuals who had diagnoses of autism. Of the total respondents for whom diagnostic information was available (11,151), 7.1% (N=791) had diagnoses of autism, while 92.9% (N=10,360) did not.

As a proportion of the total number of individuals with developmental disabilities responding to the 2006-2007 NCI surveys, the percentage of individuals with autism varied among the 20 states from 2.5% in Wyoming to 16.9% in West Virginia. The other states that collected NCI consumer data during this period were: Alabama, Arkansas, Connecticut, Delaware, Georgia, Hawaii, Indiana, Kentucky, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Washington, and the Regional Center of Orange County, California. The State of Maine participated in the survey, but did not collect any data on the other disability diagnoses of the consumers.

The results reveal interesting and significant differences in consumer outcomes between individuals with and without autism diagnoses. Additionally, surprising differences were found between the two groups with respect to demographics, medical/psychological information, services received, and supports needed. Unless noted, all differences reported are significant at the $p < .05$ level. At the end of this data brief, observations are listed in order to stimulate discussion about the findings.

PROFILE

Demographics

The demographics of those with and without autism were very similar with little difference in race, ethnicity, marital status, etc. Significant differences were found to exist, however, in many other areas.

As shown in Figure 1, the majority of people in the sample with autism are male (78%) compared to those without autism (54%). Respondents with autism were significantly younger, with a mean age of 33 years vs. 42 years (see Figure 2), and were more likely to be in school (8% vs. 2%).

Figure 1. Gender

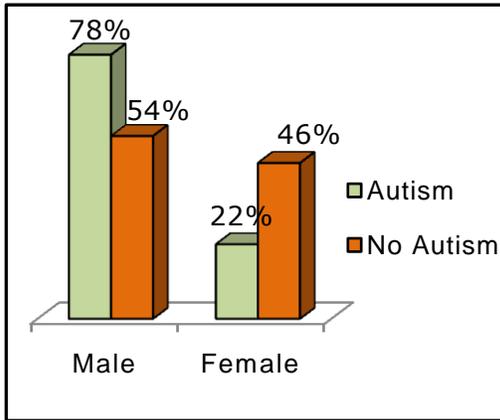


Figure 2. Age

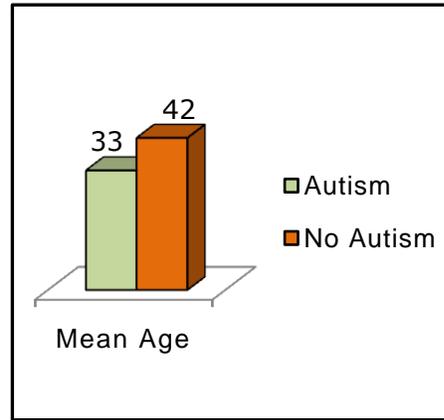
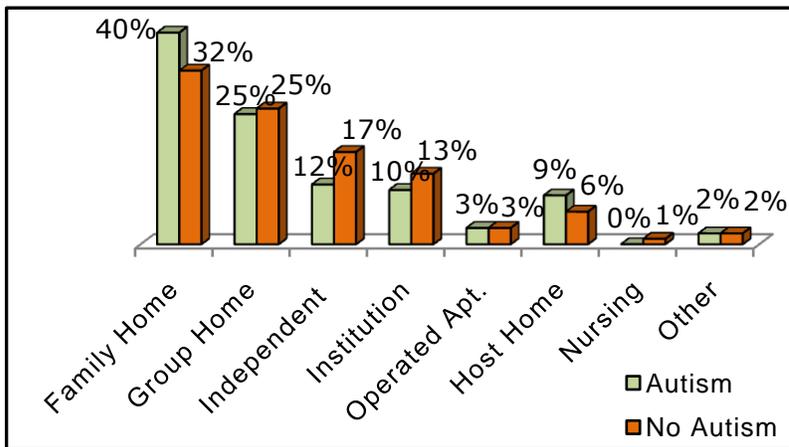


Figure 3. Type of Residence



As a group, individuals with autism were more likely to live at home with family, 40% compared to 32%, and also more likely to live with a foster family or in a host home, 9% compared to 6% (see Figure 3). Figure 4 shows that individuals with an autism diagnosis were much less likely to

speak (55% vs. 76%) and almost twice as likely to use nonverbal communication such as gestures (32% vs. 17%). They were also much less likely to be independent of guardianship (Figure 5).

Figure 4. Primary Means of Expression

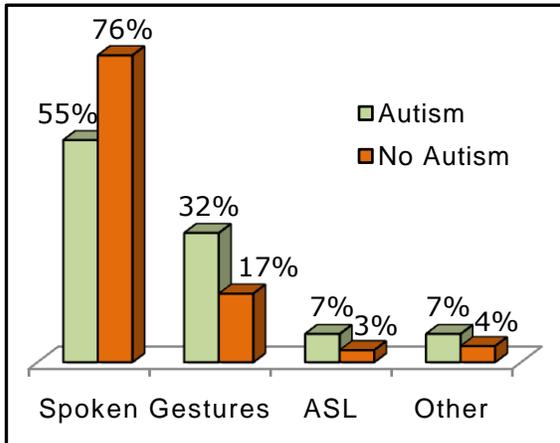
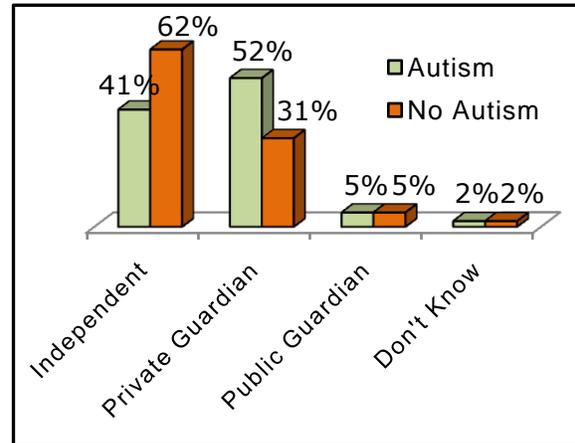


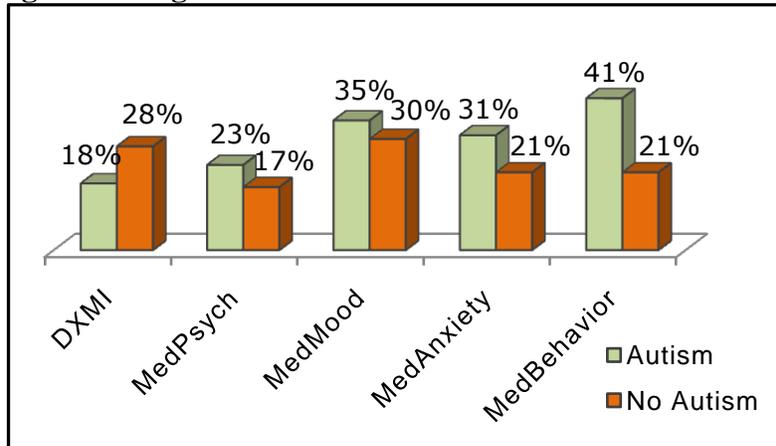
Figure 5. Legal Status



Medical/Psychological Information:

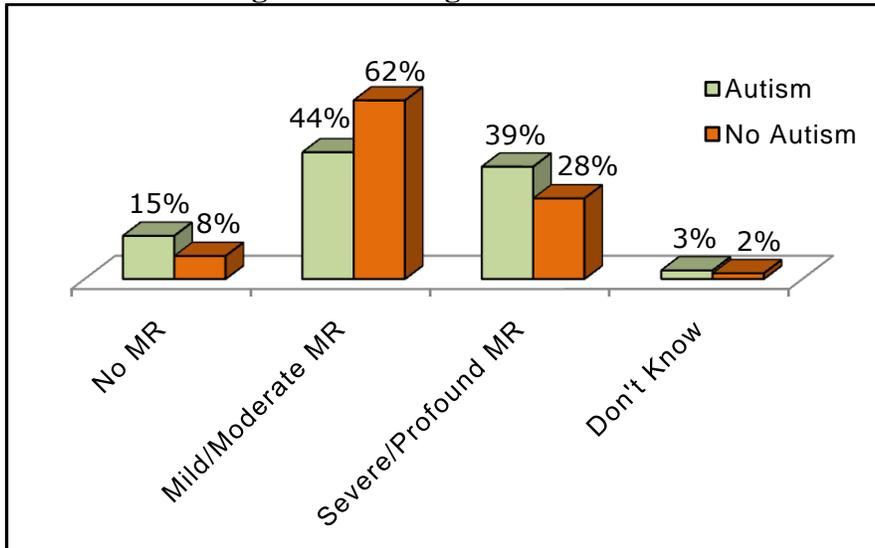
Interestingly, people surveyed with autism were much less likely to have a diagnosis of mental illness (18%) than people without autism (28%). Thus it was striking to find that a *higher* percentage of people with autism were taking all types of psychotropic medications. Notably, people with autism were almost twice as likely to be taking medications to treat behavioral disorders (41% compared to 21%). See Figure 6 below.

Figure 6. Diagnosis of Mental Illness and Use of Medication



Findings related to diagnosis of intellectual disability were not surprising. As indicated in Figure 7, almost twice as many respondents with autism were reported to have no ID diagnosis. Individuals with an ID diagnosis were more likely to have a label of severe or profound disability (39% vs. 28%).

Figure 7. ID Diagnosis and Level



Services Received

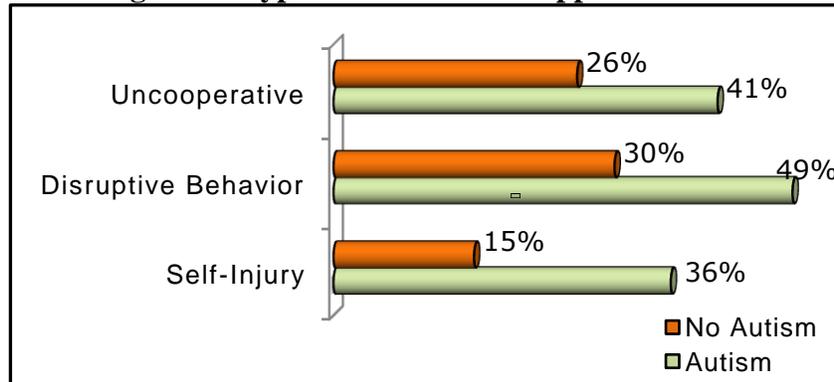
Individuals with autism diagnoses generally received the same types of services as those received by persons without autism. However, individuals with an autism diagnosis were more likely to receive respite and clinical services (see Table 1). Surprisingly, people with autism were *less* likely to report receiving assistive technology supports. Individuals with autism were more likely report that they were directing their own services.

Table 1. Services Received				
	Respite Services	Clinical Services	Assistive Technology	Self-Directed Services
Autism	33%	51%	14%	16%
No Autism	18%	42%	18%	9%

Supports Needed

Not surprisingly, there are more people with autism who were reported to need supports to prevent self-injury, disruptive behavior, and uncooperative behavior than those without autism. See Figure 8 below. The intensity of needed supports was also much greater for those individuals with autism. Of those who need support to prevent self-injury, people with autism were more than three times as likely to report needing supports at least once per week, compared to their counterparts without an autism diagnosis (26% vs. 8%); twice as many respondents with autism were reported to need supports at least once per week to prevent disruptive behavior (30% vs. 16%) and uncooperative behavior (29% vs. 15%).

Figure 8. Types of Behavioral Supports Needed



CONSUMER OUTCOMES

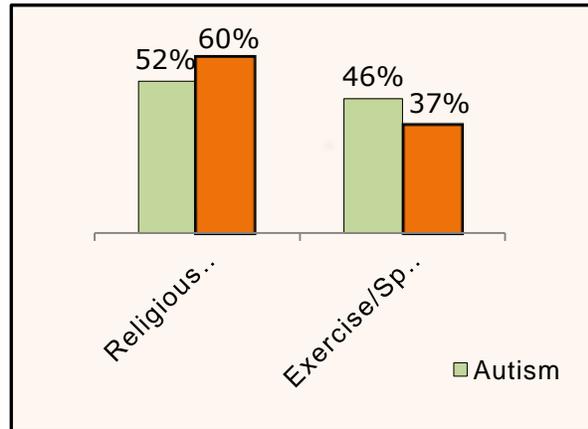
The NCI Consumer Survey measures over 60 core indicators that were established to enhance state-level performance in providing services to people with developmental disabilities. These indicators are divided into several domains, the main domain being Consumer Outcomes. The Consumer Outcomes domain separates core indicators into several sub-domains: Community Inclusion, Choice and Decision Making, Self-Determination, Relationships, and Satisfaction. No significant differences were found

between respondents with autism and those without autism in the Self-Determination and Satisfaction indicators. However, significant differences were evident in the remaining indicators. It should be noted that for the Community Inclusion and Choice and Decision Making questions, a proxy could answer those questions if the person was unable to. Again, all numbers are percentages.

Community Inclusion

To determine the extent to which people with developmental disabilities are included in their communities, the NCI Consumer Survey asks if individuals sampled have participated in the following *integrated* community activities: shopping, running errands, going out for entertainment, going out to eat, going to religious services, going to community meetings, and exercising or playing sports. For many of these Community Inclusion items, there was no significant difference between respondents with and without autism; most responses indicating that persons are participating in community activities. However, as shown in Figure 9, there were significant differences concerning going to religious services and exercising/playing sports in an integrated setting.

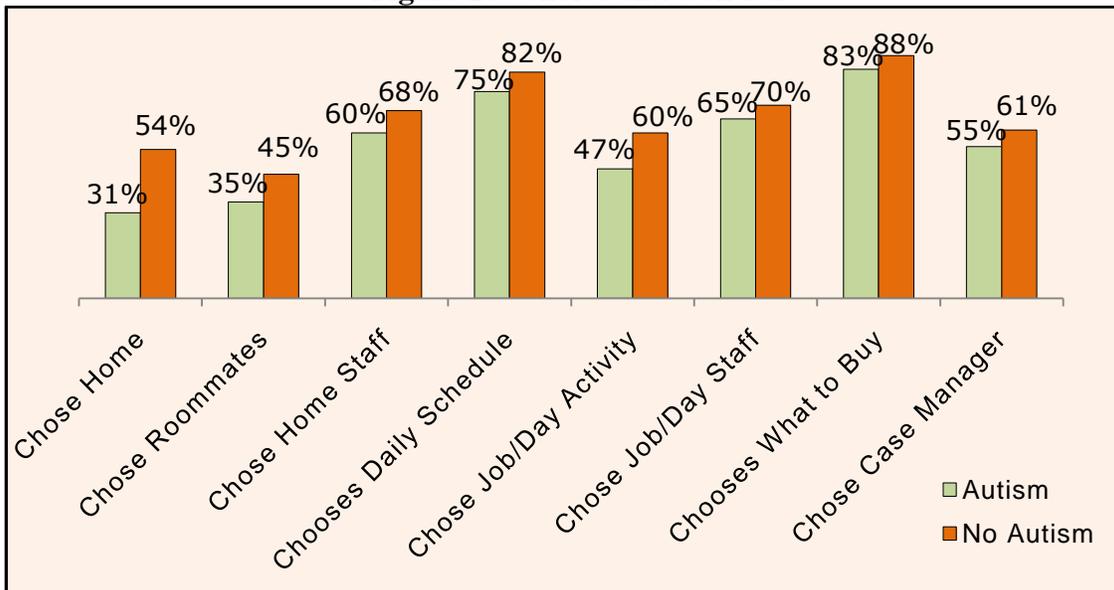
Figure 9: Community Inclusion



Choice and Decision Making

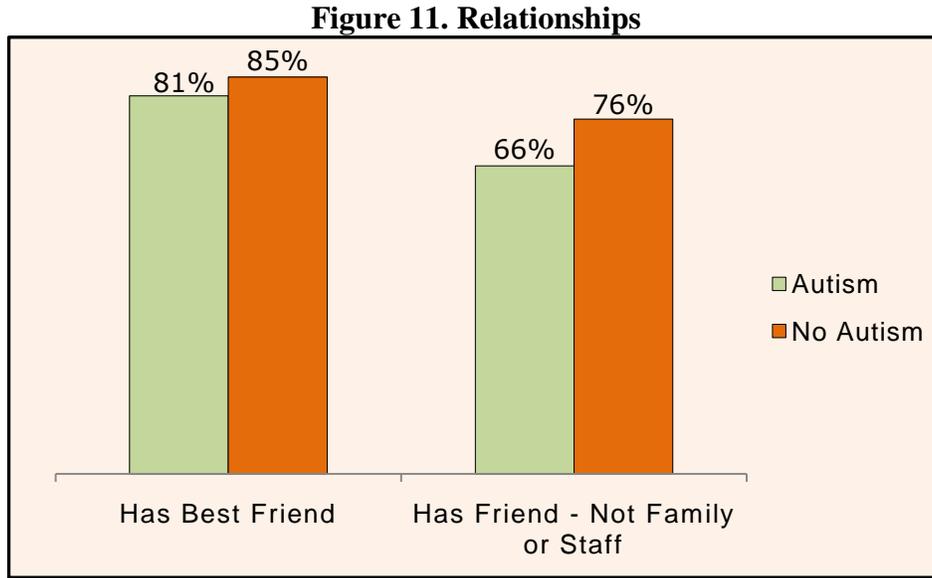
There were large differences between the groups regarding people making choices about their lives and decisions about their services and supports. Figure 10 displays the results of whether the person chose or had some input in choosing a variety of activities.

Figure 10. Choice and Control



Relationships

Although there was no significant difference between respondents with autism and those without the diagnosis concerning loneliness (around half in each group said they were never lonely), persons with autism were less likely to have a best friend and less likely to have a friend who was not a family or staff member. See Figure 11 below.



Respect/Rights

Health, welfare, and rights indicators in the Consumer Survey are divided into sub-domains: Safety, Health, Medications, and Respect/Rights. Some of the health and medications indicators were discussed in the profile section of this data brief. Regarding the safety indicators, there were very small, non-significant differences between the two groups. People with autism were only slightly more afraid at home (21% to 16%) and in their neighborhoods (20% to 17%) than were respondents without autism.

A significant separation of responses existed in the areas of respect and rights. Respondents with autism were much more likely to report that staff do not respect them at home, that they were not permitted to be alone with guests and that their mail was read by others (see Table 2). It should be noted that for the questions asking if the person can be alone at home and whether the mail is read by others, a proxy could answer if the person was unable to.

Table 2. Respect/Rights			
	% Home Staff that Does Not Respect Person	% Persons Who Can Not be Alone with Guests	% Mail is Read by Others Without Permission
Autism	8%	22%	21%
No Autism	5%	12%	12%

CONSTRAINTS AND LIMITATIONS

A comparison of findings between adults with and without autism revealed large differences among factors such as age, physical disability, behavioral supports needed, and where the persons lived. Thus, some of the differences noted may be explained by factors other than the diagnosis of autism. Furthermore, only 38% of the respondents with an autism diagnosis were able to provide responses to the survey, compared to 69% of respondents without an autism diagnosis.

SUMMARY OF FINDINGS

The data gathered through the current NCI Consumer Survey raise important issues. People with autism appear to be less likely to exercise choice and control in their lives, a striking but not surprising finding given the greater likelihood that people with autism also have greater communication and behavioral challenges. The findings also underscore the need to make sure that during the NCI interview process, every effort is made to accommodate people with limited verbal communication. Additional findings include:

- ✚ Respondents with autism were less likely to have a mental illness diagnosis (18% to 28%), but more likely to be taking medications for mood (35% to 30%), anxiety (31% to 21%), behavior (41% to 21%) and psychotic disorders (23% to 17%).
- ✚ Individuals in the sample with autism were more likely (16%) to participate in self-directed services than those without autism (9%).
- ✚ For those respondents with autism who also have a diagnosis of intellectual disability, the diagnosis is more likely to be more severe or profound than for those who do not have autism (39% to 28%).
- ✚ Respondents with autism were less likely to go to integrated religious services in the community (52% to 60%).
- ✚ Respondents with autism were less likely to report being treated with respect.
- ✚ Significantly fewer people with autism completed questions in Section 2 of the Consumer Survey (38%), compared to people without autism (69%).

