

NCI DATA BRIEF

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What does NCI tell us about people with autism? – An update

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The 2008-2009 National Core Indicators Consumer Survey Report provides descriptive and outcome data on 11,569 adults (18 years and older) receiving publicly financed developmental disabilities services in 26 states and four sub-state entities. This Data Brief revisits a topic previously addressed in the May 2008 Data Brief, which looked at people with a diagnosis of autism. This update explores characteristics and responses of individuals who had a diagnosis of autism spectrum disorder (which includes Autism, Asperger Syndrome, and Pervasive Developmental Disorder) and contrasts them with characteristics and responses of individuals who did not. Of the total respondents for whom diagnostic information was available (10,629), 10.6% (N=1,128) had diagnosis of autism spectrum disorder, while 89.4% (N=9,501) did not. As a proportion of the total number of individuals with developmental disabilities responding to the 2008-2009 NCI surveys, the percentage of individuals with autism spectrum disorder varied among the states from 4.0% in Wyoming to 18.9% in New Jersey. It is important to note that the broader diagnostic category was used in the 2008-2009 survey. A higher proportion (10.6%) of the sample in 2008-2009 had an autism spectrum disorder diagnosis compared with 7.1% of the sample diagnosed with autism (using the stricter definition) in the 2006-2007 data.

The results reveal interesting and significant differences in consumer outcomes between individuals with and without autism spectrum disorder diagnosis. Additionally, 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.

PROFILE

Demographics

The demographics of the two groups were very similar in terms of race, ethnicity, and marital status. Significant differences were found to exist, however, in many other areas.

Respondents with autism spectrum disorder were significantly younger, with a mean age of 34.7 years vs. 43.7 years (see Figure 1), and were more likely to be transition age adults who were still enrolled in school (10% vs. 3%). A much larger proportion of people with autism spectrum disorder was male (73%) compared to those without the diagnosis (54%).

As a group, individuals with autism spectrum disorder were more likely to live at home with family (38%, compared to 29%), and less likely to live independently (5% vs. 13%) (see Figure 3).

Figure 1. Age

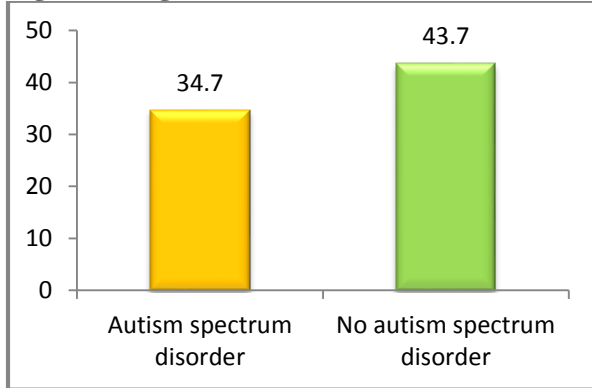


Figure 2. Gender

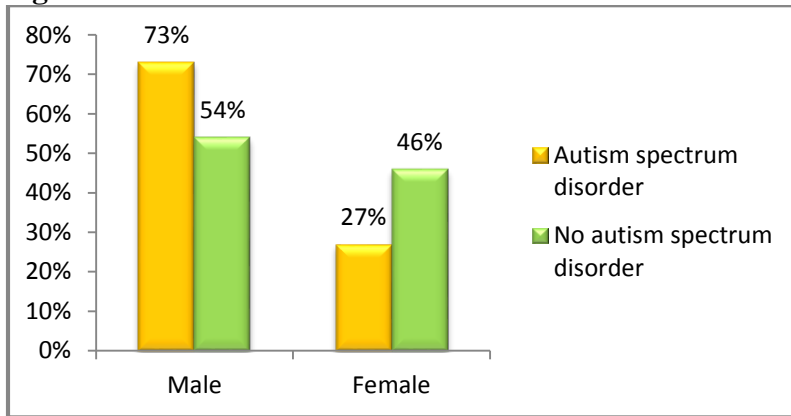


Figure 3. Type of Residence

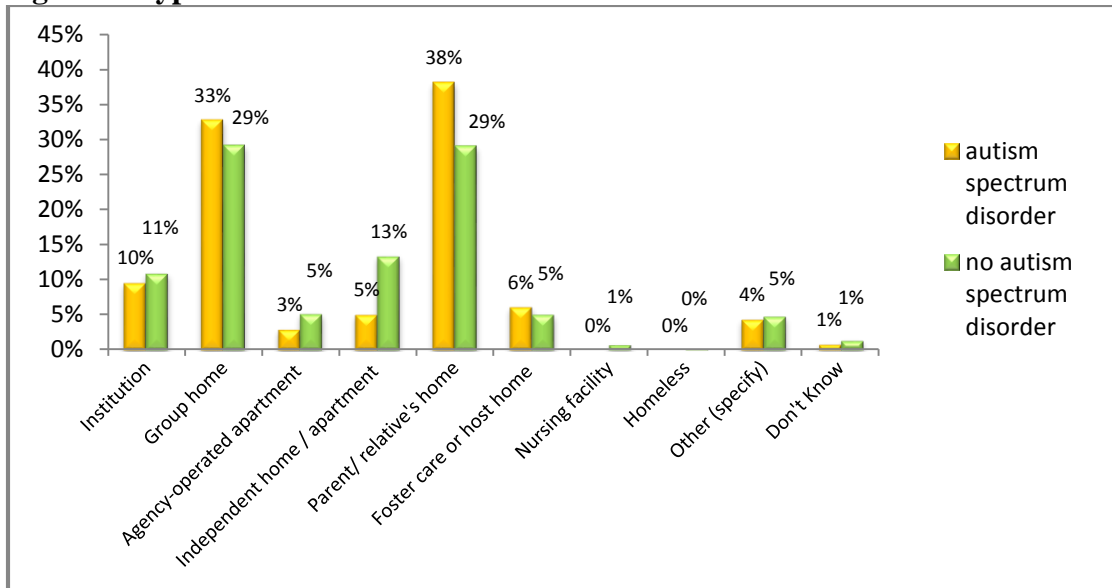
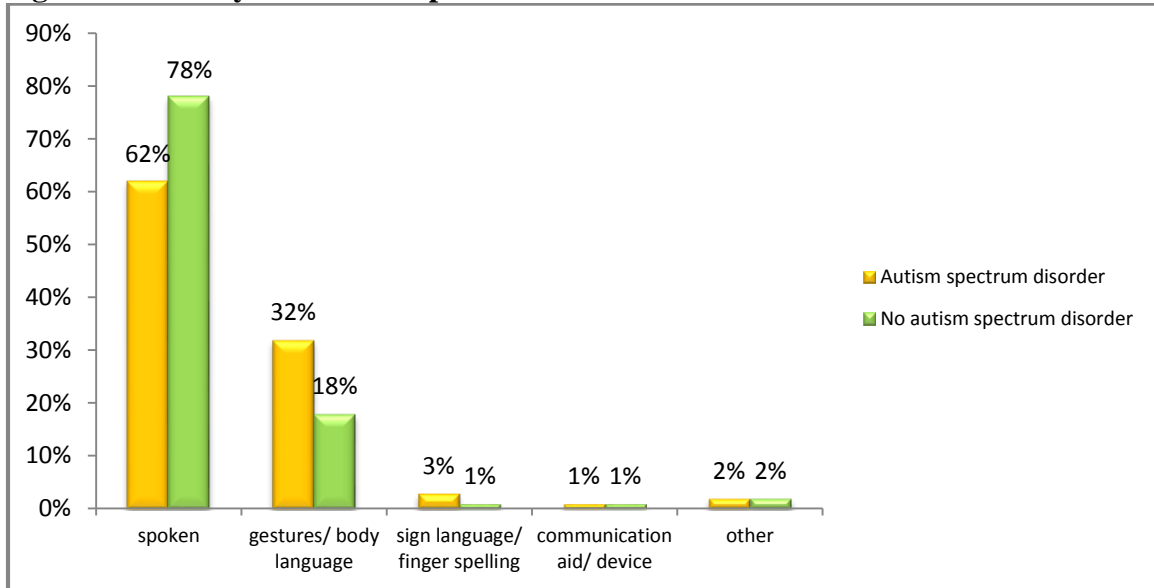


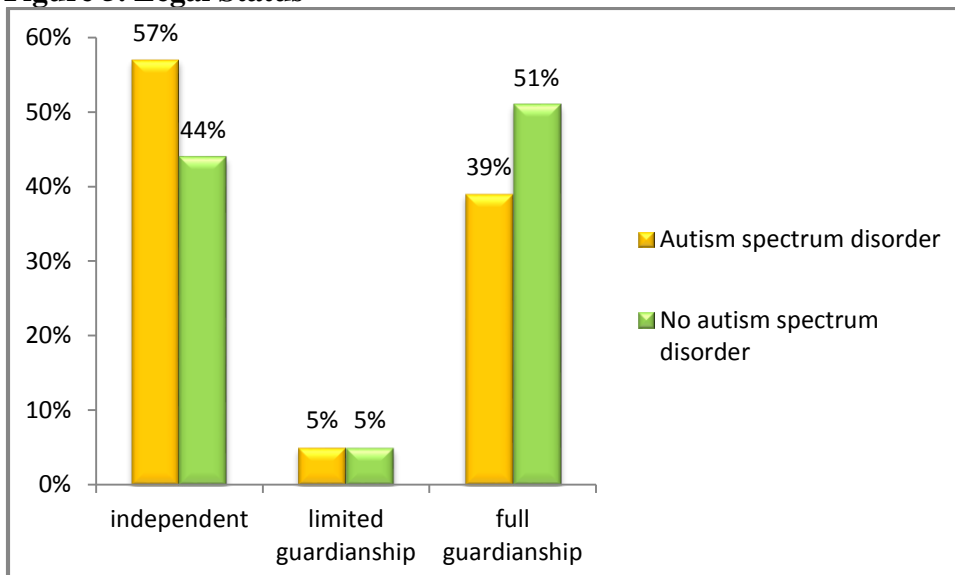
Figure 4 shows that individuals with a diagnosis of autism spectrum disorder were much less likely to speak (62% vs. 78%) and almost twice as likely to use nonverbal communication such as gestures (32% vs. 18%).

Figure 4. Primary Means of Expression



They were also much more likely to be independent of guardianship (Figure 5).

Figure 5. Legal Status

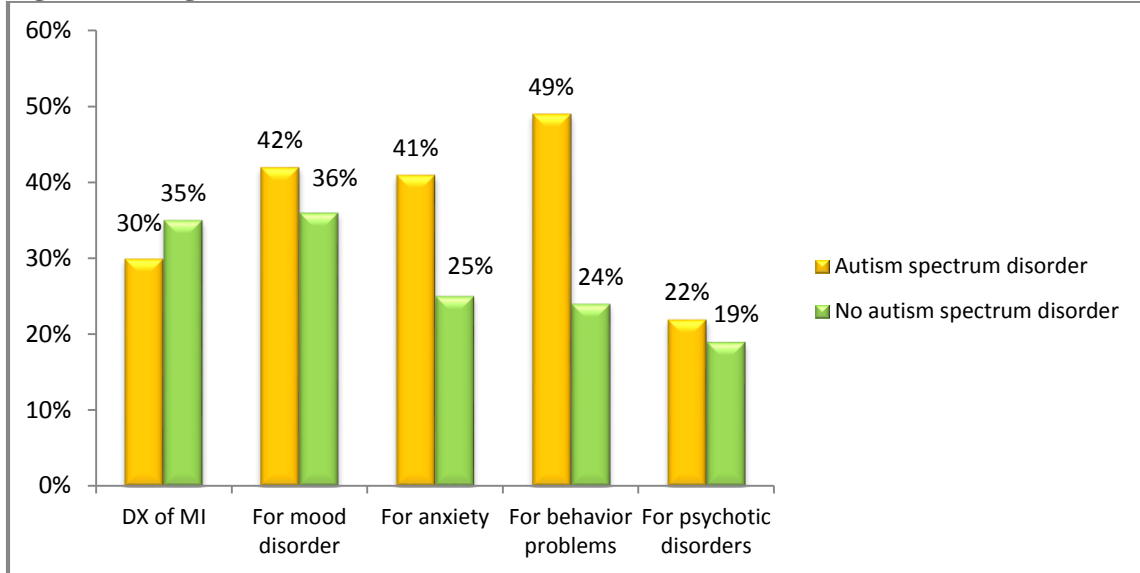


Medical/Psychological Information:

Interestingly, people surveyed with autism spectrum disorder were somewhat less likely to have a diagnosis of mental illness (30%) than people without autism (35%). Thus it was

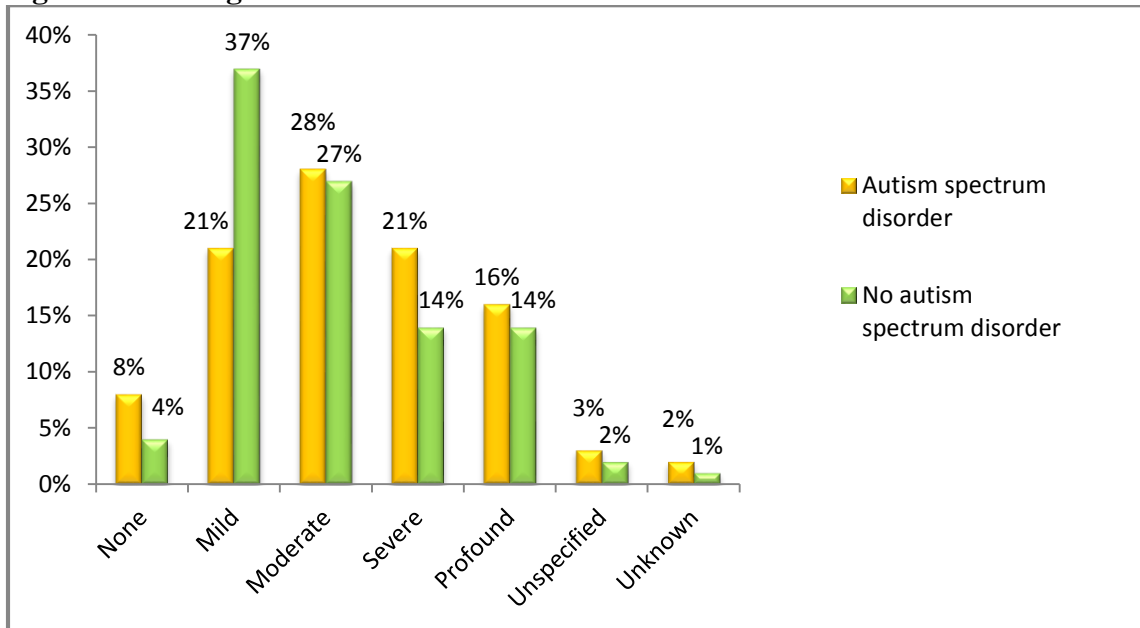
striking to find that a *higher* percentage of people with autism spectrum disorder were taking all types of psychotropic medications. Notably, they were twice as likely to be taking medications for behavioral disorders (49% compared to 24%). See Figure 6 below.

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, twice as many respondents with autism spectrum disorder were reported to have no ID diagnosis (8% vs. 4%). However, those with diagnoses of both autism spectrum disorder and ID were more likely to have a label of severe or profound disability than those without autism spectrum disorder.

Figure 7. ID Diagnosis and Level



Services Received

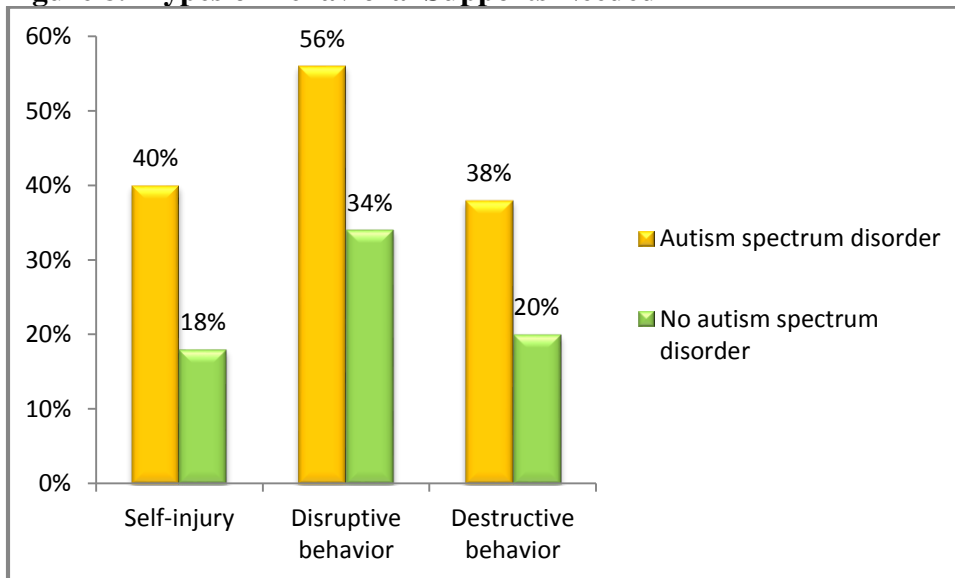
Individuals with autism spectrum disorder generally received the same types of services as those received by persons without such diagnosis. However, those with autism spectrum disorder were more likely to receive respite and clinical services, and less likely to receive assistive technology (see Table 1) even though they were less likely to use language to communicate. Individuals with autism spectrum disorder were as likely to be directing their own services as individuals without the diagnosis.

Table 1. Services Received						
	Case Management	Transportation	Respite Services	Clinical Services	Assistive Technology	Self-Directed Services
Autism spectrum disorder	95%	60%	30%	55%	11%	5%
No autism spectrum disorder	94%	63%	20%	48%	19%	4%

Supports Needed

Not surprisingly, more people with autism spectrum disorder are reported to need supports to prevent self-injury, disruptive behavior, and destructive behavior than those without autism spectrum disorder (see Figure 8 below).

Figure 8. Types of Behavioral Supports Needed



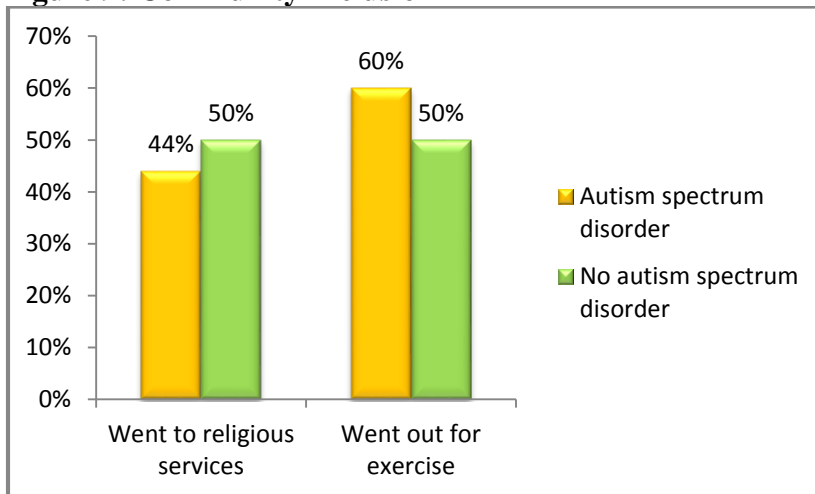
CONSUMER OUTCOMES

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, with 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 and without autism spectrum disorder in the Satisfaction indicators. The sample size of people with autism spectrum disorder who were self-directing was much too small to find any significant differences in any of the Self-Determination 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. 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 sometime in the past month: shopping, running errands, going out for entertainment, going out to eat, going to religious services, going out to exercise, and going on vacation. For most of these Community Inclusion items, there was no significant difference between respondents with and without autism spectrum disorder; most responses indicating that persons are participating in community activities. However, as shown in Figure 9, people with autism spectrum disorder were less likely to go religious services and more likely to go out for exercise.

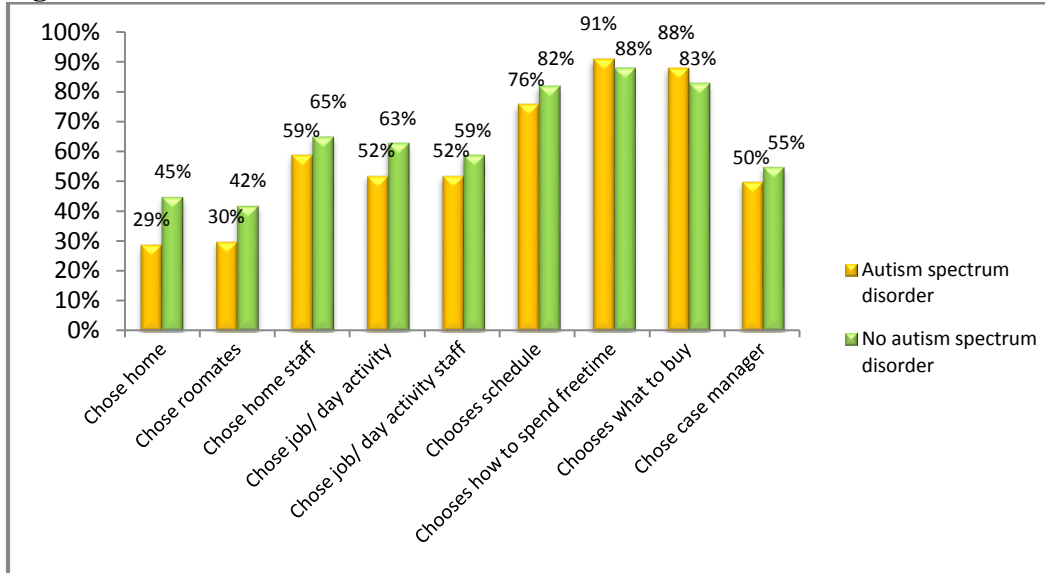
Figure 9: Community Inclusion



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 – people without a diagnosis of autism spectrum disorder were more likely to exercise choice, especially in major life decision areas. Figure 10 displays the results of whether the person chose or had some input in choosing a variety of activities.

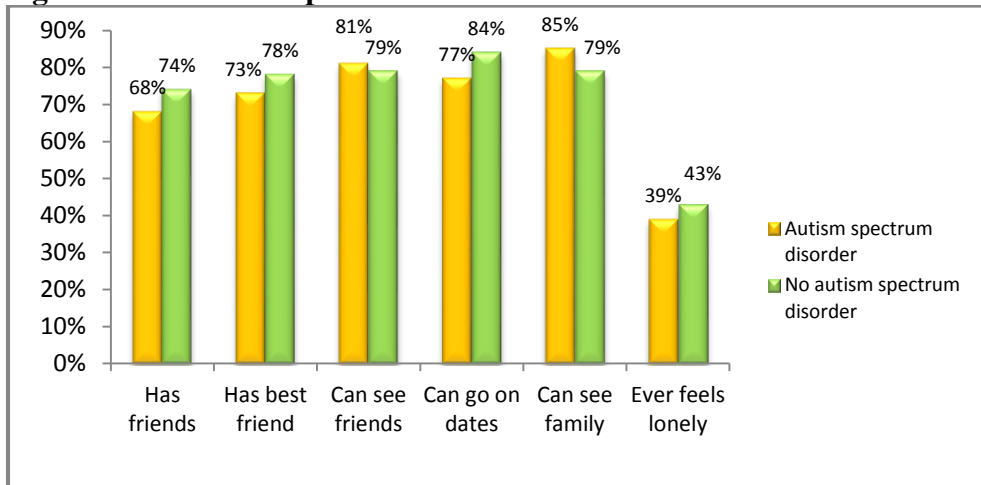
Figure 10. Choice and Control



Relationships

Although there was no significant difference between respondents with autism and those without the diagnosis concerning loneliness (around 60% in each group said they were never lonely), persons with autism spectrum disorder were less likely to have a best friend and less likely to have a friend who was not a family or staff member. They were also less likely to be able to go on dates without restrictions. On the other hand, they were more likely to be able to see family whenever they wanted to. See Figure 11 below.

Figure 11. Relationships



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. There were no significant differences in terms of the safety indicators between the two groups.

However, there were some significant differences in the area of respect and rights. Respondents with autism spectrum disorder were much more likely to report that their mail is read without permission and to have some restrictions on being alone with guests (see Table 2). It should be noted that for these questions a proxy could answer if the person was unable to.

Table 2. Respect/Rights		
	% Persons Who Can Not be Alone with Guests	% Mail is Read by Others Without Permission
Autism spectrum disorder	22%	17%
No autism spectrum disorder	15%	11%

CONSTRAINTS AND LIMITATIONS

A comparison of findings between adults with and without autism spectrum disorder revealed large differences among factors such as age, 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 spectrum disorder. Furthermore, only 47% of the respondents with the diagnosis were able to provide responses to the survey, compared to 69% of respondents without it.

SUMMARY OF FINDINGS

The data gathered through the current NCI Consumer Survey raise important issues. People with autism spectrum disorder 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 spectrum disorder also have greater communication and behavioral challenges. Additional findings include:

- ✚ Respondents with autism spectrum disorder were less likely to have a mental illness diagnosis (30% to 35%), but more likely to be taking medications for mood (42% to 36%), anxiety (41% to 25%), behavior (49% to 24%) and psychotic disorders (22% to 19%).

- ✚ For those respondents with autism spectrum disorder 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 spectrum disorder.
- ✚ Respondents with autism spectrum disorder were less likely to go to integrated religious services in the community (44% to 50%) and more likely to go out for exercise (60 vs. 50%).
- ✚ Respondents with autism spectrum disorder were less likely to report having their rights respected.
- ✚ Significantly fewer people with autism spectrum disorder completed questions in Section 1 of the Consumer Survey (47%), compared to people without autism (69%).



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